Evaluating the Effects of Information Provision on Hypodontia Patients’ Expectations of the Process and Outcome of Combined Orthodontic and Restorative Treatment

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Evaluating the Effects of Information Provision on Hypodontia Patients’ Expectations of the Process and Outcome of Combined Orthodontic and Restorative Treatment

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King’s College London, Dental Institute

2017

This thesis is submitted to fulfil the requirement for the award of Doctor of Philosophy at King’s College London
Declaration

I declare that the work presented in this thesis is my own.

Signed…………………………… Dated……………………
Dedication

I dedicate this thesis to my parents (Manal Al-Harbi and Abdulfattah Ben Gassem) and husband (Mohammad Alhejaili) who stood by me throughout this long journey and whom without their continuous support, encouragement, and prayers this thesis would not have been possible. I also dedicate this thesis to my lovely daughters Deem and Jana who filled me with joy and endless love at the most difficult of times.
Acknowledgements

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Thank you mama for being there for me. I know that for the whole four years you have not stopped thinking of me and praying for me. Your moral support and encouragement is what helped me get through this. You were there in every way imaginable, and you sacrificed so much. Even when I delivered my two girls, you left everything behind and you stayed by my side. I know it must have not been easy putting up with my continuous complaining and I’m sorry for the pain I have caused you. Thank you baba for being strong for me and for pushing me to the limits. You knew I had potential and you believed in me. I hope I have made you proud. Thank you Mo for being such a great and understanding husband, you were always strong in my moments of weakness, and you were always there every step of the way, without you this thesis would not have been possible.

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Abstract

Aim: The ultimate goal of the research was to improve information delivered to hypodontia patients regarding their condition and its’ treatment by understanding their expectations of the process and outcome of combined orthodontic/restorative treatment and the effects of patient education in modifying these expectations.

Methods: A mixed method research design was adopted with three stages: (a) Study one: semi-structured interviews with 24 hypodontia patients who were either new, in-treatment, or had reached the end of their treatment to determine their information needs and their perceptions of the process and outcome of their combined orthodontic/restorative treatment. (b) The results of the interviews were used as the basis for the creation of a hypodontia specific interactive computer based education material (ICB-EM) together with a valid and reliable hypodontia treatment expectation questionnaire (HTEQ). Both materials were piloted on a sample of new hypodontia patients (n=10) and a selected panel of experts to assess readability and content validity. The questionnaire was distributed to 32 new hypodontia patients to assess its internal consistency. (c) Study two: a prospective randomised controlled trial was conducted on 96 new hypodontia patients randomly assigned to the intervention group (n=47) who received the ICB-EM or the control group (n=49) who received a standard hypodontia leaflet. The main outcome measure was the change in the participants’ self-reported expectations of the process and outcome of combined orthodontic/restorative treatment as measured by the HTEQ. All participants completed the questionnaire at baseline (T1), post-intervention (T2) and 3-4 weeks follow up (T3). As a secondary outcome, the patients’ acceptability of the method of information provision was measured using the treatment evaluation inventory (TEI) at T2.

Results: (a) Themes relating to the participants’ information needs included; ‘what is hypodontia’, ‘treatment of hypodontia’, ‘hypodontia clinic’ and ‘educational material’. Themes relating to perceptions of the treatment process included: ‘hypodontia clinic’, ‘orthodontic treatment’, and ‘restorative treatment’, while themes relating to the treatment outcome included: ‘changes in appearance’, ‘functional changes’, and psychosocial changes’. (b) The ICB-EM and the HTEQ were found to have good face and content validity. The overall Cronbach’s alpha for
the questionnaire was 0.80 while for the treatment process and treatment outcome subscales it was 0.71 and 0.88 respectively. (c) The final sample comprised 76 participants; control group (n=38) and the intervention group (n=38). The mean age of the sample was 19 (SD = 7.24) years for the control group and 20.3 (SD = 6.9) years for the intervention group. With regards to the categorical response questions of the questionnaire, Chi square analysis revealed that both groups were similar in their expectations at baseline (T1). At T2, the intervention group conveyed better recall of the number of clinicians in the hypodontia clinic ($X^2 = 9.72, p = 0.021$), the types of clinicians (restorative dentist $X^2 = 9.01, p = 0.003$, dental nurse $X^2 = 5.23, p = 0.022$) and were less likely to answer ‘I don't know’ ($X^2 = 4.03, p = 0.045$). In addition, a significantly higher proportion of participants in the intervention group expected to receive restorative treatment compared to the control ($X^2 = 8.75, p = 0.013$). At T3, the intervention group conveyed better recall of having a check-up and diagnosis in the hypodontia clinic ($X^2 = 4.52, p = 0.033$), the number of clinicians in the clinic ($X^2 = 19.93, p < 0.001$), and the types of clinicians in the clinic (restorative dentist $X^2 = 5.05, p = 0.025$, oral surgeon $X^2 = 6.41, p = 0.011$ and dental nurse ($X^2 = 6.09, p = 0.014$). With regards to the visual analogue scale items of the questionnaire a mixed-analysis of variance (ANOVA) revealed that there were statistically significant effects of time for the majority of the items meaning that patients expectations changed over the course of the study (T1 to T3), while there was no statistically significant effect of intervention and no significant interaction between time and intervention was detected. Participants in the intervention group were significantly more satisfied with the ICB-EM than individuals in the control group who received the leaflet ($t = -3.53, p = 0.001$).

**Conclusion:** A new patient based 25-item HTEQ as well as a patient based hypodontia specific ICB-EM were developed. Both displayed good face and content validity. The questionnaire also displayed satisfactory internal consistency. Provision of information via the ICB-EM was more effective than provision by leaflet in terms of the participants’ recall of the hypodontia clinic. There was no difference between the ICB-EM and the leaflet in terms of patient expectations of the process and outcome of orthodontic and restorative treatment. Patients expressed a preference for the ICB-EM.
Table of Contents

Declaration ............................................................................................................................................. ii
Dedication.............................................................................................................................................. iii
Acknowledgements .......................................................................................................................... iv
Abstract ............................................................................................................................................... vi
Table of Contents ............................................................................................................................. viii
List of Figures ....................................................................................................................................... xiii
List of Tables ......................................................................................................................................... xiv
List of Common Abbreviations ....................................................................................................... xvi

Chapter 1: Introduction ..................................................................................................................... 1
  1.1 Introduction .................................................................................................................................. 1
  1.2 Overview of the Research ......................................................................................................... 2
  1.3 Research Aims ......................................................................................................................... 3
  1.4 Structure and Organisation of the Thesis ............................................................................... 6

Chapter 2: Literature Review .......................................................................................................... 8
  2.1 Hypodontia and its Management ............................................................................................... 8
    2.1.1 Definition ............................................................................................................................ 8
    2.1.2 Prevalence .......................................................................................................................... 8
      2.1.2.1 Primary Dentition ........................................................................................................ 8
      2.1.2.2 Permanent Dentition .................................................................................................. 9
    2.1.3 Aetiology ........................................................................................................................... 9
      2.1.3.1 Environmental ............................................................................................................ 9
      2.1.3.2 Genetic ........................................................................................................................ 10
    2.1.4 Syndromes and Systemic Conditions ............................................................................... 11
    2.1.5 Associated Skeletal Features ....................................................................................... 11
    2.1.6 Associated Dental Anomalies ........................................................................................... 11
      2.1.6.1 Tooth Size and Shape ................................................................................................. 11
      2.1.6.2 Ectopic Eruption ......................................................................................................... 12
      2.1.6.3 Delayed Eruption and Development ......................................................................... 12
      2.1.6.4 Retention of Deciduous Teeth and Ankyloses ............................................................ 12
      2.1.6.5 Lack of Alveolar Development .................................................................................. 12
    2.1.7 Impact of Hypodontia on Oral Health Related Quality of Life (OHRQoL) ..................... 13
    2.1.8 Management of Hypodontia .............................................................................................. 21
    2.1.9 Hypodontia Care Pathway ................................................................................................. 22
    2.1.10 Impact of Treatment Process on the Hypodontia Patient ........................................... 24
    2.1.11 Impact of Treatment Outcome on OHRQoL ................................................................. 26
  2.2 Patient Expectations ..................................................................................................................... 31
    2.2.1 Definition ............................................................................................................................ 31
    2.2.2 Taxonomy of Expectations ............................................................................................... 31
Chapter 4: Materials Development

Development and Testing the Hypodontia Treatment Expectation Questionnaire and the Interactive Computer Based Hypodontia Educational Material ........................................... 135

4.1 Introduction .................................................................................................................................................................................. 135
4.2 Materials and Methods ...................................................................................................................................................................... 136

4.2.1 Development of the HTEQ ......................................................................................................................................................... 138
4.2.1.1 Selection of Scales .................................................................................................................................................................. 138
4.2.1.2 Format of the Questionnaire .............................................................................................................................................. 143
4.2.1.3 Outcome Measures of the Questionnaire ................................................................................................................................. 143
4.2.1.4 Questionnaire Layout ............................................................................................................................................................ 148
4.2.1.5 Panel Review of the Questionnaire .................................................................................................................................. 148
4.2.1.6 Pilot Test .................................................................................................................................................................................... 149
4.2.1.7 Reliability of the Questionnaire .................................................................................................................................... 150

4.2.2 Development of the ICB-EM ...................................................................................................................................................... 151
4.2.2.1 Background ............................................................................................................................................................................. 151
4.2.2.2 Design of ICB-EM .............................................................................................................................................................. 152
4.2.2.3 Format of the ICB-EM ......................................................................................................................................................... 153
4.2.2.4 Structure of the ICB-EM ...................................................................................................................................................... 156
4.2.2.5 Panel Review of ICB-EM ................................................................................................................................................... 161
4.2.2.6 Piloting the ICB-EM ........................................................................................................................................................... 161

4.2.3 The Treatment Evaluation Inventory ......................................................................................................................................... 162

4.3 Results .............................................................................................................................................................................................. 163

4.3.1 Development of the Questionnaire ........................................................................................................................................ 163
4.3.1.1 Panel Review of the Questionnaire .................................................................................................................................. 163
4.3.1.2 Pilot Test .................................................................................................................................................................................. 164
4.3.1.3 Reliability of the Questionnaire ................................................................................................................................... 165

4.3.2 Development of the ICB-EM ...................................................................................................................................................... 166
4.3.2.1 Panel Review ......................................................................................................................................................................... 166
4.3.2.2 Piloting the ICB-EM ........................................................................................................................................................... 167

4.3.3 The Treatment Evaluation Inventory ......................................................................................................................................... 169

4.4 Discussion ........................................................................................................................................................................................ 171

4.4.1 Development of the HTEQ ......................................................................................................................................................... 171
4.4.2 Properties of the Questionnaire .............................................................................................................................................. 171
4.4.3 Development of the ICB-EM ...................................................................................................................................................... 172
4.4.4 The Treatment Evaluation Inventory ........................................................................................................................................ 174

4.5 Conclusion ....................................................................................................................................................................................... 174

Chapter 5: Study Two

Impact of Computer Based Information Provision on Expectations of Treatment Process and Outcome Compared to Clinician Delivered Information: A Randomised Prospective Controlled Trial ............................................................................................................................... 175

5.1 Introduction ....................................................................................................................................................................................... 175
5.2 Methods ......................................................................................................................................................................................... 178
Chapter 6: Discussion .............................................................................................................. 211

6.1 Introduction ....................................................................................................................... 211

6.2 Study One: Qualitative Study of Hypodontia Patients .................................................... 212
   6.2.1 Impact of Hypodontia on the Patients’ QoL ............................................................. 212
   6.2.2 Information Seeking Behaviour ............................................................................. 212
   6.2.3 Information Needs .................................................................................................. 213
   6.2.4 Expectations and Experiences of Treatment Process and Outcome ...................... 214

6.3 Materials Development: Developing and Testing the HTEQ and the ICB-EM .............. 216

6.4 Study Two: Randomised Prospective Controlled Trial ............................................... 217

6.5 Methodological Critique ................................................................................................ 219
   6.5.1 Study One: Hypodontia Patient Interviews ............................................................ 219
       Strengths ....................................................................................................................... 219
       Limitations .................................................................................................................. 220
   6.5.2 Materials Development ......................................................................................... 220
       Strengths ....................................................................................................................... 220
       Limitations .................................................................................................................. 221
   6.5.3 Study Two: Randomised Controlled Trial ............................................................. 222
       Strengths ....................................................................................................................... 222
       Limitations .................................................................................................................. 223

6.6 Recommendations and Future Implications .................................................................... 224
6.6.1 Implications for Practice.......................................................... 224
6.6.2 Directions for Future Research............................................. 225
6.7 Conclusions ............................................................................ 227

References.................................................................................. 229

Appendices ................................................................................... 251

Appendix 1: Ethical approval for Study One from NRES committee London-Chelsea .................. 251
Appendix 2: Ethical approval for Study One from R&D Department at Guy’s and St Thomas’ NHS
Foundation Trust............................................................................ 253
Appendix 3: Topic guide for patient interviews ........................................ 254
Appendix 4: Letter of invitation ........................................................... 256
Appendix 5: Participant information sheet parent/guardian ............................... 257
Appendix 6: Participant information sheet 16+ ........................................ 260
Appendix 7: Participant information sheet 12-16 ......................................... 263
Appendix 8: Assent and consent forms .................................................. 265
Appendix 9: Participant demographic sheet ............................................. 268
Appendix 10: HTEQ .......................................................................... 269
Appendix 11: TEI ............................................................................ 279
Appendix 12: Ethical approval for Study Two from NRES committee London-Chelsea ............... 282
Appendix 13: Ethical approval for Study One from R&D Department at Guy’s and St Thomas’ NHS
Foundation Trust............................................................................ 284
Appendix 14: BOS Hypodontia Leaflet .................................................. 285
List of Figures

Figure 1.1 Framework for the proposed studies of the current thesis. ........................................4
Figure 2.1 The hypodontia patients’ referral pathway .................................................................24
Figure 2.2 Conceptual model of patient expectations and requests .............................................32
Figure 2.3 The consumer model ..................................................................................................34
Figure 2.4 The cognition-affect model of satisfaction ..................................................................35
Figure 2.5 The assimilation-contrast model of perception ............................................................36
Figure 2.6 The zone of tolerance model .......................................................................................37
Figure 2.7 The assimilation-contrast model of satisfaction ............................................................38
Figure 3.1 The formal analysis process ........................................................................................94
Figure 4.1 Flow diagram of the development process of the HTEQ and the ICB-EM ......................137
Figure 4.2 Screenshot of the section ‘What is Hypodontia?’ ........................................................157
Figure 4.3 Screenshot of the section ‘Treatment’ .........................................................................159
Figure 4.4 Screenshot of the section ‘Hypodontia Clinic’ .............................................................161
Figure 5.1 CONSORT flow diagram of participant progress through the phases of the study ........183
Figure 5.2 Bar chart representing the participants’ expectations of receiving a check-up and diagnosis at T1 and their recall of receiving it at T2 (post-intervention) and T3 (3-4 weeks follow up) ..............188
Figure 5.3 Bar chart representing the participants’ expectations of the number of clinicians that will be seen in the clinic at T1 and their recall of the number seen at T2 (post-intervention) and T3 (3-4 weeks follow up). .................................................................................................................................190
Figure 5.4 Bar chart representing the participants’ expectations of the duration of orthodontic treatment at T1, T2, and T3. .................................................................................................................................195
Figure 5.5 Bar chart representing the participants’ expectations regarding the item ‘Do you expect to receive restorative treatment?’ at T1, T2, and T3. .................................................................................................................................198
List of Tables

Table 2.1 Studies investigating the impacts of hypodontia and its treatment on the OHRQoL of the effected patients. .......................................................................................................................................................... 16
Table 2.2 Studies investigating the impact of treatment process on the hypodontia patient ........................................... 28
Table 2.3 Studies investigating the patients’ expectations of orthodontic treatment. ...................................................... 48
Table 2.4 Studies investigating the patients’ expectations of restorative treatment. ....................................................... 66
Table 3.1 Interview participants’ characteristics. .................................................................................................................. 91
Table 3.2 Coding tree obtained from analysing the interviews showing the main themes, their subthemes, and elements .............................................................................................................................................. 98
Table 3.3 The effects of hypodontia on the participants QoL. ............................................................................................... 99
Table 3.4 The information seeking behaviour of the participants. .................................................................................... 104
Table 3.5 The information needs of the participants. ........................................................................................................ 111
Table 3.6 The participants’ expectations and experiences of the process of orthodontic/restorative treatment. ........................................................................................................................................ 120
Table 3.7 The participants’ expectations and experiences of the outcome of orthodontic/restorative treatment. ........................................................................................................................................... 126
Table 4.1 Content development of HTEQ. ........................................................................................................................ 140
Table 5.1 Baseline characteristics of all participants recruited in the trial, those lost to follow-up, and those remaining in the trial to the end. ........................................................................................................ 185
Table 5.2 The type of procedure the participants expect to receive at T1 and their recall of the procedures actually experienced at T2 and T3 by control and intervention groups ........................................... 187
Table 5.3 The number of clinicians the participants expect to see at T1 and their recall of the number actually seen at T2 and T3 by control and intervention groups .................................................. 189
Table 5.4 The types of clinicians the participants expect to see at T1 and their recall of the types of clinicians actually seen at T2 and T3 by control and intervention groups ........................................ 191
Table 5.5 Results of VAS items related to the expectations of the process of orthodontic treatment by control and intervention groups. ........................................................................................................ 193
Table 5.6 The expected duration of orthodontic treatment at T1, T2, and T3 by control and intervention groups .............................................................................................................................................. 194
Table 5.7 The expectations of receiving restorative treatment at T1, T2, and T3 by control and intervention groups ................................................................................................................................................. 197
Table 5.8 The type of restoration the participants expect to receive by control and intervention groups.. .......................................................................................................................................................... 199
Table 5.9 Results of VAS items related to the expectations of restorative treatment by study and control group 200
Table 5.10 Results of VAS items related to expected benefits of treatment by study and control group 202
Table 5.11 Results of VAS items related to importance held to each benefit by intervention and control group. ........................................................................................................................................... 203
Table 5.12 Reliability analysis of the TEI ................................................................................................................................................................................. 204
Table 5.13 The participants’ evaluation of the intervention received by intervention and control groups ........................................................................................................................................................................... 205
### List of Common Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>HTEQ</td>
<td>Hypodontia Treatment Expectation Questionnaire</td>
</tr>
<tr>
<td>ICB-EM</td>
<td>Interactive Computer Based-Educational Material</td>
</tr>
<tr>
<td>TEI</td>
<td>Treatment Evaluation Inventory</td>
</tr>
<tr>
<td>OHRQoL</td>
<td>Oral Health Related Quality of Life</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomised Controlled Trial</td>
</tr>
<tr>
<td>BOS</td>
<td>British Orthodontic Society</td>
</tr>
<tr>
<td>CONSORT</td>
<td>CONSOLIDATED Standards of Reporting Trial</td>
</tr>
<tr>
<td>OHIP</td>
<td>Oral Health Impact Profile</td>
</tr>
<tr>
<td>CPQ</td>
<td>Child Perception Questionnaire</td>
</tr>
<tr>
<td>COAS</td>
<td>Children Orthodontic Attitude Survey</td>
</tr>
<tr>
<td>ADHS</td>
<td>Adult Dental Health Survey</td>
</tr>
<tr>
<td>IOTN</td>
<td>Index of Treatment Need</td>
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<tr>
<td>VAS</td>
<td>Visual Analogue Scale</td>
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<tr>
<td>P</td>
<td>Probability Value</td>
</tr>
<tr>
<td>SD</td>
<td>Standard Deviation</td>
</tr>
<tr>
<td>X2</td>
<td>Chi-Square Test</td>
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<tr>
<td>t</td>
<td>Observed t Value t-test</td>
</tr>
<tr>
<td>RR</td>
<td>Relative Risk</td>
</tr>
<tr>
<td>ANOVA</td>
<td>Analysis of Variance</td>
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<tr>
<td>SPSS</td>
<td>Statistical Product and Service Solutions</td>
</tr>
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Chapter 1: Introduction

1.1 Introduction

This thesis examined hypodontia patients’ expectations of the process and outcome of combined orthodontic/restorative treatment and the effects of patient education in modifying these expectations using both qualitative and quantitative research approaches.

Clinicians involved in the treatment of hypodontia patients are usually faced with a multitude of challenges in their pursuit of the best possible outcome for each patient. Investigating factors that can influence the achievement of successful outcomes have become an essential component of effective clinical practice. In addition to identifying the physical signs and symptoms of hypodontia, there are hidden psychosocial issues which are more difficult to identify and can have an impact upon the treatment process and outcome.

The dental profession is increasingly realising the importance of understanding the psychosocial influences on successful treatment. Expectations form an integral part of the patients’ psychosocial make-up and although some studies have shown that the relationship between expectations and satisfaction is complex, others have reported that decreased satisfaction is associated with expectations that have not been fulfilled (Linder-Pelz, 1982, Jackson et al., 2001, Kravitz, 2001). Furthermore, theories of patient expectations have all displayed a high association between patients’ prior expectations of a service and their satisfaction or evaluation of the service received afterwards (Thompson and Sunol, 1995, Bergendal et al., 2011). Studies have also shown that effectively targeted patient education has the capacity to adjust these expectations and increase the likelihood of achieving patient satisfaction (Friedman et al., 2011). While satisfaction is clearly an outcome related to the expectations with which patients present, the focus of this thesis will be on expectations rather than satisfaction.

When it comes to hypodontia patients in particular, their condition and its treatment can be very complex and difficult to comprehend, adding an extra burden on the clinicians involved in their treatment to make sure their expectations are met and ultimately achieve treatment success.
(Meaney et al., 2012, O’Keeffe et al., 2016). Although, studies have investigated the expectations of orthodontic and restorative dental patients separately, to our knowledge, no previous study has investigated the expectations of patients affected by hypodontia regarding the process and outcome of their combined orthodontic / restorative treatment. Furthermore, there is a paucity of studies within the dental field investigating the effects of providing different forms of patient information material on expectations of the treatment process and outcome but particularly pertaining to the effects of interactive computer-based information material.

The specific purpose of this research was to develop a hypodontia treatment expectation questionnaire (HTEQ) that measures the participants’ expectations of the process and outcome of combined orthodontic / restorative treatment as well as a hypodontia specific interactive computer-based education material (ICB-EM) about the condition and treatment of hypodontia. These materials were used to conduct a randomised controlled trial to measure the effects of provision of an ICB-EM on the patients’ expectations of the process and outcome of their combined treatment.

1.2 Overview of the Research

The ultimate goal of the research was to improve information delivered to hypodontia patients regarding their condition and its’ treatment by understanding their expectations. A mixed method study design was adopted in order to achieve the aims of the study. The study provided an insight into the expectations of hypodontia patients regarding the process and outcome of the combined orthodontic / restorative treatment they are yet to receive. In addition, the effects of providing hypodontia specific information via interactive computer-based software on the patients’ expectations of the process and outcome of their combined treatment was compared to the traditional paper leaflet in addition to measuring their perceived acceptability of the form of patient information they received.
1.3 Research Aims

The aims of this research were to:

1. To develop a HTEQ that measures the hypodontia patients’ expectations of the process and outcome of their combined orthodontic and restorative treatment.

2. To develop an ICB-EM specifically for patients affected by hypodontia.

3. To conduct a randomised controlled trial comparing the effect of information delivery through the ICB-EM to a paper leaflet on the expectations of the process and outcome of treatment among hypodontia patients using the HTEQ and to compare patients’ acceptability of methods of information delivery using the treatment evaluation inventory (TEI).

To achieve these aims, three processes were used (see Figure 1.1).
Figure 1.1 Framework for the proposed studies of the current thesis.
Study One: A Qualitative Study of Hypodontia Patients’ Information Needs and their Perceptions of the Process and Outcome of Care

In this study, a qualitative exploratory descriptive design was adopted to describe the information needs and perceptions of hypodontia patients regarding the process and outcome of their combined orthodontic and restorative treatment through semi-structured interviews. This was then used to develop both the HTEQ and ICB-EM. The interviews were conducted with three groups of patients at different stages in their treatment journey.

Development and Testing of the Research Materials Following Study One

During this stage of the research, the development process of all the materials that were used in Study Two (RCT) was described in detail. These materials were the HTEQ, the ICB-EM, and the TEI.

Study Two: Impact of Computer-Based Information Provision on Expectations of Treatment Process and Outcome Compared to Clinician Delivered Information: A Randomised Prospective Controlled Trial

This study determined the effects of the ICB-EM on the patients’ expectations of the process and outcome of their combined treatment compared to a standard paper leaflet. The study comprised two groups; the intervention group received the ICB-EM while the control group received a standard British Orthodontic Society (BOS) hypodontia leaflet. Both groups completed the expectation questionnaire at baseline, post intervention, and at 3-4 weeks follow up, as well as the TEI, a measure of treatment acceptability immediately following the intervention to measure their acceptability of the educational material received.
1.4 Structure and Organisation of the Thesis

The thesis is presented in seven chapters and organised as follows:

The current chapter provides an outline of the research including a brief background to the research and its’ significance to clinical practice. The chapter concludes with a description of the overall aims and objectives of the study.

Chapter 2 is divided into two main parts; the first provides a detailed literature review of the condition of hypodontia including its associated syndromes, skeletal and dental features as well as its impact on the oral health related quality of life (OHRQoL) of the affected patients. The chapter also describes the management of hypodontia including the hypodontia care pathway within the UK and the impact the treatment process and outcome has on patients. This provides information on the clinical context of information provision within which any proposed intervention will operate.

The second part provides an overview of the concepts and theories relating to expectations and as there are to date, no previous published studies that have looked into the expectations of the hypodontia patients, a detailed review of the literature on orthodontic and restorative patient expectations in relation to the treatment process and outcome including the effects of patient education in modifying the expectations is provided.

Chapter 3 provides a description of Study One (semi-structured interviews with new, in-treatment, and end of treatment hypodontia patients). The chapter includes the research design, methods used including the recruitment of the participant sample, the data collection process, and, transcription and coding. In addition, the results, and the discussion of the findings are presented. The results obtained from this study informed the content of the HTEQ and the ICB-EM.

Chapter 4 describes the development process of all the material that will be used in Study Two (RCT). The development of the HTEQ and ICB-EM is reported including the process of refining its content in response to feedback obtained from a panel of experts and hypodontia patients. Piloting for both materials is reported in terms of setting, sampling and results. The
process of reliability testing of the HTEQ is also reported in terms of setting, sampling and results.

Chapter 5 presents Study Two, a randomised controlled trial conducted to measure patient expectations of the process and outcome of their combined treatment and the effects of the ICB-EM on these expectations compared to a standard paper leaflet. The participants’ perceived acceptability of the intervention received is also reported. The research design, materials and methods including setting, participants and data collection and data analysis methods are described. In addition, the results in relation to the study objectives are reported followed by a discussion of the main findings and limitations of the study. Reporting will follow the CONSORT guidelines.

Chapter 6 summarises the findings of the study and discusses it in relation to the aims of the research. In addition, the strengths and limitations of the study and the implications for clinical practice in relation to hypodontia patients are highlighted together with recommendations for future research. The chapter concludes by displaying the overall conclusions of the research.
Chapter 2

Literature Review

2.1 Hypodontia and its Management

2.1.1 Definition

The term “Hypodontia” is used to describe patients with developmentally absent primary or secondary teeth, excluding the third molars. Mild and moderate cases have usually less than three and less than six teeth missing, respectively, while severe cases have six or more teeth missing (Goodman et al., 1994, Dhanrajani, 2002, Nunn et al., 2003, Hobkirk et al., 2010). It usually presents complex clinical problems and is considered the most common congenital dental anomaly. Other terminology that may be used include oligodontia “developmentally missing teeth in the presence of systemic manifestations”, and anodontia “congenital absence of the entire dentition” (Hobkirk et al., 2010).

2.1.2 Prevalence

2.1.2.1 Primary Dentition

Previous studies have shown that hypodontia in the primary dentition is relatively uncommon with a prevalence of 0.1-0.9% and an equal distribution between males and females (Järvinen and Lehtinen, 1981, Carvalho et al., 1998, Dhanrajani, 2002, Nunn et al., 2003). Patients who are affected by hypodontia in the primary dentition are often diagnosed with hypodontia in the permanent dentition as well (Daugaard-Jensen et al., 1997, Arte and Pirinen, 2004, Marinelli et al., 2012).

The mandibular and maxillary lateral incisors have been found to be the most common missing teeth in the primary dentition (Järvinen and Lehtinen, 1981, Daugaard-Jensen et al., 1997, Carvalho et al., 1998).
2.1.2.2 Permanent Dentition

Prevalence of hypodontia in the permanent dentition has been reported in retrospective studies with wide variation, however studies conducted on Caucasian populations have shown a prevalence that ranged from 4.0-6.0% with a predominance of hypodontia in females (Polder et al., 2004, Larmour et al., 2005, González-Allo et al., 2012).

The prevalence of severe hypodontia, where six or more teeth are missing is rare and has been reported to range from 0.14-0.3% (Hobkirk and Brook, 1980, Polder et al., 2004). In the meta-analysis carried out by Polder et al. (2004) which looked at 33 studies on the prevalence of hypodontia, the mandibular second premolar was found to be the most frequently missing permanent tooth (3.0%) followed by the maxillary lateral incisor (1.7%) and the maxillary second premolar tooth (1.5%).

2.1.3 Aetiology

Hypodontia can either appear as an isolated non-syndromic condition or as a feature of a syndrome. The condition can run in families but it may also occur without any family history. The exact aetiology of hypodontia is currently unknown but the causes that are thought to be involved are environmental, genetic or of a mixed aetiology.

2.1.3.1 Environmental

The environmental factors that have been shown to play a role in arrested tooth development include local factors such as jaw surgery and fractures as well as extractions of overlying deciduous teeth resulting in iatrogenic damage to the developing permanent tooth germ (Nunn et al., 2003). Drugs taken by mothers such as Thalidomide® (N-phthaloylglutamimide) during pregnancy have shown to be associated with developmentally missing teeth in their children (Axrup et al., 1966). Other environmental factors include chemotherapy (Maguire et al., 1987, Näsman et al., 1997) and radiotherapy (Näsman et al., 1997) during childhood.

Hypodontia is also usually associated with clefts of the lip and palate which is predominantly localized to the maxillary lateral incisor area along the line of the alveolar cleft (Dhanrajani, 2002). Although this was considered as a localized physical obstruction of tooth germ
development, other studies have shown that defects in the Msx1 gene were associated with hypodontia as well as an isolated cleft lip and palate (van den Boogaard et al., 2000, Alappat et al., 2003).

2.1.3.2 Genetic

It is known that the structure and development of the human dentition are tightly controlled by genetics, and a number of twin and family studies have confirmed the role of genetics in the aetiology of hypodontia (Markovic, 1982, Brook, 1984, Kotsomitis et al., 1996). Brook (1984) identified hypodontia as a familial trait with a greater frequency of hypodontia appearing among relatives of probands than in the general population.

Hypodontia has also been shown to occur with no family history as an isolated condition. This has been theorised to be the result of a spontaneous gene mutation (Kupietzky and Houpt, 1995, Dhanrajani, 2002).

A study conducted by Arte and Pirinen (2004) reported that hypodontia occurs through an autosomal dominant process with 86% incomplete penetrance and variable expression. Studies have also observed the relationship between peg-shaped lateral incisors and hypodontia where the former is considered to be a modified manifestation of the same genotypes as hypodontia. This was based on the theory of an underlying continuum of tooth size with thresholds, where the progressive reduction in tooth size reaches a particular threshold whereby the developing tooth germ degenerates resulting in hypodontia (Suarez and Spence, 1974, Bailit, 1975, Brook, 1984, Nieminen, 2009).

Homeobox genes determine the shape and position of teeth, and studies have proposed defects in a number of these homeobox genes to be responsible for or associated with hypodontia, most commonly Msx1, Pax9, and Axin2 (Arte and Pirinen, 2004, Mostowska et al., 2006, Cobourne, 2007, Nieminen, 2009). Each of these genes code for a specific transcription factor regulating downstream target genes. Msx1 and Pax9 interact during odontogenesis and the mutations of these genes results in tooth agenesis in mice and may result in hypodontia in humans (Cobourne, 2007, Nieminen, 2009). In a study carried out on a Finnish family affected by
autosomal dominant oligodontia, linkage analysis identified a candidate region on chromosome 17 containing approximately 80 genes and the AXIN2 gene was selected as the strongest gene for the condition (Lammi et al., 2004, Cobourne, 2007, Nieminen, 2009).

2.1.4 Syndromes and Systemic Conditions

A large number of syndromes have been reported to be associated with hypodontia. Most commonly, ectodermal dysplasia, cleft lip and palate, Van Der Woude syndrome and Down’s syndrome (Nieminen, 2007).

2.1.5 Associated Skeletal Features

Previous studies have shown that patients with congenitally missing teeth often demonstrate different craniofacial morphology when compared to individuals with a normal number of teeth. Some of these features include bimaxillary retrognathism, a Class III skeletal relationship resulting from maxillary retrusion and mandibular prognathism as well as an anteriorly positioned chin. The overall anterior face height is reduced due to a forward mandibular growth rotation and an overall decrease in the vertical and transverse dimensions of the dental arches (Woodworth et al., 1985, Nodal et al., 1994, Bondarets and McDonald, 2000).

2.1.6 Associated Dental Anomalies

2.1.6.1 Tooth Size and Shape

It has been generally agreed that hypodontia is often associated with smaller sized or microdont teeth and patients affected with severe hypodontia may also demonstrate conical or tapered incisal edges (Hobkirk and Brook, 1980, Brook, 1984, Goodman et al., 1994). This feature may result in spacing between the teeth and sometimes rotations and displacement of the adjacent teeth.

Another feature which may be associated with hypodontia is taurodontism whereby the tooth suffers from an enlarged and an elongated pulp chamber which extends vertically down to the roots. The most commonly affected teeth are the mandibular molars (Lai and Seow, 1989).
2.1.6.2 Ectopic Eruption

Hypodontia is commonly associated with ectopic eruption of the permanent teeth and studies have shown a strong association between congenitally missing or diminutive lateral incisors and ectopic canines. This has been explained by a lack of guidance by the roots of the adjacent teeth during the eruption process due to their absence (Becker et al., 1981, Peck et al., 1998). This may result in an aesthetically unsatisfactory appearance as a result of spacing between the teeth as well as shifting of the remaining teeth into inappropriate positions. Where the teeth are ectopic and have not erupted, surgical exposure may be required to assist the eruption process.

2.1.6.3 Delayed Eruption and Development

Studies have shown that delayed eruption and development of the permanent dentition is associated with hypodontia, even though the exact aetiology behind this is unknown (van der Weide et al., 1993, Dhanrajani, 2002).

2.1.6.4 Retention of Deciduous Teeth and Ankyloses

In cases where a permanent tooth is congenitally missing, the normal resorption process of the primary predecessor root is often delayed and in some of the cases the tooth may become ankylosed and infra-occluded (Haselden et al., 2001). With time the tooth may gradually appear more and more in infra-occlusion, and in some cases may lead to it being completely covered with gingivae (Antoniades et al., 2002). If this occurs, then there will be an increased risk of occlusal disturbances such as tipping of adjacent teeth or over eruption of the opposing teeth. Also, the alveolar bone may fail to develop, in which case, treatment should be planned early with a combined orthodontic and restorative assessment to consider the potential treatment options (Sidhu and Ali, 2001).

2.1.6.5 Lack of Alveolar Development

Patients who present with hypodontia may also suffer from a lack of alveolar bone development. This may be localized to a specific area of the alveolar bone where the tooth is missing, or it can be generalized to the whole alveolar process including the areas where teeth are present. In this case the affected patient may appear older due to a more protruded mandible
and prominent lips giving an edentulous appearance. These patients may also suffer from an increased freeway space which may have an effect on appearance, speech, and mastication (Gravely and Johnson, 1971).

2.1.7 Impact of Hypodontia on Oral Health Related Quality of Life (OHRQoL)

As mentioned earlier, there are a number of skeletal and dental features associated with hypodontia, and these factors could have a great impact on the lives of the affected patients. Table 2.1 displays all the studies that have investigated the impacts of hypodontia on the OHRQoL. Most of these studies used the Oral Health Impact Profile (OHIP) or the Child Perception Questionnaire (CPQ). Patients were significantly affected functionally, emotionally and psychosocially (Wong et al., 2006, O’Brien et al., 2007, Locker et al., 2010, Kotecha, 2012, Hashem et al., 2013, Anweigi et al., 2013a, Anweigi et al., 2013b, Heads, 2016). These findings are in contrast with those revealed by Laing et al. (2010) who did not find any differences between a group of hypodontia patients and a group of routine orthodontic patients. They did however find that the hypodontia patients had more difficulty in chewing when the deciduous teeth associated with the missing permanent teeth exfoliated. They concluded that the psychosocial status of the hypodontia group was not affected as compared to other malocclusion traits. Hobkirk et al. (1994) reported in their retrospective study that looked into the concerns of 451 hypodontia patients, that dissatisfaction with appearance was a major concern due to the presence of gaps between the teeth whereas functional problems were reported by only 8.7% of the participants.

Some of these studies found that gender was a significant predictor of OHIP-49 with females being more affected (Anweigi et al., 2013a, Heads, 2016). In addition, being older and social deprivation were found to be correlated with lower OHRQoL (Heads, 2016). The location of the missing teeth was also found to be a predictor of psychological discomfort (Anweigi et al., 2013a). Wong et al. (2006) revealed that the number of missing teeth was moderately correlated with OHRQoL and when taking into account retained deciduous teeth, the number of missing
teeth become highly correlated with OHRQoL highlighting the importance of retained deciduous teeth in children with severe hypodontia.

Other studies used qualitative methodologies to investigate the perceptions of the hypodontia patients about their condition. Meaney et al. (2012) who conducted semi-structured interviews on patients aged 16-25 with hypodontia, found that participants thought that the primary motivating factor for treatment was to gain the ‘cosmetic look’ in order to become less self-conscious and more comfortable with the social surroundings. These patients also mentioned that as they became older, they became more conscious of their physical appearance and development of their teeth and felt the need to modify their behaviour to conceal their teeth. This is in agreement with a previous study that explored the experiences of young people with their orofacial conditions as they transitioned from primary to secondary education through qualitative interviews. The sample included patients with untreated caries, cleft lip and palate, traumatic injuries to upper incisors and developmental defects of enamel and hypodontia. Some of the participants reported that they had developed concerns about aspects relating to their appearance around the time of transition as a result of their desire to gain approval from their peers (Marshman et al., 2009).

Akram et al. (2011) conducted five focus groups on 22 hypodontia patients aged 11-18 years to identify issues of importance to hypodontia patients with the aim of developing a hypodontia specific quality of life measure. The patients reported difficulties in specific daily activities such as tooth brushing, eating, speech, sports and playing musical instruments. Appearance was also a major concern due to the presence of gaps and smaller than average size of natural teeth. They also reported incidences of bullying by their peers in school. Bullying has become a very common problem among school children and bullies tend to focus on a specific feature of a victim considering it a weakness (Hawker and Boulton, 2000). In the case of hypodontia, spacing between the teeth may be an obvious focus for bullies and the parents of the victims tend to insist on treatment on this basis (Gill et al., 2008). A similar study was conducted more recently by O’Keeffe et al. (2016) who interviewed 20 hypodontia patients to understand their experiences of the hypodontia care pathway following the completion of orthodontic treatment
and before commencing the prosthodontic part of their treatment. One of the themes identified from the interviews was the ‘impact of the original malocclusion’ on the hypodontia patient, where the majority of the participants did not like the appearance of their teeth due to the presence of the gaps as well as the shorter and darker retained deciduous teeth compared to the rest of the permanent teeth.
Table 2.1 Studies investigating the impacts of hypodontia and its treatment on the OHRQoL of the effected patients.

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Sample size</th>
<th>Age and gender</th>
<th>Study Design</th>
<th>Measure and Outcome</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>O’Keeffe et al</td>
<td>2016</td>
<td>20 hypodontia patients post orthodontic treatment</td>
<td>16-47 years 14M 6F</td>
<td>Qualitative</td>
<td><strong>Measure</strong>: Semi-structured interviews&lt;br&gt;&lt;br&gt;<strong>Outcome</strong>: Patients’ experiences of the hypodontia care pathway at key stages: specifically, patient expectations/experience following the diagnosis of hypodontia. Patient satisfaction with the orthodontic care received and the outcome at the end of active orthodontic treatment.</td>
<td>Four main themes were identified: perceptions of treatment, impact of the original malocclusion and the treatment process, the care team and communication. Positive feedback was received and the importance of patient–clinician rapport was highlighted in all interviews. The main areas that could be enhanced related to the importance of ensuring optimum communication, particularly with a cohort of patients who are often undergoing complex multidisciplinary treatment.</td>
</tr>
<tr>
<td>Heads Unpublished MSc thesis</td>
<td>2016</td>
<td><strong>Group 1</strong>: 71 hypodontia patients&lt;br&gt;<strong>Group 2</strong>: 15 friend control&lt;br&gt;<strong>Group 2</strong>: 999 age matched control derived from 2009 adult dental health survey (ADHS)</td>
<td>16-30 years&lt;br&gt;<strong>Group 1</strong>: 42.3%M 57.7%F&lt;br&gt;<strong>Group 2</strong>: 33.3%M 66.7%F&lt;br&gt;<strong>Group 3</strong>: 44.8%M 55.2%F</td>
<td>Cross-sectional</td>
<td><strong>Measure</strong>: Oral Health Impact Profile 14 (OHIP-14), OHIP-49 questionnaire.&lt;br&gt;&lt;br&gt;<strong>Outcome</strong>: Evaluate the psychosocial impact of tooth agenesis in adults and investigate the effect of sex, age, ethnicity, social deprivation, severity of tooth agenesis and presence of retained deciduous teeth on OHRQoL.</td>
<td>Participants with tooth agenesis had significantly higher total OHIP-14 in all domain scores, in comparison to the ADHS control. In comparison with the friend-control, participants with tooth agenesis had significantly higher scores in total OHIP-49 in all domains except physical pain and handicap. Lower OHRQoL was associated with being female, of an older age and increased social deprivation.</td>
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<tr>
<td>Study</td>
<td>Year</td>
<td>Sample Description</td>
<td>Age</td>
<td>Gender</td>
<td>Study Design</td>
<td>Measure</td>
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<tr>
<td>Hashem et al</td>
<td>2013</td>
<td>41 moderate to severe hypodontia, 27 amelogenesis imperfecta (AI), 68 control group (routine dental care).</td>
<td>18-45 years</td>
<td>29F 12M for Hypodontia, 19F 8M for AI</td>
<td>Cross-sectional</td>
<td>OHIP-49, Rosenberg self-esteem scale</td>
</tr>
<tr>
<td>Anweigi et al</td>
<td>2013a</td>
<td>82 hypodontia patients (mild/mod/severe)</td>
<td>16-34 years</td>
<td>43F 39M</td>
<td>Cross-sectional</td>
<td>OHIP-49</td>
</tr>
<tr>
<td>Anweigi et al</td>
<td>2013b</td>
<td>Test group (40) post orthodontic treatment, tooth spaces restored with resin bonded bridge. Control group (42) in treatment.</td>
<td>16-34 years (median 19)</td>
<td>43F 39M</td>
<td>Before/after</td>
<td>OHIP-49 prior to treatment, follow-up OHIP-49</td>
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<tr>
<td>Study</td>
<td>Year</td>
<td>Sample Description</td>
<td>Age</td>
<td>Gender</td>
<td>Study Design</td>
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<tr>
<td>Kotecha et al</td>
<td>2012</td>
<td>86 children with mild to moderate hypodontia</td>
<td>11-14 years</td>
<td>36M 50F</td>
<td>Cross-sectional</td>
<td>CPQ, Parental-caregiver perception questionnaire.</td>
</tr>
<tr>
<td>Akram et al</td>
<td>2011</td>
<td>22 hypodontia patients five focus groups</td>
<td>Average 12.6 years 11-16 years</td>
<td>Gender: N/S</td>
<td>Qualitative</td>
<td>Focus group interviews</td>
</tr>
<tr>
<td>Meaney et al</td>
<td>2012</td>
<td>10 hypodontia patients (mild/mod/severe)</td>
<td>16-25 years</td>
<td>5M 5F</td>
<td>Qualitative</td>
<td>Semi structured interviews</td>
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<tr>
<td>Study</td>
<td>Year</td>
<td>Sample Description</td>
<td>Mean Age</td>
<td>Measure</td>
<td>Outcome</td>
<td>Findings</td>
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<td>Laing et al</td>
<td>2010</td>
<td>123 children, Hypodontia (n=62), Routine orthodontic patient IOTN 4 or 5 (n=61)</td>
<td>13.6 SD 1.6y</td>
<td>Cross-sectional</td>
<td>Hypodontia: n=62, 35% M 27% F, Non hypodontia: n=61, 26% M 35% F</td>
<td>There were no statistically significant differences between the hypodontia and the routine orthodontic groups. Difficulty with chewing was associated with severity of hypodontia. Hypodontia did not affect the psychosocial status of patients any more than other features of a malocclusion. Patients have more difficulty chewing when deciduous teeth associated with the missing teeth had been exfoliated.</td>
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<tr>
<td>Locker et al</td>
<td>2010</td>
<td>36 hypodontia patients (1-14 missing teeth)</td>
<td>11-14 years</td>
<td>Cross-sectional</td>
<td>Measure: CPQ (functional and psychosocial impact of oral disorders).</td>
<td>Over three-quarters of the participants experienced one or more functional and psychosocial impacts. Hypodontia children have worse OHRQoL than children with dental decay and malocclusion, but better OHRQoL than children with orofacial conditions.</td>
</tr>
<tr>
<td>Marshman et al</td>
<td>2009</td>
<td>17 participants (untreated caries, cleft lip and palate, traumatic to upper incisors, developmental defects of enamel, hypodontia)</td>
<td>11-12 years</td>
<td>Qualitative interview and diary study</td>
<td>Measure: Completed a two-week diary during transition and interviewed about the diary.</td>
<td>Themes: 1. Changes in school environment 2. Changes in social interaction with peers and friends 3. Concerns about own appearance (for some young people these were about orofacial conditions). No links between gender, severity of condition and experiences of school were apparent. Transition to secondary education affected young people to varying degrees.</td>
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<tr>
<td>Study</td>
<td>Year</td>
<td>Sample Description</td>
<td>Sample Characteristics</td>
<td>Measure</td>
<td>Outcome</td>
<td>Findings</td>
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<td>O'Brien et al</td>
<td>2007</td>
<td>116 patients presenting with crowding, overjet or hypodontia</td>
<td>Group 1: 11-14 years</td>
<td>Cross-sectional</td>
<td>Measure: CPQ, including global ratings of oral health and satisfaction.</td>
<td>Adolescents with malocclusion had a significantly higher total CPQ score, and hence worse OHRQoL compared to a non-malocclusion group, specifically social and emotional well-being. Patients in the hypodontia group showed a significant correlation with the emotional subscale only.</td>
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<td>Group 2: 31 patients with IOTN 1 and 2, and DMFT ≤2, with no history of orthodontic treatment.</td>
<td>Group 1: 11-14 years</td>
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<td>Outcome: Explore the validity and reliability of the CPQ as an OHRQoL measure in adolescents with malocclusion.</td>
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<td></td>
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<td>Group 2: 11-14 years</td>
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<td>Total CPQ scores and responses in the four domains. Self-perceived AC scores and responses to global rating of oral health, life overall and satisfaction rating were recorded.</td>
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<td>41.4%M 58.6%F</td>
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<td></td>
<td>There were no significant correlations between any of the total or sub-domain CPQ scores and the patient-determined aesthetic component, with the exception of the emotional subscale in the hypodontia group.</td>
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<td>48.4%M 51.6%F</td>
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<td></td>
<td></td>
<td></td>
<td>Cross-sectional</td>
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<tr>
<td>Wong et al</td>
<td>2006</td>
<td>25 patients with severe hypodontia</td>
<td>11-15 years (mean 13.5; SD 2.7)</td>
<td>Cross-sectional survey</td>
<td>Measure: CPQ</td>
<td>Participants with severe hypodontia report considerable OHQOL impact. The number of missing permanent teeth was moderately correlated with OHQOL. However, when retained primary teeth were taken into account, the number of missing teeth was highly correlated with OHQOL.</td>
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<td></td>
<td></td>
<td></td>
<td>16M 9F</td>
<td></td>
<td>Outcome: Assess OHQOL impact among patients with severe hypodontia and to determine the association between OHQOL and the number of missing teeth.</td>
<td></td>
</tr>
<tr>
<td>Hobkirk et al</td>
<td>1994</td>
<td>451 hypo patients</td>
<td>Not stated</td>
<td>Cross-sectional survey</td>
<td>Measure: Not stated</td>
<td>The most common complaints were missing teeth, spacing in the dental arches, and poor appearance.</td>
</tr>
</tbody>
</table>
2.1.8 Management of Hypodontia

It can be inferred from the above table that the psychosocial, functional, and dental impacts of hypodontia can be very complex and difficult to manage especially in severe cases. The treatment of hypodontia usually requires a multidisciplinary approach, involving general dental practitioners, specialist paediatric, orthodontic and restorative dentists together with oral surgeons. Treatment options vary depending on the severity of the condition (Jepson et al., 2003). Closing spaces arising from missing teeth using orthodontic treatment is the preferred option if available; long term maintenance of this option is considered low compared to restorative options. However, this solution is sometimes not achievable or desirable for aesthetic or functional reasons. Opening or redistributing edentulous spaces in preparation for replacement using either fixed or removable prostheses or implant-retained restorations is often the treatment of choice. Missing single teeth in the anterior dentition are often replaced using minimally-invasive adhesive bridges. In a partially dentate patient, implant placement is usually delayed until facial growth is complete and this may differ between males and females.

The decision to close, open or accept the spaces is dependent upon a number of factors which include:

- The age of the patient: interceptive treatment and elective extractions of deciduous teeth may help in spontaneous closure of the spaces when the permanent teeth erupt facilitating orthodontic treatment in the future (Carter et al., 2003).

- Severity of hypodontia: as the number of missing teeth increases, the ability to close the spaces orthodontically decreases and therefore, the aim would be to redistribute the position of the teeth orthodontically into more favourable positions facilitating future prosthetic replacement (Bergendal et al., 1996, Carter et al., 2003).

- Degree of crowding: if the patient presents with a non-crowded dentition then the space could either be accepted or restored prosthetically depending on the patient’s wishes and the clinician’s discretion. In cases where the primary tooth is retained and in good condition, it could be left in situ potentially preserving the alveolar bone.
However, in cases where the patient presents with crowding of the dentition, and space is required to accommodate and align the permanent teeth, then it may be logical to close the spaces of the missing teeth allowing the rest of the permanent dentition to align (Carter et al., 2003).

