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University College Cork, Ireland Coláiste na hOllscoile Corcaigh

# What are the effects of acquired hearing loss in older people?

Amy Katherine Walsh

CARL Research Project in collaboration with Cork Deaf Association



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# What is Community-Academic Research Links?

Community Academic Research Links (CARL) is a community engagement initiative provided by University College Cork to support the research needs of community and voluntary groups/ Civil Society Organisations (CSOs). These groups can be grass roots groups, single issue temporary groups, but also structured community organisations. Research for the CSO is carried out free of financial cost by student researchers.

CARL seeks to:

- provide civil society with knowledge and skills through research and education;
- provide their services on an affordable basis;
- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and
- enhance the transferrable skills and knowledge of students, community representatives and researchers (www.livingknowledge.org).

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We define CSOs as groups who are non-governmental, non-profit, not representing commercial interests, and/or pursuing a common purpose in the public interest. These groups include: trade unions, NGOs, professional associations, charities, grass-roots organisations, organisations that involve citizens in local and municipal life, churches and religious committees, and so on.

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The research agreement between the CSO, student and CARL/University states that the results of the study must be made public through the publication of the final research report on the CARL (UCC) website. CARL is committed to open access, and the free and public dissemination of research results.

# How do I reference this report?

Author (year) *Dissertation/Project Title*, [online], Community-Academic Research Links/University College Cork, Ireland, Available from: <u>http://www.ucc.ie/en/scishop/completed/</u> [Accessed on: date].

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CARL is part of an international network of Science Shops called the Living Knowledge Network. You can read more about this vibrant community and its activities on this website: <u>http://www.scienceshops.org</u> and on Twitter @ScienceShops. CARL is also a contributor to Campus Engage, which is the Irish Universities Association engagement initiative to promote community-based research, community-based learning and volunteering amongst Higher Education students and staff.

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#### Abstract

Background: Acquired hearing loss (AHL) is defined as a hearing loss which is acquired after birth or at any other time in one's life. In Ireland, one in every twelve adults has a permanent hearing loss as a result of aging or exposure to noise. Aim: The experiences of the older Irish population has not yet been researched, therefore this study aimed to investigate the experiences of members of the Cork Deaf Association (CDA) who have an acquired hearing loss (AHL). Methods: This study was a pilot study in collaboration with CARL and the Cork Deaf Association which used a qualitative research design. Data was gathered using an open ended questionnaire which was distributed by the CDA to 30 potential participants. Data was analysed using a latent thematic approach. Results: 12 members of the CDA responded to the questionnaires. From these responses four themes were identified. They included emotional well-being, management strategies and habilitation, alienation and promoting awareness. This study supported the hypothesis that AHL can have a negative effect on older people Conclusion: Further research is needed in this area in order to get a deeper insight into the effects AHL has on the older Irish population as a whole. Promoting awareness within communities may help older people with AHL to re-integrate into society and help eliminate the feeling of isolation and alienation.

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#### Introduction

Acquired hearing loss is defined as a hearing loss which is acquired after birth or at any other time in one's life (American Speech Hearing Association, 2017). Risk factors associated with acquired hearing loss include viral infections, chronic otitis media, age, exposure to loud noise, ototoxic medication and head injury (ASHA, 2018). The World Health Organisation (WHO, 2017), reported that more than half of the world's population over the age of sixty five years are affected by a disabling hearing loss. In Ireland, one in every twelve adults has a permanent hearing loss as a result of aging or exposure to noise (Irish Society of Hearing Aid Audiologists, 2018). The effects acquired hearing loss can have on the person therefore requires further investigation.

Community based research is an evolving method of research in Ireland which has benefits for the higher educational institution, the student researcher and the community partner (Bates & Barnes, 2013). This was a community based research project in partnership with Community Academic Research Links (CARL) in UCC, the Cork Deaf Association (CDA) and the author who is a student researcher. CARL has a mission "to provide independent, participatory research support in response to concerns experienced by civil society" (CARL, 2018. http://carl.ucc.ie). This is achieved by following a particular research process (see Appendix I). The Cork Deaf Association is an organisation which aims to empower Deaf and Hard of Hearing people by providing people with information about hearing loss and support services (CDA, 2018). In compliance with the contract between the stakeholders, the CDA proposed a research project within the area of acquired hearing loss (see Appendix II). The CDA requested documented evidence with regard to the experiences of persons with acquired hearing loss. The CDA witness these experiences first hand within their service, however no studies of this kind have been carried out in the Irish context to date. The goal of this study was to investigate the experiences and perspectives of people who have acquired a hearing loss in later life. The research aimed to identify the effects of an acquired hearing loss on quality of life. This was a pilot study which aimed to test the methodology of this small scale preliminary study. The general hypothesis was that an acquired hearing loss has a negative effect on a person's life.

#### Study aims

This study aimed to investigate into the experiences and perspectives of people who acquired a hearing loss in later life. Another aim of the study was to identify the effects an acquired hearing loss can have on a person and on their quality of life. The researcher wished to discover what coping strategies these people use and what supports are available. This study was the first of its' kind within Irish context. Studies have been conducted in other countries which reported that acquired hearing loss (AHL) had a negative effect on an older person's mental health and well-being. People with acquired hearing loss (AHL) reported experiencing depression, anxiety, social isolation and cognitive decline (Ciorba, A., Bianchini, C., Pelucchi, S., & Pastore, A., 2012; Garnefski, N., & Kraaij, V. ,2012). The aim of this study was to ascertain if the same experiences occur within the Irish population.

#### **Literature Review**

Garnfski & Kraaij (2012) reported that acquired hearing loss had negative effects on a person's life; their social functioning, their ability to perform daily tasks. Additionally it had a negative effect on their mental health potentially leading to symptoms of depression and anxiety. Hearing loss in the elderly was the most common sensory deficit (Ciorba, Bianchini, Pelucchi & Pastore, 2012). Studies demonstrated that acquired hearing loss (AHL) in the elderly had an effect on their communication abilities and therefore on the individual socially and emotionally (Mulrow, Aguilar, Endicott, Velez, Tuley, Charlip, & Hill, 1990).

