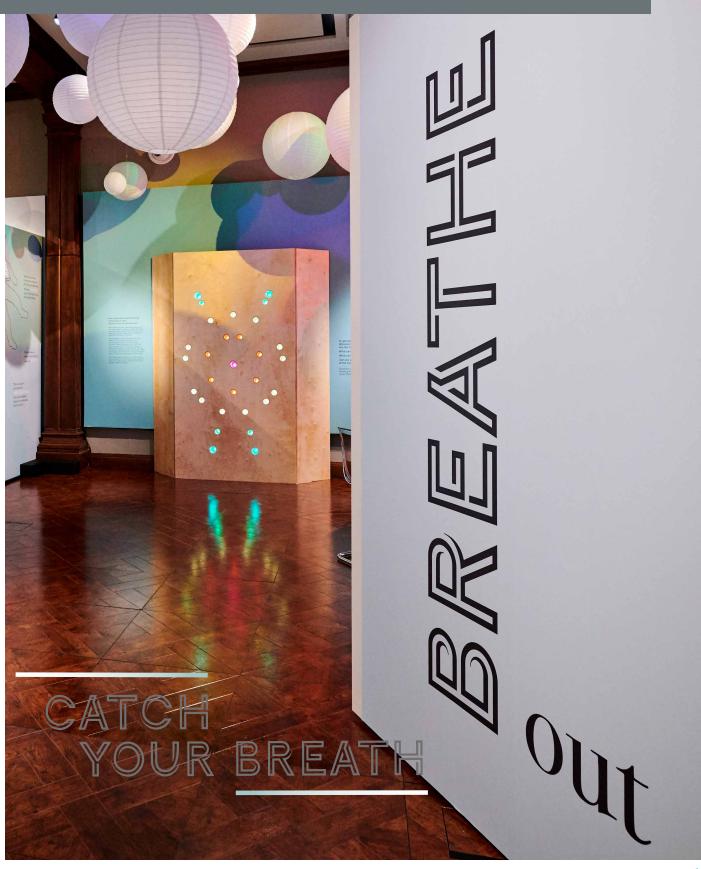
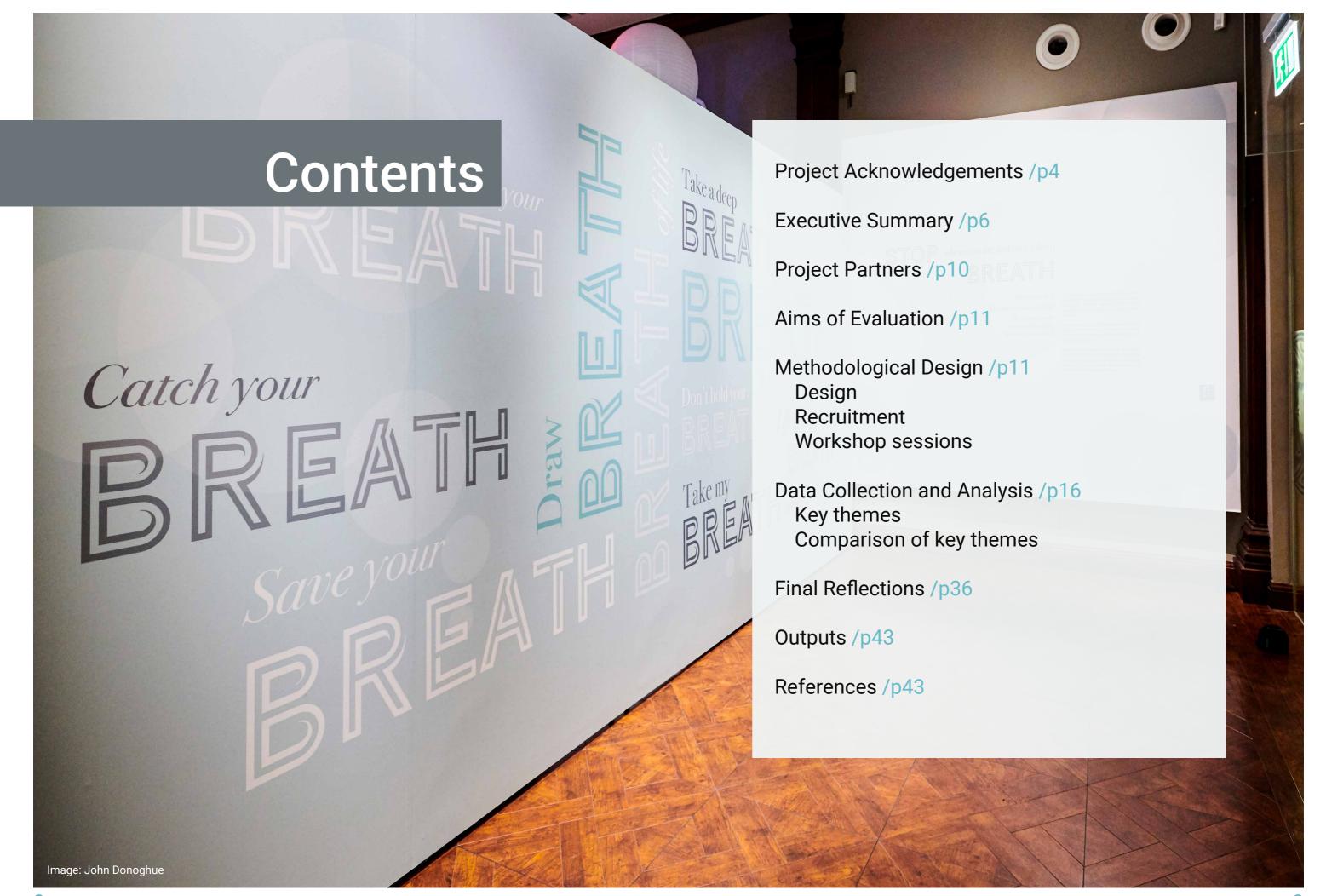
# Writer-in-Residence Evaluation





## **Project Acknowledgements**

We wish to warmly thank all <u>Durham & Derwentside Breathe Easy Group</u> members who generously offered their time, stories, and words as part of the project.

Special thanks to writer-in-residence <u>Christy Ducker</u> and filmmaker <u>Kate Sweeney</u> who creatively represented selected stories in poetic and visual form.

The project and this evaluation would not have been possible without the financial support of Durham University's Research Impact Fund.

Both the evaluation and report were completed by Nelli Stavropoulou with input from Sarah McLusky and Jade Westerman.

Design by Nelli Stavropoulou and Sarah McLusky.

