Portfolio of Doctorate in Health Psychology

By

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For the qualification of
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I would like to start by thanking my academic supervisor Dr Renata Pires-Yfantouda. Not only has Renata been supportive in terms of time and involvement, but she has also created some much appreciated opportunities. On a number of occasions she has gone the “extra mile” and never missed an opportunity to be helpful. A thank you also goes to Dr Esther Murray for her guidance in the early stages of my training.

Having the opportunity to use my role of an Assistant Psychologist and Support Worker within the Scallywags service as a work placement would not have been possible without Moira Broadhead (Senior Educational Psychologist & Scallywags Manager) and the team at Scallywags.

I would like to thank the Cornwall Diabetes and Endocrine Centre and the Royal Cornwall Hospitals Trust for allowing me to conduct my research. Also the Paediatric Diabetes Team, in particular Mrs Anita England (Lead Paediatric Diabetes Clinical Nurse Specialist) who was instrumental in the process and created a number of additional teaching, training and consultancy opportunities. Not forgetting Ms Patsy Hughes who initially agreed the research in the early stages. Thank you to all the young people who agreed to take part in the research for their time and insights into the self-management of type 1 diabetes.

Professor Anthony Woolf (Consultant Rheumatologist, Director of Research and Development, Royal Cornwall Hospitals Trust), who has been very generous with his time, for providing consultancy and systematic review opportunities within the area of musculoskeletal health. Additional thanks to Dr Mark Wylie (Clinical Psychologist) who assisted with the systematic review’s quality assessment, as well as his support throughout my training.

Finally, a huge thank you to my parents for getting me to this stage.
DECLARATION

I grant powers of discretion to the University Librarian to allow this thesis to be copied in whole or in part without further reference to me. This permission covers only single copies made for study purposes, subject to normal conditions of acknowledgement.
SECTION A

Preface
PREFACE

Throughout the Stage 2 training a number of opportunities were negotiated to demonstrate the competencies required to achieve the Doctorate in Health Psychology. This has involved working across local authority and NHS organisations and holding workplace contracts within Children, Young People and Family Services, a Paediatric Diabetes Team and the Department of Rheumatology. This has provided a variety of experiences, which are reflected within this thesis, in order to demonstrate the expertise and skills required to achieve health psychologist status.

Research
The research study was developed from an interest in the promotion and engagement of psychological interventions and being able to connect with individuals in a meaningful and productive way, as such motivational factors are of particular relevance for effective and sustainable behavioural and psychological change. The aim of the research was to explore the motivational factors associated with type 1 diabetes and how they exist within a 13–17 year old age group. In order to utilise existing motivational concepts and theoretical frameworks, established measures were selected to form a quantitative methodology. In addition, a social constructionist version of grounded theory was utilised to investigate adaption and self-management from the perspectives of the young people that participated in the investigation. The findings created a process-based model with which to describe changes from a position of having difficulties with self-management to successful self-management. The research represents a constructive application of health psychology-based skills to an existing area of healthcare and contributes to the type 1 diabetes evidence-base. The Adaption and Self-Management Model is to be presented at the UK Society of Behavioural Medicine 7th Annual Scientific Meeting in December 2011.

Consultancy
Having conducted a number of consultancies during training, enclosed is a piece of work exploring parental stress within the Scallywags service for children with emotional and behavioural difficulties. This involved implementing a consultancy
model and theoretical framework described by Schein (1998) as the “expert model”, whereby I acted as the expert providing a service to the client. My role, as a team member within the research study, was to analyse a dataset pre- and post-intervention in order to produce a report in an appropriate format for publication within a peer-reviewed journal. The analysis contained a profile of parental stress levels, describing whether they increased, decreased or did not change throughout the programme and how this related to conduct difficulties. A clear working contract was developed while operating within a team environment and a number of advanced research skills attained from Stage 1 MSc Health Psychology training were utilised.

Teaching and Training
Teaching and training provided an opportunity to impart health psychology knowledge across a number of applied settings. Two pieces of work have been selected which offer good representations of this quality. The first was a full afternoon’s training for 30–40 staff attached to the Scallywags service involving an introduction to motivational interviewing. The second involved sharing the findings from research conducted within the Paediatric Diabetes Team using measures assessing Stages of Change (Prochaska, DiClemente & Norcross, 1992) and Self-Determination Theory (Deci & Ryan, 2000) to understand motivational factors linked to young people aged 13–17 years with type 1 diabetes.

Optional Competency 5.3
Following a discussion with a Professor of Rheumatology at a research conference, a meeting was held to discuss working together on a piece of consultancy to facilitate Optional Competency Unit 5.3 (Communicate the Processes and Outcomes of Psychological Interventions and Consultancies). Motivational interviewing was discussed as an approach to working with individuals that have musculoskeletal conditions. The use of feedback within this modality was described and it was agreed that the role of lifestyle and the impact it may have upon musculoskeletal health would be an area for further investigation. It was on this basis that a literature search was conducted to locate a suitable lifestyle measure that fit the requirements of a Bone and Joint Healthy Lifestyle (2005). The findings of the search are to be used in an application for National Institute for Health Research funding as part of their Research for Patient Benefit (RfPB) programme.
Optional Competency 5.8
Disseminating findings within peer-reviewed journals is an important skill and one that has been developed during training and evidenced within Optional Competency Unit 5.8 (Disseminate Psychological Knowledge to Address Current Issues in Society). This competency provided an opportunity to share research conducted within the Scallywags service investigating parental stress and conduct difficulties among children aged 3–7 years referred to the service. The journal Emotional and Behavioural Difficulties was selected, as it caters for a wide audience, in response to the diverse nature of professionals who work with children in this area. It is also the official journal of the Social, Emotional and Behavioural Difficulties Association (SEBDA). It was very rewarding to have a paper accepted for publication within this journal (Broadhead, Chilton & Crichton, 2009).

Systematic Review
Motivational interviewing (MI) has been investigated within a range of healthcare environments (Rollnick, Miller & Butler, 2008), although to date no studies have systematically assessed its application and effectiveness within musculoskeletal health. In order to support work with the Professor of Rheumatology, a systematic review was conducted to develop a more informed understanding of the application of MI within musculoskeletal health. The findings highlighted the need for well-designed randomised controlled trials, suitably powered to measure the effectiveness of MI within musculoskeletal health. The study was accepted for publication within the peer-reviewed journal Psychology, Health & Medicine (Chilton & Pires-Yfantouda, in press).
References


SECTION B

Research
Understanding the Motivational Characteristics of Type 1 Diabetes Regime Management during Adolescence

Abstract

Background – It is acknowledged that the management of diabetes in children and young people is significantly different and more complex than that of adults. It has been suggested that services are to be person-centred and recognise the importance of self-management and the role of psychological services within the diagnosis and management of type 1 diabetes. Currently there is little clear guidance regarding effective behavioural interventions to enhance self-care, particularly during adolescence.

Aim – Develop a person-centred care pathway and conceptual framework based on existing motivational and behavioural change theories, as well as utilising a qualitative methodology to explore motivational factors among adolescents with type 1 diabetes.

Recruitment - Participants aged between 13–17 years of age with a diagnosis of type 1 diabetes were selected using purposive sampling from six NHS diabetes clinics within the South West of England. A questionnaire pack was administered at clinic to 44 potential participants, of which 34 were completed, 13 consented to be interviewed.

Design - The research utilised a mixed-method, within subjects, cross-sectional design for both quantitative Stages of Change (SoC) and Self-Determination Theory (SDT) and qualitative social constructionist grounded theory approaches.

Results and Findings – Information from SoC and SDT measures describe readiness to change and an understanding of current psychological needs regarding diabetes, motivation, demographic and biomedical factors. The qualitative findings describe a continuum of two opposing categories reflecting themes that describe difficulties with self-management and in contrast, successful self-management. Movement between these categories is described through specific stages and various process mechanisms and expressed within an Adaption and Self-Management Model.

Conclusion – Utilising SoC and SDT measures allow healthcare professionals and caregivers to match the needs and requirements of individuals. The Adaption and Self-Management Model provides a framework with which to contextualise the process of adaptation and self-management of type 1 diabetes during adolescence. It allows an understanding of psychological and psychosocial factors which impact upon self-management and has clinical implications for improving understanding, communication and engagement within consultation and community settings.
SECTION 1

Overview

It is estimated that 25,000 young people under the age of 25 have type 1 diabetes in the UK (DoH, 2007b) and that the prevalence of type 1 and type 2 diabetes in children is increasing (Diabetes UK, 2008). To respond to these increased numbers the government has developed The National Service Framework (NSF) for Diabetes (DoH, 2001), which describes the standards, interventions and delivery strategies (DoH, 2003) required to create uniformity of high quality care across NHS diabetes services.

It is acknowledged that the management of diabetes in children and young people is significantly different and more complex than that of adults (DoH, 2007a). These services are to be person-centred and recognise the importance of self-management to effective diabetes care. The role of psychological services within clinical guidelines for the diagnosis and management of type 1 diabetes has been clearly stated (Delamater, 2007; NICE, 2004). Unfortunately, Diabetes UK (2006) reported that only 7% of children and young people with diabetes who required psychological support were given access to services. With referrals to general psychology services involving extensive waiting times, there is a greater need for psychological input to achieve the aims of better diabetes care.

In respect of the efficacy of educational and psychosocial interventions for adolescents, a systematic review concluded that these interventions had small to moderate beneficial effects on various diabetes management outcomes (Hampson, 2001). This confirms the significance of developing a comprehensive research base of appropriate educational and psychological interventions to promote patient self-management (DoH, 2002). To date psychological treatments have demonstrated only weak evidence for improving glycaemic control in children and adolescents with type 1 diabetes. This suggests that psychological interventions are still in their infancy and need to be specific to diabetes, incorporating patient preferences (Winkley, 2006). This supports the recommendations of the NSF for Diabetes (DoH, 2001) that patients need to be supported and empowered to improve self-management in order to create behavioural change.
Currently there is still little clear guidance regarding effective behavioural interventions to enhance self-care, particularly for adolescents and how they manage their treatment regimes. This research focuses on the development of a person-centred care pathway and conceptual framework, based on existing motivational and behavioural change theories, as well as using a qualitative research methodology to explore the motivational factors among adolescents with type 1 diabetes. This will help practitioners understand and promote the motivational and behavioural change characteristics of adolescents with type 1 diabetes. Such an approach supports the principles of the NSF for Diabetes by developing and implementing standard 3 (empowering people with diabetes) and standard 5 (clinical care of children and young people with diabetes).

**Transtheoretical Model**

The conceptual framework is constructed from two well-established theories. Firstly, Prochaska, DiClemente and Norcross’s (1992) Transtheoretical Model (TTM) describes five stages that people go through when changing behaviour (pre-contemplation, contemplation, preparation, action and maintenance). Pre-contemplation describes the stage where there is no intention to change and individuals are unaware of or unable to accept their problems. Contemplation is when people are aware a problem exists and consider taking steps to change. Preparation combines the individual’s intention and behavioural criteria required to take action in the next month. Action describes the modification of behaviour, experience or the environment in order to overcome the problems. Maintenance is the stage in which individuals work to prevent relapse, consolidating the gains attained during action. A recent review article on the challenges and applications of the Transtheoretical Model in patients with diabetes (Andrés, Gómez & Saldaña, 2008) has stated that the model has made a positive contribution to interventions within diabetes.

**Self-Determination Theory**

Secondly, Self-Determination Theory (SDT) (Deci & Ryan, 2000) provides a framework for understanding the psychological requirements for enhanced self-motivation. Deci and Ryan believe this is sustained through autonomy (the personal endorsement of behaviours), competence (individuals experience the confidence and competence to change) and relatedness (being respected, understood, and cared for...
within the practitioner-patient relationship is essential for forming the experiences of connection and trust that allow change to occur). Within this approach social contexts and individual differences relate directly to the aforementioned constructs and can facilitate or impede an individual’s motivational performance and well-being (Ryan & Deci, 2000).

Previous research utilising SDT as a process model for the self-management of type 2 diabetes and the promotion of glycaemic control indicated that perceptions of autonomy and competence were increased by perceived autonomy support, and that change in autonomous motivation and in perceived competence were found to predict improvement in glycaemic control over a 12-month period (Williams, Freedman & Deci, 1998; Williams, McGregor, Zeldman, Freedman & Deci, 2004). This demonstrates that the SDT model is applicable for adults with type 1 and type 2 diabetes and provides a framework with which to explore the motivational characteristics amongst children and adolescents with type 1 diabetes. By using the Transtheoretical Model and exploring Stages of Change (SoC) it is possible to identify which stage and how ready the individual is to change their behaviour. In addition, Self-Determination Theory describes the psychological factors that influence intrinsic and self-motivational change.

**Grounded Theory**

In order to explore and understand how adolescents with type 1 diabetes manage their regime a qualitative methodology was incorporated into the study. A grounded theory approach allows for the development of a specific motivational perspective to be created based specifically upon the values, beliefs and perspectives of participants within the study. In particular, a social constructionist version of grounded theory (Charmaz, 2006) was employed, as it acknowledges that categories and theories are constructed by the researcher (Willig, 2008) rather than being discovered (see Glaser & Strauss, 1967). The application of a social constructionist framework also ensures that the interpretations and theoretical construction of the discourse utilises the socially constructed realities that adolescents exist and function within (Burr, 2003).
Research

Rationale

Individual motivation to adhere to treatment is a key factor for improving health outcomes within diabetes among children and adolescents (Ryan, Patrick, Deci & Williams, 2008). Using Self-Determination Theory can provide an initial understanding of the psychological factors that may impinge on this process. In addition, by understanding the specific stage of change that someone is located within for a particular behaviour, it becomes possible to match resources and knowledge accordingly. Utilising these existing theoretical perspectives can identify features specific to the individual, focussing predominantly on the requirements tailored to their psychological needs and providing a unique person-centred approach to diabetes treatment. Incorporating a grounded theory approach allows for the generation of a new theory based on motivational features that support the values and beliefs held by participants in the self-management process.

Aims

Initially, the aim is to explore the motivational factors (SDT) and behavioural readiness to change stages (SoC) for adolescents with type 1 diabetes. Secondly, to develop an understanding of the relationship between SDT and SoC. Thirdly, to generate a motivation-based theory based on grounded theory. Finally, to discuss and evaluate the findings in the context of a care pathway, supported by materials that match SDT, SoC and the findings from the qualitative research.

Objectives

Stage 1 – data collection

1) Assess the appropriateness of the SDT Model for identifying the status of motivational factors within the area of autonomy, competence and relatedness.
2) Assess the appropriateness of the Transtheoretical Model for identifying specific Stages of Change (pre-contemplation, contemplation, preparation, action and maintenance) within a range of behaviours (exercise, monitoring blood glucose levels, insulin injections and diet).
3) Describe the findings from SDT and SoC data.
4) Conduct semi-structured interviews and use grounded theory to generate a theory expanding motivational factors.
Stage 2 – data interpretation

5) Explore the relationship between SDT and SoC, in the context of how specific Stages of Change relate to the motivational properties within this sample.

6) Explore the implications of the findings generated from the grounded theory study.

Stage 3 – care pathways / person-centred resources

7) Using the data collected from the sample (SDT and SoC), develop materials to support individuals within certain Stages of Change and explore options for promoting motivational changes where appropriate.
SECTION 2
Stages of Change & Self-Determination Theory

Methodology

Recruitment, Sample and Demographics
Participants were selected using purposive sampling from the Cornwall Diabetes and Endocrine Centre (CDEC). The CDEC operates six diabetes clinics throughout Cornwall (Penzance, Redruth, Falmouth, Truro, St Austell and Bodmin). The Lead Paediatric Diabetes Clinical Nurse Specialist was initially approached in order to explore whether the service would be interested in participating in research to explore the motivational factors associated with adolescents that have type 1 diabetes. The service was keen to get involved and it was agreed between the researcher and the team that the age range most suitable would be between 13-17 years. This age range supports other qualitative research conducted in the area of type 1 diabetes (Hentinen & Kyngäs, 1996; Karlsson, Arman & Wikblad, 2008). Individuals aged 18 are transferred to adult services.

The recruitment took place between September 2009 and April 2010, this ensured that all service users within the 13-17 year old age group were offered a clinic appointment and therefore given the opportunity to partake in the research. It had been established prior to data collection, based on current figures from CDEC, that there would be 44 potential participants for the study, eligible due to the 13-17 year old inclusion criteria. In total 34 participants completed the questionnaire packs, representing 77% of the overall 13–17 year old population identified within the Cornwall Diabetes and Endocrine Centre (CDEC). For full demographic characteristics see Table 1. For the remaining number of potential participants, eight did not attend (DNA), and two were unaccounted for.
Table 1. Participants’ Demographic and Biomedical Information

<table>
<thead>
<tr>
<th>Participants N=34</th>
<th>Male</th>
<th>Female</th>
<th>Overall</th>
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<tr>
<td>N</td>
<td>23 (68%)</td>
<td>11 (32%)</td>
<td>34 (100%)</td>
</tr>
<tr>
<td>Age</td>
<td>$\bar{x}$ 15 years, SD 0.8</td>
<td>$\bar{x}$ 15 years, SD 1.1</td>
<td>$\bar{x}$ 15 years, SD 0.89</td>
</tr>
<tr>
<td>Duration of diabetes</td>
<td>$\bar{x}$ 6.67 years, SD 4.51</td>
<td>$\bar{x}$ 6.73 years, SD 4.0</td>
<td>$\bar{x}$ 6.69 years, SD 4.3</td>
</tr>
<tr>
<td>Age of onset</td>
<td>$\bar{x}$ 8.33 years, SD 4.49</td>
<td>$\bar{x}$ 8.27 years, SD 3.8</td>
<td>$\bar{x}$ 8.31 years, SD 4.22</td>
</tr>
<tr>
<td>HbA1c *</td>
<td>$\bar{x}$ 10.14, SD 1.72</td>
<td>$\bar{x}$ 8.9, SD 1.36</td>
<td>$\bar{x}$ 9.74, SD 1.7</td>
</tr>
<tr>
<td>Clinic attendance **</td>
<td>$\bar{x}$ 5.48, SD 1.53</td>
<td>$\bar{x}$ 4.64, SD 1.43</td>
<td>$\bar{x}$ 5.21, SD 1.53</td>
</tr>
</tbody>
</table>

$x$ - Mean, SD - Standard Deviation, HbA1c - Mean blood glucose level for 12-month period prior to completion of questionnaire pack.

* NICE guidelines for type 1 diabetes (2004) recommend - children and young people with type 1 diabetes and their families should be informed that the target for long-term glycaemic control is an HbA1c level of less than 7.5% (p. 18) / highest measurable reading is 14.

** NICE guidelines for type 1 diabetes (2004) recommend - children and young people with type 1 diabetes should be offered testing of their HbA1c levels two to four times per year (more frequent testing may be appropriate if there is concern about poor glycaemic control) (p. 18).

Design

The research utilised a mixed-method, within subjects, cross-sectional design for both quantitative (this section) and qualitative (Section 3) approaches. Both perspectives utilise different techniques for data collection, extraction, analysis and interpretation. Quantitative data collection will be reported first and then a separate section will focus upon the qualitative findings. The implications and relationships between both perspectives will then be summarised and discussed to provide a comprehensive understanding of the motivational characteristics of adolescents with type 1 diabetes. Finally, Section 4 will consider the application of a selection of appropriate materials that can support the findings from the research in order to promote a more theoretically informed care pathway.

Procedure

Data Collection Procedure (Questionnaire Pack)

Discussions were held with the Lead Paediatric Diabetes Liaison Nurse and the Consultant Paediatrician for Diabetes within the Royal Cornwall Hospital in Truro, Cornwall to consider the most effective and clinically ethical approach to collecting data for the study. It was agreed that the questionnaire data would be collected at the clinic between the individual’s appointment with the nurse and the paediatrician. The normal procedure for a clinic visit would be for individuals to be seen by the nurse and then wait in the clinic to be seen by the paediatrician (NICE, 2004).

All individuals within the 13-17 year age group would be potentially suitable for the study. It was considered by Cornwall and Plymouth Research Ethics Committee on
behalf of the NHS National Research Ethic Service that potential participants should be given sufficient notice, prior to being asked if they would like to participate in the research. It was agreed by the diabetes nurse and in conjunction with the ethics committee that this would occur approximately 1 month before attending their next clinic appointment, as part of the nurse’s routine telephone communication with individuals.

The questionnaire pack was handed to suitable individuals at clinic after they had attended their nurse-based appointment. Whether or not the pack was completed, individuals were asked to return it to the diabetes nurse, sealed to ensure confidentiality, prior to attending their paediatrician’s appointment. Only one questionnaire pack was completed at home due to non-attendance at the clinic. For identification and confidentiality purposes, no numbers were placed on the questionnaire pack envelope until it was returned. Once returned the diabetes nurse wrote a number on the envelope which matched a list that only the nurse held, so that the researcher did not know the respondent’s name.

Pilot Data Collection

It was agreed with the diabetes nurse that a pilot data collection phase would be helpful in order to assess how participants understood the information on the Participant Information Sheet, to time questionnaire completion and whether the administration process was effective and had any impact upon how the clinic operated. In addition, the diabetes nurse was asked to collect information regarding demographic and diabetes history (age, gender, council district, duration of diabetes, average HbA1c and clinic attendance).

Once the data collection phase had been completed a meeting between the trainee health psychologist and the Lead Paediatric Diabetes Liaison Nurse was held to discuss the outcome. The nurse reported that administering the questionnaires had been successful and took approximately 10 minutes for each participant to complete. Of the eight individuals scheduled to take part, one did not attend (DNA), four completed the questionnaire packs and three were not given them as the nurse was unsure whether the packs were applicable to individuals that were transferring to adult services. It was explained that as the questionnaires were being used to gather a cross-
sectional view of the sample it was relevant to give them to this group and that these individuals could still be included in the study.

When the demographic and diabetes history was collected it was unclear whether council district related to where participants lived or referred to clinic location. It was suggested that this should be where participants lived, in order to provide a more representative understanding of the population. Duration of diabetes had been collected from January of that year and it was explained that it may be more representative if the figure was over a year prior to the point the questionnaires were administered. For the newly diagnosed participants a note stating that they were newly diagnosed and the date were also recorded. The date that all questionnaires were completed was recorded, and it was considered that HbA1c levels should be recorded for each clinic visit over the last year in order to create a mean figure. It was agreed that individuals that DNA on their clinic appointment would be given the questionnaire pack and opportunity to participate the next time they attended the clinic. This would then provide them with the opportunity to participate or not, rather than to assume non-participation.

**Materials**

**Stages of Change (Appendix 1)**

The Transtheoretical Model (Prochaska & DiClemente, 1982; Prochaska, DiClemente & Norcross, 1992) describes five specific Stages of Change (pre-contemplation, contemplation, preparation, action and maintenance), which act as a core construct within the model to assess readiness to change (Prochaska, DiClemente & Norcross, 1992). The Stages of Change Model has been used to assess individuals’ readiness to change within a number of healthcare behaviours, including diabetes and diabetes-related behaviours such as exercise and diet (Andrés, Gómez & Saldaña, 2008; Prochaska & Velicer, 1997; Prochaska et al., 1994; Ruggiero, 2000). While there can be variation in how the Stages of Change are stated (Highstein, O’Toole, Shetty, Brownson & Fisher, 2007), the following statements represent those used for individuals with type 1 diabetes (Vallis et al., 2003):
a) Yes, I have been for MORE than 6 months (Maintenance)
b) Yes, I have been for LESS than 6 months (Action)
c) No, but I intend to in the next 30 days (Preparation)
d) No, but I intend to in the next 6 months (Contemplation)
e) No, and I do NOT intend to in the next 6 months (Pre-contemplation)

Specifically within the area of diabetes, Stages of Change have allowed intervention strategies to be tailored to the individual’s particular readiness for change (Berg-Smith et al., 1999; Peterson & Hughes, 2002), and therefore readiness to change was gauged by asking the following questions relating to blood glucose levels, diet, insulin and exercise:

Question 1 - Do you monitor your blood glucose levels at least once or twice a day?
Question 2 - Do you eat appropriately to manage your diabetes (e.g. regular carbohydrates and a bedtime snack)?
Question 3 - Do you inject yourself with insulin as recommended by your diabetes team?
Question 4 – Do you exercise regularly?

For the purposes of clarity exercise was defined within question 4 as: “Regular Exercise is any planned physical activity (e.g. brisk walking, aerobics, jogging, bicycling, swimming, rowing, etc.) performed to increase physical fitness. Such activity should be performed 3 to 5 times per week for 20-60 minutes per session. Exercise does not have to be painful to be effective but should be done at a level that increases your breathing rate and causes you to break a sweat” (Marcus, Selby, Niaura & Rossi, 1992).

The Health Care Climate Questionnaire (HCCQ) (Appendix 2)
The HCCQ indicates the level of autonomy support versus control within a healthcare environment, namely the diabetes team. The original version, the 15-item scale, has been used in a number of studies, such as smoking, medication adherence and weight loss (Williams & Deci, 2001; Williams, Gagné, Ryan & Deci, 2002; Williams, Grow, Freedman, Ryan, & Deci, 1996; Williams, Rodin, Ryan, Grolnick, & Deci, 1998).
For this study the shorter 6-item questionnaire was opted for, with the aim of reducing administration time between clinic appointments. Each item is rated on a 7-point Likert scale, ranging from 1 (strongly disagree) to 7 (strongly agree), and the scores are calculated by averaging the individual item scores. Higher scores indicate the diabetes team provide greater perceived autonomy support. The measure has good internal consistency with a Cronbach α of 0.80 (Williams, Freedman & Deci, 1998).

**Perceived Competence for Diabetes Scale (PCDS) (Appendix 3)**

Participants’ perceived competence in their ability to manage their diabetes was measured using the Perceived Competence for Diabetes Scale. The questionnaire contains four items which are specific to diabetes and each item is rated on a 7-point Likert scale, ranging from 1 (not at all true) to 7 (very true). The scores are totalled, with higher scores indicating greater perceived competence and lower scores indicating less perceived competence in diabetes management.

The PCDS has been used to examine a Self-Determination Theory process model for promoting glycaemic control through diabetes self-management (Williams, McGregor, Zeldman, Freedman & Deci, 2004). The measure was found to have good internal consistency (Cronbach α between 0.83 and 0.86). Perceived competence has also been used as a measure in a number of diabetes-related investigations (Williams & Deci, 1996; Williams, Freedman & Deci, 1998; Williams, Lynch & Glasgow, 2007; Williams et al., 2009).

**Treatment Self-Regulation Questionnaire (TSRQ) (Appendix 4)**

The TSRQ for diabetes is a 19-item scale exploring autonomous versus controlled motivation for exercise, diet, taking medications and/or checking blood glucose levels in the context of diabetes. Providing a score on a 7-point Likert scale, ranging from 1 (not at all true) to 7 (very true), the responses to the autonomous items (2,3,7,10,13,16,18,19) are averaged to form the autonomous regulation score and the responses to the controlled items (1,4,5,6,8,9,11,12,14,15,17) are averaged to form the controlled regulation score.

The TSRQ has been used to examine patient perceptions of autonomy supportiveness in the context of diabetes care providers and how this relates to improved glucose
control (Williams, Freedman & Deci, 1998). The measure reported excellent internal consistency (Cronbach α between 0.81 and 0.85 for autonomous regulation and 0.85 and 0.86 for controlled regulation) and has been used to test a Self-Determination Theory process model for promoting glycaemic control within diabetes self-management (Williams, McGregor, Zeldman, Freedman & Deci, 2004).

Results

Self-Determination Theory

Descriptive information regarding mean and standard deviations for HCCQ, PCDS and TSRQ are located in Table 2. For the full table of mean and standard deviations per question see Appendix 5 (no outliers were detected outside of the scale parameters). The findings represent above average levels of autonomy support, with a rating of 5.55 out of 7 on the Health Care Climate Questionnaire, indicating that participants feel that their autonomy towards their diabetes is promoted, rather than being controlled by the diabetes team. Similarly, a rating of 5.36 out of 7 for the Perceived Competence for Diabetes Scale indicates that participants feel competent in their ability to manage their diabetes. The Treatment Self-Regulation Questionnaire suggests that participants are more intrinsically motivated (autonomous regulation) than extrinsically motivated (controlled regulation), indicating that they consider their motivation regarding diabetes management to be more autonomous or self-determined than controlled by external factors.

Table 2. Mean and Standard Deviations for HCCQ, PCDS and TSRQ Measures

<table>
<thead>
<tr>
<th></th>
<th>Mean (SD)</th>
<th>Minimum</th>
<th>Maximum</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>HCCQ (Autonomy Support)</td>
<td>5.55 (1.07)</td>
<td>2.67</td>
<td>7</td>
<td>33</td>
</tr>
<tr>
<td>PCDS (Competence)</td>
<td>5.36 (1.41)</td>
<td>1</td>
<td>7</td>
<td>33</td>
</tr>
<tr>
<td>TSRQ - Autonomous</td>
<td>4.66 (0.98)</td>
<td>2.38</td>
<td>6.50</td>
<td>32</td>
</tr>
<tr>
<td>TSRQ - Controlled</td>
<td>4.05 (1.29)</td>
<td>1.18</td>
<td>6.73</td>
<td>32</td>
</tr>
</tbody>
</table>

HCCQ = The Health Care Climate Questionnaire, PCDS = Perceived Competence for Diabetes Scale, TSRQ = Treatment Self-Regulation Questionnaire.

In order to assess the relationship between the Self-Determination measures, demographic and biomedical data within the sample, Spearman’s rho correlation was conducted between HCCQ, PCDS and TSRQ mean scores and age, duration of
diabetes, age at onset, number of clinic attendances and average yearly HbA1c levels (Table 3). The strength of the relationship was based on strong (−1.0 to −0.5 or 1.0 to 0.5), moderate (−0.5 to −0.3 or 0.3 to 0.5), weak (−0.3 to −0.1 or 0.1 to 0.3) or none or very weak (−0.1 to 0.1) values (Choudhury, 2009).

Demographic and Biomedical Relationship

The findings demonstrated a significant strong, positive correlation between HbA1c levels and duration of diabetes (rho = 0.517, N = 34, p < 0.01, two-tailed); HbA1c levels increased with diabetes duration. This suggests poorer levels of glycaemic control (HbA1c levels increase) the longer the individual has had diabetes. There was a significant strong, negative correlation between HbA1c levels and age at diabetes onset (rho = -0.538, N = 34, p < 0.01, two-tailed); HbA1c levels reduced as age of onset increased. There was also a significant strong, positive correlation between HbA1c levels and clinic visits (rho = 0.594, N = 34, p < 0.01, two-tailed); increased clinic attendance represented higher HbA1c levels. This suggests that individuals attend the clinic more frequently when their glycaemic control (HbA1c levels) becomes worse. Duration of diabetes and age at onset were also found to have a strong, negative relationship (rho = -0.976, N = 34, p < 0.01, two-tailed). Finally, age was not correlated to HbA1c levels.

SDT

When the demographic and biomedical data were correlated to the Self-Determination measures a number of relationships were observed. There was a moderate to strong negative correlation between diabetes duration and autonomous regulation (rho = -0.500, N = 32, p < 0.01, two-tailed); autonomous regulation reduced as diabetes duration increased. This suggests that individuals are less internally motivated to manage their own diabetes the longer they have had diabetes. There was a moderate positive correlation between age at onset and autonomous regulation (rho = 0.449, N = 32, p < 0.01, two-tailed); autonomous regulation increased with age at onset. This suggests that individual’s’ internal motivation to manage their own diabetes regime increases the older they are diagnosed with the condition. There was a moderate negative correlation between HbA1c levels and perceived competence (rho = -0.394, N = 33, p < 0.01, two-tailed); HbA1c levels reduced with an increase in perceived competence. There was a moderate negative correlation between clinic attendance and
perceived competence (rho = -0.415, N = 33, p < 0.01, two-tailed); clinic attendance reduced with increased perceived competence. This suggests that individuals’ perceived competence in their ability to manage their diabetes is related to reduced clinic attendance. Finally, there was a moderate correlation between autonomous and controlled regulation (rho = 0.419, N = 32, p < 0.01, two-tailed). This suggests there is a relationship between participants being internally motivated (autonomous regulation) to manage their diabetes, as well as receiving motivation from external factors (controlled regulation).

Table 3. Correlations for SDT, Demographic and Biomedical Information

<table>
<thead>
<tr>
<th></th>
<th>Duration</th>
<th>Onset</th>
<th>HbA1c</th>
<th>Clinic</th>
<th>HCCQ</th>
<th>PCDS</th>
<th>TSRQ (A)</th>
<th>TSRQ (C)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>0.143</td>
<td>0.035</td>
<td>-0.107</td>
<td>-0.055</td>
<td>-0.030</td>
<td>0.095</td>
<td>-0.106</td>
<td>-0.193</td>
</tr>
<tr>
<td>Duration</td>
<td>-</td>
<td>0.976**</td>
<td>0.517**</td>
<td>0.109</td>
<td>-0.288</td>
<td>-0.311</td>
<td>-0.500**</td>
<td>-0.239</td>
</tr>
<tr>
<td>Onset</td>
<td>-</td>
<td>-</td>
<td>-0.538**</td>
<td>-0.133</td>
<td>0.246</td>
<td>0.299</td>
<td>0.449**</td>
<td>0.220</td>
</tr>
<tr>
<td>HbA1c</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.594**</td>
<td>-0.021</td>
<td>-0.394*</td>
<td>-0.231</td>
<td>-0.032</td>
</tr>
<tr>
<td>Clinic</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.073</td>
<td>-0.415*</td>
<td>-0.088</td>
<td>0.107</td>
</tr>
<tr>
<td>HCCQ</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-0.028</td>
<td>0.259</td>
<td>0.280</td>
</tr>
<tr>
<td>PCDS</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.026</td>
<td>-0.181</td>
</tr>
<tr>
<td>TSRQ (A)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.419*</td>
</tr>
</tbody>
</table>

**. Correlation is significant at the 0.01 level (two-tailed)
*. Correlation is significant at the 0.05 level (two-tailed)

Stages of Change

Regional relationship based on location of the clinic, or council-defined district or parish locality had no association to any of the stages concerning blood glucose monitoring, diet, insulin injections or exercise. To understand the distribution of stages within diabetes’ behaviours a frequency profile was constructed (see Table 4).
Table 4. Frequency Table of Stage of Change for Blood Glucose Monitoring, Diet, Insulin Injection and Exercise

<table>
<thead>
<tr>
<th>Participants N=34</th>
<th>Blood Glucose Monitoring (at least once or twice a day)</th>
<th>Diet (eat appropriately to manage your diabetes, e.g., regular carbohydrates and a bedtime snack)</th>
<th>Insulin Injections (as recommended by your diabetes team)</th>
<th>Exercise (exercise regularly)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintenance</td>
<td>23 (67.6%)</td>
<td>27 (79.4%)</td>
<td>33 (97.1%)</td>
<td>27 (79.4%)</td>
</tr>
<tr>
<td>Action</td>
<td>3 (8.8%)</td>
<td>2 (5.9%)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Preparation</td>
<td>3 (8.8%)</td>
<td>1 (2.9%)</td>
<td>-</td>
<td>3 (8.8%)</td>
</tr>
<tr>
<td>Contemplation</td>
<td>4 (11.8%)</td>
<td>2 (5.9%)</td>
<td>-</td>
<td>2 (5.9%)</td>
</tr>
<tr>
<td>Pre-contemplation</td>
<td>-</td>
<td>1 (2.9%)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>(Incomplete)</td>
<td>1 (2.9%)</td>
<td>1 (2.9%)</td>
<td>1 (2.9%)</td>
<td>2 (5.9%)</td>
</tr>
</tbody>
</table>

The frequencies in Table 3 reflect a robust level of basic self-care, with the majority of participants operating within the maintenance and action stages of behaviour. While it is expected that insulin injections are conducted, it is reassuring that they are conducted in line with the recommendations of the diabetes team. The results indicate that this behaviour is at the maintenance stage, which indicates an active attempt to sustain this behaviour. Similarly, participants are clearly located within the maintenance stage for blood glucose monitoring, diet and exercise-related behaviours. In contrast, only one person was at the pre-contemplative stage regarding diet, which indicates no intention to change their behaviour or a denial that their diet requires changing. Participants locating themselves within the preparation and contemplation stages, indicate they want (contemplation) and plan (preparation) to change their behaviour in a direction that promotes self-management of their diabetes.

Success and Difficulty with Self-Management Motivational Profiles

It is acknowledged that identifying individuals as either successful self-managers or having difficulties with self-management based specifically upon their HbA1c levels alone would be inherently problematic, due to the presence of endocrine changes during puberty (Ahmed, Conners, Drayer, Jones & Dunger, 1998; Dungar, 1992; Mann & Johnston, 1982). In addition, utilising a single measure such as HbA1c may reflect a simplistic approach to the complexities of regime management (Coffen & Dahlquist, 2009). It has also been highlighted that to use solely metabolic outcome measures may underestimate any psychological considerations (Woodcock & Bradley, 2007). These factors were notable within this research, as upon inspection of
the actual HbA1c levels collated from participants, the validity of splitting the database via HbA1c levels seemed questionable, with only three participants having a mean HbA1c reading within the recommended NICE (2004) target guideline of 7.5% or below.

It is due to the endocrinal factors associated with puberty, the knowledge gained from conducting the semi-structured interviews within this investigation and in the absence of a defining modality upon which to reliably discern successful status based solely upon biomedical data, that it seemed inappropriate to define self-management in the context of either HbA1c levels or clinic attendance (higher number of visits indicating greater monitoring from the diabetes team).

Due to these aforementioned concerns, in order to understand the relationship between self-management, SDT and SoC measures, groups were divided according to the success and difficulty with self-management categories which emerged from the grounded theory research interviews. Table 5 and Table 6 represent self-management categories in the context of biomedical, demographic and motivational characteristics (SDT & SoC) as defined by the researcher. The findings are representative of 92% of the interviewed sample; one participant was not included as it was unclear which category they would be assigned to.

Table 5. Mean and Standard Deviation for Self-Management Groups

<table>
<thead>
<tr>
<th>Demographic &amp; Biomedical</th>
<th>Successful Self-Management (N=6) Mean (SD)</th>
<th>Difficulty with Self-Management (N=6) Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>15.17(0.98)</td>
<td>15.17(0.75)</td>
</tr>
<tr>
<td>Gender</td>
<td>Male (4) Female (2)</td>
<td>Male (3) Female (3)</td>
</tr>
<tr>
<td>Duration of diabetes</td>
<td>4.42(3.02)</td>
<td>8.92(5.00)</td>
</tr>
<tr>
<td>Age of onset</td>
<td>10.75(2.73)</td>
<td>6.25(4.83)</td>
</tr>
<tr>
<td>HbA1c</td>
<td>8.30(0.24)</td>
<td>10.65(1.01)</td>
</tr>
<tr>
<td>Clinic attendance</td>
<td>4.33(1.03)</td>
<td>6.00(1.41)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Self-Determination Theory</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>HCCQ</td>
<td>5.53(1.53)</td>
<td>5.33(1.15)</td>
</tr>
<tr>
<td>PCDS</td>
<td>6.13(0.75)</td>
<td>4.95(1.24)</td>
</tr>
<tr>
<td>TSRQ (A)</td>
<td>5.48(0.71)</td>
<td>4.73(1.49)</td>
</tr>
<tr>
<td>TSRQ (C)</td>
<td>4.00(1.20)</td>
<td>4.35(1.73)</td>
</tr>
</tbody>
</table>
Due to the limited sample size the findings are discussed in the context of direction rather than utilising statistical tests for difference. While age and gender were similar between groups, the difficulty with self-management category consisted of participants that had diabetes for a longer period of time and had been diagnosed at an earlier age. HbA1c and clinic attendance were also higher within the difficulty with self-management category as opposed to the successful self-management category. The Self-Determination measures describe both categories as expressing similar levels of autonomy support from the diabetes team. While the successful self-management group expressed a higher level of perceived competency in managing their regime as well as internal autonomous self-regulation, in contrast the difficulty with self-management group considered their self-regulation to be more externally controlled.

<table>
<thead>
<tr>
<th>Stages of Change</th>
<th>Successful Self-Management (N=6)</th>
<th>Difficulties with Self-Management (N=6)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Glucose Monitoring</td>
<td>Diet</td>
</tr>
<tr>
<td>Maintenance</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Action</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Preparation</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Contemplation</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Pre-contemplation</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Incomplete data</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

The frequency data from Table 4 demonstrates slightly higher levels of maintenance-based behaviours for the successful self-management group, more so for glucose monitoring, while there is a level of contemplation noted for both groups. The small sample size and incomplete data limit the level of interpretation that can be made.

Discussion

The results indicate a number of interesting relationships between motivational, demographic and biomedical factors. Firstly, the relationship between average HbA1c levels across the last 12 months, duration, onset of diabetes and how it relates to participants’ internal levels of autonomy regulation. The finding that HbA1c levels increase linearly with the duration of the condition, while autonomous regulation reduces as the duration increases, is consistent with the literature that suggests that
between the first and fifth years adolescents are more likely to deny their diabetes, infrequently attend clinic and conceal their illness from their peers. Similarly, as time progresses, individuals became more accepting of their condition and the need for improved self-care (Gardiner, 1997). Kovacs et al. (1990) also suggested that the duration of the disease was a salient factor regarding adjustment and as duration increased, young patients appraised the implications of diabetes as more upsetting and difficult to manage. Kovacs found that age at onset did not appear to influence adjustment for the subsequent 6-year period within their longitudinal study. The relationship between HbA1c and age at onset indicates that as age at onset increases HbA1c levels reduce. In addition, autonomous regulation also increases with age at onset. This is interesting as it could be that the increase in age reflects a more adaptive response to the diagnosis and a greater ability to integrate the condition into their lives.

It is thought that the relationship between HbA1c and clinic attendance reflects the diabetes team’s emphasis on increased monitoring for individuals whose HbA1c levels start to increase; part of this involves providing more clinic appointments. This would also explain the negative relationship between improved competence and reduced clinic attendance. Perceived competence has also been shown to be significantly linked to HbA1c levels, with a reduction in HbA1c levels associated with an increase in perceived competence. While this relationship is unclear within the literature in the context of adolescents, it supports the findings of other researchers that have studied Self-Determination Theory within type 1 and type 2 diabetes in adults (William, Freedman & Deci, 1998).

While a number of health behaviour interventions have utilised the Transtheoretical Model (Bridle et al., 2005), the lack of published, UK-based research regarding the application of SoC to self-management behaviour in type 1 diabetes has been noted (Wilson, 2009). This limits the availability of literature in which to discuss the findings located within this sample of young people with diabetes. The intention for understanding participants’ particular Stage of Change was to be able to match the different stages of the model with different types of intervention strategies (La Greca & Mackey, 2009). By focussing upon adolescents this may expand the application of the SoC model within an additional age group, in contrast to the emphasis on adult
services (Andrés, Gómez & Saldaña, 2008; Jones et al., 2003; Vallis et al., 2003). In considering the findings from the Stages of Change questionnaire, what appears from Table 4 is that the majority of behaviours can be located within the maintenance and action stages. While this may well be the case for insulin injections, within the area of blood glucose monitoring the findings should be considered tentatively. This is noted, as the item descriptor used within the SoC measure stated, “do you monitor your blood glucose levels at least once or twice a day?” One limitation may be that this phrasing was too conservative to identify those that do not attend to their blood glucose monitoring beyond one or two tests per day. It is therefore unclear how sensitive this measure is.

The successful and difficulty profiles, as created from the researcher’s interpretations of the participants’ experiences of managing their diabetes, provided a way to distinguish between the two positions of self-care. While age and gender appear uncharacteristic, the remaining demographic and biomedical data are appropriately distributed either side of the overall mean and standard deviations (see Table 5). In terms of the Self-Determination measures, they too reflect opposing representations of the characteristics. While not statistically confirmed, the contrasting profiles of successful and difficulty categories support the theory of Self-Determination (Deci & Ryan, 2004). In particular, the concept of basic psychological needs for competence, autonomy and relatedness located within Self-Determination Theory suggests that these characteristics are essential in order to promote personality and cognitive growth in respect to the participants studied in this investigation.

In considering the limitations of this investigation, studies exploring the relationship between current age, onset age and disease duration provide insights into how individuals manage the condition. Cross-sectional forms of investigation have been questioned on methodological grounds due to poor control of these variables (Johnson & Meltzer, 2002). One of the issues in interpreting these variables is that knowing current age and age at onset predicts duration, a feature that was observed within this research. While correlations have been used to understand relationships and groups have been split according to assigned criteria (successful and difficulty), there are limitations within this research for controlling for these factors on the basis of sample size and the inference that can be taken from this. In terms of the Transtheoretical
Research

Model, inferential insight was not the emphasis for administering the SoC questionnaires, rather it was to gather an understanding of which stage the participant could be located at as a way of matching the potential level of intervention.
SECTION 3

Grounded Theory Approach to Understanding Motivational Factors among Adolescents with Type 1 Diabetes

Reflexivity Preface

While studying as a trainee health psychologist, one of the approaches I found helpful in working with the issue of behavioural change was Motivational Interviewing (MI), because of its recognition of and emphasis on working with individuals’ ambivalence and readiness to change. This approach provided an awareness of the importance of working with the individual rather than imposing ideas and beliefs upon them. This prior awareness provided an understanding of the range of motivational techniques currently available within this approach. In addition, knowledge of the Stages of Change (SoC) Model supported the principles for readiness to change, while Self-Determination Theory (SDT) suggested that individuals were more likely to adopt healthy behaviours when their basic psychological needs for autonomy, competence and relatedness were supported. Therefore, I was keen to use a qualitative methodology in order to discover the way individuals construct and understand their diabetes around the developmental period of adolescence. While I had a good knowledge of motivational and change models (MI, SoC, SDT), I wanted to generate a specific theory containing not only their language, but also their issues concerning self-management. The social constructionist approach to grounded theory (Charmaz, 2006) allowed for this opportunity, and would support and extend the knowledge within the pre-existing theories. I was also keen that the findings should have a practical or practice-based application attached to them, specifically that the results could be utilised to both understand and work with individuals in a way that incorporates their beliefs and values to promote greater self-management and understanding of the disease.
Introduction

The National Institute for Clinical Excellence (NICE) recommends that the target for long-term glycaemic control in children and young people is a glycated haemoglobin (HbA1c) level of less than 7.5% (NICE, 2004). A recent survey by The Royal College of Paediatrics and Child Health (RCPCH, 2009) established that the number of children and young people under the age of 18 with diabetes in England was 22,947, with 76.8% within the 10–17 age group having type 1 diabetes. This research is interested in exploring the age group between 13 and 17, in order to understand more about the development period of adolescence.

Research has indicated that children with insulin-dependent diabetes mellitus (IDDM) have normal onset of puberty progression, independent of the age at onset, glycaemic control or the insulin required during the pubertal period (Salerno et al, 1997). Du Pasquier-Fediaevsky, Chwalow, the Paediatric Endocrinology and Diabetology (PEDIAB) Collaborative Group and Tubiana-Rufi (2005) explored the time course of respective deterioration of adherence to treatment and demonstrated that metabolic control deteriorated prior to the worsening of adherence behaviours. It has also been suggested that the deterioration in metabolic control during early adolescence due to hormonal factors may seriously discourage self-management efforts, and that healthcare providers should avoid attributing poor metabolic control to poor adherence (Du Pasquier-Fediaevsky & Tubiana-Rufi, 1999). Due to the level of deterioration in metabolic control around the period of adolescence, it is possible that such a relationship may also impact upon the motivational factors attributed to diabetes management and how the individual views their diabetes within a developmental and psychosocial context.

When diabetes management is conceptualised within a medicalised, stress-based framework, it provides evidence for the existence of certain developmental cognitive trends that emerge as a reflection of cognitive maturity. Children at pre-formal levels of cognitive development show greater emphasis on primary control coping such as trying to directly change stressful conditions, whereas secondary control coping such as trying to adjust to circumstances as they are, increase with cognitive maturity (Band, 1990). While some researchers have studied the specific role that coping and
coping styles play for children and adolescents (Graue, Wentzel-Larsen, Bru, Hanestad & Søvik, 2004; Reid, Dubow, Carey & Dura, 1994), there are limitations in the longitudinal transition-based conclusions that can be drawn from these results. Surwit (1993) states that, although stress may affect glucose control within type 1 diabetes, there is a greater need to understand the effects of individual differences within the diabetes field. Furthermore, while diabetes-related stress has been found to mediate the relationship between HbA1C (glycated haemoglobin), diabetes quality of life and well-being (Malik, 2009), the limitations of construct-based psychometric measures restrict the depth of understanding of adjustment or process-based insights required to expand on this relationship (Aldwin, 2007). One exception to this incorporates an ecological momentary assessment methodology (diary-based approach), allowing for a more detailed interpretation of positive and negative aspects of peer relationships to be collated, and concludes that stressful life events can impact upon metabolic control, more so in older adolescents (Helgeson, Escobar, Siminerio & Becker, 2010). While a stress-based model identifies the relationship between stressful events and physiological responses, there is a need to explore how psychosocial factors impact upon individuals with type 1 diabetes, and how they can be utilised to integrate the condition into their lives.

Methodologically, a number of studies have employed predetermined hypotheses and specific outcomes measures to highlight relationship, associational and indicator-predictor-based insights. These designs have been aimed at understanding the relationship between children and young people, glycaemic control, mental health and cognitive functioning (Dantzer, Swendsen, Maurice-Tison & Salamon, 2003; Fonagy, Moran, Lindsay, Kurtz & Brown, 1987; Gonzalez et al., 2008; Hood et al., 2006; Lustman et al., 2000; McGrady, Laffel, Drotar, Repaske & Hood, 2009; Ohmann et al., 2010). Coffen and Dahlquist (2009) cautioned about the use of employing single scores or overly simplistic measures to assess or understand self-care and not taking into consideration the complexity of regimen management. Indeed, one of the barriers to a chronic disease model is “understanding of the personal and social-environmental factors that lead to long-term sustained self-directed behaviour change” (Glasgow et al., 2001, p. 126).
From a methodological perspective, qualitative forms of enquiry provide an opportunity to explore the complexities of regimen management raised by Coffen and Dahlquist (2009) and Glasgow et al. (2001) by investigating the perceptions, beliefs and values of individuals as well as their relationships to family and peers. For example, Lowes, Gregory and Lyne (2005) investigated the grief responses and process of adaption in the context of parents whose children had recently received a diagnosis of diabetes. They theoretically underpinned the investigation using Parkes’ Theory of Psychosocial Transitions (Parkes, 1993), which suggests that people need emotional support, protection through periods of helplessness and assistance in discovering new models of the world. Lowes et al. (2005) described diabetes as intruding upon the parents’ lives both emotionally and practically, while they successfully adjusted and adapted to the diagnosis and created a new model of the world with diabetes in it. The authors also noted that emotions re-surfaced in the parents when discrepancies or triggers emerged highlighting their children’s condition and “casting doubt on the extent to which they could emotionally bridge the disparity caused by the chronicity and unpredictability of diabetes” (p. 259).

Wennick and Hallström (2007) reported the impact upon the family 1 year after their child was diagnosed with diabetes. One of the findings was that with periods of well-balanced blood glucose levels the family experienced acceptance, health, independence and confidence. This was in contrast to times of unbalanced levels when they experienced frustration, invisible illness, supervision and insecurity. Wennick and Hallström commented that diabetes was not a static illness and that its psychological impact changed over time, which could have increased psychosocial implications.

When teenagers were asked about their perceptions of peer support, Lowes, Eaton, Bill and Ford (2007) found that they considered their friends to be mostly positive and supportive of their diabetes; this has also been found by La Greca et al. (1995). It was also noted from discussions with teenagers that friends could sometimes misinterpret the nature of type 1 diabetes, for example assuming a link between obesity and the development of the disease. In addition, at times teenagers also felt resentment about feeling different. La Greca, Bearman and Moore (2002) suggest that the vast majority of young people with a chronic health condition do not appear to be at risk of
developing problems in their peer relationships or close friendships and highlight a focus upon research emphasising social adjustment within the condition, rather than comparing with healthy samples.

A number of studies have focussed on adolescents’ experiences of managing their diabetes in order to raise awareness that diabetes affects all parts of the individual’s life (Christian, D’Auria & Fox, 1999; Huus & Enskär, 2007; Kyngäs & Hentinen, 1995; Meldman, 1987). Kyngäs and Barlow (1995) noted that all the adolescents they interviewed reported a fear of complications associated with diabetes, for which they reported not receiving adequate support to help cope or come to terms with. They felt stressed, isolated and alone, but were unsure how to voice their fears and concerns. Kyngäs and Barlow also referred to the limitations imposed by diabetes: “limitations, control and dependence upon self-care and other people led adolescents to view themselves as “different”. They believed that peers without IDDM did not experience the same level of control and dependence” (p. 945).

Kyngäs and Hentinen (1995) focussed on the identification and development of four conceptual categories based on a grounded theory methodology (Glaser & Straus 1967) in order to construct a hypothetical model of compliance to self-care which they described as:

*Good compliance* - Adolescents took care of themselves and followed their health regimes regularly.
*Imposed compliance* - Adolescents felt self-care was an obligation forced upon them.
*Conscious non-compliance* – Self-care constantly deviated and adolescents were conscious of the negative effects of neglecting their health regimes.
*Non-compliance* - Adolescents were passive and indifferent to themselves and their self-care.

Further research has suggested a framework in which to understand compliance including factors such as responsibility for treatment, intention to pursue the treatment and collaboration with the physician. This is to be largely determined by motivation, experience of the results of treatment and having the energy and willpower to pursue
the treatment, as well as a sense of normality and fear in connection to control of diabetes (Kyngäs, 1999; Kyngäs, Hentinen, Koivukangas & Ohinmaa, 1996)

Within the diabetes literature there has been a movement towards the concept of self-management as opposed to adherence or compliance. This is described by Schilling, Grey and Knafl (2002) as:

Self-management of type 1 diabetes in children and adolescents is an active, daily and flexible process in which youth and their parents share responsibility and decision-making for achieving disease control, health and well-being through a wide range of illness-related activities (p. 92).

Schilling et al. highlight age, gender, motivation, knowledge, skills and cognitive ability as being important variables for future study. Additionally, research exploring glycaemic control trajectories from adolescence to emerging adulthood indicate the need to strengthen adolescent’s self-concept, in order to improve glycaemic control (Luyckx & Seiffge-Krenke, 2008). This suggests a need to contextualise these features within a flexible process-based framework in order to expand upon the developmental aspects as stated by La Greca, Bearman and Moore (2002), which can support and promote motivational movement towards increased autonomy and psychological integration of an individual’s diabetes.

Research has started to incorporate new conceptual approaches into process-based aspects of development. Hanna and Decker (2010) conducted a concept analysis based on a methodology provided by Walker and Avant (2005) in order to clarify and define the concept of assuming responsibility for self-care within diabetes. They concluded that:

Assuming responsibility for self-care among adolescents with type 1 diabetes is defined as a process specific to diabetes within the context of adolescent development that is gradual, daily, individualised for each adolescent and unique to specific diabetes care tasks. The goal of the process is ownership of diabetes care that involves autonomy in behaviours and decision-making. Assuming responsibility is influenced by the diabetes condition and/or treatment regimen,
the adolescent’s readiness, expectations for responsibility and interactions with others. The consequences of assuming responsibility for self-care are diabetes management, short and long term health outcomes, psychosocial quality of life and adolescents’ beliefs in themselves and their diabetes (Hanna & Decker, 2010, p. 104).

Hanna and Decker stipulated that assuming responsibility for self-care is different from compliance, adherence and self-management, in that it revolves around becoming autonomous in self-care and developmentally focussed towards the ownership of one’s care. The implications of this position were described in an earlier study in which a number of perceived barriers, such as the burden of responsibility for managing the condition, were identified. Alternatively, perceived benefits were also identified, such as having the knowledge and confidence to conduct the self-management tasks independently (Hanna & Guthrie, 2000). By focussing upon the realities and experiences of young people with type 1 diabetes and how they construct diabetes within their lives, research can expand upon ways to contextualise this knowledge and develop a greater process-based understanding of how the condition is managed.

This investigation will utilise a social constructionist perspective as a conceptual framework with which to explore how adolescents with type 1 diabetes understand and participate in the construction of their perceived social realities. Burr (2003) refers to the work of Gergen (1985) by proposing four tenets that best describe the theoretical position of a social constructionist perspective:

1) Social constructionists take a critical stance towards taken-for-granted knowledge of the world and how we understand it.
2) Historical and cultural specificity suggests that the way we understand the world, its categories and concepts can have a historical and cultural impact dependent upon where and when we lived.
3) Knowledge is sustained by social processes and language.
4) Knowledge and social action go together, in that knowledge may mean different things to different people, which may in turn produce a varied response. There is the implication for power-based relationships within this context, as our constructions are
related to what is considered permissible for people to do and how they may treat others.

A social constructionist approach assumes that there are no essences within things or people, it is anti-essentialism; rather than attributing terms or labels such as personality or identity to ourselves, we are constructed within a social context. For example, an individual described as non-compliant may be perceived in a specific way due this definition of their self, which may have an impact upon how they are responded to or perceived by healthcare professionals. Researchers have acknowledged the implications of constructs such as compliance and adherence as being counter-productive (Glasgow & Anderson, 1999). All knowledge is derived from looking at the world from a certain perspective and our ways of understanding the world come from other people and our contact with them. Language is seen as having practical implications and consequences upon the individual, and there is a strong focus upon the dynamic of social interaction, interpretation and process, rather than structures and entities such as personality traits. In utilising this theoretical approach to the understanding of how adolescents manage their diabetes, one can construct an awareness of the forms of reality that exist for individuals in the context of their social world and how they locate their diabetes and construct an existence with it.
Research

Methodological Approach

In considering the most appropriate approach for this investigation a range of differing methodologies and epistemological perspectives were explored (Smith, 2008; Willig, 2008). So as not to impose pre-existing theoretical concepts, and in order to generate an understanding of motivation that could contextualise diabetes and its management within the individual’s life, a grounded theory methodology was selected. Grounded theory has been used within a number of peer-reviewed studies over the last decade to investigate physical health-related areas (Cagnetta & Cicognani, 1999; Corbit-Owen & Kruger, 2001; Grant, St John & Patterson, 2009; Long, Sque & Addington-Hall, 2008; McLane, Jones, Lydiatt, Lydiatt & Richards, 2003; Wersch & Walker, 2009), which also supports its utility as a method for studying diabetes.

In order to select the most suitable version of grounded theory, three were considered. The original “classical” approach developed by Glaser and Strauss (1967), Strauss and Corbin’s more “prescriptive” approach (Strauss & Corbin, 1994), and Charmaz’s (2006) constructivist version. For the purposes of this study constructivist grounded theory was selected, as it provides a flexible set of inductive strategies for collecting and analysing qualitative data, as well as generating inductive theoretical categories that are grounded in the data, with an emphasis on the subjective inter-relationship between the researcher and participant (Charmaz & Henwood, 2008; Mills, Bonner & Francis, 2006).

Epistemologically, social constructionist knowledge is not concerned with what is really going on, as in a realist approach to knowledge; or how something is actually experienced, as in a phenomenological approach. Willig (2012) describes social constructionist knowledge as “how people talk about the world and, therefore, how they construct versions of reality through the use of language” (p. 8). Charmaz’s (2006) version of grounded theory, assumes that:

Neither data nor theories are discovered. Rather, we are part of the world we study and the data we collect. We construct our grounded theories through our past and present involvements and interactions with people, perspectives, and research
practices. My approach explicitly assumes that any theoretical rendering offers an interpretive portrayal of the studied world, not an exact picture of it (p. 10).

Charmaz (2006) states that a “constructivist approach places priority on the phenomena of study and sees both data and analysis as created from shared experiences and relationships with participants” (p. 130). This approach acknowledges that the resulting theory is an interpretation, which depends on the researcher’s view, and encourages reflexivity in terms of the researcher’s own interpretations, as well as those of participants.

In assessing the suitability of Charmaz’s social constructivist approach in relation to alternative grounded theory approaches (Heath & Cowley, 2004), it was noted that key epistemological differences exist between the modalities. In order to confirm suitability and expand on these differences, it has been suggested that such epistemological roots can be identified by asking three questions (Willig, 2008).

Epistemological Questions:

What kind of knowledge does the methodology aim to produce?

Prior to constructivist grounded theory the researcher was considered to be objective within the research process, removing any preconceptions or external features from the situation (Glaser & Strauss, 1967; Strauss & Corbin, 1994). It was considered that this would allow the grounded theory to be truly “grounded” in the data, creating a realist orientation to the process. The data acted as an objective product to be observed and recorded by the researcher, with grounded theory providing a positivist perspective to the knowledge.

From a constructivist grounded theory perspective, Charmaz (2000) affirms studying individuals within natural settings, aiming to move away from a positivist perspective by stating three factors:

1) Grounded theory strategies need not be rigid or prescriptive.
2) A focus on meaning while using grounded theory furthers, rather than limits, interpretive understanding.
3) We can adopt grounded theory strategies without embracing the positivist leanings of earlier proponents of the theory.

What kinds of assumptions does the methodology make about the world?
Grounded theory draws on a symbolic interactionist perspective (see Blumer, 1969; Cooley, 1902; Mead, 1934), which assumes that social realities are participated in and negotiated by an individual’s interpretation of events. This is a perspective that is consistent with the constructivist approach to grounded theory that assumes individuals are active, creative and reflective and that social life consists of processes (Charmaz, 2005, 2006).

How does the methodology conceptualise the role of the researcher in the research process?
Historically, the researcher acts in an objective manner observing, taking notes and asking questions in order to understand what is going on; their identity and viewpoint remains secondary. Within the constructivist perspective, the researcher’s discipline, relationships and interactions with respondents all influence the collection, context and analysis of data.

The application of grounded theory within psychological research has been critiqued by Willig (2008), and therefore the suitability of a constructionist perspective will be discussed in the context of these suggested limitations in order to support its selection for the study. Firstly, grounded theory has been criticised for its use of induction to generate new understandings of phenomena, yet insisting that the researcher exists within an objective position. This criticism arises from a lack of acknowledgement regarding the role of the researcher within the data collection process. The constructivist approach accepts these comments and addresses them by acknowledging the role of the researcher within the participant-researcher relationship and emphasising reflexivity within the approach.

The second limitation relates to the observation that grounded theory was designed to study social processes. Willig (2008) indicates that in the context of psychological research:
When applied to questions about the nature of experience, as opposed to the unfolding of social processes, the grounded theory method is reduced to a technique for systematic categorization. That is, studies concerned with capturing the meanings that a particular experience holds for an individual tend to use one-off interviews with participants, transcribe them and code the transcript using the principles of the grounded theory method. The result is a systematic map of concepts and categories used by the respondents to make sense of their experience (p. 47).

While there is an acceptance of the aforementioned features in the context of capturing individual experience, as a grounded theory approach, Strauss and Corbin (1994) state quite clearly that grounded theorists are “Interested in patterns of action and interaction……not especially interested in creating theory about individual actors as such (unless perhaps they are psychologists or psychiatrists). They are also much concerned with discovering process” (p. 278). As social constructionist grounded theory embraces the acknowledgement of the researcher within the process and as the researcher within this study brings a psychological background into the relationship, there is an awareness of the structural development of concepts and categorisation that a grounded theory generates as indicated by Willig (2008). There is also the awareness that the researcher’s psychological knowledge can affect the type of data collected, and, as one of the aims of the investigation is to generate understanding regarding diabetes management as a process, the social constructionist perspective complements the psychological orientation of the study.

Bringing a psychological perspective to the investigation acknowledges that there are individual characteristics and psychosocial determinants which may impact on how participants manage their diabetes. The researcher is well placed to observe and identify the distinction between individual and more generic process-based approaches to self-care and utilise this knowledge within the coding, categorisation and memo-writing stages of theoretical development. Indeed, Charmaz and Henwood (2008) have also discussed the role and development of grounded theory in psychology as an accepted methodology, and also as a new way of understanding and describing participants in a more analytic context.
Literature Review

For this investigation, the timing of the literature review was delayed. Charmaz (2006) notes “the intended purpose of delaying the literature review is to avoid importing preconceived ideas and imposing them on your work. Delaying the review encourages you to articulate your ideas” (p. 165). The review was withheld until categories and analytic relationships were developed. The findings were then discussed and incorporated into the relevant existing literature.

Researcher Reflexivity

As the primary researcher, I conducted the interviews and interpreted the data. It is important to highlight my ethnicity, gender, age and personal experience in terms of working with children and young people. This provides a sense of how such features relate to data collection and analysis (Willig, 2008).

I am a white, British male and at the time of conducting the interviews was aged 36-37 years. The interviews were conducted in dress trousers, shirt and sweater in order to convey a smart, professional, yet not too conservative image. I have several years’ experience working within psychological services. Prior to working with children and young people, I worked within adult services in a Regional Department of Psychotherapy, as well as a Behavioural Analysis and Intervention Team for adults with learning disabilities, whose behaviour challenges services. Since then, I have been working with children and young people in a variety of posts. These include Paediatric Liaison Psychology, Child and Adolescent Mental Health, Schools Multi-Agency Resources Team and most recently the Scallywags service for children with emotional and behavioural difficulties. All these posts involved engaging with children and young people in an assistant clinical psychologist capacity, enabling me to develop a range of therapeutic skills and approaches for engaging them and exploring their experiences. It was envisaged that the clinical experience of working alongside young people would be of benefit during the interview stage of this investigation. It is also acknowledged that I have a range of academic knowledge regarding clinical and behavioural change models from studying health psychology at MSc level.
Participants were selected using purposive sampling (Patton, 1990) from the Cornwall Diabetes Endocrine Centre (CDEC) within the Royal Cornwall Hospitals NHS Trust. The CDEC operates six diabetes clinics throughout Cornwall (Penzance, Redruth, Falmouth, Truro, St Austell and Bodmin). The Paediatric Diabetes Clinical Nurse Specialist was initially approached in order to explore whether the service would be interested in participating in the research. The service was keen to get involved, and it was agreed between the researcher and the team that the age range most suitable would be between 13 and 17 years. The rationale was that individuals younger than 13 years of age may struggle with engaging in the interview process and at the age of 18 individuals are transferred to adult services.

The recruitment took place between September 2009 and April 2010, which ensured that all potential 13-17 year old participants were offered a clinic appointment and therefore given the opportunity to partake in the research. It had been established prior to data collection, based on current figures from CDEC, that 44 individuals would be eligible based on age and a diagnosis of type 1 diabetes. In total, 34 participants completed the questionnaire packs, representing 77% of the overall 13-17 year old population identified. Of those that attended clinic or were seen by the diabetes nurse, 94% completed the questionnaire packs. For the remaining number of potential participants, eight DNA and two were unaccounted for.