Severity of hearing loss was a common theme throughout the literature. In a study by Mulrow et al. (1990) the participants reported their hearing loss as a severe disabling factor in their lives, regardless of the actual severity, in audiological terms, of the hearing loss itself. In the Blue Mountain Study by Chia et al. (2007), the severity of the hearing loss was linked with lower Short-Form Health Survey (SF-36) scores suggesting a poorer quality of life amongst those with severe acquired hearing losses. The Blue Mountain study was a comprehensive study with a large sample size and from a reputable source. Research conducted by Garnefski & Kraaij (2012), indicated that the severity of the acquired hearing loss had an impact on a person's anxiety levels. Souza (2009) also highlighted the impact of a severe acquired hearing loss. These included grief and withdrawal from society, leading to isolation. The loss of a person's ability to communicate can result in seclusion, feelings of aggravation and reliance on others (Ciorba et al., 2012). Monzani, Galeazzi, Genovese, Marrara & Martini (2008) like Mulrow et al. (1990), found that people with mild to moderate acquired sensorineural hearing loss were also disposed to depressive feelings and fretfulness, more so than their hearing counterparts.

Meyer & West (2013) studied the well-being of those who acquired a hearing loss later in life. Their participants' perception of the severity of their hearing loss and not the calculated hearing loss was the factor that impacted on their well-being. The more severe their hearing loss was perceived, the more negative emotional responses these people experienced. This research also suggested that reflecting on one's hearing impairment can result in additional feelings of depression and anxiety and that transferring thoughts to more pleasant matters could help to lessen depression and anxiety in people with acquired hearing loss (AHL) (Garnefski & Kraaij, 2012). Those who acquired a hearing loss later in life were more at risk from suffering from depression than their hearing counterparts (Jones & White, 1990).

The literature also addressed how people with AHL to manage with their hearing loss. Amplification as a management strategy for hearing loss has been widely researched. Chia et al. (2007) reported that people who wear their hearing aids daily had a better quality of life than those who wear their hearing aids sporadically, or not at all. In a paper by Frank Lin (2012), he argued that the treatment of hearing loss is more than just wearing a hearing aid. He emphasised the importance of multiple therapeutic approaches and patience in conjunction with hearing aid use. Lack of awareness about the impact that hearing aids can have on a person and knowledge of the advantages of assistive devices was an issue amongst healthcare professionals as well as the public, according to Lin (2012). Frank Lin stressed the importance of further clinical trials which integrate the aging population with the effect of hearing loss in order to appropriately manage and treat age related hearing loss. Wattamwar et al (2017) discovered that few over the age of 80 years availed of hearing aids despite the known benefits. The types of rehabilitation used with this age group were questioned and it was suggested that different methods of rehabilitation should be used with this age group in order for them to be encouraged to wear hearing aids.

Meyer & West (2013) described the adaptation process that people who acquire a hearing loss have to go through in order to gain the mental ability to cope with their disability. This study highlighted that each person's ability to adapt can differ, therefore their ability to cope differs. Meyer & West (2013) recommended that rehabilitation should be used for those who have acquired a hearing loss in order for them to be able to adapt to a new reality. This adaptation process may lead to different choices in the types of rehabilitation in conjunction with other factors. Laplante-Levesque, Hickson & Worall (2010) identified factors that influenced a person's choice of rehabilitation, e.g. convenience, expected outcomes, cost, hearing disability, recommendations and support from others. The study had a large sample size and few limitations. This study highlighted the importance of the clinicians' relationship with their client in order for the client to make informed shared decisions with regard to their choice of rehabilitation.

Society's awareness of hearing loss and the challenges that comes with it was another topic which was evident throughout the literature. Graaf and Bijl (2002), explained that people who acquired a hearing loss later in life saw themselves as having more of a disability than those who had a lifelong hearing impairment. It was difficult for these people to learn how to communicate in a different manner previous to acquiring a hearing loss (Meyer & West, 2013). These views and changes in socialisation could have impacted on a person's sense of identity and belonging. Ciorba et al. (2012) highlighted that public awareness was key in relation to hearing loss, in particular Presbyacusis, as this had an impact on how the person communicated with others. If the general population understood these communication difficulties, they could have been more aware of how they interacted with people with an acquired hearing loss (AHL). This could in turn have led to a better quality of life for those with a hearing loss. In a systematic review of the literature Ciorba et al. (2012) highlighted the effects Presbycusis can have on the elderly person, however only one database was searched which can be interpreted as a limitation. Meyer and West (2013) and Ciorba et al. (2012) were the only studies that examined self-identity and societal awareness and it will be interesting to discover if the Irish population feel the same.

#### Rationale

It was evident from the literature, that the experiences of people with acquired hearing loss have been well researched globally, however there was a gap in the literature. The experiences of the Irish population had not yet been researched, therefore this study aimed to investigate the experiences of members of the Cork Deaf Association (CDA) who have an acquired hearing loss. Such research will provide valuable information for audiology professionals and other support. It will contribute to their knowledge and understanding which will guide them in meeting the needs of these clients.

#### Methods

#### **Research design**

This study design was a qualitative research design which used thematic analytical methods. Thematic analysis "offers an accessible and theoretically-flexible approach to analysing qualitative data" (Braun & Clarke, 2006, p. 2). The researcher used this specific research design in order to understand the experiences and attitudes of a targeted population whilst also gaining an insight into how experiences, attitudes and life circumstances affect their behaviour.

# Data collection

A questionnaire was developed with reference to previous studies and additional questions were developed by the investigators for the purpose of this study (see Appendix III). This study was used to pilot the questionnaire.

The questionnaire was distributed to participants by the Cork Deaf Association along with an information leaflet about the study (see Appendix IV) and consent form (see Appendix V) to ensure anonymity. The participants were informed that their identity would remain anonymous throughout the study and that information they provided would only be seen by the Chief investigator, the co-investigator and the Cork Deaf Association (CDA).

The participants were given four weeks to complete the questionnaire and returned to CDA. Following a two week period, a reminder message was sent to all participants to encourage participation in the questionnaire. Participants were not asked to provide their names. All questionnaires were transformed from paper to electronic files and stored on a password protected computer of the investigator for data analysis.

