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# Designing Technologies to Support Young People's Online Help-Seeking for Mental Health Difficulties

## **Claudette Pretorius**

16212035

This thesis is submitted to University College Dublin in fulfilment of the requirement for the degree of Doctor of Philosophy

UCD School of Computer Science

Head of School: Dr. Chris Bleakley Principal Supervisor: Dr. David Coyle Co-Supervisor: Professor Gary O'Reilly

Doctoral Studies Panel Members: Mr. Derek Chambers, Dr. Marguerite Barry, Dr. Julian Edbrooke-Childs

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## Abstract

The mental health of young people aged 12 to 25 is of key concern at a global level, with the emergence of many mental illnesses taking place during this time. Help-seeking is recognized as an important protective factor in young people's mental health. Evidence suggests that positive help-seeking experiences contribute to an increased likelihood of future help-seeking and improved mental health outcomes. However, help-seeking is a complex process, often impeded by a number of barriers. Alongside traditional sources, digital technologies offer additional pathways to help but also introduce unique challenges, that have to date not yet been explored. Young people face unique challenges in finding help appropriate to their level of need.

This thesis provides an in-depth investigation of young people's needs from technologies that facilitate the online help-seeking process. Through a series of studies, empirically grounded guidelines for online help-seeking tools have been developed and are presented. The research in this thesis provides insight into the online help-seeking experiences of young people, the opportunities technology provide as well as its challenges. It details a mixed-methods, user-centred approach, using techniques from both the health and Human Computer Interaction domains, to explore sensitive topics with young people. The Centre for eHealth Research Roadmap (CeHRes Roadmap) was used as a framework to guide the research. Four studies were conducted in order to achieve the thesis aims: a narrative systematic literature review; a large-scale online survey; a co-design study; and finally, a user study to evaluate design recommendations.

Building on prior theories this thesis provides a consolidated, theoretically grounded model to understand the online help-seeking process. This model makes use of Rickwood's help-seeking model to illustrate the online help-seeking process and Self-Determination Theory to identify key design elements that can either facilitate or impede online help-seeking. The design recommendations presented in this thesis can be applied to both help-seeking tools and online mental health resources. The five recommendations include: provide opportunities for connectedness; provide credible and accessible information; provide personalization, but respect autonomy; provide 'just-in-time' support options; and emphasize clear, professional design. Resources that meet these recommendations will better meet the online help-seeker's needs; contribute positively to online help-seeking experiences; and facilitate the identification of resources that are both engaging and provide appropriate levels of care.

## Statement of Authorship

I hereby certify that the submitted work is my own work, was completed while registered as a candidate for the degree stated on the Title Page, and I have not obtained a degree elsewhere on the basis of the research presented in this submitted work

Signed:

Date: 1 September 2020

## **Role of Candidate and Collaborators**

**Claudette Pretorius**: Whole thesis: study design, participant recruitment, data collection, data management, data analysis, design of prototypes, manuscript preparation and manuscript submission.

**Dr. David Coyle:** Whole thesis: study design, data analysis, manuscript preparation, manuscript proofing

**Mr. Derek Chambers:** Chapter 4: study design and data analysis. Chapter 5: Study design.

Dr. Benjamin Cowan: Chapter 5: quantitative data analysis

**Mr. Darragh McCashin**: Chapter 5: qualitative data analysis. Chapter 6: qualitative data analysis and manuscript preparation

Ms. Naoise Kavanagh: Chapter 6: participant recruitment and data collection

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## **Related Publications**

**Journal Papers** 

- Pretorius, C., Chambers, D., & Coyle, D. (2019). Young People's Online Help-Seeking and Mental Health Difficulties: Systematic Narrative Review. *Journal of Medical Internet Research*, 21(11), e13873. <u>https://doi.org/10.2196/13873</u>
- Pretorius, C., Chambers, D., Cowan, B., & Coyle, D. (2019b). Young People Seeking Help Online for Mental Health: Cross-Sectional Survey Study. *JMIR Mental Health*, 6(8), e13524. <u>https://doi.org/10.2196/13524</u>

