RESPONSE SHIFT AND DENTINE HYPERSENSITIVITY

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Abstract

Objectives: Response shift refers to the changes in the meaning of self-evaluation of quality of life (QoL) as a result of changes in internal standards of measurement (recalibration), changes in relative importance of component domains of quality of life (reprioritisation) or redefinitions of QoL (reconceptualisation). Response shift can therefore undermine the comparison of QoL within individuals over time and between individuals, for example when assessing treatment effects. The aim of this research was to investigate response shift in people with dentine hypersensitivity (DH).

Methods: Two studies were conducted. A quantitative study investigated recalibration and its influence on the assessment of treatment effect in 114 participants of an 8-week randomised controlled trial of mouthwashes for DH. Two approaches: the THEN TEST and a novel approach; the IDEALS were incorporated into the Dentine Hypersensitivity Experience Questionnaire (DHEQ) to assess recalibration. A qualitative study longitudinally explored response shift and its underlying psychosocial mechanisms in 20 individuals with self-reported DH. Two semi-structured interviews were conducted 6-9 months apart and Framework analysis was used to analyse the transcripts.

Results: The quantitative study found recalibration in the treatment groups. The THEN TEST indicated a downward shift in participants' internal standards of measurement whereas the IDEALS suggested a shift upwards. Individuals shifted upwards, downwards and not at all. Additionally, recalibration was similar in the treatment and placebo groups. Accounting for recalibration reduced the apparent treatment effect in all groups. In the qualitative study two main findings emerged. First, the study described adaptation to DH and its influence on the assessment of oral health related quality of life (OHQoL). Second, a modified model of response shift emerged that distinguished between the influence of adaptation and measurement error on the assessment of QoL.

Conclusion: The two studies described response shift, its psychosocial determinants and influence on the assessment of treatment effects in people with DH as an example of a mild health condition. Moreover, the two studies challenged the current conceptualisation and the dominant approach to the measurement of the phenomenon. A modified model of response shift was proposed and a novel way of its assessment, the IDEALS was initially validated.

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Abbreviations

DH	Dentine hypersensitivity
DHEQ	Dentine Hypersensitivity Experience Questionnaire
PGI	Person Generated Index
MID	Minimally Important Difference
OHQoL	Oral health quality of life
QoL	Quality of life
Q-TWiST	Quality-Adjusted-Time Without Symptoms and Toxicity
SEIQoL	The Schedule for the Evaluation of Individual Quality of Life
SEM	Structural Equation Modelling

1 Introduction

Oral health quality of life (OHQoL) has been increasingly used in dentistry to assess impacts of oral health and disease on the person's everyday life and as an outcome measure to evaluate oral health care (Locker and Allen, 2007). Use of OHQoL adds value because it introduces a person-centred perspective and allows for representations of the impacts of oral conditions on peoples' quality of life. However, assessment of OHQoL can be problematic. People's understanding of what quality of life means to them, can change, thus threatening the validity of comparisons of OHQoL between individuals and within individuals over time. The concept of response shift offers an explanation of how the meaning of one's self-evaluation changes over time as a result of recalibration, reprioritisation or reconceptualisation and how this shifts affect the assessment of change in OHQoL.

Dentine hypersensitivity (DH) is characterised by episodes of pain in the teeth in response to external stimuli (Dababneh *et al.*, 1999). However, the impacts of DH go beyond the experience of pain to include impacts on: eating, drinking, talking, tooth brushing and social interactions (Gibson *et al.*, 2010). As these impacts cannot be captured solely by clinical indicators, it is important to use subjective measures such as OHQoL to capture the effect of the condition on the everyday life of an individual. Response shift is very relevant for people with DH. First, the central role of the person in identifying the subjective experiences of pain and other impacts make the condition susceptible to response shift. Second, response shift might play a role in evaluations of treatments, either as a part of formal assessment in clinical trials, or informally for example when purchasing a new oral care product. Third, the availability of a precise and valid measure of OHQoL for people with DH (the DHEQ) allows the examination of response shift. Finally, response shift has predominantly been studied in relation to severe and life threatening conditions. Therefore, investigating response shift in relation to relatively mild health condition, such as DH, will provide insights into the role of the phenomenon in many more minor conditions.

The aim of this research was to investigate response shift in people with DH.

This thesis is structured as follows:

Chapter Two reviews the literature on response shift and on DH. The chapter starts with a review of DH in terms of its prevalence, impacts on quality of life, diagnosis, aetiology and treatment. This is followed by a section introducing the theory regarding response shift and the model of response shift. The subsequent sections present results of a structured review of empirical studies of response shift, review the psychosocial contributors to response shift and detail the available approaches to the measurement of the phenomenon. The chapter finishes by making recommendations for the current research and stating the aims of two studies to be undertaken.

Chapter Three describes a quantitative study of one type of response shift: recalibration in participants in a clinical trial for treatments for DH. This study aimed at examining recalibration and its attributes such as magnitude, direction and timing. Additionally, the study investigated the role of recalibration in the assessment of change in OHQoL during the trial and in the assessment of treatment effect. The study compared and validated two methods of measurement of recalibration: the THEN TEST and IDEALS.

Chapter Four presents a longitudinal qualitative study of response shift and its underlying psychosocial mechanisms in people with DH. Individuals with DH were interviewed to learn about their experiences of DH, how they adapt to DH and the impact of the conditions on their OHQoL. During each interview participants completed a measure of OHQoL for people with DH (i.e. the DHEQ) and were asked to describe how they approached answering the items from the measure. The cognitive process of answering the items (i.e. appraisal) was analysed to learn about its role in response shift.

Chapter Five discusses the findings and draws together conclusions from both studies.

Chapter Six highlights the major conclusions and summarises recommendations for research in response shift, research in DH and for the management of DH.

2 Literature review

2.1 Dentine hypersensitivity (DH)

Dentine hypersensitivity is a condition in which individuals experience episodes of short sharp pain in response to stimuli such as cold air or hot food. The concept of dentine hypersensitivity (DH) (also called dentine sensitivity) emerged at the beginning of the 20th century, although accounts of sensitive dentine can be traced back as far as 3000 years ago and can be found in Chinese and Babylonian writings (Rosenthal, 1990; Paul, 2011). Dentine hypersensitivity is a common condition and yet its mechanism, is not fully understood (Dowell and Addy, 1983; Bamise and Esan, 2011). For these reasons some refer to the condition as 'an enigma' (Dababneh *et al.*, 1999; Paul, 2011).

The currently agreed definition of DH states that:

> *'dentine hypersensitivity is characterised by short, sharp pain arising from exposed dentine in response to stimuli, typically thermal, evaporative, tactile, osmotic or chemical and which cannot be ascribed to any other dental defect or disease' (Canadian Advisory Board on Dentin Hypersensitivity, 2003, p. 221)*

The above definition repeats the definition proposed by Holland and colleagues (1997), but the original *'pathology'* was replaced with *'disease'*. Holland and colleagues' definition was formulated based on the suggestions by Dowell and colleagues (1985) after the international workshop for the design and conduct of clinical trials for the treatment of DH that took place in 1994.

Although the profession has accepted the term dentine hypersensitivity to describe the condition (Holland *et al.*, 1997), some continue to use the term dentine sensitivity (Dababneh *et al.*, 1999; Addy, 2005). Dababneh and colleagues (1999) argue that this term is more appropriate as there is no evidence that the dentine of person with DH differs in any substantial way from the normal dentine and that some degree of sensations can be expected from a normal tooth.

2.1.1 Prevalence

Dentine hypersensitivity has been reported to affect as many as 4% to 74% of the population (Graf and Galasse, 1977; Flynn *et al.*, 1985; Orchardson and Collins, 1987; Fischer *et al.*, 1992; Irwin and McCusker, 1997; Liu *et al.*, 1998; Gillam *et al.*, 1999; Clayton *et al.*, 2002; Rees and

Addy, 2002; West *et al.*, 2013). The estimates may vary according to the mode of data collection. Self-reported questionnaire studies report higher figures than studies based on clinical assessment. For example, one clinical study estimated the prevalence of the condition within the UK population to be as low as 3.8 - 4.1% (Rees and Addy, 2002). This contrasts with estimates by Gillam and colleagues (1999) who found, in a self-report study, that the prevalence of DH is as high as 52%.

Women report DH slightly more often than men (Fischer *et al.*, 1992; Gillam *et al.*, 1999), which might be linked to their higher health awareness (Dababneh *et al.*, 1999). Most people with DH are between 20 and 40 years old, and within this range, reports suggests that the majority of cases occur at the end of the third decade of life (Graf and Galasse, 1977; Flynn *et al.*, 1985). The prevalence of the condition seems to be higher among people with periodontal disease (Chabanski *et al.*, 1997), which is presumably associated with the exposure of dentine consequent to periodontal attachment loss.

It is possible that the prevalence of the condition will increase as more adults retain their teeth for longer so that there will be more exposed dentine to be affected. The popularity of teeth whitening products might also contribute to the increase. Moreover, people might become more aware of sensations in their teeth as a result of the increased advertising of desensitising oral health care products and information obtained from oral health professionals.

2.1.2 Dentine Hypersensitivity and Quality of Life

To date, most studies on DH have been conducted from a clinical perspective, focusing on such aspects as its aetiology, prevalence or modes of treatment. There has been little research exploring the impact of DH from patient-centred perspectives. Usually, inclusion of a patient's perspective has been limited to rating pain in response to stimuli in clinical settings (Gillam *et al.*, 2002; Rees and Addy, 2002; Taani and Awartani, 2002).

Nevertheless, Bekes and colleagues (2009) found that individuals with DH had poorer oral health and experienced more impacts that the general population. This study was performed in Germany with 656 individuals seeking treatment for DH in dental practices using an adapted version of OHIP-49. However, OHIP-49 is a generic oral health measure designed to capture a variety of impacts associated with oral health and might not be suitable for capturing the impacts of a specific condition (Wong *et al.*, 2007).

Gillam and colleagues (1999) administered a questionnaire on DH to 277 regular attenders of general dental practices in the UK. Among those experiencing some degree of sensitivity, 87%

were able to brush their teeth without discomfort. Drinking cold water was a source of discomfort to 28.2% and 26% were unable to eat ice cream without discomfort. Some of the results of this survey are difficult to explain. Whilst 52% of participants stated they had sensitive teeth, within the remaining sample 43% did not answer the question, and 1.8% declared they never experienced any sensations.

One qualitative study investigated personal and functional aspects of having DH, through semi-structured interviews with 23 adults with DH (Gibson *et al.*, 2010). Dentine hypersensitivity had a significant impact on the everyday life in areas such as: eating, drinking, talking, being outside on a cold day, tooth brushing and social interactions. Participants had problems performing these activities because of the sensations in their teeth. For example one participant reported limitations associated with eating and social interactions:

> *'If it comes [food] and it is too warm or too cold I have to wait which invariably means I delay everybody else at the table as I finish last. Or I end up only eating half the meal because everybody has finished and I am conscious of holding everybody else up'* (Gibson *et al.*, 2010, p. 16).

Functional impacts were often inseparable from the coping strategies participants employed to manage the condition. For example, one participant reported coping by restricting her diet:

> *'I just try to avoid having ice, too much ice in my drinks and you just sort of learn not to have things that set it off really and a bit like ice-cream, I will have the odd one'* (Gibson *et al.*, 2010, p. 16).

Participants used a variety of expressions, such as *sensations*, *needless* or *nails on a blackboard*, to refer to the symptoms of DH. The unpredictable nature of the pain had a particular impact. For example, some participants were constantly aware of the possibility of pain and as a result adjusted their daily routines to avoid painful stimuli. Others did not expect the pain and were surprised every time they experienced it. Annoyance, frustration and sometimes guilt were linked with DH. Relatively minor pain was still associated with significant impacts. Gibson and colleagues suggested that this characteristic of the condition (unpredictable episodes of pain occurring over an extended period of time) indicates that DH should be considered a chronic health condition similar to asthma or diabetes.

In a secondary analysis of the accounts of DH, Gibson and colleagues (2012) noted that, despite the fact that people experience significant impacts of DH, it is difficult to communicate about these impacts to other people and the person is confined to experiencing them in

private. This is because the condition functions as a non-problem problem; it is a problem to the person, but it is not a problem to the health care organisations.

Porritt and colleagues (2014) found that higher impacts of DH at follow-up were predicted by baseline low levels of DH illness coherence (i.e. whether the persons' internal representation of DH is coherent), negative emotional representations of DH, greater health anxiety (i.e. worrying about one's health) and use of passive coping strategies (i.e. tendency to restrict activities because of the pain and/or dependence on others for help in pain control) to cope with DH related pain.

The Dentine Hypersensitivity Experience Questionnaire (DHEQ) is a health related quality of life measure designed specifically for individuals with DH (Boiko *et al.*, 2010). DHEQ measures psychosocial impacts of DH from the person's subjective perspective. It was developed based on based on the qualitative data collected by Gibson and colleagues (2010) and informed by the Wilson and Cleary (1995) model of health and quality of life. The measure consists of 48 items assessing: sensitivity related pain (intensity, tolerability and bothersomeness), impacts (restrictions, coping, social impact, emotional impact and Identity), global oral health and overall effect on quality of life. The DHEQ had good internal reliability and criterion validity (Boiko *et al.*, 2010) and it is responsive to change (Baker *et al.*, 2014). A short form of DHEQ (DHEQ-15) consisting of 15 items is also available (Machuca *et al.*, 2014). To date, DHEQ and DHEQ-15 are the only available questionnaires measuring specifically quality of life in individuals with DH.

2.1.3 Diagnosis

Generally, the diagnosis of DH occurs in a dental practice based on clinical examination by a dental practitioner and on patient's report of the experience of pain. However, the Canadian Advisory Board on Dentine Hypersensitivity (2003) suggested that it is more appropriate to rely on a patient's own perceptions of their everyday DH, rather than on clinical tools for diagnosis. Dentine hypersensitivity is a diagnosis of exclusion, meaning that other conditions that have symptoms in common (such as dental caries) must be excluded before DH is diagnosed. Alternatively, individuals self-diagnose DH based on the information available to them, for example through mass media and advertising.

In clinical trials two types of assessment, stimulus-based and response-based, are used to quantify DH (Holland *et al.*, 1997). In stimulus-based assessments, individuals are exposed to an increasing intensity of stimulus. The threshold of stimulus required to evoke pain is an

indicator of the existence and severity of DH. Response-based assessments rely on a participant's subjective evaluation of pain produced by a constant (same for all participants) stimulus. Such assessments use a pain scale such as a visual analogues scale (VAS). Holland and colleagues (1997) suggest that when evaluating treatments for DH the participant's assessment of their overall 'sensitivity' in response to everyday stimuli should be used.

2.1.4 Aetiology and Mechanisms

The aetiology of DH is not yet fully understood. Individuals experience pain when the dentine is exposed, and the tubule system in dentine is open to the mouth (Dowell and Addy, 1983; Dababneh *et al.*, 1999; Addy, 2005). This allows external stimuli to initiate the neural responses in the pulp via a hydrodynamic mechanism, which in turn produces pain. However, many individuals have exposed dentine, only a proportion of whom experience symptoms (West *et al.*, 2002). This suggests that DH has a multi factorial aetiology.

Erosion is considered a key cause of enamel loss and dentine exposure (Addy, 2002). It is caused by acids present in foods and drinks or from the stomach. Abrasion and attrition also contribute, and might act in synergy with erosion. Abrasion is loss of tooth caused by mechanical forces from foreign objects and can be caused by tooth brushing. Attrition is loss of tissue caused by mechanical forces from opposing teeth. Gingival recession, can also contribute to DH via dentine exposure (Dababneh *et al.*, 1999; Addy, 2002; Addy, 2005).

The question of how a stimulus to exposed dentinal tubules produces pain is unclear. Several explanations have been considered (Dowell and Addy, 1983). At present, the hydrodynamic theory is the most widely accepted (Brannstrom and Astrom, 1972; Addy, 2002). According to the hydrodynamic theory, the flow of fluids in the tubules (caused by the thermal, tactile, osmotic, chemical or evaporative stimuli), activates sensory nerves of the pulp or inner dentine producing a sensation of pain. Supporting evidence for this theory comes from the work of Absi and colleagues (1987) who found that in hypersensitive teeth, as compared with normal teeth, there were around eight times more tubules per unit area and their diameter was on average two times higher. This allows for the fluid flow to be approximately 100 times greater than in normal teeth.

2.1.5 Management

Strategies to manage DH are varied. Dentine hypersensitivity can be managed by the individual themselves (through relevant behavioural coping strategies), desensitising home care products can be used and, finally, clinical techniques can be applied.

Boiko and colleagues (2010) found that individuals with DH use a variety of coping strategies on a daily basis, including avoiding cold and hot drinks and foods, cooling and warming foods and drinks that otherwise could cause pain when eaten, cutting food in small pieces, putting a scarf over one's mouth when it is cold, avoiding contact with affected teeth and changing tooth brushing patterns. These coping strategies form a part of the Impact subscales from the DHEQ questionnaire. Reducing dietary acids is a strategy that focuses on tooth preservation.

Desensitising agents such as potassium nitrate or potassium chloride can be used in toothpastes (Orchardson and Gillam, 2006). The two most commonly recognised toothpastes brands for the management of DH are Colgate Sensitive or Sensodyne. Mouthwashes and chewing gums containing desensitising agents can also be used (Orchardson and Gillam, 2006).

Finally, desensitising agents can be applied directly to the tooth in the dental clinic (Orchardson and Gillam, 2006). More invasive techniques including: mucogingival surgery for root coverage, application of resins or pulpectomy, might be considered as treatment options in unremitting cases (Canadian Advisory Board on Dentin Hypersensitivity, 2003).

2.1.6 Conclusion

The prevalence of DH among the general population is expected to rise due to the retention of more teeth that can be affected by the condition, due to the increased popularity of tooth whitening products causing sensitivity (Tredwin *et al.*, 2006) and the greater awareness about oral health.

Dentine hypersensitivity alters people's behaviour and impacts on their QoL (Gibson *et al.*, 2010; Porritt *et al.*, 2014). Gibson and colleagues (2010) suggested that individual experience of the condition, as well as its impact on everyday life, changes over time as a result of adaptation, which might indicate response shift.

2.2 Response shift: Theory

This section introduces the concept of response shift. Response shift refers to changes in the meaning of self-evaluations of quality of life (QoL) over time.

2.2.1 Quality of life (QoL) and oral health quality of life (OHQoL)

Quality of life (QoL) relates to the 'goodness' of one's life (Diener and Suh, 1997; Bowling, 2005). Although this term has intuitive appeal, there is no one definition of the concept. It has been defined in terms of life satisfaction (Andrews, 1974), subjective well-being (Diener and Suh, 1997), happiness (Veenhoven, 1991) or availability of resources necessary to the satisfaction of individual's needs (Shin and Johnson, 1978). Despite these differences there is a general agreement that QoL is a multidimensional construct encompassing physical, psychological and social dimensions. This is reflected in the definition of QoL proposed by the World Health Organisation (1995, p. 1405), who defined the concept as: 'an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns'. This definition stresses the subjective aspect of QoL.

Health related quality of life (HRQoL) refers to the subjective view of QoL in relation to health (Bowling, 2005). HRQoL allows for the assessment of the impacts of the person's health status or illness on their QoL from that person's point of view. The concept draws on the bio-psychosocial model of health, which shifts attention from clinical measures of health to include subjective measures that incorporate broader psychological and social aspects of functioning (Engel, 1980). Quality of life and HRQoL overlap. For example, one cannot fully describe the impacts of an illness on QoL without considering issues not related to health, for example, the person's socioeconomic status or the available health care infrastructure.

Finally, oral health quality of life (OHQoL) is a subset of HRQoL defined here as 'impacts of oral conditions on everyday life that are important to people and of sufficient magnitude to affect perception of their life overall' (Locker and Allen, 2007). Oral health quality of life is increasingly used in dentistry to capture peoples' subjective experiences of their oral health, as an outcome measure to evaluate oral health care.

The use of QoL measures, including OHQoL, adds value by introducing a person-centred perspective into medicine and dentistry. In so doing, it allows for representation of the impact of health conditions on peoples' QoL. Nevertheless, it is not without challenges. When a

person's understanding of QoL changes, this can undermine assessment of QoL over time. The concept of 'response shift' provides a way of understanding how the meaning of QoL can change over time and how this affects the subjective assessments of quality of life.

2.2.2 Concept of response shift and theoretical model of response shift

The term 'response shift' was first introduced into QoL research in a series of articles published in 1999 (Daltroy *et al.*, 1999; Gibbons and Buunk, 1999; Schwartz and Sendor, 1999; Schwartz and Sprangers, 1999; Sprangers and Schwartz, 1999; Wilson, 1999) and in a book (Schwartz and Sprangers, 2000).

Response shift was defined as a change in the meaning of one's self-evaluation of QoL as a result of:

- change in the person's internal standards of measurement (recalibration)
- change in the person's values, i.e. change in the relative importance of component domains of quality of life (reprioritisation)
- redefinition of quality of life (reconceptualisation) (Sprangers and Schwartz, 1999)

As an example of recalibration, one might rate the severity of a headache as '8' on a pain scale where '0' is no pain and '10' is the worst pain imaginable. This person might later experience an episode of severe migraine, which he or she might rate as extremely severe, close to '10'. This person might then realise that their earlier headache was only '5', indicating recalibration.

With reprioritisation, a person might value their professional over their family life and leisure. After an episode of angina, this person might find family and leisure more important than professional life, indicating reprioritisation.

Finally, with reconceptualisation, what contributes to the person's QoL may be physical functioning, professional achievements and a nice house. After a diagnosis of cancer and subsequent treatment these things might no longer be important for that person. What now contributes to their QoL are family and friends, little everyday life pleasures and level of pain, indicating reconceptualisation.

The three types of response shift (recalibration, reprioritisation and reconceptualisation) are distinct but at the same time interconnected (Sprangers and Schwartz, 1999). That is, one or more can occur together. For example, as a result of cancer treatment a person may recalibrate assessments of fatigue and reprioritise the importance of friends and family.

The concept of response shift was meant to explain apparently paradoxical findings about the QoL of people with chronic illnesses and disabilities, who were often found to report quality of life comparable with healthy individuals (Brickman *et al.*, 1978; Albrecht and Devlieger, 1999). Likewise, the QoL of people with life threatening conditions was found to be stable over time, despite deteriorating health (Bach and Tilton, 1994). Finally, proxy assessments by significant others and lay caregivers underestimated the self-assessed QoL of people with chronic conditions (Sprangers and Aaronson, 1992; Spiller and Alexander, 1993; Sneeuw *et al.*, 1997).

The conceptualisation of response shift and recalibration, reprioritisation and reconceptualisation is grounded in the field of educational and organisational research (Golembiewski *et al.*, 1976; Armenakis and Zmud, 1979; Howard and Dailey, 1979). Sprangers and Schwartz drew on the typology of change proposed by Golembiewski and colleagues (1976) who distinguished between three types of change:

> *"Alpha change involves a variation in the level of some existential state, given constantly calibrated measuring instrument related to a constant conceptual domain.*
>
> *Beta change involves a variation in the level of some existential state, complicated by the fact that some intervals of the measurement continuum associated with a constant conceptual domain have been recalibrated.*
>
> *Gamma change involves redefinition or reconceptualisation of some domain, a major change in the perspective or frames of reference within which phenomena are perceived and classified in what is taken to be relevant in some slice of reality."* (p. 134-135).

According to Golembiewski and colleagues' the usual analysis of change that involves comparing 'Pre' and 'Post' self-reports only accounts for the Alpha change. If Beta or Gamma change occurs then the assessment becomes invalid. For example, if a person changes their understanding of what it means to be a good leader as a result of leadership training, then it is possible that the 'Post' self-assessment might indicate lower leadership skills than the 'Pre' assessment. Therefore, it is important to develop approaches to the assessment of change that account for all three types of change (Golembiewski *et al.*, 1976).

The Golembiewski and colleagues' typology inspired several studies assessing different types of change (Zmud and Armenakis, 1978; Howard and Dailey, 1979; Schmitt *et al.*, 1984; Van de Vliert *et al.*, 1985). Despite that, the typology has not been adopted outside organisational and educational research.

In, Schwartz and Sprangers' typology, Beta change became recalibration whereas Gamma change was divided into reprioritisation and reconceptualisation. Alpha change can be equated to a change in perceived QoL that is not affected by response shift.

In addition to introducing a definition, Sprangers and Schwartz (1999) also proposed a theoretical model of response shift and QoL (Figure 2.2.1). This model explains how response shift comes about using five components:

(1) Catalyst: a change in health such as an improvement or deterioration or receiving a health intervention or treatment that initiates the process of response shift
(2) Mechanisms: behavioural, cognitive, and affective processes to accommodate catalyst
(3) Response shift: including recalibration, reprioritisation and reconceptualisation
(4) Antecedents: stable dispositional characteristics of a person
(5) Perceived QoL: defined as a multidimensional construct including physical, psychological and social domains

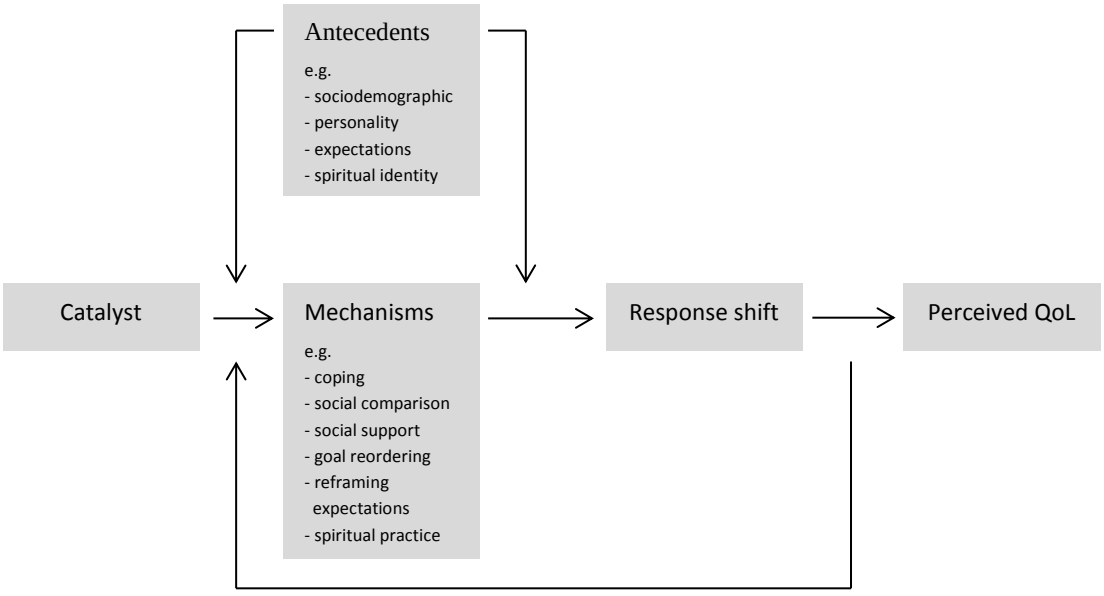


Figure 2.2.1 Model of response shift and QoL, Sprangers and Schwartz (1999) p. 1509

The model has a feedback loop in which perceived QoL is monitored. If the level of QoL is considered suboptimal specific mechanisms are initiated to restore the optimal level (through the occurrence of response shift) (Sprangers and Schwartz, 1999). If the initiated mechanisms are unsuccessful, response shift does not occur and there is no improvement in perceived QoL.

Conversely, if the mechanisms successfully induce response shift, then an acceptable level of QoL is restored. As such, response shift is involved in adaptation to changing health.

2.2.3 Further developments in response shift

In 2004, Rapkin and Schwartz updated the Sprangers and Schwartz model by adding an additional component, namely appraisal (Figure 2.2.2). Appraisal was defined as a cognitive process involved in the self-assessment of one's QoL on an item or a dimension in a quality of life questionnaire (Rapkin and Schwartz, 2004). Appraisal mediates between mechanisms and response shift (direct response shift). Alternatively, changes in appraisal alone can result in response shift (moderated response shift).

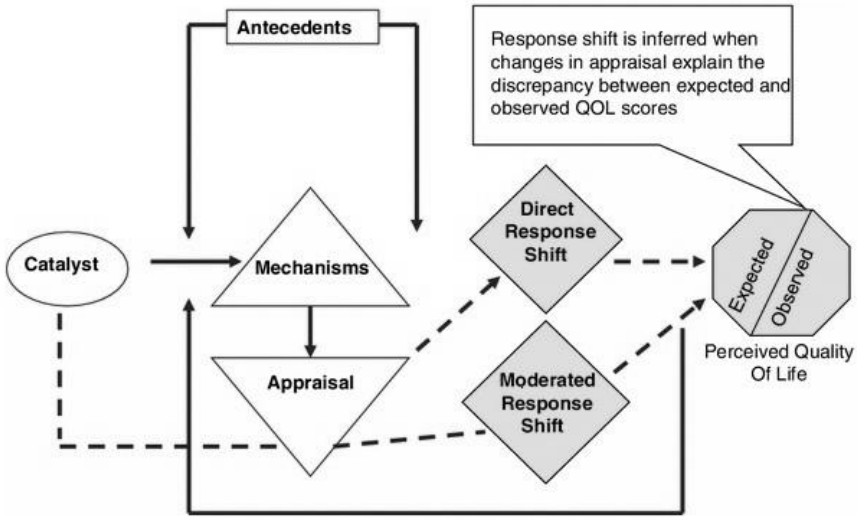


Figure 2.2.2 Model of appraisal and QoL according to Rapkin and Schwartz (2004), taken from Schwartz et al 2013 p. 2665

Rapkin and Schwartz (2004) proposed that the appraisal process involved in answering the QoL item is based on four parameters: frames of reference, sampling strategy, standards of comparison and a combinatory algorithm.

Frames of reference are induced when a person attempts to answer an item. They encompass all the experience the person considers to be relevant at that time. Frames of reference depend on the meaning the person attaches to the question and the characteristics of the testing situation. A sampling strategy involves selecting specific experiences relevant for the item, within the frames of reference. Standards of comparison are then used to judge the sampled experience. Prior functioning or other people in the same situation might be selected as standards of comparison. A combinatory algorithm is employed to position oneself on the

answer categories provided for the item. One algorithm is that a person might allocate different weights to different sampled experiences in order to arrive at a final score (Schwartz and Rapkin, 2004). A tool to measure appraisal in people with HIV/AIDS that consisted of open ended questions and Likert scale items was provided by the authors (Rapkin and Schwartz, 2004).

Rapkin and Schwartz suggested that changes in the appraisals between assessments corresponded to response shift. That is, response shift and changes in appraisals are 'epiphenomena'. Changes in standards of comparison relate to recalibration. Changes in the sampling strategy and in factors that determine the relative salience of different experiences (i.e. changes in combinatory algorithm) relate to reprioritisation. Finally, changes in the frame of reference related to reconceptualisation.

Further theoretical developments distinguishing between trait and state components of response shift have been proposed (Sprangers and Schwartz, 2008; Schwartz and Sprangers, 2009). The state component refers to a return to the prior level of QoL after experiencing deterioration in health. The prior level is determined by a person's set point for QoL (similar to the set point for happiness or life satisfaction). The set point is fairly stable and immutable and can be thought of as being a personality trait. Quality of life may vary temporally between the upper and lower limits of a set range established around the set point, but eventually a balance will be re-established in most cases. The trait component of response shift is defined as a sustainable increase of a set point as a result of an intended intervention. Although the set point for QoL is believed to be largely genetically determined, many interventions have proved successful in increasing the permanent level QoL. Schwartz and Sprangers (2009) suggest that the trait component is responsible for long term accommodations of health change by recalibrating, reprioritising and reconceptualising individual's QoL concepts. These theoretical suggestions have not been investigated empirically.

2.2.4 Directions for further research and critiques of the concept

Ten years after the introduction of the term response shift, Barclay-Goddard and colleagues (2009a) analysed the available data and formulated five priorities that should be addressed to advance the field:

1. Obtaining a consensus on the terminology and theoretical models used. This includes development and testing of theoretical models, analysis of appraisal and investigation of attributes of response shift, such as timing.

2. Determining the clinical importance of response shift. This includes determining the extent to which response shift influences the evaluation of change in QoL by estimating its magnitude and direction and by investigating the influences of catalysts, antecedents and mechanisms of this magnitude and direction.

3. Determining the best way to measure and account for response shift as a clinically important confounder.

4. Ascertaining how response shift can be best identified when it is a focus of a clinical intervention.

5. Establishing methods to translate response shift knowledge into real-world settings.

Some criticism of response shift is also present in the literature. Ubel and colleagues (2010) suggested that in order to advance the field, the term response shift needs to be abandoned, because it creates conceptual confusion by combining measurement error (e.g. scale recalibration) and true change in QoL (e.g. hedonic adaptation). Additionally, the response shift literature is not clear whether response shift represents measurement error or whether people obtain true change in QoL through response shift. Finally, although unintentionally, the term response shift has misleading connotations suggesting that people with illnesses and disabilities are not really experiencing good QoL, but rather the response had 'shifted'. Ubel and colleagues suggested adopting more precise terms such as scale recalibration and adaptation to bring conceptual clarity.

In response, Sprangers and Schwartz (2010) suggested that, rather than abandoning the term, conceptualisations of response shift should be refined and advanced within the existing framework.

Since the introduction of the concept of response shift into quality of life research, numerous studies have been published exploring it. These studies have identified response shifts in relation to serious chronic and life threatening conditions such as cancers, arthritis, HIV and stroke, and to some extent, in the general population (Schwartz *et al.*, 2006; Westerman *et al.*, 2007b; Mayo *et al.*, 2009; Razmjou *et al.*, 2009; Galenkamp *et al.*, 2012; Ogden and Lo, 2012; Schwartz and Rapkin, 2012). The following section reviews empirical studies of response shift.

2.3 Response shift: Structured review

Following the introduction of the term 'response shift' into QoL research, numerous studies have explored its various aspects, using a variety of methods in different health conditions and populations.

Schwartz and colleagues (2006) conducted a meta-analysis of the clinical significance of response shift. From the 19 included studies, the authors found considerable evidence of response shift in domains of fatigue (mean ES = 0.31, n of studies = 8), global QoL (mean ES = 0.30, n of studies = 13), physical role limitation (mean ES = 0.23, n of studies = 8), psychological well-being (mean ES = 0.12, n of studies = 10) and pain (mean ES = 0.07, n of studies = 7.

A meta-analysis is a useful tool to evidence a phenomenon (Moher *et al.*, 1999). However, there are some limitations to this study. It was based on studies employing mainly the THEN TEST (i.e. a retrospective assessment), or in some cases structural equation modelling (SEM), but excluded studies using qualitative methods and individualised measures which didn't allow for the calculation of the effect sizes. These latter methods detect reprioritisation and reconceptualisation while the THEN TEST allows only for the measurement of recalibration, thus the study relates mainly to recalibration. The authors also pointed that, because different studies indicated opposite directions of response shifts in the same QoL domain, it was not possible to draw conclusions on its clinical significance. Additionally, this meta-analysis only reviewed evidence up to 2005. More studies investigating the phenomenon have been published since.

This literature review contains a structured review conducted to gain a comprehensive understanding of the evidence of response shift since the term was first introduced to date, to inform the design of studies investigating response shift in DH.

AIM: To systematically identify and analyse empirical studies in which one or more aspects of response shift was assessed.

2.3.1 Searching procedure

A search of articles published between 1999 (when the term was first introduced into the QoL literature) and May 2014 (time of the search) was conducted using Web of Knowledge – a comprehensive electronic citation index that provides access to databases covering science, social sciences arts and humanities. Only articles written in English were considered.

The initial search terms were: ‘response shift’ AND (‘quality of life’ OR ‘QoL’ OR ‘health related quality of life’ OR ‘HrQoL’ OR ‘oral health related quality of life’ OR ‘OHQoL’ OR ‘OHrQoL’).

Inclusion criteria:

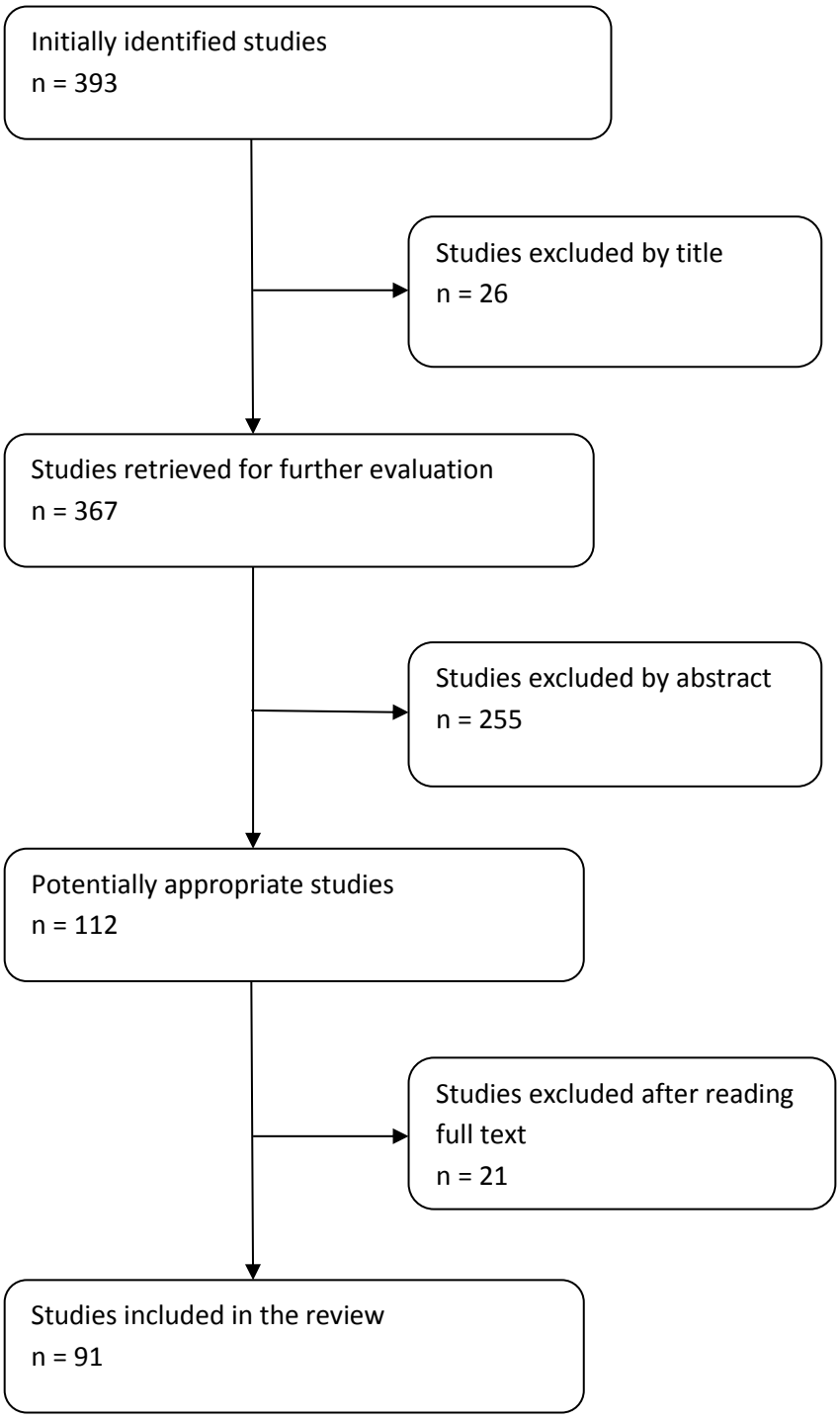
- Published in English language in a peer-reviewed journal between 1999 and May 2014
- Primary or secondary analysis of one or more aspects of response shift
- Response shift was assessed in relation to QoL

Exclusion criteria:

- Theoretical papers
- Response shift only mentioned in the discussion of the article, for example as a possible explanation of the results, but not measured in the study
- Response shift assessed in constructs other than QoL

Overall, the search yielded 393 results (Figure 2.3.1). Screening of titles and abstracts was undertaken. Articles that failed to meet the inclusion criteria were excluded. Articles that passed the preliminary screening were obtained and assessed for eligibility. Those that failed to meet the inclusion criteria were again excluded. Ninety one studies meet the inclusion criteria and were included in the review.

