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Doctoral Thesis

An Exploration Of The Way In Which Services Support Adolescents With Eating Disorders

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Word Count

Thesis Section	Abstract	Main Text	Appendices (including tables, figures and references)	Total
Abstract	286	-	-	286
Literature Review	169	7823	6064	14,056
Research Paper	125	7874	6734	14,718
Critical Review	-	3965	333	4298
Ethics Section	-	5534	8193	13,727
Total	581	24,901	20,030	47,085

Abstract

This thesis explores the way in which Eating Disorder (ED) services provide and deliver interventions aimed at supporting adolescents with an ED diagnosis. Within the systematic review, a meta-synthesis was conducted exploring eight papers presenting the experiences of parents and carers of family based therapies (FBTs) for people with an ED. Three themes were identified: i) we're different as a family now; ii) finding strength in interactions with others; and iii) we aren't all better yet. These results were discussed within the context of existing research, and the implications for services were discussed.

The main research paper uses thematic analysis to explore the experiences of 8 adolescents with anorexia nervosa (AN) or eating disorder not otherwise specified – restrictive subtype (EDNOS-R). Semi-structured interviews were held with participants in order to think about their experiences of services alongside their social identity. Three main themes were identified: i) battling with the identity of being having an eating disorder; ii) the ups and downs of deciding to recover; and iii) I want to be treated like a normal person. These results were discussed within the context of existing literature into social identity and of service provision for EDs. Clinical implications are discussed.

Within the critical appraisal, reflections of the research process are considered. The appraisal provides a space to reflect upon the process of conducting a thesis, and draws upon reflections documented throughout the research journey. The process of developing a research idea is discussed, as are methodological and ethical issues and other issues which were salient to the project. Overall, the thesis presents an exploration of the services currently available to young people with EDs and their families and considers the importance of taking a holistic approach to service design and provision.

Declaration

This thesis report research undertaken between January 2015 and June 2015 as a requirement of the Doctorate in Clinical Psychology at Lancaster University. The work presented here is my own except where due reference is made.

The work has not been submitted for the award of any higher degree elsewhere.

Bethan Roberts

Signed:_____

Dated:_____

Acknowledgements

This thesis is dedicated to the 8 inspiring people who so kindly have up their time to participate in this project. I hope that my writing has represented well the thoughts, feelings and stories that you so bravely were willing to share with me. It is also dedicated to Harry, Alice, Edna and Cliff.

Thank you to all of those services who gave their time and efforts to supporting this project. I also need to acknowledge the support that my field and research supervisors have given me – Craig, Catherine and Helena your advice and guidance has been invaluable and this project couldn't have been done without you. Thanks also to others on the course who have been so supportive over the last year and throughout the course as a whole. Jen, I am so lucky to have had your guidance and support throughout.

Finally, I would like to thank all of my friends, course mates and family for helping me throughout the course. In particular, thank you mum for an endless supply of phone calls and encouragement, not to mention the much needed desserts in Jamie's Italian. Paul – I can't say enough about how patient, kind and supportive you've been, and even when things have been tough your humour (and cooking) have got me through it, thank you.

Contents

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Section One: Literature Review

How Do Carers Experience Family-Based Interventions For Managing Eating-Disorders? A Meta-synthesis of Qualitative Research

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Abstract

Objectives: A number of studies have explored interventions which aim to develop skills or awareness in parents and carers of people with an eating disorder diagnosis. This meta-synthesis aims to bring together the results of qualitative studies in this area in order to contribute to the existing research base.

Method: Electronic databases were systematically searched between September 2014 and January 20th 2015. Eight papers were found which met the study inclusion and exclusion criteria. The results of these studies were synthesised in line with guidance by Noblitt and Hare (1988).

Results: Three main concepts were identified following analysis of the papers. These were: 1) we're different as a family now; 2) finding strength in interactions with others; and 3) we aren't there yet.

Discussion: The themes indicate that there were commonalities between the different studies which could inform future service design and develop understanding in the area. Results are discussed within the context of existing literature relating to parent and carer experiences and to eating disorder service provision.

How do carers experience family-based interventions for managing eating disorders? A meta-synthesis of qualitative research

Eating disorders (EDs) are characterised by atypical eating patterns alongside pervasive conflicts with body image (Brown & Keel, 2013). Traditionally EDs have been understood within the context of social and cultural factors (Nasser, Katzman & Gordon, 2000). Families, and mothers in particular, were seen as directly responsible for the development of EDs. This blame was often attributed to parenting styles seen as highly controlling and perfectionist (Minuchin et al., 1978; Smith & Cook-Cottone, 2011). Gradually, the role of wider cultural pressures became more prevalent with issues such as media messages and social pressures on women coming under scrutiny (Bliss & Branch, 1960). Over recent years the role of genetics within ED development has been increasingly highlighted and currently ED development may be best conceptualised as an interaction between complex cultural, genetic and environmental factors (Collier & Treasure, 2004).

Whilst the role of parents, carers and families in the development of EDs has shifted over time, parents and families can still be crucial in supporting recovery (Simic & Eisler, 2012, p.263). Treasure and Schmidt (2013) proposed the interpersonal maintenance model of EDs which suggests that the high levels of anxiety, depression and rumination often seen in carers of people with EDs, alongside an uncertainty in parents in terms of how to manage ED related behaviours, can act as maintenance factors. Psychological interventions for young people who have an ED diagnosis often include elements of family based interventions, partly in recognition of the role that parents can have in helping their children to recover (Downs & Blow, 2013).

Many of these family based therapies (FBTs) aim to help parents and carers learn more about EDs and develop strategies to help manage them (e.g. Cairns, Styles, & Leichner, 2007; Hibbs, Rhind, Lappanen, & Treasure, 2014). The interventions hope to both increase

the efficacy with which family members can help their child to recover and to support carers in managing their own emotional needs (Haigh & Treasure, 2003). However, the design and delivery of these approaches has been demonstrated to be highly variable. For example, the "New Maudsley Approach" of FBTs (Treasure, Smith, & Crane, 2007) is a programme which is aimed at families of service users, both young people and adults, and is intended to develop skills in parents and carers with the aim of empowering them to feel confident in providing care and reducing stress. This approach has been widely used (Wade, Treasure, & Schmidt, 2011) and adapted (Rhodes, Baillee, Brown, & Madden, 2008). However, other interventions such as family psycho-education or behavioural family systems therapy are also common (Downs & Blow, 2013). These approaches demonstrate a similar underpinning but focus on different aspects of the caring relationship and are often adapted to meet specific service requirements (Downs & Blow, 2013), making like-for-like comparison of interventions difficult.

As well as variations in content, the delivery methods of interventions are variable. Some services have utilised carer support groups which can be led by professionals such as psychologists (Dare, Eisler, Russell, Treasure, & Dodge, 2001), or can be unstructured with a peer-led approach (McCormack, 2010). Guided self-help has also been used, where carers access written or visual information from services independently and are coached over the telephone by ED clinicians (Schmidt et al., 2007). Services have trialled using DVDs or booklets as ways of delivering guided self-help programmes (Sepulveda, Lopez, Macdonald, & Treasure, 2008). Some services provide one-to-one psychological input to carers specifically focussed on helping them to support family members with an ED diagnosis (Downs & Blow, 2013), while others invite parents to educational groups (Holtkamp, Herpertz-Dahlmann, Vloet, & Hagenah, 2005).

Given the wide variety of interventions and methods of delivery, it is difficult to reach a consensus on what approach is most helpful. Research has shown that, in general, family based therapies (FBTs) are beneficial to both service users and families. For service users, observed changes in the physical aspects of an ED diagnosis and in wellbeing have been observed (McLean, Griffin, Toney, & Hardeman, 2003). Reviews in the area have demonstrated that when parents use a range of behaviour change techniques with support from services this leads to positive weight changes for service users which are sustained over several months (McLean et al. 2003) and that it can lead to general ED symptom reduction (Downs & Blow, 2013). FBTs have also been shown to be superior to treatment as usual where no FBTs are utilised (Smith & Cook-Cottone, 2011).

In addition to thinking about which interventions lead to a reduction in ED symptomology, it is useful to consider the impact that taking part has on parents and carers themselves. Caring for someone with an ED has been demonstrated to negatively affect carer wellbeing, with carers displaying high levels of anxiety, rumination and fear as well as a higher likelihood of low mood (Sepulveda et al., 2012; Zabula, Macdonald, & Treasure, 2009). Denial or deferral of one's own needs as well as becoming overly involved in trying to control and manage eating habits is common (Coomber & King, 2012) and can lead to conflict, loneliness or loss, which in turn can cause further tension and contribute to ED maintenance (Treasure & Schmidt, 2013).

FBTs have led to parents reporting an improvement in both their confidence in managing ED behaviour and in their mood and emotional stability (Downs & Blow, 2013; McLean et al., 2003; Smith & Cook-Cottone, 2011). Hibbs et al. (2014) reviewed quantitative studies in this area and identified that carer distress was reduced following interventions and that they felt less burdened by the caregiver role.

One problem commonly reported in reviews of FBTs is that participant numbers in studies are low (e.g. Ball & Mitchell, 2004) and that it can be difficult to engage parents and families in interventions (Downs & Blow, 2013). Many reasons have been hypothesised for this disengagement. It may be due to problems in engaging families in services in general, perhaps as a result of the afore mentioned "blaming" discourse so predominant within early theories of EDs which is still present within media representations (Eisler, 2005). There was also a high drop-out rate observed within the studies reviewed by Downs and Blow (2013). Reasons given for the drop out included families wanting to see quicker results (Lock, Agras, Bryson, & Kraemer, 2005) or families not being comfortable with the treatment that they were being offered (Eisler et al., 2000). Thinking about these reasons is important in terms of trying to develop interventions which are more acceptable and useful to participants. This could increase participation and reduce drop out for future interventions.

The number of qualitative studies in this area is relatively small, with the majority of existing research relating to carer interventions using quantitative methods to investigate the impact of interventions on specific symptomology rather than exploring carer experiences (Hibbs et al., 2014). Meta-syntheses can be a way to contribute to an existing knowledge base and to offer fresh insights into practice (Hallberg, 2009). It can also be a method through which a new and more complete interpretation of existing findings from studies can be formed (Walsh & Downe, 2005). Given the issues in recruiting carers to participate in interventions, using a meta-synthesis to bring together the limited number of papers in this area may provide important information and it will be possible to summarise and build on existing findings as well as generating new insights and understanding (Walsh & Downe, 2005).

This review aims to build on existing research through directly examining the experiences of parents and carers who have attended psycho-education groups, training,

guided self-help, or other interventions aimed at teaching them strategies to cope with living with someone who has an ED and helping them better support their loved one. While previous studies have examined the efficacy of these interventions in terms of reducing ED symptomology, the experiences of the parents and carers attending these groups has not yet been collated. Existing reviews have identified the need to include more parents and carers in interventions for people with EDs and thinking about the way in which parents and carers experience existing treatments could help to inform this process.

Method

This review was conducted in line with guidance written by Noblitt and Hare (1988) for conducting meta-syntheses. The review aims to explore the experiences of parents and carers who have received interventions aimed at helping them better support a person with an ED. As such, it will aim to provide interpretations and insight building on existing reviews and will bring together and present information from a range of sources.

Study Selection

Studies were selected based on five inclusion criteria: a) they included a focus on the experience of parents or carers of people who had a diagnosis of an ED; b) these parents or carers must have attended a family based intervention which was aimed, at least in part, at developing understanding of how to manage disordered eating in their family member; c) they utilised a named and referenced qualitative approach and outlined their adherence to this approach. It was also necessary for themes to be demarcated by titles and to include quotes which evidenced participant views; d) the papers were published in a peer reviewed journal; e) they were available in English. The following exclusion criteria were used: a) papers where the views of parents were given only indirectly, e.g., via professional views of their involvement; b) papers where education was given to parents and carers of people without an

ED diagnosis, e.g., at school prevention sessions; c) papers that were reviews of existing studies. No restriction was put in place in terms of the age of the person with an ED as the focus here was on the approaches themselves, which are designed for use with parents and carers of children, adolescents and adults (Treasure, Smith & Crane, 2007).

Journals appropriate for inclusion within the review were located through a systematic literature search using Boolean operators within a number of major bibliographical databases. The databases utilised were: PsycInfo (searchable years 1589 – present); PsycArticles (searchable years 1894 - present); Child Development and Adolescent Studies (1927 - present); EMBASE (searchable years 1947 – present); and Medline (searchable years 1995 – present). The search terms used to locate papers were: (eating disorder OR anorexia OR bulimia OR ednos) AND (parent OR carer OR family) AND (training OR skills OR workshop OR intervention OR psycho-education OR family-based intervention OR family therapy OR family-based therapy). There were no limits put in place in terms of the date of publication. Specific searches were carried out within each database and used a combination of keyword search terms and subject headings specific to each database. Hand searching of reference lists was also utilised and the number of studies identified through each method are reported in Figure 1. The search was conducted on January 20th, 2015.

Searching these terms returned 2,196 papers. All papers were initially screened through reading their title and abstract and where it was not possible to determine whether the paper met the inclusion/exclusion criteria for the study the full paper was sought and read. A total of eight studies were identified which met all criteria (Figure 1).

(Insert Figure 1 here)

Characteristics of the Studies

Eight papers were identified as relevant for this review (Table 1). They were all published between 2006 and 2015. Five of the studies were conducted in the United Kingdom (UK), with one in the United States of America and two in Australia. Sample sizes varied between 10 and 101. Data collection processes varied, with six studies utilising semi-structured interviews (one of these used telephone interviews), one using written qualitative data obtained via open-ended questionnaires, and one using a focus group. The majority of the studies (six) described carers' responses to specific training packages, while two interviewed parents about their experiences of service provision of carer interventions. The average age of the service users with an ED diagnosis was 18 years. Across all studies, 119 of 231 participants were parents. 101 were identified as being primary caregivers. Of those who were primary caregivers, the study did not provide the demographics of the group but stated that they were primarily mothers. The remaining 11 participants within studies were siblings, step-parents, partners, or children of the person with an ED. Interventions included those delivered to single families and within multi-family settings. More details on the interventions explored within the studies can be found in Table 2.

Thematic analysis was used for four of the eight studies, while three utilised interpretative phenomenological analysis and one used a constant comparative method. All of the studies focused on the stories and language expressed by participants as being representative of their experiences, thoughts and feelings and provided interpretations and discussions based on this assumption.

(Insert Table 1 here)

(Insert Table 2 here)

Data Synthesis and Analysis

In order to analyse the articles, a seven step process was undertaken, in line with guidance by Noblitt and Hare (1988). These stages consisted of: a) getting started; b) deciding what is relevant to the initial interest; c) reading the studies; d) determining how the studies are related; e) translating the studies into one another; f) synthesising the translations; and g) expressing the synthesis.

In terms of the first stage, getting started, this involved selecting an area of interest and identifying a research question. Within the introduction, research within this area has been discussed and a research question presented. The second stage, deciding what is relevant to the initial interest, consisted of choosing which type of studies to focus on in order to best answer the research question. Here, in order to produce a synthesis which was relevant to those who might apply its results, a decision was made to focus on those studies that focussed on approaches which fitted within the bracket of "family based therapies". These search process underlying this stage has been described previously, and a quality appraisal was undertaken in order to evaluate the standard of the studies included. This process is described below.

The third stage involved reading the studies, and determining which information within the studies was relevant to the review. As well as carefully exploring the content of all of the studies and becoming familiar with it, the studies were looked at with the research question in mind in order to start the process of highlighting that information which was relevant. At this stage, demographic information was extracted from the studies in order to assist the reader in contextualising the results.

Following this stage, a process of determining how the studies were related took place. This involved re reading the studies and making notes of key themes, ideas, metaphors

and concepts which related to the research question in a process of reciprocal translation. Common and recurring concepts were identified and noted. This stage involved starting to determine whether these ideas were common across papers and how they related to each other, as well as identifying and describing any agreements or dissonance within and across papers.

Following this, the fifth stage, translating the studies into one another, took place. Translating the studies into one another involved a process of maintaining the important concepts and metaphors present within each paper and considering the way in which these ideas compare and interact with those themes and concepts from other studies. The sixth stage, synthesising the translations, involved using the existing data extracted from the studies and continuing the process of reading the identified concepts and interpretations in order to establish the relationships which underpinned the studies.

For example, reading the studies and identifying common themes had revealed that parents within all of the studies had noticed some changes in the way in which the ED symptoms manifested within the person with the ED diagnosis. Synthesising the papers enabled the identification of the theme "we're different as a family now". At this stage, the data started to be formed into specific themes which reflected the content of the reviewed papers. A search was undertaken for these themes within all papers included in the synthesis. Quotes and existing themes were brought together to represent key concepts which answered the research question. All papers were re-examined to check that the selected themes accurately reflected paper content and all themes were presented alongside data which supported their inclusion within the review. Table 3 includes an illustration of how this process worked in practice for the development of one of the identified themes.

(Insert Table 3 here)

The final stage, expressing the synthesis, involved considering the audience of the review and presenting the results in a way which best allowed the findings to contribute to the existing research base and influence clinical practice. Within the results and discussion here, it was important to consider not only the theoretical impact of the synthesis, but also to consider the practical implications of the results.

Quality Appraisal

In order to ensure that all studies included within the review were of sufficient quality, the three step quality assessment process proposed by the Cochrane collaboration qualitative methods group (Hannes, 2011) was used. The first stage of this process is to limit studies included to those which are empirical studies and meet basic standards, which took place at the initial screening stage.

The second stage of the process involved utilising the Critical Appraisal Skills Programme (CASP) tool (Public Health Research Unit, 2006). This tool has been advocated for use with qualitative syntheses, is widely used, and has been evaluated to be suitable for use within health research (National Collaborating Centre for Methods and Tools, 2011). The CASP consists of 10 questions which evaluate the validity and rigour of each study. Each paper was assessed in terms of these questions and assigned a score out of three for each area (Table 4). The average score on the quality assessment was 17.4 (standard deviation: 2.2; range: 13-20). This suggests that the quality of the studies was generally very good. Most of the variability between studies related to whether the chosen method of qualitative data collection was described in enough detail to determine whether it was the most appropriate methodology. This variability may be explained in part by journals not including information reported in studies at the point of publication.

(Insert Table 4 here)

The third stage of the process is to appraise theoretically the paper in order to examine the way in which the research paradigms related to the findings presented and to think about the quality of the decisions made by the researchers, the reasons they presented for these and the way in which researchers interacted with the data. This appraisal was not done through use of a specific tool, but was based on the judgement of the researcher in response to the content of the papers included.

This quality appraisal process demonstrated that while there was some variability in the quality demonstrated by the various papers, all were of a satisfactory level to warrant inclusion within the review. Within the analysis process, the quality of the different papers did not affect the weighting given to their content. The analysis process explored concepts presented by all of the papers, and no theme was reliant on information gathered from only one or a few papers. It was clear that there was consistency across papers in terms of the broad ideas and concepts identified, and no one paper was represented more heavily than others within the analysis process.

Results

Three main concepts were identified following analysis of the papers. These were: a) we're different as a family now, b) finding strength in interactions with others, and c) we aren't there yet. All themes and sub-themes are presented in Table 5. Here, each concept is presented and discussed alongside quotes from the original papers.

We're different as a family now

Participants across all of the papers were keen to emphasise the changes that they had experienced as a family as a result of attending FBTs. These changes included positive effects on functioning for both carers and service users, as well as reported improvements in communication, relationships and understanding.

In terms of functional improvement, carers noted changes in the way in which the ED would manifest in their child: "For the first time since the start of her illness, she will have the kind of future most of us regard as a norm" (Macdonald et al., 2014, p. 436). Participants were encouraged by these perceived improvements, and felt that they were better placed to manage obstacles when they arose. This was common between the papers, and even where the changes observed were less significant participants felt relieved to see a change in behaviours that had often been present for long periods of time.

Many carers noted improvements in communication as a result of the interventions – an improvement which was observable through more open conversations taking place within families, and carers recognising that they were able to utilise specific skills taught within groups.

> I find myself, particularly with the open-ended questioning…I'm using those sorts of statements more often right now and I think about my response before I say anything. So I've found it really helpful. (Goodier et al., 2014, p. 371)

A clear improvement in relationships within families were observed by many participants, which was attributed in part due to an increased ability to empathise with and recognise the perspective of the person with the ED (Goodier et al., 2014; Macdonald et al., 2014; Rhodes, Brown, & Madden, 2009). Participants were also able to separate their child from the ED, which was a change in perspective which many found useful: "I see that it's anorexia, not Amy, so it's a lot easier to keep cool, calm and collected" (Rhodes, Brown, & Madden, 2009, p. 185).

A theme common across papers was the impact of acquiring and learning new skills through the groups (Goodier et al., 2014; Macdonald et al., 2011, 2014; Rhodes, Brown, & Madden, 2009; Tierney, 2005; Voriadaki et al., 2015; Whitney et al., 2012). The skills learnt

included assertiveness and boundary setting, which were specifically attributed to the skills training sessions. An improvement in self-care was also identified, as were action planning and goal setting, taking a firm calm stance, and acting confidently (Goodier et al., 2014; Macdonald et al., 2011; Rhodes, Brown, & Madden, 2009; Tierney, 2005; Voriadaki et al., 2015). This skill acquisition led participants to report feeling better informed and led to a greater level understanding and empathy for the person with an ED. Participants communicated that through learning specific skills, such as better boundary setting, they were able to change their whole approach to communicating and dealing with the person with the ED. They spoke of increased parental cooperation (Patel et al., 2014), better team problem solving (Voriadaki et al., 2015), increased patience (Voriadaki et al., 2015; Whitney et al., 2012) and reduced fears for the future (Macdonald et al, 2011, 2014).

In terms of how this skill acquisition took place, workshops, DVDs, booklets, psycho-education, group work and suggested reading were all identified as contributing factors. Carers identified that practical activities such as role plays were useful, but only where these role plays were demonstrated by facilitators first: "I think we got stuck when we had to do role-plays, because we weren't quite sure - they need more role-plays from the team leaders" (Goodier et al., 2014, p. 371).

This theme demonstrates the sense communicated by participants that taking part in the interventions had contributed to significant changes within their functioning as a family. These changes included more easily quantifiable elements such as changes in ED related behaviours and reduced anxiety and burden in carers. In addition to these were a number of less tangible changes, such as increased levels of understanding and empathy for the person with the ED and an increased ability to attune into the feelings and mood of the person with an ED. These changes helped to empower carers to better support the person with an ED.

Finding strength in interactions with others

A common theme across the papers reviewed was the way in which working with and alongside other families, carers or professionals affected their individual experiences of the groups. An idea that was strongly communicated by many participants was the way in which being around others with similar experiences could prove to be normalising and reassuring (Goodier et al., 2014; Macdonald et al., 2011; Voriadaki et al., 2015). Some carers attributed this normalisation specifically to the group processes present when working alongside other families (Goodier, 2014; Voriadaki et al., 2015). In addition to being provided through hearing from others, normalisation could occur for participants when they were given the opportunity to share their own experiences (Goodier et al., 2014; Macdonald et al., 2011; Patel et al., 2014; Rhodes, Brown & Madden, 2009; Tierney, 2005):

> I think you are on the same emotion. You don't feel like you are the only person out there. You feel normal, you're not getting the look like . . . what's up with you? What are you upset about? (Rhodes, Brown, & Madden, 2009, p. 186)

"Feeling supported" was identified as a crucial element of the interventions within many of the studies (Goodier et al., 2014; Macdonald et al., 2011, 2015; Rhodes, Brown, & Madden, 2009; Voriadaki et al., 2012). Feeling supported held different meanings for participants. Common elements included feeling that there was someone there to help with the practical and emotional elements of caring for a loved one with an ED, and that other people could empathise with and understand the challenges of taking on that role. Both sharing experiences and hearing the experiences of others contributed to this feeling of being supported, as did being able to communicate openly and honestly in an environment that felt safe and containing (Macdonald et al., 2010; Rhodes et al., 2009; Whitney et al., 2012). Interpersonal contact was highly valued by participants across the studies, with many reporting that the support which came from working alongside other families and with

professionals was central to the value they placed on the groups. This was particularly important for those participants who had reported reduced social support at home, such as carers who were single parents (Rhodes, Brown & Madden, 2009).

Many carers were able to speak about the elements of being in a group which made it successful, as well as the difficulties that groups could bring. Some participants reported that in order for groups to work well, a culture of honesty and openness was helpful: "I think everyone was really open and frank. I think that really fostered that kind of atmosphere of sharing and caring for each other" (Goodier et al., 2014, p. 371). Within some groups, participants did not report this culture of openness and honesty, and noted that being in the groups could be challenging, in particular when other group members held opposing views. In the main participants reported these incidents being managed by the facilitators, but did note that there were occasions where the groups felt tense and were unhelpful as a result.

The way in which therapists interacted with families was important both in supporting the development of skills, but also in contributing to the way in which families communicated within groups. Participants valued having therapists who they felt were skilled at identifying problems and managing them effectively and who were able to skilfully manage group dynamics and address any issues which arose (Goodier et al., 2014; Voriadaki et al., 2015; Whitney et al., 2012). Carers valued working with professionals who they perceived as "experts" and found this reassuring: "We had two of the most experienced people there. They were professional and they were very sincere and they were very controlled, I felt very safe with them" (Whitney et al., 2012, p.135).

Therapists who mediated between parents and their children were perceived as useful, especially when they reinforced the role of the parent: "(the therapist) tells Jess 'look I am just here to listen or advise or whatever, but really you have to listen to your Mum'. So I think that's a good thing. She's not taking that role away from me" (Rhodes, Brown, &

Madden, 2009, p.184). Therapist factors were reported by participants across most of the studies, suggesting that this was central to the experiences of many.

Participants across all of the studies spoke about the way in which being around other people made a significant contribution to their experiences of attending a FBT, be this other families or professionals. The normalising effect of hearing other's experiences was valued, as was the way in which being around others contributed to a sense of being supported and encouraged. When considered alongside the previous theme, it is useful to note that participants who received less social support within their groups did not report a reduction in skill acquisition or fewer changes to their communication or relationships. They did however find the interventions to be less acceptable to them. The interpersonal elements of the groups contributed significantly to the engagement with the groups reported by families, and in particular contributed to a feeling of being supported which was very important across all of the studies.

We aren't there yet

This theme considers the message reported by participants that although in general they valued the group there was a sense of needing to communicate that things weren't completely better yet and that they still needed support. It also captures many of the elements that participants felt were less positive and detracted from their overall experiences of the groups.

While participants in many of the studies focussed on the positive changes that had taken place as a result of participation in the interventions, many also wanted to articulate that they were still experiencing difficulties and wanted this to be recognised (Goodier et al., 2014; Macdonald et al., 2011, 2015; Tierney, 2005). Some linked these difficulties to the relative success or failure of the intervention, but also recognised that the process of recovery

is long and difficult: "I don't feel as if anything's worked particularly well because she's still unwell so…until she's better, I suppose I don't feel that anything's worked but it's not like that because it's a gradual process, isn't it?" (Macdonald et al., 2011, p. 481). The difficulties discussed above related to factors such as a prevailing sense of loss, to concerns for the future and to feeling that there was a lack of progress in any sense (Goodier et al., 2014; Macdonald et al., 2014; Tierney, 2005).

Across the studies participants noted the need for greater post-discharge support following the groups, and there was a sense for many that support from services would end at the completion of the groups (Macdonald et al., 2014; Rhodes et al., 2009; Tierney et al., 2005; Voridaki et al., 2015). There was also a sense that longer duration or increased frequency of the groups would be beneficial – with many valuing the interventions and being reluctant to end the support provided by attending (Rhodes et al., 2009; Voriadaki et al., 2015; Whitney et al., 2012).

Although the interventions were generally experienced as acceptable by participants, many identified elements of the design and delivery which they felt negatively affected their engagement and participation. There was a sense that in some cases initial interactions with services and invitations to the group needed to be considered more carefully. Some participants reported that they were not given any other options as an alternative to the FBTs, which had led to them feeling pressured. Others felt that rather than making an informed decision to attend they were "told" to attend by services: "I think the way it was broached to me probably wasn't a good idea… I was told "you will be having family therapy with another family" and all I wanted to say was "oh no I won't" (Whitney et al., 2012, p. 138). For some participants across the studies this led to anxiety about attending the groups, and to a feeling of being blamed for the difficulties (Macdonald et al., 2014; Whitney et al., 2012).

Participants also felt that consideration of personal barriers to participation would have been helpful in engaging them in the interventions. Factors such as individual health and wellbeing, time constraints, stigma from others in the community and financial concerns were all identified as elements which would make engagement difficult, and these were not suitably addressed by services within the studies reported here (Macdonald et al., 2011, 2014; Rhodes et al., 2009; Voridaki et al., 2015; Whitney et al., 2012). There were also many more concerns about the interventions themselves experienced by participants, who often felt that they did not have a platform to discuss these prior to agreeing to participate. These included concerns about the impact of the intervention on loved ones, a fear of making existing symptoms worse, guilt about helping themselves rather than just their loved ones and feeling overwhelmed and pressured by the levels of information that they might be presented with (Macdonald et al., 2014; Patel et al., 2014; Rhodes et al., 2009; Whitney et al., 2012).

In terms of the delivery of the interventions themselves there were some concerns which were common across the studies, with many participants identifying elements that they felt were less helpful. These generally centred around participants not feeling included within the interventions – often because the materials, role plays and examples were very different from their own experiences (Goodier et al., 2014; Macdonald et al., 2012, 2014; Tierney, 2005; Voriadaki et al., 2015): "A lot of the information seemed directed at children with eating disorders who behave very differently from my own daughter, to some extent the information that was being delivered was not particularly relevant" (Goodier et al., 2014, p. 372).

This theme encapsulates the fact that although generally participant experiences of the interventions were positive, there were many elements that could be improved. It was important for carers that their ongoing difficulties were recognised and many expressed a desire for ongoing support following the groups. It was also clear that many felt they were

not consulted fully about their potential involvement in the groups and this felt alienating. This sense of alienation was reinforced by the use of materials or discussions which were not tailored to the needs of individual group members.

Considering this theme alongside the other two themes identified within this analysis allows for a holistic view of the experience of participants. While many were keen to stress the positive elements of their participation, in particular the changes they had observed and the support they had encountered, there was a sense that consideration of the way in which interventions are presented and of the way in which support can be delivered on an ongoing basis could contribute to a greater overall sense of acceptability of the interventions.

Summary of Results

In order to summarise the findings the key concepts and themes identified across the papers will be brought together here. This will aid in developing a framework in order to better understand the experiences of carers of attending FBTs aimed at supporting them in caring for a relative with an ED.

It is proposed that the primary experience of participants within FBTs relates to the way in which they observe and undergo changes – both individually and as a family. These changes can be attributed in part to psychoeducation and to learning new skills for caring for a person with an ED. Learning specific communication and relational skills aids carers in being able to empathise with and better understand the perspective of the person with an ED. Skill acquisition can also aid carers in being able to cope with the emotional demands of providing care to a person with an ED. This in turn improves relationships and communication within families, and also contributes to an observable reduction in ED related behaviours. Thinking about the delivery of these skills is central to the experience of

participants, with those groups run by professionals who were able to balance and work with complex group dynamics proving more successful.