From the 34 possible participants, 15 (44%) consented to be interviewed by the researcher for the qualitative element of the research, representing 34% of the overall 13–17 year old sample. The final interviewed sample represented 13 participants (38% of potential and 30% of overall sample), as one participant withdrew and one DNA. Participants comprised seven males (average age 15 years 4 months) and 6 females (average age 14 years 7 months). In order to contextualise the cross-sectional nature of the recruitment procedure, full demographic and biomedical characteristics were collated in Table 7. Participants were approached by the diabetes nurse once the research project had been approved by the Cornwall and Plymouth Research Ethics Committee and registered with the Royal Cornwall Hospitals NHS Trust Research and Development Directorate.
Table 7. Interviewed Participants’ Demographic and Biomedical Information

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Gender</th>
<th>Age (current)</th>
<th>Age (at onset)</th>
<th>Duration of diabetes (years)</th>
<th>Average % HbA1c * (min-max) (last 12 months)</th>
<th>Clinic attendance ** (last 12 months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>Female</td>
<td>14</td>
<td>2</td>
<td>12</td>
<td>10.6 (9.3-10.9)</td>
<td>6</td>
</tr>
<tr>
<td>P2</td>
<td>Female</td>
<td>13</td>
<td>10</td>
<td>3</td>
<td>9.2 (8.0-9.9)</td>
<td>6</td>
</tr>
<tr>
<td>P3</td>
<td>Male</td>
<td>15</td>
<td>14</td>
<td>1</td>
<td>9.5 (6.4-14.0)</td>
<td>5</td>
</tr>
<tr>
<td>P4</td>
<td>Male</td>
<td>16</td>
<td>15</td>
<td>1</td>
<td>8.1 (6.4-11.2)</td>
<td>5</td>
</tr>
<tr>
<td>P5</td>
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<td>3</td>
<td>13</td>
<td>11.3 (9.9-12.2)</td>
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<td>P6</td>
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<td>9</td>
<td>8.6 (8.0-9.4)</td>
<td>3</td>
</tr>
<tr>
<td>P7</td>
<td>Male</td>
<td>15</td>
<td>12½</td>
<td>2½</td>
<td>8.4 (7.7-8.8)</td>
<td>5</td>
</tr>
<tr>
<td>P8</td>
<td>Female</td>
<td>15</td>
<td>6</td>
<td>9</td>
<td>10.6 (9.1-12.2)</td>
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<td>12</td>
<td>2</td>
<td>8.1 (7.3-8.4)</td>
<td>5</td>
</tr>
<tr>
<td>P10</td>
<td>Female</td>
<td>14</td>
<td>9½</td>
<td>4½</td>
<td>8.5 (8.3-8.7)</td>
<td>3</td>
</tr>
<tr>
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<td>10</td>
<td>5</td>
<td>10.1 (9.3-11.1)</td>
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<td>5</td>
</tr>
<tr>
<td>P13</td>
<td>Male</td>
<td>16</td>
<td>3</td>
<td>13</td>
<td>12.3 (10.6-14)</td>
<td>8</td>
</tr>
</tbody>
</table>

* NICE guidelines for type 1 diabetes (2004) recommend that children and young people with type 1 diabetes and their families should be informed that the target for long-term glycaemic control is an HbA1c level of less than 7.5% (p. 18) / highest measurable reading is 14.

** NICE guidelines for type 1 diabetes (2004) recommend that children and young people with type 1 diabetes should be offered testing of their HbA1c levels two to four times per year (more frequent testing may be appropriate if there is concern about poor glycaemic control) (p. 18).

Procedure

Pre-interview Contact

One of the first stages in the interview process was gaining informed consent (National Patient Safety Agency, 2007). It was agreed with the diabetes nurse and consultant paediatrician that this would be implemented within the protocol used for the questionnaire pack administration (see Section 2, Procedure). In keeping with ethical guidelines stipulated by the Cornwall and Plymouth Research Ethics Committee, potential participants were provided with notification about the research prior to attending clinic. This was done approximately 1-4 weeks before attending clinic and agreed with the diabetes nurse to be conducted as part of a routine telephone conversation with individuals.

The normal procedure for attending clinic is that individuals initially see the diabetes nurse then wait to see the consultant paediatrician. At the end of the individual’s appointment with the diabetes nurse, they were handed the questionnaire pack that contained four questionnaires. If the individual was aged 16 or above they were given a Young Persons – Participant Information Sheet and Young Persons – Consent Form (see Appendices 6 and 7). If the individual was under 16 years of age their parent was given a Parent – Participant Information Sheet and Parental Consent Form (see...
Appendices 8 and 9), while the individual was given a Young Persons – Participant Information Sheet (Caldicott Committee, 1997). The questionnaire packs were completed in the waiting room prior to meeting with the consultant paediatrician and then returned to the diabetes nurse in a sealed envelope (non-identifiable coding system described Section 2, Procedure).

At the initial stage of the data collection process, only consent-to-approach was gathered using the Young Persons – Participant Information Sheet. Within this sheet individuals were asked if they were happy for the researcher to contact them to discuss their diabetes in more detail at a future date at a location convenient for them, responses were gathered by circling either Yes or No. A circled Yes meant that the researcher then gained the participant’s name, telephone number, address and postcode from the diabetes nurse. As data collection continued it was felt that a formal consent form should be introduced, enabling parents of children under the age of 16 to be made aware that their child had agreed to the researcher contacting them. This was conducted in conjunction with Cornwall and Plymouth Research Ethics Committee.

_Contacting Participants_

The researcher contacted participants by telephone to confirm that they still wanted to participate in the interview. It was reiterated that the interview was to discuss their diabetes regime, and the format of recording the interview was also discussed. Initially, participants were asked if they would be comfortable having the interview video-recorded, in order to ensure the content of the interview could accurately be typed up at a later date by the researcher. If this was not agreeable, participants were then given the option to be tape-recorded (audio only). The rationale for using a video recorder was to note behavioural gestures such as smiling, pointing towards the interviewer and the visual content of pauses, which would not necessarily be detected by audio alone (Bailey, 2008).

Confidentiality was also explained within the context of the recorded material and that the tapes would be held by the researcher for interpretation purposes only. In total, 11 participants agreed to be videotaped and 2 participants requested audio recording only. Once this had been agreed, a location was confirmed. Regardless of age the
participant’s parent was also consulted about the interview, and it was explained that although the interview was between the researcher and the child, it was requested that they be present within the vicinity while the interview was being conducted. In total, all 13 participants were interviewed at their homes.

Interview

The actual recorded interview duration was on average 26 minutes (minimum 11 minutes and maximum 35 minutes). The format was a semi-structured interview (Coolican, 1999). This approach allowed for the researcher to focus on chosen areas of interest, yet allowed for new forms of direction to be explored. The questions were open-ended to allow participants as much opportunity to express themselves as possible. The researcher responded using a combination of reflective statements (Miller & Rollneck, 2002) and further open-ended questions to stimulate and pursue possible avenues of relevance regarding the motivational features associated with the participant’s diabetes regime. Additional techniques involved expanding and clarifying ambiguous or implicit assumptions and expectations held by participants (Willig, 2008), as well as exploring meaning within a social constructionist context in respect to how participants construct their realities. There was also the acknowledgement of how meaning can be constructed within the researcher-participant interaction (Charmaz, 2006).

Ethically, Brinkman and Kvale (2008) discuss a number of issues regarding the conduct of qualitative psychological research from the initial formulation of the research question through to the dissemination stage. In particular, they emphasise “the researcher’s integrity, his or her ability to sense, judge and act in an ethically committed fashion” (p. 279). Ethical considerations while conducting the interviews were monitored throughout the allotted time for any indication of unease in responding to questions or queries.

Topic Guide

Due to the methodological characteristics of grounded theory and the simultaneous involvement with the data early in the collection process, the interview topic guide developed as more participants were interviewed, with emerging analyses leading and
shaping future ideas and questions (Charmaz, 2006). The initial questions from the topic guide for participant 1 were as follows:

1) What is it like to manage your diabetes, how do you find it?
2) How do you feel about managing your diabetes?
3) Can you remember when you first started managing your diabetes?
4) How do you find managing your diabetes now (current day)?
5) What sort of things have you learnt about managing your diabetes?

From the initial interview with participant 1, I felt the topic guide was too brief and needed to be expanded to stimulate conversation. As the interviews progressed, questions were continually added and explored. The following provides an overview of how the topic guide developed across the interviews, based on my reflexivity and the development of memos (notes regarding emerging categories and how to code data). The process of reflexivity and memo-writing created greater analytic depth, in terms of how diabetes self-management was socially constructed, and assisted in the development of theoretical categories required to support the grounded theory. Interviews 2-3 moved towards the practical aspects of self-management, i.e. focussing on feelings, self-esteem, difficulties, changes and learned experience. Interview 4 integrated the management of specific elements of the regime (i.e. blood glucose monitoring, diet and exercise), created a question regarding independence to discuss critical points or times associated with self-management, and also explored the impact of others (parents and health professionals) and what was and was not motivating. Interviews 5-6 focussed on exploring the motivational aspects (development and techniques) in order to expand upon the adaption element of self-management. Interviews 7-8 inquired about any advice participants could offer to others regarding the management of type 1 diabetes. Interview 9 asked how participants currently perceived their own self-management. Finally, interview 10 asked when and why self-esteem was affected.

The final topic guide used for participant 13 is reproduced in Appendix 10, and includes related reflexivity regarding additional items and sub-sections.
Data Interpretation

The taped interviews were transcribed into a word document. Coding provides a way of defining the data, and during initial coding Charmaz (2006) suggests sticking closely to the data. She highlights coding with words that reflect action and notes the use of gerunds (verbs ending in “ing”) to detect processes. Each line of the transcribed document was subsequently named. These initial line-by-line codes are considered provisional and to be compared across the interviews.

The second major phase of coding is focussed coding, which is more directed, selective and conceptual. This is described by Charmaz (2006) as “using the most significant and/or frequent earlier codes to sift through large amounts of data. Focused coding requires decisions about which initial codes make the most analytic sense to categorize your data incisively and completely” (p. 57). Charmaz discusses the use of “in vivo” codes, which refer to participants’ special, innovative terms for describing and condensing meaning and experience. The interview transcripts were coded by myself (RC). Line-by-line and focussed codes were then checked by a second coder (health psychology supervisor) to confirm their validity (Yardley, 2008); using 25% of the transcripts which were randomly assigned via SPSS Statistics 17. Behavioural gestures such as smiling, pointing and pauses were included in the transcription to extenuate and highlight salient features.

I constantly moved between the initial and focussed forms of coding following each interview (constant comparative analysis) to develop the theoretical concepts. As categories started to emerge, they were pursued and discussed with participants until no new information or theoretical insight was revealed (this was limited to the existing 13 participants). Memo-writing provided a way to analyse the codes and reflect upon how the data was co-constructed and generated throughout the research process (Mills et al., 2006). Charmaz (2000) notes how memo-writing provides an aid for “linking analytic interpretation with empirical reality” (p. 517). She describes the use of “action codes” within memos for highlighting inter-related processes and connecting categories.
Theoretical Sampling and Saturation

While interview questions were amended to explore emerging categories and concepts, theoretical sampling and saturation was not possible, as access was limited to those 13-17 year olds with type 1 diabetes who consented to be interviewed. Additionally, of the 13 consenting participants, only one (P12) had the breadth of experience in terms of moving from a position of having difficulties with to one of successful self-management and could add further understanding of how movement occurred within the adaption and self-management model. It was due to these limitations that theoretical sampling and saturation were not possible. From a methodological perspective, the investigation reflects what Willig (2008) refers to as an abbreviated version of grounded theory: “the researcher does not have the opportunity to leave the confines of the original data set to broaden and refine the analysis” (p. 39). It is at this point that the investigation departs from the full version of Charmaz’s (2006) grounded theory, as it was not possible to interview additional individuals who could describe the process of moving from having difficulties with to successful self-management. Therefore, this investigation utilises an abbreviated version of social constructionist grounded theory.

Post-interview Reflexivity

Once the interview had ended, a moment of reflection was taken, away from the interview situation, in order to record any salient thoughts or feelings regarding either the outcome of the interview or experiences during the interaction. This approach added a level of transparency to the effects of interactions between the participant and researcher in order to promote theoretical sensitivity (Hall & Callery, 2001). While psychoanalytical approaches to qualitative psychology have been discussed in some detail by Frosh and Saville Young (2008), the post-interview reflexive space was used to consider any transference, counter-transference, projective or free-association-based processes that may have existed within the researcher-participant interaction.

Reflexivity Across the Research

In order to ensure that data collection and analysis was documented in a transparent and valid way, reflexivity was actively implemented throughout the study (Hall & Callery, 2001; Yardley, 2008). The use of reflexivity demonstrates how the
researcher’s assumptions, values, sampling decisions, analytic technique and interpretations of context are evident and acknowledged. Reflexivity was utilised and emphasised throughout the grounded theory process within the initial and focussed coding and constant comparative analysis stages of the research in order to add depth to the content. Willig (2008) has specified two types of reflexivity:

*Personal reflexivity*

Personal reflexivity provides a way of reflecting upon one's own values, experiences, interests, beliefs, political commitments, wider aims in life and social identities and how they may impact upon the development of the research.

*Epistemological reflexivity*

This involves reflecting on the assumptions made within the research in the form of the context of epistemological factors. For example, what the considerations were regarding the nature and type of question used to explore the subject area, how the design and method of analysis impacted on the data and findings, whether the research question could have been investigated differently and would have provided a different interpretation of the subject area.
CHAPTER 1

Self-Management

*Information Type*

It is important to emphasise that although all participants were able to talk and discuss experiences in the current tense, a significant amount of the information is retrospective, in order to capture experience and memories associated to living with the condition.

*Outline of Structure*

In order to reflect on the full depth of information that a grounded theory approach generates and to ensure that the various categories link together in a coherent and fluid manner, they have been grouped into more substantive headings with which to form the basis of forthcoming chapters. Each chapter provides an aspect of diabetes management in order to describe and understand self-management in a pragmatic and interpretive manner, which reflects the researcher’s interpretation and construction of the data.

Initially, Chapter 1 aims to differentiate between two distinct categories, referred to as *successful self-management* and *difficulties with self-management*, that reflect psychological, psychosocial and motivational themes identified as being unique to each category and that serve to illuminate both end points of what can best be described as a diabetes and regime management continuum. The additional chapters aim to develop a theoretical explanation on how and why participants move from the characteristics identified within the difficulties with self-management category to those represented within the successful self-management category. Chapter 2 describes the presence of specific stages that were considered salient in contextualising change within participants. Chapter 3 explains the particular characteristics of both psychological and behavioural process mechanisms that exist to best describe how participants understand their diabetes, and how these mechanisms operate within the stages to move towards a more accepting and positive diabetes regime. Within Chapter 4 a case study is used to highlight the application of stage and process mechanisms and how they relate to change in the context of the identified self-management categories. Chapter 5 applies stage and process
mechanisms to the adaption model in order to describe movement and change within the diabetes management continuum.

Epistemological Reflexivity

One of the initial issues when considering how young people with type 1 diabetes construct their realities of having diabetes and managing their regimes was how to identify and conceptualise their experiences. What became evident from the interviews was that to group participants together specifically on the basis of a medicalised term such as adherence (namely whether participants did or did not follow the recommended guidance for diabetes management) or based on biomedical data such as HbA1c levels over the last 12 months, would not have reflected any associated factors such as time of onset, age, psychosocial or environmental considerations. Therefore, in keeping with the principles of social constructionism, the following self-management categories reflect the perspectives of participants as defined by the category descriptions, rather than a pre-disposed allocation to a specific group based solely upon biomedical data to define adherent status. Instead, successful and difficulties with self-management categories emerged as an overarching framework in which to describe the collective themes and characteristics associated with promoting and sustaining healthy diabetes care, in contrast to reduced levels of care.

Methodologically, by exploring and contrasting the themes of difficulties with self-management to successful self-management, this approach allowed for a greater level of contextualising in order to expand on the issue of process further on in the study. It was also helpful in order to create the framework for understanding various stages and processes located throughout the transition of self-management.

As the primary inclusion criteria for being interviewed by the researcher was that participants were aged between 13 and 17 years, attached to the Cornwall Diabetes Endocrine Centre (CDEC) within the Royal Cornwall Hospitals NHS Trust and had a diagnosis of type 1 diabetes, additional supporting demographic information is also included within this chapter to further describe aspects of participants’ diabetes history. This chapter aims to tentatively explore the distinction in psychological,
psychosocial and motivational characteristics that were noted between the difficulties with and successful self-management themes.

Successful Self-Management

In previous research the term compliance has been utilised as a framework for contextualising how adolescents manage their diabetes. Kyngäs & Hentinen (1995) identified four behavioural pattern-based categories, which they conceptualised as good compliance, imposed compliance, conscious non-compliance and non-compliance. While Kyngäs & Hentinen used compliance as their core category to distinguish meaning, what emerged from the current interviews were a distinct set of core categories which highlighted a number of themes specifically reflective of the attitudes, beliefs and values of participants. This chapter is interested in the successful self-management category which contained themes that promoted diabetes management. Successful self-management in this context is not fundamentally linked to a healthcare-based relationship such as the term adherence, rather it is more a representation of the motivational factors individually assigned to positive and productive self-management and of the orientation of the study, namely to understand the motivational factors among adolescents. It also reflects the researcher’s interpretation and construction of the most salient and distinctive characteristics to emerge from the interviews (Charmaz, 2006). In addition to the qualitative material used to define the themes, Table 8 represents a description of participants in the context of gender, age and biomedical diabetes history.

Table 8. Diabetes and Demographic Categories of Participants in the Successful Self-Management Category

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Gender</th>
<th>Age (current)</th>
<th>Age (at onset)</th>
<th>Duration of diabetes (years)</th>
<th>Average % HbA1c * (min-max) (last 12 months)</th>
<th>Clinic attendance ** (last 12 months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>P2</td>
<td>Female</td>
<td>13</td>
<td>10</td>
<td>3</td>
<td>9.2 (8.0-9.9)</td>
<td>6</td>
</tr>
<tr>
<td>P4</td>
<td>Male</td>
<td>16</td>
<td>15</td>
<td>1</td>
<td>8.1 (6.4-11.2)</td>
<td>5</td>
</tr>
<tr>
<td>P6</td>
<td>Female</td>
<td>16</td>
<td>7</td>
<td>9</td>
<td>8.6 (8.0-9.4)</td>
<td>3</td>
</tr>
<tr>
<td>P7</td>
<td>Male</td>
<td>15</td>
<td>12½</td>
<td>2½</td>
<td>8.4 (7.7-8.8)</td>
<td>5</td>
</tr>
<tr>
<td>P9</td>
<td>Male</td>
<td>14</td>
<td>12</td>
<td>2</td>
<td>8.1 (7.3-8.4)</td>
<td>5</td>
</tr>
<tr>
<td>P10</td>
<td>Female</td>
<td>14</td>
<td>9½</td>
<td>4½</td>
<td>8.5 (8.3-8.7)</td>
<td>3</td>
</tr>
</tbody>
</table>

* NICE guidelines for type 1 diabetes (2004) recommend - children and young people with type 1 diabetes and their families should be informed that the target for long-term glycaemic control is an HbA1c level of less than 7.5% (p. 18) / highest measurable reading is 14. ** NICE guidelines for type 1 diabetes (2004) recommend - children and young people with type 1 diabetes should be offered testing of their HbA1c levels two to four times per year (more frequent testing may be appropriate if there is concern about poor glycaemic control) (p. 18).
Taking Ownership

The term ownership is used by Hanna and Decker (2010) within their concept analysis of assuming responsibility for self-care. Ownership is considered the goal in assuming responsibility for self-care and reflects autonomy for behaviours and decision making. Within successful self-management there was a strong sense of taking ownership over having diabetes, individuals felt that they were in control and responsible for its maintenance, which had strong implications for how it was managed: “I’ve never really let it slip and stuff” (P6, p3). There was an awareness that diabetes could get out of control. Having a sense of ownership provided a way of ensuring that this did not happen and participants did not become overwhelmed: “like to be in control of my life rather than diabetes in control of me” (P7, p8). A good example of how control and ownership operate was noted in the following statement, when for P4 there was a change in diabetes readings: “they (READINGS) started to go a bit dodgy . . . I had to make sure they were better” (P4, p1). This highlights the awareness of a decline in readings which is then followed by ownership and responsibility of the result in an effort to return the status to improved readings; this was followed by an element of regret that this had happened: “I was getting lazy with it and I shouldn’t really of done that to be honest” (P4, p1), emphasising a sense of ownership and responsibility.

Following a discussion with a participant around the knowledge that age can have an impact upon how glucose levels respond to insulin, control and ownership acted as important factors for maintaining the regime: “I don’t really mind it’s part of the challenge really I, I’m not too worried about it cos there’s nothing I can do, so as long as I just keep it under control” (P10, p1). This allowed for the continuation of the regime in what otherwise may be perceived as a hopeless, self-defeating exercise, in which participants may not see the benefits of continuing with their regime. Ownership served as a way of taking control and responsibility for having diabetes, by constructing their diabetes within themselves there is a drive to promote it in a positive way.

Becoming Independent

Meldman (1987) reported that individuals described a level of self-satisfaction attained from their ability to manage their diabetes; this was also a reflection of the ability to judge physical need and make decisions regarding self-care. One of the
more common themes which participants described was becoming independent in terms of regime self-management. This could be seen in respect to administering injections and blood glucose monitoring: “I don’t rely on my mum and dad . . . with my readings and injections and stuff like that, totally independent on myself cos I just want to get used to that cos when in the future I’m not going to have them by my side so all the time so, I’d rather they get used to it” (P4, p7) This statement highlights the self-preserving nature of wanting to be able to manage one’s diabetes independently, yet also takes into consideration the feelings of parents, allowing them to feel comfortable in their child’s ability to manage their diabetes.

The following statement emphasises the additional ways in which independence is utilised in communications with healthcare professionals to maintain the regime: “I’m always like erm go to clinic, like I go in on my own and stuff now, and erm like I’m always on the phone to my nurse, like I’m the one talking to her and like she’s saying do this maybe like change this, so I’ve kind of hear a lot more about kind of how to make it better or how to sustain it” (P6, p2); this also represents a sense of belonging and involvement within the management process. Medication was the one feature of the regime process that was assigned to the parents: “there are things like ordering, ordering the actual medicines you need, which I don’t do, which I should really start doing and like take control of that” (P7, p9). This theme highlights the presence of becoming independent within the regime management process. It also supports the previous theme of taking ownership, where one can start to see independence intertwining with ownership to incorporate more successful self-management behaviours.

Perceived Difficulty in Managing Regime

While discussing how participants managed their diabetes regime, there was a sense that diabetes co-existed within their lives in a manageable way: “oh it’s fine . . . er when I first got my diabetes, my readings were really good, like for the months I had had it (DIABETES) they were really really good” (P4, p1) and “I’ve never really struggled with it” (P6, p7), which supports the acceptance of a co-existence and reduced difficulty in its maintenance. This has been noted in other studies with individuals contextualising diabetes as “one part of their lives” (Davidson, Penney, Muller & Grey, 2004, p. 76). The following statement reflects a pre-existing
representation and expectation of the difficulty associated with diabetes: “I didn’t really know much about what diabetes was like when I first got it erm but I thought it would be a lot worse than it was” (P9, p3). For this participant the expectation of difficulty had been overestimated and the reality of diabetes proved to be less concerning.

The level of commitment required and inconvenience of the regime were also reduced in favour of the increased benefits of good health: “Yeah, then your blood testing as well, yeah so overall it takes like a minute, like 5-10 minutes a day rather than years off your life if you have ill health whatever and I wouldn’t say . . . that much difference on your life” (P7, p10). In addition, managing the diabetes was not perceived as a compromise or debilitating factor upon lifestyle: “I wouldn’t say that erm diabetes has changed anything that I do really, cos I, I still do everything I did before I was diabetic, before I had diabetes” (P9, p3). Participants did not appear overwhelmed by their diabetes or its management, and as such this was reflected in their attitude. Psychologically, this served to reduce the level of difficulty for participants who seemed not to perceive it as a debilitating feature within their lives.

Prioritising Diabetes

In ensuring that the diabetes regime was given a significant level of importance to accommodate its management in a productive and positive manner, it was noted that participants held a commitment towards the prioritisation of their diabetes which ensured this was achieved. School is a major part within a young person’s life and accommodating the requirements of the regime into this environment can be challenging. Prioritising diabetes in a way that promotes improved diabetes outcomes indicates the intention towards improving the management status of their diabetes: “I know it’s important to get my studies done but it’s more important to look after myself” (P4, p1-2). From the initial diagnosis stage it was also noted that shifts in perspective impacted upon how diabetes was prioritised: “yeah, well even when I first got diagnosed I was thinking in the short-term I won’t be able to go, go out with my friends and play football and stuff but then since then I thought about actual adult life and thought well I’m not going to be able to drive, I’m not going to be able to go to university and people are just going to see me as a hindrance, rather than like everyone else and I thought well I’m not going to want to be left out” (P7, p8).
represents a strong link between perspective and the motivation to act and create behavioural change.

**Exposing Diabetes to Others**

La Greca, Bearman and Moore (2002) suggested that there was little research into how and when adolescents disclose their disease condition to friends and classmates. One study by Meldson (1987) described the major theme of *informing others* to explain how individuals with diabetes informed others of their condition. Features of this theme related to concerns about how and what to tell others, and that a consequence of lack of knowledge by others may have an impact in an emergency. Within this study the *exposing diabetes to others* theme emerged as an expression of the process and factors that surrounded making others aware that they had diabetes and what it entailed to manage it; it was also noted that diabetes could attract attention towards the participant. It was a major feature for participants, regardless of how they managed their regime. Those that successfully managed their regimes were able to add depth to this theme through being able to function around others, while some were also able to recall experiences when this theme was inhibiting and problematic within their lives.

The following statement represents a recollection of an interaction during blood glucose monitoring: “*everyone’s seen like seen me do a blood test and people might be like, why you doing that? kind of thing, er but because I’ve got diabetes and there like, oh OK and it’s just kind of they accept it as well cos, like they know about it kind of thing*” (P6, p5). This represents a basic awareness in others regarding the role of having diabetes and how the participant felt able to place themselves in the position of exposing their diabetes to them. For another participant the exposure attracted a positive curiosity: “*everyone finds it pretty cool to be honest...they like like to watch and stuff*” (P4, p2). It also served as a protective factor should difficulties arise: “*erm its fine, its like going out and that, it doesn’t really bother me, they all know what to do erm and they, its just taking 5 minutes before you’ve had a meal just to do an injection*” (P4, p4). Karlsson, Arman and Wikblad, (2008) suggested that peer acceptance and their willingness to adapt to the self-management requirements of diabetes reduced the feeling of being different for individuals with the diabetes. The

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key feature of these recollections highlights how participants have positioned themselves, as well as allowed their diabetes to be noticed by others.

For some the process of exposure was gradual and focussed around working through how they felt about having diabetes: “I went back to school (FOLLOWING DIAGNOSIS) people were asking me questions and I would not directly speak to them, I would just go, yeah I was a bit ill I had a stomach bug, I would make up reasons about it and then as I got older and thought oh there is no need to be ashamed of it” (P7, p6). When the feeling of being ashamed was expanded upon it related to the expectation that one would be viewed in a stigmatised way: “erm the stigma of like, of having diabetes attached like having a hypo and if you think, oh people are going to think you’re a bit weird having a fit” (P7, p1). There was the expectation that diabetes existed to others in a way that depicted the negative and humiliating aspects of the condition. The intention of concealing this part of one’s identity was to reduce the risk of this association occurring. Christian, D’Auria and Fox (1999) reported an increased desire for adolescents to disclose more information about their diabetes with friends in order to create a supportive environment. La Greca, Bearman and Moore (2002) noted that although youngsters with chronic conditions may not encounter more problems within peer relationships, children with medical conditions that are stigmatising may encounter peer difficulties.

For P2 the gradual process involved dealing with how other people might perceive her managing diabetes in public, and also highlighted the contrasting side of exposing diabetes to others in the form of hiding it away: “I don’t hide myself I do it like quietly and do it in my stomach . . . we were out with, at McDonalds once, cos like came back from holiday or something and this lady was staring at me and I just like blanked her and ignored her cos I just didn’t want like snidely remarks” (P2, p7). These instances describe not only the process of moving into a more accepting position with regards to having diabetes and managing the regime in public, they also reflect a motivation and intention to want to move towards a more adaptable position in order to manage their diabetes successfully in a variety of environments. Exposing diabetes to others may be affected by how competent individuals feel about responding to others, yet there is also evidence within these statements to suggest that this can be a gradual learned process, attained over time.
Achieving Success

Previous research has commented on the sense of accomplishment and pride that can be obtained from managing diabetes (Davidson, Penney, Muller & Grey, 2004). The achieving success theme represents how, when participants felt they were managing their diabetes, they experienced a feeling of satisfaction in getting good readings within their regime: “it’s good to know that your getting it right” (P4, p3). This also created a sense of achievement, and the feelings gained from this acted as a motivating factor for improving their performance: “in a way it’s a sense of achievement when you do think . . . had really good control over my results, have come back even better than last time” (P6, p2), as though providing a reward for the success of good control. Achieving in life was also an important attribute in which diabetes and its management played an important part in terms of attaining goals in the future: “obviously you want to get as far in life as you can, so I thought well, if I do this, or not don’t do it then I’m not going to go to university, I’m not going to do what I want to do and then I am just going to be disappointed with myself” (P7, p8). This statement also reflects the previous theme of taking ownership, and can be seen to place responsibility for management within the self, and how they construct diabetes in terms of its part in future achievements. This theme is supported by Delamater (2006), who also commented that individuals will adhere to their treatment regimes when they feel they have the ability to succeed.

Being Challenged

Successful self-management of their diabetes was considered in terms of a challenge, different instances created the opportunity for them to test and explore with the aim of achieving success, a characteristic that formed part of the motivating factors that ensured the regime was managed within differing environments: “it was interesting to see like what would change from their food (BEING ABROAD) to ours” (P4, p3). Even when glucose levels did not respond to insulin injections this was perceived as, “makes it more interesting” (P10, p1). Others seek out additional sources of information in order to ensure that regime management was effective: “well I seen on the internet that erm, the amount of, the amount of insulin you should take for the amount of carbohydrate and stuff” (P7, 1p), and “well yeah I know all the time I like if I didn’t know something then I learnt more about” (P9, p5) represents a drive to locate and understand issues relating to their diabetes.
Utilising Incentives to Promote Self-Care

The fear of complications was found to be connected to having sufficient energy and willpower to implement individuals’ health regimes (Hentinen & Kyngäs, 1996). Hentinen and Kyngäs suggested that fear of complications may strengthen self-discipline in situations where a neglect of self-care might normally occur. This threat also improved their motivation for self-care. The utilising incentives to promote self-care theme identified in this research highlights how participants’ awareness of the physical and psychological problems that can occur due to poor diabetes health care was acknowledged and acted upon, and as such became an incentive to sustain a state of healthy diabetes care: “I watched a show about a guy, er well not a guy, a kid that got diabetes and he just gave up on life and he got really fat and stuff like and it’s just I don’t really want to do that, I don’t really want to become that” (P4, p6). The experience of living with diabetes created the awareness that health was the prime factor that would be affected if the diabetes was not managed appropriately: “from the years of doing it I know . . . it will be my health that suffers, nothing else kind of thing” (P6, p6). This knowledge instilled in the participant the negative outcome of poor management.

Participants’ own goals acted as incentives to maintain their diabetes in a healthy way: “without like kind of controlling it well and without being on top of things like obviously I wouldn’t be able to like have the opportunity that I’ve got to kind of drive and stuff so that and like recently has been like a motivation” (P6, p6). More longer term goals were also regarded as incentives: “I know now like that I want to go to university, so I mean I’m going to have to keep my sugar well and do stuff with my friends and I will do like drive and if I don’t have good health and good sugar then erm, they are not going to let me drive then I wouldn’t be able to do those certain things which again is going to leave me out and, well not really normal compared to other people are” (P7, p7). The aforementioned statements reflect the issue of being different and left out because of diabetes. By maintaining a healthy level of self-management there is a reduction in the presence of impeding symptoms associated with diabetes that can impact upon activities such as driving.

Maturity and awareness of health prior to the onset of diabetes was also considered important for one participant, as it allowed for an understanding of the importance of
good diabetes management: “got diabetes when I think I was in year 8 at the school which I think was like 12 or 13 . . . so I’d been through normal, well non-diabetic life and then I, like I could understand more about the effects and how much it can do with my, erm my, adversely affect my health more than like people that contracted it earlier so then I knew what I had to do and what I didn’t do, if you understand to keep a good health” (P7, p3). There is a sense from his statement that with a later onset there is a greater awareness and acceptance of the impact diabetes can have on oneself, and that this can act as a comparable experience from which to focus on maintaining a healthy level of self-management.

**Momentum - Getting on with it**

Psychologically, having to regularly self-manage a diabetes regime can be a draining process. Momentum acted as a driving force to promote continuance of the regime: “some days you just can’t be arsed to do anything and it’s just like it happens and you just like . . . but you still do it” (P4, p7). This statement highlights the participant’s acceptance of those times when motivation is low and yet the regime still gets attended too rather than being neglected. Another representation of this theme describes how momentum operates in a fluid manner: “I just if I do any sports I check my blood and have snacks and I just go along with it, sort of just control it as it goes” (P10, p1). This allows self-management to operate in a more controlled way, reducing the possibility of becoming overwhelmed.

For one participant the “getting on with it” quality was noted from an early age: “I don’t know I think I got on with it pretty well (FROM DIAGNOSIS)” (P6, p4). Additionally, duration and experience of living with diabetes was considered an important factor in promoting acceptance and continuance of the regime: “obviously you’re not going to enjoy it and stuff but like I suppose as the longer you have it the more you accept like that it is important and you have to do it” (P6, p2). In addition, positive thinking was also considered an important part in promoting continuance: “think of like the positives that you can do and don’t think of like the negatives about really” (P9, p7). The momentum (getting on with it) theme acted as a psychological driver for moving through and promoting continuance of the regime.

**Summary**
These themes describe a distinctive set of psychological and psychosocial constructs which serve to promote and motivate participants so that they can live with and manage their diabetes in a productive and healthy manner. Within the literature it has also been suggested that adolescents with good stable metabolic control are characterised by lower levels of minor stressors that decrease over time, while those with stable or poor metabolic control experienced continuously higher levels of stress. The adolescents with good metabolic control also employed less avoidant coping in dealing with the minor stressors (Seiffge-Krenke & Stemmler, 2003). Within Meldman’s (1987) study of adolescents’ experiences of diabetes there is a focus on the developmental context, and the theme of independence was described. Individuals expressed self-satisfaction with their ability to manage the disease, with reference to the ability to make decisions about their self-care, having self-responsibility and being self-reliant. It is also noted that some of the aforementioned statements used to evidence the themes are interlinked with other themes, which serve to highlight their overall presence within the successful self-management category.

Kyngäs and Hentinen (1995) identified that individuals within the good compliance category for self-care took care of themselves and followed their health regimes regularly. They did so voluntarily, were proactive and took responsibility for their self-care. The successful self-management category identified similar themes. By taking ownership and positioning diabetes within the person, control and responsibility can be guided by participants; this in turn was expressed and supported by a strong sense of independence. There was a perceived reduction in the level of difficulty that diabetes posed, a reflection in part gained through the experience of successfully managing the regime, or indeed a mindset that allowed diabetes to be managed in a way that did not require much effort upon the part of the participants. The intention to consciously prioritise diabetes was contextualised within participants’ lives in such a way that it also promoted the condition. Effectively managing their diabetes in a range of environments meant participants were also more comfortable and able to do this, a feature that was either a gradual or an instant characteristic dependent on how the participant felt about receiving and dealing with the attention that diabetes can bring. Motivationally, experiencing success, being challenged and being able to identify different types of incentives also featured to promote diabetes management, which in turn assisted in the overall momentum that
allowed for the continuance of diabetes management. Karlsson, Arman and Wikblad (2008) also found that motivation was connected to success in blood glucose regulation and that self-management was related to achieving adequate blood glucose values.

**Difficulties with Self-Management**

Within this chapter the difficulties with self-management category contains a number of themes that emerged as a reflection of reduced levels of self-management towards diabetes. While the Kyngäs and Hentinen’s (1995) study conceptualised good compliance, imposed compliance, conscious non-compliance and non-compliance as categories, it is noted that the latter three represent deviations from compliance in adolescents’ self-care. Imposed compliance represents how adolescents felt self-care was forced upon them as opposed to being a voluntary activity based on their own will. The consciously non-compliant category describes a constant neglect of health regimes, where individuals experienced poor health, fears and indifference, lack of motivation to comply, as well as feeling the requirements of the regime were too demanding and tightly regimented. Finally, the non-compliance category refused to follow their regime, behaviour was perceived as freedom, and the authors reported that individuals’ friends controlled their lives.

For both consciously non-compliant and non-compliant categories, Kyngäs and Hentinen (1995) suggested that individuals should be provided with more support, while the individuals themselves felt that they did not get enough support from parents and healthcare staff, as they were only interested in blood glucose levels and not the individuals themselves. Delamater (2006) has stated that to improve patient adherence it is important to understand why non-adherence occurs, and that it is helpful to consider demographic, psychological and social factors, as well as healthcare provider, medical, disease and treatment-related factors. Delamater describes adherence in the context of “patients internalize treatment recommendations and then either adhere to these internal guidelines or do not adhere” (Delameter, 2006, p. 72). An alternative to this statement is that the themes in this chapter represent an opposing side to the successful self-management category and reflect a dichotomous position based on the researcher’s interpretation and construction of how the specific
themes relate to each other (Charmaz, 2006). The categories produce what can best be referred to as a diabetes management continuum, with successful and difficulties with self-management categories positioned at either end (see Chapter 5). Table 9 represents a description of participants in the context of gender, age and biomedical diabetes history. It contains not only those in the difficulty position, but also those that have moved into a more successful position from experiencing difficulties with their self-management, and describes their experiences.

Table 9. Diabetes and Demographic Categories of Participants in the Difficulties with Self-Management Category

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Gender</th>
<th>Age (current)</th>
<th>Age (at onset)</th>
<th>Duration of diabetes (years)</th>
<th>Average % HbA1c * (last 12 months)</th>
<th>Clinic attendance ** (last 12 months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>Female</td>
<td>14</td>
<td>2</td>
<td>12</td>
<td>10.6 (9.3-10.9)</td>
<td>6</td>
</tr>
<tr>
<td>P2</td>
<td>Female</td>
<td>13</td>
<td>10</td>
<td>3</td>
<td>9.2 (8.0-9.9)</td>
<td>6</td>
</tr>
<tr>
<td>P3</td>
<td>Male</td>
<td>15</td>
<td>14</td>
<td>1</td>
<td>9.5 (6.4-14.0)</td>
<td>5</td>
</tr>
<tr>
<td>P4</td>
<td>Male</td>
<td>16</td>
<td>15</td>
<td>1</td>
<td>8.1 (6.4-11.2)</td>
<td>5</td>
</tr>
<tr>
<td>P5</td>
<td>Female</td>
<td>16</td>
<td>3</td>
<td>13</td>
<td>11.3 (9.9-12.2)</td>
<td>4</td>
</tr>
<tr>
<td>P6</td>
<td>Female</td>
<td>16</td>
<td>7</td>
<td>9</td>
<td>8.6 (8.0-9.4)</td>
<td>3</td>
</tr>
<tr>
<td>P7</td>
<td>Male</td>
<td>15</td>
<td>12½</td>
<td>2½</td>
<td>8.4 (7.7-8.8)</td>
<td>5</td>
</tr>
<tr>
<td>P8</td>
<td>Female</td>
<td>15</td>
<td>6</td>
<td>9</td>
<td>10.6 (9.1-12.2)</td>
<td>7</td>
</tr>
<tr>
<td>P9</td>
<td>Male</td>
<td>14</td>
<td>12</td>
<td>2</td>
<td>8.1 (7.3-8.4)</td>
<td>5</td>
</tr>
</tbody>
</table>

* NICE guidelines for type 1 diabetes (2004) recommend - children and young people with type 1 diabetes and their families should be informed that the target for long-term glycaemic control is an HbA1c level of less than 7.5% (p. 18) / highest measurable reading is 14.  
** NICE guidelines for type 1 diabetes (2004) recommend - children and young people with type 1 diabetes should be offered testing of their HbA1c levels two to four times per year (more frequent testing may be appropriate if there is concern about poor glycaemic control) (p. 18).

Blood Glucose Monitoring – They are so Annoying!

A phenomenological approach to listening to 7-12 year old children with diabetes described finger pricking as one of the less pleasant and particularly disliked aspects of the condition (Miller, 1999). In addition, research investigating how adolescents cognitively appraise their diabetes, suggested that when individuals felt unable to alter their health status because their blood glucose was out of control, they responded by using avoidance or not checking their blood glucose levels (Bennett-Murphy, Thompson & Morris, 1997). Within the current interviews, key attitudes existed amongst participants regarding the issue of blood glucose monitoring (BM’s). Most participants were aware and able to make a judgement on the status of their blood glucose monitoring: “I’m OK (CHECKING BM’s), I wouldn’t say I’m the best” (P3, p3). This reflected an understanding of the expected procedure and frequency for blood glucose monitoring. With healthcare professionals’ awareness and focus on
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achieving specific blood glucose levels (NICE, 2004), participants may gauge their blood glucose status against these criteria.

Some of the factors that led to a reduced level of blood glucose monitoring were highlighted by the following participant: “I don’t like doing BM’s because there annoying . . . I just don’t cos they hurt . . . and I want to like want to get on . . . normally they’re not very good” (P1, p1 & 4). This statement describes issues such as annoyance, discomfort, time consuming and standard of reading. Additional features related to individuals’ intention: “I just don’t choose to do it (BM’s), erm, I don’t feel the need do” (P8, p1) or: “I just can’t be bothered basically” (P1, p4). These were all common attitudes that kept blood glucose monitoring below what was recommended and expected by healthcare professionals. In such a context there is inevitably a conflict between health professionals’ expectations and the intentions and motivations of participants with diabetes.

The value associated with blood glucose monitoring seemed to be one of the factors which affected why it was not utilised to its full potential in order to promote the effective regulation of blood glucose levels. There was almost a sense that it could be considered separate: “well kind of my diabetes I am (MANAGING) and stuff like that but everything else is, just don’t like doing BM’s, I do my injections because I feel ill but my BM’s are just can’t be bothered to do them at the minute” (P1, p6), as though it had a separate priority and was not considered an integral part of the diabetes management process.

In exploring some of the environmental factors associated with these attitudes and intentions, existing parental involvement, accommodating school and integrating diabetes around others were common themes that affected BM and insulin self-management. The following themes therefore serve to represent, and add a level of depth upon which to expand, how BM and insulin self-management is not maintained, in such a way as to promote and maintain participants’ diabetes in a healthy and productive manner.
Existing Parental Involvement

Family support was investigated by La Greca et al. (1995) and indicated that instrumental or tangible involvement, i.e. providing services or resources such as reminding, helping with tasks, occasionally doing tasks, mainly within the areas of insulin injections, blood glucose monitoring and meals, was the most prominent form of support utilised by adolescents. Within this study a level of parental involvement was notably interlinked with both BM and insulin-based behaviours; one element within this relationship showed dependency on the parent ensured that the regime was conducted: “my mum has to remind me most of the time . . . sometimes just if I’m out and ma mum she normally rings me or texts me to go home for tea and I just come in and sit down sometimes I just sit there and eat it and then go upstairs have my insulin injection then go straight back out” (P3, p1 & 4). In one case, due to a reduced ability to administer the injections independently, dependency extended beyond ensuring that the regime was conducted and took the form of assisting in the administration process: “not independent, cos half the time I cannot do me units myself cos my mum’s got to do them . . . cos every time when I do them, apparently I’m doing something wrong that makes me sugar levels go up high too much, so that’s half the time I don’t normally do them but then if I’m low I do them myself cos it pushes the sugar levels up” (P5, p5). Parents’ focus on BM’s also had an impact upon the motivational component of the regime: “I always have to do them (BM), my mum and dad always make me do them so I do as little as I can” (P1, p1). In this situation there is a reduced emphasis on the participant to conduct monitoring independently. These statements reflect discussions where the parent is perceived as having a distinct role and is actively involved within the regime management process. Davidson, Penney, Muller and Grey (2004) have commented that parents can become a source of stress when nagging, being overprotective, worrying, blaming or not providing enough tangible help with aspects of diabetes care.

Accommodating School

An integrative review of managing type 1 diabetes in school identified communication, after-school support, education of staff and peers, school nurse availability and lunch choices to be areas for further improvement (Tolbert, 2009). This theme considers the social and academic sub-themes that affected participants’ diabetes regime while at school. Due to the requirements of the regime and the
structure of the school environment there could be competing priorities for time: “I wasn’t hungry and I wanted to go out and see my friends so like I missed my dinner, missed my lunch just so I could go see my friends and go outside for a bit” (P1, p2). This statement describes how following the administration of an insulin injection, a decision then existed as to whether to have lunch or spend the remaining time socially with friends. This type of prioritisation may also be academically driven: “sometimes at school I do do my injections after I’ve ate lunch, just because I’ve just been caught up with the work and I don’t want to fall behind on it” (P4, p5). Alongside managing the regular daily requirements of the regime, diabetes could also impact academically, due to time spent in hospital: “I’m in and out (HOSPITAL) like a yoyo sometimes . . . when I was young I was in hospital for quite a long time and I’ve missed hell of a load in school, that’s way I’m going college cos I need to catch up on my Maths and my English, just doing all the stuff or whatever again cos I missed it when I was young” (P5, p1). These statements highlight the difficulty in managing competing demands associated with diabetes and its management within a structured and busy environment such as school. This was summed up by one participant: “sometimes it’s difficult to do them (BM’s), cos if I’m in a lesson and like it’s before lunch, and like everyone running about and like stressing and I suddenly like just eat a bit and like oh no I forgot to do my sugars” (P2, p3).

**Integrating Diabetes around Others**

The impact diabetes had on relationships created stress when friends became overprotective, asked intrusive questions or attracted unwanted attention to an individual’s diabetes (Davidson, Penney, Muller & Grey, 2004). Recent research has highlighted that social anxiety can interfere with behavioural adherence and quality of life among adolescents with type 1 diabetes (Di Battista, Hart, Greco & Gloizer, 2009). Huus and Enskär (2007) also noted that adolescents felt embarrassed using diabetes-related equipment that could help in their treatment; even though they knew it may make them feel better, they might choose not to use it as they did not want to feel different. For some participants having diabetes and managing their regime was difficult in a social context. The attention that managing diabetes brought was uncomfortable, and as such they chose not to inject or monitor blood around others: “it’s embarrassing, like when some people say you have to take injections and stuff” (P1, p4). There was also evidence to suggest that these anxieties could, in part, be
created by assuming the responses of others and how they may perceive diabetes: “I don’t want them to like, look look at me like I’m a bit strange cos I’ve had a fit or, or and then then they don’t understand why and they just see me, see me as a bit weird” (P7, p2). These beliefs represent aspects of overgeneralising and catastrophised thinking, which acted to reduce the likelihood of this participant exposing others to the knowledge that he had diabetes, concerned that the response received would be negative.

There was also an element of anxiety attached to being around individuals that did not have diabetes and being involved in activities or behaviours that conflicted or impacted upon aspects of the diabetes regime: “when you like go out with your friends and they’re all there just like eating like or doing what they do and your like, you’ve got that extra worry, like you know that your going to do it (EATING) but you know that your not supposed to do it but it’s the fact that you know that it is going to affect it and your going to, your going to have a downside to it, so it’s always there in the back of your mind, like knowing that you shouldn’t do it cos it’s gonna affect you differently” (P9, p2). This type of thinking represents an instance where there are two competing thoughts: “I want to do what my friends are doing” and “if I do what my friends are doing, it will negatively impact upon my diabetes”, known as cognitive dissonance. Being around individuals who did not have diabetes also highlights the issue of difference, and therefore the concept of being different also has to be understood and incorporated within both oneself and socially around others. A number of similar beliefs were identified within Meldman’s (1987) study through the informing others theme, here others’ lack of knowledge regarding diabetes was considered a risk factor in case any difficulties arose. Concern about how and what to tell others, as well as being different and identified as “freaks” or “weird” were also noted. La Greca et al. (1995) also commented that those who felt uncomfortable telling friends about their diabetes or with limited friendships may miss a significant source of support (Hans, Berlin, Davies, Parton, & Alemzadah, 2006).

**In the Future**

One of the questions asked of participants who did not follow their regimes was regarding their thoughts on the duration and stability of their difficulties with self-management. The responses focussed around a future period in their lives: “probably
be easier like not at school and as I get older really . . . I don’t know probably like learn to understand it more and like mature a bit more like to look after myself a bit better” (P1, p6) Although in one case the time scale was not clear, the intention was still present: “I’m gonna deal with my blood sugars I’m always going to do them it’s just sometimes I forget” (P3, p4). The construct of being adolescent also played an important role in contextualising the issues surrounding difficulties with self-management: “I’ll mature and you will stop going to parties all the time and you’ll start like living independently and find like getting your diet right and eating healthily and stuff, exercising more and stuff right now it’s just the teenage years where you want to have fun but you’ve still got to look after it” (P8, p6). This represents a clear understanding of the location of diabetes within this participant’s time of life. Reliance upon parents was also indicated as a future factor associated with regime management: “well I’ll need to . . . when I like haven’t got mum or dad or anything I don’t know I’m just going to have to do learn to do it on my own” (P1, p8). The in the future theme signifies key features impacting upon the direction of participants’ regime management and relates to the impact of school, the developmental and social aspects of being adolescent and the process of becoming more mature. Reassuringly, following a 10-year follow-up of young adults with type 1 diabetes, with the exception of lower self-esteem, the type 1 diabetes group appeared to be psychologically well adjusted in comparison to the young adults without a chronic illness (Jacobson et al., 1997).

Summary
Within the difficulties with self-management category, participants’ blood glucose monitoring and the integration of diabetes into school and social environments were considered major themes. This perspective is shared by Wentworth, Hoekstra and Devries (2007), who stated that “self-control measurements are mostly painful and bothersome” (p. 399). Research has also demonstrated that adolescents with negative attributions regarding expected friends’ reactions to their self-care are more likely to anticipate adherence difficulties, and that these anticipated difficulties are also associated with increased diabetes-related stress, which was also related to poorer metabolic control (Hans et al., 2006). Huus and Enskår (2007) described how adolescents compared themselves to their friends and how this is analogous to a pendulum swinging between being normal and different. Miller (1999) also noted that
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differences were accentuated between individuals with diabetes and their friends. These findings correspond with and highlight the impact of social and environmental factors, which can be important factors in how individuals construct their diabetes management and the developmental aspects of their self.

It was also noted that parents were perceived to have specific roles and levels of input for the management of diabetes tasks. Berg et al. (2008) refers to Miller-Johnson et al. (1994) and Skinner, John and Hampson (2000) to highlight that children and adolescents benefit from supportive and accepting parent-child relationships, while Vesco et al. (2010) notes the importance of responsibility-sharing between adolescents with type 1 diabetes and their caregivers. The findings from this investigation suggested an element of dependency within parental relationships. Berg et al. (2008) has discussed the role of parental monitoring as a factor within the parent-child relationship and contextualised parental involvement and parental monitoring as unique characteristics. Adolescents may have low parental task involvement due to high levels of independence yet could have high parental monitoring, whereby the parent actively monitors their successful independent actions. This suggests that although parents can provide a level of support and monitoring within the parent-child relationship, there still exists a place within the individual’s self-construct to want to develop an autonomous component to their diabetes management. In relation to the findings of La Greca et al. (1995), the existing parental involvement theme highlights a number of similarities associated with parental involvement, such as reminding of and assisting with diabetes-related tasks. Within the difficulties with self-management category, parental support seemed to be present, yet operated and was perceived by the individual to exist alongside a reduced level of autonomy, motivation or volition.

There was also the awareness that diabetes was not being managed as it could be and the intention to improve upon this in later life. Karlsson, Arman and Wikblad (2008) noted that teenagers felt self-management became complicated with fluctuating blood glucose levels that occurred without explanation and became difficult to control. This lack of control created frustration and hopelessness, which had the effect of reducing motivation towards self-care. Meldman (1987) was struck by the levels of ambivalence to self-management when exploring the perspectives of adolescents with
type 1 diabetes; guilt about their lack of control and a level of self-blame for not taking appropriate care of themselves were also identified.

This chapter forms a way of describing some of the key themes which affect how participants relate to and perceive diabetes and its management. It provides for the generation of two distinct categories of themes with which to understand how participants deal with and socially construct their diabetes, at both ends of the diabetes management continuum. The following chapters will start to explain the integration and process of adaption, to expand on the movement from a position of having difficulties with self-management to one of successful self-management and acceptance of the condition.
CHAPTER 2

Stage

The aim of this chapter is to present a number of specific stages that were created in order to represent a broad framework for describing the process of adaption. Due to the multidimensional way in which type 1 diabetes can be located within individuals’ lives, the term adaption refers to either a total or partial form of acceptance for both the condition itself or what it means to have diabetes. It also relates to the various elements of the diabetes management regime (insulin injections, blood glucose monitoring, exercise and diet). Previous research has investigated the psychological functioning of children with type 1 diabetes in the context of duration and suggested the implications of having diabetes were upsetting, and as such the regime became more difficult to manage with time (Kovacs et al., 1990). Additional research which proposed a stage-based model, suggested a period of initial practical coping, which was followed by rejection of the diabetes that lasted between 1 and 5 years, timid acceptance and then adaptive acceptance (Gardiner, 1997).

The stages represent conceptual categories that emerged to explain and accommodate participants’ perceptions and experiences of having diabetes. Analytically, they serve not only to explain participants’ perceptions, they also provide a framework in which to inform and match the emotional and psychological considerations that can impact upon motivation. This approach allows for life events, beliefs, values and attitudes to be contextualised alongside the reality of managing a diabetes regime. It also promotes the integration of diabetes into the participants’ life which is person-centred, in contrast to singularly focussing on one aspect of the regime, notably blood glucose levels (Delamater, 2006; Kyngäs & Hentinen, 1995).

Impact - Impact of Diabetes at Onset

Previous research using a qualitative methodology explored children’s beliefs about the impact of their diabetes upon parents, siblings and friends, and suggested that children and adolescents believed their diabetes had an impact upon family and friends. A significant minority of children perceived parents as feeling anxious, which sometimes caused them to feel anxious as well. Parents, siblings and friends were also found to be key providers of social support (Povey, Hallas, White, Clarke & Samuel,
Miller (1999) described a finding out theme around the point of diagnosis and highlighted disbelief, confusion, sadness and relief as elements of this time. For this piece of research the impact stage reflects the initial response period and how it is understood around the time of diagnosis by the participant. It also describes the way in which the diagnosis and diabetes were perceived in the context of cognitive and emotional factors. Gaudieri, Chenm, Greer and Holmes (2008) found that for children with type 1 diabetes, cognitive effects are most pronounced and pervasive with early-onset diabetes. It also, certainly in the context of self-esteem, describes the factors that extend from the onset of the condition, to represent the way in which diabetes can continue to impact upon self-esteem beyond diagnosis.

Impact at Onset

Participants that were diagnosed at a very early age had no recollection of their diagnosis: “I don’t know...... my mum knows more about that” (aged 3 at onset) (P5, p4), and as such, having diabetes could be seen to form part of their self-identity: “I don’t really know, because I can’t remember when I didn’t have it, cos I was so little, so it’s normal for me really, so I don’t have nothing to compare it with really . . . I can’t imagine my life without being diabetic” (aged 2 at onset) (P1, p1). As age increased, participants had greater recollection of being diagnosed, there was also an element of the diagnosis not impacting upon them, which allowed for a greater acceptance of the condition: “I don’t know cos I was quite young you think you’d be like, oh no but cos I was young for some reason it didn’t really bother me that much, like I just really got on with it” (aged 6 at onset) (P8, p3).

Indeed, although there seemed to be an increase in recollections with age, there were variations. For one participant diabetes formed part of their self-identity, with diagnosis being made at age 7: “I’ve always, like obviously at the start cos I was just 7 and things but it’s kind of like, you don’t really remember, like I can’t remember not having it kind of thing, cos it’s like, yeah I cannot remember not having to do it, so it’s kind of that’s just like nature to me” (P6, p7). This suggested a lack of comparative life experience against which to contextualise diabetes in future years, and therefore no sense of loss or mourning of a non-diabetic self or life prior to diabetes was felt.
Within the later stages of childhood and into adolescence the diagnosis came as a shock for some and was exacerbated by the permanence of the condition: “it was a big shock at first, I thought, well I thought it was like a cold or something what would like just go away and then I realised after months it would definitely like an illness that was going to be with me for life” (aged 10 at onset) (P2, p2). This also suggests that there may be a hope that it is not diabetes and that, like a cold, it would pass: “just thinking about having to take injections and come home all the time” (P3, p1), and the life-threatening potential of having diabetes: “it can kill you can’t it” (aged 14 at onset) (P3, p1). Others were upset by the diagnosis: “I was pretty gutted to be honest, just because erm, just the age you are its just not one of the things you want to go around with to be honest” (aged 15 at onset) (P4, p4). Where a parental family member had a diagnosis of diabetes this only acted as a partial buffer to the reality of it: “well my dad has got diabetes so I thought, to start off with, oh it’ll be alright but then I actually learnt more about it and that’s it for me for the rest of my life and how it could actually affect me and then I got a bit upset about it” (aged 12 at onset) (P7, p5). While for those that didn’t know anything about diabetes, the diagnosis did not concern them: “I didn’t know anything about diabetes, I’d never heard of it so I just had to have like a lot of help from my mum but I wasn’t really worried cos I didn’t understand what it really meant” (aged 10 at onset) (P10, p2).

**Self-Esteem at Onset**

Self-esteem was a theme that also seemed to have an age-related component to it, possibly due to the associated developmental factors regarding being diagnosed at such an early age and not being able to recall this period. The diagnosis did not affect everyone, and indeed some reported no recollection regarding their self-esteem. For those that did recall a noticeable effect, duration varied according to participants. Nonetheless there did appear to be common themes that underlined participants’ emotional and psychological perceptions of diabetes around this time, which may have impacted upon their self-esteem. One such theme was the way in which others might perceive participants having diabetes: “it had a big impact at first, cos like one I thought my friends would think I’m a freak like taking my injections” (aged 10 at onset) (P2, p7). Others were more concerned with the requirements of the regime: “it did at first (IMPACT ON SELF-ESTEEM) but know I don’t think it does . . . just for
the first 4 months maybe, it’s just thinking about how much exercise it would be a lot harder but it’s not” (aged 14 at onset) (P3, p2). This represented the expectation that integrating the requirements of the regime into one’s life would be difficult. While for some, there was an element of not wanting to discuss and explain their diabetes to others: “well as I say about, about half a year (IMPACT ON SELF-ESTEEM) I suppose because I was just thinking if people ask me it’s just annoying people asking me why I was always going to the toilet drinking loads and stuff” (aged 12 at onset) (P7, p6). It was also noted that causation of the disease was also questioned around the time of diagnosis: “like kind of why I had it (DIABETES) and stuff, like if what was wrong with me and things” (P6, p4). The phrase “what was wrong” suggests the notion that something is broken or faulty.

Summary
Previous findings have demonstrated the emotional resiliency of families during the first year of the onset of diabetes (Kovacs et al., 1985). They also indicate that in school-aged children the onset of diagnosis created minimal emotional upheaval (Kovacs, Brent, Steinberg, Paulauskas & Reid, 1986). The evidence from the participants was that age was a factor which related to the level of recall around the time of diagnosis, with younger children having no or little recollection of this moment in their lives. There was also evidence to suggest that acceptance of the diagnosis and the integration of diabetes within participants’ self-identity was also influenced by age, with younger children taking on the diagnosis in a more accepting way. Certainly within early childhood there was no evidence to suggest a recollection or sense of loss for a non-diabetic self. Towards later childhood and adolescence the diagnosis came as a shock, and for some was upsetting. Participants spoke about the perceived reality of having diabetes and the permanence of the condition.

Self-esteem could also be seen to be connected to the onset of diabetes; being concerned that you will be perceived in a negative way by others, thinking that the regime is going to be difficult to manage, not wanting others to know about your diabetes and questioning yourself in respect to causality can be a draining process both emotionally and psychologically. These factors represent some of the features that explain how self-esteem can be affected at the impact stage. They describe the
context of time scales and the far-reaching way in which self-esteem can continue to be affected beyond the initial diagnosis period.

Reflexivity

Initially, within the first few interviews I thought there may be a relationship between impact at diagnosis and future self-management or diabetes acceptance. For example if participants accepted the condition at onset they would move towards a more productive self-management position. Within the Kovacs et al. (1990) study, researchers found that child’s age at onset did not appear to influence their adjustment over the subsequent 6 years. A later study supported these findings, that at 12, 24 and 36-month periods after diagnosis, age at diagnosis and gender had no significant effect upon glycaemic status (Hochhauser, Rapaport, Shemesh, Schmeidler & Chemtob, 2008). While conducting more interviews I gathered a greater level of evidence through the way language was being used, and considered that impact at diagnosis would be more suited as a stage within the adaption process, rather than a standalone indicator of self-management. For example P9’s comment in a question relating to loss in having diabetes: “yeah because I do everything the same as what I used to do I still play football (yeah), go fishing (yeah), play a bit of cricket (yeah) well everything”.

This statement was insightful, as it is based on P9’s experience of having diabetes, namely what has been learnt, i.e. P9 has learnt that he can “do everything the same”. This supports the presence of a process approach towards understanding adaption, rather than a cause-and-effect relationship, i.e. if you accept diabetes at the onset you will follow your treatment regime. This helped to consolidate the direction of a process-based approach to self-management, starting at the impact stage. This was also noted by Kovac et al. (1990), who found that duration of the illness to be more salient than age of onset.

Turning Point – Time of Change for Behaviour and Beliefs

Between the impact and turning point stage, a number of processes were utilised to create change, and these will be discussed within the following process mechanism chapter. It is the intention of this chapter to focus upon the key stages that support the change process. The turning point stage reflects an improvement in participants’
diabetes self-management, subsequently leading to a change in their psychological and/or behavioural features, which impacts upon how diabetes management is attended too. It is a pivotal time in their diabetes management process, as it signifies a motivational shift towards a more productive set of attitudes and behaviours.

Within the literature, Rasmussen, O’Connell, Dunning and Cox (2007) described transitional processes and turning points within a group of young women with type 1 diabetes, aged 20-36 years, who had lived with diabetes between 4 and 28 years. They referred to Clausen (1995), who defined a turning point as “an event that results in a fundamental shift in the meaning, purpose or direction of a person’s life and must include a self-reflective awareness of or insight into the significance of the change” (p. 300). In the context of adolescence, Kyngäs and Barlow (1995) reported a fear not only about hypoglycaemia, but also about future complications that may develop later on in their lives, and suggested that it may be relevant to explore this fear in greater depth in future research. One such implication of this fear is how and when individuals choose to respond to it and whether it can create behavioural and psychological change for the individual. Christian, D’Auria and Fox (1999) commented that adolescents recalled a turning point in their lives in which they wanted to learn more about their diabetes. The following discourse represents interviews from both participants that had moved into a more psychological and behaviourally productive position, as well as those that were working through this stage, therefore representing a clearer understanding of the change process and the motivational factors associated with it.

Speaking with P7 and P12 created an opportunity to develop an understanding of the processes involved in moving into a more productive position and to expand on the theme of a turning point. P7 had moved through and experienced a turning point following a period of illness and recalled: “I had a 2-day period where my sugar was really high, and I felt really bad and erm it, my sugar wouldn’t actually go down, and I thought, oh I’m not going to do this again, cos I felt really ill. So then . . . I was doing like my injection more, and then I understood, that, if I keep on doing it my sugars going to be really high all the time and I’m going to become ill, and, if I’m gonna like, well not do well in life but if I’m gonna lead a fulfilling life I suppose, I need to have good health otherwise it’s not going to happen, and you’re not going to
be able to drive or whatever, which I’d want to do” (P7, p7). The awareness of previous difficulties with self-management and the long-term implications of diabetes culminated to create a change towards a more productive level of regime management.

P12’s account provides a recent perspective of the transition process which occurred over a 2-month period: “from having, err some control over it a little bit of control to having good control over it probably took about erm about er 2 months I think” (P12, p 4), and was part of a more gradual process into a more productive and successful position: “not like immediate turning point but like erm gradually me actually acknowledging that I need to do something and then . . . acting upon it really” (P12, p4). This highlights both the psychological and behavioural factors involved in creating change and the importance of acknowledging the need for change, which was then followed by actual change. This was also accompanied by an interest in health and a motivation to want to respond to ill health in order to create change: “I think it was me becoming more interested in my health I think really it’s completely recent to be honest as in the last . . . 4 months probably, yeah yeah since I’ve been more interested in my health and actually managing it cos when its been making me feel bad erm I just want to do something about it so I don’t feel so bad basically” (P12, p4).

For P8 there was also a reiteration of the health concerns and gradual status of change which led to a turning point in improved self-management: “only recently, only like about 6 months I’ve come to like, I’m starting to like get my sugars down a lot more like realising that if don’t start looking after it, it is getting to the time now when it is going to effect me when I am older and I want to like healthy when I’m older” (P8, p4). This awareness followed a period of poor self-management “it was getting to the stage when all my meters were getting to high high like off the charts and I was like cannot carry on like this and then I was like I’ve just got to start looking after it and it takes a while but you get there eventually I’m still doing it” (P8, p6). This shift in attitude highlights how following this, there may still be a period of time before completely moving into a more consistently successful position, while learning to implement the additional behaviours such as increased blood glucose monitoring into daily life.
For the remaining instances in which change occurred, the evidence suggested change within specific aspects of the regime rather than an overall shift. For one participant having to do injections and not being able to attain a level of normality in blood glucose levels became too annoying at times and created feelings of being fed up, this could then be followed by times of not injecting insulin: “I don’t know, occasionally I just do it (DON’T TAKE INSULIN) and I feel awful because I haven’t taken the insulin” (P5, p7) and lead to having to attend hospital. It was the awareness and experience of going through this process that had altered the perception of periodically poor self-management towards insulin injections: “I’ve learnt not to do it again . . . I’m taking it more often know” (P5, p7). Similarly, following a period of not managing their insulin, it was the warning from health professionals that P3’s blood glucose levels were similar to those at his initial diagnosis that acted as a turning point to regain control of insulin injections: “scared me when she (DIABETES NURSE) said I was close to going into hospital again” (P3, p3).

Summary
Kyngäs and Hentinen (1995) suggested that fear of complications from diabetes acted as a powerful incentive in helping adolescents maintain their health regimes. Within this theme, the turning point represents the end stage of a previous period of reduced levels of diabetes maintenance. It can be considered as either the short-term or long-term process of considering and working through aspects of participants’ diabetes, and how they manage it within their lives. The mechanisms for this are discussed in greater detail within the following chapter on process. In considering the permanency of this stage, there was no evidence to inform on this feature, only to identify that the turning point represented the culmination of previous experience and that there was a strong sense that this was a time of change, grounded in participants’ own experiences of living with diabetes.

Reflexivity
In order to understand the diversity of how participants experienced a turning point within their lives, the aforementioned extracts (P7, P12) represent participants that have gone through the turning point stage in quite a major way. While for P8, having gone through a turning point, there was a distinct change in direction regarding the management of her diabetes she was aware that this may take time to implement. P3
and P5’s experiences further support the gradual nature of this stage and exemplify the differing contexts in which changes can occur, i.e. within the area of insulin injecting. As the researcher, it felt that highlighting these experiences provided a representative picture of how this category operated.

Acceptance - Accepting Diabetes
At the acceptance stage participants had come to terms with either all or some of their issues surrounding diabetes and its management; it was the start of a more positive attitude and a healthier management regime. While acceptance has been identified within the literature (Meldman, 1987; Miller, 1999), it has been suggested that individuals have adapted to their health regime when it becomes part of their lifestyle (Kyngäs & Hentinen, 1995). The process of gaining acceptance and working towards this position will be discussed in the following Process Mechanisms chapter, in order to expand and explain its validity within the context of coming to terms with having diabetes and its management.

