Understanding and Promoting Help-Seeking Behaviour for Mental Health Difficulties in Young People: A Qualitative Study

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has
been derived from other sources, I confirm that this has been indicated in the thesis.
Signature:
Name: Kirsty-Louise Labuschagne
Date: 22 nd June 2018

Overview

Despite mental health difficulties being common and accounting for the highest disease burden in young people, they often do not seek help or support for these difficulties. This thesis focuses on exploring the mental health difficulties and help-seeking behaviour of young people.

Part 1 is a systematic review of the literature on time trends in the prevalence of mental health difficulties in young people. Four published studies and four national epidemiological surveys are included in the review. The findings suggest an increase in the burden of reported common mental health difficulties in both males and females over the past 30 years. Various socio-cultural and economic factors such as increased social inequality, internet use, and educational pressures, are suggested to have contributed to the observed increases. However, additional research is needed to explore these further.

Part 2 reports a qualitative study exploring, from the perspective of young people, the facilitators and barriers to help-seeking and the potential ways in which an online intervention could support and promote their decisions to seek help. A thematic analysis identified 11 themes within the domains of: socio-cultural ambivalence surrounding mental health, the personal help-seeking process, and online messages and prompts to overcome barriers and support help-seeking.

Finally, Part 3 presents a discussion of how the researcher shaped and was shaped by the research process and findings as well as an exploration of the challenging narratives observed in the data.

Impact Statement

Young people in the UK experience high rates of mental health difficulties for which they often do not seek help. This thesis explores time trends in the mental health difficulties of young people and aims to develop our understanding of the help-seeking behaviour of young people living in the UK. Further, it investigates the potential for an online decision aid to promote mental health help-seeking. A systematic review of UK prevalence data was conducted and findings suggest an increase over the past 30 to 40 years in the reported mental health difficulties of young people aged 15-24. Also, a qualitative study of young people was conducted, and findings suggest that socio-cultural constructs of mental health difficulties are changing yet there remain significant barriers to help-seeking for young people. The findings of this thesis have the potential to positively impact young people, their families and social networks, youth and mental health services, future researchers and academics, and policy makers.

This thesis is the first to review time trends in the prevalence of young people aged 15-24 living in the UK and provides new insights into the growing burden of mental health on this population. These findings have important implications for research, clinical practice, and policymakers. Firstly, the review findings highlight a dearth of high quality epidemiological studies in this area and offers support for the notion that young people are often neglected as a population which is unique from children and adults. Further, it suggests a need for future research to examine the contributory factors influencing observed trends and for services and policymakers to invest in developing and providing targeted and effective interventions which focus on promoting resilience, prevention and early help.

The findings of the qualitative study highlight the influential role of sociocultural narratives on help-seeking and suggest a growing dichotomy in which
mental health difficulties are both stigmatised and glorified within youth culture. It
adds to the literature by providing new insights into the ways in which an internet
based intervention can promote mental health help-seeking and also the potential
challenges of this. Specifically, this study identified that help-seeking interventions
should address the socio-cultural narratives surrounding young people, mental health,
and help-seeking and should improve the mental health literacy of young people by
providing them with normalising and validating information, which can empower
them to seek support for their difficulties. Also, this study provides evidence of a
need for potential help providers, such as parents and teachers, to be given support in
knowing how to recognise and respond to the mental health needs of young people,
as they are often cited as the key facilitators to help-seeking. Further, the study
findings highlight a need for social and individual interventions to strike a balance
between normalising mental health difficulties without glamorising them.

A written summary of the key findings of this thesis will be disseminated to teams and services providing mental health support for young people in East Sussex. This will also be sent to participants who asked to be informed of the research outcome. In addition, they will be reported online on various websites including a youth mental health website (www.isanyoneelselikeme.org.uk) to contribute to public awareness. Finally, the research findings will be shared via presentations and publications to maximise the dissemination of the research to all relevant parties.

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Finally, I want to express my most profound gratitude to Samantha, for always believing that I could do it and for her unwavering patience and support.

Part 1: Literature Review

Are the Mental Health Difficulties of Young People Living in the UK Increasing? A Systematic Review.

Abstract

Aims

There is growing social concern of a mental health epidemic in young people living in the UK. A comprehensive review of global population and cohort studies suggests an increase in internalizing problems in girls aged 18 years and under (Bor, Dean, Najman, & Hayatbakhsh, 2014). However, no review to date has examined the evidence to support the narrative that young people, aged 15-24 and living in the UK, are experiencing more mental health difficulties today than previous cohorts. As such, this review is the first to consider the time-trends in the prevalence of mental health difficulties experienced by this population.

Method

A systematic literature search for both published and unpublished literature was conducted. Inclusion criteria were cohort or population studies, where participants were aged 15-24-years and data were reported for at least two time points. Studies were assessed for quality and findings summarised.

Results

Four studies and four national survey reports were included in the review. These focused on adolescent and young adult cohorts and included young people from England, Scotland, Wales, and Northern Ireland. They examined common mental health difficulties. The majority of studies and surveys report an increase in mental health difficulties in both males and females aged 15-24 years. However, females were more likely to experience mental health difficulties than males across all time points.

Conclusions

The findings of this review suggest that recent cohorts of 15-24-year-olds, living in the UK, are reporting increased mental health difficulties compared to previous cohorts. Few studies have examined the potential causal factors for an increase in mental health difficulties, however, it is possible that significant sociocultural and economic changes over the past few decades may go some way to explaining current trends. Such shifts include, but are not limited to, increased social inequality, social media use, and academic pressures. Further research is required to explore causal explanations for this change and effective interventions aimed at prevention and early intervention should be introduced.

Introduction

Young people are at a stage of life in which they experience significant biological and social changes, which can lead to feelings of hope and excitement and also of fear and uncertainty (Arnett, Žukauskienė, & Sugimura, 2014). In addition, studies suggest that significant social and cultural changes regarding the economy, family, education, values, and lifestyle, may have resulted in young people being at increased risk for developing mental health difficulties in the 21st century (Sweeting, West, Young, & Der, 2010). Indeed, there is a burgeoning social narrative that more young people are experiencing greater psychological distress, as evidenced by current media headlines such as 'Generation perfection: are twentysomething millennials suffering a mental health crisis?' (Holden, 2018) and 'Why young people are more likely to suffer mental health issues than any other generation' (Harvey-Jenner, 2018).

Despite rising public concern of a youth mental health epidemic, and evidence of increased risk factors in the 21st century, the research literature appears to be less clear about the ongoing trajectory of mental health difficulties in young people. Whilst some studies show evidence of increasing prevalence rates (Fombonne, 1998; Smith, Larkin, & Southwick, 2008), others report that there is no evidence for an increase in mental health difficulties and that prevalence rates have remained relatively stable over time (Baxter, et al., 2014; de Graaf, ten Have, van Gool, & van Dorsselaer, 2012). A comprehensive review of global population and cohort studies suggests an increase in internalizing problems in girls aged 18 years and under but found mixed results relating to boys (Bor et al., 2014). Having a clearer understanding of the psychological needs of young people is vital for

informing local commissioning and service design and delivery (Nyman, 2017). With this in mind, the following review focuses on exploring the time-trends of mental health difficulties in young people living in the UK. To the author's knowledge, no such review exists within the current literature.

Defining Young People

The terms young people, adolescents, youth and young adults are regularly used interchangeably in both clinical and research contexts. However, they are also used to distinguish between people from different age categories. It is essential, therefore, for this review to be clear about what is meant by the term 'young people' and why.

Erikson (1950; 1968) proposed eight stages of development with those aged 12-18 described as adolescents, and those aged 18 to 35 described as young adults. Erikson proposed that adolescents face the unique challenge of identity exploration which is influenced by a dual desire for individuality and social inclusion. Alongside significant biological changes, this makes adolescence a time of significant change and considerable uncertainty. Erikson went on to propose that young adulthood is a time in which people become preoccupied with developing intimate relationships. He suggested that it is during this stage that people tend to get married and start their own families. However, since the time of publishing his model, significant social and economic changes in developed countries have resulted in a more ambiguous transition to adulthood, with the assumption of adult roles such as marriage and parenthood often being achieved later in life (Sheehy, 1996; Arnett, 2000; Syed, 2012; Zastrow & Kirst-Ashman, 2010).

Arnett (2000) argues that Erikson's model of development is outdated and suggested that many people today could not be considered young adults, as defined by Erikson, with record numbers of 20-33-year-olds still living with their parents (Office for National Statistics: ONS, 2017), waiting longer to get married (ONS, Marriages in England and Wales: 2015, 2018), and having children later (ONS, 2017). He proposes a new theory of development, in which he suggests that young people, aged roughly between 18 and 25, are at a stage of 'emerging adulthood'. He describes this as a unique time at which young people are neither adolescent nor entirely adult, and proposes that there are five distinctive features of emerging adulthood; identity exploration, instability, self-focus, feeling 'in-between' and possibilities. Many have criticised Arnett, suggesting that his emerging adult theory is specific to its time (Hendry & Kloep, 2007) and not generalisable to young people who do not enter the higher education system (Bynner, 2005). Furthermore, it has been argued that social and cultural processes significantly influence the meaning and experience of age at both the individual and societal level (Wyn & White, 1997). As such, some argue that theories should promote the idea of continuous development and acknowledge the importance of social context, as opposed to focusing specifically on distinct stages (Elder, 1998; Lerner, 1996).

There is ongoing uncertainty around exactly what age group captures 'young people' and it has been argued that using a stage model based purely on age categories is insufficient for representing the complexity of psychosocial development. Despite this, categorical definitions can allow for targeted research to investigate the specific needs of particular groups. In their 2017 publication on young people's well-being, the ONS defined young people as those aged 16-24, and the United Nations (UNESCO. 2002), for "statistical reasons", defines those aged 15-24

as 'youth'. As such, the current review will focus on exploring the mental health prevalence of young people aged 15 to 24.

Defining Mental Health Difficulties

It is generally accepted that mental illness refers to changes in ones thoughts, emotions and behaviours, which cause distress and/or prevent a person from living a meaningful and fulfilling life (Mental Health Foundation, 2016). However, there has been much debate over the years around what is mental illness. For a long time the disease-model of mental illness has dominated and definitions have focused on diagnosis using such manuals as the Diagnostic and Statistical Manual of Mental Disorders (DSM), now in its 5th edition (American Psychiatric Association, 2013) and the International Statistical Classification of Diseases and Related Health Problems (ICD), in its 10th edition (World Health Organization, 1992). In more recent years, there has been a growing shift in which these definitions are being challenged by dimensional approaches with the individual being placed at the centre of understanding mental health difficulties (Manderscheid at al., 2010; Kinderman, 2014; Van Os et al., 1999). Despite these important developments in our understanding of mental health difficulties, most, if not all, epidemiological studies assess for mental health difficulties using interviews or questionnaires that have been developed to identify the presence of disorders, in line with the disease-model. The potential implications of this will be discussed later.

Mental Health Difficulties in Young People

Mental health difficulties are amongst the leading causes of disability worldwide (World Health Organization, 2001) and account for a large proportion of the disease burden in young people (Patel, Flisher, Hetrick, & McGorry, 2007). The

most common mental health difficulties (collectively referred to as common mental disorders, CMDs), include anxiety disorders; such as panic disorder, phobias, social anxiety disorder, obsessive-compulsive disorder, generalised anxiety disorder, and post-traumatic stress disorder; and depression (NICE, 2011). Other mental health difficulties such as psychosis and eating disorders also commonly occur in young people (Hoek, 2009; Perälä, et al., 2007). In a national cross-sectional survey conducted in the United States with 9282 participants aged 18 and older, retrospective age-of-onset reports obtained via interview regarding age of onset of both important symptoms and full syndromes, suggested that 75% of all existing mental health difficulties had emerged by age 24 (Kessler, Berglund, Demler, Jin, Merikangas, & Walters, 2005).

Risk factors.

As discussed earlier, there is a drive for understandings of mental health difficulties to move away from predominantly biological models of disease to models of health that include consideration of the social and psychological determinants of health and wellbeing (Kinderman, 2014). Patel et al. (2007) present a summary of biopsychosocial risk factors associated with the development of mental health difficulties in young people aged 12-24; including poverty and social disadvantage, parental mental disorder or substance abuse, marital violence or breakdown, child sexual abuse, educational pressures and unemployment, and globalisation of the media.

It is beyond the scope of this review to report on all socio-economic and cultural changes which have occurred since the past century; however, significant increases in many of the risk factors presented by Patel et al. (2007) are evident. For

example, increases have been reported in rates of parental emotional problems (Schepman et al., 2011), the proportion of children and young people living in poverty and with single parents (Darton & Strelitz, 2003), and the number of young people reporting worry about their weight and appearance (Sweeting et al., 2010). There is evidence that women, and minority populations, such as ethnic and sexual minorities, are exposed to a disproportionate amount of negative social determinants and are consequently at greater risk of developing mental health difficulties (Elliott, 2016; Freeman & Freeman, 2015).

In more recent years, there has been growing interest in understanding the impact that social media may have on the mental health of young people, with 16-24 year olds accessing social media for around two hours 26 minutes per day (Frith, 2017). Whilst some have suggested social media use to be associated with mental health problems (Office for National Statistics, 2015), Berryman, Ferguson, and Negy (2017) argue that social media use alone is a poor predictor of mental health difficulties. Though time spent on social media may not be predictive of mental health difficulties, research does seem to suggest that the quality of social media use can put young people at increased risk for mental health difficulties (Feinstein, et al., 2013). Furthermore, cyberbullying has been associated with an increased risk of suicide (Hinduja & Patchin, 2010).

Review Aims and Questions

In mental health research and clinical practice, despite being a separate category in ONS surveys, young people are often neglected as a unique demographic group in research review, being instead separated to fit into the children and adolescent or general adult populations. Given the added developmental and social

challenges faced by this age group, this seems inadequate and Goddard (2015) suggests that this has resulted in a poor understanding of, and failure to meet, the specific needs of young people. However, the reluctance of many young people to seek help can make it difficult to have a clear understanding of the true prevalence of their mental health difficulties. Identifying if mental health difficulties are indeed increasing in young people in the UK is a crucial first step to understanding service need and ensuring that services are commissioned and structured in a way that they are able to reduce the individual and social burden of current and future mental health difficulties.

This review is the first to consider the time-trends in the prevalence of mental health difficulties of young people aged 15-24 living in the UK. The following questions were investigated systematically by reviewing recent population and community studies reported in both peer reviewed journal articles and government survey reports.

- 1. What is the current prevalence of mental health difficulties in young people living in the UK?
- 2. What is the evidence that the prevalence of mental health difficulties has increased over time in young people living in the UK?

Method

Search Terms

A systematic search for both published and unpublished literature was conducted on three primary databases (Ovid MEDLINE, Embase and PsycINFO), Google Scholar and NHS Digital. The search terms used were 'mental disorders' OR 'psychological disorders' OR 'psychiatric disorders' OR 'mental illness' OR

'depress*' OR 'anxiety' OR 'psychosis' OR 'psychotic' OR 'traumatic stress' OR 'Anorexi*' OR 'bulimi*' OR 'obsessive' OR 'bi-polar' OR 'bipolar' OR 'manic' OR 'mania') AND ('epidemiology' OR 'prevalence' OR 'survey' OR 'incidence' OR 'cohort studies' OR 'population') AND ('United Kingdom' OR 'England' OR 'Northern Ireland' OR 'Scotland' OR 'Wales') AND ('increase' OR 'decrease' OR 'time factors' OR 'over time' OR 'time trend' OR 'secular trend'). Syntax was adjusted for specific databases and search terms were piloted to maximise sensitivity and specificity. References of papers found, and related literature reviews were screened for additional papers of interest.

Inclusion and Exclusion Criteria

This review included general population prevalence and incidence studies meeting the following criteria:

- 1. Studies were reported in the English language.
- Data was reported for young people aged between 15 and 24 years from a UK population.
- 3. Use of representative community or school samples.
- 4. Studies reported prevalence estimates for at least two time points
- Studies reported using comparable recruitment and assessment methods for each time period.

Studies were excluded from the review if:

 They were published before January 2000: this review focused on investigating recent time-trends and studies published before the year 2000 would not report contemporary data.

- They did not report age-specific prevalence rates and this could not be ascertained from the data.
- They included non-UK samples or did not delineate between UK and non-UK populations in their analysis.
- 4. They only examined convenience or sub-cultural samples.
- 5. They only reported figures related to hospitalisation, suicide, crime or drug use.
- 6. They reported prevalence of neurodevelopment disorders only.
- Studies did not report Odds Ratios or did not report information needed to calculate Odds Rations e.g. number of participants included at each time point.

Data extraction

Information related to the study methodology and findings were extracted into an excel spreadsheet for all articles meeting the inclusion criteria. Using reported prevalence and sample size, it was possible to calculate effect sizes for each study (where this had not already been done), expressed as odds ratios (OR). The OR is 'an indicator of the change in odds resulting from a change in the predictor' (Field, 2009, p. 270) and is widely used in epidemiological studies (Chen, Cohen, & Chen, 2010).

Quality assessments of each study were conducted using an 8-point checklist (see Appendix A) suggested by Loney, Chambers, Bennett, Roberts, and Stratford (1998) in their guidelines for the critical appraisal of studies estimating the prevalence or incidence of a health problem. This checklist assesses criteria related to the validity of the study methods (including study design, sampling frame and size, outcome

measures and measurement approach, and response rate) and the interpretation and applicability of the study findings. Total scores range from 0 to 8 with higher scores representing higher quality. While many appropriate tools exist for assessing the quality of epidemiological studies (Sanderson, Tatt, & Higgins, 2007), the checklist developed by Loney et al. (1998) has been used in a similar systematic review of the changes in mental health over time in young people under the age of 18 (Bor et al., 2014), and was chosen for this review due to its applicability to various observational study designs, it's focus on a small number of key domains (i.e. sampling, measurement and analysis), and it's relative simplicity due to the equal weighting of items.

Results

A search of the main databases, conducted on 31st October 2017, yielded a list of 2966 journal abstracts, articles and book chapters and a further 2 articles and 6 survey reports were identified through searching reference lists, google scholar, and NHS digital. Duplicates were removed and the remaining results were systematically screened first by title and abstract and then by full-text articles, using the inclusion and exclusion criteria, outlined above. Figure 1 provides specific details of this process.

A total of 12 studies were found to meet the inclusion criteria for this review, however four of these reported duplicate prevalence data. Where this was the case, papers reporting the same data were compared side by side and an individualised decision was made to include the paper with the most available data. In two cases, the primary (i.e. first published) papers reported prevalence at fewer time points than the secondary papers. Therefore, a decision was made to exclude the primary papers

and include the secondary papers. In the remaining two cases, it was thought appropriate to exclude the secondary papers and include the primary papers as these reported key mental health outcomes in more detail. Thus, a final total of four reported studies and four national surveys, listed in Table 1, were included in this review.

