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British Tinnitus
Association

Time to listen:

A manifesto for

tinnitus

Three steps the Government
must take to give people with
tinnitus hope for a cure

About tinnitus

- Tinnitus - the perception of noises in the ear/head - affects one in eight people in the UK
- It can have a huge impact on mental health and quality of life
- There is no cure for tinnitus and eight out of 10 patients are dissatisfied with the current treatment options
- Tinnitus research receives 40 times less funding than comparable conditions like depression, anxiety and hearing loss, which has led to huge gaps in understanding

Time to Listen 2020

New findings from the 'Time to Listen' research of 1,620 people with tinnitus, conducted by the British Tinnitus Association in January 2020 include:

- One in five people think about their tinnitus at least 'every few minutes'
- Common sound comparisons include the noise of a jet engine, a whistling kettle, a dentist's drill, buzzing bees and fire alarms
- For some the noise is intermittent, for some it is near-constant
- Many experience low mood and sadness and feelings of hopelessness, many socialise less and feel misunderstood and one in seven experience suicidal thoughts
- One in three say their tinnitus is trivialised by their partner, family, friends, colleagues and health professional
- Eight in 10 say the low level of funding for research shows it isn't seen as important
- Seven in 10 say increased funding would give them hope that a cure is possible.

Tinnitus Roundtable

In January 2020 a Tinnitus Roundtable event was hosted by the British Tinnitus Association at the House of Commons, sponsored by Sir John Hayes MP, who has tinnitus himself. The event brought together leading academics, politicians, research-funders, patient support groups, clinicians and people with tinnitus. The group helped to map out a way forward for tinnitus research, leading to three clear calls for Government, which would enable them to seize the opportunity to grow the field and make the huge leaps forward that are so close and so important to people with tinnitus.

Calls to action

- 1.** Commit 1% of the health service cost of treating tinnitus towards research to find cures - a total of £7.5m per year to be dedicated to research
- 2.** Build a long-term infrastructure to ensure that there is the capacity to deliver the quality and volume of research needed to make real progress, building on the work of the committed research community
- 3.** Prioritise studies that will help establish the key foundational knowledge for tinnitus research, and enable the community to move forward to find cures, including:
 - a.** Identifying tinnitus biomarkers
 - b.** Developing reliable objective measures of tinnitus
 - c.** Identifying tinnitus subtypes

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About The British Tinnitus Association

The British Tinnitus Association is an independent charity and the primary source of information for people with tinnitus. 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 also supports companies and individuals to manage noise exposure to prevent the development of tinnitus.

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

Tinnitus is the perception of noises in the ear/head that have no external source. It is often described as a buzzing, hissing, ringing or whistling sound and the sensation can be constant or intermittent and can vary in volume.

Some 7.1m people in the UK have tinnitus [1] and for some people the condition can be completely life-changing. Studies have found that people with tinnitus score significantly higher on the depression and anxiety scale and lower on self-esteem and wellbeing [2].

Seven in 10 people who develop tinnitus visit their doctor in the first year [3], however, there is currently no cure for the condition. And with tinnitus currently receiving 40 times less funding than comparable conditions like depression, anxiety and hearing loss [4], there are still huge gaps in scientific knowledge and little prospect of a breakthrough.

The lack of medical options means that eight out of 10 patients [83%] are unhappy with the treatment they receive from their health professional [4], creating a revolving door of returning patients [3], which increases the cost to the NHS further.

The stark situation places huge strain on the health service, with tinnitus treatment costing the NHS £750m per year and the cost to wider society is estimated at £2.6 billion per year [5].

Yet tinnitus has a committed research community that has made great strides in recent years to bring the field to the edge of real progress. There is an opportunity for the Government to facilitate huge leaps forward by investing to grow the field and fund the kinds of studies and activity that will bring forward the day when cures will be found.

Tinnitus affects 1 in 8 people in the UK

Tinnitus research receives 40 times less funding than comparable conditions

Tinnitus treatment is costing the NHS £750m per year

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Time to Listen research

In January 2020, the British Tinnitus Association conducted the 'Time to Listen' research [6], polling 1,620 people with tinnitus to find out more about their feelings on the current state of tinnitus research and how living with the condition affects them.

Helping others to imagine

When asked to describe the sound of their tinnitus there was, naturally, a huge variety of responses. People compared the sound of their tinnitus with the noise made by jet engines, bees buzzing, whistling kettles, fire alarms, hoovers, dentist's drills, washing machines, drum cymbals, humming fridges, breaking glass, crickets, water falls, screeching pipes, TV static, heartbeats and popping candy, among other things.

Many people stressed the impact of this sound being constant or ongoing over long-periods and some talked about how they hear different sounds in each ear, which can add to the impact.

