



# Listening to patients

The suitability of BAHA® for single sided deafness

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Single sided deafness was new to us when we were approached by Entific to conduct a patient study to support BAHA. As an established marketing research and consulting company we are used to working on a wide variety of assignments for FMCG, healthcare and business-to-business markets. We are frequently looking for new ways to conduct research and find answers that would not be so clear through a more traditional approach. The brief from Entific was to provide a patient perspective when looking for a single sided deafness indication for BAHA. We were not conducting clinical trials; these were

already in progress in Europe and the USA. Instead we were asked to look at the patient's perception of BAHA and to gain an insight into its likely acceptance and take-up amongst single sided deaf patients.

Working closely with Entific through the German and UK offices, we developed a research methodology with a four-stage process. This would enable us to identify and quantify the different issues involved and provide recommendations for Entific based on the feeling and attitudes of single sided deaf patients.

**The four different stages were as follows:**

1. Initial focus groups in UK and Germany.
2. Large-scale quantitative study in the UK.
3. Follow-up focus groups.
4. Individual depth interviews.



## Stage 1

With the help of audiology clinics, we recruited a sample of single sided deaf patients, with different indications such as Acoustic Neuroma surgery or sudden deafness. The groups followed a standard focus group format where a moderator would conduct a two-hour discussion that covered a number of areas. The respondents were encouraged to speak freely about the issue of single

It often took a while to correctly diagnose their problems. The symptoms varied and included gradual hearing loss, facial “tingling”, loss of taste or balance, headaches or tinnitus. The range of symptoms meant that the patients approached different medical professionals such as the doctor or dentist in the first instance. The symptoms were attributed to various causes such as the nature of work or simply that the ear needed syringing:

*“For 5–6 years I had my ear syringed at the doctors. It started with facial tingling, loss of taste, sensitivity around the lips and the side of the face started to go numb and the penny dropped that I was going deaf.”*

*UK respondent*

It often took them some time to come to terms with their hearing loss although, for some respondents with an Acoustic Neuroma, they had been prepared for far worse once they knew they had a tumour. They had to relearn many basic skills such as balance or making a phone call.

Although they still had hearing in one ear, often 100%, the lack of hearing on one side had changed their lives considerably. Many had had to give up their work or, at least, reduce their hours. One reason for this was the difficulty coping with background noise. This factor also has a major impact on their social lives. It is difficult to attend a social gathering where many people are likely to be talking at the same time.

Friends, family and work colleagues who are aware of their problems are able to help, to some degree, by sitting or walking on the appropriate side. Relationships with those who are unaware of the condition are more fraught. The lack of a hearing aid or other sign of disability means that the condition is “invisible.” Consequently, the patient may be seen to be behaving in an unusual way.

*“People think I’m healthy but they don’t know what I feel inside.”*

*German respondent*

There was little use of existing aids such as a cross-aid. In Germany some respondents noted that a cross-aid exaggerated their problems rather than helping them.

*“I have a cross-aid, difficult to know from where the sound comes!”*

*German respondent*

## Stage 2

Stage 1 gave us a strong feeling for the key issues surrounding single sided deafness. We now looked to quantify these issues and ascertain whether they were representative of the overall single sided deaf population as well as provide an indication of the proportion of patients who would like to have BAHA fitted. We conducted this stage in the UK only. We were very fortunate to have the support of the British Acoustic Neuroma Association (BANA) who agreed to distribute our questionnaire amongst their membership. Their help was crucial to the success of this exercise. All patients recruited for Stage 2 had undergone Acoustic Neuroma surgery.

We were very pleased with the response received. While a postal questionnaire may normally elicit a low response rate (less than 5%), around 48% of the questionnaires were returned to us. This was a strong indication of the interest in the subject. It also means that the results are highly meaningful.

We confirmed that the respondents had suffered from a variety of symptoms prior to diagnosis (Figure 1) and therefore it may be some time before they are referred to an ear, nose & throat specialist. 93% turned to their general practitioner in the first instance.