In addition to a recognition of the changes observed within families, another central element of carer group experience which should be considered relates to the way in which interactions between families and carers occur. Sharing experiences can prove to be normalising and can provide much needed reassurance and validation to carers. For carers, the benefits of talking to other people in similar circumstances can be great, and include an increased sense of being supported, reduced anxiety and a reduction in concerns about the future. Interventions may be much more acceptable to carers when there is a level of interpersonal contact – most commonly provided from other carers but also from professionals. This can help to foster a sense of being supported in carers – another crucial part of the group experience which can contribute to carers continuing to engage with interventions rather than choosing to leave.

The framework speculates that it is important to recognise that many carers will experience ongoing difficulties, and may find it difficult to continue to engage in groups for a number of reasons. Recognising this and naming these difficulties may be crucial in fostering carer engagement. Ensuring that the stated goals of interventions are realistic and achievable may be helpful in avoiding a sense of failure or disappointment in attendees. Consideration of the way in which participants are invited to groups should also be made, and avoidance of coercion should be ensured. Provision of support following discharge from the groups will also be beneficial in maintaining family engagement with services and in supporting the continued application of skills and strategies.

Discussion

Some of the results presented here support many of the assumptions seen within FBT literature, such as the impact of psychoeducation on the ability of carers to communicate and relate to the person with an ED and the reduction in stress and anxiety experienced by participants (Downs & Blow, 2013). There were however some findings which were identified as a result of the meta-synthesis of the included studies. Those findings will be discussed here.

The value of interpersonal contact and of the therapeutic relationship has been well documented within individual therapeutic work (Baldwin, Wampold, & Imel, 2007), with the "common factors" of empathy, warmth and genuine regard often highlighted as a main facilitator of change within therapy (Rogers, 1957). However, within therapeutic groups and within the literature surrounding FBTs the impact of the therapeutic relationship has not been considered to the same extent and most research has focussed on the outcomes of the groups rather than the impact of factors such as the therapeutic relationship in achieving this change (Downs & Blow, 2013; Smith & Cook-Cottane, 2007; Treasure, Smith & Crane, 2007). Within this review there emerged a common theme that positive relationships with professionals were key to the positive experiences of participants and contributed to their learning. Many participants across the studied explored here noted the lack of support they were offered following the interventions. This was in part due to their positive relationship with the staff team and a fear that they would no longer gain support. This may be an important element of the interventions which contributes to existing research in this area.

While the aims of many of the carer interventions discussed here were largely based around tangible changes in functioning (e.g., Macdonald et al., 2011; Macdonald et al., 2014; Whitney et al., 2012), it is important to note that for carers many of their positive experiences related to interpersonal factors such as normalisation and validation of experiences.

Although qualitative results from existing studies suggest that carers prefer coaching to non-coaching groups as interventions, the quantitative results suggest similar efficacy of the interventions (Macdonald et al., 2014). However, in thinking about how to best engage carers in groups and to help them feel able to participate, thinking about the positive impact of interpersonal elements may be important.

While these positive interpersonal elements may be of benefit to participants, it may also be important to note that this may make group members reluctant to leave the safety of the groups. As discussed above, many participants here experienced a feeling of being unsupported following group endings. Becoming dependant on therapist support within individual psychotherapy has been well-documented (e.g. Bornstein & Bowen, 1995; Fowler, 2014). A similar process has been observed within group settings (Burlingame, Fuhriman & Johnson, 2001). Many of the groups included here included "empowerment" as one of their aims. However, it may be that the reluctance to leave the safety of the group by participants suggests that they had become dependent on attendance and on the relationship with peers and staff. Dependence within therapy can act as an obstacle for service users in terms of making changes, and so the reasons for this potential dependence may be useful to explore within future research. Reasons outlined within existing research surrounding dependency include a reluctance to leave an environment which is accepting and nourishing, and a lack of confidence in the ability to apply skills in real life settings (Bornstein & Bowen, 1995). There may be a role for group facilitators in exploring this relationship between empowerment and dependency and encouraging participants to take steps to become independent of the group and identify external sources of support prior to the completion of groups.

This ability to engage in the groups was another theme common across many of the studies reported here. LeGrange et al., (1992) recognised that engaging families in FBTs was difficult. Squire-Dehouck (1993) recognised that within sessions participants may experience

guilt or feelings of being blamed as a result of confrontations with other group members. Here however, it was apparent that for many families these feelings of guilt and blame were intrinsic, and that the manner in which they were invited to participate in groups often proved to reinforce these feelings. LeGrange and Lock (2001) have hypothesised that manualising group content may go some way in reducing the potential for parental criticism, with results suggesting that this approach may be beneficial.

Within family therapy literature the role of existing carers or service users in designing and delivering interventions is not emphasised (Eisler, 2005). However here participants were keen to emphasise the need for individually tailored materials. The impact of service users as fellow group members was recognised within the studies here, and it may be that there is a role for service users in the facilitation of groups. Service user literature and the "experts by experience" movement suggests that those people who have had previous experience of a phenomenon are well placed to use those experiences to support others (Noorani, 2013). Participants across the studies here spoke of the value they placed in hearing others' experiences. Considering broadening the role of families within the delivery and design of interventions may contribute to an increased sense of normalisation and validation in group members.

It is also important to consider the elements which participants felt contributed to groups working well, such as professionals helping to facilitate a culture of honesty and openness through providing clear boundaries and setting the expectations for the group. Within the groups investigated here, as with the groups discussed within quantitative reviews, the professional background of the group facilitators was variable, as was their level of training (Smith & Cook-Cottone, 2011; Downs & Blow, 2013). Being able to balance the competing needs of individuals within groups as well as creating a contained environment where honesty and openness are attributes of a skilled group leader, developed through

training and experience (Rapin, 2004). Recognising the value of these skills in improving the experience and outcomes of participants is crucial and points to the importance of services considering the impact of facilitators on groups.

Study Limitations

There were limitations to this meta-synthesis which should be taken into account when considering the results. Firstly, the number of studies included within the review was comparatively small. When evaluating papers for inclusion, there were a number of other studies which did attempt to reflect the experiences of carers of being in the groups, but the standard of the analysis of qualitative responses was frequently at a level which discounted them for inclusion within this review. This meant that some potentially important and relevant information was missed and not represented within the results here. While meta-synthesis provides a useful tool for bringing meaning and expanding on even small numbers of papers (Walsh & Downe, 2005) and some interesting results have been presented which contribute to the literature base in the field, the generalisability of the results is questionable. This does however highlight the need for more good quality qualitative research in this area.

Additionally, it is important to note that all of the studies here were conducted within westernised cultural backgrounds and issues of cultural adaptation were not addressed. The ethnicity of carers who took part in the studies was not reported within many of the papers, meaning that there is little information available about the way in which cultural background may impact upon group experience. Research has identified that there are significant differences in the aetiology and presentation of EDs across different cultural groups (Lester, 2007) and that factors such as family patterns of communication impacted by cultural and religious factors may have a key role to play in this. It is therefore important to consider whether parents from non-westernised backgrounds may benefit from a different approach and whether FBTs in their current format would be universally applicable.

Conclusions

This meta-synthesis of the experiences of carers across a range of FBTs demonstrated that the primary experiences reported related to the positive changes in communication and family relationships that they experienced as a result of their participation. These changes were attributed to psychoeducation and to learning new skills, supporting existing literature in this area. There was however an additional focus on the importance of interpersonal support from both other families and from therapists which was highlighted more than might be expected from existing literature. The relationships formed within the groups were experienced as supportive and encouraging and contributed to many parents feeling that their experiences had been validated and normalised. There was also a sense that many participants would have preferred a longer lasting or more intensive interaction. This is in contrast to the efforts of many service to provide FBTs which are more condensed and brief in nature.

In terms of implications for services, it may be important to consider the way that families are introduced to the concept of FBTs, both to ensure that they are aware of the purpose of the intervention, but also avoid reinforcing the "blame" that carers often felt in relation to their family member. Involving carers in the development and delivery of interventions may aid this process, as would developing interventions which gave carers opportunity to feedback on some of these issues.

References

* Indicates those studies included within the review.

Baldwin, S.A., Wampold, B.E., & Imel, Z.E. (2007) Untangling the alliance-outcome correlation: exploring the relative importance of therapist and patient variability in the alliance. *Journal of Consulting and Clinical Psychology, 75* (6): 842-52. http://dx.doi.org/10.1037/0022-006X.75.6.842

Ball, J. and Mitchell, P. (2004) A randomized controlled study of cognitive behaviour therapy and behavioural family therapy for anorexia nervosa patients. *The Journal of Treatment & Prevention*, 12: 303–314. doi: 10.1080/10640260490521389

Bannister, P., Bunn, G., Burman, E., & Daniels, J. (2011) *Qualitative Methods in Psychology: A Research Guide.* McGraw-Hill: UK

Bornstein, R. F., & Bowen, R. F. (1995). Dependency in psychotherapy: Toward an integrated treatment approach. *Psychotherapy: Theory, Research, Practice, Training*, *32*(4), 520 doi: 10.1037/0033-3204.32.4.520

Burlingame, G. M., Fuhriman, A., & Johnson, J. E. (2001). Cohesion in group psychotherapy. *Psychotherapy: Theory, Research, Practice, Training*, *38*(4), 373. doi: 10.1037/0033-3204.38.4.373

Cairns, J. C., Styles, L. D., & Leichner, P. (2007). Evaluation of meal support training for parents and caregivers using a video and a manual. *Journal Of The Canadian Academy Of Child And Adolescent Psychiatry. 16*(4), 164-166. Retrieved from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2247457/

Collier, D. A., & Treasure, J. L. (2004). The aetiology of eating disorders. *The British Journal of Psychiatry*, *185*(5), 363-365. doi: 10.1192/bjp.185.5.363

Coomber, K., & King, R. M. (2012). Coping strategies and social support as predictors and mediators of eating disorder carer burden and psychological distress. *Social Psychiatry And Psychiatric Epidemiology*, *47*(5), 789-796. doi:10.1007/s00127-011-0384-6

Cordero, E. D., & Israel, T. (2009). Parents as protective factors in eating problems of college women. *Eating Disorders*, *17*(2), 146-161. doi: 10.1080/10640260802714639

Dare, C., Eisler, I., Russell, G., Treasure, J., & Dodge, L. (2001). Psychological therapies for adults with anorexia nervosa: Randomised controlled trial of out-patient treatments. *The British Journal of Psychiatry, 178*(3), 216-221. doi: 10.1192/bjp.178.3.216

Downs, K. J., & Blow, A. J. (2013). A substantive and methodological review of family-based treatment for eating disorders: The last 25 years of research. *Journal Of Family Therapy, 35*(Suppl 1), 3-28. doi:10.1111/j.1467-6427.2011.00566.x

Eisler, I. (2005). The empirical and theoretical base of family therapy and multiple family day therapy for adolescent anorexia nervosa. *Journal of Family Therapy, 27*(2), 104-131. doi: 10.1111/j.1467-6427.2005.00303.x

Eisler, I., Dare, C., Hodes, M., Russell, G., Dodge, E., & Le Grange, D. (2000). Family therapy for adolescent anorexia nervosa: the results of a controlled comparison of two family interventions. *Journal of Child Psychology and Psychiatry, 41*(06), 727-736. doi: 11039685

Fowler, S. L. (2014). Dependency, psychopathology, and difficult doctor-patient relationships in primary care patients. *Doctoral dissertation*. University of Detroit

*Goodier, G. G., McCormack, J., Egan, S. J., Watson, H. J., Hoiles, K. J., Todd, G., & Treasure, J. L. (2014). Parent skills training treatment for parents of children and

adolescents with eating disorders: A qualitative study. *International Journal Of Eating Disorders*, *47*(4), 368-375. doi:10.1002/eat.22224

Gowers, S., & Bryant-Waugh, R. (2004). Management of child and adolescent eating disorders: the current evidence base and future directions. *Journal of Child Psychology and Psychiatry*, *45*(1), 63-83 10.1046/j.0021-9630.2003.00309.x

Haigh, R., & Treasure, J. (2003). Investigating the needs of carers in the area of eating disorders: Development of the Carers' Needs Assessment Measure (CaNAM). *European Eating Disorders Review*, *11*(2), 125-141. doi:10.1002/erv.487

Hallberg J. R. (2009) Moving nursing research forwards towards a stronger impact on health care practice. *International Journal of Nursing Studies 46*, 407–412. doi: 10.1016/j.ijnurstu.2009.02.005

Hannes, K. (2011) Chapter 4: Critical appraisal of qualitative research. In: J. Noyes, A. Booth, K. Hannes, A. Harden, J. Harris, S. Lewin, & C. Lockwood (editors), *Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions.* Retrieved from: http://cqrmg.cochrane.org/supplemental-handbook-guidance

Hepworth, J. (1999). *The social construction of anorexia nervosa*. Sage: UK.

Hibbs, R., Rhind, C., Leppanen, J., & Treasure, J. (2014). Interventions for caregivers of someone with an eating disorder: A meta-analysis. *International Journal of Eating Disorders*. doi:10.1002/eat.22298

Hill, A. J., & Franklin, J. A. (1998). Mothers, daughters and dieting: investigating the transmission of weight control. *British Journal of Clinical Psychology*, *37*(1), 3-13. doi: 10.1111/j.2044-8260.1998.tb01275.x

Holtkamp, K., Herpertz-Dahlmann, B., Vloet, T., & Hagenah, U. (2005). Group Psychoeducation for Parents of Adolescents with Eating Disorders: The Aachen Program. *Eating Disorders*, *13*(4), 381-390. doi:10.1080/10640260591005263

Krautter, T., & Lock, J. (2004). Is manualized family-based treatment for adolescent anorexia nervosa acceptable to patients? Patient satisfaction at the end of treatment. *Journal of Family Therapy*, *26*(1), 66-82. doi:10.1111/j.1467-6427.2004.00267.x

Lester, R.J. (2007). Critical therapeutics: Cultural politics and clinical reality in two eating disorder treatment centers. *Medical Anthropology. 21,* 368-387. Retrieved from: http://www.jstor.org/stable/4499740

Lock, J., Agras, W. S., Bryson, S., & Kraemer, H. C. (2005). A comparison of short-and long-term family therapy for adolescent anorexia nervosa. *Journal of the American Academy of Child & Adolescent Psychiatry*, *44*(7), 632-639 doi: 10.1097/01.chi.0000161647.82775.0a

*Macdonald, P., Murray, J., Goddard, E., & Treasure, J. (2011). Carer's experience and perceived effects of a skills based training programme for families of people with eating disorders: A qualitative study. *European Eating Disorders Review*, *19*(6), 475-486. doi:10.1002/erv.1065

*Macdonald, P., Rhind, C., Hibbs, R., Goddard, E., Raenker, S., Todd, G., & Treasure, J. (2014). Carers' assessment, skills and information sharing (CASIS) trial: A qualitative study of the experiential perspective of caregivers and patients. *European Eating Disorders Review*, *22*(6), 430-438. doi:10.1002/erv.2320

McCormack, A. (2010). Individuals with eating disorders and the use of online support groups as a form of social support. *Computers Informatics Nursing*, *28*(1), 12-19. doi: 10.1097/NCN.0b013e3181c04b06

McLean, N., Griffin, S., Toney, K., & Hardeman, W. (2003). Family involvement in weight control, weight maintenance and weight-loss interventions: a systematic review of randomised trials. *International Journal of Obesity*, *27*(9), 987-1005. doi:10.1038/sj.ijo.0802383

Micali, N., Hagberg, K.W., Petersen, I., & Treasure, J. (2013) The incidence of eating disorders in the UK in 2000–2009: findings from the General Practice Research Database. *British Medical Journal* 3(5), e002646. doi: 10.1136/bmjopen-2013-002646

Minuchin, S., Baker, L., Rosman, B. L., Liebman, R., Milman, L., & Todd, T. C. (1975). A conceptual model of psychosomatic illness in children: Family organization and family therapy. *Archives of General Psychiatry*, *32*(8), 1031-1038. doi:10.1001/archpsyc.1975.0176026009500

Nasser, M., Katzman, M., & Gordon, R. (2001). *Cultures in transition: eating disorders as a global marker*. London: Routledge

National Collaborating Centre for Methods and Tools (2011). *Critical appraisal tools to make sense of evidence*. Hamilton, ON: McMaster University. Retrieved from http://www.nccmt.ca/registry/view/eng/87.html.

National Institute for Health and Care Excellence (NICE) (2013). *Patient and public involvement policy*. NICE: UK

Noblit, G. W., & Hare, R. D. (1988). *Meta-Ethnography: Synthesizing Qualitative Studies*. Sage Publications: London, UK.

Noorani, T. (2013). Service user involvement, authority and the 'expert-by-experience' in mental health. *Journal of Political Power*, *6*(1), 49-68. doi: 10.1080/2158379X.2013.774979

*Patel, S., Shafer, A., Brown, J., Bulik, C., & Zucker, N. (2014). Parents of children with eating disorders: Developing theory-based health communication messages to promote caregiver well-being. *Journal Of Health Communication*, *19*(5), 593-608. doi:10.1080/10810730.2013.821559

Public Health Resource Unit (2006) Critical Appraisal Skills Programme (CASP): Making sense of evidence. Public Health Resource Unit: England; Retrieved from: http://www.casp-uk.net/wp- content/uploads/2011/11/CASP_ Qualitative _Appraisal_ Checklist_14oct10.pdf

Rapin, L. S. (2004). Guidelines for ethical and legal practice in counseling and psychotherapy groups. In: J. L. DeLucia-Waack, C. R. Kalodner, & M. Riva, (Eds.). (2013). *Handbook of group counseling and psychotherapy*. (pp. 151-165) UK: Sage Publications.

Rhodes, P., Baillee, A., Brown, J., & Madden, S. (2008). Can parent-to-parent consultation improve the effectiveness of the Maudsley model of family-based treatment for anorexia nervosa? A randomized control trial. *Journal of Family Therapy*, *30*(1), 96-108. Doi: 10.1111/j.1467-6427.2008.00418.x

*Rhodes, P., Brown, J., & Madden, S. (2009). The Maudsley Model of Family-Based Treatment for Anorexia Nervosa: A Qualitative Evaluation of Parent-to-Parent Consultation. *Journal Of Marital And Family Therapy*, *35*(2), 181-192

Rogers, C.R. (1957). The necessary and sufficient conditions of therapeutic personality change. *Journal of Consulting Psychology, 21* (2): 95-103. doi: 10.1037/h0045357

Rodgers, R., & Chabrol, H. (2009). Parental attitudes, body image disturbance and disordered eating amongst adolescents and young adults: A review. *European Eating Disorders Review*, *17*(2), 137-151. doi: 10.1002/erv.907

Schmidt, U., Lee, S., Beecham, J., Perkins, S., Treasure, J., Yi, I., & Eisler, I. (2007). A randomized controlled trial of family therapy and cognitive behavior therapy guided self-care for adolescents with bulimia nervosa and related disorders. *American Journal of Psychiatry, 164*(4), 591-598. Retrieved from: http://ajp.psychiatryonline.org/doi/pdf/10.1176/ajp.2007.164.4.591

Sepulveda, A. R., Graell, M., Berbel, E., Anastasiadou, D., Botella, J., Carrobles, J. A., & Morandé, G. (2012). Factors Associated with Emotional Well-being in Primary and Secondary Caregivers of Patients with Eating Disorders. *European Eating Disorders Review, 20*(1), e78-e84. doi:10.1002/erv.1118

Sepulveda, A. R., Lopez, C., Macdonald, P., & Treasure, J. (2008). Feasibility and acceptability of DVD and telephone coaching-based skills training for carers of people with an eating disorder. *International Journal Of Eating Disorders, 41*(4), 318-325. doi:10.1002/eat.20502

Smith, A., & Cook-Cottone, C. (2011). A Review of Family Therapy as an Effective Intervention for Anorexia Nervosa in Adolescents. *Journal Of Clinical Psychology In Medical Settings, 18*(4), 323-334. doi:10.1007/s10880-011-9262-3

Spettigue, W., Maras, D., Obeid, N., Henderson, K. A., Buchholz, A., Gomez, R., & Norris, M. L. (2014). A Psycho-Education Intervention for Parents of Adolescents With Eating Disorders: A Randomized Controlled Trial. *Eating Disorders*, 20(2) 1-16. doi: 10.1080/10640266.2014.940790

*Tierney, S. (2005). The Treatment of Adolescent Anorexia Nervosa: A Qualitative Study of the Views of Parents. *Eating Disorders, 13*(4), 369-379. doi:10.1080/10640260591005254

Treasure, J., & Schmidt, U. (2013). The cognitive-interpersonal maintenance model of anorexia nervosa revisited: a summary of the evidence for cognitive, socio-emotional and interpersonal predisposing and perpetuating factors. *Journal of Eating Disorders*, *1*(13), 10. Retrieved from: http://www.biomedcentral.com/content/pdf/2050-2974-1-13.pdf

Treasure, J., Smith, G., & Crane, A. (2007). *Skills-based learning for caring for a loved one with an eating disorder: The new Maudsley method*. London: Routledge

Ventura, A. K., & Birch, L. L. (2008). Does parenting affect children's eating and weight status?. *International Journal of Behavioral Nutrition and Physical Activity*, *5*(1), 15. doi:10.1186/1479-5868-5-15

*Voriadaki, T., Simic, M., Espie, J., & Eisler, I. (2015). Intensive multi-family therapy for adolescent anorexia nervosa: Adolescents' and parents' day-to-day experiences. *Journal Of Family Therapy*, *37*(1), 5-23. doi:10.1111/1467-6427.12067

Wade, T. D., Treasure, J., & Schmidt, U. (2011). A case series evaluation of the Maudsley Model for treatment of adults with anorexia nervosa. *European Eating Disorders Review*, *19*(5), 382-389. doi: 10.1002/erv.1078

Walsh, D., & Downe, S. (2005). Meta-synthesis method for qualitative research: a literature review. *Journal of Advanced Nursing*, *50*(2), 204-211. doi: 10.1111/j.1365-2648.2005.03380.x

*Whitney, J., Currin, L., Murray, J., & Treasure, J. (2012). Family Work in Anorexia Nervosa: A Qualitative Study of Carers' Experiences of Two Methods of Family Intervention. *European Eating Disorders Review*, *20*(2), 132-141. doi:10.1002/erv.1077

Willig, C. (2013). *Introducing qualitative research in psychology*. McGraw-Hill: UK

Zabala, M. J., Macdonald, P., & Treasure, J. (2009). Appraisal of caregiving burden, expressed emotion and psychological distress in families of people with eating disorders: a systematic review. *European Eating Disorders Review*, *17*(5), 338-349 doi: 10.1002/erv.925

Zucker, N. L., Ferriter, C., Best, S., & Brantley, A. (2005). Group parent training: a novel approach for the treatment of eating disorders. *Eating Disorders*, *13*(4), 391-405. doi: 10.1080/10640260591005272

Figure 1: A flow diagram indicating the number of journal articles found at each stage of the search process.

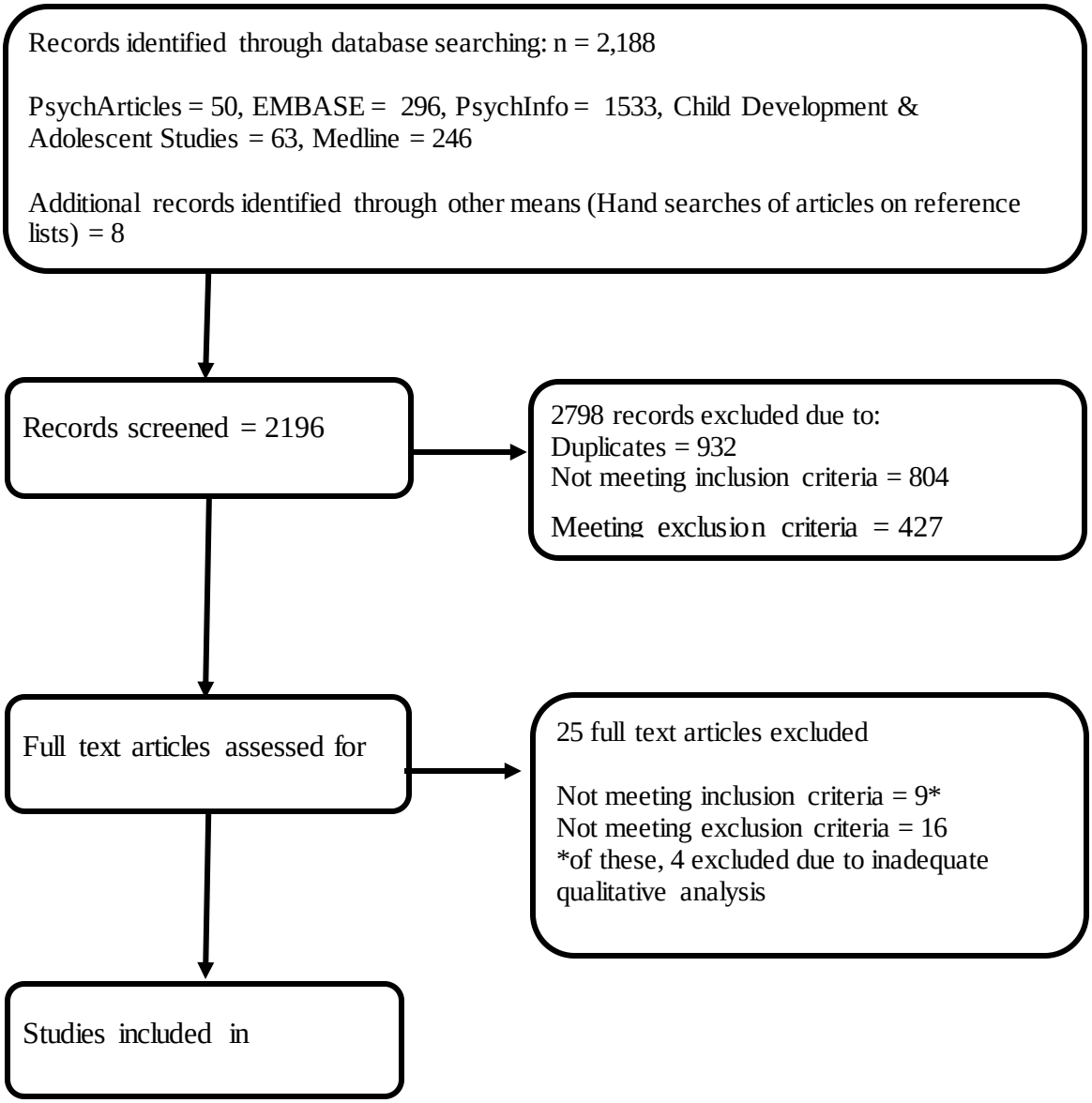

Table 1: Study Characteristics

Authors	Year	Nationality	Number of Participants	Average Age of person with ED (Years)	Average duration of ED at start of intervention	Participants relationship to the person with an ED	Type of Analysis	Method of interview
Goodier et al.	2014	Australia	11	13.3 (SD = 0.83, Range = 11–14)	5.8 months (SD 2.2 months)	6 mothers, 1 step-mother, 5 fathers	Inductive Thematic Analysis	Semi-structured phone interviews
Macdonald et al.	2011	UK	19	23 (Range = 15–51)	Average not specified (Range = 5 months and 32 years)	8 mothers, 6 fathers, 2 sisters, 3 partners	Interpretative Phenomenolo-gical Analysis	Semi-structured interviews
Macdonald et al.	2014	UK	101	26.88 (SD = 10.03)	9.39 years (SD = 8.31 years)	All were primary caregivers	Thematic Analysis	Written responses
Patel et al	2014	USA	19	Not specified	Not specified	15 mothers, 4 fathers	Constant Comparative Method	Semi-structured interviews
Rhodes, Brown & Madden	2009	Australia	34	14 (Range = 12.2–16.1)	Less than one year (Range = <1 year - >two years)	14 parent pairs, 6 single parent attendees (gender not stated)	Thematic Analysis	Semi-structured interviews

Tierney	2005	UK	14	Average not specified (Range = 12-19)	Average not specified (Range = 6 months - 6 years)	8 mothers, 6 fathers	Thematic Analysis	Semi-structured interviews
Voriadaki et al.	2015	UK	10	Average not specified (Range = 15-16)	Not specified	6 mothers 4 fathers	Interpretative Phenomenological Analysis	Focus Group
Whitney et al.	2012	UK	23	25 (SD = 9 Range = 18–53)	8.7 years (SD = 5.4 years, Range = 2-20 years)	17 parents, 4 siblings, one partner, one daughter,	Interpretative Phenomenological Analysis	Semi-structured interviews

Table 2: Intervention Details

Study Name	Intervention Details	Type of Intervention	Underlying Principle	Delivered By
Goodier et al. (2014)	Two day workshop, Parent Skill s Training Treatment (PSTT), group training including meals over two consecutive days, practical skills based on motivational interviewing. Participants asked to read two chapters of "skills based learning for a loved one with an Eating Disorder" beforehand, copies of slides and materials provided.	Multi-group	Maudsley Method (adapted)	Senior clinical team members in the Child and Adolescent Mental Health Service (CAMHS)
Macdonald et al. (2011)	Five psycho-educational DVDs and a book given to participants, with material delivered over six evening sessions, two hours in length each. A coaching group received an additional three telephone support sessions - where coaching was based on motivational interviewing techniques	Single family	The New Maudsley Method	Co-facilitated between health professionals (non-specified) and "expert carers"
Macdonald et al. (2014)	Experienced Caregivers Helping Others (ECHO), skills training, guided self-help intervention, added in addition to treatment as usual for service-users. Carers are encouraged to reflect on their responses to the illness and to build awareness about how altering their behaviour could have positive implications. They are also taught to be role models and to engage in self-care and reflective practices.	Single family	Experienced Carers Helping Others (ECHO)	Expert carers, alongside health professionals (non-specified)
Patel et al. (2014)	Varied - included reports from parents who had experienced a range of interventions - both in- and out-patient. These were all family based interventions, with no specific details of interventions given.	Undefined/ variable	Varied	Varied
Rhodes, Brown & Madden (2009)	Treatment as usual, alongside parent-to-parent consultations facilitated by a therapist. These consultations were three hours in length and included a structured interview building on consultant experiences and including role-plays	with parent-to-parent consultation	Maudsley Method (adapted)	Therapists alongside parents providing consultation
Tierney (2005)	All families in the study had taken part in family-based therapy. They had a child who had experienced in- and out-patient services and were not drawn from the same service	Single family therapy	Various	Various
Voridaki et al. (2015)	Six families took part in a multi-family therapy, which consisted of ten days of therapy over nine months, with the first four days being consecutive within the first week. The treatment programme involved a range of psychotherapeutic interventions utilising experiential and creative activities and psycho-education, as well as daily multi-family meals.	Multi-family group	Maudsley Method (adapted)	Two experienced family therapy clinicians and two trainee family therapists.

