“And it's just a move that I wish I didn't have to make but I've got to”: Making Sense of Young People’s Journeys from Child and Adolescent Mental Health Services

And Clinical Research Portfolio

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Chapter One: Systematic Review

Exploring children and adolescents' lived experiences of mental health services: A Meta-synthesis

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Abstract

Aim: The perspectives of young people are increasingly being sought for service development. To date, there has been no synthesis of the empirical literature solely focused on young people with lived experience of mental health care. This review's aim was to synthesize findings from qualitative studies exploring young people's experiences of their mental health care.

Methods: Qualitative studies were identified from CINAHL, EMBASE, PsychINFO, PsychARTICLES, MEDLINE and Psychological & Behavioral Sciences Collection. A meta-study approach was undertaken incorporating both methodological critique and synthesis of research findings.

Results: Nine studies were identified. The meta-synthesis yielded an over-arching theme, ethos of warmth and responsiveness, along with four overlapping and mutually dependent themes: wanting to be "met" as a unique person; attunement and consistency in relationships; choice and empowerment; and the need for space(s). In addition, a model of the key features, or desired ethos and characteristics of a *good* mental health service was generated from the perspective of young people.

Conclusions: The features that young people desire are not novel nor are they impossible to achieve. Thus, even small changes in the direction of attuned young person-centred care will likely make a positive difference to those who access child and adolescent mental health services. The challenge we are faced with now is the translation of research evidence into practice in a complex health service context.

Key Words: adolescent, child, mental health services, patient satisfaction, qualitative research

Introduction

In Westernized countries, in any 3-6 month period, approximately 1 in 4 children meet the diagnostic criteria for a psychological disorder, with rates increasing with age (Carr, 2015). Mental ill-health can disrupt normative developmental trajectories (McGorry and Goldstone, 2011) with many established negative short- and long-term consequences that can extend into adulthood (Reardon et al., 2017), such as greater risk of subsequent mental health problems (Pine et al., 1998), impaired social functioning, poor educational achievement, substance abuse and self-harm (McGorry and Goldstone, 2011).

In order to mitigate these potential long-term effects, engagement with specialist mental health services is often required (Royal College of Paediatrics and Child Health (RCPCH), 2003; National Scientific Council on the Developing Child, 2007). It is therefore imperative that children and adolescents have access, if required, to high-quality mental health services that are designed to meet the distinct needs of young people (Day, 2008) with developmentally appropriate provision (Woolford et al., 2015). Moreover, young people's satisfaction with services has a strong link to functional improvement, reduced symptoms (Garland, Haine and Boxmeyer, 2007; Ronzoni and Dogra, 2012) and treatment completion (Oruche et al., 2014).

There has been increased focus on mental health services being more attuned to the needs of young people (World Health Organisation, 2012). Within UK healthcare policy and practice, a salient development has been the increased prominence given to the role and views of service users (Day, 2008). Thus, young people are important stakeholders in service design and development. A key objective of children and adolescents' participation can be to improve service quality and effectiveness (Day, 2008). The National Service Framework for Children, Young People and Maternity Services (Department of Health, 2004) stresses that the views of children and young people should be sought and considered during service-planning and development. Research supports this position as caregivers and their children have different mental health needs and evaluate services based on distinct perspectives, therefore, it is essential to capture both viewpoints (Garland, Haine and Boxmeyer, 2007; Aarons et al., 2010; Biering, 2010).

In line with this relatively recent paradigm shift towards young people being key stakeholders within service development (RCPCH, 2012), the literature base is only beginning to build in this area. Existing studies have generally focused on young people's views of healthcare staff more broadly, barriers to access, and some have focused on the transition to other services (Street, 2013). Dogra's (2005) review of young people's views of Child and Adolescent Mental Health Services (CAMHS) highlights the limited literature but does suggest that young people have different expectations of services compared to providers and caregivers. Concern has been raised by Worrall-Davies and Marino-Francis (2008) about the impact of young people's perspectives, as none of the thirteen studies in their review reported on changes resulting from the recommendations made by participating children and young people. Similarly, individual qualitative studies often produce meaningful information, but can have limited impact due to concerns about generalizability. Synthesizing the information from several studies can overcome this perceived limitation (Mills et al., 2005).

Plaistow et al.'s (2014) systematic review of young people's views of mental health services in the United Kingdom included thirty studies (both quantitative and qualitative), with a total of 13,605 young people. However, only 625 had experience of mental health services. Their findings suggested that young people have strong and consistent views of mental health services, with positive views of mental health professionals' personal qualities, such as being approachable, genuine, friendly, warm, kind, as well as skilled and knowledgeable. Negative views were held about stigma of mental illness, lack of information about CAMHS, medicalization of their difficulties and discontinuity of care.

Goodwin, Savage and Horgan (2016) published a systematic review on adolescents' and young adults' (13-25 years old) beliefs about mental health services and care, whilst also exploring the factors that positively and negatively influenced these beliefs. This was based on a *general population* sample and not those specifically experiencing mental health problems or using services. They found that young people held inaccurate and stigmatizing views about mental health interventions, professionals and access to care with some of these beliefs appearing to be influenced by the cultures from where the samples were drawn from (e.g. Israeli Arab Communities, Palestine, South Africa etc.). The authors stated that participants were uninformed about psychiatric medication and believed that accessing

mental healthcare was a sign of weakness. Moreover, participants perceived psychiatric hospitals and various mental health professionals negatively. As this study solely focused on young people from the general population, a clear limitation was that the beliefs of these participants were not based on personal experience of services. Thus, it would seem logical to systematically examine literature on the beliefs of young people who *have* used mental health services.

Aims of the Current Study

The aim of this systematic review was to synthesize current qualitative research in relation to the lived experiences of young people who have received care from mental health services. This review will answer the following question: how do young people experience generic multidisciplinary mental health services?

Methods

Search Strategy

Prior to beginning the scoping search, databases were searched for any existing reviews. No existing reviews were found specifically looking at the experiences of young people who had used mental health services and therefore, the initial scoping search proceeded. Electronic databases searched up to 30th January 2017. Databases included were CINAHL, EMBASE, PsychINFO, PsychARTICLES, MEDLINE and Psychological & Behavioral Sciences Collection. The databases were chosen due to their relevance to the research questions and to qualitative methodology. A subject librarian was consulted on the development of the search strategy used. Key words and subject headings using various combinations included: adolescence, adolescen*, teen*, youth, young person, young people, child, children, mental health services, "mental health servic*", "CAMHS", "child and adolescent mental health services", psychiatric services/care/treatment, psychological services/care/treatment, mental health treatment, qualitative research, lived experience, lived exper*, patient exper*, attitude, attitude*, patient attitude*, children's views, young people's views, patient satisfaction, satisfaction, quality improvement, and feedback. See Appendix 1.2 – 1.7 for full search results in each database. The reference lists of a previous systematic review (Plaistow et al., 2014) and all identified papers were hand searched for relevant papers. In addition, citation searches of two key papers in the area (Buston, 2002; Plaistow et al., 2014) were carried out using Scopus to identify any additional papers in order to improve the sensitivity of the search strategy.

Studies identified through this search strategy were reviewed in accordance with the inclusion and exclusion criteria. Papers were initially reviewed by title. Those that the title indicated as not being appropriate were excluded. Those which remained were then reviewed by abstract. Papers for which the abstract content indicated the inclusion criteria were met, were then reviewed by reading the full article. From this, the final set of papers meeting the inclusion criteria was found.

Inclusion and Exclusion Criteria

The following inclusion criteria were employed (i) focus of the research was the lived experience of using generic community-based child and adolescent mental health services,

(ii) based in secondary care services which were multi-professional and provided a range of services, and (iii) participants were young people up to 20 years old. Furthermore, (iv) qualitative research methods had to be employed, (v) with quotations/excerpts reported, (vi) in the English language, (vii) with full text available. In the case of studies that utilised multiple perspectives, (vii) the findings from children/young people had to be explicit and substantive.

Studies were excluded based on the following criteria: (i) the research focused on a single modality or treatment (e.g. Bury, Raval and Lyon, 2007), (ii) the primary focus was on expectations of mental health services (rather than experiences) or on the first appointment, (iii) inpatient experiences, (iv) experiences of transitions between services, (v) experiences of particular sub-groups such as offending youths or ethnic minorities, (vi) or experiences of primary care. In addition, studies were excluded if the data collected were predominately from adults (in multi-perspective studies).

Methodological Critique

Walsh and Downe (2006) reviewed existing quality checklists in order to develop a comprehensive framework for the assessment of the quality of qualitative data. As this quality framework (Appendix 1.8) is frequently used in meta-syntheses, it was employed as a guide to critique the included studies. Walsh and Downe's (2006) quality framework focuses on eight key domains, namely scope and purpose; design; sampling strategy; analysis; interpretation; reflexivity; ethical dimensions; and relevance and transferability.

To ensure consistency, an independent rater reviewed four purposively selected papers. There was 100% agreement between the lead researcher and the independent rater in relation to particular domains being absent (i.e. a score of 0). In addition, there was 100% agreement in relation to particular domains being present in the studies. However, there was variation between the raters with regard to whether the domains were fully present (i.e. a score or 2) or partially present (i.e. a score of 1) as it was difficult to disentangle the quality of the methodology from the quality of the write-up. Based on this, it was decided not to numerically present the findings but to provide examples of each domain sampled across the papers to focus discussion on methodological strengths and weaknesses. The total quality ratings derived from Walsh and Downe's framework were used to guide the order of the synthesis process (i.e. papers were incorporated into the meta-synthesis in order of their total quality rating).

Data Synthesis

The data from the studies were synthesised drawing on Noblit and Hare's (1988) method of meta-ethnography. This is essentially a constant comparative method, in which the themes and concepts from each study are compared and translated into each other to form an overall synthesis. Data from the strongest studies methodologically were initially analysed. The process involved reading each paper multiple times in order to enable the researcher to become immersed in the data. Emerging themes were recorded for each paper with substantiating author and participant excerpts. Through careful examination of emerging themes and concepts, the researcher was able to relate the papers to one another in a process described as 'translating them into one another'. The final steps involved synthesizing the translations and using interpretation to move from descriptive to explanatory. An audit trail of the data extraction (a sample is given in Appendix 1.9) and meta-synthesis was kept and reviewed as a means of checking the reliability of the data. Emerging coding frameworks were discussed in research supervision in order to refine codes and relationships.

Results

The process of the systematic review search method is displayed in Figure 1. A total of 9 papers were included in the meta-synthesis. The studies are summarised in Table 1. The included studies varied between those with a specific focus on a particular aspect of mental health services (e.g. the assessment process) whilst others were more general.

Figure 1: Prisma Flow Diagram

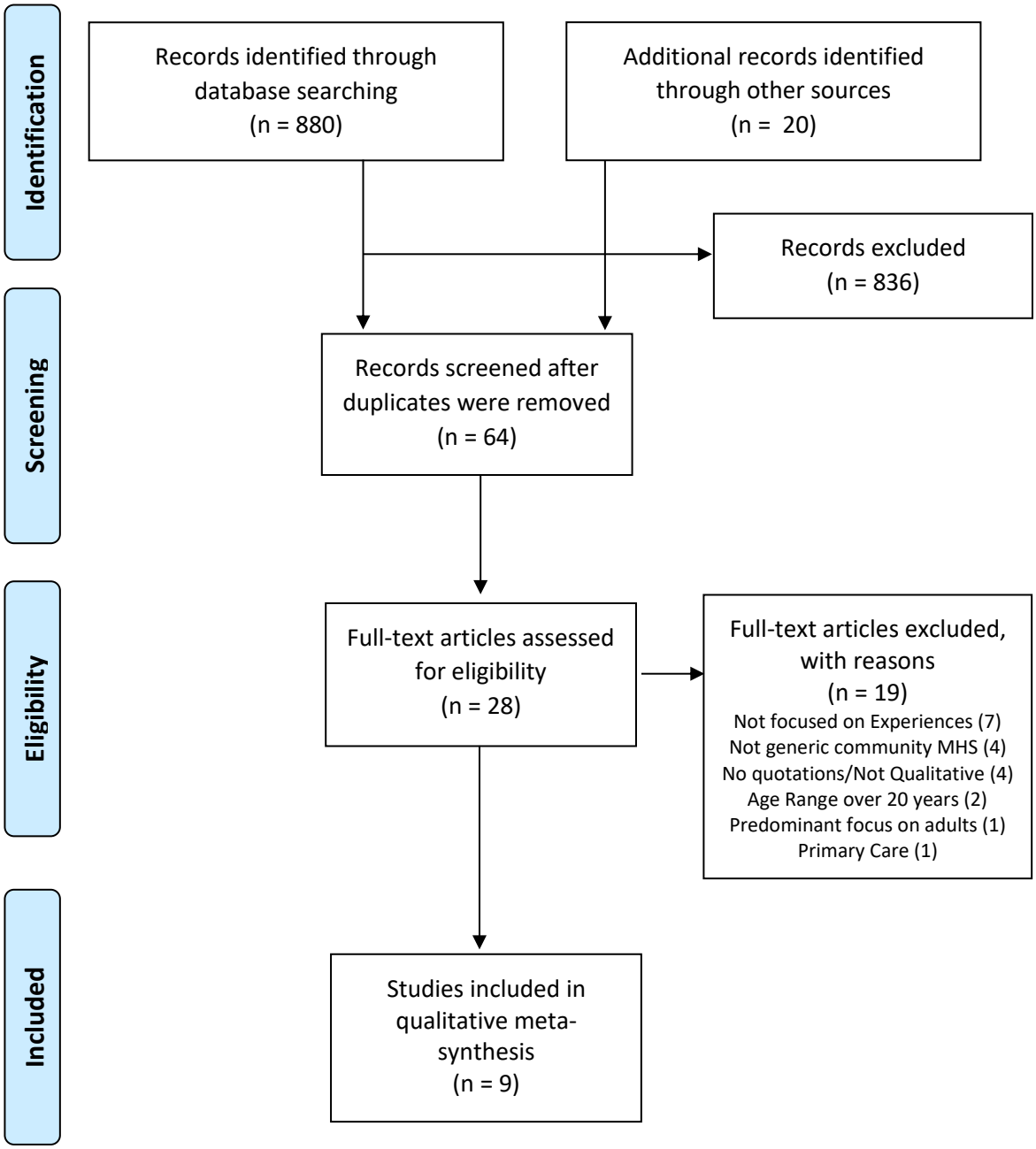


Table 1: Summary of included studies

Author (Year)	Country	Participants	No. of Young People	Age Range of Young People	Method	Brief Summary of Results
Binder et al. (2013)	Norway	Young People	14 (6 males)	16-18 years	Interview Thematic Analysis	4 themes related to experiences of assessment and diagnosis process: 1) standardized assessment obscuring contact with individuality, 2) hope through trust in therapist's competence, 3) relational authenticity enabling collaboration, 4) systemic pressure.
Bone et al. (2015)	England	Young People Parents	11 (9 males)	8-12 years	Interview Thematic Analysis	3 themes: 1) emotional apprehension and fear of the unknown in CAMHS, 2) therapeutic engagement - importance of being listened to and building good relationships, 3) making services child-centred.
Buston (2002)	Scotland	Young People	32 (11 males)	14-20 years	Interview Grounded Theory	Negative and positive comments related to: the doctor-patient relationship, treatment received, the health-care system, and the hospital/clinic environments.
Coyne et al. (2015)	Ireland	Young People Parents	15 (6 males)	11-17 years	Focus Groups Interview Thematic Analysis	5 themes: 1) getting help, 2) having a voice, 3) building a therapeutic alliance, 4) the impact of stigma, and 5) meeting support needs.
Day et al. (2006)	England	Young People	11 (5 males)	9-14 years	Focus Groups Thematic Content Analysis	4 categories were reported relating to key concerns and child-centred care: 1) basic expectations about appointments, 2) the process of therapy, 3) the content of appointments, 4) outcomes of appointments.
Harper et al. (2014)	England	Young People	10 (3 males)	16-18 years	Interview IPA	5 superordinate themes: 1) power differentials, 2) parental involvement, 3) developmentally attuned services, 4) developing self-expression, 5) continuity and loss of relationships.

Henriksen (2014)	Norway	Young People Professionals	21 (5 males)	13-17 years	Interview IPA	6 superordinate themes: 1) understanding own suffering, 2) readiness for change, 3) expressing agency, 4) co-creation in treatment, 5) contextual factors, 6) changes after psychotherapy
Oruche et al. (2014)	USA	Young People Parents	12 (NR†)	13-17 years	Focus Groups Content Analysis	Adolescents regarded caregiver involvement and positive qualities of staff as facilitators to treatment participation. Reported barriers were negative interactions with staff, staff turnover and medication dissatisfaction.
Persson et al. (2017)	Sweden	Young People	7 (3 males)	10-18 years	Focus Groups Written Task‡ Content Analysis	3 over-arching themes: 1) accessibility (more convenient appointment times in welcoming settings), 2) being heard and seen (opportunities to communicate more openly), 3) usefulness of sessions (treatments that are relevant to mental health and developmental needs).

† NR = Not reported ‡Different participants than those in focus groups

In aiming to synthesize current qualitative research in relation to the lived experiences of young people who have received care from generic multidisciplinary mental health services, a meta-study approach was undertaken incorporating both methodological critique and synthesis of research findings.

Methodological Review of Studies

Methodological strengths and weaknesses will be discussed drawing on Walsh and Downe's (2006) eight key domains. All nine papers clearly documented their scope, purpose and explicit aims. In relation to design, only four papers (Binder et al., 2013; Harper, Dickson and Bramwell, 2014; Henriksen, 2014; Bone et al., 2015) discussed the epistemological underpinnings behind their chosen qualitative methodology. Some papers, such as Buston (2002), clearly justified the use of qualitative methodology and chosen method but did not mention epistemology. Sampling strategy, data collection methods and analytic approach were generally well described. However, both Henriksen (2014) and Day, Carey and Surgenor (2006) lacked sufficient detail in describing the process of carrying out their analytic approaches. Meanwhile, Persson, Hagquist and Michelson (2017) were unclear in describing their participants. There were clear differences in the level of interpretation used across the studies, with some being more descriptive in nature which is likely to be due to their chosen qualitative method (e.g. Buston, 2002; Day, Carey and Surgenor, 2006; Oruche et al., 2014; Persson, Hagquist and Michelson, 2017). Harper, Dickson and Bramwell (2014) in particular, provided both a clear description of the IPA analytical process and evidence of interpretation: "*Our emergent themes represent commonalities and variations within the data, reflecting participants' narrative accounts more succinctly and at a higher level of abstraction than their original narratives (Reid et al., 2005)*" (p.92).

Four papers addressed 'researcher reflexivity' (Day, Carey and Surgenor, 2006; Binder et al., 2013; Henriksen, 2014; Coyne et al., 2015). A particularly good example was Binder et al. (2013) where the interviewers kept process notes and the authors were explicit about their parallel roles as clinicians and the potential for bias: "*It brings the possibility of a bias in the form of being critical toward some current trends in clinical practice. In the analysis, we have taken care to listen and to highlight positive experiences with instruments and frameworks that fall outside our own range of preferences; for example, constructive uses of ICD diagnosis in the therapeutic dialogue*" (p.117). All studies considered and discussed ethical dimensions. Coyne et al. (2015) provided a particularly good example of ethical

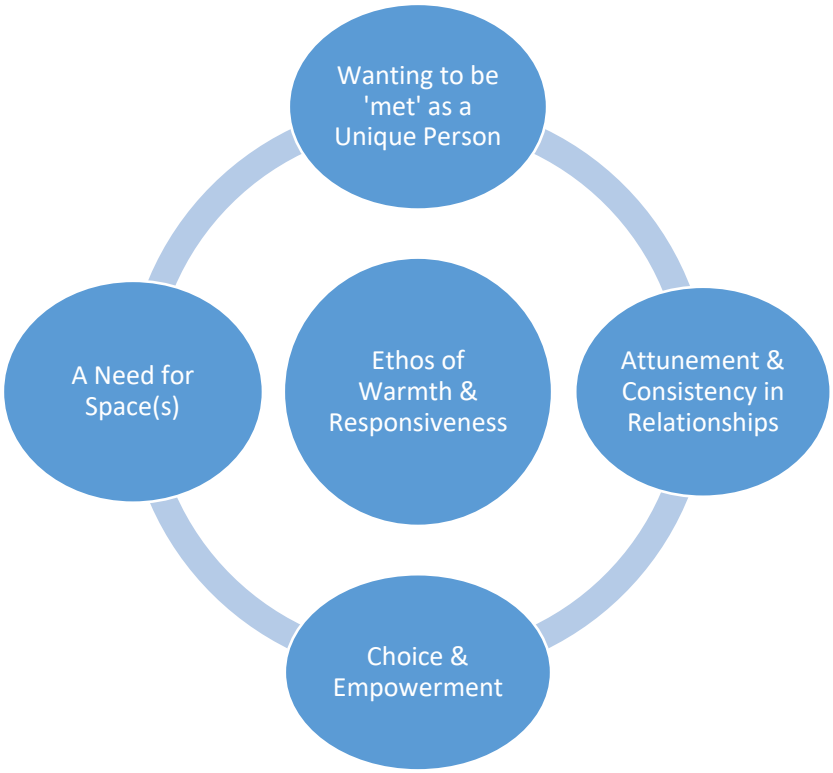
conduct by obtaining written consent from both parents and adolescents, whereas in another multi-perspective study only parental informed consent was obtained (Bone et al., 2015) when it may also have been appropriate to get informed consent from the children themselves. Relevance and transferability of findings were generally discussed well across the papers. The meta-synthesis started with the methodologically strongest studies (e.g. Binder et al., 2013; Harper, Dickson and Bramwell, 2014; Henriksen, 2014; Bone et al., 2015; Coyne et al., 2015) before the remaining studies were incorporated into the synthesis using the techniques of looking for data saturation (i.e. no new themes emerging) and active searching for data that disconfirmed the initial interpretations.

