THE SOUND OF SCIENCE

The urgent need for a Tinnitus Biobank

(T)

British Tinnitus
Association

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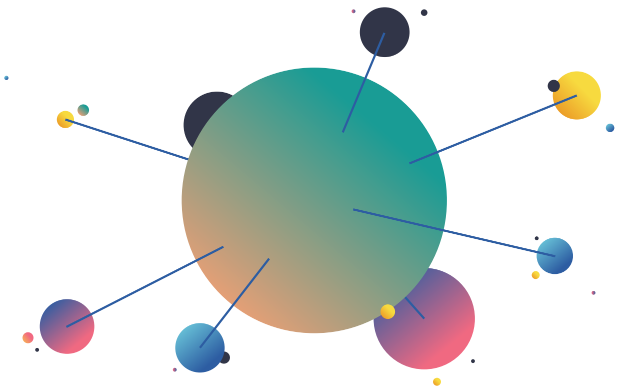


Executive summary

About tinnitus

- Tinnitus - the perception of noises in the ear/head - affects one in eight people and is one of the most misunderstood conditions in our society
- Symptoms vary, but the impact of tinnitus on quality of life and mental health can be severe
- There is no cure for tinnitus and more than eight out of ten people are unhappy with their treatment options, creating a ‘revolving door’ for the NHS and costing the health service £750m
- Tinnitus research receives 40 times less funding than comparable conditions such as depression, anxiety and hearing loss, resulting in huge gaps in scientific knowledge and little prospect of a breakthrough
- Tinnitus has been recognised by NICE as a symptom of long Covid.

Progress

- In February 2020, the British Tinnitus Association (BTA), published its Tinnitus Manifesto to call for more funding to find cures. This was supported by 135,000 petition signatures
- In March 2020, the National Institute of Clinical Excellence (NICE) published new guidance and advice on the assessment, investigation, and management of tinnitus in primary, secondary and community care
- In March 2021, the Department of Health and Social Care (DHSC) appointed a Working Group to discuss Research on Adult Hearing Loss and Tinnitus

Research

The BTA conducted new research of 2,600 people with tinnitus in November 2021 to see how things have changed in the two years since it published its Tinnitus Manifesto. It revealed:

- Tinnitus is relentless - more than one in three people think about their condition every hour, causing anxiety and sadness
- 9.3% of people with tinnitus have had suicidal thoughts or thoughts of self-harm in the last two years
- Only 1.8% believe the NICE guidance has had a positive impact on their tinnitus
- People remain unhappy with the treatment options. Of those that don't return to their GP following a tinnitus consultation, 40% think there isn't any point and only 2.4% say this is because their treatment worked
- 66% say the speed with which Covid-19 vaccines have been developed has given them fresh hope that science could hold the answer for tinnitus
- A majority of people think that research-funders (85%), Government (63%) and drug/pharmaceutical companies (59%) should be doing more to develop cures for tinnitus.

Call to action
The British Tinnitus Association recommends:

Establishing a Tinnitus Biobank to deliver a step-change in the race to find tinnitus cures. This would enable researchers to deliver key foundational information such as identifying underlying causes, recognising different tinnitus subtypes and uncover the biomarkers that would enable tinnitus, and the impact of treatments, to be objectively measured.

This would require £4m, equivalent to just 0.53% of the £750m it costs the NHS each year to treat tinnitus and would be supported by politicians, researchers and 98.8% of people with tinnitus

About the British Tinnitus Association

The BTA is an independent charity and the primary source of information for people with tinnitus in the UK. It helps to facilitate an improved quality of life for people with tinnitus through a range of support options including support groups, a helpline and its website, while also taking steps to bring forward the day when tinnitus is cured. The charity works to inform and educate medical professionals and the community on what tinnitus is and how to manage it. It aims to encourage prevention through its educational programme.

The British Tinnitus Association wants "a world where no one suffers from tinnitus". They want to find better ways to manage tinnitus and, ultimately, to help find a cure.

About tinnitus

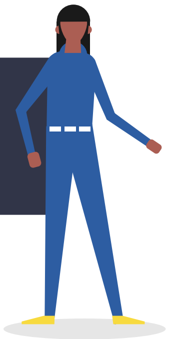
One in eight people have tinnitus.[1] Tinnitus is defined as hearing a sound such as a ringing, whooshing, humming or buzzing where there is no external source.[2] It can be continuous or come and go.

