

# Evaluating the process of change:

## Studies on patient journey, hearing disability acceptance and stages-of-change

Vinaya Kumar Channapatna Manchaiah



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Vinaya Kumar Channapatna Manchaiah  
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***“There is nothing more practical than a good theory”***

Immanuel Kant (1724 – 1804), German Philosopher

***“It is a capital mistake to theorize before one has data. Insensibly one begins to twist facts to suit theories, instead of theories to suit facts”***

Arthur Conan Doyle (1859 – 1930), Scottish Physician and Fictional writer

***“In theory, there is no difference between theory and practice. But in practice, there is”***

Attributed to multiple people

***“How empty is theory in the presence of fact!”***

Mark Twain (1835-1910), American author and Humourist

***“Before I got married I had six theories about raising children; now, I have six children and no theories”***

John Wilmot (1647 – 1680), English Poet and Writer



## ABSTRACT

Person with hearing impairment (PHI) and their Communication partners (CPs) have a range of experiences and milestones before, during and after their audiological assessment and/or rehabilitation sessions. The term 'patient journey' refers to understanding the experiences and the processes the patient goes through during the course of the disease and the treatment regime. The aims of the current thesis were: (1) to further develop patient journey models of individuals with gradual-onset hearing impairment and CPs by taking their views into consideration; (2) to develop the patient journey model for PHI of sudden-onset; (3) to develop a self-reported measure of hearing disability acceptance and to study its construct and concurrent validity; (4) to investigate the health behaviour change characteristics of people noticing hearing difficulties using the stages-of-change model.

Papers I (n=32) and III (n=9) were aimed at further developing the journey model of PHI and their CPs proposed by the Ida Institute. Both studies employed qualitative methods (i.e., focus groups and interviews for data collection and thematic analysis for data analysis), and defined the models based on the perspectives of PHI and CPs both of which had seven main phases. These data were compared with the professionals' perspectives of the journey as reported in the Ida Institute model which had six main phases. The studies highlight new phases (i.e., self-evaluation in PHI journey and adaptation in CP journey) and also various commonalities and differences in the perspectives expressed by professionals and patients.

Paper II included a pilot study to explore the patient journey of sudden-onset acquired hearing impairment from both professionals (n=16) and patients (n=4) perspectives. Both identified all the six main phases, which include: awareness; movement; diagnostics; rehabilitation; self-evaluation; and resolution. The pre-awareness phase may hinder the realisation of hearing loss in persons with gradual onset hearing loss, whereas it is far more straightforward in persons with sudden-onset due to its nature of onset.

Papers IV and V employed a cross-sectional design (n=90). Paper IV was aimed at developing a Hearing Disability Acceptance Questionnaire (HDAQ), and to study its construct and concurrent validity. Results suggested that the HDAQ has a two factor structure which explains 75.7% of the variance and had good internal consistency (Cronbach's alpha of 0.86). Also, the scale had good concurrent validity in relation to self-reported hearing disability, self-reported anxiety and depression and readiness to change measures. Paper V was aimed at understanding the stages-of-change in adults with hearing disability using the University of Rhode Island Change Assessment Scale. As predicted a high percentage of participants (over 90%) were in the contemplation and preparation stages, supporting the stages-of-change model.

Overall, the papers presented in this thesis may contribute to a better understanding of *process of change* through hearing impairment in PHI and their CPs.



## LIST OF PUBLICATIONS

- I. Manchaiah, V.K.C., Stephens, D. & Meredith, R. (2011). The patient journey of adults with hearing impairment: the patients' view. *Clinical Otolaryngology*, 36, 227-234.
- II. Manchaiah, V.K.C. & Stephens, D. (2012). The patient journey of adults with sudden-onset acquired hearing impairment: A pilot study. *The Journal of Laryngology & Otology*, 126(5), 475-481.
- III. Manchaiah, V.K.C., Stephens, D. & Lunner, T. (2013). Journey of communication partners of person with hearing impairment. *International Journal of Otolaryngology*, 1-11.
- IV. Manchaiah, V.K.C., Molander, P., Rönnerberg, J., Andersson, G. & Lunner, T., (Submitted). Acceptance of hearing disability in adults noticing hearing difficulties.
- V. Manchaiah, V.K.C., Rönnerberg, J., Andersson, G. & Lunner, T., (Submitted). Stages of change in adults noticing hearing difficulties but not using hearing aids.

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## **LIST OF ABBREVIATIONS**

AAQ	Acceptance and Action Questionnaire
CAQ-R	Chronic Pain Acceptance Questionnaire - Revised
CP	Communication Partner
CPHI	Communication Profile for the Hearing Impaired
CSS	Communication Strategies Subscale
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
HBM	Health Behaviour Model
HDAQ	Hearing Disability Acceptance Questionnaire
HHQ	Hearing Handicap Questionnaire
ICF	International Classification of Functioning, Disability and Health
KMO	Kaiser-Meyer-Olkin
OXO	One-group-pre-post
PCA	Principle Components Analysis
PHI	Person with Hearing Impairment
TAQ	Tinnitus Acceptance Questionnaire
TTM	Transtheoretical Model
UK	United Kingdom
URICA	University of Rhode Island Change Assessment
WHO	World Health Organisation



## INTRODUCTION

Hearing impairment is one of the most common chronic conditions in adults and may have various consequences to both person with hearing impairment (PHI) and their communication partners (CPs; Manchaiah & Stephens, 2013; Manchaiah, Stephens, Zhao, & Kramer, 2012a). Despite the consequences of hearing impairment, demographic studies in developed countries have shown that only a small percentage (about 20-25%) of those with hearing impairment use amplification devices (Humphrey, Gilhorne Herbst, & Faruqi, 1981; Davis, 1995; Davis, Smith, Ferguson, Stephens, & Gianopoulos, 2007; Kochkin, 2009). Various factors may influence the PHIs help-seeking behaviour and their decision to enter rehabilitation, with self-reported hearing disability being the most important (Knudsen, Öberg, Nielsen, Naylor, & Kramer, 2010; Jensted & Moon, 2011; Saunders, Chislom, & Wallhagen, 2012; Meyer & Hickson, 2012). Studies in this area have generally focused on understanding the association between these factors and outcome, and there is a limited scientific literature on how experiences of PHI and their CPs through hearing loss change over a period of time.

The World Health Organisation (WHO) – International Classification of Functioning, Disability and Health (ICF) is a framework based on the biopsychosocial model that describes consequences of a particular health condition and/or disability in terms of various levels of disablement and functioning (World Health Organisation, 2001), which may include: body function and structure at the organ level, activities at the personal level and participation at the person-in-society level. Also, these levels will interact with each other and be could further influenced by personal and environmental factors. This model suggests that it is important to understand consequences of a particular health condition or disability from multiple perspectives (Rimmer, 2006).

It has been suggested that “*impact of acquired hearing impairment cannot be understood simply by measuring its intensity and documenting the objective limitations that imposes*” (Kerr & Cowie, 1997, p. 177). Moreover, most of the research on hearing impairment has been on clinical populations (i.e., those who come to consult hearing healthcare professionals). Also, the research focus has been mainly to understand the consequences of hearing loss and/or effect of treatment at that point in time. However, there are only a few longitudinal studies and also limited research on the process of change with respect to this chronic and long lasting condition (Manchaiah, Danermark, Rönnerberg, & Thomas, 2013a). For this reason, studies on hearing impairment with different theoretical perspectives are needed to better understand the process of change.

The Ida Institute in Naerum, Denmark, is a non-profit organisation with a mission to foster better understanding of the human dynamics associated with hearing loss. The institute conducts various activities to create and share innovative, actionable knowledge to help hearing care professionals address the psychological and social challenges of hearing loss, and implement patient-centered care practices. The Ida Institute developed the journey models for PHI and CPs based on the perspectives of professionals’.

This thesis investigated the process of change (i.e., process evaluation) through hearing impairment in PHI and their CPs using both qualitative and quantitative research methods. Papers I and III were aimed at further developing the journey model of PHI

and their CPs proposed by the Ida Institute. Paper II was aimed at developing the patient journey model of people with sudden onset acquired hearing impairment. Papers IV and V were focused on acceptance of hearing disability and stages-of-change in adults who are noticing hearing difficulties but not using hearing aids.

## **BACKGROUND**

### ***Person with Hearing Impairment***

It has been reported that on average PHIs take approximately ten years from onset to notice hearing difficulties and decide to seek help (Davis et al., 2007). Also, a PHI has a range of experiences before, during and after their audiological assessment and/or rehabilitation sessions. In the process of help-seeking, an individual with hearing impairment passes through several stages such as becoming aware of the problem, deciding to seek help, and achieving the referral to audiology (Stephens & Kramer, 2009). Edgett (2002) highlighted that the process of making the decision to seek help can involve four main stages: (1) Understanding hearing loss; (2) Personal experiences; (3) Interaction with society; and (4) Taking action. Also, some individuals would have to overcome several hurdles in this process before they start seeking help. In addition, Englund (2006) identified four main stages experienced by individuals who are noticing hearing difficulties before they make the decision to seek help, a process which she termed the 'time for hearing'. These stages include: (1) Attracting attention; (2) Becoming suspicious; (3) Sensing tribulation; and (4) Jeopardising fundamental self. These studies provide insights into the process involved in hearing help-seeking. However, much work is needed to understand this process better, especially after the initial consultation. In addition, although onset of hearing impairment in the majority of the adult population is gradual, there are cases of sudden-onset hearing loss, with an incidence estimated to range from 5 to 20 per 100,000 people per year (Byl, 1984). Due to abrupt onset of this condition, it can become a frightening experience and can have a significant impact on psychosocial aspects of individual's life. This highlights that there may be some difference in the consequences experienced among people with sudden-onset, as opposed to gradual, acquired hearing loss.

### ***Communication Partners***

CPs are those with whom the PHI communicates on a regular basis. The term communication partner has been used to refer to the significant others which may include their spouse, siblings, children, friends, relatives, colleagues and carers. It is suggested that hearing impairment is a communication problem which affects everyone in the communication situation, not only the PHI (Gregory, 2011). It can result in various physical, mental and psychosocial effects on PHI and their CPs. According to the WHO-ICF spouses of a PHI, although they do not have the health condition themselves, may experience activity limitations and participation restrictions due to their spouse's health condition which is referred to as 'third-party disability' (World Health Organisation, 2001). Studies have shown that CPs may undergo various experiences through their partners' hearing loss and that they also may often influence the help-seeking behaviour of the PHI (Mahoney, Stephens, & Cadge, 1996; van den Brink, Wit, Kempen, & van Heuvelen, 1996; Duijvestijn et al., 2003; Donaldson, Worrall, & Hickson, 2004; Scarinci, Worrall, & Hickson, 2008, 2009). A recent review identified various impacts on CPs due to their partners hearing loss on and suggested that involving CPs in the audiological enablement/rehabilitation process will result in mutual advantages for both the PHI and their CPs (Manchaiah et al., 2012a).

## ***Patient Journey***

The term 'patient journey' refers to understanding the experiences and the processes that the patient goes through during the course of the disease and the treatment regime. It is believed that understanding the patient journey can help the clinician to gain an insight into the unique experiences of patients. In the last decade, with increased focus on patient-centred treatment approaches in healthcare, studies of the patient journey have become popular. The patient journey has been studied in various conditions including: Parkinson's disease (Baker & Graham, 2004), locked-in syndrome (Chisholm & Gillet, 2005), pertussis (Levenson, 2007), gastrointestinal stromal tumours (Macdonald, Shapiro, Bender, Paolantonio, & Coombs, 2012), and rheumatoid arthritis (Simpson, Franks, Morrison, & Lempp, 2005; Oliver et al., 2008).

The Ida Institute developed the journey models for PHI and CPs in collaboration with the efforts of hearing healthcare professionals around the world (Ida Institute, 2009, 2012). The professionals' perspectives of the patient journey (Ida Institute, 2009) include six main phases: (1) pre-awareness, (2) awareness, (3) movement, (4) diagnostics, (5) rehabilitation, and (6) post-clinical. As discussed earlier, the studies from Edgett (2002) and Englund (2006) also shed some light into the process the PHI may go through. Ida Institute also developed the professionals' perspective of the CPs journey (Ida Institute, 2012), which include six main phases: (1) what is going on?, (2) awareness, (3) persuasion, (4) validation, (5) rehabilitation, and (6) maintenance. It was suggested that this model/template recognises the emotional reactions and practical activities the PHIs and CPs experience during the onset of hearing loss, successful management and learning to live with the condition. The Ida Institute patient journey model focused on gradual-onset acquired hearing impairment and further work is necessary to explore a patient journey model of sudden-onset acquired hearing impairment.

Furthermore, DePlacido (2010) used the Ida Institute patient journey tool in a qualitative study to facilitate interviews of 21 people with hearing loss. The aim of this study was to explore the qualitative aspects of acquired hearing loss and its implications for rehabilitation. The data showed that the self-construct plays a part in adapting to acquired hearing loss, as does the relationship with family and professionals. Possible barriers to effective rehabilitation included: inconsistent and restricted information and choice, and attitudes of professionals. Participants felt that audiologists provided hearing aids rather than rehabilitation services and expressed a need for audiologists to move toward providing a range of rehabilitation services that were not focused solely on amplification. Although the patient journey model was used here, this study was not focused on developing and/or validating the patient journey model.

Studies in medical anthropology reflect variations in patient and professional perspectives, which may be due to differences in educational, ethnic and socioeconomic backgrounds (Hunt & Arar, 2000). These differences in opinion and perspectives can have important implications for the effective management of illness (Singer & Weeks, 1996). Understanding such differences may help healthcare providers to achieve a better appreciation of their patients' viewpoints (Tjørnhøj-Thomsen, 2009). For this reason, it is important to explore the patients' perspectives of the journey.

Furthermore, even though the onset of the disease may differ, the process and the stages experienced by most typical patients are assumed to be broadly similar. Some information about the patient journey can be obtained whilst taking the case history. However, such information is often very limited due to time constraints. In addition, the content of the interview is generally led by the clinician rather than by the patient. It is very important for healthcare providers to understand and distinguish between illness (i.e., how the patients, family members and the wider society view the problem) and disease (i.e., how the healthcare providers view the patient's problems) (Kleinman, 1980). A recent WHO document about 'engaging in process of change' advocates patient empowerment based on research from theories of stages of change and decision balance in order to facilitate the process of change (World Health Organisation, 2012).

