

# Revealing the struggle for silence:

Tinnitus UK highlights  
the alarming mental  
health crisis amid a  
void of support

#TinnitusWeek  
#StruggleForSilence #SilentStruggle

**TINNITUS**   
Support • Research • Prevent

**“(I would have) felt somewhat abandoned had I not realised so many of the people I know also had tinnitus and had I not joined Tinnitus UK”**

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**"It's had a  
catastrophic  
impact on my  
mental health."**



# Executive summary

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## Introduction

Tinnitus UK, an independent charity, serves as the primary support and information hub for individuals coping with tinnitus in the UK. Operating without direct government funding, the organisation aims to enhance the quality of life for those affected by providing diverse support options, funding research and advocating for progress toward a cure.

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## Key statistics:

Tinnitus affects  
**1 in 7**  
adults in the UK,  
with severe  
impact on  
**1 in 6**  
of those living  
with the  
condition.

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An estimated  
**8 million**  
people  
will be affected  
by tinnitus by 2025

There are over  
**1 million**  
tinnitus-related GP  
appointments annually,  
costing the NHS  
**£750 million**

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**No**  
**known**  
**cure**  
exists, and  
dissatisfaction  
with current  
treatments is  
widespread.

Tinnitus UK conducted new research with 478 people with tinnitus in December 2023 to examine the experiences they had of tinnitus, and of accessing healthcare support for the condition. They found that:

### Patient experiences:

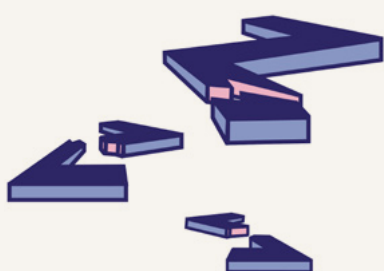
Symptoms vary, but the impact of tinnitus on quality of life and mental health can be severe.



**Over 1 in 5 of the people living with tinnitus surveyed had had thoughts of suicide or harming themselves in the last year.**



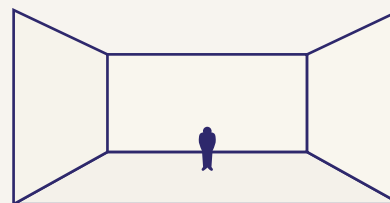
More than 8 out of 10 respondents experienced low mood or anxiety in the last year, with 7 out of 10 feeling hopeless or helpless.



Sleep disturbances affect 85.7% of respondents.



The emotional impact of tinnitus is significant, with 68.4% reporting low self-esteem and 54.9% struggling to think rationally.

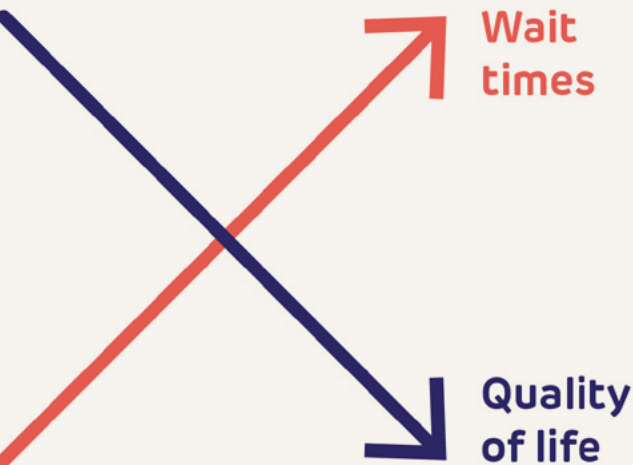


Tinnitus is linked to social isolation, impacting relationships and daily life.

## Healthcare support:

There is no cure for tinnitus. In March 2020, the National Institute for Health and Care Excellence (NICE) published their first guidelines for the assessment and management of tinnitus in primary, secondary and community care.

- Half of respondents obtained GP appointments within a week, but 16% waited over a month.
- Referrals to secondary care decreased to 57.9%, with 11.7% not offered a referral.



- There is limited mental health support from GPs, with only 5% offered Cognitive Behavioural Therapy (CBT) as recommended in the NICE guidelines.
- The number of people reporting that they waited more than 12 months for an appointment in secondary care has tripled from 2019 to 2023, with 1 in 6 facing waits of more than a year.
- The increase in waiting times for audiology appointments impacted quality of life for two thirds of respondents.