It changes from a high pitched hiss like a pressure cooker going off to a high pitched whiny ringing.

It's like a combination of there being a loud party next door with whooshing and a high whistle.

It's like a screaming loud high pitch.

It's a constant white noise.



For one in twenty people with tinnitus, the condition severely affects their ability to lead a normal life and there are significant associated societal and healthcare costs. Home, work and social life are all impacted. At present, there is no known cure for tinnitus, and the great majority of tinnitus sufferers feel current treatment options are insufficient and often ineffective.

Based on population projections, the number of people with tinnitus in the UK will grow by over half a million in a decade, up to nearly 8 million people.[3] That's 8 million people living with a condition that can often be debilitating.

Yet treatment options are inadequate. In total there are more than 1 million tinnitus GP appointments each year,[4] demonstrating a huge cost to the healthcare system. The lack of treatment options creates a 'revolving door' whereby more than one in three people return to their GP after discharge,[5] mostly within a year.

The fact that so many patients return to their GP time and again also carries an extensive cost to the health service. Tinnitus healthcare is estimated to cost the NHS £750m each year,[6] while the cost to wider society is around £2.3 billion annually.

NICE published new Tinnitus Guidance in March 2020. This should help healthcare professionals to ensure a standardised care pathway and give patients appropriate reassurance, information and referrals. However, it does not resolve the central issue, that there simply aren't enough effective cures for a condition that can be very traumatic.

Tinnitus Manifesto recommendations

In January 2020, leading academics, politicians, research funders, patient support groups, clinicians and people with tinnitus came together at a Tinnitus Roundtable event, hosted by the BTA at the House of Commons to map out a way forward for tinnitus research.

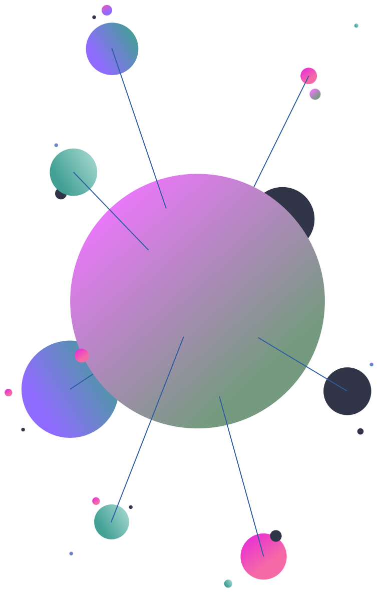
These discussions provided the blueprint for the BTA's Tinnitus Manifesto,[7] in which it set out three clear asks of the government to enable them to seize the opportunity to grow the tinnitus research field and make significant leaps forward to support people with tinnitus.

The BTA asked for

- 1% of the health service cost of treating tinnitus to be committed to research to find cures (£7.5m per year)

- A long-term infrastructure to ensure capacity to deliver the quality and volume of research to deliver real progress and build on the work of a committed research community

- Prioritise studies that establish key foundational knowledge, including identifying biomarkers, reliable objective measures and subtypes, enabling the community to move forward to find cures.



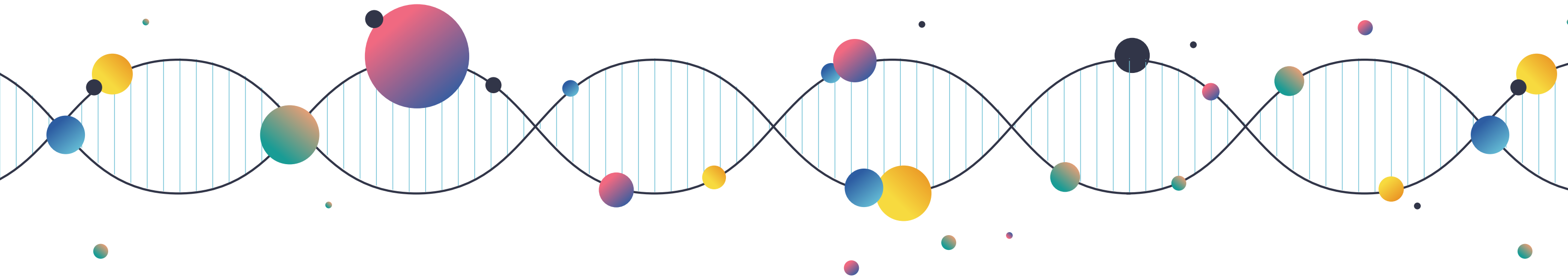
The Tinnitus Manifesto was supported by more than 135,000 petition signatures, which led to the Secretary of State for Health committing to a funding review[8] for tinnitus research. In early 2021, a new working group was established by the DHSC to develop an action plan.[9] The BTA is a member.