All-encompassing

One in five respondents [19%] said that they think about their tinnitus "every few minutes" or "every waking moment" and 84% said that they think about it "every day". One in five [19%] said that their tinnitus affects most or all of their decisions and 72% said it affects at least some of their life decisions. 57% of respondents said they had lived with tinnitus for more than five years.

Mental health and quality of life impact

People with tinnitus said that, since developing the condition, they were more likely to experience feelings of low mood and sadness [57%], anxiety and worry [46%] and hopelessness and helplessness [39%]. More than one in seven [15%] said they are more likely to have suicidal thoughts.

A large proportion of people said that they now avoided contact with friends and took part in fewer social activities [42%], while the same proportion said that they now felt more irritable and intolerant of others. One in three [32%] said they felt like their partner or family don't understand, one in five [21%] said it had reduced their motivation at work and one in four [25%] said they feel like they have no one they can turn to.

One in five think about their tinnitus "every few minutes" or "every waking moment"

More than one in seven said they are more likely to have suicidal thoughts

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Not taken seriously

Around a third of respondents reported that their tinnitus was often trivialised or underestimated by people including their partner (32%), their family (38%), their friends (40%), their colleagues (31%) and even their health professional (44%).

While over half of people with tinnitus said they had been on the receiving end of positive interactions, where others had been sympathetic about the condition (54%) or listened to how they felt (47%), many also described how they had been made to feel like they were exaggerating (28%), been laughed at (11%) and had people roll their eyes at them (11%) as a result of their tinnitus.

The message sent by lack of investment

Eight in 10 people with tinnitus said that the gap in funding between research into tinnitus and other comparable health conditions shows that it is seen as less important (79%), while six in 10 (59%) said that it reduced their hope that there will ever be a cure.

Eight in 10 people (81%) felt that a cure for tinnitus would have a big impact on them, with one in four (28%) saying it would “completely change” their life and 98% saying it would make their life better.

People with tinnitus feel that increasing investment into tinnitus research would send really positive messages, with 85% saying it would show that tinnitus is being taken seriously, 81% saying it would show that the wellbeing of people with tinnitus matters, 71% saying that it would help society to understand that it is a serious condition and 69% saying it would show that a cure is possible. Only one in 10 (10%) people polled in this survey said they are satisfied with the current treatment options.

***A third say their
condition is trivialised***

***28% say a cure would
“completely change
their life”***

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The Tinnitus Roundtable

Devised by the British Tinnitus Association and kindly hosted by Sir John Hayes MP, who has tinnitus himself, The Tinnitus Roundtable event took place at the House of Commons in January 2020 to discuss the state of tinnitus research and what is needed to move things forward.

The event brought together leading academics, politicians, research-funders, patient support groups, clinicians and people with tinnitus in a working group-setting, with participants sharing knowledge and experiences in order to find practical solutions.

The roundtable event raised some interesting points about the current state of tinnitus research, including:

- Tinnitus is common and can be debilitating and yet it receives little in the way of attention and funding
- Current treatments are merely a 'stopgap' - they mask the symptoms but don't treat the cause, and so patients are being let down
- The current level of funding for research is very poor compared to other conditions - one researcher revealed that their funding grant is equivalent to just £30,000 over four years - bigger grants are needed to fund larger studies
- Research-funding organisations are currently not receiving enough grant applications for research into tinnitus and those they do receive are not of sufficient quality
- Not enough research is being done and the research community is not large enough or well-developed enough to do what is needed
- Though small, the tinnitus research community is hugely committed and its creative use of funds has enabled great strides to be made - now is the time to invest to take things to the next level



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The group then discussed the priorities for tinnitus research as well as the practical steps needed to make a genuine impact. Key points raised included:

- Long-term funding and infrastructure are needed to attract promising young academics to commit to a career researching tinnitus, rather than other conditions with established funding
- Many of the foundations of tinnitus research aren't there - definitions are needed as is the identification of biomarkers, objective measures and subtypes
- The community needs to work together further - possibly internationally - to consensus-build, share resources and projects and to agree definitions, classifications and sub-typing
- A Tinnitus Biobank that builds on what is available through the UK Biobank would be a huge step forward
- Identifying objective measures and biomarkers would attract pharmaceutical companies and researchers, creating a knock-on effect
- A UK Tinnitus Registry would aid human research. Tinnitus is behind other conditions in this area too
- Researchers must remain open-minded - different causes may have different mechanisms and we need to recognise that. Likewise, existing drugs should be revisited as cures may lie away from current thinking
- Cures are needed in order to give patients genuine options and restore quality of life. Efforts should be made to demonstrate what a rewarding and interesting area of work this is for prospective researchers



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Calls to Government

1. *Commit 1% of the health service cost of treating tinnitus towards research to find cures - a total of £7.5m per year to be dedicated to research*

Tinnitus has been grossly underfunded for many years, resulting in huge gaps in understanding and leaving the 7.1m people with the condition without the hope of a cure.

