What’s that noise?

A profile of personal and professional experience of tinnitus in NI

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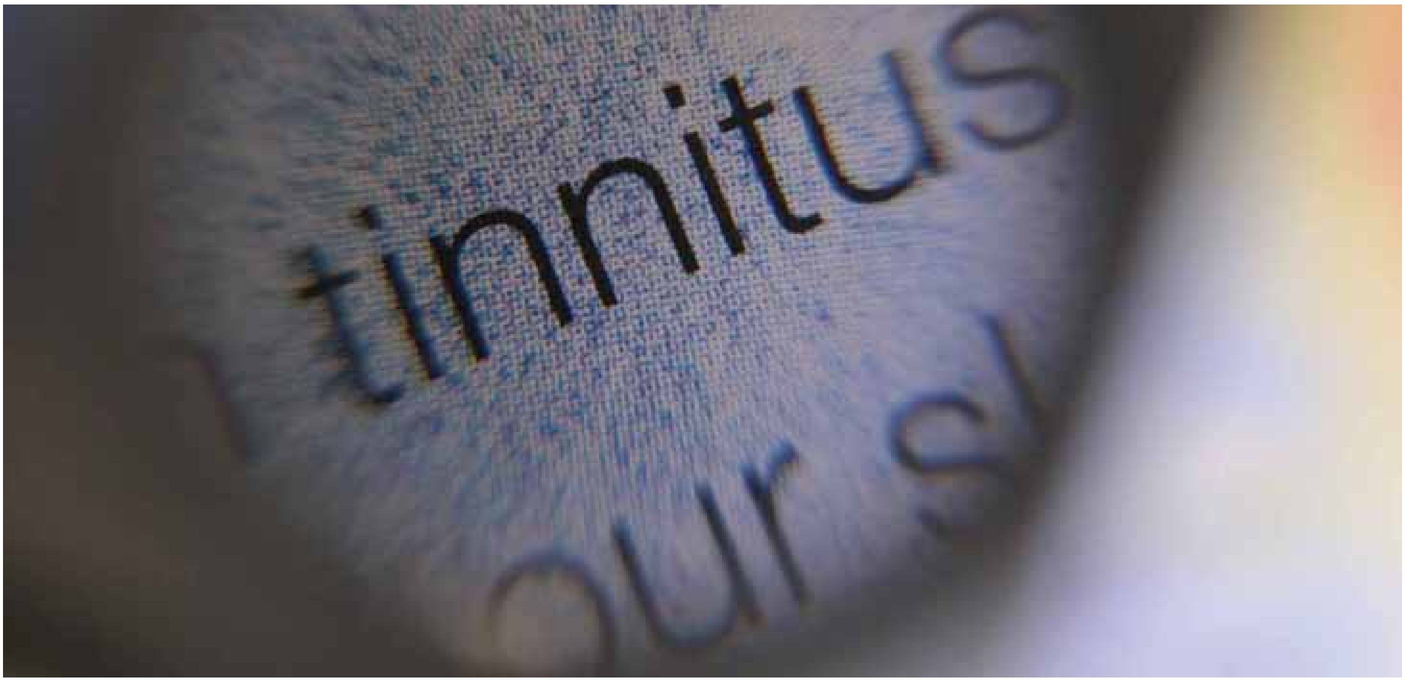
Introduction

> "One time I remember saying to myself, whenever it was very bad, how am I ever going to live with this noise in my head non-stop. I can't go on with life. I was going to take an overdose, I just couldn't hack it. It really, really got to me." (R)

Between April 2008 and March 2010, there was a 50% increase in the number of people who contacted RNID Northern Ireland requesting information about tinnitus. Most of those who contacted us were extremely distressed because of their tinnitus. Their anecdotal evidence suggested that there was limited support available for people with tinnitus in Northern Ireland. This, together with the increased demand for information about tinnitus from RNID, prompted us to undertake research for two key reasons:

1. To gain a better understanding of people's experience of living with tinnitus in Northern Ireland.
2. To gain an overview of statutory and voluntary sector service provision for people with tinnitus in Northern Ireland.

Key findings: people with tinnitus



Qualitative data was collected via interviews with 20 participants with tinnitus.

From our research, we can estimate that there are approximately 178,900-357,800 people with tinnitus in Northern Ireland, and that tinnitus severely affects 8,945 of them.

Over half **(51%)** of the 88 GPs surveyed for this research stated that they see between one to three patients a month with tinnitus.

Tinnitus can have a significant impact on people, leading to a real deterioration in their quality of life. It can have a negative effect on mood; in some cases resulting in depression, suicide ideation and attempts to take their own life.

At onset, some participants were unaware that the noise they were hearing was tinnitus, while others were concerned that it was a symptom of an underlying medical condition. Most participants were unable to identify what had caused their tinnitus. Many were aware of tinnitus at night when trying to fall asleep or when alone in a quiet environment.

