

Let's Talk About Cough

A Public Engagement with Research Project
Project Outcomes & Lessons Learnt

"It is because cough is familiar, because everyone gets them now and again and because everyone has a bad cough once in a while, it is because people think that they know and understand cough, that it isn't taken seriously. [Chronic] Cough is trivialised, brushed under the carpet, dismissed and belittled, because it's 'just a cough'".

Let's Talk About Cough project



Dr Lesley Paterson and Dr Louise Webb
Mesh Associates, May 2024
External Evaluators for the *Let's Talk About Cough* project

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In Brief

Let's Talk About Cough is a public engagement with research project exploring *Chronic Cough*.

This engagement project is coupled to the research project, *What is the role of ATP in driving Chronic Cough?*, investigating the biology of cough and potential new treatments. One of the key aims of *Let's Talk About Cough* is to raise the profile of *Chronic Cough* by sharing diverse stories, knowledge, and perspectives in creative ways.

Following the initial scoping phase, the second phase of the project brought a small community of people with lived experience of *Chronic Cough* together with those who engage with cough professionally, either as a researcher, clinician and/or healthcare provider. These participants shared their knowledge and perspectives in creative ways through a series of online workshops and activities to exchange stories about cough, facilitated by a cohort of engagement practitioners.

The third phase of the project brought together a sub-group of the participants to develop and deliver the plans, outputs, and activities to share their stories of *Chronic Cough* to wider public audiences. The key output was an Immersive Audio Production called '*One in Ten*': a 30-minute narrated audio recording featuring the participants' stories.

The fourth phase of the project, taking place in 2024, will engage wider audiences through a variety of engagement activities.

Let's Talk About Cough is led by the University of Manchester in partnership with Imperial College London and is funded by Wellcome. The evaluation was led by *Mesh Associates*, a consultancy that enables and supports knowledge exchange and engagement.

Chronic Cough

A cough that has lasted for more than 8 weeks is known as a *Chronic Cough* and affects around 12% of the population, although for some individuals it can last for decades. At the start of the *LTAC* project, no widely available cough treatments had been proven to be more effective than honey and lemon.

Let's Talk About Cough, Project Documentation

'Let's Talk About Cough aims to raise the profile of Chronic Cough as a condition to be taken more seriously. We want to tell the story of Chronic Cough far and wide. What Chronic Cough is, how we understand it, what it feels like, what it's like to live with and how it affects people.'

Ellen Dowell, Creative Producer, Introduction to Workshop 1, Story Exchange

Box 1: **Public Engagement with Research** refers to a range of ways of engaging members of the public with the design, conduct and sharing of research. High-quality engagement is a two-way process with the goal of generating mutual benefit between the public and researchers. Public Engagement with Research is part of the wider spectrum of [Knowledge Exchange](#), which can be defined as a ‘*collaborative endeavour that translates knowledge and research into impact in society and the economy*’.

The *Let’s Talk About Cough* project was underpinned by the following key approaches:

- Multi-directional engagement between those with lived experience of *Chronic Cough*, cough researchers, healthcare professionals and engagement practitioners.
- A focus on storytelling to share personal and professional knowledge, reflections, and experiences of *Chronic Cough*.
- Using creative activities to support the participants in narrating and sharing their stories.
- A collaborative way of working for the development of the wider public engagement outputs and activities.

Box 2: ‘The **vision** of *Let’s Talk About Cough* is to raise the profile of cough as a condition to be taken seriously by researchers, patients, healthcare professionals and the public. We aim to generate multidirectional engagement, bringing together these four groups to share knowledge and perspectives about: the experience of cough; the biology of cough and the treatment of cough.’

Professor Jaclyn Smith (University of Manchester) & Ellen Dowell (Creative Producer), Provision for Public Engagement Grant Application, 2017, Wellcome Trust

1.0 Introduction and Context

1.1 Welcome

Let's Talk About Cough began with a funding application, written in early 2017. Back then it wasn't called *Let's Talk About Cough*. We didn't settle on a name and an identity until midway through 2021. It wasn't just the global pandemic that caused delays - although this definitely had a big impact. Participatory engagement takes time. And a genuinely participatory process also needs flexibility and freedom. Planning is important but there comes a point when you have to trust the process and see where it takes you.

Many things have changed since that original funding application. Plans have been reimaged and reinvented. Our process has adapted, evolved, and grown. What has remained throughout is a commitment to creativity, creative skills, and creative methodologies, alongside the equal participation of people who live with cough and people who work to understand and treat cough.

Seven years on, this project and the community of people created along the way, are still going strong. We remain on a journey together, to talk about cough. We have created engagement experiences about cough that we are proud of and that we are ready to share with the world. We are looking forward to asking others to join the conversation.

It is a privilege to be part of *Let's Talk About Cough*. We are hugely grateful to the participants who have shared their stories of both life and research with such generosity and commitment, to the creative collaborators who have brought their skills and care to the process and the engagement experiences, to Vocal whose expertise and support for lived experience participants were vital, and to our external evaluators for capturing the essence of a messy and complex thing. All of which could not have happened without the generous support of Wellcome who have funded this work.

You can explore www.letstalkaboutcough.net to find out more and listen to our immersive audio experience, *One in Ten*.

Ellen Dowell, Creative Producer for *Let's Talk About Cough*

Professor Jacky Smith, Lead Researcher for *Let's Talk About Cough*

1.2 About this report

This evaluation report captures the project's key outcomes, to date, in addition to its successes and challenges. It illustrates the many benefits of adopting a creative approach to facilitate public engagement with research and has recommendations for what could be improved with regard to future projects of this nature. It has been written particularly for those that are part of the wider research community and who may be 'engagement-curious' and thinking of developing their own work in this area, in addition to those who already have engagement experience and may benefit from our shared learning.

A heartfelt thank you to all of the people that took part in this evaluation – your time, insight, expertise, and reflections are hugely appreciated and are so valuable. Thanks also to the *Let's Talk About Cough* Team for being so open and inviting an independent evaluation of your work and ways of working, and for the many thought-provoking and interesting discussions along the way.

Dr Lesley Paterson, Director, *Mesh Associates*

Dr Louise Webb, Consultant, *Mesh Associates*

1.3 About the *Let's Talk About Cough* Project

Let's Talk About Cough is a public engagement project that was funded by a Wellcome '[Provision for Public Engagement](#)' grant (ca. £166k) in 2017. The aims of the scheme¹ at that time were to provide funding for those with an existing Wellcome research grant (see Box 3) to: engage the public with Wellcome research in a compelling way; develop Wellcome researchers' public engagement skills and expertise; create and strengthen partnerships between Wellcome researchers and the public; explore different ways that engagement can enhance research; create ambassadors for engagement within research fields and organisations.

Box 3: *Let's Talk About Cough* is coupled to the Wellcome-funded research project - ***What is the role of ATP in driving Chronic Cough?***: for many people with a *Chronic Cough*, the nerves controlling cough may be overactive due to the presence of Adenosine Triphosphate (ATP, the chemical source of energy at the cellular level) in the airways. Previous studies had shown that a treatment that blocks the effect of ATP on these nerves improved the condition by 75% in those with a *Chronic Cough*. The aims of this research project are to: understand why this new treatment works in some individuals and not others; develop tests to understand which patients and types of coughs might respond best to this new treatment; and to explore other potential new treatments for *Chronic Cough*.

Professor Jaclyn Smith (University of Manchester) and Professor Maria Belvisi (Imperial College London) Investigator Awards in Science, 2017, £2.9M, Wellcome Trust

The development and delivery of the *Let's Talk About Cough* project can be divided into four key stages:

Stage 1 - Project Scoping (2019–2021): including 2 x face-to-face **Exploratory Focus Groups** in Manchester with **Lived Experience Participants** and **Research & Healthcare Participants** to share *Chronic Cough* experiences and to explore expectations, priorities, and ideas for the engagement programme.

Box 4: The **aims** of *Let's Talk About Cough*:

‘Through a process of multidirectional engagement, bringing together researchers, people with lived experience, healthcare professionals and the public, we aim to:

- Stimulate reflection and conversation about the experience, sensation and feeling of cough, the impact of cough on quality of life and the social stigma surrounding *Chronic Cough*.
- Generate interest and curiosity through creative engagement with the biological mechanisms of cough: the protective function of cough, the role of the nervous system and the brain in cough, and the role of ATP in cough.
- Initiate discussion and debate about existing cough treatments, novel research exploring new effective treatments for cough, and how those treatments work.’

Professor Jaclyn Smith (University of Manchester) and Ellen Dowell (Creative Producer), Provision for Public Engagement Grant Application, 2017, Wellcome Trust

Stage 2 – Story Exchange (2022): A series of online sessions, developed and facilitated by the **Engagement Practitioners**, including the Creative Facilitators who were recruited to ensure a range of skills, including poetry, creative writing, story-telling, and comedy. The team used a range of creative techniques to enable the **Participants** to unearth, articulate and share their perspectives and experiences of *Chronic Cough* with one another:

- **Lived Experience Participants:** those with personal experiences of *Chronic Cough* (i.e. as an individual with the condition or that is close to someone with the condition, such as a family member).

- **Research & Healthcare Participants:** those with professional experiences of *Chronic Cough* (i.e. researchers, research students, clinicians, and health professionals).

'Step one is to understand the story of Chronic Cough. We need to build a really rich picture of what Chronic Cough is, from different perspectives, from different people, different viewpoints, different lives, different experiences, different ways of understanding cough.'

Ellen Dowell, Creative Producer, *Let's Talk About Cough* Project

Story Exchange Workshop Series Overview

All workshops included: a scene-setting introduction; terms of engagement; an introductory ice-breaker activity; group work and sole activities to explore and share the biology, treatment and impact of *Chronic Cough*; an interim break; and time at the end for reflections, feedback, and next steps.

Workshop One

- Getting to know each other, hopes and expectations
- Creative Activities

Workshop Two

- Exploring Unique Perspectives
- Creative Activities

Workshop Three

- Exploring New Insights
- Creative Activities

Workshop Four

- What is our story of *Chronic Cough*?
- Who do we most want to share our story with?
- How will we share our story?

Stage 3 – Scoping, Development & Production (2022 – 2023): The core **Engagement Practitioners** worked in collaboration with a sub-group of the **Story Exchange Participants** (including those with lived and professional perspectives on cough) to develop resources and activities to engage a wider public audience with their stories of *Chronic Cough*.

‘Through exchanging diverse stories about Chronic Cough in creative ways, we will gain a rich picture of Chronic Cough. We will then decide: What are the most important stories to tell about Chronic Cough to a wider public audience? What creative approach is the best way to convey stories about Chronic Cough to a wider public audience? Who are the most important people to reach with these stories?’

Story Exchange Participant Information Document, 2020

The key output was an **Immersive Audio Production – ‘One in Ten’**: a 30-minute narrated audio recording featuring the Participants’ stories on the biology, impact and treatment of *Chronic Cough*. The team also developed and delivered a pilot to engage wider publics with the Immersive Audio Production as part of a series of one-hour live events at the Great Exhibition Road Festival (GERF), London.

