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Young people's experiences of mental health difficulties

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Young people's experiences of mental health difficulties

By Freya Leanne Spicer-White

This thesis is submitted as part fulfilment for the degree of the Doctorate in
Clinical Psychology.

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Young people's experiences of mental health difficulties

This thesis contains three related pieces of work that considered young people's experiences of mental health difficulties. The first is an original piece of qualitative research. Semi-structured interviews were used to investigate the lived experience of eight females with mental health difficulties, aged between 15 and 17 years. Through interpretative phenomenological analysis, five themes emerged; these were 'keep it hidden', 'the stickiness of a diagnosis', 'life is different now', 'relationships are different now' and 'other young people with difficulties'. How these young women related to their diagnosis became a topic of interest and therefore the focus of the second piece of work, a literature review. This review identified 15 studies. Ten studies employed quantitative methods to assess mental health literacy and attitudes in young people in the general population. Five studies used qualitative methods to investigate the attitudes of young people who had received a mental health diagnosis. The results suggested that many young people in the general population displayed poor, at best moderate, mental health literacy and that many young people held negative preconceptions about mental health diagnoses. Individuals who had received a diagnosis described themes that suggested high levels of shame and an altered sense of identity. Both the research

and review papers considered the concept of pre and post diagnostic counselling as a potential clinical implication and this was discussed in the third piece of work. The discussion paper summarised that there are few specific recommendations for sharing a mental health diagnosis with adults or young people. It was suggested that further research is required to assess whether pre and post diagnostic counselling could be an effective way of improving the diagnosis experience for young people. Finally my personal reflections of completing the thesis are shared.

Declarations

This work has not been previously accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed

Date

Statement 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A list of references is appended.

Signed

Date

Statement 2

I hereby give consent for my thesis, if accepted, to be available: I agree to deposit an electronic copy of my thesis (the Work) in the Bangor University (BU) Institutional Digital Repository, the British Library ETHOS system, and/or in any other repository authorized for use by Bangor University and where necessary have gained the required permission for the use of third party material.

Signed

Date

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SECTION 2: Research paper: A qualitative investigation into the lived experience of eight 15-17 year old females experiencing mental health difficulties.

Notes for Contributors

The aim of the *JOURNAL OF ADOLESCENT RESEARCH* is to publish lively, creative, and informative articles on development during adolescence (ages 10-18) and emerging adulthood (ages 18-25). The journal encourages papers that use qualitative, ethnographic, or other methods that present the voices of adolescents. Few strictly quantitative, questionnaire-based articles are published in the journal, unless they break new ground in a previously understudied area. However, papers that combine qualitative and quantitative data are especially welcome. In order to be considered for review, papers must meet at least one of the following criteria:

- Combine quantitative and qualitative data.
 - Take a systematic qualitative or ethnographic approach.
 - Use an original and creative methodological approach.
 - Address an important, but rarely studied topic (this could include papers with strictly quantitative data).
 - Present new theoretical or conceptual ideas.
- In addition, all articles must show an awareness of the cultural context of the research questions asked, the population studied, and the results of the study. **Each paper submitted MUST include a cover letter indicating how the paper meets at least one of these criteria and the cultural requirement.**

In addition to journal articles, the *JOURNAL OF ADOLESCENT RESEARCH* publishes **Editorial Essays**, which are short pieces (3,000 words or less) in which an author presents challenging new ideas. There will be few or (preferably) no citations, and authors of the essays will be encouraged to draw upon opinions, insights, and even personal experience. Scholars may present new ideas that may have limited empirical support, but inspire new thinking and research. Some essays may provide a thoughtful critique of a research area while making constructive suggestions for new ways of approaching it. Other essays could analyze a recent event, commenting on the developmental context when adolescents or emerging adults are in the news for involvement in something widely discussed. Policy discussions and advocacy also are welcome in the essays. Scholars interested in writing and submitting an Editorial Essay should query the editor first to confirm the appropriateness of the proposed topic. The journal accepts **ELECTRONIC SUBMISSIONS ONLY**. Manuscripts should be submitted online

at <http://mc.manuscriptcentral.com/jar>. The editor (or associate editor) will review all manuscripts within 1 month and then inform the lead author whether or not the paper has met the *JOURNAL OF ADOLESCENT RESEARCH* criteria. The manuscript then will be sent out for peer review. Submission of a manuscript implies commitment to publish in the journal. Authors submitting manuscripts to the journal should not simultaneously submit them to another journal, nor should manuscripts have been published elsewhere in substantially similar form or with substantially similar content. Authors in doubt about what constitutes prior publication should consult the editor. In general, manuscripts should not exceed 30 typed, double-spaced pages, including references, tables, and figures. Figures and tables should be included as part of the manuscript, not as separate files. Five to six keywords, to be used in archival retrieval systems, should be indicated on the title page. The title page should also include contact information for the lead author, including affiliation, mailing address, e-mail address, and phone and fax numbers. Manuscripts should include three- to four-sentence biographical paragraphs of each author at the bottom of the title page. Following the title page, an abstract of no more than 120 words should be included. Text and references must conform to American Psychological Association style, as stated in the ***Publication Manual of the American Psychological Association (Fifth Edition)***. Permission for use of the copyrighted material is the responsibility of the author. All artwork must be camera ready. Authors who want to refine the use of English in their manuscripts might consider utilizing the services of SPi, a non-affiliated company that offers Professional Editing Services to authors of journal articles in the areas of science, technology, medicine or the social sciences. SPi specializes in editing and correcting English-language manuscripts written by authors with a primary language other than English. Visit <http://www.prof-editing.com> for more information about SPi's Professional Editing Services, pricing, and turn-around times, or to obtain a free quote or submit a manuscript for language polishing. Please be aware that SAGE has no affiliation with SPi and makes no endorsement of the company. An author's use of SPi's services in no way guarantees that his or her submission will ultimately be accepted. Any arrangement an author enters into will be exclusively between the author and SPi, and any costs incurred are the sole responsibility of the author.

A qualitative investigation into the lived experience of eight 15-17 year old females experiencing mental health difficulties

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Title

A qualitative investigation into the lived experience of eight 15-17 year old females experiencing mental health difficulties.

Abstract

The number of young people experiencing mental health difficulties is increasing however little is known about their lived experiences. This study conducted semi-structured interviews with eight females, aged between 15 and 17, who had received a mental health diagnosis and had been an inpatient within a residential unit. The interviews were transcribed and analysed using Interpretative Phenomenological Analysis. Five themes emerged; these were 'keep it hidden', 'the stickiness of a diagnosis', 'life is different now', 'relationships are different now' and 'other young people with difficulties'. Clinical implications and the limitations to this research are discussed.

Key words: Young people; adolescents; mental health experience; diagnosis; qualitative.

Introduction

Mental health difficulties in young people have doubled since the 1980s; at ages 15 to 16, approximately 2 in 30 boys and 2 in 10 girls report feelings of anxiety or depression (Collishaw et al., 2010). A number of these young people will require treatment in specialist child and adolescent mental health services. As users of health care services young people should be consulted regularly (Claveriole, 2003). However, implementing consultation with young people has been slow and until relatively recently little was known about young people's experiences of mental health difficulties (Hinshaw, 2005).

A current initiative within the United Kingdom, the Care Quality Commission's five-year strategy (2010-2015), aims to encourage an increase in the consultation of children and young people regarding their health and social care experiences; particularly in the domain of mental health. The majority of research examining young people and mental health has focused on clinical characteristics and treatment outcomes (Curtis et al., 2001; Fox & Berrick, 2007; Whitney et al., 2008). Increasingly experiential data has been collected from parents, (Jivanjee et al., 2009; Knock et al., 2011; Geraghty et al., 2011), siblings (Sin et al, 2008) and professionals (Buckley, 2010).

Young people are not only able to provide experiential accounts, but also keen to discuss their experiences (McPherson and Thorne, 2000), even 'hard-to-reach' young people (Vander Laenan, 2008). Adolescent consultation has already been successful in health research. A meta-analysis by Robinson (2010) revealed that young people wanted physical health care professionals to be familiar, accessible, informed, competent, to provide accessible information, to be good communicators, to ensure confidentiality and to demonstrate acceptance and empathy.

One of the first qualitative investigations using grounded theory was conducted by Leavey (2005). She interviewed 13 young Canadians with mental health difficulties and analysed their dialogues and from her analysis emerged the themes of Emergence, Loss, Adaption and Recovery. 'Emergence' contained ideas the young people expressed about receiving the correct diagnosis, that being labelled was problematic and they felt stigmatised. The theme of 'loss' included the loss of identity, independence, academic functioning, family status, friends and future prospects. 'Adaption' referred to the coping strategies that the young people developed as a result of their difficulties, including taking medication, asking for help and acceptance. 'Recovery' referred to young people wanting the right medication, the right therapist, a good doctor, a supportive family, community-based youth centred-support, reintegration, volunteering opportunities and hope for the future.

Mixed-method research by Moses (2009) conducted in the USA investigated whether 54 young people diagnosed with a mental health difficulty used diagnostic labels. The young people's qualitative responses were categorised into three groups for quantitative analyses. Those who did not use psychiatric labels to describe their difficulties used lay terms, behavioural descriptions or considered themselves 'normal'. Others were uncertain about what a diagnostic term meant or they only identified with a label when they were experiencing symptoms. Others were self-labellers, these young people accepted they had a mental health disorder and they described their experiences as different from normal experiences. This type of self-labelling was associated with decreased well-being and increased levels of depression.

Kranke and colleagues (Kranke et al., 2010; Kranke et al., 2011) investigated self-stigma in young people experiencing difficulties. Self-stigma refers to the prejudice which people with mental illness turn against themselves. Most of the research into self-stigma has been conducted with adults and proposes three composite elements, stereotype, prejudice and discrimination. Self-stigma is also associated with shame, secrecy and limited interactions with others (Link et al., 1989). Following their qualitative study, Kranke et al., (2011) identified three themes. Consistent with adult literature, young people described feeling stereotyped and used words like

“crazy” and “psycho” within their discourse. Distinct from their adult counterparts, young people felt their difficulty had transformed their sense of self, they were ‘different’ now. Finally the young people described ways to protect themselves; they described that by hiding their difficulties they were attempting to avoid shame and isolation.

To date the findings indicate that young people can express their ideas and concepts about their experiences. However the research has been small in number and limited to North American samples. Therefore this study aims to 1) begin to address the paucity of UK data on young people's views of their mental health difficulties and 2) to explore the experience of living with a mental health difficulty as a young person.

Qualitative methodology provides a rigorous and systematic procedure to conduct such an exploratory study (Nelson & Quintana, 2005). Interpretative Phenomenological Analysis (IPA) was used because it places those who have lived an experience as the expert sources. There is no goal in IPA to test a pre-determined hypothesis, rather the aim is to explore, flexibly and in detail, an area of interest (Smith et al., 2009) which fits the purpose of this study.

Method

Participants

After receiving ethical approval from the National Health Service (NHS) Research Ethics Committee, participants were purposively sampled from an NHS Adolescent Inpatient Service Unit in the United Kingdom. Service-users accessing the Unit were selected because it was considered their difficulties and their use of inpatient services would have caused a significant impact on their lives. As is the norm in IPA, the sample was small (n=8) and broadly homogenous; all participants were female, aged between 15 and 17, lived in the same local health authority and had been an inpatient within the Unit. All had received a mental health diagnosis. The young women differed in terms of their diagnostic category, the length of time spent at the Unit and whether they were an inpatient or outpatient at the time of their interview (see research paper appendix 1: Table 1 for details).

A mental health practitioner within the service, who knew each young person well, judged they had the capacity to take part. All the young people were given written information and a verbal account describing the research. If participants were 15 years old, their parents/guardians were

also given the written information and needed to assent to participation. The final decision always rested with the young person.

Interviews

There was no purposeful review of the current literature when developing the interview schedule because the researchers did not want their questions to lead the participants to specific responses (Robson, 2002). Loosely structured questions enabled the young people the freedom to explore their own experiences using their own language.

The first author, who had worked within CAMHS departments for two and a half years and was experienced at working with adolescents, developed the questionnaire. The second and third authors, whose areas of expertise are adolescent mental health and qualitative research, then reviewed the initial schedule. The interview questions evolved through discussion between the authors. The schedule included 3 demographic questions followed by 12 qualitative questions. The first question was considered a warm-up question in which the participant could begin to talk about themselves and the interviewer could begin to establish a rapport. The second question asked how the young person conceptualised personality, this question was asked to ascertain the participant's understanding in preparation for question 5. Questions 3 and 4 aimed to assess what the young person understood

about their own difficulties and question 5 asked how much the participant understood their difficulties as part of their personality. Questions 6, 7 and 8 aimed to investigate the young person's perception of receiving a diagnosis. Questions 9, 10 and 11 aimed to explore the individual's experiences of living with mental health difficulties. Question 12 hoped to investigate how their difficulties had impacted their relationships with others.

The first author then sought consultation from a 16-year-old female, who did not have a mental health diagnosis, to check if the questions were clear. Some alterations were made to the vocabulary and all authors agreed the final schedule. The qualitative questions are included in research paper appendix 2.

The interviews were conducted over a five-month period by the first author. Each young person engaged in one audio-recorded semi-structured interview, ranging from twenty-eight to sixty minutes. They were conducted in rooms within the Unit and at a time that did not interfere with participants' schoolwork or therapeutic interventions. Before starting the interview participants were reminded about the aim of the research, shown the audio-recording equipment and consent forms were signed. Participants were asked to identify a supportive member of staff who they could access should the interview distress them in any way. Participants were reassured they could terminate their involvement at any time and received a gift of £5

for their participation.

Qualitative Analysis

The interviews were transcribed and as is consistent with hermeneutic phenomenological approaches, data collection and data analysis proceeded concurrently. This resulted in an interview structure that evolved to include topics from previously completed interviews that warranted further exploration.

The data was analysed using a style described by Smith et al. (2009). Each interview was read and then re-read as three types of exploratory comments were added to the transcripts. Descriptive comments were a face value interpretation of the participant's story. Linguistic comments focused on the participant's use of language, for example if they repeated themselves or used metaphors. Conceptual comments opened the interview to a range of provisional interpretations and themes. Any emerging themes were identified by re-reading the exploratory comments with the aim of reducing the volume of the detail but maintaining the complexity of the data. Connections in the emergent themes within one transcript were then considered and recorded. This process was repeated with all transcripts. (See General Appendix for complete analysed transcript).

Convergence and divergence from the emergent themes were then considered across multiple transcripts. The creation of themes and subthemes emerged via two processes. Some quotations and descriptions were interpreted as belonging to a larger theme and therefore grouped together. Within over-arching themes, certain variations were identified and therefore were interpreted as a subtheme.

The analysis was predominantly conducted by the first author, however transcripts, analysis, theme tables and detailed process memos were shared during consultation between all the authors at regular intervals. The third author analysed one transcript and this was discussed as part of the analytical procedure. This strengthened the validity and ensured that the analyses could be 'recognised' and shared by others (Hollway & Jefferson, 2000).

Results

Overview

The analysis yielded five ~~key~~ themes: 'keep it hidden', 'the stickiness of a diagnosis', 'life is different now' 'relationships are different now' and 'other young people with difficulties'. The following sections describe each ~~key~~

theme and component subthemes including representative quotations as illustrative examples; table 2 displays which participants identified with which themes. (See research paper appendix 3: Table 2 for details).

Keep it hidden:

Secrets

All participants discussed that they wanted to keep their mental health difficulties hidden to varying degrees. Seven described their difficulties as shameful experiences that should not be revealed. Polly explained that she was so determined to keep her difficulties hidden that even members of her immediate family were unaware that she was receiving inpatient care for mental health difficulties.

“no one has to know really, my sisters don’t even know that there is anything wrong with me?”

Olive, although she was keen to be interviewed, found it especially hard to verbalise her difficulties and wanted to keep some details secret:

“it just feels weird saying, coz like, then you know you’re talking about yourself, and it makes you feel like rubbish”

One interpretation for this avoidance was that by not saying her difficulties aloud, Olive was able to keep some distance between herself and her difficulties. She did not want to identify and share difficulties that made her feel like a worthless, unwanted thing that people reject ("like rubbish"). It was suggested that by hiding her difficulties, Olive was attempting to limit her personal feelings of worthlessness and to prevent other people from rejecting her. As demonstrated by Olive, but reflected in all the interviews, keeping their difficulties secret was interpreted as a conscious or unconscious method used by the young people to protect their self-esteem.

Lies

These young women described a false 'front' so that those around them were not aware of their true feelings. Their outside appearances were different to their internal, emotional experiences.

"how someone actually feels inside... I mean they can portray themselves as being OK but you know you ... you never know what's going on in somebody else's head" Abigail

"I'll tell everybody everything's fine I'll put a front on nobody would ever know outside what's going on for me or how I'm struggling inside so erm until something big happens" Suzy

These quotations demonstrate that some young people do not only refuse to disclose their difficulties but they actively provide a false representation of themselves. The interpretation of this deception was that these young people are extremely ashamed of their thoughts and emotional reactions. By ensuring they present as 'ok' or 'fine', their difficulties go unnoticed; they avoid negative social judgement and interference from others. The young people considered this deception as beneficial.

However, their descriptions conveyed loneliness because no one has access to their troubled internal world. Suzy's quotation highlighted the associated risk because family members, friends and even professionals working with these young people, may only become aware of the severity of their difficulties when 'something big happens' (e.g. a suicide attempt).

Negative consequences of hiding difficulties

The negative consequences associated with hiding emotions were expanded upon. Suzy acknowledged that she would have a better chance of successfully harming herself if she kept it a secret.

“Cos when I told people, they were going to stop, they would probably stop me and watch me and try and stop me from like before I do something, that’s part of the reason you get very sneaky about it, you just keep it to yourself”

Polly was more concerned that without explaining her difficulties, other people may attribute her lack of concentration to another cause. She was clearly concerned about which would be a worse label to have, one of a mental health difficulty or one of a having low intelligence.

“Say I went crazy again and like say I was at Uni doing like studying then I couldn’t do it any more and then everyone would just think I’m thick when it’s like I’m not thick it’s just like can’t do stuff sometimes”

This suggests that although the young people wished to keep their difficulties hidden, some of them were very aware that this strategy was not solely protective. These quotations indicate that these participants were aware that if they did not share their difficulties, this could have a negative impact on their lives.

The stickiness of a diagnosis

Diagnoses are stuck on young people by professionals

The following quotations illustrated that diagnoses are given to young people by professionals, often in a way that is not collaborative, supportive or optimistic.

“they told me I’ve got severe depression ” Suzy

“they’ve diagnosed me with Depression I think and sort of said oh right this is a problem we (professionals) need to be looking at” Kim

“someone tells you, some professional tells you you’ve got it” Francine

“like the doctor came round and like said it” Olive

“that’s what they called you and you have to carry that with you the rest of your life” Abigail

Abigail’s use of the word “carry” was suggestive of something that was handed over to her by a professional and she had little choice whether she could accept it. These recollections of receiving a diagnosis included a clear distinction between the professionals, who made the diagnosis, and the young person, who received the diagnosis. These descriptions highlighted

that these participants experienced a diagnosis as something that was done to them, rather than shared with them.

The world expects you to be whatever diagnosis is stuck to you

These young people described that once a professional had categorised their difficulties with a diagnosis they lost parts of their individuality and uniqueness. Both Kim and Tess used the word “stereotype” to describe how they felt perceived by others. Whereas Suzy highlighted the pressure to conform to the expected depressed presentation and how she felt fraudulent when she acted in a way inconsistent with her diagnosis. Polly’s quotation illustrated that she did not want to be considered as her disorder.

“like I’m more than just that really, I am, I can do, I’m like a person. Like I’m not just a disease. Like I don’t know. I have feelings and stuff, so I’m not just like a walking ... what’s it called ... you know when people do experiments on you. Like an example of my whatever, my disease or whatever not just like something doctors can look at and stuff.” Polly

The young people described how they felt pigeonholed by a diagnostic category. An interpretation suggested these young people felt they were no longer considered by others on the basis of their personality, rather their diagnosis and corresponding symptoms. Almost as if their diagnosis

masked their individuality and that other people did not see past their list of symptoms.

Diagnostic stickiness and hope

There was some divergence across this theme. Some participants felt quite strongly that they were unable to get rid of a diagnosis once they had received it.

"It's scary, it's really scary coz as well as having them (diagnoses) they are stuck with you for the rest of your life" Abigail

"You're stuck with being in it, like an Anorexic forever, even if you get healed you're stuck with being one". Tess

An interpretation suggested that for these young people receiving a diagnosis of a mental health difficulty felt like getting a life sentence. Tess described feeling that even if she no longer experienced the difficulties, the label would always be attached to her.

However, others described finding solace from receiving their diagnosis, because it meant that they were able to conceptualise their difficulties as separate from themselves.

"I think being diagnosed with it, it always gives you that distance from it. It's sort of like, it makes you realise that isn't the way things are always have to be, it's an illness and it's not, it's not you, sort of thing " Kim

(without a diagnosis) "I wouldn't have a name for the illness I had" Erin

These young people found it soothing that their difficulties could be named and identified, rather than their difficulties being their personal responsibility or identity. Also in receiving a diagnosis, this removed some of the stickiness. These young people conceptualised a diagnosis as something that can be placed on a person but can also be removed. Francine understood a diagnosis as a concept that was always accompanied by treatment and cure.

"So you are not just going on thinking like I don't know what it is, it will make it easier for you to get rid of it and what things you need to do" Francine

These opposing views of diagnostic pessimism and hope give valuable insight into what maybe unhelpful and helpful about receiving a diagnosis. All the young people interviewed reported that they would want to know if professionals considered their difficulties met diagnostic criteria, regardless of whether they viewed a diagnosis as positive or negative.

Life is different now*My life changed*

The young people described feeling that their realities had been altered as a result of their difficulties. Experiencing their difficulties, receiving a diagnosis and undergoing treatment had made them feel different.

“like, sort like different from everybody else, well not everybody, but like most people” Olive

“I just feel like it makes me different sometimes. But sometimes it's a good different and sometimes it's a bad different” Polly

This concept of difference and change was extended by some of the young people who gave examples of the differences in their lives. Many of them described their hobbies using the past tense, suggesting the enjoyable components of their lives had stopped because of their difficulties. Some of these young people also acknowledged that they were limited by the restrictions put in place because they were service-users of an inpatient unit. This compounded the difficulties for these young people; they had to manage mental health symptoms, the stress of feeling different to their

peers and the restrictions. These young people were aware that their lives had followed a different trajectory compared to their contemporary's experiences but also compared to their own expectations of adolescence. Tess and Erin lamented their own life losses.

".. the ability to go out more often and longer cos I can't go out like to restaurants or anything or with my family or anything cos I wouldn't eat because it's not very social and then certain like losing hair and everything and stuff like that" Tess

"well I haven't had a chance to get a job .. erm ..most of my friends have boyfriends so and I don't and erm erm could have had a job." Erin

The young people spoke with sadness, anguish and anger. There was an overwhelming sense that these young people considered themselves and their life experience changed as a result of having difficulties. A touching quotation from Francine emphasised that these young people still felt a strong sense of their 'before' identity and this was not lost to them.

"at times I just feel like myself, like I was before" Francine

Loss of control

This theme emphasised that the young people felt different because they had lost full control over their own thoughts and actions. In briefer comments, Francine stated that her difficulty “overpowers” her and Tess described difficulties that “spiralled” out of control. The visual imagery of these descriptions suggested these symptoms were experienced as something utterly dominating that quickly picked up momentum and kept increasing in size. These young people felt controlled by their difficulties and at times they described their difficulties as a separate entity. Kim and Suzy questioned where their thoughts originated; they considered that these thoughts were so strong it was difficult, sometimes impossible, for them to be stopped or challenged.

“Why am I doing this? You sort of think ... this thought keeps coming back and it comes back and it comes back and it’s quite difficult and it’s quite strange cos it’s sort of like, this is my thought, this is my head it’s coming from?” Kim

“Erm .. probably just erm I dunno like doing what my head tells me to do probably, I can’t really like .. I let my... if I’ve got things and stuff in my head, I like, let it take over... I don’t do anything to like stop the negative thoughts” Suzy

This concept of difficulties being considered as separate was taken a step further by two young people. They described their thoughts being like an external voice.

“like a voice, but not actually a voice but something in your head telling you not to eat it” Francine

“sometimes get voices in your head erm and erm depression .. you sort of get paranoid, your mood is quite low and... and it's making your brain isn't right or something” Erin

When expressing this theme, some young people spoke of times when this separate entity exercised restraint over their behaviour, for example forbidding them to eat. Other times it gave directions, for example instructing self-harm. An interpretation of this returns to the idea that these young people do not want to be responsible for their maladaptive behaviours. However, this way of externalising difficulties is also a therapeutic technique and this concept may also be reflective of the interventions the young people have experienced.

Relationships are different now

Loved ones will worry about you

Participants expressed a genuine concern and regret that their difficulties were causing their loved ones distress. Tess and Abigail's description of their family member's reactions appeared to embody the upset and worry felt by loved ones.

"she (sister) was just so upset I didn't realise how upset she would have been like I didn't, when I came in here I didn't even think of that, I knew she was like crying, she was the one that got all my stuff ready to come in and everything and apparently she was so frantic" Tess

"I don't feel that I'm able to say self harm because of the effect it will have on my family and no I don't want to do that to them anymore. So I suppose that's really difficult, hurting everyone else" Abigail

The worry expressed by loved ones also had consequences. Olive best illustrated that worrying caused her loved ones to demonstrate certain behaviours.

"your family are constantly worrying about you so they are like constantly watching you" and "she (mother) always wants to know what's wrong but I don't always know what's wrong... so we just don't usually speak... because of that"

The young people who voiced this theme saw themselves as individuals who were the source of worry for people they love and therefore they were subjected to closer scrutiny and supervision. Olive's repeating of "constantly" emphasised she experienced the worrying and watching over as relentless; that had a huge impact on her relationship with her family.

Others will judge me negatively because of my difficulties

There are some parallels with the earlier theme of 'keeping it hidden'; however the focus of this subtheme was related to the social anxiety associated with negative social judgements of others. There are two strands in the interpretation of this subtheme. The first reveals that these young people were concerned about other people's preconceived ideas about individuals with mental health difficulties.

"they'll (sisters) just think I'm just crazy and that, think I'm a different person than I am and it's like I'm not" Polly

"Just like they (friends) might think of me in like a negative way once I tell them" Suzy

This first strand highlighted that stigma continued to influence these young people's decision to disclose their difficulties. They described concerns that had elements of reality; if others knew about their difficulties they would mostly likely be treated differently.

The second strand focused on how other people would view the young person themselves. Tess and Erin talked about the personal characteristics that were attributed to them because of their difficulties.

"She (sister) thinks I'm an attention seeker for it so she just doesn't understand it at all." Tess

"I know a lot of people think that ... erm .. this is stupid and selfish and stuff, I don't see why people do" Erin

Tess and Erin's experiences of their difficulties were not validated by some of the people in their lives. The words "attention seeker" and "selfish" alluded to blame and responsibility for their difficulties, rather than support and understanding. Being misunderstood and invalidated was echoed throughout this subtheme.

Other young people with difficulties

Having difficulties helps you to understand other people better

After having experienced their own difficulties, several young people felt they had gained a new, improved perspective to life and a genuine empathy and understanding for people.

“Probably you understand other people a lot more... like coz if you haven’t been through it then you wouldn’t know” Olive

“But like I suppose it’s good to feel like you know what other people go through, like people with other difficulties” Francine

“because like the professionals and that, like they don’t really know, they’ve just read what’s from a book and you know, they don’t know how it actually feels” Suzy

Participants believed that only people who had lived through a mental health difficulty would truly understand their experiences. This belief was interpreted as protective because their difficulties had resulted in at least one positive outcome. It could be suggested that these young people felt the need to gain something from an experience that has taken away so much from their lives, including their independence, relationships and educational opportunities.

Many of them elaborated further on their specialist insight and reported future plans to work with people with difficulties, as illustrated by Abigail.

“I want to be an art er art therapist I wanna be able to help other people and then I know I’ll probably meet teenagers who’ll say, “you don’t know what I’m going through” but I will, you know, it’s something you can relate to other people with... you can help other people through it”

This desire to help others in a similar position to themselves was interpreted as an empathic reaction. Abigail’s description of a teenager she may encounter in her future as an Art Therapist demonstrated that she appeared to recognise the benefits of talking to someone who has lived through a mental health difficulty. She highly valued her skill of being able to relate to others and she believed that her unique experiences placed her in the best position to help others.

The impact of being around other young people with difficulties

Various types of impact were described in this subtheme. Some of the young people felt that being around others with challenging behaviours was difficult.

“Well I just feel awkward when like they’ve had, they’ve self harmed or something and then they quite, when their behaviour gets out of control, I feel really awkward and I don’t know what to do with myself.” Tess

Tess described feeling embarrassed when she had witnessed behavioural manifestations of mental health difficulties. Her repetition of ‘awkward’ highlighted the discomfort she felt when she witnessed certain behaviours. The impact of others went beyond awkwardness as demonstrated by Abigail and Erin.

“they can influence you to do other things like maybe aren’t the best thing to do in that situation” Abigail

“I ended up here in (Name of Unit) and erm Got treatment and stuff but I sort of was copying the people ... so erm ... so my Mum pulled me out” Erin

Abigail and Erin described that other young people with difficulties had a negative impact on them. They recognised peer pressure and copying had encouraged them to act in a way that was not beneficial to them. In Erin’s case this had caused an exacerbation of her difficulties.

