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Supported Hearing in Elderly Citizens

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SHiEC

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Abbreviations

Term	**Definition**
App	Application
CBAS	Cochlear Bone Anchored Solutions
CI	Cochlear Implant
dB	decibel
DHL	Disabling Hearing Loss
E-mail	Electronic mail
ENT	Ear Nose Throat
Etc.	Etcetera
Fig.	Figure
GPS	Global Positioning System
H	Hours
HRF	*Hörselskadades Riksförbund* (National association for individuals with a hearing impairment)
IT	Information Technology
N	Number
OPCI	*Onafhankelijk Platform voor Cochleaire Implantatie* (Independent Platform for Cochlear Implantation)
OTE	Over-The-Ear
SDT	Self-determination theory
SHiEC	Supporting Hearing in Elderly Citizens
U.K.	United Kingdom
WHO	World Health Organisation

1 Background

1.1 Hearing loss

The World Health Organization (WHO) defines a disabling hearing loss as a hearing loss greater than 40 dB (decibel) in adults or greater than 30 dB in children. Approximately 5% of the world population is affected by a disabling hearing loss, amounting to a staggering 360 million people worldwide. It is a chronic condition – almost all damage to our hearing (e.g. due to long overly loud noise or music exposure) is irreversible - and prevalence increases with increasing age. This phenomenon, known as presbyacusis, is illustrated in Figure 1. Above 65 years approximately 1 out of 3 persons is affected.

The impact of hearing loss on people's life extends way beyond the issue of hearing alone. A recent report "The Real Cost of Adult Hearing Loss" states it as follows: "*The impact of hearing loss in adulthood is little recognized. However, it is linked with higher unemployment, poor health, depression, dementia and increased mortality. Hearing loss is unusual in that its effects cross the health, social care and education domains of service provision and affect every aspect of people's lives.*"
(Partially) losing the possibility to communicate with people around you indeed creates difficulties to maintain and build new relations with people surrounding the person. This in turn may lead to feelings of depression, cause withdrawal (social isolation) and lead to loss of a job or reduced income potential. The higher chance for onset of dementia suffering from disabling hearing loss is an illustration of the increase in comorbidities associated with hearing loss.

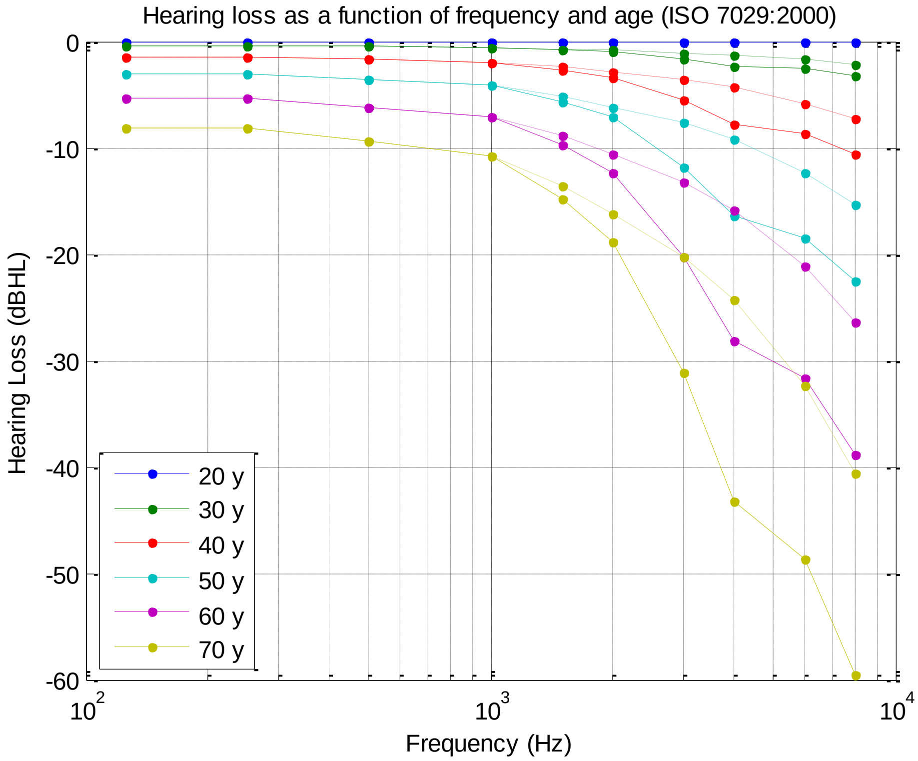


Figure 1. Average hearing loss as a function of age. Full line: males. Dashed line: females. Source ISO 7029:2000 standard.

In 2004 the prevalence of disabling hearing loss was such that it ranked at position 15 in the list of global health issues (2). As the world population is aging and hearing loss is linked to older age, it is expected that DHL will shift to position 6, reflecting the increased clinical need.

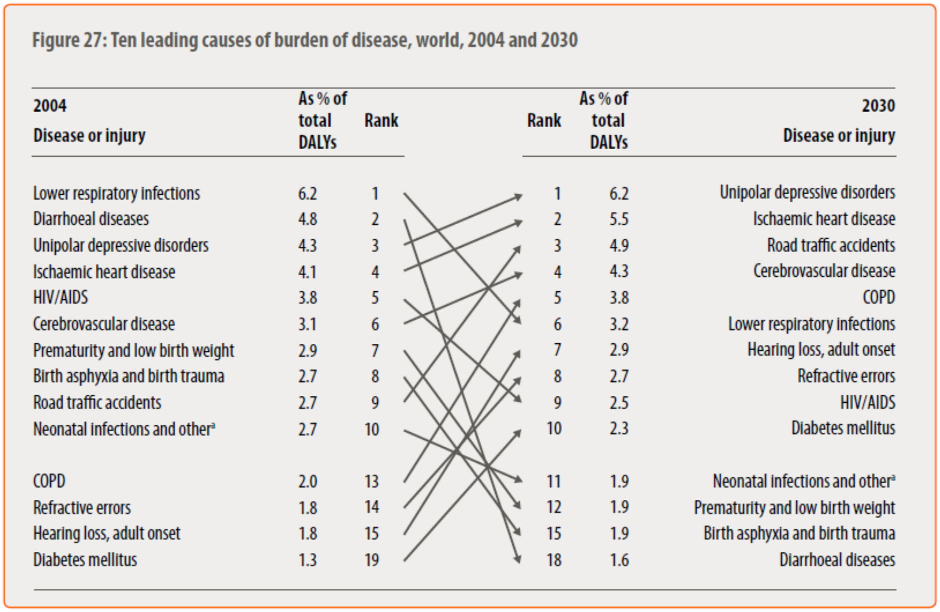


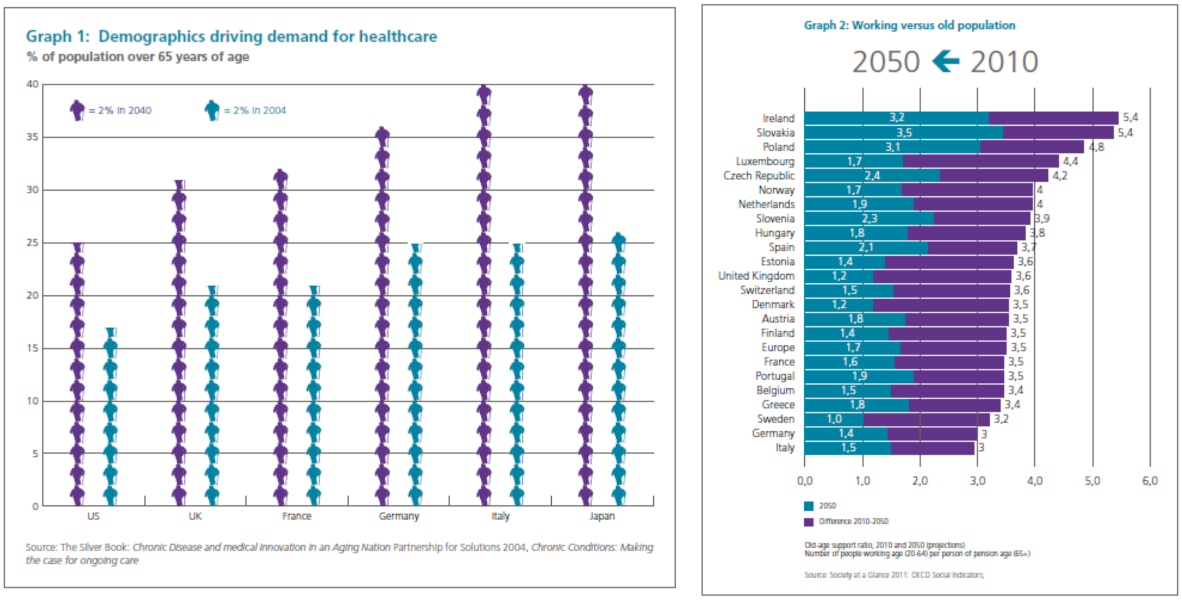
Figure 27: Ten leading causes of burden of disease, world, 2004 and 2030

2004 Disease or injury	As % of total DALYs	Rank	Rank	As % of total DALYs	2030 Disease or injury
Lower respiratory infections	6.2	1	1	6.2	Unipolar depressive disorders
Diarrhoeal diseases	4.8	2	2	5.5	Ischaemic heart disease
Unipolar depressive disorders	4.3	3	3	4.9	Road traffic accidents
Ischaemic heart disease	4.1	4	4	4.3	Cerebrovascular disease
HIV/AIDS	3.8	5	5	3.8	COPD
Cerebrovascular disease	3.1	6	6	3.2	Lower respiratory infections
Prematurity and low birth weight	2.9	7	7	2.9	Hearing loss, adult onset
Birth asphyxia and birth trauma	2.7	8	8	2.7	Refractive errors
Road traffic accidents	2.7	9	9	2.5	HIV/AIDS
Neonatal infections and other[a]	2.7	10	10	2.3	Diabetes mellitus
COPD	2.0	13	11	1.9	Neonatal infections and other[a]
Refractive errors	1.8	14	12	1.9	Prematurity and low birth weight
Hearing loss, adult onset	1.8	15	15	1.9	Birth asphyxia and birth trauma
Diabetes mellitus	1.3	19	18	1.6	Diarrhoeal diseases

Figure 2. Hearing Loss is a top global health issue. From WHO, Global Burden of Disease Report, 2004

Most people with a disabling hearing loss can be helped with non-surgical solutions, such as conventional hearing aids. Hearing implants are indicated if hearing performance remains unsatisfactory under the best aided condition (a bilateral hearing aid). Cochlear implantation is indicated for people with a severe (61 dB or higher) to profound hearing loss (81 dB or higher).

Moreover, the world population is rapidly ageing. Figure 3 illustrates the challenge of the silver wave in terms of the increase of retired people and as an effect the lower ratio of working versus retired people.



Graph 1: Demographics driving demand for healthcare

% of population over 65 years of age

Source: The Silver Book: *Chronic Disease and medical innovation in an Aging Nation* Partnership for Solutions 2004, *Chronic Conditions: Making the case for ongoing care*

Graph 2: Working versus old population

Old-age support ratio, 2010 and 2050 (projections)
Number of people working age (20-64) per person of pension age (65+)

Source: Society at a Glance 2011: OECD Social Indicators;

Figure 3. Demographic evolution in EU countries. Source: Contract for a Healthy Future, Eucomed, 2012.

Gradually the shift towards the senior population becomes more and more apparent in the hearing implant industry. Figure 4 illustrates that tendency in the sales numbers that the senior segment is constantly growing over the last decade.

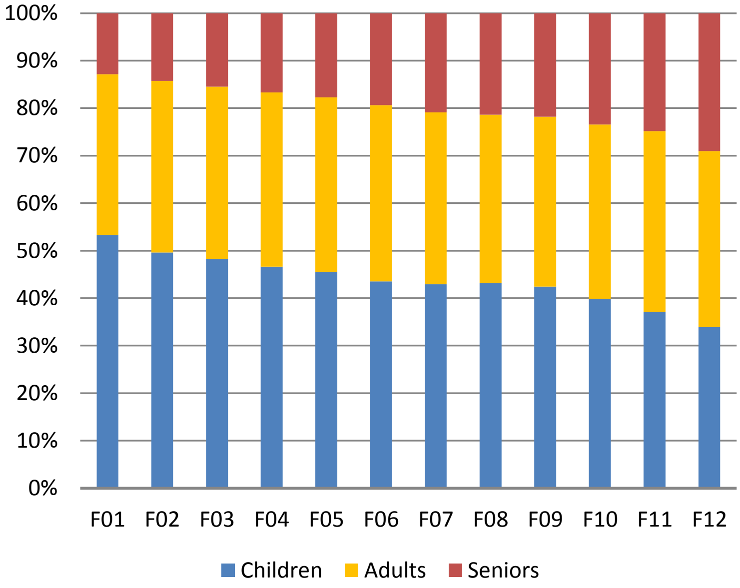


Figure 4. Percentage of cochlear implants sold per annum to children (<18y), adults (<65y) and seniors (>=65y). Internal company data (data up to 2012, Cochlear Ltd).

1.2 Challenges in hearing implant care

Since CI involves lifelong management of the technology, and has a large impact on CI recipients' lives, it is essential that CI recipients become involved in their treatment and have proper self-care practices.

In health care outcomes, human behavior is the largest source of variance (Schroeder, 2007). Literature from chronic health domains suggests that individuals' motivations play a significant role in treatment adherence (Vermeire et al., 2001). Motivation controls and sustains goal-directed behaviors, with three main components; activation (the decision to initiate the behavior), persistence (continued effort toward a goal even though obstacles may exist), and intensity (the concentration and vigor that goes into pursuing a goal).

Self-Determination Theory (SDT; Deci and Ryan, 1985) is an approach to motivation that is concerned with supporting people's natural tendencies to behave in effective and healthy ways. SDT distinguishes between different types of motivation based on the different reasons or goals that give rise to an action. The basic distinction is between intrinsic motivation, which refers to doing something because it is inherently interesting or enjoyable, and extrinsic motivation, which refers to doing something because it leads to a separable outcome (Ryan and Deci, 2000). As such, intrinsic motivation is important for completing a task, whereas extrinsic motivation reflects acceptance of the value or utility of a task. This can be conceptualized as a self-determination continuum (Figure 5). SDT emphasizes processes through which a person internalizes health behaviors so that they may be self-determined (Ryan et al., 2008). The theory highlights three basic human psychological needs, which when satisfied yield enhanced motivation and well- being (Ryan and Deci, 2000):

- Autonomy: the feeling of psychological freedom or choice
- Competence: perceived self-efficacy (i.e., one's belief in one's ability to succeed)
- Relatedness: the need to feel belongingness and connectedness with others

SDT has previously been employed to examine individuals' motivations for hearing aid use (Ridgeway et al., 2013, 2015), and may provide a useful framework to better understand individuals' motivations for engagement and adherence to other hearing interventions, such as cochlear implants.