Stage 4 – Engagement (2024): This part of the project focuses on raising awareness and debate on *Chronic Cough* with wider audiences via online means and through festivals and conferences. In the words of the Project Team and the Participants, the aim, is 'to create empathy and understanding about *Chronic Cough* and its impact on people's lives'. These activities are taking place in 2024.

Evaluation: The evaluation has been embedded throughout the *Let’s Talk About Cough* project. The formative evaluation was carried out by both the external Evaluation Team and the Project Team, and explored the successes and challenges as the work progressed, enabling ongoing reflection and continuous improvement throughout. The summative evaluation for Stages 1, 2 and 3 was led by the Evaluation Team and focused on gathering data and evidence to understand the project’s outputs, outcomes, impacts, successes, challenges and what could be improved with regard to future engagement work of this nature. Evaluation of Stage 4, in which wider public engagement will take place, will be led by the Project Team utilising some of the tools created by the Evaluation Team. **This report provides a summary of the findings from the summative evaluation to date.**

2.0 Outcomes and Impacts

The following section focuses on the key outcomes and impacts of the *Let's Talk About Cough (LTAC)* project to date, noting that activities will continue throughout 2024 and further outcomes and impacts will no doubt arise. By outcomes and impacts, we mean in what ways has *LTAC* influenced and resulted in changes, on whom/what and why.

2.1 Academic impact: benefits to Researchers and Healthcare Professionals

A total of **19 Research-Healthcare Participants** (RH Participants) took part in at least one *LTAC* activity¹. The findings below focus on the **12 RH Participants**² that had a deeper and longer-term engagement with the Project through taking part in the **Story Exchange**, in addition to other activities. Further details on the make-up of this cohort³ are as follows:

- 12 participants with research and/ or clinical practice and/or healthcare roles
- 8 from the University of Manchester/ Manchester University NHS Foundation Trust and 4 from Imperial College London
- A mixture of career levels and roles including: PI/ senior academic/ clinician; research associates; clinical/ research fellows; speech/ language therapist; technicians and PhD students
- The majority of participating researchers/ research students were directly involved in the research project on which this engagement work was based – the Wellcome Research Investigator Award, *What's the Role of ATP in driving Chronic Cough?*

The **motivations** for the **RH Participants** to get involved encompassed: interest in public engagement; to increase their engagement experience, including with creative approaches; to engage with patients; and awareness of the expectations of the funder to take part in engagement activities:

We were really keen to do some public engagement and so we jumped at the chance. In terms of what we've done before, I'd call it more traditional public engagement.....where we do events and present to patients and involve patients in the design of our studies.....but never done anything like this. That's certainly my first time with poets and comedians, it's completely different!

RH Participant, Focus Group

¹ This includes one or more of the following activities: Evaluation Workshop; Exploratory Focus Groups; *Story Exchange*; Scoping, Development & Production; GERF Pilot (See Section 3.0 for further details). Data Source: Project Team's spreadsheet tracker: participant attendance and engagement.

² This does not include the one research student who joined the project for the first workshop only.

³ Data source: Project Team's spreadsheet summary: researchers/ healthcare professional key details.

I think it's so important to hear directly from the patients and really important to get a wider range of thoughts and opinions and views from the patient.

RH Participant, Focus Group

We [as Wellcome-funded researchers] are encouraged to do some public facing and engagement work.

RH Participant, Focus Group

One of **key benefits** for the **RH Participants** from taking part in *LTAC* was gaining **new, rich, nuanced and diverse perspectives, increased knowledge and understanding on *Chronic Cough***. Participation also increased RH Participants' understanding on the variety and significance of the **negative impacts on overall quality of life** and how it **impacts on individuals in many different ways**. In particular, there was increased awareness on the negative impact of LE Participants' social and family lives due to cough's auditory nature. This increased understanding, in turn, resulted in **greater empathy** from the RH Participants for those with the condition.

All the RH Participants that completed the online survey (n=10 from a total of 12, 83% response rate) stated that their participation provided them with new perspectives and increased knowledge and understanding on *Chronic Cough*. Further qualitative evidence is provided below:

I learnt about how the condition is so variable from person to person, and the significant debilitation faced and loss of enjoyment of life.

RH Participant, Online Survey

*Even though I've seen patients with *Chronic Cough* for about 20 years now, it still expanded my knowledge of how it affects people and how they perceive their cough. It's quite different to the interactions that you have with patients in the clinic or even when they take part in the research, this was yet another way of interacting with patients that does give you a different perspective.*

RH Participant, Summative Focus Group

As a researcher I am not in contact with the patient as my colleagues are that are clinicians. It was a surprise for me to see the violence of the disease and how violent it was on the patient's quality of life.

RH Participant, Summative Focus Group

Anything that helps maintain and increase your empathy with patients is good and it certainly does that.

RH Participant, Summative Focus Group

One RH Participant also gained awareness with the regard to the people who were not yet accessing the healthcare system for their cough:

One of the scoping focus groups was in a more socially deprived area of Manchester with patients whoI don't think any of them had, ever been near a Cough Clinic in their lives! And it really struck me that they were describing the exact same problems that the patients in the clinic are describing, but they're not accessing healthcare in the same way. I thought, oh, good grief, there's loads of people out there with this problem who are just not even in our line of sight because they don't know how to negotiate the healthcare system.

RH Participant, Focus Group

Having a broader perspective and enhanced understanding of the social impacts of cough and greater empathy resulted in further benefits to the RH Participants professionally. RH Participants reported that it put their **work into context**, and **reinforced** the **relevance** and **importance** of **what they do**. This, in turn, resulted in a feeling of **enrichment** and **increased motivation** and **enthusiasm** for their work. This was for both those that were patient-facing and those who focus on basic research or working with animal models and rarely got the opportunity to interact directly with patients. Furthermore, several of the RH Participants noted that they were **changing their practice** as a result.

A massive boost in motivation to pursue research....the motivation was there but there is a massive boost when you engage. It's given me a boost to achieve a lot and get a better outcome for every patient.

RH Participant, Focus Group

You get much more context for writing introductions to papers and other outputs by knowing and sharing the patient impact of cough.

RH Participant, Focus Group

I shared the poem that was developed by the participants with other cough professionals, such as those working in primary care and speech and language therapists. It improved their understanding of Chronic Cough and enhanced their training. So many people came back to me to say that it was so impactful, it really got across what it was like to live with a Chronic Cough.

RH Participant, Focus Group

For our patient assessments, I now give a bit more time so we don't just talk about the physical elements but the bigger impacts it's having on patients...and not only just the patients themselves....their families and friends and giving them the time to tell their story.

RH Participant, Focus Group

Before, when I am chatting to patients about research, I would be like 'we're doing this and this and this' and not waiting for anything to come back from them. While now...it's a much more open conversation.

RH Participant, Focus Group

Participation in the project also resulted in a **significant increase in understanding the value of**, and their **enthusiasm for, public engagement/ public and patient involvement** (PPI). Some of the RH Participants also reported **enhanced public engagement knowledge** and **skills**. Furthermore, they learnt about and appreciated the **benefits of creative approaches**, over more traditional public engagement/ PPI methods.

There is no question that it has increased my enthusiasm even further for public and patient events and to share what we've done with other researchers to encourage them to take some unusual approaches to [public and patient] involvement.

RH Participant, Focus Group

I want to include public engagement with every project we do - it raised awareness of what we do....as we live in an open world and we need to share what we are doing.

RH Participant, Focus Group

That was quite a challenge to talk to the public about something new and try and discover an aspect that may captivate..... and so they can relate to it. That was quite a challenge and also very good training.

RH Participant, Focus Group

I achieved/ am most proud of developing creative skills, explaining research to wider audience.

RH Participant, Online Survey

Other reported benefits included: **building relationships** between the **two research groups** (Manchester and Imperial); **new ideas for research**; and the **potential to influence** the **medical profession** and the **wider public** to appreciate the seriousness of *Chronic Cough* through sharing of the outputs from *LTAC*.

Linking with other researchers in a slightly less formal environment was really beneficial. I had met them [researchers in the other institution] briefly but had not met them a huge amount and this project enabled us to get to know one another both from a social point of view and in a fun way.

RH Participant, Focus Group

I gained new ideas for my research by speaking to the Chronic Cough patients, especially by hearing from them what different environmental stimuli acted as triggers for their cough.

RH Participant, Email Feedback

We have created something that we involved the patients in and that we can then enlighten the wider public and the medical profession more about their problem – which feels like quite an extraordinary thing really.

RH Participant, Focus Group

2.2 Research Impact: benefits to Lived Experience Participants

A total of 20 **Lived Experience' Participants (LE Participants)** took part in at least one activity in the Project⁴. The findings below focus on the **12 LE Participants** that had a deeper and longer-term engagement with the Project through taking part in the **Story Exchange**, in addition to other activities. The demographics of the **12 LE Participants** were as follows⁵:

- 10 had *Chronic Cough*; 2 had relatives or partners with *Chronic Cough*
- 7 Female; 5 Male
- Age range: 4 (60 – 69); 4 (50 – 59); 2 (70 – 79); 1 (40 – 49); 1 (20 – 29)
- Disability: 6 (no); 5 (yes) and 1 (prefer not to say)
- Employment status: 6 working; 5 retired; 1 unable to work
- Ethnicity: 8 British; 2 Asian or Asian British; 1 White Irish; 1 Mixed Background
- Region/ Location: 5 (North-west England); 2 (North-east England); 2 (London & Greater London); 1 (Scotland); 1 Midlands) and 1 (East of England)
- No. of years with *Chronic Cough*: 21 – 30 years (5 participants); 11 – 20 years (3 participants); 2 – 10 years (4 participants)

One of the LE Participants was also recruited as a **PPI Collaborator**, to provide advice, guidance, and feedback to the Project Team on their plans.

The LE Participants' **motivations**⁶ for getting involved were varied and included: to meet and be with others who have the condition; to help others; to learn more about *Chronic Cough* (biology, science, treatment etc); to gain support and advice and manage their cough better; to share experiences and perspectives; to support the research taking place; to engage the wider public about *Chronic Cough*.

To meet people that know exactly what you are going through, which is wonderful because you are looked at as a complete nutter in some respects[with people thinking] it's all in your mind!

LE Participant, Focus Group

It's the attitude of the general public that takes any normal life away for coughers and takes their happiness away.....it's those type of things I wanted to help...so [for someone else] to hear someone cough and not immediately jump out their seat....or stick up their hand to say 'keep

⁴ This includes one or more of the following activities: Exploratory Focus Groups; Story Exchange; Scoping, Development & Production; GERF Pilot (See Section 3.0 for further details). Data Source: Project Team's spreadsheet tracker: participant attendance and engagement.

⁵ Data source provided by the Project Team: Excel spreadsheet that summarised the content from the Expression of Interest forms and Interview notes.

⁶ Data source: Expression of Interest forms; Recruitment Interviews; LE Participant Focus Group.

your distance!'.