**ACM CHI Full Conference Papers** 

Pretorius, C., McCashin, D., Kavanagh, N., & Coyle, D. (2020). Searching for Mental Health: A Mixed Methods Study of Young People's Online Help-seeking. In 2020 ACM annual conference on Human Factors in Computing Systems - CHI '20. ACM Press. https://doi.org/https://doi.org/10.1145/3313831.337632

**Short Conference Papers** 

- Pretorius, C., Chambers, D., Cowan, B., & Coyle, D. (2019) A Survey of Online Helpseeking in Young People. Technology for Youth Mental Health: Involving users, Opportunities and Ethical Implications Symposium. *European Society Child and Adolescent Psychiatry,* Vienna, Austria.
- Pretorius, C., Coyle, D. & Chambers, D. (2018), Intelligent Techniques to Support Online Mental Health Communities: Resource Recommendations for 4 Levels of Stepped Care. In Proceedings of the Second African Conference for Human Computer Interaction: Thriving Communities (AfriCHI '18). ACM Press. Article 42, 1–4. <u>https://doi.org/10.1145/3283458.3283509</u>

- Pretorius, C., Chambers, D., Cowan, B., & Coyle, D. (2018). A Survey on Online Help-Seeking in Young Adults. *Children's Research Network PhD Conference*. Dublin, Ireland (Oral Presentation)
- Pretorius, C., Chambers, D., & Coyle, D. (2017). Intelligent Techniques to Support Online Mental health Communities and Signpost to Four Levels of Stepped Care. *Technology for Wellbeing Conference*. Dublin, Ireland (Oral Presentation)
- Pretorius, C., Chambers, D., & Coyle, D. (2017). Intelligent Techniques to Support Online Help-Seeking. International Association for Youth Mental Health Conference. Dublin, Ireland (Oral Presentation)

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# Abbreviations

ACM	Association for Computing Machinery
CASP	Critical Appraisal Skills Program
CeHRes	Centre for eHealth Research and Disease Management
DSM	Diagnostic and Statistical Manual of Mental Disorders
GDPR	General Data Protection Regulation
GHSQ	General Help-Seeking Questionnaire
HCD	Human Centred Design
HCI	Human Computer Interaction
HSE	Health Service Executive
ISO	International Organization for Standardization
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta- Analyses
RCT	Randomised Control Trial
SDT	Self-Determination Theory
SPSS	Statistical Package for the Social Science
SWEMWBS	Short Warwick–Edinburgh Mental Well-being Scale
TENS	Technology-based Experience of Need Satisfaction
TPD	Theory of Planned Behaviour
WHO	World Health Organisation

# Chapter 1: Introduction

#### **1.1 Introduction**

It is well established that the emergence of mental health concerns in young people aged between 12 and 25 is of a global concern (McGorry et al., 2007). Mental health difficulties developed in adolescence and young adulthood may persist into adulthood and in some instances develop into longer lasting chronic illnesses (Collishaw, 2015). Research suggests that mental health concerns are not limited to those experiencing diagnosable mental health illnesses but that psychological distress is increasing for this population in general (Dooley & Fitzgerald, 2012; Dooley, O'Connor, Fitzgerald, & Oreilly, 2019). In the context of rising levels of distress and its implications for future wellbeing, the need and importance of providing interventions and supports to this age group specifically is paramount (ACAMH Special Interest Group in Youth Mental Health, 2013).

Help-seeking is recognised as an important protective factor in young people's mental health (Gulliver et al., 2012; Rickwood et al., 2005). However traditional offline help-seeking is often impeded by barriers such as stigma, lack of access and poor mental health literacy (Wilson et al., 2005). The prevalence of poor mental health is increasing whilst the engagement in help-seeking behaviour remains low (Gulliver et al., 2010). This highlights the need to facilitate help-seeking and create more opportunities for successful help-seeking to take place.