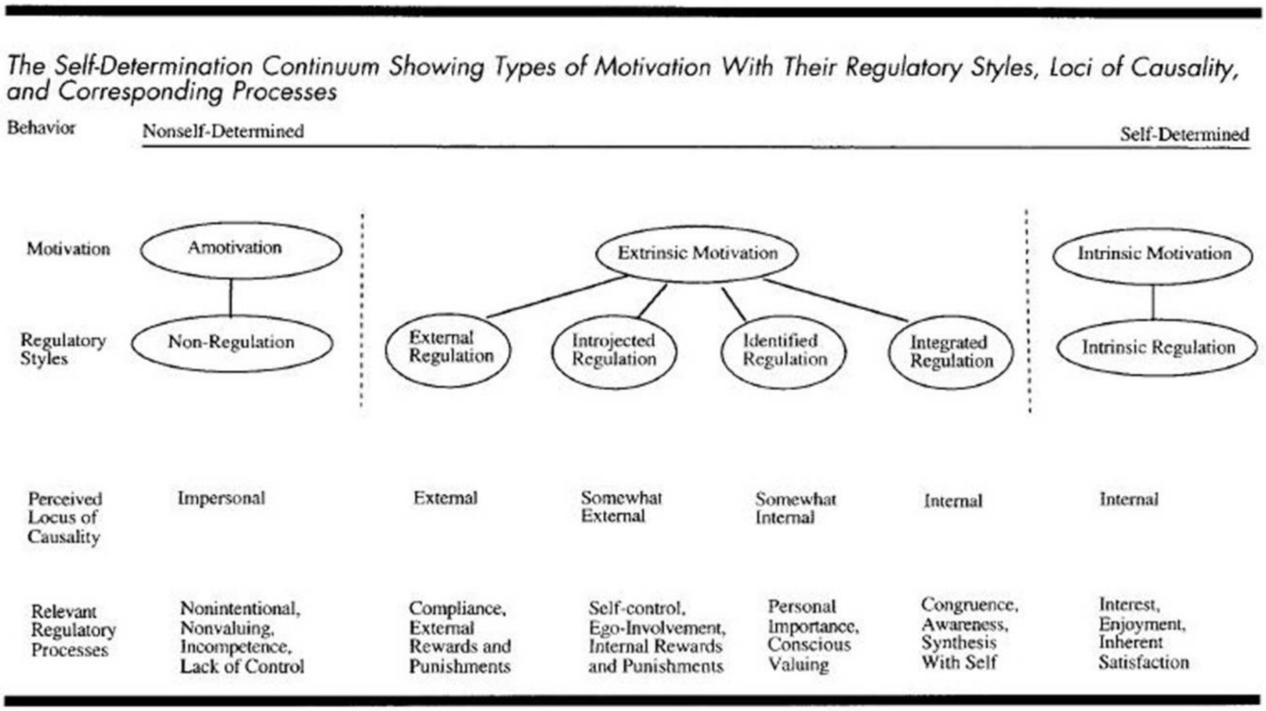


Figure 5. The self-determination continuum, Ryan and Deci (2000). Copyright © 2000 by the American Psychological Association. Reproduced with permission. The official citation that should be used in referencing this material is Ryan and Deci (2000).

Moreover, in order to keep costs under control, increasing patients' responsibilities and autonomy is essential for the redesign of health services, from current disease- and institutional-centered models to patient-centered models of care (Ruland et al, 2013; Wagner et al, 2001).

As the numbers of implanted recipients grow, long-term intensive provision becomes unsustainable, with implant centres questioning their specialized methods of service delivery as an effective means of provision (e.g. Backous et al., 2005). Currently, CIs are typically provided in specialized ENT clinics requiring a multi-disciplinary team consisting of clinical audiologists, ENT surgeons, radiologists, implant audiologists, psychologists and speech and language therapists. These skill sets are scarce.
E.g. the audiologist are the specialized medical staff performing all diagnostic tests to identify the cause of the hearing loss and quantify its severity and fitting the hearing implant to the individual needs of the patient. The projected growth for audiologists in the US over the period 2012-2022 is 22%.

Recently, Athalye and colleagues (2015) explored the perspectives of CI users, parents of CI recipients and professionals at CI centers in the UK. This research used a questionnaire with closed- and open-ended responses to explore the views of the current cochlear implant service delivery and the potential issues in the long term. Seven hundred and forty-eight responses were obtained. The majority of respondents (69%) were CI professionals. The remaining respondents were parents (19%) and CI users (12%).

The study showed that current services are perceived to be predominantly led by CI centers where decisions related to appointments, provision of standard care, treatment, accessories, management, and long-term maintenance are made by the team at the CI center. In the future, participants in the Athalye study would like these decisions to be predominantly led by the users themselves, with a more proactive role. Moreover, this study revealed that the majority of participants (whether user, parent, or professional) wanted the CI rehabilitation services to be part of local audiology services and CI care be available locally. This was supported by both qualitative and quantitative results. The majority of participants opted for care to take place closer to home and local audiology services where educational and other support services are integrated into CI provision. Asked if this was currently the case, participants felt not, but rather that care was available and determined by the center. Other researchers (Archbold and O'Donoghue 2007; Archbold et al.,2008; Punch and Hyde, 2011) have emphasized the importance of close liaison between CI centers and local educational services to ensure the best management and continuing use of the CI.

Cochlear implants have a positive effect on quality of life and appear to result in net savings to society (Cheng et al., 2000). When these services are made available locally and integrated with other services, it may ensure optimum use of the current resources, increase cost effectiveness, and help long-term sustainability. At the same time, the CI centers can maintain their technological expertise for those newly implanted, and the more complex cases that need their expertise.

This also holds for the bone anchored hearing aid (or Baha). This device is beneficial for people suffering from conductive hearing losses (reduced sound transmission through the middle ear), or mixed hearing losses where some of the hearing loss is also sensorineural (damage to the hair cells in the inner ear) or single-sided sensorineural deafness (SSD).

Hence, the future care delivery will therefore be much more distributed, centered on the patient, and involving other actors, closer to the home, for part of the care. For such a model to be successful, it is important that common digital platforms exist, where each of the parties has access to the relevant information.

We envision the following four prototype care models as shown in Figure 6. Their applicability will depend on the local context in the clinic and the country.

- **Expert care** model: care is provided in the specialized hearing implant center. The patient has to take an appointment in the clinic and travel there physically. The care is provided by top experts. Time investment by the patient is high, as travel is involved and most likely waiting time in the expert center. Likely the patient has to take time off from work. Cost is high, both for the patient and for the health care system (as care is delivered in the most expensive center).
- **Local care** model: some parts of the hearing implant care (e.g. routine equipment maintenance) are performed in a less specialized center, close to the home of the patient. The health care professional in the local care model is less specialized, e.g. could be a hearing aid audiologist working in the local hearing aid dispenser. From the patient perspective, time investment and cost are lower, as the travel is much less. Maybe it is not needed to take an appointment. The skill set of the local audiologist is not as high as in the expert center.
- **Remote care**: through ICT (e.g. videoconferencing and remote desktop technologies) the patient is in contact with a health care professional (typically the expert from the expert care center) from the home environment. This model avoids the travel. This is a convenience and cost reduction for the patient. However the time investment and the cost for the expert remain high.

Potentially there is more flexibility in the time schedule and a convenient time can be found, e.g. off-working hours.

- **Self-care**: the patient, facing a hearing related issue, can access a reliable information source from the home at a convenient time (ideally 24/7) to solve the issue. This is the most convenient and ubiquitous model. Information, e.g. trouble shooting guide or counseling, can be provided at anytime from anywhere.

To enable model 2 to 4, an enabling eHealth system is needed to provide the parties involved with the required information, e.g. the patient's specific hearing implant settings.

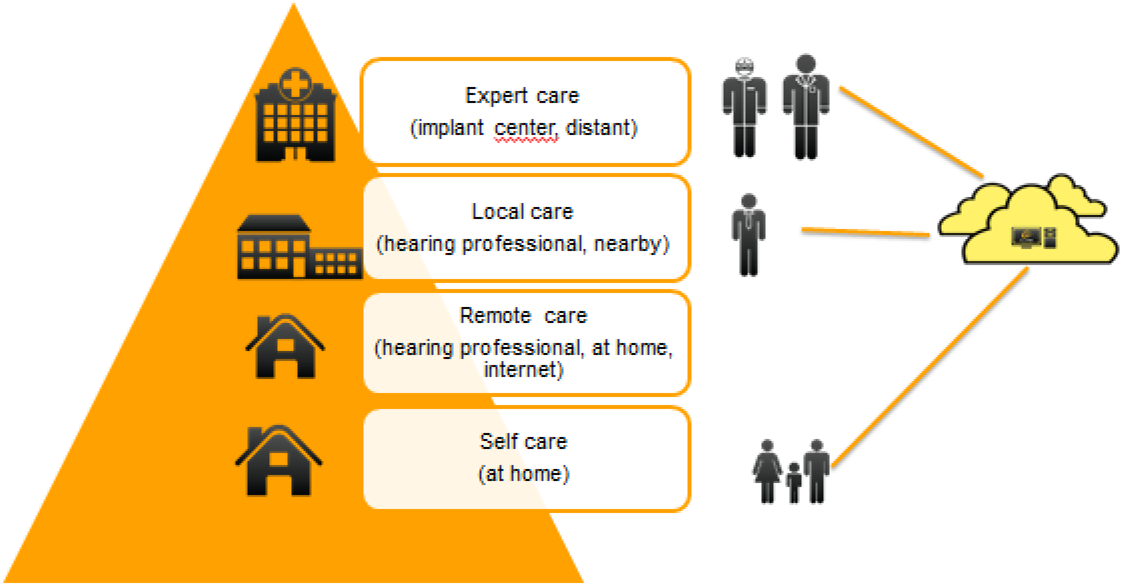


Figure 6. Different care delivery models

2 Clinical evaluations in Work package 1- Research on Data Logging, Device Diagnostics and Counselling

The first work package of the SHiEC project focuses on the research to support the services of a web channel between recipient and clinician to improve remote counselling and diagnostics in a home environment ("self care" in Figure 6). Several evaluations have been set up with CI recipients (2.1) (Table 1) and Baha recipients (2.2) (Table 2).

Table 1. Number of CI participants in clinical evaluations in WP1

Number of CI participants in clinical evaluations in WP1			
	Study 1	**Study 2**	**Study 3**
Number of CI participants	266	24	28
Number of senior CI participants (>60y)	91	24	16

Table 2. Number of Baha participants in clinical evaluations in WP1

Number of Baha participants in clinical evaluations in WP1		
	Study 1	**Study 2**
Number of Baha participants	74	26
Number of senior Baha participants (>60y)	74	26

2.1 Clinical evaluations with CI recipients

2.1.1 Outline of performed studies with CI recipients

Prior to going forward with digital platforms for senior CI recipients (as outlined in the SHiEC project), we wanted to gain insight in the technology used by these senior CI users (study 1). Afterwards, focus groups have been organized in order to provide more in-depth information on how senior CI recipients experienced their first year after implantation. Moreover, they will be asked and how they think the use of technology might CI recipients plan to use personal computer technology with their cochlear implant and what types of technology might improve their CI performance or satisfaction (study 2). Finally, the feedback from the focus groups was gathered in a recipient portal. The recipient portal is a secure web portal providing the information that is classically delivered through user manuals and the in-clinic counseling by the audiologist in a more convenient and easily accessible form. The evaluation of this recipient portal has been carried out in study 3.

All participants have been contacted via OPCI (*Onafhankelijk Platform voor Cochleaire Implantatie*), the Dutch CI user society. Data from CION states that by 2012 only 3176 adults in the Netherlands have cumulatively received a CI.

2.1.2 Study 1 - Survey on Cochlear Implants and Technology within senior CI recipients

2.1.2.1 Introduction

Computer technological developments are increasing the opportunities for remote cochlear implant (CI) care and rehabilitation. What types of mobile technology are CI recipients currently using and do they see remote CI-care as useful? To get answers to these questions OPCI ("*Onafhankelijk Platform Cochleaire Implantatie"* based in The Netherlands) developed the questionnaire "CI and Technology".

2.1.2.2 Survey Respondents

A total of 266 people, almost all CI recipients themselves, filled out the on-line questionnaire. Thirty-eight percent of the CI recipients were 60 years or older (Figure 7). Seventy-five percent became deaf later in life or were born with severe hearing loss and 86% were unilateral CI recipients. The majority of recipients chose the implant brand Cochlear (57%), while 29% chose Advanced Bionics, 11% MED-EL and 2% Neurelec/Oticon Medical. Recipients reported high levels of satisfaction with their CI performance (Figure 8) and the majority, 79%, reported wearing their processors for 12 hours or more per day.

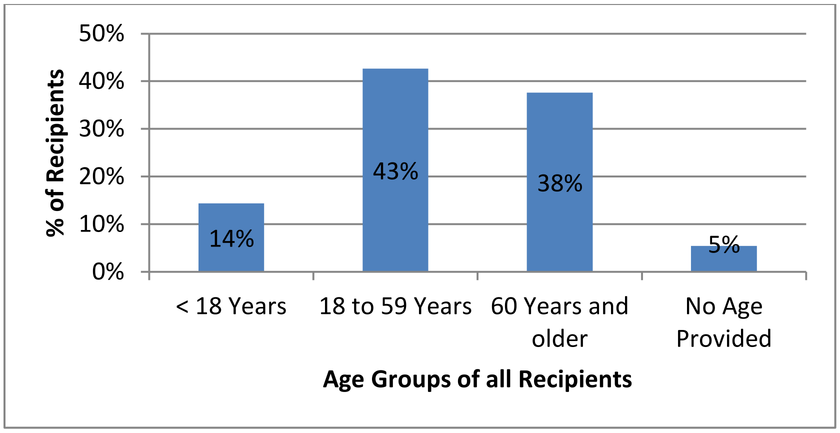


Figure 7. Recipient Age Distribution

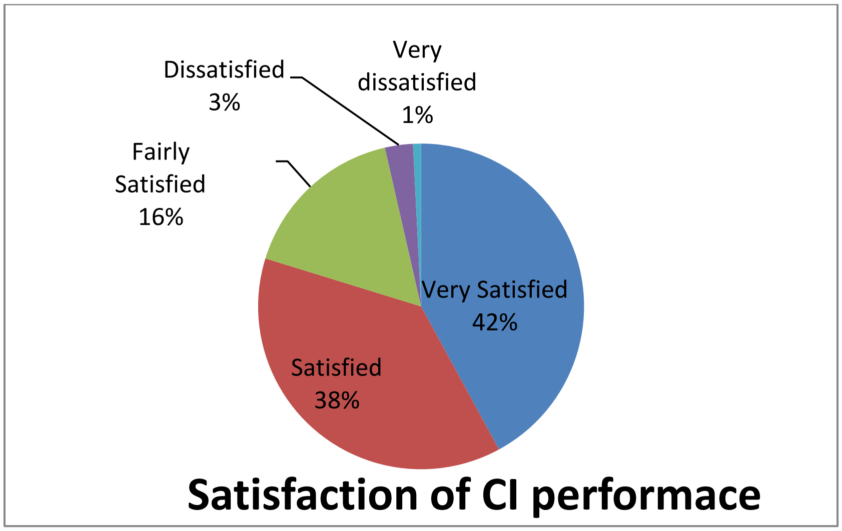


Figure 8. Distribution of Satisfaction of CI Performance amongst Recipients

2.1.2.3 Knowledge of Computers, Tablets and Smartphones

The survey showed that CI recipients make extensive use of computer technology in their personal lives. The recipients report using one or more computers devices for personal use : 71% use a laptop, 61% a tablet, 52% a smartphone, and 40% a desktop computer (Figure 9). They use these devices frequently, 42% use for 1-3 hours per day and 46% use more than 3 hours per day (Figure 10). Over 91% of recipients use the Internet regularly. A small percentage of respondents (9%) report they already use their devices to monitor some aspect of their health.