There appeared to be no fixed, concrete rule similar to the impact stage. There was no evidence of timings or stages operating as indicators for future behaviours on how participants accepted their diabetes and its management in the form of a linear process. For example, if the condition was accepted at the diagnosis stage then it remained that way. What was more noticeable was the process and fluidity with which participants learned to integrate and adapt to their diabetes, both at a psychological and psychosocial level. These were the key features that defined the acceptance process and how it operated. For some it happened quickly, yet for others it was a gradual and changeable process. The acceptance theme describes participants’ experiences of moving from a position of non-acceptance to one of acceptance. It reflects the acknowledgement of this theme as a stage within the process of coming to terms with having diabetes and highlights a shift in both behavioural and psychological processes.

For P12, acceptance had come at the end of a long period of working through a number of issues, such as additional illness and dietary factors that affected blood glucose levels. The following statement sums up what acceptance meant for him: “erm cos, just accepting it is, has helped, basically so kept on with it done a lot of
thinking about it, erm, yeah just coming to a conclusion that I should, just accept other peoples points of view a bit more” (P12, p7). In particular, acceptance incorporated learning about and taking on board the advice and guidance of others, rather than operating in isolation and disregarding the offer of help.

While talking with P8, the process of learning through experience, as well as actively fighting diabetes, in the context of being a teenager was very clear: “erm, experience like everyone one have to go through that point like fighting it at first and then it will just get to that stage when one day you’ll be like, ar I do have it and I do want to have children when I am older and you and then you’ll realise that you can do things just as, the same as other people but you’ve just got to take that little bit of care and then, also there’s people in the world with much worse stuff than diabetes” (P8, p6). Following an acceptance of having diabetes, there is a re-conceptualisation of the severity and level of effort required to manage the condition. This was in-line with the process of distancing diabetes (which will be discussed in the following theme), in order to allow the diabetes to become psychologically more manageable. It was also observed that following the awareness of an increased risk to health also created a shift in ownership: “now I’ve like started to come to terms with, oh I’m going to have it so I might as well look after it or it’s just going to make it worse” (P8, p4). Finally, the process of fighting diabetes and the analogy of battle was used to summarise acceptance: “go with it (HAVING DIABETES) cos it’s always going to be there instead of fighting it and losing the battle” (P8, p4). This theme will be discussed in the next chapter.

The period before P7 was able to accept his diabetes consisted of learning about and understanding the requirements of the regime, in addition to allowing others the awareness that he had diabetes in a way and at a pace that he was comfortable with. Working through these factors and accepting diabetes ensured that the regime was able to be administered and managed in a more efficient and consistent manner: “I’ve come to terms, well not that I’ve come to terms with it but I, was understanding that I should have been coming to terms with it and realised what I should be doing and I was actually like carrying it out but it was getting better throughout that time but like I actually it was like being like a lot more strict after the 6 months” (P7, p7).
The aforementioned participants represent those that have moved from a position of non-acceptance to acceptance and currently represent utilising a number of features that will be discussed in greater detail in the Process Mechanisms chapter. Taking ownership of their diabetes and feeling able to manage it in a way that was not restricted by other people’s responses, namely exposing their diabetes to others, represents some of the previous characteristics highlighted in Chapter 1. These features collectively create a more versatile and adaptable capacity within participants in which to manage their diabetes. They also provide a very clear representation of a more empowered position, in which participants feel more in control. This is very much in contrast to the feelings of being out of control and unable to manage the demands of the regime, as well as bringing unwanted attention towards participants, which they found difficult to cope with.

**Distancing - When Diabetes Plays a Small Part in Life**

At the distancing stage diabetes had become integrated into participants’ lives. Miller (1999) described the term *absorption* to refer to when diabetes becomes part of the individual, so much so that the extra things that need to be conducted as part of having diabetes are not even noticed. The diabetes has been accepted and is not perceived as having a major negative impact upon emotional, cognitive or physical resources. It sits at the back of participants’ awareness and is managed in a successful, almost autonomous matter-of-fact way, to such an extent that participants can respond to other priorities within their lives while the diabetes is attended to in parallel. A similar set of features was noted by Kyngäs and Hentinen (1995), who observed that individuals with good compliance described the meaning of their diabetes and self-care as not creating a hindrance. They had flexibility, could vary their regime according to lifestyle and were able to fully participate in hobbies and with friends.

The overall perception of the management of diabetes was reduced in the context of its place within the participant’s life: “you don’t want them (OTHER PEOPLE WITH DIABETES) to go just get down on life because they’ve got diabetes because its not really that much of a bother” (P4, p8). This statement recognises the sense of impact diabetes can have on other individuals with diabetes, and contrasts this with the perspective of someone that is able to distance the impact of diabetes management on their lives.
The removed emphasis and psychological state that distancing can appear to reflect was highlighted in the following interaction with a healthcare professional when reference was made to the participant’s causal approach to managing their diabetes: “he’d (DOCTOR) always be like ar I think you er wear your diabetes on your shoulder you, its kind of not important but at the same time like nobody wants it to kind of take over everyone’s life cos he kind of sees it as central like you have to do this, and this is the most important thing and you have to keep concentrating on it and blaa blaa blaa and kind of doesn’t see this other like college work and stuff like that that you’ve got to cope with as well” (P6, p3). This statement highlights how P6’s distancing of diabetes was misattributed to being “not important”. It also describes how diabetes is perceived and constructed within this participant’s mind. Having previously discussed in Chapter 1 the level of prioritisation that individuals give to their diabetes, understanding the presence of distancing allows one to reconsider the context within this statement. In terms of distancing, diabetes is still given priority, yet when diabetes is being managed in a more autonomous manner it can be misconceived as “wear you’re diabetes on your shoulder”, and in this case the healthcare professional was perceived as not understanding the full breadth of how diabetes was being managed and failed to take into consideration that in fact it was being managed even at a difficult time, “doesn’t see this other like college work and stuff like that that you’ve got to cope with as well”. There were two features within distancing that served to promote its existence for participants, namely the presence of a routine and reducing the negative aspects of the diabetes at a cognitive level.

Routine
One of the structures that exists to support the action of distancing and reduce the energy required to remember to do the regime is a routine: “just getting into a routine helps a lot, like if you get into a routine it’s like day-to-day life it’s like tying a shoe lace you just get used to it so its just like do that, do that and then its done over and done with” (P4, p7). This also supports the presence of conducting the regime in an automatic manner. For this participant it was also noted that getting into a routine followed quite a short period from being diagnosed: “I would say a month or so just at the start you need to get used to it a bit more and then get into the routine” (P4, p7). Davidson, Penney, Muller and Grey (2004) found that individuals set up routines,
which acted as coping strategies to remember to carry out their regime. While the home environment supported a routine, being out of it caused an interruption to it.

The next statement expands on the utility of the routine in facilitating an existence that is normal: “it’s just there it’s part of the routine that you have, lot of people have different routines and if you keep it in check then, it’s going to be normal like everyone else and you can do what you want rather than, obviously not doing what you want and the diabetes in control of you” (P7, p10). Indeed when there is a change in routine, this could be more difficulty to manage: “sometimes it’s hard to keep up with it (INSULIN) especially in the holidays when your active” (P9, p4). This highlights the role of the routine in distancing the diabetes control in the participant’s life and describes how a change to the routine can impact upon this.

Cognitive Mechanisms
The cognitive processes associated with distancing can be described from the following interview with P7, in which the negative aspects of diabetes and its management are reduced within a number of areas, therefore representing the sense of distance. Routine - “I didn’t see it as that bad, I see it as a bit of like erm, just something, it's not, just a bit of a routine you have to go through, like just a bit of extra work” (P7, p2). Others’ perception of diabetes - “I don’t think people notice the diabetes rather than a thing like epilepsy and some people notice stuff like that or if you’ve got an allergy or even like people like tolerances to certain things, I think that’s a lot more noticeable than diabetes, so yeah” (P7, p1). Management - “I didn’t see it as that bad . . . some people have to have a pill and I just have to have a jab so that’s nothing different to just like having, OK if you always get headaches or something serious like that” (P7, p2). The process is in operation across a number of domains with the emphasis on distancing diabetes in order to promote its management.

Summary
The distancing theme provides a way of understanding diabetes which is not too overwhelming and draining upon participants’ resources. Two of the key components to this category incorporate the presence of a routine, which provides a structure in which to operate, and also a specific cognitive mechanism, which operates by
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reducing the significance of negative thinking regarding diabetes and its management. Together these psychological and structural factors allow the participant to reduce the difficulty in managing the regime, which in turn promotes healthier levels of adherence.

In considering the Stages chapter, the issue of proposed time scales as utilised by Gardiner (1997) was not considered to fit, on the basis that it may be considered too prescriptive to the experiences of participants and any future generalisability the model may offer. Gardiner concluded that the length of time the individual had diabetes was a significant factor within their stages model. It was suggested that those with less than a year’s history of having diabetes were likely to comply fully with practitioners and work hard to achieve stable blood glucose levels. Adolescents were found to be more likely to deny their diabetes, attend clinics infrequently and conceal their illness from their peers for 1-5 years of being diagnosed.

It is hoped that this chapter provides a deeper understanding of the psychological and behavioural characteristics attributable to each stage. While this investigation used a qualitative approach to define the stage characteristics, Gardiner predominantly utilised a questionnaire-based approach to define stages of acceptance which were described as practical coping, rejection, timid acceptance and adaptive acceptance.

This research was interested in gaining a deeper understanding of individuals’ beliefs and attitudes. It was felt that considering a quantitative, time-scaled approach to particular stages may contrast with the unique and person-centred approach the qualitative material represents. What this chapter, and indeed the adaption and self-management model, aims to provide is a more detailed structure with which to describe self-management, which is grounded in participants’ constructions of how they self-manage their diabetes and the process of adaption. In doing so it provides a qualitative context within which healthcare professionals and family members can understand in greater detail the self-management issues faced by adolescents.
CHAPTER 3

Process Mechanisms

This chapter discusses the identification of a number of conceptual themes that were utilised by participants in order to understand and explain the process of learning about their diabetes and its management. They are referred to as process mechanisms as they form the tools for moving within the stages previously described in Chapter 2. Adolescence provides a huge variety of experiences, changes and challenges that can create marked feelings of ambivalence, impulsiveness and mood swings, with a struggle to separate from parents and the need to be accepted by peers (Silverstein et al., 2005). The awareness of these process mechanisms provides a way of contextualising participants’ experiences in order to validate and support a person-centred perspective on how participants construct and interpret such experiences and associations within the stages framework.

Fighting Diabetes - Trying to be “Normal”

The fighting diabetes mechanism represents an active attempt to challenge the symptoms of diabetes and the requirements for its maintenance. One of the times this process could be seen was shortly after diagnosis. When onset was in childhood there could be a lack of understanding about the need and purpose of maintaining the regime, which was the experience for P6 (diagnosed at age 7): “and then I remember one time I just erm I was really hungry but my mum was like you’ve got to do your injection first and this was just a few months after I think and then erm I was like I’m not doing it, like I don’t see why I have to and everything” (P6, p4). Initially, P2 (diagnosed at age 10) was shocked by the diagnosis, which was then proceeded by anger and a refusal to follow her regime: “well at first I like, I started saying oh I’m not going to do my insulin and all of this but then I got told off, so I just thought well” (P2, p2). This was similar for P3 (diagnosed at age 14), which followed an initial period of successful self-management after being diagnosed: “we started to get the hang of it, it went real, real well and then, I had a thing where I just . . . stopped taking my insulin . . . I just got annoyed of it” (P3, p2). Annoyance was a key theme associated to managing the regime and is mentioned a great deal in conjunction with diabetes. P2, P3 and P6 exemplify an active attempt to challenge the requirements of the regime shortly after the diagnosis period. Prompted by a lack of understanding,
anger and the annoyance of conducting the regime, not only does the fighting diabetes mechanism represent a reflection of how the participants feel, it also acts as a way of exploring and checking out the reality and consequences of not adhering to treatment.

The teenage years were noted as a specific time within participants’ development that could impact upon how their diabetes was responded to: “like a couple of years ago like obviously when I first turned a teenager it was like, oh erm I just want to be normal so I won’t inject or I wouldn’t do normal blood tests and like just eat loads of sugar” (P8, p4). Just wanting to be normal was also a key theme for participants, and fighting diabetes was perceived as a way of aligning oneself with that position. Additionally, adolescence provided a greater level of freedom and change, this was experienced through wider social situations such as parties and drinking. All have an impact on the developing individual, which can create conflict between maintaining their diabetes and existing in an environment were the majority of people did not have diabetes. By fighting diabetes the effects could be unpleasant: “I was feeling grumpy all the time cos I was always high and I was just feeling ill and not good in myself it was always, cos I wasn’t doing it (REGIME) it was always in the back of my mind, like ar you should be doing it cos like affect you when you are older because I was fighting it, it was just bad” (P8, p4). This describes the physical and psychological battles located within the participant as they fought their diabetes. Additional psychological features related to the awareness that their diabetes was not being attended too as regularly as they considered it should be: “it’s kind of like nagging, like kind of knowing that you have to do it” (P8, p3).

In considering the maintaining factors surrounding high blood glucose levels, one participant that had lived with diabetes throughout his life expressed a level of fear and anxiety about reducing his blood glucose levels: “cos I feel more normal when I’m hyper . . . cos I’ve higher overall blood sugars, if my blood sugars are high at the time I feel more normal, but if my blood sugars are the normal (gesturing quotation marks) of such, the diabetic team’s normal, between 10 and 5 I feel quite odd, yeah when it gets to like 7 / 8 were it’s meant to be normal I feel quite, start to go hypo” (P13, p3). This highlights a clear understanding of and reluctance towards reducing overall blood glucose levels, leaving the participant in a paradoxical position: “in a way yes (TO WANTING TO REDUCE BLOOD GLUCOSE LEVELS) but in
another way no as I know if I get my blood sugars down I’m going to hypo a lot more” (P13, p6). This transition was one that P13 did not wish to experience, and evidence suggests that intensive diabetes treatments can increase severe hypoglycaemia (DCCT, 1994). This concern acted to maintain high blood glucose levels for fear of experiencing and existing within a more vulnerable, alternate state, and represents how the fear of hypoglycaemia can limit glycaemic and insulin management (Cryer, 2002; Di Battista, Hart, Greco & Gloizer, 2009).

Summary

The fighting diabetes mechanism serves as a way for participants to challenge the presence of diabetes, to experiment and test out reality in order to assess the limits and boundaries of this new part of their existence. There were strong psychosocial factors that impacted upon participants’ diabetes particularly around the time of adolescence (Kakleas, Kandyla, Karayianni & Karavanaki, 2009). Fighting diabetes reflects an aspect of still wanting to be normal and not different from other individuals. Maharaj, Daneman, Olmsted and Rodin (2004) refer to social acceptance being problematic for girls with diabetes, as it makes them feel different to their peers. They refer to (Thomas, Peterson & Goldstein, 1997) to note that vulnerable girls seeking social acceptance may conform to social pressures to engage in behaviours that impact upon their regimes. This research found the issue of difference located within both male and female participants. Kyngäs, Hentinen and Barlow (1998) refer to the difficulty of adolescents to feel part of a peer group when their lifestyle does not fit with that of their peer group, they may then neglect their health regime and self-care in favour of peer acceptance. Similar findings were noted by Kyngäs and Hentinen (1995), who described a non-compliance category, in which they stated that “their friends determined their life, in the sense that they wanted to live according to their friends’ lifestyle” (p. 734). All these aspects reflect a lack of acceptance of the disease, and at a time when there are a great number of competing demands upon participants’ resources, it is because of these factors that fighting diabetes forms such an important conceptual category in order to understand the motivational beliefs that participants may hold about having diabetes.
Body Regulator - Using the Body to Detect Diabetes Status

The theme to know one’s body identified by Huus and Enskär (2007), in their study of the lived experience of having diabetes, described how adolescents learned to know their own body since being diagnosed. Kyngäs and Hentinen (1995) noted that for young people with diabetes who were considered to represent good compliance, they liked to feel when their blood glucose level was either too low or too high rather than blood glucose monitoring. Within the interviews for the current investigation the body regulator refers to the use of the body for detecting physiological and psychological changes associated with diabetes. Within the interviews there were a number of references to using the body as a means of exploring, understanding and assessing diabetes status. The factors which drove participants to consider and utilise bodily physiology were predominantly associated with supporting existing medical devices, such as blood glucose meters, and in some cases, to some extent, replacing them.

For one participant blood glucose monitoring had become inconsistent and assessment had moved towards observing bodily sensation in order to gauge blood glucose status: “I guess I think like sometimes that I know what it’s like (BLOOD GLUCOSE), like I feel, I feel like I’m like I feel fine so my BM’s alright so I don’t need to do one (BLOOD GLUCOSE MONITORING) so I just take my injection and have an insulin and that’s it” (P1, p6). When exploring P1’s judgement on the effectiveness of this approach, it was also felt that the level of accuracy was questionable both in respect to the monitoring of blood glucose levels: “well I think I know (BLOOD GLUCOSE LEVEL) but normally I’m not right” (P1, p7) and also in terms of the reliability of the technique: “well I don’t really know (IF BLOOD GLUCOSE LEVEL IS ACCURATE) because I don’t, I might do a test like when I get home, so and if I’m high or low then, then I kind of know” (P1, p7). Within the context of a reduced commitment towards blood glucose monitoring, this approach offered only a basic way of monitoring diabetes status.

Participants were aware of the physiological and psychological responses to diabetes and how they related to regime management, as this could be quite noticeable through the body and mind: “when I’m high I’m really thirsty and like need to go to the toilet a lot and not hungry and very irritable and when I feel low I’m really like tired and, can’t like walk properly or anything” (P8, p1). The relationship between intellectual
performance and functioning was something that was evident and could be detected through differing levels of administered insulin: “I was 14 (INSULIN LEVEL) in the morning before I go to school and the next I started feeling shaky in lessons put the insulin down to 13 and I’ve noticed that I’ve been like on the ball and like haven’t had any hypos or anything so I’ve kept on that so far” (P2, p5). In this statement the participant was able to notice the relationship between bodily response and insulin levels and administer accordingly to regulate performance. Psychologically, going without insulin was perceived as having a noticeable impact upon mood: “when I like don’t have my injections and stuff I get like headaches and don’t feel very well and can’t concentrate and stuff, so it like sometimes affects my school work, school work and my moods” (P1, p2). This indicates a clear identification of the relationship between diabetes and psychological functioning.

For P4, newly diagnosed at age 15, there was a keenness to explore the impact diabetes had upon the body in order to differentiate between diabetic and non-diabetic bodily states: “like say I felt a bit low like like when you’re low you feel hungry and stuff like that and I’d test then but it wouldn’t always be because I was low, it would be sometimes just because I was hungry so I didn’t want to eat Glucotab or anything like that without testing so I’d test then” (P4, p5). This reflects a difficulty in misattributing diabetic and non-diabetic causality for someone that is newly diagnosed. In addition there was also an interest in experiencing bodily responses to high or low glucose levels: “I wanted to know what I felt like before erm (USING A MACHINE)” (P4, p5). This differentiation and observing of diabetes symptoms was something that P4 wanted to experience: “that helped me a lot, erm just with little subtle things, like when, what I find when my sugars are high, my veins normally erm come out a bit more and when I’m low erm, I get angry with my friends and stuff like that and I get really irritated, so just little things like that and that’s how my friends know like when I’m low or I’m high, just cos they know I get irritated easy and stuff like that” (P4, p5). Not only does this reflect the importance of being able to notice and respond to subtle cues, but it also emphasises the value of an experiential approach using the body as a regulator for self-learning, adapting and moving towards a greater acceptance of diabetes.
As with P4, P9 (aged 14), who had been diagnosed at age 12, also had an awareness of life before diabetes and was therefore able to compare bodily sensation pre-diabetes in order to gauge the presence of diabetes symptoms. This also provided a cue to perform further blood glucose monitoring: “I now if my blood sugar’s gone too low . . . I feel a bit I always feel a bit shaky sort of I don’t really know nothing that I’ve ever felt before I had diabetes” (P9, p6).

Summary
The way in which the body responds to diabetes was an aspect of having diabetes that was of interest to a number of participants, it provided a non-medicalised, less mechanical approach to detecting basic diabetes symptoms. It was felt that although there may have been a wish to be able to assess the status of blood glucose levels without having to formally conduct blood glucose monitoring, using this technique in isolation could be inaccurate, whereas observing bodily cues did act as a helpful indicator prior to monitoring blood glucose levels.

Trial and Error - Learning Through Experience
Silverstein et al (2005) refers to adolescents engaging in experimentation and risk-taking behaviours, some of which may impact adversely upon levels of self-care (Anderson, Brackett, Finkelstein & Laffel, 1997). While Christian, D’Auria and Fox (1999) stated that adolescents need to have the opportunity to validate choices, to practise complex decision making and to spend time away from family to practise new skills. The trial and error mechanism exemplifies the process of testing through acting, observing the outcome and amendment in order to attain one’s required goal. In the case of diabetes, it is the motive, intention and beliefs of the participant which shaped the orientation for which trial and error was utilised. For example, someone fighting diabetes may trial and error various blood glucose monitoring or insulin injecting combinations in order to test boundaries or assess the minimum requirements, with the aim of keeping themselves out of hospital. This was noted for one participant who was aware that there had been a gradual reduction in the amount of daily insulin injections taken: “well the funny thing is I’m meant to be on 4 (INJECTIONS) a day but I found myself doing alright on 1” (P13, p4). A later discussion on this single injection confirmed an attempt to test “my limits of how much” (P13, p8) and extend boundaries.
Being aware of the process of testing before and after eating via paired readings provided the knowledge of how to attain an understanding of blood glucose levels, the trial and error element allowed for experimenting with a variety of different foods in order to accurately calculate the correct amount of insulin to inject: “just making sure you do the right amount of units for what you’re eating, like say I eat a jacket potato I normally take about 14 units and like say I had, don’t know, erm spaghetti bolognaise, cos I have that sometimes at school, I take 16 units because I don’t know what it is, I think its just the bulk of the meal I have to take the more units, just to make sure I get the er readings correct” (P4, p3).

Rather than following the recommended guidance from professionals regarding the monitoring of blood glucose levels, being able to make informed decisions based on personal experiences was also important. Using the trial and error approach informed the decision making process: “they (PROFESSIONALS) just say to test, oh (INTERVIEWER - why, why didn’t you?) I just didn’t, like I said er before, when you’re not, you’re holding back on some of the treats and stuff like that you don’t you don’t really need to test as much, I did (BLOOD GLUCOSE MONITORING), when I first on the first couple of days but when I realised my readings were pretty good I would just test smaller and smaller amounts then I eventually just got to breakfast, lunch, dinner before bed and when I felt a bit iffy” (P4, p5). This represents the importance of self-learning for this participant. Similarly, this was found for assessing the correct units of insulin: “sometimes erm, I might take a bit more insulin than they (PROFESSIONALS) suggested because it, I’ve been taking what they’ve suggested but it, it hasn’t worked completely” (P9, p5). This highlights the ability to utilise this approach in order to manage the regime more effectively.

Socially attending parties where alcohol was available and learning about the impact it can have upon participants’ diabetes was a common factor for those predominantly within the adolescent age group. For a number of participants, alcohol was consumed under the legal limit, and as such they had no formal knowledge of how it impacted upon their diabetes: “like I remember obviously when you’re like starting going to parties and things and like you have the odd drink (ALCOHOLIC) then like, yeah, obviously like when your parents and stuff don’t know, then it like at the time I didn’t know it could erm affect you but then obviously like I had to learn that erm, that
alcohol can kind of bring your levels down afterwards and kind of what drinks, like Alcopops and stuff isn’t really like good to drink and things but I only got a proper talk on it when I turned 16” (P6, p6). The active process of implementing and learning from this mechanism serves to expand on the coping and learning skills participants have available to them, particularly when engaging in behaviour that may not be identified or acknowledged until a later time in their lives.

Summary
Trial and error can be seen throughout the regime management process, with participants testing and learning from their experiences in order to assess various relationships between diabetes and other factors within their lives. Funnell and Anderson (2004) promote the process of behavioural experiments in their philosophy of creating a more empowered relationship between healthcare professionals and service users. For participants, trial and error provided an approach to better understand the perimeters and boundaries of their condition; for some it helped to improve their regime levels and for others it served to test boundaries. The regime management process is an adaption process, and trial and error allows participants the autonomy to experiment with the way in which they want to integrate diabetes and its management into their lives.

Self-Learning - Experiential-Based Learning
Self-learning symbolises an awareness and acceptance that the fighting diabetes, body regulator and trial and error mechanisms serve to support and promote an overarching mechanism, which is learning through experience. This theme is supported by Hill-Briggs and Gemmell (2007), who define problem solving in diabetes self-management as a learned skill. Glasgow and Anderson (1999) have commented that “diabetes, including its self-management, belongs to the person with the illness” (p. 2091). It was one of the most prominent concepts throughout discussions with participants that existed to generate change and has been noted in other interview-based methodologies (Christian, D’Auria & Fox, 1999). It also highlights the importance and value of learning about diabetes and how to manage the regime in order to both attain and retain a sense of control and orientation around participants’ diabetes at a pace which was manageable for them. Karlsson, Arman and Wikblad (2008) also noted that “teenagers felt they were their own experts in making
decisions about self-management” (p. 568) and that “acquiring experiential knowledge is an essential process in building self-determination” (p. 568). Similarly, within the family structure there were very few instances of informational support (i.e. giving advice or information) reported by adolescents, and it was suggested that this type of support may not be perceived in a positive way (La Greca, et al., 1995).

The self-learning category started to come through in the interviews, and P12 exemplifies this process from the perspective of someone that had not been following the guidance of professionals and moved from the position of reduced self-management to one of successful self-management: “erm, emm that’s quite a tough thing actually cos the way I’ve done it er the the fall’s actually helped me to to take control of it (INTERVIEWER - the what has?) the falls, like falling down and er losing control and stuff like that has helped me to er manage it cos I know that I shouldn’t do what I did that day again” (P12, p8). In considering the presence of this mechanism, it was felt that this was similar to the process of trial and error, yet rather than focussing on the experimental factor in which the variable is tested and the outcome assessed then re-tried, self-learning is simply the process of learning through and alongside experience: “I think it is better to self-learn than to learn from someone else cos I think it’s a bit superficial when you learn from someone else a little bit” (P12, p8). This perspective was mirrored by Delamater (2006), who stated that the process of providing information to increase knowledge does not guarantee that behavioural change will follow.
CHAPTER 4

Case Study

After the identification of theoretical categories in the form of stages and process mechanisms, it was important to be able to describe them at an analytical level, how they function together, while contextualising them into the successful and difficulties with self-management categories identified in Chapter 1. It is the aim of this chapter to utilise statements from one of the interviews in the form of a case study, to highlight and provide a level of analytical support to the conceptual nature of the categories. By keeping with a constructivist approach, it is possible to describe the way in which the categories operate, providing a level of depth to how change is constructed from a position of reduced self-management to one of a more positive and healthier form of self-management.

Brief History

Participant 12 (P12) was male and had been diagnosed with type 1 diabetes at the age of 9. He was 16 years of age at the time of the interview, had an average HbA1c reading of 8.1% and had attended clinic five times (HbA1c and clinic attendance calculated in the last 12 months).

Reflexivity

One of the reasons for discussing this interview was due to the high level of insight P12 was able to provide. The level of reflection, in respect to the interaction between conceptual stage and process categories, was invaluable; it also described movement within the self-management continuum. The aim of utilising a case study approach rather than embedding statements into previous chapters was to utilise the interview to describe how process and stage interact, therefore providing a more fluid representation of the adaption process. By presenting statements in a sub-category frame, as they occurred through the interview, it is possible to emphasise categories and themes that relate to diabetes and its management.

Highlighting the impact stage, control, exposing diabetes to others and the process of how it can disable, then moving through that
The following statement was the response to a question regarding how P12 recalled being told about the management of diabetes, following his recent diagnosis: “erm, I think I thought it was quite daunting . . . and it troubled me what everyone else would think of me when I was doing like (MANAGING REGIME) yeah what everyone else would think like if I erm cos I think I think they (HEALTH PROFESSIONALS) put it to me that I’d have to do blood tests in class and stuff which I don’t think I ever did anyway cos I was just too worried about what everyone would do if I did, erm I can do that now its fine but at the time that was a really weird stage . . . I don’t like people focussing on me really” (12, p2). The attention that diabetes could attract from other people, both the condition and its management, for P12 was an uncomfortable position to be in. It highlighted the issue of being out of control, finding oneself in the position of having diabetes and required or requested to behave in a way that could potentially invoke the attentions of other people. Attention, being judged or thought about, describes how exposing diabetes to others can have a disabling effect upon carrying out the requirements of the regime, while trying to regain some level of control of the situation around the impact stage. The discourse then moved to the present and described how adaption had occurred in the context of managing the regime in the presence of others.

After the impact stage, ignoring, wanting to be normal, make diabetes go away, fighting diabetes, trial and error, body regulator, self learning

Following the initial impact stage there was a period of trying to ignore the diabetes: “sometimes I ignored it....almost entirely really except from the injections I’d always do my injections” (P12, p2). There was a strong psychological desire to be normal and make the diabetes go away. The following represents an attempt to assess whether this was possible: “I just wanted to feel normal I just wanted to somehow make the diabetes go away I’ve always wanted to do that and erm and the thing that I found that attracted me to do that was that I could just take extra insulin at tea time so I could eat sugar in the day but erm then I found out that that wasn’t good for me it was making me feel really unwell and not able to do the things I wanted to do” (P12, p3). This form of self-learning was significant, as it describes the consequences of this approach to managing the diabetes, yet it was important to P12 to explore this possibility. Amidst this time of ignoring and challenging or fighting diabetes, the body regulator became the primary form for assessing blood glucose levels: “I’d sort
of predict my levels without actually doing them erm cos I knew if I took a lot of sugar then they’d be high if I knew I didn’t take my sugar and do a lot of exercise then you’d be low and that’s just basically how I managed it for a while” (P12, p3).

No motivation to do BM’s
An aspect of diabetes management that was commonly referred to as annoying was blood glucose monitoring: “like er having having to well erm being asked to do something when I don’t see the point in it erm and it hurting my finger as well” (P12, p4). This attitude reflected a lack of awareness and acceptance regarding the purpose of regular blood glucose monitoring and as such deterred P12 from carrying out the test. It was considered of secondary importance to insulin, and therefore when it came to monitoring there was a level of trepidation associated to it: “I just manage it basically with my erm with my insulin and erm, yeah I was sort of erm fearing having to do blood tests cos I new they’d be bad and I didn’t want to see this large number of the erm the blood test screen cos that sort of scared me a bit how I was managing it” (P12, p4).

Regime difficulty, lack of control, futility, rewards
There were periods in which P12 made a concerted effort to maintain healthy blood glucose levels, yet the following statements describe how his intentions became diminished, leading to feeling that the regime was unmanageable: “I think I had like erm a few phases of of doing it well but then at at the time I found it too hard work to keep it under control when it wasn’t always under control so take quite drastic measures to keep it under control like with exercise and er forgetting the chocolate and stuff but erm still it wouldn’t always be under control erm and I wouldn’t know what to do about that erm so I guess quite recently when I managed to figure out my own insulin levels then I’ve been a lot more er happy with that” (P12, p5). In part these feelings of futility were expressed due to a lack of understanding of how to address and attain a level of control over the regime. This seems to resemble learned helplessness, in which the individual develops helplessness following repeated exposure to negative events over which they have no perception of control (see McLaughlin, Lefaivre & Cummings, 2010). Such futility was then accompanied by various negative thoughts that served to challenge the initial intention for regular monitoring: “erm it it made me feel like what’s the erm like what’s the point in erm in
like sacrificing my free time to manage it sacrificing my thoughts that should be on other things to manage my diabetes erm to still get no reward from it cos I’d never get any er good results really that really annoyed me” (P12, p5). By not experiencing rewards, the effort focussed around achieving this goal became demoralising and indeed, annoying. This statement reflects how the commitment towards maintaining healthy blood glucose levels deteriorated when efforts become unrewarded and failed to achieve the desired outcome (Du Pasquier-Fediaevsky, Chwalow, the PEDIAB Collaborative Group & Tubiana-Rufi, 2005; Du Pasquier-Fediaevsky & Tubiana-Rufi, 1999; Salerno et al., 1997).

I was keen to understand the motivational factors that surrounded and moved P12 from these feelings of futility and annoyance towards a more successful and self-motivating position. This was explained through a more active and effective participation within the insulin management process and was experienced through evidencing change between insulin management and blood glucose readings: “when I started to manage my own insulin I’d sort of bring it up and take it down and stuff and erm that would start to work on most occasions sometimes it wouldn’t when I have like low blood sugar I take a little bit too much . . . and just take less in the morning or evening erm and er so taking more insulin I wouldn’t have all these highs that I’d have before and em, yeah just just seeing a good number on the on the blood screens yeah a good feeling really” (P12, p5-6). The improved reading on the blood screen was able to act as an external reward, indicating that insulin management had been effective, this in turn produced a feeling of achievement.

Combination of things adding up, turning point, self-learning, prioritising, incentives

The following evidence provides an understanding of and describes the development and momentum of a turning point to be a gradual process incorporating a number of factors: “I think it was part of a turning point I think a few things added up and then erm and then erm yeah I decided to . . . taking more interest in my diet and er my appearance and erm my er erm blood sugars I guess” (P12, p7). It also describes how P12 had to work through these issues in order to get to the turning-point position of change, with self-learning being the key feature throughout this period, at a pace that was led by him. It was also possible to witness the theme of prioritising diabetes and how receiving “good numbers” acted as an incentive for maintaining the change: “I
Research

think yeah yeah I think my motivation before was erm was like to er I’d do a blood test and then do my insulin to erm be able to eat chocolate so my motivation at the time was chocolate and sweets and stuff and like erm its changed to erm my my er blood testing is to keep control of my diabetes to keep good numbers on the screen to erm to er keep my health in check really” (P12, p7). This paragraph highlights P12’s recollections of the movement into a more successful position, being able to articulate the factors surrounding the change process.

Independence, arrogance, self-learning, personality

The following statement describes how personality and intention interact with independence to provide an important mechanism for reinforcing self-learning: “I think I had independence before but I was just a bit ignorant a bit arrogant to it cos erm I felt I could do it in a way I wanted without actually doing it the right way cos I I didn’t really know the right way at the time . . . I I didn’t like being told that I didn’t know best by the diabetes nurses” (P12, p7). Other researchers have noted that teenagers felt that they were their own experts when it came to decisions about self-management (Karlsson, Arman & Wikblad, 2008). This describes a level of conflict between P12 and the professionals, which from P12’s perspective was driven by the arrogance that he could manage his diabetes independently without any help, regardless of effectiveness; the learning had to be driven from within.

Self-esteem, lack of control

For P12 one of the aspects that impacted upon self-esteem was a feeling of helplessness, that he could not control or manage his own body: “when I didn’t manage it (DIABETES) it affected it (SELF-ESTEEM) badly as erm I just found that I couldn’t control my own body and that’s quite a bad feeling really erm couldn’t control what I should be automatically doing erm was quite bad erm but yeah now I’ve got control of it I’ve accepted that it’s a hard thing to manage actually and to manage it is quite a boost” (P12, p7). Not being able to control one’s own body was seen to have a strong and profound impact upon self-esteem. This may explain the need to maintain a level of control in other aspects of the management process and why self-learning was so important in order to hold onto some part of the decision making process, in the form of actions or judgements on how to interact with the diabetes.
CHAPTER 5
Adaption Model

In previous chapters the emphasis has been on describing conceptual categories in depth and defining properties, in order to create boundaries and expand on the analytic content to support each category. The Stage and Process Mechanisms chapters provide the independent characteristics for the “at what point” (stage) and “how” (process mechanism) behaviours and psychological change criteria, which were identified by the researcher to represent the participants in this study. To highlight these characteristics, the case study in Chapter 4 describes the interaction and operation of stage and process mechanisms, not only as conceptual categories, but also as theoretical categories in which to explain change over time. This chapter aims to support and expand on the association between stage and process mechanisms by adding supporting evidence from participants’ perspectives with which to highlight the validity of an adaption model and the movement within it, therefore developing analytic and theoretical content and ensuring the model is grounded within the data.

A number of studies have considered investigating specific aspects regarding the change process. Kyngäs, Hentinen, Koivukangas and Ohinmaa’s (1996) compliance-based framework suggested four important indicators: self-care behaviour; collaboration with the physician; an active, responsible role taken by the patient; and the intention to take a part in their own self-care. The primary factors in determining compliance were motivation, experience of the results of treatment, a sense of normality and having energy and willpower to pursue the treatment (Hentinen & Kyngäs, 1996; Kyngäs, 1999). Christian, D’Auria and Fox (1999) explored the process of gaining responsibility and independence for diabetes self-care. They identified three themes: firstly, integrating diabetes into their lives; secondly, a readiness and willingness to become more involved in making decisions about their diabetes management; and thirdly, having a safety net of friends as a transitional support network other than the parental relationship. Christian et al. (1999) found that the process of independence “involved a gradual change in cognitive and emotional readiness to accept responsibility, level of peer knowledge and support and both factual and experiential knowledge regarding self-care management” (p. 258). Within the longitudinal research literature, one of the observations that Kovacs et al. (1990)
made was that with an increase in duration of diabetes, the implications of diabetes became more upsetting and management tasks were perceived as harder to perform.

While previous studies have focussed on aspects of process to determine how individuals manage their diabetes, the adaption model is underpinned by the principles of social constructionist thinking. In addition, the theoretical origins of the model are constructed in a constructivist learning theory, which explains the findings from this investigation by constructing a flexible adaption model in the form of non-prescriptive stage and heuristic-based process mechanisms. This contextualises the learning and experience-based features of how participants perceive and construct both their diabetes and its management.

Background
The adaption model was initially developed to contextualise the concepts emerging from the interviews. It developed from a figurative illustration of concepts to being considered a more valid approach to explain the process of movement from a position of reduced regime management to a more positive and healthier attitude towards regime management.

Within the early stages of the research, speaking to participants describing poor levels of self-management, it was unclear whether there was even any evidence to suggest an overarching model or progressive method in which to describe improved regime management. It was through further contact with participants who were able to recall difficulties with self-management and moving into a position of successful self-management that the comparative theoretical insights were generated. Earlier interviews were then reconsidered and evidence generated for specific stages and process mechanisms that would inform an adaption-based model within the research.

This model exists on the basis that the interviews captured a variety of participants experiencing diabetes in a range of ways, due to diabetes duration, lifestyle and capacity to manage both having diabetes and its regime requirements. A major component for making sense of this information was the constant comparative method (Glaser & Strauss, 1967). This approach allowed for participants to recall their experiences and for the research to consider the construction of various stages to
accommodate these experiences, in the context of behavioural change and improved regime management.

**Process**

Chapter 1 reflected themes that emerged to describe “successful self-management”. Participants who described productive regime management also held an attitude that promoted their diabetes. In contrast, the “difficulties with self-management” themes reflected a reduced level of diabetes self-management. These differing levels of self-management reflect the dynamic nature of the adaption process (Davidson, Penney, Muller & Grey, 2004). Both successful and difficulties with self-management categories sit at either end of what can best be described as a type 1 diabetes regime management continuum (see Figure 1). While the categories form dichotomous positions, the themes contained within them are applicable to a number of behaviours throughout the self-management process. Each category describes a number of themes that are intended to be descriptive, not prescriptive to each category, i.e. one does not require all the themes contained within the successful self-management category to reflect successful self-management. Due to the multidimensional nature of learning new behaviours and accepting diabetes into participants’ lives, it was essential that the continuum conveyed the fluid nature of this process. It is also important that the continuum reflects this multidimensional aspect of self-management, in terms of a single or variety of behaviours. For example, one may be challenged (*being challenged* theme) by carbohydrate counting, this theme may then lead to successful self-management for the carbohydrate-counting behaviour. It is important to note that participants moved backwards and forwards within the continuum while learning and experiencing new situations.

**Figure 1. Type 1 Diabetes Regime Management Continuum**

<table>
<thead>
<tr>
<th>Difficulties with Self-management</th>
<th>Successful Self-management</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Difficulties Themes</strong></td>
<td><strong>Successful Themes</strong></td>
</tr>
<tr>
<td>Blood Glucose Monitoring – They are so Annoying!, Existing Parental Involvement, Accommodating School, Integrating Diabetes around Others, In the Future</td>
<td>Taking Ownership, Becoming Independent, Perceived Difficulty, Prioritising, Exposing Diabetes to Others, Achieving Success, Being Challenged, Utilising Incentives to Promote Self-Care, Momentum - Getting on with it</td>
</tr>
</tbody>
</table>
It is the adaption model (see Figure 2) and the processes held within it that describe the stages and process mechanisms to explain movement within the continuum, at both behavioural and psychological levels. These components operate within a psychosocial context in direct conjunction with the participants’ lived experience, and as such facilitate change as a fluid process.

The following statements represent abstracts from two participants’ interviews, and with the aid of supporting text highlight movement within the model. It is observed that a key area in which difficulties with self-management occur is prior to the turning-point stage. Around this stage, and following, body regulator, trial and error and self-learning continue to function, while fighting diabetes is no longer in operation.

**Participant 8**

For P8, difficulties with self-management were focussed around being a teenager, as well as finding it difficult to inject in the presence of others; both these factors ensured the difficulties position was maintained. Coming to terms and accepting the requirements of having diabetes, and the implications that this may involve exposing others to her diabetes was a major part of the adaption process: “well I used to when I was like first turned a teenager and was fighting it, I never used to inject in front of
Everyone so then I’d miss injections (right) wouldn’t do blood tests but now I don’t really care I just get it out and there’s people with worse problems that’s what I’m like so just get it out and do it” (P8, p4). Making this transition generated a new set of cognitions that allowed P8 to re-conceptualise the status of her diabetes and how it fitted into her life, it also reflected an aspect of distancing.

Further discussions yielded information that supported changes associated with developmental growth in the context of parental relationships, responsibility and change: “when I was younger it was easier (MANAGING REGIME), even though I was only 6 when I got diagnosed it was easier cos like your parents would always be there and you’d always be with your parents like for them to nag you and stuff but now that I am like a teenager I want to like go out with my friends and do the stuff they do and try new things”. There is also the awareness that the teenage years bring a level of increased autonomy and a wish to explore and experiment, which support the process mechanisms trial and error and self-learning: “now I’m older cos I’m doing things more like trying new things and stuff now it’s more harder than when I was little”. These experiences in turn led P8 to the position of increased acceptance and distancing that facilitated a more positive and productive level of regime management: “yeah I’ve realised now that I can do, still do the same stuff I’ve just got to take extra care, than everyone else”.

**Participant 7**

When P7 was asked to provide advice regarding the motivational aspects of managing his diabetes, an acceptance of the permanency of having diabetes was provided and was discussed in the context of type 1 diabetes being a controllable condition that the individual is capable of managing: “well I would say, it’s going to be there forever, well it might not be due to like scientific advancement, in like more modern times but if you keep it at a good level erm which it should be, which like the, the scientists know and the doctors know it’s a good level and it’s not going to affect your health, then you should do it and just be like normal people, otherwise it’s going to effect your life more than it is already and then you are going to have to have the knock on effect of like ill health and then the further, erm detriment of illness so then if you keep it normal then you should you will be alright and erm, you can do whatever you want cos it’s not going to stop you doing anything unless you let it stop you doing stuff”
(P7, p9-10). This describes a positive outlook on having diabetes, the focus of a life in which diabetes does not hinder normal activities. These features describe an acceptance and level of distancing in which to focus on normality, in contrast to the difficult aspects of management. Self-learning and trial and error have also served to witness the impact of not managing diabetes and move towards a more productive and positive position.

The process of developing confidence and an acceptance of having diabetes created the motivation to expose others to this awareness: “oh erm I’ve lost friends, well I’ve not lost friends but I’m not friends with the same people which I first told and then I thought I’ll have to tell new friends so then I know like I could, I could tell more people I was more comfortable telling other people after telling people beforehand and then I just thought oh just, if people ask I’ll just tell them the truth” (P7, p6). This reduced the need to keep the diabetes hidden. Exposing diabetes to others allowed P7 the opportunity to take a reality check with people’s responses. It provides an example of how self-learning has created the inclination to allow others the awareness of living with diabetes.

This final statement describes how P7’s self-esteem changed with acceptance and feeling more comfortable with having diabetes: “I felt more comfortable in myself, in diabetes actually because of the education about it and like there’s nothing to be ashamed about, cos other people have problems and they get on with it so I should just get on with it as well” (P7, p6). This not only describes distancing, it also describes a change in momentum (getting on with it), another characteristic from within the “successful self-management” category. P7 and P8’s statements are significant as they represent the capacity of participants to change both their behavioural and psychological outlook around diabetes.

Reflexivity

Initially, when considering the successful and difficulties with self-management categories, the issue of personality types and traits was in my mind, and whether the characteristics identified reflected type and trait features rather than process. These participants’ statements are significant as they represent not only a transitional phase for participants, but also the movement towards the characteristics associated with the
successful self-management category, and support the presence of process, as opposed to type and trait features. In support of this position, an article regarding improving patient adherence by Delamater (2006) stated that there was no evidence of a particular personality style being associated to adherence. Furthermore, this query reflects one of the tenets of social constructionism regarding anti-essentialism. Essentialism being “the view that objects (including people) have an essential, inherent nature which can be discovered” (Burr, 2003, p. 202), the anti-essentialism position reflects that in a social world people do not have an essential nature.

**Generality**
Empirically based, cross-sectional methodologies within diabetes-related studies have been critically commented upon for not appropriately disentangling current age, age of onset and duration of illness (Johnson & Meltzer, 2002). Due to the retrospective interview-based approach in which information was collected for this research, the conceptual and theoretical categories serve to inform an overarching understanding of the process from the impact of diagnosis to the acceptance and distancing stages of diabetes, and as such represent the researcher’s interpretation of the available data (Charmaz, 2006). The level of generality the model may hold to other young people with type 1 diabetes outside this investigation was considered in the context of the models permanence, and how it facilitates movement through it in the context of the adaption process and the utility of the model.

**Permanence of Stages**
One of the initial considerations in contemplating the relationship between the model and different levels of self-management relates to the permanence of the stages and how this equates to regime management. Notably, permanence is described as the stability of the model for reflecting the characteristics of individuals across time. For example, once individuals have accepted their diabetes and are demonstrating distancing features to its management, does that mean their regime is fixed at this level and will not decline or regress to a state of less successful self-management? It would be unrealistic to conceive that individuals’ lives will not change in such a way as not to impact on their diabetes.
Christian, D’Auria and Fox (1999) stated that by ignoring developmental factors that are of relevance to the individual and by using strict stage-oriented developmental approaches, clinicians may miss the learning needs that are most suited to the individual. This model was constructed to describe and understand participants’ lives, which involved issues surrounding school and development of social skills and identity, within which context diabetes had to be accommodated. The research found that participants who accepted their diabetes and described the features of distancing did so of their own choosing, and therefore was learnt, based on previous life and diabetes experience, as noted by the self-learning mechanism. If individuals accept their diabetes and reflect the characteristics of distancing, yet their level of successful self-management declines, it is hypothesised that this would then form a further aspect of development. Adaption would continue to evolve within the context of their self-learning, in order to accommodate events within their lives, whether it is at a physiological, psychological or psychosocial level. In this context it would not mean that acceptance had not occurred, nor that distancing did not continue to operate. The model represents the movement and features that exist theoretically to get to a position of acceptance. The model exists to describe acceptance and distancing as characteristics that reflect a more positive attitude in which to promote a healthier diabetes regime, the impact of this being a significant improvement in the behavioural characteristics associated with improved regime management.

**Movement Through the Model**

As Delamater (2006) has noted, the diabetes regime is multidimensional and may or may not be related to another component within the regime. One of the questions when producing the adaption model was how stage and process mechanisms interacted within the various behavioural components associated with diabetes management, namely insulin injections, blood glucose monitoring, diet and exercise. Paradoxically, where does the model fit for someone that reports having accepted their diabetes, yet does not conduct blood glucose monitoring in front of others, and as a consequence doesn’t routinely assess blood glucose levels? How can such psychosocial factors exist and be described within the model?

One way of considering this issue is that there are differing aspects of acceptance. Chapter 1 illustrated that exposing diabetes to others improved the level of blood
glucose monitoring due to a reduced level of inhibition. This indicates that in reality there are differing levels of acceptance, acceptance for having diabetes and acceptance for exposing others to diabetes, and these can occur at different times according to the individual. In reference to the turning-point category, volition for change can occur gradually over a period of time, influenced by a number of factors: “I think it was part of a turning point I think a few things added up and then erm and then erm yeah I decided to . . . taking more interest in my diet and er my appearance and erm my er erm blood sugars I guess” (P12, p7). It was also noted that change could occur over a short period of time, following the actual or perceived awareness of something more serious: “I had a 2-day period where my sugar was really high, and I felt really bad and erm it, my sugar wouldn’t actually go down, and I thought oh I’m not going to do this again, cos I felt really ill. So then . . . I was doing like my injection more, and then I understood, that, if I keep on doing it my sugars going to be really high all the time and I’m going to become ill” (P7, p7). This provides evidence to suggest that the model may be best served in application, not only to diabetes as a holistic entity, but also to acceptance across a range of combined behaviours and attitudes which contribute to an overall movement of change, which is then represented within self-management levels.

**Summary**

The adaption model provides a framework to understand psychosocial factors that may impact on self-management from the point of diabetes diagnosis, the impact stage, until acceptance is attained and regime management is conducted in a routine, adaptive and positive manner. Throughout this process, self-esteem may impact on psychological functioning in the form of ability and intention to take on new information or acceptance of the diagnosis. Motivational factors may also be influenced by poor or limited self-management skills. From a developmental perspective, Dabadghao, Vidmar and Cameron (2001) have suggested that entering adolescence for the majority of patients will represent either a constant retention of metabolic control or deterioration. While Maharaj, Daneman, Olmsted and Rodin (2004) have noted that developmental changes occur within psychosocial transitions amidst emotional, cognitive, familial and social domains, they refer to the individuation and development of an integrated sense of self, being the primary developmental tasks of adolescence (Grotevant & Cooper, 1985). Karlsson, Arman
and Wikblad (2008) concluded that the transition towards autonomy in self-management of diabetes involved having distance from others, yet still retaining support, having the knowledge to perform the management of diabetes and also being able to handle different situations.

While social constructionist thinking expands upon the way knowledge and language are utilised and understood within a social context, the adaption model and the process mechanisms also expand on fundamental constructivist principles. Constructivists consider that “each person perceives the world differently and actively creates their own meaning from events” (Burr, 2003, p. 19). In this way, knowledge is constructed from personal experiences and hypotheses of the environment, within the context of diabetes process management, the adaption model of integration supports this paradigm of learning.

The psychosocial factors that surround adolescents are primary considerations in how participants move within the model and learn to adapt to their diabetes. It has also been suggested that the positive and negative aspects of peer relationships may be related to both psychological well-being and the physical health of adolescents with type 1 diabetes (Helgeson, Lopez & Kamarck, 2009). Behavioural problems, such as aggression and antisocial conduct, have also been reported as important in influencing later glycaemic control from adolescence into young adulthood (Bryden et al., 2001). La Greca et al. (1995) described the role of friends for providing emotional support, which predominately helped the individual feel accepted, and also showing sensitivity for an individual’s feelings about having diabetes. In a later review article detailing the peer relations of youths with paediatric conditions (La Greca, Bearman & Moore, 2002), it was considered that the conditions for disclosing information regarding medical status to classmates was unclear. Disclosure was identified within this research in the context of the exposing diabetes to others theme, and could occur gradually, dependent upon the participant sharing and allowing others the awareness of their condition as part of the self-learning or trial and error process mechanisms.

The development of an adaption model contextualises the “stage” and “process mechanisms” that individuals may utilise. This awareness could reduce misattribution of reduced self-management, which could have a positive effect on both medical staff
and families, as behaviour is seen as a process or continuum within which the individual exists. The individual then has a framework and direction (within the model) in which to work towards adaption and acceptance. Understanding the complexities and confounding factors that young people with type 1 diabetes have to operate within can aid support, rather than viewing difficulties with self-management as a fixed feature of the child’s behaviour. Davidson, Penney, Muller and Grey (2004) describe how non-compliance could represent careful consideration of conflicting stressors and ambivalent use of care alternatives to balance competing demands, suggesting that this is dynamic in nature. Without considering the perceived realities of how individuals construct their social worlds in the context of their diabetes, it is unlikely that those individuals are going to want to communicate their actual issues and concerns regarding the self-management of their condition.
CHAPTER 6

Final Summary

Discussion

The grounded theory explored how 12 adolescents aged between 13 and 17 years with type 1 diabetes managed their diabetes regimes. It generated two distinct and opposing categories (successful self-management and difficulties with self-management), which described how participants dealt with and socially constructed their diabetes on what was referred to as a diabetes self-management continuum. A number of specific stages were identified to represent a broad framework for describing the process of adaption, as well as a number of process mechanisms for moving within the stages. A case study was used to highlight a level of additional analytical support to the conceptual nature of the categories. Finally, the development of an adaption model contextualised stage and process mechanisms in order to understand psychosocial factors, and how they relate to self-management from the point of diabetes diagnosis until regime management is conducted in a routine, adaptive and positive manner.

Within the research literature it is suggested that having type 1 diabetes does not delay psychosocial maturation in young adults compared to healthy adults, nor is it associated with major psychosocial difficulties from early to middle adolescence (Helgeson, Synder, Escobar, Siminerio & Becker, 2007; Pacaud et al., 2007). However, adolescents with type 1 diabetes do have different healthcare needs than non-diabetic individuals. While the literature suggests that both diabetes and general stress are critical predictors of the adjustment of adolescents with type 1 diabetes (Malik & Koot, 2009), and Bryden et al. (2001) state that behavioural problems in adolescence seem to be important in influencing later glycaemic control in adulthood, there is a lack of research detailing how adolescents understand their diabetes within a social constructionist context. In the past researchers indicated a need to develop a model and framework within which to understand the complex issue of adaption for individuals with diabetes, which can be tailored to the individual (Coates & Boore, 1998). A social constructionist perspective promotes a person-centred approach, as it
Research

assumes that people create social reality through individual and collective actions (Charmaz, 2006).

Tilden, Charmen, Sharples and Fosbury (2005) suggested that diabetes can be perceived as a separate identity, which has to be integrated, highlighting the importance of identity formulation, which could be seen as a significant aspect of the adolescent’s development. One aspect of this integration that is notable from qualitative-based research is the feeling of difference (Huus & Enskär, 2007; Kyngäs & Barlow, 1995; Kyngäs, Hentinen, Koivukangas & Ohinmaa, 1996; Lowes, Eaton, Bill, & Ford, 2007; Miller, 1999). This exemplifies the experience of having diabetes and represents how feeling different exists within a social and cultural context due to the demands of regime management. Indeed, Anderson and Robins (1998) have stated that by asking individuals about the psychosocial contexts in which they care for their diabetes a better understanding can be obtained. This study highlights the importance of acknowledging both learning and socially constructed realities that reflect the motivations of participants living with diabetes, as they construct their identities through interaction with others.

Hamilton and White (2010) noted the importance of interactions with others in order to shape one’s knowledge of the world, and how it can influence patterns of action. This study utilised a social constructionist orientation of grounded theory in order to produce a framework which can facilitate and accommodate participants’ interpretations of reality within a social context, offering an interpretation of the change process towards a more adaptive and positive form of regime management.

Within the diabetes literature the parental relationship has been given a great deal of attention (Dashiff, Hardeman & McLain, 2008). The way in which the individual’s self-concept can emerge is in part dependent upon the parent-adolescent relationship, with maternal parenting style associated with well-being in adolescents with diabetes (Butler, Skinner, Gelfand, Berg & Wiebe, 2007). While researchers have highlighted the importance of encouraging parental support (Anderson, Ho, Brackett, Finkelstein & Laffel, 1997), the evidence suggests that the way in which the relationship is constructed by the adolescent may have an important impact upon the effectiveness of diabetes self-management. Wiebe et al. (2005) state that “optimal diabetes care across
schilling and grey (2006) tentatively described three stages of self-management between parent and youth (parent-dominant, transitional and adolescent-dominant), which progressively occurred across four developmental stages (pre-adolescence, early adolescence, mid-adolescence and late adolescence). aspects of the transferring of responsibility were explored by palmer et al. (2004) in the context of the role of autonomy and pubertal status. they found that the mother’s reasons for transferring responsibility were only in part due to autonomy or physical maturity, other factors included child’s competency, to promote competence and maturity and to minimise hassles and conflict. palmer et al. also noted that when responsibility was transferred without sufficient autonomy and when pubertal status was low, this impacted upon higher hba1c values. similarly, when mother and father were accepting, communicative and encouraging of the adolescent’s independence, they were less likely to seek peer acceptance and peer advice over their parents (drew, berg & wiebe, 2010). indeed, what has been suggested by sparud-lundin, öhrn and danielson (2009) is that young people with diabetes reconsider themselves and reconstruct supportive relationships in relation to their self-management of diabetes during emerging adulthood.

within the theme of social constructionist thinking, language acts as a way of constructing and interpreting reality (burr, 2003). diabetes researchers have noted the implications of using specific types of language and the implications for disempowerment and conformist attitudes that can be associated to these forms of reference. delamater (2006) stated that “non-compliance then essentially means that patients disobey the advice of their health care providers” (p. 72). this indicates an intentional act as opposed to an inability to cope or manage their regime. delamater also notes that “the concept of non-compliance not only assumes a negative attitude toward patients, but also places patients in a passive, unequal role in relationship to
their care providers” (p. 72). Similarly, Glasgow and Anderson (1999) refer to Anderson’s (1985) comments regarding the constructs of compliance and adherence as being counter-productive, as they consider the problem to be in the patient’s behaviour. Instead, the terms “self-care” or “self-management” have been considered more appropriate, as they reflect the behaviours that patients engage in to manage their health condition (Delamater, 2006). Coates and Boore (1998) also highlighted the importance of individuals being partners in their care, having the power and right of decision making. They also suggest the term “self-management as a dynamic means of maintaining health, rather than the submission to prescribed orders implied by the term ‘compliance’” (p. 529).

The diabetes literature also acknowledges the role of power-based relationships and how such dynamics can impact upon the doctor-patient relationship. Glasgow and Anderson (1999) refer to the need for a collaborative relationship between patient and doctor, rather than a hierarchical approach. Similarly, Kyngas, Hentinen and Barlow (1998) suggested that healthcare professionals should ensure that consultations do not appear to be dominated by disease-monitoring activities such as blood glucose monitoring. Davidson, Penney, Muller and Grey (2004) reported that if teens felt that healthcare providers did not listen to their points of view, they would respond by doing what they thought was best. Furthermore, conflicts arose when individuals with diabetes felt either the parent or members of the healthcare staff were more interested in the disease than the person. (Kyngäs & Barlow, 1995; Kyngäs & Hentinen, 1995).

A fundamental aspect of this approach was noted by Funnell and Anderson (2004), who emphasised that in the past health professionals were trained according to the medical model of healthcare, in which the health professional was the authority responsible for diagnosis, treatment and patient outcomes. The findings within this research offer an interpretation of process and insight into the acceptance and adaption process that exists for adolescents with type 1 diabetes, which is primarily based upon listening to participants’ experiences of managing their diabetes. It provides a multidimensional, rather than unitary perspective, of diabetes management, and therefore is more fluid than a compartmentalised perspective (Delamater, 2006).

The initial intentions of this study were to utilise a social constructionist perspective to understand the motivational factors among adolescents with type 1 diabetes. While
conducting the interviews, what became apparent was that participants appeared to express differing attitudes to their diabetes. While there were individual relationships and contexts in which diabetes impacted upon their lives, there appeared to be distinct attitudes and beliefs which defined the way in which diabetes was managed. It was on this basis that a diabetes continuum was realised, with a set of themes that described the characteristics of successful and difficulties with self-management. The adaption model is a tentative interpretation of movement within this process, based on the evidence collated from the interviews.

The limitations of this investigation related to the subjective and interpretive nature of how the discourses from the interviews were understood and constructed by the researcher. While the sample size is relatively small, when considering those that moved from a position of having difficulties to successful self-management, it was adequate enough to contextualise the process in a way that supported the model. While it is possible that age of participant or the researcher may have been constructed in a way that did not facilitate engagement in the interview process, e.g. the interviewer wanting information, details of participants’ life that they were not comfortable in or had the insight to provide, are factors to consider, and this may have been the case for some participants, if not for all.

Due to the limited availability of 13-17 year olds with type 1 diabetes, it was not possible to engage in theoretical sampling in order refine movement within the adaption and self-management model. While participant 12 was interviewed with the model in mind, he was an exception within this sample. Furthermore, it was not possible to revisit existing interviewed participants, as their experiences were limited and did not contain the breadth of knowledge to refine the model.

Future research could focus on theoretically sampling individuals who had experienced difficulties with self-management and moved to a more successful self-management position. Variations upon this transitional process may expand upon the notion of a diabetes self-management continuum and add depth to the adaption and self-management model, in order to move closer to attaining a level of theoretical saturation. It may be that an adult type 1 diabetes population can provide a level of
retrospective insight into the adaption and self-management process, in contrast to the 13-17 year old age group.

In conclusion, while the difficulties with and successful self-management categories that signify the diabetes continuum, as well as the adaption model, do not and should not be considered prescriptive explanations for diabetes adaption, what is considered is that they offer a flexible and alternate way in which to understand how participants construct their realities within the context of having diabetes, and how they learn to manage and accept their condition in a social world. With this knowledge parents, healthcare professionals and peers are able to understand the issues and processes that can facilitate productive engagement, in order to generate understanding, solution-focused and empowering forms of interaction that can impact upon the motivational aspects of diabetes self-care.

Reflexivity
Following the literature search I felt that there was a distinct lack of longitudinal studies that provided descriptive, analytical accounts of young people’s experiences of diabetes. This was in contrast to association and difference-based levels of explanation via psychometric or survey testing. I felt that in bringing a social constructivist perspective to this area, I was able to provide a much needed depth to the adaption process. This depth, although small in participant numbers, is enough to extend and challenge some of the generalised findings previously generated by limited quantitative methodologies.
SECTION 4

Person-Centred Resources to Supplement SoC and SDT Information

The following material is aimed at supplementing the information gathered from the Stages of Change (SoC) and Self-Determination Theory (SDT) measures. It has been primarily sourced from existing literature on SoC (Prochaska, Norcross & DiClemente, 2006; Prochaska & Velicer, 1997; Rosen, 2000), SDT and Motivational Interviewing (MI) (Miller & Rollnick, 2002; Rollnick, Miller & Butler, 2008; Sheldon, Williams & Joiner, 2003). It is beyond the scope and the intention of this section to provide a standardised “one-size-fits-all” intervention package. Rather, it is the aim of the material to provide new insight into and awareness of behavioural and psychological characteristics that are informed by SoC and SDT, to facilitate change at an individual, person-centred level. Using this approach can inform and allow healthcare professionals and caregivers to match the needs and requirements of individuals at a level and pace that suits them, in order to promote a more positive and productive care pathway.

Stages of Change

The Stages of Change questionnaire highlights a number of stages that individuals move between in order to consolidate behavioural change. While Prochaska, Norcross & DiClemente (2006) include a termination stage within their literature, only the pre-contemplation, contemplation, preparation, action and maintenance stages have been described within this research due to the developmental nature of the age group. The following material describes the characteristics of each stage and details the nature and level of communication suggested to assist the individual move forward. Initially, Prochaska, Norcross & DiClemente considered that self-changers moved in a linear manner through each of the stages, they later learned that it was more realistic to expect individuals to move between the stages, as opposed to linearly through them.

Within the SoC literature (Prochaska, Norcross & DiClemente, 2006; Prochaska & Velicer, 1997), distinct processes of change are described as either covert or overt activities that people use to progress through the stages. It is important to note that the structure of the processes across differing studies is not as consistent as the structure of the stages, and no one single trajectory of change processes has been observed.
across a range of health behaviours (Prochaska & Velicer, 1997; Rosen, 2000). On this basis it is appropriate to use the process of change descriptions in a cautionary and non-prescriptive manner, more so in the context of such a developmental age group as adolescence, and in the context of type 1 diabetes, which involves a multidimensional approach to regime management. It is also anticipated that not all the processes of change will be either suitable for or able to be adequately delivered to this age group, due to the constraints on time, nonetheless the options are provided.

SDT
The information gathered from the SDT measures provides insight into three areas. Firstly, an understanding of autonomy support versus control within a healthcare environment within the diabetes team; secondly, perceived competence in participants’ ability to manage their diabetes; and thirdly, the level of autonomous versus controlled motivation for exercise, diet, taking medications and/or checking blood glucose levels. Within a chapter on Self-Determination Theory applied to medical practice, Sheldon, Williams and Joiner (2003) summarise the qualities of an autonomous-supportive healthcare climate (see Table 10), which may be helpful in working with young people in respect of self-management and the promotion of this construct.

Table 10. Health Care Practitioner Behaviours that Support Patients’ Feelings of Competence, Autonomy and Relatedness

- Listening to patients
- Eliciting patients’ perspective
- Acknowledging patients’ feelings and ideas
- Supporting patients’ choice and providing a menu of options
- Encouraging patients’ initiative and responsibility
- Minimizing control
- Giving patients information and/or a rationale for change
- Being non-judgemental

In addition to the information within Table 10, Vansteenkiste and Sheldon (2006) have suggested the implementation of a number of practical techniques from the Motivational Interviewing literature that may help facilitate and promote change in a
positive direction in the context of autonomy support. It is also important to note that while the following three techniques are taken from the MI literature, they are not a full reflection of the MI approach to behavioural change; for a more detailed understanding of this approach see Miller and Rollnick (2002).

*Mutual agenda setting*
Creating an environment that allows the individual to feel their specific concerns and goals are being heard, reflected and agreed upon between the individual and the healthcare provider. (Vansteenkiste and Sheldon refer to the word “therapist”, for the purposes of this research the term “healthcare provider” has been supplemented.)

*Reflective listening*
Vansteenkiste and Sheldon note three forms of reflective listening (*simple, amplified* and *double*) for increasing the individual’s self-awareness and placing them in a greater position to make autonomous choices. Sheldon, Williams and Joiner include an additional form of reflection referred to as *summary reflection*. All four types are noted below:

1) *Simple reflection*. Re-stating the person’s most recent comment back to them.
2) *Amplified reflection*. When individuals are distraught, reflect back and exaggerate the intensity of the individual’s emotion.
3) *Double reflection*. When individuals appear ambivalent about an issue, reflect back both sides of their ambivalence.
4) *Summary reflection*. A summarised version of what the listener has heard over a period of time, in order to clarify what the individual has been saying, to check the validity of its content and also increase self-awareness.

*Open-ended questions*
Using open-ended questions allows the individual to express themselves and their concerns. This is in contrast to the use of closed, single response questions that close down the communication.
Stages of Change

**PRE-CONTEMPLATION**

**ATTITUDES** – pre-comtemplators represent an active resistance to change, may become defensive about their problems, uncomfortable with vividly imagining the consequences of their behaviour and rarely take responsibility for the negative consequences of their actions.

**PRE-CONTEMPLATOR DEFENCES:**
1) Denial and minimisation (*making the least of it*) – refusing to acknowledge unpleasant outcomes as an effect of their behaviour.
2) Rationalisation and intellectualisation (*good excuses*) – using plausible explanations to sustain the behaviour and using abstract, impersonal information in order to avoid emotional reactions or responses to the behaviour.
3) Projection and displacement (*turning outward*) – re-directing the problem behaviour against someone or something else.
4) Internalisation (*turning inward*) – taking the problem and turning it inward, failing to express negative feelings appropriately.