LE Participant, Focus Group

I have been fighting this on my own with no advice help or support from the doctor. I sort of took it on myself....when I first saw the advert it was just major pull for me....this is going to be the place where I can get some information....and sort of start my journey.

LE Participant, Focus Group

Came in with an open mind, researching into understanding more about Chronic Cough, and was not thinking I am going to get a miracle cure.

LE Participant, Focus Group

All of the **LE Participants** that completed the online survey (9 from a total of 12, 75% response rate) reported that they had **increased their knowledge** as a result of their participation in the project. This comprised of a **variety of learning outcomes** including increased understanding on: the biology and science of *Chronic Cough*; *Chronic Cough* research, including how the research is conducted, potential treatments and avenues of study; new and different perspectives and experiences of *Chronic Cough*; and for one, the realisation that it is a recognised condition. Furthermore, the project supported a number of participants to **make sense of and articulate their own personal story** of *Chronic Cough*.

I didn't even know what Chronic Cough was.

LE Participant, Focus Group

I learnt about the various avenues being explored by the professionals to try to find good treatments to help with and ultimately cure Chronic Cough.

LE Participant, Online Survey

They are trying to develop some sort of treatment that they can block the brain signal....so the brain does not say 'cough – you've got a cough again'. I just hadn't thought along those wavelengths and thought 'wow this is like science fiction stuff!'. That was really, really interesting.

LE Participant, Focus Group

I learnt about the biology of cough. I had no idea and the complexity of the receptors within the lungs, or how much it was a nerve-based function.

LE Participant, Online Survey

I am proud of the creative work that helped me develop a sense of how to articulate [how] I was living with cough, what cough is like for me, and what matters to me.

LE Participant, Online Survey

In terms of experiential outcomes, the majority of **LE participants** respondents (7/9) had, overall, **very positive experiences** and reflections on the project using adjectives to describe their experiences or the project as: *'fun'*; *'enjoyable'*; *'amazing'*; *'laughter'*; *'glad'*; *'lovely'*; *'interesting'*; *'brilliant'*; *'wonderful'*. The **LE Participants** reflected how they felt they were in a **safe, open, and trusted space** in which they developed a **strong sense of community**. They also valued the camaraderie that resulted through sharing their experiences, felt **supported** and that it was **beneficial**:

The workshops flew by. I hadn't expected to have fun and enjoy myself but I did.

LE Participant, Online Survey

This whole 3-month experience has been absolutely amazing. I would like to thank each and every one who has been involved in the running and preparing the group. You all have done an amazing job and helped so many people on their journey. I will never forget the help, support and understanding that I have received THANK YOU ALL.

LE Participant, Online survey

I am so glad that we did this together, trusted one another, were open and vulnerable, laughed together, had really warm, caring supportive facilitators who looked out for every person.

LE Participant, Online Survey

The main word that comes to mind straight away is support because that is what I have got so much of from everyone concerned.

LE Participant, Focus Group

Two of the **LE participant** respondents had found the activities/ workshops either more challenging or less enjoyable than the other participants:

I think had I understood the format of the project I may not have agreed to take part. Given that, I am glad I have completed the four sessions although I don't think I have been as enthusiastic or got as involved as some of the other members of the group.

LE Participant, Online Survey

For the majority that had positive outcomes and experiences, this led to **other positive outcomes**, whereby the increased knowledge and understanding, together with the camaraderie and support, resulted in many participants feeling that they are **no longer alone**; and several participants reporting one or more of the following: an increase in **confidence**; **empowerment**; more **hopeful** and **positive** and/ or more **resilience**.

I learnt about other people's experiences. I'm not alone. To have hope.

LE Participant, Online Survey

Beginning to understand this has helped me have a much better sense of what is actually happening in my body. It makes it less frightening, and have a stronger sense of being able to live/work with and know how to try and ameliorate it.

LE Participant, Online Survey

It's brought much confidence out of me, as you do all these things and then you have to talk to people and tell them all about it....that's the top thing that has changed about me....the confidence.

LE Participant, Focus Group

I can put into context that I have been doing this, and I've been trying to find answers, and that there are other people like me. So, yeah, it has been empowering and enjoyable.

LE Participant, Focus Group

I have discovered how empowering they [the workshops] can be, when before I was a little afraid and unsure of whether I could really do it. I think they have the capacity to really improve wellbeing and quality of life when

Furthermore, a small number of participants were keen to point out that the **impact** on them has been **significant**, and in at least one case, life-changing:

Thank you for letting me be part of it, it has had quite a significant impact on my life. I feel more hopeful for the future now in lots of ways.

LE Participant, Online Survey

I can't express enough how much confidence I have got from it. The knowledge that I've now got has, it has, its completely changed my life. It's a major step forward. I feel like I've been on this journey for many, many years, over 15 [years], but now feel that my journey has only just started. Because now I've got that confidence to go back to my doctor, which I am going to do next week actually.

LE Participant, Focus Group

It is only now that doing the course that I see actually I am very strong person. And I have defied this cough, and I don't think I would have thought like that [previously]. Only an incident a few weeks ago when I was on a course and I was coughing. A lady said 'you, you are probably going to give everyone Covid and I can't stand it and I am leaving.' I stood my ground and said 'I am not infectious. I have not got this; I have not got that. I have a Chronic Cough.' And she said 'oh you're talking rubbish', and out the door she went. I hard-faced it out and I don't think I would have done that [if I hadn't been engaged in this project]. You know, that's quite something.

LE Participant, Focus Group

2.3 Research Impact: benefits to the Engagement Practitioners

The **Engagement Practitioners**⁷ also benefitted from their participation in the project by building capacity in public and patient engagement in one or more of the following ways: **developed** or **learnt new creative engagement approaches and techniques**;

⁷ 1 x Creative Producer, 1 x Patient Involvement Practitioner and 5 x Creative Facilitators

enhanced their **engagement practice, facilitation skills** and **experience** in effective **online engagement**; an **increased understanding** of **using arts** to help **engage people** with **health-related** topics; **learning** with regards to the **communications** and **marketing** of engagement projects and **recruitment** of participants; or increased their experience with regard to providing participant **pastoral support**. Some of the **Engagement Practitioners** have already utilised what they learnt in other projects, and in one case, shared their learning with colleagues in their organisation.

I learnt a lot from other facilitators about different methods and also new exercises to try - especially visual.

I've written [for] lots of different genres, but I've never written for immersive audio and that was fun. And that was good you know to listen to a different genre and get to know it and give it a go. And that's a different kind of set of writing skills to writing for other genres, but it was good for my learning.

I would never have used the improv stuff in my workshops, but I've actually used that since in workshops with young people and felt confident to be able to do that in a way that I probably wouldn't have been able to before. So, that was great.

In terms of supporting people, it's definitely been a learning for me, but it's a learning that I passed on to my team as well.

I definitely enhanced my facilitatory skills during the programme, working with XXX, XXX and the co-facilitation team has been a joy, although a challenging and at times a process filled with lots of uncertainty, it has also been incredibly rewarding. It's allowed me to ease up more and be able to go along for the process of the creative journey, and be adaptable to what that process brings.

All quotes: Engagement Practitioners, Online Survey or Focus Group

The Engagement Practitioners also **increased** their **awareness** and **understanding** of *Chronic Cough*, its significant negative impacts, and developed **empathy** towards those who had lived experience of it. They had a **greater awareness** of it as a condition, **increased their knowledge** of the **science** relating to cough and the **research** into its treatment, and also the **impact** on those carrying out *Chronic Cough* research.

I learnt so much about cough from both those with cough and those researching it. I learned a huge amount of both medical and scientific information which I did not know and the huge impact and emotional effect it has on people's lives.

I also learned a lot about cough, the triggers, the experiences people have in society especially since COVID, and some of the research that is going on and how difficult that is due to the many different types and triggers for cough.

All quotes: Engagement Practitioners, Online Survey or Focus Group

3.0 Piloting the Public Engagement Activities

THE GREAT EXHIBITION ROAD FESTIVAL

A series of *LTAC* engagement events took place as part of the [Great Exhibition Road Festival](#) (GERF), to pilot the activities for the wider public engagement programme, which aims to target ‘everyday people who spend time in everyday places’.

- GERF is a free annual public festival celebrating science and the arts that takes place in South Kensington, London.
- 7 x 60 minute *LTAC* public engagement events, entitled ‘[Not Just A Story: Aliens, Avalanches & ATP](#)’ took place on Saturday 17 and Sunday 18 June 2023 in the members’ library of the Royal Geographical Society. Each session had a maximum of 20 places, with a recommended age of 14yrs+.
- A library setting was purposefully selected (which is also one of the preferred venues/ settings going forwards for future events), reflecting the aim to reach ‘everyday places’. This was also to support the immersive audio experience which uses a library setting to set the scene - for example, the narrator asks listeners to think about “all the stories within the books” that surround them. It was also chosen as a place where quiet or silence is expected, which is challenging for someone with *Chronic Cough*.

‘Purpose: to create an immersive audience experience that feels like walking in the shoes of people with Chronic Cough and researchers working on cough, and to share the story of Chronic Cough through creative and artistic excellence.’

LTAC Public Engagement Brief

- At the event, the attendees listened to the Immersive Audio Production via headphones, to hear the *Chronic Cough* stories through the voices of the LE Participants and RH Participants along with guidance from the narrator. Attendees were also provided with a small notebook as additional stimulus material and to jot down any comments.



- The attendees were then invited to take part in informal discussions on *Chronic Cough* with a small number of the LTAC LE Participants and RH Participants that were present, and to reflect on the event.
- A total of 58 festival-goers took part in the events over the two days, along with members of the LTAC Project Team. Attendees were a mixture of festival-goers who booked in on the day (on a first come, first served basis) and those that had been invited by a member of the Project Team.



- Reflections were captured using feedback postcards, observations, and flip-chart notes from the small group conversations. 50 postcards were completed over the weekend.

- The summarised findings from the postcards are provided below and for context - ca. 20% were completed by the LTAC Project Team, LE and RH Participants, who were also in attendance and participating in the events.

- The majority of participants had **positive experiences** and **reflections** (see Figure 1) in which they found the event interesting, informative, and educational.

Really enjoyed the interactive experience with audio, listening to stories & the way it was done, was amazing.

I had no expectation of this event, but found it fascinating.