For a much misunderstood and often overlooked condition like tinnitus, this represents incredible progress and the BTA, on behalf of the tinnitus community, thanks the government for their efforts to support the discussion.

However, the situation remains that tinnitus research is still chronically underfunded. It receives 40 times less funding than equivalent conditions like hearing loss and anxiety, despite the huge impact it can have on mental health.

The Covid-19 pandemic has increased the urgency of this situation. It has been reported that Covid-19 symptoms exacerbate tinnitus in 40% of cases.[10] It is recognised as a symptom of long Covid in the NICE 'COVID-19 rapid guideline: managing the long-term effects of COVID-19.'[11]

The development of new treatments takes time and, in the case of pharmaceutical treatments, it typically takes up to 12 years.



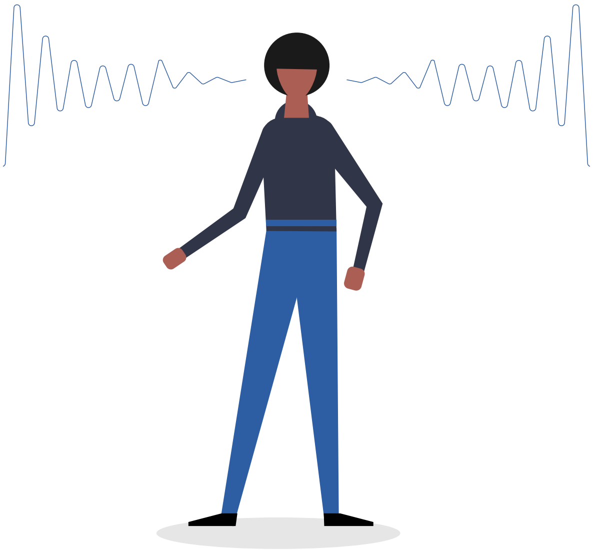
The BTA and the wider tinnitus community has, for some time, been discussing the idea of a Tinnitus Biobank. This would allow researchers to fast-track efforts to establish the biomarkers and objective measures that will provide the foundational knowledge needed to attract the pharmaceutical industry to begin development on developing tinnitus cures. Evidence is emerging that tinnitus is caused by factors other than hearing loss, and is at least partly genetic.[13]

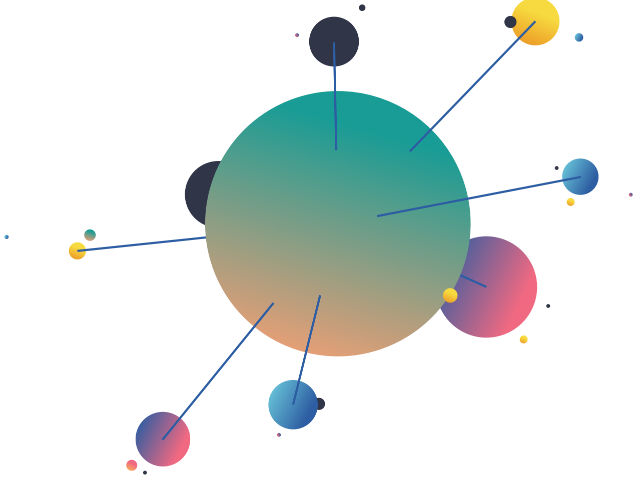
What is a biobank?

A biobank is defined as “an organised collection of human biological material and associated information stored for one or more research purposes˝.[14]

Professor David Baguley, Professor of Hearing Sciences at the University of Nottingham, says a Tinnitus Biobank would enable great progress in "studying the genotype (including the molecular biology of tinnitus) and the phenotype (symptoms and test results)", and would enable "improved diagnostics, closer examination of lesion sites, study of mechanisms and targets for treatments."