Managing hypodontia can incur a lifetime of treatment, and frequently cannot be managed completely by early intervention. In order to produce the best possible outcomes, longitudinal treatment planning, which includes a combination of active and long-term maintenance phases is required. Therefore, the clinical team involved in the treatment of such cases must possess the necessary skills to provide treatment plans with a clear anticipation of current and future needs of the patient (Hobkirk et al., 2010).

2.1.9 Hypodontia Care Pathway

The complex and multidisciplinary nature of hypodontia care suggests that providing this treatment through a single healthcare professional or specialty is not logical. Integrated care is therefore arguably best delivered by an experienced team of specialist dentists ideally working together within a dedicated facility together with the outside support of the patient’s general dental practitioner. The benefits of providing treatment through a hypodontia multidisciplinary clinic have been reported in the literature (Meaney et al., 2012, Tams and Ashley, 2013, O’Keeffe et al., 2016, McSwiney et al., 2017). To our knowledge, the first hypodontia clinic to be developed was in 1977 by the Eastman Dental Institute, London, after which it has been considered the gold standard for the clinical care of patients when the required resources are available (Hobkirk et al., 2010). At Guy’s and St Thomas’ NHS Foundation Trust, there is also a dedicated clinic for multi-specialist care of patients with hypodontia, and clinicians attending this clinic include orthodontists, restorative dentists, paediatric dentists, oral surgeons (implantology), prosthodontists, dental nurses and specialty trainees.

According to Hobkirk et al. (2010), the role of the hypodontia team during the clinic should be to diagnose and develop an interdisciplinatory treatment plan, patient and parent / carer counselling as well as educating the specialty trainees. The clinic at Guy’s and St Thomas’ NHS
Foundation Trust often has in excess of fifteen patients attending on average and during the assessment and exam, the clinician is required to know which specialties are likely to be involved in the treatment, come to a combined preliminary treatment plan and subsequently explain this plan and its implications to the patient, parent / guardian as well as the possible alternative treatment options. This could be challenging during a busy clinic because different specialists may be examining patients at the same time and often one clinician has to take a leading role in bringing all the necessary specialist clinicians together, which may extend the examination time. For the patient and any accompanying parent or carer, being surrounded by several clinicians at once, could possibly be viewed as an intimidating situation that may discourage questions from the patient. To overcome this, one senior clinician therefore makes the decision to explain to the patient the results of the examination, discuss any possible options and encourage questions and feedback from the patient and any accompanying parent or carer.

Figure 2.1 illustrates a typical referral pathway with all of the possible management routes within, or coordinated through a hypodontia clinic. The patient can be referred to the hypodontia clinic by a general dental practitioner (GDP), a specialist practitioner or from a hospital based medical or dental specialist. In cases where the referring clinician requests a treatment plan only, then the hypodontia team will devise a care pathway for treatment that can then be organised by the GDP who may for example arrange for the orthodontic or restorative components of the care to be completed by a local orthodontist and/or restorative specialist. Alternatively, the hypodontia team may carry out the orthodontic treatment after which they may refer the patient back to the GDP to complete the intermediate and/or definitive restorative treatment. In more severe cases, the hypodontia team may offer to provide the entire treatment (Barkhordar et al., 2000, McSwiney et al., 2017).

In cases of referrals from a local orthodontist, the hypodontia team may form a treatment plan for the orthodontist to implement who then refers the patient to the GDP, a local restorative specialist or hypodontia team to provide the restorative treatment. Likewise, a restorative specialist may refer the patient to the hypodontia team requesting the provision of the orthodontic treatment before delivering the final restorative treatment. Maintaining clarity as to
where the responsibility lies for the overall plan and its various elements is of utmost importance. It is also essential that the treatment is provided in a flexible way reflecting the individual needs of the patients, enabling the maximum use of the available resources and increasing the chances of patient satisfaction by improving their experience with their treatment process and outcome (Hobkirk et al., 2010).

![Figure 2.1](image_url) The hypodontia patients’ referral pathway adopted from Hobkirk et al. (2010).

### 2.1.10 Impact of Treatment Process on the Hypodontia Patient

The complex nature of the treatment may make it difficult for the patients to comprehend and visualise the treatment especially during the diagnostic stages. This may have an impact on patients’ experiences with the process of treatment and satisfaction with the treatment outcome (Meaney et al., 2012, O’Keeffe et al., 2016). Two studies were located that considered the views of the hypodontia patients regarding the process of their integrated care (Akram et al., 2011, Meaney et al., 2012), while one study was located that considered the hypodontia patients’ views of the orthodontic part of their treatment (O’Keeffe et al., 2016). The results of the studies are shown in Table 2.1.

The treatment can be prolonged considerably and requires tremendous commitment from the patient and the family (Akram et al., 2011, Meaney et al., 2012, O’Keeffe et al., 2016). In addition, the treatment duration can sometimes be unpredictable especially in multidisciplinary cases and hence, this should be made clear to the patients from the outset (O’Keeffe et al., 2016). Patients who have undergone combined treatment reported strong feelings of frustrations.
due to the waiting times between the different phases of treatment with some feeling forgotten (Meaney et al., 2012). Furthermore, the prolonged nature of the treatment may affect the recall of information given in the initial consultation. In the study conducted by O’Keeffe et al. (2016) the patients discussed how they were very young at the time of the initial consultation and did not understand, or were not aware of the magnitude of the condition and treatment. Responsibility at that stage lies with the parents to act in the best interests of their child and therefore it is important that there is good communication with both patients and parents.

It is important to note that orthodontic treatment is usually undertaken during an educationally critical period lasting up to two to three years where the patient has to be reviewed at regular intervals. After completion of the orthodontic phase of treatment, these patients may still be required to continue attending the dental clinic for prosthetic replacements and in some cases these patients may have other associated medical conditions, which would also require additional hospital appointments. All of these factors may have a significant impact on the child’s educational status as a result of significant time taken off from school (Hobkirk et al., 1994, Gill et al., 2008, O’Keeffe et al., 2016).

Another potential impact of treatment is cost. Currently in the United Kingdom, the National Health Service funds dental care for children as well as implant related treatment for young adults with missing teeth (Alani et al., 2012). However, in some cases, such as an adult hypodontia patient, the treatment may not be funded which could have a significant impact on the financial situation of that patient. In addition, any time taken off work by family members to accompany the patient may have an effect on finance as well (Gill et al., 2008, O’Keeffe et al., 2016).

In addition to the practical impacts of undergoing treatment for hypodontia, psychosocial impacts have also been reported in the literature. O’Keeffe et al. (2016) reported that although some patients commented positively on their fixed appliances especially when pontics were placed, others reported that fixed appliances negatively affected their confidence. Adults felt more conscious of the appliances with some reporting that they felt it may have impacted on
their ability to get a job, with one patient stating that they did not receive a job offer until after the fixed appliances were debonded.

One way of reducing the practical and psychosocial impacts of the treatment of hypodontia is to enhance the clinician / patient relationship through good quality communication. This was highlighted by O’Keeffe et al. (2016) who found that patients tended to believe that good communication led to good clinical care, and that by including them in the decision-making process throughout the treatment led them to feeling ‘empowered’ and enhanced their satisfaction with the care they had received. They concluded that a patient information material specific to the hypodontia patient depicting the typical care pathway for treating hypodontia patients would be beneficial in reducing the negative impacts of treatment.

2.1.11 Impact of Treatment Outcome on OHRQoL

Table 2.2 displays all the studies located by the researcher that investigated the impact of treatment outcome on the lives of the affected patients. A systematic review conducted by (Filius et al., 2016) reported that the majority of the hypodontia outcome studies focused on implant treatment only, even though other forms of tooth replacements such as resin bonded bridges are very commonly used for this group of patients. Only one study was located that partly aimed to investigate the hypodontia patients’ satisfaction with the outcome of orthodontic treatment received (O’Keeffe et al., 2016).

In the study conducted by O’Keeffe et al. (2016), the participants reported being satisfied with the outcome of their orthodontic treatment as the gaps had disappeared, improving their appearance which led to increased self-confidence and the ability to smile more confidently.

Stanford et al. (2008) evaluated patient specific outcomes and satisfaction after receiving dental implants in a population affected with Ectodermal Dysplasia. 109 participants were included in the study who reported several complications including infection, mechanical problems and implant loss. However, the majority reported satisfaction with the outcome. This is in agreement with a study conducted by Goshima et al. (2010) who also revealed that patients’ satisfaction with implant supported prostheses was high and experienced a significant overall improvement
in their OHRQoL. They reported that the treatment resulted in higher bite force, increased masticatory ability and performance. However, as these values corresponded to values in participants with complete dentitions, the functional importance of the increase may be questioned.

Similar results were found by Zou et al. (2014) who evaluated the oral function rehabilitation in 25 patients with hypohydrotic ectodermal dysplasia who received implant supported prostheses based on bone augmentation. They reported that the patients expressed high degrees of satisfaction with their facial contours, comfort with the implant-supported prostheses, masticatory function, and pronunciation ability.

Fewer studies have investigated patients' perceptions of other forms of restorative treatment not focusing solely on implant supported restorations. Dueled et al. (2009) investigated the subjective perception of 129 orally rehabilitated hypodontia patients who had received implant or tooth supported reconstructions. They concluded that a better aesthetic outcome and satisfaction was obtained with implant supported reconstructions than with tooth supported reconstructions. Anweigi et al. (2013b) assessed the impact of restoring tooth spaces with resin bonded bridgework on the quality of life of 82 patients with hypodontia as compared to their quality of life before treatment. They found that the pre- and post treatment changes were moderate to large and concluded that provision of resin bonded bridges has a positive impact on OHRQoL of patients with hypodontia.
Table 2.2 Studies investigating the impact of treatment process on the hypodontia patient

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Sample size</th>
<th>Age and gender</th>
<th>Study Design</th>
<th>Measure</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Filius et al</td>
<td>2016</td>
<td>21 eligible studies</td>
<td>N/A</td>
<td>Systematic literature review</td>
<td>Medline, Embase and the Cochrane Central Register of Controlled Trials were searched. To be included, studies had to describe dental treatment outcome measures in patients with severe hypodontia. The methodological quality was assessed using MINORS criteria. Twenty-one studies were eligible, seventeen studies had a retrospective design; sixteen studies described the results of implant treatment. Treatment with (partial) dentures, orthodontics, fixed crowns or bridges was sparsely presented in the eligible studies. Implant survival, the most frequently reported treatment outcome, ranging from 35.7% to 98.7%, was influenced by ‘location’ and ‘bone volume’. Due to heterogenic presentation, its low prevalence and the poor quality of the studies, evidence-based decision-making in the treatment of severe hypodontia is not yet feasible.</td>
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</table>
| Zou et al   | 2014 | 25 hypohydrotic ectodermal dysplasia (HED) patients. With >5 missing teeth | >16 years Gender: N/S | Prospective Longitudinal study                   | Measure: N/S  
Outcome: Follow-up evaluations were initiated from the time of implant prosthetic placement and scheduled annually for 3-5 years. The effects of oral function reconstruction were assessed based on the cumulative survival and success rates of implants, the health of the peri-implant area, and the degree of patient satisfaction.  
Twenty-five HED patients received 169 conventional implants and 10 zygomatic implants. During 3-5 years, 5 of the implants failed and 3 were removed. The 3-year success and cumulative survival rates were 97.2% and 98.3%. Periodontal probing and radiographic assessments showed that the 3-year incidence of peri-implantitis was 4.5%. Patients expressed high satisfaction with facial contours, masticatory function, pronunciation ability, and comfort with the implant-supported prostheses. Oral function of HED patients can be effectively reconstructed using bone augmentation and implant-supported prostheses; however, long term studies are warranted. |
<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Test Group</th>
<th>Control Group</th>
<th>Measure</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anweigi et al</td>
<td>2013b</td>
<td>Test group (40) post orthodontic treatment and tooth spaces restored with resin bonded bridges.</td>
<td>Control group (942) in the process of orthodontic treatment.</td>
<td>OHIP-49 prior to treatment. Follow-up OHIP-49</td>
<td>The primary outcome was the impact of hypodontia on OHRQoL. Assess the impact of restoring tooth spaces with resin bonded bridgework on QoL. Between and within group comparisons were made. 43 patients had more than 4 congenitally missing teeth and 39 had ≤4 congenitally missing teeth. For the test group, there was a significant improvement in median OHIP summary scores after treatment. OHIP scores deteriorated to a significant degree for the control group. The effect sizes for the pre–post treatment change in both groups were moderate to large. Hypodontia has a significant impact on oral health related quality of life. Provision of resin-bonded bridges has a positive impact on oral health related quality of life of patients with hypodontia.</td>
</tr>
<tr>
<td>Dueled et al</td>
<td>2009</td>
<td>Test group: 129 patients receiving implants or tooth-supported reconstructions.</td>
<td>Control group: 58 patients visiting a private practitioner for check-up.</td>
<td>Professional objective assessment: clinical parameters, biological variables with x-rays and aesthetic index score. Subjective and oral health variables (OHIP-49).</td>
<td>To describe the objective measure and subjective perception of oral rehabilitation in patients with tooth agenesis. Patients with tooth agenesis had a high risk of severe root resorption after orthodontic treatment. A better aesthetic outcome was obtained with implant-supported reconstructions than with tooth-supported reconstructions. A positive but not significant correlation was observed between the professional and patient-based evaluations of aesthetic outcomes.</td>
</tr>
<tr>
<td>Goshima et al</td>
<td>2010</td>
<td>18 hypodontia patients with 1-9 missing teeth. All were treated with 1-4 implant supported single crowns (ISSC).</td>
<td></td>
<td>Clinical assessment, OHIP-49, Mastication index. T1= after implant placement before crown cementation T2= one month after cementation</td>
<td>To investigate whether and how treatment with ISSC affects masticatory function and OHQoL in participants with tooth agenesis. Replacement of 1-4 missing teeth, mainly premolars, with ISSCs was associated with development of higher bite force, increased masticatory ability and performance. Also, the OHRQoL was improved 1 month after crown cementation. Patients with tooth agenesis may benefit from this type of treatment, both on subjective and objective levels.</td>
</tr>
</tbody>
</table>
| Stanford et al | 2008 | 109 individuals with various forms of ectodermal dysplasia. | Cross sectional survey | **Measure:** Self-reported survey instrument.  
**Outcome:** Evaluate patient satisfaction, outcomes, and potential complications using dental implants. | Affected individuals receiving tooth replacement therapy with dental implants reported satisfaction with the outcome. A higher level of complications, including infection, mechanical problems, and implant loss, relative to the unaffected population was reported. |
2.2 Patient Expectations

2.2.1 Definition

It is agreed in the literature that a clear and single definition of patient expectations within a healthcare setting does not actually exist. The term “patient expectations” can be better defined within a typology (Newton and Cunningham, 2013).

2.2.2 Taxonomy of Expectations

The first type of expectations reported in the literature is the “ideal” expectation, where an idealistic state of belief drives the person to visualise or expect a preferred outcome. Although the person may believe that the chances of meeting this ideal expectation are low, he/she would be very satisfied if they were to be achieved. The second type is “predicted” expectation, which can be described as any realistic experience or outcome a person may anticipate will happen.

The third type is termed “normative” that develops as a result of social norms, be they societal, familial or any other social group. It is an expectation that a person is positive about will happen such as expecting to see a dental chair in a dental clinic. The fourth and final type of expectations is termed “unformed” that occurs when the person is not particularly able or willing to articulate their expectations which may be a result of no expectations held by the person, difficulties in expressing the expectation, or due to fear or anxiety preventing them from expressing their feelings. This type of expectation is common among patients seeking healthcare because new users may not hold prior knowledge or experience that would help shape their expectations and the actual experience of the treatment would help unfold and develop these expectations (Thompson and Sunol, 1995, Newton and Cunningham, 2013).

Each of these expectations can be subdivided further into expectations of treatment “process”, meaning the steps and procedures involved to achieve the treatment, and, the expectations of treatment “outcome”, meaning the benefits expected to be achieved as a result of the treatment (Newton and Cunningham, 2013).
2.2.3 Models of Patient Expectations

2.2.3.1 Kravitz’s Conceptual Model of Patient Expectations and Requests

This model was developed by Kravitz (1996) in an effort to explain the relationship between the patients’ symptoms, their expectations and their evaluations after receiving medical care (see Figure 2.2). The model illustrates the centrality of the patients’ expectations being placed between the symptoms of the patients and their evaluation of care. The patients’ expectations are largely affected by the patients’ perceptions of the acquired illness both in the cognitive and emotional states. The model also shows that the patients’ expectations are influenced by their perceived vulnerability to the illness, past experience with healthcare and acquired knowledge by changing their interpretations of the symptoms and developing an implicit standard of care.

During a medical encounter, the patients evaluate the service received from the beginning of the encounter and they continue to evaluate the medical encounter even after it has ended where the patient undergoes a comparative process where their beliefs about the probability of an occurrence of ‘expectancies’ and their attitudes to potential occurrence ‘values’ are contrasted with a perceived occurrence. The evaluation may also be a result of a comparison between what was expected and what was actually experienced (Kravitz, 2001).

![Figure 2.2 Conceptual model of patient expectations and requests (Kravitz, 1996).](image-url)
2.2.3.2 Expectancy Disconfirmation Theory

This theory was developed by Richard Oliver (1980) who postulates that by comparing previous expectations with the perceptions of the service or product actually received, the person may develop a sense of satisfaction or dissatisfaction depending on the degree of divergence between the two and the direction of this divergence. ‘Confirmation’ occurs when perceived outcomes and expectations are matching while ‘disconfirmation’ occurs when there is a difference between expectations and outcomes. ‘Negative disconfirmation’ occurs when the resultant outcome is perceived as less than expected while ‘positive disconfirmation’ occurs when the resultant outcome is more or better than what it is expected. ‘Satisfaction’ is the result of either confirmation or positive disconfirmation. The literature revealed mixed views regarding this theory (Carman, 1990, Bolton and Drew, 1991, Babakus and Mangold, 1992). Basically, the disconfirmation model is based on a cognitive process assuming that people entering an exchange relationship carry preformed expectations and eagerness to judge the quality of that relationship (Thompson and Sunol, 1995).
2.2.3.3 The Consumer Model

This model is somewhat similar to the expectancy disconfirmation theory where the patients were considered consumers and applied the theory to health service. The model assumes that patients have pre-formed expectations of their visit to the clinician and measuring the degree of achievement of these expectations is possible (Baron - Epel et al., 2001). Higher satisfaction occurs when the perceived fulfilment of the expectation is higher than the expectation and vice versa (see Figure 2.3). When the patients arrive with high expectations then fulfilment of these expectations becomes more difficult and the chances of lower levels of satisfaction are high, however, when the patient arrives with low expectations, meeting them will be easier and the chances of patient satisfaction is high and according to the model, patient satisfaction is also correlated with the patients reported intention to change physicians (Baron - Epel et al., 2001). However, not many researchers strongly support this model suggesting that any changes in the healthcare system should not only be based on the expectations of the patients (Williams, 1994, Thompson and Sunol, 1995).

![Diagram of the consumer model](image)

**Figure 2.3** The consumer model (Baron - Epel et al., 2001).
2.2.3.4 Cognition-Affect Model of Satisfaction

This model was described by Richard Oliver (1993) in an attempt to integrate attribute experience with existing frameworks showing a composite model that illustrates the relationships between the different components of satisfaction (see Figure 2.4). In this model, the disconfirmation model is positioned in the centre between preformed expectations and attributes performance from one side and the outcome of satisfaction from the other side. The model also shows a direct relationship between attribute performance and satisfaction suggesting it explains more of the variation in satisfaction than disconfirmation which is supported by other authors (Cronin Jr and Taylor, 1992).

The affect domains, both positive and negative, are considered intermediaries between attribute performance, attribution, and satisfaction. The model also shows that equity is a separate contributor to satisfaction. In his study, Oliver (1993) compared people who are intending to buy a car with students attending a course in marketing. It was revealed that the best predictor of satisfaction was disconfirmation and affect for the car buyers and students respectively. For example, the students’ fear of failure in their course may lead to their dissatisfaction. Within the context of healthcare, these results may explain why the disconfirmation paradigm may not be as effective in explaining satisfaction as the affective factors of the model assuming that patients and students have more in common than patients and car buyers.

![Figure 2.4](image.png)

**Figure 2.4** The cognition-affect model of satisfaction (Oliver, 1993).
2.2.3.5 Assimilation-Contrast Model of Perception

This was developed by Anderson (1973) in an attempt to explain the effect of the disconfirmed expectancy theory on satisfaction. This model suggests that when there is only a slight difference between the perceptions of attribute performance and expectations then the individual is likely to displace his/her perceptions towards their expectations ‘assimilation effect’. Conversely, the ‘contrast effect’ occurs when the difference between the perceptions of attribute performance and expectations is large and the displacement is not possible.

Figure 2.5 represents the model, where the horizontal axis represents the objective attribute performance while the vertical axis represents the performance of the perceived attribute. From the model, it can be seen that perception is influenced by the level of expectations represented by the diagonal axis so that when there is a minor difference between them, an assimilation affect will result while a contrast affect will occur when the differences is outside this range (Anderson, 1973).

Figure 2.5 The assimilation-contrast model of perception (Anderson, 1973).
2.2.3.6 Zone of Tolerance Model

This model was proposed by Parasuraman et al. (1991) where they introduced a range between the adequate and desired levels of service provision termed ‘the zone of tolerance’ (Figure 2.6). The model proposes that between the person’s achievable normative expectations and minimum predictable expectations, the perceptions of service provision will be satisfactory to an extent. The model also clearly distinguishes between the expectations of process and outcome contrary to the previous models that consider expectations in terms of outcome only, which makes this model favourable in the context of health care where patients may hold high expectations of outcome and at the same time the expectation is in a much narrower range.

Figure 2.6 The zone of tolerance model (Parasuraman et al., 1991).
2.2.3.7 Assimilation-Contrast Model of Satisfaction

This model was developed by Thompson and Sunol (1995) in an effort to combine the assimilation contrast theory and the zone of tolerance (see Figure 2.7). The author proposes that the objective performance can only be judged in perceptual terms. For example, a relatively objective measure such as waiting time can be evaluated more appropriately by the observer as long / short or acceptable / unacceptable rather than an absolute time, which is subjective. Therefore, the horizontal axis represents the initial perception of attribute performance, and the vertical axis represents the modified perception of attribute performance. After the axes was rotated by $45^\circ$ in a clockwise direction, the resultant horizontal axis was given the label of predicted expectations which was then surrounded with a band. The bands’ upper and lower boundaries represent the achievable normative level and the minimum predicted level respectively. Beyond the zone of tolerance there is an increasingly amplified effect towards high satisfaction in instances where the predicted expectations were found to be well below the initial perceptions. There is an exaggerated effect towards dissatisfaction when the opposite occurs, meaning the predicted expectations are considerably above the initial perceptions of attribute performance.

![Image of the assimilation-contrast model of satisfaction](image)

*Figure 2.7* The assimilation-contrast model of satisfaction (Thompson and Sunol, 1995).
While there are numerous models of the role of patient expectations in healthcare encounters, at their core they share the common assumption that disconfirmation of expectations leads to patient satisfaction. Furthermore, as the models have developed they have sought to explore the role that thoughts, attitudes and values play in mediating the relationship between expectations, their disconfirmation or confirmation, and patient satisfaction. In this thesis I have chosen to adopt the assimilation-contrast model of expectations as the underlying model, since this thesis explores the role that provision of information can modify initial patient expectations, in the way that this model suggests information is either assimilated to reinforce initial expectations or, through contrast, gives rise to modified expectations.

2.2.4 Studies of Patient expectations

It can be discerned from the expectation theories described in the previous section, that expectations of the process or outcome of treatment are highly correlated with patient satisfaction and to achieve success in terms of patient-reported clinical outcomes, understanding and measuring the expectations of patients prior to treatment is critical (Yao et al., 2014).

Linder-Pelz (1982) conducted a study that aimed to identify the expectations and satisfaction of patients attending a primary clinic. 125 new patients were included in the study. It was found that only 8% of patients’ satisfaction variance could be explained by the patients’ expectations, which increased to 10% when the values and perception of the services were included. This meant that expectations had an independent effect on satisfaction irrespective of the patients’ fulfilment. It was concluded that knowledge of patients’ expectations can help ensure patient satisfaction. By gaining knowledge of the patient’s expectations the health provider may be able to alter the process and outcome of a service in order to meet and manage the expectations of the patients (Clow et al., 1995).

It is also important that clinicians establish a rapport with their patients and improve the quality of their communication and any information given in order to enhance patient satisfaction (Mellor and Milgrom, 1995). Studies have shown that the technical competence of the clinician is an important factor in guaranteeing treatment satisfaction and while patients may find it
difficult to evaluate the technical skills of the clinician, they do rely on their evaluation of the interpersonal skills such as empathy, quality of information provided and communication (Corah et al., 1984, Newsome and Wright, 1999, O’Keeffe et al., 2016).

As mentioned in section 2.1, hypodontia has a wide range of impacts on the lives of those affected and the clinical treatment is often very complex, which may make it difficult for clinicians to accurately manage their patients’ expectations. Although the literature search revealed many studies that investigated patient expectations of orthodontics and restorative treatment separately, to date no studies have been found that investigated the combined orthodontic/restorative care of the hypodontia patient. The majority of the studies identified were observational in design. The concept of expectations was not very clear in many of the studies and its definition was rarely discussed. Sometimes, other terms were used interchangeably with the term ‘expectation’ such as ‘motivations’ and ‘needs’, etc. (Tepper et al., 2003b, Pommer et al., 2011a, Pommer et al., 2011b, Hof et al., 2014). Although these terms may sound similar to a layperson and can be used in daily language, they are in fact scientifically very different and can confuse the reader when the concept is not well integrated and defined. As a result of the ambiguous concept of expectations within the studies, the methodologies used and sample types included were very diverse, thereby increasing the risk of bias in the results.

In the following section, all the research relating to the expectations of the process and outcome of orthodontic and restorative treatment will be presented. The search for the literature was similar in its strategy as a systematic literature review. Literature search results originated from Google scholar and Pubmed, and hand searching the reference lists included in the studies. Certain terms were used to identify suitable studies such as patient expectation, treatment expectation, outcome expectation, restorative expectation, orthodontic expectation, patient knowledge, and oral health knowledge. The researcher screened the title and abstract of each citation to determine its relevance after which the full text was retrieved. The following data was extracted and included in the tables: author, year of publication, sample size and characteristics (age and gender), study design, measures used, outcome variables and findings.
2.2.4.1 Expectations of Orthodontic Treatment

The literature search revealed few studies, which directly measured patients’ expectations of orthodontic treatment. Most of the studies identified, explored the patients’ motivations for seeking orthodontic treatment and their expectations of the treatment outcome while significantly fewer studies investigated the patients’ expectations of the process of orthodontic treatment. Table 2.3 displays all the expectations of orthodontic treatment studies identified by the researcher including the sample characteristics and the main findings.

The majority of the studies were quantitative and cross-sectional in nature. Only two prospective cohort studies, two longitudinal and one randomised control trial were found. Very few studies were qualitative in nature and mainly aimed at developing questionnaires although two of the qualitative studies found were purely descriptive.

The parents’ views were taken into account in some of these studies by comparing them to the patients’ views while other researchers investigated the effects of different forms of information on the patients’ expectations. Socio-demographic variables such as ethnicity, age, gender, income / social class, educational level were evaluated in relation to the patients’ expectations in some studies while other studies investigated the relationship between the severity of the malocclusion and the patients’ satisfaction with their dental and facial appearance and their expectations.

Patients Expectations of the Treatment Process

Fourteen studies were located that investigated the patients’ expectations of orthodontic treatment experience as well as its expected impact on the quality of life of the patients. One of these studies was qualitative in nature and included a sample size of 40 patients and their parents (Khan and Williams, 1999), while another study adopted a mixed method study design (Marshman et al., 2016). The rest of the studies were quantitative in nature of which six used an expectation measure that was developed by Sayers and Newton (2006) through qualitative interviews and displayed good reproducibility and internal consistency (Sayers and Newton, 2006, Sayers and Newton, 2007, Hiemstra et al., 2009, Duggal and Bansal, 2010, Nasr et al., 2011, Sadek et al., 2015, Marshman et al., 2016).
Bennett et al. (1997) used the results of qualitative telephone interviews to develop their measure and reported on the psychometric properties of the questionnaire while Zhang et al. (2007) used the CPQ to measure patient expectations on oral health related quality of life during treatment procedures. The remaining studies did not report on how the items of the questionnaires were chosen or the psychometric properties of the measures (Firestone et al., 1999, Pratelli et al., 1996, Thomson et al., 2001, Thickett and Newton, 2006, Souza et al., 2013). The sample sizes reported varied widely between the studies and ranged from 30 to 217 participants with a patient age range from 9 to 39 years with the age range of the majority of the studies falling between 12 and 14 years of age.

The expectancy variables that were investigated within the above-mentioned studies included: the procedures involved during the initial visit; types of treatment; purpose of orthodontic treatment; restrictions on oral function such as eating, speech and playing musical instruments; restriction on oral hygiene; the experience of pain; the duration of the treatment; the frequency of appointments and its effects on life; treatment risks (long and short term); reactions of others; relationship with the clinician and proficiency of the dentist.

The expectations of patients and their primary care-givers have been compared in a number of studies. The first of these was conducted by Sayers and Newton (2007) who found that parents tend to hold more realistic expectations when compared to their children such as their awareness of the dietary restrictions required with treatment. This was then confirmed by a number of studies who found that in general, patients and parents’ expectations do not match, emphasising the importance of communicating with both parents/carers and patients to optimise informed consent and accurate management of expectations (Hiemstra et al., 2009, Duggal and Bansal, 2010, Sadek et al., 2015, Marshman et al., 2016).

The relationship between ethnicity and expectations has also been the focus of some studies such as Khan and Williams (1999) who conducted qualitative interviews with white Caucasian and Pakistani Muslim parents, their children and orthodontists. It was found that Pakistani patients displayed less knowledge regarding the duration of treatment, its impacts on oral health and dietary requirements. They also found that the parents of Pakistani children were less
involved in the treatment conversations due to language barriers, which may result in more pressure being placed on the patients. They concluded that information during the consultation should be tailored to the patients and their parents to ensure their understanding. They also concluded that reducing inequalities to access implies that polices should be in place to support compliance by providing better communication, information and quality of care to families whose first language is not English. This was supported by Sayers and Newton (2007) who investigated 100 patients and their parents and also revealed that ethnicity significantly affected patients’ expectations. They found that the white patient group had more realistic expectations of their initial visit compared to the non-white group. The non-white group also expected to wear headgear and anticipated more pain and dietary restrictions associated with orthodontic treatment and a more positive reaction from other people compared to the white group.

Similar results were found by Hiemstra et al. (2009) who compared the expectations of a Dutch sample with a UK sample using the same questionnaire and found that different health systems could have an impact on patient expectations. This was also identified by Sadek et al. (2015), who concluded that black British and white British patients had different expectations of the initial appointment where black British patients expected to have a brace fitted instead of just a consultation discussion.

Other socio-demographic variables that have been investigated, include; gender and income and their relationship to the expectations of the treatment process. Part of the study conducted by Bennett et al. (1997) was aimed at investigating parents’ and orthodontists’ expected risks of treatment and inconveniences associated with treatment and how these are related to the socio-demographic variables. The study included 220 parents and 220 orthodontists who completed two separate questionnaires that were developed through qualitative interviews. The parents’ questionnaires revealed that parents with a higher income expected more treatment related inconveniences while females expect higher treatment risks reflecting their closer role with their child’s general health. As for the orthodontists, more short-term risks (e.g. breakages and pain) were expected by the younger orthodontists. Other studies on the other-hand compared the
expectations of the male and female patients rather than the parents and found that they were similar (Hiemstra et al., 2009, Nasr et al., 2011).

In a prospective cohort study conducted by Zhang et al. (2007), 217 orthodontic patients with a mean age of 13.1 years completed the CPQ before they started treatment, at 1 week, 1 month, and 6 months after insertion of the fixed appliances. The questionnaire was aimed at measuring Impact of orthodontic treatment on oral symptoms (OS), functional limitations (FL), emotional well-being (EWB), and social well-being (SWB). The impact on OHRQoL following the placement of fixed orthodontic appliances was considerably less than what child patients were expecting. However, when the data was compared across the different time points, it was revealed that OS and FL were significantly less affected than what they expected. EWB and SWB did not have an effect on OHRQoL as was expected.

These results are in contrast to an older prospective cohort study conducted by Firestone et al. (1999), which investigated the relationship between the expected pain and its’ side effects before orthodontic treatment and the reported pain after the placement of the initial arch-wires. The results revealed that the difference between the anticipated levels and the maximum pain levels in the week following arch-wire insertion did not differ significantly. It was also found that patients significantly underestimated the changes they would have to make to their diets in order to counteract the perceptions of pain. Females anticipated more impact of pain on their daily activities compared to males. However, due to the small sample size and the fact that participants were not selected at random, the results should be interpreted with caution. Also, the patients were screened prior to completing the pre-treatment questionnaire, which introduces bias into their responses.

Souza et al. (2013) conducted a retrospective cross-sectional survey to assess expectations of adult patients in relation to orthodontic treatment, as well as to the responsible professional. They found that treatment time was considered within the prediction by 46.7% of the participants. Most participants believed the orthodontist to be a professional concerned about their health and to be more qualified to treat them when compared with the GDP concluding that the relationship between the orthodontist and the patient allows an understanding of the
expectations of orthodontic treatment, resulting in higher motivation and cooperation which can lead to a successful treatment outcome.

**Patients Expectations of the Treatment Outcome**

Twenty-one studies were identified that investigated patients’ expectations of orthodontic treatment outcome. The Sayers and Newton expectation measure was the most widely used by researchers (Sayers and Newton, 2006, Sayers and Newton, 2007, Hiemstra et al., 2009, Duggal and Bansal, 2010, Nasr et al., 2011, Marshman et al., 2016) which as previously mentioned, did report on the process of development and psychometric properties (Sayers and Newton, 2006).

A number of studies used a questionnaire which was originally developed by Kiyak et al. (1988) to assess expectations with regards to orthognathic surgery and was modified to reflect orthodontic treatment (Tung and Kiyak, 1998, Bos et al., 2003, Kiyak, 2006, van Wezel et al., 2015).

Petrone et al. (2003) used a psychometrically validated questionnaire which was developed by Bennett et al. (1997), while Williams et al. (2005) used a questionnaire developed by Travess et al. (2004) to measure the expectations of the process and outcome of orthognathic treatment. In the study conducted by Sheats et al. (1995), a modified version of the psychometrically tested Children Orthodontic Attitude Survey (COAS) developed by Fox et al. (1982) was used. The remaining studies did not report on the psychometric properties of the questionnaires they used (Dorsey and Korabik, 1977, Shaw et al., 1979, McKiernan et al., 1991, Becker et al., 2000, Pabari et al., 2011, Souza et al., 2013, Tuncer et al., 2015).

The sample sizes reported varied widely between the studies and ranged from 46 to 890 participants with a reported patient age range from 7 to 60 years, with the majority of studies falling between 12 and 14 years of age.

The literature review revealed that in the majority of the studies conducted, improving appearance whether dental or facial was the primary motivating factor for undergoing treatment including the desire to straighten the teeth, improve the smile and improve self-confidence (Dorsey and Korabik, 1977, Shaw et al., 1979, Tulloch et al., 1984, McKiernan et al., 1991, Sheats et al., 1995, Tung and Kiyak, 1998, Becker et al., 2000, Williams et al., 2005, Kiyak,
Other expectations of outcome mentioned in the literature, but to a lesser extent, include improving function such as eating, speech and tooth brushing (Shaw et al., 1979, Tung and Kiyak, 1998, Kiyak, 2006, Sayers and Newton, 2006, Duggal and Bansal, 2010), reducing the risk of dental health problems in the future such as caries (Shaw et al., 1979, Bennett et al., 1997, Williams et al., 2005), improving social life (Sheats et al., 1995, Tung and Kiyak, 1998, Becker et al., 2000, Williams et al., 2005, Kiyak, 2006), improving general health and wellbeing (Kiyak, 2006) and finally, achieving occupational success (Dorsey and Korabik, 1977, Shaw et al., 1979).

Parents and patients’ expectations were compared in a number of studies such as the study conducted by Tung and Kiyak (1998) who reported that children's perceived reasons for treatment were consistent with their parents' reports. However, they claimed that parents seemed to expect greater improvement than their children. This disagrees with a number of studies, which found that parents and patients’ expectations were largely similar (Shaw et al., 1979, Sheats et al., 1995, Kiyak, 2006, Hiemstra et al., 2009).

Some authors investigated the effects of ethnicity on the patients’ expectations of treatment outcome. Tulloch et al. (1984), compared the expectations of a UK (Cardiff) sample to a US (Kentucky) participant sample composed of 385 sixth grade children and 123 parents. They found that significantly more Cardiff children rated straight teeth as more important than good hearing, good eyesight, teeth free from cavities, good memory and nice eyes. Hiemstra et al. (2009) and Sayers and Newton (2007) also found differences in expectations where the former reported that Dutch parents did not expect that orthodontic treatment would make it easier to eat and they expected less improvement in social confidence as compared to English parents, while the latter reported that the non-white (white and black Caribbean, Pakistani, Caribbean, African, and Chinese) group had higher expectations of speech improvement as a result of treatment.

Bos et al. (2003) and van Wezel et al. (2015) investigated the impact on patient satisfaction with general facial / dental appearance, and the effect of demographic characteristics on patient
expectations through multiple regression analysis. It was found that the dental-related satisfactions of patients significantly affected their expectations on general wellbeing, their future dental health, in addition to the improvement of their self-image / appearance. These correlations were not affected by gender, but were affected by age. Williams et al. (2005) compared the expectations of males and females and found that females sought treatment to improve self-confidence and their smile while males wanted treatment to improve their social life.

Other demographic variables such as income and educational level, social class, severity of the malocclusion and cost of treatment, and their relationship to patient expectations were studied by a number of researchers including Bennett et al. (1997) who developed two versions of expectation questionnaires, one for the orthodontist and the other for the parents. After obtaining the results of the qualitative interview, pilot test and factor analysis, four factors were yielded: long-term risks; short-term risks; benefits of treatment and inconvenience. The results revealed that the parents’ expectations of the benefits of treatment were highest and related to the family’s income, father’s level of education, and the respondent’s gender. This was further supported by Tuncer et al. (2015) who investigated a sample of 491 patients and 399 parents and found that parents with a higher education level put more emphasis on oral function. Kiyak (2006) and Dorsey and Korabik (1977) also found differences between lower and upper middle class participants with the former expecting greater improvements in their children’s general health and reasoned that this may be due to their significantly greater need for social acceptance and their higher levels of aspiration for their children.

Petrone et al. (2003) used a modified version of Bennett et al.’s (1997) questionnaire and investigated the expectations of 92 patients above the age of 18, three months before the treatment. The associations between cost, malocclusion severity and benefits expectations were analysed. The results revealed that patients’ expectations of the benefits from treatment were significantly associated with the severity of the malocclusion (dental midline and overjet) but not the treatment fees, concluding that it was important to identify patients’ expectations before the treatment as sometimes they may be exaggerated and not related to the treatment outcomes.
**Table 2.3** Studies investigating the patients’ expectations of orthodontic treatment.

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Sample size</th>
<th>Age and Gender</th>
<th>Study Design</th>
<th>Measures and Outcome</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Marshman et al   | 2016 | Phase 1: 10 patients and parents, 23 stakeholders  
Phase 2: 30 patients and 30 parents | Phase 1: 12-16 years  
4M 6F  
Phase 2: Patients were 12-16 years  
13(43%)M  
17(57%)F | Phase 1: Qualitative  
Phase 2: Quantitative quasi-experimental (Pre/post-test) | **Phase 1:** Individual interviews with patients and parents to investigate treatment decision making and inform the content of fixed appliance decision aid (FADA). This was followed by focus groups with expert groups of stakeholders (patients and clinicians) to critique the FADA’s content, structure and utility.  
**Phase 2:** Measure: Demographic questionnaire; Decisional Conflict Scale (DCS); Sayers and Newton expectation questionnaire.  
**Outcome:** Index of multiple deprivation; perception of satisfaction with information provided before and after the FADA; patient-reported outcomes of informed decision making about healthcare decisions before and after FADA; patients’ expectations of orthodontic treatment before and after FADA. | Qualitative analysis identified two informational needs: effectiveness of treatment on orthodontic outcomes and treatment consequences for patients’ lives.  
Quantitative analysis found decisional conflict reduced in both patients (mean difference − 12.3, SD 15.3, 95% CI 6.6– 17.9; p < 0.001) and parents (mean difference — 8.6, SD 16.6, 95% CI 2.5– 14.8; p = 0.002); knowledge about duration and frequency of orthodontic treatment increased; expectations about care were unchanged.  
**Conclusions:** Using the FADA may enable dental professionals to support patients and their parents, decisions about fixed appliance treatments more effectively, ensuring young people’ s preferences are integrated into care planning. |
<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Sample Size</th>
<th>Age Range</th>
<th>Participation Gender</th>
<th>Research Design</th>
<th>Measure</th>
<th>Outcome</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sadek et al</td>
<td>2015</td>
<td>50 white / 50 Black new patients and parents</td>
<td>12-14 years</td>
<td>61% F 39% M</td>
<td>Cross-sectional survey</td>
<td>Sayers and Newton expectation questionnaire.</td>
<td>Compare expectations of Black British children and their primary carers compared with White British children and their primary carers.</td>
<td>Greatest difference was between Black British patients and their carers, and between Black British carers and White British carers. Patients had similar expectations. No differences between White British children and their carers. White British primary carers had higher expectations of initial visit and expected dental extractions to be a part of the plan.</td>
</tr>
<tr>
<td>Tuncer et al</td>
<td>2015</td>
<td>491 patients 399 parents</td>
<td>Patients: 14-22 years 274 F</td>
<td>Parents: 245F</td>
<td>Cross-sectional</td>
<td>Questionnaire</td>
<td>Preferences, needs and expectations about orthodontic treatment. To examine patients' and parents' perceptions and expectations from orthodontic treatment.</td>
<td>Dental aesthetics were the determinant factor for treatment demand from patients and parents. Improvement in oral function was more important for Class III patients than Class I patients. Adult patients/parents with higher education gave more importance to oral function as well as dental aesthetics. There was no difference among Angle classifications.</td>
</tr>
<tr>
<td>van Wenzel</td>
<td>2015</td>
<td>146 participants applying for orthodontic treatment</td>
<td>19.6 years (SD, 13.49; age range, 8-60)</td>
<td>93 F 53M</td>
<td>Cross-sectional</td>
<td>Two questionnaires</td>
<td>Dento-facial satisfaction and the expectations of orthodontic treatment</td>
<td>The mean scores in the present study were compared with the mean scores obtained by (Bos et al., 2003).</td>
</tr>
</tbody>
</table>
Souza et al 2013

60 adult patients post orthodontics or in final stages. 18-25 years 74.1%F 25.9%M

Cross-sectional

Measure: Questionnaire
Outcome: Assess expectations of adult patients in relation to orthodontic treatment, as well as to the responsible professional.

Nasr et al 2011

80 new orthodontic patients 12-14 years 36M 44F

Prospective RCT

Measure: Sayers and Newton expectation questionnaire completed before and after the consultation.
Control group: Received information about fluoride Intervention group: Received leaflet about orthodontic treatment.
Outcome: Impact of information leaflet on expectations.

Pabari et al 2011

Stage one: 3 orthodontists and 2 GDPs Stage two: 12 patients and 13 clinicians Stage three: 172 patients

Stage one: N/S Stage two: >18yrs Gender: N/S Stage three: mean age=33.8 years 26.7%M 73.3%F

Qualitative: focus groups and interviews Quantitative: cross-sectional survey

Stage One: Focus group to generate open-ended questions for stage two.
Stage Two: Face to face interviews to generate items of questionnaire to assess motivating factors for adults seeking orthodontic treatment.
Stage three: Questionnaire (Motivating factors for orthodontic treatment) combined with 3 questionnaires to measure self-esteem, anxiety or depression, and body image and facial body image. Data compared with data on orthognathic patients from the same hospital and with data from members of the public.

Occlusion deviation was pointed out as the main reason for seeking treatment, and aesthetics ranked as second. Treatment time was considered within the prediction by 46.7% of the interviewees. The orthodontist/patient relationship enables an understanding of the expectations regarding orthodontic treatment, resulting in greater motivation and cooperation, leading to a successful outcome.

No significant differences between the control group and the intervention were found, except for one item related to the expectation of a discussion about treatment at the initial appointment. Information leaflets did not have an immediate impact on patients’ expectations of orthodontic treatment.

Expectations of outcome: Desire to straighten the teeth, improve the smile, improve the bite, improve facial appearance, and close (dental) spacing.
With respect to the psychological characteristics of self-esteem, body image, and facial body image, the adult orthodontic group was comparable with the general public. However, differences were noted when comparing data from the adult orthodontic group with previously collected data on orthognathic patients.
Duggal and Bansal 2010

- 100 new orthodontic patients
- 100 parents
- Mean age 12.6 years
- Gender: N/S
- Cross-sectional

**Measure:** Sayers and Newton questionnaire.

**Outcome:** Compared children and parent responses with regards to expectations of orthodontic treatment.

Expectations of the parents differ from the patients in treatment duration and frequency of appointments where the patients were quite vague about the duration in comparison to their parents and were unaware of the visit frequency required.

Hiemstra et al 2009

- 168 participants (84 patients and 84 parents)
- Patients: 10 to 14 years. Mean age 11.4yrs SD 1.3
- 55%M 45%F
- Parents: Age: N/S
- 18%M 82%F
- Cross-sectional survey

**Measure:** Sayers and Newton orthodontic expectation questionnaire (translated to Dutch).

**Outcome:** The responses of the children and parents and differences between boys and girls were examined using parametric statistical methods. The data from the Dutch sample were compared with a similar UK sample.

Patients and parents differed in several aspects with the exception of expectations of having a brace fitted at the first appointment, orthodontic treatment involving headgear, any problems with orthodontic treatment, duration of orthodontic treatment and concerning reactions from the public. Boys and girls only differed in their expectations of orthodontic treatment involving jaw surgery. Differences between Dutch and English participants were found regarding the first visit, type of orthodontic treatment, reactions from the public, and pain and problems with orthodontic treatment.