The growing accessibility of the Internet has resulted in young people making use of online resources to meet many of their needs. This has extended to help-seeking. It is now possible for young people to engage in help-seeking both online and offline. It is accepted that technology has a role to play in the delivery of mental health services. This integration can be particularly successful when technology is integrated into existing services and structures (Stretton et al., 2018). Although there is a growing amount of web-based information and services available, this does not mean that these resources are easily found, have high engagement rates or facilitate the help-seeking process (Feng & Campbell, 2011). As is the case with offline help-seeking, young people have distinct preferences for online resources and their preferred pathways in locating and accessing these resources.

A number of opportunities exist to facilitate young people's help-seeking through the carefully considered design of help-seeking technologies. To date research in this area is limited. This thesis addresses gaps in the literature through a series of studies that investigate young people's online help-seeking behaviours. The studies in this thesis aimed to determine design recommendations that can be implemented in order to facilitate young people's online help-seeking for mental health concerns.

### **1.2 Thesis Aims and Objectives**

The primary aims of the research presented in this thesis were to explore young people's online help-seeking behaviours for mental health concerns and how their online help-seeking can be supported through technology. In order to achieve these aims, the following objectives were identified:

- To systematically review and synthesize the literature regarding young people's experiences of online help-seeking for mental health concerns. This includes providing an overview of young people's behaviours and identify benefits and limitations of online help-seeking for young people.
- To develop a comprehensive understanding of the experiences and preferences of young people when seeking help online for mental health concerns.
- To develop design recommendations for technologies and online mental health resources that facilitate young people's help-seeking to match their current level of need.
- To evaluate help-seeking technology prototypes that embody these design recommendations and reassess these design recommendations in light of these findings.
- To provide an overall theoretical framework to understand and guide the design of online help-seeking technologies.

## 1.3 Interdisciplinary Research and Design

Interdisciplinary research and design provide rich opportunities to develop and deploy interventions that meet the needs of users in novel and effective ways.

However, Blandford et al. (2018) highlight that interdisciplinary health research is not without its challenges, listing differences in terminology, methods and culture as important areas in which clarity needs to be obtained. Much of the work in this thesis is as a result of interdisciplinary collaboration between the disciplines of HCI and psychology. In order for this collaboration to have been successful, an interdisciplinary understanding and mutual respect for the contribution each discipline added to the project was key.

The collaboration between disciplines in health research is integral to challenging the status quo and prompting growth and evolution in traditional health spaces (Mohr et al., 2017). A successful digital health intervention will draw on the knowledge of users, health professionals and HCI specialists. Health research emphasizes the importance of theory when developing health interventions; whereas HCI allows for and recognises the importance of the iterative nature of design and development of the intervention (Blandford et al., 2018).

HCI and health researchers have different approaches to the development and evaluation of health technologies. Health research prioritises randomised controlled trials (RCT) to determine effectiveness; although RCTs are lauded as the gold standard in health research they are not without their shortcomings. It has been reported that RCTs do not reflect real-world use or engagement, which can negatively impact effectiveness once digital interventions are executed outside of a controlled environment. (Blandford et al., 2018; Mohr et al., 2017). HCI however, includes users throughout the design process and evaluates the technology throughout its design and development. This ensures the technology meets the user's needs and will play an important role in improving engagement outside of lab or study environments.

Knowledge from each discipline can contribute to the development of digital health technologies in different ways. Throughout the research studies included in this thesis, skills from both HCI and health domains have been utilised in order to answer research questions and to best achieve the overall aims of the thesis. In some instances in the thesis, this is represented by interdisciplinary collaboration and other instances, it's represented in interdisciplinary skills that the researcher has had to acquire. This was especially necessary in Study 3 and 4, which involved co-design and user testing methods. This was possible as the researcher was supervised by a leading researcher in the field of HCI. Collaborations with individuals from different disciplines was valuable in study 1 and 2. These studies were possible through

collaborations between three co-authors, one from psychology (the researcher), one from sociology (Derek Chambers) and one HCI (Dr David Coyle). Throughout the studies, advisors working the field of youth mental health were also consulted, an important practice highlighted by CeHRes roadmap, further discussed in Chapter Three.