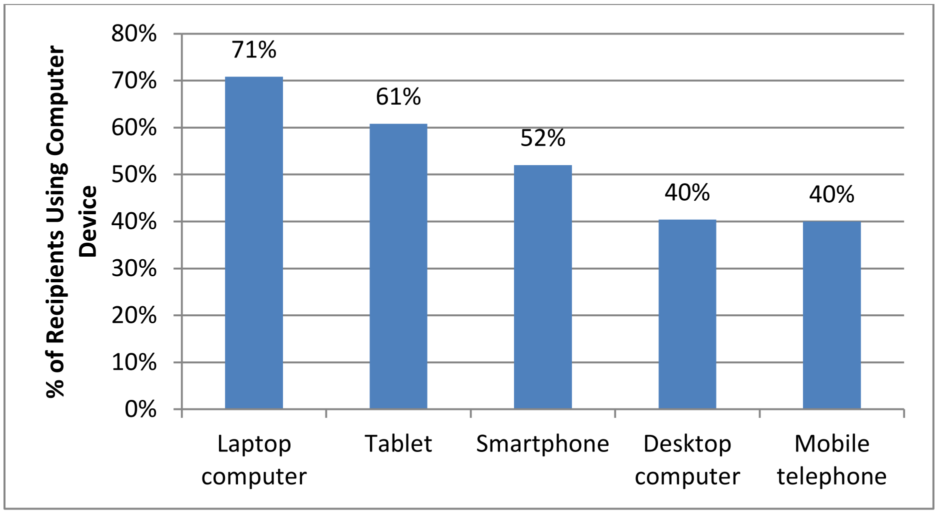


Figure 9. Percentage of Recipients Using Different Computer Technology for Personal Use

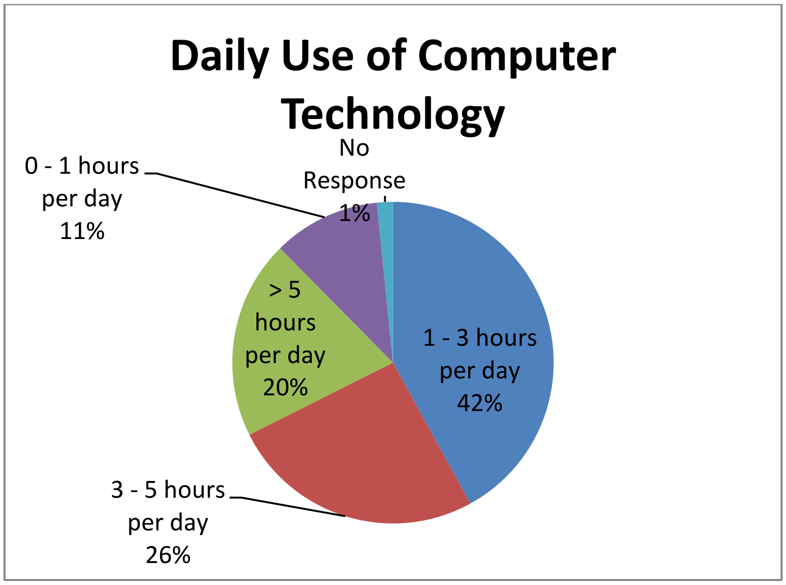


Figure 10. Daily Use of Computer Technology

2.1.2.4 *Hearing Situation*

The survey indicated that in one-on-one situations, in a quiet environment, the majority of CI recipients report their speech understanding is good to very good. When in a noisy environment, such as around a television, radio, sounds from outside, or in a room with several people, their speech understanding is greatly reduced. Most recipients reported they never or rarely change their CI programs; only 15% reported changing their program several times a day (Figure 11). A large majority (65%) reported interest in using information such as data logging to provide them guidance on how to better use their CI. Recipients do not yet know whether they would like to use a smartphone to operate their CI, but 29% expect that using a smartphone would make it easier to change programs.

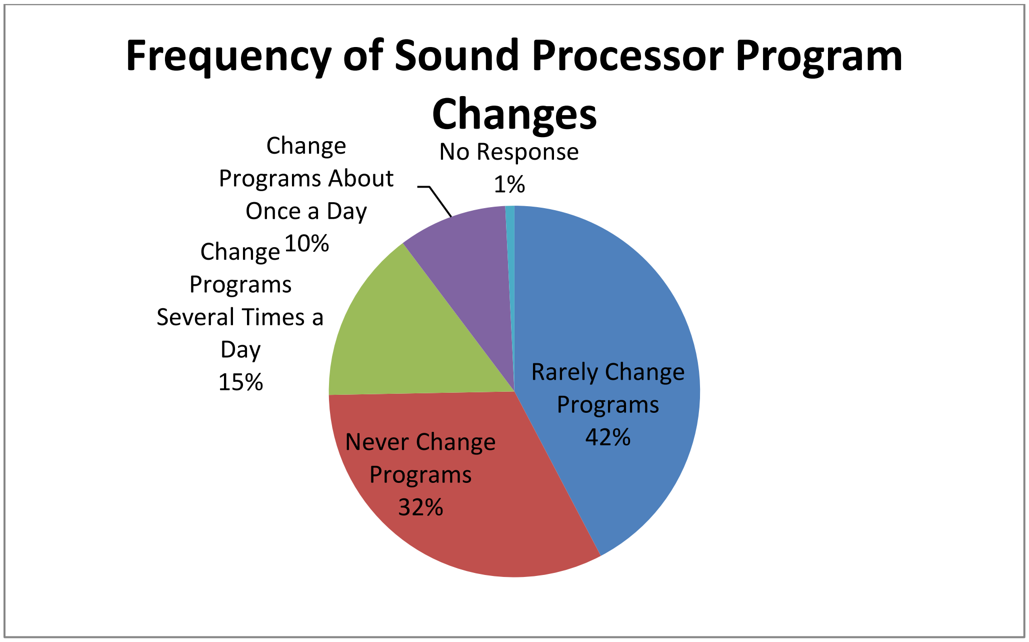


Figure11. Percent of Recipients Changing Programs on their Sound Processor

2.1.2.5 *Care and Rehabilitation at Home*

The survey showed that over half of the recipients think that they would benefit from more rehabilitation training. Fifty-six percent of recipients indicated that, if available via computer or tablet, they would be willing to do hearing training at home. They also indicated that they are interested in doing hearing tests and digital troubleshooting of their CI equipment from home.

2.1.3 Study 2- Focus groups

The aim of the second study was gaining insight in needs of CI recipients concerning several stages in the CI journey. Therefore, 3 focus groups of 8 senior CI recipients have been organized in the Netherlands.

During these focus groups, the participants were asked to share their experiences during the first year of their CI hearing journey. Each focus group session consisted of three sections: selection and surgery phase, rehabilitation phase and bottlenecks and technology wish list.

The complete report of these focus groups can be found in an additional deliverable (Additional deliverable Focusgroup dd.27.02.2015). The most important items flagged during these focus groups can be found in Figure 12.

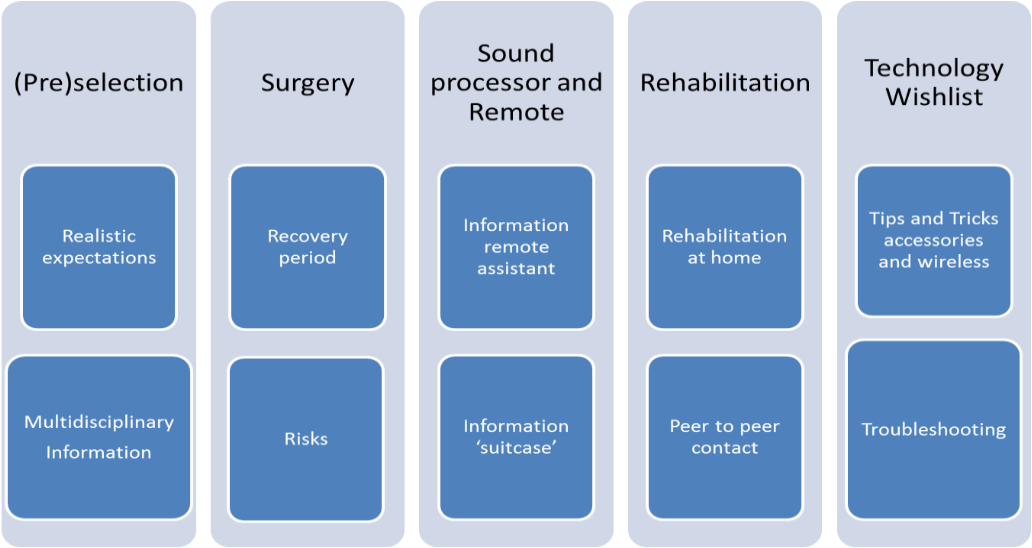


Figure 12. Bottlenecks flagged by senior CI recipients during focus groups

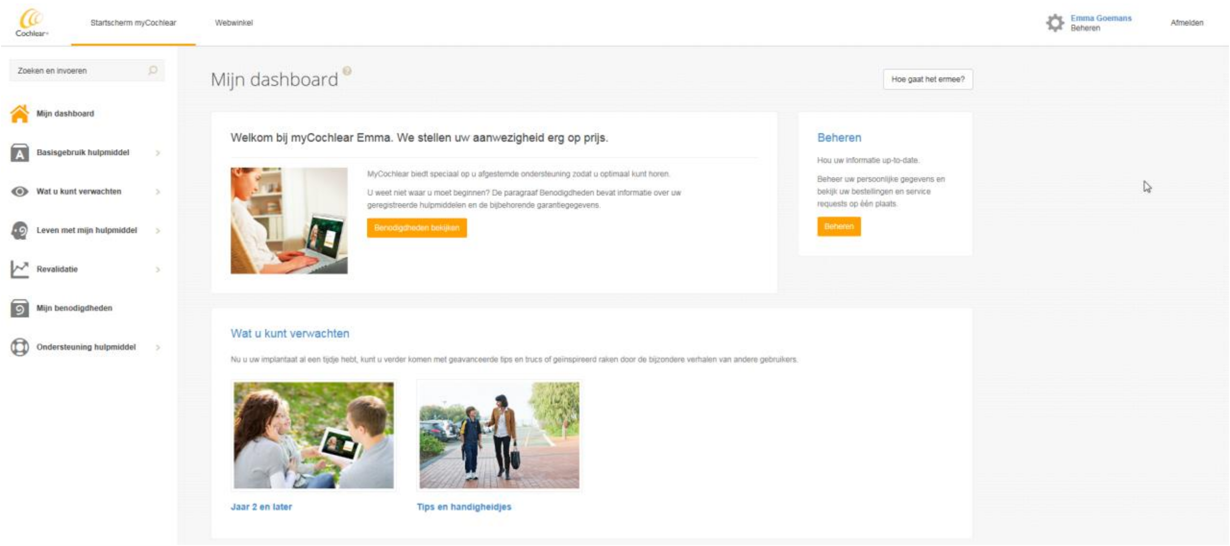
2.1.4 Study 3 - Evaluation of a recipient portal by senior CI recipients

2.1.4.1 Introduction

The recipient portal (Fig. 13) is a secure web portal providing the information that is classically delivered through user manuals and the in-clinic counseling by the audiologist in a more convenient and easily accessible form. E.g. the first fitting session of a cochlear implant, when the sound processor is activated and people hear again something, is an emotional moment. In the same session the user receives a big box containing the sound processor and many accessories and components. This also requires a lot of information to be shared. Users will only retain a fraction of the information they receive. A better model is to gradually deliver this information at their own pace in the home environment. The idea is to gradually evolve the recipient portal into an eLearning platform.

The portal is personalized as it is aware of the specific device type the user is wearing. E.g. for a Nucleus 6 cochlear implant user, the system will specifically display the information on this device type, and not an overview of all possible hearing implants. Another example is the warranty information, which is also specific to this user.

A full description of the Recipient Portal is provided in the deliverable 1.3.



Mijn dashboard

Welkom bij myCochlear Emma. We stellen uw aanwezigheid erg op prijs.

MyCochlear biedt speciaal op u afgestemde ondersteuning zodat u optimaal kunt horen.

U weet niet waar u moet beginnen? De paragraaf Benodigdheden bevat informatie over uw geregistreerde hulpmiddelen en de bijbehorende garantiegegevens.

Beheren

Hou uw informatie up-to-date.

Beheer uw persoonlijke gegevens en bekijk uw bestellingen en service requests op één plaats.

Wat u kunt verwachten

Nu u uw implantaat al een tijdje hebt, kunt u verder komen met geavanceerde tips en trucs of geïnspireerd raken door de bijzondere verhalen van andere gebruikers.

Figure 13. Screen shot of the Recipient Portal

2.1.4.2 Materials and Methods

A pretest-posttest design was used, conducting a survey prior to having access to the portal, and after six weeks of portal use.

2.1.4.2.1 Subjects

Participants were recruited through the Dutch CI user society OPCI (“*Onafhankelijk Platform voor Cochleaire Implantatie*”). An invitation to participate was posted on their website and in their newsletter. Inclusion criteria were having a Nucleus cochlear implant and having access to the Internet.

Twenty-eight CI recipients were willing to take part in the evaluation of the Recipient Portal. Four recipients did not found the time to access the portal and hence didn’t fill in the post questionnaire. Hence data analysis was performed on the remaining 24 subjects. These 24 participants (11 male, 13 female) with a mean age of 58.92 years (range 42-77 y) had on average had 6.4 years of CI experience (range 3m-25y).

2.1.4.2.2 Questionnaires

As no questionnaires existed in the literature to address the evaluation of a CI recipient portal, two specially designed questionnaires (pretest and posttest) were used. Following questionnaire design, both questionnaires were piloted with three professionals and ambiguities or necessary clarifications in wording were addressed.

The **pretest questionnaire** (46 questions in total) comprised of two parts. The first part consisted of socio-demographics (age, gender, education level, marital status and employment), Internet use (quantity of use, experience and self-perceived skills) and hearing characteristics (onset of hearing loss, duration of CI use, CI characteristics, duration of current speech processor (SP) usage, daily listening hours with current SP, last appointment with CI clinic, self-perceived speech understanding with SP and self-perceived CI knowledge). The second part consisted of questions asking about participants’ CI actions (7 items) and CI knowledge (7 items). The CI action items were scored using a 5-point Likert scale ranging from 1 (“*very easy*”) to 5 (“*very difficult*”). The CI knowledge items were also scored using a 5-point Likert scale ranging from 1 (“*I’m very sure*”) to 5 (“*I’m not sure at all*”). Furthermore, participants had to indicate where they would look for information in case they wanted help or information about these 14 CI actions and knowledge items. The response options were: 1 *Surfing on the Internet*; 2 *Contacting my audiologist/SLP*; 3 *Asking a family member/friend*; 4 *Posting a question on an Internet* *forum*; 5 *Reading the paper CI manual*; 6 *Visiting the CI team's or CI company's website*. Participants were instructed to tick only one answer in the second part of the pretest questionnaire.

The **posttest questionnaire** (58 questions in total) also comprised of two parts. Part 1 questioned their recipient portal usage (frequency and average time spent per visit), System Usability Scale and self-perceived impact of the portal. The System Usability Scale (SUS) (Digital Equipment Co Ltd., Reading, United Kingdom) is a simple, ten-item scale giving a global view of subjective assessments of usability. It makes use of a 5-point Likert scale ranging from 1 "*strongly disagree*" to 5 "*strongly agree*". In order to gain more insight in the evaluation of the recipient portal, the term "*system*" in the SUS was replaced by "*recipient portal*". SUS yields a single number (range 0-100) representing a composite measure of the overall usability of the recipient portal with a higher score indicating higher usability. Furthermore, 10 questions concerning self-perceived impact were posed. Also here a 5-point Likert scale was applied (1 "*Totally disagree*" to 5 "*Totally agree*"). Part two of the posttest questionnaire included questions regarding (anticipated) use and completeness of the portal. Also the 14 items concerning CI actions and CI knowledge from the pretest questionnaire were included. Finally, the participants had to indicate where they would look for information in case they wanted help or information about these 14 CI actions and knowledge items. The response options were the same as in the pretest questionnaire, however an additional 7th response was added, namely: 7 "*Looking it up on the recipient portal*".