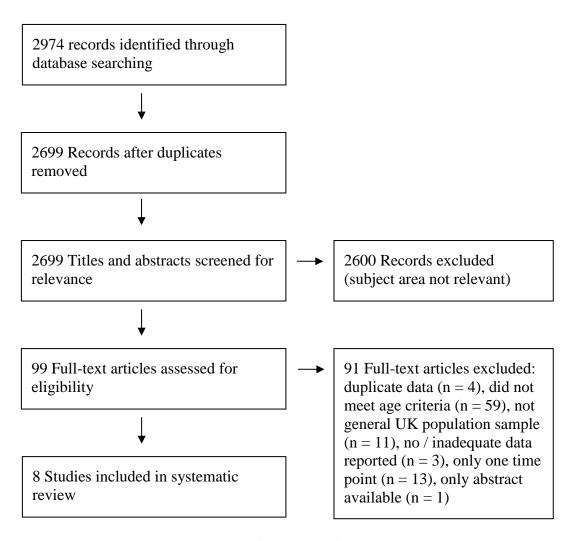


Figure 1. Flow Diagram of Studies Yielded from Systematic Search

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Table 1Summary of Studies and Surveys Included in the Review

							Key findings			
Age range	Sampling frame and site	Years	Data sourced from	Sample size	Response rates	Key assessment instruments	Males and females	Males	Females	Quality rating
15	Cohort and Cross- sectional School population Scotland	1987 1999 2006	Twenty-07 ^a 11 to 16 ^b PaLS ^d	505 2196 3194	65% 79% 81%	Self-reported GHQ-12 _c	↑ between 1987 and 1999 (OR = 2.62) ↑ between 1999 and 2006 (OR =	No significant change 1987 and 1999 ↑ between 1999 and 2006 (OR = 1.94)	↑ between 1987 and 1999 (OR = 3.26) ↑ between 1999 and 2006 (OR =	5
15 -16	Cohort and Cross- sectional Population UK	1974 1986 1999	NCDS° BCS70 ^f B- CAMHS99 ^g	10499 7293 868	87% 44% 83%	Parent report Rutter A scale or SDQ ^h	No significant change between 1974 and 1986	No significant change between 1974 and 1986	No significant change between 1974 and 1986	4
	range	range frame and site 15 Cohort and Cross-sectional School population Scotland 15 -16 Cohort and Cross-sectional Population	range frame and site 15 Cohort and Cross- 1999 sectional 2006 School population Scotland 15 -16 Cohort and Cross- 1986 sectional Population	range frame and site from 15 Cohort and Cross-sectional School population Scotland 15 -16 Cohort and Cross-sectional Population Scotland 15 -16 Cohort and Cross-sectional Population Scotland 1974 NCDS° Sectional Population Population CAMHS99g	range frame and site sourced from size 15 Cohort and Cross- 1999 11 to 16b 2196 2196 2196 2196 2196 2196 2196 2196	range site sourced from size rates 15 Cohort and Cross- 1999 11 to 16b 2196 79% sectional School population Scotland 2006 PaLSd 3194 81% 15 -16 Cohort and Cross- 1986 BCS70f 7293 44% sectional Population Scotland BCS70f 7293 44% sectional 1999 B- 868 83% CAMHS99g	range frame and site sourced from size rates instruments 15 Cohort and Cross- 1999 11 to 16b 2196 79% sectional School population Scotland 2006 PaLSd 3194 81% Self-reported GHQ-12c 15 -16 Cohort and Cross- 1986 BCS70f 7293 44% Rutter A scale sectional Population Scotland 1999 B- 868 83% or SDQh	Age range Sampling frame and site Years Data sourced from Sample size Response rates Key assessment instruments Males and females 15 Cohort and Cross-sectional School population Scotland 1999 11 to 16 ^b 2196 79% GHQ-12c 1987 and 1999 (OR = 2.62) 1987 and 1999 (OR = 2.62) 15 -16 Cohort and Cross- 1986 BCS70 ^f 7293 44% 1997 Parent report No Significant CAMHS99 ^g STQ9 Rutter A scale significant or change between 1999 and 2006 (OR = 1.66) 15 -16 Cohort and Cross- 1986 BCS70 ^f 7293 44% Rutter A scale significant or change between 1974 and 1986 Population UK CAMHS99 ^g CAMHS99 ^g To between 1974 and 1986 ↑ between	Sampling frame and site	No Sampling frame and site Sample sourced from Size Sample sourced from Sourced from Sourced from Sourced size Sample sourced from Sourced from Sourced size Sample sourced from Sourced from Sourced size Sample sourced from Sourced size Sourced size

Collishaw et al. (2010)	16-17	Cohort and Cross- sectional Population UK and England only	1986 2006	BCS70 HSE ⁱ	5436 716	46% 51%	Self-reported frequent feelings of anxiety and depression	† between 1986 and 2006 (OR = 2.68)	↑ between 1986 and 2006 (OR = 1.84)	↑ between 1986 and 2006 (OR = 2.40)	4
Jokela et al. (2013)	15-24	Cross- sectional Population UK	91-94 95-99 00-04 05-09	BHPS ^j	2573 3182 4572 2567	Data not available	Self-reported GHQ-12	No significant change across all time points	Data not available	Data not available	4
McManus et al. (2014)	16-24	Cross- sectional Population first two: England, Scotland and Wales, last two: England only	1993 2000 2007 2014	APMS ^k	1200 666 568 560	79% 63% 57% 57%	CIS-R ¹ conducted by trained researchers	No significant change across all time points	No significant change across all time points	† between 1993 and 2014 (OR = 1.53)	5
Morris & Earl (2017)	16-24	Cross- sectional Population England	2012 2016	HSE	742 626	55% 55%	Self-reported GHQ-12	↑ between 2012 and 2016 (OR = 1.60)	↑ between 2012 and 2016 (OR = 1.94)	↑ between 2012 and 2016 (OR = 1.46)	4
McLean et al. (2016)	16-24	Cross- sectional Population Scotland	1995 1998 2003 2008	SHeS ^m	1007 920 709 531	81% 76% 60%	Self-reported GHQ-12			↑ between 1995 and 2014 (OR = 1.67)	3

			2009 2010 2011 2012 2013 2014 2016		602 603 614 341 405 396 336	54% 56% 55% 56% 56% 56% 56% 51%		† between 1995 and 2016 (OR = 1.72)	↑ between 1995 and 2016 (OR = 2.21)	No significant change between 1995 and 2016	
Department of Health (2017)	16-24	Population Northern Ireland	10/11 11/12 13/14 14/15 15/16 16/17	HSNI ⁿ	339 318 315 232 249 149	62% 65% 66% 64% 60% 59%	Self-reported GHQ-12	No significant change across all time points	† between 2010/11 and 2016/17 (OR = 2.68)	No change between 2010/11 and 2016/17 \$\\$\\$\\$\\$\\$\\$\\$\\$\\$\\$\\$\\$\\$\\$\\$\\$\\$\\$	3

^a West of Scotland Twenty-07 Study: Health in the Community (Benzeval et al., 2008). ^b West of Scotland 11 to 16 Study: Teenage Health (West & Sweeting, 2003). ^c 12 item General Health Questionnaire (Goldberg & Williams, 1988). ^d Peers and Levels of Stress study (Sweeting, Young, & West, 2008). ^e National Child Development Study (Power & Elliott, 2005). ^f 1970 British Cohort Study (Elliott & Shepherd, 2006). ^g 1999 British Child and Adolescent Mental Health Survey (Meltzer, Gatward, Goodman, & Ford, 2000). ^h Strengths and Difficulties Questionnaire (Goodman, 1997). ^I Health Surveys for England (Department of Health, 2003; Morris & Earl, 2017). ^j British Household Panel Survey (University of Essex. Institute for Social and Economic Research, 2010). ^k Adult Psychiatric Morbidity Survey (McManus, Bebbington, Jenkins, & Brugha, 2016). ¹ Clinical Interview Schedule-Revised (Lewis, Pelosi, Araya, & Dunn, 1992). ^m Scottish Health Survey (McLean, Christie, & Gray, 2017). ⁿ Health Survey Northern Ireland (Department of Health, 2017).

Table 2

Critical Appraisal of Studies and Surveys

Study	Sampling method	Sampling frame	Sample size	Appropriate measurement	Is health outcome measured in unbiased fashion? ^a	Response rate	Results report confidence intervals	Study subjects and non- responders described	Overall Quality Score
Collishaw (2004)	✓	✓	✓	×	×	×	×	✓	4
Sweeting (2009)	✓	✓	✓	×	*	*	✓	✓	5
Collishaw (2010)	✓	✓	✓	×	×	×	×	✓	4
Jokela (2013)	✓	✓	✓	×	×	×	×	✓	4
APMS ^b (2014)	✓	✓	✓	✓	*	*	*	✓	5
HSE ^c (2018)	✓	✓	✓	×	*	*	*	✓	4
SHeS ^d (2016)	✓	✓	*	×	*	*	*	✓	3
HSNI ^e (2017)	✓	✓	*	×	*	*	*	✓	3

Note. Sample size and response rate data has been rated based on any data sets used in the study or survey being below threshold, however it is of note that some time comparisons will have a stronger rating of quality

^a Assessed by independent interviewers who are not aware of the participant's clinical status. ^b Adult Psychiatric Morbidity Survey (McManus, Bebbington, Jenkins, & Brugha, 2016). ^c Health Surveys for England (Department of Health, 2003; Morris & Earl, 2017). ^d Scottish Health Survey (McLean, Christie, & Gray, 2017). ^e Health Survey Northern Ireland (Department of Health, 2017).

Data Quality

The data quality scores for each study and survey included in this review are summarised in Table 2. Quality scores ranged from 3 to 5 (mean =4, s.d. =0.71). Study limitations resulting in reduced quality included inadequate sample sizes, and possible bias introduced by low response rates, use of screening measures rather than formal diagnostic interviews, and use of predominantly self-report measures. Furthermore, only one study reported confidence intervals (CIs) for prevalence rates.

Methods of Included Studies and Surveys

Four studies, reporting data from a total of seven separate data sources at different time points, and four surveys reporting multiple time points from the same data source are included in this review. As such, data is presented from 11 separate data sources. The methods used for each of these 11 data sources are discussed in further detail below.

Study design and sampling method.

Seven of the 11 data sources reported in this review used a cross-sectional study design and four used cohort studies, which provided cross-sectional data (see Table 1.). Most of these studies utilised a multistage stratified random sampling strategy, whilst two of the cohort studies, the 'National Child Development Study' (Power & Elliott, 2005) and the '1970 British Cohort Study' (Elliott & Shepherd, 2006) included all children born in England, Scotland and Wales in a single week in March, 1958 and April, 1970 respectively. Multistage sampling is a strategy often

used in large survey studies and involves smaller groups of the overall population (e.g. postcode sectors) being randomly selected and then randomly selecting the final sample from within these groups (e.g. by address).

Though there are significant benefits to cross-sectional studies which use multistage sampling; such as providing a flexible and cost effective strategy for sampling a highly dispersed population; this sampling strategy is considered to be less robust than true random sampling, as portions of the population are excluded from the study. Thus study findings cannot be considered fully representative of the population (Acharaya, Prakash, Saxena, & Nigam, 2013). It is also possible that the two cohort study samples, which included all children born in March or April, may not be representative of the general population as although all babies in a particular week were included, it is possible that babies born in the spring months may have different health outcomes to those born at other times of the year (Torrey, Miller, Rawlings, & Yolken, 2000).

Sampling frame and size.

Most data sources came from studies which were conducted using an unbiased community household (n = 7) or school (n = 2) based sampling frame. For the purpose of the quality assessment, the simple formula suggested by Naing, Winn, and Rusli (2006) was used to calculate a conservative sample size needed for a population study, using multistage sampling, to provide an accurate estimate of prevalence. Naing et al. (2006), suggest that an error rate of 5% is typically appropriate if the prevalence rate is likely to fall between 10% and 90%, and that if

there is a range of estimated prevalence rates, the highest should be used as this will give a larger sample size. Further, they propose that studies using cluster or multistage sampling require larger sample sizes to account for increased error and achieve the same precision. The sample size for such study designs needs to be multiplied by the design effect: i.e. the impact of deviations of the sampling frame from a simple random sample on the statistical estimates from the sample.

Following their recommendations, the sample size needed, with the estimated prevalence of common mental health disorders set at 28% (Jokela, Batty, & Kivimäki, 2013), precision rate set at 5% and a confidence interval of 95%, would be 309 multiplied by the design effect (estimated to be 1.47 based on the Health Survey for England [Morris & Earl, 2017]). This equates to a final sample size of 454. All but two of the studies met this threshold at all reported time points, with sample sizes ranging from 149 to 10499 (mean = 1611.21, s.d. = 2199.63).

Sample characteristics.

The four large-scale national surveys included in this review report prevalence rates of mental health difficulties in young people aged 16-24 years at several different time points. These were the Adult Psychiatric Morbidity Survey (APMS: McManus, Bebbington, Jenkins, & Brugha, 2016), the Health Surveys for England (HSE: Department of Health, 2003; Morris, & Earl, 2017), the Scottish Health Survey (SHeS: McLean, Christie, & Gray, 2017), and the Health Survey Northern Ireland (HSNI: Department of Health, 2017). Of the four reported studies, one examined time-trends in the prevalence of mental health difficulties in 15 year

olds (Sweeting, Young and West, 2009); one in 15-16 year olds (Collishaw, Maughan, Goodman and Pickles, 2004); and one in 16-17 year olds (Collishaw, Maughan, Natarajan and Pickles, 2010). Finally, Jokela et al. (2013) reported prevalence data for 15-24 year olds. Samples consisted of an average of 44% males (s.d. = 4.70).

Outcome measures used by studies and surveys.

Loney et al. (1998) propose that whilst formal diagnostic tests, conducted by blinded interviewers, may be the gold standard for epidemiological studies, it is often not feasible to do this when researching large populations. As such, they suggest that measures should be reliable and valid and should have high sensitivity and specificity. Studies should also ensure that participants include both those who may have the disease/disorder and those who do not. Several measures were used in the review studies and surveys and are presented in Table 3 and discussed below. It is of note that the use of parent or self-report measures by all but one study may have introduced response bias (Rosenman, Tennekoon, & Hill, 2011).

Table 3

Outcome Measures used by Included Review Studies and Surveys

Outcome Measure	Study	Cut Off
Clinical Interview Schedule- Revised (CIS-R) ^a	Adult Psychiatric Morbidity Survey ^b	≥ 12
12 item General Health Questionnaire (GHQ-12) ^c	British Household Panel Survey ^d	≥ 2
	West of Scotland Twenty-07 Study: Health in the Community ^e	4/5
	West of Scotland 11 to 16 Study: Teenage Health ^f	4/5
	Peers and Levels of Stress study ^g	4/5
	Health Survey for Englandh	≥ 4
	Scottish Health Survey	≥ 4
	Health Survey Northern Ireland ^j	≥ 4
Rutter-A scale ^k	1970 British Cohort Study ¹	≥ 3
	National Child Development Study ^m	≥ 3
Strengths and Difficulties Questionnaire (SDQ) ⁿ	1999 British Child and Adolescent Mental Health Survey ^p	≥ 3
Frequency of anxiety and depression ^p	1970 British Cohort Study ^p Health Surveys for England ^p	'often' or 'most of the time'

^a Lewis, Pelosi, Araya, and Dunn (1992). ^b McManus, Bebbington, Jenkins, and Brugha (2016). ^c Goldberg and Williams (1988). ^d Jokela et al. (2013). ^eBenzeval et al. (2008). ^fWest and Sweeting (2003). ^g Sweeting, Young, and West (2008). ^h Morris & Earl (2017) ⁱ McLean, Christie, and Gray (2017). ^j Department of Health (2017). ^k Rutter, Tizard, and Whitmore, (1970). ¹ Elliott and Shepherd (2006). ^m Power and Elliott (2005). ⁿ Goodman (1997). ^o Meltzer, Gatward, Goodman, and Ford (2000). ^p Collishaw et al. (2010).

Clinical Interview Schedule-Revised (CIS-R).

Only one of the studies and surveys included in this review used a standardised diagnostic interview. The APMS used the Clinical Interview Schedule-Revised (CIS-R: Lewis, Pelosi, Araya, & Dunn, 1992); a fully structured interview schedule, which was administered by trained researchers and used to identify the presence of specific CMDs in the previous week. The CIS-R has been shown to have an estimated reliability of 0.74 (Lewis et al., 1992) and to be moderately valid (Jordanova, Wickramesinghe, Gerada, & Prince, 2004).

12 item General Health Questionnaire (GHQ-12).

Seven of the studies and surveys from which data were sourced used the GHQ-12 (Goldberg & Williams, 1988) to assess for probable CMDs. The GHQ-12 is a self-report measure which is widely used in both clinical practice and research as a screening tool aimed at identifying current non-psychotic mental health difficulties in the general population. The questionnaire asks participants to report how often they have experienced various difficulties, such as with sleep, appetite and mood, over the previous four weeks. Responses are given a score of zero or one resulting in a maximum possible score of 12, with higher scores indicative of greater psychological distress. Goldberg (1972) showed this measure to be valid and reliable, reporting a sensitivity score of 93.5% and a specificity score of 78.5%. It is of note that three of the surveys used a score of four or more to indicate probable mental ill health and one study from which data were sourced used a score of two or more. Sweeting et al. (2009) provided prevalence rates using three different cut offs including 2/3, 3/4, and

4/5. For the purpose of this review, the highest threshold reported by studies was used.

Rutter-A scale.

Two studies from which data were sourced used the Rutter A scale (Rutter, Tizard, & Whitmore, 1970; Elander & Rutter, 1996), which is a parent report measure of behaviour and emotional difficulties in children and adolescents. The parental questionnaire consisted of 31 questions, related to the child's behaviour, which parents were asked to respond to using a three point scale (0 = 'does not apply', 1 = 'applies somewhat' and 2 = 'certainly applies'). Rutter (1970) reported good inter-rater reliability (r = 0.64) and test retest reliability (r = 0.74) for the parent report scale. Collishaw et al. (2004), in the current review, combined the misery, worries and fearful of new situations items to create a six-point emotional difficulties subscale with a cut off of three indicating marked emotional difficulties. This six-point scale was found to be strongly correlated with the standard SDQ subscale for emotional difficulties (correlation was .84), and is utilised in the current review.

Strengths and Difficulties Questionnaire (SDQ).

The 1999 British Child and Adolescent Mental Health Survey (Power & Elliott, 2005), as reported in this review by Collishaw et al. (2004), used the parent report Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) to assess emotional difficulties of young people. The SDQ is a brief behavioural screening tool, designed to measure mental health difficulties in children and adolescents aged between 3 and 16. A "total difficulty score", ranging from 0 to 40, is obtained by the

sum of 20 items (each with a 0- to 2-point scale) relating to emotional symptoms, conduct problems, hyperactivity and peer problems. An internal consistency rating of .73 and a test-retest reliability of .62 was shown for this scale (Goodman, 2001).