#### **1.4 A Mixed-Methods Approach to HCI Research**

In line with the interdisciplinary nature described above, digital health research requires the use of methods from different associated disciplines. It is important that the methods of data collection and analysis fit the research question and in order to do this, appropriate methods need to be taken from both quantitative and qualitative research approaches (Blandford, 2013). This includes making use of both small and large scale studies. It is common to use qualitative methods to gain an understanding of the use of technology in context. These methods often include ethnographic studies and allow the inclusion of design features that are appealing and relevant to users (Blandford et al., 2016). Qualitative studies usually consist of smaller numbers of participants but provide rich, descriptive data. Quantitative methods often involve large numbers of participants and are often used in the evaluation of technologies. Quantitative methods are useful in that they provide data that is descriptive and is useful for understanding large datasets. Whilst, a mixed-methods approach adds complexity to the planning and conducting of the research, it provides the opportunity to explore connections and contradictions between quantitative and qualitative data (Regnault et al., 2018). A mixed-methods approach has been used throughout this thesis with the intention to provide depth and a more panoramic understanding of young people's needs when seeking help online. The CeHRes Roadmap provided the structure within which to select the appropriate methods at each stage of the research.

#### 1.5 Terminology

As the field of digital health technologies for mental health matures, the range of terminology increases. This is reflective of the interdisciplinary nature of the field. The lack of an agreed upon lexicon often results in miscommunication or misunderstandings. It has been argued that the field needs to move to a place where there is more consistency of terminology used (Smoktunowicz et al., 2020). Key terms are defined and outlined below in order to avoid misunderstanding and ensure clarity.

#### 1.5.1 Online Mental Health Resource

The increased use of the Internet over recent years is accompanied by the increased availability of not only online mental health information, but also online resources on managing one's mental health. Previous research has found distinct benefits to the use of online mental health resources including improved mental health literacy and reduced bias towards mental health illnesses (Griffiths & Christensen, 2007). Throughout this thesis any online resource, including a website, web/mobile application, discussion forum or online mental health service, will be referred to as an 'online mental health resource'.

#### 1.5.2 Help-Seeking Technology

The use of any technological tool that intends to guide and facilitate online helpseeking will be referred to as help-seeking technology. These technologies are characterised by their referral to relevant online mental health resources. These resources may be external or internal to the service hosting the help-seeking technology. The help-seeking technology can be seen as an additional service offered by some organisations.

#### 1.5.3 Contextual Enquiry

The term will be used with reference to the CeHRes Roadmap. It is acknowledged that contextual enquiry is also a user-centred design research method used to gain an understanding of the context of use (Dekker et al., 2003). However in this thesis the term refers to the first stage of the CeHRes Roadmap, the framework used in this thesis.

#### 1.5.4 Value Specification

Similarly, to 'contextual enquiry', this term will be used with reference to the CeHRes Roadmap. Value specification is not related to Value Sensitive Design, an approach applied in the design of technology. Value specification speaks to a specific phase in the development process in the CeHRes Roadmap that focuses on ensuring that the design needs identified in the contextual enquiry are valued by stakeholders and intended users of the technology.

## **1.6 Contributions**

The primary contributions of this thesis include:

- An enhanced understanding of the design needs to support young people's online help-seeking. The design needs are reflected in design recommendations for both help-seeking technologies and online mental health resources. These design recommendations have been operationalised into early prototypes which provide the foundation for the development and evaluation of more sophisticated models of the technology.
- A consolidated, theoretically grounded model to support the design of help-seeking technology. Currently, no unifying model of online help-seeking exists. The model proposed in this thesis, builds on Rickwood's help-seeking model which is commonly applied to understand the help-seeking process in an offline context; and also uses Self-Determination Theory as a means through which to move help-seekers through one stage of help-seeking to the next in an online context.
- The use of personas as methods for the design of help-seeking technologies and online mental health resources. In the context of the research done in this thesis, personas, informed by empirical research, have been found to be a valuable means through which to explore sensitive topics, especially topics related to mental health, with young people. It is proposed that personas could be used as valuable tools for the design of other mental health technologies.