2.1.4.2.3 Procedure

The paper-and-pencil pretest questionnaires were provided to all participants on T0. On receipt of a completed pretest questionnaire, each participant received an invitation by email to log in to the recipient portal with his/her personal account. At first login, participants were instructed to change their password. Participants had six weeks access to the recipient portal. Afterwards (T1), participants' accounts were deactivated and paper-and-pencil posttest questionnaires were provided.

Participation in the evaluation of the recipient portal did not need Ethical Committee approval, because no clinical information was sought. Patient Informed Consent forms and Privacy Policy declarations were taken into account.

2.1.4.2.4 Data analysis

Analyses were performed using the Statistical Package for Social Sciences (IBM SPSS Statistics 20). Descriptive statistics were used to summarize socio-demographics, internet use, CI characteristics, …

For all analyses, p-values <0.05 were used as criterion for statistical significance.

2.1.4.3 Results

2.1.4.3.1 Participants

Half of the respondents were working, a quarter was retired and the remaining recipients were volunteering. The majority (80%) was a unilateral CI user, the others were bimodal users (i.e. CI in one ear and a hearing aid in the contralateral ear) (Table 3).
The majority used the internet on daily basis (91.7%) and indicated having good internet skills (62.5%). See table 4 for further details.

Table 3. Participants' CI characteristics

Characteristic	Percentage of sample (N=24)
Current CI processor	
Nucleus Freedom	8.3%
Nucleus N5	54.2%
Nucleus N6	37.5%
Experience with current sound processor	
<6m	8.3%
6m-12m	8.3%
1y-2y	29.2%
>2y	54.2%
Current self-estimated CI use	
6h-12h	8.3%
>12h	91.7%
Current self-estimated speech understanding	
very dissatisfied	0.0%
dissatisfied	4.2%
neutral	4.2%
satisfied	45.8%
very satisfied	45.8%
Last appointment with CI clinic	
<1m ago	16.7%
1m-3m ago	20.8%
3m-6m ago	20.8%
6m-12m ago	37.5%
>1y ago	4.2%

Table 4. Participants' details on education and internet/computer use

Characteristic	Percentage of sample (N=24)
Education	
Secondary vocational school	12.5%
Secondary education	8.3%
MBO	37.5%
College	33.3%
University	4.2%
Other	4.2%
Internet use	
Daily	91.7%
Couple days per week	8.3%
Internet experience	
1-5 years	8.3%
>5 years	91.7%
Self-perceived internet skills	
weak	4.2%
average	16.7%
good	62.5%
very good	16.7%
Pc/Tablet/Smartphone use per day	
0-1h	4.2%
1-3h	41.7%
3-5h	16.7%
>5h	37.5%

2.1.4.3.2 Recipient portal use

The majority of the participants (62.5%) indicated visiting the portal once a week. Twenty-one percent stated visiting the portal more frequently, namely 3 to 5 times a week. The remaining 16% only visited the portal one a month. Once logged in on the portal, 75% stayed tuned for 15 to 30 minutes, 12.5% for 30 to 60 minutes or even more than an hour (12.5%).

2.1.4.3.3 System Usability Score

The mean System Usability Score was 73 (range 58-88 and SD 7.45) indicating a good usability of the recipient portal.

2.1.4.3.4 Self-perceived impact

Ten questions regarding self-perceived impact were posed. Frequencies of participants' responses the 10 statements are summarized in Table 5.

Table 5. Self-perceived impact of the recipient portal

Statement	strongly disagree	disagree	neither agree nor disagree	agree	strongly agree
I feel more involved in the health care concerning my CI	0	2	5	16	1
The quality of CI care has increased	0	3	8	13	0
I am more worried about a particular aspect of my CI	4	14	5	1	0
My self-efficacy in communicating with CI professionals has increased	2	2	7	11	2
My communication with others about my CI has increased	2	3	12	6	1
I have a better knowledge concerning my CI	0	1	3	17	3
I feel more confident in handling my CI	1	2	6	14	1
I have decided to seek further information about my CI	1	0	8	11	4
I am confused about a particular aspect of my CI	4	10	6	3	1
I understand better what has previously been discussed at my CI appointments	0	4	10	10	0

The majority of participants agreed that they feel more involved in their CI care, that their self-efficacy in communicating with their CI team has increased and an increase of CI quality. Also they indicate having a better CI knowledge and feeling more confident in handling their CI. A minority states being confused about particular aspect of their CI.

2.1.4.3.5 Pre-posttest CI actions and knowledge comparison

Fourteen questions asking participants about CI actions (7 items) and CI knowledge (7 items) were posed prior and post having access to the recipient portal. These questions are listed in Table 6.

Table 6. Questions concerning CI actions and CI knowledge posed prior and post access to the recipient portal.

Question	CI actions	CI knowledge
	How easy/difficult is it for you to…	**Do you know…**
1	replace disposable batteries of your sound processor	how to protect your sound processor when you want to go swimming?
2	replace the microphone protectors of your speech processor	whether you can set up a wireless connection with your telephone or TV?
3	use the Dry and Store Breeze kit	whether you can switch on your sound processor during a flight?
4	lock your sound processor	whether you can have an MRI scan?
5	pair your sound processor with your remote assistant/control	whether you can go scuba diving with your sound processor?
6	replace the earhook	how long the warranty of your sound processor lasts?
7	replace the magnet	how long the warranty of your battery charger lasts?

Recipients were asked prior and post having access to the recipient portal to score these questions. The CI action items were scored using a 5-point Likert scale ranging from 1 (“very easy”) to 5 (“very difficult”). The CI knowledge items were also scored using a 5-point Likert scale ranging from 1 (“I’m very sure”) to 5 (“I’m not sure at all”).

Results of the participants’ responses are shown in Figure 14 (CI actions) and Figure 15 (CI knowledge). Since most recipients already had quite some CI experience, average duration of CI use was 6.4 years, it is not surprising to see that no shift in prior CI actions to post CI actions nor CI knowledge could be found.

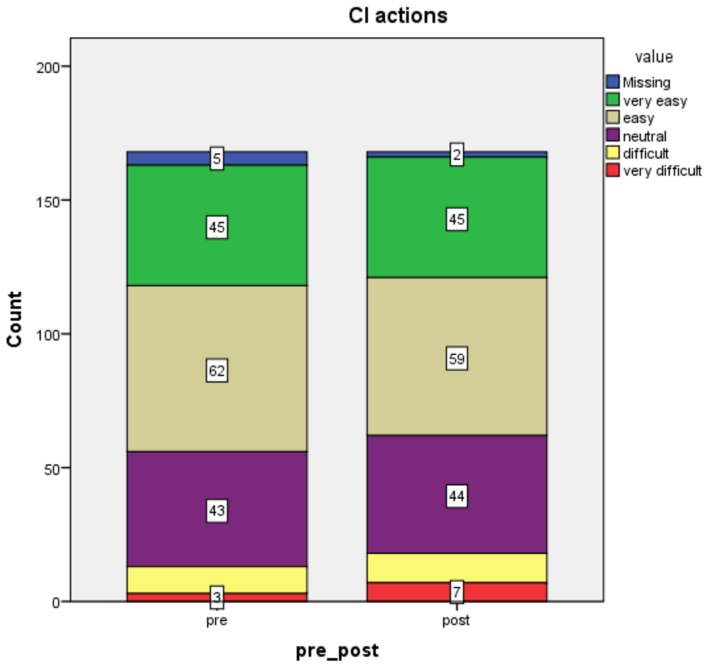


Figure 14. Pre and posttest results of 7 questions concerning CI actions.

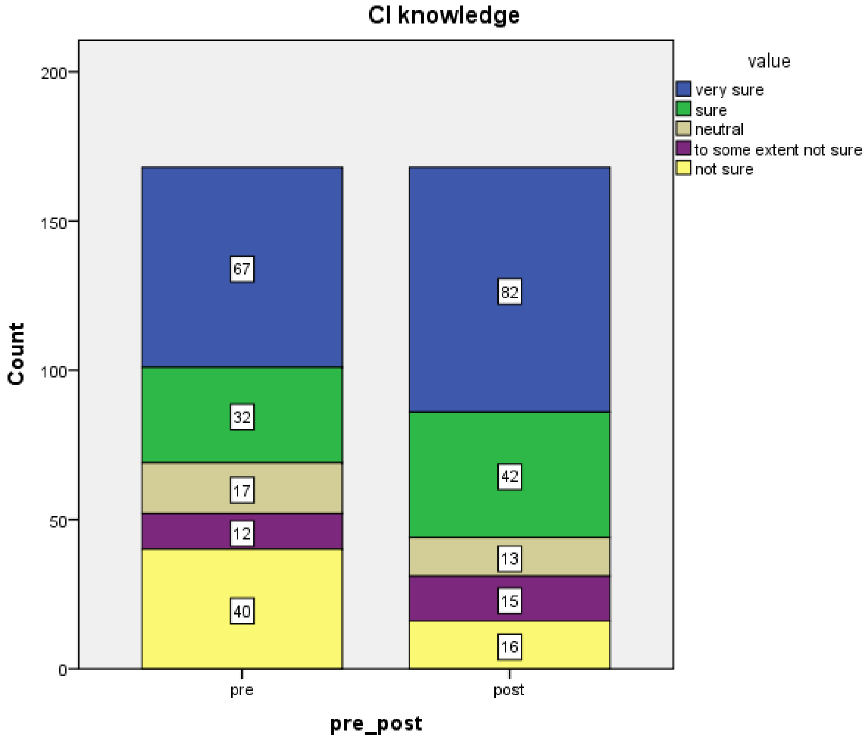


Figure 15. Pre and posttest results of 7 questions concerning CI knowledge.

2.1.4.3.6 Seeking help

Participants were asked prior and post having access to the portal which channels they would use to find help/information with respect to the 14 questions posed concerning CI actions and CI knowledge. Possible response options prior to having access to the portal were: 1.“I would surf on the internet”, 2.“I would contact my audiologist/speech and language pathologist”, 3.“I would ask a friend or family member”, 4.“I would post my question on an internet forum”, 5.“I would read the paper manual of my sound processor”, 6.“I would surf to the website of my CI team or CI manufacturer”. The same response options were shown at the post questionnaire, with an additional 7th, namely “I would surf to my recipient portal”. The CI action items were scored using a 5-point Likert scale ranging from 1 (“very easy”) to 5 (“very difficult”). The CI knowledge items were also scored using a 5-point Likert scale ranging from 1 (“I’m very sure”) to 5 (“I’m not sure at all”). Results of the participants’ responses are shown in Figure 16 (CI actions) and Figure 17 (CI knowledge).

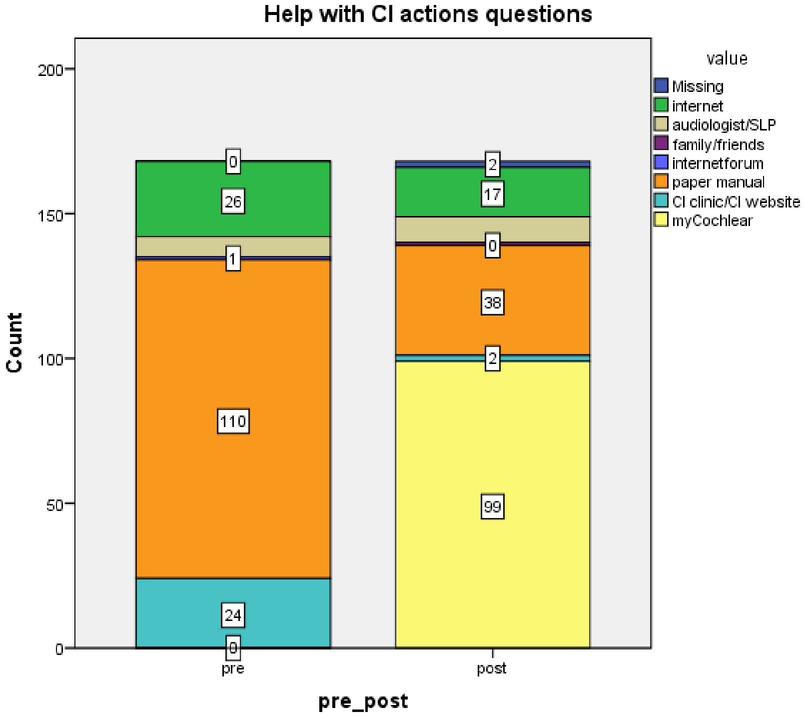


Figure 16. Pre and posttest results of seeking help for CI action questions

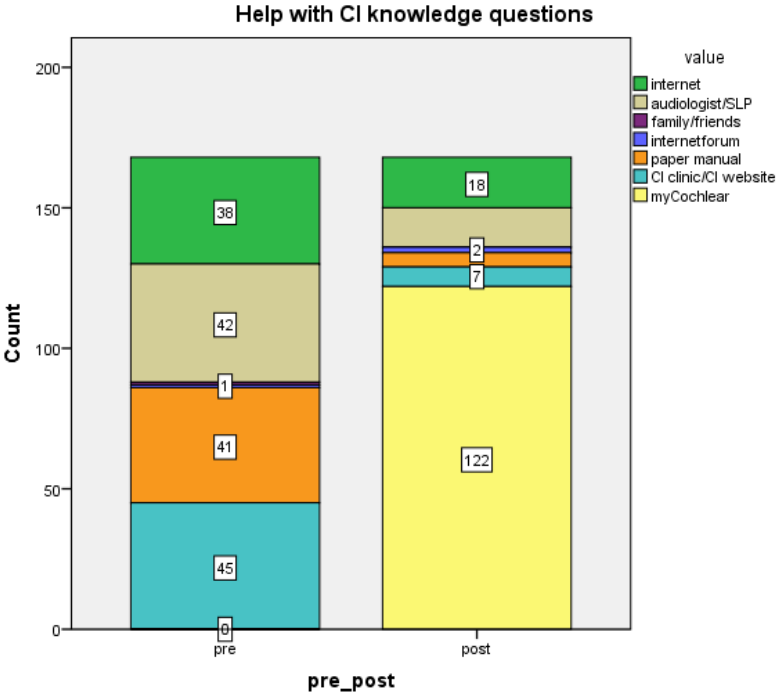


Figure 17. Pre and posttest results of seeking help for CI knowledge questions

Prior to having access to the recipient portal, resources of where to find help are diverse among the participants. After having access to the portal, results indicate that both for CI actions (58.9%) and CI knowledge items (72.6%), the participants will visit the recipient portal in order to find an answer.

2.1.4.4 Discussion

This evaluation shows that there is a large interest among senior CI users for a personalized recipient portal. Most recipients found it very useful having personalized information (eg. Warranty information) at a single location, accessible 24/7. Also previous studies found that having access to personal information is more useful compared to general information in patients with chronic conditions (Urowitz et al, 2012). In the future, it might be very interesting to include even more recipient detailed information, such as audiological test results.

We also evaluated the patient empowerment and autonomy impact of the portal and have showed that the majority of participants agreed feeling more involved in their CI care, that their self-efficacy in communicating with their CI team has increased and an increase of CI quality. Also they indicate having a better CI knowledge and feeling more confident in handling their CI. A minority states being confused about particular aspect of their CI.

In the future, we are planning giving recipient portal access to newly implanted recipients. We assume the influence on their autonomy will be larger since they are at the beginning of their hearing journey with a CI, as opposed to the current portal participants (having on average 6.4 years of CI experience). Gaining insight in recipients’ autonomy, competence and relatedness will be carried out by means of SDT questionnaires.

2.2 Clinical evaluations with Baha recipients

2.2.1 Study 1 - Use of internet and computers among individuals with a bone conduction sound processor

2.2.1.1 Purpose

The primary objective of this survey was to gather insight on the use of internet and computers among users of bone conduction hearing solutions, focusing on recipients at the age of 61 years and older. An additional aim was to gather insight concerning hearing situation and rehabilitation needs.