Frequency of anxiety and depression.

Collishaw et al. (2010) assessed self-reported anxiety and depression by asking young people if, and how often, they had felt anxious, depressed or unhappy for more than one day in the previous year (Collishaw, 2010). Participants who responded 'often' or 'most of the time' were considered to have self-reported anxiety or depression and were compared with participants who reported 'occasionally only' or 'never'. This could be considered a rather crude measure of mental health due to the wide scope for interpretation by participants.

Response rates.

Response rates of the included studies ranged from 44% to 87%. Marshall (1987) suggests that a response rate of two-thirds to three quarters is likely to lead to findings that can be generalized to the population sample. This would suggest that a response rate of 66.67% would be acceptable in this review. However, there is clear evidence in the literature that response rates for epidemiological studies have substantially fallen in the 21st Century (Galea & Tracey, 2007). Indeed, Morton, Bandara, Robinson and Carr (2012) suggest that additional factors such as details of non-responders, attempts made to improve participation, and denominators used to calculate response rates, should be considered alongside response rates when

assessing the quality and usefulness of study findings. All of the studies included in this review provided details on the characteristics of non-responders and most used weighted data to account for potential bias introduced by this.

Major Findings

Overall prevalence of mental health difficulties in young people.

Overall prevalence of mental health difficulties in young people was reported at a total of 35 time points, and at 23 unique time points (i.e. separate years), between 1974 and 2017 (see Appendix B). Reported prevalence ranged from 5% in 1987 to 27.8% in 2009. Prevalence at each time point was most commonly reported to be between 11 and 20% (n = 27 time points) and between 21 and 30% (n = 6 time points). A prevalence of below 10% was reported at only two time points (Collishaw et al., 2010; Sweeting et al., 2009). Figure 2 provides a visual synthesis of the reported prevalence.

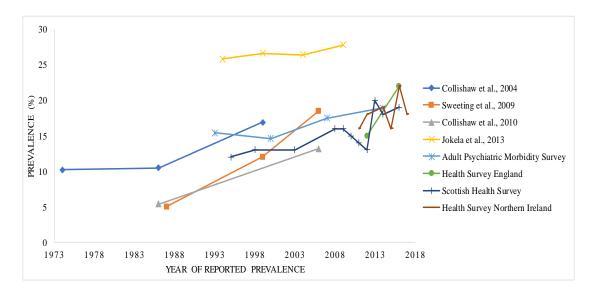


Figure 2. Prevalence of Mental Health Difficulties of Young People

Evidence of a significant increase over time in the prevalence of mental health difficulties in young people was provided by five of the reported studies and surveys included in this review. Collishaw et al. (2004) showed that the prevalence of high emotional problems in young people significantly increased between 1986 and 1999. Sweeting et al. (2009) showed a significant increase in the prevalence of young people scoring 4/5 on the GHQ-12 between 1987 and 1999, and between 1999 and 2006. Further, Collishaw et al. (2010) showed that youth reports of frequent anxiety and depression almost tripled between 1986 and 2006. The Health Survey for England (Morris & Earl, 2017) showed that young people were significantly more likely to experience probable mental health difficulties in 2016 compared to 2012. Finally, the Scottish Health Survey (McLean, Christie, & Gray, 2017) showed a significant increase in the prevalence of high GHQ-12 scores (score of four or more) between 1995 and 2008; 2009; 2013; 2014; and 2016. The studies and surveys reporting a significant increase received quality scores of three (n = 1), four (n = 2), and five (n = 2).

Though there appears to be an upward trend in the prevalence of mental health difficulties in all reported studies and surveys, further analysis suggests that in three of these, prevalence may in fact have remained relatively stable. Jokela et al. (2013) hypothesised that the prevalence of CMDs, identified as a score of two or more on the GHQ-12, may have increased in more recent years, however they showed no significant change in prevalence between 1994 and 2009. These findings are further supported by the Health Survey for Northern Ireland (Department of Health, 2017), which suggests that the prevalence of young people scoring four or

more on the GHQ-12 has not significantly increased between 2010 and 2017. Finally, the Adult Psychiatric Morbidity Survey, which was the only study to use diagnostic interviews for the assessment of CMDs, also showed that increases in prevalence between 1993 and 2014 appear to be non-significant. The studies reporting no significant increase in prevalence received a quality rating of four, three, and five respectively.

Prevalence of mental health difficulties by age group.

Prevalence data from studies of young people aged 15-17 were reported for eight time points between 1987 and 2006. Reported prevalence ranged from a low of 5% in 1986 to a high of 26.4% in 2006. When studies and surveys reported prevalence for a wider age group, that included young adults as well as adolescents (i.e. 15-24 or 16-24), the prevalence was higher, ranging from a low of 12% in 1995 to a high of 27.8% in 2009.

Trends in mental health difficulties by age group.

All three of the reported studies investigating young people aged 15-17 showed a significant increase in the prevalence of mental health difficulties between 1986 and 2006 (Collishaw et al., 2004; Collishaw et al., 2010; Sweeting et al. 2009). Three of the studies and surveys looking at the wider age group (15-24 and 16-24) reported no significant change in prevalence over time (Jokela et al., 2013; McManus, Bebbington, Jenkins, & Brugha, 2016, Health Survey Northern Ireland: Department of Health, 2017) while two reported a significant increase between 1995

and 2016 (Scottish Health Survey: McLean, Christie, & Gray, 2017) and between 2012 and 2016 (Health Survey for England: Morris & Earl, 2017).

Prevalence of mental health difficulties by gender.

Data was available by gender for all but one of the studies and surveys included in this review, with prevalence of mental health drawn from 10 separate data sources. Gender specific prevalence was reported at a total of 30 time points (see Appendix C), and at 20 unique time points (i.e. separate years), between 1974 and 2017 for both males and females.

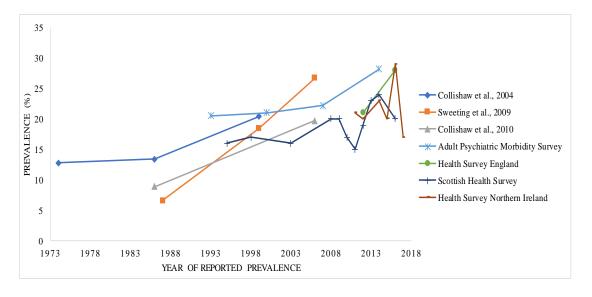


Figure 3. Prevalence of Mental Health Difficulties of Females aged 15-24

The prevalence of mental health difficulties in females ranged from 6.6% in 1987 to 29% in 2016 (see Figure 3.). In males, prevalence ranged from 2.9% in 1986 and 21% in 2017 (see Figure 4.).

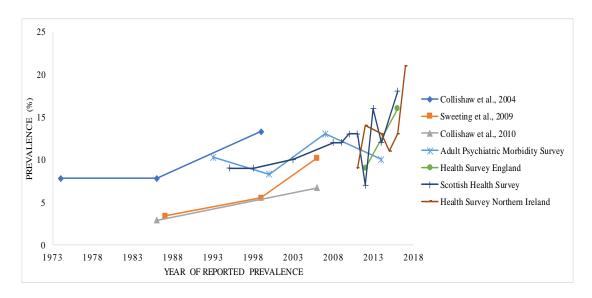


Figure 4. Prevalence of Mental Health Difficulties of Males aged 15-24

Trends in mental health difficulties by gender.

Evidence of an increase over time in the prevalence of mental health difficulties in females was presented by six of the seven studies and surveys for which gender specific data were available. Sweeting et al. (2009), Collishaw et al. (2010), the Adult Psychiatric Morbidity Survey (McManus, Bebbington, Jenkins, & Brugha, 2016), and Scottish Health Survey (McLean, Christie, & Gray, 2017) all showed a significant increase in mental health prevalence between the 1980s and 1990s and between the 1990s and 2000s. Furthermore, the Health Survey for England (Morris & Earl, 2017) reported an increase within the 21st century, with

prevalence reported at 21% in 2012 and 28% in 2016. Interestingly, findings from the Health Survey for Northern Ireland (Department of Health, 2017) suggest a significant decrease in high GHQ-12 scores in females between 2015/16 and 2016/17.

Similarly to females, an increase in the prevalence of mental health difficulties in males was reported by six of the seven studies and surveys for which gender specific data were available. Prevalence was shown to increase from within the 20th century (Collishaw et al., 2004), between the 20th century and the 21st century (Sweeting et al., 2009; Collishaw et al., 2010; SHeS: McLean, Christie, & Gray, 2017) and within the 21st century (Health Survey for England: Morris & Earl, 2017; Health Survey Northern Ireland: Department of health, 2017). In contrast, findings from the Adult Psychiatric Morbidity Survey (McManus, Bebbington, Jenkins, & Brugha, 2016) suggests that, though prevalence has been trending upwards, there has been no significant increase in the prevalence of common mental health difficulties in males between 1993 and 2014.

Prevalence of mental health difficulties by geographic area.

Prevalence rates were reported for the following populations: England (n = 5 time points), Scotland (n = 13 time points), and Northern Ireland (n = 6 time points). There was variation in the lowest and highest reported prevalence across geographic region. Reported prevalence ranged between 15 and 26.4% (mean = 19.96, s.d. = 4.4) in England, 5 and 20% in Scotland (mean = 14.61, s.d. = 3.85), and 16 and 22% (mean = 18.17, s.d. = 2.03) in Northern Ireland. In 2016, the prevalence of high

GHQ-12 scores was 22% in England and Northern Ireland and 19% in Scotland.

These findings suggest no significant differences in the current prevalence of mental health difficulties across different UK regions.

Trends in mental health difficulties by geographic area.

The Health Survey for England (Morris & Earl, 2017), Scottish Health Survey (McLean, Christie, & Gray, 2017), and Health Survey for Northern Ireland (Department of Health, 2017) all reported prevalence of mental health difficulties in 2012 and 2016. Further analysis of data from these time points, showed that prevalence increased significantly in England, from 15 to 22%, Scotland from 13 to 19%, and Northern Ireland from 18 to 22%. Interestingly, the prevalence of high GHQ-12 scores dropped between 2016 and 2017 in Northern Ireland.

Discussion

This review aimed to investigate time-trends in the prevalence of mental health difficulties in young people living in the UK. A systematic exploration of four published journal articles and four national surveys provided prevalence data for 23 unique time points (i.e. separate years), between 1974 and 2017. Overall, the results of this review indicate that the burden of reported mental health difficulties in young people has increased both since the 1980s, and within the 21st century. However, closer examination of the findings suggests that the degree of increase may vary across such variables as age and gender.

Whilst the majority of studies reported an increase in the number of young people aged 15-17 reporting mental health difficulties between 1986 and 2006, the evidence of an increase in the wider age groups (i.e. 15-24 and 16-24) was present but not so strong. Females appear to be consistently more burdened by mental health difficulties than males, with all studies and surveys reporting significantly higher prevalence rates at all but one time point. Nonetheless, the majority of studies and surveys included in the review provide evidence of an increase over time in the mental health difficulties of both females and males aged 16-24.

Various explanations for reported increases in the prevalence of mental health difficulties in young people overall, and for the widening gender gap, have been suggested. Collishaw et al., 2004 argue that evidence of increasing prevalence over time is unlikely to be explained fully by changes in the gene pool alone and so provide support for the importance of the role of environmental influences on mental health. As discussed earlier, various economic, societal and family changes, occurring over the last 50 to 60 years, are considered to be associated with an increased risk of mental health difficulties in young people. These include, but are not limited to, significant increases in the UK in: the number of lone parent and stepfamilies (ONS, 2015), inequalities of income, wealth and opportunities between social classes, geographical regions and generations (Office for National Statistics, 2016), the proportion of young people living in households at risk of poverty (ONS, 2017), the emphasis on educational attainment and increased educational stress, with record numbers of young people attending university (ONS, 2017; Rutter & Smith, 1995). In addition, young people living in the UK have been disproportionately

affected by the government's austerity agenda with millions of pounds being cut from youth services, cuts to the Education Maintenance Allowance and housing benefit, and rates of unemployment being particularly high in young people aged 16 to 24 (UNISON, 2016). The negative impact of austerity on psychological well-being is well documented within the field of psychological research and it is likely that cuts to youth services have contributed to the increases seen in reported prevalence of mental health difficulties in young people (McGrath, Griffin, & Mundy, 2015).

The potential role of the internet cannot be ignored, with 96% of 16-24 year olds reporting to have set up their own social media page in 2016 and cyberbullying being found to be a common experience, with profound consequences on a young person's mental health and well-being (Hinduja & Patchin, 2010). Furthermore, growing evidence links social media use to feelings of anxiety and low mood (Anxiety.org, 2016), poor sleep quality (Woods & Scott, 2016), and increased worry about body image (Fardouly, Diedrichs, Vartanian, & Halliwell, 2015). Freeman and Freeman (2015) suggest that the environmental determinants of mental health difficulties, such as exposure to childhood sexual abuse and cultural attitudes to weight, may have a greater impact on women than men leading to a higher prevalence of mental health difficulties in women.

A continuing decline in the use of illicit drugs since 1996 to 2017 (Webb, 2017) and in overall alcohol consumption and binge drinking since the year 2000 (Smith & Foxcroft, 2009) suggests that these factors may not be critical contributors to an increase of mental health difficulties in young people. However, few studies have scientifically examined the potential causal factors for an increase in mental

health difficulties of young people and those which have suggest that trends are likely to result from a complex interaction between "multiple risk factors of relatively small effect size" (Schepman et al., 2011, p. 298). As such, further research is needed to identify the ways in which the various changes in the lives of young people over time, interact and result in increased mental health difficulties.

When interpreting the results of this review, it is important to consider that they may not represent a true reflection of the prevalence of mental health difficulties in young people. Kessler, Wittchen, Abelson, Zhao, and Stone (2000) suggest that because of continuing high levels of stigma, people's responses to mental health assessments may be influenced by feelings of embarrassment and fear of discrimination. This has been shown to be true for both self-report measures (Latkin, Edwards, Davey-Rothwell, & Tobin, 2017) and interview based measures (Davis, Couper, Janz, Caldwell & Resnicow, 2009). As such, Kessler goes on to argue that the prevalence of mental health difficulties reported in epidemiological surveys should generally be considered lower bound estimates. In addition, though qualitative research suggests that young people continue to experience high levels of stigma and struggle to recognise and talk about mental health difficulties (Greenwood, Berry, Labuschagne, Chandler, Peters, Field, & Garety, 2014), it is not possible to discount that the observed increases in prevalence reported in this review may reflect changes in the way that young people conceptualise, express, and respond to assessments of mental health (Sweeting et al, 2009) rather than reflecting a true increase in the prevalence of mental health difficulties.

Limitations

There are several limitations of this review that need to be considered. Firstly, though the search conducted for this review allowed for psychosis, eating disorder and bipolar disorder, a lack of such studies meeting the inclusion criteria resulted in the review being largely focussed on anxiety and depression. Indeed, only four published studies and four national epidemiological surveys met the inclusion criteria for this systematic review. Thus, though the review findings are based on the best available data of the time, they are somewhat constrained by the few studies reporting prevalence in young people. Due to the low number of studies looking at time trends in young people aged 15-24, studies and surveys of relatively low quality (score of 3) were included in this review. Furthermore, despite appropriate study design and generally large sample sizes, various methodological issues were identified with each study and survey included in the review. Low response rates were reported for at least one time point of all included studies, possibly reducing the reliability and validity of their findings (Fincham, 2008). In order to address this potential limitation, most studies investigated differences in the characteristics of responders and non-responders and weighted their data in order to be representative of the population (Brick and Kalton, 1996). Finally, the predominant use of mental health screening tools as opposed to diagnostic interviews is considered to lower the quality of the study findings.

It could be argued that it would be valuable to combine the datasets included in this review and to conduct a meta-analysis, however, there are also significant challenges with combining observational epidemiological studies due to the issues of

confounding, selection bias, differences in the presentation of data and difficulties in detecting heterogeneity across study design, data collection and analysis (Blettner, Sauerbrei, Schlehofer, Scheuchenpflug, & Friedenreich, 1999; Blettner et al., 2014). For the purpose of this review, a meta-analysis was decided against due to the aforementioned complexities of combining different datasets, the challenges of combining datasets which cover a different series of dates, and the potential that by producing a single odds ratio the data may be overly simplified and fail to show the gradual trends across years as seen in Figure 1.

Clinical and Research Implications

The findings of this review highlight important clinical and research implications. For example, young people as a unique demographic group appear to have been somewhat neglected, with most research and clinical services being targeted at children and adolescence (0-18 years) or working age adults (18-65 years). As such, and despite young people being particularly vulnerable to experiencing mental health difficulties, the specific needs of young people continue to be misunderstood and unmet. Many argue that this has resulted in a 'treatment gap' with young people finding current services inaccessible and unresponsive to their particular needs. McGorry, Hickie, Yung, Pantelis, and Jackson (2006) argue that interventions which focus on supporting the mental health of young people can lead to greater personal, social and economic benefits than interventions at any other time in the lifespan. Future research should therefore focus on further exploration of the mental health needs of young people, addressing both the prevalence of mental

health difficulties, and the possible contributing factors to this. In addition, clinicians are advised to hold in mind the potential stressors that young people face today and to promote and provide early interventions for young people. Here, it may be important to draw on community psychology models and theory, which place a focus on exploring the interaction of the individual and their environment, prevention, strengths, inter-agency collaboration, diversity, and building socially just, inclusive and empowered communities (Jason, Stevens, Ram, Miller, Beasley, & Gleason, 2016; Moritsugu, Vera, Wong, & Duffy, 2013).

Conclusion

This systematic review of the time-trends of mental health difficulties in young people suggests that the prevalence of mental health difficulties has increased both since the 20th century and in the 21st century. Females had consistently higher prevalence rates than their male counterparts, however an increase in prevalence was observed in both males and females aged 15-24. Environmental factors may go towards explaining observed trends, however further research is needed to fully understand the impact of social, cultural and economic changes on the mental health of young people. Furthermore, the review findings highlight the need for a greater understanding of the specific needs of young people and for targeted early intervention. Involving young people in the design and delivery of mental health services and drawing on community-based models of intervention may go some way to reducing the current barriers that young people experience when trying to access services.

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Part 2: Empirical Paper

Understanding and Promoting Help-Seeking Behaviour for Mental Health
Difficulties in Young People: A Qualitative Study

Abstract

Aims

Mental health difficulties are common, and account for the highest disease burden, in young people. Despite this, young people often don't seek support for their mental health difficulties (Donald, Dower, Lucke, & Raphael, 2000; Merikangas, et al., 2011). This qualitative study aimed to explore, from the perspective of young people, the facilitators and barriers to help-seeking and the ways in which an online intervention could support help-seeking decision making in young people.

Method

Twelve young people within the 15-24 age range and with experience of mental health difficulties were interviewed. Transcripts were analysed using Thematic Analysis (Braun & Clarke, 2006).