## **1.7 The Structure of the Thesis**

The remainder of this thesis is outlined below:

**Chapter 2** provides an account of current competing paradigms of mental health, offering a rationale for using a contextual understanding throughout the thesis. This Chapter also provides an overview of Rickwood's Help-seeking Model and Self-Determination Theory, two key theoretical models applied throughout the thesis.

**Chapter 3** provides a description of the methodological approach used in this thesis. A description of the CeHRes Roadmap is presented in the context of the overall thesis design. A discussion on eHealth and its role in society's growing healthcare needs is also presented.

**Chapter 4** synthesizes the literature investigating young people's online help-seeking behaviours and experiences through a narrative systematic review. This review highlights the potential benefits of online help-seeking, but also outlines the facilitators and barriers experienced by young people when seeking help online.

**Chapter 5** presents the findings from a large-scale online survey conducted with 1308 young people living in Ireland to investigate their online help-seeking preferences and experiences.

**Chapter 6** reports the findings from a co-design study conducted in collaboration with a national youth organisation, to explore young people's design needs from a help-seeking technology. Initial design recommendations for help-seeking technologies are presented.

**Chapter 7** details the findings from an empirical study to investigate whether prototypes, which embody the design recommendations listed in Chapter 6, support effective help-seeking. The validated and revised design recommendations are offered in light of these findings.

**Chapter 8** discusses the empirically grounded theoretical, methodological and design contributions of this thesis. The theoretical contribution includes the presentation of a conceptual model of online help-seeking using Rickwood's Help-seeking Model and Self-Determination Theory. Considerations for future work is also presented.

# **Chapter 2:** Conceptualising Mental Health and the Role of Online Help-seeking

#### 2.1 Introduction

This chapter introduces the key theoretical frameworks that were applied to the design and analysis of studies in this thesis. These theories and concepts will be elaborated on throughout the thesis. The aim of this chapter is to provide an overview and context for the subsequent studies. An overview of the importance of the focus on youth mental health is also provided. Definitions on mental health and mental illness are examined, providing a rationale for using a more contextual understanding of mental health in the thesis.

#### 2.2 Competing Paradigms in Mental Health

The importance of mental health in a person's overall wellbeing is widely accepted; however, different definitions and understandings of mental health exist. Historically, mental health has often been viewed through a pathogenic lens, with the term's mental health and mental illness often being used interchangeably. This section aims to clarify, for the purposes of this thesis, why the researcher has moved away from the disease model of mental health. Instead, a holistic view of the person has been adopted; maintaining that mental health is impacted by the person's context and experiences.

Historically, definitions arising out of psychiatry have suggested that mental health is the absence of mental illness. This understanding suggests that mental health and mental illness exist on opposite ends of the same dimension (Keyes, 2012). Whilst mental illness and mental health are related, they are two distinct concepts. Mentally healthy individuals will have periods in which they will experience low mood or distress. Concurrently, good mental health cannot only be equated with periods of happiness, positive affect and productivity. In fact, people with good mental health also experience negative feelings such as anger, frustration, disappointment and sadness as appropriate emotional reactions to different life events.

The term 'mental illness' refers collectively to all diagnosable mental disorders. Mental Illness is characterized by significant changes in mood, behaviour, emotion and thinking and a marked impairment in functioning. The DSM 5 defines a mental disorder as:

A mental disorder is a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behaviour that reflects a dysfunction in the psychological, biological, or develop mental processes underlying mental functioning. Mental disorders are usually associated with significant distress in social, occupational, or other important activities. (American Psychiatric Assocation, 2013, p.20).