Whitney et al. (2012)	Participants took part either in individual family work or in multi(dual)-family day workshops - both provided as a supplement to inpatient care. Individual family therapy consisted of 18 hours worth of contact delivered in 1-2 hour sessions, with three follow-up sessions. A combination of psycho-education, normalising and management strategies are used. In multi-family therapy, families receive a very structured intervention delivered over two days, where families are encouraged to learn from each other about how to support their child.	Comparison of individual and dual-family workshops	Family Therapy	Six experienced ED therapists from different backgrounds including social work, nursing and doctors, all with training in family work.

Table 3: Illustration of theme development for theme 1 “we’re different as a family now”

	Goodier et al. (2014)	Macdonald et al. (2011)	Macdonald et al. (2014)	Patel et al. (2014)	Rhodes, Brown & Madden (2009)	Tierney (2005)	Voriadaki et al. (2015)	Whitney et al. (2012)
We're different as a family now								
Open/improved communication	*	*	*				*	*
Improved relationships	*	*	*		*		*	*
Improved skills	*	*	*		*	*	*	*
Externalising	*	*		*	*		*	
Improved functioning of SU		*				*		*
Feeling empowered	*			*				
More self-reflection			*		*		*	*
Reduced anxiety/stress		*	*					*
Greater knowledge/understanding		*	*		*			*
Positive perceptions of care		*		*				
Less ED talk		*						
Specific Skill Acquisition	*		*		*		*	*
Practical activities	*							*
Supporting materials helpful	*							
Consolidating learning	*				*			
Supporting independence		*		*	*			
Control over intervention	*	*						*
Reflecting on progress	*		*				*	
Therapist mediates with parents					*			
Therapist skills			*		*	*		

Table 4 – Quality Appraisal

	Domains Checklist for Measuring Quality										
	Clear Statement of Aims	**Qualitative Methodology Appropriate**	**Research Design Appropriate**	**Recruitment Strategy Appropriate**	**Data Collected in way which addressed question**	**Researcher/ Participant Relationship Addressed**	**Ethical Issues Considered**	**Rigorous Data Analysis**	**Clear Statement of Findings**	**How Valuable is the Research**	**Total Score**
Maximum Score	**2**	**2**	**2**	**2**	**2**	**2**	**2**	**2**	**2**	**2**	**20**
Goodier et al. (2014)	2	2	2	1	2	2	2	2	2	2	19
Macdonald et al. (2011)	1	2	2	2	2	1	1	2	2	2	17
Macdonald et al. (2014)	2	2	1	2	1	1	1	2	2	1	15
Patel et al. (2014)	2	2	1	2	1	1	1	1	1	1	13
Rhodes, Brown & Madden (2009)	2	2	2	2	2	1	2	2	2	2	19
Tierney (2005)	2	2	2	2	2	2	2	2	2	2	20
Voridaki et al. (2015)	2	2	2	2	2	1	2	2	2	1	18
Whitney et al. (2012)	2	2	2	2	2	1	2	2	2	2	19

Table 5 – Initial Themes from Studies

Superordinate Theme	Subordinate Themes
We're different as a family now	Open/improved communication
	Improved relationships
	Improved skills
	Externalising
	Reduces burden
	Improved functioning of service user
	Feeling empowered
	More self-reflection
	Reduced anxiety/stress
	Greater knowledge/understanding
	Positive experiences
	Positive perceptions of care
	Less ED talk
	Specific Skill Acquisition
	Practical activities
	Supporting materials helpful
	Consolidating learning
	Supporting independence
	Control over intervention
	Reflecting on progress
	Physical processes
	Therapist mediates with parents
	Therapist skills
Finding strength in interactions with others	Group Dynamics
	Group safety
	Awareness of family positions
	Conflict in session
	Family dynamics
	Working with families
	Feeling supported and validated
	Personal connection with facilitator
	Sharing experiences
	Normalisation
	Affirmation
	Feeling supported
	Encouraging
	Family dynamics in group work
	Support for fathers
	Prefer separate session
	Engaging service users

	Including whole family
	Inconsistencies between carers
	Impact on wider family
We aren't there yet	Suggestions for improvement
	Balancing content - theory vs. practice
	Duration of intervention
	Structure of interventions
	Ongoing difficulties
	Stages of recovery
	Concerns for future
	Implementing in real world
	Negative elements of intervention
	Training not inclusive
	Facilitator criticisms
	Content irrelevant
	Feeling overwhelmed by content
	Negative Perceptions of care
	Negative experiences
	Criticism of role plays
	Exclusive AN focus
	Negative impact of intervention
	Deterioration in communication/rels
	Lack of progress
	Intervention ineffective
	Cause and effect

Appendix A: Author Guidelines for Qualitative Health Research

http://mc.manuscriptcentral.com/qhr

Manuscript Submission Guidelines: *Qualitative Health Research* (QHR)

Qualitative Health Research (*QHR*) is an international, interdisciplinary, refereed journal for the enhancement of health care and furthering the development and understanding of qualitative research methods in health care settings. We welcome manuscripts in the following areas: the description and analysis of the illness experience, health and health-seeking behaviors, the experiences of caregivers, the sociocultural organization of health care, health care policy, and related topics. We also consider critical reviews; articles addressing qualitative methods; and commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.
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This Journal recommends that authors follow the Uniform Requirements for Manuscripts Submitted to Biomedical Journals formulated by the International Committee of Medical Journal Editors (ICMJE)

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Each issue of QHR provides readers with a wealth of information - book reviews, commentaries on conceptual, theoretical, methodological and ethical issues pertaining to qualitative inquiry as well as articles covering research, theory and methods in the following areas:
Description and analysis of the illness experience

Experiences of caregivers
Health and health-seeking behaviors
Health care policy
Sociocultural organization of health care

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Mixed Methods: This section includes qualitatively-driven mixed-methods research, and qualitative contributions to quantitative research.
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Evidence of Practice: Theoretical or empirical articles addressing research integration and the translation of qualitatively derived insights into clinical decision-making and health service policy planning.
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(ii) Drafted the article or revised it critically for important intellectual content,
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Participant descriptors should not be listed individually. Because qualitative research is descriptive, it is recommended that participant quotations not be linked to identifiers in the manuscript.

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The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed Consolidated Standards of Reporting Trials (CONSORT) flow chart as a cited figure, and a completed CONSORT checklist as a supplementary file.

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Vanessa Shannon, Managing Editor, vshannonqhr@gmail.com.

Submitted In Partial Fulfilment Of The Lancaster University Doctorate In Clinical Psychology, June 2015

Section Two – Research Paper

How Adolescents Experience Treatment And Intervention For Restrictive Eating Disorders: Keeping Social Identity In Mind

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Prepared for submission to International Journal of Eating Disorders (see Appendix A for author guidelines).

Abstract

Objective**:** This study explored the way in which adolescents experience eating disorder services and interventions and related this to their developing social identity.

Method**:** To achieve this, semi-structured interviews were held with eight female adolescents who attended eating disorder services in the North West. Interviews were analysed using thematic analysis.

Results**:** The three main themes identified were: a) battling with the identity of having an eating disorder; b) the ups and downs of deciding to recover; and c) I want to be treated like a normal person.

Discussion**:** These themes were discussed within the context of existing literature into social identity and of service experiences. Ways in which services could consider social identity within interventions and treatment for adolescents with anorexia nervosa were considered.

How adolescents experience treatment and intervention for restrictive eating disorders: keeping social identity in mind

Eating disorders (EDs) are conditions which can have a long lasting and profound impact on the lives of those who experience them (Steinhausen, 2002). Most people with EDs begin experiencing difficulties during adolescence (Hoek & van Hoeken, 2003) and the difficulties of engaging young people with an anorexia nervosa (AN) diagnosis in services have been well documented (Fassino & Abbate-Daga, 2013) with estimates of the number of people with AN who "drop out" from services ranging between 20% and 73% (Kaplan & Garfinkel, 1999). This engagement is important to consider as evidence suggests that "recovery" from an ED is more likely if support is offered quickly (Treasure & Russel, 2011)

Bardone-Cone et al. (2010) examined physiological and psycho-social functioning amongst service users who considered themselves "recovered". They suggested that interventions supporting "full recovery" with a reduced chance of relapse would encompass exploring body mass index (BMI), weight and shape, as well as thinking about psychological aspects of recovery. While there is a lack of clear consensus on what recovery from an ED might look like (Hertzog et al., 1993; Walsh, 2008), this definition by Bardone-Cone et al. brings together elements discussed elsewhere (Bachner-Melman, Zohar, Ebstein, & Bachar, 2007; Couturier & Lock, 2006).

Intervening during adolescence when unusual eating patterns first start to manifest could have positive implications. Evidence suggests that there are distinctions in the way in which EDs are addressed within adult and adolescent services, for example family therapy approaches are more robustly supported within child and adolescent populations (Treasure & Russell, 2011). Issues relating to social identity formation and peer relationships have been identified as important within this age group (Offord, Turner & Cooper, 2006).

These studies have implications for services, in that the importance of developing an understanding of a person as a whole, including a person's identity is highlighted. Identity issues have been explored in relation to the development and maintenance of EDs. Different frameworks have been used to aid this exploration, including the stage theory of identity development (Erikson, 1968, Marcia, 1966), self-psychological perspectives (Kohut, 1971) and social identity theory (Tajfel, 1982). These will be briefly explored here.

Erikson (1968) described the human life cycle in terms of distinct phases of ego development. Erikson proposed that each stage of ego development is accompanied by a crisis where the psychological needs of an individual conflict with the demands placed upon them by society. Successful completion of each stage results in a healthy personality, while conflict and failure to complete a stage can result in a reduced ability to complete further stages and to achieve a healthy personality. Auslander and Dunham (1996) drew on Erikson's theory and suggested that EDs may partly be the result of an individual failing to overcome the "identity vs role confusion" stage of identity development, a stage thought to be of particular importance during adolescence. They point to commonalities between people who had a diffused identity status and who had an ED diagnosis.

While Erikson framed identity as a stage process, self-psychological perspectives on identity (Kohut, 1977) understand identity as a psychological structure which is shaped by experiences, but also a means through which to understand experiences (Strober, 1991). The theory suggests that when growing up, a young person is denied the opportunity for autonomous functioning by their parenting in order to protect them and keep them safe. During adolescence when responsibility shifts and an individual is faced with feelings of incompetence and self-doubt. This makes it difficult to find a new sense of self (Kohut, 1977). Bruch (1978) suggests that during this period of conflict an adolescent might turn to body weight in order to seek self-definition, as this is a construct which is highly culturally

valued (Bruch, 1981). This approach has been supported through clinical material and case studies (e.g. Bruch, 1979, Strober, 1991).

An area that has received comparatively little attention is that of social identity. Social identity theory proposes that in order to enhance or maintain positive self-esteem individuals have a need to achieve, maintain or enhance a positive social identity in relation to others (Tajfel, 1982; Tajfel & Turner, 1979). In order to strengthen and protect individual self-image a process of enhancing the status of the in-group or discriminating against an out-group may take place (Tajfel & Turner, 1979). This process consists of three stages. Firstly, social categorisation involves the attribution of social labels or categories to groups of people or phenomena which meet our pre-existing concepts. Secondly, social identification is the process through which an individual adopts the identity of the group to which they categorise themselves as belonging to. Finally, social comparison involves maintaining self-esteem through ensuring that the in-group compared favourably to other groups (Tajfel & Turner, 1979). In the case of EDs, an individual who has categorised themselves as having an ED will likely then adopt that identity and act in ways which conform to the expected norms of this group. In order to maintain positive self-esteem in relation to this identity an ED identity will be seen as positive. This is supported by research suggesting that some people with an ED diagnosis will see themselves as "special" and superior to others without an ED (Rich, 2006).

While research has investigated the role of wider identity impairment in the development and maintenance of EDs (Bruch, 1978; Kohut, 1977; Stein & Corte, 2007) and has considered the role social identity in maintaining EDs (Giles, 2006; Ison & Kent, 2010; Rich, 2006), little attention has been given to the role of social identity in the development of an ED. Being slim is often associated culturally with control, success and positive achievement (Brownell, 2001). These are positive characteristics and may be categorised as

desirable, leading to a pressure to lose weight or to restrict eating in order to conform to this ideal "in group" of thinness. For some young people these pressures may be keenly felt and belonging to this group may take priority over other identities –perhaps due to an individual self-concept or self-esteem that is unstable or inconsistent (Stein & Corte, 2007). When this process of using weight loss as a form of control becomes embedded an individual may then act to maintain positive self-esteem through the process of social identification and re-evaluating their views of having an ED.

In terms of ED maintenance and social identity, Giles (2006) explored the way in which individuals with EDs use online "pro-Ana" websites. He suggested that an ED diagnosis might allow people to be part of a special group from which they get positive reinforcement. This reinforcement might encourage people to want to become and remain attached to an identity as a person with an ED. Rich (2006) explored the identities of adult women with an AN diagnosis and suggested that the more ingrained an ED identity becomes, the greater their "struggle" to leave the diagnosis behind. Stein and Corte (2007) explored the idea of wider identity impairment and reported that a strong identification with an ED diagnosis also makes it harder for individuals to see themselves as someone with an identity not solely reliant on that diagnosis. This idea was supported by Ison and Kent (2010) who explored social identity and EDs and proposed that the way that an individual identifies with their ED might influence their likelihood of engaging in treatment. These ideas have implications for the way in which services relate to people with EDs and merit further exploration within a service context.

It is particularly important to consider the role of adolescence within social identity. Existing research has explored social identity and EDs within adults (Ison & Kent, 2010; Rich, 2006; Stein & Corte, 2007). However, adolescence has been described as a time during which social identity conflicts are at their peak (Berndt, 2014) and the desire to be part of the

in-group is at its strongest in comparison to any other stage of life (Tarrant et al., 2001). When individuals first start to experience an ED there is evidence to suggest that they may withdraw from others, and this may partly relate to physical restrictions on mobility or energy levels (Fairburn & Harrison, 2003). This may mean that they have limited other social groups with which to identify other than those in a similar position to themselves. If we consider that social pressures are crucial at this point then belonging to an ED group may gain increased importance. The differential experiences which might be present within this age group suggest that research in this area would be beneficial.

In order to explore social identity within EDs it is important to consider the methodology which is best able to reflect this phenomenon. Qualitative methodologies are able to explore individual experiences in a way that quantitative methodologies cannot (Pathak, Jena, & Kalra, 2013). While measures of cognitive organisational-identification (social identity) have been developed (Bergami & Bergozi, 2000), quantitative measures tend to think about identity at a particular static moment in time. In order to think about how social identity might evolve, as is intended here, qualitative methods are better suited.

The aim of the study is to build on existing findings by investigating how social identity relates to the way in which EDs manifest during adolescence. Thematic analysis will be used to explore young people's social identity and how this relates to the way that they experience and engage with services (Braun & Clarke, 2006). The main research question was: "how do adolescents experience social identity in relation to attending ED services".

Method

Design

This study used a qualitative design. Thematic analysis is a method which can be used within a range of theoretical frameworks and was therefore deemed an appropriate

choice for this study, where participant reports were collected through semi-structured interviews and themes were generated from a critical realist phenomenological perspective (Braun & Clarke, 2006).

Sampling

Participants were drawn from services in two UK National Health Service (NHS) Trusts. These services included both community and inpatient Child and Adolescent Mental Health Services (CAMHS) as well as specialist adult ED services. Inpatient care was usually provided by external private services. Individual teams identified service users who met the inclusion and exclusion criteria and research packs were posted to them. These packs consisted of: a) cover letters from the service[1]; b) letters to parents of those service users aged under 16 explaining the study and giving them the option of passing on the packs to their child or not[1]; c) separate cover letters for service users aged 16 or over[1]; d) information sheets[1]; e) expression of interest form[1] for service users to return if they wished to discuss participating; and f) consent forms[1] for service users to read.

Inclusion and Exclusion Criteria

The inclusion criteria for the study specified that participants must: a) be adolescents aged between 12 and 19 years old: b) have a diagnosis of AN or eating disorder not otherwise specified (EDNOS) with restrictive features: and c) have accessed ED services for a minimum of six months within the last three years. Participants who were under 16 years old required parental permission to take part. The exclusion criteria were defined such that service users would not be invited to participate if: a) they could not speak English; b) they

[1] Please see Section 4: Ethics Section pages 73 – 89 for all recruitment materials

were currently on an inpatient ward; or c) they were identified by services as currently being at high risk emotionally or physically.

Participants

A total of 120 packs were sent out, with 12 service users expressing an initial interest in participating. Eight participants took part in the study. The interviews were analysed on an on-going basis using a process of constant comparison. Braun & Clarke (2006) suggest that data saturation can occur when using thematic analysis at between eight to 12 participants. Here, by the eighth interview there were no new themes being identified. On revisiting the transcripts, all themes were represented within the first seven papers. Guest, Bunce & Johnson (2006) argue that within a relatively homogeneous group it is possible to assume that when no new themes are being identified data saturation has occurred. As such, a decision was made to stop recruitment at this point and no further volunteers were invited to participate.

All participants were females who identified as white British. The mean age of participants was 17 years. Four had accessed inpatient care in addition to community services. Six participants were still accessing ED services in some form. Six participants had received a diagnosis of AN, while two had a diagnosis of EDNOS and would severely restrict their food intake. No participants opted to be accompanied to the interview by an advocate. Table 1 provides a summary of participant information.

(Insert Table 1 here)

Data Collection

Individual semi-structured interviews lasting around an hour were held with all participants. These interviews were held in participants' homes, although they were offered

the option to meet within an alternate location such as a clinic room. An interview schedule[2] was developed in line with the research aims.

All interviews were conducted using a digital recorder. During the interviews the wellbeing of participants was monitored continually for signs of distress or reluctance to discuss topics. In order to ensure the safety of the researcher a colleague was nominated to act as a "buddy". The buddy was contacted at the beginning and end of each interview and a plan was written up that both researcher and buddy would follow[3]. The lone working policy from Lancaster University[3] was also followed. Following the interviews, audio files were transcribed by the researcher and any identifying information about participants was removed.

Analysis

Data was explored and analysed using thematic analysis based on the guidelines proposed by Braun and Clarke (2006). Thematic analysis is a flexible approach which can be applied across a range of epistemological approaches (Braun & Clarke, 2006). Here, principles of phenomenological approaches were used to inform the analysis (Wertz, 2005). Phenomenological approaches privilege the experiences of participants and aim to cultivate an understanding of an individual's personal experiences in order to gain a more in-depth insight into a particular phenomenon (Braun & Clarke, 2006; Holloway & Todres, 2003).

Themes were derived from a critical-realist perspective. That is, it can be assumed that the way in which individuals use language to express their thoughts and describe their behaviour can be said to be reflective of their inner experience (Willig, 1999). This

[2] Please see Section 4: Ethics Section page 62

[3] Please see Section 4 – Ethics Section pages 90-97

perspective acknowledges the role that individuals have in shaping their own perspectives, as well as the impact of wider cultural context upon an individual's perception.

The method adopted within this study aims to reflect this phenomenological and critical realist approach through attempting to be descriptive and letting participant experiences "speak for themselves" rather than applying preconceptions of the phenomenon drawn from scientific theories or hypotheses. The role of wider influences upon participant experiences were considered throughout, and the role of the researcher within the analysis process and the influence that this may have had on results has been discussed below.

The first step in analysis was familiarisation with the data. This was achieved through listening to recordings prior to transcription and transcribing the data manually. The first reading of the transcripts was done with the research question in mind, and the data were then re-visited in order to generate initial codes. The codes were identified inductively, in that they were assumed to be direct representations of the data used as much as possible. An excerpt of a transcript demonstrating the way in which comments were generated can be found in Table 2. Each initial code was then copied to a spreadsheet and allocated an individual cell. These cells were moved around within the spreadsheet in order to start grouping codes into themes.

(Insert Table 2 here).

Once codes had been grouped into initial themes they were grouped into the final categories identified (Table 3). A thematic map was used to aid in the process of generating categories (Figure 1). To ensure that the categories captured all of the generated data they were reviewed several times and compared to the data set. The final stage of the analysis process involved naming and defining each category and summarising their different qualities.

(Insert Table 3 here)

(Insert Figure 1 here)

Rigour

In order to ensure that this research was conducted in a methodologically rigorous way, guidelines for the publication of qualitative research were adhered to (Elliot, Fischer & Rennie, 1999). These guidelines outline considerations necessary during the process of conducting qualitative research and informed each stage of the research process. For example, it was suggested that researchers should outline their own perspective in order to develop an understanding of the way in which researcher perspectives may have influenced results.

Reflexivity involves reflecting on the impact of the researcher on the research process (Yardley, 2008). Here, I recognised that my own personal experience of working within ED services might impact upon my interpretations of participant reports. I had been drawn to research within this area following an observation that service user voices were often unheard or un-listened to within services and this was an on-going frustration. In order to mediate this influence, anonymised transcripts and initial themes were read by the project supervisor. No differences in interpretation were identified and my research supervisor was able to recognise where I had drawn themes from and how they contributed to the overall analysis.

While it is important to consider that the epistemological position of the researcher could have influenced the codes that were generated an attempt was made to allow the data to guide the information gathered. An assumption of a phenomenological approach is that researchers must, as much as possible, try to enter the world of participants and "share" their

experiences (Wertz, 2005). Recognition of pre-existing attitudes and assumptions is an important part of this process.

Ethical Issues

The study was reviewed by the Faculty of Health and Medicine Research and Ethics Committee at Lancaster University as well as by the National Research Ethics Service. It was then approved by the Research and Development offices for each trust that participated in the project. A summary of the key ethics considerations are provided below, with further in-depth discussion provided within the accompanying ethics section.

Risk to Participants

Discussing difficult experiences within research projects can be distressing for participants and it is important for researchers to consider the impact that the interviews can have (Orb, Eisenhauer, & Wynaden, 2000). Smith (1999) described the importance of ensuring that consent is sought continually in order to make it easier for participants to withdraw if the interview content becomes difficult to tolerate. This principle was adhered to throughout this research process.

As part of the debrief process participants were offered the opportunity to discuss their participation. All participants were offered support in relation to managing difficult emotions and were directed to the information sheets which included information about relevant services which they could access if necessary, including helplines and websites.

Results

Three superordinate themes were identified from the data. These were: a) battling with the identity of having an eating disorder; b) the ups and downs of deciding to recover; and c) I want to be treated like a normal person. A summary of the superordinate themes

alongside the subordinate themes which contributed to them is presented in Table 3. Pseudonyms are used throughout.

Battling with the identity of having an eating disorder

Initially many participants did not recognise that they had difficulties with eating and weight which had progressed to the level of meeting the criteria for an ED. Participants spoke of recognising that they had lost weight and of knowing that others were concerned but found it difficult to accept these concerns as valid. This suggests that at this point participants did not consider having an ED to be part of their identity, although others in society may have ascribed this category to them: "Well at first it felt really weird because I didn't properly see myself as ill. I knew something wasn't right but I don't think I thought it was life threatening at that point" (Olivia).

A transition occurred at this stage, whereby participants started changing their outlook and defining themselves as someone with an ED. In terms of social identity, participants re-categorised their understanding of an ED and began to recognise characteristics in themselves that related to their eating behaviours "I saw that I was really controlled about my eating, that I was good at restricting" (Philippa). Slowly, as this sense of self became more ingrained they began to describe people with an ED as "determined" (Sophie) or "strong" (Philippa). Once participants had started to attribute positive characteristics to others with EDs they would start to identify as belonging to this group, and then affirm their identification through seeing people without EDs as "different" and as inferior: "I can do this (keep restricting) and you can't is what you think when you're not in remission" (Amelia)

When participants did embrace an ED diagnosis, for many it became their whole and they felt that it represented them as a person. Some spoke about losing a sense of other

elements that were important to their identity, such as interests or friendships, and focussed completely on the ED diagnosis. Gemma spoke about how she saw herself only in terms of her ED and that she felt that it took over other aspects of her life: "it were my whole, I was like Gemma the anorexic, you know what I mean. It was like my whole, everything I did was to do with my eating disorder" (Gemma). Gemma also spoke about developing AN at such a young age that she couldn't remember life without it, suggesting that she had not had the opportunity to develop a strong sense of identity that did not relate to having an ED: "like I'm 17 now and I've had it since I was 11. It's a long time, nearly half my life has been taken up by something that I didn't really want but I don't know anything else" (Gemma).

People spoke about becoming so attached to the diagnosis that they could not imagine life without it and were not sure how they would fill the gap that it would leave. "Anorexia kind of became my purpose…when I was slowly putting on weight and I thought of not having it, I was like, who am I? I don't know who I am without it" (Amelia). Although participants often reported a strong attachment to the ED diagnosis, many reported feeling "unworthy" as a result of it. This feeling was often inadvertently reinforced by services or by other people around them. For some, this related to the criteria set by services which could inadvertently re-enforce the idea that you had to be "ill enough" to access services:

> I was diagnosed with an eating disorder when my BMI was borderline healthy weight and I just thought oh my god, I can't be diagnosed because I'm not thin enough. So in that month, I lost like a stone and a half and yeah, I ended up in the worst place that I possibly could be. (Philippa)

For some, being around other people with an ED reinforced the feeling of being inferior at having an ED and that other people were better at it because they ate or weighed less: "It just makes you feel like you're worthless and you need to be doing the same and that

they're like a better anorexic than you. You're just a fake anorexic" (Olivia). Participants often had very mixed feelings about being around others with an ED diagnosis, but this theme of competitiveness and inadequacy was common to many. This idea of not being ill enough or thin enough was present at all stages of their ED, even when people were at their most unwell and at their lowest weight.

The results in this theme demonstrate that while initially participants struggled to integrate the idea of having AN into their identity, in part because they did not view themselves as the type of person who might get an ED, it then became an important part of how they saw themselves. Participants initially were dismissive and derogatory about those people with an ED diagnosis, but over time they started to value characteristics common to many people with an ED such as being able to control eating behaviour. As they valued these behaviours they re-categorised having an ED as positive and started to identify with this diagnosis. This process of categorisation and identification is part of a process of social identity formation and was common to many participants. Once it had been accepted a fear of losing the identity became a motivator to remain attached to the diagnosis. Some participants had few other possible groups with which to identify, meaning that the presence of the ED identity was crucial.

The ups and downs of deciding to recover

Before being able to make changes in their lives and addressing their ED many reported that there came a moment of realisation that there was something about the current situation that was not comfortable. For some people this related to thoughts about the future:

> Like going to university, I doubted obviously that I would be able to do things like that. I wanted to do volunteering at that point I wanted to do volunteering in another

> country. I wouldn't have been able to do that, things like having children, meeting new people. (Olivia)

For others, factors such as worrying about other family members or worrying about missing out on life contributed to their decision to change: "I just kind of knew that I didn't want to be like this for the rest of my life" (Hattie). Some felt that services had a very limited role in facilitating this shift in mindset and that the change had to come from within:

> I don't think there is anything really (that services can do), cos I think like that decision to change and like get better, it has to come from you…yeah people can force you to eat…but they can't force you to want to change that mentality and actually want to get better. (Natasha)

In terms of what this "getting better" meant, recovery held different meanings to individuals, but common themes included changing physical weight and no longer having distressing thoughts telling them not to eat. In terms of social identity, some participants also spoke of recovery as re-building a life that had been lost and of reintroducing activities, friendships and experiences that they had been missing. This suggests that for participants, part of the process related to finding other ways to define themselves and other groups with which to identify.

Once the initial decision to change had been made, participants spoke of the difficulty in maintaining this perspective and of the ambivalence that they often experienced. They described battling with themselves to continue eating and of the distress that weight gain could cause:

> Well, I kind of wanted to get better, I think I wanted to get better to a certain point…I didn't really want my eating disorder to go away completely. I was fine with putting a little bit of weight on, but not too much. It was scary. (Natasha)

A common theme for many was the difficulty of maintaining the process of getting better. This ambivalence and "battle" with the ED was difficult to manage: "sometimes I just feel like giving up but then other times I don't want to and it's a bit annoying; some days are better than others." (Sophie).

This theme encapsulates that for participants the process of deciding to recover was challenging. Participants recognised the role of services in providing support during this process but felt that the decision needed to be made independently. However, fulfilling this decision was difficult and participants reported battling with themselves to keep "getting better" – a term which held individual meaning for each participant. Within this process of recovery participants began to find other activities, friendships or groups to identify with. For participants being able to hold on to identities separate to the ED was helpful in maintaining positive eating behaviours and moving away from the all-encompassing nature of the diagnosis.

I want to be treated as a normal person

Wanting to be treated like an individual was central to the experiences of most participants. Being treated like an individual referred to creating individualised care plans rather than generic ones, talking to people about their personal experiences, hopes and goals and not imposing pre-existing pathways where these were not suitable:

> I think it should have been more individualised. Erm, like, you should have had your own meal plan… like at one point I was on the yellow plan and I was gaining about .4 kilos and then they put me on the standard blue plan and I was gaining 2 kilos which was quite a big jump and like it was too much. They should have had … like something more individual for each of us. (Gemma)

While having an ED identity was important to participants, recognition that within this they had individual features was important. This may suggest that while the ED identity was prevalent, participants were still able to hold onto other aspects of their identity. In addition to being treated as individuals, there was a clear preference for services and professionals who addressed everyone as peers by including them in decisions and asking for their opinions. Some felt that this allowed them to be more open and honest, as well as helping them to feel more understood.

> I've had some really really nice ones, who just treat you like a human… and I did notice that they were the ones who helped me a lot more, and then some who were… kind of are more in tune to what's good for you than others. (Hannah)

Some reported feeling that they were not taken seriously by services and some felt that they were perceived as "criminals" (Gemma) or as "crazy" (Sophie). This communication with services was central to helping participants feel heard and validated, which was crucial to many. Occasions where experiences were not valued by services were felt to be detrimental to the recovery process. Participants felt that they had struggled to share their story with others and this had not led to the response which they had expected. Many spoke of having to tell their story multiple times to different professionals and of the frustration that this caused:

> It's really annoying, cos you kind of expect that you tell it once and you're never gonna have to talk about it again, cos it's not a nice thing to talk about… it's repetitive and makes you feel like no one is listening, like no one cares. (Hannah)

This theme captured the way in which participants expressed a preference for those services that provided care which felt individualised and tailored to participant needs. Participants felt that being treated as an individual helped them to make the changes that they

needed to do and helped them to feel listened to, suggesting that even while identifying strongly with an ED identity participants recognised other aspects of themselves. Feeling listened and validated was an important part of this process as was being given choice and control over important decisions relating to care.

Discussion

This study aimed to investigate the way in which adolescents with a restrictive ED experienced treatments and interventions and to think about these experiences within the context of social identity. This work builds upon previous research which has looked at experiences of services (Downs & Blow, 2013; Espindola & Blay, 2009) and social identity and EDs (Ison & Kent, 2010; Rich, 2006; Stein & Corte, 2007) but has not considered how these experiences might relate, especially during adolescence. The results presented here indicate that young people with AN often follow a journey which starts with a denial of the severity of their problems followed by a feeling that their whole identity is consumed by the ED diagnosis. Participants spoke about the way in which they would then struggle to leave this identity, in part due to fears that once it had gone there would be nothing left for them.