Sayers and Newton 2007

- 50 new patients and 50 parents
- Patients: 12-14 years 63%F
- Parents: mean 41 years 68%F
- Cross-sectional survey

**Measure:** Questionnaire measure of orthodontic expectations.

**Outcome:** Comparisons of children’s and parents’ expectations, in addition to ethnicity.

Parents are more realistic in their estimation of the duration of treatment and the initial visit. Patients and parents differ with regard to dietary and drink restrictions in relation to orthodontic treatment. Ethnicity significantly influences expectations, and this may relate to differences in the patients’ and their parents’ assessed outcome of care.
<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Study Population</th>
<th>Measures</th>
<th>Outcome</th>
<th>Notes</th>
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</thead>
<tbody>
<tr>
<td>Zhang et al</td>
<td>2007</td>
<td>217 patients Chinese ethnicity</td>
<td>Prospective cohort study</td>
<td>Measure: 37 item CPQ. Outcome: Impact of treatment on OHRQoL. Compare pre-treatment values and experiences at 1 week, 1 month, 3 months, and 6 months post-insertion of fixed appliances.</td>
<td>Patients expected fixed appliances to considerably compromise overall OHRQoL compared to pre-treatment. At 1 week, emotional and social well-being were less compromised than expected. At 1, 3, and 6 months, functional limitations, emotional and social well-being, and overall OHRQoL were less compromised than expected.</td>
</tr>
<tr>
<td>Kiyak</td>
<td>2006</td>
<td>Children and adults undergoing orthodontic treatment and orthognathic surgery</td>
<td></td>
<td>Measure: 14-item questionnaire. Outcome: Oral function, appearance, social interactions, and general health. Strength of a person’s desire to make specific changes.</td>
<td>Only in general health do children and their parents expect very little change. On the remaining 3 dimensions, parents expect greater improvements in their children than do the children themselves. These differences are significant for both middle-class and lower-income families. Lower-income parents also expect significantly greater improvements in their child’s general health. Among middle-class parents, mean expectation scores for children were lower but maintained the same rank order. Parents’ expectation scores were slightly higher, and children’s scores much higher than among the middle-class sample. No significant parent-child differences were found in any expectations. Improvements in social interactions were less important in these 2 samples, but still relatively high, especially among children whose treatment was paid for by Medicaid.</td>
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<td>Study</td>
<td>Year</td>
<td>N, Demographics</td>
<td>Design</td>
<td>Measure</td>
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<tr>
<td>Sayers and Newton</td>
<td>2006</td>
<td>Stage one: 15 new patients and their parents Stage two: 11 new patients and 11 parents</td>
<td>Qualitative Stage Two: Cross-sectional survey</td>
<td>Sayers and Newton Questionnaire. Stage One: Interviews to develop the items of the questionnaire Stage Two: Testing the questionnaire. Outcome: assess the validity and reliability of the questionnaire using Cronbach’s alpha and test-retest.</td>
<td>Main themes of Interviews: Initial visit; types of treatment; experiences of treatment; reactions of other people; duration; frequency of appointments. Results of testing the instrument: The questionnaire developed had good face validity. Cronbach’s alpha, produced an overall inter-item reliability &gt; 0.7 along with item-total correlations &gt;0.3 in over 50% of questions. Test-retest reliability was statistically significant using Spearman’s correlation.</td>
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<tr>
<td>Thickett and Newton</td>
<td>2006</td>
<td>30 new orthodontic patients 12-14 years mind map 10M 19F, acronym 8M 21F, leaflet 12M 18F</td>
<td>Longitudinal survey</td>
<td>Interventions: Mind map, acronym, information leaflet (BOS) in addition to their consultation appointment. Measure: Nine item questionnaire. Outcome: Short and long term retention of the information T1 (10-15 min after receiving the info), T2 (6 weeks later).</td>
<td>Significant differences between the three methods at both time 1 and time 2. Participants who were given a written information leaflet recalled less information on both occasions of testing. The three methods did not differ in the rate of forgetting of the material. Mind maps and acronyms convey a small but significant advantage in patient recall of information over written information leaflets.</td>
</tr>
<tr>
<td>Williams et al</td>
<td>2005</td>
<td>326 patients receiving combined orthognathic/orthodontic treatment 16-63 years (median=24 years) 74%F</td>
<td>Retrospective questionnaire survey</td>
<td>Measure: Questionnaire. Outcome: Motivations for treatment and perception of information about treatment and experiences of orthodontic aspects of treatment.</td>
<td>Improving dental appearance and preventing future dental problems are major motivators for orthognathic patients. Patients felt informed about what to expect from treatment, but a significant proportion, particularly younger patients and males, were surprised at the length of treatment and the need to wear retainers.</td>
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<td>Study</td>
<td>Year</td>
<td>Sample Description</td>
<td>Methodology</td>
<td>Intervention</td>
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<td>Bos et al</td>
<td>2003</td>
<td>154 patients who applied for orthodontic treatment</td>
<td>Cross-sectional survey</td>
<td>Written/visual/verbal information</td>
<td>2 questionnaires, containing 16 items on satisfaction with facial appearance (modification of the body cathexis scale) and 23 items on expectations of orthodontic treatment (originally developed for patients undergoing orthognathic surgery). <strong>Outcome:</strong> Structure of questionnaires analysed. Correlations between patients' expectations, satisfaction with facial appearance, age, and sex were examined. Assess the effect of the initial facial satisfaction on expectations of orthodontic treatment.</td>
</tr>
<tr>
<td>Petrone et al</td>
<td>2003</td>
<td>91 Parents of new patients in private orthodontic clinic</td>
<td>Cross-sectional survey</td>
<td>Written/visual/verbal information</td>
<td>Questionnaire regarding outcome expectations for their child's treatment. Pre-treatment orthodontic study models of each child were evaluated with the peer assessment rating. <strong>Outcome:</strong> The relationship between outcome expectations and treatment variables, including cost of treatment and malocclusion severity.</td>
</tr>
<tr>
<td>Thomson et al</td>
<td>2001</td>
<td><strong>T1:</strong> 84 new patients and parents <strong>T2:</strong> 22 written, 21 verbal, 20 visuals</td>
<td>Longitudinal survey</td>
<td>Written/visual/verbal information</td>
<td>Questionnaire</td>
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<tr>
<td>Study</td>
<td>Year</td>
<td>Participants</td>
<td>Part one:</td>
<td>Part two:</td>
<td>Measure:</td>
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<tr>
<td>Becker et al</td>
<td>2000</td>
<td>Part one: parents of 46 disabled patients treated orthodontically. Part two: 27 parents of 1 year post treatment patients.</td>
<td>12.9yrs ranging 7-21</td>
<td>12.7 yrs ranging 7-18</td>
<td>Cross-sectional</td>
</tr>
<tr>
<td>Firestone et al</td>
<td>1999</td>
<td>50 adolescent patients</td>
<td>Median age 13.6 (8.9-39.3) years</td>
<td>28F 22M</td>
<td>Prospective cohort study</td>
</tr>
<tr>
<td>Khan and Williams</td>
<td>1999</td>
<td>30 patients and 10 parents of white and Pakistani origin and 4 dentists</td>
<td>Not stated</td>
<td>Not stated</td>
<td>Semi-structured interviews</td>
</tr>
<tr>
<td>Study</td>
<td>Year</td>
<td>Sample Details</td>
<td>Measure</td>
<td>Outcome</td>
<td>Findings</td>
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<tr>
<td>Tung and Kiyak</td>
<td>1998</td>
<td>75 children and their parents</td>
<td>Cross-sectional</td>
<td>Assessing personality characteristics, motives, and aesthetic values of young phase I patients.</td>
<td>Children’s perceived reasons for treatment were consistent with parents. Body image and self-concept scores within the normal range, but children and their parents expected the most improvement in self-image and oral function, with greater expectations by parents on self-image, oral function, and social life than children. Minority children were similar in their self-ratings and expectations from orthodontics. Younger children have high self-esteem and body-image, and expect orthodontics to improve their lives. White children appear to have a narrower range of aesthetic acceptability than minority children.</td>
</tr>
<tr>
<td>Bennett et al</td>
<td>1997</td>
<td>220 orthodontists and 220 parents at a university orthodontic clinic</td>
<td>Qualitative interviews</td>
<td>Assess what parents and orthodontists value about and expect from orthodontic treatment. How expectations and values pertaining to orthodontic treatment relate to socio-demographic variables.</td>
<td>Eight scales were examined: expected treatment benefits, expected treatment risks (short- and long-term), expected treatment inconveniences, value of treatment benefits, value of risks (short- and long-term), and value of treatment inconveniences. For parents, the reliability for all scales was in the acceptable range. For orthodontists, only the “short-term risks” scale failed to attain an acceptable reliability. For parents, income, father’s education level, and sex of respondent were related to treatment expectations and values.</td>
</tr>
<tr>
<td>Pratelli et al</td>
<td>1996</td>
<td>430 parents of children</td>
<td>Cross-sectional</td>
<td>Survey of parental knowledge of the complications of orthodontic treatment.</td>
<td>Few ‘experienced’ parents knew that dental decay could occur beneath an appliance or that, after treatment ceased, there might be some relapse. Only 41 per cent of them knew that decay could occur beneath a fixed appliance and less than a third that relapse could occur after treatment ceased.</td>
</tr>
<tr>
<td>Study</td>
<td>Year</td>
<td>Sample Size</td>
<td>Sample Characteristics</td>
<td>Methodology</td>
<td>Measure</td>
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<tr>
<td>Sheats et al</td>
<td>1995</td>
<td>78 and 54 parents</td>
<td>all children third graders 33 F 44 M</td>
<td>Cross-sectional survey</td>
<td>Modified version of the COAS.</td>
</tr>
<tr>
<td>McKiernan et al</td>
<td>1991</td>
<td>Not stated</td>
<td>Not stated</td>
<td>Not stated</td>
<td>N/S</td>
</tr>
<tr>
<td>Tulloch et al</td>
<td>1984</td>
<td>385 sixth grade children and 123 of their parents from Lexington, Kentucky and Cardiff, Wales</td>
<td>11-12 years Gender N/S</td>
<td>Qualitative interviews</td>
<td>Interviews</td>
</tr>
<tr>
<td>Study</td>
<td>Year</td>
<td>Population Details</td>
<td>Demographics</td>
<td>Methodology</td>
<td>Measure:</td>
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<td>Shaw et al</td>
<td>1979</td>
<td>200 patients and their parents during active orthodontic treatment in South Wales</td>
<td>Mean age 12.9 years, Gender N/S</td>
<td>Cross-sectional survey</td>
<td>Questionnaire that measures expectations of orthodontic treatment.</td>
</tr>
<tr>
<td>Dorsey and Korabik</td>
<td>1977</td>
<td>177 St Louis Ortho clinic, 37 from orthodontist with middle class clientele, 85 from upper middle class practice</td>
<td>Age N/S, Gender predominantly female</td>
<td>Not stated</td>
<td>N/S</td>
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</tbody>
</table>

No differences found between patients and parents regarding expectations of improved appearance and benefits. American and British parents expected orthodontic treatment to improve dental health, mastication and speech. In South Wales, parents of female patients felt straight teeth would enhance their popularity. Professional fathers and those in management thought aesthetics were very important and enhanced chewing ability. Fifty percent of parents thought that straight teeth would produce future occupational success.

The most important motivation for treatment was improvement of appearance because of the feeling that increased social and occupational opportunities would result. Lower-middle-class people considered orthodontic treatment to be more important than upper-middle-class people.
2.2.4.2 Expectations of Restorative Treatment

Very few studies were identified by the researcher that measured patients’ expectations of restorative or prosthodontic treatment. Similar to the orthodontic expectations, the vast majority of the studies investigated patients’ expectations of the treatment outcome while very few investigated expectations of different aspects of the treatment process. It is interesting to note that most of the studies described the expectations of implant treatment compared to other forms of prosthetic rehabilitation. It was also found that the majority of the studies were quantitative in nature using either a before/after study design to measure expectations before and satisfaction after treatment or a cross-sectional research design measuring expectations either before or after treatment. Two studies used qualitative research methods while only one study was a randomised controlled trial. Table 2.4 displays all the expectations of prosthodontic treatment studies located by the researcher including the characteristics and the main findings.

Expectations of Treatment Process

The researcher was able to locate only 5 studies that investigated patients’ perceptions of the various aspects of the treatment process. All of these studies mainly focused on implant treatment. The parameters investigated in the different questionnaires were very diverse among the studies. The most frequently used questions were about the expected alternatives to replace missing teeth, the site of implant placement, the possibility of rejection, duration and cost of treatment, frequency of appointments, healing period, oral hygiene and maintenance.

Leles et al. (2008) developed a questionnaire through qualitative interviewing of 39 patients to assess the patients’ views of the possible outcome of prosthodontic treatment. The questionnaire consisted of 41 five-point Likert scale items concerning the benefits/risks of treatment and the author reported good internal consistency. A few of the questions were related to the process of treatment such as the cost and duration, and the expected drawbacks of treatment such as injury, rejection, and harming bone and gums. The second stage of the study involved the completion of the questionnaire by 126 participants to investigate the influence of age, gender, and clinical variables. Patients’ mean scores ranged from 2.37 to 4.88 (mean=4.25; SD=0.65), indicating that participants tended to agree with the proposed affirmatives (scores 4 and 5). These scores
were influenced by edentulous spaces, use of prosthodontics, gender and age. It was found that older participants, females, those with higher number of teeth missing, and those previously treated prosthetically had greater perception of benefits and risks of prosthodontic treatment.

Tepper et al., (2003a, 2003b) and Pommer et al., (2011a, 2011b) conducted a cross sectional study using the same questionnaire to measure the awareness of the Australian Population regarding dental implant treatment. 1000 participants were randomly selected to represent the Australian population. According to (Tepper et al., 2003b), 72% of the participants knew about dental implants although most of those questioned felt poorly informed about the options for replacing missing teeth and many knew less about implants than about other alternatives. The majority of the participants did not know whether the dentist could provide implant therapy while 44% thought that it should be provided by a specially trained clinician. Only 29% incriminated poor oral hygiene as a cause of implant failure, while half of those questioned attributed implant failures to allergies and incompatibilities and the other half to poor medical care.

Pommer et al., (2011a, 2011b) on the other hand, found that the awareness rate of dental implants was significantly higher compared with Tepper et al., (2003a, 2003b). Implant awareness rates differed significantly between income categories, the level of education, as well as the size of residence. A significantly lower level of information about implants as well as treatment alternatives was recorded in the young population, while no gender differences could be observed. They also found that the estimated costs of implant treatment were significantly higher than those in 2003. Both studies agreed on the importance of improving communication strategies to provide their patients with comprehensible, legally tenable information on dental implants and bridge information gaps in the future. A drawback of both studies is the fact that the origins of the questionnaire items were not mentioned including its’ psychometric properties and therefore the results should be interpreted with caution.

Hof et al. (2014) conducted a cross sectional survey on a sample of 150 patients seeking implant treatment to assess their up-to-date expectations and preferences with regards to implant related treatment. The patients’ ages ranged from 18-84 and they were asked to fill in two
questionnaires, one of which contained expectation items regarding the cost and duration of treatment and the healing period. Although no information was provided regarding the origins of the questions used, the authors did report on the psychometric properties of the questionnaire including its’ face validity and internal consistency. The results revealed that patient expectations on implant success and predictability are high compared with their reluctance towards treatment costs and duration. They also found that 89% of the participants anticipated a healing period of at least 2 months following tooth extraction compared to 96% following implant placement. This highlights the importance of good communication between clinicians and patients in order to accurately manage patients’ expectations.

**Expectations of Treatment Outcome**

Seventeen studies investigated patients’ expectations of prosthodontic treatment outcome. Six of these studies conducted an expectation before and satisfaction after treatment design using the same questionnaire that contained four main items: aesthetics, mastication, comfort, and phonetics (Fromentin and Boy-Lefevre, 2000, Bellini et al., 2009, Marachlioglou et al., 2010, Baracat et al., 2011, de Lima et al., 2011, de Siqueira et al., 2013). The questionnaire was originally developed by Fromentin and Boy-Lefevre (2000) through patient interviews and reviewing the literature which was then tested on a group of patients to determine reliability through test-retest.

Another three studies were located that reported on the development process of the questionnaires including their psychometric properties. Hakestam et al. (1996) developed their questionnaire in cooperation with prosthodontic staff members and group of experienced GDPs followed by pilot testing the questionnaire on a group of patients to establish content validity. Smith and McCord (2004) selected their items from prosthodontic textbooks using features taken to represent the normative view of what dentists thought edentulous patients were likely to expect from their dentures and tested its internal consistency using Cronbach’s alpha. The development process of the questionnaire presented by Leles et al. (2008) was previously mentioned in the expectations of restorative treatment process section. The remaining 8 studies did not report on the development process or the psychometric properties of the questionnaires.
used (Conny et al., 1985, Davis et al., 1986, Zimmer et al., 1992, Allen et al., 1999, Tepper et
al., 2003a, 2003b, Rustemeyer and Bremerich, 2007, Heydecke et al., 2008, Pommer et al.,
2011a, 2011b).

The expectancy variables that were investigated within the above studies included: expected
function (e.g. speech, mastication and brushing), aesthetic (e.g. shape colour and size),
psychosocial (e.g. professional opportunities and confidence) and general health (e.g. pain,
sensitivity and digestion) benefits as well as future maintenance of the prosthesis. The sample
sizes reported varied widely between the studies and ranged from 22 to 1000 participants with a
patient age range from 14 to 89 years with mean ages most commonly falling between 50 to 70
years.

The literature review revealed that in the majority of the studies conducted, appearance was the
primary motivating factor to seek treatment in addition to functional improvements such as
achieving a good bite, improving mastication and improving speech (Conny et al., 1985, Davis
et al., 1986, Zimmer et al., 1992, Hakestam et al., 1996, Allen et al., 1999, Smith and McCord,
2004, Rustemeyer and Bremerich, 2007, Grey et al., 2013). Other factors that have been
mentioned but to a lesser extent were to enhance the general well-being of the individual
(Hakestam et al., 1996), achieve comfort through a better fit of the prosthesis and better tooth
contact (Conny et al., 1985, Davis et al., 1986, Smith and McCord, 2004) and eliminate feelings
of pain (Conny et al., 1985, Smith and McCord, 2004).

The studies also revealed that patients tended to favour, accept and hold higher expectations of
implant treatment over other forms of tooth replacements available. Zimmer et al. (1992)
reported that younger interviewees were significantly more in favour of implants. This was in
agreement with the study conducted by Pommer et al., (2011a, 2011b) where the majority of the
participants did not accept removable dentures especially those who are younger and with high
income. There was a general belief that implants are less annoying, more attractive and will not
feel like foreign bodies. While 30% of the participants thought implants would last up to 20
years, 24% expected implants to last for a lifetime. With regards to the care requirements of the
implants, 49% believed that care would be similar to natural teeth while only 39% thought
special care and hygiene were necessary. These results were similar to those reported by Tepper et al., (2003a, 2003b) however, a higher proportion of participants (34%) believed that implants last for a life-time. The participants displayed better awareness with regards to care requirements of implants.

Rustemeyer and Bremerich (2007) conducted a cross-sectional survey of 315 new implant patients to assess their perceptions of implant supported overdentures and found that 31% expected special oral hygiene and care requirements while 58% expected the care requirements to be similar to natural teeth. They also found that majority of the participants expected them to last between 11-20 years and 7% expected the lifespan to be more than 25 years. Similar results were reached by Grey et al. (2013) who conducted qualitative interviews on a group of 9 patients to explore their expectations of dental implants. They were found to believe that dental implants are just like natural teeth which can be concerning if this belief leads them to treat them as such, and thus not follow the recommended specialist care they require. This finding highlights the importance of good clinician / patient communication in assessing expectations of treatment and its outcomes.

Allen et al. (1999) compared the effects of implant supported overdentures (IOD) and conventional dentures (CD) on patients’ expectations. They found that expectations of patients receiving IOD were significantly greater than the CD group. Heydecke et al. (2008) compared expectations before and satisfaction after treatment of 102 participants receiving IOD and 60 patients receiving CD. Although both groups did not differ in their level of expectations before the treatment, they found that post-treatment CD satisfaction failed to meet patients’ pre-treatment expectations of satisfaction; this was not the case for IODs, for which expectations were largely met.

As mentioned earlier, some authors investigated the relationship between pre-treatment expectations and post-treatment satisfaction levels and the results were not always positive. Specific items like mastication, phonetic, comfort use and retention issues showed lower satisfaction after treatment than pre-treatment expectations (Fromentin and Boy-Lefevre, 2000, Heydecke et al., 2008, Marachlioglou et al., 2010, de Lima et al., 2011, de Siqueira et al., 2013).
One of the reasons may be that patients with more detailed considerations of functional experiences may be more sensitive to the change in oral conditions. This was in contrast to other researchers who reported post-treatment completion ratings to be significantly exceeding expectations (Bellini et al., 2009, Baracat et al., 2011). They explained that this result may be due to previous unpleasant experiences with dental treatments and patients’ personal motives.

The effect of certain demographic characteristics such as age, gender, education, income and place of residence on patients’ expectations have also been investigated in a number of studies. While some studies did not find significant correlations between the patients’ ages, genders, educational levels and their expectations (Bellini et al., 2009, Marachlioglou et al., 2010, Baracat et al., 2011, de Siqueira et al., 2013), other studies were able to identify certain characteristics effecting the patients’ expectations. Rustemeyer and Bremerich (2007) found significant gender differences in the importance of aesthetic benefits of implant supported overdentures. Fromentin and Boy-Lefevre (2000) demonstrated that the place of residence or level of income variable had some influence on the level of expectations. These results are in agreement with Pommer et al. (2011a) who found that implant awareness rates differed significantly between income categories, level of education, age differences as well as the size of the residence.

Baracat et al. (2011) aimed to find out the effects of smoking habits and the influence of the life partner on the expectations of 50 patients seeking implant treatment and found no significant associations. The role of implant placement area was also found to be insignificant in determining pre-treatment expectations. Similarly, de Siqueira et al. (2013) explored the influence of arch involved in RDP treatment on aesthetic and functional expectations and were not able to find correlations.

In the study conducted by Bellini et al. (2009), the perceptions of 64 patients seeking complete denture therapy were explored in order to test for a correlation between locus of control profiles and expectations before and satisfaction after treatment. They found that the majority of the participants were internally oriented but were not able to detect a significant correlation with the scores of expectations before treatment and satisfaction after therapy.
Smith and McCord (2004) compared the expectations of 214 patients receiving a complete denture either in a dental practice or a dental hospital. Significant differences emerged between the groups in their expectations of pain relief, absence of slackness and achieving a good bite where the dental hospital group had higher expectations. However, variables such as ease of chewing, speech and good appearance were similarly high for both groups. They further explained that the difference found in the expectations may be a result of past negative experiences with the dental practice that resulted in the referral to the hospital and therefore believing that these specific aspects will be addressed.

The relationship between patients’ evaluations of their clinicians’ conduct and their expectations of treatment was the focus of research by de Lima et al. (2011). Fifty-two individuals receiving either implant supported fixed partial dentures or single crowns were included in the study. They reported a positive relationship for the majority of questions concerning patients’ evaluations of clinician conduct and visual analogue scale (VAS) scores concluding that patient’s evaluation of clinician conduct appears to be an important factor that influences their expectations before and satisfaction after receiving implant-supported fixed partial dentures (FPD) and single crowns.
Table 2.4 Studies investigating the patients’ expectations of restorative treatment.

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Sample size</th>
<th>Age and gender</th>
<th>Study design</th>
<th>Measure and Outcome</th>
<th>Findings</th>
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</thead>
</table>
| Hof et al   | 2014 | 150 patients seeking implant treatment                | 18-84 years     | Cross-sectional survey                                                              | **Measure:** 2 questionnaires  
**Outcome:** Assess up-to-date expectations and preferences of patients seeking dental implants.  
**Questionnaire One:** Rank their concerns regarding implant therapy by priority.  
**Questionnaire Two:** Expectation items / acceptance and preferences items / second-opinion seeking items. | Patient expectations on implant success and predictability are high compared with their reluctance towards treatment costs and duration.  
Acceptance of treatment morbidity is high among patients reporting low denture satisfaction  
Minimally invasive treatment alternatives are generally preferred. |
| de Siqueira et al | 2013 | 44 patients who received RDP therapy                     | 52.7 years (SD 10.4), range 74-32 | Before / after | **Measure:** VAS scores (chewing, aesthetics, comfort and phonetics), and questionnaire concerning the dentists’ conduct.  
**Outcome:** Expectations before and satisfaction after RDP, influence of perceptions of clinician conduct, gender, age, Kennedy’s classification of the arch supporting the RDP, the number of RDP adjustments after delivery. | The average VAS scores were high for both expectation and satisfaction; however, the scores for expectations were higher than those for satisfaction.  
There was no statistically significant difference among scores concerning different genders, age, number of post-delivery settings and arch involved in the RDP.  
Regarding patients’ evaluation of the dentists’ conduct, there was a predominance of positive evaluations, but only different answers to the statement ‘The dentist I saw thoroughly explained the recommended treatment before it commenced’ present statistically significant different scores for chewing and phonetics. |
<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Participants</th>
<th>Age</th>
<th>Gender</th>
<th>Measure</th>
<th>Outcome</th>
<th>Themes</th>
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<tbody>
<tr>
<td>Grey et al</td>
<td>2013</td>
<td>9 Adults who consulted a restorative dental specialist with an interest in implantology</td>
<td>49-69 years</td>
<td>6F 3M</td>
<td>Qualitative</td>
<td><strong>Outcome</strong>: Understand patients’ motivations for seeking implants and their expectations of treatment. Rigorous qualitative methods were employed in order to gain detailed insight into patients’ experiences.</td>
<td><strong>Themes</strong>: 1. Appearance: teeth and the individual, teeth and the social self. 2. Function: Awareness, speaking, eating. The main theme to emerge was ‘normality’. Participants expected implants to restore their oral-related quality of life to ‘normal’ either in appearance or function. Several participants who had completed implant treatment regarded their new prostheses as ‘just like natural teeth’ which could be cause for concern if it leads them to treat them as such, and thereby not follow the recommended specialist care they require.</td>
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<tr>
<td>Baracat et al</td>
<td>2011</td>
<td>50 patients seeking dental implant treatment</td>
<td>Mean 49yrs +/- 11.45 (23-80yrs) 32F</td>
<td>Before /after</td>
<td>Questionnaire VAS</td>
<td><strong>Outcome</strong>: Compare patients’ expectations before with their satisfaction regarding (aesthetic and functional: mastication, comfort, retention results) after (one week) dental implant therapy.</td>
<td>The post-treatment completion ratings significantly exceeded expectations. Positive correlations were found between expectations and post treatment completion ratings for aesthetics and function. An inverse correlation was found between age and functional expectations.</td>
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<tr>
<td>de Lima et al</td>
<td>2011</td>
<td>52 individuals who received: implant-supported FPDs (n=25) single crowns (n=27)</td>
<td>28–77 years; Mean = 51.2; SD = 10.6 Gender N/S</td>
<td>Before /after</td>
<td>Two questionnaires</td>
<td><strong>Outcome</strong>: Expectation before and satisfaction after treatment with regards to mastication, aesthetics, phonetics and comfort of use. Investigate other variables involved in the treatment, which may affect patient satisfaction and their evaluation of their clinician’s conduct.</td>
<td>Expectations before treatment were higher than satisfaction after treatment, but this difference was significant only for aesthetics in patients who had received implant-supported FPDs. Negative correlations were found between satisfaction and age and between number of absent teeth and number of post-delivery adjustments, but only for implant-supported FPDs. A positive relationship was found for the majority of questions concerning patients’ evaluations of clinician conduct and VAS scores.</td>
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<td>Study</td>
<td>Year</td>
<td>Sample Description</td>
<td>Method</td>
<td>Measure</td>
<td>Outcome</td>
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<td>Pommer et al part 1&amp;2</td>
<td>2011a,b</td>
<td>1000 adults representative of the Austrian population</td>
<td>Cross-sectional survey</td>
<td>19 item questionnaire</td>
<td>Assess the up-to-date information level and evaluate recent progress and trends in patients' mindset on dental implants and draw comparisons with the results published by Tepper et al. (2003a, b). Questionnaire includes: <strong>part one:</strong> Implant information items; sources of information; need for patient information about dental implants. <strong>Part two:</strong> Acceptance and perceived costs of dental implant treatment and patient satisfaction with implant-supported rehabilitation.</td>
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<td>Sample was selected by pre-stratified multi-tiered cluster sampling.</td>
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<td>Over 14 years of age</td>
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<tr>
<td>Marachlioglou et al</td>
<td>2010</td>
<td>20 edentulous patients seeking complete denture therapy</td>
<td>Before/after</td>
<td>Questionnaire</td>
<td>The patients had higher expectations than the dental technician and the dentists’ perceptions for both aesthetic and function. The patients also presented higher post-treatment completion ratings than the dental professionals’ perception for final aesthetics and function. There was no correlation between expectations and post-treatment completion ratings according to the patients’ age. There was also no correlation between the patients’ gender and expectation scores. The dentist believed that dentures would bring fewer benefits than patients did.</td>
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<td>1 prosthodontist</td>
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<td>1 dental technician</td>
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<td>Average age 62.35 (SD = 9.33 ranging 45-79).</td>
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Part 1: Questioned about alternatives for replacing missing teeth, 79% of the interviewees mentioned dental implants, 45% removable partial dentures, 77% removable complete dentures and 91% fixed partial dentures. The awareness rate of dental implants was significantly higher compared with the investigation in 2003, while awareness of removable dentures has significantly decreased. Implant awareness rates differed significantly between income categories, level of education, and size of residence. A significantly lower level of information about implants and treatment alternatives was recorded in the young population, and no gender differences could be observed.

Part 2: The estimated costs of implant treatment were significantly higher than those in 2003, and three-quarters felt that the prize was too high and that the sick fund or social security agencies should bear them.
<p>| <strong>Bellini et al</strong> | 2009 | 64 patients seeking complete denture therapy | Mean 60 years (SD 10.77) ranging 37-87 59% F | Before / after | <strong>Measure:</strong> Three questionnaires. <strong>Outcome:</strong> Test for a correlation between locus of control profiles and expectations before and satisfaction after complete denture therapy. Before treatment, expectations were significantly lower than the post-treatment completion ratings, both for aesthetics and function. There was no correlation between locus of control profiles and patients’ ratings or between gender and VAS scores. No correlation was found between locus of control profiles and scores for expectations before and satisfaction after complete dentures. |
| <strong>Heydecke et al</strong> | 2008 | 162 edentulous patients separated into two groups: <strong>IOD:</strong> 2-implant-supported over denture (102) <strong>CD:</strong> conventional over denture (60) | Middle aged 35-65, 51%M 49%F Senior ages 65–75 40%M 60%F | Before / after | Before randomization, each subject rated their satisfaction with their current denture and expectations of satisfaction with both IOD and CD treatment. 6 months’ post-treatment, all rated their satisfaction with their new prostheses on similar VAS. Expectations and satisfaction with treatment were compared. Post treatment satisfaction with CD treatment was significantly lower than pre-treatment expected satisfaction in both study populations. There was no significant difference between pre-treatment expectation and post treatment satisfaction for patients receiving IODs in both study populations. Post treatment CD satisfaction failed to meet patients' pre-treatment expectations of satisfaction; this was not the case for IODs, for which expectations were largely met. |
| <strong>Leles et al</strong> | 2008 | Part one: 39 in varying stages of treatment Part two: 126 with single to complete edentulous arches treated with prosthodontics or not. | Part one: 27-74 years (mean 48.6) 83% F Part two: 25-85yrs (mean 51.8) 73.8% F | Mixed qualitative/quantitative | Part One: Interviews assessing patients’ views about possible outcome of prosthodontic treatment. Part Two: Questionnaire measuring demographics and 41 Likert scale items (5 point) asking about benefits/risks of treatment and perceived consequence of no treatment psychometrically tested. Influence of age, gender and clinical variables were tested Cronbach’s alpha coefficient of the scale and subscales ranged from 0.70 to 0.90. Patients’ mean scores ranged from 2.37 to 4.88 (mean=4.25; SD=0.65), indicating that participants tended to agree with the proposed affirmatives (scores 4 and 5). Perception scores were influenced by age, gender, edentulous spaces and use of prosthodontics. Older participants, females, those with higher number of missing teeth and who have been previously treated had greater perception of benefits and risks of prosthodontic treatment. The proposed instrument was suitable for measuring participants’ perception of potential outcomes of prosthodontic treatment. |</p>
<table>
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<tr>
<th>Study</th>
<th>Year</th>
<th>Study Design</th>
<th>Sample Size</th>
<th>Sample Description</th>
<th>Measure</th>
<th>Outcome</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rustemeyer and Bremerich</td>
<td>2007</td>
<td>Cross-sectional survey</td>
<td>315 possible new implant patients</td>
<td>Mean age 55 +/-14.7 years (184F 131M)</td>
<td>Questionnaire</td>
<td>Oral hygiene considerations, durability and costs of an implant-supported overdentures, the importance held to the aesthetic and functional outcome of the denture as well as the influence of laymen and media in these perceptions.</td>
<td>61% expected an additional payment of 2000 Euro or less, 80% held the function of an implant-supported overdentures as very important, 54% attached great importance to the aesthetics. The expectations that patients have for an implant-supported overdenture are high in contrast to their willingness to make additional payments. There are still misconceptions regarding costs, and these must be resolved individually in practice.</td>
</tr>
<tr>
<td>Smith and McCord</td>
<td>2004</td>
<td>Cross-sectional survey</td>
<td>214 edentulous participants received replacement complete dentures at: Dental Practice (DP) 125 Dental Hospital (DH) 89</td>
<td>Age range 48-89 years and mean age of 69.25 (104F)</td>
<td>Questionnaire</td>
<td>Determining whether patients wearing complete dentures in DH and DP had different expectations from their dentures, together with their requirements for information about denture construction as well as oral and denture care.</td>
<td>82% of the DH group thought it essential that their dentures caused no pain compared with 59% of the DP group; for ‘absence of slackness’ (DH 87%; DP 65%), and ‘good bite’ (DH 82%; DP 55%). Both groups had high expectations for ease of chewing, speech, and good appearance. Differences between the groups also emerged with respect to the demand for more information regarding the stages involved in denture construction (DH 57%, DP 76%) and how to care for dentures (DH 75%, DP 89%). Large proportions of patients from both groups would prefer to have more information about the selection of teeth (71% DH, 72% DP), and how to care for their mouths (84% DH, 86% DP), but there were no differences between the groups in these parameters.</td>
</tr>
</tbody>
</table>
Tepper et al. 2003a,b

| 2003 a,b | 1000 adults representative for the Austrian population through random sampling | 255 less than 30 years, 367 between 30 and 50 years, and 378 more than 50 years old | Cross-sectional survey | Measure: Two questionnaires
Outcome:
Part one: Level of information about implant-supported and conventional rehabilitation, sources of information, perceived and objective need for information.
Part two: Dental status, crowns, bridges, and dentures if any, and general attitude towards prosthodontic rehabilitation for evaluating implant acceptance, cost of implants, first or second hand experience with implants and satisfaction.

<p>| Part one: 72% knew about dental implants. Most felt poorly informed about the options for replacing missing teeth and many knew less about implants than about other alternatives. More than 79% did not know whether their dentist worked with implants. 44% percent thought that implants should only be placed by specially trained doctors. 61% thought that dentists who provide implant dentistry were better qualified than their colleagues who did not place implants. Half of those questioned attributed implant failures to allergies and incompatibilities, the other half to poor medical care. Only 29% incriminated poor oral hygiene as a cause of implant failure. |
| Part two: Of those familiar with implants as one of the treatment alternatives, 61% reported they would accept implants if the need arose. Implant acceptance was highest among males and interviewees below the age of 30 years. The interest in implants increased with increasing family incomes. All those questioned found implant-supported rehabilitation to be very expensive. Many of them blamed the dentists for the high cost. |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Sample Size</th>
<th>Design</th>
<th>Measure</th>
<th>Outcome</th>
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<tr>
<td>Fromentin and Boy-Lefevre</td>
<td>2000</td>
<td>162 patients attending for prosthetic rehabilitation, 94 replies (response rate: 62%)</td>
<td>Not stated</td>
<td>Before/after</td>
<td>Two questionnaires: pre-treatment level of expectation and attitude (questionnaire 1) and post treatment level of satisfaction with different types of prosthetic treatment (questionnaire 2) according to socio-economic and demographic factors.</td>
</tr>
<tr>
<td>Allen et al</td>
<td>1999</td>
<td>Group 1: Patients requesting IOD (n=27) Group 2 (control): patients requesting CD (n=34)</td>
<td>Cross-sectional survey</td>
<td>Questionnaire</td>
<td>After attending appointment and discussing treatment options verbally + leaflets + video: Demographics + jaw bone status (radiographs) assessed. Questionnaire: Satisfaction with current denture and expectations of IOD and CD treatment. Baseline satisfaction with current dentures was low in both groups, with the implant group being significantly less satisfied with comfort and stability of their mandibular dentures. Perceived ability of the implant group to chew hard foods was less than the control group. Implant group’s expectations of an implant-retained prosthesis were significantly greater than for a conventional denture.</td>
</tr>
<tr>
<td>Hakestam et al</td>
<td>1996</td>
<td>489 patients waiting for major prosthodontic treatment with 84.2%</td>
<td>Cross-sectional</td>
<td>Questionnaire / Further information</td>
<td>Describe the patient group from a socio-economic standpoint and to identify factors affecting the patient’s expectations concerning prosthodontic treatment. Patient group differed significantly from the general population only in regard to educational level, which was lower. Patients expected the forthcoming therapy to enhance their general well-being. Subgroup of patients awaiting implants, expectations of a better chewing function were salient. A number of economical, cultural and social conditions could have a major impact on attitudes regarding prosthodontic treatment.</td>
</tr>
<tr>
<td>Authors</td>
<td>Year</td>
<td>Sample</td>
<td>Design</td>
<td>Measure</td>
<td>Outcome</td>
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<td>77% had heard about dental implants, mostly through media and colleagues/friends. Persons with many missing teeth were not more aware of implants than those with fewer missing teeth. Aesthetics was the most frequent motivating factor favouring implants, while high cost was the most frequent argument against them. Younger interviewees were significantly more often in favour of implants than older persons. It was concluded that public awareness and acceptance of dental implants are high. Dentists and physicians, however, play only a minor role as sources of information.</td>
</tr>
<tr>
<td>Davis et al</td>
<td>1986</td>
<td>63 denture patients randomly assigned to: videotape (29) control (34)</td>
<td>Randomised control trial</td>
<td>Measure: Questionnaire&lt;br&gt; Outcome: Measure expectations and satisfaction with the dentures received before and after treatment and follow up. And measure the effect of information videotape on altering expectations.</td>
<td>Most frequent reason for seeking treatment was poor fit of present dentures, followed by need for new dentures and structural or functional problems. No significant treatment by time interaction for either expectations or satisfaction. No significant overall change in expectations from pre-to post treatment to follow-up and no significant difference in expectations between videotape and control groups at the three time points. Patients’ expectations of dentures before treatment were unrealistically high stating that they should fit perfectly and not move, that they should be able to eat, chew, and speak as with natural teeth. These expectations are realistic only for the ability to speak. Expectations regarding appearance were more realistic, but patients still expected dentures to look just like natural teeth. In addition, most people thought that having dentures was “about like” or “better than” natural teeth.</td>
</tr>
<tr>
<td>Study</td>
<td>Year</td>
<td>Participants</td>
<td>Region</td>
<td>Study Design</td>
<td>Measure</td>
</tr>
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<td>-------</td>
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</tr>
<tr>
<td>Conny et al</td>
<td>1985</td>
<td>220 patients who completed fixed prosthodontic treatment within 2 years</td>
<td>Maxillary anterior region most frequently involved</td>
<td>Cross-sectional survey</td>
<td>Measure: Questionnaire (Likert type scales).</td>
</tr>
</tbody>
</table>

- Conny et al
- Cross-sectional survey
- 220 patients
- Maxillary anterior region
- 32% M 68% F
- 16-18 years and mean age 46
2.2.5 Effect of Patient Education on Expectations of Orthodontic and Restorative Treatment

According to the Bartlett (1985), patient education is “any set of planned educational activities, using a combination of methods (teaching, counselling, and behaviour modification), that is designed to improve patients’ knowledge and health behaviours”.

Establishing a good rapport between the clinician and patient as well as providing enough relevant verbal and non-verbal information are key elements for informed consent and successful completion of treatment. According to Witt and Bartsch (1996) the main tasks of the clinician during a consultation appointment is to adequately inform the patients of the problems, need for and timing of treatment in an easily understood and recalled manner. The patients usually retain information that concerns and affects their everyday life keeping in mind that this information should be tailored to the individual’s psychological and cognitive state as well as the intellectual and verbal abilities of the patient.

Mortensen et al. (2003) interviewed 29 children and their parents within thirty minutes of leaving their consultation appointment with the orthodontist. It was found that these patients recalled significantly fewer reasons for treatment, procedures, and risks compared to the information given by the orthodontist. This raises issues of effectiveness and validity of the informed consent process, treatment compliance and subsequently success.

Informed consent has become an essential component of treating patients and is not only important from an ethical point of view, but also from a legal point of view being a prerequisite prior to any surgical procedure. In the UK, the main medical regulatory and legal institutions such as the Department of Health (2009) and the General Medical Council (2013) have reinforced the need for informed consent prior to treating any patients. This has also been reinforced by the Royal Colleges of Surgeons who state that the patients should be given enough information about the treatment proposed, alternatives, risks side effects and complications of treatment, as well as giving them enough time to make a fully informed decision on treatment, which should ideally be indicated by a signature.
However, consent is an ongoing process and is not defined by a single event (i.e. the signature), especially when providing complex treatment delivered over prolonged periods of time. According to the General Dental Council (2005), ‘Consent should be part of an ongoing discussion between you and the patient’ who should be informed of the treatment to be delivered before every appointment as well as any changes in the treatment plan that occurs during the treatment journey’.

Several factors have been postulated in the literature to affect the recall ability of an individual. Older people are less able to retain information successfully and may require the need for repetitions as well as written information material to assist recall (Mcguire, 1996). The patient’s emotional status is also an important factor and anxiety levels can impact on recall potential (Kessels, 2003). In addition, the amount of information presented and the order of presentation impacts recall, whereby the information given towards the beginning and end of a list is the most remembered. It is also important to consider the mode and context of the information. Verbally communicating medical information may be quick but providing patients with information material can lead to greater recall (Watson and McKinstry, 2009).

Studies have proved that providing patients with information material can aid in the decision-making process and therefore, achieving informed consent (Ashraff et al., 2006, Johnson et al., 2006, Wollinger et al., 2012, Marshman et al., 2016). This view is supported by the National Health Service (NHS) England stating that good patient information material has the effect of involving patients and their carers in the decision-making process of their treatment with more confidence, improving information recall and overall experience throughout the treatment journey.

The literature review revealed a paucity of studies investigating the effects of information material on patients’ knowledge and expectations of orthodontic as well as prosthodontic treatment. Davis et al. (1986) conducted a randomised controlled trial to compare expectations and satisfaction with the dentures received before and after treatment and measured the effect of information videotape on altering expectations. A sample of 63 denture patients 40-81 years of age were included in the study who were randomly assigned to the videotape or control
group. The authors reported no significant differences in the overall change of expectations from pre-treatment to post-treatment to follow up as well as no differences detected between the videotape and control groups at the three time points. They concluded that patients’ expectations of dentures before treatment were unrealistically high and that informational videotapes did not significantly affect these expectations. A limitation of this study is the fact that the sample included experienced denture wearers (average of 22 years of experience) and that the videotapes probably would have had a greater impact on first-time or less-experienced denture patients.

Nasr et al. (2011) conducted a prospective randomised controlled study including 80 patients aged 12-14 years who had not received orthodontic treatment. Patients’ expectations were measured before their initial consultation with a questionnaire designed by Sayers and Newton (2006). They were randomly assigned to 2 groups. The control group received additional information about fluoride, whilst the intervention group received additional information about orthodontic treatment. After their new patient consultation both groups competed the patient expectation questionnaire for a second time. The results revealed that there were no significant differences in expectations between the two groups, except related to receiving treatment at the initial visit. They concluded that information leaflets did not have an immediate impact on patient’s expectations of orthodontic treatment. However, the information presented was limited to information leaflets and other methods such as videos and computer-based information might have had a bigger and more positive impact on patients’ expectations’.

Other studies compared different forms of information material on the patients’ level of knowledge. Thomson et al. (2001) conducted a longitudinal survey on a sample of 84 new orthodontic patients and their parents who randomly received either written, visual, or verbal information about the process of orthodontic treatment. Retention of the information was assessed both in the short term (10-15 minutes after receiving the information) and the long term (8 weeks later). They reported that overall, little difference was detected between the three methods of information delivery. The majority of the questions were answered well by
the patients and parents in all the three groups except for the questions asking about the importance of oral hygiene, impact of brace on day-to-day life and the importance of retention. Overall, parents were found to respond better to verbal information than their children and the authors recommended that verbal information given to patients should always be supported by written and/or visual information. A limitation of this study is the fact that the patient’s baseline knowledge was not measured and therefore the actual knowledge enhancement was not detected.

A similar study was conducted by Thickett and Newton (2006) on a sample of 30 new orthodontic patients 12-14 years of age who randomly received information in the form of mind map, acronym, or, standard leaflet. They reported significant differences in patients’ recall between the three methods in both the short term and long term. Participants who were given a written information leaflet recalled less information on both occasions of testing. They also found that the three methods did not differ in the rate of forgetting the material over time. They concluded that mind maps and acronyms convey a small but significant advantage in patient recall of information over written information leaflets. This study has a similar limitation to the study conducted by Thomson et al. (2001) where the participants’ knowledge at baseline was not measured, hence, preventing an accurate detection of the true improvement in knowledge.

More recently Marshman et al. (2016) conducted a mixed method study where qualitative interviews and focus groups were conducted in order to develop a patient-based Fixed Appliance Decision Aid (FADA). This was then evaluated by conducting a quasi-experimental (pre/post-test) study with 30 patients (12-16 years old) and 30 parents. After attending their consultation appointment with the orthodontist and reading standardised information about fixed appliances, all the participants were asked to complete a Decisional Conflict Scale as well as an Orthodontic Patient Expectation Questionnaire (T1). At their follow-up appointment, approximately four weeks later, both young person and parent were taken through the FADA, and completed both questionnaires for the second time (T2). The results revealed that decisional conflict reduced in both patients and parents by nearly 50%
after exposure to the FADA. The participants’ knowledge about duration and frequency of orthodontic treatment increased while their expectations about care were unchanged. They also found that the FADA increased participants’ knowledge of the risks of orthodontic treatment with few being aware of these risks before seeing the FADA. They concluded that using the FADA may enable dental professionals to support patients and their parents, decisions about fixed appliance treatments more effectively, ensuring young peoples’ preferences are integrated into care planning.

2.2.6 Interactive Computer Based Education Materials

Interestingly, in a time where there is a rapid growth and advancement of computer technology, there is a paucity of studies that have attempted to measure the effect of interactive computer based information on the patients’ expectations of treatment even though the literature has demonstrated advantages of this form of patient information over the traditional patient leaflets. Friedman et al. (2011) conducted a systematic review on effective teaching strategies and methods of delivery for patient education. Twenty-three systematic reviews and meta-analyses were included in the study which concluded that the most effective teaching strategies were computer technology (e.g. interactive computerised programmes, computer-based software programmes), audio and video media (CD, DVD), written materials and demonstrations. They recommended that using these strategies in combination with verbal instructions can increase knowledge, reduce levels of anxiety and increase satisfaction levels of the patient.

The benefits of using computer technology to support and enhance patient education has been recognised by health practitioners. Although the initial cost to produce multimedia patient information may be relatively high, software tools have become cheaper, easier to use, and can be customized and updated at a low cost. If created using web-compatible tools, they can be widely distributed at no extra cost allowing patients and their families to refer to the information at their convenience (Barkhordar et al., 2000, Keulers et al., 2007).
As an educational tool the computer provides a private learning experience, that is readily available and can be considered an immediate reinforcement of what has been learnt in the clinic. It can also support the decision-making process, and the information presented can be potentially individualized to each patient (Lewis, 1999).

Barkhordar et al. (2000) conducted a study to compare the effectiveness of an information leaflet with a multimedia program in informing potential implant patients attending a dental hospital. The results revealed that both methods of patient information were effective in informing patients. However, the multimedia presentation had a more positive short-term effect than the leaflet due to the visual nature of the information presented.

2.3 Conclusion

Hypodontia is the most common congenital dental anomaly and a wealth of literature on the aetiology, prevalence and management of the condition has been published. Studies have demonstrated the effects of the condition on the OHRQoL of those affected mainly affecting their emotional and psychosocial well being due to its impact on appearance. In addition, the treatment of hypodontia is complex in nature and prolonged which has an additional negative effect on the patient’s quality of life.

The complexity of the condition and its treatment may make it difficult for dental professionals involved in treating hypodontia to manage the expectations of their patients which could have a negative influence on their final satisfaction with the provided treatment. Theories of patient expectations have revealed that expectations of the process or outcome of treatment is highly correlated with patient satisfaction, and by measuring patients’ expectations before the start of treatment, clinicians might be able to manage those who have unrealistically high or low expectations enabling them to deliver high quality services that patients are satisfied with.

In dentistry, qualitative studies are not common and particularly with regards to the hypodontia patients. Expectation studies that have been conducted relate either to orthodontic treatment or restorative treatment separately and only a small number of these studies used psychometrically validated questionnaires. Furthermore, most of these studies focused on the expectations of the
patients in relation to the treatment outcome as opposed to the treatment process. To date, there are no qualitative studies that have investigated hypodontia patients’ expectations of the process and outcome of combined orthodontic / restorative treatment.

The accuracy of patients’ expectations can be influenced by a number of factors. One of these factors reported in the literature is the mode and context of the patient information provided by the clinicians. However, there is a lack of research especially in the dental field that has investigated the effects of different patient information formats on knowledge and expectations of patients regarding their treatment, and in particular the effects of ICB-EM compared to other traditional formats of patient information.

The aim of this research was to develop an expectation measure of the process and outcome of combined orthodontic / restorative treatment of hypodontia patients as well as a hypodontia specific ICB-EM about the condition and treatment of hypodontia through qualitative patient interviews. These materials will be used to conduct a randomised controlled trial to measure the effects of provision of an ICB-EM on patients expectations of the process and outcome of their combined treatment.
Chapter 3: Study One
A Qualitative Study of Hypodontia Patients’ Information Needs and their Perceptions of the Process and Outcome of Care

3.1 Introduction

Since the 1970s, quality assurance in healthcare delivery has emphasised patients’ perceptions of medical interventions and treatments (Bowling, 2004, Muse et al., 2012). More recently, the practice of patient-centred care has required patients to engage actively in making decisions pertaining to their treatment. In addition, to achieve success in terms of patient-reported clinical outcomes, understanding and measuring the expectations of patients prior to treatment is critical (Yao et al., 2014).

Patients’ expectations are critical determinants of their satisfaction with treatment and unrealistic expectations may indicate the need for additional support (Yao et al., 2014). Whereas previous research has explored the expectations of patients seeking orthodontic (Bennett et al., 1997, Becker et al., 2000, Bos et al., 2003, Sayers and Newton, 2007, Zhang et al., 2007, Marshman et al., 2016) and restorative treatment (Allen et al., 1999, Rustemeyer and Bremerich, 2007, Baracat et al., 2011, de Lima et al., 2011), to date there are no published studies exploring the expectations of individuals with hypodontia of their pathway of care. To our knowledge, there is currently no known measure that evaluates the expectations of treatment process and outcome in patients affected by hypodontia. It is important to explore what patients anticipate because, as for orthodontic and restorative treatments more generally, they are likely to affect treatment perception and overall satisfaction. Expectations also impact on patients’ understanding of the far-reaching implications for changes to their quality of life, with more realistic expectations facilitating higher treatment satisfaction (Sayers and Newton, 2006).

As reviewed in Chapter Two, hypodontia has a number of impacts on the lives of those affected. Patients often require multidisciplinary treatment and the duration of the treatment may be
protracted. In addition to his or her unique dental treatment needs, each patient is also likely to have different information needs. Some patients may have a high level of existing knowledge, due to active information-seeking behaviour, but others may have accessed only information which may be incorrect or no information at all.

Patients who do not have adequate information before the start of treatment, particularly high quality information, may have unrealistic expectations about the treatment process and outcomes, which could lead to patient complaints (Marshman et al., 2016). An online review of websites representing hospitals, private clinics, dental professional groups (e.g. the British Orthodontic Society, the American Dental Association) and support groups revealed that information specific to hypodontia was deficient in both quantity and quality. While the search identified a few examples of information materials targeting hypodontia patients, such as a British Orthodontic Society hypodontia leaflet and a one-page information sheet from the Eastman Dental Hospital in London, it is unknown how these were developed and whether patients’ views were taken into account. Generally, once patients’ views are taken into account, information is better tailored to their actual needs and helps to facilitate realistic expectations, thereby improving treatment satisfaction (Grey et al., 2013). This means that there is a need to develop information material that is both scientifically based and specific to the information needs of the hypodontia patient. The patient-centred nature of medical information is seen as so important that in 1995 the General Medical Council made it a requirement that patients being asked to consent to treatment be given the information they want and ought to have, not just the information that the doctor assumes the patient needs. While existing knowledge and information about dental needs have been researched for orthodontic treatment (Habibian et al., 2003, Marshman et al., 2016), the specific individual information needs of hypodontia patients are unknown.

To address this lack of understanding of hypodontia patients, the present study sought to delineate the key aspects of hypodontia treatment, using a patient-centred approach. The ultimate goal of this line of research is to use the qualitative information obtained through the
interviews in the present study to develop a hypodontia-specific expectation measure and a patient education material. For this to be achieved, the following aims were set:

1. To explore the information needs from the perspective of new, in-treatment, and end of treatment patients. The information obtained will be used to develop a hypodontia specific information material.

2. To explore the expectations and experiences of new, in-treatment, and end of treatment hypodontia patients of the process and outcome of their combined treatment.

3.2 Research design

Healthcare practitioners and policymakers have been increasingly interested in the insights of social science research into human health, utilising the qualitative methods of social research to improve understanding of health, health services and health behaviour (see for example, Hsieh, 2010, Bergendal et al., 2011, Drummond and Drummond, 2012). The use of qualitative methods in the development and validation of questionnaires as well as patient educational material has become increasingly common, in an effort to produce evidenced-based information and measures that are customised to patients’ needs and characteristics.