### ***Stages-of-Change (Transtheoretical) Model***

Health behaviour change refers to facilitating changes of habits and/or behaviour related to health. There are several models proposed which provide a theoretical framework when studying and understanding health behaviour change (Nieuwenhuijsen, Zemper, Miner, & Epstein, 2006; Ravensloot et al. 2011), and one example is the Transtheoretical Model of Change (TTM; Prochaska & DiClemente, 1983; Prochaska & DiClemente, 1984; Velicer, Prochaska, Fava, Norman, & Redding, 1998). Even though some researchers suggest that the health behaviour change models (HBM) could be useful in audiology research and practice (Erdman, wark, & Montano, 1994; Noh, Gagné, & Kaspar, 1994; Babeu, Kricos, & Lesner, 2004; Sobel & Meikle, 2008; Manchiaiah, 2012), only a few empirical studies exist (van den Brink et al., 1996; Milstein & Weinstein, 2002; Rawool & Colligon-Wayne, 2008; Kaldo, Richards & Andersson, 2006; Gilliver & Hickson, 2011; Laplante-Lévesque Hickson, & Worrall, 2013). These studies have generally used either the Health Belief Model (HBM) and/or TTM to study attitudes to hearing help-seeking and stages of change through this process (van den Brink et al., 1996; Milstein & Weinstein, 2002; Laplante-Lévesque et al., 2013), beliefs of college students in relation to exposure to loud music (Rawool & Colligon-Wayne, 2008), attitudes of medical practitioners towards hearing rehabilitation of older adults (Gilliver & Hickson, 2011), and readiness and attitudes of tinnitus patients to change their behaviour (Kaldo et al., 2006).

The stages-of-change model (also referred to as 'transtheoretical model of change') is based on the assumption that behaviour change is achieved via various stages and it mainly focuses on an individual's readiness to make a change (Prochaska & Velicer, 1997). The model was originally developed by Prochaska and DiClemente (1983) when they were studying how smokers were able to give up their smoking habits or addiction. The transtheoretical concepts include various aspects such as process of change, decision imbalance, self-efficacy, and temptation (Prochaska, Johnson, & Lee, 2009). However, the focus in the current thesis is on the stages of change aspect of this model. Over the years different versions of this model have been proposed. However, a four stage model has been used most often to describe different stages of change (McConaughy, Prochaska, & Velicer, 1983). The four stages include: (1) precontemplation – not thinking seriously about changing a specific behaviour and not interested in help (i.e., often in denial); (2) contemplation – aware of the consequences of the problem and spends time thinking about the problem; (3) action – taking active steps to change their behaviour; and (4) maintenance – successfully avoiding any temptation to give up the change they have made. In some stages-of-change models,

additional stages such as 'preparation' (i.e., a stage in between contemplation and action where people are making preparation to take action by seeking information), as well as 'relapse' after e.g. 'maintenance' (i.e., failure to comply with the change made and return to old habit) have also been included (DiClemente et al., 1991; Etter, Perneger, & Ronchi, 1997). Overall, the stages-of-change model suggests that the individuals in later stages are most likely to help-seeking, adopt intervention, adhere to the intervention, and possibly to display successful outcome (Prochaska et al., 2009).

A recent study investigated the application of the stages-of-change model in audiological rehabilitation in a sample of 153 adults with acquired hearing impairment seeking help for the first time (Laplante-Lévesque et al., 2013). They used the generic 24-item University of Rhode Island Change Assessment (URICA) scale as a measure of stages-of-change (Lam, McMahon, Priddy, & Gehred-Schultz, 1988; Treasure et al., 1999) and identified four stages (i.e., precontemplation, contemplation, preparation and action). Moreover, the study suggested that the URICA scale had good construct validity, together with concurrent and predictive validity. Based on their observation, researchers in this study suggested that change might be better represented on a continuum rather than movement in discrete steps. Furthermore, the preparation stage was found to have the best concurrent and predictive validity, and this was also identified as an area for future research (Laplante-Lévesque et al., 2013).

With the stages-of-change model, it can be predicted that most individuals with hearing disability who see a clinician for help will be in the action stage (Laplante-Lévesque et al., 2013). Assuming that this model also has good predictive validity with people from the general population, it is reasonable to assume that the rest of the population with hearing disability who are not seeking hearing-help actively may be in precontemplation, contemplation or preparation stages. If they are not aware of their hearing difficulties and/or in denial, they are likely to be in the precontemplation stage. However, if they are aware of their difficulties but not actively seeking hearing-help, then they are likely to be in contemplation or preparation stages. This assumption was supported by another study where 72% of older adults attending hearing screening were in precontemplation and contemplation stage (Milstein & Weinstein, 2002). However, they did not use the full URICA scale and instead used four questions (one for each stage) derived from the URICA. Participants had to choose one stage indicating their readiness to change. This may raise concerns about the construct validity of the questionnaire used in that study. For this reason the results must be viewed with caution and the differences in these studies make it difficult to compare them directly. Much work needs to be done in audiology to explore stages-of-change characteristics of PHIs.

### ***Hearing Disability Acceptance***

As discussed earlier, the process of help-seeking may have several stages and this is a long process as the PHI may on an average take up to 10 years or more to seek help after first noticing hearing difficulties (Davis et al., 2007). Further research is necessary to better understand this process. However, patient journey studies provide insights into stages of adjustment to hearing loss, which may be an indirect (or secondary) indicator of the process of acceptance. In addition, those studies may indicate that becoming aware and accepting a hearing disability plays an important role in progressing further in their journey when managing the condition.

There are some studies in the audiology literature which focus on self-assessment of hearing loss (for a review see Knudsen et al., 2010), immediate reactions to diagnosis of hearing loss (Martin, Krall, & O'Neal, 1989; Light & Looi, 2011), actions taken after failing a screening tests (Meyer et al., 2011), attitudes to hearing loss and the use of hearing aids (Brookes, 1989; Jerram & Purdy, 2001), and ways in which people with hearing loss cope with their condition (Hallberg & Carlsson, 1991; Andersson, Melin, Lindberg, & Scott, 1995, 1996). These studies provide further insights into the initial onset of the condition and how people with hearing disability may manage their condition. A recent literature review suggested that acceptance of hearing loss prior to hearing aid fitting would positively influence both hearing aid uptake and subsequent hearing aid use (Knudsen et al., 2010). However, there are still large numbers of people with hearing disability who aware that they have a problem, but are still not seeking help and/or not taking up intervention strategies. The previous literature can be confusing as the term 'acceptance' was used in those studies (i.e., acceptance is used synonymously with adherence to treatment/management options) rather than studying 'acceptance' using validated scales which capture different dimensions of the construct.

In psychological terms, 'acceptance' can be defined as '*a process of actively taking in thoughts, memories, feelings and bodily sensations in a specific situation without having to follow or change them*' (Hayes, Strosahl, & Wilson, 1999). Acceptance may have various dimensions including self- and social acceptance which may require both emotional and behavioural adaptations. For instance, the different views of what the term acceptance actually entails can be made visible by looking at studies of education and academic success, where the term peer acceptance is used in reference to what degree a pupil is seen as someone who is desirable to interact with (Wentzel & Caldwell, 1997). In disability studies, acceptance has been proposed to be the key component of adjusting to a disabling condition (Li & Moore, 1998). Although it is suggested that acceptance of chronic conditions has often been studied from the perspective of grief and loss, it is also important to study the acceptance of chronic conditions in relation to perspectives of those living with a chronic condition with focus on adaptation to and acceptance of change in one's life (Stuifbergen, Becker, Blozis, Beal, & Park, 2008).

Experiential avoidance is similar to the concept of avoidance coping, and can be seen as the opposite reaction to acceptance, that is, the person attempts to ignore and minimize the problems caused by hearing impairment (Andersson & Willebrand, 2003). However, some researchers argue that coping and experiential avoidance are unique but overlapping constructs (Karekla & Panayiotou, 2011). For example, in a recent study on anxiety disorders, although acceptance (i.e., experiential avoidance) loaded on the same factors as emotional-focused and avoidant coping, acceptance did explain some additional variance when predicting psychological distress and well-being (Karekla & Panayiotou, 2011). Both acceptance and experiential avoidance in relation to hearing impairment can be interpreted in the light of stigma theory (Goffman, 1963), which has previously been applied in research on hearing impairment (e.g., Héту, 1996; Danermark & Gellerstedt, 2004).

The term 'acceptance' in relation to hearing disability has not been well defined and often it is used and/or referred in relation to help-seeking and intervention adoption (e.g., hearing aids). In effect, differences exist in terms of psychological and audiological



ways of defining the term 'acceptance' in relation to hearing disability. There are however various scales to study the acceptance of other disabilities and chronic conditions (Linkowski, 1971; Li & Moore, 1998; McCracken, Vowles, & Eccleston, 2004; McCracken & Vowles, 2006; Stuifbergen et al., 2008; Westin, Hayes & Andersson, 2008). There are few studies in audiology that focuses on coping, although they generally measure coping indirectly using questions related to communication problems (Andersson & Willebrand, 2003). For example, the Communication Strategies Subscale (CSS) in the questionnaire Communication Profile for the Hearing Impaired (CPHI; Demorest & Erdman, 1987). The CPHI-CSS focuses on maladaptive behaviours, verbal strategies and non-verbal strategies that give insight to poor adjustment to hearing impairment and poor social support (Gomez & Mandey, 2001). Furthermore, a qualitative study conducted in Sweden explored how elderly people with presbycusis experience living with that condition (Karlsson Espmark & Hansson Scherman, 2003). The study suggested that participants protect their identity using various strategies (e.g., blaming poor hearing due to age), but they showed interest in obtaining help in the form of hearing technology (e.g., hearing aids) only when they started seeing lack of sound as lack of contact with life. This study may provide some understanding of coping, adjustment and intention to adopt hearing technology in older adults with hearing loss. However, to our knowledge there is no published validated scale to study the acceptance of hearing disability.

### ***Outcome Measurement Vs Process Evaluation***

It is quite common to study and evaluate change when it comes to health and health interventions. Outcome measures are tools used in assessing the change over time. However, in healthcare practice they are mainly used a baseline measurement during the initial consultation with the patient and after the intervention. The change in the outcome measures is usually assumed to be due to treatment and/or interventions. This is the typical design used in research trials with classical OXO (one-group-pre-post) model (Campbell & Stanley, 1963). Outcome measures can have various purposes. For example: (a) to measure rehabilitative outcomes of an individual person with disability; (b) to assess the effectiveness of the service provided by a particular clinical unit or agency; (c) to assess the effectiveness of new technologies and treatment methods; and (d) to assess the effectiveness of rehabilitation services on quality of life (Cox et al., 2000). In addition, outcome measures have also been used in formulating intervention strategies (Stephens, Jones, & Gianopoulos, 2000). Whilst the outcome measures can be used longitudinally to measure change over time, they are mainly used just before and after the treatment. Furthermore, some researchers suggest that there is "*almost no research on the rate of change in outcome measures throughout the episodes of treatment or how much treatment is required to produce a valued outcome*" (Grimmer-Somers, Milanese, & Kumar, 2012, p. 75).

Process evaluation refers to studying the experiences of person with disability in the form of a timeline, to understand the main phases/stages they go through during the disease and the treatment. The term 'process evaluation' in this thesis has been used in the context of understanding and monitoring the change longitudinally (e.g., several days to several years) and relates mainly to how the experiences of people with disability or a particular health condition change over time.

In general, the practice of healthcare and disability management is dominated by the use of 'outcome measures'. In a recent study focusing on the development of ICF core sets for hearing loss, it was found that there are over 100 different outcome measures in the literature related to adults with hearing impairment (Granberg, 2012). It was also highlighted that there are very few longitudinal studies in relation to adults with hearing loss. Although the value of outcome measures is not in question, there seems to be little focus on understanding the process of change over time in relation to health and disability, which may highlight the need for studies on patient journey of PHI and their CPs.

Furthermore, it is important to note that there are benefits and shortcomings of both outcome measurement and process evaluation. A discussion paper by Mant (2001) compares process and outcome measures as performance indicators in healthcare and suggested that healthcare is one determinant of health and there could be other factors (e.g., nutrition, environment, lifestyle, etc) which may influence the health outcomes. The differences in outcomes (which are measured using outcome measures and can reflect a wide range of aspects) may be due to various reasons such as types of cases on which the treatment was administered, how the data was collected, chance, quality of care given, etc. However, process evaluations could have some advantages as they are more sensitive to differences in quality of care and may act as a direct measure of quality.

### ***Rationale for the Studies***

It is suggested that acquired deafness is multi-dimensional (Kerr & Cowie, 1997) and it requires varieties of approaches to better understand its consequences. From the above discussion it is clear that the concepts such as 'patient journey', 'acceptance' and 'stages-of-change' are relatively new in hearing healthcare. Although there is some literature which focuses on similar aspects, studies using these concepts as a main theoretical base are rather limited. Besides, considering that the risk of memory dysfunction (Rönnerberg et al., 2011) and cognitive decline (Lin et al., 2013) increases with hearing loss, it is very important to identify those who are in the early stages of developing hearing loss and facilitate them through hearing rehabilitation process. Furthermore, hearing aids have been one of the most widely used treatment and/or management options for PHI. Although, hearing aids bring significant positive functional outcomes and quality of life (Vuorialho et al., 2006), the adoption rates of hearing aids are not optimal (Humphrey et al., 1981; Davis, 1995; Davis et al., 2007; Kochkin, 2009). A recent review, which looked at rehabilitation interventions available for older people with hearing impairment, suggests that the range of interventions should be improved (Laplante-Lévesque, Hickson, & Worrall, 2010). Some researchers argue that there is a paradigm shift in hearing healthcare from focus on technological aspects to a more person-centred approach to rehabilitation (Hickson, 2012). However, a first step towards moving to patient-centred rehabilitation is to better understand the process of change, patients' expectations and the factors affecting their health behaviour decisions and rehabilitation outcomes. This identifies a need for more research on PHI and their CPs with the aim to better understand their journey through hearing loss and the factors facilitating and hindering this journey.

## **AIMS & THE EMPIRICAL STUDIES**

The general aim of this thesis was to better understand the process of change (i.e., process evaluation) through hearing impairment in PHI and their CPs. The following papers have more specific aims related to the general aim. Papers I, II and III were focused on studying the process of change through initial onset of the disease to rehabilitation using qualitative methods. The focus of papers IV and V were to assess parts of this process by quantitative means.

**Paper I:** Qualitative study with the aim of exploring the perspectives of adults with acquired hearing impairment on the journey through their hearing loss and to develop the PHI journey model.

**Paper II:** Pilot study (qualitative) to develop the patient journey model of people with sudden-onset acquired hearing impairment by considering perspectives of both professionals and patients.

**Paper III:** Qualitative study with the aim of exploring perspectives of CPs through their partners' hearing impairment and to develop the CP journey model.

**Paper IV:** Cross-sectional quantitative study to develop a self-reported measure of hearing disability acceptance and to study its construct and concurrent validity. The focus on acceptance in this study was more on psychological terms (i.e., experiential avoidance).

**Paper V:** Cross-sectional quantitative study aiming to investigate the health behaviour change characteristics based on the transtheoretical stages-of-change model in adults noticing hearing difficulties but not using hearing aids using the URICA scale.

The thesis includes the above five empirical studies. In addition, a few other studies which were conducted with the general thesis aim are used as supplementary evidence where appropriate.