GERF attendees, Feedback Postcard

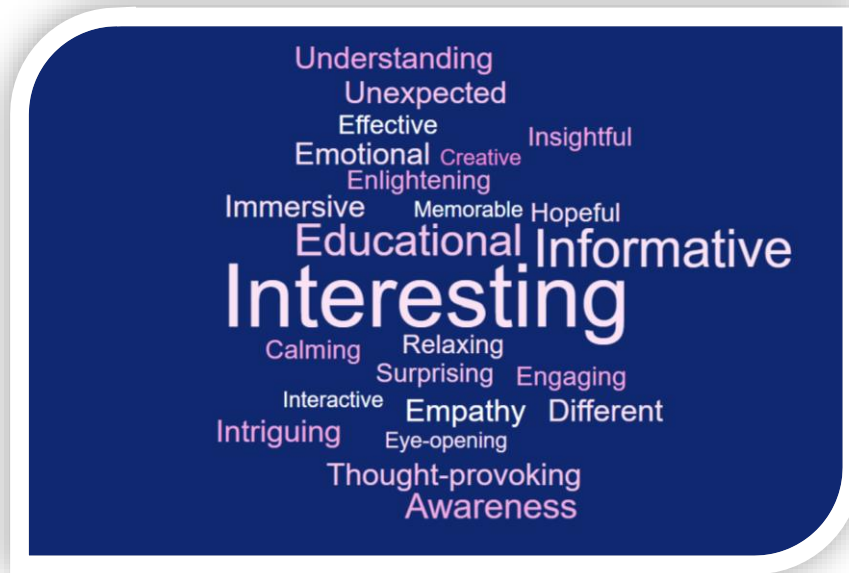


Figure 1: Word Cloud showing the Feedback Postcard responses to ‘What three words best describe your experiences?’. Words shown are those mentioned at least twice; the larger the word the more frequently it was mentioned.

- A number of participants also described the event as a calming and absorbing environment *“helping a lot to immerse yourself in the experience”*.

I wasn't sure what to expect. I wasn't familiar with the subject. Found it a relaxing exercise in a safe environment.

Voice over was so calming! Great way to introduce to CC. Really felt for the people who had CC.

GERF attendees, Feedback Postcard

- The majority reported that they had learnt about the treatment, science, and experiences of *Chronic Cough* (see Fig. 2). Attendees also noted in the open comments that they had learnt about the impact of cough on people’s lives and were surprised by how long people could suffer from it, and how this had brought the ‘subject to life’. A small number of attendees (n = 4, ca 8%) reflected that they didn’t really understand the activity.

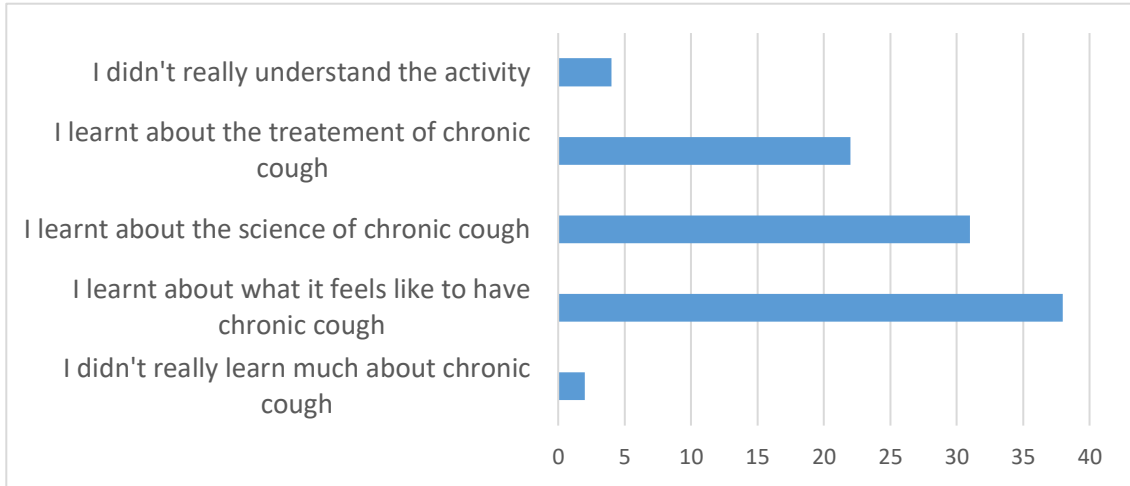


Figure 2: Bar Chart showing the Feedback Postcard responses to 'What best describes what you have learnt, if anything, about Chronic Cough.' Total responses = 50

*Enjoyed listening and walking about and following the notebook.
Surprising hearing the experiences + what people go through with
Chronic Cough.*

*The anecdotes integrated into cough's scientific learnings help me
better understand its impact on lives.*

*Great that the subject matter is brought to life with real people. Adds to
the reality of the issue.*

*I wasn't aware about Chronic Cough and its lasting effects on people,
especially that it can last for decades.*

GERF attendees, Feedback Postcards

- 7 Attendees expressed an appetite for more information on the science, research, and treatment of *Chronic Cough*:

*Would prefer to learn how new treatment works + science than
peoples' experience - when you also have a chronic condition it's not
new to hear stories like these.*

GERF attendees, Feedback Postcard

4.0 Successes, Challenges and Lessons Learnt: recommendations for future projects

LTAC has had many demonstrable successes, with strong evidence that the project has achieved its anticipated key outcomes to date and made significant progress towards its objectives to date, noting that the project is ongoing.

Analysis and synthesis of the findings provides strong evidence that the project's **successes** were underpinned by **two 'critical enablers'** (see 4.1.1. and 4.1.2.), in addition to a number of other **key enablers** that, when combined, resulted in the positive outcomes reported in sections 2 and 3. This section also summarises the **key challenges** faced, and **lessons learnt**.

The aim of this section is to provide insights and recommendations for those **thinking about** and **planning future public engagement and community engagement activities**.

4.1 Key Ingredients for Success

4.1.1 Skilled and experienced Engagement Professionals

The cohort of very experienced, highly-skilled, and creative Engagement Professionals, including the Creative Producer that led and coordinated the project, was a **critical enabler** to the project's success, resulting in the following fruitful project processes and outputs:

- An in-depth, effective, and targeted marketing and recruitment process that resulted in a cohort of committed and enthusiastic **LE Participants** and **RH Participants** (see also 4.1.2)
- A thoughtful and well-designed engagement process throughout.
- A responsive and flexible approach, together with the experience and capability of the **Engagement Practitioners**, enabled the project to not only *proceed*, but to *succeed*, despite the huge challenges faced by the Covid-19 pandemic. For example, the team took the decision to make fundamental changes to the original plans for face-to-face regional-based engagement to online UK-wide engagement.
- First-rate facilitation of the sessions and development of the highly-effective creative activities enabled both **LE Participants** and **RH Participants** to share their personal and professional stories of *Chronic Cough*. Furthermore, the **Engagement Practitioners**, as a group, had a diverse range of skills and

experiences to bring to the project including poetry, creative writing, story-telling, and comedy, which paid dividends.

It felt safe and felt confidential and felt very well 'held' by the team – in terms of the time boundaries, managed nicely and safely, and the structure - there was a beginning and middle and end....and the actual approach of the [facilitation] team... it felt like a good safe space.

LE Participant, Focus Group

I thought the facilitators were so good.....not pushing people too much. I also it felt like a very friendly environment and no one was going to judge you.

RH Participant, Focus Group

The online LTAC sessions were consistently fun and very well organised. Often a highlight of my day.

RH Participant, Focus Group

This whole workshop was amazing as everyone had the opportunity to join in, say their bit and be a part of this awesome project.

Participant, Phase 2 Online Survey

Actually recognising that facilitation is important to create safe spaces was really good, and also employing experienced skilled facilitators as well I think was really helpful in that.

Engagement Practitioner, Focus Group

I think we need to mention the specific skills of the Story Exchange facilitators - creative writing, poetry, storytelling, comedy and visual storytelling. The specific creative expertise of these skills are part of the successes/enablers. Acknowledging the creative disciplines, approaches and skills that were key to the project's success is important.

Project Team, Written Reflections

The qualitative feedback from the Participants and Engagement Professionals above, is corroborated by the findings from the observations of the workshop sessions by the Evaluation Team:

There was a clear, structured and fairly ambitious agenda together with good time-management; all the planned activities within each workshop were achieved.

The facilitators demonstrated empathy, support and active listening and utilised lots of questions and prompts to encourage people to share their experiences. Lots of encouragement to share was given and to share in different ways, but without putting the participants ‘on the spot’. Did move the conversation on when required. Made it clear that everyone’s views and creative writing was valued and valid.

The sessions were a mix of ‘serious’ and ‘fun/ light-hearted’ activities, but the latter were always meaningful [e.g. create your own ‘cough monster’ – which revealed additional understanding of the participants’ perceptions of cough]. This mix was perceived to have enabled the session participants to be ‘lifted’ after discussing very personal sensitive/ challenging topics – there were strong indicators that mix of serious and fun was a key ingredient to the success of the workshops.

Having three facilitators per online workshop worked really well. It was very clear on who was leading each part of the session, they supported each other throughout and had clearly defined roles. For example: one facilitator provided the verbal introduction; as another contributed to the ‘chat’; while the other took notes.

Extracts from Observation Notes, Evaluation Team

4.1.2 Committed and enthusiastic LE Participants and RH Participants

The cohort of dedicated and willing **LE Participants** and **RH Participants** was another **critical enabler** of the Project’s success in which the participants:

- engaged deeply with the Project, and embraced the creative and storytelling activities, even when this was out of their comfort zone;
- were very open and shared their creative outputs and personal and professional stories of *Chronic Cough*, actively listened to each other, and were very considerate of and supportive of one another;

- brought a diverse range of perspectives and experiences on *Chronic Cough*;
- were fully committed and stayed engaged throughout the Project.

A key success was the stories shared....the incredible openness of participants and facilitation by experienced creative practitioners.

Engagement Practitioner, Email Feedback

I thought the nature of the relationships between the LE participants and the researchers/medical professionals was warm, amicable, empathetic, trusting and curious; all in all, excellent.

RH Participant, Email Feedback

It's all been enjoyable, the methods that they used and workshops we've had had throughout. When I heard about the craft side and comedy workshops, I thought 'oh dear what have I let myself in for!' But having going through it... it was brilliant really....

LE Participant, Focus Group

The qualitative feedback from the Participants and Engagement Professionals above is backed-up by the observations of the session by the Evaluation Team:

Many participants were keen to engage and come forwards with their personal stories and views and emotions – including both positive and negative – and the majority seemed confident and keen to 'step-up' and share with a very open heart/ attitude. All participants contributed and while one or two were often quick off the mark to share their stories/ thoughts – it did not appear that anyone was particularly dominant.

Extracts from Observation Notes, Evaluation Team

There are strong indicators that the two **critical enablers** above, in turn, resulted in the following **key enablers** (which can also be thought of as process outcomes), which together contributed to the Project's successes:

- **Effective creative activities and good power dynamics**

The **creative activities** were **highly effective** in providing diverse ways to support the Participants in unearthing, articulating, and sharing their experiences and stories of *Chronic Cough*. The findings indicate that the creative activities were also a ‘**leveller**’ between the **LE Participants** and the **RH Participants**, resulting in nearly everyone being out of their comfort zone - in a positive way. This was felt by some to have helped towards the Project’s aim to have **equity** across these two stakeholder groups with regards to power dynamics, and to counteract the sometimes (mis-)perception that the researchers and health professionals are the ‘experts’. When of course those with Lived Experience are also expert in their own condition, but with a different forms of knowledge.

Enjoyed every minute, loved doing the creative tasks.