2.2.1.2 Methodology

A questionnaire was designed and created by the SHiEC project group at CBAS, focusing on users of a bone conduction hearing solution, independently of age. Questionnaires completed by individuals of the age 61 years and older was sorted out in order to compare results from older individuals with results from all individuals.

The aim was to obtain a sample size of minimum 50 individuals since it was considered sufficiently to receive a trustworthy result in this survey. A sample size of 74 individuals was obtained.

2.2.1.2.1 Inclusion criteria

The test subjects should be;

- Current or intended users of a bone conduction hearing solution, alternatively;
- Relatives, spouses, parents or close friends to users of a bone conduction hearing solution, answering the questionnaire as the recipient would have.

2.2.1.2.2 Questionnaire

The questionnaire consisted of 27 questions divided into three parts, as follows;
Part I: Questions concerning demographics.
Part II: Questions concerning experience and knowledge of internet and computers.
Part III: Questions concerning hearing situation and rehabilitation needs.
The questionnaire was available both in Swedish and English, in paper versions and as online versions, during a 2 month period.

2.2.1.2.2.1 Swedish paper version

The Swedish paper version was handed out, in association with another survey, to users of a bone conduction hearing solution at the CBAS office in Mölnlycke, Sweden. The paper version offered the participant the choice to answer the questionnaire on paper and send it back in an attached envelope, or to conduct the Swedish online version. The web address for the online version could be found on the paper version. A total of nine paper questionnaires were handed out.

2.2.1.2.2.2 Swedish online version

The Swedish online version was advertised once, January 30th 2015, on the Baha Blog. No other advertises were made for the Swedish online version.

2.2.1.2.2.3 English paper version

The English paper version was supposed to be handed out at a user’s organization meeting in the United Kingdom. However, no paper versions of the questionnaire were handed out due to participants deciding to help each other fill in the online version instead.

2.2.1.2.2.4 English online version

The English online version was advertised once, January 30th 2015, on the Baha Blog. In addition, the online version was also advertised once on Cochlear Twitter in the U.K. A user organization called The Ear Group also sent the questionnaire via e-mail to all members using a bone conduction hearing solution.

2.2.1.2.2.5 Exclusion criteria

The exclusion criteria for questionnaires were as follows;

- If only part I of the survey was completed and no other question in the following sections answered, the result from that questionnaire would not be included.
- If the key-questions in part one (question 1, 2, 4 and 9) and more than one question on each part (part II and part III) were answered, the questionnaire would not be excluded.
- If a single question was not answered, that question would be excluded in that specific questionnaire.
- If a question with multiple answers was ticked in with more than one answer (when multiple answers were not intended), that question would be excluded in that specific questionnaire.
- If information was added outside the area designated for answers, this information would not be collected.
- If information added by a participant made it obvious that a question had been misunderstood, that question would be excluded in that specific questionnaire.
- If the box “I’m not a Bone conduction sound processor user” was ticked in, answers from that entire questionnaire would be excluded.
- If a follow up question was answered although it shouldn’t have been according to previous answers, that question would be excluded on that specific questionnaire.

2.2.1.2.2.6 Survey Monkey

The program used for creating the questionnaire as well as collecting and sorting answers was Survey Monkey®.

The following settings for the online version were used:

- Skip Logic; allowing test subjects to move directly from one question to another, based on answers.
- Information about URL/web address was not collected, leaving the user untraceable.
- No restriction concerning number of times possible to answer the questionnaire from the same computer was undertaken.

2.2.1.2.3 Test setup

Setup for the test was as follows;

1. Questionnaires were distributed both via internet and handouts to users of a bone conduction hearing solution.
2. The questionnaires were available both in paper versions and online for a period of 2 months (January 15th to March 15th 2015).
3. The internet links to the Swedish and English questionnaires were checked once a week to ensure possible errors were discovered.
4. Amount of collected answers was checked once a week to determine if any actions to receive more answers were needed. A sample size of 50 individuals was considered sufficiently to obtain a trustworthy result in this survey.
5. The submitted answers were only counted, not read, until the survey was closed.
6. During the night (at 12 o´clock), between March 15th and March 16th 2015, the survey automatically closed.

7. On March 19th 2015, total number of answers were counted and sorted according to exclusion criteria. A total of 77 individuals answered the questionnaire; 9 individuals via the Swedish paper version, 1 individual via the Swedish internet version, 0 individuals via the English paper version and 67 individuals via the English internet version.
8. To make sure all results were handled in the same way, results from both the Swedish paper version and online version were manually entered into the English internet version, since it held the most responses.
9. The manually entered information was quality controlled.
10. A total of 77 questionnaires were submitted but 3 questionnaires were deleted due to insufficient data according to the exclusion criteria, leaving a total of 74 questionnaires to be analysed.
11. Users of a bone conduction hearing implant at the age of 61 years and older, were sorted out by Survey Monkey.

2.2.1.3 Synthesis

The primary objective of this survey was to gather insight on the use of internet and computers among users of bone conduction hearing solutions, focusing on recipients at the age of 61 years and older. An additional aim was to gather insight concerning hearing situation and rehabilitation needs.
A total of 74 questionnaires were gathered and analysed. Individuals participating in the study were mainly adult users of a bone conduction hearing solution and originated from the United Kingdom or Sweden. Slightly more females than males participated and the majority were over 50 years of age.

Overall, the results indicated that almost all participants used a computer, smartphone, tablet or laptop for personal use. A laptop/ desktop computer was most commonly used, followed by a tablet. When learning to use a new device, participants found it most helpful to explore the device on their own. Among older participants (61 years and older) it was also considered helpful to learn from children/grandchildren. The most common features to use on the devices were internet, e-mail and Wi-Fi. A smartphone application to use in association with the bone conduction hearing solution was of interest among a majority of participants. Most participants were pleased with the information given to them in association with receiving the bone conduction hearing solution. Hearing strategies was the topic most participants required more information about.

The following sections summarize the results of the questionnaire. In order to separately analyse results from older individuals, answers from participants at the age of 61 years and older (henceforth called the target group) will be declared as well as the results from all participants. The results are based on 74 questionnaires whereof 26 questionnaires belonged to recipients at the age of 61 years and older; the target group.

2.2.1.3.1 Results part I: Demography

The following section summarizes the results from the first part of the questionnaire, including demographic questions.

2.2.1.3.1.1 Hearing situation

A majority of participants (71 individuals) were users of a bone conduction sound processor. Remaining participants (3 individuals) were parents to a child with a bone conduction sound processor.
In the target group, all participants (26 individuals) were users of a bone conduction sound processor.

2.2.1.3.1.2 Gender

Slightly more females (43 individuals) than males (31 individuals) were represented in the survey.
In the target group, men and female were equally represented (13 individuals each).

2.2.1.3.1.3 Origin

This section outlines which country the participants stated to come from.

Country	Number of participants
The United Kingdom	49
Sweden	10
Australia	5
The United States	4
Netherlands	3
Iceland	1
Belgium	1
Canada	1

The participants in the target group came from United Kingdom (20 individuals), Sweden (5 individuals) and Australia (1 individual).

2.2.1.3.1.4 Age

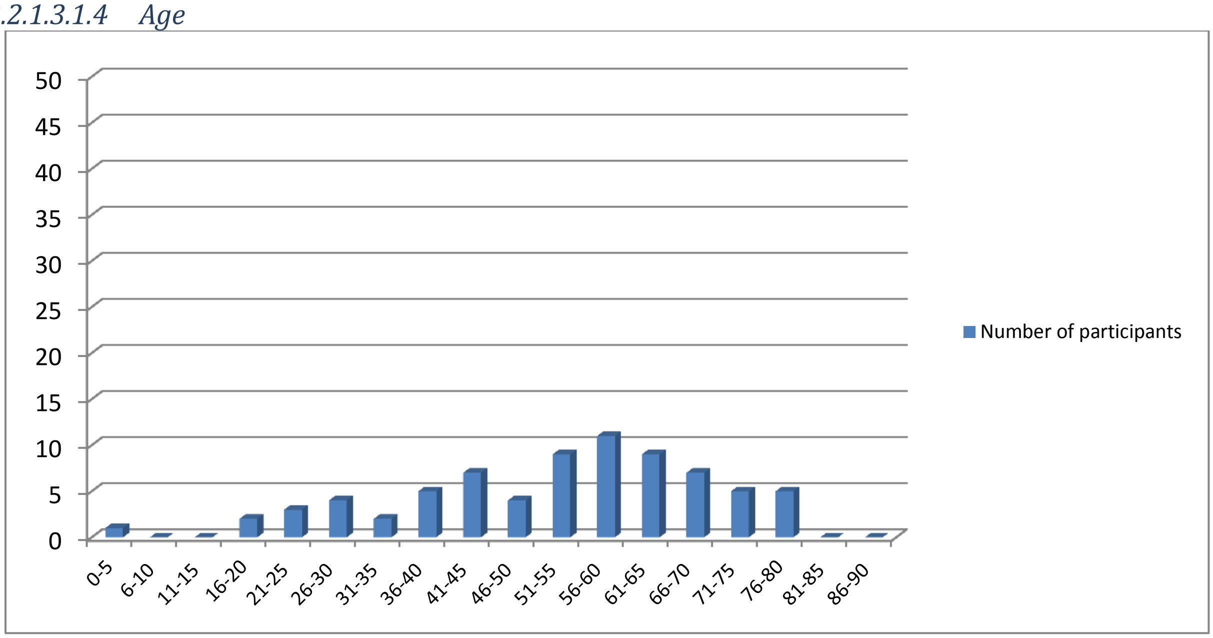


Figure 18. Age spread among participants (n=74)

The age of participants was widely spread but ages 51- 70 years were slightly more represented (36 individuals). Participants younger than 21 years consisted only of 3 individuals.
A majority of participants (16 individuals) in the target group were between 61- 70 years old.

2.2.1.3.1.5 Etiology

A majority of participants (42 individuals) were born with or acquired their hearing impairment/deafness as a child whereas 30 participants acquired their hearing impairment/deafness as an adult. Two participants stated “other” as reason for the hearing impairment/deafness.
In the target group, most participants (16 individuals) acquired their hearing impairment/deafness as an adult and 10 participants were born with or acquired the hearing impairment as a child.

2.2.1.3.1.6 Experience with a bone conduction hearing implant

A total of 22 participants stated to have had the bone conduction sound processor for 10 years or more, 29 participants stated to have had the bone conduction sound processor for between 0-4 years and 23 participants for between 5-9 years.

In the target group, 10 participants stated to have had the bone conduction sound processor for 10 years or more, 6 participants stated to have had the bone conduction sound processor for between 0-4 years and 6 participants for between 5-9 years.

2.2.1.3.1.7 Implantation side

An equal number of participants stated the right side to be implanted as the left side (29 individuals each). A fifth of the participants (16 individuals) stated to have an implant on both sides.

In the target group, 11 participants had the implant on the left side, 10 participants had the implant on the right side and 5 participants had an implant on both sides.

2.2.1.3.1.8 Brand of sound processor

A majority of participants (51 individuals) had a bone conduction sound processor from Cochlear. The remaining participants stated to have either a bone conduction sound processor from Oticon Medical (17 individuals) or another brand/did not know the brand (6 individuals). No participants stated that they used a sound processor from MED-EL, Sonitus Medical or Sophono.

In the target group, a majority of participants had a bone conduction sound processor from Cochlear (18 individuals). Remaining participants stated to have a sound processor from Oticon Medical (5 individuals) or a different brand/ did not know the brand (3 individuals).

2.2.1.3.1.9 Sound processor use time

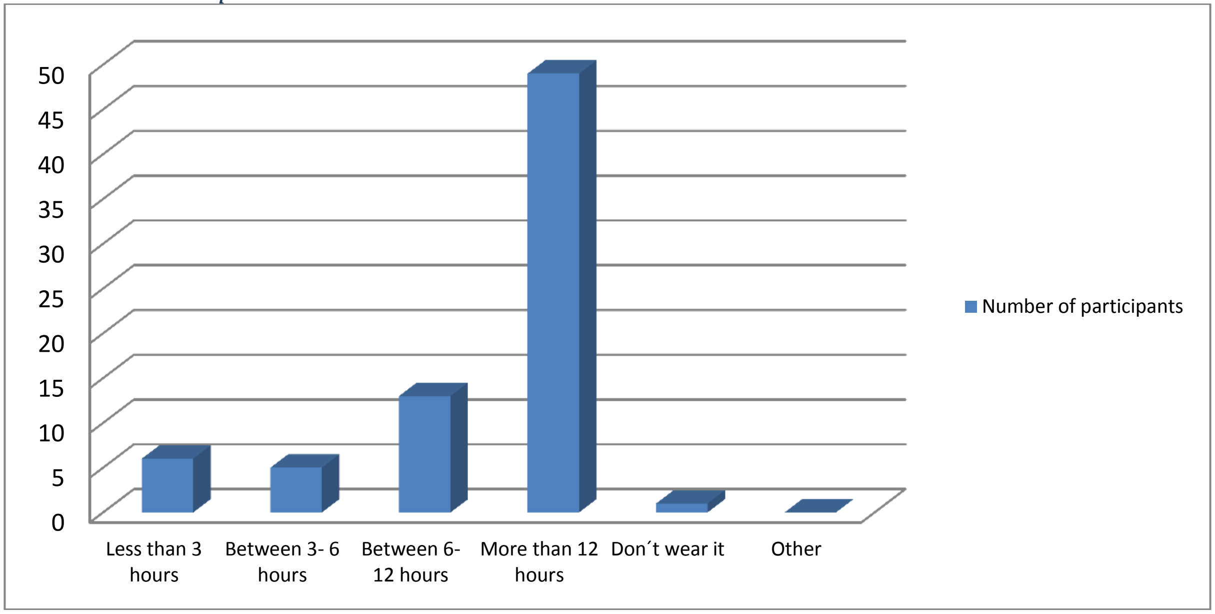


Figure 19. Sound processor use in hours/day (n=74)

A majority of participants (49 individuals) used their bone conduction sound processor for more than 12 hours per day, 13 participants used their sound processor for 6- 12 hours per day, 6 participants less than 3 hours per day, 5 participants between 3-6 hours per day and 1 participant didn´t wear it.

In the target group, a majority of participants (18 individuals) used their bone conduction sound processor for more than 12 hours per day, 3 participants used their sound processor for 3-6 hours per day, 3 participants for 6-12 hours per day, 1 participant for less than 3 hours per day and 1 participant didn´t wear it.