## MATERIALS & METHOD

### *Ethical Considerations*

All the studies discussed in this thesis were conducted during 2010-13 in Wales and received ethical approval from the Research Ethics Committee, College of Human and Health Sciences, Swansea University.

### Qualitative Studies (Papers I-III)

#### *Participants and Data Collection*

The data for qualitative studies were collected from PHIs, CPs and the professionals (i.e., audiologists) in various stages using focus groups and semi-structured interviews. Table 1 presents the demographic details and data collection method used.

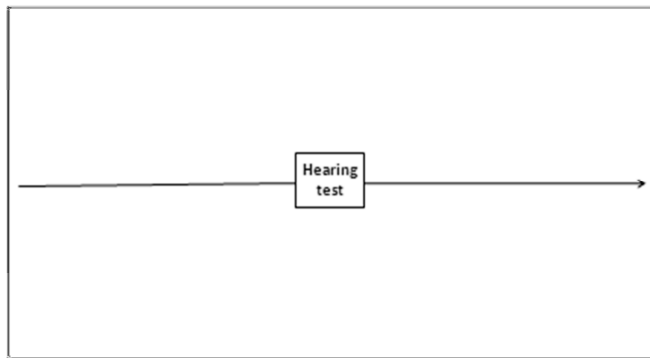
**Table 1: Participants' demographic details and data collection method in qualitative studies**

Paper	Participants	Age in years Mean (range)	Gender (Male/ Female)	Data collection method
I	<ul style="list-style-type: none"><li>32 people with gradual-onset acquired hearing impairment in <i>stage 1</i></li><li>15 people with gradual-onset acquired hearing impairment in <i>stage 2</i></li></ul>	77.1 (48-90)	13/19	Focus groups
		76.8 (69-82)	7/8	Focus groups
II	<ul style="list-style-type: none"><li>16 audiologists in <i>stage 1</i></li><li>4 people with sudden-onset acquired hearing impairment in <i>stage 2</i></li></ul>	42.3 (25-55)	6/10	Focus groups
		63.0 (61-67)	1/3	Interviews
III	CPs (e.g., spouse, children, colleague) of PHI	44.4 (19-74)	2/7	Interviews

#### *Paper I*

The data was collected in two main stages. In *stage 1* the patient journey model basic template (see Figure 1) which had been developed by the Ida Institute, was used to collect the data from members of support groups of people with hearing impairment. This model used process mapping to understand the patient journey (Damelio, 1996). Process mapping is a way of representing a sequence of actions involved in a process (or a journey). This method is popular in business and administration to understand the activities involved in the form of a timeline. In recent years, this method has also been used in healthcare to map the patient journey. Thirty-two adult patients (i.e., 18 years and above) with acquired hearing impairment participated in this activity. All the participants were hearing aid users. They were recruited from the Swansea Hard of Hearing Club and the Bridgend Hearing Impaired Support Group. The average duration of their hearing impairment was 18.8 years (ranging from 2 to 59 years). Those who volunteered to participate were divided into small groups. They were provided with the study information sheet; the purpose of the session was explained, and their written

consent was obtained. They were then given the template shown in Figure 1 and asked to list their experiences throughout their journey with hearing loss (before, during and after the hearing assessment) in the form of a timeline. They worked in small groups discussing their experiences and wrote about all the stages and experiences on POST-IT note papers and pasted them on the template. Participants' writings on POST-IT notes were used as the raw data. The group sessions were held at the regular meeting place of hard of hearing groups after their monthly meetings. One of the researchers acted as a facilitator to run these sessions and the sessions lasted for about 45 minutes.



**Figure 1: Baseline template for studying the patient journey**

In *stage 2* the patient journey template developed using the qualitative data (see Figure 2) was taken back to the Swansea Hard of Hearing Club to see whether the members agreed with it and to ensure that it was an accurate representation of the range of experience they reported. They were given a separate page to write any comments they might have. This provided an opportunity for the participants to reflect on the responses provided in the previous activity. Necessary changes were made to the patient journey template taking the feedback into account. Fifteen individuals participated in this activity with an average duration of hearing impairment of 17 years (ranging from 6 to 40 years).

### ***Paper II***

The data were collected in two main stages. In *stage 1*, the data were collected from experienced audiologists, using the Ida Institute patient journey model basic template to obtain professional perspectives on the journey. Sixteen audiologists from Wales with a mean duration of audiological experience of 16.5 years (range, 4 to 30 years) participated. All the audiologists had at least one experience of dealing with adults with sudden-onset acquired hearing impairment. The audiologists were given the empty template shown in Figure 1, and were asked to list their opinions as to what experiences the adult patients with sudden-onset acquired hearing impairment might have (before, during and after the hearing assessment), in the form of a timeline. They worked in small groups, discussing their experiences and writing down all relevant stages and experiences on adhesive notes, and then attaching these notes on to an empty template.

In *stage 2*, data were collected from four adults with sudden-onset acquired hearing impairment through semi-structured interviews. These individuals were recruited from

hard of hearing support groups based in South-Wales, using a convenience sampling strategy (Marshall, 1996). The convenience sampling involves recruiting participants based on their availability and/or ease of volunteering. The average duration of their hearing impairment was 18.8 years (ranging from 2 to 59 years). They all had a severe-to-profound degree of hearing loss with two of them being bilateral hearing impairment. The participants were first asked to tell the story of their experiences with hearing impairment. The interviewer then asked questions related to the topics that had arisen during the patient's narrative. This was followed by broad questions to explore the patient's general problems. Finally, more directed questions were asked, to obtain an in-depth understanding of the patient's experiences. Interviews lasted approximately 60-90 minutes, and were recorded using portable digital recorders in order to facilitate checking of researcher's notes. However, it proved impossible to identify and recruit a larger numbers of participants from the surrounding area, within the time-frame available for the study.

### ***Paper III***

A purposeful sampling strategy (i.e., selection of sample individuals with particular purpose in mind) was used in order to recruit CPs of the hearing aid users through the Swansea Hard of Hearing Support Group (Patton, 1990). Most members of this group are health care users of National Health Services, experienced hearing aid users (i.e., over two years) and they meet once a month for a few hours in a designated place. The participants included nine CPs which involved spouses (n=4), children (n=2), friend (n=1), colleague (n=1) and a carer (n=1). Whilst there was a wide range of people within the participants, all were reported to spend a significant amount of time communicating with the PHI (i.e., during most days of the week). However, CPs typically do not attend the support group meetings. The duration of contact of the CP with the PHI varied from 1 year to 58 years with an average of 25.6 years and the duration of PHI's hearing loss varied from 6 years to >30 years. Only three of the nine CPs in the study had accompanied the PHI to an audiological appointment on at least one occasion. All the PHI's were reported to have bilateral hearing loss with mild to severe degrees. However, we were unable to obtain the exact degree of hearing loss in each case.

All the participants were supplied with an information sheet usually a week before the interview and scheduled an appointment. In addition, on the day of interview they were given a short introduction to the study, an opportunity was given to ask questions, informed about confidentiality and a written consent was obtained. The data were collected through semi-structured interviews. A questionnaire was developed based on the literature review and from previous experience of studies on journey of PHI, which was used as guide during the interview. Initially CPs were asked to narrate their journey (tell their story) through their partner's/friend's/father's hearing loss. This was followed by some general questions (i.e., all the questions in the questionnaire were asked to each participant) to explore the CPs experiences broadly. In addition, more directed questions based on their reports during the interview were asked to obtain an in-depth understanding of their experiences. Interviews typically lasted for about 60-90 minutes. The interviews were recorded using portable digital recorders to recheck the notes taken by the researcher. It was noticed that many CPs had prepared notes about their experiences before the interview, even though it was not requested in the information sheet.

## **Data Analyses**

The qualitative data (both from focus groups and interviews) were analysed using thematic analysis which involves identifying, analysing and reporting patterns within the data (Braun & Clarke, 2006). The main task in thematic analysis is to identify a limited number of themes which adequately reflect the data. A hybrid of inductive and deductive approaches was used for coding and the development of themes (Fereday & Muir-Cochrane, 2006). The Ida Institute PHI and CP journey model was used as a theoretical base (Ida Institute, 2009, 2012). Such an approach allowed the researcher to focus on important aspects of the data based on theory and also to look for new themes which emerged from the data.

The main steps in data analysis included: familiarization with the data by repeated reading of notes and/or by listening to the voice recordings repeatedly, generating the initial codes (i.e., the participants' reports were shortened to simple and meaningful units), categorising the data and searching for sub-themes and themes, on-going review, defining and naming of themes and sub-themes, and identifying some extracts which could be used in reporting the data. In qualitative studies, the terms '*phase*' and '*stage*' have been used to refer to themes and sub-themes respectively. In papers I and II, the analysis and naming of themes and sub-themes were solely driven towards capturing the essence of participants' reports, but the frequency of occurrence of codes was also considered in paper III. For example, the sub-themes were categorised into *most* (i.e., approximately two thirds), *many* (i.e., approximately half), *several and/or few* (i.e., less than half) based on how frequently there were reported. The rule of most of the participants reporting was considered for a theme (i.e., phase) and many participants reporting for a sub-theme (i.e., stage). The data saturation was not checked in papers I and II. However, in paper III the working model with seven main phases was developed with interview data of seven participants. Two new participants were interviewed to check for data saturation and the data collection was stopped as there were no new themes identified (Morse, 1995).

An on-going matching of sub-themes was done with the Ida Institute model to see if the same code names could be assigned. However, where new sub-themes (i.e., stages) were identified new names were assigned to reflect the meaning and essence of the reported experiences. The sub-themes were grouped together to identify themes and the themes were further confirmed by repeatedly reading notes and by listening to interviews to check if the identified themes captured the reported experiences. Furthermore, the patients' and professionals' perspectives of the journey of PHI and CPs were compared in all three studies to determine whether there was any relationship.

## **Presentation of the Qualitative Data**

The process mapping (i.e., a way of representing a sequence of actions involved in a process) was used to define these themes in appropriate phases to represent the PHI and CP's journey model (Damelio, 1996). Process maps can be an effective way to demonstrate either individual or organisational process about virtually any aspect. The visual approach used in presenting the information makes it easier for readers to understand the process and may also help in identifying any constraints and/or bottle necks. Whilst the use of process mapping in healthcare seems to be relatively new, it has increased mainly in clinical audits to identify how we manage the patient journey, using patient perspectives to identify issues and suggested improvements to healthcare

(Kollberg, Dahlgard, & Brehmer, 2007; Trebble, Hansi, Hydes, Smith, & Baker, 2010; Macdonald et al., 2012).

## **Quantitative Studies (Papers IV & V)**

### ***Study Design and Participants***

Studies IV and V had the same design: they both used cross-sectional data obtained during a clinical trial (i.e., pre-intervention data) of a pre-fitting counselling program (Manchaiah, Stephens, Andersson, Rönnerberg & Lunner, 2013b; Manchaiah, Rönnerberg, Andersson & Lunner, 2013c). A study advertisement was made in the United Kingdom through various sources including national newspapers, hearing loss charity websites (i.e., Action on Hearing Loss and Hearing Link), and local general practitioner (GP) practice notice boards requesting those who are noticing hearing difficulties but not using hearing aids and who had access to internet to participate in this study. Interested participants were encouraged to access the study website using the URL supplied. A total of 90 participants completed the informed consent form, provided demographic information and also completed some questionnaires via the internet. The questionnaires used were: Hearing Disability Acceptance Questionnaire (HDAQ), Hearing Handicap Questionnaire (HHQ), Hospital Anxiety and Depression Scale (HADS), University of Rhode Island Change Assessment (URICA) Scale.

### ***Outcome Measures***

*Self-reported hearing disability acceptance* was assessed using the Hearing HDAQ. The HDAQ was developed based on the Tinnitus Acceptance Questionnaire (TAQ) which was developed in Sweden for studying tinnitus acceptance (Westin et al., 2008). The TAQ was influenced by the Acceptance and Action Questionnaire (AAQ; Hayes et al., 2004) and the Chronic Pain Acceptance Questionnaire - Revised (CAQ-R; McCracken et al., 2004) and adding a few additional questions. The 12-item TAQ has two factors which were named '*activity engagement*' and '*tinnitus suppression*,' and had good internal consistency with Chronbach's alpha  $\alpha=0.89$  (Westin et al., 2008). Resembling TAQ, HDAQ is a measure of experiential avoidance/acceptance. All the 12-items were taken from the TAQ by replacing the word 'tinnitus' with 'hearing problem'. However, the 12-items were further reduced to 7-items (see the results section). Each item is rated on a 7-point Likert scale (1 = never true, 7 = always true). Total scores range from 7 to 49 with higher scores indicative of more acceptance of hearing disability (see Appendix 1).

*Self-reported hearing disability* was assessed using the HHQ (Gatehouse & Noble, 2004). The HHQ has 12-items with two subscales (emotional and social). Each item is rated on a 5-point Likert scale (1=never, 5=almost always) and the total scores in each subscale can range from 6 to 30 with higher scores indicative of more self-reported hearing disability (i.e., activity limitations and participation restrictions). The HHQ has been found to have good internal consistency, Cronbach's alpha of .95 for emotional and .93 for social subscales (Noble, Tyler, Dunn, & Bhullar, 2008).

*Self-reported anxiety and depression* symptoms were assessed using the HADS (Zigmond & Snaith, 1983). The HADS has 14 items with two subscales (anxiety and depression). Each item is rated on a 4-point Likert scale (0=not at all, 3=most of the time), and the total scores in each subscale can range from 0 to 21 with higher scores indicative of more self-reported anxiety and depression in respondents. The HADS has been found to



have good internal consistency, Cronbach's alpha of .80 for anxiety and .81 for depression subscales (Herrmann, 1997).

*Stages-of-change* were assessed using the URICA scale (McConaughy et al., 1983), which is the most commonly used stages-of-change measure that can be applied for most populations. The original URICA scale has 32 items (four stages with 8-items corresponding to each stage). Each item is rated on a 5-point Likert scale (1=strong disagreement, 5=strong agreement) and the total scores for each stage (i.e., subscale) can range from 8 to 40. In populations where the 'maintenance' stage is not appropriate a 24-item URICA has been used, which has three stages with 8-items corresponding to each stage (i.e., precontemplation, contemplation and action) (Lam et al., 1988; Treasure et al., 1999). The generic URICA scale was used in this study by replacing the phrase 'the problem' with 'the hearing problem' to make it suitable for the current population. The same scale was used by Laplante-Lévesque et al. (2013) who identified four stages (i.e., precontemplation, contemplation, preparation and action). However, in the four stage model the precontemplation and actions stages had 8-items each and contemplation and preparation had 3-items and 5-items respectively (see Appendix 2). In order to be able to compare the scores in each stage, weighted means were calculated for the contemplation and preparation stages as they had fewer numbers of items. The URICA scores were analysed and presented in four ways:

- Stage scores: These scores are used as a measure of stage endorsement and respondents can score high on more than one stage of change (e.g., Amodei & Lamb, 2004; Dozois, Westra, Collins, Fung, & Garry, 2004).
- Composite scores: Two composites can be obtained using the different stage scores (e.g., Velasquez, Carbonari, & DiClemente, 1999; Pantaloni & Swanson, 2003; Pantaloni, Nich, Frankforter, Carroll, & University of Rhode Island Change Assessment, 2002; Field, Duncan, Washington, & Adinoff, 2007). *Readiness to change composite* can be obtained by adding the scores of contemplation and action stage and subtracting the precontemplation score. *Committed action composite* can be obtained by subtracting contemplation stage scores from action stage scores. The higher the scores in these composites, the further along the participants are assumed to be in the stages-of-change model.
- Stage with the highest scores: This can be used to describe a respondent's stage of change (e.g., Etter et al., 1997; Treasure et al., 1999). With this, the respondent can only be in one stage at a given point in time. For this reason, if two stages have equal scores then the stage furthest from precontemplation is considered to have the highest score.
- Stages-of-change clusters: Cluster analysis of URICA scores can produce stages-of-change clusters (e.g., McConaughy et al., 1983; Keefe et al., 2000). Cluster analysis is a statistical technique which is used to group participants with similarity in their results. The sub-groups generated can help in better understanding the characteristics of the study population.