Figure 2.3.1 Structured review process for studies measuring response shift



2.3.2 Findings

Table 2.3.1 Overview of the studies investigating response shift

No	Study	Sample	N (N females)	Mean age (SD/Range)	Design	Method of response shift assessment	Measurement points	QoL measure	Aspect of response shift measured	Response shift
1	AHMED, BOURBEAU, MALTAIS & MANSOUR (2009)	Individuals with chronic obstructive pulmonary disease	252 (112)	66 (SD: 9.0)	Longitudinal observational study	SEM (Structural Equation Modelling)	Baseline; 12 weeks & 1 year follow-up	Chronic Respiratory Questionnaire (CRQ), St George's Respiratory Questionnaire (SGRQ)	Recalibration Reprioritisation Reconceptualisation	Yes
2	AHMED, MAYO, SCOTT, KUSPINAR & SCHWARTZ (2011)	Individuals with multiple sclerosis	1556 (1307)	40 (SD: 7.0)	Longitudinal observational study	Latent trajectory of residuals	Baseline; 2 or 3 follow-ups	SF-12, the Performance Scale (PS), the Patient-Derived disease step (PDDS)	Not specified	Yes
3	AHMED, MAYO, CORBIERE, WOOD-DAUPHINEE, HANLEY & COHEN (2005a)	Post-stroke patients	238 (84) + 392 controls	67 (SD: 12.1)	Longitudinal observational study	Confirmatory factor analysis	Baseline; 6 months follow-up	SF-36	Recalibration Reconceptualisation	No
4	AHMED, MAYO, WOOD-DAUPHINEE, HANLEY & COHEN (2005b)	Post-stroke patients	92 (39)	69 (SD:15)	Longitudinal observational study	Patient Generated Index (PGI), Semi-structured interviews	Baseline; 6 & 24 weeks follow-ups	PGI: Patient Generated Index (PGI), semi-structured-interview	Reprioritisation Reconceptualisation	Yes
5	AHMED, MAYO, WOOD-DAUPHINEE, HANLEY & COHEN (2004)	Post-stroke patients & control group of 50 care givers	146 (88) + 50 controls	71 (SD: 13.8)	Longitudinal observational study	THEN TEST	First weeks after stroke; 6 & 24 follow-ups	EQ-5D	Recalibration	Yes

6	AHMED,MAYO, WOOD-DAUPHINEE, HANLEY & COHEN (2005c)	Post-stroke patients	?	?	Longitudinal observational study	SEM, THEN TEST, Patient Generated Index (PGI)	Baseline; 6 & 24 weeks follow-ups	Patient Generated Index (PGI), EQ-VAS, SF-36	Recalibration Reconceptualisation	Yes
7	ANDRYKOWSKI, DONOVAN & JACOBSEN (2009)	Women with early stage breast cancer receiving chemotherapy and/or radiotherapy	102 (102)	54.7 (SD: 10.6)	Longitudinal observational study	THEN TEST	Baseline at the beginning of the therapy; at the end of first and second stages of the therapy, 2 and 4 months from the end of therapy	Fatigue Symptom Inventory (FSI)	Recalibration	Yes
8	ANOTA, BASCOUL-MOLLEVI, CONROY, GUILLEMIN, VELTEN, JOLLY, MERCIER, CAUSERET, CUISENIER, GRAESSLIN, HAMIDOU & BONNETAIN (2014)	Women with breast cancer receiving treatment	381 (381)	58.4 (SD: 11)	Longitudinal observational study	THEN TEST Two factor analysis approaches: Principal Component Analysis (as part of SEM) and Multiple Correspondence Analysis (as part of Item Response Theory)	Baseline before surgery; Follow-up immediately after the surgery & 3-6 months follow-up	EORTC QLQ – C30 EORTC QLQ – BR23	Recalibration Reprioritisation Reconceptualisation	Yes
9	BALAIN, ENNIS, KANES, SINGHAL, ROBERTS, REES & KUIPER (2009)	Individuals receiving treatment for full thickness knee cartilage defects	53 (17)	42	Longitudinal observational study	THEN TEST	Baseline before surgery; follow-up after surgery	Visual analogue scale for pain, modified International Knee Documentation Committee form (IKCD), Lysholm (knee status) score	Recalibration	Yes

10	BARCLAY-GODDARD, LIX, TATE, WEINBERG & MAYO (2009b)	Poststroke patients	677 (305)	67 (SD: 15)	Longitudinal observational study	SEM	Baseline; 1,3,6 & 12 months follow-ups	SF-36,EQ-5D, Stroke Impact Scale (SIS), Preference Based Stroke Specific Index (PBSI) (mental health components)	Recalibration Reprioritisation Reconceptualisation	Yes
11	BARCLAY-GODDARD, LIX, TATE, WEINBERG & MAYO (2011)	Poststroke patients	677 (305)	68 (SD: 14.8)	Longitudinal observational study	SEM	Baseline; 1,3,6 & 12 months follow-ups	SF-36,EQ-5D, Stroke Impact Scale (SIS), Preference Based Stroke Specific Index (PBSI), Health Utilities Index (HUI) (physical health physical health components)	Recalibration Reprioritisation Reconceptualisation	Yes
12	BARCLAY-GODDARD & TATE (2014)	Older men with and without stroke	735 (0)	>70	Longitudinal observational study	SEM	Baseline and approx. 4 years follow-up	SF-36	Recalibration Reconceptualisation	Yes
13	BAR-ON, LAZAR & AMIR (2000)	Individuals with hypertension	450 (?)	Adults	Longitudinal observational study	Semi-structured interviews	Baseline; 1 year follow-up	N/a	Recalibration	Yes
14	BEEKEN, EISER & DALLEY (2011)	Post haematopoietic stem cell transplant patients	28 (15)	(22-71)	Cross-sectional observational study	Semi-structured interviews	One measurement point	N/a	Recalibration Reprioritisation Reconceptualisation	Yes
15	BERNHARD, HURNY, MAIBACH, HERRMANN & LAFFER (1999)	Colon cancer patients	187 (77)	Adults (?)	Longitudinal observational study	THEN TEST	Baseline before surgery; 2 months after surgery follow-up	Linear Analogue Self-Assessment (LASA)	Recalibration	Yes

16	BERNHARD, LOWY, MAIBACH & HURNY (2001)	Colon cancer patients	130	(27-88)	Longitudinal observational study	THEN TEST	Baseline; 12 days follow-up	Linear Analogue Self-Assessment (LASA)	Recalibration	Yes
17	BERNHARD, LOWY, MATHYS, HERRMANN & HURNY (2004)	Colon cancer patients	99 (42)	Adults?	Longitudinal observational study	THEN TEST, Regression based method (Multilevel modelling)	Baseline before surgery and at 2 follow-ups	Overall QoL rating, modified Linear Analogue Self-Assessment (LASA)	Recalibration Reprioritisation	Yes
18	BITZER, PETRUCCI, LORENZ, HUSSEIN, DOERNING, TROJAN & NICKEL (2011)	Hernia patients & laparoscopic cholecystectomy patients	315	Adults	Longitudinal observational study	THEN TEST	Baseline before surgery ; 14 days & 6 months follow-ups	Hernia & cholecystectomy symptoms	Recalibration	Yes
19	BLAIR, WILSON, GOUICK & GENTLEMAN (2010)	Individuals after traumatic brain injury	28 (9)	42.14 (SD: 13.97)	Cross-sectional observational study	THEN TEST, SEIQoL-DW	One measurement point (12-120 months post injury)	SEIQoL-DW, Hadorn's overall 1-10 QoL scale, SF-36, Glasgow Outcome Scale-Extended (GOS-E), The Hospital Anxiety and Depression Scale (HADS)	Reprioritisation Reconceptualisation	Yes
20	BOUCEKINE, LOUNDOU, BAUMSTARCK, MINAYA-FLORES,PELLETIER, GHATTAS & AUQUIER (2013)	People with multiple sclerosis	580 (419)	41.3 (SD: 10.2)	Longitudinal observational study	Recursive partitioning and regression tree analysis	Baseline and 6, 12, 18 and 14 months follow-ups	Multiple Sclerosis International Quality of Life questionnaire (MusiQoL) SF-36	Reprioritisation	Yes

21	BRINKSMA, TISSING, SULKERS, KAMPS, ROODBOL & SANDERMAN (2014)	Children with cancer and their parents (proxy)	37 (20) (children)	14 (8-17) (children)	Longitudinal observational study	THEN TEST	Baseline withitn to weeks after diagnosis Follow-up 3 months after diagnosis	Play Performance Scale (PPS) Memorial Symptom Assessment Scale (MSAS) PedsQL 4.0 Generic Corel Scale	Recalibration	Yes
22	BROBERGER, SPRANGERS & TISHELMAN (2006)	Individuals with newly diagnosed advanced lung cancer	126 (56)	64 (SD: 10)	Longitudinal observational study	THEN TEST	Baseline before start of the treatment; 3 & 6 months follow-ups	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30)	Recalibration	Inconclu-sive
23	BROBERGER, TISHELMAN, VON ESSEN, DOUKKALI & SPRANGERS (2007)	Individuals with lung cancer	46 (20)	66 (SD: 12)	Longitudinal observational study	Individualised measure of concerns spontaneously reported as most distressing (free listing), baseline, follow-up and retrospective assessment	Baseline; 6 months follow-up	EORTC QLQ-C30, Lung-cancer 13 (LC13), Individualised measure of concerns spontaneously reported as most distressing (free listing)	Reprioritisation	Inconclu-sive
24	BROSSART, CLAY & WILLSON (2002)	Children with juvenile rheumatoid arthritis, diabetes & healthy controls	309 (163)	8.72 (SD: 4.36)	Longitudinal observational study	Growth curve modelling	Baseline at time of diagnosis; 6, 12 & 18 months follow-ups	Differential Emotions Scale (DES-IV, proxy) assessment)	Not specified	Yes

25	CELLA, HAHN, & DINEEN (2002)	Cancer patients	197 (99)	?	Longitudinal observational study	THEN TEST	Baseline; 2 months follow-up	Functional Assessment of Cancer Therapy (FACT-G), Global Rating of Change	Recalibration	Yes
26	CHIN, FUKUHARA, TAKAHASHI, SUMI, NAKAMURA, MATSUMOTO, NIIMI, HATTORI, MISHIMA & NAKAMURA (2004)	Individuals receiving treatment for obstructive sleep apnea	31 (3)	53 (44-61)	Longitudinal observational study	THEN TEST	Baseline before treatment; 10 months after treatment follow-up	Epworth Sleepiness Scale	Recalibration	Yes
27	CHOW, CHIU, DOYLE, HRUBY, HOLDEN, BARNES, TSAO, MALLIA, HARRIS & DANJOUX (2007)	Cancer patients undergoing palliative radiotherapy	270 (87)	66 (28-88)	Longitudinal observational study	THEN TEST	Baseline before the start of the treatment, 2 months follow-up	Pain questionnaire	Recalibration	Yes
28	DABAKUYO, GUILLEMIN, CONROY, VELTEN, JOLLY, MERCIER, CAUSERET, CUISENIER, GRAESSLIN, GAUTHIER & BONNETAIN (2013)	Women with breast cancer receiving treatment	320 (320)	58.4 (SD: 11)	Longitudinal observational study	THEN TEST Assessment of change in expectations towards health & QoL Assessment of change in the importance of health related domains for QoL	Baseline Follow-up at the end of hospitalisation	EORTC QLQ – C30 EORTC QLQ – BR23 EuroQOL – ED-5D	Recalibration Reprioritisation	Yes
29	DEMPSTER, CARNEY & MCCLEMENTS (2010)	Individuals with heart disease undergoing cardiac rehabilitation	57 (17)	62.9	Longitudinal observational study	THEN TEST, SEIQoL-DW	Baseline at the beginning of the program, follow-up at the end of the program (10 weeks later)	SEIQoL-DW	Recalibration Reprioritisation Reconceptualisation	Yes

30	ECHTELD, DELIENS, OOMS, RIBBE & VAN DER WAL (2005)	Palliative care unit patients	9	?	Longitudinal (pilot) observational study	SEIQoL-DW	Baseline 1 week after admission to the palliative care unit; 3 weeks after admission follow-up	SEIQoL-DW	Reprioritisation Reconceptualisation	Yes
31	ECHTELD, VAN ZUYLEN, BANNINK, WITKAMP & VAN DER RIJT (2007)	Palliative care unit patients	16	?	Longitudinal observational study	SEIQoL-DW	Baseline at the admission to the palliative care unit, 1 week follow-up	SEIQoL-DW	Reprioritisation Reconceptualisation	Yes
32	GALENKAMP, HUISMAN, BRAAM & DEEG (2012)	General population of older adults	1274 (669)	66.1 55-89)	Longitudinal observational study	THEN TEST, Regression based method (Linear regression analysis)	Baseline; 3.6 years follow-up	1 item measure "How is your health in general?"	Recalibration Reprioritisation Reconceptualisation	Yes
33	GANDHI, RIED, CHANG HUANG, KIMBERLIN & KAUF (2013)	Individuals with coronary artery disease	902 (?)	?	Longitudinal observational study	SEM	Baseline; 1 year follow-up	SF-36	Recalibration Reprioritisation Reconceptualisation	Yes
34	GILLISON, SKEVINGTON & STANDAGE (2008)	General population of healthy adolescents	356 (176)	14.05 (SD: 0.31)	Longitudinal observation study	THEN TEST, SEM	Baseline; 1 year follow-up	The Kidscreen	Recalibration Reprioritisation Reconceptualisation	No
35	GREGORY, GIBSON & ROBINSON (2005)	Individuals with visually decayed, broken or missing teeth	20	?	Longitudinal observational study	Semi-structured interviews	Baseline; 3 months follow-up	N/a	Recalibration Reprioritisation Reconceptualisation	Yes
36	HAGEDOORN, SNEEUW & AARONSON (2002)	Cancer patients	193 (107)	50.5 (SD: 14.4)	Longitudinal observational study	Regression based method (Linear regression analysis)	Baseline, 3 months follow-up	EORTC QLQ-C30	Not specified	Yes

37	HINZ, BARBOZA, ZENGER, SINGER, SCHWALENBERG & STOLZENBURG (2011)	Urologic cancer patients	275	63.7 (SD: 8.3)	Longitudinal observation study	THEN TEST, question "In the last 3 months has your opinion about what health is changed?"	Baseline during the stay at the hospital; 3 months follow-up	Generalised Anxiety disorder Questionnaire-2, Patients Health Questionnaire-2, Questionnaire on Life Satisfaction	Recalibration Reconceptualisation	Yes
38	HOEFER, PFAFFENBERGER, RENN, PLATTER & RING (2011)	Cardiac patients undergoing coronary intervention	64 (18)	61.4 (SD: 7.5)	Longitudinal observational study	THEN TEST, SEIQoL-DW	Baseline before the surgery, 6 months follow-up	SEIQoL, MacNew Heart Disease Health Related Quality of Life Instrument	Recalibration Reprioritisation Reconceptualisation	Yes
39	Inman & Ogden (2011)	Individuals who suffered a range of life traumas	11	?	Cross-sectional observational study	Semi-structured interviews Thematic analysis	One measurement point	N/a	Recalibration	Yes
40	INOUE, KASAI, KAWANA & NARUI (2007)	Individuals with obstructive sleep apnea syndrome receiving treatment	232 (18)	52.9 (SD: 11.5)	Longitudinal observational study	THEN TEST	Before start of the treatment, 4 weeks follow-up	Epworth Sleepiness Scale (ESS)	Recalibration	Yes
41	ITO, ISHIGURO, TANAKA, TOKUNAGA, SUGIHARA & KAZUMA (2010)	Patients undergoing surgical resection with resultant permanent colostomy	13	?	Longitudinal observational study	THEN TEST	Before the surgery, 2 months follow-up	SF-36	Recalibration	Yes
42	JANSEN, STIGGELBOUT, NOOIJ, NOORDIJK & KIEVIT (2000)	Breast cancer patients undergoing radiotherapy	46 (46)	55 (39-76)	Longitudinal observational study	THEN TEST	Baseline before radiotherapy; follow-up in the last week of radiotherapy	SF-36, RSCL-Rotterdam Symptom Checklist	Recalibration	Yes

43	JOORE, POTJEWIJD, TIMMERMAN & ANTEUNIS (2002)	Individuals with impaired hearing after receiving hearing aid	98 (45)	67 (28-95)	Longitudinal observational study	THEN TEST	Baseline when receiving prescription for hearing aid; follow-up after the fitting of the hearing aid (12 weeks)	EQ-5D, Audiological Disabilities Preference Index (ADPI)	Recalibration	Yes
44	KIEVIT, HENDRIKX, STALMEIER, VAN DE LAAR, VAN RIEL & ADANG (2010)	Rheumatoid arthritis patients	197	Adults	Longitudinal observational study	THEN TEST	Baseline; 3 months follow-up	Visual analogue scale for general health	Recalibration	No
45	KIMURA, ARAKAWA, NODA, YAMAZAKI, HARA, MINO, MATSUKA, MULLIGAN & KUBOKI (2012)	Individuals receiving partial denture treatment	138 (101)	61.4 (SD: 11.8)	Longitudinal observational study	THEN TEST	Baseline before treatment; follow-up after treatment	Oral Health Quality of Life Questionnaire	Recalibration	Yes
46	KING-KALLIMANIS, OORT, NOLTE, SCHWARTZ & SPRANGERS (2011)	Individuals with multiple sclerosis (2 studies)	2952 (2031) & 1767 (1464)	40.82 (SD: 9.35) & 45.56 (SD: 9.31)	Longitudinal observational study	SEM	Three random measurement points	SF-12	Recalibration Reprioritisation Reconceptualisation	Inconclu-sive
47	KING-KALLIMANIS, OORT, VISSER & SPRANGERS (2009)	Newly diagnosed cancer patients undergoing surgery	202 (98)	57.3 (SD: 14.2)	Longitudinal observational study	SEM	Baseline before surgery; 3 months after surgery follow-up	SF-36	Recalibration Reprioritisation Reconceptualisation	Yes
48	KORFAGE, DE KONING & ESSINK-BOT (2007)	Individuals receiving a prostate cancer diagnosis	52 (0)	67.3 (60-74)	Longitudinal observational study	THEN TEST, Vignette ratings	Baseline two months prior to diagnosis; 1 and 7 months after diagnosis follow-ups	EuroQoL, SF36, Vignettes displaying side effects of a prostate cancer treatment	Recalibration	Yes

49	KORFAGE, HAK, DE KONING & ESSINK-BOT (2006)	Prostate cancer patients	33 (0)	?	?	Semi-structured interviews	One measurement point	EQ-5D, SF-36	Not specified	Yes
50	KUBOTA, YONEDA, NAKAI, KATSUURA, MORIUE, MATSUOKA, MIYAMOTO & OHYA (2009)	Individuals with paediatric atopic dermatitis	31 (13)	7.1 (SD: 4.2)	Longitudinal observational study	THEN TEST	Baseline at the start of the treatment; 12 weeks follow-up	Children Dermatology Life Quality Index (CDLQI) or Infant Dermatology QoL Index(IDQOL, proxy assessment)	Recalibration	Yes
51	KUIJER, DE RIDDER, COLLAND, SCHREURS & SPRANGERS (2007)	Individuals with asthma and diabetes participating in an intervention programme	78	Adults	Experimental	THEN TEST	Baseline before the start of the programmes; 6 months follow-up	SF-12, question "All things considered, where on the ladder do you feel you stand at present?" (0 - worst imaginable QoL, 10 best imaginable QoL)	Recalibration	Yes
52	KVAM, WISLOFF & FAYERS (2010)	Patients with multiple myeloma	239 (111)	66 (36-89)	Longitudinal observational study	THEN TEST	Baseline; 3 months follow-up	EORTC QLQ-C30	Recalibration	Yes
53	LI & SCHWARTZ (2011)	Individuals with multiple sclerosis	3008 (2497)	42.2	Longitudinal observational study	Recursive partitioning and regression tree analysis	Six measurement points over a 6 months period	SF-12	Recalibration Reprioritisation Reconceptualisation	Yes
54	LIX, SAJOBI, SAWATZKY,LIU, MAYO, HUANG, GRAFF, WALKER, EDIGER, CLARA, SEXTON, CARR & BERNSTEIN (2013)	Individuals with active and inactive inflammatory bowel disease	242 (62.1%) (active disease) 115 (52.3%) (inactive disease)	40.3 (SD: 15.0) (active disease) 41.8 (SD: 14.2) (inactive disease)	Longitudinal observational study	Regression based methods (Descriptive discriminant analysis, Logistic regression)	Baseline and 6 months follow-up	Inflammatory Bowel Disease Questionnaire (IBDQ) SF-36	Reprioritisation	Yes

55	LOWY & BERNHARD (2004)	Individuals with early colorectal cancer patients	186	Adults	Longitudinal observational study	Regression based method (Multilevel modelling)	Baseline before surgery; before therapy and during therapy follow-ups	Linear Analogue Self-Assessment	Reconceptualisation	No
56	MAYO, SCOTT & AHMED (2009)	Post stroke patients	160	?	Longitudinal observational study	THEN TEST, Latent trajectory of residuals, Factor analysis	Baseline; 6 weeks & 6 months follow-ups	EQ-5D VAS, SF-36	Recalibration Reprioritisation Reconceptualisation	Yes
57	MAYO, SCOTT, DENDUKURI, AHMED & WOOD-DAUPHINEE (2008)	Post stroke patients	387	?	Longitudinal observational study	Latent trajectory of residuals	Baseline, 3, 6 & 12 months follow-ups	EQ-5D VAS	Not specified	Yes
58	MCPHAIL & HAINES (2010)	Community-dwelling older adults, admitted to hospital as a results of a fall	101 (48)	73.3 (SD: 11.2)	Longitudinal observational study	THEN TEST	Baseline; 6 months follow-up	EQ-5D, VAS	Recalibration	Yes
59	NAGL & FARIN (2012)	Patients with chronic back pain and chronic ischaemic heart disease	?	?	Longitudinal observational study	THEN TEST, SEM	?	?	Recalibration Reprioritisation Reconceptualisation	No
60	NEUMAN, PARK, FUZESI & TEMPLE (2012)	Patients with rectal cancer who have a temporary stoma	26 (12)	54	Cross-sectional observational study	In-depth interviews, Grounded theory	One measurement point	N/a	Recalibration Reconceptualisation	Yes
61	NIEUWKERK, TOLLENAAR, OORT & SPRANGERS (2007)	Individuals with HIV starting antiretroviral therapy	268 (38)	39.9 (SD: 8.6)	Longitudinal observational study	THEN TEST	Baseline at the beginning of the therapy and at 36 weeks follow-up	Medical Outcomes Study HIV health survey (MOS-HIV)	Recalibration	Yes

62	NOLTE, ELSWORTH, SINCLAIR & OSBORNE (2009)	Individuals with chronic disease participating in the chronic disease self-management course	314 (236)	63 (20-86)	Longitudinal observational study	THEN TEST	?	Health Education Impact Questionnaire (heiQ)	Recalibration	No
63	OGDEN & LO (2012)	Homeless, first year university students, town population	75 (21) for homeless 301 (188) for first years university students 72 (42) for town population	?	Cross-sectional observational study	Free text questions Content analysis	One measurement point	Items assessing mood, health status and life satisfaction	Not specified	Yes
64	OORT, VISSER & SPRANGERS (2005)	Newly diagnosed cancer patients undergoing surgery	170 (83)	57.5 (SD: 14.1)	Longitudinal observational study	SEM	Baseline before surgery and 3 months follow-up	SF-36, short version of the multidimensional fatigue inventory	Recalibration Reprioritisation Reconceptualisation	Yes
65	OSBORNE, HAWKINS & SPRANGERS (2006)	Individuals with chronic disease participating in the chronic disease self-management course	121 for questionnaire (112); 40 for interview (34)	63 (SD: 11.9) & 59 (SD: 11.0)	Longitudinal observational study	THEN TEST, Cognitive interviews	?	Health Education Impact Questionnaire (heiQ)	Recalibration	Yes
66	PERSSON, ENGSTROM, RYDEN, LARSSON & SULLIVAN (2005)	Chronic obstructive pulmonary disease patients	46	Adults	Longitudinal observational study	Factor analysis	Baseline; 1 year follow-up	Questionnaire describing 82 different life values	Reconceptualisation	No
67	POSTULART & ADANG (2000)	Patients undergoing kidney transplant	22 (4)	39.9	Longitudinal observational study	THEN TEST	Baseline before transplant; 5, 12 & 18 months follow-ups	Visual analogue scale (VAS), time trade-off (TTO), standard gamble (SG)	Recalibration	Yes

68	RAZMJOU, SCHWARTZ & HOLTBY (2010)	Patients undergoing rotator cuff surgery	107 (41)	57 (?)	Longitudinal observational study	THEN TEST	Baseline before the surgery; 2 months follow-up	American Shoulder and Elbow Surgeons questionnaire (ASES), Western Ontarion Rotator Cuff index (WORC)	Recalibration	Yes
69	RAZMJOU, SCHWARTZ, YEE & FINKELSTEIN (2009)	Patients undergoing total knee replacement surgery	231 (154)	67 (SD:10)	Longitudinal observational study	THEN TEST	Baseline before surgery; 6 & 12 months follow-up	SF: 36, Western Ontario and McMasters Universities Osteoarthritis questionnaire (WOMAC)	Recalibration	Yes
70	RAZMJOU, YEE, FORD & FINKELSTEIN (2006)	Patients undergoing total knee replacement surgery	125 (91)	68 (SD: 9.5)	Longitudinal observational study	THEN TEST	Baseline two weeks before the surgery; 6 months after surgery follow-up	Western Ontario and McMasters Universities Osteoarthritis questionnaire (WOMAC)	Recalibration	Yes
71	REES, CLARKE, WALDRON, O'BOYLE, EWINGS & MACDONAGH (2005)	Patients newly diagnosed patients with prostate cancer and controls	76 + 17 controls	72.8 (SD: 8.5) for patients & 71.8 for controls	Longitudinal observational study	THEN TEST	Baseline at the start of the treatment; 3 and 6 moths follow-ups	Prostate Symptom Score (IPSS), Symptom Score Index (SPI)	Recalibration	Yes
72	REISSMANN, REMMLER, JOHN, SCHIERZ & HIRSH (2012)	Individuals receiving partial or full prosthodontic treatment	126 (62)	54.8 (SD: 19.9)	Longitudinal observational study	THEN TEST	Baseline at the start of the treatment; 1 month after the end of treatment follow-up	Oral Health Impact Profile (OHIP)	Recalibration	Yes

73	RING, HOFER, HEUSTON, HARRIS & O'BOYLE (2005)	Edentulous patients receiving prosthodontic treatment	117 (78)	64 (SD: 8)	Longitudinal observational study	THEN TEST, SEIQoL-DW	Baseline, before the start of the treatment; 3 months follow-up	SEIQoL-DW	Recalibration Reprioritisation Reconceptualisation	Yes
74	SCHWARTZ, QUARANTO, RAPKIN, HEALY, VOLLMER & SPRANGER (2014)	Individuals with multiple sclerosis	859 (74.3%)	54.6 (SD: 9.2)	Longitudinal observational study	Regression based method (Multilevel mixed-effects regression modelling)	Baseline and 6 months follow-up	N/a	Not specified	Yes
75	SCHWARTZ & RAPKIN (2012)	Individuals with HIV/AIDS	521 (245)	45.36	Longitudinal observational study	THEN TEST	Baseline; 6 months follow-up	SF-36	Recalibration	Yes
76	SCHWARTZ, SAJOBI, LIX, QUARANTO & FINKELSTEIN (2013)	Individuals undergoing spine surgery	169 (75)	51 (16.46)	Longitudinal observational study	Regression based method	Baseline before the surgery and 3 weeks, 3 months & 6 months after the surgery follow-up	Visual Analogue Scale (VAS) for pain SF-36 Oswestry Disability Index (ODI)	Reprioritisation	Yes
77	SCHWARTZ, SPRANGERS, CAREY & REED (2004b)	Individuals with multiple sclerosis	93 (70)	43.01 (SD:9.19)	Longitudinal observational study	THEN TEST, Factor analysis	Baseline, 2 & 5 years follow-ups	Sickness Impact Profile (SIP), Multidimensional Assessment of Fatigue (MAF), Ryff happiness scale	Recalibration Reconceptualisation	Yes
78	SCHWARTZ, SPRANGERS, OORT, AHMED, BODE, LI & VOLLMER (2011)	Individuals with multiple sclerosis	3008	?	Cross-sectional observational study	SEM, Latent trajectory of residuals, Recursive partitioning and regression tree analysis	One measurement point	SF-12v2, PDDS: Patient Derived Disease Steps, The performance Scale (PDDS)	Recalibration Reprioritisation Reconceptualisation	Yes

79	SHARPE, BUTOW, SMITH, MCCONNELL & CLARKE (2005)	Individuals with a metastatic cancer receiving palliative care	38	?	Longitudinal observational study	SEIQoL-DW	Baseline, 3 & 6 months follow-ups	SEIQoL-DW	Reconceptualisation	Yes
80	SHI, LEE, LEE, UEN & CHIU (Shi *et al.*, 2011)	Patients receiving laparoscopic cholecystectomy	353 (206)	55.58 (SD:14.59)	Longitudinal observational study	THEN TEST	Baseline before surgery ; follow-up after surgery	Gastrointestinal Quality of Life Index (GIQLI)	Recalibration	Yes
81	SINCLAIR & BLACKBURN (2008)	Women with rheumatoid arthritis	19 (19)	47 (24-68)	Cross-sectional observational study	Semi-structured interviews Thematic analysis	One measurement point	N/a	Recalibration Reprioritisation Reconceptualisation	Yes
82	SPRANGERS, VAN DAM, BROERSEN, LODDER, WEVER, VISSER, OOSTERVELD & SMETS (1999)	Cancer patients undergoing radiotherapy	105 (63)	63 (28 - 89)	Longitudinal observational study	THEN TEST	Baseline before radiotherapy; after radiotherapy (4 or 7 weeks) follow-up	EORTC QLQ-C30, scale measuring fatigue; multidimensional fatigue inventory (MFI-20)	Recalibration	Yes
83	TIMMERMAN, ANTEUNIS & MEESTERS (2003)	Children with otitis media undergoing a surgery (proxy assessment by the parents)	77 (28)	? (12-38 months)	Longitudinal observational study	THEN TEST	Baseline before surgery; 6 weeks after the surgery follow-up	The otitis media-6 inventory (OM-6)	Recalibration	Yes
84	VISSER, OORT & SPRANGERS (2005)	Cancer patients undergoing surgery	170 (83)	57.5 (27-83)	Longitudinal observational study	THEN TEST, SEM, Self-anchoring task (Cantril's ladder)	Baseline; 3 months follow-up	SF-36	Recalibration	Yes
85	VISSER, OORT, VAN LANSCHOT, VAN DER VELDEN, KLOEK, GOUMA, SCHWARTZ & SPRANGERS (2013)	Individuals with cancer	202 (49%)	57.28 (SD: 14.2)	Longitudinal observational study	SEM	Baseline before surgery and 3 months after the surgery follow-up	Two-item Bodily Pain scale from the SF-36	N/a	Yes

86	VISSER, SMETS, SPRANGERS & DE HAES (2000)	Patients undergoing radiotherapy	199 (165)	64 (SD: 13)	Longitudinal observational study	THEN TEST	Baseline 2 weeks before radiotherapy; 2 weeks after radiotherapy follow-up	1 item scale measuring tiredness	Recalibration	Yes
87	WAGNER (2005)	Children with diabetes	38 (23)	11.9 (SD: 1.8)	Longitudinal observational study	THEN TEST	Baseline before two weeks camp for children with diabetes, follow-up after the camp	Problem Areas in Diabetes (PAID)	Recalibration	Yes
88	WESTERMAN, HAK, THE, ECHTELD, GROEN & VAN DER WAL (2007a)	Individuals receiving palliative care	21 (12)	58 (39-72)	Longitudinal observational study	SEIQoL-DW	Baseline start of chemotherapy; 4 weeks , after end of chemotherapy and 6 months follow-ups	SEIQoL-DW	Reconceptualisation	Yes
89	WESTERMAN, THE, SPRANGERS, GROEN, VAN DER WAL & HAK (2007b)	Individuals with small cell lung cancer	23	55 (42-69)	Longitudinal observational study	Thinking aloud when answering "Were you tired?"	Baseline at the start chemotherapy; 3 follow-ups: 4 weeks from the start, at the end of chemotherapy & 6 weeks from the end of chemotherapy	EORTC QLQ-C30	Recalibration	Yes
90	YARDEL & DIBB (2007)	Individuals with Meniere's disease, that are members of a self-help group	301 (182)	57.7 (21-86)	Longitudinal observational study	THEN TEST	Baseline; 10 months follow-up	SF-36	Recalibration	Yes

91	ZHANG, LI, XIE, LO, YANG, YEO, FONG & THUMBOO (2012)	Patients undergoing total knee replacement surgery	74 (60)	68 (63-76)	Longitudinal observational study	THEN TEST	Baseline; 18 months after surgery follow-up	EuroQoL, modified SF-36	Recalibration	Yes

The included studies are summarised in Table 2.3.1. In order to gain better insight into the current state of research on response shift each study was analysed in terms of the sample, study design, timeline (i.e. times between assessments), QoL measures used and types of response shift investigated. Each study was assessed on whether response shift was identified. Three options were available: “Yes”, “No”, “Inconclusive”. The following sections consider the findings of this review, referring to studies by using the index number in Table 2.3.1.

2.3.2.1 Sample

Sample sizes ranged from 9 (30) to 3008 (53, 78). Response shift was measured across the life span including children (e.g. 24, 50), adolescents (e.g. 34), adults (e.g. 19, 85) and older adults (e.g. 4, 58). Some studies investigated response shift in females only (e.g. 42, 81), whereas some others sampled only men (e.g. 48, 71). Studies were conducted in Canada (e.g. 1-5), USA (e.g. 87) UK (e.g. 90), the Netherlands (e.g. 37), Switzerland (e.g. 30), Japan (e.g. 36) or Germany (e.g. 72).

Most studies investigated response shift in relation to serious chronic and life threatening conditions and treatment or rehabilitation for these conditions. Response shift was most researched in relation to cancers (7, 8, 14-17, 21-23, 25, 27, 28, 36, 37, 41, 42, 47-49, 52, 55, 60, 64, 71, 79, 82, 84-86, 89), followed by arthritis (9, 24, 44, 68-70, 81, 91), stroke (3-6, 9, 10-12, 56, 57), multiple sclerosis (2, 46, 53, 74, 77, 78), cardiovascular disease (13, 29, 33, 38, 59), diabetes (24, 51, 87), obstructive pulmonary disease (1, 66), HIV/AIDS (61, 75) and sleep apnoea (26, 40). Very few studies investigated response shift in relatively mild health conditions, including individuals receiving hearing aids (43), and participants of a self-help group for Meniere’s disease (a disorder of the inner ear that causes temporal vertigo and partial hearing loss) (89). Additionally, two studies investigated response shift in the general population (32, 34).

Four studies investigated response shift in relation to oral health. One study in people with visibly broken, decayed or missing teeth (35) and three in people receiving partial or full prosthodontic treatment (45, 72, 73).

Overall, the review indicated that response shift was mostly explored in relation to serious chronic or life threatening health conditions (e.g. 52, 62) and much less in relation to relatively mild health conditions (e.g. 89).

2.3.2.2 Design

With few exceptions (14, 19, 39, 49, 60, 63, 78, 81) longitudinal designs were used. Most studies using one data collection point involved qualitative interviews (14, 39, 60, 63, 81). The length of time between assessments varied considerably with a minimum 1 week (31) and a maximum of 5 years (77). Most longitudinal studies used two (e.g. 29, 54) or three (e.g. 18, 79) assessment points. Few used four (24, 57, 67, 89), five (10, 11) or six (53) assessment points.

In most cases response shift was assessed among patients receiving treatment or undergoing a surgery. Other studies investigated response shift in relation to self-help or psychosocial interventions (51, 62, 90), rehabilitation (29) or palliative care (27, 30, 31, 79, 88). Some interventions were administrated as part of randomised clinical trial. However since the response shift was not the object of randomisation, these studies were classified as longitudinal observational studies. Some studies involved a secondary analysis of data from one (3, 54) or more studies (78).

2.3.2.3 QoL measures used to assess response shift

Studies used condition specific measures (e.g. 61, 71, 83), generic measures (e.g. 12, 56, 84) or a mixture of both (e.g. 11, 42, 76). Some studies used individualised QoL measures such as the Patient Generated Index (PGI) (4, 6) or Schedule for Evaluation of Individualised Quality of Life (SEIQoL) (19, 29, 30, 31, 38, 73, 79, 88). Finally, some studies identified response shift qualitatively relying on participants' accounts to search for evidence of response shift without administering a QoL questionnaire (13, 14, 35, 39, 60, 81).

2.3.2.4 Methods used to assess response shift

The most commonly used method to assess response shift was the THEN TEST, used by 54 of 91 studies (5-9, 15-19, 21, 22, 25-29, 32, 34, 37, 38, 40-45, 48, 50-52, 56, 58, 59, 61, 62, 65, 67-73, 75, 77, 80, 82-84, 86, 87, 91). Statistical methods were used in 31 studies including structural equation (14 studies 1, 6, 10-12, 33, 34, 46, 47, 59, 64, 78, 84, 85), regression based methods (7 studies 32, 36, 54, 55, 74, 76), factor analysis (5 studies 3, 8, 56, 66, 77), latent trajectory of residuals (4 studies 2, 56, 57, 78), recursive partitioning and regression tree analysis (3 studies 20, 53, 78) and growth curve analysis (1 study 24). Individualised methods (SEIQoL and PGI) were used in 10 studies (4, 6, 19, 29, 30, 31, 38, 73, 79, 88) and qualitative interviews in 9 studies (4, 13, 14, 35, 39, 49, 60, 65, 81). Additionally, one study each used free text questions (63), vignette rating (48) or a self-anchoring task (84). Only 17 studies used more than one approach (4, 6, 8, 17, 19, 28, 29, 32, 34, 38, 48, 53, 56, 59, 65, 73, 78).

2.3.2.5 Type of response shift measured

The most common type of response shift studied was recalibration which was considered in 43 studies (5, 7, 9, 13, 15, 16, 18, 20-22, 25-27, 39-45, 50-52, 58, 61, 65, 67-72, 75, 80, 82-84, 86, 87, 89-91). Reprioritisation was measured in 5 (23, 55, 20, 54, 76) and reconceptualisation in 3 (66, 79, 88).

Some studies measured more than one aspect. Recalibration and reconceptualisation were measured in 5 studies (6, 12, 37, 60, 77). Reprioritisation and reconceptualisation were measured in 4 (4, 19, 30, 31) and recalibration and reprioritisation were measured in 2 (17, 28). All three aspects of response shift were measured in 20 studies (1, 8, 10, 11, 14, 29, 32-34, 35, 39, 46, 47, 53, 56, 60, 64, 73, 78, 81). Seven studies did not specify which aspect of response shift was measured (2, 24, 36, 49, 57, 63, 74). Types of response shift measured were determined by the methods used. Studies that investigated more than one type used more than one method or relied on a method that allowed for assessing two or more types of response shift.

In addition to measuring one or more types of response shift some studies also investigated psychosocial contributors to response shift including antecedents, mechanisms and appraisal (7, 14, 29, 39, 45-47, 60, 63, 69, 74, 81, 85).

2.3.2.6 Evidence of response shift

The authors concluded that response shift occurred in most studies. Only 7 of the 91 studies did not detect response shift (3, 34, 44, 55, 59, 62, 66) and in 3 others the results were inconclusive (14, 22, 46). The studies that didn't reveal response shift used the THEN TEST, statistical techniques or both. In the case of the THEN TEST, response shift was not identified in those studies that tested alternative explanations for the score (e.g. 44, 62). Alternatively, in those studies using the THEN TEST in which alternative explanations were not analysed the occurrence of recalibration was automatically concluded (e.g. 41, 43).

In some studies, investigating more than one aspect, not all of the measured aspects were found. For example, in a study of cardiac patients using the THEN TEST (to assess recalibration) and Schedule for the Evaluation of Individual Quality of Life (to assess reprioritisation and reconceptualisation) reprioritisation and reconceptualisation but not recalibration were found (38). Additionally, response shift was found in some but not all participants in those studies that measured response shift at an individual level (e.g. 5, 53, 57, 65, 67).

2.3.2.7 Evidence of response shift in OHQoL

As noted earlier, four studies investigating response shift in relation to OHQoL were identified in the systematic search (35, 45, 72, 73).

One study (35) investigated how the subjective understanding of OHQoL varied between and within individuals through semi-structured interviews with people with noticeably broken, missing or decayed teeth. Grounded theory and systems theory were used to interpret the data. The subjective meaning of OHQoL depended on margins of relevance (varying from super-relevant to non-relevant) and the person's own positioning on seven dimensions: positioning of the norm, positioning of attribution, positioning of dentistry, positioning of accessibility, positioning of commodity, positioning of authenticity and positioning of character. The margins of relevance and the person's own position on the dimensions varied between people and within people over time, with the latter being an indication of response shift.

The remaining three studies investigated response shift in fully or partially edentulous patients receiving dentures (45, 72, 73). In two studies the THEN TEST was used to investigate recalibration (45, 72). Both studies found significant recalibration. On average, participants retrospectively rated their baseline OHQoL as worse than at the initial assessment. Additionally, one study (45) found that younger age, fewer replaced teeth and lower OHQoL at baseline were significant predicators of recalibration. Finally one study (73) combined an individual measure of QoL (i.e. Schedule for the Evaluation of Individual Quality of Life) and the THEN TEST to measure recalibration, reprioritisation and reconceptualisation. The participants retrospectively rated their QoL as lower than they had at the initial assessment indicating recalibration. Evidence of reprioritisation and reconceptualisation was also found. The way response shift was measured in this study poses some methodological concerns because it confused the assessments of reprioritisation, reconceptualisation and recalibration by adopting a method only designated to measure reprioritisation and reconceptualisation (i.e. Schedule for the Evaluation of Individual Quality of Life) to also measure recalibration by incorporating the THEN TEST into it.

2.3.3 Conclusion

Ninety one studies were found that had investigated one or more aspects of response shift across a range of conditions, age groups, geographical locations and time frames. A variety of methods have been applied. Overall, these studies found evidence of response shift.

Despite this, some gaps in the available evidence can be recognised. First, only a small number of studies used more than one method to measure response shift, which restricted the validity of the findings. Second, response shift was investigated in serious conditions so that little evidence is available in relation to relatively mild conditions. Third, most of studies focused on the measurement of response shift and a small number investigated the psychosocial factors influencing response shift. Finally, it should be noted that this review is restricted to the published data. Negative results (no evidence of response shift) might not have been published due to publication bias (Easterbrook *et al.*, 1991) and would therefore not be included in this review.

2.4 Response shift: Psychosocial contributors

The Sprangers and Schwartz (1999) and Rapkin and Schwartz (2004) models (Figure 2.2.1 and Figure 2.2.2) propose psychosocial mechanisms that contribute to the occurrence of response shift. Four groups of contributors are reviewed in this section:

- Catalyst
- Antecedents
- Mechanisms
- Appraisal

The review is based on studies that have investigated these contributors that were identified in the structured review, supplemented by relevant theoretical papers.

2.4.1 Catalyst

A catalyst is a change in health status such as a deterioration or an improvement, receiving treatment or experiencing any other event that might impact on QoL (Rapkin and Schwartz, 2004). Time might also be sufficient to act as a catalyst (Sprangers and Schwartz, 1999). According to Sprangers and Schwartz (1999) a catalyst initiates behavioural, cognitive and affective processes to accommodate the illness.

Most studies in the structured review implicitly accounted for the catalyst, as they investigated people undergoing changes in their health, including individuals newly diagnosed with disease (Rapkin and Schwartz, 2004; Broberger *et al.*, 2006), undergoing surgery (Balain *et al.*, 2009), receiving treatment (Andrykowski *et al.*, 2009), palliative care (Chow *et al.*, 2007; Echteld *et al.*, 2007), rehabilitation (Dempster *et al.*, 2010), psychosocial interventions (Osborne *et al.*, 2006; Kuijer *et al.*, 2007) and being members of a self-help group (Yardley and Dibb, 2007). In general, these studies supported the role of these catalysts. Most studies investigated individuals already diagnosed with an illness. An interesting exception compared QoL before and after receiving a diagnosis of a prostate cancer, in which response shift was identified in more than half of the participants (Korfage *et al.*, 2007).

The impact of the variability in catalysts has been investigated. Yardley and Dibb (2007) found that more severe symptoms at baseline indicated greater recalibration in self-assessed symptoms at follow-up. Andrykowski and colleagues (2009) investigated the impact of radiotherapy and chemotherapy on recalibration in women with breast cancer and found greater recalibration in those who received chemotherapy than in those who received

radiotherapy. The authors suggested that this was because chemotherapy caused more fatigue than radiotherapy and therefore provided more room for response shift. Stage of disease was not associated with recalibration. Finally, a meta-analysis by Schwartz and colleagues (2006) did not link the type of condition (cancers, neurological disease, primary care or other serious conditions such as liver transplant) and the magnitude of response shift. However, this is not surprising since most of the studies focused on serious conditions, with few studies addressing less severe ones.

Some studies employed control groups. Ahmed and colleagues (2004) found that recalibration took place in individuals with stroke but not in a control sample from the general population. Similarly, Chin and colleagues (2004) found that recalibration occurred in individuals who received treatment for obstructive sleep apnoea but not in those who didn't.

Limited evidence is available on response shift in the general population. Studies have conceptualised catalyst as life events such as: transition into adulthood (Gillison *et al.*, 2008), getting older (Galenkamp *et al.*, 2012), major life traumas (Inman and Ogden, 2011) and transition into university and homelessness (Ogden and Lo, 2012).The evidence is mixed. There was no evidence of response shift in community dwelling adolescents (Gillison *et al.*, 2008) or older adults (Galenkamp *et al.*, 2012). Response shift was found in people experiencing major life traumas (Inman and Ogden, 2011), in homeless and among first year university students (Ogden and Lo, 2012). However, the first two studies investigated response shift in relation to health related quality of life, whereas the latter two investigated the phenomenon in relation to QoL in general.

To conclude, the available evidence suggests that changes in a health status and receiving interventions act as a catalyst for response shift. Less evidence is available regarding other important life events in this role.

2.4.2 Antecedents

Antecedents refer to stable characteristics of the person including sociodemographic factors, personality, expectations and spiritual identity (Sprangers and Schwartz, 1999).

Age did not predict response shift in three studies (Yardley and Dibb, 2007; Andrykowski *et al.*, 2009; King-Kallimanis *et al.*, 2009). Conversely, Kimura and colleagues (2012) found that younger age predicted greater response shift. Gender did not predict response shift in two studies (Yardley and Dibb, 2007; Kimura *et al.*, 2012). Occupation (Andrykowski *et al.*, 2009) and educational level (Yardley and Dibb, 2007) did not predict response shift. Ogden and Lo

(2012) found that both homeless people and first year university students recalibrated their understanding of well-being, but the nature of recalibration was different for the two groups (i.e. different internal standards of measurement were adopted).

Optimism, defined in psychology as a general tendency to believe that more good than bad will happen to a person in the future (Carver *et al.*, 2010), was the most commonly investigated personality trait in relation to response shift. Yardley and Dibb (2007) found high optimism to be associated with less response shift whereas Kimura and colleagues (2012) concluded that optimism did not predict response shift. King-Kallimatis and colleagues (2011) found that although optimism was related to higher QoL across time, it was not related to response shift. Beeken and colleagues' (2011) qualitative study among stem cell transplant cancer survivors concluded that participants felt that optimism was important for their post-transplant adjustment. How this was linked to response shift was not explored.

Two other personality traits have been studied: self-esteem and health locus of control. Yardley and Dibb (2007) found that high self-esteem predicted greater response shift. Dempster and colleagues (2010) identified no relation between health locus of control and response shift. Additionally, Yardley and Dibb (2007) found that perceived control over illness did not predict response shift. No studies investigating expectations or spirituality were found.

Overall, there is limited evidence on the role of antecedents in response shift, and the available evidence is variable.

2.4.3 Mechanisms

Coping, social comparison, social support, goal reordering, reframing expectations and spiritual practice have all been proposed as mechanisms of response shift (Sprangers and Schwartz, 1999).

2.4.3.1 Coping

Coping is the process of managing stressors that have been appraised as taxing or exceeding a person's resources (Lazarus and Folkman, 1984). Coping can influence adaptation to illness. Seeking social support was associated with better adjustment whereas passive coping strategies predicted worse adjustments in patients with rheumatoid arthritis, chronic obstructive pulmonary disease and psoriasis (Scharloo *et al.*, 1998). Different classifications and typologies of coping have been proposed. Roth and Cohen (1986) distinguished between

avoidant and approach focused coping whereas Lazarus and Folkman (1984) described problem oriented, emotional and avoidant coping.

Richards and Folkman (2000) provided a possible explanation of how coping leads to response shift by linking it to adaptive coping theory and implicated one specific type of adaptive coping. Meaning-based coping occurs when a person draws on their values, beliefs and goals to modify the meaning of stressful situations (Folkman and Moskowitz, 2004). It is composed of 4 stages: (1) recognising that beliefs and expectations about things are unrealistic, (2) giving up those beliefs and expectations, (3) developing new beliefs and expectations, (4) adjusting goals and plans in accordance with the new beliefs and expectations.

To support their hypothesis, Richards and Folkman (2000) reinterpreted the results of a qualitative longitudinal study of coping among gay men who were primary care givers for partners diagnosed with AIDS, using the language of response shift. Some but not all caregivers maintained high levels of psychological well-being despite experiencing deteriorating and stressful circumstances, which was consistent with the notion of response shift.

In one case study, the partner of the caregiver entered the terminal stage of AIDS. The caregiver relinquished his expectations that his partner would live and then substituted his goals and expectations to ease the pain of his partner and focused on the spiritual aspects of preparing for his partner's death. Consequently, he was able to find meaning in this difficult situation. In the long term the experience of providing care didn’t adversely affect his well-being.

Richards and Folkman determined that all three types of response shift were apparent in the case histories. As participants lowered their expectations about their partners’ activity it can be argued that recalibration occurred. With the progression of their partners’ disease, participants shifted their focus towards more spiritual aspects of their relationship, suggesting reprioritisation. Finally, redefining the meaning of the situation can be seen as reconceptualisation.

Apart from listing meaning-based coping as a mechanism, Richards and Folkman don’t discuss how it fits into the model any further. It appears that meaning-based coping with its four stages and response shift might be overlapping phenomena.

Beeken and colleagues (2011) ascertained that participants with myeloma who received stem cell transplant engaged mainly in avoidant coping, which was positively associated with their QoL. How particular coping strategies related to response shift was not discussed. Dempster

and colleagues (2010) investigated 14 coping strategies (self-distraction, active coping, denial, substance use, emotional support, instrumental support, disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame) among 57 individuals attending cardiac rehabilitation. Only active coping strategies correlated with response shift.

Overall, little evidence is available on the role of coping in response shift.

2.4.3.2 Social comparison

Social comparison, a term first introduced by Festinger (1954), refers to the process in which individuals compare their own characteristics with those of others (Buunk and Gibbons, 1997). Depending on the situation, social comparison serves as a source of information on where one stands in the social world, a source of information on how to adapt to challenging situations or a way of making one feel better about oneself. Social comparison may be: downward (comparing oneself with someone who is worse-off) and upward (comparing oneself with someone who is better-off).

Social comparison, and especially downward social comparison, can influence adaptation to illness. Van der Zee and colleagues (1996) identified that downward social comparison was linked to better well-being among cancer patients. Upward social comparison might also positively influence well-being. For example, it prompted a sense of hopefulness and inspiration among cardiac patients (Helgeson and Taylor, 1993).

Gibbons (1999) suggested that social comparison mediates between significant life events such as changes in health status (i.e. a catalyst) and response shift. Alterations in social comparison, such as increases in the amount of social comparison and shifts in the level of the comparator result in response shift.

Gibbons' review of the social comparison literature suggested that some studies might implicitly reveal response shift. In one study, healthy participants became more satisfied with their health status after comparing themselves with hypothetical others with serious health problems (Dermer *et al.*, 1979). Gibbons suggested that this might have been indicative of recalibration as participants' standards of comparison altered. In another study, social comparison with a person with a visible physical disability resulted in a shift from focusing on academic abilities to focusing on physical health when judging overall well-being (Campbell *et al.*, 1978). This, according to Gibbons was indicative of reprioritisation.

Gibbons' review provided substantial evidence for the involvement of social comparison in response shift based on the available studies but he concluded that the exact nature of the relationship between the two requires further investigation. As in the case of meaning-based coping earlier, it is hard to distinguish between changes in social comparison and response shift as the two terms seem to be describing similar processes.

To test Gibbons' hypothesis, Hagedoorn and colleagues (2002) investigated the link between downward social comparison and response shift in individuals with cancer. Response shift occurred in those who thought they were doing better than others in a similar situation, but not in those who thought they were doing worse. This result supported Gibbon's hypothesis that social comparison mediates between change in health status and response shift.

Yardley and Dibb (2007) included 5 measures of social comparison in their study of 301 individuals with Ménière's disease: negative upward comparisons, positive upward comparison, negative downward comparison, positive downward comparison and comparison for information. Only negative upward comparison and comparison for information were associated with response shift. More social comparison predicted greater response shift. Beeken and colleagues (2011) found that more than half of their participants engaged in social comparison, most of whom found it to be helpful. However, the links between social comparison and response shift were not discussed. King-Kallimatis and colleagues (2009) found that although upward social comparison was associated with worse QoL at each measurement point, it was not associated with the occurrence of response shift.