Meta-Synthesis

Four overlapping and mutually dependent themes were identified from the synthesis: wanting to be "met" as a unique person; attunement and consistency in relationships; choice and empowerment; and the need for space(s). An over-arching theme (OA) entitled ethos of warmth and responsiveness, provided a foundation for the discussion of these four themes. See Figure 2 for a diagrammatic representation of a *good* mental health service, which has been inferred from both positive and negative experiences shared by the participants across the themes. Themes are presented with substantiating excerpts and any material that has been omitted is indicated by ellipsis points (…). For clarity, quotes from participants are italicised, quotes from authors are not.

In terms of the overarching ethos, a picture emerged across seven of the included studies that services should be characterized by warmth and responsiveness (Day, Carey and Surgenor, 2006; Binder et al., 2013; Harper, Dickson and Bramwell, 2014; Henriksen, 2014; Oruche et al., 2014; Coyne et al., 2015; Persson, Hagquist and Michelson 2017). Participants provided consistent descriptions of what constituted a *good* clinician. The qualities outlined included being warm, genuine, friendly, approachable, trustworthy, engaging, capable and non-judgemental. Essentially, *"it's important to feel that you can talk to the person you meet"* (Participant Quote, page 7, Persson, Hagquist and Michelson, 2017). A *good* clinician is helpful and provides hope, whilst also acknowledging the complexity of the treatment process for the young person.

Figure 2: Key Features of a *Good* Mental Health Service



Wanting to be 'met' as a Unique Person

Seven studies contributed to the development of this theme of wanting to be 'met' as a unique person (Buston, 2002; Day, Carey and Surgenor, 2006; Binder et al., 2013; Harper, Dickson and Bramwell, 2014; Bone et al., 2015; Coyne et al., 2015; Persson, Hagquist and Michelson, 2017). Participants articulated the importance of wanting to be listened to and understood by clinicians. Essentially this meant wanting the focus to be on them as a *whole* individual, and not solely on their diagnosis, as depicted by Persson, Hagquist and Michelson (2017) that young people "expressed the importance of feeling that the clinician was genuinely interested in them as a person, beyond the nature of their problem(s): "*If he hadn't focused on just one thing [the problem], but also had showed concern for how I was feeling in general"* (Author and Participant Quote, page 8). The participants also want therapists to see what is "unique" and "healthy" about them (Binder et al., 2013, page 7). Day, Carey and Surgenor (2006) denoted that "a sense of being understood was very important and appeared to be a prerequisite for being helped" (Author Quote, page 148).

Participants consistently highlighted the importance of feeling listened to and being heard, which builds trust, and importantly, a connection: "Children…made positive comments on

the value of feeling listened to and of being able to express themselves" (Author Quote, page 453, Bone et al., 2015). Some quotations provided tended to reflect more on negative and inconsistent experiences but from this it is possible to infer what young people want from services. For example, "*If you talk with a buddy in a café, then you just talk. But the therapist just sits there and writes!...And you just don't feel met. Not at all...*" (Participant Quote, page 111, Binder et al., 2013). Persson, Hagquist and Michelson (2017) articulated that perceptions of the clinician not really listening or not taking the young person seriously were related to feeling like an object or like someone who should be 'fixed' (page 8). Young people want their interactions with professionals to feel genuine and authentic and not prescriptive or routine.

Attunement & Consistency in Relationships

The relationship between young people and professionals was a core feature in eight of the included studies (Buston, 2002; Day, Carey and Surgenor, 2006; Binder et al., 2013; Bone et al., 2014; Harper, Dickson and Bramwell, 2014; Oruche et al., 2014; Coyne et al., 2015; Persson, Hagquist and Michelson, 2017). For example, "all participants placed a high value on the relationship with their therapist both in CAMHS and in 16-18 mental health service" (Author Quote, page 93, Harper, Dickson and Bramwell, 2014). Oruche et al. (2014) outlined that a good relationship made young people more willing to attend and actively participate in sessions (page 565). A key feature of this theme is the consistent message articulated in the studies that relationships need to develop through a gradual process. This is denoted by the reference to 'building' relationships: "adolescents spoke about the importance of building a trusting and therapeutic relationship with healthcare professionals (Author Quote, page 565, Coyne et al., 2015). Furthermore, professionals need to be attuned to the stage of the relationship in order to tailor sessions and questions - "*build a relation before starting to talk"* (Participant Quote, page 7, Persson, Hagquist and Michelson, 2017). In essence, it can take time for young people to begin trusting and opening up as professionals start "as strangers" (Author Quote, page 148, Day, Carey and Surgenor, 2006), thus, there is an onus to pace questions and activities. "Personal questions became more permissible and tolerable once an initial relationship had been established…."*you don't know them and they want you to tell them what's going on in your life and you don't really know them…they should get to know you first and you get to know them and then they can ask"* (Author & Participant Quotes, page 148, Day, Carey and Surgenor, 2006).

Of critical importance is the consistency of relationships in light of the aforementioned gradual process required for relationships to develop. Many young people shared negative experiences related to having to see different professionals, sometimes without warning. There was a sense of having to 'start from scratch' or being 'back to square one' with negative emotions associated with having to retell one's story. For instance, "*It's very hard cos you're used to them, or you're just getting used to them, and they go. It's a real step you're opening your heart, you're exposing yourself and then they're gone and you're thinking God you were just getting to know them, you have to start all over again"* (Participant Quote, page 565, Coyne et al., 2015). A sense of injustice is also evident in Harper, Dickson and Bramwell (2014): *"It was awful moving through those services, you feel like you've got to re-tell your story to every fucker you meet. I hated feeling so exposed"* (Participant Quote, page 93).

Choice and Empowerment

All but two studies (Binder et al., 2013; Oruche et al., 2014) contributed to this theme centred on young people wanting more choice and power in relation to their mental healthcare. At the earliest point, information about mental health services is desired, as essentially in the absence of information, fear and anxiety prevails which may be linked to the well-documented stigma of services that some studies referenced. "The majority of children expressed feeling nervous or scared and additionally worried that it would be a negative experience" (Author Quote, page 452, Bone et al., 2015). Furthermore, "*I saw MHS* [Mental Health Services] *as something negative and scary, but I really did not know anything about it"* (Participant Quote, page 563, Coyne et al., 2015). More than half of the adolescents in Coyne et al.'s (2015) study expressed dissatisfaction with their exclusion from the decision to attend and commence treatment. There appeared to be a shift in most young people's perceptions of CAMHS after they had attended CAMHS, such as giving advice to others that it is not something to fear. Participants felt that with information they would have been better prepared for the assessment process, and not daunted or overwhelmed: *"If they sent a letter or something or phoned…(I) would have been more aware…could think of the questions…and then think of the answers"* (Participant Quote, page 146, Day, Carey and Surgenor, 2006).

A perceived power imbalance intensified the negative aspects of the assessment experience, "the children's discomfort was intensified by the implicit expectation that these questions [during early stages of assessment] should, of course, be answered" (Author Quote, page 146, Day, Carey and Surgenor, 2006). The following excerpt from Harper, Dickson and Bramwell (2014) also depicts the power differentials with an "us-and-them dynamic" between the participants and professionals. "Vicky, like many participants, described feeling disempowered and unable to challenge professionals in CAMHS: *"I had 9 doctors telling me erm they diagnosed me with 9 different things in a day and I was absolutely fuming because they wouldn't listen to me, it was like it didn't matter cause I was a child"* (Author and Participant Quote, page 9). Henriksen et al. (2014) further highlighted that as young people did not know what to expect during therapy, it was difficult for them to propose potential treatment techniques or therapeutic modalities (page 289). Participants appeared keen to have a choice in relation to their treatment, to be involved in decision-making processes, and those in Henriksen's (2014) study desired professionals to adjust the treatment based on their preferences. There was a clear link in many of the participants' quotations between the absence of choice and a sense of powerlessness.

A Need for Space(s)

All but two studies (Buston, 2002; Binder et al., 2013) contributed to this theme which relates to the need for different types of spaces to be offered by services. Firstly, a private space for young people which afforded them the opportunity to freely express themselves without feeling constrained or restricted by the presence of others. Participants reported finding it easier and less inhibiting if they met with clinicians without their parents: *"If your mum or dad's there you can't really say anything cos you think that you might upset them and you'll get told off at home"* (Participant Quote, page 150, Day, Carey and Surgenor, 2006). Similarly, a participant quote from Coyne et al. (2015) highlights the difficulty of discussing sensitive information in the presence of parents and also other professionals with whom the young person does not have a relationship with: *"...they were asking me really personal questions that I didn't want to answer in front of my parents let alone a load of strangers"* (Participant Quote, page 565). Moreover, for some participants the presence of others in *their* space can dictate the conversation and make young people feel overlooked and disempowered: *"...so if they make appointments it's with your parents so the child is just there to talk about what the parents say is the problem…it's always like the child is an afterthought kind of thing. When I got to about 13 or 15 that was getting very frustrating*

that you know they're here to see you and they're just talking to everyone else" (Participant Quote, page 93, Harper, Dickson and Bramwell, 2014).

An integral aspect of the space for young people is that it is developmentally attuned. Unsurprisingly, younger children can find talking with professionals difficult. Day, Carey and Surgenor (2006) suggested that activities are *preferred* to talking but perhaps it is more appropriate to say that activities *enabled* talking: *"When it's fun you could tell them anything cos they're letting you play with toys and do what you want while they speak to you"* (Participant Quote, page 149, Day, Carey and Surgenor, 2006). Similarly the length of sessions and the physical environment need to be tailored to the young person's developmental stage, which is highlighted well by Bone et al. (2015), "Clinicians need appropriate training, and opportunity to adapt their consultations in a way that engages children and is developmentally appropriate. In addition, the physical environment needs to be appropriate for developmental and chronological differences..." (Author Quote, page 455). Adolescents, meanwhile, desired a "collaborative and 'adult' approach" (Author Quote, page 92, Harper, Dickson and Bramwell, 2014) that fostered understanding in keeping with their developmental stage: "All participants expressed the desire for deeper collaboration at this stage in their lives and recognition of their desire for increased independence [16-18 MHS]" (Author Quote, page 93, Harper, Dickson and Bramwell, 2014).

Participants also recognised that other spaces are required to enable systemic working, such as family work and school work. They appeared to value this systemic working, but perhaps as long as it does not impact on their individual space. For example, *"It was good for me to have a separate space where I could explore my own struggles. To know that my parents had the same opportunity in a different setting was satisfactory"* (Participant Quote, page 290, Henriksen, 2014). An excerpt from Oruche et al. (2014) emphasised that clinicians can play an important role in de-blaming and modifying parental behaviour: *"they bring your parents in [to discuss] ...what your parents are doing wrong, not only us doing wrong. See, when parents send us to therapy, they make us look like it's all the kids' fault"* (Participant Quote, page 244, Oruche et al., 2014). Similarly, clinicians can be instrumental in executing change in the school system that benefits the young person: "They appreciated HCPs [health care professionals] liaising with their schools to discuss strategies and explain their

difficulties to teachers. *"…she set up something in school for me so I'd have someone to talk to about stuff so it's grand"* (Author and Participant Quote, page 566, Coyne et al., 2015). Some participants articulated that they did not want their appointment times clashing with activities or school, which suggests the need for professionals to be flexible in accommodating young people's preferences for their different spaces.

Composition of the Meta-Synthesis

For the purpose of transparency, Table 2 displays how each study contributed to the development of the discussed themes. The majority of data from each study was used in the meta-synthesis. However, four themes across the papers did not contribute, relating to systemic pressure influencing therapy (Binder et al., 2013), changes after psychotherapy (Henriksen, 2014), medication dissatisfaction (Oruche et al., 2014), and the hospital environment as experienced by a subgroup of participants who had been admitted as inpatients (Buston, 2002).

Table 2: Contribution of Studies to each Theme

Studies	Themes				
	OA*	1	2	3	4
Binder et al. (2013)	x	x	x		
Bone et al. (2015)		x	x	x	x
Buston (2002)		x	x	x	
Coyne et al. (2015)	x	x	x	x	x
Day, Carey and Surgenor (2006)	x	x	x	x	x
Harper, Dickson and Bramwell (2014)	x	x	x	x	x
Henriksen (2014)	x			x	x
Oruche et al. (2014)	x		x		x
Persson, Hagquist and Michelson (2017)	x	x	x	x	x

*OA = Over-arching theme

Discussion

This review aimed to synthesize qualitative findings related to the lived experiences of children and adolescents who had received care from mental health services, and in doing so understand how young people experienced these services. A clear picture emerged from the themes generated of both positive and negative aspects of young people's lived experiences. Importantly, it was often the negative experiences that young people highlighted or perhaps that studies chose to focus on. This meta-synthesis, which produced one over-arching theme and four interrelated themes, has attended to these negative experiences but has also inferred what is required from mental health services to create the opportunity for positive experiences which has obvious clinical significance and utility. Essentially the findings operationalise the key features, or desired ethos and characteristics, of a *good* mental health service, from the perspective of young people.

The themes are interdependent and overlapping, such that all are required rather than one being sufficient on its own. Thus, mental health services should have an ethos of warmth and responsiveness as a foundation for interactions and relationships between young people and professionals that are genuine, understanding, attuned and consistent. Individuality should be respected in services by supporting young people to have their *own* space, providing sufficient information for them to have choice, and encouraging their involvement in decision-making processes which will all foster a sense of empowerment. Moreover, person-centred care is not a new term by any means but perhaps young person-centred care is. Findings support aforementioned literature that clinicians need to alter their practice in order to be attuned to the young person's distinct needs (Day, 2008; World Health Organisation, 2012) and developmental stage (Woolford et al., 2015). Being routine or prescriptive in approach will not make young people feel *met*.

The findings are very much in line with Plaistow et al.'s (2014) systematic review that young people have strong and consistent views of mental health services. Their reported positive views of professionals' personal qualities echo the findings from this synthesis, namely approachability, genuineness, friendliness, kindness and warmth, whilst also being competent and skilled. Moreover, their review highlighted the negative impact of a lack of information about services and discontinuity of care which both emerged strongly in the current synthesis.

Methodological Strengths and Weaknesses

Within this meta-synthesis, the papers included came from seven different countries. Therefore, it is with caution that these findings are amalgamated as different cultural norms are likely to have been a factor. However, clear inclusion and exclusion criteria were enforced to ensure that the services experienced were as similar as possible. Secondly, unpublished or grey literature studies were excluded and it may be that inclusion of these would have added to the breadth and depth of studies. To counter this selection bias, the included studies were peer-reviewed which gave reassurance as to the overall quality of methodologies. Thirdly, a decision was made not to exclude papers on the basis of quality as there is no consensus on the application of quality criteria to qualitative research (Atkins et al., 2008). All papers were critically appraised prior to beginning the meta-synthesis and themes emerging from methodologically weaker studies were largely consistent with the more methodologically sound studies. It is also important to acknowledge that the included studies incorporated a range of different epistemologies and methodologies which contributed to the development of the overall meta-synthesis. The researcher was aware and reflective of the heterogeneity of how researchers constructed their individual themes, such as the extent of theorizing from the data permitted, while carrying out the meta-synthesis. Finally, qualitative meta-synthesis is an interpretive undertaking (Noblit & Hare, 1988) meaning it can yield different interpretations in line with its philosophical and epistemological underpinnings. A conscious effort was made to make the interpretive process transparent, open to scrutiny, and grounded in the primary data at each stage of analysis.

Clinical, Policy and Research Implications

The value of synthesizing qualitative data is the advancement of knowledge and conceptual theory beyond a collection of individual studies which heightens the potential for impact on policy and practice (Finfgeld, 2003). The findings reported here clearly identify the factors young people perceive as positive and negative in relation to their experiences of mental healthcare. The outlined features of a *good* mental health service are not novel but instead resonate with Carl Roger's (1951) eminent model of person-centred care. It would be too simplistic to argue that services should be modifying their practice without addressing the massive complexity and challenges involved when services are not necessarily aligned to incorporating a person-centred approach. Clearly service managers and clinicians can strive

to meet young people's needs by being more flexible, offering different spaces, providing consistent relationships, carrying out holistic assessments that focus on the *whole* person and not assigned or assumed diagnostic labels. Farrelly et al. (2015) highlighted that clinicians working in an adult context were aware of the fundamental aspects of person-centred care. However, drawing on Stryker's (2008) structural symbolic interactionism theory, the health service context comes with organisational priorities, policies and factors (e.g. time constraints), as well as profession-specific and role factors, all of which can act as a barrier to or undermine person-centred care and interactions (Farrelly et al., 2015).

The current findings provide supporting evidence that young people are instrumental in service evaluation and development and should be afforded opportunities to engage as key stakeholders. It is significant that the current findings concur with the available evidence on what young people value regarding their mental healthcare. Due to concerns raised about the impact of young people's contribution to service development (Day, 2008; Worrall-Davies and Marino-Francis, 2008), the focus should now be on marrying the evidence from lived experience accounts with the many stakeholders and processes occurring in the health service context. One such avenue that could be worthy of exploration in future studies is Normalisation Process Theory (May and Finch, 2009), which could support the identification of implementable changes in routine care.

Conclusion

To the authors' knowledge, this is the first review and meta-synthesis of young people's lived experiences of mental health services. The synthesis produced a model of the key features of a *good* mental health service from the perspective of young people. The features that young people desire are not novel nor are they impossible to achieve. The challenge we are faced with now is the translation of research evidence into practice in a complex health service context in order to have satisfactory young person-centred care in our mental health services.

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Chapter Two: Major Research Project

"And it's just a move that I wish I didn't have to make but I've got to": Making Sense of Young People's Journeys from Child and Adolescent Mental Health Services

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Plain English Summary

Background: Young people who are using Child and Adolescent Mental Health Services (CAMHS) are required to be discharged from those services when they reach 18 or earlier if they leave school. Young people who have continuing mental health needs are often transferred to Adult Mental Health Services (AMHS). This is one of many changes that young people face as they move into adulthood. This transition can be experienced as difficult because of breaks in therapeutic relationships, changes in the ethos of services, and waiting times to be seen.

Aims: This study aimed to explore young people's experiences of transitioning out of CAMHS. This involved understanding how young people experience and make sense of the transition process.

Methods: Six young people who were currently undergoing the transition out of CAMHS were interviewed. If feasible, young people were interviewed more than once. Semi-structured interviews were used, enabling the researcher to explore the process of transitioning in greater depth. The interviews were recorded, transcribed and analysed using interpretative phenomenological analysis.

Results: The transition out of CAMHS is a significant life event for young people. They held informed and uninformed expectations about their next destination, felt loss at leaving CAMHS and experienced a range of emotions at different stages of the process. Importantly, the sense that this was one transition among many for young people emerged from the analysis.

Conclusions: In addition to yielding young people's experiences of service transition, important insights into this group making sense of the wider transition to adulthood may also have emerged. The findings have clinical relevance and could support clinicians in aiding transition-age youth to negotiate not just the service transition but also future life transitions.

Abstract

Background: Young people who are using Child and Adolescent Mental Health Services (CAMHS) are required to be to be discharged from those services when they reach 18 or earlier if they leave school. Those who have continuing mental health needs are often transferred to Adult Mental Health Services (AMHS). Given the potential importance of this period, this study explored young people's lived experiences of the transition process.

Method: Semi-structured interviews were carried out with young people (n=6) who were currently undergoing the transition out of CAMHS. A qualitative methodology, Interpretive Phenomenological Analysis (IPA), was employed to elicit and analyse their experiences.

Results: Four superordinate themes captured the contrast between CAMHS and AMHS; young people's struggle with uncertainty; a sense of being left versus letting go; and the different stages of the transition process.

Conclusions: The transition out of CAMHS is a significant life event for young people amid the wider transitions they are negotiating as they enter adulthood. In addition to yielding young people's experiences of service transition, important insights into this group making sense of the wider transition to adulthood may also have emerged.

Key Practitioner Message

- Service transition is more than the act of transfer.
- Young people experienced a sense of loss of the familiarity of CAMHS, struggled with uncertainty or 'the unknown', and experienced a myriad of emotions at different stages of the process.
- Clinicians could support young people to use the focal service transition process as a model to learn about concurrent and future life transitions.

Keywords: transition, mental health, young people, adolescent, mental health services, qualitative research

Introduction

Transition can be viewed from distinctive perspectives (Singh et al., 2010a). Developmentally, adolescence is a pivotal stage of emotional, psychosocial, personal and physiological development as young people embark on acquiring adult roles through tasks such as separating from family, deciding on a career path and identity formation (Lee, 2001). In health care, young people move from one service to another upon reaching certain age milestones (Singh et al., 2010a). Here, the term transition is used explicitly to refer to this healthcare transition which can be defined as the process of moving from child to adult services. It refers to the full process including initial planning, the actual transfer between services when responsibility for providing care moves from a child to an adult provider, and support throughout (National Institute for Health and Care Excellence (NICE), 2016).

Adolescence is a risk period for higher psychological morbidity (Singh et al., 2010b) with most mental health problems beginning or having their origins in the teenage years (Paul et al., 2015). Young people with mental health problems have the highest rates of long-term morbidity and mortality (Royal College of Paediatrics and Child Health, 2003). Therefore, it can be particularly important that care remains consistent and uninterrupted throughout this time of heightened vulnerability, yet this is the period when young people are expected to move from CAMHS (Paul et al., 2015) where they may have established strong and positive relationships.

There has been longstanding concern that young people with mental health difficulties who fall between child and adolescent mental health services (CAMHS) and adult mental health services (AMHS) may get 'lost', disengage, or fall through the 'transition gap' during their move between services (Singh, 2009; Singh et al., 2010b). Many have argued that disruption of care during transition adversely affects the health, wellbeing and potential of this group (Lamb et al., 2008; Singh, 2009), occasionally referred to as vulnerable and high risk within the literature (e.g. Lamb et al., 2008; Singh et al., 2010b). Authors have presented various potential outcomes of poor transitions, namely disengagement from services, crisis-driven reconnection with services, and the development of severe and enduring mental health problems (Richards and Vostanis, 2004; Singh, 2009; Cappelli et al., 2016). Based on the available literature, adolescents are more likely than other groups to disengage from treatment (Harpaz-Rotem, Leslie and Rosenheck, 2004) and a decline in service utilisation

for transition-age youth has been found (Pottick et al., 2008), however, it can only be speculative to suggest that young people who disengage (either by choice or due to poor transitional processes) are more likely to return with more severe mental health problems.