This study follows in the steps of previous research in the belief that qualitative research methodologies such as undertaking patient interviews, are a valuable way of eliciting the perceptions of patients when developing patient information materials and condition-specific measures (Charnock, 1998, Shepperd et al., 1999, Travess et al., 2004, Asbury and Walshe, 2005, Akram et al., 2011, Marshman et al., 2016). This method is appropriate for obtaining information about the characteristics of particular participants, groups, institutions or situations. Qualitative research is also seen as particularly appropriate for the present study, because it allows for an exploratory approach in an area that has to date been insufficiently researched (Ritchie et al., 2013).

According to Ritchie et al. (2013), qualitative research possesses key features that clearly distinguish it from quantitative research. It investigates how people understand and interpret their social surroundings, using a variety of methods that are interactive and developmental in
nature, involving close contact with the research participants. The data created is usually rich and detailed, generating issues and ideas that can be analysed to produce descriptions, classifications, patterns of association, typologies and explanations, facilitating a deeper understanding of social phenomena.

Because of these benefits, the present study utilised an exploratory descriptive design with semi-structured interviews. The research design chosen had the capacity to provide more information about characteristics within the hypodontia patient group, focusing on the proposed research aims.
3.3 Methods

3.3.1 Ethical Considerations

As this research involved human participants, ethical approval was obtained from the National Research Ethics Committee London – Chelsea, REC Reference number: 13/LO/1146 (Appendix 1). The Research and Development Department of Guy’s and St Thomas Hospital also granted approval for the research (Appendix 2).

There were no foreseeable or known physical or psychological risks to participants in this study. However, some patients were expected to react sensitively to discussing their condition, so it was made clear from the beginning that if they found any particular question sensitive they had the option of not answering it. Patients were advised that their participation would have no impact on their current or future treatment and they would not be identified by name in any way in any future publication. They were informed that their participation would not be noted on any medical record and that the researcher was not an employee of, or in any way affiliated with, the healthcare setting. The potential risks were minimised in the study by taking the following precautions:

1. The researcher obtained a fully informed consent of all participants;

2. It was made clear that participation was voluntary and that participants were free to withdraw at any time before or during the study without explanation, as well as not to answer any question that they might find sensitive;

3. Written consent was obtained prior to the audio recording of patient interviews;

4. All data from the study were anonymised, participant names were recorded and stored separately from participant data, and participants were assigned an identifying number. No names of any participants appeared on any transcripts. No participants will be identified in any publication or presentations arising from this study;

5. Patients who appeared distressed in any way were not approached for participation in the study;
6. All participants were given information letters before their first contact, including the contact details of the researcher in case they had questions regarding the study;

7. Participants who required further support or who wanted to submit an official complaint were given details of the hospital counselling service;

8. All the interviews were downloaded from the audio recorder onto an encrypted password-protected USB device, and physical copies were locked in a filing cabinet in an office. All data collected will be kept for one year from the end of the PhD programme, after which it will be destroyed in accordance with the guidelines of the National Research Ethics Committee and the Research and Development Department of Guy’s Hospital for the responsible conduct of research.

3.3.2 Interview Guide

This study used an interview guide that functioned both as a prompt and to maintain narrative focus. The guide was based on the recommendation of Ritchie et al. (2013), who assert that semi-structured interviews are beneficial because the posing of predetermined questions is useful in facilitating responses.

The topic guide, which was formulated as a written document to be utilized during the interview sessions, was reviewed and refined with the assistance of the three research supervisors and a social researcher from the National Centre of Social Research London. The content of the interview guide was based on the research aims. The questions of the topic guide differed slightly according to at what stage of treatment the patient was in, whether new, in-treatment, or end of treatment (See Appendix 3 for the topic guide).

3.3.3 Defining participant groups

A series of semi-structured interviews were conducted with three groups: new patients, those in treatment and those at the end of treatment. All the patients were attending a specialist hypodontia clinical service at a secondary care facility (Guy’s & St Thomas’ NHS Foundation Trust, London). Patients were classified as “new” if they had never received orthodontic or restorative treatment from any institution for their condition. Those classified as “in treatment”
were nearing the end of their orthodontic treatment phase, all being ready for bracket debonding. Depending on the unique patient needs, this meant that some were about to end their treatment, while others were entering the next phase of treatment, the restorative phase, which involved replacing the missing teeth. Patients were classified as at the “end of treatment” if they had completed their orthodontic and restorative phases of treatment. These participants were interviewed after their final review appointment, before being discharged.

It was considered necessary to interview patients at different points in the treatment process to be able to gauge the full range of expectations from the viewpoints of those who never had treatment to those who experienced some or all of the treatment as those who had experience of treatment would be able to discuss aspects of treatment with unformed expectations at commencement. The information needs would also likely be different according to the stage of treatment the patient was in.

### 3.3.4 Recruitment

During the first round of interviews, held in the first two months of the study, only new patients were invited to participate. In the second round, during the third and fourth months of the study, only patients who were nearing the end of their orthodontic phase of treatment were interviewed. During the third round of interviews, held in the fifth and sixth months of the study, only patients who had completed their restorative phase of treatment were considered. Temporary ‘staggering’ of participants’ treatment phases was undertaken to allow the researcher to maintain focus on each type of participant group. Suitable participants were invited via a letter sent to their home address at least two weeks in advance of their consultation appointment. For participants over the age of 16, the letter contained an invitation to participate in the study along with a participant information sheet. Participants under the age of 16 received a child-friendly information sheet as well as an information sheet for their parent or legal guardian (Appendices 4, 5, 6 and 7).
New and In-treatment Participants

Recruitment of new and in-treatment participants was conducted in the orthodontic department of Guy’s and St Thomas’ NHS Foundation Trust. At the time of the study, the multidisciplinary hypodontia clinic ran once a week within the orthodontic department, in the mornings. On average, 16 patients were seen in this clinic during each session. Interviews took place from February 2014 to May 2014. The selection of appropriate participants began by referencing the hypodontia computer log of patients who were given an appointment to attend the hypodontia clinic at Guy’s and St Thomas’ NHS Foundation Trust, then the dental notes of suitable participants were screened to determine whether they were new to treatment or in treatment, as well as to establish whether they fulfilled the inclusion criteria.

End-of-Treatment Participants

Participants at the end of treatment were chosen by approaching restorative or prosthodontic specialists and asking them to provide details of patients who had received restorative treatment and were scheduled for a final review appointment before being discharged. Their notes were screened to confirm that they had completed their treatment and that they fulfilled the inclusion criteria. On the day of their appointments, the researcher approached potential participants towards the end of their appointment, asking them whether they had read the invitation letter and participant information sheet and whether or not they wanted to participate.

3.3.5 Participant Sample

In the absence of clear criteria regarding sample size in qualitative research, participant numbers for our investigation were founded on consideration of adequacy, appropriateness and data saturation (Polit and Beck, 2013, Ritchie et al., 2013). Adequacy refers to the sufficiency and quality of the data that the sample yields, according to Polit and Beck (2013), who identified a nexus between adequacy and sample size, which is determined by the quality of the data yielded. An appropriate sample is defined as resulting from the identification and use of participants who can best supply information according to the requirements of the study (Polit and Beck, 2013, Ritchie et al., 2013). According to Ritchie et al. (2013), qualitative researchers
should generally continue to collect data until they reach saturation, when the collection of new
data sheds no further light on the issue under investigation.

Since the interviews were conducted in stages and based on the number of patients who agreed
to participate, the sample could not be considered random. This necessitated the use of a
purposive sampling approach, whereby only those hypodontia patients meeting the
requirements were invited to participate, allowing the researcher to collect all the desired
information in accordance with the study aims. Individuals were included in the study if they
were patients and their parents/carers of any ethnicity, were able to read and speak English at
the level required for a typical consultation, aged 10 years and above, and having no
craniofacial deformity or syndromes associated with hypodontia. Patients were excluded from
the study if they were not able to read or speak English, were below 10 years of age or
presented with an accompanying craniofacial deformity and when consent for participation was
refused by the adult patient or by his or her legal guardian if below the age of 16. A wide age
range was included in the study, as it was felt important to capture the full range of views by the
patients.

Data saturation from the on-going analysis of themes guided the final sample size. No new
themes emerged from the data after 25 patients were interviewed. In order to recruit these 25
patients, 48 patients were approached with 23 declining to participate (see Table 3.1 for patient
characteristics). One of the male and 15 of the female participants were accompanied by a
parent / guardian.
### Table 3.1 Interview participants’ characteristics – patients only (n=25).

<table>
<thead>
<tr>
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<th>Male n (%)</th>
<th>Female n (%)</th>
<th>TOTAL n (%)</th>
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<tr>
<td><strong>Stage of Treatment</strong></td>
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<tr>
<td>Pre-treatment</td>
<td>4 (40%)</td>
<td>6 (60%)</td>
<td>10 (40%)</td>
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<tr>
<td>Mid-treatment</td>
<td>3 (27.3%)</td>
<td>8 (72.7%)</td>
<td>11 (44%)</td>
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<tr>
<td>Post-treatment</td>
<td>1 (25%)</td>
<td>3 (75%)</td>
<td>4 (16%)</td>
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<tr>
<td><strong>Age group (year)</strong></td>
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<td></td>
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<tr>
<td>10-18</td>
<td>7 (43.8%)</td>
<td>9 (56.2%)</td>
<td>16 (64%)</td>
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<tr>
<td>&gt;18</td>
<td>1 (11.1%)</td>
<td>8 (88.9%)</td>
<td>9 (36%)</td>
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<tr>
<td><strong>Severity of hypodontia</strong></td>
<td></td>
<td></td>
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<tr>
<td>Mild</td>
<td>4 (66.7%)</td>
<td>2 (33.3%)</td>
<td>6 (24%)</td>
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<tr>
<td>Moderate</td>
<td>1 (10%)</td>
<td>9 (90%)</td>
<td>10 (40%)</td>
</tr>
<tr>
<td>Severe</td>
<td>3 (33.3%)</td>
<td>6 (66.7%)</td>
<td>9 (36%)</td>
</tr>
<tr>
<td><strong>Site of hypodontia</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Anterior</td>
<td>3 (42.9%)</td>
<td>4 (57.1%)</td>
<td>7 (28%)</td>
</tr>
<tr>
<td>Posterior</td>
<td>2 (25%)</td>
<td>6 (75%)</td>
<td>8 (32%)</td>
</tr>
<tr>
<td>Anterior and posterior</td>
<td>3 (30%)</td>
<td>7 (70%)</td>
<td>10 (40%)</td>
</tr>
<tr>
<td><strong>Total number of males/females</strong></td>
<td>8 (32%)</td>
<td>17 (68%)</td>
<td>N=25 (100%)</td>
</tr>
</tbody>
</table>

### 3.3.6 Data Collection: the interview process

A single researcher (AB) conducted the interviews and had no involvement in the treatment of the hypodontia patients during that time. The interviewer was a qualified orthodontist who had good knowledge of the treatment required by hypodontia patients.

The researcher approached new and in-treatment patients in the waiting area of the orthodontic department on the day of the hypodontia clinic, while end-of-treatment participants were approached after they had completed a review appointment in the restorative clinic.

All participants were asked whether they had read the invitation letter and the information sheet and if they agreed to participate. The researcher allowed participants to ask any questions arising from the information sheet they had received before they agreed. They were then asked to sign a consent form and to fill in a short demographic sheet (Appendixes 8 and 9). The parent or legal guardian of any patient under 16 years of age was also asked to give consent.

Then participants were invited to enter a separate room that the researcher had booked. For participants under the age of 16, parents or legal guardians were also required to attend; the parents or legal guardians of patients over 16 years of age were allowed to attend if they wished.

Before each interview the researcher introduced herself, welcomed the interviewees and thanked them for agreeing to participate, then requested that all mobile phones be turned off. The researcher then gave the participants a short introduction to the study and the main aims
and objectives of the interview, before covering the ethical considerations mentioned in section 3.3.1. Interviewees were reminded that the interview would take approximately 30-60 minutes.

Each interview began with the researcher asking participants to say their names, to differentiate between children’s and parents’ voices for the purpose of transcription. This was followed by ice-breaker questions asking the patient and the parent (if present) to state their age, what they did day to day and what their hobbies were. As these questions were intended to establish rapport with the interviewees, the researcher would also answer the same questions, to make participants feel more comfortable in disclosing information.

All the participants were interviewed about how the condition affected their everyday life. This also aimed at determining whether these patients had engaged in information-seeking behaviour and if they had, what sources were used. It was considered important to explore these areas in order to make the participants think more deeply about their condition and how much information they had already, which eventually led them to identify their information needs including what information they thought was relevant and should be informed of before the start of treatment and the format of delivery of this information. The information obtained regarding the participants’ information needs was used to develop the ICB-EM.

“New patients” were also asked to express their expectations of the process and outcome of the treatment they would be receiving. “In treatment” participant interviews were aimed at identifying what patients expected from the process and outcome of the combined treatment they were yet to receive, while the “end of treatment” participant interviews focused on their experiences of the combined treatment they had received as a whole, in addition to their perceptions of the treatment outcome and the relationship of these views with their initial expectations. Information generated regarding the expectations and experiences of the treatment process and outcome were used to develop the HTEQ.

The researcher received training in conducting in-depth interviews at the National Centre of Social Research London and had therefore developed the necessary skills to conduct the interviews without influencing the opinions of the participants and maintaining neutrality throughout the discussion. This was done by the researcher avoiding confirmatory feedback.
(such as nodding and praise), taking care not to reveal her own opinions and allowing participants enough time to generate their own responses without extra prompting. The researcher ended each interview by summarising the main points raised.

### 3.3.7 Transcription and Coding

All the interviews were recorded, downloaded onto a password-protected computer, transcribed verbatim and entered into QSR NVivo 10 software to facilitate data management during analysis. For the purpose of the study, the analysis combined both inductive and deductive approaches, drawing on the existing literature on patient expectations and information needs to derive categories deductively, as well as inferring novel categories from the data. In a thematic analysis, the researcher identifies and reports patterns of themes or groups of meaning within the data. This allows the systematic categorization of the data into higher-order key themes addressing the overall research question. To ensure the reliability of the data, each transcript was independently coded by at least two members of the research team. Analysis of themes occurring in the interviews proceeded in parallel with the interviews until no new topics arose (data saturation); (Ritchie et al., 2013).

To analyse the interview transcripts, the researcher applied the following phases of data analysis, drawing on the process outlined by Ritchie et al. (2013); (Figure 3.1):

- **Phase 1:** Getting familiar with the data
- **Phase 2:** Constructing an initial thematic framework
- **Phase 3:** Indexing and sorting
- **Phase 4:** Reviewing data extracts
- **Phase 5:** Constructing categories.
Figure 3.1 The formal analysis process, adapted from (Ritchie et al., 2013).
Phase 1: Familiarisation with the data

In order to become familiar with the data, the researcher read through three transcripts twice. The first reading involved no note taking or coding, but allowed the researcher to understand the depth and breadth of the content. During the second systematic reading, the researcher made notes of what was significant about each response and coded for the topic being discussed and for as many potential themes and patterns as possible. It was common that responses addressed more than one topic of discussion. Hence, responses with several topics were coded under multiple headings. If a response covered the topics of patients’ information needs and expectations of treatment, for example, then it was coded under each of these topic headings. The familiarisation process continued until it was felt that the diversity of the circumstances and characteristics within the dataset had been understood (Ritchie et al., 2013).

Phase 2: Constructing an initial thematic framework

In the second phase, the researcher generated a list of all the topics that had emerged from the responses in Phase 1, then organised the responses meaningfully by grouping them under each topic. The researcher then rearranged the topics by identifying underlying ideas or ‘themes’ that linked particular items which were then used to group and sort the items according to different levels of generality. Organising the data in this way generated an initial thematic framework with a hierarchical arrangement of themes and subthemes, enabling the researcher to hold the overall structure in her head, rather than becoming lost in a proliferation of more specific labels (Ritchie et al., 2013). In this study, the researcher identified six major themes, under which more detailed subthemes were nested.

Independent parallel coding: In order to enhance the validity of the results a member of the research team was given two transcripts from which the initial thematic framework was developed. Without seeing the framework, the second coder is asked to create a second set of themes and subthemes from the raw text. This is then compared with the first framework to establish the extent of overlap. The two frameworks were merged into a combined set.
Phase 3: Indexing and sorting

Next, indexing was accomplished with the assistance of NVivo, each phrase or sentence of the data being assigned to the appropriate theme and labelled accordingly. The data was then charted and rearranged so that items with similar content or properties were located together, using a thematic structure that allowed the analyst to focus on each subject in turn, as well as allowing intensive review of the content, a process called ‘fractured discourse’. The advantage of NVivo is that the link with the original location is always retained, enabling the researcher to view the data transcripts highlighted as they occurred in the transcripts as well as in thematic sets.

Phase 4: Reviewing data extracts

After dividing the topics into themes, the researcher repeatedly re-read all the responses and considered the validity of their assignment to each theme. During this review process, it was carefully determined whether any topics had been missed or misclassified in the earlier coding. In other words, the researcher ensured that all responses were grouped under the appropriate themes. Topics under the ‘miscellaneous’ theme were carefully examined to see if they would fit another theme (Ritchie et al., 2013). Themes that seemed irrelevant were discarded. The researcher also merged themes that fitted together. Large themes with many topics or separate elements were subdivided to make them more specific.

Phase 5: Constructing categories

In the final phase, the researcher identified the different elements of the responses, as well as the dimensions that differentiated them, and grouped the responses that were judged to be similar. The data was examined again and the elements were combined into different types of responses to yield a set of categories and higher order classifications that discriminated between different manifestations of the data (Ritchie et al., 2013).
3.4 Results

This section presents the results of the exploration of the areas of discussion during the interviews, with reference to the categories generated during thematic analysis. There is a discussion of the way in which participants’ lives were affected by their condition, their information-seeking behaviour, as well as the information needs of the participants. The participants’ expectations of the treatment process and its outcome were explored, and finally, for those participants who had undergone treatment, their experiences of the treatment process and its outcomes were considered. Table 3.2 lists all the major themes and subthemes that were identified from the analysis of the interview data. In what follows, each theme is presented with a quotation as an example; to give the reader an idea of the characteristics of the person speaking, each quotation is identified by the participant’s number, whether it was the parent or the patient speaking, the stage of treatment, the severity of the patient’s condition (mild, moderate or severe) and the site of the missing teeth (anterior [ant], posterior [post] or anterior-posterior [ant-post]).
<table>
<thead>
<tr>
<th>Effects of Hypodontia</th>
<th>Information-Seeking Behaviour</th>
<th>Information Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychosocial impacts</td>
<td>Barriers to looking up information</td>
<td>What is hypodontia</td>
</tr>
<tr>
<td>Practical impacts</td>
<td>Motivations for looking up information</td>
<td>• Prevalence</td>
</tr>
<tr>
<td>Coping strategies</td>
<td>Sources of information</td>
<td>• Diagnosis</td>
</tr>
<tr>
<td></td>
<td>Attitudes towards information</td>
<td>• Aetiology</td>
</tr>
<tr>
<td></td>
<td>Judging the accuracy of information</td>
<td>• Side Effects</td>
</tr>
<tr>
<td>Treatment of hypodontia</td>
<td>Treatment Options</td>
<td>Treatment of hypodontia</td>
</tr>
<tr>
<td></td>
<td>Treatment Process</td>
<td>• Treatment Options</td>
</tr>
<tr>
<td></td>
<td>Treatment Outcome</td>
<td>• Treatment Process</td>
</tr>
<tr>
<td>Hypodontia clinic</td>
<td>Purpose</td>
<td>• Treatment Outcome</td>
</tr>
<tr>
<td></td>
<td>Nature of the clinic</td>
<td>Hypodontia clinic</td>
</tr>
<tr>
<td></td>
<td>Procedures</td>
<td>• Purpose</td>
</tr>
<tr>
<td></td>
<td>Outcome of the clinic</td>
<td>• Nature of the clinic</td>
</tr>
<tr>
<td>Patient Education Material</td>
<td>Advantages</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Layout</td>
<td>• Advantages</td>
</tr>
<tr>
<td></td>
<td>Content</td>
<td>• Layout</td>
</tr>
<tr>
<td></td>
<td>Format</td>
<td>• Content</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Expectations and Experiences of Treatment Process</th>
<th>Expectations and Experiences of Treatment Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypodontia Clinic</td>
<td>Changes in Appearance</td>
</tr>
<tr>
<td>• Nature of the clinic</td>
<td>• Better smile/Gaps closed</td>
</tr>
<tr>
<td>• Procedures</td>
<td>• Teeth straightened</td>
</tr>
<tr>
<td>• Outcome of the clinic</td>
<td>• Better appearance</td>
</tr>
<tr>
<td>Orthodontic Treatment</td>
<td>Functional Changes</td>
</tr>
<tr>
<td>• Purpose</td>
<td>• Improved eating</td>
</tr>
<tr>
<td>• Practical impacts</td>
<td>• Improved speech</td>
</tr>
<tr>
<td>• Psychosocial impacts</td>
<td>• Improved brushing</td>
</tr>
<tr>
<td>Restorative Treatment</td>
<td>Psychosocial Changes</td>
</tr>
<tr>
<td>• Type of restorative treatment</td>
<td>• Improved confidence</td>
</tr>
<tr>
<td>• Practical impacts</td>
<td>• More sociable</td>
</tr>
<tr>
<td>• Psychosocial impacts</td>
<td>• Positive effect on career</td>
</tr>
</tbody>
</table>

Table 3.2 Coding tree obtained from analysing the interviews showing the five main themes, their subthemes (bold) and elements (bullet points).
3.4.1 Effects of Hypodontia

The participants were asked to express how their condition affected them and their everyday life which resulted in the identification of three main themes: ‘Psychosocial impacts’, ‘Practical impacts’ and ‘Coping strategies’, with subthemes for each (Table 3.3). A few interviewees from the in-treatment and end-of-treatment groups reported that they were not affected by the missing teeth. However, further exploration revealed that they were actually affected, but to a lesser extent, and that the problems that they mentioned tended to be practical, in contrast to the psychosocial impacts discussed later in this section. The remaining participants reported psychosocial impacts as a result of the practical impacts, and a variety of coping strategies were identified.

<table>
<thead>
<tr>
<th><strong>Effects of hypodontia</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Practical Impacts</strong></td>
</tr>
<tr>
<td>Structural</td>
</tr>
<tr>
<td>Functional</td>
</tr>
<tr>
<td>Daily activities</td>
</tr>
<tr>
<td><strong>Psychosocial Impacts</strong></td>
</tr>
<tr>
<td>Appearance</td>
</tr>
<tr>
<td>Emotional feelings</td>
</tr>
<tr>
<td>Impact on confidence</td>
</tr>
<tr>
<td>Impact on interpersonal relationships</td>
</tr>
<tr>
<td>Impact on career</td>
</tr>
<tr>
<td><strong>Coping strategies</strong></td>
</tr>
<tr>
<td>Positive copers</td>
</tr>
<tr>
<td>Negative copers</td>
</tr>
</tbody>
</table>

*Table 3.3 The effects of hypodontia on the participants QoL.*
Practical Impacts

The practical impacts were manifested as being either; structural, functional, or affecting daily activities.

Structural: this included the participants being objectively aware of the physical condition and where the problem was, such as the presence of gaps, small teeth, retained deciduous teeth, poor development, delayed eruption of permanent teeth and finally, small jaws. Examples of such problems are presented below:

“That other people would fixate on my mouth when I was speaking because obviously there were two like massive black gaps either side of my front teeth”. (Patient participant 20: in-treatment/moderate/ant) [gaps]

“Yes and the shape of course because I have quite a lot of conical teeth and quite a few baby teeth as well, so milk teeth.” (Patient participant 11: in-treatment/severe/ant-post) [small teeth]

“She also has one tooth at the back which I can’t remember what the medical term is but it didn’t have any enamel so it was decayed quite badly at the very back which doesn’t help because a number of teeth are also missing, adult teeth.” (Parent participant 7: new/moderate/post) [poor development of permanent teeth]

Functional: Functional problems included difficulty with eating and speech. Some participants reported problems with biting and chewing into certain foods such as tough meats, apples and hard sweets, while others described food getting stuck between the teeth due to the presence of gaps, which some considered embarrassing:

“Eating was slightly more difficult I think. It is slightly difficult to assess because I don’t really know how it is to eat normally with teeth but I know that I couldn’t eat apples because I didn’t have teeth here to bite into an apple and carrots and anything that is sort of crunchy. I like had to eat really far back because I couldn’t eat it completely normally, so I think that was an issue.” (Patient participant 23: end/severe/ant-post)

Problems with speech included the presence of a lisp and not being able to pronounce certain letters, as expressed by the following parent:

“He used to say ‘gaggy’ for ‘daddy’ because he didn’t have the teeth to use the tongue against his teeth, so I think probably you might not have been aware of that and we probably weren’t, but just knowing something about that myself it must have affected him.” (Parent participant 24: end/severe/ant-post)

Daily activities: The ‘daily activities’ subtheme included elements relating to the impact of missing teeth on daily activities such as tooth brushing and playing musical instruments. The
participants reported that they found tooth brushing to be especially difficult in areas where the teeth were malformed or sensitive. A participant even reported that he had to stop playing the saxophone as a result of his condition. This is an excerpt of one transcript on this theme:

“Definitely it was harder to brush because they were a lot smaller and they were quite spongy as well, so there wasn’t much surface area to clean.” (Patient participant 24: end/severe/ant-post)

Psychosocial Impacts

The psychosocial impacts were wide ranging, with patients’ appearance affecting their emotional feelings, their confidence, their relationships with others and their work. These impacts were particularly dominant in participants whose condition was easily noticeable because of the presence of gaps.

Appearance: The effects on appearance were mostly related to structural problems. The participants concerned were not happy with their appearance; some only mildly disliked their appearance, while others expressed stronger feelings, using terms such as “ugly duckling”. This consciousness and awareness of appearance formed the basis of the other psychosocial impacts of the condition. An example of the impact of hypodontia on appearance is given in the following quote:

“Well, because if you look in the mirror you just notice it… The missing teeth are very visible.” (Patient participant 13: in-treatment/severe/ant-post)

Emotional feelings: As a result, a few participants stated that their problems were more related to their emotional feelings, ranging from isolation to victimization; their sense of difference from others was conveyed with expressions such as “I was the only one”, “ostracised”, “weirdo” and “alien”:

“Yes, because when you say my second teeth haven’t come through, really, they treat you like some weirdo.” (Patient participant 1: new/moderate/ant) [isolation]

“I think sometimes that upset me a bit actually, when I was younger and when I was a teenager, especially that my family didn’t treat me differently because I kind of thought you should be more sympathetic for me… In a way it’s good and in a way it’s bad because I kind of suppressed a lot of my feelings about my teeth.” (Patient participant 11: in-treatment/severe/ant-post) [victimisation]
Impact on confidence: While a few reported that their confidence was not affected by the condition, others identified the main effect of having missing teeth as reduced confidence, which became more of an issue as they entered the teenage years:

“But then I became a teenager and it was a massive issue all the time...I struggled with it. It was quite difficult. It made me feel really insecure. I think I was a bit less confident.” (Patient participant 23: end/severe/ant-post)

Impact on interpersonal relationships: The interviews revealed that the impact on interpersonal relationships was greater in those participants whose confidence was more affected. These participants revealed that they were not confident in front of strangers and that they would avoid going out of their comfort zone by staying at home. Some participants said that they were teased by their friends, while others mentioned bullying:

“The lisp is kind of embarrassing if I don’t know the person I’m talking to. Like I’m at uni now and will go to parties and things and I’m still quite shy. I don’t confidently hold a conversation with somebody I don’t know because then I will start to notice that I have a lisp.” (Patient participant 20: in-treatment/moderate/ant)

“I got bullied a lot in school... People made fun of me because of it. Well, everyone just made fun of the gaps.” (Patient participant 12: in-treatment/severe/ant-post)

Others stated that although they did experience some teasing, it did not have a negative impact on their confidence or social life:

“I got a few comments from people. When you’re a teenager there’s often these arguments and things like that from people, but I have never really felt bullied because of it... but generally I do have a good social life. I have very good friends. I don’t struggle in my social sphere.” (Patient participant 16: in-treatment/moderate/ant)

A few participants were more positive, explaining that the delayed exfoliation of the primary teeth concealed the problem and people did not notice they had missing teeth; therefore teasing was not a problem they faced.

“No, because no-one has really noticed... because I have the baby teeth.” (Patient participant 12: in-treatment/severe/ant-post)

Impact on career: Some participants revealed a sense or fear of being discriminated against, due to the visible defects, feeling that these might negatively affect their chances of employment or career progression, as expressed here by a parent:
“I think as well they say it’s only cosmetic, but if you meet somebody with missing teeth or rotting teeth if you go for a job interview, and I have been in this position myself where I have interviewed people, if they come in like you say it’s appearance. It makes a difference in how they will feel in the future. You go on appearances first, whether you like it or not.” (Parent participant 5: new/severe/ant-post)

Coping strategies

Participants reported a range of coping mechanisms and it was found that patients could be divided into positive and negative copers. Positive copers did not allow the condition to affect them negatively. Some found other ways to build their confidence, such as going into theatre, while others did not allow the condition to prevent them from socializing, meeting new people and doing whatever they wanted to do. The following excerpt is an example of a positive coper:

“But then I just remember when I was younger my parents put me into the theatre so I would build my confidence in another way, so it’s just kind of like finding other avenues to build that confidence and even if you don’t have it, to look like you have it.” (Patient participant 11: in-treatment/severe/ant-post)

The remaining participants were labelled negative copers, who allowed the condition to impact on their lifestyle negatively by altering their behaviour and using avoidance mechanisms such as not talking, not socializing, not going out, not eating in front of people and not smiling. Others modified their behaviour to conceal their condition by, for example, covering the mouth while smiling and talking, smiling with a closed mouth and mumbling; they described these actions as subconscious, becoming part of a learnt habit. The following quotes are illustrative:

“I don’t smile or anything because I feel like people can notice it.” (Patient participant 18: in-treatment/mild/ant) [Not smiling]

“I don’t smile with my mouth open at all. … I used to be able to when I was little, I just didn’t want to because of the missing teeth, but now it has got to the stage where I have trained myself. I physically can’t smile with my mouth open. I haven’t done it for so many years it’s not possible anymore, I have to do it with my mouth shut, because I never like photos of myself with my mouth open, because you can see gaps and things.” (Patient participant 20: in-treatment/moderate/ant) [Smiling with mouth closed]
### 3.4.2 Information-Seeking Behaviour

Analysis of data relating to the information-seeking behaviour of the participants revealed five main themes: ‘barriers to looking up information’, ‘motivations for looking up information’, ‘sources of information’, ‘attitudes towards information’ and ‘judging the accuracy of the information’ (Table 3.4).

<table>
<thead>
<tr>
<th>Information seeking behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Barriers to looking up information</strong></td>
</tr>
<tr>
<td>Emotional factors</td>
</tr>
<tr>
<td>Quality of information</td>
</tr>
<tr>
<td>Perceived need</td>
</tr>
<tr>
<td>Responsibility of treating clinician</td>
</tr>
<tr>
<td><strong>Motivations for looking up information</strong></td>
</tr>
<tr>
<td>Lack of information</td>
</tr>
<tr>
<td>Peace of mind</td>
</tr>
<tr>
<td><strong>Sources of information</strong></td>
</tr>
<tr>
<td>Internet</td>
</tr>
<tr>
<td>Dentist</td>
</tr>
<tr>
<td>Friends and family</td>
</tr>
<tr>
<td>NHS</td>
</tr>
<tr>
<td>Help groups / Societies</td>
</tr>
<tr>
<td>Leaflets</td>
</tr>
<tr>
<td><strong>Attitudes toward information</strong></td>
</tr>
<tr>
<td>Lacking</td>
</tr>
<tr>
<td>False</td>
</tr>
<tr>
<td>Overwhelming</td>
</tr>
<tr>
<td>Not tailored</td>
</tr>
<tr>
<td><strong>Judging the accuracy of information</strong></td>
</tr>
<tr>
<td>Sources of information</td>
</tr>
<tr>
<td>Cross-checking</td>
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<tr>
<td>Self-judgement</td>
</tr>
</tbody>
</table>

**Table 3.4** The information seeking behaviour of the participants.
Barriers to looking up information

Some participants stated that they had not looked up information about their condition and its treatment. When they were asked what prevented them from searching, four subthemes emerged from their answers: emotional factors, information quality, perceived need and the belief that this is the responsibility of the treating clinician. Participants were particularly worried about the nature of the information that they would find and how that information might affect them emotionally. For example, a participant expressed a fear of the unknown:

“I think looking on the internet, really, or reading into something that you don’t really know is not a good idea, because there have been many occasions that I’ve searched the internet for symptoms that I’ve had and worried myself over nothing, so the best thing is just to wait and see what the outcome is.” (Patient participant 9: new/mild/ant)

Others were not sure of the quality of the information that they would find, stating that it might be incorrect or not tailored to their individual needs:

“It’s hard because you want the information, you want to look it up, but sometimes, as you know, it’s a game of Chinese whispers, what one says doesn’t mean what the other one’s going to do for you.” (Parent participant 5: new/severe/ant-post)

Some of the participants did not consider it necessary to look up information, because either they were simply not interested, they did not have the time to do so, they did not think that they had a major problem, or they trusted the doctors to provide them with the correct information:

“I don’t generally tend to look things up. If you are talking about the internet, I don’t really do that, I go to the doctor and I trust what the doctor says, or the dentist says, and I try not to look.” (Patient participant 8: new/severe/ant-post)

Finally, a few patients explained that it was the responsibility of the treating clinician to provide patients with the required information:

“He said ‘Well, what are they going to do?’ I said ‘I don’t know. We’ll go. It’s a consultation and that’s what happens in a consultation, it’s like going to the doctor’s, you go to the doctor’s because you’ve got an earache. Well, can he deal with it there and then or has he got to refer you on?’ You don’t know, and I said you often get that in all consultations. So I said ‘Today will be a consultation so you will know whether today they might take an x-ray and you will see somebody and then from there on we will have a bit more information about what’s going to happen’.” (Parent participant 5: new/severe/ant-post)
Motivations to look up information

Those participants who stated that they had searched for information about the condition prior to their appointment were asked to explain their motivations for doing so. Some of them expressed the need to find certain information that had not been provided by the dentist, such as the aetiology and prevalence of the condition and the options for treating it:

“I didn’t know anything about it at all and I didn’t know that this was (as I now know) that this is fairly common. I don’t know if it has always been the same or if there is a change now but I looked into the options maybe that I was fairly old during pregnancy that it may have had something to do with it…. I checked with our dentist at the time what can be done and she gave us some very very limited information about possible implants later on in life but that’s all the information we got.” (Parent participant 7: new/moderate/post)

A parent reported having been shocked by the diagnosis and needing to search for information in order to come to terms with it:

“From the initial x-ray, it was all a bit of a shock, and so I walked out trying to come to terms with it, and what it would mean, and then I went away and researched it myself.” (Parent participant 10: new/severe/ant-post)

Sources of Information

When asked where they had found their information, the internet was considered their primary resource, as it was readily available and they were surrounded by a media environment:

“It’s all on the internet, isn’t it, so you can’t really get away from the internet anymore, it’s kind of all around you.” (Patient participant 4: new/moderate/ant-post)

Although participants identified the dentist as another major source of information, they felt that the information provided by the dentist was either insufficient or too basic:

“I would sometimes run something past our normal dentist and you are right, it is not his area of speciality and suffice to say that he is interested to look at Lara’s teeth because it is something he doesn’t see very often. And he tries to be helpful, and if I have got a general question about implants, or how things are developing and, then he is very nice and does his best to answer it, but it is not really his area.” (Parent participant 2: new/severe/ant-post)

Other participants considered their friends and family to be suitable sources of information. However, the information shared was not specific to hypodontia and was primarily related to the general aspects of treatment, such as cost:
“Yes, I just spoke to a girl who is only a friend who has had a brace put on and my other friend’s son has had a brace put on but she didn’t say there was any cost at all, but then she is on her own anyway. She has split from her husband. Her husband is in Cyprus and he is still out there. So whether she wouldn’t have to pay because of her circumstances I am not too sure.” (Parent participant 6: new/moderate/ant)

Others reported that they had visited an orthodontist in order to obtain more information:

“I have seen an extremely nice orthodontic lady… and she had talked about various options and, for us, temporary options because we are now getting to the age where, all of a sudden, we are very conscious of the cosmetic looks of teeth.” (Parent participant 2: new/severe/ant-post)

In addition to websites belonging to support groups and societies, interviewees reported that the NHS websites had been a valuable source of information:

“I have had quite a lot of help from the Ectodermal Dysplasia Society, because missing teeth is a big thing for those kids. Even though I am not sure we fit in the group, I am very happy to get information from them and they link in with the Eastman, so I think they are a good source of information.” (Parent Participant 2: new/severe/ant-post)

Finally, a few participants reported receiving leaflets explaining the fixed appliance phase of treatment only, but these leaflets were not specifically about hypodontia:

“I was given a brochure about braces and what to do in case of an emergency or how to clean my teeth.” (Patient participant 1: new/moderate/ant)

Attitudes toward information

When participants were asked for their opinions of the information that they had been able to obtain, all of the views expressed were negative. The participants reported that the information was either lacking or false:

“It’s like saying someone’s got cancer without knowing what type of cancer, you know they do so much now for cancer, they explain to you what the procedures could be and what you might have to go through, I don’t think we have had that really. I just got told this was his condition, we are referring you to Guy’s and that was it — no contact no nothing.” (Parent participant 6: new/moderate/ant)

Others felt worried after searching for information. The overwhelming and frightening nature of the information found triggered unwarranted anxiety about her child:

“A lot of the research on the internet is very scary, because it talks about it being genetic and maybe having lots of teeth missing like Charlotte can be linked to other things as well, so I was quite worried about what might be involved... And when you look it up on the internet, there is lots of information, too much almost, and it does say that there might be other problems - that it’s linked with other health
issues as well. So that was a big concern for us.” (Parent participant 10: new/severe/ant-post)

Finally, one participant explained that she did not know if she could believe the information that she found on the internet, as it was not tailored to her condition:

“But I did find that the information on the internet wasn’t brilliant for me. I think it was either very very basic or very specialised... I read on the Internet that treatment can take 8 years, treatment can take 3 years, 5 years and, you know, you don’t know what to believe... There are so many things that maybe I have that somebody else doesn’t have and the internet doesn’t really cater [to that].” (Patient participant 11: in-treatment/severe/ant-post)

Judging the accuracy of information

The interviewer asked the participants to state how they knew whether or not the information that they had obtained was trustworthy. Some participants were more confident about accepting information originating from credible healthcare institutions, such as the NHS websites, and would steer away from websites created by individuals or which appeared to be biased:

“Usually, if you look for a specific item like this one, you get lots of weird and wonderful things which you then look at, but most of them are irrelevant. But I think the NHS site is usually quite informative. If it is a site advertising, for example, I would not necessarily pay much attention to it. If I look up any symptom of an illness, I would always stay away from a site that advertises a product, but that is really all.” (Patient participant 7: new/moderate/post)

Others suggested comparing information that was obtained from the internet with information from other sources, or from more than one website, in order to cross-check the consistency of the information:

“...by comparing it with lots of other information, and if it says the same thing then I’m pretty hopeful that it’s accurate... You just have to take a chance with the internet and just read lots of different things to get an average really.” (Patient participant 10: new/severe/ant-post)

Reflections upon the advantages and disadvantages of traditional media were also shared. Participants were more inclined to trust internet-based information than books. This was due to the preferred currency of the data, as information is updated more frequently online:

“Apart from books, books aren’t really any help any more. They are not very up to date.” (Parent participant 5: new/severe/ant-post)

“I suppose you could look to see when it was last updated and go from there really. You would have to just take what’s on the screen.” (Patient participant 8: new/severe/ant-post)
While some of the participants would rely on their own judgement to evaluate the accuracy of the data, others did not feel able to do so. Below are two examples:

“You just go by what you feel in your heart I think, it’s your own judgement, you are relying on your own judgement.” (Parent participant 5: new/severe/ant-post)

“You can’t decide if it is accurate.” (Patient participant 9: new/mild/ant)
3.4.3 Information Needs

The interviews revealed that participants had very limited pre-existing information about their condition. Those who appeared to be more knowledgeable were either active information seekers, had a family member who had experienced the same problems, or were part of the in-treatment or end-of-treatment interview groups.

New patient participants were asked what information they needed in order to be able to make informed decisions about their treatment, while the in-treatment and end-of-treatment participants were asked to express their information needs based on their experience of the treatment process and its outcome.

Analysis of the data on information needs revealed four main themes: ‘what is hypodontia’, ‘treatment of hypodontia’, ‘hypodontia clinic’ and ‘patient education material’. Each of these four themes contained several subthemes (Table 3.5). The themes revealed in this section addressed the first aim of this study and was used to develop the ICB-EM, which will be explained in Chapter 4, section 4.2.2 of this thesis.
<table>
<thead>
<tr>
<th>Information Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What is Hypodontia</strong></td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
</tr>
<tr>
<td><strong>Aetiology</strong></td>
</tr>
<tr>
<td><strong>Side effects</strong></td>
</tr>
<tr>
<td><strong>Treatment of Hypodontia</strong></td>
</tr>
<tr>
<td>• Temporary options</td>
</tr>
<tr>
<td>• Orthodontic</td>
</tr>
<tr>
<td>• Restorative</td>
</tr>
<tr>
<td>• Surgical</td>
</tr>
<tr>
<td><strong>Treatment process</strong></td>
</tr>
<tr>
<td>• Coordination between specialities</td>
</tr>
<tr>
<td>• Duration of treatment</td>
</tr>
<tr>
<td>• Appointment frequency</td>
</tr>
<tr>
<td>• Impact of treatment on lifestyle</td>
</tr>
<tr>
<td>• Location</td>
</tr>
<tr>
<td>• Funding</td>
</tr>
<tr>
<td>• Risks of treatment</td>
</tr>
<tr>
<td>• Patient responsibilities</td>
</tr>
<tr>
<td><strong>Treatment outcome</strong></td>
</tr>
<tr>
<td>• Longevity of false teeth</td>
</tr>
<tr>
<td>• Longevity of deciduous teeth</td>
</tr>
<tr>
<td>• Difficulties faced in adjusting to new teeth</td>
</tr>
<tr>
<td>• Benefits of treatment</td>
</tr>
<tr>
<td><strong>Hypodontia Clinic</strong></td>
</tr>
<tr>
<td><strong>Nature</strong></td>
</tr>
<tr>
<td>• Number of clinicians</td>
</tr>
<tr>
<td>• Types of clinicians</td>
</tr>
<tr>
<td>• Procedures involved in the clinic</td>
</tr>
<tr>
<td><strong>Patient Education Material</strong></td>
</tr>
<tr>
<td><strong>Content</strong></td>
</tr>
<tr>
<td>• Before / after photos</td>
</tr>
<tr>
<td>• Child friendly</td>
</tr>
<tr>
<td>• Reassurance</td>
</tr>
<tr>
<td><strong>Layout</strong></td>
</tr>
<tr>
<td>• Colourful</td>
</tr>
<tr>
<td>• Child friendly</td>
</tr>
<tr>
<td>• Short and sweet</td>
</tr>
<tr>
<td>• Table of contents</td>
</tr>
<tr>
<td><strong>Format</strong></td>
</tr>
<tr>
<td>• Videos</td>
</tr>
<tr>
<td>• Written</td>
</tr>
<tr>
<td>• Available online</td>
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<tr>
<td>• Emails</td>
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<td>• Apps</td>
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<td>• Posters</td>
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**Table 3.5** The information needs of the participants.
What is Hypodontia?

All of the participants expressed their desire to learn more about hypodontia as a condition. They reported that the information, which had been given to them by the various health practitioners tended to focus on the treatment of their condition, rather than giving facts about the condition itself:

“Thinking about it, I don’t know that much about hypodontia… I have googled it a few times but I don’t know if I was given information specifically about the condition. I was given information on my own treatment but not the condition. It would be interesting to know a bit more about the condition.” (Patient participant 23: end/severe/ant-post)

Issues related to NHS funding made participants eager to know about other aspects of the condition, such as its prevalence, and how and when it can be diagnosed:

“It seems to me, now that I have looked into it, and also even from your interview, that it is not a very uncommon condition and she didn’t seem to know anything about it. So even maybe in terms of information you give to your general practicing dentists not just to the general public… Another consideration, I have to say, was that I was a bit worried that, beyond a certain age, there is no NHS treatment for these things… so I wanted to find out if this could be diagnosed as a medical issue at a young age, but I don’t really know how it operates.” (Parent participant 7: new/moderate/post)

Other patients thought that it was important to find out the aetiology of hypodontia, either for their own reassurance or in order to know if it could be prevented:

“Just for kind of self-knowledge, I don’t know, I would say closure but that’s not the right word. Like when they said it could be in your genes. Obviously if you don’t know, I don’t know if there is anything that could prevent that, but just so that you have that pre-warning of how it could affect the rest of your life, even if it’s not for you personally.” (Patient participant 22: end/mild/ant)

Moreover, some patients considered that it was important to gain an understanding of the impact of having missing teeth, such as the effect that this condition could have on eating:

“It affects the way a person eats. If you don’t have normal teeth, it’s like the molars in the back — you can’t chew and you can’t swallow. Well you can, but the dynamics of the digestion change and perhaps that should be enlightened a little bit, the biology.” (Parent participant 3: new/mild/ant)
Treatment of Hypodontia

Options: In this section, the most important subtheme was concerned with options for treatment. Patients were keen to learn their options for treatment. In the case of younger patients, they wished to know if any temporary options for treatment were available until they were old enough to receive the final treatment:

“That was one of the issues that we had… You know what the problem is but nothing can happen until she’s sort of 18, 19 and fully grown, so it’s really a case of what you do in the interim.” (Parent participant 10: new/severe/ant-post)

The participants agreed that a summary of treatments would be helpful which should include information on the different aspects of treatment, such as the need for orthodontic treatment, restorative options and whether or not surgical treatment involving extractions was required:

“How is it going to be resolved? Is he going to have an implant? If not, which kind of other options do you have to resolve the gap that he has? Is he going to wear braces and, if not, why?” (Parent participant 3: new/mild/ant)

“If I knew they were going to take two more teeth out, I would probably have reconsidered it.” (Patient participant 19: in-treatment/mild/ant)

Process: In general, the participants expressed the need to understand the process of treatment and to be given an explanation of the different procedures they would have to go through in order to achieve the treatment objectives:

“Yes, guidance is probably the best way to explain it. Clear guidance as to the route that is going to be taken… I think maybe something that just kind of outlines the journey in the sense of the kind of treatment you will be receiving over the course.” (Patient participant 24: end/severe/ant-post)

More specifically, participants wanted clear guidance on which specialists would be involved in their treatment and on how members of different specialities coordinate the treatment:

“Yes, and like how many people will be working with me, like you said about a team of people.” (Patient participant 7: new/moderate/post)

“Because there is a lot of overlap between different departments of hypodontia, which is something I wasn’t really very aware of when I began my treatment, I wasn’t aware of how the orthodontic team and the restorative team have to work in harmony with each other and have to communicate with each other. It’s very much a joint thing. I think if that was made clear from the beginning, it would just be a lot easier to understand why your treatment was going in a certain direction or why things were being done.” (Patient participant 11: in-treatment/severe/ant-post)
The duration of the different aspects of the treatment was considered by the participants to be important; this included receiving information about the waiting time between different stages of treatment and the frequency of appointments, in addition to being told what impact the treatment would have on their lifestyle:

“Timescale. I know we knew the timescale, but we didn’t appreciate... how much it would impact on our lives with hospital visits... We have had 10 or 12 appointments on this lower jaw to get it right and for Jonathan it impacted on his gap year simply because he couldn’t travel. He couldn’t do any of the things that he wanted to do because every 3 or 4 weeks he had an appointment, and although we knew that, because we made those appointments at the beginning, that didn’t mean anything to us. So if somebody had said to us ‘Look, this is going to impact enormously on your lifestyle but it will be worth it’, I think that might be helpful.” (Parent participant 24: end/severe/ant-post)

Participants also wished to know where the treatment would be undertaken. Would it have to take place at a hospital, or could it be performed at a local dentist’s surgery or specialist practice?

“And also whether treatments would need to be done here. Would it have to be done in a specific place or would it be possible to be done local?” (Patient participant 13: in-treatment/severe/ant-post)

The financial implications of treatment, in particular the probability of receiving funding from the NHS, was considered to be an important factor in decision-making:

“...and also finance. This was something that my husband was very worried about and something that we talked about first time round because, obviously, we didn’t know if it would be covered under the NHS or if we would need funding, and that would have been helpful to know in a leaflet about what may or may not be funded and what it would include.” (Parent participant 10: new/severe/ant-post)

The participants also highlighted the importance of understanding the risks of undergoing treatment. For example, they wished to be informed of the pain associated with it:

“Perhaps whether or not it would be painful.” (Patient participant 17: in-treatment/moderate/post)

Furthermore, participants believed that it was important to understand the consequences of choosing not to undergo treatment:

“I think what would be very interesting also would be knowing about potential problems if the treatment is not done, because some people might feel ‘I don’t mind if I have a missing tooth at the back’, but if there were any orthodontic implications with teeth moving or whatever — possible problems that may arise if you don’t have treatment.” (Patient participant 14: in-treatment/mild/post)
Finally, participants expressed their confusion regarding their responsibilities during treatment. They required information on how to look after their deciduous teeth, if their diets need to be modified and what to do in emergency situations:

“We need to protect our milk teeth as long as we can and so what should you be doing? If you have just got milk teeth, do you change to adult toothpaste or do you keep them on children’s toothpaste if the teeth are not strong enough to take the extra fluoride, do you avoid apples and things?” (Parent participant 2: new/severe/ant-post)

“Yes, perhaps advice on how to care for your braces and your composites if you are having them, what to avoid and what not to avoid… What to do in emergency situations.” (Parent participant 13: in-treatment/severe/ant-post)

Outcome: Another dominant subtheme that emerged from the participants’ responses was the need to visualise the outcome of treatment. They requested more clarity on how they would look after receiving the final treatment and wished to see some examples of previous patients:

“Yes, I think we didn’t have a crystal ball so we couldn’t see the end result and, of course, I think anybody who is going to start on anything like that, they want to know. All I kept saying is ‘Can you show me pictures of what it will look like?’” (Patient participant 24: end/severe/ant-post)

Others wanted to know how long their false teeth would last and, if deciduous teeth were maintained, how long they would last:

“How long it [her bridge] would last.” (Parent participant 21: end/moderate/post)

“How long a baby tooth might last.” (Patient participant 15: in-treatment/moderate/post)

Finally, participants from the “end-of-treatment” group conveyed the importance of clarifying the difficulties that might be faced in adjusting to the false teeth:

“I didn’t know that after having the bridge fitted, that obviously having the impressions taken you kind of take it for granted that it is something alien in your mouth. At first it felt really odd and things like eating were a bit of a struggle and it was uncomfortable for a few days.” (Parent participant 21: end/moderate/post)
The Hypodontia Clinic

When asked if they knew what the hypodontia clinic was, the majority of participants responded negatively, in spite of the fact that most of them had attended the clinic previously. Consequently, they expressed a desire to understand the purpose of the clinic:

“If we have a little booklet explaining what the initial appointment is for, what would go on to being and from there you would say ‘Look, once you have seen the consultants they will put a plan together.” (Parent participant 5: new/severe/ant-post)

Participants also requested more information on the nature of the clinic, including the number of clinicians, their specialities and the procedures that would take place during the clinic. For example, the following participant was surprised by the nature of the clinic and therefore recommended providing future patients with more information on this subject:

“I didn’t expect all of those people and I didn’t expect it to be such a hospital environment where there were people in surgeons’ scrubs and things. I didn’t ever think people who perform surgery would have to sit in on dental appointments. That just didn’t occur to me, so no, I didn’t expect that.” (Patient participant 20: in-treatment/moderate/ant)

Patient Education Material

The participants were asked to provide their view-points on whether or not they though a patient education material would be beneficial and how the information should be delivered including the layout, content and format.