## Calls to action:

Tinnitus UK are calling for:

- 1 A review and evaluation of the status of secondary care services.**
- 2 A standardised nationwide management model for tinnitus.**
- 3 Increased tinnitus education for medical professionals.**

# About Tinnitus UK

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Tinnitus UK, an independent charity dedicated to providing information and support for individuals living with tinnitus in the United Kingdom, plays a crucial role in enhancing the quality of life for those affected by this condition.

Through a variety of support avenues, including online and in-person support groups, a helpline featuring a chatbot and live webchat, and an informative website, the charity strives to facilitate improved well-being.

Importantly, Tinnitus UK, who receive no direct government funding, is committed to educating both medical professionals and the wider community about tinnitus, advocating prevention, funding research and working towards finding a cure.

This report aims to shed light on the challenges faced by people living with tinnitus in the UK and to provide actionable recommendations to enhance the quality of care and support for those affected by the condition.

**Tinnitus UK 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

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Tinnitus, characterised by hearing sounds such as ringing or buzzing without an external source<sup>1</sup>, affects one in seven adults in the UK<sup>2</sup>. While it can be a temporary annoyance for some, for others, it becomes a persistent and distressing companion.

For one in six people with tinnitus, the condition severely affects their ability to lead a normal life. This proportion is considerably higher in those that contact Tinnitus UK for support. Home, work and social life can be disrupted, leading to significant associated societal and healthcare costs.

Tinnitus-related healthcare costs in the UK amount to £750 million annually<sup>3</sup>, with an anticipated increase as eight million people are expected to be affected by 2025<sup>4</sup>.

At present, there is no known cure for tinnitus, and many tinnitus sufferers feel current treatment options are insufficient and often ineffective, and that health care professionals lack knowledge of the condition, and do not understand the impact it has<sup>5</sup>.

**The National Institute for Health and Care Excellence (NICE) published new tinnitus guidance in March 2020<sup>6</sup>. This was designed to help healthcare professionals ensure a standardised care pathway and give patients appropriate reassurance, information and referrals.**



# People's experiences of tinnitus

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People's experiences of tinnitus vary widely across four main aspects<sup>7</sup>:

## 1. **How the sound is experienced:**

This includes where the sound is heard, its pitch (whether high or low), the type of sound, and its duration.

## 2. **Possible causes:**

Various factors, such as hearing loss, issues with the jaw joint, age, and other health conditions like depression or sleep problems, can contribute to tinnitus.

## 3. **Emotional impact:**

Individuals react differently to the distress caused by tinnitus, impacting mental well-being and emotions.

## 4. **Response to treatment:**

Different individuals respond in unique ways to treatments for tinnitus.

Although not officially classified as a disability, tinnitus aligns with the description of an 'invisible disability' by the Invisible Disability Association<sup>8</sup>.

Respondents were asked about feelings they have experienced more frequently since developing tinnitus, both at any time since diagnosis and in the last year. Findings revealed that:

- More than two-thirds (68.4%) experienced feelings of low self-esteem in the last year.
- Over half (54.0%) found it challenging to make decisions,

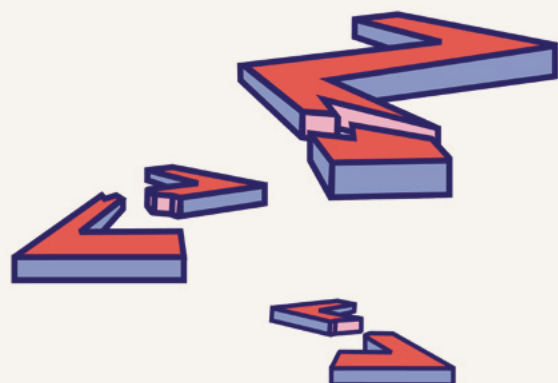
and a similar percentage (54.9%) struggled to think rationally.

- A significant number (52.3%) reported no longer deriving enjoyment from life.

Contrary to expectations that these impacts would diminish over time, only self-esteem varied. Almost 9 out of 10 individuals diagnosed in 2023 reported more frequent feelings of low self-esteem compared to 2 out of 3 of those diagnosed in 2019 or earlier.

Sleep difficulties emerged as a prevalent issue, with 85.7% struggling to fall asleep or stay asleep due to tinnitus in the last year, compared to 69% in a similar survey in 2020<sup>5</sup>.