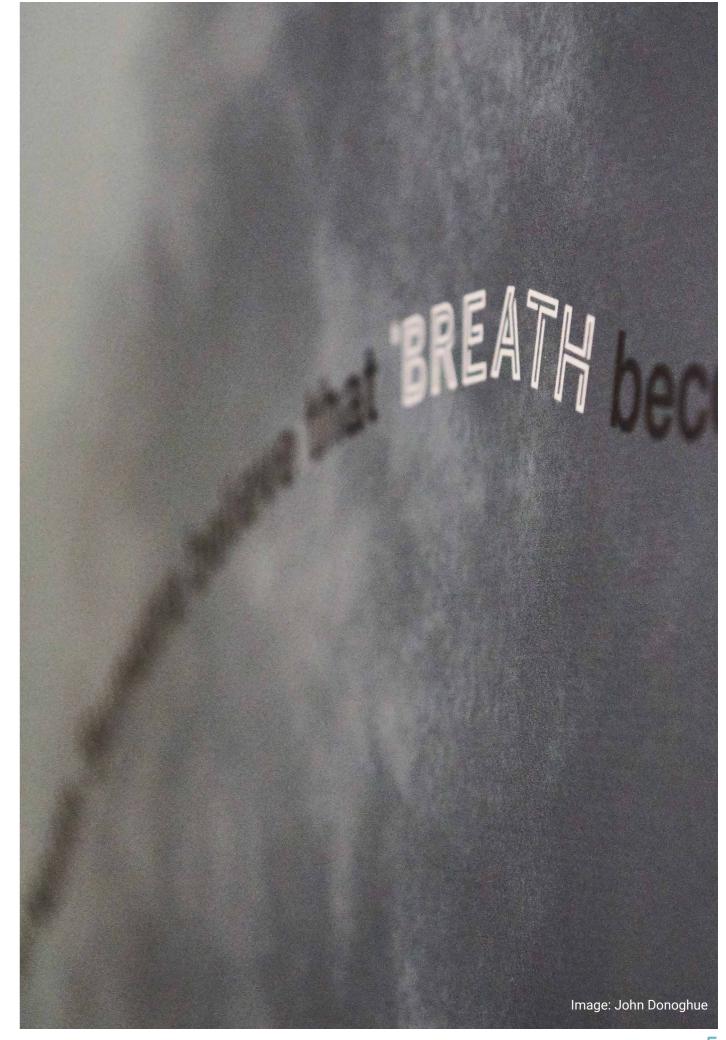
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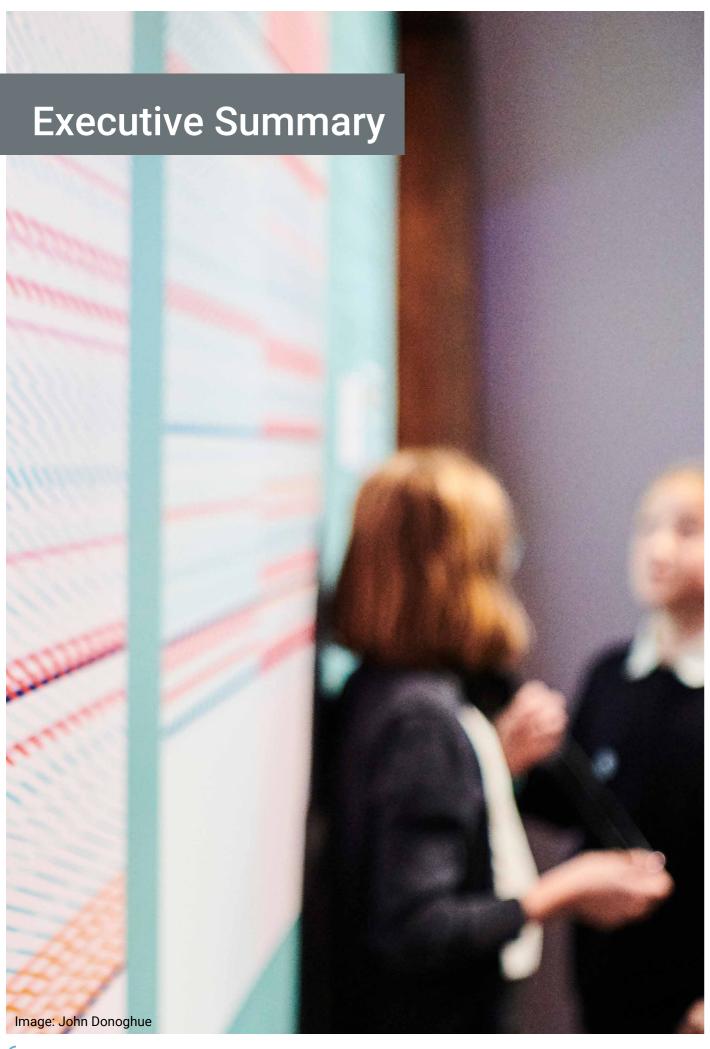
#### A Chance

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?

Jill Gladstone





#### **Catch Your Breath Exhibition**

This report evaluates a creative writing programme in response to the exhibition <u>Catch Your Breath</u> (24 November 2018 - 17 March 2019) at <u>Palace Green Library</u>, Durham University. <u>Catch Your Breath</u> explored the work of <u>Life of Breath</u>, a medical humanities research project, jointly led by <u>Durham University</u> and the <u>University of Bristol</u>, and funded by <u>Wellcome</u>. Bringing together medical history, philosophy, art, literature and music, the exhibition combined new artist commissions with objects from the Durham University collections and beyond to discover new ways of thinking about breath and breathlessness, and their relationship to both illness and wellbeing. Catch Your Breath Durham attracted an audience of 3,592 visitors.

#### The Writer-In-Residence Programme

The creative writing programme was facilitated by Northumberland poet and writer-in-residence <a href="Christy Ducker">Christy Ducker</a>, who was appointed under a competitive tender process. Christy led a series of workshop sessions responding to the exhibition and inviting participants to think about their relationship with their breath. The writer-in-residence project was funded by Durham University's <a href="Research Impact Fund">Research Impact Fund</a>.

Over a period of five months, Christy collaborated with a total of 45 individuals: 29 general public members and 16 Breathe Easy support group members. The project involved visits to the <u>Catch Your Breath</u> exhibition and 6 writing workshops.

#### **Evaluation Methods and Findings**

Employing mixed methods (participant observation, interview and feedback cards among others), this evaluation examined the extent to which the project offered individuals the opportunity to develop a new language to allow them to communicate and make sense of their experiences while feeling heard and validated.

Participants employed the poetic form to communicate memories, lived experiences of stigmatisation, pain and fear as well as engaging in meaning-making and representation. The table below outlines the key themes articulated across both the general public and support groups.

General Public (P)	Breathe Easy (BE)
1(P/BE). Reflecting on connections between lived experience and exhibition objects	
2(P/BE). Increased understanding of and empathy for experiences of breathlessness	
3(P). Recognising significance of breath in relation to socialisation, vitality, mobility and ability to live independently	5(BE). Building confidence to resist invisibility
4(P). Appreciating the therapeutic value of creative writing in representing experiences of breathlessness	6(BE). Deepening interpersonal relationships within the group

#### **Evaluation Methods and Findings (cont'd)**

Both groups realised the potential of poetry to achieve a deeper and more empathetic reaction to experiences of breathlessness as well as serving as a platform for self-representation. The main differences occurred as members of the general public were only briefly inhabiting the experience of breathlessness (e.g. by breathing through a straw), whereas the patient group invested more in the linguistic nature of their experiences while engaging in poetry as a pathway for self-representation and validation.

#### **Outputs**

Project outputs included a collection of poems by general public and Breathe Easy support group workshop participants, a body of work by writer-in-residence Christy Ducker, two short films produced by Christy and filmmaker Kate Sweeney and three blog posts. Some of the poems are included in this report. See p43 for a full list of outputs and links.