## ***Statistical Analyses***

Statistical analysis was performed using a statistical the software package (IBM - SPSS Version 19 for Windows). In the first stage, descriptive statistics were used to examine demographic factors and the assumption of normality was tested where appropriate. An alpha level of 0.05 was determined significant for all the statistical analysis.

For paper IV, principal components analysis (PCA) with Varimax rotation was performed to study the factor structure with the limit for eigenvalues set at 1.0 and a limit for factor loadings at .40 (Kline, 1994). The initial number of factors of interest was determined using Kaiser's rule of eigenvalues of >1 (Kaiser, 1960). Subsequently, a scree plot was examined to decide on the number of factors to extract (Cattell, 1966). Cronbach's alpha was calculated to study the internal consistency of HDAQ. Pearson's correlations were performed to study the association between factors: hearing disability acceptance, self-reported hearing disability, self-reported anxiety and depression and readiness to change.

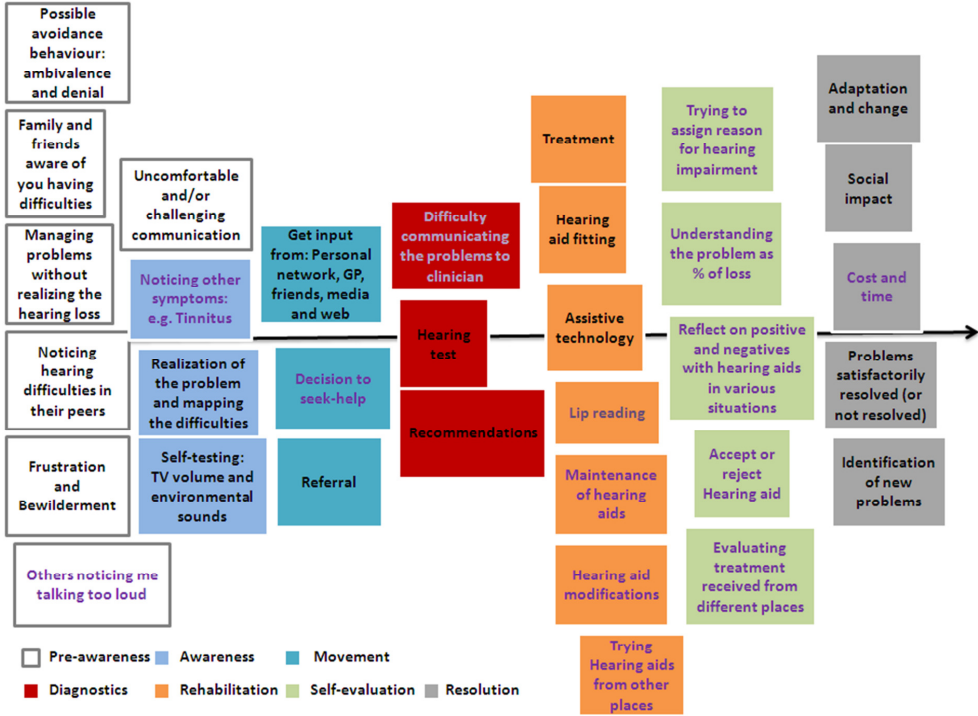
For paper V, statistical tests were performed which include: (1) t-test to compare means between groups; (2) Pearson's correlation coefficient to study correlation between composite scores and other factors; and (3) Hierarchical cluster analysis using Ward's method (Ferreira & Hitchcock, 2009), and standardised Z-scores to investigate the stages-of-change clusters. Evaluation of the cluster results were done with visual inspection of the dendrogram (i.e., a tree diagram which shows a hierarchy of categories based on the degree of similarity or number of shared characteristics). Also, where applicable, published data (means, standard deviations) from the previous study (Laplante-Lévesque et al., 2013) was used to calculate t-tests when hypothesis testing the differences between the current study and the previous study.

# RESULTS & DISCUSSION

## Results of Qualitative Studies (Papers I-III)

### Paper I

Paper I includes qualitative study aiming to explore the perspectives of adults with acquired hearing impairment on the journey through their hearing loss, and to develop the PHI journey model. Figure 2 shows the phases of the patient journey developed from the patients’ responses with seven main phases that were identified.



**Figure 2: Patients perspective of their journey through hearing impairment** (stages identified only by patients are indicated in purple text)

**Pre-awareness:** This phase includes patients’ experiences before they become aware of their problems. The patients may show avoidance behaviour, but their family and friends may become aware of hearing difficulties experienced by the individual.

**Awareness:** Eventually, the person may start to become aware of their hearing loss following various experiences such as symptoms of tinnitus. They may also begin to self-test their hearing by varying the TV volume and listening to environmental sounds.

**Movement:** After becoming aware of the problem and going through various experiences the person may choose to do something about the problem. This could

include obtaining input from GP, friends, media and web. They could then make a decision to seek help and arrange referral to a hearing healthcare professional.

**Diagnosics:** This is a phase which may be regarded as an active phase by hearing healthcare professionals, but patients identified some difficulties in communicating their problems to the clinician during hearing tests.

**Rehabilitation:** In this phase the patients were able to identify many stages which included: obtaining treatment and hearing aid fitting, access to assistive technology such as telephone amplifiers and FM systems, attending lip reading classes, and so on.

**Self-evaluation:** This is a new phase which was identified only by patients. In this phase patients were actively doing things such as: trying to assign reasons for their hearing impairment, understanding the problem in terms of percentage of hearing loss, etc.

**Resolution (or Post-clinical):** This phase includes patients undergoing adaptation and change, considering social impact, considering cost and time, problems satisfactorily resolved or not resolved, and identification of new problems.

**Comparison to professionals' perspectives of the PHI journey:** Table 2 shows the differences in the key stages and/or milestones identified only by either patients or with the previously developed template using professionals' responses (Ida Institute, 2009).

**Table 2: Key stages identified only by either patients or professionals**

Key phases in patient journey	Stages and/or milestones identified only by patients	Stages and/or milestones identified only by professionals
<b>Pre-awareness</b>	Others noticing me talking too loud	
<b>Awareness</b>	Noticing other symptoms: e.g. Tinnitus	Recognising social impact
<b>Movement</b>	Decision to seek help	Tipping point: "I will consult somebody concerning my hearing difficulties"
<b>Diagnosics</b>	Difficulty communicating the problems to clinician	Interview and case history; Decision making
<b>Rehabilitation</b>	Lip reading; Maintenance of hearing aids; Hearing aid modifications; and trying hearing aids from other places	Counselling
<b>Self-Evaluation</b>	Trying to assign reason for hearing impairment; Understanding the problem as % of loss; reflect on positive and negative aspects of hearing aids in various situations; accept or reject hearing aid; and Evaluating treatment from different places	
<b>Resolution (Post-clinical)</b>	Cost and time	

## **Paper II**

Paper II includes a pilot study (qualitative) which was aimed at developing the patient journey model of people with sudden-onset acquired hearing impairment by considering perspectives of both professionals and patients. Figure 3 shows the representation of the audiologists' perspectives on the patient journey and Figure 4 shows a representation of the patients' perspectives on the patient journey. Both identified six main phases that include: awareness, movement, diagnostics, rehabilitation, self-evaluation and resolution.

**Awareness:** The person may realise they have a hearing loss, typically with a rapid onset. They may experience other symptoms such as tinnitus and dizziness. They may self-test to see if they have hearing loss. They may experience various feelings such as shock, fear, confusion and anxiety. They may also experience significant communication difficulties.

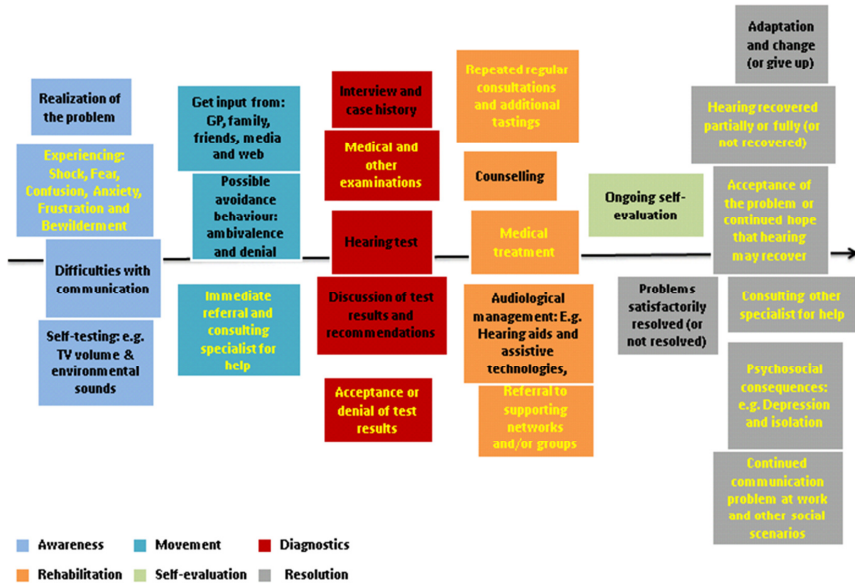
**Movement:** Even though patients have realised that their hearing is not right, they may have apprehension of accepting this hearing loss, and may use coping strategies to deal with communication difficulties. However, they may receive some input from their family and friends, and as a result decide to get help from a specialist. They may also be unaware of dangerous situations when they occur, and be curious to know the cause and likely outcome of their condition; furthermore, they may believe that their hearing might recover.

**Diagnostics:** In the diagnostic phase, patients may consult specialists for help and may undergo various medical, audiological and other investigations. They may experience difficulty communicating their problems to the professionals; discussion of results and the treatment recommendations may be accepted or denied.

**Rehabilitation:** During this phase, patients may continue to visit various professionals for regular testing, and may receive both medical and audiological treatment and management. In many cases, they may also be referred to seek help from various support networks and groups for help.

**Self-evaluation:** In this phase, patients may take a lot of time to reflect back on the experiences they have had. They may reflect on the positive and negative experiences of hearing loss and its treatment, try to assign a reason for their hearing impairment, and may also evaluate treatment and support received from different sources and professionals. Discussing this with their communication partners may lead to possible differences.

**Resolution:** In this phase, patients may start to accept their hearing loss and start to adapt to changes. However, in some cases they may still believe that their hearing will recover, or alternatively may give up adapting to new changes. They may make several life adjustments including finding alternative ways to communicate (e.g. by writing) and changing their social networks. They may also experience repeated psychological consequences such as depression and isolation, and may have continued difficulties with communication, leading to partial or total dependency on communication partners.



**Figure 3: Representation of professionals' perspective on stages of the 'patient journey' of sudden-onset acquired hearing impairment (stages unique to sudden-onset compared with gradual-onset patient journey are indicated by yellow text)**



**Figure 4: Representation of patients' perspective of stages of the 'patient journey' of sudden-onset acquired hearing impairment (stages unique to sudden-onset compared with gradual-onset patient journey are indicated by purple text)**

The perspectives of professionals and patients were compared to identify any differences and commonalities in their responses. Table 3 shows the stages and milestones identified only by patients or only by audiologists.

**Table 3: Differences in professionals’ and patients’ perspectives**

<b>Key phases in patient journey</b>	<b>Stages and/or milestones identified only by professionals</b>	<b>Stages and/or milestones identified only by patients</b>
<b>Awareness</b>		Noticing symptoms: Tinnitus, and dizziness; Feeling helpless
<b>Movement</b>	Possible avoidance behaviour: ambivalence and denial	Primitive fear of accepting hearing loss; Using coping strategies; Acutely unaware of dangerous situations; Curious to know the cause and outcome; Belief that hearing may recover
<b>Diagnostics</b>	Interview and case history	Difficulty communicating the problems to the clinician; Relief of diagnosis (or not)
<b>Rehabilitation</b>	Counselling	
<b>Self-Evaluation</b>		Reflect on positive and negative experiences of hearing loss and its treatment; Try to assign the reason for hearing impairment; Differences in opinions of patient and their communication partner; Evaluating treatment/support received from different places and professionals
<b>Resolution</b>	Problems satisfactorily resolved (or not resolved)	Using alternative ways to communicate: e.g. Writing; Life adjustments; Changes to social networks; Total or partial dependency on communication partner

**Paper III**

Paper III includes qualitative study with the aim of exploring perspectives of CPs though their partners’ hearing impairment and to develop the CP journey model. Figure 5 shows the CPs’ perspective on their journey through their partners hearing impairment. Seven main phases and various stages were identified, which included: contemplation, awareness, persuasion, validation, rehabilitation, adaptation, and resolution. Also, CPs talked more about contemplation, awareness, adaptation, and resolution phases compared to other phases (i.e., persuasion, validation and rehabilitation).



**Figure 5: Communication partners perspectives of their journey through their partners hearing impairment** (stages identified only by CPs are highlighted in yellow text and stages which are reported in multiple phases are highlighted with red outline)

**Contemplation (or What is going on?):** In this phase CPs may start noticing the PHI's communication difficulties and reduced social interactions. This may sometimes result in feeling embarrassed, angry and frustrated but later they also may start making some accommodation to the PHI's hearing loss.

**Awareness:** In this phase CPs become aware that the PHI has genuine difficulties with their hearing. This may be by noticing clear changes in the PHI's communication behaviour and changes in the family dynamics.

**Persuasion:** After CPs become aware of the PHIs hearing loss they often start making attempts to make the PHI aware of their communication problems. They also may start searching for information and start persuading the PHI to seek help.

**Validation:** This phase was not widely discussed by the CPs. However, in this phase CPs mainly confirm whether or not the PHI had hearing loss, although the results may not always surprise them.

**Rehabilitation:** Most CPs were relieved that the PHIs were seeking help. They started realising that they also have an important role to play in the rehabilitation process, mainly in supporting the PHI (e.g., in using hearing aids).