Perceived Advantages: With the exception of one participant who believed that information guides were unnecessary, all of the patients thought that providing them with a leaflet would be beneficial to their treatment:

“I am not sure really. I haven’t really found that I have needed much information on it. You just kind of know that you don’t have these teeth and you have got options to pick from and that’s ok really. I suppose, because it’s not that uncommon, that you just accept that to some people it happens and to some people it doesn’t and that’s ok.” (Patient participant 15: in-treatment/moderate/post)

However, those who replied positively believed that materials providing specific information about the condition and treatment of hypodontia would have several benefits for patients. Better quality information would provide them with a better understanding of their condition and its treatment and would enable them to ask better questions during their consultations. It would
also help patients with information recall, manage their expectations and lead to improved decision making and cooperation. The following quotes are examples of such benefits:

“To have a leaflet or booklet prior to any consultation, it just brings you up to speed a little bit more, as a patient or a patient’s dad or mum, so you don’t have to keep explaining things 3 or 4 times. At least it sort of affiliates us a little bit to what you guys can do.” (Parent participant 4: new/moderate/ant-post) [better understanding]

“It enforces it because the orthodontist would tell you and give you certain information but by the time you get home you might have forgotten but you would have it there. To remind yourself.” (Patient participant 17: in-treatment/moderate/post) [information recall]

“Yes plan for the future. Yes, then I would know more information about what they are going to do. Helps to prepare you for what could happen.” (Patient participant 8: new/severe/ant-post) [manage expectations]

“You would co-operate much better with the professionals in this instance and I think things would run more smoothly, because everybody is aware of exactly what is happening.” (Parent participant 6: new/moderate/ant) [improved cooperation]

Content: In addition to their information needs discussed above, some participants thought that the material should be colourful with the addition of cartoon images, as this would make the information material more child friendly. They also suggested that the leaflet could provide reassurance by showing examples of other children who had successfully completed their treatment:

“Don’t know, lots of pictures. She liked the front of the leaflet you’ve got with the big smiley face with the missing tooth. She loved that. She wants to cut it out and take it in to school.” (Parent participant 8: new/severe/ant-post)

“Maybe there could be a little documentary of someone who has already had it from when they were about our age and then grown up [showing] it’s been fine.” (Patient participant 2: new/severe/ant-post)

Layout: The participants revealed that it is essential for the material to be laid out properly so that it is more appealing to the reader by using colours and images and not too much text. They expressed their desire for an educational material that is not too lengthy but as short as possible. A few reported that it would be beneficial to place a table of content so the reader can choose what to read rather than go through the entire material.

“Yes, I think as well keeping things quite short helps, because I think if you go into things in too much detail people don’t understand or don’t know what you are talking about then you lose track.” (Parent participant 8: new/severe/ant-post)
Format: Finally, the participants were asked for their views on the best format for the delivery of this information. Although some requested the use of videos, explaining that it would be more memorable, other participants expressed a preference for written information, as it would be physically available and could be referred to at any time:

“I would rather watch something... if someone talks to you, that is still good but you kind of forget what they say. I think I would remember it a lot more if it was shown to me on a video.” (Patient participant 15: in-treatment/moderate/post)

“No, I think the leaflets. To be honest with you, I was speaking for myself. Well it’s the kind of thing you could leave on the side of the sofa at home or whatever.” (Patient participant 4: new/moderate/ant-post)

Those who preferred to receive written information also requested that it be made available online or on the hospital website, so that patients could refer to the information in their own time:

“Maybe a website that we can look at in our own time without people pushing us to read it, we can just look it up and not have to be told anything. You can just look it up when you want to look it up.” (Patient participant 6: new/moderate/ant)

Other forms that were reported but to a lesser extent were to present it as poster to be placed in the waiting area, as emails, and as mobile applications:

“Some sort of app, if you are going to make an app, it has got to be detailed but also make it free because then more people can download it. You are not going to spend 69p on an app to go and help you with your teeth are you, although it would be nice to get some money off that but then not many people would download it if it was going to be 69p.” (Patient participant 15: in-treatment/moderate/post)
3.4.4 Expectations and Experiences of Treatment Process

In this area, “new patient participants” were asked what they expected from the treatment process in general, while the “in-treatment participants” were asked to express their expectations of the treatment they were yet to receive. “End-of-treatment participants” were asked to discuss their experiences of the combined treatment they had received considering their initial expectations. In general, new patients revealed a lack of clarity with regard to the specialties that would be involved in their treatment in general; a few did not know how many specialties would be involved, while others thought that there would only be one specialist responsible for their entire treatment. Two participants reported that they had no expectations at all regarding their treatment process and that it would be difficult for them to anticipate what might happen, as they had not received this kind of treatment before:

“He hasn’t had any dental treatment before, so he is not aware of what might happen. That’s a difficult one to think about, because he has not had anything done before.” (Patient participant 9: new/mild/ant)

However, from the information obtained from the rest of the participants, three main themes were revealed under this category including: ‘hypodontia clinic’, ‘orthodontic treatment’, and ‘restorative treatment’, with a number of subthemes under each theme (Table 3.6).
<table>
<thead>
<tr>
<th>Hypodontia Clinic</th>
<th>Nature of the clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Consultation appointment</td>
</tr>
<tr>
<td></td>
<td>Discuss treatment options</td>
</tr>
<tr>
<td></td>
<td>Number of clinicians</td>
</tr>
<tr>
<td></td>
<td>Types of clinicians</td>
</tr>
<tr>
<td>Procedures</td>
<td>Brace fitted</td>
</tr>
<tr>
<td></td>
<td>Dental exam</td>
</tr>
<tr>
<td></td>
<td>Radiographs</td>
</tr>
<tr>
<td></td>
<td>Photographs</td>
</tr>
<tr>
<td></td>
<td>Impressions</td>
</tr>
<tr>
<td>Outcome of the clinic</td>
<td>No treatment</td>
</tr>
<tr>
<td></td>
<td>Joint treatment plan</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Orthodontic Treatment</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Redistribute the spaces</td>
</tr>
<tr>
<td></td>
<td>Make it easier to fill the gaps</td>
</tr>
<tr>
<td></td>
<td>Reduce number of fake teeth needed</td>
</tr>
<tr>
<td></td>
<td>Close the gaps/ no replacement teeth needed</td>
</tr>
<tr>
<td>Practical impacts</td>
<td>Pain</td>
</tr>
<tr>
<td></td>
<td>Eating</td>
</tr>
<tr>
<td></td>
<td>Treatment duration</td>
</tr>
<tr>
<td></td>
<td>Funding for treatment</td>
</tr>
<tr>
<td></td>
<td>Appointment frequency effecting school / job attendance</td>
</tr>
<tr>
<td>Psychosocial Impacts</td>
<td>Other people’s reactions</td>
</tr>
<tr>
<td></td>
<td>Effect on appearance (positive/negative)</td>
</tr>
<tr>
<td></td>
<td>Effect on confidence (positive/negative)</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Restorative Treatment</th>
<th>Type of restorative treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Implants</td>
</tr>
<tr>
<td></td>
<td>RBB</td>
</tr>
<tr>
<td></td>
<td>Build ups</td>
</tr>
<tr>
<td></td>
<td>Removable dentures</td>
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<tr>
<td></td>
<td>No restoration</td>
</tr>
<tr>
<td></td>
<td>I don’t know</td>
</tr>
<tr>
<td>Practical Impacts</td>
<td>Location of treatment</td>
</tr>
<tr>
<td></td>
<td>Funding for treatment</td>
</tr>
<tr>
<td></td>
<td>Eating and drinking difficulties</td>
</tr>
<tr>
<td></td>
<td>Effects of appointment on school/job attendance</td>
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<tr>
<td></td>
<td>Longevity of the restoration</td>
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<tr>
<td></td>
<td>Maintenance</td>
</tr>
<tr>
<td>Psychosocial Impacts</td>
<td>Inability to engage in social activities</td>
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<td></td>
<td>Other people’s reactions</td>
</tr>
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Table 3.6 The participants’ expectations and experiences of the process of orthodontic/restorative treatment.
**Hypodontia clinic**

When asked if they were aware of the hypodontia clinic, some new patients replied negatively. The interviewer explained that it was the consultation clinic that they would be attending on the day of the interview, then asked them what they expected to happen in that clinic. The analysis revealed three themes: ‘the nature of the clinic’, the ‘procedures’ and the ‘outcome’.

*Nature of the clinic*: The new and in-treatment participants were asked to comment on what they thought the purpose of the clinic was and their answers revealed their awareness of the fact that it would be a consultation appointment to discuss the treatment options available for their condition. Participants were aware they would be seen by more than one person but others were not expecting to see as many people as they did, which they described as ‘daunting’ and ‘hectic’. Those who had attended the hypodontia clinic before, had not anticipated the hospital environment, and were unfamiliar with the uniforms worn by the team and what specialties they belonged to:

“I didn’t expect it to be such a hospital environment where there were people in surgeons’ scrubs and things.” *(Patient participant 20: in-treatment/moderate/ant)*

*Procedures*: When participants were asked what procedures they expected to be carried out at the hypodontia clinic, one new patient participant expected to have the orthodontic appliance fitted, while the rest of the participants stated that they expected a dental examination to be carried out, x-rays and photos taken and perhaps impressions of the jaws:

“I mean in the clinic do you know why you’ve been given an appointment?” [interviewer] I believe it’s to fix braces on my lower teeth.” *(Patient participant 1: new/moderate/ant)*

*Outcome of the clinic*: A few of the new participants stated what outcome they expected from the clinic. Participants were aware that no treatment would be undertaken during the initial assessment clinic but a joint treatment plan would be put in place:

“That they are all going to make a decision and try and work things out between them and then they will put a plan together for my son.” *(Parent participant 3: new/mild/ant)*

121
Orthodontic treatment

The majority of the new patient participants expected to receive orthodontic treatment, while only one participant did not think she needed orthodontic treatment and another did not know whether he would receive it or not. The patients were then asked to comment on their expectations of the process of orthodontic treatment if they were to receive it. In-treatment and end of treatment participants were asked to describe their experience of the orthodontic treatment they had received. The analysis revealed three subthemes: ‘purpose’, ‘practical impacts’ and ‘psychosocial impacts’.

Purpose: While the new patients expressed that they did not know what the exact purpose of the treatment was, those who have received orthodontic treatment thought the purpose was to either close the gaps or redistribute the spaces.

“To move the teeth around in order to later on put implants in or bridges or whatever they decide is the best option.” (Patient participant 12: in-treatment/severe/ant-post)

Practical Impacts: New patient participants reported a range of practical expectations regarding the process of orthodontic treatment. A few patients anticipated that the treatment would be prolonged, especially because the final restorative treatment is usually only done when growth is complete. Others gave an exact timeframe that ranged from 9 months to two years. One participant expressed her awareness that her son would have to come every six weeks during the treatment, while another expected that several appointments would be needed in order to fit the orthodontic appliance. A few participants expected to experience pain from the orthodontic appliance or if extraction of teeth is part of the orthodontic treatment plan:

“I also didn’t know I was starting university really shortly afterwards and I was already really nervous about doing that and so I desperately didn’t want anything that was going to make me stick out more and I thought that not only having braces but having massive gaps in my teeth would make me stick out.” (Patient participant 20: in-treatment/moderate/ant)

Those who had experienced all or part of the treatment reported a range of practical impacts, which included the experience of pain due to ulceration and after tightening the brace. Some had problems eating certain foods due to fear of pain or breakage, while others were not comfortable eating in public for fear that food would adhere to the brace, the alternative being
to take out the brace before eating, which might be embarrassing. Many of the respondents reported that the treatment took longer than they had anticipated. New patients as well as those who experienced treatment reported that they were not sure if they were eligible to receive funding from the NHS. With regard to missing school, the majority of participants found that the treatment had affected their school attendance. The following quote describes the participants’ unrealistic expectations of treatment duration:

“Initially I think I had unrealistic expectations, which even though some doctors were telling me the truth, this is going to take years, this is going to be a long process, whereas I didn’t want to believe it, so I was hoping that my unrealistic expectations would be met, but they didn’t.” (Patient participant 11: in-treatment/severe/ant-post)

Psychosocial Impacts: A range of positive and negative impacts were identified, with the majority finding that wearing a brace negatively affected their appearance. Terms such as; ‘I hated them’, ‘very ugly’, ‘imposing’ and ‘large shiny metal’ were used. The participants felt that their braces were very visible and obvious, that they could not hide them. In fact, a few felt that other people would fixate on their mouths when they were speaking and some had experienced teasing at school.

“I think they are very imposing. Like they are large metal, shiny. It’s in your mouth. You can’t really hide it.” (Patient participant 19: in-treatment/moderate/post)

Some participants reported that wearing an orthodontic appliance made them feel isolated and different from other people. This was a particular finding in older participants who had an orthodontic appliance fitted after their teenage years. Others stated that their confidence was significantly affected, making them feel insecure and uncomfortable in front of other people:

“I think it is an insecure feeling because at a young age you have braces, not when you are older and you have braces.” (Patient participant 19: in-treatment/moderate/post)

In contrast, some found their appearance improved during the orthodontic treatment phase, using terms such as ‘look better’, ‘happier’, ‘look normal’, ‘looked cute’. They found that they were more confident when smiling, especially after gaps had been closed or reduced. Participants who had false teeth attached to the brace had found that they looked natural and improved their overall appearance Some participants even felt that people tended not to notice
orthodontic appliances, because they had become much more common recently. One participant had worn hers for so long that it had become invisible to her and to her friends.

“I really liked them, because it meant that whilst I still had to have the braces, no one could really tell why I was having them and I just had like a full set of teeth and no one… Just there is not massive holes.” (Patient participant 20: in-treatment/moderate/ant)

**Restorative treatment**

*Type of restorative treatment:* New and in-treatment participants were expecting to receive some form of restorative treatment. The type most commonly expected was implants, followed by resin-retained bridges, and finally, build-ups. Other participants either did not know, or had had a course of orthodontic treatment to close the spaces and were therefore confident that restorative treatment was not needed.

“Yes, but nothing is set in stone yet, but I have been told there is going to be a lot of build-up and some implants.” (Patient participant 11: in-treatment/severe/ant-post)

With regards to the end of treatment participants, they tended to confirm the expectations of those at the start of treatment - a range of restorative procedures including build-ups, resin-retained bridges, removable dentures and implants had been received.

*Practical Impacts:* The participants were aware that the final restorative treatment (implants) could be done only when the patient was fully grown; however, they expressed uncertainty as to where the treatment will take place; whether hospital or local dental surgery or specialist practice, and whether funding for the replacement teeth would be received or not. Those who had experienced the treatment reported that they faced difficulties eating and drinking during the course of treatment. The experience of pain was a significant practical impact especially if surgery was involved such as implants and bone grafts which was described as ‘upsetting’ and ‘horrible’. Others also reported that the number of appointments needed to complete the treatment had a direct impact on school and job attendance. Participants were generally not certain of the longevity of the replacement teeth and their role in its maintenance. The following quote represents the effect of treatment on the patients’ school attendance:
“We didn’t really appreciate the knock-on effect of it all really, from the recovery and the coming up. You see, we have to travel two and a half hours to come here for an appointment so it is a whole day. If he had an appointment at 1.30 pm, then he would be leaving school at 11 am and not going back and if you have a late appointment you still leave school at about midday… I think it did affect his schooling to be perfectly honest.” (Parent participant 24: end/severe/ant-post)

Psychosocial impacts: Psychosocial impacts as a result of the treatment included the reactions of other people such as friends and family to having the false teeth placed where some were enthusiastic and positive about it while others feared its effect on their appearance as they went through the process to getting the final restoration. One participant reported inability to engage in social activities or travel as a result of the frequency of the appointments:

“She couldn’t travel…she couldn’t do any of the things that she wanted to do because every 3 or 4 weeks she had an appointment.” (Parent participant 24: end/severe/ant-post)
3.4.5 Expectations and Experiences of Treatment Outcome

New and in-treatment participants were generally optimistic, expecting the treatment to be worthwhile and to produce the best outcome. However, end-of-treatment participants’ views regarding how they felt about the outcome of treatment received were mixed. The analysis revealed three main themes; ‘changes in appearance’, ‘functional changes’ and ‘psychosocial changes’ (See table 3.7).

<table>
<thead>
<tr>
<th>Expectations and Experiences of Treatment Outcome.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Changes in Appearance</strong></td>
</tr>
<tr>
<td>Better smile/Gaps closed</td>
</tr>
<tr>
<td>Teeth straightened</td>
</tr>
<tr>
<td>Better appearance</td>
</tr>
<tr>
<td><strong>Functional Changes</strong></td>
</tr>
<tr>
<td>Improved eating</td>
</tr>
<tr>
<td>Improved speech</td>
</tr>
<tr>
<td>Improved brushing</td>
</tr>
<tr>
<td><strong>Psychosocial Changes</strong></td>
</tr>
<tr>
<td>Improved confidence</td>
</tr>
<tr>
<td>More sociable</td>
</tr>
<tr>
<td>Positive effect on career</td>
</tr>
</tbody>
</table>

Table 3.7 The participants’ expectations and experiences of the outcome of orthodontic/restorative treatment.

Changes in Appearance

People wanted their teeth to look better, using terms such as ‘improved look’, ‘beautiful teeth’, ‘Hollywood teeth’, ‘perfect teeth’ and ‘normal-looking teeth’. They wanted a better smile by having the gaps closed and the teeth straightened. The following words of a parent exemplify such expectations:

“I think for us, it’s just the way we are in our family that good teeth makes a big difference. You’ve got a lovely smile, you’ve got beautiful teeth, and you notice it. People notice teeth now, don’t they? And I think it’s just really important… I suppose because we’re presented with everybody has got beautiful teeth, it’s the way it is presented in the world now, flashing American smiles.” (Patient participant 13: in-treatment/severe/ant-post)

The changes experienced by the end of treatment participants were generally positive in nature, being happy with their appearance especially after the closing of gaps. Some, however, noted a few negative aspects of appearance. For example, one participant thought that her restoration work did not look completely natural, while another had expected “perfect Colgate teeth”.

126
“It’s just like, I thought the teeth would be a bit more like perfect Colgate teeth, but obviously it depends on everyone’s different teeth.” (Patient participant 22: end/mild/ant)

**Functional Changes**

New and in-treatment participants expected the treatment to mainly improve their ability to chew and to speak more comfortably. However, some of the end of treatment participants had difficulties eating; some were worried that the restoration was not secure enough, especially those who had resin-retained bridges. One participant had broken her bridge while eating and had since been cautious about eating certain foods, while another found it easier to eat with the new implants. With regard to speech, participants found that diction became clearer. Finally, brushing was found to be easier after receiving the final restoration.

“Eating was uncomfortable because my bite isn’t as it was and it’s still taking time to adjust. I wasn’t aware that it would be like that, you kind of just think they have taken one out and put one back in and it’s the same. It’s not bad now but at first it was quite strange.” (Patient participant 21: end/moderate/post)

**Psychosocial changes**

Participants expected to feel happier and better about themselves with many anticipating that treatment would play a role in improving their confidence, allowing them to become more sociable and more confident about engaging in social events. Others expected more tangible changes such as a career change or being positively viewed by employers and that there physical appearance would not be an issue when seeking jobs.

“I think as well they say it is only cosmetic but if you meet somebody with missing teeth or if you go for a job interview I think appearance can affect your job…you go on appearances first whether you like it or not.” (Patient participant 5: new/severe/ant-post)

The end of treatment participants found that their confidence had significantly improved following the final restoration; it became easier for them to engage and socialize with other people.
3.5 Discussion

Qualitative research is increasingly being recognised as making a valuable contribution to patient-based care in medicine generally, but it has been found to be still lacking in some fields, especially dentistry (Malterud, 2001, Yamazaki et al., 2009, Masood et al., 2011). The dental literature reports the adoption of qualitative methodologies to gain understanding of topics such as the impact of dento-facial deformity on quality of life (Cunningham et al., 2000, Marshman et al., 2009, Akram et al., 2011, Meaney et al., 2012), motivation for treatment (Ryan et al., 2012a, Grey et al., 2013) and expectations of the process and outcome of treatment (Travess et al., 2004, Ryan et al., 2012b). However, the literature review revealed a paucity of qualitative studies conducted specifically on hypodontia patients, even though this can prove to be very useful when the full range of opinions and attitudes of patients are considered (Meadows et al., 2003); therefore, this area needs to be addressed. The interview data gathered in this study provides valuable insight into the views of hypodontia patients on their quality of life, information-seeking and information needs, as well as their expectations and experiences of the process and outcome of care. The themes generated by the analysis will be used to develop patient-centred, hypodontia-specific educational material and an expectation questionnaire, which to our knowledge has not been done before.

The interviewer in this study had no care-providing role, which minimized bias. Conversely, the interviewer’s pre-existing general understanding of the patients’ situation made it easier to ask the appropriate follow-up questions, thus enhancing the credibility of the study. However, a limitation that was faced was that the risk of bias when interpreting the data was not eliminated completely, because of the pre-existing understanding of the researchers, especially from an orthodontic point of view. This risk was kept to a minimum by having the data analysed independently by two members of the research team, one of whom was not a dental professional and therefore had no experience of the treatment of hypodontia patients.

The evidence suggests that living with a dento-facial deformity can have significant impacts on the lives of the individuals affected. Hypodontia in particular can disable the patient both physically and psychosocially (Hobkirk et al., 1994, Laing et al., 2010, Akram et al., 2011,
Kotecha, 2012, Meaney et al., 2012, Hashem et al., 2013, O’Keeffe et al., 2016). This study has revealed a range of impacts that were categorized as either psychosocial (including impacts on appearance, emotional wellbeing, confidence, interpersonal relationships and career) or practical (including structural, functional and daily activities). The majority of these emergent themes were relevant to the domains of Locker’s conceptual model of oral health (Locker, 1988), with the exception of the impact of the condition on the patient’s appearance, which formed the basis of the rest of the psychosocial impacts and which was considered one of the main factors motivating patients to seek treatment. These themes are largely similar to those generated by previous studies of the impacts of hypodontia (Akram et al., 2011, Meaney et al., 2012, O’Keeffe et al., 2016) and confirm the findings of studies that used quantitative techniques to investigate the impact of hypodontia on patients’ quality of life (Wong et al., 2006, Laing et al., 2010, Locker et al., 2010, Kotecha, 2012). However, an interesting finding unique to this study is that the patients were classified as either positive or negative copers. Some, despite being affected by severe hypodontia and reporting a range of practical and psychosocial impacts, were able to transform these impacts into proactive strategies, as exemplified by the participant who confronted her lack of confidence by going into theatre. Although this finding has not been reported in previous studies of hypodontia, it is well documented in the literature on the coping strategies of patients suffering from general disfigurement, who are reported to employ ‘self-presentation strategies’ that are either avoiding/concealing or proactive in nature, to maintain a sense of acceptability or self-esteem against the impact of others’ reactions (Partridge, 1990, Thompson and Kent, 2001). Studies have shown that those who have strong social skills were viewed more favourably by others, thereby reducing the social impact of a disfigurement (Rumsey et al., 1986, Kapp-Simon et al., 1992, Robinson et al., 1996, Thompson and Kent, 2001).

As to participants’ information-seeking behaviour, although the internet was considered the primary source of information, very few mentioned websites belonging to support groups and societies, or NHS websites. This is consistent with previous studies, which found that specific dental websites are not routinely recommended to patients during hospital consultations, due to the lack of a central resource to which patients can be referred, as well as practitioners’
concerns as to the quality of information presented on the internet (Chestnutt and Reynolds, 2006, Stephens et al., 2013). Other sources that were mentioned, but to a lesser extent, were talking to a health professional, talking to family and friends, and reading information leaflets, which reflects patients’ preference for information that is easy to access and stresses the importance of making information readily available.

Some participants were more active in seeking information for a variety of reasons, including the lack of information they had received from their dentist, as well as the need to come to terms with their condition. This was more evident in participants who were affected by severe hypodontia or those who had anterior teeth missing. Such patients are often more affected functionally as well as by their appearance and this may have triggered their search for information. However, participants were generally concerned with the reliability of information they had obtained, whether from the internet, a general dental practitioner or their family and friends. There was also a lack of clarity and consistency in judging the accuracy of information; some participants were able to display a level of sophistication when analysing the credibility of the information, while others simply did not know. This finding is consistent with previous studies (Gray et al., 2005, Stephens et al., 2013), which stress the role of the clinician in determining the information-seeking behaviour of their patients and directing them to the appropriate websites accordingly. It also serves to highlight the importance of patient education and information that would complement any verbal information given by practitioners (Coulter et al., 1999). It is important for the clinician to investigate and correct any false or misleading beliefs that their patients may have acquired, to prevent the subsequent development of unnecessary anxieties or false expectations of treatment.

The interviews were also aimed at identifying the information needs of the hypodontia patients and their parents/guardians, as the basis for the development of a patient-centred, hypodontia-specific information material. Participants expressed their need for more information on hypodontia, including its prevalence, aetiology, diagnosis and side effects. They were also eager to gain more information on aspects of their treatment process and outcome, in addition to their temporary and long-term options for treatment. More information regarding the hypodontia
clinic including its purpose and nature was expressed as being important to understand. Participants also expressed their desire for a more child friendly and reassuring material by the addition of colour, cartoons and before and after pictures. These findings are consistent with those of previous research, that clinicians’ views of the information needs of patients may not be congruent with the patients’ own views (Habibian et al., 2003, Paul et al., 2004, Asbury and Walshe, 2005) and that integrating the two perspectives will enable the production of high quality, evidence-based information that is sensitive to patients’ needs, thus maximizing the use of available resources. When asked about the format of delivery, the majority of participants said that they preferred written material that would be easily accessible online, while younger participants requested material in video format. This also shows that clinicians involved in treating hypodontia patients should be educated with regards to their information needs, in order to deliver the best possible information, facilitating informed consent and managing patients’ expectations of the treatment process and outcome.

In order to develop a hypodontia-specific expectation measure, the study investigated the expectations of treatment-naïve and treatment-active participants as well as the experiences of patients who had completed treatment. Items investigated included the process and outcome of care, an aspect where there has been little previous research. In general, the new patients expressed greater uncertainty regarding their expectations of the process of care, and were also likely to emphasise the expected functional and psychosocial benefits of treatment. Future studies could explore the degree to which such differences hold true in large surveys of hypodontia patients. The majority of previous studies that have investigated this area have adopted a clinician-based quantitative methodology. Very few studies that would be comparable to the present study have used qualitative techniques to explore patients’ expectations and experiences of the process and outcome of care from an orthodontic, or restorative perspective. To our knowledge, this is the first study to provide information on the expectations and experiences of the hypodontia patient regarding the process and outcome of care.
The current participants revealed a wide range of expectations regarding the process of orthodontic and restorative treatments. The lack of studies in this area makes it difficult to compare our results with previous studies; however, a few of the themes identified here have been reported in studies of the expectations of dental patients with regard to orthodontic, surgical or restorative treatments separately. Themes generated under the expectations of orthodontic treatment were largely similar to those found by other studies (Bennett et al., 1997, Sayers and Newton, 2006). Themes relating to the participants’ expectations of the hypodontia clinic—in particular, the procedures involved—were also similar to those reported under the expectations of the initial orthodontic visit in the same study (Sayers and Newton, 2006). However, we were able to generate more themes that were specific to the hypodontia clinic, such as the nature of this clinic and the expected outcome. This is an important finding, as hypodontia patients are usually seen multiple times in the hypodontia clinic during their course of treatment, usually before they start the treatment and when they reach specific milestones, and if they have accurate knowledge as to what to expect in the clinic, their stress may be reduced, helping them to focus on what is explained during the clinic.

A few patients reported their expectations regarding the surgical treatment they were to receive as part of their restorative treatment plan and pain was considered a primary consequence of the various expected procedures, a realistic expectation as reported by the literature (Rousseau et al., 2002). This underlines the importance of good quality communication when clinicians describe the dental procedures, to manage patients’ expectations and control their anxieties. With regards to patients’ expectations of the restorative treatment they were to receive, the majority expected to receive implants and all their expectations were focused on the process of implant placement, even though this did not apply in the majority of cases, as the patient must meet specific and strict criteria to receive funding for implant-retained restorations. This finding reflects the fact that patients in general view implants as the ideal treatment and therefore expect it to be the first option proposed by clinicians. A study by Cronin et al. (2009) also found that patients tended to favour implants primarily, followed by fixed bridges, because patients are increasingly influenced by the abundance of media advertising implant therapy.
Finally, the new and in treatment participants expressed their expectations of the outcome of the combined treatment they will be receiving while the end of treatment participants expressed their experience with the treatment outcome. While the new and in treatment participants were mainly expecting a positive outcome, the end of treatment participants expressed a range of positive as well as negative experiences of outcomes. The themes identified under this area were largely similar to other qualitative studies investigating the expectations of orthodontic (Tulloch et al., 1984, Bennett et al., 1997, Bos et al., 2003, Sayers and Newton, 2006, Pabari et al., 2011, Marshman et al., 2016), orthognathic (Travess et al., 2004) and restorative (Leles et al., 2008, Grey et al., 2013) treatment outcomes. It is important to ascertain these factors to aid the clinician’s understanding of why the patient is seeking treatment, hence reducing a possible mismatch in thinking between the patient and the clinician (Pabari et al., 2011).

A weakness of the qualitative method reported here is that it was not possible for practical reasons to contact patients to ask for their reflections on the themes identified. Such a review is good practice in qualitative research. However, the researchers did show the final questionnaire and patient education material that were derived from the qualitative study to patients in the hypodontia clinic and received positive feedback. This will be discussed in chapter 4 of this thesis which describes the development process of the research materials.
3.6 Conclusions

- The effects of hypodontia on patients’ quality of life have been explored and three main themes were identified: ‘practical’, ‘psychosocial’, and ‘coping strategies’.

- Patients’ information seeking behaviour was determined and revealed the need to provide good quality information that is reliable, readily available, and easy to access. The results of this area also highlighted the importance of the role of the clinician in determining the information seeking behaviour of their patients, as well as their baseline knowledge, to establish whether it should be modified to avoid the development of false expectations of treatment.

- Patients’ information needs were explored and they expressed a need for more information regarding the condition of hypodontia (prevalence, diagnosis, aetiology, and side effects), its treatment (options, process, and outcome), the hypodontia clinic (purpose and nature), and the patient education material (content, layout, and format). These areas will form the basis of the ICB-EM development, which will be discussed in the following chapter.

- Patients’ expectations and experiences of the process and outcome of their combined orthodontic and restorative treatment were explored. Themes relating to the treatment process were in relation to the hypodontia clinic (nature, procedures, outcome of the clinic), the process of orthodontic treatment (purpose, practical impacts, and psychosocial impacts), and the process of restorative treatment (type of restoration, practical impacts, and psychosocial impacts). Themes relating to the treatment outcome were changes in appearance, functional changes and psychosocial changes. These areas will form the basis of the HTEQ development, which will be discussed in the following chapter.
Chapter 4: Materials Development
Development and Testing the Hypodontia Treatment Expectation Questionnaire and the Interactive Computer Based Hypodontia Educational Material

4.1 Introduction

The development and testing of the HTEQ and the ICB-EM was conducted in preparation for the randomised controlled trial, which will be discussed in Chapter 5 of this thesis.

As there were no existing instruments measuring the hypodontia patients’ expectations of the process and outcome of their combined orthodontic / restorative treatment, a new instrument was developed that was based on the relevant literature as well as the findings of the patient interviews described in Study One. The objectives regarding the HTEQ were to determine the content, whereas the results of the analysis of the data from the interviews were used to generate the items of the HTEQ. In addition, the validity and reliability of the HTEQ was assessed by subjecting the measure to a pilot test and a reliability test. The testing of the research instrument is reported in terms of setting, sampling, and results.

It has been argued that computer-based patient education programs may effectively enhance delivery of health care (Keulers et al., 2006). As reported in the literature, providing computer based education material has several advantages which includes being efficient, potentially inexpensive, readily available, patient focused and inherently effective (Barkhordar et al., 2000, Keulers et al., 2006). Although an ICB-EM may seem worthwhile, its development is usually based on the clinicians’ assumption of ‘what a patient needs to know’ (Waitzkin, 1984, Breemhaar and Van den Borne, 1991).

The objectives regarding the development of the ICB-EM were to ensure the relevance and effectiveness of both its content and presentation. While a variety of techniques within the available literature on the development of patient education materials have been employed, such
as use of interactivity, illustrations and layout, the content was further refined in this preparatory phase by seeking the opinions of a panel of experts and a pilot test. The resources utilised in this preparatory phase included data from the patient interviews, relevant literature, data from the panel review and the pilot test. The designing process that the ICB-EM went through, including its review by the panel of experts and its piloting and how the content was refined will be discussed in what follows.

4.2 Materials and Methods

The development process of both materials ran in parallel to each other and Figure 4.1 displays a flow diagram of the development process both materials went through. However, to ensure clarity for the reader, the development of the HTEQ and the ICB-EM have been explained separately.

In addition, as part of the RCT’s objectives, which will be discussed in Chapter 5, the researcher assessed the participants’ acceptability of the intervention by asking them to fill in the Treatment Evaluation Inventory (TEI). As the TEI in its current format does not adequately reflect the intervention received, a few changes were made to the wording and the number of items used, all of which will be described in detail in section 4.2.3 of this chapter.
**Figure 4.1** Flow diagram of the development process of the HTEQ and the ICB-EM
4.2.1 Development of the HTEQ

4.2.1.1 Selection of Scales

An extensive search using relevant databases was conducted in order to locate expectation questionnaires relevant to hypodontia. The criteria included suitability of the items regarding the intended sample and the capability of addressing the issues identified during the interviews. The research instrument should reflect the patient journey as closely as possible by exploring their treatment expectations chronologically from their initial visit of the hypodontia clinic to the completion of treatment.

Sayers and Newton (2006) provide a psychometrically tested questionnaire that contains elements that were used in this study, however no tool emerged that provided insight into the sequence of patient experiences. The core aim of the questionnaire was to record and characterise the patients’ expectations of orthodontic treatment. The questionnaire was comprised of ten main questions using a VAS for all questions except two where categorical response formats were used. Questions were asked about expectations of their initial visit, the type of treatment expected, problems associated with orthodontic treatment, duration and frequency of attendance and the expected benefits of treatment.

The psychometric properties of the questionnaire was reported by Sayers and Newton (2006) including face and content validity, reliability using test-retest and internal consistency using Cronbach’s alpha. It was found that the questionnaire had good face and content validity, internal consistency produced an overall inter-item reliability > 0.7 and item-total correlation > 0.3 in over 50% of the questions. With regards to test-retest reliability, it was found to be statistically significant using Spearman’s Rank Correlation Coefficient.

Seven items were chosen for use in the following domains: hypodontia clinic (6 items), orthodontic treatment (5 items), benefits of treatment (7 items). Items which were not used concerned: the type of orthodontic treatment expected (5 items), problems with orthodontic treatment (2 items), appointment frequency (1 item) and benefits of treatment (1 item). These items were considered outside the scope of the study (in that they were too specific to orthodontic treatment only and not hypodontia treatment in general), repetitive, or not identified...
as major issues in the interviews. The questionnaire is in the public domain and can be used without breaking copyright law.

Additional items were added pertaining to the issues brought up by the participants as well as the frequency of occurrence of the themes (Table 4.1). The first section of the questionnaire asked about personal information including the patients’ demographic and treatment history. The main themes and subthemes identified from the interviews were used to form the sections of the questionnaire while the elements were used to inform the wording of the questions. The final draft contained a total of 25 items for use in the following domains: hypodontia clinic (3 items, 7 sub-items), orthodontic treatment (3 items, 7 sub-items), restorative treatment (9 items, 5 sub-items) and benefits of treatment (2 items, 16 sub-items). The full scale can be found in Appendix 10. The questionnaire posed the items in two parallel formats. Those participants completing the questionnaire prior to their appointment are given the wording “… do you expect to have?” whereas those who received it after their appointment had the wording “…did you actually have?” This enables the comparison of expected versus actual experience.

An additional personal information section (8 items) was added to the beginning of the questionnaire. The final draft was divided into five sections of which three sections were questions about treatment process and one section about treatment outcome:

A. Personal information

Expectations of treatment process

B. Hypodontia clinic

C. Orthodontic treatment

D. Restorative treatment

Expectations of treatment outcome

E. Benefits of treatment
Table 4.1 Content development of HTEQ.

<table>
<thead>
<tr>
<th>Concepts/areas to be covered</th>
<th>Areas covered by Sayers and Newton (2006)</th>
<th>Areas to be developed in the current study</th>
<th>Total number of items</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hypodontia Clinic</strong></td>
<td>1. Expectations of initial appointment (expected purpose and procedures involved), 7 items: a. Have a brace fitted b. Have a check-up and diagnosis c. Have a discussion about treatment d. Have x-rays e. Have impressions f. Photographs g. Have oral hygiene checked</td>
<td>Nature of the clinic (2 items): 2. Number of clinicians a. 1-2 b. 3-5 c. 6-8 d. I don’t know 3. Types of clinicians a. Orthodontist b. Restorative dentist c. Oral surgeon d. Children dental specialist e. Dental nurse f. Dentist in training g. I don’t know</td>
<td>3 items 7 sub-items</td>
</tr>
<tr>
<td><strong>Expectations of treatment Process</strong></td>
<td>What do you think it will be like? Practical Impacts (3 sub-items): a. Wearing a brace will be painful b. Orthodontics will produce problems eating and drinking c. Duration of orthodontics</td>
<td>1. Do you expect to receive orthodontic treatment? (1 item) 2. Purpose of orthodontic treatment (2 sub-items): a. Easier to fill the gap b. Avoid the need for replacement teeth 3. Practical Impacts (2 sub-items): a. g. I don’t know</td>
<td>3 items 7 sub-items</td>
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<tr>
<td><strong>Orthodontic Treatment</strong></td>
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<tr>
<td>Restorative Treatment</td>
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<tr>
<td>1. Do you expect to receive restorative treatment? (1 item)</td>
<td>2. Types of restorative treatment (5 sub-items):</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>a. No replacement</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>b. Tooth coloured filling material to build up small teeth</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>c. Removable denture</td>
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<tr>
<td></td>
<td>d. Adhesive bridges</td>
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<td></td>
<td>e. Implants</td>
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<tr>
<td>Practical Impacts (6 items)</td>
<td>3. Location of treatment</td>
<td></td>
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<td>4. Funding for treatment</td>
<td>5. Effect on school/job attendance</td>
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<td>6. Problems eating and drinking</td>
<td>7. Longevity of the restoration</td>
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<td>8. Maintenance</td>
<td>Psychosocial Impacts (1 item):</td>
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<td></td>
<td>9. Other people’s reactions</td>
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<tr>
<th>Expectations of treatment outcome</th>
<th>Benefits of treatment</th>
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</thead>
<tbody>
<tr>
<td>1. Expected benefits of treatment</td>
<td>Changes in appearance (2 sub-items):</td>
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<tr>
<td></td>
<td>a. Straight teeth</td>
<td></td>
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<td></td>
<td>b. Better smile</td>
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<tr>
<td>Functional changes (3 sub-items):</td>
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<td></td>
<td>c. Improved eating</td>
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<td></td>
<td>d. Improved speech</td>
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<tr>
<td></td>
<td>e. Improved brushing</td>
<td></td>
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<tr>
<td>Psychosocial changes (2 sub-items):</td>
<td>Changes in appearance (1 sub-item):</td>
<td></td>
</tr>
<tr>
<td></td>
<td>h. close the gaps</td>
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<tr>
<td>2. Importance of each benefit</td>
<td>Changes in appearance (3 sub-items):</td>
<td></td>
</tr>
<tr>
<td></td>
<td>a. Straight teeth</td>
<td></td>
</tr>
<tr>
<td></td>
<td>b. Close the gaps</td>
<td></td>
</tr>
<tr>
<td></td>
<td>c. Better smile</td>
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</tbody>
</table>
|   | f. Improved confidence/more sociable | g. Positive effect on career | Functional changes (3 sub-items):  
|   |   |   | d. Improved eating  
|   |   |   | e. Improved speech  
|   |   |   | f. Improved brushing  
|   |   |   | Psychosocial changes (2 sub-items):  
|   |   |   | g. Improved confidence/more sociable  
|   |   |   | h. Positive effect on career  
|   |   |   |
4.2.1.2 Format of the Questionnaire

The questions included used either VAS or multiple-choice response formats. The VAS questions consisted of a 10mm long scale and were labelled at either end with the two most extreme responses, e.g.: ‘extremely likely/extremely unlikely’. Scores were calculated by measuring the distance to the participants’ mark in mm manually from the left hand. Multiple choice responses and VAS techniques were employed in tandem, as these have not been proven to be more or less efficient than each other. Utilising more than one format provided additional validity to response groupings (Bowling, 2002).

4.2.1.3 Outcome Measures of the Questionnaire

Personal Information

As previously noted in the literature review, patient expectations can be dependent on demographic factors such as age, gender, ethnicity, income and level of education (Bennett et al., 1997, Khan and Williams, 1999, Fromentin and Boy-Lefevre, 2000, Phillips et al., 2001, Bos et al., 2003, Reichmuth et al., 2005, Kiyak, 2006, Sayers and Newton, 2007, Kiyak, 2008, Hiemstra et al., 2009, Sadek et al., 2015). The literature also revealed that severity of the condition can also play a role in forming the patients’ expectations of treatment outcome (Albino et al., 1981, Shaw et al., 1991). In addition, expectations are dependent on previous experiences, therefore previous orthodontic or restorative treatments of the participants or their friends and family members, and familiarity with the treatment process and outcomes were considered to be pertinent to the study. Items included under personal information were: gender, age, ethnicity, number of missing teeth, participant previous experience with orthodontic and/or restorative treatment and finally, family or friends’ previous experience with orthodontic and/or restorative treatment.
Hypodontia Clinic

It has been established over the past few years that running a multidisciplinary hypodontia clinic is considered the gold standard for treating patients with hypodontia and is now occurring in many UK-based NHS hospitals with orthodontic, restorative and oral-surgery units.

According to Hobkirk et al. (2010) attending the MDT is the first step of the patients’ treatment journey after being referred from their local dentist. The patient interviews revealed that participants were not sure what to expect from this clinic and that they required more information on its nature and purpose. Therefore, it was considered important to include a separate section that measures what the patient may expect from this clinic.

This section consisted of 3 items and 7 sub-items of which the first item was included to find out what the participants expect to happen in the clinic (purpose of the clinic and procedures involved) and were incorporated in the questionnaire according to what the participants expected to happen in the clinic during the interviews which included: fitting the brace, check-up and diagnosis, discussion about treatment, x-rays, moulds, photographs and checking of oral hygiene. This was in a categorical response format with yes/no/I don’t know for each of the sub-items. The 2nd item asked the participants how many people they expected to see in the clinic and was in a scaled response format (1-2 / 3-5 / 6-8 / I don’t know). The 3rd and final item in this section asked the participants who they expected to see using a categorical response format where they were able to choose more than one answer from a list that included:

1. Orthodontist (provides braces)
2. Restorative dentist (provides replacement teeth)
3. Oral surgeon
4. Children dental specialist
5. Dental nurse
6. Dentist in training
7. I don’t know
Orthodontic Treatment

The first item in this section asked the participants if they expected to receive orthodontic treatment with ‘extremely unlikely / extremely likely’ on either end of the VAS. The next item was concerned with how the participants thought orthodontic treatment would help their condition (purpose), which also used a VAS and included:

1. Make it easier to fill the gaps (extremely unlikely / extremely likely).
2. Avoid the need for replacement teeth (extremely unlikely / extremely likely).

With regards to the practical impacts of orthodontic treatment, 5 items were included:

1. Pain: wearing a brace will be painful (extremely unlikely / extremely likely).
2. Problems eating and drinking: treatment will produce problems eating and drinking (extremely unlikely / extremely likely).
3. Duration of treatment (scaled response format that ranged from 1 month to 4 years with an ‘I don’t know’ option available).
4. Funding for treatment: Do you think you will be paying for the brace treatment (extremely unlikely / extremely likely).
5. School/job attendance: will treatment effect school/job attendance (extremely unlikely / extremely likely).
**Restorative Treatment**

This section comprised of 9 items and 7 sub-items. The first item asked the participants if they expected to receive orthodontic treatment with a ‘yes / no / I don’t know’ categorical response format. The 2nd item also used a ‘yes / no / I don’t know’ categorical response format and was concerned about the type of restorative treatment the participants expected to receive including: no replacement, tooth coloured filling material to build up small teeth, removable denture, adhesive bridge and implants. The next six items concerned the practical impacts of having restorative treatment using a VAS response format, which included:

- Location of treatment: at a specialist in a practice or local hospital if my case is complex (extremely unlikely / extremely likely).

- Funding for treatment: approval of funding needed from local authority (extremely unlikely / extremely likely).

- School/job attendance: will treatment effect school/job attendance (extremely likely / extremely unlikely).

- Eating and drinking: will treatment produce problems with eating and drinking (extremely unlikely / extremely likely).

- Longevity of the restoration: how long will the replacement tooth/teeth last (1 year or less / 10 or more years).

- Maintenance: how much do you have to do to ensure replacement tooth/teeth last as long as possible (it does not matter what I do / it entirely depends on what I do).

The ninth and final item of this section was concerned with the psychosocial impact of the process of restorative treatment asking the participants how they think people will react to having the false teeth placed and also uses VAS format with ‘negative reaction / positive reaction’ on either ends of the scale.
**Outcome of Treatment**

This section included 2 items and 16 sub-items of which the 1st was concerned with what the participants would expect the benefits of treatment to be:

Changes in appearance

1. Straightening teeth
2. Close the gaps
3. Smile more easily

Functional changes

4. Easier to eat
5. Easier to speak
6. Easier to keep teeth clean

Psychosocial changes

7. Improve chances of good career
8. More confidence socially

The 2nd item was concerned with finding out how important each benefit was to the participants and contained the same previous sub-items:

Changes in appearance

1. Straightening teeth
2. Close the gaps
3. Smile more easily

Functional changes

4. Easier to eat
5. Easier to speak
6. Easier to keep teeth clean
Psychosocial changes

7. Improve chances of good career

8. More confidence socially

All of the sub-items used a VAS format with ‘extremely likely / extremely unlikely’ on either ends of the scale.

4.2.1.4 Questionnaire Layout

The questionnaire was professionally printed on A4 size paper and the front cover was designed with a colourful logo to be visually appealing and inviting to the respondents (Dillman, 1979) with the subsequent page providing directions for use. The questionnaire itself was 11 pages in total (including front cover and directions for use). A number of strategies were used to avoid intimidating the participants with the size of the questionnaire. The instrument was divided into 5 discrete units; each dealing with a specific dimension of the patients’ expectations. This breakdown also enabled the numbering of items to recommence at the beginning of each unit and therefore the questions were considered in small groups ranging from 8 to 13 items, which was considered an effective way of overcoming the psychological hurdle the participants may deal with when confronted with a large amount of information.

4.2.1.5 Panel Review of the Questionnaire

The draft questionnaire was reviewed by fellow researchers, academics and a number of clinicians who were members of the hypodontia team to check the relevance as well the wording of each question for relevance, clarity, absence of bias and reading levels. Once the questionnaire had been designed and approved, it was returned to the National Research Ethics Committee-Chelsea and the hospitals’ research and development department for approval.
4.2.1.6 Pilot Test

The purpose of pilot testing the research instrument was to evaluate its validity. Validity can be defined as the capability of the research instrument to measure what it is intending to measure. Content and face validity are two ways to determine the validity of an instrument. Content validity is concerned with the actual content of the measure (does it represent all the elements of a given construct?). Face validity is the extent to which an instrument is considered to cover the concept it is measuring i.e. the relevance of the instrument to the participants (does it “look like” it is measuring what it is supposed to measure); (Cohen et al., 2011).

The first version of the questionnaire was piloted on a purposive sample of 10 new patients/parents over a period of two weeks. The inclusion and exclusion criteria were identical to that described in Study One for the patient interviews. Potential participants were approached by the researcher in the waiting area of the hypodontia clinic where the purpose and aims of the research as well as the confidential nature of their participation was explained in addition to showing the participants a patient information sheet.

Face and content validity, along with ease of comprehension, were assessed by using the thinking aloud technique where participants discussed their experience of filling in the questionnaire with the researcher as they completed it (Ericsson and Simon, 1980). Parents were also asked to read the questionnaire with their children and their views were taken in consideration. Any queries or areas that posed difficulty to the respondent or that were not answered were recorded. The participants were also asked to comment on the layout and whether they think any items should be added or deleted form the questionnaire and the duration of time taken to complete the survey was recorded. Microsoft Word® was employed to test the readability of the survey according to the Flesch Reading Ease score and Flesch-Kincaid grade.
4.2.1.7 Reliability of the Questionnaire

A total of 40 consecutive new hypodontia patients were invited to participate over a period of three months; inclusion criteria were: 14 years and above and able to read and speak English at a reading level of 12 years. Participants affected by other craniofacial conditions were excluded. The process of patient recruitment was identical to that described in the pilot test, however, the patients were asked to complete the questionnaire themselves without the assistance of their parents / legal guardians.

The responses were entered into SPSS© and Cronbach’s alpha (α) was calculated on the questionnaire as a whole and on the different sections of the questionnaire to test internal consistency (Bowling, 2002). Only the VAS questions were included in the calculation. Items in the Personal Information section were not included, as were the following individual items:

- Treatment Process: Hypodontia clinic questions (B.1, B.2, B.3), How long do you think orthodontic treatment will take (C.3.c), Do you expect to receive restorative treatment (D.1), and, what type of tooth replacement do you expect to have to fill the gaps (D.2).