Of the six mechanisms of response shift listed by Sprangers and Schwartz, social comparison has received the most attention. The empirical evidence suggests a links between social comparison (mainly downward) and response shift, good QoL and adaptation to the condition.

2.4.3.3 Social support

Social support refers to the help one can obtain from others and help we give to others. It has been defined as 'the existence or availability of people on whom we can rely, people who let us know that they care about, value and love us' (Sarason *et al.*, 1983) or 'a social network's provision of psychological and material resources intended to benefit an individual's ability to cope with stress' (Cohen, 2004). Social support has also been conceptualised through its possible dimensions. Cook and colleagues (1988) distinguished between emotional (i.e. providing empathy, caring, love, trust and esteem and listening), instrumental (i.e. providing aid in money, labour, time or any other direct help), informational (providing advice,

suggestions, directives and information) and appraisal support (i.e. providing affirmation, feedback, social comparison and self-evaluation).

Social support can influence QoL and facilitate adaptation to health conditions. Friedland and colleagues (1996) found that receiving emotional support was positively associated with QoL in a sample of HIV positive individuals.

Some evidence on the role of social support in response shift is available. A secondary analysis of a 2 year trial of peer social support in multiple sclerosis suggested that providing social support induced response shift, resulting in successful adaptation and an improvement in QoL among the providers (Schwartz and Sendor, 1999). The authors suggested that providing social support prompts downward social comparison which can result in recalibration and changed values (reprioritisation) by encouraging a community orientation. Self-transcendence experienced by the providers might reflect reconceptualisation. However, receiving social support did not cause similar changes or improve QoL in this study.

Beeken and colleagues (2011) reported that most of their participants said that they required support from others (mainly friends and family) in order to cope with their situations. Some declared that they would like somebody to talk to about their situations but lacked such a person. How social support might link to response shift was not discussed in this study.

Limited evidence is available regarding the role of social support in the occurrence of response shift. The available evidence suggests that social support fosters other mechanisms such as social comparison which then enable response shift. Additionally, social support is linked with improved QoL.

2.4.3.4 Goal reordering

Personal goals are central to subjective well-being and QoL (Brunstein, 1993; Diener *et al.*, 1999; Carver and Scheier, 2000). Assessment of one's QoL can be seen as a process in which current situation and goals are compared (Calman, 1984; Diener, 1984; Carr *et al.*, 2001). Scaling back goals or reordering the importance of goals is adaptational if deteriorating health no longer allows the pursuit of existing goals and can help to maintain satisfactory QoL (Schmitz *et al.*, 1996; Schroevers *et al.*, 2008).

Carver and Scheier (2000) suggested that many aspects of response shift can be explained in terms of adaptational changes in internal self-regulatory system responsible for the pursuit of personal goals. In the face of negative life changes, such as deteriorations in health, the pursuit

of previously established personal goals can no longer be possible. Upon noticing this, the self-regulation system will 'scale down' personal goals. Carver and Scheier theorised that if the self-regulatory system reports that the personal goals are pursuit the person experiences positive emotions and well-being. If the personal goals are not successful pursuit then negative emotions and decrease well-being results. Therefore, scaling back goals re-establishes well-being.

Studies exploring goal reordering were found in the structured review. Among individuals with AIDS changes in personal goals reflected reconceptualisation (when the person changes their personal goals) and reprioritisation (when a person changes a relative importance of their personal goals) (Rapkin, 2000). Participants changed their personal goals mainly by adding additional goals in different life domains in response to changed health, which resulted in deteriorations or improvements in health.

Beeken and colleagues (2011) found that new goal setting (often small and easily available goals but not necessarily related to health) among post stem cell transplant individuals served as a source of distraction and fostered a sense of achievement, therefore assisting in adaptation to deteriorating health.

Additionally, studies using individualised measures such as SEIQoL or PGI (see Section 2.5.1.2 and Section 2.5.1.3) are directly interpretable in terms of changes in personal goals. Sharpe and colleagues (2005) used SEIQoL and found that individuals with advanced cancer limited the number of the nominated important life domains (on average they provide three goals out of the required five). This can be interpreted in terms of 'scaling back goals' as described by Carver and Scheier (Carver and Scheier, 2000; Sharpe and Curran, 2006).

Overall, the available evidence on goal and reordering and response shift suggests that the two concepts describe very similar phenomena, so that it is difficult to distinguish between goal reordering as a mechanism and as an indicator of response shift.

2.4.3.5 Reframing expectations

Reframing expectations can be understand in terms of increases or decreases in expectations towards QoL (Allison *et al.*, 1997; Carr *et al.*, 2001).

In one study, most participants identified reframing expectations as an important part of adjustment to life after stem cell transplant (Beeken *et al.*, 2011). Several examples of reframed expectations were provided: accepting a shortened lifespan, focusing on a short

term future and lowering expectations of physical health. For some participants, reframing expectations was easy whereas others found it difficult.

2.4.3.6 Spiritual practice

Sprangers and Schwartz (1999) suggested that engaging in spiritual practice (e.g. praying or reading religious texts) might result in response shift. Spiritual practice has been identified as a successful approach to coping with health conditions (Folkman and Moskowitz, 2004; Buessing *et al.*, 2009). It was also associated with better QoL (Visser *et al.*, 2010). However, the literature search revealed no studies investigating its role in response shift.

2.4.3.7 Appraisal

Appraisal is a recent addition to the response shift model (Rapkin and Schwartz, 2004) (Section 2.2.3.). Rapkin and Schwartz (2004) proposed that changes in the appraisal (including changes in frames of reference, sampling strategy and standards of comparison) indicate response shift and are responsible for bias in the assessment of QoL over time. The data on appraisal can be collected using interviews (Taminiau-Bloem *et al.*, 2010), open ended questions in a questionnaire (Ogden and Lo, 2012) and questionnaires using both open ended and multiple choice questions such as the QoL appraisal profile prosed by Rapkin and Schwartz (2004) to measure appraisal in people with HIV/AIDS (Li and Rapkin, 2009; Schwartz and Rapkin, 2012; Schwartz *et al.*, 2014). The data can be analysed qualitatively (Taminiau-Bloem *et al.*, 2010; Ogden and Lo, 2012) or quantitatively (after the initial coding of the quantitative data) using techniques such as classification and regression tree analysis (Li and Rapkin, 2009), factor analysis (Schwartz and Rapkin, 2012) and regression analysis (Schwartz *et al.*, 2014).

Overall, studies have found that changes in appraisal occur as a result of illness or receiving treatment (Li and Rapkin, 2009; Taminiau-Bloem *et al.*, 2010; Schwartz *et al.*, 2014). However, these studies also indicated that changes go beyond those associated with such catalysts to include changed appraisals by people whose symptoms are constant (Schwartz *et al.*, 2014), differences between people on the same measurement occasion (Taminiau-Bloem *et al.*, 2010; Ogden and Lo, 2012) and within a person at one measurement point but for different QoL items (Taminiau-Bloem *et al.*, 2010). Generally, changes in appraisal that occurred over time were interpreted as indicating response shift.

2.4.3.8 Response shift as a mechanism of adaptation.

In addition to studies investigating psychosocial mechanisms of response shift, several studies have qualitatively identified response shift as a mechanism of adaptation (Sinclair and Blackburn, 2008; Inman and Ogden, 2011; Neuman *et al.*, 2012).

For example, Sinclair and Blackburn (2008) investigated adaptive coping in women with rheumatoid arthritis using in-depth interviews and thematic analysis. The authors decided that the most suitable framework to describe the pattern of adaptive coping in the study was response shift, with its three types (recalibration, reprioritisation and reconceptualisation). Successful adaptation was marked by regaining a sense of control over one's life and illness in three stages. First, recalibration occurred through accepting more realistic expectations towards one's performance and abandoning perfectionism. Second, reprioritisation occurred through reconsideration of life goals and adopting more reasonable goals as well as putting more emphasis on personal growth. Finally, reconceptualisation occurred through reconsidering the meaning of life with a progressive debilitating condition.

2.4.4 Conclusion

Despite many studies in response shift, only a small number have investigated catalyst, antecedents, mechanisms or appraisal. Therefore, little evidence is available on their role or in empirically supporting the existing models of response shift.

The available evidence provides a complex picture of links between the psychosocial contributors and response shift. Different catalysts (e.g. the onset of the condition, self-help interventions of major life traumas) initiated response shift. The link between antecedents and response shift is unclear. For example, optimism could be unrelated to response shift (Kimura *et al.*, 2012), related to lower response shift (Yardley and Dibb, 2007) and not related to response shift but predicting better QoL (King-Kallimanis *et al.*, 2011).

Mechanisms including coping, social comparison, social support and goal reordering appeared to be implicated in response shift. However, the distinction between the mechanism and the response shift itself was often unclear, so that the two seemed to overlap. For example, the similarity between goal reordering and reprioritisation is striking (Rapkin, 2000).

Finally, changes in appraisal indicative of response shift were found in a number of studies. However changes in appraisal were prevalent not only within individuals as a result of

catalysts, but also between individuals, within individuals with constant health and within individuals during one assessment for different items.

To conclude, research is needed to explore the links between catalyst, antecedents, mechanisms, appraisal and response shift (including recalibration, reprioritisation and reconceptualisation). Thus, the models of response shift require investigation.

2.5 Response shift: Assessment

This section discusses methods to assess response shift.

The first suggestions on how to measure response shift were formulated in educational and organisational research. The THEN TEST, the IDEALS and different variants of factor analysis were proposed (Golembiewski *et al.*, 1976; Zmud and Armenakis, 1978; Howard and Dailey, 1979; Schmitt *et al.*, 1984).

In the area of QoL, potentially useful methods to measure and account for response shift were proposed by Schwartz and Sprangers (1999). Along with the approaches already used in educational and organisational research, the authors also described new techniques they believed were potentially useful. These approaches were classified into six groups: (1) individualised methods, (2) preference based methods, (3) successive comparison approaches, (4) design approaches, (5) statistical approaches, and (6) qualitative methods. Within each group specific techniques were described. Barclay-Goddard and colleagues (2009a) later updated the list with approaches that were commonly used in the field or showed promise for future research. Most recently, in 2013 Schwartz and colleagues (Schwartz *et al.*, 2013) reviewed the available statistical techniques.

The approaches proposed by these authors are summarised in Table 2.5.1. The comparison across columns shows how the field of response shift in QoL has evolved since its formulation in 1999. The methods discussed by Schwartz and Sprangers and by Barclay-Goddard and colleagues overlap only to an extent. The methods mentioned by both groups include: SEIQoL, the THEN TEST, factor analysis and growth curve modelling. Some methods (e.g. preference based methods) proposed by Schwartz and Sprangers have not been employed and therefore were not discussed by Barclay-Goddard and colleagues. New methods, such as PGI, SEM and qualitative interviews were discussed by Barclay-Goddard and colleagues but not by Schwartz and Sprangers. Finally, since the publication of Barclay-Goddard and colleagues' review new statistical methods, such as recursive partitioning and regression tree analysis have been employed (Schwartz *et al.*, 2013).

The available approaches are described in the sections that follow. The discussion is guided by the initial Schwartz and Sprangers classification (Table 2.5.1) and by the results of the structured review performed in Section 2.3. The ability to capture different types of response shift, to measure response shift at the individual vs. group level and the advantages and disadvantages of each method are described.

Table 2.5.1 Method to assess of response shift

Method	Schwartz & Sprangers (1999)	Barclay-Goddard & colleagues (2009)	Schwartz & colleagues (2013)*
Individualised measures			
Repertory grid technique	✓	-	n/a
Cantril's ladder	✓	-	n/a
SEIQoL: The Schedule for the Evaluation of Individual Quality of Life	✓	✓	n/a
PGI: Person Generated Index	-	✓	n/a
Preference based methods			
The Extended Q-TWiST	✓	-	n/a
The Preference Mapping Method	✓	-	n/a
Successive Comparison Approaches			
Pairwise comparison	✓	-	n/a
Card sort approach	✓	-	n/a
Design approaches			
THEN TEST	✓	✓	n/a
IDEALS	✓	-	n/a
Questionnaires with direct questions assessing response shift	-	✓	n/a
Statistical approaches			
Factor analysis	✓	✓	-
Growth curve modelling	✓	✓	✓
Latent trajectory of residuals	-	✓	✓
SEM: Structural Equation Modelling	-	✓	✓
Recursive Partitioning and regression tree analysis	-	-	✓
Regression based methods	-	✓	✓
Rasch analysis	-	✓	-
Qualitative methods			
Idiographic assessment of personal goals	✓	-	n/a
In-depth and semi-structured interviews	-	✓	n/a

*statistical methods only

2.5.1 Individualised methods

Schwartz and Sprangers (1999) defined individualised methods as approaches that 'recognise and respect the individual's own values and relative importance of life domains'. These methods identify the values and life domains that are important for the particular person and note their relative importance at that point in time. Therefore, individualised methods can be used to detect reprioritisation and reconceptualisation. This is with the exception of Cantril's ladder, which can measure recalibration.

Individualised methods allow for the assessment of response shift at the individual level and any changes in values and life domains for a person can be described qualitatively. Representing the changes in values in a numerical way and aggregating them at a group levels required further translation of qualitative data into numerical representations and the performance of additional statistical techniques (e.g. factors analysis).

Four types of individualised methods are discussed:

- The Repertory Grid Technique
- The Schedule for Evaluation of Individual Quality of Life (SEIQoL)
- Patients Generated Index (PGI)
- Cantril's Ladder

2.5.1.1 The Repertory Grid technique

Repertory Grid Technique measures the person's individual construct system (i.e. the mental representational system used to interpret a particular aspect of reality and to predict future events) (Kelly, 1963).

A repertory grid is created during a semi-structured interview (Bannister and Fransella, 1966). The grid consists of four elements (Figure 2.5.1) :

- Topic, represents a particular aspect of reality (e.g. QoL)
- Elements, represent examples of a topic (e.g. individuals experiencing different levels of QoL including the participants)
- Bipolar constructs, represent a way in which a person interprets their reality (e.g. different aspects of QoL, such as having a lot of energy all day vs. feeling weak all day)
- Scores, that the person awards to the different elements on their nominated constructs.

During the interview the person nominates elements and constructs for a particular topic and then scores the elements.

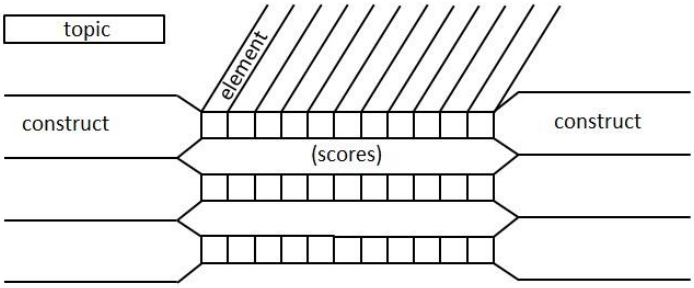


Figure 2.5.1 The Repertory Grid Technique (Kelly, 1963)

Two QoL measures: the Thunedborg Grid and SmithKline Beecham Quality of Life Scale are based on the repertory grid technique.

The Thunedborg Grid was designed to assess QoL in clinical trials (Thunedborg *et al.*, 1993). Administrated at the end of the trial, it delivers a single QoL score for each person representing the proportion of the perceived improvement (assessed retrospectively by comparing the scores for the 'as you are now' and 'as you were before the treatment') and the improvement a person would wish to obtain as a result of the treatment ('as you wish you were'). The method was accepted by patients, and showed good discriminant validity (Thunedborg *et al.*, 1993). Most of the constructs are predefined, which limits its applicability to detect reprioritisation and reconceptualisation. Because of its retrospective nature this method shares some characteristics with the THEN TEST (Section 2.5.4.2). The comparison between the actual improvement and the improvement the person would like is also shared with the IDEALS (Section 2.5.4.1).

The SmithKline Beecham Quality of Life Scale consists of 23 predetermined constructs representing different domains of QoL and 3 elements: self now, ideal self and sick self (Stoker *et al.*, 1992). The final score can be calculated in several ways: the total score over 23 elements for the self now, or the scores for ideal self and self now can be compared. This scale was validated in individuals experiencing mental health problems (Stoker *et al.*, 1992). Test retest reliability and internal consistency were high, criterion validity was good. As in the case of the Thunedborg Grid, this method shares characteristics with the IDEALS (Section 2.5.4.1).

No studies using a repertory grid to measure response shift were identified through the structured review.

2.5.1.2 SEIQoL: The Schedule for the Evaluation of Individual Quality of Life

SEIQoL is an individualised QoL scale that allows individuals to nominate, assess and weight those life domains that have the greatest impact on their overall QoL (Browne *et al.*, 1994). It is not a health related or disease specific approach. However it is mainly used in the area of health related quality of life. SEIQoL is administered as a semi structured interview (O'Boyle, 1994). Individuals nominate five domains that have the greatest impact on their overall QoL. Then, they assess their current level of functioning within each domain on a 0-100 vertical scale (0 being the worst and 100 being the best possible). The anchors enable the use of individuals' own criteria within each domain. Then, individuals weight the relative importance of each domain using either a Judgement Analysis (O'Boyle, 1994) or Direct Weightings procedure (SEIQoL-DW) (Farquhar *et al.*, 2010), depending on the version of a questionnaire. A comprehensive QoL profile (including the nominated domains, their relative importance and scoring for each domain) as well as a single 0-100 score can be obtained.

Eight studies using SEIQoL to investigate response shift were found in the structured review (Echteld *et al.*, 2005; Ring *et al.*, 2005; Sharpe *et al.*, 2005; Echteld *et al.*, 2007; Westerman *et al.*, 2007a; Blair *et al.*, 2010; Dempster *et al.*, 2010; Hoefer *et al.*, 2011). Overall, these studies indicated reprioritisation and reconceptualisation. For example, Westerman and colleagues (2007a) investigated 21 patients receiving palliative care for cancer on four occasions using SEIQoL-DW. In most participants between one and three life domains changed from baseline to the follow-up, indicating reconceptualisation. The relative importance of health changed in most participants with some weighting health as more and others as less important at follow-up, indicating reprioritisation. Overall QoL improved from baseline to follow-up which is another indicator of response shift. The adaptive nature of response shift was also evident as, with time, participants refocused on more positive aspects of their lives. That is, those domains weighted higher in relative importance were those where participants were more satisfied.

2.5.1.3 PGI: Patient Generated Index

The Patient Generated Index (PGI) is an individualised quality of life measure that allows individuals to quantify the difference between their hopes and ambitions, and the extent to which these are matched considering their current situation (Ruta *et al.*, 1994). First, participants nominate five life domains that they find most affected by their health condition. A sixth domain is provided to cover all the other aspects of life. In the newer versions a seventh domain is used to differentiate between health-related areas and non-health related

areas not already nominated (Martin *et al.*, 2007). Then participants assess the extent to which they are affected by the health condition in each nominated area on a scale with the bottom anchor being the worst and top anchor being the best they can imagine. Finally, participants distribute 'points' among the nominated areas to indicate which domain they would like to improve most, or which domain is most important for their QoL, depending on the version (Ruta *et al.*, 1994; Martin *et al.*, 2007). The final scores range between 0 - 100.

Two studies employing PGI were found in the structured review (Ahmed *et al.*, 2005b; Ahmed *et al.*, 2005c). Ahmed and colleagues (2005b) followed-up 92 post stroke patients 6 and 24 weeks post stroke. Most participants nominated entirely different life domains as being affected by the stroke on the two occasions, which was interpreted as indicative of reprioritisation.

2.5.1.4 Cantril's Ladder

In Cantril's ladder (Cantril, 1965), participants are first asked to define the bottom and the top of the scale using their own assumptions, perceptions, goals and values. For example, to imagine and to describe the best and the worst possible life. These descriptions are used to define the bottom and the top of the ladder. Thus, the continuum is self-defined with 11 steps on a ladder numbered from 0 to 10 (Figure 2.5.2). Participants assess themselves three times: with respect to the way things are at present, with respect to the way things were in the past (e.g. five years ago) and finally, with respect to the way they predict things will be in the future (e.g. in five years' time). Although generally used to assess life satisfaction, Cantril's ladder can be used to assess QoL.

The ladder follows the assumption that standards may differ with time as well as across individuals, groups of people and societies. The instrument was designed to encompass the reality in which people's views are expressed in their own terms to allow comparison between groups of individuals and societies (Cantril, 1965).

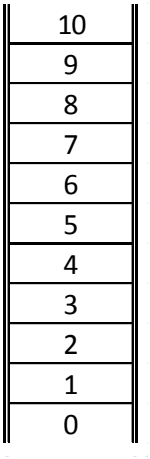


Figure 2.5.2 Cantril's ladder (Cantril's, 1965)

In contrast to other individualised methods, Cantril's ladder is most suited to detect recalibration by comparing the definitions of the top and bottom reference points given over time (Schwartz and Sprangers, 1999) and can be used at the individual level. Additional techniques are applied to aggregate the data at a group level.

Visser and colleagues (2005) investigated the convergent validity of the THEN TEST, SEM and the Cantril's ladder (which the authors labelled as the anchor recalibration task) to assess response shift. While the first two approaches showed similar results in the detection of recalibration, the Cantril's ladder differed substantially and seemed to detect a different concept. However, no other studies using Cantril's ladder were identified, therefore it is not possible to establish its validity.

2.5.2 Preference based methods

Preference based methods draw on the tools used in health economics, such as time trade off, utilities and Quality Adjusted Life Years (QALY's). In these methods an individual places values on a particular health state or QoL domain at different points in time (Schwartz and Sprangers, 1999). Because preference based methods trace shifts in preferences Schwartz and Sprangers suggested that these methods can be used to detect reprioritisation.

Two examples of preference based methods were proposed by Schwartz and Sprangers (1999): The Extended Q-TWiST (Quality-Adjusted-Time Without Symptoms and Toxicity) approach and the Preference Mapping Method. In the Extended Q-TWiST approach the preferences or utilities for particular health states or QoL domains are collected at different time points over the course of an illness and turned onto Quality Adjusted Life Years (QALY's) (Schwartz *et al.*, 1995; Schwartz and Sprangers, 1999). The Preference Mapping Method records preferences or

utilities for a predefined health state, the person's self-assessed health state and their 'objective' health state (measured via objective criteria) (Sugar *et al.*, 1998; Schwartz and Sprangers, 1999). These data indicate change in the person's preference as a function of their 'objective' health state. The reliability and validity of both approaches depends on the QoL measures and clinical indicators integrated into the two methods.

While health economics often finds discrepancies between valuations of health state between sick people and the general public that might indicate response shift (Ubel *et al.*, 2003; Krabbe *et al.*, 2011), no studies were identified explicitly measuring response shift using these methods. They were also not mentioned in the narrative review by Barclay-Goddard and colleagues (2009a).

2.5.3 Successive comparison approaches

Successive comparison approaches involve a series of judgements on the relative importance of different QoL domains over time (Schwartz and Sprangers, 1999). These methods can be used to indicate reprioritisation and reconceptualisation at the individual level. However, accounting for reprioritisation or reconceptualisation, when calculating QoL, is not possible.

2.5.3.1 Pairwise comparison

Pairwise comparisons require individuals to compare pairs of different QoL domains, to decide which QoL are domains placed higher. Once each QoL domain is compared with all others a statistical analysis constructs an interval scale describing a continuum of the importance of different QoL domains. Repeated assessments over time will indicate reprioritisation and reconceptualisation. This method was first described by Thurstone (1927) and named a 'law of comparative judgement'. The method of pairwise comparisons is well established and its validity has been demonstrated in many areas such as psychology, educational studies, economics and health care. No studies using pairwise comparison in response shift were identified through the systematic search.

2.5.3.2 Card sort approach

In the card sort approach participants are given a sorting sheet to rate the importance of different QoL domains (Schwartz and Sprangers, 1999). The sorting sheet contains boxes ordered from "not at all important" to "extremely important". Participants place a card representing a particular domain in each box. As with the pairwise comparison, the card sort

approach is a well-established method in psychological research. No studies using it to study response shift were identified in the systematic search.

2.5.4 Design approaches

Three study design approaches to investigate response shift were described in the literature:

- IDEALS
- THEN TEST
- Questionnaires with direct questions about response shift

2.5.4.1 IDEALS

In the IDEALS study design a person evaluates their QoL twice at each assessment:

- at baseline
    - on how they are at the moment ('actual')
    - on how they would like things to be ideally ('ideal')
- at follow-up
    - on how they are at the moment ('actual')
    - on how they would like things to be ideally ('ideal')

The IDEALS approach was first proposed to measure the effectiveness of organisational interventions such as leadership training, taking into account potential recalibration (Zmud and Armenakis, 1978; Armenakis and Zmud, 1979). The IDEALS measures recalibration, by comparing 'ideal' scores over time (Sprangers and Schwartz, 1999). It is also possible to measure change adjusted for recalibration by this approach (Schmitt *et al.*, 1984).

There are several advantages to the use of the IDEALS. First it can be incorporated into an existing QoL instrument. Second, response shift can be investigated for any two measurement points for which QoL was assessed using the IDEALS approach. Finally, the distance between the 'actual' and 'ideal' scores can be determined for each measurement point. Therefore, the IDEALS is compatible with the view of QoL as the discrepancy between the experienced QoL and the QoL a person would like to have (Calman, 1984; Carr *et al.*, 2001). An effect size representing the magnitude of recalibration can be calculated.

The IDEALS approach has been criticised for being prone to ceiling effects, and its inability to distinguish between recalibration and reconceptualisation (Terborg *et al.*, 1982). However, the IDEALS discriminated between groups than had and had not received an intervention to

prompt recalibration, no ceiling effect was found in this study (Buckley and Armenakis, 1987). Additionally, this method places a burden on the participants as the number of items is doubled at each assessment.

No studies using the IDEALS approach to measure response shift in the area of QoL were found in the structured review.

2.5.4.2 THEN TEST

In the THEN TEST, a person evaluates their QoL on two occasions:

- at baseline
    - on how they are at the moment ('pre')
- at follow-up
    - on how they are at the moment ('post')
    - on how they now think they were at the baseline assessment ('then')

The THEN TEST was also proposed to overcoming response shift bias in educational and organisational research (Howard and Dailey, 1979; Terborg *et al.*, 1980).

In one study, a conventional assessment of interviewing skills showed little improvement following training and some participants rated their interviewing skills as lower after the training (Howard and Dailey, 1979). This was attributed to the change in participants' understanding of what 'good interviewing skills' mean. That is, the 'post' assessment was based on higher standards than the 'pre' assessment. These different standards represented response shift causing an underestimation of the effect of the training.

The THEN TEST method was proposed to overcome this recalibration. This method assumes that 'then' and 'post' assessments are based on the same internal standard of measurement and are free of response shift bias. Indeed, Howard and Dailey obtained greater estimates of change due to the training using the THEN TEST than using the conventional approach (Howard and Dailey, 1979).

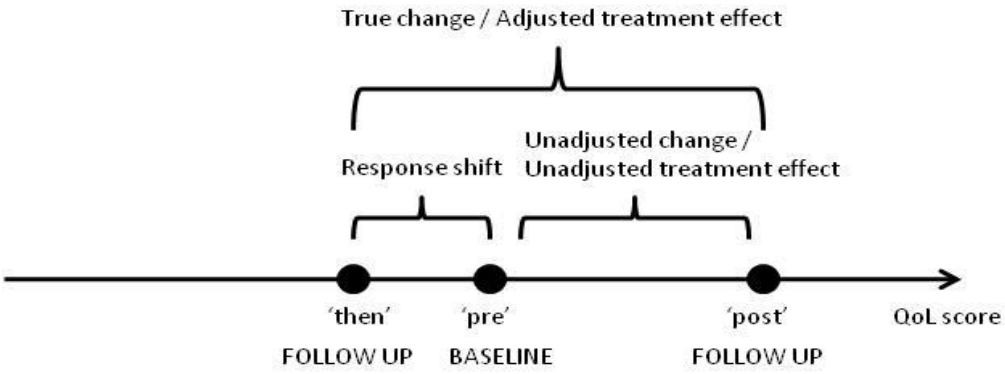


Figure 2.5.3 The THEN TEST design

Schwartz and Sprangers (1999) suggested that the THEN TEST could be used to measure recalibration in QoL assessment. The results 'pre', 'post, and 'then' scores are used to calculated unadjusted change, adjusted change and recalibration (Schwartz and Sprangers, 1999; Sprangers *et al.*, 1999) (Figure 2.5.3). The distance between the 'pre' and 'post' scores indicates unadjusted change. The distance between 'then' and 'post' indicates adjusted change and recalibration is indicated by the distance between the 'pre' and 'then' scores.

The THEN TEST is among the most frequently used methods to assess response shift as it offers several advantages. It can be applied to any QoL measure and only one additional version of the measure has to be administered at follow-up, which minimises the burden for participants. The instructions have been repeatedly found to be easy to understand (Schwartz and Sprangers, 2010). Simple statistical analyses such as t-tests and ANOVA (or its non-parametric equivalents) can be used to analyse the data. Finally, the THEN TEST allows for the calculation of the adjusted change and the effect size for recalibration.

Another possible advantage of the THEN TEST is that it tends to indicate greater improvements in QoL as a result of interventions than conventional assessments (Joore *et al.*, 2002; Timmerman *et al.*, 2003; Hill and Betz, 2005). While these greater improvements can be interpreted as a result of more valid assessment they may also result from multiple biases including: recall bias, effort justification, social desirability and implicit theory of change (Hill and Betz, 2005; Streiner and Norman, 2008).

Recall bias occurs when the 'then' rating (the retrospective rating) is distorted by the person's difficulty recalling past events (Schwartz and Rapkin, 2004). In one study, people with poor memory post stroke showed a greater variability in their 'then' scores than post stroke individuals with good memory (Ahmed *et al.*, 2004). This suggests that cognitive functioning influences the susceptibility to recall bias. Neuropsychological and subjective memory tests

were recommended to detect potential problem with memory functioning (Schwartz and Sprangers, 2010).

Social desirability bias relates to the wish to 'look good to other people' (Furr, 2010). Such as showing improvement from an intervention. Therefore, social desirability bias might lower retrospective ratings ('then') One way of controlling for social desirability it to use a social desirability questionnaire to measure its levels in participants (Norman and Parker, 1996).

Impression management bias occurs when people are generally more critical about their past self than their present self, regardless of whether an actual improvement has taken place (Wilson and Ross, 2001; Hill and Betz, 2005). Therefore, impression management bias will make retrospective ratings ('pre') worse to make people look better now, regardless of whether there has been an intervention, change in health or shift in the internal standards of measurement (recalibration) (Hill and Betz, 2005).

Effort justification bias may occur when a has person invested time and other resources in an intervention especially if the treatment have been particularly unpleasant and involved significant side effects (Hill and Betz, 2005). As part of effort justification bias, a person might retrospectively ('then') assess themselves as worse off to justify undergoing the treatment.

According to the implicit theory of change, in most cases a person is unable to recall past experiences, especially if the referent time was not salient or memorable. Instead, the person applies a specific heuristic in order to assess QoL in the past. First, the person assesses their present state and then asks how things might have changed to produce the retrospective ('then') QoL score (Norman, 2003).

Sprangers and Schwartz (2010) produced guidelines on study design, data analysis and testing for alternative explanations when assessing response shift via the THEN TEST and suggested using other methods to triangulate the findings from the THEN TESTs. Additionally the use of cognitive interviewing (when a person 'thinks aloud' when answering an item) can be used to investigate the potential biases of the THEN TEST (Rapkin and Schwartz, 2004; Bloem *et al.*, 2008; Schwartz and Sprangers, 2010).

Over 50 studies have employed the THEN TEST alone or in combination with other methods and its validity was investigated in a number of them (Table 2.3.1). The estimated levels of changes obtained with THEN TESTs were more strongly associated with objective criteria (e.g. clinical assessments or change in behaviours assessed by external observers) both in QoL and educational research (Howard *et al.*, 1979; Sprangers and Hoogstraten, 1989; Sprangers, 1996).

The THEN TEST also had good convergent validity with other methods of response shift measurement, such as SEM (Ahmed *et al.*, 2005a).

2.5.4.3 Questionnaires with direct questions assessing response shift

Barclay-Goddard and colleagues (2009a) suggested direct questioning about recalibration, reprioritisation and reconceptualisation as a possible way of investigating response shift. The direct questions could be incorporated into questionnaires or asked in semi-structured interviews. Using this method response shift can be investigated both at an individual and a group level. A possible limitation of this method is that it requires the person to be cognitively aware of their response shift (Barclay-Goddard *et al.*, 2009a), which they may not be.

No studies that explicitly used this method were found in the structured review. However, one study, that used a questionnaire with items designed specifically to capture response shift (e.g. 'I now realise I was better off than I thought I was'), found evidence of recalibration as a result of participating in a self-help intervention for chronic disease (Osborne *et al.*, 2006).

2.5.5 Statistical approaches

In statistical approaches longitudinal questionnaire data are analysed to find evidence of response shift. Naturally, restrictions on the sample size and number of measurement points exist (Schwartz *et al.*, 2013). Statistical methods can be used to secondary analyse existing data and more than one technique can be applied to the same data set (Schwartz *et al.*, 2013). Indeed, a number of secondary analyses to investigate response shift have been conducted (Hagedoorn *et al.*, 2002; Mayo *et al.*, 2009; Boucekine *et al.*, 2013; Lix *et al.*, 2013). One or more aspects of response shift can be measured using statistic approaches, although some approaches (i.e. growth curve analysis) only infer the occurrence of response shift without indicating its particular type. Depending on the technique, response shift can be analysed at a group level (e.g. SEM, factor analysis) or at an individual level (e.g. latent trajectory of individuals). Two (e.g. factor analysis, SEM) or more (e.g. growth curve analysis) assessment points are needed to perform the analysis. Statistical methods allow for the assessment of the magnitude of response shift by calculating effect sizes, with the exception of recursive partitioning and regression tree analysis, for which no way to calculate effect sizes has been proposed to date (Schwartz *et al.*, 2013). The available techniques were recently, summarised by Schwartz and colleagues (2013) who also produced guidelines on secondary analysis to search for response shift.

In this review 7 types of statistical approaches are described: factor analysis, growth curve modelling, structural equation modelling (SEM), latent trajectory of residuals, regression based method (multivariate multilevel methods), recursive partitioning and regression tree analysis and Rasch analysis.

2.5.5.1 Factor analysis

Factor analysis was proposed to measure response shift in educational and organisational research (Golembiewski *et al.*, 1976; Howard and Dailey, 1979; Schmitt *et al.*, 1984). Changes in the factor structure of questionnaires between baseline and follow-up may indicate reconceptualisation, whereas changes in the factor loadings may indicate recalibration (Schmitt *et al.*, 1984; Ahmed *et al.*, 2005a). Factor analysis can only detect response shift at a group level if significant proportion of the individuals manifest a similar pattern of response shift (Oort, 2005). Schwartz and Sprangers (1999) discussed several drawback of factory analysis, including dependence on large samples and the lack of clear guidelines on how to distinguish between recalibration and reconceptualisation. Additionally, because it relies on the administration of the same items it might not detect reconceptualisation that is not captured by those items. Finally, recalibration is not assessed explicitly but inferred based on analyses that were initially developed to measure reconceptualisation (Schwartz and Sprangers, 1999).

Several studies using factor analysis were identified in the structured review (Schwartz *et al.*, 2004b; Ahmed *et al.*, 2005a; Persson *et al.*, 2005; Mayo *et al.*, 2009; Anota *et al.*, 2014). Overall, these studies detected response shift. In contrast, Ahmed and colleagues (2005a) found no evidence of recalibration and reconceptualisation in individuals post intervention or in healthy controls. The authors suggested that this was due to a lack of sensitivity of the factor analysis to detect these shifts. Factor analysis has recently been replaced by more advanced approaches employing greater computational power.

2.5.5.2 Growth curve modelling

This method compares the growth curves of external and subjective assessments, to detect the disengagement between the two at a group level (Brossart *et al.*, 2002). A variety of patterns between the subjective and external assessments can be detected (Brossart *et al.*, 2002). However, this method does not distinguish between the three types of response shift. For this reason Schwartz and Sprangers (1999) suggested that it can be used during initial analysis to screen for potential response shifts. Data from three or more time points are

needed (Schwartz *et al.*, 2013). The method requires data on an external criterion. Self-reported symptoms can also be used as this external criterion, but the relationship between symptoms and perceived QoL is often weak (Albrecht and Devlieger, 1999).

To the author's knowledge this method has only been used in one study, where modelling showed a discrepancy between subjective QoL assessments and an external criterion of health, providing evidence of response shift in children with juvenile rheumatoid arthritis and diabetes (Brossart *et al.*, 2002).

2.5.5.3 Latent trajectory of residuals

Latent trajectory analysis (residual analysis) allows for investigating response shift at an individual level, based on the results of growth curve modelling (Mayo *et al.*, 2008). In this method each individual from the sample is assigned a residual for each assessment point, based on the discrepancy between the predicted (based on external criteria or self-assessment of symptoms) and self-reported QoL. Larger discrepancies indicate response shift at an individual level. Individuals can also be classified into groups based on the direction and timing of response shift (Mayo *et al.*, 2008). However, similar to growth curve modelling, this method does not allow inference about recalibration, reprioritisation and reconceptualisation. It also relies on data from numerous measurement points and an external criterion or self-assessment of symptoms.

Use of latent trajectory of residuals detected response shift in the samples of individuals with stroke (Mayo *et al.*, 2008; Mayo *et al.*, 2009) and multiple sclerosis (Ahmed *et al.*, 2011; Schwartz *et al.*, 2011).

2.5.5.4 SEM: Structural Equation Modelling

Structural equation modelling can measure recalibration, reprioritisation and reconceptualisation at a group level between two or more measurement points. Currently, it is the most popular statistical method to measure response shift; the structured review identified 14 studies using this approach alone (Barclay-Goddard *et al.*, 2009b; King-Kallimanis *et al.*, 2009) or in combination with other methods (Gillison *et al.*, 2008; Schwartz *et al.*, 2011).

Oort (2005) drew on earlier work by Schmitt (1982) to use different parameters of SEM (e.g. factor loading patterns, the intercepts) as indicators of recalibration (uniform or non-uniform), reprioritisation and reconceptualisation.

Overall, response shift was detected in several conditions using SEM, with few exceptions (Gillison *et al.*, 2008; Nagl and Farin, 2012). The advantage of this method is that it detects all three types of response shift and accounts for them when calculating change in QoL (2009). However, SEM parameters used to infer about response shift may not be indicative of the phenomena (Oort, 2005). Additionally, this method requires large samples. Most individual within the sample must manifest a uniform pattern of response shift for it to be detected (Schwartz *et al.*, 2013). Both evidence for (Oort *et al.*, 2005; Schwartz *et al.*, 2011) and against (Ahmed *et al.*, 2005c) convergent validity with other methods are available in the literature.

2.5.5.5 Recursive partitioning and regression tree analysis

The recursive partition and regression tree method was adapted by Li and Rapkin (2009) and by Li and Schwartz (2011) to investigate the patterns of response shift at an individual level and specifically, how changes in condition specific subscales explain changes in general mental and physical health scores. Individuals are iteratively separated into increasingly homogenous sub-groups using non-parametric statistics (Li and Schwartz, 2011). Each sub-group is characterised by distinct patterns of changes in the disease specific and generic QoL scores between two measurement points. Li and Schwartz (2011) suggested that these patterns might indicate recalibration, reprioritisation and reconceptualisation and other types of measurement bias.

Schwartz and colleagues (2013) noted that because this method seeks to maximise the explained variance within a sample, it might have limited external validity. Additionally, it relies on large samples (Li and Schwartz, 2011).

Only Li and Schwartz (2011) have used recursive partitioning and regression tree analysis to detect response shift. They concluded that one fifth of their sample underwent response shift and that all three types of response shift were present. Recursive partition and regression tree was also used to investigate how changes in appraisal explained changes in QoL scores (Li and Rapkin, 2009).

2.5.5.6 Regression based methods

This is a relatively heterogeneous group of methods that use logistic regression and discriminant analysis to investigate response shift at a group level between two measurement points. A disadvantage is that they are limited to detecting only reprioritisation and therefore, should be used with complementary methods (Galenkamp *et al.*, 2012).

Several studies have used regression based methods to investigate reprioritisation (Hagedoorn *et al.*, 2002; Bernhard *et al.*, 2004; Lowy and Bernhard, 2004; Galenkamp *et al.*, 2012; Lix *et al.*, 2013) and appraisal (Schwartz *et al.*, 2014). Generally, response shift was detected. However, regression based methods have not always detected response shift. Lix and colleagues (2013) compared two methods (descriptive discriminant analysis and logistic regression with bootstrap interference) and found that only the first method was able to detect reprioritisation among individuals with active bowel disease. No reprioritisation was detected in people with inactive disease.

2.5.5.7 Rasch analysis

Barclay-Goddard and colleagues (2009a) suggested that Rasch analysis might be useful in response shift assessment. Changes in the differential item functioning (DIF) detected by Rasch analysis can, according to the authors, indicate response shift. No studies applying Rasch analysis to measure response shift were found in the structured review.

2.5.6 Qualitative methods

Qualitative methods consist of in-depth and semi-structured interviews.

2.5.6.1 Idiographic assessment of personal goals

Schwartz and Sprangers (1999) suggested adapting the idiographic assessment of personal goals instrument to investigate reprioritisation and reconceptualisation at an individual level. In this approach participants' personal goals at a given point in time are elicited in semi-structured interviews (Schwartz *et al.*, 2004a). The goals are then rated on predefined criteria to define their relative importance for overall QoL and to assess the extent to which these goals are met (Schwartz *et al.*, 2004a). While studies investigating personal goals in relation to response shift exist (see Section 2.4.3.4), no studies using ideographic assessment of personal goals were identified through the structured review.

2.5.6.2 In-depth and semi-structured interviews

Overall, evidence of response shift has been found in qualitative studies. Several studies using semi-structured and in-depth interviews to investigate response shift, were acknowledged in the Barclay-Goddard and colleagues (2009a) narrative review.

Use of qualitative methods allows a flexible approach that would not be possible using more structured, techniques. Therefore, a variety of issues such as the psychosocial contributors to the occurrence of response shift, and the nature of response shift can be investigated using

these methods. Qualitative methods were used to investigate the role of response shift in adaptation to chronic health conditions (Sinclair and Blackburn, 2008) and traumatic life events (Inman and Ogden, 2011), to investigate the psychosocial contributors to response shift and investigate appraisal (Westerman *et al.*, 2007b; Ogden and Lo, 2012) and to find qualitative evidence of response shift (Gregory *et al.*, 2005; Korfage *et al.*, 2006; Osborne *et al.*, 2006).

Qualitative methods allow for investigation at the individual level and do not require large samples. However, in comparison with other methods, they are more time consuming and place a burden on participants. Qualitative methods do not allow quantitative generalisation of findings to the group level and cannot express magnitude.

Because the investigation of response shift is a relatively new field of enquiry, qualitative methods seem appropriate as the available evidence is limited. They allow thorough exploration of the nature of response shift, the appraisal, its mechanisms and other relevant factors.

2.5.7 Conclusion

An array of methods has been applied to response shift research. The THEN TEST and statistical techniques (especially SEM) are the most commonly used. Qualitative interviews have only recently been applied and may provide valuable insights which cannot be obtained using other approaches.

Structural equation modelling allows investigators to measure and account for all three types of response shift, but does not provide individual level data. It is also possible that response shift might not be detected at a group level if it occurs only in a subsample of individuals or the response shifts in different individuals cancel each other out. A large sample is required. As with other statistical methods, SEM can be used in secondary analysis of data. Finally, SEM has mainly been applied to SF-36 data and the validity of this method for other QoL measures remains unknown.

The THEN TEST, which detects recalibration, is the most popular method, especially to measure the effects of health interventions. Contrary to SEM, the THEN TEST can be applied at both individual and group levels. It is easy to apply and usually produces desirable outcomes. However, it may be susceptible to bias, which might undermine its validity. The IDEALS appear to be a possible alternative to the THEN TEST. Similar to the THEN TEST, it can be incorporated

into any existing QoL measure and it measures recalibration both at individual and group levels. Despite the potential of this method it has received little attention to date.

Recently, several studies using qualitative interviews have been conducted. Contrary to most methods, which only detect response shift, qualitative methods also provide the possibility of investigating the underlying psychosocial mechanisms leading to response shift.

2.6 Strategic decisions for the investigation of response shift in people with DH

Response shift is a new area of enquiry with few empirical studies applied to OHQoL. Therefore, investigating DH provides an opportunity to advance the understanding of response shift in OHQoL. Additionally, response shift has been mainly studied in severe health conditions. Investigating a relatively mild condition such as DH might bring new insights to the field.

A broad methodological perspective needs to be adopted because the nature of response shift is complex. Little is known of the underlying psychosocial processes and the methods to investigate it are not well validated.

The literature review revealed little agreement on how best to measure and account for response shift. This is especially relevant when evaluating health interventions, for example in clinical trials. Not accounting for response shift might underestimate or even not detect the effects of treatment.

The THEN TEST is the most popular method for measuring and accounting for response shift but its validity has been questioned. Structural equation modelling might be an alternative, but it is not applicable at the individual level and response shift might remain undetected if it only occurs in a proportion of participants or different response shifts cancel each other out. Another study design approach: the IDEALS seems a promising alternative, but to the author's knowledge, it has not been used to measure response shift in relation to QoL.

The review of the psychosocial contributors provided evidence on the role of mechanisms such as coping or social comparison, but overall knowledge on other contributors (including antecedents, catalysts, mechanisms and appraisal) is limited. As the role of the psychosocial mechanisms is not yet well understood, methods that allow broader exploration of the topic such as qualitative methods seem most appropriate. Qualitative methods to explore response shift and its psychosocial mechanisms have been recommended (Barclay-Goddard *et al.*, 2009a).

Based on this literature review, two studies are proposed to investigate response shift in people with DH. A quantitative study will measure response shift and its characteristics within a clinical trial. A qualitative study will explore response shift and its psychosocial determinants in people with DH.

AIM OF THE QUANTITATIVE STUDY (STUDY A): Explore recalibration and its influence on the assessment of change in OHQoL and treatment effect in a clinical trial of treatments for DH.

AIM OF THE QUALITATIVE STUDY (STUDY B): Describe response shift and its underlying psychosocial mechanism in people with DH.

The quantitative study will employ the THEN TEST and the IDEALS to assess response shift and its attributes (e.g. direction, magnitude, timing) and to account for response shift. The use of two methods will allow triangulation of data to compare the two methods' applicability and validity. As both methods measure recalibration, the study will be limited to this form of response shift. However, since DH is a relatively mild health condition, reprioritisation and reconceptualisation may be less likely than in more severe conditions. As response shift is largely a measurement phenomenon, a DH specific measure of OHQoL: DHEQ will be used. The THEN TEST and the IDEALS will be incorporated into the DHEQ to obtain numerical estimates of response shift.

The qualitative study will explore response shift and its underlying psychosocial mechanisms including catalysts, antecedents, mechanisms and appraisal longitudinally in people with DH using semi-structured interviews.