**Adaptation:** This was a new phase identified from CP reports. This phase was noticed soon after the hearing assessment and rehabilitation session, when CPs started



exploring new ways to communicate with the PHI, adaptation to regular role sharing, and reflecting on positive and negative consequences of the hearing impairment.

**Resolution:** CPs started noticing continued difficulties experienced by the PHI in social situations and started realising that crisis may not necessarily hearing related. In this phase hearing loss had just become a way of life compared to the earlier phase (i.e., adaptation) in which they were exploring new ways of communication.

**Comparison to professionals’ perspectives of the CP journey:** Table 4 shows the differences and similarities in the key stages and/or milestones identified by CPs and in comparison to professionals (Ida Institute, 2012).

**Table 4: Difference and similarities between phases/stages identified by CPs and professionals**

Phases	Stages identified only by CPs	Stages identified only by professionals
<b>Contemplation (or What is going on?)</b>	Noticing the PHI’s communication difficulties	Is the PHI losing interest in their relationship?
<b>Awareness</b>	Recognising the PHI’s dependency on other senses (e.g., visual)	Observes declining relationships with family members
<b>Persuasion</b>	Exploring the information about hearing loss and its treatment; Act of persuasion changing relationship dynamics	Implications considered of moving forward (cost, time, etc).
<b>Validation</b>		Consider attending a hearing test
<b>Rehabilitation</b>	Helping the PHI with their hearing instruments; Realising hearing instruments do not solve all the problems	Hearing aids make the impairment public
<b>Adaptation</b>	Exploring new ways of dealing with the PHI’s communication difficulties; Adapting to regular role sharing to act as interpreter for the PHI; Noticing hearing difficulties themselves and comparing this to the PHI’s difficulties; Recognising and reflecting on positive and negative experience of hearing loss	
<b>Resolution (or Maintenance)</b>	Continued difficulties in communication during social situations; Noticing and adapting to gradual progression of hearing loss of PHI	Realization that life has changed and adaptation is not easy; Joy, relief

## **Discussion of Qualitative Studies (Papers I-III)**

In paper I, seven main phases were identified through the course of the disease and the treatment regime in gradual-onset hearing impairment. In paper II, six key phases that patients with sudden-onset acquired hearing impairment are likely to go through were identified by analysing the perspectives of both patients and professionals. Also, paper III identified seven main phases in the CPs' journey through their partners hearing impairment.

In papers I and III, the professionals did not identify the stages the PHI and CPs would go through during the 'self-evaluation' and 'adaptation' phases respectively. The stages recognized by PHI and their CPs during this phase were mainly in relation to reflecting on their experiences, evaluating the services received and assigning reasons for hearing loss. It clearly highlights the fact that even experienced hearing healthcare professionals may have much to learn with respect to the experiences of PHI and their CPs. Also, there were many differences in perspectives of PHI and CPs when compared to those of professionals in all three papers (i.e., papers I-III). For example, PHI and CPs reported more stages in the initial and latter parts of the journey (i.e., preawareness, awareness, resolution) and professionals reported more stages during the middle parts of the journey (i.e., diagnostics). This could have resulted from differences in personal experience (Hunt & Arar, 2000), as the hearing healthcare professionals cannot directly experience the day-to-day life of their patients. However, professionals can attempt to discover this through professional questioning (Tjørnhøj-Thomsen, 2009). Because of limited availability of time, it may not be possible to fully explore this within many normal clinical settings. For this reason, such models of PHI and CPs journey could be a good starting point for clinicians.

The identification of a new phase (i.e. adaptation phase in the CP journey; and self-evaluation phase in the PHI journey) in papers I and III may be significant in terms of clinical practice which may highlight the need to have review appointments soon after the initial assessment and rehabilitation session. This is important as both PHI and CPs are actively assessing if their condition has changed after rehabilitation, reflecting on positive and negative experience they may have had and also actively trying to change their lifestyle to adapt to new technologies. For this reason, the review sessions should be focused on assessing and modifying expectations of PHI and their CPs, providing psychosocial support, helping them to adapt to new technologies and teaching communication tactics.

In papers I and III, the PHI and CPs responses emphasised both the early and the later phases of the journey with less emphasis on the middle phases, especially on what happens during diagnostic testing. Similar results have been found in a recent international study which explored the perspectives of PHI during hearing help-seeking and rehabilitation (Laplante-Lévesque et al., 2012a). However, professionals' emphasis was more on what happens during the diagnostic and rehabilitation phases. Some of the differences can be attributed to differences in educational, ethnic and socio-economic backgrounds between professionals and patients (Hunt & Arar, 2000), although, the personal experiences of professionals and patients could be one of the biggest contributing factors. The commonality in the perspectives can, to an extent, be explained by findings of other researchers who have argued that patients often develop

concepts of disease which are quite similar to those of healthcare providers, due to long term interactions between them (Hunt, 1994; Hunt, Pugh, & Valenzuela, 1998).

Some studies have suggested that patients with sudden-onset hearing loss are much different compared to those with gradual-onset hearing loss and they may require careful attention during audiological rehabilitation (Chiossoine-Kerdel, Baguley, Stoddart, & Moffat, 2000; Carlsson, Hall, Lind, & Danermark, 2011). Although based on a literature review it was anticipated that significant differences may exist. The absence of pre-awareness phase was the main difference in sudden-onset patient journey when compared to the journey of adults with gradual-onset acquired hearing impairment. Also, patients with these two conditions may have overlapping stages and milestones, and may not follow the exact phase sequence shown in the patient journey template. Some stages may occur in more than one phases (e.g. total or partial dependency on CPs). Patients with sudden-onset acquired hearing impairment generally had a more rapid progress from one stage to the next, compared with patients with gradual-onset hearing impairment. This may indicate that patients with sudden-onset may require more frequent consultation with hearing healthcare professionals when compared to patients with gradual-onset acquired hearing loss.

Paper I suggested that PHIs have difficulty realising they have a hearing loss. Also, in paper III, it was identified that in the early stages of hearing loss CPs may attribute the difficulties experienced by PHIs to cognitive impairment. Some recent studies have suggested that hearing loss may result in cognitive decline (Lin et al., 2013), for example impaired episodic memory (Rönnberg et al., 2011), which may be an early indication of disorders such as dementia. This could be one reason why it is hard to identify hearing loss in the early stages. Also, a recent qualitative study, which was aimed at understanding the client perspective of their hearing impairment and their active participation throughout the hearing aid rehabilitation process, identified a concept called “client labour” (Knudsen, Nielsen, Kramer, Jones, & Laplante-Lévesque, 2013). Client labour had nine sub-themes, which were grouped into three main categories: cognitive labour, emotional labour and physical labour. The cognitive labour focuses on aspects of participants’ report where they try to find reasons for improving their rehabilitation process (e.g., problem solving, strategy creating, and decision making). Although these aspects were not studied like a process leading to a common goal, the findings relate well to initial phases of the patient journey as reported in qualitative studies (i.e., papers I-II). For this reason, it may be useful to employ cognitive strategies during audiological rehabilitation sessions (e.g., consciousness raising, encouraging self-evaluation), which may help in facilitating change in PHI (Babeu et al., 2004).

The interview data from papers II and III suggested that, in general, the intensity of psychological, emotional and social consequences reported by each PHI with sudden-onset loss and CP varied greatly and the patient journey model did not represent this aspect well: for example, the degree to which the CPs experienced communication difficulties during social situations. Although the CP journey model represents the main experience of CPs through their partner’s hearing loss (i.e., phases and stages) over a period of time, it may not clearly differentiate to what extent individual CP’s were affected. For this reason, informal questioning, use of open ended questionnaires and use of structured questionnaires can be useful during clinical encounters to gather information about the effect of hearing impairment on PHI’s and CPs in different

dimensions. For this reason, the combination of such approaches may be necessary in practice and they may complement each other.

Furthermore, in paper III, aspects such as frequency of communication and emotional closeness played an important role in the extent to which the CP was affected by the PHI's hearing impairment. For example, three of the participants (a carer, a friend and a colleague) reported very few psychological consequences on them. In addition, three of the CPs (two daughters and a friend) talked about the impact of the PHI on their spouse and expressed the fact that the spouses of PHIs were most affected in communication, social and emotional aspects. This identifies the need for understanding more about the social networks of the PHI and their communication behaviour with CPs. For this purpose, tools such as 'Communication World' and/or 'Communication Rings' could be helpful (Manchaiah & Stephens, 2011a; Gregory, 2011).

### ***Strengths and weakness of the qualitative studies***

Although these studies help identify some new perspectives from PHI and their CPs, they also have some limitations. In papers I and II all the participants were recruited through hearing impaired support groups. The same included only those who had chosen to use hearing aids, which may not represent the full spectrum of people with hearing impairment. For example, many individuals may choose to manage their hearing loss without using any amplification devices. For this reason some stages experienced by people with hearing impairment, especially in the early phases pre-awareness, awareness, movement and diagnostics may not have been fully explored. Also, the main limitation in the paper II was the small number of participants, which did not allow us to check for data saturation.

The methodologies employed in these studies (i.e., papers I-III) have some advantages and drawbacks which may have influenced the results and the development of the PHI and CP journey models. For example, whilst thematic analysis offers a theoretically flexible approach to analysis of the data, narrative or other biographical approaches may have tapped into different aspects of the data (i.e., being able to retain a sense of continuity and contradiction through any one individual account) (Braun & Clarke, 2006). However, thematic analysis helped in focusing on specific themes derived from the data and to highlight overlaps in themes in the journey model (i.e., stages appearing in multiple phases). Also, this method of data analysis is more generalizable when compared to ideographic approaches. Moreover, a recent qualitative study with the aim of exploring perspective of adults with hearing impairment through help-seeking and hearing rehabilitation suggests that participants reported experiences that could be classified in three different dimensions (Laplante-Lévesque et al., 2012a): (1) description - focuses on what; (2) intention - focuses on why; and (3) evaluation - focuses on evaluating experiences and decisions as good or bad. The same study findings also suggested that the participants' reports were more on 'intention' and 'evaluation' than 'descriptions'. For this reason, thematic analysis, which is more interpretive, and focuses on 'why' and 'how' aspects of the data was more suitable method for data analysis when compared to other frequently used methods such as content analysis, which focuses on 'what' aspects of the data (Graneheim & Lundman, 2004; Morse, 2008).

Considering the nature of the thesis, the author did the data collection and analysis of the qualitative studies. However, the results of analysis were discussed with supervisors regularly in various stages. This allowed consistency in the method employed but may have failed to provide multiple perspectives and rechecking of the coding. However, discussion among researchers helped to ensure that the way the data were shortened (i.e., generating codes), categorised and labelled was appropriate. In paper I, the data analysed were taken back to participants to see their reaction. They were generally in agreement with the patient journey template as an accurate model representing their experiences. These steps (i.e., discussion of data among researchers and participants recognition of the findings) add to the credibility and trustworthiness of the reported findings (Woods & Catanzaro, 1988; Graneheim & Lundman, 2004).

The Ida template, used as the baseline in process mapping may have influenced participants' responses and the model may not have captured all the aspects of the journey. In addition, epistemological positioning of researchers' and their knowledge of the patient journey may have influenced the analysis to a certain degree (Braun & Clarke, 2006). Furthermore, the use of a hybrid inductive and deductive method allowed us to look for the emergence of new themes whilst focusing on important data which was based on the professionals perspective of the PHI and CP journey models.

Generally, the idea of qualitative research is to generate theories, models and hypotheses rather than testing them. In other words, "*qualitative research has the ability to generate new information that may have otherwise have been overlooked*" (Knudsen et al., 2012, p. 83). The aims of papers I-III were indeed developing the PHI and CP journey models rather than testing them. The initial phases of the patient journey model (i.e., paper I) to some degree have been validated with recent quantitative research that suggests there are four phases in the initial part of the PHI journey until the point of consultation (Laplante-Lévesque et al., 2013). However, the complete journey of PHI and CPs with seven phases has not been validated using quantitative means. Although results of the studies, ideas developed and the models proposed are transferable, caution must be taken since factors such as culture and hearing healthcare system specific to the participants may have influenced the reported journey.

### ***Clinical applicability of the qualitative studies***

It is suggested that defining a patient experience as a journey is one of the most meaningful ways to approach hearing loss (Ruzixka, 2006). Studies from anthropology have shown that patients are better able to cope with their challenges when they receive care that combines shared understanding and an appreciation of their unique and personal experiences of health issues (Mattingly, 2006). This would suggest that there is a need in hearing healthcare to consider the patient's journey during the enablement process. Identifying the phase currently occupied by the PHI and CPs during the audiological enablement process would be an important clinical application for hearing healthcare professionals. Creating patient-centred individual management plans based on this would increase the likelihood of patient satisfaction. Furthermore, patients' knowledge of their journey's steps and stages reduces their anxiety and fear (Layton, Moss, & Morgan, 1998), although hard evidence to support this statement is lacking.

Understanding which phase the PHI and CPs could be helpful for clinicians in planning rehabilitation strategies. Studies (i.e., papers I-III) strengthen the argument that patients and their CPs use their life experiences to relate to the chronic condition rather than the experiences during clinical encounters (Laplante-Lévesque et al., 2012a). This has important clinical implications in that clinicians may have to employ the strategy of talking more about life experiences to find common ground between the PHI and CPs rather than about the disease, clinical tests and other technical details. Also, the observations such as CPs having different expectations from the PHI (i.e., paper III), needs more exploration in terms of new ways to improve their communication with the PHI at the beginning of the condition. However, in practice, the straightforward way to understand the individual patient journey is by taking a detailed case history. However, due to the limited time usually available, it may not be possible to obtain an in-depth history from each patient. For this reason, starting off with a template for a 'typical journey' for patients with such a condition and then obtaining in-depth insights into their individual experiences (process) during the case history can be helpful. Moreover, when dealing with sudden-onset hearing impairment careful attention should be given to each individual patient, in order to better understand individual impact of the condition and the patient journey template should be used as a baseline.

The main aim of journey models developed by the Ida Institute was to train hearing healthcare professionals. Understanding of the patient journey could help professionals to address the wider aspects of patient experiences, to develop long-term relationships with patients, and could be useful in developing a patient-centred treatment approach by taking each individual's needs and expectations into consideration. This, in turn may help to achieve better outcomes. In addition, understanding the patient journey may help future planning and service development and in developing care pathways (Layton et al., 1998). A recent survey of hearing healthcare professionals suggested that the use of Ida Institute tools could act as a facilitating factor in person-centred care (Danermark, 2013). However, this survey questioning was not specific to patient journey models. Also, currently there are no well controlled and published studies which evaluate the utility of patient journey models on training of hearing healthcare professionals, although some are underway. Furthermore, in a recent study it was hypothesised that the PHI and CP journey models can be useful in pre-fitting counselling of a person with hearing disability (Manchaiah et al., 2013b, 2013c). However, even though some participants were able to appreciate this model, the study highlighted that generally people with hearing disability found it hard to use this tool on their own.