Many of the young people drew strength and friendship from being with other young people with difficulties. Suzy best summarised some of the issues in her relationships with other people who have difficulties.

“I always think that the best people to talk to are the people who are going through it but you don't want to talk to them because you don't want to make them stress out or get upset for you or anything so .. you know. It's like, I can talk to like a girl who has a different illness that will be fine like someone, like a girl that used to come here she had anorexia so and I had depression so like two different things so we used to talk to each other about our different illness's”

She identified the strength and empathy she drew on from an individual who also had difficulties. She eliminated the negative aspects of competition and a too close to home stress reaction by sharing with an individual who experienced difficulties but not the same difficulties that she struggled with. Suzy demonstrated that she was able to recognise the benefits but also she was able to solve the problems caused by a friendship between individuals with had mental health difficulties.

Discussion

These data revealed many of the complexities of the lived experiences of a young person who develops a mental health difficulty and receives a diagnosis. Some findings were consistent with the current literature and some novel themes emerged. Overall the young people frequently described their experiences as negative. They used words like “crazy” and “psycho”, words that echoed earlier findings of Leavy (2005) and Kranke et al. (2011). Some young people also identified positive aspects; these were feeling hopeful for successful treatment once they received a diagnosis and acquiring an insight into the lived experiences of others.

The subthemes of ‘keeping it hidden’ echoed the themes of “secrecy of diagnosis” and “shame of diagnosis” as identified by Kranke et al., (2010). Shame was associated with young people wishing to hide their difficulties. Participants were so determined to keep their difficulties secret, they not only hid their difficulties, they became skilled at presenting a false self to those around them. Some participants were able to recognise the risks and drawbacks associated with keeping secrets and telling lies.

The second ~~key~~ theme of ‘Diagnostic Stickiness’ indicated that young people felt that their diagnostic labels were done to them, rather than shared with them. These labels were conceptualised by the young people

as a construct designed by medical professionals to aid professionals' work and in the wider context, society to understand and categorize those who are different. Participants described feeling limited and condensed by their diagnosis; that people expected them to behave in ways consistent with a diagnostic symptom-set. These negative aspects of receiving a diagnosis were made more powerful when the 'stickiness' aspect was emphasised; a diagnosis can stay with some people forever. However, not all young people found a diagnosis unhelpful; some young people described that a diagnosis facilitated treatment and the amelioration of symptoms. Overall, when considering this ~~key~~ theme as whole, a positive aspect identified for receiving a mental health diagnosis, was that it could be taken away.

The theme of difference was reflected when young people described how their lives had changed. Participants described that they had lost control. This was reflected in Leavey's (2005) subtheme of 'Loss of identity'. Participants in Leavey's (2005) and the present study described an old self, one before difficulties began, and a new self, one that experienced difficulties and had a diagnosis. This new self was no longer in full control of themselves; their difficulties had taken over and their life was changed.

The concept of change and loss was reiterated throughout the young people's descriptions of their family and peer relationships. Participants in Leavey's (2005) and Kranke et al.'s (2010) study described that their

families and friend's perception of them had changed. Participants in the present study similarly described that family members became their supervisors or carers and their friends became a potential source of negative judgement. At a time when most adolescents usually begin to assert their own independence, develop their identity and conform with peers; young people with difficulties have an antithesis experience. Participants described that they spent more time with parents and lived in restricted environments causing a loss of independence. They spent less time with peers and became guarded against negative judgement when they were with friends. These factors are associated with the core components of self-stigma; shame, secrecy and limiting their interactions with others (Link et al, 1989).

Interactions with other young people with difficulties was the final ~~key~~ theme identified. These young people felt that only people who had experienced difficulties would be able to understand their experiences. These young people may have felt misunderstood by many people around them, including professionals. Feeling understood and validated was important to these young people and they valued the skill of empathy. Participants described that their unique experiences placed them in the best position to use this skill appropriately and effectively. However there was also a downside to interacting with peers with difficulties, including copying their behaviours and being distressed by witnessing their behaviours.

Clinical Implications

The themes of 'keeping it hidden', 'life is different now' and 'relationships are different now' appear to represent issues associated with the shame of feeling different and therefore the desire to maintain secrecy. A clinical implication of these themes is that professionals working with young people should strive towards a balance of protecting their self-esteem but also encouraging them to share their difficulties to elicit support and appropriate interventions. Professionals and care staff supporting young people with difficulties need to be constantly aware of this shame and secrecy when interacting with them, particularly when considering a young person's risk of self-harm or suicide.

The theme of 'other young people with difficulties' had a different focus. A clinical implication of these findings is that staff on inpatient units should remain vigilant to the positives and negatives when young people with difficulties reside together. In addition, this theme highlighted an area of personal strength for these young people. They believed their personal experiences have resulted in greater understanding and empathy of other individuals with difficulties. These skills should be promoted in these young people to increase their self-esteem.

The remaining theme of 'diagnostic stickiness' highlighted that the process of giving a young person a diagnosis needs to receive much greater consideration by mental health professionals. This paper posits that current practice could be improved if young people's views and understanding of diagnoses were sought before a professional gave them their diagnosis. As young people experienced some benefits from receiving a diagnosis, pre-diagnostic counselling may capitalise on these benefits and enable a person-centred approach. Pre-diagnostic counselling would also encourage the young person to ask questions to create a more collaborative stance. Post diagnostic counselling could include psycho-educative work and consultation with the young person about their preferred labels. Young people should be given the opportunity to discuss their emotional reactions to their diagnosis and have open discussions about with whom, when and how they wish to share this information.

Limitations

The sample was not ethnically diverse and only included female participants; therefore the views expressed may not be representative of all young people with difficulties. A further limitation may be that all participants were sampled from the same inpatient unit. The researchers cannot be assured that the young people did not discuss their participation with each other, which could have led to cross contamination. It may also be the case

that some of the themes were more pertinent for this group of young females because of 1) the way this particular inpatient unit functions and 2) these young women had difficulties at a level of severity that required inpatient treatment. Future research addressing the lived experiences of young people with mental health difficulties needs to consider investigating the perspectives of young males, those from ethnic minority groups and individuals accessing outpatient Child and Adolescent Mental Health Services.

References

Buckley, S. (2010). Caring for those with mental health conditionals on a children's ward. *British Journal of Nursing*, **19**, 1226-1230.

Care Quality Commission (2010). Our strategy for 2010 to 2015. Retrieved from http://www.cqc.org.uk/sites/default/files/media/documents/strategy_2010-2015_0.pdf on 3rd April 2012.

Claveirole, A. (2004). Listening to young voices: challenges of research with adolescent health service users. *Journal of Psychiatric and Mental Health Nursing*, **11**, 253-260.

Collishaw, S., Maughan, B., Natarajan, L., & Pickles, A. (2010). Trends in adolescent emotional problems in England: a comparison of two national cohorts twenty years apart. *Journal of Child Psychology and Psychiatry*, **51**, 885-895.

Curtis, K., Liabo, K., Roberts, H., & Barker, M. (2004). Consulted but not heard: a qualitative study of young people's views of their local health service. *Health Expectations*, **7** 149–156.

Fox, A. & Berrick, J. (2007). A response to No One Ever Asked Us: A review of children's experiences in out-of-home care. *Child and Adolescent Social Work Journal*, **24**, 23-51.

Geraghty, K., McCann, K., King, R. & Eichmann, (2011). Sharing the load: parents and carers talk to consumer consultants at a child and youth mental health inpatient unit. *Journal of Mental Health Nursing*. **20**, 253-262.

Hindshaw, S. (2005). The stigmatization of mental illness in children and parents: development issues, family concerns, and research needs. *Journal of Child Psychology and Psychiatry*, **46**, 714-735.

Hollway, W. & Jefferson, T. (2000). Doing qualitative research differently: free association, narrative and the interview method. London: Sage.

Jivanee, P., Kruzich, J.M & Gordon, L.J. (2009). The age of uncertainty: Parental perspectives on the transitions of young people with mental health difficulties to adulthood. *Journal of Child and Family Studies*, **18**, 435-446.

Knock, J., Kline, E., Schiffman, J., Maynard, A. & Reeves, G. (2011). Burdens and difficulties experienced by care-givers of children and adolescents with schizophrenia-spectrum disorder: A qualitative study. *Early Intervention in Psychiatry*, **5**, 349-354.

Kranke, D., Floersch, J., Kranke, B. & Munson, M. (2011). A qualitative investigation of self-stigma among adolescents taking psychiatric medication. *Psychiatric Services*, **62**, 893- 899.

Kranke, D., Floersch, J., Townend, L., & Munson, M. (2010). Stigma experience among adolescents taking psychiatric medication. *Children and Youth Services Review*, **32**, 496-505.

Leavey, E. (2005). Youth experiences of living with mental health problems: Emergence, Loss, Adaption and Recovery (ELAR). *Canadian Journal of Community Mental Health*, **24**, 109-126.

Link, B., Cullen, F., Struening, E., Shrout, P. & Dohrenwend, B. (1989). A modified labelling theory approach to mental disorders: An empirical assessment. *American Sociological Review*, **54**, 400-423.

Matza, L., Swensen, A., Flood, E., Secnil, K. & Kline Leidy, N. (2004). Assessment of Health-Related Quality of life in Children: A review of conceptual, methodological and regulatory issues. *Value in Health*, **7**, 79-92.

McPherson, G. & Thorne, S. (2000). Children's voices: can we hear them? *Journal of Paediatric Nursing*, **15**, 22-29.

Moses, T. (2009). Self-labelling and its effects among adolescents diagnosed with mental disorders. *Social Science and Medicine*, **68**, 570-578.

Nelson, M. & Quintana, S. (2010). Qualitative clinical research with children and adolescents. *Journal of Clinical Child & Adolescent Psychology*, **34**, 344-356.

Robinson, S. (2010). Children and young people's views of health professionals in England. *Journal of Child Health Care*, **14**, 310-326.

Sin, J., Moone, N. & Harris, P. (2008). Siblings of Individuals with First-Episode Psychosis: Understanding their experiences and needs. *Journal of Psychosocial Nursing*, **46**, 33-40.

Smith, J., Flowers, P. & Larkin, M. (2009). Interpretative phenomenological analysis: Theory, Method and Research. SAGE Publications Ltd: London.

Vander Laenen, F. (2008). 'I don't trust you, you are going to tell', adolescents with emotional and behavioural disorders as participants in qualitative research. *Child: Care, Health and Development*, **35**, 323-329.

Whitney, J., Easter, A., & Tchanturia, K. (2008). The patient's experiences in cognitive exercise intervention for anorexia nervosa: qualitative findings. *International Journal of Eating Disorders*, **41**, 542-550.

Research paper appendix 1Table 1: Demographic information of the participants.

'Name'	Age	Length of time since last admission to Tier 4 Services	Inpatient or day patient	Formal Diagnosis
Olive	15	1 week	Inpatient	Depression
Polly	17	7 months	Inpatient	Psychotic symptoms
Abigail	16	1 year	Inpatient	Depression PTSD
Suzy	16	9 months	Day	Depression
Kim	17	1 year	Day	Anorexia Depression
Tess	17	1 week	Inpatient	Anorexia OCD
Erin	15	1 month	Day	Anorexia
Francine	15	1 week	Inpatient	Anorexia

Research paper appendix 2

Semi-structured interview schedule

1. Tell me something about who you are as a person and your personality?
2. When I say the word, personality- what does this word or concept mean to you?
3. Can you tell me about the difficulties that you are currently experiencing?
4. Why do you think you have these difficulties?
5. How much do you see these difficulties as part of your personality?
6. Do your difficulties have name?
7. How do you feel about these difficulties being called _____?
8. What is helpful / unhelpful about these difficulties having a name?
9. What does having these mental health difficulties mean to you?
10. What is the hardest thing about having these difficulties?
11. Is there anything you like about experiencing these things?
12. Can you tell me how these mental health difficulties impact on your relationships with others?

Research paper appendix 3**Table 3: Themes and subthemes identified by each participant.**

Theme	Super-Ordinate	Olive	Polly	Abigail	Suzy	Kim	Tess	Erin	Francine	Total
Keep it hidden	Secrets	X	X	X	X	X	X	X	X	8
	Lies	X		X	X				X	4
	Negative consequences		X	X	X					3
Stickiness of a diagnosis	Diagnosis are stuck on young people	X	X	X	X	X		X	X	6
	The world expects you to be your diagnosis		X	X	X	X	X			5
	Diagnostic stickiness and hope		X	X	X	X	X	X	X	7
Life is different now	My life changed	X			X	X	X	X	X	6
	Loss of control	X		X		X	X	X	X	6
Relationships are different now	Loved ones will worry about you	X		X	X	X	X		X	6
	Others will judge me negatively	X	X	X	X	X	X	X		7
Other young people with difficulties	Having difficulties helps you to understand others	X		X	X	X			X	5
	The impact of being around others with difficulties.		X	X	X	X	X	X		6

SECTION 3: Young people's perceptions of a mental health diagnosis: a review of current literature including the general population and young people with a diagnosis.

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**Young people's perceptions of a mental health diagnosis:
a review of current literature including the general population
and young people with a diagnosis.**

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Title

Young people's perceptions of a mental health diagnosis: a review of current literature including the general population and young people with a diagnosis.

Abstract

This paper reviewed the literature from 2003 until 2012 to investigate young people's perceptions of a mental health diagnosis. Fifteen articles were identified. Ten studies employed quantitative methods to assess mental health literacy and attitudes towards mental health difficulties in young people in the general population. Five studies used qualitative methods to investigate the attitudes and perceptions of young people who had received a mental health diagnosis. The review concluded that many young people in the general population displayed poor, at best moderate, mental health literacy and that many young people hold negative preconceptions about mental health diagnoses. Individuals who received a diagnosis described themes that suggested high levels of shame associated with their diagnosis and an altered sense of identity. Suggestions for improving the experience of receiving a mental health diagnosis include the introduction of effective mental health awareness initiatives in secondary schools and evidence-based pre- and post-diagnostic counselling.

Research highlights

- Quantitative general population studies revealed poor/moderate mental health literacy.
- Young people with and without mental health difficulties held derogatory views about mental health difficulties.
- Young people who received a mental health diagnosis felt ashamed and lost some sense of their identities.

Key words

Young people; adolescent; mental health; diagnosis; label; review.

Introduction

Within the language and culture of the medical model (Laing, 1971), a mental health diagnosis can carry the weight of a scientific truth. Regardless of whether one subscribes to the credibility of the Diagnostic and Statistical Manual, fourth edition, text revision (DSM-IV-TR, APA, 2000), which provides standard criteria for the classification of mental health disorders; a psychiatric diagnosis is a powerful construct. In acquiring such a diagnosis, an individual may feel they have been assessed and understood by one who truly knows, or feel inappropriately labelled; either way there has been a judgement on their state of functioning (Hayne, 2003). After receiving a diagnosis an individual may be: subjected to stigma (Corrigan, 2007); prescribed medication (Paulose-Ram et al., 2007); be forced to have compulsory treatment through 'involuntary status' (Audini & Lelliot, 2002); and considered to have a legitimate illness to receive care benefits (Fone et al., 2007). Yet the impact of the diagnosis experience within the field of mental health research has been largely ignored.

Hayne (2003) was one of the first to recognize the dearth of research into the psychiatric diagnosis experience. Hayne (2003) conducted qualitative research using hermeneutic phenomenology to investigate the lived experience of fourteen adults who had received a psychiatric diagnosis. Four key themes emerged from his data. The first, "a knowledge that knows", suggested that some participants initially heard their diagnosis as devastating news. The medical terminology made

their difficulties feel like an indisputable fact that affected how they understood themselves and their futures. This new knowledge could not be unknown and left individuals feeling their own sensibilities and usual way of knowing themselves had been changed forever.

The second theme, the “Destructive (gift) of difference”, highlighted the duality of receiving a diagnosis. Some participants described how the symptom characteristics of their diagnosis made them feel unique and special. However, their diagnosis defined them as mentally unwell, thereby invalidating and delegitimizing them. The third theme, “Making visible the invisible”, reflected the healing that individuals felt upon being given their diagnosis; it confirmed their difficulties were real, it restored hope and generated the prospect of recovery.

The final theme, a “Knowledge made knowledgeable”, suggested that some participants found their diagnoses helpful because their new knowledge resulted in them feeling more informed of ways to improve their functioning. Their diagnosis affirmed their symptoms; it allowed them to reinterpret themselves and was a guide back to ‘normality’. This research emphasised that receiving a diagnosis could not be conceptualised as a wholly negative or positive experience. Hayne (2003) stated that there is something important about the “distinctness of diagnosis as a phenomenon of the illness experience that calls for particular considerations of care” (Hayne, 2003, p. 722).

Hayne's (2003) research demonstrated that receiving a mental health diagnosis in

adulthood was an experience of consequence. Additional research conducted with adults has demonstrated that negative perceptions of mental health diagnoses were associated with a reduced willingness to seek counselling (Vogel et al., 2007), poor acknowledgment of treatment needs (Sorgadd et al., 2011), and non-concordance and disengagement from psychosocial (Sirey et al., 2001) and medication interventions (McCann et al., 2008). This indicated that an individual's experience and understanding of their diagnosis can negatively affect the trajectory of their help-seeking, treatment adherence and thereby recovery.

In light of the adult research, the aim of this paper was to review the literature that examined how young people in the general population and those young people with difficulties viewed a mental health diagnosis. Adolescence is a time when young people want to be socially accepted (Wisdom et al., 2006), therefore any experience that is different from the norm may cause additional stresses and be judged in a negative way.

Method

The present review was approached systematically. The Web of Knowledge (including Web of Science and Medline) and ScienceDirect electronic databases were searched in February 2012. The search terms used were “child and adolescent mental health” OR “young people” AND “psychiatric diagnosis” OR “mental health diagnosis” OR “mental health label”. Only journals published in English after 2003 were searched. This date was selected because Hayne's (2003)

literature search found that very few studies had investigated the client's perspective of receiving a mental health diagnosis. This initial search generated 2,857 articles. 'Limit to' and 'Refine' restrictions were used on each database to remove health-related articles, by excluding the topics "HIV", "Alzheimer's", "breast cancer" and "health care". The remaining 2,120 titles and abstracts were scanned. Forty-seven articles were deemed appropriate for further consideration and attempts were made to acquire the complete article. Authors were contacted in attempt to access six of the articles however three of these did not respond and the articles could not be obtained within the time frame of the review.

Forty-four articles were read and reference lists were searched, which generated a further 4 articles. After reading, 31 articles were rejected: 16 studies were conducted with adult participants; 6 investigated parental experiences; 3 focused only on stigma experiences of living with a mental health difficulty; 2 focused on forensic labelling; 2 focused on treatment outcomes; 1 was a single case study not written from the young person's point of view; 1 focused on the mental health of individuals diagnosed with HIV; and 1 investigated perceptions of suicide. A final paper was rejected because the same research team conducted three of the identified papers (Jorm & Wright, 2008; Wright & Jorm, 2009; Wright et al., 2011). All three papers were based on findings from a national telephone survey of young people, aged 15 to 25, in Australia collected in 2006. The paper by Jorm & Wright (2008) was excluded because the findings were a briefer version of those described by Wright et al. (2011). (see General Appendix: Figure 1 for a graphic representation of the search and refinement process).

In total 15 papers were included in this review (those marked with * in the reference list). The Critical Appraisal Skills Programme: CASP (2006) tools were used to ensure all studies were of an adequate quality. A data extraction table was developed (see General Appendix Tables 4a and 4b) and the studies fell into two distinct categories of research that addressed the question: "How might a young person view mental health diagnosis?". The first category of research included only quantitative data from a general population sample. It was hoped these studies would shed light onto the preconceptions a young person may have, which would affect how they may experience a mental health diagnosis. Since the data were not homogenous in quantitative studies a meta-analysis was inappropriate, instead the findings were collated and summarised.

The second category included 5 qualitative studies that used clinical samples of young people who had experienced mental health difficulties and investigate their views. The themes that emerged within these qualitative studies were grouped to create overarching themes.

Results

Non-clinical and Quantitative Articles

Overall, 10 quantitative studies revealed variable mental health knowledge amongst the youth general population. Five studies focused primarily on the

investigation of mental health literacy in youth: Hess et al. (2004), Burns and Rapee (2006), Wright and Jorm (2009), Olsson and Kennedy (2010) and Klineberg et al. (2011). The remaining five studies also focused on young people's views, preconceptions and attitudes: Schulze and Angermeyer (2005), Rose et al. (2007), Arbanas (2008), Wright et al. (2011), and Caelear et al. (2011). The results are discussed in terms of three pertinent findings: 1) knowledge of mental health difficulties, 2) preconceptions of mental health difficulties, and 3) gender differences.

Knowledge of mental health difficulties

Hess and colleagues (2004) found that young people's knowledge of depression was variable when assessed by a survey. Participants answered 80% of the dichotomous statements ("A person with depression always feels sad") incorrectly and 4.3% of participants answered all of these questions correctly. When asked to list symptoms, fewer than half of the young people were able to list four or five correct symptoms of depression, and the majority were not able to list more than two correct symptoms of mania. This early study revealed a lack of knowledge and understanding, although a small number of individuals displayed a good awareness. These findings may reflect the time period in which they were collected. Mental health awareness initiatives have been steadily increasing since the introduction of World Mental Health Day in 1992 (World Federation for Mental Health). Specific to America and targeting young people, 'Active Minds', a charity dedicated to raising awareness and combating stigma amongst students, was set

up in 2001. Therefore mental health awareness initiatives were only in their infancy in 2004, and this may be one explanation for the young people's poor knowledge. Consistent with this explanation were findings by Arbanas (2008) and Wright and Jorm (2009). Wright and Jorm (2009) assessed participants' exposure to mental health advertising and the Australian national depression initiative, 'Beyondblue' (established in 2000). They found that greater exposure was associated with correct label use. Arbanas (2008) also noted that it was medical students, with a higher level of knowledge of psychiatry and mental disorders, rather than regular students with higher levels of IQ, who displayed less stigmatising attitudes. However, this study did not take into account that the young people attending the medical school may have been those more interested and possibly more empathetic towards individuals with both physical and mental illness. Hence their chosen field of study, and it was possible that this resulted in their different attitudes rather than their advanced knowledge.

Wright and Jorm (2009), Burns and Rapee (2006), Olsson and Kennedy (2010) and Klineberg et al. (2011) used vignettes to assess how well young people could recognise and label a disorder. The results of their studies indicated that young people had variable knowledge regarding psychiatric diagnostic categories and some young people could correctly link symptoms with a diagnostic term. Across the studies depression vignettes were identified correctly by 69.1% (Wright & Jorm, 2009), 67.5% (Burns & Rapee, 2006), 55% (Olsson & Kennedy, 2010) and 61.4% (Klineberg et al., 2011) of the participants. This suggested that at least 30% of the participants across all studies were unable to recognise and label depression.

Social phobia was assessed in two studies, it was recognised and identified as an anxiety disorder by 5% (Wright & Jorm, 2009) and 4% (Olsson & Kennedy, 2010) of participants. This suggested that young people displayed lower mental health literacy for social anxiety symptoms compared to depression symptoms.

Wright and Jorm (2009) also included a psychosis vignette, which was identified correctly by 33.4% of participants. This suggested that psychosis was less familiar to young people compared to depression but more familiar compared to social anxiety. Schulze and Angermeyer (2005) found that 35.4% of participants acknowledged schizophrenia as an illness: 7.5% of participants displayed higher levels of mental health literacy, demonstrated by associating schizophrenia with delusions, hallucinations and persecution complexes. However, 20.5% of participants had no knowledge of schizophrenia (Schulze & Angemeyer, 2005).

Preconceptions of mental health difficulties

Regardless of the level of knowledge a young person displays, the opinions and preconceptions that they hold may affect how they react to receiving a diagnosis. Schulze and Angermeyer (2005) found that only 3.8% of participants used derogatory words like crazy or mad to characterise schizophrenia. The authors summarised that the young people in their study appeared to perceive schizophrenia in positive terms. However this was not replicated in the following studies.

The study by Rose et al. (2007) used a simple methodology to investigate young people's views by the words they associated with a mental health problem. Popular derogatory slang terms, "nuts", "loony" or "Strait jacket", represented approximately half of the words generated compared to only 6% of psychiatric diagnostic terms. The word list also included words that demonstrated confusion between learning disabilities, physical disabilities, and mental health. This suggested that many young people had a lack of factual knowledge about mental illnesses. This was supportive of the findings of variable mental health literacy in youth. In addition, the young people generated words relating to a negative emotional state and violence, which suggested that the participants associated mental health difficulties with negative feelings and behaviours. The amount of derogatory terms and negative associations expressed indicated that many young people had strong negative opinions about mental illness.

Arbanas (2008) also investigated young people's attitudes towards people with depression, schizophrenia and post-traumatic stress disorder. All the participants in this study displayed significantly more stigmatising attitudes towards schizophrenia compared to depression and PTSD. Examples of negative attitudes most commonly agreed with included "I would never marry a person with schizophrenia", "I think people with schizophrenia are not capable to work properly" and "People with schizophrenia should be placed in a hospital or an institution".

Calear et al. (2011) and Wright et al. (2011) investigated attitudes and personal and perceived stigma. Personal stigma is an individual's thoughts and beliefs about a

mental health difficulty, while perceived stigma represents an individual's perception of what other people think and believe about a mental health difficulty. Wright et al. (2011) findings suggested that social distancing and the belief that a person with a mental health difficulty was weak rather than sick reduced with age. Perceived dangerousness, perceptions of stigma and reluctance to disclose increased with age. It was found that individuals with a personal history of mental health difficulties or individuals with a friend or family member who had sought help for a mental health issue, displayed reduced scores on the social distance and weak rather than sick items. However a personal history was also associated with increased perception of stigma in others. Individuals whose friends or family had a mental health difficulty also scored higher on the reluctance to disclose items.

The research conducted by Caelear et al. (2011) investigated stigma in relation to depression. They found that higher levels of personal stigma was associated with being male, younger, living with both parents, having no personal history of depression, speaking English as a second language, lower levels of mastery, higher levels of alcohol consumption and perceived depression stigma. Higher perceived stigma was associated with being female, having a history of parental depression and higher levels of anxiety and personal depression stigma. The findings by Wright et al. (2011) and Caelear et al. (2011) suggested that although familiarity with mental health difficulties can have a positive effect, it does not reduce all aspects of stigma. In both studies participants with a personal history displayed increased perceived stigma. One explanation for this finding, could be that these young people have been subjected to stigmatising attitudes from those

around them and their first hand experiences emphasised that stigma remained a cause for concern.

Gender differences

In studies where gender differences were examined, findings mostly suggested significant differences. Burns and Rapee (2006), Wright and Jorm (2009) and Klineberg et al. (2011) found that female participants were more likely to recognise symptoms, suggesting that females displayed a higher level of mental health literacy. Consistent with these studies, there were significant gender differences noted in attitudes. Arbanas (2008), Wright et al. (2011), Klineberg et al. (2011) and Caelear et al. (2011) reported that females displayed less stigmatising views. Wright et al. (2011) and Caelear et al. (2011) also found distinctions in the type of stigmatising beliefs: personal stigma was higher in males whereas perceived stigma was higher in females.

These gender differences could occur because young females are more likely to experience mental health difficulties compared to young males (Collishaw et al., 2010). Therefore, some females will have had greater exposure to mental health issues, either through personal experience or contact with female peers. This was supported by Arbanas (2008), as the medical high school males and females displayed similar stigmatising views. These students had high levels of knowledge of psychiatry and mental health difficulties and demonstrated no differences in attitudes according to gender. Arbanas (2008) suggested that learning about

mental disorders or having contact with patients reduced the negative attitudes of these males. However, the findings of Rose and colleagues (2007) demonstrated poor mental health literacy and negative attitudes among a predominantly female sample (73%).

Clinical and Qualitative Articles

Five papers were identified that used qualitative methods whereby young people were interviewed about their experiences of mental health difficulties. The themes reported in the studies were reviewed and 7 overarching themes were identified. Each study did not necessarily contribute to each theme, and as is the nature of qualitative research the themes are not weighted according to prevalence. The themes that emerged were: 'doubting the diagnosis'; 'it's not the same for everyone'; 'a negative label'; 'negative judgement from others'; 'life losses'; 'relationships change' and 'life interrupted'.

Doubting the diagnosis

The first subtheme described in Leavey's (2005) stage of 'Emergence' was "Problem getting the Correct Diagnosis". The young people were questioning the validity of the diagnostic criteria. This concept of whether a diagnosis can be trusted also emerged in Polvere's (2011) research. Participants described their experiences of receiving multiple and inconsistent diagnoses, which caused them

to doubt their current diagnosis and question the social construction of mental health disorders more broadly.

It's not the same for everyone

The theme of the 'therapeutic value' of a diagnostic label emerged in Polvere's (2011) interviews. Some young people acknowledged a feeling of relief and hope that accompanied a diagnosis. This reflected similar concepts that emerged from Hayne's (2003) adult research; that receiving a diagnosis can have positive implications as well as negative.

Brooks and Dallos (2009) analysed their participants' opening narratives and further duality to the diagnosis experience emerged. Some participants began with a contextual life story; they described connections between their thoughts, emotions and behaviours when looking back with hindsight at the development of their difficulties. Other participants 'opened' with their diagnosis as an explanation for their difficulties. This difference emphasised that young people with difficulties, who go on to receive a diagnosis, may have different conceptualisations of their difficulties. Some may see it in terms of a consequence of life events, whereas others will assign cause to a diagnosis, a recognised medical difficulty. How a young person attributes the cause of their difficulties may have an impact on their engagement with services and treatment adherence, but also their sense of identity and self-esteem.