**HELPING RELATIONSHIPS DURING PRE-CONTEMPLATION:**
1) *Don’t push someone into action* – a pre-contemplator is not ready to take action, though they may be ready to consider changing.
2) *Don’t nag* – nagging weakens the relationship between the helper and the changer.
3) *Don’t give up* – to a pre-contemplator apathy may look like approval of the behaviour or that their behaviour is not serious.
4) *Don’t enable* – helpers may want to understand the concerns of the changer, but enabling occurs when they fear that challenging the problem behaviour may impact on their relationship.
PROCESSES OF CHANGE:

**Consciousness-raising** – this involves increasing awareness about the causes, consequences and cures (in the context of type 1 diabetes, cure may represent alternative positive or improved diabetes self-care), becoming aware of defences, and checking defences. It also includes interventions that include feedback, education, confrontation, interpretation, bibliotherapy (the use of carefully selected reading material to assist in solving personal problems or for other therapeutic purposes) or media campaigns.

**Dramatic relief** – the experience of an increased emotional event or experience which is followed by reduced emotion if appropriate action is taken. Suggested interventions include psychodrama (an event, social interaction or narrative that manifests psychological forces or problems), role-playing, grieving, personal testimonies and media campaigns, all of which represent techniques that can emotionally move individuals.

**Environmental re-evaluation** – re-evaluating how the presence of or absence of the problem behaviour impacts upon the individual’s social environment. Empathy training, documentaries and family interventions can lead to these re-assessments.

**Social liberation** – becoming aware of more alternatives and choices available for individuals within society. For example, providing more information about problem behaviours and offering public support for those that want it (i.e. no smoking areas for smokers), advocating for the rights of repressed individuals, and empowering and policy-based interventions. To use the process of social liberation, individuals must resist the efforts of others (i.e. advertising) to coerce them into negative behaviours and use restrictions (e.g. no smoking areas) for promoting change.
Stages of Change

CONTEMPLATION

**ATTITUDES** – contemplators are more aware of the pros of changing; they are also aware of the cons. This awareness of the pros and cons creates a level of ambivalence that can keep individuals within the contemplation stage for long periods of time.

**SOME NEGATIVE RESPONSES TO CONTEMPLATION:**
1) *The search for absolute certainty* – waiting for complete certainty before changing.
2) *Waiting for the magic moment* – waiting for a magic or absolutely perfect time to change.
3) *Wishful thinking* – being able to continue living as they have without any consequences.
4) *Premature action* – being pushed or moving directly into the action stage too quickly.

**CONSCIOUSNESS-RAISING** – moving from a position of pre-contemplation to contemplation through consciousness-raising should have created an awareness of defences and resistances, which allows for more knowledge about the problem and reduced defensiveness.

*Asking the right question* – only focus on the question that is applicable to the behaviour you wish to change.

*Define your own goals* – what is the behaviour you want to change, how can it be measured and progress tracked (don’t let others dictate what is important).

*Collect the right data* – monitoring the problem is important throughout the whole of the change process, not just the contemplation stage.

*Functional analysis: learn your ABC’s* – track events that immediately precede and follow the problem behaviour. Functional analysis can illustrate these events: A (antecedent), what triggers the behaviour; B (behaviour), what is the behaviour; and finally C (consequence), what is the consequence of the behaviour.
HELPING RELATIONSHIPS DURING CONTEMPLATION:
1) *Empathy* – the ability to understand another person at an emotional and cognitive level. Contemplators seek and welcome the fact that others have experienced similar concerns. While the contemplator has moved from the stage of pre-contemplation, they are still not ready for action. They need support, listening to and feedback rather than advice.
2) *Warmth* – this is defined as the non-possessive caring and prizing of another without imposing conditions.
3) *Solicit input* – ask others to assist in the quest for more information, awareness and self-motivation.

PROCESSES OF CHANGE:

**Emotional arousal** – a critical barrier to changing many problem behaviours is that the seriousness of consequences can seem distant or too long term to matter. Emotional-arousing techniques can be used, such as going to the cinema to arouse emotions, making your own propaganda in order to arouse emotion, using imagination to concentrate on the negative aspects of the problem to highlight the dangers and drawbacks of the problem behaviour.

**Self-re-evaluation** – the cognitive and emotional assessment of the individual’s self-image with and without a particular unhealthy habit or behaviour, i.e. healthy diabetes management in contrast to non-healthy management approaches. Once you are well-informed on your behaviours and the consequences through consciousness–raising, you can question whether you wish to continue with those behaviours. Techniques such as imagery, value clarification and healthy role models can move people, additional techniques include:

*Think before you act* – when behaviours have become habitual, stopping to think about what the behaviour means to you. A period of such reflection can add to a level of control and allow a greater understanding for the reason behind the behaviour.

*Create a new self image* – imagine a scenario where you don’t change and your health and other aspects deteriorate, and then imagine how you would think and feel if you did change.
*Make a change* – the decision to make a change is usually preceded by an evaluation of the pros and cons of a problem behaviour. A decisional balance is best made using the following categories *:

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If the pros seem greater or stronger than the cons, then you are probably not ready to move to the preparation stage; spend more time gathering information on the cons of your problem behaviour.

(* The notion of decisional balance is discussed at length in the book *Decision Making*, by Irving Janis and Leon Mann (New York: Free Press, 1977).)
Stages of Change

**PREPARATION**

**ATTITUDES** - individuals in the preparation stage have a plan and are intending to take action in the immediate future. They are ready for action-oriented programmes. Any remaining ambivalence regarding change should be resolved during this stage, as preparation is vital for successful self-change.

**CONTINUING SELF-RE-EVALUATION** - in the preparation stage you can increase the chances of success by focussing on the future, the new self and what life will be like once change has occurred. Two frequently used techniques for self-evaluation in the preparation stage are:

*Turn away from old behaviour* – let go of the past and look forward, creating new images of your future self will make this process easier.

*Make change a priority* – the change must be given priority in your life, as it requires energy, effort and attention.

**HELPING RELATIONSHIPS DURING PREPARATION:**
Let those closest to the individual know how they can help; offer them a list of what to do and not to do. For example, don’t keep asking how they are doing, don’t nag, offer to help when they look overwhelmed and tell them how proud you are that they are doing this. Let them know when you plan to implement the plan and ask for their tolerance.

**PROCESSES OF CHANGE:**

*Commitment* – this is not only a willingness to act, but also an ability to change. A number of stumbling blocks are associated with commitment. Willingness needs to be strengthened and encouraged, it can be weakened by putting action off for too long by relying exclusively on willpower.
Research

Make the tough choices – regardless of the good work conducted in the contemplation stage, you may still feel ambivalent about the pros and cons of a particular problem. Making a commitment increases the likelihood of success, and the more that contributes to the decision, the more you will learn that it is the best path to follow.

Commitment and anxiety – commitment at the preparation stage makes success more likely. One must accept the anxiety and recognition that action may fail regardless of the commitment.

Take small steps – in order to manage action, successful preparation of the small steps are important. In terms of diabetes, if not wanting to follow the same dietary patterns when out with friends, practise how you will accomplish that.

Set a date – choosing a time frame and date to begin behavioural change is important, and should be realistic. Once the commitment has been made, be aware of finding excuses or reasons to delay it and be realistic about the nature of the tasks ahead. Choose a date that will best provide a supportive external environment.

Go public – don’t keep the commitment secret, going public (family, friends, work colleagues and neighbours) creates increased anxiety in case you fail; public commitments are more powerful than private ones.

Prepare for a major operation – yourself. Others commit the time to support you at this important time, and accept the consequences, such as changes in mood, work performance and relationships, which may cause disruption for a period of time.

Create your own action plan – containing all the information from the contemplation stage, helpful hints from others who have been through a similar change, and tips from friends, books, other literature and support groups. A main feature is that the individual has confidence in their plan and believes it will work. The plan should also contain a variety of techniques for coping with any expected barriers to change, and it is important to review past attempts, as they will reveal your own barriers.

Self-liberation – the belief that one can change and the commitment to act on that belief.
Stages of Change

**ACTION**

**ATTITUDES** – individuals in the action stage modify their behaviour, experiences or environment in order to overcome their problems.

**PITFALLS:**
1) *Taking preparation lightly* – action without preparation only lasts a short while.
2) *Cheap change* – real change takes work, the more effort committed to the contemplation and preparation stage, the more likely action will result in success.
3) *The myth of the “magic bullet”* – there is no single solution to complex behavioural problems.
4) *More of the same* – combine a variety of techniques at the proper time, rather than a single method.

**HELPING RELATIONSHIPS DURING ACTION:**
There are a number of ways in which helpers can assist during the action stage:
1) *Exercise together* – various types of exercise are more fun if conducted with a partner or friend.
2) *Buddy-up* – working as part of a team can be an option.
3) *Re-arrange your home* – create an agreement with others in the home to remove any forms of temptation.
4) *Put it in writing* – in order to bind yourself and your helpers to your contract, write it down and distribute it to those involved. This can include a start date, your goals and the countering techniques and rewards you will be employing. Also specify the commitments of the helpers.
5) *Get “stroked”* – get rewards from helpers for even small amounts of progress; verbal praise, monetary rewards, extra hugs, small presents, are all ways of providing rewards.
6) *Don’t take guilt trips* – scolding, nagging, preaching and embarrassing can be written into the contract as methods that should not be used by the helper.
7) **Keep it positive** – let the helpers know that reinforcement is superior to punishment in the area of behavioural change and ask them to monitor the ratio of positive to negative comments (recommend at least three compliments to every criticism).

8) **Seek support for life** – if there is a shortage of significant others (family or friends) consider the use of a support group. Helping relationships are of vital importance during the action stage.

**PROCESSES OF CHANGE:**

**Countering** - the substituting of healthy behaviours for problem behaviours. The following five techniques are often used by self-changers:

- **Active diversion** – is sometimes referred to as “keeping busy” or “re-focusing energy”, in other words finding an activity that precludes the problem behaviour. It should be an activity that is incompatible with your problem.

- **Exercise** – can provide a substitute for the problem behaviour.

- **Relaxation** – when exercise is not possible or appropriate relaxation is an option. For example, mediation, yoga or progressive muscle relaxation all share the same four elements: a quiet environment, a comfortable position, an internal focus and a “letting go”.

- **Counter thinking** – freeing yourself from rigid thought patterns and replacing troubled thoughts with more positive ones.

- **Assertiveness** – self-changers can feel helpless in response to external pressures to maintain their problem behaviours. By asserting oneself you communicate your thoughts, feelings, wishes and intentions, thereby countering feelings of helplessness when you feel you are not being heard or respected.

- **Environmental control** – changing or removing the cues associated with unhealthy habits or behaviours, and re-structuring your environment so that the occurrence of a problematic stimulus is reduced (i.e. if you drink alcohol don’t frequent a bar every night).

- **Avoidance** – this technique is effective for self-control, as it avoids a problem from starting.
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*Cues* – inevitably you will experience the cues that trigger your problem behaviour. To prepare for this, gradually expose yourself to the cues without responding in self-defeating ways, this will increase your resistance (one alternative method is using imagination).

*Reminders* – place reminders in your environment to prompt the desired behaviour.

**Reward** – the rewarding of positive behaviour includes three techniques:

*C covert management* – when cues arise that relate to the problem behaviour, breathe deeply, tell yourself to be calm and immediately follow your relaxation response with words of congratulations.

*Contracting* – creating a written contract that encourages the individual not to engage in a problem behaviour, and rewarding yourself for substituting a healthier behaviour (i.e. for every pound in weight you lose you agree to put £5 into a shopping account).

*Shaping up* – the gradual shaping of a new desirable behaviour; a step-by-step approach, with reinforcement following each successive movement, is more likely to be successful. Well-practised, well-rewarded earlier steps ensure that if any slips or lapses do occur, they will be brief rather than complete relapses.
Stages of Change

**MAINTENANCE**

**ATTITUDES** - at the maintenance stage individuals are still working to prevent relapse. There is not as much emphasis on change processes as in the action stage. There is less temptation to relapse and greater confidence that they can continue the changes.

**DANGER TIMES, DANGER SIGNS:**
The most common threats to maintenance are social pressures (those that engage in the problem behaviour or don’t realise its impact upon you), internal challenges (over-confidence or cognitive appraisal) and special situations (unusual intense temptation). Awareness of these responses is important for successful maintenance.

**HELPING RELATIONSHIPS DURING MAINTENANCE:**
1) *Revise your contract* – use the contract to provide the helper with permission or responsibility to challenge you if you become over-confident or expose yourself to tempting situations.
2) *Put your helper on-call* – produce a piece of information or a card highlighting what to do if you become seriously tempted, and a list of the negative aspects of your problem behaviour, i.e. review the problem list, substitute positive thinking for negative statements, remember the benefits of changing, engage in vigorous distraction or exercise and call your helper.
3) *Practise new behaviour* – practise confronting temptations before they actually occur.
4) *Help someone else* – helping others can also prove a way of helping oneself.
5) *Patience and persistence* – these are the characteristics of the maintenance stage.

**PROCESSES FOR MAINTAINING CHANGE:**
*Continued commitment and use of the change processes* - recall and write down the difficulties you encountered in the early stages of your change efforts, keep them
Research

in a safe place and look at them periodically or at the first sign of slipping. Also, celebrate or mark a time to reflect on your commitment and success.

**Keeping a healthy distance** – continue with environmental control by avoiding people and places that will compromise change, especially in the early stages of maintenance.

**Creating a new lifestyle** – countering is still important for the development and application of alternative behaviours, with exercise and relaxation offering useful stress-reduction techniques.

**Check your thinking** – as thinking has an important role to play in relation to behaviour, negative thinking can pose serious problems. Features such as denial, distortion and rationalisation can all appear at the maintenance stage when reflecting on previous problem behaviour, underplaying the level of difficulty it created in one’s life.

**Self-efficacy** - check the level at which you rate your ability to manage various tasks relating to your problem. List a range of situations that tempt you to abandon your behaviour and rate them according to your ability to manage, i.e. 1 (*not at all confident*) to 10 (*confident*). This will allow you to understand the situations that are more challenging and develop a strategy to deal with them.

**Guarding against slips** – slips can be the result of overwhelming stress or insufficient coping skills. Slips can be recovered from and learnt from. It is important that you realise that slips indicate vulnerability and develop a plan to address them. It is also important not to consider a single lapse in the same context as a total relapse. It is also valid that one may feel a level of mourning for old behaviours.
Stages of Change

RELAPSE

In terms of relapse, Prochaska, Norcross & DiClemente (2006) suggest that following relapse and before going back into the action stage, individuals benefit from a period of self-evaluation in which they learn from their mistakes. They describe 10 lessons to be learnt from relapse:

1) *Few changers terminate the first time round* - it is rare to overcome a problem the first time.

2) *Trial and error is inefficient* - trial and error can be frustrating. Relapse allows you to learn from the experience and then learn about how to prevent the relapse occurring again, through guided learning (speaking to others and reading) rather than trial and error.

3) *Change costs more than you budgeted* - self-changers can underestimate the cost, time and effort required to change.

4) *Using the wrong processes at the wrong time* – the following describe three ways in which psychological processes can be used incorrectly:
   a) *Becoming misinformed* – gaining self-help material at the consciousness-raising stage may be inaccurate or out-dated.
   b) *Misusing willpower* – the misattribution that a failure to succeed in changing behaviour is that they have not used enough willpower, as opposed to using a variety of other change processes.
   c) *Substituting one bad behaviour for another* – the movement from one problem behaviour to another.

5) *Be prepared for complications* – while problems can co-exist and one impacts upon another, common problems have common solutions and the processes remain the same.
6) *The path to change is rarely a straight one* – change takes a cyclical pattern.

7) *A lapse is not a relapse* – many people give up as soon as they lapse because of how they view the event; they consider stopping the behaviour to be an absolute event and if a lapse occurs it is a total failure. This leads to guilt, recrimination and self-blame, which are not effective change processes. Guilt can then turn a lapse into a relapse.

8) *Mini decisions lead to maxi decisions* – making mini decisions such as, in respect to drinking, only keeping a few drinks in the house in case guests come around, is moving the direction of the change towards relapse.

9) *Distress precipitates relapse* – distress (anger, anxiety, depression, loneliness and other emotional problems) is the most common cause of relapse. This may lead to the regression of a less mature and rational way of thinking and behaving. Social pressure is the other major form of relapse. As such, these factors should be part of your action plan.

10) *Learning translates into action* – people can get stuck in the contemplation stage. The strength of relapsers is that they are usually prepared to take action in the future.
Summary

In considering the applicability of the aforementioned material, thought was given to the context in which the information could be best utilised. Initially, consideration was given to the development of a package-based intervention that could be administered to individuals using the diabetes service. It was quickly dismissed on the basis of the limited time which healthcare staff, i.e. consultant paediatrician and diabetes nurse-led services, could commit to delivering such a programme. Rather, the material discussed in this section provides insights and perspectives that can be used when contact is limited. The findings from the qualitative study provide a tentative interpretation of the adaption process, in order to produce a level of context regarding the issues of how young people construct diabetes within their lives. The information from the established theories, namely SoC and SDT, offer cross-sectional perspectives that describe readiness to change and an understanding of current psychological needs regarding their diabetes.

In terms of the SoC material it is important to reflect on the best way in which it should be used and understood. While the SoC questionnaire may indicate or place an individual within a certain stage of change, it is not possible to assume that they will have used all the techniques attached to each stage prior to completing the measure in relation to earlier stages completed. At best the material can be used as a prompt to recall how the individual got to their particular stage, and then the material provided in this section utilised to move the individual forward, dependent on the time and facilities available.

While constructing the qualitative grounded theory and then studying the SoC literature, it was interesting to note that while the literature describes a set of techniques for behavioural change within each of its various stages, participants moved from a position of having difficulties with self-management to achieving successful self-management assumingly without knowledge of those techniques described. In particular, one aspect that was highlighted and mentioned in the SoC literature was the process of trial and error, a feature that was categorised in the process mechanism category of the qualitative study. Prochaska, Norcross & DiClemente (2006) indicated the frustration created by using this approach in
comparison to the methods and process of change utilised from their approach to behavioural change. This is insightful, as it suggests that the trial and error category, while a learning or process mechanism, could be significantly improved upon by an awareness of the processes of change, which in turn could improve levels of self-care among young people with type 1 diabetes. This also highlights the importance and suitability of having the facilities and resources to be able to administer interventions using approaches that could possibly significantly improve patient care and outcomes, in relation to self-management and quality of life.

In the context of SDT, Vansteenkiste and Sheldon (2006) have suggested that the three psychological needs of competence, autonomy and relatedness (Deci & Ryan, 2000) play an important role in the health care relationship:

> From this perspective, it is incumbent upon clinical and health care providers to help clients feel that they have autonomously chosen their treatment, that they can succeed at the treatment, and that they feel a sense of relationship with the therapist and others while doing the treatment (p. 72).

The matching of stages and the basic motivational techniques of reflective listening and open-ended questioning can provide a means of collecting further information and insights into the issues that young people with diabetes have to deal with, in order to further motivate and add to the process of change.
References


Research


SECTION C

Professional Practice
Unit 1.1 Implement and maintain systems for legal, ethical and professional standards in applied psychology

Throughout my time as a trainee health psychologist I have been able to establish, maintain and review systems for the security and control of information within both local authority and NHS organisations. This has provided me with an understanding of the different protocols required to ensure legal, ethical and professional standards. Maintaining confidentiality has been a key factor across organisations and impacted upon the storage, access and movement of patient information in accordance with the Data Protection Act 1998. Similarly, the Caldicott Report (1997) reports on patient information and identification and has been updated recently to account for developments in the NHS and Councils with Social Service responsibilities (Department of Health, 2010). Achieving these standards was attained in conjunction with Research and Development staff, as well as on-site colleagues, to ensure data was fully anonymised and all appropriate consents were gained.

Compliance with legal, ethical and professional practices for both myself and others was ensured through working in line with Research Governance (2001, 2005) and National Patient Safety Agency (2007) policy. As a member of the British Psychological Society, I also follow a Code of Conduct which promotes ethical behaviour and standards of professionalism (Ethics Committee of the British Psychological Society, 2006, 2009). While I have previous experience of operating within such guidelines, I utilised and applied my existing knowledge to develop these requirements within the Stage 2 competencies.

Obtaining ethical approval from the local NHS Research Ethics Committee formed a significant aspect of the research process. Upon reflection, while I found the experience frustrating due to the time and amount of paperwork involved, one of the main learning outcomes was being able to communicate in writing as well as verbally at a lay person’s level. Developing this skill ensured the investigation was understood by those sitting on the committee. I also learned to be assertive and proactive in asking for assistance in completing elements of the application form, as well as
requesting feedback regarding additional changes to my application. Throughout the experience I reflected upon a previous time I had applied for ethical approval as part of my MSc project with a different ethics committee. I recall attending one of their meetings and being surprised by the nature of the questioning. In particular, how it seemed to use lay terms rather than research-based terminology. In contrast, I found my current experience to be significantly improved, primarily as I developed a good relationship with the Ethics Committee Co-ordinator who was able to answer a number of queries and concerns I had throughout my application.

In order to establish, implement and evaluate procedures ensuring my competence in psychological practice and research, my thesis and systematic review provided evidence that these pieces of work were conducted in an effective and structured manner. The experience of successfully performing research within the NHS, in terms of conforming to ethical and NHS Trust Research and Development Directorate requirements, provides evidence of the knowledge and skills needed to operate within this environment. Using validity checks throughout the systematic review (Downs & Black, 1998) and the qualitative aspect of the research (Yardley, 2008) ensured that scientific rigour was applied to the findings. In terms of peer-review evaluation, the systematic review was recently accepted for publication within the journal Psychology, Medicine and Health, while the qualitative findings were accepted for an oral presentation at the 7th Annual Scientific Meeting of the UK Society for Behavioural Medicine (UKSBM) in Stirling, Scotland. I felt the process of peer review added to the integrity of the findings, and presenting at the UKSBM conference will provide an excellent opportunity to impart information to interested parties.

As a trainee psychologist, being able to access, evaluate and implement data and information is a key characteristic which forms the basis for informed opinion, supporting the role of the psychologist within a working environment. Both the research thesis and the systematic review provide evidence of utilising these skills and support previous years’ experience of working within a range of psychology-based environments, such as psychotherapy, behavioural intervention and analysis, child and adolescent mental health and paediatric liaison psychology. Such knowledge is supported by Stage 1 MSc Health Psychology training, which facilitates the
application of evidence-based practice. I feel that regular communication with clients across all the competencies, as well as the process of formal and informal evaluation, has provided insightful opportunities to develop effectiveness within the competencies. Using the skills of reflective listening and clarifying the client’s aims and objectives throughout the process has ensured my learning has been as proficient as possible.

**Unit 1.2 Contribute to the continuing development of self as a professional applied psychologist**

There have been many opportunities to establish, evaluate and implement processes to develop oneself professionally. The Stage 2 training at City University has provided excellent opportunities to attend competency-based workshops to supplement training, which I found very helpful, both in content and having the opportunity to discuss training issues with other trainees. One feature of the training I particularly valued was the application of psychological models within each of the competencies. This provided clarity and a much valued framework within which to contextualise theoretical and psychological perspectives, as well as legitimising their usage in an applied sense. I am also clearer in terms of my career aims within health psychology. I have focussed aspects of my training on areas which have a clinical application. Notably, I attended training at Cardiff in the area of Motivational Interviewing (MI) which was delivered by Stephen Rollnick and William Miller. This approach to creating change has been applied to a number of healthcare settings (Rollnick, Miller & Butler, 2008) and will be a good skill to be able to utilise as a psychologist. I have also attended cognitive behavioural therapy workshops, which provide clinically transferrable skills applicable to health contexts.

Having held a number of clinical posts as an assistant psychologist prior to the Stage 2, training I am keen to work in both a research and clinical setting. An example of how this may be possible is, following a piece of consultancy, the client and I aim to apply for funding to investigate the application of MI within a NHS Rheumatology Department. I feel that having gone through the health psychology, as opposed to the clinical psychology, training, I am more aware of the limited career opportunities which exist within an applied setting for qualified health psychologists. On this basis, I am keen to develop employment opportunities rather than wait for positions to be
formally advertised. I think a quality of my professional development is related to the ongoing skill and experience of having to locate opportunities to complete competencies. This feature creates a level of knowledge and assertiveness about discussing health psychology and its application within different environments.

I feel confident in my ability to actively seek and obtain feedback from others. An example of this relates to when I conducted the analysis of parental stress and its relationship to conduct difficulties using data from the Scallywags dataset. While I carried out the analysis, so as to assure the credibility of the results, I discussed it with an individual employed at the Research and Development Department, in order to get a second opinion on the analysis.

I used my health psychology supervision sessions to discuss approaches to conducting the competencies and exploring options and ideas. Feedback was a large part of the supervision process and in increasing my confidence in moving to a more autonomous position as a psychologist. This was achieved as the sessions were not focussed specifically upon giving direction, rather the attainment of professional skills. My experience of supervision was a positive and constructive one. Having worked in clinical settings over the past several years, the level of supervision in the context of Stage 2 training was significantly less and notably different, in that it is void of a clinical caseload. Once I had come to terms with the logging of competencies and felt comfortable in the accuracy of how and what I should record, I was able to function more freely as a trainee. I think one of the invaluable qualities of supervision was the supervisor’s knowledge and guidance regarding an appropriate experience or activity to highlight the competencies. I felt the key attribute within the supervision relationship was the ability to apply constructive feedback to pieces of work in an objective and informed manner. Also, as a trainee one is focussed on obtaining opportunities to demonstrate the health psychology competencies, not fully realising the professional change that has occurred. I felt that logging experiences and discussing progress in a supervisory context provided depth to one’s experience and progression upon which to reflect on such changes.

In contrast to being a supervisee, I felt the Supervising Others workshop run by City University was hugely informative, transferrable and relevant to becoming a health
psychologist. Primarily as supervising others could play a distinct part of a health psychologist’s role. The workshop highlighted the characteristics of successful, productive and skillful supervision; a role not essentially focussed around the supervisor being an expert in their field.

In order to organise, clarify and utilise access to competent consultation and advice, I have been able to identify sources of consultation to facilitate learning, assess my levels of existing knowledge and discuss particular ideas in terms of developing pieces of health psychology work. In relation to my research thesis, I met with the lead diabetes nurse whom I had come into contact with through a previous role as an assistant psychologist. The consultation and advice related to the suitability of conducting research within the team and the feasibility of the research area. The outcome was hugely insightful in developing my research protocol. In contrast, I have been approached by other professionals who have assumed that, as I am training as a psychologist, I am able to provide mental health assessment; an assumption I have been able to clarify.

Throughout training I have been able to develop and enhance myself as a professional applied psychologist. I have felt that within the NHS there is an element of confusion regarding the role of health psychology, possibly due to the majority of psychologists being employed in a mental health capacity, as clinical psychologists. As such, I have found it important to distinguish between the way clinical and health psychologists are trained, highlighting the emphasis upon teaching and training, consultancy, generic professional skills and research. I am more assured about the role health psychology can provide within the aforementioned competencies, which has added to my interest in creating opportunities through obtaining funding. I hope being involved in preparing and applying for funding may develop opportunities in the future.

Incorporating best practice into one's work has occurred in varied ways. I have joined the UK Society of Behavioural Medicine, the Division of Health Psychology (DHP) and recently applied to become involved in the Standing Conference Scientific Committee (SCSC) as an early career researcher, to assist in the organisation of the Division of Health Psychology’s 2012 conference. This will allow me to make a contribution to the DHP using the skills developed from training which promote best
practice, as well as meeting other health psychologists and learning about conference organisation.

**Unit 1.3 Provide psychological advice and guidance to others**

There have been a number of opportunities to specifically provide psychological advice and guidance to others throughout training. I recall one opportunity during a piece of consultancy where the client had requested assistance in identifying a self-esteem measure for their service. My knowledge of self-esteem, and experience of being clear at the onset of the consultancy regarding the parameters of the work, ensured that we were clear about the differing types of self-esteem while developing the consultancy contract. I used part of the meeting to explain that self-esteem could be considered as either “state” (temporal characteristic) or “trait” (personality characteristic) and then identified the most relevant dimension suitable for the team. Similarly, during a presentation to a group of diabetes professionals, I provided guidance on the application of Motivational Interviewing for young people with type 1 diabetes based on the most up-to-date references. Both examples demonstrate my ability and the development of my skills to assess opportunities to provide psychological advice, as well as discuss and evaluate the advice provided. I feel this ability, and the learned experience of utilising this quality, support the psychological input offered to the client.

**Unit 1.4 Provide feedback to clients**

Throughout the time I spent in my main work placement at Scallywags, I had several opportunities to provide feedback to clients as well as members of staff. One such example was being involved in the service’s review process. Due to the 6-month intervention period upon which the service operates, a review meeting is conducted with parents and school following each intervention to assess effectiveness and level of change. This allowed for the structured delivery of feedback, by incorporating my findings with those of parents and school in a triangulated manner, using the Boxall Profile (Bennathan & Boxall, 1998) to assess developmental and diagnostic characteristics. Information from the Profile has a pictorial aspect which can be presented in a graphical format. This is completed at pre- and post-stages and enables individuals the opportunity to visually understand levels of change across the intervention. This process is structured in conjunction with the objectives initially set.
at the beginning of the intervention. The client is asked if there are any questions relating to the feedback and contributions are welcomed. Nearing the end of the feedback, discussions are held regarding any additional work required to meet the needs of the objectives, completing the feedback process.

Additional feedback opportunities existed in communicating findings from the Scallywags team audit on clinical effectiveness. I was able to develop my communication skills, delivering the findings to approximately 30-40 members of staff. While the audit used a structured format, which existed prior to my employment, I felt I could contribute to its development by evaluating and interpreting findings in a way that provided the team with options for understanding the data in new ways. A simple example was to demonstrate the amount of data missing from the dataset, therefore impacting upon the representativeness of the overall findings.

While Scallywags offered a number of opportunities for providing feedback to clients, other opportunities existed throughout the majority of the competencies, notably the teaching and training, consultancy and optional competencies. I was also fortunate to present my research findings to the diabetes nurses as well as the consultants, providing insight into the team’s understanding of motivational issues from the perspective of young people with type 1 diabetes, which offered a form of evaluation and feedback not normally available. I have found that providing feedback to clients is of particular relevance to my professional competency, in terms of personal growth and applied development for communicating meaningful material. This has expanded my interest in developing communication skills that promote feedback, such as Socratic questioning and reflective listening, in order to promote motivational concordance with the aims and expectations of the client.

In conclusion, working through the competencies has allowed me to gather further insight into the theoretical and practical underpinnings of applied health psychology and how it can exist within a range of environments and populations. This conceptualisation adds a level of legitimacy when considering issues or problems and utilises psychologists’ skills in a concrete manner. On The British Psychological Society website the title of chartered status is referred to as “the benchmark of
professional recognition for psychologists. It reflects the highest standards of knowledge and expertise” (BPS, 2010). Going through Stage 2 training, with an awareness of Stage 1, creates the tools with which to feel that this status is possible. The regular logging of competencies, while very specific, has the associated value of providing clear explanations and guidelines on how to behave and conduct oneself in a professional manner. In considering the advances in electronic access to high quality theoretical and evidence-based information, the training is as important as ever in ensuring that this material is used in an accurate and professional manner. I certainly feel that my experiences of conducting and working through the competencies at Stage 2 have created a varied range of generic professional skills to take into the workplace.
References


Consultancy Competency Case Study

To Understand Parental Stress within the Scallywags Service for Children with Emotional and Behavioural Difficulties

Unit 3.1 Assessment of requests for consultancy

The Scallywags scheme works with young children at risk of developing emotional and/or behavioural difficulties. Between August 2001 and early 2005, the team contracted an outside agency to evaluate the service, using a variety of measures and approaches (see Appendix 1). The evaluation was successfully completed, published (Lovering, Frampton, Crowe & Linn, 2006) and the dataset retained within the service. Following the evaluation, the Scallywags manager maintained her interest in the relationship between parental stress and conduct difficulties and how it functioned within the Scallywags service at before, after and 6-month periods of the intervention. She was keen to produce a research paper describing this relationship and disseminate it within a peer-reviewed journal. As the manager did not have the research knowledge or skills to perform the analysis, I was approached in a consultancy capacity as a trainee health psychologist to collate, analyse and write up the results for publication. Primarily, as I had experience working within a research context, had been involved in getting research published, was familiar with SPSS software and had studied applied research methods during my MSc in Health Psychology.

Initially, I was concerned about the feasibility of conducting the research, as it would be based primarily on collected evaluation data. On this basis, during the initial assessment meeting I felt it important to be clear about the available data type and the limitations of the conclusions we could realistically make. I suggested the standardised measures should include the Parenting Stress Index (PSI) (Abidin, 1995) and the Eyberg Child Behaviour Inventory (ECBI) (Eyberg & Pincus, 1999), as both measures had been psychometrically evaluated and detailed within their respective manuals. The PSI produced a Total Stress score and three subscales (Parental Distress, Parent-Child Dysfunctional Interaction and Difficult Child) and had been used among high-risk families (Saltaris, Serbin, Stack, Karp & Schwartzman, 2004).

The ECBI assessed conduct problems in children aged between 2 and 16 years and consisted of two scales: an Intensity scale (frequency of behaviour) and a Problem scale (whether behaviour is problematic for the parent or not). It had also been used to
evaluate a parenting programme for parents of pre-school children considered to be at risk of developing conduct disorder (Hutchings et al., 2007). Both the client and I agreed on the suitability of the PSI and ECBI for exploring the relationship between parental stress and conduct difficulties within the Scallywags service.

While the PSI and ECBI would inform on parental stress and conduct difficulties, demographic information (area, child’s age, gender, ethnicity, number of siblings and marital status) and attendance levels from the WAGS (Where Adults Get Support) groups would provide an understanding of the relationship between such variables. The client confirmed this would be relevant to both the research and for service development purposes, i.e. does the attendance level at WAGS groups impact upon parental stress? Finally, there was discussion about whether the findings could inform service development, in terms of developing a parental stress program. The client agreed this might be worth considering following the outcome of the research.

It was agreed it would be my role to conduct a literature review to assess the context in which parental stress related to conduct difficulties. I conducted a brief search in PsycINFO, an abstract and indexing database of peer-reviewed literature within the areas of behavioural science and mental health. Utilising my electronic access via City University London, I filtered articles using keywords (parent$ and conduct) within the title, between the years 2000 and 2007. The literature was critiqued for methodological quality and representative sampling within the area of conduct difficulty and parental stress. Additional factors considered study design, i.e. multi-centre or randomised controlled trials. The results were analysed for appropriateness and collated to create meaningful aims and objectives for the research. The search indicated that evidence-based parenting programmes, delivered within the community and in the voluntary sector, were effective interventions for children at risk of developing a conduct disorder. They also suggested that child behaviour may be mediated through parent behaviour and the learning of key parenting skills (Gardner, Burton & Klimes, 2006; Hutchings, 2007).

The client explained that she would be on holiday until February 2008 and it was agreed the findings would be presented when she returned. The findings and references were typed up and given to the client to read upon her return (see Appendix
2). We both discussed and agreed that the literature search supported the continuance of the research and could expand upon the knowledge-base regarding the relationship between parental stress and conduct difficulties within the Scallywags scheme. I then wanted to explore the consultancy’s feasibility in terms of the Research Governance Framework for Health and Social Care (2005), in particular, data protection, ethical approval and informed consent. The client provided the name of the Research Governance Framework Co-ordinator that Scallywags had previously liaised with for the service evaluation. Following the general principles recommended by the Caldicott Committee (1997), I met with the co-ordinator, and it was confirmed that consent had been obtained to use the data for research and dissemination purposes, as such, ethical approval was not required. It was also mentioned that the dataset would be stored in conjunction with the principles advised in the Caldicott Report, as well as on a password-protected computer.

Following these initial discussions, I considered the consultancy was feasible. The client also said she might be able to get SPSS for Windows installed within the office; I said I was happy to follow this up. While I would have obtained SPSS through my connection with the university, we agreed it would be advantageous to have it in the office as well. We also agreed I should use the client’s computer facilities as they were secured through a specific username and password, as well as being regularly backed up through the Local Authority intranet. In addition, home-based working could also be considered, as both my PC and laptop were security password-protected.

**Reflection**

I felt the client was informed on the issues we discussed in terms of research governance and the availability of statistical software. I learnt the importance of being clear about the focus of the research question. In particular, whether the expectations of the client were realistic, namely using data to explore parental stress and conduct difficulties from measures and a methodology identified primarily for evaluation purposes. Being able to recall and think constructively about how the data type could be analysed from a methodological and statistical perspective was invaluable, as was prior knowledge of confidentiality, ethics and data protection. Such thinking provided the opportunity to prompt discussions about the possible value of the results and the benefits of the findings, for both publication and service development purposes.
Unit 3.2 Plan consultancy

Following initial discussions with the client regarding the feasibility of the consultancy, we discussed the aims and objectives in greater detail.

Aims:

- To analyse parental stress levels within the Scallywags dataset.
- To understand levels of parental stress at both start and finish of the Scallywags program.
- To produce a report in the appropriate format for publication within a peer-reviewed journal.

Objectives

- To provide a profile of parental stress levels, whether they increase, decrease or do not change throughout the Scallywags program.
- To explore the relationship between parental stress and conduct difficulties within the service.

It was agreed that the client required specific knowledge in the areas of data transfer, statistical analysis and report writing to a level acceptable for submission to a peer-reviewed journal for publication. This type of consultancy model is best described, in part, by Schein (1999) as the “purchase of information or expert model.” This provides a theoretical framework for the consultancy, with me acting as the expert providing a service for the client. This model assumes “the client knows what the problem is, that the client has communicated the real problem, that the helper has the needed information, and that the client has thought through the consequences of asking the question and receiving the answer” (Schein, 1990, p. 59). Additionally, Schein highlights that the consultant should always start in the process consultation mode. This was demonstrated within the initial assessment period with the client; it reflected a “spirit of inquiry” (p. 61), which allowed me to ascertain the feasibility of the consultancy work. While the expert and process models of consultancy can be seen as distinctive in terms of the assumptions that underlie them, the helper may
move between the models throughout the consultancy: “the helper has to make on-line choices about which model to use from moment to moment” (p. 59). While I did not need to meet with the client to conduct the data transfer, statistical analysis and writing up, she did request we hold regular, weekly progress meetings, and this was added to the budget.

A scheduled three-stage timetable was constructed:

- Stage one - transfer data to SPSS by January 8th 2008.
- Stage two - conduct statistical analysis and outcomes by 29th January 2008.
- Stage three - write up results, in a journal format, by 19th February 2008.

Computer facilities were considered a major factor in completing the work, and with limited availability within the client’s office, I offered to work from home at times. I drafted a contract, including the aims and objectives, tasks to be completed, time scales, resources, outcomes and a budget (see Appendix 3), and presented it to the client. We both agreed the contract was workable and provided a good framework within which to complete the tasks.

Reflection
While the client felt the timetable was quite tight, she was agreeable to a level of flexibility if required, and suggested the regular meetings could be used to highlight such aspects. I felt we had developed a good working relationship and identified a clear consultancy structure in which the client had been very helpful and informative.

Unit 3.3 Establish, develop and maintain working relationships with clients
Initially, the client requested that we meet weekly, primarily to update on progress and respond to questions. Following the assessment meeting, contact became sporadic and occasional as the client had started to work from home. This reflects a clear expert model position in terms of minimum contact and how the relationship moved from a process to expert position: “the client expects expert help and expects to pay for it but not to get involved in the process of consultation” (Schein, 1978, p. 340). As the weekly meetings were only aimed at updating on progress rather than performing
the analysis, I was not too concerned as it did not impact upon the project. While I have reflected upon this incident, we did agree to meet weekly within the consultancy contract, but I felt that consistently challenging the client to attend regular updates of 5-10 minutes would have been inappropriate.

When the consultancy contract was initially discussed, it was agreed that the timetable would provide a way of monitoring progress and that a final evaluation would occur at the end of the consultancy. Due to the client’s lack of attendance at meetings, when the client and I did meet, minutes were taken; non-attendance was also recorded as I felt it was important to reflect my attendance as evidence, since the budget reflected these additional meetings.

Reflection
Initially the client and I established a good relationship. Throughout the consultancy process regular evaluation and monitoring was not possible, as the client did not attend the research meetings regularly. Although this was frustrating, in terms of being able to use my time in other ways, I learned to accept and adapt to the working practice of the client, and if I required organisational or managerial information, I communicated with the administration staff. When I addressed the non-attendance with the client during the meetings we did have, the client reported issues relating to ill health, which made it difficult for her to attend. In hindsight, being aware of what the expert model entailed, I think I would have requested that the additional meetings were not required, or suggested that they occurred less frequently in this case.

I also think it is important to note that the Scallywags service was going through major changes, in conjunction with the Local Authority. This may also have been a factor regarding the amount of time the manager was spending working at home, as this non-attendance was not specifically related to the research meetings.

Unit 3.4 Conduct consultancy
As agreement had been obtained from the Research Governance Framework Coordinator regarding the ethical and consent aspects of conducting the consultancy, I could pursue obtaining access to a statistical software package. I expected to obtain a licence for a statistics package to be difficult, as I had hoped to obtain permission to
use SPSS version 15.0 (SPSS, 2006). On this basis, I initially contacted via telephone and email two different departments. One department explained it would not be possible to gain the software within the assigned time scales for the consultancy. The other department agreed it would be possible, and following negotiations regarding the financial continuance of the licence, SPSS was secured. Following an email to the Local Authority Information Services Group (ISG), the software was installed remotely, prior to starting the data transfer.

For Stage one, the data was transferred from its original source within Excel (2002) into the SPSS software. Prior to this, an SPSS database was assembled to transfer and store the dataset for analysis, and data measurement categories were matched to data type and organised to allow descriptive and inferential statistical tests to be conducted. The data was then transferred and checked to ensure credibility had been maintained throughout the transfer process. This was achieved by comparing various rows of data across SPSS and Excel datasets. This was completed within the assigned time scales, and no amendments were required for the consultancy plan.

For Stage two, descriptive statistics were completed first, followed by the inferential analysis. This was achieved using knowledge obtained from studying applied research methods at a Masters (MSc) level of the Health Psychology Stage 1 training. The technical considerations regarding the manipulation of the datasets within SPSS and the appropriateness of the test selection were confirmed throughout the data analysis process (Faul, Erdfelder, Lang & Buchner, 2007; Hinton, Brownlow, McMurray & Cozens, 2004; Howell, 1997).

In accordance with the findings from the Caldicott Committee (1997) and in conjunction with Research Governance (2005), I felt it appropriate to meet and discuss the validity of my methodology with a colleague from the National Health Service (NHS) Research and Development Support Unit (RDSU). Due to timings in which we could meet, I considered it appropriate to combine Stage two and three of the timetable together, rather than conduct them as separate stages. In addition, it seemed more accurate to write up Stage three while conducting Stage two, combining both stages and time scales. It was not possible to meet with the RDSU until the scheduled completion date, and therefore I organised a meeting with the statistic’s
Consultancy

clinic within City University. This acted as a confirmatory discussion and provided the quality assurance regarding the credibility of the methodology and analysis provided.

In line with the scheduled timetable of actions, a final meeting was held within the workplace to review progress and discuss the findings of the consultancy. A hard (paper) copy of the results’ section was shown to the client (see Appendix 4) in the agreed format. Both the client and I agreed it was beyond the initial contracted agreement to carry out ongoing changes to the results beyond the assigned consultancy period, i.e. changes required for submitting to a different journal title. This should be done in the time assigned to the Assistant Psychologists within the service, as the period for adjustment once the article had been sent off for publication was unknown.

It was suggested, based on the findings of the analysis, that although clinically higher levels of parental stress were related to higher levels of conduct difficulties, within the intervention parental stress was not the sole factor in reducing levels of conduct difficulty. Parents whose stress levels decreased did have significantly greater reductions in conduct difficulties than those where levels did not change or increased, although all categories did experience reductions in conduct difficulty across the intervention. On this basis, the client considered it was not relevant to implement a parental stress-based program to support the scheme.

Reflection

I think knowing that the expert model involves a level of separateness from the client, this meant that the level of contact within this piece of work could have been minimal. It was, nonetheless, disappointing that the client had requested the additional contact and did not attend, as I had enjoyed listening to and working with her in the initial stage to agree the contract. While I was comfortable in asserting myself with colleagues to ensure the validity of the work was of a good standard, I did feel that this form of consultancy could be quite isolating. I did think that either a support network or good communication skills to engage with other professionals would be important while working within this model of consulting.
Unit 3.5 Monitor the process of consultancy
As part of the research meetings, minutes were used to monitor the process (see Appendix 5). While determining the appropriateness of combining the tasks assigned to Stages two and three, the decision was made on the basis that this would not affect the completion dates agreed in the consultancy contract.

As the minutes had acted as a form of attendance level monitoring, I could note the number of meetings with the client. Due to the poor level of attendance, it was clear a meeting had to be re-organised to keep the scheduled timetable deadlines. The decision to make changes to the results’ section once it was written as a journal article were reviewed and affirmed in the final meeting with the client.

Supervision, and recording information within the supervision logs, provided a valuable opportunity to air the client’s non-attendance. The timetable provided a helpful framework to monitor and assess progress at each stage and move towards completion of the consultancy targets. Working with the data, regarding transfer, storage, analysis and interpretation, as well as data protection and ethical concerns, were all conducted within the Research Governance (2005) and Caldicott Committee (1997) guidelines.

Reflection
I found the timetable provided an excellent framework to move towards reaching the objectives of the consultancy, primarily because using the regular meetings as a way of monitoring became ineffective. I developed helpful networking skills to seek out advice, guidance and support from supervision and colleagues. This was a positive experience and allowed me the opportunity to clarify my thoughts about the analysis.

Unit 3.6 Evaluate the impact of the consultancy
The evaluation requirements were based predominantly on a verbal appraisal regarding the quality, timing and usefulness of the work and as such, no additional evaluation was undertaken. As the consultancy was based predominantly on the expert model within a one-to-one relationship, representative sampling was not considered appropriate to evaluate it.
In conducting the verbal evaluation, a semi-structured interview was held in which I used reflective listening to enquire about the effectiveness of the consultation. The outcomes of the interview were recorded in the minutes and discussed with my Health Psychology supervisor. The evaluation was successful and there were no amendments required in relation to the administration and quality of the service provided.

Reflection

I felt the consultancy was successful and conducted in a professional and timely manner; it was reassuring to have this confirmed by the client. In particular, I was pleased with the findings and the conclusions which demonstrated that parental stress, although greater among parents whose children had higher levels of conduct difficulties, was not the sole factor in reducing levels of conduct difficulty throughout the scheme. In keeping with the expert model, the results were given to the client and the idea of whether to implement an additional stress reduction program within the scheme was dismissed.
References


Teaching and Training 1 Competency Case Study

Motivational Interviewing (MI) for Support Workers
Within the Scallywags Service

Background
As a trainee health psychologist within the Scallywags service, I gained invaluable insight into how the scheme worked with children aged between 3 and 7 years who were at risk of developing emotional and/or behavioural difficulties. The scheme was structured so that a support worker met with a child for 3 hours at home and 5 hours at school per week for 6 months, followed by 1, 3 and 6-monthly follow-up meetings. As I was employed in a support worker capacity, I had experience upon which to reflect about how, and in what context, health psychology could best benefit the role of a support worker.

Unit 4.1. Plan and design training programmes that enable students to learn about psychological knowledge, skills and practices
For some time I had wanted to share with the rest of the team the knowledge I had gained from studying behavioural change within health psychology. The team have a good grounding in evidence-based practice associated with working with children who have emotional and behavioural difficulties, and I felt a psychological perspective may be of value to them. More specifically, I was familiar with some of the challenges the role presented, in terms of creating sustainable behavioural change within children, school or families where there was ambivalence to change regarding existing attitudes or behaviours. It was on this basis that I felt an awareness of Motivational Interviewing (MI) (Miller & Rollnick, 2002) would be helpful to the team.

The MI approach promotes motivation by eliciting change from within the client, rather than for example the support worker resolving any ambivalence the child, parent or school may have regarding a change in behaviour or attitude. A number of review articles have demonstrated the role of Motivational Interviewing within physical healthcare settings for children and young people, such as type 1 diabetes (Anderson, Svoren & Laffel, 2007; Borus & Laffel, 2010), paediatric obesity (Perrin, Finkle & Benjamin, 2007; Resnicow, Davis & Rollnick, 2006) and paediatric health
behaviour change (Suarez & Mullins, 2008), indicating that the principles of this approach may be of interest to working within an emotional and behavioural difficulties-based service.

Twice a year Scallywags held a staff training week to update on service development, provide in-house professional development or bring in speakers (i.e. massage in schools, child participation, art therapy). Nearing training week I approached the Scallywags manager to discuss the possibility of providing an afternoon’s teaching and training around Motivational Interviewing. My manager was very happy to approve the training and I was given a slot on the 21st July 2008 between 1.30pm and 4.30pm; attendance was estimated at 30-40 support workers.

As MI has such a strong research base within both the academic and applied research literature (Motivational Interviewing Bibliography, 2011), I wanted to get a sense of the group’s minimum level of academic attainment. The manager explained that the support worker post required a minimum National Vocational Qualification 3 (NVQ 3) in Early Years Care and Education, which is academically equivalent to A-level standard (City & Guilds, 2012). I then constructed a Needs Assessment Form (see Appendix 1) to survey current awareness within the team about MI, learning objectives and the preferred format for delivering training. This was completed at one of the monthly whole-team meetings, representing 65% of the overall Scallywags team. The findings indicated that 100% knew nothing about MI and that the design of training (68-89% of the group) should be interactive, i.e. presentation, questions, exercises and group work. This seemed feasible, as the training room had adequate facilities to operate a projection system with PowerPoint media and space for group work. I discussed securing the availability of the equipment with the scheme’s administrator. Both the administrator and I had difficulty operating the projection system and overcame this by involving the Information Technology Department attached to the team.

In terms of learning objectives, three were proposed by 70% of the group: background knowledge, relevance of MI to support work and MI techniques. These are best classified within Bloom’s (1956) taxonomy of learning domains. More specifically, Bloom identified three domains of educational activity:
- Cognitive, i.e. mental skills (knowledge).
- Affective, i.e. growth in feelings or emotional areas (attitude).
- Psychomotor, i.e. manual or physical skills (skills).

This piece of teaching belongs to the cognitive domain, representing the acquisition of applied knowledge. Kolb’s (1984) theory of experiential learning provides a training model to integrate support workers’ existing experiences within the training and inform the teaching process. I spent several weeks acquiring the MI subject knowledge from Miller & Rollnick’s (2002) book and via the Motivational Interviewing website. This enabled me to understand how the core elements of MI could be positioned within the presentation, while facilitating the learning process and being guided by the support workers’ experiences. In this sense, the learning was informed by a constructivist teaching approach (Hsiu-Mei Huang, 2002), whereby learning occurs on top of existing knowledge regarding ambivalence. In doing so, the process forms a type of scaffolding (Wood, Bruner & Ross, 1976), whereby the experience of being involved in the exercises progresses the development of learning beyond the learner’s existing knowledge. Materials and exercises were obtained from the Motivational Interviewing: Training for New Trainers, Resources for Trainers (2004) handbook and were incorporated into the teaching plan. One example of this is the “road blocking” exercise developed by Thomas Gordon (2000), which provides an effective way for the learner to experience negative interactions that block communication. A week prior to delivery, I made up the road blocking cards, dialogue sheets, handouts (see Appendix 2b) and evaluation forms. I got permission from the Scallywags administrator to laminate the road blocking sheets and photocopy the MI conversations, which were downloaded from the MI website.

Once the teaching plan was complete (Appendix 2a), I met with the Scallywags manager to gauge her opinion and emphasise that the teaching and training would be a brief overview of MI. It would be beyond the scope of a single afternoon’s training to attain MI proficiency (Miller & Mount, 2001; Rollnick, Miller & Butler, 2008). She was happy with both the content and format and suggested including a handout at the end of the training.
Reflection

Showing the training plans to the manager was very encouraging; she felt knowing more about the area of ambivalence would be a valuable addition to the team’s knowledge and skills. Similarly, I was happy that the teaching and training structure would facilitate the support workers’ intellectual development and applied skills, through the application of an experiential training model that matched the learners’ identified learning preferences. In addition, this teaching style confirmed my previous experience of earlier training weeks and reflected how the team valued an interactive approach to learning.

Unit 4.2. Deliver training programmes encompassing psychological knowledge, skills and practices

On the morning of the training, I came in early to arrange the projector and seating. After lunch, I asked the learners to re-group and explained how the training session would be interactive, focussing on what MI was, how it was relevant to Scallywags and exploring the spirit, principles and interaction techniques of the approach. I wanted to use paired exercises and brainstorming to stimulate learners’ experiences, in order to develop skill acquisition. Socratic questioning (Miller & Rollnick, 2002) was used to stimulate and elicit discussion regarding support workers’ experiences, as well as guide the learning process where possible. In doing so, the process provided a scaffold (Wood, Bruner & Ross, 1976) to enable the experience of being involved in the tasks to progress the development of learning beyond the learners’ existing knowledge.

While I was aware from the needs assessment that the group had no MI subject knowledge, I wanted to understand and establish whether there were any misconceptions about what MI was, or expectations around the training, so I discussed this with the group. I then moved on to the relevance of MI within Scallywags and asked the support workers how they understood and worked with the issue of ambivalence to behavioural change. I asked for this to be completed in pairs, in order to facilitate a greater consensus of responses. The learners seemed to enjoy and engage in this process, and I followed on with a brainstorming exercise to collect their responses. It was during this task I recall feeling both unnerved and a little worried that the group was further ahead in terms of their understanding of how to
work with ambivalence than I anticipated. I dealt with this by expanding on specific responses that matched the requirements of the training. It was at this point that I realised there would be limitations to the flexibility of the training structure, and I focussed upon the responses that supported my teaching plan. Upon reflection, I think I was expecting quite a prescriptive set of responses that reflected the views and beliefs of the MI originators (Miller & Rollnick, 2002), and in doing so underestimated the high level of existing knowledge and skills the team already held. Following this incident, I proceeded to describe the spirit and principles of MI, using role-play and getting the learners to practise the interaction techniques using a range of exercises.

**Reflection**

I learnt the importance of being able to stay calm when an element of the training did not go to plan, and in doing so was able to develop a strategy to continue with the teaching plan, i.e. focussing on the positives that support the required aims of the task.

**Unit 4.3. Plan and implement assessment procedures for training programmes encompassing psychological knowledge, skills and practices**

As the training was focussed primarily on continuing professional development rather than academic attainment, I did not think it was appropriate to assess the training in relation to an overall qualification.

**Unit 4.4. Evaluate training programmes encompassing psychological knowledge, skills and practices**

I gathered verbal feedback throughout the training and at the end of the training, by constructing an Evaluation Form (see Appendix 3). The Evaluation Form was designed to assess outcomes relating to the acquisition of training needs, presentation style, and strengths and weaknesses of the training. I shared the evaluation findings with the senior support workers, and a number of other support workers, in order to gauge additional verbal feedback; those I spoke to were very positive and supportive on both the quality and content of the material presented. I also completed a 500 word reflective report (see Appendix 4) on a specific aspect of the training, as well as the overall strengths and weaknesses.
There were no negative themes described within the Evaluation Form (see Appendix 5). Two people felt handouts might have been helpful, to have something to write on. One person suggested small group exercises could have been used, someone thought the presentation contained jargon and another picked up that it was difficult to elicit specific information from the learners in the initial stages of the training. I felt I would like to consider a small group exercise in addition to pair and group work, and also provide a basic framework plan of the training in a handout for people to write notes on throughout the session, if they wished.

Reflection
I was pleased with the nature of the comments on the Evaluation Form and the verbal discussions with team members. My main concern was that the support workers felt that they already worked in this way and so the training was inappropriate; I was relieved the feedback did not confirm this. I felt that gaining the feedback was helpful, as it allowed me to interpret how the learners had found the training and provided a level of objectivity to the experience.
References


Teaching and Training 2 Competency Case Study

Application of Stages of Change (SoC) and Self-Determination Theory (SDT) within a Group of Young People with Type 1 Diabetes

Background
The Paediatric Diabetes Nurses’ team is located in the Cornwall Diabetes and Endocrine Centre and provides an NHS service to children and young people with type 1 diabetes. The team also works alongside two paediatric consultants who have a special interest in diabetes and run seven clinics throughout Cornwall. I had been conducting my doctoral research within the team with the aim of exploring the motivational characteristics of young people aged 13-17 years and how they self-managed their regimes. It is on this basis that I thought the findings from the research may be of interest to the team.

Unit 4.1. Plan and design training programmes that enable students to learn about psychological knowledge, skills and practices
As a trainee health psychologist intermittently working within the diabetes team, it was both interesting and invaluable to hear how professional’s and participants’ perspectives regarding diabetes self-management differed in terms of prioritising particular aspects of the regime. As part of my role as a trainee health psychologist and as chief investigator for the project, I had familiarity with the data collection and analysis procedures, as well as with the motivational and Stages of Change literature. The lead diabetes nurse was approached to discuss the possibility of providing some teaching and training within the team; the aim being to share the outcome data retrieved from the study, describing how competent, autonomous and related to the diabetes team 13-17 year olds felt. In addition, to describe which particular stages of change participants could be positioned within regarding their existing regime management behaviours. Past meetings with team members had highlighted how engaging with service users could be difficult during adolescence; understanding their readiness to change and how the team functioned from a motivational perspective was considered to be helpful. While the lead diabetes nurse felt that this was acceptable, she explained that the nurses met each month and, while a training slot could be accommodated, there would be a 45-minute time restriction, and it was unclear whether the consultants would be able to attend.
Preliminary discussions emphasised the importance of a clearly structured presentation with no technical language and a focus upon the applied clinical relevance of the results. Once the teaching plan (see Appendix 1) was confirmed, it was agreed that a PowerPoint presentation would be the most concise format to convey the material; a presentation was assembled and submitted for approval, one particular slide being amended as it contained too much information. To determine the learning objectives of the training, a Needs Assessment Form (see Appendix 2a) was constructed to explore current awareness of the theoretical models, presentation content and training format. Three learning objectives were identified: provide background knowledge (Self-Determination Theory (Deci & Ryan, 2000, 2004) and Transtheoretical Model (Prochaska, DiClemente & Norcross, 1992); describe the research outcomes; and explain their applicability to the diabetes service. The requested teaching format was interactive (lecture with questions and answers); due to the limitation on time, I proposed a PowerPoint presentation would be an effective way to convey detailed information.

The PowerPoint presentation was informed by a number of psychological principles aimed at promoting perceptual, memory and cognitive learning within the session, namely: connect with the learners; direct and hold attention; and promote understanding and memory (Kosslyn, 2007). As the nurses have several years’ experience working with children and young people with type 1 diabetes, a constructivist teaching approach was incorporated. This approach acknowledges the nurses’ existing experiences and knowledge, and, rather than being a transmitter of knowledge, the aim was to guide the facilitation of learning (Kaufman, 2003). This was achieved by creating regular spaces in the presentation to discuss and facilitate responses to the teaching material. This also supports one of Knowles’ (1980) assumptions of andragogy, i.e. adults are more motivated to learn by internal drives than by external ones. This is supported within this teaching approach, as the nurses had an interest in learning different and new methods to engage with young people during adolescence. It was also important that the teaching and training acknowledged the nurses’ knowledge both as adults as well as professionals (Merriam, Caffarella & Baumgartner, 2007). In this sense, the content of the presentation was arranged to incorporate questions that focussed on particular aspects of the research, i.e. “are there any questions regarding the findings from the motivational characteristics of service
Questions were structured to follow each major section of the presentation, enabling the nurses to integrate their existing knowledge alongside the research results regarding motivation and the self-management of type 1 diabetes.

To ensure the presentation’s compatibility and accessibility with the nurses’ computer system, I emailed the presentation (see Appendix 2b) to the lead diabetes nurse and copied it to my email account. On the day of delivery I took a mobile storage device containing the presentation as a back-up. As the presentation was viewed on a computer monitor as opposed to a projection system, font sizes were enlarged and the slides’ colour schemes were defined to distinguish the information being presented. This procedure is described by Kosslyn (2007) as the principle of salience, whereby attention is drawn to large perceptible differences in the material being presented.

Reflection

I felt the small group size and high level of knowledge and skills the diabetes nurses could bring to the teaching and training would be invaluable. A constructivist model of learning would therefore recognise, as well as provide a way of contextualising, the research findings, in order to facilitate the learning process.

Unit 4.2. Deliver training programmes encompassing psychological knowledge, skills and practices

On the day of the presentation, the seating arrangements meant not all the nurses could see the computer monitor. I asked them to re-arrange their seating into a horseshoe formation, therefore promoting an environment for questions and answers (Jacques, 2003). I started the presentation by asking an open-ended question in order to gauge the diabetes nurses’ experiences of dealing with young children’s poor self-management. This was followed by explaining how the research utilised a health psychology framework, in terms of a scientific modality for studying the psychological processes of health, illness and health care (BPS, DHP, 2012). I reiterated the three main aims of the presentation, in order to contextualise the learning process and allow for questions pertaining to each aim. I felt this promoted a cognitive constructivist approach to the learning and provided a vital aspect of the teaching, in order to negotiate new meaning and contextualise the research findings.
within the nurses’ existing knowledge and skills. Tusting and Barton (2003) cite the work of Bruner to highlight a cognitive constructivist theory of instruction:

The basic principles of any subject can be grasped very early on in its study, if the learner is helped to discover the underlying cognitive structure of the subject in a way that both fires their imagination and fits with their existing models of thinking (p. 9).

One of the nurses was keen to understand how the findings related to her caseload. I was able to clarify and validate this point by contextualising the question within the results section of the presentation. Notably, the findings indicated that the nurse promoted young people’s competence and autonomy in terms of self-management; in relation to clinical practice I was able to re-affirm her approach to engaging with service users. This clarification allowed me to facilitate her learning by building on an existing understanding of her impact upon and the nature of her involvement with young people.

Following a description of the theoretical models and how they informed the research and its findings, I wanted to talk about the Stages of Change handouts (Prochaska, Norcross & DiClemente, 2006), in order to demonstrate and facilitate a discussion regarding the practical application of these measures, in terms of identifying self-management-based readiness to change behaviours. This led to the nurses providing some examples of how they had tried in the past to raise young people’s motivation during clinic settings, with the aim of increasing self-management behaviours such as blood glucose monitoring. In addition, I added a slide highlighting healthcare behaviours that support patients’ feelings of competence, autonomy and relatedness (Sheldon, Williams & Joiner, 2003), in order to further promote the practical applications of the findings. Finally, I provided an overview of reflective listening techniques from Miller & Rollnick (2002), in order to highlight some practical ways to promote better communication and engagement with young people during diabetes consultations.
Reflection

During the delivery process I felt it important that the learners gained a context within which to understand Stages of Change and Self-Determination Theory. I provided a number of examples to expand on this knowledge so it became more familiar, e.g. individuals that smoke in the pre-contemplation stage may not be interested in attending a stop smoking intervention. I felt comfortable discussing the models with the nurses as I had previously interviewed a number of children for the qualitative section of my research and was familiar with some of their issues.

Unit 4.3. Plan and implement assessment procedures for training programmes encompassing psychological knowledge, skills and practices

As the training was focussed primarily on continuing professional development rather than academic attainment, it was not appropriate to assess the training in relation to an overall qualification.

Unit 4.4. Evaluate training programmes encompassing psychological knowledge, skills and practices

The feedback procedures for evaluating the teaching were discussed with the lead diabetes nurse in the initial meeting and it was agreed that an Evaluation Form (see Appendix 3) would be used. Following delivery of the presentation, learners were verbally asked about how the information was portrayed. The Evaluation Form used a template from a previous piece of teaching and training which had worked well to gauge training needs, presentation style and the strengths and weaknesses of the training. After I had delivered the presentation, the evaluation findings were summarised and emailed to the lead diabetes nurse (see Appendix 4). A reflective report containing a commentary on the first 15 minutes of the videoed session was completed, along with the identification and consideration of the strengths and weaknesses of the teaching (see Appendix 5).

Within the evaluation report, the average rating for training needs being met was 8.25 out of 10 (1 = not at all, 10 = completely), and the average rating for presentation style was 8 out of 10 (1 = very poor, 10 = very good). The strengths of the training were the descriptions of different theories and frameworks, how explanations were provided for understanding difficult areas and how the presentation related to diabetes.
care. The weaknesses were having the session video-recorded, having too much
detailed information within one slide, needing more patient evaluation and that the
time was too short.

In considering the nature of the feedback, I think the key point that I learnt from the
experience was that, while there were a number of slides in this delivery, most were
included to assist in signposting and to reinforce learning. In future, it would be
interesting to focus delivery specifically on the content slides and to provide more
interaction within small groups, rather than a more lecture-style approach. While the
interactive approach is my preferred style of engagement, I felt that due to the level of
information being conveyed and the time restrictions, a lecture-style approach was
best suited to these circumstances. In ensuring that audience engagement is promoted
and PowerPoint slide content is continuously developed, I shall continue to refer to
Kosslyn (2007).

Reflection
I felt the time constraints placed upon the presentation were unfortunate, as this was
beyond my control. I constructed the slide content to promote learning based on
Kosslyn (2007), and opted for the reiteration of key points and clear signposting to
new information throughout the PowerPoint presentation. In the future, I would like to
experiment with more audience involvement as the medium for information
attainment, rather than reliance upon PowerPoint. Overall, I was pleased the audience
asked questions throughout the presentation, and I attributed this to a genuine interest
in the material.
References


Optional Competency
Unit 5.3

Communicate the Processes and Outcomes of Psychological Interventions and Consultancies

While attending the Cornwall Research Forum Conference, I met a Professor of Rheumatology and arranged to discuss the role of Motivational Interviewing (MI) within musculoskeletal health. During the meeting, the conversation moved towards whether it was possible to develop a way of promoting lifestyle changes for individuals with musculoskeletal health conditions. I highlighted that one of the approaches to utilising MI was a feedback-based approach, whereby the recipient receives feedback from a standardised measure in conjunction with MI. It was from this interaction that we agreed to work on a piece of work to assess whether any standardised lifestyle measures existed within the literature. While I agreed I would conduct the search, the Professor agreed to meet throughout the process.

The aim of the consultancy was to locate one or a number of instruments in order to assess lifestyle, as contextualised by the Bone and Joint Healthy Lifestyle (2005). The objectives were that the instrument should be standardised and/or have normative data applicable to an adult general population. The Bone and Joint Healthy Lifestyle consists of physical activity, ideal weight, balanced diet, smoking and alcohol; where possible, this should also include accident prevention and abnormal or overuse of the musculoskeletal system. Following completion of the consultancy, the results may be used to inform a Brief Intervention (BI), based on Motivational Interviewing (Miller & Rollnick, 2002), within a musculoskeletal population.

In order to investigate the aims and objectives of the consultancy, electronic resources were utilised as the primary source of information-gathering. A number of factors were considered prior to utilising this approach. Firstly, most instruments would probably be described within the materials section of articles, rather in the abstract alone, and gaining full text articles (where database access was restricted) via inter-library loans would not be a viable option because of financial constraints. Secondly, due to the vast search capacity of various host platforms, it would be beyond the scope of this consultancy to explore each result. On this basis, a specific search
strategy was developed that involved accessing any existing systematic or review-based papers, exploring survey-based instruments and searching specific behavioural instrument-based electronic databases.