## Results of Quantitative Studies (Papers IV & V)

Table 5 shows the sample characteristics for papers IV and V. The average age of participants and the average duration of hearing disability were 63.4 and 11.7 years respectively. There was an equal spread of males and females. Also, nearly two-thirds of the participants had consulted hearing healthcare professionals previously.

**Table 5: Sample characteristics in the papers IV and V**

<b>N</b>	90
<b>Sample</b>	Adults noticing hearing difficulties
<b>Age (yrs; M ± SD)</b>	63.41 ± 10.49
<b>Gender (% male)</b>	50
<b>Years since hearing disability onset (yrs; M ± SD)</b>	11.67 ± 10.83
<b>Education (%)</b>	
▪ Compulsory education	13.3
▪ Secondary education	48.9
▪ Tertiary education	37.8
<b>Consulted hearing healthcare professional (%)</b>	
▪ Yes	65.6
▪ No	34.4
<b>Computer experience (%)</b>	
▪ Basic	35.6
▪ Intermediate	61.1
▪ Expert	3.3
<b>Change assessment (URICA)</b>	
<b>Stages-of-change (Scores ± SD)</b>	
▪ Precontemplation	18.41 ± 3.30
▪ Contemplation	31.55 ± 4.17
▪ Preparation	30.66 ± 4.24
▪ Action	26.80 ± 5.30
Readiness to Change composite (Scores ± SD)	39.41 ± 8.63
Committed Action composite (Scores ± SD)	-4.20 ± 4.77
<b>Participants with highest scores in each stage (%)</b>	
▪ Precontemplation	0
▪ Contemplation	45.6
▪ Preparation	47.8
▪ Action	6.7
<b>Self-reported hearing disability (HHQ; M ± SD)</b>	34.96 ± 9.95
▪ HHQ – Emotional	20.61 ± 5.75
▪ HHQ – Social	14.32 ± 4.85
<b>Self-reported anxiety and depression (HADS; M ± SD)</b>	14.77 ± 7.50
▪ HAD – Anxiety	7.04 ± 4.43
▪ HAD – Depression	7.70 ± 3.81
<b>Self-reported hearing disability acceptance (HDAQ; M ± SD)</b>	36.88 ± 7.85
▪ HDAQ – Activity engagement	22.72 ± 4.36
▪ HDAQ – Avoidance and suppression	14.16 ± 4.65

## Paper IV

Paper IV includes a cross-sectional quantitative study aimed at developing a self-reported measure of hearing disability acceptance and to study its construct and concurrent validity.

### *HDAQ factor structure*

In the first instance, the PCA resulted in a 3 factor model for the 12-items. However, cross-loadings were noted for a few items (i.e., items for which two or more factors loaded at an eigenvalue of .40 or above). PCA was also performed using Direct Oblimin rotation which also resulted in cross-loading of items. In the next stage, items which resulted in cross-loadings were removed from analysis until no cross-loadings were found which resulted in removal of 5-items in the original 12-item scale (see Appendix 1). Subsequently, the 7-item HDAQ resulted in a two-factor model with no cross loading and no outliers (see Table 6). The sampling adequacy was assessed with KMO statistics, with a value of 0.82. The two factors explained 75% of variance in the HDAQ. The first factor accounted for 42.94% of the variance and the second factor accounted for 32.75%. The factors were named: (1) *activity engagement* – defined as the pursuit of life activities regardless of hearing disability; and (2) *avoidance and suppression* – defined as the attempts to avoid difficult listening situations and attempts to control and suppress thoughts and feeling related to hearing disability. For the factor '*avoidance and suppression*' a low score indicates more avoidance and suppression, as the items are reversed in the scoring. Cronbach's alpha was 0.90 for factor 1, 0.82 for factor 2 and 0.86 for the overall HDAQ, showing good internal consistency.

**Table 6: HDAQ principle components analysis (n=90)**

<b>Scale: 7-item HDAQ</b>	<b>Factor 1: Activity engagement</b>	<b>Factor 2: Avoidance and suppression</b>
<b>Item 1</b>	0.85	
<b>Item 2</b>	0.89	
<b>Item 3</b>	0.86	
<b>Item 4</b>	0.76	
<b>Item 5</b>		0.88
<b>Item 6</b>		0.86
<b>Item 7</b>		0.73
<b>Cronbach's alpha</b>	0.90	0.82
<b>Percentage of variance</b>	42.9	32.7
<b>Eigenvalue</b>	3.0	2.3

Further, PCA was performed in the split samples to study the generalizability (i.e., split sample validation). The sample of 90 was randomly divided into two groups of 45 each. PCA for the first group (sample of 45) with 12-items resulted in a three factor model with cross-loadings. However, the PCA with 7-items after removal of items with cross-loadings resulted in a two-factor structure which explained 76.4% of variance with no cross-loadings. PCA was also performed on the second group (sample of 45) which also resulted in two factor structure which explained 75.9% of variance. The results from both split samples and the full sample were in close agreement (see Table 7), strongly supporting the two factor structure.



**Table 7: Split sample validation for 7-item HDAQ**

	Full sample (n=90)	Split sample 1 (n=45)	Split sample 2 (n=45)
<b>Percentage variance explained</b>			
▪ Factor 1	42.94	43.48	44.13
▪ Factor 2	32.75	32.93	31.80
▪ Combined	75.69	76.41	75.93
<b>Eigenvalue</b>			
▪ Factor 1	3.0	3.0	3.0
▪ Factor 2	2.3	2.3	2.2
<b>Cronbach's alpha</b>			
▪ Factor 1	0.90	0.83	0.82
▪ Factor 2	0.82	0.89	0.90
▪ Combined	0.86	0.88	0.86

***Correlation among HDAQ and other scales***

Table 8 shows the Pearson's correlation coefficients between HDAQ and other scales. The results suggest a moderately strong negative but statistically significant correlation between acceptance and hearing disability, moderate negative but statistically significant correlation between acceptance and anxiety and depression, and a weak negative but statistically significant correlation between acceptance and readiness to change. This may suggest that those with higher hearing disability acceptance had lower self-reported hearing disability, lower self-reported anxiety and depression, and lower readiness to change. Also, a weak positive but statistically significant correlation was observed between self-reported hearing disability and self-reported anxiety and depression, indicating that those with higher self-reported hearing disability are likely to have higher self-reported anxiety and depression.

**Table 8: Correlation among different scales** (\* indicates a significant correlation with  $\alpha < 0.01$ )

	HDAQ	HDAQ - 1	HDAQ - 2	HHQ	HADS	URICA-R
<b>Self-reported hearing disability acceptance (HDAQ)</b>	1.00					
<b>HDAQ Factor 1: Activity engagement</b>	0.86*	1.00				
<b>HDAQ Factor 2: Avoidance and suppression</b>	0.88*	0.51*	1.00			
<b>Self-reported hearing disability (HHQ)</b>	-0.70*	-0.50*	-0.71*	1.00		
<b>Self-reported anxiety and depression (HADS)</b>	-0.58*	-0.62*	-0.39*	0.36*	1.00	
<b>Readiness to change (URICA-R)</b>	-0.27*	-0.26*	-0.29*	0.20	0.18	1.00

## **Paper V**

Paper V includes a cross-sectional quantitative study the aim being to investigate the health behaviour change characteristics based on the transtheoretical stages-of-change model, in adults noticing hearing difficulties but not using hearing aids using the URICA scale. Table 5 shows the sample characteristics. The current study sample varied in a number of ways (e.g., country of study, sample population, and average age of the study sample) when compared to a previous study by Laplante-Lévesque et al. (2013). The average age of participants in the current study was significantly lower than the participants' average age in the previous study [ $t(89) = -6.56, p < 0.001$ ].

### ***Analysis according to stage scores***

As predicted, a high percentage of participants (over 90%) in this study had highest scores in the contemplation and preparation stages, compared to the previous study where most participants (about 80%) were in the action stage (Laplante-Lévesque et al., 2013). These differences were also apparent from the stages-of-change scores. For example, in the current study the participants had higher mean scores in contemplation and preparation stages when compared to the previous study where participants had high mean scores in the action stage.

### ***Analysis according to composite scores***

The readiness to change composite score was 39.4 and committed action composite score was -4.2 in the current study sample. Pearson's correlation coefficient was performed to study the correlation among URICA composites with other factors. The readiness to change composite showed a moderate positive statistically significant correlation with the committed action composite [ $r(90) = .33, p < 0.01$ ] and a weak negative and statistically significant correlation with self-reported hearing disability acceptance [ $r(90) = -.27, p < 0.01$ ]. This indicates that URICA scores relate well to committed action composite scores and hearing disability acceptance measure. However, no statistically significant correlation was observed among other variables.

### ***Analysis according to the stage with the highest scores***

Table 9 shows scores for various factors according to the stage with the highest scores. The precontemplation stage was excluded from analysis as no participants in this study were found to have highest score in this stage. No statistically significant differences were observed among groups of stage with highest scores and factors such as: years since hearing disability, self-reported hearing disability, self-reported anxiety and depression, self-reported hearing disability acceptance and committed action composite. However, the participants with the highest scores in the action stage had significantly higher readiness to change composite scores when compared to participants with the highest score in the preparation stage,  $t(47) = -2.17, p < 0.05$ .

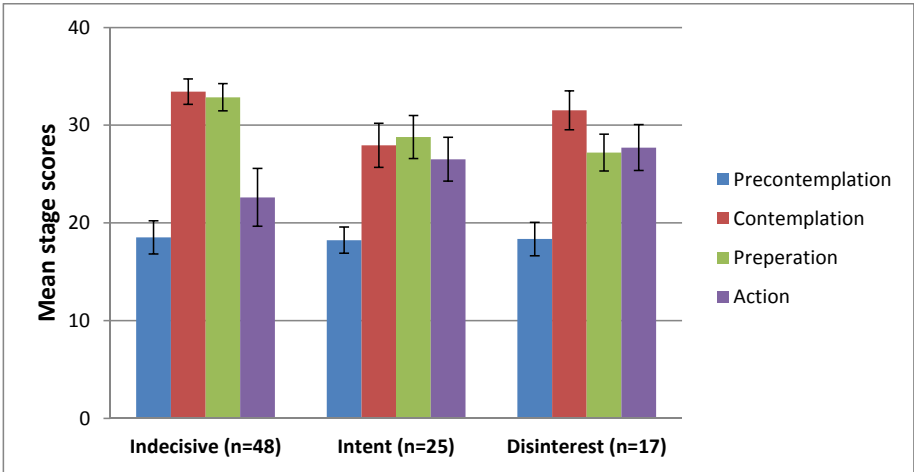
### ***Analysis of stages-of-change clusters***

Hierarchical cluster analysis was performed using Ward's method and standardised Z-scores to identify the stages-of-change clusters in the sample participants. Cluster analysis can identify individuals who share similar characteristics in the same group when compared to other groups (i.e., sub-grouping individuals in a sample based on a set of criteria). Inspection of the dendrogram identified three unique clusters. Figure 6 shows the mean stage scores for each of the clusters. Based on the profiles they represent, they were named as: (1) indecisive; (2) intent; and (3) disinterest. Scores of

the precontemplation stage did not vary among the three groups. However, differences in other stage scores (contemplation, preparation and action) made the groups distinct.

**Table 9: Years since hearing disability, self-reported hearing disability, self-reported anxiety and depression, self-reported hearing disability acceptance, readiness to change composite and committed action composite according to stage with highest scores (NA – not applicable as n=0 in this stage)**

	Precontemplation (n=0)	Contemplation (n=41)	Preparation (n=43)	Action (n=6)
Years since hearing disability (M ± SD)	NA	11.49±8.4	12.07±12.97	10.00±10.52
Self-reported hearing disability (HHQ) (M ± SD)	NA	35.46±11.38	34.91±8.85	31.83±7.41
Self-reported anxiety and depression (HADS) (M ± SD)	NA	15.63±7.09	13.65±7.35	16.83±11.12
Self-reported hearing disability acceptance (HDAQ) (M ± SD)	NA	35.80±8.14	37.84±7.61	37.33±7.94
Readiness to change composite (Scores ± SD)	NA	40.27±8.80	37.74±8.51	45.50±4.88
Committed action composite (Scores ± SD)	NA	-4.49±18.10	-4.09±5.47	-3.00±2.53



**Figure 6: Stages-of-change clusters according to cluster analysis (Note: Error bars represent standard deviation)**

## Discussion of Quantitative Studies (Papers IV & V)

Papers IV and V were focused on acceptance of hearing disability and stages of change in adults noticing hearing difficulties but not using hearing aids.

### *Acceptance of hearing disability*

Some researchers have identified the usefulness of psychological acceptance in reliving the impact of chronic health conditions (McCracken & Vowles, 2006; Westin et al., 2011, Hayes, Villatte, Levin, & Hildebrandt, 2011; Hesser et al., 2012). Paper IV offers the first attempt of extending this concept to hearing disabilities. This study showed that HDAQ has a two-factor structure, in line with the TAQ (Westin et al., 2008) and some of the similar self-report measures related to acceptance (Bond & Bunce, 2003). Internal consistency is equal to that of the commonest general acceptance scale, the AAQ-I (Hayes et al., 2004). The first factor, *activity engagement*, is assumed to entail in what way the subject maintains a desired level of activities even though facing obstacles. For example, a low level of activity engagement can be described by a person who stops going with his or hers friends to visit restaurants due to fear of not being able to follow the conversation in that context. The other factor, avoidance, can be described as the unwillingness to experience events because of the related emotional harm that the event causes. This concept can be thought of as the opposite of acceptance (Hayes, Strosahl, & Wilson, 2012).

The items in the current acceptance scale (i.e., HDAQ) were taken from the scale used for studying acceptance in people with tinnitus, which originates from general acceptance questionnaires (i.e., AAQ & CAQ-R). Although there are most likely differences in how people may cope with 'tinnitus' and 'hearing disability', there are similarities on how people cope with chronic conditions in general and acceptance is proposed to be key component of adjustment to a disabling condition (Li & Moore, 1998). For this reason, studying the construct 'acceptance' in various chronic conditions including 'hearing disability', within a general framework as defined and used in psychology would be valuable to both researchers and clinicians.