2.2.1.3.1.10 Satisfaction

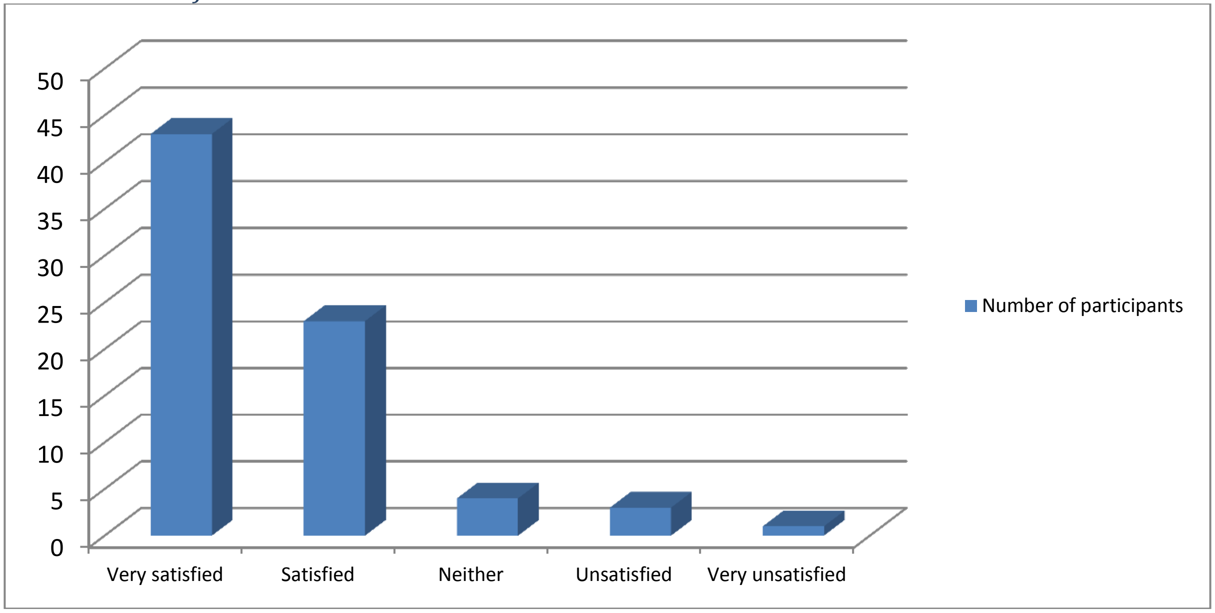


Figure 20. Satisfaction with sound processor (n=74)

A majority of participants (66 individuals) stated to be satisfied or very satisfied with their bone conduction sound processor. Remaining participants stated to be either neutral (4 individuals) or unsatisfied or very unsatisfied (4 individuals).
In the target group, a majority of participants (23 individuals) also stated to be either satisfied or very satisfied with their bone conduction sound processor. Remaining participants stated to be either neutral (1 individual) or unsatisfied or very unsatisfied (2 individuals).

2.2.1.3.1.11 Dissatisfaction

Participants stating to be unsatisfied or very unsatisfied with their bone conduction sound processor, had the possibility to answer a follow up question to explain the reason for not being satisfied. It was an open-ended question answered by 4 participants.
The answers were as follows;

1. *“I like Baha, Cochlear, better but it was too big since I have ear prosthesis but I hope to soon get a Baha again, since they’ve become smaller”.*
2. *“I have difficulty coordinating voices indoors and in groups also, when outside I cannot wear a hat and the slightest wind makes it unbearable”.*
3. *“My Hearing aid seems to overpower the BAHA”.*
4. *“Cannot wear it for any length of time. Totally useless in a noisy crowded situation. This is where I would most want it to help me”.*

Comments 2 and 4 were made from participants in the target group.

2.2.1.3.1.12 Household configuration

The most common household configuration consisted of two adults living without children.

2.2.1.3.2 Knowledge and use of internet and computers

The following section summarizes the results from the second part of the questionnaire, including questions concerning knowledge and use of internet and computers.

2.2.1.3.2.1 Computer use

Almost all participants (69 individuals) reported to use one or more computers, smartphones, tablets, laptops etc. for personal use, 3 participants stated not to use any of these and 2 participants didn´t answer the question.

A majority of the participants (23 individuals) in the target group reported to use one or more computers, smartphones, tablets, laptops etc. for personal use, 2 participants stated not to use any computers and 1 participant didn´t answer the question.

2.2.1.3.2.2 Reasons for not using computers

The participants, who stated not to use computers, smartphones, tablets, laptops etc., either preferred other forms of communication or knew too little about it.

2.2.1.3.2.3 Devices and operating systems

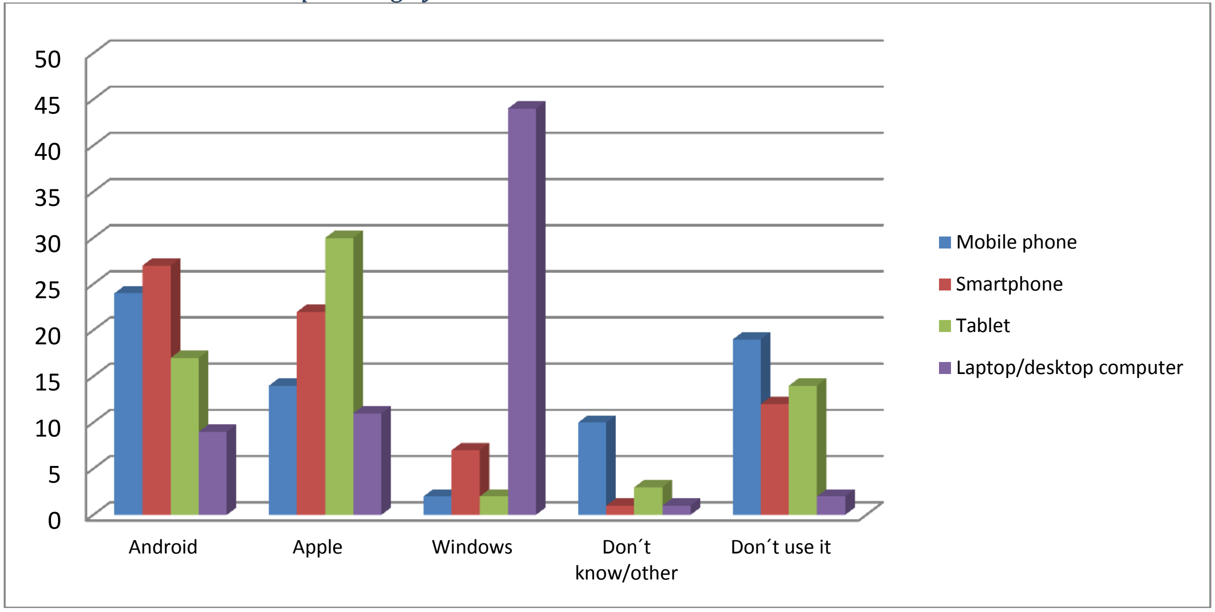


Figure 21. Use of different devices and operating systems (n=71). Multiple choices were available

Participants who used computers, smartphones, tablets, laptops etc. were asked to specify which devices and operating systems they used. Most commonly used was a Laptop/Desktop computer with Windows (44 individuals), a tablet from Apple (30 individuals) and an Android Smartphone (27 individuals).

In the target group, a Laptop/Desktop computer with Windows was used by a majority of participants (15 individuals). A tablet from Apple was used by 8 participants and an Android Smartphone by 8 participants.

2.2.1.3.2.4 *Learning methods for new devices*

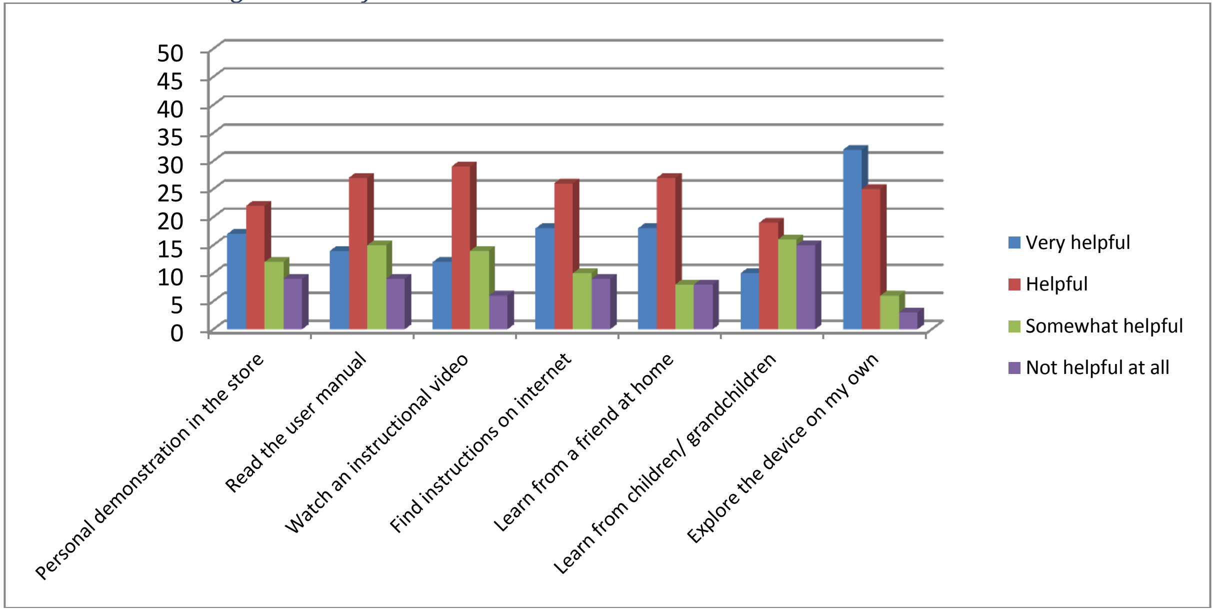


Figure 22. Learning methods for new devices (n=71). Multiple choices were available

When learning how to use a new device, 57 participants found it helpful or very helpful to explore the device on their own, 45 participants to learn from a friend at home, 44 participants to find instructions or information on the internet, 41 participants by reading the user manual, 41 participants by watching an instructional video, 39 participants by personal demonstration in the store and 29 participants by learning from children/grandchildren.

In the target group, 16 participants found it helpful or very helpful to explore the device on their own, 16 participants to learn from a friend at home, 15 participants to learn from children/grandchildren, 15 participants by personal demonstration in the store, 13 participants by reading the user manual, 11 participants by watching an instructional video and 11 participants by finding instructions or information on the internet.

2.2.1.3.2.5 *Easy to use*

The participants stated to be most comfortable with helping others on a Laptop/Desktop computer (43 individuals) and considered themselves to be good at using a mobile phone (25 individuals). The technology most reported never to be used was the Smartphone (11 individuals).

In the target group, participants stated to be most comfortable with helping others on a Laptop/Desktop computer (9 individuals). A total of 14 participants considered themselves to be good at using a mobile phone. In the target group, the Smartphone was the technology most participants stated never to use (8 individuals).

2.2.1.3.2.6 Amount of use

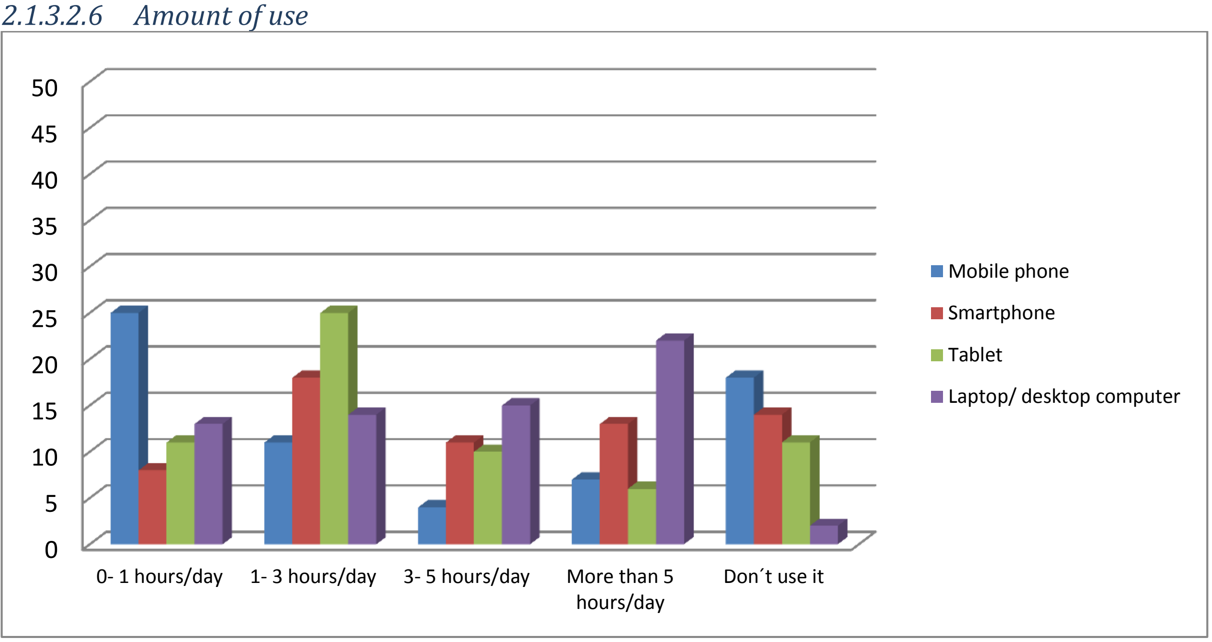


Figure 23. Hours/ day with different devices (n=71). Multiple choices were available

A tablet was most commonly used between 1-3 hours/day (25 individuals), a mobile phone between 0-1 hours/day (25 individuals), a laptop computer more than 5 hours/day (22 individuals) and a smartphone between 1-3 hours/day (18 individuals).

In the target group, a tablet was most commonly used 1-3 hours/day (9 individuals), a mobile phone 0-1h/day (14 individuals), a laptop computer between 0-1 hours/day (7 individuals) or 3-5 hours/day (7 individuals). A smartphone was the device that most participants' didn´t use (9 individuals).

2.2.1.3.2.7 Use of features

The features participants stated to use often on the devices were Internet (47 individuals), e-mail (46 individuals) and Wi-Fi (45 individuals). The feature most participants stated never to use was the GPS/Navigation (17 individuals).

In the target group, the features often used were Internet (11 individuals), e-mail (11 individuals), Wi-Fi (10 individuals) and phone calls (10 individuals). The feature most recipients stated never to use was GPS/Navigation (11 individuals).

2.2.1.4 Part III – Hearing situation

The following sections summarize the results from the third part of the questionnaire, including hearing situation.

2.2.1.4.1 Satisfaction concerning information received

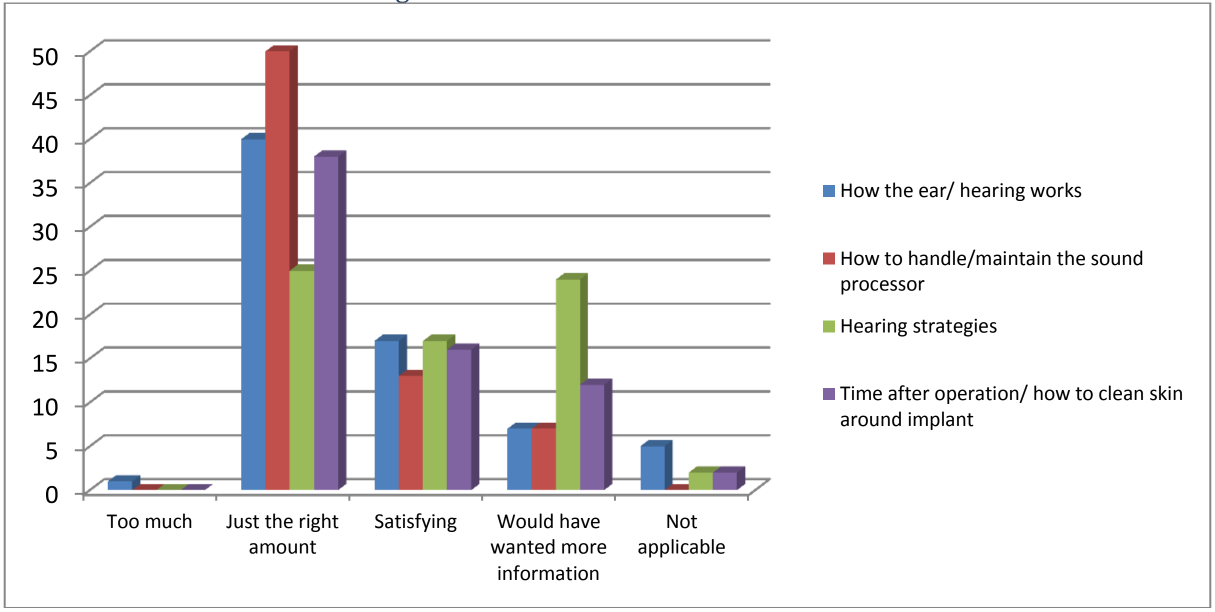


Figure 24. Satisfaction with amount of information received in association with the bone conduction sound processor (n=70)

A majority of participants thought the information given to them in association with receiving the bone conduction sound processor, was either just the right amount or satisfying. Participants were most pleased with the amount of information about how to handle and maintain the sound processor (63 individuals), and the amount of information about how the ear and hearing works (57 individuals). A total of 7 participants would have wanted more information concerning each of these topics. Concerning information about the time after operation and how to clean the skin around the implant, 54 participants were pleased with the amount of information. A total of 12 participants would have wanted more information. Concerning information about hearing strategies, a total of 42 participants were pleased with the amount of information and 24 participants would have wanted more information.