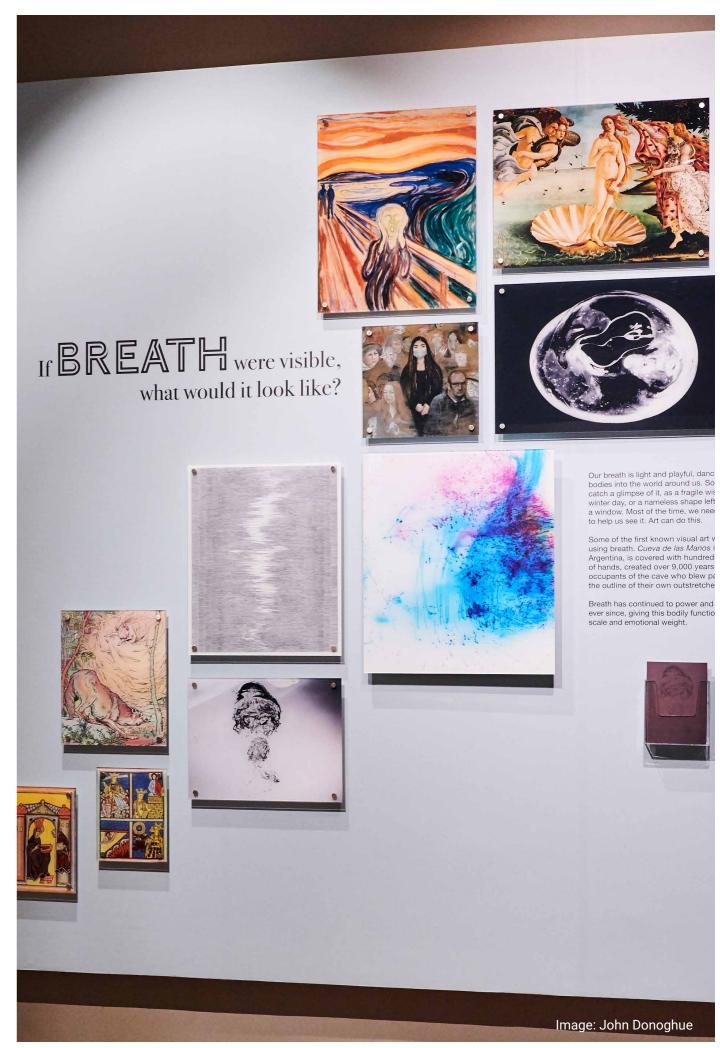
#### Conclusions

Ultimately, this report critically evaluates the project's participatory processes and pays attention to the challenges (time and recruitment) and possibilities (self-representation and empowerment) for transformation through the development of new forms of expression that challenge the clinical language and descriptions of breathlessness.

#### **Impact and Legacy**

The evidence presented here makes a compelling case that the creative writing workshops and deep engagement with the exhibition and its themes have helped people with breathlessness feel heard, validated and empowered. It also demonstrates that general public participants were challenged to address their relationship with their breath, increasing their empathy for those who find the apparently simple act of breathing difficult at times.

The poems are already feeding back into Life of Breath project research and will now be shared more widely. They will be used to open up conversations with healthcare professionals and the wider public, to challenge the assumptions, stigma, shame and blame laid on the breathless.



#### **Christy Ducker**

Christy Ducker is a poet and teacher of creative writing. Her first full-collection Skipper was ed in 2015, and includes

published in 2015, and includes work commended by the Forward Prize judges. Her pamphlet Armour (2011) was a PBS Pamphlet Choice. 2 further pamphlets – Heroes (2016) and Messenger (2017) – have since followed. Her commissions include residencies with Port of Tyne, English Heritage, Edinburgh Surgeons' Hall Museum, and York University's Centre for Immunology and Infection. Christy also devised and directed North East Heroes, an archives and education project funded by Arts Council England.

Christy has recently been working as a research fellow on poetry and health at Newcastle's <u>Institute for Creative</u>
Arts Practice.

#### **Breathe Easy**

Durham & Derwentside
Breathe Easy Support
Group provides support

and information for people living with a lung condition, and for those who look after them. The group holds monthly group meetings during which members can socialise, share experiences about living with their condition and learn from each other. The group also arranges special events, including guest speakers and activities. This group is currently associated with the British Lung Foundation and helps to raise awareness locally about lung conditions and the work of the British Lung Foundation.

#### **Kate Sweeney**

Kate Sweeney is a visual artist who has been working in participatory settings for several years. She graduated from Northumbria University with a BA in Fine Art in 1999 and went on to complete her MA at the same university in 2009, achieving a distinction. Kate is currently undertaking a fully funded REA (Research Excellence Award) PhD exploring video practice in literary archives at Newcastle University. Her studio practice is based in the Star and Shadow Cinema in Newcastle.

#### Life of Breath

BREATH Life of Breath is a 5-year (2015-20) medical humanities project, funded by Wellcome. The project is led jointly by Professor Jane Macnaughton (Durham University) and Professor Havi Carel (University of Bristol). The Life of Breath project brings together researchers from medical humanities, philosophy, anthropology, history of science, English, respiratory medicine, general practice, dance and drama, arts and health, as well as collaborators who are composers, visual artists, writers, poets, yogis and music therapists. The project also works in partnership with the British Lung Foundation, people affected by lung disease and healthcare professionals to find new ways of answering questions about breathing and breathlessness and their relationship to illness and wellbeing.

### Aims of Evaluation

The aim of this evaluation was to examine the use of creative writing as a way of engaging more deeply with the themes of the exhibition and as a self-expression pathway, offering participants new ways of relating and representing their experiences of breathing and breathlessness.

As Tribe (2008: 941) argues, '[a]rt extends our insights beyond the literal and more easily allows the symbolic, the impressionistic, the imaginative, the ironic and the surreal to challenge and extend our thinking'. Employing creative means unlocks the possibility of creating multi-vocal texts within the 'same' group, as each response is shaped by the participant's individual autobiography.

In particular, this report critically evaluates the project's processes in relation to offering new possibilities for self-expression, with a focus on the notion of 'voice' — in terms of both linguistic expression and the decision to resist invisibility. Additionally, it addresses challenges and limitations and presents key learning points.

Employing a mixed methodology of participant observation, semi-structured interviews, diaries and questionnaires, this evaluation also examines the extent to which the workshops supported skills acquisitions (with a focus on transferability), as well as enhanced interpersonal relationships through opening up collective dialogues amongst participants.

## Methodology

#### Design

This evaluation adopted a participatory research approach, emphasising the importance of working with participants and ensuring that their needs, ideas and suggestions shaped and redefined the evaluation's methodology and focus. The evaluation was invested in recognising and valuing the knowledge, lived experience and expertise of participants.

A combination of qualitative methods was recognised as the most appropriate and reflexive way to observe and to explore the impact of the exhibition and the creative writing workshops on participants' relationship to, and perception of, their breath and breathlessness, as well as their relationship with their body as a site of experience and a source of inspiration and reflection.

The methodological design included participant observation of the creative writing workshops as well as participants' engagement and interaction with the exhibition, recorded group discussions about the poems, short qualitative interviews, feedback cards, and photographs of participants' navigations in the exhibition space.

#### Recruitment

The project engaged two principal groups. Firstly, individuals experiencing breathlessness due to chronic respiratory conditions and attending the <u>Durham and Derwentside Breathe Easy support group</u> in Lanchester, County Durham. Secondly, the programme involved members of the public, including Durham University students, academic staff, individuals interested in poetry and/or creative writing. The workshops were publicised through the <u>research project's official website</u> and <u>social media channels</u>, the various online event advertising websites, <u>Durham University's website</u>, <u>Palace Green Library's website and social media channels</u>, as well as through direct invitation to interested groups.

#### Workshops

Underpinned by <u>Life of Breath's</u> research on the language of breathlessness, the project responded to the 'uneasy tension that exists between the personal and the clinical languages of breathlessness and the clear evidence of a distinction between measured and experienced symptoms of respiratory disease' (Malpass et al 2019: 8).

Over a period of five months, Christy collaborated with several groups to engage with the exhibition and the corporal reality of breathing and breathlessness through poetry, and in doing so explored new vocabularies for capturing embodied and internal experience.

It was important that the workshops were designed and delivered in accordance with the particularities, needs and expectations of each group. As Christy explained, her approach was different:

I think we were exploring a broader range of themes with the general public. There was scope for people to inhabit the experience of breathlessness — almost like tourists. To write about that interaction with that experience by replicating an element of that experience through the straws and looking. I don't think it could really begin to do the same as we were doing with the support group, which was providing a space for a language, which had to come from them entirely and create a space which would support their creativity and their voice.(Christy Ducker)

Christy employed poetic, visual and material cues to encourage participants' engagement with the poetic line and provided a range of activities for them to start thinking about themselves, their bodies and their breath through the use of symbols, imagery, words and metaphors.