The study results indicate that lower acceptance was associated with increased emotional distress. This relationship between the HDAQ and HADS is interesting when compared to similar studies that have pointed to the pivotal role of acceptance in relationship to suffering. For example, acceptance is known to be a greater predictor of psychosocial disability rather than the degree of experienced pain in patients with chronic pain (McCracken, 1998). Studies have also found that greater acceptance is related to psychological well-being (Ruiz, 2010). In paper IV, greater acceptance was correlated with a more modest rating of one's hearing problems and could thus possibly serve as an analogue to the above-mentioned finding regarding pain. Also, a recent systematic review showed that self-reported hearing disability is one of the robust predictors of hearing help-seeking, hearing aid uptake, hearing aid use and satisfaction with hearing rehabilitation (Knudsen et al., 2010). This suggests self-reported hearing disability is an important factor in the process of accepting hearing loss and seeking appropriate intervention. Furthermore, problems with depression and anxiety were elevated in those who scored higher on the HHQ (i.e., self-reported hearing disability), which illustrates the far-reaching consequences a hearing loss might have. The relationship between HDAQ (i.e., acceptance) and readiness to change was both negative and significant, implying that those who were more accepting of their current

status were, in addition, less prone to seek a change of their current situation. This is possibly because the HDAQ measures acceptance more in line with psychological acceptance (i.e., recognising a condition without attempting to change it) rather than in help-seeking and hearing aid uptake. The association between HDAQ subscales and other factors did not differ much. This may be due to the fact that both subscales were found to have strong association with the full scale and moderate association among each other.

Overall, results from paper IV indicate that further exploration of the possible role of acceptance in the impact of, and willingness to adjust to hearing problems could be a fruitful endeavour, particularly in understanding what role the acceptance might play in the patient journey of PHI.

### ***Stages-of-change***

Paper V presents results of a stages-of-change measure and relates this measure to some additional factors of hearing disability and acceptance, as well as possible related factors of anxiety and depression in adults who are noticing hearing difficulties but not using hearing aids. As predicted by the stages-of-change model, most participants had their highest URICA scores in the contemplation or preparation stages. If the participants had been in denial, they may have been in the precontemplation stage. However, the fact that they were aware of difficulties and started to make efforts to seek information, and also, as shown by volunteering to participate in this study suggests that they were in contemplation or preparation stages. This is in contrast to previous studies in relation to hearing impairment where most participants were in precontemplation (Milstein & Weinstein, 2002) and also in action stages (Laplante-Lévesque et al., 2013).

There was a significant difference in URICA composite scores (i.e., readiness to change and committed action) between the current study population and those with hearing impairment seeking the help for the first time in previous study by Laplante-Lévesque et al. (2013). However, the study recruitment strategy (i.e., advertisement via national newspaper, charity websites, etc) may have attracted a mixture of participants from the general population and also those who decide to come to clinics for further help. This may have had some influence on the comparative results as the previous study by Laplante-Lévesque et al. (2013) was focused on the clinical population with confirmed hearing impairment. Also, statistically significant positive correlations were seen between readiness to change and committed action composites in paper V. Furthermore, no linear relationship was found between other factors such as duration of hearing disability, self-reported hearing disability, self-reported anxiety and depression, and self-reported hearing disability acceptance among groups based on the stage with highest scores. This may to some degree be related to not having any participants in precontemplation stage and having very few participants in the action stage. Nevertheless, these findings may raise some concerns about the concurrent validity of the stages-of-change measure. Further studies are necessary to evaluate if other factors have linear relationship with stages-of-change as indicated in the previous study (Laplante-Lévesque et al., 2013).

Cluster analysis identified three distinct stages-of-change clusters (see Figure 6), which included: indecisive, intent and disinterest. These were very different from the clusters

(i.e., active change, initiation, disengagement, ambivalence) reported by Laplante-Lévesque et al. (2013). However, some similarities and differences can be noticed when comparing these results to clusters reported with adults engaged in psychotherapy (McConaughy et al., 1983) and in people with arthritis (Keefe et al., 2000). In paper V, most participants were in the indecisive cluster (i.e., equal but significantly higher scores in contemplation and preparation stages when compared to action stage) and they are still probably not ready to take action, but rather they are seeking information. Approximately one fourth of the population were in the intent cluster (i.e., equal scores in contemplation, preparation and action stages with no statistically significant difference among these scores) who would probably be close to taking action. The rest of the participants were in the disinterest cluster (i.e., significantly higher values for contemplation stage scores when compared to preparation and action stage scores). People in this group may be thinking about the problem but not seeking information actively and this group may take longer to make a change. However, due to the cross-sectional design of the study no firm conclusions can be drawn about the longitudinal predictive validity of these findings.

Furthermore, some studies have highlighted that the staging algorithms in stages-of-change model might be based on arbitrary time periods and may not be measuring discrete stages-of-change (Sutton, 2001). A recent study on hearing impairment suggests that the change might be better represented as a continuum (i.e., stages-of-change scores and the cluster analysis results) rather than discrete stages (Laplante-Lévesque et al., 2013). Although these aspects need to be further explored, in general, paper V results support the stages-of-change model.

### ***Implications of the quantitative studies***

The quantitative studies (i.e., paper IV & V) could have number of applications. First, they provide information on a population about which not much is known (i.e., those who are noticing hearing difficulties in the general population). This could be useful information for various stakeholders such as the government, the hearing aid industry, hearing-related charities, who could use this information while planning hearing health awareness, promotion and education by developing targeted approaches to different groups of the population if these results are replicable in further studies. Second, it is common that some people with hearing difficulties who are not motivated to seek help come to see hearing healthcare professionals due to various other reasons (e.g., persuasion from CPs). For this reason it is important to better understand the characteristics of such population. Thirdly, paper V strengthens the results of qualitative studies (i.e., paper I; Manchaiah & Stephens, 2011b) indicating that there are four main stages in the initial parts of the patient journey of PHI (i.e., pre-awareness/precontemplation, awareness/contemplation, movement/preparation and diagnostics/action).

Furthermore, it is suggested in the literature that adults with hearing impairment take approximately ten years on average to seek help after they have started to notice hearing difficulties (Davis et al., 2007). However, an international online survey suggests that the number of years taken for those to help seek after they started noticing hearing difficulties does not have a normal distribution (Schum, 2012). Rather, the study identified clusters in the population showing a bimodal distribution, with some seeking help in the first few years (i.e., 1-3 years) and others taking action for the

first time after 10 years or more. This makes the average duration to be about 7 years. These findings suggest that there are different groups of people and it is important to identify those who are in the earlier stages (i.e., precontemplation, contemplation and preparation), to understand their acceptance of hearing impairment and readiness to change, and also provide them with necessary information which may help them to make appropriate decisions about hearing help-seeking. Finally, the validated scales such as HDAQ and URICA could be helpful in further research while studying constructs such as 'acceptance' and 'readiness to change'.

### ***Limitations of the quantitative studies***

Although papers IV and V focused on an important area where there is a dearth of literature, it has some limitations that were unavoidable, mainly due to the nature of the study population chosen. In paper IV, acceptance in relation to hearing disability has not been well-defined and this scale may only focus on some components of acceptance (i.e., more in line with psychological acceptance). This may, to some degree, explain why those with greater acceptance show less readiness to change. However, this is indeed an important component to understand as it may explain why many people who are aware of their hearing disability still refrain from seeking professional help and receive appropriate interventions. The HDAQ was found to have good construct (based on factor structure and internal consistency) and concurrent validity (based on its association with other scales). Although there are measures that study coping indirectly, there is no well-established acceptance scale to study the concurrent validity of the HDAQ with the same construct (i.e., acceptance). It would have also been interesting and useful to study the association between 'acceptance' and other constructs such as 'cognitive functions' and 'psychological well-being'. Furthermore, the predictive validity of the scale needs to be further explored.

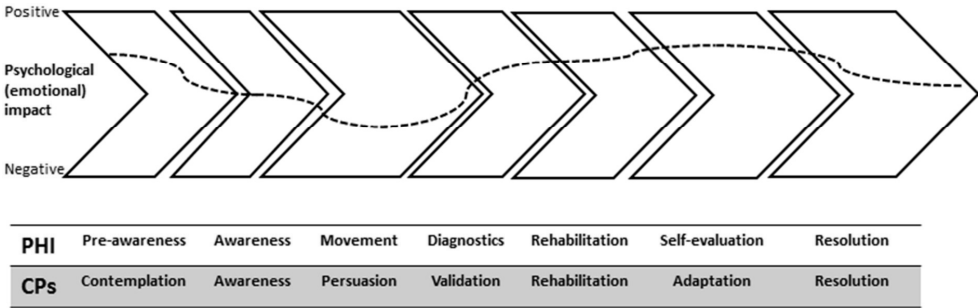
In papers IV and V, the data was collected using self-reported measures using the internet. This method of data collection may have eliminated people who do not have access to internet and also those who cannot use internet due to other disabilities (e.g., visual impairment) and may not be representative of the general population (Whitehead, 2007; Glasgow, Nelson, & Kearney, 2007). Even though this is a limitation, it is very challenging to reach this population who do not come to see clinicians. For this reason, and to obtain data from across the country this method was regarded as appropriate. Also, results obtained via an online format of questionnaire completion may not be identical to the pen-and-paper format (Thorén, Andersson, & Lunner, 2012), even if measurement characteristics tend to be the same or even better for internet administration (Buchanan, 2002). Additionally, results are only related to the sample population who are noticing hearing difficulties rather than those who are typically seen in clinical situations, even though there may be some overlap since nearly two-thirds of the current study sample had previously consulted hearing healthcare professionals. In paper V, comparison of results with the previous study by Laplante-Lévesque et al. (2013) may reveal some additional limitations due to the sample used (i.e., confirmed hearing impairment vs those who are noticing hearing difficulties). It was also limited in terms of the main factors included (i.e., stages-of-change, duration of hearing disability, self-reported hearing disability, self-reported anxiety and depression and self-reported hearing disability acceptance). Other factors such as attitude and motivation could have also been useful in better understanding the population characteristics.

**GENERAL DISCUSSION**

This thesis presents a series of qualitative and quantitative studies which focus on the patient journey, hearing disability acceptance and stages-of-change. These studies fit into the overall research aim of understanding the ‘process of change’ (or process evaluation).

The process evaluation refers to studying the experiences of a person with disability in the form of a timeline in order to understand the main phases/stages they go through during the disease and the treatment. Studies on the patient journey represent good examples of process evaluation (papers I-III; Manchaiah & Stephens 2011b). It can be argued that the use of outcome measures at multiple intervals may act as process evaluation (i.e., continuous monitoring of outcomes using outcome measures). However, devising a single measurement tool to capture different dimensions of outcome and process could be challenging.

It appears that in recent years studying the lived experiences of persons with disability has become popular. Also, there is an insistence from people with disabilities that their views should be heard or considered in all stages of research about their lives (Oliver, 1998; Barnes & Mercer, 1997). Studies on the patient journey represent one way of capturing the lived experiences of people with disability. In addition, such studies also explore the process of change by considering various experiences a person may have during the initial onset of the disease and realising that they have the condition, acceptance and help-seeking, assessment, rehabilitation and continued experience living with a particular disability. Reported experiences can be analysed to identify relevant themes and be represented in the way the themes reflect the data. Such an approach is often used in disability research while attempting to understand the lived experiences of a person. A recent international study on perspectives of adults with hearing impairment towards help-seeking and rehabilitation is a good example of such an approach (Laplante-Lévesque et al., 2012a). In a clinical setting this is done informally through the case history.



**Figure 7: Models of a person with hearing impairment (PHI) and their communication partner’s (CPs) journey through hearing impairment**  
 (Note: The various stages are not drawn to any scale with regard to duration, and time spent in each stage may vary between individuals. Also, the dotted line representing the psychological impact is hypothetical)



The Ida Institute initially developed the possible patient journey of PHI and their CPs by considering the professionals' perspective (Ida Institute 2009, 2012). Papers I and III further developed these models by considering perspectives of PHIs and their CPs. These models are indicated in Figure 7 which demonstrates the main phases the PHI and their CPs go through from the initial onset of the disease, diagnosis, treatment and then continuing to live with the hearing impairment. It is important to note that the various stages in the model are not drawn to any scale and the progression from one phase to other may vary from person to person quite considerably (i.e., several days to several years). Even though the above model demonstrates the process of change from the perspective of PHI and their CPs, it does not measure the intensity at which they are affected at any one stage/point. For this reason, outcome measures would be helpful in measuring the intensity at which the person is affected at any point of time.

Furthermore, a preliminary model of patient journey of sudden-onset acquired hearing impairment was developed (i.e., paper II). There were differences and commonalities in perspectives of patients and professionals, but both identified all six main phases. The initial assumption was that the patients with sudden-onset hearing loss would have a significantly different journey when compared to patients with gradual-onset hearing loss. However, the main difference was the absence of a pre-awareness phase in sudden-onset acquired hearing impairment. This may suggest that the pre-awareness phase may hinder the realisation of hearing loss in persons with gradual onset hearing loss, whereas it is for more straightforward in persons with sudden-onset due to its nature of onset.

The phases represented in these patient journey studies related to hearing impairment seem to relate well with the stages-of-change model which was proposed in relation to health behaviour change (Prochaska & DiClemente 1983; Prochaska & Velicer 1997). This theory suggested that health behaviour change involves six main stages, which include: precontemplation, contemplation, preparation, action, maintenance and termination. This model is cyclic or spiral model, rather than linear, which accounts for relapse and a re-start. Such a model could be helpful for understanding the process of change through a disease and its treatment. Although paper V only focused on initial parts of the PHI journey, the findings support the stages of change model. The four stages (Laplante-Lévesque et al., 2013) in this model (i.e., pre-contemplation, contemplation, preparation and action) relate well to initial phases (i.e., pre-awareness, awareness, movement and diagnosis and action) in qualitative studies of PHI journey (paper I; Manchaiah & Stephens 2011b).

Both acceptance and stages-of-change are important factors in help-seeking and hearing rehabilitation. However, as mentioned in earlier sections, 'acceptance' in audiological terms is different to the definition in psychological terms. In paper IV, which was focused on acceptance in terms of experiential avoidance, it was evident that acknowledging the hearing disability and learning to manage and live with the condition does not mean that individuals are ready to seek help (i.e., negative correlation between hearing disability acceptance and readiness to change constructs). For this reason, it is important to further explore the role of acceptance (both in audiological and psychological terms) in help-seeking and rehabilitation outcomes of PHI. However, in paper V it was noted that most participants in the current study were in contemplation and preparation stages and also that participants with highest scores

in the action stage had significantly higher *readiness to change* composite scores. This indicates that the stages-of-change model could help us understand the progression of a patient in terms of help-seeking. In adults with hearing impairment seeking help for the first time, stages-of-change scores were associated with intervention uptake and successful outcome (Laplante-Lévesque, Hickson, & Worrall, 2012b), although they were not associated with intervention decisions (Laplante-Lévesque, Hickson, & Worrall, 2011). However, studies related to 'acceptance' and 'stages-of-change', due to its cross-sectional design did not allow us to predict any outcomes (i.e., papers IV & V).