The two studies will address the priorities for research identified by Barclay-Goddard and colleagues (2009a) (Section 2.2.4). The quantitative study will address the second and third priorities: to determine the clinical importance of response shift and to determine the best way to measure and account for response shift. The qualitative study will address the first priority: to obtain a consensus on the terminology and a theoretical model of response shift.

The two studies will advance the understanding of response shift, its underlying mechanisms and methods of measurement and will contribute to the knowledge on response shift and its effects on OHQoL and the assessment of treatment effect in oral health.

3 Study A: Quantitative study

3.1 Aim and objectives

The aim of this study was to explore recalibration and its influence on the assessment of change in OHQoL and treatment effect in a clinical trial of treatments for DH.

The primary objective was to analyse the magnitude and direction of recalibration in the participants of a clinical trial. The secondary objectives were to:

- Explore the properties of recalibration including: timing, the areas of OHQoL most sensitive to recalibration and the influence of antecedents (e.g. age, gender)
- Examine whether accounting for recalibration impacts on the assessment of change in OHQoL and the treatment effect
- Validate and compare the THEN TEST and the IDEALS approaches to the assessment of recalibration

3.2 Method

This study was nested within a clinical trial of mouthwashes for DH. It was aimed to nest this quantitative study in a randomised controlled trial for treatments for DH that employed the DHEQ to measure change in participants' DH related QoL during the trial. GlaxoSmithKline, the sponsor of this PhD, offered to incorporate this qualitative study into one of the randomised controlled trials for their products. A clinical trial occurring at the time frame appropriate for this PhD was selected. While the study and trial shared the same data, the aim, objectives, measures and the approach to data analysis were unique to the nested study.

3.2.1 Clinical trial overview

This 8 week, randomised, controlled, four treatment arm, parallel design trial of mouthwashes for DH sponsored by GlaxoSmithKline took place between March and July 2011 in Hamburg, Germany. Participants were recruited from the general population. Table 3.2.1 summarises the inclusion and exclusion criteria. Assessments took place during the participants' visits to clinical trial centre at Screening, Baseline, Week 4, Week 6 and Week 8. A written consent was provided at Screening. The randomisation for the nested study also occurred at Screening. Participants were either allocated to the THEN TEST or the IDEALS versions of the DHEQ in an alternate manner as they were assigned a number for the clinical trial.

Table 3.2.1 Summary of the inclusion and exclusion criteria for the clinical trial

Inclusion criteria	Exclusion criteria
• Consent • Age 18 – 55 years • Willingness to participate and understanding of the study procedures • Good general health • Self-reported history of DH lasting more than 6 months but no more than 10 years • Minimum of 20 natural teeth • At least two adjacent teeth with clinical signs of DH as measured by tactile (Yeaple probe of ≤ 20g) and evaporative stimuli (Schiff Sensitivity Score of ≥ 2)	• Pregnancy at the time of the study or intention to become pregnant over the duration of the study • Breast-feeding • Allergy/Intolerance to the study materials • Participating in another clinical study during the duration of the study • Substance abuse • An employee of the sponsor of the study or the study site or their immediate family • Presence of chronic debilitating disease or a condition which causes xerostomia • Evidence of current or recent caries or gross periodontal disease • Use of a sensitivity toothpaste within 8 weeks of screening • Use of medication which could interfere with the perception of pain, antibiotics or medication that could cause xerostomia

They then completed the respective versions of the questionnaire. The DHEQ version administered at Screening was supplemented with the questions about the duration of the condition, parts of the mouth affected, triggers of the sensations (e.g. cold food) as well as about frequency and average duration of the sensations. Participants were also asked to select words that best described their sensations from a given list (e.g. itchy, tingly). Participants underwent an oral examination that included soft tissue examination and assessment of erosion, abrasion, recession, gingival status and tooth mobility. Demographic data (age and gender) were also collected at this point. Participants were supplied with generic toothpaste and took part in a supervised tooth brushing. From this point onwards, participants were asked to brush their teeth twice a day with the supplied toothpaste and to keep a diary of their oral hygiene routine. An acclimatisation period between Screening and Baseline lasted between 4 and 6 weeks, depending on the participant. At Baseline, participants completed the respective versions (THEN TEST or IDEALS) of DHEQ and, once more, underwent an oral examination. At this point, the clinical status regarding DH was assessed, using an evaporative (Schiff *et al.*, 1994) and tactile stimuli (Polson *et al.*, 1980). Following the administration of DHEQ and oral examination, the inclusion criteria were reviewed and eligible participants were allocated into one of four treatment arms (Table 3.2.2). The two investigational arms used a mouthwash containing a desensitising substance used to treat DH, with different frequencies of use in each arm. The mouthwash in the exploratory arm contained a test substance. All mouthwashes contained sodium fluoride. At this stage, participants were provided with their mouthwash to use throughout the study.

Table 3.2.2 Description of the study treatment arms

Treatment arm	Description
A	Exploratory treatment
B	Investigational treatment
C	Investigational treatment
D	Placebo treatment

Clinical status for DH was again assessed using tactile and evaporative stimuli at Week 4, Week 6 and Week 8. The DHEQ (THEN TEST or IDEALS versions) was administered at Weeks 4 and 8. Participants were reimbursed for taking part. Approval to carry out the trial was obtained from a local independent ethical commission review board based in Freiburg, Germany in accordance with local requirements.

3.2.2 Nested study: overview

3.2.2.1 Procedure and participants

The nested study used DHEQ data collected at Screening, Baseline, Week 4 and Week 8 and clinical data for DH collected at Baseline and Week 8. Figure 3.2.1 presents the study profile. Only four of 118 participants were lost, thus the sample was very similar at the beginning and at the end of the trial. Only data from those who completed the entire trial were included in the analysis.

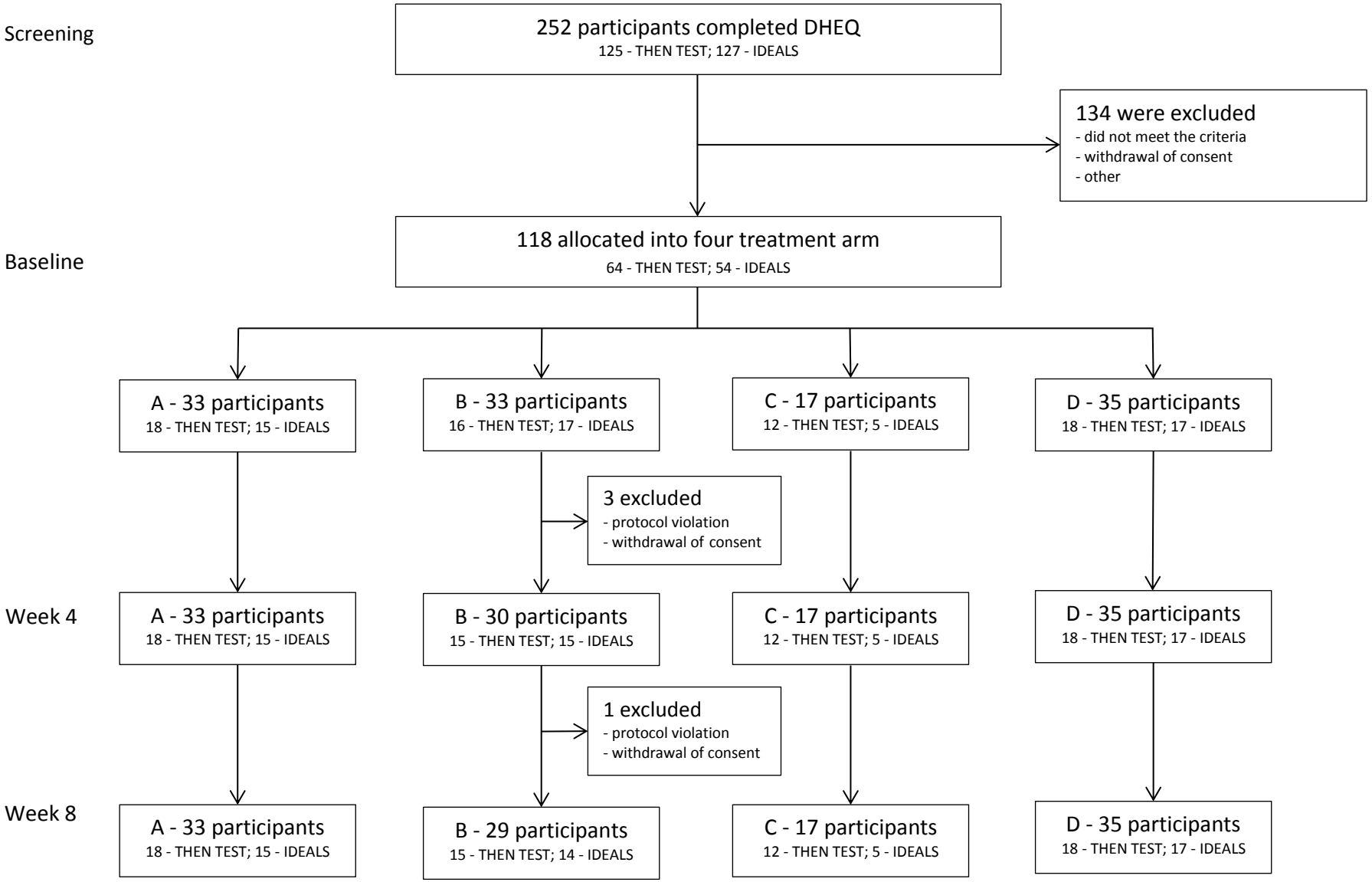


Figure 3.2.1 Study profile

3.2.2.2 Measures

3.2.2.2.1 DHEQ

Participant's OHQoL was measured using the DHEQ: Dentine Hypersensitivity Experience Questionnaire, which was developed specifically to assess the impacts of DH on OHQoL (Boiko *et al.*, 2010). This measure comprises of 48 items. Thirty four items assess the impacts of DH on 5 impact subscales: Limitations (4 items), Coping (12), Social impact (5), Emotional impact (8) and Identity (5). These items are answered on a 7 point Likert scale: 1 = 'Strongly disagree', 2 = 'Disagree', 3 = 'Disagree a little', 4 = 'Neither agree nor disagree', 5 = 'Agree a little', 6 = 'Agree', 7 = 'Strongly agree'. A summary measure: 'Total score' is calculated as the sum of the scores from the impact items for each participant, with a possible range of 34 to 238. Additionally, DHEQ contains questions assessing pain, global oral health and effects of DH on life overall. Three items assess aspects of DH related pain (Intensity, Tolerability and Bothersomeness), on a 1 to 10 Likert scale where 1 indicates the positive end of the scale (e.g. 'Not at all intense') and 10 the negative end of the scale (e.g. 'The worst imaginable'). Self-reported global oral health is assessed by 1 item on a 6 point Likert scale from 1 = 'Excellent' to 6 = 'Very poor'. Finally, the effect of DH on life overall is measured using 4 items rated on a 5 point Likert scale: 0 = 'Not at all', 1 = 'A little', 2 = 'Somehow', 3 = 'Quite a bit', 4 = 'Very much', creating a possible range of 0 to 16. High scores on DHEQ indicate greater pain, more negative impacts of DH on OHQoL and worse OHQoL.

Cross-sectional psychometric validation of DHEQ was based on data from the general population and a clinical sample (Boiko *et al.*, 2010) as well as from a randomised controlled trial of treatment for DH (Boiko *et al.*, 2010; Baker *et al.*, 2014). Additionally, Baker and colleagues (2014) assessed the measure's responsiveness to change and determined the minimally important difference (MID) (Revicki *et al.*, 2008) based on longitudinal data from three randomised controlled trials.

Overall, DHEQ showed excellent reliability and validity across the investigated samples. With regards to the internal consistency, the Cronbach's alphas were high for Total score (range 0.82 - 0.96) and impact subscales (range 0.70 - 0.91) across the three samples (general population, clinical sample and three randomised controlled trials). Similarly, the test-retest reliability was generally high. The intraclass correlation coefficient was 0.92 for Total score and varied between 0.75 - 1.0 for the impact subscales in the general population. In the three randomised controlled trials, the intraclass correlation coefficient was 0.77 for the Total score and varied between 0.43 - 0.89 for the impact subscales.

Convergent validity of DHEQ has been investigated by correlating the Total score and impact subscales with global oral health rating, with self-reported effects of DH on life overall and with clinical measures of DH related pain (Schiff Sensitivity Score, Tactile Sensitivity Score and VAS (Boiko *et al.*, 2010; Baker *et al.*, 2014). The correlations between global oral health rating and Total score were r = 0.23 ($p \leq 0.01$) and r = 0.26 for the general population and the clinical samples respectively. In the general population, the correlations varied between r = 0.16 ($p = 0.04$) - 0.25 ($p \leq 0.01$) for the impact subscales. In the randomised controlled trial, global oral health rating was not correlated with Total score, or the Limitations, Coping or Emotional impact subscales at a significant level. However, the correlations were significant for Social impacts (r = 0.30, $p < 0.05$) and for Identity (r = 0.29, $p < 0.05$). In the three randomised controlled trials, the correlation between effects of DH on life overall and Total score was r = 0.80 ($p \leq 0.001$) and the correlation between impact subscales varied between r = 0.64 ($p \leq 0.01$) and r = 0.72 ($p \leq 0.01$). While the Total score and impact subscales were significantly and moderately correlated with Tactile Sensitivity Score, there was no correlation between Total score or impact subscales and VAS or Schiff Sensitivity Score (with the exception of a correlation between 'Coping' and the Schiff Sensitivity Score of r = 0.28, $p < 0.05$).

The longitudinal validation of DHEQ revealed the measure to be responsive to change within individuals participating in randomised controlled trials and with regards to the external criterion (change in self-reported QoL from baseline to final follow-up: better, same or worse). Some impacts were more (e.g. Coping) while others were less (e.g. Identity) responsive over time. DHEQ detected a treatment effect in two clinical trials where effect was expected and in one when it was not. Baker (2013) also established a minimally important difference (MID) of 8 for four week follow-up and of 19 for eight week follow-up using the improvement in Tactile Sensitivity Score (Yeaple probe) as an external criterion.

The version of the DHEQ used in this study was translated into German by a professional agency using backward and forward translation. The reliability and validity of the German version of DHEQ has not been examined to date. However, this study cross-sectionally examines these characteristics.

3.2.2.2.2 Clinical assessment of DH

Two clinical measures were used to assess DH related pain: the Schiff Sensitivity Score and the Tactile Sensitivity Score.

The Schiff Sensitivity Score is obtained by applying an evaporative stimulus to the tooth surface 1 cm up from the gingival margin, for 1 second. The level of pain is self-rated by an individual using a 0 - 3 Schiff sensitivity scale (Schiff *et al.*, 1994)

The Tactile Sensitivity Score is obtained by directing Yeaple probe to the tooth and slowly drawing it across the tooth surface with an initial force of 10g. The force is then increased until the participant indicates that they experience pain, or until the maximum force for the assessment of DH is reached. The gram force eliciting pain is recorded as the Tactile Sensitivity Score (tactile threshold) (Polson *et al.*, 1980).

3.2.2.2.3 Approaches to assessing recalibration and adjusted change

Two approaches: the THEN TEST and the IDEALS were used to assess recalibration and adjusted change.

Both the THEN TEST and the IDEALS are study design approaches that rely on the design of the questionnaire to measure recalibration. In the THEN TEST, the traditional study design involving self-assessment of one's QoL at baseline ('pre') and at follow-up(s) ('post') is supplemented with a retrospective reassessment ('then') of one's initial QoL at follow-up(s).

In the IDEALS design, individuals complete the questionnaire twice at both baseline and follow-up(s), first with regards to how they are at the moment ('actual') and second with regards to how they would want things to be ideally ('ideal'). An example of both designs applied to an item from DHEQ is presented in Table 3.2.3.

For both designs appropriate instructions on to how to answer the 'then' or 'ideal' items were provided at the beginning of the questionnaire.

Table 3.2.3 Example THEN TEST and IDEALS implementation in the DHEQ item

THEN TEST	IDEALS
Baseline: Thinking about yourself over the last month to what extent would you agree or disagree with the following statement: *"Having sensations in my teeth takes a lot of pleasure out of eating and drinking."* ('pre')	Baseline: Thinking about yourself over the last month, to what extent would you agree or disagree with the following statement: *"Having sensations in my teeth takes a lot of pleasure out of eating and drinking."* ('$actual_{baseline}$') What would your ideal be? *"Having sensation in my teeth takes a lot of pleasure out of eating and drinking."* ('$ideal_{baseline}$')
Follow-up Thinking about yourself over the last month to what extent would you agree or disagree with the following statement: *"Having sensations in my teeth takes a lot of pleasure out of eating and drinking."* ('post') How do you now think you were at the time of the Screening assessment: *"Having sensations in my teeth takes a lot of pleasure out of eating and drinking."* ('then')	Follow-up: Thinking about yourself over the last month, to what extent would you agree or disagree with the following statement: *"Having sensations in my teeth takes a lot of pleasure out of eating and drinking"* ('$actual_{follow\text{-}up'}$') What would your ideal be? *"Having sensations in my teeth takes a lot of pleasure out of eating and drinking."* ('$ideal_{follow\text{-}up'}$')

3.2.3 Analytical strategy

The data were analysed in the 8 stages described below. The analytical strategy was informed by the aim and objectives of the study as well as by the guidelines for improving the stringency of recalibration research using the THEN TEST (Schwartz and Sprangers, 2010). Data were analysed using SPSS VERSION 20. A *p*-value of 0.05 was selected as the level of significance for all the tests performed. The normality of the data was checked using visual and statistical means. If the assumption of normality was not met non-parametric tests were applied. If not indicated otherwise, calculations were performed separately for the THEN TEST and the IDEALS study designs.

3.2.3.1 Description of the study sample and cross-sectional validation of the DHEQ

First, the demographics (age and gender), duration of the condition, frequency and average duration of the sensations (at Screening) and the clinical status for DH (at Baseline) were described. Initial levels of impact were assessed by calculating scores for Total score and DHEQ subscales at Screening. Additionally, the values of the 'ideal' assessment at Screening were calculated.

Cross-sectional validation of DHEQ included investigation of internal consistency (subscale-total correlation, Cronbach's alpha) and convergent validity (correlation with clinical status for DH) for DHEQ Total score and impact subscales. Internal consistency was calculated using the Screening data. However, since the clinical assessment of DH did not take place at Screening, data from Baseline were used to calculate convergent validity.

3.2.3.2 Calculating the values of recalibration, unadjusted change and adjusted change for each participants

Secondly, the dependent variables were calculated. Specifically, recalibration, unadjusted change and adjusted change were computed for each participant. The calculations were performed for 3 time periods: t1, t2 and t3; so that for each time period, data from the Screening assessment was considered as the baseline assessment and the data from Baseline, Week 4 or Week 8 as the follow-up assessments (

Table 3.2.4). Separate scores were calculated for the Total score and for the impact subscales.

Table 3.2.4 Description of t_1, t_2 and t_2

Time period	
t_1:	period between Screening and Baseline
t_2:	period between Screening and Week 4
t_3:	period between Screening and Week 8

There were two reasons why Screening rather than Baseline was selected as the baseline. First, the guideline on research using the THEN TEST states that 'the referent time for the then test should be salient and memorable' (Schwartz and Sprangers, 2010 p. 458). It was believed that as the Screening assessment took place during the first visit to the clinical trial centre, this time point would be more memorable for participants than the Baseline assessment. Second, the Screening rather that Baseline can be considered as the beginning of the study from the participants' perspective. This is because at Screening participants underwent an oral examination, completed the DHEQ and started following the study protocol with regards to their oral hygiene routine. Therefore, using data from Screening allows for investigating recalibration and changes in OHQoL throughout the entire study.

The way in which recalibration, unadjusted change and adjusted change are calculated differ between the THEN TEST and the IDEALS. For the THEN TEST 'pre', 'post' and 'then' values are used for the calculations. For the IDEALS both 'actual' and 'ideal' values are employed. The way in which recalibration and unadjusted and adjusted change are calculated for both approaches is summarised in Table 3.2.5.

Two approaches were used to calculate the adjusted change using the IDEALS. In the first approach (formula A), adjusted change was obtained by comparing the discrepancy between the 'actual' and 'ideal' scores at baseline and at follow-up. This approach has previously been proposed in the literature on the use of the IDEALS (Zmud and Armenakis, 1978; Norman and Parker, 1996). In the second approach (formula B), the adjusted change was calculated by subtracting the discrepancy between 'actual' and 'ideal' score at follow-up and the discrepancy between 'ideal' scores at follow-up and baseline from the discrepancy between 'actual' and 'ideal' scores at follow-up. This approach has not been previously suggested as a possible way of calculating adjusted change. However, it attempts to combine the change in QoL of participants (as measured using the 'ideal' as a referent) and the recalibration (calculated as the change in 'ideal' between baseline and follow-up).

If measured using the THEN TEST, the recalibration score points to the change in perceived OHQoL between the baseline assessment and the retrospective reassessment. A person retrospectively reassessing themselves as having fewer impacts than they thought at baseline, i.e. revising their baseline OHQoL upwards, is marked by a negative sign of the recalibration score. A positive sign of the recalibration score indicates that a person retrospectively reassessed themselves as having more impacts that they thought at baseline, i.e. he or she revised their baseline OHQoL downwards. The value of recalibration points to its magnitude.

If measured using the IDEALS, the recalibration score points to changes in the person's willingness to accept impacts of DH on OHQoL that occurred between baseline and follow-up. In other words, the recalibration score represents a shift in the person's 'ideal' standards of measurement that occurred over time. A person's willingness to accept fewer impacts at follow-up than at baseline (i.e. the person raised their ideal standards at follow-up) is indicated by a negative sign of the recalibration score. Conversely, a person's willingness to accept more impacts at follow-up (i.e. the person decreased their ideal standards over time) is indicated by a positive sign of the recalibration score. Again, the value of the recalibration points to the magnitude of that change.

While the THEN TEST is concerned with the retrospective reassessment of one's OHQoL and the IDEALS is concerned with the assessment of one's 'ideal' standard of comparison in addition to the assessment of the 'actual' OHQoL, both approaches can be used to assess shifts in standards of measurement (i.e. recalibration) occurring over time. In the THEN TEST, the upward shift of standards of measurement can be assumed when a person retrospectively reassess themselves as worse-off and a downward shift of standards of measurement can be assumed when a person retrospectively reassess themselves as better-off (Schwartz *et al.*, 2006). In the IDEALS, an upward shift of standards of measurement can be assumed when a follow-up 'ideal' score is higher than the baseline 'ideal' score. A downward shift of standards of measurement can be assumed when a follow-up 'ideal' score is lower than the baseline 'ideal' score (Schwartz and Sprangers, 1999). In this study, an upward shift of standards of measurement over time is marked by the positive value of recalibration score for THEN TEST and by the negative value for the IDEALS. A shift downwards of standards of measurement is indicated by the negative value of the recalibration score for the THEN TEST and a positive value for the IDEALS.

As a higher DHEQ score means more impacts of DH on OHQoL (i.e. worse OHQoL), a decrease in the DHEQ score over time, marked by a negative score for the adjusted/unadjusted change,

indicates a decrease in impacts (i.e. an improvement of OHQoL) over time. Conversely, an increase in the DHEQ score over time, marked by a positive score for the adjusted/unadjusted change, indicates an increase in impacts (i.e. worsening of OHQoL) between baseline and follow-up. The '0' value indicates no change.

Table 3.2.5 Approach to calculating 'Recalibration', 'Unadjusted change' and 'Adjusted change' for the THEN TEST and the IDEALS

	THEN TEST	IDEALS
Recalibration	'then' – 'pre'	'$ideal_{follow\text{-}up}$' – '$ideal_{baseline}$'
Unadjusted change	'post' – 'pre'	'$actual_{follow\text{-}up}$' – '$actual_{baseline}$'
Adjusted change	'post' – 'then'	Formula A* ('$actual_{follow\text{-}up'}$ – '$ideal_{follow\text{-}up}$') – ('$actual_{baseline}$' – '$ideal_{baseline}$') Formula B** ('$actual_{follow\text{-}up'}$ – '$ideal_{follow\text{-}up}$') – ('$actual_{baseline}$' – '$ideal_{baseline}$') – ('$ideal_{follow\text{-}up}$' – '$ideal_{baseline}$')

*This equation can also be written as: ('$actual_{follow\text{-}up}$' – '$actual_{baseline}$') – ('$ideal_{follow\text{-}up'}$ – '$ideal_{baseline}$')
** This equation can also be written as: ('$actual_{follow\text{-}up}$' – '$actual_{baseline}$') – 2 ('$ideal_{follow\text{-}up'}$ – '$ideal_{baseline}$')

3.2.3.3 Investigating magnitude and direction of recalibration at the group level

The third phase of the analysis investigated the effects of recalibration. Recalibration values were calculated for groups A, B, C and D as well as all the three treatment groups together (A + B + C) for the Total score for t3 (Screening – Week 8). Paired t-tests investigated the significance of the recalibration. To examine the magnitude of the recalibration effect sizes (Cohen's d, Cohen, 1988) were calculated using the following equation, regarded as suitable for both paired and independent t-tests (Nakagawa and Cuthill, 2007):

$$d = \frac{m_1 - m_2}{s_{\text{pooled}}}$$

$$s_{\text{pooled}} = \sqrt{\frac{(n_2 - 1)s_2^2 + (n_1 - 1)s_1^2}{n_1 + n_2 - 2}}$$

Where m_1 and m_2 represent the means of the two values compared (e.g. 'then' and 'pre') and SD_{pooled} is the pooled standard deviation for the two samples (Hedges, 1981). Effect sizes from

0.2 to 0.49 were classified as small, from 0.5 to 0.79 as medium and larger than 0.8 as large (Cohen, 1988). A one-way ANOVA was performed to investigate possible differences in recalibration between the four study arms.

In order to compare the values of recalibration between the three treatment groups (A + B + C) a one-way ANOVA was performed. The magnitude of recalibration was also compared. Since the value of recalibration was similar in the three treatment groups the subsequent analysis of properties of the recalibration (e.g. timing, areas sensitive to change) were performed with data for the three aggregated groups (A + B + C).

3.2.3.4 Investigating the direction of recalibration at the individual level

Fourth, in order to investigate the direction of recalibration at an individual level, participants were divided into three groups based on their 'Total score' for t_3 (Screening – Week 8). The minimally important difference (MID) of 19 for an 8 week follow-up, reported by Baker (2013) was used to classify participants into three groups; Group 1 - those who shifted their internal standards of measurement upwards (THEN TEST: recalibration ≥ -19; IDEALS: recalibration ≤ -19). Group 2 - those who shifted their internal standards of measurement downwards (THEN TEST: recalibration ≤ -19; IDEALS: recalibration ≥ -19). Group 3 - no recalibration (THEN TEST and IDEALS: -19 < recalibration > 19).

3.2.3.5 Investigating areas of OHQoL sensitive to recalibration

Fifth, in order to investigate the areas of OHQoL sensitive to change, values of recalibration for t_3 (Screening – Week 8) were calculated for each DHEQ subscale. Paired t-tests were calculated to investigate the significance and effect sizes of the magnitude of recalibration for each subscale.

3.2.3.6 Investigating the timing of recalibration

Sixth, in order to investigate the timing of the recalibration, values of recalibration for 'Total score' for t_1, t_2 and t_3 were calculated. Paired t-test and effect sizes were used to compare the significance and magnitude of recalibration for the three time periods.

3.2.3.7 Investigating the role of antecedent (e.g. age, duration of the condition) on the magnitude of recalibration

Seventh, a multiple linear regression analysis was conducted in order to investigate the influence of antecedents (age, gender, duration of the condition, frequency and average

duration of the sensations) on the magnitude and direction of recalibration for 'Total score' for t_3 (Screening – Week 8).

3.2.3.8 Investigating the impact of recalibration on the assessment of change in OHQoL during the trial and on the assessment of treatment effect

Eighth, in order to investigate the impact of recalibration on the assessment of change in OHQoL during the trial, values of adjusted and unadjusted change were calculated for groups A, B, C and D separately and for the three aggregated treatment groups (A + B + C) for 'Total score' for t_3 (Screening – Week 8). Paired t-tests assessed the significance of the adjusted and unadjusted change. Effect sizes were calculated to investigate the magnitude of the change.

To further validate the IDEALS approach the treatment effect was calculated using the t-test and the analysis of covariance approach (ANCOVA, Assmann *et al.*, 2000). While the t-tests compare the scores at the end of the trial between the treatment and placebo groups, ANCOVA allows for comparing those scores while adjusting for the baseline scores. This results is more accurate estimates of the treatment effect (Assmann *et al.*, 2000). The DHEQ total score at the end of the trial (Week 8) was compared between the treatment groups (A + B + C) and the placebo group (D) using the conventional approach and the IDEALS formulae A and B (Table 3.2.6).

Table 3.2.6 Approaches to calculating DHEQ total score at the end of the trial (Week 8)

Unadjusted score	'$actual_{Week\ 8}$'
Adjusted scores:	
IDEALS formula A	('$actual_{Week\ 8'}$ – '$ideal_{Week8}$')
IDEALS formula B	('$actual_{Week\ 8'}$ – '$ideal_{Week\ 8}$') – ('$ideal_{Week\ 8}$' – '$ideal_{Screening}$')

3.3 Results

3.3.1 Description of the study sample

This section presents the results of the first step of the analytical strategy; describing the study sample and the psychometric properties of DHEQ.

Of the 114 participants who completed the study 93 (81.6%) were female. The mean age was 38.11 years (SD = 9.66, min = 20, max = 55). The mean Schiff Sensitivity Score at Baseline was 2.36 (SD = 0.44, min = 2, max = 3.00) and the mean Tactile Sensitivity Score at Baseline was 12.06 (SD = 3.18, min = 10, max = 20.00). Duration of the condition and the frequency and duration of the sensations among the sample are presented in Table 3.3.1.

Table 3.3.1 Duration of DH, duration and frequency of the sensations

	N (%)
Duration of the condition	
Less than a month	1 (0.9)
More than a month but less than a year	8 (7.3)
More than a year but less than five years	47 (43.1)
More than five years but less than 20 years	41 (37.6)
More than 20 years	12 (11.0)
Frequency of sensations	
Several times a day	33 (29.2)
Once a day	16 (14.2)
Several times a week	43 (38.1)
Once a week	3 (2.7)
Several times per month	17 (15.0)
Once a month	1 (0.9)
Average duration of sensations	
Few seconds	76 (67.3)
About a minute	26 (23.0)
Several minutes	10 (8.8)
About half an hour	1 (0.9)

Participants demonstrated impacts as recorded by DHEQ Total score and impact subscales (Table 3.3.2).

Table 3.3.2 Mean score, SD and range for Total score and impact subscales at Screening

	No. of items	No. of participants	Mean score (SD)	Range	Possible range
Total score	34	108	128.58 (36.31)	34 - 198	34 - 238
Impact subscales:					
Limitations	4	112	17.79 (5.18)	4 - 27	4 - 28
Coping	12	113	49.86 (14.51)	12 - 78	12 - 84
Social impacts	5	112	17.00 (6.37)	5 - 29	5 - 35
Emotional impacts	8	113	31.88 (9.63)	8 - 52	8 - 56
Identity	5	114	12.54 (7.03)	5 - 30	5 - 35

Regarding the 'ideal' assessment, on average participants were willing to accept some impacts as ideal for the Total score and for all the impact subscales (Table 3.3.3).

Table 3.3.3 'Ideal' assessment at Screening: Mean score, SD and range for Total score and impact subscales

	No. of items	No. of participants	Mean 'ideal' score (SD)	Range	Possible range
Total score	34	48	51.79 (23.66)	34 - 140	34 - 238
Impact subscales:					
Limitations	4	52	6.06 (4.06)	4 - 24	4 - 28
Coping	12	53	18.26 (9.35)	12 -58	12 - 84
Social impacts	5	54	7.30 (3.17)	5 - 18	5 - 35
Emotional impacts	8	52	12.63 (6.19)	8 - 32	8 - 56
Identity	5	53	7.32 (3.46)	5 - 20	5 - 35

Screening data used to assess the measurement properties of DHEQ supported its internal consistency. The correlations between Total score and impact subscales were: r = 0.91 for Coping, r = 0.90 for Social impacts, r = 0.83 for Emotional impacts, r = 0.71 for Identity and r = 0.77 for Limitations (N = 108). All the correlations between impact subscales and Total score were significant at $p < 0.05$. The values of Cronbach's alpha were very good for the Total score and impact subscales: $\alpha = 0.95$ for Total score (N = 108), $\alpha = 0.91$ for Identity (N = 111), $\alpha =$

0.89 for Coping (N = 113), α = 0.86 for Emotional impacts (N = 113), α = 0.79 for Limitations (N = 112) and α =0.78 for Social impacts (N = 112).

With regards to the convergent validity, the correlation between global oral health rating and Total score was r = 0.23 ($p < 0.05$). For the impact subscales the correlations were significant for Coping (r = 0.22) and Social impacts (r = 0.23). The correlation between effects on life overall and Total score was r = 0.68, and varied between r = 0.55 – 0.62 for the impact subscales (all $p < 0.05$).

Total score and impact subscales did not correlate with clinical assessments of DH. The correlation between the Schiff sensitivity Score and Total score was r = -0.02 and varied between r = -0.05 and 0.07 (N = 111 - 114) for the impact subscales. The correlation between the Tactile Sensitivity Score and Total score was r = -0.11 (N = 108) and varied between r = -0.04 and -0.16 (N = 111 - 114) for the impact subscales.

3.3.2 Magnitude and direction of recalibration

The second step consisted of calculating the recalibration and adjusted and unadjusted change values for the THEN TEST and the IDEALS for each participant. This was followed by the third step of calculating the mean recalibration for groups A, B, C and D as well as for all the three treatment groups together (A + B +C).

Overall, the results suggest that recalibration occurred in the participants. The negative sign of recalibration values suggest that, on average, participants who completed the THEN TEST version of DHEQ shifted their internal standards of measurement downwards, during the trial i.e. they reassessed themselves as having fewer impacts than they thought at baseline (Table 3.3.4). Recalibration was significant for one of the treatment groups (B), for the placebo group (D) and for the three treatment groups combined (A + B + C). The effect sizes varied from small to medium.

Table 3.3.4 Magnitude and direction of recalibration for treatment group A, B, C, D and A + B + C, for t_3 for 'Total score' (THEN TEST)

Treatment group	N	Mean recalibration	SD	*t*-value	*p.*	ES
A + B + C	43	-15.91	32.32	-3.23	< 0.05*	0.44
A	17	-14.24	29.79	-1.97	0.07	0.32
B	14	-17.71	28.60	-2.32	< 0.05*	0.57
C	12	-16.17	41.52	-1.35	0.20	0.55
D	16	-28.62	21.95	-5.22	< 0.05*	0.78

*Statistically significant at level $p < 0.05$ or above (two-tailed)

For the IDEALS, the negative sign of the recalibration value indicated that, on average, participants shifted their internal standards of measurement upwards (Table 3.3.5). However the values of recalibration did not reach significance for any of the groups, nor the three treatment groups combined (A + B + C). The effect size varied from small to medium.

Table 3.3.5 Magnitude and direction of recalibration for treatment group A, B, C, D and A + B + C, for t_3 for 'Total score' (IDEALS)

Treatment group	N	Mean recalibration	SD	*t*-value	*p.*	ES
A + B + C	31	-6.19	20.26	-1.70	0.10	0.32
A	14	-3.79	10.59	-1.34	0.20	0.26
B	12	-4.08	19.99	-0.71	0.49	0.21
C	5	-18.00	37.52	-1.07	0.34	0.53
D	14	-7.64	14.52	-1.97	0.07	0.28

*Statistically significant at level $p < 0.05$ or above (two-tailed)

For the THEN TEST, there was no significant difference between the three active groups (A, B and C) with regards to the value of recalibration for the Total score at t_3 (Screening – Week 8) as indicated by the one-way ANOVA, F (2, 40) = 0.04, $p = 0.96$. For the IDEALS, there was no significant difference between the three active groups (A, B and C) with regards to the value of recalibration for the Total score for t_3 (Screening – Week 8) as indicated by the one-way ANOVA, F (2, 28) = 1.01, $p = 0.38$. As the three treatment groups were similar both for the THEN TEST and the IDEALS, further investigation of the attributes of recalibration was performed for the three treatment groups (A + B + C) aggregated.

3.3.3 Individual direction of recalibration

This section presents the results of the fourth step of the analytical strategy investigating recalibration at the individual level.

Of the 43 participants from the three treatment groups (A + B + C), who completed the THEN TEST, 44.2% (19 individuals) shifted their internal standards of measurement downwards, 9.3% (4 individuals) shifted their internal standards of measurement upwards, 46.5% (20 individuals) did not undergo recalibration.

Of the 31 participants from the three treatment groups (A + B + C), who completed the IDEALS, 6.5% (2 individuals) shifted their internal standards of measurement downwards, 16.1% (5 individuals) shifted their internal standards of measurement upwards and 77.4% (20 individuals) did not undergo recalibration.

3.3.4 Areas of OHQoL sensitive to recalibration

The fifth step of the analytical strategy investigated the sensitivity of DHEQ impact subscales to recalibration.

For the THEN TEST, recalibration was significant for all impact subscales (Table 3.3.6). As in the case of the recalibration for the Total score, on average, participants shifted their standards of measurement downwards over the duration of the study. The effect sizes were small for Limitations, Coping, Social impacts and Emotional impacts.

Table 3.3.6 Magnitude of recalibration for A + B + C, for t_3 for DHEQ subscales (THEN TEST)

	N	Mean recalibration	SD	t-value	*p.*	ES
Impact subscales:						
Limitations	44	-1.70	4.21	-2.69	< 0.05*	0.30
Coping	45	-6.47	13.55	-3.20	< 0.05*	0.44
Social impacts	45	-2.51	5.90	-2.86	< 0.05*	0.41
Emotional impacts	44	-4.18	8.82	-3.15	< 0.05*	0.42
Identity	45	-1.04	5.79	-1.21	< 0.05*	0.16

*Statistically significant at level p < 0.05 or above (two-tailed)

Using the IDEALS, there was significant recalibration for one subscale (Emotional impacts) (Table 3.3.7). Similar to the Total score, on average, participants shifted their internal standards of measurement upwards during the trial. The effect sizes were small for Limitations, Coping, Social impacts and Emotional impacts.

Table 3.3.7 Magnitude of recalibration for A + B + C, for t_3 for DHEQ subscales (IDEALS)

	N	Mean recalibration	SD	t-value	*p.*	ES
Impact subscales:						
Limitations	33	-1.03	3.73	-1.59	0.12	0.37
Coping	34	-2.41	7.90	-1.78	0.08	0.28
Social impacts	34	-0.76	2.88	-1.55	0.13	0.28
Emotional impacts	32	-2.16	5.15	-2.37	< 0.05*	0.45
Identity	34	0.09	3.65	0.14	0.89	0.03

*Statistically significant at level $p < 0.05$ or above (two-tailed)

3.3.5 Timing

In the sixth step of the analytical strategy, for both the THEN TEST and the IDEALS, the magnitude of recalibration was highest between Screening and Week 8 (t_3) (Table 3.3.8 and Table 3.3.9).

Table 3.3.8 Recalibration for A + B + C, for Total score between Screening and three end points (t_1: Screening – Baseline, t_2: Screening – Week 4, t_3: Screening – Week 8) (THEN TEST)

	N	Mean recalibration	SD	t-value	*p.*	ES
t_1 Total score	43	-1.09	26.28	-0.27	0.77	0.03
t_2 Total score	42	-6.74	24.39	-1.79	0.08	0.19
t_3 Total score	43	-15.91	32.32	-3.23	< 0.05*	0.44

*Statistically significant at level $p < 0.05$ or above (two-tailed)

For the THEN TEST, the magnitude of recalibration increased over the three time periods whereas for the IDEALS the magnitude was comparable for t_1 and t_2 but it increased for t_3 (Figure 3.3.1and Figure 3.3.2). For the THEN TEST, recalibration was significant for t_3 but not for t_1 or t_2 (Table 3.3.8). For IDEALS, recalibration did not reach significance for any of the three time periods (Table 3.3.9).

Table 3.3.9 Recalibration for A + B + C, for Total score between Screening and three end points (t_1: Screening – Baseline, t_2: Screening – Week 4, t_3: Screening – Week 8) (IDEALS)

	N	Mean recalibration	SD	t-value	*p.*	ES
t_1 Total score	30	-2.77	19.42	-0.78	0.44	0.14
t_2 Total score	30	-1.50	14.92	-.055	0.59	0.10
t_3 Total score	31	-6.19	20.26	-1.70	0.10	0.32

*Statistically significant at level $p < 0.05$ or above (two-tailed)

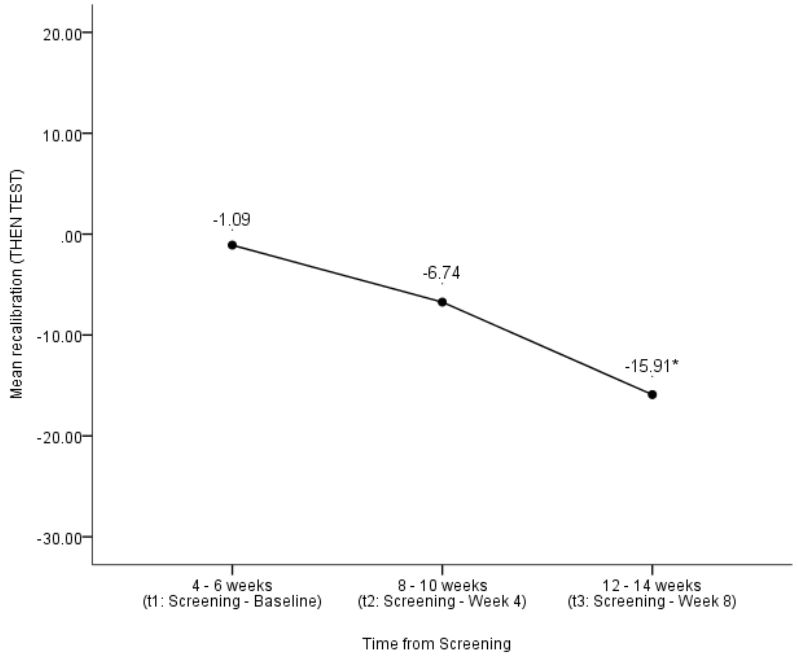


Figure 3.3.1 Mean recalibration across three time periods (THEN TEST)
* $p < 0.05$ (two tailed)

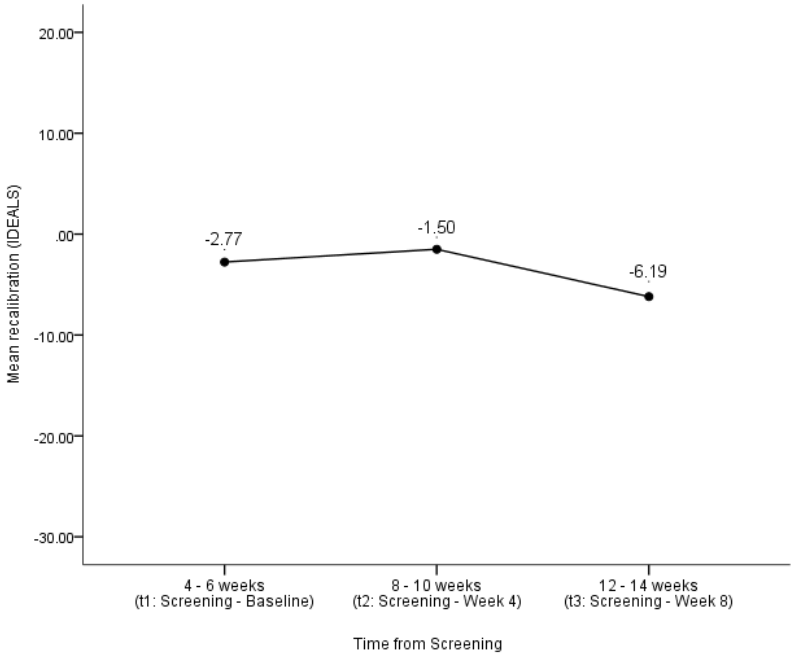


Figure 3.3.2 Mean recalibration across three time periods (IDEALS)
* $p < 0.05$ (two tailed)

3.3.6 Variables associated with the magnitude and direction of recalibration

In the seventh step, the possible antecedents (age, gender, duration of the condition) did not predict the magnitude or direction of recalibration for the Total score between Screening and Week 8 (t_3) for THEN TEST (R^2 = .12; F (3, 37) = 1.56, p = 0.21) or for IDEALS (R^2 = .02; F (3, 26) = 0.19, p = 0.90), in the combined treatment groups (A + B + C). The standardised beta values and the significance for each of the predictors for the THEN TEST and for the IDEALS are presented in Table 3.3.10.

Table 3.3.10 Possible predictors of recalibration (THEN TEST and IDEALS)

Predictors	THEN TEST		IDEALS	
	Standardised beta	*p.*	Standardised beta	*p.*
Age	.17	0.29	.01	0.97
Gender	-.28	0.08	.04	0.85
Duration of the condition	-.06	0.69	.13	0.52

3.3.7 Adjusted and unadjusted change

This section presents the results of the eighth step of the analytical strategy to compare the adjusted and unadjusted change in the DHEQ Total scores.

Overall, adjusting for recalibration reduced the value, magnitude and significance of change for the treatment and placebo groups in the trial when using either the THEN TEST or the IDEALS (Table 3.3.11 and Table 3.3.12).

Adjusting for recalibration using the THEN TEST resulted in the sign of the adjusted change reversing in comparison with the unadjusted change, with an exception for treatment group B, for which the sign of adjusted change pointed to an improvement in OHQoL (Table 3.3.11). The sign of adjusted change suggested deterioration rather than improvement in OHQoL over the duration of the trial. For example, the value of unadjusted change for the three aggregated treatment groups (A + B + C) had a negative sign indicating an improvement in OHQoL during the trial, whereas the value of adjusted change had a positive sign indicating a deterioration in OHQoL.

For the IDEALS, the values of adjusted change were smaller than the values of unadjusted change for all the groups either for formula A or formula B (with an exception of the values of adjusted change for group D calculated using formula B where the opposite was the case) (Table 3.3.12 and Table 3.3.13). For the three aggregated treatment groups (A + B + C), the value of adjusted change for formula A was -10.48 and for formula B -4.29, whereas the value

of unadjusted change was -16.68. As in the above example, the values of adjusted change indicated by formula B were smaller than the values indicated by formula A. Additionally, for formula B the values of adjusted change in groups C and D indicated deterioration rather than improvement in OHQoL during the trial (indicated by the positive sign of the adjusted change) (Table 3.3.13).

Adjusted changes did not reach significance for any of the groups, for neither the THEN TEST nor the IDEALS (formula A or formula B). Unadjusted change was significant for the three combined treatment groups (A + B + C) for both the THEN TEST and the IDEALS, it was also significant for the placebo groups (D) for the THEN TEST.