Participants from both groups were given the opportunity to share their poems and ideas at each session, which prompted meaningful discussions amongst participants, as well as initiating storytelling exchanges across the group.

### Public Workshops (Sunday 10th February 2019 at 10am-12pm, 2pm-4pm and Sunday 24th February 2019 at 2pm-4pm)

The evaluation of the public workshops was primarily focused on how the creative writing programme's dialogue with the exhibition changed perspectives, increased empathy and invited participants to see the 'bigger picture'.

Participants were introduced to 5 themes from the exhibition:

- 1. Making the invisible visible and the politics of breath
- 2. Breath as the connection between inside and outside, between self and other
- 3. Understanding the experience of breathlessness
- 4. Pollution
- 5. How breath influences the poetic line

The participants' background included poetry, children's novels, psychology, philosophy, English literature, creative writing (MA and PhD students and professionals), curatorial and museum work, among others.

In her reflective <u>blog post</u>, Christy describes how participants' poetic responses constructed images of birth-rooms, deathbeds, seething arguments, meditation, miners' lung disease, social exclusion, teaching the ocarina, Ella Fitzgerald, kissing, smoking, and being in love.

Prompted by the work of Great Stoddart, Julia Darling and David Tait among others, a total of 29 participants across all three sessions were asked to think about manifestations of their breath, the relationship between inside/outside, and to recall times where they might have breathed in a different way, close to another person or shared a breath.

According to Christy, their poems revealed various 'differently-breathing pairs: a calm doctor and a nervous patient; a dying father and a grieving daughter; a keen lover and a bored, snoring lover; an argumentative pair of hikers; a constricted Victorian woman and an educated 21st century woman'.

They described and re-imagined their breath as ice cream, condensation, puff pastry, blades, incense, a lion and precious jade. It acquired taste, temperature, was felt against one's skin, it became a place, a person, a cloud.

They were also asked to visit the exhibition gallery at Palace Green Library and pick an object that best resonated with them. Holding their notebooks, they walked across the space, carefully examining all exhibits and jotting down thoughts that would serve as building blocks for their final poems.

Participants were also invited to produce short poems that could be shared in one breath. This exercise was then repeated through a folded straw to compromise their breaths and attempt to convey what breathlessness might feel like and how it might impact one's choice of words. As one participant noted, 'You are forced to consider your breath'.



#### Breathe Easy Workshops (28th January, 14th February, 2nd April and 13th June 2019)

The project engaged members of respiratory support group <u>Durham & Derwentside Breathe</u> <u>Easy</u>. All Breathe Easy group members have a chronic breathing difficulty themselves or support others who do: for some this has been a result of childhood tuberculosis (TB), others have chronic obstructive pulmonary disease (COPD), whereas some are living with pulmonary fibrosis or lung cancer.

These workshops focused on the embodied, subjective and phenomenological experience of breath and breathlessness - voicing what has often been silenced, hidden or ignored. Over the three sessions, a total of 16 participants responded to the idea of making the invisible visible through images and prose. Participants included individuals with long-term respiratory conditions, partners, family members and primary carers.

During their initial meeting at The Red Lion pub in Plawsworth, County Durham, Christy suggested the following activities: responding to Julia Darling's poem 'Too Heavy' and juxtaposing favourite words vs. medical language; considering expectations of creative writing, and how it might help to amplify experiences of breathlessness; reading Darling's 'Ways of Discussing my Body'; and finally, agreeing to keep a metaphor journal for the duration of the programme.

Breathe Easy members explained how they have experienced stigma and silencing as a result of and in response to their chronic breathing difficulties. They shared the tendency to hide their conditions to avoid becoming a burden, but also because of the fact that breathing difficulties can be judged, ignored or misunderstood by others.

The latter was encapsulated in <u>Christy's story</u> about a waitress at the pub responding to a member who was having a coughing fit by saying 'don't worry, a few germs never hurt.' As Christy remarks, her response highlights the lack of understanding of what it means to live with breathlessness and how such a 'common' experience is indeed an invisible and ongoing battle with one's lungs.

On Thursday 14th February, Breathe Easy members were invited to visit the <u>Catch Your Breath</u> exhibition at <u>Palace Green Library</u>. Project manager <u>Sarah McLusky</u> and <u>Christy Ducker</u> offered an introduction to the exhibition and creative writing programme respectively. For the next 40 minutes, participants navigated the different exhibition spaces and spent time interacting with several exhibits and reading the accompanying information. Christy had equipped everyone with their metaphor journals in which they could make notes on particular exhibits that caught their attention as well as any words or thoughts that came to mind. Walking in pairs or small groups, participants shared their thoughts and commented on interesting facts: 'Did you know that lung disease is killing 1 person every five minutes?' asked one participant to her fellow member.

The visit also included an initial collective conversation about the exhibition and the introduction of metaphors as ways of describing one's body. After introducing themselves, each participant commented on the exhibition in terms of what was interesting, new, what had resonated with them, made them recall a personal memory, as well as how they had felt. In line with challenging the invisibility of breathlessness and focusing on opening up the space of representation, Christy also posed the question of 'what was missing?' For one of the participants, Dorothy Maskery (Babs), that would be her walking frame, Fred.

The group met again with Christy in early April 2019 at Willowburn Hospice where they translated lived experiences into poetic provocations in an attempt to capture the corporeality of breath and breathlessness.

On Thursday 13th June 2019, members of the <u>Durham & Derwentside Breathe Easy</u> support group showcased their poetry created with <u>Christy Ducker</u> as part of the Words from the Breath poetry reading event at <u>Lanchester Community Centre</u>.

The event involved poems by participants, work produced by Christy, as well as two short films by Christy and North East photographer and filmmaker <u>Kate Sweeney</u> exploring the politics of breath. The event was attended by a total of 7 participants, 1 carer, 2 family members, 6 members of the academic project and exhibition management team, as well as the 2 facilitators.

Following an introduction by project manager <u>Sarah McLusky</u>, Christy provided an overview of the workshops' sessions and creative approach before inviting participants to share their poems and thanking them for their contributions. Their readings explored complexities of caring, negotiated the invisibility of lungs and examined everyday objects that have become necessary and familiar support systems.

As part of her output, Christy collaborated with <u>Kate Sweeney</u> to create two short films: *The Secret* – a piece written by Christy reflecting on the <u>Life of Breath</u> research, and her interactions and conversations around stigma and invisibility of individuals experiencing breathlessness; and *To Breathe* – a showcase of poetry featuring members of the <u>Durham & Derwentside Breathe Easy</u> group. Both films were screened for the first time during the poetry event and will continue to tour alongside the exhibition and public poetry readings. The poetry created by the Breathe Easy group was collated into a post on the <u>Catch Your Breath</u> website.



### **Data Collection & Analysis**

The evaluator conducted participant observation throughout the workshop sessions for both groups. She also documented individuals' remarks, responses to the exhibition and reflections on the creative writing process. She noted their reflections after sharing poems, including their dialogues with other members, and visually documented these creative and physical encounters through photography. The evaluation was also supported by Impact Assistants (funded by Durham University's Research Impact Fund), who documented the participants' navigations across the exhibition space and conducted surveys.

Workshop participants were asked to complete a double-sided feedback postcard upon completion of the workshop. In some cases, verbal feedback was offered as an alternative.

The feedback questions focused on how participants had experienced the creative writing programme, how it might have changed their perceptions of breath and breathlessness, and what they might have gained from their participation.

All recorded data was transcribed verbatim, whereas all written data (*i.e.* notes, feedback cards) were transcribed and categorised according to the date of the session and the group. The themes were identified, codified and organised in categories. Preliminary findings were discussed with the project manager <u>Sarah McLusky</u> and exhibition project officer <u>Jade Westerman</u> at different stages of the evaluation. The principal themes were also drawn out during interviews with members of the Breathe Easy group.