#### Participants

A questionnaire was distributed by the Cork Deaf Association (CDA) to 30 of their members. Participants for this study were found through purposive sampling. The sample was selected from the CDA database, and the CDA ensured that these people met the inclusion criteria (see Table 1). To recruit participants, an information letter and consent form was sent to the potential participants.

| Inclusion Criteria                    | Exclusion Criteria         |
|---------------------------------------|----------------------------|
| 65 years and older                    | Under 65 years             |
| Acquired Hearing Loss                 |                            |
| No communication difficulties         | Congenital Hearing Loss    |
| CDA members                           |                            |
| No additional needs                   | Communication difficulties |
| Male and Female                       |                            |
| Unilateral, Bilateral Hearing loss    | Non CDA members            |
| Hearing aid wearers & Non Hearing aid |                            |
| wearers                               |                            |
| Mild, moderate, severe, profound      | Additional needs           |
| hearing loss                          |                            |

#### Table 1: Inclusion and exclusion criteria of the sample

# Questionnaire

The questionnaire utilised for the study was designed by the chief investigator, the co-investigator and the community partner. Following a series of earlier drafts and reiterations a questionnaire was finalised by all stakeholders. The questions were designed to gather valuable demographic information about the participants while also encouraging the participants to elaborate on their experiences (See table 2). In order to give the participants the opportunity to share these feelings and experiences, open ended questions were chosen. Open ended questions were selected to eliminate

bias as much as possible and to gain authentic responses from participants without the help of prompts Reja, Manfreda, Hlebec, & Vehovar (2003).

| Age of diagnosis                      | Q. 1             |
|---------------------------------------|------------------|
| Type and Severity of hearing loss     | Q. 2, Q. 3, Q. 5 |
| Psychosocial impact                   | Q. 6, Q.7, Q. 10 |
| Rehabilitation, Management and Coping | Q. 4, Q.8, Q. 9  |
| Strategies                            |                  |
| Positive Experiences                  | Q. 11            |

 Table 2: Information gathered from questionnaire

#### Data analysis

Ethical approval was granted for the study by the Social Research Ethics Committee (see Appendix VI). The data collected from the questionnaires was analysed using a latent thematic approach. Using a latent approach allowed the researcher to discover any fundamental norms from the data (Braun & Clarke, 2006). Latent thematic analysis involves the researcher interpreting the data and thus developing themes. The researcher also adopted the Braun & Clarke (2006) six step framework when analysing the data. Familiarisation with the data was the first step before generating initial codes. Following the coding process, preliminary themes were identified (see Appendix VII). These preliminary themes were reviewed further which led to more specific ideas and finally naming the themes.

#### Results

#### Demographic details of the sample

Cork Deaf Association distributed 30 questionnaires to members of the CDA who are over the age of 65 years. The response rate was 40%. Respondents consisted of seven hearing aid wearers and 5 non hearing aid wearers. The sex of the respondents was unknown.

# Age of diagnosis

The majority of respondents (83.3%) were diagnosed with a hearing loss before the age of 65 years. None of the respondents were diagnosed with a hearing loss between the ages of 65 years and 80 years old. 18.7% of the respondents were diagnosed when they were over 80 years (see Table 3).

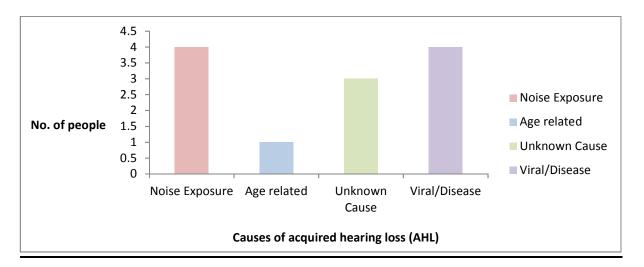
| Age of diagnosis | Number of respondents |
|------------------|-----------------------|
| 55-65 years      | 10                    |
| 65-80 years      | 0                     |
| 80+ years        | 2                     |

#### Table 3: Age of diagnosis

#### **Cause of hearing loss**

The cause of acquired hearing loss (AHL) amongst respondents varied. They included noise exposure, age, unknown causes, flu virus and Meniere's disease. Table 4 illustrates the number of participants and the corresponding causes of hearing loss. Noise exposure and a virus/disease reported as the most common causes. Age related hearing loss was reported as the least common cause of hearing loss. Three participants did not know the cause of their hearing loss.

All participants reported a bilateral hearing loss. Of the participants that wear hearing aids four reported having a moderate loss and five reported a severe hearing loss. Of the three participants who do not wear hearing aids one reported a mild loss and two reported having a moderate hearing loss. None of the participants had a profound hearing loss.



#### Table 4: Causes of hearing loss

#### Themes

Four themes were identified from data in the questionnaires: emotional well-being, management strategies, alienation and promoting awareness. The preliminary themes and codes are included in appendix VII.

# Theme 1: Emotional well-being

The first theme was emotional well-being. For the purpose of this study, emotional well-being referred to the different feelings and emotions conveyed by the participants as a response to having an acquired hearing loss. Participants documented and described their responses to their AHL. The emotions experienced by ten out of the twelve participants were negative emotions, with only two reporting positive feelings.

#### Negative responses

Isolation was a recurrent complaint. Four of the participants who wear hearing aids, reported feeling isolated. Only one of the participants who wears a hearing aid recounted that they "do not feel isolated anymore" since being fitted with hearing aids. Two thirds of the respondents who were not hearing aid wearers described that they felt "isolated" as a result of their hearing loss. The reason they gave was not only their hearing loss but also as a result of avoidance of socialising; relinquishing their hobbies and making efforts to avoid people:

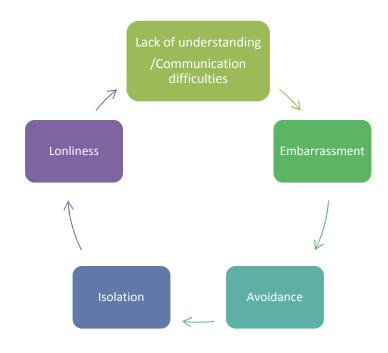
"...avoided so many places" "Very isolated, I feel that I am missing out on communication" "I get confused when talking in a group, I feel isolated at times" "...lost in conversation. Miserable in more than one in company" "It makes me feel isolated. You are inclined to avoid places such as the pubs, restaurants or wherever people congregate"

These emotional responses were evident in over 50% of the participants. Participants reported having a lack of understanding during conversations due to communication difficulties as a result of their AHL. Participants also reported missing out in groups and feeling lost in coversation. One respondant reported "feeling miserable if there is more than one person". This resulted in embarassment and two of the responadants reported feeling too embarrassed to identify themselves as having a hearing loss making group conversations and conversation in noise more difficult. This lack of understanding also led to participants feeling irritated. Some (4) reported feeling confused in group conversation.

Avoidance was the main approach used by the participants throughout the data. Some admitted to avoiding social occasions, avoiding public places, missing out on their hobbies and limiting their social life. This avoidance led to isolation and resulted in the person feeling lonely. Social isolation led to other emotional feelings and these could have had an impact on a person's emotional well being. Many of the respondants reported having lowered feelings. One of the participants described not being able to cope. Examples of lowered feelings include:

| "Feeling down"          |
|-------------------------|
| "Longing for normality" |
| "feeling confused"      |
| "Fear"                  |
|                         |

 Table 5: Cycle of lonliness



#### Positive Responses

Two of the respondants had a positive outlook on their circumstances, both were hearing aid users with a moderate hearing loss. The only participant to mention a family member expressed gratitude to her husband whom she said was very patient with her. One of the participants conveyed determination and stated that the hearing loss would not make her feel bad. Another respondant expressed her satisfaction with her hearing aids and stressed the importance of compliance regarding the use of prescribed hearing aids.