LE Participant, Online Survey

Because we were all out of our comfort zone, both the researchers and the LE participants.....I think that really helped as well because everybody was just in the same boat and I think it really helped to kind of level things up.

RH Participant, Focus Group

I am most proud of creating genuine creative exchange between two groups of participants with very different perspectives, without an obvious power imbalance, and with an incredible level of openness and generosity of participation - and that it all happened online!

Engagement Practitioner, Online Survey

There were a whole variety of different creative activities, tasks and techniques utilised, enabling participants to engage in different ways e.g. pictorially; writing; visualisation; verbally etc.

Extracts from Observation Notes, Evaluation Team

All participants took part in telling, sharing and exchanging cough stories. In workshop 3, the majority were very proactive and confident in doing so - several participants noted that their confidence grew over the workshops and other sessions. Very good indicators that the creative activities were instrumental in helping LE Participants articulate and share their stories.

Extracts from Observation Notes, Evaluation Team

- **A safe, open and trusted space**

Another key enabler is that excellent facilitation together with a very engaged participant cohort, who embraced the project's 'terms of engagement', all contributed to the *LTAC* project feeling like a **safe, supportive, and entrusted space** – the latter is with regard to trust both in each other and the process. There is excellent evidence that this led to the building of **good to excellent relationships** and a **strong sense of community** (between all three stakeholder groups – the LE Participants; RH Participants and the Engagement Professionals) and enabled the perceived ease in which they **shared their stories**. Furthermore, all three stakeholder groups were not afraid **to try new approaches, experiment and take risks**: whether this was changing the creative workshops to be online; trying new facilitation techniques; taking part in the creative activities (no matter how unusual); and sharing very personal, and sometime saddening, experiences. Interestingly, for several of the LE Participants, **being online** enabled them to **open up** in ways that they felt they would not have been able to, had they been in a face-to-face environment.

When you are a patient and you're going to the doctor's, there is a different relationship, it's a doctor-patient relationship. But as soon as I joined this project, it was just such a non-judgmental, safe space that you could really be yourself within it and not kind of, you know, there was no awkward moments.

LE Participant, Focus Group

Being asked to leave a restaurant is quite shocking and upsetting for sure. I think if I was in a room full of people, I might have been more visibly emotional [in telling this story], with all these people staring at you. You can tell it without as much emotion..... step back.....online helped in that respect.....

LE Participant, Focus Group

Some of them [creative activities] did seem a bit whacky and you did wonder how am I going to relate to this and how am I going to tell a story! But that was really good as sometimes things came out, that verbally you would not share that well, but if you had to draw something or write a poem and things came out of that and that was so much better to share things.....

RH Participant, Focus Group

Success was creating a supportive space in which people could experiment safely and connect with other people who had had similar

experiences to them and share their stories in powerful ways.

Engagement Practitioner, Focus Group

Noticeable how far the group has come since the first workshop, the trust that has built up between participants and the familiarity with creative approaches such as free writing.

Engagement Practitioner, Facilitators Reflective Diary

- **Depth of Engagement**

Participants were also keen to point out that it was due to the depth and length of engagement that enabled these **strong** and **trusted relationships** between the different stakeholders to develop. This, in turn, contributed the production of the **high-quality collective key project outputs**, in which there was a **shared sense of ownership**, that captured the diverse range of *Chronic Cough* perspectives and stories. The key project outputs included:

- The *Story Exchange* synthesis of the LE and RH Participants' *Chronic Cough* stories, curated by the Creative Producer.
- The Poem that captured the Participants' diverse stories, produced by the Creative Facilitators.
- The co-developed Immersive Audio Production – *One in Ten*.

Having time to work together and get to know each other was actually really important, I think, and meant that that was taken seriously.

Engagement Practitioner, Focus Group

It good to meet up with the same people who make you feel confident to share your thoughts.

Participant, Phase 2 Online Survey

The way that is organised – that is on the long term – and many meetings – it helps a lot and to develop relationships with people – much richer; profound and deeper outcomes; and more 'human' – it was not mechanical re: you just talk about research or medication.

RH Participant, Focus Group

- **An ethical approach**

Another key finding was that there was a clear commitment to ethics that was evident throughout *LTAC*, with the Project Team identifying potential issues and having a plan to address these and being very proactive in this regard. Activities included:

- Clear internal communications about *LTAC* and its approach, and, just as importantly, what the Project was not about. For example, it was not to provide medical advice. At least one RH Participant found this challenging in the beginning, but was able to overcome this due to the guidance and the equitable relationships that developed:

Sometimes I found it hard to keep out of your professional role at the beginning, when people tell you about their problem and you get that itch to suggest something or help. I think one of the ways that the project really worked was that you built relationships with everybody over time; and that got that out of the way and settled down and then it did it feel a lot less like a professional relationship.

RH Participant, Focus Group

- Seeking informed consent with the participants, regarding their engagement, personal information use and privacy.
- The provision of pastoral care for the LE Participants, anticipating that they would be sharing/ revisiting some negative experiences when reflecting on the impact of *Chronic Cough*.
- The Terms of Engagement that were developed, articulated, and restated at the start of each creative workshop.
- Encouraging participants to share their stories and creative outputs, but not ‘pushing’ them to do so.

I thought the way that the sessions were handled by the facilitator, I was up for anything! I felt that they handled it really well and careful and you can share what you have drawn or written or not.

RH Participant, Focus Group

An emotional session, participants made themselves quite vulnerable in their writing, we would not want to push this vulnerability any further.

Engagement Practitioner, Facilitators Diary

I felt very proud of the accessibility and safeguarding considerations

we made to make the groups feel as included as possible, hearing everyone's feedback was incredibly valuable.

Engagement Practitioner, Feedback Form

We thought very carefully in advance and shared a lot of different views about how we create that safe space. Having things like the breathing space room and ground rules and that kind of thing. It took quite a long time over that and thinking about how do we create a space that power, not just the power dynamic between the researchers and the LE participants, but also we thought about the power balance between the facilitator and the participants. ...we discussed all that quite carefully and we were given the time to do that.

Engagement Practitioner, Focus Group

4.2 Lessons learnt

The following section draws from both the challenges, successes and lessons learnt into a set of recommendations for future projects:

4.2.1 Recruitment of Lived Experience Participants

Recommendations

- **Plan your recruitment process very carefully** – achieving a targeted, highly-engaged committed cohort that meet your selection criteria and embrace the activities will pay significant dividends.
- Keep a **record of the selection process** including taking notes on which selection criteria that each 'applicant' met/ partly met/ did not meet, and take notes where other factors came into consideration. This will not only provide clear evidence to make the final short-listing decisions on who to invite to participate, but also provides a transparent record of your selection process.
- Once the short list of who to invite to participate is created, **review the demographic make-up** of your **cohort**, and **compare** this against those that were **not selected – before deciding on the final list of participants** to be invited. This will ensure that your selection criteria did not, unintentionally, create a barrier for any particular demographic groups. If the latter does occur, remedial action can be taken if appropriate, to then decide on the final short list.

LTAC Lessons Learnt

Marketing and recruitment of the **LTAC LE Participants** was a thoughtful, well-planned, and thorough process with agreed selection criteria.

Shortlisting was done based on how long people had had a cough, what the impact of cough was for them, why they wanted to be involved and if they were able to attend daytime workshops. 16 people were interviewed.'

Data source: Documentation – Vocal: activities & recruitment & challenges [Word.doc] sent to the Evaluation Team in Sept 2022

This resulted in an engaged and committed cohort with the required attributes and evident diversity across a number of demographics.

One key success was that we included a diverse range of patients and staff.
RH Participant, Focus Group

However, following completion of the *Story Exchange*, an analysis of the demographics of the LE Participants selected to take part (n = 12) was compared with those that had also submitted an EOI but were not selected (n = 11). The findings indicated that one of the criteria (coughing for 2+ years) had been a barrier to some of the BME individuals being selected. This was because those individuals that were BME were less likely to have had a cough of > 2 years. However, this was not known at the time of shortlisting, as the demographic analysis only happened once the *Story Exchange* had been complete, as part of the interim evaluation. Had they known at the time, one member of the Project Team reflected that they would have taken remedial action as a result, to enable more BME individuals to participate. Most importantly, they saw this as a learning point for future projects.

I think I would have loosened it [i.e. the selection criteria re: coughing for 2 years+] also because, you know, what is a Chronic Cough? How long does it have to have been there? It's all a little bit arbitrary that stuff. So, I wouldn't have felt that was something that we needed to be so rigid about on reflection. You do want [participants to have had] a Chronic Cough, not just somebody who felt cold a couple of weeks ago, obviously. But, you know, I think one year, two year it's all a bit

muchness really.
Project Team Member, Focus Group

Other Project Team members were keen to note that they felt those with over 2 years of lived experience of *Chronic Cough* was also an advantage, given the longevity of their condition and the powerful stories they were able to share:

I think that the stories that we needed to generate needed that longer life experience of understanding what it is to live with Chronic Cough
Engagement Practitioner, Focus Group

The following questions can be used to help identify your target participants and audiences and to shape recruitment plans:

- *Who do we want to reach?* This can be in terms of demographics; the ‘hats’ people wear (e.g. parent, patient, carer, pupil, activist); interests and attitudes or other characteristics, attributes and considerations (such as capacity to attend the activities). Remember, there is no such thing as the ‘General Public’ – be as specific as you can. Thinking about ‘who’ you want to engage is critical to planning meaningful engagement work.
- *Why do you want to reach these particular individuals/ groups/ communities?*
- *What is the best way to reach these individuals /groups/ communities?*
- *Why would these individuals /groups/ communities want to engage?*
- *What is the participant selection criteria? Why?*
- *Who is responsible for developing and delivering the recruitment and marketing process and for supporting the participants throughout?*
- *Who could be excluded from taking part and are there ways to overcome this?*

4.2.2 Equity and power dynamics

Recommendations

- During the project scoping and planning phases, and prior to any engagement taking place, **think carefully about any potential power imbalances**

beforehand that could develop across different groups of stakeholders, and how to avoid, overcome or lessen these, and facilitate equity. If differences do occur once engagement is underway, put plans in place to aim to address these.

- Be realistic about how much of a ‘one single’ united community can be created – it may be natural for the similar **stakeholders** (e.g. LE Participants) to have **more affinity with one another**, while still being able to have a coherent community as a whole.
- Consider how to **encourage researchers to share their experiences** in their stories, and not ‘just’ the science; and aim to ensure that they see their stories as equally valuable as those of the LE Participants.

LTAC Lessons Learnt

Interestingly, while some engagement activities find that power dynamics can be skewed towards research participants rather than those with lived-experience, this was not the case for the *LTAC* project. Indeed, there were some indicators⁸ that the converse was true – with some of the **RH Participants** seemingly deferring to the **LE Participants**. For example, during workshop observations, some always responded to the LE Participants’ stories, rather than proactively sharing their own stories and experiences. The **Engagement Practitioners** put plans in place to help change that dynamic and encouraged researchers to open up and talk about their own experiences and feelings around *Chronic Cough* (in addition to the science) and **to manage the balance of stories** being shared. There are good indicators to show this approach was effective, with the RH participants that took part in the evaluation all reflecting that they felt that they had their voices heard.