#### **Key Themes**

The poems and feedback responses presented in this evaluation are a sample of the greater range of poetic responses that emerged through the creative writing process. Participants' reflections are grouped thematically as shown below, highlighting over-arching as well as different themes. The identified themes for each group are:

General Public (P)	Breathe Easy (BE)
1(P/BE). Reflecting on connections between lived experience and exhibition objects	
2(P/BE). Increased understanding of and empathy for experiences of breathlessness	
3(P). Recognising significance of breath in relation to socialisation, vitality, mobility and ability to live independently	5(BE). Building confidence to resist invisibility
4(P). Appreciating the therapeutic value of creative writing in representing experiences of breathlessness	6(BE). Deepening interpersonal relationships within the group

#### **Comparison of Key Themes**

Across the two groups there were overlapping responses in relation to how the exhibition and creative programme increased understanding of their bodies, their relationship with their breath, as well supported an appreciation of the mechanics of breathing. Through their engagement in a collective dialogue and poetic sharing-cycle with other participants, they experienced empathetic reactions towards others and acquired greater sensitivity and awareness of breathing difficulties.

Participants commented on how their participation enriched their skill-sets (for both first-timers as well as more experienced writers), expanded their imagination and offered them new ideas and inspiration cues.

The exhibition served as an incubator of ideas, inviting individuals to navigate across different conceptual and physical spaces while engaging with different parameters of the breathing experience: sociocultural, historical, economical/industrial, environment and pollution, mind and body balance, meditation, sleeping and breathing in sync with others.

Principal differences between the two groups emerged in relation to the potential for self-expression and fighting invisibility. For individuals who experience breathlessness on a daily basis, it opened up a platform to exhale those experiences, finding new vocabularies that capture the sensory, embodied and tacit lived experience of how it feels to experience breathlessness.





Theme 1: Reflecting on the connections between lived experience and exhibition objects (Public & Breathe Easy)

#### **Public Workshops**

Positioned at the centre of the exhibition's gallery space, workshop participants were placed at the core of meaningful conversations about the role of breath and breathlessness in our lives. Participants commented on the role of the exhibition as a source of inspiration which allowed them to engage with tangible objects to create something new moulded by their own understandings, creativity and unique viewpoints:

[Responding to what they enjoyed most about the workshop] The end activity where we had to pick an item and write about it. As this allowed something tangible to really inspire our creative process. Literally making the invisible, visible. (Anonymous feedback postcard response)

The exhibition was a stimulating source of inspiration and I like the challenge to take away our ideas to work on. Thank you. (Anonymous feedback postcard response)

Inspiration ideas, a deeper understanding of our body. (Anonymous feedback postcard response)

Meeting the exhibit at the end to ignite thought. (Anonymous feedback postcard response)

#### **Breathe Easy Workshops**

During their visit to the <u>Catch Your Breath</u> exhibition, participants were asked to respond to the exhibition and share with the group what resonated with them. Participants established connections between particular items (objects, words, sounds, images) and past experiences. In doing so, they entwined their autobiographical memories with the wider narratives across the gallery space.

There was this quote in the exhibition about how breath becomes wind when the soul leaves the body. I remember when my husband passed away, the nurse opened the window for his soul to leave. (BE Participant remarking during exhibition visit)

#### **Breathe Easy Workshops (cont'd)**

The machine they used for patients with tuberculosis. To me that was everything. This exhibition helps making the story [of TB] visible. I'm really pleased to be here. (BE Participant remarking during exhibition visit)

Only instrument I've used is a spirometer. Now it is electronic. All these things I don't notice them. From the age of two I've been in and out of hospitals. You get used to it. (BE Participant remarking during exhibition visit)

The exhibition's range of topics, objects and facets of breath offered multiple cues for interpretation and meaning-making; no two selected objects or remarks were the same as each person would offer their own world-view.

It has pushed us into thinking more deeply. (BE Anonymous feedback postcard response)

Tremendously impressed by display. Each person 'catching' something different. Reminder of how appallingly big industries behave. (BE Participant during exhibition visit)

Participants also reflected on the complex relationship between smoking, lung cancer and other respiratory difficulties. They interrogated the projected stigma and assumed sense of responsibility that others attach to smoking and the problematic parameter of not recognising the role of big industries and instead holding the individual accountable:

The misunderstanding. To be told you are responsible because you smoked but no responsibility by tobacco companies. (BE Participant remarking during workshop)

I went to the exhibition at Palace Green and I just found that so powerful. I was in tears most of the way. I left in tears. COPD and other conditions, they're so underrated and it was wonderful for people to be given a voice. To understand the industrial problems associated with breathlessness and diseases. I was incredibly struck by the information about asbestos and how dangerous it can be. It was seen as this wonder material but then you realise how bad it was. (S. G. Interview response).

#### The Breathing Box

Now: an exhibit at the library – a box with doors which open to display a cylinder, tubes, needles, a plunger on top to blow up 'magic' to inflate an air duct

to collapse

my diseased lung and promote healing.

Back then: I would lie on a table and wait in dread for the needle to be inserted, the plunger to be pressed, while staring at the ceiling.

Now: I stare at the scarring of pin holes left after years of needles. Was all this worth it?

Yes.

All to breathe.

Sylvia Hocking



Image: John Donoghue





#### Theme 2: Increased understanding of and empathy for experiences of breathlessness (Public & Breathe Easy)

#### **Public Workshops**

Prior to visiting the exhibition and participating in the workshop, the majority of participants, especially those who've never experienced breathing difficulties, explained that they had never really thought about how breathlessness can act as a barrier for some individuals.

As one participant noted it offered an

...awareness, a respect. Amongst reverence for breathing and associated emotion. (Anonymous feedback postcard response)

For another person it allowed them to challenge the 'mundane' nature of breathing - so important yet so taken for granted:

Thought it was all really thought-provoking to write about something we take so much for granted. Thanks very much:) (Anonymous feedback postcard response)

Listening to people describe the difficulties of fighting for breathing when it is something many of us take for granted and never think about. (Anonymous feedback postcard response)

The act of sharing experiences of breathlessness due to asthma or panic attacks underpinned by anxiety over one's breath created a shared space between participants that promoted understanding, dialogue, as well as empathetic reactions towards others' experiences.

I feel more empathetic to different breathing experiences. I have understood breathlessness as a tool that can prove as useful as being able to breathe 'normally'; so much of my personal writing comes from plight feeling like I cannot breathe. (Anonymous feedback postcard response)

#### **Breathe Easy Workshops**

At the centre of the exhibition space a projector played on repeat a series of short films. One of the films featured interviews with members of various Breathe Easy support groups. Hearing their stories against the exhibition's wall under the sound of breaths echoing against the gallery's glass walls, participants watched their peers share stories about what breathlessness feels like.

Seeing my friends in film and how their life is affected or have no life. It made a big impression on me. Didn't realise how bad it could be to breathe through a straw cranked. (BE Participant remark through exhibition visit)

You get used to it. You just live with it, it becomes part of your life. Later on, in life you see what has affected you. (Anonymous feedback postcard response)

I know I get short of breath, I know I don't breathe deeply enough. I know I'm a shallow breather. It is very much teaching me to appreciate that I have to breathe deeply, I need to let the breath go down. I can't just breathe in the upper bit. I actually have to appreciate my lungs. One of the things I learned at the exhibition was that your lung capacity says so much more about the length of your life. So, you need good lung capacity otherwise you're chopping years off from your life. So, I've learned on a personal level as well as learned in relation to my mother. I've loved being part of this journey, it's been absolutely phenomenal. So many high-flying people who've come here today and taken it so very seriously I think has given the people here a great deal of confidence in what they have to say about what they are experiencing. (S. G. Interview response)

# Caring

Caring is sharing an illness.

Caring is worrying, eating away at you like rust on metal.

Caring is helplessness.