A negative label

Within Leavey's (2005) theme of "Emergence" emerged the subtheme of "Labelling", which demonstrated that young people felt it was problematic to receive a mental health difficulty label. This theme emphasised that the young people believed mental health difficulties were associated with 'badness'. Participant N13 reflected this in the following quotation; "when I say the word "mental illness", it reminds me of bad" (Leavey, 2005, p.114).

Participants in O'Reilly et al.'s (2009) study also had strong negative associations with mental health difficulties. Many of the young homeless people they interviewed did not recognise or consider their difficulties to be related to mental health difficulties. This was clearly demonstrated by the quotation: "I 'ad problems I didn't 'ave mental health problems" (O'Reilly et al., 2009, p. 1740). The findings do not provide an answer to whether these young people responded in such a way because of their poor mental health literacy or because of their negative preconceptions about mental health difficulties. However, regardless of the reason for their reaction, these young people considered mental health difficulties as something 'bad' and undesirable. This was emphasised by their use of derogatory stereotypical language. A member of staff interviewed described that young homeless people considered mental illness as "nuts, schiz and psycho" (O'Reilly et al., 2009, p. 1740).

Negative judgement from others

Leavey's (2005) subtheme of 'Stigma' related to the change in social status the young people felt as a result of people's reactions to their diagnosis. These young people disliked, possibly feared, the negative judgement of others and believed that these negative views were widespread throughout society. One young person described: "society used mental illness as something crazy or disturbed people have" (Leavey, 2005, p.114). This was echoed in Polvere's (2011) findings; several young people in this study described that many of their friends and family considered them as crazy or bad since their diagnosis. One young person in Polvere's (2011) study described how she felt her difficulties and self-harm scars were never going to be accepted by society. These themes of stigma and negative judgements were associated with feelings of shame. Kranke et al., (2010) demonstrated this with their themes of shame of diagnosis and shame of medication use. A participant in Kranke et al.'s (2010) study used the word ashamed to describe how she felt about her difficulties.

One strategy these young people used to protect themselves from negative judgement and shame was to disguise or conceal their mental health difficulties from others. Brooks and Dallos (2009) described this as 'hidden distress' and Kranke et al., (2010) termed it 'secrecy of diagnosis' and 'secrecy of medication use'. Several young people across the studies vocalised this desire for secrecy: "I just kept it to myself because I didn't want people to know" (Brooks & Dallos, 2009, 106) and "I don't want anyone to know I have a mental illness" (Leavey, 2005, p.114). It appeared as if the young people wanted to avoid experiencing stigma and

shame by distancing themselves from the stigmatising difficulty. When the young people started to recognise and acknowledge their difficulties, they continued to hide them from people around them.

Identity Loss

Leavey's (2005) theme of "Loss" contained subthemes that focused on specific types of losses encountered due to the development of their mental health difficulties and receiving a diagnosis. A subtheme within the concept of loss was "loss of identity", which highlighted the change in how the young people understood themselves. Leavey (2005) described this as a descent into a 'foreign self'. Young people struggled to integrate the difficulties they viewed as shameful with their sense of self. Often the young people described themselves using self-critical and self-deprecatory terms. They had lost the sense of being normal and this was reflected in the comment: "knowing who you are, which most people take for granted had suddenly vanished " (Leavey, 2005; p.115). This was comparable to Hayne's (2003) theme of "a knowledge that knows". Receiving a diagnosis left the adults (Hayne, 2003) and young people (Leavey, 2005) feeling that their usual way of understanding of themselves had been changed forever.

Relationships change

Young people described changes in relationships with friends and family members because of their mental health diagnosis. Words such as "overprotective" (Leavey,

2005, p.116) and “caution” (Polvere, 2011, p.333) within the young people's dialogues when discussing their family members' reactions emphasized that they felt they were being treated differently. Family members also displayed negative reactions, referring to the young people as crazy and bad (Polvere, 2010). The derogatory words used to describe a mental illness were also emphasised in this quotation from a 13-year-old female: “Crazy. Psycho. Nuts. ‘Cause that's what I heard from everyone” (Kranke et al., 2010, p.500). Kranke et al. (2010) suggested that shame and stereotyping was reinforced by these negative family perceptions.

In addition to losses or changes in relationships with family members, the young people also described differences in friendships. This was reflected in social withdrawal and distancing from peers. The young people's expression of this loss was lamented in the following statements: “I'm not as popular as I used to be” (Leavey, 2005, p.116) and “I was really popular with friends... Now, no more friends” (Polvere, 2011, p. 331). Kranke et al. (2010) described these changes in relationships with peers as a continuum. The varying ways a young person limited their interactions with others ranged from withdrawing totally from social interactions, limited interactions with trusted friends, limited interactions with others with a similar difficulty and interactions with those who they do not trust.

Life interrupted

Throughout many of the young people's accounts, they described that developing aspects of their lives were disrupted. Adolescence is a time when individuals begin

to increase their independence, engage in intimate relationships and consider future prospects. In contrast these young people described that they were increasingly required to utilise residential, financial and emotional support from family members (Kranke et al., 2010). Similarly, at a time when many adolescents were progressing through their education, the young people in Leavey's (2005) study acknowledged a loss of their academic functioning and abilities. One female participant (N13) from Leavey's (2005) research described that her marks had plummeted and she was unable to think clearly at school. Participants in Kranke et al.'s (2010) study also commented on their school lives. This theme focused on the social aspects of school rather than academic performance. The young people wanted to fit in and not get bullied by their peers because of their diagnosis. One participant described an unsympathetic teacher's response to him: "shove that medication down your throat, you keep on acting crazy" (Kranke et al., 2010, p. 501).

The behavioural and emotional difficulties displayed by the young people must be considered instrumental in the changes and interruption in their lives. The receiving of a diagnosis was not solely responsible. However the issues associated with the receiving of a diagnosis can cause additional problems. These issues include wondering whether their diagnosis was correct, making sense of what the diagnosis means, negative associations with the label, other people's judgements, a lost sense of self and changes to relationships. These are significant issues for a young person to understand and manage, whilst also attempting to understand and manage their mental health symptoms.

Discussion

Overall, the results were consistent with the adult literature that receiving a diagnosis was an experience of consequence for young people. This review has revealed four important contributing factors. Each factor is discussed in more detail.

The first factor was that youth in the general population displayed varied levels of mental health literacy. A substantial amount of participants were unable to recognise mental health symptoms or knew the correct diagnostic label. Young people who had very poor awareness and understanding, who then went on to develop mental health difficulties, may be unlikely to recognise their difficulties as outside the normal experience. For example, participants in O'Reilly et al.'s (2009) study denied their difficulties were related to a mental health issue. Young people who do not recognise the seriousness of their difficulties may be unlikely to seek help. This concern was emphasised by Hess et al.'s (2004) finding that young people did not know where to go to seek help or what kind of professional help would be appropriate.

The second factor was that the majority of young people (including participants from the general population studies and individuals who had a direct experience of receiving a diagnosis) demonstrated negative and derogatory preconceptions about people with mental health difficulties. The young people throughout all the studies talked using stereotypical descriptions of mental illness. They used internalised

images “men in white coats to lock me away” (O’Reilly et al., 2009 p.1740) and “Strait jacket” (Rose et al., 2007; p.99): they also used popular slang terms, “fruit loop” (O’Reilly et al., 2009; p.1740) and “crazy” (Kranke et al., 2010 p.499). These findings indicated that the label of a mental health difficulty can be heard as a negative judgement on the self that may cause significant identity disruptions. If an individual that holds these beliefs develops difficulties, they may struggle to integrate their understanding of their difficulties and their identity with their preconceptions. Even if the young person themselves did not hold negative opinions, as many of the participants in Schulze and Angermeyer’s (2005) paper, they may be aware of their peers and the general zeitgeist that mental health was not viewed in a positive way. This could bring further complications and possible discomfort for a young person in receiving a mental health diagnosis.

The findings that youth in the general population have poor mental health literacy and negative preconceptions, predicts that a young person could be confused and distressed in receiving a diagnosis about which they know very little, other than their negative preconceptions. This was borne out by the themes that emerged from qualitative investigations of young people who experienced difficulties and had received a diagnosis. Consistent with findings from adult literature (Hayne, 2003), young people experienced both positive and negative aspects to receiving diagnosis. However, the research included within this review predominantly reported negative experiences. This may suggest that compared to adults, receiving a diagnosis was considered more negatively by young people.

The third factor was that the individuals who did receive a diagnosis described high levels of shame associated with the diagnosis and wanted to keep their diagnosis a secret. The young people were very aware of the stigma associated with a mental health difficulty and reported feeling ashamed of their difficulties. In an attempt to manage this shame, many young people kept their difficulties a secret. This was not a theme reported in Hayne's (2003) research with adults. A possible explanation for this is that young people's priorities are their friends and fitting in with a social group so an experience that labelled them different from their peers would be more pertinent. A diagnosis threatens their sense of belonging: by receiving a diagnosis a young person would belong to what many participants in this review would regard as a deviant and defective group.

The fourth and final factor was that the experience of receiving a diagnosis was also associated with feelings of loss. Losses were noted in an individual's sense of identity and independence, their relationships and future expectations. The experience of receiving a diagnosis changed the way they understood themselves. Similar themes emerged in Hayne's (2003) research with adults whereby a diagnosis altered how people perceived themselves. Young people may be more vulnerable than adults because adolescence is a time of identity consolidation, potentially increased competencies and making future life decisions.

A way forward

One clinical implication could be the introduction of mental health awareness teaching in secondary schools, which could aim to increase mental health literacy and decrease derogatory attitudes. Young people may benefit from education in the basic symptoms of mental health difficulties. It would be important for the young people to be taught how to recognise these symptom experiences in themselves but also to recognise the behavioural manifestations of these symptoms in their peers. It would also be important to advise young people about how to access appropriate assessment and treatment. This is consistent with the Children's and Young People's Mental Health Coalition (Mental Health Foundation UK, 2010) aim for mental health promotion in primary and secondary schools. Such mental health initiatives may be the way forward to challenge some of the derogatory preconceptions held by many young people. Contact with individuals who have experienced difficulties was associated with reduced stigma responses (Wright & Jorm, 2009). It is possible that adult mental health service users could play an important role in delivering the mental health awareness teaching sessions.

A second clinical implication could be that the process of sharing a diagnosis with a young person could be given greater consideration by the professionals involved. It is suggested that practice may alter if professionals were more aware of the factors associated with receiving a psychiatric diagnosis as a young person. It may be beneficial for professionals to speak to the young person about their understanding of their diagnosis and how it felt to hear and be labelled with a psychiatric

diagnosis. The young person's future expectations of the diagnosis and the effect on their future life could be discussed, balancing recovery prognosis with hope and optimism. The shame young people felt surrounding their diagnosis is likely to cause them a great deal of discomfort, therefore these discussions must be handled sensitively. The introduction of pre- and post-diagnostic counselling could be considered an appropriate strategy to address these issues.

Future research

There is scope to improve mental health literacy and reduce stigmatising attitudes in young people throughout the general population. Future research needs to focus on assessing what components of a mental health awareness and education programme in secondary schools would be most effective in achieving these goals. Research would need to address teaching delivery methods: for example classroom discussion compared to watching an educational DVD; teacher profession, for example whether young people would benefit from the programme being delivered by a teacher with whom they were familiar, a mental health professional or a current or past service-user; and content, for example the level of detail required for young people to develop an appropriate mental health literacy without feeling overwhelmed.

Future research addressing how professionals share a diagnosis with a young person needs to focus on developing an evidence-based practice when sharing a diagnosis. The key characteristics when advancing an evidence base are

increasing the current amount of data, and rigorous intervention studies that prospectively demonstrate improved outcomes. Such intervention studies need to evaluate which components of pre- and post-diagnostic counselling best improve a young people's psychosocial well-being, engagement with services and recovery prospects.

Limitations of current review

This review acknowledges several limitations. The first limitation was that the review did not employ a fully systematic system therefore it is possible that some relevant studies were not included. In addition, the results gathered from the quantitative data were limited because rather than looking at mental health diagnoses in general, four of the studies only looked at depression and one only looked at schizophrenia. Several diagnostic categories were not included in any of the quantitative papers, including eating disorders, personality disorders and obsessive-compulsive disorders. Therefore assumptions about the mental health literacy of these mental health difficulties cannot be generalised. A limitation of the qualitative studies was the inclusion of O'Reilly et al.'s (2009) study because it was unclear whether these young people had actually been recipients of a mental health diagnosis.

Summary

Recognising its limitation, this review modestly suggests that a diagnosis is experienced by a young person as an experience that labels them with a name they may not understand, that can be shameful because of the derogatory stereotypical preconceptions they hold, and that it disturbs their sense of identity and their hopes for the future. Due to the identified gender differences, it is suggested that these factors would be increased for young males. Suggestions for improving the experience of receiving a mental health diagnosis include the introduction of effective mental health awareness initiatives in secondary schools and pre- and post-diagnostic counselling.

References

American Psychiatric Association. (2000). Diagnostic and statistical manual of mental disorders (4th ed., text revision). Washington, DC: Author.

*Arbanas, G. (2008). Adolescents' Attitudes toward schizophrenia, depression and PTSD. *Journal of Psychosocial Nursing*, **46**, 45-50.

Audini, B., & Lelliot, P. (2002). Age, gender and ethnicity of those detained under Part II of the Mental Health Act 1983. *British Journal of Psychiatry*, **180**, 220-226.

*Brooks, E., & Dallos, R. (2009). Exploring young women's understanding of the development of difficulties: A narrative biographical analysis. *Clinical Child Psychology and Psychiatry*, **14**, 101-115.

*Burns, J., & Rapee, R. (2006). Adolescent mental health literacy: Young people's knowledge of depression and help seeking. *Journal of Adolescence*, **29**, 225-239.

*Calear, A., Griffiths, K., & Christensen, H. (2011). Personal and perceived depression stigma in Australian adolescents: Magnitude and predictors. *Journal of Affective Disorders*, **129**, 104-108.

CASP: Critical Appraisal Skills Programme tools (2006) Retrieved from <http://www.sph.nhs.uk/what-we-do/public-health-workforce/resources/critical->

[appraisals-skills-programme](#) on 1st February 2012.

Collishaw, S., Maughan, B., Natarajan, L., & Pickles, A. (2010). Trends in adolescent emotional problems in England: a comparison of two national cohorts twenty years apart. *Journal of Child Psychology and Psychiatry*, **51**, 885-895.

Corrigan, P. (2007). How clinical diagnosis might exacerbate the stigma of mental illness. *Social work*, **52**, 31-39.

Fone, D., Lloyd, K., & Dunstan, F. (2007). Measuring the neighbourhood using UK benefits data: a multilevel analysis of mental health status. *BMC Public Health*, **7**, 69-82.

Hayne, Y. (2003). Experiencing psychiatric diagnosis: client perspectives on being named mentally ill. *Journal of Psychiatric and Mental Health Nursing*, **10**, 722-729.

*Hess, S., Cox, T., Gonzales, L., Kastelic, E., Mink, S., Rose, L., & Swartz, K. (2004). A survey of adolescents' knowledge about depression. *Archives of Psychiatric Nursing*, **18**, 228-234.

Jorm, A., & Wright, A. (2008). Influences on young people's stigmatising attitudes towards peers with mental disorders: national survey of young Australians and their parents. *The British Journal of Psychiatry*, **192**, 144-149.

*Klineberg, E., Biddle, L., Donovan, J., & Gunnell, D. (2011). Symptom recognition and help seeking for depression in young adults: a vignette study. *Social Psychiatry and Psychiatric Epidemiology*, **46**, 495-505.

*Kranke, D., Floersch, J., Townend, L., & Munson, M. (2010). Stigma experience among adolescents taking psychiatric medication. *Children and Youth Services Review*, **32**, 496-505.

Laing, R. D. (1971). The politics of the family and other essays. Pantheon books: New York.

*Leavey, E. (2005). Youth experiences of living with mental health problems: Emergence, Loss, Adaption and Recovery (ELAR). *Canadian Journal of Community Mental Health*, **24**, 109-126.

McCann, T., Deans, C., Clark, E., & Lu, S. (2008). A comparative study of antipsychotic medication taking in people with schizophrenia. *International Journal of Mental Health Nursing*, **17**, 428-438.

Mental Health Foundation (2010). Children's and Young People's Mental Health <http://www.childrenengland.org.uk/upload/Policy%20Paper.pdf> on 20th May 2012.

Miles, M. B., & Huberman, A. M. (1994). Qualitative data analysis: An expanded sourcebook. Thousand Oaks, CA: Sage.

*Olsson, D. & Kennedy, M. (2010) Mental health literacy among young people in a small US town: recognising of disorders and hypothetical responses. *Early Intervention in Psychiatry*, **4**, 291-298.

*O'Reilly, M., Taylor, H., & Vostanis, P. (2009). "Nuts, schiz, psycho": An exploration of young homeless people's perceptions and dilemmas of defining mental health. *Social Science and Medicine*, **68**, 1737-1744.

Paulose-Ram, R., Safran, M., Jonas, B., Gu, Q., & Orwig, D. (2007). Trends in psychotropic medication use among US adults. *Pharmacoepidemiology and Drug Safety*, **16**, 560-570.

*Polvere, L. (2011). Youth Perspectives on Restrictive Mental Health Placement: Unearthing a Counter Narrative. *Journal of Adolescent Research*, **26**, 318-343.

*Rose, D., Thornicroft, G., Pinfold, V., & Kassam, A. (2007). 250 labels used to stigmatise people with mental illness. *BMC Health Services Research*, **7**, 97-104.

Sirey, J., Bruce, M., Alexopoulos, G., Perlick, D., Raue, P., Friedman, S., & Meyers, B. (2001). Perceived stigma as a predictor of treatment discontinuation in young and older outpatients with depression. *American Journal of Psychiatry*, **158**, 479-481.

Sorgaard, K., Nivison, M., Hansen, V., & Oiesvold, T. (2011). Acknowledging illness and treatment needs in first-time admitted psychiatric patients. *European Psychiatry*, **26**, 446-451.

*Schulze, B. & Angermeyer, M. (2005). What is Schizophrenia? Secondary school students' associations with the word and sources of information about the illness. *American Journal of Orthopsychiatry*, **75**, 316-323.

Vogel, D., Wade, N., & Hackler, A. (2007). Perceived Public Stigma and the Willingness to Seek Counselling: The Mediating Roles of Self-Stigma and Attitudes Toward Counseling. *Journal of Counseling Psychology*, **54**, 40-50.

Wisdom, J., Clarke, G., & Green, C. (2006). What teens need: barriers to seeking care for depression. *Administration and Policy in Mental Health and Mental Health Services Research*, **33**, 133-145.

*Wright, A. & Jorm, A. (2009). Labels used by young people to describe mental disorders: factors associated with their development. *Australian and New Zealand Journal of Psychiatry*, **43**, 946-955.

*Wright, A., Jorm, A., & Mackinnon, A. (2011). Labeling of mental disorders and stigma in young people. *Social Science and Medicine*, **73**, 498-506.

Zarrett, N. & Eccles, J. (2006). The passage to adulthood: Challenges of late adolescence. *New Directions for Youth Development*, **111**, 13-28.

SECTION 4: Contributions to Theory and Clinical Practice: Considering pre and post diagnostic counselling.

Contributions to Theory and Clinical Practice

Considering pre and post diagnostic counselling

Introduction

The findings of the research paper, “A qualitative investigation into the lived experience of eight 15-17 year old females experiencing mental health difficulties” and the literature review paper, “Young people’s perceptions of a mental health diagnosis: a review of current literature including the general population and young people with a diagnosis” led to the consideration of several clinical implications. The diagnosis experience and ways to improve this were present across both papers.

Within the research paper the theme of ‘diagnostic stickiness’ included several negative aspects of the diagnosis experience. Participants felt their diagnosis was something a professional had stuck on them; was a set of symptoms they had to conform to: and was something so sticky they would not be able to get rid of it. The literature review also highlighted negative aspects. These results suggested that a mental health diagnosis was associated with negative preconceptions, shame, a loss of identity and ruined future expectations. It was considered that professionals should be aware of the negative aspects associated with receiving a diagnosis and that diagnoses should not be disclosed with little regard for psychosocial outcomes. However, young people in both the research paper and literature review described that receiving a diagnosis gave them a sense of hope for successful treatment and

recovery. Therefore the concept of giving a young person a diagnosis cannot be judged as wholly negative therefore non-disclosure of a diagnosis would be inappropriate. The concept of pre and post diagnostic counselling appeared to address some of the negative aspects of receiving a diagnosis, whilst maintaining and possibly increasing the positive aspects.

Clinical psychologists often work using formulations rather than diagnostic labels to understand and conceptualise an individual's difficulties. However, at present the child and adolescent mental health outpatient and inpatient services in North Wales use mental health diagnoses within standard practice and young people have been receiving mental health diagnoses. The validity of mental health diagnoses is not discussed, rather the psychosocial wellbeing of these young people (who had received a mental health diagnosis) was considered paramount. The concept of pre and post diagnostic counselling became of particular interest to me, and therefore will be the focus of this discussion paper. First this paper reviews the current best practice guidelines for professionals who are involved in giving mental health diagnoses. Second the clinical implications suggested from the findings of the research paper and literature review are integrated into this review. Third the implications for future research are considered. Finally personal reflections upon completing the thesis are discussed.

Current Guidelines

Increasing mental health literacy and decreasing stigma perceptions are national

priorities in Wales as established within the Raising the Standard: Revised Adult Mental Health National Service Framework and an Action Plan for Wales (2005). This document stated an aim to “promote the understanding of mental health issues, in order to reduce the stigma associated with mental illness” (Raising the Standard, 2005, p. 10). Specific to young people, the National Service Framework for Children, Young People & Maternity Services (Department of Health, 2006) stated that it was important for young people to be “treated with respect by service providers and are provided with information and support appropriate to their needs and ability that assists them in making decisions about the care that they receive” (Department of Health, 2006, p. 7). These initiatives show that increasing the knowledge and understanding of individuals accessing mental health services is a current national priority. Increasing understanding and decreasing stigma are targets that could be addressed in pre and post diagnostic counselling. However, before advocating pre and post diagnostic counselling, the current best practice guidelines for mental health professionals when giving a mental health diagnosis were reviewed.

A comprehensive examination of several National Institute of Clinical Excellence (NICE) guidelines for adults, children and young people was conducted in order to identify recommendations relating to the sharing of a mental health diagnosis. The NICE guideline for Schizophrenia (2009) does not acknowledge the sharing of a diagnosis other than to state professionals need to be competent in “explaining the causes of schizophrenia and treatment options (NICE clinical guideline 82, 2009, p.12). This guidance is limited in its instruction. It does not include the aspects that

should be included or the techniques a practitioner should employ. There is no comment on the emotional impact that receiving a diagnosis of Schizophrenia may have on the Service-user. More detailed recommendations are included within the NICE guideline for Dementia (2006): “healthcare professionals should make time available to discuss the diagnosis and its implications with the person with dementia and also with family members (usually only with the consent of the person with dementia). Healthcare professionals should be aware that people with dementia and family members may need ongoing support to cope with the difficulties presented by the diagnosis” (NICE clinical guideline 42, 2006, p.27). Increasingly the disclosure of a diagnosis of dementia is being recognized as a process, rather than a one-off behaviour (Lecouturier et al., 2008). Lecouturier et al. (2008) identified 8 behaviours associated with best practice when disclosing a diagnosis of dementia. These were preparing for disclosure, integrating family members, exploring the patient's perspective, disclosing the diagnosis, responding to the patient's reactions, focusing on quality of life and well-being, planning for the future and communicating effectively. Dementia is a more concrete diagnosis compared to mental health diagnoses, however on face value these 8 behaviours appear to be transferable to sharing a mental health diagnosis with a young person, however specific research would need to assess this.

The NICE Guidelines for Attention Deficit Hyperactivity Disorder (2008), Depression (2005), Anxiety (2007), Obsessive Compulsive Disorder (2005) and Eating Disorders (2004) make no comment about diagnosis sharing. These guidelines are focused on treatment interventions so perhaps this is no surprise, but could pre and

post diagnostic counseling be considered as contributing to an effective intervention?

Overall, there is a lack of advice and guidance for practitioners to effectively manage the mental health diagnosis experience. Currently it appears that only the guideline for Dementia, which is primarily a medical diagnosis of a condition which is lifelong, severe, degenerative and treatment resistant, contains sharing diagnosis recommendations. Mental health conditions in young people may be conceptualized differently and diagnosis may not be definitive. However some of the difficulties and symptoms associated with a mental health diagnosis could be considered lifelong, severe, degenerative and treatment resistant. In addition, it should be noted that young people may experience a diagnosis as an experience of consequence regardless of the nature of their difficulties.

Two recent NICE consultation documents have acknowledged the diagnosis experience in more detail. The "Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services" (NICE clinical guideline Draft: June, 2011) and the Autism Spectrum Disorder (ASD) Guideline (NICE clinical guideline Draft: January 2011). The service user document acknowledges stigma and negative views associated with a mental health diagnosis and advocates a framework for person-centred care. The Autism Spectrum Disorder (ASD) document includes clear guidance for communicating with parents, carers and professionals the results of an ASD diagnostic assessment. The results of an ASD diagnostic assessment should be shared

without delay, even if a diagnosis is not certain yet. It also states that “generic guidelines for sharing and disclosing diagnosis to children and young people” (NICE clinical guideline DRAFT: January 2011, P. 28) should be applied. The information shared needs to take into account their age, their ability to understand and be specific to the young person based on their profile. These consultation documents indicate that NICE has started to recognize that receiving a mental health diagnosis could be an experience of consequence and needs to be sensitively considered by professionals. However it remains questionable what is best practice and what is the current standard practice?

Implications for clinical practice

The following clinical implications should be considered as tentative interpretations based on the current data; however further investigation is required before any firm conclusions can be reached and this is discussed within the ‘Future Research’ section.

The research paper and literature review suggested that receiving a diagnosis could be an experience of consequence. Psychiatrists, Mental Health Nurses and Clinical Psychologists regularly share and talk about mental health diagnoses with their young clients. General Practitioners, children's ward teams and A&E staff may also be required to share mental health diagnoses with young people. Therefore these implications could be considered for any health care practitioner in contact with a young person with mental health difficulties.

Practitioner awareness

The level of practitioner awareness of young people's knowledge and views needs to be considered. Derogatory views were voiced by the participants in the research paper and literature review. These views appeared to be associated with shame and secrecy for the individual experiencing difficulties, these themes also present throughout the both papers. Within the research paper, the themes of 'Keeping it Hidden', 'Life is different now' and 'Relationships are different now' were associated with shame and the consequent desire to maintain secrecy. Within the literature review, this was reflected in the themes 'a negative label' and 'negative judgement from others'. Practitioners need to be constantly aware of the shame and secrecy dynamics and should use sensitive communications when sharing a diagnosis. Effective communications could encourage young people to share their difficulties in order to elicit additional support, manage risks and access appropriate interventions.

Practitioner awareness could be targeted during a professional's initial qualification training. Perhaps this is an area where specific training could be beneficial in preparing newly-qualified practitioners for sharing mental health diagnosis. In contrast, individuals who frequently share mental health diagnoses with young people may become accustomed to diagnostic terms and they may use these terms with little regard for the young person's level of understanding or the emotional impact hearing those words applied to them. Therefore, diagnostic

awareness initiatives could constitute mental health professionals' continual professional development.

Pre-diagnostic Work

The findings of the literature review suggested that young people in general displayed low to moderate mental health literacy. Practitioners working with young people need to be aware that any young person in their care may have a limited understanding of a mental health difficulty. For example, a young person may not know what certain mental health phrases mean or what symptoms are associated with a particular diagnosis. In addition, the young person may also display stereotypical derogatory views about mental health difficulties; for example they may believe an individual with psychosis is a “freak” (Rose et al., 2007), who is “dangerous” (Wright et al., 2011) and “should be placed in an institution or hospital” (Arabanas, 2008). Pre-diagnostic work could aim to address and possibly resolve these issues before a diagnosis is given. Discussions that challenge negative stereotypes and derogatory views may help to reduce the stigma and shame a young person associates with a mental health diagnosis. Pre-diagnostic work could also include an assessment of the young person's views and understanding of diagnosis before being given a diagnostic label. Psycho-education regarding the symptoms a young person is experiencing, along with information about their prognosis and treatment options may increase their mental health literacy before they receive a diagnosis they do not understand.

In both the research and the review papers, young people reported benefits from receiving their diagnosis, particularly the aspect relating to how diagnosis gives them hope for a successful recovery. Pre-diagnostic counselling could increase the focus of hopefulness and put the young person's goals for recovery at the forefront. This work would also encourage the young person to ask questions and to be experts in their own experiences in order to create a more collaborative person-centred stance.

Post-diagnostic Work

Once a diagnosis has been shared it is possible that further supportive work could ease the diagnosis experience. The theme of 'diagnostic stickiness' within the research paper highlighted that the process of a young person hearing a diagnosis needs to receive greater consideration by mental health professionals. The young people described that professionals stuck a diagnosis to them rather than shared it with them.

Hayne (2003) concluded that practitioners need to demonstrate 'discernment', meaning that a practitioner should display an ability to know what is helpful and what is unhelpful for the client. In the aftermath of receiving a diagnosis, a young person may display grief and relief concurrently; the discerning practitioner would anticipate their client's reactions and be able to convey genuine interest and empathy for a young person's reaction. Practitioners could ask questions such as

“how has hearing this diagnosis made you feel?” to facilitate supportive conversations.