Initially, the search focussed on locating any existing systematic or review-based papers that may have performed searches to identify lifestyle instruments. This was carried out within four electronic host platforms (EMBASE, Allied and Complementary Medicine, British Nursing Index and OVID Medline), followed by the Cochrane Library:

- **EMBASE (1980 week 20, 2011)**
  A database of references from international literature covering all aspects of psychology and psychiatry.

  A bibliographic database produced by the healthcare information service of the British Library. It covers a selection of journals in complementary medicine, palliative care and several professions allied to medicine.

- **British Nursing Index (BNI) (date not stated)**
  A database of references from popular British nursing and midwifery journals, including a range of nursing, midwifery, health visiting and community healthcare topics.

- **OVID Medline (1948 – May week 2, 2011)**
  A database of references from over 5,000 international health, biomedical and life sciences journals, covering a range of medically-related subjects including nursing, midwifery and dentistry.

The Cochrane Library contained the following resources:

- **Cochrane Database of Systematic Reviews (Cochrane Reviews)**
The CDSR includes all Cochrane Reviews (and protocols) prepared by Cochrane Review Groups in The Cochrane Collaboration.

- **Database of Abstract of Reviews and Effects (Other Reviews)**
  Contains abstracts of systematic reviews that have been quality-assessed. Each abstract includes a summary of the review together with a critical commentary about the overall quality. DARE covers a broad range of health-related interventions and thousands of abstracts of reviews in fields as diverse as diagnostic tests, public health, health promotion, pharmacology, surgery, psychology and the organisation and delivery of healthcare.

- **Cochrane Central Register of Controlled Trials (Clinical Trials)**
  Includes details of published articles taken from bibliographic databases (notably MEDLINE and EMBASE) and other published and unpublished sources.

- **Cochrane Methodology Register (Technology Assessments)**
  A bibliography of publications that report on methods used in the conduct of controlled trials. It includes journal articles, books and conference proceedings, the content is sourced from MEDLINE and hand searches.

- **Health Technology Assessment Database (Technology Assessments)**
  Brings together details of completed and ongoing health technology assessments (studies of the medical, social, ethical and economic implications of healthcare interventions) from around the world.

- **NHS Economic Evaluation Database (Economic Evaluations)**
  Systematically identifies economic evaluations from around the world, appraising quality and highlighting relative strengths and weaknesses.

Once the search for existing systematic and review-based papers had been completed, survey searches were conducted within the following databases:
- **UK National Statistics Publication Hub**
  Contains the latest statistics from government departments in the UK and is the central website for hosting all first releases of National Statistics.

- **NHS Information Centre for Health and Social Care**
  A source of health and social care information, releasing over 120 official and National Statistics every year.

- **Department of Health**
  Contains archived and the latest publications from the Department of Health.

Finally, the remaining electronic searches were carried out using the following databases:

- **European Health Surveys Information Database (EUHSID)**
  Maintains and updates a database of the characteristics of major Health Interview Surveys (HIS) and Health Examination Surveys (HES) in Europe.

- **Health and Psychosocial Instruments (HaPI)**
  HaPI provides abstracted information to approximately 15,000 measurement instruments such as questionnaires, interview schedules, checklists, coding schemes, rating scales, etc. Information is abstracted from hundreds of leading journals covering health sciences and psychosocial sciences, as well as instruments from Industrial/Organisational Behaviour and Education. Coverage is from 1985 to present and contains 145,000+ records.

- **Buros Institute of Mental Measurements: Test Reviews Online**
  Provides access to test reviews online from the Mental Measurements Yearbook and contains 3,500 commercially available tests.

There were no issues regarding confidentiality or security that impacted upon the type of information available to either conduct or present the consultancy outcomes. This allowed for transparency throughout, in terms of communicating the search strategy,
results and conclusions. A technical report (Appendix 1a) was developed predominantly to gather and record information and outcomes relating to the search strategy, it also contains a summary of the consultancy meetings and how decisions informed the search.

Information was entered, edited and stored within Microsoft Word (2003), while the computer system (Hewlard Packard Pavilion PC a6101) was security password-protected. All major decisions regarding process and the direction of the search were taken with the client and summarised within meeting minutes, which were signed by both the client and myself. They were stored in the technical report appendices and all information was used for dissemination purposes; there was no need to store or archive any information.

Consideration was given to assessing the utility of the information, so that it matched the client’s needs. The technical report contained both specific detail relating to how and which resources were searched, as well as guidelines for how the information could be applied in relation to the consultancy aims and objectives. I considered that the consultation relationship between the client and myself, best described by Schein (1999), as the process or helper model, in which the client and the consultant work together to achieve a solution. I felt that in order to create a level of transparency throughout the search process regular review meetings were required; this was agreed with the client. Due to the level of detail and the numerous decisions required to conduct the electronic database search (field types, keyword definitions, truncation and combined searches), the technical report held the majority of data regarding literature search output and process-based decisions. Meetings served to communicate summary-based information and facilitate the decision making process. For example, the lifestyle literature search produced 695 results which were then reduced to 100 items. I was concerned about the level of time and financial resources (inter-library loan fees) required to retrieve and critique potentially 100 items, and discussed with the client whether it may be feasible to consider a realistic strategy for assessing these items. It was agreed at the review meeting that these items should be referenced within the database more than once, which reduced the search to a manageable 21 items and the outcome was reported at the following meeting.
In preparing the technical report for submission to the client, consideration was given to the level of depth to include in the document, and as a result a number of appendices were constructed. In terms of the structure of the technical report, it was agreed at the beginning of the consultancy between the client and myself that the report would contain all the information regarding the search process and the source documents used in the decision making process. On this basis, website links to key documents were added both for reference and ease of access. Minutes were also included in the report and, while they provided a clear summary of the content of meetings, a level of reflexivity was also documented throughout. Reflexivity provides the reader with an additional insight into the decisions made while working within the consultancy process and conducting searches, therefore providing a level of transparency.

In considering the most effective format to structure meetings, I used Kolb’s (1984) theory of learning to facilitate the process of learning and communicate how best to move towards achieving the objectives of the consultancy. The review meetings were contextualised through the learning cycle (concrete experience, reflective observations, abstract conceptualisation and active experimentation):

- **Concrete experience**
  Specific objectives for the consultancy were agreed and a strategy decided and acted upon by the trainee health psychology consultant (i.e. literature searching strategy).

- **Reflective observations**
  Information from literature searches was then fed back to the client at review meetings.

- **Abstract conceptualisation**
  Results were then considered in terms of whether they achieved the consultancy objectives and how further to progress, in terms of practical steps to deal with the information collected, as well as how best to move forward in achieving the aims of the consultancy.
• Active experimentation

The outcome from the review meetings was actively implemented within the search strategy and influenced the future directions of the consultancy process.

My assessment of the client’s learning style was that of Kolb’s accommodator. The learning characteristics of an accommodator are utilising concrete experience, active experimentation and doing things. My experience from working alongside the client was their skill in taking the information collated from the literature search and suggesting options on where best to direct the search, based on the available evidence. On this basis, the meetings were directed and guided by the outcome of my literature searches, rather than the details of the search process.

In order to respond to issues regarding copyright, I felt it important to inform the client that to use information from a number of survey-based documents (Health Survey for England, 2008-9; Drinking: Adults Behaviour and Knowledge in 2009; General Lifestyle Survey, 2009; Office of National Statistics Omnibus Surveys), authors would have to be contacted in order to discuss how and whether it would be possible to gain access to their data collection tools (instrument and data collection software). While the Smoking Related Behaviour and Attitudes (2008-9) Survey does provide questions, once again possible issues regarding how items were formed and compiled, as well as copyright and access were to be taken into account. These are important factors should the application of these documents be considered in terms of further integration within the dissemination process.

I was aware at this stage that the searches and strategies employed had not achieved the required outcomes for locating one or a number of lifestyle measures. On this basis, I met with the client to discuss the level of information gained, highlight the issues regarding existing survey-based information and consider gaining access to an additional database which could specifically focus upon identifying instruments relevant to the consultancy. In order to resolve these concerns, a particular database (Health and Psychosocial Instruments, HaPI) had been identified, which primarily contained behavioural measurement instruments; however; I did not have access to this resource. To resolve this issue, in conjunction with City University and through communications with the Subject Librarian for Social Sciences, trial access was
obtained for a 1-month period. This allowed access to a searchable product with which to identify the status of a number of instruments (i.e. questionnaires, interview schedules, checklists, coding schemes, rating scales, etc.). This contributed to a substantial aspect of the information collated within the technical report, prior to being disseminated.

In considering the most appropriate format to present the findings of the consultancy, I selected Microsoft PowerPoint (2010). It offered a visual format with which to contextualise the varied searches conducted, in order to sustain the maximum level of attention. It also provided a variety of different visual approaches to presenting material, and the 2010 version has a greater selection of slides and transitional applications, as well as a screenshot facility whereby information can be inserted directly onto slides, which may increase the level of visual interest.

While constructing the presentation Kosslyn (2007) was referred to as a key reference guide. Kosslyn uses information based specifically upon perception, memory and cognition and suggests three goals when delivering PowerPoint presentations:

- **Goal 1: Connect with your audience**
  The message should connect with the goals and interests of the audience.

- **Goal 2: Direct and hold attention**
  The presentation should lead the audience to pay attention to what is important.

- **Goal 3: Promote understanding and memory**
  The presentation should be easy to follow, digest and remember.

These goals are achieved through eight psychological principles described as follows:

1) The principle of relevance - Communication is most effective when neither too much nor too little information is presented.
2) The principle of appropriate knowledge - Communication requires prior knowledge of pertinent concepts, jargon and symbols.

3) The principle of salience - Attention is drawn to large perceptible differences.

4) The principle of discriminability - Two properties must differ by a large enough proportion or they will not be distinguished.

5) The principle of perceptual organisation - People automatically group elements into units, which they then attend to and remember.

6) The principle of compatibility - A message is easiest to understand if its form is compatible with its meaning.

7) The principle of informative changes - People expect changes in properties to carry information.

8) The principle of capacity limitations - People have a limited capacity to retain and to process information, and so will not understand a message if too much information must be retained or processed.

These eight principles were incorporated into the presentation in order to achieve the three aforementioned goals.

During the 5th July 2011 review meeting, it was agreed that the PowerPoint presentation would be delivered to the client, as the key recipient of the consultancy. This was achieved on the 1st August 2011, once all electronic searches had been completed and a discussion had been held regarding the final requirements of the consultancy. No specific time scales had been allocated for completion of the consultancy; however within review meetings, targets and dates were identified in order to move towards achieving the consultancy aim. As the consultancy was focussed around the identification of an instrument to assess lifestyle, it was considered that confidentiality would not impact upon this piece of work. The technical report was formatted according to the Publication Manual of the American Psychological Association (APA style fifth edition), and presentation slides were branded with the City University London logo in order to acknowledge my institutional affiliation.

It was considered that an evaluation of the consultancy would be appropriate in order to assess and understand the work completed in terms of what had been achieved.
Collectively it was agreed that the most effective form of evaluation would be for the client to complete a self-report questionnaire and to combine this with a verbal discussion with myself, based on the outcome of the measure. On this basis a questionnaire was developed to accommodate a variety of factors (whether the objectives were met, how the client found the presentation, the technical report and the overall process, as well as any strengths and weaknesses). Likert-type response scales were used, along with a qualitative comments section (Appendix 10).

The evaluation form was completed by the client at the evaluation meeting and used to structure the verbal discussion. There were no weaknesses attributed to any aspect of the consultancy, and a strength was that it had been an iterative process addressing all issues identified. From the evaluation form, one question required clarification as it related to whether the objectives of the consultancy had been achieved. Specifically, the client had rated this question 6 out of 10 (1 - objectives were not at all achieved and 10 - completely achieved). He explained that this was because a lifestyle instrument had not been retrieved from within the literature searches. Nonetheless, the client and I were assured that this reflected that an instrument was not available, rather than that the search strategy had not located one. Finally, we were both pleased with the outcome of the consultancy, as an alternative solution had been achieved in the absence of a suitable lifestyle instrument. While I felt disappointed that we had not retrieved an appropriate measure from the search process, I had explicitly noted from the initial meeting and recorded within the minutes that this consultancy was focused around locating an existing measure, rather than developing one, and I had been clear about this in the early stages of the consultancy process. On this basis, there was always a possibility that a suitable lifestyle measure may not exist within the literature, a feature that had surprised both me and the client.

In terms of dissemination activity, the findings from the consultancy are to be used to support a research proposal for funding towards a pilot study to develop a clinical service aimed at creating lifestyle changes in line with the objectives of the Bone and Joint Healthy Lifestyle (2005). Specifically, the use of the SF-36v2 health survey would be utilised in conjunction with a clear Motivational Interviewing-based question, which focuses on the Bone and Joint Healthy Lifestyle recommendations:
Question - “if we think about different areas of lifestyle such as physical activity, ideal weight, balanced diet, smoking and alcohol (accident prevention and abnormal overuse of musculoskeletal) which would you like to think about changing?”

It was agreed that the SF-36v2 could facilitate a structured discussion with individuals, as well as providing normative data regarding physical and mental health-related factors. This would act as a comparative factor for promoting a Motivational Interviewing-based Brief Intervention for individuals with musculoskeletal difficulties. In conjunction, a Lifestyle Information Sheet (Appendix 8), which was also produced as part of the solution in the absence of an established lifestyle instrument, would be implemented to assess and collect baseline lifestyle information.
References


Optional Competency
Unit 5.8

Disseminate Psychological Knowledge to
Address Current Issues in Society

The presence of stress and its relationship to children was a feature of the 3-year follow-up survey regarding the emotional development and well-being of children and young people (Office of National Statistics, 2008). This supported the second national survey assessing prevalence of children’s mental health and well-being (Office of National Statistics, 2005). The 2008 findings indicated that children experiencing three or more stressful life events, such as family bereavement, divorce or serious illness are significantly more likely to develop emotional and behavioural disorders. It found that 3% of children who did not have an emotional or behavioural disorder in 2004 developed one by 2007, with family, household and social characteristics strongly linked to the onset of one or more disorders. Among these factors, exposure to stressful life events was strongly linked with the development of emotional disorders.

The onset of emotional disorders included family structure, namely those living within single-parent households being more likely to develop disorders, number of children in the family and the mental health of the mother. The study also reviewed factors associated with the persistence of existing disorders, with 30% of children diagnosed as having emotional disorders in 2004 still experiencing them by 2007, and family, household and social characteristics were again strongly linked to persistence (Office of National Statistics, 2008).

Having identified the societal factors within the United Kingdom, such as prevalence levels and some of the associated factors influencing the onset of emotional and behavioural disorders within children, we were interested in understanding the impact parental stress had on young children referred to the Scallywags scheme. This was primarily, as Lovering & Caldwell (2003) had identified, because the aim of the scheme was to intervene as early as possible with children identified as at risk of developing behavioural and emotional problems. Cited research from Egeland (1990) suggested that children up to the age of 8 had less entrenched difficulties, and with
entry into pre-school and primary school being such an important time, the age range for referral was placed at between 3 and 7 years of age.

Earlier research suggested that, as the frequency of children’s disruptive behaviours increased, spouse support may be less effective in buffering maternal parenting stress (Eyberg, Boggs & Rodriguez, 1992). A review article into parental stress and externalised child behaviours suggested that it was likely that the more parental stress increased, perceptions of current child behaviour diminished in accuracy and parents were then more likely to be influenced by their long-standing beliefs about the child’s behaviour. Parents were also likely to focus on negative aspects of their child’s behaviour, attributing the stress to the child rather than the situation (Morgan, Robinson & Aldridge, 2002). It has also been demonstrated that cumulative parental stress affects parenting behaviour and the quality of parent-child interactions within naturalistic settings for children aged 3-5 years of age (Crnic, Gaze & Hoffman, 2005).

Research also indicates that evidence-based parenting programmes such as the Webster-Stratton Incredible Years (see The Incredible Years website http://www.incredibleyears.com), delivered within the community and in the voluntary sector, provide effective interventions for children at risk of developing conduct disorders (Gardner, Burton & Klimes, 2006; Hutchings, 2007). Both studies suggest that child behaviour might be mediated through parent behaviour and the learning of key parenting skills. This was highlighted in an evaluation of the Parents Plus Early Years Programme (Sharry, Guerin, Griffin & Drumm, 2005), working with children that have behavioural and developmental difficulties, which found significant reductions in conduct problems and reduced parental stress through the use of a combination of parent-child video feedback and parenting group sessions over a 12-week period. Additional intervention components aimed at addressing parental stress and supplementing existing evidence-based therapy for children referred for aggressive and antisocial behaviour have also been effective. They provided enhanced therapeutic change for child and parent, as well as reducing barriers that they might experience during the intervention process (Kazdin & Whitley, 2003).
The Scallywags scheme (Lovering, Frampton, Crowe, Moseley & Broadhead, 2006) is a multi-component intervention for young children who are at risk of developing emotional and/or behavioural difficulties (for a detailed structural description of the scheme see Lovering & Caldwell, 2003). It is tailored to the needs of young children, and as part of the scheme it also conducts work with and alongside the child’s parents and teachers, to promote and develop greater competencies to prevent the development of more serious problems. On this basis, it has always been of interest to understand the relationship between parental stress and how it impacts on emotional difficulties in the context of the scheme.

The scheme is based in Cornwall and works with children aged 3-7 years who have emotional and/or behavioural difficulties. Each family is allocated a support worker that works with a child for 6 months, offering 8 hours per week between the home and school environment (5 hours at school and 3 hours at home). The scheme initially utilised a range of approaches (Rhodes, 1993; Slough & McMahon, 2008; Webster-Stratton, 1992), and both the scheme and its support workers continually utilise an evidence-based approach to inform their practice and create change as defined by targets agreed at the start of the intervention, in conjunction with an educational psychologist. Parents are also offered the opportunity to attend the Where Adults Get Support (WAGS) group. This runs for 10 weeks throughout the 6-month intervention and is aimed at sharing successes, teaching coping skills and providing a supportive environment.

In 2003, Lovering & Caldwell published a research review and project evaluation of Scallywags at time 1 (pre-intervention), time 2 (post-intervention) and time 3 (6-month follow-up), which contained findings from the 103 participants (parents and children aged 3-7 years) who completed the scheme between the period of January 2000 and August 2001. The results demonstrated that children involved in the intervention had significant reductions in emotional and behavioural problems at both home and school, which was maintained up to 6 months after completion of the scheme. In addition, parents showed a significant improvement in their parental stress levels post-intervention, as measured by the Abidin Parenting Stress Index (Abidin, 1995). In 2006, Lovering, Frampton, Crowe, & Linn published the long-term effectiveness of Scallywags with 81 families. The study used the core measures
utilised in the original study (Lovering and Caldwell, 2003) with the addition of the Strengths and Difficulties Questionnaire (Goodman, 1997), to compare comparisons with the Office of National Statistics’ survey data on the mental health of children (Meltzer, Gatward, Goodman & Ford, 2000). One of their findings was that 2-3 years after finishing the scheme, parents still reported significant reductions in stress levels compared to when they initially started.

Based on the support for evidence-based programmes and the research relating to the psychological factors associated with parental stress, the efficacy of the Scallywags scheme provides a unique opportunity to explore the relationship between parental stresses and conduct difficulties in children involved with the service. With such good outcomes associated with the scheme, this adds to the relevance of the parental stress question: whether parental stress creates or promotes conduct difficulties in younger children, or indeed whether the conduct issues create stress for the parent. The efficacy of the scheme may help to answer this question, as it allows a constant factor to measure improved behaviour and parental stress levels.

Psychological stress and coping have been studied and well documented within the academic literature for a number of years. A great deal of consideration and thought has gone into the differing methodological approaches, both qualitative and quantitative, in order to accurately measure the construct of stress (Aldwin, 2007). Within this study we were interested in understanding the relationship between parental stress (parental distress, parental-child dysfunctional interaction and difficult child sub-scales) and conduct difficulties (intensity and problem sub-scales) before and after the Scallywags scheme. This methodology was possible as the previous evaluation studies supported the efficacy of the intervention, and the dataset contained information regularly collected by the service for their own audit purposes, and as such was accessible for analysis.

The design of the study focussed on the 6-month period of the scheme. Questionnaires were completed within cohorts 2–14 (no questionnaires were administered within the first year of the service and the parental stress measure was no longer used following cohort 14). The design was within-subjects, and parents completed the psychometric questionnaires at pre- and post-intervention stages. To ensure the statistical validity
and reliability of the parental stress construct and conduct difficulties, psychometrically standardised measures were used.

Parental stress was assessed using the Parenting Stress Index/Short Form 3rd Edition (PSI/SF) (Abidin, 1995). This is a standardised self-report measure containing 36 items. Items can be calculated to obtain a Total Stress score from three sub-scales. The first sub-scale is Parental Distress, which assesses the level of distress a parent experiences within their role as the parent, due to personal factors associated with parenting. The second sub-scale assesses Parent-Child Dysfunctional Interaction, which measures the parent’s perception that their child does not meet their expectations and the relationship between parent/child is not reinforcing. Finally, the third sub-scale is called the Difficult Child and assesses the behavioural features of the child. Psychometrically, the factor structure, reliability (test/re-test and internal consistency), and validity are described within the manual (Abidin, 1995). It has also been used to assess parental stress among high-risk families in relation to the nurturing of cognitive stimulation among pre-school children (Saltaris, 2004).

Conduct difficulties were measured with the Eyberg Child Behaviour Inventory (ECBI) (Eyberg & Pincus, 1999), which assesses conduct problems in children aged between 2 and 16 years of age. This is a standardised questionnaire containing 36 items rated on two scales. The Intensity scale indicates frequency of behaviour and the Problem scale identifies whether the child’s behaviour is problematic for the parent or not. Psychometrically, the manual describes good internal consistency for both intensity and problem scales, test/re-test reliability and inter-rater reliability (Eisenstadt, McElreath, Eyberg & McNeil, 1994). Convergent and discriminant validity have also been assessed within a number of studies, as well as sensitivity to treatment (Boggs, Eyberg & Reynolds, 1990; Eyberg, Boggs & Rodriguez, 1992; McNeil, Eyberg, Eisenstadt, Newcomb & Funderburk, 1991). The measure has successfully been used to evaluate a parenting programme for parents of pre-school children considered to be at risk of developing conduct disorders (Hutchings et al., 2007).

To ensure the analyses were meaningful and statistically representative, both PSI and ECBI datasets were screened for outliers to ensure the minimum/maximum scores
were in the appropriate range for each sub-scale. Scores from the PSI utilise a raw-to-percentile conversation, while the ECBI uses T scores as the standardised linear transformation for each raw score. The assumption that the data was normally distributed was assessed using the Kolmogorov-Smirnov test for goodness of fit. Distributions not normally distributed had parallel analyses run to assess the impact of normality using transformed data (Hinton, 2004). Unless the distributions impacted upon significance levels, original distributions were used throughout. Post-hoc power analyses were conducted based on a large effect size (Faul, Erdfelder, Lang & Buchner, 2007; Howell, 1997).

The thinking regarding how best to work with the dataset in order to accurately understand parental stress and its relationship to the children’s emotional and behavioural difficulties was discussed with other colleagues involved in the research. These consisted of the senior educational psychologist/senior manager for the Scallywags service and an assistant psychologist. It was agreed that initially a paired samples t-test could be used to understand the level of difference between mean scores pre- and post-intervention. The findings demonstrated significant reductions across the PSI (total stress, parental distress, parent-child dysfunctional interaction and difficult child sub-scales) as well as the ECBI (intensity and problem scores).

The dataset was then split according to clinical and non-clinical levels of parental stress, as defined by the ECBI (a raw score of 90 or above represented clinical significance). The findings demonstrated that clinically stressed parents at the start of the intervention reported significantly higher levels of conduct difficulty (intensity and problem) than the non-clinical group. Significantly higher levels of stress were also located within the PSI (total stress, parental distress, parent-child dysfunctional interaction and difficult child sub-scales). The same findings were found at the post-intervention stage.

In order to understand the relationship between parental stress and conduct difficulties throughout the intervention, parental stress was assessed pre-intervention and later at post-intervention according to whether stress levels increased, decreased or did not change. At the post-intervention stage, conduct difficulty was also assessed according to increased, decreased or no change status. Within these groupings the mean
differences in conduct difficulties for both intensity and problem categories were in a negative direction following completion of the intervention, regardless of changes in parental stress. Upon statistical analysis, the findings demonstrated that for parents whose stress levels had decreased, conduct difficulties also significantly reduced, more than when there were no changes or an increase in parental stress.

These findings suggest that reductions in parental stress occur regardless of direction of change (increased, decreased or no change); stress alone is not the sole factor associated to behaviour difficulties in the scheme. The findings also demonstrate the relationship between high levels of stress and high levels of disruptive behaviour. This reinforces the structure of the Scallywags service in providing dedicated time to home and school environments, in order to work with adults (parents and school staff) as well as children to understand and change behaviours.

Finally, the analyses explored the relationship to demographic variables (region, child’s age/gender/ethnicity, marital status, number of siblings) using regression analysis. In preparation for the analysis, only a small percentage of the items were black/mixed ethnicity on both parental and child variables, therefore these were combined. For region, marital status and siblings, dummy categories were created and base categories were selected using the largest variable within each category. Mahalanobis distances and box plots were used to assess and control for outliers.

Upon analysis, siblings, marital status, ethnicity (child, mother and father), age (mother and father) and child’s gender did not represent significant models for predicting parental stress. Models that were significant suggested that parental stress levels increased with the number of WAGS sessions attended. To explore this in greater detail, parental stress was assessed pre- and post-intervention amongst those who attended WAGS. The results indicated that for those parents who attended WAGS at the end of the scheme, 84.2% had decreased parental stress scores. The child’s age was another significant model and indicated that the younger the child the greater the level of parental stress. Finally, the region the parent came from was also a significant model for indicating parental stress, with the most westerly (Penwith) and northerly (North Cornwall) regions of Cornwall showing a significant correlation with total stress ratings at the post-intervention stage.
In discussing these findings, the results matched the experiences of the scheme. The regional effect was considered to be intriguing, and further investigation revealed no particular region stood out as an independent predictor. This was described through staff turnover impacting on the regional teams, levels of conduct difficulty and socio-economic status.

In thinking about the options for working with the dataset, and to monitor the validity of the data analyses, discussions were held through City University in the form of statistics drop-in sessions. In addition, the final results were discussed with the NHS Research and Development Department, who had agreed to offer an opinion on the techniques and findings. The overall content was regularly discussed amongst those in the Scallywags service, and opinions on the outcome of the results discussed with a range of colleagues within the team, to assess the credibility of the findings attained in the paper.

It had always been the aim of researchers to disseminate the paper to a wider audience, and therefore a journal format seemed the appropriate option. In particular, a title that was interested in the findings and had an association with children that had emotional and behavioural difficulties. One such journal is Emotional and Behavioural Difficulties (EBD). The publisher, Taylor & Francis, describe the aim and scope of the journal:

The central intention of *Emotional & Behavioural Difficulties* (EBD) is to contribute to readers' understanding of social, emotional and behavioural difficulties, and also their knowledge of appropriate ways of preventing and responding to EBDs, in terms of intervention and policy.

The journal aims to cater for a wide audience, in response to the diverse nature of the professionals who work with and for children with EBDs, this audience includes:

- Teachers in mainstream, non-mainstream and special schools/facilities.
- Social workers in residential and field settings.
- Professionals concerned with EBDs in medical and psychiatric settings.
- Educational and clinical psychologists, counsellors and psychotherapists.
Those concerned with the training and support of workers in the above groups, such as teacher and social work trainers, consultants and advisers.

- Researchers and academics concerned with the needs and interests of the above groups.
- Professionals from the above groups engaged in in-service training as part of their professional development, including those pursuing award-bearing courses (see Taylor & Francis website).

The manuscript was accepted by the journal in light of the reviewers’ comments. The Editorial Assistant stated that changes were to be made using the Central Article Tracking System (CATS) within a specific time scale. CATS was developed for Taylor and Francis in order to track the status of journal articles, contact the production editor, review page proofs and submit corrections online, as well as downloading forms and ordering reprints. As an author I was provided with a username and password to access the system and work within it to make changes. These were successfully achieved (see Appendix 1) in conjunction with the other assisting authors.

There were minor changes to be made and a summary of these are as follows:

- An expansion of the term WAGS within the abstract.
- In the introduction, more information regarding the scheme to be included and the word paternal to be changed to parental, as well as adding the sample size of a previous study (Lovering, Frampton, Crowe, Moseley & Broadhead, 2006).
- Within the method section, further details of the participants (age and gender), as well as explaining the missing data in more detail.
- For the instruments paragraph, more detail provided regarding the psychometric qualities of both the Abidin (PSI) and Eyberg (ECBI) measures.
- For the results section, the reviewers were unclear why there were more questionnaires completed at the post- rather than pre-stage, and a single word was changed regarding the terminology used within the regression analysis.
• Within the discussion section, more reference to existing knowledge was required.

Once the changes had been agreed and proofs corrected for the publisher, the offer of 50 free reprints was accepted in order to further disseminate to interested individuals and/or groups. Copyright was assigned to the Social, Emotional and Behavioural Difficulties Association (SEBDA); therefore ensuring full copyright protection and allowing for a wider dissemination of the article, via print and electronic formats. The paper was published in the June 2009 issue (see Appendix 2, in portfolio):

References


SECTION D

Systematic Review
A Systematic Review of Motivational Interviewing within Musculoskeletal Health

Abstract

Motivational Interviewing (MI) has been investigated within a range of healthcare environments, though to date no studies have systematically assessed its application and effectiveness within musculoskeletal health. The aim of this study is to identify interventions that have utilised MI to create change within musculoskeletal healthcare, evaluate quality and effectiveness, as well as identify the level of training received by those utilising the approach. The search strategy identified both published and unpublished or grey literature through electronic resources, reference list and content searches. Five studies were identified for quality assessment. Due to variations in delivery modality, musculoskeletal condition and type of MI application, it was not possible to provide direct comparative interpretations for these factors. A data synthesis was used to provide a summary of study characteristics, a narrative overview and conduct a quality assessment, as well as considering authors’ comments on study limitations. The results of the quality assessment highlighted a number of methodological issues, which supported and expanded upon those expressed by the studies’ authors. None of the studies contained children or young people, and in terms of training, there were variations in training provider, duration and competency, as well as variation in the fidelity of MI. The findings have highlighted the need for well-designed randomised controlled trials that are suitably powered to measure the effectiveness of MI within musculoskeletal health. Future studies may consider the application of MI within musculoskeletal conditions in terms of self-management and its application to creating lifestyle changes (e.g. diet, exercise) for adults, as well as children and young people. Research currently being conducted may expand upon the evidence, feasibility and validity of MI within areas such as fibromyalgia, osteoporosis, arthritis, understanding of knee replacement and rehabilitation.
Background

The Department of Health’sMusculoskeletal Services Framework (DoH, 2006) highlights over 200 musculoskeletal conditions responsible for an estimated 30% of general practitioner (GP), primary care consultations, affecting nearly one-quarter of adults and approximately 12,000 children. It is the aim of the Musculoskeletal Service Framework to provide an appropriate level of information, support and treatment for those with musculoskeletal conditions. While at a European level, a Bone and Joint Decade report (Bone and Joint Decade, 2005a) produced guidance for the prevention and treatment of musculoskeletal conditions aimed at the healthcare practitioner, this was accompanied by a public health strategy to reduce the burden of musculoskeletal conditions (Bone and Joint Decade, 2005b). While these reports provide recommendations and frameworks relating to public health, prevention and treatment, there is also a need to understand how to best convey this guidance and information in order to engage with people either experiencing, or at risk of, musculoskeletal difficulties, and to create sustainable behavioural change at a person-centred level.

The Bone and Joint Decade (2005a, 2005b) noted a number of interventions for the prevention and management of musculoskeletal conditions, which they considered within four main groups (lifestyle, pharmacological, surgical and rehabilitative). In terms of lifestyle, a variety of strategies for the prevention and reduction of the impact upon different musculoskeletal conditions include behaviours such as physical activity, ideal body weight, balanced diet, smoking, alcohol, accident prevention, abnormal use and overuse of the musculoskeletal system, as well as raising public and individual awareness. Creating behavioural change to accommodate treatment recommendations or lifestyle-based changes can be particularly confounded when individuals appear ambivalent to making changes within their lives that may alter the burden of their condition.

Within the literature a number of articles (Connelly & Ehrlich-Jones, 2010; Dart, 2011; Shannon & Hillsdon, 2007) have stated that clients respond readily to Motivational Interviewing (MI), and that it seems well-suited for use within consultations by healthcare professionals working with musculoskeletal problems. Motivational Interviewing (Miller & Rollnick, 2002; Rollnick, Miller & Butler, 2008)
is described by Rollnick and Miller (1995) as “a directive, client-centered counseling style for eliciting behavior change by helping clients to explore and resolve ambivalence” (p. 326). Previous reviews have considered MI in a number of different applications, such as Brief Interventions (BI) (Dunn, Deroo & Rivara, 2001), and meta-analysis of controlled clinical trials investigated Adaptations of Motivational Interviewing (AMI) (Burke, Arkowitz & Menchola, 2003). Hettema, Steele and Miller (2005) suggested that, in terms of addictive and health behaviour, MI is useful both as a BI and also as a way of improving outcomes when added to other treatment approaches.

MI has been investigated in a range of healthcare environments (Britt, Hudson & Blampied, 2004; Martins & McNeil, 2009; Rollnick, Miller & Butler, 2008). Knight, McGowan, Dickens and Bundy (2006) systematically reviewed MI within physical care settings and located studies within type 1 diabetes (adolescents) and type 2 diabetes (overweight adults, overweight women), asthma, hyperlipidaemia, hypertension, coronary artery bypass surgery and cardiac rehabilitation (coronary artery disease). While the authors concluded that MI had the potential to be an effective intervention, due to the inadequate quality of trials, such as low levels of internal content validity amongst RCTs and other studies, small sample sizes, lack of power, use of disparate multiple outcomes, a need for the universal use of validated questionnaires and poorly defined therapy and training, further research was required. Rubak, Sandboek, Lauritzen & Christensen (2005) concluded that in 80% of studies investigated (smoking cessation, weight loss/physical activity, alcohol abuse and psychiatrics/addiction), MI outperformed traditional advice giving.

In terms of musculoskeletal health, recent systematic reviews have investigated behavioural treatments for chronic low back pain (Henschke et al., 2010), as well as interventions to improve adherence to exercise for chronic musculoskeletal pain in adults (Jordan, Holden, Mason & Foster, 2010). To date no studies have systematically assessed the application and effectiveness of MI specifically within musculoskeletal health. Understanding the current use and effectiveness of MI within specific areas of musculoskeletal health would inform the direction of future research, in order to understand the effectiveness of utilising this approach within musculoskeletal healthcare.
As musculoskeletal conditions are not solely located within the adult age group (DoH, 2006), children and young people will also be included in the inclusion criteria. It has been suggested that, from a developmental perspective, children require appropriate interventions within a healthcare setting that acknowledges their capacity of causal reasoning, language ability, self-understanding and their environmental context, in order to fully integrate interventions that match the child’s development characteristics. Furthermore, in the context of Motivational Interviewing, it has been queried whether younger children, who may have limited ability to form long-term goals and experience ambivalence between future goals and current behaviour, would benefit from Motivational Interviewing-based interventions (Erickson, Gerstle & Feldstein, 2005). A number of later review articles have demonstrated the role of Motivational Interviewing within physical health care settings for children and young people, such as type 1 diabetes (Anderson, Svoren & Laffel, 2007; Borus & Laffel, 2010), paediatric obesity (Perrin, Finkle & Benjamin, 2007; Resnicow, Davis, Rollnick, 2006) and paediatric health behaviour change (Suarez & Mullins, 2008), and therefore this age group will not be excluded from the current review.

In terms of the level of training required to attain proficiency within MI, it has been demonstrated that attendance at a training workshop may only produce limited skill improvement (Miller & Mount, 2001). It has been suggested that proficiency in MI occurred only when systematic feedback on performance and/or personal skill coaching is involved (Rollnick et al., 2008). It has also been suggested that future studies should adequately report how those implementing the intervention were trained (Hetterma et al., 2005). On this basis, the level and competency of MI delivery within interventions will also be assessed in this study, as this may have an important impact on outcome and provide helpful insight for practitioners considering using MI within a clinical context. A basic scoping exercise located no existing review articles relating to motivational interviewing and musculoskeletal health (see Appendix A).

**Objectives**

To summarise the available literature and provide a detailed overview of the application and effectiveness of Motivational Interviewing within musculoskeletal conditions. Specific objectives were as follows:
• Identify all interventions that have utilised MI to create change within musculoskeletal health.
• Evaluate the quality and effectiveness of these interventions.
• Identify the level of MI training received by those utilising the approach.

*Inclusion Criteria*

The systematic review question was framed in terms of Population, Intervention, Comparator, Outcome and Study design (PICOS) (Centre for Reviews and Dissemination (CRD), 2009). The requirements of inclusion in the initial stages of the search were to be as broad as possible to fulfil the aims of the study:

• Population – Identify individuals that have a musculoskeletal condition (no age restrictions).
• Intervention – The intervention should contain all or partial elements of MI and can be in combination with another intervention.
• Outcome – All outcomes to be recorded (e.g. physical and psychological).
• Study designs – No search restrictions to be placed on study design or language

*Exclusion Criteria*

In order to allow the search to be as inclusive as possible, no formal exclusion criteria were placed on the search criteria.
Search Strategy

A range of sources were selected to appropriately identify studies matching the inclusion criteria (CRD, 2010). The search strategy identified both published and unpublished or grey literature through electronic resources and reference list searches. Language bias was reduced by not placing language restrictions upon the search strategy. Dissertation and thesis-based articles were not included in this search.

Electronic Searches

To ensure as accurate a representation of musculoskeletal conditions as possible, two search strategies were employed. Firstly, the keyword *musculoskeletal* was entered and a search conducted using the databases indexing facility, or Medical Subject Heading (MeSH) descriptors (see Appendix B for MeSH search strategy). Secondly, a number of free text terms were collated from the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) (Version 2007), Chapter 10 - Diseases of the musculoskeletal system (see Appendix C for ICD-10 search strategy). Each search was combined with the phrase *motivational interviewing*. For clarity and transparency of content, each database was searched individually. A full description of characteristics for each database is provided in Appendix D. The electronic search was conducted between 25th February and 15th March 2011.

Search Sensitivity

In order to access the maximum amount of relevant results within the search strategy, a number of permutations using a variety of search tools (map term, thesaurus, permuted index, scope note, explode, subheadings) and keyword functions were experimented with. Pilot searches were conducted on EMBASE and Medline predominantly with exploded/indexed functions. In order to assess the validity of the pilot search, it was repeated by an external individual (Subject Librarian for Social Sciences at City University). Recommendations from this process related to the use of MeSH (Medical Subject Headings), a review of truncated ICD-10 terms and the possible use of quotation marks (“…”) rather than OR and AND Boolean operators. In addition, while conducting searches across differing databases, each one was
reviewed in terms of how it utilised truncation, Boolean operators and special characters.

Published Literature
The following databases were searched without language restrictions: Allied and Complementary Medicine (AMED) (1985 – February 2011); British Nursing Index (BNI) (1985 - 2011); Cochrane Library - Cochrane Database of Systematic Reviews (CDSR), Database of Abstracts of Reviews of Effects (DARE), Cochrane Central Register of Controlled Trials (CENTRAL), Cochrane Methodology Register (CMR), Health Technology Assessment (HTA); Cumulative Index to Nursing and Allied Health Literature (CINAHL) (1982 – 2011); EMBASE Psychiatry (10 years ago to present); MEDLINE (1948 to February week 3 2011); and PsycINFO (1800’s - 2011). The bibliography section of the Motivational Interviewing website (see Motivational Interviewing website) was also searched. See Appendix C for full keyword and search strategy per database.

Unpublished or Grey Literature and Conference Proceedings
In order to minimise publication bias, unpublished or grey literature was also searched without language restrictions, using the following sources: National Research Register (NRR) Archive (early 2000 to September 2007) – NRR Records from Regional and National Research Programmes, NRR Records from Research Centres: Lead Centres for Multi-centre projects, NRR Records from Research Centres: Single-centre projects, NRR Records from Research Centres: Participating Centres for Multi-Centre Projects; ClinicalTrials.gov; System for Information on Grey Literature (OpenSIGLE); National Technical Information Service (NTIS) (1964 - 2011); Health Management Information Consortium (HMIC) (1979 - 2011); and ISI Web of Science – with Conference Proceedings. Due to the varied range of journals in which Motivational Interviewing articles are published, the PubMed Journals Database (1950 - 2011) was also used to identify any journals that required hand-searching. Finally, all records from the Index of Conference Proceedings at the British Library were checked as part of the Document Supply Conference File on the Integrated Catalogue.
**Study Selection**

Both MeSH and ICD-10 free text search results were screened by the author (RC) for reference to a musculoskeletal condition and the phrase motivational interviewing. If there was doubt about the presence of a musculoskeletal condition or the phrase motivational interviewing, then the full text article was retrieved to provide an accurate representation of study content (Chokkalingam, Scherer & Dickersin, 1998; Hopewell, Eisinga & Clarke, 2008). Once relevant studies had been identified, they were then assessed for duplication across databases. This was then followed by an assessment of the article in terms of it being a review, original article, article, letter, commentary, practice, evidence-based practice, protocol, book, chapter, design paper, conference material or a registered trial. These articles were removed and later screened for additional references (content and reference list search).

**Quality Assessment**

In order to evaluate the quality and effectiveness of the interventions, both assessors (RC & independent psychologist [MW]) reviewed the included studies. An inter-rater reliability analysis using the Kappa statistic was performed to determine agreement between the two raters. Differences were discussed until agreement was met, where this was not possible a third assessor was approached (health psychology supervisor [RP]).

Quality assessment was carried out through a checklist approach, rather than the use of a scale-based and summary-score approach, to assess high and low quality, which is considered questionable on the basis of a lack of standardisation regarding validity and reliability (CRD, 2009). In selecting an appropriate checklist for this study, consideration was given to a range of methods and related evidence for evaluating bias, such as selection bias within non-randomised studies (Deeks et al., 2003). A checklist by Downs and Black (1998) was selected as it was developed for both randomised as well as non-randomised studies (see Appendix E). It has also been used in other systematic reviews to collate and interpret information (Cusimano, Nassiri & Chang, 2010).
Summary of Search Effectiveness

Electronic Databases

Following the initial MeSH and ICD-10 title and abstract screening, 62 full text articles were retrieved (unless abstract was sufficient, i.e. Broderick, 2011). From the 62, six articles were removed as they were not a musculoskeletal population, non-intervention-based or had no Motivational Interviewing content. See Table 1 for results of the electronic database search.

Table 1. Results of Initial and Combined MI and MeSH/ICD-10 (Title/Abstract) Search

<table>
<thead>
<tr>
<th>Database</th>
<th>Results (Combined MI/MeSH)</th>
<th>Screened (Title/Abstract)</th>
<th>Results (Combined MI/ICD-10)</th>
<th>Screened (Title/Abstract)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pub Med</td>
<td>90</td>
<td>12</td>
<td>47</td>
<td>16</td>
</tr>
<tr>
<td>The Cochrane Library</td>
<td>34</td>
<td>2</td>
<td>47</td>
<td>3</td>
</tr>
<tr>
<td>PsycINFO</td>
<td>0</td>
<td>0</td>
<td>64</td>
<td>10</td>
</tr>
<tr>
<td>Cumulative Index to Nursing and Allied Health Literature (CINAHL)</td>
<td>45</td>
<td>6</td>
<td>47</td>
<td>8</td>
</tr>
<tr>
<td>British Nursing Index (BNI)</td>
<td>8</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Allied and Complementary Medicine (AMED)</td>
<td>20</td>
<td>2</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>MEDLINE</td>
<td>64</td>
<td>12</td>
<td>26</td>
<td>13</td>
</tr>
<tr>
<td>EMBASE Psychiatry</td>
<td>158</td>
<td>14</td>
<td>48</td>
<td>19</td>
</tr>
<tr>
<td>Health Management Information Consortium (HMIC)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>MI Bibliography</td>
<td>-</td>
<td>-</td>
<td>1236**</td>
<td>28</td>
</tr>
<tr>
<td>ISI Web of Science</td>
<td>-</td>
<td>-</td>
<td>40</td>
<td>16</td>
</tr>
<tr>
<td>British Library – Index of Conference Proceedings</td>
<td>-</td>
<td>-</td>
<td>3*</td>
<td>3</td>
</tr>
<tr>
<td>ClinicalTrials.gov</td>
<td>-</td>
<td>-</td>
<td>330*</td>
<td>8</td>
</tr>
<tr>
<td>OpenSIGLE</td>
<td>-</td>
<td>-</td>
<td>2*</td>
<td>0</td>
</tr>
<tr>
<td>National Technical Information Service (NTIS)</td>
<td>-</td>
<td>-</td>
<td>9*</td>
<td>0</td>
</tr>
<tr>
<td>National Research Register (NRR)</td>
<td>-</td>
<td>-</td>
<td>0*</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>419</td>
<td>49</td>
<td>1905</td>
<td>126</td>
</tr>
</tbody>
</table>

Total results - title and abstract screened (Duplicates) 
49 (29) 126 (65)

Remainings studies
20 61

MeSH and ICD-10 studies combined (17 duplicates, 2 non-musculoskeletal population removed)
62

Removed (not musculoskeletal population, non-intervention based, no MI content)
6

Excluded (reviews, original articles, articles, letters, commentaries, practice, evidence-based practice, protocols, books, chapters, design papers, supplement, conference material, registered trial)
46

Overall total for QA (sub-group)
8 (2)

*Not a combined search, motivational interviewing used only. **Not combined, only reference checked.
1See Appendix H for full reference list and article categorisation.
Reference List and Content Search

In order to locate any additional references not identified by the electronic search, the reference lists and content of the remaining 56 articles were searched. Table 2 provides a summary of the reference list and content search.

Table 2. Summary of Full Text Reference List and Content Search

<table>
<thead>
<tr>
<th>Article type</th>
<th>Number of articles</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full text articles retrieved</td>
<td>16</td>
</tr>
<tr>
<td>Article assessed online or from abstract</td>
<td>27</td>
</tr>
<tr>
<td>Suitable for quality assessment</td>
<td>1</td>
</tr>
</tbody>
</table>

*See Appendix H for full reference list and article categorisation.*

Conference Proceedings

Three conferences were identified as possible sources of information relevant to the inclusion criteria:

1) First International Conference on Motivational Interviewing (ICMI): Helping people change - latest research, leading experts and practical workshops, across a broad range of problems and settings. Interlaken, Switzerland 9th - 11th June, 2008.
2) 70th Annual Scientific Meeting of the American College of Rheumatology/41st Annual Scientific Meeting of the Association of Rheumatology Health Professionals, Washington, DC, 10th - 15th November, 2006.

Where possible authors were contacted to enquire about study status (published/unpublished, study ongoing) and whether further information was available (Braun et al., 2006; Ehrlich-Jones, Mallinson, Fischer & Chang, 2006; Kesavalu, Lydon, Bigatti, Lane & Ang, 2006a, 2006b).

ClinicalTrials.gov

Nine studies were identified for further investigation (ClinicalTrials.gov identifiers: NCT00968266, NCT00573612, NCT00248105, NCT00249587, NCT00324857, NCT00567294, NCT00979719, NCT00170118, NCT00365404). Where it was unclear whether clinical research or clinical trials were ongoing or completed and not
published, authors were contacted where possible to enquire about study status (published/unpublished, study ongoing) and whether any further information was available.

Language
Other than English, German (Rau, Ehlebracht-Konig & Petermann, 2008; Rau & Petermann, 2008) and French (ICMI Conference Report, 2008) were the other forms of language identified. In order to ascertain whether the content met the inclusion criteria for this study, the text was extracted from scanned articles and transferred into Microsoft Word using optical character recognition (OCR) software (http://f59inereader.abbyy.com/) It was then copied from Microsoft Word and pasted into a free online translation program (http://translate.google.com/#). Due to the quality of the translation, it was not possible to identify whether Rau, Ehlebracht-Konig and Petermann (2008) was suitable for inclusion. The French ICMI Conference Report (2008) did not contain material that matched the inclusion criteria.
Results

Included Studies
The search strategy identified five studies where MI was used to create change, specifically with chronic pain (Habib, Morrissey & Helmes, 2005), low back pain (Leonhardt et al., 2008; Vong, Cheing, Chan, So & Chan, 2011), fibromyalgia (Ang, Kesavalu, Lydon, Lane & Bigatti, 2007) and osteoporosis (Cook, Emiliozzi & McCabe, 2007).

Excluded Studies
Four studies were identified that contained participants with a musculoskeletal condition and where MI had been utilised to create change. While these studies met the objectives and inclusion criteria for the systematic review, they were not included for further quality assessment on the basis of population composition, study design and insufficient information regarding the study (ClinicalTrials.gov identifier NCT00249587; Heapy, Stroud, Higgins & Sellinger, 2006; Linden, Butterworth & Prochaska, 2010; Ravesloot, 2009). Similarly, a poster abstract entitled Longstanding Pain and Brief Motivational Multidisciplinary Intervention was also excluded due to a limitation on study information (Surtevall, Lindstrm & Sterner, 2009).

Ongoing Research
A number of ongoing investigations were located (Ang et al., 2011; ClinicalTrials.gov identifier NCT00324857; ClinicalTrials.gov identifier NCT00979719; Ehrlich-Jones et al., 2010; Solomon et al. 2010).

Data Synthesis
The final search results indicated that, due to the variation of studies in terms of delivery modality, musculoskeletal condition and type of MI application, for the purposes of this investigation a meta-analysis would not be suitable. A narrative overview is therefore provided to incorporate greater detail regarding the nature of the intervention (aims, description, design, follow-up, training). A summary of the authors’ limitations was also noted, along with outcomes from the quality assessment process. Table 3 provides a summary of study characteristics, and to minimise
extraction errors and reduce bias, both RC and MW independently completed the Data Extraction Form (see Appendix G). Once complete, the findings were compared and any disagreements, uncertainties or N/A responses (31% overall) were discussed until consistency was achieved. While a third person (RP) was available should any unresolved disagreement occur, this was not required.

Table 3. Study Characteristics of Included Studies

<table>
<thead>
<tr>
<th>Article (author, location, setting, intervention, recipients)</th>
<th>Musculoskeletal Condition</th>
<th>Study Design</th>
<th>Intervention (type, delivery role)</th>
<th>Outcome Measures</th>
<th>Results (summary)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leonhardt et al. (2008) – German primary care setting, Adult</td>
<td>Low back pain</td>
<td>Multi-centre cluster-randomised trial</td>
<td>TTM-based motivational counselling</td>
<td>FQPA, Self-efficacy*, Stages of change*</td>
<td>No evidence of an intervention effect</td>
</tr>
<tr>
<td>Yong et al. (2011) – Physical therapy department, Adult</td>
<td>Low back pain</td>
<td>Double-blinded randomised controlled trial</td>
<td>Motivational Enhancement Therapy (MET)</td>
<td>PSEQ, PRES, Pain intensity (VAS), Physical function* RMDQ, SF-36, Home exercises log</td>
<td>MET significantly improved aspects of motivation, physical capacities, self-perceived general health and exercise compliance</td>
</tr>
<tr>
<td>Habib et al. (2005) – Setting unclear (prior to community-based pain management workshop), Adult</td>
<td>Chronic pain **</td>
<td>Randomised controlled trial</td>
<td>Preparation for Pain Management Intervention-Brief Intervention (BI)</td>
<td>Workshop attendance</td>
<td>Participants in the treatment group were significantly more likely to attend workshops</td>
</tr>
<tr>
<td>Cook et al. (2007) – Community-based (telephone), Adult</td>
<td>Osteoporosis</td>
<td>Non-randomised trial</td>
<td>ScriptAssist Telephonic Counselling Program</td>
<td>Adherence levels, Pharmacy fill records</td>
<td>Participants referred to ScriptAssist were significantly more adherent than the general population</td>
</tr>
</tbody>
</table>

*See article for full description/reference. **Diagnosis characteristics (N - control/intervention group) - disc condition (23/14), neuropathic (7/8), rheumatoid arthritis (1/1), fibromyalgia (4/3), osteoarthritis (4/6), headache (0/1), congenital abnormality (0/3), unknown diagnosis (0/3). FQPA - Freiburger Questionnaire on Physical Activity; PSEQ - Pain Self-Efficacy Questionnaire; PRES - Pain Rehabilitation Expectation Scale; VAS - Visual Analogue Scale; RMDQ - Roland Morris Disability Questionnaire; SF-36 - Short-Form Health Survey; FIQ - Fibromyalgia Impact Questionnaire; BPI - Brief Pain Inventory (short-form); AIMS - Arthritis Impact Measurement Scale.

Results of Quality Assessment

The two assessors (RC & MW) independently completed the quality assessment. Inter-rater reliability was $\kappa = 0.328$ ($p < 0.001$), 95% CI (0.1587, 0.4975) and was interpreted (Landis & Koch, 1977) as a fair level of agreement (see Appendix I for calculation details). Discussions were held in order to collate a final opinion; any
disagreements or missing data were discussed and a consensus agreed upon between both assessors, no aspects of the process required a third party (RP).

The findings for all included studies were collated into a Quality Assessment Summary Table (see Appendix F). The following comments relate specifically to limitations regarding Reporting, External Validity, Internal Validity (bias), Interval Validity (confounding - selection bias) and Power as identified by the Downs and Black (1998) checklist, and are presented in two formats:

1) A summary of findings that relate to a clear consensus across all or 80% of the studies.
2) Remaining findings presented per study.

This format also allows for a comparison to be gauged in relation to the study authors’ limitations, providing an overall combined assessment.

**Summary of Findings**

( ) = question number (Downs & Black, 1998).

While this section provides a summary account, where there is a consensus across all or 80% of studies, due to the diversity of the MI applications, musculoskeletal findings and study design, the findings should be considered on an individual basis.

**Reporting**

(5) None of the studies provided a list of, or identified, any principal confounders at the onset of the study.
(8) No adverse events as a consequence of the intervention were provided.

**External Validity**

(11) It was not possible to determine whether the subjects asked to participate in the studies were representative of the entire population from which they were recruited.
(12) Studies did not state, or it was not possible to determine, whether those participants recruited had a similar distribution of confounding factors as the source population.
(13) Studies did not state, or it was not possible to determine whether, the staff, places or facilities with which the participants were treated were representative of those that the majority of patients receive.

**Internal Validity - bias**

(14)(15) With the exception of Vong et al. (2011), studies did not state, or it was not possible to determine, whether participants and those measuring the main outcomes were blinded to the intervention.

(19) It was not possible to determine whether compliance with the intervention was reliable.

**Transtheoretical Model (TTM)-Based Motivational Counselling**

*(Leonhardt et al., 2008)*

This study aimed to assess the effects of a TTM-based motivational counselling approach to increasing physical activity in patients with low back pain. Interventions based on the TTM were tailored to the patient’s motivation and readiness to change.

The study contained three study arms: for groups A and B, General Practitioners (GPs) delivered a German Low Back Pain guideline, with practice nurses inviting participants in group B for up to three counselling sessions (duration 15-20 minutes per session); the control group (group C) received the guideline by mail. Follow-up was conducted at 6 and 12-month periods.

In terms of training, practice nurses were trained in general counselling skills (such as active listening, paraphrasing, verbal affirmation and reinforcement), TTM-based counselling and the Motivational Interviewing style. They learned to identify particular stages of change and use stage-specific counselling strategies. Through the pre-action stages, they learned to focus on active listening, expressing empathy and identifying ambivalence, while at the action stages, to incorporate a more direct style using reinforcement and direct advice, and an emphasis was placed on change coming from the patient. Emphasis was placed on interactive exercises and role-play. Nurses received supportive material such as factsheets, wording suggestions and reminders, and were provided with all written material used throughout the training. The training
was evaluated by paper and pencil test (stage identification and matching of specific counselling procedure to stage).

Authors’ Study Limitations
The authors noted that there was a reliance on self-report data, low response rate from physicians (14% of invited practices) and that informed consent favoured participation of individuals interested in physical activity. They concluded that the findings were most probably due to the initially high motivation of physicians, nurses and the participants involved in the study, and therefore likely to be a biased sample.

Quality Assessment (Downs & Black, 1998)
Reporting
(2) Partial information reported regarding outcome measures used in the study.

Internal Validity - bias
(20) Due to partial reporting, unable to determine the validity or reliability of all the main outcome measures.

Internal Validity - selection bias
(24) Unable to determine whether intervention assignment was concealed from both patients and healthcare staff until recruitment was complete.
(25) Unable to determine whether there was adequate adjustment for confounding within the analyses of the main findings.

Power
(27) Power not reported.

Motivational Enhancement Therapy (MET)
(Vong et al., 2011)

The aim of this study was to investigate whether the addition of MET to conventional physical therapy (PT) produced better outcomes than PT alone for individuals with chronic low back pain. The MET content was based on MI strategies and a review of
the research literature for motivation-enhancing factors. It was piloted to assess validity for individuals with pain and modified according to feedback. Both participants and the assessor were blinded to either MET plus PT or PT only. The PT group received 10, 30-minute PT sessions in 8 weeks, which included 15 minutes of interferential therapy and a tailor-made back exercise program. For the MET group, participants received MET within their PT sessions. The physical therapists incorporated MET into the PT sessions using MI skills and psychosocial components aimed at enhancing motivation to engage in treatment and creating behavioural change. Treatment time for both groups was kept within the 30 minutes, and participants were followed up at 1 month.

Training was provided by a clinical psychologist, who provided MET or general communication skills training (PT only group). Therapist communication was observed and evaluated using a checklist (5-point MET strategy scale) by an investigator who had received MI and counselling training. The results reflected the requirements of either the MET plus PT group or the PT group.

Authors’ Study Limitations
The authors noted that the study had a limited follow-up (1 month). Due to the “intention to treat” method of managing the data, the results may not represent the 10 participants (MET plus PT group) and 11 participants (PT group) that dropped out. While the training hours of the physical therapists were shorter than the MI Network of Trainers recommend, this was addressed by the training being similar to other studies, as well as including a 2-week trial to standardise performance. Authors stated that participants were screened in a formal interview and by checking medical records. People with obvious depression and anxiety problems or a history of psychiatric problems were excluded from the study, and therefore there may be limitations on generalising findings to patients with such conditions.

Quality Assessment (Downs & Black, 1998)
Internal Validity - selection bias
(22) Unable to determine the time period over which participants were recruited.
Preparation for Pain Management Intervention  
(Habib et al., 2005)

The aim of this pilot study was to develop and evaluate the Preparation for Pain Management Profile (PPMP) for increasing engagement in pain management workshops within the community. The PPMP was developed and administered in a Motivational Interviewing, Brief Intervention-based format by psychologists. The treatment group received a brief (two-session) intervention containing a semi-structured assessment (approximately 1-1.5 hours) and feedback interview (approximately 1.5 hours) based on the PPMP and delivered in a Motivational Interviewing style. The control group received a standard plan assessment (approximately 1-1.5 hours) and an attention placebo interview (up to 1 hour). There was no follow-up in this study. In terms of training, the study described the interviewers as registered, practising psychologists having intensive training in Motivational Interviewing techniques.

Authors’ Study Limitations
The authors noted that 12 participants (5 control and 7 treatment group) had a diagnosis of osteoarthritis or rheumatoid arthritis and suggested that being in a remission or acute phase during the study had the potential to slightly affect the findings, only self-managing when symptoms were present. Researchers re-analysed the data with these participants excluded and found no significant change. Demand characteristics were questioned, as both interviewers had intensive training in MI. To control for this, the interviews were semi-structured and interviewers were required to follow that format. Future recommendations involved excluding individuals who have chronic conditions, characterised by fluctuations between remission and recurrent acute phases, and also using the Motivational Interviewing Skill Code (Moyers, Martin, Catley, Harris & Ahluwalia, 2003) to ensure treatment fidelity to Motivational Interviewing.

Quality Assessment (Downs & Black, 1998)
Reporting
(9) No follow-up.
(10) Actual $p$ values not stated (only <05, <01).

*Internal Validity - bias*

(17) No follow-up.

*Internal Validity - selection bias*

(24) Unable to determine whether randomised intervention assignment was concealed from both participants and healthcare staff until recruitment was completed.

(26) No follow-up.

*Power*

(27) Power was not reported.

**Exercise-Based Motivational Interviewing**

*(Ang et al., 2007)*

The aim of this pilot study was to investigate the effect of Exercise-Based Motivational Interviewing on patients’ self-reported pain and physical function. Participants received two, weekly educational classes (30 minutes each, weeks 1-2). The first class provided information on fibromyalgia and the importance of exercise a handwritten, individualised exercise prescriptions and heart rate monitors were also given out. The second class focussed on barriers to exercise adherence. Both classes were taught by a rheumatology fellow, and at the end of each lecture participants received a 15-minute supervised exercise session with a fitness instructor. Over the following 10 weeks (weeks 3-12), participants received six sessions of telephone-delivered counselling (each averaging 25 minutes). Participants were followed up at week 30.

In terms of training, the motivational interviewer was a third-year doctoral student in clinical psychology. Prior to the intervention their MI training was within a classroom environment, with further training through videotapes and textbooks. While delivering the intervention, they received weekly supervision with a clinical psychologist; activities related to the fidelity of treatment, discussion of each
participant’s progress, and evaluation of techniques, in which audiotapes and role-play were used. Finally, there were discussions regarding the differences between MI and other frequently used techniques, such as cognitive behavioural therapy (CBT). It is also noted in the study that an MI technique for chronic pain (Jensen, 2002b) was also adapted to promote exercise adherence.

Authors’ Study Limitations
In respect of study limitations, the authors stated that as there was no control group, the findings may be subject to regression to the mean, and that the use of self-report measures to assess outcomes limited objectivity. Finally, they stated that research participants are usually more motivated than non-research fibromyalgia patients, and therefore the influence of a selection bias was also questioned.

Quality Assessment (Downs & Black, 1998)
Internal Validity – selection bias

Power
(27) Power was not reported.

ScriptAssist Telephonic Counselling Program
(Cook et al., 2007)

The aim of this study was to evaluate the ScriptAssist telephonic program to improve osteoporosis medication adherence. The intervention was delivered via telephone by one of four registered nurses at the ScriptAssist call centre. Participants were screened either as at-risk (for future non-adherence) and received a median of five telephone contacts, or low-risk (for future non-adherence) and received a median of three telephone contacts; the average call duration for both groups was 15.3 minutes. Participants were followed up for an average of 4.1 months after the start of the treatment. In terms of training, the patient counselling was described as being delivered by “call centre nurses trained in motivational interviewing and cognitive-behavioural therapy techniques” (p. 446).
Authors’ Study Limitations

The authors commented that the lack of a randomised control group impacted on the internal validity of the study. They attempted to address this by using two valid, but independent measures of treatment adherence and comparing the participants to a national reference group and a small group of non-participants. The authors suggested that future research could consider the effect of patient education within psychologically based interventions, to address high attrition rates and follow up high-risk participants.

Quality Assessment (Downs & Black, 1998)

Reporting

(4) Interventions were not clearly described.

(7) No data regarding estimates of random variability were given for the main outcomes.

(9) The characteristics of patients lost to follow-up were not described.

Internal Validity - bias

(17) Unable to determine if analyses were adjusted for different lengths of follow-up, or whether the time period between intervention and outcome was the same for the cases and controls.

Internal Validity - selection bias

(21) Participants were not from the same population, and a national baseline was used as comparison data.

(22) Unable to determine whether participants were recruited over the same period of time.

(23) Participants were not randomised to an intervention group.

(24) Participants were not randomised.

(25) Unable to determine whether adequate adjustment for confounding was conducted in the analysis, no confounding factors were mentioned.
Discussion

The objective of this systematic review was to provide a detailed overview of the application and effectiveness of Motivational Interviewing within musculoskeletal conditions. Specifically, to identify all interventions that utilised MI to create change within musculoskeletal health, evaluate the quality and effectiveness of those interventions and identify the level of MI training received by those utilising the approach. The data synthesis provided a summary of study limitations expressed by the investigating authors themselves, as well as independent quality assessment (Downs & Black, 1998) by two assessors (RC and MW). In order to understand and interpret the findings, they will be discussed in terms of quality and effectiveness, children and young people, training and ongoing research considerations.

Due to the variation in delivery modality (telephone, face-to-face, assessment/feedback, within treatment), musculoskeletal condition (low back pain, chronic pain, fibromyalgia, osteoporosis) and type of MI application (TTM-based motivational counselling, Motivational Enhancement Therapy, Preparation for Pain Management Intervention, Exercise-Based Motivational Interviewing, the ScriptAssist Telephonic Counselling Program), it was not possible to provide direct comparative interpretations on delivery modality, musculoskeletal condition or type of motivational intervention.

Quality and Effectiveness of Studies

While the Down and Black (1998) checklist highlighted a number of study-specific features, described in the results section, there were also commonalities identified across the studies. The studies did not report any principal confounders at the onset of investigation, or whether there were any adverse effects as a consequence of the intervention. In terms of external validity, it is not possible to accurately understand how representative the findings were and whether they could be generalised to the population from which the participants were derived. With the exception of Vong et al. (2011), studies did not state, or it was not possible to determine, whether participants and those measuring the main outcomes were blinded to the intervention. It was also not possible to determine whether compliance with the intervention was reliable.
The authors provided some salient comments regarding methodology. In terms of a TTM-based motivational counselling approach for individuals with low back pain (Leonhardt et al., 2008), they suggested a need to provide a representative study, as well as use objective non-self report measures in order to reliably assess validity of findings. Vong et al. (2011) noted that limited follow-up restricted understanding of the long-term impact of their application of Motivational Enhancement Therapy (MET) for individuals with low back pain, and due to the exclusion of psychiatric problems, could not comment on those individuals who had low back pain with depression or anxiety. For both Ang et al. (2007) and Cook et al. (2007), the lack of a comparative or control group limited the validity of the findings due to concerns regarding internal validity. These methodological issues mean it is not possible to draw firm conclusions regarding the outcomes of these studies.

In contrast, Habib et al. (2005) provide evidence in their pilot study of the Preparation for Pain Management Intervention for attaining enhanced engagement for community-based CBT pain management workshops (74.4% of participants in the intervention group attended workshops, in comparison to 41% in the control group). These findings reflect a feedback-based approach or Adaptation of Motivational Interviewing (AMI) (Burke et al., 2003), whereby the individual is given feedback based on individualised results from a standardised assessment measure, which is delivered in a Motivational Interviewing style (Miller & Rollnick, 2002). Further research may explore other adaptations of the feedback approach as a supplement to engagement in other musculoskeletal health-related interventions.

While there are limitations in methodological quality within the studies assessed, the literature does reflect an interest in Motivational Interviewing and how it can be applied to musculoskeletal health. This interest can be observed within a range of articles covering such areas as osteoporosis (Gleeson et al., 2009), pain (Jensen, 1996, 2000, 2002a, 2006; Kerns, Bayer & Findley, 1999; Kerns & Habib, 2004; Novy, 2004; Okifuji & Ackerlind, 2007; Osborne, Raichle & Jensen, 2006; Sanders, Donahue & Kerns, 2007; Turk, Swanson & Tunks, 2008), fibromyalgia (Gowans & deHueck, 2006; Jones, Burckhardt & Bennett, 2004) and arthritis (Hammond, 2003).
Children and Young People

While a body of research exists in terms of reviewed literature exploring the application of MI for children and young people within healthcare (Anderson et al., 2007; Borus & Laffel, 2010; Perrin et al., 2007; Resnicow et al., 2006; Suarez & Mullins, 2008), the findings from this systematic review did not locate any research specifically aimed at understanding the impact of Motivational Interviewing within musculoskeletal health for children or young people; nor were there any 0-17 year olds located within any of the selected studies.