> "Well since I purchased my hearing aids my life has changed so much for the better"

"Now I am proud to tell people I wear them"

"If they have to get aids wear them"

# Theme 2: Management strategies and habilitation

Different management strategies were used by the participants to help them manage and cope with their hearing loss. Management was divided into three sub-themes: strategies for communication, managing communication and habilitation. Habilitation refers to strategies used by the participants to help them to cope with their feelings.

# Strategies for Communication

Out of the nine (9) participants who wore hearing aids, only one reported using the loop system. Another described using a streamer for their telephone, mobile phone and television. This respondent described this device as "a life saver".

# Managing communication

Six (6) of the participants both hearing aid wearers and non-hearing aid wearers demonstrated ways in which they manage communication. (See figure 1)

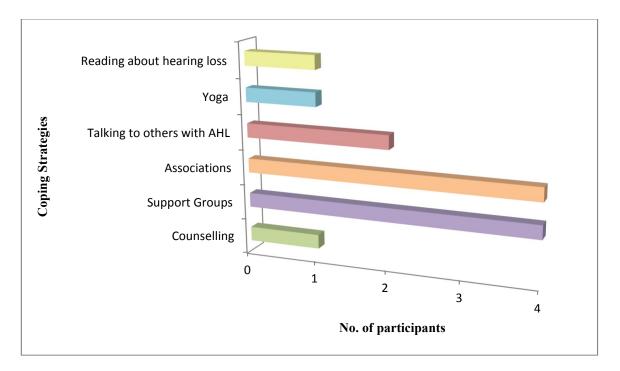
**Figure 1: Management strategies** 



# Habilitation: coping strategies

*Coping Strategies* used by the respondents' can be defined as ways in which the respondents help themselves to deal with the emotions they experience as a result of their hearing loss. The different strategies reported can be seen on Table 6 (below). Two of the participants found that talking to others who are going through the same experience helped them to manage with their AHL. One participant reported that counselling helped, while four participants stated that they attend support groups with one participant describing the support groups as *"invaluable"*. Joining associations such as the Tinnitus Association and the Cork Deaf Association was seen as beneficial to four participants. One participant highlighted the benefits of the *"social aspect"* to joining such associations. Another found it helpful to read about their AHL. Being informed about their loss helped them to manage. Yoga was used by a participant as a way of helping them to manage and cope with their AHL.

#### **Table 6: Coping strategies**



#### Theme 3: Alienation

Where this group of people position themselves in society was a recurring concept in the data. This was evident from the language used by the respondents which portrayed an idea of "*us*" and "*them*". It seemed as though the participants didn't see themselves as members of the societal group that they used to be part of before their AHL i.e. they now belong to a different and minority group. They separated those with a hearing loss from those who do not have a hearing loss. One person longed for normality, which indicated that they viewed themselves of being "not normal as they were before they acquired a hearing loss.

"they tend to speak too quickly" "if the **general public** were more considerate, if **they** stood in front of us and spoke slowly" "tell people of **our** difficulties" "I love to be **normal** again" "more consideration from **other** people" "be more tolerant of people in general, those with full hearing and those with hard of hearing"

#### Theme 4: Promoting awareness

Promoting awareness was the fourth theme that was identified from the data collected. Lack of awareness amongst those who have AHL and lack of knowledge amongst the general public about AHL.

#### Prior lack of knowledge, awareness and regret

Lack of knowledge about hearing aid benefit and risk factors for AHL was seen amongst three of the participants. Two of the participants portrayed a sense of regret, stating that they would have protected their hearing in the past if they had known it would have had an effect on their hearing. This suggested that they had not been aware of the factors that can cause hearing loss. If these participants had been informed about noise induced hearing loss, they would have protected their hearing and there may have been different consequences for these two participants. Lack of knowledge and awareness about their own hearing loss was also apparent as one participant documented that they would like to have read about their hearing loss. Lack of awareness about what could help with their hearing loss was also evident, e.g. one participant questions the ability of a hearing aid to help him hear the higher frequencies again. They stated:

# "If I could hear tones I probably never heard, high pitch i.e. with aids if they can do that?"

One of the respondents highlighted the importance of promoting awareness and providing more information to the public.

#### Anger and annoyance

Two of the participants expressed their anger towards the private audiology sector with one participant called them "sales driven organisations" and another participant expressed how *"awful"* their experiences were with hearing aids from the private sector.

Seven of the respondents expressed annoyance at society for their lack of knowledge about their communication difficulties and lack of knowledge about hearing loss and its' effects. Whereas, three respondents portrayed a sense of anger at society and suggested they need to be more considerate and that they feel let down by society. These comments include:

"people speak into their chests"
"the need is with the listener"
"more awareness and information needs to be publicised and available to the public"
"if the general public were more considerate"
"you can tell people you are deaf, quite frequently they ignore you"
"Tell people of our difficulties"

**Figure 2: Themes Identified** 



#### Discussion

The aim of this study was to collect and analyse data on the experiences of older people with AHL, documented by them about their own personal journeys. The initial study was a pilot study to test the qualitative method of data collection and analysis with members from the Cork Deaf Association as the targeted sample.

The results of the pilot study demonstrated that when a hearing loss is acquired in later life, both subtle and obvious consequences for the individual become apparent. The first was the emotional impact on the individual. Some of these emotions were triggered by how they identified themselves in society. The results suggested that many of the participants in this study viewed themselves as members of a different minority group than the general public and as a result of this view along with difficulties in communication, they isolated themselves from society. This social isolation can generate more negative emotions which could potentially have had an impact on the person's mental well-being. A sense of annoyance was evident from over 50% of respondents i.e. annoyance at society and at the public's lack of knowledge and awareness about hearing loss. In addition to this, the need for more promotion of awareness about hearing loss throughout society was evident.

The results from this study had compared and contrasted to previous studies from other countries. Four themes emerged from the data; emotional well-being, management strategies and habilitation, alientation and promoting awareness. All of the themes identified relate to each other and influence each other.