The research and review papers also found that young people described how their lives had changed and how they had lost their identity since receiving their diagnosis. Again using Hayne's (2003) language, the discerning practitioner could focus on the young person's strengths, to instil a confidence in their own coping strategies and inspire hopeful possibilities. Upon hearing a diagnosis the young person may be struggling to understand the diagnostic knowledge they have just received whilst also trying to conceptualise their way forward. Questions such as “I am wondering how you understand your diagnosis?” may help to encourage a young person to think about these issues with a supportive practitioner, who can provide them with answers, reassurance and hope. Even consultation with the young person about their preferred labels to describe their difficulties may give the young person a sense of control, for example Abigail (research paper participant) preferred to refer to her difficulties as ‘low mood’ rather than ‘depression’.

Implications for future research

The above clinical implications would require further investigation before any definitive conclusion could be reached. Within the field of physical health diagnoses, ‘breaking bad news’ has received significantly more research attention than mental health. Girgis and Sanson-Fisher (1995) discussed the advantages and disadvantages of nondisclosure, full disclosure and individualized disclosure of

diagnosis to clients. They concluded that individualized disclosure appeared to be the ideal model because, although time consuming, the amount of information given and the rate of disclosure is tailored to the needs of the individual. In addition a supportive relationship with the practitioner is developed in which the client can feel confident to ask questions. There is a growing body of research in physical health, however a review by Paul et al. (2009) on breaking bad news to cancer patients found the research was still limited. Both in terms of quantity and rigor, Paul et al. (2009) concluded that current research was insufficient to develop an evidence-based guideline for sharing a diagnosis of cancer.

The field of mental health has far more limited research to draw on compared to physical health and therefore it is hoped that research efforts will advance over time to inform a potential evidence-based practice. Such intervention studies need to evaluate pre and post diagnostic counselling strategies for improving young people's psychosocial well-being, engagement with services and recovery rates. Current practice and training regarding the sharing of a diagnosis cannot be regarded as evidence-based until this further research is completed. The most pertinent research questions are discussed below.

- 1) What is the current standard practice amongst both mental health and general health professionals? This would provide a baseline at which to consider whether improvements were needed. This would also establish the level of training required during initial qualifications and as part of continual professional development.

- 2) Does pre-diagnostic counselling alone, post-diagnostic counselling alone or a combination of both, result in a measurable difference to how young people perceive and understand their diagnosis? Are the principles of psychoeducation, anti-stigma work and being a 'discerning' practitioner effective for improving a young person's well-being? This would establish which effective components should be implemented when sharing a mental health diagnosis.
- 3) If a young person is able to demonstrate an increased understanding of their difficulties, does this result in a measurable increase in their self-esteem, quality of life and engagement with services whilst experiencing their difficulties? This would establish the efficacy of pre and post diagnostic counselling.
- 4) Do young people who have experienced pre and post diagnostic counselling display any differences in their recovery and relapse rates? This would also contribute to establishing the efficacy pre and post diagnostic counselling.

Reflections

At the start of this thesis, I had one focal question: what issues do I need to be aware of when working clinically with a young person who experiences mental health difficulties and has received a psychiatric diagnosis. During the completion of this thesis I kept a reflective journal in order to record my thoughts, responses and emotions with this question in mind. Aspects of this journal are now shared in relation to the research study and the literature review papers.

Research paper

During the initial stages of generating potential ideas for a piece of original research, I decided early on that I wanted to conduct a qualitative piece of research. This decision was based on two factors; the first was that I had no experience of conducting qualitative research and wanted to develop my skills in this methodology. The second was that I found I was particularly drawn to research that focused on the lived experience and personal narratives that qualitative research would uncover. In early discussions with supervisors it was agreed that I would investigate the topic of young people's experiences of mental health difficulties. During the development of my proposal it became clear that Interpretative Phenomenological Analysis (IPA) would be the most appropriate methodology to investigate young people's experiences. Looking back at my reflective journal, the time of writing proposals and completing ethics procedures was characterised by two types of reflections. The first was my trepidation at starting my own project, the excitement and anxieties that one feels when beginning something new. The second reflections were associated with the thoroughness and detail required in completing a University proposal and an NHS Ethics application. I initially felt frustration when having to account for pennies when completing expenses proposals but this instilled in me the importance of clear and concise budgeting when spending some-one else's money: a skill that will be invaluable when working under the budgetary restrictions of the National Health Service.

Following my ethics review meeting, I noted feeling disappointed that 17 professionals had criticised my use of overly technical language when I had strived to write with a young person audience in mind. I have always felt strongly that my written communications were accessible and jargon free, but their comments made me realise how one can become so familiar with psychological terminology, and I had forgotten there was a time in my life when I did not know what 'cognition' meant. This experience reminded me to keep my writing clear and meaningful for the audience they are intended. This awareness will hopefully stay with me upon completion of the DClinPsy .

I conducted my interviews at a local inpatient unit. During the data collection phase of my project, my reflective journal displayed two clear themes. The first theme was the initial difficulty in getting nursing and support staff interested and willing to help with the research. The managers of each ward were extremely helpful in signing the capacity forms and introducing me onto the wards. The staff on the ward were friendly but often unhelpful when it came to obtaining parental assent forms for young people aged 15 or under. This was particularly apparent for one young lady who chose not to take part because her assent form had not been obtained from her parent from ward staff on several occasions. My reflections at this point were frustration that had to be balanced with an understanding that my research was not a priority for some staff members. A learning point from this experience was to ask the young person themselves to obtain their parents/carers assent to take part. The

young people were more successful at this, perhaps because they were motivated to take part.

I also reflected on how my priorities and my psychological understanding may not always be shared by other professionals when working in multi-disciplinary teams. Perhaps I needed to be less focused on my own research goals initially and more in tune with the ward staff. By regularly making myself available (and bringing packets of biscuits!) on the wards, staff were able to ask informal questions, raise their concerns and consequently were more amenable to helping me. Many staff changed from being uninterested to asking when I was coming back to share the findings. I think this demonstrated my increasing skills in liaising with professionals.

The second theme in my reflections during the data collection phase was my appreciation towards the young women I interviewed. They shared their very personal life stories and experiences with me and I felt very privileged to hear their accounts. I noted during the first few interviews I felt a strong pull towards a therapist response rather than a researcher response. My role in speaking to these young women was to listen rather than conduct an assessment or offer solutions. I noticed as well that when a young person was providing short one-word answers I would begin to ask more closed questions. It was helpful to notice this in consultation with one of my supervisors (Dr Jaci Huws). By being aware and noticing my responses I was able to change my approach and purposely ask open questions if an interview was becoming difficult.

During the transcription process I noticed my own responses during the interviews. An amusing reflective note made in a memo whilst transcribing the fourth interview was my embarrassment at hearing my voice throughout the transcripts typed so far repeat certain phrases: “mmm... that’s really interesting, can you tell me a bit more about that?”. The process of listening to myself increased my self-awareness; I was able to recognise times when a different response may have been beneficial or when I was struggling to respond. In the first interview with Olive, she wrote down “suicidal ideation” because it was uncomfortable for her to say it aloud. In my response I noted I repeated ‘sort’ and stumbled over my words, I was aware that she was uncomfortable and this made me feel uncomfortable when using the words ‘suicidal ideation’ in front of her. It was helpful for me to realise this for the following interviews. I aimed to strike a balance between a sensitive and genuine response. Equally I was also able to recognise some of my strengths when interviewing with young women. I felt proud of my engagement skills particularly with some of the less talkative young women.

During the analysis phase I was again struck by feelings of privilege that I had heard these young women’s stories. My reflective journal contained a passage that described a real sense of responsibility to interpret their words in a way that truly reflected their experiences. I felt accountable to their stories and felt that the themes that emerged from my analysis maintained the integrity of the original transcripts.

Literature Review

I conducted my research paper before completing my literature review because I wanted to use the literature review as an opportunity to expand upon a particularly interesting theme that emerged from the analysis of the interviews. The theme of 'diagnostic stickiness' caught my interest for further exploration and led to my decision to review the literature of how young people experience receiving a mental health diagnosis.

Upon re-reading my reflective journal during the time of writing the literature review, I noticed I was surprised by the number of negative views and derogatory preconceptions expressed by young people in the general population. This really emphasised the experiences of the young ladies who took part in the research study. It highlighted why they wanted to keep their difficulties hidden from their peers and the world in general; and perhaps why they felt such a high degree of shame. In addition, it made me question my own mental health literacy and preconceptions when aged 15 to 17 years. My insights from the findings of the literature review have definitely had an impact on my approach to working with children and young people. While I feel I have always been sensitive when talking about a young person's diagnosis, now I will give this extra consideration.

Ending reflection

Upon completing the final polish to both the research paper and the literature review, my reflective journal was filled with descriptions of relief to have completed both projects but also anxieties about the quality of the work produced. I am sure this mixture of pride and self-doubt are a commonplace muddle of emotions to experience when completing a DClinPsy thesis. The findings of both my papers are not definitive, however this project has begun to answer the question I started out with when commencing this project. I feel this knowledge and the many lessons learned over the last three years of project development, execution and summary will stay with me throughout my career.

References

Arbanas, G. (2008). Adolescents' Attitudes toward schizophrenia, depression and PTSD. *Journal of Psychosocial Nursing*, **46**, 45-50.

Department of Health (2006) Promoting the mental health and psychological well-being of children and young people: report on the implementation of Standard 9 of the National Service Framework for Children, Young People and Maternity Services. Retrieved from

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_062778 on 1st April 2012.

Girgis, A. & Sanson-Fisher, R. (1995). Breaking Bad News: Consensus guidelines for medical practitioners. *Journal of Clinical Oncology*, **13**, 2449-2456.

Hayne, Y. (2003). Experiencing psychiatric diagnosis: client perspectives on being named mentally ill. *Journal of Psychiatric and Mental Health Nursing*, **10**, 722-729.

Lecouturier, J., Bamford, C., Hughes, J., Francis, J., Foy, R., Johnston, M. & Eccles, M. (2008). Appropriate disclosure of a diagnosis of dementia: identifying the key behaviours of 'best practice'. *BMC Health Services Research*, **8**, 95-105.

National Institute for Health and Clinical Excellence (2004). Eating Disorders: Core interventions in the treatment of treatment and management of anorexia nervosa,

bulimia nervosa and related eating disorders. NICE clinical guideline 9. London: National Collaborating Centre for Mental health.

National Institute for Health and Clinical Excellence (2005). Obsessive-compulsive disorder: Core interventions in the treatment of obsessive-compulsive disorder and body dysmorphic disorder. NICE clinical guideline 31. London: National Collaborating Centre for Mental health.

National Institute for Health and Clinical Excellence (2005) Depression in children and young people: Identification and management in primary, community and secondary care. NICE clinical guideline 28. London: National Collaborating Centre for Mental health.

National Institute for Health and Clinical Excellence (2005). Schizophrenia: Core interventions in the treatment and management of schizophrenia in adults in primary and secondary care. NICE clinical guideline 82. London: National Collaborating Centre for Mental health.

National Institute for Health and Clinical Excellence (2006). Dementia: Supporting people with dementia and their carers in health and social care. NICE clinical guideline 42. London: National Collaborating Centre for Mental health.

National Institute for Health and Clinical Excellence (2007). Anxiety (amended): Management of anxiety (panic disorder with or without agoraphobia and generalized anxiety disorder in adults, in primary, secondary and community care. NICE clinical guideline 22 (amended). London: National Collaborating Centre for Mental health.

National Institute for Health and Clinical Excellence (2008). Attention deficit hyperactivity disorder: Diagnosis and management of ADHD in children, young people and adults. NICE clinical guideline 72. London: National Collaborating Centre for Mental health.

National Institute for Health and Clinical Excellence (2011). Autism Spectrum Disorders: recognition, referral and diagnosis in children and young people. NICE guideline: Draft for consultation, January 2011. London: National Collaborating Centre for Mental health.

National Institute for Health and Clinical Excellence (2011). Service user experience in adult mental health: Improving the experience of care for people using adult NHS mental health services. Draft for consultation, June 2011. London: National Collaborating Centre for Mental health.

Raising the standard. The revised adult mental health national service framework and an action plan for Wales (2005). Welsh Assembly Government. Retrieved from

<http://www.rcpsych.ac.uk/pdf/WAG%20Raising%20the%20Standard2.pdf> on 26th May 2012.

Paul, C., Clinton-McHarg, T., Sanson-Fisher, R., Douglas, H. & Webb, G. (2009). Are we there yet? The state of the evidence base for guidelines on breaking bad news to cancer patients. *European Journal of Cancer*, **45**, 2960-2966.

Rose, D., Thornicroft, G., Pinfold, V. & Kassam, A. (2007). 250 labels used to stigmatise people with mental illness. *BMC Health Services Research*, **7**, 97-104.

Wright, A., Jorm, A., & Mackinnon, A. (2011). Labeling of mental disorders and stigma in young people. *Social Science and Medicine*, **73**, 498-506.

SECTION 5: Ethics Appendix

Email confirming Bangor University ethics approval

Email received on 9th February 2011.

Dear Freya Leanne,

2011-1548 Young people's experiences of mental health difficulties

Your research proposal number 2011-1548 has been reviewed by the School of Psychology Ethics and Research Committee and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of five years from this date. Ethical approval is granted for the study as it was explicitly described in the application. If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere. Governance approval is granted for the study as it was explicitly described in the application and we are happy to confirm that this study is now covered by the University's indemnity policy. If any new researchers join the study, or any changes are made to the way the study is funded, or changes that alter the risks associated with the study, then please submit an amendment form to the committee.

Yours sincerely

Everil McQuarrie

Sponsorship letter: not available in electronic format (1 page).

NHS ethics proposal: IRAS form

Welcome to the Integrated Research Application System
IRAS Project Filter
The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.
Please enter a short title for this project (maximum 70 characters) Young People's Experiences of Mental Health Difficulties
1. Is your project research? <input checked="" type="radio"/> Yes <input type="radio"/> No
2. Select one category from the list below: <input type="radio"/> Clinical trial of an investigational medicinal product <input type="radio"/> Clinical investigation or other study of a medical device <input type="radio"/> Combined trial of an investigational medicinal product and an investigational medical device <input type="radio"/> Other clinical trial or clinical investigation <input type="radio"/> Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology <input checked="" type="radio"/> Study involving qualitative methods only <input type="radio"/> Study limited to working with human tissue samples, other human biological samples and/or data (<i>specific project only</i>) <input type="radio"/> Research tissue bank <input type="radio"/> Research database If your work does not fit any of these categories, select the option below: <input type="radio"/> Other study
2a. Please answer the following question(s): a) Does the study involve the use of any ionising radiation? <input type="radio"/> Yes <input checked="" type="radio"/> No b) Will you be taking new human tissue samples (or other human biological samples)? <input type="radio"/> Yes <input checked="" type="radio"/> No c) Will you be using existing human tissue samples (or other human biological samples)? <input type="radio"/> Yes <input checked="" type="radio"/> No

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

- England
- Scotland
- Wales
- Northern Ireland

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

- ☐ England
- ☐ Scotland

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- ☒ Wales
- ☐ Northern Ireland
- ☐ This study does not involve the NHS

4. Which review bodies are you applying to?

- ☒ NHS/HSC Research and Development offices
- ☐ Social Care Research Ethics Committee
- ☒ Research Ethics Committee
- ☐ National Information Governance Board for Health and Social Care (NIGB)
- ☐ Ministry of Justice (MoJ)

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

- ☒ Yes ☐ No

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

- ☒ Yes ☐ No

7. Do you plan to include any participants who are adults unable to consent for themselves through physical or mental incapacity? *The guidance notes explain how an adult is defined for this purpose.*

- ☐ Yes ☒ No

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

- ☐ Yes ☒ No

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

- ☒ Yes ☐ No

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

- ☒ Yes ☐ No

10. Is this project financially supported by the United States Department for Health and Human Services?

- ☐ Yes ☒ No

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

- ☐ Yes ☒ No

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

Application to NHS/HSC Research Ethics Committee

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

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
 Young People's Experiences of Mental Health Difficulties

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

REC Name:

Betsi Cadwaladr University Health Board

REC Reference Number:

11/WA/0036

Submission date:

07/03/2011

PART A: Core study information
1. ADMINISTRATIVE DETAILS
A1. Full title of the research:

A qualitative investigation into identity, personality, diagnosis and relationships of young people with mental health difficulties.

A2-1. Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:

North Wales Clinical Psychology Doctoral Programme

Name of educational establishment:

The University of Bangor

Name and contact details of academic supervisor:

	Title	Forename/Initials	Surname
	Dr	Michaela	Swales
Address	North Wales Adolescent Service		
	Llansfair Road		
	Abergele		
Post Code	LL22 8DP		

Young people's experiences of mental health difficulties

E-mail m.swales@bangor.ac.uk
 Telephone 01745448700
 Fax

Name and contact details of student:

	Title	Forename/Initials	Surname
	Mrs	Freya	Spicer-White
Address	Oak Lodge		
	Graig		
	Glan Conwy		
Post Code	LL28 5TW		
E-mail	pspab8@bangor.ac.uk		
Telephone	07891625773		
Fax			

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

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

- ☒ Student
☐ Academic supervisor
☐ Other

A3-1. Chief Investigator:

	Title	Forename/Initials	Surname
	Mrs	Freya	Spicer-White
Post	Trainee Clinical Psychologist		
Qualifications	BSc Psychology (Hons)		
Employer	Betsi Cadwaladr University Health Board		
Work Address	North Wales Adolescent Service		
	Abregele Hospital		
	Llansfair Road		
Post Code	LL22 8DP		
Work E-mail	pspab8@bangor.ac.uk		
* Personal E-mail			
Work Telephone	07891625573		
* Personal Telephone/Mobile	01492582538		
Fax			

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*

A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?

This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

	Title	Forename/Initials	Surname
	Professor	Oliver	Turnbull

Young people's experiences of mental health difficulties

Address Adeliad Brigantia
Pentrallt Road
Bangor

Post Code LL57 2AS

E-mail o.turnbull@bangor.ac.uk

Telephone 01248 383670

Fax 01248 38 2599

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

Applicant's/organisation's own reference number, e.g. R & D (if available): 11/WA/0036

Sponsor's/protocol number:

Protocol Version:

Protocol Date:

Funder's reference number:

International Standard Randomised Controlled Trial Number (ISRCTN):

ClinicalTrials.gov Identifier (NCT number):

European Clinical Trials Database (EudraCT) number:

Project website:

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

☐ Yes ☒ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

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

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. This summary will be published on the website of the National Research Ethics Service following the ethical review.*

This study hopes to interview between 8-10 adolescent residents of the North Wales Adolescent Service (NWAS). The interview aims to collect detailed information about the adolescent's perspective of their mental health difficulties, their identity and their personality. Also some questions will focus on how their mental health difficulties effect the relationships with others. It is hoped the findings will inform clinical therapies with adolescents and the therapeutic relationship.

If I am unable to recruit at least 8 participants from NWAS, it is planned to recruit participants from Denbighshire CAMHS teams in North Wales.

A6-2. Summary of main issues. *Please summarise the main ethical and design issues arising from the study and say how you have addressed them.*

Capacity: As these are vulnerable adolescents with complex mental health issues, it was decided crucial to ascertain whether a participant had capacity to consent to take part before they were approached by the researcher. Therefore a capacity form has been developed and this will be completed by a qualified clinician known to the adolescent.

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Consent: Information sheets have been developed and will be given to all potential participants. These forms invite the adolescent to ask further questions should they have any. After reading the information all adolescent participants will be asked to read and sign a consent form.

Assent: Information sheets for parents/guardians of potential participants have been developed. Assent forms have been developed for parents/guardians to read and sign if the adolescent is under 16 years of age.

Incentives: It has been noted in various journals that adolescents, particularly adolescent males have been difficult to engage in research (Rosenstein and Horowitz, 1996). Therefore, the use of incentives is planned as a way of encouraging a variety of participants to take part. It is accepted that ethical considerations must be taken into account when incentives are involved in research. Grant and Sugarman (2004) provide a detailed examination of the ethical issues when using incentives with human subjects. The authors indicate that incentives only become ethically inappropriate if 1) the incentive will constitute undue influence or act as a coercive inducement to participate and 2) if the use of the incentive will compromise the dignity of the subject. The relatively small value of the incentive (£5) within this research study is considered not to cause undue influence on an adolescent to take part. Additionally, the adolescent's dignity will not be compromised as the incentive will be described within the participant information sheet as a thank you for their time and sharing their experiences.

Confidentiality: Information gathered during the interviews will not be shared with the clinician or mental health practitioner working with the participant or their parents/guardians. The only exception to this would be if a risk issue were discussed. As Dr Michaela Swales' name will appear on the participant information sheet, and it is noted some participants may see Dr Swales as a therapist, all participants will be informed that their details will be anonymised and all identifiers will be removed before it is shared with the research team.

Risk: Individual adolescents will already be known to either NWAS or CAMHS and risk assessments will have already been completed. In the case of individuals where risk has been identified, these individuals will either be excluded from the study or interviews will be conducted with another member of staff present. It is hoped all interviews will be conducted in consulting rooms within departments rather than home visits to minimise risk.

Will the interview interfere with therapy: Some individuals may be attending Dialectical Behavioural Therapy (DBT) and are learning to focus on the present and not past events. In order to limit any issues arising from this, the interview will take a "here and now" approach. By adopting this approach, this will also have other benefits. It will mean that individuals are talking about their experiences as adolescents and not remembering experiences from childhood. Also it may be less distressing for the adolescent to focus on the present rather than past difficulties.

De-briefing: Due to the nature of the topics that will be covered in the interview, it is possible that individual may become distressed. A comprehensive debriefing will be conducted at the end of session regardless of whether the participant is visibly distressed to ensure every participant leaves the interview in a satisfactory state of well-being.

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

This project will attempt to increase the psychological understanding of the experience of the mental health issues within an adolescent population. Therefore, the principle aim of this research project is to qualitatively assess how adolescents' view themselves, their difficulties, their identity and their personality.

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

The secondary aims of this project are

- to consider whether adolescents would find a diagnosis useful or useless to their understanding of their mental health difficulty.
- to qualitatively assess how adolescents with mental health difficulties view the challenges within their relationships, and the impact these challenges may have on their mental health difficulties.
- to look at individual's relational aspects of themselves, how they appraise their personalities in the light of how others see them.

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

Mental health difficulties in adolescents are associated with significant impairments in functioning in school, at home, with peers and within society. It is hoped service recommendations following this research project, will suggest more

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diagnosis and their relationships with others. This can then inform clinical interventions with adolescents, the potential sharing of a diagnosis and the therapeutic relationship.

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

A qualitative research design has been selected because of the wealth of information hoping to be collected. Qualitative methods provide techniques to more precisely represent the complex interactions that occur between contexts and individuals. It allows participants to freely identify the factors that are influential in their experiences and describe how these factors interact with other situational and individual factors which impact on their psychological experience.

All adolescents taking part in the study will be known to clinicians within either NWAS or CAMHS, therefore only those considered to have capacity will be approached to take part. However as a safeguard, the participant consent form will act as an additional capacity to consent check and if there is any doubt whether a participant has the capacity to consent the research interview will not take place.

Participants recruited from the inpatient unit at North Wales Adolescent Service (NWAS), Abergele. Adolescents within this service will be approached by Freya and will receive information about the research project and asked to take part.

If it is required to recruit participants from CAMHS, Freya will visit Denbighshire CAMHS to inform the team of the research and ask the clinicians if they have any appropriate adolescents who could be approached to take part. The possibility of taking part in the research will be first raised by the clinician with the adolescent.

The interested individuals will be sent or given information sheets and asked to meet with the Freya, to discuss their potential involvement. Participants will be informed they will not receive any individual feedback from their interview, however they will be offered a brief review of the topics that were raised in the research in general should they request it. Each participant will be offered a small incentive of a £5 voucher of his or her choice, to take part.

Parents/guardians will be consulted and permission will be obtained should the adolescent be under 16 years of age. Both the adolescent and parent/guardian must consent for the adolescent to take part. Once informed consent is obtained the interview will be arranged, however consent will also be checked at the start of the interview.

Although it is not expected that an individual will find the interview distressing, before commencing the interview participants will be asked to identify a supportive individual they can access should they be distressed after the interview. If they are unable to name such an individual, the interview will not take place.

The interview will consist of 2 parts. A demographic questionnaire will be administered at the start of the session to ascertain each participant's age, ethnicity, diagnosis (if they have received one) and other relevant information. These questions will be sensitive to any individual issue noted within clinical files.

A semi-structured interview will then be conducted. This interview schedule has been developed with Jaci Huws (Research Fellow); the interview will cover themes of insight into current level and type of difficulty, identity, personality, ideas of receiving a diagnosis and difficulties within relationships. The interview will be flexible, open and participant lead to enable the richest data to be collected. It is estimated that the interviews will not last more than one and a half hours.

All interviews will be audio-recorded.

At the end of each session all participants will have the opportunity to discuss their feelings about the interview and if it effected them in any way. Should the participants require further support after the interview has ended they will be reminded to speak to their supportive individual.

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

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- ☒ Design of the research
☐ Management of the research
☐ Undertaking the research
☐ Analysis of results
☐ Dissemination of findings
☐ None of the above

Give details of involvement, or if none please justify the absence of involvement.

It has been decided that in order to shape some of the questions, the questionnaire would be administered to 1 or 2 adolescents from the general public and ascertain their views on the questions, language used and structure.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

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

Inclusion criteria for the study will be individuals between the ages of 12 to 17 years with a range of psychological difficulties, including anxiety, depression, eating disorders, and emerging personality disorder.

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

Individuals with Autistic Spectrum Disorders, single episode PTSD and learning disabilities will not be included because the researcher feels these are distinct groups that should be investigated independently.

RESEARCH PROCEDURES, RISKS AND BENEFITS

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

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

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

Intervention or procedure	1	2	3	4
Discussing the research and asking potential participants to take part	1	NA	20 mins	Freya Spicer-White at NWAS or within a CAMHS department
Seeking consent	1	NA	20 minutes	Freya Spicer-White at NWAS or within a CAMHS department
Audio-recorded interview	1	NA	90 minutes approx.	Freya Spicer-White at NWAS or within a CAMHS department

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

It is hoped that the time span between first introducing a participant to the research and completing the interview will not be more than 2 weeks. The interviews themselves should not take longer than 90 minutes.

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

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

Distress: It is possible as participants will be discussing their mental health difficulties, some may become distressed as a result. The interviews will focus on their present day experiences as this may limit distress associated with any past trauma. All participants will be told they can withdraw at any time during the interview and that they can opt out of answering a question if they will be unduly distressed by it. All participants will be given an opportunity to discuss their experience of the interview and any distress that has arisen as a result. As an additional safeguard, all participants will be asked to identify a supportive individual before the interview takes place in order to ensure each participant has some support should they require it.

Inconvenience: As far as possible the interview times will be arranged to best suit the participant. The interviews times will also be sensitive to the times of the year when adolescents are sitting scholastic examinations.

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

☒ Yes ☐ No

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

Sensitive issues: All participants will be told they can withdraw at any time during the interview and that they can opt out of answering a question if they will be unduly embarrassed or upset by it.

Criminal disclosures: Participants will be informed in the consent form that confidentiality will only be broken if either the participant or someone else is at risk of harm or if the participant discloses they have committed a serious crime.

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

It is not planned for the participants to benefit from taking part in the interview. However some participants may experience the interview as enjoyable and/or cathartic. The participants may also like the idea of having their voices heard in relation to their own difficulties and also contributing to a body of research that may have an impact on future adolescent mental health care.

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

As the chief investigator will be conducting interviews with adolescents who may display challenging behaviours there is a small risk to the researcher but this would not exceed risk in typical clinical practice. All participants will already be known to services and risk assessments will have been completed. In the case of individuals where risk has been identified, these individuals will either be excluded from the study or interviews will be conducted with another member of staff present. It is hoped all interviews will be conducted in consulting rooms within departments rather than home visits to minimise risk.

RECRUITMENT AND INFORMED CONSENT

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

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

Potential participants will be recruited initially from NWAS. Freya, the chief investigator will first inform staff at NWAS of the project and staff will be asked to identify all adolescents who meet the inclusion criteria and would be appropriate to take part in the interview. Should it be necessary to use participants from Denbighshire CAMHS, Freya visit this CAMHS department, any adolescents identified by the clinicians will receive a letter outlining the research,

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including a reply slip and stamped addressed envelope. If a potential participant opts in, Freya will then arrange a meeting with them.

Freya will meet with the adolescents to inform them about the research and discuss the incentive. If agreeable but the adolescent is under 16 years of age, the adolescent's parent/guardian will be contacted by Freya, who will give information about the research. All adolescent participants will be required to sign a consent form and parental/guardian assent forms must be signed should the participant be under 16.

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

☐ Yes ☒ No

Please give details below:

It will not be required for the researcher to review any identifiable personal information as the potential adolescent participants will be recommended by clinicians who are aware of the research's aims and the inclusion and exclusion criterion.

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

☐ Yes ☒ No

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

Freya will usually be the first to approach a potential participant. However the research may be mentioned to potential participants by the clinician who has recommended them but this will be up to individual clinician.

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

☒ Yes ☐ No

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

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

All adolescents taking part in the study will be known to clinicians within either NWS or Denbighshire CAMHS, therefore only those considered to have capacity will be approached to take part.