In the target group, results were similar. A majority of participants (23 individuals) found the amount of information about ear and hearing to be pleasing. The amount of information concerning how to handle and maintain the sound processor was also found to be adequate by most participants (22 individuals). A total of 18 participants found the information about the time after operation and cleaning of skin/ implant adequate and 5 participants would have wanted more information. In the target group, more information about hearing strategies was requested by most participants (8 individuals). A total of 14 participants were pleased with this information.

2.2.1.4.2 Information preference

A majority of participants (62 individuals) preferred to receive information about the bone conduction hearing solution from their hearing care professional and/or from the company that manufactured their sound processor (20 individuals). A total of 20 participants also preferred to find information on the internet and 13 participants preferred to get information from the instruction manual.

In the target group, results were similar; a majority of participants (22 individuals) preferred to get information about the bone conduction sound processor from their hearing care professional and/or from the company that manufactured their sound processor (5 individuals). A total of 3 participants preferred to find information on the internet and 3 participants in the instruction manual.

2.2.1.4.3 Smartphone app

When answering the question; If your smartphone, tablet or computer had a program (application) to use with your bone conduction sound processor, how useful would you find the following suggestions? A majority of participants found all given suggestions either useful or very useful. A total of 65 participants found the suggestion “give you support (troubleshoot problems, maintenance, contact with hearing care professional)” useful, 64 participants found the suggestion “give you practical advise on how to hear better in different situations” useful, 64 participants found the suggestion “give you possibility to adjust (change program/volume) useful and 63 participants found the suggestion ”give you information about your hearing, your hearing solution and accessories” useful.

In the target group, the results were similar; a majority (20- 21 individuals) found all given suggestions either useful or very useful.

2.2.1.4.4 Monitoring sound processor use

A majority of participants (53 individuals) stated that they would use a smartphone application to monitor their sound processor, 16 participants stated that they wouldn´t use an application and 5 participants didn´t answer the question.

In the target group, a total of 15 participants stated that they would use such an application, 9 participants stated that they wouldn´t use an application and 2 participants didn´t answer the question.

2.2.1.4.5 Opinions about datalogging

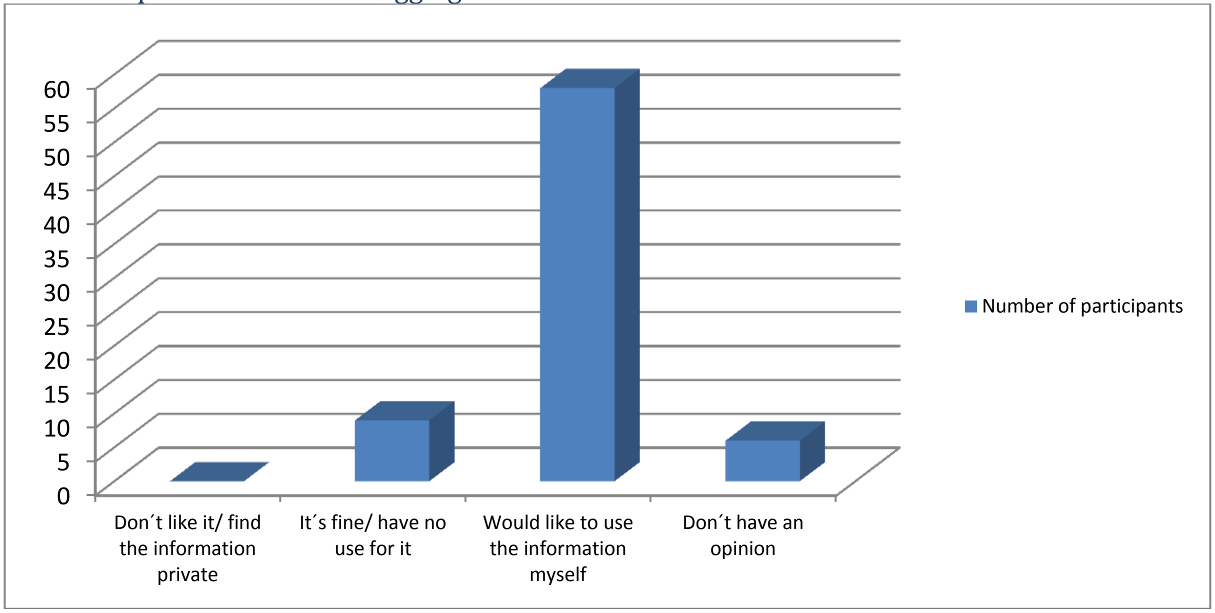


Figure 25. Opinion about data logging (n=70)

The following question was given to all participants; in the latest generation of sound processors there is an option available for the hearing care professional to look at your individual programs, in different listening environments. This information can be used to give you better advice on how to use your Bone conduction sound processor. What is your opinion on this?

None of the participants (0 individuals) stated not to like it because they found this information private. A majority of participants (58 individuals) stated that they wanted to use the information themselves and 9 participants didn´t find any use for the information themselves. A total of 6 participants stated not to have an opinion.

In the target group, a majority of participants (20 individuals) would have liked to use the information themselves and a total of 3 participants' didn´t find any use for the information themselves. A total of 2 participants stated not to have an opinion.

2.2.1.4.6 Assistive listening device

A majority of participants (45 individuals) didn´t have any assistive listening device together with their bone conduction sound processor. Reported assistive listening devices were wireless systems for phone calls (12 individuals), wireless systems with an extra hand held microphone (9 individuals), wireless systems for TV (7 individuals), Telecoils (7 individuals) and remote controls (3 individuals).

In the target group, a majority of participants (18 individuals) didn´t have any assistive listening device either. Reported assistive listening devices were wireless systems with an extra hand held microphone (3 individuals), wireless systems for TV (2 individuals), telecoils (2 individuals) and wireless systems for phone calls (1 individual).

2.2.1.4.7 Management

A majority of participants (41 individuals) didn´t find anything challenging when handling the sound processor. Challenges reported by participants were; adjusting the volume (12 individuals), changing batteries (9 individuals), changing programs (7 individuals), attaching the sound processor (7 individuals) and turning the sound processor on/off (3 individuals).

In the target group, most participants (16 individuals) didn't find anything challenging when handling the sound processor either. Challenges reported were; adjusting the volume (4 individuals), attaching the sound processor (3 individuals), changing programs (2 individuals) and changing batteries (1 individual).

2.2.1.4.8 Website of manufacturer

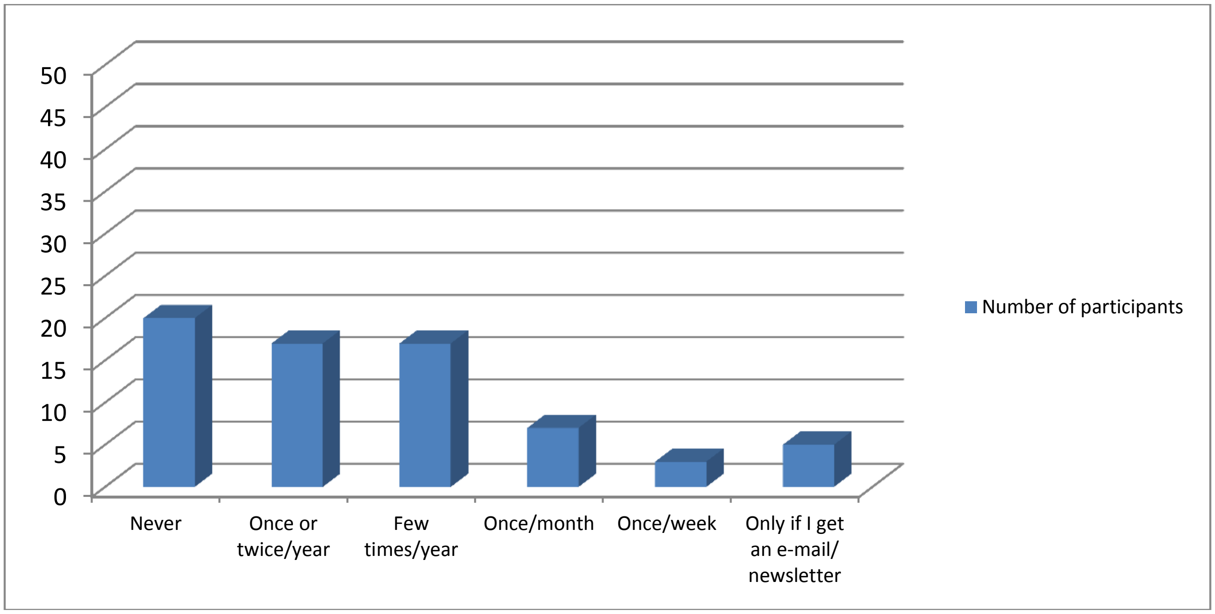


Figure 26. Amount of visits to the website of the manufacturer (n=69)

How often the participants visited the website of the manufacturer varied. A total of 20 participants stated never to visit the website, 34 participants stated to visit the website one to a few times per year, 10 participants stated to visit the website on a regular basis (monthly to weekly) and 5 participants stated only to visit the website when receiving an e-mail/newsletter from the manufacturer.

In the target group, 11 participants stated never to visit the website, 11 participants stated to visit the website one to a few times per year and 2 participants stated to visit the website on a regular basis (monthly to weekly).

2.2.1.4.9 Comments regarding the survey

At the end of the questionnaire, participants had an opportunity to leave comments or feedback on the survey. A total of 22 participants chose to do so. Four comments with only the word “no” written were excluded.

A selection of comments regarding the bone conduction sound processors:

“I would love to hear if there is work being done to make the Baha 4 even smaller. And I would love it if you could adjust the tilt of the baha, so you could let the contours of the baha follow the contour of your head (mine is sticking outwards)”

“Make the devices smaller and less obvious”

“My processor is the best thing that I have. In my opinion it is by far and away superior to digital OTE and cochlear implant devices. I am lost without it of I have to revert back to digital OTE devices. I miss much more with that than I do with my BAHA”.

A selection on comments regarding the survey:

“Long time coming. BAHA user for almost 15 years and don’t ever remember been asked my opinion before."

“A good investigation, could help many”

“It is good to see people looking into the future development for my daughter’s benefit!”

2.2.1.5 Discussion

2.2.1.5.1 Execution

Both the Swedish and the English questionnaire were available online as well as in paper versions. The response rate concerning the Swedish paper version was higher than for the English paper version which is probably due to the paper version being physically handed out to the Swedish participants, in an environment lacking access to a computer. Different circumstances applied to the English participants, who had a computer available when told about the survey. In fact, a large group of English participants received information about the survey during a monthly meeting and chose to help each other answer the questionnaire online via a computer that had been set up.

For participants outside Sweden and the United Kingdom, advertise was only made online and no paper version of the questionnaire was available, explaining why all these participants answered the survey electronically.

The questionnaire being conducted solely in English and Swedish, excluded individuals lacking skills in these languages.

2.2.1.5.2 Bias

A number of factors, that may have affected the results, should be considered before discussing the findings in this survey. First, most of the advertisement (including a link to the questionnaire) was found online, indicating users of a bone conduction sound processor without access to the internet wouldn´t have knowledge of the survey. Consequently, individuals without access to a computer or to internet may not be represented in this survey. Second, as with all questionnaires, there’s a risk of misinterpretation of questions and misrepresentation of one or more questions. Response choices such as “often”, “regular” and “sometimes” are subjective and therefor open to interpretation of the surveytaker. Consequently, the question concerning how often different features are used on a variety of devices are difficult to interpret. Third, the questionnaire did not gather any information concerning how long the participants had used their current sound processor or which year they had received it. It is reasonable to assume, that information given in association with receiving the sound processor, differ depending on when the sound processor is received. Consequently, it is hard to interpret how relevant the information given in association with receiving the sound processor is today, since the information participants are referring to may have been given many years ago. Finally, the terminology used at some stages in the questionnaire, may have required specific knowledge about technology. More accurate answers may have been obtained, had the participants been given the opportunity to define reflections concerning terminology.

2.2.1.5.3 Response rate

Advertise, including a link to the survey, was mainly found on the internet. There has been no attempt made to log number of individuals who have seen the survey but decided not to participate. A response rate can therefore not be calculated. For the Swedish paper version however, the response rate was 100% (9 individuals).

2.2.1.5.4 Results part I

A majority of participants stated to have a bone conduction sound processor from Cochlear. Although the survey wasn´t marked with Cochlear, it was available and advertised in environments and by persons related to Cochlear, which may have influenced the overrepresentation. The brand of the sound processor might have affected responses to questions concerning satisfaction, management challenges or daily use; hence a wider spread of brands would have been preferred in this survey.

A majority of participants stated to use their bone conduction sound processor for over 12 hours per day. This is consistent with former research, indicating individuals with a bone conduction hearing solution commonly uses it most of the day (over 8 hours per day) (Gardell et al., 2015; Rasmussen et al., 2012). It should however be noted, that participants in this survey self-estimated the time of use and that no data logging was used to verify given responses. Several studies comparing results from data logging with self-reported time of use, have displayed evidence that individuals tend to overestimate hearing aid use time (Laplante- Lévesque et al., 2014; Muñoz et al., 2014; Walker et al, 2012).

A vast majority of participants were either satisfied or very satisfied with their bone conduction sound processor which is consistent with former research, revealing over 86% to be satisfied or very satisfied with their sound processor (Rasmussen et al., 2012).

2.2.1.5.5 Results part II

A vast majority of participants in this survey stated to use computers, smartphones, tablets, laptops etc. for personal use. These results were not unexpected, considering a majority of participants answered the survey electronically. Kaye (2000) suggests computer technologies can offer great potential for individuals with disabilities by offering an increased independence, but that elderly individuals are less likely to take advantage of them. In this survey, reasons for not using computers, smartphones, tablets, laptops etc., was related to it being too complicated or preferring other ways of communicating, suggesting some individuals may lack awareness concerning potential benefits.

A majority of participants found it best to explore a new device on their own when trying to find out how it works. Learning from a friend or from children/grandchildren was also considered helpful, especially in the target group. Younger individuals use internet and computers more often than older individuals (Thorén et al., 2013; Kaye, 2000) which may explain why their help is required. It is reasonable to assume that a higher use of smartphones, tablets and computers results in a higher degree of knowledge about how they function. Consequently, older individuals wanting to learn from younger individuals may be an effect of different knowledge degrees in these groups.

The device most commonly used among participants was a computer with Windows as operating system. Participants stated to use the computer more than 5 hours per day. In the target group however, it was more common to use the computer between 0-5 hours per day. A smartphone was never used by 14 participants whereof 9 belonged to the target group. This is in line with earlier research, indicating younger individuals who are deaf and hard of hearing make use of smartphones while less young individuals make use of computers (Maiorana-Basas & Pagliaro, 2014). The computer was also the device most participants stated to know well how to use in this survey. Computers have been available for a long time and are also a common feature at work places, which can explain why participants stated to know more about how to use them. Features commonly used on devices were internet and e-mail which is consistent with earlier research, showing e-mail, surfing the internet and text messaging to be the most common purposes for using technology (Maiorana- Basas & Pagliaro, 2014).