Results

Young people spoke about the negative impact of mental health stigma and also mental health glamorisation on their help-seeking behaviour. They discussed the difficulty of recognising a 'problem', knowing where to go for help and believing that the process of help-seeking will be challenging and could lead to a negative outcome as barriers to help-seeking. Encouragement from others was identified as the predominant facilitator. Young people wanted an online decision aid to support them in making an informed choice about help-seeking by providing them with validating and reassuring knowledge.

Conclusions

Young people reported that an online decision aid could, in principle, be helpful in promoting help-seeking if it addresses both the socio-cultural narratives surrounding mental health and help-seeking and provides information and prompts to take action whilst prioritising choice and autonomy. Further research is needed to investigate the perspectives of different sub-populations such as young people from black and minority ethnic backgrounds and to explore the way in which an online decision aid could draw on the facilitative role of potential help providers.

Introduction

Adolescents and young people are considered to be navigating a crucial transitional period in which they experience various biological, behavioural and social changes, which can lead to an increased vulnerability to mental health difficulties (Dahl, 2004; Rickwood D., 2014). Indeed, the evidence suggests that mental health difficulties typically emerge before the age of 24 (Kessler, et al., 2005) and account for the greatest health burden within young people aged 16-24 (Erskine, et al., 2015; Patel, Flisher, Hetrick, & McGorry, 2007). Despite the high prevalence of mental health difficulties and the availability of effective interventions shown to improve outcomes, surveys suggest that many young people do not seek professional help and get the support they need (Donald, Dower, Lucke, & Raphael, 2000; Merikangas, et al., 2011). A recent online cross-sectional survey found that 35% of 18-25-year-olds from the general UK population did not seek any form of help despite reporting experiences of an emotional or mental health difficulty (Salaheddin & Mason, 2016). Further, research suggests that those who do seek help typically wait an average of 10 years following the first onset of symptoms before seeking support from mental health services (Kessler et al., 2005). Delayed help-seeking can lead to increased individual, social and economic burden as symptoms decline and the need for more intensive health interventions increase (Tedstone Doherty & Karalova-O'Doherty, 2010).

As well as suicide being the leading cause of death in young people, poor mental health during this stage of life has been found to be related to an increased risk of future unemployment, substance misuse, and recurring mental health

difficulties (Kim-Cohen, et al., 2003; Patel et al., 2007). It is crucial therefore to develop interventions that successfully promote help-seeking in young people to reduce both the individual and social burden of ongoing mental health difficulties. This study explores, from the perspective of young people, the facilitators and barriers to help-seeking and views on the use of an online intervention aimed at supporting help-seeking decision making.

Help-Seeking

Definition.

Cornally and McCarthy (2011) conducted a review of the help-seeking literature and found that help-seeking for physical and mental health difficulties is consistently defined as "a process, that begins in response to a problem... and involves the active pursuit of, and interaction with a third party" (p. 282). In their review in which they focus on the mental health literature, Rickwood and Thomas (2012) identify several common components of previous definitions of help-seeking. They propose that "in the mental health context, help-seeking is an adaptive coping process that is the attempt to obtain external assistance to deal with a mental health concern" (Rickwood & Thomas, 2012, p. 180). Help can be sought directly from informal helpers, such as friends and family, formal helpers, such as health and mental health professionals, and from indirect sources such as the internet (Rickwood, Deane, Wilson, & Ciarrochi, 2005). In this study, the term help-seeking

refers to behaviour in which support from an external source, direct or indirect, personal or professional, is sought in relation to emotional or psychological distress.

Models of help-seeking.

Many models attempt to understand and explain the complexity of help-seeking behaviour such as the theory of planned behaviour (Ajzen, 1991), the health belief model (Hochbaum, 1958), Anderson's behavioural model of health service use (Anderson, 1995), and the cycle of avoidance model (Biddle, Donovan, Sharp, & Gunnell, 2007). Across these models, the process of help-seeking behaviour is characterised mainly by three distinct attributes: problem focus, intentional action and interpersonal interaction (Cornally & McCarthy, 2011). It is first necessary for an individual to recognise the existence of a problem and the need for help (Anderson, 1995; Biddle et al., 2007; Glossop, 2012; Kirscht, 1974; Rickwood et al., 2005). Following this, the person then decides whether to seek support, selects a source of help, and discloses the problem to another person (Biddle et al., 2007; Rickwood et al., 2005).

This decision, and thus help-seeking behaviour, is influenced by one's beliefs about the severity and normality of the problem (Biddle et al., 2007; Glossop, 2012; Hochbaum, 1958) and the process and outcome of help-seeking (Ajzen, 1991; Hochbaum, 1958; Glossop, 2012), and the availability of help sources, and ability and willingness to seek external support (Rickwood et al., 2005). Also, contextual factors related to the healthcare system and the individual (e.g. cultural factors such as stigma and demographic factors such as age and gender) are likely to influence an

individual's help-seeking beliefs and behaviour (Anderson, 1995). Finally, the decision to seek help can be influenced by motivational factors such as self-efficacy (Ajzen, 1991; Glossop, 2012; Hochbaum, 1958; Liang, Goodman, Tummala-Narra, & Weintraub, 2005; Nelson-Le Gall, 1985). As such, interventions that hope to promote help-seeking should focus not only on developing knowledge and awareness but also on the other aspects of the help-seeking process, namely the decision to seek help, the selection of a source, and the disclosure of a problem (Cornally & McCarthy, 2011).

Facilitators and Barriers to Help-Seeking

Many studies have explored the facilitators and barriers to professional help-seeking in adolescents and young people. Using their conceptual framework of help-seeking discussed above, Rickwood and colleagues investigated factors that promote and hinder professional help-seeking in young people aged between 10 and 24 years (Rickwood et al., 2005; Rickwood, Deane, & Wilson, 2007). They highlighted recognition and understanding of mental health difficulties, emotional competence, positive attitudes and past experiences of mental health, and social encouragement and established and trusted relationships with family and health professionals as facilitators to professional help-seeking. Barriers to help-seeking included difficulties in identifying and describing emotions, a need for self-reliance and autonomy, and negative attitudes and fears related to seeking professional support.

More recently, Gulliver, Griffiths, and Christensen (2010) conducted a metathematic analysis of the qualitative literature on the facilitators and barriers to helpseeking from the perspective of young people themselves. They identified stigmatising attitudes, difficulties in identifying mental illness, reliance on self, concerns about confidentiality and trust, and the characteristics of the help-provider to be the most prominent barriers to help-seeking. Conversely, positive past help-seeking experiences, social support and encouragement, confidentiality, and positive relationships with staff were identified as facilitators to help-seeking. A limitation of their review is that it failed to consider the influence of culture and context on help-seeking by reporting cross-cultural studies together (Mitchell, McMillan, & Hagan, 2017).

Salaheddin and Mason (2016) included in their online survey, a qualitative question which asked "in your own words, please describe why you chose not to ask for help for your emotional or mental health needs, there is no right or wrong answer" (e687). They conducted a thematic analysis on the qualitative feedback using an inductive approach and assessed barriers to future formal help-seeking using the Barriers to Access to Care Evaluation (BACE) scale (Clement, et al., 2012). In line with previous research, they identified stigma, poor knowledge and awareness of mental health difficulties and services, a preference for self-reliance, and difficulty accessing help as prominent barriers (Salaheddin & Mason, 2016). A limitation of their study was that they did not explore the facilitators to help-seeking in their study.

The Role of Internet Based-Interventions

A recent report published by the Office of National Statistics (ONS, 2017) suggests that in 2017 nearly all young people aged 16-34 in the UK regularly used

the internet (99%). Furthermore, research shows that the internet is becoming a primary resource for accessing health information (Eysenbach, Powell, Kuss, & Sa, 2002; Powell & Clarke, 2006; Wood, Benson, LaCroix, Siegel, & Fariss, 2005), especially for young people (Fergie, Hilton, & Hunt, 2015; Kris Gowen, 2013; Gray, Klein, Noyce, Sesselberg, & Cantrill, 2005; Lal, Nguyen, & Theriault, 2016; Rickwood et al., 2007). As such, there has been growing interest in the potential for Internet-based interventions to facilitate help-seeking in young people. A systematic literature review of 18 studies, including three randomised control trials, concluded that online mental health services do not increase help-seeking behaviour in young people (Kauer, Mangan, & Sanci, 2014). However, the studies included in the review had many limitations, only four included help-seeking as their primary outcome, and none investigated the effectiveness of online interventions aimed at supporting decision making around mental health help-seeking.

Several studies have shown that decision aids can support people to actively participate in health decisions through increasing their understanding of their options, providing realistic expectations of the potential risks and benefits of different choices, and reducing decisional conflict; a state of personal uncertainty about the course of action to take (O'Connor, 1993; Perestelo-Perez, et al., 2017; Simmons, Elmes, McKenzie, Trevena, & Hetrick, 2017; Stacey, et al., 2017). Rowe et al. (2018) examined the acceptability and feasibility of an internet-based decision aid for supporting young people in making help-seeking decisions related to self-harm. They conducted a randomised controlled trial of 12-18-year-olds allocated to receive the decision aid intervention or general information about mood and feelings. They

reported that while their decision aid had good acceptability, qualitative interviews suggested that participants felt a decision aid targeted towards broader mental health issues such as depression and anxiety may be of greater benefit (Rowe, et al., 2018).

Context for the Study

Despite growing interest and research into the help-seeking behaviours of young people, few qualitative studies have specifically investigated the views of young people aged 16-25 from the UK. Instead, studies of young adults have focused predominantly on American and Australian populations where service availability, help-seeking opportunities, and attitudes to help-seeking may differ due to differing cultural and contextual influences (Cauce, et al., 2002). This study aims to address this research gap and builds on a series of related studies in this area, which aim to support the help-seeking decisions of young people who experience mental health difficulties with the use of an online decision aid.

With the development of a web-based help-seeking decision aid in mind, Moon and Greenwood (in prep) conducted a qualitative study in which they explored how young people's recognition and understanding of mental health difficulties affects help-seeking. They conducted interviews and focus groups with 37 young people aged 15-28 from local NHS and community services. Using thematic analysis (Braun & Clarke, 2006), they identified six superordinate themes which highlighted that young people struggle to identify mental health difficulties, struggle to express themselves, and feel that their experiences are oftentimes invalidated. Young people showed a preference for youth specific services, which are

holistic and support individual choice and agency. They concluded that an online intervention to promote help-seeking needs to address both the individual and social factors that influence help-seeking and suggest that further research is needed to investigate how this can be done most effectively. However, they did not address what an online decision aid should specifically entail in order to effectively promote help-seeking.

Research Aims and Questions

The current study focuses on understanding the help-seeking decisional process of young people, as influenced by facilitators and barriers to help-seeking, and aims to expand on the research by Moon and Greenwood (in prep) by investigating how, if at all, an online decision aid can effectively support decision making and promote mental health help-seeking in young people living in the UK.

The study aims to address the following research questions:

- 1. How do young people seek help and who do they speak to regarding their mental health difficulties?
- 2. What do young people think are the factors that influence help-seeking for mental health difficulties?
- 3. How, if at all, can an online decision aid effectively promote help-seeking in young people experiencing mental health difficulties?

Method

Design

This study used an exploratory, qualitative, interview methodology to answer the research questions. A qualitative study design was chosen, which allowed the researcher to develop knowledge grounded in human experience (Sandelowski, 2004). Specifically, qualitative research enables the exploration of behavioural phenomena and events in depth and can lead to a greater understanding of how individual meaning and context may influence behaviour (Maxwell, 2009), which is especially relevant in the context of help-seeking behaviours for mental health. Building on previous qualitative studies of help-seeking, an exploratory approach was used to investigate this phenomena within a UK youth population, related to a broad spectrum of mental health difficulties, and in reference to an online help-seeking decision aid. Moreover, the use of an inductive and exploratory approach allows information that might otherwise be missed to surface and expand understanding of complex processes and phenomena (Pistrang & Barker, 2012).

Ethics

A substantial amendment was submitted to the London - Dulwich Research

Ethics Committee for this additional project on help-seeking in young people (see

Appendix D for letter of approval).

Inclusion and Exclusion Criteria

Young people were eligible to take part in this study if they met the following criteria:

- 1. They were aged between 16 and 25 years.
- 2. Though many of the questions being asked in this research could likely be answered by young people within the general population, one aim of the research was to explore young people's reflections of their lived experiences of help-seeking for their mental health difficulties. This, alongside feasibility issues and attempts to ensure a homogenous sample, resulted in the decision to include only participants who had experience of mental health difficulties and had accessed mental health services.
- 3. They were able to speak fluent English.

Young people were excluded from the study if:

- 1. They were considered by service clinicians to be too unwell to participate.
- They were considered by service clinicians to be unable to provide informed consent either as a result of a lack of cognitive capacity or due to insufficient capacity with the English language.

Recruitment

A purposive sample (Miles & Huberman, 1994) of young people aged 16-25, who had experienced mental health difficulties, were recruited from Early Intervention in Psychosis (EIP) services, an inpatient Child and Adolescent Mental Health Service (CAMHS), a community CAMHS service based in South East

England and from a pool of participants who had taken part in a previous linked study (Moon & Greenwood, in prep). Young people from the EIP and CAMHS services were first identified and approached by relevant service clinicians and asked if they would be interested in learning more about the study. Participants from the Help-Seeking Study who had agreed to be contacted for future research were approached directly and invited to participate in a follow-up interview. The researcher contacted participants by phone or email and sent them a copy of the participant information sheet (see Appendix E). Participants had the opportunity to ask any questions and were given a minimum of 48 hours to consider the information presented before the interview took place. Participants gave informed written consent before participation (see Appendix F for copy of consent form).

Data Collection

The researcher conducted semi-structured interviews with study participants. The semi-structured interview was chosen as it uses open-ended questions to address the specific interests of the researcher while allowing for flexibility and the potential for participants to provide new meanings to the research topic (Fylan, 2005). An initial draft of the interview topic guide, based on the research questions and informed by existing literature, was first produced by the researcher in consultation with the 'Help-Seeking Study' steering committee. It was later finalised in consultation with a young person who has personal experience of help-seeking for mental health difficulties (see Appendix G).

There were broadly two parts to the developed interview schedule. First, the researcher asked participants to describe their experiences of accessing mental health services. They were asked to think in detail about their thoughts, feelings and behaviours related to this. Furthermore, they were asked to provide their views on what made speaking to others about their mental health easier and harder. Finally, they were encouraged to discuss the factors they thought may influence the help-seeking behaviour of other young people who may be experiencing mental health difficulties.

The second part of the interview focused on exploring the general views and ideas that young people had about using online decision aids for help-seeking, and whether they would consider using an online decision aid. Lastly, participants were asked to provide their views about the central themes and dilemmas raised in the previous help-seeking study and to provide their thoughts about potential content to promote a decision to seek help. Participants were shown examples of already existing youth targeted decision aids and online tools as well as mock-up ideas created by the researcher and asked to comment on these (see Appendix H). The researcher included within these examples a variety of designs and structures to provide participants with concrete examples of the research concept while reducing potential bias introduced by the examples shown.

The interview followed a topic guide from which the participants and the interviewer could deviate in order to explore interviewees' ideas and responses further. Open and non-directive questions were asked to allow for individual meanings and personal experiences to be expressed and explored while limiting the

influence of the interviewer on participant answers. At times, more directive questions and follow-up prompts were required in order to clarify meanings and to elicit detailed descriptions (Britten, 2006).

The interviews ranged from between 49 and 85 minutes and were held at an NHS service or location that was known and convenient to the participant. All interviews were audio recorded and transcribed verbatim. The researcher transcribed seven interviews, and a graduate psychology student transcribed the remaining five.

Data Analysis

The process of data analysis is often considered to be the most complex stage of qualitative research (Thorne, 2000). It is thus the responsibility of the researcher to create sensitive and insightful research findings and to ensure rigour and trustworthiness with the use of a systematic approach that is clearly and transparently reported (Malterud, 2001; Nowell, Norris, White, & Moules, 2017). For this research, interview transcripts were analysed using thematic analysis (TA); a qualitative research method that can be used to identify, organise, describe and report patterns within data (Braun and Clarke, 2006). TA was the chosen method of analysis as it has the advantage of being a highly flexible yet well-structured approach, which can be used to explore the varying perspectives of different research participants and generate unanticipated insights (Braun & Clarke, 2006; King, 2004; Nowell et al., 2017). Table 1 describes the process of analysis, which was conducted in six stages as suggested by Braun & Clarke (2006) and as applied in the current research project. Appendix I provides examples of the stages of analysis.

Epistemological position.

Nowell et al. (2017) argue that the potential for TA to lack consistency and coherence (Holloway & Todres, 2003) can be reduced with the transparent application of an epistemological position that can coherently underpin the study findings. Epistemology is a branch of philosophy concerned with providing a framework for understanding what constitutes valid knowledge and how it can be obtained (Crotty, 1998; Maynard, 1994). This study, including the theoretical perspectives and methodology, is underpinned by the epistemological position of critical realism (Bhaskar, 2009; Collier, 1994). Critical realists recognise that while reality exists, all knowledge is socially produced and is influenced by the observer's context and worldview (Bhaskar, 2009; Ponterotto, 2005). As such, multiple yet equally valid accounts of the same phenomenon are always available (Hammersley, 2004) and reality can only be imperfectly known (Porter, 2007).

Table 1Process of Thematic Analysis

Phase	Description of process
1. Familiarisation with the data:	The researcher conducted all the research interviews but did not transcribe them all herself. As such, the first stage of analysis involved the researcher checking all the transcripts against the audio recordings to ensure accuracy. Alongside this, the researcher read through all interview transcripts and noted down her initial ideas for possible coding schemes.
2. Generating initial codes:	Using NVivo, a qualitative data analysis software programme, the researcher re-read all transcripts and made note of (coded) all interesting information. The data set was coded in its entirety and equal time and attention was given to all interview transcripts.
3. Searching for themes:	All codes of interest were organised into related categories and potential themes identified using an iterative process.
4: Reviewing themes:	The researcher checked that the themes were representative of the coded extracts and the data set as a whole.
5: Defining and naming themes:	The researcher, with the support of her supervisor, generated the final themes, ensuring that theme names were illustrative of the underlying meaning of each theme.
6: Producing the report:	Finally, the researcher checked the themes against the research questions for meaning and significance, and selected extract examples that could be used to provide a rich description of the data.

Quality.

Guidelines for good practice in qualitative research were followed to ensure trustworthy and methodologically rigorous research (Barker & Pistrang, 2005; Elliott, Fischer, & Rennie, 1999). The researcher used a reflexive approach to the analysis. The thesis supervisors read three transcripts and reviewed the themes to ensure that the findings were grounded in the data and interpreted credibly. Further, accounts of differing participant views, as captured in the transcripts, were considered important and included in the analysis process (Kitto, Chesters, &

Grbich, 2008). It is important to note that the researcher has attempted not to produce 'reliable' or 'accurate' findings, but instead to provide an in-depth and transparent report of the interpretation of the data as seen through her own personal, professional and theoretical lens (Clarke, 2017).