It has also been suggested that MI interventions are versatile enough to be viable in a variety of different settings, such as primary care, with preliminary evidence suggesting the clinical utility of MI approaches for young people in both healthcare and non-health-care settings (Sindelar, 2004). To date, limited studies exist that have utilised randomised controlled trials in order to understand the application of MI for young people within clinical practice (Edwards & Titman, 2010). This was also confirmed in this review regarding musculoskeletal health, where no children’s studies were located. It has been suggested that the non-judgemental, supportive, non-coercive and exploratory approach of Motivational Enhancement Therapy (MET) could be adopted within the paediatric clinic when assessing issues of adherence (Lask, 2003; Taddeo, Egedy & Frappier, 2008), and that MI could also be used as a behavioural intervention to improve treatment adherence for paediatric patients, as well as their families (Gance-Cleveland, 2005).

Training

While it is not possible to speculate on the relationship between training provision and outcome due to variations across studies, with the exception of limited descriptive information from Habib et al. (2005): “psychologists trained in Motivational Interviewing” (p. 51) and Cook et al. (2007): “call center nurses trained in motivational interviewing and cognitive-behavioural techniques” (p. 446), differences were observed with regards to training provider, duration and competency. Supervision was not mentioned as a component of training for the physical therapists (Vong et al., 2011), while the interviewer within the Ang et al. (2007) study received weekly supervision with a clinical psychologist and the nurses in the Leonhardt et al. (2008) study received between one and three supervision sessions (profession
unknown). Current research suggests that the most effective methods for training and learning Motivational Interviewing include a combination of traditional workshops followed by extended coaching and clinical supervision. Additionally, clinical sessions can be coded to identify strengths and areas for improvement (see Motivational Interviewing website).

**Ongoing Research**

While this review has identified a number of methodological considerations which impact on the validity of the findings, it has also identified a number of currently ongoing investigations that report using more robust RCT-based study designs. Firstly, following on from the pilot study (Ang et al., 2007), Ang et al. (2011) are investigating the application of telephone-delivered Exercise-Based MI counselling for fibromyalgia. Secondly, Solomon et al. (2010) are investigating the application of telephone-based counselling informed by MI to improve adherence to osteoporosis treatment. Thirdly, Ehrlich-Jones et al. (2010) are researching the impact of a tailored health promotion programme to increase physical activity among individuals with arthritis. Fourthly, ClinicalTrials.gov identifier NCT00324857 (Principal Investigator Ibrahim, S.A.) is exploring the efficacy of interventions (Motivational Interviewing and a decision-aid video) to improve understanding of knee replacement risks, benefits and expected outcomes amongst primary care African Americans. Finally, ClinicalTrials.gov identifier NCT00979719 (Principal Investigator Lippke, S.) is investigating how a computer expert system can assist in helping rehabilitation patients to adopt and maintain a physically active lifestyle. It is hoped that due to improved research design, once completed, these studies may provide greater validity to the varied applications of MI within musculoskeletal health.

**Conclusion**

This systematic review has provided an understanding of the current evidence-base, as well as the diverse nature with and applications upon which MI can be utilised within musculoskeletal health. While there are limitations regarding study quality in a number of the included studies, there is limited evidence to support the application of a feedback-based Adaptation of Motivational Interviewing to enhance engagement in community-based CBT pain management workshops (Habib et al., 2005).
The search strategy identified a number of ongoing studies in which MI is being applied to improve exercise for fibromyalgia patients, adherence to osteoporosis treatment, increase physical activity among individuals with arthritis, improve understanding of knee replacement risks, benefits and expected outcomes, and help rehabilitation patients to adopt and maintain a physically active lifestyle. Such studies may help expand and evidence the feasibility and validity of MI within the area of musculoskeletal health. Future studies may consider the application of MI for children and young people with musculoskeletal conditions, in terms of direct applications to the condition (self-management regimen) or lifestyle changes (e.g. diet, exercise), as well as for adult populations.

In terms of clinical practice, the evidence at the point of conducting the systematic review is limited, predominantly because of methodological factors and specific applications of MI within particular areas of musculoskeletal health. Ongoing research currently being undertaken may provide much needed evidence to clarify that status of utilising MI for musculoskeletal conditions.
References


http://apps.who.int/classifications/apps/icd/icd10online/


## Appendix 1 - Research

### Stages of Change Questionnaire

For each question, please tick one box that best describes your behaviour.

<table>
<thead>
<tr>
<th>Question 1 - Do you monitor your blood glucose levels at least once or twice a day?</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Yes, I have been for <strong>MORE</strong> than 6 months.</td>
</tr>
<tr>
<td>b) Yes, I have been for <strong>LESS</strong> than 6 months.</td>
</tr>
<tr>
<td>c) No, but I intend to in the <strong>next 30 days</strong>.</td>
</tr>
<tr>
<td>d) No, but I intend to in the <strong>next 6 months</strong>.</td>
</tr>
<tr>
<td>e) No, and I do <strong>NOT</strong> intend to in the <strong>next 6 months</strong>.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question 2 - Do you eat appropriately to manage your diabetes (e.g. regular carbohydrates and a bedtime snack)?</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Yes, I have been for <strong>MORE</strong> than 6 months.</td>
</tr>
<tr>
<td>b) Yes, I have been for <strong>LESS</strong> than 6 months.</td>
</tr>
<tr>
<td>c) No, but I intend to in the <strong>next 30 days</strong>.</td>
</tr>
<tr>
<td>d) No, but I intend to in the <strong>next 6 months</strong>.</td>
</tr>
<tr>
<td>e) No, and I do <strong>NOT</strong> intend to in the <strong>next 6 months</strong>.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question 3 - Do you inject yourself with insulin as recommended by your diabetes team?</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Yes, I have been for <strong>MORE</strong> than 6 months.</td>
</tr>
<tr>
<td>b) Yes, I have been for <strong>LESS</strong> than 6 months.</td>
</tr>
<tr>
<td>c) No, but I intend to in the <strong>next 30 days</strong>.</td>
</tr>
<tr>
<td>d) No, but I intend to in the <strong>next 6 months</strong>.</td>
</tr>
<tr>
<td>e) No, and I do <strong>NOT</strong> intend to in the <strong>next 6 months</strong>.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question 4 – Do you exercise regularly?</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Regular Exercise is any <em>planned</em> physical activity (e.g., brisk walking, aerobics, jogging, bicycling, swimming, rowing, etc.) performed to increase physical fitness. Such activity should be performed <em>3 to 5 times</em> per week for <em>20-60 minutes</em> per session. Exercise does not have to be painful to be effective but should be done at a level that increases your breathing rate and causes you to break a sweat).</td>
</tr>
<tr>
<td>a) Yes, I have been for <strong>MORE</strong> than 6 months.</td>
</tr>
<tr>
<td>b) Yes, I have been for <strong>LESS</strong> than 6 months.</td>
</tr>
<tr>
<td>c) No, but I intend to in the <strong>next 30 days</strong>.</td>
</tr>
<tr>
<td>d) No, but I intend to in the <strong>next 6 months</strong>.</td>
</tr>
<tr>
<td>e) No, and I do <strong>NOT</strong> intend to in the <strong>next 6 months</strong>.</td>
</tr>
</tbody>
</table>
### Appendix 2 - Research
#### The Health Care Climate Questionnaire - HCCQ

This questionnaire contains items that are related to your diabetes team. Diabetes teams have different styles in dealing with patients, and we would like to know more about how you have felt about your encounters with your diabetes team. Your responses are confidential. Please be honest and candid.

1. I feel that my diabetes team has provided me choices and options.
   - 1: strongly disagree
   - 2: strongly disagree
   - 3: Neutral
   - 4: strongly agree
   - 5: strongly agree
   - 6: strongly agree
   - 7: strongly agree

2. I feel understood by my diabetes team.
   - 1: strongly disagree
   - 2: strongly disagree
   - 3: Neutral
   - 4: strongly agree
   - 5: strongly agree
   - 6: strongly agree
   - 7: strongly agree

3. My diabetes team conveys confidence in my ability to make changes.
   - 1: strongly disagree
   - 2: strongly disagree
   - 3: Neutral
   - 4: strongly agree
   - 5: strongly agree
   - 6: strongly agree
   - 7: strongly agree

4. My diabetes team encourages me to ask questions.
   - 1: strongly disagree
   - 2: strongly disagree
   - 3: Neutral
   - 4: strongly agree
   - 5: strongly agree
   - 6: strongly agree
   - 7: strongly agree

5. My diabetes team listens to how I would like to do things.
   - 1: strongly disagree
   - 2: strongly disagree
   - 3: Neutral
   - 4: strongly agree
   - 5: strongly agree
   - 6: strongly agree
   - 7: strongly agree

6. My diabetes team tries to understand how I see things before suggesting a new way to do things.
   - 1: strongly disagree
   - 2: strongly disagree
   - 3: Neutral
   - 4: strongly agree
   - 5: strongly agree
   - 6: strongly agree
   - 7: strongly agree
Appendix 3 - Research
Perceived Competence for Diabetes Scale - PCDS

Please respond to each of the following items in terms of how true it is for you with respect to dealing with your diabetes. Use the scale:

1. I feel confident in my ability to manage my diabetes.
   
   1 2 3 4 5 6 7
   not at all true somewhat true very true

2. I am capable of handling my diabetes now.
   
   1 2 3 4 5 6 7
   not at all true somewhat true very true

3. I am able to do my own routine diabetic care now.
   
   1 2 3 4 5 6 7
   not at all true somewhat true very true

4. I feel able to meet the challenge of controlling my diabetes.
   
   1 2 3 4 5 6 7
   not at all true somewhat true very true
### Appendix 4 - Research
**Treatment Self-Regulation Questionnaire - TRSQ**

There are a variety of reasons why patients take their medications, check their glucose, follow their diet, or exercise regularly. Please consider the following behaviours and indicate how true each of these reasons are for you. The scale is:

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>not at all true</td>
<td>somewhat true</td>
<td>very true</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**A) I take my medications for diabetes and/or check my glucose because:**

(Please write score in box)

1. Other people would be mad at me if I didn't.
2. I find it a personal challenge to do so.
3. I personally believe that controlling my diabetes will improve my health.
4. I would feel guilty if I didn't do what my doctor said.
5. I want my doctor to think I'm a good patient.
6. I would feel bad about myself if I didn't.
7. It's exciting to try to keep my glucose in a healthy range.
8. I don't want other people to be disappointed in me.

**B) The reason I follow my diet and exercise regularly is that:**

9. Other people would be upset with me if I didn't.
10. I personally believe that these are important in remaining healthy.
11. I would be ashamed of myself if I didn't.
12. It is easier to do what I'm told than to think about it.
13. I've carefully thought about my diet and exercising and believe it's the right thing to do.
14. I want others to see that I can follow my diet and stay fit.
15. I just do it because my doctor said to.
16. I feel personally that watching my diet and exercising are the best things for me.
17. I'd feel guilty if I didn't watch my diet and exercise.
18. Exercising regularly and following my diet are choices I really want to make.
19. It's a challenge to learn how to live with diabetes.
# Appendix 5 - Research

Table of Mean and Standard Deviations for HCCQ, PCS and TSRQ Questionnaires

<table>
<thead>
<tr>
<th>Question</th>
<th>Mean (SD)</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HCCQ</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. I feel that my diabetes team has provided me choices and options.</td>
<td>5.58(1.370)</td>
<td>33</td>
</tr>
<tr>
<td>2. I feel understood by my diabetes team.</td>
<td>5.52(1.460)</td>
<td>33</td>
</tr>
<tr>
<td>3. My diabetes team conveys confidence in my ability to make changes.</td>
<td>5.58(1.324)</td>
<td>33</td>
</tr>
<tr>
<td>4. My diabetes team encourages me to ask questions.</td>
<td>5.61(1.321)</td>
<td>33</td>
</tr>
<tr>
<td>5. My diabetes team listens to how I would like to do things.</td>
<td>5.50(1.285)</td>
<td>34</td>
</tr>
<tr>
<td>6. My diabetes team tries to understand how I see things before suggesting a new way to do things.</td>
<td>5.39(1.368)</td>
<td>33</td>
</tr>
<tr>
<td><strong>PCS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. I feel confident in my ability to manage my diabetes.</td>
<td>5.42(1.62)</td>
<td>33</td>
</tr>
<tr>
<td>2. I am capable of handling my diabetes now.</td>
<td>5.42(1.56)</td>
<td>33</td>
</tr>
<tr>
<td>3. I am able to do my own routine diabetic care now.</td>
<td>5.58(1.46)</td>
<td>33</td>
</tr>
<tr>
<td>4. I feel able to meet the challenge of controlling my diabetes.</td>
<td>5(1.77)</td>
<td>33</td>
</tr>
<tr>
<td><strong>TSRQ</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>B) I take my medications for diabetes and/or check my glucose because:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Other people would be mad at me if I didn’t. Other people would be mad at me if I didn’t. (C)</td>
<td>3.97(2.10)</td>
<td>32</td>
</tr>
<tr>
<td>2. I find it a personal challenge to do so. (A)</td>
<td>2.81(1.77)</td>
<td>32</td>
</tr>
<tr>
<td>3. I personally believe that controlling my diabetes will improve my health. (A)</td>
<td>6.34(1.04)</td>
<td>32</td>
</tr>
<tr>
<td>4. I would feel guilty if I didn’t do what my doctor said. (C)</td>
<td>3.84(2.07)</td>
<td>32</td>
</tr>
<tr>
<td>5. I want my doctor to think I’m a good patient. (C)</td>
<td>4.47(1.72)</td>
<td>32</td>
</tr>
<tr>
<td>6. I would feel bad about myself if I didn’t. (C)</td>
<td>4.44(1.92)</td>
<td>32</td>
</tr>
<tr>
<td>7. It’s exciting to try to keep my glucose in a healthy range. (A)</td>
<td>2.97(2.07)</td>
<td>32</td>
</tr>
<tr>
<td>8. I don’t want other people to be disappointed in me. (C)</td>
<td>4.75(1.97)</td>
<td>32</td>
</tr>
<tr>
<td><strong>B) The reason I follow my diet and exercise regularly is that:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Other people would be upset with me if I didn’t. (C)</td>
<td>3.47(2.05)</td>
<td>32</td>
</tr>
<tr>
<td>10. I personally believe that these are important in remaining healthy. (A)</td>
<td>5.69(1.47)</td>
<td>32</td>
</tr>
<tr>
<td>11. I would be ashamed of myself if I didn’t. (C)</td>
<td>4.31(1.91)</td>
<td>32</td>
</tr>
<tr>
<td>12. It is easier to do what I’m told than to think about it. (C)</td>
<td>3.84(2.26)</td>
<td>32</td>
</tr>
<tr>
<td>13. I’ve carefully thought about my diet and exercising and believe it’s the right thing to do. (A)</td>
<td>4.44(1.81)</td>
<td>32</td>
</tr>
<tr>
<td>14. I want others to see that I can follow my diet and stay fit. (C)</td>
<td>4.94(1.87)</td>
<td>32</td>
</tr>
<tr>
<td>15. I just do it because my doctor said to. (C)</td>
<td>2.72(1.85)</td>
<td>32</td>
</tr>
<tr>
<td>16. I feel personally that watching my diet and exercising are the best things for me. (A)</td>
<td>5.38(1.64)</td>
<td>32</td>
</tr>
<tr>
<td>17. I’d feel guilty if I didn’t watch my diet and exercise. (C)</td>
<td>3.8(1.95)</td>
<td>32</td>
</tr>
<tr>
<td>18. Exercising regularly and following my diet are choices I really want to make. (A)</td>
<td>5.06(1.85)</td>
<td>32</td>
</tr>
<tr>
<td>19. It’s a challenge to learn how to live with diabetes. (A)</td>
<td>4.56(2.26)</td>
<td>32</td>
</tr>
</tbody>
</table>
Appendix 6 - Research
Young Persons – Participant Information Sheet

Young Person - Participant Information Sheet

Motivation among adolescents with diabetes

Background/Aim
As a Trainee Health Psychologist I am keen to understand how supported and in control you feel about
your diabetes. What we know from adults with diabetes is that they are more likely to be motivated to
manage their diabetes if they feel supported and capable of doing so - questionnaires 2, 3 & 4 ask about
this. We also know that some people are at different stages in managing their diabetes than others and this
is what questionnaire 1 looks at. This research is interested in finding out about motivation and the
different stages 13 – 17 year olds are at in managing their diabetes.

Involvement
You have been invited to complete the questionnaires because you are in this age range. I will be asking all
13 – 17 year olds that come to the diabetes clinics in Cornwall to get involved by completing the
questionnaires you have been given. It is important to know that involvement in the research is voluntary
and will not affect the care you receive.

What do I do
Complete the four questionnaires provided while you wait at the clinic then return them to the diabetes nurse before
you leave.

Please seal the envelope to ensure confidentiality, the nurses will then pass the envelope to myself (researcher). The
diabetes staff (nurse/consultant) will not see the questionnaires as you have been given a unique number rather than
your name and address. Any additional information such as age, gender, duration of diabetes, council district, average
Hb1c over the year and clinic attendance can be gathered from the clinic.

Would you be happy for the researcher to contact you to discuss your diabetes in more detail at a future date, at a
location convenient to yourself:

Please circle
Yes or No

I will be writing the research up as part of my university coursework, the results will also be available to the diabetes
service and may be published at a future date.

Should you wish to speak to me about the research in more detail or would like a copy of the findings you can contact
me at:

Mr Roy Chilton

School of Social Sciences
Northampton Square
London EC1V 0HB
T +44 (0)20 7040 5060
F +44 (0)20 7040 8562
www.city.ac.uk
Appendix 7 - Research
Young Person - Consent Form

You have been invited to participate in an interview about your diabetes because you are in the age range for this research. I will be asking all 13 – 17 year olds that come to the diabetes clinics in Cornwall if they would like to participate in an interview about their diabetes. It is important to know that involvement in this research is voluntary and will not affect the care you receive by the service.

Purpose of interview
To provide a detailed understanding of the motivational factors relating to your diabetic regime. If you agree to be interviewed your name, telephone and address will be obtained from the diabetes centre and the researcher will contact you to arrange a location that is convenient to meet for both yourself and a parent (although the interview is conducted with you, it is asked that a parent is also present in the house or location). From previous interviews with other young people the estimated time for an interview is in the region of 15 – 30 minutes. The content of the interview is focused around generating a discussion about your diabetic regime, this will normally be initiated by questions from the researcher.

Risks / benefits – We do not expect any risks to you in participating in this research. One of the benefits is that you can discuss your diabetes regime in greater detail.

Confidentiality
In order that the interview is recorded as accurately as possible, the choice is given to whether the interview is video-taped or recorded using audio (tape recorded). All recordings are kept with the researcher in order to ensure confidentiality, the content may be viewed by university staff connected with the researcher to check the researcher’s interpretation of the interviews.

If you decide to participate in the interview please sign, print and date this form below. It is important to know that the interview can be cancelled at any stage prior to or during the actual interview, should you change your mind. Should you wish to speak to me about the research in more detail or would like a copy of the findings you can contact me at:

Mr Roy Chilton

I have read the above information and agree to participate in this research

Signature of Young ………………………(Print Name)……………………Date……………………
Person (Participant)
Appendix 8 - Research
Parent - Participant Information Sheet

Motivation among adolescents with diabetes

Background/Aim
As a Trainee Health Psychologist I am keen to understand how supported and in control children feel about their diabetes. What we know from research about adults with diabetes is that they are more likely to be motivated to manage their diabetes if they feel supported and capable of doing so - questionnaires 2, 3 & 4 ask about this. We also know that some people are at different stages in managing their diabetes than others and this is what questionnaire 1 looks at. This research is interested in finding out about motivation and the different stages 13 – 17 year olds are at in managing their diabetes.

Involvement
Your child has been invited to complete the questionnaires because they are in this age range. I will be asking all 13 – 17 year olds that come to the diabetes clinics in Cornwall to get involved by completing the questionnaires. It is important to know that involvement in the research is voluntary and will not affect the care they receive by the service.

Confidentiality
In order to maintain confidentiality no names or addresses have been used. Instead I have given your child a unique number. Once completed the questionnaires should be placed in the envelope provided, sealed and returned to the diabetes nurse before leaving the clinic. The diabetes nurse will then pass the envelope to me. Any additional information such as age, gender, duration of diabetes, council district, average Hb1c over the year and clinic attendance can be gathered by the nurses using the unique number, although they will not have access to the questionnaires your child completes.

I will be writing the research up as part of my university coursework, the results will also be available to the diabetes service and may be published at a future date.

Should you wish to speak to me about the research in more detail or would like a copy of the findings you can contact me at:

Mr Roy Chilton

School of Social Sciences
Northampton Square
London EC1V 0HB
T +44 (0)20 7040 5060
F +44 (0)20 7040 8562
www.city.ac.uk
Appendix

Appendix 9 - Research
Parent - Consent Form

Parent - Consent Form

Your child has been invited to participate in an interview about their diabetes because they are in the age range for this research. I will be asking all 13 – 17 year olds that come to the diabetes clinics in Cornwall if they would like to participate in an interview about their diabetes. It is important to know that involvement in this research is voluntary and will not affect the care they receive by the service.

Purpose of interview
To provide a detailed understanding of the motivational factors relating to your child’s diabetic regime. If you agree for your child being interviewed their name, telephone and address will be obtained from the diabetes centre and the researcher will contact you to arrange a location that is convenient to meet for both yourself and your child (although the interview is conducted with the child, it is asked that the parent is also present in the house or location). From previous interviews with other children the estimated time for an interview is in the region of 15 – 30 minutes. The content of the interview is focused around generating a discussion about your child’s diabetic regime, this will normally be initiated by questions from the researcher.

Risks / benefits – We do not expect any risks to your child in participating in this research. One of the benefits is that they can discuss their diabetes regime in greater detail.

Confidentiality
In order that the interview is recorded as accurately as possible, the choice is given to whether the interview is video-taped or recorded using audio (tape recorded). All recordings are kept with the researcher in order to ensure confidentiality, the content may be viewed by university staff connected with the researcher to check the researcher’s interpretation of the interviews.

If you decide to allow your child to participate in the interview please sign, print and date this form below, you will only be contacted if consent is given by yourself and your child. It is important to know that the interview can be cancelled at any stage prior to or during the actual interview, should either you or your child change their mind. Should you wish to speak to me about the research in more detail or would like a copy of the findings you can contact me at:

Mr Roy Chilton
Cornwall Diabetes Endocrine Centre
Royal Cornwall Hospital
Truro
Cornwall
TR1 3LJ

I have read the above information and agree to participate in this research

Signature of Parent ………………………..(Print Name)……………………..Date……………………

Signature of Young ………………………..(Print Name)……………………..Date……………………

Person (Participant)
Appendix 10 - Research
Final Topic Guide

Introduction
Thank you for agreeing to meet with me to discuss your diabetes. I am interested in hearing about how you manage and feel about your diabetes regime.

Questions
1) Can you tell me about your diabetes regime/program:
   - What do you have to do to manage yours?
   - How often/what’s the practical side of it?

2) What is it like to manage your diabetes, how do you find it:
   - How do you feel about managing your diabetes?
   - What’s the difficult side of managing your diabetes?

3) Can you tell me about managing the different bits of your regime:
   - Blood glucose, exercise, diet?

4) Can you tell me about when you first started managing your diabetes:
   - What was it like? Was it difficult?
   - How did you manage it?

5) How do you find managing your diabetes now (current day):
   - What has changed?
   - What have you learnt?

6) Can you tell me what your adherence levels are like at the moment:
   - Percentage (%), 100% being perfect?

7) Can you tell me how your motivation has developed:
   - What has improved?
   - What hasn’t improved?
   - What sort of techniques or things help you to manage your regime?

8) How independent do you think you are in managing your regime:
   - In relation to others, such as parents, diabetes nurse?
   - How and when do you want to become independent?

9) Do you think your diabetes has an impact out how you feel about yourself:
   - What’s your self-esteem like, when and why?

10) Is there any advise you would give to other people that have type 1 diabetes on how to manage their regime?

End of interview
Thank each individual for participating, reiterate that it is confidential and mention that a copy of the research will be available upon request. Would they be happy for me to contact them again in the future if I had any additional questions?
Appendix 1 - Consultancy
Evaluation Measures and Approaches

1) Standardised questionnaires

Eyberg Child Behaviour Inventory (ECBI) and Sutter-Eyberg Student Behavior Inventory-Revised (SESBI-R) (Eyberg & Pincus, 1999) - Assess frequency and severity of disruptive behaviours at home (ECBI, completed by parent) and school (SESBI-R, completed by teacher) among 2-16 year olds.

Parenting Stress Index (PSI-III) (Abidin, 1995) - Completed by the parent to assess levels of parental stress.

Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997) - A behavioural screening questionnaire for 3-16 year olds, completed by parents and teachers.

Recent Life Events Questionnaire (Department of Health, 1999) - Explores recent life events and the impact on individuals and families.

2) Semi-structured interviews - Conducted between an independent researcher and the parents.

3) Service use data – Containing educational, health and social services information.
Appendix 2 - Consultancy
Literature Recommendations

Recent research suggests that evidence-based parenting programmes, delivered within the community and in the voluntary sector, provide effective interventions for children at risk of developing conduct disorders. These findings suggest that child behaviour may be mediated through parent behaviour and the learning of key parenting skills (Gardner, Burton & Klimes, 2006; Hutchings et al., 2007).

The Scallywags program has demonstrated the effectiveness of applying multi-modal, evidence-based practice in both school and home environments to reduce conduct difficulties in children aged between 3 and 7 years of age (Lovering, Frampton, Crowe & Linn, 2006).

The aim of this consultancy was to assess the incidence of parental stress and conduct difficulties following the completion of the 6-month program, in addition to exploring the direct relationship between conduct difficulties and levels of parenting stress.


Appendix 3 - Consultancy
Consultancy Contract

Aims
- To analyse parental stress levels within the Scallywags dataset.
- To understand levels of parental stress at both start and finish of the Scallywags program.
- To produce a report in the appropriate format for publication within a peer-reviewed journal.

Objectives
- To provide a profile of how parental stress levels are impacted on by involvement in the Scallywags program (increased, decreased or no change).
- To explore the relationship between parental stress levels and conduct difficulties within the dataset.

Rationale
The client has requested specific help from the trainee health psychologist to perform and complete the consultancy task.

Timetable
The data analysis is to start on January 7th 2008, working 2 days per week, using the following stages to completion:

- Stage one - data transferred to SPSS by January 8th 2008.
- Stage two - statistical analysis conducted and outcomes obtained by 29th January 2008.
- Stage three - results written up in journal format by 19th February 2008.

Data cleaning and coding, meetings with the client and literature referencing are included in the scheduling, based on regular 1 hour per week meetings with the client until completion.

Technical constraints relating to access to computer facilities (office network difficulties) are accommodated by the trainee health psychologist utilising personal resources if required, i.e. working from home.

Budget
Daily rate:
Trainee Health Psychologist - £25,000 per year (£68 per day).

Number of days (based on above timetable):
Stage 1 (2 days / meetings included)
Stage 2 (6 days / meetings included)
Stage 3 (6 days / meetings included)
Total = 14 days.

Materials:
Photocopying, printing, computer facilities and software access (SPSS version 15) to be provided by client.

Total Expenditure = 14 days x £68 = £952.
Appendix 4 - Consultancy

Results Section

METHOD

Design
The design was within-subjects and parents completed the psychometric questionnaires at pre and post intervention stages. Once a child is selected for a place on the scheme the Eyberg Child Behaviour Inventory (ECBI) is completed by the parent, while attending a semi-structured interview with the Psychologist. A month later when the scheme starts, the Parental Stress Index/Short Form (PSI/SF) is completed, approximately two weeks into the intervention with the support worker involved with the child. Within the last two weeks, at the end of the six-month period the PSI/SF and ECBI are completed by the parent.

Participants
The referral criteria for children referred to Scallywags are that they are aged between three–seven years and attend a playgroup, pre-school, nursery or school in the Cornwall area. The emotional and behavioural criteria are that the child is at risk of exclusion or educational failure, becoming socially isolated and unhappy in an educational setting, needing to further develop their pro-social skills or emotional intelligence. Additional referral criteria could be that they respond poorly to routines, rules of conduct or limit setting, seem unready to cope with large group or structured situations or are anxious insecure or withdrawn, highly demanding, attention seeking, impulsive or destructive, aggressive or abusive when challenged and finally are not currently in court proceedings.

Tables I and II provide demographic information for child and parent, collected at the initial stage of the intervention using the referral form and the PSI/SF.

Table I. Children demographic for cohorts two - fourteen

<table>
<thead>
<tr>
<th></th>
<th>Overall</th>
<th>Male/Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of child</td>
<td>N=802  Mean age=5.14</td>
<td>Male N=637  Mean age=5.13</td>
</tr>
<tr>
<td></td>
<td>SD=1.26</td>
<td>SD=1.26</td>
</tr>
<tr>
<td>Number of children</td>
<td>N=802</td>
<td>Male N=636</td>
</tr>
<tr>
<td>Number of siblings</td>
<td>N=794  Mean=1.49</td>
<td>Female N=166</td>
</tr>
<tr>
<td></td>
<td>SD=1.23</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td>N=522  White=64%</td>
<td>Male N=410  White=63%</td>
</tr>
<tr>
<td></td>
<td>Black=0%</td>
<td>Black=0%</td>
</tr>
<tr>
<td></td>
<td>Mixed Race=1%</td>
<td>Mixed Race=1%</td>
</tr>
<tr>
<td></td>
<td>Missing=35%</td>
<td>Missing=36%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>N=112  White=65.7%</td>
<td>Female N=112  White=65.7%</td>
</tr>
<tr>
<td></td>
<td>Black=0.6%</td>
<td>Black=0.6%</td>
</tr>
<tr>
<td></td>
<td>Mixed Race=1.2%</td>
<td>Mixed Race=1.2%</td>
</tr>
<tr>
<td></td>
<td>Missing=32.5%</td>
<td>Missing=32.5%</td>
</tr>
</tbody>
</table>
Table II. Parents demographic for cohorts two – fourteen

<table>
<thead>
<tr>
<th>Age of parent</th>
<th>Mother $N=568$ Mean age=32.3 SD=6.59</th>
<th>Father $N=28$ Mean age=36.8 SD=7.92</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of</td>
<td>Mother $N=753$</td>
<td>Father $N=304$</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Mother $N=465$ White=60% Black=0% Mixed Race=0% Missing=40%</td>
<td>Father $N=79$ White 24.3% Black=0.3% Mixed Race=0% Missing=75.3%</td>
</tr>
<tr>
<td>Marital Status</td>
<td>$N=628$ Married=37.3% Single=21.5% Divorced=9% Living with partner=6.3% Separated=3.6% Widow=0.4% Missing=21.9%</td>
<td></td>
</tr>
</tbody>
</table>

Materials

The Parental Stress Index/Short Form 3rd Edition (PSI/SF) (Abidin, 1995)
The PSI/SF is a direct derivative of the Parenting Stress Index (PSI) (Abidin, 1995), developed in response to clinicians and researchers requesting a valid measure of parental stress, able to be administered within ten minutes. The PSI/SF is a 36 item self-report questionnaire containing a Total Stress score obtained from three subscales:

- **Parental Distress** – Assesses the level of distress a parent experiences within their role as the parent due to personal factors associated with parenting.

- **Parent-Child Dysfunctional Interaction** – Assesses the parent’s perception that their child does not meet their expectations and the relationship between parent/child is not reinforcing.

- **Difficult Child** – Assesses the behavioural features of the child.

The measure has been used to assess parental stress among high-risk families in relation to the nurturing of cognitive stimulation among preschool children (Saltaris, 2004).

The Eyberg Child Behaviour Inventory (ECBI)
The Eyberg Child Behaviour Inventory (ECBI) (Eyberg & Pincus, 1999) measures conduct problems in children aged between two – sixteen years and can be completed within ten minutes by the parents. The questionnaire contains 36 items rated on two scales, a seven-point Intensity scale indicating frequency of behaviour and a yes/no Problem scale identifying whether the behaviour is problematic for the parent or not.

The measure has successfully been used to evaluate a parenting programme for parents of pre-school children considered to be at risk of developing conduct disorder (Hutchings, 2007).

RESULTS

Sampling distribution

Each cohort of children taken on by Scallywags lasts for a period of six-months, followed by a one, three and six month follow-up meeting. This research is interested
Appendix

in the initial six-month period. The Abidin (1995) and Eyberg (1999) questionnaires were administered within cohorts two – fourteen (no questionnaires were administered within the first year of the service and the Abidin questionnaires were no longer used following cohort fourteen). The dataset is representative of 73% (Adibin) and 96% (Eyberg) questionnaires administered by the scheme. Post-hoc power analyses were conducted where appropriate, before each analysis based on a large effect size (Faul, 2007; Howell, 1997).

Data Screening
Both PSI and Eyberg datasets were screened to ensure that minimum / maximum scores were in the appropriate range for each subscale. To interpret scores the PSI utilises a raw-to-percentile conversation, while the Eyberg uses $T$ scores as the standardised linear transformation for each raw score.

Although the sample size was quite large, the assumption that the data was normally distributed was assessed using the Kolmogorov-Smirnov test for goodness of fit. If distributions were not normally distributed parallel analyses were run to assess impact of normality using transformed data (Hinton, 2004), unless the distribution impacted upon significance levels, original distributions were used throughout.

Pre / Post Intervention
Table III provides a summary of the mean scores pre and post Scallywags, utilising the paired samples $t$-test to analyse differences. The findings demonstrate that both PSI Total Stress scores and ECBI Intensity / Problem scores significantly reduce from clinically significant levels to below clinical significance post intervention. In addition, Parental Distress, Parent-Child Dysfunctional Interaction and Difficult Child sub-scales also significantly reduce at the post intervention stage of the Scallywags scheme.

Table III. Summary of mean PSI / ECBI pre and post Scallywags intervention.a

<table>
<thead>
<tr>
<th></th>
<th>Pre-Intervention</th>
<th>Post-Intervention</th>
<th>Differences (Pre / Post)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$N$</td>
<td>Mean (SD)</td>
<td>$N$</td>
</tr>
<tr>
<td>PSI</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Score</td>
<td>58</td>
<td>105.9 (23.6)</td>
<td>62</td>
</tr>
<tr>
<td>Parental Distress</td>
<td>58</td>
<td>32.9 (9.7)</td>
<td>62</td>
</tr>
<tr>
<td>Parent-Child Dysfunctional Interaction</td>
<td>58</td>
<td>31.1 (8.8)</td>
<td>62</td>
</tr>
<tr>
<td>Difficult Child</td>
<td>58</td>
<td>41.7 (9.3)</td>
<td>62</td>
</tr>
<tr>
<td>ECBI</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intensity</td>
<td>78</td>
<td>67.1 (10.3)</td>
<td>75</td>
</tr>
<tr>
<td>Problem</td>
<td>78</td>
<td>63.2 (11.6)</td>
<td>75</td>
</tr>
</tbody>
</table>
Appendix

a Power analysis based on $d=0.8$, $\alpha=0.05$, $N=518$, power=1.0 (Faul, 2007)

b Parents with a Total Stress raw score of 90 or above are experiencing clinically significant levels of stress

c Parents with Intensity or Problem $T$ scores of 60 or above are in the clinically significant range

Clinical/Non Clinical Levels of Parental Stress Pre and Post
To explore the relationship between level of parental stress and conduct difficulties prior to the intervention the overall dataset was split into clinical (a raw score of 90 or above) and non-clinical (a raw score of below 90) groups at the assessment stage of the scheme. An Independent Sample $T$-Test was used in the analysis to gauge the nature of the differences between the two groups (Table IV).

Table IV. Clinical and non-clinical parental stress levels (pre-assessment) a

<table>
<thead>
<tr>
<th>PSI</th>
<th>Clinical</th>
<th>Non-Clinical</th>
<th>Differences (Clinical / Non-Clinical)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSI</td>
<td>$N$</td>
<td>Mean (SD)</td>
<td>$N$</td>
</tr>
<tr>
<td>Total Score</td>
<td>44</td>
<td>115.6 (18.1)</td>
<td>14</td>
</tr>
<tr>
<td>Parental Distress</td>
<td>44</td>
<td>36.2 (8.6)</td>
<td>14</td>
</tr>
<tr>
<td>Parent-Child Dysfunctional Interaction</td>
<td>44</td>
<td>34 (7.9)</td>
<td>14</td>
</tr>
<tr>
<td>Difficult Child</td>
<td>44</td>
<td>45.2 (7.1)</td>
<td>14</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ECBI</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Intensity</td>
<td>43</td>
<td>70.3 (8.6)</td>
<td>37</td>
</tr>
<tr>
<td>Problem</td>
<td>43</td>
<td>66.5 (10.1)</td>
<td>37</td>
</tr>
</tbody>
</table>

a Power analysis based on $d=0.8$, $\alpha=0.05$, $N=431$ (clinical), $N=142$ (non-clinical), power=1.0 (Faul, 2007)

b All statistical output assessed for equal variance using Levene’s Test for Equality of Variance

The findings indicate that clinically stressed parents prior to starting the intervention reported significantly higher levels of conduct difficulty regarding severity (Intensity) and level of concern (Problem) than the non-clinical group, in addition to significantly higher levels of stress within Parental Distress, Parent-Child Dysfunctional Interaction and Difficult Child sub-scales.

Table V Clinical and non-clinical parental stress levels (post-assessment) a

<table>
<thead>
<tr>
<th>PSI</th>
<th>Clinical</th>
<th>Non-Clinical</th>
<th>Differences (Clinical / Non-Clinical)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSI</td>
<td>$N$</td>
<td>Mean (SD)</td>
<td>$N$</td>
</tr>
<tr>
<td>Total Score</td>
<td>25</td>
<td>107.3 (12.9)</td>
<td>37</td>
</tr>
<tr>
<td>Parental Distress</td>
<td>25</td>
<td>34.7 (7.6)</td>
<td>37</td>
</tr>
<tr>
<td>Parent-Child Dysfunctional</td>
<td>25</td>
<td>31.6 (6.2)</td>
<td>37</td>
</tr>
</tbody>
</table>

a Power analysis based on $d=0.8$, $\alpha=0.05$, $N=518$, power=1.0 (Faul, 2007)
To explore more about whether clinical levels of parental stress reflect higher levels of conduct difficulty, the dataset was once again split by clinical / non-clinical levels of stress, this time at the post intervention stage. The findings support the pre-intervention findings, that clinical levels of parental stress are significantly greater for conduct difficulty and parental stress total and sub-scales than non-clinical parents.

**Parental Stress / Conduct Difficulty Interaction**

To understand more about the longitudinal relationship between parental stress and conduct difficulties throughout the intervention, parental was assessed at the start and then measured at the end of the intervention to see if stress levels increased, decreased or there were no changes and how this related to their perceptions of conduct difficulties within their children.

As such, parental stress levels at the post stage of the intervention were split in three groups, those that increased, decreased or were there was no change across the intervention. Table VI indicated that 84.5% of parental stress levels reduced, 13.8% increased and 1.7% remained unchanged from the pre stage. In addition, the table describes the levels of change for conduct difficulties (problem and intensity) from pre to post stage of the intervention.

**Table VI. Parental stress and conduct difficulty change pre and post intervention.**

<table>
<thead>
<tr>
<th>Parental Stressa (N)</th>
<th>Conduct Difficulties (Problem) Mean/SD (N)</th>
<th>Conduct Difficulties (Intensity) Mean/SD (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decreased 84.4% (438)</td>
<td>-13.79 / 11.28 (430)</td>
<td>-13.04 / 9.42 (430)</td>
</tr>
<tr>
<td>Increased 13.9% (72)</td>
<td>-6.69 / 9.72 (71)</td>
<td>-6.20 / 8.5 (71)</td>
</tr>
<tr>
<td>No change 1.7% (9)</td>
<td>-7.44 / 8.88 (9)</td>
<td>-7.33 / 8.246 (9)</td>
</tr>
</tbody>
</table>

a Based on total stress score

T-tests were conducted to explore whether the decreased, increased or no change grouping differed across conduct difficulty problem and intensity categories. The analysis indicated that there were significant differences within the problem category between increased / decreased (t = 5.005, df = 499, p < 0.0005, one-tailed) and no change / decreased (t = 1.676, df = 437, p = 0.047, one-tailed) categories. For the intensity category there also significant differences between increased / decreased (t = 273
Within these groupings the findings demonstrate that for parents were stress levels have decreased, conduct difficulties have also reduced significantly more than were there are no changes or an increase in parental stress has occurred. The negative direction of the mean differences in conduct difficulties for both intensity and problem categories is in the negative direction following the completion of the intervention.

**Demographic Variables**

To predict the impact of demographic characteristics on parental stress a regression analysis was conducted using the simultaneous (enter) method, with parental stress (post-intervention) as the criterion /dependent variable and demographic (area, child’s age / gender / ethnicity, number of siblings) as predictor / independent variables. Demographic variables were selected individually into the regression analysis to ascertain there validity for model generation.

**Preparatory Coding**

To predict the impact of demographic characteristics on parental stress a regression analysis was conducted using the simultaneous (enter) method, with parental stress (post-intervention) as the criterion /dependent variable and demographic (area, child’s age / gender / ethnicity, number of siblings) as predictor / independent variables. Demographic variables were selected individually into the regression analysis to ascertain there validity for model generation. Due to the small percentage of Black / Mixed ethnicity on both parental and child variables, these were combined. Dummy categories (N-1) were created for region, marital status and siblings, base categories were selected using the largest variable within each category. Outliers were assessed and controlled using Mahalanobis distances and box plots; child’s age and WAGS group sessions did not have any outliers.

Siblings, marital status, ethnicity (child, mother and father), age (mother and father) and child’s gender were not significant models in predicting parental stress within this sample.

**Group (sessions)**

The analysis showed that number of sessions attending the WAGS group was a significant model for predicting parental stress levels, suggesting that the parental stress levels increase with number of WAGS attended. The model was a poor fit accounted for 0.8% of the variance \( F_{1,452} =4.527, p = <0.05, \text{Adjusted R square} = 0.08 \).

**Age (child)**

The analysis showed that child’s age was a significant model for predicting parental stress levels, suggesting that the younger the child the greater the levels of parental stress. The model was a poor fit accounted for 1.2% of the variance \( F_{1,619} =8.739, p = <0.05, \text{Adjusted R square} = 0.012 \).
Appendix

Region
The analysis showed that there was a significant association between the region parents came from and parental stress levels. The model was a poor fit accounted for 1% of the variance ($F_{5,616} = 2.250$, $p = <0.05$, Adjusted R square = 0.010). A Univariate Analysis indicated no the significant interaction effects between group, child’s age and region.

Summary
Clinically higher levels of parental stress were related to higher levels of conduct difficulties. Age, region and number of WAGS groups attended were significant independent predictors in accounting for parental stress levels. Within the intervention, parental stress was not the sole factor in reducing levels of conduct difficulty, parents whose stress levels decreased did have significantly greater reductions in conduct difficulties than were levels did not change or increased, although all categories did experience reductions in conduct difficulty across the intervention.

References


Appendix 5 - Consultancy
Research Meeting Minutes

Minutes of Consultancy Meeting
Date: 15.10.07
Present: Client and Trainee Consultant

Minutes
- The client explained that she would like a piece of work conducted to understand the relationship between levels of parental stress and conduct difficulties within the program. The main reference points for data collection would between the start and end (6-months later) of the intervention. The aim of the consultancy is to inform future service provision by providing a clearer profile of the impact the intervention has on parental stress levels.
- The type of data available is psychometric, developmental/diagnostic, as well as basic demographic.
- Psychometric data already exists on a database within the service, and developmental/diagnostic and basic demographic will need to be included.
- The amount of time provided for conducting the consultancy will be 1 day per week until completion. It will be appropriate to meet on a weekly basis at the client’s office to update on progress and respond to any questions or queries the client or the trainee consultant may have; communication will be solely based on face-to-face meetings, minutes to be collected by the trainee consultant.
- Regular weekly meetings will provide a level of continuity and an atmosphere in which both parties can raise concerns.
- Confidentiality will be assured, as the dataset is stored on the Local Authority network, accessed by specific ID and password. At the data analysis stage, the data will be anonymised by removing name, address and current ID number. Only aggregated questionnaire data and basic demographic information, such as age and sex, will be required.
- Confidentiality will be maintained throughout the consultancy process, as the SPSS software will be installed on a standalone PC on the Local Authority network within the client’s office.

Minutes of Consultancy Meeting
Date: 22.10.07
Present: Client and Trainee Consultant

Minutes
The trainee consultant suggested that there was a need to have access to appropriate statistics software to analyze the data. It was suggested that SPSS would be suitable software for data analysis and for the trainee consultant to contact the Local Authority Statistics Department to determine access.

29.10.07 – Cancelled
05.11.07 – Trainee Consultant in training
12.11.07 – Cancelled
Minutes of Consultancy Meeting  
Date: 19.11.07  
Present: Client and Trainee Consultant  

Minutes  
The Trainee Consultant has been in contact with the Local Authority and been offered SPSS software (client to pay for installation); awaiting installation.  

26.11.07 – Client did not attend  
03.12.07 – Trainee Consultant in training  

Minutes of Consultancy Meeting  
Date: 10.12.07  
Present: Client and Trainee Consultant  

Minutes  
The SPSS software has been installed on the Local Authority computer.  

Date: 18.12.07 – Training  

Minutes of Consultancy Meeting  
Date: 19.12.07  
Present: Client and Trainee Consultant  

Minutes  
The trainee consultant met with the client to present the consultancy contract. The client thought the timescales for the work were quite tight and offered to accommodate extra time should any problems arise. The trainee consultant agreed this would be helpful and suggested that the regular meetings would provide an opportunity to discuss progress and extensions if required. The client will be on holiday until February 2008.  

Date: 04.02.08 – Client not present  
Date: 11.02.08 – Client not present  
Date: 18.02.08 – Client not present  

Minutes of Consultancy Meeting  
Date: 22.02.08  
Present: Client and Trainee Consultant  

Minutes  
• Trainee consultant described the theoretical background to the consultancy work, obtained from a literature search.  
• The results section was presented on time, in accordance with the scheduled timetable agreed between the client and the consultant.  
• The findings were described by the consultant and discussions held regarding the possible meanings to the service.
• It was decided that as the results section had been completed on time, the next stage would be to evaluate the work conducted.
• It was agreed that the evaluation should take the form of a verbal discussion. The nature of the discussion should be aimed at assessing the quality, timing and usefulness of the completed work.
• The client expressed satisfaction with all of the aforementioned points.
• Any additional adjustments, i.e. changes required for submitting to a different journal title, would be done in the time assigned to the assistant psychologists within the service.
Appendix 1 - Teaching and Training 1
MOTIVATIONAL INTERVIEWING
(Needs Assessment Form)

Dear All,

In order for me to provide training that is relevant to you, I need to understand your current awareness of Motivational Interviewing (MI), what you’d like to achieve from the training and the best way to deliver it to you.

Current Awareness (please circle)

I currently know nothing a little a lot about MI

What you want to know (learning objectives) (please tick those of interest)

- Background
- Relevance to Scallywags/Support Work
- How to do Motivational Interviewing
- Other (please comment)

What format would you like the training to follow? (please tick)

- Lecture (presentation only)
- Interactive (presentation, questions, exercises, group work)
- Other (please comment)

Many thanks for your time and help

Roy
Appendix 2a - Teaching and Training 1
Teaching Plan

Training Session
(1.30 – 4.30pm Monday 21st July 2008)

What is MI

How is it relevant to Scallywags

Understand the spirit, principles and interaction techniques of MI

Summary
--------
What is MI
Training plan, training approach
(Q to audience – what do you think it is – whole group)
Definitions

How is it relevant to Scallywags
Scallywags Service Request Information
(Q to audience – How do you as Support Workers work with ambivalence – in pairs)
(Q to audience - What is the most effective way of changing behaviour – brainstorm
The righting reflex – case study

Understand the spirit, principles and interaction techniques of MI
Spirit of MI
Principles of MI
(Exercise – Roadblocking in pairs)
Interaction techniques (OARS)
Open-ended questions
Affirmations
Reflective listening
Summaries
(Exercise – OARS in pairs)
(Exercise Dialogue – OARS)
(Dialogue – Roy, roadblock, redirect)
Principles of MI
Eliciting change behaviour

Summary
References
**Appendix 2b - Teaching and Training 1**

**Road Blocking**

Some typical responses that communicate unacceptance are:

1. Ordering, commanding, directing.
   *Example: "You are going to buy that then"

2. Warning, threatening.
   *Example: "If you don’t buy that someone else will"

3. Moralizing, preaching, giving "shoulds" and "oughts".
   *Example: "You should get the red one it’s the best one."

4. Advising, offering solutions or suggestions.
   *Example: "Have you tried the other size."

5. Teaching, lecturing, giving logical arguments.
   *Example: "Brighter colours look fresher in the Summer time."

These next responses tend to communicate inadequacies and faults:

   *Example: "I think that top looks better on you."

7. Name-calling, stereotyping, labelling.
   *Example: "You are not very decisive."

8. Interpreting, analyzing, diagnosing.
   *Example: "Most people go for that style."

Other messages try to make the individual feel better or deny there is a problem:

9. Praising, agreeing, giving positive evaluations.
   *Example: "If you don’t buy it today you can get it another time."

10. Reassuring, sympathizing, consoling, supporting.
    *Example: "I don’t know what to get either."

This response tends to try to solve the problem for the individual:

11. Questioning, probing, interrogating, cross-examining.
    *Example: "Can I get you a different colour, what is wrong with that one."

These messages tend to divert the individual or avoid the individual altogether:

12. Withdrawing, distracting, being sarcastic, humouring, diverting.
    *Example: "Got out of the wrong side of the bed today, did we."
# Appendix 2b - Teaching and Training 1

## Road Blocking

1. Ordering, commanding, directing.
2. Warning, threatening.
3. Moralizing, preaching, giving "shoulds" and "oughts".
4. Advising, offering solutions or suggestions.
5. Teaching, lecturing, giving logical arguments.
7. Name-calling, stereotyping, labelling.
8. Interpreting, analyzing, diagnosing.
9. Praising, agreeing, giving positive evaluations.
10. Reassuring, sympathizing, consoling, supporting.
11. Questioning, probing, interrogating, cross-examining.
12. Withdrawing, distracting, being sarcastic, humouring, diverting.
Appendix 2b - Teaching and Training 1
Road Blocking

Client – I’ve had a terrible day, Bobby has been running all over the place

Interviewer – That sounds difficult

Client – Yeah, he always does this every time we get in from school

Interviewer – Why do you think this happens?

Client – School get them all hyper and then just let them go!

Interviewer – How would you like things to be when Bobby gets home

Client – Just act, well you know, sensible, normal, not as crazy

Interviewer – More manageable

Client – Yeah, I think he has ADHD, I can never get him to settle down

Interviewer – What have you tried then?

Client – Everything!! Telling him off, grounding him if he doesn’t listen to me, taking his toys off him. He just keeps on going, what do you think?

Interviewer – Can you think of any other things?

Client – Oh yes, and I have said I will take him to the Police station if he doesn’t behave!!

Interviewer – Is there anything else?

Client – That’s it really
Appendix 3 - Teaching and Training 1
Evaluation Form
(Motivational Interviewing)

Did you feel your training needs were met? *(please circle)*

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How did you find the presentation style? *(please circle)*

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What would you say the strengths of the training were?

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What would you say the weaknesses of the training were?

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Appendix 4 - Teaching and Training 1
Reflective Commentary

What is happening during the video recording?
The training lasted for 3 hours. A section at the beginning of the video (tape 1) included a period which I found quite challenging. This was unnerving, as I primarily wanted to provide training to the Scallywags support workers focussed around the application of Motivational Interviewing (MI), and intended to incorporate open-ended Socratic questioning, as in the style of MI. The incident occurred while I was trying to elicit themes from the group around changing ambivalent behaviour, such as advising, counselling, listening, etc. Instead, the responses from a group brainstorming exercise described principles very similar to those of MI; for example, waiting until the person is motivated to change, developing a relationship and not being an expert. These responses threw me, and I was concerned that the training would end up telling the group things that they already knew and were practising, at such an early stage in the session.

These thoughts occurred as I was standing up writing the group’s suggestions on a flip chart, which provided time for me to process the unexpected responses. I expressed these insights to the group in two ways: firstly, I contextualised the group’s responses by explaining how a number of their answers were similar to the principles found within MI, and that this approach provided a combination of varied techniques that the team and individuals may already be using; secondly, in order for me to continue with my presentation, I focussed primarily on the group’s responses that were consistent with the themes. I needed to move the session forward, and explained that I would pick up the remaining themes at a later stage.

Strengths and weaknesses during the delivery of the training session
I felt the training was successful; discussions with the team afterwards and the evaluation forms supported this belief (see Appendix 5). I was concerned that, within the delivery process, I would reduce the level of interaction between myself and the group by reading from my notes. This did not happen, as I was able to think and respond to the group’s questions as and when they occurred. The cues from the PowerPoint slides were enough to initiate discussion between myself and the group without referring to, or reading, my notes. I consider this a major strength.

While looking back at the video footage and reflecting on the incident, I thought there were moments I reiterated the same point a number of times. I think this occurred because I did not get an instant response from the group and interpreted this as uncertainty or confusion, which may have been a reflection of my own state of mind rather than that of the group.

In summary, I had known I was going to deliver this training for 4 months; it had been in the back of my mind for that length of time, and the anticipatory anxiety in the last few days was not as intense as I had thought it might be. A factor may be that I focussed on the fact that I had prepared and a proportion of the delivery was Socratic and interactive. I was pleased I was able to express myself openly at the start of the training regarding the issue of existing knowledge, and that I regained my direction throughout this initial incident.
Appendix

Appendix 5 - Teaching and Training 1
Small Scale Evaluation

A small scale evaluation was achieved by initially administering the Needs Assessment Form (see Appendix 1, N=19 completed), and then completing an Evaluation Form (see Appendix 3, N=24 completed) following the training session. There were 24 support workers present at the training.

The learning objectives were aimed at providing Scallywags support workers with background knowledge of Motivational Interviewing (MI), how it was relevant to them and how to conduct MI. In order to assess whether these learning objectives had been achieved, the following questions and Likert rating scale were used:

1) Did you feel your training needs were met? (please circle)

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The mean rating (N=24) was 8.5.

The comments section contained responses from 15 individuals:
1) Yes, I felt you were considerate of the whole group + individual understanding pitched at a good level.
2) Didn’t realize how useful this could be for own work.
3) Helped to be reminded of a different approach.
4) Yes, I had been looking forward to it and it was what I expected it be Thankyou.
5) Needs met, confirmed we do this
6) Interesting explanation of how to approach people who want to change but are finding it difficult.
7) Matched up with another approach that I have been very interested in using a technique & language used are very much the same.
8) I understand more about the practice I use in everyday working life.
9) Must admit to thinking it would be “teaching grandmother to suck eggs” but it certainly wasn’t it revisited information already known and built on and reflected.
10) Was pertinent to our job – theory behind practical / what we do.
11) Yes something new to work with.
12) Came away with a greater understanding of MI & how it fits into the work of the Scallywags programme.
13) Yes, just a few big words on the slide show!!!
14) Yes.
15) Yes.

2) How did you find the presentation style? (please circle)

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Appendix

The mean rating ($N=24$) was 9.125.

The comments section contained responses from 19 individuals:
1) **Good calm manner, dealt with questions well-thorough response.**
2) **Very relaxed easy to listen to.**
3) **Clear easy to understand, always good to use activities.**
4) **Really liked balance of discussion / presentation / role play.**
5) **Easy to follow.**
6) **Very interesting.**
7) **Good time keeping whilst allowing those that wanted to have a say, to do so.**
8) **Found the red/ green writing on overhead difficult to see.**
9) **Good interaction of participate & powerpoint.**
10) **Appeared very confident with group – used humour appropriately style [...] of relaxed, informal presentation with knowledge about content & ability to explain quite complicated terminology.**
11) **Relaxed, informative – good at getting grp back on track.**
12) **Engaging & interesting.**
13) **Really clear introduction to MI and good time.**
14) **Well balanced with visual aids & activities.**
15) **Yes time for discussion + to interact + work through scenerios.**
16) **Varied presentation styles used, keeping us active and [...] .**
17) **Confirmation of strategies pleasant easy speaker.**
18) **Showed understanding / empathy with conversations between sw + parents.**
19) **Made psychology interesting + understandable.**

3) What would you say the strengths of the training were?

The comments section contained responses from 23 individuals:
1) **A really good reminder to use these techniques when I feel I [...] readily with children but my work would benefit from using more frequently with adults / parents / teachers.**
2) **A pleasant speaking voice did not speak above us using language not easily understood checked that we understood language used, made relevant to our work.**
3) **Ideas put into a format rather than just done.**
4) **I liked the style of the training, the way you put the points across, giving verbal communication and using interactive whiteboard – also non-threatening, relaxed and interesting content.**
5) **Good planning & clear explanations, confirmed audience understood.**
6) **Clear presentation style and interesting description.**
7) As above a revision or reminder of previous study.
8) Having practical activities to enable us to understand easier.
9) Powerpoint was kept to a minimum conversational style.
10) Liked the paired activities – helpful / non – threatening very empathic trainer who has done the job of a support worker.
11) Knowing the knowledge base.
12) Linked very well to the Scallywags programme Drew on real life scenarios audience described – appropriate level to meet audience’s needs – slides were not too overloaded with information.
13) Knew subject material very well pace involved us in non-threatening way.
14) Varied & quick moving (?).
15) Relationship with the group and the ability to relate to everyone taking on board the comments and suggestions effectively.
16) Explained MI well.
17) Some practical tasks to help understanding of particular techniques of new subject.
18) Easy to follow, able to ask questions plus info given out at the end able to use with home visits.
19) Can be […] to our work with children & their families.
20) The knowledge that the trainer had of the Scallywags scheme.
21) Relevant to interactions adults / children in sw role. I liked link to practice will use in future conversations & helpful way of reflecting on support for families. I liked approach i.e. quiet / reflective / questioning empowering.
22) I enjoyed the interactive bits, explanations of some of the words used & examples given useful.
23) Using regular terms that I could understand + confirming + summarising techniques I have been trying, plus giving ideas for extensions.

4) What would you say the weaknesses of the training were?

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The comments section contained responses from 15 individuals:
1) None – good to have handouts to recap thankyou well done !
2) Assumption of desire to change and non acknowledgement of resistant responses continuously.
3) Difficult to concentrate towards end – probably due to too much food ! so really good there are handouts to refer back to thankyou !
4) Was not any weaknesses.
5) None.
6) In the beginning it was difficult to elicit from the trainees the correct information (wanted information) but with patience got what he wanted.
7) No handouts to start with – I find I need to write notes as a go along !
8) Not enough leading […] & went off a […].
9) Could have been a few more interactive exercises + include teaching resources to meet all learning style. – some questions could have been small group exercises.
10) Initial grp involvements (things we do with ambivalent clients) could have been explained clearer.
11) Would be interested in learning more.
12) I would have liked handouts to refer to during the presentation so I could write notes.
13) None except for a bit too much jargon “self-efficacy” etc.
14) None.
15) Might be nice to revisit topic + problem solve in a future team meeting.

Summary

I felt the feedback reflected an engaging, relaxed and empathic style, which suited the audience. There were no consistently negative themes regarding the training, either described on the Evaluation Form or within discussions with the trainees during breaktime, or subsequently after the training. Two people felt handouts might have been helpful at the start of the training to add notes. One person suggested that small group exercises could have been used; someone else thought that the presentation contained jargon; and another picked up that it was difficult to elicit specific information in the initial part of the training.

Due to the lack of consensus regarding negative themes, I am not sure if I would respond to all the comments. I would like to consider a small group exercise, in addition to pair and group work, and also provide a basic framework of the training for people to add comments throughout, if they wished. One of the learners also enquired about how to locate the book referenced in the handout; I spoke to a member of the administration staff and they agreed to purchase the book for the team. I thought the feedback was constructive and positive.
Appendix 1 - Teaching and Training 2

Teaching Plan

Training Session
(10.00 – 10.45am Tuesday 28th September 2010)

Title Slide
(Question to audience, feelings, health psychology framework)

Three Main Areas

Theoretical Background 1
Overview of Stages of Change Model
Key Features
Various stages - pre-contemplation, contemplation, preparation, action, and maintenance

Theoretical Background 2
Overview of Self-Determination Theory
(Basic Psychological Needs – relatedness, autonomy, competence)

Summary
Questions

Three Main Areas

Research Project
Aims
Rationale
Measures (Stages of Change and SDT)
Results (SDT, SoC)
Results (adherer and non-adherer, motivational profiles - SoC, SDT, demographic, biomedical)

Summary
Questions

Three Main Areas

Applications to Service
Stages of Change Handouts (e.g. precontemplation)
Self-Determination Theory (health care climate, MI and reflective listening)

Summary
References
Questions
Title Slide

---------
Dear All

In order for me to provide training that is relevant to you, I need to understand your current awareness of Stages of Change (SoC) and Self-Determination Theory (SDT), what you’d like to achieve from the training and the best way to deliver it to you.

Current Awareness *(please circle)*

<table>
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<tr>
<th>I currently know</th>
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<th>a little</th>
<th>a lot</th>
<th>about SoC</th>
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<tr>
<td>I currently know</td>
<td>nothing</td>
<td>a little</td>
<td>a lot</td>
<td>about SDT</td>
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What you want to know *(learning objectives)* *(please tick those of interest)*

- SoC and SDT Background
- Findings from result
- Supplementary resources to finding
- Other *(please comment)*

What format would you like the training to consist of? *(please tick)*

- Lecture (presentation only)
- Interactive (presentation, questions, exercises, group work)
- Other *(please comment)*

Many thanks for your time and help

Roy
Appendix

Appendix 2b – Teaching and Training 2
PowerPoint Presentation

Understanding Readiness to Change and Motivational Characteristics within Regime Management:
Young People (13-17 year old) with Type 1 Diabetes

Roy Chilton
Trainee Health Psychologist

Question
What is it like dealing with poor self-management? ????

Frustrating
Puzzling

Three Main Areas
- Theoretical Background
- Research Project
- Applications to service

Theoretical Background
- Stages of Change (SoC)
- Self-Determination Theory (SDT)

Health Psychology Framework
Understanding Self-Management

Stages of Change Model

"How people intentionally change their behaviour with or without psychotherapy ... searching for the structure of change"  
(Prochaska, DiClemente & Norcross, 1992)

Theoretical Background

Stages of Change Model

Key Features:
- Behavioural change is thought to occur as a progression through a series of stages.
- The Stages of Change address how change occurs as a process over time.
- The processes of change help to explain how these changes occur.

Theoretical Background

Self-Determination Theory

Assumes:
- Tendency toward growing.
- Mastering ambient challenges.
- Initial ability to experience a coherent sense of self.
- Natural developmental tendency towards choosing personal affiliations and support.
- Relationship between the person and the social context is the basis for SDT's predictions about behaviour, experience, and development.

Theoretical Background

Summary

- Stages of Change
- Assess Readiness to Change
- Self-Determination Theory – Motivational Characteristics
- Provides insight into the individuals intentions

Research Project

Aims

- Assess Stages of Change in relation to specific Type 1 diabetes related behaviour
- Assess Self-Determination Theory motivational characteristics in relation to Autonomy, Competence, and Relatedness

Theoretical Background

Stages of Change Model

- Stages of Change (SoC)
- Self-Determination Theory (SDT)

Theoretical Background

Determination Theory

- SDT's

Theoretical Background

Theoretical Background

Research Project

Assess Readiness to Change

Questions????

Three Main Areas

- Theoretical Background
- Research Project
- Applications to Service

Theoretical Background

Stages of Change Model

Assessment

Rationale

- being the perceived origin or source of one's own behaviour
- a felt sense of confidence and effectance in action
- feeling connected to others

Theoretical Background

Stages of Change (SoC)

Relationship between the person and the social context is the basis for healthy development and functioning is specified using the concept of Basic Psychological Needs.

Integrating new experiences into coherent sense of self

Relatedness

Autonomy

Competence

The requirement for healthy development and functioning is specified using the concept of Basic Psychological Needs.

Autonomy
- Competence
- Relatedness

Assess Readiness to Change

- Masters ambient challenges
- Initial ability to experience a coherent sense of self
- Natural developmental tendency toward choosing personal affiliations and support
- Relationship between the person and the social context is the basis for SDT's predictions about behaviour, experience, and development.

Questions????

Research Project

Aims

- Assess Stages of Change in relation to specific Type 1 diabetes related behaviour
- Assess Self-Determination Theory motivational characteristics in relation to Autonomy, Competence, and Relatedness

Theoretical Background

Stages of Change Model

- Stages of Change (SoC)
- Self-Determination Theory (SDT)
Understanding Stages of Change would allow insight into such activity should be. Exercise does not have to be perceived competence for diabetes scale (PCDS). Stages of change as your breathing rate and causes you to break a sweat. Slightly more intrinsically motivated than extrinsically motivated. Participants felt autonomy towards their diabetes was promoted, regulated 4.05 out of 7 indicating that they consider motivational features regarding regime management. Participants feel autonomy towards their diabetes is promoted, regulated 4.05 out of 7 indicating that they consider motivational features regarding regime management.

**Rationale**

- Understanding Stages of Change would allow insight into such activity should be. Exercise does not have to be perceived competence for diabetes scale (PCDS). Stages of change as your breathing rate and causes you to break a sweat. Slightly more intrinsically motivated than extrinsically motivated.

**Measures**

- **Exercise**
  - The Health Care Climate Questionnaire (HCCQ)
  - Perceived Competence for Diabetes Scale (PCDS)
  - Physician's perceived competence is their ability to manage their diabetes.
  - The Health Care Climate Questionnaire (HCCQ) Exploring autonomous versus controlled motivation for exercise, perceived competence for diabetes, and regulation of diabetes.

**Results**

- **Table 3. Adherer and Non-Adherer Motivational Profiles**
  - Adherer (N=6)
  - Non-Adherer (N=6)
  - Mean (SD)
  - Robust level of basic self-care
  - Majority of participants operating within the maintenance stages of behavior.

**Summary**

- **Stages of Change**
  - Majority of participants operating within the maintenance stages of behavior.
  - Important to use accurate questioning for blood glucose monitoring.

- **Self-Determination Theory**
  - Participants felt autonomy towards their diabetes was promoted.
  - Competent in their ability to manage their diabetes.
References


Questions????

Understanding Readiness to Change and Motivational Characteristics within Regime Management:

Young People (13-17 year old) with Type 1 Diabetes

Ray Chilton
Trainee Health Psychologist

Appendix
Appendix 3 – Teaching and Training 2
Evaluation Form
(SoC and SDT)

Did you feel your training needs were met? (please circle)

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How did you find the presentation style? (please circle)

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What would you say the strengths of the training were?

Comment……………………………………………………………………………………………………………………………………………………………………

What would you say the weaknesses of the training were?