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

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

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

☒ Yes ☐ No

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

When participants first meet with Freya to discuss taking part, if a potential participant declines no further contact will be made, if the potential participant accepts an appointment will be made to conduct the interview. However, the client will be reminded they can change their mind at any time. If the client is unsure they will be given one week to consider taking part, after which Freya will contact them either by telephone or in person to see if they wish to take part or not.

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

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Individuals with a Learning Disability are excluded from the research because it is assumed they would have a different experience to adolescents with a mental health difficulty. Additionally, due to the qualitative nature of the research, participants will need to display adequate receptive and expressive English language skills.

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?

Unfortunately, as the chief research, Freya does not currently speak fluent Welsh, all participants will be need to understand/use written and spoken English.

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

- ☐ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ☒ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ☐ The participant would continue to be included in the study.
- ☐ Not applicable – informed consent will not be sought from any participants in this research.

Further details:

Informed consent will be checked before the participant takes part in the interview. If at a later date a participant loses capacity this would not be considered a problem because they would not be required to take part in any further research.

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

CONFIDENTIALITY

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

Storage and use of personal data during the study

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

- ☐ Access to medical records by those outside the direct healthcare team
- ☒ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☒ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☒ Publication of direct quotations from respondents
- ☐ Publication of data that might allow identification of individuals
- ☒ Use of audio/visual recording devices
- ☒ Storage of personal data on any of the following:
- ☒ Manual files including X-rays
 - ☐ NHS computers
 - ☐ Home or other personal computers
 - ☐ University computers
 - ☐ Private company computers

☒ Laptop computers

Further details:

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

All consent and assent forms will have a participant's name and a unique identification number.

All notes kept by Freya during the interview, the audio-recordings and the transcripts will be identified by number only.

Transcripts will have all identifying data removed.

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

Only the research team, including Dr Swales, Dr Huws and Freya Spicer-White, will have access to the participants personal data.

Storage and use of data after the end of the study

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

- ☐ Less than 3 months
- ☐ 3 – 6 months
- ☐ 6 – 12 months
- ☒ 12 months – 3 years
- ☐ Over 3 years

If longer than 12 months, please justify:

The data will be kept for two years, this is because as stated in the information sheet, a wealth of data can be obtained using qualitative data and Dr Michaela Swales may wish to re-visit the data.

INCENTIVES AND PAYMENTS

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

☒ Yes ☐ No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.

McGrant and Sugarman (2004) provide a detailed examination of the ethical issues when using incentives with human subjects. The authors indicate that incentives only become ethically inappropriate if 1) the incentive will constitute undue influence or act as a coercive inducement to participate and 2) if the use of the incentive will compromise the dignity of the subject. The relatively small value of the incentive (£5) within this research study is considered not to cause undue influence on an adolescent to take part. Additionally, the adolescent's dignity will not be compromised as the incentive will be described within the participant information sheet as a thank you for their time and sharing their experiences. The adolescent will receive a £5 voucher upon completion of the interview.

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

☐ Yes ☒ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g.

Young people's experiences of mental health difficulties

financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

☐ Yes ☒ No

NOTIFICATION OF OTHER PROFESSIONALS

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

☐ Yes ☒ No

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

PUBLICATION AND DISSEMINATION

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

☐ Yes ☒ No

Please give details, or justify if not registering the research.
It is hoped the data will be published in an academic journal.

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

- ☒ Peer reviewed scientific journals
- ☐ Internal report
- ☒ Conference presentation
- ☐ Publication on website
- ☐ Other publication
- ☐ Submission to regulatory authorities
- ☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- ☐ No plans to report or disseminate the results
- ☐ Other (please specify)

A53. Will you inform participants of the results?

☐ Yes ☒ No

Please give details of how you will inform participants or justify if not doing so.
However, as stated in the information sheet, if participants requests some feedback from the research they will be given a brief outline of the findings and clinical implications.

5. Scientific and Statistical Review

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

- ☐ Independent external review
- ☐ Review within a company
- ☐ Review within a multi-centre research group
- ☒ Review within the Chief Investigator's institution or host organisation

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- ☐ Review within the research team
☐ Review by educational supervisor
☐ Other

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

Bangor University has given ethical approval for this study.

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

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

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

Total UK sample size: 10

Total international sample size (including UK):

Total in European Economic Area:

Further details:

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

The study will require between 8-10 participants. It is felt this is the optimum amount of participants for two reasons. Firstly on a methodological level, fewer participants will enable the project to gather detailed, rich data about the complex experiences of individuals with mental health difficulties. Interpretative Phenomenological Analysis usually has a small number of participants in order to reveal something of the experience of each participant. Therefore by using this reasonably heterogeneous sample, the project can examine the convergence and divergence within the group.

Secondly, the North Wales Adolescent Service (NWAS) has 18 beds therefore at any one time there will be 18 adolescents as potential participants. It is hoped, as my study will run over a year, that the population within the inpatient unit will not be static, thus allowing access to more adolescents as some are discharged and others are admitted. However it is realistically anticipated that at least half of adolescents within the unit may decline or be inappropriate for inclusion within the study.

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

Interpretative phenomenological analysis (IPA) has been selected as the qualitative research method because the research question is investigating the lived experience of adolescent's with mental health difficulties, and hoping to develop an understanding of how they make sense of their difficulties. Within IPA the researcher is engaged in a double hermeneutic, because the researcher is trying to make sense of the participant trying to make sense of their lived experience. Through this, IPA is committed to a detailed examination of each individual's experience. IPA also allows the semi-structured interview to be used flexibly to allow a greater wealth and richness of data to be collected. Therefore, this project is hoping to collect detailed data regarding the complexities and ranges of issues within the experience of an adolescent with mental health difficulties.

The audio-taped interviews will be transcribed as a verbatim record of the data. Smith, Flowers and Larkin (2009) state there is no clear right or wrong way to analysis the data, but they encourage IPA researchers to be innovative to their approach to analysis. This project is hoping to use either a line-by-line analysis of the discussed experiences and understandings of each participant or by identifying emerging themes and patterns within the data and addressing the convergences and divergences that occur.

6. MANAGEMENT OF THE RESEARCH

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

	Title Forename/Initials Surname
	Dr Jaci Huws
Post	Lecturer in Adult Nursing/ Research Fellow
Qualifications	
Employer	The University of Bangor
Work Address	Fron Heulog Bangor
Post Code	LL57 2EF
Telephone	01248383155
Fax	
Mobile	
Work Email	j.huws@bangor.ac.uk

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status: ☐ NHS or HSC care organisation

Commercial status:

☒ Academic

☐ Pharmaceutical industry

☐ Medical device industry

☐ Local Authority

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

☐ Other

If Other, please specify:

Contact person

Name of organisation School of Psychology, Bangor University

Given name Oliver

Family name Turnbull

Address Brigantia Building

Town/city Bangor

Post code LL57 2EF

Country UNITED KINGDOM

Telephone 01248383670

Fax 01248382599

E-mail o.turnbull@bangor.ac.uk

Is the sponsor based outside the UK?

☐ Yes ☒ No

Where the lead sponsor is not established within the UK, a legal representative in the UK may need to be appointed. Please consult the guidance notes.

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

☐ Yes ☒ No

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

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

	Title Forename/Initials Surname
	Dr Michaela Swales
Organisation	Besti Cadwaldr University Health Board
Address	North Wales Adolescent Service
	Llanfair Road
	Abergele
Post Code	LL22 8DP
Work Email	m.swales@bangor.ac.uk
Telephone	01745448700
Fax	
Mobile	

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

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

Planned start date: 03/01/2011

Planned end date: 31/07/2012

Total duration:

Years: 1 Months: 6 Days: 28

A71-1. Is this study?

☐ Single centre
☒ Multicentre

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

- ☐ England
☐ Scotland
☒ Wales
☐ Northern Ireland
☐ Other countries in European Economic Area

Total UK sites in study 2

Does this trial involve countries outside the EU?

☐ Yes ☒ No

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

- ☐ NHS organisations in England
- ☒ NHS organisations in Wales 2
- ☐ NHS organisations in Scotland
- ☐ HSC organisations in Northern Ireland
- ☐ GP practices in England
- ☐ GP practices in Wales
- ☐ GP practices in Scotland
- ☐ GP practices in Northern Ireland
- ☐ Social care organisations
- ☐ Phase 1 trial units
- ☐ Prison establishments
- ☐ Probation areas
- ☐ Independent hospitals
- ☐ Educational establishments
- ☐ Independent research units
- ☐ Other (give details)

Total UK sites in study:

A76. Insurance/ indemnity to meet potential legal liabilities

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

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

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

- ☐ NHS indemnity scheme will apply (NHS sponsors only)
- ☒ Other insurance or indemnity arrangements will apply (give details below)

Bangor University has the appropriate level of insurance cover for this research project.

Please enclose a copy of relevant documents.

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

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

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

Young people's experiences of mental health difficulties

Bangor University has the appropriate level of insurance cover for this research project.

Please enclose a copy of relevant documents.

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

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

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

Bangor University has the appropriate level of insurance cover for this research project.

Please enclose a copy of relevant documents.

PART B: Section 7 - Children

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

Some participants may be within the 12-15 years age group. This is because the research is specifically focusing on the lived experiences of young people with a mental health difficulty.

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

There are no control participants as this is a qualitative design.

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

Both the young person and their parents/guardians will be required to read the participants information sheets and sign the consent and assent forms. Only if both parties agree will the interview take place.

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

Both the participant information and consent forms have been written according to the developmental appropriate level of young people between the ages of 12-15. The researcher will meet all participants individually to explain the information and consent forms in further detail, which can be simplified and repeated should a young person require this.

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

PART C: Overview of research sites

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

Research site		Investigator/ Collaborator/ Contact	
Institution name	North Wales Adolescent Service	Title	Mrs
Department name	N/A	First name/ Initials	Freya
Street address	Llansfair Road	Surname	Spicer-White
Town/city	Abergele		
Post Code	LL22 8DP		
Institution name	Denbighshire CAMHS	Title	Mrs
Department name	The CAMHS Clinic	First name/ Initials	Freya
Street address	Sarn Lane	Surname	Spicer-White
Town/city	Bodelwyddan		
Post Code	LL18 5UJ		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
 - 1 Will be held by the main REC or the GTAC (as applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
 - 1 May be disclosed to the operational managers of review bodies, or the appointing authority for the main REC, in order to check that the application has been processed correctly or to investigate any complaint.
 - 1 May be seen by auditors appointed to undertake accreditation of RECs.
 - 1 Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

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

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

- ☒ Chief Investigator
- ☐ Sponsor
- ☐ Study co-ordinator

Young people's experiences of mental health difficulties

- ☐ Student
- ☐ Other – please give details
- ☐ None

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

Optional – please tick as appropriate:

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

Signature:

Print Name: Freya Spicer-White

Date: (dd/mm/yyyy)

D2. Declaration by the sponsor's representative

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

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.
7. I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Signature:

Print Name:

Post:

Organisation:

Date: (dd/mm/yyyy)

D3. Declaration for student projects by academic supervisor

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.
2. I undertake to fulfil the responsibilities of the Chief Investigator and the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.
3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.
4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Signature:

Print Name:

Post:

Organisation:

Date: (dd/mm/yyyy)

North Wales Research Ethics Committee - West: Provisional opinion letter: not
available in electronic format (5 pages)

R&D Internal Review Panel approval letter: not available in electronic format (2 pages)

Letter detailing amendments

Mrs Freya Spicer-White
Trainee Clinical Psychologist
North Wales Adolescent Service
Abergele Hospital
Llansfair Road
LL22 8DP

North Wales Research Ethics Committee - West
Bangor
Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor
LL57 2PW

13th April 2011

Dear Mr David Owen

Study Title: **A qualitative investigation into identity, personality, diagnosis and relationships of young people with mental health difficulties.**

REC reference number: 11/WA/0036

Following the recommendations of the Research Ethics Committee from the meeting held on 17th March 2011, I am writing to clarify some of the steps I have taken to meet the committee's concerns.

The participant and parent/guardian information sheets and consent and assent forms have been reviewed and a second version has been developed that follows the format recommended in the NRES guidelines. A copy of each form is attached, these include:

Participant Information Sheet: Version 2
Participant Consent Form: Version 2
Parent/ Guardian Information Sheet: Version 2
Assent Form: Version 2

ii. The revised information sheets now contain less complex language and the expression "voices heard" has been changed to "views heard".

iii. The information sheets have been re-phrased to emphasis participation rather than completion in order to obtain the £5 voucher.

iv. The Parent/ Guardian Information Sheet now contains less jargon and complex expressions, also attempts have been made to make it as accurate as possible when focusing on the child's participation and decision to withdraw.

v. The Parent/ Guardian Information Sheet now contains more information on what will occur should a child become distressed.

vi. The Consent and Assent forms now both explicitly ask consent for audio-recording.

vii. All Information and Consent forms now state that "Please note, **if you choose not to take part or withdraw from the research, this will not affect your current or future treatment in any way**".

viii. The Assent forms now state "Do you understand that your child can stop taking part at any time?".

ix. All forms will be translated into Welsh once the final versions have been approved by the Research Ethics Committee.

I hope you will find that my revised forms meet your recommendations. I look forward to hearing from you.

Yours sincerely

Freya Spicer-White

North Wales Research Ethics Committee - West: Confirmation of ethical opinion

letter: not available in electronic format (3 pages).

R&D Internal Review Panel approval to continue letter: not available in electronic format (1 page)

Forms

Capacity Form

COLEG IECHYD A GWYDDORAU YMDDYGIAD
COLLEGE OF HEALTH AND BEHAVIOURAL SCIENCES

YSGOL SEICOLEG
SCHOOL OF PSYCHOLOGY

RHAGLEN SEICOLEC CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME



PRIFYSGOL
BANGOR
UNIVERSITY

Young People's Experiences of Mental Health Difficulties

My name is Freya Spicer-White, I am a Trainee Clinical Psychologist at [Bangor University](#) and I work within the Betsi Cadwaladr University Health Board. Myself, Dr Michaela Swales (Consultant Clinical Psychologist) and [Dr Jaci Huws \(Lecturer\)](#) are working on a qualitative research project investigating how [young people](#) experience mental health difficulties. I will be interviewing approximately [8-10](#) adolescents about their experiences, their views and their understanding of what it is like to have a mental health difficulty. The interviews should take between 60 to 90 minutes. Participants will be asked questions about their personality, their difficulties and their relationships with others. The sessions will be audio-recorded and later transcribed.

If you have any questions or concerns please raise these with myself or a member of the research team. If, after further discussion, you would like additional information about the study, a copy of the research proposal can be provided.

Capacity Assessment

Before approaching I am requesting your professional opinion about whether he/she has capacity to give consent to take part in this study.

I,, believe that does/does not have the capacity to consent to take part in this study.

Signed Date

Participant Information Sheet: English

COLEG IECHYD A GWYDDORAU YMDDYGIAD
COLLEGE OF HEALTH AND BEHAVIOURAL SCIENCES

YSGOL SEICOLEG
SCHOOL OF PSYCHOLOGY

RHAGLEN SEICOLEC CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME



PRIFYSGOL
BANGOR
UNIVERSITY

Young People's Experiences of Mental Health Difficulties

Participant Information Sheet: Part 1.

My name is Freya Spicer-White, I am a Trainee Clinical Psychologist at Bangor University and I work within the Betsi Cadwaladr University Health Board. I am inviting you to take part in a research project that is looking at how young people experience mental health difficulties.

Before you decide if you want to take part, it's important to understand why the research is being done and what is involved for you. So please consider this leaflet carefully. Talk to your family, friends, or a staff member from CAMHS if you want to.

Why is this research being done?

I am part of a research team, including Dr Michaela Swales (Consultant Clinical Psychologist) and Dr Jaci Huws (Lecturer at Bangor University) and we want to find out what it is like for a young person, like yourself, to have mental health difficulties. We

hope to find out things such as have you found receiving a diagnosis helpful?

There is no medical procedure or medicine that we are testing- we simply want to find out your point of view.

Why have I been invited to take part?

You have been chosen because you are currently receiving treatment for some difficulties you have been having. I am hoping to speak to between 8 and 10 other young people like you about their experiences.

Do I have to take part?

No, taking part is completely up to you. I will ask you for your consent and then ask you to sign a form. I will give you a copy of this information sheet and your signed sheet to keep.

If you do not want to take part, you do not have to give a reason and you will not be pressured into taking part. Also you are free to stop taking part at any point during the research without giving a reason. Please note, **if you choose not to take part or withdraw from the research, this will not affect your current or future treatment in any way.**

If you participate in the interview, you will be given a £5 voucher as a thank you for your time and effort.

What will happen to me if I take part?

If you agree to take part, I will ask you to answer some questions. There aren't any right or wrong answers, I just want to hear your

opinion and about your experiences. The discussion should take between 60 to 90 minutes. You will be asked questions about the type of person you see yourself as, any difficulties you may have and your relationships with others. Please be aware that the sessions will be audio-recorded using a digital recorder and later recordings will be written out on a computer.

Is there anything to be worried about if I take part?

It is possible you may become upset or unsettled during the interview, as you may discuss emotional topics. Before we start I will ask you to identify someone in your life who could support you if you feel upset. If you do become upset, I will spend some time with you either during the interview when you are upset or at the end of the interview to help you. I will also help you access the person you identified as a source of support if you are still distressed when we are finished.

What are the benefits of taking part?

The interview will not be part of a CAMHS intervention and it is not assumed that it will be of direct benefit to you. However, some young people may wish to have their views heard, and the interview may be a positive experience. It is hoped the research will give us ideas about how best we can work with young people. We can then try to make services for young people better.

My contact details are:

Freya Spicer-White, Trainee Clinical Psychologist
School of Psychology
Bangor University
Brigantia Building

LL57 2AS
Telephone: 07586860919

Thank you for reading this so far- if you are still interested, please read part 2.

Young People's Experiences of Mental Health Difficulties

Participant Information Sheet: Part 2

This part of the information sheet contains more information that you need to know if you want to take part.

What happens when the research stops?

Nothing, once the interview is finished you will not be asked for anything further.

What if there is a problem or something goes wrong?

The only problem that might occur is that you may become distressed during the interview. We have tried to make sure that the questions will not make you upset, however if you do become upset the interview can be paused or stopped should you want. Also at the end of the interview you will be given a chance to discuss anything that may have upset you and hopefully you will leave the interview feeling OK. However, if you still feel upset then I will help to find the person you identified at the start as someone who could provide you with more support.

Will anyone else know I'm doing this?

All the information you share with me will be confidential- this means that no-one outside the study will know what we talked about.

Confidentiality will only be broken in circumstances where you or other people may be at serious risk, and the researcher may have to tell the appropriate people.

What will happen to what I say?

What you discuss with me in the interview will be recorded on a Digital recorder. This recorder will be kept by me and I will then type out everything we said onto a computer word document. Once your interview has been written up, I will delete your recording.

When your interview is written up, I will take out all the information that may identify you, such as your name. The written interviews will then be looked at by Dr Jaci Huws (a University lecturer) and me. We will then look at the things that you spoke about and the things you felt were important. Whatever we find out from this research will be used as part of my training as a Clinical Psychologist. The findings may also be published in an academic journal (which is like a newspaper that reports new research). Any information in reports or journals would always be used in a way that would not allow you to be identified individually by anyone else.

The written interviews will be kept at the North Wales Adolescent Service for up to 2 years and then they will be

destroyed. The information may be looked at again during those years by one of the researchers.

Who is organising and funding the research?

Bangor University are organising and funding this research. It is forming part of my training on the North Wales Clinical Psychology Programme.

Who has reviewed the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure the research is fair. This project has been checked by the North Wales Research Ethics Committee- West.

What do I do now?

Think about the information on this sheet, and ask me if you have any questions. If, after our discussion, you would like more information about the research this can be provided.

If you agree to take part, please sign the consent form. The consent form will be the only form with your name on and it will be filed separately from all other information.

If you wish to complain following reading this information sheet or at any point during the research the contact details are below.

If you have a complaint to the NHS you can write a letter to...

Complaints Department
Betsi Cadwaladr University Health Board

Ysbyty Gwynedd
Bangor
Gwynedd
LL57 2PW

Email...

complimentsandcomplaints.bcu@wales.nhs.uk

Or telephone...

Hospital and community services in Conwy and Denbighshire
(01745) 534140

If you have a complaint to Bangor University you can write a letter to...

Isabel Hargreaves
School of Psychology
Bangor University
Brigantia Building
LL57 2AS

Email...

i.hargreaves@bangor.ac.uk

Or telephone 01248 388365

Thank you for your time.

Participant Information Sheet: Welsh

COLEG IECHYD A GWYDDORAU YMDDYGIAD
COLLEGE OF HEALTH AND BEHAVIOURAL SCIENCES

YSGOL SEICOLEG
SCHOOL OF PSYCHOLOGY

RHAGLEN SEICOLEC CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME



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UNIVERSITY

Profiadau Pobl Ifanc o Anawsterau Iechyd Meddwl

Taflen Wybodaeth i'r Rhai sy'n Cymryd Rhan: Rhan 1.

F'enw i ydy Freya Spicer-White. Rwyf yn Seicolegydd Clinigol dan Hyfforddiant ym Mhrifysgol Bangor ac rwyf yn gweithio ym Mwrdd Iechyd Prifysgol Betsi Cadwaladr. Rwyf yn eich gwahodd i gymryd rhan mewn prosiect ymchwil sy'n edrych ar brofiadau pobl ifanc o ran anawsterau iechyd meddwl.

Cyn i chi benderfynu a ydych chi'n dymuno cymryd rhan, mae'n bwysig eich bod yn deall pam y gwneir yr ymchwil a beth fydd yn ei olygu i chi. Felly ystyriwch y daflen hon yn ofalus. Siaradwch efo'ch teulu, ffrindiau neu aelod o staff CAMHS os hoffech chi.

Pam fod yr ymchwil hwn yn cael ei wneud?

Rwyf i'n rhan o dîm ymchwil, sy'n cynnwys Dr Michaela Swales (Seicolegydd Clinigol Ymgynghorol) a Dr Jaci Huws (Darlithydd ym Mhrifysgol Bangor) ac rydym eisiau darganfod pa fath o brofiad ydy i rywun ifanc, fel chi, gael anawsterau iechyd meddwl. Rydym

yn gobeithio darganfod pethau fel a oedd cael diagnosis yn help i chi?

Dydyn ni ddim yn profi unrhyw driniaeth feddygol neu feddyginiaeth - yn syml rydym am gael eich barn.

Pam gefais i wahoddiad i gymryd rhan?

Cawsoch eich dewis oherwydd eich bod yn cael triniaeth ar hyn o bryd at rai anawsterau. Rwyf yn gobeithio siarad efo rhwng 8 a

10 o bobl ifanc eraill fel chi am eu profiadau.

Oes raid i mi gymryd rhan?

Na, eich dewis chi ydy cymryd rhan. Byddaf yn gofyn i chi am eich cydsyniad ac yna'n gofyn i chi arwyddo ffurflen. Byddaf yn rhoi copi o'r daflen wybodaeth hon i chi a'r daflen a arwyddwyd gennych chi i'w cadw.

Os nad ydych chi am gymryd rhan, does dim rhaid i chi roi rheswm ac ni fydd pwysau arnoch i gymryd rhan. Rydych hefyd yn rhydd i roi'r gorau i gymryd rhan ar unrhyw adeg yn ystod yr ymchwil heb roi rheswm. Sylwer, **os ydych chi'n dewis cymryd rhan neu'n tynnu'n ôl o'r ymchwil, fydd hyn ddim yn effeithio ar eich triniaeth bresennol neu driniaeth yn y dyfodol o gwbl.**

Os ydych chi'n cymryd rhan yn y cyfweiliad, byddwch yn cael tocyn £5 i ddiolch i chi am eich amser a'ch ymdrech.

Beth fydd yn digwydd i mi os byddaf yn cymryd rhan?

Os ydych chi'n cytuno i gymryd rhan, byddaf yn gofyn i chi ateb rhai cwestiynau. Does dim atebion cywir nac anghywir, yr unig beth ydw i am ei glywed ydy'ch barn ac am eich profiadau. Dylai'r drafodaeth gymryd rhwng 60 a 90 munud. Byddwch yn cael cwestiynau am y math o unigolyn ydych chi yn eich barn chi, unrhyw anawsterau sydd gennych a'ch perthynas efo pobl eraill. Cofiwch y caiff y sesiynau eu recordio ar dâp sain gan ddefnyddio peiriant recordio digidol ac yn ddiweddarach bydd y recordiadau'n cael eu hysgrifennu ar gyfrifiadur.

Oes yna unrhyw beth i boeni amdano os ydw i'n cymryd rhan?

Mae'n bosib y bydd hyn yn eich gwneud chi'n anhapus neu'n ansicr yn ystod y cyfweiliad, gan y byddwch efallai'n trafod pynciau emosiynol. Cyn i ni ddechrau byddaf yn gofyn i chi enwi rhywun yn eich bywyd a allai'ch cefnogi chi os ydych chi'n teimlo'n anhapus. Os ydych chi'n anhapus, byddaf yn treulio ychydig o amser efo chi un ai yn ystod y cyfweiliad pan ydych chi'n anhapus neu ar ddiwedd y cyfweiliad i'ch helpu. Byddaf hefyd yn eich helpu i gysylltu â'r un a enwyd gennych i'ch helpu os ydych yn dal i deimlo'n ddrwg ar ôl i ni orffen.

Beth yw manteision cymryd rhan?

Fydd y cyfweiliad ddim yn rhan o ymyriad gan CAMHS ac nid yw'n cael ei honni y bydd o fantais uniongyrchol i chi. Ond efallai y bydd rhai pobl ifanc yn dymuno mynegi eu barn ac efallai y bydd y cyfweiliad yn brofiad cadarnhaol. Y gobaith ydy y bydd yr ymchwil yn rhoi syniadau i ni am y ffordd orau o weithio efo pobl ifanc. Yna gallwn drio gwella gwasanaethau i bobl ifanc.

Dyma fy manylion i:

Freya Spicer-White, Seicolegydd Clinigol dan Hyfforddiant
Yr Ysgol Seicoleg
Prifysgol Bangor
Adeilad Brigantia
LL57 2AS
Ffôn: 07586860919

Diolch i chi am ddarllen hwn hyd yn hyn - os ydych yn dal i fod â diddordeb, darllenwch ran 2 os gwelwch yn dda.

Profiadau Pobl Ifanc o Anawsterau Iechyd Meddwl

Taflen Wybodaeth i'r Rhai sy'n Cymryd Rhan: Rhan 2

Yn y rhan hon o'r daflen wybodaeth mae mwy o wybodaeth y mae angen i chi ei gwybod os ydych am gymryd rhan.

Beth sy'n digwydd pan fo'r ymchwil yn gorffen?

Dim. Unwaith y bydd y cyfweiliad wedi gorffen ni fyddaf yn gofyn unrhyw beth arall i chi.

Beth os oes problem neu os aiff rhywbeth o'i le?

Yr unig broblem a allai ddigwydd ydy y gallech chi deimlo'n ddrwg yn ystod y cyfweiliad. Rydym wedi trio gwneud yn siŵr na fydd y cwestiynau'n eich gwneud yn anhapus, ond os ydych chi'n anhapus gellir rhoi'r gorau iddo am ychydig neu'n gyfan gwbl os hoffech chi. Hefyd ar ddiwedd y cyfweiliad byddwch yn cael siawns i drafod unrhyw beth a allai fod wedi'ch gwneud yn anhapus a'r gobaith ydy y byddwch yn gadael y cyfweiliad yn teimlo'n iawn. Ond os ydych chi'n dal i deimlo'n anhapus yna mi wnafr helpu i ddod

o hyd i'r un a enwyd gennych ar y dechrau fel rhywun a allai roi mwy o gefnogaeth i chi.

Fydd unrhyw un arall yn gwybod fy mod i'n gwneud hyn?

Bydd yr holl wybodaeth y byddwch yn ei rhannu efo fi yn gyfrinachol - mae hyn yn golygu na fydd neb y tu allan i'r astudiaeth yn gwybod am yr hyn y buom yn siarad amdano.

Yr unig adeg y caiff cyfrinachedd ei dorri ydy mewn amgylchiadau lle gallech chi neu bobl eraill fod mewn perygl mawr, ac y bydd yn rhaid i'r ymchwilydd ddweud wrth y bobl briodol.

Beth fydd yn digwydd i'r hyn fyddaf i'n ei ddweud?

Bydd yr hyn yr ydych yn ei drafod efo fi yn y cyfweiliad yn cael ei recordio ar beiriant digidol. Mi fydd y peiriant recordio'n cael ei gadw gen i ac mi fyddaf i wedyn yn teipio popeth a ddywedwyd gennym ar ddogfen word cyfrifiadur. Unwaith y bydd eich cyfweiliad wedi ei ysgrifennu, byddaf yn dileu'ch recordiad.

Pan fydd y cyfweiliad wedi ei ysgrifennu, byddaf yn tynnu allan yr holl wybodaeth a allai'ch adnabod, fel eich enw. Yna bydd Dr Jaci Huws (darlithydd yn y Brifysgol) a minnau'n edrych ar y cyfweiliadau ysgrifenedig. Byddwn wedyn yn edrych ar y pethau y buoch chi'n siarad amdanynt a'r pethau oedd yn bwysig yn eich barn chi. Bydd beth bynnag y byddwn yn ei ddarganfod o'r ymchwil hwn yn cael ei ddefnyddio fel rhan o'm hyfforddiant fel Seicolegydd Clinigol. Efallai hefyd y cyhoeddir y darganfyddiadau mewn cylchgrawn academiaidd (sydd yn debyg i bapur newydd sy'n adrodd am ymchwil newydd). Byddai unrhyw wybodaeth mewn adroddiadau neu gylchgronau bob amser yn cael eu defnyddio

mewn modd na fyddai'n gadael i unrhyw un arall eich adnabod yn unigol.