**"I was very stressed, suicidal and unable to sleep"**



Tinnitus was identified as a highly isolating condition, with:

- Two-thirds (66.7%) of respondents avoiding contact with friends and minimising social activities.
- 67.8% reporting difficulties in home, work, or family life.
- Three-quarters (73.6%) expressing that their partner or family did not understand their situation.
- Three-quarters (73.6%) also felt they had no one to turn to, compared to 1 in 3 in 2021<sup>9</sup>.

**“My mental health plummeted. My career was affected. I was signed off work for a month because I couldn’t mentally cope anymore. Still no help offered.”**

These findings underscore the profound impact of tinnitus on various aspects of individuals’ lives, highlighting the urgent need for enhanced support and understanding.

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## The impact on mental health

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Tinnitus exerts a significant influence on an individual’s overall quality of life, with severe repercussions on mental health.

Survey findings reveal a substantial majority (83.3%) of respondents reporting feelings of low mood or sadness in the past year, a striking increase from 51.9% in 2021<sup>9</sup>.

A concerning aspect emerges as almost 4 out of 10 respondents (37.8%) admit to experiencing suicidal thoughts or thoughts of self-harm since being diagnosed. Further analysis indicates a significant rise, with 1 in 5 individuals (21.3%) grappling with these thoughts in the last year, marking an extraordinary increase from 9.3% in 2021<sup>9</sup>. These statistics underscore the profound impact of tinnitus on individuals’ mental well-being.

**“I was having thoughts of ending my life – I did not see how I was going to live with the noise in my ear.”**

The majority of respondents (83%) report heightened levels of anxiety, surpassing the 71% reported in 2020<sup>5</sup>. Additionally, 7 out of 10 individuals (69.8%) express feelings of hopelessness or helplessness, reflecting a marked increase from 36% in 2020<sup>5</sup>.

These figures serve as a stark visual representation of the substantial toll tinnitus can take on mental health, emphasising the urgent need for comprehensive support and intervention measures to address the psychological challenges associated with this condition.



**"I was  
basically  
told I have  
tinnitus and  
to just live  
with it.  
No support,  
no advice."**



# People's experiences of healthcare support for tinnitus

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The initial contact with a health professional plays a crucial role in shaping the progress and outcome of an individual's condition. Our survey highlights the importance of the first GP appointment in determining the effectiveness of subsequent care.

## Getting an appointment

Approximately half of the respondents successfully secured a GP appointment in less than a week from their initial call. This trend remained consistent across the 2020-2023 period, showing a slight increase from 47.0% in 2019 and prior to 47.6%. However, a notable proportion, nearly one in six individuals (16.0%), faced a waiting period exceeding one month for a GP appointment in both time periods.

Face to face appointments were almost universally offered, even throughout the pandemic, and equally as universally preferred, although some patients accepted telephone

consultations. A small number of GPs began to offer video consultations in 2021.

## Improved messages of reassurance

The survey reveals a positive shift in the reassurance provided by GPs. In 2020<sup>5</sup>, only 27% of GPs offered reassurance, which has now increased to 30%. However, this still falls short of the recommended level in the NICE guidance, which recommends that reassurance should be given at first point of contact.

Dissatisfaction with initial GP consultations is evident, with almost 4 out of 10 individuals (37.3%) expressing unhappiness with the advice received, citing insufficient knowledge or information about the condition from the health professional. Comments from respondents painted a picture of a negative outlook and a lack of hope.

**"I felt dismissed and at some points that I'd had enough and couldn't cope/carry on as I was."**

## Access to information

The availability of information about tinnitus from GPs remains a concern. Our 2020 survey indicated that only 14% of respondents received information from their GPs<sup>5</sup>, a percentage that has marginally increased to 15% in the current survey but still remains low.

There is a pressing need for healthcare professionals to provide patients with comprehensive information on tinnitus.

While the sharing of printed materials diminished during the pandemic, technological advancements offer alternative solutions. Operating systems enabling GPs to send text messages with links to websites or digital information leaflets can bridge the information gap. However, this is contingent on GPs being aware of available resources through organisations like Tinnitus UK, as only 7.5% of respondents reported receiving details about tinnitus charities.

**"I've been very upset by it, the only way I'm learning to live with it is from looking at the internet."**

## Referrals to secondary care

In our 2020 survey, approximately two-thirds of patients (64%) were referred to secondary care<sup>5</sup>. The current proportion is slightly lower, standing at fewer than 6 out of 10 (57.9%). Even before the pandemic, a recognised lack of clinical capacity in secondary care services had been identified. The pandemic further exacerbated the situation, leading to increased rejections of referrals to specialist care. Presently, approximately 1 in 10 individuals (11.7%) report not being offered a referral, indicating persistent challenges in accessing timely specialist support.