Participants spoke of the dilemmas they would often experience in the early stages of their difficulties where they did not recognise that their eating had reached a stage where it was harmful to their health. Ambivalence is well documented within EDs (Britt, Hudson & Blampied, 2004) and participant reports here indicated that this struggle for acceptance was in part related to taking on a new identity as someone with an ED, an identity which was often at odds with the perception that participants had of themselves. Tajfel (1981) state that an individual's social identity may be either beneficial or detrimental to self-esteem. This is dependent on how they evaluate the group that they belong to. Here, participants initially evaluated an ED identity as undesirable and attributed negative connotations to it. Participants spoke about not being "the type" of person who would get an ED. This may

have contributed to their initial reluctance to take on an ED identity. However, over time all participants gradually recognised in people with an ED characteristics that they valued in themselves. This led them to start ascribing positive assertions to the ED group, which contributed to them wanting to take on this identity.

Within the study participants were often given an implicit response from services that they were not "ill enough" yet. For the young people in this study, being able to accept their difficulties and embracing an ED diagnosis was an important step in the recovery process. Being given this message by services that they were "unworthy" of the diagnosis was not deemed helpful and led to further weight loss for some participants. While limited resources and service structures dictate that strict inclusion criteria be in place for those being referred to mental health services (National Institute for Health and Care Excellence, NICE, 2011; American Psychiatric Association, APA, 2012) perhaps the impact of this inability to accept service users in the earlier stages of their difficulties should be considered to help avoid feelings of unworthiness.

The feeling of being unworthy of fitting into the desired in-group was also reported by participants in relation to their experiences of being around other people with EDs. Previous work by Koski (2014) used social movement theory to investigate the use of support groups for individuals with EDs. She reported that while having clear a diagnostic framework was crucial in facilitating involvement and commitment from group members, it also served to strengthen collective and individual illness identities. As individual illness identities were strengthened participants became more committed to the groups, and became more committed to displaying behaviours which would allow them continued group membership – i.e. behaviours associated with an ED diagnosis. This process may mirror that experienced by participants here, who responded to the sense of competitiveness elicited by the groups through further weight loss or restrictive behaviour.

Giles (2006) discussed that within ED online communities, in particular so called "pro-Ana" websites, there exists a hierarchy in terms of which EDs are the most desirable or well-respected. AN sits at the top of this hierarchy and within this there is a desire to demonstrate that you are the "best" anorexic through belonging to a group which experienced the most support or has been the most physically unwell. Giles (2006) suggests that these categories exist within groups outside of the online communities, including within inpatient units. Social identity theory outlines the process of enhancing the status of the in-group and discrimination against an out group in order to enhance social identity (Tajfel, 1982). Here, within the support groups the "in group" of being very thin as a result of AN is seen as ideal and is the identity desired and adopted by many of the adolescents within the study. The process of social comparison then occurs, whereby the restrictive AN in-group is compared favourably against a BN or "recovering" AN out-group. Participants may be judging themselves against this highly restrictive AN standard and will fear being perceived as a "fake anorexic" if they do not meet it. This desire to not be perceived as unworthy of the ED diagnosis could lead to restrictive behaviours, an assumption supported by participants reporting a similar pattern.

Participants who had decided to make changes to their eating, thoughts and behaviours spoke about the difficulty in battling against their AN. A key aspect of this worry was the concern that without the ED there would be nothing meaningful left because the ED had become their whole. Some participants spoke about developing their ED at such a young age that they had not yet developed a sense of themselves before it had taken hold. This idea resonates with the exploration of EDs and self-psychological states conducted by Bruch (1978), where adolescents were said to turn to body weight in order to seek self-definition in the absence of any other way of defining themselves (Bruch, 1979, Strober, 1991).

Social identity is of particular importance during adolescence due to increased peer pressure (Berndt, 2014). Many adolescents have a range of interests (Tarrant et al., 2001) and it has been suggested that the pressure to belong in these different groups and to be accepted is a primary way through which positive social identity is achieved (Tarrant et al., 2001). Within this study, as has been reported elsewhere (e.g., Fairburn & Harrison, 2003), individuals who were beginning to take on symptoms of an ED such as restricting food intake often wanted to hide these symptoms from others. This urge to hide symptoms, alongside possible physical consequences of food restriction such as a lack of energy, led in this case to participants withdrawing from social activities, thereby starting to limit the number of social identities available to participants.

If the social activities of adolescents are severely limited as a result of the ED then it is likely that belonging to the ED in-group gains increased importance. We all belong to multiple social groups at any one time (Hog & Vaughan, 2002). It has been suggested that the strength of identification with any one group can be affected by multiple factors including the level of threat to group identity posed by external factors, or the number of available alternative groups (Hog & Vaughan, 2002). It is also influenced by the value and emotional importance attached to group memberships (Tajfel, 1982). Here, the limited number of alterative identities available to adolescents may aid in strengthening their sense of belonging to the ED in-group. However, participants also communicated a strong sense of wanted to be treated as individuals, suggesting that the ED identity was not the only identity available to them.

Within the study participants reported not feeling heard and validated by the people around them and that this was important as it meant that they felt out of control and that they weren't being taken seriously. For many people, EDs act as a way of gaining control in an otherwise uncontrollable situation (Dalgliesh et al., 2001). It has been suggested that

individuals with an ED may perceive themselves as having less control over external events than do people without an ED diagnosis (Dalgliesh et al., 2001). For participants within this study being in control of their eating was a key part of the social identity of having an ED and they would pride themselves on being able to be "better" at controlling themselves than people without an ED. However, being in control of eating may act as a replacement for a lack of control in other areas (Dalglish et al., 2001) and so through not involving service users in decisions about their care, or not providing them with the information that they need to make informed choices, services may be inadvertently strengthening the role of the ED as the sole form of control.

Many participants spoke about feeling criticised and blamed by services which may have been inadvertently reinforcing the blame discourse that is common in EDs (Crisafulli, Holle, & Bulik, 2008). Participants reported that feeling blamed made them less likely to engage with services, leading to the ED identity becoming even more strongly ingrained in an individual's view of themselves. This is in line with social identity theory which suggests that an individual's sense of belonging to an in-group may be reinforced by perceived attacks from an "othering" out-group (Hog & Vaughan, 2002). Through explicitly or implicitly blaming young people for their own ED their sense of identity as an individual with an ED is likely to be strengthened, which in turn reduces the likelihood of them deciding to leave that identity behind or changing their relationship with the label.

Clinical and Service Implications

There are a number of important clinical implications which should be considered as a result of the study. Firstly, the results here suggest that young people find it difficult to feel rejected from services during the early stages of their difficulties. There may be work to be done here in providing ways to validate young people's experiences when they first seek support, to recognise with them that their difficulties are being taken seriously and that they

are in need of further support. If support cannot be provided by services due to inclusion criteria, then working with parents and young people at this stage to access further resources or external support may be a helpful step in avoiding continued weight loss. Early intervention for ED leads to higher rates of sustained recovery (Treasure & Russell, 2001) and so extending this assumption to the stage before an ED identity is fully ingrained may be a useful approach to consider.

Another area that participants noted as challenging was being alongside other people with an ED. While it may not be possible to avoid placing young people alongside others with similar diagnoses, and indeed this may not be ideal as participants also spoke about the value of support from others, it may be important for services to consider the role of these relationships in strengthening the identification that participants have to particular in-groups.

The findings here may also provide implications for the way in which psychological interventions are chosen and applied within services. Clinical guidelines recommend Family Therapy and Cognitive Behavioural Therapy as primary interventions for adolescents with AN (NICE, 2006; APA, 2012) and other interventions such as Compassion Focussed Therapy, Cognitive Analytic Therapy and Motivational Interviewing are also commonly used alongside more physiological approaches such as medication (Fairburn & Harrison, 2003). These interventions use a range of different approaches to explore the thoughts and cognitions related to an ED. Reports from participants suggested that they generally experienced the interventions as helpful. However, thinking about developing an alternative social identity to the ED identity so strongly entrenched may be a useful way to consolidate some of the findings discussed here. Developing alternative interests and pursuits already forms part of many therapeutic approaches used within ED services (Fairburn, Cooper & Shafran, 2003), and considering the importance of this within the context of social identity may be useful. In particular, helping individuals to nurture and foster alternative identities at

the early stages of their treatment journey may be beneficial in helping to avoid the ED becoming their primary source of social identity.

Participants were keen to stress the importance of being treated with respect and were positive about those clinicians who spent time getting to know them. Clinical psychologists regularly draw upon the so called "common factors" of empathy, warmth and genuine regard (Rogers, 1951) to form and maintain therapeutic relationships. Using these skills to build social identity into formulations may be a useful avenue to help provide individuals with an attractive alternative social identity to the existing fixation with the ED.

Study Limitations

While the results of this study provide information which may be useful in informing treatment and interventions for restrictive EDs, it is important to consider these results within the context of methodological limitations. Firstly, while efforts were made to speak to participants who represented a range of individuals, the sample was drawn from young people who had all accessed services within the same geographical region. Although they had accessed a range of both private and NHS inpatient and outpatient services, it may not be possible to generalise these results more widely.

This study was open to both male and female participants, which was in line with recommendations that ED research should seek and value voices from both genders (Andersen & Holman, 1997). However, although one male service-user did volunteer to participate, he did not choose to take part in the study and so all participants were female. While this is common within ED research (Andersen & Holman, 1997), it is important to note that the experiences of those interviewed may not necessarily be applied to males with EDs. Many more females than males receive an ED diagnosis (Hoek & van Hoeken, 2003), which raises the possibility that being a male with AN may bring its own challenges in

relation to identity formation and development, particularly in relation to developing an identity which is socially acceptable.

Thirdly, as within all qualitative research it is important to consider the impact of the researcher on the accounts given and the experiences shared. Participants were aware that the researcher was training to be a psychologist and although efforts were made to reassure that both positive and negative accounts of psychological interventions would be welcome it is possible that some participants chose to limit their accounts for fear of causing offense. Within the interviews, participants did voice negative feelings about clinical psychology and so it is possible to conclude that many did overcome this potential barrier, however giving them the opportunity to talk to someone from a different background may have yielded different results.

Conclusions

This study aimed to explore the experiences of adolescents with EDs in relation to services and interventions and to explore these results within the context of identity development. The results demonstrated that for many young people their social identity shifts and changes over the course of the ED. The way in which this identity influences their recovery may be affected by services. Factors such as validating experiences, working on alternate identities and helping young people to think about life beyond their ED may all be useful in contributing to sustained recovery.

Currently, services are often restrained by resource factors such as long waiting times or restrictive inclusion criteria. This study suggests that more should be done to work with young people to ensure that these factors do not lead to them feeling rejected or "unworthy" of services. The results here build upon existing research by exploring the way in which identity and experiences of services may overlap and provides a starting point for

services to think about changes that can be made in order to integrate social identity into existing interventions and approaches.

References

Andersen, A. E., & Holman, J. E. (1997). Males with eating disorders: Challenges for treatment and research. *Psychopharmacology Bulletin*, *33*(3), 391. Retrieved from: http://www.ncbi.nlm.nih.gov/pubmed/9550883

Auslander, B. A., & Dunham, R. M. (1996). Bulimia and the diffusion status of ego identity formation: similarities of the empirical descriptors of self and parent. *Journal Of Adolescence*, *19*(4), 333-338. doi:10.1006/jado.1996.0031

Bachner-Melman, R., Zohar, A. H., Ebstein, R. P., & Bachar, E. (2007). The relationship between selflessness levels and the severity of anorexia nervosa symptomatology. *European Eating Disorders Review*, *15*(3), 213-220. doi:10.1002/erv.740

Bardone-Cone, A. M., Harney, M. B., Maldonado, C. R., Lawson, M. A., Robinson, D. P., Smith, R., & Tosh, A. (2010). Defining recovery from an eating disorder: Conceptualization, validation and examination of psychosocial functioning and psychiatric comorbidity. *Behaviour Research And Therapy*, *48*(3), 194-202. doi:10.1016/j.brat.2009.11.001

Bergami, M., & Bagozzi, R. P. (2000). Self-categorization, affective commitment and group self-esteem as distinct aspects of social identity in the organization. *British Journal of Social Psychology*, *39*(4), 555-577. doi: 10.1348/014466600164633

Berndt, T. J. (2014). Friendships in adolescence. In D. Faulkner, K. Littleton & M. Woodhead (eds) *Making sense of social development* (51-71). Routledge: UK

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in psychology*, *3*(2), 77-101. doi: 10.1191/1478088706qp063oa

Britt, E., Hudson, S. M., & Blampied, N. M. (2004). Motivational interviewing in health settings: a review. *Patient Education And Counselling*, *53*(2), 147-155 doi: 10.1016/S0738-3991(03)00141-1

Bruch, H. (1978) *The Golden Cage*, Harvard University Press: Cambridge

Bruch, H. (1979). Developmental deviations in anorexia nervosa. *Israel Annals of Psychiatry and Related Disciplines*, 17, 255–261. Retireved from: http://www.ncbi.nlm.nih.gov/pubmed/94321

Bruch, H. (1981). Developmental considerations of anorexia nervosa and obesity. *Canadian Journal of Psychiatry*, 26, 212–217. Retrieved from: http://www.ncbi.nlm.nih.gov/pubmed/7296431

Colton, A., & Pistrang, N. (2004). Adolescents' experiences of inpatient treatment for anorexia nervosa. *European Eating Disorders Review*, *12*(5), 307-316. doi: 10.1002/erv.587

Couturier, J., & Lock, J. (2006). What is Recovery in Adolescent Anorexia Nervosa? *International Journal Of Eating Disorders*, *39*(7), 550-555. doi:10.1002/eat.20309

Crisafulli, M. A., Von Holle, A., & Bulik, C. M. (2008). Attitudes towards anorexia nervosa: The impact of framing on blame and stigma. *International Journal Of Eating Disorders*, *41*(4), 333-339. doi: 10.1002/eat.20507

Dalgleish, T., Tchanturia, K., Serpell, L., Hems, S., de Silva, P., & Treasure, J. (2001). Perceived control over events in the world in patients with eating disorders: a preliminary study. *Personality and Individual Differences*, *31*(3), 453-460. doi: 10.1016/S0191-8869(00)00150-1

Diehl, M. (1990). The minimal group paradigm: Theoretical explanations and empirical findings. *European Review Of Social Psychology*, *1*(1), 263-292. doi: 10.1080/14792779108401864

Doll, H. A., Petersen, S. E., & Stewart-Brown, S. L. (2005). Eating disorders and emotional and physical well-being: Associations between student self-reports of eating disorders and quality of life as measured by the SF-36. *Quality Of Life Research: An International Journal Of Quality Of Life Aspects Of Treatment, Care & Rehabilitation*, *14*(3), 705-717. doi: 10.1007/s11136-004-0792-0

Downs, K. J., & Blow, A. J. (2013). A substantive and methodological review of family based treatment for eating disorders: The last 25 years of research. *Journal Of Family Therapy*, *35*(Supplement 1), 3-28. doi:10.1111/j.1467-6427.2011.00566.x

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, *38*(3), 215-229. Retrieved from: http://onlinelibrary.wiley.com.ezproxy.lancs.ac.uk/doi/10.1348/014466599162782/epdf

Erikson, E. (1968). *Youth: Identity and crisis.* New York, NY: WW

Espindola, C. R., & Blay, S. L. (2009). Anorexia nervosa treatment from the patient perspective: A metasynthesis of qualitative studies. *Annals Of Clinical Psychiatry*, *21*(1), 38-48. Retrieved from: https://www.aacp.com/pdf%2F2101%2F2101ACP_Review1.pdf

Fairburn, C. G., Cooper, Z., & Shafran, R. (2003). Cognitive behaviour therapy for eating disorders: A "transdiagnostic" theory and treatment. *Behaviour research and therapy*, *41*(5), 509-528. doi: 10.1016/S0005-7967(02)00088-8

Fairburn, C. G., & Harrison, P. J. (2003). Eating disorders. *The Lancet*, *361*(9355), 407-41. doi: 10.1016/S0140-6736(03)12378-1

Fassino, S., & Abbate-Daga, G. (2013). Resistance to treatment in eating disorders: a critical challenge. *BMC Psychiatry*, *13*(1), 282. doi: 10.1186/1471-244X-13-282

Favaro, A., Caregaro, L., Tenconi, E., Bosello, R., & Santonastaso, P. (2009). Time trends in age at onset of anorexia nervosa and bulimia nervosa. *The Journal Of Clinical Psychiatry*, *70*(12), 1715-172110.4088/JCP.09m05176blu

Giles, D. (2006). Constructing identities in cyberspace: The case of eating disorders. *British Journal Of Social Psychology*, *45*(3), 463-477. doi: 10.1348/014466605X53596

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, *18*(1), 59-82. doi: 10.1177/1525822X05279903

Herzog, D. B., Sacks, N. R., Keller, M. B., Lavori, P. W., Von Ranson, K. B., & Gray, H. M. (1993). Patterns and predictors of recovery in anorexia nervosa and bulimia nervosa. *Journal Of The American Academy Of Child & Adolescent Psychiatry*, *32*(4), 835-842. doi: 10.1097/00004583-199307000-00020

Hoek, H. W., & van Hoeken, D. (2003). Review of the prevalence and incidence of eating disorders. *International Journal Of Eating Disorders*, *34*(4), 383-396. doi:10.1002/eat.10222

Hogg, M.A. & Vaughan, G.M. (2002). *Social Psychology (3rd ed.)* London: Prentice Hall.

Holloway, I., & Todres, L. (2003). The status of method: flexibility, consistency and coherence. *Qualitative Research*, *3*(3), 345-357. doi: 10.1177/1468794103033004

Hugo, P., Kendrick, T., Reid, F., & Lacey, H. (2000). GP referral to an eating disorder service: why the wide variation? *British Journal of General Practice, 50*(454), 380-383. Retrieved from: http://bjgp.org/content/bjgp/50/454/380.full.pdf

Hutchinson, S.A., Wilson, M.E., & Wilson, H.S. (1994). Benefits of participating in research interviews. *Journal of Nursing Scholarship, 26*, 161-164. doi: 10.1111/j.1547-5069.1994.tb00937.x

Ison, J., & Kent, S. (2010). Social identity in eating disorders. *European eating disorders Review, 18*(6), 475-485. doi:10.1002/erv.1001.

Jacobson, N. (2001). Experiencing recovery: A dimensional analysis of recovery narratives. *Psychiatric Rehabilitation Journal, 24*(3), 248-256. doi: 10.1037/h0095087

Kaplan, A. S., & Garfinkel, P. E. (1999). Difficulties in treating patients with eating disorders: a review of patient and clinician variables. *Canadian Journal of Psychiatry, 44*, 665-670. doi: 35400008784473.0020

Kohut, H. (1971). *The Analysis of the Self: A Systematic Approach to the Psychoanalytic Treatment of Narcisstic Personality Disorders*. International Universities Press

Marcia, J. E. (1966). Development and validation of ego-identity status. *Journal of personality and social psychology*, *3*(5), 551. doi: 10.1037/h0023281

MacLeod, R. D. (2001). On reflection: doctors learning to care for people who are dying. *Social Science & Medicine, 52*(11), 1719-1727. Doi: 10.1016/S0277-9536(00)00289-6

Mehler, P. S. (2003). Osteoporosis in anorexia nervosa: prevention and treatment. *International Journal of eating disorders*, *33*(2), 113-126. doi: 10.1002/eat.10119

Murray, C. D., Turner, A., Rehan, C., & Kovacs, T. (2014). Satisfaction following immediate breast reconstruction: Experiences in the early post-operative stage. *British Journal Of Health Psychology*. doi: I:10.1111/bjhp.12112

National Institute of Clinical Excellence (2011). *Common mental health disorders: Identification and pathways to care.* https://www.nice.org.uk/guidance/cg123/chapter/guidance

Offord, A., Turner, H., & Cooper, M. (2006). Adolescent Inpatient Treatment for Anorexia Nervosa: A Qualitative Study Exploring Young Adults' Retrospective Views of Treatment and Discharge. *European Eating Disorders Review*, *14*(6), 377-387. doi:10.1002/erv.687

Orb, A., Eisenhauer, L., & Wynaden, D. (2001). Ethics in qualitative research. *Journal Of Nursing Scholarship*, *33*(1), 93-96 doi: 10.1111/j.1547-5069.2001.00093.x

Pathak, V., Jena, B., & Kalra, S. (2013). Qualitative research. *Perspectives In Clinical Research*, *4*(3), 192. doi: 10.4103/2229-3485.115389

Petrie, K. J., & Weinman, J. (1997). *Perceptions of health and illness: Current Research And Applications*. UK: Taylor & Francis

Rich, E. (2006). Anorexic dis(connection): Managing anorexia as an illness and an identity. *Sociology Of Health & Illness*, *28*(3), 284-305. doi:10.1111/j.1467-9566.2006.00493.x

Rogers, C. R. (1951). *Client-centered therapy: Its current practice, implications and theory*. Boston: Houghton Mifflin.

Ryff, C. D., & Singer, B. (1996). Psychological well-being: Meaning, measurement and implications for psychotherapy research. *Psychotherapy And Psychosomatics*, *65*(1), 14-23. doi:10.1159/000289026

Smink, F. R., van Hoeken, D., & Hoek, H. W. (2012). Epidemiology of eating disorders: incidence, prevalence and mortality rates. *Current Psychiatry Reports, 14*(4), 406-414. doi: 10.1007/s11920-012-0282-y

Smith, T. (1999). *Ethics in medical research: a handbook of good practice*. UK: Cambridge University Press.

Stein, K. F., & Corte, C. (2007). Identity impairment and the eating disorders: Content and organization of the self-concept in women with anorexia nervosa and bulimia nervosa. *European Eating Disorders Review*, 15*(*1), 58-69. doi:10.1002/erv.726

Steinhausen, H. (2002). The outcome of anorexia nervosa in the 20th century. *The American Journal Of Psychiatry, 159*(8), 1284-1293. doi:10.1176/appi.ajp.159.8.1284

Street, C., & Svanberg, J. (2003). *Where next? New directions in inpatient mental health services for young people.* London: Young Minds.

Strober, M. (1991). *Disorders of the self in anorexia nervosa: an organismic-developmental paradigm*. UK: Guilford Press

Tajfel, H. (1982). Social psychology of intergroup relations. *Annual Review Of Psychology, 33*(1), 1-39. doi: 10.1146/annurev.ps.33.020182.000245

Tajfel, H., & Turner, J. C. (1979). An integrative theory of intergroup conflict. *The Social Psychology Of Intergroup Relations, 33*(47), 74. Retrieved from: http://ark143.org/wordpress2/wp-content/uploads/2013/05/Tajfel-Turner-1979-An-Integrative-Theory-of-Intergroup-Conflict.pdf

Tarrant, M., North, A. C., Edridge, M. D., Kirk, L. E., Smith, E. A., & Turner, R. E. (2001). Social identity in adolescence. *Journal Of Adolescence, 24*(5), 597-609. doi: 10.1006/jado.2000.0392

Treasure, J., & Russell, G. (2011). The case for early intervention in anorexia nervosa: theoretical exploration of maintaining factors. *The British Journal of Psychiatry*, *199*(1), 5-7. doi: 10.1192/bjp.bp.110.087585

Walsh, B. T. (2008). Recovery from eating disorders. *Australian And New Zealand Journal Of Psychiatry*, *42*(2), 95-96. doi:10.1080/00048670701793402

Wertz, F. J. (2005). Phenomenological research methods for counseling psychology. *Journal Of Counseling Psychology*, *52*(2), 167. doi: 10.1037/0022-0167.52.2.167

Wilson, G. T., Grilo, C. M., & Vitousek, K. M. (2007). Psychological treatment of eating disorders. *American Psychologist, 62*(3), 199-216. doi:10.1037/0003-066X.62.3.199

Yager J, et al. (2012) Practice guideline for the treatment of patients with eating disorders, 3rd edition. *American Psychiatric Association*. Retrieved from http://psychiatryonline.org/content.aspx?bookid=28&sectionid=39113853.

Yardley, L. (2008). Chapeter 11: Demonstrating validity in qualitative psychology. In J. Smith (Eds) *Qualitative psychology: A practical guide to research methods* (pp: 235-251) London: Sage

Table 1: Participant Information

Name (pseudonymn)	Age (mean: 16.9; sd: 2.03)	Eating Disorder Diagnosis	Community CAMHS Service	Paediatric Hospital Ward	Child/Adult Private Inpatient	CAMHS NHS Inpatient	Adult ED Service	Adult NHS Inpatient
Amelia	18	Anorexia Nervosa					✓	
Gemma	17	Anorexia Nervosa	✓	✓	✓	✓	✓	
Hannah	17	Anorexia Nervosa	✓				✓	
Hattie	18	EDNOS (restrictive)					✓	
Natasha	18	Anorexia Nervosa	✓	✓	✓	✓	✓	✓
Phillipa	18	Anorexia Nervosa	✓		✓	✓	✓	
Olivia	17	EDNOS (restrictive)	✓			✓ (as outpatient)		
Sophie	12	Anorexia Nervosa	✓	✓	✓	✓		

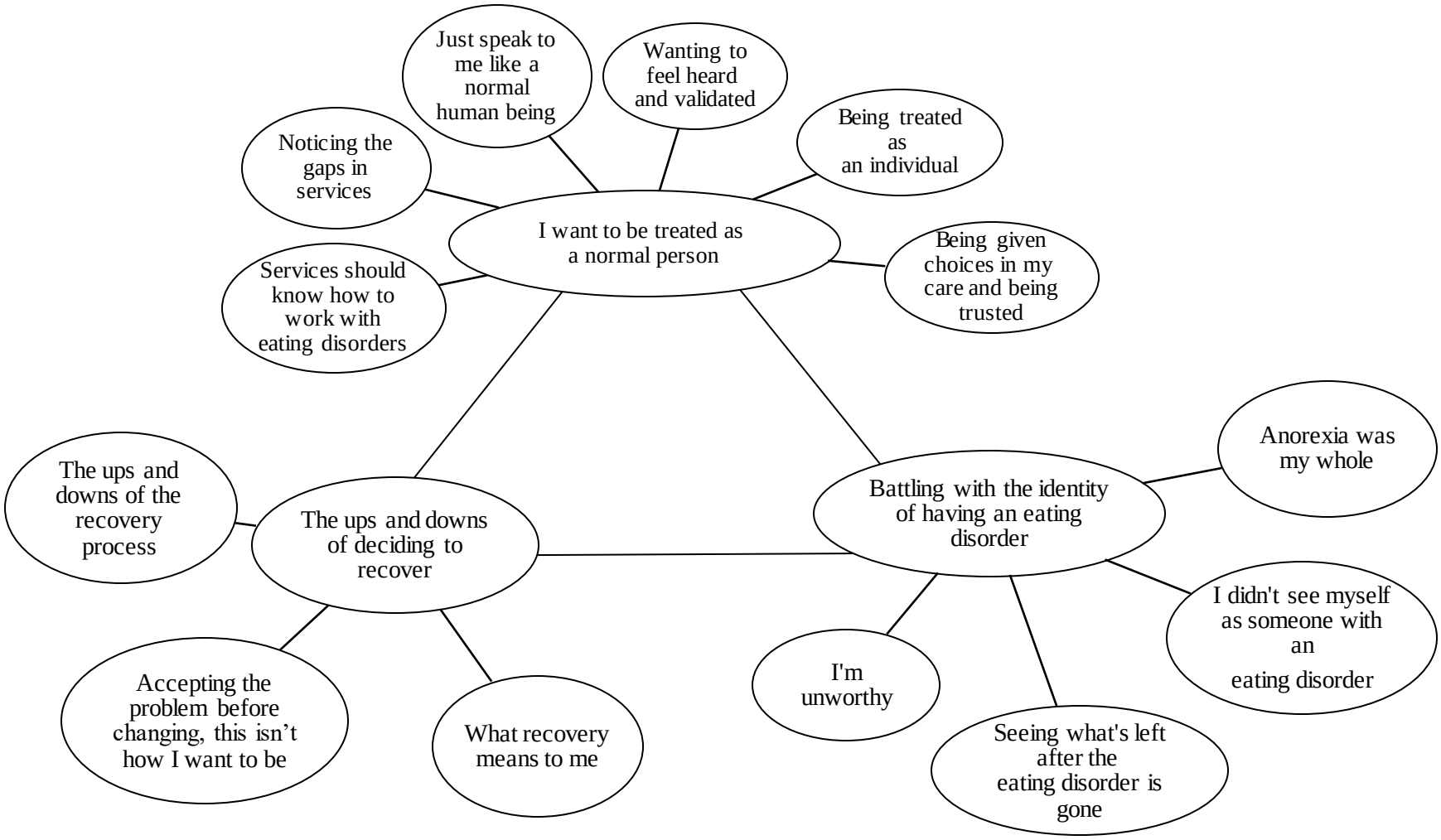
Table 2: Excerpt from a transcript demonstrating the notations and codes generated at this stage

	246	I: Can you think back to when you first went to
	247	services, what did you understand about what was
	248	happening to you?
	249	
Being in services a way of learning a lot about myself	250	P: Um, I was actually talking to my mum about this
I respect myself now	251	last night. I was saying that I've learnt a lot more about
Used to do things that weren't in my best interest and weren't respectful to myself	252	myself now, and I respect myself, cos I was doing
I didn't used to understand my eating disorder	253	things that weren't, that weren't in my best interest,
Recognising the distinction between thoughts and ED thoughts important	254	and weren't respectful for myself. And I didn't
Weight wise I haven't changed, but mindset different	255	understand my eating disorder. And I didn't recognise
	256	between my thoughts and my eating disorder
	257	thoughts, and saying that even though weight wise I'm
	258	not any different from when I was starting to get really
	259	ill, my mindset is sort of different? I think in that way
	260	it's good thing?
	261	
	262	I: In what sort of way is your mindset different?
Learning what you can and can't do came from being in services	263	
Socialising with people from inpatient	264	P: I think I just know a lot more about myself and what
I realised I couldn't do it – self awareness	265	I can do and what I can't. Like actually, I was
I'm not like them, I'm not at the stage where they are	266	supposed to be going to Leeds festival this summer,
Predicting I won't be able to eat by myself	267	and I had a house party on the weekend. And the two
Getting better a stepped process	268	girls from my inpatient came to stay for this house
Needing to make change from not eating anything on my own to eating everything on my own	269	party and they slept over, and they're the people I was
	270	meant to go to leeds with. And, um, I sort of realised
	271	that I couldn't do it. I'm not, not like them, I'm not at
	272	the stage where they are, and I know that if I went to
	273	Leeds I probably wouldn't be able to cope with eating
	274	by myself. I know its four months away, but that Is a
	275	lot of steps to take. From going you know, not eating
Worried that people will think I'm sad for not being able to do the stuff they are doing	276	anything on my own to eating everything on my own
	277	and having no sleep and being in a crowd of 50,000
	278	people so I've decided that I'm just gonna go for the
	279	day, which is sort of… I think is better. So I don't want
	280	to tell them yet, cos I think they'll be like oh my god
	281	she's so sad if you know what I mean, and why can't
	[20]	she do that and stuff like that, but…
	282	
	283	I: You said you know that you're not like them?
	284	
See self as different to other people with an eating disorder – "they're different"	285	P: I think that they're diagnoses are a bit different. I
"calorie counters" as distinctive subset of eating disorder	286	mean they've got depression and they're, they can be
See self as someone who is very controlled about eating. Surprise at speed of change in others – hard to understand. Doesn't fit with understanding of them.	287	really high and really low where I'm more like, quite
	288	steady. With my emotions. I mean I have down times,
	289	but…Um, but they're not, they're not calorie counters
	290	let's say. I'm very controlled about what I eat and
	291	what I won't, like, for instance, which my mum found
Shocked that others with an ED would not understand that I can't eat like they are	292	really surprising too, like they just, went into the
Hard to understand how quickly others change – was like them but no longer am	293	kitchen, considering these two people were on NG
	294	two weeks ago. They went into the kitchen and got
They were worse than me but not they're not now	295	three bowls of cereal, sat down and ate in front of the
	296	telly and were like, why aren't you doing that? And I
	297	was like you know that I can't do that. And it shocked
	298	me and my mum, we thought that, I mean good on
	299	them, I'm not saying it's a bad thing, but the fact that
	300	

Table 3: Overview of superordinate and subordinate themes from a thematic analysis of adolescents' experiences of social identity and of eating disorder interventions

Superordinate Themes	Subordinate Themes
Battling with the identity of having an eating disorder	• I didn't see myself as someone with an eating disorder • Anorexia was my whole • Seeing what's left after the eating disorder has gone • I'm unworthy
The ups and downs of deciding to recover	• Accepting the problem before changing, this isn't how I want to be • What recovery means to me • The ups and downs of the recovery process
I want to be treated as a normal person	• Being treated as an individual • Just speak to me like a normal human being • Wanting to feel heard and validated • Being trusted and helping me to make choices about my care • Noticing the gaps in services • Services should know how to work with eating disorders

Figure 1: Thematic map from a thematic analysis of adolescents' experiences of social identity and of eating disorder interventions



Appendix 1: Author Guidelines for International Journal of eating disorders

Author Guidelines

ORIGINALITY

The journal accepts for review manuscripts that have not been published or are not currently elsewhere under review.