I thought the group worked well and mixed as well... obviously the coughers had very much similar experiences.

LE Participant, Focus Group

A challenge - researchers sometimes sat back a bit and were more reluctant to share stories at the start - this definitely eased up.

Engagement Professional, Focus Group

When you talk as a researcher – you do put your researcher cap on – and it’s very hard to remove it – it does not come easy.

RH Participant, Focus Group

⁸ Data/evidence source: observation of the online workshops conducted by the evaluators; Facilitators Reflective Diary and observations; Focus Groups.

I think that researchers did have equal opportunities to share their experience of working in cough, but much of the time (and rightly so) the conversations were more likely to be about what it was like to live with Chronic Cough.

RH Participant. Focus Group

Finding different ways to allow space for the research and the science to have its own space within the project became one of the ways that we created the balance. So, it didn't always have to come within each individual workshop and sometimes it was important to do more listening.

Engagement Practitioner, Focus Group

4.2.3 Internal and external communications

Recommendations

- Set up **Project Team meetings** to bring together all the key individuals involved in development and delivery (e.g. the PI, Engagement Professionals, Evaluators etc) to keep everyone updated on progress and plans, and to discuss successes, challenges, and issues.
- Consider the benefits of including a team member with the specific role of **Project Manager** to bring together all the different strands of the Project, keep track of the proposed timeline and to identify and raise awareness of any anticipated gaps or issues.
- Plan your **external communications and social media activities** at the outset.

LTAC Lessons Learnt

Internal communications for the LTAC project were **challenging** given: the open-ended/ participatory nature of the project; the numbers of people involved with a whole variety of roles and different stakeholders involved in different stages of the project; and the breadth and depth of the responsibilities of the Creative Producer, who was responsible for overall coordination and communications in addition to the creative aspects.

While multiple meetings took place with the different groups of stakeholders, the project would likely have benefitted from a team member with sole responsible for **Project Management**, in addition to occasional **Project Team meetings**, that brought all the key members together for project management updates and discussion.

So it's a project that has had lots of peaks and troughs in terms of intensity of work and phases. And it hasn't always been possible to do everything we wanted to do in each phase, because there just wasn't the time.

Engagement Practitioner, Focus Group

The [internal] communications were quite difficult to manage. Because there was the volume of stuff coming out, and it was a little bit confusing I think for some people getting their head around all.... the different days and different tasks and what am I supposed to be doing this and when we need to be here, and what link am I following? You know, there was a lot of information, and it was quite difficult to get the comms right.

Engagement Practitioner, Focus Group

Creation of a **website** and **social media** activity had been planned to take place early on in the Project, but due to various challenges faced, the website was launched in March 2024. However, it was felt by some Participants and Team Members that this was one area that the Project could have been improved:

One thing that was too late – was the website. We did talk about it a good lot and what to put on it and the content and think that should have come first, even before we started the engagement even before we started to engage. So the public had access and had a forum – they could put their thoughts on there- that would have helped a lot I think during the whole process. Access to social media as well – it should have come first.

RH Participant, Focus Group

I didn't want to share much on social media without the 'official' account being there. It would have been great to document and share the process online as the story exchange developed (e.g. in a blog/ social media posts) but I know there were key resource issues and logistical issues connected with capacity to build this and the need to prioritise the workshops/ info gathering etc that meant that this simply wasn't possible.

Engagement Practitioner, Focus Group

4.2.4 Format of the activities

Recommendations

- Ensure that there is contingency within the engagement sessions with the participants to allow time for **'breathing space'** (i.e. time for people to collect their thoughts) and **to allow for longer discussions, when required.**
- Consider and discuss the best way to receive or respond to negative experiences that were saddening and challenging for the Participants, and 'tune in' to what seems to suit which participants in terms of how to respond.
- Discuss and articulate the 'pros' and 'cons' to online engagement and face-to-face engagement, before deciding which may work best for your project, or whether a mixture of both would suit.

LTAC Lessons Learnt

The engagement sessions and workshops were highly effective and very positively received. Lessons learnt for improvements for the future are in reducing the number of activities per session, allowing for some discussions to reach a 'natural end' and responding to the Participants' stories in which they had had a challenging experience. For example, while the facilitators were highly regarded, it was noted from several LE Participants that they would have preferred more of a 'straightforward' response to some of their *Chronic Cough* stories, rather than receiving *'sympathy'* or being described as *'beautiful'*.

[Would have preferred]..... more time to discuss things. Some activities triggered a lot of conversation, it would have been nice to be able to carry some of those on.

Story Exchange Participant, Workshop Feedback

Seemed a little rushed on occasion and feeling that participants could not reach the end of their thought processes/ mini-journeys before moving to the next task.

Extracts from Observation Notes, Evaluation Team

I tried to tell a story about my cough...now we can all clear a train carriage but that must have come to a bit a shock for them [the facilitators] – [me] being screeched [at like] that and being asked to leave restaurants. The facilitators didn't expect that and they did feel for me...but no – I am not telling you the story for sympathy!

LE Participant, Focus Group

At times – there was a wee bit – too much – ‘it’s wonderful...wonderful...’. You are trying to offload yourself and then told its beautiful and wonderful – and you thought –‘it’s not’!

LE Participant, Focus Group

Running the majority of LTAC sessions **online** was very effective and had many benefits including:

- LE Participants reporting that it enabled them to be open and share their stories.
- RH Participants noting that it was a time-effective way to engage (i.e. no travel time etc.) and easier to fit into their working day.

In terms of access, the Project Team reflected that the online approach had both pros and cons, noting that it can be a barrier to some (e.g. without a laptop/ Wi-Fi access or IT skills) but can also open up access for others. In the case of this project, it enabled those from across the UK to engage, as opposed to the original pre-pandemic plans for face-to-face activities, which would have been for those based in Manchester or London. Furthermore, as mentioned earlier in this report, some of the LE Participants found it easier to open up in an online session.

It also helps in terms of finding the time – find a couple of hours in the middle of day – you could still do what you wanted to do rather than plan the whole day – so much easier to do.

RH Participant, Focus Group

We did really well to get the diversity that we did, but I think there were voices that were missing. People from those underserved communities and, yeah, people who might have struggled with accessibility, so people who were put off by it being online.

Engagement Practitioner, Focus Group

Online workshops can also help access in some ways, especially for people with mobility issues, and for geographical spread and rural areas; there were some people in the Story Exchange who wouldn’t have been able to attend if it was an in-person exchange. I agree that it was a totally different project online and that this affects access in complex ways.

Engagement Practitioner, Focus Group

4.2.5 Public engagement activities

LTAC Lessons Learnt

The pilot GERF events were deliberately marketed without mentioning *Chronic Cough* in the title as a way of being intriguing people and encouraging those who may have had the perception that there would be of little interest in this condition. However, the selected title, '*Aliens. Avalanches & ATP*', had mixed reactions from the attendees, with some agreeing that it led to them not knowing what to expect but being pleasantly surprised, and others feeling it was misleading or off-putting.

I had no expectation of this event, but found it fascinating.

GERF Attendee, Feedback Postcard

Surprised it's about cough (regarding the title)

GERF Attendee, Flipchart Feedback

'Aliens' was off-putting, scared it was sci-fi but enjoyed it. Needs a subtitle relating to cough specifically.

GERF Attendee, Flipchart Feedback

Learnt something new. Title of the workshop is misleading. New experience.

GERF Attendee, Feedback Postcard

As a result, the Project Team has changed the title of the immersive audio experience to '*One in Ten*, reflecting the approximate proportion of people who have *Chronic Cough*. One team member also noted that there may be occasions in which it would be beneficial to be explicit about the subject matter.

The digital version of the audio experience that [is] hosted on the website is the key way that we can share the piece with anybody who is interested in Chronic Cough. I think it's still really important that when we're reaching our target audience of 'Everyday People and Everyday Places' in libraries and community libraries next year, that we stick to our guns about the not putting Cough in the title and intriguing people in different ways, because that was the target audience.

Engagement Practitioner, Focus Group

I think there are opportunities that we could specifically target people with Chronic Cough. I think it would work very well for that and in contrast to the more of general ways we're trying to highlight Chronic Cough to the public and people who mainly don't know about it and will think it's not very interesting.

Project Team Member, Focus Group

5.0 Inputs and Outputs

5.1 Funding:

- 1 x Wellcome **Provision for Public Engagement grant** (£166k)

5.2 Key People/ Organisations:

- **Research Institutions:**
 - **University of Manchester** and **Imperial College London**.
- **Engagement Practitioners:**
 - 1 x **Creative Producer**: overall lead for the development and delivery of the *Let's Talk About Cough (LTAC)* project.
 - 1 x **Patient Engagement Specialist**: recruited the LE Participants and provided pastoral care for these participants; supported workshop facilitation.
 - 5 x **Creative Facilitators**: co-developed and co-facilitated the *Story Exchange*; also led the writing and narration of the script for the Immersive Audio Production.
- **Participants:**
 - A total of **22 Lived Experience Participants** and **19 Research-Health Participants**, including the PI (who also had a key role as a member of the Project Team) took part in the Project.
 - One of the Lived Experience Participants was recruited to the project as the **PPI Collaborator** to provide the Project Team with guidance.
- **Evaluation Team:**
 - 2 x **External and Independent Evaluators**.
- **Creative Collaborators:**
 - 1 x **Composer**; 1 x **Sound Designer**.
- **Communications Team:**
 - 2 x **Graphic Designers**; 2 x **Communications Consultants**

Exploratory Focus Groups - Storytelling Activity Example:

Participants were asked to bring an object, photo, or prop to help share their story of *Chronic Cough*. Participants were put into pairs to share their stories, using the prompts that they had brought.

5.3 Timeline of Activities

November 2019: 1 x **Evaluation Workshop** (half-day, face-to-face) to co-create the **Evaluation Framework**; 8 x contributors [2 x Evaluators, 3 x Engagement Practitioners; 3 x Researchers].

February 2020: 2 x **Exploratory Focus Groups**ⁱⁱ (face-to-face, 2 hours each) took place in community venues in Manchester to share and reflect on *Chronic Cough* experiences and to explore expectations, priorities, and ideas for the engagement programme. 20 x Contributors [3 x Engagement Practitioners 10 x LE Participants; 7 x RH Participants].

Spring 2020 – Summer 2021: Project put **on hold** due to the Covid Pandemic.

Autumn 2021: **Review** and **updating** of the **plans** and **timeline** for *LTAC*, in light of the pandemic situation - the original plans for face-to-face regional workshops were changed to UK-wide online sessions. **Draft communications strategic plan** created, and logo developed (see right). **Recruitment** of the Creative Facilitators.