Three values of Cronbach’s alpha were calculated: Whole scale (items from sections B, C, D and E); Process subscale (items from section B, C, D); Outcome subscale (items from section E).
4.2.2 Development of the ICB-EM

The content of the material was the result of a thorough literature review of the condition of hypodontia and its treatment as well as an internet web search for publically available hospital materials. However, the main content was driven by the themes relating to the patient information needs that were revealed from the patient interviews discussed in Study One.

4.2.2.1 Background

As has been shown in the literature review, there have to date, been no studies conducted that have looked into the information needs of the hypodontia patients. However, from reviewing the literature on the hypodontia care pathway it was found that the most important areas of hypodontia treatment is the hypodontia clinic, orthodontic treatment and restorative treatment (Hobkirk et al., 2010). Therefore, it has been decided that the information material developed should contain these three main elements.

With regards to existing information material, no literature was available suggesting that the information materials were constructed from the perspective of the patient. The content of the located hypodontia information materials appears to be determined by the perspectives of those who developed it, be they hospital administrators or clinicians on the basis of what is assumed patients should be informed about. However, the existing materials located by the researcher, from a range of healthcare settings, were examined carefully to assist the researcher in determining the content.

The majority of information materials examined were obtained through web searches or were in use in hospital hypodontia clinics in the UK. During the initial stages of the current research, only one leaflet was found on the website of the British Orthodontic Society and is a standard two-page leaflet, which forms part of a series of information leaflets produced to educate orthodontic patients. These leaflets are used widely in the UK and it is considered standard care to provide orthodontic patients with the relevant leaflet whenever possible. The remaining information materials located were web based (e.g. hypodontia clinic web page in University College London Hospital website).
As described in Study One, the participants suggested the following content to be included in the patient EM:

- What is hypodontia
  - Definition
  - Diagnosis
  - Side effects
  - Aetiology

- Treatment of Hypodontia
  - Options for treatment
  - Treatment process
  - Treatment outcome

- Hypodontia Clinic
  - Purpose
  - Nature

The next stage of development was to present these concepts in a format to maximize comprehension and accessibility.

4.2.2.2 Design of ICB-EM

Given that the context in which the programme is being employed is likely to be persistently changing, it must provide information that retains its utility to the user regardless. The design of an intervention including its format, layout and language used significantly influences a programme’s comprehensibility and ability to engage the user (Kušec et al., 2006, Ivnik and Jett, 2008). Factors that have been reported in the literature to be important when developing patient information material include clear communication, legibility of print, the use of up-to-date information based on available evidence, and direct patient involvement in content. The available literature consistently advocates the use of simple language and that comprehension
by the user is hindered by medical jargon and complex terminology. As patients are likely to have a wide range of learning abilities, simple language ensures it is accessible to all (Wizowski et al., 2002, Caress, 2003, Paul et al., 2004).

The text used in the material was based on simple vocabulary within short and easily comprehensible sentences. Using short sentences divided into small sections is also recommended by the Adult Literacy and Basic Skills Unit (ALBSU), responsible for assessing rates of literacy in Wales and England (Walsh and Shaw, 2000). Winslow (2001) proposed that in the USA, particular comprehensibility assessments such as the Flesch—Kincaid grade level and the Flesch Reading Ease scores should be utilised. It is recommended that an average sixth grader should be able to easily comprehend the material. The readability of specific material may also be assessed by gaining feedback from the user.

Design of the page, font, pictures and white spaces were all noted as being advocated by the ALBSU to assist readability (Walsh and Shaw, 2000). As has been postulated by many researchers, text comprehension can be facilitated by maximizing the use of white blank spaces (Paul et al., 2004). Moreover, Doak et al. (1985) proposed that illustrations should be utilised as visual cues, to keep the reader focused, as well as to separate key points within the text. It has been found that a document comprised of plain text will not be as appealing to a reader as one that also contains images (Bernardini et al., 2001). In addition, using different colours for text and pages may also enhance clarity (Paul et al., 2004).

4.2.2.3 Format of the ICB-EM

The interviews revealed that the patients prefer the information to be presented in written format as opposed to a video format, and that it should be available online so they could refer to the information in their own time. The author decided to use Articulate Storyline 2© (Articulate Global Inc., New York, NY) software package, which is an interactive learning tool having similar functions to Microsoft© PowerPoint© but with the added functionalities of building it with slide layers and triggers to add interactivity for learners. It also allows for dynamic personalized content and custom interactivity. The published material can be opened by any Microsoft© (Microsoft Corporation, Redmond, WA) based computer platform, Apple Mac©
An individual is able to join in with shaping their education through interactivity. Multimedia-based education seems to be considerably improved if it comprises of an interactive component, by engaging the reader, enhancing their curiosity and satisfaction during the learning process (Lovell and Celler, 1999). Furthermore, Dede and Fontana (1995) argued that learners can shift with relative ease between the different components of a programme, as well as choose the order in which components are learnt, thus making for a much more learner-guided and less rigid educational process.

An ICB-EM will be enhanced in terms of its effectiveness if a number of mechanisms to increase interactivity are utilised. This research has incorporated several of Mayer’s (2002) recommendations with regards to the most effective use of multimedia, which are centred on a number of theoretical concepts:

- The “multiple presentation concept” holds that rather than simply providing an idea as text, it is more effective to also provide related images. Associations can then be formed between the images and text, while also having the advantage of building two different mental representations i.e. visual and verbal models.

- The “temporal contiguity concept” relates to the proximity of associated images and text during a multimedia presentation. If associated material is situated closer to each other, the user will also form the association more easily during their comprehension.

A crucial consideration is how to most effectively design the graphics and layout. Rob (1997) explained that formulating screen-based presentations through attractive messages and
presentation is the role of graphic design. Nevertheless, Keulers et al. (2006) argued that a computer program will never deliver the interactive capabilities of a human being. Similarly, Pellone (1995) emphasised that a computer cannot provide emotional or rational information to the learner in the way that a person can, through various physical language such as expressions or tone of voice while speaking. Therefore, effective graphic designing should attempt to present information in a manner that allows ease of access and be visually appealing in a way that maintains the focus and curiosity of a learner. The following graphic design principles as reported by Keulers et al. (2006) have been followed during the development process:

- **Simplicity**: keeping the messages as simple as possible using only the number of graphics that are necessary. Also, reducing the usage of colours and fonts to a minimum to avoid distracting the learner.

- **Consistency**: consistent layout throughout the material to reduce the cognitive load placed on the reader. This includes consistency in placing the items of the material, the colours and fonts used, style of headings and graphics and terminology used.

- **Clarity**: in addition to using simple language and short sentences, which has been discussed in the previous section, it is important to use enumeration marks whenever possible, avoid negative statements if possible, and use personal pronouns.

- **Balance**: there should be a balance in terms of the size and layout of the objects as well as their value such as the degree of lightness and darkness. Asymmetrical layouts can sometimes be more interesting visually but can be more difficult to design when compared to layouts that are symmetrical.

- **Harmony and unity**: pages designed utilising consistency and repetition. Using similar fonts and colours, and pictures that match the topic. It is also important to use graphics that have a similar tone so that all items presented on the screen appear to belong together.
4.2.2.4 Structure of the ICB-EM

A professional graphic design artist (KK), who had successfully helped with the visual decoration of a new paediatric dental facility at St. Thomas’ Hospital and who specialised in designing Japanese-style cartoon “manga” images was employed to produce a total of 12 cartoon drawings in order to make the material more appealing and child friendly. Another 12 graphics were added in order to illustrate the text such as pictures of radiographs and before and after consented clinical pictures as per the patients’ request in the interviews.

The first page of the ICB-EM featured an illustration of a young girl who is smiling and showing spacing between her teeth suggesting missing lateral incisors. This would help the reader, children in particular, identify with the character. The software provides a table of contents to allow the reader to transfer directly to the information they think is most relevant for them thereby customising the information delivered. They could also navigate through the slides by clicking on the next and back buttons placed on the lower right hand corner of the slides. The title used the descriptor word ‘Hypodontia’ in blue. All the slides in general used a white background with blue borders and the colours of the headings were blue while the text under each heading was dark grey. The material was divided into three main sections: What is hypodontia; Treatment; and the Hypodontia clinic. The following describes the content of the ICB-EM under each heading used within the material:

What is Hypodontia

Figure 4.2 shows a screenshot of the first slide in this section which was divided into four parts:

1. What is hypodontia (definition): the first section provided a brief definition of hypodontia and a frontal intra-oral view of a hypodontia patient in occlusion presenting with missing canines and peg-shaped lateral incisors to allow the reader to visualise the condition.

2. How might this affect me (effects of hypodontia): the main impacts of having missing teeth including its impact on appearance and the functional impacts such as chewing and speech.
3. How is it recognised (diagnosis): this section explains the role of the dentist in the initial diagnosis. A DPT (dental panoramic tomography) view of a hypodontia patient is presented with areas of missing teeth circled in blue. This will help the patient gain a general idea of what to look for when they are shown their own DPT in the clinic.

4. Can hypodontia be inherited (aetiology): this slide describes the genetic basis of the condition and most common condition of which hypodontia can be associated with. A colourful drawing of a family with a DNA strand is placed above the text.

![Figure 4.2 Screenshot of the section ‘What is Hypodontia?’](image)

**Treatment**

This section contained the most complex arrangement of material. Figure 4.3 displays a screenshot of the initial slide in this section. In order to assist comprehension, the first three sections were divided into: my front teeth are missing, my back teeth are missing, and my front and back teeth are missing. The reader chooses the most relevant section according to their condition, which directs them to a number of treatment options presented as buttons. The reader clicks on one of the treatment option buttons to learn more. For example, by clicking the button ‘filling the gaps/no braces’, the reader is directed to a new slide that lists all the options for filling the gaps in buttons. By pressing one button, e.g. “dental implants”, the treatment option
is described in more detail in a new slide. Wherever possible, before and after intra-oral photos, were added to supplement the text and to enhance understanding.

1. My front teeth are missing: this section provides all the treatment options available for someone with missing front teeth including the option of ‘no treatment’. The options that were listed for someone with missing front teeth were: closing the gaps using braces, redistributing the space using braces and filling the gaps/no braces. The options for filling the gaps listed in this section were: dentures, bridges and dental implants.

2. My back teeth are missing: the options for missing back teeth listed were: no treatment, closing the gaps using braces, redistributing the brace using braces and filling the gaps/no braces. The options for filling the gaps described in this section were: dentures, bridges and dental implants.

3. My front and back teeth are missing: the options for treatment included were redistributing the brace using braces and filling the gaps/no braces. The options for replacing the missing teeth were as previously mentioned in the above two sections, dentures, bridges and dental implants.

4. Tooth shape and size: building up teeth with tooth coloured material when the teeth are small or pointed. A before and after intra oral view of this treatment is provided under the text.

5. Will my baby teeth be taken out: the situations where the baby teeth are left in situ or extracted are described in this section. A cartoon image of a dentist holding giant forceps with a molar attached to it is added to the lower right corner of the slide.

6. How long will my treatment last (duration of treatment / frequency of appointments): a brief explanation of the duration of treatment and frequency of appointments. The fact that the duration is variable between patients and is usually extended if it involves combined orthodontic and restorative treatment is explained. Spacing between the two sentences were used to assist clarity.
7. Where can I get my treatment (location of treatment): situations where the patient can be treated in a specialist practice / hospital or at the local dentist is described in this section. An illustration of a lady with a question mark above her head with two arrows on either side pointing at a hospital and a dental clinic is added below the text to enhance the attractiveness of the slide.

8. Will my false teeth last forever (longevity of restorations): the fact that there is no permanent solution to replace missing teeth is stressed in this section as well as the importance of routine check-ups with the local dentist to enhance the longevity.

9. Patients’ comments (impacts of treatment process / outcome of treatment): the most common impacts of undergoing treatment as discovered from the patient interviews are listed as well as the most common benefits of treatment. A significant amount of information was presented in this section, therefore bullet points and spacing between the sentences were used to assist clarity and prevent information overload.

Figure 4.3 Screenshot of the section ‘Treatment’.
**Hypodontia Clinic**

Figure 4.4. shows a screenshot of the first slide in this section which was divided into five parts:

1. **Hypodontia clinic at Guy’s Hospital (purpose of the clinic):** this section describes the main purpose of the clinic. A cartoon image of a group of clinicians representing the hypodontia team is placed above the text.

2. **Your appointment (nature of the clinic):** a brief description of the nature of the clinic including the number and types of clinicians involved is described in this section.

3. **Procedures involved:** the main and most common procedures conducted during this clinic is described.

4. **The team of dentists involved:** this slide contains five buttons with illustrations representing the different clinicians involved in the treatment of hypodontia. The reader is directed to click on the clinician of interest to find out more about their role in the treatment process.

5. **The hypodontia specialist team:** this section provides an overview of the hypodontia team members at Guy’s and St Thomas’ NHS trust including their clinical positions. This will help the reader gain a general idea of who he/she will be seeing when attending the hypodontia clinic and reducing the chances of confusion.

After determining the content, layout and design of the ICB-EM, the material was published by converting the file to Hypertext Mark-up Language (HTML5) to be able to display it on a web browser. The final version of the ICB-EM can be viewed in the flash drive attached to the back of this thesis. With the flash drive, an A4 page is present that provides a detailed explanation on how to open and view the ICB-EM.
4.2.2.5 Panel Review of ICB-EM

The final draft of the ICB-EM was displayed to members of the hypodontia clinic, which comprised of two orthodontic and two restorative consultants, a surgical consultant and a paedodontic consultant. The panels’ opinions with regards to the relevance, wording, clarity and reading levels of the material was taken under consideration. Their opinions regarding the layout, was also taken into account.

The next step was to present this material to hypodontia patients to determine content and face validity. Once the material had been designed and approved, it was returned to the National Research Ethics Committee-Chelsea and the hospitals’ research and development department for approval.

4.2.2.6 Piloting the ICB-EM

In order to determine the face and content validity of the ICB-EM, it was important to show the material to the target population and gain their views regarding its’ acceptability. The ICB-EM was shown to a purposive sample of 10 new and in-treatment patients/parents over a period of three weeks. The inclusion and exclusion criteria were identical to that described in Study One for the patient interviews.
Potential participants were approached by the researcher in the waiting area of the orthodontic
deptartment of Guy’s hospital on the day of the hypodontia clinic. Temporary staggering was not
followed at this stage, and any patients ‘new or in-treatment’ were invited to participate
simultaneously. The purpose and aims of the research as well as the confidential nature of their
participation was explained in addition to showing the participants a patient information sheet.
The researcher allowed participants to ask any questions arising from the information sheet they
had received before they agreed. They were then asked to sign a consent form and the parent or
legal guardian of any patient under 16 years of age was also asked to consent.

The researcher first asked the participants and their parents to go through the ICB-EM. Any
queries or areas that posed difficulty to the reader were recorded. They were also encouraged to
comment on the content of the material and whether they thought there was any information
that should be added or omitted. In addition, the participants’ views regarding the layout of the
material were recorded by the researcher.

Microsoft Word© was employed to test the readability of the survey according to the Flesch
Reading Ease score and Flesch-Kincaid grade. The former was set to 60 or higher and the latter
to a reading age of 12-13, equivalent to a grade level of 7 or less (Flesch, 1979).

4.2.3 The Treatment Evaluation Inventory

This is a commonly used measure of the perceived acceptability of behavioural treatments and
contains 19 items with a 5-point Likert scale answer format. As advised by Newton and
Sturmey (2004), the wording of the measure can be modified to accurately reflect the
interventions received. For example, the term ‘information’ was used to replace the term
‘intervention’ in all the items of the TEI. To ensure the validity of the measure, the researcher
gained the views of the research team one of whom is considered an expert in this measure in
particular. The main purpose of using this questionnaire was to measure the participants’ level
of acceptance of the information they received as assessed by the TEI, which will be discussed
in detail in Chapter 5 of this thesis.
4.3 Results

4.3.1 Development of the Questionnaire

4.3.1.1 Panel Review of the Questionnaire

The review process resulted in some changes that were made to some of the sections of the questionnaire, which included:

Hypodontia Clinic

1. Items B1 – B9: was intended to measure the patients’ expectations of the clinic only however, as will be described in Chapter 5, the patients will have to record their actual experience of the clinic the second time they fill out the questionnaire as they would have entered the clinic. Therefore, the questions were reformatted to ask the participants what they expect from the clinic and what their actual experiences were, e.g. How many people do you expect to see in the clinic? / How many did you actually see?

2. Items B1 – B7: the items were originally VAS formats and were changed to categorical response format (yes / no / I don’t know) which was considered more accurate in recording the experience of the participants.

3. Item B4: this was originally radiographs taken, and x-rays between brackets was added for clarity.

4. Item B9: one of the options was specialist trainee, which was changed to ‘dentist in training’.

Orthodontic Treatment

5. Elimination of one item from the orthodontic section concerning the purpose of treatment (In which ways do you think orthodontic treatment may help your condition?): Originally there were three items related to this section: 1. reduce the number of fake teeth needed, 2. It will make it easier for the gaps to be filled, and 3. It will help avoid the need for replacement teeth. The first item was eliminated as it was considered a repetition of the second item.
Restorative Treatment

6. Item D1- D6: changed from VAS to categorical response format (yes/no/I don’t know).

7. Item D12: this item was originally in a categorical response format that ranged from 1 year to forever. It was changed to a VAS with ‘1 year or less / 10 or more years’ at either ends of the scale as it was considered more accurate in recording the expectation of the participants with regards to the expected longevity of the restoration.

4.3.1.2 Pilot Test

Content and face validity: After completing the questionnaire, the participants were asked to comment on the relevance of its’ content and whether there is any aspect of the survey instrument they would change including the addition and deletion of questions. One participant thought the question on ethnicity was not relevant and that it may be a sensitive question, however, it was only raised by one participant and after considering the possible effect of this dimension on the expectations of the patients, the researcher elected to preserve the question. The researcher took into consideration the participants’ comments and the following changes were made to the questionnaire:

Personal Information

1. Item A7: ‘straightening/moving teeth’ was added to the question between brackets to clarify the meaning of orthodontic treatment.

2. Item A9: ‘false teeth / filling the gaps’ was added to the question between brackets to clarify the meaning of restorative treatment.

Hypodontia Clinic

3. Item B5: changed the word ‘impression’ with ‘moulds’ for simplicity.

4. Item B9: added ‘I don’t know’ to the list of options. In addition, ‘provides braces’ and ‘provides replacement teeth’ were added to the options orthodontist and restorative dentist respectively to add clarity.
Restorative Treatment

5. Originally there was an item that asks ‘Do you think people will notice you have false teeth in your mouth?’ which a couple of participants noted that it may be repetitive to item D11 of the current questionnaire that asks ‘how do you think people will react to you having false teeth in your mouth’. The researcher agreed with the participants and therefore deleted this item.

The time taken by the participants to complete the questionnaire ranged between 10 and 20 minutes (median 15 minutes). It was found that the ease of administration of the questionnaire in general was acceptable. The overall Flesch—Kincaid grade level was 4.3 (equivalent to the reading ability of a 9–10-year-old). The introductory pages were graded at 7.8 (12–13-year-old reading ability). The Flesch Reading Ease scores for the questionnaire and the introductory pages were 78 and 68.5, respectively (equivalent to the reading ability of an 11-12-year-old) (Flesch, 1979).

4.3.1.3 Reliability of the Questionnaire

In total, 32 out of the 40 invited patients completed the questionnaire (78%), 13 were male and 19 were female and their ages ranged from 14 to 34 years. Cronbach’s alpha was used to test the internal consistency for the 32 participants who completed the questionnaire on the day of their consultation appointment in the hypodontia clinic. It was carried out for the questionnaire as a whole and for the questions relating to the treatment process and the treatment outcome separately. The overall inter-item value was 0.8, 0.71 for the treatment process items and 0.88 for the treatment outcome items. These results suggest that both the overall scale and the two sub scales are internally consistent.
4.3.2 Development of the ICB-EM

4.3.2.1 Panel Review

The majority of the comments obtained from the panel were positive with the exception of a few comments that were received suggesting the need to adjust grammar and the rewording of a few terms to avoid jargon. Some comments were also received suggesting the deletion and addition of some information. The review process resulted in some changes that were made to some of the sections of the material, which included:

1. A slide containing information about the prevalence of hypodontia was removed as this information is constantly changing and is not consistent between different geographic areas. This was also done to reduce the length of the information material and this information in particular will not help the patient with their understanding of the treatment, which is the main aim of the material.

2. A slide containing information about retention following orthodontic treatment was deleted as it was available in other orthodontic brochures.

3. Under the title ‘Redistributing the space using braces’ an extra purpose was added: to reduce the number of fake teeth at the end of treatment.

4. A slide containing information about bone grafts was removed. This was expressed as an information need by two interviewees only and because we had to exclude some information to avoid a lengthy information material this was considered less important than other information. It is carried out on a proportionately lower number of the hypodontia population. In addition, clinicians thought that it might be frightening to the patients and might unnecessarily put them off especially if they were not going to receive this kind of treatment.

5. Information about location, cost, longevity and maintenance of restoration was under one heading. This was divided into three separate sections: ‘where can I get my treatment’, ‘will I have to pay for my treatment’, ‘will my false teeth last forever’. This was done to avoid cognitive load placed on the reader.
6. Under the slide titled ‘Your appointment’, deleted ‘You will be led by the team nurse into the clinic where you will be seen by a number of clinicians’ as this may differ between different hospitals. We also added a specific number of clinicians ‘8’ to add clarity and assist the patients in predicting what will happen rather than being overwhelmed when entering the clinic.


4.3.2.2 Piloting the ICB-EM

The participants were shown the ICB-EM and were asked for their feedback on its content, layout and comprehensibility. The participants seemed to accept the overall layout of the material and its comprehensibility, stating that it was user friendly. The participants thought that the ICB-EM was easy to understand and were happy with the addition of a table of contents. The majority of the participants thought that the addition of the cartoon images was beneficial, making the information material more child friendly. However, two participants suggested that the material could provide more reassurance by presenting a documentary with examples of other children who had successfully completed the treatment. This was not incorporated as it was beyond the scope of the material to provide a documentary due to the time and cost that this will add to the development process.

With regards to the actual content of the material, six participants indicated that all the information was relevant and that there was nothing further they would add. On the other hand, four of the ten participants suggested clarifying a few terminologies and adding information.

As a result, the following changes were made to the ICB-EM:

1. A few terminologies were simplified to add clarity and avoid jargon. Some examples include replacing ‘restoring function’ with ‘improving function’, ‘tooth coloured composite resin’ with ‘tooth coloured filling material’, and ‘primary teeth’ with ‘baby teeth’.

2. On the slides where the reader is required to press the buttons to find out more, some participants skipped to the next slide not knowing that if they pressed they would find more information. This was clarified by adding a sentence to the slide ‘press the buttons to find
out more’ to avoid the chance of the reader overlooking some information.

3. On the slide titled ‘procedures involved’: this was originally written in two paragraphs. Patients thought that the paragraphs were too lengthy and writing the procedures that may happen in bullet points will be much clearer and easier to remember by the patients.

4. The patients wanted to add a section where the members of the hypodontia team in Guys’ and St Thomas’ Hospitals are clarified. This would help them identify who they need to talk to whilst in treatment if any problems arise.

The time taken for the participants to go through the information material was found to be 15-20 minutes. The overall Flesch - Kincaid grade level was 7.8 (12–13-year-old reading ability). The Flesch Reading Ease scores for the ICB-EM was 69.8 (equivalent to the reading ability of an 11-12-year-old); (Flesch, 1979).
4.3.3 The Treatment Evaluation Inventory

After gaining the views of the research team, a few items from the TEI were not used as they were considered not relevant to the study, which included the following items:

1. How much did you look forward to your appointments?
2. In your opinion, during the treatment how much did you want it to be over as soon as possible?
3. Were you glad you went for treatment?
4. How would you rate your relationship with the person who did your treatment?
5. How well do you think the person who did your treatment understood your feelings and problems?
6. How much do you think you will change as a result of this intervention?
7. How much do you think your problems have improved?

Three items were added to the TEI, which included:

1. How much did you learn about the hypodontia clinic?
2. Was the information easy to understand?
3. Please give a rating of the layout of the information you received.

The internal consistency of the TEI was measured during the RCT and reported in section 5.3.7 of this thesis. The final version of the TEI contained the following items (Appendix 11):

1. Please rate how much you think you learned from the information you were given?
2. How much did you learn about the treatment of your missing teeth?
3. How much did you learn about the hypodontia clinic?
4. Please rate how much new information you now have about how to deal with your problems?
5. How much did you enjoy the information given?
6. How interesting was the information for you?

7. Was the information easy to understand?

8. Please rate how much you feel you can use what you learned from the information given to you?

9. To what extent do you think you will be able to use what you learned from the information material?

10. Do you think that the information given to you will reduce your level of anxiety if you have any?

11. Do you think you will react differently to your treatment now compared to before you read the information?

12. Do you think you will now handle your treatment better?

13. Please give a rating of the layout of the information you received.

14. Please give an overall rating of the information you received.
4.4 Discussion

4.4.1 Development of the HTEQ

To obtain patient expectation data for the process and outcome of orthodontic-restorative therapy available through the NHS, a patient-oriented questionnaire was formulated in the present study, employing both quantitative and qualitative research methodologies. Addressing a variety of patient-relevant aspects, the questionnaire was confirmed to be suitable in terms of acceptability, appropriateness, content validity, and internal consistency. The proportion of female participants in both components of the study was higher than male – this is typical of the hypodontia population (Polder et al., 2004).

This tool is designed to serve a number of purposes within both clinical practice and research. As a tool to identify patients’ expectations of treatment it can both highlight areas where patients would benefit from further information to support their understanding and may also identify unrealistic expectations of outcome and thus the possibility for additional support (such as psychological counselling) to rectify such expectations, though the scale may require some development (such as the derivation of short forms) for routine clinical use. As a research tool, the questionnaire can help to identify the process of change in expectations over time as the patient becomes more involved with the treatment process and better informed. Questionnaires are cost-effective and are accepted by the majority of participants (Mays and Pope, 2000), they facilitate the comparison of data between and within different studies and populations. However, a limitation of self-reported questionnaires is the likelihood of intrinsic manipulation and by formulating the items of the questionnaire on the basis of a detailed and comprehensive data derived from in-depth interviews, this researcher bias is minimised (Creswell, 2013).

4.4.2 Properties of the Questionnaire

Face and content validity were judged during the pilot study by subjective assessment and relevance of the questionnaire to the participants. Ten patients were included in the pilot study and as a result, the questionnaire was re-written and shortened to make it easier for the participants to complete. However, it was thought to have good face value and content validity.
Internal consistency reliability assesses the consistency of results across items within a test. All of the items should be tapping different aspects of the same attribute and not different parts of different traits. Current thinking in test development holds that there should be a moderate correlation between the items in a scale (Saw and Ng, 2001). If the items are chosen without regard for homogeneity, then the resulting scale could possibly end up tapping a number of traits.

Thirty-two participants completed the questionnaire to test reliability. Patients who had hypodontia as part of a syndrome were excluded from the study, as it is difficult to differentiate issues related to a syndrome from those related to the missing teeth. Cronbach’s alpha values for both the overall questionnaire and the sections of the questionnaire were equal or greater than the generally accepted value of 0.7 (Kline, 2014), suggesting the questions in the different sections of the questionnaire were consistent.

### 4.4.3 Development of the ICB-EM

The development and evaluation of the ICB-EM was primarily based on the views and opinions of the patients and their parents / carers. It also involved collaboration with a number of specialists from the hypodontia multidisciplinary team, which has been a positive experience for those who were involved in the project and enabled the research team to incorporate evidence from the literature into practice. As has been discussed in section 2.1 of the literature review, hypodontia can significantly affect the individual in terms of skeletal and dento-alveolar development as well as their quality of life. The treatment can be quite complex and extended in terms of duration, which may further complicate the quality of life of the affected individual. This information material can assist patients and their parents / carers in better understanding their condition and its treatment and hence enabling them to make decisions on an informed basis. It can act as a guide throughout their treatment journey and can assist the patients in asking questions during the course of treatment. However, it is acknowledged that this form of communication does not replace verbal advice and support (Griffiths & Jones, 1999).

When developing a new intervention, challenges can be faced due to the differing viewpoints and perspectives of those involved in the development process. From the patients’ feedback, it
was concluded that the content of the material as well as its layout and presentation was acceptable given the fact that only minimal alterations were necessary as a result of their feedback and a positive opinion was obtained with regards to its relevance and comprehensibility. Overall the objectives of the ICB-EM design were fulfilled in that patients indicated that the material was readily understood and useful. In addition, from the positive feedback obtained from the panel of experts, the researcher was able to conclude that the final draft of the ICB-EM would be suitable for use in the RCT which will be discussed in Chapter 5 of this thesis.

The formal evaluation of the material was more difficult and longer than expected. In some instances, due to the fast pace nature of the clinic, it was difficult to allow the participant enough time to understand the purpose of the project, ask questions, read the ICB-EM and comment on its content without interrupting the flow of the multidisciplinary clinic. Therefore, the researcher was only able to recruit 4-5 participants per week to avoid this interruption.

Another limitation was that it was presumed that those who were included during the pilot testing of the ICB-EM were literate, therefore the readability level of the ICB-EM was likely to have been appropriate for them. However, the researcher did not ask the participants about their level of education or their reading skills, as this may have been perceived as insensitive. However, the researcher did assess the Flesch—Kincaid grade level of the ICB-EM, which was 7.8 (12–13-year-old reading ability) and the Flesch Reading Ease score which was 69.8 (equivalent to the reading ability of an 11-12-year-old) and considered this as an acceptable reading level.

All the participants were able to read and speak English. In future projects, the material can be further developed to provide the option of other formats and languages as required for non-English speaking, and visually impaired patients. In addition, providing an audiotape with the information would be helpful, for illiterate patients.

The material was developed using Articulate Storyline© software which is supported by King’s College London, and as a result the material was developed with minimal financial cost. However, the hypodontia multidisciplinary team will not be able to use it in its current format as
it requires transferring the material to a web server in order to allow the public to view the material with ease and from any device. The research team is currently in the process of introducing the material to Guy’s and St Thomas’ NHS Foundation Trust in order to publish the material on their website.

4.4.4 The Treatment Evaluation Inventory

The assessment of the acceptability of treatments including behavioural interventions by those experiencing it has been identified important in evaluation of treatments (Kazdin et al., 1981, Newton and Sturmey, 2004). The form was modified to reflect the interventions that will be received in the RCT. The modified form will be used in the RCT described in Chapter 5 of this thesis to measure and compare the participants’ acceptability of the ICB-EM and a paper leaflet. The internal consistency of the measure will also be reported in section 5.3.7 of the following chapter.

4.5 Conclusion

- This chapter presents the development of a new questionnaire to assess expectations of patients with hypodontia regarding the process and outcome of combined orthodontic and restorative treatment, primarily for use in research. The proposed questionnaire has good face and content validity and satisfactory internal consistency.

- The development of a new patient-based, hypodontia specific computer based information material has been described. The material has satisfactory face and content validity and an acceptable reading level.
Chapter 5: Study Two

Impact of Computer Based Information Provision on Expectations of Treatment Process and Outcome Compared to Clinician Delivered Information: A Randomised Prospective Controlled Trial

5.1 Introduction

Hypodontia affects approximately 6.4% of the population and has a potentially long lasting and serious impact on an individuals’ quality of life (Khalaf et al., 2014). It also requires complex multidisciplinary treatment over a protracted period which may be difficult to comprehend by the patients and their carers (Hobkirk et al., 2010, O’Keeffe et al., 2016).

Patients’ expectations of the process and outcome of their care are likely to be determinants of both their satisfaction of care received and their perceived benefits of treatment (Newton and Cunningham, 2013). It is important that health care professionals have appropriate skills to communicate with these patients and they need to be well informed about prospective treatment for ethical reasons, to reduce anxiety, increase their trust in and compliance with treatment, ensure informed consent and improve satisfaction (Bishop et al., 1997, Morgan et al., 2016). In order to establish a good and stable relationship, patients should be informed of the nature of a procedure, its purpose, the outcomes and risks, and alternatives from their initial appointment (Hirsch and Gert, 1986). It can be considered unfortunate to find that patients can be unhappy with the amount of information they receive from their health provider, and often the information that is given is forgotten or misinterpreted (Witt and Bartsch, 1993).

The form of information delivery could influence the accuracy of patients’ expectations. Patients may be informed in several ways including, verbally, by leaflet, by video, or, by computer-based materials. The challenge for the profession is to provide information that takes into consideration the patient views and their preferred format to reduce the chances of
misinterpretation and enhance the relevance of the information provided (Ley and Spelman, 1967, Merritt, 1990, Thickett and Newton, 2006, Marshman et al., 2016). Within the medical field, there is a widening literature on the effect of interactive computer-based education materials on the patients’ level of knowledge and has been proven to be more effective than written materials especially with the rapid advancement of information technology (Ryhänen et al., 2010).

To our knowledge, no studies have addressed the expectations of hypodontia patients regarding their combined orthodontic / restorative treatment. The authors developed and validated a hypodontia specific questionnaire as a measure of patients’ expectations concerning the process and outcome of orthodontic / restorative treatment (Ben Gassem et al., 2016). It was argued that expectations of treatment can influence patients’ satisfaction with treatment. Furthermore, to date there are no published studies that have explored the impact of information delivery on a patient’s expectations of the process and outcome of hypodontia treatment.

The aim of this study was to compare the effect of information delivery through an interactive computer-based programme versus a paper-based leaflet on the expectations of the process and outcome of treatment among hypodontia patients. As a secondary goal, this study also sought to compare the patients’ acceptability of methods of information delivery using the TEI.

The specific objectives of the study were:

- To describe specific demographic and personal profile characteristics of the participants in the study at baseline;

- To measure and compare the effects of provision of an information leaflet and ICB-EM on the participants’ expectations of the hypodontia clinic at baseline (T1) and their recall of their experience post-intervention (T2) and follow up (T3);

- To measure and compare the expectations of orthodontic treatment, restorative treatment and outcome of treatment held by the participants in the study between the three time points: T1, T2 and T3;
• To measure and compare the effects of provision of an information leaflet and ICB-EM on participants’ expectations of orthodontic treatment, restorative treatment and outcome of care over the three time points: T1, T2 and T3;

• To measure and compare the participants’ acceptability of the two interventions used in the study.

The null hypotheses were:

• There is no difference in expectations of the hypodontia clinic between patients who received an information leaflet and those who received the ICB-EM.

• There is no difference between patients who received an information leaflet and those who received an ICB-EM in their recall of their experience of the hypodontia clinic.

• There is no difference in expectations of the process and outcome of orthodontic / restorative treatment between patients who received an information leaflet and those who received the ICB-EM over the three time points: T1, T2 and T3.

• There is no difference in the patients’ acceptability of the intervention received between those who received the information leaflet and those who received the ICB-EM.
5.2 Methods

5.2.1 Trial Design and any Changes After Trial Commencement

This was a 2-arm parallel group, prospective, randomized controlled trial with a 1:1 group allocation ratio, designed in accordance with the CONSORT guidelines. The setting was the Orthodontic Department of Guys and St Thomas NHS Trust, UK. Ethical approval was obtained from the National Research Ethics Committee London – Chelsea, REC Reference number: 13/LO/1146 (Appendix 12). The trial was registered with the Research & Development Office at Guy’s & St Thomas’s NHS Foundation Trust, and on the REDA database (Appendix 13). No changes were made to the trial design after commencement.

5.2.2 Participants, Eligibility Criteria, and Settings

The medical records of patients aged 14 and above presenting as new patients in the hypodontia clinic, were viewed for suitability to participate in the study. Patients who were included in the study were all attending a specialist hypodontia service at Guy’s and St Thomas’ NHS Foundation Trust, a secondary care facility in the UK. The recruitment procedure took place between 1 January 2015 and 31 December 2015. The inclusion criteria were:

- New patients with developmentally missing teeth,
- Male or female of any ethnicity,
- Able to read and speak English,
- Aged 14 years and above.

Patients were excluded from the study if they presented with an accompanying craniofacial abnormality.

Of the 225 patients who were eligible to participate, 96 agreed to take part in the study. Potential participants were provided with verbal and written information describing the purpose of the study. They were informed that all information was confidential and that they were free to withdraw at any time and were given the opportunity to ask questions after which they were asked to sign a consent form.
The participants were randomly allocated to either the intervention group (n=47) who received the ICB-EM or the control group (n=49) who received the BOS leaflet. The participants were asked to complete the previously developed HTEQ at baseline before they entered the clinic for their consultation appointment. The researcher allowed the participants 10 minutes to read the intervention and they were not allowed to ask any additional questions relating to the intervention. They were then asked to enter the clinic for their consultation appointment. No restrictions were placed on the content of the consultations.

The participants were then asked to complete the HTEQ immediately after their consultation appointment to assess the short-term effects of the information. They were also asked to complete the TEI at this point after which they were free to leave. In order to assess the long-term effect, participants were asked to complete the HTEQ 4 weeks later by posting it with a covering letter and a stamped addressed envelope to facilitate its return. Those who did not reply within one week were reminded to do so over the telephone as well as posting a further questionnaire and a stamped addressed envelope. All the participants were asked to complete the questionnaire and read the intervention independently.
5.2.3 Interventions

ICB-EM (Active intervention)

The development process as well as the description of the content, layout and format of the ICB-EM was described in section 4.2.2 of the thesis.

British Orthodontic Society (BOS) Hypodontia Leaflet (Control intervention)

This is a standard two-page leaflet created by the BOS which forms part of a series of information leaflets produced to educate orthodontic patients. These leaflets are used widely in the UK and it is considered standard care to provide orthodontic patients with the relevant leaflet whenever possible (see Appendix 14).

The hypodontia leaflet covers in particular the following topics: Definition; aetiology; prevalence; diagnosis; issues with retained deciduous teeth; treatment options including orthodontics (accept / open / close the space) and restorative treatment (build-up of small teeth / dental bridges / dental implants / dentures); and finally, the importance of maintaining regular contact with the general dental practitioner. The leaflet is available at:

http://www.bos.org.uk/Portals/0/Public/docs/PILs/hypondontiaaug14.pdf

5.2.4 Outcomes

Primary Outcome:

Patient reported expectations of the treatment process and outcome as measured by the HTEQ. This was administered at three time points (Time 1: Pre-intervention; Time 2: Immediate post intervention; Time 3: Three to four weeks post Time 2). The development process as well as the description of the scales selection, format, layout, and outcome measures of the questionnaire is described in section 4.2.1 of the thesis.

Secondary Outcome:

Patient reported acceptability of the intervention as assessed by the TEI. This was administered at Time 2 (immediate post intervention). A detailed description of this measure including the
main changes that were made to be compatible with the current study is described in section 4.3.3. of this thesis.

There were no changes to trial outcomes made after trial commencement.

5.2.5 Sample Size Calculation

An *a priori* sample size calculation was performed. The primary outcome is the patient self-reported expectations of treatment process and outcome as measured by the HTEQ. In the absence of previous studies on the effectiveness of interventions to modify patient expectations, the authors were unable to identify the standard deviation or variance of the primary outcome. Therefore, the sample size was based on determining a medium effect size of 0.7, (with a power of 0.80 and significance level of 0.05) (Cohen, 1992). The sample size calculation was performed using G*power (Faul et al., 2007). This determined that a sample size of 34 was required in each of the two groups (total sample size 68 participants). To allow for patient drop out, a sample size of 45 was chosen for each group.

5.2.6 Randomisation

Participants were randomly allocated to either the intervention or the control group by a researcher not involved in recording data from patients or delivering the intervention using a random number generator (www.random.org). Allocation was concealed using sealed envelopes. The allocated intervention was written on a card and sealed in an envelope. The envelopes were opaque and sequentially numbered and opened.

5.2.7 Blinding

It was not possible to blind the participants and their parents to the intervention. The clinicians involved in the consultation appointment as well as the statistician undertaking the statistical analysis were blinded to group allocation. Outcome measurements were recorded by the same investigator who delivered the intervention.
5.2.8 Subject Dropout

Participant flow through the trial is summarized in Figure 5.1. Eleven participants from the control group and 9 from the intervention group were lost to follow-up giving a total of 38 participants in each of the control and intervention groups who completed all parts of the study.

5.2.9 Statistical Analysis

Data analysis was undertaken on a per protocol basis. Descriptive statistics were used to describe the demographic characteristics, severity of the condition and the treatment history of the participants. Chi-square tests were used to determine the similarity of the aforementioned variables between the two groups with the exception of the age variable where the difference between the two groups was measured using independent sample t-test.

The means and confidence intervals were calculated for each question with a VAS response format while frequencies and percentages were calculated for each categorical response question. To compare the effects of the two interventions on the expectations across the three time points, Chi-square tests were used to measure the difference in the categorical response questions, and, 3 x 2 mixed-analysis of variance (ANOVA) was used to measure the differences in the VAS questions. The within-subject factor was time of completing the questionnaire (T1, T2, and T3) and the between-subject factor was intervention received (control group: BOS leaflet, or intervention group: ICB-EM).

With regards to the TEI, the internal consistency of the modified version was calculated using Cronbach’s alpha. In addition, the means and standard deviations were calculated for each item of the measure and an independent sample t-test was used to detect differences between the two groups.

No subgroup analyses or adjusted analyses were planned or performed.
Figure 5.1 CONSORT flow diagram of participant progress through the phases of the study.
5.3 Results

5.3.1 Demographic Characteristics of the Participants

Recruitment to the trial ended when the recruitment target was achieved. At baseline, information regarding age, gender, ethnicity, number of missing teeth and treatment history was collected. The distribution of the demographic characteristics of those recruited (n=96), lost to follow up (n=20), and those who remained in all parts of the study (n=76) are presented in Table 5.1. The mean age of the remaining 76 participants was 19 years (SD=7.24) for the control group and 20.3 (SD=6.9) years for the intervention group. There were no differences between the control and intervention groups in their demographic or clinical characteristics.

The average follow up time between T1 and T2 was 32.3 days (SD=5.5) for the control group and 32.8 days (SD=4.4) for the intervention group. There was no difference between the control and intervention groups with regards to the follow up time ($U=660, p=0.52$).
Table 5.1 Baseline characteristics of all participants recruited in the trial, those lost to follow-up, and those remaining in the trial to the end. Unless otherwise indicated, data are reported as number (percentage) of participants.
5.3.2 Expectations and Experience of the Hypodontia Clinic

Table 5.2 demonstrates the participants’ expectation of the procedures involved during the hypodontia clinic at T1 and their recall of the procedures they received at T2 and T3. At T1 the participants’ expectations of the procedures involved in the hypodontia clinic were similar with no significant differences between the two groups. This was also the case at T2, where the participants recall of what procedures they have received during the clinic were similar with no significant differences between the two groups. However, at T3 a significant difference between the two groups was found regarding the item ‘check-up and diagnosis’ where only 84.2% of the participants in the control recalled having a check-up and diagnosis compared to 100% of the participants in the intervention group ($X^2=4.52$, $p=0.033$); (see Figure 5.2).

Table 5.3 displays the participants’ answers regarding the number of clinicians they expect to see at T1 as well as their recall of the number actually seen at T2 and T3 in both groups. The analysis revealed similar expectations between the two groups at T1. However, they significantly differed at T2 and T3 where the control group were more likely to recall fewer numbers ‘1-2’ or answer ‘I don’t know’ while the intervention group conveyed better recall where they were more likely to answer ‘3-5’ or ‘6-8’ at both time points (T2: $X^2=9.72$, $p=0.021$ / T3: $X^2=19.93$, $p < 0.001$); (Figure 5.3).

Table 5.4 displays the participants’ answers regarding the types of clinicians they expect to see in the clinic at T1 as well as their recall of the types actually seen at T2 and T3 in both groups. The analysis revealed similar expectations between the two groups at T1. However, at T2 and T3 the intervention group was generally more likely to recall seeing the clinicians and less likely to answer ‘I don’t know’. In particular, at T2, significant differences between the two groups were found regarding the presence of the restorative dentist ($X^2=9.01$, $p=0.003$), dental nurse ($X^2=5.23$, $p=0.022$) and between those who reported ‘I don’t know’ in the two groups ($X^2=4.03$, $p=0.045$). At T3, significant differences were detected between the two groups regarding the presence of the restorative dentist ($X^2=5.05$, $p=0.025$), oral surgeon ($X^2=6.41$, $p=0.011$) and dental nurse ($X^2=6.09$, $p=0.014$).
<table>
<thead>
<tr>
<th>At your initial appointment, do you expect to have / What did you have?</th>
<th>T1 n (%)</th>
<th>T2 n (%)</th>
<th>T3 n (%)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Intervention</strong> (n=47)</td>
<td><strong>Control</strong> (n=49)</td>
<td><strong>Intervention</strong> (n=46)</td>
<td><strong>Control</strong> (n=48)</td>
<td><strong>Intervention</strong> (n=38)</td>
</tr>
<tr>
<td>Brace fitted</td>
<td>Yes</td>
<td>2 (4.7%)</td>
<td>8 (16.3%)</td>
<td>6 (13%)</td>
</tr>
<tr>
<td></td>
<td>No / Don’t know</td>
<td>45 (95.7%)</td>
<td>41 (83.7%)</td>
<td>40 (87%)</td>
</tr>
<tr>
<td>Check up and Diagnosis</td>
<td>Yes</td>
<td>38 (80.9%)</td>
<td>33 (67.3%)</td>
<td>41 (89.1%)</td>
</tr>
<tr>
<td></td>
<td>No / Don’t know</td>
<td>9 (19.1%)</td>
<td>16 (32.7%)</td>
<td>5 (10.9%)</td>
</tr>
<tr>
<td>Discussion about treatment</td>
<td>Yes</td>
<td>42 (89.4%)</td>
<td>43 (87.8%)</td>
<td>44 (95.7%)</td>
</tr>
<tr>
<td></td>
<td>No / Don’t know</td>
<td>5 (10.6%)</td>
<td>6 (12.2%)</td>
<td>2 (4.3%)</td>
</tr>
<tr>
<td>Radiographs</td>
<td>Yes</td>
<td>19 (40.4%)</td>
<td>21 (42.9%)</td>
<td>26 (56.5%)</td>
</tr>
<tr>
<td></td>
<td>No / Don’t know</td>
<td>28 (59.6%)</td>
<td>28 (57.1%)</td>
<td>20 (43.5%)</td>
</tr>
<tr>
<td>Moulds of teeth</td>
<td>Yes</td>
<td>10 (21.3%)</td>
<td>15 (30.6%)</td>
<td>7 (15.2%)</td>
</tr>
<tr>
<td></td>
<td>No / Don’t know</td>
<td>37 (78.7%)</td>
<td>34 (69.4%)</td>
<td>39 (84.8%)</td>
</tr>
<tr>
<td>Photos</td>
<td>Yes</td>
<td>15 (31.9%)</td>
<td>21 (42.9%)</td>
<td>10 (21.7%)</td>
</tr>
<tr>
<td></td>
<td>No / Don’t know</td>
<td>32 (68.1%)</td>
<td>28 (57.1%)</td>
<td>36 (78.3%)</td>
</tr>
<tr>
<td>Check Oral Hygiene</td>
<td>Yes</td>
<td>20 (42.6%)</td>
<td>23 (46.9%)</td>
<td>28 (60.9%)</td>
</tr>
<tr>
<td></td>
<td>No / Don’t know</td>
<td>17 (57.4%)</td>
<td>26 (53.1%)</td>
<td>18 (39.1%)</td>
</tr>
</tbody>
</table>

Table 5.2 The type of procedure the participants expect to receive at T1 and their recall of the procedures experienced at T2 and T3 by control and intervention groups represented by number and percentage. The p values represent the significance of the intervention across the three time points. All p-values are non-significant unless marked with asterisk(s).
Figure 5.2 Bar chart representing the participants’ expectations of receiving a check-up and diagnosis at T1 and their recall of receiving it at T2 (post-intervention) and T3 (3-4 weeks follow up). The data are presented as percentages and 95% confidence intervals for both the intervention and control group.
| How many clinicians will you see / have you seen in the clinic? | T1 n (%) | T2 n (%) | T3 n (%) | Significance | Interven (n=47) | Control (n=49) | Interven (n=47) | Control (n=49) | Interven (n=38) | Control (n=38) | Significance |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1-2 | 20 (42.6%) | 22 (44.9%) | 8 (17.4%) | 12 (25%) | $X^2 = 2.72$ | $p=0.437$ | 8 (21.1%) | 10 (26.3%) | 17 (44.7%) | 21 (55.3%) | $X^2 = 9.72$ | $p=0.021^*$ |
| 3-5 | 10 (21.3%) | 14 (28.6%) | 18 (39.1%) | 27 (56.3%) | 14 (30.4%) | 3 (6.3%) | 10 (26.3%) | 2 (5.3%) | $X^2 = 19.93$ | $p<0.001^{**}$ |
| 6-8 | 6 (12.8%) | 2 (4.1%) | 5 (10.9%) | 6 (12.5%) | 3 (7.9%) | 5 (13.2%) |
| I don’t know | 11 (23.4%) | 11 (22.4%) | 5 (10.9%) | 6 (12.5%) | 3 (7.9%) | 5 (13.2%) |

**Table 5.3** The number of clinicians the participants expect to see at T1 and their recall of the number seen at T2 and T3 by control and intervention groups represented by number and percentage. The p values represent the significance of the intervention across the three time points. All p-values are non-significant unless marked with asterisk(s).
Figure 5.3 Bar chart representing the participants’ expectations of the number of clinicians that will be seen in the clinic at T1 and their recall of the number seen at T2 (post-intervention) and T3 (3-4 weeks follow up). The data are presented as percentages and 95% confidence intervals for both the intervention and control groups.
<table>
<thead>
<tr>
<th>Who do you expect to see in the clinic?</th>
<th>T1 n (%)</th>
<th>Significance</th>
<th>T2 n (%)</th>
<th>Significance</th>
<th>T3 n (%)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Intervention (n=47)</td>
<td>Control (n=49)</td>
<td></td>
<td>Intervention (n=47)</td>
<td>Control (n=49)</td>
<td></td>
</tr>
<tr>
<td>Orthodontist</td>
<td>16 (34.0%)</td>
<td>24 (49%)</td>
<td>(X^2= 2.2) (p= 0.138)</td>
<td>33 (71.7%)</td>
<td>34 (70.8%)</td>
<td>(X^2= 0.01) (p= 0.923)</td>
</tr>
<tr>
<td>Restorative dentist</td>
<td>22 (46.8%)</td>
<td>15 (30.6%)</td>
<td>(X^2= 2.65) (p= 0.103)</td>
<td>41 (89.1%)</td>
<td>30 (62.5%)</td>
<td>(X^2= 9.01) (p= 0.003^*) (RR=1.43(1.12,1.81))</td>
</tr>
<tr>
<td>Oral surgeon</td>
<td>9 (19.1%)</td>
<td>8 (16.3%)</td>
<td>(X^2= 0.13) (p= 0.717)</td>
<td>24 (52.2%)</td>
<td>16 (33.3%)</td>
<td>(X^2= 3.41) (p= 0.065)</td>
</tr>
<tr>
<td>Children dental specialist</td>
<td>13 (27.7%)</td>
<td>14 (28.6%)</td>
<td>(X^2= 0.01) (p= 0.921)</td>
<td>18 (39.1%)</td>
<td>15 (31.3%)</td>
<td>(X^2= 0.64) (p= 0.424)</td>
</tr>
<tr>
<td>Dental nurse</td>
<td>26 (55.3%)</td>
<td>22 (44.9%)</td>
<td>(X^2= 1.04) (p= 0.307)</td>
<td>30 (65.2%)</td>
<td>20 (41.7%)</td>
<td>(X^2= 5.23) (p= 0.022^*) (RR=1.56(1.05,2.32))</td>
</tr>
<tr>
<td>Dentist in training</td>
<td>12 (25.5%)</td>
<td>17 (34.7%)</td>
<td>(X^2= 0.95) (p= 0.328)</td>
<td>18 (39.1%)</td>
<td>12 (25%)</td>
<td>(X^2= 2.15) (p= 0.142)</td>
</tr>
<tr>
<td>I don’t know</td>
<td>11 (23.4%)</td>
<td>11 (22.4%)</td>
<td>(X^2= 0.01) (p= 0.911)</td>
<td>3 (6.5%)</td>
<td>10 (20.8%)</td>
<td>(X^2= 4.03) (p= 0.045^*) (RR=0.31(0.09,0.98))</td>
</tr>
</tbody>
</table>

**Table 5.4** The types of clinicians the participants expect to see at T1 and their recall of the types of clinicians seen at T2 and T3 by control and intervention groups represented by number and percentage. The p values represent the significance of the intervention across the three time points. All p-values are non-significant unless marked with asterisk(s).
5.3.3 Expectations of Orthodontic Treatment

Table 5.5 displays the results of the VAS questions related to the expectations of orthodontic treatment. The results revealed that there were statistically significant main effects of time for all but two items; ‘do you expect to receive orthodontic treatment’ \((F=9.31, p=0.002)\); ‘treatment will make filling the gaps easier’ \((F=8.67, p=0.003)\); ‘problems with eating and drinking’ \((F=4.58, p=0.02)\); ‘paying for the brace treatment’ \((F=4.4, p=0.014)\); and ‘effect of treatment on school/job attendance’ \((F=10.6, p=0.002)\). This means that the participants’ answers change similarly with time within each group for the majority of the items, while no statistically significant differences were detected between the two groups across the three time points in any of the VAS scale items related to orthodontic treatment.