Moreover, in papers IV and V it is interesting to note that, even though participants were not using hearing aids, two-thirds of the study sample had consulted a hearing healthcare professional on at least one occasion. The reasons for their consultation are likely to be: (1) having accepted their condition (i.e., hearing disability); (2) in a dilemma of whether or not they have the condition and wanted to confirm this with clinicians; or (3) persuasion from their CPs. However, reasons for non-consultation from some participants could be that they feel there is no need to hear everything and they may demand adaptation from their others (e.g., CPs). Alternatively they may feel that they know their friends and family well and what they hear is sufficient to understand them. Although the reasons for non-consultation and for not using intervention (e.g., hearing aids) are not clear, it may be related to their perceived seriousness of their hearing problems. Previous research suggests that there is no linear relationship between hearing disability and its effects on activities and participation (Swan & Gatehouse, 1990), which may help explain why not all people with hearing disability may uptake interventions. This may highlight the importance of studying hearing disability acceptance more in line with psychological terms. Besides, it is also important to note that an individual becoming suspicious or aware of their hearing disability does not mean that they perceive their difficulties to be significant enough to affect their communication and quality of life. This is something clinicians must be aware of when they are planning and making recommendations about interventions, especially for patients who are coming to the hearing clinic for the first time. Also, much work is needed to understand how 'hearing disability acceptance' may either facilitate or hinder the journey through this condition.

Overall, it is important to note that even though the approaches discussed above provide similar information (i.e., patient journey, stages-of-change and acceptance), they give different perspectives in understanding the same condition. It can be argued that the combination of such approaches may give better understanding of a person with disability than any one approach alone.

### ***Study Implications***

The studies on the journey of PHI and their CPs and also the studies on hearing disability acceptance and stages-of-change may have various clinical and research implications.

Firstly, patient journey studies may help us see the patients from a different perspective (i.e., in the time domain). For example, it has been suggested that the patient with hearing loss can be broadly categorised into 4 groups based on their rehabilitation types (Stephens & Kramer, 2009), which include: (1) Positively motivated without complicating factors; (2) Positively motivated with complicating factors; (3) Want help,

but reject a key component; and (4) Deny any problems. The above classification suggests that there are four unique groups of patients. However, looking at the same patients using the journey model of PHI (paper I), it can be suggested that the patients in category 3 could be in the movement and/or diagnostic phase and the patients in category 4 could be in pre-awareness phase (Manchaiah, 2012). Even though it is challenging to prove which of this is more accurate and there may be an overlap, the patient journey model helps account for the natural progression of patients in terms of help-seeking over time. Furthermore, qualitative studies discussed in this thesis identified new phases (i.e., self-evaluation and adaptation) within the journey of both PHI & CPs (papers I & III). Although self-assessment of hearing in PHI may occur before, during and after help-seeking for the hearing problems (Carson, 2005), papers I and II suggested that soon after the hearing assessment and rehabilitation session they spend a significant amount of time self-evaluating their problems and if the audiological rehabilitation has made a difference. These findings strengthen the arguments for frequent and regular follow-up soon after the intervention to provide necessary support.

Secondly, some inspirations about the use can be drawn from similar concepts in other areas of social sciences. For example, the concept of “product life cycle” refers to the stages through which product or its category passes, which may include stages such as: introduction to the market, growth, maturity and decline (Segerstrom, Anant, & Dinopoulos, 1990; Klepper, 1996). This model provides important information about the product in the temporal dimension even though the length of each cycle in each product varies greatly. Despite the shortcomings that it may be difficult to identify where the product is in its life cycle and almost impossible to know with certainty when a product moves from one stage to other stage, the model is still very popular in the area of marketing and business management in formulating strategy. With a similar idea, the patient journey model could be helpful as a theoretical framework for clinicians to formulate intervention strategies. For example, perhaps it may be a good strategy to provide information and motivate people in early stages of their journey (e.g., pre-awareness and awareness) rather than offering them treatment recommendations (e.g., hearing aids) straight away which may often result in non-compliance with such recommendations.

Thirdly, patient journey studies can help us understand the facilitators and barriers to the help-seeking process. For example, in paper II which was focused on developing the patient journey model of sudden-onset acquired hearing impairment, it was reported that medical professionals did not always give the patients correct information about the condition and expected prognosis. This raises some general, ethical and legal issues and potentially delays the patients progressing in their journey through hearing loss (Manchaiah, Stephens, & Lunner, 2012b). In addition, considering the diverse nature of experiences reported by PHIs the patient journey model of sudden onset hearing impairment highlighted the need for taking an ideographic approach in order to better understanding the extent to which psychological and emotional impact between individual patients (paper II).

Fourthly, these models could be helpful in training hearing healthcare professionals and also in promoting discussion with patients and their family members. However, the usefulness of these models in counseling has to be further explored. A recent study

suggested that the patient journey model by itself may not be very popular with patients as a counseling material (Manchaiah et al., 2013c). Considering this the possibility and effectiveness of using these materials in addition to other information typically provided (e.g., disease specific, technical, treatment options, etc) during counseling needs to be further explored.

Fifthly, the quantitative studies (i.e., paper IV & V) on 'acceptance of hearing disability' and 'stages-of-change' may provide secondary evidence to the process of help-seeking and the journey through hearing impairment. Understanding these characteristics in different populations (e.g., those who may have difficulties but not conscious awareness of them, those noticing hearing difficulties but not actively seeking help, those who are noticing difficulties and actively seeking help, those with successful hearing rehabilitation and those with unsuccessful rehabilitation and or significant residual problems) are necessary in order to get a better picture of what may happen to people with hearing disability through their journey through initial onset of the disease to continuing to live well with such a long standing chronic condition. As suggested in paper IV, accepting hearing disability does not mean that the people with hearing disability are ready seek-help and adopt intervention strategies. For this reason, it is important to study various dimensions of acceptance and how they may relate to patient journey process.

Lastly, even though studies on the patient journey uncover important information about the process of change in persons with disability and factors influencing them, they may not capture the intensity to which each person is affected at one point of time. This may highlight the importance of using appropriate outcome measures. Also, it is important to note that even though both 'process evaluation' based on patient journey studies and the 'outcome measurements' provide similar information, they give different perspectives in understanding the same condition. It can be argued that the combination of such approaches may give better understanding of a person with disability than any one approach alone. Further, it is also important to establish a link between such combined approaches in order to better understand what information they are specifically providing.

### ***Methodological Considerations and Future Directions***

Process evaluation can be studied and understood from perspectives of person with disability, their significant others, clinicians and in the wider context of society. However, it is important to note that priorities from each of these perspectives could be different. For example: (a) for people with disability and their significant others – their activity, participation and quality of life could be key factors; (b) for clinicians - cure of impairment, reducing disability and to some extent quick fix to the problems reported could be important; and (c) for society - less dependency of people with disability on society and a larger contribution from them could be important. Even though it is difficult and to some extent impossible to answer which of these perspectives are more important, considering the emphasis on 'shared decision making' in recent years, the combined approach could be helpful. Moreover, the process of change can also be evaluated from different analytical levels, which may include: biological, psychological, psychosocial, and socio-economic (Manchaiah et al., 2013a). Papers presented in this thesis (i.e., papers I-III) have focused on the individual level by studying the reports of the PHI, their CPs and clinicians.

In this thesis, the *process of change* has been approached from a health behaviour point of view using theories such as stages-of-change and other concepts such as acceptance. However, much work has been done in the areas of business, economics and marketing in relation to consumer decision making behaviour which stem from 'theory of consumer behaviour' (Blackwell, Minard, & Engle, 2006). The studies from such an approach have focused on individuals, groups and organisations and the process involved in decision making behaviour. Although some similarities exist among qualitative studies in this thesis (papers I-III) and how consumer behaviour has been investigated using consumer behaviour theory, it would be useful and interesting to approach the 'patient journey' from this theoretical viewpoint.

In addition, the patient journey model of PHI and their CPs was developed based on the perspectives reported retrospectively (Papers I-III; Manchaiah & Stephens, 2011b). Although, this method is convenient, it has some limitations. For example, reported experiences may have been influenced by various aspects including perceptions and reconstructive memory functions of the individuals. Considering that the journey of PHI and their CPs may take several years, longitudinal designs may be more appropriate. Also, the qualitative studies had relatively small sample sizes and evaluating such models in a large population is necessary. In addition, the journey of PHI and CPs were studied separately. It would be interesting to study the journey with a couple with the emphasis on understanding how they may influence each other's journey.

In the current thesis (i.e., papers I-III), choice has been made to present the reported experiences in a logical order (i.e., in the time domain) using the process mapping approach. This choice was made as many patients reported the experiences in a chronological order even though not all of them presented their story in that way. A recent international study suggested that patients do not always describe their experiences as a chronologically-ordered series of steps relating to a common goal (Laplante-Lévesque et al., 2012a), which is contrary to the results of qualitative studies presented in this thesis. However, this may have been influenced by aspects such as: the type of questions asked during the interview process; and if the participants were given information about the study well in advance so that they had the opportunity to think about their journey before attending the interview. Furthermore, the previous study suggests that "*participants who reported awareness of steps in hearing help-seeking and rehabilitation usually did so when considering chronological personal events such as gradual awareness of hearing difficulties and self-adaptation to hearing aids*" (Laplante-Lévesque et al., 2012a, p. 102). In this thesis, the patient journey was studied based on the individual's personal experiences through the process of help-seeking and hearing rehabilitation. This may, to some degree explain why participants reported their experiences as a process unlike the previous study. Also, this discussion highlights that the methodology employed may significantly influence the results obtained.

Studies with the stages-of-change model suggest that the change might be better represented as a continuum rather than movements in discrete stages (Laplante-Lévesque et al., 2013). However, the discrete stages might be useful to understand the change in a simple way and also for counselling purpose as suggested in studies on the journey of PHI and CPs (papers I-III; Manchaiah & Stephens, 2011b). In addition, considering that the stages of change model could predict the 'readiness to change' and

'committed action' in different populations, such composites could help the clinicians to plan the treatment strategy for different groups of patients. However, further studies are necessary to determine feasibility. Further studies are also necessary to establish if there is a linear relationship between the stage with highest scores and composites scores such as 'readiness to change' and 'committed action' and also with other factors such as self-reported hearing disability and self-reported anxiety and depression.

Studies on 'hearing disability acceptance' and 'stages-of-change' employed a cross-sectional design (i.e., papers IV & V). Although they provide important information and add to the limited literature in this area, much work needs to be done using longitudinal and experimental designs with focus on predictive validity of the scales (i.e., HDAQ, URICA) and the models used (i.e., stages-of-change). Primarily, a coherent theoretical framework is needed that accounts for what role, if any, acceptance may play in the adjustment to hearing problems. One cannot simply assume that successful management of other conditions that involve the introduction of painful experiences (e.g., tinnitus, chronic pain, anxiety) is relevant to hearing disability that instead is characterized by the loss of (auditory) experiences. Also, the scientific legwork of examining the longitudinal stability of the concept, its relevancy to objective measures of hearing disability, the utility of the current structure of the HDAQ, as well as if it can be successful in alleviating the suffering that is usually connected to hearing disability remains to be further explored. Furthermore, the population used in qualitative studies (i.e., papers I & II – confirmed hearing impairment) and quantitative studies (i.e., papers IV & V – those noticing hearing difficulties) varied. For this reason, further studies need to explore if the results of paper IV and V are replicable with a sample of individuals with confirmed hearing impairment. Such studies may help in further developing the audiological enablement/rehabilitation models currently in practice (Stephens & Kramer, 2009).

Theoretical developments and the experimental work in the area of psychology of time with focus on the 'time perspective' attempt to categorise people by how they differ in their perception of time (Grondin, 2008; Hancock & Block, 2012). In other words how individuals may vary in how they orient themselves towards, think about and value the future. It is suggested that the time perspective of an individual influences the way that they live their life, especially the decisions and choices they make. There are examples of studies with time perspectives in other health conditions (Rothspan & Read, 1996; Keough, Zimbardo, & Boyd, 1999; Adams & Nettle, 2009). However, the applications of time perspective in the 'process evaluation' and/or 'patient journey' of PHI and their CPs needs to be further explored. In particular, it would be worthwhile investigating if the time perspectives of different PHI would be used as a predictor of their help-seeking behavior and rehabilitation outcome.

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**APPENDICES**

**Appendix 1:  
Hearing Disability Acceptance Questionnaire (HDAQ)**

**Direction**

Below you will find a number of statements. Please rate the truth of each statement as it applies to you. Use the following rating scale to make your choices:

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>
Never true	Very rarely true	Seldom true	Sometimes true	Often true	Almost always true	Always true

For instance, if you believe a statement is “Often true”, you would circle number 5 on the row following the statement.

**Items**

1. I am leading a full life, even though I have hearing problem...
2. My life is going well, even though I have hearing problem ...
3. Despite hearing problem, I can draw up and stick to a certain course in my life....
4. When my hearing problem increases I can still take care of my responsibilities...
5. My hearing problem leads me to avoid certain situations...
6. My hearing problem changes me as a person...
7. I spend a lot of time thinking about how things would be for me, without a hearing problem...

**Scoring**

Reverse score items: 5, 6 & 7.

**Removed items**

- My hearing problem has led me to decrease my engagement in former activities...
- It is necessary for me to control my negative thoughts and feelings concerning my hearing problem....
- I will be in better control of my life if I can control my negative thoughts about my hearing problem....
- I have to struggle to get things done when I have a hearing problem ...
- I strive to suppress aversive thoughts and feelings related to my hearing problem...

## Appendix 2: University of Rhode Island Change Assessment (URICA) Scale

### URICA items with four stages as defined by Laplante-Lévesque et al. (2013)

Original 24-item URICA scale had three stages (precontemplation, contemplation and action) in which both contemplation and preparation stages were grouped together as contemplation stage.

#### ***Precontemplation stage***

- As far as I'm concerned, I don't have any hearing problems that need changing. (1)
- I'm not the problem one. It doesn't make much sense for me to be here. (5)
- Being here is pretty much a waste of time for me because the hearing problem doesn't have to do with me. (9)
- I guess I have faults, but there's nothing that I really need to change. (11)
- I may be part of the hearing problem, but I don't really think I am. (18)
- All this talk about psychology is boring. Why can't people just forget about their hearing problems? (21)
- I have worries but so does the next guy. Why spend time thinking about them? (22)
- I would rather cope with my faults than try to change them (24)

#### ***Contemplation stage***

- I think I might be ready for some self-improvement. (2)
- It might be worthwhile to work on my hearing problem. (4)
- I have a hearing problem and I really think I should work at it. (13)

#### ***Preparation stage***

- I've been thinking that I might want to change something about myself. (7)
- I'm hoping this place will help me to better understand myself. (10)
- I wish I had more ideas on how to solve the hearing problem. (15)
- Maybe this place will be able to help me. (17)
- I hope that someone here will have some good advice for me. (19)

#### ***Action stage***

- I am doing something about the hearing problems that had been bothering me. (3)
- I am finally doing some work on my hearing problem. (6)
- At times my hearing problem is difficult, but I'm working on it. (8)
- I am really working hard to change. (12)
- Even though I'm not always successful in changing, I am at least working on my hearing problem. (14)
- I have started working on my hearing problems but I would like help. (16)
- Anyone can talk about changing; I'm actually doing something about it. (20)
- I am actively working on my hearing problem. (23)

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