NICE (2016) advocated for the need for a smooth and gradual transition for young people moving from child to adult services. Hovish et al. (2012) explored the concept of a 'good' transition by carrying out a multi-perspective qualitative study with young people, professionals and parents. They identified that informal and gradual preparation, transfer-planning meetings, periods of parallel care and consistency in key-workers promoted positive experiences of transition. Despite the existence of agreed principles of good transitional care, there is evidence that these principles are often not reflected in routine practice (NICE, 2016) and the transition process may be seen simply as an administrative event between CAMHS and AMHS (Vostanis, 2005) with young people not being well supported (Singh et al., 2010b; Paul et al., 2015). Singh (2009) argued that for many young people transition is poorly planned and lacks co-ordination leading to discontinuities in care. Studies have revealed a lack of comprehensive transition planning (Jivanjee and Kruzich, 2011) and patchy transitional care provision that is often not prioritised within mental health services (Paul et al., 2015), echoing NICE's (2016) statement that transition support in the UK can be inconsistent.

Young people can face significant obstacles in obtaining services as they negotiate the transition from adolescence to adulthood (Jivanjee and Kruzich, 2011). While developmental processes occur gradually, institutional transitions are "abrupt, arbitrary changes in status" linked to eligibility for services, often related to age (Vander Stoep, Davis and Collins, 2000, p.6). Ideological, clinical and organisational differences exist between CAMHS and AMHS, particularly in their theoretical and conceptual view of diagnostic categories, in treatment focus, in service organisation, delivery and availability, all of which can produce and perpetuate difficulties at the interface (Singh et al., 2005; Singh, 2009). McLaren et al. (2013) explored health professionals' perspectives on the organisational factors which facilitate or impede the transition finding a cultural divide between CAMHS and AMHS. Services were 'talking a different language' characterized by different beliefs, attitudes, mutual misperceptions and a lack of understanding of different service structures. Similarly, Richards and Vostanis (2004) identified that the different nature of child and adult

services and poor information exchange between these services created difficulties in transfer arrangements. Hovish et al. (2012) identified that further transfers between different adult mental health services, changes of key-worker and waiting lists were viewed negatively by those with experience of CAMHS-AMHS transitions.

Health services have been slow to respond to recommendations made by young people with mental health problems (Hovish et al., 2012). One factor suggested by Hovish et al. (2012) could be the general scarcity and poor quality of research aimed at eliciting young people's views of CAMHS. There are gaps in the knowledge about the process, outcomes and experience of transition from CAMHS-to-AMHS in the UK (Singh et al., 2010a). While such transition is widely accepted as a critical aspect of continuity of care, research is only beginning to identify the predictors, facilitators, barriers and outcomes of successful transition. We know relatively little about how the process of transition is experienced by young service users. Without such evidence, the voice of young people as a stakeholder is potentially missing from efforts to develop and implement service models that promote successful transition. The current study therefore focussed on young people's experiences of the transition process. Qualitative research is particularly appropriate for examining process through its attention to context and particularities (Holland, Thomson and Henderson, 2006). From the available literature, participants have been asked to talk about their experiences retrospectively. There are disadvantages associated with this; for example, participants may tend to view the past from the perspective of their present situation and viewpoint (Coyle, 2007). A gap in the literature is exploring the lived experiences of young people who are in the process of transitioning.

Aims

Therefore this study aimed to explore young people's idiographic experiences and expectations of the transition process, and identify barriers and aids to the transition process.

Research Questions

1. How do young people experience the transition process from CAMHS-to-AMHS?
2. How do young people make sense of the transition process?

Method

Design

The present study adopted a qualitative design to enable exploration of the transition process for young people. Interpretative phenomenological analysis (IPA), with its theoretical foundations in phenomenology, hermeneutics and idiography, is concerned with meaning-making and understanding subjective lived experience. IPA attempts to analyse and then present an account of the ways in which people experience specific and important events in their lives. It complements data collection methods, which invited participants to offer a rich, detailed, first-person account of their experiences. Interviews can give participants the opportunity to tell their stories, to speak freely and reflectively, and to develop their ideas and express their concerns at some length (Smith, Flowers and Larkin, 2009).

One-to-one semi-structured interviews were used with a topic guide. The aim of the interview was for the interaction to be defined more by the young person rather than researcher-led assumptions or questions in order to implement IPA's inductive epistemology (Smith, Flowers and Larkin, 2009). Highland Users Group (HUG), a network of users of mental health services in the Highlands, were consulted and reviewed the research materials prior to commencement of recruitment, to help develop the relevance of interview topics and accessibility of language. Separate interview guides (see Appendix 2.2 and 2.3) were developed for those transitioning to adult services and those who were in their final 12 months in CAMHS and a transition to adult services was being considered. The duration of interviews ranged from 23-61 minutes. Participants were re-interviewed, if feasible, to explore their unfolding experiences.

Ethical Considerations

The study was reviewed by the North of Scotland Research Ethics Committee (16/NS/0080) and sponsored by NHS Highland Research and Development Department (1226) (Appendix 2.4). Written informed consent was obtained prior to each interview, and all participants consented to the anonymised use of quotations (Appendix 2.5). Participants were re-consented at each interview. The Scottish Children's Research Network (2012) guidance on obtaining informed consent for clinical research with children and young people under 16 was followed, such that if considered competent by CAMHS clinicians to give an informed view on the question of participating in a research study they should be allowed, and facilitated to do so.

Procedure

The purpose of the study was explained to CAMHS clinicians who then identified potential participants from their caseload. Clinicians then provided potential participants with an information sheet (Appendix 2.6) and verbal consent was obtained before the researcher made contact to discuss participation further. Recruitment posters were also placed in CAMHS waiting rooms and circulated to Highland Users Group (HUG) to advertise the study. Prior to the interview(s), the researcher explained issues of confidentiality, anonymity, and the voluntary nature of participation. All interviews were conducted by the first author (C.F.) and took place in NHS Highland settings. A participant honorarium of £10 per interview was given. Field notes were recorded after each interview.

Participants

Smith, Flowers and Larkin (2009) recommend, in accordance with the philosophy of the analytic approach (IPA), that samples should be small to enable sufficient idiographic analysis. Six participants were recruited (see Table 1). Inclusion criteria were that participants had to (i) be age 15 years and over, (ii) be fluent in English, (iii) receiving services from CAMHS in NHS Highland, (iv) scheduled to transfer to AMHS within the next 12 months or in their final year with the CAMHS service and transition to AMHS is being considered, (v) aware that the transition is going to occur or aware that transition is being considered, and (vi) deemed by the clinical team to be competent to give own consent to participate in the study. Young people who had a diagnosis of a learning disability or social-communication disorder were excluded.

Table 1. Participants' Demographic Information

Participant*	Age (years)	Gender	Approximate length of time in CAMHS	Transition Status	Number of Interviews
Cara	17	Female	16 months	Transferred to AMHS**	2
Alastair	16	Male	2 years	AMHS transfer pending	2
Natasha	17	Female	2 years	Not decided	1
Kathleen	17	Female	3 years	AMHS transfer pending	1
Amy	15	Female	2 years	Decided not to go to AMHS	1
Naomi	17	Female	15 months	AMHS transfer pending	1

*Pseudonyms **First interview prior to transfer to AMHS

Data Analysis

Interviews were audio-recorded and transcribed verbatim. Data analysis was an iterative and inductive cycle, guided by Smith, Flowers and Larkin (2009). The researcher (C.F.) became immersed in the data by re-reading the transcripts and field notes, and listening to the audio recordings. Line-by-line analysis (i.e. coding) was carried out focusing specifically on descriptive, linguistic and conceptual coding of data (Appendix 2.7). The second-level coding involved an analytic shift to working primarily with the initial notes to generate concise and meaningful statements reflecting what was important from various codes (Appendix 2.8). Each participant's data were analysed separately in order to respect their individuality and emerging themes were identified. Finally, the researcher looked for patterns across the participants by identifying shared higher-order qualities whilst also capturing the unique idiosyncratic instances within the data. As suggested by Smith, Flowers and Larkin (2009), an analysis diary was kept throughout this process to support the bracketing or suspension of beliefs, expectations and ideas to adhere to IPA's idiographic commitment.

Researcher Reflexivity

In terms of role reflexivity, the lead researcher is a trainee clinical psychologist who has worked in both child and adult mental health services in NHS Highland, which afforded an informed perspective on what participants referred to in their interviews. The researcher made an attempt to explicitly acknowledge any preconceptions, biases or assumptions that were acquired through working in these services prior to data collection and analysis. For example, one documented assumption related to the belief that waiting times for adult services were extensive which could lead to young people voicing frustrations about this. None of the participants were known clinically to the researchers. IPA explicitly recognises that the analytical process involves researchers trying to understand how others make sense of their experiences. The researcher adopted a reflexive stance to be transparent about her conceptions, manage expectations created from the rhetoric in the literature base (i.e. the framing of this group as vulnerable or that a smooth transition is required for positive mental health outcomes), and better understand her positioning and approach to the data. The interpretative process was carefully documented using an analysis diary to capture the 'dialogue' between the researchers, their coded data, and their psychological knowledge about what it might mean for participants to have these concerns in this context. Research

supervision was used to help test validity and develop the coherence and plausibility of the interpretation.

Results

The analysis resulted in the development of four interrelated superordinate themes. For the purpose of transparency within the analysis these themes are presented with participant narratives and substantiating excerpts[1]. See Table 2 for a summary of the superordinate themes and their corresponding subordinate themes.

Table 2. Superordinate and Subordinate Themes

Superordinate	**Subordinate**
Contrasting CAMHS to AMHS	Different approaches Variation in seriousness Getting a diagnosis
The Struggle with Uncertainty	Lack of information Issue of time Emotional and cognitive consequences
Being Left versus Letting Go	Role of a safety net Unpredictability of mental health Multiple transitions
The Different Stages of the Transition Process	Multiple factors influence the process Loss of familiarity and relationships Ambivalence and multiple emotions Processing time

"..seems more like a grown up world than a kid world" (Kathleen, 4.93) - Contrasting CAMHS to AMHS

Different Approaches

Participants understandably tended to use CAMHS as a point of reference when attempting to consider what adult services would be like. CAMHS was conveyed as being friendly, more relaxed, with an all-around more informal approach. For example, Amy described her CAMHS clinician as *"really lovely"* (3.64) and the initial appointment as *"we just had a natter and got to know each other a little bit"* (2.38). AMHS, on the other hand, was portrayed as being more direct and *"much more to the point"* (Kathleen, 14.330). The

[1] In quotations, material that has been omitted is indicated by ellipsis points (...). Words inserted for clarity are represented by square brackets [ ]. Words that have been underlined (_) indicate that they were emphasised. Participant name, transcript page and line number are provided for each quotation.

young people appeared to make sense of this difference in approaches in terms of seriousness. AMHS was presented as being "*a bit more of a serious place"* (Alastair, Interview 2, 12.315) where there are more people to see and "*so many more like bigger cases"* (Naomi, 18.518) which meant CAMHS' "*friendly sort of feel to it"* (Kathleen, 14.330) would be lost. The disparate approaches seemed to be understood as necessary due to the greater severity and complexity of cases in adult services:

> *"...I just feel like the child's services is like nicer (laugh). Ahm (sigh) adult services I think they are going to be a lot more to the point and quite brutal but like because they have to because they need to like. They've got so many more- I think they probably have so many more like bigger cases."* (Naomi, 18.518)

Variation in Seriousness

Some young people described feeling frightened and daunted by the different nature of the services, and appeared to question whether one was *serious* enough to go to AMHS: "*And I don't want to waste their time by me being like oh I'm sad"* (Naomi, 18.529). Similarly, it can be daunting to consider the shift in developmental expectations "**...** *it's almost worrying that you're moving on into this service that seems more like a grown up world than a kid world* (Kathleen, 4.93). A world that can seem to have more severe consequences – "*they would be like really strict (laughs).....that they'd like section me or something drastic…"* (Cara, Interview 1, 17.340). There was an apparent unease from some participants at the idea of being 'out of one's depth' in AMHS which may have been perpetuated by not yet identifying as an *adult*, such as Cara who recalled feeling *"pretty petrified…*[because of the] *word adults"* (Cara, Interview 1, 17.343). Arguably, the CAMHS-AMHS transition could be a metaphor for the wider transition these young people are negotiating as they enter adulthood, which is perhaps daunting and akin to a different more *serious* world.

Getting a Diagnosis

For Alastair and Cara, AMHS afforded the opportunity to explore more *serious* diagnoses – "*…the main thing is probably just like the fact of actually just being that much closer to a diagnosis"* (Alastair, Interview 1, 6.151). This was interpreted as diagnoses perhaps also being understood in terms of severity, with AMHS dealing with more serious problems. Both discussed feeling hopeful for AMHS *"…cos there's obviously more opportunities* (Alastair, Interview 1, 6.151)…[as] *they are a lot more specialized up there for a bit more serious cases which I hope should be helpful"* (Alastair, Interview 1, 10.251). Cara was more critical

of CAMHS' approach in her second interview, having attended her initial appointment with AMHS, suggesting that CAMHS opted to avoid discussing or dealing with more *severe* issues which she saw as a barrier to her recovery: "*...they just avoid pinpointing it. Because they feel that because we're kids we can't cope with it but I dunno I think kids know a lot more than they think"* (Cara, Interview 2, 16.386). Thus, in terms of diagnoses, AMHS was portrayed as having a more direct approach in contrast to CAMHS where *"...they kind of baby it down if you know what I mean but they* [AMHS] *just get straight to the point* (Cara, Interview 2, 1.20). However, Alastair talked about CAMHS as having a filtering function to explain their reluctance to deal with more *serious* mental health problems, as they are "*trying to like weed out some of the people who are just trying to get attention"* (Interview 2, 13.337), such that it is "*like the trials"* whereas AMHS is "*the actual competition…where you can sort of get more help"* (Interview 1, 11.289-293). Perhaps these young people are engaging in concurrent meaning-making processes; utilising services as a reference point to try and actively make sense of their own mental health problems in terms of what they are and how serious they are.

"*Fear of the unknown"* (Cara, Interview 1, 29.648) – The Struggle with Uncertainty

Lack of Information

Many participants highlighted a lack of information, sometimes even the most basic information, about the transition process and AMHS: *"I'm basically clueless about the transition"* (Alastair, Interview 1, 4.100). Questions raised related to the location of AMHS, the professionals who might be involved, the approach that might be used, and one participant was even worried about the cost of AMHS. This sense of unknown was highlighted in Natasha's excerpt through repetition of the phrase "I dunno":

> *"Just like like I dunno if it will be here or somewhere else I don't know how much it will cost ahm I dunno like ahm I dunno. Like will they have to start from scratch or will they get like like documents that say what has happened and stuff. Ahm also like will I keep getting my medication ahm will I have to stop getting medication."* (Natasha, 9.202)

Issue of Time

The transition process did not appear to have a clear time-scale, which was difficult for young people to contend with. Some were expecting the move to AMHS but were frustrated

at the uncertainty of when it would *actually* happen: "*sort of just like when's it actually going to happen"* (Alastair, Interview 2, 6.130). For example, Kathleen was transitioning to AMHS in another health board to attend University which added an additional layer of complexity and uncertainty for both her, her parents, and her CAMHS clinician:

> *"...my Mum was quite keen on knowing what was going to happen**.** Ahm but it felt like a lot of the answers when we asked Professional 1 he didn't know. There was no way to be sure of the waiting list. There was no way to be sure how long it was going to take. Ahm so when we asked to try and clear some uncertainties we got more uncertainties."* (Kathleen, 10.226)

Emotional and Cognitive Consequences

As a result of limited or absent information, young people described worrying, were "*just really confused about how it will happen* [as] *I just have no idea"* (Natasha, 8.191), and felt *"fear of the unknown"* (Cara, Interview 1, 29.648). Anxiety and a sense of being daunted was apparent, with some referring to blocking out or avoiding the subject of transition altogether: "*Cos I didn't want to bring it up cos I'm so scared"* (Naomi, 20.583). This sense of unknown also perpetuated a hesitancy to attend AMHS, "*Most of me was like you don't want to do it cos you don't know what it's like and you don't want to get involved in it"* (Cara, Interview 1, 22.487).

One participant's experience, Amy, was a contrast to that of the other participants. She described a supportive transition, out of CAMHS and mental health services completely, characterized by more certainty and less fragmented information. She emphasised the comfort and benefit of being informed and updated from the start of the process to the eventual ending of appointments:

> *"I was informed by Professional 2 that when I was leaving school I would also have to leave CAMHS but warned me <u>months</u> in advance* (5,131)*... I always knew that I only had so many appointments left so I wasn't like worried about it because me not knowing things worries me same that it would any other person (laugh) but just the fact that she always kept me updated"* (Amy, 6.165).

"*oh please don't leave me"* (Natasha, 5.118) – Being Left versus Letting Go

Role of a Safety Net

Some participants expressed fear and anxiety at the idea of being left without support. Leading on from Theme 2 and the uncertainty of the transition process, for some participants the end point with CAMHS was experienced as abrupt. It appeared that it may not be regular, scheduled appointments that would be missed but rather the knowledge that someone is there *if needed*. Losing this was experienced as isolating, "*quite daunting and lonely cos I get really scared like what if I feel bad who will I go to"* (Naomi, 11.314). There was heightened distress if the young person did not feel as if they had other avenues of support to draw on.

Unpredictability of Mental Health

Participants' experiences of their mental health as a fluctuating concept made it far more difficult to contemplate or experience coping without support, for instance, "*I'd be completely fine but then other times I'd be like rock bottom"* (Cara, Interview 1, 8.177). The potential element of risk, such as possible self-harm or suicidality, could feel unmanageable or overwhelming – "*ahm sometimes I can be unpredictable ahm so like it'd be like it might get really bad and I might do something"* (Natasha, 12.275). It is this unpredictability of mental health coupled with the absence of support that is most anxiety-provoking and distressing:

> *"Cos like some weeks it can just be like kinda normal like you can deal with it another week it can just be completely crap and you're like I kinda don't know what I'm doing."* (Alastair, Interview 2, 6.162)

There was a sense of needing a safety net to buffer against the unpredictability of mental health. For example, Kathleen planned to have private psychology appointments in place while she waited to access AMHS in order *"to have a sort of safety net if it wasn't didn't go great when I first got there I could speak to someone about it* (15.352).

Multiple Transitions

It is important to bear in mind that these young people were negotiating more than just the transition out of CAMHS. There is the felt loss of the bridging support of school, often identified as a key referring agency or source of support between appointments, with young people worrying about this void going forward. "*I think my biggest concern is being alone.*

About like when I'm there that's fine. But coming back and leaving [appointments] *and not having school"* (Naomi, 21.602). Furthermore, we understood their expressed anxieties as perhaps being related to more than just healthcare and educational transitions, but rather their wider transition from childhood to adulthood, a process that requires the developmental acquisition of increasing autonomy over time. Arguably, a process of learning to self-support may occur as young people negotiate these transitional processes. Cara, for example, described *"going with the flow"* (Interview 2, 8.182) and not feeling able to voice her opinion regarding discharge from CAMHS to now feeling able to say "*look I'm not ready* (Interview 2, 8.188) …*I know that like even though I can cope with some things there are some things I can't*" (Interview 2, 9.201), suggesting an increased sense of agency and awareness of personal threshold.

Again, it is relevant to contrast Amy's experience of transitioning out of CAMHS where *"it wasn't like th- the end was like right around the corner it was a progression"* and "*it was just this sort of like gradual letting go"* (Amy, 5.133). Moreover, she referred to being equipped to leave with her clinician providing her with information about different support avenues and information leaflets that she could draw on in the future should they be required – "*….but they could still come in handy say if college gets a bit rough or something"* (8.211). It may be that being aware that support is available and how to access it could reduce the anxiety and stress experienced by some of the other young people. In addition, opportunities to self-support may be required to learn that *"there's no point in using crutches if you don't have a broken leg"* (Amy, 22.612), suggesting a reduction in reliance on others.

"*and then I realised…*" (Amy, 7.194) – The Different Stages of the Transition Process

Multiple Factors influence the Process

Participants can be described as being at different stages, at different time points, on what was a process of transitioning out of CAMHS. This process was influenced by a number of interlinked factors previously discussed in Themes 1-3, such as awareness of the move, information acquired, and the timing of the process. It was also essential to consider the young person's perception of their own recovery or capability to manage their mental health, which will impact on their sense of readiness for leaving CAMHS.

For some participants, there was a sense of inevitability about having to move on from CAMHS - "*Ahm I always knew that I wasn't going to stay on in CAMHS forever aw cos it's just unrealistic (laugh)"* (Amy, 5.130). Thus, they were very much anticipating a move of some sort with some expecting it to happen when they moved out of CAMHS eligibility criteria –*"....I knew since I got to about fifteen that when I turned sixteen if I was still here then I'd be having to make the move*" (Alastair, Interview 2, 9.241). For others, like Cara or Natasha, the thought of having to transition to AMHS appeared to be unexpected which is likely to have affected their readiness for the process.

Loss of Familiarity and Relationships

There can be understandable hesitation at moving from the familiarity of CAMHS to the novelty of adult services or life without a mental health service. "*And it's just a move that I wish I didn't have to make but I've got to so it's something that has to be done. It's almost part of growing up"* (Kathleen, 11.258). We interpreted this again as a reference to the ambivalence that may be felt at the wider transition to adulthood. Losing the comfort of familiarity that CAMHS offers can be compounded by having to get "*used to a new way of working…"* (Kathleen, 11.255). There can be frustration or dismay due to "*starting from scratch"* again (Cara, Interview 1, 22.489) and losing relationships that can take a long time to form. Similarly, there can be a sense of weariness at the thought of having to re-tell one's story: "*I'm just so tired of speaking and meeting new people to explain what the hell is going on and them to say the exact same thing that everyone else has said I just I don't really want to do it"* (Naomi, 21.591). Some thought it would be beneficial for their CAMHS clinician to prepare them for or accompany them to their first AMHS appointment, for both supportive and continuity purposes.