#### Theme 1: Emotional well-being

It was evident from the results that isolation was major difficulty for older people with acquired hearing loss. Older people isolated themselves or felt isolated as a result of their acquired hearing loss. People felt isolated whether they wore hearing aids or not, with 50% of the respondents reporting feeling isolated. This compared to findings from previous studies in which isolation was a recurrent consequence of having an AHL. Beattie (1984) performed an assessment on the social effects of a hearing loss on adults in the UK. Similar to this study, Beattie discovered that elderly adults become increasingly isolated from society as a result of their hearing

loss. It is over thirty years since Judith Beattie carried out this study, which may lead one to conclude that the experiences for older people with AHL is not being addressed. This was in agreement with Hallam et al (2006), who concluded that the psychological needs of this cohort are not being met.

The emotions reported by the participants included frustration, anger, embarrassment and misery. These reported emotions compared with previous studies which examined the potential effects of a hearing loss on a person's quality of life. In a study by Ciorba et al (2012), they highlighted that people with a hearing loss reported loneliness, anger, depression, frustration, isolation and guilt. Similarly in this study, lowered feelings were conveyed by the participants of this study yet there was no direct reference made to feelings of anxiety and depression which contrasted with previous studies. For example, Hallam et al (2006) reported that amongst their respondents there were a significant number of participants who experienced depressed or anxious mood. Hallam's study focused on people with profound AHL only, however in this current study none of the participants reported having a profound hearing loss. A specific feature to this pilot study was that the AHL fitted into all the categories of degrees of hearing loss with the exception of profound hearing loss.

A relationship was noted between the severity of hearing loss and the level of lowered feelings the participants experienced in our study, as participants with losses ranging from moderate to severe expressed lowered feelings. Participants with mild hearing losses did not report lowered feelings but did report feeling isolated. These findings corresponded with the literature stating the severity of the loss can have different impacts on the individual. Chia et al (2007), the Blue Mountain study discovered that the severity of the hearing loss had an impact on a person's QOL scores. In Monzani et al (2008), adults with mild to moderate hearing losses were assessed and it appeared these people were disposed to experiencing depression, anxiety and feelings of inferiority in comparison to their hearing counterparts. These feelings may have occurred as a result of the person's ability or inability to adapt to their situation as well as how they perceived the severity of their loss, as discussed in a study by Meyer and West (2013). One of the participants in this current pilot study had a positive outlook on their situation and showed determination that the hearing loss would not make them feel bad. This may suggest that this participant had reached the point of adaptation and now had a more positive mental attitude and had learned how to cope with their loss. This is an area which could be researched further, how an individual's perception of their loss impacts on their ability to adapt and to cope.

## Theme 2: Management strategies and habilitation

Management strategies and habilitation was a theme that was identified from the data in this study. It highlighted the different management strategies the participants used to manage their hearing loss and helped them to cope with the experiences associated with having an acquired hearing loss. Contrary to other studies which discussed management and habilitation, it could not be determined from the results how these management strategies impacted on the individual's quality of life as no health benefit or quality of life questionnaire was used.

Communication strategies were a method of management for the majority of participants. These included lip reading, informing people about their hearing loss, reducing background noise, use of visuals and subtitles and positioning themselves in social situations, i.e. with their back to a wall. These communication tactics were also used by people in other studies with lip reading as a primary method of communication (Hallam et al, 2006, p.721).

75 % of the participants in the study wear hearing aids to manage their hearing loss and expressed their satisfaction with the hearing aids. The reason why the remaining three participants did not wear hearing aids remains unknown. One suggestion could be in relation to the findings in Laplante-Levesque et al (2010) study, where the individuals' perception of their hearing disability was a factor which influenced their decisions of management and rehabilitation. All of the non-hearing aid wearers had a mild hearing loss, therefore may not have perceived that they needed hearing aids. This relates to lack of knowledge amongst those with a hearing loss with regard to the benefits of hearing aids. This was evident in this pilot study, when one participant, without hearing aids questioned if hearing aids could help him to hear high pitch sounds again. Only one participant used the loop system and a streamer device, which was reported as being of benefit to him. Why the other hearing aid wearers were not getting the benefits from using this device remains to be discovered. Cost may be a factor if the hearing aids were purchased privately, this would be supported by the Laplante-Levesque et al (2010) study which discovered that cost of services was one of the factors that influenced a person's choice in rehabilitation. This suggestion warrants further research. Frank Lin (2012) suggested that the lack of information and awareness concerning the benefits and limitations of hearing aids, and such systems as the loop system were important contributory factors for their lack of use. Lin (2012) also stressed the importance of a multidisciplinary approach to managing hearing loss i.e. in addition to fitting a hearing aid, people needed habilitation and counselling in order to help them to adapt. The lack of counselling and habilitation used by our participants may have had an effect on how well they managed and adapted to their acquired hearing loss.

Evidently, from the results of this study there is a need for additional counselling services for this cohort. Similarly to a study by Hallam et al (2006), where counselling was reported as least useful when asked about the types of professional help obtained, only one of the participants in our study sample reported using counselling as a management strategy to manage and cope with their hearing loss. As in Hallam's study, the respondents sought out more information about their hearing loss. This suggested that there was a lack of information provided to people about their hearing loss and may have been the reason participants joined the CDA. Support groups and joining associations was the method of management amongst our sample.

Yoga was a method used by one participant, a method which has not been explored in the literature. Other management strategies included talking with others who shared the same experiences as the person. This may have helped them to find an identity and feel a sense of belonging, rather than feeling isolated. There was a sense of an "us" and "them" evident from the data collected in this study. The theme of alienation emerged from these ideas throughout the data and the comments made by the participants in relation to this.

#### **Theme 3: Alienation**

The most noteworthy finding from our study was the perception amongst the respondents that they were no longer part of society. They placed themselves into a different sub group in society as a result of their hearing loss. Their sense of identity had altered and this in turn had a negative effect on their emotional well-being. Contrary to much of the literature, where this concept was not identified apart from in a study by Meyer and West (2013) where the participants viewed themselves as differently abled to those who were born deaf. Monzani et al (2008) found that their sample reported feeling inferior to their hearing counterparts which may have related to the theme of alienation which emerged amongst the participants of this study. The feeling of alienation may stem from the lack of knowledge and awareness that was acknowledged in this study but also in previous studies to date. This alienation also stemmed from societies lack of awareness of what difficulties people who are hard of hearing face, which was evident through the annoyance the respondents portrayed throughout the data.

#### **Theme 4: Promoting awareness**

Lack of awareness was not an unexpected theme that was identified from this study. This lack of awareness amongst society played a factor in how the person with the hearing loss responded to their AHL. Difficulty communicating in groups and in public places was a complaint amongst all the participants, which led to them experiencing the negative emotions, isolation and lowered feelings which has already been addressed in relation to emotional well-being. Annoyance and anger at society for not understanding the participants' difficulties and needs was another important finding in this study. It might also have contributed to how the participants view themselves as members of a different sub group than the general public.