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Appendix 4 – Teaching and Training 2
Small Scale Evaluation

A small scale evaluation was carried out with the learners using the Needs Assessment Form (see Appendix 2a, N=4 completed). This was later followed up using the Evaluation Form (see Appendix 3, N=4 completed) directly after the teaching session. The learning objectives consisted of three main areas: firstly the theoretical background for SoC and SDT; secondly, the findings from the research using the theories within a type 1 diabetes 13-17 year old sample; and thirdly, looking at ways in which SoC and SDT relate to practice. Evaluation entailed a Likert scale and open-ended questions concentrating on strengths and weaknesses of the training.

Did you feel your training needs were met? *(please circle)*

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The mean rating (N=4) was 8.25.

The comments section contained responses from 2 individuals:
1) *Theoretical guidance only available in lecture of limited time.*
2) *Very informative.*

How did you find the presentation style? *(please circle)*

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The mean rating (N=4) was 8.

The comments section contained responses from 1 individual:
1) *One slide too busy. Would be improved by more slides with less information on each?*

What would you say the strengths of the training were?

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The comments section contained responses from 4 individuals:
1) Informat[xx] received.
2) Explanations were given for areas that were difficult to understand + related to our areas of care.
3) Identification of framework / theories.
4) Descriptions of different theories.

What would you say the weaknesses of the training were?

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The comments section contained responses from 4 individuals:
1) One busy slide too much info.
2) Being taped!
3) Too short time.
4) More patient evaluation.

Summary

One of the main features of the feedback related to the limited period of time in which the teaching was conducted. This is unfortunate, as it was arranged and agreed with the lead diabetes nurse that a 45-minute time frame was the only available time when all nurses met together. The strengths of the training highlighted a recognition and value for the explanation and use of SoC and SDT theories, in particular how the information was conveyed. Finally, when recording the session the camera was specifically placed so as not to identify members of the team, as while they had agreed the session could be filmed, they were not totally comfortable with it, and as such I only focussed the camera on me.

I was happy that the teaching ran to schedule and that all the points I had hoped to communicate were covered; with more time the teaching experience could have engaged the learners in terms of their own experiences. When I watched the session on video, I felt that in future less time should be spent referring to the presentation and more time focused on expanding information verbally. This supports the work of Kosslyn (2007), which was influential in the development of the presentation, and reinforces the role of PowerPoint in providing cues to communication rather than sentences that the audience are required to read. I would like to continue to develop slides that can facilitate the communication of cue-based information.

Appendix 5 – Teaching and Training 2
Reflective Commentary
(15 minutes)

What is happening during the video recording?
The video recording starts from the beginning of the presentation. As my contact had primarily been with the lead diabetes nurse, I wanted to get an understanding of the level of awareness the other learners had of my research. This would help to increase the level of engagement within the teaching session. It was clear from my initial questioning that not all were aware of the study, and I immediately updated this discrepancy. I had purposely started the presentation with a question to the audience, both to increase attention and engagement, and also to allow me to become comfortable, as a form anxiety reduction within the early stages of the presentation. While observing the video of the session, it appeared as though I was focussed upon getting into the presentation material and not engaging in eye contact as much as I would have liked. This may be due to the initial anxiety and awkward fixed seating from which the presentation was delivered. I did feel as the teaching progressed, slide transition and verbal communication became more interactive, and with it came improved eye contact.

An interesting comment from one of the learners related to the similarities of the Stages of Change and Self-Determination Theory and how it fitted with Maslow’s Hierarchy of what I suspect is “need”, yet referred to as “change” by the learner and me. While I had a basic understanding of Maslow’s work, I did not correct the sentence, as I felt the learner had thought there was a similarity between the theories and as such I focussed on differentiating them.

While moving through the presentation, I explained that the results would reveal how the 13-17 year old age group perceived their experiences within the diabetes service. There was an awareness at that point that the findings may be perceived as relating directly to the lead diabetes nurse. I expressed this point, and a team member noted that the young people may have been seen by other nurses prior to moving over to the lead diabetes nurse’s caseload, which helped to reduce the lead diabetes nurse’s anxiety.

Strengths and weaknesses during the delivery of the training session
One of the strengths of the teaching was that it stimulated questioning amongst the learners. In viewing myself on video, I thought I appeared quite relaxed and in control of the teaching. In terms of weaknesses, one of the observations from the video related to my use of language. I noted a few regional terms or words that may not be fully considered appropriate use of the English language; for example - am going to rather than I am going to. In the future it may be important to be aware of this. I also noted using the word basically quite often in a short space of time.

In summary, I had reduced my initial presentation significantly, in line with the suggestions of Kosslyn (2007), yet I still felt that having a full sentence to read from the slides was uncomfortable and unnatural. I think in future I may not rely on reading directly from the slides for any prolonged period and use them as a cue, focusing more on promoting an interactive style, particularly within a small group setting.
Appendix

Appendix 1a – Opt. 5.3
Consultancy Report
(technical report)

The following consultancy report (technical report) provides both technical and descriptive information concerning the decisions and results of a piece of consultancy work aimed at the identification of a measure or measures for assessing lifestyle status. This report is presented in a chronological manner in order to reflect the decision making process in consultation with the client.

Aim
To locate one or a number of instruments that assess lifestyle status.

Objectives
The identified measure/s should have the following features:

- Instrument(s) should be standardised and/or have normative data attached to it.
- Instrument(s) should be applicable to the general population (not musculoskeletal-specific) and for adults (18 years or above).
- Instrument(s) should assess (individually or collectively) the following factors, based on recommendations from the Bone and Joint Healthy Lifestyle (2005):
  - Physical activity
  - Ideal weight
  - Balanced diet
  - Smoking
  - Alcohol
  - Accident prevention
  - Abnormal/overuse of musculoskeletal system.

Search Strategy
Regardless of the search term used for instrument retrieval (inventory, rating scale, questionnaire or measure), an electronic pilot search returned too great a number of results to assess individually, and it was not realistic to pursue this approach (too time consuming and too wide a search parameter). In addition, while instruments were most probably described within the materials section of articles, related information may not be located in the abstract alone, and gaining full text articles (where database access was restricted) via inter-library loans, again, was not a viable option. The following approaches were therefore investigated in order to achieve a successful outcome:

- Systematic or review-based articles
- Survey-based instruments
- Health and Psychosocial Instruments (HaPI) Database
- European Health Surveys Information Database (EUHSID)
- Buros Institute of Mental Measurements: Test Reviews Online (Lifestyle, Health)
Systematic or Review Articles

To explore whether any systematic reviews or review-based articles currently existed that specifically assessed lifestyle measures, the following approach was selected (Appendix 1b):

1) A search of four electronic databases (EMBASE, AMED, BNI and OVID Medline) did not locate a general lifestyle or specific (exercise/physical, diet/weight, smoking, alcohol) lifestyle-based systematic review or review article highlighting available measures.

2) All of the Cochrane Library was searched for existing systematic or review-based articles.

Conclusion
The findings from both the EMBASE, AMED, BNI and OVID Medline databases, as well as all of the Cochrane Library, did not locate any existing systemic or review-based articles describing either lifestyle or particular elements of lifestyle.

Reflexivity
While the instrument should be able to provide a comparative feature (i.e. individual’s status in contrast to general population), this may limit the feasibility of instruments that identify or assess a particular construct (i.e. readiness to exercise), in terms of limitations on normative data upon which to compare the constructs. On this basis, survey-type measures may be more suitable, as the aims are more related to general lifestyle information, rather than specific construct-based information.

Survey-Based Instruments

In order to explore the suitability of survey-based information, the following surveys were identified through the UK National Statistics Publication Hub and accessed for their suitability in achieving the aims of the consultancy.

UK National Statistics
By selecting the “Health and Social Care” theme and viewing the “Health of the Population” topic page, then choosing “Lifestyles and Behaviours”, it was possible to locate a number of relevant surveys (Figure 1) covering smoking, alcohol, physical activity and diet (ONS, 2011).
Appendix

Figure 1. Represents the Distribution of Publications Relating to Lifestyle as Highlighted Through the UK National Statistics Publication Hub *

UK National Statistics (Publication Hub)

Health (Department of Health) - Health Profile of England (2009)


Office of National Statistics - Drinking: Adults Behaviour and Knowledge (2009); Smoking Related Behaviour and Attitudes (2008-9); General Lifestyle Survey (2009)*; The Omnibus Survey (Monthly)

* Document not sourced from UK National Statistics Hub

The following information represents details of the aforementioned surveys and their suitability in relation to the aims of this consultancy, namely the identification of instruments that could be used to provide comparative information obtained from a UK-based general population (excluding Welsh, Scottish and Irish-related populations).

Health Survey for England (HSE) (2009)

Data type – original source

A series of annual surveys containing core elements (every year) and special topics (selected years):

- Core topics include: general health; smoking; drinking and fruit and vegetable consumption; height; weight; blood pressure measurements; and blood and saliva samples
- Special topics include: cardiovascular disease; physical activity and fitness (HSE, 2008); accidents; lung function measurement; and certain blood analytes.

Measures located
No, unless further communication taken.
Appendix

Conclusion
Material is copyrighted, administered by interviewer (also self-completion booklets during interview) and entered into a computer (possibly data was interpreted through the computer, combined responses). Due to the use of computers for data entry purposes, an understanding of how the data was interpreted would be paramount, specifically whether item response were co-collated (Appendix 2).

NOTE: Contact would have to be made with the NHS Information Centre to obtain permission to use materials (copyrighted). Further permission may have to be gained to use computer-related software to generate results that are comparable to the overall survey findings.

Drinking: Adults Behaviour and Knowledge in 2009

Data type – sourced from Office of National Statistics Omnibus Survey
Presents results from questions about drinking which have been included in the Office of National Statistics Opinions (Omnibus Survey). Main topic areas are what people drink, patterns of drinking and drinking in the last week, drinking-related knowledge and behaviour, purchase of alcoholic drink and awareness of the effect of drinking.

Measures located
No, unless further communication taken.

Conclusion
Interviews were conducted in private households (interviewers trained to conduct a range of ONS surveys). Overall, 28 pages of questions (copyright status to be confirmed).


Data type – data located from various sources
http://www.ic.nhs.uk/pubs/alcohol10
A compendium of information on alcohol use and misuse from a variety of sources, which includes additional analysis by the NHS Information Centre for Health and Social Care.

Measures located
Yes, Alcohol Use Disorders Identification Test (AUDIT) assesses hazardous and harmful drinking. It consists of 10 questions, and anyone scoring over 8 is considered a hazardous drinker, while those scoring over 16 are considered harmful drinkers. It was designed by the World Health Organisation (WHO) to identify hazardous, harmful and dependent drinkers.


Statistics on Obesity, Physical Activity and Diet, England (2011)

Data type – located from various sources
http://www.ic.nhs.uk/pubs/opad11
The document contains information on obesity, physical activity and diet from a variety of sources. The following sources were investigated for lifestyle-based measures within physical activity and diet.
Appendix

Chapter 2 – Obesity
Body Mass Index (BMI) is assessed by dividing a person’s weight in kilograms by the square of their height in metres. A BMI of 25 to 29.9kg/m² is considered overweight, and a BMI of 30kg/m² or above is considered obese. The WHO database http://apps.who.int/bmi/index.jsp provides national and sub-national prevalence rates for adults who are underweight, overweight and obese by country, year of survey and gender.

Chapter 4 - Physical activity
Main source of data is the Health Survey for England (as above):

  Questions on charitable giving and qualitative depth interviews on competitive sport (N/A)
- **The National Travel Survey**
  Published by the Department of Transport, but not general lifestyle-based (N/A)
- **The Active People Survey**
  Sport and recreation-based, not general lifestyle (N/A)

Chapter 6 - Diet
Main source of data on fruit and vegetable consumption from the Health Survey for England (2007; 2008; 2009):

- **Living Costs and Food Survey (LCF)**
  Interviews conducted using Computer Assisted Personal Interviewing (CAPI) using portable computers (N/A)
- **National Diet and Nutrition Survey (NDNS)**
  Face-to-face interview, then asked to keep a 7-day record of what they have eaten and drunk (N/A)

**Measures located**
No measures located within the document or within aforementioned documents.

*Smoking Related Behaviour and Attitudes (2008/9)*
**Data type** - located from various sources
Contains results from questions about smoking which were included in the ONS Omnibus Survey (interview questions provided). Chapters include smoking behaviour and habits, giving up smoking, attempts to give up smoking, awareness of health issues related to smoking, attitudes related to smoking and views about restrictions on smoking in public.
Measures located
The questions provided to supplement the interview were included in the document (pp. 97-144). No measures located within the document were suitable; ONS Omnibus Survey to be searched.

Data type - main source is the General Household Survey
http://www.ic.nhs.uk/pubs/smoking10
Health issues related to smoking, smoking habits, behaviour and attitudes, smoking-related ill health, mortality and smoking-related costs derived from a variety of sources. Main source of data on smoking prevalence is the General Household Survey (GHS).

Measures located
No measures located within the document; GHS to be searched.

Office of National Statistics (ONS)
General Lifestyle Survey (GLF) (2009)
Data type – original source
GLF is an interview-based, multi-purpose, continuous survey (including smoking and drinking behaviour). Since 1994 the survey has been carried out by Computer Assisted Personal Interviewing (CAPI) on laptop computers and Blaise software by face-to-face interviewers. Since 2000, telephone interviewers have converted proxy interviews to full interviews using CAPI from a central unit. Face-to-face and telephone interviewers are given initial training.

Measures located
Contact would have to be made with the Office of National Statistics to obtain permission to use possibly copyrighted questions. Further permission and access would have to be gained to use the computer-related software to generate results that are comparable to the overall survey findings, which may be co-constructed.

The Omnibus Survey (Monthly)
Data type – original source
Multi-purpose interviews conducted per month using computer-aided personal interviewing.

Measures located
Due to computer-related interviewing, similar issues relate to gaining access to and permission to use software.

Health Profile of England (2009)
Data type - located from various sources
Data is sourced from other surveys such as the General Lifestyle Survey and Health Survey for England. Therefore no measures are used specifically within this document.
Appendix

Measures located
No measures located within the document.

NHS Information Centre for Health and Social Care
The “Health and Lifestyles” topic was selected from the “Statistics and Data Collection” section of the NHS Information Centre for Health and Social Care homepage. Selecting key lifestyle-related headings such as alcohol, diet, obesity, physical activity and smoking (statistics on the NHS Stop Smoking Services were not appropriate, as they were monitored via quarterly returns), no additional documents were retrieved that had not been identified within the UK National Statistics Publications Hub.

Department of Health
The “Surveys” section located within the “Publication” section of the Department of Health homepage did not provide any additional documents to those identified within the UK National Statistics Publication Hub (the National Survey of NHS Patients was not included).

Conclusion
While conducting the survey searches, a number of factors were noted. Firstly, in order to utilise the information from these documents (Drinking: Adults Behaviour and Knowledge in 2009; GLF, 2009; HSE, 2008/9; ONS Omnibus Surveys), the authors would have to be contacted in the initial stages to discuss how and whether it was possible to gain access to their data collection tools (instrument and data collection software). The Statistics on Alcohol, England (2010) survey highlighted a measure in the public domain (AUDIT), which may be more appropriate in terms of access and outcome measurement of the alcohol-related aspects of lifestyle (hazardous, harmful and dependent drinkers). The Smoking-Related Behaviour and Attitudes (2008/9) survey does provide questions, though once again possible issues regarding how items are formed and compiled, as well as copyright and access are to be considered. The remaining surveys (Health Profile of England, 2009; Statistics on Obesity, Physical Activity and Diet, England, 2011; Statistics on Smoking, England, 2010) utilised data sourced from other surveys and did not identify any appropriate measures.

In summary, the AUDIT measure may be considered, and while other surveys and data collection techniques may be pursued, they may not be practical for the purposes of this consultancy due to access and administration issues.

Reflexivity
At this stage the searches conducted and the strategies employed had not achieved the required outcomes for completion of the consultancy aims. On this basis, a meeting with the client was needed to discuss the level of information gained, highlight the issues regarding existing survey-based information and consider gaining access to an additional database which could specifically focus upon identifying instruments that were of relevance to this piece of consultancy. One such database is the Health and Psychosocial Instruments (HaPI) database.
Consultancy Meeting  

(7th June 2011)

The aforementioned conclusion was discussed, and it was agreed that, if possible, HaPI access should be obtained. In addition, Dr Erwin attended the meeting, and it was agree that I would contact him to gather additional contact information relating to survey-based options (see Appendix 9).

Health and Psychosocial Instruments (HaPI)
Access to the Health and Psychosocial Instruments database was provided between 15th June and 14th July 2011. HaPI provides abstracted information to approximately 15,000 measurement instruments, such as questionnaires, interview schedules, checklists, coding schemes and rating scales. Information is abstracted from hundreds of leading journals covering health sciences and psychosocial sciences, as well as instruments from industrial/organisational behaviour and education. Coverage is from 1985 to present and contains 145,000+ records. I gained access via contact with the Subject Librarian at City University, London.

Reflexivity
I spent a bit of time getting to know the database in terms of field descriptions, advanced searching and limits, as well as identifying each field’s indexing features:

OR
AND
NOT
$ = unlimited truncation, i.e. car$
$ = limited truncation following $, i.e. car$4 = cartoon
# = mandated wildcard, i.e. wom#n = woman and women
? = optional wildcard, i.e colo?r = color or colour
“ “ = literal strings that contain special character, i.e. “black/white”

Search 1
A basic pilot search (Table 1) using specific terms was conducted to assess the extent of results identified by the HaPI database.

Table 1. Pilot Search of Lifestyle-Based Terms

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<tr>
<th>Search term</th>
<th>Results – keyword (abstract)</th>
<th>Results – title (abstract)</th>
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<tbody>
<tr>
<td>lifestyle</td>
<td>1250 (582)</td>
<td>223 (95)</td>
</tr>
<tr>
<td>physical OR exercise</td>
<td>7607 (3964)</td>
<td>1399 (555)</td>
</tr>
<tr>
<td>diet OR weight OR nutrition</td>
<td>3069 (1506)</td>
<td>528 (200)</td>
</tr>
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It is important to note that one of the limitations of a basic search is, that while it may locate a high number of results, it is also quite specific, i.e. only focussing on the word physical, and therefore possibly missing other descriptions that relate to physical.
Search 2
In order to target the full extent of possible terms that relate to lifestyle or its associated features, the descriptor field was utilised. The following is a description of the descriptor field:

Descriptors (DE) – contains controlled vocabulary (Thesaurus of Psychological Index Terms and National Library of Medical Subject Headings MeSH), which is independent of specific words, e.g. a search for arthritis retrieves all documents about arthritis, though they might not specifically mention the word “arthritis”.

Pilot search:
Entering lifestyle as a keyword and searching within the descriptor field retrieved 695 items. A pilot search was then conducted on the items in order to develop an approach with which to categorise and assess the suitability of relevant instruments. A 10% check (initial 70 items) was conducted by viewing title then abstract (where possible) to create exclusion criteria, in order to further understand the remaining items in the search prior to collecting full text articles (Appendix 3). The following categories were identified:

- Disease-specific categories
- Non-lifestyle-related
- Single lifestyle measure
- Single factor measure
- Quality of life
- Gender-specific
- Measure not provided in article
- Varied factors
- Secondary source

Full search:
A full search was then conducted on all remaining 625 items using the aforementioned criteria; the final search produced 57 items. When this number was explored in more detail regarding the instruments’ authors, the total figure came to 100 items. Items were tabulated with the primary source reference and the number of references associated with the instrument on the HaPI database (Appendix 4).

Consultancy Meeting
(21st June 2011)

Within the consultancy meeting it was agreed that initially only items referred to in the HaPI database more than once (i.e. beyond the initial paper’s reference) should be retrieved. This would result in 21 instruments being located in full text format, and tabulated in terms of what they measured and their psychometric qualities. In addition, the focus was to be on a single instrument for assessing lifestyle in contrast to a battery of individual measures (i.e. physical activity, diet, smoking, drinking) (see Appendix 9).
Summary of lifestyle investigation:

An investigation of the identified 21 items (Appendix 5) allowed for the following categorisations of non-UK and UK-based surveys, as well as specific lifestyle and population items:

- UK survey (Cox & Whichelow, 1993; Cox et al., 1987; Krause, Jay & Liang, 1991; National Center for Health Statistics, 1985)
- Specific lifestyle factors (Blair, Piserchia, Wilbur & Crowder, 1986; Paffenbarger, Wing & Hyde, 1978; Sandoz Nutrition Company, 1988)
- Specific populations (Colditz et al., 1986; Giammattei, Blix, Marshak, Wollitzer & Pettitt, 2003; VanAntwerp, 1995; Willett et al., 1987)

In addition, one item focussed on clinical factors (Millon, Green & Meagher, 1979), one item identified an earlier version of the Health Promoting Lifestyle Profile (Walker, Sechrist & Pender, 1987) and one item was an unpublished manuscript (Epperson & Zytowski, 1980). The aforementioned instruments were excluded on the basis that non UK-based surveys were not comparable in terms of population data or age at which the survey was completed. Clinical instruments did not meet the requirements of the consultancy, and the Health Promoting Lifestyle Profile had been revised (Health Promoting Lifestyle Profile II).

One item could not be located (Donovan, Jessor & Costa, 1989), another item was a book chapter describing computer lifestyle assessment (Allen & Skinner, 1987) and another was a conference reference (Muhlenkamp & Brown, 1983).

The item most commonly referred to (Walker, Sechrist & Pender, 1995) contained six sub-scales (health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations and stress management) and provides a score for overall health-promoting lifestyle, psychometric features:

- Walker (1987) used factors analysis (correlations between items and internal consistency)
- Walker (1988) compared health-promoting behaviours of older adults with young and middle-aged adults
- Walker (1990) conducted a psychometric evaluation of the Spanish version of the Health Promoting Lifestyle Profile

While the aforementioned articles (from the author’s website) provided a level of psychometric evaluation, the instrument did not appear to be assessed against other measures assessing similar constructs, nor did it reflect a musculoskeletal or UK-based population, being sampled from a “general adult population in two mid-western states” Walker (1987).

Conclusion to lifestyle search:

If survey data is to be considered, it may be more appropriate to obtain recent, updated UK-based survey material. The remaining items retrieved from the search did not assess all of the lifestyle areas required for the consultancy.

Additional lifestyle search strategy:
On the basis that an appropriate instrument had not been located which represented all of the lifestyle features required for this consultancy, the following approach was added to the search strategy. Using the HaPI database and the compendium source field:

“Information from an instrument collection, such as Test Critiques and handbooks on instruments for a certain topic. These records often indicate whether reliability and validity information is included in the source”. OVIDSP (27th June 2011)

The compendium field could not be located, and therefore the review source field was selected, described as:

“Information about articles that use an instrument; information from a review source such as Mental Measurements Yearbook and journal articles that review instruments; these records do not indicate whether reliability and validity information is included in the source.” OVIDSP (27th June 2011)

Within the HaPI database 19,744 review sources were located; when combined with lifestyle this was reduced to 94 items. All 94 items were assessed via title, and the following were identified:


Mental Measurements Yearbook:

Observation:
While conducting the searches, an instrument was noted that provided outcome measurements, provided comparisons to the general population and was well established within the literature:
Appendix

- SF-36v2, SF-12v2, SF-8 Health Survey, measures physical and mental health within eight domains (physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional and mental health).


Conclusion
This search identified a number of books which would have to be obtained via inter-library loan; NHS catalogues held only one title (Waltz & Strickland, 1988). The SF-36v2 health survey could be supplemented with a behaviour-based plan containing the lifestyle categories assigned to the consultancy.

European Health Surveys Information Database (EUHSID)
A search within the European Health Surveys Information Database (EUHSID) was carried out to assess the type and nature of information and whether it could be utilised for the purposes of this consultancy. A single search using physical activity provided the following information:

2008-2011, Europe: EU Member States, United Kingdom, National Surveys, Health Code Topic (412 – Physical Activity):
- Health Survey for England – 2008: Physical Activity and Fitness

- Welsh Health Survey
- Health Survey for England
- Health Survey for England – 2008: Physical Activity and Fitness
- The Scottish Health Survey

(Welsh and Scottish Health Survey removed)

A number of questions were identified from the search:
- Health Survey for England UK35 (attitudes towards physical activity)
- Health Survey for England – 2008: Physical Activity and Fitness UK36 (physical activity, employment status, working conditions, other living and working conditions, daily activities and leisure time activities – excluding physical exercise)

Conclusion
The Health Survey for England (HSE) asks specific questions relating to attitudes towards physical activity. Questions within the Health Survey for England – 2008: Physical Activity and Fitness were also specific (Q - Have you done any gardening, DIY or building in the past four weeks - yes/no), with a level of detail (I’d like you to think about all the walking you have done in the past four weeks either locally or away from here…….). Also, some questions informed and led to the next question.

The Health Survey may not be suitable, as it focusses specifically upon attitudes to physical activity. Similarly, it was difficult to consider the value in being able to contrast specific or single questions from the HSE – 2008: Physical Activity and Fitness survey, due to their specific nature and the focus on one question informing the next; therefore limiting the suitability of utilising specific questions in a static
questionnaire format (possibly restricting administration to an interview-only format). Nonetheless, it is still unclear how these questions are calculated to produce the overall results, and while a survey may, if this formula or access were provided, allow comparisons, it could not provide categorisations, i.e. healthy physical activity or unhealthy physical activity, and a rating scale would most probably not be possible.

**Buros Institute of Mental Measurements: Test Reviews Online (Lifestyle, Health)**
The Buros Institute of Mental Measurements: Test Reviews Online database provides access to test reviews online from the Mental Measurements Yearbook. It contains 3,500 commercially available tests and reviews are available at a cost of $15 per test title: [http://buros.unl.edu/buros/jsp/search.jsp](http://buros.unl.edu/buros/jsp/search.jsp)

Entering the search term *health* as a keyword in all fields retrieved 267 items, which were then searched by title, followed by a brief measurement description where possible. The Rand-36 Health Status Inventory (2001 - 14th Mental Measurements Yearbook) was identified.

Then the search term *lifestyle* was entered as a keyword in all fields and retrieved 19 items, which were then searched by title, followed by a brief measurement description. The Computerized Lifestyle Assessment (2003 – 15th Mental Measurements Yearbook) was identified.

**Conclusion**
To obtain further information on the Rand-36 Health Status Inventory and the Computerized Lifestyle Assessment would require an inter-library loan.

**Health and Psychosocial Instruments (HaPI) Database**
In light of the lack of findings for an inclusive lifestyle instrument, searches were conducted to identify instruments that focus on specific aspects of lifestyle (physical activity, ideal weight, balanced diet, accident prevention and abnormal/overuse of musculoskeletal system). Smoking was not pursued, as a previous discussion with the client had indicated that no level of smoking could be considered healthy. In terms of alcohol, the World Health Organisation (AUDIT) was to be discussed with the client regarding suitability. Items were keyword-searched using specific descriptors (NOT survey OR diary) to locate primary sources and retrieved if there was more than one reference to the article. It was important that wide searches were not conducted in order to conserve time and effort; instead, specific descriptor searches were conducted. If descriptor options were not available, specific words were entered and searched in all fields:

- Rather than search through *diet* (581) - *diet AND balance* were searched
- Rather than *exercise* (553) - *physical OR physical activity OR physical exercise* were searched

Physical activity:
Entering *physical OR physical activity OR physical exercise* – descriptor (42 items), NOT *survey OR diary* – all fields (38 items) as a keyword, items were retrieved using the 10% check criteria conducted in the lifestyle search; three items were identified (Appendix 6).
Ideal weight:
Entering weight OR weight control OR weight gain OR weight loss OR weight reduction – descriptor (184 items), NOT survey OR diary - all fields (168 items) as a keyword, items were retrieved using the 10% check criteria conducted in the lifestyle search; five items were identified (Appendix 6).

Balanced diet:
Entering diet - descriptor (581 items), no descriptor terms related, or were similar, to balanced diet. Multi-field searches were conducted with diet - descriptor, AND balance$ - all fields (1 item). No items were retrieved using the 10% check criteria conducted in the lifestyle search.

Accident prevention:
Entering accident prevention as a descriptor identified 30 items, with NOT survey OR diary - all fields (23 items). Nine items were retrieved using the 10% check criteria conducted in the lifestyle search; items referenced more than once identified three items (Appendix 6).

Abnormal/overuse of musculoskeletal system:
Entering all musculoskeletal-related descriptors (musculoskeletal abnormalities OR musculoskeletal disabilities OR musculoskeletal diseases OR musculoskeletal disorder OR musculoskeletal disorders OR musculoskeletal system) identified 66 items. When combined with abnormal OR overuse, this retrieved one item which was not referenced more than once. For reference and/or further information purposes only, instruments with the term musculoskeletal were listed (Appendix 7).

Conclusion of individual lifestyle factors
Following on from the initial search, in which all references to lifestyle were searched, due to the specific nature of the individual lifestyle features (physical activity, ideal weight, balanced diet, drinking, accident prevention and abnormal/overuse of musculoskeletal system), searches were conducted independently. A lack of instruments identified prompted a different approach, and specific terms were searched for within the descriptor index; the following were identified:

- Health behaviour (1521)
- Health promotion (436)
- Health status (1383)

A combined search (health behaviour, health promotion and health status) (3,044 items), excluding survey OR diary (2101 items), and entering additional keywords to condense the search (physical, smoking, alcohol) (all fields), was conducted and identified 20 items. All items were checked for suitability and whether they had been referenced more than once; one item remained (Appendix 6).

Consultancy Meeting
(5th July 2011)

It was agreed within the consultancy meeting that, as no ideal measures had been located for the individual aspects of lifestyle, not to pursue inter-library loans on those
items that could not be located otherwise. The use of the SF-36v2 was discussed, and it was considered in conjunction with a clear Motivational Interviewing-based question which focussed on lifestyle, such as:

Question - “if we think about different areas of lifestyle, such as physical activity, ideal weight, balanced diet, smoking and alcohol (accident prevention and abnormal overuse of musculoskeletal), which would you like to think about changing?”

It was agreed that the SF-36v2 could facilitate a structured discussion and provide normative data regarding health-related factors, therefore acting as a compatible factor. The Motivational Interviewing based question could then focus upon the recommendations from a Bone and Joint Healthy Lifestyle for lifestyle change. The client also identified that it would be relevant to have a basic measure of lifestyle status, i.e. whether the individual smoked or drank alcohol. On this basis, it was agreed that I would construct a Lifestyle Information Sheet (Appendix 8) to collect this information. It was agreed that the next meeting would involve a summary of the consultation process using a PowerPoint presentation (see minutes Appendix 9).

Presentation
(1st August 2011)

A summary of the consultancy was presented and discussions held regarding the Lifestyle Information Sheet. An evaluation meeting was arranged for the 16th August 2011 to discuss the technical report and evaluate the overall consultancy process.

Consultancy Costing

**Search time**
Total = 18.5 days (1 day = 8 hours)
Overall = 148 hours

**Lifestyle Information Sheet**
Total = 1 day
Overall = 8 hours

**Meeting time (approximate)**
12th May 2011 – 30 minutes
7th June 2011 - 1 hour 30 minutes
21st June 2011 – 1 hour
5th July 2011 – 1 hour
1st August 2011 – 1 hour
16th August 2011 – 1 hour (evaluation)
Overall = 6 hours

**Presentation**
Total = 1 day
Overall = 8 hours

Overall Total = 148 + 8 + 6 + 8 = 170 hours
Daily rate: Trainee Psychologist
(Band 6 – Non-Clinical Psychologist)
Point 21 (scale 21 of 29) - £25,528 per year (as of 1st April 2011)
(£25,528 ÷ 365 = £69.94 per day)
170 hours ÷ 8 hours = 21.25 days
21.25 days x £69.94 = £1486.23

The consultancy was completed on the 16th August 2011.

References


Appendix 1b – Opt. 5.3
Systematic Review Search

Aim
The aim of this search was to locate systematic or non-systematic review articles that identified existing lifestyle instruments.

Databases (Ovid SP host platform)

Electronic Databases
The following four databases were searched:

- EMBASE (1980 - week 20, 2011) - A database of references taken from international literature covering all aspects of psychology and psychiatry.
- British Nursing Index (BNI) (date not stated) - A database of references from popular British nursing and midwifery journals, including a range of nursing, midwifery, health visiting and community health care topics.
- OVID Medline (1948 – May week 2, 2011) - A database of references taken from over 5,000 international health, biomedical and life sciences journals, covering a range of medically related subjects, including nursing, midwifery and dentistry.

Search History
The search aimed to identify either general lifestyle factors or specific lifestyle factors, such as exercise/physical, diet/weight, smoking or alcohol.

1) General LIFESTYLE search:

Keyword - “lifestyle” in title, limits (human, English language, review article) (5,977 results)
Keyword - “questionnaire OR instrument OR scale OR inventory OR measure” in title, limits (human, English language, review article) (56,042)
COMBINE AND (81 results)
Keyword - “review” in title, limits (human, English language, review article) (248,367 results)
COMBINE AND (0 results)

2) Specific lifestyle factors search (exercise/physical, diet/weight, smoking or alcohol):

EXERCISE/PHYSICAL
Keyword - “exercise OR physical” in title, limits (human, English language, review article) (104,764 results)
Keyword - “questionnaire OR instrument OR scale OR inventory OR measure” in title, limits (human, English language, review article) (56,042)
COMBINE AND (1,050 results)
Keyword - “review” in title, limits (human, English language, review article) (248,367 results)
COMBINE AND (5 results), remove duplicates (3 results)

Description of three studies:
1) What is the best way to change self-efficacy to promote lifestyle and recreational physical activity: A systematic review (Ashford, Edmunds & French, 2010).

Summary:
To systematically gather and meta-analyse intervention studies aimed to increase self-efficacy for physical activity.

2) Lifestyle factors and colorectal cancer risk (2): A systematic review and meta-analysis of associations with leisure-time activity (Harris et al., 2009).

Summary:
Systematic review and meta-analysis of prospective observational studies to quantify gender-specific risk associated with increased leisure-time physical activity.

3) Introduction to the review papers pertaining to components of the Canadian Physical Activity, Fitness and Lifestyle Appraisal (Gledhill, 2001).

Summary:
No information available.

Conclusion:
None of these studies were suitable for this investigation.

DIET/WEIGHT
Keyword - “diet OR weight” in title, limits (human, English language, review article) (58,647 results)
Keyword - “questionnaire OR instrument OR scale OR inventory OR measure” in title, limits (human, English language, review article) (56,042)
COMBINE AND (328 results)
Keyword - “review” in title, limits (human, English language, review article) (248,367 results)
COMBINE AND (3 results), remove duplicates (2 results)

Description of two studies:
1) The Four Quadrants Weight Scale: A technical and procedural review (Vernon, 1984).

Summary:
A postural analysis unit developed to evaluate weight-bearing in the sagittal and frontal body planes.

2) Is it important or even useful to measure weight gain in pregnancy? (A literature review and criticism of current practice) (Hytten, 1990).
Appendix

Summary:
No information available.

Conclusion:
Neither of these studies were suitable for this investigation.

SMOKING
Keyword - “smok$” in title, limits (human, English language, review article) (48,268 results)
Keyword - “questionnaire OR instrument OR scale OR inventory OR measure” in title, limits (human, English language, review article) (56,042)
COMBINE AND (263 results)
Keyword - “review” in title, limits (human, English language, review article) (248,367 results)
COMBINE AND (2 results), remove duplicates (1 result)

Description of one study:
1) A critical review of the Reasons for Smoking Scale (Tate, Schmitz & Stanton, 1991).

Summary:
Review of studies bearing on the psychometric characteristics and clinical utility of the Reasons for Smoking Scale (RFS).

Conclusion:
This study was not suitable for this investigation.

ALCOHOL
Keyword - “alcohol” in title, limits (human, English language, review article) (39,984 results)
Keyword - “questionnaire OR instrument OR scale OR inventory OR measure” in title, limits (human, English language, review article) (56,042)
COMBINE AND (440 results)
Keyword - “review” in title, limits (human, English language, review article) (248,367 results)
COMBINE AND (6 results), remove duplicates (3 results)

Description of three studies:
1) A narrative review of the Beck Depression Inventory (BDI) and implications for its use in an alcohol-dependent population (Martin & McPherson, 2010).

Summary:
A psychometric evaluation of the Beck Depression Inventory (BDI) was carried out on contemporary studies to ascertain its suitability for use in an alcohol-dependent population.

Summary:
Review of the reliability and validity of the CAGE questionnaire across different patient populations and its role in the detection of alcohol-related populations.

3) Sensitivity of the CAGE questionnaire for the DSM diagnosis of alcohol abuse and dependence in general clinical populations was 71% at cut points >=2 (Aertgeerts, Buntinx, Kester & Schortling, 2005).

Summary:
Specifically related to the CAGE questionnaire.

Conclusion:
None of these studies were suitable for this investigation.

Conclusion
The aforementioned search strategy did not locate a general lifestyle or specific (exercise/physical, diet/weight, smoking or alcohol) lifestyle-based systematic review or review article focussed specifically on the identification of available measures.

The Cochrane Library
All of the following Cochrane Library databases were searched:
- Cochrane Database of Systematic Reviews (Cochrane Reviews)
- Database of Abstract of Reviews and Effects (Other Reviews)
- Cochrane Central Register of Controlled Trials (Clinical Trials)
- Cochrane Methodology Register (Technology Assessments)
- Health Technology Assessment Database (Technology Assessments)
- NHS Economic Evaluation Database (Economic Evaluations)

Advanced Search

A) General LIFESTYLE search:

Search terms “questionnaire OR instrument OR scale OR inventory OR measure” in record title AND “lifestyle” in record title (9 results).

The following are the titles of the retrieved studies using the term “lifestyle”:
(Assessed title and abstract to ascertain suitability)

1) Improvement in quality of life questionnaire in obese adolescent females with polycystic ovary syndrome treated with lifestyle changes and oral contraceptives, with or without metformin (Specific population) - N/A, the effect of metformin or placebo in a lifestyle modification program.

2) Changes in cognitive measures associated with a lifestyle program for treated hypertensives: A randomised controlled trial (ADAPT) - N/A, cognitive changes in a lifestyle program for drug-related hypertensions.

3) Effects of a physical activity intervention on measures of physical performance: Results of the Lifestyle Intervention and Independence for Elders Pilot (LIFE-P) study
- N/A, assessing the effect of a physical intervention on the Short Physical Performance Battery.

4) Influence on lifestyle measures and five-year coronary risk by a comprehensive lifestyle intervention programme in patients with coronary heart disease - N/A, whether a programme of lifestyle modification could influence dietary and exercise habits.

5) Path analysis model of lifestyle factors and subjective health: The Healthy Japan 21 questionnaire survey Obihiro - Japan-based population (locate UK-based measure).

6) Rosiglitazone amplifies the benefits of lifestyle intervention measures in long-standing type 2 diabetes mellitus - N/A, evaluating a lifestyle programme.

7) Relationships of quality of life measures to long-term lifestyle and drug treatment of mild hypertension study - N/A, comparing five antihypertensive drugs.

8) Impact of a postcard versus a questionnaire as a first reminder in a postal lifestyle survey - N/A, considering the impact of two different types of reminder.

9) Assessing alcohol consumption in general practice patients: A comparison between questionnaire and interview (findings of the Medical Research Council’s general practice research framework study on lifestyle and health) - describes Health Survey Questionnaire (HSQ).

   B) Specific lifestyle factors (exercise/physical, diet/weight, smoking, alcohol):

Search terms “questionnaire OR instrument OR scale OR inventory OR measure” in record title AND the following terms:
(Assessed title to ascertain suitability)

<table>
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<tr>
<th>Theme</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise</td>
<td>(98)</td>
</tr>
<tr>
<td>Physical</td>
<td>(64)</td>
</tr>
<tr>
<td>Diet</td>
<td>(38)</td>
</tr>
<tr>
<td>Weight</td>
<td>(1)</td>
</tr>
<tr>
<td>Smoking</td>
<td>(73)</td>
</tr>
<tr>
<td>Alcohol</td>
<td>(1)</td>
</tr>
</tbody>
</table>

Additional Search

Searched two Cochrane databases expanding field from title to abstract search:

- Cochrane Database of Systematic Reviews (Cochrane Reviews)
- Database of Abstracts of Reviews of Effects (Other Reviews)

   A) General:

Keyword term “questionnaire OR instrument OR scale OR inventory OR measure” in abstract AND “lifestyle” in abstract/title (28 results) - N/A.
B) Specific:

Keyword term “questionnaire OR instrument OR scale OR inventory OR measure” in abstract AND “exercise/physical, diet/weight, smoking, alcohol” (entered individually) in abstract/title:

Exercise (165) - N/A
Physical (238) – N/A
Diet (59) – N/A
Weight (417) – N/A
Smoking (70) – N/A
Alcohol (52) - N/A

Overall Conclusion
No systematic review or review-based articles were located that focussed on the identification of measures to assess either general or specific aspects (exercise/physical, diet/weight, smoking, alcohol) of lifestyle.
## Appendix 2 – Opt. 5.3

**Health Survey for England (HSE) 2009* 2008**
(Results Samples)

**Note:** Not all categories (or dates) are represented, and have been edited for the purposes of this appendix.

**Smoking (cigarette status)**
(Self-reported cigarette smoking status, by survey year and sex)

<table>
<thead>
<tr>
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<tr>
<td>Cigarette smokers</td>
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<tr>
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<td>7</td>
<td>8</td>
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<td>8</td>
</tr>
<tr>
<td>10 to under 20 cigarettes a day</td>
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<td>11</td>
<td>9</td>
<td>9</td>
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<td>10</td>
</tr>
<tr>
<td>20 or more cigarettes a day</td>
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<td>11</td>
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<td>6</td>
</tr>
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<td>11</td>
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### Alcohol (units)
(Estimated alcohol consumption on heaviest drinking day in the last week, by survey year, age and sex)

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<th>2009 REVISED</th>
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<tr>
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<td>42</td>
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<td>Up to and including 3</td>
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<td>40</td>
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Fruit and Vegetables (portions per day)
(Fruit and vegetable consumption, by survey year, age and sex)

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<th>2002</th>
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<td>16</td>
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<td>4 portions or more but less than 5</td>
<td>14</td>
<td>14</td>
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<tr>
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<td>5 portions or more</td>
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<td>29</td>
<td>28</td>
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<td>1 portion or more but less than 2</td>
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<td>15</td>
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<td>5 portions or more</td>
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Physical Activity
(Levels of physical activity, by survey year, age and sex)

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</tr>
<tr>
<td>Meets recommendations</td>
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<td>34</td>
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<td>16-24, - 75+</td>
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<td>16-24, 75+</td>
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Appendix 3 – Opt. 5.3
Lifestyle 10% Checks

The term *lifestyle* was entered in the descriptors field:

“The Descriptors (DE) field contains controlled vocabulary terms or subject headings from the Thesaurus of Psychological Index Terms as well as the National Library of Medicine Medical Subject Headings (MeSH). Descriptors enable you to locate documents by assigned controlled vocabulary and are independent of the occurrence of specific words in any field. For example, the search arthritis.de. retrieves all documents about arthritis, although they might not specifically mention the word “arthritis.”

As an alternative to searching with the field label (DE), you can browse and search for them directly from the index.

For a word indexed version of vocabulary searching, including Sample Descriptors and Measure Descriptors, use the Heading Word (HW) field.” (OVIDSP)

Table 1 contains the results of the 10% check on 695 results (initially 70 results). It describes those items excluded from further searches (retrieval of full text article or source material). Exclusion was assessed by viewing the title, then the abstract; items were then categorised.

**Table 1. Description of Excluded Results from 10% Checks**

<table>
<thead>
<tr>
<th>Item title (results number)</th>
<th>Categorisation</th>
<th>Assessed by (title / abstract*)</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Carolina Cardiovascular Disease Prevention Project Interview (1)</td>
<td>Disease specific</td>
<td>Title/abstract</td>
</tr>
<tr>
<td>Drunkenness Offender Questionnaire (2)</td>
<td>Single lifestyle measure</td>
<td>Title</td>
</tr>
<tr>
<td>Quality of Life Index (12)</td>
<td>Quality of life</td>
<td>Title</td>
</tr>
<tr>
<td>Unified Parkinson’s Disease Rating Scale (16)</td>
<td>Disease specific**</td>
<td>Title /abstract</td>
</tr>
<tr>
<td>National Study of Health and Life Experiences of Women (18)</td>
<td>Gender specific</td>
<td>Title/abstract</td>
</tr>
<tr>
<td>National Study of Health and Life Experiences of Women (20)</td>
<td>Gender specific</td>
<td>Title/abstract</td>
</tr>
<tr>
<td>Coronary Artery Risk Development in Young Adults Study (24)</td>
<td>Disease specific</td>
<td>Title</td>
</tr>
<tr>
<td>Food Frequency Questionnaire (25)</td>
<td>Single lifestyle measure** (diet)</td>
<td>Title/abstract</td>
</tr>
<tr>
<td>Pulmonary Preventive Academic Award Attitude Survey (26)</td>
<td>Disease specific</td>
<td>Title</td>
</tr>
<tr>
<td>Diet History Questionnaire (27)</td>
<td>Single lifestyle measure** (diet)</td>
<td>Title/abstract</td>
</tr>
<tr>
<td>Lifetime Smoking History Interview (30)</td>
<td>Single lifestyle measure** (smoking)</td>
<td>Title/abstract</td>
</tr>
<tr>
<td>Checklist of Recommended Skin Self-Examination Steps (33)</td>
<td>Disease specific</td>
<td>Title</td>
</tr>
<tr>
<td>Improving Quality of life of Older Age Groups (37)</td>
<td>Quality of life</td>
<td>Title/abstract</td>
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</table>
Appendix

<table>
<thead>
<tr>
<th>Item title (results number)</th>
<th>Categorisation</th>
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</thead>
<tbody>
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<td>National Health and Leisure Time Survey (17)</td>
<td>Single lifestyle measure (alcohol)</td>
</tr>
<tr>
<td>National Health and Leisure Time Survey (19)</td>
<td>Single lifestyle measure (alcohol)</td>
</tr>
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<td>Health Self-Determination Index (31)</td>
<td>Secondary source *</td>
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<td>Life-Style Risk Assessment Interview (34)</td>
<td>Single lifestyle measure (substance use)</td>
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<tr>
<td>Dartmouth Assessment of Lifestyle Instrument (35)</td>
<td>Single lifestyle measure (substance use)</td>
</tr>
<tr>
<td>Older Americans Status and Needs Assessment Survey (38)</td>
<td>Varied (seven factors, only one health-care)</td>
</tr>
<tr>
<td>Images of Older People Battery (39)</td>
<td>Non-lifestyle related (perceptions of older people)</td>
</tr>
<tr>
<td>Psychap Inventory (40)</td>
<td>Varied (six factors, only one lifestyle)</td>
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<td>Psychap Inventory (41)</td>
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<td>Varied (six factors, only one lifestyle)</td>
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<td>Problem Situations Checklist (43)</td>
<td>Disease specific (adherence to diabetic regimen)</td>
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<tr>
<td>Geriatric Functional Rating Scale (45)</td>
<td>Non-lifestyle related (physical and mental disability)</td>
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<tr>
<td>Migration Decision (46)</td>
<td>Non-lifestyle related (reasons from leaving communities of origin)</td>
</tr>
<tr>
<td>Incapacity for self-Care (47)</td>
<td>Non-lifestyle related (incapacity-based)</td>
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<td>Modes of Adaptation Patterns Scale (48)</td>
<td>Non-lifestyle related (adaptation in terms of activity and morale)</td>
</tr>
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</table>

* Abstract always searched when located in search results (i.e. available).
** Limited information within abstract to make full assessment of content.

**Note:** Where only the title was available, a judgement was made about title content or nature. Only single categorisation was used (may contain more than one category, i.e. disease-specific and single lifestyle factor).

Remaining items (assessed via title) were abstract-checked and excluded where possible (Table 2).

Table 2. Abstract or Full Text Searches of Remaining Items

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<td>Morale Scale (50)</td>
<td>Single factor measure (morale)</td>
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<td>Frequency of Death Thoughts (52)</td>
<td>Single factor measure (death thoughts)</td>
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<tr>
<td>Mensana Clinic Back Pain Test (54)</td>
<td>Disease specific</td>
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<tr>
<td>Body Knowledge Test (56)</td>
<td>Single factor measure (body knowledge)</td>
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<tr>
<td>Epilepsy Self-Help Groups (59)</td>
<td>Disease specific</td>
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<tr>
<td>Need Priorities of Adrenalectomy Patients (63)</td>
<td>Disease specific</td>
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<tr>
<td>Coffee Drinking and Cancer (67)</td>
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<tr>
<td>Inflammatory Bowel Disease Stress Index (69)</td>
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* Abstract always searched when located in search results (i.e. available).
** Limited information within abstract to make full assessment of content.
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<th>Appendix</th>
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<td><strong>Dean Morale Index (49)</strong></td>
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<td><strong>Change Seeker Index (51)</strong></td>
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<td><strong>Leisure Participation (53)</strong></td>
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<td><strong>Students Health Survey (55)</strong></td>
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<td><strong>Medical Students Life-Styles and Interpersonal Relationships (58)</strong></td>
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<td><strong>Lifestyle Orientation (60)</strong></td>
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<td><strong>Daily Activities Diary (64)</strong></td>
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<td><strong>Compliance Behavior Interview Schedule (65)</strong></td>
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<td><strong>Current Health Behaviors and Practices (68)</strong></td>
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1 Only assessed when abstract present and enough information provided to exclude.

* Primary reference retrieved.

Primary source item:


Summary:
24 (plus 2 from primary source) out of 70 results were to be pursued for further suitability.

An additional search was conducted using the following criteria for exclusion:

- Disease-specific categories
- Non-lifestyle-related
- Single lifestyle measure
- Single factor measure
- Quality of life
- Gender-specific
- Measure not provided in article
- Varied factors
- Secondary source
## Appendix 4 - Opt. 5.3
Findings from 100-Item Lifestyle Search

### Table 1. Tabulated Findings from Lifestyle Search

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<tr>
<td>Health Promoting Lifestyle Profile--II</td>
<td>Walker, S. N., Sechrist, K. R., &amp; Pender, N. J. (1995). The Health Promoting Lifestyle Profile--II. Omaha, NE: University of Nebraska Medical Center, College of Nursing. (ENGLISH)</td>
<td>No</td>
<td>23</td>
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<tr>
<td>Computerized Lifestyle Assessment</td>
<td>MHS/Multi-Health Systems, Inc., 908 Niagara Falls Boulevard, North Tonawanda, NY 14120-2060. (ENGLISH) – Publishers Catalogue</td>
<td>No</td>
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### Inventory

<p>| Health And Lifestyle Questionnaire | Farrell, S. W., Kohl, H. W., &amp; Bogdanffy, G. M. (1989). Incidence and reasons for medical referral in a worksite health promotion program. American Journal of Health Promotion, 3, 6-10. (ENGLISH) | Yes | 1 |
| Appendix |
|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Prototype Percepti... |............. |.................. |............. |.................. |............. |.................. |
| Neig... |............. |.................. |............. |.................. |............. |.................. |
| - modified version of Menzies, Gibbons and Goldberg@s (1989) measure. |............. |.................. |............. |.................. |............. |.................. |</p>
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<th>Appendix</th>
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<tr>
<td>Lifestyle and Your Health Questionnaire</td>
<td>Ableson, J., Chinappa, B. N., Praught, E., &amp; Richardson, I. D. (ENGLISH)</td>
<td>No 1</td>
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<tr>
<td>Life-Style Inventory</td>
<td>Epperson, D. L., &amp; Zytowski, D. (1980). Life Style Inventory. Unpublished manuscript. Awe's Iowa State University, Department of Psychology. (ENGLISH)</td>
<td>No 2</td>
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<td>Lifestyle Survey--Form A</td>
<td>Behavioral Measurement Database Services (BMDS) – Castro, F. G. (SPANISH)</td>
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<td>Lifestyle Survey--Form B.</td>
<td>Behavioral Measurement Database Services (BMDS) – Castro, F. G. (SPANISH)</td>
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**Appendix**

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<tr>
<th>Questionnaire</th>
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<tr>
<td></td>
<td>Dickerson, S. S., Mycek, P. J., &amp; Zaidivar, F. (2008). Negative social evaluation, but not mere social presence, elicits cortisol responses to a laboratory stressor task. Health Psychology, 27(1), 116-121. (ENGLISH)</td>
<td>Yes</td>
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<td>Questionnaire</td>
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<td>Source</td>
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### Appendix 5 - Opt. 5.3

**Identification and Descriptive Characteristics**  
Initial “Lifestyle” HaPI Search (21 items)

#### Table 1. References Pursued for Further Content

<table>
<thead>
<tr>
<th>Instrument title</th>
<th>Primary source (LANGUAGE)</th>
<th>N*</th>
<th>Measure</th>
<th>Psychometrics</th>
<th>Rating</th>
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<tr>
<td>Health Promoting Lifestyle Profile—II (HPLP II)</td>
<td>Walker, S. N., Sechrist, K. R., &amp; Pender, N. J. (1995). The Health Promoting Lifestyle Profile—II. Omaha, NE: University of Nebraska Medical Center, College of Nursing. (ENGLISH)</td>
<td>23</td>
<td>Health-promoting lifestyle, health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations, stress management – 52 items</td>
<td>Questionnaire attached (11 page bibliography available online) <a href="http://www.unmc.edu/nursing/Health_Promoting_Lifestyle_Profile_II.htm">http://www.unmc.edu/nursing/Health_Promoting_Lifestyle_Profile_II.htm</a></td>
<td>Mean</td>
<td>Maybe</td>
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<tr>
<td>Survey/Questionnaire</td>
<td>Study References</td>
<td>Data/Construct used</td>
<td>Review Source</td>
<td>Survey Type</td>
<td>Notes</td>
<td></td>
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<td>----------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------</td>
<td>-----------------------------</td>
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<tr>
<td>National Health Interview Survey—Supplement on Aging</td>
<td>National Center for Health Statistics. (1985). National Health Interview Survey (NHIS). Hyattsville, MD. (ENGLISH) – Also SOA / SOA11</td>
<td>7 - Information on National Centre for Health Statistics (NCHS) retrieved</td>
<td>Survey-based</td>
<td>Survey</td>
<td>No NCIS survey (use UK-based)</td>
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<tr>
<td>Nurses' Health Study Questionnaire (Both items HaPi assigned)</td>
<td>Colditz, G. A., Martin, P., Stampfer, M. J., Willett, W. C., Sampson, L., Rosner, B., Hennekens, C. H., &amp; Speizer, F. E. (1986). Validation of questionnaire information on risk factors and disease outcomes in a prospective cohort study</td>
<td>6 Cancer, heart disease and other serious illness</td>
<td>No questionnaire located, Colditz et al. (1986) reported upon sub-studies to validate self-report of medical conditions</td>
<td>Unsure</td>
<td>No (women nurses only)</td>
<td></td>
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<tr>
<td>Inventory/Survey</td>
<td>Authors</td>
<td>Description</td>
<td>Language</td>
<td>Required?</td>
<td>Physical Activity &amp; Lifestyle Focussed?</td>
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<td>--------------</td>
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<tr>
<td>Weight and Lifestyle Inventory</td>
<td>Sandoz Nutrition Company. (1988). Weight and Lifestyle Inventory (WALI). Minneapolis: Author (ENGLISH)</td>
<td>Weight and diet history, eating and exercise habits, relationships with family and friends (tobacco and alcohol use)</td>
<td>Information collecting</td>
<td>No</td>
<td>No (weight and lifestyle focussed)</td>
<td></td>
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</table>

*Notes:*
- **Abstract located:** Indicates if an abstract for the source is available.
- **Likert scale:** Indicates if the data collection method includes Likert scales.
- **Nominal:** Indicates if the data collection method is nominal.
- **Survey-based:** Indicates if the data collection method is survey-based.
- **Second-hand:** Indicates if the source is available second-hand.
- **Use UK-based:** Indicates if the survey is based in the UK.
- **Inter-library loan:** Indicates if the source is available through inter-library loan.
### Notes (from 24th June 2011):

1. Unless construct-based measures are retrieved, consider survey-based comparative measures.
2. Retrieval of instruments has been via internet and electronic database sources, in order to assess basic descriptive features, such as type of instrument (questionnaire, survey) and what it measures. Further retrieval approaches may be considered if required, i.e. inter-library loan or contacting the author. Not all retrieved articles are from primary sources.
3. Following retrieval of the National Center for Health Statistics (1985) survey, non-UK-based surveys were not pursued, as they were not comparable in terms of population data or age (Canada Fitness Survey, 1982; Health and Welfare Canada, 1981; National Center for Health Statistics, 1984) (Table 2).
Table 2. References not Pursued for Further Content

<table>
<thead>
<tr>
<th>Instrument title</th>
<th>Primary source (LANGUAGE)</th>
<th>N*</th>
<th>Measure</th>
<th>Psychometrics</th>
<th>Rating</th>
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<tr>
<td>Life-Style Inventory</td>
<td>Epperson, D. L., &amp; Zytowski, D. (1980). Life Style Inventory. Unpublished manuscript. Ames Iowa State University, Department of Psychology. (ENGLISH)</td>
<td>2</td>
<td>NOT PURSUED (Unpublished manuscript)</td>
<td>NOT PURSUED (Unpublished manuscript)</td>
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<td>Lifestyle Questionnaire</td>
<td>Canada Fitness Survey (1982). Canada’s fitness: Preliminary findings of the 1981 survey. Canadian Federal Ministry of Fitness and Amateur Sport, Ottawa, Canada. (ENGLISH)</td>
<td>2</td>
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Table 2. Ideal Weight References Pursued for Further Content

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<td>Instrument title</td>
<td>Primary source (LANGUAGE)</td>
<td>N</td>
<td>Measure</td>
<td>Psychometrics</td>
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<tr>
<td>Personnel Selection Inventory—35</td>
<td>London House, Inc., 1550 Northwest Highway, Park Ridge, IL 60068. (reference from 3 &amp; 3S – one ref. each)</td>
<td>2</td>
<td>From HaPI abstract – identify candidates for employment with tendencies toward dishonest, drug abuse and violent behaviour. Also attitudes toward safety and how it may cause or prevent on-the-job accidents</td>
<td>PDF retrieved</td>
<td>Unsure</td>
<td>Unsure (possibly not appropriate)</td>
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<td>Instrument title</td>
<td>Primary source (LANGUAGE)</td>
<td>N</td>
<td>Measure</td>
<td>Psychometrics</td>
<td>Rating</td>
<td>Suitable Y/N/Maybe/Unsure</td>
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</tbody>
</table>
Appendix 7 - Opt. 5.3
List of Musculoskeletal-Related Items
(For Reference and /or Further Information Purposes)

Conducted 02\textsuperscript{nd} July 2011

Database: Health and Psychosocial Instruments <1985 to April 2011>

Search Strategy:

1. (musculoskeletal abnormalities or musculoskeletal disabilities or musculoskeletal diseases or musculoskeletal disorder or musculoskeletal disorders or musculoskeletal system or musculoskeletal disorders or musculoskeletal disorders).de. (66)

1. Carpal Tunnel Syndrome Questionnaire.

Carpal Tunnel Syndrome Questionnaire is designed to assess risk factors that may contribute to the development of carpal tunnel syndrome among dental hygienists and dental assistants. The questionnaire derives from Kuorinka, Jonsson, Kilbom, Vinterberg, Biering-Sorenson, Andersson, and Jorgensen@’s (1987) measure.

2. Upper Limb Soft Tissue Disorders Questionnaire.

Items in the Upper Limb Soft Tissue Disorders Questionnaire* are included in the source.

3. Standardized Nordic Questionnaire.

4. Medical Research Council Grading Scale of Muscle Weakness.
5. Screen.

Screen-- is designed to assess symptoms and correlates of craniomandibular dysfunction (CMD). Included are questions about: "(1) qualitative and quantitative aspects of pain in the head, neck and shoulders as well as factors increasing or decreasing pain; (2) other symptoms of CMD...and precipitators of CMD such as parafunctional habits like grinding, clenching and nail biting; (3) correlates of CMD, such as dizziness and symptoms of the ears, nose, eyes and throat; (4) psychosocial factors, such as nervousness, depression, anxiety and life events; and (5) general health" (p. 657).


Hopkins Symptom Checklist-- is a translated/adapted version of Derogatis, Lipman, Rickels, Uhlenhuth, and Covi's (1979) measure. Hopkins Symptom Checklist-- is included in the Musculoskeletal Pain Questionnaire* (see source).

*Instrument appears untitled in source--Title assigned by HaPI staff.

7. Occupational Prestige Rating Scale.

*Instrument appears untitled in source--Title assigned by HaPI staff.

8. Sickness Impact Profile.
9. Preliminary Diagnostic Questionnaire.

10. Minnesota Multiphasic Personality Inventory.

11. Ontario Health Survey.


13. Pain Questionnaire.

14. Locomotor System Questionnaire--"modified".

Locomotor System Questionnaire*--"modified"-- is an adapted version of Brattberg's (1989) measure.

*Instrument title assigned by HaPI staff--title not easily identified in the Isacsson, Hanson, Ranstam, Rastam, and Isacsson (1995) source.

15. Sickness Impact Profile.
16. State-Trait Anxiety Inventory.

State-Trait Anxiety Inventory--is a translated/adapted version of Spielberger's (1983) measure.

17. Pendulum Test--"quantified version".

Pendulum Test--"quantified version"--is a translated/adapted version of Bajd and Vodovnik's (1984) measure, derived from Wartenberg's (1951) measure to "distinguish spasticity and rigidity" (p. 1356).

18. Social Support Questionnaire.


20. Medical Research Council Grading Scale of Muscle Weakness.

22. Ontario Health Survey--Measures of Health State.

   Ontario Health Survey--Measures of Health State consists of two measures. "The first records number of kinds of prescription medications taken, and the second, number of diagnosed physical or mental impairments or health problems" (p. 447).

23. MOS 36-Item Short Form Health Survey--Mental Health Scale.

   MOS 36-Item Short Form Health Survey--Mental Health Scale-- is a translated/adapted version of Ware's (1993) measure.


   Musculoskeletal Problems scale is designed to assess the severity of patients' musculoskeletal problems. Items deal with diagnoses, symptoms, and disease manifestations. Items are rated on 3- or 4-point ordinal scales reflecting severity levels.

25. State-Trait Anxiety Inventory.

26. Respiratory and Musculoskeletal History Questionnaire.

*Instrument appears untitled in source--Title assigned by HaPI staff.
Appendix


Eysenck Personality Inventory-- is a translated/adapted version of Eysenck and Eysenck's (1969) measure. Eysenck Personality Inventory-- is included in the Musculoskeletal Pain Questionnaire* (see source).

*Instrument appears untitled in source--Title assigned by HaPI staff.


Items in the Vocational Rehabilitation Services Disability Codes are included in the Straaton, Maisiak, Wrigley, and Fine (1995) source.

33. Ursin Health Inventory.

Ursin Health Inventory--is included in the Musculoskeletal Pain Questionnaire* (see source).

*Instrument appears in untitled in source--Title assigned by HaPI staff.

34. Musculoskeletal Pain Diary.

Musculoskeletal Pain Diary*--asks participants to record "every evening for a week (including the weekend) symptoms of musculoskeletal pain from any part of the body (neck, shoulder, back, hip, arms, hands, and feet) using a 4-point scale (1 = 'no pain,' 4 = 'severe pain')" (p. 248).

*Instrument appears untitled in source--Title assigned by HaPI staff.

35. Modified Health Assessment Questionnaire.

Modified Health Assessment Questionnaire (MHAQ) is an adapted version of Fries, Spitz, Kraines, and Holman's (1980) measure,

36. Modified Health Assessment Questionnaire.

Modified Health Assessment Questionnaire--is an adapted and translated/adapted version of Pincus, Summey, Soraci, Wallston, and Hummon's (1983) measure.
37. Symptom Checklist--90--Shortened.

Symptom Checklist--90--Shortened-- is an abbreviated and translated/adapted version of Derogatis's (1992) measure.

38. Symptoms And/Or Musculoskeletal Conditions.


41. Family Configuration.

42. Musculoskeletal-Specific Signs And Symptoms.
43. Four-Factor Index of Social Status.

44. Multiple Affect Adjective Checklist--Revised.

45. Western Ontario and McMaster University Osteoarthritis Index--"modified".

Western Ontario and McMaster University Osteoarthritis Index--"modified" is an adapted version of Bellamy, Buchanan, Goldsmith, Campbell, and Stitt's (1988) measure.

46. Functional Abilities Measure.

47. Ontario Health Survey.

48. Questionnaire About Musculoskeletal Pain in the Neck.

49. Pendulum Test.
50. Ashworth Scale.

51. Rett Syndrome Questionnaire.

Rett Syndrome Questionnaire* is "designed to obtain the following information: the participant's birth date and questionnaire completion date, presence of abnormal hand or arm movements..., laterality or symmetry in hand and arm movements..., laterality or symmetry in arm and shoulder positions..., descriptive scoliosis information of the direction and degree of curve..., and current ambulation status" (p. 198). *Instrument appears untitled in source--Title assigned by HaPI staff.

52. Musculoskeletal Symptom Scale.

53. Depression Symptoms Inventory.

54. Dutch Personality Questionnaire.

55. Pain Intensity Scale.

*Instrument appears untitled in source--Title assigned by HaPI staff.
Musculoskeletal Pain History Questionnaire.

Musculoskeletal Pain History Questionnaire* is designed to gather "information concerning exercise history, musculoskeletal injuries, medical history, dietary history (especially with regard to calcium and fat), and other variables" (p. 66).

*Instrument appears untitled in source--Title assigned by HaPI staff.

Sickness Impact Profile.

Interpersonal Support Evaluation List.

State-Trait Anxiety Inventory.

State-Trait Anxiety Inventory-- is a translated/adapted version of Spielberger's (1983) measure. State-Trait Anxiety Inventory-- is included in the Musculoskeletal Pain Questionnaire* (see source).

*Instrument appears untitled in source--Title assigned by HaPI staff.

Ashworth Scale--"modified".

Ashworth Scale--"modified"-- is a translated/adapted version of Bohannon and Smith's (1987) revision of Ashworth's (1964) measure.
61. Musculoskeletal Symptoms Questionnaire.

*Instrument appears untitled in source--Title assigned by HaPI staff.


63. Musculoskeletal System Interview Schedule.

Musculoskeletal System Interview Schedule* includes "questions on pain and disorders, and their affects" (p. 497).

*Instrument appears untitled in source--Title assigned by HaPI staff.

64. Medical Research Council Grading Scale of Muscle Weakness.

65. Arthritis Self-Efficacy Scale.

Arthritis Self-Efficacy Scale-- is a translated/adapted version of Lorig, Chastain, Ung, Shoor, and Holman's (1989) measure.

66. Medical Research Council Grading Scale of Muscle Weakness.
Appendix 8 - Opt. 5.3
Lifestyle Information Sheet

1) Alcohol
a) Do you ever drink alcohol nowadays, including drinks you brew or make at home? (please circle) .............................................................................................................. Yes or No
(if No, go to question 2)

b) Thinking now about all kinds of drinks, how often have you had an alcoholic drink of any kind during the last 12 months? (please tick)
- Almost every day
- Five or six days a week
- Three or four days a week
- Once or twice a week
- Once or twice a month
- Once every couple of months
- Once or twice a year
- Not at all in the last 12 months

2) Smoking
a) Do you smoke? (please circle) ................................................................................... Yes or No
(if No, go to question 3)

b) What do you smoke? (please tick)
- Cigarettes (either hand or factory-rolled)
- Pipe
- Other (please state) .........................

c) On average, how many times per day do you smoke?
........................................................................................................