Ambivalence and Multiple Emotions

It is likely that young people can feel ambivalent or *"mixed emotions"* about the process, such as "*part of me was like you're finally going to get better but then half of me was like everything going to change"*(Cara, Interview 1, 25.559). Others can feel more hopeful, "*after you get transitioned then it should be a little bit better. So I'm hoping anyway. Hoping that it should be good"* (Alastair, Interview 1, 11.264). There can also be a shift in young people's stances over the course of the transition process. At the second interview, Cara was feeling "*a lot better* (laughs)" having attended her first appointment with AMHS and was optimistic

for her recovery as "*I know that they are going to try and help me"* (Interview 2, 3.64). In contrast, Alastair's hope for AMHS appeared depleted to some extent due to the length of the gap between appointments, a lack of information about what was happening with his transition, and a deterioration in his mental health: "*I don't think it should be too bad. Ahhh ya hopefully it'll be alright*" (Interview 2, 29.775).

Processing Time

Perhaps with both information and time to process the move from CAMHS, young people are better able to prepare themselves for the move to AMHS or, indeed, life without services. Furthermore, both time and space for discussion can enable young people to move through the different stages, each with accompanying emotions, akin to a reframing process:

> *"..so I thought I could stay on until September but then we talked about it some more and then I realised that moving on would actually be a good thing. It would be quite sort of you know like ahh like I've done it. It would be quite rewarding."* (Amy, 7.194)

Discussion

The above analysis reveals that the transition out of CAMHS is a significant life event for young people involving informed and uninformed expectations about the novel, felt loss of the familiar and a myriad of emotions at different stages of the process. Whilst tending to the subjective and individual meanings, important patterns emerged from the data. It was evident that information was highly valued by young people who were undergoing the transition process. Participants' fear of the unknown, and subsequent heightened anxiety, was similar to young people navigating the transition from paediatric to adult healthcare (Warnell, 1998; Massey-Chase et al., 2015; Wright et al., 2016). Findings suggest that young people, generally, do not feel adequately prepared for or supported during the transition, lack information about AMHS, feel threatened at the loss of the familiar and fear the unfamiliar, which is in keeping with existing literature (Singh et al., 2010a; Hovish et al., 2012; Fegran et al., 2014). As such, a common barrier to transitions would appear to be a lack of information as it hinders preparation and can heighten anxiety. Of key importance is that timely information affords young people more choice and power in relation to their mental healthcare, which was identified as a key feature of a *good* mental health service from the perspective of young people (Feehan and Gumley, 2017). Dunn (2017) highlighted that scant details were available as to what information young people would find helpful during transition. This study's findings have not only emphasised young people's need for information but also furthered our understanding of the specific information desired and valued. Participants also appeared to value relationships, particularly during the transition process. The difficulty of ending relationships and forming new ones in adult services has again been highlighted by young people with physical health conditions (e.g. Wright et al., 2016).

The findings were consistent with the notion of transition as a process, as asserted by NICE (2016). Participants described experiencing various emotions during this process influenced by many factors (e.g. availability of information, timing, sense of readiness etc.). This resonates with Fisher's (2012) model of transition. To echo Viner (2003), the notion of transfer is redundant and has been replaced with the need for the transition out of CAMHS to be a guided, educational and therapeutic process rather than an administrative event. An important finding from this study is the sense that this is one transition among many for young people. Thus, through the lens of service transition, important insights into this group making sense of the wider transition to adulthood may also have emerged. A similar over-

arching framework of developing autonomy and independence has also been highlighted by other authors (Viner, 2003; Fegran et al., 2014). The transition out of CAMHS could be viewed as an opportunity to foster resilience in young people to support them with prospective transitions. This echoes Cappelli et al.'s (2016) sentiments that the CAMHS-AMHS transition is a significant life event for a young person and must be recognized as part of a wider transition from dependent child to independent adult (Viner, 1999). There is an opportunity to empower young people not just for service transition but emerging adulthood in general.

Methodological Strengths and Limitations

A strength of this study was that participants were in the transitional process, which enabled an insight into the lived experience, as opposed to a retrospective account which would likely have biases due to additional insights or experiences. When considering IPA methodology, a limitation could be the heterogeneity of included sample as the participants differed in relation to stage of transition and one in terms of destination. However, a deep and rich insight into the transitional process emerged by virtue of the young people being at different stages of the process, which is reflective of transitional-age youth in clinical practice. The use of different interview topic guides, which was dependent on the participant's stage at the point of interview, was to increase the relevance of questions asked but it is important to highlight that this may have impacted on what young people shared in the interviews. The re-interviewing of two participants enabled a fuller account of the process. It would, of course, have been desirable to do this for all participants.

The findings represent the experiences of a particular group, and so are suggestive as opposed to conclusive when considering their relevance to other young people embarking on the transition process. However, as suggested by Smith, Flowers and Larkin (2009), the analyst attempted to provide a transparent and contextualised analysis of the participants' experiences to enable readers to evaluate its transferability to others. The chosen qualitative methodology and IPA analysis is deemed a strength as the aim was to explore lived experiences. As this form of analysis is open to additional interpretations, an audit trail and substantiating excerpts were used for transparency. In terms of the broader context, the extant literature framed transition-age youth as vulnerable which may have steered the researcher to interpreting the experiences in a particular way. This narrative of

'vulnerability' may also have influenced young people to tell particular aspects of their experiences. However, reflective discussions between the research team supported the bracketing of created expectations.

Implications for Clinical Practice

The findings have clinical relevance and could support clinicians in aiding transition-age youth. As service transition is one amongst many that young people are negotiating, clinicians could be well placed to support young people to use the focal transition process as a model to learn about concurrent and future life transitions. Whilst it is essential to focus on young people's mental health needs, it is also imperative to foster their strengths and resilience to support them as they enter adulthood. Services can value young people's right to choice and preferences, and respect their developing autonomy by providing information about the transition process in an accessible format. Of key importance is the timely dissemination of information to support young people's preparation. Information could be collaboratively developed by CAMHS, AMHS and indeed young people to make some of the highlighted *unknowns* known in terms of the envisioned set up for adult services (i.e. location, cost, potential interventions). Dunn (2017) demonstrates the key role of young people as stakeholders and co-producers of information booklets for all CAMHS leavers.

Many of the participants expressed valuing the space to discuss the transition process during data collection. Perhaps services could consider a group format for young people to obtain information, reflect, and listen to others' experiences to support them with the many transitions they are navigating. For young people who choose to engage with AMHS, services should endeavour to create continuity in terms of information overlap or initial joint appointments if possible. It must be acknowledged that policy, research, clinicians and young people largely agree on the fundamentals of good transitional practice. However, clinicians highlight a policy-practice gap due to funding, inflexible NHS procedures and policies (Dunn, 2017) that indicate system-level challenges (Sukhera, Fisman and Davidson, 2015) to the implementation of young people's recommendations which need to be addressed.

Future Research

As outlined in the Introduction, authors have presented various potential outcomes of poor transitions which are largely unsubstantiated. Many have argued that this group have increased vulnerability but research focused on their strengths and resilience is also warranted. Future longitudinal research ought to test some of the predictions from the extant literature that disengaging from mental health services, which is ultimately young people's choice, yields negative outcomes whereas engaging yields positive outcomes. There is also a need to track the transition experience across health boards which would be an extension of the literature base.

Conclusion

In addition to yielding young people's experiences of service transition, important insights into this group making sense of the wider transition to adulthood may also have emerged. Young people value information, hold expectations for the novel, feel discomfort at the loss of familiarity and can experience a range of emotions at different stages of the process. The findings have clinical relevance and could support clinicians in aiding transition-age youth to negotiate not just the service transition but also future life transitions.

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Appendices

Appendix 1.1: Submission Requirements for Early Intervention in Psychiatry

EDITORIAL CONSIDERATIONS
The acceptance criteria for all papers are the quality and originality of the research and its significance to our readership. Manuscripts should be written in a clear, concise, direct style.

Reviews which synthesize important information on a topic of general interest to early intervention in psychiatry. (maximum word count for text 5000; abstract 250);

Parts of the Manuscript
The manuscript should be submitted in separate files: title page; main text file; figures.

Title page
The title page should contain**:** (i) a short informative title that contains the major key words. The title should not contain abbreviations; (ii) the full names of the authors; (iii) the author's institutional affiliations at which the work was carried out; (iv) the full postal and email address, plus telephone number, of the author to whom correspondence about the manuscript should be sent; (v) acknowledgements. The present address of any author, if different from that where the work was carried out, should be supplied in a footnote.

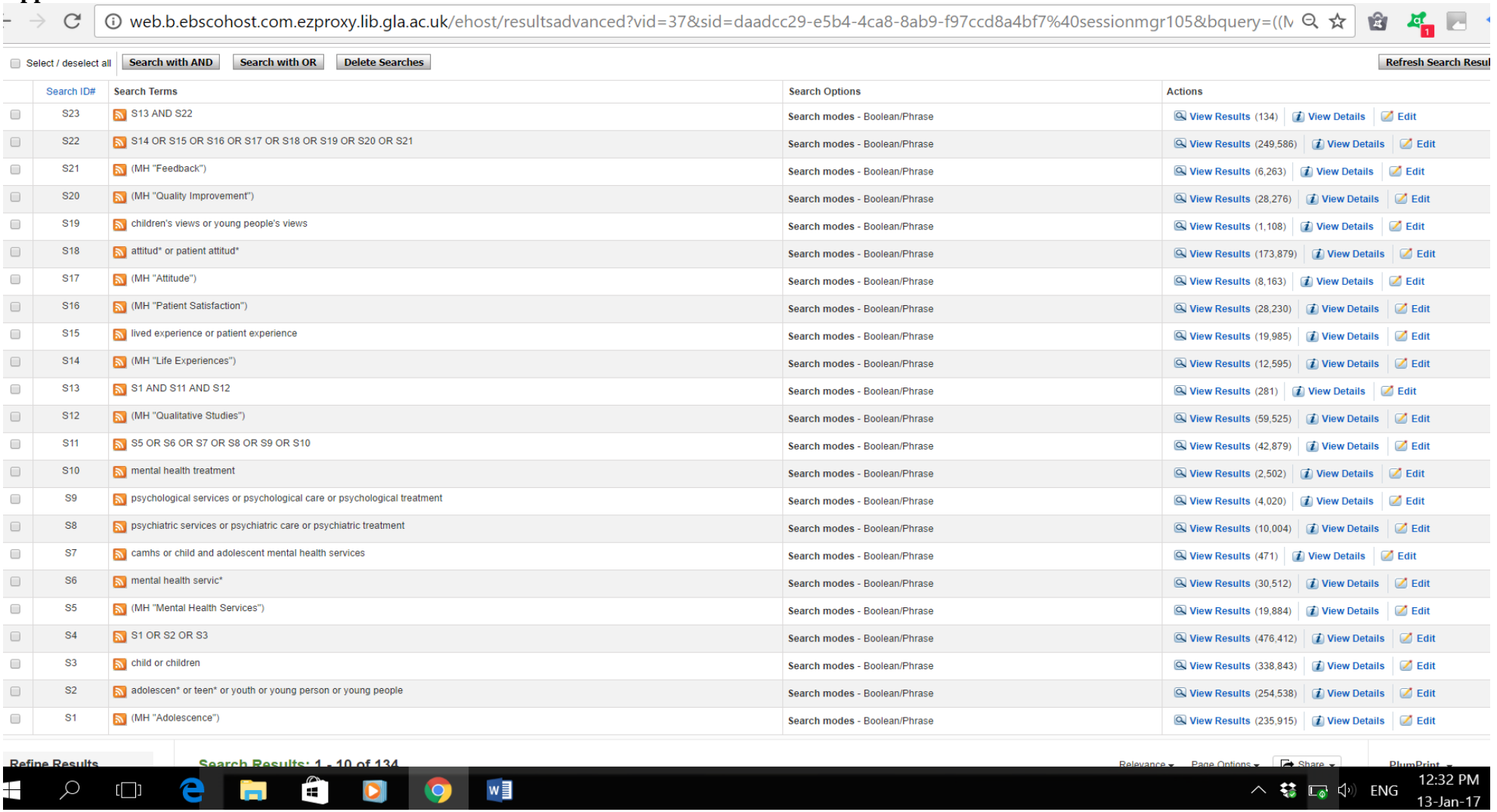
Main text
As papers are double-blind peer reviewed the main text file should not include any information that might identify the authors. The main text of the manuscript should be presented in the following order: (i) abstract and key words, (ii) text, (iii) references, (iv) tables (each table complete with title and footnotes), (v) appendices, (vii) figure legends. Figures should be submitted as separate files. Footnotes to the text are not allowed and any such material should be incorporated into the text as parenthetical matter.

Abstract and key words
All articles must have a structured abstract that states in 250 words (150 words for Brief Reports) or fewer the purpose, basic procedures, main findings and principal conclusions of the study. Divide the abstract with the headings: Aim, Methods, Results, Conclusions. The abstract should not contain abbreviations or references. Five key words, for the purposes of indexing, should be supplied below the abstract, in alphabetical order, and should be taken from those recommended by the US National Library of Medicine's Medical Subject Headings (MeSH) browser list at http://www.nlm.nih.gov/mesh/meshhome.html.

Text
Authors should use the following subheadings to divide the sections of their manuscript: Introduction, Methods, Results and Discussion.

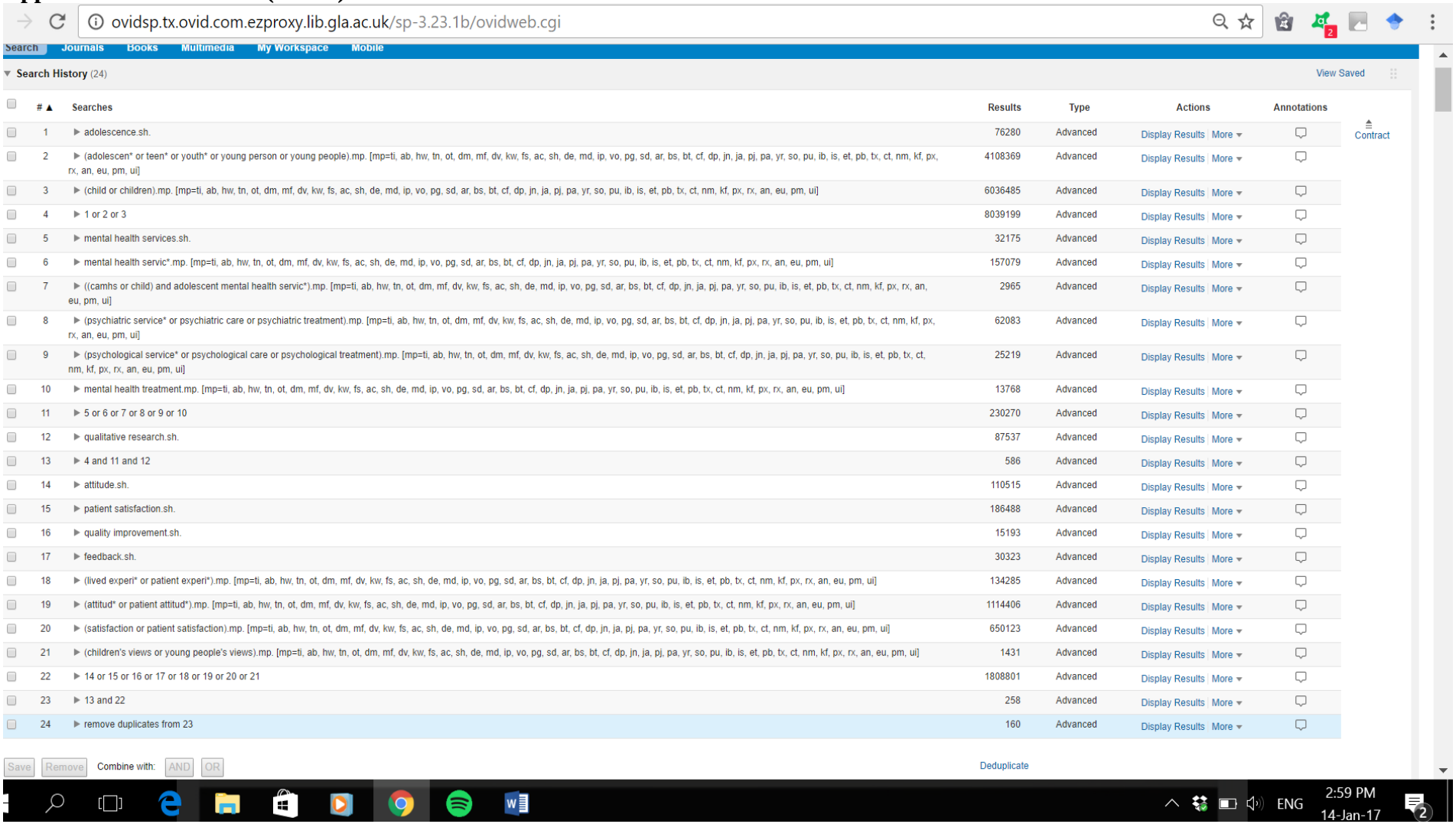
Full Details at:
http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1751-7893/homepage/ForAuthors.html

Appendix 1.2: CINAHL Search Results



	Search ID#	Search Terms	Search Options	Actions
☐	S23	S13 AND S22	**Search modes** - Boolean/Phrase	View Results (134) | View Details | Edit
☐	S22	S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21	**Search modes** - Boolean/Phrase	View Results (249,586) | View Details | Edit
☐	S21	(MH "Feedback")	**Search modes** - Boolean/Phrase	View Results (6,263) | View Details | Edit
☐	S20	(MH "Quality Improvement")	**Search modes** - Boolean/Phrase	View Results (28,276) | View Details | Edit
☐	S19	children's views or young people's views	**Search modes** - Boolean/Phrase	View Results (1,108) | View Details | Edit
☐	S18	attitud* or patient attitud*	**Search modes** - Boolean/Phrase	View Results (173,879) | View Details | Edit
☐	S17	(MH "Attitude")	**Search modes** - Boolean/Phrase	View Results (8,163) | View Details | Edit
☐	S16	(MH "Patient Satisfaction")	**Search modes** - Boolean/Phrase	View Results (28,230) | View Details | Edit
☐	S15	lived experience or patient experience	**Search modes** - Boolean/Phrase	View Results (19,985) | View Details | Edit
☐	S14	(MH "Life Experiences")	**Search modes** - Boolean/Phrase	View Results (12,595) | View Details | Edit
☐	S13	S1 AND S11 AND S12	**Search modes** - Boolean/Phrase	View Results (281) | View Details | Edit
☐	S12	(MH "Qualitative Studies")	**Search modes** - Boolean/Phrase	View Results (59,525) | View Details | Edit
☐	S11	S5 OR S6 OR S7 OR S8 OR S9 OR S10	**Search modes** - Boolean/Phrase	View Results (42,879) | View Details | Edit
☐	S10	mental health treatment	**Search modes** - Boolean/Phrase	View Results (2,502) | View Details | Edit
☐	S9	psychological services or psychological care or psychological treatment	**Search modes** - Boolean/Phrase	View Results (4,020) | View Details | Edit
☐	S8	psychiatric services or psychiatric care or psychiatric treatment	**Search modes** - Boolean/Phrase	View Results (10,004) | View Details | Edit
☐	S7	camhs or child and adolescent mental health services	**Search modes** - Boolean/Phrase	View Results (471) | View Details | Edit
☐	S6	mental health servic*	**Search modes** - Boolean/Phrase	View Results (30,512) | View Details | Edit
☐	S5	(MH "Mental Health Services")	**Search modes** - Boolean/Phrase	View Results (19,884) | View Details | Edit
☐	S4	S1 OR S2 OR S3	**Search modes** - Boolean/Phrase	View Results (476,412) | View Details | Edit
☐	S3	child or children	**Search modes** - Boolean/Phrase	View Results (338,843) | View Details | Edit
☐	S2	adolescen* or teen* or youth or young person or young people	**Search modes** - Boolean/Phrase	View Results (254,538) | View Details | Edit
☐	S1	(MH "Adolescence")	**Search modes** - Boolean/Phrase	View Results (235,915) | View Details | Edit