Researcher perspective and reflexivity.

When conducting qualitative research, reflexivity and disclosure of the researcher's perspective are considered essential components of producing quality research (Caelli, Ray, & Mill, 2003; Starks & Brown Trinidad, 2007). The researcher was a 30-year-old, White British woman who had experience of working with young people experiencing mental health difficulties and as a research assistant on a study exploring the facilitators and barriers to engagement of young people with early intervention for psychosis services (Greenwood, et al., 2014). It is likely that these experiences will have influenced her approach to the research process (Harper, 2008). Rather than attempt to discount the influence of her prior beliefs and experiences on the research findings, she strived to maintain self-awareness and continued reflection so as not to impose personal meaning on the data (Fischer, 2009). This was supported by regular supervision and involvement from her thesis supervisors.

Results

Fifteen young people expressed an interest in taking part in the study and gave verbal consent to be contacted by the researcher. One participant was excluded from the study as she did not meet the age criteria and two others were unable to find

a suitable time to meet. As such, a final total of 12 young people consented to take part in the study and completed the research interview.

Participant Characteristics

Participant demographic and service use information are presented in Table 2. Participants ranged in age from 17 to 24, with a mean age of 20 years, and were predominantly White British (n = 10). There was diversity in the sample with regards to mental health difficulties with participants reporting having experienced both common mental health difficulties such as depression and anxiety (n = 7) and severe and enduring mental health difficulties such as psychosis and borderline personality disorder (n = 5). There were more females (n = 7) than males in the sample, however this is representative of the mental health population of young people in the UK with females being disproportionately affected by mental health difficulties (Freeman & Freeman, 2015).

Table 2

Participant Demographic Information

Participant number and pseudonym	Age	Gender	Ethnicity	Employment status	Services used
HS001: Luca	23	Male	White Italian	Unemployed	Early Intervention Psychosis
HS002: James	21	Male	White British	PT volunteering	Community CAMHS
HS003: Charlie	23	Male	White British	FT employment	Community CAMHS
HS004: Georgia	17	Female	White British	FT student	Community CAMHS
HS005: Dan	17	Male	White British	FT student	Community CAMHS
HS006: Aaron	24	Male	White British	Unemployed	Early Intervention Psychosis
HS007: Sammi	17	Female	White British	Unemployed	CAMHS Inpatient
HS008: Grace	21	Female	Black African	PT employed	Early Intervention Psychosis
HS009: Lily	17	Female	White British	Unemployed	CAMHS Inpatient
HS010: Katie	17	Female	White British	Unemployed	CAMHS Inpatient
HS011: Jenny	23	Female	White British	PT employment	Community CAMHS*
HS012: Sarah	22	Female	White British	FT student	Community CAMHS*

^{*} Participants recruited from linked study (Moon & Greenwood, in prep)

Although all participants had previous (n = 3) or current (n = 9) engagement with mental health services at the time of the interview, their pathways to help varied on several dimensions. Almost all waited until they no longer felt able to cope alone before speaking to someone about their mental health. Most sought formal help only after being prompted to by someone else. The primary sources of prompts and support included parents, teachers, General Practitioners, friends, and the internet. Two participants did not speak to anyone at all about their difficulties until they were

hospitalised under a mental health section. It was clear that who young people spoke to, if indeed they chose to at all, was a profoundly personal decision influenced by several key factors.

Analysis of the interview transcripts yielded 11 themes organised into three domains (see Table 3). Throughout the interviews, young people raised the importance of information being relatable and personal. Therefore, quotations are attributed to participants using pseudonyms assigned by the researcher as opposed to numerical labels as are typically used in thematic analysis.

Table 3Themes Generated by Thematic Analysis

Domains	Themes		
1. Socio-cultural ambivalence surrounding mental health	1.1. Cool and accepted vs an outcast and attention seeker		
	1.2. Encouraged to seek help vs dis-believed and dismissed		
	1.3. Other's responses will be mixed		
2. The personal help-seeking process	2.1. Moving towards vs pulling back		
	2.2. Acceptance is complex		
	2.3. Knowing where to go		
	2.4. Help-seeking will be hard		
3. Messages and prompts to overcome	3.1. Knowing I'm not the only one		
barriers and support help-seeking	3.2. No problem is too small		
	3.3. Information giving requires a delicate balance		
	3.4. Barriers to overcoming barriers		

1. Socio-Cultural Ambivalence Surrounding Mental Health

This domain captured the way in which participants personal and social contexts could both promote and or inhibit help-seeking decisions and behaviour in young people. It encapsulated within it the influencing effect of cultural beliefs and messages, social support, and the responses of others.

1.1. Cool and accepted versus an outcast and attention seeker.

Stigma was discussed by many participants as being a significant concern when contemplating help-seeking for mental health difficulties. For many, beliefs about what it means to experience mental health difficulties raised feelings of shame and fear and, as a result, participants often spoke of wanting to hide their experiences from others.

"Well because there's a stigma isn't there. There's a stigma against mental health and I was already a crazy, strange, boy. The fact that I was going to a mental health service wouldn't have helped, my reputation anymore". (James)

Though many participants discussed the importance of socio-cultural narratives on help-seeking, Grace, as the only participant from a minority ethnic group, was also the only person to speak about the inhibiting impact of culture with regards to religious beliefs.

"I think also culture and religion is another thing, because I think in some religions, like people think 'oh, you're mental health illness, like this or that', I don't know how to explain it but it's just, in a way, I felt like, - if I go and say to anyone that 'oh, maybe I had bipolar disorder' or something, they might be like 'oh, this child, like there's something strange', you know". (Grace)

As well as the stigma surrounding mental health specifically, participants spoke of the inhibiting impact of cultural narratives around young people more generally. Participants spoke of feeling that the societal view of young people as over-sensitive, over-dramatic, hormonal teenagers often led others, and indeed themselves, to doubt the legitimacy of their emotional experiences.

"... It's partly because, you know, we're told from quite an early age I guess... that like, young people are dramatic and have like, uh, dramatic reactions to things, that they may overreact, and, um, I definitely feel that happens with me... it's a lot of second guessing. So I think that makes it quite hard". (Georgia)

In contrast, some participants spoke positively about a cultural shift in which mental health has become talked about more openly in various contexts such as in schools and within the media. Several young people spoke of the critical role of the internet in increasing access to and awareness of mental health information and support for young people.

"... Just for, especially young people the, the internet is such a great resource. Um, like because it is; you can, you can find it all over Facebook and stuff, resources to help. But um, also where it's, like at schools and stuff it's not being brushed under the carpet, so! much. Um, and it's like there's been like awareness sessions and stuff". (Lily).

Interestingly, other's felt that the increase of social communication around mental health difficulties has potentially led to a type of 'me too' culture, which could lead young people to doubt their experiences of mental health difficulties and thus prevent them from seeking help.

"Well a lot of people throughout... like my age group... like there's a lot of drunk or even attention seekers. People throw depression around like it's nothing. So, that's, you question it. You think 'do I have it, do I have it?' Because and because people use it so much, you'll never know. It's just yeah, just people use it too much and it kind of just like takes it away. (Dan)

Furthermore, several young people felt that mental health difficulties have been glamorized within youth culture and discussed the challenges this can create for young people who may want to seek help.

"I think there's a culture around it and I'm not sure where it comes from exactly, um, I mean it might come from pop music, or rap music, but you know, mental health is 'cool' now, with a lot of young kids... so, you're fighting a battle against the whole culture of yeah, 'mental illness is cool now'... And so when you do think that, it becomes a part of your identity, and it becomes um, you don't see it as a problem, you see it as; it's not a problem". (Charlie)

Charlie went on to speak about how young people who feel socially isolated may gain desired access to a new social network if they identify their mental health difficulties as "cool" or "seeing things for how they really are". Not wanting to lose these newly gained social connections may lead young people to avoid help-seeking.

"Yeah, it becomes an identity, and then for a lot of young people as well, you're alone, so you going onto this online community and suddenly now you're getting recognised, and you're getting friends and stuff. So um, yeah there's... a few kind of interesting communities online that deal with that, that are quite interesting, but yeah, it becomes like an identity... and you think it's actually how you see the world, like, you know, in quotes". (Charlie)

1.2. Encouraged to seek help versus dis-believed and dismissed.

The role of social support from others was raised by almost all participants as the most prominent facilitator to help-seeking. Young people reported that it was often someone such as a teacher, friend, or parent who prompted them to seek formal help and facilitated this process.

"... My mum noticed what was going on, and since my brother was, like, got mental health issues, my older brother and that, and she confronted me about it and uh, told me to go to the doctors and she made me an appointment". (Aaron)

Those interviewed also spoke about the facilitative impact of having someone else with experience of mental health difficulties within their personal network on them feeling more encouraged to seek support.

"... If you come across somebody that, is struggling as well, you know sort of having that, connection together umm and bond together... Yeah and perhaps, you know, encouragement to try and, reach out and try and seek support. Um, even if that's just beginning by, speaking to each other. Um, on sort of mutual level". (Jenny)

In contrast to the facilitative role that others can play, many participants reported that previous negative experiences of formal and informal help-seeking were a barrier to future help-seeking decisions. It was common for young people to give accounts of being dis-believed and dismissed by both personal and professional others and they often had to seek help from various sources before they were successful.

"I went to my GP when I was about 13. Um but that was because I had a panic attack in school, and I got told by the GP that it was just normal. Um, and then I went to the GP, again... and then my GP just didn't believe me about anything and thought; she straight up said to me that I was making it up as well so. (Lily)

1.3. Other's responses will be mixed.

When contemplating seeking help for their mental health difficulties, many participants considered the potential impact that this would have on both themselves and others. Beliefs that help-seeking would make them feel worse, or that others would respond in a dismissive and judgemental way were considered to hinder help-seeking.

"I'm not going to open up to people if I can't trust that they're going to like, take me seriously, and they're not just going to think it's all a laugh and everything. That's probably one of my! biggest worries about it, like having people know, because I don't want them to mock me for it". (Katie)

Beliefs that others would listen, understand and respond without judgement, and that talking to others about one's difficulties would be beneficial promoted help-seeking.

"What helped me was thinking, you know, he's a doctor, he's not going to dismiss it, he's going to listen". (Aaron)

The beliefs of young people about the potential impact of help-seeking on others was a further consideration of theirs when thinking about seeking help.

Several participants reported that they believed that others would feel "upset" and "burdened" by the disclosure of their mental health difficulties and this was a reason for them not to seek help.

"My mum had mental health problems when I was growing up, um, around alcohol as well, so I grew up around that and um, she's recovered now, and she's a lot better, but I saw the damages of that, and I knew that if I put another burden onto that pile at the time, it could have just not been helpful" (Sarah)

In contrast, Luca's belief that seeking help would benefit his parents was a factor that motivated him to seek professional support.

"I just wanted to uh, help my mum, give her a break really. Give my family a break because it was too; it was really full on for them to have me around all the time".

(Luca)

2. The Personal Help-Seeking Process

This domain encompasses the themes raised by young people which relate to the process of help-seeking. It includes within it themes concerning the individual characteristics of young people, recognition and acceptance of a problem, the awareness, availability, and selection of support sources, and beliefs about the helpseeking process.

2.1. Moving towards or pulling back.

The personal characteristics of young people, including their personal identities, coping styles, strength of mind, and self-confidence was raised as having a key influence on their help-seeking decision making and behaviour. Young people spoke about the difficulty of seeking help when this challenged their internal view of themselves.

"This is the thing, um, I did feel so stressed, and felt like I should talk to someone, but I wasn't; I'm the type of person where, I'm very strong and I don't really share such things with people, so it was quite difficult to even consider talking to someone about, you know, like having mental health difficulties". (Grace)

The individual coping styles of young people also played a vital role in their help-seeking process and appeared to be connected to their understanding of themselves and the world. Some participants spoke about wanting to avoid their difficulties through distraction.

"Some people just throw themselves into work and it would just be like, yeah, and, then when they think there's something wrong, they go 'yeah, there might be something wrong' then they just put themselves into more work so it's just piling up". (Aaron).

Others felt more confident and able to speak openly about their difficulties.

"[I'm] quite like, impulsive, and open, so like... depending on what's happening, or the situation, I could talk to pretty much anyone about it, um, including like; not strangers! strangers, but like people who I barely know". (Georgia)

2.2. Acceptance is complex.

This theme highlighted the importance of young people's recognition and acceptance of mental health difficulties in the help-seeking process. Perhaps unsurprisingly, a lack of recognition by participants that they were experiencing a mental health difficulty was identified as a key barrier to help-seeking. Whether or not participants were aware of their difficulties was influenced not only by the sociocultural factors discussed above, but also by the type and severity of their mental health symptoms.

"Yeah, I was completely psychotic you know, I was uh was really paranoid. But for me, it was everyone else was wrong. Do you know what I mean? I believed that what was going on around me was uh was actually happening". (Luca)

The issue of acceptance was most often spoken about as being a barrier to help-seeking. On the one hand, participants reported that it was difficult for them to accept that they were experiencing mental health difficulties due to their beliefs about what this might mean for them socially and personally.

"I think, often we don't want to accept that there is a problem because then that means we have to do something about it". (James)

On the other hand, others said that it was accepting their difficulties as "normal" or as "a part of my identity" that acted as a barrier to help-seeking, as they no longer viewed their difficulties as a problem that needed fixing.

"For me it was, it was mental health but it was also, um, kind like a, you know, a lifestyle a bit, and so you come to accept it, or you don't see it as an issue". (Charlie)

In contrast, Aaron spoke about how he was able to recognise that "there was something wrong" and that by accepting that "not everyone's perfect" he was able to seek-help more easily.

"It just got to the point where every day I was just getting up and I was just feeling...
like less than a 100%, and like I didn't want to get up, I didn't want to do anything, I
just wanted to stay in my room, so then I got up and I thought yeah... obviously
there's something wrong, and I went to the GP". (Aaron)

2.3. Knowing where to go.

This theme summarises the impact of young people's knowledge and beliefs about who they can and can't speak to regarding their mental health difficulties on their help-seeking behaviour. Several participants said they didn't seek help as they "didn't know who to tell" about their emotional experiences. For example, Luca said:

"I didn't know where to [look], who to ask for help. I didn't even know that there would be help available you know, I thought I had to resolve it on my own". (Luca)

A few participants reported having knowledge of where to go for formal help and typically obtained this information from friends or family members.

"I was talking to friends and they were like, 'You need to go somewhere, so you can go to your GP... or a walk-in service'". (Georgia)

2.4. Help-seeking will be hard.

Beyond having knowledge of available sources of help, beliefs about the accessibility, approachability and trustworthiness of help sources influenced young people's decisions of whether or not to seek help. Many interviewees believe help-seeking would be difficult and practically, personally, and cognitively effortful.

Participants were less likely to actively seek help if they believed that they wouldn't be able to explain their difficulties in a way that others would understand.

"I think um what also, isn't great is no one knows what the right words are to use to describe how they're feeling. Um so they like, people might feel a bit silly bringing it up to doctors, if they don't actually know how to describe what, they think is going on with their brain". (Lily)

The practical challenges of formal help-seeking, such as having to make phone calls and attend appointments, were discussed by many participants as a barrier. This was made more difficult when participants had limited social support from friends and family.

"You know most kids... they don't, they don't want to sacrifice the very little time after school or on the weekends that they do get with their friends disappearing off to go to some strange building". (James)

Believing that support would be confidential, non-judgemental, and available when you needed it could facilitate help-seeking. When talking about her experience of using mental health questionnaires online, Sammi said:

"I think it's always helpful if you can kind of be assured that it's confidential, and that's a big thing. Um, so I found ones that don't ask for your name and your address

and things like that quite helpful. I mean first names is fine but I feel like if you, are trying to do it so you want help but you don't want, everyone to know. I found putting all my details hard and I wouldn't use it". (Sammi)

3. Messages and Prompts to Overcome Barriers and Support Help-Seeking

Throughout the interviews, but particularly when speaking about the potential role of an online decision aid, the need for young people to understand their experiences, have awareness of their support options, be able to communicate their difficulties to others, and weigh up the pros and cons of help-seeking was raised.

3.1. Knowing I'm not the only one.

All interviewees said that being able to read or hear about other people's experiences of mental health help-seeking, via an online decision aid, could be beneficial in reducing stigma and helping them to know that other people seek help for mental health difficulties too.

"I just think, emphasising that it's not something that... happens to just a few people, like it happens to a lot of people, maybe helps, in a way, for the person to see that oh, um, you know... this is something that a lot of people do go through, if I do talk to someone about it, it's not like I'm the only one, saying it". (Grace)

Participants also highlighted the potential for stories to support their understanding of their own difficulties and help them to find the words to express themselves to others.

"I guess I think the, stories are good. I like the stories... You're like giving these people these words that they may not like have thought about, and you're putting it into sentences; because sometimes the thing is, you know, you may not be able to have the words to explain it but when someone else says something like 'is it this?' then you're like 'yeah that's it, like that's what, how I feel' you know?" (Katie)

At the same time, many participants spoke about how knowledge of other people's mental health experiences could lead them to question if they are as bad as others, or if others needed help more than themselves.

"I think it's difficult, because; 'so there's over 1.5 million young people, that's great because I'm not alone, but, am I as bad as them? Do I need help?' It's that comparison again, that was my immediate thought". (Sarah)

3.2. No problem is too small.

Participants felt that an online decision aid could potentially help them to overcome their fears that their struggles did not warrant support and that they were "over-reacting" or would be "wasting GPs time". They felt that this could be

achieved by emphasising that "no problem is too small" and encouraging participants to "to talk to someone and let your feelings out" regardless of their difficulties.

"I think it's really important to not say that they have to fit in a box, to meet a certain criteria, in needing help, like you don't have to get A, B and C to need help, if you're feeling slightly worried or slightly down or just like you need to talk to someone, then communicate, because that could just, you know, help in the long run". (Sarah)

3.3. Information giving requires a delicate balance.

Young people felt that an online decision aid will need to get the correct balance when providing information and advice regarding mental health help-seeking. Participants felt the information conveyed should provide hope, reassurance and validation and should not cause them to feel overwhelmed or frightened.

"... Just don't make it out to be like a huge problem like. I think when you're mentioning like GPs, you're like 'oh god, that's quite scary'. When you're just like, 'you can talk to anyone about it, you could talk to your family, you could talk to your friends' just reassure them that it's not a really big problem. Just make sure they feel comfortable..." (Dan)

Overall, there was consensus that young people wanted the information provided to strike a balance between acknowledging and validating their experiences whilst avoiding overwhelming them with a suggestion of a diagnosis.

"... Of course they need to be given an answer, or an invitation that something could be better. I don't think, this thing should be a diagnosis tool, because people will already have a lot of problems with, kind of self-diagnosing online. And that can be quite dangerous and sort of hypochondriac or something". (James)

Furthermore, participants said that they wanted the online decision aid to prompt them to seek help but stressed the need for this message to be sensitive and empowering with a focus on choice. They did not want to feel pressured or forced into one particular course of action.