Caring is a warm blanket.

Caring is tiring, Atlas holding up the world.

Caring is putting something down then not being able to find it again.

Caring is draining, like a dripping tap.

Caring is patience, it's waiting for something that's never going to happen.

Caring is walking on eggshell carpets.

Irene Waggott



# The quality of the and BREATHE

has a profound effect on our health and wellbeing.
For people all over the world, breathing in dangerous levels of polluted air is a part of daily life and accounts for millions of deaths per year.

# Theme 3(P): Recognising significance of breath in relation to socialisation, vitality and the interrelationship between bodies, breath and emotional worlds

As <u>Christy</u> notes, 'Apart from our skin, only our lungs facilitate a constant exchange of the interior and exterior worlds. Breath becomes a tool of connection, not only spiritual but physical and emotional.' An important realisation occurred in terms of the fundamental role of breath in relation to socialisation, vitality, mobility and the ability to live independently.

Breath is not simply an internal process hidden within our bodies: it is also a source of life, energy and the foundation of one's voice. To be deprived of one's breath limits mobility within physical, emotional and potentially narrative landscapes.

Yes, has made me think more deeply about the emotional significance of breath and all the different difficulties caused by breathlessness. (Anonymous feedback postcard response)

It really got me, in particular, thinking about our breath as a connection to our inner selves and our outer bodies. (Anonymous feedback postcard response)

Yes, think about it in a deeper way — how all senses correspond to the universal fear of loss of breath. (Anonymous feedback postcard response)

I had not thought much about the socio-political implications of ideas about breathing (Anonymous feedback postcard response)

How diverse breath / breathlessness is as a topic. The social + political significance e.g. poverty, illness, mental health. (Anonymous feedback postcard response)

# Theme 4(P): Appreciating the therapeutic value of creative writing in representing experiences of breathlessness

For individuals amongst the group who have experienced respiratory challenges the workshops serve as an opportunity to deeply engage with their own embodied experiences and physical sensations in order to translate the sensory into poetic line. In doing so, some experienced a healing effect achieved through externalising such ideas whereas others recognised the pivotal role of their breath in their lives:

A deep sense of the need to write about the experiences so I can heal. (Anonymous feedback postcard response)

I have thought about breath as a tangible thing and explored in my own experiences of it as well as those of others in the workshop and the exhibition. (Anonymous feedback postcard response)

I understand the <u>huge</u> impact it has had on my life and my choices due to health issues! (Anonymous feedback postcard response)

The different ways that I was encouraged to think about the otherwise very simple act of breathing. (Anonymous feedback postcard response)

New ideas to reignite a period of writing, I hope, after a couple of months off. It will keep my mind ticking (...) (Anonymous feedback postcard response)

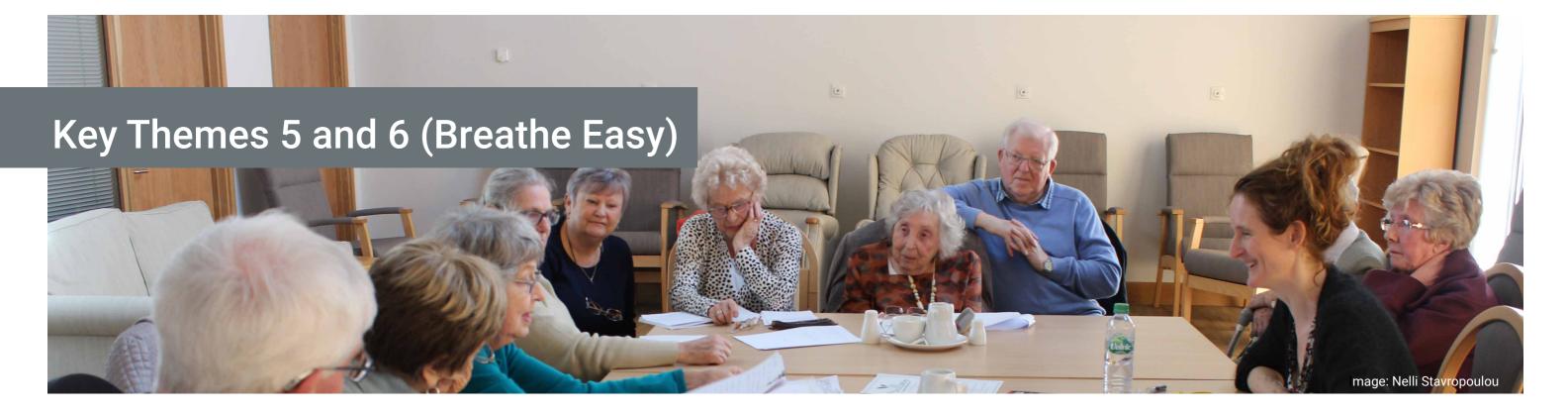
#### **Drawing Breath**

The window is weeping: softly-tipped fingers have traced its surface where the passion of our love has heated the air to opalescence, and condensation, in rivulets, runs down the panes of glass as silent sobs for a love which will never be more permanently etched than this.

The mingling of breath lingers in the ethers, long after our bodies have unfurled, and I see our union and its cloudy, billowing oblivion for the transitory illusion it is – yet I have breathed your air, and you my love, have breathed mine.

Barbara-Ann Whiting





#### Theme 5(BE): Building the Confidence to Resist Invisibility

Sharing stories also allowed participants to resist invisibility and combat feelings of loneliness or the need to hide:

Hearing other people's experiences and the fact that a lot resonates with yours, maybe not exactly the same but it still resonates, makes you feel less lonely. Because you know there are lots of others out there and apart from the little circle that we have here at Breathe Easy — and hearing it on the film always makes it more powerful than hearing it normally, it makes you realise that people you pass on the streets very possibly have it as well. You're just not aware of it. It's quite good to, well what this project was all about really, to raise awareness. And it makes me feel slightly better. (BE Participant L. H. Interview response)

A shared sense of recognition was experienced as individuals commented on the role of the exhibition in raising awareness and resisting invisibility which is often the daily reality for many individuals.

Good to see things written on walls. Because people experience health issues and remain invisible because they don't get out. It is a big effort to get out and go on with life as normal. Great to see this up here. (BE Participant remarking through exhibition visit)

'We've never been asked before. This project [poetry] allows us to talk about these experiences.' (BE Participant J. G. Interview response)

# Theme 6(BE): Deepening Interpersonal Relationships Within the Group

The project accomplished the creation of a collective space supporting the exchange of stories, poems and ideas while also redefining relationships amongst participants and their sense of belonging within the Breathe Easy group.

Somehow, we didn't even sit and talk about our personal issues, talked generally, the local respiratory nurses would come in and keep us up to date with what was going on, we would have speakers and have a good chat but what has come up through the project is stuff we've all been thinking about but never actually expressed to each other. So, I think that's quite good. (BE Participant L. H. Interview response)

People have been so lovely and supportive and enthusiastic and protective towards each other. It's been absolutely phenomenal because these are people with health conditions and it would have been so easy to say "I'm not feeling well enough to do this." I think it is incredible the quality of work that has been produced. When your brain is a little bit hungry for oxygen and to still come up with these amazing things. As a daughter, it's enabled me to understand my mum so very much more and it's given me the courage to be more understanding but also to push one of my brothers back and explain that she is not being slow or difficult but it's because of the condition.' (S. G. Interview response)

We went to the Red Lion where we met Christy — we'd never met a poet and we'd never been asked to find words or even think about our experiences. It did change. When went to the Hospice and had lunch that was really different. People listened to each other. Because we don't really talk about illness. (BE Participant J. G. Interview response)

# Fred, the three wheel walking frame

Fred is my long-suffering friend, smart in his blue paint.
He is having trouble with a funny front wheel.
He is Fred the Second, so I put up with his puffing.
He still tries to move like a ballroom dancer.