Appendix 1.3: EMBASE (OVID) Search Results



ovidsp.tx.ovid.com.ezproxy.lib.gla.ac.uk/sp-3.23.1b/ovidweb.cgi

Search | Journals | Books | Multimedia | My Workspace | Mobile

Search History (24) — View Saved

# ▲	Searches	Results	Type	Actions	Annotations
1	▶ adolescence.sh.	76280	Advanced	Display Results | More	
2	▶ (adolescen* or teen* or youth* or young person or young people).mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fs, ac, sh, de, md, ip, vo, pg, sd, ar, bs, bt, cf, dp, jn, ja, pj, pa, yr, so, pu, ib, is, et, pb, tx, ct, nm, kf, px, rx, an, eu, pm, ui]	4108369	Advanced	Display Results | More	
3	▶ (child or children).mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fs, ac, sh, de, md, ip, vo, pg, sd, ar, bs, bt, cf, dp, jn, ja, pj, pa, yr, so, pu, ib, is, et, pb, tx, ct, nm, kf, px, rx, an, eu, pm, ui]	6036485	Advanced	Display Results | More	
4	▶ 1 or 2 or 3	8039199	Advanced	Display Results | More	
5	▶ mental health services.sh.	32175	Advanced	Display Results | More	
6	▶ mental health servic*.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fs, ac, sh, de, md, ip, vo, pg, sd, ar, bs, bt, cf, dp, jn, ja, pj, pa, yr, so, pu, ib, is, et, pb, tx, ct, nm, kf, px, rx, an, eu, pm, ui]	157079	Advanced	Display Results | More	
7	▶ ((camhs or child) and adolescent mental health servic*).mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fs, ac, sh, de, md, ip, vo, pg, sd, ar, bs, bt, cf, dp, jn, ja, pj, pa, yr, so, pu, ib, is, et, pb, tx, ct, nm, kf, px, rx, an, eu, pm, ui]	2965	Advanced	Display Results | More	
8	▶ (psychiatric service* or psychiatric care or psychiatric treatment).mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fs, ac, sh, de, md, ip, vo, pg, sd, ar, bs, bt, cf, dp, jn, ja, pj, pa, yr, so, pu, ib, is, et, pb, tx, ct, nm, kf, px, rx, an, eu, pm, ui]	62083	Advanced	Display Results | More	
9	▶ (psychological service* or psychological care or psychological treatment).mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fs, ac, sh, de, md, ip, vo, pg, sd, ar, bs, bt, cf, dp, jn, ja, pj, pa, yr, so, pu, ib, is, et, pb, tx, ct, nm, kf, px, rx, an, eu, pm, ui]	25219	Advanced	Display Results | More	
10	▶ mental health treatment.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fs, ac, sh, de, md, ip, vo, pg, sd, ar, bs, bt, cf, dp, jn, ja, pj, pa, yr, so, pu, ib, is, et, pb, tx, ct, nm, kf, px, rx, an, eu, pm, ui]	13768	Advanced	Display Results | More	
11	▶ 5 or 6 or 7 or 8 or 9 or 10	230270	Advanced	Display Results | More	
12	▶ qualitative research.sh.	87537	Advanced	Display Results | More	
13	▶ 4 and 11 and 12	586	Advanced	Display Results | More	
14	▶ attitude.sh.	110515	Advanced	Display Results | More	
15	▶ patient satisfaction.sh.	186488	Advanced	Display Results | More	
16	▶ quality improvement.sh.	15193	Advanced	Display Results | More	
17	▶ feedback.sh.	30323	Advanced	Display Results | More	
18	▶ (lived experi* or patient experi*).mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fs, ac, sh, de, md, ip, vo, pg, sd, ar, bs, bt, cf, dp, jn, ja, pj, pa, yr, so, pu, ib, is, et, pb, tx, ct, nm, kf, px, rx, an, eu, pm, ui]	134285	Advanced	Display Results | More	
19	▶ (attitud* or patient attitud*).mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fs, ac, sh, de, md, ip, vo, pg, sd, ar, bs, bt, cf, dp, jn, ja, pj, pa, yr, so, pu, ib, is, et, pb, tx, ct, nm, kf, px, rx, an, eu, pm, ui]	1114406	Advanced	Display Results | More	
20	▶ (satisfaction or patient satisfaction).mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fs, ac, sh, de, md, ip, vo, pg, sd, ar, bs, bt, cf, dp, jn, ja, pj, pa, yr, so, pu, ib, is, et, pb, tx, ct, nm, kf, px, rx, an, eu, pm, ui]	650123	Advanced	Display Results | More	
21	▶ (children's views or young people's views).mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fs, ac, sh, de, md, ip, vo, pg, sd, ar, bs, bt, cf, dp, jn, ja, pj, pa, yr, so, pu, ib, is, et, pb, tx, ct, nm, kf, px, rx, an, eu, pm, ui]	1431	Advanced	Display Results | More	
22	▶ 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21	1808801	Advanced	Display Results | More	
23	▶ 13 and 22	258	Advanced	Display Results | More	
24	▶ remove duplicates from 23	160	Advanced	Display Results | More	

Contract

Save | Remove | Combine with: AND | OR | Deduplicate

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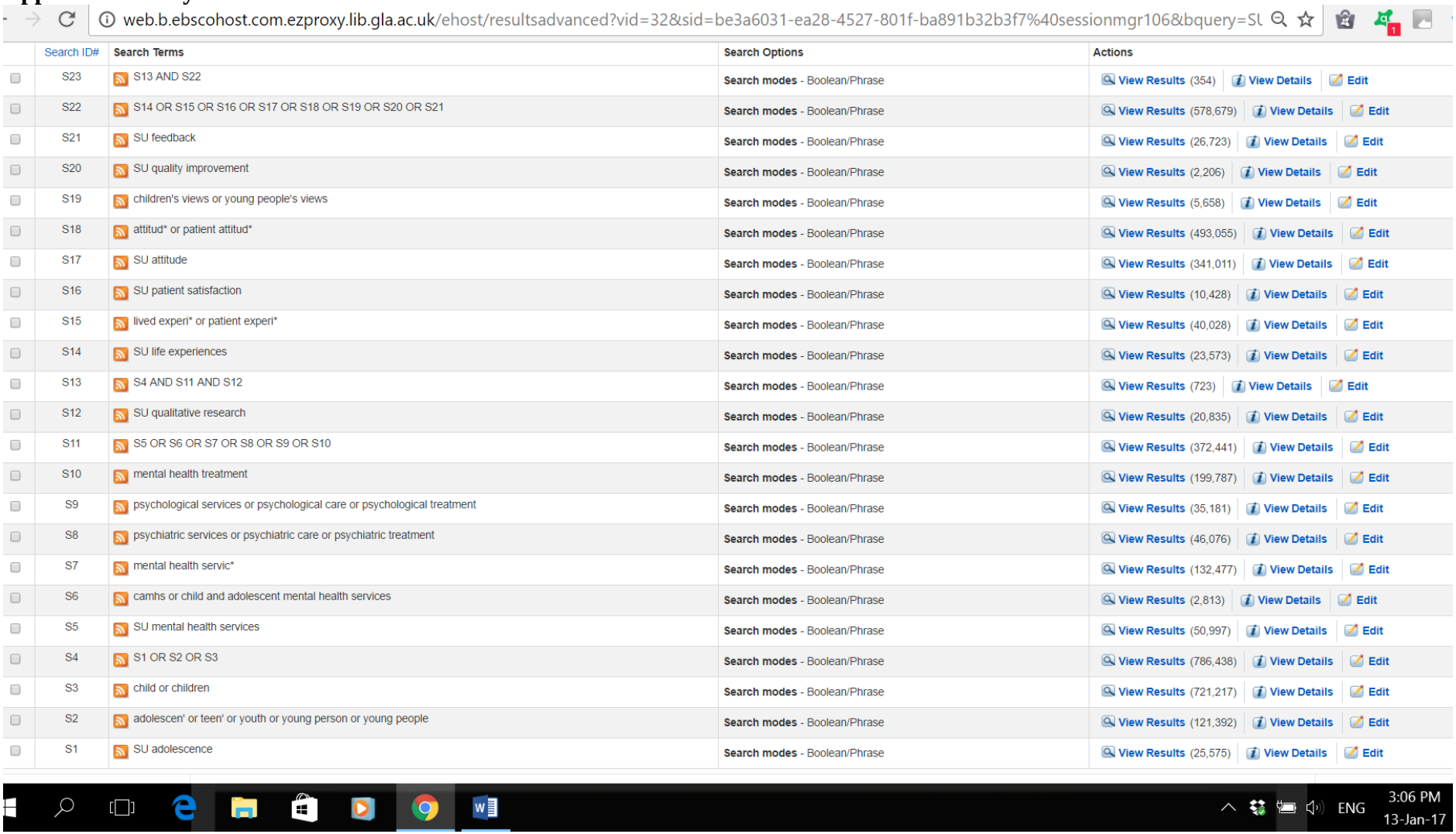
Appendix 1.4: PsychINFO Search Results



web.b.ebscohost.com.ezproxy.lib.gla.ac.uk/ehost/resultsadvanced?vid=32&sid=be3a6031-ea28-4527-801f-ba891b32b3f7%40sessionmgr106&bquery=SU

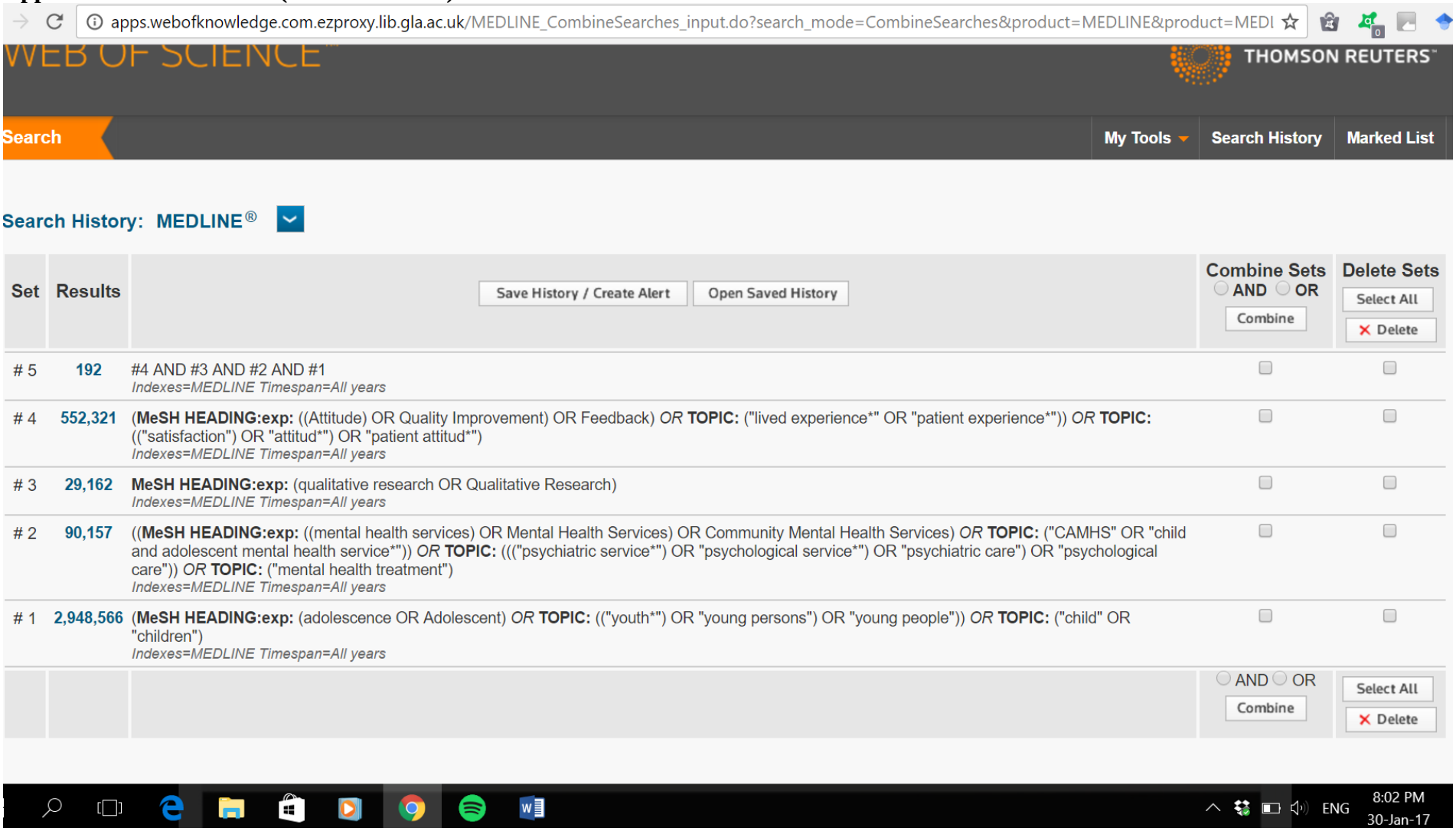
Search ID#	Search Terms	Search Options	Actions
S23	S13 AND S22	**Search modes** - Boolean/Phrase	View Results (354) | View Details | Edit
S22	S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21	**Search modes** - Boolean/Phrase	View Results (578,679) | View Details | Edit
S21	SU feedback	**Search modes** - Boolean/Phrase	View Results (26,723) | View Details | Edit
S20	SU quality improvement	**Search modes** - Boolean/Phrase	View Results (2,206) | View Details | Edit
S19	children's views or young people's views	**Search modes** - Boolean/Phrase	View Results (5,658) | View Details | Edit
S18	attitud* or patient attitud*	**Search modes** - Boolean/Phrase	View Results (493,055) | View Details | Edit
S17	SU attitude	**Search modes** - Boolean/Phrase	View Results (341,011) | View Details | Edit
S16	SU patient satisfaction	**Search modes** - Boolean/Phrase	View Results (10,428) | View Details | Edit
S15	lived experi* or patient experi*	**Search modes** - Boolean/Phrase	View Results (40,028) | View Details | Edit
S14	SU life experiences	**Search modes** - Boolean/Phrase	View Results (23,573) | View Details | Edit
S13	S4 AND S11 AND S12	**Search modes** - Boolean/Phrase	View Results (723) | View Details | Edit
S12	SU qualitative research	**Search modes** - Boolean/Phrase	View Results (20,835) | View Details | Edit
S11	S5 OR S6 OR S7 OR S8 OR S9 OR S10	**Search modes** - Boolean/Phrase	View Results (372,441) | View Details | Edit
S10	mental health treatment	**Search modes** - Boolean/Phrase	View Results (199,787) | View Details | Edit
S9	psychological services or psychological care or psychological treatment	**Search modes** - Boolean/Phrase	View Results (35,181) | View Details | Edit
S8	psychiatric services or psychiatric care or psychiatric treatment	**Search modes** - Boolean/Phrase	View Results (46,076) | View Details | Edit
S7	mental health servic*	**Search modes** - Boolean/Phrase	View Results (132,477) | View Details | Edit
S6	camhs or child and adolescent mental health services	**Search modes** - Boolean/Phrase	View Results (2,813) | View Details | Edit
S5	SU mental health services	**Search modes** - Boolean/Phrase	View Results (50,997) | View Details | Edit
S4	S1 OR S2 OR S3	**Search modes** - Boolean/Phrase	View Results (786,438) | View Details | Edit
S3	child or children	**Search modes** - Boolean/Phrase	View Results (721,217) | View Details | Edit
S2	adolescen' or teen' or youth or young person or young people	**Search modes** - Boolean/Phrase	View Results (121,392) | View Details | Edit
S1	SU adolescence	**Search modes** - Boolean/Phrase	View Results (25,575) | View Details | Edit

Appendix 1.5: PsychARTICLES Search Results

	Search ID#	Search Terms	Search Options	Actions
☐	S26	S16 AND S25	**Search modes** - Boolean/Phrase	View Results (5)
☐	S25	S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24	**Search modes** - Boolean/Phrase	View Results (22,398)
☐	S24	SU feedback	**Search modes** - Boolean/Phrase	View Results (1,342)
☐	S23	SU quality improvement	**Search modes** - Boolean/Phrase	View Results (37)
☐	S22	children's views or young people's views	**Search modes** - Boolean/Phrase	View Results (218)
☐	S21	attitud* or patient attitud*	**Search modes** - Boolean/Phrase	View Results (19,748)
☐	S20	SU attitude	**Search modes** - Boolean/Phrase	View Results (12,768)
☐	S19	SU patient satisfaction	**Search modes** - Boolean/Phrase	View Results (27)
☐	S18	lived experience or patient experience	**Search modes** - Boolean/Phrase	View Results (541)
☐	S17	SU life experiences	**Search modes** - Boolean/Phrase	View Results (852)
☐	S16	S4 AND S11 AND S15	**Search modes** - Boolean/Phrase	View Results (16)
☐	S15	S12 OR S13 OR S14	**Search modes** - Boolean/Phrase	View Results (497)
☐	S14	SU qualitative	**Search modes** - Boolean/Phrase	View Results (497)
☐	S13	SU qualitative studies	**Search modes** - Boolean/Phrase	View Results (15)
☐	S12	SU qualitative research	**Search modes** - Boolean/Phrase	View Results (315)
☐	S11	S5 OR S6 OR S7 OR S8 OR S9 OR S10	**Search modes** - Boolean/Phrase	View Results (15,306)
☐	S10	mental health treatment	**Search modes** - Boolean/Phrase	View Results (7,714)
☐	S9	psychological services or psychological care or psychological treatment	**Search modes** - Boolean/Phrase	View Results (3,682)
☐	S8	psychiatric services or psychiatric care or psychiatric treatment	**Search modes** - Boolean/Phrase	View Results (940)
☐	S7	mental health servic*	**Search modes** - Boolean/Phrase	View Results (4,845)

S6	camhs or child and adolescent mental health services	**Search modes** - Boolean/Phrase	**View Results** (26)
S5	SU mental health services	**Search modes** - Boolean/Phrase	**View Results** (2,310)
S4	S1 OR S2 OR S3	**Search modes** - Boolean/Phrase	**View Results** (29,371)
S3	child or children	**Search modes** - Boolean/Phrase	**View Results** (26,919)
S2	adolescen' or teen' or youth or young person or young people	**Search modes** - Boolean/Phrase	**View Results** (3,740)
S1	SU adolescence	**Search modes** - Boolean/Phrase	**View Results** (893)

Appendix 1.6: MEDLINE (Web of Science) Search Results



apps.webofknowledge.com.ezproxy.lib.gla.ac.uk/MEDLINE_CombineSearches_input.do?search_mode=CombineSearches&product=MEDLINE&product=MEDI

WEB OF SCIENCE™ THOMSON REUTERS™

Search | My Tools | Search History | Marked List

Search History: MEDLINE®

Set	Results	Save History / Create Alert / Open Saved History	Combine Sets (AND / OR) Combine	Delete Sets Select All / Delete
# 5	192	#4 AND #3 AND #2 AND #1 *Indexes=MEDLINE Timespan=All years*		
# 4	552,321	(**MeSH HEADING:exp:** ((Attitude) OR Quality Improvement) OR Feedback) *OR* **TOPIC:** ("lived experience*" OR "patient experience*")) *OR* **TOPIC:** (("satisfaction") OR "attitud*") OR "patient attitud*") *Indexes=MEDLINE Timespan=All years*		
# 3	29,162	**MeSH HEADING:exp:** (qualitative research OR Qualitative Research) *Indexes=MEDLINE Timespan=All years*		
# 2	90,157	((**MeSH HEADING:exp:** ((mental health services) OR Mental Health Services) OR Community Mental Health Services) *OR* **TOPIC:** ("CAMHS" OR "child and adolescent mental health service*")) *OR* **TOPIC:** ((("psychiatric service*") OR "psychological service*") OR "psychiatric care") OR "psychological care")) *OR* **TOPIC:** ("mental health treatment") *Indexes=MEDLINE Timespan=All years*		
# 1	2,948,566	(**MeSH HEADING:exp:** (adolescence OR Adolescent) *OR* **TOPIC:** (("youth*") OR "young persons") OR "young people")) *OR* **TOPIC:** ("child" OR "children") *Indexes=MEDLINE Timespan=All years*		
			AND / OR Combine	Select All / Delete

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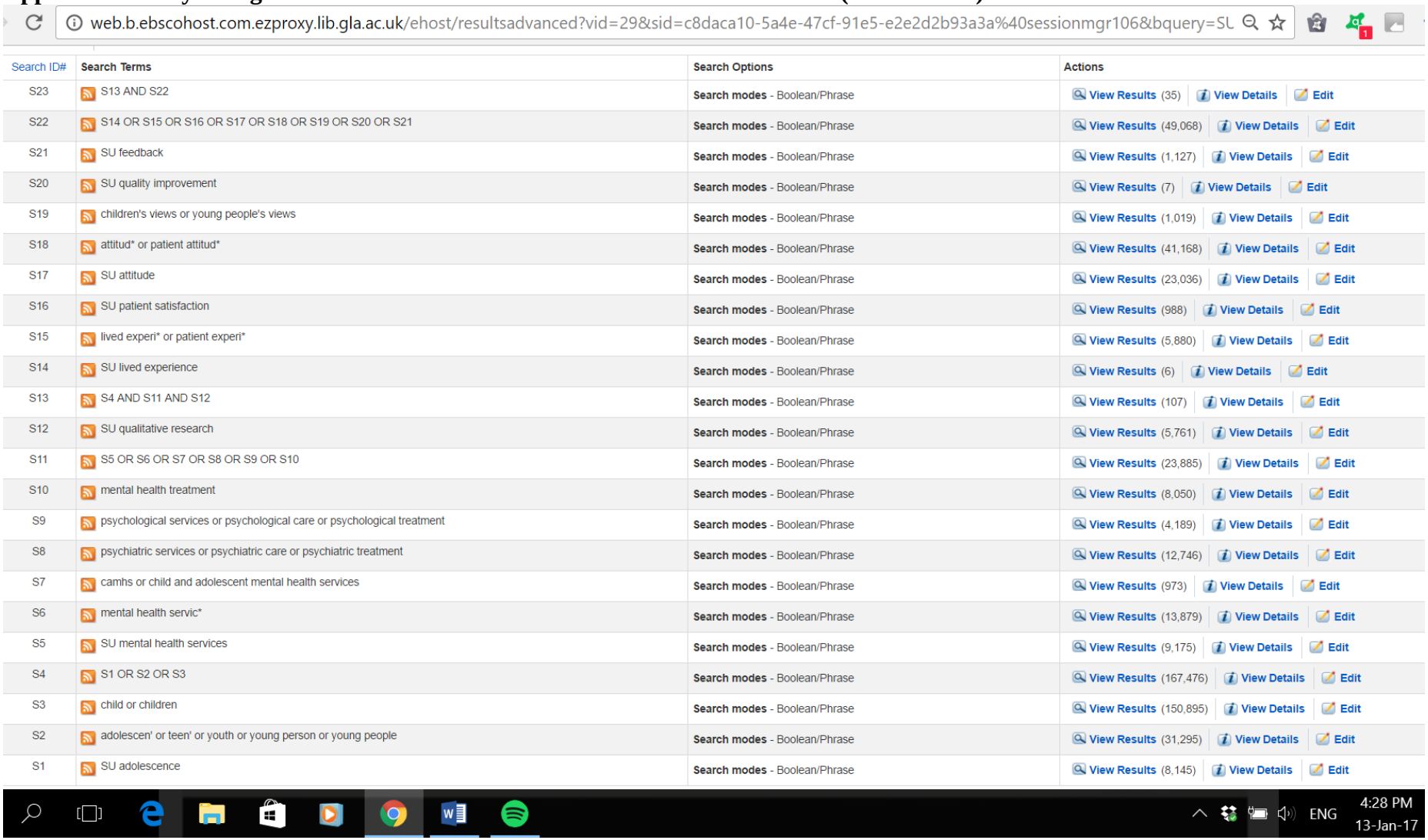
Appendix 1.7: Psychological and Behavioral Sciences Collection Search Results (EBSCOhost)