2.2.1.5.6 Results part III

A majority of participants in this survey were satisfied with the amount of information given to them in association with receiving the bone conduction hearing solution. The subject most participants, both in the group as a whole and in the target group, would have wanted more information about was hearing strategies. The reason for wanting more information about hearing strategies may be that although participants experience satisfaction with their bone conduction sound processor, hearing in noise may be challenging. Gardell et al (2015) revealed in a survey that only 33% of the users of a bone conduction hearing solution understood “always well or usually well” when communicating one-on-one in noisy surroundings and no more than 25% when taking part in group conversations. Rasmussen et al (2012) had similar findings in his survey; 46% reported they could conduct a conversation in noisy surroundings and 25% stated they were able to understand conversation in a group.

When answering questions concerning an application to use with the bone conduction sound processor, participants found all suggestions given concerning content (give you information, give you possibility to adjust your bone conduction sound processor, give you practical advice on how to hear better in different situations and give you support) as useful, suggesting such an application would be well received.

None of the participants stated not to like the fact that hearing care specialists can look at use of individual programs in different environments, because the information was considered private. A majority of participants stated that they also wanted to use the information themselves. The reason for no participant stating not to like data logging, may be due to formation of the question. The term data logging was not used in the question and only potential positive aspects were mentioned which may reflect results.

Listening devices as complement to the bone conduction sound processor were not used at all by a majority of participants. The most common assistive listening device that was used, was a wireless system for phone calls. Earlier studies (Rasmussen et al., 2012; Gardell det al., 2015) have indicated phone conversations to be a difficult task among users of bone conduction hearing solutions, due to ambient noise. In this survey, the difficulty most reported in association with handling the bone conduction sound processor was changing the volume (12 individuals) which makes it noteworthy that only 3 participants reported to be in possession of a remote control. These results indicate that there are individuals lacking assistive devices, who could benefit from them. Reasons for not using any assistive devices were not examined in this survey, but it may be due to cost or lack of knowledge for devices available.

Challenges with managing the bone conduction sound processors were not reported frequently which is consistent with earlier findings by Rasmussen et al (2012), reporting most individuals being able to change the battery, adjust the volume and mount the bone conduction sound processor without difficulty.

2.2.1.6 Conclusion

In this survey, almost all participants stated to use one or more computers, smartphones, tablets, laptops etc. for personal use. The reasons for not using any of the devices were either lack of knowledge or a preference for other forms of communication. A laptop/desktop computer with windows was most commonly used, followed by a tablet from Apple and an Android Smartphone. Participants also reported to spend most time using a laptop computer compared to other devices. Features commonly used were internet, e- mail and Wi-Fi.

Information given in association with receiving the bone conduction sound processor was considered to be either the right amount or satisfying by most participants. More information was mainly requested concerning hearing strategies. However, the questionnaire did not gather any information concerning how long the participants had used their current sound processor or which year they had received it. This makes it difficult to interpret if more information concerning hearing strategies is needed today or if it was needed years ago. Likewise, it is hard to know if the information concerning how to handle and maintain the sound processor is considered adequate today or if it was so several years ago.

2.2.1.7 Source data

Source data is available in an analogue file at the Research and Application department at Cochlear BAS, Mölnlycke, Sweden.

2.2.2 Study 2 - Focus Group Survey- Summary and Evaluation - Thoughts and ideas about support tools, gathered from users of bone conduction hearing implants

2.2.2.1 Background

2.2.2.1.1 Datalogging

The first commercially available hearing aid with a data logging feature was the 3M MemoryMate introduced in the late 1980´s. Today data logging is a common feature and some of the major manufacturers' estimates that about 60-70% of the hearing aids they sell include this feature (Mueller, 2007).

The most popular aspect to monitor with the data logging feature is hearing aid use which can include total use, average daily use, use of different programs and use of special features such as noise reduction (Mueller, 2007).

Data logging can be used at different times and for various purposes during the hearing aid fitting process, for example when troubleshooting patient complaints or when changing the programming of the hearing aids (Mueller, 2007). The data logging feature has also been used as part of the counselling process which has shown to be beneficial, as to increasing both awareness and hearing aid use (Muñoz et al., 2014).

2.2.2.2 Purpose

The primary objective of the focus group meetings was to gather thoughts and ideas about support tools, including a draft for a website, data logging and internet-based contact with audiologists, from experienced users of bone conduction hearing implants. An additional aim was to investigate difficulties experienced by individuals with a bone conduction hearing implant as well as informational needs.

2.2.2.3 Methodology

To gather thoughts and ideas from users of bone conduction hearing implants, 4 focus group meetings were organized with an interval of 1 week. All meetings were held in Swedish, in a secluded room at the Cochlear office in Mölnlycke, and lasted between 2-2, 5 hours. The participants were encouraged to speak freely from given questions or topics. The total number of participants ranged from 8-9 persons and number of organizers from the Cochlear office ranged from 1-3 persons. Detailed information about number of participants during the different meetings can be found in appendix A. All participants were offered free lunch and covered expenses for travel costs as compensation for participating in the survey. No other compensation was offered. Participation in this study was voluntary and all participants could choose to leave the meetings whenever wanting to do so. Both oral and written information concerning the purpose with the focus group meetings, voluntarism and handling of personal information, was communicated. The design of the written consensus, signed by all participants, can be found in appendix B. All group meetings were recorded and transliterated.

2.2.2.3.1 Recruitment of participants

An advertisement was published in a local newspaper in Gothenburg (Nyheter & bulletiner) and also sent to the Cochlear Nordic user register. All respondents fulfilling the inclusion criteria were considered in this survey and ten individuals, five male and five females, were raffled out to take place in the focus groups. If any of the individuals offered a place in the focus groups couldn´t participate, another individual was raffled out.

2.2.2.3.2 Inclusion criteria

The selected individuals should;

- Use a bone conduction hearing implant on an abutment
- Be 60 years or older
- Have received the bone conduction hearing implant in Sweden
- Be fluent in Swedish

2.2.2.3.3 Confidentiality

The information collected during the focus group meetings were confidential and coded as to avoid personal information being spread to others. The recorded and written material was kept in a locked cabin with strict limited access. All participants were asked not to talk about the experiences and thoughts expressed by other participants, outside the group. During all visits the participants received the same information concerning guide lines during focus group meetings. The guide lines included confidentiality, focus group manners, avoiding personal information being spread and keeping a nice tone during the meetings.

2.2.2.3.4 Disposition of meetings

Four meetings took place, each meeting focusing on a given topic and/or given questions. The following sections summarize the agenda for each meeting.

2.2.2.3.4.1 First meeting

In the beginning of the first meeting, participants were asked to introduce themselves by name, age, interests and time since hearing implantation. Thereafter, the organizers gave a short introduction of themselves, before the SHiEC project was presented.
Questions introduced for discussion during the first meeting were as follows:

- When did you receive your bone conduction hearing implant? What kind of information/rehabilitation did you receive in association with it?
- How would you explain your need for rehabilitation/information today?
- What information would you like to receive?
- Where do you want to receive that information?
- From whom would you like to receive that information?

2.2.2.3.4.2 Second meeting

The second meeting focused on the website. Participants were shown, via screen shots on a big screen, how the draft for the website looked like and some of its suggested content. Except being presented with information on a big screen, all participants were offered a paper version that included the screen shots. The participants were requested to share their thoughts and ideas about what they had been presented with. Subjects being discussed during the second meeting were design aspects of the website, information that could be available on the website and applications. At the end of the second meeting, participants got to know the topic for the third meeting and also received written information to bring home.

2.2.2.3.4.3 Third meeting

The third meeting focused on data logging. A short introduction about what data logging is, how it can be used and how the results thereof can be presented were shared by the organizers. Thereafter the participants were requested to share their thoughts and ideas concerning what had been presented to them.
Questions introduced for discussion during the third meeting were as follows:

- What are your thoughts about this information being gathered?
- How would you like the information to be used?
- With whom can you imagine sharing this information?
- What information would you want gathered?
- Benefits and downsides with data logging?

2.2.2.3.4.4 Fourth meeting

The fourth meeting focused on the support tools as a whole, including data logging, the webpage, help tool for data logging and possibility to receive contact and support from an audiologist via internet. The participants were given a short presentation of the support tools and were thereafter requested to share their thoughts and ideas about it and its content.

2.2.2.4 Synthesis

The primary objective of the focus group meetings was to gather thoughts and ideas about support tools, including a draft for a website, data logging and internet-based contact with audiologists, from experienced users of a bone conduction hearing implant. An additional aim was to investigate difficulties experienced by individuals with a bone conduction hearing implant as well as informational needs.
A total of 4 focus group meetings were conducted, consisting of 8-9 participants each. All participants were experienced users of a bone conduction hearing implant and at the age of 60 years or older.
Overall, during the focus group meetings, it became apparent there is a need for sharing experiences with other individuals in similar situations. It was also apparent that the participants would like to increase the understanding among others about difficulties often experienced by individuals with a hearing disability. The following sections summarize the thoughts and ideas from participants based on given topics and questions.

2.2.2.4.1 Time of surgery and information given in association

The majority of participants underwent surgery and received their first bone conduction hearing implant during the 1980´s, with a few participants receiving their bone conduction hearing implant later on. Information received in association with the bone conduction hearing implant, was often given by an ENT- doctor and focused on the surgery. One participant mentions information being conducted by an audiologist a bit further on during the rehabilitation process, where e-mail contact was held between the two. The participant perceived this as a positive experience and phrased it in the following way; "We could have contact via mail and stuff, it felt very very good".

2.2.2.4.2 Difficulties experienced and informational needs

Several participants expressed difficulties hearing grandchildren, the radio and phone calls from different governments.

A variation of informational needs was expressed by the participants. A few mentioned a need to know more about technical appliances, such as what exists and how it would be possible to get hold of it. Information about new and upcoming products was also of interest. Another subject mentioned was acoustical environments, mainly proposing other people should know more about acoustics before starting to plan and build new rooms at for example working places. A need to share experiences with other users of a bone conduction hearing implant was expressed, as well as a need to include relatives, aiming at increasing their understanding concerning difficulties often experienced by individuals with a hearing impairment.

Concerning where or from who the information needed should be emitted; the school was mentioned as well as gatherings for users of a bone conduction hearing implant. Several participants mentioned receiving information from HRF (National association for individuals with a hearing impairment), both from employees and members thereof. Difficulties getting in contact with an audiologist are brought up by a participant, suggesting the estimated waiting time to get an appointment is far too long and that some audiologists lack knowledge about bone conduction hearing implants.

One participant expresses concerns that there is too much information in the beginning of the rehabilitation process, from different people, resulting in difficulties to remember everything.

2.2.2.4.3 Thoughts and ideas concerning website and app

Concerning the design of the website, it was noted at some places that the colours and size of letters made it hard to assimilate the information conveyed. For instance, some participants had a hard time identifying words covered in an orange or yellow background. One participant found it hard to know what the different headlines covered; suggesting it probably would make more sense after having looked around on your own for a while.

The difference between the draft for a website and the existing website seemed a bit unclear; one participant asked if two different sites really were necessary since all information could also be found on the official cochlear website.

Concerning information available on the website, participants had a variety of suggestions, including information about repair, products available, airplane status, musical experience with bone conduction hearing implants and indications for 1 respectively 2 hearing aids. Further suggestions consisted of contact details, feedback and management, for example how the volume button functions. A discussion about difficulties living with a hearing loss unravelled during one of the meetings, leading to suggestions about also including information concerning how to tell others about the hearing loss as well as describing difficulties associated with hearing loss.

Discussions about Apps resulted in a range of questions, such as what it is, how they are used and with what kind of phones they are compatible. Most participants found it a good idea being able to do the same thing on a computer as in an app. All participants expressed confidence in finding information on the internet and also found it useful to do so. A wish to program the hearing aids by themselves via an app was expressed.

2.2.2.4.4 Thoughts and ideas concerning datalogging

During meetings, several questions and concerns about the data logging feature were expressed. Questions included what information that could be recorded, if there was a choice to turn the recording off and if it was optional who had access to the information recorded. Concerns regarding the data logging feature, was purpose with recording and possibilities to record personal conversations.

Several participants seemed to find the data logging feature positive, given they could control who had access over it and that it was used for research and not to find out any personal details about the user of a bone conduction hearing solution. Some participants thought it might be useful to see how much the bone conduction hearing implant had been used and in which environments.

When the question arises with whom the participants would like to share the data logged information, the closest family is mentioned as well as developers of hearing aids and researchers. Participants also suggested it could be useful for employers in elderly care to get access since some individuals have difficulties expressing their own needs. Participants found it positive that the data logging feature might inspire new users of a bone conduction hearing implant in a way that increased use time.

One participant came up with an idea about being able to see battery status via the data logging feature. Another participant thought it would be great if the hearing aid could adapt to different situations, for example to enhance speech recognition when there is a lot of people talking.

After examples were shown on how a tip can show up on the screen of the smartphone, for example with the text “You seem to often be in environments with speech in noise. Would you like to know more about how you could hear better in these environments? Click here!” the participants reacted in a positive way. One participant expressed; “Wow that would have been something. It sounds fantastic!”

2.2.2.4.5 Thoughts and ideas concerning internet based contact with audiologists

Discussions about internet-based contact with audiologists led to questions concerning what would happen if you didn´t have a computer and also who should provide a computer if this was needed. Some participants thought the internet-based contact would be a good alternative if you had a long way to travel to the audiologist. Another participant expressed the possibility that there could be something physically wrong with the processor that couldn´t be fixed over the internet, which would have lead to complications. Suggestions that contact over the internet would suit younger people better than elderly are expressed and also that support tools have to be easy to use. One participant mentioned the importance of having a physical contact between the audiologist and patient and found it important that this didn´t disappear. Several of the participants seemed to want to visit the audiologist regularly and especially for certain occasions, among others to perform a hearing test. Concerning minor adjustments, participants seemed positive being able to resolve these over the internet.

2.2.2.5 Bias

A number of factors, that may have affected the outcome, will be addressed. First, the rather large group size (consisting of 8-9 individuals) made it hard to keep everyone’s attention. Large focus groups can result in decreasing influence from participants, and probably also decreasing involvement. The reason for continuing with the large group size was to gather as many thoughts and ideas as possible. In retrospect, a smaller group size would have been preferred in order to keep everyone´s attention and involvement. Second, individuals’ who are part of a group may edit responses and adapt to other opinions presented in the group, suggesting not all spoke their mind. All questions were kept neutral to encourage participants to share their opinions in a non-judgemental way, suggesting honest responses have been received. Third, the non-verbal communication can be an important complement to the verbal communication in group situations. No video camera was used for recording during the focus group meetings and therefor it is difficult to know the importance of the non-verbal communication. However, using a video camera for recording may also be intimidating for some individuals and it is reasonable to assume that not all participants would appreciate such a feature. Finally, some individuals may have concerns about how personal details are handled and therefor afraid to speak their mind. The ethical aspects of the study were explained early on to compensate for this.

2.2.2.6 Conclusions

A concern about the purpose and use of data logging in bone conduction hearing implants exists, suggesting more information on the subject is needed. The participants could find benefits with data logging in the purpose of research and development but also as a way to motivate new hearing aid users. Information suggested for the website was, among others, existing and upcoming products, guidelines as how to explain to others about the hearing impairment, information on how to repair the bone conduction hearing implant and contact information when assistance is needed. Some participants seemed to find it problematic that a computer is needed for the support tools and are suggesting this would suit younger individuals better than elderly. For individuals having a long journey to and from the audiologist, the internet-based contact is perceived as a flexible solution.

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