Table 5.6 demonstrates the effect of the intervention on the participants’ expectation of the duration of orthodontic treatment and the level of difference between the two groups at each time point. The analysis revealed that both groups were similar in their expectations at baseline \((X^2=0.92, p=0.922)\), post-intervention \((X^2=6.39, p=0.172)\) and at follow up \((X^2=2.11, p=0.716)\). However, a higher proportion of participants in the intervention group were more likely to believe that orthodontic treatment will take more than 24 months, which was the case along the three time points. However, the control group were more likely to answer ‘I don’t know’ at T1 and T3, and '>24 months’ at T2 only (see Figure 5.5).
## Table 5.5

Mean values and 95% confidence intervals of VAS items related to the expectations of the process of orthodontic treatment by control and intervention groups. All p-values are non-significant unless marked with asterisk(s).

<table>
<thead>
<tr>
<th></th>
<th>Intervention Mean (95% CI)</th>
<th>Control Mean (95% CI)</th>
<th>Repeated Measures ANOVA</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>T1 (n=47)</td>
<td>T2 (n=47)</td>
<td>T3 (n=38)</td>
</tr>
<tr>
<td>Do you expect to receive orthodontic treatment?</td>
<td>62.16 (54.2-70.1)</td>
<td>76.84 (67.9-85.8)</td>
<td>76.18 (67.5-84.9)</td>
</tr>
<tr>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Orthodontic treatment will make filling the gaps easier</td>
<td>67.16 (58.5-75.8)</td>
<td>74.58 (66.7-82.5)</td>
<td>73.84 (66.4-81.3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Orthodontic treatment helps avoid the need for replacement teeth</td>
<td>46.03 (36.5-55.6)</td>
<td>44.92 (33.1-56.7)</td>
<td>41.16 (31.4-50.9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment will be painful</td>
<td>55.9 (47.5-64.3)</td>
<td>52.1 (42.8-61.4)</td>
<td>59.42 (50.6-68.2)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problems with eating and drinking</td>
<td>50.32 (41.7-58.9)</td>
<td>50.63 (40.9-60.4)</td>
<td>57.84 (49.4-66.3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paying for the brace treatment</td>
<td>26.87 (19.5-34.3)</td>
<td>19.29 (12.3-26.3)</td>
<td>18.45 (12.2-24.9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Effect of treatment on school/job attendance</td>
<td>34.5 (24.4-44.6)</td>
<td>53.47 (42.9-64.1)</td>
<td>51.66 (41.4-61.9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 5.6 The expected duration of orthodontic treatment at T1, T2, and T3 by control and intervention groups represented by number and percentage. The p values represent the significance of the intervention across the three time points. All p-values are non-significant unless marked with asterisk(s).
Figure 5.4 Bar chart representing the participants’ expectations of the duration of orthodontic treatment at T1, T2, and T3. The data are presented as percentages and 95% confidence intervals for both the intervention and control groups.
5.3.4 Expectations of Restorative Treatment

Table 5.7 demonstrates the participants’ responses regarding the question ‘do you expect to receive restorative treatment’. At T1, the majority of the participants in the intervention group did expect to receive restorative treatment (55.3%) while the largest proportion of the participants in the control group did not know (49%) however this difference was not statistically significant. Significant differences were detected at T2 where a significantly higher proportion of participants in the intervention group expected to receive restorative treatment compared to the control ($X^2=8.75, p=0.013$); (see Figure 5.6).

Table 5.8 displays the effect of the intervention on participants’ expectations of the restorative treatment option that will be received. The analysis revealed that at baseline (T1) a significant difference was detected with one item only ‘expect no replacement’, where the intervention group were more likely to believe that no replacement is not an option which was significantly different from the control group ($X^2=4.40, p=0.036$). However, at T2 and T3, the intervention did not seem to have a significant effect on the participants and no differences were detected between the two groups.

Table 5.9 displays the results of the VAS questions related to the expectations of the process of restorative treatment. It shows that time had a significant effect on the participants’ responses for three items including whether or not the treatment will affect school/job attendance ($F=13.01, p=<0.001$) as well as eating and drinking ($F=5.61, p=0.005$) and the expected longevity of the replacement tooth ($F=4.06, p=0.02$). However, no statistically significant differences were detected between the two groups across the three time points in any of the VAS scale items related to restorative treatment.
<table>
<thead>
<tr>
<th>Do you expect restorative treatment</th>
<th>T1 Intervention (n=47)</th>
<th>T1 Control (n=49)</th>
<th>Significance</th>
<th>T2 Intervention (n=47)</th>
<th>T2 Control (n=49)</th>
<th>Significance</th>
<th>T3 Intervention (n=38)</th>
<th>T3 Control (n=38)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>26 (55.3%)</td>
<td>18 (36.7%)</td>
<td>$X^2 = 3.43$</td>
<td>$p = 0.18$</td>
<td>38 (82.6%)</td>
<td>26 (54.2%)</td>
<td>$X^2 = 8.75$</td>
<td>$p = 0.013^*$</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>4 (8.5%)</td>
<td>7 (14.3%)</td>
<td></td>
<td></td>
<td>4 (8.7%)</td>
<td>11 (22.9%)</td>
<td></td>
<td>5 (13.2%)</td>
<td>6 (15.8%)</td>
</tr>
<tr>
<td>I don’t know</td>
<td>17 (36.2%)</td>
<td>24 (49%)</td>
<td></td>
<td></td>
<td>4 (8.7%)</td>
<td>11 (22.9%)</td>
<td></td>
<td>5 (13.2%)</td>
<td>11 (15.8%)</td>
</tr>
</tbody>
</table>

Table 5.7 The expectations of receiving restorative treatment at T1, T2, and T3 by control and intervention groups represented by number and percentage. The $p$ values represent the significance of the intervention across the three time points. All $p$-values are non-significant unless marked with asterisk(s).
Figure 5.5 Bar chart representing the participants’ expectations regarding the item ‘Do you expect to receive restorative treatment?’ at T1, T2, and T3. The data are presented as percentage scores and confidence intervals for both the intervention and the control groups.
<table>
<thead>
<tr>
<th></th>
<th>T1</th>
<th>Significance</th>
<th>T2</th>
<th>Significance</th>
<th>T3</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Intervention (n=43)</td>
<td></td>
<td>Control (n=42)</td>
<td></td>
<td>Intervention (n=33)</td>
<td></td>
</tr>
<tr>
<td>No replacement</td>
<td>Yes</td>
<td>0 (0%)</td>
<td>4 (9.5%)</td>
<td>$X^2 = 4.40$</td>
<td>$p = 0.036^*$</td>
<td>0 (0%)</td>
</tr>
<tr>
<td></td>
<td>No &amp; Don’t know</td>
<td>44 (100%)</td>
<td>38 (90.5%)</td>
<td></td>
<td>42 (100%)</td>
<td>38 (97.4%)</td>
</tr>
<tr>
<td>Build up small teeth</td>
<td>Yes</td>
<td>4 (9.1%)</td>
<td>5 (11.9%)</td>
<td>$X^2 = 18$</td>
<td>$p = 0.67$</td>
<td>16 (38.1%)</td>
</tr>
<tr>
<td></td>
<td>No &amp; Don’t know</td>
<td>40 (90.9%)</td>
<td>37 (88.1%)</td>
<td></td>
<td>26 (61.9%)</td>
<td>24 (61.5%)</td>
</tr>
<tr>
<td>Removable denture</td>
<td>Yes</td>
<td>2 (4.5%)</td>
<td>3 (7.1%)</td>
<td>$X^2 = 0.26$</td>
<td>$p = 0.607$</td>
<td>7 (16.7%)</td>
</tr>
<tr>
<td></td>
<td>No &amp; Don’t know</td>
<td>42 (95.5%)</td>
<td>39 (92.9%)</td>
<td></td>
<td>35 (83.3%)</td>
<td>36 (92.3%)</td>
</tr>
<tr>
<td>Adhesive bridge</td>
<td>Yes</td>
<td>9 (20.5%)</td>
<td>3 (7.1%)</td>
<td>$X^2 = 3.17$</td>
<td>$p = 0.075$</td>
<td>24 (57.1%)</td>
</tr>
<tr>
<td></td>
<td>No &amp; Don’t know</td>
<td>35 (79.5%)</td>
<td>39 (92.9%)</td>
<td></td>
<td>18 (42.9%)</td>
<td>22 (57.9%)</td>
</tr>
<tr>
<td>Implants</td>
<td>Yes</td>
<td>25 (56.8%)</td>
<td>17 (40.5%)</td>
<td>$X^2 = 2.30$</td>
<td>$p = 0.13$</td>
<td>18 (43.9%)</td>
</tr>
<tr>
<td></td>
<td>No &amp; Don’t know</td>
<td>19 (43.2%)</td>
<td>25 (59.5%)</td>
<td></td>
<td>23 (56.1%)</td>
<td>22 (56.4%)</td>
</tr>
</tbody>
</table>

Table 5.8 The type of restoration the participants expect to receive by control and intervention groups represented by number and percent. The p-values represent the significance of the intervention at each time point. All p-values are non-significant unless marked with asterisk(s). The sample size is based on the number of participants responding ‘yes’ or ‘I don’t know’ in the previous question.
<table>
<thead>
<tr>
<th>A specialist in practice or hospital will do the treatment</th>
<th>Control</th>
<th>Mean (95% CI)</th>
<th>Intervention</th>
<th>Mean (95% CI)</th>
<th>Repeated Measures ANOVA</th>
<th>F</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>T1 (n=42)</td>
<td>T2 (n=39)</td>
<td>T3 (n=33)</td>
<td>T1 (n=43)</td>
<td>T2 (n=42)</td>
<td>T3 (n=33)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>80.4 (74.6-86.2)</td>
<td>81.67 (76.1-87.2)</td>
<td>83.03 (77.7-88.4)</td>
<td>F time = 0.77</td>
<td>0.47</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>78.37 (71.3-85.5)</td>
<td>84.82 (78.1-91.6)</td>
<td></td>
<td>F int = 0.38</td>
<td>0.54</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>85.13 (79.5-90.7)</td>
<td>83.03 (77.7-88.4)</td>
<td></td>
<td>F int x F time = 1.36</td>
<td>0.26</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Approval of funding from local authority needed</td>
<td>33.1 (22-44.3)</td>
<td>40.06 (29.6-50.6)</td>
<td>F time = 0.42</td>
<td>0.66</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>T1 (n=43)</td>
<td>T2 (n=42)</td>
<td>T3 (n=33)</td>
<td>T1 (n=43)</td>
<td>T2 (n=42)</td>
<td>T3 (n=33)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>39.49 (28.5-50.5)</td>
<td>53.12 (41.5-64.7)</td>
<td>55.58 (45.1-66)</td>
<td>F time = 0.30</td>
<td>0.56</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>58.13 (47.2-69.1)</td>
<td></td>
<td></td>
<td>F int = 0.07</td>
<td>0.79</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40.07 (28.5-51.6)</td>
<td></td>
<td></td>
<td>F int x F time = 0.61</td>
<td>0.55</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment will affect my school/job attendance</td>
<td>40.07 (28.5-51.6)</td>
<td>39.49 (28.5-50.5)</td>
<td>F time = 13.01</td>
<td>0.001**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>T1 (n=43)</td>
<td>T2 (n=42)</td>
<td>T3 (n=33)</td>
<td>T1 (n=43)</td>
<td>T2 (n=42)</td>
<td>T3 (n=33)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>40.73 (28.4-51.6)</td>
<td>60.83 (48.7-73)</td>
<td>58.13 (47.2-69.1)</td>
<td>F time = 0.42</td>
<td>0.66</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>56.7 (47.3-66.1)</td>
<td></td>
<td></td>
<td>F int = 0.07</td>
<td>0.79</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problems eating and drinking</td>
<td>40.73 (28.4-51.6)</td>
<td>42.82 (33.8-51.8)</td>
<td>F int x F time = 0.61</td>
<td>0.55</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>T1 (n=43)</td>
<td>T2 (n=42)</td>
<td>T3 (n=33)</td>
<td>T1 (n=43)</td>
<td>T2 (n=42)</td>
<td>T3 (n=33)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>42.7 (33.3-52.1)</td>
<td>40.07 (28.5-51.6)</td>
<td>42.82 (33.8-51.8)</td>
<td>F time = 5.61</td>
<td>0.005**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40.73 (30.5-51)</td>
<td></td>
<td></td>
<td>F int = 0.01</td>
<td>0.92</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>56.7 (47.3-66.1)</td>
<td></td>
<td></td>
<td>F int x F time = 1.28</td>
<td>0.28</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How will people react to false teeth</td>
<td>52.97 (43.5-62.4)</td>
<td>55.76 (46.7-64.8)</td>
<td>F time = 0.22</td>
<td>0.78</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>T1 (n=43)</td>
<td>T2 (n=42)</td>
<td>T3 (n=33)</td>
<td>T1 (n=43)</td>
<td>T2 (n=42)</td>
<td>T3 (n=33)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>49.07 (39.3-58.8)</td>
<td>57.18 (47.9-66.5)</td>
<td>52.82 (44.2-61.5)</td>
<td>F int = 0.15</td>
<td>0.70</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>57.3 (48.2-66.4)</td>
<td></td>
<td></td>
<td>F int x F time = 2.33</td>
<td>0.11</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How long will replacement teeth last</td>
<td>71.37 (68.8-85.1)</td>
<td>76.53 (68-85.1)</td>
<td>F time = 4.06</td>
<td>0.02*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>T1 (n=43)</td>
<td>T2 (n=42)</td>
<td>T3 (n=33)</td>
<td>T1 (n=43)</td>
<td>T2 (n=42)</td>
<td>T3 (n=33)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>71.77 (62.5-81)</td>
<td>69.31 (60.3-78.3)</td>
<td>63.13 (54.6-71.7)</td>
<td>F int = 0.01</td>
<td>0.91</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>67.7 (58.9-76.5)</td>
<td></td>
<td></td>
<td>F int x F time = 1.44</td>
<td>0.24</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much do you have to do to maintain replacement teeth</td>
<td>74.93 (67.1-82.8)</td>
<td>76.53 (68-85.1)</td>
<td>F time = 1.43</td>
<td>0.25</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>T1 (n=43)</td>
<td>T2 (n=42)</td>
<td>T3 (n=33)</td>
<td>T1 (n=43)</td>
<td>T2 (n=42)</td>
<td>T3 (n=33)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>82.53 (75.3-89.7)</td>
<td>69.31 (60.3-78.3)</td>
<td>77.49 (70.9-84.1)</td>
<td>F int = 0.01</td>
<td>0.93</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>78.17 (71.3-85.1)</td>
<td></td>
<td></td>
<td>F int x F time = 1.26</td>
<td>0.29</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Table 5.9** Mean values and 95% confidence intervals of VAS items related to the expectations of restorative treatment by study and control group. All p-values are non-significant unless marked with asterisk(s). The sample size is based on the number of participants responding ‘yes’ or ‘I don’t know’ in the previous question.
5.3.5 Expected Benefits of Treatment

Table 5.10 demonstrates the participants expected benefits of treatment. The results are comparable to those found in the expectations of treatment process where over time there were changes in the patients’ expectations on the following items: straightening teeth ($F=3.60$, $p=0.03$), eating more easily ($F=3.60$, $p=0.03$), improve chances of a good career ($F=3.67$, $p=0.03$) and giving confidence socially ($F=3.28$, $p=0.04$). However, no statistically significant differences between the two groups were detected.

5.3.6 Importance Held to Each Benefit (Motivation for Treatment)

As for how important each benefit is to the participants, time had a significant effect on the participants answer in one item only which was ‘eating more easily’ ($F=4.59$, $p=0.01$) where the participants’ in both groups gave a higher importance to easier eating initially and over time the importance assigned to that benefit was reduced (see Table 5.11). However, no statistically significant differences between the two groups were detected.
Do you think treatment will help:  

<table>
<thead>
<tr>
<th></th>
<th>Control Mean (95% CI)</th>
<th>Intervention Mean (95% CI)</th>
<th>Repeated Measures ANOVA</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>T1 (n=49)</td>
<td>T2 (n=49)</td>
<td>T3 (n=38)</td>
</tr>
<tr>
<td>Straighten teeth</td>
<td>73.92 (65-82.8)</td>
<td>76.55 (67.6-85.6)</td>
<td>80.13 (72.7-87.6)</td>
</tr>
<tr>
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<tr>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Close gaps</td>
<td>79.45 (72.6-86.3)</td>
<td>80.84 (73.6-88.1)</td>
<td>78.97 (74.2-85.6)</td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
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</tr>
<tr>
<td>Smile more easily</td>
<td>70.26 (61.2-79.3)</td>
<td>75.11 (66.2-84)</td>
<td>69.53 (61.5-77.6)</td>
</tr>
<tr>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eat more easily</td>
<td>56.26 (47-65.5)</td>
<td>52.39 (43.1-61.7)</td>
<td>48.34 (38.6-58.1)</td>
</tr>
<tr>
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<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speak more easily</td>
<td>49.58 (40.6-58.6)</td>
<td>50.03 (40.2-59.8)</td>
<td>46.53 (36.9-56.2)</td>
</tr>
<tr>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Keep teeth clean</td>
<td>57.5 (47.9-67.2)</td>
<td>55.82 (45.7-56.9)</td>
<td>56.29 (46.8-65.8)</td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improve chances of good career</td>
<td>52.34 (42.5-62.2)</td>
<td>56.53 (46.8-66.2)</td>
<td>56.16 (45.7-66.6)</td>
</tr>
<tr>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Give confidence socially</td>
<td>69.18 (60.2-78.2)</td>
<td>73.18 (63.9-82.4)</td>
<td>71.26 (62.8-79.7)</td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 5.10 Mean values and 95% confidence intervals of VAS items related to expected benefits of treatment by study and control group. All p-values are non-significant unless marked with asterisk(s).
How important are each of these benefits to you?

<table>
<thead>
<tr>
<th>Benefits</th>
<th>Control Mean (95% CI)</th>
<th>Intervention Mean (95% CI)</th>
<th>Repeated Measures ANOVA</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>T1 (n=49)</td>
<td>T2 (n=49)</td>
<td>T3 (n=38)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Straightening teeth</td>
<td>73.55 (64.1-83)</td>
<td>74.32 (65.4-83.2)</td>
<td>78.16 (69.5-86.8)</td>
</tr>
<tr>
<td>Close gaps</td>
<td>78.87 (71.3-86.4)</td>
<td>78.74 (71.4-86.1)</td>
<td>79.42 (72.5-86.4)</td>
</tr>
<tr>
<td>Smile more easily</td>
<td>76.97 (69.6-84.3)</td>
<td>74.76 (65.8-83.7)</td>
<td>75.39 (66.7-84.1)</td>
</tr>
<tr>
<td>Eat more easily</td>
<td>62.74 (52.5-73)</td>
<td>57.68 (47.3-68.1)</td>
<td>56.13 (45.5-66.8)</td>
</tr>
<tr>
<td>Speak more easily</td>
<td>59.26 (48.4-70.1)</td>
<td>52.47 (41.8-63.1)</td>
<td>54.47 (43.9-65.1)</td>
</tr>
<tr>
<td>Keep teeth clean</td>
<td>68.18 (58.1-78.3)</td>
<td>61.42 (51.4-71.4)</td>
<td>61.9 (52.1-71.7)</td>
</tr>
<tr>
<td>Improve chances of good career</td>
<td>61.71 (51.2-72.2)</td>
<td>60.55 (49.8-71.3)</td>
<td>61.03 (49.9-72.1)</td>
</tr>
<tr>
<td>Give confidence socially</td>
<td>75.76 (65.7-85.8)</td>
<td>73.95 (64.4-83.5)</td>
<td>73.37 (64.2-82.6)</td>
</tr>
</tbody>
</table>

**Table 5.11** Mean values and 95% confidence intervals of VAS items related to importance held to each benefit (motivation for treatment) by intervention and control group. All p-values are non-significant unless marked with asterisk(s).
5.3.7 Participants Acceptability of the Intervention Received: Results of the TEI

As described in Chapter 4 of this thesis, some changes were made to the TEI, hence, it was felt important to first assess the internal consistency of the inventory from the data obtained in the trial using Cronbach’s alpha. The results revealed that the overall inter-item value was 0.92 and the corrected item-total correlation of 0.6 was achieved in over 50% of the items, producing a good level of internal consistency (see Table 5.12).

Table 5.13 displays the results of the TEI. It shows that the participants gave the ICB-EM higher scores in the majority of the items, hence, a higher total TEI score was given to the ICB-EM compared to the BOS leaflet, which was statistically significant \((t= -3.53, p=0.001)\).

<table>
<thead>
<tr>
<th>Question</th>
<th>Corrected item total correlation</th>
<th>Alpha if item deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much did you learn from the information given?</td>
<td>0.60</td>
<td>0.91</td>
</tr>
<tr>
<td>How much did you learn about the treatment of missing teeth?</td>
<td>0.64</td>
<td>0.91</td>
</tr>
<tr>
<td>How much did you learn about the hypodontia clinic?</td>
<td>0.71</td>
<td>0.91</td>
</tr>
<tr>
<td>How much new information do you have about how to deal with your problems?</td>
<td>0.60</td>
<td>0.91</td>
</tr>
<tr>
<td>How much did you enjoy the information given?</td>
<td>0.63</td>
<td>0.91</td>
</tr>
<tr>
<td>How interesting was the information?</td>
<td>0.71</td>
<td>0.91</td>
</tr>
<tr>
<td>Was it easy to understand?</td>
<td>0.29</td>
<td>0.92</td>
</tr>
<tr>
<td>How much can you use what you learned?</td>
<td>0.71</td>
<td>0.91</td>
</tr>
<tr>
<td>To what extent do you think you will be able to use what you learned from the information material?</td>
<td>0.58</td>
<td>0.91</td>
</tr>
<tr>
<td>Will the information reduce the level of anxiety if you have any?</td>
<td>0.68</td>
<td>0.91</td>
</tr>
<tr>
<td>Will you react differently to your treatment compared to before you read the information?</td>
<td>0.74</td>
<td>0.90</td>
</tr>
<tr>
<td>Do you think you will handle your treatment better?</td>
<td>0.74</td>
<td>0.91</td>
</tr>
<tr>
<td>Rating of the layout of the information received.</td>
<td>0.56</td>
<td>0.91</td>
</tr>
<tr>
<td>Overall rating of the information you received.</td>
<td>0.64</td>
<td>0.91</td>
</tr>
</tbody>
</table>

Table 5.12 Reliability analysis of the TEI (Cronbach’s alpha)
<table>
<thead>
<tr>
<th>Treatment Evaluation Inventory</th>
<th>Intervention Mean (SD)</th>
<th>Control Mean (SD)</th>
<th>t</th>
<th>p value</th>
<th>95% CI for difference of mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much did you learn from the information given?</td>
<td>3.24 (0.95)</td>
<td>2.73 (0.893)</td>
<td>2.687</td>
<td>0.009**</td>
<td>(0.13, 0.89)</td>
</tr>
<tr>
<td>How much did you learn about the treatment of missing teeth?</td>
<td>3.22 (0.96)</td>
<td>2.79 (1.05)</td>
<td>2.044</td>
<td>0.044*</td>
<td>(0.01, 0.84)</td>
</tr>
<tr>
<td>How much did you learn about the hypodontia clinic?</td>
<td>3.8 (4.5)</td>
<td>2.19 (1.23)</td>
<td>2.398</td>
<td>0.019*</td>
<td>(0.28, 2.96)</td>
</tr>
<tr>
<td>How much new information do you have about how to deal with your problems?</td>
<td>2.96 (0.99)</td>
<td>2.29 (1.24)</td>
<td>2.872</td>
<td>0.005**</td>
<td>(0.20, 1.12)</td>
</tr>
<tr>
<td>How much did you enjoy the information given?</td>
<td>2.89 (0.9)</td>
<td>2.40 (0.96)</td>
<td>2.576</td>
<td>0.012*</td>
<td>(0.11, 0.88)</td>
</tr>
<tr>
<td>How interesting was the information?</td>
<td>3.02 (0.77)</td>
<td>2.98 (0.84)</td>
<td>0.256</td>
<td>0.799</td>
<td>(-0.29, 0.37)</td>
</tr>
<tr>
<td>Was it easy to understand?</td>
<td>3.65 (0.6)</td>
<td>3.29 (0.8)</td>
<td>2.462</td>
<td>0.016*</td>
<td>(0.07, 0.65)</td>
</tr>
<tr>
<td>How much can you use what you learned?</td>
<td>3.11 (0.97)</td>
<td>2.75 (0.98)</td>
<td>1.783</td>
<td>0.078*</td>
<td>(-0.04, 0.76)</td>
</tr>
<tr>
<td>To what extent were you able to use information?</td>
<td>2.87 (0.96)</td>
<td>2.63 (1.0)</td>
<td>1.209</td>
<td>0.230</td>
<td>(-0.16, 0.65)</td>
</tr>
<tr>
<td>Will the information reduce the level of anxiety if you have any?</td>
<td>2.28 (1.28)</td>
<td>1.85 (1.29)</td>
<td>1.619</td>
<td>0.109</td>
<td>(-0.01, 0.95)</td>
</tr>
<tr>
<td>Will you react differently to your treatment compared to before you read the information?</td>
<td>2.48 (0.98)</td>
<td>1.96 (1.11)</td>
<td>2.400</td>
<td>0.018*</td>
<td>(0.09, 0.95)</td>
</tr>
<tr>
<td>Do you think you will handle your treatment better?</td>
<td>2.89 (1.04)</td>
<td>2.21 (1.17)</td>
<td>2.995</td>
<td>0.004**</td>
<td>(0.23, 1.14)</td>
</tr>
<tr>
<td>Rating of the layout of the information received.</td>
<td>3.59 (0.72)</td>
<td>3.17 (0.86)</td>
<td>2.569</td>
<td>0.012*</td>
<td>(0.09, 0.74)</td>
</tr>
<tr>
<td>Overall rating of the information you received.</td>
<td>3.69 (0.6)</td>
<td>3.10 (0.81)</td>
<td>3.988</td>
<td>&lt;0.001**</td>
<td>(0.29, 0.88)</td>
</tr>
<tr>
<td><strong>Total TEI Score</strong></td>
<td><strong>3.08 (0.6)</strong></td>
<td><strong>2.60 (0.7)</strong></td>
<td><strong>-3.53</strong></td>
<td><strong>0.001</strong>**</td>
<td>(-0.75, -0.21)</td>
</tr>
</tbody>
</table>

**Table 5.13** The participants’ evaluation of the intervention received by intervention and control groups represented as means and SD. All p-values are non-significant unless marked with asterisk(s).
5.4 Discussion

To our knowledge, this study was the first to compare two methods of presenting patient information about the care of hypodontia patients on their expectations of the process and outcome of treatment. The proportion of female participants was higher and the proportion of individuals with mild hypodontia was greater than those suffering from moderate and severe hypodontia in both groups which is typical of the hypodontia population (Polder et al., 2004).

Randomisation is a fundamental component of any controlled trial, and it is critical to eliminate bias and confirm validity of the outcome. In the current study, randomisation was done using a random number generator; therefore, there was no significant difference in the sample characteristics between different intervention groups. The allocation is another integral aspect of any trial to avoid bias in assigning participants to a particular intervention. Allocation was concealed using sealed opaque envelopes, which were numbered, and the name of the intervention was written on a card on the sealed envelopes.

With regards to the ‘hypodontia clinic’ section of the questionnaire, it was found that the ICB-EM had a significant impact on the recall of the participants of what was actually experienced during the clinic. The intervention group were more likely to portray accurate responses regarding the number and type of clinicians seen in the clinic. However, the ICB-EM did not generate any difference in patients’ expectations for the majority of the questionnaire items relating to the orthodontic treatment process, restorative treatment process, the expected treatment outcome (benefits of treatment) and the motivation for treatment (level of importance of each benefit) compared to a paper leaflet. Although these findings are in agreement with other studies (Phillips et al., 2001), the majority of studies within the medical field, were able to report significant differences in expectations when comparing multimedia patient information to other methods of information delivery where the groups who received the multimedia information were better informed and held more realistic expectations (Barkhordar et al., 2000, Deyo et al., 2000, Francis et al., 2009, Tait et al., 2009, Wollinger et al., 2012).

The inability to detect differences between the two groups may be due to the reduced sensitivity
of the categorical response questions, or due to a lack of power as the result of the sample size. The effect size of 0.7 chosen as the basis for the sample size calculation is bordering on a large effect size and may have meant that the sample size was not as large as it needed to be to detect smaller differences. However, the authors felt that the value of 0.7 reflected a clinically significant change.

The results revealed a definite effect of time, where for the majority of the VAS items there was a shift in expectations between T1 and T2, which demonstrates the importance of the clinical encounter and how it can change patients’ perceptions. Patient expectations are critically dependent on the engagement with the clinical team highlighting the importance of building positive relationships with the patients and ensuring that they clearly and accurately understand all the implications related to their treatment in order to guarantee informed consent.

The participants’ perceived acceptability of the intervention received was measured using a modified form of the TEI. As it was modified, the researcher first assessed the reliability of the modified version by testing the internal consistency of the inventory using Cronbach’s alpha. Saw and Ng (2001) proposed that a good scale should demonstrate at least moderate correlation between its items. The results revealed that the overall inter-item value was 0.92 and the corrected item-total correlation of 0.6 was achieved in over 50% of the items, suggesting that the items of the inventory is internally consistent as it is greater than the generally accepted value of 0.7 (Kline, 2014).

As for the results of the TEI, the ICB-EM was given a higher total score of 3.08 out of 4 as opposed to 2.6 for the BOS leaflet group, even though there were no significant differences on their effects on expectations. Systematic reviews have revealed that computerised educational interventions for chronic conditions such as arthritis, diabetes mellitus, and asthma are positively perceived by patients and provoke a greater sense of understanding and control over their conditions (Krishna et al., 1997, Lewis, 1999, Shaw et al., 2007). Ryhänen et al (2010) conducted a systematic review of the effects of interactive computer-based patient education in the field of breast cancer and found that the use of the information and interactive services independently contributed to perceived information competence and positive effects on
healthcare participation.

A potential advantage of interactive computerised information is the ability to tailor it to the preferences of the individual receiving it. The concept of tailoring has been shown to be effective in allowing individuals to better understand their condition and its treatment in the dental field as well as the medical field (Barkhordar et al., 2000, Tait et al., 2009). The program used in this study allowed for some degree of tailoring in that patients were able to access different information based on their individual needs. Understanding of interactive computer-based information is greater among those who are younger, which is interesting because the majority of patients attending the hypodontia clinic are within the younger age group (Tait et al., 2009). In the present study, 78% of the participants were below the age of 25, which may be one reason why the participants preferred the ICB-EM over the leaflet.

Despite the evident acceptability of these technologies, there is a clear lack of data related to their effectiveness, especially in the dental field. While studies in the medical field, reported positive effects of interactive computer health information on knowledge acquisition and skill development (Lewis, 1999, Jibaja et al., 2000, Green et al., 2004, Green et al., 2005, Heller et al., 2008, Tait et al., 2009), other studies have shown that use of interactive computer technology in informing patients may not have a direct effect on knowledge acquisition and patient involvement in consultations when compared to traditional forms of patient information (Street et al., 1995, Huss et al., 2003, Campbell et al., 2004, Gerber et al., 2005). In the current study, a number of factors may have contributed to this lack of effectiveness of the ICB-EM on the patients’ expectations. Firstly, factors related to the features of the ICB-EM may have played a role in the results. Although the programme employed a number of features to enhance its effectiveness such as the integration of still pictures, animation, interactive user interface, and touch screen functionality, other features that were not included may have had an impact on the extent of the programs’ effectiveness such as voice over to accommodate low literacy levels and questions and answers embedded within the material to reinforce knowledge and promote interaction (Fox, 2009). Secondly, factors related to the learning environment and viewing protocols have also shown to have an effect. Viewing the material in private settings to increase
comprehension was considered an important feature by some researchers, in addition to allowing the participants to read the intervention more than once to enhance their learning (Evans et al., 2000, Marsch and Bicket, 2004, Fox, 2009). In the current study, the participants viewed the material in the waiting room, which was inevitable as multiple participants at different stages of the trial were being supervised by the researcher at once. In addition, in an effort to standardise the procedures of the RCT between the two groups, the participants in both groups were allowed to view the material one time and for 10 minutes only.

5.4.1 Limitations of the Study

There is a potential that non-response bias affected the findings of this study; of the 225 individuals approached, 96 (42.6%) participated. Such rates of non-recruitment are usual for such trials (Treweek et al., 2013). Overall, 20 (20.8%) participants dropped out from the study resulting in 76 participants completing all parts of the study. According to Schulz and Grimes (2002), researchers should consider the possibility of bias in the results when the loss to follow-up is beyond 20% and that losses between 5% and 20% may still be an intermediate source of bias. However, the dropout rate was similar in both groups, in addition, the baseline characteristics of those remaining in all parts of the study were similar in both groups reducing the possibility of this affecting the results. According to Solberg et al. (2011), patients who only received postal questionnaires were 3 times less likely to respond than those who were summoned for follow-up visits mainly due to forgetfulness. In the current study, this was minimised by reminding the participants over the telephone as well as posting a further questionnaire and a stamped addressed envelope.

As for the statistical tests used, with a repeated measures design there are only a limited number of statistical tests available, which rely on assumptions of data distribution (normality) and skewness. Inspection of the data suggested it fulfilled the criteria of the tests used to assess the test used except in the case of the categorical data. There was multiple statistical testing which may have led to Type 1 error. A total of 117 tests were performed which would suggest that on average 6 would be significant at the 5% level or 1 at the 1% level. In total, there were 22 significant findings between the 5% and 1% levels; 10 significant between 1% and 0.1% and 3
significant at less than 0.1%. Those findings where significance levels are closest to 0.05 should perhaps be interpreted with caution. One way of reducing the chances of type one error that could have been used is by applying the Bonferroni correction to the \( p \) values obtained (Weisstein, 2007).

A larger number of patients would improve the power of the study however this might be challenging to achieve. The study was single-centred, taking place at the orthodontic department at Guy’s and St Thomas’ NHS Foundation Trust. A multi-centred study would allow recruiting a larger number of patients, which may result in detecting a greater difference between the two groups of participants.

5.4.2 Generalizability

Although the study was conducted in a single setting, it is considered one of the major teaching institutions and tertiary referral centres with multidisciplinary clinics within the greater London area. Patients come from hundreds of miles and are from different economic, educational and ethnic backgrounds. Therefore, the results can be regarded as representative and generalizable.

5.5 Conclusions

- Provision of information via the ICB-EM was more effective than provision by leaflet in terms of the participants recall of their experience of the hypodontia clinic.

- There was no difference between the ICB-EM and the leaflet in terms of patient expectations of the process and outcome of orthodontic and restorative treatment.

- Patients expressed a preference for the ICB-EM.
Chapter 6: Discussion

6.1 Introduction

This thesis describes the design and conduct of a randomised controlled trial to measure the impact of a hypodontia specific ICB-EM on hypodontia patients’ expectations of the process and outcome of their combined orthodontic / restorative treatment (Chapter 5). For this to be achieved a mixed methods approach was undertaken whereby qualitative research methods were adopted first (Chapter 3), and individual interviews were conducted with three groups of hypodontia patients to explore their information needs. These needs formed the basis of the hypodontia specific ICB-EM. The interviews also explored key aspects of hypodontia treatment through understanding patients’ expectations and experiences of the process and outcome of their integrated care and the results were used to develop the HTEQ. This was then followed by the materials development phase of the research (Chapter 4) which described the development of the HTEQ, and a detailed description of the ICB-EM development process was provided.

In what follows, a summary of the main findings obtained from the interviews, the materials development phase, and the RCT will be described and discussed in relation to the wider body of evidenced based literature. The limitations of the studies and the methodological issues encountered throughout the phases of the research will be addressed including the strengths of the research. The implications of the findings in relation to policy and practice and any recommendations for future research will also be discussed, before finally, laying out the main conclusions of the thesis.
6.2 Study One: Qualitative Study of Hypodontia Patients

In this study, semi-structured interviews were conducted on 25 patients and their parents. The patients were either new to treatment, in-treatment, or, had reached the end of their treatment. The interviews revealed the impacts of hypodontia on the quality of life of the affected patients, their information seeking behaviour, information needs, expectations and experiences of the treatment process, and expectations and experiences of the treatment outcome. The findings of the interviews were used to develop both the ICB-EM and the HTEQ.

6.2.1 Impact of Hypodontia on the Patients’ QoL

A range of psychosocial and practical impacts have been identified that impact on the quality of lives of the affected patients, all of which confirm previous qualitative and quantitative studies that investigated the effects of hypodontia on the patients (Wong et al., 2006, Laing et al., 2010, Locker et al., 2010, Akram et al., 2011, Kotecha, 2012, Meaney et al., 2012, O’Keeffe et al., 2016). The interviews also revealed that patients employ self-presentation strategies that can be either positive or negative in an attempt to enhance their self-esteem against the reactions of the surrounding people towards their condition. Therefore, the patients were classified as being either negative or positive copers, a finding that has been reported in the literature but is new with regards to the hypodontia patient (Partridge, 1990, Thompson and Kent, 2001).

6.2.2 Information Seeking Behaviour

The interviews also explored the information seeking behaviour of the participants and revealed that some were active information seekers due to the lack of information given to them by their health practitioners and their need to come to terms with their condition especially those suffering from severe hypodontia or missing front teeth. Others revealed they were inactive in seeking information mainly due to the questionable quality of the information they may find, how it may affect them emotionally, their perceived need to do so, and their belief that it is the responsibility of the treating clinician to provide them with all the information they need. A general concern was reported by all the participants regarding the reliability of the information that is available online and while some participants were more sophisticated in judging the
credibility of the information, others were not. These findings are in agreement with previous studies of health information seeking behaviour within the medical field and highlights the need for the clinician to determine the baseline knowledge of their patients and whether it is negatively influenced by their information seeking behaviour (Gray et al., 2005, Stephens et al., 2013, Kimiafar et al., 2016). False knowledge should be modified and corrected to avoid developing false treatment expectations which may have a negative impact on their experience and satisfaction of treatment (O’Connor et al., 2003, Whelan et al., 2004). The interviews also revealed the need to provide information about hypodontia and its treatment that is reliable, readily available and easy to access, all of which have been reported in the literature as being desired characteristics of health information (Gray et al., 2005, Stephens et al., 2013, Kimiafar et al., 2016).

6.2.3 Information Needs

The participants were asked to express their information needs in order to determine the content, layout, and format of the education material based on their views. A wide range of information needs were expressed by the participants but were mainly categorised as information regarding the ‘condition of hypodontia’ including the aetiology, prevalence, diagnosis and side effects, information regarding the ‘treatment of hypodontia’ including the options, process and outcome, and finally information regarding the ‘hypodontia clinic’ including its purpose and nature. The participants also provided suggestions regarding the layout of the material such as adding cartoon images and before and after photos. With regards to the format of delivery, the majority of the participants expressed their desire for written materials that could be available online.

To our knowledge, this is the first study to explore the information needs of the hypodontia patients and as suggested by previous research, the benefits of a patient educational material can be maximised by integrating the views of the target population with the views of those who are experts in the field as they might not be congruent (Habibian et al., 2003, Paul et al., 2004, Asbury and Walshe, 2005, Marshman et al., 2016). This produces educational materials that are sensitive to the patients’ needs and at the same time, evidenced based. The results were used to
develop a hypodontia-specific educational material that was based on the information needs of the target population.

6.2.4 Expectations and Experiences of Treatment Process and Outcome

To our knowledge, this is the first study to explore the expectations and experiences of the hypodontia patients regarding the process and outcome of their integrated care. New patients were asked to express their expectations regarding the process and outcome of treatment. In-treatment patients expressed their views regarding their experience of the treatment they had received so far and their expectations of the treatment process and outcome they were yet to receive, while the end of treatment participants were asked to express their views regarding their experiences with their treatment process and outcome and its relation to their initial expectations. The findings were used as the basis for the development of the HTEQ.

With regards to the process of treatment, the main themes identified were: ‘hypodontia clinic’ (including its nature, procedures involved, and outcome of the clinic), ‘orthodontic treatment’ (including its purpose, practical and psychosocial impacts of the treatment process), and, ‘restorative treatment’ (including the type of restoration, practical and psychosocial impacts of the treatment process). Subthemes that were related to orthodontic treatment have been reported in qualitative studies investigating the patients’ expectations of orthodontic treatment (Bennett et al., 1997, Sayers and Newton, 2006, O’Keeffe et al., 2016), and themes relating to the procedures involved in the hypodontia clinic have also been described in the literature but with reference to the initial orthodontic appointment (Sayers and Newton, 2006). Subthemes generated under the theme ‘restorative treatment process’ are unique to the current study and cannot be compared to previous literature as all of the published studies identified, which had investigated aspects of the treatment process were quantitative in nature. However, it was noticed that most of the patients’ views that were expressed in relation to their expectations of the restorative treatment process were regarding implant treatment which is in agreement with previous studies, which reported that implant treatment is considered the ideal treatment and the
number one choice for patients whether or not they are good candidates due to the increased media influence in advertising implant treatment (Cronin et al., 2009).

As for the outcome of treatment, the main themes identified were: ‘changes in appearance’, ‘functional changes’, and ‘psychosocial changes’. It was found that new and in-treatment patients expressed only positive expectations of treatment outcome while those who had completed their treatment expressed a range of positive as well as negative views. The themes identified confirms the findings of previous research that explored the patients’ expectations of orthodontic, orthognathic, and restorative treatment outcomes (Tulloch et al., 1984, Bennett et al., 1997, Bos et al., 2003, Travess et al., 2004, Sayers and Newton, 2006, Leles et al., 2008, Pabari et al., 2011, Grey et al., 2013, Marshman et al., 2016, O’Keeffe et al., 2016).

The findings that were revealed in this section are considered very important and add to the body of knowledge available regarding dental treatment in general and in particular the treatment of hypodontia patients. It is important to note that all the patient participants were treated at GSTT, which currently has the biggest postgraduate centre in Europe. The vast majority of patients would have been/will be treated by postgraduate dental students and dentists undergoing specialist training under supervision by NHS hospital consultants and this may have had an impact on their experiences and expectations. The patients revealed new information regarding their expectations and experiences of the hypodontia clinic which stresses the significance of this clinic in shaping their experience and the importance of acquiring accurate knowledge regarding its purpose and nature to reduce their level of anxiety and ensure their proper engagement during their time in the clinic. The findings related to the process of orthodontic and restorative treatment highlight the importance of good quality communication between the patient and clinician in order to avoid developing unnecessary anxieties or unrealistic expectations that may have a negative impact on the patients’ compliance and ultimately satisfaction with treatment. Finally, the findings related to the treatment outcome highlight the fact that the patients’ initial expectations may not match their actual experience of the outcome and hence, understanding why patients would seek treatment and what they expect
to gain from the treatment are very important during the clinical encounter to reduce the level of mismatch between their expectations and what can actually be achieved (Pabari et al., 2011).

6.3 Materials Development: Developing and Testing the HTEQ and the ICB-EM

During this phase of the research, all the materials that were used in the RCT were developed and refined. The HTEQ was developed adopting both qualitative and quantitative research methods. After developing the first draft of the questionnaire using the findings of the patient interviews, face and content validity were assessed by presenting the questionnaire to a selected panel of experts and piloting it on ten hypodontia patients. As a result, the questionnaire was revised, some items were eliminated and some were re-written to ensure easier understanding and completion of the questionnaire by the participants. The time taken to complete the questionnaire was recorded and found to be 10-20 minutes, the ease of administration was found to be acceptable, and the overall Flesch-Kincaid grade level was 4.3 (equivalent to the reading ability of a 9–10-year-old), while the Flesch Reading Ease scores for the questionnaire was 78 (equivalent to the reading ability of an 11-12 year old) (Flesch, 1979). This level of readability is higher than the most recent Flesch Kinkaid score given to the Sun newspaper which is considered the easiest newspaper in terms of readability (Simpson, 2009). Therefore, the questionnaire was thought to have an acceptable face value and content validity. As for the internal consistency, this was measured by allowing 32 participants to complete the questionnaire and the internal consistency assessed using Cronbach’s alpha and the overall inter-item value was 0.8, 0.71 for the treatment process items and 0.88 for the treatment outcome items. These results suggested that both the overall scale and the two sub scales were internally consistent and hence the questionnaire was considered reliable and ready to be used in the RCT (Kline, 2014).

As for the ICB-EM, qualitative research methods were used in its development process. The material went through a similar process to the HTEQ. After developing the first draft from the patient interviews, the content was transferred to Articulate Storyline 2 © software package with
the assistance of an information technology expert. The face and content validity of the ICB-EM was then assessed by showing the material to a selected panel of experts and piloting it on a further 10 hypodontia patients. As a result, the material was revised in a similar way to the HTEQ. The feedback obtained from the participants was generally positive and suggested that the material was well laid out and its presentation was acceptable and the information, relevant, easy to understand and useful. The Flesch - Kincaid grade level of the ICB-EM was 7.8 (12–13-year-old reading ability) and the Flesch Reading Ease score was 69.8 (equivalent to the reading ability of an 11-12-year-old). Therefore, the ICB-EM was considered to have satisfactory face and content validity, an acceptable reading level, and was ready to be used in the RCT.

6.4 Study Two: Randomised Prospective Controlled Trial

The RCT was aimed at investigating the effects of the ICB-EM on the patients’ expectations of the process and outcome of their combined treatment and compared these to a paper-based hypodontia BOS leaflet. With regards to the hypodontia clinic section of the questionnaire, the results revealed a significant effect of the ICB-EM on the participants’ recall of what was actually experienced during the clinic. The intervention group was more likely to demonstrate accurate responses with regards to the number and type of clinicians seen in the clinic and less likely to answer ‘I don’t know’. However, for the majority of the remaining items of the questionnaire, both the intervention and control groups demonstrated similar expectations of orthodontic and restorative treatment process as well as the expectations of the treatment outcome across the three time points. These results are in agreement with a study conducted by Phillips et al. (2001), who found that a computer simulation programme did not have a significant effect on the patients’ expectations of orthognathic surgery and attributed this to the psychosocial well-being of the individuals. On the other hand, several studies in the medical field have reported significant differences in expectations as a result of multimedia patient information when compared to other methods of information delivery (Barkhordar et al., 2000, Deyo et al., 2000, Francis et al., 2009, Tait et al., 2009, Wollinger et al., 2012).

The RCT also revealed that time had a significant impact on the patients’ expectations and revealed a shift in their expectations from T1 to T2. These findings are thought to be due to the
effects of the clinical encounter in addition to the information provided and highlights the importance of a positive engagement between the patients and their clinicians in order to obtain informed consent.

A modified form of the TEI was used to assess the participants’ acceptability of the intervention received. The internal consistency of the modified version was first assessed using Cronbach’s alpha and it was found to be internally consistent as the overall inter-item value was 0.92 and the corrected item-total correlation of 0.6 was achieved in over 50% of the items (Kline, 2014). The results of the TEI revealed that hypodontia patients tended to favour the ICB-EM and gave it a higher total score as compared to the BOS leaflet group. This accords with other studies who found that computerised patient information is more positively perceived by patients and provokes a greater sense of understanding and control of their condition especially in younger patients (Krishna et al., 1997, Lewis, 1999, Shaw et al., 2007, Tait et al., 2009, Ryhänen et al., 2010).

Although the ICB-EM was perceived as more acceptable than the BOS leaflet, it did not have an effect on the expectations of the hypodontia patients in the present study. The literature has revealed mixed outcomes with regards to the effectiveness of interactive computer health information where some studies within the medical field, reported positive effects of interactive computer health information on knowledge acquisition and skill development (Lewis, 1999, Jibaja et al., 2000, Green et al., 2004, Green et al., 2005, Heller et al., 2008, Tait et al., 2009), while other studies were not able to report differences between interactive computer and traditional forms of patient health information on knowledge (Street et al., 1995, Huss et al., 2003, Campbell et al., 2004, Gerber et al., 2005).