A clear definition of mental disorders plays an important role in making treatment available to those who need it. It provides guidance to mental health professionals in order to determine the pathological versus normal responses to the events of life. This definition takes steps to prevent the over-medicalisation of everyday distress (Telles-Correia et al., 2018).

The World Health Organisation (WHO) updated their definition of mental health in an attempt to take steps to move away from the conceptualisation of mental health as the absence of illness. They propose that mental health is a "state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community" (World Health Organization, 2004, p.10). This definition takes steps in moving away from a binary understanding of mental health i.e. you either have it or not. Rather their intention was to highlight "health as a state of balance" that is influenced by the individual, their community and their environment.

Galderisi et al. (2015) also propose a definition for mental health that allows for varying emotional states which also recognises that it is not the absence of mental illness alone:

Mental health is a dynamic state of internal equilibrium which enables individuals to use their abilities in harmony with universal values of society. Basic cognitive and social skills; ability to recognize, express and modulate one's own emotions, as well as empathize with others; flexibility and ability to cope with adverse life events and function in social roles; and harmonious relationship between body and mind represent important components of mental health which contribute, to varying degrees, to the state of internal equilibrium. (Galderisi et al., 2015 p.231).

This definition acknowledges that through the course of life, the individual will face adverse events which are likely to impact on their internal equilibrium. It emphasises that various skills are required to maintain this dynamic equilibrium but also that a person's mental health doesn't exist within a vacuum; a person's mental health will be influenced by their context and the norms of their surrounding society.

Keyes (2005) puts forward an alternative model through which to understand mental illness and mental health in which they exist on two continua. One continuum indicates the presence or absence of mental illness, whilst the other continuum indicates the presence or absence of mental health (Keyes, 2005). From this perspective, Keyes argues that mental health is a complete state and not merely the absence of mental illness. Personal or emotional concerns that are part of everyday life will impact a person's mental health although it might not be to the severity of a mental illness. Keyes (2002) highlights that mental health similarly to mental illness, consists of a pattern of symptoms characterised by positive feelings and positive functioning. Symptoms can be grouped into three areas of wellbeing necessary for mental health: emotional wellbeing, psychological wellbeing and social wellbeing (Keyes, 2002). A disturbance in any one of these areas will impact up the individual's overall mental health and as Keyes terms it, towards 'a state of languishing'.

#### Figure 2.1 Keyes' Two Continua Mental Health Model



*Note:* Commissioned by the Mental Health Promotion Team of the Winnipeg Regional Health Authority and created by That 2 Graphics, Winnipeg, Manitoba. Copyright 2007 by Corey L. M. Keyes

While current treatments and interventions focus mostly on those who are on the high end of the illness axis, it has been argued that a shift needs to be made in order to offer solutions to those struggling with poor mental health also (Kinderman, 2014). Kinderman (2014) continues by suggesting that reform is needed in the form of a 'psychosocial model' of care that must focus on health promotion and prevention in order to improved mental health outcomes.

#### 2.3 The Importance of Youth Mental Health

Young people face unique challenges as they make the transition into adulthood. Emerging adulthood is the term used to describe young people from late teens into the early twenties, more specifically the age range of 18 to 25, a transitional period between adolescence and adulthood (Arnett, 2000). It is marked by change and instability; exploration and experimentation; and increased independence without the full responsibility of adulthood. This period in a person's life is acknowledged as a time where the foundations for psychological, social and occupational trajectories are laid. Whilst it can be an exciting period as many young people explore different pathways; it can also be a very difficult time, as young people struggle to make sense of the numerous changes taking place in their lives.

Poor mental health continues to be an important issue when considering the difficulties facing young people. The prevalence and aetiology of poor mental health affecting young people is of great concern at a global level. It has been suggested that 25% of young people, aged between 12 and 25, will experience a mental illness such as a depressive or anxiety disorder (McGorry et al., 2007). A review by Collishaw (2015) found a sustained increase in reported diagnosis of affective disorders over the last thirty years. A systematic review by Ibrahim et al (2013) found that students, most of whom were between the ages of 18 to 25, experienced higher rates of depression than other age groups from the general population. In Ireland specifically, research conducted by the Royal College of Surgeons found that by the age of 24 years, one in two young people will have experienced a mental health difficulty (Cannon et al., 2013). This corroborates existing evidence that the onset for many mental illnesses often takes place before the age of 25 (Kessler et al., 2007; McGorry et al., 2007).