Table 3.3.11 Adjusted and unadjusted change for Total score for t_3 (THEN TEST)

Treatment group	N	Adjusted change					Unadjusted change				
		Mean change	SD	t-value	*p.* paired t-test	ES	Mean change	SD	t-value paired t-test	*p.* paired t-test	ES
A + B + C	42	3.10	29.24	0.69	0.50	0.08	-12.17	29.93	-2.64	< 0.05*	0.34
A	17	4.65	27.84	0.69	0.50	0.11	-9.59	30.57	-1.30	0.21	0.24
B	13	-2.23	10.47	-0.77	0.46	0.07	-18.00	34.87	-1.86	0.09	0.52
C	12	6.67	43.44	0.53	0.61	0.19	-9.50	24.38	-1.35	0.20	0.29
D	16	8.81	16.41	2.15	0.05	0.23	-19.81	14.22	-5.57	<0.05*	0.56

*Statistically significant at level $p < 0.05$ or above (two-tailed)

Table 3.3.12 Adjusted and unadjusted change for Total score for t_3 (IDEALS) Formula A

Treatment group	N	Adjusted change					Unadjusted change				
		Mean change	SD	t-value paired t-test	*p.* paired t-test	ES	Mean change	SD	t-value paired t-test	*p.* paired t-test	ES
A + B + C	31	-10.48	33.83	-1.72	0.10	0.25	-16.68	35.02	-2.65	<0.05*	0.40
A	14	-15.36	32.42	-1.77	0.10	0.46	-19.14	39.00	-1.84	0.09	0.56
B	12	-7.25	38.29	-0.66	0.52	0.19	-11.33	33.43	-1.17	0.27	0.26
C	5	-4.60	31.24	-0.33	0.79	0.07	-22.60	32.07	-1.58	0.19	0.41
D	12	1.00	47.21	0.07	0.94	0.02	-7.50	42.20	-0.62	0.55	0.16

*Statistically significant at level $p < 0.05$ or above (two-tailed)

Table 3.3.13 Adjusted and unadjusted change for Total score for t3 (IDEALS) Formula B

Treatment group	N	Adjusted change					Unadjusted change				
		Mean change	SD	t-value paired t-test**	*p.* paired t-test	ES	Mean change	SD	t-value paired t-test	*p.* paired t-test	ES
A + B + C	31	-4.29	43.40	0.55	0.59	0.10	-16.68	35.02	-2.65	<0.05*	0.40
A	14	-11.57	28.39	1.53	0.15	0.35	-19.14	39.00	-1.84	0.09	0.56
B	12	-3.17	51.12	0.21	0.83	0.07	-11.33	33.43	-1.17	0.27	0.26
C	5	13.40	61.14	-0.49	0.65	-0.21	-22.60	32.07	-1.58	0.19	0.41
D	12	9.50	55.46	-0.59	0.57	-0.20	-7.50	42.20	-0.62	0.55	0.16

*Statistically significant at level $p < 0.05$ or above (two-tailed)

** The t-test was calculated by comparing the values of DHEQ Total score using 'ideal' as a referent at Screening ('$actual_{Screening}$' – '$ideal_{Screening}$') and at follow-up ('$actual_{Week\ 8}$' – '$ideal_{Week\ 8}$') – ('$ideal_{Week\ 8}$' – '$ideal_{Screening}$').

The values of the correlations between the adjusted and unadjusted change and the change in the clinical assessments of DH (Schiff and Tactile Sensitivity Scores) were inconclusive about whether the assessment of adjusted or unadjusted change in OHQoL was linked with the changes in the clinical measures of DH (Table 3.3.14 and Table 3.3.15)

Table 3.3.14 Correlations between adjusted and unadjusted change vs. clinical measures of DH (Schiff and Tactile sensitivity scores) for A + B + C, for t_3 (THEN TEST)

	N	Schiff sensitivity score		Tactile sensitivity score	
		r	*p*	r	*p*
Adjusted change t_3	42	.18	0.25	-.16	0.32
Unadjusted change t_3	42	.14	0.38	.15	0.36

*Statistically significant at level $p < 0.05$ or above (two-tailed)

Table 3.3.15 Correlations between adjusted and unadjusted change vs. clinical measures of DH (Schiff and Tactile sensitivity scores) for A + B + C, for t3 (IDEALS)

	N	Schiff sensitivity score		Tactile sensitivity score	
		r	*p*	r	*p*
Adjusted change t_3 formula A	31	-.09	0.62	.28	0.12
Adjusted change t_3 formula B	31	-.02	0.93	-.03	0.88
Unadjusted change t_3	31	.20	0.28	-.51	<0.05*

*Statistically significant at level $p < 0.05$ or above (two-tailed)

DHEQ total scores at the end of the trial (Week 8) were compared between treatment groups (groups A + B + C) and placebo group (group D) using the unadjusted scores, and the IDEALS formulae A and B (Table 3.2.6). Overall, there was no significant difference between treatment and placebo groups for any of the approaches (Table 3.3.16). No treatment effect was found using the conventional approach (unadjusted score) the IDEALS formula A or the IDEALS formula B. Controlling for the Screening scores also did not produce the significant difference between the treatment and placebo groups (Table 3.3.17).

Table 3.3.16 T-test for the treatment effect for unadjusted score, adjusted score using IDEALS formula A and adjusted score IDEALS formula B

	DHEQ Total score at Week 8 for treatment groups (A + B + C), N = 31	DHEQ Total score at Week 8 for placebo group (D), N = 14	Mean difference between treatment and placebo groups at Week 8	t-value	*p.* t-test	ES
Unadjusted score	116.68 (SD = 45.27)	119.92 (SD = 49.08)	-3.25	-0.22	0.83	-0.07
Adjusted score: IDEALS formula A	72.97 (SD = 41.96)	69.00 (SD = 56.14)	3.97	0.26	0.79	0.10
Adjusted score: IDEALS formula B	79.16 (SD = 40.77)	76.64 (SD = 61.02)	2.52	0.16	0.87	0.05

Table 3.3.17 ANCOVA for the treatment effect using for unadjusted score, adjusted score using IDEALS formula A and adjusted score IDEALS formula B

	Independent variables	Beta	Standard error	*p.* value	R^2
Unadjusted score	Screening DHEQ total score	0.78	0.15	<0.05*	0.42
	Treatment vs. placebo	7.59	12.46	0.55	
Adjusted score: IDEALS formula A	Screening DHEQ total score**	0.66	0.13	<0.05*	0.40
	Treatment vs. placebo	7.69	12.10	0.53	
Adjusted score: IDEALS formula B	Screening DHEQ total score**	0.45	0.15	<0.05*	0.19
	Treatment vs. placebo	7.63	14.01	0.59	

Degrees of freedom = 2 for all models

* Statistically significant at level $p < 0.05$ or above (two-tailed)

**For formula A and formula B the Screening DHEQ total score was calculated by subtracting the 'ideal' score from the 'actual' score ('$actual_{DHEQ\ total\ Screening}$' - ('$ideal_{DHEQ\ total\ Screening}$')

3.4 Discussion

3.4.1 Introduction

The purpose of this study was to explore recalibration and its influence on the assessment of treatment effects in participants in a clinical trial of treatments for DH. Additionally, the study aimed to compare and validate two approaches to the measurement of recalibration: the THEN TEST and the IDEALS.

Recalibration occurred in the participants, with the two methods pointing to opposite directions of shift in the internal standards of measurement. The THEN TEST indicated a shift downwards in participants' internal standards of measurement, whereas the IDEALS suggested a shift upwards during the trial. The overall magnitude of recalibration for the three aggregated treatment groups was small for both methods.

The magnitude of recalibration varied from small to medium across DHEQ subscales and between the THEN TEST and the IDEALS. Emotional impacts were most sensitive and Identity least sensitive to recalibration. The magnitude of recalibration was highest between Screening and Week 8 (t_3) in both the THEN TEST and the IDEALS. For the THEN TEST the magnitude increased steadily during the trial, whereas for the IDEALS the magnitude between Screening and Baseline (t_1) and between Screening and Week 4 (t_2) was comparable and smaller than the magnitude between Screening and Week 8 (t_3). At the individual level, shifts upwards, downwards and no recalibration were observed using both the THEN TEST and the IDEALS versions of DHEQ. None of the investigated antecedents predicted the magnitude or direction of recalibration.

Adjusting for recalibration reduced the magnitude and significance of improvements in OHQoL occurring during the trial. Additionally, in some cases (the THEN TEST and the IDEALS formula B) adjusted change indicated a decrease in participants' OHQoL during the trial. Both adjusted and unadjusted changes were unrelated to changes in clinical status as indicated by Schiff and Tactile Sensitivity Scores. No treatment effect was found either for the conventional approach to its calculation, for the IDEALS approach formula A or for the IDEALS approach formula B (Table 3.3.16 and Table 3.3.17).

Comparison of the values of recalibration in the treatment and placebo groups suggests that recalibration might be a part of placebo effect in this trial.

The comparison of the THEN TEST and the IDEALS suggested that the THEN TEST, while being a well-established method to measure recalibration can be subject to bias; whereas the IDEALS, a new method to assess recalibration, seems a promising approach but requires further validation.

3.4.2 Discussion of recalibration

This section discusses the evidence on recalibration and its attributes that emerged from the results. In particular, the magnitude, direction, recalibration at individual level, sensitivity of different DHEQ subscales to recalibration, timing and predictors of recalibration are considered.

3.4.2.1 Magnitude of recalibration

Over the entire duration of the trial (t_3: Screening to Week 8) the magnitude of recalibration was small (both for the THEN TEST and the IDEALS). The following factors may have impacted on the magnitude of recalibration detected in this study:

- the significance of the catalyst
- the use of a disease specific rather than a generic OHQoL measure
- the methods used to assess recalibration

These three factors are discussed in the following sections.

3.4.2.1.1 Significance of the catalyst

To date, most evidence regarding the magnitude of recalibration comes from studies investigating severe or life threatening conditions. In Schwartz and colleagues' (2006) meta-analysis, based largely on studies in serious conditions, the average magnitude of recalibration was small (ES = 0.30, for the Global QoL). As the studies used mainly the THEN TEST, it can be assumed that the magnitude found referred mainly to recalibration. Fewer studies have been conducted in relation to mild conditions. However, the available evidence suggests that a considerable shift in internal standards of measurement can occur in these conditions as well (e.g. Joore *et al.*, 2002; Yardley and Dibb, 2007; Kubota *et al.*, 2009). Comparison of the studies of recalibration in severe and relatively mild conditions suggests that recalibrations of a comparable and considerable magnitude occur in both.

The results of this study indicated that a recalibration of at least small magnitude occurred in this relatively mild oral health condition. The results therefore add to the evidence of

recalibration of considerable magnitude in relatively mild oral health conditions or interventions for them.

3.4.2.1.2 Use of disease specific vs. generic QoL measures

The use of a condition specific measure could have influenced the magnitude of recalibration detected in this study. One can assume that recalibration is more likely to occur and its magnitude is likely to be larger in domains of QoL affected by the condition or the intervention. Condition specific measures, such as DHEQ, that focus on specific areas of QoL affected by a condition are therefore more likely to capture recalibration than generic measures. Indeed, DHEQ is successful in capturing impacts of DH on OHQoL (Boiko *et al.*, 2010), while OHIP (a generic OHQoL measure), was less insensitive to those impacts (Bekes *et al.*, 2009).

Evidence that condition specific measures are more sensitive to recalibration can also be drawn from the literature. In one study, in individuals with impaired hearing, recalibration proved significant in all 6 subscales of a condition specific measure, but in only one out of six subscales of a generic measure (Joore *et al.*, 2002). In individuals receiving total knee replacement for arthritis, the magnitude of recalibration detected by the condition specific measure was greater than that assessed by a generic measure (Razmjou *et al.*, 2006).

It is important to notice that, for more severe conditions such as cancers or end stage renal disease, the relation between condition specific and generic measures and the magnitude of recalibration detected by the two types might be different. The reason for this is that more severe health conditions might result in response shift across more general impacts, which are well assessed by generic measures. Additionally, it is possible that response shift in a severe health condition might take the form of reprioritisation or reconceptualisation, which can be better captured using techniques that don't allow for the calculation of the magnitude of the response shift (Sprangers and Schwartz, 1999).

3.4.2.1.3 Methods used for the assessment of recalibration

Another factor potentially influencing the magnitude of recalibration is the method used to assess it. The two methods used in this study revealed different magnitudes: the effect sizes based on the IDEALS assessment were consistently lower than those based on the THEN TEST. Additionally, they did not reach statistical significance.

There are two possible reasons why the two methods produced different estimates.

First, the methods might differ with respect to which aspects of response shift they target (Schwartz and Sprangers, 1999). For example, one method might focus on recalibration while another might be more comprehensive, accounting for all three aspects of response shift. The method that measures more aspects of response shift could presumably reveal greater magnitude (provided that the different aspects of response shift would not cancel each other out).

Second, it is possible that the methods differ in how well they are able to measure response shift (Norman, 2003). The THEN TEST has been criticised because it is subject to bias such as recall bias (Ahmed *et al.*, 2005c), effort justification (Hill and Betz, 2005) or social desirability bias (Furr, 2010), which can diminish its reliability and validity. To date, the IDEALS methods has not received such criticism (Visser *et al.*, 2005). The quality of the method used determines the validity and reliability with which the phenomenon is measured. If the quality is poor than the magnitude of recalibration can be under or overestimated.

It is important to note that some methods used to assess response shift such as qualitative interviews and individualised measures (e.g. SEIQoL: Schedule for the Evaluation of Individual QoL and PGI: Patient Generated Index) do not allow for the estimation of the magnitude of response shift in the form of an effect size. Instead, these methods allow for investigation of reprioritisation and reconceptualisation. By their nature reprioritisation and reconceptualisation are less quantifiable as they represent qualitative changes.

Several studies have compared different methods of response shift assessment, with most comparing the THEN TEST and SEM (e.g. Ahmed *et al.*, 2005c; Visser *et al.*, 2005; Nagl and Farin, 2012). Visser and colleagues (2005) supported the convergent validity of the THEN TEST and SEM with regards to detecting and determining the direction of recalibration in people with cancer. Conversely, Ahmed and colleagues (2005a) found that the THEN TEST detected recalibration in a study sample post-stroke, whereas SEM did not detect significant changes in internal standards of measurement.

3.4.2.2 Average direction

The two approaches identified different average directions of recalibration during the trial. The THEN TEST indicated a downward shift, whereas the IDEALS indicated an upward shift in internal standards of measurement.

In addition to proposing a model of response shift, Sprangers and Schwartz (1999) also suggested that response shift can be a mechanism of adaptation to changed health and

psychological self-regulation. As such it can be incorporated into existing models of adaptation such as a set point theory, control theory or prospect theory (Carver and Scheier, 2000; Schwartz *et al.*, 2006; Rapkin, 2009). Viewed as a self-regulation mechanism, the direction of the shift depends on the direction of the change in health. Improved health results in an upward shift in the standards of measurement to accommodate the change. Correspondingly, deterioration in health results in a decrease in standards of measurement to allow maintenance of a satisfactory QoL.

Given that this was a clinical trial of treatments for DH aiming to improve the participants' OHQoL, one might expect an upward shift in internal standards of measurement, or potentially no shift in those participants for whom the treatment was not effective. It may also be assumed that the treatment used in this study did not have a harmful effect and therefore a downward shift should not occur. When using the IDEALS, the average shift in internal standards of measurement occurred in the expected direction, whereas for the THEN TEST the average direction of the shift was in the opposite than expected direction.

To the authors' knowledge, there are no studies using the THEN TEST in which there was an average downward shift among participants who received an intervention for their condition. In fact, a number of studies using the THEN TEST have indicated an upward shift in the internal standards of measurement in response to intervention (Ring *et al.*, 2005; Kimura *et al.*, 2012; Reissmann *et al.*, 2012).

One possible reason why there are no studies indicating a downward shift in people receiving an intervention is the bottom drawer effect. That is, such results were not published because they were counterintuitive and because accounting for a downward shift in internal standards of measurement using the THEN TEST approach does not improve the treatment effect.

Another possible reason why no studies with downward shifts occur were found is that the downward shift in this study might not be detected in more serious conditions. Because DH is a relatively mild health condition, it allowed for the manifestation of different aspects of recalibration than upward shifts in internal standards of measurement.

Yet another possible reason why participants retrospectively reassessed themselves as better off is that, at the beginning of the trial, they overestimated the impacts of DH on their OHQoL. Then, when performing the retrospective reassessments, they made a more adequate assessment of their previous OHQoL, reporting fewer negative impacts.

There may be two explanations for why participants initially overestimated their level of impacts. First, it is possible that following the decision to participate in a clinical trial that required a time and energy commitment, participants might have overestimated the level of impacts and therefore the attractiveness of participating in a study investigating treatments for DH, to justify their decision to take part. This ' effort justification' occurs because people are likely to increase the attractiveness of a goal or an outcome if a considerable effort is required to obtain it (Aronson and Mills, 1959). Second, participants may have overestimated impacts of DH on their OHQoL to ensure that they could participate, and in turn receive the financial reimbursement. Concerns regarding whether, and how much, to pay for participation in a clinical trial have been raised in the literature (e.g. Bentley and Thacker, 2004; Grady, 2005).

Additionally, it is possible that, during the trial, participants started paying more attention to their sensations and their impacts on everyday life and, in consequence, noticed them more during the trial than they had before. As a result they might have retrospectively assessed themselves as being less impacted by the sensations at the beginning than during and at the end of the trial.

For the IDEALS, the shift in standards of measurement occurred in the expected direction. That is the standards of measurement shifted upwards, during the trial. The IDEALS approach measures the shift in the participants' willingness to accept impacts. In this study, participants' willingness decreased, on average, over the duration of the trial. In other words, participating in the clinical trial resulted in participants raising their expectations of oral health. One possible reason for this is that, as suggested by the response shift model, participants' willingness to accept impacts decreased as a result of improvements in their oral health. However, two other reasons should also be considered. First, it is possible that, as a result of taking part, participants started to believe that their DH could be successfully treated to improve their oral health. Second, participating may have made their oral health more central to their quality of life and therefore raised their expectations of it.

In the language of response shift, the second explanation indicates the occurrence of reprioritisation of the value of oral health for the persons overall quality of life. The design of this study did not allow for an investigation of whether the reprioritisation occurred. However, Gregory and colleagues (2005) found that people's expectations towards their oral health did change over time. They used the term 'horizon of possibilities' to describe that phenomenon. The authors found that people differ in their ability to recognise the possible meanings their

oral health might have and that this ability can change over time within a person. The 'horizon of possibilities' increased when an individual became aware of the possibility of better oral health available to them. It decreased when the room for improvement available to that individual reduced.

3.4.2.3 Recalibration at the individual level

In addition to investigating the average recalibration, this study also investigated the occurrence and direction of recalibration at the individual level. The minimally important difference (MID) was used as a threshold to classify participants who shifted their internal standards of measurement upwards, downwards or not at all.

Many participants did not undergo recalibration, and of those who experienced it, some shifted upwards, whereas others shifted downwards. This is in contrast with the average recalibration, which indicated shifts in a defined direction (downwards for the THEN TEST and upwards for the IDEALS).

Similar results of heterogeneous shifts were found in other studies measuring recalibration at the individual level (e.g. Wagner, 2002; Osborne *et al.*, 2006; Mayo *et al.*, 2008; Razmjou *et al.*, 2009; Hinz *et al.*, 2011). Osborne and colleagues (2006) found that after participating in a self-help intervention to manage chronic health conditions, such as arthritis and osteoporosis, approximately one third of participants shifted their internal standards of measurement upwards, one fifth shifted downwards and half did not recalibrate. Similarly, Razmjou and colleagues (2009) found that approximately one third of the participants shifted their internal standards upwards, one tenth shifted downwards and most did not shift after an elective surgery (knee replacement).

The heterogeneity of shifts found in this and other studies suggests that different people respond to the same catalyst in different ways. Only a subset of individuals shifts their internal standards and within this subset some shift upwards whereas others shift downwards. Another possible explanation is that different people need different amount of time to shift (Carver and Scheier, 2000), so that shifts in people who need more time than the duration of the trial were not detected.

Different people may react to the same catalyst differently because of their personal characteristics (antecedents), as suggested in the response shift model (Sprangers and Schwartz, 1999). In their discussion of trait vs. state aspects of response shift, Schwartz and Sprangers (2009) suggested that only some individuals have an innate capacity to

accommodate change in health status by shifting their internal standards of measurement. Additionally, different people may have different thresholds for the catalyst that is able to elicit change (Schwartz and Sprangers, 2009). Rapkin (2009) suggested that personality traits such as extraversion, anxiety, resilience and rigidity might determine shifts in the internal standards. Optimism might play a role in the direction of the shift (Carver and Scheier, 2000).

Yet another reason why different people reacted to the same catalyst with different shifts is that the oral health of participants may have improved, deteriorated or stayed the same. In other words, the shifts in the internal standards of measurement depended on the actual change in the person's health status rather than on receiving the intervention. The literature on response shift suggests that the relationship between changes in health status and changes in the internal standards of measurement is not straightforward. For example, Ahmed and colleagues (2004) compared the average recalibration between those whose functioning assessed by an objective measure deteriorated, improved and stayed the same after experiencing a stroke even though, on average, participants shifted their internal standards of measurement downwards in all groups. Mayo and colleagues (2009) found that individuals who experienced stroke rated their health as better (shift downwards); worse (shift upwards) or did not change their rating (no shift) in the months after stroke, regardless of whether their functioning improved or deteriorated over that time period.

Finally, the heterogeneity of shifts might be related to the complex nature of the appraisal process involved in assessing ones' QoL. Other factors than those related to the catalyst might have influenced the appraisal process and the particular standards of measurement selected for the assessment of one's QoL at any particular point in time. For example, the ability to recall past health status can influence appraisals (Ahmed *et al.*, 2004; McPhail and Haines, 2010). Similarly, external events might influence appraisals of one's OHQoL. Gregory (2003) described how a woman's evaluation of the importance of her teeth decreased after her husband was diagnosed with a life-threatening disease.

The heterogeneity of shifts occurring at an individual level in a sample will impact on the average recalibration. A similar number of shifts of a comparable magnitude but of different direction will cancel each other out, so that the average recalibration is close to zero (Schwartz *et al.*, 2006). In that case, assessments of average recalibration would not detect recalibration, whereas in reality it took place. On the other hand, attempts to estimate recalibration on the individual level based on the average recalibration in the sample might be susceptible to ecological fallacy (when false conclusions are derived about individuals based on the analysis

of group data), because of the heterogeneity of the shifts. Therefore, it is not possible to accurately predict the occurrence and direction of recalibration at individual level based on the value of the average recalibration in a particular sample.

One problem with assessing recalibration at the individual level is how to choose a threshold for which a shift is assumed for the particular person. In this study, the minimally importance difference (MID) was selected as the threshold. Minimally important difference is the smallest change in the QoL score that is clinically meaningful (Revicki *et al.*, 2008). The rationale behind selecting the MID as a threshold was that, in the context of the measuring QoL using questionnaires, recalibration equal to or greater than the MID would largely influence the assessment of change in OHQoL over time. However, MID is a conservative measure of recalibration at the individual level. Recalibration smaller than MID also contributes to the change in perceived QoL over time. Using MID as a criterion for the assessment of recalibration at the individual level leaves these shifts undetected. Indeed, the relatively large number of individuals for whom no shift was detected at the individual level in this study can be attributed to MID being a conservative criterion. Additionally, minimally clinically important differences can vary between populations, yet its context value in a particular study might not be available.

Other methods can be used to assess individual recalibration. Mayo and colleagues (2008) used statistical modelling to compare reported and predicted health status (based on measures of symptoms and functioning), over four time points to make inferences about individual response shift. Osborne and colleagues (2006) used direct questions to investigate whether individuals shifted their internal standards of measurement upwards or downwards. Both studies identified heterogeneous shifts at the individual level.

It is important to note that not all methods of assessing response shift allow its estimation at the individual level. Statistical methods such as SEM or factor analysis allow only the estimation of an average response shift. Conversely, methods such as individualised measures (e.g. SEIQoL), qualitative interviewing and some statistical methods (e.g. regression tree analysis) allow only for the investigation at an individual level. The THEN TEST and the IDEALS (both study design methods) allow for estimation of response shift at both individual and group levels.

3.4.2.4 Timing

With regards to the timing of recalibration, the results differed to some extent for the THEN TEST and the IDEALS. Both approaches suggested that little recalibration occurred during the initial stage of the trial, before allocation into the treatment groups (Screening to Baseline) and that the largest recalibration occurred over its entire duration of the trial (Screening to Week 8). The THEN TEST, suggested that the magnitude of recalibration increased steadily as the trial progressed. Whereas for the IDEALS, no recalibration occurred until towards the end of the trial (Table 3.3.10, Figure 3.3.2). It has been suggested that response shift can occur as a simple function of time (Sprangers and Schwartz, 1999).

Several studies have compared response shift over consecutive periods of time using the THEN TEST (Andrykowski *et al.*, 2009), SEM (Ahmed *et al.*, 2005b) and qualitative methods (Ahmed *et al.*, 2005b). The duration of periods varied between two weeks and five years. Overall, the data suggested that response shift is a longitudinal process occurring during different time periods.

One possible reason why the THEN TEST indicated that recalibration increased as the study progressed might be the longer intervals between the assessments later in the study (4-6 weeks for t_1, 8-10 weeks for t_2 and 12-14 weeks for t_3). It is possible that the length of time between the assessments might influence the magnitude of recalibration, so that the longer the period between the assessments the larger the magnitude of recalibration.

To the author's knowledge, no studies have directly investigated the influence of the length of time between the assessments and the magnitude of recalibration. However, a comparison of two studies with different intervals between assessments but otherwise very similar suggests that greater intervals allow more apparent recalibration (Kimura *et al.*, 2012; Reissmann *et al.*, 2012). Both studies investigated recalibration in edentulous individuals receiving prosthodontic treatment, and used a generic OHQoL questionnaire. There was a one month follow-up in the study conducted by Reissmann and colleagues (2012) and an average follow-up of 2.3 years in the study conducted by Kimura and colleagues (2012). The magnitude of recalibration with a short follow-up was small while the magnitude of the study with a long follow-up was large. As these two studies used the THEN TEST to assess recalibration it is possible that if other methods were used the length of time between the assessments would not influence the magnitude of recalibration. Additionally, in these two studies recalibration was measured after the intervention (denture fitting) whereas in the present study recalibration was assessed during the intervention (i.e. clinical trial). Comparison of the two

studies offers some evidence that the length of time between the assessment influences the magnitude of recalibration when measured using the THEN TEST, but as two different studies were compared this inference should be regarded with caution.

In this study the investigation of the timing of recalibration was limited to the duration of the trial. Future research could investigate recalibration beyond the duration of trials.

3.4.2.5 Sensitivity of different DHEQ subscales to recalibration

As indicated by the differences in the effect sizes, the magnitude of recalibration varied across the DHEQ subscales: Emotional impacts were most sensitive and Identity was least sensitive to recalibration (Table 3.3.6 and Table 3.3.7).

Two factors may have influenced this variation in the sensitivity to recalibration of different DHEQ subscales: the first relates to the degree of subjectivity involved in the subscale and the second relates to their varying susceptibility to floor and ceiling effects.

The idea that more subjective assessments (i.e. the one that require from the individual to rely more on their own evaluations, subjective experiences and internal standards of measurement) are more susceptible to recalibration, was discussed by Rapkin and Schwartz (2004). They classified self-reported measures into three types: performance-based (measuring of the quality and quantity of effort; e.g. 'How long does it take you to walk a flight of stairs?'), perception-based (measuring individual judgments concerning the occurrence of an observable phenomenon; e.g. 'How often do you walk up stairs?') or evaluation-based (rate experience as positive or negative with an internal standard; e.g. 'How difficult it is for you to walk up a flight of stairs?'). Only evaluation-based assessments are susceptible to recalibration. Based on this classification, Barclay-Goddard and colleagues (2011) hypothesised that recalibration would not be found in performance- and perception-based items. However, contrary to their hypothesis, recalibration was found in such scales completed by participants who had stroke. The authors speculated that this finding was due to some of the items being evaluation-based.

In the present study the subscale most sensitive to recalibration (i.e. Emotional impacts) was also one of the most subjective, as it related to the assessment of one's emotions. A number of factors, related or unrelated to DH, might have influenced emotions experienced at the time of assessment and participants' standards of comparison used to score oneself (Robinson and Clore, 2002).

Another factor influencing the sensitivity of different DHEQ subscales is their susceptibility to floor and ceiling effects. For the THEN TEST, the location of the score on the scale during the initial assessment ('pre') determines how much a retrospective assessment ('then') can differ from the baseline. If a person's baseline rating was near the bottom of the scale (floor effect) then that person cannot retrospectively ('then') reassess themselves as worse off because there is no scale left for that shift. Similarly, a person rating themselfs near the upper limit has no scope to reassess themselves as better off. At Screening the average level of impacts for Identity was low (ceiling effect), which might explain why Identity was least sensitive to recalibration when measured by the THEN TEST.

Similarly for the IDEALS, whether recalibration can occur, and to which degree, depends on the baseline 'ideal' assessment. If the 'ideal' assessment is made at the upper limit of the scale (i.e. the participant is not willing to accept any impacts; ceiling effect) then that person cannot accept even fewer impacts as 'ideal' at follow-up. In consequence the shift can only occur downwards. At baseline participants were willing to accept some impacts as ideal on all subscales (Table 3.3.3), allowing some room for an upward shift in internal standards, and a lot of room for a downward shift during the trial.

3.4.2.6 Predictors of recalibration

None of the Sociodemographic (age, gender) or clinical variables (duration of the condition) predicted the magnitude or direction of recalibration. However, this was an exploratory study of recalibration embedded into a clinical trial of treatment for DH and it was not powered to detect response shift or its predictors.

To date, the influence of antecedents on recalibration has not been explored widely. The existing literature provides evidence of recalibration in all age groups (Wagner, 2002; Gillison *et al.*, 2008; Galenkamp *et al.*, 2012), in both men and women (Hagedoorn *et al.*, 2002; Korfage *et al.*, 2006) and among people of different socioeconomic status (e.g. Ogden and Lo, 2012).

The recalibration model does not specify how gender, age or socioeconomic status influence response shift. No significant relationship was found between gender and response shift in two studies (Ahmed *et al.*, 2004; Razmjou *et al.*, 2006). Lower age predicted greater recalibration in one study (Kimura *et al.*, 2012). Other studies did not find relationships between age and response shift (Ahmed *et al.*, 2004; Yardley and Dibb, 2007; King-Kallimanis *et al.*, 2009). Longer duration of the condition predicted less and more severe symptoms predicted greater response shift in one study (Yardley and Dibb, 2007).

Further investigation is needed to establish the relationship between antecedents and response shift.

3.4.3 Recalibration and assessment of change in OHQoL

The values of unadjusted change in the trial indicated an improvement in all groups (treatment and placebo, Table 3.3.11, Table 3.3.12 and Table 3.3.13). Adjusting for recalibration, either by the THEN TEST or the IDEALS (formula A and formula B) reduced the value, magnitude and significance of change in OHQoL during the trial. Additionally, applying the THEN TEST and the IDEALS formula B resulted in the value of change in OHQoL indicating a deterioration rather than improvement for most (THEN TEST) or some (IDEALS) groups in the trial.

These findings conflict with those from other studies comparing adjusted and unadjusted change in QoL. Adjusted changes in other evaluations have indicated greater improvements in QoL that the unadjusted changes (e.g. Razmjou *et al.*, 2009; Bitzer *et al.*, 2011). Additionally, adjusted change was lower for both the THEN TEST and the IDEALS, despite the fact that the THEN TEST indicated a downward and the IDEALS an upward shift in the internal standards of measurement. These apparently contradictory results can be explained by the way the THEN TEST and the IDEALS account for recalibration.

The THEN TEST attempts to minimise the influence of recalibration by comparing the retrospective ('then') and the follow-up ('post') assessments. In this study, recalibration reduced the value of change in OHQoL because, on average, participants retrospectively assessed themselves as better off than at the beginning of the study (Screening) and also as better off than at the end of the study (Week 8). Whereas in other studies, where adjusted change indicated greater improvement in QoL, participant's tended to retrospectively assess themselves as worse off than at baseline and at follow-up (e.g. Shi *et al.*, 2011).

In contrast to the THEN TEST, which tries to minimise the effect of recalibration, the IDEALS attempts to incorporate the shift. In the IDEALS formula A adjusted change compares the discrepancy between the 'actual' and 'ideal' scores at baseline with the discrepancy between 'actual' and 'ideal' scores at follow-up. Therefore in the IDEALS formula A, adjusting for recalibration reduced the improvement in OHQoL because of an upward shift in internal standards occurring along an improvement in the 'actual' scores. The difference between the 'ideal' score at Screening and the 'ideal' score at Week 8 was larger than the improvement in the 'actual' score (the difference between the 'actual' score at Screening and the 'actual' score

at Week 8). In other words, the participants' expectations of their ideal OHQoL increased more than the improvement in their actual OHQoL, during the trial.

In the case of the IDEALS formula B the values of adjusted change in OHQoL were even smaller than in the case of the IDEALS formula A and, in some cases, they indicated a deterioration rather than an improvement over time (Table 3.3.12 and Table 3.3.13). This can be attributed to the way in which recalibration is accounted for when calculating change using formula B (Table 3.2.5). In formula B the importance of recalibration for the value of adjusted change is doubled in comparison with formula A. This can be seen by comparing the equations for formula A: ('$actual_{follow\text{-}up}$' – '$actual_{baseline}$') – ('$ideal_{follow\text{-}up}$' – '$ideal_{baseline}$') and for formal B: ('$actual_{follow\text{-}up}$' – '$actual_{baseline}$') – 2 ('$ideal_{follow\text{-}up}$' – '$ideal_{baseline}$'). Therefore an increase in the 'ideal' between baseline and follow-up would have double the impact on the value of adjusted change in comparison with the IDEALS formula A. If an increase in the 'ideal' score becomes large over time (i.e. at least half as large the an increase in the 'actual' scores) than the values of adjusted change can indicate a deterioration rather than an improvement as in the case of groups C and D in this study (Table 3.3.13).

To validate the use of the THEN TEST and the IDEALS (formula A and formula B) to adjust for recalibration, the values of adjusted and unadjusted change were compared with changes in the Schiff and Tactile Sensitivity Scores. The correlations between the adjusted and unadjusted change and the changes in the clinical measures suggested that neither adjusted nor unadjusted change were related to the changes in the clinical status (Table 3.3.14 and Table 3.3.15).

The use of external criteria has been recommended to validate values of adjusted and unadjusted change (Schwartz and Sprangers, 2010). However, only a few studies have followed these suggestions. Nieuwkerk and colleagues (2007) found, using the THEN TEST, that adjusted change was more strongly associated with clinical change in individuals with HIV starting antiretroviral therapy. In another study, investigating recalibration in individuals with rheumatoid arthritis starting a new drug regimen, participants were divided into three groups: those who had good, moderate or no improvement or deterioration in their health based on a clinical criterion (Kievit *et al.*, 2010). On average, participants from all groups retrospectively rated their health as worse.

The use of clinical criteria to validate the OHQoL measures has been criticised, because of the weak relationship between clinical status and self-reported OHQoL (Locker and Slade, 1994;

Baker *et al.*, 2007; Baker *et al.*, 2010). The weak relationship between the clinical criteria and the DHEQ scores at Baseline, values of adjusted change and values of unadjusted change in this study, is explained by the clinical assessment measuring induced pain in the dental chair, whereas OHQoL encompasses broader emotional and social impacts and coping (Boiko *et al.*, 2010). Additionally, clinical assessments might not necessarily correspond with pain experienced by the individual on a day to day basis. That is to say, clinical and subjective assessments consider two very different aspects of health. Finally, evaluation of pain in clinical trials for DH is also not without problems (Curro *et al.*, 2000). Baker and colleagues (2014) found that the there was a small significant correlation between DHEQ Total score and the impact subscale and the Tactile Sensitivity Score but no correlation between the values of DHEQ and Schiff Sensitivity Score, and the self-assessment of the intensity of DH related pain on a visual analogue scale, in three clinical trials of treatment for DH.

The weak relationship between the clinical indicators of DH and the impacts of DH on QoL points to the importance of the use of both approaches as complementary when assessing DH.

3.4.4 Recalibration and the assessment of a treatment effect

In this study, the treatment effect was calculated by comparing the values of DHEQ total score at the end of the trial (Week 8) between treatment (A + B + C) and placebo (D) groups. Three approaches were used: the conventional approach, the IDEALS approach formula A and the IDEALS approach formula B (Table 3.2.6). None of the approaches indicated a significant treatment effect (Table 3.3.16 and Table 3.3.17). One possible reason for this is that no actual treatment effect occurred in the trial. This was an exploratory trial of a new treatment for DH so that is not possible to determine whether this treatment if effective or not. Additionally, the sample size was small. Applying the three approaches to calculating the treatment effect in studies of treatment know to be effective could help to evaluate the approaches.

3.4.5 Recalibration vs. Placebo and Hawthorne effects

Similar recalibration occurred in both the treatment and placebo groups (Table 3.3.4 and Table 3.3.5). The values of unadjusted and adjusted change in OHQoL were also similar across groups (Table 3.3.11 and Table 3.3.12).

The occurrence of recalibration of similar size in all groups is at odds with the postulation of the response shift model (Schwartz and Sprangers, 1999). When the notion of response shift was introduced to educational research, it referred to the difference between the initial ('pre') and retrospective ('then') in experimental and control groups (Howard and Dailey, 1979). Any

difference between 'pre' and 'then' assessment in the control group was attributed to history, maturation and testing, whereas shifts in the experimental group were attributed to response shift induced by the experimental factor. Sprangers and Schwartz suggested that comparing the difference in response shift between the two groups allows for testing alternatives to response shift to explain the difference between the 'pre' and 'then' assessments (Schwartz and Sprangers, 2010).

In other controlled studies response shift did occur in the treatment but not the control groups (Chin *et al.*, 2004; Ahmed *et al.*, 2005c; Rees *et al.*, 2005). However, these studies comprised control groups consisting of healthy, same age, untreated controls (Rees *et al.*, 2005) or individuals with the condition but not receiving the treatment (Chin *et al.*, 2004; Ahmed *et al.*, 2005c). Whereas in this study, recalibration was compared between treatment and placebo groups.

Significant and consistent placebo effects are found in clinical trials of treatment for DH (West *et al.*, 1997; Yates *et al.*, 2004; Addy *et al.*, 2007). With regards to these findings, these are explained in terms of regression to the mean, spontaneous temporal improvement (Yates *et al.*, 1998) and anxiety reduction and subsequent decrease in the experienced pain (Curro *et al.*, 2000).

It is possible that the recalibration that occurred in the placebo group was a result of a placebo effect associated with participating in a clinical trial whereas recalibration in the treatment groups combined both placebo and treatment effects.

Another way of looking at the links between recalibration and placebo effects is to regard recalibration as part of a placebo effect. Wilson (1999) defined placebo effects as 'therapeutic effects that cannot be attributed to the natural history of the condition or to a known pathophysiological mechanism' and suggested that recalibration was a mechanism by which 'self- assessed health can remain stable in the presence of change in physiological health'.

3.4.6 Comparison of the two methods

One of the objectives of the study was to compare the THEN TEST and the IDEALS approaches to assess recalibration.

The THEN TEST is a well-established method for recalibration assessment. Numerous studies have employed it, alone (e.g. Chin *et al.*, 2004; Andrykowski *et al.*, 2009; Balain *et al.*, 2009) or in combination with other methods (e.g. Korfage *et al.*, 2007; Blair *et al.*, 2010; Dempster *et al.*,

2010; Hoefer *et al.*, 2011) and it has been validated against other methods such as SEM (e.g. Gillison *et al.*, 2008; Mayo *et al.*, 2009) and individualised measures (Ahmed *et al.*, 2005c).

Based on the large amount of data available, guidelines on how to conduct and analyse studies using the THEN TEST were formulated (Schwartz and Sprangers, 2010). However, the method has been criticised for its susceptibility to bias (Norman, 2003; Hill and Betz, 2005; Barclay-Goddard *et al.*, 2009a).

The IDEALS approach, on the contrary, has not been widely used (Visser *et al.*, 2005). Most data on the IDEALS come from the areas of education and management research (e.g. Schmitt *et al.*, 1984; Buckley and Armenakis, 1987; Granier *et al.*, 1991).

In terms of feasibility, incorporating the THEN TEST and the IDEALS into the study protocol was relatively easy, and only required implementing the relevant versions of the questionnaire. Both approaches carried a participant burden due to the doubled length of the questionnaire.

Guidelines on instruction for participants on how to complete a questionnaire were formulated for the THEN TEST (Schwartz and Sprangers, 2010) but have not been developed for the IDEALS. The pilot work for this study helped to choose an optimal formulation for the instructions for both the THEN TEST (based on the guidelines) and the IDEALS. The results of which indicated that the instructions for the THEN TEST and the IDEALS were well understood by the participants.

The THEN TEST appeared to be more sensitive to recalibration than the IDEALS indicating more recalibration (Table 3.3.4, Table 3.3.5), detecting more cases of recalibration at an individual level (p. 92) and showing a steadier pattern of shifts during the trial (Figure 3.3.1and Figure 3.3.2). However, this apparent sensitivity and the THEN TEST indicating the opposite direction of the shift than the IDEALS might result from its susceptibility to bias.

The apparent opposite directions may reflect the two approaches assessing different aspects of recalibration, one being more susceptible to biases or, one measuring concepts other than recalibration.

Some evidence, on the convergent validity of the two methods can be found in the literature. Schmitt and colleagues compared the two approaches to the assessment of recalibration in students' attitudes towards a university course (Schmitt *et al.*, 1984). The THEN TEST indicated recalibration whereas the IDEALS did not. Visser and colleagues compared the THEN TEST, anchor recalibration approach and SEM (Visser *et al.*, 2005). The THEN TEST and SEM were

largely comparable unlike the anchor recalibration approach, which involved participants defining anchors on a QoL scale (1- best imaginable, 10- worst imaginable) at baseline and at follow-up. This approach has similarities with the IDEALS as it demands participants to reflect on their 'ideal' state. There was considerable variation in the definitions of anchors between baseline and follow-up, with both upward and downward shifts. The authors concluded that anchor recalibration approach might detect a different concept than recalibration.

The THEN TEST's susceptibility to bias is well documented, including recall bias (Ahmed *et al.*, 2004; Schwartz *et al.*, 2004b; McPhail and Haines, 2010), effort justification (Hill and Betz, 2005) and social desirability bias, related to a tendency for the study participants to attempt to act in a way that make them 'look good to other people' (Sprangers and Hoogstraten, 1989; Furr, 2010; Schwartz and Sprangers, 2010). Furthermore, the basic assumption of the THEN TEST: that the individuals answer 'then' and 'post' questions from the same perspective i.e. they use the same internal standards of measurement is not fully supported (Sprangers *et al.*, 1999; Nolte *et al.*, 2009).

Finally, the implicit theory of change, postulating that a person infers about their past state from their current health through a cognitive heuristic, has been proposed as an alternative explanation for recalibration and for the discrepancy between the initial ('pre') and retrospective ('then') assessments (Ross, 1989; Norman, 2003; Streiner and Norman, 2008). The specific biases of the THEN TEST in relation to DH were discussed earlier (p. 90).

Overall, the validity of the THEN TEST relies on the assumption that a person is genuinely reassessing their previous health state rather than using his or her current health state to infer about the past, and that biases such as recall, social desirability and effort justification bias and the implicit theory of change do not influence this retrospective assessment considerably.

Two other problems with the validity of the THEN TEST also arise. First, the THEN TEST infers the value of recalibration indirectly from the self-assessed QoL. The indirect assessment makes this method prone to measurement error. The second problem links to the first; that recalibration and the QoL of the person are estimated based on the same set of indicators (i.e. 'pre' for the initial QoL, 'then' for the retrospectively assessed initial QoL, 'post' for the follow-up QoL, 'then' and 'pre' for recalibration), meaning that one indicator is used to estimate the value of two concepts.

In the IDEALS approach, on the other hand, recalibration is assessed directly by measuring participants' 'ideal' standards at baseline and at follow-up. Separate indicators are used to

measure QoL ('actual' assessment at baseline and at follow-up) and recalibration ('ideal' assessment at baseline and at follow-up). Additionally, the IDEALS is free from bias linked to retrospective assessment, such as recall bias or implicit theory of change, which the THEN TEST is prone to.

Nevertheless, threats to validity also exist for the IDEALS. Participants might indicate the highest possible score as their 'ideal' at baseline, so that there is no room for an upward shift in their internal standards of measurement, making the IDEALS prone to ceiling effects. However, as discussed earlier, ceiling effects were limited in this study as participants were willing to accept some impacts as their 'ideal' on all impact subscales (Table 3.3.3). Other studies using the IDEALS did not report ceiling effects (Schmitt *et al.*, 1984; Visser *et al.*, 2005).

Another potential threat arises from people not understanding the 'ideal' approach. While the THEN TEST was intuitive for individuals (Schwartz and Sprangers, 2010), such data do not exist for the IDEALS approach. The instructions for the IDEALS version of DHEQ were piloted in this study, and the results showed good understanding of the instructions and the IDEALS approach. However, the large standard deviations for the 'ideal' assessment at baseline (Table 3.3.3) and for the recalibration assessed using the IDEALS (Table 3.3.5), suggest that participants might not have understood how to complete the IDEALS, which might have introduced random assessment error. Future validation of the technique should include investigation of how people understand the approach and how to best write the instructions on completing the IDEALS assessment.

Additionally, as noted by Visser and colleagues, the IDEALS approach relies on the assumption that response shift only takes place at the upper end of the scale (ideal), but not at the lower end. This assumption and the IDEALS approach in general is rooted in the gap theory of QoL, which postulates that a person's QoL is defined by the distance between the actual level and the person's expectations towards their QoL (Calman, 1984; Carr *et al.*, 2001).

One practical disadvantage of the IDEALS is that, contrary to the THEN TEST, when calculating the adjusted change it incorporates rather than accounts for recalibration, which was discussed earlier (p. 114). Therefore, if the shift in the internal standards occurs in the same direction as the change in QoL (i.e. both change upwards, or downwards), as was the case in this study, then the value of adjusted change is lower than the value of unadjusted change. This might pose problems, when, for example, the IDEALS is used to capture treatment effects in clinical trials. However, this problem is not inherent to the IDEALS, but it is related to the

way in which the scores of adjusted change are calculated. One might think of potentially different ways of calculating the adjusted change using the IDEALS that would allow for accounting for rather than incorporating the recalibration into the value of adjusted change. The available data did not allow for the evaluation of the IDEALS approach (formula A and formula B) to the assessment of the treatment effect.

In summary, the comparison between the THEN TEST and the IDEALS suggests that in this study, the IDEALS was a more valid approach to assess recalibration and that it should be further validated in future studies.