CONTENT TYPES

Manuscripts published by IJED include: (1) Original Articles; (2) Brief Reports; (3) Critical analysis and Synthesis (systematic reviews and meta-analyses); (4) Commentaries; (5) Clinical Case Reports; (6) and "An Idea Worth Researching". All word limits relate to the body of the text (i.e., not including abstract, references, tables or figures). These are maximum lengths and authors are encouraged to keep their reports as short as possible while communicating clearly. The review criteria will include appropriateness of length.

When uploading their manuscripts, authors will be asked to complete a brief checklist indicating that the authors have followed the author guidelines pertaining to the article type.

To summarize, the article types are:

(1) Original Articles reporting substantive research that is novel, definitive or complex enough to require a longer communication. Note that only a subset of research papers are expected to warrant full length format.

Word Limit: 7,000 words, excluding abstract, references, tables and figures
Abstract: 250 words
References: 40 are recommended; more are permissible, for cause
Figures/Tables: a maximum of 8 essential tables/figures, overall

The methods section should include a statement about sample selection, response rate and other factors that would impact selection or response bias and in turn, representativeness of the sample. Inclusion of small samples requires justification and authors should be mindful of the recommendations concerning minimal sample sizes in subfields (e.g., genetic research, instrument development, etc., where adequate samples may number in the hundreds). If the study involves qualitative data, authors need to include a statement about sample size in relation to theme saturation. Authors also are asked to provide information about reliability and validity of study measures. If the work involves cross-cultural assessment or assessment in a new language or study population, authors should provide information about local literacy in the language of assessment, the validity of (or process for validating) a translation of an assessment and for inclusion of regional samples, a statement about the representativeness of the regional sample (or distinction from) the national sample. If statistical analyses are employed, effect size estimates should be reported in the results section.

(2) Brief Research Reports. This manuscript format is intended for manuscripts describing studies with straightforward research designs, pilot or "proof of concept" studies and replications.

Word Limit: 1,500 words, excluding abstract, references, tables and figures
Abstract: 200 words
References: 20 are recommended; more are permissible, for cause
Figures/Tables: a maximum of 2 essential tables/figures, overall

The methods section should include a statement about sample selection, response rate and other factors that would impact selection or response bias and in turn, representativeness of the sample. Inclusion of small samples requires justification and authors should be mindful of recommendations concerning minimal sample sizes in subfields (e.g., genetic research, instrument development, etc., where adequate samples may number in the hundreds). If the study involves qualitative data, authors need to include a statement about sample size in relation to theme saturation. Authors also are asked to provide information about reliability and validity of study measures. If the work involves cross-cultural assessment or assessment in a new language or study population, authors should provide information about local literacy in the language of assessment, the validity of (or process for validating) a translation of an assessment and for inclusion of regional samples, a statement about the representativeness of the regional sample (or distinction from) the national sample. If statistical analyses are employed, effect size estimates should be reported in the results section.

(3) Critical Analysis and Synthesis/Review articles critically review the status of a given research area and propose new directions for research and/or practice. Both systematic and meta-analytic review papers are welcomed if they review a literature that is advanced and/or developed to the point of warranting a review and synthesis of existing studies. Reviews of topics with a limited number of studies are unlikely to be deemed as substantive enough for a Critical Review paper. Moreover, the journal is not interested in papers that merely

describe or compile a list of previous studies without a critical synthesis of the literature that moves the field the forward.
Word Limit: 7,000 words, excluding abstract, references, tables and figures
Abstract: 250 words
References: 100
Figures/Tables: no maximum, but should be appropriate to the material covered

All review papers must follow the PRISMA guidelines (see Moher et al. (2009) below) and authors must complete and submit the Critical Analysis and Synthesis/Review Checklist upon submission of the paper. The rationale for any unchecked items on the Checklist must be explicitly described in the manuscript Cover Letter.
Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-
Analyses: The PRISMA Statement. J Clin Epidemiol 2009; doi:10.1016/j.jclinepi.2009.06.005).
**Please note that this paper can be downloaded for free in both English and Spanish **

(4) Commentaries are written only at the invitation of the Editors, when multiple perspectives on or critical appraisal of an article would assist in placing that article in context.

Word Limit: 800 - 1,500 words, excluding abstract, references, tables and figures
Abstract: no abstract
References: 5, using the footnote format rather than the journal's standard format
Figures/Tables: none

(5) Clinical Case Reports detail key elements of cases where there is novelty in the presentation, pathology or treatment and where that novelty will inform clinicians and researchers about rare presentations or novel ideas. This category will often be appropriate to rare biological or psychological presentations. Every effort should be taken to ensure the anonymity of the patient concerned and any clinicians not involved as authors. If there is any potentially identifiable information, then it is the responsibility of the authors to seek and obtain approval from the local Institutional Review Board (IRB) (or equivalent) for the case to be reported and a copy of that approval should be made available to the Editor on request.

Word Limit: 3,000 words, excluding abstract, references, tables and figures
Abstract: 150 words
References: 20
Figures/Tables: a maximum of 2 essential tables/figures, overall

(6) "An idea Worth Researching" is a format where authors propose an idea that may not yet have adequate empirical support or be ready for full empirical testing, but holds great promise for advancing our understanding of eating disorders. Authors are encouraged to write a piece that is bold, forward looking and suggestive of new and exciting avenues for research and/or practice in the field.

Word Limit: 1,500 words maximum, excluding abstract, references, tables and figures
Abstract: no abstract
References: 5 maximum, in footnote format
Figures/Tables: a maximum of 2 essential tables/figures, overall

PREPARATION OF MANUSCRIPT & MANUSCRIPT FORMAT

General Format

Manuscripts must be typed in English and double-spaced throughout, with margins of at least one inch at the top, bottom and both sides of each page. All manuscripts are subject to copyediting; however, it is the primary responsibility of the authors to proofread thoroughly and ensure correct spelling and punctuation, completeness and accuracy of references, clarity of expression, thoughtful construction of sentences and legible appearance prior to the manuscript's submission. Preferred spelling follows Webster's New Collegiate Dictionary or Webster's Third New International Dictionary. The manuscript should conform to accepted English usage and syntax. Use headings to indicate the manuscript's general organization. Do not use a heading for the introduction. In general, manuscripts will contain one of several levels of headings. Centered upper case headings are reserved for Methods, Results and Discussion sections of the manuscript. Subordinate headings (e.g., the Participants or Procedure subsection of Methods) are typed flush left, underlined, in upper case and lower case letters. The text begins a new paragraph. Number all pages of the manuscript except the figures (including title page and abstract) consecutively. Manuscripts that do not conform to the author guidelines stated here will be unsubmitted.

Number all pages of the manuscript except the figures (including title page and abstract) consecutively. Parts of the manuscripts should be arranged in the following sequence:

(1) Title page. (numbered 1) Titles should be short and specific, conveying the main point of the article. The title page should include the full names, titles and affiliations of all authors and an abbreviated title (Running Head) that should not exceed 50 characters, counting letters, spacing and punctuation. The Running Head should be typed in upper case letters centered at the bottom of the title page. Each page of the manuscript (excluding figures) should be identified by typing the first two or three words of the full title in the upper right-hand corner above the page number. No running head is required for letters to the editor. Indicate the word count for the abstract and the word count for the manuscript (excluding figures, tables and references).

(2) Abstract. (word maximum varies by article type) For article types requiring an abstract, the abstract should be typed as a single paragraph on a separate page, numbered 2. Type the word "Abstract" in upper and lower case letters, centered at the top of page 2. Provide the following information in the form of a structured abstract, using these headings: **Objective:** briefly indicate the primary purpose of the article, or major question addressed in the study. **Method:** indicate the sources of data, give brief overview of methodology, or, if review article, how the literature was searched and articles selected for discussion. For research based articles, this section should briefly note study design, how participants were selected and major study measures. **Results:** summarize the key findings. **Discussion:** indicate main clinical, theoretical, or research applications/implications.

The *Journal* requires structured abstracts with one exception: the *Journal* will continue to use unstructured abstracts for case reports.

(3) Text. Begin the text on page 3 and be sure to identify each page with the short title typed in the upper right-hand corner above the page number. Type the full title of the manuscript centered at the top and then begin the text. The full title appears on page 3 only. Indent all paragraphs. The maximum length for article submissions is specified for each manuscript type. Authors are advised that content be conveyed as concisely as possible.

(4) References. Begin on separate page, with the word "References" typed in upper and lower case letters, centered at the top of the page. References must be double spaced.

(5) Appendices. Type each appendix on a separate page labeled "Appendix A, B", etc., in the order in which they are mentioned in the text.

(6) Footnotes. Start on separate page.

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Section Three: Critical Appraisal

Reflections On The Process Of Conducting Research Within Eating Disorder Services

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Reflections On The Process Of Conducting Research Within Eating Disorder Services

The purpose of this critical appraisal is to provide an information resource for those planning to conduct similar research in the future through discussing methodological, procedural and ethical issues which affected the process of completing this thesis. It is also a space in which to explore in more detail some of the key issues which arose within the empirical paper. To this end, I plan to use it as a space to reflect on the process of conducting a thesis exploring the experiences of young people with an eating disorder (ED) of services while considering their social identity.

I will begin by summarising the results of the research paper and providing suggestions for areas of future research. I will then discuss the process of developing an initial research idea and consider the process through which research aim was developed and a methodology selected. Finally, I will include my own reflections on salient issues raised within the recruitment and research process.

Summary of Research Paper

Summary of Results

Three themes were identified within the research paper: a) battling with the identity of being anorexic, b) the ups and downs of deciding to recover and c) I want to be treated like a normal person and get what I need to get better. The results suggest that the social identity of adolescents with an ED changes over time and that the way in which services interact with service users can influence and be influenced by these changes. Participants reported that until they had accepted the ED diagnosis in to their identity they were unlikely to address it, but also reported that once this acceptance had taken place the ED could become their whole identity. They reported that when they didn't meet service criteria, this could feel very rejecting and could serve to contribute to the feeling that they were "unworthy" of having an

ED. This feeling of unworthiness was mirrored in participants' experiences of group work or of being around others with EDs and often led to further weight loss. The results suggested that services had a role in thinking about social identity within their wider understanding of EDs and to consider the way in which services act holistically.

Suggestions for future research

This study contributes to the existing research base through bringing together an exploration of social identity alongside service experiences and considers the way in which services can respond to changes in social identity. In order to develop knowledge in this area further, it would be useful to consider the experiences of others with EDs. Male voices are generally under-represented within ED research (Andersen& Holman, 1997) and although this project was open to both males and females, only female service users participated. Research has explored gender differences in the ways in which EDs manifest (Carlat, Camargo & Herzog, 1997). Difficulties were particularly clear in relation to aetiology, with males and females experiencing significantly different societal pressures and expectations. Males who identified themselves as homosexual or bisexual were identified at being of higher risk of developing an ED (Carlat, Camargo & Herzog, 1997). These differences could conceivably lead to differences in social identity development and relationships with services, with sexuality in particular demonstrated as being a strong influence over social identity development in adolescents (Seidman, 2003). Exploration of male experiences of EDs and social identity could therefore add an alternative perspective when working with this group.

Differential experiences could also be explored through looking at the way in which people with non-restrictive EDs relate to their social identity and to services. Giles (2006) suggested that Anorexia Nervosa (AN) was a more desirable identity for young people with EDs in comparison to bulimia nervosa (BN) or eating disorders not Otherwise Specified (EDNOS). This lack of desirability for alternative diagnoses may make the way in which

adolescents relate to BN or EDNOS and integrate it into their own identity more problematic. Exploration of social identity and BN or EDNOS could provide useful insights into the way in which interventions could support people with an ED diagnosis in overcoming their difficulties.

Another way in which further research could build upon the results presented here would be to consider the use of quantitative measures in exploring identity, such as Karasawa's Idenfication Scale (1991) or Bond & Hewstone's (1988) Social Identity Scale. Measures of social identity can provide a snapshot of an individual's experience at a specific point in time. Thinking about using these measures to explore the impact of changes to services or interventions on social identity development and ED presentation could help further support the use of these measures on a wider basis. Recommendations for services from this research included thinking about supporting people who are not eligible for services to access further support, integrating social identity issues into existing therapeutic approaches and considering the set-up of groups so that service users are less likely to be around people at very different stages of recovery to themselves. The impact of these changes on the strength of an individual's attachment to an ED identity could be explored.

Development of the Research Idea and Methodology

Inspiration for the research

I was initially interested in conducting research in the field of EDs due to clinical experience which I gained prior to doctoral training. I worked as an assistant psychologist within a community adult ED service and became interested in thinking about the experience of people with an ED diagnosis of services. My role involved co-facilitating several parent and carer support groups and this led me to think about the way in which parents are supported in caring about young people at a very difficult stage of their lives. Parents would

struggle to understand their child's ED and young people would report not feeling understood by both their families and by services. This led me to consider the importance of conducting research directly with service users so that this understanding could be developed further.

I have previously conducted research with service user groups and found this process to be interesting. I learnt much about the need for services to work in a way which is not tokenistic, but instead values service user contributions and use these carefully. Williams and Lindley (1996) discuss that the gap between obtaining the views of service users and then acting on them can be large and so I was motivated to not only hear people's stories but to make sure that their views were shared with services and were listened to. To this end, during the planning process of this project I was keen to stress to services that I would like to return to feed back results and offered all participants the option of receiving a summary of the results to use as they wished. I have discussed opportunities to disseminate the results and conferences and ED clinician networks and hope to publish the thesis in order to widen the dissemination potential for the results.

Development of the research aim

While I wanted to ensure that the experiences of young people with EDs were clearly heard within my research project I was less sure about what specific focus my research might have. I spoke to ED services and thought about the things that would be useful in informing their work. From my own experience I had seen that the way in which a person with an ED sees themselves can fluctuate throughout the recovery process and stories about holding different perspectives during this time are common (Wilson & Schlam, 2004).

I was drawn to literature which thought about the important stages of identity development which often take place during this time and started to think about the way that an individual's identity and sense of self might relate to the way in which they think about

their ED and access support to manage it. I had heard reports such as "the eating disorder is my life" within my work and had thought about the impact that this must have for an individual accessing treatments to take away this important part of their identity. I thought about how this might contribute to feelings of ambivalence, a well-documented difficulty reported by both service users and services (Cockell, Geller & Linden, 2003). I felt that exploring whether social identity might affect this ambivalence would be useful.

There is a body of research which theoretically explores the way in which social identity in particular relates to eating disorder development and maintenance. Factors such as the media, internet forums and familial relationships have been considered within this frame (Giles, 2006). However, to date no research had specifically explored the way in which social identity fluctuations could relate to the way in which service users accessed ED services. I spoke to services and learnt that while an individual's social identity might be considered when thinking about formulation or interventions, this was not done on the basis of clinical research and the idea of developing understanding in this area could be valuable. We thought about exploring participant experiences of services and thinking about these experiences through the lens of identity to think about whether services should include identity more explicit within interventions or treatments.

Selecting a form of analysis

During the planning stages of the project I was keen to consider methods of analysis early on so that they could help to inform the study design as a whole. I decided that an exploration of experiences would be most beneficial in achieving my research aims as it would allow for participant's voices to be heard in a way which quantitative methods do not. Many methods of analysing qualitative data exist, they are diverse and bring with them their own strengths, weaknesses and existing assumptions (Creswell, Hanson, Plano-Clark & Morales, 2007).

In selecting an appropriate method of analysis, I first explored my own philosophical assumptions and thought about epistemology, before considering this in light of my chosen methodology. This was in line with guidance from Creswell (2005) who states that consideration of these elements is crucial. I reflected that my own critical-realist perspective led me to assume that while culture and social elements impact upon an individual's experience their spoken word can be said to be representative of their inner thoughts, feelings and understanding. I also believe that although many research aims to "give voice" to participants (Ashby, 2011), there exists a process through which researchers select and present that data which fits with their own understanding, and this process should be named and addressed. I was keen to use a method of analysis which would allow for a thorough exploration of participant experiences.

While Interpretative Phenomenological Analysis (IPA) is a methodology which works within a critical realist framework (Larkin, Watts & Clifton, 2006) in order to explore individual experiences, and could have been suitable here, I opted instead to choose phenomenologically informed thematic analysis (TA). While IPA provides a specific framework for conducting analysis (Smith, Flowers & Larkin, 2009) (TA) has traditionally been viewed as more flexible (Boyatzis, 1998). A key assumption of IPA is that the data analysed must be homogenous in nature (Larkin, Watts & Clifton, 2006). Within this study, I aimed to recruit participants with experiences of a range of different services. While initially the inclusion criteria specified that all participants had experienced inpatient care, it was necessary to widen these criteria and the participants who took part had very different journeys through services. I had also planned from the start to represent the voices of participants of different ages and at different stages of the recovery process. Although the final sample was solely female I had also hoped to recruit participants of both genders. I hypothesised that these differences in age, background and stage of recovery would all

contribute to differential experiences of social identity and of service experiences. This lack of homogeneity meant that IPA was not a suitable choice of methodology. I was however keen to maintain a phenomenological approach where experiences were presented from a service user perspective and so opted to use a TA approach informed by guidance from Braun and Clarke (2006).

Recruitment of Participants

I had discussions with supervisors about which services I should approach in order to recruit participants. I wanted to be able to reach a wide range of participants, to this end I spoke to a manager who oversaw all of the Child and Adolescent Mental Health Services (CAMHS) within one trust who agreed to support the project. However, although the service directly linked to my field supervisor did participate in the study, when I approached the CAMHS teams to start the recruitment process only one other team agreed to send out research packs. At this stage, I only had one participant and so quickly realised that engaging services would be crucial to the recruitment process.

Engaging services in recruitment

Initially, I focussed this engagement effort within the CAMHS teams who I had already had some contact with. However, while services were keen for the research to go ahead in principle, they felt constricted by barriers such as a lack of resources to send out the packs, a lack of time to identify appropriate potential participants and a lack of time to meet me to discuss it further. These barriers may be reflective of the high pressure and limited resources which affect many health services nationally (Roberts, Marshall, & Charlseworth, 2012). They also indicated to me that people had little investment in the research or motivation to take part, which I found difficult to manage at the time as I was so keen to meet and talk to service users.

I reflected on the different positions that myself and the services were in and considered that for me this project was very high on my list of priorities for many reasons, including a desire to further my knowledge in the area; to be able to represent the views of participants who might not otherwise have a voice; to produce a publishable piece of work and to complete a project which would contribute to my doctoral qualification. However, research suggests that health professionals working within the National Health Services (NHS) have many competing demands and are under increased pressure to complete these within very limited time (Roberts, Marshall, & Charlseworth, 2012).

This conflict in our priorities led me to feel that there was little motivation for staff to put aside time to assist with the project. It also led me to consider research which points to the role of "gatekeepers" within recruitment for projects, whereby there are often one or two people who are crucial in the recruitment process in terms of motivating others to take part and helping projects move forward (Jessiman, 2013). Jessiman identifies a need for researchers to be highly visible in order to influence teams (Jessiman, 2013). I reflected that as I had not contacted individual services directly early on in the recruitment process, but had instead relied upon the influence of a team manager who I had limited contact with, I had not filled this role and had therefore decreased the likelihood that services would take part. Despite attempting to influence services at this stage of the recruitment process through further e-mails and phone calls, I had no further offers to help and I felt that it was important to respect the decisions of services to not take part.

Overcoming these barriers

In order to recruit more participants I reflected on the process so far and tried to apply my learning to the next stage of the process, which was recruiting through a new NHS trust. I had identified that a key barrier had been my lack of direct contact with services early on in

the process of engaging them to help with recruitment. I attempted to correct this within the process of identifying further services to recruit through.

I approached a number of services across the region with an e-mail outlining the study and what the expectations of the services in the recruitment process would be. I was mindful of the limited time and resources that had been earlier identified as a barrier and made very clear in my e-mail what the expected involvement from services would be and that I had tried to minimise service involvement as much as possible. I received interest from a number of services and offered to go and meet each individual service lead in person, rather than making arrangements only via e-mail. I also made a decision to communicate with individual services rather than with regional managers alone. I met with services and identified that there were a number of enthusiastic and motivated people within the same trust. I felt that this motivation from individuals was closer to my own values related to the project and that it was promising in terms of ensuring that the project was advocated for. I decided to pursue an ethics application to recruit within their NHS Trust and ensured that I kept all staff members up to date at every stage of this process.

At this stage, the research support office for the trust requested that each individual service contact the research and development team directly to confirm that they were happy to take part and understood the expectations upon them. This process was very helpful in that it provided a written confirmation from services that they would participate. It led me to think that if I were conducting research within a trust which did not request this from services in the future it might be something that I put into place from an individual level, as this written confirmation provided an additional commitment from services to take part – something that had been missing within my first recruitment stages.

This learning which I applied to my second stage of recruitment proved valuable, in that all of the new services were highly motivated to send my recruitment packs out and

within a month I had received 11 further opt-ins to the study in addition to the one participant I had recruited from the first trust. This demonstrated to me the value of engaging services in the recruitment process and I have continued to involve them through providing regular updates regarding the progress of the project and offering to return to the services to disseminate the results. Although this was an offer I had also made to the earlier services, this time I had presented the dissemination as an opportunity for discussion and learning and had related the project to the specific needs of the services, which I explored through conversations with managers.

Managing difficult stories in research

This section relates to a the particular challenge of interviewing people about stories which may be difficult to communicate, an issue which I feel was central to this research and thus merits further discussion here.

Distinction between clinician and researcher

Whilst interviewing the young people in this study about their experiences, I was given an insight into stories and experiences which were at times distressing and were at times difficult for participants to talk about. Following participant interviews, I noticed that I would often feel a sense of helplessness that I could not support them with their difficulties and would feel a strong sense of empathy. I noticed a sense of guilt that I was asking questions that were potentially distressing but was not providing the usual support that my clinical role would provide. I thought about this within the frame of a counter-transference reaction, where my usual role of working as a clinician looking to improve the psychological wellbeing and quality of life of individuals could affect my experience of the researcher role.

I reflected on this and thought about the way in which clinician and researcher roles are similar and can become difficult to separate. A researcher role involves drawing out

information and reflections from participants. I noticed that I would use skills developed within my clinical roles to achieve this through reflecting back and expanding on participant responses, as well as using skills in relationship and trust building to create a safe space for discussion. Murray (2003) noted the therapeutic benefits to participants that taking part in research can bring, particularly where research interviews are in-depth. Some reports from participants in this study supported this assumption, with several noting during the debrief process that they had enjoyed the opportunity to talk things through as it helped them to "get a perspective" on things and that although things had been difficult to talk it had been good to feel listened to and understood. Murray proposed that this benefit to participants can be greater where researchers make an effort to reduce the power differential within relationships (Murray, 2003). Within the research process I made conscious efforts to reduce my own power through using strategies such as being friendly and open and answering any questions from participants openly and honestly. I tried to share with them the rationale behind the research and to help them experience their participation as an empowering opportunity to allow their personal stories to shape future service provision.

My previous work and research experiences have led me to feel that this redistribution of power within therapy wherever possible is crucial in order to facilitate trusting relationships which can facilitate change. However, within clinical settings, as within research, I have reflected that with those situations there is an inherent power differential which remains present despite efforts to address it. Carrick, Mitchell and Lloyd (2001) note that researchers need to be aware of the power that they hold within interviews and encourage researchers to consider the impact that this can have. Within several of the interviews that I conducted with participants, service users became briefly upset and, in one case, tearful. While I offered them the opportunity to pause or suspend the interview and actively tried to give the choice of how to proceed with the interview to participants, I was

also aware that given my own power in the situation it might have been difficult for participants to ask to stop.

This dilemma has been difficult to reflect upon and has encouraged me to explore ways to more actively ensure that participants have as much power within research interviews as possible. Murray (2003) suggests that one way that this power can be distributed is through appropriate disclosures from researchers, particularly where these are in response to direct questions. This is an interesting area to consider when thinking about designing future research, particularly in terms of the implications that personal disclosures might have on the stories that participants choose to share.

Conclusions

Throughout the research process I have considered my own role as a clinical psychologist and a researcher. While I have always considered research to be a crucial element of my identity as a psychologist, this thesis has aided me in appreciating the value that this research can bring. This value refers not only to the improvements in service development which can occur, but also to the opportunity for service users to feel heard and understood and for families and carers and be listened to. I have learnt this through observing first hand the impact of sharing stories on each participant. For me, the way in which I will choose to conduct research has changed in that I am more motivated than ever to strive to hear and represent the stories of those people who access the services in which I am a clinician.

This critical appraisal has presented the process through which I identified a research topic and aim, developed a methodology and managed the numerous challenges which were present throughout. While these challenges proved difficult to manage at times, they provided me with a valuable learning opportunity and I feel that it will inspire me to

continue to advocate and work with people who may struggle to be heard within services in the future.

References

Andersen, A. E., & Holman, J. E. (1997). Males with eating disorders: Challenges for treatment and research. *Psychopharmacology bulletin*, *33*(3), 391. Retrieved from: http://www.ncbi.nlm.nih.gov/pubmed/9550883

Ashby, C. E. (2011). Whose" voice" is it anyway?: Giving voice and qualitative research Involving individuals that type to communicate. *Disability Studies Quarterly*, *31*(4). Retrieved from: http://dsq-sds.org/article/view/1723/1771

Bond, M. H., & Hewstone, M. (1988). Social identity theory and the perception of intergroup relations in Hong Kong. International Journal of Intercultural Relations, 12, 153-170.

Carlat, D. J., Camargo, C. A., & Herzog, D. B. (1997). Eating disorders in males: a report on 135 patients. *American Journal of Psychiatry*, *154*(8), 1127-1132. doi: 10.1176/ajp.154.8.1127

Carrick, R., Mitchell, A., & Lloyd, K. (2001). User involvement in research: power and compromise. *Journal of Community & Applied Social Psychology*,*11*(3), 217-225. doi: 10.1002/casp.623

Cockell, S. J., Geller, J., & Linden, W. (2003). Decisional balance in anorexia nervosa: Capitalizing on ambivalence. *European eating disorders Review*,*11*(2), 75-89. doi: 10.1002/erv.493

Creswell, J. W. (2005). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research*. NY: Pearson Education.

Creswell, J. W., Hanson, W. E., Plano, V. L. C., & Morales, A. (2007). Qualitative research designs selection and implementation. *The counseling psychologist*, *35*(2), 236-264. doi: 10.1177/0011000006287390

Giles, D. (2006). Constructing identities in cyberspace: The case of eating disorders. *British Journal Of Social Psychology*, *45*(3), 463-477. doi:10.1348/014466605X53596

Jessiman, W. (2013). "To be honest, I haven't even thought about it" – recruitment in small-scale, qualitative research in primary care. *Nurse Researcher*, *21*(2), 18-23. doi: 10.7748/nr2013.11.21.2.18.e226

Karasawa, M. (1991). Toward an assessment of social identity: The structure of group identification and its effects on ingroup evaluations. British Journal of Social Psychology, 30, 293-307.

Murray, B. (2003). Qualitative research interviews: therapeutic benefits for the participants. *Journal of Psychiatric and Mental Health Nursing*, *10*(2), 233-236. doi: 10.1046/j.1365-2850.2003.00553.x

Roberts, A., Marshall, L., & Charlesworth, A. (2012). A decade of austerity? The funding pressures facing the NHS from 2010/11 to 2021/22. *London: Nuffield Trust*.

Seidman, S. (2003). *The social construction of sexuality*. New York: Norton.

Williams, J., & Lindley, P. (1996). Working with mental health service users to change mental health services. *Journal of community & applied social psychology*, *6*(1), 1-14. doi: 10.1002/(SICI)1099-1298(199602)6:1

Wilson, G. T., & Schlam, T. R. (2004). The transtheoretical model and motivational interviewing in the treatment of eating and weight disorders. *Clinical Psychology Review*, *24*(3), 361-378. doi:10.1016/j.cpr.2004.03.003

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Section Four – Ethics Section

How Adolescents Experience Treatment And Intervention For Restrictive Eating Disorders: Keeping Social Identity In Mind

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Research Protocol

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1.1: Introduction

Eating Disorders (EDs) are conditions which can have a profound and long lasting impact on the lives of those who experience them. They are also widely acknowledged to have one of the highest mortality rates in comparison to other psychiatric disorders (Herzog, Rathner, & Vandereycken, 1992). This is usually as a result of a severe and sustained weight loss which can lead to heart or other organ failure, or due to chemical imbalances in the blood occurring as a result of purging behaviour (Herzog et al, 2000). Many psychiatric disorders were historically managed from a medical perspective, which focused primarily on the reduction of positive symptoms (Ryff & Singer, 1996). Within the field of EDs, this meant that treatment may focus on factors such as weight or body mass index (BMI) and disordered eating behaviours such as food restriction or purging (Doll, Petersen & Stewart-Brown, 2005).