Laplante-Levesque (2010) emphasised the importance of shared decision making between the clinician and the client when choosing management and rehabilitation strategies. This shared decision making cannot be successful without knowledge from both sides about how the hearing loss is affecting a person's life as well as the benefits and limitations of all the different methods of management. The participants in this study laid emphasis on the need for more public awareness of AHL and its' implications on older people. This has previously been well documented by Ciorba et al (2012) and Meyer and West (2013). As discussed, lack of knowledge about the supports that were available for people with AHL was a factor that needed to be addressed. Many people with a hearing loss were unaware of the different forms of help that is available to them (Beattie, 1984). Beattie (1984) also stressed the value of an informed hearing society about how hard of hearing people can be supported. Frank Lin (2012) recommended that community involvement programmes should be used to help older people with a hearing loss remain as active participants within the community. This paper also advised that hearing loss in the elderly is a public health issue and public health programs need to be put in place to inform society about age related hearing loss and its' implications. The results of this study underscored the need for such recommendations to be carried out.

#### Limitations

The sample size for the study was a small sample, however as it was a pilot study including only members of the CDA this may not be considered a limitation. The response rate was under 50%; therefore a different method of data collection may be trialled in future research in order to increase the response rate. This may include face-to-face interview or a follow up telephone interview in conjunction with the questionnaire. A follow up telephone interview may also add to the richness of the data and provide an opportunity for the researcher to probe further into some of the responses given.

#### **Future research**

This study was the first of its' kind in the Irish context which can help to promote awareness of the difficulties faced by this population within our society For future research, an enquiry into why people chose different methods of management would be interesting. Another interesting question to ask would be why do people seek free support? Is there a lack of professional support out there and as a result must these people need to seek their own support? This study's findings can stimulate to future research in this area with a larger nationally represented sample. In turn this will add to the knowledge base of the public and to professionals working with older people with AHL.

#### Conclusion

To conclude, this study supported the hypothesis that AHL can have a negative effect on older people. Promoting awareness within communities may help older people with AHL to re-integrate into society and help eliminate the feeling of isolation and alienation. Further research is needed in this area in order to get a deeper insight into the effects AHL has on the older Irish population as a whole. This kind of research will guide services and professionals, informing them when planning their service to meet the needs of the service users.

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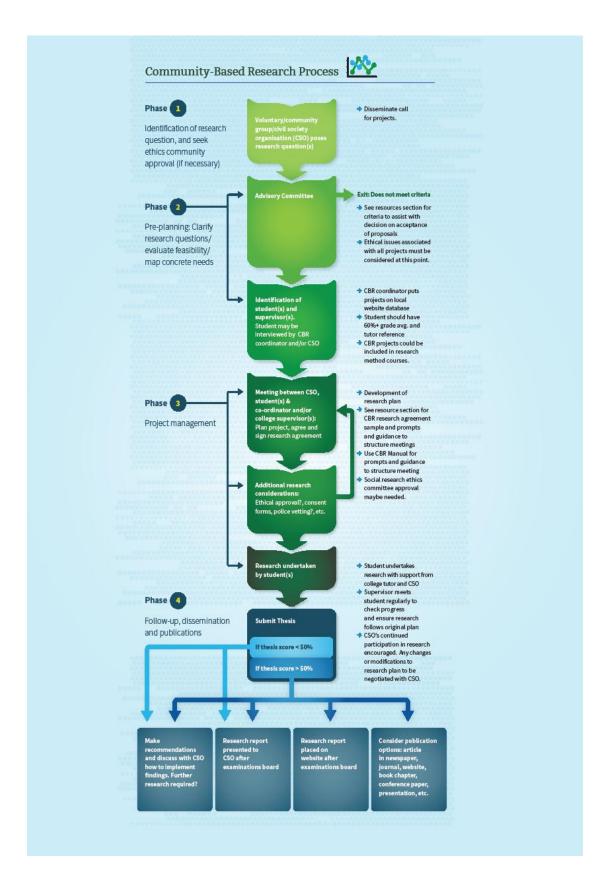
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#### **Appendix I: Research Process**



**Appendix II:CARL Research Agreement** 



# Research Agreement Community-Academic Research Links

http://www.ucc.ie/en/scishop/ Twitter: @CARL\_UCC



University College Cork, Ireland Coláiste na hOllscoile Corcaigh

| Name of community and voluntary group: | Cork Deaf Association         |
|--|-------------------------------|
| Community and voluntary group liaison: | Gerrie O'Grady                |
| Name of student(s):                    | Amy Walsh                     |
| Name of academic supervisor(s):        | Dr Siobhán Laoide-Kemp        |
| University course and module:          | MSc Audiology                 |
| Date:                                  | November 7 <sup>th</sup> 2017 |

An agreement between **Cork Deaf Association** and **Amy Walsh MSc Audiology** at University College Cork, Cork, Ireland.

This agreement relates to arrangements agreed between the student and the group for the execution of a research project entitled: The effects of acquired hearing loss on older people in Cork

- 1. It has been agreed that Amy Walsh will carry out research on behalf of and in participation with Cork Deaf Association as follows:
- 1. A qualitative study using a questionnaire and potentially a small number of follow up interviews
- 2. Gerrie O'Grady will recruit participants by distributing the questionnaires to the target sample
- 3. The questionnaires will be sent following ethical approval by 1<sup>st</sup> of January 2018
- 4. Dissemination of results will be decided after the examination process
- 2. The time of the academic supervisor of the student undertaking the research will normally be provided without charge as part of the student's degree course at the University.
- 3. The University will provide accommodation, the use of equipment, the services of technical and other supplies to the extent that is normally provided for internally based student projects. Where the provision required for the timely and efficient execution of the project exceeds the normal allowance for student projects or exceeds the host department's budget, the community and voluntary group may be asked to pay for such provision or to join with the University / Community-Academic Research Links (CARL) in securing provision from a third party source. No costs will be incurred *without prior* agreement. (These additional provisions will be listed in an appendix at the end of the Agreement or in point 1 above, if deemed necessary).
- 4. The name of the student(s) will be listed below. The names of the students, the academic supervisor, or the University / Community-Academic Research Links (CARL) may only be used after obtaining prior approval. Permission to refer to the University will not be unreasonably withheld.
- 5. The copyright, or any other intellectual property rights, created by the project will rest with the University. Free and full use by the Community Partner for the purpose declared when the project was initiated is agreed in advance. Use for any further purpose(s) will be for negotiation and approval on a case-to-case basis. Permission will not be unreasonably withheld.