The questionable validity of the THEN TEST potentially challenges the findings of this study. However, except from the direction of the shift, the findings obtained through the two approaches were comparable, therefore suggesting that, overall, the findings regarding recalibration and adjusted change are valid. Nonetheless, the findings on the direction of the shift found using IDEALS (i.e. an upward shift in the internal standards of measurement) should be given precedence.

The IDEALS is a promising approach for assessing recalibration, but requires further validation and, perhaps, some modification. In order to validate the IDEALS, this method should be administered across a broader range of conditions and interventions including more severe illnesses. Convergent validity with other approaches assessing response shift including: statistical techniques (e.g. SEM) individual measures (e.g. SEIQOL) and the THEN TEST, should be investigated. How people understand the 'ideal' question should be explored and guidelines for the instructions for participants should be established. The sensitivity to change of the 'ideal' score over time should be measured. Finally, the susceptibility of the IDEALS to the ceiling effect should be addressed.

One possible way of addressing the ceiling effect problem is to substitute 'ideal' with expectations. The two concepts are similar as both can be seen as points of reference to assess one's 'actual' QoL. However, expectations are potentially more amenable to change over time, allowing for the capture of more shifts. It can also be assumed that expectations are a step lower than 'ideal' in people's mental hierarchy and therefore are less prone to ceiling effects. Finally, the use of expectations to assess change in internal standards of comparison would correspond with the conceptualisation of QoL as a gap between what one experiences and what one expects (Calman, 1984; Carr *et al.*, 2001).

3.4.7 Strengths and limitations

To the author's knowledge this was the first study to use the IDEALS approach to investigate response shift in QoL. It was also the first study to compare two study design methods, the well-established THEN TEST and the new to the field IDEALS.

Another strength of this study was that it assessed response shift in a clinical trial for an intervention for a relatively mild health condition, while in the past response shift was investigated mainly in relation to interventions for severe and life threatening health conditions. This has helped to bring new insight into the role of response in clinical trials for interventions for relatively mild health conditions.

The use of DHEQ, a robust and precise measure of OHQoL for DH, and the fact that the study was embedded in the controlled environment of a clinical trial for treatment for DH with carefully selected participants added to the validity of the study results.

The excellent reliability and validity of DHEQ was demonstrated in previous studies (Boiko *et al.*, 2010; Baker *et al.*, 2014; Machuca *et al.*, 2014) and in the current study (p. 88). The trial participants were purposively selected from general population of adults who considered themselves to have DH and who met the inclusion criteria for DH related pain indicated by clinical measures and the impacts of DH on QoL. The selected participants varied with regards to the sociodemographic characteristics (age, gender), initial level of impacts (Table 3.3.2), and clinical characteristics including duration of the condition, frequency of sensations and average duration of sensations Table 3.3.1).

Finally, the study added to the limited evidence of the role of response shift in the assessment of QoL in dentistry.

This study was not, however, without limitations. First, this study was not powered to detect recalibration in the investigated sample, as it was nested within a clinical trial to evaluate the efficacy of mouthwashes for DH. Second, the relatively small samples available could have affected the power of the performed tests. Third, this study did not investigate and account for other potential explanations of the values of recalibration such as recall bias, implicit theories of change, effort justification or adaptation. Fourth, the results of the trial did not allow for establishing whether improvement occurred in the treatment groups in comparison to the placebo groups, which could have included the values of recalibration found in the study. The main reason for this difficulty was the occurrence of a strong placebo effect (Table 3.3.11 and Table 3.3.12). Additionally, no treatment effect was detected in the trial.

4 Study B: Qualitative study

4.1 Aim and objectives

The aim of this study was to describe response shift and its underlying psychosocial mechanism in people with DH.

The objectives of this study were:

- Investigate, via semi-structured interviews, the narrative accounts of response shift including recalibration, reprioritisation and reconceptualisation in people with DH
- Explore the role of psychosocial mechanisms including catalyst, antecedents, mechanism and appraisal, in the occurrence of response shift
- Obtain numerical values for recalibration by administering the THEN TEST or the IDEALS versions of the DHEQ

4.2 Method

4.2.1 Design overview

This was a qualitative longitudinal study with participants taking part in two in-depth interviews, over a 6 to 12 month period, exploring their experiences of DH. During each interview, participants also completed the DHEQ (THEN TEST or IDEALS version) as well as a DH specific illness perception and social comparison questionnaire, for descriptive purposes.

4.2.2 Participants

Interviews were conducted with 20 participants (19 females) (Table 4.2.1). English was the first language for 16 participants and the remaining 4 were proficient users. The inclusion criteria were: considering oneself to have sensitive teeth, having sensitivity at least several times a week and willingness to participate. The exclusion criteria were: being pregnant or breastfeeding, attending the dental hygienist in the preceding 2 weeks or undergoing periodontal surgery in the last 6 months or a root canal treatment planned in the next 3 months.

Participants were sampled to recruit both individuals who had only recently recognised themselves as having sensitive teeth and those with sensitive teeth for a long time. This

strategy was based on the possibility that response shift might depend on the duration of the condition. Eight participants had DH for less than a year and 12 had it for more than 3 years. Participants were recruited until saturation of the views and experiences in the sample was obtained.

4.2.3 Procedure

Data collection took place between March 2012 and August 2013. Potential participants were first contacted via the University of Sheffield volunteering mailing list (Appendix A). This volunteering mailing list is used to send out invitations to participate in studies to all students and staff with the University of Sheffield' email address (unless a person chooses to unsubscribe). Since this recruitment strategy resulted in sample homogeneity in terms of age and socioeconomic background, an additional advert was placed on the Sheffield Teaching Hospital staff mailing list to increase the diversity of the sample and to ensure a variety of views represented. An online screening survey assessed participants' eligibility (Appendix B). In total 294 (255 from the University and 39 from the Hospital) individuals completed the screening survey, of whom 172 (150 from the University and 22 from the Hospital) were eligible. Finally, 44 (32 from the University and 12 from the Hospital) were contacted and 20 (13 from the University and 7 from the Hospital) took part in the study.

Participants were given an information sheet (Appendix C) and consented before the first interview (Appendix D). Each participant received a £15 gift card after each interview as compensation for their time. Interviews were conducted by the author. All but 3 interviews took place at the School of Clinical Dentistry, University of Sheffield. The remaining 3 were conducted in a café outside of Sheffield, at the University of Sheffield library or the participant's workplace. Interviews lasted between 60-90 minutes, including the completion of the questionnaires (10 to 30 minutes). Interviews were recorded and transcribed verbatim. Ethical approval was obtained from the University of Sheffield Research Ethics Committee (UREC) in January 2012 (Appendix E).

4.2.4 Researchers training in qualitative methods

To obtain the necessary skills and knowledge in qualitative research, the research participated in postgraduate courses on qualitative data collection and qualitative data analysis organised by the University of Sheffield and in a one day workshop on qualitative interviewing organised at the University of Surrey, before undertaking this qualitative study. The structured training was supplement by an independent reading of the relevant

literature. Furthermore, the supervisors of this PhD project provided a comprehensive feedback on the interview transcripts and initial coding of the first 5 interviews, to further enhance the researcher's qualitative research skills. Finally, the research kept a reflective diary, where she reflected on the research process and on her interviewing and analytical skills, through the duration of the qualitative study.

Table 4.2.1 Characteristics of the study participants

Name	Gender	Age	Time since sensitivity first started	Time between the interviews	Mode of recruitment
Amy	Female	20	More than 3 months but less than 6 months	8 months	University of Sheffield
Abigail	Female	25	Between 3 and 5 years	7 months	University of Sheffield
Lucy	Female	24	More than 5 years but less than 10 years	10 months	University of Sheffield
Towkey	Female	42	Between 3 and 5 years	7 months	University of Sheffield
Julian	Male*	22	More than 3 months but less than 6 months	6 months	University of Sheffield
Helen	Female	49	More than 10 years	6 months	University of Sheffield
Caroline	Female	33	More than 5 years but less than 10 years	8 months	University of Sheffield
Lizzy	Female	22	Between 6 months and a year	10 months	University of Sheffield
Tilly	Female	27	Between 6 months and a year	6 months	University of Sheffield
Biscuit	Female	31	More than 10 years	6 months	University of Sheffield
Anna	Female	24	More than 3 months but less than 6 months	11 months	University of Sheffield
Olivia	Female	33	Between 6 months and a year	11 months	University of Sheffield
Agnes	Female	39	Between 6 months and a year	12 months	Sheffield Teaching Hospital

Aldbrough	Female	55	More than 10 years	9 months	Sheffield Teaching Hospital
Michelle	Female	50	Between 3 and 5 years	10 months	Sheffield Teaching Hospital
Margaret	Female	53	More than 10 years	9 months	Sheffield Teaching Hospital
Yasmin	Female	38	More than 5 years but less than 10 years	9 months	Sheffield Teaching Hospital
Doreen	Female	58	More than 5 years but less than 10 years	9 months	Sheffield Teaching Hospital
Moira	Female	34	Between 6 months and a year	9 months	Sheffield Teaching Hospital
Sue	Female	53	More than 10 years	9 months	Sheffield Teaching Hospital

*Although only one man participated, several others were invited to do so but did not reply or did not attend appointments.

4.2.5 Interview guides and measures

Semi-structured interviews were used to collect the data (Ritchie and Lewis, 2003). In addition, during each interview, participants were asked to complete a questionnaire composed of the DHEQ (with the THEN TEST or the IDEALS versions) and other psychosocial measures.

Separate interview guides were used for baseline and follow-up (Appendix F). The guides were informed by the Sprangers and Schwartz (Sprangers and Schwartz, 1999) and Rapkin and Schwartz (Rapkin and Schwartz, 2004) models of response shift. The areas explored during the baseline interview included: views on the influence of DH on QoL (i.e. perceived QoL), how this can change and possible catalysts, mechanisms, antecedents and appraisal. In addition to the areas explored in the baseline interview, the follow-up interview also explored changes since the first interview and participants' reflection on taking part in the study. Appraisal was investigated in relation to 3 items from the DHEQ:

- On a scale of 1 to 10, how intense are the sensations?
- Overall, how would you rate the health of your mouth, teeth and gums?
- Overall, how much do the sensations in your teeth affect your quality of life?

The appraisal was explored with regards to the original question and in relation to the THEN TEST or the IDEALS part of the question.

During each interview, participants completed the DHEQ (the THEN TEST or the IDEALS version), the Revised Illness Perception Questionnaire (IPQ-R) for DH and a questionnaire measuring social comparisons with regards to teeth, gums and mouth (Appendix G). There were three versions of the questionnaire; one for the baseline with the IDEALS version of DHEQ and for the follow-up: one with the IDEALS and one with the THEN TEST version of DHEQ. At follow-up 10 participants completed the THEN TEST version and 9 the IDEALS version. The role of the questionnaires was threefold. First, it served as a prompt to facilitate the discussion. Second, it allowed investigation of the appraisal of the selected items. Third, it allowed exploration of the links between evidence of response shift and its psychosocial mechanisms from the participants' accounts, the QoL scores and the response shift scores (calculated based on the THEN TEST and the IDEALS). The individual results for the DHEQ Total score and recalibration score can be found in Appendix H.

4.2.6 Data analyses

The framework method (Ritchie and Lewis, 2003), supplemented with the constant comparative method (Corbin and Strauss, 2008) was used to analyse the data.

Analysis started with a familiarisation phase, during which the author read and reread the transcripts. After familiarisation with the first five interviews, a theoretical framework was constructed based on the models of response shift (Sprangers and Schwartz, 1999; Rapkin and Schwartz, 2004; Barclay-Goddard *et al.*, 2012) and categories that emerged from the data. As analysis progressed, the framework was revised to reflect new categories emerging from the data. The final version was ready after labelling the first half of the baseline interviews and was used to label data from all remaining interviews. The labelled data were then summarised using thematic charts with a separate chart for each category from the response shift model (e.g. catalysts, antecedents etc.). Further analysis produced descriptive and explanatory accounts.

Analysis of each category was based on all available data in that category, with the exception of one category. The analysis of the appraisal process was based only on participants' answers to questions asked after completing the questionnaire. This allowed a clear distinction between the mechanisms of response shift and the appraisal process. The analysis of the appraisal process was guided by the Rapkin and Schwartz (2004) classification of appraisal, comprising four parameters: frame of reference, sampling strategy, standards of comparison and combinatory algorithm. Data analysis was performed in hard copy and using MS Office software.

4.3 Results

The aim of this study was to explore response shift and its underlying psychosocial mechanisms in people with DH. Evidence of response shift emerged in the data within two themes: 'Adaptation' and 'Self-assessment (appraisal)'. While recalibration, reprioritisation and reconceptualisation manifested itself in the data, they were present in such a way that required modification of how response shift is conceptualised and to the existing models of response shift (Sprangers and Schwartz, 1999; Rapkin and Schwartz, 2004).

Categories from both themes were used to formulate a modified model of response shift (Figure 4.3.1). Within the modified model, aspects of response shift are present in the 'Adaptation' and 'Self-assessment (appraisal)' parts of the model. In the 'Adaptation' part, three aspects of response shift (recalibration, reprioritisation, reconceptualisation) are re-interpreted into changes in social comparison (recalibration), goal reordering (reprioritisation) and changes in health and illness cognitions (reconceptualisation) and are considered to be mechanisms of adaptation to changed health. In the 'Self-assessment (appraisal)' part of the modified model, response shift is re-interpreted into (1) the influence of adaptation on the QoL score, and (2) measurement error, representing changes in the appraisal and QoL score that are not related to adaptation.

Therefore, the modified model postulates that two independent factors: adaptation and measurement error influence the QoL score and the assessment of change in QoL over time. Adaptation, which is initiated by a catalyst, influenced by the personal (Antecedents) and environmental (Context) characteristics occurs through a number of mechanisms and represents a true change in the person's experience of their QoL. Consequently, changes in QoL score over time due to adaptation reflect true changes in the person's experience of their QoL. Measurement error, on the contrary, is a source of bias in the assessment of QoL and in the assessment of change in QoL over time.

In addition to the changes in the way in which response shift is conceptualised, the modified model introduces two novel mechanisms: habits and acceptance, not included in the existing models of response shift (Sprangers and Schwartz, 1999; Rapkin and Schwartz, 2004) (Figure 2.2.1 and Figure 2.2.2). Furthermore, the Antecedents category from the existing models has been extended to include Context, defined as the physical, social and cultural aspects of the person's environment relevant for his or her adaptation. Finally, the modified model also describes different types of catalysts.

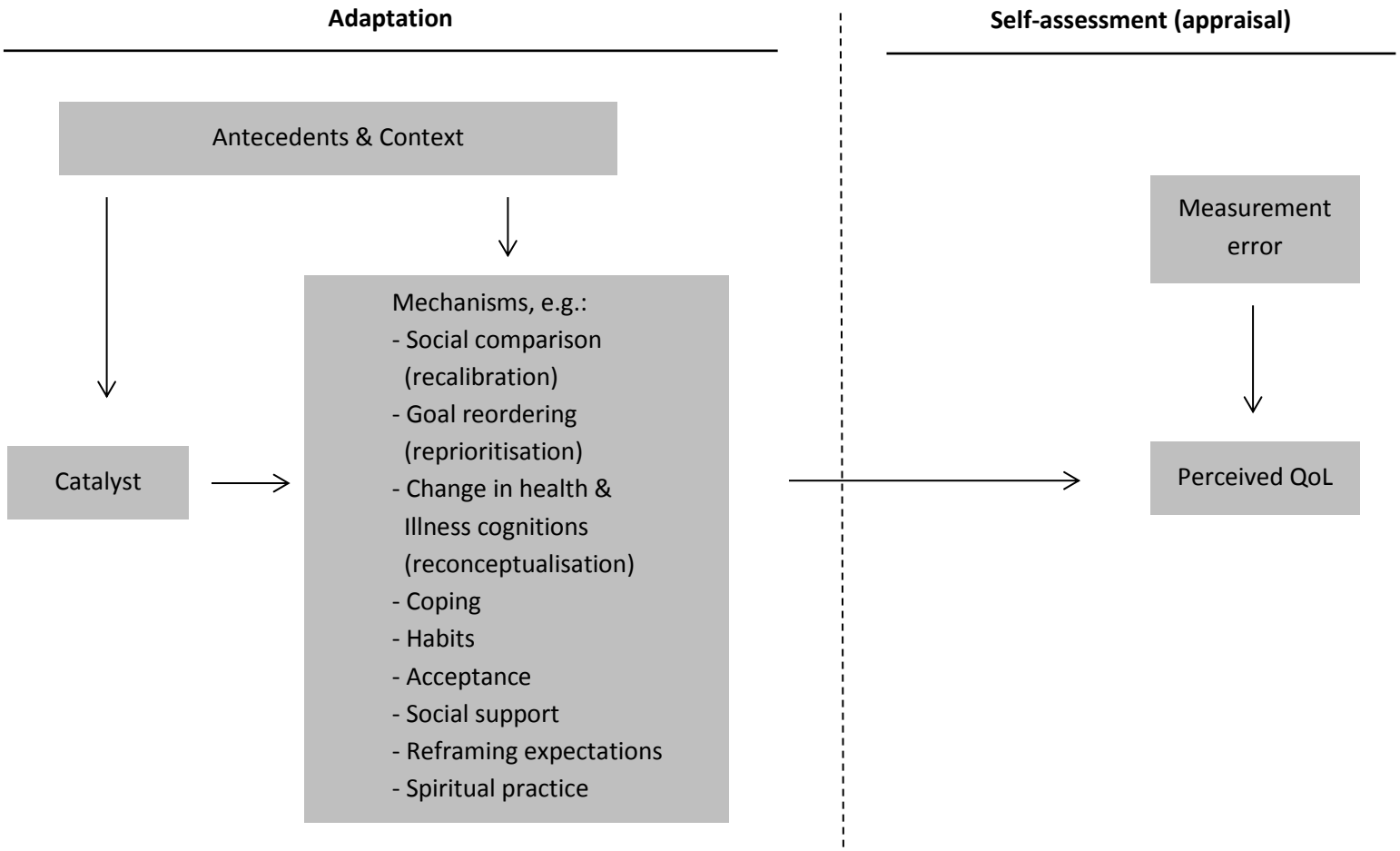


Figure 4.3.1 Modified model of response shift

4.3.1 Adaptation

The data provided evidence of adaptation to DH that was initiated by the onset of the condition or other particular events, through a combination of different psychosocial mechanisms and occurring in the particular environmental context. Successful adaptation was marked by an individual no longer perceiving DH as having a significant negative effect on their QoL:

> *"I think that [having DH as a result of receding gums] made me feel rather more kind of depressed about my age than it is really justified by the circumstances. But that was sort of temporary, it didn't really last (…). After a while I kind of forgot about that aspect of it, and just got on with my life really."*
>
> (Olivia, Baseline)

The subthemes evident within the theme of adaptation were:

- Mechanisms
- Context
- Catalysts

These subthemes are discussed in the following sections.

4.3.1.1 Mechanisms

Eight mechanisms involved in the adaptation to DH were identified: downward social comparison (recalibration), goal reordering (reprioritisation), change in health and illness cognitions (reconceptualisation), acceptance, coping, habits and social support.

Downward social comparisons (recalibrations) were performed within the domain of DH-related pain and impacts of DH on everyday life. They represented shifts in the frames of reference participants used to assess their DH and related pain. Downward social comparisons resulted in decreases of the importance of DH on one's QoL:

> *"The pain is probably the same as you said but it's just the way I see it is different I guess. (…) I think it's a consequence of our discussion, you see, like thinking that some people are worse than me made me think 'oh yeah that's fine'. I guess. (…)*

Cause last time we were talking made me realise some people are much worse than that. Like some people they can't even eat anything too hot or anything too cold you know like they just can't do it cause it's too painful. I guess mine's not that bad."

(Olivia, follow-up)

Personal goal reordering (reprioritisation) involved changes in the relative importance of DH and goals related to managing DH for the person's QoL. Changes in the importance of the DH-related factors were part of a global shift in personal priorities and goals or were initiated by the onset of the condition and occurred over its duration.

Changes in the relative importance of the DH-related goals that formed part of global goal reordering were initiated by events such as having children, children leaving home or getting older. As a result, the importance of DH-related goals for the person's QoL could decrease:

"I'm so busy because I've got two young children that I haven't got time to be anxious about something that is going to hurt."

(Agnes, baseline)

Conversely, the importance of DH-related goals could increase:

"Well, I think the thing is that when you've got children and especially young children like I had close together your priority is there. (…) Whereas now when you get older and you haven't got children to think about (…) you've got the opportunity to eat what you want. (...) But then you think more rationally about it and just get on with things because, you've got other priorities if you know what I mean. But obviously as you get older, you've got more time to think about what you're doing and when you're doing it for less people or just for yourself."

(Doreen, baseline)

When initiated by the onset of the condition, changes in the relative importance of the DH-related goals were linked to changes in illness cognitions.

If occurring at the beginning of the condition, changes in illness cognitions involved labelling previously unnamed symptoms, sometimes perceived as a *'part of life',* as *'sensitive teeth'*. This was linked with an increased importance of DH related goals such as management of the condition:

"I think it took me a little while before I sort of admitted that I had sensitive teeth. (…) But I think certainly once you start getting told that you've got sensitive teeth and you start admitting you've got sensitive teeth, it definitely becomes more of an issue. When like you got this external label attached to it I think that starts to condition your mind to think about it in a certain type of way. Rather than just it being like a sort of thing that's just part of your life, it now becomes a sort of external 'Sensitive-teeth this is an issue, got to deal with it thing'."

(Julian, follow-up)

Changes in the cognitions that occurred over the duration of the condition were concerned with shifts from the negative end of the continuum with DH viewed as *'a big negativity'* or *'a big problem'* towards the neutral end with DH viewed as *'normal'*, *'part of a normal life'* or a *'normal thing'*.

This resulted in decreases in the importance of the DH-related goals and marked a successful adaptation to the condition. For example, Caroline, who perceived DH to have substantial negative impact on her QoL at baseline, reported that her understanding of DH changed from perceiving it as a *'big problem'* to seeing it as something *'a lot smaller'* at follow-up. Thus, DH no longer had a negative impact on her QoL:

"Before, when we last met it felt like a really big problem or a really big negativity in my life, whereas now it feels a lot smaller. … It doesn't affect my quality of life that much as I perceived at that time."

(Caroline, follow-up)

Similarly, Lucy changed her understanding of DH into something that is *'normal'*, which was associated with a decrease in the importance of DH:

"It's not really high on my priority list and it's been going for so long that I kind of accept it as normal now"

(Lucy, follow-up)

Acceptance, another mechanism of adaptation, encompassed acknowledging that the cure for DH was unlikely, as well as shifting attention away from DH:

"I've accepted it a lot more because (…) I think if there was something you could do about it, you'd pay that money and have it done definitely. But the only thing you

can do is to put as many things in place to try and counter act is as you possible can, because you know there is no cure for it. You know that it is something you've got to deal with personally."

(Doreen, baseline)

In this instance, accepting that there was currently no cure for DH and one *'should learn to live with it'* contributed to successful adaptation.

Two main types of coping were identified: problem oriented coping and cognitive avoidance. Problem-oriented coping involved strategies to minimise the occurrence of the sensations, such as eating on one side of the mouth or using a straw. Coping strategies to prevent the progression of the condition, such as avoiding acidic food or using the DH specific oral health care products were also evident. They were often performed automatically or as habits:

"It doesn't go through my head 'Be careful how you eat this' I don't think. But I think I probably do eat more with the back of my teeth because it's less sensitive, but I don't eat an apple in that particular way because I choose deliberately to do it. Well I have chosen deliberately to do it, but I think it's more at a subconscious level than me thinking: 'I'm going to eat this apple now but I must make sure that I eat' it's not something I think about, I just do it as just part of the way I eat."

(Towkey, follow up)

Problem-oriented strategies becoming habitual were linked to changes in illness cognitions, from viewing DH as something that is 'bothering' into viewing it as *'normal'*:

"If I think of eating normally I think of like eating on both sides of the mouth and I think now I eat more towards the right hand side because the most sensitive teeth are on the left but I just, as I say I just sort of do it automatically now so it has kind of become normal."

(Olivia, follow-up)

Problem-oriented coping strategies gave a sense of control over the condition, which also contributed to successful adaptation:

"But I think it's relatively under control, my symptoms. (…) I use sensitive toothpaste, I try and cut down on acidity and I've altered my diet to accommodate what are triggers for me, and to me now it is there, but it's more part of my life."

(Doreen, follow-up)

Cognitive avoidance involved ignoring the symptoms when they happened or not thinking about DH on a day to day basis:

"I try to like forget about it, I just keep thinking if you don't think about pain it just goes away, it's like you don't really feel it unless you really think about it."

(Abigail, baseline)

How did I get used to it? I think probably by just kind of putting it to the back of your mind, you know instead of thinking 'ooow that will hurt' every time you're eating and knowing it's there but not thinking about it. Kind of trying to just shut it off.

(Sue follow-up)

Social support, including emotional, instrumental and informational support was also involved in adaptation to DH. As social support was closely linked with context it is discussed in the next section (p. 136).

Mechanisms of adaptation were interlinked so that a combination of different mechanisms facilitated successful adaptation to the condition.

For example, as a result of participating in the study, Yasmin changed her cognitions, from seeing DH as something to *'put up with'* to a condition that is *'manageable'*. As a result she started to employ problem-oriented coping strategies, such as using sensitivity specific toothpaste and mouthwash and avoiding food that could trigger the symptoms:

"It's a condition and I think I wasn't looking at it like that. I was just, I wasn't dealing with it, I was just sort of coping whenever it flared up, whereas coming and taking part in the study made me look at it differently and look at it like it is a condition and that it can be more, it can sort of be managed better."

(Yasmin, follow-up)

4.3.1.2 Catalysts

Three types of catalysts for adaptation were present in the data: onset of the condition, external catalysts (e.g. important life changes) and participating in the study (which acted as an intervention).

Onset of the condition was a primary catalyst for adaptation to DH. It was perceived as gradual, sudden or cyclical

> *'It doesn't start suddenly, it sort of starts more gradually'*
>
> (Tilly, baseline)

> *'Since I had that treatment done on my tooth, and since then it has been affecting me'*
>
> (Caroline, baseline)

> *'it's always been on and off'*
>
> (Amy, baseline)

External catalysts such as important life changes initiated global reordering of personal goals including DH-related goals.

Finally, and as revealed in the previous section on mechanisms, participation in the study also facilitated adaptation to DH. It prompted a reflection on what QoL meant for the participant and the role of DH in QoL:

> *"Since we met last time, and I think because occasionally it bothers me, like in my mind it bothers me a lot but then when I think about everyday life actually it doesn't affect me as bad as I thought. I think I see it differently now than I did then, so I think I've changed a bit how I think about it. (…) Maybe the point you made about, I said my quality of life was my family and everything and then it doesn't have a big effect on my family."*
>
> *(Caroline, baseline)*

Participating fostered mechanisms such as seeking social support, problem-oriented coping and downward social comparison:

“Cause last time we were talking made me realise some people are much worse than that. You know like we were talking about also like other people and you know? And you know I guess like some people they can’t even eat anything too hot or anything too cold you know like they just can’t do it cause it’s too painful. I guess mines not that bad.”

(Abigail, follow-up)

No evidence was found of participation impacting negatively on participants’ QoL or their perception of their condition. However, heightened awareness of pain in the teeth was observed during and preceding the interviews:

"But I've noticed recently, an area on my left side is more sensitive at the moment, like literally within the past week, it's become really sensitive. Maybe it's because I've been thinking about the interview."
(Lucy, follow-up)

4.3.1.3 Context

Context, including immediate social environment (family and friends), dentists, DH related oral health products (toothpastes and mouthwashes), and advertisements for these products played an important role in adaptation to DH through involvement in mechanisms such as social support, social comparison and problem-oriented coping.

Immediate social environment, including family and friends, was a source of social support:

“I started using the Pronamel because my friends had told me that their dentist had recommended it”
(Lizzy, follow-up)

However, social support was not always sought or received at a desired level from the immediate social environment. This was linked to viewing DH as *‘insignificant’* and *‘not talked about’:*

“I don’t know why people don’t talk about it. You know if they’ve got sensitive teeth they are not like ‘Oh, I’m not drinking this right now because I have sensitive teeth’. They just say ‘I’m not drinking it right now’ and then they don’t have it (…).

You don't mention it because it's only an insignificant part of what you're doing; it's not affecting you or anyone else directly."

(Amy, baseline)

Experiencing DH in public was also linked with embarrassment:

"Cause I don't really talk to other people about it (…) the worst thing is when if I'm out with somebody eating or drinking and by accident I get a shock (…) and I know I make a face so I don't want them to see. So that I worry about it when it happens sometimes."
(Caroline, baseline)

In addition to being described as unimportant and not talked about in public, DH was perceived as not directly observable, which hindered the possibility of finding other people in a similar situation who could be a source of social support:

"I'm sure I know people with sensitive teeth but it is not something you notice. So if you don't ask people if they have sensitive teeth then they wouldn't know."

(Biscuit, baseline)

Dentists were another source of social support. Participants visited the dentist, especially shortly after developing symptoms, to obtain a diagnosis and to find out about treatment:

"So after the sensitivity started I went to the dentist and they said (…) your teeth are absolutely fine (…) they just said it's sensitivity"

(Tilly, baseline)

Dentists provided information about DH, toothpastes and mouthwashes, brushing techniques to prevent gum recession and dietary advice. Some participants received specific in-clinic treatment to reduce symptoms. However, help received from the dentist was often seen as unsatisfactory, when, for example, the dentist said that there was nothing else that could be done to treat DH apart from using the DH specific toothpaste:

"They [dentists] say that there is nothing to do about it other than try this toothpaste and see if it works. No one has actually recommended any other treatment or any cure or anything else."

(Biscuit, baseline)

Views that communicating issues related to DH to the dentist is not straightforward were also expressed:

> *"If it's not bothering me at the time it's not something I think to mention [to the dentist].It might sound silly that, but if it's not bothering me at the time and it's at the back of my mind because I've got everything else going off at work and what have you, so therefore I wouldn't bring it up. If it was hurting me at the time I probably would."*
>
> (Michelle, baseline)

As the need for social support might not have been met through the immediate social environment or dentists, the mass media became an important source. The role of advertisements for DH products in the adaptation to DH was twofold. First, advertisements contributed to changes in the DH-related cognitions, by providing information about DH and its symptoms. Based on this information a person was able to attach a label of *'sensitive teeth'* or *'sensitivity'* to their symptoms:

> *"I just felt one day and I knew myself what it was even then cause you read things and you know about thing and sensitive teeth there were adverts on telly you know. You know, you do see adverts of toothpaste and I can always remember that there is this women, I don't know if it's still on, but she is eating something and she just that tick of 'ugh' and that. I think because of advertising and everything, I think you are more aware with things like that as you wouldn't before. So, I already knew from things that I had seen that I have got sensitive teeth"*
>
> (Agnes, baseline)

Second, advertisements were a source of social support throughout the duration of DH. Advertisements provided information about ways of managing DH with specific toothpastes and mouthwashes:

> *"Adverts like the Sensodyne advert, that's where I've got my information from, as opposed to getting it from the dentist and I would have thought that they would come from the dentist."*
>
> (Tilly, baseline)

They were also a source of emotional support as they allowed the person to feel that their experiences were shared by others:

> *"Now also people talk about it a lot on TV, you know it's a big thing at the minute. Everybody is talking about it, so it makes me think 'oh yeah I'm one of them too', like you see it on TV. A person says 'Okay, yeah I can't eat ice.' and you think 'Oh yeah me too! I can't eat ice!' You know and things like that. So that's why it makes me say 'Oh yes I have sensitive teeth.' It's because I'm like these people on TV I would say that I have sensitive teeth."*
>
> (Abigail, baseline)

While some participants viewed advertisements as a valuable source of information, others where more cautious:

> *"They always make me laugh a little bit because, they get some 'professional' who tells you about toothpaste and I don't know if there will ever be anybody who's gonna fall for that, because obviously the professionals are employed by the people who made the adverts to say this is really good toothpaste and you should use it. Even if there might be a little bit of science that accompanies the toothpaste at the end of the day they have paid this person to give the endorsement."*
>
> (Julian, Baseline)

DH related products were used in problem-oriented coping to prevent the sensations and the progression of DH. Views about their effectiveness varied. Some believed them to be effective, others thought that the toothpaste was ineffective and some were uncertain:

> *"Using sensitive toothpaste regularly I think does help, because I don't really get the sensitivity. I don't know how it works but I don't get the sensitivity very often."*
>
> (Tilly, baseline)
>
> *"I tried almost anything, like sensitivity toothpaste, which I think they don't really work"*
>
> (Biscuit, baseline)
>
> *"If I'm using the sensitive toothpaste does it make it better? Cause I think you know you start using it and you can't really remember. Was it worse? So is it slightly*

better? You forget don't you? So I'm not really sure to be honest. But I think if it's toothpaste, it is still cleaning my teeth, it's got a bit that in it then. If it is helpful then that's a plus, and if it's not then I still have got to clean my teeth, so it's not like I'm doing something that is, you know, bad, to try to remedy it. I mean I'm still cleaning my teeth. So I just think, well I'll carry on using it so that's what I've done but whether it doesn't or it doesn't I don't know or is it one of those things, if I didn't use it, would it be worse."

(Agnes, baseline)

Financial concerns restricted the accessibility of DH specific products:

"I don't really do anything apart from (…) using sensitive toothpaste which is more expensive, so it's a little bit of bother because you obviously have to pay a little bit extra."

(Amy, baseline)

Adaptation was dynamic and bidirectional as successful adaptation to DH could reverse, after a period without symptoms. For example, Anna, went without symptoms for several months. Once she started to experience them again she changed her understanding of DH into something *'bothering'* and DH-related goals such as management of DH became important for her, so that DH again impacted negatively on her QoL:

"You know a good 5 months of not having anything and then to have something again it's just like oh why is that there, it's frustrating. It's like having an itch you can't scratch and it's like, why is that there? It's annoying, and now I kind of want to do things to sort it out more, whereas before it was like oh it's fine like I'll just use my mouth, so what I normally do. Whereas now, it's like, what toothpaste can I find? What mouthwash can I use? What can I do to stop it? Yeah, I think it's just like I said, because it was a different mind-set because it was you know, you were used to it and then you're not so the sensitivity is more of an issue when you don't have it for ages."

(Anna, follow-up)

Additionally, changes in the perceived levels of stress increased the negative impact of DH on QoL. Following the same pattern, when the person experienced less stress the importance of DH diminished:

"So I think at times when I'm more worried I would kind of almost like maybe fixate on something like sensitive teeth or like you know age related deterioration of my faculties sort of, and I would worry about it more. But really it might be about other things going on in my life. And then at times when I'm generally happier and feeling stronger I would be able to kind of push the teeth to the back of my mind a lot more."

(Olivia, baseline)

4.3.2 Self-assessment (appraisal)

Self-assessment or appraisal was added as a distinct set of factors in the modified model of response shift (Figure 4.3.1). Two subthemes emerged within the theme of self-assessment. The first was the influence of adaptation on self-assessment of DH related QoL and on the change in the DH related QoL over time. The second subtheme was measurement error in the assessment of DH related QoL and change in DH related QoL over time.

4.3.2.1 Response shift as part of adaptation (true change) and self-assessment of QoL

Adaptation to DH was reflected in changes in appraisals of the DHEQ items, and consequently in DHEQ scores. For example, as a result of a number of mechanisms initiated through participating in the study, Tilly's assessment of how much she was bothered by the sensations decreased from '6' at baseline to '4' at follow-up. This is how she commented on it:

> *"I think that's it's either education of just talking to you, so being aware that it affects more people than, yeah so an awareness of how many people are affected and likewise say chatting to my dentist about you know that it is actually quite a normal thing. So I'd say it bothers me less now because I don't think that there is actually anything wrong. Whereas before it was sort of I didn't really know very many people who had sensitive teeth and because I didn't really talk about it so much. So I feel that the changes is on a basis that it bothered me a lot more before because I didn't know as much so it's like a level of education."*
>
> (Tilly, follow-up)

In another example, when asked how much the sensations affected her QoL, Lucy referred to changes in the cognition of DH into something *'normal'* as a reason for answering *'not at all'* to this item:

> "Just because I don't think they impact what I do, maybe because it's become more normal for me now."
>
> (Lucy, follow-up)

4.3.2.2 Measurement error in self-assessment of QoL

In addition to the changed appraisals as a result of adaptation or changed symptoms, there were other changes in appraisals and DHEQ scores that could not be attributed to them. These changes reflected measurement error rather than true change, because they did not reflect changes in participants' views. A number of these changes were concerned with the assessment of DH related pain. These changes occurred between the two interviews, as in the case of Julian, who changed his standards of comparison between the baseline and follow-up interviews. At baseline, Julian compared his sensations with *'day to day pain'* whereas during the follow-up interview his point of reference was *'the most intense pain out of the total range of pains'*. This resulted in lower perceived intensity of pain from '6' at baseline to '3' at follow-up.

These changes in the appraisal could also occur during a single interview. For example, Towkey, changed her points of reference when deciding on her evaluation of the intensity of pain from the actual intensity of pain at the moment of it happening to a reference point between the normal activity and child birth. This resulted in changing the evaluation from '7' to 4':

> *"If you talk about the actual intensity of sensations than I would say '7' but if you're talking about like on a grand scale of things between normal activity and child birth I would probably say '4'."*
>
> (Towkey, baseline)

4.4 Discussion

This study explored response shift and its underlying psychosocial mechanisms in people with DH using a qualitative longitudinal approach.

Two themes 'Adaptation' and 'Self-assessment (appraisal)' emerged from the analysis and categories from both themes were used to formulate a modified model of response shift (Figure 4.3.1). The modified model proposed a new conceptualisation of the response shift phenomenon that distinguished between the influence of adaptation and the influence of measurement error on the self-assessment of QoL (and the assessment of changes in QoL over time). The modified model also introduced two novel mechanisms: acceptance and habits. The Antecedents component also was extended to include the external context in which adaptation occurs. Additionally, the study provided a description of adaptation to DH and the influence of adaptation to DH on self-assessments of QoL.

The discussion of the results is divided into two. Section 4.4.1 discusses adaptation to DH and its influence on the self-assessment of QoL. Section 4.4.2 discusses the modified model of response shift and its possible applications beyond DH.

4.4.1 Adaptation to DH and self-assessment of OHQoL

Adaptation to DH influenced self-assessment of OHQoL in people with DH.

There is no one definition of psychological adaptation (or adjustment) to a health condition, but it is generally understood as a 'psychological process that occurs over time as an individual learns from and adapts to the changes caused by illness and its treatment' (Brennan, 2001). The theories of psychological adaptation postulate that it is a process through which a person re-establishes a state of psychological equilibrium characterised by good or satisfactory well-being and QoL, that had been disrupted by the onset of the condition (Taylor, 1983; Moos and Schaefer, 1984; Leventhal *et al.*, 1997). Personal growth resulting from an illness is also possible (Tedeschi and Calhoun, 2004).

This study detailed several important attributes of adaptation to DH. First, DH and its management were not always a central priority for the person as there might have been other, more important, priorities. Therefore, in order to understand how people experience and adapt to DH, the wider context of people's lives had to be considered. Second, adaptation to DH occurred as a result of the interplay between different mechanisms including: downward social comparison, goal reordering, changes in illness cognitions, coping, acceptance, habits

and social support. Third, adaptation to DH occurred in physical, social and cultural environments (context) that shaped the available strategies of management and adaptation to DH. Fourth, the onset of DH initiated adaptation, but external catalysts such as life events and participating in the study were equally important. Fifth, the results indicated that there was no definite end to the adaptation to DH, and successful adaptation can reverse after a period with no symptoms or when a person is experiencing high levels of psychological stress. These findings are in line with the view of adaptation as a process that occurs over time rather than an end point that is achieved at some point in time (Sharpe and Curran, 2006). Adaptation to DH resulted in a decrease in the negative impact of DH on the person's OHQoL, which was reflected in the appraisal and DHEQ scores. Additionally, measurement error also impacted on the assessment of OHQoL in people with DH.

4.4.1.1 Mechanisms

Several mechanisms involved in adaptation to DH were identified in the study.

Downward social comparison in the domain of DH-related pain and impacts of DH on everyday life was a mechanism of adaptation to DH. Social comparison is an established mechanism of adaptation to chronic health conditions (VanderZee *et al.*, 1996). Possible objects of comparison include comparison with oneself in the past, others in a similar situation and hypothetical others. In this study, comparisons with hypothetical others were prominent. This was linked to the perceived characteristics of DH as something that is not talked about so that participants did not know many other individuals with DH in their immediate social environment. Additionally, due to the nature of DH, it is not possible to say if a person has the condition or not unless they share that information.

Change in the relative importance of DH-related goals (reprioritisation) was another mechanism of adaptation to DH. This change in the relative importance was either part of global goal reordering initiated by events not related to DH or was initiated by the onset of the DH and occurred over the duration of the condition.

The results of the study showed that managing DH was important for the person only if there were no other more significant areas of life that demanded attention at the time. Similar findings regarding the relatively low importance of oral health compared to other issues in peoples' lives emerged in the Gregory's (2003) study on how assessments of OHQoL vary between and change within individuals. For example, the importance of the teeth for one of the participants decreased with her husband's diagnosis of life threatening disease. This

suggests that the importance of oral health and oral health conditions depends not only on the clinical status of the teeth but also on other areas in the person's life which might be more important at a particular point in time.

Changes in DH-related cognitions (reconceptualisation) contributed to the adaptation to DH. In this study, changes in the cognitions regarding DH, rather than changes regarding more general concepts such as health or QoL were observed. This might be due to the relatively mild nature of the DH, which may not have sufficiently negative impacts to alter people's subjective understanding of health or QoL.

Participants' views on their DH and how they changed over time can be understood through the concept of illness representations. Illness representations are common sense schematic representations held by an individual about a particular health problem (Leventhal *et al.*, 1997). To date, six cognitive (identity, cause, timeline, consequences, cure/control, illness coherence) and one emotional (emotional representation), components of illness representations have been identified (Leventhal *et al.*, 1997; Moss-Morris *et al.*, 2002). A meta-analysis of 45 empirical studies suggested that illness representations are involved in adaptation to health conditions and influence health outcomes (Hagger and Orbell, 2003).

There is also evidence suggesting that illness representations play a role in adaptation to DH. Porritt and colleagues (2014) found that illness representations, together with coping strategies, predicted OHQoL in relation to DH. More specifically, low levels of illness coherence, and negative emotional representation predicted lower OHQoL in people with DH.

Another way of understanding changes in the participants' views on DH is through the concept of normalisation. Normalisation is a process through which a person attempts to function effectively in his or her environment and to be perceived as normal, despite their health condition or disability (Deatrick *et al.*, 1999; Joachim and Acorn, 2000). The concept of normalisation emerged in studies of adaptation to illness or disability, where participants described their attempts to establish 'normalcy' in their everyday functioning and to be perceived as 'normal' by others. They stated that, apart from the particular illness or disability, they were 'normal', meaning just like everybody else (Robinson, 1993; Deatrick *et al.*, 1999; Joachim and Acorn, 2000). In this study, changes in cognitions such that DH became *'normal'* to a person, can be seen as normalisation of DH.

Problem-oriented coping and cognitive avoidance were identified as mechanisms of adaptation to DH. These strategies were also identified in earlier work by Boiko and colleagues

(2010) and Gibson and colleagues (2010) and the DHEQ incorporates items on coping for this reason (Boiko *et al.*, 2010).

Problem-oriented coping strategies were related to minimising the DH-related pain (e.g. by waiting for the food to reach room temperature before eating it) and to preventing the progression of DH (e.g. by adopting an appropriate brushing technique). Problem-oriented coping was linked with gaining sense of control over the condition. Cognitive avoidant coping was related to not thinking about the DH-related pain on a day to day basis and to distracting oneself from the pain when it occurred.

Problem-oriented coping, including self-management of the condition has been linked with adaptation to chronic health conditions (Bailey *et al.*, 1999; Williams *et al.*, 2004) and with positive health outcomes (Friedland *et al.*, 1996; Desmond and MacLachlan, 2006). Gaining a sense of control over a condition and its management has also been recognised as a mark of successful adaptation to it (Sinclair and Blackburn, 2008). Problem-oriented coping involve reducing the stressor (health condition) and increasing the available resources to deal with the stressor (health condition) (Ogden, 2012, p. 326). Therefore, if successful, problem-oriented coping can improve the QoL of a person by minimising the negative impacts of the health condition on the person's life. As has been said above, problem-oriented coping is linked with gaining sense of control which can further improve the person's wellbeing. In the area of oral health, problem-oriented coping reduced the negative impact of perceived stress on periodontal disease (Genco *et al.*, 1999). However, Rodd and colleagues (2012) did not find a link between problem-oriented coping and OHQoL in 10-11 years old children. A possible reason for that is that in children the link between the coping strategies and QoL is different than in adults.

Cognitive avoidance strategies, characterised by not thinking about the condition and its consequences and therefore avoiding targeting the problem using more problem oriented focus, are sometimes considered to have negative impacts on adaptation and on QoL (e.g. Leary *et al.*, 1998). However, 'avoidant' strategies might have positive outcomes when coping with chronic pain. Strategies such as 'not thinking about the pain' were adaptive in people with chronic pain (Jensen and Karoly, 1991). Similarly, Porritt and colleagues (2014) found that coping strategies such as efforts to function in spite of pain, or active distraction from pain predicted better QoL in people with DH. Avoidant strategies might be adaptive in relation to chronic pain, because this kind of pain cannot be controlled by the person, so that problem oriented strategies cannot be applied successfully. Indeed, avoidant coping strategies are

considered to be more effective than problem oriented strategies in relation to health conditions characterised by low controllability (Lazarus and Folkman, 1987).

Habit formation emerged from the analysis as a novel mechanism, not recognised in existing response shift models. Habits are behaviours that are triggered automatically, by cues present in the person's everyday life (Wood and Neal, 2007). The formation of habits is marked by a move from 'conscious voluntary control over the behavior to a lower-order behavioural control that is scarcely available to consciousness' (Graybiel, 2008).

Habit formation related to problem-oriented coping strategies to prevent DH-related pain and the progression of the condition. This included behaviours regarding eating and drinking: eating on one side of the mouth, avoiding acidic food, and oral hygiene: using DH specific products and adoption of appropriate brushing techniques. Habit formation in relation to oral hygiene and eating and drinking contributed to the successful adaptation to DH. At the same time, habits related to unhealthy behaviours such as over-brushing, had to be changed in an attempt to manage the condition.

Acceptance was another novel mechanism, not previously recognised in the existing models of response shift. It is defined as 'allowing, tolerating, embracing, experiencing, or making contact with a source of stimulation that previously provoked escape, avoidance or aggression' (Cordova, 2001, p215) and as 'an active an aware embrace of thoughts, feelings and memories, without unnecessary attempts to change their frequency or form, especially when doing so would cause harm' (Hayes *et al.*, 2006).