"I think um, just being, like sensitive with the wording, like not say 'you need help right now', because that would probably scare someone and then they won't disclose their, yeah, or they'd run in the opposite direction, but saying, yeah... like 'it might be a good idea to consider this', and I think again, giving them the option, so using words like 'consider', rather than saying 'you have to do this', yeah". (Sarah)

Those interviewed wanted to be given advice about not only where but also how to seek help, as well as information about the potential outcomes related to the help-seeking choices they make. They spoke about there being "different levels of difficulty" when seeking help and it was important to them to be given options to choose from.

"I don't think it has to be that straight away hard option of 'there's a problem, we need to cut it out'. I think it could be a lot more softer and say (- -) 'if you feel like you can deal with it on your own, here is the tools to do so. But, if you want help, or you feel you need help, here are the options'. I think, it almost needs to be like sort of three bears of a like a warm a cold and a medium and people can choose the level of help that they're willing to accept". (James)

Simultaneously, they said that giving too many options and too much information about what to expect could be overwhelming and difficult to engage with.

"Because I feel like if you've just finished the quiz and you're bombarded with this huge long page of all sorts of things, then you might be like 'what?' and you might just be a bit overwhelmed. Whereas like having a separate page that's like got the main things then you know, that might feel more easy for the, people to look at for them to understand and take in..." (Katie)

Despite many of the interviewees having had negative past experiences of help-seeking, there were differing views on the level of transparency that young people wanted with regards to the information given. For example, when asked if the decision aid should be honest about the possibility for people to respond in an unhelpful way to disclosures around mental health difficulties, Lily said:

"I don't really think that should go on there because if you just put like 'they might not believe you' or whatever then that would just be like 'well I might as well not go'". (Lily)

Sammi felt that it was important for people to know that help-seeking might be a challenging process, but also that it would be worth the effort.

"I think they should be like, they should know that it will be hard. I think it's quite an important thing but they should know that it will help in the long run and that's what they need, kind of thing".

Barriers to overcoming barriers.

Despite most participants saying that they liked the idea of an online decision aid and that they thought it would be helpful for other young people, some

participants raised doubts about the usefulness of the tool for promoting help-seeking for themselves. The barriers related to help-seeking were also considered by some participants to apply to the use of an online decision aid. Luca said that he wouldn't use the online decision aid unless he already knew he had a problem, and Katie said:

"Like I think it's good but for me personally I probably wouldn't use it just because, it's more that thing about I don't want to accept help." (Katie)

Discussion

This study explored young people's experiences of accessing mental health support and their views on the factors influencing help-seeking decisions and behaviours. Furthermore, the study investigated the ways in which an online decision aid could effectively support the help-seeking process.

Links to Previous Research and Theory

Pathways to help-seeking.

Interviewees described diverse pathways to help-seeking, however, almost all participants had delayed or avoided help-seeking. Many participants described waiting for others to notice and comment on their difficulties whilst others actively sought support only once they no longer felt able to cope alone. These findings offer support to Kessler et al. (2005), who report that young people often experience long delays between first onset of mental health symptoms and help-seeking. When

participants did choose to speak to somebody about their difficulties, parents, peers, and school staff were highlighted as the main sources of support. This is consistent with research which suggests that young people are more likely to seek mental health support from somebody they know and trust (Boldero & Fallon, 1995; Booth, et al., 2004).

Facilitators and barriers to help-seeking.

In line with the existing literature, young people in the current study often delayed or avoided help-seeking due to: a lack of recognition that they were experiencing a mental health difficulty which warranted help (Biddle et al., 2007; Glossop, 2012; Gulliver et al., 2010), difficulties identifying, understanding and expressing their emotions (Ciarrochi & Deane, 2001; Rickwood et al., 2005), a lack of knowledge, awareness, and availability of accessible support options (Fox, Blank, Rovnyak, & Barnett, 2001; Rickwood et al., 2007), and anticipated negative social and personal repercussions of help-seeking (Glossop, 2012). Facilitators to help-seeking included: having social support and encouragement (Gulliver et al., 2010), recognising one's difficulties as a problem (Rickwood et al., 2005; 2007), being confident and open to express one's emotions (Rickwood, Cavanagh, Curtis, & Sakrouge, 2004), knowing where and how to seek help (Wilson & Deane, 2001) and believing that help-seeking would lead to a beneficial outcome (Gulliver et al., 2010).

Mental health literacy.

Mental health literacy, defined as "knowledge and beliefs about mental disorders which aid their recognition, management or prevention" (Jorm, et al., 1997, p. 182) has been shown to have a significant influence on help-seeking. Mental health literacy relates not only to ones knowledge and awareness of mental health symptoms and the need for help but includes knowledge of support options and an understanding of what to expect from different sources of help. The current study lends support to and expands on previous research, which has identified that young-people typically have poor mental health literacy and that this presents a substantial obstacle to help-seeking (Moon & Greenwood, in prep; Gulliver et al., 2010; Rickwood et al., 2005; 2007; Salaheddin & Mason, 2016).

In the present study, many participants reported that their help-seeking was delayed or avoided as they did not recognise their emotional difficulties as being linked to a mental health problem. Some participants' lack of knowledge about mental health symptoms led them to believe that their difficulties were simply a normal part of life which they needed to accept and manage alone. While others reported that although they understood that others might consider them to have a mental health difficulty, they believed that the 'problem' was with others and not with themselves. Beyond recognition of a problem, help-seeking was further impeded by a lack of knowledge and awareness of support options and by beliefs that the help-seeking process would be too challenging and would have negative consequences for the individual and those around them. Young people's personal

understanding of their difficulties and help-seeking behaviours appeared to be linked to their personal socio-cultural contexts.

Influence of the social environment on mental health literacy and helpseeking.

Having people in one's personal network who could prompt and encourage help-seeking was the most commonly discussed facilitator to reaching out for formal support. In addition, social interventions aimed at increasing awareness and normalising mental health difficulties, such as 'Time to Talk' were described by some participants as enabling help-seeking. Conversely, many interviewees spoke about the inhibiting effect of mental health stigma and the negative social narratives surrounding young people on their help-seeking behaviour. Furthermore, having had a previous negative experience in which their help-seeking attempts were dismissed, further strengthened the hindering effect of social attitudes and beliefs on participants help-seeking. These findings are consistent with those presented by Moon and Greenwood (in prep) and previous reviews of help-seeking in young people (Gulliver, et al., 2010; Rickwood et al, 2005).

This study introduces new information regarding the impact of socio-cultural understandings of mental health on young people's help-seeking decisions and behaviour. Participants discussed a social narrative whereby help-seeking is discouraged due to a shift in youth culture such that mental health difficulties are glamorised and revered. Interviewees spoke about the role of the media, pop culture, and online communities in presenting an idealised image of mental health

difficulties, leading to a potential phenomenon whereby such difficulties are constructed as a "cool" and desirable aspect of ones personal and social identity and help-seeking is seen as unnecessary. Furthermore, this shift in the social narrative had the effect of introducing doubt about the authenticity of young people's mental health difficulties for both the young people themselves and their potential sources of help. As such it was considered a significant barrier to help-seeking as young people struggled to identify if they "had a problem" and worried that others would dismiss them.

Previous research has shown that social networking about mental health difficulties can normalise and glamorise risk behaviours such as self-harm and suicide (Cavazoz-Rehg et al., 2017) and this was alluded to by some participants in the current study. However, research is needed to further explore the impact of such a phenomenon on mental health help-seeking. These findings highlight the need for mental health help-seeking interventions to acknowledge and address the highly influential role of the media and social context on shaping personal narratives about health and health behaviour (Atkin & Wallack, 1990; Holman, Lynch, & Reeves, 2017). One potential way that existing 'unhelpful' narratives surrounding mental health difficulties can be challenged may be to ensure that young people are exposed to alternative and balanced ideas through the use of first person narratives, social media, education, and entertainment (Hinyard & Kreuter, 2007).

Promoting help-seeking with an online decision aid.

There has been growing interest in the potential for web-based interventions to support the mental health needs of young people (e.g. Burns et al., 2010; Cahill et al., 2007; Rowe et al., 2018). This study suggests ways in which an online decision aid, which recognises the complex nature of help-seeking and addresses the many factors found to influence help-seeking behaviour may encourage young people to seek support for their mental health difficulties. Participants highlighted the need for the help-seeking intervention to increase young people's mental health literacy and emotional competence, reduce stigma, and challenge the inhibiting socio-cultural narratives surrounding mental health and help-seeking. Young people were generally reluctant to seek support from others due to concerns that they would be considered to be 'attention seeking' and 'over-sensitive' and they feared negative responses from others. This resulted in a delay in help-seeking for almost all participants, who generally only accessed help when their symptoms had become too difficult to manage alone. These findings map onto various theories of help-seeking which suggest that if a person believes they will not get the support they need, and or that they will be judged negatively by others, they are not likely to act out help-seeking behaviour (Ajzen, 1991; Hochbaum, 1958; Glossop, 2012).

Several participants reported using the internet to 'research' their difficulties and the majority expressed interest and endorsement for the development of an online decision aid to promote help-seeking. Young people wanted to know that they weren't alone in their experiences, which could be achieved through stories and information about the number of young people who have these difficulties, but also wanted some indication of the level of severity of their own experiences, and to have

these validated. They wanted a clear message that no problem is too small, and that any concern is worthy of a discussion, and they wanted to be provided with information and choices on where they could get help and what they could expect from help-seeking. Participants had very personal preferences with regards to the content and tone of messages, however all were clear that the decision aid should prompt them to seek help, while ensuring, through the use of sensitive language, that they felt that they had autonomy over their final decision.

Overall, participants suggested that an online decision aid would likely be used by young people and may promote mental health help-seeking and this is in line with other study findings (Rowe et al., 2018). However, this study highlighted that, as with help-seeking, there may be several obstacles that may prevent young people from engaging with the online decision aid. Though research suggests that many young people search online for mental health information (Fergie, Hilton, & Hunt, 2015; Kris Gowen, 2013; Gray, Klein, Noyce, Sesselberg, & Cantrill, 2005; Lal, Nguyen, & Theriault, 2016; Rickwood et al., 2007), the findings of this study suggests that this typically occurs only once young people have already begun to consider that they may be experiencing a mental health difficulty. An online decision aid, targeted solely at young people themselves may therefore be unsuitable in promoting help-seeking for those young people who do not independently recognise their difficulties as a problem.

Furthermore, this study provides some evidence to support the Cycle of Avoidance Model of help-seeking (Biddle et al., 2007), which suggests that young people often avoid defining their symptoms as "real" mental illness and therefore do

not seek help for their difficulties. Stigma is thought to play a significant role in influencing non-help seeking behaviour within this model as young people would go to great lengths to avoid being marked as "not normal". It seems then that it would be important to consider how a mental health decision aid is positioned so as not to add to feelings of abnormality when using it. One suggestion for how this could be achieved is for the decision aid to be universally rolled out in schools so everyone at certain ages completes a health screen. While this may normalise the use of such an intervention, this is likely to require considerable national resource. The benefit of an online decision aid is that it can be accessed by young people anonymously and in private and as such this may reduce the impact of stigma on seeking help (Stephens-Reicher, Metcalf, Blanchard, Mangan, & Burns, 2011), however this remains to be tested.

Study Limitations

Though it is not the aim of qualitative research to produce generalizable results, participants included in this study came from predominantly White-British and middle-class backgrounds. Furthermore, participants were recruited through service clinicians and self-selection and though not all participants included in the study had opted to seek help, all were receiving help at the time of the interview. As such, it is important to note that the study findings represent a particular sub-population of young people. In addition, it is possible that recruiting some participants from a 'previous linked study' may have introduced further bias in the study findings as these young people may be more accustomed to talking about

mental health difficulties and help-seeking based on their previous experiences of doing so. Finally, as with previous research findings, this study identified few facilitators to help-seeking as compared to barriers (Gulliver et al., 2010). It may be prudent for researchers to consider ways in which young people can be supported to consider and discuss potential facilitators to help-seeking as this will likely be key to developing effective interventions.

Research and Clinical Implications

The study findings indicate the potential for services to support mental health help-seeking by providing interventions which aim to educate people on the recognition of mental health difficulties and the process of help-seeking. Given the socio-cultural impact on mental health knowledge and beliefs, it is important for help-seeking interventions to be targeted towards not only young people themselves, but also their potential helpers (Jorm, 2012). In addition, to challenging unhelpful narratives around mental health, it may be necessary for services to consider ways of challenging social narratives around young people more generally. Finally, given the many barriers to help-seeking, and indeed the potential barriers to using a help-seeking decision aid, it may be important for clinicians to consider alternative methods of engaging with young people on the topic of mental health difficulties. One suggestion for how this could be achieved may be to draw on ideas from community psychology and for clinicians to actively take mental health services to young people in their typical environments as opposed to requiring young people to find and access services themselves (Durcan, Zlotowitz, & Stubbs, 2017).

The findings of this study suggest that an online decision aid may be able to support the decision to seek help in young people experiencing mental health difficulties, however, further research is needed to investigate whether the use of such a tool will lead to increased help-seeking. Future research is also needed to explore the views of young people from differing sub-populations, including young people from black and ethnic minority backgrounds and those who do not seek help. This is particularly important for exploring further the ways in which a young person's socio-cultural context may influence their help-seeking decisions. It may also be of benefit for research to further explore the facilitators to help-seeking so as to identify alternative factors that may promote help-seeking. In addition, given the influential role of young people's social networks, future research may wish to explore the views of help-providers with regards to how they can be supported to recognise mental health difficulties and have increased knowledge of what to do if they think a child is struggling.

Conclusion

This study provides support for, and adds to, the existing literature which examines the barriers and facilitators to help-seeking in young people. In addition, this study identified that an online decision aid, aimed at promoting mental health help-seeking in young people, should address socio-cultural narratives surrounding young people, mental health, and help-seeking and should improve the mental health literacy of young people by providing them with normalising and validating information, which can empower them to seek support for their difficulties. Further

consideration of how an online decision aid can make use of the facilitative role of young people's support networks is needed, particularly as the findings of this study suggest that there are likely to be barriers to using the online decision aid, which are similar to those of help-seeking.

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Part 3. Critical appraisal

This critical appraisal consists of two main sections and presents an account of the ways in which I found the research process and findings to be particularly thought-provoking. The first section focuses on the concept and process of reflexivity and acknowledges the presumptions that I brought to the research project and the ways in which I attempted to manage these. The second section presents an exploration of the various narratives, both that were challenging to me and also that may need challenging, observed in the research data.

Reflexivity

Reflexivity is both a concept and a process (Dowling, 2006), which concerns the "analytic attention to the researcher's role in qualitative research" (Gouldner, 1971, p. 16, as cited in Dowling, 2006). When doing qualitative research, reflexivity is considered a crucial component of producing quality research (Caelli, Ray, & Mill, 2003; Starks & Brown Trinidad, 2007). Nonetheless, in their review of the strategies used to enhance the rigour of qualitative research, Barush, Gringeri and George (2011) noted that the use of reflexivity was reported in only 16% of the 100 papers sampled. In their reflections on, and attempts to understand, this "surprising" finding, they suggest that "Perhaps the authors feared it would be unprofessional or intrusive to disclose their personal characteristics, or perhaps they thought personal disclosure would be inconsistent with editorial demands." (Barusch et al., 2011, p.7).

Reflexivity as a concept refers to a level of consciousness (Palaganas, Sanchez, Molintas, Visitacion, Caricativo, 2017) and self-awareness (Lambert, Jomeen, & McSherry, 2010) of the way in which the researchers shape, and are

shaped by, the research process and findings (Palaganas et al. 2017). Reflexivity as a process refers to the active and continuous attempts of the researcher to reflect on their personal and social context and to recognise, examine and understand how their own perceptions, values and behaviours interact with those of the participant's and influence, intentionally or unintentionally, the entire research process (Jootun, McGhee, & Marland, 2009). It is through increased personal awareness and understanding of how we, as researchers, influence and are influenced by the research process, and our willingness to report this explicitly, that the quality of our research is improved (Jootun et al., 2009).

Authors Positionality

I am a 30-year-old, White-British female currently completing my final year of Doctoral training in Clinical Psychology at the University College London. It has long been a goal of mine to train and practice as a Clinical Psychologist and I have worked in the field of mental health for many years, in various clinical and research settings and with people at all stages of life. These experiences have highlighted to me the diverse issues across the lifespan and have raised my awareness of the diverse ways in which people 'make sense of' or come to understand their experiences of distress and recovery. My main areas of interest have always been child development and Autism, however through my work experiences, both before and during training, my interests have broadened.

Prior to starting my training, and indeed conducting this piece of research, I worked on two major research studies; the National Institute for Health Research

(NIHR) funded EYE project (reference) aimed at improving the engagement of young people with early intervention for psychosis services, and the nationally run randomised control trial investigating the use of contingency management as a tool for supporting young people with psychosis to stop using cannabis (reference). These research experiences exposed me to the crucial role of early intervention in improving long-term outcomes (Membride, 2016) but also to the particular difficulties of engaging young people in mental health services.

Rather than attempt to deny the influence of my personal identity, prior beliefs, and experiences on the research findings, I strived to maintain self-awareness and continued reflection so as not to impose overly personal meaning on the data (Fischer, 2009). This was supported by regular supervision and involvement from my thesis supervisors.

Shaping and Being Shaped

As discussed, a critical part of reflexivity is to acknowledge the degree to which the researcher shapes the interview by the questions and topics of conversation they choose to ask about, expand upon, and avoid during the interview process (Willig, 2001). As such, some of the potential ways in which I shaped, and was shaped by, the interview process are presented.

My experience of working on a previous research study which looked at exploring the facilitators and barriers to engagement with early intervention for psychosis services inevitably shaped my views and led me to hold various presupposed ideas and assumptions about the potential process and outcome of the

current study. For example, despite including a different sub-section of young people in the two studies, I assumed that there would be considerable overlap between the facilitators and barriers to accessing and engaging with mental health services reported in both. In addition, I was aware of other research that suggested young people would find a help-seeking decision aid for general mental health helpful (Rowe et al., 2018), and my personal experiences of using the internet to search for health-related information, meant that I began this research with an assumption that an online decision aid would be a helpful tool for young people experiencing mental health difficulties. Though I attempted to be aware of, and respond to, the ways in which my previous experiences may have been influencing the interview process, it is possible that I may have unconsciously interpreted or given more attention to young people's responses that confirmed my existing biases (Nickerson, 1998).

The idea that individual researcher characteristics have the potential to influence the interview findings is well acknowledged within the research field (Pezalla, Pettigrew, Miller-Day, 2012) and it is important to recognise the qualitative interview as a social interaction in which both the researcher and interviewee bring and omit parts of themselves. Though I no longer fall within the age category of 'young people' as defined by my research, I have often been told that I look younger than I am, and the following comment suggests that the participants of the study may also have perceived me to be younger.