- 6. Use of the project report in other than its complete form will be checked with the University / Community-Academic Research Links (CARL) in reasonable and sufficient time before the intended date of such use to allow discussion as to the accuracy or suitability of the modified form.
- 7. Students will normally carry out the project. Notwithstanding the contributions by the University and its staff, the University / Community-Academic Research Links (CARL) gives no warranty as to the accuracy of the project report or the suitability of any material contained in it for either general or specific purposes. It will be for the Community Partner, or users, to ensure that any outcome from the project meets safety and other requirements. The Community Partner agrees not to hold the University responsible in respect of any use of the project results. Notwithstanding this disclaimer, it is a matter of record that many student projects have been completed to a very high standard and to the satisfaction of the Community Partner.
- 8. Upon completion of the project the student (as well as completing the requirements of his or her University course) and CARL will be responsible for providing the Community Partner with a completed copy of their project report. The student and CARL shall provide the Community Partner with the completed project report within a reasonable amount of time, but not more than two months after the final Examination board.
- 9. Upon completion of the project, students should meet with the Community Partner within one month of the submission of the dissertation to the University to discuss the study findings, to explore actions / implementation plan arising from the study and to discuss future public presentations and publications related to the study by the student and/or the Community Partner.
- 10. All parties agree that upon completion of the project, that the research report will be placed with the approval of the course tutor providing it reaches the requisite academic and presentation standards on the University College Cork, Community-Academic Research Links website: <u>http://carl.ucc.ie</u>. No party has the right to veto the publication of the research report.

| Student dissertation submission date:   | 2018 - May 315t |
|---|-----------------|
| Completion date of research report to<br>community group: (normally after the Examinations<br>Board has formalised the dissertation grade, which is usually<br>2 months after submission of dissertation) | 2018 U<br>DUNC  |
| Date report to be published on the CARL<br>website:<br>(normally after the Examinations Board has formalised the<br>grade, which is usually 2-3 months after submission of<br>dissertation)               | 00.00           |

Signed by the liaison person from the community and voluntary group partner

| Signature (By signing this Agreement you are<br>confirming that you have sought and secured the<br>requisite permissions to proceed with this project within<br>your organisation): | San O Tril                       |
|---|----------------------------------|
| Print Name:   | Gérrie O'Grady                   |
| Title/Role in Group:  | 1/ Manajer - 1.                  |
| Date:   | 7 <sup>th</sup> of November 2017 |

| Signed by s   | tudent(s)                        |
|---|----------------------------------|
| Signature(s): (By signing this Agreement you are<br>confirming that you have sought and secured the<br>requisite permissions from your tutor and/or course<br>team to participate in a CARL project): | Almy a KISM                      |
| Print Name(s):  | Amy Walsh                        |
| University Course(s) and Year:  | MSc Audiology                    |
| Date:   | 7 <sup>th</sup> of November 2017 |

Signed by CARL Coordinator / Academic Supervisor(s)

| Signature:                     | anna Mugz                        |  |
|--------------------------------|----------------------------------|--|
| Print Name:                    | Anna Kingston                    |  |
| University Course(s) and Year: | CARL coordinator                 |  |
| Date:                          | 7 <sup>th</sup> of November 2017 |  |

Version 5. Updated June 2016. http://www.www.mis form is based upon a version of the QUB Science Shop CBR contract - used with permussion.

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## Appendix III: Questionnaire

| 1. At what ag                               | e were you diagnosed wit      | h a hearing loss?     |                |
|---|-------------------------------|-----------------------|----------------|
| 55-65 🗆                                     | 65-80 years                   |                       | 80+ years 🛛    |
| 2. Do you hav                               | ve a hearing loss in: (tick a | appropriate box)?     | ,              |
| Right Ear 🛛                                 | Left Ear                      |                       | Both Ears      |
| 3. Is your hea                              | ring loss?                    |                       |                |
| Mild 🗆                                      | Moderate 🗆                    | Severe 🗆              | Profound       |
| 4. Do you we                                | ar hearing aids?              |                       |                |
| 5. What was the cause of your hearing loss? |                               |                       |                |
| 6. Describe h                               | ow having a hearing loss      | makes you feel.       |                |
| 7. Has the he                               | aring loss affected your Q    | uality of life? If so | , explain how. |
| 8. Describe w                               | vhat helps you manage yo      | ur hearing loss?      |                |
| 9. How can p                                | eople's experiences with      | a hearing loss be i   | mproved?       |

10. What would you change about your experiences? Why?

11. Were there any positive aspects to your experience? If so, can you tell me about them?

#### **Appendix IV: Information leaflet**

#### **Participant Information Leaflet**

#### Introduction

My name is Amy Walsh and I am a student at University College Cork. I am currently conducting a research study in partnership with the Cork Deaf Association that wishes to explore the effects that an acquired hearing loss has on people over that age of 55 years. You have been invited to participate in the study. This study will use a questionnaire in which you will be asked to "tick a box" or answer a question in your own words about your experiences with having a hearing loss. This study will provide us with valuable information about the experiences of people with acquired hearing loss.

#### Nature of the Research Project

We will collect the information through a questionnaire. The questionnaire will contain "tick the box" questions and questions where you will be asked for your opinion or experiences. The questionnaire will take approximately 20 minutes to complete. To comply with Data Protection legislation and confidentiality only the Cork Deaf Association has your details. I will not have access to the names of the participants; they will remain anonymous throughout the research. Your identity will not be revealed at any stage of the research project but the information that you provide on the questionnaire will be used throughout the research project. Quotations from the questionnaires may be used as well as summaries of information from the questionnaire. These will only be used with your consent. The information will be transformed into electronic files and stored in a password encrypted laptop in University College Cork for ten years. The information that has been collected will only be accessible to the chief investigator, Dr. Siobhan Laoide Kemp, the Cork Deaf Association and I, the student during analysis. The research findings will be published once the project has been completed.