**"Took me five appointments before I could get an ENT referral as each GP before the fifth visit wanted to prescribe anti-depressants, tranquilisers or beta blockers"**

A British Medical Association (BMA) study indicates that patients are currently facing "significant backlogs" for specialist care which will take "years to clear."<sup>10</sup>. Anecdotal reports from both patients and GPs suggest a concerning trend of refusals for referrals, highlighting the ongoing difficulty in obtaining prompt access to specialised support.

For those fortunate enough to secure a referral, almost 9 out of 10 individuals found themselves without additional support from their GP during the waiting period. This underscores a gap in continuity of care that requires attention.

## Referrals to mental health support

Despite the evident negative impact of tinnitus on the mental well-being of the majority of respondents, very few received corresponding support from their GP.



Only 1 in 20 individuals (5.0%) were offered cognitive behavioural therapy (CBT), a well-researched and effective treatment for tinnitus, as recommended by the National Institute for Health and Care Excellence (NICE) guidelines<sup>6</sup>.

These guidelines suggest offering CBT therapies to individuals experiencing continued emotional and social distress or disruptions in day-to-day activities despite receiving tinnitus support.

Notably, GPs made no referrals to mindfulness-based therapies, but 1 in 15 respondents received other forms of psychological support. The Association of Clinical Psychologists has reported "severe and longstanding deficits in the numbers of clinical psychologists throughout the NHS,"<sup>11</sup> potentially explaining the GPs' limitations in making referrals for mental health support. This highlights a systemic challenge that needs to be addressed to ensure comprehensive mental health care for individuals grappling with tinnitus.

**In summary, these findings underscore the imperative for enhancements in the initial stages of tinnitus care, including timely access to appointments, improved reassurance, increased dissemination of information by healthcare professionals and increased access to psychological support.**

**"I still struggle every day"**

**“Whilst I  
could see my  
GP quickly, it  
took months  
and months to  
see the ENT  
specialist.”**

# Audiological services provision

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## Getting an appointment

Responses to our survey suggest there has been an increase in waiting times to see Ear, Nose, and Throat (ENT) or audiology specialists over the past five years. For those diagnosed in 2019 or earlier, a majority (56.5%) received attention within two months, a figure that dropped to a third (34.1%) between 2020 and 2023.

**“[I’m] awaiting follow up appointment and hearing aids. Told it’s a 15 month wait.”**

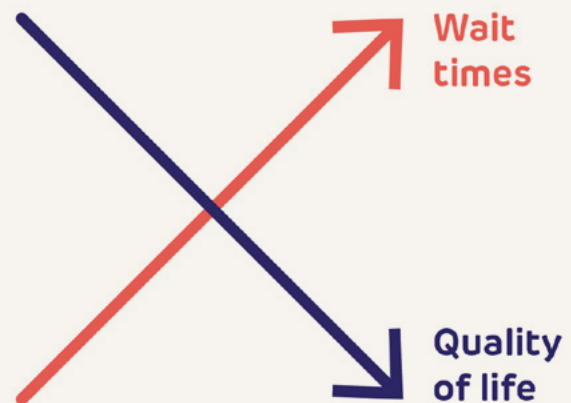
The percentage of individuals waiting more than 12 months for secondary care appointments has surged from 5.8% to 17.1%, particularly impacting those diagnosed in 2023.

This rise aligns with the British Association of Audiovestibular Physicians’ assertion that audiological capacities faced limitations pre-pandemic<sup>12</sup>, and the BMA’s findings of “a stubbornly high number of unfilled vacancies”<sup>10</sup>, a challenge that persists.

### a. Impact on quality of life

A significant majority (65.8%) of respondents noted that the wait for ENT/audiology appointments negatively affected their quality of life. Among those diagnosed between 2020 and 2023, a quarter (25.0%)

described the impact as “severe,” in stark contrast to only 12.4% of those diagnosed in 2019 or earlier, possibly reflecting the recent increase in waiting times.



**“In hindsight, the waiting time undoubtedly made the condition worse, as I now understand the link with anxiety. I got into a negative feedback loop.”**

### b. Appointment preferences

Face to face appointments were consistently offered by ENT and audiology departments. Telephone appointments became more routinely offered in 2020 and video consultations in 2021.