Acceptance is an effective mechanism of adaptation to chronic health conditions. A meta-analysis of 32 studies found that higher levels of acceptance were positively related to better adjustment to health conditions and better QoL (Hayes *et al.*, 2006). Acceptance is especially likely to be effective when efforts to directly control one's experiences are not adaptive as they are unlikely to result in an improvement and exert excessive costs (Herbert *et al.*, 2009). This is especially a case of chronic pain (such as DH-related pain), for which there is no immediate cure (McCracken and Eccleston, 2003; Keefe *et al.*, 2004).

One study demonstrated that greater acceptance of chronic pain was associated with better adjustment to it, involving less pain related anxiety, less depression, less physical and psychosocial disability, more daily uptime and better work status among individuals seeking help for chronic pain (McCracken, 1998).

It is important to note that, when exactly acceptance is more adaptive than problem-oriented coping and efforts to gain sense of control depends on the degree to which the negative impacts of the condition or pain can be minimised and controlled. Therefore, often a balance between acceptance and problem-oriented coping is most adaptive (Cordova, 2001; McCracken *et al.*, 2004). This is the case for DH, where sensations can be minimised and controlled only to a degree (Cummins, 2009). As noted earlier, cognitive avoidance can also be beneficial in adaptation to chronic health conditions. Indeed, the results of this study showed that acceptance, problem-oriented coping strategies and cognitive avoidant strategies were used jointly to manage DH.

Social support was perceived as insufficient by the participants. As in the case of social comparison (p. 132), this was linked with perceiving DH as something that is not talked about. This perception of DH has been supported in previous research. In their analysis of the accounts of illness in people with DH, Gibson and Boiko (2012) described the difficulty of communicating about impacts of DH by people with the condition. They named this phenomenon 'the imperative of sensitivity' (p. 171) which meant that DH is a problem that is experienced independently and in private and communication about the impacts of DH to others is limited. These limits to communication and the necessity of experiencing the problem in private were linked to the 'non-problem - problem' status of DH in society. DH was a problem to the person experiencing it, but it was not seen as a problem by others, for example dentists. Therefore, it is difficult for affected people to find the appropriate language to discuss DH and to obtain help and support.

Research in the wider area of the psychosocial determinants of OHQoL suggests that social support is an important determinant of oral health and OHQoL (Baker *et al.*, 2009; Brennan and Spencer, 2009; Lamarca *et al.*, 2012; Gupta, 2014). For example, in a longitudinal observational study of psychosocial determinants of OHQoL Gupta (2014) found that adults with lower perceived social support at baseline had worse OHQoL at follow-up. Therefore, based on these results it can be said that deficiencies in social support can have a substantial negative impact on OHQoL.

4.4.1.2 Catalyst

Three types of catalysts initiated adaptation to DH: the onset of the condition, important life events and participating in the study.

The onset of the condition was an expected finding, both intuitively and because of its central role in the response shift models (Sprangers and Schwartz, 1999; Rapkin and Schwartz, 2004). A number of studies investigating response shift have documented that onset of the condition initiated adaptation and changed the way in which a person assessed their QoL (e.g. Ahmed *et al.*, 2004; Korfage *et al.*, 2007; Sinclair and Blackburn, 2008) (see section 2.4.2).

Important life events such as having children or getting older changed the relative importance of DH-related goals. Important life events, not directly related to the condition, are not explicitly mentioned in the existing response shift models, although Barclay-Goddard and colleagues (2012) listed 'events' and 'experiences' as possible catalysts in their theoretical comparison of response shift and transformative learning theories.

This study provided empirical evidence of role of the important life events, not related to the condition, in the shift of the importance of the conditions for the person's QoL. In other words, the findings of this study showed that it is not only the onset of the condition that changes views on QoL (as have been postulated by the response shift model), but also important life events changed the views on the condition. Investigating response shift in a relatively mild health condition such as DH allowed capturing the importance of external events on adaptation. This may not have been possible had catalysts been investigated in relation to a serious health condition which impacts on people's lives more broadly.

The findings also indicated that ageing influenced the importance of DH-related goals. This adds to previous evidence that views on oral health change with age (MacEntee *et al.*, 1997; Locker *et al.*, 2009). For example, in their study of the significance of the mouth in old age, MacEntee and colleagues (1997) found that getting older brings a need of constant adaptation to arising dental problems and pain and that which aspects of oral health are most important to the person changes with age.

Participating in the study did not seem to have any negative effects on the participants. However, some participants seemed to be more than usually aware of their symptoms around the time of the interview. This increased awareness can be interpreted as the Hawthorne effect, in which some aspect of the behaviour or performance of participants temporarily changes as a result of taking part in research (Wickstrom and Bendix, 2000).

Finally, the results of this study suggest that psychosocial interventions (taking part in the study can be seen as one) can foster adaptation to DH and improve OHQoL in people with the condition. Psychosocial interventions were found to improve functioning and QoL in people

with chronic health conditions such as diabetes (Thors Adolfsson *et al.*, 2007) or cancer (Osborn *et al.*, 2006). OHQoL can also be improved through psychosocial interventions. Nammontri and colleagues (2013) found that enhancing sense of coherence through classroom activates improved OHQoL in school children. Another study suggested improved well-being in people with oral cancer who received an educational booklet providing information about their disease, its treatment and effective coping strategies (Katz *et al.*, 2004).

In the area of response shift research, participating in self-management interventions for chronic health conditions, that taught the participants about their condition and how to manage it, resulted in changes in internal standards of measurement of QoL in two studies (Osborne *et al.*, 2006; Kuijer *et al.*, 2007) but not in a third study (Nolte *et al.*, 2009). Notle and colleagues (2009), who used the THEN TEST to measure response shift, concluded that they were not able to find evidence of response shift because of the poor validity of the method they used (i.e. the THEN TEST).

The study findings point to several types of psychosocial interventions that could be effective in fostering adaptation to DH and improving OHQoL through targeting the specific mechanism.

Dental health education programmes for people with DH, educating them about DH and how to manage it (e.g. through appropriate diet, brushing techniques and use of DH-specific products) are self-management interventions that could foster problem-oriented coping. Self-management interventions have proved to be an effective way of improving health outcomes in a range of chronic health conditions such as diabetes and asthma (Warsi *et al.*, 2004). However, the benefits of self-management programs are less clear in relation to conditions characterised by chronic pain and complex symptoms, such as arthritis (Warsi *et al.*, 2003; Newman *et al.*, 2004). In the area of oral health, behavior change strategies incorporated into interventions to promote oral health were effective in improving adherence to tooth brushing routines (Jonsson *et al.*, 2009). However, behavior change interventions are not considered to be effective over the longer term in oral health (Watt, 2005).

Another type of psychosocial intervention promoting adaptation to DH might alter DH-specific illness representations. For example, cognitive behavioral therapy aims to modify unhelpful cognitions and behaviours (Westbrook *et al.*, 2011). This type of intervention has been successful in different chronic health conditions. Moss-Morris and colleagues (2007) changed illness representations as part of cognitive behavioural chronic pain management programme which resulted in an improvement of the physical and mental functioning of the participants.

Acceptance could be fostered through interventions incorporating the principles of mindfulness (Baer, 2003) or through acceptance and commitment therapy (Hayes *et al.*, 2006). Both approaches were effective in improving QoL in people with chronic health conditions and chronic pain (Grossman *et al.*, 2007; Johnston *et al.*, 2010).

Social support, perceived as insufficient by the participants, can be promoted through creating on-line communities of people with DH or through interventions encouraging participants to talk about DH with their friends and family. Online support groups for people with different health conditions are rapidly growing. A meta-analysis of 27 interventions involving participating in an online support group suggested that these groups can improve QoL of its participants (Rains and Young, 2009).

4.4.1.3 Context

Context, including physical, social and cultural environment influenced adaptation to DH. Context was involved in social support, social comparison and problem-oriented coping. It determined the strategies and resources available to the person to make sense of and manage DH.

As was discussed earlier, experiences of DH were not always shared with family and friends, which was linked to the status of DH as something that is not talked about (Gibson and Boiko, 2012). In addition, dentists were not always able to provide enough information or to offer treatment.

Improvement of dental care for people with DH might be a way to foster the oral health and OHQoL of people with DH. The results of this study indicated that the help regarding the diagnosis and treatment provision from the dentists was often perceives as insufficient. These results are in line with the findings from the recent literature review on the diagnosis of DH in the dental practice. Gillam (2013) concluded that dentists were often uncertain about the diagnosis of DH and were not confident on how to effectively treat the condition, which was related to the lack of a commonly accepted approach to the diagnosis and treatment of DH. As a result, the dentists relied on the patient's self-report to make a diagnosis, rather than on a clinical examination to exclude other possible sources of the pain in teeth. Additionally, the screening for the condition was not routinely conduced. Cumulatively, this evidence suggests that there is a room for improvement of dental care for people with DH. For example, Gillam (2013) suggested a standardised approach to the diagnosis and treatment of DH that included providing dental health education advice, advice on the use of DH specific oral health products,

regular monitoring and, if necessary, a clinical treatment such as topical agents (e.g. fluorides) or adhesive materials. As indicated earlier, there may be scope for the professional development and enhanced training of students in both clinical and non-clinical management of DH.

Rather than being met by the immediate social environment or oral health care professionals the need for information, support and treatment was catered for by the commercially available products such as DH specific toothpastes and mouthwashes that were used to treat the condition at home and by advertisements of these products that were used as a source of information and support. Again, previous research on DH complements the above findings. Gibson and Boiko (2012) found that mass media and advertising play a significant role in the way DH is viewed and talked about. These findings were further supported by Hall and Gibson's (2014) analysis of the advertisements for DH specific toothpaste. The authors found that mass media and advertisements shaped the way in which people make sense of their condition. Considering the above evidence, it is possible that advertisements for DH-specific products could increase the role they play in facilitating adaptation to DH, by providing information about the condition and its treatment. This form of intervention can be especially effective for those individuals with DH who decide not to present their symptoms to the dentist. Indeed, it has been found that most of individuals do not seek dental treatment for DH, as they do not perceive their condition to be severe enough (Addy, 2002). Additionally, commercially available DH specific toothpastes offer an accessible way of treating the condition that would otherwise be unavailable.

Culture plays an important role in how people experience, react to and communicate their pain (Helman, 2007). Pain is a private experience that cannot be known to other people unless it is communicated (verbally or non-verbally). Whether and how it is communicated is determined by the person's cultural background. In some cultures, for example Italian or Spanish cultures, communicating one's pain is encouraged and acceptable, whereas in other such as British or Irish cultures, pain often remains mainly a private experience (Zborowski, 1952; Fabrega and Tyma, 1976). Therefore, it is possible that the participant's cultural background impacted on their difficulty communicating about DH and DH-related pain.

This study did not provide direct evidence of the role of personal characteristics on adaptation to DH. However, some indirect evidence suggests that health anxiety might have played a role in experiencing and adapting to DH (one participant reported that she felt less or more worried about DH depending on her perceived levels of stress , p. 136).

One way of looking at the link between perceived stress and worry about DH is through the concept of health anxiety. Health anxiety, also called hypochondria, is characterised by an increased focus on bodily symptoms and a worry that one has a serious illness based on misinterpretations of those symptoms (Taylor and Asmundson, 2004). Health anxiety is a personal characteristic that is relatively stable over time, though levels of health anxiety may vary between people (Salkovskis *et al.*, 2002). Individuals with high levels tend to scan their bodies in search of symptoms that are then interpreted as sign of a serious illness. Thus, DH related pain might be interpreted as a symptom of a serious oral health problem. It is possible that in people with high health anxiety, greater perceived stress triggers anxiety towards sensations in one's teeth. So that it might be more difficult for people with greater health anxiety to adapt to DH because they continue to worry that their sensations are a sign of a serious health problem. Indeed, Porritt and colleagues (2014) found that greater health anxiety at baseline predicted lower OHQoL at follow-up in people with DH.

However, an alternative explanation is that exposure to psychological stress can exaggerate pain experiences (Michelotti *et al.*, 2000; Dufton *et al.*, 2008), such as that in DH. Increased symptoms of DH might then lead to increased worry about pain. Eccleston and colleagues found that worry about chronic pain is triggered by an increase in pain and is not related to a general disposition to health anxiety or worry (Eccleston *et al.*, 2001).

In the area of oral health, evidence of the role of the personal (antecedents) and environmental (context) factors in OHQoL exist. Gupta (2014) found that psychological stress and socioeconomic status (SES) at predicted OHQoL overtime employees of an automobile parts manufacturer in India. A study comparing OHQoL in UK and Australia found that people in Australia reported more of impacts and more severe impacts than people in the UK, which might reflect a socio cultural difference between the two countries (Slade *et al.*, 2005).

4.4.1.4 Influence of adaptation on self-assessment of OHQoL in people with DH

As a result of adaptation participants' experience of DH and OHQoL improved. This improvement in the experience was reflected in the DHEQ scores.

Three ways in which participants' experiences of their DH and OHQoL improved can be identified. First, it was possible that through mechanisms such as problem-oriented coping and acceptance the symptoms of DH decreased. The use of DH toothpaste and mouthwash, as part of problem-oriented coping, may have reduced DH-related pain (Yates *et al.*, 1998). Additionally, experimental data have demonstrated that attempts to control pain lead to less

pain tolerance and greater self-reported pain compared to accepting pain (Gutierrez *et al.*, 2004). Therefore, accepting sensations in the teeth can result in higher pain threshold.

Second, adaptation may have reduced the impacts of DH. Acceptance can reduce emotional impacts (once the person accepts their sensations, they are less likely to experience negative emotions associated with them). Similarly, social support can reduce social impacts (if the person receives adequate support they don't have to hide their sensations during a meal or a conversation). For habits, managing the condition no longer required the cognitive effort from the person.

Third, adaptation may have changed a way in which a person sees their condition. Changing a referent from an upward comparison with a hypothetical person with 'perfect teeth' to a downward one with a hypothetical person with severe dental pain and impacts due to DH can change the way in which a person experiences the condition.

Finally, other areas of the person's life might become more important, reducing the negative impact of DH the QoL.

While adaptation changes the experience of DH and OHQoL, representations of those changes in the appraisal remain unclear and requires further investigation. The evidence from this study suggests that one possible way is through changes in the internal standards of comparison (that are one of the parameters of the appraisal described by Rapkin and Schwartz (2004)) as a result of downward social comparison.

In addition to the influence of adaptation, measurement error also impacted on DHEQ scores. The results revealed changes in appraisals between the baseline and follow-up interview, that could not be attributed to adaptation or change in clinical status for DH. These changes in the appraisal were a source of error.

4.4.2 Application of the modified model of response shift beyond DH

The new conceptualisation of the response shift phenomenon that distinguishes between the influence of adaptation and the influence of measurement error on the assessment of QoL and change in QoL over time was proposed based on the analysis. The analysis also resulted in a modified model of response shift that reflects the new conceptualisation. Thus, implications for the field of response shift research emerge from this study.

The modified model shares some characteristics with the previous models (Sprangers and Schwartz, 1999; Rapkin and Schwartz, 2004) (Figure 2.2.1 and Figure 2.2.2) but it differs in a number of ways.

Both the modified and the previous models recognise that not only clinical status, but also factors such as coping, social comparison, personal characteristics and appraisal influence the self-assessment of QoL. Therefore, according to both the modified and previous models, changes in self-assessments of QoL might result not only from changes in symptoms, but also from psychosocial mechanisms and changes in the appraisal.

The modified model differs from the existing ones in the following ways. First, the modified and previous models differ in their view on recalibration, reprioritisation and reconceptualisation. The previous models of response shift situate recalibration, reprioritisation and reconceptualisation as separate components (Sprangers and Schwartz, 1999) or as changes in the appraisal (Rapkin and Schwartz, 2004). The modified model does not view recalibration, reprioritisation and reconceptualisation as separate entities. Instead, they are reinterpreted as mechanisms of adaptation including: changes in social comparison (recalibration), goal reordering (reprioritisation) and changes in health and illness cognitions (reconceptualisation).

Second, the modified and previous models differ in their view of whether response shift is a source of a measurement error. Sprangers and Schwartz defined response shift as 'change in the meaning of one's self-evaluation of QoL as a result of recalibration, reprioritisation or reconceptualisation' (Sprangers and Schwartz, 1999). They then suggested that as a result of these, three aspects of response shift, the meaning of the assessed construct (QoL) changes for the person which, in turn, undermines the validity of the assessment of change in QoL. Conversely, the modified model states that self-assessment of QoL over time is influenced by adaptation and by measurement error. Changes as a result of adaptation reflect true change in the person's experience of their QoL. Whereas a measurement error is a source of error

Third, the modified and previous models differ in their view on the role of appraisal. Rapkin and Schwartz (2004) theorise that the three aspects of response shift are reflected in changes in appraisal and that these changes are a source of bias in the assessment of change. The modified model postulates that measurement error can be seen as changes in the appraisal not related to adaptation or change in a health condition. For example, changes in internal standards of comparison selected at the two time points as a result of the instructions given by

the administrator of the questionnaire. The effect of adaptation on the appraisal is more complex and requires further investigation. The influence of adaptation might include long-term changes in appraisal, symptoms, impacts and how a person experiences their condition.

Fourth, while the previous model recognises the impact of personal characteristics (Antecedents) the modified model also includes environmental characteristics (Context) as an important factor influencing adaptation to the condition.

This recognition that context influences adaptation is an important addition to the model. Physical, social and cultural factors play an important role in the adaptation to health conditions, which was recognised in models of health and quality of life such as the International Classification of Functioning, Disability and Health (ICF), which defines environmental factors in terms of barriers and facilitators (taking a physical or social form) for performance of actions and tasks in everyday life (WHO, 2001; Ustun *et al.*, 2003). Also, Wilson and Cleary links clinical factors with health-related and overall QoL (Wilson and Cleary, 1995; Ferrans *et al.*, 2005). In the model, characteristics of the environment (and characteristics of the person), were recognised as determinants of health-related and overall QoL.

With regards to social aspects of the environment, the availability of social networks to a person, the frequency of contact as well as the satisfaction and quality of those contacts (Fratiglioni *et al.*, 2000), has been positively associated with life satisfaction in older adults (Pinquart and Sorensen, 2000) and with better health outcomes (Merchant *et al.*, 2003). Physical aspects of the environment, for example, the availability of assistive technologies such as wheelchairs and specialised software can foster adaptation and improve the QoL of people with disabilities (Scherer, 1996). Culture plays an important role in how people experience and adapt to illness. Cultural factors can determine the mechanisms of adjustment to an illness. For example, ethnicity was related to the frequency of engagement in spiritual practices among women with breast cancer receiving a treatment (Lee *et al.*, 2000).

Fifth, the modified model included two novel mechanisms of adaptation: acceptance and habits. While not mentioned in the existing models of response shift, habits and acceptance are recognised mechanisms of adaptation to health conditions and disability.

Other views that the concept of response shift brings together phenomena that are conceptually different, such as adaptation to changed health and measurement error, have been expressed in the literature.

Ubel and colleagues (2010) suggested abandoning the term response shift altogether as it allowed conceptual confusion by using the same term to describe both measurement error (represented by scale recalibration), and true changes occurring as a result of adaptation. For the sake of conceptual clarity, Ubel and colleagues suggested replacing the term response shift with a 'scale recalibration' as a source of measurement bias, and 'adaptation' involving mechanisms such as hedonic or emotional adaptation, through which a person's' experience a true change in QoL over time. The findings from the current study support Ubel and colleagues' suggestions.

This study indicated that both adaptation, and more specifically changes in social comparison and measurement error, can all result in changes to the internal standards of measurement used to assess QoL. However, these changes seem to have different temporal characteristics. Changes resulting from adaptation are long-term. On the other hand, changes constituting measurement error are less stable and different internal standards of comparison can be adopted for different self-assessment occasions. This view is supported in the literature on adaptation and self-assessment. Inman and Ogden (2011) found that adaptation to a range of traumas involved shifts in the objects of comparison towards worse off friends and abstract others. This 'recalibration' allowed participants to appreciate life more and to maintain good QoL in the long term. Locker and colleagues (2009) found that different frames of reference to assess one's oral health were used depending on age and on whether a person assessed their oral health as 'excellent' or 'fair/poor'. Younger participants were more likely to refer to self-care, other health behaviours, dental problems, needs and treatment histories, whereas older participants were more likely to involve tooth loss and denture wearing. Additionally, those who rated their oral health as 'excellent' were more likely to refer to health behaviours. Those who rated their oral health as 'fair' or 'poor' were more likely to refer to dental problems, treatment needs tooth loss and denture wearing.

Inconsistencies in the internal standards of comparison between and within individuals are considered as a source of measurement error in QoL assessment (Streiner and Norman, 2008). Streiner and Norman (2008) described five cognitive stages involved in answering an item: (1) understanding the question (including choosing the referents), (2) recalling the relevant behaviour, attitude or belief, (3) inference and estimation of the answer, (4) mapping the answers onto the response alternatives, (5) editing the answers. As has been described earlier, Rapkin and Schwartz (2004) proposed that the appraisal involved in answering a QoL item consists of four stages (choosing frames of reference, sampling experience, choosing standards

of comparison and deciding on the combinatory algorithm). Error can occur at each cognitive step. One can imagine someone might score themselves differently depending on whether they have read an article about people perceived as much worse off or much better off than them.

4.4.3 Strengths and limitations

As in all research the methods selected bring both advantages and disadvantages. The strengths and limitations of this work can be considered from their effect on the findings. Two main findings emerged from this study. First, the study described adaptation to DH and the influence of that adaptation on the assessment of OHQoL in people with DH. Second, a modified model of response shift including the novel conceptualisation of the phenomenon was proposed based on the study findings.

There are several advantages of the method used. First, use of the qualitative method allowed for more in-depth exploration of the phenomenon that would not have been possible using quantitative approaches. Second, use of the longitudinal approach with two interviews 6-11 months apart provided the opportunity to capture response shift, not only retrospectively, but also prospectively, during the study. Third, incorporating the assessment of the THEN TEST and the IDEALS versions of DHEQ allowed comparison of the evidence of response shift from the participants' narrative accounts, from their appraisal and from their DHEQ scores. This variety of data provided a comprehensive picture of the phenomenon and enabled a new conceptualisation and the proposal of a modified model. Finally, investigating the phenomenon in relation to a relatively mild condition allowed insights into the role of factors such as external life events which could have been missed if a more serious condition was investigated.

Nevertheless, the potential limitations of this study need to be considered. These limitations relate to whether the study findings can be generalised beyond the study sample.

Views differ on whether the findings of a qualitative study can be considered relevant beyond the context of the study (Seale, 1999). This study followed the assumptions of the framework method which state that it is possible to generalise from qualitative research, but its reliability and validity needs to be considered.

Three types of generalisations: representational, inferential and theoretical can be considered in qualitative research (Ritchie and Lewis, 2003). This study involves the first two types. Representational generalisation involves the extent to which the findings can be generalised to

the population from which the sample was drawn. In the context of this study, this means to what extent can the findings about adaptation to DH and its influence of the assessment of OHQoL can be generalised to the population of people with DH. Inferential generalisation involves the question of whether the findings can be generalised beyond the investigated population to involve other contexts. In this study, this means whether the modified model of response shift that emerged from the analysis can be applied to investigating adaptation and its influence on the assessment of QoL in other health conditions.

To assess whether the findings on adaptation to DH and its influence on the assessment of OHQoL can be generalised to all with DH requires consideration of two issues regarding reliability and validity (Ritchie and Lewis, 2003). First, the quality of the research process including data collection (interviews) and analysis needs to be reviewed. Second, the degree to which the sample was representative (not in terms of statistical representation but in terms of whether it reflected the diversity of views and experiences present in the population, i.e. whether it was 'symbolically representative') for the population should be examined.

In terms of the quality of the research process, the interviews were conducted in a friendly and attentive manner, in a quiet and comfortable space. There was no time limit to the interview so that participants were given as much time as they needed to described their experiences. The interviewer completed training in qualitative interviewing and data collection to strengthen her interviewing technique. Additionally, the transcripts from the initial interviews were read by two qualified researchers and feedback to the interviewer was provided. The longitudinal approach obtained prospective accounts of the investigated phenomenon and provided greater opportunity to the participants to reflect on and communicate their experiences. In terms of the analysis, the framework method, an established qualitative approach in the area of health and patients experiences, was adopted to ensure its stringency. Additionally, the constant comparative method was employed to enhance the validity of the findings. Along the entire research process the researcher kept a log book containing her own reflective accounts regarding the research process and the development of her research ideas and skills. With regards to the study sample, several measures were undertaken to ensure the diversity and representativeness of views and experiences. Participants were sampled to include both those who had DH for a long time and those who had developed the condition only recently as this factor was believed to impact on the person's experiences. Participants were recruited until saturation of views was obtained. Additional recruitment strategy was employed to ensure that participants from a variety of socioeconomic backgrounds were

included. Nevertheless, the sample was limited to university or hospital employees or university students. It is therefore possible that some views linked with low socioeconomic status were not represented in the sample. Similarly, only one male participant was included, which might have limited the availability of views related to gender. Additionally, most participants were English (there were 4 non-English participants), which limits the intercultural generalisability of the findings regarding adaptation to DH.

Considering the above it can be said the research process and sampling strategy ensured the reliability and validity of the findings. That is, the findings of this study are a valid source of information about adaptation to DH and its influence on the assessment of OHQoL. Limitations regarding the socioeconomic status, gender and cultural background of the person have to be considered. Additionally, the role of the personal characteristics in adaptation to DH and assessment of OHQoL were not explored in this study as not enough evidence emerged from the data. In future studies, the role of the personal characteristics should be explored.

The inferential generalisation builds on the issues of reliability and validity discussed earlier, but is concerned with a higher level of conceptualisation. Inferential generalisation occurs at the level of the modified model of response shift and its components. This means that while the specific mechanisms of adaptation may vary between conditions (e.g. it is possible that for more serious health conditions changes in health and illness cognitions will be related to broad concepts of health and QoL, whereas in DH, which is a minor condition, they are limited to the concepts of DH) the general views that adaptation influence the assessment of QoL should be transferrable to other health conditions. This study follow the view that the applicability of a model based on qualitative data has to be established by further empirical enquiry (Seale, 1999). While the findings from this study have been used to modify the model of response shift, further research is needed to validate the model in relation to other health conditions. It is possible that further research will result in the refinement of the model (e.g. the specific ways in which adaptation influences assessment of QoL can be introduced) or changes to the model will be proposed.

5 Overall discussion

This chapter brings together the findings of the two studies constituting this thesis and discusses the implications of the strategic choices taken. The discussions for the individual studies are presented in their respective chapters (chapters 3 and 4).

This work has investigated response shift in people with DH in two complimentary studies. The rationale for that choice was that response shift was a relatively new area of enquiry, thus there was little agreement on how to best measure and account for the phenomenon. Its nature, while not yet fully understood, appeared complex. Therefore, a mixed approach combining the quantitative measurement of recalibration within a clinical trial and the qualitative exploration of the nature of response shift and its underlying mechanism were selected. The aims of these two studies were compatible with the research priorities identified by Barclay-Goddard and colleagues (2009a).

To recap the literature review, response shift is important because it influences self-assessments of QoL. If not accounted for, response shift can undermine the validity of assessments of change in QoL and comparisons of QoL between people. Therefore, response shift is relevant in the areas where QoL measures are used to assess health and well-being from the person's subjective point of view. This may include monitoring change in QoL or responses to treatment, identifying preferences for treatment, prioritising health problems and communicating about health and illness between patients, health care staff and the general public (Higginson and Carr, 2003). In addition to improving the validity of assessments of QoL from a subjective perspective, investigating response shift can also enhance understanding of the process of self-assessment of one's QoL (i.e. appraisal) and the adaptation to changed health.

5.1 Summary of the findings from the two studies

Study A examined recalibration and its influence of the assessment of treatment effects within a clinical trial of treatments for DH, using the THEN TEST and the IDEALS. Recalibration occurred in the treatment and placebo groups. Emotional impacts were the most and Identity the least sensitive to recalibration. The magnitude of recalibration increased as the study progressed. The two methods pointed to different average directions of recalibration. The THEN TEST indicated a downward shift in participants' internal standards of measurement, whereas the IDEALS suggested an upward shift. Nevertheless, for both methods, accounting

for response shift reduced the apparent treatment effect. At the individual level shifts upwards, downwards and no recalibration were observed for both methods. Finally, no links were detected between changes in the conventional scores, adjusted scores and changes in clinical indicators of DH. Additionally, study A provided evidence that the IDEALS is a promising way to measure recalibration. The THEN TEST, on the other hand, appeared to be susceptible to bias, and therefore, a potentially less valid approach to measure and account for recalibration.

Study B explored response shift and its underlying psychosocial mechanisms qualitatively in people with DH. A modified model of response shift was proposed (Figure 4.3.1) which distinguishes between the impacts of adaptation and the impacts of measurement error on the assessment of QoL. The modified model identified two novel mechanisms: acceptance and habits. The modified model also recognised the importance of context (i.e. physical, social and cultural environment of the person) in the adaptation to health conditions. Additionally, the data provided a detailed description of adaptation to DH and its influence on the assessment of change in OHQoL. The analysis revealed that in order to understand how people adapt to DH, it is important to recognise the wider context of the person's life and their environment. More specifically, other areas of life and life goals as well as the physical, social and cultural context have to be considered. Finally, this study suggested that the adaptation to DH can be fostered through psychosocial interventions.

5.2 Discussion of the findings from the two studies

These combined findings contribute to a better understanding of response shift, with study A focusing mainly on its measurement and study B on its mechanisms.

Both studies yielded evidence of response shift. Cumulatively, both studies show that response shift is an individual phenomenon and should be measured on an individual level. Study A showed that upward, downward and no shift occurred. In study B different people responded to having DH differently, which, in turn, impacted on their self-assessment of OHQoL. For example, taking part in the interviews fostered adaptation for some, but not other participants. This heterogeneity at the individual level has also been recognised in some studies measuring recalibration in clinical trials (Osborne *et al.*, 2006; Razmjou *et al.*, 2009; Hinz *et al.*, 2011) and in studies of appraisal in relation to response shift (Li and Rapkin, 2009; Taminiau-Bloem *et al.*, 2010; Schwartz and Rapkin, 2012). For example, Li and Rapkin (2009) classified participants with AIDS into nine groups for which distinct patterns of changes in appraisal and QoL score occurred over time. Additionally, recursive partition and regression tree analysis was recently

proposed to be used in the field as a statistical methods that is sensitive to individual differences in response shift (Li and Schwartz, 2011).

The findings of the two studies challenged current practices and conceptualisations of response shift. Study A suggested that the THEN TEST (currently the most commonly used method to measure and account for recalibration) is susceptible to bias. An initial validation of an alternative method: the IDEALS showed promise but the method has not previously been used to measure response shift in QoL. Additionally, study A highlighted the links between recalibration occurring during the clinical trial and placebo effect. It is possible that recalibration might be a part of the placebo effect.

The qualitative analysis delivered a modified model of response shift (Figure 4.3.1) in place of the existing models (Figure 2.2.1 and Figure 2.2.2). This modified model introduces a distinction between the influences of adaptation and measurement error on self-assessments of QoL. Changes in appraisal and self-assessed QoL as a result of adaptation are considered a true change in the person's experience of their QoL. Measurement error represents changes in appraisal unrelated to adaptation or changed health. The main difference between the modified and the existing models is how adaptation is conceptualised. In the modified model, contrary to the existing models, adaptation is not a threat to the validity of the assessment of change in QoL, but represents a true change in the person's experience. The modified model also highlights the role of the measurement error in the assessment of QoL through self-report, which have not been considered in previous models.

The quantitative data now require further discussion in the light of this new conceptualisation of recalibration proposed in the modified model from Study B. In the modified model, recalibration (as well as reprioritisation and reconceptualisation) is not a separate component. Instead, recalibration equates to changes in social comparison. From this perspective, the THEN TEST and the IDEALS capture changes in social comparison. Or, more specifically, they reflected changes in appraisals with regards to the internal standards of measurement that occurred as a result of social comparisons. However, it can also be speculated that the two methods capture wider changes in appraisal occurring as a result of adaptation in general. For example, the IDEALS asks participants about their 'ideal' QoL. Lowering or increasing the 'ideal' expectations can be seen as an outcome of adaptation. Identifying the link between adaptation, appraisal and the IDEALS assessments requires further investigation.

5.3 Limitations of the approach

As mentioned in chapters 3 and 4, a possible limitation of the approach adopted in this thesis is that response shift was investigated in a relatively mild health condition. This may be seen as a limitation, because it made it less relevant to serious conditions. However, it can also be seen as an advantage. Investigating the phenomenon in relation to DH enabled a first look at response shift and adaptation to a condition where impacts are relatively small and where there is not great deterioration or improvement over time. As a result, the wider contexts of people lives may have become relatively important for adaptation and response shift. The findings from the two studies should be confirmed in other health conditions, of varying severity, in future research.

Another limitation of the overall approach is that only one type of response shift: recalibration, was measured within the clinical trial. Therefore, it is not possible to say whether evidence of the other two types of response shift would have also been found. Nevertheless, this decision allowed a sharper focus on one particular aspect of response shift. The reason why recalibration was selected was that from previous studies it was evident that recalibration was most likely to occur and to impact on the assessment of the treatment effect within a clinical trial. Additionally, study B, in which response shift was assessed qualitatively, provided an opportunity to explore all three types of response shift.

The final limitation is related to the separation of the quantitative assessment of response shift and the qualitative exploration of its nature and underlying mechanisms into two studies. Additionally, in study A participants were treated for DH, whereas in study B there was no planned intervention. Because the underlying mechanisms of response shift were not investigated in study A, data on the mechanisms responsible for changes in the THEN TEST and the IDEALS are not available. Future studies should investigate the links between mechanisms of adaptation and appraisal in the quantitative assessment of response shift.

5.4 Conclusion

The two studies advanced the understanding of response shift by fundamentally challenging its conceptualisations and the dominant approach to its assessment. Additionally, the studies provided a detailed insight into response shift in people with DH, therefore contributing to the understanding of response shift not only in relation to OHQoL but also for the first time in a relatively mild health problem. Further validation of the IDEALS approach and the modified model of response shift are required.

6 Recommendations and conclusions

6.1 Summary of findings

This PhD described response shift in people with DH in two longitudinal studies. The quantitative study found recalibration among participants of a clinical trial of treatments for DH in both the treatment and placebo groups. Two methods used to assess recalibration indicated opposite directions of the average shift. The THEN TEST, a long established method, indicated a downward shift in participant's internal standards, whereas the IDEALS, a novel approach, indicated an upwards shift. This might be due to the THEN TEST being subject to bias. At the individual level upward, downward and no shift were found and the magnitude of average recalibration varied across DHEQ subscales. The qualitative study found that both adaptation to DH and measurement error impacted on the assessment of OHQoL. The role of the wider context of the person's life in adaptation to DH was highlighted in the study. Based on the findings of the qualitative study a modified model of response was proposed (Figure 4.3.1). This model distinguishes between the influence of adaptation and measurement error on the assessment of change in QoL.

This thesis has contributed to current knowledge by describing response shift, its psychosocial determinants and influence on the assessment of OHQoL. Moreover, the two studies challenge the current conceptualisations and dominant approach to the measurement of the phenomenon. The modified model of response shift and the IDEALS are also novel.

This chapter summarises the findings and recommendations arising from the two studies.

6.2 Conclusions

1) Response shift was found in people with DH in two studies and influenced the assessment of OHQoL.
2) The two studies highlighted the links between response shift and adaptation to changed health. As a result a modified model of response shift (Figure 4.3.1) was proposed that distinguishes between the influence of adaptation and the measurement error for the assessment of QoL.
3) Within the modified model response shift is not seen as a threat to the validity of the assessment of change in QoL but rather it should be incorporated into the assessment.
4) Additionally, the modified model adds two new mechanisms: habits and acceptance.

5) Habits concerned an automatisation of behaviours involved in problem-oriented coping with the condition.
6) Acceptance involved accepting rather than trying to actively cope with the impacts of the condition.
7) A new component: context was added to the modified model. Context represents the physical, social and cultural aspects of the person's environment relevant for the adaptation to the changed health.
8) The findings from both studies indicate that response shift occurs at the individual level. In the quantitative study upward, downward or no shift was detected among participants. In the qualitative study, different catalysts, mechanisms and contexts were involved in adaptation to DH for different people.
9) The findings from both studies indicate that response shift can occur at any point in time over the duration of the condition. In the qualitative study response shift occurred at different points in time over people's lives and over the duration of the condition. The findings of the quantitative study suggested that response shift occurs at different points in time for different people.
10) The quantitative study challenged the currently most popular approach to measure and account for response shift. The comparison of the two methods suggests that the THEN TEST might be subjected to bias and may therefore not be a valid approach. The IDEALS, a novel method received a preliminary validation and seems a promising approach.
11) The occurrence of recalibration in the treatment and control groups in the quantitative study suggests a link between response shift and the placebo effect. It is possible that response shift is a part of a placebo effect.
12) The qualitative study also indicates that adaptation can be fostered through a range of psychosocial interventions and that the care of people with DH provided by oral health professionals could be improved.

6.3 Recommendations

The recommendations based on the findings of the two studies are as follows:

6.3.1 Recommendations for research

6.3.1.1 Recommendations for the research in the area of response shift

- The role of adaptation in the assessment of QoL should be further explored.

- There should be further exploration of how changes in the appraisal, not related to changed symptoms or adaptation, impact on the assessment of QoL.
- The modified model of response shift should be further validated across different health conditions.
- The links between response shift and the placebo effect in response to treatment and in clinical trials should be further explored.
- The IDEALS approach to assessing and accounting for response shift should be further validated.

6.3.1.2 Recommendations for the DH related research

- Links between treatment effects and response shift within clinical trials should be further explored.

6.3.2 Recommendations for the assessment of QoL and response shift in clinical practice

- Response shift should be considered when measuring QoL.
- The validity and reliability of QoL measures should be considered when measuring QoL in order to minimise the impacts of measurement error on assessments.
- The THEN TEST might be subjected to bias and therefore may not be a reliable approach to measuring and accounting for response shift. Thus, other methods should be considered when considering response shift in the area of QoL assessment.

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8 Appendices

Appendix A:	Invitation email for Study B
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8.1 Appendix A: Invitation email for Study B

Dear Colleagues,

Do you have twinges in your teeth when you have something hot, cold or sweet?

I am a PhD student at the School of Clinical Dentistry conducting research to better understand how people see their quality of life in relation to their sensitive teeth over time, and I would like to invite you to participate in a study.

The actual study will involve 2 face to face meetings, about six months apart. Each meeting will last for about 1 hour and a half.

At each meeting you will be asked to:

- Complete a set of questionnaires in relation to your sensitive teeth and your quality of life
- Participate in an interview during which your views about sensitive teeth and quality of life will be discussed

If you are interested in taking part please click the following link and complete a brief screening survey to find out if you are eligible for the study.

http://www.surveymonkey.com/s/2TMKMXZ

Those who are eligible will be further contacted to arrange a date for the first meeting.

As a compensation for their time and effort, all participants will receive a £15 Boots voucher after finishing the first interview and another £15 Boots voucher after finishing a second interview.

All the information that you provide will be completely confidential and the study has received ethical approval from the School of Clinical Dentistry Ethics Sub-Committee.

If you have any questions about the study please email Marta Krasuska (m.krasuska@sheffield.ac.uk).

For information about this email list, including how to remove your name, please visit http://www.shef.ac.uk/cics/email/distributionlists.html and click the list name.

Kind regards,
Marta Krasuska

8.2 Appendix B: Online screening survey for Study B

Sensitive Teeth and Quality of Life over Time Screening Questionnaire

Having sensitive teeth is described as experiencing sensations such as tingles, twinges or pain in your teeth often as a response to having hot or cold drinks, eating sweets, tooth brushing or inhalating cold air. This can be experienced in one tooth or more than one tooth at a time.

Please tick the answer for the following questions which best describes your experience:

1 How much do you think you have sensitive teeth (please tick one)?

- ❑ Very much$_5$
- ❑ Quite a bit$_4$
- ❑ Somewhat$_3$
- ❑ A little$_2$
- ❑ Not at all$_1$

If you think you have sensitive teeth please answer the questions below that would to give more details about your sensitivity and about your health in general.

2 How old are you? ☐ years

3 Are you? Female$_1$ Male$_0$

4 How long have you been experiencing any sensation in your teeth (please tick one)?

- ❑ Less than 3 months$_1$
- ❑ More than 3 months but less than 6 months$_2$
- ❑ Between 6 months and a year$_3$
- ❑ More than a year but less than 3 years$_4$
- ❑ Between 3 and 5 years$_6$
- ❑ More than 5 years but less than 10 years$_6$
- ❑ More than 10 years$_7$
- ❑ None$_0$

5 How often do you have sensation in your teeth? (please tick one)?

- ❑ Several times a day$_6$
- ❑ Once a day$_5$
- ❑ Several times a week$_4$
- ❑ Once a week$_3$
- ❑ Several times a month$_2$
- ❑ Once a month or less$_1$

6	Have you been to the dentist to ask about your sensitive teeth?	Yes_1	No_0
7	Do you use special toothpaste for the sensations in your teeth?	Yes_1	No_0
8	Are you currently pregnant or breastfeeding?	Yes_1	No_0
9	Have you had a visit to the dental professional hygienist within the previous 14 days?	Yes_1	No_0
10	Have you had your teeth whitened/bleached in the past 2 months?	Yes_1	No_0
11	Have you had periodontal surgery within the past 6 months or have your teeth been scaled/root planed the past 3 months?	Yes_1	No_0

If you would like to participate in the study please leave your, email address or phone number so that we could contact you and arrange the meeting.

Name:

Email address:

Phone number:

Please indicate if you would prefer to be contacted by any specific way or at particular hours of the day

Thank you for your time!!!!!

8.3 Appendix C: Information sheet for Study B

The University Of Sheffield.

School of Clinical Dentistry.

Information sheet

Changes in quality of life assessment in people with sensitive teeth

You are being invited to take part in a research study. Before you decide if you would like to participate, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

We want to look at how people with sensitive teeth see their quality of life and how these views change over time. We would like to compare views of people who only recently realised they have sensitive teeth with views of those who have had sensitive teeth for a long time.

Why have I been chosen?

You have been chosen because you indicated in the screening survey that you think you have sensitive teeth.

Do I have to take part?

It is completely up to you to decide whether or not to take part. If you choose to take part in the study you will be asked to sign a consent form and you will be given this information sheet to keep. You will still be able to withdraw from the research at any time and you will not have to give a reason for that.

What will happen to me if I take part?

If you take part in the study you will be asked to complete a questionnaire twice on how your sensitive teeth impact on your everyday life and to participate in two interviews over a period of six months.

Specifically you will be asked to:

- Arrange for a convenient date for the first **face to face meeting** with the study investigator
- Participate in the first **face to face meeting** during which you will be asked to:
    - complete a questionnaire (this could take up to 45 minutes)

      and
    - participate in an interview during which you will be asked a series of questions about how you form judgment on how sensitive teeth affect your everyday life (this could take up to an hour and a half)

- Arrange for a convenient date for the second face to face meeting together with the study investigator
- Participate in a second **face to face meeting** during which you will be asked to:

- complete the same questionnaire as previously (this could take up to 45 minutes)

and

- participate in a second interview during which you will be asked a series of questions about how your judgments about the impact of your sensitive teeth has changed since the time of the first interview (this could take up to an hour and a half)

What do I have to do?

Participating in this study will not pose any restrictions to your lifestyle. The only adjustment you will have to make will be to find an appropriate time to participate in two interviews (that will last around two hours and a half) over a six months period.

Will I be recorded, and how will the recorded media be used?

Both interviews you will take part in will be recorded. The tape records of the interviews will be transcribed into written text, and the written text will then be analysed. No other use will be made of the data without your written permission and no one from outside of the project will be allowed an access to the original recordings. You will have the right to see the data held about you at any time (the data will be stored for 30 years).

What are the possible disadvantages and risks of taking part?

There are no known risks. However, you may find some of the questions quite personal and may not wish to answer them. If there are any questions in the questionnaire you find upsetting, you do not have to answer them. Similarly, if you will feel uncomfortable to discuss any specific topic during the interview, for example because you feel it is too personal, you don't have to discuss them.

What are the possible benefits of taking part?

There might be no immediate or direct benefits to you. However this research will help us to understand better how people with sensitive teeth form their judgments about their quality of life.
If you do decide to take part in this study your time and effort will be compensated and you will receive a £15 Boots voucher after first interview as well as after second interview.

Will my taking part in this study be kept confidential?

All information that you provide us with during this study will be kept strictly confidential. To protect your privacy the following measures will be taken to ensure that no-one, apart from the research team has access to your identity:

- Your **name** will **not** appear on any questionnaire. At the beginning of the study you will choose a new name which will be used as an identifier. Only you and the research team will know your name and your pseudonym.

- Your **real name** will **not** be used in the analysis or writing up of the findings derived from your interviews and questionnaires.

- Your personal information will be kept in a safe locked cabinet and will only be seen by the researchers.
- All anonymous data will be kept for thirty years before being destroyed.
- All information supplied by you will be kept confidential.

However, if there is any information disclosed during the course of the study that concerns the researcher, regarding a participant's safety, confidentiality may be broken.

What will happen to the results of the research study?

Following completion of the study we will write to you giving you a summary of our findings (and details of how you can obtain a full copy of the report). We will also produce publications based on the results of the study.

Who is organizing and funding the research?

The study is a part of the PhD project of Marta Krasuska based at the School of Clinical Dentistry, University of Sheffield. The project is being supervised by Prof Peter G Robinsons and Dr Sarah Baker from the Unit of Dental Public health within the School of Clinical Dentistry. The research is being funded by GlaxoSmithKline Consumer Healthcare.

Who has reviewed the study?

The study's protocol has been reviewed and approved by the School of Clinical Dentistry Ethics Sub-Committee, University of Sheffield.

Who can I contact for further information?

Further information about the study is available from Marta Krasuska, Academic Unit of Dental Public Health, School of Clinical Dentistry, University of Sheffield, Sheffield, S10 2TA. Phone: 0114 271 7877 or email: m.krasuska@sheffield.ac.uk.
Alternatively, you can contact Prof Peter G Robinson, Academic Unit of Dental Public Health, School of Clinical Dentistry, University of Sheffield, Sheffield, S10 2TA. Phone: 114 271 7885 or email: peter.g.robinson@sheffield.ac.uk.

What if I wish to complain about the way in which the study has been conducted?

If you have any cause to complain about any aspect of the way in which you have been approached or treated during the course of this study please contact either Marta Krasuska (0114 271 7877) or the project supervisor Prof Peter G Robinson (114 271 7885). In case you have felt that your complaint was not handled in a satisfying way you may further contact the University's Registrar and Secretary: Office of the Registrar and Secretary, Firth Court, Western Bank, Sheffield, S10 2TN, phone: 0114 222 1100, fax: 0114 222 1103, or email: registrar@sheffield.ac.uk.

Thank you for reading this!

8.4 Appendix D: Consent form for Study B

The University Of Sheffield.