Search ID#	Search Terms	Search Options	Actions
S23	S13 AND S22	**Search modes** - Boolean/Phrase	View Results (35) | View Details | Edit
S22	S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21	**Search modes** - Boolean/Phrase	View Results (49,068) | View Details | Edit
S21	SU feedback	**Search modes** - Boolean/Phrase	View Results (1,127) | View Details | Edit
S20	SU quality improvement	**Search modes** - Boolean/Phrase	View Results (7) | View Details | Edit
S19	children's views or young people's views	**Search modes** - Boolean/Phrase	View Results (1,019) | View Details | Edit
S18	attitud* or patient attitud*	**Search modes** - Boolean/Phrase	View Results (41,168) | View Details | Edit
S17	SU attitude	**Search modes** - Boolean/Phrase	View Results (23,036) | View Details | Edit
S16	SU patient satisfaction	**Search modes** - Boolean/Phrase	View Results (988) | View Details | Edit
S15	lived experi* or patient experi*	**Search modes** - Boolean/Phrase	View Results (5,880) | View Details | Edit
S14	SU lived experience	**Search modes** - Boolean/Phrase	View Results (6) | View Details | Edit
S13	S4 AND S11 AND S12	**Search modes** - Boolean/Phrase	View Results (107) | View Details | Edit
S12	SU qualitative research	**Search modes** - Boolean/Phrase	View Results (5,761) | View Details | Edit
S11	S5 OR S6 OR S7 OR S8 OR S9 OR S10	**Search modes** - Boolean/Phrase	View Results (23,885) | View Details | Edit
S10	mental health treatment	**Search modes** - Boolean/Phrase	View Results (8,050) | View Details | Edit
S9	psychological services or psychological care or psychological treatment	**Search modes** - Boolean/Phrase	View Results (4,189) | View Details | Edit
S8	psychiatric services or psychiatric care or psychiatric treatment	**Search modes** - Boolean/Phrase	View Results (12,746) | View Details | Edit
S7	camhs or child and adolescent mental health services	**Search modes** - Boolean/Phrase	View Results (973) | View Details | Edit
S6	mental health servic*	**Search modes** - Boolean/Phrase	View Results (13,879) | View Details | Edit
S5	SU mental health services	**Search modes** - Boolean/Phrase	View Results (9,175) | View Details | Edit
S4	S1 OR S2 OR S3	**Search modes** - Boolean/Phrase	View Results (167,476) | View Details | Edit
S3	child or children	**Search modes** - Boolean/Phrase	View Results (150,895) | View Details | Edit
S2	adolescen' or teen' or youth or young person or young people	**Search modes** - Boolean/Phrase	View Results (31,295) | View Details | Edit
S1	SU adolescence	**Search modes** - Boolean/Phrase	View Results (8,145) | View Details | Edit

Appendix 1.8: Walsh & Downe's (2006) Quality Framework

Scoring key: Not present = 0 Partially present = 1 Present = 2

Stages	Essential Criteria	Specific Prompts	Score
Scope and Purpose	Clear statement of, and rationale for, research question/aims/purposes Study thoroughly contextualised by existing literature	• Clarity of focus demonstrated • Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing • Link between research and existing knowledge demonstrated	
Design	Method/design apparent, and consistent with research intent Data collection strategy apparent and appropriate	• Rationale given for use of qualitative design • Discussion of epistemological/ontological grounding • Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology) • Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims • Setting appropriate • Were data collection methods appropriate for type of data required and for specific qualitative method? • Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail? • Was triangulation of data sources used if appropriate?	
Sampling strategy	Sample and sampling method appropriate	• Selection criteria detailed, and description of how sampling was undertaken • Justification for sampling strategy given • Thickness of description likely to be achieved from sampling • Any disparity between planned and actual sample explained	
Analysis	Analytic approach appropriate	• Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory) • Was it appropriate for the qualitative method chosen? • Was data managed by software package or by hand and why? • Discussion of how coding systems/conceptual frameworks evolved • How was context of data retained during analysis • Evidence that the subjective meanings of participants were portrayed • Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance • Did research participants have any involvement in analysis (e.g. member checking) • Evidence provided that data reached saturation or discussion/rationale if it did not • Evidence that deviant data was sought, or discussion/ rationale if it was not	
Interpretation	Context described and taken account of in interpretation	• Description of social/physical and interpersonal contexts of data collection	

	Clear audit trail given Data used to support interpretation	• Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena • Sufficient discussion of research processes such that others can follow 'decision trail' • Extensive use of field notes entries/verbatim interview quotes in discussion of findings • Clear exposition of how interpretation led to conclusions	
Reflexivity	Researcher reflexivity demonstrated	• Discussion of relationship between researcher and participants during fieldwork • Demonstration of researcher's influence on stages of research process • Evidence of self-awareness/insight • Documentation of effects of the research on researcher • Evidence of how problems/complications met were dealt with	
Ethical dimensions	Demonstration of sensitivity to ethical concerns	• Ethical committee approval granted • Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants • Evidence of fair dealing with all research participants • Recording of dilemmas met and how resolved in relation to ethical issues • Documentation of how autonomy, consent, confidentiality, anonymity were managed	

Relevance and transferability	Relevance and transferability evident	• Sufficient evidence for typicality specificity to be assessed
		• Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies Discussion of how explanatory propositions/emergent theory may fit other contexts
		• Limitations/weaknesses of study clearly outlined
		• Clearly resonates with other knowledge and experience
		• Results/conclusions obviously supported by evidence
		• Interpretation plausible and 'makes sense'
		  • Provides new insights and increases understanding
		  • Significance for current policy and practice outlined
		  • Assessment of value/empowerment for participants
		  • Outlines further directions for investigation
		  • Comment on whether aims/purposes of research were achieved	

Total Score			

Appendix 1.9: Sample Data Extraction

Coyne et al. (2015) Results Section
pages 564-565

Data Extracted by Researcher

Theme 1: getting help

Seeking help for a child who is experiencing mental health difficulties proved challenging for parents. For many, this was their first experience and they reported being unsure where to access help. Parents mentioned consulting with family members, teachers and other acquaintances for advice about services. General practitioners (GPs) and private counsellors were typically the first point of contact for help. Parents were critical of the length of time it took to access CAMHS, which in some cases extended to 18 months. Several parents noted that they had been advised that they could access support much more quickly by either going to private services or asking their GP to write an urgent referral letter:

> '*I remember going to my own doctor crying and I said, you have to do something you know? I'm sick listening to the teachers, I've a path worn to the school, they all know there's some kind of problem and she said the waiting list is so long you're better off going privately*' (parent 3C).

Indeed, a number of parents felt that they had no option but to use private services while waiting for an appointment, as they felt they needed some form of support for their child during this waiting period:

> '*Our experience was that we were having difficulties with our child in school and we were put on a waiting list. And the waiting list was going to take so long we went and got a private diagnosis ourselves and in fact it was 18 months before we got an appointment here but we needed to intervene when we intervened, so we had to go to [name of private service] and get our own diagnosis*' (parent 5B).

Parent Data (not applicable)

Waiting for an appointment proved to be a particularly stressful time for parents. There was a perception that this concern was not shared by those in the CAMHS, and in one clinic, parents felt that those who made a fuss often get an appointment faster than those who stayed silent. These same concerns were not evident in the adolescents' data. It emerged that many were unaware they would be attending CAMHS until just prior to their first appointment, suggesting they were not involved in this part of the decision-making process. More than half of the adolescents expressed dissatisfaction with exclusion from the decision to commence treatment.

Unaware they would be attending appointment.
Not involved in decision-making process.
More than half = dissatisfaction

> '*I didn't have any say in it. I didn't want to go the first time I felt nervous*' (adolescent 6C).

"Nervous" and reluctant to attend appointment.
Felt unprepared and uninformed about attending.
Could potentially be avoided if given choice

However, the findings showed that two of the adolescents' parents did involve their child in the decision-making process and gave them the option of declining:

> '*Yeah my mom asked me did I want to come and I said what's it going to be about, cos I can't remember now, it was ages ago. But I said I'd come anyway*' (adolescent 2B).

Thus, it is important to note that the sense of reluctance described by some of the adolescents could have potentially been avoided if they had been made to feel that it was partially their choice to attend. Overall, adolescents reported feeling uninformed and unprepared prior to commencing their treatment.

Theme 2: having a voice

Some parents felt fully informed by HCPs on all aspects of their child's care and believed that their opinions and requests were listened to, as indicated by this parent:

> '*Oh 100% satisfied, I mean I couldn't be any happier with the help that daughter got or the help that I got because without them I don't know where I'd have been*' (parent 3C).

> '*I think we met with the psychiatrist first and she put some different options to us with regard to [child] and then we discussed them with her and we let her know what we were going to do*' (parent 4B).

Other parents felt suboptimal involved, and described having to 'fight' for their voices to be heard or to obtain information on their child's progress. They did not feel empowered to question their child's care, to raise specific issues and felt pressurized into accepting HCP's advice. Some adolescents felt similarly excluded from the decision-making process, and did not feel empowered to voice their views.

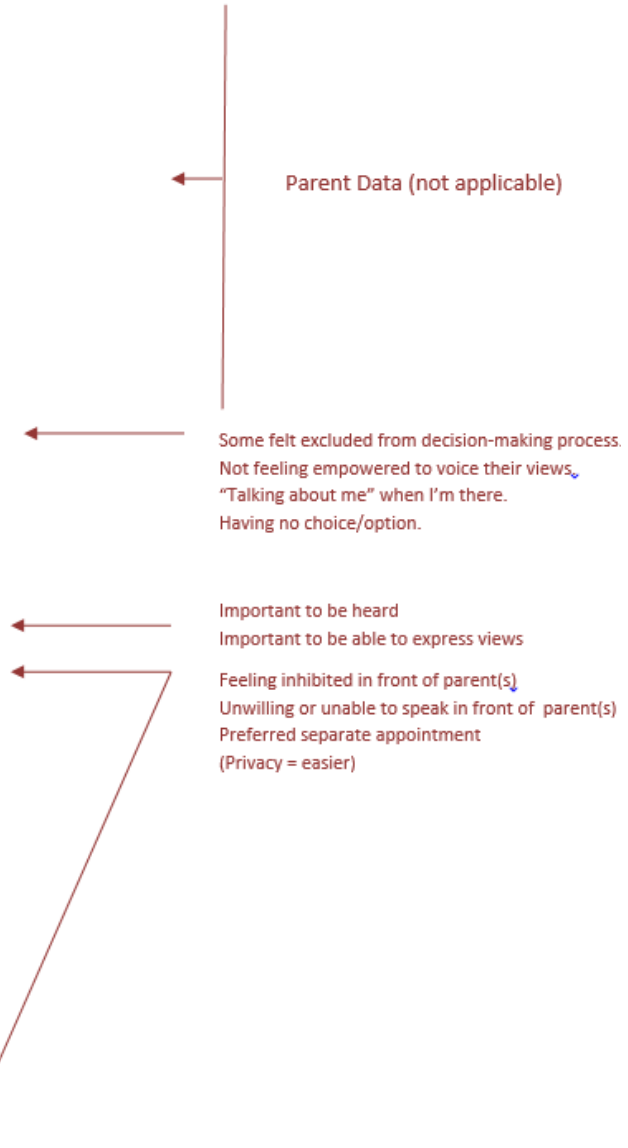
> '*I feel like everyone just kind of talks at me or about me when I'm right there and they might ask me "is that ok" and they ask me in such a way that I kind of feel like I don't have any other option but agree with them*' (adolescent 3A).

Both adolescents and parents felt it was important to be heard and be able to express their views during sessions. However, they reported feeling inhibited speaking in front of each other and often engaged in self-censorship. Sometime parents had to disclose intimate details about their child's behaviour which they would prefer not to reveal with their child present. They worried that speaking openly could cause their child's distress, lead to loss of their child's trust in them as parents and possibly hinder progress. Consequently, they reported limiting what they shared and/or asking to speak to the HCP alone (which was not always available).

> '*I actually think it would be a good idea if parents could have a private session just because anytime we went in there, we had [child] with us. And while I suppose we learnt how to talk about things because maybe we didn't before cos we never had to deal with it, I think for me personally, I'd have liked the opportunity to have half an hour or an hour just about how do I really feel about this? What am I supposed to be feeling? What was I doing wrong?*' (parent 1B).

Adolescents were equally unwilling or unable to speak openly with a parent present and preferred separate consultations with HCPs.

> '*Explain things better and like on your first session don't be asking such personal questions when there is loads of other people in the room cos when I was brought in there were four counsellors sitting there and a doctor who my parents met and they were asking me really personal questions that I didn't want to answer in front of my parents let alone a load of strangers*' (adolescent 2A).



Appendix 2.1: Submission Requirements for Child and Adolescent Mental Health

Contributions from any discipline that further clinical knowledge of the mental life and behaviour of children are welcomed. Papers need to clearly draw out the clinical implications for mental health practitioners.

The first page of the manuscript should give the title, name(s) and address(es) of author(s), and an abbreviated title (running head) of up to 80 characters. Specify the author to whom correspondence should be addressed and provide their full mailing and email address.

Summary: Authors should include a structured Abstract not exceeding 250 words under the sub-headings: Background; Method; Results; Conclusions.

Keywords: Please provide 4-6 keywords (use MeSH Browser for suggestions).

Key Practitioner Message: (in the form of 3-6 bullet points) should be given below the Abstract, highlighting what's known, what's new and the direct relevance of the reported work to clinical practice in child and adolescent mental health.

Papers submitted should be concise and written in English in a readily understandable style, avoiding sexist and racist language. Original Articles should not exceed 5,500 words, including References and Tables. Occasionally, longer articles may be accepted after negotiation with the Editors. Authors should include a word count of their paper.

Headings: Original articles should be set out in the conventional format: Methods, Results, Discussion and Conclusion. Descriptions of techniques and methods should only be given in detail when they are unfamiliar. There should be no more than three (clearly marked) levels of subheadings used in the text.

Tables: These should be kept to a minimum and not duplicate what is in the text; they should be clearly set out and numbered and should appear at the end of the main text, with their intended position clearly indicated in the manuscript.

Full Details at:
http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)14753588/homepage/ForAuthors.html

Appendix 2.2: Interview Topic Guide for Young People Transitioning to AMHS

Interview Preparation

Action points: Make sure the audio recorder is working
Remind participants that participation in this study is voluntary
Remind participant about the parameters of confidentiality
Remind participants that we can stop at any time if they get distressed
Remember the interview questions below are to be used as a guide

Beginning

Thank you for agreeing to be interviewed today. My name is _____. For this research study, I am interested in what you have to say about yourself, your experiences and your understandings of moving from CAMHS to adult services in as much detail as you are able to give. It's important for you to know that there are no right or wrong answers. I'm interested to hear your story, your thoughts and feelings about the move. To make the research most useful, I would like to know any positive or negative things. I will try to say as little as possible to give you the space to share your story. Some of the questions I ask might seem obvious but I am trying to get to grips with how you understand your experience. Take as much time as you need to think and talk. Lastly, feel free to ask any questions at any time if there is anything I say today that doesn't make sense or is not clear.

- To start off can you please tell me about yourself?
- Can you tell me the story about how you first came to see someone at CAMHS?
- Could you tell me about your experiences of using CAMHS?
- Are you receiving any support or service at the moment?

First Interview

- Can you describe when you first became aware of being transferred to adult services?
- What was that like for you?
  Prompts: How did you feel? What kind of thoughts did you have around this time?
- What did you expect the move to be like?
- What does the move mean for you?
- Can you describe to me what you think will happen next? What will that mean for you?
- Is there anything you would like to say about your experience of moving to adult services that we didn't touch on so far?
- How did you find the interview today?

Second Interview

Last time we met you told me about <insert content from first interview>.

- How have things been since we last spoke? How have things been?
- How do you feel now about moving from CAMHS to adult services?
- What does the move mean for you?

- How has the preparation been for your move to adult services?
  Prompts: have you done anything to prepare? Has CAMHS or adult services done anything?
- To what extent, has the process of transitioning so far lived up to what you originally thought it would be like?
- How are you feeling about the next few months? What do you think will happen?
- Is there anything you would like to say about your experience of moving to adult services that we didn't touch on so far?
- How did you find the interview today?

Third Interview

Last time we met you told me about <insert content from second interview>.

- How have things been since we last spoke? How have things been?
- What has been helpful for you regarding your move from CAMHS to adult services?
- What has made things difficult for you?
- How has the process of moving from CAMHS to adult services affected you?
- To what extent, has the process of transitioning lived up to what you originally thought it would be like?
- Is there anything you would like to say about your experience of moving to adult services that we didn't touch on?
- How did you find the interview today?

Probes to use throughout the interview

How did that make you feel?

Can you tell me more about that?

What is/was that like for you?

Tell me what you were thinking?

How did you feel?

Appendix 2.3: Interview Topic Guide for Young People in their Final 12 months with CAMHS

Beginning

Thank you for agreeing to be interviewed today. My name is _____. For this research study, I am interested in what you have to say about yourself, your experiences and your understandings of moving on from CAMHS in as much detail as you are able to give. It's important for you to know that there are no right or wrong answers. I'm interested to hear your story, your thoughts and feelings about the move. To make the research most useful, I would like to know any positive or negative things. I will try to say as little as possible to give you the space to share your story. Some of the questions I ask might seem obvious but I am trying to get to grips with how you understand your experience. Take as much time as you need to think and talk. Lastly, feel free to ask any questions at any time if there is anything I say today that doesn't make sense or is not clear.

- To start off can you please tell me about yourself?
- Can you tell me the story about how you first came to see someone at CAMHS?
- Could you tell me about your experiences of using CAMHS?

First Interview

- Can you describe when you first became aware of moving on from CAMHS?
- What was that like for you?
  Prompts: How did you feel? What kind of thoughts did you have around this time?
- What is your understanding of whether or not your care will transfer to adult services?
  Prompts: What thoughts do you have about this? How do you feel about this decision?
- What does moving on from CAMHS mean for you?
- Can you describe to me what you think will happen next? What will that mean for you?
- How has the preparation been for you moving on from CAMHS?
- Is there anything you would like to say about your experience of moving on from CAMHS that we didn't touch on so far?
- How did you find the interview today?

Subsequent Interviews (if required)

Last time we met you told me about <insert content from first interview>.

- How have things been since we last spoke? How have things been?
- How do you feel now about moving on from CAMHS to adult services?
- What does the move mean for you?
- How has the preparation been for your move?
  Prompts: have you done anything to prepare? Has CAMHS or adult services done anything?
- Could you tell me more about the decision that was made for your care going forward (i.e. to transfer or not to transfer to adult services?

- How are you feeling about the next few months? What do you think will happen?
- Is there anything you would like to say about your experience of moving to adult services that we didn't touch on so far?
- How did you find the interview today?

Probes to use throughout the interview

How did that make you feel?

Can you tell me more about that?

What is/was that like for you?

Tell me what you were thinking?

How did you feel?

Appendix 2.4: Letters of Approval (R&D and REC)

Document: AM Approval letter 14/12/16

R&D Ref No:	1226
REC Ref No:	16/NS/0080
NRS Ref No:	NA
EudraCT Ref No:	NA
MHRA Ref No:	NA
Today's Date:	31/01/2017

Frances Hines
Research, Development & Innovation Manager
NHS Highland Research, Development & Innovation Department
Centre for Health Science
Old Perth Road
Inverness
IV2 3JH

Tel: 01463 255821
E-mail: frances.hines@nhs.net

NHS Highland

Ms Clodagh Feehan
Trainee Clinical Psychologist
Dept of Psychological Services
Drumossie Unit
New Craigs
6 - 16 Leachkin Road
IV3 8NP
By email: clodagh.feehan@nhs.net

Dear Ms Feehan,

LETTER OF APPROVAL OF YOUR RESEARCH PROJECT AMENDMENT

PROJECT TITLE: Making Sense of Young People's Journeys from Child and Adolescent Mental Health Services (CAMHS)
REC: 16/NS/0080
NHS Highland R&D Ref Number: 1226

Amendment Type:	**Substantial (SA)**	√
	Modified SA	
	Non-substantial (NSA)	
Amendment No:	**AM 01**	
Amendment Date:	**12/01/2017**	
Current Protocol Version No:	**V1.2 Date 11/11/2016**	

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North of Scotland Research Ethics Service
Summerfield House
2 Eday Road
Aberdeen
AB15 6RE

Telephone: 01224 558458
Facsimile: 01224 558609
Email: nosres@nhs.net

23 January 2017

Miss Clodagh Feehan
Trainee Clinical Psychologist
NHS Highland
Department of Psychological Services
Drumossie Unit, New Craigs Hospital, 6-16 Leachkin Road
INVERNESS
IV3 8NP

Dear Miss Feehan

Study title:	**Making Sense of the Transitional Process of Young People moving from Child and Adolescent Mental Health Serivces (CAMHS) to Adult Mental Health Services (AMHS)**
REC reference:	**16/NS/0080**
Protocol number:	**N/A**
Amendment number:	**AM01**
Amendment date:	**12 January 2017**
Amendment Summary:	**Include NHS staff perspectives on transitioning from CAMHS to Adult Services. include young people who were coming to the end of their time in the CAMHS service Alter the study title to "Making sense of Young People's Journeys from Child and Adolescent Mental Health Services (CAMHS)".**
IRAS project ID:	**208136**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Covering letter on headed paper		16 December 2016
Notice of Substantial Amendment (non-CTIMP)	AM01	12 January 2017

Interview Topic Guide for CAMHS Clinicians	1.0	11 November 2016
Interview Topic Guide - Young People in their Final 12 Months with CAMHS	1.0	11 November 2016
Invitation to Participate Email	1.0	11 November 2016
Recruitment Poster - Brief accompanying Information sheet for young people in their final 12 months in CAMHS	1.0	11 November 2016
Recruitment Poster - young people in their final 12 months in CAMHS	1.0	11 November 2016
Participant consent form	1.1	11 November 2016
Participant consent form - CAMHS Clinician	1.0	11 November 2016
Participant information sheet	1.2	11 November 2016
Participant information sheet CAMHS Clinicians	1.0	11 November 2016
Research protocol or project proposal	1.2	11 November 2016

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

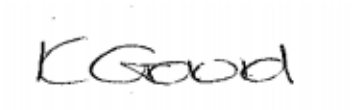
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

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

16/NS/0080:	**Please quote this number on all correspondence**

Yours sincerely



Pp'd on behalf of
Dr Georgina Hold
Vice-Chair

Enclosures: List of names and professions of members who took part in the review

Copy to: NHS Highland – R&D Department

Appendix 2.5: Participant Consent Form

v1.1 11/11/2016

NHS Highland

University of Glasgow
Institute of Health & Wellbeing

Identification Number for this Study: 208136

CONSENT FORM

Project: Making Sense of Young People's Journeys from Child and Adolescent Mental Health Services (CAMHS)

Chief Investigator: Clodagh Feehan

Please initial box

1. I confirm that I understand the nature of the study proposed, having read and understood the information sheet provided (version 1.2 dated 11/11/2016). I have had opportunity to ask questions, and am satisfied with the answers I received. ☐
2. I understand that my participation is voluntary, and that I am free to withdraw from the study at any time. Should I wish to with draw, I understand that I can do so without giving reason, and without my medical care or legal rights being *affected*. ☐
3. I agree to take part in the above study. ☐
4. I agree that you may inform my CAMHS clinician(s) of my involvement in this study. ☐
5. I am aware that what I say in my interview will remain confidential. The only situation where this would not apply is if I say something that makes the researcher concerned that there is a risk of serious harm to me or someone else. ☐
6. I agree to my interview being audio-recorded. ☐
7. I would like to receive a copy of the recorded interview. ☐
8. I agree that fully annonymised quotations may be used in the final written report, which may be submitted for publication in an academic journal. ☐
9. I would like to receive a copy of the study results. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Researcher	Date	Signature

Appendix 2.6: Participant Information Sheet

Study Title: **Making Sense of Young People's Journeys from Child and Adolescent Mental Health Services (CAMHS).**

1. **Invitation Paragraph**
   You are being invited to take part in a research study. Before you decide if you would like to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with other people if you wish. Please ask if there if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part. Thank you for reading this.