"And I think it's great that it's not being run by (- - -) older people who maybe didn't have the same experiences. Or, just simply aren't as in touch with the current generation who are going to be the ones that use it". (James)

If this was the case, it is likely that it may have had both advantages and disadvantages for the research (Merriam et al, 2001). A potential advantage may be that participants considered me a peer with a common language and shared understanding and that this may have led them to speak more openly about their views. One participant in the current study spoke about how she finds it easier to speak about her mental health with professionals who are closer to her own age as she felt that they could relate to and understand her better.

"I find it easier like, there are certain people that I just feel more comfortable talking around and I think maybe like, I find it... personally, more easier talking to, younger people like close my age. So like... in their 20s and stuff, like early 30s. I find it more \easy talking to them, than talking to like the, older people". (Katie)

Conversely, this may have led both the interviewees, and indeed myself, to collude with an idea that I *had* 'understood' them and to fail to acknowledge the ways in which our differences (e.g. me as 'researcher' and them as 'participant'), linked to status and power, are likely to have influenced the answers provided and obtained (Anyan, 2013). That some participants were open in saying that they did not think the use of an online decision aid would be useful to them, and to raise the issue of potential barriers to using such a tool, gives me some hope that interviewees felt empowered to voice their honest opinions. However, if I were to conduct the research again, I would attempt to be more active in creating opportunities for young people to provide alternative narratives and challenge the implicit ideas presented by the researcher (e.g. that young people need to be supported to seek help for mental health difficulties from mental health services).

Challenging Narratives

Social constructionism is a theory that centres on the notion that reality is constructed in our social interactions through language; it acknowledges that there is a physical world but that we actively construct it's meaning (Burr, 2003). These constructs are learned within relationships and cultural contexts and have significant consequences for how we understand, experience and respond to the world (Gergen, 1985). As such, one's constructs of reality are open to change with fluctuations of the dominant narratives, the stories we tell and are told, within time and cultural contexts.

While conducting both the literature review and the empirical paper, I was conscious of the various personal and cultural narratives that appeared to be influencing the way that young people construct their understanding of mental health and help-seeking. This led me to wonder more deeply about my own constructions of these concepts from the various positions that I inhabit and to explore the ways in which these constructions, and the stories I tell, may have been influenced by the research process and findings. Further, given the power of our communications, I also wondered about the role that my study findings may have in influencing future narratives surrounding youth mental health and help-seeking.

Narratives Concerning Young People

One of the first challenges I faced, after deciding on my research area, was to consider the way in which I would define 'young people'. This was a particularly interesting challenge for me both academically and personally as it led me to

consider and question my personal narratives of my own identity within my social context. From my research and clinical work, I had various constructs of young people and these were sometimes competing. I attended a conference a few years ago in which Jeffrey Arnett spoke about his emerging adult theory and this resonated with me both professionally and personally. As such, I knew that for this research I wanted to focus on and give voice to a group of people who I believed to be oftentimes mistakenly merged with children or adults. Yet, I wasn't sure who exactly would be considered 'in' or 'out' of this group and how this could be decided upon.

When reading more around this topic, it became clear to me that various definitions of young people exist. I am aware from my clinical experience of working in Child and Adolescent Mental Health Services (CAMHS), that it is often the case that once a person turns 18 they are required to make the transition to adult services suggesting that, within the mental health system at least, they are considered 'adult' at that time. There have been many debates about whether this is an arbitrary cut off, which has resulted in a treatment gap for young people aged 16-24 (Youth Access, 2017). It is of note that it is not always the case that the transition needs to be made at 18. For example, early intervention for psychosis services typically work with people aged 14-35 and in places such as Birmingham there appears to be a move towards providing mental health services for 0-25 year olds. The stories that I was reading in the media about the mental health of young people typically referred to people aged 16-24. This is likely due to the fact that the national survey findings they are reporting on typically categorise young people within this age range. However, I could not find any clear explanation for why this was the case other than

that it was "for statistical purposes". I personally believe that what it means to be 'young', and indeed 'old', is personally and socially constructed and as such it can shift and change. Perhaps unsurprisingly, this view of mine has strengthened as I have got older! Nonetheless, for the purpose of this research, I decided to take a pragmatic approach and defined 'young people' as those aged 15-24. This was to ensure that the prevalence data from national surveys and research studies could be used in my literature review.

When conducting the qualitative study, young people spoke often about concerns of being thought of as attention seeking, over-sensitive, and over-dramatic. This was a dominant narrative of the young people involved in my study and I wondered about where this narrative came from and when it started. When I was listening to the young people talking about the challenge that this narrative poses for them in speaking out about their distress and seeking help, I couldn't help but feel overwhelming sadness and frustration for them. I found myself thinking about the term 'snowflakes', which is something of which I was only loosely aware. As I researched this further, my frustrations grew as I found further support for the narratives that young people were telling me about. The term 'snowflake' has become a commonly used pejorative term used in British society to describe young people, who are considered to be over-sensitive. It seemed from my research that this dominant narrative of young people was influencing the way they made sense of themselves and their experiences and also whether or not they sought help. I wondered about how this unhelpful and potentially damaging social narrative could be challenged and what would need to happen in society for there to be a shift from

considering the 'sensitivity' of young people as a problem to seeing it as a strength.

Perhaps the first stage in this process would be to identify how widespread these views are, who holds them, and why they have become the dominant narratives.

Narratives Concerning Mental Health Difficulties

When interviewing young people about their experiences and beliefs about mental health difficulties and help-seeking, I was told stories that both strengthened and challenged my own narratives about these concepts. All participants spoke about the stigma associated with mental health difficulties and this reinforced my belief that despite various interventions aimed at reducing stigma, we still live in a society where it is incredibly difficult for people to own and be open about their experiences of mental health difficulties. Though this was challenging to hear, it was not particularly surprising to me, nor was it a novel concept. It did, however, remind me about the power that social stories can have in influencing the way we make sense of ourselves and the actions we take. I was particularly struck in the interviews by how often young people spoke about concerns that their mental health difficulties would not be taken seriously and at the same time discussed their own suspicions and judgements about the authenticity of other young people's mental health experiences.

The tendency for young people to question their own and other people's mental health difficulties appeared to be further influenced by a growing narrative that mental health difficulties are cool and desired. Several participants spoke about the glorification of mental health difficulties in the media and pop culture and the ways that these social constructs of mental health difficulties delayed their help-

seeking. This was a particularly difficult idea for me to understand and I was aware that my previous exposure to the distress associated with mental health difficulties led to an initial reaction in which I disbelieved that others could truly wish to experience mental health difficulties. I struggled to understand how the narrative that mental health difficulties are 'cool' could prevent people from seeking help and I wondered if it was only young people who were not distressed who would hold this view. At the same time, I began to wonder about how this narrative may further reflect the specific challenges that young people face and how the glorification of mental health difficulties may be a 'manic defence' against the stigma associated with mental health difficulties.

Who or What Needs to Change?

When I started this research project I had an idea, from the literature and conversations with my supervisor, about a 'problem' that needed solving and a way in which this could be achieved. The problem was that young people were not engaging with mental health services, despite having a high need for support, and the potential solution was to use an online decision aid which they could access independently and which could encourage help-seeking decisions. I held the belief that young people would be excited to hear about this web-based intervention and that it could be very helpful to them. However, as the interviews progressed, I was reminded of the particular barriers that young people face when accessing mental health services, and I began to question whether an online decision aid could actually make much difference.

Young people consistently spoke about the challenge of recognising mental health difficulties in themselves and reported the role of others in encouraging them to seek help as the primary facilitator that led to actual help-seeking. Through my interviews with young people, I was encouraged by them to consider the potential barriers to using the tool, something I seem to have forgotten to do. Interviewees talked about the potential overlap between barriers to help-seeking and barriers to using the decision aid, stating that they probably wouldn't use it if they didn't think, or want to accept, that they had a problem. In discussions with my supervisor, we began to wonder about the potential limits of the intervention and she suggested that perhaps rather than targeting the decision aid towards young people, perhaps the intervention needs to be targeted towards potential help-providers. This was an interesting idea to me and it resonated with findings from my previous research in which carers often spoke about feeling neglected and unsupported by youth services.

At the same time, I wondered about the message that this might give to young people, who are fighting for autonomy and respect in a world that often belittles them. This got me thinking about alternative ways of conceptualising the 'problem' and I wondered about whether I had fallen into accepting a narrative that the problem of mental health help-seeking lies with young people, of course within their contexts, but that they, or their parents and teachers etc., are the ones who need to change. Perhaps this is because it is easier to contemplate changing individual people than changing society as a whole. I also wondered about the role of the mental health system in perpetuating the difficulties of young people by continuing to focus predominantly on finding ways of engaging young people with services, rather than

considering ways in which services can more effectively engage with young people (e.g. by taking services to them).

Conclusion

Qualitative research enables a detailed exploration of complex processes and phenomena (Pistrang & Barker, 2012) related to the human experience and can lead to a greater understanding of how individual meaning and social context may influence behaviour (Maxwell, 2009). Reflexivity is considered a crucial component when conducting qualitative research for producing quality findings (Caelli et al., 2003; Starks & Brown Trinidad, 2007). Throughout the research process, I attempted to remain cognisant of the ways in which my personal contexts and narratives may have influenced the research and to respond to this with reflexivity and openness. I found that in many ways, my personal and professional constructs of young people, mental health, and help-seeking were challenged by the research process. Finally, the interviews with young people led me to wonder about whether psychologists need to use their power to achieve greater social and service level changes rather than focusing on individuals.

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Appendix A

Loney, Chambers, Bennett, Roberts, and Stratford (1998) Quality Appraisal Checklist

TABLE 1

Guidelines for critically appraising studies of prevalence or incidence of a health problem

A. ARE THE STUDY METHODS VALID?

- Are the study design and sampling method appropriate for the research question?
- Is the sampling frame appropriate?
- 3. Is the sample size adequate?
- 4. Are objective, suitable and standard criteria used for measurement of the health outcome?
- 5. Is the health outcome measured in an unbiased fashion?
- 6. Is the response rate adequate? Are the refusers described?

B. WHAT IS THE INTERPRETATION OF THE RESULTS?

7. Are the estimates of prevalence or incidence given with confidence intervals and in detail by subgroup, if appropriate?

C. WHAT IS THE APPLICABILITY OF THE RESULTS?

8. Are the study subjects and the setting described in detail and similar to those of interest to you?

TABLE 2 Methodological scoring system used to rate studies reviewed²⁰

lter	n	Score
1.	Random sample or whole population	1 point
2.	Unbiased sampling frame (i.e. census data)	1 point
3.	Adequate sample size (>300 subjects)	1 point
4.	Measures were the standard	1 point
5.	Outcomes measured by unbiased assessors	1 point
6.	Adequate response rate (70%), refusers described	1 point
7.	Confidence intervals, subgroup analysis	1 point
8.	Study subjects described	1 point
	Maximum score	8 points

Appendix B

Table of Overall Reported Prevalence Rates for Each Time Point

Overall Prevalence of Mental Health as Reported at each Time Point

	Collisha w 2004	Sweetin g 2009	Collishaw 2010	Jokela 2013	APMS	HSE ^b	SHeSc	HSNI ^d
1974	10.2							
1986	10.5		5.4					
1987		5						
1993					15.4			
1994				25.8				
1995							12	
1998							13	
1999	16.9	12		26.6				
2000					14.6			
2003							13	
2004				26.4				
2006		18.5	13.2					
2007					17.5			
2008							16	
2009				27.8			16	
2010							15	
2011							14	16
2012						15	13	18
2013							20	
2014					18.9		18	19
2015								16
2016						22	19	22
2017								18

^aAdult Psychiatric Morbidity Survey. ^bHealth Survey for England. ^cScottish Health Survey. ^dHealth Survey Northern Ireland.

Appendix C

Table of Reported Prevalence Rates by Gender for Each Time Point

		ishaw 004		eeting 009		ishaw 010	AI	PMS	Н	SE	Sl	HeS	HSNI	
=	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
1974	7.8	12.8												
1986	7.8	13.4			2.9	8.9								
1987			3.4	6.6										
1993							10.3	20.5						
1995											9	16		
1998											9	17		
1999	13.3	20.4	5.5	18.4										
2000							8.3	21						
2003											10	16		
2006			10.2	26.7	6.7	19.7								
2007							13	22.2						
2008											12	20		
2009											12	20		

		ishaw 004		eting)09		ishaw 010	APN	MS ^a	H	SE ^b	SHeS ^c		HSNI ^d	
•	Male	Female	Male	Female	Male	Female	Male		Male	Female	Male	Female	Male	Female
2010											13	17		
2011											13	15	9	21
2012									9	21	7	19	14	20
2013											16	23		
2014							10	28.2			12	24	13	23
2015													11	20
2016									16	28	18	20	13	29
2017													21	17

^aAdult Psychiatric Morbidity Survey. ^bHealth Survey for England. ^cScottish Health Survey. ^dHealth Survey Northern Ireland.

Appendix D

Confirmation of Research Ethics Committee Approval Letter



London - Dulwich Research Ethics Committee

Health Research Authority Skipton House 80 London Road London SE1 6LH

Tel: 020 797 22567

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

11 August 2017

Dr. Kathryn Greenwood Consultant Cilnical Psychologist and Cilnical Research Fellow Sussex Partnership NHS Foundation Trust R&D R1.09 Sussex Education Centre Mill View Hospital Nevill Avenue BN3 7HZ

Dear Dr. Greenwood

Study title: The development of a Youth Mental Health Help Seeking

decision aid: Promoting help-seeking to reduce long term

disability

REC reference: 15/LO/0646

Amendment number: 1

Amendment date: 26 July 2017 IRAS project ID: 174646

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

Ethical opinion

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

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP)	1	26 July 2017
Other [Information+and+consent+sheet+phase1+Interviews+v3]	3	26 July 2017
Other [InterviewSchedule10_07_2017KL]	1	17 July 2017
Research protocol or project proposal	3	18 July 2017

Membership of the Committee

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

Working with NHS Care Organisations

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

Statement of compliance

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

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

15/LO/0646:	Please quote this number on all correspondence	
I Jarlunu646.	Prease quote triis riuriibei on all correspondence	

Yours sincerely

Dr Michael Philpot Chair

E-mail: nrescommittee.london-dulwich@nhs.net

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

review

Copy to: Mrs Taffy Bakasa, Sussex Partnerships NHS Foundation Trust

Appendix E

Participant Information Sheet



Study title: The development of a youth mental health help-seeking decision aid

Information sheet: Phase 1 Version 2, 26/07/17

Invitation: You are being invited to take part in a research study. It is up to you to decide whether or not you want to take part. Before you decide, we would like to tell you about the study, answer any questions that you may have, and give you time to think about it and discuss it with family, friends, your school/college or care team if you wish. Information on how to contact us and other independent advice is at the end of this information sheet.

What is this study about? This research aims to find out your views on questionnaires that check for mental health problems, and about guidance for getting help. It also aims to find out your views about the development of a decision aid for young people to use themselves to guide them in their decision to seek help. The outcome of the research project will be to produce this decision aid working with young people, so that young people in the future can use this on their own to help them decide if they have a problem, and if they do, who to turn to for help.

Why bother doing this study? Research has shown that most mental health problems emerge during adolescence, but young people are the least likely to seek help for their problems. Much of this barrier to help-seeking stems from lack of appropriate information and stigma. This study aims to produce a user-friendly decision aid with linked information about seeking help, and self-help. This will guide young people in decisions about help-seeking for mental health.

Why me? You have been invited to take part because you are a young person who is currently using mental health services.

What would taking part mean? Taking part would involve taking part in an interview and telling us your views about screening questionnaires for mental health, your experiences of help-seeking, and the sorts of information and guidance that would be helpful for young people seeking help for mental health problems. There's no right or wrong answer. It's what you think that matters. The interview would be led by Trainee Clinical Psychologist and would take 60-90 minutes with a short break in the middle.

The discussion will be tape recorded so that we can remember what you've said accurately, but we will store the tape in an anonymous way so that you cannot be identified. We will

also ask you to provide further feedback on the questionnaire as we develop it. You can choose whether you would prefer to do this by telephone or email. Each feedback session will take 15- 30 minutes.

Where would I have to go and when? You would meet at a time and place that is convenient for you and the others in the group. This could be at an NHS or a community venue.

Reimbursement. You would be reimbursed £10 per hour for your time, plus basic travel expenses.

Do I have to take part? No, it's up to you. If you decide to take part, someone from the research team will contact you. If you decide to take part and then change your mind, you are free to withdraw at any time without having to give a reason. Whether you decide to take part or not will not affect your care through the NHS

What are the advantages of taking part? Whilst there are no immediate advantages to taking part in this study, we've found that some people enjoy taking part in these types of projects, where you can share your views. The findings will add to our knowledge about decision aids to mental health help-seeking for young people. It will lead to the production of a new decision aid to guide help-seeking.

What are the disadvantages of taking part? It is possible that talking about your views of mental health services might make you feel upset and may be tiring. You can stop at any time during the meeting, without having to give a reason. You can also talk to us, someone else who you trust like friends or family, your care team or someone from the Patient Advice and Liaison service if you have any concerns.

Confidentiality. Any information you give will be treated confidentially. This means that we will not tell anyone about anything that you tell us as part of this research study. We will use the answers you give to provide general guidelines for developing the questionnaire. We may use quotes to back this up but these will be anonymous – your name will not be attached. The only exception to this is if you say something that suggests there is a risk to your own or someone else's safety. In that case we are obliged to tell a GP or your care team. A researcher will always try to talk to you before contacting these services.

Who will know if I decide to take part? Your care-team or care co-ordinator will know you have been invited to take part in the study but they will not have any information about what you say in the group. No-one else apart from the study team will know you are taking part.

What would happen to the results? The results of the study will be published in a mental health journal, but the information will be anonymous and your name will not be included. If you would like one, we will send you a summary of the findings of the study.

What will happen if I am unable or don't want to carry on with the study? You can withdraw from the study at any time without having to give a reason. Any data that you have provided up until that point will be included in the study.

Who is funding this study? This study is funded by a grant from the Sussex Partnership NHS Foundation Trust charitable committee.

What if there is a problem? If you have a concern about any aspect of the study, you should ask to speak to the researchers, using the contact information below. They will do their best to answer your questions. If you remain unhappy you can contact the R&D department, or Patient Advice and Liaison Service using the contact information below.

What if I have a complaint? If you have a complaint about the way you are approached or treated during the course of this research study, you may want to talk to the Patient Advice and Liaison Service (PALS) above who will advise you on what to do.

Who has reviewed this study? This research study has been reviewed and approved by the Research and Development department within your local NHS Trust and by London-Dulwich Research Ethics Committee (Ref no. 15/LO/0646). It has also been reviewed by people who use services for unusual distressing experiences.

Who can I contact to talk about taking part in this study?