This medical model is still highly influential and important in helping service users to address the positive symptoms of their distress. However, with the growing focus within mental health services on the importance of the whole of an individual's experience, such as their general wellbeing (Tomba, Offidani, Tecuta, Schumann & Ballardini, 2014) and identity (Keski-Rahkonen & Tozzi, 2005), the way in which services work has evolved. The National Institute of Health and Care Excellence (NICE) guidelines around the treatment and management of people with and ED diagnosis state that psychological interventions for EDs should both address the active symptoms and focus on facilitating full psychological recovery (NICE, 2004).

Despite the recognition of the importance of taking a psychological approach to treatment, research within this area has yet to identify any one intervention which is effective for Anorexia Nervosa (AN), with NICE making the decision not to identify any intervention

as belonging within category A, the section reserved for interventions with strong empirical data to support them (NICE, 2004). Steinhausen (2002) reviewed 119 studies in this area with follow ups of between 2 and 40 years and estimated that among 5,590 SUs with Anorexia Nervosa (AN) over around 5% had died as a result of the condition, 49.6% had recovered fully, 33.5% had improved and 20% remained chronically ill. There therefore remains a strong incentive to further research and address this issue.

This issue is particularly relevant for AN and for Eating Disorders Not Otherwise Specified (EDNOS) where SUs present with restrictive behaviours (EDNOS-RS). EDs which present alongside restrictive behaviours have been demonstrated as distinct to other EDs, ie Binge Eating Disorder (BED) and Bulimia Nervosa (BN). Research suggests that AN, and EDNOS-RS are more resistant to recovery (Smink, van-Hoeken & Hoek, 2006), pose a greater threat to the wellbeing and physical health of SUs (Bulik, 2006) and are associated with distinct changes to cognitive functioning in SUs (Karem & Katzman, 2003). Further, although it has been demonstrated that SU's may transition between diagnoses throughout their journey from ED to recovery and some theories take a transdiagnostic approach , there are distinct differences between restrictive and non-restrictive ED subtypes which lead to significant differences in the way in which conditions are understood by both SUs and clinicians (Monica, 2011).

The definition of "recovery" used by Steinhousen focused primarily on the physical symptoms of EDs, but significant attention has been given elsewhere to thinking about what might represent complete recovery from an ED, with researchers pointing to a lack of clear consensus on the issue (Hertzog et al, 1993, Walsh, 2008). Bardone-Cone et al (2009) attempted to define recovery as a whole through examining various aspects of physiological and psycho-social functioning amongst SUs who considered themselves "recovered". They suggested that in order to achieve "full recovery" with a reduced chance of relapse, an

intervention would encompass looking at BMI, weight and shape, as well as thinking about specific psychological pieces of recovery in relation to psychosocial measures and re-defining an individual identity.

This review has implications for services, in that the importance of a holistic approach is emphasised. This may be of particular relevance for some inpatient services that have been criticised for focussing too heavily on changes to weight alone rather than on facilitating a generalised recovery in SUs (Offord, Turner and Cooper, 2006). Fenning, Fenning and Roe (2002) discuss recovery specifically within inpatient services and point to the tendency of services to discharge SUs when they have achieved their "target weight" as problematic in that it ignores other aspects of recovery. It has been hypothesised that this may lead to high rates of relapse and then re-admission following discharge (Offord, Turner and Cooper, 2006; Vandereycken, 2003).

Several reviews have been conducted of SU experiences of recovery within ED services, with evidence suggesting that recovery from an ED is a multi-factoral process that spans further than the treatment style alone (Espindola & Blay, 2009). Generally, approaches which were able to work within a psychological model encompassing various theoretical models were found to be more successful than those which worked within a more medical model (Bell, 2003). The importance of focussing on SU views of recovery and of interventions has been recognised (Street & Svanberg, 2003), with Espindola and Blay (2009) identifying additional factors such as visits from family and friends and work on self-esteem as central to full recovery for adults with EDs. Jenkins and Ogen (2011) explored the views of adults within services and focussed on the importance of therapy in helping to facilitate a sense of "wholeness" in individuals, which they report was best experienced within services which attended to the importance of therapy and re-forming the personal relationships which may have been impacted by periods of unwellness. This work has been particularly important

within inpatient services, as the more medical model of treatment and intervention focusing on physical features of an ED can often be more prominent than in community teams (Bardon-cone et al, 2010).

An inpatient admission is often a necessary part of the treatment and intervention of SUs with EDs and with AN in particular and many admissions to such services are preceded by a specific incident or medical crisis (Wilson, Grilo & Vitousek, 2007). It has been suggested that this rushed admission could contribute to a lack of clarity in terms of what the ultimate goal of an admission is (Wilson, Grilo & Vitousek, 2007). In the past, services have been criticised for focussing solely on the achievement of a target weight as a condition of discharge with a reduced focus on other aspects of an individual's recovery (Bardon-Cone et al, 2010). Keski-Rankonen and Tozzi (2005) suggest that this can lead to a risk that SUs enter a state of "pseudo recovery" where individuals comply with instruction to facilitate a discharge, but the ED symptoms and thought processes remain present. This concept is supported by evidence that suggests that the process of recovery does not and cannot start until SUs are discharged into the community away from the institutionalised care of a residential ward (Gowers & Bryant-Waugh, 2004). This evidence suggests that a renewed focus on the processes of wards may be helpful in improving their long term outcomes for SUs. Further research that explores the relationship between inpatient and community experiences of treatment may develop understanding in this area and contribute to the formation of a treatment process which reduces the likelihood of relapse for individuals following inpatient admissions.

Although helpful in encouraging a focus on service delivery and planning much research in this area and in particular the majority of quantitative research in relation to recovery has focused on the views of adults within services. While the lifespan of an ED commonly extends for many years, they most commonly emerge in adolescence, with

research suggesting that the most common age to develop an eating disorder is between 15 and 19 years (Hoek and van Hoeken, 2003). It is known that recovery from an ED becomes increasingly difficult with each intervention or inpatient admission and that early intervention and management significantly impacts long term prognosis (Bakker et al, 2011). Tobin, Gilroy and Dennis (1998) suggest that research to improve the interventions provided to young people when they first display ED symptoms may be helpful in improving long term outcomes for this client group.

There is some existing research conducted with adolescents that looks at processes involved in treatment and discharge, where issues related to identity formation and peer relationships were found to be a fundamental aspect of recovery (Offord, Turner & Cooper, 2006). Additionally, the majority of existing research has focussed on the experience of having an ED, rather than on the experiences of services and of the recovery process (Bezance & Holliday, 2013). This distinction is important when thinking about the impact that services have on recovery for individuals and when considering governmental initiatives highlighting the importance of SU input to services (NICE, 2004). The relevance of identity formation in the recovery process of adolescents is an area which has received little attention within qualitative research to date, although some researchers (Bezance & Holiday, 2013; Crisp, 1983; & Striegel-Moore & Bulik, 2007) highlighting the fact that existing research has neglected to include adolescent literature such as life cycle theory or identity development to highlight the way in which AN can be conceptualised as a challenge to typical adolescent development. Within adults, AN has been understood as related to the formation of identity (Stein & Corte, 2007) and so further exploration of this area within adolescents may help to inform the way in which identity development is addressed within adolescent treatment.

It may be that due to differences in developmental stages, as well as distinctions in areas such as identity formation or relationships with others, that treatment for adolescent AN may require differential approaches to that of adults. Family therapy has been identified as a treatment which is effective for adolescents where it may not be for adults (NICE, 2004), but in terms of the specific aspects of other treatments, further research in this area is necessary. Bezance and Holiday (2013) conducted a review of qualitative studies of adolescent experiences in relation to treatment and recovery from AN and identified that for the adolescents within the studies, an emphasis on the psychological rather than physical aspects of recovery was important. They concluded that the existing research contributes information which should be included within service planning and provision in order to improve services for young people. They identified several areas on which services should focus, including the importance of the perceived ED competency within staff (Halvorsen & Heyerdahl, 2007) and thinking about how staff can provide a secure base for SUs within the context of alien setting such as inpatient services (Haynes, Eivr & Crossley, 2011).

The present study will attempt to expand upon the existing knowledge about the way in which AN and EDNOS-R manifest in adolescents, and how this manifestation relates to adolescent development. Knowledge of this process will help inform theories of recovery within adolescent services and will aid understanding of the way in which adolescent treatment should be distinct from adult services. This understanding shall be sought through exploration of the experiences of adolescents who have accessed Child and Adolescent Mental Health Services (CAMHS) across the North West. Current NICE guidelines (NICE, 2004) provide some structure to the way in which services should be set up, through the recommendation of a holistic approach and through highlighting the importance of inpatient admission where necessary for SU safety. However, there remain significant differences in the way in which services are set up (Treasure, Schmidt & Hugo, 2007) and it is envisioned

that these differences will be present between the five CAMHS teams which form the Central Manchester Foundation Trust (CMFT) services. Through talking to adolescents about their experiences from entry into services, through inpatient services and potentially to discharge then it is expected that their narratives will allow exploration of the different aspects of treatment and intervention that are useful and conductive to the recovery process.

Existing research into recovery within adolescent services is limited, and there is a particular absence of research which relates life-cycle theory and ideas of identity development to existing interventions and to the way in which young people recovery from an ED diagnosis. As discussed above, the relationship between inpatient services and recovery processes is of particular importance as this is a stage of treatment which is often related to relapse and to a reduced focus on holistic processes. Through looking at the way in which adolescents have experienced treatment as a whole, including inpatient experiences, this study hopes to add insight into the way in which inpatient admissions feature as part of adolescent recovery, including the way in which an inpatient admission might impact identity development.

1.1.2: Research Question

- *How do adolescents experience the process of treatment and intervention for an eating disorder and how does this relate to the process of recovery.*
    - *What factors relate specifically to adolescent recovery as distinct from adult recovery*
    - *How differences in interventions are experienced by adolescents over time.*
    - *How can/do services keep recovery in focus within treatments and interventions.*

1.2: Method

1.2.1: Design

A qualitative method will be used, whereby individual interviews will be held with all participants. These interviews will last around one hour and will explore participants' own views on their experiences of the treatment process and the factors which they feel relate to this journey. An interview schedule can be found in Appendix H. The interviews will be semi-structured and will be based on the areas identified within the interview schedule, but will also include additional questions from the researcher to help to achieve a deeper level of understanding of participant experiences. Data will be analysed using thematic analysis, as this methodology allows for an exploration of the themes presented by participants, without assuming homogeneity within the group.

1.2.2: Participants

It is anticipated that between 8 and 12 participants will be interviewed as part of the study. Guest, Bunce and Johnson (2006) investigated data saturation within interviews analysed using Thematic Analysis and determined that data saturation occurs within the first 12 interviews, but can happen from as early as six interviews, suggesting that aiming for 8-12 participants will allow opportunity to reach data saturation within the sample. Service users who meet the inclusion/exclusion criteria and who return expression of interest forms will be considered as participants. In order to ensure that participants are drawn from a range of ages within the adolescent age span, service-users will be selected by the researcher in order to fulfil this range where possible. Service users will be made aware that returning an expression of interest form may not necessarily lead to inclusion within the project. This information will be included within the recruitment material.

1.2.3: Inclusion Criteria

- Participants will have been managed within community services and for the first stage of recruitment will also have experienced and inpatient admission. For the second stage of recruitment an inpatient admission will not be a compulsory part of their treatment process.
- They will have received this intervention within eating disorder services in the North West at any point within the last three years. This includes current service-users.
- Participants will have been diagnosed with either Anorexia Nervosa (AN) or with Eating Disorder Not Otherwise Specified (EDNOS) with restricting behaviours.
- Participants must have been part of the relevant services for a minimum of 6 months prior to the study's start date.
- Participants must have accessed services during adolescence to be able to participate. Adolescence is defined by the World Health Authority (WHO, 2004) as any young person aged between 12 and 19 years old.
- If aged under 16 they should either be able to demonstrate capacity to consent or have parental permission to take part.

1.2.4: Exclusion Criteria

- Service-users who are not able to speak English will not be invited to participate. This is due to a lack of funds for translation or interpretation services.
- Service users identified who are still in inpatient services will be excluded due to an accepted higher risk within this group.
- Service users identified as being of particularly high risk by services will not be invited to participate.

1.2.5: Procedure

All study materials have been reviewed by two service users identified by the field supervisor. These service users were adolescents who had an eating disorder and they assisted in ensuring that the materials sent out were sensitive to the needs of potential participants and that information was presented clearly. These participants were selected by the field supervisor from a pool of service users accessing the inpatient services at [redacted].

Eligible participants will be identified by any of the [redacted] teams based within [redacted] through use of lists generated by electronic record systems. The researcher will attend a team meeting at each CAMHS service to share information about the study with teams. This is in order to ensure that once the participants have been identified using electronic records clinicians will be able to identify those SU's who are high risk and ensure they are not sent a research pack.

The researcher will create research packs which will include information sheets for parents and for young people (Appendix A and B) and letters for service-users and their parents to read (Appendices C and D), as well as a cover letter from the CAMHS service stating clearly that the researcher has not had any access to patient records (Appendix E). The research packs will include an expression of interest form (Appendix F), which service-users should return to the investigator if they would like to participate. The cover letter to service users will state that a second research pack will be sent to them two weeks after the first one, regardless of whether or not they have opted into the study. It is anticipated that by sending a second research pack, service-users will be prompted to return an expression of interest form if they did want to participate. Where participants are under 16, research packs will be sent to parents or carers by the CAMHS team administrators and carers will decide whether or not to pass these on to service-users.

For the first stage of recruitment, packs will be sent to all service-users who meet the initial inclusion criteria – including that they must have experienced an inpatient admission as part of their treatment. If fewer than 8 service users volunteer to participate, then recruitment will be widened to include all those service users who have accessed community services (and meet other inclusion/exclusion criteria) but it will not be necessary that they have experienced an inpatient admission.

Interested service-users will be contacted via telephone by the researcher and a date to meet will be arranged. During this phone call service-users will be encouraged to ask any questions that they might have and also asked to re-read the information sheets prior to the potential interview. At the meeting the researcher and service-user will read the consent form (Appendix G) together and there will be an opportunity to ask questions. If service-users would still like to participate then they will be asked to sign a consent form. Service users will be given the opportunity to be accompanied in the interview by a parent or carer. If they choose to do so, then the expectations of the parent/carer role within this context will be discussed. It is expected that parents or carers would take an observational rather than a participatory role in interviews.

If not enough service-users volunteer within the one month time limit then an additional community service within the trust will be identified and packs will be sent out to all eligible participants within this service. There are [redacted] services from which participants can be sought in the [redacted] locality and it is anticipated that this will lead to enough participants volunteering.

Participants will then take part in an interview lasting around one hour, based on the pre-designed interview schedule (Appendix h). Interviews will be recorded using a digital recorder. They will be offered the opportunity of a break at any point during the interview and will be reminded that they are able to stop the interview at any point.

During the interviews, the researcher will monitor the wellbeing of participants. If any participants disclose any information which might lead the researcher to be concerned, such as thoughts of low mood, self-harming or suicidality then this will initially be managed through further investigation by the researcher. Questions will be asked to ascertain the immediacy and level of risk and participants will be encouraged to use their usual forms of support to help them manage any distress.

Where possible, service users will be encouraged to discuss their feelings with the practitioner that they work with within services. They will be encouraged to share concerns with their GP if they feel that they require further support. Additional support can be accessed either via using the helplines identified on the information sheet, or through encouraging participants to discuss their participation in the study with people close to them such as parents or relatives. In the case that risks are more immediate, participants will be encouraged to visit A&E where more urgent attention can be given. I would contact my own field supervisor immediately following any disclosures at all and seek further guidance from the university.

Participants will be given the option of a location to conduct interviews. These could either be held within participants' homes, or at a mutually agreed location. Participants will be reimbursed up to £20 for any travel costs incurred. These additional locations will include pre-booked rooms at community centres or a pre-booked meeting room within [redacted]. There is no additional charge related to these locations. In order to ensure the safety of the researcher, they will nominate a colleague to be a "buddy". The buddy will be informed at the beginning and end of each interview and will follow a pre-agreed plan to contact the researcher if they are late. If they are unable to make contact with the researcher on either their research or personal mobile telephone and have not heard from them within a pre-agreed time period then they will seek further support from the police. Lancaster

University's lone working policy (Appendix I) and a pre-agreed buddy system (Appendix J) will be followed.

Audio files from the digital recorder will be uploaded to the university's secure server as soon as possible following the interview. The files will be password protected, anonymised and encrypted and will only be accessible to the researcher, except where anonymised recordings and/or transcripts are shared with the university project supervisor. Audio files will then be transcribed anonymously and saved on secure university files. Audio files will be deleted once the work has been formally assessed. Any other information, such as consent forms, will be kept in a locked file until such a time that they can be scanned into a computer linked to the university secure server. All files will be uploaded and encrypted and sent to be kept by the university following submission of the project. These files will be kept for 10 years from the study's completion date and then destroyed. This is in line with Lancaster University Faculty of Health and Medicine research guidance.

1.2.6: Materials

A digital recorder will be used to record participant responses and research packs will be sent to all potential participants prior to their inclusion in the study. Research packs will include pre-franked envelopes for participants to return expression of interest forms. A mobile phone will be loaned from the University for use throughout the study. There is no additional cost attached to this. It is not anticipated that any other materials will be required.

1.2.7: Proposed analysis

Data will be analysed using a form of qualitative thematic analysis (Braun and Clarke, 2006). If participants are homogenous, then a particular form, namely interpretative thematic analysis (REF), will be used. It is anticipated that through using thematic analysis the ideas of all participants will be represented and discussed in depth.

The analysis will be conducted with the research questions in mind and it will be acknowledged at the analysis and discussion stage that the preconceptions and experiences of the researcher may inform the way in which data is analysed. This issue will be acknowledged as present and methods to help mediate this personal influence on the results will be used. For example, a copy of a completed transcript will be read by the project's research tutor, as will the themes brought out by the researcher. A discussion of these themes will allow the researcher to check the warrantability of the analysis.

1.2.8: Practical issues

- Travel costs of up to £20 per participant will be allowed, although it is anticipated that most interviews will take place in participants' homes.
- The cost of sending out the research packs and the cost of providing stamped envelopes to participants will be met by the Lancaster University Doctorate in Clinical Psychology course.

1.3: Ethical concerns

1.3.1: Risk to Participants

It is important to consider the impact on participants of discussing topics which are potentially emotive in content. Prior to starting the interviews the subject matter to be discussed will be shared with participants and they will be encouraged to think about what the impact of this might be. Where possible, conversations with relatives, friends or carers prior to interviews will be encouraged so that participants are able to fully think through their participation.

Prior to the interview the right to withdraw will be reiterated and they will be offered a break during the interview process. At the end of the interviews participants will be asked if

they need any support in relation to managing difficult emotions. The clinical judgement of the researcher will be used as part of this process to help identify participants who may be struggling to express any needs. The procedure to address any perceived distress has been discussed within the section 1.2.5 of this application.

1.3.3: Risk to the Researcher

As stated within section 1.2.5, lone working brings with it a risk to researchers and this will be addressed through following the procedure outlined above.

1.3.2: Informed Consent

Due to the fact that some participants could potentially be aged between 12 and 16, issues of informed consent must be considered. Any participants aged 16 or over will be assumed to have informed consent unless there is any evidence to suggest otherwise. In such cases permission will be sought from participants to access the measure of capacity completed as part of their outpatient treatment programme, with further decisions made on the basis of this report. In cases of limited capacity, parental permission will be needed for participation. For participants aged between 12 and 16, participants will be asked to provide parental consent to participate.

1.4: Timescale

	July 2014	Aug 2014	Sep 2014	Oct 2014	Nov 2014	Dec 2014	Jan 2015	Feb 2015	Mar 2015	Apr 2015	May 2015	June - Sept 2015
Thesis Topic/Prep	Finalise contract	Finalise design										
Thesis Ethics	1st draft of protocol & ethics docs	Submit to RSO & Ethics	Ammedts.	Obtain ethics approval								
Thesis Recruit & Data Col.					Recruit & begin data col.	Continue data col.						
Thesis Data Analysis						Data Analysis	Data analysis					

Thesis Write up res. paper				Begin intro & methods		1st draft intro & methods	2nd draft intro & methods	1st draft results & discuss.	2nd draft results & discuss.	Final complete draft	Submit	

1.5: References

Bardone-Cone, A. M., Harney, M. B., Maldonado, C. R., Lawson, M. A., Robinson, D. P., Smith, R., & Tosh, A. (2010). Defining recovery from an eating disorder: Conceptualization, validation and examination of psychosocial functioning and psychiatric comorbidity. *Behaviour research and therapy, 48*(3), 194-20 doi:10.1016/j.brat.2009.11.001

Bell, L. (2003). What can we learn from consumer studies and qualitative research in the treatment of eating disorders? Eating and Weight Disorders, 8, 181–187

Bulik CM, et al. Prevalence, heritability, and prospective risk factors for anorexia nervosa. Arch Gen Psychiatry. 2006;63(3):305–12.

Doll, H. A., Petersen, S. E., & Stewart-Brown, S. L. (2005). Eating disorders and emotional and physical well-being: Associations between student self-reports of eating disorders and quality of life as measured by the SF-36. *Quality Of Life Research: An International Journal Of Quality Of Life Aspects Of Treatment, Care & Rehabilitation, 14*(3), 705-717. doi:10.1007/s11136-004-0792-0

Espíndola, C. R., & Blay, S. L. (2013). Long term remission of anorexia nervosa: Factors involved in the outcome of female patients. *Plos ONE, 8*(2), doi:10.1371/journal.pone.0056275

Fennig, S., Fennig, S., & Roe, D. (2002). Physical recovery in anorexia nervosa: is this the sole purpose of a child and adolescent medical-psychiatric unit?. *General hospital psychiatry, 24*(2), 87-92. doi: 10.48703/8937528

Gowers, S., & Bryant-Waugh, R. (2004). Management of child and adolescent eating disorders: the current evidence base and future directions. *Journal Of Child Psychology And Psychiatry*, *45*(1), 63-83. doi:10.1046/j.0021-9630.2003.00309.x

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field methods*, *18*(1), 59-82. DOI: 10.1177/1525822X05279903

Guinzbourg, M. (2011). Eating disorders–A current concern: Similarities and differences among the anorexia, bulimia, and EDNOS categories.*Rorschachiana*, *32*(1), 27. doi: 10.235/2X052799e

Herzog, D. B., Greenwood, D. N., Dorer, D. J., Flores, A. T., Ekeblad, E. R., Richards, A., ... & Keller, M. B. (2000). Mortality in eating disorders: a descriptive study. *International Journal of Eating Disorders*, *28*(1), 20-26. doi: 38333-06A4

Herzog, W., Rathner, G., & Vandereycken, W. (1992). Long-term course of anorexia nervosa: A review of the literature. In *The course of eating disorders* (pp. 15-29). Springer Berlin Heidelberg. doi: 333.456.3

Herzog, D. B., Sacks, N. R., Keller, M. B., Lavori, P. W., von Ranson, K. B., & Gray, H. M. (1993). Patterns and predictors of recovery in anorexia nervosa and bulimia nervosa. Journal of the American Academy of Child and Adolescent Psychiatry, 32, 835–842 doi: 10.4039.43

Hoek, H., & van Hoeken, D. (2003). Review of the prevalence and incidence of eating disorders. International Journal of Eating Disorders, 34, 383–396. DOI: 10.1002/eat.10222

Jenkins, J., & Ogden, J. (2012). Becoming 'whole'again: A qualitative study of women's views of recovering from anorexia nervosa. *European Eating Disorders Review*, *20*(1), e23-e31 doi: 10.1001r34

Kerem, N. C., & Katzman, D. K. (2003). Brain structure and function in adolescents with anorexia nervosa. *Adolescent medicine (Philadelphia, Pa.)*,*14*(1), 109-118. doi: 10.2034/53.4

Keski-Rahkonen, A., & Tozzi, F. (2005). The Process of Recovery in Eating Disorder Sufferers' Own Words: An Internet-Based Study. *International Journal Of Eating Disorders*, *37*(Suppl), S80-S86. doi:10.1002/eat.20123

Natioal Institute of Health and Care Excellence (2004) Eating disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders. NICE: UK

Offord, A., Turner, H., & Cooper, M. (2006). Adolescent Inpatient Treatment for Anorexia Nervosa: A Qualitative Study Exploring Young Adults' Retrospective Views of Treatment and Discharge. *European Eating Disorders Review*, *14*(6), 377-387. doi:10.1002/erv.687

Ryff, C. D., & Singer, B. (1996). Psychological well-being: Meaning, measurement and implications for psychotherapy research. *Psychotherapy and psychosomatics*, *65*(1), 14-23. doi: 10.1159/000289026

Steinhausen, H. C. (2002). The outcome of anorexia nervosa in the 20th century. *American journal of Psychiatry*, *159*(8), 1284-1293. doi: 10.1016/j.chc.2008.07.013

Stein, K. F., & Corte, C. (2007). Identity impairment and the eating disorders: content and organization of the self-concept in women with anorexia nervosa and bulimia nervosa. *European Eating Disorders Review*, *15*(1), 58-69. doi: 10.204.3508

Smink, F. R., van Hoeken, D., & Hoek, H. W. (2012). Epidemiology of eating disorders: incidence, prevalence and mortality rates. *Current psychiatry reports*,*14*(4), 406-414 . doi: 10.1028.4024

Street, C., & Svanberg, J. (2003). *Where next? New directions in in-patient health services for young people: report 1: different models of provision for young people: facts and figures*. London (United Kingdom): YoungMinds. doi: 10068/581623

Thomas, J.J., Vartanian, L. R. & Brownell, K.D. (2009) The relationship between eating disorder not otherwise specified (EDNOS) and officially recognized eating disorders: meta-analysis and implications for DSM. *Psychological Bulletin.* 135(3):407–33. doi: 10.1037/a0015326

Tomba, E., Offidani, E., Tecuta, L., Schumann, R., & Ballardini, D. (2014). Psychological well-being in out-patients with eating disorders: A controlled study. *International Journal Of Eating Disorders*, *47*(3), 252-258. doi: 10.1037/t06908-000

Treasure, J., Schmidt, U., & Hugo, P. (2005). Mind the gap: service transition and interface problems for patients with eating disorders. *The British Journal of Psychiatry*, *187*(5), 398-400. doi: 10.1192/bjp.187.5.398

Vandereycken, W. (2003). The place of inpatient care in the treatment of anorexia nervosa: Questions to be answered. *International Journal Of Eating Disorders*, *34*(4), 409-422. doi:10.1002/eat.10223

Walsh, B. T. (2008). Recovery from eating disorders. Australian and New Zealand Journal of Psychiatry, 42, 95–96. doi: 10.10385/47938

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)
Adolescent experiences of Eating Disorder Interventions

1. Is your project research?

(●) Yes ( ) No

2. Select one category from the list below:

( ) Clinical trial of an investigational medicinal product

( ) Clinical investigation or other study of a medical device

( ) Combined trial of an investigational medicinal product and an investigational medical device

( ) Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice

( ) Basic science study involving procedures with human participants

( ) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

(●) Study involving qualitative methods only

( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)

( ) Study limited to working with data (specific project only)

( ) Research tissue bank

( ) Research database

If your work does not fit any of these categories, select the option below:

( ) Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?	( ) Yes	(●) No
b) Will you be taking new human tissue samples (or other human biological samples)?	( ) Yes	(●) No
c) Will you be using existing human tissue samples (or other human biological samples)?	( ) Yes	(●) No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

[✓] England
[ ] Scotland
[ ] Wales
[ ] Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- (●) England
- ( ) Scotland
- ( ) Wales
- ( ) Northern Ireland
- ( ) This study does not involve the NHS

4. Which review bodies are you applying to?

- [x] NHS/HSC Research and Development offices
- [ ] Social Care Research Ethics Committee
- [x] Research Ethics Committee
- [ ] National Information Governance Board for Health and Social Care (NIGB)
- [ ] National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

(●) Yes ( ) No

5a. Are all the research costs and infrastructure costs for this study provided by an NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC) or NIHR Research Centre for Patient Safety & Service Quality in all study sites?

( ) Yes (●) No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) support and inclusion in the NIHR Clinical Research Network (CRN) Portfolio? Please see information button for further details.

( ) Yes (●) No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP) and you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form immediately after completing this project filter and before completing and submitting other applications.

6. Do you plan to include any participants who are children?

(●) Yes ( ) No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

( ) Yes (●) No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ◉ No

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes ○ No

Please describe briefly the involvement of the student(s):
Student will ask as chief investigator and will be conducting all interviews and analysis.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

◉ Yes ○ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes ◉ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes ◉ No

Integrated Research Application System
Application Form for Research involving qualitative methods only

NHS
Health Research Authority

Application to NHS/HSC Research Ethics Committee

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Adolescent experiences of Eating Disorder Interventions

Please complete these details after you have booked the REC application for review.

REC Name:
Greater Manchester West

REC Reference Number:
14/nw/1469

Submission date:
05/12/2014

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

Adolescent experiences of intervention and treatment for Eating Disorders

A2-1. Educational projects

Name and contact details of student(s):

Student 1

	Title	Forename/Initials	Surname
	Ms	Bethan M	Roberts
Address	Division of Health Research, Faculty of Health & Medicine		
	Furness College, Lancaster University		
	Lancaster		
Post Code	LA1 4YG		
E-mail	b.roberts2@lancs.ac.uk		
Telephone	07725836693		
Fax			

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:
Doctorate in Clinical Psychology

Name of educational establishment:
Lancaster University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Dr	Craig	Murray
Address	Division of Health Research, Faculty of Health & Medicine		
	Furness College, Lancaster University		
	Lancaster		
Post Code	LA1 4YG		
E-mail	c.murray@lancaster.ac.uk		
Telephone	(0)1524 592730		
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Ms Bethan M Roberts	Dr Craig Murray

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- (•) Student
- ( ) Academic supervisor
- ( ) Other

A3-1. Chief Investigator:

	Title	Forename/Initials	Surname
	Ms	Bethan M	Roberts
Post	Trainee Clinical Psychologist		
Qualifications	Upper Class Second Degree with Honours in Human Psychology with Integrated Placement Year BSc		
Employer	Lancashire Care NHS Foundation Trust		
Work Address	Division of Health Research, Faculty of Health & Medicine		
	Furness College, Lancaster University		
	Lancaster		
Post Code	LA1 4YG		
Work E-mail	b.roberts2@lancs.ac.uk		

* Personal E-mail	b.roberts2@lancs.ac.uk
Work Telephone	07725836693
* Personal Telephone/Mobile	07725836693
Fax	

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

	Title	Forename/Initials	Surname
	Ms	Debbie	Knight
Address	Research Support Office, B58 Bowland Main		
	B58 Bowland Main, Lancaster University		
	Lancaster		
Post Code	LA1 4YT		
E-mail	ethics@lancaster.ac.uk		
Telephone	01524 592605		
Fax			

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):
Sponsor's/protocol number:
Protocol Version: 1
Protocol Date:
Funder's reference number:
Project website:

Additional reference number(s):

Ref.Number	Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

○ Yes ◉ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.*

This study aims to investigate how adolescents experience being part of Eating Disorder Services. The study will look specifically at the journey which adolescents take through services, and in particular how service users experience transitions from inpatient to community services. The study will investigate how this links to literature around recovery models.