3) Diet
How many portions of fruit and vegetables do you eat on a typical day?
........................................................................................................

4) Physical Activity
At least once a week, do you engage in regular activity akin to brisk walking, jogging, cycling, swimming, etc., long enough to work up a sweat, get your heart thumping or get out of breath?
- Yes
  How many times per week? ..................................................................................
  Activity: ................................................

- No
  Why not? ........................................................................................................

5) Ideal Weight
Would you say that you are at your ideal weight? (please circle) ................. Yes or No

6) Weight and Height
Appendix

a) What is your weight…………stone………pounds………date weighed…………

b) What is your height……………………………...feet................inches.....................

THANK YOU FOR COMPLETING THIS SHEET
Appendix 9 - Opt. 5.3
Consultancy Minutes
(Monday 12th May 2011)

The following minutes are a record of the meeting held on 12th May 2011 between Professor Anthony Woolf (Consultant Rheumatologist) and Mr Roy Chilton (Trainee Health Psychology Consultant) to identify the content of a piece of consultancy work.

- Roy to search and identify one or a number of standardised lifestyle instruments for the development of a pilot project incorporating Motivational Interviewing within musculoskeletal health.
- Roy to supply electronic resources via City University, London.
- The main criteria for the lifestyle instrument(s) are as follows:
  - Instrument(s) should be standardised and/or have normative data attached.
  - Instrument(s) should be applicable to the general population (not musculoskeletal-specific) and for adults (18 years or above).
  - Instrument(s) should assess (individually or collectively) the following factors:
    - Physical activity
    - Ideal weight
    - Balanced diet
    - Smoking
    - Alcohol
    - Accident prevention*
    - Abnormal/overuse of musculoskeletal system*.
* Recognised by Professor Woolf that instruments may not be available for these factors.

- Roy to compile a technical report identifying search, decision making and final selection procedures.
- This piece of consultancy is to demonstrate Optional Competency 5.3 – Communicate the Processes and Outcomes of Psychological Interventions and Consultancies.
- Correspondence is to be via Professor Woolf (either by email or telephone).
- Future meetings will consist of a progress meeting(s), presentation preparation meeting and a final presentation of findings.
- No restrictions placed on time or budget.

I agree that the aforementioned points are accurate and acceptable to form a working consultancy contract between Professor Anthony Woolf and Mr Roy Chilton (Trainee Health Psychology Consultant).

The following actions were agreed:

Roy:
- To provide consultancy contract and minutes from initial meeting.
- To start consultancy on Wednesday 18th May 2011, working 3-5 days per week.

Professor Woolf:
- To assess consultancy contract and minutes from meeting, sign and return if acceptable.
Postal address: Mr Roy Chilton, Higher Ventongimps Farm, Callestick, Truro, Cornwall, TR4 9HE. Comments should be communicated to Mr Roy Chilton either via telephone 07763 488016 or by email Roy.Chilton@Cornwall.NHS.UK.

Next meeting arranged for Tuesday 7th June 2011, 2.30pm at the Knowledge Spa, Truro.

Professor Anthony Woolf………………………………………………(signature)…………………………(date)
(Consultant Rheumatologist)

Mr Roy Chilton…………………………………………………………(signature)…………………………(date)
(Trainee Health Psychology Consultant)
Consultancy Minutes
(Tuesday 7th June 2011)

The following minutes are a record of the meeting held on 7th June 2011 between Professor Anthony Woolf (Consultant Rheumatologist) and Mr Roy Chilton (Trainee Health Psychology Consultant), with brief attendance by Dr Josephine Erwin (Researcher), to discuss progress on the identification of a number of lifestyle instruments.

- Previous minutes were signed by both Professor Woolf and Mr Roy Chilton. Professor Woolf also read the consultancy contact (no amendments were made).
- Roy described the search strategy as including the following approaches:
  - Locate any systematic reviews identifying lifestyle-based instruments.
  - Pilot electronic database searches (EMBASE, AMED, BNI, OVID Medline).
  - Search English-based surveys for lifestyle-based instruments or items.
  - Determine access of the Health and Psychosocial Instruments (HaPI) database.
- No systematic review articles were located that specifically identified lifestyle-based instruments.
- Roy explained that to use electronic database searches (EMBASE, AMED, BNI, OVID Medline), it would be impractical, in terms of both access to full text articles and the time needed, to locate and search all items retrieved.
- While English-based surveys used specific questions to assess lifestyle status, identifying items and copyright meant that further contact would be needed to consider utilising this approach.
- Roy explained he had identified a database (Health and Psychosocial Instruments) that specifically focused on providing access to 15,000 measurement instruments, although he did not have access through his university resources.
- Professor Woolf wondered whether he may have access (to be discussed with a member of his staff).
- Professor Woolf asked Dr Erwin to join the meeting, as she was working with and had experience of survey-based measures. It was agreed that Roy would email Dr Erwin to retrieve contact details regarding possible contacts to follow up on survey-based approaches.

The following actions were agreed:

Roy:
- To email Dr Erwin to gather information on survey-based options.
- To follow up on HaPI database access via Professor Woolf.

Professor Woolf:
- To enquire whether HaPI database access is possible.

Next meeting arranged for Tuesday 21st June 2011, 2.30pm at the Knowledge Spa, Truro.

Professor Anthony Woolf………………………………….…..………(signature)………………………….…………(date)
(Consultant Rheumatologist)

Mr Roy Chilton…………………………………….….....
(Trainee Health Psychology Consultant)
Roy has gained access to the Health and Psychosocial Instruments (HaPI) database for a trial period until the 14th July 2011. The trial subscription has been obtained through the Subject Librarian at City University, where Roy is a doctoral student.

Roy has identified, from 695 results using the keyword “lifestyle” within the descriptor field, 100 possible instruments.

In order to screen these 100 possibilities, it was agreed that, initially, full text articles should be retrieved from those instruments that have been referenced more than once in the search. This would increase the likelihood that they have been utilised beyond the initial author’s reference.

With this search strategy, 21 instruments were identified, and are to be collected and tabulated according to measurement criteria and psychometric quality.

In addition, Roy suggested he could investigate whether the HaPI database would allow further exploration of measures via specific books that may contain descriptions of instruments.

The following actions were agreed:

Roy:
- To assemble a table of psychometric and descriptive features for the screened instruments.
- Explore additional sources (i.e. books) via the HaPI database.

Next meeting arranged for Tuesday 5th July 2011, 2.30pm at the Knowledge Spa, Truro.

Consultancy Minutes
(Tuesday 5th July 2011)

The following minutes are a record of the meeting held on 5th July 2011 between Professor Anthony Woolf (Consultant Rheumatologist) and Mr Roy Chilton (Trainee Health Psychology Consultant), which followed from a meeting with Mrs Paula Pender (Physiotherapist) from the 3 Spirens Surgery in Truro (minutes not taken from the Paula Pender meeting).

Roy has completed searches within the Health and Psychosocial Instruments (HaPI) database for instruments that assess individual aspects of lifestyle (physical activity, ideal weight, balanced diet, smoking, alcohol, accident prevention and abnormal/overuse of musculoskeletal). No ideal measure was located, and it was agreed not to pursue inter-library loans regarding those instruments or articles that could not be retrieved.

Roy showed Professor Woolf the SF-36v2 Health Survey and discussed how, in light of a lack of instrumentation for gauging lifestyle, the SF-36v2 could be applied to fit the requirements of the consultation.

It was agreed that the SF-36v2 could be utilised as a way of generating a discussion around health and that this could be supplemented by a key Motivational Interviewing-based question that specifically focussed on lifestyle change:

Question - “If we think about different areas of lifestyle, such as physical activity, ideal weight, balanced diet, smoking, alcohol (accident prevention, abnormal/overuse of musculoskeletal), which would you like to think about changing?”

Professor Woolf wondered about the identification of lifestyle status, i.e. would we know if the person smoked or drank alcohol. On this basis, it was agreed that Roy would construct a basic data collection sheet, in order to collect information on lifestyle status, for example:

Smoking:
1) Do you smoke? Yes or No
Appendix

2) If yes, what do you smoke and how many a day? (average)

- It was agreed that this could be administered prior to the Brief Intervention (BI) and act as a way of understanding the data used to investigate the BI.
- Roy will assemble a PowerPoint presentation for the next meeting to summarise the consultancy, this will then be followed by an evaluation.

The following actions were agreed:

Roy:
- To assemble a PowerPoint presentation for the next meeting.
- To construct a basic lifestyle data collection sheet.

Next meeting arranged for Monday 1st August 2011, 2pm at the Knowledge Spa, Truro.

Consultancy Minutes
(Monday 1st August 2011)

The following minutes are a record of the meeting held on 1st August 2011 between Professor Anthony Woolf (Consultant Rheumatologist) and Mr Roy Chilton (Trainee Health Psychology Consultant).

- Roy provided a PowerPoint presentation which summarised the work conducted in the consultancy. It contained a description of the instrument requirements, a search strategy, summary of findings and conclusions, as well as recommendations.
- The remainder of the meeting consisted of discussions regarding how to utilise the findings in order to consider applying for funding for a pilot clinical service.
- It was agreed that the following meeting would act as an evaluation of the consultancy.
- Professor Woolf provided Roy with a copy of a data collection sheet that he had used within his clinical service.

The following actions were agreed:

Roy:
- Email Professor Woolf the technical report, evaluation form and lifestyle information sheet.

Next meeting arranged for Monday 17th August 2011, 2pm at the Knowledge Spa, Truro.

Consultancy Minutes
(Monday 17th August 2011)

The following minutes are a record of the meeting held on 17th August 2011 between Professor Anthony Woolf (Consultant Rheumatologist) and Mr Roy Chilton (Trainee Health Psychology Consultant).

- This was an evaluation meeting, and therefore final contact in terms of the consultancy.
• An evaluation form was completed by Professor Woolf and a discussion held regarding the way in which the evaluation was conducted, the work completed, the outcomes and how they would be implemented.
• Roy showed Professor Woolf the Lifestyle Information Sheet, and it was agreed that it would be appropriate for the purposes of the consultancy.
• It was agreed that Professor Woolf and Roy would continue meeting in order to produce a research proposal to apply for funding for a pilot study to develop a clinical service utilising aspects of the consultancy.

Professor Anthony Woolf………………………….(signature)………………………….(date)
(Consultant Rheumatologist)

Mr Roy Chilton………………………………………..(signature)………………………….(date)
(Trainee Health Psychology Consultant)
Appendix 10 - Opt. 5.3
Evaluation Form

Did the consultancy achieve its objectives? *(please circle)*

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Comment – *This task was thoroughly undertaken but no instrument could be identified that fulfilled the pre-stated requirements. However, an alternative solution was found* 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Appendix 1 – Opt. 5.8
Emotional and Behavioural Difficulties
Journal Amendments

Reviewer’s Comments/Amendments:

• In abstract and text, authors should define WAGS the first time they use the term.
  *Amendment* - WAGS defined within the abstract and on p.2.

• The literature review is well documented and very instructive.
  *Amendment* – N/A

• However, the scheme description is not done in a very clear manner in the article. Authors should describe their service in detail at the beginning of the article, and then refer to what has been described when appropriate. When reading the text, the reader does not have a global view of what the program is, and they are not always in measure to appreciate references done in the text. The reader must sometimes guess what the offered services were. For example, p.3, 4th paragraph, it is not clear if the support offered in the child’s home and school was a weekly service.
  *Amendment* – Paragraphs describing the service have been re-structured to describe the service at the beginning of the article.

• P.4, 2nd paragraph, authors should be precise about the size of the sample in the Lovering et al. (2006) study.
  *Amendment* – “Previous research of 253 (pre-intervention) and 278 (post-intervention) participants reported that stress levels of the parents of children on the Scallywags scheme significantly was reduced by the end of the 6-month intervention (Lovering et al., 2006), as measured by the PSI-III (Abidin, 1995).”

• P.4, 3rd paragraph, authors use “paternal stress level” rather than “parental stress level”.
  *Amendment* – “Paternal” changed to “parental”.

• In the description of participants, in the Method section, authors should be precise in the text about how many participants were included, their age and their gender. They also should explain why the dataset does not represent 100% of the questionnaires administered by the scheme.
  *Amendment* – Age and gender included in the Participant section and explanation provided to why return rates were not 100% (P5).

• In the Materials description, psychometric proprieties of the instrument should be given.
  *Amendment* – Psychometric properties included for both Abidin and ECBI (references obtained from the manual).

• In the Results section, it is difficult to understand how there may be more participants post-intervention than pre-intervention. If participants have been introduced to the scheme without any pre-test, they should not be included in the
post-test group. Authors should review their sample description or, at least, explain why it is so.

*Amendment* – “It is thought that more parental stress questionnaires are completed post intervention as parents are more comfortable and confident to share how they feel with their support worker” – this was included in the Participant section.

- In the description of regression analysis results, authors talk about some variables as being a “model for predicting”. When using only one variable in a regression model, it is preferable to talk about a variable rather than a model.

*Amendment* – “Variable” replaces the word “model” within P7, paragraph 3, 4 (Group) and 5 (Age). (Not sure if this extends to other references of the word *model* within these paragraphs).

- In the Discussion, authors should go deeper in the analysis of their results, by referring to the literature and explaining how their results replicate or stand out from the existing knowledge in this field.

*Amendment* – Please see Discussion for additional comments.
### Appendix A – Systematic Review
#### Basic Scoping Search

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Appendix B – Systematic Review
MeSH Search Strategy per Database

Results of MeSH search, duplicates located and removed between the databases. EMBASE acting as a comparison for other databases, and articles removed in relation to EMBASE. To await results of ICD-10 keyword search before screening content of articles (so as not to influence ICD-10 keyword search, i.e. if familiar or looking for content beyond title and abstract search, then this differs from procedure used in MeSH search), in order to retain consistence. Await keyword search before detailed final screening (7th March 2011).

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* Conducted on 03rd March 2011 using Ovid Online (3rd attempt)

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### Appendix

**Results** - title and abstract screened for reference to a Motivational Interviewing and a Musculoskeletal population

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Results - title and abstract screened for reference to a Motivational Interviewing and a Musculoskeletal population

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Results - title and abstract screened for reference to a Motivational Interviewing and a Musculoskeletal population

Studies excluded (description of studies - located in other databases)

Total retrieved

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* Conducted on 03rd March 2011 using Ovid Online (3rd attempt)

* Conducted on 04th March 2011 using Ovid Online

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Appendix

EBSCO host Cumulative Index to Nursing and Allied Health Literature (CINAHL) (1982 – 2011)*
(All searched without limits or language restrictions)

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#3 (TX “motivational interviewing”) and (S1 and S2) 45

Results - title and abstract screened for reference to a Motivational Interviewing and a Musculoskeletal population
6

Studies excluded (description of studies - located in other databases) 4
Total retrieved 2

* Conducted on 04th March 2011 using EBSCO host

Database

EBSCO host PsycINFO (1800’s - 2011)*
(All searched without limits or language restrictions)

#1 TX motivational interviewing 1327
#3 #1 and #2 0

Results - title and abstract screened for reference to a Motivational Interviewing and a Musculoskeletal population
0

Studies excluded (description of studies) 0
Total retrieved 0

* Conducted on 04th March 2011 using EBSCO host

Database

The Cochrane Library*
(All searched without limits or language restrictions)

#1 MeSH descriptor Musculoskeletal Abnormalities explode all trees 347
#2 MeSH descriptor Musculoskeletal Manipulations explode all trees 1450
#3 MeSH descriptor Musculoskeletal and Neural Physiological Phenomena explode all trees 54473
#4 MeSH descriptor Musculoskeletal Development explode all trees 502
#5 MeSH descriptor Musculoskeletal Diseases explode all trees 19598
#6 MeSH descriptor Postural Balance explode all trees 919
#7 MeSH descriptor Musculoskeletal Physiological Processes explode all trees 22457
#8 MeSH descriptor Musculoskeletal System explode all trees 19427
#9 MeSH descriptor National Institute of Arthritis and Musculoskeletal and Skin Diseases (U.S.) explode all trees 0
#10 (#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9) 75301
#11 “motivational interviewing” 458
#12 (#10 AND #11) 34

Results - title and abstract screened for reference to a Motivational Interviewing and a Musculoskeletal population
### Musculoskeletal population

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Results - title and abstract screened for reference to a Motivational Interviewing and a Musculoskeletal population

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Results - title and abstract screened for reference to a Motivational Interviewing and a Musculoskeletal population

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Appendix C – Systematic Review
ICD-10 Free Text Terms Search Strategy per Database

Duplicates located differently to MeSH duplicate search; rather than cross-referencing each document, all documents compared singularly against EMBASE. As ICD-10 and MeSH duplicate screen were completed, ICD-10 and MeSH can be screened together for duplication (14th March 2011).

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#2  exp motivational interviewing/ or "motivational interviewing".mp. 1272
#3  1 and 2 48

Results - title and abstract screened for reference to a Motivational Interviewing and a Musculoskeletal population 19

Studies excluded (description of studies) 0
Appendix

Total retrieved 19

* Conducted on 10th March 2011 using Ovid Online (2nd attempt)

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Appendix

Results - title and abstract screened for reference to a Motivational Interviewing and a Musculoskeletal population

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* Conducted on 10th March 2011 using Ovid Online (2nd attempt)

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Appendix

Results - title and abstract screened for reference to a Motivational Interviewing and a Musculoskeletal population

Studies excluded (description of studies - located in other databases)

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* Conducted on 10th March 2011 using Ovid Online (2nd attempt)

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#3 #1 and #2 (2)

Results - title and abstract screened for reference to a Motivational Interviewing and a
Appendix

Musculoskeletal population

Studies excluded (description of studies - located in other databases)

Total retrieved

* Conducted on 10th March 2011 using Ovid Online (2nd attempt)

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Results - title and abstract screened for reference to a Motivational Interviewing and a
Appendix

Musculoskeletal population

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Total retrieved

* Conducted on 12th March 2011 using EBSCO host (2nd attempt)

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<td>#1 TX algoneurodystrophy OR angiitis OR apophysitis OR arrest OR arteritis OR arthritis OR arthrosis OR arthropathies OR arthropathy OR arthritis OR bone OR bursa OR bursal OR bursitis OR bursopathies OR bursopathy OR calcaneal spur OR calcification OR capsulitis OR cartilage OR cervical OR cervicalgia OR cervicobrachial OR cervicocranial OR chondrolysis OR chondrocalcinosis OR chondromalacia OR collagen OR connective tissue OR costochondritis OR coxa plana OR coxarthrosis OR deformities OR deformity OR dermatoarthritiis OR dermatomyositis OR dermatopolymyositis OR discitis OR disuse atrophy OR dosalgia OR dorsopathies OR dorsopathy OR enthesopathies OR enthesopathy OR epicondylitis OR epiphyseal OR epiphysis OR epiphysisis OR erythematous OR fascia OR fascial OR fasciitis OR fibroblastic OR fibromatosis OR fibromyalgia OR fibromyositis OR fibroserosion OR fibrosis OR fibrous OR fluorosis OR foramina OR fracture OR ganglion OR gonarthrosis OR gout OR gouty OR granuloma OR granulomatosis OR haemarthrosis OR hyperostoses OR hyperostosis OR hypertrophy OR iliac crest spur OR joint OR knee OR knuckle pads OR kyphosis OR lateral OR lesion OR ligament OR ligamentous OR lordosis OR lumbago OR lupus OR meniscus OR metatarsalgia OR microangiopathy OR monoarthritis OR muscle OR musculoskeletal OR myalgia OR myofibrosis OR myositis OR neural canal OR neuritis OR nontraumatic OR ossificans OR ossification OR osteitis OR osteoarthropathy OR osteoarthritis OR osteochondritis OR osteochondropathies OR osteochondrosis OR osteolysis OR osteomalacia OR osteomyelitis OR osteonecrosis OR osteopathies OR osteopathy OR osteophyte OR osteoporosis OR osteosclerosis OR pachydermoiropathy OR pain OR panniculitis OR paraplegic OR patella OR patellofemoral OR periartthritis OR periostitis OR polyangiitis OR polyarthritis OR polyarthitis OR polyarthropathy OR polyarthritis OR polychondritis OR polymyalgia OR polymyositis OR protrusio acetabuli OR pseudarthrosis OR pseudocoxalgia OR radioculopathy OR rheumatism OR rheumatoid OR rupture OR sacrococcygeal OR sacroiliitis OR sciatica OR sclaroderma OR sclerosis OR scoliosis OR segmental OR shoulder OR skull OR soft tissue OR somatic OR spinal OR spine OR spondylitis OR spondylolysis OR spondylopathies OR spondylodynia OR spondylosis OR stenosis OR subluxation OR subperiosteal OR sympathetic reflex dystrophy OR synovial OR synovitis OR synovium OR tear OR tendinitis OR tendinous OR tendon OR tenosynovitis OR thrombotic OR torticollis OR trochanteric OR vasculitis OR vasculopathies OR vasculopathy OR vertebra OR vertebral OR aortic arch syndrome OR cervicobrachial syndrome OR chondrocostal junction syndrome OR compartment syndrome OR crest syndrome OR flemish syndrome OR flatback syndrome OR goodpasture syndrome OR hypermobility syndrome OR iliotibial band syndrome OR immobility syndrome OR impingement syndrome OR mucocutaneous lymph node syndrome OR overlap syndrome OR postlaminectomy syndrome OR rotator cuff syndrome OR shoulder hand syndrome OR sicca syndrome OR tibial syndrome OR autoimmune disease OR behçet disease OR calvé disease OR kaschin beck disease OR kienböck disease OR libman sacks disease OR marie bamberger disease OR paget disease OR reiter disease OR scheuermann disease OR still disease OR bouchard nodes OR beberden nodes OR schmorl nodes OR baker OR brodie abscess OR cauliflower ear OR churg strauss OR de quervain OR dupuytren OR forestier OR hallux OR Kawasaki OR lequesne OR pyogenic OR sjögren OR sudeck atrophy OR takayasu OR tietze OR weber christian OR claw hand OR claw foot OR club hand OR club foot OR flat foot OR foot drop OR hammer toe OR tennis elbow OR trigger finger OR wrist drop</td>
<td>224540</td>
</tr>
<tr>
<td>#2 TX motivational interviewing</td>
<td>1334</td>
</tr>
<tr>
<td>#3 #1 and #2</td>
<td>64</td>
</tr>
</tbody>
</table>

Results - title and abstract screened for reference to a Motivational Interviewing and a Musculoskeletal population
### Appendix

Studies excluded (description of studies - located in other databases)

| Total retrieved | 5 |

* Conducted on 11th March 2011 using EBSCO host (2nd attempt)

<table>
<thead>
<tr>
<th>Database</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Cochrane Library*</td>
<td>133012</td>
</tr>
<tr>
<td>#1</td>
<td>algoneuropathy OR angiitis OR apophysitis OR arrest OR arteritis OR arthritis OR arthrosis OR arthropathies OR arthropathy OR arthritis OR bone OR bursa OR bursal OR bursitis OR bursopathy OR bursopathy OR “calcaneal spur” OR calcification OR capsulitis OR cartilage OR cervical OR cervicalgia OR cervicobrachial OR cervicocranial OR chondrolysis OR chondralcinosis OR chondromalacia OR collagen OR “connective tissue” OR costochondritis OR “cox plana” OR coxarthrosis OR deformities OR deformity OR dermatoarthritis OR dermatomyositis OR dermatopolymyositis OR discitis OR “disuse atrophy” OR dorsalgia OR dorsopathies OR dorsopathy OR enthesopathy OR enthesopathy OR epicondylitis OR epiphyseal OR epiphysis OR epiphysitis OR erythematous OR fascia OR fascial OR fasciitis OR fibroblastic OR fibromatosis OR fibromyalgia OR fibromyositis OR fibrosclerosis OR fibrosis OR fibrous OR fluoration OR foramina OR fracture OR ganglion OR gonoarthrosis OR gout OR gouty OR granuloma OR granulomatosis OR haemarthrosis OR hyperostoses OR hypertrophy OR “iliac crest spur” OR joint OR knee OR “knuckle pad” OR kyphosis OR lateral OR lesion OR ligament OR ligamentous OR lordosis OR lumbago OR lupus OR meniscus OR metatarsalgia OR microangiopathy OR monoarthrosis OR muscle OR musculoskeletal OR myalgia OR myofibrositis OR myositis OR “neural canal” OR neuralgia OR neuritis OR nontraumatic OR ossificans OR ossification OR ositis OR osteopathies OR osteoarthritis OR osteochondritis OR osteochondropathies OR osteoarthritis OR osteolysis OR osteomalacia OR osteomyelitis OR osteonecrosis OR osteopathies OR osteopathy OR osteophyte OR osteoporosis OR osteosclerosis OR pachydermoperiostosis OR pain OR panniculitis OR paraplegic OR patella OR patellofemoral OR periarthritis OR periostitis OR polyangiitis OR polyarthritides OR polyarthristis OR polyarthritis OR polyarthropathy OR polyarthrosis OR polychondritis OR polychondropathy OR polyneuropathy OR polynomalgia OR polynomysitis OR “protrusio acetabuli”</td>
</tr>
<tr>
<td>#2</td>
<td>pseudarthrosis OR pseudocoxalgia OR radiculopathy OR rheumatism OR rheumatoid OR rupture OR sacrococcygeal OR sacroiliitis OR sciatica OR scleroderma OR scoliosis OR scoliosis OR segmental OR shoulder OR skull OR “soft tissue” OR somatic OR spinal OR spine OR spondylitis OR spondylolysis OR spondylolithesis OR spondylolytic OR spondylomalacia OR spondylolysis OR stemositis OR subluxation OR subperisteal OR “sympathetic reflex dystrophy” OR synovial OR synovitis OR synovium OR tear OR tendinitis OR tendinous OR tendon OR tenosynovitis OR thrombotic OR torticollis OR trochanteric OR vasculitis OR vasculopathies OR vasculopathy OR vertebral OR vertebral OR “aortic arch syndrome” OR “cervicothoracic syndrome” OR “chondrocostal junction syndrome” OR “compartment syndrome” OR “crest syndrome” OR “felothy syndrome” OR “flatback syndrome” OR “goodpasture syndrome” OR “hypermobility syndrome” OR “iliobibial band syndrome” OR “immobility syndrome” OR “impingement syndrome” OR “mucocutaneous lymph node syndrome” OR “overlap syndrome” OR “postlaminectomy syndrome” OR “rotator cuff syndrome” OR “shoulder hand syndrome” OR “sicca syndrome” OR “tibial syndrome” OR “autoimmune disease” OR “behet disease” OR “caly? disease” OR “kaschin beek disease” OR “kienb?ck disease” OR “libman sack disease” OR “marie bamberger disease” OR “paget disease” OR “reiter disease” OR “scheuermann disease” OR “still disease” OR “bouchard node” OR “heberden node” OR “schmor node” OR “baker OR brodie abscess” OR “cauliflower ear” OR “churg strauss” OR “de quervain” OR “dupuytren” OR “foretiser” OR “hallux” OR “kawasaki” OR “lequesne” OR “pyogenic” OR “sjo?gren” OR “sudeck atrophy” OR “takayasu” OR “tietze” OR “weber christian” OR “claw hand” OR “claw foot” OR “club hand” OR “club foot” OR “flat foot” OR “foot drop” OR “hammer toe” OR “tennis elbow” OR “trigger finger” OR “wrist drop”</td>
</tr>
<tr>
<td>#3</td>
<td>(#1 OR #2)</td>
</tr>
<tr>
<td>#4</td>
<td>“motivational interviewing”</td>
</tr>
<tr>
<td>#5</td>
<td>(#3 AND #4)</td>
</tr>
</tbody>
</table>

Results - title and abstract screened for reference to a Motivational Interviewing and a
Appendix

Musculoskeletal population

Studies excluded (description of studies - located in other databases)

Total retrieved

* Conducted on 12th March 2011 (2nd attempt)

<table>
<thead>
<tr>
<th>Database</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ovid online Health Management Information Consortium (HMIC) (1979 – January 2011)* (All searched without limits or language restrictions)</td>
<td></td>
</tr>
<tr>
<td>#1 (algoneurodystrophy or angiitis or apophysitis or arrest or arteritis or arthritis or arthrosis or arthropathies or arthropathy or artrosis or bone or bursa or bursal or bursitis or bursopathies or bursopathy or calcaneal spur or calcification or capsulitis or cartilage or cervical or cervicalgia or cervicoabradial or cervicoarticular or chondrolysis or chondrocalcinosis or chondromalacia or collagen or connective tissue or costochondritis or coxa plana or coxarthrosis or deformities or deformity or dermatoarthrosis or dermatomyositis or dermatopolymyositis or discitis or disuse atrophy or dorsalgia or dorsopathies or dorsopathy or enthesopathies or enthesopathy or epicondylitis or epiphysial or epithepsis or epiphysitis or erythematosus or fascia or fascial or fasciitis or fibroblastic or fibromatosis or fibromyalgia or fibromyositis or fibroscerosis or fibrosis or fibrous or fluorosis or foramina or fracture or ganglion or gonarthrosis or gout or gouty or granuloma or granulomatosis or haemarthrosis or hyperostoses or hyperostosis or hypertrophy or iliac crest spur or joint or knee or knuckle pads or kyphosis or lateral or lesion or ligament or ligamentous or lordosis or lumbago or lupus or meniscus or metatarsalgia or microangiopathy or monoarthritis or muscle or musculoskeletal or myalgia or myofibrosis or myositis or neural canal or neuralgia or neuritis or nontraumatic or ossificans or ossification or osteitis or osteoarthropathy or osteoarthrosis or osteochondritis or osteochondropathies or osteochondrosis or osteoarthrosis or osteoarthropathy or osteoarthritis or osteosclerosis or osteosclerotic or osteonecrosis or osteopathies or osteopathy or osteophyte or osteoporosis or osteosclerosis or pachydermoperiostosis or pain or panniculitis or paraplegic or patella or patellofemoral or periarthrarthritis or periositis or polyangitis or polyanarthropathy or polyanarthropathy or polyarthrythropy or polychondritis or polynymalgia or polyymyositis or protrusio acetabuli or pseudarthrosis or pseudocoxalgia or radiculopathy or rheumatism or rheumatoid or rupture or saccroccygeal or sacroiliitis or sciatica or scieroderma or sclerosis or scoliosis or segmental or shoulder or skull or soft tissue or somatic or spinal or spine or spondylitis or spondylolisthesis or spondylolysis or spondylopathies or spondyloarthrosis or spondylosis or stenosis or subluxation or subperiostal or sympathetic reflex dystrophy or synovial or synovitis or synovium or tear or tendinitis or tendinous or tendon or tenosynovitis or thrombotic or torticollis or trochanteric or vasculitis or vasculopathies or vasculopathy or vertebra or vertebral or aortic arch syndrome or cervicobrachial syndrome or chondrocostal junction syndrome or compartment syndrome or crest syndrome or feslers syndrome or flatback syndrome or goodpasture$ syndrome or hypermobility syndrome or iliobial band syndrome or immobility syndrome or impingement syndrome or mucocutaneous lymph node syndrome or overlap syndrome or postlaminectomy syndrome or rotator cuff syndrome or shoulder hand syndrome or sicca syndrome or tibal syndrome or autoimmune disease or beh<em>er$ disease or calv</em>$ disease or kaschin beck disease or kienb*ck$ disease or libman sacks disease or marie bamberger disease or paget$ disease or reiter$ disease or scheuermann$ disease or still$ disease or bouchard$ nodes or heberden$ nodes or schmorl$ nodes or baker or brodie$ abscess or cauliflower ear or churg strauss or de quervain or dupuytren or forestier or hallux or kashwaki or lequesne or pyogenic or s$gren or sudeck$ atrophy or takaasaru or tietze or weber christian or claw hand or claw foot or club hand or club foot or flat foot or foot drop or hammer toe or tennis elbow or trigger finger or wrist drop).mp. [mp=title, other title, abstract, heading words]</td>
<td>13543</td>
</tr>
<tr>
<td>#2 motivational interviewing.mp. [mp=title, other title, abstract, heading words]</td>
<td>58</td>
</tr>
<tr>
<td>#3 #1 and #2</td>
<td>0</td>
</tr>
</tbody>
</table>

Results - title and abstract screened for reference to a Motivational Interviewing and a Musculoskeletal population

Studies excluded (description of studies - located in other databases)

0
### Appendix

<table>
<thead>
<tr>
<th>Database</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pub Med (1950 – 2011)*</td>
<td>(All searched without limits or language restrictions)</td>
</tr>
</tbody>
</table>

* Conducted on 10th March 2011 using Ovid Online host (2nd attempt)

Results - title and abstract screened for reference to a Motivational Interviewing and a Musculoskeletal population

Studies excluded (description of studies - located in other databases)

Total retrieved

383
Appendix

* Conducted on 10th March 2011

<table>
<thead>
<tr>
<th>Database</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>ISI Web of Science (1970 – present)* *(All searched without limits or language restrictions)</td>
<td></td>
</tr>
<tr>
<td>#1 Topic=(algoneurodystrophy OR angitis OR apophysitis OR arrest OR arteritis OR arthritis OR arthrodesis OR arthropathies OR arthropathy OR arthrosis OR bone OR bursa OR bursal OR bursitis OR bursopathies OR bursopathy OR calcaneal-spur OR calcification OR capsulitis OR cartilage OR cervical OR cervicalgia OR cervicobrachial OR cervicocranial OR chondrolysis OR chondrocalcinosis OR chondromalacia OR collagen OR connective-tissue OR costochondritis OR coxa-plana OR coxarthrosis OR deformities OR deforming OR dermatarthitis OR deratomymyositis OR dermatopolyomyositis OR discitis OR disuse-atrophy OR dorsalgia OR dorsopathies OR dorsalpathy OR entheseopathies OR enthesis OR epicondylitis OR epiphyseal OR epiphysis OR epitheal OR erythematous) AND Topic=(“motivational interviewing”)</td>
<td>10</td>
</tr>
<tr>
<td>#2 Topic=(fascia OR fascial OR fasciitis OR fibroblastic OR fibromatos OR fibromyalgia OR fibromyositis OR fibrosclerosis OR fibrosis OR fibrous OR fluorosis OR foramina OR fracture OR ganglion OR gomartorrhesis OR gout OR gouty OR granuloma OR granulomatosis OR haemarthrosis OR hyperostosis OR hyperostosis OR hypertrophy OR iliac-crest-spur OR joint OR knee OR knuckle-pads OR kyphosis OR lateral OR lesion OR ligament OR ligamentous OR lordosis OR lumbago OR lupus OR meniscus OR metatarsalgia OR microangiopathy OR monoarthitis OR muscle OR musculoskeletal OR myalgia OR myofibrositis OR myositis OR neural OR neuritic OR nontraumatic OR ossificans) AND Topic=(“motivational interviewing”)</td>
<td>14</td>
</tr>
<tr>
<td>#3 Topic=(ossification OR osteitis OR osteoarthropathy OR osteoarthrosis OR osteochondritis OR osteochondropathies OR osteochondrosis OR osteolysis OR osteomalacia OR osteomyelitis OR osteonecrosis OR osteopathies OR osteopathy OR osteophyte OR osteoporosis OR osteosclerosis OR pachydermoiperiostosis OR pain OR panniculitis OR paraplegic OR patella OR patellofemoral OR periarthitis OR periostitis OR polyangiitis OR polyarthritis OR polyarthritus OR polyarthropathy OR polyarthritis OR polychondritis OR polymyalgia OR polymyositis OR protrusion-acatubili OR pseudarthrosis OR pseudochondrolysis OR radiucopathy OR rheumatism OR rheumatoid OR rupture OR saccroccocygeal OR sacroiliitis OR sciatica OR scleroderma OR sclerosis OR scoliosis OR segmental OR shoulder OR skull OR soft-tissue) AND Topic=(“motivational interviewing”)</td>
<td>26</td>
</tr>
<tr>
<td>#4 Topic=(somatic OR spinal OR spine OR spondylitis OR spondylolysis OR spondylysis OR spondylopathies OR spondylopathy OR spondylolysis OR stenosis OR subluxation OR subperiostal OR sympathetic-reflex-dystrophy OR synovial OR synovitis OR synovium OR tear OR tendinitis OR tendinous OR tendon OR tenosynovitis OR thrombotic OR torticollis OR trochanteric OR vasculitis OR vasculopathies OR vasculopathy OR vertebra OR vertebral OR aortic-arch-syndrome OR cervicobrachial-syndrome OR chondrocostal-junction-syndrome OR compartment-syndrome OR crest-syndrome OR defy OR syndrome OR flatback-syndrome OR goodpasture* OR hypermobility OR iliobial-hand-syndrome OR immobility OR impingement OR osseous OR mucocutaneous OR lymph-node-syndrome OR overlap-syndrome OR postlaminectomy-syndrome OR rotator-cuff-syndrome OR shoulder-hand-syndrome OR sicca-syndrome OR tibial-syndrome OR autoimmune-disease) AND Topic=(“motivational interviewing”)</td>
<td>3</td>
</tr>
<tr>
<td>#5 Topic=(libman-sacks-disease OR marie-bamberger-disease OR paget*-disease OR reiter*-disease OR scheuermann*-disease OR still*-disease OR bouchard*-nodes OR heberden*-nodes OR schmorl*-nodes OR baker OR brotic*-abscess OR cauliflower-ear OR churg-strauss OR de-quervain OR dupuytren OR forestier OR hallux OR kawasaki OR lequesne OR pyogenic OR sj³gren OR sudeck*-atrophy OR takayasu OR tietze OR weber-christian OR claw-hand OR claw-foot OR club-hand OR club-foot OR flat-foot OR footdrop OR hammer-toe OR tennis-elbow OR trigger-finger OR wrist-drop OR beh?et*-disease OR calv* OR kaschin-beck-disease OR kienb?ck*-disease) AND Topic=(“motivational interviewing”)</td>
<td>1</td>
</tr>
<tr>
<td>#6 #5 OR #4 OR #3 OR #2 OR #1</td>
<td>40</td>
</tr>
</tbody>
</table>

Results - title and abstract screened for reference to a Motivational Interviewing and a Musculoskeletal population | 16      |
Appendix

Studies excluded (description of studies - located in other databases) 12 or 13

Total retrieved 3 or 4

* Conducted on 13th March 2011

ClinicalTrials.gov
Conducted 1st March 2011:
(No subject indexing or MeSH terms available)

ICD-10
Conducted 12th March 2011:
- “Motivational interviewing” retrieved 330 results, all screened via condition, followed by title then abstract if required – 8 results

Index of Conference Proceedings (via the British Library’s Integrated Catalogue)
Conducted 2nd March 2011:
(No subject indexing or MeSH terms available)

ICD-10
Conducted 12th March 2011:
Conference proceeding - 1 result (RETRIEVED via inter-library loan at the Knowledge Spa, Truro)
## Appendix D – Systematic Review

### Description of Databases

All database descriptions were retrieved on the 17th February 2011 directly from their corresponding source (in brackets).

### Table 1. Electronic Databases

<table>
<thead>
<tr>
<th>Database</th>
<th>Description</th>
<th>Coverage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allied and Complementary Medicine (AMED)</td>
<td>A unique database covering the fields of complementary or alternative medicine</td>
<td>Allied Health Professions, Complementary Medicine</td>
</tr>
<tr>
<td>British Nursing Index (BNI) (1985 – 2011)</td>
<td>Comprises over 250 of the most popular and important journal sources in the nursing and midwifery fields</td>
<td>Nursing, Midwifery, Health Visitors</td>
</tr>
<tr>
<td>(<a href="http://www.library.nhs.uk/default.aspx">http://www.library.nhs.uk/default.aspx</a>)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cumulative Index to Nursing and Allied Health Literature (CINAHL) (1982 – 2011)</td>
<td>Covers all aspects of nursing and allied health disciplines</td>
<td>Nursing &amp; Allied Health</td>
</tr>
<tr>
<td>(<a href="http://www.library.nhs.uk/default.aspx">http://www.library.nhs.uk/default.aspx</a>)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EMBASE (1980 – 2011)</td>
<td>Provides current and comprehensive information on drugs and pharmacology, and all other aspects of human medicine and related disciplines</td>
<td>General Medical with European focus, pharmacology</td>
</tr>
<tr>
<td>(<a href="http://www.library.nhs.uk/default.aspx">http://www.library.nhs.uk/default.aspx</a>)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MEDLINE from PubMed (1950 – 2011)</td>
<td>A vast source of medical information, covering the whole field of medicine including dentistry, veterinary medicine and medical psychology</td>
<td>General Medical</td>
</tr>
<tr>
<td>(<a href="http://www.library.nhs.uk/default.aspx">http://www.library.nhs.uk/default.aspx</a>)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PsycINFO (1806 – 2011)</td>
<td>The PsycINFO database provides extensive international coverage of the literature on psychology and allied fields</td>
<td>Psychiatry, Psychology, Social Sciences</td>
</tr>
<tr>
<td>(<a href="http://www.library.nhs.uk/default.aspx">http://www.library.nhs.uk/default.aspx</a>)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motivational Interviewing Library (1983 – 2009)</td>
<td>A detailed bibliography from the Motivational Interviewing library website</td>
<td></td>
</tr>
<tr>
<td>(<a href="http://www.motivationalinterview.org/library/biblio.html">http://www.motivationalinterview.org/library/biblio.html</a>)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Table 2. The Cochrane Library Databases

The Cochrane Library

http://www.thecochranelibrary.com/view/0/index.html

| Database                                                      | Description                                                                 | *
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Cochrane Database of Systematic Reviews (CDSR)</td>
<td>The CDSR includes all Cochrane Reviews (and protocols) prepared by Cochrane Review Groups in The Cochrane Collaboration</td>
<td></td>
</tr>
<tr>
<td>Database of Abstracts of Reviews of Effects (DARE)</td>
<td>The only database to contain abstracts of systematic reviews that have been quality-assessed. Each abstract includes a summary of the review together with a critical commentary about the overall quality. DARE covers a broad range of health related interventions and thousands of abstracts of reviews in fields as diverse as diagnostic tests, public health, health promotion, pharmacology, surgery, psychology, and the organization and delivery of health care</td>
<td></td>
</tr>
<tr>
<td>Cochrane Central Register of Controlled Trials (CENTRAL)</td>
<td>Includes details of published articles taken from bibliographic databases (notably MEDLINE and EMBASE), and other published and unpublished sources</td>
<td></td>
</tr>
<tr>
<td>Cochrane Methodology Register (CMR)</td>
<td>A bibliography of publications that report on methods used in the conduct of controlled trials. It</td>
<td></td>
</tr>
</tbody>
</table>
includes journal articles, books, and conference proceedings, and the content is sourced from MEDLINE and hand searches

<table>
<thead>
<tr>
<th>Database</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Technology Assessment (HTA)</td>
<td>Brings together details of completed and ongoing health technology assessments (studies of the medical, social, ethical, and economic implications of healthcare interventions) from around the world</td>
</tr>
</tbody>
</table>

* Descriptions checked for accuracy of content on 17th February 2011.

### Table 3. Unpublished, Grey Literature and Conference Proceedings Databases

<table>
<thead>
<tr>
<th>Database</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Research Register (NRR) Archive (up to 2007) (<a href="http://www.nihr.ac.uk/Pages/NRRArchive.aspx">http://www.nihr.ac.uk/Pages/NRRArchive.aspx</a>)</td>
<td>The archive is a searchable copy of the records that used to be held in the National Research Register (NRR) Projects Database. It was created using the final issue of the NRR published in October 2007, based on records collected up to September 2007</td>
</tr>
<tr>
<td>ClinicalTrials.gov (<a href="http://clinicaltrials.gov/">http://clinicaltrials.gov/</a>)</td>
<td>A registry of federally and privately supported clinical trials conducted in the United States and around the world (103,109 trials in 174 countries on 17th February 2011)</td>
</tr>
<tr>
<td>System for Information on Grey Literature (OpenSIGLE) (<a href="http://opensigle.inist.fr/">http://opensigle.inist.fr/</a>)</td>
<td>Open access to SIGLE bibliographical references of reports and other grey literature (GL) produced in Europe until 2005</td>
</tr>
<tr>
<td>National Technical Information Service (NTIS) (<a href="http://www.ntis.gov/about/index.aspx">http://www.ntis.gov/about/index.aspx</a>)</td>
<td>The National Technical Information Service serves as the largest central resource for government-funded scientific, technical, engineering, and business related information available today. Approximately 3 million publications covering over 350 subject areas.</td>
</tr>
<tr>
<td>Health Management Information Consortium (HMIC) (1979 - 2011) (<a href="http://www.library.nhs.uk/booksandjournals/">http://www.library.nhs.uk/booksandjournals/</a>)</td>
<td>Brings together data from two sources, the Department of Health's Library and Information Services (excess of 174,000 records) and King’s Fund Information and Library Service (over 70,000 records from 1979 to date). Includes official publications, journal articles and grey literature on health and social care management. Coverage: Hospitals, nursing, primary care, public health, health service buildings, occupational health, control and registration of medicines, medical equipment. Health management and services, social care, service development, NHS organisation and administration</td>
</tr>
<tr>
<td>ISI Web of Science with Conference Proceedings (<a href="http://wok.mimas.ac.uk/">http://wok.mimas.ac.uk/</a>)</td>
<td>Coverage of over 10,000 high-impact journals in the science, social science, and art and humanities, as well as international proceedings coverage for over 120,000 conferences. Includes - Science Citation Index Expanded - 1970-present - Social Sciences Citation Index - 1970-present - Arts &amp; Humanities Citation Index - 1975-present - Conference Proceedings Citation Index-Science-1990-present - Conference Proceedings Citation Index-Social Science &amp; Humanities - 1990-present</td>
</tr>
<tr>
<td>Index of Conference Proceedings (via the British Library’s Integrated Catalogue) (<a href="http://www.bl.uk/bibliographic/nbspubs.html">http://www.bl.uk/bibliographic/nbspubs.html</a>)</td>
<td>The British Library acquires the proceedings of all significant conferences held worldwide regardless of subject or language and currently holds the proceedings of over 450,000 conferences. All records included in the index are now available free of charge via the Website as part of the Document Supply Conference File on the Integrated Catalogue</td>
</tr>
</tbody>
</table>

* Descriptions checked for accuracy of content on 17th and 23rd February 2011.
Appendix E - Systematic Review
Quality Assessment Checklist

Checklist for measuring study quality

**Reporting**

1. Is the hypothesis/aim/objective of the study clearly described?

<table>
<thead>
<tr>
<th></th>
<th>yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>no</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

2. Are the main outcomes to be measured clearly described in the Introduction or Methods section?
If the main outcomes are first mentioned in the Results section, the question should be answered no.

<table>
<thead>
<tr>
<th></th>
<th>yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>no</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

3. Are the characteristics of the patients included in the study clearly described?
In cohort studies and trials, inclusion and/or exclusion criteria should be given. In case-control studies, a case-definition and the source for controls should be given.

<table>
<thead>
<tr>
<th></th>
<th>yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>no</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

4. Are the interventions of interest clearly described?
Treatments and placebo (where relevant) that are to be compared should be clearly described.

<table>
<thead>
<tr>
<th></th>
<th>yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>no</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

5. Are the distributions of principal confounders in each group of subjects to be compared clearly described?
A list of principal confounders is provided.

<table>
<thead>
<tr>
<th></th>
<th>yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>partially</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

6. Are the main findings of the study clearly described?
Simple outcome data (including denominators and numerators) should be reported for all major findings so that the reader can check the major analyses and conclusions.
(This question does not cover statistical tests which are considered below).

<table>
<thead>
<tr>
<th></th>
<th>yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>no</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

7. Does the study provide estimates of the random variability in the data for the main outcomes?
In non normally distributed data the inter-quartile range of results should be reported. In normally distributed data the standard error, standard deviation or confidence intervals should be reported. If the distribution of the data is not described, it must be assumed that the estimates used were appropriate and the question should be answered yes.

<table>
<thead>
<tr>
<th></th>
<th>yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>no</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

8. Have all important adverse events that may be a consequence of the intervention been reported?
This should be answered yes if the study demonstrates that there was a comprehensive attempt to measure adverse events. (A list of possible adverse events is provided).

<table>
<thead>
<tr>
<th></th>
<th>yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>no</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

9. Have the characteristics of patients lost to follow-up been described?
This should be answered yes where there were no losses to follow-up or where losses to follow-up were so small that findings would be unaffected by their inclusion. This should be answered no where a study does not report the number of patients lost to follow-up.

<table>
<thead>
<tr>
<th></th>
<th>yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>no</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

10. Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?

<table>
<thead>
<tr>
<th></th>
<th>yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>no</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

**External validity**

All the following criteria attempt to address the representativeness of the findings of the study and whether they may be generalised to the population from which the study subjects were derived.

11. Were the subjects asked to participate in the study representative of the entire population from which they were recruited?
The study must identify the source population for patients and describe how the patients were selected. Patients would be representative if they comprised the entire source population, an unselected sample of consecutive patients, or a random sample. Random sampling is only feasible where a list of all members of the relevant population exists. Where a study does not report the proportion of the source population from which the patients are derived, the question should be answered as unable to determine.

<table>
<thead>
<tr>
<th></th>
<th>yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>no</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

12. Were those subjects who were prepared to participate representative of the entire population from which they were recruited?
The proportion of those asked who agreed should be stated. Validation that the sample was representative would include demonstrating that the distribution of
the main confounding factors was the same in the study sample and the source population.

13. Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?
For the question to be answered yes the study should demonstrate that the intervention was representative of that in use in the source population. The question should be answered no if, for example, the intervention was undertaken in a specialist centre unrepresentative of the hospitals most of the source population would attend.

14. Was an attempt made to blind study subjects to the intervention they have received?
For studies where the patients would have no way of knowing which intervention they received, this should be answered yes.

15. Was an attempt made to blind those measuring the main outcomes of the intervention?

16. If any of the results of the study were based on "data dredging", was this made clear?
Any analyses that had not been planned at the outset of the study should be clearly indicated. If no retrospective unplanned subgroup analyses were reported, then answer yes.

17. In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls?
Where follow-up was the same for all study patients the answer should be yes. If different lengths of follow-up were adjusted for by, for example, survival analysis the answer should be yes. Studies where differences in follow-up are ignored should be answered no.

18. Were the statistical tests used to assess the main outcomes appropriate?
The statistical techniques used must be appropriate to the data. For example nonparametric methods should be used for small sample sizes. Where little statistical analysis has been undertaken but where there is no evidence of bias, the question should be answered yes. If the distribution of the data (normal or not) is not described it must be assumed that the estimates used were appropriate and the question should be answered yes.

19. Was compliance with the intervention/s reliable?
Where there was non compliance with the allocated treatment or where there was contamination of one group, the question should be answered no. For studies where the effect of any misclassification was likely to bias any association to the null, the question should be answered yes.

20. Were the main outcome measures used accurate (valid and reliable)?
For studies where the outcome measures are clearly described, the question should be answered yes. For studies which refer to other work or that demonstrates the outcome measures are accurate, the question should be answered as yes.

21. Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?
For example, patients for all comparison groups should be selected from the same hospital. The question should be answered unable to determine for cohort and case-control studies where there is no information concerning the source of patients included in the study.

22. Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?
For a study which does not specify the time period over which patients were recruited, the question should be answered as unable to determine.
23. Were study subjects randomised to intervention groups?
Studies which state that subjects were randomised should be answered yes except where method of randomisation would not ensure random allocation. For example alternate allocation would score no because it is predictable.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>yes</td>
<td>1</td>
</tr>
<tr>
<td>no</td>
<td>0</td>
</tr>
<tr>
<td>unable to determine</td>
<td>0</td>
</tr>
</tbody>
</table>

24. Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?
All non-randomised studies should be answered no. If assignment was concealed from patients but not from staff, it should be answered no.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>yes</td>
<td>1</td>
</tr>
<tr>
<td>no</td>
<td>0</td>
</tr>
<tr>
<td>unable to determine</td>
<td>0</td>
</tr>
</tbody>
</table>

25. Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?
This question should be answered no for trials if: the main conclusions of the study were based on analyses of treatment rather than intention to treat; the distribution of known confounders in the different treatment groups was not described; or the distribution of known confounders differed between the treatment groups but was not taken into account in the analyses. In nonrandomised studies if the effect of the main confounders was not investigated or confounding was demonstrated but no adjustment was made in the final analyses the question should be answered as no.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>yes</td>
<td>1</td>
</tr>
<tr>
<td>no</td>
<td>0</td>
</tr>
<tr>
<td>unable to determine</td>
<td>0</td>
</tr>
</tbody>
</table>

26. Were losses of patients to follow-up taken into account?
If the numbers of patients lost to follow-up are not reported, the question should be answered as unable to determine. If the proportion lost to follow-up was too small to affect the main findings, the question should be answered yes.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>yes</td>
<td>1</td>
</tr>
<tr>
<td>no</td>
<td>0</td>
</tr>
<tr>
<td>unable to determine</td>
<td>0</td>
</tr>
</tbody>
</table>

Power
27. Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?
Sample sizes have been calculated to detect a difference of $x%$ and $y%$.

<table>
<thead>
<tr>
<th>Size of smallest intervention group</th>
</tr>
</thead>
<tbody>
<tr>
<td>A $&lt; n_1$</td>
</tr>
<tr>
<td>B $n_1 - n_2$</td>
</tr>
<tr>
<td>C $n_3 - n_4$</td>
</tr>
<tr>
<td>D $n_5 - n_6$</td>
</tr>
<tr>
<td>E $n_7 - n_8$</td>
</tr>
<tr>
<td>F $n_9+$</td>
</tr>
</tbody>
</table>

Reproduced from:
# Appendix F – Systematic Review

## Quality Assessment Summary Table

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Is the hypothesis/aim/objective of the study clearly described?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>2. Are the main outcomes to be measured clearly described in the Introduction or Methods section?</td>
<td>Partially</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>3. Are the characteristics of the patients included in the study clearly described?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>4. Are the interventions of interest clearly described?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>5. Are the distributions of principal confounders in each group of subjects to be compared clearly described?</td>
<td>No</td>
<td>No</td>
<td>Partially</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>6. Are the main findings of the study clearly described?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>7. Does the study provide estimates of the random variability in the data for the main outcomes?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>8. Have all important adverse events that may be a consequence of the intervention been reported?</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>9. Have the characteristics of patients lost to follow-up been described?</td>
<td>Yes</td>
<td>Yes</td>
<td>N/A</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>10. Have actual probability values been reported (e.g. 0.035 rather than &lt;0.05) for the main outcomes except where the probability value is less than 0.001?</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>11. Were the subjects asked to participate in the study representative of the entire population from which they were recruited?</td>
<td>Unable to determine</td>
<td>Unable to determine</td>
<td>Unable to determine</td>
<td>Unable to determine</td>
<td>Unable to determine</td>
</tr>
<tr>
<td>12. Were those subjects who were prepared to participate</td>
<td>No</td>
<td>Unable to determine</td>
<td>Unable to determine</td>
<td>Unable to determine</td>
<td>Unable to determine</td>
</tr>
<tr>
<td>Question</td>
<td>13. Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?</td>
<td>Unable to determine</td>
<td>Unable to determine</td>
<td>Unable to determine</td>
<td>Unable to determine</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------</td>
<td>--------------------</td>
<td>--------------------</td>
<td>--------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td>14. Was an attempt made to blind study subjects to the intervention they have received?</td>
<td>Unable to determine</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Unable to determine</td>
</tr>
<tr>
<td>15. Was an attempt made to blind those measuring the main outcomes of the intervention?</td>
<td>Unable to determine</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Unable to determine</td>
</tr>
<tr>
<td>16. If any of the results of the study were based on “data dredging”, was this made clear?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>17. In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls?</td>
<td>Yes</td>
<td>Yes</td>
<td>N/A</td>
<td>Yes</td>
<td>Unable to determine</td>
</tr>
<tr>
<td>18. Were the statistical tests used to assess the main outcomes appropriate?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>19. Was compliance with the intervention/s reliable?</td>
<td>Unable to determine</td>
<td>Unable to determine</td>
<td>Unable to determine</td>
<td>Unable to determine</td>
<td>Unable to determine</td>
</tr>
<tr>
<td>20. Were the main outcome measures used accurate (valid and reliable)?</td>
<td>Unable to determine</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>21. Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>N/A</td>
<td>No</td>
</tr>
<tr>
<td>22. Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?</td>
<td>Yes</td>
<td>Unable to determine</td>
<td>Yes</td>
<td>N/A</td>
<td>Unable to determine</td>
</tr>
<tr>
<td>23. Were study subjects randomised to intervention groups?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>N/A</td>
<td>No</td>
</tr>
<tr>
<td>24. Was the randomised</td>
<td>Unable to determine</td>
<td>Yes</td>
<td>Unable to determine</td>
<td>N/A</td>
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</tr>
</tbody>
</table>
### Appendix

<table>
<thead>
<tr>
<th>Question</th>
<th>RC - Not reported</th>
<th>RC - Low power described</th>
<th>RC - Not reported</th>
<th>RC - Not reported</th>
<th>MW - 5</th>
<th>RC - Yes, to detect small effect sizes</th>
<th>MW - 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>25. Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?</td>
<td>Unable to determine</td>
<td>Yes</td>
<td>Yes</td>
<td>N/A</td>
<td>Unable to determine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. Were losses of patients to follow-up taken into account?</td>
<td>Yes</td>
<td>Yes</td>
<td>N/A</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?</td>
<td>MW - 5</td>
<td>MW - 5</td>
<td>MW - 5</td>
<td>MW - 5</td>
<td>MW - 5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Appendix G – Systematic Review

### Data Extraction Form

Completed by *(assessors name)* ………………….. Date of completion ……………………

<table>
<thead>
<tr>
<th>Information located <em>(please circle)</em></th>
<th>Detail</th>
<th>Agreement with 2nd Assessor</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Article</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author/s</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td>Location of study (e.g. county)</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td>Intervention Setting (e.g. service, institution, community)</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td>Participant age range</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td>Recipients of intervention (child, young person, adult or combination)</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td>Eligibility (inclusion/exclusion)</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td><strong>Musculoskeletal Condition</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Name of condition</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td>Duration of condition</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td><strong>Intervention</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intervention package (e.g. name of intervention)</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td>Duration (e.g. length of sessions, number of sessions)</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td>Delivery (e.g. role person delivering the intervention)</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td><strong>Study design</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Description (e.g. RCT, cohort, case study)</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td><strong>Provider training</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Name/profession of training provider</td>
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<td>Yes / No</td>
</tr>
<tr>
<td>Duration of training</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td>Training competency / level</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td><strong>Outcome measures</strong></td>
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<td></td>
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<tr>
<td>Psychological / psychometric</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td>Medical / physical</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td>Other</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td><strong>Results</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Main findings from study (e.g. outcome measures)</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>---------</td>
<td>---------</td>
</tr>
<tr>
<td>Study Quality</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Downs &amp; Black (1998)</td>
<td>Completed</td>
<td>YES / NO</td>
</tr>
</tbody>
</table>

Completed by (assessors name) ................ .... Date of completion ................ ........
Comment .................................................................................................................................
## Appendix H – Systematic Review
### Database Search, Reference List and Content Search

#### Database Search

<table>
<thead>
<tr>
<th>Database</th>
<th>Results (Combined MI / MeSH)</th>
<th>Screened (Title / Abstract)</th>
<th>Results (Combined MI / ICD-10)</th>
<th>Screened (Title / Abstract)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pub Med</td>
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<td>12</td>
<td>47</td>
<td>16</td>
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<tr>
<td>The Cochrane Library</td>
<td>34</td>
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<td>PsycINFO</td>
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<td>10</td>
</tr>
<tr>
<td>Cumulative Index to Nursing and Allied Health Literature (CINAHL)</td>
<td>45</td>
<td>6</td>
<td>47</td>
<td>8</td>
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<tr>
<td>British Nursing Index (BNI)</td>
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<td>3</td>
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<td>ClinicalTrial.gov</td>
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<td>330*</td>
<td>8</td>
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<td>OpenSigle</td>
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<td>National Technical Information Service (NTIS)</td>
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<td>9*</td>
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<td>49</td>
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<td>(65)</td>
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<td>MeSH and ICD-10 studies combined (17 duplicates, 2 non-musculoskeletal population removed)</td>
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<tr>
<td>Removed (not musculoskeletal population, non-intervention based, no MI content)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excluded (reviews, original articles, articles, letters, commentaries, practice, evidence-based practice, protocols, books, chapters, design papers, supplement, conference material, registered trial)</td>
<td></td>
<td></td>
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<tr>
<td>Overall total for QA (Sub-group)</td>
<td></td>
<td></td>
<td>8 (2)</td>
<td></td>
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</table>

* Not a combined search, motivational interviewing used only. **Not combined, only reference checked.

Removed as Duplicates from ICD-10 and MeSH Combined Searches (14<sup>th</sup> March 2011)


(Supplement)


(Supplement)

Appendix


 *Non-Musculoskeletal Conditions (14th March 2011)*


 *Final List (to be Quality Assessed) (8 articles)*


Appendix


Sub-Group (2 articles)


Reviews (9 reviews)


Combined (reviews, original articles, articles, letters, commentaries, practice, evidence-based practice, protocols, books, chapters, design papers, supplement, conference material, registered trial) (37 articles)


(Article)


(Protocol)


(Conference material)


(Chapter)


(Protocol)


(Book)

(Conference material)


(Chapter)


(Article)


(Article)


(Chapter)


(Chapter)


(Chapter)


(Article)
Appendix


(Evidence-based practice)


(Book)


(Chapter)


(Commentary)


(Language – German, not translated)


(Article)


(Chapter)


(Design paper)

(Supplement)


(Original article)


(Practice)


(Letter)

1 result – 1st Annual Conference on the Motivational Interview
(Conference material)

ClinicalTrial.gov identifier (Nine results):
NCT00968266
NCT00573612
NCT00248105
NCT00249587
NCT00324857
NCT00567294
NCT00979719
NCT00170118
NCT00365404
(Registered trial)

Removed (Not Appropriate - Not Content or Reference List Screened) (6 articles)


(Regression analysis)

(Long standing illness excluded, orthopaedic and arthritis most common exclusions)


(Questionnaire development)


(Participatory Action Research study)


Only 1 reference to motivational interviewing in abstract, no further detail “... but he responds to motivational interviewing”)


(Not a musculoskeletal population)

<table>
<thead>
<tr>
<th>Reference list / Content search</th>
<th>Number of articles</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full text articles retrieved</td>
<td>16</td>
</tr>
<tr>
<td>Assessed online or from abstract</td>
<td>27</td>
</tr>
<tr>
<td>Suitable for quality assessment</td>
<td>1</td>
</tr>
</tbody>
</table>

*Full Text Article Retrieved*

Appendix


*Assessed Online or from Abstract*
- Costa (2005) – in Ang 2011 (no mention of “motivation” in text)
- Douaihy (2005) – in Patterson 2010 (no addition references obtained p229 missing)
- Hoffman (*in press*) – in Heapy 2006 (no mention of MI in abstract or full-text)
- Jacobson (1979) – in Okifuji 2007 (first page retrieved, no mention of MI)
- Lemanek (2001) – in Erickson 2005 (no mention of “motivation” in text)
- Maisiak (1996) – in Cook 2007 (no mention of MI in abstract)
- Roelofs (2002) – in Osborne 2006 (only 1968 ref. to “motivation” in text)
Appendix I – Systematic review
Calculation Details

Data Preparation
To prepare the data for the Kappa calculation using the Quality Assessment Checklist (Downs & Black, 1998), 26 items were utilised (item 27 was excluded as not coded in 0/1 format) and collated across all five included studies. This produced 130 items. From these, 11 items contained missing data from at least one of the assessors, which were excluded. While all the 26 items contained a 0/1 coding response, item 5 used 0/1/2 coding, and the presence of the 2 resulted in an unsymmetrical table when running the analysis. There were four responses within this item, for which there was no agreement, and therefore they were removed to allow the analysis to run (fake or dummy substitutions were not made). On this basis, the total amount of items entered into the analysis was 115. The collated data set is represented in Figure 1:

Figure 1. Both Assessors (MW & RC) Collated Ratings

<table>
<thead>
<tr>
<th>Assessor (MW)</th>
<th>0</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessor (RC)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>25</td>
<td>26</td>
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<td>1</td>
<td>11</td>
<td>53</td>
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<tr>
<td></td>
<td>36</td>
<td>79</td>
</tr>
</tbody>
</table>

The data was entered into SPSS version 17 (see output below). To obtain lower and upper limits, the VassarStats website was utilised, which also confirmed the SPSS analysis.

Output (SPSS version 17):  
WEIGHT BY Count1. CROSSTABS /TABLES=RaterMW3 BY RaterRC3 /FORMAT=AVALUE TABLES /STATISTICS=KAPPA /CELLS=COUNT /COUNT ROUND CELL.
## Appendix

### Crosstabs

<table>
<thead>
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<th>Output Created</th>
<th>Notes</th>
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</thead>
<tbody>
<tr>
<td>10-Jun-2011 21:30:43</td>
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</tbody>
</table>

**Input**
- **Data**: C:\Users\Roy\Documents\Doctorate Health Psychology\COMP\Research - systematic review\Musculoskeletal\Data Extraction\Inter-rater\InterRater - 10Jun11.sav
- **Active Dataset**: DataSet1
- **Filter**: <none>
- **Weight**: Count1
- **Split File**: <none>

**Missing Value Handling**
- **Definition of Missing**: User-defined missing values are treated as missing.
- **Cases Used**: Statistics for each table are based on all the cases with valid data in the specified range(s) for all variables in each table.

**Syntax**
```plaintext
CROSSTABS
/TABLES=RaterMW3 BY RaterRC3
/FORMAT=AVALUE TABLES
/STATISTICS=KAPPA
/CELLS=COUNT
/COUNT ROUND CELL.
```

**Resources**
- **Processor Time**: 0:00:00.016
- **Elapsed Time**: 0:00:00.027
- **Dimensions Requested**: 2
- **Cells Available**: 174762

**Case Processing Summary**

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<th>Missing</th>
<th>Total</th>
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<tbody>
<tr>
<td>N</td>
<td>Percent</td>
<td>N</td>
<td>Percent</td>
</tr>
<tr>
<td>RaterMW3 * RaterRC3</td>
<td>115</td>
<td>100.0%</td>
<td>0</td>
</tr>
</tbody>
</table>

**RaterMW3 * RaterRC3 Crosstabulation**

<table>
<thead>
<tr>
<th>RaterRC3</th>
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<th>2</th>
<th>Total</th>
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<tbody>
<tr>
<td>RaterMW3</td>
<td>25</td>
<td>11</td>
<td>36</td>
</tr>
<tr>
<td>2</td>
<td>26</td>
<td>53</td>
<td>79</td>
</tr>
<tr>
<td>Total</td>
<td>51</td>
<td>64</td>
<td>115</td>
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</table>

**Symmetric Measures**

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<th>Value</th>
<th>Asymp. Std. Error</th>
<th>Approx. T</th>
<th>Approx. Sig.</th>
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</thead>
<tbody>
<tr>
<td>Kappa</td>
<td>.328</td>
<td>.086</td>
<td>3.657</td>
<td>.000</td>
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</table>

a. Not assuming the null hypothesis.
b. Using the asymptotic standard error assuming the null hypothesis.

>Warning # 3211 >On at least one case, the value of the weight variable was zero, negative, or missing. Such cases are invisible to statistical procedures and graphs which need positively weighted cases, but remain on the file and are processed by non-statistical facilities such as LIST and SAVE. CROSSTABS /TABLES=RaterMW1 BY RaterRC1 /FORMAT=AVALUE TABLES /STATISTICS=KAPPA /CELLS=COUNT /COUNT ROUND CELL.
Appendix

Reference