January - February 2022: Story Exchange Participant Recruitment and Development

- **LE Participants** were recruited to take part in the **Story Exchange** through targeted marketing, submission of an 'Expression of Interest' online form, interviewing the long-listed candidates and a selection process to short-list the final participants to be invited to take part. LE Participants were provided with £450 to compensate them for their time on the project. A total of 23 LE individuals applied to take part in the *LTAC* project by completing an EOI form; of these 16 were interviewed by telephone and 12 participants were selected to join the workshops.
- **RH Participants** were recruited from the two cough research teams in Manchester and Imperial and their Health Professional colleagues; time on the project was as part of their salaried roles.



Story Exchange – Storytelling Activity Example

Participants were asked to imagine if *Chronic Cough* was a **monster** and to draw their creature. Prompts to help with the task included: What would it look like, feel like and smell like? What does it do, say, and how would it move?

Descriptions included: 'a slimy alien from another planet'; 'big, black, spikey, gooey and with an empty heart'; 'double-headed alien that is sly and mischievous'; 'a dust-ball that zips around with a goal to be annoying'. Participants used their creations to further explain their experiences of *Chronic Cough*.

- **Five online workshops** involving the **Engagement Practitioners** took place to develop plans, ideas, and approaches for the *Story Exchange* and to support each other and share skills/ experience.

March 2022 – June 2022: The **Story Exchange** took place which comprised a series of online activities in which participants shared their experiences of *Chronic Cough*:

The **core Story Exchange** programme consisted of **24 online Creative Workshops** (2 hours each) via Zoom:

- 4 Workshops took place for each of the 3 groups of 8 participants (4 x **LE participants** and 4 x **RH participants**), designed and facilitated by the **Engagement Practitioners** (typically 3 per workshop).
- The participants took part in creative activities, in plenary or breakout rooms, and shared their stories through their creative outputs, feedback, and discussion.
- Activities included creative writing, freewriting, poetry, and drawing.
- Participant attendance for each workshop was between 83 – 100% across all 3 groups (20 to 24 participants).
- No LE Participants dropped out of the Project; and only one RH Participant dropped out after attending the first workshop.

The following **optional activities** enabled participants to continue their engagement with *the Story Exchange* in a variety of ways, and to meet one another from across the three groups.

- **Story Conversations:** These facilitated online 1-hour one-to-one conversations took place between one LE Participant and one RH Participant, enabling more in-depth and intimate discussions.
- **Comedy Workshops**
- **Visual Storytelling Workshops**
- **Story Exchange Socials:** 8 x One-hour online sessions took place: informal chats with some creative activities included. A facilitator was present but there was no agenda.

Creative Workshop - Storytelling Activity Example

Spiral of Cough Connections

Participants mapped the different people that they engaged with in their ‘everyday’ lives or were connected to their cough in some way. Using paper and a pencil, they mapped these connections out on an annotated spiral, with the closest connections near the centre of spiral (family, friends, colleagues); moving steadily outwards e.g. someone at a bus stop etc.

Participants then added notes to describe the experiences and interactions that they had with each of these individuals or groups, including both positive and/ or negative.

Participants were invited to share their ‘spiral of cough connections’ and their positive and negative experiences with each of these groups.

- **Story Exchange Tasks:** Participants were also invited to take part in a creative task individually and at home in their own time - a number of participants took part in these activities.

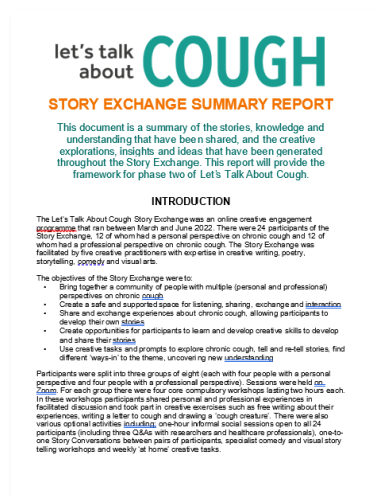
Session	No. of sessions	Total no. that attended
Workshop 1	3	24
Workshop 2	3	21
Workshop 3	3	22
Workshop 4	3	20
Story Exchange Socials	8	15 unique participants attended at least once; many attended several times. Total attendance = 15 participants attended a total of 43 times over 8 different sessions.
Comedy	2	7
Visual storytelling	2	6
Story Conversations	8	16

Table: Participant attendance – Story Exchange Activities

- ❖ **Key Collective Outputs from the Story Exchange:**
Synthesis of the Participants’ Chronic Cough stories, curated by the Creative Producer; **Poem** created by the Creative Facilitators.

July 2022 to November 2023: Scoping, Development & Production: exploring ideas, shaping, and planning the PE programme, development and production of the PE outputs and activity plans and piloting. The following sessions took place, with typically at least 2 facilitators and other creative collaborators as appropriate, along with the LE and RH Participants, for the development, recording and production of the Immersive Audio Production (e.g. Sound Designer or Composer).

- **Brief Setting Workshop** (3 hours, online) to develop a brief for the public engagement plans and discuss key priorities (n = 8 attendees).
 - ❖ **Key Collective Output: Public Engagement Brief** articulating the aims, key priorities, and target audiences for the wider public engagement programme.
- **Research and Development Day** (7 hours, face-to-face) to explore ideas in relation to the brief (n = 4 attendees).
- **4 x Development Workshops** (2 hours, online) to develop ideas and plans for the Immersive Audio Production (each one – 2 hours, online):
 - Introductory Development Workshop (n = 9 attendees)



- Sound Development Workshop – Sound (n = 6 attendees)
- Imagery & Metaphor Development Workshop (n = 7 attendees)
- Story Development Workshop (n = 7 attendees)
- Public Events Development Workshop (n = 5 attendees).
- **In Person Creative Decisions Meeting** (3 hours, face-to-face) to make key creative decisions about the audio artwork (n = 4 attendees).
- An ongoing series of meetings to discuss the work-in-progress, for script development, online recording sessions and editing.
- **Pilot of Immersive Audio Production - Great Exhibition Road Festival** (n = 7 attendees), followed by a debrief meeting.

❖ **Key Collective Outputs from the *Scoping, Development & Production* phase: Immersive Audio Production; 7 x Public Engagement Events.**

- **Due to demand and popularity, the *Story Exchange* Socials also continued during this Phase.** 8 x *Story Exchange* Socials took place, with typically 2 Engagement Practitioners (as facilitators) and with between 2 to 7 LE and RH Participants at each one, averaging 3 Participants per session.

6.0 Evaluation Approach

6.1 Evaluation – Background & Context

Mesh Associates was appointed to conduct an external and independent evaluation of the *Let's Talk About Cough* project. The evaluation has been embedded throughout the Project and was both formative and summative.

The overall aim was to collect data and evidence and enable critical reflection to support the Project Team in understanding the dynamics and effects of the project, including outcomes, and learn from their experiences.

The formative evaluation was carried out by both the external Evaluation Team and the Project Team, and explored the successes and challenges as the project progressed, enabling ongoing reflection and continuous improvement throughout. The summative evaluation for Stages 1, 2 and 3 was led by the Evaluation Team and focused on gathering data and evidence to understand the project's outputs, outcomes, impacts, successes, challenges and what could be improved regarding future engagement work of this nature. Evaluation of Stage 4 will be continued by the Project Team utilising some of the tools created by the Evaluation Team.

An evaluation framework was co-developed with the Project Team at a face-to-face workshop (November 2019), including development of a Logic Model that articulated the key stakeholders and beneficiaries and anticipated outcomes, in addition to a set of high-level evaluation questions (i.e. what did we want to find out and why?). The Framework was also shaped by the original vision, aims and objectives of the Project.

As this was a participatory project that would evolve, the plans for the evaluation approach, methodology and development of the tools

(example of the GEF attendee feedback postcard provided above) were iterative.

Once the Project was reinitiated following the Covid-19 pandemic, no fundamental changes were required to the overall Evaluation Framework, but changes were made in terms of the format of the evaluation methods and tools that were appropriate to the move to online.



6.2 Evaluation Strategy and Framework

6.2.1 Evaluation questions

The following five questions provided the focus for the evaluation:

Box 5: Evaluation Questions

1. Did the Project deliver the key anticipated outcomes on the researchers, healthcare professionals and patients (i.e. those with lived experience of *Chronic Cough*)?
2. Did the publics engaging with the activities increase their awareness of the experience, biological mechanisms, and treatment of cough?
3. What are the successes, challenges and lessons learnt with regard to the development and delivery of the Project? [Inc. exploring the impacts of the changes in approach e.g. pros/cons; benefits/ disbenefits of the move to online etc.]
4. Did the engagement result in enriching or enhancing the research in any way?
5. What is the legacy of the programme? [Inc. the following sub-questions: Did the researchers build capacity for public engagement? Were new collaborations and partnerships developed?]

6.2.2 Key stakeholders and outcomes

The key anticipated outcomes identified for the four priority stakeholder groups are provided in Section 9.

6.2.3 Evaluation methodology

The approaches, tools and data and evidence sources used by the Evaluation Team are summarised in the table overleaf:

Method	Activity
Evaluation Framework & Planning	<ul style="list-style-type: none"> • Workshop to develop the <i>LTAC</i> Evaluation Framework to agree the key priorities, outputs, outcomes and stakeholders and Evaluation Questions with the Project Team. • Development of an ‘evaluation and reflection’ framework and action plan specifically for the <i>Story Exchange</i> (that ‘sat within’ the <i>LTAC</i> Evaluation Framework and Plan), with input from the Creative Producer and Creative Facilitators at an online workshop. • Development of methodology, tools & resources, as the Project progressed.
Trackers	<ul style="list-style-type: none"> • Template metrics trackers created by the Evaluation Team for use by Project Team throughout the project to capture and track the demographics, engagement, and details on the following: Researchers, Healthcare Professionals, Patients/ Lived-Experience, Activities, Communications & Public audiences engaged.
Data Mining	<ul style="list-style-type: none"> • Mined documentation, data and evidence created/ collected by the Project Team as part of their activities to develop and deliver <i>LTAC</i>. These included: <ul style="list-style-type: none"> ○ Grant scheme and application documents. ○ Summarised and anonymised data from the EOI forms (including demographics); notes from interviews with those that had submitted an EOI. ○ Activity/ session/ workshop planning documents (e.g. Workshop agendas; communications plans; Slide-decks; Briefings; flipcharts from the GERF events). ○ Key <i>LTAC</i> collective Outputs: Synthesis of Stories; Poem; Immersive Audio Production. ○ Outputs from the Project Team’s formative evaluation (e.g. feedback collected after each online session, Creative Facilitators’ reflections diary). ○ Padlets that were created (e.g. used by the Engagement Practitioners and/ or Participants to share thoughts, creative outputs, content for inspiration and to brainstorm),
Observations	<ul style="list-style-type: none"> • Observation Topic Guide created for each session. • The Evaluators observed: <ul style="list-style-type: none"> ○ Scoping Focus Group 1 ○ Two <i>Story Exchange</i> workshops (workshop 3 of 4) for groups 1 and 3 for evaluation purposes and for the Evaluators to get a deeper sense of the nature of workshops; 13 LE and RP participants (out of a total