Research suggests that a bio-psycho social approach which looks at both psychological and physical change is likely to be most beneficial for service-users in terms of recovery, but there is evidence to suggest that services often focus on more medical and physical aspects of care due to service restrictions and fears around risk.

Interviews will be held with between 8 and 12 participants, drawn from the [redacted] Participants will be aged between 12 and 19, and will have been in services for a minimum of one year. For the first stage of recruitment, participants must have experienced inpatient treatment as part of their care. If not enough participants are found then recruitment will extend to service-users who have not used inpatient services. Interviews will be analysed using Thematic Analysis, with themes drawn out to reflect the views of all participants who take part.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Informed Consent

The participant group is made up of adolescents, and so issues of informed consent must be carefully considered. Capacity will be assumed for all participants aged 16 or over unless there is evidence to suggest otherwise. For participants aged under 16, parental consent must be attained before they are able to participate in the study.

To address this, research packs for service-users aged under 16 will be sent to their parents/carers in the first instance, and they will be responsible to choosing whether to pass on the information to the service-user. Consent must be given by both the young person and by the parent/carer.

Recruitment material will reflect the age range of participants being approached, with documentation being written in accessible language with the use of pictures where appropriate to aid understanding.

Risk to Participants

No direct risk to participants is anticipated. However, due to the sensitive subject matter, there is a risk that participants may become distressed as a result of the interviews. The clinical judgement of the researcher will be used to help identity distress in participants, alongside parental/carer input where appropriate.

If any thoughts of low mood, self-harming or suicidality are expressed then this will be managed appropriately by the researcher. The level and immediacy of any risk will be determined through conversations with participants, and they will be encouraged to use their usual forms of support to help them manage any distress.

Where possible, service users will be encouraged to discuss their feelings with the practitioner that they work with within services. They will be encouraged to share concerns with their GP if they feel that they require further support. Additional support can be accessed either via using the helplines identified on the information sheet, or through encouraging participants to discuss their participation in the study with people close to them such as parents or relatives. In the case that risks are more immediate, participants will be encouraged to visit A&E where more urgent attention can be given. I would contact my own research supervisor immediately following any disclosures at all and seek further guidance from the university.

A6-3. Proportionate review of REC application *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there*

are ethical issues that require consideration at a full REC meeting.

○ Yes - proportionate review ◉ No - review by full REC meeting

Further comments (optional):

I understand that due to the adolescent population and the sensitive topic matter a full review may be more appropriate.

Note: This question only applies to the REC application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply:*

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☑ Qualitative research
- ☐ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

To investigate how adolescents experience community and inpatient treatment for an Eating Disorder in order to inform how services can best help with the recovery process.

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

In what way is adolescent identity development related to the manifestation and management of Eating disorder presentation.

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

Several reviews have been conducted of SU experiences of recovery within ED services, with evidence suggesting that recovery from an ED is a multi-factoral process that spans further than the treatment style alone (Espindola & Blay, 2009). Generally, approaches which were able to work within a psychological model encompassing various theoretical models were found to be more successful than those which worked within a more medical model (Bell, 2003). The importance of focussing on SU views of recovery and of interventions has been recognised (Street & Svanberg, 2003), with Espindola and Blay (2009) identifying additional factors such as visits from family and friends and work on self-esteem as central to full recovery for adults with EDs. Jenkins and Ogen (2011) explored the views of adults within services and focussed on the importance of therapy in helping to facilitate a sense of "wholeness" in individuals, which they report was best experienced within services which attended to the importance of therapy and re-forming the personal relationships which may have been impacted by periods of unwellness. This work has been particularly important within inpatient services, as the more medical model of treatment and intervention focusing on physical features of an ED can often be more prominent than in community teams (Bardon-cone et al, 2010).

Although helpful in encouraging a focus on service delivery and planning much research in this area and in particular the majority of quantitative research in relation to recovery has focused on the views of adults within services. While the lifespan of an ED commonly extends for many years, they most commonly emerge in adolescence, with research suggesting that the most common age to develop an eating disorder is between 15 and 19 years (Hoek and van Hoeken, 2003). It is known that recovery from an ED becomes increasingly difficult with each intervention or inpatient admission and that early intervention and management significantly impacts long term prognosis (Bakker et al, 2011). Tobin, Gilroy and Dennis (1998) suggest that research to improve the interventions provided to young people when they first display ED symptoms may be helpful in improving long term outcomes for this client group.

There is some existing research conducted with adolescents that looks at processes involved in treatment and discharge, where issues related to identity formation and peer relationships were found to be a fundamental aspect of recovery (Offord, Turner & Cooper, 2006). Additionally, the majority of existing research has focussed on the experience of having an ED, rather than on the experiences of services and of the recovery process (Bezance & Holliday, 2013). This distinction is important when thinking about the impact that services have on recovery for individuals and when considering governmental initiatives highlighting the importance of SU input to services (NICE, 2004). The relevance of identity formation in the recovery process of adolescents is an area which has received little attention within qualitative research to date, although some researchers (Bezance & Holiday, 2013; Crisp, 1983; & Striegel-Moore & Bulik, 2007) highlighting the fact that existing research has neglected to include adolescent literature such as life cycle theory or identity development to highlight the way in which AN can be conceptualised as a challenge to typical adolescent development. Within adults, AN has been understood as related to the formation of identity (Stein & Corte, 2007) and so further exploration of this area within adolescents may help to inform the way in which identity development is addressed within adolescent treatment.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

A qualitative methodology will be used, whereby all participants will take part in individual interviews which will take up to one hour.

Research packs will be given to services by the researcher, and will be sent out by services to all service-users who meet the exclusion/inclusion criteria (see A17.1 and A17.2). Service-users will be identified by the services involved in the study. These will be the [redacted] Trust.

The research packs will include invitation letters to parents/carers as well as letters for young people. For those service-users over 16, research packs will be addressed directly to them. For service-users aged between 12 and 16, packs will be sent to parents to pass on to young people if they choose to do so. Research packs will also include detailed information sheets, written in easily accessible language. If they choose to take part, service-users must return expression of interest forms to the researcher. Service-users will be chosen to participate based on the need to recruit participants of a range of ages and from a range of services. This process will be clearly outlined to participants within information sheets.

After they have returned the expression of interest forms, the researcher will contact participants via telephone and choose a mutually agreeable interview date and location. The location could be at participants homes, or at a private bookable room at a community centre near the participants home. They will also be given the option of using a private meeting room at [redacted] Participants will be given the option of bringing a parent/carer with them to the interview. In these cases the role of the parent/carer will be explained. It is envisioned that this role will be primarily observational.

Consent forms will be included within research packs, and will be read with participants prior to interviews. They will then be asked to sign a consent form before participating. The opportunity to withdraw from the study or have a break during the interviews will be reiterated.

Participants will then be interviewed by the researcher. Interviews will be semi-structured in that they will follow a pre-written interview schedule, but additional follow-up questions will be used throughout. Interviews will be recorded using a dictaphone, and uploaded onto secure university servers as soon as possible before being deleted from the dictaphone.

Interviews will be transcribed by the researcher, before being analysed using Thematic Analysis. One anonymised transcript will be read by the academic supervisor, and an anonymised analysed transcript will be shared with the academic supervisor and with the field supervisor. This is done in order to help ensure that any researcher bias is noticed and addressed and in order to help guide the analysis process.

Electronic files will be transferred to a university data custodian following the study's completion date. Data will be kept for 10 years, in line with the University of Lancaster Faculty of Health and Medicine data protection and research guidelines.

Thematic analysis has been selected for this study as it provides a forum for giving voice to participant experiences whilst also allowing participants of a range of ages and service-backgrounds to take part. The researcher has previous experience in working within Eating Disorder services, and so this form of analysis will allow for these pre-conceptions to be addressed and corrected for. In order to ensure that the questions asked are able to bring out a range of both positive and negative experiences, the interview schedule will be reviewed by the field and academic supervisor, as well as by the service users reviewing the recruitment documentation. It is envisioned that this multiple input on questions will help create a balanced interview.

A timeline for the study is as follows:

April-June 2014 – Write up ethics proposal forms, talk to R&D departments, finalise proposals.

July 2014 - Submit to ethics and gain ethical approval

August – December 2014 – Recruitment and interviewing. Start transcription and analysis.

January – March 2015 – Hand in draft of introduction and methods. Continue with data analysis and write up of results and discussion.

April – May – 2015 – Get back draft of results and discussion. Hand in completed project by May deadline.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- [x] Design of the research
- [ ] Management of the research
- [ ] Undertaking the research
- [ ] Analysis of results
- [x] Dissemination of findings
- [ ] None of the above

Give details of involvement, or if none please justify the absence of involvement.
Two current inpatient service-users were identified by the field supervisor. These service-users were given the opportunity to read and give feedback on all recruitment material, including consent forms and information sheets. They were asked to provide advice in relation to:
- Readability
- Understandability
- Clarity of the request
- How accessible the information was
- The way in which language was used

They were also asked to review the interview schedule and comment on any areas which they felt might be useful to explore.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

- Participants will have been service-users of community eating disorder services in the North West at any point within the last three years. This includes current service-users.
- For the first stage of recruitment participants must have accessed inpatient services as part of their care. If after the first wave of recruitment the study has not recruited a minimum of eight participants then recruitment will be widened to

include service-users who have accessed only community services.
- Participants must have been part of the relevant services for a minimum of 6 months prior to the study's start date.
- Participants must have accessed services during adolescence to be able to participate. Adolescence is defined by the World Health Authority (WHO, 2004) as any young person aged between 12 and 19 years old.
- If aged under 16 they should either be able to demonstrate capacity to participate or have parental permission to take part.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

- Service-users who are not able to speak English will not be invited to participate. This is due to pragmatic reasons in relation to interpreters.
- Service users identified who are still in inpatient services (excluded due to accepted higher risk within this group).
- Service users identified as being of particularly high risk by services.

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Receiving recruitment packs and choosing to participate	1	0	1 hour	Participants and their parents/carers will read the recruitment material. If they choose to take part then they will return an expression of interest form within the included stamped envelope.
Signing the consent forms	1	0	30 mins	Participants will read the consent forms alongside the researcher prior to interviews, and will sign it if they agree with the conditions within it. They will be given the opportunity to ask questions and seek clarification.
Taking part in interview	1	0	1 hour	Individual interviews lasting approximately one hour will be held with each participant. This will take place at a location chosen by the participant. This could either be at their home, at a pre-booked room within a community centre near the participant's home, or within a pre-booked meeting room at Manchester Central Library. Participants may bring a parent/or carer with them to the inverview.

A21. How long do you expect each participant to be in the study in total?

It is anticipated that all interviews will be held within two weeks of participants returning expression of interest forms - dependant on participant and researcher availability.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Interview questions while relate to participants' experiences of a potentially very difficult time in their lives and so may be difficult to think about or discuss. Any distress will be minimised through encouraging service-users to think about their participation carefully before they agree to take part, and to think about potential topics prior to the interviews.

The researcher will use their clinical judgement within the interviews to help identity when a participant may need support. Breaks will be offered throughout the interview process, and the right to withdraw from the study reiterated

immediately prior to each interview. If participants appear distressed or report any thoughts of distress, low mood, self harm or suicidality then the researcher will address this immediately. Participants will be encouraged to use their usual forms of support in such situations, such as talking to a member of their mental health team or talking to a carer/parent. They will be encouraged to discuss concerns with others as soon as possible, and advised to visit a&e if they feel they need immediate and urgent support. Telephone support numbers will be included within the information sheets and participants will be asked to identify potential avenues of support before interviews start. The researcher will discuss any concerns with the academic supervisor and follow any advice given.

A23. Will interviews/questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

(●) Yes ( ) No

If Yes, please give details of procedures in place to deal with these issues:

Please see answer to question A22.

A24. What is the potential for benefit to research participants?

There will be no direct benefit to participants from taking part in the study.

A26. What are the potential risks for the researchers themselves? *(if any)*

Interviews will be held in participant homes or in community buildings, and so there is a minimal risk to researchers from participants themselves. This risk will be minimised through following the university's lone working policy, as well as through using a pre-agreed lone working strategy with colleagues. This strategy is as follows:

Prior to each interview:
- Ensure that all mobile phones are charged and switched on.
- Ensure that the car has enough fuel to attend the interview and leave safely.
- Ensure that the car is parked in a way which enables an easy departure from the interview location.

- Identify a buddy before each interview, and inform them of the following details:
  - Date, time, and location that the interview will be taking place
  - Name and contact number of the interviewee, and state how long the interview will last
  - Personal and work phone number, car make and registration.

- Call the buddy before the interview to let them know you have arrived at the location and what strength of signal you have on your phone.
- Let the buddy know what time you are expected to complete the interview.
- Inform the interviewee that the interview will last x amount of time, and you will have to call your colleague to let them know if you need more time.
- If the interviewee has any pets that make you feel uncomfortable, politely ask if they can be put in another room during the interview.
- Try to sit as near to your exit as possible.
- Keep your phone out, but on silent so that you are able to see if your buddy is trying to make contact.
- Call buddy after the interview has finished and you are safe in your car, with the doors locked.

- If the interview takes more time than expected, text buddy or call buddy to let them know the expected completion time.
- If you feel that you are in any danger at any point during the interview- make your excuses and leave. If you need to, call your buddy and ask them if your next appointment has arrived at the service to help facilitate this. If you feel that you are in danger and you can't get out, text or call your buddy using the code word Mavis, to let them know that you are in trouble.

- If your buddy who is carrying out the interview has not called you after the given time, call both numbers you have for them. If you do not get a response, text both numbers. If you are still unable to make contact with your buddy, call the interviewee and ask to speak to your X (your buddy).
- If you have not been able to make contact with your buddy through these means, contact the police.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Clinicians working within the [redacted] will use electronic records to identify all service users who meet the inclusion and exclusion criteria. It is anticipated that this process will be straightforward as it uses records already kept by the teams.

The services will then be asked to send out the research packs to all eligible participants. For participants who are under 16 letters will be addressed to parents or carers. For those aged 16 or over packs will be addressed directly to service users.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

○ Yes ◉ No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

○ Yes ◉ No

A29. How and by whom will potential participants first be approached?

Within the research packs will be an expression of interest form. Those service users who are interested in participating will be asked to return the expression of interest form to the lead researcher, who will then contact participants via telephone using the contact details which they provide.

A30-1. Will you obtain informed consent from or on behalf of research participants?

◉ Yes ○ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Fully informed consent will be sought from all service users who wish to participate. For those who are aged 16 or over, they will be assumed to have full capacity to consent unless there is evidence or suggestion from services to suggest otherwise. In these cases parental consent will be sought.

For those participants aged under 16, research packs will be sent to parents/carers who will choose whether to share the information with them. Consent will need to be given by both young people and their parents/carers for them to participate in the study.

The consent form will be read with service users by the researcher prior to requesting consent, and opportunity to ask questions will be given.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form (s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

(•) Yes ( ) No

A31. How long will you allow potential participants to decide whether or not to take part?

Participants will be asked to return expression of interest forms within four weeks of them being sent out.

Consent forms will be signed at the point of interview, and participants must have completed a consent form before taking part in the study.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? *(e.g. translation, use of interpreters)*

Due to time and cost restraints as part of this study, participants who are unable to read English and be interviewed in English will be excluded from the research.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

( ) The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.

(•) The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.

( ) The participant would continue to be included in the study.

( ) Not applicable – informed consent will not be sought from any participants in this research.

( ) Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? *(Tick as appropriate)*

- [ ] Access to medical records by those outside the direct healthcare team
- [x] Electronic transfer by magnetic or optical media, email or computer networks
- [ ] Sharing of personal data with other organisations
- [ ] Export of personal data outside the EEA
- [ ] Use of personal addresses, postcodes, faxes, emails or telephone numbers
- [ ] Publication of direct quotations from respondents
- [ ] Publication of data that might allow identification of individuals

☐ Use of audio/visual recording devices

☑ Storage of personal data on any of the following:

- ☐ Manual files including X-rays
- ☐ NHS computers
- ☐ Home or other personal computers
- ☑ University computers
- ☐ Private company computers
- ☑ Laptop computers

Further details:
Interviews recorded on dictaphone will be transferred into password protected filed on secure university servers as soon as possible following each interview. It is not possible to encrypt files while they are still on the recorder, and so transcriptions will be transferred as quickly as possible and then deleted from the dictaphone. Data will be uploaded to the university servers on a personal laptop belonging to the researcher, but no personal data will be saved on this laptop. All files will be encrypted and password protected throughout.

In order to allow for field and academic supervisors to access the anonymised transcripts, they will be briefly transported between computers using a password protected and encrypted USB data stick.

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

All data will be saved without the use of participant name or identifiable information. When the field supervisor is given access to an analysed transcript, all identifiable information will be removed in it's entirety, and researcher discretion will be used in selecting appropriate segments of transcripts to share.

When writing up the research project, pseudonyms will be used throughout. Participants will be given the option to select their own pseudonyms, otherwise these will be selected by the researcher. Direct quotes will be used within the final project, but not where these quotes might provide information which directly identifies a participant. When feeding back information to services, additional care will be taken to ensure that quotes may not be recognised by clinicians who have had direct contact with participants.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

The lead researcher will have access to the personal telephone numbers of participants where these are given within the expression of interest forms. These forms will be scanned into the computers along with consent forms and kept on secure university servers within password protected files. No one else will have access to the forms. Paper copies will be shredded as soon as they have been scanned. Data will be kept until the end of the study, before being transferred to the data custodian for the university.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

- ○ Less than 3 months
- ○ 3 – 6 months
- ○ 6 – 12 months
- ○ 12 months – 3 years
- ◉ Over 3 years

If longer than 12 months, please justify:
Data will be kept on secure university servers for 10 years in line with the University of Lancaster Faculty of Health and Medicine data policy.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

(●) Yes ( ) No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.
Reimbursement of any travel expenses up to a maximum of £10 will be allowed for each participant.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

( ) Yes (●) No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

( ) Yes (●) No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

( ) Yes (●) No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

(●) Yes ( ) No

Please give details, or justify if not registering the research.
Research will be registered via the Central Manchester Foundation NHS Trust Research and Development Unit database.

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

- [x] Peer reviewed scientific journals
- [x] Internal report
- [ ] Conference presentation
- [ ] Publication on website
- [ ] Other publication

☐ Submission to regulatory authorities

☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators

☐ No plans to report or disseminate the results

☑ Other (please specify)

Presentation within all teams who took part in the study.

A53. Will you inform participants of the results?

◉ Yes ○ No

Please give details of how you will inform participants or justify if not doing so.

Participants will be given the option to receive a summary report of the results. They will be asked to indicate if they wish to receive this when they sign the consent form. If they do not indicate that they would like a copy at this stage but later change their mind they will be able to contact the researcher and request a copy.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

☐ Independent external review

☐ Review within a company

☐ Review within a multi-centre research group

☑ Review within the Chief Investigator's institution or host organisation

☑ Review within the research team

☑ Review by educational supervisor

☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:

The project was reviewed within the University of Lancaster Doctorate in Clinical Psychology research meeting. The study was initially presented to a group of peers and researchers where advice for any amendments was given, before preliminary approval was given to go ahead with an ethics application for the study.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size:	10
Total international sample size (including UK):	10
Total in European Economic Area:	10

Further details:

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

Thematic analysis will be used to transcribe the data. This will be done in line with the method put forward by Braun and Clarke (2001). Anonymised transcripts will be read by the academic supervisor, and an analysed transcript will be seen by and discussed with the field supervisor.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title	Forename/Initials	Surname
	Ms	Helena	Rose
Post	Clinical Tutor and Clinical Psychologist		
Qualifications	Doctorate in Clinical Psychology		
Employer	Lancashire Care		
Work Address	Division of Health Research, Faculty of Health & Medicine Furness College, Lancaster University Lancaster		
Post Code	LA1 4YG		
Telephone			
Fax			
Mobile			
Work Email	h.rose@lancs.ac.uk		

	Title	Forename/Initials	Surname
	Ms	Sarah	Cawtherley
Post	Dietician		
Qualifications	BSe MSc		
Employer			
Work Address	[redacted]		
Post Code			
Telephone			
Fax			
Mobile			
Work Email			

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status: ○ NHS or HSC care organisation ◉ Academic ○ Pharmaceutical industry ○ Medical device industry ○ Local Authority

Commercial status: Non-Commercial

○ Other social care provider (including voluntary sector or private organisation)

○ Other

If Other, please specify:

Contact person

Name of organisation	Lancaster University
Given name	Debbie
Family name	Knight
Address	Research Support Office, B58 Bowland Main
Town/city	Lancaster University
Post code	LA1 4YT
Country	UNITED KINGDOM
Telephone	(01524) 592605
Fax	
E-mail	ethics@lancaster.ac.uk

Is the sponsor based outside the UK?

○ Yes ◉ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

☐ Funding secured from one or more funders

☐ External funding application to one or more funders in progress

☑ No application for external funding will be made

What type of research project is this?

◉ Standalone project

○ Project that is part of a programme grant

○ Project that is part of a Centre grant

○ Project that is part of a fellowship/ personal award/ research training award

○ Other

Other – please state:

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

○ Yes ◉ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

Title Forename/Initials Surname

[redacted]

Organisation
Address

Post Code
Work Email
Telephone
Fax
Mobile

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

A69-1. How long do you expect the study to last in the UK?

Planned start date: 22/09/2014
Planned end date: 19/12/2014
Total duration:
Years: 0 Months: 2 Days: 28

A71-2. Where will the research take place? *(Tick as appropriate)*

- [x] England
- [ ] Scotland
- [ ] Wales
- [ ] Northern Ireland
- [ ] Other countries in European Economic Area

Total UK sites in study

Does this trial involve countries outside the EU?
( ) Yes (•) No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? *Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:*

- [x] NHS organisations in England 1
- [ ] NHS organisations in Wales
- [ ] NHS organisations in Scotland
- [ ] HSC organisations in Northern Ireland
- [ ] GP practices in England
- [ ] GP practices in Wales
- [ ] GP practices in Scotland
- [ ] GP practices in Northern Ireland
- [ ] Social care organisations
- [ ] Phase 1 trial units
- [ ] Prison establishments
- [ ] Probation areas

- [ ] Independent hospitals
- [ ] Educational establishments
- [ ] Independent research units
- [ ] Other (give details)

Total UK sites in study: 1

A76. Insurance/indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

- [ ] NHS indemnity scheme will apply (NHS sponsors only)
- [x] Other insurance or indemnity arrangements will apply (give details below)

Lancaster University Legal Liability cover will apply

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

- [ ] NHS indemnity scheme will apply (protocol authors with NHS contracts only)
- [ ] Other insurance or indemnity arrangements will apply (give details below)

Lancaster University Legal Liability cover will apply

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

- [ ] NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
- [x] Research includes non-NHS sites (give details of insurance / indemnity arrangements for these sites below)

Lancaster University Legal Liability cover will apply

Please enclose a copy of relevant documents.

PART B: Section 7 - Children

1. Please specify the potential age range of children under 16 who will be included and give reasons for carrying out the research in this age group.

The age range of participants will be 12-19 years. Research with this group in relation to Eating Disorders is limited in comparison to that conducted with adults, and there is evidence to suggest that the identity formation processes taking place during this age range may directly impact the way in which adolescents experience care.

2. Indicate whether any children under 16 will be recruited as controls and give further details.

N/A

3-2. Please describe the arrangements for seeking informed consent from a person with parental responsibility and/or from children able to give consent for themselves.

Children aged 16 and over will be asked to give consent for themselves unless there is any evidence to suggest that they are limited in capacity.

For those under 16, full and informed consent will be required from both parents and young people prior to participation in the study.

4. If you intend to provide children under 16 with information about the research and seek their consent or agreement, please outline how this process will vary according to their age and level of understanding.

Amended information and consent sheets have been developed for those who are under 16. This was done with the assistance of service users within this age range who helped ensure that information was accessible and understandable.

Copies of written information sheet(s) for parents and children, consent/assent form (s) and any other explanatory material should be enclosed with the application.

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.*

Research site	Investigator/ Collaborator/ Contact
Institution name	[redacted]
Department name	
Street address	
Town/city	
Post Code	

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:

    - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
    - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
    - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
    - May be sent by email to REC members.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication *(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

(●) Chief Investigator

( ) Sponsor

- ○ Study co-ordinator
- ○ Student
- ○ Other – please give details
- ○ None

Access to application for training purposes *(Not applicable for R&D Forms)*

Optional – please tick as appropriate:

☑ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Ms Bethan Roberts on 20/11/2014 15:36.

Job Title/Post:	Trainee Clinical Psychologist
Organisation:	Lancaster University
Email:	b.roberts2@lancs.ac.uk

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.
7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.
8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by An authorised approver at ethics@lancaster.ac.uk on 21/11/2014 16:54.

Job Title/Post:	Research Support Officer
Organisation:	Lancaster University
Email:	s.c.taylor@lancaster.ac.uk

D8. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by Dr Craig Murray on 20/11/2014 15:50.

Job Title/Post:	Senior Lecturer
Organisation:	Lancaster University
Email:	c.murray@lancaster.ac.uk

Appendix A – Participant Information Sheet – Adults/Over 16s

Information Sheet

Adolescent experiences of intervention and treatment for Eating Disorders

My name is Bethan Roberts and I am a Trainee Clinical Psychologist at Lancaster University.

I am conducting this research project as part of my training. Here is some information about the study and some answers to some of the questions that you might have about it.

What is the study about?

The study wants to find out what adolescents think about having been in an eating disorder service.

It is also to think about how you might have felt about the journey from first getting help to the stage where you are now. What has been helpful? What hasn't?

Why have I been approached?

You have been approached because the study will need information from people aged between 12 and 19 who have an eating disorder.

The study is approaching people who have used services in the North West and who have been in services for a minimum of six months.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. If you don't want to take part it won't affect your treatment in any way.

If you agree to take part you can change your mind before or after you have been interviewed. If you change your mind after you have taken part in the interviews I will remove your responses from the final study. I will be able to do this until one month before the study is submitted to the University of Lancaster in May 2015.

What will I be asked to do if I take part?

If you decide you would like to take part, I will get in touch with you to arrange an interview.

If you are aged under 16 you will need to have agreement from your parents or carer to take part.

I will meet you either at your home, or at another place where it is private for us to talk.

I will ask you some questions about your experiences and record the interview using a Dictaphone. The interview will take about one hour.

Will my data be confidential?

The information you provide is confidential.

Your name will not be used anywhere in the research and I will change the details of any information which might lead to people knowing who you are.

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will destroyed and/or deleted after they have been transcribed and analysed and the work has been assessed.

- The files on the computer will be encrypted and password protected (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
- At the end of the study, hard copies of consent forms will be kept securely in a locked cabinet for ten years. At the end of this period, they will be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this.

If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported and may be submitted for publication in an academic or professional journal when the study is finished.

Are there any risks?

There are no risks anticipated with participating in this study.

However, some of the questions I ask might remind you of things that are difficult to think about.

If you experience any distress following the interviews you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

I will ask you throughout the interview if you feel happy to continue and you will be able to stop at any time.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

However, your answers may help services to think about any new ways that they could help people in similar situations in the future.

Who has reviewed the project?

This study has been reviewed by an NHS Research and Ethics Committee and by the Research and Development Committee linked to the NHS trust that your service was based in. Lancaster University has acted as a sponsor for this study.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact me via e-mail or by calling me.

My email address is b.roberts2@lancaster.ac.uk and my work telephone number is: [X]

You can also write to me at:
Doctorate in Clinical Psychology
Faculty of Health and Medicine
Furness Building
University of Lancaster
Lancaster
LA1 4YF

If you like you can also contact my research project supervisor, Craig Murray:
Email: c.murray@lancaster.ac.uk or 01524 592730.

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr. Jane Simpson
Research Director
Doctorate in Clinical Psychology, Division of Health Research
Faculty of Health & Medicine
Furness Building – C20
Lancaster University
Bailrigg
Lancaster LA1 4YT
Email: j.simpson2@lancaster.ac.uk
Tel: (0)1524 592858

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

Professor Bruce Hollingsworth
Head of Division
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YD

Tel: (01524) 593718
Email: p.bates@lancaster.ac.uk

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Taking part in the study could be difficult as it will involve talking about aspects of your eating disorder that are emotional or upsetting. Throughout the interviews I will keep checking that you feel ok, and you will be able to stop the interview at any time. If you feel able to, then you should let me know how you are feeling and I will be able to help you get some support.

However, if you feel upset following the interview it is important that you should talk about this with someone who works in the Eating Disorder Service, such as a psychologist or nurse. If you need more urgent help, call your GP or visit A&E where you can get some immediate support.

These resources might also be helpful to you:

B-eat
Website: www.b-eat.co.uk
Helpline: 0845 634 1414

Mind
Website: www.mind.org.uk
Helpline: 0300 123 3393

Sane Line
Website: www.sane.org.uk
Helpline: 0845 7678000

Samaritans:
Website: www.samaritans.org.uk
Helpline: 08457 909090

Appendix B – Participant Information Sheet – Young Person Version

Information Sheet

Adolescent experiences of intervention and treatment for Eating Disorders

Hello.

My name is Bethan Roberts and I am a Trainee Clinical Psychologist at Lancaster University.

- As part of my training to be a psychologist I am doing a research project.
- I am interested in finding out what teenagers think about having an eating disorder.
- If you think you might want to take part, I would like to talk to you as part of the project.
- Here is some information to help you decide if you want to take part or not.

What is the study about?

The study wants to find out what teenagers think about having an eating disorder and about being in eating disorder services.

Why have I been asked to take part?

You have been approached because the study will need information from people aged between 12 and 19 who have an eating disorder now, or have had one in the past.

I am interested in talking to people who have used the services in the North West of England recently, and who were using the services for at least six months.

Do I have to be in the study?

No. **It's completely up to you** to decide whether or not you take part.

You will still be able to use the CAMHS services if you don't want to be interviewed.

If you agree to take part you can change your mind before or after you have been interviewed.

If you change your mind after you have taken part in the interviews I will remove your answers from the final study. I will be able to do this until one month before the study is submitted to the University of Lancaster in May 2015.

What will I be asked to do if I take part?

If you decide you would like to take part, I will get in touch with you or with your parents to arrange an interview.

You should talk to your mum or dad or carer to check that they are happy for you to be in the study. They will need to agree for you to take part.

I will meet you either at your home, or at another place where it is private for us to talk.

I will ask you some questions about your experiences and record the interview using a voice recorder.

The interview will take about one hour.

Will my data be private?

The information you provide is confidential. This means that it is private.