The majority of participants sought support from their GP within the first six months of their tinnitus starting. Some stated that their GP was sympathetic and supportive. Others stated that their GP was sympathetic, but did not have an understanding of tinnitus and as a result was unable to support them. More than half of participants were dissatisfied with the support they received from their GP, audiologist and/or ENT consultant.

The majority of participants who had been referred to a hearing therapist and the one individual who had been referred to a mental health service stated that they benefited greatly from the support they received.

A number of participants stated that they had to wait for an extended period of time, following referral from their GP, before been seen by an audiologist, ENT consultant or hearing therapist. One individual waited eight months before been seen by a hearing therapist.

All participants who had contact with Health and Social Care (HSC) Trusts were satisfied with the support they received. They benefited greatly from knowing that they had a contact at the Trust to whom they could turn and talk to. Those attending a tinnitus support group and/or tinnitus course also found the support beneficial and expressed concern about losing it. A number of participants were unaware that HSC Trusts provided support for people with tinnitus. Some participants who were aware of Trust support stated that they would consider attending a group and/or course if their tinnitus became worse.

The majority of participants found tinnitus most difficult to manage in the first two to three years. Often it was a case of trial and error before they developed coping strategies or found a method of relief which worked for them. Some participants were unsuccessful in developing coping strategies or finding relief. Some developed strategies or found relief independently, while others did so in conjunction with health and social care professionals.

Coping strategies included:

- creating a distraction
- keeping mentally and physically occupied
- ignoring, avoiding or reducing trigger factors
- maintaining a sense of control
- adopting a positive mental attitude.

Methods of relief included:

- wearing hearing aids
- listening to sound generators
- using complementary therapies
- taking medication
- avoiding noisy environments
- seeking noisy environments
- maintaining a routine, especially at night
- drinking alcohol
- reducing caffeine, chocolate, sugar and salt intake.

There is a lack of information available to people with tinnitus and the information that is available may be inaccessible to sign language users who are deaf. Most participants found information about tinnitus on the internet. Some participants sourced information directly from RNID and the British Tinnitus Association (BTA). Others had never heard of RNID or the BTA and were unaware that these organisations could provide them with information.

In general, members of the public, including family and friends of people with tinnitus, have limited understanding and knowledge of tinnitus. Many participants had never discussed tinnitus with family and/or friends.

Key findings and recommendations: GPs, audiologists, ENT consultants and HSC Trusts

Quantitative data was collected via questionnaires.

- 15% (174) (n=1,154) GPs returned questionnaires.
- 91% (10) (n=11) heads of Audiology returned questionnaires.
- 33% (10) (n=30) ENT consultants returned questionnaires.
- 56% (5) (n=9) sensory support team leaders within Health and Social Care (HSC) Trusts returned questionnaires.

Key findings

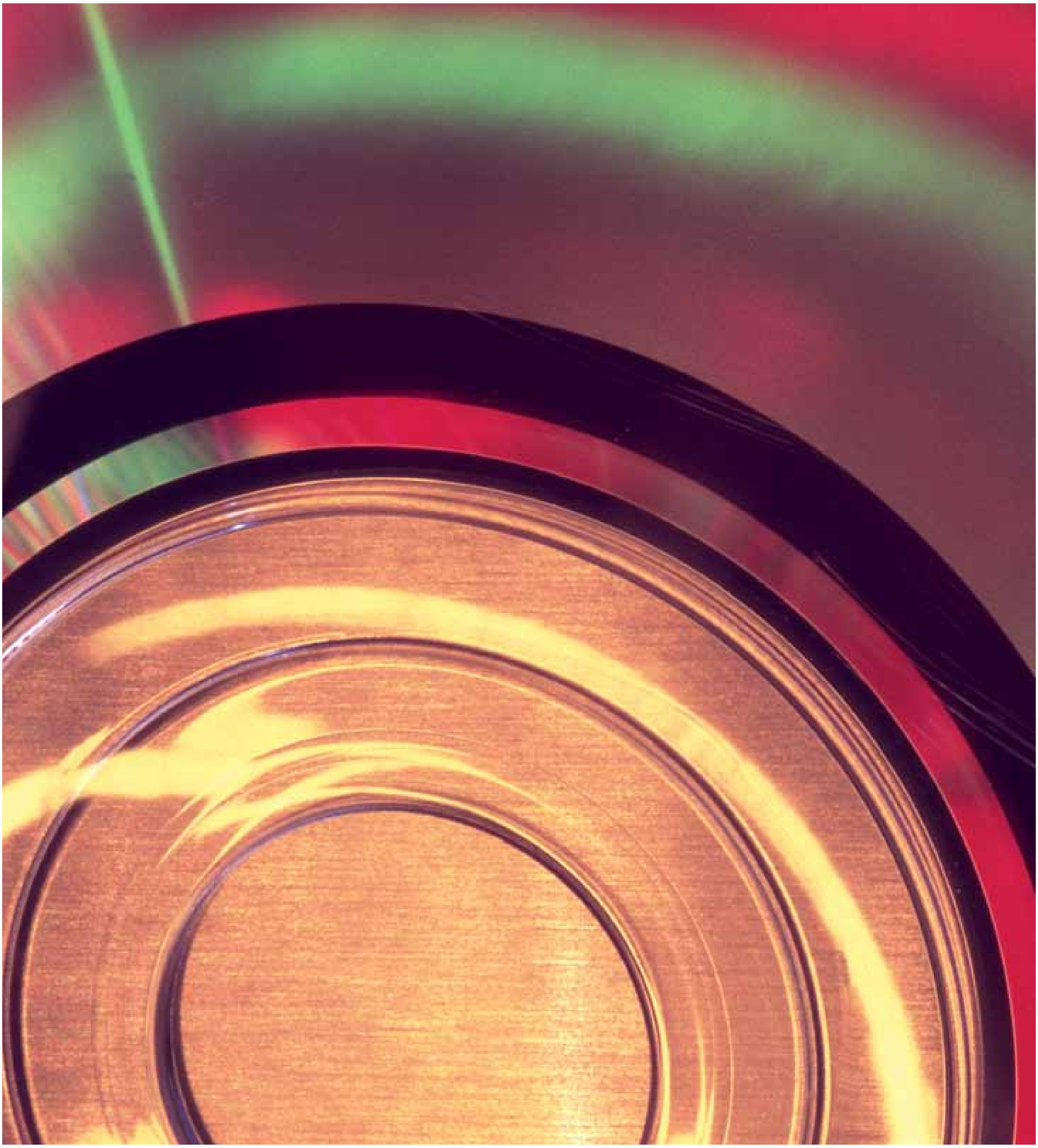
(57%) 99 GPs had never received tinnitus training.