A young person's mental health, educational achievement and their social relationships are impacted upon by the availability of personal and contextual resources that can support them through this period (Wood et al., 2017). However, emerging adults often face many barriers in accessing appropriate resources, including mental health services. The services that exist have been suggested to be a mismatch for young people's needs (McGorry, Bates, & Birchwood, 2013). Many existing mental health services are designed either for children or adults, few exist specifically for young people i.e. those aged 12-25. At the age of 18 many young people have to make the transition from children's services to adult services which can be difficult. Additionally, just when services are most needed, they can be difficult to access due to a number of additional barriers including long waitlists; restrictive qualifying criteria and unfamiliarity with how to navigate the system. The consequences of young people not receiving the help they need can be dire including developing chronic mental health conditions; lower educational attainment and poor interpersonal relationships (Fergusson & Woodward, 2002; Patel et al., 2007).

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#### 2.4 Addressing the Gaps in Youth Mental Health

To address the mental health challenges of this population and improve long term outcomes, two key approaches have been highlighted: early intervention and youth specific design of services. McGorry et al. (2007) assert that in terms of improving the impact of interventions and burden of disease numbers, it is key that this age group be given specific attention. However, to do this, systems, services and interventions require a youth specific design. Several international initiatives have highlighted the need to address this population specifically. The WHO emphasizes that poor mental health is one of the important problems facing young people and that an international effort is needed to address this (World Health Organisation, 2018). The World International Declaration of Youth Mental Health was instituted in 2013. It is a document that outlines 11 measurable targets for youth mental health services (these can be found in Appendix A) and emphasizes the importance of the youth voice and including young people in the redesign of systems and services. It recognises the potential of young people and asserts that they can "navigate their way through a period of mental ill-health and go on to live meaningful lives" (The International Declaration on Youth Mental Health, 2013, p.2). Mental health care systems and services need to be redesigned to recognise young people's capabilities and autonomy in relation to their own care and mental health.

The incorporation and use of technology has been identified as a tool which can be used to help achieve these targets. This age group is characterised by their engagement with digital technologies and device ownership (Montague et al., 2015; Odgers & Jensen, 2020; Uhlhaas & Torous, 2019). Whilst access to mobile technology and the Internet varies from high to low income countries, it is estimated that 71% of young people worldwide aged 15-24 have access to the Internet (Keeley & Little, 2017). This creates the opportunity for scalable and accessible technological solutions, informed by youth specific design, to be incorporated in the prevention, detection and treatment of mental health difficulties (Christensen & Hickie, 2010; Uhlhaas & Torous, 2019). Digital interventions can augment traditional health systems to address barriers such as waitlists, stigma and poor accessibility. Thus, there are a growing amount of opportunities to utilise consumer-based technology to deliver mental health interventions to this population.

#### 2.5 Understanding Help-Seeking

Help-seeking can be understood as an adaptive coping process with the goal of addressing a mental health difficulty by reaching out or seeking external assistance (Rickwood & Thomas, 2012). A positive help-seeking experience encourages future help-seeking and contributes to improved health outcomes (Gulliver et al., 2010; Mitchell et al., 2017). Similarly, the opposite is true, negative experiences of help-seeking, personal or that of someone known to the young person, is likely to decrease the likelihood of future help-seeking (Kearns et al., 2015; Rickwood et al., 2005). Failing to seek help has been associated with negative health outcomes, including substance abuse, self-harm, poor quality of life and premature death (Divin et al., 2018).