Cedwir y cyfweiliadau ysgrifenedig yng Ngwasanaeth Pobl Ifanc Gogledd Cymru am hyd at 2 flynedd ac yna cânt eu dinistrio. Efallai y bydd un o'r ymchwilwyr yn edrych ar y wybodaeth eto yn ystod y blynyddoedd hynny.

Pwy sy'n trefnu ac yn ariannu'r ymchwil?

Prifysgol Bangor sy'n trefnu ac yn ariannu'r ymchwil. Mae'n rhan o fy hyfforddiant i yn Rhaglen Seicoleg Glinigol Gogledd Cymru.

Pwy sydd wedi adolygu'r astudiaeth?

Cyn i unrhyw ymchwil fynd yn ei flaen mae'n rhaid i Bwyllgor Moeseg Ymchwil ei wirio. Maent yn gwneud yn siŵr fod yr ymchwil yn deg. Cafodd y prosiect hwn ei wirio gan Bwyllgor Moeseg Ymchwil Gogledd Cymru - Gorllewin.

Beth ydw i'n ei wneud yn awr?

Meddyliwch am y wybodaeth ar y daflen hon, a gofynnwch i mi os oes gennych chi unrhyw gwestiynau. Os, ar ôl ein trafodaeth, yr hoffech chi fwy o wybodaeth am yr ymchwil, gellir darparu hyn.

Os ydych chi'n cytuno i gymryd rhan, arwyddwch y ffurflen gydsynio os gwelwch yn dda. Y ffurflen gydsynio fydd yr unig ffurflen â'ch enw chi arni a chaiff ei ffeilio ar wahân i bob gwybodaeth arall.

Os hoffech chi gwyno ar ôl darllen y daflen wybodaeth hon neu ar unrhyw adeg yn ystod yr ymchwil mae'r manylion cyswllt isod.

Os oes gennych chi gwyn i'r *GIG* gallwch ysgrifennu llythyr at

Adran Cwynion
Bwrdd Iechyd Prifysgol Betsi Cadwaladr
Ysbyty Gwynedd
Bangor
Gwynedd
LL57 2PW

Ebost...

timpryderon.bcu@wales.nhs.uk

Neu ffoniwch ...

Gwasanaethau ysbytai a chymuned yng Nghonwy a sir Ddinbych
(01745) 534140

Os oes gennych chi gwyn i Brifysgol Bangor gallwch ysgrifennu llythyr at...

Isabel Hargreaves
Yr Ysgol Seicoleg
Prifysgol Bangor
Adeilad Brigantia
LL57 2AS

Ebost...

i.hargreaves@bangor.ac.uk

Neu ffoniwch 01248 388365

Diolch yn fawr am eich amser.

Participant Consent Form: English

COLEG IECHYD A GWYDDORAU YMDDYGIAD
COLLEGE OF HEALTH AND BEHAVIOURAL SCIENCES

YSGOL SEICOLEG
SCHOOL OF PSYCHOLOGY

RHAGLEN SEICOLEC CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME



PRIFYSGOL
BANGOR
UNIVERSITY

Freya Spicer-White, Trainee Clinical Psychologist
School of Psychology, Bangor University,
Dept. of Clinical Psychology, University of Bangor
Brigantia Building, LL57 2AS
Telephone: 07586860919

Young People's Experiences of Mental Health Difficulties
Participant Consent Form

Participant Number:

Has somebody else explained this project to you?	Yes/No
Do you understand what this project is about?	Yes/No
Have you asked all the questions you want?	Yes/No
Have you had your questions answered in a way you understand?	Yes/No
Do you understand it is OK to stop taking part at any time?	Yes/No
Are you happy to take part?	Yes/No
Are you happy to be audio-recorded as part of the research?	Yes/No

If any answers are "no" or you don't want to take part, don't sign your name!

If you do want to take part, you can write your name below

Participant Signature **Date**

Print Name

Signed on behalf of the researchers

Signed **Date**

Print Name

Participant Consent Form: Welsh

COLEG IECHYD A GWYDDORAU YMDDYGIAD
COLLEGE OF HEALTH AND BEHAVIOURAL SCIENCES

YSGOL SEICOLEG
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Profiadau Pobl Ifanc o Anawsterau Iechyd Meddwl
Ffurflen Gydsynio i'r Un sy'n Cymryd Rhan

Rhif yr Un sy'n Cymryd Rhan

Oes rhywun arall wedi egluro'r prosiect hwn i chi?	Oes/Na
Ydych chi'n deall am beth mae'r prosiect hwn?	Ydw/Nac ydw
Ydych chi wedi gofyn yr holl gwestiynau sydd gennych?	Do/Naddo
A atebwyd eich cwestiynau mewn ffordd yr ydych chi'n ei deall?	Do/Na
Ydych chi'n deall ei bod hi'n iawn i roi'r gorau i gymryd rhan ar unrhyw adeg?	Ydw/Nac ydw
Ydych chi'n fodlon cymryd rhan?	Ydw/Nac ydw
Ydych chi'n fodlon cael eich recordio ar dâp sain fel rhan o'r ymchwil?	Ydw/Nac ydw

Os oes unrhyw atebion yn "na" neu os nad ydych chi am gymryd rhan,
peidiwch ag arwyddo'ch enw!

Os ydych chi am gymryd rhan, gallwch ysgrifennu'ch enw isod

Llofnod yr Un sy'n Cymryd Rhan Dyddiad

Printiwch yr Enw

Arwyddwyd ar ran yr ymchwilyr

Arwyddwyd Dyddiad

Printiwch yr Enw

Diolch

Manylion Cysylltu

Freya Spicer-White, Seicolegydd Clinigol dan Hyfforddiant
Yr Ysgol Seicoleg, Prifysgol Bangor, Adran Seicoleg Glinigol, Prifysgol
Bangor
Adeilad Brigantia, LL57 2AS
Ffôn: 07586860919

Parental/Guardian Information Sheet: English

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Young People's Experiences of Mental Health Difficulties

Parental/Guardian Information Sheet: Part 1.

My name is Freya Spicer-White, I am a Trainee Clinical Psychologist at Bangor University and I work within the Betsi Cadwaladr University Health Board. I am inviting your child to take part in a research project that is looking at how young people experience mental health difficulties.

Before you agree that your child can take part, it's important that you understand why the research is being done and what is involved for your child. So please consider this leaflet carefully. Talk to your child, family, friends, or a staff member from CAMHS if you want to.

Why is this research being done?

I am part of a research team, including Dr Michaela Swales (Consultant Clinical Psychologist) and [Dr Jaci Huws](#) (Lecturer at Bangor University) and we want to find out what it is like for a young person to have mental health difficulties. We hope to find

out things such as whether a young person has found receiving a diagnosis helpful.

There is no medical procedure or medicine that we are testing- we simply want to find out your child's point of view.

Why has my child been invited to take part?

They have been selected because they are currently receiving treatment for some difficulties they have been having. I am hoping to speak to between 8 and 10 other young people about their experiences.

Does my child have to take part?

No, taking part is completely up to you and your child. I will ask you for your consent that your child can take part and then ask you to sign a form. I will give you a copy of this information sheet and your signed sheet to keep. Your child will also be asked to read an information sheet and sign a consent form.

I understand that if my child does not want to take part, they do not have to give a reason and they will not be pressured into taking part. Also my child is free to stop taking part at any point during the research without giving a reason. Please note, **if your child chooses not to take part or withdraws from the research, this will not affect their current or future treatment in any way.**

If your child participates in the interview, they will be given a £5 voucher as a thank you for their time and effort.

What will happen to my child if they take part?

If your child agrees to take part, I will ask them to answer some questions. There aren't any right or wrong answers, I just want to hear their opinion and about their experiences. The discussion should take between 60 to 90 minutes. Your child will be asked questions about the type of person they see themselves as, any difficulties they may have and about their relationships with others. Please be aware that the sessions will be audio-recorded using a digital recorder and later recordings will be written out on a computer.

Is there anything to be worried about if my child takes part?

It is possible your child may become upset or unsettled during the interview, as they may discuss emotional topics. Before we start I will ask your child to identify someone in their life who could support them if they felt upset. If your child does become upset, I will spend some time with your child either during the interview when your child is upset or at the end of the interview to help your child. I will also help your child access the person they identified as a source of support if they are still distressed when we are finished.

What are the benefits of taking part?

The interview will not be part of a CAMHS intervention and it is not assumed that it will be of direct benefit to your child. However, some young people may wish to have their views heard, and the interview may be a positive experience. It is hoped the research will give us ideas about how best we can work with young people. We can then try to make services for young people better.

My contact details are:

Freya Spicer-White, Trainee Clinical Psychologist
School of Psychology
Bangor University
Brigantia Building
LL57 2AS
Telephone: 07586860919

Thank you for reading this so far- if you are still interested, please read part 2.

Young People's Experiences of Mental Health Difficulties

Parental/Guardian Information Sheet: Part 2

This part of the information sheet contains more information that you need to know if your child wants to take part.

What happens when the research stops?

Nothing, once the interview is finished your child will not be asked for anything further.

What if there is a problem or something goes wrong?

The only problem that might occur is that your child may become distressed during the interview. We have tried to make sure that the questions will not make your child upset, however if your child does become upset the interview can be paused or stopped should they want. Also at the end of the interview your child will be given a chance to discuss anything that may have upset them and

hopefully they will leave the interview feeling OK. However, if your child still feels upset then I will help them to find the person they identified at the start as someone who could provide support.

Will anyone else know my child is doing this?

All the information your child shares with me will be confidential- this means that no-one outside the study will know what we talked about.

Confidentiality will only be broken in circumstances where your child or other people may be at serious risk, and the researcher may have to tell the appropriate people.

What will happen to what my child says?

What is discussed with me in the interview will be recorded on a Digital recorder. This recorder will be kept by me and I will then type out everything that was said onto a computer word document. Once the interview has been written up, I will delete your child's recording.

When the interview is written up, I will take out all the information that may identify your child, such as their name. The written interviews will then be looked at by Dr Jaci Huws (a University lecturer) and me. We will then look at the things that your spoke about and the things they felt were important. Whatever we find out from this research will be used as part of my training as a Clinical Psychologist. The findings may also be published in an academic journal. Any information in any reports or journals would always be used in a way that would not allow your child to be identified individually by anyone else.

The written interviews will be kept at the North Wales Adolescent Service for up to 2 years and then they will be destroyed. The information may be looked at again during those years by one of the researchers.

Who is organising and funding the research?

Bangor University are organising and funding this research. It is forming part of my training on the North Wales Clinical Psychology Programme.

Who has reviewed the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure the research is fair. This project has been checked by the North Wales Research Ethics Committee- West.

What do I do now?

Think about the information on this sheet, and ask me if you have any questions. If, after our discussion, you would like more information about the research this can be provided.

If you agree that your child can take part, please sign the consent form. The consent form will be the only form with your child's name on and it will be filed separately from all other information.

If you wish to make a formal complain following reading this information sheet or at any point during the research the contact details are below.

If you have a complaint to the NHS you can write a letter to...

Complaints Department
Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Bangor
Gwynedd
LL57 2PW

Email...

complimentsandcomplaints.bcu@wales.nhs.uk

Or telephone...

Hospital and community services in Conwy and Denbighshire
(01745) 534140

If you have a complaint to Bangor University you can write a letter to...

Isabel Hargreaves
School of Psychology
Bangor University
Brigantia Building
LL57 2AS
Email...
i.hargreaves@bangor.ac.uk

Or telephone 01248 388365

Thank you for your time.

Parental/Guardian Information Sheet: Welsh

COLEG IECHYD A GWYDDORAU YMDDYGIAD
COLLEGE OF HEALTH AND BEHAVIOURAL SCIENCES

YSGOL SEICOLEG
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Profiadau Pobl Ifanc o Anawsterau Iechyd Meddwl

Taflen Wybodaeth i Rieni/Gwarcheidwaid Rhan 1.

F'enw i ydy Freya Spicer-White. Rwyf yn Seicolegydd Clinigol dan Hyfforddiant ym Mhrifysgol Bangor ac rwyf yn gweithio ym Mwrdd Iechyd Prifysgol Betsi Cadwaladr. Rwyf yn gwahodd eich plentyn i gymryd rhan mewn prosiect ymchwil sy'n edrych ar brofiadau pobl ifanc o ran anawsterau iechyd meddwl.

Cyn i chi gytuno bod eich plentyn yn gallu cymryd rhan, mae'n bwysig eich bod yn deall pam y gwneir yr ymchwil a beth fydd yn ei olygu i'ch plentyn. Felly ystyriwch y daflen hon yn ofalus. Siaradwch efo'ch plentyn, teulu, ffrindiau neu aelod o staff CAMHS os hoffech chi.

Pam fod yr ymchwil hwn yn cael ei wneud?

Rwyf i'n rhan o dîm ymchwil, sy'n cynnwys Dr Michaela Swales (Seicolegydd Clinigol Ymgynghorol) a Dr Jaci Huws (Darlithydd ym Mhrifysgol Bangor) ac rydym eisiau darganfod pa fath o brofiad

ydy i rywun ifanc gael anawsterau iechyd meddwl. Rydym yn gobeithio darganfod pethau fel a oedd cael diagnosis yn help i'r un ifanc?

Dydyn ni ddim yn profi unrhyw driniaeth feddygol neu feddyginiaeth - yn syml rydym am gael barn eich plentyn.

Pam gafodd fy mhlentyn wahoddiad i gymryd rhan?

Cafodd ei (d)dewis oherwydd ei fod/bod yn cael triniaeth ar hyn o bryd at rai anawsterau. Rwyf yn gobeithio siarad efo rhwng 8 a 10 o bobl ifanc eraill am eu profiadau.

Oes raid i'm plentyn gymryd rhan?

Na, eich dewis chi a'ch plentyn ydy cymryd rhan. Byddaf yn gofyn i chi am eich cydsyniad i'ch plentyn allu cymryd rhan ac yna'n gofyn i chi arwyddo ffurflen. Byddaf yn rhoi copi o'r daflen wybodaeth hon i chi a'r daflen a arwyddwyd gennych chi i'w cadw. Byddaf hefyd yn gofyn i'ch plentyn ddarllen taflen wybodaeth ac arwyddo ffurflen gydsynio.

Rwyf yn deall os nad ydy fy mhlentyn am gymryd rhan, does dim rhaid iddo/iddi roi rheswm ac ni fydd pwysau arno/arni i gymryd rhan. Hefyd mae fy mhlentyn yn rhydd i roi'r gorau i gymryd rhan ar unrhyw adeg yn ystod yr ymchwil heb roi rheswm. Sylwer, **os ydych chi'n dewis peidio â chymryd rhan neu'n tynnu'n ôl o'r ymchwil, fydd hyn ddim yn effeithio ar eich triniaeth bresennol neu driniaeth yn y dyfodol o gwbl.**

Os ydy'ch plentyn yn cymryd rhan yn y cyfweliad, bydd yn cael tocyn £5 i ddiolch i chi am ei (h)amser a'i (h)ymdrech.

Beth fydd yn digwydd i'm plentyn os ydy ef/hi yn cymryd rhan?

Os ydy'ch plentyn yn cytuno i gymryd rhan, byddaf yn gofyn iddo/iddi ateb rhai cwestiynau. Does dim atebion cywir nac anghywir, yr unig beth ydw i am ei glywed ydy ei f/barn ac am ei b/phrofiadau. Dylai'r drafodaeth gymryd rhwng 60 a 90 munud. Bydd eich plentyn yn cael cwestiynau am y math o unigolyn ydy o neu hi yn ei f/barn o/hi, unrhyw anawsterau sydd ganddo/ganddi ac am ei b/pherthynas efo pobl eraill. Cofiwch y caiff y sesiynau eu recordio ar dâp sain gan ddefnyddio peiriant recordio digidol ac yn ddiweddarach bydd y recordiadau'n cael eu hysgrifennu ar gyfrifiadur.

Oes yna unrhyw beth i boeni amdano os ydy fy mhlentyn yn cymryd rhan?

Mae'n bosib y bydd eich plentyn yn anhapus neu'n ansicr yn ystod y cyfweiliad, gan y bydd efallai'n trafod pynciau emosiynol. Cyn i ni ddechrau byddaf yn gofyn i'ch plentyn enwi rhywun yn ei f/bywyd a allai ei g/chefnogi os ydy o/hi'n teimlo'n anhapus. Os ydy'ch plentyn yn anhapus, byddaf yn treulio ychydig o amser efo'ch plentyn un ai yn ystod y cyfweiliad pan yw'n anhapus neu ar ddiwedd y cyfweiliad i helpu'ch plentyn. Byddaf hefyd yn helpu'ch plentyn i gysylltu â'r un a enwyd ganddo/ganddi i'w helpu os ydy o/hi yn dal i deimlo'n ddrwg ar ôl i ni orffen.

Beth yw manteision cymryd rhan?

Fydd y cyfweiliad ddim yn rhan o ymyriad gan CAMHS ac nid yw'n cael ei honni y bydd o fantais uniongyrchol i'ch plentyn. Ond efallai y bydd rhai pobl ifanc yn dymuno mynegi eu barn ac efallai y bydd y cyfweiliad yn brofiad cadarnhaol. Y gobaith ydy y bydd yr ymchwil yn rhoi syniadau i ni am y ffordd orau o weithio efo pobl

ifanc. Yna gallwn drio gwneud gwasanaethau i bobl ifanc yn well.

Dyma fy manylion i:

Freya Spicer-White, Seicolegydd Clinigol dan Hyfforddiant
Yr Ysgol Seicoleg
Prifysgol Bangor
Adeilad Brigantia
LL57 2AS
Ffôn: 07586860919

Diolch am ddarllen hwn hyd yn hyn - os ydych yn dal i fod â diddordeb, darllenwch ran 2 os gwelwch yn dda.

Profiadau Pobl Ifanc o Anawsterau Iechyd Meddwl

TAFLEN WYBODAETH I GLEIFION: Rhan 2

Yn y rhan hon o'r daflen wybodaeth mae mwy o wybodaeth y mae angen i chi ei gwybod os ydy'ch plentyn am gymryd rhan.

Beth sy'n digwydd pan fo'r ymchwil yn gorffen?

Dim. Unwaith y bydd y cyfweiliad wedi gorffen ni fyddaf yn gofyn unrhyw beth arall i'ch plentyn.

Beth os oes problem neu os aiff rhywbeth o'i le?

Yr unig broblem a allai ddigwydd ydy y gallai'ch plentyn deimlo'n ddrwg yn ystod y cyfweiliad. Rydym wedi trio gwneud yn siŵr na fydd y cwestiynau'n gwneud eich plentyn yn anhapus, ond os ydy'ch

plentyn yn anhapus gellir rhoi'r gorau i'r cyfweiliad am ychydig neu'n gyfan gwbl os hoffai. Hefyd ar ddiwedd y cyfweiliad bydd eich plentyn yn cael siawns i drafod unrhyw beth a allai fod wedi ei (g)wneud yn anhapus a'r gobaith ydy y bydd yn gadael y cyfweiliad yn teimlo'n iawn. Ond os ydy'ch plentyn yn dal i deimlo'n anhapus yna mi wnaf ei helpu i ddod o hyd i'r un a enwyd ganddo/ganddi ar y dechrau fel rhywun a allai roi cefnogaeth.

Fydd unrhyw un arall yn gwybod bod fy mhlentyn yn gwneud hyn?

Bydd yr holl wybodaeth y bydd eich plentyn yn ei rhannu efo fi yn gyfrinachol - mae hyn yn golygu na fydd neb y tu allan i'r astudiaeth yn gwybod am yr hyn y buom yn siarad amdano.

Yr unig adeg y caiff cyfrinachedd ei dorri ydy mewn amgylchiadau lle gallai'ch plentyn neu bobl eraill fod mewn perygl mawr, ac y bydd yn rhaid i'r ymchwilydd ddweud wrth y bobl briodol.

Beth fydd yn digwydd i'r hyn fydd fy mhlentyn yn ei ddweud?

Bydd yr hyn sy'n cael ei drafod efo fi yn y cyfweiliad yn cael ei recordio ar beiriant digidol. Mi fydd y peiriant recordio'n cael ei gadw gen i ac mi fyddaf i wedyn yn teipio popeth a gafodd ei ddweud ar ddogfen word cyfrifiadur. Unwaith y bydd y cyfweiliad wedi ei ysgrifennu, byddaf yn dileu recordiad eich plentyn.

Pan fydd y cyfweiliad wedi ei ysgrifennu, byddaf yn tynnu allan yr holl wybodaeth a allai adnabod eich plentyn, fel ei (h)enw. Yna bydd Dr Jaci Huws (darlithydd yn y Brifysgol) a minnau'n edrych ar y cyfweiliadau ysgrifenedig. Byddwn wedyn yn edrych ar y pethau y bu'ch plentyn yn siarad amdanynt a'r pethau oedd yn

bwysig yn ei f/barn o neu hi. Bydd beth bynnag y byddwn yn ei ddarganfod o'r ymchwil hwn yn cael ei ddefnyddio fel rhan o'm hyfforddiant fel Seicolegydd Clinigol. Efallai hefyd y cyhoeddir y darganfyddiadau mewn cylchgrawn academiaidd. Byddai unrhyw wybodaeth mewn adroddiadau neu gylchgronau bob amser yn cael eu defnyddio mewn modd na fyddai'n gadael i unrhyw un arall adnabod eich plentyn yn unigol.

Cedwir y cyfweiliadau ysgrifenedig yng Ngwasanaeth Pobl Ifanc Gogledd Cymru am hyd at 2 flynedd ac yna cânt eu dinistrio. Efallai y bydd un o'r ymchwilwyr yn edrych ar y wybodaeth eto yn ystod y blynyddoedd hynny.

Pwy sy'n trefnu ac yn ariannu'r ymchwil?

Prifysgol Bangor sy'n trefnu ac yn ariannu'r ymchwil. Mae'n rhan o fy hyfforddiant i yn Rhaglen Seicoleg Glinigol Gogledd Cymru.

Pwy sydd wedi adolygu'r astudiaeth?

Cyn i unrhyw ymchwil fynd yn ei flaen mae'n rhaid i Bwyllgor Moeseg Ymchwil ei wirio. Maent yn gwneud yn siŵr fod yr ymchwil yn deg. Cafodd y prosiect hwn ei wirio gan Bwyllgor Moeseg Ymchwil Gogledd Cymru - Gorllewin.

Beth ydw i'n ei wneud yn awr?

Meddyliwch am y wybodaeth ar y daflen hon, a gofynnwch i mi os oes gennych chi unrhyw gwestiynau. Os, ar ôl ein trafodaeth, yr hoffech chi fwy o wybodaeth am yr ymchwil, gellir darparu hyn.

Os ydych chi'n cytuno bod eich plentyn yn gallu cymryd rhan, arwyddwch y ffurflen gydsynio os gwelwch yn dda. Y ffurflen

gydsynio fydd yr unig ffurflen ag enw eich plentyn arni a chaiff ei ffeilio ar wahân i bob gwybodaeth arall.

Os hoffech chi wneud cwyn ffurfiol ar ôl darllen y daflen wybodaeth hon neu ar unrhyw adeg yn ystod yr ymchwil mae'r manylion cyswllt isod.

Os oes gennych chi gwyn i'r *GIG* gallwch ysgrifennu llythyr at ...

Adran Cwynion
Bwrdd Iechyd Prifysgol Betsi Cadwaladr
Ysbyty Gwynedd
Bangor
Gwynedd
LL57 2PW

Ebost...

timpryderon.bcu@wales.nhs.uk

Neu ffoniwch ...

Gwasanaethau ysbytai a chymuned yng Nghonwy a sir Ddinbych
(01745) 534140

Os oes gennych chi gwyn i Brifysgol Bangor gallwch ysgrifennu llythyr at...

Isabel Hargreaves
Yr Ysgol Seicoleg
Prifysgol Bangor
Adeilad Brigantia
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Ebost...

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Neu ffoniwch 01248 388365

Diolch yn fawr am eich amser.

Parental/Guardian Assent Form: English

COLEG IECHYD A GWYDDORAU YMDDYGIAD
COLLEGE OF HEALTH AND BEHAVIOURAL SCIENCES

YSGOL SEICOLEG
SCHOOL OF PSYCHOLOGY

RHAGLEN SEICOLEC CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME



PRIFYSGOL
BANGOR
UNIVERSITY

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Brigantia Building, LL57 2AS
Telephone: 07586860919

Young People's Experiences of Mental Health Difficulties
Parental/Guardian Assent Form

Participant Number:

Name of Child:

Has somebody else explained this project to you? Yes/No

Do you understand what this project is about? Yes/No

Have you asked all the questions you want? Yes/No

Have you had your questions answered in a way you understand? Yes/No

Do you understand that your child can stop taking part at any time? Yes/No

Are you happy for your child to take part? Yes/No

Are you happy for your child to be audio-recorded as part of the research?

Yes/No

If any answers are "no" or you don't want your child to take part, don't sign your name!

If you agree that your child can take part, you can write your name below

Parent/Guardian Signature **Date**

Print Name

Signed on behalf of the researchers

Signed **Date**

Print Name

Parental/Guardian Assent Form: Welsh

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UNIVERSITY

Profiadau Pobl Ifanc o Anawsterau Iechyd Meddwl
Ffurflen Gydsynio Rhiant/Gwarcheidwad

Rhif yr Un sy'n Cymryd Rhan:

Enw'r Plentyn:

Oes rhywun arall wedi egluro'r prosiect hwn i chi?
Oes/Na

Ydych chi'n deall am beth mae'r prosiect hwn?
Ydw/Nac ydw

Ydych chi wedi gofyn yr holl gwestiynau sydd gennych?
Ydw/Nac ydw

A atebwyd eich cwestiynau mewn ffordd yr ydych chi'n ei deall? Do/Na

Ydych chi'n deall y gall eich plentyn roi'r gorau i gymryd rhan
ar unrhyw adeg? Ydw/Nac
ydw

Ydych chi'n fodlon i'ch plentyn gymryd rhan?
Ydw/Nac ydw

Ydych chi'n fodlon i'ch plentyn gael ei recordio ar dâp sain fel
rhan o'r ymchwil? Ydw/Nac
ydw

Os oes unrhyw atebion yn "na" neu os nad ydych chi am i'ch plentyn gymryd
rhan, peidiwch ag arwyddo'ch enw!