This research is the first of its' kind in the Ireland, therefore it will be beneficial to the participants involved, to the Cork Deaf Association and to future researchers. Your participation in this study would be greatly appreciated however participation is voluntary. You may withdraw from participating in this research study at any time. If you have any further questions or concerns regarding this study please do not hesitate to contact us at numbers below.

| Chief Investigator                      | <b>Co-Investigator</b> |
|---|------------------------|
| Siobhán Laoide-Kemp PhD (Audiology)     | Amy Walsh (Student)    |
| Dept. of Speech and Hearing Sciences    |                        |
| Email: <u>siobhan.laoidekemp@ucc.ie</u> | Email:                 |
| <u>107799918@umail.ucc.ie</u>           |                        |
| Tel: 021-420-5624/086-701-4986          | Tel: 085-7112793       |

Signed:

Chief Investigator

Co- Investigator

Date:\_\_\_\_\_

Date:\_\_\_\_\_

#### **CONSENT FORM:**

## CONSENT BY RESEARCH SUBJECT FOR PARTICIPATION IN RESEARCH PROJECT

**Title of Research Project**: "What are the effects of acquired hearing loss in older people":

A pilot study in collaboration with CARL and the Cork Deaf Association

| Chief Investigator: | Siobhán Laoide-Kemp PhD (Audiology)                                      |  |
|---------------------|--|--|
|                     | Dept. of Speech and Hearing Sciences<br>Email: siobhan.laoidekemp@ucc.ie |  |
|                     | Tel: 021-420-5624/086-701-4986   |  |
| Co- Investigator:   | Amy Walsh  |  |
|                     | Tel: 085-7112793   |  |
|                     | Email: 107799918@umail.ucc.ie  |  |
|                     |  |  |

You are being asked to participate in a research study. In order to decide whether or not you want to be a part of this research study, you should understand enough about its risks and benefits to make an informed judgment. This process is known as informed consent. This consent form gives detailed information about the research study, which will be discussed with you. Once you understand the study, you will be asked to sign this form if you wish to participate.

#### NATURE AND DURATION OF PROCEDURE(S):

This study is a student project being conducted through UCC and in partnership with the Cork Deaf Association as part of a Masters programme. The aim of this study is to gain an insight into the experiences and perspectives of people who acquire a hearing loss in later life. The study should help us gain valuable information, so that we as audiologists determine ways we can help people who acquire a hearing loss to manage and cope with their hearing loss. Participation in the study will involve you completing an anonymous questionnaire. The questionnaire contains 'tick the box' questions and some questions which ask you to tell us about your experiences with your hearing loss. It should take no more than twenty minutes. Confidentiality and anonymity will be in place at all times, using no names. The information provided in the questionnaires will be treated as confidential at all times. The information given on the questionnaires will be transformed into electronic copies. Data will only be accessed by the Chief Investigator, the Co- Investigator and the Cork Deaf Association. It will be stored on a password encrypted laptop in the Assert building in University College Cork for ten years and disposed of in accordance with the Data Protection Act 1988 and 2003.

#### AGREEMENT TO CONSENT

The research project and the participating procedures associated with it have been fully explained to me. I have had the opportunity to ask questions concerning any and all aspects of the Research Project and any related matters or issues of concern. I am aware that my participation is voluntary and that I may withdraw my consent at any time.

I, the undersigned, hereby consent to participate as a subject in the above described Research Project conducted at University College Cork. I have received a copy of this Consent Form and Research Subject Information Sheet for my records. I understand that if I have any questions concerning this research, I can contact the Chief Investigator or Co-Investigators listed above.

Signed:

Witnessed:

Date:

| <u>Chief Investigator</u>  | <u>Co-Investigator</u> |
|--|------------------------|
| Siobhán Laoide-Kemp PhD (Audiology)  | Amy Walsh (Student)    |
| Dept. of Speech and Hearing Sciences   |                        |
| <i>Email: <u>siobhan.laoidekemp@ucc.ie</u><br/><u>107799918@umail.ucc.ie</u></i> | Email:                 |
| Tel: 021-420-5624/086-701-4986   | Tel: 085-7112793       |
| Signed   |                        |
| Chief Investigator   | Co- Investigator       |

#### Appendix VI: Social Research Ethics Committee (SREC) Approval Letter

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Sciences

Dr. Siobhán Laoide-Kemp Audiology Programme Dept. Speech & Hearing Sciences UCC

14<sup>th</sup> November, 2017

Dear Dr. Laoide-Kemp,

This is to confirm that your research proposal entitled "What are the effects of acquired hearing loss in older people: A pilot study in collaboration with CARL and the Cork Deaf Association" (CT-SREC-2017-34)" (co-investigator: A. Walsh) has been approved by the UCC Social Research Ethics Committee (Clinical Therapies sub-committee).

With best wishes

Nenttuck

Prof. Nicole Müller On behalf of SREC (Clinical Therapies sub-committee)

Professor Fiona Gibbon PhD FRCSLT Head

Ollscoil na hÉireann, Corcaigh National University of Ireland, Cork

## Appendix VII: Preliminary themes and codes

### Preliminary Themes and codes

| Theme 1: Emotional Impact   | Theme 2: Isolation  |
|---|---|
| <u>Codes</u>  | <u>Codes</u>  |
| Fear for safety   | Avoidance of occasions  |
| Frustration   | Avoidance of public places; pubs, resteraunts; supermarkets         |
| Feeling ignored   | Missing out on what is being said in groups                         |
| Feeling isolated  | Feeling lost in conversation  |
| Feeling down  | Feeling miserable if more than one person                           |
| Feeling confused  | Negative impact on hobbies  |
| Irritable   | Expressing difficulty in class situation                            |
| Longing for normality   | Limits social life  |
| Determination   |   |
| Regret (didn't protect hearing when<br>younger)   |   |
| Theme 3: Promoting Awareness/Annoyance  | Theme 4: Management   |
| at society<br><u>Codes</u><br>Society need to be made aware of what can<br>help d/Deaf HoH people | <u>Codes</u><br>Emphasising satisfaction with ALD's<br>Subtitles TV |
| Use of visuals in public places   | Face to face communication  |
| Frustrated with society   | Use of visuals  |
| Inform people about deafness (when in conversation)   | Satisfaction with HA  |
| Inform people about difficulties associated with deafness   | Limits communication; text instead of calling on the phone          |
| People with hearing loss need to be made aware of cost of aids                                    | Quietness<br>Sharing experiences with other people in               |
| Anger at dispensers and lack of education about options   | the same position<br>Informing others about the hearing loss        |

| Lack of consideration from others            |                       |
|--|-----------------------|
| Theme 4: Recommendations                     | Positive Experiences  |
|  |                       |
| Codes  | Codes                 |
| Support groups                               | 'Limited' reports     |
|  | Joining CDA           |
| Counselling                                  |                       |
|  | Being understood      |
| Advising to seek help and to protect hearing |                       |
|  | Getting hearing aids  |
| Emphasising importance of compliance         |                       |
| (wearing hearing aids if you have them)      | Helping with tinnitus |
|  |                       |
| Being informed about ones' own loss          |                       |
|  |                       |
| Yoga   |                       |