(82%) 143 GPs did not have opportunities to undertake continuing professional development (CPD) courses on tinnitus.

(77%) 134 GPs stated that they would like to receive tinnitus training. All audiologists agreed that undertaking additional training in psychological approaches to tinnitus management would be beneficial.

Key recommendations

- As part of their undergraduate degree, medical students, audiology students and social work students to receive tinnitus training.
- Resources to be secured to ensure that GPs, audiologists, ENT consultants and HSC Trust staff have opportunities to undertake tinnitus training as part of their CPD.
- Tinnitus retraining therapy (TRT), cognitive behavioural therapy (CBT) and counselling to be considered as options for training.
- The Regional Sensory Impairment Training Strategy Group, responsible for designing a pathway for training sensory support staff employed in HSC Trusts to ensure that pathways are developed which provide opportunities for staff to develop expertise in tinnitus.



Key findings

(81%) 141GPs refer patients with tinnitus to an ENT consultant, (37%) 63 refer patients with tinnitus to an audiologist and (3%) five refer patients to other professional services (for example, counselling or mental health).

Key recommendations

- Clear referral pathways to professional services to be established and made known to GPs, audiologists, ENT consultants and HSC Trusts.
- Waiting times for professional services, such as audiology, ENT and hearing therapy to be reduced and standardised across Trusts.

Key finding

Seven audiologists stated that they do not have sufficient resources to provide an effective tinnitus service.

Key recommendations

- Additional audiologists to be trained to support patients with hearing loss and patients with tinnitus.
- One audiologist in each clinic to be trained to provide specialist support to patients with tinnitus.
- A specialist tinnitus service to be established in Northern Ireland.
- Additional hearing therapists to be trained to support patients with tinnitus

Key finding

The Department of Health Social Services and Public Safety (DHSSPS) does not record the number of people with tinnitus that present to HSC Trusts in Northern Ireland. The SOSCARE (Social Services Client Administration and Retrieval Environment) system that Trusts use to record service user information does not allow for the accurate recording of service users with tinnitus.

Key recommendation

- The DHSSPS and HSC Trusts to develop systems to accurately record the number of service users with tinnitus.

Key finding

None of the GPs surveyed signpost patients to community or voluntary organisations for additional tinnitus support.

Key recommendations

- HSC professionals and community and voluntary organisations to promote their tinnitus services to the general public.
- All HSC Trusts to continue to sustain existing tinnitus services and to develop new services. All Trusts to liaise with RNID to explore partnership opportunities to support service users with tinnitus, including service users who are deaf.

Final comment

Given the increase in people's life expectancy and the link between repeated exposure to loud noise and tinnitus, we can expect the number of adults and young people with tinnitus in Northern Ireland to increase. These factors, combined with a better educated public, suggest that there will also be an accompanying increase in demand for tinnitus services. It is therefore essential that a range of services are developed to meet this demand. Health and social care professionals could potentially work in partnership with each other and with community and voluntary sector providers to maintain existing tinnitus services and develop new services.

In order to do this, the prevalence of people with tinnitus needs to be accurately recorded to ensure that service providers have the evidence they need to plan services and prepare a sufficiently-trained workforce. This research indicates that HSC professionals are aware that they need to improve their knowledge and understanding of tinnitus. Many are keen to undertake CPD courses on tinnitus. It is therefore imperative that they are provided with opportunities to learn more about tinnitus and to develop specialism in this area.

The full copy of this report is available in hard copy. It can also be accessed online at **www.rnid.org.uk**

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