Survey respondents generally preferred in-person appointments, although 21.9% opted for telephone consultations, and 10% embraced video appointments at least once.



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## Current treatments for tinnitus in secondary care

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Although there is no cure for tinnitus eliminating the perception of sound, proven methods exist to minimise its impact. The National Institute for Health and Care Excellence (NICE) guidelines outline standardised care pathways, which involve offering patients appropriate reassurance, information, and referrals<sup>6</sup>.

As tinnitus is a very individual condition, the techniques which are successful will also vary from person to person, and a combination of management strategies may be necessary.

These approaches include information sharing, talking therapies or psychological support, relaxation and stress reduction techniques, sound amplification (via hearing aids) and sound therapy<sup>13</sup>.

Hearing loss is very common in people with tinnitus. For those experiencing hearing loss and tinnitus, a hearing aid can be very effective<sup>14</sup>. Hearing aids and combination devices that blend therapeutic sounds with amplification, were the most offered treatment devices (50.7%).

Ear-level sound generators (maskers) are an alternative for those with normal or near-normal hearing, providing low levels of white noise without built-in amplification. Bedside sound generators emitting soothing environmental sounds can be helpful for those struggling with tinnitus at night. Sound therapy devices were offered to around 1 in 5 (18.1%) of respondents, which perhaps reflects

that many options are commercially available at reasonable cost.

To address psychologist shortages, some audiologists provide basic psychological management, while plans for internet-based Cognitive Behavioral Therapy (CBT) are underway. However, only 6% of respondents were offered CBT or internet-based CBT. Mindfulness-based cognitive therapy (MBCT) was offered to 1 in 20 (4.7%) respondents.

The BMA's analysis of data provided by NHS England shows that more people are asking for mental health support than ever before but that the mental health workforce and funding is not rising at the rate needed to meet current demand<sup>10</sup>.

Despite a greater provision of information and reassurance in secondary care compared to primary care, less than one-third (29%) felt practitioners provided advice and reassurance, with a similar number (27.3%) being provided with information leaflets. Few patients were given details of tinnitus charities (4.7%) or tinnitus self-help groups (6%).

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## Insights from audiology services

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Tinnitus UK contacted all audiology services in their database through email, their regular newsletter FOCUS, and social media channels. We received ten responses representing nine NHS services in England and Wales and as just two completed the survey in full, we were not able to draw comparisons with patient-reported experiences.

# NICE guidelines

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The publication of NICE guidelines<sup>6</sup> in March 2020 addressing tinnitus assessment and management was unfortunately overshadowed by the onset of the Covid-19 pandemic and the subsequent national lockdown.

The capacity of healthcare professionals to engage with the guidelines and to follow some of the key principles was reduced.

Our intended investigation into the engagement with NICE guidelines and others, including the British Society of Audiology Practice Guidance – Tinnitus in adults<sup>15</sup>, faced limitations due to a lack of responses to our survey.

## Tinnitus and Covid-19

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In December 2020, NICE officially recognised tinnitus as a common symptom of Covid-19 and long Covid<sup>16</sup>.

A study in November 2020, supported by Tinnitus UK (then known as the British Tinnitus Association), found that Covid-19 and associated safety measures were exacerbating existing

tinnitus symptoms<sup>17</sup>. Additionally, pandemic-induced stressors, such as financial concerns and anxiety, contributed to heightening the distress caused by tinnitus. The surge in both the number of people experiencing tinnitus and the severity of symptoms has intensified the demand for tinnitus support services.

# Tinnitus UK support and services

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Tinnitus UK is dedicated to providing a range of services backed up by the latest research to help people to live well with tinnitus. These services include support groups, a telephone helpline, a chatbot named Axel, web chat support and advice and a relaunched website. They also offer training and resources for medical professionals to ensure people with tinnitus get the right information and advice.

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## Tinnitus Support Team

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Tinnitus UK's Tinnitus Support Team respond to those reaching out via a freephone helpline, webchat (with Axel, a 24-hour chatbot, launched in January 2023), email and SMS/text.

Figures from Tinnitus UK's Annual Report 2022/23 show that 11,000 people contacted the Tinnitus Support Team<sup>18</sup>.

Calls, chats and emails are becoming more complex as more callers present with several interlinked conditions, exacerbated by their anxiety and stress. 11% of callers are medically signed off work due to their tinnitus or tinnitus-related issues.