Participant Consent Form

Title of Research Project: Changes in quality of life assessment in people with sensitive teeth

Name of Researcher: Marta Krasuska

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated October 2011 explaining the above research project and I have had the opportunity to ask questions about the project. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐

3. I understand that the research team will keep my responses strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that I will not be identified or identifiable in the report or reports that result from the research. ☐

4. I agree for the data collected from me to be used in future research ☐

5. I agree to take part in the above research project. ☐

_____	_____	_____
Name of Participant	**Date**	**Signature**

_____	_____	_____
Name of person taking consent	**Date**	**Signature**

Copies:
Please sign both copies of this consent form.

You will need to keep **one copy** of this consent form for your own records and **return one copy** to the research team (details below)

Marta Krasuska, Academic Unit of Dental Public Health, School of Clinical Dentistry, Claremont Crescent, Sheffield. S10 2TA. Tel: 0114 271 7877 Email: m.krasuska@sheffield.ac.uk

8.5 Appendix E: Ethics approval letter for Study B

The University Of Sheffield.

School Of Clinical Dentistry.

Ms Marta Krasuska
Unit of Dental Public Health
University of Sheffield
School of Clinical Dentistry
Claremont Crescent
Sheffield
S10 2TA

23rd Febraury 2012

University Research Ethics Committee (School of Clinical Dentistry)

Research Ethics Lead - Dr Lynne Bingle
Claremont Crescent
Sheffield S10 2TA
Telephone: +44 (0)114 271 7954/51
Fax: +44 (0)114 271 7894
Email: l.bingle@sheffield.ac.uk

Full title of study: Changes in quality of life assessment in people with sensitive teeth
Reference number: 37

On behalf of the committee, I am pleased to confirm a favourable ethical opinion for the above research based on the application form, protocol and supporting documentation. If any further changes are made to these documents the Ethics Committee should be informed and their opinion requested.

With the Committee's best wishes for the success of this project

Yours sincerely

Lynne Bingle
Research Ethics Lead

THE QUEEN'S

8.6 Appendix F: Interview guides for Study B

- Baseline interview guide
- Follow-up interview guide

BASELINE INTERVIEW GUIDE FOR STUDY B

AIMS OF THE STUDY:

- Identify response shift
- Identify psychosocial mechanisms of response shift

THREE ASPECTS OF THE INTERVIEW:

1) Administration of the baseline questionnaire
2) In depth exploration of possible areas relevant to response shift
3) Discussion of the answers to the current & baseline questionnaire

There is no definite order to the three parts of the interview. The questionnaire might be administrated at the beginning or during the interview depending on which order the participants feels most comfortable about.

AREAS OF EXPLORATION IN THE FIRST PART

EXPLORATION OF THE EXPERIENCES RELATED TO DH

Ask about describing usual symptoms, the last time a person experienced the sensations

EXPLORATION OF THE POSSIBLE RESPONSE SHIFTS
Ask about how a person sees their DH. Ask about their teeth, mouth and gums. Ask about the pain.

COPING AND ADAPTATION
Ask about how they cope with their DH

CATALYST
Ask about the onset of DH, changes in symptoms, change in oral health, health.

QUESTIONS MEASURING APPRAISAL

- How do you understand that question?
- Can you tell me why you responded in this particular way?
- What did you have in mind when answering this question?
- Did you refer to any specific situation or experience?
- Why did you respond to the IDEALS part of the question in this particular way?
  Asked with regards to the following items:
  - "Overall, how much do the sensations in your teeth affect your quality of life?"
  - "Overall how would you rate the health of your mouth, teeth and gums?"
  - "On a scale of 1 to 10 how intense are the sensations?"
  - "On a scale of 1 to 10 how bothered are you by any sensations?"
  - "On a scale of 1 to 10 how well can you tolerate sensations?"

FOLLOW-UP INTERVIEW GUIDE FOR STUDY B

AIMS OF THE STUDY:

- Identify response shift
- Identify psychosocial mechanisms of response shift

THREE PARTS OF THE INTERVIEW:

4) In depth exploration of possible areas relevant to response shift
5) Administration of the follow-up questionnaire
6) Discussion of the answers to the current & baseline questionnaire

In order to avoid priming the questionnaire will be administrated after the in-depth discussion of RS and QoL issues and at the same time point of the interview for each participant. The administration of the questionnaire will be followed by a discussion of participant's answers to the follow-up and baseline questionnaires. If the participants will get anxious about not giving same responses on both occasions the researcher will reassure them that this is to be expected and also use it as a possibility to further explore where these differences might come from.

AREAS OF EXPLORATION IN THE FIRST PART

REFLEXION ON THE FIRST INTERVIEW
Ask if the person would like to say what she or he thinks about the previous interview, if they have something to add.

EXPLORATION OF THE POSSIBLE RESPONSE SHIFTS
Ask about how a person sees their DH now and as compared to first interview. Ask about their teeth, mouth and gums. Ask about the pain.

COPING AND ADAPTATION
Ask about how they cope with their sensitivity nowadays and as compared to the time of first interview.

CATALYST
Ask about changes in symptoms, change in oral health, health, important life events.

QUESTIONS MEASURING APPRAISAL IN THE 3rd PART OF THE INTERVIEW

- How do you understand that question?
- Can you tell me why you responded in this particular way?
- What did you have in mind when answering this question?
- Did you refer to any specific situation or experience?
- Why did you respond to the IDEALS/THEN part of the question in this particular way?
  Asked with regards to the following items:
  - "Overall, how much do the sensations in your teeth affect your quality of life?"
  - "Overall how would you rate the health of your mouth, teeth and gums?"
  - "On a scale of 1 to 10 how intense are the sensations?"
  - "On a scale of 1 to 10 how bothered are you by any sensations?"
  - "On a scale of 1 to 10 how well can you tolerate sensations?"

8.7 Appendix G: Questionnaires for Study B

- Baseline questionnaire and follow-up questionnaire(IDEALS)
- Follow-up questionnaire (THEN TEST)

Sensitive Teeth and Quality of Life

You will be asked to complete a set 4 of questionnaires asking about:

- your assessment of pain you experience in relation to your sensitive teeth
- your everyday experience of living with sensitive teeth
- your own personal views about your sensitive teeth
- your views on how you compare yourself with other who you think have sensitive teeth

Please follow the instructions for each of the questionnaire.

Your pseudonym: _____
Today's date: _____

Pain severity

For each question, there are two parts:

- **Part a** asks about how things ACTUALLY are for you. Please give your answer by circling the number that comes closest to what is true for you.
- **Part b** asks how you would like things to be IDEALLY. We want you to say how **you would like things to be** if they were **exactly what you hope for.** As before please circle the answer that comes closest to how you would like things to be ideally.

1a) On a scale of 1 to 10 how intense are the sensations? (Please circle your answer)

1 2 3 4 5 6 7 8 9 10

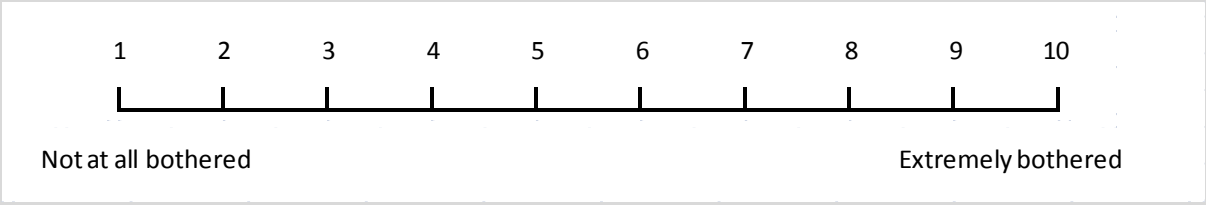
Not at all intense — The worst imaginaible

1b) What would your ideal be? (Please circle your answer)

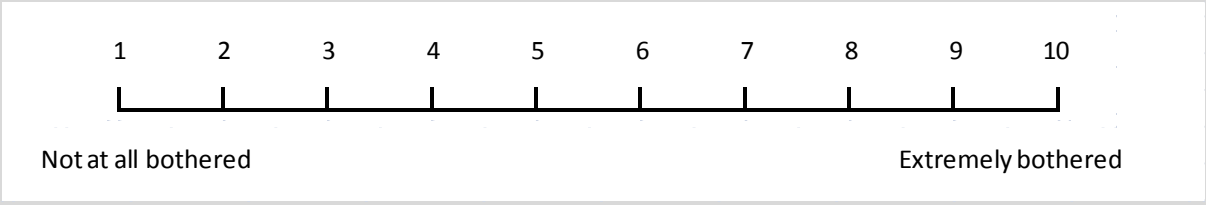
1 2 3 4 5 6 7 8 9 10

Not at all intense — The worst imaginaible

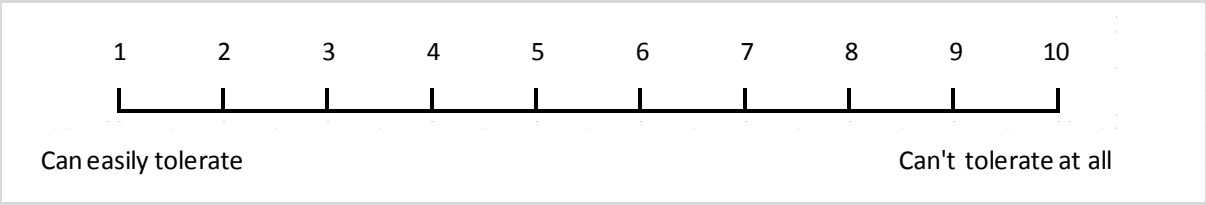
2a) On a scale of 1 to 10 how bothered are you by any sensations? (Please circle your answer)



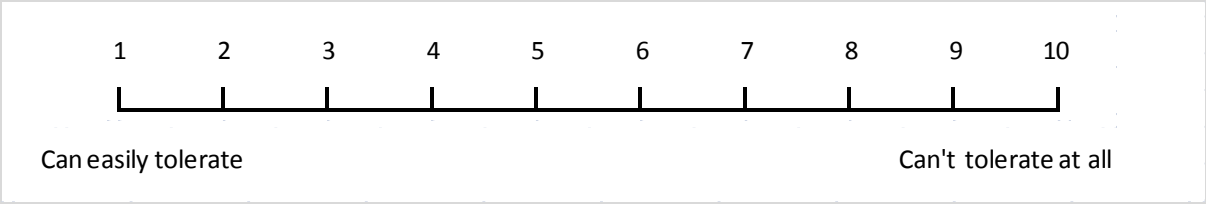
2b) What would your ideal be? (Please circle your answer)



3a) On a scale of 1 to 10 how well can you tolerate sensations? (Please circle your answer)



3b) What would your ideal be? (Please circle your answer)



Dentine Hypersensitivity Experience Questionnaire

The follow questions are about your sensitive teeth, and the impact it has on your everyday life.

For each question, there are two parts:

- **Part a** asks about how things ACTUALLY are for you. Please give your answer by circling the number that comes closest to what is true for you.
- **Part b** asks how you would like things to be IDEALLY. We want you to say how **you would like things to be** if they were **exactly what you hope for.** As before please circle the answer that comes closest to how you would like things to be ideally.

There are no right or wrong answers, so please tell us what is true for you.

The following questions are about the ways in which any sensations in your teeth affect you in your daily life.
Thinking about yourself over the last month to what extend would you agree or disagree with the following statements (please tick only one response for each questions)

	Strongly agree (7)	**Agree (6)**	**Agree a little (5)**	**Neither agree nor disagree (4)**	**Disagree a little (3)**	**Disagree (2)**	**Strongly disagree (1)**
1a) Having sensations in my teeth takes a lot of the pleasure out of eating and drinking.	❑	❑	❑	❑	❑	❑	❑
1b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
2a) There have been times when I can't finish my meal because of the sensations.	❑	❑	❑	❑	❑	❑	❑
2b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
3a) It takes a long time to finish some foods and drinks because of sensations in my teeth.	❑	❑	❑	❑	❑	❑	❑
3b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
4a) There have been times when I have had problems eating ice cream because of these sensations.	❑	❑	❑	❑	❑	❑	❑
4b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
5a) I have to change the way I eat or drink certain things.	❑	❑	❑	❑	❑	❑	❑
5b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑

The following questions are about the ways in which the sensations in your teeth have forced you to change things in your daily life.
Thinking about yourself over the last month to what extend would you agree or disagree with the following statements (please tick only one response for each questions)

	Strongly agree (7)	Agree (6)	Agree a little (5)	Neither agree nor disagree (4)	Disagree a little (3)	Disagree (2)	Strongly disagree (1)
6a) I have to be careful how I breathe on a cold day.	❑	❑	❑	❑	❑	❑	❑
6b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
7a) I have to leave some cold foods or drinks to warm up before I can have them.	❑	❑	❑	❑	❑	❑	❑
7b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
8a) I have to cool some foods or drinks down before I can have them.	❑	❑	❑	❑	❑	❑	❑
8b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
9a) I have to cut up some fruits before being able to eat them.	❑	❑	❑	❑	❑	❑	❑
9b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
10a) I have to wear a scarf over my mouth on cold day.	❑	❑	❑	❑	❑	❑	❑
10b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑

The following questions are about the things you do in your daily life to avoid experiencing the sensations in your teeth.
Thinking about yourself over the last month to what extend would you agree or disagree with the following statements (please tick only one response for each questions)

	Strongly agree (7)	Agree (6)	Agree a little (5)	Neither agree nor disagree (4)	Disagree a little (3)	Disagree (2)	Strongly disagree (1)
11a) I have avoided very cold drinks or foods.	❑	❑	❑	❑	❑	❑	❑
11b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
12a I have avoided very hot drinks or foods.	❑	❑	❑	❑	❑	❑	❑
12b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑

	Strongly agree (7)	Agree (6)	Agree a little (5)	Neither agree nor disagree (4)	Disagree a little (3)	Disagree (2)	Strongly disagree (1)
13a) When eating some foods I have made sure they don't touch certain teeth.	❑	❑	❑	❑	❑	❑	❑
13b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
14a) I have changed the way I brush my teeth.	❑	❑	❑	❑	❑	❑	❑
14b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
15a) The sensations in my teeth have been irritating.	❑	❑	❑	❑	❑	❑	❑
24b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
16a) When eating some foods I have made sure I bite in small pieces.	❑	❑	❑	❑	❑	❑	❑
16b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
17a) There are other foods I have avoided.	❑	❑	❑	❑	❑	❑	❑
17b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑

The following questions are about the way the sensations affect you when you are with other people or in a certain situations.
Thinking about yourself over the last month to what extend would you agree or disagree with the following statements (please tick only one response for each questions)

	Strongly agree (7)	Agree (6)	Agree a little (5)	Neither agree nor disagree (4)	Disagree a little (3)	Disagree (2)	Strongly disagree (1)
18a) Because of the sensations I take longer than others to finish a meal.	❑	❑	❑	❑	❑	❑	❑
18b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
19a) I have to be careful what I eat when I am with others because of the sensations in my teeth.	❑	❑	❑	❑	❑	❑	❑
19b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑

	Strongly agree (7)	Agree (6)	Agree a little (5)	Neither agree nor disagree (4)	Disagree a little (3)	Disagree (2)	Strongly disagree (1)
20a) I hide a way I am eating when I am with others because of the sensations in my teeth.	❑	❑	❑	❑	❑	❑	❑
20b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
21a) I am unable to fully take part in conversations because of the sensations in my teeth.	❑	❑	❑	❑	❑	❑	❑
21b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
22a) Going to the dentist is hard for me because I know it is going to be painful as a result of sensations in my teeth.	❑	❑	❑	❑	❑	❑	❑
22b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑

The following questions are about the way the sensations in your teeth makes you feel.
Thinking about yourself over the last month to what extend would you agree or disagree with the following statements (please tick only one response for each questions)

	Strongly agree (7)	Agree (6)	Agree a little (5)	Neither agree nor disagree (4)	Disagree a little (3)	Disagree (2)	Strongly disagree (1)
23a) I've been frustrated because I can't find anything that deals with the sensations I have in my teeth.	❑	❑	❑	❑	❑	❑	❑
23b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
24a) I've been anxious that something I eat or drink might cause sensations in my teeth.	❑	❑	❑	❑	❑	❑	❑
24b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
25a) The sensations in my teeth have been irritating.	❑	❑	❑	❑	❑	❑	❑
25b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
26a) I have been annoyed with myself because I did something that I knew caused these sensations.	❑	❑	❑	❑	❑	❑	❑
26b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑

	Strongly agree (7)	Agree (6)	Agree a little (5)	Neither agree nor disagree (4)	Disagree a little (3)	Disagree (2)	Strongly disagree (1)
27a) I felt guilty because I might have contributed to the sensations I am having with my teeth.	❑	❑	❑	❑	❑	❑	❑
27b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
28a) The sensations in my teeth have been annoying.	❑	❑	❑	❑	❑	❑	❑
28b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
29a) I have been anxious because of the sensations in my teeth.	❑	❑	❑	❑	❑	❑	❑
29b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑

The following questions are about what the sensations in your teeth mean for you.
Thinking about yourself over the last month to what extend would you agree or disagree with the following statements (please tick only one response for each questions)

	Strongly agree (7)	Agree (6)	Agree a little (5)	Neither agree nor disagree (4)	Disagree a little (3)	Disagree (2)	Strongly disagree (1)
30a) I find it difficult to accept that I am that person who has these sensations in my teeth.	❑	❑	❑	❑	❑	❑	❑
30b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
31a) Having these sensations in my teeth make me feel different from others.	❑	❑	❑	❑	❑	❑	❑
31b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
32a) Having these sensations in my teeth makes me feel old.	❑	❑	❑	❑	❑	❑	❑
32b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑

	Strongly agree (7)	Agree (6)	Agree a little (5)	Neither agree nor disagree (4)	Disagree a little (3)	Disagree (2)	Strongly disagree (1)
33a) Having these sensations in my teeth makes me feel damaged.	❑	❑	❑	❑	❑	❑	❑
33b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑
34a) Having these sensations in my teeth makes me feel as though I am unhealthy.	❑	❑	❑	❑	❑	❑	❑
34b) What would your ideal be?	❑	❑	❑	❑	❑	❑	❑

The last five questions ask about how much the sensations in your teeth affect your life overall.

	Excellent (1)	Very good (2)	Good (3)	Fair (4)	Poor (5)	Very poor (6)
35a) Overall how would you rate the health of your mouth, teeth and gums?	❑	❑	❑	❑	❑	❑
35b) What would your ideal be?	❑	❑	❑	❑	❑	❑

	Very much (5)	Quite a bit (4)	Some-what (3)	A little (2)	Not at all (1)
36a) Overall how much do the sensations in your teeth bother you?	❑	❑	❑	❑	❑
36b) What would your ideal be?	❑	❑	❑	❑	❑
37a) Overall, how much do the things you do to manage the sensations bother you?	❑	❑	❑	❑	❑
37b) What would your ideal be?	❑	❑	❑	❑	❑
38a) Overall, how much do the sensations in your teeth affect your quality of life?	❑	❑	❑	❑	❑
38b) What would your ideal be?	❑	❑	❑	❑	❑
39a) Overall, how much do the things you do to manage the sensations in your teeth affect your quality of life?	❑	❑	❑	❑	❑
39b) What would your ideal be?	❑	❑	❑	❑	❑

Illness Perception Questionnaire – Revised (adapted for the condition of sensitive teeth)

Identity – 5 items from Revised DHEQ

Causes

We are interested in what you consider may have been the cause of your sensitive teeth. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused the sensitivity in your teeth rather than what others including dentists or family may have suggested to you. Please list in rank order the three most important factors that you now believe caused the sensitivity in your teeth. You may use any of the items from the box below, or you may have additional ideas of your own:

1. The most important causes for me include:

    1. _____
    2. _____
    3. _____

Examples may include: Stress or worry, hereditary – it runs in the family, a germ or virus, diet or eating habits, chance or bad luck, poor dental care in my past, my own behaviour, toothbrushing, ageing, alcohol, smoking, accident or injury, altered immunity

We are interested in your own personal views about your condition (sensitive teeth). Please indicate how much you agree or disagree with the following statements about your sensitive teeth by ticking the appropriate box.

1. I will have sensitive teeth for a short time (in my life)

    - ☐ Strongly disagree$_5$
    - ☐ Disagree$_4$
    - ☐ Neither agree nor disagree$_3$
    - ☐ Agree$_2$
    - ☐ Strongly agree$_1$

2. My condition (sensitive teeth) is likely to be permanent rather than temporary

    - ☐ Strongly disagree$_1$
    - ☐ Disagree$_2$
    - ☐ Neither agree nor disagree$_3$
    - ☐ Agree$_4$
    - ☐ Strongly agree$_5$

3. I will have sensitive teeth for a long time (in my life)

    - ☐ Strongly disagree$_1$
    - ☐ Disagree$_2$
    - ☐ Neither agree nor disagree$_3$
    - ☐ Agree$_4$
    - ☐ Strongly agree$_5$

4. My condition (sensitive teeth) will pass quickly

   - ☐ Strongly disagree$_5$
   - ☐ Disagree$_4$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Agree$_2$
   - ☐ Strongly agree$_1$

5. I expect to have sensitive teeth for the rest of my life

   - ☐ Strongly disagree$_1$
   - ☐ Disagree$_2$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Agree$_4$
   - ☐ Strongly agree$_5$

6. My tooth sensitivity is a serious condition

   - ☐ Strongly disagree$_1$
   - ☐ Disagree$_2$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Agree$_4$
   - ☐ Strongly agree$_5$

7. My sensitive teeth have major consequences on my life

   - ☐ Strongly disagree$_1$
   - ☐ Disagree$_2$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Agree$_4$
   - ☐ Strongly agree$_5$

8. My sensitive teeth do not have much effect on my life

   - ☐ Strongly disagree$_5$
   - ☐ Disagree$_4$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Agree$_2$
   - ☐ Strongly agree$_1$

9. My sensitive teeth strongly affect the way others see me

   - ☐ Strongly disagree$_1$
   - ☐ Disagree$_2$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Agree$_4$
   - ☐ Strongly agree$_5$

10. My sensitive teeth have serious financial consequences

    - ☐ Strongly disagree$_1$
    - ☐ Disagree$_2$
    - ☐ Neither agree nor disagree$_3$
    - ☐ Agree$_4$
    - ☐ Strongly agree$_5$

11. My sensitive teeth cause difficulties for those who are close to me

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

12. There is a lot which I can do to control my symptoms

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

13. What I do can determine whether my tooth sensitivity gets better or worse

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

14. The course of my oral condition (i.e. tooth sensitivity) depends on me

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

15. Nothing I do will affect my sensitive teeth

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

16. I have the power to influence my sensitive teeth

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

17. My actions will have no effect on the outcome of my sensitive teeth

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

18. My sensitive teeth will improve over time

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

19. There is very little that can be done to improve my sensitive teeth

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

20. My treatment (e.g. sensitivity toothpaste) will be effective in curing my sensitive teeth

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$
- ☐ Not using/taking any treatments

21. The negative effects of my sensitive teeth can be prevented (avoided) by my treatment (e.g. sensitivity toothpaste)

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$
- ☐ Not using/taking any treatments

22. My treatment (e.g. sensitivity toothpaste) can control my sensitive teeth

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$
- ☐ Not using/taking any treatments

23. There is nothing which can help my sensitive teeth

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

24. The symptoms of my sensitive teeth are puzzling to me

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

25. My tooth sensitivity is a mystery to me

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

26. I don't understand my tooth sensitivity

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

27. My tooth sensitivity doesn't make any sense to me

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

28. I have a clear picture or understanding of my sensitive teeth

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

29. The symptoms of my sensitive teeth change a great deal from day to day

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

30. My tooth sensitivity comes and goes in cycles

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_4$

31. My sensitive teeth are very unpredictable

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

32. I go through cycles in which my sensitive teeth get better and worse

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

33. I get depressed when I think about my sensitive teeth

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

34. When I think about my sensitive teeth I get upset

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

35. My sensitive teeth make me feel angry

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

36. My sensitive teeth do not worry me

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

37. Having sensitive teeth makes me feel anxious

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

38. My sensitive teeth make me feel afraid

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

Social Comparisons

Most people compare themselves from time to time with others. For example they may compare the way they feel, their opinions, their abilities, and/or their situation with those of other people. There is nothing particularly 'good' or 'bad' about this type of comparisons, and some people do it more than others and some people use different type of comparisons more other than other ones. We would like to find out what is your specific way of comparing yourself wilt other people in relation to your sensitive teeth. To do that we would like to ask you to indicate how much you agree with following statements:

1. When it comes to my sensitivity, I always pay a lot of attention to how I do things compared with how others do things

   - ☐ Strongly agree$_1$
   - ☐ Agree$_2$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Disagree$_4$
   - ☐ Strongly disagree

2. When it comes to my sensitivity, I often try to find out what others think who face similar problems as I face

   - ☐ Strongly agree$_1$
   - ☐ Agree$_2$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Disagree$_4$
   - ☐ Strongly disagree

When I think about others whose teeth, mouth and gums are <u>worse</u> than mine, I...

(1)...experience fear of decline

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

(2)... fear that my future will be similar

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

(3)...fear that I will go along the same way

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

When I think about others whose teeth, mouth and gums are <u>worse</u> than mine, I...

(4)...am happy that I am doing so well myself

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

(5)... fell relieved about my own situation

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

(6)... realise how well I am doing

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

When I think about others whose teeth, mouth and gums are <u>better</u> than mine, I...

(7)...realise that it is possible to improve

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

(8)... am pleased that things can get better

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

(9)...have good hope that my situation will improve

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

When I think about others whose teeth, mouth and gums are <u>better</u> than mine, I...

(10)...it is threatening to notice that I am doing not so well

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

(11)... fell frustrated about my own situation

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

(12)... feel depressed realising that I am not so well

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

This was the last question.
Thank you for your time!

Sensitive Teeth and Quality of Life Follow-up

You will be asked to complete a set 4 of questionnaires asking about:

- your assessment of pain you experience in relation to your sensitive teeth
- your everyday experience of living with sensitive teeth
- your own personal views about your sensitive teeth
- your views on how you compare yourself with other who you think have sensitive teeth

Please follow the instructions for each of the questionnaire.

Your pseudonym: _____
Today's date: _____

Pain severity

For each question, there are two parts:

- **Part a** asks about how things are NOW for you. Please give your answer by circling the number that comes closest to what is true for you.
- **Part b** asks how do you **now think** you were six months ago. When answering this part of the question please take a minute and think how you were in relation to that question when we first meet for the interview six months ago.

1a) On a scale of 1 to 10 how intense are the sensations? (Please circle your answer)

1 2 3 4 5 6 7 8 9 10

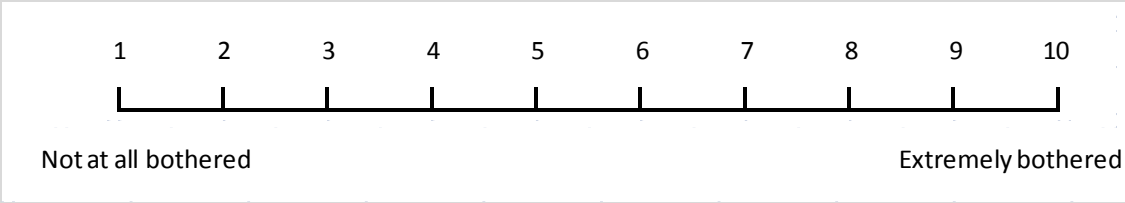
Not at all intense — The worst imaginaible

1b) How do you now think you were six months ago? (Please circle your answer)

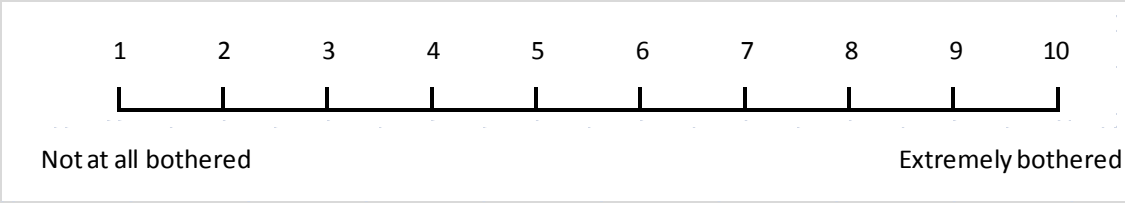
1 2 3 4 5 6 7 8 9 10

Not at all intense — The worst imaginaible

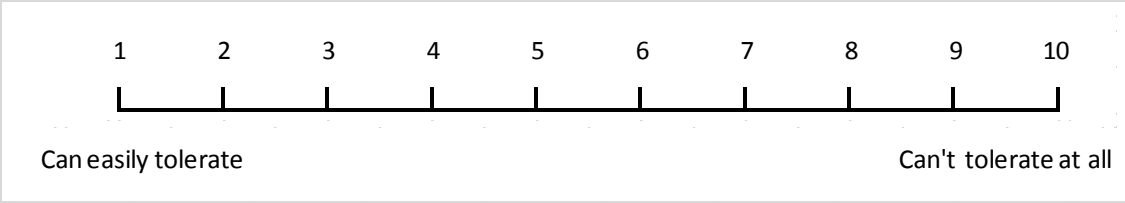
2a) On a scale of 1 to 10 how bothered are you by any sensations? (Please circle your answer)



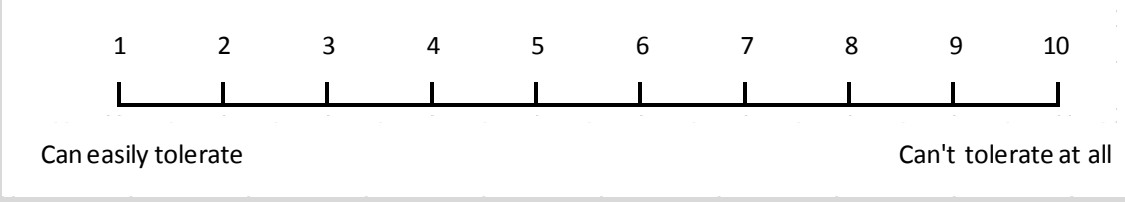
2b) How do you now think you were six months ago? (Please circle your answer)



3a) On a scale of 1 to 10 how well can you tolerate sensations? (Please circle your answer)



3b) How do you now think you were six months ago? (Please circle your answer)



Dentine Hypersensitivity Experience Questionnaire

The follow questions are about your sensitive teeth, and the impact it has on your everyday life.

For each question, there are two parts:

- **Part a** asks about how things are NOW for you. Please give your answer by circling the number that comes closest to what is true for you.
- **Part b** asks how do you **now think** you were six months ago. When answering this part of the question please take a minute and think how you were in relation to that question when we first meet for the interview six months ago.

There are no right or wrong answers, so please tell us what is true for you.

The following questions are about the ways in which any sensations in your teeth affect you in your daily life.
Thinking about yourself over the last month to what extend would you agree or disagree with the following statements (please tick only one response for each questions)

	Strongly agree (7)	**Agree (6)**	**Agree a little (5)**	**Neither agree nor disagree (4)**	**Disagree a little (3)**	**Disagree (2)**	**Strongly disagree (1)**
1a) Having sensations in my teeth takes a lot of the pleasure out of eating and drinking.	❑	❑	❑	❑	❑	❑	❑
1b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
2a) There have been times when I can't finish my meal because of the sensations.	❑	❑	❑	❑	❑	❑	❑
2b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
3a) It takes a long time to finish some foods and drinks because of sensations in my teeth.	❑	❑	❑	❑	❑	❑	❑
3b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
4a) There have been times when I have had problems eating ice cream because of these sensations.	❑	❑	❑	❑	❑	❑	❑
4b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
5a) I have to change the way I eat or drink certain things.	❑	❑	❑	❑	❑	❑	❑
5b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑

The following questions are about the ways in which the sensations in your teeth have forced you to change things in your daily life.
Thinking about yourself over the last month to what extend would you agree or disagree with the following statements (please tick only one response for each questions)

	Strongly agree (7)	Agree (6)	Agree a little (5)	Neither agree nor disagree (4)	Disagree a little (3)	Disagree (2)	Strongly disagree (1)
6a) I have to be careful how I breathe on a cold day.	❑	❑	❑	❑	❑	❑	❑
6b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
7a) I have to leave some cold foods or drinks to warm up before I can have them.	❑	❑	❑	❑	❑	❑	❑
7b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
8a) I have to cool some foods or drinks down before I can have them.	❑	❑	❑	❑	❑	❑	❑
8b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
9a) I have to cut up some fruits before being able to eat them.	❑	❑	❑	❑	❑	❑	❑
9b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
10a) I have to wear a scarf over my mouth on cold day.	❑	❑	❑	❑	❑	❑	❑
10b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑

The following questions are about the things you do in your daily life to avoid experiencing the sensations in your teeth.
Thinking about yourself over the last month to what extend would you agree or disagree with the following statements (please tick only one response for each questions)

	Strongly agree (7)	Agree (6)	Agree a little (5)	Neither agree nor disagree (4)	Disagree a little (3)	Disagree (2)	Strongly disagree (1)
11a) I have avoided very cold drinks or foods.	❑	❑	❑	❑	❑	❑	❑
11b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
12a I have avoided very hot drinks or foods.	❑	❑	❑	❑	❑	❑	❑
12b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑

	Strongly agree (7)	Agree (6)	Agree a little (5)	Neither agree nor disagree (4)	Disagree a little (3)	Disagree (2)	Strongly disagree (1)
13a) When eating some foods I have made sure they don't touch certain teeth.	❑	❑	❑	❑	❑	❑	❑
13b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
14a) I have changed the way I brush my teeth.	❑	❑	❑	❑	❑	❑	❑
14b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
15a) The sensations in my teeth have been irritating.	❑	❑	❑	❑	❑	❑	❑
24b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
16a) When eating some foods I have made sure I bite in small pieces.	❑	❑	❑	❑	❑	❑	❑
16b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
17a) There are other foods I have avoided.	❑	❑	❑	❑	❑	❑	❑
17b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑

The following questions are about the way the sensations affect you when you are with other people or in a certain situations.
Thinking about yourself over the last month to what extend would you agree or disagree with the following statements (please tick only one response for each questions)

	Strongly agree (7)	Agree (6)	Agree a little (5)	Neither agree nor disagree (4)	Disagree a little (3)	Disagree (2)	Strongly disagree (1)
18a) Because of the sensations I take longer than others to finish a meal.	❑	❑	❑	❑	❑	❑	❑
18b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
19a) I have to be careful what I eat when I am with others because of the sensations in my teeth.	❑	❑	❑	❑	❑	❑	❑
19b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑

	Strongly agree (7)	Agree (6)	Agree a little (5)	Neither agree nor disagree (4)	Disagree a little (3)	Disagree (2)	Strongly disagree (1)
20a) I hide a way I am eating when I am with others because of the sensations in my teeth.	❑	❑	❑	❑	❑	❑	❑
20b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
21a) I am unable to fully take part in conversations because of the sensations in my teeth.	❑	❑	❑	❑	❑	❑	❑
21b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
22a) Going to the dentist is hard for me because I know it is going to be painful as a result of sensations in my teeth.	❑	❑	❑	❑	❑	❑	❑
22b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑

The following questions are about the way the sensations in your teeth makes you feel.
Thinking about yourself over the last month to what extend would you agree or disagree with the following statements (please tick only one response for each questions)

	Strongly agree (7)	Agree (6)	Agree a little (5)	Neither agree nor disagree (4)	Disagree a little (3)	Disagree (2)	Strongly disagree (1)
23a) I've been frustrated because I can't find anything that deals with the sensations I have in my teeth.	❑	❑	❑	❑	❑	❑	❑
23b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
24a) I've been anxious that something I eat or drink might cause sensations in my teeth.	❑	❑	❑	❑	❑	❑	❑
24b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
25a) The sensations in my teeth have been irritating.	❑	❑	❑	❑	❑	❑	❑
25b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
26a) I have been annoyed with myself because I did something that I knew caused these sensations.	❑	❑	❑	❑	❑	❑	❑
26b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑

	Strongly agree (7)	Agree (6)	Agree a little (5)	Neither agree nor disagree (4)	Disagree a little (3)	Disagree (2)	Strongly disagree (1)
27a) I felt guilty because I might have contributed to the sensations I am having with my teeth.	❑	❑	❑	❑	❑	❑	❑
27b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
28a) The sensations in my teeth have been annoying.	❑	❑	❑	❑	❑	❑	❑
28b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
29a) I have been anxious because of the sensations in my teeth.	❑	❑	❑	❑	❑	❑	❑
29b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑

The following questions are about what the sensations in your teeth mean for you.
Thinking about yourself over the last month to what extend would you agree or disagree with the following statements (please tick only one response for each questions)

	Strongly agree (7)	Agree (6)	Agree a little (5)	Neither agree nor disagree (4)	Disagree a little (3)	Disagree (2)	Strongly disagree (1)
30a) I find it difficult to accept that I am that person who has these sensations in my teeth.	❑	❑	❑	❑	❑	❑	❑
30b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
31a) Having these sensations in my teeth make me feel different from others.	❑	❑	❑	❑	❑	❑	❑
31b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
32a) Having these sensations in my teeth makes me feel old.	❑	❑	❑	❑	❑	❑	❑
32b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑

	Strongly agree (7)	Agree (6)	Agree a little (5)	Neither agree nor disagree (4)	Disagree a little (3)	Disagree (2)	Strongly disagree (1)
33a) Having these sensations in my teeth makes me feel damaged.	❑	❑	❑	❑	❑	❑	❑
33b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑
34a) Having these sensations in my teeth makes me feel as though I am unhealthy.	❑	❑	❑	❑	❑	❑	❑
34b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑	❑

The last five questions ask about how much the sensations in your teeth affect your life overall.

	Excellent (1)	Very good (2)	Good (3)	Fair (4)	Poor (5)	Very poor (6)
35a) Overall how would you rate the health of your mouth, teeth and gums?	❑	❑	❑	❑	❑	❑
35b) How do you now think you were six months ago?	❑	❑	❑	❑	❑	❑

	Very much (5)	Quite a bit (4)	Some-what (3)	A little (2)	Not at all (1)
36a) Overall how much do the sensations in your teeth bother you?	❑	❑	❑	❑	❑
36b) How do you now think you were six months ago?	❑	❑	❑	❑	❑
37a) Overall, how much do the things you do to manage the sensations bother you?	❑	❑	❑	❑	❑
37b) How do you now think you were six months ago?	❑	❑	❑	❑	❑
38a) Overall, how much do the sensations in your teeth affect your quality of life?	❑	❑	❑	❑	❑
38b) How do you now think you were six months ago?	❑	❑	❑	❑	❑
39a) Overall, how much do the things you do to manage the sensations in your teeth affect your quality of life?	❑	❑	❑	❑	❑
39b) How do you now think you were six months ago?	❑	❑	❑	❑	❑

Illness Perception Questionnaire – Revised
(adapted for the condition of sensitive teeth)

Identity – 5 items from Revised DHEQ

Causes

We are interested in what you consider may have been the cause of your sensitive teeth. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused the sensitivity in your teeth rather than what others including dentists or family may have suggested to you. Please list in rank order the three most important factors that you now believe caused the sensitivity in your teeth. You may use any of the items from the box below, or you may have additional ideas of your own:

1.The most important causes for me include:

1. _____
2. _____
3. _____

Examples may include: Stress or worry, hereditary – it runs in the family, a germ or virus, diet or eating habits, chance or bad luck, poor dental care in my past, my own behaviour, toothbrushing, ageing, alcohol, smoking, accident or injury, altered immunity

We are interested in your own personal views about your condition (sensitive teeth). Please indicate how much you agree or disagree with the following statements about your sensitive teeth by ticking the appropriate box.

1. I will have sensitive teeth for a short time (in my life)

   - ☐ Strongly disagree$_5$
   - ☐ Disagree$_4$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Agree$_2$
   - ☐ Strongly agree$_1$

2. My condition (sensitive teeth) is likely to be permanent rather than temporary

   - ☐ Strongly disagree$_1$
   - ☐ Disagree$_2$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Agree$_4$
   - ☐ Strongly agree$_5$

3. I will have sensitive teeth for a long time (in my life)

   - ☐ Strongly disagree$_1$
   - ☐ Disagree$_2$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Agree$_4$
   - ☐ Strongly agree$_5$

4. My condition (sensitive teeth) will pass quickly

   - ☐ Strongly disagree$_5$
   - ☐ Disagree$_4$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Agree$_2$
   - ☐ Strongly agree$_1$

5. I expect to have sensitive teeth for the rest of my life

   - ☐ Strongly disagree$_1$
   - ☐ Disagree$_2$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Agree$_4$
   - ☐ Strongly agree$_5$

6. My tooth sensitivity is a serious condition

   - ☐ Strongly disagree$_1$
   - ☐ Disagree$_2$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Agree$_4$
   - ☐ Strongly agree$_5$

7. My sensitive teeth have major consequences on my life

   - ☐ Strongly disagree$_1$
   - ☐ Disagree$_2$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Agree$_4$
   - ☐ Strongly agree$_5$

8. My sensitive teeth do not have much affect on my life

   - ☐ Strongly disagree$_5$
   - ☐ Disagree$_4$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Agree$_2$
   - ☐ Strongly agree$_1$

9. My sensitive teeth strongly affect the way others see me

   - ☐ Strongly disagree$_1$
   - ☐ Disagree$_2$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Agree$_4$
   - ☐ Strongly agree$_5$

10. My sensitive teeth have serious financial consequences

    - ☐ Strongly disagree$_1$
    - ☐ Disagree$_2$
    - ☐ Neither agree nor disagree$_3$
    - ☐ Agree$_4$
    - ☐ Strongly agree$_5$

11. My sensitive teeth cause difficulties for those who are close to me

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

12. There is a lot which I can do to control my symptoms

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

13. What I do can determine whether my tooth sensitivity gets better or worse

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

14. The course of my oral condition (i.e. tooth sensitivity) depends on me

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

15. Nothing I do will affect my sensitive teeth

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

16. I have the power to influence my sensitive teeth

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

17. My actions will have no effect on the outcome of my sensitive teeth

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

18. My sensitive teeth will improve over time

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

19. There is very little that can be done to improve my sensitive teeth

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

20. My treatment (e.g. sensitivity toothpaste) will be effective in curing my sensitive teeth

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$
- ☐ Not using/taking any treatments

21. The negative effects of my sensitive teeth can be prevented (avoided) by my treatment (e.g. sensitivity toothpaste)

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$
- ☐ Not using/taking any treatments

22. My treatment (e.g. sensitivity toothpaste) can control my sensitive teeth

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$
- ☐ Not using/taking any treatments

23. There is nothing which can help my sensitive teeth

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

24. The symptoms of my sensitive teeth are puzzling to me

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

25. My tooth sensitivity is a mystery to me

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

26. I don't understand my tooth sensitivity

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

27. My tooth sensitivity doesn't make any sense to me

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

28. I have a clear picture or understanding of my sensitive teeth

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

29. The symptoms of my sensitive teeth change a great deal from day to day

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

30. My tooth sensitivity comes and goes in cycles

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_4$

31. My sensitive teeth are very unpredictable

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

32. I go through cycles in which my sensitive teeth get better and worse

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

33. I get depressed when I think about my sensitive teeth

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

34. When I think about my sensitive teeth I get upset

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

35. My sensitive teeth make me feel angry

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

36. My sensitive teeth do not worry me

- ☐ Strongly disagree$_5$
- ☐ Disagree$_4$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_2$
- ☐ Strongly agree$_1$

37. Having sensitive teeth makes me feel anxious

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

38. My sensitive teeth make me feel afraid

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

Social Comparisons

Most people compare themselves from time to time with others. For example they may compare the way they feel, their opinions, their abilities, and/or their situation with those of other people. There is nothing particularly 'good' or 'bad' about this type of comparisons, and some people do it more than others and some people use different type of comparisons more other than other ones. We would like to find out what is your specific way of comparing yourself wilt other people in relation to your sensitive teeth. To do that we would like to ask you to indicate how much you agree with following statements:

3. When it comes to my sensitivity, I always pay a lot of attention to how I do things compared with how others do things

   - ☐ Strongly agree$_1$
   - ☐ Agree$_2$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Disagree$_4$
   - ☐ Strongly disagree

4. When it comes to my sensitivity, I often try to find out what others think who face similar problems as I face

   - ☐ Strongly agree$_1$
   - ☐ Agree$_2$
   - ☐ Neither agree nor disagree$_3$
   - ☐ Disagree$_4$
   - ☐ Strongly disagree

When I think about others whose teeth, mouth and gums are <u>worse</u> than mine, I...

(1)...experience fear of decline

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

(2)... fear that my future will be similar

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

(3)...fear that I will go along the same way

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

When I think about others whose teeth, mouth and gums are <u>worse</u> than mine, I...

(4)...am happy that I am doing so well myself

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

(5)... fell relieved about my own situation

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

(6)... realise how well I am doing

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

When I think about others whose teeth, mouth and gums are <u>better</u> than mine, I...

(7)...realise that it is possible to improve

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

(8)... am pleased that things can get better

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

(9)...have good hope that my situation will improve

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

When I think about others whose teeth, mouth and gums are <u>better</u> than mine, I...

(10)...it is threatening to notice that I am doing not so well

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

(11)... fell frustrated about my own situation

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

(12)... feel depressed realising that I am not so well

- ☐ Strongly disagree$_1$
- ☐ Disagree$_2$
- ☐ Neither agree nor disagree$_3$
- ☐ Agree$_4$
- ☐ Strongly agree$_5$

This was the last question.
Thank you for your time!

8.8 Appendix H: Individual results for the DHEQ in Study B

Table 8.8.1 Individual DHEQ total score and recalibration scores for Study B

Pseudonym	THEN TEST/IDEALS	DHEQ total score baseline (possible range: 34-238)	DHEQ total score follow-up (possible range: 34-238)	Recalibration*
Aldbrough	THEN TEST	160	126	-34
Amy	THEN TEST	145	145	4
Biscuit	THEN TEST	100	10	2
Caroline	THEN TEST	175	131	-13
Doreen	THEN TEST	208	182	-5
Julian	THEN TEST	106	108	-3
Lizzy	THEN TEST	51	43	-5
Margaret	THEN TEST	134	104	-9
Tilly	THEN TEST	107	132	20
Yasmin	THEN TEST	175	85	8
Abigail	IDEALS	114	81	14
Agnes	IDEALS	111	53	-19
Anna	IDEALS	111	111	.00
Helen	IDEALS	103	53	-23
Lucy	IDEALS	100	100	23
Moira	IDEALS	127	56	-8
Olivia	IDEALS	168	75	4
Sue	IDEALS	197	204	-5
Towkey	IDEALS	147	131	-22
Michelle**	IDEALS	146	n/a	n/a

*For the THEN TEST recalibration was calculated as the difference between the retrospective assessment at follow-up ('then') and the initial assessment at baseline ('pre'). For IDEALS recalibration was calculated as the difference between the ideals assessment at baseline ('$ideal_{baseline}$') and at follow-up ('$ideal_{follow\text{-}up}$').

**This person only took part in the baseline interview.