Studies show that tinnitus receives around 40 times less funding than conditions like depression, anxiety and hearing loss, despite the fact that the impact on mental health and quality of life is comparable.

Tinnitus treatment costs the NHS around £750 million per year and the cost to wider society is estimated at £2.6 billion.

Committing just 1% of the health service cost of treating tinnitus towards research to find cures would enable a much-needed step-change in the quality of research projects that could be undertaken. It would allow this small but committed community of researchers to implement the big projects that are necessary to establish the foundations for finding future cures for tinnitus.

This level of investment would also send an important message to talented young researchers - that tinnitus is an area that is being taken seriously and where there is an opportunity to carve a career while doing important life-changing work.

If tinnitus is going to avoid continually missing out on promising academics who naturally go into research areas with more established funding streams, it needs to invest at a level that attracts those students. It can then build towards achieving critical mass so that the community becomes sustainable.

2. *Build a long-term infrastructure to ensure that there is the capacity to deliver the quality and volume of research needed to make real progress, building on the work of the committed research community*

A range of other measures are needed alongside increased funding to build the infrastructure needed to ensure that research-funders receive the quality and volume of grant applications needed.

The Medical Research Council, which does excellent work in funding research, is already discussing how it can communicate to the research community that it is very interested in the subject of hearing. We believe that tinnitus should be specifically named in these communications, in order to elevate the subject in the eyes of young and established academics.

Across all research-funders, repositioning 'hearing loss' research as 'hearing loss and tinnitus' research in all communications would also help, as would consideration of tinnitus as a research focus at the next review of strategic or themed priorities.

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Young academics need to be inspired and nurtured to commit their future career to this important area of research. A series of workshop events should take place in universities with a hearing loss specialism in order to communicate what a growing and interesting field this is, with the opportunity to do life-changing work.

The existing research community, which has achieved so much despite limited funds, also needs to be utilised and educated on how to maximise their chances of securing larger funding grants for tinnitus research. Talented researchers who are at a transition point in their careers and who have the potential to be future leaders should be encouraged to apply for a Fellowship. The field could also be grown if researchers were to tie applications in to areas already recognised as strategic research priorities, such as living brain research by the Medical Research Council or by building tinnitus research into studies around multi-morbidities. However, it is important that initial studies remain focused on establishing the key foundational knowledge of tinnitus that years of underfunding has caused.

3. *Prioritise studies that will help establish the key foundational knowledge for tinnitus research, and enable the community to move forward to find cures, including:*

- a. Identifying tinnitus biomarkers
- b. Developing reliable objective measures of tinnitus
- c. Identifying tinnitus subtypes

The gross underfunding of tinnitus research has resulted in big gaps in foundational knowledge that must be made a priority if cures are to be found.

Identifying biomarkers and objective measures would enable clear diagnoses and offer the potential for researchers and medical professionals to judge whether particular treatments are working. This would have a huge knock-on effect in attracting both the pharmaceutical industry and researchers and so needs to be a key priority.

Being able to identify the different subtypes of tinnitus would enable more targeted research and reduce the dead-ends that can occur when a seemingly promising treatment is found to not work with a certain group of people or certain individuals.

A Tinnitus Biobank that builds on the excellent work done by the UK Biobank would aid with subtyping and also provide a route to answer many of the other identified challenges.

Putting steps in place to prioritise research proposals in these key areas would enable the tinnitus research community, which has brought us to the edge of great progress in the field, to build consensus and key foundational knowledge. It would put it into the best possible place to do the important work needed to find cures for tinnitus.

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**British Tinnitus
Association**

References

1. The British Tinnitus Association. *More people living with tinnitus than previously thought.* 2019
2. Krog NH, Engdahl B, Tambs K. *The association between tinnitus and mental health in a general population sample: results from the HUNT study.* Journal of Psychosomatic Research. 2010.
3. Don McFerran, Derek J. Hoare, Simon Carr, Jaydip Ray and David Stockdale. *Tinnitus services in the United Kingdom: a survey of patient experiences.* BMC Health Services Research. 2018.
4. Don. McFerran, David Stockdale, Ralph Holme, Charles H. Large, David M Baguley. *Why is there no cure for tinnitus?* Frontiers in Neuroscience. 2019.
5. Stockdale, D, McFerran D, Brazier P, Pritchard C, Kay T, Dowrick C, Hoare DJ. *An economic evaluation of the healthcare cost of tinnitus management in the UK.* BMC Health Services Research. 2017.
6. A survey of 1,620 people with tinnitus conducted by the British Tinnitus Association in January 2020 using SurveyMonkey. The survey comprised 17 questions.

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