Os ydych chi'n cytuno bod eich plentyn yn gallu cymryd rhan, gallwch ysgrifennu'ch enw isod

Llofnod Rhiant/Gwarcheidwad Dyddiad

Printiwch yr Enw

Arwyddwyd ar ran yr ymchwilwyr

ArwyddwydDyddiad

Printiwch yr Enw

Diolch

Manylion Cysylltu

Freya Spicer-White, Seicolegydd Clinigol dan Hyfforddiant
Yr Ysgol Seicoleg, Prifysgol Bangor, Adeilad Brigantia, LL57 2AS
Ffôn: 07586860919

SECTION 6: General Appendix

Example of Analysed Transcript

Analysis: Transcript 2 "Polly"

Exploratory comments : Descriptive = Normal text
 Linguistic = Bold text
 Conceptual = Underlined text

Original	Exploratory Comments	Emergent themes
<p>F: so that's recording now. So if I put it by you is that OK?</p> <p>2: Yeah</p> <p>f: Fine and...</p> <p>2: Are people going to hear this?</p> <p>F: Just me.</p> <p>2: Just you?</p> <p>F: Yeah...</p> <p>2: OK</p> <p>f: and my voice sounds awful on these things I sound like Lloyd Grossman</p>	<p>Worries about people hearing; <u>people judging?</u></p> <p>Seeking confirmation</p> <p>Attempting to reassure and be humorous</p>	

<p>2: I sound like a man on them</p> <p>f: I do well we'll sound like men together. So some of my first questions are kinda boring ones really. How old are you now?</p> <p>2: 17</p> <p>f: 17... and how would you describe your ethnicity?</p> <p>2: white?</p> <p>F: White British would you say?</p> <p>2: yeah</p> <p>F: ok and how long have you been at NWAS?</p> <p>2: mmm about 5, 5, 6, I have been here since February</p> <p>f: since February OK now some of the things we might talk about today might upset you or anger you or distress you in some way. Now I hope this doesn't, but if it does can you give me the name</p>	<p>Negative self image?</p> <p>Further attempts to reassure and be humorous</p> <p>Temporal confusion</p>	
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<p>of somebody here that is on duty at the moment that you could maybe go and talk to</p> <p>2: OK</p> <p>f: who would that be do you think?</p> <p>2: mmm... probably <u>Name</u></p> <p>f: <u>Name</u>. Right ok so I'm going to ask you sort of some warm up questions to start with, so could you tell me about some of your hobbies?</p> <p>2: like writing and playing guitar and I like playing musical instruments like, I play piano and drum kit</p> <p>f: yeah?</p> <p>2: and reading</p> <p>f: ok and I already know some of thee things but what kind of music do you like?</p> <p>2: mmm I like grunge, like Nirvana and Pearl Jam and Alice in Chains and stuff like that</p>	<p>Present tense hobbies doesn't say whether she is skilled at these pursuits</p> <p>reading</p> <p>Rock/ grunge music</p>	
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<p>F: Cool. You've got really good taste in music. Right so if you could use just three words to describe yourself what three words might they be do you know?</p> <p>2: mmm weird, loud and competitive</p> <p>f: OK so I suppose those kind of words are things that people might describe their personality as but when I say that word personality, what kind of... what does that word or that concept mean to you?</p> <p>2: like the way people are and stuff and like their qualities and you know that makes them who they are.</p> <p>F: Yeah. I think that's a really good answer can you tell me anything else about that?</p> <p>2: mmm, don't know... no.</p> <p>f: that's fine its quite a difficult thing to describe. OK so you've told me a little bit about who you are but could you tell me a bit more about you as a person and</p>	<p>Weird = different? odd? Loud = positive or negative? Competitive = strong? spirited? <u>Does she see the attributes as good or bad? Does she like to define herself using these terms?</u></p> <p>Describes it in relation to others not herself Qualities - <u>quality</u>?</p> <p>Sense of fun at other's expense</p>	
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<p>your personality?</p> <p>2: mmm I like playing jokes on people</p> <p>F: ok what kind of jokes?</p> <p>2: and sometimes I'm like I go over the top</p> <p>f: right</p> <p>2: like, I don't know, like make up really inappropriate jokes and stuff and mmm and get on with people and I like people and I can be quiet sometimes, that's about it</p> <p>F: that's fine, that's loads, so today as you know I'm talking about coz you've got some difficulties and that's why you're here at NWAS erm... and this is the time when you can write things down coz I know some of your difficulties coz you asked me to find out some of them before coz it's a little bit difficult to talk about so do you think you could share with me some of those difficulties, would you like to write them down or do you want to just think about them.</p>	<p>Acknowledgment of a personal attribute that isn't necessarily positive</p> <p>Different sense of humour compared to others</p> <p>Positive social skills-</p> <p>Contradicts earlier statement of describing self as 'loud'</p>	
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<p>2: mmm... are you going to ask me a question?</p> <p>F: Like I'm going to sort of going to ask you some questions about the difficulties, so if you want to write them down or do want to think about how you might like to share them with me.</p> <p>2: I'll just see</p> <p>F: K OK so what kind of difficulties do you have at the moment</p> <p>2: erm sleepin</p> <p>F: yeah</p> <p>2: I don't sleep very well and like (unsure speech)</p> <p>F: yeah</p> <p>2: like you know</p> <p>F: yeah like some of those difficulties as well</p> <p>2: yeah</p>	<p>Non committal to disclosure at this point</p> <p>First difficulty not Mental health related <u>Does she not want to share? Or does she see this as a real difficulty that impacts on her life.</u> Repeated</p> <p>She is referring to the fact I am aware of her mental health difficulties</p>	
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<p>F: OK erm what do you call these difficulties, do you like have a special name for them all? Or a special name for some of them</p> <p>2: (4sec pause) erm no no</p> <p>F: no, that's fine cos sometimes these sorts of things may have some technical terms, they have technical names or or other times people use their own language to describe them. Do know er which ones do you prefer to call sort of terms technical or do prefer them er to be called more relaxed terms you might use.</p> <p>2:Erm I don't like it when <u>nurse</u> says I have psychosis by my mum</p> <p>F: right</p> <p>2: but erm I just like to called them difficulties</p> <p>F: yeah</p> <p>2: coz it's just easier</p>	<p>Not about the name but about how that word effects her mother. <u>Disclosure and words are out of her control</u></p> <p>'Just' used to minimise likes no names "difficulties" things that are causing her problems</p> <p>less problems without name</p> <p>Aware that psychosis is a label</p>	<p>Wants to keep things hidden from her mum</p> <p>A diagnosis is placed upon you.</p>
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<p>F: yeah I think that describes them quite well, for you mm ok, so you kinda mentioned that to somebody else or someones mentioned the word psychosis and have they mentioned that to you or like mentioned to your mum</p> <p>2: to me as well when I'm there and Dr <u>Name (Psychiatrist 1)</u> said it</p> <p>F: oh</p> <p>2:sigh</p> <p>F: OK How does that make you feel that word</p> <p>2: crap, don't like it, feels like psycho, so it's so...</p> <p>F: right, would you prefer if it was called a different name? Is it the name itself or is it what the name stands for?</p> <p>2: Dunno it makes me sound like I'm like nothing to do with reality or nothing, like I'm always crazy and stuff but I'm not, it's like, I'm like never I'm always like like I know whats going on...stuff like I dunno</p>	<p>professionals use about her. Psychiatrists use labels</p> <p><u>Disappointment at label?</u></p> <p>Negative reaction to label- links with similar word 'psycho'. This word triggers many visual and semantic associations, which are mostly negative. <u>Does she identify with 'psycho' - social comparisons and judgments</u></p> <p>'Sounds like' -she has a sense that she is not this label. A psycho is outside of the real world, <u>a horror film character?</u> She is worried about the permanence and misunderstanding of other people's perceptions of her difficulties. She is aware she is not these things. Repetition of permanence "always" and "never" . Her clarity that she knows what's happening, <u>she wants to get across she is not a "psycho" - step away from negative social judgments that will impact on her sense of self and self esteem.</u></p>	<p>People think I should always act in a certain way because of my diagnosis.</p>
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<p>F: Can you remember when the first time that word was used</p> <p>2: When I came here or when I was in CAMHS, I was in CAMHS before I came here</p> <p>F: Is that when they sort of shared you shared your difficulties with these people or when they said to you this is what we think is happening</p> <p>2: But thats what they call it, but they just call it like symptoms of something, I don't know what it is. I don't think they have properly to diagnose me yet.</p> <p>F: OK how would you feel if it they had may be given you, you know or they sort of had created some diagnosis and they had given you a label and they didn't share it with you, they maybe just talked about it among professionals.</p> <p>2: I rather them tell me, then I don't feel</p>	<p>Can't remember when the label was first used around her. Her need to give a little explanation of her history.</p> <p>Use of word 'they'- she separates herself from this labelling and the word psychosis. People break down the label for her to symptoms yet she still does not understand fully. She is unaware if she has diagnosis-'properly' suggests she sees there is an official way of doing things that will happen to her in the future by use of 'yet'. <u>She feels like diagnosis is something that will be done to her and she will have little or no control over.</u></p> <p>Wants transparency in her care. If it is a proper diagnosis it means to her that there is medical explanation rather than her being a freak. Again many visual and semantic associations with the word 'freak'. <u>She feels other people will treat or judge her differently if her experiences are medicalised.</u> Experiences with a diagnosis are real.</p>	<p>Diagnosis is something that happens to young people with mental health difficulties-</p> <p>Diagnosis is validation of her experiences</p>
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<p>like a freak like I know it's a natural thing and not something I'm just making up or like pretending or something</p> <p>F: OK</p> <p>2: It's like I feel like erm sometimes I like I'm making it up to myself like its not actually happening I'm just saying it is and like like it worries me as I could be wasting every ones time and stuff. (Sniff)</p> <p>F: So is it almost like, if, if it had a name then it would make it more real or make it more like other people have those things as well</p> <p>2: Yeah well like, an actual thing, not just me being freak if you get me</p> <p>F: yeah... mm ok, so kinda moving on to</p>	<p><u>She wants these experiences validated and accepted as real to her so people can emphasise with her?</u></p> <p>Struggles to start the sentence Pretending? To self so not for other's benefit or reactions. Its not real. Concerned that others are wasting their time caring for her. <u>She may see herself as a waste of time- not worthy of other's care and attention.</u> She becomes a little upset by this.</p> <p>'Actual' something that is tangible / real 'Just' to minimise / 'freak' - different/ bad Checking I have understood</p> <p>Did not understand the question</p>	<p>Questioning her own reality</p>
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<p>that what do you understand by that word you said sort of diagnosis what that what the actual word diagnosis means?</p> <p>2: What do you mean?</p> <p>F: Do know the word diagnosis,</p> <p>2: yeah</p> <p>F: wha... what does that mean?</p> <p>2: Like,</p> <p>F: To you</p> <p>2: When they like put a label whats wrong with you</p> <p>F: yep, that's pretty much yes, ok we've kind of talked about this so. So your not sure whether you've got a diagnosis, but you've heard certain words being talked about,</p> <p>2: yeah</p> <p>F: Can you tell me a little bit more about that</p>	<p>Naming something that is not normal compared to others</p> <p>Protective over what she chooses to share</p>	<p>Reality of having difficulties</p>
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<p>2: Like what</p> <p>F: Ermm just sort of that that experience you mentioned in CAMHS when you first heard these sort of words being mentions, like Psychosis, and then all the Dr's may be have discussed it here. So how does it feel when they talk to you about it .</p> <p>2: I don't know it feel like (sigh) 7 sec pause. Dunno it feels like there's something actually wrong with me. Like it's not just, I dunno it feels like I'm growing up or something. It's like something actual wrong with me</p> <p>F: Right ... OK so I'm going to ask you a couple of more questions about what you've just said because it's really really interesting and really important There's two sort of things that you said there. There was one "it makes you feel like there is really something wrong with you and two it makes you feel sort of more grown up. So I'm going to ask a couple of quick questions about those things. I think they are really important. So you said erm, it makes you feel there</p>	<p>She is trying to make sense of this, also considering how much she wants to share with me. 'actually' links with real. Diagnosis can be shared with you when you're a grown-up. Repeating phrase 'actual wrong' - emphasising her feelings that there is genuinely something negative/ defective with her.</p>	<p>Making sense, it is real</p>
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<p>'s something wrong with you, can you tell me a little bit more about what's that's about?</p> <p>2: Like you know do you mean, what's wrong with me</p> <p>F: yeah you can say that if you like but you don't have to, you can say how that feeling feels for you</p> <p>2: Like</p> <p>F: When people say you've got something wrong with you, is it a good thing or a bad thing or is it confusing</p> <p>2: It's just crap, cos I don't I can't accept that there is something wrong with me so. It just makes me feel crap because I'm doomed for life or something.</p> <p>F: right, so there's something very much about erm the the associations of what goes with that that label or or that diagnosis.</p> <p>2: mmm</p>	<p>She alludes to the fact that she asked someone else to discuss with me first what her difficulties are. <u>Embarrassment of saying it out loud.</u></p> <p>She struggles to understand and she is considering what to share still.</p> <p>'crap' as expression that the situation is negative - altering 'I don't' to 'I can't' suggesting her difficulty in accepting what she experiences. Struggling with acceptance of herself-<u>wanting to be normal. Repeating of 'crap' emphasises her frustration at situation.</u> The permanence of the her difficulties in the expression 'doomed for life'. A powerful expression <u>a powerful thought when considering how she sees her future.</u></p>	<p>Wrong</p> <p>Feels crap / negative associations</p> <p>Going to be stuck with this forever?</p>
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<p>F: Ok so do you currently feel as if there is anything wrong with you other than the difficulties you er we know you have some difficulties, do think those difficulties are sort something wrong with you? Do think they are just something you experience</p> <p>2: Something wrong with me</p> <p>F: Do want to come back to the other thing you said about feeling more grown up. Tell me a little bit about that.</p> <p>2: Like, kids they usually get diagnosed with something yeah not like properly but like I dunno, just like I'm not little anymore or something (sigh)</p> <p>F: erm erm is that a good or a bad thing</p> <p>2: erm don't know no one really wants to grow up really do they?</p> <p>F: no I suppose there are some good things about growing up</p>	<p>Leading question in an attempt to understand her, she was quite confident to disagree with me so if it wasn't either of these things she would have said.</p> <p>Intrinsically wrong/bad/ different about who she is</p> <p>Unstructured sentences feels like she is struggling to get her head around her own thoughts. 'Properly' suggesting there is right and wrong way/ or official way. I'm not a child, now I'm older <u>have more responsibility for myself and adults allow her more access into the adult world of mental illness and diagnosis.</u></p> <p>She is similar to others in that 'no-one wants to grow up'- <u>this statement normalises her. Acknowledging that things change when you grow up and life becomes harder? More real?</u></p>	<p>wrong</p> <p>Adult world of diagnosis</p> <p>Responsibility?</p>
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<p>2: yeah I suppose like me they can actually like not hide it from me if they mention in front of me so I'm more mature like I'm able to like deal with it</p> <p>F: yeah</p> <p>2: yeah that's what I mean</p> <p>F: So as you said before you wouldn't want people to hide things from you at all</p> <p>2: no</p> <p>F: How best would you like them to share stuff with you</p> <p>2: Just tell me, like this is my life so I should know what's going on</p> <p>F: yeam ..well ok there's sort of certain phrases or words that you think that would be really helpful or unhelpful</p> <p>2: mmm just whatever they thinks wrong with me. It's like fair</p> <p>F: and er who do think might be a good sort of person to have that discussion</p>	<p>People will hide things from her less- she has developed as a person and has new skills, such as coping with difficulty.</p> <p>Affirming her statement</p> <p>Wants to be told and kept informed about her mental health difficulties. <u>Ownership and responsibility</u></p> <p>Other people's/ professional's judgement of what is defective about her. 'fair' suggesting it is reasonable that things should be shared with her.</p>	<p>Wants to be treated as if she can handle it</p> <p>Wants more control</p> <p>A judgement 'they' make</p>
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<p>with?</p> <p>2: Probably Dr <u>Name (Psychiatrist 1)</u>, cos I like them better</p> <p>F: Right</p> <p>2: and like I can talk to her as well, I don't feel like I'm being judged or anything.</p> <p>F: So that's one really important thing if somebody was talking to you about your difficulties you wouldn't want to feel judged. Is there anything else that would be erm important for you to feel not that you would be feeling the person wouldn't be judging you. What else would be important for you to feel, sort of more comfortable about those things</p> <p>2: it's like, well not normal but not like a freak like it happens like I'm not the only one like ...</p> <p>F: I think that's a really good answer. Anything else they could do to make it better for you, so it would be not judgemental, make you feel as though you are not the only person in the world</p>	<p>Preference of one Psychiatrist over another- <u>bad news is easier to take from someone you like.</u></p> <p>Relationship is on more equal footing- importance of being open and not being 'judged'. <u>She has felt other people have judged negatively in past experiences of interactions about her mental health difficulties with them.</u></p> <p>Balance of explaining difficulties without branding a 'freak'. It is important for her to know that she is not alone in her experiences.</p> <p>'end of the world' is a powerful</p>	<p>It will be a mental health professional who places the diagnosis on her, but she would prefer someone she liked.</p> <p>She would prefer for the diagnosing experience to be more equal.</p> <p>Normalise experience</p>
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<p>going through this</p> <p>2: Yeah and erm .. not like making out it's the end of the world like you know not proper like saying you had to stay in here for months and months now and stuff like, give me like hope or something,</p> <p>F: yeah</p> <p>2: So not make it out to be worse than it is.</p> <p>F: mmm so to give you hope for the future, anything else you think they can do to make it better for you. I think you've come up with 3 good probably 4 or 5 actually we could count them as really good ideas... ok ... So thinking about erm sort of if they did sit down talked to you in a way you would like and they said to you (name) you have this certain diagnosis or this diagnosis is you know associated with the things you've experienced erm would you think that would be good or bad?</p>	<p>expression- <u>the end of her 'world' or normal life experiences. She may have had experiences of people discussing her difficulties with her when they have made her feel like there is no hope.</u> She links in her that her difficulties will mean she may have to stay as inpatient longer- repeating of 'months' to indicate a long time. The importance of hope and <u>a better future.</u></p> <p>Not for her mental health difficulty to be described as worse case scenario. <u>Important for people to be real but not overwhelm her</u></p> <p>Initial positive feelings towards getting a diagnosis</p>	<p>Diagnosis can sometime seem like a life sentence</p> <p>Optimistic but real</p>
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<p>2: Good</p> <p>F: But why would it be good</p> <p>2: Coz they're like letting me know like you know (sigh) so that they are not keeping secrets from me as well we have to trust each other and stuff</p> <p>F: You do yeah</p> <p>2: Coz I don't like it when people keep secrets from me</p> <p>F: Especially people that you are working with</p> <p>2: Yeah, they 've gotto work with me as well you can't just be me giving all the time they have to give back</p> <p>F: Is that something to do with being open ... OK .. what might be bad about that what might be the down side?</p> <p>2: Dunno about being labelled, for like ever, dunno like your saying this is what you got you've got it for ever you'll never get better. Bla bla bla</p>	<p>Informing her - no secrets - importance of mutual trust with the professionals she is working with. <u>She feels she needs to know what people working with her know in order to engage fully in her treatment program.</u></p> <p>Preference for people to be open. <u>Have people lied to her before and what effect has this had on her.</u></p> <p>Mutual trust and input into her treatment program from her and professionals. <u>Wording suggests she feels like at times she is the only one giving and working hard. Indicative of the power imbalance between professionals and service-users.</u></p> <p>'labelled' a name that is stuck to you and that you can't get rid of. <u>The control is very much with the professionals who give the diagnosis- she feels that once a diagnosis has been made it can't be taken away. It can take away hope of a better future.</u></p> <p>'sectioning' interesting use of word</p>	<p>Trust</p> <p>Honesty</p> <p>Diagnoses are sticky</p>
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<p>F: Tell me more about that that labelling</p> <p>2: Like just like sectioning off people that is different like you know pigeon holing people, like you are this you're that... look I don't like that</p> <p>F: mmm and does it worry you that they said that they may be stuck with you, for ever, would it worry you how that label might affect things in your future?</p> <p>2: Yeah like I used to think, I won't be allowed into University cos I'm mental or something... but I don't think like that any more, cos no one has to know really my sisters don't even know that there is anything wrong with me they just think I'm at sleep clinic.</p> <p>F: right</p> <p>2: So I don't have to go round like shouting it out do I (sniff)</p> <p>F: It's its up to you who you share these</p>	<p>since people in the inpatient unit are under legal section. She does not like the deindividualisation and categorisation that occurs with diagnosis giving. <u>Her individuality and uniqueness is taken away, she is no longer special she is part of a diagnostic category and will be treated the same as everyone else in that category, as people that will not get better and are outcasts from society.</u></p> <p>Thought at first that her future is limited because of her difficulties. 'mental' used as derogatory term. But she feels she is able to keep her difficulties a secret. <u>She has decided that instead of trying to get society to accept her difficulties, she will hide her difficulties from society, this implication that something is 'wrong' or bad or defective about her is shameful and abnormal.</u></p> <p>She acknowledges that she can tell who she wants <u>she can hide her difficulties, if they are hidden from society are they present at all?</u></p> <p>She is concerned others' will judge her negatively and her past experiences</p>	<p>You become your diagnosis for the everyone- you have been 'pigeon-holed'</p> <p>Mental health difficulties might restrict my future option?</p>
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<p>things with</p> <p>2: But it's like people might be less understanding cos in school I couldn't come to school because I was called mental and stuff and erm my this teacher who knows what's wrong with me was proper nice about it and like really understanding and stuff but say I went to Uni and then I couldn't do it then I was like failing they'd be like you're just crap but it's not my fault, so ...</p> <p>F: Emm</p> <p>2:.....so I dunno</p> <p>F: Your saying so many important thing (name) I'm trying to think which one I want to follow ... mmm... just tell me a little bit more about that sort of the the future that when you say you make a mistakes how that might feel?</p> <p>2: Say I went crazy again and like say I was at Uni doing like studying then I couldn't do it any more and then everyone would just think I'm thick when it's like I'm not thick it's just like</p>	<p>have been mixed. Positive memory of a teacher who was supportive. She is worried her difficulties will impact on her ability at University. She is proud and doesn't want people to think she is failing because she does not have the capabilities <u>but equally she does not want to tell them about her difficulties.</u> 'Not my fault' - she does not feel responsible for her difficulties or the impact they may have.</p> <p>'went crazy again' - very matter of fact, uncomfortable wording. She worries about other people thinking she is not clever if she could not study due to her difficulties. <u>She worries that her difficulties may hold her back throughout her life. Would she rather people judge her as 'thick' or 'crazy'?</u></p>	<p>Secrets</p> <p>Bad experience of sharing</p> <p>Concerned about negative judgements from others about her performance- Keeping difficulties hidden can cause problems</p> <p>Hiding your real difficulties can cause people to think other things about you.</p>
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<p>can't do stuff sometimes</p> <p>F: OK So then coming back to the whole idea of you the those things that we have been talking about, getting a diagnosis a helpful way from somebody that you trust that maybe would have some good things and maybe some some bad things, thinking about how what maybe helpful things about it, now what would be helpful for you if you had that diagnosis?</p> <p>2: then I'd know whats going on, and then I could like, see like different like meet different people who are the same and like I feel like I fit somewhere or something. Like coz in here no-one else is like me</p> <p>F: right</p> <p>2: they're all they're all they've all got similar problems and I'm like the only one who's not like them and they're all like like relating to each other and stuff and I can't. and so it feels a bit crap to be on your own.</p> <p>F: yeah I can imagine so that, that's</p>	<p>a diagnosis would help her to understand her experiences and she could meet other people with similar experiences. Contradictory ideas of meeting 'different' people who are the 'same'. <u>She would feel less alone and maybe have some of her questions about herself, her difficulties and her future answered.</u></p> <p>Other inpatients are similar but there is no-one she feels she can have a shared experience or understanding. She feels alone and this is not good. <u>She has no-one to normalise her experiences with so this makes her feel more isolated and more different which will impact on her sense of self and self esteem.</u></p>	<p>Which label would she rather have?</p> <p>She doesn't want to think of herself as alone</p> <p>Impact that others with mental health difficulties have on her-</p> <p>Isolated / different from peers</p>
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<p>something that would be helpful if you, you know, had that and you could be with another, other people that were similar, had similar difficulties to you and you could talk about them. Anything else?</p> <p>2: No</p> <p>F: Ok. What about unhelpful? Things that wouldn't help you at all if that happened</p> <p>2: If what happened</p> <p>F: if you did have that diagnosis. So the good thing would be that you would share with like minded, you know, people who had similar difficulties. What would be unhelpful?</p> <p>2: That people would think I'm just crazy, like its just you're mental, you've got a mental disorder, you're just mental. So...pause</p> <p>F: Almost like people would just write you off because of that</p> <p>2: Yeah,</p>	<p>Repeating 'just', 'crazy' and 'mental' as derogatory comments- <u>all you are is a disorder, you are part of a category of people who are different from the majority of society, you are someone who could be dangerous, to be laughed at, to be marginalised.</u></p> <p>Everyone has the potential to judge her negatively. Some friends have been helpful. Media representations of mental</p>	<p>You become your diagnosis-</p>
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<p>f: And would that be kind of people in here, professionals, or people out, you know, friends or it might be in the future</p> <p>2: Like everyone. Like my friends are dead nice about it, I doubt like people, it's just some people, like on TV like, people always make fun of things, have you seen that film about that guy who is an alien?</p> <p>F: mmm, not sure who's in it, who's famous in it?</p> <p>2: I'm not sure I've only seen it once. This guy goes to this mental place coz he says he's an alien and he really is, I think, I think he is in the end, but all the people are laughing at him and saying things like "who's it this time?" Is someone saying they're Jesus Christ or something?" and like, its like, like people laughing about it and stuff.</p> <p>F: and those sorts of things aren't really that funny if you're going through them. Ok, so sort of going on from what you've told me, what does having those</p>	<p>health difficulties are not positive. <u>She feels powerless to change people's perceptions when the media is so influential, it is almost like her against the world.</u></p> <p>'mental place' her language is not politically correct, and she uses terms that she would probably find offensive if other's used them to describe her.</p> <p>Description of the film to emphasize her point. People laugh at people who are different and have strange beliefs. <u>She feels it's unfair that films use people with delusional beliefs to create humour as it reinforces society's view and treatment of people with mental health difficulties and dehumanises them. She feel dehumanised and ostracized by society because of her different experiences, therefore she will struggle to trust people and have a negative view of herself.</u></p> <p>She strives for acceptance by herself and from others but it still feels 'crap'-repeat of word again emphasising the</p>	<p>Once you have the diagnosis you're stuck with it?</p> <p>Society thinks it fine to laugh at those with mental health difficulties.</p> <p>Her against the world</p> <p>Society's view of mental health is not positive one.</p>
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<p>difficulties ...mmm.. that you know, we both know about, what does that actually to have, to you to have those difficulties?</p> <p>2: mmm.. I just try and accept it, like a bit, it just feels like really crap, like sometimes I just dwell on it all the time but I'm just trying to get over it. But it's like really hard</p> <p>f: mmm</p> <p>2: Coz sometimes I'm like, it's like actually happens to me like I'm not like everyone else who's like this, it's like actually happening and there's nothing wrong with me its just, you get me?</p>	<p>repugnant nature of her feelings. She considers these thoughts a lot although she want to feel better. 'get over'- indicates it feels like an physical obstacle to circumnavigate, which emphasizes how hard she is finding acceptance. <u>She may worry if she can't accept and understand herself, how can she expect other people to accept and understand her, leading to worries she will be alone and unhappy in her future.</u></p> <p>She struggles with her own insight into her mental health difficulty, here she questions whether her delusional beliefs are delusional, therefore she does not have mental health difficulty but her delusional beliefs are real. <u>This is protective because then she is special rather than different which would have a positive impact on her self-esteem because she is no longer someone to be laughed at.</u></p> <p>Me summarising</p>	<p>Difficult experiences for her</p> <p>Acceptance is not easy</p> <p>She wonders if her delusions are real / is it better to have insight or not?</p>
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<p>F: so they are very separate from you?</p> <p>2: Yeah (sigh)</p> <p>F: tell me a little bit about that?</p> <p>2: like I'm more than just that really, I am, I can do, I'm like a person. Like I'm not just a disease. Like I don't know. I have feelings and stuff, so I'm not just like a walking .. whats it called ... you know when people do experiments on you. Like an example of my whatever, my disease or whatever not just like something doctors can look at and stuff. Like I don't think of it as part of me NO.</p> <p>f: So it's very much something that happens to you, something that you experience?</p> <p>2: Yeah.</p> <p>F: Somethings that's sort of quite separate?</p> <p>2: mm huh.</p> <p>F: Is it something that sort of ...mmm..</p>	<p>herself as a being with skills and qualities rather than a diagnosis, and she values this.</p> <p>'Disease' suggests she sees her difficulties as something external that could be infectious and <u>is attacking her sense of self like a disease may attack the body's white blood cells.</u></p> <p>She does not see herself as a 'walking example' of a certain diagnosis, something to be experimented on or investigated and she does not want other's to view her as this. Her language here becomes quite forceful demonstrating clear conviction in her views. <u>She does not want to lose her human quality or sense of individuality and reduced to a diagnosis.</u></p> <p>Slightly leading question but with check at end for her to disagree</p> <p>She took this analogy and made it her own. She feels that people are more than their physical diagnosis and feel people should also be more than their mental health diagnosis. <u>She does not want to be</u></p>	<p>More than an example of her condition</p> <p>Strong rejection of her difficulties as part of her identity.</p> <p>Does not want her diagnosis to define her.</p>
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<p>I'm trying to think about the best way describe it, something that's so if somebody like catches a cold they have the cold and then it goes away kind of, is it a bit like that? Or am I off the ball on that</p> <p>2: No, it's like, yeah. Say you had a cold, you wouldn't be someone like you wouldn't a cold, would you? You'd just be someone with a cold. And then sometimes it's like a bad cold and then sometimes it's just like that yeah. But like if you have a broken leg it's not, you're not all about your leg are you?</p> <p>F: No</p> <p>2: It's like that.</p> <p>F: OK, why do you think you have these difficulties?</p> <p>2: don't know, sometimes I think like, I must have done something bad in life or something but then I'm like, I don't know, it's just, sometimes I think it's like my fault and I've done something but now I'm just like it's nothing to do with that, it's just, it's no-one's fault really, it</p>	<p><u>categorised and summed up by mental health diagnostic criteria.</u></p> <p>She appears happy with her point of view and description.</p> <p>She feels she may be punished for from previous badness <u>indicating her experiences of a mental health difficulty must be extremely negative to be seen as a punishment.</u> She also feels some self-blame. Both phrases are in present tense which although she goes on to say that she n longer feels this way- this perhaps indicates that in some levels she still feels punished and to blame.</p> <p>She also feels no-one can be blamed, <u>this feels more like she is taking the blame away from people rather than away from herself.</u> She believes it is something to do with her brain- she again uses physical language to external her difficulties.</p>	<p>Seeing difficulties is different to not seeing them</p> <p>Guilt</p> <p>Comparison with physical illness</p> <p>Psychoeducation</p>
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<p>just brain or whatever.</p> <p>F: Has anyone ever sat down with you and talked to you about how, you know, where or why things like his might happen to different people?</p> <p>2: No</p> <p>f: Would you find that helpful?</p> <p>2: Not really</p> <p>f: why do you think that wouldn't be helpful?</p> <p>2: coz I just end up thinking I'd done something wrong again. And I already know like it's like chemicals in your brain and stuff so I'm just trying like not think about it.</p> <p>F: OK, so what is the hardest thing do you think about having these difficulties?</p>	<p>Even if someone were to explain the potential causes of mental health difficulties, she would not find this helpful and she feels she could still end up blaming herself. She acknowledges, using again physical language to externalise, the medical nature of her difficulties and goes on to say she tries not to consider this further. <u>The more she thinks about her difficulties the more she may blame herself and the more real and inescapable her difficulties become.</u></p> <p>Medical description / explanation</p>	<p>Blame</p>
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<p>2: like you're not being able to like live your life and like being in bed all the time and and just staying away from everybody and like just being separate from life, and then you've gone back and then you realise like you've missed out on like months of your life by doing something stupid like just believing stupid stuff and like just staying in your bedroom all the time it's like you've not been to school and like you've wrecked your whole life, it's like that.</p> <p>F: OK- anything else that's like difficult or about these difficulties, what you've just said was really important</p> <p>2: mmm</p> <p>F: what else do you think is important</p>	<p>Limits placed on her because she is in an inpatient unit- <u>her difficulties and because she is an inpatient mean her life is not her own any more, it's controlled by her mental health difficulties and her treatment program, she probably feels trapped and powerless.</u> She has been wasting life in bed and isolating herself, 'gone back' suggests she had been in an alternative reality or existence that she was in. Her realisation that she has missed out on life because of the delusions associated with her mental health difficulties and 'wrecked your whole life' is a power expression of how she feels her behaviour when unwell has effected her future prospects. <u>She seems aware that she can't get this time back and she regrets that this can't be changed- she must feel powerless.</u></p>	<p>Life will pass her by</p> <p>Life is different</p> <p>Wasting life? A wasted life?</p>
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<p>or stuff that I should know about?</p> <p>2: Just not being able to live really,</p> <p>f: OK. This might be a bit of a strange question but is there anything that you like about experiencing these things?</p> <p>2: mmm. Sometimes I'm like, it makes me different from everyone else like I'm not like a boring like working class you know like in an office like that kind of person, like I'm just, I don't, I just feel like it makes me different sometimes. But sometimes it's a good different and sometimes it's a bad different.</p> <p>F: Could you tell me a little bit more about those, the good different and the bad different?</p> <p>2: Well I don't really want to be like a normal person like, just going to work in an office and like 9 to 5, you've got 2 kids, so you don't achieve anything with your life, and you don't ever see like,</p>	<p>She says 'live' rather than live a normal life, indicating that <u>her difficulties and the restrictions placed on her in the inpatient unit can feel like she isn't even alive</u>- her quality of life has been impacted upon to the point where she feels trapped and restricted.</p> <p>She likes to think of herself as special and not like as she describes typical members of society. <u>Does she distance herself from normality as a protective factor as she feels she will not fit in so this gives her more choice and control?</u> There is something exciting about her if she is different. She also acknowledges the fine balance of being different as in unique and special with being different as in alone and odd. <u>It is likely she struggles with this concept and her own identity, does she want to fit in or does she want to be different but ultimately does she have a choice?</u></p> <p>She has negative stereotyped view of normality, <u>if normality is boring then why aspire to it? This belief enables</u></p>	<p>Loss of control</p> <p>Difference can be good Values her uniqueness</p> <p>Values the good differences in her personality.</p>
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<p>past everything, like I've seen past it, like, do you get me?</p> <p>F: I think so...</p> <p>2: they just see this is, this is what you do but it's like there's like a whole world and like no-one thinks about that, they just think about the smaller picture and it's like ...</p> <p>you know... I like astronomy and stuff and it's like, it like, there's so much more than that and no-one sees it.</p> <p>F: I think that's really important you're saying something about not wanting to just sort of settle down and live the sort of typical humdrum life</p> <p>2: yeah</p> <p>f: so that's, so that's, so that some of the</p>	<p><u>Polly to reconsiliate the other people's beliefs and her own belief that she is different but that being different is a positive thing because if you are normal you don't achieve things. Her phrase to see 'past everything' alludes to a belief that because of her difficulties she understands more about the world, rather than on a superficial level but on a higher abstract level.</u></p> <p>This makes her more skilled in certain areas compared to most people allowing her some higher ground as a protective factor for her self-esteem.</p> <p>She feels she sees things on a bigger scale, she feels she is able to take in more, like her difficulties have also given her the ability to understand life in a more complex way.</p> <p>She sees more than the world but 'no-one' else can, this indicates that this is one way she is different in a positive special way. <u>Polly feels she has higher developed skills</u></p>	<p>Difference can be confusing- especially when trying to figure out who you are and develop your own identity.</p> <p>Feeling different</p>
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<p>differences, the differences, differences...</p> <p>2: Yeah that's the good difference but the bad difference is like, is like being like a freak and like and not normal. But then like I don't wanna be normal so it goes on in circles</p> <p>F: mmm just going ask you a bit of a strange question now and it's sort of like thinking, if everybody accepted you as normal or different and it was OK, how would that feel?</p> <p>2: Good</p> <p>F: So if it was alright to be different, so if they said... you know what the things you experience doesn't matter you can just get on with it</p> <p>2: Yeah I'd like it</p> <p>f: I'm just thinking coz throughout this interview you're used a couple of words like crazy and freak and psycho, are they sort of your words to describe things or are they the things you have heard other people or like society?</p>	<p>She is able to weigh pros and cons of the differences. Repeat of 'freak' indicates there are times she feels very different and out of place. She acknowledges her own struggle between wanting to fit in and wanting to be unique. <u>She is trying to come to terms with her identity and her role in relation to society, some of this is typical teenage role confusion and identity crisis but Polly's task of figuring out who she is and who she wants to be is made even more complicated by her difficulties.</u></p> <p>Agreeing with my proposal</p>	<p>Difference</p> <p>Conflict of wanting to and not wanted to fit in</p>
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<p>2: It's just society really it's what we're all labelled as they don't like realise we're like actual people and not, it's not ...</p> <p>we didn't ask for it to happen to us and we're not just being, we're not doing it on purpose, and stuff and we're not criminals, just I don't know, you don't think someone who has a broken leg is a criminal? So it's like you just have to wait for it to get better.</p> <p>F: yeah. What do you think about those terms, those names?</p> <p>2: Well if someone called me one I wouldn't be that happy but then I think I am one any way and it makes me sad</p> <p>f: Did you ever say those sorts of things to.. do you consider yourself like err.. a freak or a psycho?</p>	<p>She comments on society as a whole labelling and categorising each other. 'actual people' emphasises the dehumanising nature of derogatory mental health terms. 'we' suggests she is using this to stand-up for other's with mental health difficulties, to place herself within a context of similar individuals and to add weight to her argument that she is not alone in feeling this way. She takes away blame from herself and does not want to be thought of as a criminal. She contrasts how difference between a visual physical health problem to her own invisible mental health problem. She speaks positively about waiting for recovery, <u>does she recognise the role she must play in her recovery?</u></p> <p>She is upset by derogatory names but she uses them to describe herself which is even more upsetting. <u>She may use these terms to punish herself for her</u></p>	<p>Negative judgements of others Labels</p> <p>Names- other people's views</p>
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<p>2: Yeah. Crazy.</p> <p>F: And what does that feel like?</p> <p>2: A bit crap.</p> <p>F: ok... so I'm going to ask you now a couple of questions about how all those difficulties and all those feelings that we've talked about, how that has effected your relationships with other people? Ok so we're going to start off with, shall we start off with friends? How has it...</p> <p>2: They're really nice about it, like they're proper supportive and stuff and it doesn't get in the way or anything, I'm still the same person as I was before I was crazy so its just its just... fine with my friends. And they like understand that sometimes I'm like not always me, myself, but it's like, it'll get better, it's not forever if you get me?</p> <p>F: right you still have a lot of contact with friends outside of here?</p> <p>2: yeah they're like my family basically</p>	<p><u>difficulties and that she is living a different life to the one she or society expects.</u></p> <p>Uses crazy to describe herself.</p> <p>Not a good feeling.</p> <p>Supportive friends are important to Polly because they accept her when she is and isn't experiencing difficulties. She can maintain her individuality and sense of self. <u>Her sense of "me" appears to be her without the difficulties.</u> Since her friends see her difficulties as temporary, she can also see then as temporary. <u>She can get on with being a teenager when with friends.</u></p>	<p>Positive relationships with friends who do not judge</p> <p>Other people with difficulties know what you are going through.</p>
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<p>f: OK and what about people here?</p> <p>2: I feel accepted round here like I've got scars on my legs and erm... I was like , I was walking round in like shorts and I felt like OK about it coz like no-one was going say "arh what's that?" or "that's minging" and stuff so it was like, it's like ok and yeah.</p> <p>F: OK what about your relationship with your family? Coz you sort of mentioned before that maybe some people don't know.</p> <p>2: only my mum knows and I don't talk to her about it now coz it's like really awkward, she like she just cries all the time</p> <p>f: right</p> <p>2: and it's just I don't like it coz she thinks coz she works with like mental adult mental health and stuff she's used to seeing people who are like proper</p>	<p>Friends as important as family members, indicating their supportive role</p> <p>She feels that she does not have to hide scars that are a result of her difficulties on the inpatient ward because people don't judge her because they understand about her difficulties. <u>Her scars are a visual representation of her difficulties and they can not removed, like her history of her personal difficulties can not be changed.</u></p> <p>Only her mother is fully aware of her difficulties and this has not been good experience of sharing, as Polly's mother is "awkward" and extremely upset. She can't share to people outside professionals <u>because having difficulties is too upsetting and overwhelming for other people to deal with.</u></p> <p>Polly's mother is aware of mental health issues because she works in the area. <u>It seems that her additional knowledge on the subject is not helpful to Polly.</u></p>	<p>Secrets</p> <p>Keep it hidden, don't share with family</p> <p>Shame?</p>
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<p>mental or like they're not like anything to do with reality and stuff if you get me and like she thinks I'm like that when I'm not so she just cries all the time and just thinks my life is doomed and I'm never going to achieve anything coz I'm mental and stuff so I don't like talking to her about it</p> <p>f: so it has effected your relationship quite a lot</p> <p>2: yeah</p> <p>f: ok so what about with your sisters and ...</p> <p>2: they don't know and if they did they would just make fun of me</p> <p>f: ok are they older or younger?</p> <p>2: older.</p> <p>F: and have you got on with them in the past?</p>	<p>'proper mental' indicates her view that she has difficulties but these are different to adults with mental health issues who are out of touch with reality.</p> <p>Her mother's view is not positive for the future- how does this impact on Polly? Makes sense that Polly does not like sharing with her mother, <u>she feels unsupported and probably frightened that her mother's concerns are right.</u></p> <p>Hasn't shared with sisters as she feels they would be unsupportive and make fun of her.</p> <p>She has better relationship with one</p>	<p>Difficulties can be and should be hidden from the world</p> <p>Negative view from family members</p> <p>Negative judgements from family</p>
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<p>2: I get on with one of them who is 18, and erm... but I haven't told her coz she gets in moods and says mean stuff so if she got in one of her moods she would just bring it up and make me feel bad on purpose so ...</p> <p>f: right</p> <p>2: And the other is just mean all the time</p> <p>F: OK</p> <p>2: So I just don't tell them coz it's easier coz they wouldn't understand, I know they wouldn't</p> <p>f: why don't... excuse me ... why don't you think they'd understand?</p> <p>2: coz they just don't they're just harsh they're just, they just think I'm just crazy and that, think I'm a different person than I am and it's like I'm not</p> <p>f: What about any other family members?</p>	<p>sister but still she believes this sister could be derogatory about her difficulties, which would make Polly feel bad. <u>Polly feels she is surrounded by family members that don't support her or understand what she is going through. Her difficulties have created a wedge between her family.</u></p> <p>Other sister has always been mean.</p> <p>She feels strongly they wouldn't understand her. She opts for an 'easier' way.</p> <p>She describes her sisters as 'harsh', this is quite a strong word that emphasises how she feels they react to her. She describes feelings that she will be judged differently if her sisters know she has difficulties. <u>She wants to keep her sense of self and not be categorised as a person with mental health difficulties.</u></p>	<p>Family will treat me differently, will use my difficulties against me</p> <p>Secrets</p> <p>Sisters treat me differently and see me as different because of difficulties-</p>
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<p>2: No none of them know. My dad doesn't even know I'm here.</p> <p>F: right</p> <p>2: he just thinks I'm at home</p> <p>f: right, do you see or speak to him often?</p> <p>2: I see him on Sundays</p> <p>F: and how is your relationship been effected with him, is it sort of not effected coz he doesn't know</p> <p>2: Not effected</p> <p>f: Is that quite nice to have that protected space where you...</p>	<p>All family members are not told about her difficulties. <u>This again suggests she wants to keep her difficulties separate from her family life, so they don't judge her or place her in the 'mental health' category, but also it indicates some shame in having to admit to these difficulties.</u> Her father is not aware she is an inpatient.</p> <p>Polly's mother and Polly conspire together to keep this secret- <u>this may confirm to Polly that it is shameful and people will treat you differently.</u></p> <p>She sees her father weekly</p> <p>Again the fact her relationship with her father is not affected will confirm to her that it's best not to tell people.</p>	<p>She is not her illness</p> <p>Lies</p> <p>Difficulties can be and should be hidden from the world</p> <p>Difficulties can be and should be hidden from the world</p>
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<p>2: Yeah but I'm always scared that he's going to find out or that I won't be able to get out of here and see him and he'll be like why? And like I have to pretend I'm like ill all the time and he's like what the hell is going on, it's like, I don't it's just like paranoid about when it's going to end if you get me?</p> <p>F: yeah. So it's that there is a good part, it's sort of a nice thing that it's not effected your relationship and that there is a bad part that goes with the secrecy.</p> <p>2: Yeah</p> <p>F: What about any romantic relationships?</p> <p>2: I don't have any</p> <p>F: Have you ever had any in the past?</p> <p>2: yeah but I've not told them... they have like no idea.</p>	<p>Fear that she will be found out, especially if she has to remain on the ward. She lies to him to protect their relationship and feels 'paranoid' that he will find out. <u>Their relationship must be filled with lies and she may believe that if he finds out he will have a negative reaction like her mother and sisters. She assumes people will treat to differently and perhaps negatively if they know you have mental health difficulties that are so severe you have to be an inpatient.</u></p> <p>No romantic relationships. <u>You can't trust people who you can be intimate with</u></p> <p>Need to keep her difficulties a secret.</p>	<p>Lies</p> <p>Secrets</p> <p>Shame</p>
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<p>F: right so that's not effected, how do you think it might effect sort of relationships in the future?</p> <p>2: Wouldn't tell them</p> <p>f: OK</p> <p>2: Coz they'd just be scared off</p> <p>F: OK so we're coming onto the last questions now... we're nearly finished... if if there was anything, there might not be, but what kind of things would you change about yourself if you could?</p> <p>2: I've gone through all this but I'd have been better, so that I've got the experience, I've got, I know like I've seen life from like a different way to other people now like I know like I just see things from a different perspective so I'd be I'd be better from this forever but I wouldn't fall into like you know have kids, die, and that without achieving anything without changing anything and that to the world or</p>	<p>Would not tell future romantic partners.</p> <p>'Scared' suggests she believes potential partners might consider her dangerous or too challenging in a relationship. <u>She probably feels they need to protect herself from future hurt as well as she believes people will abandon her or treat her differently if they are aware of her difficulties.</u></p> <p>She would not change her experience to date but she would choose to be better. 'Been' better suggests she would like to be better already, <u>maybe not have to work at her treatment plan and could be discharged.</u></p> <p>She feels has gained a valuable perspective on life due to her difficulties. <u>She is concerned about wasting her life, whether that be through mental health difficulties or merely living a typical life, she wants to make a difference. She is at</u></p>	<p>Potential romantic partners will treat you differently if they know you have mental health difficulties</p> <p>Good parts about being different</p>
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<p>anything.</p> <p>F: right so just I can just sum that up so I know I've understood that right... so it's sort of like you wouldn't change the experiences that you've already had so you'd keep them as they were as you think you've learned quite a lot from them</p> <p>2: mmm</p> <p>f: But you would change the fact that you'd then be better for the rest of your life</p> <p>2: and like be able to go to Uni and finish my A levels and you know be academic and</p> <p>F: What are your hopes for the future <u>Name</u>?</p> <p>2: I wanna write, I want ... I don't know yet. I wanna just write books and stuff or be... I don't know. I just wanna write that's all.</p> <p>F: That sounds a good plan. Right have</p>	<p><u>the start of her adult life, she wants to see potential rather than hopelessness. Her experiences both help and hinder this, because they give her perspective and drive, but they also restrict her because she has to keep her true self hidden for fear of being rejected.</u></p> <p>She is focused on future academic achievements at present. <u>These achievements will be concrete, like specific grades, that will give her a measure of her success and potential.</u></p> <p>She wants to out her views and stories down on paper, again there is something concrete about writing. Also she will be sharing her views so other people can read them. <u>She wants to change how people view things, perhaps like mental health, so she can make a difference.</u></p>	<p>Creative</p> <p>Hopes for a positive future</p>
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<p>you got anything that I haven't asked you that you think would be really important to tell me about anything before we finish?</p> <p>2: No.</p> <p>F: Right and we're done</p> <p>2: Thank you</p>	<p>She appears grateful to have had her views heard.</p>	
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Figure 1: Literature search process