	<p>possible no of 16) attended the two observed workshops; in addition to 3 Creative Facilitators at each workshop.</p> <ul style="list-style-type: none"> ○ Workshop 5 - to develop the brief for the wider public engagement activities. ○ 2 x GERF Public Engagement Events. ○ ‘Informal’ observation of various meetings and communications between the Project Team, and with the Participants.
<p>Online Survey</p>	<ul style="list-style-type: none"> ● Created an online survey, with open and closed questions, to receive feedback from the LE Participants and RH Participants on their experiences, reflections, and outcomes from taking part in the <i>Story Exchange</i>. Platform used: www.onlinesurveys.ac.uk (hard copies of the survey were also available): <ul style="list-style-type: none"> ○ The majority of questions/ statements were open questions; and were phrased to feel ‘personable’ and in keeping with the nature of engagement interventions. ○ The survey was completed by 19 LE and RP participants [10 RP Participants: 9 LE Participants] from a total possible number of 24 at the end of the fourth and final <i>Story Exchange</i> workshop [workshop 4]. ○ There were at least six survey respondents each from Groups 1, 2 and 3. ● An Online Survey, similar to the one used for the participants, was also sent to the 5 Engagement Professionals who developed, delivered and facilitated the <i>Story Exchange</i> workshops – 5/5 responses received.
<p>Feedback Postcards</p>	<ul style="list-style-type: none"> ● Feedback postcards were created and designed by the Evaluators. These were used to gather feedback from: ● Scoping Focus Groups attendees. ● GERF event attendees.
<p>Focus Groups</p>	<ul style="list-style-type: none"> ● Semi-structured Topic Guides were created for each of the Focus Groups. All Focus Group participants were sent a document that introduced the purpose of the evaluation, privacy, how the data would be used and for their consent or otherwise. All Focus Groups were recorded and transcribed. ● The Evaluators conducted the following Focus Groups: <ul style="list-style-type: none"> ○ With the participants at the end of Scoping Focus Group 1 [in person]. ○ With LE Participants (n = 4, following the <i>Story Exchange</i> [online]; with at least one from Groups 1, 2 and 3.

	<ul style="list-style-type: none"> ○ With RH Participants (n = 5), including the PI, following the completion of Stage 2 (<i>Story Exchange</i>) and Stage 3 (<i>Scoping, Development & Production</i>). ○ With the Project Team (n = 5, including the PI; 3 x Engagement Professionals and PPI Collaborator). ○ Some Focus Group participants also provided additional responses/ reflections via email, following the Focus Group taking place.
<p>Analysis, Synthesis & Reporting</p>	<ul style="list-style-type: none"> ● Collation, summarising and synthesis of data and evidence: <ul style="list-style-type: none"> ○ Quantitative data was summarised, analysed and, where appropriate, visualised. ○ Qualitative data was coded and synthesised. ○ Quotes provided in this report were initially transcribed verbatim and then edited to increase readability, clarity and reduce longevity, without losing the original meaning. ● Key evaluation reporting outputs: <ul style="list-style-type: none"> ○ Evaluation Framework Workshop summary report. ○ Evaluation Framework & Outline Plan. ○ Short summary report for the Scoping Focus Groups. ○ Summaries from the Observations activities. ○ Focus Group Transcriptions. ○ Coding Frameworks. ○ <i>Story Exchange</i> Interim Evaluation Report (sent to the Project Team for them to reflect on the findings and discuss the recommendations for next steps). ○ Final Evaluation Report [this output].
<p>Ethics and Values</p>	<ul style="list-style-type: none"> ● The evaluation was underpinned by a commitment to ethics and inclusivity, including respect for the evaluation participants; communicating the purpose, anonymity, consent, and the right to withdraw; and to ensure that the work complies with GDPR. ● As a member of the UK Evaluation Society, the <i>Mesh Associates</i> follows their Guidelines for Good Practice in Evaluation, including a commitment to reporting the findings independently and objectively.

7.0 Next Steps for LTAC

The final stage of the Project is taking place in 2024 to reach wider public audiences. The aim, as articulated by the Project Team is, to engage ‘Everyday People who spend time in Everyday Places’. A brief summary is provided below and you can find further information from the LTAC website, that was launched on 7 March 2024:

letstalkaboutcough.net | [Bringing people together to explore and share experiences of chronic cough in creative ways.](https://letstalkaboutcough.net)

Box 7: Summary of the Public Engagement Brief

KEY AIM

To create empathy and understanding about *Chronic Cough* and its impact on people's lives

KEY PRIORITIES

- **Spark interest** about cough and cough research
 - **Raise awareness** about *Chronic Cough*
 - **Combat prejudice** and misconception
- **Engage emotionally** by sharing personal stories
 - **Engage flexibly** to reach diverse audiences
- **Represent hope** and **positivity** about cough research and future treatments

PRIMARY AUDIENCE

- Everyday people who spend time in everyday places

SECONDARY AUDIENCES

- People who experience *Chronic Cough*
- Family and friends of those affected by *Chronic Cough*
 - GPs and other healthcare professionals
 - Creators of art/ entertainment/ culture
 - An international, online audience

- **Communication strategy and plan for the next phase of the Project**

The Project Team are working with a Communications Consultant to create a revised communication strategy for the project including: LTAC marketing and PR for engagement with the Immersive Audio Production for wider public engagement through live events and through the Project website.

- **Sharing the project through the website and other online means; and redevelopment of the Immersive Audio Production**

The website was launched in March 2024, and includes the Immersive Audio Production, *One in Ten*.

The digital version of the audio experience that is hosted on the website is the key way that we can share the piece with anybody who is interested in Chronic Cough.

RH Participant, Focus Group

Having the 'One in Ten' audio experience on the LTAC website will be fantastic for enabling us to disseminate the project.

Engagement Practitioner, Focus Group

- **Future Engagement events**

Planning is under way for this next stage of the *LTAC* project, with opportunities such as community festivals and events in libraries being explored.

The Project Team are working to identify other events and places to share learning about the project to healthcare professionals to increase awareness of the impact of *Chronic Cough* and as a condition to be taken seriously, such as a GP's conference. The Project Team are also exploring ways to encourage other researchers to become involved in public engagement with research, through presentations and sessions at the likes of conferences for the respiratory research community.

- **Development of a toolkit for libraries to run their own immersive audio experiences**

It is also hoped that a toolkit can be developed to accompany the audio so that anyone wishing to run their own *LTAC* events are able to do so e.g. local libraries.

...We've also got this new idea...of creating a toolkit for libraries to put the piece on themselves. Which won't involve us actively producing the events, but enabling them, creating a toolkit and a digital audio file for libraries in anywhere to put on themselves. And so, then people who perhaps want to start a conversation about Chronic Cough in their own communities could work with their local library to put an event on.

Engagement Practitioner, Focus Group

- **Continued engagement with those with lived experience of *Chronic Cough***

The online *Story Exchange* Socials will continue. This will provide further opportunities for those with lived experience and researchers and healthcare professionals to continue to share learning and experiences around *Chronic Cough*.

- **Booklet of Stories**

One of the Creative Facilitators is also working on a book re : 'Stories and Social Tricks' that has been funded by the North West Lung Centre Charity, and the aim is:

To create a short book of real life stories and anecdotes about living with chronic cough and a toolkit of social tips and tricks for living with chronic cough and supporting/responding to those with chronic cough.

Data source: email communications

8.0 Progress towards LTAC objectives and anticipated outcomes

8.1 Objectives

LTAC's objectives were updated from those provided in the original application form to take into account changes due to the Covid-19 pandemic, and an extension to the project was granted so that the programme of activities could continue into 2024:

1. Conduct two Focus Groups in February 2020 to explore expectations, priorities, and ideas for the engagement programme. **[Completed]**
2. Develop an online identity and communications strategy for the project, informed by Focus Groups, by August 2021. **[Ongoing]**
3. Deliver a series of online creative engagement workshops between September 2021 and May 2022 to exchange perspectives and explore the key engagement aims through a variety of creative methodologies. These workshops will pilot, test, and refine the process and format of delivering creative 'story sharing' participatory engagement activities via online platforms. **[Completed]**
4. Develop and deliver four small-scale public engagement experiences, between June 2022 and May 2023, exploring the experience, biology, and treatment of cough. These engagement experiences may be online, in-person or a combination, depending on what is deemed safe and appropriate at the time of planning and development. **[Ongoing. Planning underway for activities in 2024]**
5. Produce one larger-scale public engagement experience, between June 2023 and November 2023, exploring the experience, biology, and treatment of cough. This engagement experience may be online, in-person or a combination, depending on what is deemed safe and appropriate at the time of planning and development. **[Piloting of Immersive Audio Production at GEF in June 2023. Planning underway additional public engagement events and activities in 2024]**
6. Ensure that ongoing research (developments and progress) is fed into the engagement programme. **[Ongoing]**

8.2 Anticipated Outcomes

This table summarises whether there is data and evidence gathered as part of this evaluation to demonstrate or strongly indicate whether the anticipated outcomes for each of the key stakeholder groups (identified at the start of *LTAC* during the Evaluation Workshop and articulated in the Evaluation Framework) have been met, or otherwise.

Stakeholder group	Anticipated key outcome	Met
For researchers and healthcare practitioners	Built capacity for public engagement e.g. gained public engagement experience, skills, or expertise.	✓
	Influenced professional thinking or practice.	✓
	Positive perceptions of the value and benefits of (multi-directional) public engagement.	✓
	Gained new learning and multiple perspectives with regards to the experience, biological mechanisms, and treatment of cough.	✓
For patient participants	Enhanced understanding/ awareness of, and interest in, cough research [taking place at Imperial and Manchester].	✓
	Felt they contributed to the discussions and shaping of the engagement programme/ their voices had been heard.	✓
	Increased feeling of empowerment.	✓
	Positive perceptions and experiences of their participation (for example: creative; inclusive; open; enjoyable).	✓
	Gained new learning and multiple perspectives with regards to the experience, biological mechanisms, and treatment of cough.	✓
Engagement professionals	Learning and understanding about using creative approaches to facilitate multidirectional engagement between researchers, patients, healthcare professionals.	✓
Wider publics	<p>Gained new learning with regards to the experience, biological mechanisms, and treatment of cough.</p> <p>Increased interest and curiosity with regards to the experience, biological mechanisms, and treatment of cough.</p> <p>Positive perceptions and experiences of their engagement [for example: creative; enjoyable; inspiring].</p>	TBC: roll-out of the wider public engagement programme will take place in 2024. However, there are indicators of success from the Pilot activity (GERF).

ⁱ The successor for Wellcome's *Provision for Public Engagement* - the [Research Enrichment: Public Engagement](#) scheme, has since closed (May 2022). To find out more about how Wellcome support public and community engagement with research under their new strategy, see: <https://wellcome.org/>

ⁱⁱ A third Focus Group was due to take place in London but was cancelled due to the Covid pandemic/ plans changed.