*“People think I’m healthy but they don’t know what I feel inside.”*

sided deafness and the problems they faced in their everyday lives. The objective of these initial sessions was to provide a platform for the later quantitative analysis through developing an understanding of single sided deafness from the patients’ point of view.

At first we were unsure as to the level of openness and willingness to share problems and experiences amongst the group. However, this was not the case and, for many of the respondents, it seemed that this was the first real opportunity they had had to talk to people in the same situation as themselves. They welcomed the chance to discuss their problems and learn from others. The extent to which acoustic neuroma patients had been prepared for totally losing the hearing in one ear varied but, in general, the level of help and support they received, post operation, appeared to be negligible. Many respondents felt that they had been left to cope on their own and would have welcomed the opportunity to discuss single sided deafness with an existing sufferer prior to the operation.

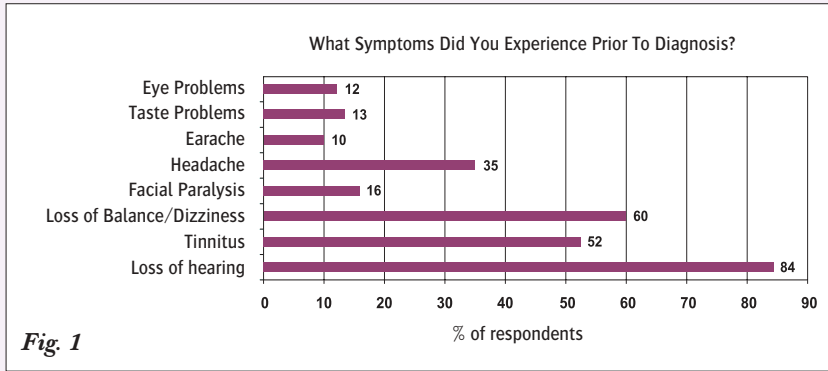


Fig. 1

Since becoming single sided deaf, the biggest problems experienced are the lack of “stereo” hearing (79% of respondents), difficulties as a pedestrian (56%), social exclusion (55%), difficulties in a group situation (54%) and difficulties with the telephone (41%). 39% said that work had become more difficult. These problems may be more common amongst those who have been single sided deaf for less than one year and this may be because others have become more used to their situation.

We asked respondents whether they agreed with different statements about living with single sided deafness. The results from this suggested there is a level of becoming accustomed with being single sided deaf. However, half of the respondents agreed that they “feel like an idiot” when they do not know who said something and 66% believe that the quality of life is more important or that being single sided deaf is not much of a problem in the “grand scheme of things” (44%). 69% said they learn to cope with the problem and part of coping is becoming more philosophical about their situation and getting on with their lives.

However, when asked what they would like to improve their quality of life, 61% opted for a device to improve their hearing. Although they have learned to cope and live their lives differently, improving their hearing is more important than coping better with the current situation

through more help and understanding.

83% of respondents said that BAHA sounded like a good idea although a lower proportion (59%) said they would like to try it. While this is nonetheless a high proportion and a strong acceptance of the BAHA concept, there may be some reluctance to upset their lives especially when they have been single sided deaf for some time or are more elderly. 82% said they would be interested in finding out more about BAHA.

Over half of respondents would be prepared to undergo a second operation to have BAHA fitted and 42% would like to have had it fitted during the initial acoustic neuroma operation.

The “invisibility” of BAHA was seen to be very important (65%). 44% agreed that it would help them regain their social life and 43% said that their family would like them to have it.

### Stage 3

But does BAHA really work for them? Around 90% of respondents from stage 2 were willing to participate in the final stages of our research. We contacted a sample of these patients and found a very real willingness, even eagerness, to help with the research. For stage 3 we returned to the discussion group. All the respondents knew they would be given the opportunity to try BAHA for themselves.