If you have any questions about the study, please contact me:

Dr. Kathryn Greenwood Tel:

School of Psychology Email: k.e.greenwood@sussex.ac.uk

Pevensey 1

University of Sussex

Brighton

BN1 9HQ

If you have any questions about taking part in research in general, you can contact your local NHS Research and Development Department:

Taffy Bakasa Tel: 01273 265909

R & D Department Email:
Taffy.Bakasa@sussexpartnership.nhs.uk
Nevill Avenue
Hove
Sussex Education Centre
BN3 7HY

If you want to talk to someone independent about research, you can contact your local Patient Advice and Liaison Service (PALS):

Aldrington House Tel: 01273 716588
35 New Church Road Email: PALS@sussexpartnership.nhs.uk

Hove, Brighton

BN3 4AF

Thank you for reading this.

Appendix F

Participant Consent Form



Consent Form: Phase 1 Version 2, 26/07/17

Study title: The development of a youth mental health help-seeking decision aid Please read the following points and tick the boxes after each point to show that you agree, and then sign your name at the bottom.

a)	I have read the information sheet (dated 26/07/17 version 2) and taken the time to think about whether or not to take part	
b)	I have been given the contact details for people with whom I can talk about whether or not to take part in this research study	
c)	I agree to take part in this research study	
d)	I understand that this involves taking part in an interview with a Trainee Clinical Psychologist for 60-90 minutes with a short break in the middle, and then taking part in two additional feedback sessions which will each take about 15-30 minutes. These feedback sessions can occur by telephone or by email depending on my preference	
5.	I understand that the discussion in the meeting will be recorded and typed out so and agree to this	
6.	I understand that research data collected during the study may be looked at by individuals from the research team. I give permission for these individuals to have access to my research data	
7.	I understand that I may change my mind and withdraw at any time without having to give a reason	
8.	I understand that if I decide to stop doing the research, the information that I have already given will still be used in an anonymised form (without my name).	
9.	I am willing to be contacted in the future to be asked about taking part in additional related research	

10. I understand that if I tell the researcher something which shows that there is a significant risk to me or someone else, the researcher may need to pass this information on to a GP or medical team. A researcher will always try to speak to me before contacting any of these services
Please sign and print your name below to show that you consent to take part in this research study and agree with the points above.
Participant's signature:
Printed name (in capitals):
Date:
Witness' signature:
Printed name (in capitals):

Appendix G

Interview Topic Guide

New Interview Schedule – Version 1 – 17/07/2017

Introduction

We are developing an online tool that can help young people to find out if they do or don't have a mental health difficulty and support them in deciding whether to seek help for this.

Seeking help means speaking to somebody, whether that be a friend, family member, teacher, or mental health professional about the difficulties that they are having.

Young people have already told us a little about what the online tool should look like and what information it should include, but we don't yet know how the tool can help young people to actively speak to somebody about their difficulties once the tool suggests that this might be useful.

I'd really like to hear your thoughts about this. I have some specific questions I would like to ask but I wonder if anything came to your mind as I was speaking?

Part 1. Experience of getting to a mental health service/help-seeking

- Can you tell me about how you came to receive a mental health service?
 Possible prompts:
 - How did you first come to use mental health services?
 - How did you think and feel about coming to use mental health services? What did it mean to you?
 - What did you think would happen when you first accessed mental health services?
 - Did what happened fit with what you thought would happen?
 - Did you speak to anyone about the difficulties that you were having? (If no, explore why not)
 - Who did you speak to? Why did you decide to speak to them? What did you think they would say/do? How did they react when you spoke to them? Why did you think this?
 - Was there anybody you didn't speak to? Why didn't you speak to them?
 What did you think they would say/do? Why did you think this?

- Did anyone speak for you/ on your behalf? How did you feel about this? If someone had done this, how would this feel?
- What do you think makes it difficult for young people to talk to others about mental health?

Possible prompts

- Severity, self-efficacy, literacy, autonomy, hopelessness, fear, social contexts/support, stigma, beliefs about outcome
- What do you think makes it easier for young people to talk to others about mental health?

Possible prompts

 Severity, self-efficacy, literacy, autonomy, hopelessness, fear, social contexts/support, stigma, beliefs about outcome

Part 2. Show elements of tool and elicit feedback

I mentioned that we are trying to develop an online tool to help young people make the decision to seek help from people around them.

I said that we had spoken to young people already about what this tool might look like and I would like to hear your opinions and ideas based on some of the things they talked about.

Show examples of what aspects of the tool might look like and get general feedback.

- What would make you more, or less likely to use an online decision aid like this to help you decide whether or not to speak to somebody about your mental health difficulties?

Prompts

access, confidentiality, peer support, autonomy, choice etc.

Role of tool in promoting active help seeking

- If you used the tool and it suggested that you seek help for your mental health, what would make you more likely to actually speak to somebody? *Explore answer*
- You said that [refer back to earlier comments about facilitators] makes it easier for young people to seek help. How might the different parts of this tool affect this?
- You said that [refer back to earlier comments about barriers] would put you off speaking to someone. How might the different parts of this tool affect this?

Only **if not covered already** ask following questions

- Is it important to you to feel that you have a sense of choice and control over who you speak to, what you say and what happens?
 - How could we best address this using an online tool? What would work?
 What wouldn't work?
- Is it important to you to know what is likely to happen if you seek help?
 - What would you want to know? How could we best address this using an online tool? What would work? What wouldn't work?
- Some young people find it hard to talk about and explain their mental health difficulties, and put it into words.
 - What are your thoughts on this? How could we best address this using an online tool? What would work? What wouldn't work?
- Some young people said that they might struggle to seek help because they don't know if their problems are just part of being a 'teenager or young person'
 - What are your thoughts on this? How could we best address this using an online tool? What would work? What wouldn't work?
- Young people sometimes compare themselves to others to try and figure out if they are different and they may have a problem
 - What are your thoughts on this? How could we best address this using an online tool? What would work? What wouldn't work?

- Some people don't seek help because they don't think anyone is going to take them and their problems seriously
 - What are your thoughts on this? How could we best address this using an online tool? What would work? What wouldn't work?
- Some people don't seek help because no-one has prompted them to do it, and they don't know if it's the right thing to do
 - What are your thoughts on this? How could we best address this using an online tool? What would work? What wouldn't work?
- Some people just don't know where to go to get help that will work for them
 - What are your thoughts on this? How could we best address this using an online tool? What would work? What wouldn't work?

F. Close and debrief

That is all the questions that I have.

- Is there anything else that you feel is important that you would like to say?
- Do you have any questions?

Thank you for taking part.

Appendix H

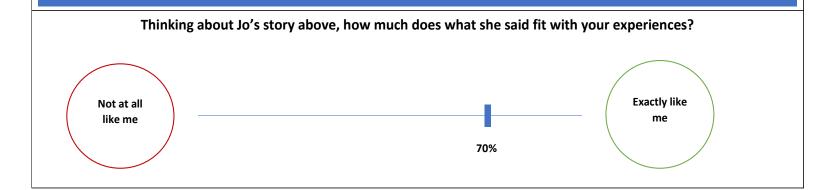
Example Materials Shown to Participants in Interview

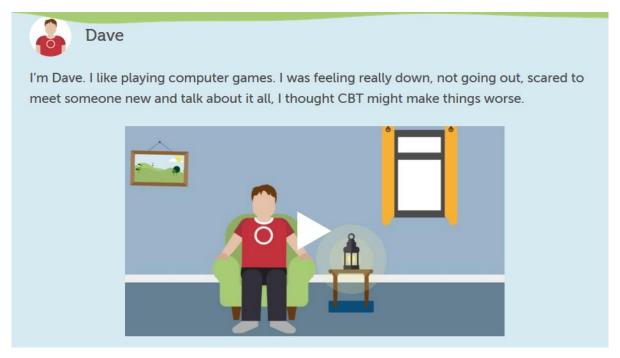
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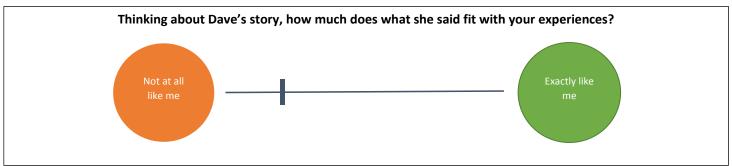
Recognising how you feel

Jo's Story, age 19

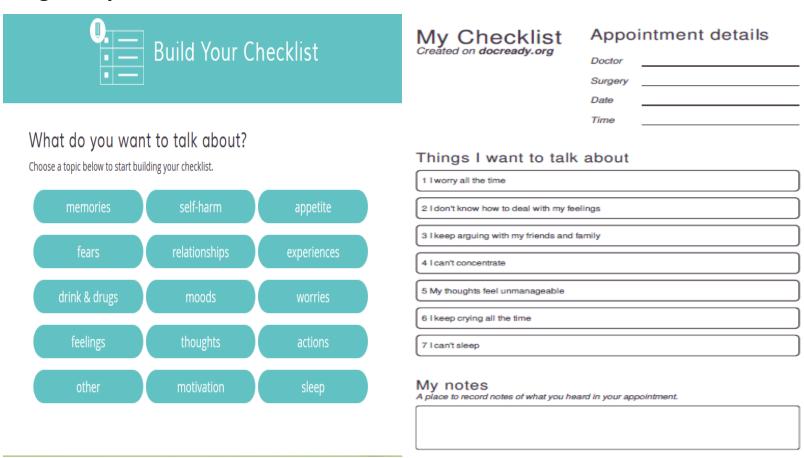
I felt so low inside that I could not possibly picture a happy future for myself, and so I began to self harm and have thoughts of suicide. It affected my relationships with family and friends, I didn't want to socialise with anyone. My performance at school became worse, achieving lower exam grades and having poor attendance. I realised afterwards that I was struggling with depression







Expressing how you feel

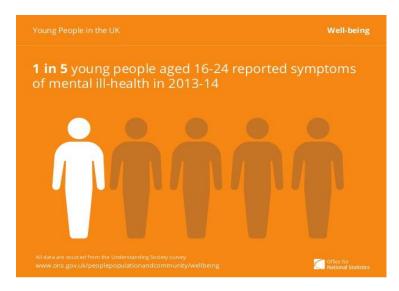


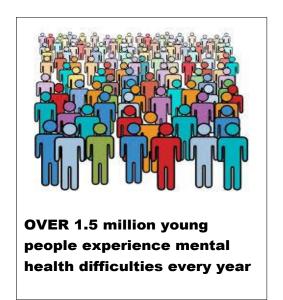
Taken from http://www.docready.org/#/picker

'It's not 'am I normal?', but 'am I bothered?''

One thing that can be hard is deciding whether you have a problem or not. How can you tell the difference, for example, between normal mood swings and a serious mental health issue? Is it normal or abnormal?

We all feel different emotions at different times. It's normal to change from feeling happy to sad, calm to stressed, energetic to unmotivated in a single week. General stresses, things that happen in the week, tiredness and hormones can all play a part in your emotions. Some people are just 'moodier' than others and that's okay too.







Appendix I

Examples of the Process of Thematic Analysis

Sher of the rest has forents and the way the way Transcript 1 2 not your Parents can support halp south to seeking young people do \$ Go to internet for advice and to look for help - "I didn't Seeking - worry notice things aren't okay morn took me to the Paronts may look online Crisis - leads to help-seeking yere. for advice and help I couldn't cope anymore ninew i didinappe I was suicidal (esychosis)
paravoid trost august I was invincible, it would
paravoid trust different never happen to me
interpret things are rimnor i didn't feel sate Decision-aid-need to know it exists and be able to find it upung people are this hard to explain what was going 4 could advertise it in GPs alway about morted on to others didn't understand I nod a mental bif I knew / insecure about houlth problem so I didn't wow entropy about morted had a problem and 1 knew it where to look for help may day was how he was how he was day? Was he I didn't what help would be as available 16) available - thought I had to SP lt. way and more resolve it or my own.

The property will have be have someone in your as the be as bad as

it was a series of thought with psychosis to be as bad as resolve it on my own. +wouldn't use ut t didnt believe ned a problem. 4 need to make - Have to build relationships to toost formuly + friends aware people before seeking help. of it as they could. ME encourage me touse of Knading somegne who's had experience focilitates help the tool could help by suggesting what things to talk about. An ordina decision The tool needs to be aid can't address Specific and relatable to the bourier of It isn't important to have chaice or Symptomscontrol around who yourspeak all young people and the 4211's difficult to to it you don't trust anyone varying difficulties convince someone ert all. that it's mental they can have. An online tool wouldn't have health difficulty. the bung people may need helped me very much if 4 Reading something it gave me choice - better if prompting to get helpthat says you need help may not have a big it out told me where to but may need support to mout on whether or not a problem use the decision aid.

Family can facultate help-seeking

omers can notice sementings wrong and direct you to help

Young people cont always realise they are experiencing mutal watth difficulties and so don't seek nelp

Seeking formal help can lead to feelings of anniety

Young people often do what they are told ladvised to do.

Young people don't like to bouk about mental health difficulties

- fear of how others might percieve them I have it night affect their identity
- It's like admitting that something is woring with you
- it makes things seem more real-fear have to act
- fear of now others would respond segregation

Having support from others with similar experiences can facilitate talking obout mental health.

The needs of others can ock as a boarrier to help seeking

Young people worry that they won't be believed or taken seriously, by others

Bestiff Lack of knowledge of mental health difficulties can be a barrier to help-seeking

44 Young people don't know how to express what is going an for their 44 Young people don't know how to express what is going an for their

Belief that others world understand and/or can't help hinders help-seeking 4 what's the point?

Knowing you are not alone in your experience can facultate help-seeki Services which are approachable facilitate help-seeking

? Lack of time alone can hinder help seeking?

Young people don't always know how to seek help or where to go Symptoms can facultate and hinder help-seeking.

40 crisis can lead to help-seeking

→ if sorere can hinder through anxiety, paranola etc.

Open and accessible services can promote help societing

Having to phone someone or book an appointment can hinder help saking Easier to seek help from someone who already knows you well

Young people do sometimes look for help linformation about mental health on the internet.

Online questionnaires can be difficult to complete and can fail to take into account the nounces of peoples experiences.

La can be frostrating if you don't feel the answers fit for you

An online decision aid should be accessible, easy to use, look good and reputable, be odvertised and engaging.

stigma and fear of people finding out you've used the tool is a barrier to engaging with it.

Young people want to be able to trust the tool and know that it is official and not just a 'random' website.

Young people use online surveys and quizzes to find answers wouldn't use a decision aid if it is children or too looning.

Xung people don't want on online decision aid to give them a diggraphic significant want to be told they have to do something-choice and information is important.

40 young people want to know their options for help-seeking

Hyoung people may be more tikely to seek help if the decision and can tell them the steps they need to take

A decision aid that can give young people the right words to describe their difficulties could facultate help-seeking

Statistics can help young people to feel they are not alone and this can make it easier to speak out about mental health difficulties.

Poverty llack of private access to the internet may be a borrier to using an ordine decision and.

An online tool won't help you'r you don't believe you are experiencing as

Young people worry about comparing themselves to others but like the idea of using vignettes as a way of exploring if they may be experiencing mental health difficulties.

Young people don't find it helpful to have to commit to one answer e.g. yes/no. Young people won't use an online decision aid if it takes up too much of their time

Young people do sometimes look for nelp linformation about mental health on the internet.

Online questionnaires can be difficult to complete and can fail to take into account the nuances of peoples experiences.

La can be frostrating if you don't feel the answers fit for you.

An online decision aid should be accessible, easy to use, look good and reputable, be advertised and engaging.

Eigma and fear of people finding out you've used the tool is a barrier to engaging with it.

Young people want to be able to trust the tool and know that it is official and not just a 'random' website.

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A decision aid that can give young people the right words to describe their difficulties could facilitate help-seeking

Statistics can help young people to feel they are not alone and this can move it easier to speak out about mental health difficulties.

Poverty/lack of private access to the internet may be a bourrier to wing an online obcision aid.

An online tool won't help you if you don't believe you are experiencing a mental health difficulty.

Young people worry about comparing themselves to others but like the idea of using vignettes as a vary of exploring if they may be experiencing mental health difficulties.

burg people clon't find it helpful to have to commit to one answer e.g. yes/no. Young people won't use an antine decision aid if it takes up too much of their time.

2/23

Mental health is hard to talk about difficulties are hard to explain

Process of help-seeking

fi you are strong-headed and don't tend to talk then won't seek help

Coping styles

Personal characteristics of young people

Stigma

Other people would view me differently Impact on self

Beliefs about negative impact of help-seeking on self and others

Beliefs about negative impact of help-seeking on self and others

Beliefs about negative outcomes of help-seeking on self and others

Beliefs about negative outcomes of help-seeking on self and others

Beliefs about negative outcomes of help-seeking on self and others

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Beliefs about negative impact of help-seeking on self and others

Beliefs about negativ

increased for you, um

P: Especially like during exam season and stuff

IIIS. P: Especially like during exam season and stuff

but didn't know at the time?

but didn't know at the time?

IIIS P: Yeah I didn't see it as 'oh, I'm unwell', I just thought 'yeah, I'm stressed' and

III kind of; I would say at times I isolated myself a bit, and I had some um, -- kind

of like, unusual um, -- ways of, explaining things, I- I don't know how to put it,

very well, (laughten), but uh, um but, there were some things that my family felt

like, you know, this is out of char; yeah so, you know, things out of character, um

that's what helped them to see that OK, there's, you know, there's something we

need to do about this, like there's something wrong here so, yeah, so I would say

the stress led to, you know, unusual characteristics being displayed, um, -- which

helped my family to kind of - spot - that things weren't so good, and that I was

you know, going through some - difficulty, yeah.

so it sounds like, kind of when you were in college, the stress levels really العادات.

118: I: Yeah absolutely, OK, um, and you said that then, things kind of escalated and then you went, you kind of found yourself in hospital, - before that point did you try to speak to anybody about the stress, or what was going on for you?

someone, but I wasn't; l'm the type of person where l'm very strong and I don't really share such things with people, so it was quite difficult to even consider talking to someone about, you know, like having mental health difficulties, like at the time that I realised that, you know, this was not so good, like I just felt, it's not something I talk about, there's so much stigma attached to mental health as well so if you talk about, there's so much stigma attached to mental health as well so if you talk about, it to other people, sometimes they may see you differently, and treat you differently, so, but for me, I thought, 'oh generally, I can talk to someone if l'm str.: you know, we're all going through stressful times, at college, but for me, I felt 'oh, am I stressed more than everyone else here or something?', but it's like I couldn't really, I felt there was a limit to how much I could say about my stress, and who I could actually talk to, about how stressed I was, so um, yeah, I-I didn't really - feel like I could talk to people that much because I just didn't want to be seen differently, because yeah.

lool: Yeah, so that stigma was a real kind of + barrier to speaking to someone?

1212 P: Yeah, + yeah, and I had learnt about mental health issues in health and social care, I studied health and social care and psychology, so I learnt about these things, and I felt, if I go and talk to someone about, you know, I'm really