2. **What is the purpose of this study?**
   The project aims to gather the experiences of young people whose care is moving from CAMHS. This includes young people who are in their final 12 months with the CAMHS service and whose care is moving to or being considered for a move to adult mental health services. I hope to get an understanding of what the process of moving from one service to another or deciding not to move is like as it happens. This will help to develop ideas on how to improve services, especially for other young people who may have to move from one service to another in the future.

3. **Why have I been chosen?**
   You have been chosen as you received care from CAMHS and are in your final year with the service. You are either due to move to adult services (either because you are turning 18 years old or because you are turning 16 years old and no longer in school) or you are being considered for a move to adult services. The study is aiming to recruit up to 8 participants.

4. **Do I have to take part?**
   No. As entry to the study is entirely voluntary, **it is up to you to decide** whether or not to take part. You should not feel under any pressure to make the decision. If you do decide to take part, you will be asked to sign a consent form. Even after signing you are still free to withdraw at any time and without giving a reason. This will not affect any care you may receive now or in the future.

5. **What will happen to me if I take part?**
   If you decide to take part, you will be asked to take part in up to three interviews at different time points during your move to adult services or during your last months with CAMHS. The interview questions will be about your experience of moving from CAMHS to adult services or your experience of coming to the end of CAMHS and being considered for transition to adult services. The interviews will be carried out by Clodagh Feehan (Trainee Clinical Psychologist and Chief Investigator). The interviews will take place at a NHS Highland setting. The interviews can also take place at your school if this would be your preference. The interviews are expected to last for up to an hour. Interviews will be audio-recorded so that your answers can be accurately typed up by the researcher. Only the research team will have access to the recording. Once the interviews are typed up they will be

anonymised, meaning no information will be included in the typed version that could identify you personally. For each interview you take part in (up to 3), you will be given £10 to cover any expenses or inconvenience.

6. **Do I have to take part in this research project?**
   No, participation in any research project is voluntary. If you do not wish to take part you do not have to. If you decide to take part and later change your mind that is also OK. You have the right to withdraw from the project at any stage. If you do decide to take part, you will be given this Participant Information Sheet/ Consent Form to sign and you will be given a copy to keep. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your care.

7. **What are the possible disadvantages and risks of taking part?**
   There is a possibility when discussing your experience of moving services or coming to the end of your time in CAMHS that you may feel upset. You would be free throughout the interview to stop and take a break or discontinue the interview at any time. If you felt that upon finishing the interview that you needed to talk to someone further information will be given regarding where best you can receive further support or advice.

8. **What are the possible benefits of taking part?**
   There are not direct benefits for you taking part in this study. However, it is hoped that from your experiences we can begin to understand what it is like for young people moving on from CAMHS. The information can then be used to help professionals and future young people as they embark on their move. It may be that some participants find the opportunity to reflect on their experiences a useful one.

9. **Will taking part in the study cost me anything?**
   No. The study will only involve your time. In order to compensate you for this and any expenses incurred, for each interview (up to 3) you take part in you will receive a payment of £10.

10. **Will my taking part in this study be kept confidential?**
    The researcher will first check with your CAMHS professional that your taking part in this study will not interfere with your ongoing care. All information collected about you during the course of the research will be kept strictly confidential. The audio-recording and transcription of your interviews will be identified by an allocated participant number only. If any quotes from your interviews are used in the final report, a pseudonym (different name) will be used. Information collected will be kept in accordance with the Data Protection Act (1998) as well as NHS Highland and University of Glasgow policy.

    However, if you say something during the interview which makes the researcher concerned that there is a risk of serious harm to you or someone else she will have to tell break confidentiality. Wherever possible this will be discussed with you first. If you share information that makes the research team concerned about your safety/other's safety we may be required to tell others involved in your care (e.g. care worker or psychiatry). We will always endeavour to notify you beforehand if we are going to do this and explain why.

11. **What will happen to information about me?**
    By signing the consent form you consent to the relevant research staff collecting and using personal information about you for the research project. Any information obtained for the purpose of this research project can identify you will be treated as confidential and securely stored. It will be disclosed only with your permission, or as required by law.

Your interviews will be audio-recorded and demographic information (e.g., age, gender, etc.) will be collected. Demographic information will be collected by talking with you. The recordings and your demographic information will be stored on a password protected computers. The audio recordings will only be accessible by members of the research team for the purpose of coding the specific responses. The codings will then be entered in an annonymised format into a database, which will be stored securely.

12. What will happen to the results of the research study?

When the research study is finished, the completed report will be submitted to the University of Glasgow 2017 as the Major Research Project of the researcher's Doctorate in Clinical Psychology degree. It is hoped that the study would also be submitted for publication in research journal. Presentations may also be given at scientific conferences. All participants will be asked if they would like to be sent a summary of the results. You will not be identified in any publication or presentation.

13. Who has reviewed the study?

The study has been reviewed by the North of Scotland Research Ethics Committee, University of Glasgow, and NHS Highland Research and Development (R&D).

14. What will happen if I decide to withdraw from the study?

You can withdraw from the study at any time. You do not have to provide a reason and if you withdraw you will continue to receive your usual care and treatment.

If you do withdraw from the study, any personally identifiable information about you will be destroyed. However, annonymised data already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected by the research team up to the time that you withdraw will be retained and used in the study to form part of the research project results. If you do not want them to do this, you should choose not to participate in this study.

15. Can I speak to someone who is not involved in the study?

Yes you can. Professor Rory O'Connor who is not involved in the study can answer questions or give advice about participating in this study. His telephone number is 0141 211 3920.

16. What will happen if I have a problem or complaint?

If you have any concerns about the study or the way it is conducted or if you want to complain about any aspect of this study, please contact Prof. Andrew Gumley, Mental Health and Wellbeing, Gartnavel Royal Hospital, 1st Floor, Admin Building, University of Glasgow, Glasgow G12 0XH, or the Research & Development Department, NHS Highland on 01463 255 822.

The normal NHS complaint mechanisms will also be available to you.

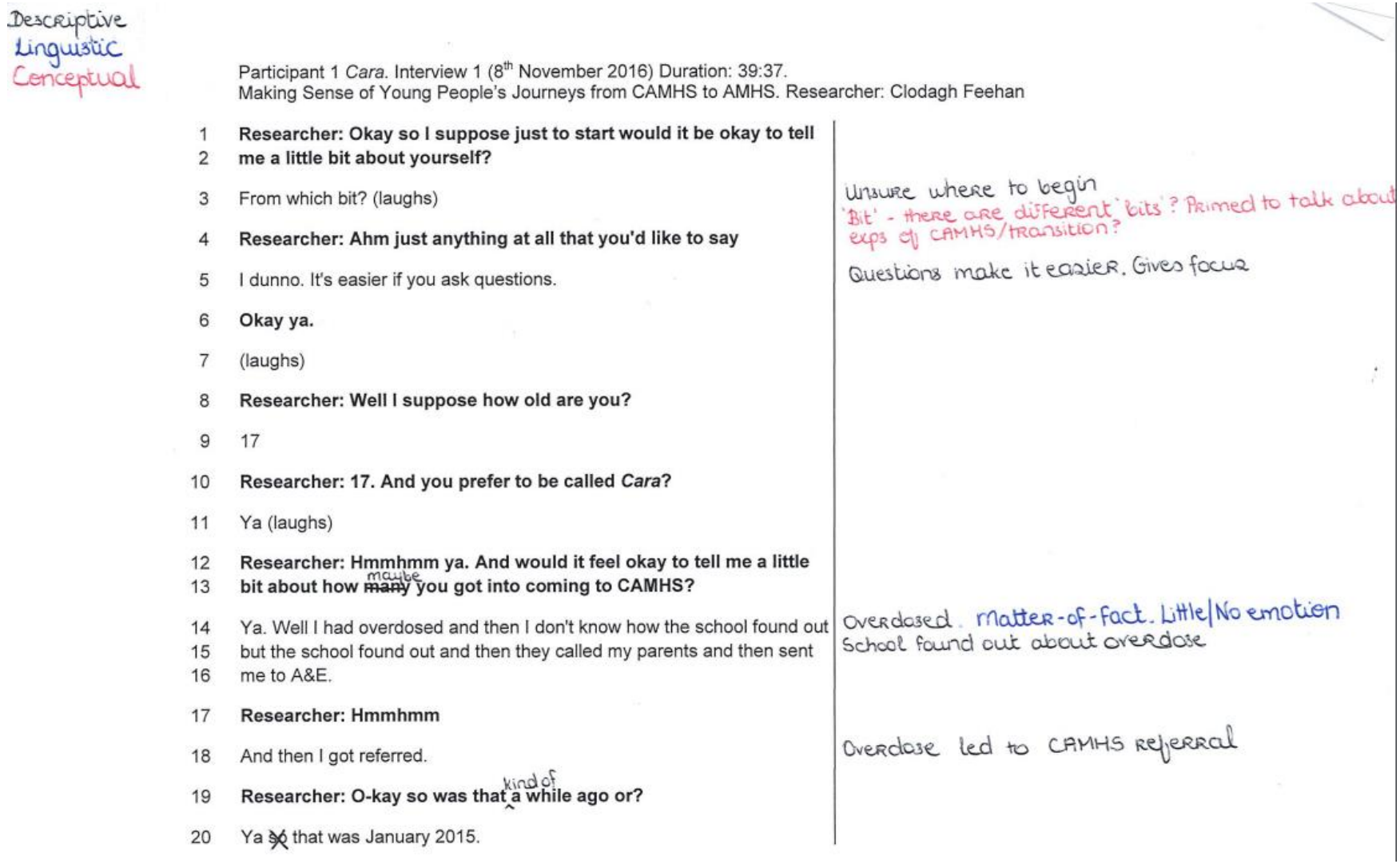
17. Contact for Further Information

If you would like any further information or have any questions please feel free to contact a member of the research team below.

For general independent information on taking part in research please visit the INVOLVE website on www.invo.org.uk/find-out-more/

Clodagh Feehan	Trainee Clinical Psychologist Chief Investigator	*Child and Adolescent Mental Health Services (CAMHS), Phoenix Centre, Raigmore Hospital, Old Perth Road, Inverness* *01463 705 597*
Prof. Andrew Gumley	Academic Supervisor	Mental Health and Wellbeing – University of Glasgow, Gartnavel Hospital, Glasgow. 0141 2113920
Dr Wendy van Riet	Field Supervisor	*Child and Adolescent Mental Health Services (CAMHS), Phoenix Centre, Raigmore Hospital, Old Perth Road, Inverness* *01463 705 597*
Prof. Rory O' Connor	Independent Contact Person	Mental Health and Wellbeing – University of Glasgow, Gartnavel Hospital, Glasgow. 0141 2113920

Appendix 2.7: Sample of IPA Initial Coding (Descriptive, Linguistic and Conceptual Codes)



Descriptive
Linguistic
Conceptual

Participant 1 *Cara*. Interview 1 (8th November 2016) Duration: 39:37.
Making Sense of Young People's Journeys from CAMHS to AMHS. Researcher: Clodagh Feehan

1	**Researcher: Okay so I suppose just to start would it be okay to tell**	
2	**me a little bit about yourself?**	
3	From which bit? (laughs)	Unsure where to begin 'Bit' - there are different 'bits'? Primed to talk about exps of CAMHS/transition?
4	**Researcher: Ahm just anything at all that you'd like to say**	
5	I dunno. It's easier if you ask questions.	Questions make it easier. Gives focus
6	**Okay ya.**	
7	(laughs)	
8	**Researcher: Well I suppose how old are you?**	
9	17	
10	**Researcher: 17. And you prefer to be called *Cara*?**	
11	Ya (laughs)	
12	**Researcher: Hmmhmm ya. And would it feel okay to tell me a little**	
13	**bit about how ~~many~~ maybe you got into coming to CAMHS?**	
14	Ya. Well I had overdosed and then I don't know how the school found out	Overdosed. matter-of-fact. Little/No emotion
15	but the school found out and then they called my parents and then sent	School found out about overdose
16	me to A&E.	
17	**Researcher: Hmmhmm**	
18	And then I got referred.	Overdose led to CAMHS referral
19	**Researcher: O-kay so was that kind of a while ago or?**	
20	Ya ~~so~~ that was January 2015.	

Researcher: Okay so you would have been..

15

Researcher: 15 okay so school found out and [Cara: ya] **And then they were the ones...so what was that like for you I suppose that the school were the ones** to

Ahm
~~I dunno~~ it was kind of like....it was so rushed they didnt really have time to think so you kind of started panicking (hm - laugh?)

Tailed off. Pace of speech reflects the "rushed"
Panicking
All happened very quickly

Researcher: Ya

Cos i just got pulled out of class and they were like right we are phoning your parents and I was like What (laughs)

"Pulled out" - descriptive + vivid. Did she have a choice? "Pulled out" - powerless in this?
School told parents
"What" + laughter - emphasised her surprise

Researcher: So was the overdose in school then or?

No it was the night before

Researcher: Okay. So how were you feeling in school?

Fine, [**Researcher: Hmm**] (laughs) you just kind of pick yourself back up and go for it.

Did she really feel fine? Laughter - stupid Q? or used to show that she wasn't fine?
Sense of getting on with it

Researcher: Hmhmm so was there a delay then between ahm kind of going to A&E and

Ya I think so

Researcher: Ya and did you see someone regularly in CAMHS after that or

Ya Professional 1

Participant 1 *Cara*. Interview 1 (8th November 2016) Duration: 39:37.
Making Sense of Young People's Journeys from CAMHS to AMHS. Researcher: Clodagh Feehan

Researcher: Aw okay.

I think I met Professional 2 a couple of times but not like an awful lot

Researcher: Ya hmmhm. So have you been in CAMHS then for maybe...I suppose it's....well over a year then or

Well Professional 1 discharged me in April but then I've got re-referred

Researcher 1: Aw so April of this year?

Ya

Researcher 1: Aw okay. So I suppose in general how would you describe your time in CAMHS?

It was alright but it only works if you like tell the truth [**Researcher: Hmmhmm**] Cos if you lie it doesn't help (laugh)

Researcher: So do did you try maybe lying a bit at the start or?

(laughs) ya you could say that (laughs)

Researcher: (laughs) ya. Was it kind of...what do you think was behind that or?

I don't know probably like the control aspect because I didnt want it to spiral out of control again. [**Researcher: Hmhmm**] Like it did in the first place

Researcher: Hmmhmm. So when you say things spiralled out of control is that

Ya. Cos like you go from like normal if you know what I mean like sitting in class and then next thing you're thrown into A&E [**Researcher:**

Discharged by Professional
"discharged me" - suggests not being involved in this
Did she want to be discharged?
Re-referred to CAMHS - I'm aware that she wasn't "re-referred" but this is YP's words

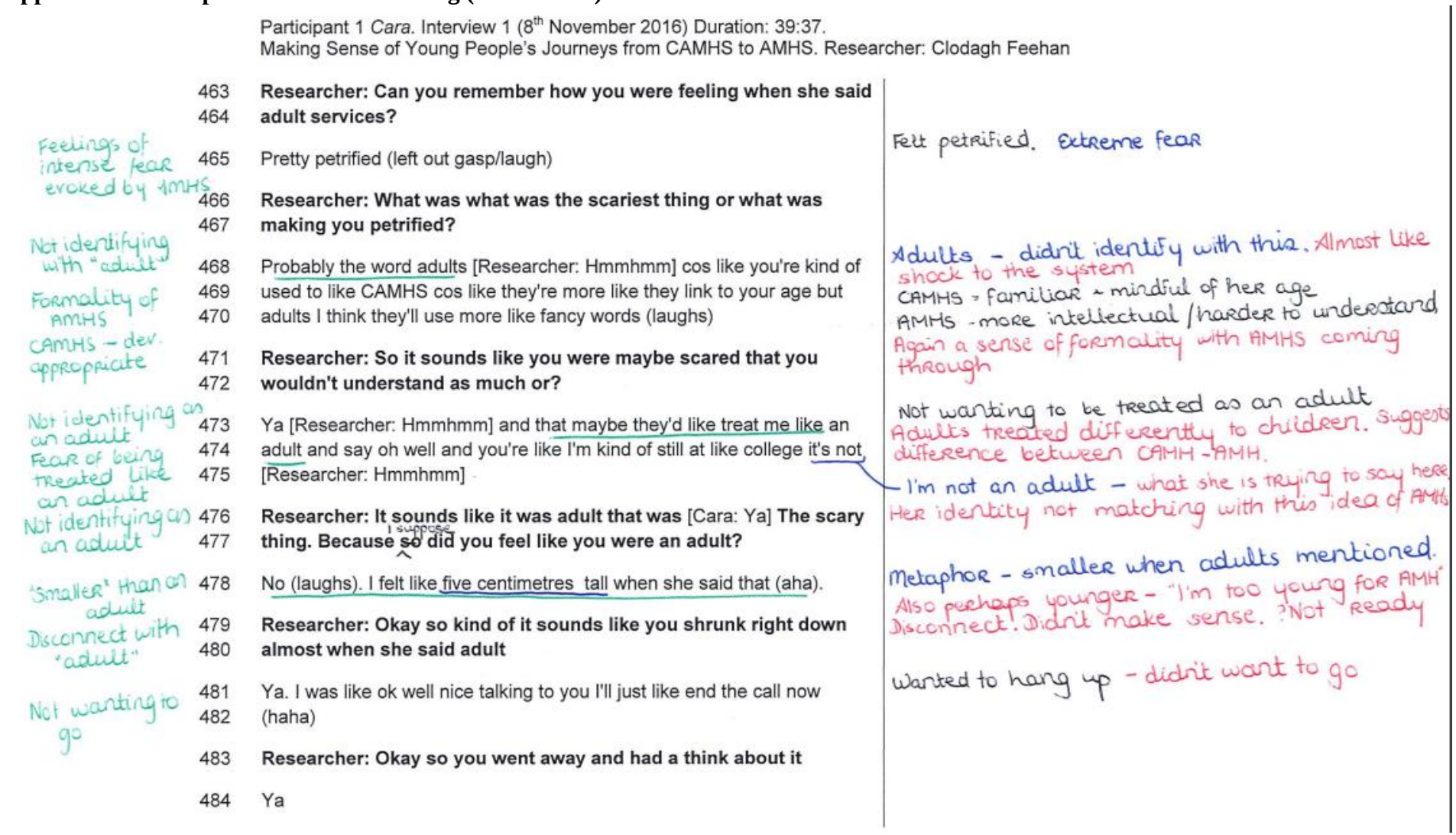
Time in CAMHS was alright. "Alright" - quite neutral
(possibly more on negative side?)
Need to tell truth for CAMHS to work. CAMHS working is conditional on telling truth
Laughter - suggestive that she lied (mischevious)

Sarcasm and laughter - lied a lot

Lies used to be in control
Possibility of things being out of control
'Spiral out of control' - vivid - suggests speed
Why was it important to be in control? What could cause things to spiral?
Things were out of control at one time

Things happened quickly
Normal to being in A&E. Didn't feel "normal" then?
"Thrown into" - suggests she had no choice
powerless? against her will?