Initial searches across both databases generated 2,857 English articles between 2004 and 2012



'Limit to' and 'Refine' restrictions were used on each database to remove health-related articles, by excluding the topics "HIV", "Alzheimer's", "breast cancer" and "health care". The remaining 2,120 titles and abstracts were scanned.



47 articles were deemed appropriate for further consideration
(3 papers could not be obtained within the time limit)



44 articles were scanned and reference list searches identified a further
4 potential articles.
48 papers were read.



31 were rejected on content, this included:
16 studies conducted with adult participants
6 investigated parental experiences
3 focused only on stigma experiences
2 focused on forensic labelling
2 focused on treatment outcomes
1 single case study not written from young person's point of view
1 focused on the mental health of individuals diagnosed with HIV
1 investigated perceptions of suicide



1 removed due to duplication of data



A total of 15 papers were included in this review.
A Critical Appraisal Skills Programme (CASP) tool ensured all studies were of adequate quality.

Table 4a: Data extraction table of quantitative studies

Authors and Date	Participant demographics	Brief description of method	Findings	Limitations
Arbanas (2008)	N= 324 Croatsians Male and Female Attending a grammar school, commercial school or specialised medical school. Aged 17 to 18 years	Assessed attitudes to depression, schizophrenia and post-traumatic stress disorder. Likert-scale questionnaire to measure attitudes towards people with depression, schizophrenia and post-traumatic stress disorder. Conducted in classroom. Descriptive analysis, Wilcoxon test of matched pairs were used to assess difference in attitude toward three disorder among students. T-tests were used to assess differences among students from different schools.	Young people displayed more stigmatised views of schizophrenia compared to depression or PTSD. Young people with specific knowledge or interest in mental health difficulties displayed less stigmatising views.	Likert-scales limited individual's response choice.
Burns and	N= 202	Assessed young	Participants:	Vignettes do not

Rapee (2006)	Australian Male and Female Aged 15 to 17 years	people's ability to recognise difficulties and correctly label. Used vignettes of 3 typical and 2 depressed young people and participants responded to questions on a Likert-scale. Conducted as written task in classroom. Descriptive analysis and two-way ANOVAs compared gender and mental health literacy, gender and expressed worry,	1) demonstrated varying ability to correctly label depression. 2) displayed greater worry for individuals with symptoms of depression 3) could differentiate between depressed and non-depressed vignettes in terms of severity and expected recovery time. 4) recognised emotional distress because of symptoms of depression, including loss of interest and appetite and low self-esteem. Females displayed better mental health literacy and more concern for the individual in the vignette.	equate to real life experience. Likert-scales limited individual's response choice. Findings limited to depression.
Calear, Griffiths and Christensen (2011)	N= 1,375 Australian Male and Female Aged 12 to 17 years Mixture of asymptomatic individuals and those with subclinical and clinical difficulties.	Assessed stigma associated with depression. Completed as part of randomised controlled trial investigating effectiveness of online programme to prevent anxiety and depression- results from the pre-measures. Personal and	Personal stigma was associated with being male, younger, living with both parents, no personal history of depression and higher levels of alcohol consumption. Perceived stigma was associated with being female, having a history of parental depression and higher levels of anxiety.	Likert-scales limited individual's response choice. Does not equate to real life experience. Findings limited to depression.

		<p>Perceived Depression Stigma Likert-scale</p> <p>Descriptive analysis.</p> <p>Paired t-tests compared participants' levels of personal and perceived depression stigma.</p> <p>Two hierarchical multiple linear regression analyses explored the predictors of personal and perceived depression stigma.</p>		
Hess, Todd, Gonzales, Kastelic, Mink, Rose & Swartz (2004)	N= 5, 646 American Male and Female High school students	<p>Assessed knowledge about depression.</p> <p>Questions 1-13 were yes/no statements ("A person with depression always feels sad?")</p> <p>Question 14 asked participants to list 5 symptoms of depression.</p> <p>Question 15 asked participants to list 2 symptoms of mania.</p> <p>Survey delivered in classroom.</p> <p>Descriptive analysis.</p>	<p>Large variability in young people's knowledge.</p> <p>Limited awareness of symptoms and treatment options.</p>	<p>Psychometric properties of survey not established.</p> <p>Dichotomous questions are limited because they may be leading and closed questions.</p> <p>Poor demographic data.</p> <p>Findings mostly limited to</p>

				depression.
Klineberg, Biddle, Donovan and Gunnell (2010)	N= 1125 English Male and Female Aged 16 to 24 years	Assessed symptom recognition and help seeking behaviours. Two part vignette described first a mildly depressed, followed by additional information suggesting severe depression. Open ended questions assessed symptom recognition and help seeking behaviours. Postal survey. Answers were coded using content analysis. Chi-Square tests examined the differences between male and female respondents, separately for the mild and severe symptoms. Logistic regression was used to examine the factors associated with symptom recognition and help seeking behaviours.	<u>Symptom recognition</u> Mild depression was recognised by 41.8% and interpreted as a mental health problem by 50.5% of participants. Severe depression was recognised by 61.4% and interpreted as a mental health problem by 70.7% of participants. Females identified both forms of depression more frequently than males. Males were more likely to use stigmatising terms and feel that the individual in the vignette was to blame for their difficulties. <u>Help seeking</u> Most frequent response was speak to friends and family (87%), followed by try going out and doing new things (56%), go to the doctor (45%), wait to see what happens (12%) and do nothing (1%). Of those who identified mental health problem, 64.7% suggested the person in the vignette should see a doctor but only 23% of the sample stated they would actually do see a doctor if in the same position.	Response bias of a postal survey because 1) a higher proportion of females replied 2) over one third of participants scored over 4 on the General Health Questionnaire indicating a minor mental health problem 3) 40% had sought help in the past for psychological problems. Findings limited to recognition of depression.

			There were no gender differences in help seeking for mild depression. 71.%% of females compared to 53.7% of males suggested that the person in the vignette should consult a doctor.	
Olsson & Kennedy (2010)	N= 281 American Male and female Aged between 11 and 17 years. Attending middle and high public schools.	Assess recognition of disorders and helping responses. Questionnaires using multiple choice responses including brief vignettes (same as those used in research by Jorm and colleagues, 2009, 2010). Conducted in classroom setting. Descriptive analysis.	27.5% correctly considered the social phobia vignette as a mental health problem 4% used the term anxiety to describe this vignette. 42.4% correctly considered depression as a mental health problem and 55% used a variant of the term depressed. Professional helpers (e.g. family doctor) were most frequently considered the best source of help. 69.8% in the depression vignette and 55.3% in the anxiety vignette would recommend that these individuals sought help.	Multiple choice limits the young people's responses. Questionnaires do not equate to real life experiences. Peer pressure within classroom setting. Poor demographic data.
Rose, Thornicroft, Pinfold and Kassam (2007)	N= 400 English Male and Female Aged 14 years	Assessed the words used to stigmatise people with mental health difficulties. Participants asked to generate list of words	250 words generated 5 key themes Popular derogatory (116 words) Negative emotional state (61) Confusion between learning and physical disability (38)	Peer pressure within classroom setting. Some words categorised as

		to describe a person with a mental health difficulty. Conducted in classroom. Descriptive analysis.	Use of psychiatric diagnosis (15) Items related to violence (9)	derogatory may hold kudos with young people.
Schulze & Angermeyer (2005)	N= 293 German Male and female Aged between 14 and 18 years Attending secondary modern or grammar schools.	Assessed associations with the word 'schizophrenia' and sources of information about the illness. Survey including open-ended questions. Conducted in classroom. Descriptive analysis. Cross-tabulations assessed the relationships between the associations and sources of information responses.	35.8% of participants associated schizophrenia with an illness. 18.8% associated schizophrenia with split personality or split consciousness. 7.5% first thought of delusions or psychosis. 4.4% associated schizophrenia with reduced intelligence. 3.8% used the words crazy or mad to characterise schizophrenia. 63.6% obtained their knowledge of schizophrenia from the media. 19.9% obtained their knowledge from family and friends and 13.2% from school. 9.9% cited books as their sources for information and 9.3% were categorised as 'other', including information leaflets at family general practitioner. No gender or age differences were found. The sources of information was not a predictor for the knowledge or	Survey may not reflect how the young people would react in real life situation. Peer pressure within classroom setting Findings limited to schizophrenia.

			attitudes displayed by the young people.	
Wright and Jorm (2009)	N= 3746 Australian Male and Female Ages 15 to 25 years	Assessed labels used to describe a mental health difficulty.. Each participant was read one vignette describing either depression, depression with alcohol misuse, social phobia or psychosis and then asked questions. Telephone survey. Descriptive analysis and multiple binary logistic regression analyses used to examine the predictor variables, including age, gender, exposure to a mental health campaign and personal history or contact with friend/family member with difficulties.	Depression labelled correctly twice as often as Psychosis. Social phobia least recognised. Females displayed better mental health literacy. Correct label use increased with age. Correct label use was associated with campaign exposure and either a personal or friend/family history of mental health difficulties and help seeking.	Vignettes do not equate to real life experience. Social desirability as the young people were in direct communication with the researchers.
Wright, Jorm and	N= 3746 Australian	Assessed the stigma associated with labels	Psychosis and depression with alcohol misuse were frequently	As above due to same data.

Mackinnon (2011)	Male and Female Ages 15 to 25 years	of mental health difficulties. Each participant was read one vignette describing either depression, depression with alcohol misuse, social phobia or psychosis and then asked questions. Telephone survey. Descriptive analysis and correlations performed using logistic regression analysis.	considered dangerous and unpredictable and elicited greater social distancing. Social phobia was considered as a weakness rather than a sickness. Males made more stigmatising responses. Familiarity with mental health difficulties reduced social distancing and weak rather than sick beliefs. Personal experience of mental health difficulties increased perception of stigma in others.	
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Table 4b: Data extraction table of qualitative studies

Author and date	Demographics of participants	Brief description of method	Themes relating to 'diagnosis experience'	Limitations
Brooks and Dallos (2009)	N=5 Females Aged 15 to 17 years Experiencing difficulties, had received a diagnosis and were accessing CAMHS.	Biographical Narrative Interview Method Transcription separated into individual clauses Narrative Analysis	Opening Narrative: How young people begin to tell their stories. Hidden Distress	Authors acknowledge they did not report all themes.
Kranke, Floersch, Townsend & Munson (2010)	N= 40 American Males and Females Aged 12 to 17 years Participants had received a DSM-IV diagnosis and were taking psychiatric medication.	Subjective Experience of Medication Interview (TeenSEMI) Transcripts entered to Atlas.ti and open coded to identify emerging themes and then create a hypothetical model in a grounded theory manner.	Secrecy of Diagnosis Secrecy of Medication Shame of Diagnosis Shame of Medication Limited interaction Changes in Family's perception Changes in School Environment	The study did not examine any potential variances, such as gender, ethnicity or severity of difficulty that may have been related to specific themes.
Leavey (2005)	N= 13 Canadian	Semi-structured interviews	" <i>Emergence</i> " Problem getting correct	Findings cannot be

	<p>Males and Females Aged 17 to 23 years Difficulties included: Schizophrenia, Psychosis, Delusional Disorder, Obsessive- Compulsive Disorder, Depression, Suicidal Ideation, Eating Disorder, Anxiety Disorder, Bipolar Disorder, Mood Disorder, Post- Traumatic Stress Disorder, Personality Disorders and Learning Disability.</p>	Qualitative grounded theory approach	<p>diagnosis Labelling Stigma “Loss” Loss of identity Loss of independence Loss of academic functioning Loss of family status Loss of friends Interrupted intimate relationship development Interrupted career development</p>	<p>generalised to all youth experiencing mental health difficulties across socio- economic status, education, race, age or severity of difficulty.</p>
O'Reilly, Taylor & Vostanis (2009)	<p>N= 25 English Male and Female Aged 15 to 22 years Participants were homeless and accessing support from a Mental Health Co-ordinator.</p>	Discourse analysis of semi-structured interviews investigating the young people's view of seeing a mental health co-ordinator at a homeless shelter.	<p>Denial of Mental Health Problems Negative Perception of Mental Health Problems</p>	<p>It is not clear whether these young people had received a diagnosis. Specific to a homeless population.</p>
Polvere (2010)	<p>N=12 Canadian Males and Females Aged 16 to 22 years Participants had</p>	<p>Semi-structured interviews Miles and Hubberman's (1994) qualitative coding of narratives.</p>	<p>Stigma and Alienation Therapeutic value of diagnosis Questioning the validity of diagnostic protocols</p>	<p>Specific to young people who have been in a residential</p>

	previously been placed in residential mental health treatment centres and received a diagnosis.			placement.
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Word Count Statement

Thesis Component	Word Count
Title	7
Thesis abstract	289
Research paper	6483
Research paper references	622
Literature review	5967
Literature review references	824
Contributions to theory and clinical practice	4171
Contributions to theory and clinical practice references	574
Word count excluding tables, figures, reference lists and appendices	16,917
Research paper appendix 1	77
Research paper appendix 2	144
Research paper appendix 3	176
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Figure 1: Literature search process (literature review) 179

Table 4a: Data extraction table for quantitative studies (literature review)
1536

Table 4b: Data extraction table for quantitative studies (literature review)
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**Appendices including figures, tables and reference lists, excluding ethics
appendix 14577**

Total word count	31494
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