Tinnitus researchers believe that a condition-specific Tinnitus Biobank would deliver a step-change by enabling speedy progress in diagnostics, treatments and mechanisms, paving the way for a novel tinnitus drug. Studies estimate that a drug treatment for tinnitus could have a market value of $680m[16] in its first year. The BTA has costed the establishment of a Tinnitus Biobank at £4 million, which is 0.53% of the £750 million that the health service spends every year treating people with tinnitus.





Sound of science research

The huge impact on mental health and quality of life means that the need for a tinnitus specific biobank is urgent, both for the research community, and for the people who experience tinnitus every day. In November 2021 the BTA conducted a survey of over 2,600 people about their tinnitus, focusing on the last two years since the Tinnitus Roundtable and the introduction of the NICE Guidance.

People's experiences of tinnitus

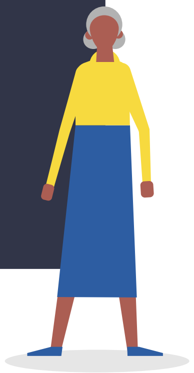
According to the BTA survey, 69% of respondents say that their tinnitus varies at certain times of day or in different situations. Tinnitus can be affected by emotions, with 43% saying it gets worse when anxious, lonely (7%) or tired (37%). For others, it is situational, and gets worse after being in a noisy environment (37%), when it is very quiet (64%) or when trying to sleep (48%).

69%
tinnitus varies

87%
think about tinnitus every day

Tinnitus can be relentless for people living with the condition. 87% think about it every day, and 35% at least every hour. The survey highlights that tinnitus can be very distressing and have a severe impact on quality of life.

> **It takes over your life and changes you as a person. Stresses you out a lot and it's very hard to cope with 24/7. You don't like telling people because you think that they will think you are crazy. And you don't want to bring people down with you when you are down and stressed with the noise 24/7.**
> **It really is so hard to live with and there is still no cure.**



It has ruined every moment of my life. It has made me feel disabled. It has made me feel that large parts of my life were stolen from me. From my ability to go to concerts or to enjoy music ever again to having to give up my daily and nightly meditation practice to being fearful of any and all loud noises. I just feel like it has changed me permanently and I have no hope of ever having peace ever again.

Impact on mental health

Tinnitus has a big influence on quality of life, and the impact on mental health can be severe. 52% of survey respondents say it results in low mood or sadness, and 39% say it makes them feel anxious or worried. 31% avoid contact with friends and minimise the number of social activities they take part in.

Tinnitus is an isolating condition, and more than a third of respondents report feeling that their partner or family don't understand. Almost one in three people say that they feel that they have no one to turn to.

One in ten respondents have had suicidal thoughts or thoughts of harming themselves since being diagnosed, with similar numbers having the same thoughts **in the last two years**. These figures graphically illustrate the impact tinnitus can have on mental health.

Tinnitus has changed my personality and a cure would perhaps make me feel like the person I used to be.

Current treatments for tinnitus

There are no cures for tinnitus and only 12% of those surveyed said they had been happy with options presented to them by their GP. Cognitive Behavioural Therapy (CBT) is the most effective form of treatment for tinnitus, yet gets presented as an option only in a fraction of cases.

Less than 2% of our respondents thought that the introduction of the NICE Guidelines for tinnitus have had a positive impact on their treatment.

One-third of people return to their GP after an initial consultation for tinnitus. Of those that don't, it might be expected that this is because their treatment was effective. However, less than 3% of survey respondents said this was the case. Almost half (46%) of those surveyed said they didn't return to their GP as they 'couldn't see the point' as there was no effective treatment.

Comments from respondents indicated a negative outlook and lack of hope.

Tinnitus and Covid-19

Tinnitus severity worsened for many during the pandemic and it is also a symptom of long Covid. In the survey, 23% of those who have had Covid-19 say that their tinnitus has got worse as a result, and 9% did not previously have tinnitus.

Given the funding and focus on Covid-19 and long Covid, there is scope to ensure that tinnitus research benefits, given its links to the two conditions. The speed at which Covid-19 vaccines have come to market shows what can happen with impetus and funding. 66% of survey respondents say the speed with which Covid vaccines have been developed has given them fresh hope that science could hold the answer for tinnitus.