Appendix 2.8: Sample Second Level Coding (Green Font)



Participant 1 *Cara*. Interview 1 (8th November 2016) Duration: 39:37.
Making Sense of Young People's Journeys from CAMHS to AMHS. Researcher: Clodagh Feehan

463 **Researcher: Can you remember how you were feeling when she said**
464 **adult services?**

Feelings of intense fear evoked by AMHS

465 Pretty petrified (left out gasp/laugh)

Felt petrified. Extreme fear

466 **Researcher: What was what was the scariest thing or what was**
467 **making you petrified?**

Not identifying with "adult"

Formality of AMHS

CAMHS – dev. appropriate

468 Probably the word adults [Researcher: Hmmhmm] cos like you're kind of
469 used to like CAMHS cos like they're more like they link to your age but
470 adults I think they'll use more like fancy words (laughs)

Adults – didn't identify with this. Almost like shock to the system
CAMHS - familiar - mindful of her age
AMHS - more intellectual / harder to understand
Again a sense of formality with AMHS coming through

471 **Researcher: So it sounds like you were maybe scared that you**
472 **wouldn't understand as much or?**

Not identifying as an adult

Fear of being treated like an adult

473 Ya [Researcher: Hmmhmm] and that maybe they'd like treat me like an
474 adult and say oh well and you're like I'm kind of still at like college it's not
475 [Researcher: Hmmhmm]

Not wanting to be treated as an adult
Adults treated differently to children. Suggests difference between CAMH-AMH.
– I'm not an adult – what she is trying to say here
Her identity not matching with this idea of AMHS

Not identifying as an adult

476 **Researcher: It sounds like it was adult that was** [Cara: Ya] **The scary**
I suppose
477 **thing. Because so did you feel like you were an adult?**

"Smaller" than an adult

478 No (laughs). I felt like five centimetres tall when she said that (aha).

Metaphor - smaller when adults mentioned.
Also perhaps younger - "I'm too young for AMH"
Disconnect. Didn't make sense. ?Not ready

Disconnect with "adult"

479 **Researcher: Okay so kind of it sounds like you shrunk right down**
480 **almost when she said adult**

Not wanting to go

481 Ya. I was like ok well nice talking to you I'll just like end the call now
482 (haha)

Wanted to hang up – didn't want to go

483 **Researcher: Okay so you went away and had a think about it**

484 Ya

(lack of info) Uncertainty of what AMHS is

Having to start all over again

Distinction between kids + adults

Familiarity of CAMHS

485 **Researcher: What sort what was going on for you when you were**
486 **having that thinking time?**

487 Most of me was like you don't want to do it cos you don't know what it's
488 like and you don't want to get involved in it because that would mean
489 starting from scratch and like putting back on meds and then the parents
490 knowing and like starting all over again really [Researcher: Hmmhmmm]
491 but if you like kept with the kids bit then my mum would be like aw ya I
492 know Professional 1 that's fine so

493 **Researcher: Okay so it sounds like it was scary because it would be**
494 **all new**

495 Ya

496 **Researcher: Hmmhmm ya. And I suppose what did it mean to you**
497 **that now ahm adult services was being talked about?**

Feeling fearful

Familiarity of CAMHS

Process of getting used to a service

Novelty is scary

498 I don't know. It was just really scary [Researcher: Hmmhmm] cos you're
499 like you get so used to one thing and then you're like oh my gosh
500 everything is so completely different

501 **Researcher: Hmmhmm what what did you expect in terms of how**
502 **did you think it would be different?**

CAMHS more warm/cushioning

AMHS more direct

503 I don't know. I think part of it is like cos Professional 1 is just like ~~she'd like~~ she'll
504 double check you understand things but I think in adults they'd be very
505 ~~strict~~ straight to the point

Not ready for adult approach

Out of depth in AMHS

506 **Researcher: Hmmhmm can you think anything else about how the**
507 **care might be different or how it might be the same?**

Uncertainty - not sure what AMHS involves
- not wanting to do it

Beginning from the start again - Repetition
Daunting for her. ?Too scary

Kids vs Adults. Identifying more with "kids bit"
CAMHS + Prof 1 = Familiar.

Emphasising how scary it was for her
CAMHS - familiar. Used to - takes time to get familiar with something
Highlighting difference. Uncertainty + New = Scary

Prof 1 (& CAMHS) - check that she understands
AMH more direct.
Wanting the checking in. Not feeling able/ready for "adult" approach in AMH. Sense that she would be lost/out of her depth/not supported as much

Increased confidentiality in AMHS
Familiarity of CAMHS
Need for control
Unsure of consequences in AMHS

508 Well I think there's more there's a higher confidentiality thing which I love
509 (laughs) but at the same time cos like I've just worked CAMHS out and
510 then knowing what to say and what not to say and I'll have to like re-plan
511 it all the next one (laughs)

512 **Researcher: It sounds like you're really careful** [Cara: Ya Professional
513 1 hates me for it (laughs)] **(laughs) so it sounds like you're really**
514 **careful about what to say** [Cara: Ya because I know the consequences]
515 **Okay so what is the big consequence that you don't want to**
516 **happen?**

"sectioning"
Hospitalization in AMHS
Fear of parents being told

517 Well there's different ones. There's like sectioning which I really don't
518 want. Or then there's like telling your parents and ^like all this other stuff as
519 well [Researcher: Hmmhmm] so

520 **Researcher: Am I understanding that maybe the higher**
521 **confidentiality in adult services that you're expecting will be a good**
522 **thing for you?**

Increased confidentiality in AMHS

523 Ya [Researcher: Hmmhmm] cos they'll not just tell my mum as much if
524 you know what I mean

525 **Researcher: And is that something...how are you feeling about that?**

526 Good [Researcher: Hmmhmm] (laughs)

527 **Researcher: Ahm....and I suppose now that you're sort of a month in**
528 **from adults services being mentioned. [**Cara: Ya**] What's being**
529 **happening since you gave the go ahead that you'd like to be**
530 **referred?**

531 I got a letter for an appointment which is December

Higher threshold for confidentiality in AMHS
Knows the score with CAMHS
Takes time to work it out & suss it out
Filtering based on wrd. how CAMHS work
Her need for control coming out again here.
Having to figure out her approach in a new service. ?Anxiety ?Fear - consequences that leads to her censoring
Sense that she can be a handful for clinicians?

Sectioning - repetition again highlighting her fear & worry
Parents being told

Not wanting parent to know as much
Higher/Different confidentiality in AMHS = positive

Participant 1 *Cara*. Interview 1 (8th November 2016) Duration: 39:37.
Making Sense of Young People's Journeys from CAMHS to AMHS. Researcher: Clodagh Feehan

Researcher: Okay so what what was that like then?

It was okay cos you're like at least I have one you're kind of sitting in the back of your mind going that's a whole month away [Researcher: Hmmhmm] of like nothing and like I'm I'm really unpredictable like I don't usually..like to Professional 1 and that I'll just like say the same thing but I'm like really unpredictable. [Researcher: Hmmhmm] Like I can change overnight (laughs)

Researcher: Hmmhmm so I suppose what were your thoughts on the waiting time then?

I dunno I just got really worried that I'd be unsafe or do something stupid

Researcher: Okay ya so am I right in understanding that you thought it was maybe too long [Cara: Ya] **to wait. What do you think would have been a good waiting time or?**

Probably a month

Researcher: Hmmhmm so is will it have been two months then?
[Cara: Ya] **Okay and that's just not feeling**
I mean
~~Like~~ it's not really bad but it's just like a couple of weeks extra long
[Researcher: Hmmhmm] And sometimes that's all it takes (haha) hhmph

Researcher: Ya so I suppose what when you got the letter then
[Cara: Ya] **and you saw the appointment date what was that like for you?**

Well at first I thought it said November and I was like that's like next week and then I was like no that's like December so I was like okay. And then I

Appt feels too far away
Void in between
Unpredictability of MH makes wait difficult
GAP causes worry due to lability of mood
issue of risk
Wait = too long
Wait = too long
issue of risk
key in view that wait is too long
Unpredictability of MH

Tension between < having appt (good) / too long away
Nothing in between - isolated/alone/waiting

"Really"
Repetition of unpredictable - sense that anything could happen in that time
Worry that it's too long with her lability

Worry about her risk. Feels risky
sense that this could be avoided with an earlier appt. time. she may not be able to control self

Not really bad → suggests it's bad - could be better
Too long to wait
Almost threatening - emphasizing how unstable/unpredictable she is? Who's fault is it if something happened?

Appendix 2.9: Major Research Project Proposal

Abstract

Background: Young people who are using Child and Adolescent Mental Health Services (CAMHS) are required to be to be discharged from those services when they reach 18 or earlier if they leave school. Those who have continuing mental health needs are often transferred to Adult Mental Health Services (AMHS). This transition can be experienced as difficult because of breaks in therapeutic relationships, changes in the ethos of services, and waiting times to be seen. Therefore, there is a risk that young people will disengage from services and go on to develop more severe problems. **Aims:** This study will explore young peoples' experiences of transition and how they make sense of these experiences. By exploring these experiences over time we aim to uncover how young people engage with and negotiate these transitions. This study will also include the perspectives of CAMHS clinicians, who are key stakeholders in the transitional process. **Methods:** A qualitative longitudinal design with 4-8 young people (15-18 years). Participants will be interviewed, using semi-structured interviews, up to three times at different time points during their move to adult services. 4-6 CAMHS clinicians will be interviewed to provide an enriched context for understanding young people's experiences. Interviews will be analysed using interpretive phenomenological analysis. **Applications:** The findings will provide an understanding of what this process is like for young people; this will be helpful for clinicians, young people, and parents.

Introduction

There has been long standing concern that young people with mental health difficulties who fall between child and adolescent mental health services (CAMHS) and adult mental health service (AMHS) may get 'lost' during their move between services (Lamb, Hall, Kelvin & Van Beinum, 2008). Disruption of care during transition adversely affects the health, wellbeing and potential of this vulnerable group (Lamb et al., 2008).

'Transition' and Young People

The concept of transition in relation to young people can be viewed from distinct perspectives (Singh et al., 2010a). From a developmental perspective, adolescence is a pivotal stage of emotional, psychosocial, personal and physiological development as young people embark on acquiring adult roles through tasks such as separating from family, deciding on a career path and identity formation (Lee, 2001). Secondly, from a health care perspective, young people have to move from one service to another upon reaching certain age milestones (Singh et al., 2010a). Here, the term transition will be used explicitly to refer to health care transition, defined as a formal transfer of care from CAMHS to AMHS. Transfer is defined as the actual point at which the responsibility for providing care and

support to a person moves from a children's to an adult provider. Meanwhile, transition is defined as the process of moving from children's to adults' services. It refers to the full process including initial planning, the actual transfer between services, and support throughout (NICE, 2015).

Transition Occurs during Adolescence

Adolescence is a risk period for higher psychological morbidity (Singh et al., 2010b) with most mental disorders beginning or having their origins in the teenage years. Young people with mental health problems have the highest rates of long-term morbidity and mortality (Royal College of Paediatrics and Child Health, 2003). It is particularly important that care remains consistent and uninterrupted throughout this time of heightened vulnerability. Yet this is the period when young people are expected to move from CAMHS, where they may have established strong and positive relationships, to AMHS, which often have very different systems and structures and work to a different ethos (Joint Commissioning Panel for Mental Health, 2012).

Barriers to Good Transition

NICE (2015) advocates the need for a smooth and gradual transition for young people moving from children's to adult's services. Hovish, Weaver, Islam, Paul and Singh (2012) explored what a 'good' transition actually is by carrying out a multi-perspective qualitative study with young people, professionals and parents. The study identified that informal and gradual preparation, transfer planning meetings, periods of parallel care, and consistency in key-workers promoted positive experiences of transition.

Young people with mental health conditions can face significant obstacles in obtaining services as they negotiate the transition from adolescence to adulthood (Jivanjee & Kruzich, 2011). While the developmental processes occur gradually, institutional transitions are "abrupt, arbitrary changes in status" linked to changes in legal status and eligibility for services, often related to age (Vander Stoep et al., 2000, p.6). Ideological, structural, functional, clinical and organisational differences between CAMHS and AMHS may become most pronounced and produce challenges for all those involved in negotiating the boundary (Singh et al., 2005; Singh, 2009). They can differ in their theoretical and

conceptual view of diagnostic categories and aetiological processes, in treatment focus, in service organisation, delivery and availability, all of which perpetuate the difficulties at the interface (Singh et al, 2005). Richards and Vostanis (2004) identified difficulties in transfer arrangements. These were attributed to the different nature of child and adult services, role duplication, information exchange, coterminous transitional age cut-offs, and lack of designated staff to manage the transition. Hovish et al.'s (2012) aforementioned study identified that further transfers between different adult mental health services, changes of key-worker and waiting lists were viewed negatively by those with experience of CAMHs-AMHs transitions.

Despite the existence of agreed principles of good transitional care, there is evidence that these principles are often not reflected in practice (NICE, 2015) and the transition process may be seen simply as an administrative event between CAMHS and AMHS (Vostanis, 2005). Research studies have demonstrated a lack of comprehensive transition planning and little service planning (Jivanjee & Kruzich, 2011) which echoes NICE (2015)'s statement that transition support in the UK is often patchy and inconsistent.

The Effects of Poor Transition

The consequences and costs of poor transition are stark. Many young people with ongoing needs disengage, fall through the transition gap or get 'lost' during this time (Singh et al., 2010b). Disruption of care during transition can negatively impact the health, wellbeing and potential of this vulnerable group (Lamb et al., 2008; Singh, 2009). The most disruptive outcome of poor transition is that young people with ongoing needs disengage from services during the transition process. Disengagement from mental health care is in many cases a major problem, with between 30%-60% of young people dropping out of treatment over time (Harpaz Rotem et al., 2004).With few arrangements in place for young people negotiating transition boundaries, some slip through the gap only to present to adult services later on, by which time they may have developed severe and enduring mental health problems (Richards & Vostanis, 2004).

Proposed Study

Health services have been slow to respond to recommendations made by young people with mental health problems (Hovish et al., 2012). One factor suggested by Hovish et al. (2012) could be the general scarcity and poor quality of research aimed at eliciting young people's views of CAMHS. There are gaps in the knowledge about the process, outcomes and experience of transition from CAMHS-to-AMHS in the UK (Singh et al., 2010a). While such transition is widely accepted as a critical aspect of continuity of care, we do not know who makes such a transition, what are the predictors and outcomes of successful transition, and what organisational factors facilitate or impede successful transition. Significantly, we know relatively little about how the process of transition is experienced by young service users. Without such evidence, we cannot develop and evaluate specific service models that promote successful transition or plan future service development (Singh et al., 2010a).

The proposed current study will therefore focus on young people's experiences of the transition process in a Health Board where there is no formal transition service in operation. Qualitative research is particularly appropriate for examining process through its attention to context and particularities (Holland, Thomson & Henderson, 2006). From the available literature, participants have been asked to talk about their experiences retrospectively. There are disadvantages associated with this; for example, participants may tend to view the past from the perspective of their present situation and viewpoint (Lyons & Coyle, 2007). Moreover, CAMHS-to-AMHS transition can best be understood as an unfolding iterative process rather than as something static or linear (at least as experienced by young people). Thus, longitudinal qualitative research which involves interviewing individuals on several occasions at different time-points is a creative way of charting and interpreting the 'lived experience' of the transitional process.

Aims

This study will explore young people's expectations of the transition process, track the idiographic experiences and perceptions of these individuals as they transition, and identify barriers and aids to the transition process. To fully capture the complexities at the CAMHS-AMHS interface, the perspectives of both CAMHS clinicians who work with transition-age youth and young people in their final year with the CAMHS service who are being considered for transition to adult services will also be explored.

Research Questions

1. What are young people's experiences of the transition process from CAMHS-to-AMHS?
2. How do young people make sense of the transition process?
3. What are CAMHS clinicians' experiences of the transition process from CAMHS-to-AMHS?

Plan of Investigation

Participants

This study will focus on 4-8 transition-age youth (15-18 years) who fall between the upper end of CAMHS and AMHS and 4-6 CAMHS clinicians working at the Tier 3/Tier 4 level.

Inclusion Criteria and Exclusion Criteria

Participants need to (i) be age 15 years and over (ii) be fluent in English (iii) receiving services from CAMHS in NHS Highland (iv) scheduled to transfer to AMH within the next 12 months or in their final year with the CAMHS service and transition to AMH is being considered (v) aware that the transition is going to occur or aware that transition is being considered (vi) deemed by the clinical team to be competent to give own consent (vii) give informed consent to participate in the study.

Exclusion criteria are young people (i) under the age of 15 years (ii) lack capacity to consent (iii) have a diagnosis of a learning disability or social-communication disorder (iv) who are scheduled to transition to LD adult services.

Participants who are CAMHS clinicians need to (i) work at the Tier 3 or Tier 4 level (ii) work regularly with transition-age young people who meet the above inclusion criteria.

Justification of sample size

4-10 interviews or sources of data are recommended for IPA professional doctorate research studies (Smith, Flowers & Larkin, 2009). IPA commits to idiography via a "less is more" approach. Thus, fewer participants examined in greater depth is preferable to a broader, shallow, descriptive analysis of many individuals (Reid et al., 2005).

Recruitment Procedures

Young People

1. CAMHS clinicians who are case managing the young person's transition will be asked to provide an information sheet to the young person with an overview of the study and the researcher's contact details. This information can be passed to potential participants in a routine appointment, or via a letter of invitation if there are no upcoming appointments scheduled. Recruitment posters may also be placed in CAMHs' waiting rooms to advertise the study.
2. The young person will contact the researcher. Alternatively, the young person can leave their contact details with the clinician to pass to the researcher.
3. The young person's CAMHS clinician (or GP if clinician is unavailable) will be contacted to establish if it is appropriate for the young person to participate in a research interview and that they are competent to give informed consent.
4. An appointment will be arranged in a convenient location (NHS Highland setting or school).
5. The young person will be provided with a more detailed participant information sheet at least 24 hours before the interview is due to take place.

CAMHS Clinicians

1. An email with an invitation to participate will be distributed to all CAMHS clinicians in NHS Highland who work at The Tier 3 or 4 level. A participant information sheet will be attached to the email.
2. CAMHS clinicians will contact the researcher if they wish to take part.

Stakeholder Engagement

CAMHS clinicians have been surveyed and their feedback has resulted in additional recruitment procedures. This will minimise the risk of recruitment bias via CAMHS clinicians only. Recruitment posters and information sheets will be used. Invitations to participate will also be given via letters. An information evening on transitions may also be organised.

Highland User Group (HUG) has been contacted with details of the study and have been given the opportunity to review the interview topic guide, participant information sheet and consent form. HUG is open to advertising the study to their network. Furthermore, HUG may also be able to organise an evening on transitioning where some service users could share their experiences which would be useful for acclimatizing to the research and would give a stronger ethnographic aspect to the project.

Setting

Interviews will take place in a NHS Highland setting or school (whichever is most convenient for the young person/CAMHS clinician).

Equipment

A digital audio recorder and transcription kit will be required from the University.

Design

A longitudinal qualitative design will be employed. Each participant will be interviewed up to 3 times beginning before the point of transfer. This would enable an exploration of individuals' evolving experiences of the transitional process as it unfolds. A participant honorarium of £10 per interview will be offered as compensation for the time commitment that is required of individuals to participate in longitudinal research.

Data Protection

The digital recorder will be encrypted to meet NHS Highland information governance standards. All interviews will be fully transcribed. Following successful transcription and anonymization, recordings will be deleted. Anonymized transcripts will be made available to both field and academic supervisors. No participant identifiable data will be stored on the laptop.

Methodology

Interpretative phenomenological analysis (IPA), with its theoretical foundations in phenomenology, hermeneutics and idiography, is concerned with meaning-making and understanding subjective lived experience. IPA attempts to analyse and then present an account of the ways in which people experience specific and important events in their lives. It is best suited to a data collection method, which will invite participants to offer a rich, detailed, first-person account of their experiences. Interviews can give participants the opportunity to tell their stories, to speak freely and reflectively, and to develop their ideas and express their concerns at some length (Smith et al., 2009).

Interview Guide

One-to-one interviews will be used to allow a rapport to be developed. Semi-structured interview style will be adopted with a limited topic guide. This will be an attempt to implement IPA's inductive epistemology to the fullest extent (Smith, et al., 2009). The aim

of the interview is for the interaction to be defined more by the young person rather than research-led assumptions or questions.

The interview will be introduced to the young person as a means of gaining an insight into their personal experience of the transition process. Broad open-ended questions will be used (e.g. could you tell me about when you first heard of being referred to adult mental health services? How was the information delivered? How did you feel?). The researcher will endeavour to engage deeply with participants and their concerns, listen attentively and probe in order to learn more about their lifeworld.

Subsequent interviews will entail reflections to what was discussed in the first interview and asking has anything changed and enquiring about the young person's current feelings on the transition process. Notes will be made after the interviews as a means of reflecting on the interaction with the participant to help contextualise the data for analysis.

Data Analysis

Data analysis will be an iterative and inductive cycle. Line-by-line analysis (i.e. coding) of each participant's experiential data will be employed. This will be followed by the identification of emergent patterns (i.e. themes), emphasising both convergence and divergence (Smith et al., 2009).

The interpretative process will be carefully documented by means of a 'dialogue' between the researchers, their coded data, and their psychological knowledge about what it might mean for participants to have these concerns in this context. Finally, a structure will be developed to reflect the relationships between these themes. Supervision will be used to help test and develop the coherence and plausibility of the interpretation.

Health and Safety Issues

Researcher: Appropriate supervision and bracketing will be used to minimise the risks associated with prolonged contact with participants. There is also a risk of the researcher feeling isolated from supervision due to the geographical distance between the place of research and the location of the academic supervisor. A clear supervision agreement will be developed to minimise this risk.

Participant: The setting of the interviews will be on NHS grounds or school where the appropriate safety procedures will be followed reducing the risk to both researcher and participant.

Ethical Submissions

NHS Highland R&D will be contacted with regard to surveying CAMHS clinicians as part of engaging them in the study. An application to the University Ethics Committee will be made if CAMHS clinicians are surveyed. A submission to IRAS will be made before commencing the study.

Ethical Issues

Informed Consent & Longitudinal Research: One of the features of longitudinal research is that it exposes the extent to which consent is a process rather than a single act. Informed consent will be obtained at the first interview. Participants will be reminded of the voluntary nature of their participation and the parameters of confidentiality at each subsequent point of data collection. Participants will be re-consented at each interview.

Informed Consent: The Scottish Children's Research Network (2012)'s guidance on obtaining informed consent for clinical research in children and young people under 16 will be followed for all young people under the age of 16. The basic principle being that if a person under the age of 16 is considered competent to give an informed view on the question of participating in a research study they should be allowed, and facilitated to do so. Participants' competence to provide informed consent will be judged by CAMHs clinicians.

Risk of Coercion: The participant may feel coerced into taking part in this study as a CAMHS clinician is inviting them to take place. This risk will be minimised as clinicians will stress that participation is voluntary and the decision to participate or not will not affect their care. Furthermore, the young person will contact the researcher if they decide to take part.

Participant Distress: There is the potential that a young person may become distressed when discussing the transition process as a sensitive or difficult issue may arise. As the researcher will be a final year clinical psychology student, the appropriate skills will be employed to manage this distress. Information regarding access to appropriate support (i.e. helpline numbers) and/or CAMHS clinicians will be given if required.

Limits of Confidentiality: The limits of confidentiality will be detailed in the information sheet that participants receive at least 24 hours before the initial interview. The young person

will be made aware that confidentiality must be broken if they disclose thoughts of harming themselves, harming others or child protection concerns.

Use of Quotations: Consent will be obtained to use anonymised quotations in the write-up of this study.

Timetable

January/February 2016: Engage CAMHS clinicians

April-August 2016: Ethics Application

September 2016 – April 2017: Data Collection

November 2016: Data Collection Review Point

January – May 2017: Data Coding and Analysis

May – July 2017: Write-Up

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