In the current study, factors that may have contributed to this lack of effectiveness of the ICB-EM on patients’ expectations includes the lack of certain features in the ICB-EM such as voice-over feature to reinforce script messaging to meet the needs of patients with limited reading skills, and questions and answers embedded within the material to reinforce knowledge and promote interaction (Fox, 2009). Other environmental factors and viewing protocols could also have had an effect on the effectiveness of the material such as viewing the material in a private
setting and allowing the participants to read the intervention more than once to enhance their learning (Evans et al., 2000, Marsch and Bicket, 2004, Fox, 2009).

6.5 Methodological Critique

6.5.1 Study One: Hypodontia Patient Interviews

Strengths

The present study comprised a novel measure of patients’ expectations as well as a hypodontia specific education material that employed a mixed-method design following the steps of previous studies in the belief that qualitative methodologies involving patient interviews is a valuable way of eliciting the perceptions of patients when developing patient information materials and condition-specific measures (Charnock, 1998, Shepperd et al., 1999, Travess et al., 2004, Asbury and Walshe, 2005, Akram et al., 2011, Marshman et al., 2016). Within the dental field, qualitative methodologies have been adopted to understand the impacts of dento-facial deformity on the quality of life of the effected patients, their motivations for treatment, and their expectations of the process and outcome of care, but the literature review revealed a clear lack of qualitative studies investigating issues specifically relating to patients with hypodontia (Cunningham et al., 2000, Travess et al., 2004, Akram et al., 2011, Meaney et al., 2012, Ryan et al., 2012a, Ryan et al., 2012b, Grey et al., 2013).

This study provided valuable information on the quality of hypodontia patients’ lives, their information seeking behaviours, information needs and their expectations of the process and outcome of care. Bias in the interviews was minimised as a result of the interviewer having no care providing role. However, as the researcher is a qualified orthodontist, the general knowledge and understanding of the patients’ condition made it easier to ask appropriate follow up questions based on the participants’ responses, which enhanced the credibility of the results. In addition, the thematic analysis was conducted in a rigorous manner and applied in line with the recommendations set out by Ritchie et al. (2013).
Limitations

The risk of bias during data analysis was not completely eliminated, due to the researcher’s specialist knowledge and understanding in the area. This risk was kept to a minimum by allowing two members of the research team to analyse the data independently, one of whom was not a professional in the dental field and hence analysed the data with no pre-existing knowledge in the management of the hypodontia patient. Another weakness of the qualitative study was that due to practical reasons, it was not possible to obtain the interviewees’ views regarding the themes that were generated from the analysis. This is considered ideal when conducting qualitative research, however, to counteract this weakness, the researcher did allow hypodontia patients to view the HTEQ and the IBC-EM, which were based on the themes identified and received positive feedback.

6.5.2 Materials Development

Strengths

The inclusion of a material development phase in the study allowed a detailed understanding of the research area to be acquired and considered in the study design. During this phase both qualitative and quantitative methodologies were employed in a series of steps to develop a patient oriented HTEQ and ICB-EM that also took into consideration the views and opinions of experts in the field. The steps involved in the development phase also insured the detection of logistical issues in the lead-up to the RCT, such as changing wordings, eliminating and adding items to the materials, and determining when and where to collect the data. Piloting both materials ensured that both the questionnaire and the patient education material were valid in terms of face value and content, comprehensible, and useful. To improve the reliability of the questionnaire, it was tested on a further sample and proved to be internally consistent.
Limitations

A limitation of this phase of the research was encountered during the pilot stage of the materials development. It was presumed that the participants taking part in the pilot test of the HTEQ and the ICB-EM were literate, therefore, the readability level of the materials were likely to have been appropriate for them. The participants were not asked to state their level of education or their reading skills as it may have been perceived as insensitive. However, the risk of this having an impact on the results was reduced by measuring the readability of the materials using the Flesch - Kincaid grade level and the Flesch Reading Ease score.

Another limitation faced during the pilot stage of both materials, was that it took longer than expected due to the nature of the clinic. It was also difficult to allow the participants enough time to understand the purpose of the project, ask questions, go through the materials, and comment on their contents without interrupting the flow of the clinic and therefore only 3-4 patients per clinic participated to minimise disruption.

It is well known in the literature that questionnaire development is exposed to researcher bias due to the increased risk of intrinsic manipulation (Creswell, 2013). This was kept to a minimum by using the themes generated from detailed and comprehensive analyses of the interview data to develop the items of the questionnaire. Furthermore, although the questionnaire’s reliability was assessed using Cronbach’s alpha to measure its internal consistency, our understanding of the consistency of individual’s responses would be enhanced by testing its repeatability or test-retest reliability. However, this was not possible in the current study for logistical reasons as it was not possible to allow enough time between the test and retest without changing the participants’ knowledge or expectations because they would have passed through the hypodontia clinic in that time. Another limitation of the questionnaire is that although it can be used in a hypodontia clinic in its current format, it may take longer than desired to complete and the development of a shorter form may prove to be more useful for routine clinical use.

As for the ICB-EM, it is only suitable for those who are able to read English. Further developing the material to include different languages and presented in other formats such as
audio for the benefit of the visually impaired and those with low levels of literacy could prove to be beneficial. In addition, the material in its current format cannot be accessed by the public and requires further copyright checks, coding and hosting on an internet server to allow web access. As mentioned in Chapter 4, the research team is liaising with Guy’s and St Thomas’ NHS trust to determine what further developments are required before it can be hosted.

6.5.3 Study Two: Randomised Controlled Trial

Strengths

The RCT was conducted in accordance with CONSORT guidelines and strictly adhered to ethical guidelines. The study employed a variety of methods to improve the reliability of the findings. The scales used were validated demonstrating good internal consistency, the interventions delivered were comparable, participants were tested in their usual environment resulting in high ecological validity (Cohen et al., 2011). In addition, to reduce external variables, the questionnaires were completed at baseline immediately before the intervention and at T2, immediately post intervention. The study also featured a three to four-week follow up, which provided valuable insight into the impact the intervention(s) could have over time. Selection bias was minimised by using a random number generator and concealing the allocation using sealed opaque envelopes to ensure appropriate random allocation to both groups. With regards to generalisation, the study was conducted in one of the largest teaching hospitals in the Greater London area comprising a hypodontia multidisciplinary clinic. The hypodontia clinic receives referrals from not only within Greater London but from a wide area of South and South-East England, and the patients who attend this clinic come from a variety of different, educational, economic and ethnic backgrounds, which enhances the generalisability of the results.
Limitations

A limitation that may have affected the study was the inability to blind the participants or the researcher to the interventions. Although this is a very important aspect to consider in an RCT, it was not possible in the current research, however, the clinicians who saw the participants in the hypodontia clinic after reading the intervention were blinded as was also the statistician who undertook the data analyses. Moreover, participants had different senior clinicians who took the lead in discussing their condition and the proposed treatment during the hypodontia clinic depending on their case, this could have affected their answers at T2 and T3 as the verbal information given to them was different between the participants, however, this was unavoidable as standardising the verbal information is considered unethical due to the different conditions presented by the participants. However, a senior clinician only took the lead after the patient had been examined and proposed treatment had been discussed and agreed by all the relevant attending specialist clinicians. Moreover, the team of clinicians met every week before the clinic started to look through the clinical notes of the patients booked in and to discuss any potential issues and share any thoughts. This helped bring about some consistency in the approach of the clinical team to managing and caring for the patients.

Another limitation that was faced during the RCT was the risk of non-response bias, which could have had an effect on the findings of the study. From the 225 potential participants that were eligible to be included in the study, only 96 (42.6%) consented to participate. Such rates of non-recruitment are common amongst trials (Treweek et al., 2013). Furthermore, 20 participants were lost to follow up and hence the final sample was 38 in both groups. This may have been a source of bias in the results, however, the dropout rate was similar in both groups, and in addition, the baseline characteristics of those remaining in all parts of the study were similar, hence reducing the possibility of this affecting the results (Schulz and Grimes, 2002). The drop-out rate in studies involving postal questionnaires is three times higher than studies who summon participants for follow up visits and is mainly due to forgetfulness (Solberg et al., 2011).

One reason for the inability to detect differences between the two groups could be the small
sample size which was calculated to detect an effect size of 0.7, which is bordering a large effect size and hence, recruiting a larger number might have been beneficial and more likely to detect smaller differences. In addition, there was multiple statistical testing which may have led to Type 1 error. A total of 117 tests were performed which would suggest that on average 6 would be significant at the 5% level or 1 at the 1% level. In total, there were 23 significant findings between the 5% and 1% levels; 10 were significant between 1% and 0.1% and 3 significant at less than 0.1%. Those findings where significance levels are closest to 0.05 should perhaps be interpreted with caution.

6.6 Recommendations and Future Implications

6.6.1 Implications for Practice

The results of the RCT demonstrated the importance of the clinical encounter and how it can change patients’ perceptions with regards to their expectations of the process and outcome of their care. Patient expectations are critically dependent on the engagement with the clinical team highlighting the importance of building positive relationships with the patients and ensuring that they clearly and accurately understand all the implications related to their treatment in order to guarantee informed consent.

This study also highlights the importance of communication between clinicians and their patients as an essential component of care. One way of improving the quality of information given to patients is the use of patient information materials. In the current study, no intervention was significantly more effective in changing the patients’ expectations, however clinicians should consider paying attention to the very different perspectives patients may have regarding their care and provide information in the best possible format for that patient. Also, as the patients expressed a clear preference for the ICB-EM, clinicians should consider the use of computer technology more often in their quest to educate patients.

With regards to the HTEQ, it can be used as a clinical tool by highlighting areas where patients would portray unrealistic expectations and hence, trigger the clinician to rectify these expectations by providing more information or additional support. As for the ICB-EM, it can
serve as a guidance tool that would help patients understand their condition and its treatment, hence enabling them to ask better questions during the clinical encounter, and make better decisions that are on an informed basis. The information can be sent to the patients in advance of their appointments at virtually no cost. It can also guide them throughout their treatment journey and help them recall the information given to them by their care providers. This information can be individualised for the patients during the treatment making it part of their ongoing informed consent. Another advantage of the ICB-EM is that it can be updated periodically and patient blogs or comments could be added.

However, it is important to note that the ICB-EM in its current format, cannot be accessed by the public as it requires transferring the material to a web server in order to allow the public to view the material with ease and from any device. The research team is currently in the process of introducing the material to Guy’s and St Thomas’ NHS trust in order to publish the material on their website. Implementation strategies for interventions developed through research need to be developed locally and with an understanding of the barriers within the local clinical environment.

6.6.2 Directions for Future Research

There are several implications for researchers to consider in this area. With regards to the HTEQ, researchers could consider assessing the test-retest reliability of the questionnaire on a new sample of hypodontia patients. This could be achieved by posting the questionnaire to new patients two to three weeks in advance of their initial hypodontia clinic appointment. They can then fill the questionnaire again on the day of the appointment before entering the clinic to reduce the chances of changes in their expectations as a result of the verbal information received in the clinic. Also, the questionnaire could be revised to create a shorter version for routine use in the clinic and tested for its reliability and validity. Furthermore, the value of the HTEQ as a clinical communication tool could be evaluated. Through identifying patients’ expectations early on in the process of care the possibility arises for developing communication protocols to enhance the patient experience. As for the ICB-EM, different versions could be developed that would be suitable for the younger age groups, illiterate, and visually impaired.
such as audio or video versions. In addition, more interactivity could be added to the ICB-EM or it may be transferred to a different software, which could provide more options for interactivity and could be easier to handle.

As for the RCT, researchers could consider repeating the test using a bigger sample to increase the chances of detecting differences between the groups. The initial sample size estimate was based on a large effect size of 0.7. It may be that a small effect size of 0.2 would be more appropriate which would require a sample size of 126. One aspect of the RCT that was not avoidable was the fact that the participants filled out the T2 questionnaire after attending the hypodontia clinic which may have had a confounding effect on the results and future studies could consider asking the participants to fill out the questionnaire immediately following the intervention to be able to better assess the effects of the ICB-EM. In addition, researchers could also use the ICB-EM to measure different outcomes such as change in behaviour (compliance with treatment).

In the current study, the questionnaire was used to measure the change of patients’ expectations before and after the ICB-EM as compared to a paper-based leaflet. Researchers could consider repeating the study and using different forms of behavioural interventions. They could also use the questionnaire to as a research tool to identify how expectations change over time when the patient is well into treatment and better informed. In addition, the questionnaire could be used to audit different services within the UK and a national survey could be conducted to compare patients’ expectations from different parts of the UK. The study could also be repeated in other countries to assess whether expectations are culturally bound.
6.7 Conclusions

- The effects of hypodontia on patients’ quality of life have been explored and three main themes were identified: ‘practical’, ‘psychosocial’, and ‘coping strategies’.

- Patients’ information seeking behaviours were determined and revealed the need to provide good quality information that is reliable, readily available, and easier to access. The results of this area also highlighted the importance of the role of the clinician in determining the information seeking behaviour of their patients, as well as their baseline knowledge to establish whether it should be modified to avoid the development of false expectations of treatment.

- Patients’ information needs were explored and they expressed a need for more information regarding the condition of hypodontia (prevalence, diagnosis, aetiology, and side effects), its’ treatment (options, process, and outcome), the hypodontia clinic (purpose and nature), and the patient education material (content, layout, and format). These areas formed the basis of the ICB-EM development.

- Patients’ expectations and experiences of the process and outcome of their combined orthodontic and restorative treatment have been explored. Themes relating to the treatment process were in relation to the hypodontia clinic (nature, procedures, outcome of the clinic), the process of orthodontic treatment (purpose, practical impacts, and psychosocial impacts), and the process of restorative treatment (type of restoration, practical impacts, and psychosocial impacts). Themes relating to the treatment outcome were changes in appearance, functional changes and psychosocial changes. These areas formed the basis of the HTEQ development.

- The study presented the development process of a new questionnaire to assess expectations of patients with hypodontia regarding the process and outcome of combined orthodontic and restorative treatment. The proposed questionnaire has good face and construct validity and satisfactory internal consistency.
• The development of a new patient based, hypodontia-specific computer-based information material has been described. The material has satisfactory face and content validity and an acceptable reading level.

• Provision of information via the ICB-EM was more effective than provision by leaflet in terms of the participants’ recall of their experience of the hypodontia clinic.

• There was no difference between the ICB-EM and the leaflet in terms of patient expectations of the process and outcome of orthodontic and restorative treatment.

• Patients expressed a preference for the ICB-EM.
References


Appendices

Appendix 1: Ethical approval for Study One from NRES committee London-Chelsea

06 November 2013

Dr. Richard Foxton
Clinical lecturer/Honorary Specialist Registrar
Kings College London, Dental Institute
Floor 25, Restorative Dentistry
Guy’s Tower, Guy’s Hospital
London Bridge, London
SE1 9RT

Dear Dr. Foxton

Study title: Improving Patient Understanding of Hypodontia
REC reference: 13/LO/1146
IRAS project ID: 128642

Thank you for your letter, responding to the Committee’s request for further information on the above research.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Danyal Enver, nrescommittee.london-chelsea@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS sites
• Notification of serious breaches of the protocol
• Progress and safety reports
• Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/LO/1146 Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members’ training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee’s best wishes for the success of this project.

Yours sincerely

P.P.

Dr Shelley Dolan
Chair

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Copy to: Mr Keith Brennan
Mk Karen Ignatian, Guy’s and St Thomas’ NHS Foundation Trust
Appendix 2: Ethical approval for Study One from R&D Department at Guy’s and St Thomas’ NHS Foundation Trust

Dear Dr Bister,

Title: Improving Patient Understanding of Hypodontia
REC Ref: 13/LO/1146
Local Collaborator: Dr Dirk Bister
CI/Co Richard Foxton
Sponsor: King’s College London University

Thank you for submitting your study to GSTT R&D Department I am delighted to inform you that NHS Permission has been issued for the above study. We have prepared a site file that will include the R&D approval letter and we will need to meet and explain your responsibilities as an investigator in order to remain compliant under the Research Governance Framework.

Please let me know when would be convenient to meet either at your office or at the R&D offices, 16th floor Tower Wing, Guy’s Hospital. It is fine for this meeting to take place with another member of the research team if more convenient. We will also need to schedule an appointment with Dr Ben Gassem for her to be issued her letter of access to allow her access to GSTT patients.

As you may be aware, the Trust is working to achieve the national and local ambition of:
- 80% studies recruiting their first participant within 30 days
- 80% of studies recruiting the agreed number of participants within the planned study duration

For your study, the targets are recruiting your first participant by 3/02/2014 and recruiting 112 patients in total by 1501.216. If you are not able to meet these targets please do contact me to discuss an extension to the end date or other options.

You will need to send by email a monthly report of the recruitment numbers to the studies i.e. the numbers of participants recruited to your studies every month. This reporting is now a Department of Health requirement and the Trust is tasked with gathering data on every active study taking place at the organisation.

The accrual notification should be sent to: RDRrecruitment@gstt.nhs.uk
Appendix 3: Topic guide for patient interviews

All patient groups

Introduction
- Introduce myself
- Introduce the study: nature and purpose/who research is for
- Introduce audio recorder
- Confidentiality

Ice Breaker
- Name /age
- What do you do day to day?
- What are your hobbies

Effects of hypodontia
- Does the condition effect your quality of life? How?

Information seeking:
- Did you look up information about your condition? Why / why not?
- Where did you look for information?
- What did you like / dislike about the information?
- Was it helpful?
- How did you judge the accuracy of the information?

Information needs
- Would a hypodontia specific information material be helpful to you? How?
- What should be included in the material?
- How should it be delivered?

New Patients

Expectations of treatment process
- Are you aware of the hypodontia clinic?
- What do you expect will happen in the clinic?
- What do you expect the options for treatment would be? Orthodontic options / restorative options including surgery
- What do you expect the treatment will involve? How will it affect you?

Expectations of treatment outcome
- Why did you seek treatment? Motivations for treatment?
- What do you expect to gain from the treatment?
In-treatment patients

Experience with treatment process
- Are you aware of the hypodontia clinic?
- What do you expect will happen in the clinic?
- Can you describe your treatment journey?
- Were your expectations met with regards to the treatment process? What aspects of the treatment weren’t you expecting?

Expectations of treatment outcome
- Why did you seek treatment? Motivations for treatment?
- What do you expect to gain from the treatment?

End of treatment patients

Experience with treatment process
- Are you aware of the hypodontia clinic?
- What do you expect will happen in the clinic?
- Can you describe your treatment journey?
- Were your expectations met with regards to the treatment process? What aspects of the treatment weren’t you expecting?

Experience with treatment outcome
- Why did you seek treatment in the start?
- How do you feel about the outcome of the treatment you had? What are the benefits gained?
LETTER TO PARTICIPANT

Name: 
Address: 
Postcode: 
Date: 

Dear 

RE: Improving Patient Understanding of Hypodontia

We are writing to ask for your kind help and invite you to participate in our study, which aims to improve the quality of the information given to patients who have missing teeth (hypodontia), enabling them to make informed decisions about their treatment and at the same time improve their experience throughout the treatment journey. We are aiming to develop a valid patient information material about hypodontia that will guide future generations of patients through treatment.

Your participation will involve joining a group of four people who are also affected by missing teeth and a group interview will take place at your next visit at the orthodontic department. The interview will allow you to talk about your opinions and views as well as discussing them with the other group members. The group interview should take no more than 45 minutes to complete.

In order for the responses to be useful they have to be recorded but these will be confidential. The recordings will be erased immediately after they have been transcribed, so the information cannot be traced back.

We hope you find this information helpful and we are looking forward to seeing you soon.

Yours Sincerely,

Afnan Ben Gassem
Postgraduate Dental Student
KCL Dental Institute
Floor 18, Guy’s Hospital
London SE1 9RT
Appendix 5: Participant information sheet parent/guardian

IMPROVING PATIENT UNDERSTANDING OF HYPODONTIA
Parent/Guardian information sheet
Researchers: Afnan Ben Gassem
Richard Foxton
Dirk Bister

We are pleased to invite you and your child to take part in a research study at King’s College London Dental Institute at Guy’s Hospital. Please take your time to read the following information and do not hesitate and contact us if you have any queries regarding the below information.

1. What is the purpose of the study?

The project aims to improve the quality of the information given to patients with missing teeth (hypodontia) and their parents before starting their treatment. This will help future generations of patients to make an informed decision about the treatment options available. It will help patients to decide on treatment with more confidence as well as improve their experience throughout the treatment journey. We are aiming to develop patient information material about hypodontia that will act as guidance throughout treatment.

2. Why I have been invited?

We invited you because we value opinions of patients who have missing teeth (and their parents) and have not yet started their treatment. Your views will be of great benefit helping us create relevant information material.

3. Do I have to take part?

It is up to you to decide whether or not to take part. If you decide not to take part this will not affect the treatment your child will receive.

4. What will happen to me if I take part?

If you decide to take part, we will ask you and your child to sign a consent form on the day of the appointment. We will ask you to join a group of five to nine people depending on how many parents/guardians participate with their youngsters and a group interview will be conducted. The group interview will take place before the consultation and will be held in a room away from the clinic. Patients below the age of 15 years must be accompanied by a person with parental responsibilities. In the group discussion, we will try to find out what you and your child already know about the condition of ‘missing teeth’. Please be aware that this is NOT a test and there are no correct or wrong answers. The interview will be 30-45 minutes long, however, gaining consent from you and the other four participants may take a little extra time.
The interview will be recorded and transcribed for analysis and what was said and by whom will remain completely anonymous. A diagram is included at the end of this sheet to show you what happens during the morning when a patient agrees to participate in the research project.

5. **What are the possible risks to take part?**
   There are no risks to taking part in this project.

6. **What are the benefits of taking part?**
   Your participation will help us find out how we can improve delivery of the content and format of the way we deliver the information given to patients affected by missing teeth (hypodontia) in the future.

7. **Will my taking part in this study be kept confidential?**
   Absolutely. All information which is collected about you and your child during the course of the research will be kept strictly confidential. Your name and personal details will be anonymised.

8. **What will happen to the results of the study?**
   The results will be used by Dr Ben Gassem as part of her PhD project. The research will be published in academic journals and presented on conferences and we will send you copies if you wish. Participants cannot be identified in any of the publications.

9. **Who has reviewed the study?**
   This project was reviewed by the Chelsea Research Ethics Committee.

10. **What will happen if I don’t want to carry on with the study?**
    You can withdraw from the study at any time and this will not affect the care your child will receive in any way.

11. **Contact for further information.**
    If you would like to get further information or if you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your question:
    Dr Ben Gassem by e-mail; aftan.ben_gassem@kcl.ac.uk or by calling the PA in Orthodontics Miss Stephanie Hann tel; 02071884415
    You are more than welcome to discuss any issues that may arise with any member of the research team.
    If you remain unhappy about any aspect of the study and wish to complain formally, you can do this by contacting Patient Advice and Liaison Service at Guy’s Hospital on the following number 020 7188 8803.
    Thank you for taking the time to read this information – please ask any questions if you need to.
Participant Journey

9:00 AM arrival.

9:15 AM consent taken in the orthodontic waiting area (15 minutes)

9:15 AM Participants taken to seminar room

9:30 Conduction of group interview (30-45 minutes)

Participants back in the orthodontic waiting area

Participants called individually into hypodontia clinic for the consultation (30-60 minutes)

Visit Completed
Appendix 6: Participant information sheet 16+

REC Reference number: 13/LO/1146
Version number: 2
15 October 2013

IMPROVING PATIENT UNDERSTANDING OF HYPODONTIA
Participants information sheet (16 years and older)

Researchers: Afnan Ben Gassem
Richard Foxton
Dirk Bister

We are pleased to invite you to take part in a research study at King’s College London Dental Institute at Guy’s Hospital. Please take your time to read the following information and do not hesitate and contact us if you have any queries regarding the information provided.

1. **What is the purpose of the study?**
   
The project aims to improve the quality of information given to patients with missing teeth (hypodontia), before starting treatment. This will help future generations of patients to make an informed decision about the treatment options available. We are planning to develop patient information material about hypodontia that will act as guidance throughout treatment. It will help patients to decide on treatment options with more confidence as well as improve their experience throughout the treatment journey.

2. **Why I have been invited?**
   
   We invited you because we value opinions of patients who have missing teeth and have not yet started their treatment. Your views will be of great benefit helping us create relevant information material.

3. **Do I have to take part?**
   
   It is up to you to decide whether or not to take part. If you decide not to take part this will not affect the treatment you receive.

4. **What will happen to me if I take part?**
   
   If you decide to take part, we will ask you to sign a consent form on the day of the appointment. We will ask you to join a group of five to nine people depending on how many parents/guardians participate with their youngsters and a group interview will be conducted.
   
The group interview will take place before the consultation and will be held in a room away from the clinic. Patients below the age of 15 years must be accompanied by a person with parental responsibilities.
   
   In the group discussion, we will try to find out what you already know about the condition of ‘missing teeth’. Please be aware that this is NOT a test and there are no ‘correct’ or ‘wrong’ answers.
The interview will be 30-45 minutes long, however, gaining consent from you and the other four participants may take a little extra time. The interview will be recorded and transcribed for analysis; what was said and by who will remain completely anonymous. A diagram is included at the end of this sheet to show you what happens during the morning when a patient agrees to participate in the research project.

5. **What are the possible risks to take part?**

There are no risks to taking part in this project.

6. **What are the benefits of taking part?**

Your participation will help us find out how we can improve the delivery of the content and format of the information to patients affected by missing teeth (hypodontia).

7. **Will taking part in this study be kept confidential?**

Absolutely. All information which is collected about you during the course of the research will be kept strictly confidential. Your name and personal details will be anonymised.

8. **What will happen to the results of the study?**

The results will be used by Dr Ben Gassem as part of her PhD project. The research will be published in academic journals and presented on conferences and we will send you copies if you wish. Participants cannot be identified in any of the publications.

9. **Who has reviewed the study?**

This project was reviewed by the Chelsea Research Ethics Committee.

10. **What will happen if I don’t want to carry on with the study?**

You can withdraw from the study at any time and this will not affect the care you receive in any way.

11. **Contact for further information?**

If you would like to get further information about any aspect of this study, please do not hesitate and contact:

Dr Ben Gassem by e-mail; afnan.ben_gassem@kcl.ac.uk or by calling the PA in Orthodontics, Miss Stephanie Hann tel; 020 71884415

You are more than welcome to discuss any issues that may arise with members of the research team.

If you are unhappy about any aspect of the study and wish to complain formally, you can do this by contacting Patient Advice and Liaison Service at Guy’s Hospital on the following number 020 71888803.

Thank you for taking the time to read this information.
Participant Journey

9:00 AM arrival.

9:15 AM consent taken in the orthodontic waiting area (15 minutes)

9:15 AM Participants taken to seminar room

9:30 Conduction of group interview (30-45 minutes)

Participants back in the orthodontic waiting area

Participants called individually into hypodontia clinic for the consultation (30-60 minutes)

Visit Completed
Appendix 7: Participant information sheet 12-16

What if I want to take more time to think or if I want to ask more questions about this research?
If you would like any further information please do not hesitate to contact me by:
phone on 07772884541 or alternatively by e-mail;
afnan.ben_gassem@kcl.ac.uk

Thank you for reading this sheet – please ask any questions if you need to.
My name is Afnan Ben Gassem and I am looking into the quality of the information that has been given to you and your parents in the Orthodontic Clinic as part of my research at King’s College London.

**What is this all about?**

My research is to find out ways of improving information about missing teeth so you can make an informed decision on what treatment option is best for you.

**What does it involve?**

I would like to ask you to join a group of three other patients who also have missing teeth. I will be asking your group a few questions about what you already know about missing teeth; we would like to improve the way we give you information before starting your treatment.

This is not a test and there are no right or wrong answers! Your opinion is important and you can say anything you want.

Your parent (carer) will also attend and we invite them to give us their opinions as well.

**Why have you invited me?**

We invited you because we need the opinions of patients who have missing teeth and have not yet started their treatment.

**What will happen if I agree to participate?**

If you agree to take part we will ask you to sign a consent form. Then we will ask you to wait with your parent/carer in the waiting area until a group of four people is created and a group interview will take place.

We will sit together and talk about missing teeth. This conversation will be confidential but we need to record what was said to help me remember our conversation. No one will know what you said apart from the group and me.

**What if I don't want to participate?**

Your treatment will go on as would do in any case! You can withdraw from the study at any time, even after the interview has taken place. We would however be very grateful for your opinion: this will help patients in the future.

**Is there any danger for me to participate?**

There is no danger in taking part in this project.
Appendix 8: Assent and consent forms

ASSENT FORM
For Participation in Research (12-16 years old)

Title of Study: IMPROVING PATIENT UNDERSTANDING OF HYPODONTIA

REC Reference: 13/LO/1146

1. I have read and understand the information sheet dated 16-07-2013 for the above study. I have had the opportunity to think about the information, ask questions and they were answered.

2. I agree to be interviewed and my voice recorded.

3. I understand that I will be talking with a group of people and I am willing to express my views within the group.

4. I understand that I can decide at any time in the research to stop participation and to have my information withdrawn without giving any reason. Withdrawal from the study will not affect the standard of care I receive.

5. I understand that relevant sections of my dental notes and my personal information may be looked at by the research team and I give permission for these individuals to have access to my records.

[I wish to be informed of the outcomes of this research study.]

E-mail address: _______________________

Participant’s Statement:

I -
Agree that the research project named above has been explained to me and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed …………………………………………………… Date……………………

Investigator’s Statement:

I -
Confirm that I have carefully explained the nature, demands and any foreseeable risks (where applicable) of the proposed research to the volunteer.

Signed………………………………………………… Date……………………
CONSENT FORM
For Participation in Research (16 years and older)

Title of Study: IMPROVING PATIENT UNDERSTANDING OF HYPODONTIA

REC Reference: 13/LO/1146

1. I confirm that I have read and understand the information sheet dated 16-07-2013 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I consent to my interview being recorded and transcribed verbatim.

3. I understand that I will be talking with a group of participants and I am willing to express my views within the group.

4. I understand that I can decide at any time in the research to stop participation and to have my information withdrawn without giving any reason. Withdrawal from the study will not affect the standard of care I receive.

5. I understand that relevant sections of my dental notes and my personal information may be looked at by the research team and I give permission for these individuals to have access to my records.

I wish to be informed of the outcomes of this research study.

E-mail address: ____________________________

Participant’s Statement:

I -
Agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed …………………………………………………………. Date…………………………

Investigator’s Statement:

I -
Confirm that I have carefully explained the nature, demands and any foreseeable risks (where applicable) of the proposed research to the volunteer.

Signed………………………………………………………. Date…………………………
CONSENT FORM
For Participation in Research (Parent/Guardian)

Title of Study: IMPROVING PATIENT UNDERSTANDING OF HYPODONTIA

REC Reference: 13/LO/1146

1. I confirm that I have read and understand the information sheet dated 16-07-2013 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I consent to my interview or my child/youngster interview will be recorded and transcribed verbatim.

3. I understand that my interview and my child’s/youngster’s interview will involve talking with a group of participants and I am willing to express my and my child’s/youngster’s views within the group.

4. I understand that I can decide at any time in the research to stop participation and to have my information withdrawn without giving any reason. Withdrawal from the study will not affect the standard of care my child will receive.

5. I understand that relevant sections of my child’s dental notes and personal information may be looked at by the research team and I give permission for these individuals to have access to my records.

☐ I wish to be informed of the outcomes of this research study.

E-mail address: __________________________

Parent’s/Guardian’s Statement:

I -
Agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed ……………………………………………………………….. Date………………

Investigator’s Statement:

I -
Confirm that I have carefully explained the nature, demands and any foreseeable risks (where applicable) of the proposed research to the volunteer.

Signed………………………………………………………………….. Date……………………..
Appendix 9: Participant demographic sheet

Participant Demographics
ID (participant number):
Age:
Sex:
• Male
• Female

What is your primary language?

Ethnic Background:

Accompanied by:
• Parent
• Carer
• Arrived alone
• Other:
Appendix 10: HTEQ

Survey of knowledge and expectations of patients with naturally missing teeth

Confidential ID number

Today’s Date

We will keep any information you give us in this questionnaire confidential.
Before you fill in this questionnaire, please read this page so that you know what to do.

This questionnaire is for people with naturally missing teeth, which is teeth that have never grown. We would like to know what you know about missing teeth treatment as well as what you expect from treatment. We are most interested in your views, so please fill in this questionnaire yourself or with the help of you parent / guardian.

If you do not want to fill in the questionnaire, or if you have already started the treatment please tick the appropriate box below and return the questionnaire to us. Whether or not you decide to fill in this questionnaire will not affect your treatment in any way.

<table>
<thead>
<tr>
<th>I do not want to take part</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I have already started treatment</td>
<td></td>
</tr>
</tbody>
</table>

**Guarantee of confidentiality**

The hospital numbers of patients taking part in this survey are held in strict confidence.

**How to fill in the questionnaire**

☐ Most questions can be answered by placing a mark on the line nearest your expectation.

For example:

- Extremely
- Unlikely
- Extremely
- Likely

☐ Some questions can be answered by ticking the most appropriate box. **You may only tick one box unless advised otherwise.**
A. Personal Information

A.1. Are you:

- male
- female

A.2. How old are you?

..............................................................

A.3. Please state your ethnic background.

..............................................................

A.6. How many missing teeth do you have?

- 1-2
- 3-5
- 6+
- I don't know

A.7. Have you ever had orthodontic treatment (straightening/moving teeth)?

- Yes
- No

A.8. Are you aware of anyone in your family or friends who have had orthodontic treatment?

- Yes
- No

If yes please state who ......................

A.9. Have you ever had restorative treatment (false teeth/ filling the gaps)?

- Yes
- No

A.10. Are you aware of anyone in your family or friends who have had restorative treatment (false teeth/filling the gaps)?

- Yes
- No

If yes please state who.......................
## Treatment Process

### B. Hypodontia Clinic

#### B.1. At your initial appointment do you expect to have? / What did you actually have?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>I don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>A brace fitted</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A check-up and diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A discussion about treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiographs taken (x-rays)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moulds taken of your teeth</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Photographs taken</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oral hygiene checked</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### B.2. How many people do you expect to see in the clinic? / How many did you actually see?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1-2</td>
</tr>
<tr>
<td></td>
<td>3-5</td>
</tr>
<tr>
<td></td>
<td>6-8</td>
</tr>
<tr>
<td></td>
<td>I don’t know</td>
</tr>
</tbody>
</table>

#### B.3. Who do you expect to see in the clinic? / Who did you actually see? (you may tick more than one box)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Orthodontist (provides braces)</td>
<td></td>
</tr>
<tr>
<td>Restorative dentist (provides replacement teeth)</td>
<td></td>
</tr>
<tr>
<td>Oral surgeon</td>
<td></td>
</tr>
<tr>
<td>Children dental specialist</td>
<td></td>
</tr>
<tr>
<td>Dental nurse</td>
<td></td>
</tr>
<tr>
<td>Dentist in training</td>
<td></td>
</tr>
<tr>
<td>I don’t know</td>
<td></td>
</tr>
</tbody>
</table>
Treatment Process

C. Orthodontic treatment (straightening/ moving teeth)

There are different possibilities for treating missing teeth. One may be orthodontics.

C.1. Do you expect to receive orthodontic treatment?

C.2 In which ways do you think orthodontic treatment may help your condition?

a. It will make it easier for the gaps to be filled.

b. It will help avoid the need for replacement (fake) teeth.

C.3. Whether you expected orthodontic treatment or not, what do you think it will be like?

a. I think wearing a brace will be painful.

b. I think orthodontic treatment will produce problems with eating and drinking.

c. How long do you think orthodontic treatment will take?

- 4 years
- 3.5 years
- 3 years
- 2.5 years
- 2 years
- 1.5 years
- 1 year
- 6 months
- 3 months
- 1 month
- Don’t Know
a. Do you think you will be paying for the brace treatment?

<table>
<thead>
<tr>
<th>Extremely</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unlikely</td>
<td>Likely</td>
</tr>
</tbody>
</table>

b. Do you expect your brace treatment to affect your school / job attendance?

<table>
<thead>
<tr>
<th>Extremely</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unlikely</td>
<td>Likely</td>
</tr>
</tbody>
</table>
Treatment Process

D. Restorative treatment (false teeth replacement/ filling the gaps)

One possibility of treating missing teeth is to replace them with false teeth (restorative treatment).

D.1. Do you expect to receive restorative treatment?

Yes
No
I don’t know

If you answered "NO" please go to section E (Benefits of treatment)

D.2. What type of tooth replacement do you expect to have to fill in the gaps?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>I don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>No replacement</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A tooth coloured filling material to build up my small teeth</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Removable denture</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adhesive (stick on) bridges</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Implants</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

D.3. Where do you think you will be receiving the replacement tooth/teeth?

A specialist in a practice or hospital will do the treatment if my case is complex.

Extremely Unlikely Extremely Likely

D.4. Do you think you will be paying for your replacement tooth/teeth?

I will need approval of funding from local authority.

Extremely Unlikely Extremely Likely
D.5. Do you think the restorative treatment will affect your school/job attendance?

<table>
<thead>
<tr>
<th>Extremely</th>
<th>Unlikely</th>
<th>Extremely</th>
<th>Likely</th>
</tr>
</thead>
</table>

D.6. Do you think the restorative treatment will produce problems with eating and drinking?

<table>
<thead>
<tr>
<th>Extremely</th>
<th>Unlikely</th>
<th>Extremely</th>
<th>Likely</th>
</tr>
</thead>
</table>

D.7. How do you think people will react to you having a false tooth/teeth placed?

<table>
<thead>
<tr>
<th>Negative Reaction</th>
<th>Positive Reaction</th>
</tr>
</thead>
</table>

D.8. How long do you think your replacement tooth/teeth will last?

<table>
<thead>
<tr>
<th>1 year or less</th>
<th>5 years</th>
<th>10 years or more</th>
</tr>
</thead>
</table>

D.9. How much do you have to do to ensure your replacement tooth/teeth lasts as long as possible?

<table>
<thead>
<tr>
<th>It does not matter what I do</th>
<th>It entirely depends on what I do</th>
</tr>
</thead>
</table>
Treatment Outcome

E. Benefits of treatment

E.1 Do you think treatment will:

a. **Straighten your teeth?**

<table>
<thead>
<tr>
<th>Extremely</th>
<th>Unlikely</th>
<th>Extremely</th>
<th>Likely</th>
</tr>
</thead>
</table>

b. **Close the gaps?**

<table>
<thead>
<tr>
<th>Extremely</th>
<th>Unlikely</th>
<th>Extremely</th>
<th>Likely</th>
</tr>
</thead>
</table>

c. **Help you smile more easily?**

<table>
<thead>
<tr>
<th>Extremely</th>
<th>Unlikely</th>
<th>Extremely</th>
<th>Likely</th>
</tr>
</thead>
</table>

d. **Make it easier to eat?**

<table>
<thead>
<tr>
<th>Extremely</th>
<th>Unlikely</th>
<th>Extremely</th>
<th>Likely</th>
</tr>
</thead>
</table>

e. **Make it easier to speak?**

<table>
<thead>
<tr>
<th>Extremely</th>
<th>Unlikely</th>
<th>Extremely</th>
<th>Likely</th>
</tr>
</thead>
</table>

f. **Make it easier to keep your teeth clean?**

<table>
<thead>
<tr>
<th>Extremely</th>
<th>Unlikely</th>
<th>Extremely</th>
<th>Likely</th>
</tr>
</thead>
</table>

g. **Improve your chances of a good career?**

<table>
<thead>
<tr>
<th>Extremely</th>
<th>Unlikely</th>
<th>Extremely</th>
<th>Likely</th>
</tr>
</thead>
</table>

h. **Give you confidence socially?**

<table>
<thead>
<tr>
<th>Extremely</th>
<th>Unlikely</th>
<th>Extremely</th>
<th>Likely</th>
</tr>
</thead>
</table>
E.2. Please rate how important each of the following is to you:

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>a. Straightening your teeth</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Important</td>
<td>Very Important</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Closing the gaps</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Important</td>
<td>Very Important</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Smiling more easily</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Important</td>
<td>Very Important</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. Eating more easily</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Important</td>
<td>Very Important</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. Speaking more easily</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Important</td>
<td>Very Important</td>
<td></td>
<td></td>
</tr>
<tr>
<td>f. Cleaning your teeth more easily</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Important</td>
<td>Very Important</td>
<td></td>
<td></td>
</tr>
<tr>
<td>g. Improving your chances of a good career</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Not Important</td>
<td>Very Important</td>
<td></td>
<td></td>
</tr>
<tr>
<td>h. Improving your confidence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Important</td>
<td>Very Important</td>
<td></td>
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</tr>
</tbody>
</table>
Appendix 11: TEI

The Treatment Evaluation Inventory

This leaflet asks for your views of information material provided.

Your answers will be anonymous and treated with the strictest confidentiality. Please complete the rating scale by circling the answer which most closely represents your response to the question. Please answer all the questions.

Thank you for your help.

1. Please rate how much you think you learned from the information you were given?

□ □ □ □ □ □
Learned nothing  Learned some  Learned a lot

2. How much did you learn about the treatment of your missing teeth?

□ □ □ □ □ □
Learned nothing  Learned some  Learned a lot

3. How much did you learn about the hypodontia clinic?

□ □ □ □ □ □
Learned nothing  Learned some  Learned a lot

4. Please rate how much new information you now have about how to deal with your problems?

□ □ □ □ □ □
No new information  Some new information  A lot of new information
5. How much did you enjoy the information given?

☐ Did not enjoy it at all  ☐ Enjoyed it about half the time  ☐ Enjoyed it very much

6. How interesting was the information for you?

☐ Very boring  ☐ Neither interesting nor boring  ☐ Very interesting

7. Was the information easy to understand?

☐ Very difficult  ☐ Neither easy or difficult  ☐ Very Easy

8. Please rate how much you feel you can use what you learned from the information given to you?

☐ Can almost never use  ☐ Use them about half the time  ☐ Can use, apply very much

9. To what extent do you think you will be able to use what you learned from the information material?

☐ Not at all able to use  ☐ Somewhat able to use  ☐ Very able to use

10. Do you think that the information given to you will reduce your level of anxiety if you have any?

☐ Not at all  ☐ Some change  ☐ Change a great deal

11. Do you think you will react differently to your treatment now compared to before you read the information?

☐ No  ☐ Somewhat  ☐ Very differently
12. Do you think you will now handle your treatment better?

<p>| | | | | | |</p>
<table>
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<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Somewhat more able</td>
<td>Very able</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

13. Please give a rating of the layout of the information you received.

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Very poor</td>
<td>OK</td>
<td>Very good</td>
<td></td>
<td></td>
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</tbody>
</table>

14. Please give an overall rating of the information you received.

<p>| | | | | |</p>
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<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Very poor</td>
<td>OK</td>
<td>Very good</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 12: Ethical approval for Study Two from NRES committee London-Chelsea

24 December 2014
Mr Keith Brennan
Hodgkin Building
King’s College London
Guy’s Hospital
SE1 0RT

Dear Mr Brennan

Study title: Improving Patient Understanding of Hypodontia
REC reference: 13/LO/1146
Amendment number: Substantial amendment 1
Amendment date: 21 November 2014
IRAS project ID: 128642

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The Sub-Committee approved the following changes:

1. Randomised controlled trial regarding hypodontia information, following results of earlier parts of study.

Approved documents

The documents reviewed and approved at the meeting were:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Covering letter on headed paper</td>
<td></td>
<td>10 November 2014</td>
</tr>
<tr>
<td>[BA cover letter]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letters of invitation to</td>
<td>2</td>
<td>10 November 2014</td>
</tr>
<tr>
<td>participant [Clean]</td>
<td></td>
<td></td>
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<tr>
<td>Letters of invitation to</td>
<td>2</td>
<td>10 November 2014</td>
</tr>
<tr>
<td>participant [Tracked]</td>
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<td></td>
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<tr>
<td>Non-validated questionnaire</td>
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<td>10 November 2014</td>
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</tbody>
</table>
Notice of Substantial Amendment (non-CTIMP) Substantial amendment 21 November 2014

Notice of Substantial Amendment (non-CTIMP) [CI signature] 24 November 2014

Other [Hypodontia BOS leaflet]
Other [Interactive hypodontia material]
Other [Treatment evaluation] 1 10 November 2014
Participant information sheet (PIS) [12-16, clean] 3 10 November 2014
Participant information sheet (PIS) [12-16, tracked] 3 10 November 2014
Participant information sheet (PIS) [16+, clean] 3 10 November 2014
Participant information sheet (PIS) [16+, tracked] 3 10 November 2014
Participant information sheet (PIS) [parent, clean] 3 10 November 2014
Participant information sheet (PIS) [parent, tracked] 3 10 November 2014
Research protocol or project proposal [protocol, clean] 2 10 November 2014
Research protocol or project proposal [protocol, tracked] 2 10 November 2014
Research protocol or project proposal [summary of changes] 10 November 2014

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members’ training days – see details at http://www.hra.nhs.uk/hrare-training/

13/L0/1146: Please quote this number on all correspondence

Yours sincerely

pp Ms Stephanie Ellis
Acting Vice Chair

E-mail: nrescommittee.london-chelsea@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Ms Karen Ignatian, karen.ignatian@gstt.nhs.uk
Dr Richard Foxton, richard.foxton@kcl.ac.uk
Appendix 13: Ethical approval for Study One from R&D Department at Guy’s and St Thomas’ NHS Foundation Trust

| STUDY TITLE: | Improving patient understanding of Hypodontia |
| Amendment Number: | Amendment 1 |
| REC REF: | 13LO'1146 |
| CI: | Dr. Richard Foxton |
| Sponsor: | King's College London University |
| Substantial or Minor: | Substantial |

Received documents:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Notice of Substantial Amendment Form</td>
<td>1</td>
<td>21/11/2014</td>
</tr>
<tr>
<td>Cover Letter</td>
<td></td>
<td>10/11/2014</td>
</tr>
<tr>
<td>Project Proposal</td>
<td></td>
<td>10/11/2014</td>
</tr>
<tr>
<td>Summary of main changes proposed</td>
<td></td>
<td>10/11/2014</td>
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<tr>
<td>Invitation letter</td>
<td></td>
<td>10/11/2014</td>
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<td>Patient Information Sheet Parent/Guardian</td>
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<td>Questionnaire</td>
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<tr>
<td>Computer based interactive hypodontia information material (converted to a word document)</td>
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<tr>
<td>Standard Hypodontia leaflet</td>
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<td>10/11/2014</td>
</tr>
<tr>
<td>Treatment Evaluation Inventory</td>
<td></td>
<td>10/11/2014</td>
</tr>
<tr>
<td>NRES Committee London – Chelsea [Favourable opinion letter]</td>
<td></td>
<td>24/12/2014</td>
</tr>
</tbody>
</table>

Dear Dr. Dirk Stier,

Following review of the above amendment, GSTFT has decided that they can accommodate this amendment.

The amendment may therefore be implemented at this site under the existing NHS permission. Please note that you may only implement changes that were described in the amendment notice or letter.

Kind regards

Mariusz Marcinkowski
Research & Development Governance Administrator
NHR GSTFT/KCL Biomedical Research Centre
T: +44 (0)20 7188 7188 Ext: 53328 | F: 0207 188 6330 | T: mariusz.marcinkowski@gstt.nhs.uk | W: www.guyandstthomas.nhs.uk

284
What type of treatment is involved?
Treatment usually involves wearing fixed braces and you may need bridges or implants to replace the missing teeth. However, the type of treatment needed depends on your age and the number of teeth that are missing. Decisions about your treatment often cannot be made until all the adult teeth have grown through the gums. This is normally when you are in your early teens (12-14 years).

Why might I need braces?
Fixed braces can be used to:
- Straighten your teeth.
- Close the gaps between your teeth.
- Create space in the right place for false teeth to be placed.
Your orthodontist will explain how they will be useful in your case.

I have noticed some of my teeth are small or pointed. Can anything be done?
Small adult, as well as baby teeth, can often be made to appear larger with a tooth-coloured filling material, called composite. Composite is the treatment of choice for small or pointed teeth. It may give a very nice appearance but the composite can change colour and chip over time and need replacement.
In adults, filling veneers or crowns may be advised depending on the shape and size of the teeth. Your general dentist or a restorative specialist can talk to you about these options.

Do I still need to see my regular dentist?
Yes. It will be important for you to continue to have check-ups with your regular dentist throughout orthodontic treatment so that your teeth can be checked for decay.

If you have any further questions please be sure to write them in the space below and ask them at your next appointment.

Your orthodontist or restorative dentist will discuss all options available to you in more detail.

For more information about Orthodontics, please visit: www.bos.org.uk

Now that you have been told you have hypodontia (missing adult teeth), you may have some questions you would like answered.

What is hypodontia?
Sometimes teeth do not develop and are missing altogether. This is called hypodontia. It can affect baby and adult teeth and vary in severity from one missing tooth to many missing teeth in very rare cases.

Why does hypodontia occur?
Hypodontia often runs in families but people affected do not always pass it onto their children. Sometimes, hypodontia may occur for no known reason.

Is it common?
Hypodontia is quite common with up to 5% of the population being affected. Most commonly, one or two teeth are missing.

How would I know if I had hypodontia?
You may have noticed gaps between your teeth or your baby teeth may still be present. Some of the teeth that are present may be small in size or appear pointed. An examination and x-ray investigation are needed to diagnose hypodontia.

How long will my baby teeth last?
This can vary but baby incisor teeth usually do not last beyond the teenage years. Baby canine and molar teeth can sometimes last into your 20s - 30s or even longer. It depends on the health of the teeth and the length of the roots.

What are my treatment choices?
There are different options that may be available to you:
1. Accept the space - this may be appropriate when back teeth are missing and the spaces are not visible.
2. Close the space - using fixed braces.
3. Create space - in the right place for a false tooth using fixed braces allowing one of the following to be fitted:
   - Dental bridges (porcelain bonded bridges) - a false tooth glued onto another tooth.
   - Dental implants - a false tooth on a titanium screw put into the jaw bone. They can only be placed once you have stopped growing and are not suitable for everyone.
   - Dentures - these are removable plates with false teeth attached.

Your orthodontist will be able to discuss these options with you.

Your general dentist or a restorative specialist will talk with you and your orthodontist about options for any further treatment needed.

Possible stages of treatment

(A) Before treatment

(R) Wearing fixed braces

(C) Following fixed braces treatment

(D) Patient with bridges in place