Dorothy Maskery (Babs)



#### **Sharing Stories**

The creative writing workshops offered a platform on which to share — for many for the very first time — the difficult and often 'messy' experiences of breathlessness in a creative form. In doing so, individuals were able to share their story and to de-familiarise and reframe experiences of breathlessness and breath.

As Macnaughton and Carel (2016: 294) remind us, 'Metaphor, emotion and the spiritual and existential dimensions are not part of the language of the clinic, but are a central part of the experience of the patient.'

Responding to <u>Jane Macnaughton</u> and <u>Havi Carel's</u> research around the tension between dominant medical narratives and personal experiences of breathlessness, using poetry opened up the potential for greater freedom of expression. As Christy notes, 'It's interesting to have worked with poetry and metaphor because metaphor is about movement, from the Greek word moving to one thing from another, it is a very mobile way of expressing yourself, it leaps across.'

The guiding principle in the workshops was to encourage individuals to invest in their lived expertise and imagination, exploring alternative languages to describe such experiences that move beyond clinical terms or popular clichés.

In doing so, participants opened up to the prospect of sharing private and often silenced stories that remain unattended or misunderstood. In Jill's words, 'Confidence. That it is okay to talk and look at lungs. This has been an afternoon when we've looked at lungs and the emotions of lungs.'

In engaging with the exhibition, participants from both groups became engaged in representation through drawing inspiration from exhibition material and reflecting on what is missing. As exhibition project officer <u>Jade Westerman</u> noted it was important to allow multi-vocality and offer different access points to not exclude any experience of breathlessness: 'The whole point of the exhibition was to be able to provide something so everyone could identify an area that connected to them and bring them all to that experience of breathlessness. You didn't want to say this is the only representation of it'.

#### **Connections and Contradictions**

Over the course of the programme, participants entered multiple dialogical relationships with their breath, bodies, selves, as well as with other group and family members, and with their wider medical, social and cultural languages of breath and breathlessness. The dialogue between the exhibition and the creative writing programme also emphasised the juxtaposition between external/internal, individual/collective and visible/invisible.

The interplay inside/outside operated on several levels: inside and outsider groups, body and breath, breathe in and breathe out. Such an interplay is integral to the experience of breathlessness, as Carel (2018: 234) reminds us: 'Breathing contains interesting tensions and juxtapositions. For example, it takes place continuously but mostly unconsciously. It is essential to life but can be artificially sustained despite the absence of consciousness. Much of the time we are unaware of it, but when it goes wrong (e.g., in respiratory disease), it takes up our entire attention.'

Lesley's poem *Ideally* dynamically captures the juxtapositions between imagined physical state and lived experience, encapsulated in the last stanzas:

Ideally, I'd be a tiger, flexible and swift - with my condition, I'm a wombat, solid and heavy -

I'm a broken concertina, a leaking bellows, and a compressed sponge.

Lesley Hughes, *Ideally, and with my condition* 

#### A Chance to be Seen and Heard

Participants' embodied presence within the exhibition space manifested itself in their physical presence as well as in their transgression of narrative spaces. A shared sense of acknowledgement and recognition occurred as a result of their participation in the wider research project and the creative writing programme. As Jill explained, participants were finally given 'this chance to speak':

Grab, grasp with gratitude this chance to speak.
To say what?
Can I do it?
Can we 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?

Jill Gladstone, A Chance

In engaging in poetic dialogues with breathlessness, participants enacted cultural citizenship - defined as 'the right to presence and visibility, not marginalization; the right to dignity and maintenance of lifestyle - not assimilation to the dominant culture, and the right to dignifying representation - not stigmatisation' (O'Neill 2018: 74).

Their stories of breathlessness also interrogate the notion of responsibility, especially for those who smoked, and the implication that they brought this upon themselves, captured by Lesley's comment 'Well you did smoke didn't you? It wasn't the whole story.'

While reflecting on her own poem about her experience of smoking, Christy commented on the visceral relationship with smoking and 'how it becomes of the body.' She also suggested that such an understanding might be a more fruitful approach as it might allow people to understand their relationship with smoking as a 'dysfunctional friendship' (see Russell, 2019).

As Co-Investigator <u>Jane Macnaughton</u> commented during the <u>Words from the Breath poetry</u> <u>readings</u> event in Lanchester, 'Whatever their background, everybody deserves compassion.' Her comments were received by clapping as she added that there is a 'need to raise awareness of lack of findings of living with breathlessness.'

#### 'Through the Lungs to Memory'

According to Philosopher <u>Petri Berndtson</u>, we 'always think with breath or according to breath.' As <u>Christy</u> notes 'Through their engagement with the workshops, participants' poems emerged within particular historical, cultural and socio-political spaces. Such a cultural awareness is embedded in the final stanza one of the poem, *My Father's Lungs* by participant Barbara-Ann Whiting;

Memories of mining, tattooed onto the landscape, cannot be erased: the memory of the miners who breathed all their love into it are reborn in every clean, fresh breath their descendants take.

Barbara-Ann Whiting, My Father's Lungs

Barbara-Ann's poetic words draw attention to the cultural, socio-political and anthropological framework of breathlessness, introducing notions of heritage, inheritance and shared humanity as breath is recognised, as one participant puts it, as 'our most human experience.' A shared experience that nevertheless is defined by ambiguity, diversity and individuality.

As Christy recalls, for some members of the general public sessions it 'brought a memory of a serious breathing difficulty and also specific to Durham as it often brought in memories of mining and industrial heritage. It's as if we had to go through the lungs to memory.'

In discussing the burden of living with an invisible illness such as breathlessness, participants also shared stories of isolation, invisibility and concern about the precarity of their health. They

also commented on the lack of understanding, empathy and urgency amongst the public, funders and the medical community. The huge funding difference between heart and lung research also reflects public opinions about the invisibility of respiratory conditions.

#### Inheritance

My great grandmother bound her hair in a cloth, Fine linen wound to worn clout, cured slight as air.

I fell heir to it in time: gauzy, gritten, Smoke snapped, the spectre of the coal man, bitter

Scent rising still, through the ghosts of black gold trade – Pit shaft and frayed seams for greener fields, purer shades.

It doesn't wind the same way for me, tethers Less, lets fly more without loosing memory.

I hold it up to the dewed winter sky's Upturned bowl of deep-breathing blue The way she lived then, The way I am now: Unveiled.

Rachael Barnwell

#### **Creating a Safe Space**

When engaging in participatory research, it is important to remain reflectively aware of the inherent power relationships between academic investigators/practitioners and community groups, both in terms of the project's role in offering a particular frame in which participants could develop and occupy a safe space, and the ways in which the project set a particular research agenda, timescale and structure. Christy explains:

I really appreciated working on a project that felt very much on their terms, even though we were offering the frame it was something that seemed designed by their experiences. It was very human-scaled. It felt very much a grass-roots project, which was nice because sometimes these things from large institutions can feel a bit imposed and I felt it was very much the opposite. (Christy Ducker)

Additionally, the project and in particular the project team, was responsive and attentive to participants' needs extending from transportation arrangements, location proximity for workshop venue to timings and scheduling. Nevertheless, important learning moments occurred in relation to how everyday spaces and situations can aggravate experiences of breathlessness (e.g. air freshener in ladies' room, smell of paint). According to Jade, working within such a project offers you an appreciation of 'How simple things and what is normal in everyday (...) is not okay in these situations. But even to yourself. Working with them has made me realise how careful you need to be with what you're breathing in and where you are.'

#### The Test of Time

Time was identified as an important parameter and a significant challenge on three levels: participant recruitment, project delivery and project duration. According to Jade, 'No matter how much time you have you'll always need more. Definitely more time to establish relationships, more time with the group and more time with different types of groups.'