We commenced the sessions with a small presentation from a qualified audiologist to explain how BAHA could help those suffering from single sided deafness. This explanation was vital to help them understand how the device works.

This was not a clinical trial and we acknowledged to the respondents that the test would have a number of constraints. These were as follows:

- The BAHA tester would not provide the same level of conductivity that a BAHA implant would be able to generate.
- It could be uncomfortable to wear, especially for an extended period, but this was necessary to provide the best possible test of the device.
- The short test would be unable to replicate any “learning effect” from using BAHA over an extended period.

*“I’ve spent so long not hearing anything that it’s quite amazing.”*

The more the respondents learned about BAHA, the keener they were to try it, noting that there were minor disadvantages that would be clearly outweighed by the hearing improvements BAHA seemed to offer.

*“I’d love the ability to hear in my right ear, sorry on my right side again.”*

*“I’ve spent so long not hearing anything that it’s quite amazing.”*

Once they had the BAHA tester there was an immediate effect for many respondents and they claimed to be hearing from the deaf side. The amount they could hear and its clarity appeared to vary although many respondents were able to hear whispered voices. The general consensus was that they could hear from the “deaf” side and that their overall hearing was improved.

We undertook a small number of non-scientific tests to better understand the impact that BAHA was having. There was some evidence that the respondents were able to judge the direction of sound and some suggestion that this improved over the course of the directional tests.

*“I could pick it (sound) up on both sides but I still kept wanting to turn my head.”*

*“It makes me feel as if I have two sides to my body.”*

*“I can hear you now. That’s amazing.”  
(With good ear blocked)*

It was felt that BAHA would be very useful in social situations, especially when there is music in the background. Other tests included having a discussion in a crowded hotel bar or in the vicinity of a busy road. The respondents were very pleased with BAHA in these situations and they claimed to have understood the discussion well. These are situations that would normally be very difficult for them.

*“I was surprised that I could hear despite the background noise.”*

The possibility of testing BAHA over an extended period at home was seen to be very useful to examine its effectiveness.

#### Stage 4

The final stage of the research, which is still in progress, allows some of the respondents from stage 3 to use the BAHA tester for a longer period so they could judge the impact of BAHA at home or at work. At the end of this we conducted a one-on-one interview with the respondent. We were also very fortunate to be able to speak with one UK patient who had recently had a BAHA fitted.

*“I can listen to music now. I can go out shopping with more confidence. It gives me the confidence to mix more with people.”*

#### BAHA wearer

While this is no claim that the quality of life returns to how it was before the hearing loss, there is clearly a distinct improvement that allows the BAHA wearer to undertake activities that were previously out of reach. Relationships with friends and family can improve as the BAHA wearer is able to join in more activities such as family social events.

#### Conclusions

The principal conclusion that we can draw is that patients believe BAHA does work and can restore a great deal of quality to their lives.

It is important that patients be prepared for the loss of hearing on one side prior to any operation that results in single sided deafness. It was evident that the level of preparation was poor. There needs to be far more support for acoustic neuroma patients prior to an operation and this should include participation in self-help groups and the opportunity to talk to those already suffering from single sided deafness and learn what it is like to live with on a daily basis.

At this point patients will be in a better position to judge whether they would like to have BAHA fitted at the same time as any other operation. There is naturally some reluctance to undergo a later operation to have BAHA fitted. The result of a combined operation is that patients will not have to relearn how to run their lives twice and will experience minimal disruption in coping with single sided deafness. This is all the more important for younger patients who still have many years of their working lives remaining.

All in all, there are clearly strong advantages for single sided deaf patients in having BAHA fitted. While BAHA cannot restore hearing in their deaf ear or even provide 100% quality of hearing on the deaf side, it does offer the potential for patients to regain a level of hearing on the deaf side, thereby solving many of the problems they face every day. The net effect looks like a substantial improvement in the quality of life.

*“I can hear you now.  
That’s amazing.”*

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