I won't use your name anywhere in the study, and I will make sure that I change any information that could help people guess who you are.

I will keep your voice recording on a private computer with a password so that no one else can listen to it.

I will delete the voice recordings from the recorder as soon as they are on the computer.

I might use quotes in the study of things that you say, but I won't use your name or let anyone know that it was you who said them.

The only time I will tell anyone else what you say is if I am worried that you or someone else are not safe and might be hurt.

If that happened I would try talk to you first, and then talk to someone else about my worries. That person would be the person you work with in the eating disorders service, or your mum or dad.

What will happen to the results?

I will write the results into a report and hand it in to my University.

Later, I might send the results to a place where they will be written up into a journal that other people can see.

Are there any risks?

In the interview I might ask you about things that sometimes make you sad.

If you get upset I will help you to feel better by helping you talk to someone about how you are feeling.

I will ask you throughout the interview if you feel happy to continue and you will be able to stop at any time, and I would like you to tell me if you feel upset.

Do I get a reward or prize for taking part?

No, you will not be paid or get any other gifts for taking part.

But I hope that the answers you give will help other people to work with other people who have eating disorders in the future.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact me via e-mail or by calling me.

You can also ask your mum, dad or carer to talk to me for you.

My email address is b.roberts2@lancaster.ac.uk and my work telephone number is: [insert]

You can also write to me at:

Doctorate in Clinical Psychology
Faculty of Health and Medicine
Furness Building

University of Lancaster
Lancaster
LA1 4YF

If you like you can also contact my research project supervisor, Craig Murray:
Email: c.murray@lancaster.ac.uk or 01524 592730.

Complaints

If you want to complain to anyone about me or about the study, then please get in touch with:

Dr. Jane Simpson
Research Director

Doctorate in Clinical Psychology

Division of Health Research

Faculty of Health & Medicine

Furness Building – C20

Lancaster University

Bailrigg

Lancaster LA1 4YT

United Kingdom

Email: j.simpson2@lancaster.ac.uk

Tel: (0)1524 592858

You can also talk to the person who is in charge at my University. His name is:

Professor Bruce Hollingsworth Tel: (01524) 593718
Head of Division Email: p.bates@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YD

Resources in the event of distress

If you get upset when doing the study, I will try to notice and I would like you to tell me if the questions are making you sad.

Here are some telephone numbers or websites that you could use if you felt upset after the study, and I would help you to tell your parents or someone who works at the eating disorder service so they can look after you.

B-eat
Website: www.b-eat.co.uk
Helpline: 0845 634 1414

Mind
Website: www.mind.org.uk
Helpline: 0300 123 3393

Sane Line
Website: www.sane.org.uk
Helpline: 0845 7678000

Samaritans:
Website: www.samaritans.org.uk
Helpline: 08457 909090

Thank you for reading these sheets.

Appendix C – Letter to service-users aged 16 or over

Bethan Roberts

Trainee Clinical Psychologist

Faculty of Health and Medicine
Furness Building
University of Lancaster
Lancaster
LA1 4YF

Dear _,

My name is Bethan Roberts and I am a Trainee Clinical Psychologist at Lancaster University.

As part of my course, I am conducting a research study in to the way that teenagers and young people feel about the way that they have had treatment for an eating disorder.

This is important to think about because it might help services to know how to help people better in the future.

I have enclosed an information sheet which explains a bit more about the study.

If you think that you might want to take part, it is a good idea to think about this with a parent or carer.

If you do think you'd like to find out a bit more, please return the "expression of interest" form to me. This lets me know that it is ok to get in touch with you.

My contact details are in the information sheet. Please get in touch if you have any questions or comments on the project.

If you would like to take part, please let me know by _.

Thank you very much for your time.

Bethan

Appendix D – Letter to parents

Bethan Roberts

Trainee Clinical Psychologist

Faculty of Health and Medicine
Furness Building
University of Lancaster
Lancaster
LA1 4YF

Dear _,

My name is Bethan Roberts and I am a Trainee Clinical Psychologist at Lancaster University.

As part of my course, I am conducting a research study in to the way that teenagers and young people feel about the way that they have had treatment for an eating disorder.

This is important to think about because it might help services to know how to help people better in the future.

I am approaching young people in the Manchester area who have accessed services within the last three years. For any young person under the age of 16 parental consent is required if they would like take part.

I have enclosed an information sheet which explains a bit more about the study.

If you think that this might be something you would like to discuss with your child then I would ask that you pass them the information sheets, along with the enclosed letter to them.

If you and your child do think you'd like to find out a bit more, please return the "expression of interest" form to me. This lets me know that it is ok to get in touch with you.

My contact details are in the information sheet. Please get in touch if you have any questions or comments on the project.

If your child would like to take part, please let me know by _.

Thank you very much for your time.

Bethan

Appendix F – Cover Letter to Participants from Services

[redacted]

[redacted]

Dear Patient/Parent,

Please find enclosed details of a study being conducted by Bethan Roberts, a Trainee Clinical Psychologist at Lancaster University.

Bethan is interested in exploring the way in which adolescents experience treatment and intervention for an Eating Disorder. The information that she collects will be written and fed back to services anonymously in order to help improve and inform Eating Disorder services.

We have not passed on any patient information to Bethan, but have sent these packs out on her behalf. If you read the information and choose not to take part in the study then Bethan will not know your name or details. If you do choose to take part, Bethan will only have access to the information which you give to her.

We will send out a routine reminder pack two weeks after the first pack, which can be ignored if you have chosen not to take part or have already agreed to participate.

You do not have to take part in this study. It will not impact upon your treatment within this service in any way.

Yours Sincerely,

(Lead clinician for each service)

Appendix F – Expression of Interest Form

Expression of Interest Form

If you have read the information sheet and think that you might want to get some more information or take part in this study, please return this form to me in the envelope provided.

If you return this form I will call you on the number that you give me to choose a time and place for us to meet.

We will talk some more about the study and then I will ask you to confirm that you would like to take part.

If you are under 16 years, then you **must have parental consent to take part.**

I agree to Bethan Roberts calling me or my parents on the telephone number below to discuss this study.

My name is _____

My date of birth is _____

Signature:_____ Date of Birth:_____

The best telephone number to use is:_____

This telephone belongs to:_____

If under 16:

My parent/carer's name is:_____

Parental Signature: I consent to my daughter/son finding out more about this research study through contacting Bethan Roberts.

Signature:_____

Date:_____

Appendix G – Consent Form

Consent Form

Study Title: Adolescent experiences of intervention and treatment for Eating Disorders

This study aims to look at how teenagers and young people experience treatment for an Eating Disorder. This information will help services know how to provide better treatment for people with Eating Disorders.

Before you agree to take part in this study, it is really important that you have read the information sheet. If you have any questions about the study then please talk about them with Bethan before signing the sheet.

If you are under 16 years old then both you and your parent/carer will need to sign this form before you can take part.

Read each sentence below and tick the sentences that you agree with.

	Me	Parent/ Carer
1. I have read the information sheet and fully understand what I will need to do in the study		
2. I have had the chance to ask any questions that I would like to be answered and know that I can keep asking questions all of the way through the process.		
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript.		
4. I understand that audio recordings will be kept until the research project has been examined.		
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving		

any reason, without my medical care or legal rights being affected.		
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be deleted. Bethan will try to remove that data as much as she possibly can, up until the point of publication.		
7. I understand that the information from my interview will be combined with other participants' responses, anonymised and may be published.		
8. I consent to information and quotations from my interview being used in reports, conferences and training events. I know that Bethan won't tell people my name or details about me that might help them guess who I am.		
9. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the Bethan will need to share this information with her research supervisor.		
10. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.		
11. I consent to take part in the above study. OR 12. I consent to my child taking part in the study.		

Name of Participant_____ Age_____

Signature_____

Date _____

If Under 16:

Name of Parent/Carer_____

Signature_____

Date_____

Name of Researcher _____

Signature _____

Date _____

Appendix H – Interview Schedule

Potential Areas to Explore:

- How did you come to be in services?
    - What helped you seek help?
    - Was it your decision?
- What has your experience of services for eating disorders been?
- What services have you accessed?
- What has been helpful?
- What hasn't been so helpful?
- What would you like to be different?
- Have you been able to speak to people about what you would like?
- Could you talk to me about your experience of first coming into services?
- Talk to me about what services you have accessed so far
- What did you want to happen when you came into services?
- What progress have you experienced in relation to that?
- How do you feel about being referred to services?
- What would you like to happen next?
- What has helped you get here?
- What hasn't been so helpful?
- What are your hopes for the future?
- What do you think has changed since you were referred to the service?
- Is anything the same or similar?
- What do you think will happen next?
- How can services help you to stay well?
- Do you want to stay well? What are the advantages?
- How can other people help you stay well?
    - How have other people like family or friends been involved in your journey?
        - What do you think they understand about your experience?
    - How do you communicate with them about this?
- What helps? What makes it worse?
- Could you tell me about your experience of having an eating disorder?
- What does having an eating disorder mean to you?
- Are there any benefits to having an eating disorder?
- Are there any disadvantages?

Appendix I – Lancaster University Lone Working Policy

Manual of Safety Section 23 Page 1 Issued: October 1996

GUIDANCE ON LONE WORKING

1 Introduction

1.1 It is inevitable that at certain times, staff, students and others will find themselves working alone. These occasions can occur, for example, at the beginning and end of flexible working periods, during holidays and during the night and at weekends.

1.2 There is no overall legal prohibition on working alone, but the general duties of the Health & Safety at Work Act and the specific duties of the Management of Health and Safety at Work Regulations still apply. These require the identification of the hazards of the work, assessment of any significant risks involved and devising and

implementing safe working arrangements to ensure that the risks are either eliminated or adequately controlled.

1.3 Many staff and students work alone at some time during their working periods at the
University and in the majority of cases they do so without significant risk. For example, persons working alone in offices carrying out typical office activities outside normal working hours are unlikely to be at significant risk, provided the appropriate fire precautions are in place (see para 5.4). However, there are occasions when it is not possible to devise arrangements for work to be done safely
by one person. In these cases, alternative arrangements involving help or back-up
have to be put into place.

1.4 This document lays down guidelines for departments to assess which tasks may be
undertaken by a lone worker and which may not.

2 What is a 'Lone Worker'?

2.1 Persons are considered to be working alone if they have neither visual nor audible

communication with someone who can summon assistance in the event of an
accident or illness. This guidance applies only to work carried out on University premises and similar locations. The guidance is not appropriate to fieldwork. The
University has a separate Code of Practice for Safety in Fieldwork.

3 When are special arrangements required?

3.1 Where a person may have to, or chooses to, work alone, it is the responsibility of the
Head of Department to ensure that a risk assessment is carried out and, if appropriate, that clear written arrangements are drawn up and put into place to
ensure that the work can be carried out safely. Where there is a departmental
Safety Handbook in existence, it would be appropriate for those arrangements to
form part of the Handbook.Manual of Safety Section 23 Page 2 Issued: October 1996

3.2 Lone working must not be undertaken where there is a reasonably foreseeable risk

that the work might result in an accident which would be sufficiently serious to require a second person to be available to summon help. Those tasks which are deemed unacceptable to be performed by a lone worker under any circumstances must be documented in either the written record of risk assessments kept by the department or in the departmental Safety Handbook, together with the local arrangements for safety for those tasks which are deemed acceptable.

4 Situations where 'Lone Working' is prohibited by law

The following examples specify systems of work which require more than one person.

4.1 Entry into confined spaces

Confined spaces include tanks, manholes, pipes, flues, ducts, ceiling voids, enclosed basement rooms and other spaces where there may be inadequate natural ventilation

4.2 Use of ladders which cannot be secured and require "footing" by a second person

4.3 Erection of scaffolding

4.4 Use of specified dangerous machines

Persons are prohibited from working alone at the following machines unless they

have received sufficient training in work at those machines:

Woodworking machines

Dough mixers

Meat mincing machines

Metal milling machines

Wire stitching machines

Guillotine machines (both powered and manual)

Platen printing machines (both powered and manual)

Slicing machines used in catering (both powered and manual)

Hydraulic and pneumatic power presses

Potato chipping machines

Food mixing machines when used with attachments for mincing, slicing, chipping or

any other cutting operations or for crumbling

"Sufficient Training" in the context of these machines must include an appropriate

period of 1:1 instruction on the hazards associated with them and the measures

required to minimise the risks. The correct use of guards, safety devices and

protective clothing where appropriate must be demonstrated. A written record of
the training must be kept. Manual of Safety Section 23 Page 3 Issued: October 1996

4.5 Work on or near live electrical conductors

The Electricity at Work Regulations give as examples the following electrical work
where it is likely that the person carrying out the work should be accompanied:

• electrical work involving manipulation of live, uninsulated power conductors
using insulated tools

• other work on or near bare live conductors where a person working on his/her
own would not be capable of undertaking the work safely without assistance in,
for example, keeping other persons from the work area.

5 Safe working arrangements for Lone Workers

5.1 Establishing safe working arrangements for lone workers is no different from

organising the safety of other staff or students. The obvious question that has to be
asked is whether the risks of the work can be adequately controlled by one person,
or are more people necessary?

5.2 Lone workers should not be exposed to significantly higher risks than others who
work together. Precautions should take account of normal working conditions and
foreseeable emergency situations, e.g. fire, equipment failure, illness and accidents.

5.3 If situations which are legally prohibited arise (see para 4) then lone working must
not be carried out. If the workplace presents a special risk to the lone worker then
lone working may be permissible provided additional control measures are put in
place to minimise the risk.

5.4 There should be safe access and exit from buildings for lone workers. In the
evenings and at weekends, many doors which provide an exit from buildings during

normal working hours are locked for security reasons. All means of escape required
during normal working hours must be available wherever a person works in the
building outside normal working hours. However, the mechanism for opening doors
on exit routes may be different outside normal working hours. The lone worker should be made aware that aspects of his/her route out of the building in an emergency may be different.

5.5 A person working alone should be able to handle safely all the plant and equipment
needed. It may be heavy, awkward, unstable, large, etc. More than one person may
be necessary to operate essential controls for the safe running of equipment.

5.6 All substances and materials involved in the work should be able to be handled
safely by one person. Hazardous substances, for example, substances which are
subject to the Control of Substances Hazardous to Health (COSHH) Regulations,
flammable, cryogenic and radioactive materials, must be considered carefully. These

are substances that have, for example, the potential to cause severe acute injury,
either alone or as a component of a reaction, to cause burns, or to affect the respiratory, cardiovascular, or central nervous system. The term 'handling', in this Manual of Safety Section 23 Page 4 Issued: October 1996
context, refers to a manipulative procedure or the supervision of a chemical reaction
that has not reached a stable state. It would not normally include moving a closed
container from one point to another.

5.7 If cash is handled there may be a risk of violence. The risk assessment should take
this into account and lone working may be considered inappropriate.

6 Medical Fitness

6.1 Both routine work and foreseeable emergencies should be considered when
assessing whether a person is medically fit to work alone. Persons who have declared a health problem may be considered unsuitable for lone working in certain
circumstances since emergencies may impose additional physical and mental

burdens on the individual.

7 Training

7.1 The University's Statement of Safety Policy notes that risk assessments should help to determine the level of training needed for each type of work.

7.2 Training is particularly important where there is limited supervision in order to control, guide and help in situations of uncertainty. It may be critical to avoid panic reactions in unusual situations and lone workers, therefore, need to understand fully the risks involved in the work, the necessary precautions and be sufficiently experienced. Departments should, therefore, establish clear procedures to set limits as to what can and cannot be done whilst working alone, and, where appropriate, when to stop the work and seek advice.

8 Supervision

8.1 Although lone workers cannot be subject to constant supervision, there is still a duty
on the University to provide appropriate control of the work. Supervision complements information, instruction and training and helps to ensure that staff and
students understand the risks associated with their work and that the necessary
safety precautions are carried out. It can also provide guidance in situations of
uncertainty.

8.2 The extent of the supervision required depends upon the risks involved and the
proficiency and experience of the person carrying out the work to identify and
handle safety issues. Persons new to a job, undergoing training, doing a job which
presents special risks, or dealing with new situations may need to be accompanied at
first.

8.3 The extent of the supervision required is a management decision - it should not be

left to individuals to decide they require assistance.Manual of Safety Section 23 Page 5 Issued: October 1996

9 Illness, accidents and emergencies

9.1 Lone workers should be capable of responding correctly in emergency situations.

Emergency procedures should be established in departments and the appropriate

persons given clear and concise training and instructions on how to implement them.

Similar information should be given to contractors or service engineers who may be

working alone (see also paragraph 2.4 of the guidance concerning Access into

Hazardous Areas).

9.2 Where a risk assessment of lone working, either during or outside normal office

hours, indicates that additional significant risks will be created, these additional risks

must be addressed and procedures put in place to monitor lone workers to ensure

that they remain safe. These procedures must be written and communicated to all staff and students who may at any time be required to undertake lone working. The procedures may include

• Periodic visits by a member of supervisory staff to monitor visually lone workers.

• Logging in and out of lone workers with Security (with an indication of likely duration of work).

• Regular visual checks by Security.

• Regular telephone contact with Security.

• The use of automatic warning devices which operate if specific signals are not received periodically from the lone worker.

• The use of other devices which are designed to raise the alarm in the event of an emergency and which can be operated either manually or automatically in the absence of activity.

This section of the Manual of Safety was approved by the Health and Safety Committee at its meeting on 22 May 2007

Appendix J – Lone Working Arrangement

Thesis lone worker strategy

This procedure is to be followed for each interview held as part of the research process. A buddy will be agreed prior to interviews and this strategy shared with them.

Prior to each interview, interviewer to ensure that:

- Your mobile phone is switched on and is fully charged and that your work and personal mobile numbers have been made available to your buddy.
- Check that your car has enough petrol to get there and back and inform your buddy of the car make, colour and registration.
- Ensure your car is parked in an accessible location that allows you to leave easily following the interview.
- Inform your selected "buddy" of the following information:
    - Date, time and specific location (including specific room location if possible) that the interview will be taking place.
    - Write the name and contact number of the interviewee in a sealed envelope and hand to buddy before interview. This will only be opened by them in case of emergency (see procedure below). Otherwise, the sealed envelope will be handed back to interviewer and then shredded.
    - A pre-agreed word to include within contact following interviews to ensure that they know that you are safe.
    - A pre-agreed word to include within contact if you feel that you are in danger at any point.
- When you arrive at the location, contact your buddy to let them know that you have arrived and inform them of any issues e.g. signal problems.
- Let your buddy know what time you are expected to complete the interview.
- Inform the interviewee that the interview will last x amount of time and you will have to call your colleague to let them know if you need more time.
- Ensure that you are sitting in the seat closest to the exit and that doors remain unlocked.
- Keep your phone on silent, but place within view so that you are aware if your buddy is trying to contact you. Use work mobile for this if possible, but if signal is low and a personal mobile is needed ensure that phone background is neutral.

- When the interview is finished and you have returned to your car, with the doors locked, call your buddy to let them know that you are safe.
- If you need to extend the length of the interview, let your buddy know via call or text. Use a pre-agreed word within the text or phone call to signal that you are safe and well.
- If you feel that you are in any danger at any point during the interview- make your excuses and leave. If you need to, call your buddy and ask them if your next appointment has arrived at the service to help facilitate this. If necessary use the pre-agreed code word to communicate that you are in danger.

For buddies:

- If you have not been contacted by the interviewer after the given time, contact them using both of the telephone numbers provided. If you are unable to make contact, send a text to both of the phones. If at this point you are still unable to get in touch then open the envelope provided and contact the interviewee and ask to speak to them.
- If you have not been able to make contact with your buddy through these means, contact the police.

Appendix K – REC Approval Letter

National Research Ethics Service

NRES Committee Northwest – Greater Manchester West

3rd Floor Barlow House

4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7434

12 December 2014

Ms Bethan M Roberts
Trainee Clinical Psychologist
Lancashire Care NHS Foundation Trust
Division of Health Research, Faculty of Health & Medicine Furness College, Lancaster University
Lancaster LA1 4YG

Dear Ms Roberts

Study title:	**Adolescent experiences of intervention and treatment for Eating Disorders**
REC reference:	**14/NW/1469**
IRAS project ID:	**147606**

The Research Ethics Committee reviewed the above application at the meeting held on 05 December 2014. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so.

Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager Anna Bannister, nrescommittee.northwest-gmwest@nhs.net.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

1. The Committee would like the Consent form to include the standard regulatory clause - I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from [COMPANY NAME], from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
2. The Committee would like all participants to have the information sheet currently developed for older participants rather than the 'Young Person' version.
3. Under 'Do I have to take part?' delete the sentence starting 'It's completely up to you to decide ….' so that the information sheet will be suitable for the full age range of participants.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on question 2 of the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.
To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Summary of discussion at the meeting

Ethical issues raised by the Committee in private discussion, together with responses given by the researcher when invited into the meeting

The Chair welcomed you to the meeting and thanked you for attending to discuss the study. The Committee said they had enjoyed reading the study.

Social or scientific value; scientific design and conduct of the study

The Committee queried what the maximum sample size would be. You confirmed the maximum number of participants recruited would be 12.

Recruitment arrangements and access to health information, and fair participant selection

The Committee noted high risk participants were excluded at pre-screening.

The Committee queried the reference to children without capacity at question 3-2 Part B section 7 of the IRAS form. You confirmed that you will not include anybody who cannot consent for themselves.

Informed consent process and the adequacy and completeness of participant information

The Committee thought the PIS for older children and parents was written so well that it would be suitable for younger children as well and though that only one PIS could be used with a minor change as detailed in the decision.

The Committee noted the standard regulatory clause was missing off the consent

from. You had no questions.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Certificate of Sponsor Insurance]	1	23 October 2014
Interview schedules or topic guides for participants [Interview schedule]	1	23 October 2014
IRAS Checklist XML [Checklist_19112014]		19 November 2014
Letter from sponsor [Letter from sponsor]	1	23 October 2014
Letters of invitation to participant [Letters of Invitation - Young Person]	1	23 October 2014
Letters of invitation to participant [Letters of Invitation - Parents]	1	23 October 2014
Letters of invitation to participant [Letter to participants from services]	1	23 October 2014
Participant consent form [Participant Consent Form]	1	23 October 2014
Participant consent form [Expression of Interest Form]	1	23 October 2014
Participant information sheet (PIS) [Participant Information Sheet - Young Person]	1	23 October 2014
Participant information sheet (PIS) [Participant Information Sheet]	1	23 October 2014
REC Application Form [REC_Form_24112014]		24 November 2014
Research protocol or project proposal [Research Protocol v2]	2	23 October 2014
Summary CV for Chief Investigator (CI) [Bethan Roberts CV]	1	23 October 2014
Summary CV for supervisor (student research) [Supervisor CV]	1	23 October 2014

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality- assurance/

HRA Training

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

14/NW/1469	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this

project. Yours sincerely

Dr Lorraine Lighton
(Chair) Chair

E-mail: nrescommittee.northwest-gmwest@nhs.net

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

"After ethical review – guidance for researchers"

Copy to: *Ms Debbie Knight*
[redacted]

Appendix L: Trust 1 Approval Letter

[redacted]

[redacted]

[redacted]

Lorraine.Broadfoot@cmft.nhs.uk

Bethan Roberts
Trainee Clinical Psychologist Lancaster Care NHS Foundation Trust
Division of Health Research, Faculty of Health & Medicine
Furness College, Lancaster University
Lancaster LA1 4YG

Dear Ms Roberts Ref. [redacted]

PIN: R03836

REC Reference: 14/NW/1469

Research Study: Adolescent experiences of intervention and treatment for Eating Disorders

Sponsor: Lancaster University

Chief Investigator: Bethan Roberts

Local Liaison: [redacted]

We have received a request for authorisation for our Trust to become involved as a

Participant Identification Centre (PIC) for the above study.

Following receipt of the documentation listed at the foot of this letter, we can confirm the Trust's authorisation.

I would like to take this opportunity to wish you well with your research.

Yours sincerely

LABroadfoot

[redacted]

Research Operations Manager

9th January 2015

Date:……..

cc [redacted]

Documents Acknowledged/Approved

Documents	Version	Date
Interview schedules or topic guides for participants [Interview schedule]	1	23 October 2014
Letters of invitation to participant [Letters of invitation – Young Person]	1	23 October 2014
Letters of invitation to participant [Letters of invitation - Parents]	1	23 October 2014
Letters of invitation to participant [Letters to participants from services]	1	23 October 2014
Participant consent form [Expression of Interest Form]	1	23 October 2014
Participant consent form	2	23 October 2014
Participant information sheet (PIS) [Participant Information Sheet]	1	23 October 2014
Participant information sheet (PIS)	2	23 October 2014
Research protocol or project proposal [Research Protocol v2]	2	23 October 2014
Summary CV for Chief Investigator (CI) [Bethan Roberts CV]	1	23 October 2014
R&D Form		20 November 2014
Summary CV for supervisor (student research) [Supervisor CV]	1	23 October 2014
NRES Approval Letter		30 December 2014

Appendix M: Trust 2 R&D approval letter

22nd April 2015

Ms Bethan M Roberts
Trainee Clinical Psychologist
Division of Health Research, Faculty of Health & Medicine
Furness College
Lancaster University
Lancaster
LA1 4YG

Dear *Ms Roberts*,

Re: NHS Trust Permission to Proceed

Project Reference: 15/03

Project Title: Adolescent experiences of intervention and treatment for Eating Disorders

Thank you for submitting your responses following the research governance review of your research project. I am pleased to inform you that the Chair of the Research Governance Committee has granted permission.

Please take the time to read through this letter carefully and contact me if you would like any further information. You will need this letter as proof of your permission.

Trust R&D permission covers all locations within the Trust; however you will only be allowed to recruit from the sites/services you have indicated in section 3 of the SSI application form. If you would like to expand recruitment into other services in the Trust that are not on the original SSI then you must contact the R&D department immediately to discuss this before doing so.

You also must ensure you have liaised with and obtained the agreement of individual service/ward managers before commencing recruitment in that service and you must contact the relevant service/ward managers prior to accessing the service to make an appointment to visit before you can commence your study in the trust.

Please make sure that you take your Trust permission letter with you when accessing Trust premises and please include the Trust reference number on any correspondence/emails so that the services are assured permission has been granted.

[redacted]

Honorary Research contracts (HRC)
All researchers with no contractual relationship with any NHS body, who are to interact with individuals in a way that **directly affects the quality of their care**, should hold Honorary Research NHS contracts. Researchers have a contractual relationship with an NHS body either when they are employees or when they are contracted to provide NHS services, for example as independent practitioners or when they are employed by an independent practitioner (*Research Governance Framework for Health and Social Care,* 2005). If a researcher does not require an HRC, they would require a Letter of Access (LoA). For more information on whether you or any of your research team will require an HRC or LoA please liaise with this office. It is your responsibility to inform us if any of your team do not hold Honorary Research NHS contracts/Letters of Access.

Staff involved in research in NHS organisations may frequently change during the course of a research project. Any changes to the research team or any changes in the circumstances of researchers that may have an impact on their suitability to conduct research MUST be notified to the Trust immediately by the Principal Investigator (or nominated person) so that the necessary arrangements can be put in place

Research Governance
The Research Governance Sponsor for this study is Lancaster University. Whilst conducting this study you must fully comply with the Research Governance Framework. This can be accessed at: http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4108962&chk=Wde1Tv
For further information or guidance concerning your responsibilities, please contact your research governance sponsor or your local R&D office.

Good Clinical Practice (GCP)
GCP is an international ethical and scientific quality standard for designing, conducting, recording and reporting trials that involve the participation of human subjects. It is the responsibility of all researchers who are carrying out a research project involving NHS patients and carers to complete GCP training and to update this every 2 years. All training certificates must be forwarded to the R&D department to comply with Trust permission. Please note that student projects are exempt in this process.

Risk and Incident Reporting
Much effort goes into designing and planning high quality research which reduces risk; however untoward incidents or unexpected events (i.e. not noted in the protocol) may occur in any research project. Where these events take place on trust premises, or involve trust service users, carers or staff, you must report the incident within 48 hours via the Trust incident reporting system. If you are in any doubt whatsoever whether an incident should be reported, please contact us for support and guidance.

Regardless of who your employer is when undertaking the research within Lancashire Care NHS Foundation Trust you must adhere to trust policies and procedures at all times.

[redacted]

Confidentiality and Information Governance
All personnel working on this project are bound by a duty of confidentiality. All material accessed in the trust must be treated in accordance with the Data Protection Act (1998) For good practice guidance on information governance contact us.

Protocol / Substantial Amendments
You must ensure that the approved protocol is followed at all times. Should you need to amend the protocol, please follow the Research Ethics Committee procedures and inform all NHS organisations participating in your research.

Monitoring / Participant Recruitment Details
If your study duration is less than one year, you will be required to complete an end of study feedback report on completion. However if your study duration is more than one year, you will be required to complete a short electronic progress report annually and an end of study report on completion. As part of this requirement, please ensure that you are able to supply an accurate breakdown of research participant numbers for this trust (recruitment target, actual numbers recruited). To reduce bureaucracy, progress reporting is kept to a minimum; however, if you fail to supply the information requested, the trust may withdraw permission.

Recruitment
Please provide the trust details of your recruitment numbers when requested. If you have any concerns with recruitment please contact the R&D team immediately for assistance.

Final Reports
At the end of your research study, we will request a final summary report so that your findings are made available to local NHS staff. The details from this report may be published on the NHS Trust internet site to ensure findings are disseminated as widely as possible to stakeholders. You may also be invited to present your findings to the Trust at an event or meeting.

On behalf of this Trust, may I wish you every success with your research. Please do not hesitate to contact us for further information or guidance.

Yours sincerely,

[redacted]

Appendix N: REC Email Confirming Ammendments

From: GMWest NRESCommittee.NorthWest- (HEALTH RESEARCH AUTHORITY) [nrescommittee.northwest-gmwest@nhs.net]
Sent: 26 February 2015 11:13
To: Roberts, Bethan
Subject: RE: 14/NW/1469 - GM West Ethics

Dear Bethan

We would have no problem with you extending the recruitment date, it would just be a minor amendment and we can use your email below as an acknowledgment. If you want to add another NHS hospital site you will need to fill out a new SSI form in IRAS and submit to the R&D of that hospital. We would not need to see the form or approve this.

I hope this helps.

Kind regards

Anna

Anna Bannister | REC Manager
Health Research Authority
HRA NRES Centre Manchester
3rd Floor Barlow House
4 Minshull Street
Manchester
M1 3DZ
Email: nrescommittee.northwest-gmwest@nhs.net | T: 0161 625 7434
HRA NRES Centre Manchester | www.hra.nhs.uk

IMPORTANT – **Click here** for details of significant changes to the REC booking and submission process

The HRA is keen to know your views on the service you received – our short feedback form is available **here**

Please note: From 30 September 2013, registration of clinical trials (first 4 categories in the IRAS filter) in a publicly accessible register will be a condition of the favourable ethical opinion. Further information is available by accessing the following link http://www.hra.nhs.uk/EasySiteWeb/GatewayLink.aspx?alId=179321