Instances of suicidal ideation expressed during calls or chats have increased fourfold since 2020.

Discussions about talking therapies like CBT and mindfulness have risen by 47% since 2019, reflecting increased awareness and demand. Calls focusing on psychological and emotional support have increased by 21% during the same period.

The duration of calls has also seen an uptick, with approximately 42% lasting over 15 minutes in the last quarter, and some extending to an hour. The average webchat duration stands at 18 minutes.

**“[I would have] felt somewhat abandoned had I not realised so many of the people I knew also had tinnitus and had I not joined Tinnitus UK”**

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## Peer support

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Recognising the importance of peer support in tinnitus management, Tinnitus UK facilitates connections between individuals facing similar challenges. Despite some regional groups closing due to pandemic restrictions, Tinnitus UK currently has 85 affiliated support groups. Four online support groups, including one for individuals dealing with both tinnitus and hyperacusis, are hosted. An active online forum has witnessed a 48% growth in users in the past year.

The Tinnitus UK Befriending service pairs vulnerable and isolated individuals with tinnitus with volunteers who are successfully managing the condition. The demand for Befrienders exceeds the available volunteers, resulting in a waiting list for support.

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## Information and education

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Tinnitus UK offers an extensive library of over 40 information sheets, 75 treatment checker sheets, and a program of online workshops and webinars. These resources are freely accessible, with nominal charges for workshops and webinars to enhance accessibility.

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## Resources for professionals

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In addition to supporting those affected by tinnitus, Tinnitus UK aids professionals in providing optimal support to their patients through education and patient resources.

The Tinnitus UK Annual Conference, now conducted virtually, features the latest research developments, practical advice for service improvement, and specialist sessions.

The Tinnitus Adviser Training course, a longstanding and respected initiative, continues to be delivered online, attracting 38 attendees from audiologists, ENT specialists, and other healthcare professionals during the year.

This commitment underscores Tinnitus UK's dedication to advancing tinnitus management.

# What needs to change?

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The findings of this report have been discussed with practicing health professionals from a range of disciplines who have worked with Tinnitus UK to develop key calls to action that would be the most impactful when it comes to improving the patient experience.

**1** Commissioners need to invest in proven secondary tinnitus services.

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**2** Evaluate and investigate tinnitus services in secondary care.

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**3** Introduce a standardised nationwide management model for tinnitus.

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**4** Elevate tinnitus within medical education.

# 1

## **Commissioners need to invest in proven secondary tinnitus services.**

Health commissioners are urged to allocate resources to established secondary tinnitus services, ensuring GPs can refer patients without subjecting them to prolonged waiting times.

Adequate funding for specialist secondary tinnitus services is essential for implementing NICE guidance, offering crucial support for effective tinnitus management.

Recognised as highly effective, support from psychologists and other secondary care specialists, particularly through psychological treatment modalities, is a key part of successful tinnitus management and reduces the mental health burden.

# 2

## **Evaluate and investigate tinnitus services in secondary care.**

Despite the UK's well-developed tinnitus services, patient dissatisfaction and a lack of psychological treatments persist. Patient experience surveys, while valuable, have limitations.

A new large-scale study, focusing particularly on the availability of psychological treatments, could identify areas of good practice and reveal unmet needs, providing a more nuanced understanding of the existing landscape.

# 3

## **Introduce a standardised nationwide management model for tinnitus.**

By introducing a standardised nationwide management model, based on research into best practice, as recommended by the NICE guidance, we would ensure a better standard of care and a more consistent patient experience.

The NICE tinnitus guidelines recommend further research into standardising the assessment of tinnitus in general practice across the UK. We would urge funding bodies, researchers and clinicians to collaborate to develop a wider management model encompassing primary and secondary care.

# 4

## **Elevate tinnitus within medical education.**

Generalist medical practitioners face the challenge of maintaining broad knowledge on numerous conditions. The limited inclusion of tinnitus in medical education—often a single lecture or an online webinar—should be expanded due to tinnitus’s prevalence and severe impact on mental health and quality of life. Increased exposure to tinnitus education at all levels of medical training, with assessment, is recommended.

Additional educational resources, such as the Royal College of General Practitioners’ tinnitus module and Tinnitus UK’s training, are available for GPs.

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Please email [research@tinnitus.org.uk](mailto:research@tinnitus.org.uk) if you have any questions about our survey data.

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