As Jade explained, the team had initially planned to work with two or three Breathe Easy groups across the North East. As they were already collaborating with a Breathe Easy group on a related dance project, they ultimately opted to reach out to different groups and institutions across County Durham and Newcastle-upon-Tyne, hoping to attract a more varied range of backgrounds and experiences (*i.e.* support groups, mining associations). However, insufficient time to establish those relationships, and ultimately the project's linguistic focus on how individuals experiencing breathlessness can express themselves, led to prioritising particular voices. As Jade explained, 'In either case you want to prioritise the quality of the engagement and the interactions, the networks that you create throughout the project. More time would have allowed more sessions with the Breathe Easy group members and potentially would have involved more voices in the poetic process, as the majority of poets were female'.

Christy explained how she tried to develop an ex-mining community of individuals who might have suffered industrial injury or disease. However due to lack of time and lack of existing networks and contacts, in the end she worked only with Breathe Easy group members.

Time was also a challenge in relation to the project's evaluation process. The evaluator had to collect testimonials or conduct interviews after the workshop sessions, which in many cases proved more challenging due to participants' schedules. Equally, the evaluator was aware of participants' potential fatigue and therefore conducted shorter interviews (15-20 min) than originally planned and with fewer Breathe Easy group members.

#### **Ending Well?**

An important ethical consideration that emerged following completion of the workshops with the Breathe Easy group, was the after-care responsibility and the exit process. As Christy reflected, 'when you become emotionally invested, it is difficult to just leave it.' From the outset of the project, the parameters were clearly explained to all participants in relation to time-scale, activities and outcomes. Nevertheless, as Christy observed it can be quite complex to finalise engagement with such an emotionally invested project.

Letters from people in the group and people asking 'Are we going to see you again?' It just feels unfortunate but it's always understood. But this is what happens I suppose when you become emotionally invested, it is difficult to just leave it. But then I suppose on the other hand, there is the work: there is their body of work, there is the work Kate and I did and I suppose that remains there as a thing to articulate. It is a shame when you can see how you can do more, explore other angles or you might be able to tease out the potential to have an even broader impact in the everyday world. (Christy Ducker)

#### A New Way of Talking about Breathlessness?

It is important to recognise that the new vocabulary that emerged through this process was predominantly located within the safe space of the creative programme. Perhaps, the next step for participants might be to reveal what is normally hidden with new audiences, such as clinicians, families and friends.

Possibly yes, although I'm still, other than talking to people in the group/involved in project, I'm still not that keen on bringing up the subject to other people. I think I might do now but as I said you are always conscious you don't want to be a moaner or a complainer but if someone asked me directly I certainly would feel a bit more able to express it. (L. H. Interview response)

In many ways, the transformative potential of this project moved beyond the idea of a new language and instead emerged as the confidence to resist invisibility and find the words to describe one's lived experience. As Jade suggests:

In terms of this idea of new language it was a bit adventurous. (...) you are creating a third language [poetry] that could potentially not be understood. It is not so much about the language, but more about the confidence of writing, that poetry it has given to those people, to talk about [breathlessness] and to maybe even face up to clinicians. (...) I think a lot of time with that sense of invisibility the problem is that you don't have control over it. The idea of invisibility is sort of dominating and even if you give someone 10 seconds of confidence that might be all they need to speak out and express themselves or change the way someone sees them. (Jade Westerman)

#### A New Way of Talking about Breathlessness? (Cont'd)

For Christy, participants' engagement also allowed a sense of validation and a re-negotiation of power relationships:

It's making you more mobile, more nimble within power relationships. I think if you can talk about your experiences and advocate for yourself and then you're not a sitting duck any more so wherever you position within the social system, your relationship to power is going to be changing and hopefully improved. Slightly more agency involved. If you have the words. Because you 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. (Christy Ducker)

Like any other genuine participatory project, there were certain practical and ethical limitations in terms of participant recruitment and not having adequate time for relationship building or additional engagement sessions. Nevertheless, the project allowed a deep and meaningful conversation with individuals experiencing breathlessness through inviting them to occupy a new narrative space and discover a language that allowed them to uncover words and metaphors to represent their experiences. In doing so, they experienced validation and recognition, assumed their role as experts on their own bodies, breath and words. Although the project is complete, there is scope for future engagement to further develop the relationships with the Breathe Easy group and their body of work.

#### **Conclusions**

The overall aim of this project was to help visitors, particularly those who have personal experiences of breathlessness, engage more deeply with the exhibition and the underlying research. The hope was that seeing their personal experiences reflected in creative writing would help people affected by breathlessness feel heard, validated and empowered. The poems and quotes shared here present a compelling case that this has been achieved, although perhaps only within the safe space of the support group. Sharing their experiences with friends, family, healthcare professionals and the wider world is still a challenge, but perhaps one that the Life of Breath project can facilitate.

The responses from the public workshops show that, when visitors engage with the exhibition and the personal stories of breathlessness, their empathy and understanding increases. The Life of Breath project research has already revealed the gulf between the way breathlessness is experienced and the way it is medically defined and discussed (Macnaughton & Carel, 2016; Malpass et al, 2019). These poems provide new insight into the lived experience of breathlessness and a renewed mandate to share these stories.

This report demonstrates the impact on the participants in this programme, but that is far from the end of the story. The poems are already feeding back into Life of Breath research and will now be shared as widely as possible. They will be used to open up conversations with healthcare professionals and the wider public, to challenge the assumptions, stigma, shame and blame laid on the breathless.

# Outputs

- 1. A collection of poems by participants of the General Public workshops.
- 2. A collection of poems by participants of the Breathe Easy Support Groups.
- 3. A reflective blog post by writer-in-residence Christy Ducker on the public workshops. Available at <a href="https://catchyourbreath.org/making-the-invisible-visible/">https://catchyourbreath.org/making-the-invisible-visible/</a>
- 4. A reflective blog post by writer-in-residence Christy Ducker on the Breathe Easy Support Group workshops. Available at <a href="https://catchyourbreath.org/sharing-the-unshareable/">https://catchyourbreath.org/sharing-the-unshareable/</a>
- 5. Two short films *The Secret* and *To Breathe* produced by Christy Ducker and Kate Sweeney. *The Secret*: <a href="https://www.youtube.com/watch?v=dqnyawxtmdl">https://www.youtube.com/watch?v=dqnyawxtmdl</a> and *To Breathe*: <a href="https://www.youtube.com/watch?v=41-yLaSfRpo">https://www.youtube.com/watch?v=41-yLaSfRpo</a>
- 6. A blog post by Exhibition Project Officer Jade Westerman on the project's films *The Secret* and *To Breathe*. Available at <a href="https://catchyourbreath.org/the-secret-to-breathe/">https://catchyourbreath.org/the-secret-to-breathe/</a>
- 7. A conversation piece between Christy Ducker and Kate Sweeney reflecting on the production of their two collaborative films (forthcoming via <a href="https://catchyourbreath.org">https://catchyourbreath.org</a>)
- 8. A series of printed postcards featuring poems by Breathe Easy Support Group members

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### Catch Your Breath

Through objects, visual, sound, interactive materials and event, the Catch Your Breath exhibition tells the story of how our relationship with and understanding of the breath has developed over time, from ancient philosophers who equated breath with life itself to the latest advances in medicine.

The exhibition launched in Durham, at Palace Green Library (24 Nov 2018 – 17 Mar 2019), before moving on to Royal College of Physicians in London (2 Apr – 21 Sep 2019) and venues in Bristol (24 Sep 2019 - 28 Feb 2020).

The original Catch Your Breath project team was led by Sarah McLusky (Project Manager), David Wright (Curator), Jade Westerman (Project Officer) and Carolyn Gaw (Designer). Catch Your Breath as funded by Wellcome, via the Life of Breath project, with additional support from Durham University, Bristol University, the Royal College of Physicians and other key partners.