Support for a tinnitus biobank

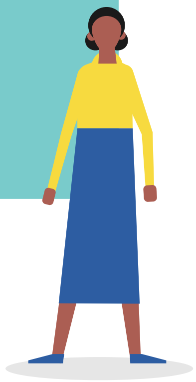
Tinnitus receives 40 times less funding than comparable conditions. This makes those with tinnitus angry and frustrated, and 52% believe it is unfair that tinnitus receives so much less funding. More than half (56%) say it reduces their hope of a cure, and 68% say it shows that tinnitus is seen as less important than other conditions.

Many were surprised to learn that existing biobanks, which have been established to support research into a range of health conditions, do not collect sufficient audiological data,[16] with 42% of respondents saying this feels unfair.

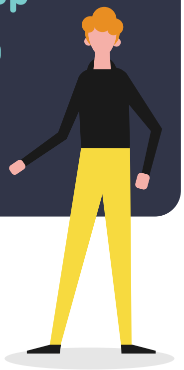
A majority of people think that research-funders (85%), Government (63%) and drug/pharmaceutical companies companies (59%) should be doing more to develop cures.

Support for increased tinnitus research is almost universal among people living with tinnitus. The establishment of a Tinnitus Biobank is supported by 98.8% of survey respondents. Nine out of ten people believe that it would be a good use of funding.

Finding a cure not, just for myself but for others who have just started on their journey or haven't yet, would be incredible and completely life changing.



A tinnitus biobank would make a vast difference, it would eradicate the fear of suffering for the rest of my life, to sleep normally and ease the mental strain of constantly trying to distract my brain to lessen the impact.



Call to government

The BTA is calling on the government and research funders to:

- Fast-track their support for tinnitus research-funding and expedite the work of the DHSC Adult Hearing Loss and Tinnitus Working Group
- Support the BTA to establish a Tinnitus Biobank to find cures and treatments
- Commit £4m towards the creation of a Tinnitus Biobank. This figure is equivalent to 0.53% of the annual cost to health service of treating tinnitus.

Up until now tinnitus research has consisted of either small-scale studies, where lots of data is taken from a few individuals, or larger studies where small amounts of data are taken from lots of individuals. A Tinnitus Biobank would enable the best of both worlds.

A Tinnitus Biobank has the potential to give researchers access to the data needed to develop improved treatments and ultimately find a cure for tinnitus.

Key goals will be the identification of the underlying mechanisms of tinnitus, classification of tinnitus subtypes, development of objective measures of tinnitus and the discovery of biomarkers. These have been determined as requirements to attract investment from the pharmaceutical industry.

Additionally, the identification of biomarkers and objective measures would be able to provide sufferers with a clear diagnosis and enable clinicians to monitor the effectiveness of any treatments.

A Tinnitus Biobank is an investment in the future. It would form part of a long-term infrastructure to enable innovation and real progress in research.

This will inspire young academics to commit their future careers to academic research which will be life-changing for millions of people.

Investment in a Tinnitus Biobank will also reassure those living with tinnitus - many of whom who have done so for decades - that their condition is being taken seriously.

> **A Tinnitus Biobank would have detailed and rigorous tinnitus data from very large numbers of people. It could therefore move the field forwards in ways that have not been possible so far, for instance in pinning down underlying mechanisms, and identifying distinct subtypes which may have different causes, impacts, prognoses and treatment responses.**

Dr Will Sedley, Academic Clinical Lecturer in Neuroscience,
Newcastle University

> **We have to do what the psychiatry field has started doing 30 years ago. I believe a Tinnitus Biobank such as the one conceived by the BTA is an essential step forward**

Christopher Cederroth, Karolinska Institutet
Department of Physiology and Pharmacology PhD

A Tinnitus Biobank could allow us to understand the condition much better and answer many questions that, thanks to chronic underinvestment, so far remain unanswered. It could fast-track our route to finding the underlying causes, ways to test, identifying genetic biomarkers and uncovering the links between tinnitus and other comorbidities. We know that particular challenges, such as the lack of an objective measure of tinnitus, hold back investment in the pursuit of a cure. If we are able to level the playing field, give the pharmaceutical companies the tools they need and communicate effectively that these tools are available then we can usher in a new era in tinnitus treatment development. When you consider that we could do all of this for around 1% of the annual cost of treating tinnitus, it represents excellent value for the health service too.

David Stockdale, Chief Executive, British Tinnitus Association

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