The My World 2 study, a large scale survey administered to young people throughout Ireland by Jigsaw Youth Mental Health Services and University College Dublin, found that nearly 40% of young people reported that they would not talk about their problems when experiencing difficulty and 25% indicated that they did not seek professional help despite thinking that they needed it (Dooley et al., 2019). A study performed by the Royal College of Psychiatrists indicated similar results. 12.4% of young people that had been advised to access professional help hadn't done so (Cannon et al., 2013). At the time of that particular study, only one in four of those with a current mental disorder were in treatment. Gulliver, Griffiths, & Christensen (2010) reported similar findings with roughly one third of young people experiencing depression and anxiety seeking help. Whilst prevalence of poor mental health is increasing, help-seeking behaviour remains low and this appears to be a consistent trend over time. Help-seeking is personal and dynamic process, which can often be a difficult one, complicated by a number of personal and contextual factors, such as access, stigma and mental health literacy (Gulliver et al., 2010).

There are two broad types of help sources available: informal and formal sources. Informal sources include informal support networks such as family and peers; whilst formal supports include professionals such as mental health practitioners; teachers and members of the clergy (Rickwood et al., 2005). Previous research in this area has indicated that young people prefer informal sources of help, with friends being preferred over parents. Most young people do not access professional services for mental health problems (Rickwood et al., 2012). Young people from affluent homes are more likely to be referred to formal services than those of poorer economic status

(Benjet et al., 2016). Overall, females are more likely to seek help than males, whilst those young men that do seek help are more likely to seek help from family than other sources (Rickwood et al., 2005).

Help-seeking plays an important role in suicide prevention. It has been found to be an important protective factor for those struggling with suicidal thoughts and behaviours (Rickwood et al., 2005). However, the help-negation effect means that often as suicidal ideation intensifies, help-seeking decreases (Deane et al., 2001). It is thought that young people tend to make negative appraisals of the availability and suitability of help sources during such times (Wilson & Deane, 2010). This situation deteriorates as young people are less likely to seek help from informal sources, such as family and peers, in this situation but rather prefer anonymous and less personal forms of help.

While many authors are cautious about the use of technology and the Internet for online mental health services (Burns & Birrell, 2014); the accessibility of the Internet has created the opportunity for more resources and sources of help and information to become available to young people, thereby changing the nature of help-seeking (Kauer, Mangan, & Sanci, 2014). Offline resources remain an important source of help to young people, however it is now possible for young people to engage in helpseeking behaviour both online and offline, with the online option reducing the need for interpersonal interactions. It is inevitable that technology and the Internet will play a role in the delivery of mental health services particularly if they are developed in partnership with young people and integrated into existing services (Stretton et al., 2018).

#### 2.6 Using Theoretical Frameworks to Understand Help-Seeking

#### 2.6.1 Theory of Planned Behaviour

The Theory of Planned Behaviour (TPD) (Ajzen, 1985), originally introduced as the Theory of Reasoned Action, has previously been applied to understand helpseeking behaviour (Bohon et al., 2016; Damghanian & Alijanzadeh, 2018; Kauer, Buhagiar, & Sanci, 2017; Mak & Davis, 2014; Zorrilla et al., 2019). Whilst it is not applied in this thesis, it is outlined here for completeness. TPD is a behavioural model which proposes that behaviour is determined by constructs such as attitude, social norms, projected behavioural control all of which impact upon behavioural intentions.

#### Figure 2.2 Conceptual Framework of Theory of Planned Behaviour



*Note:* Adapted from "From Intentions to Actions: A Theory of Planned Behavior," Ajzen, I. (1985), In: In: Kuhl J., Beckmann J. (eds) Action Control. SSSP Springer Series in Social Psychology. Springer, Berlin, Heidelberg. https://doi.org/10.1007/978-3-642-69746-3\_2

It has been suggested that, by changing a person's attitude towards helpseeking through improving their mental health literacy and changing their subjective norms (i.e. reducing the stigma), you can positively influence their intention to seek help (Bohon et al., 2016). However, the change from intention to behaviour is moderated by the individual's perceived behavioural control, which in the case of helpseeking are factors such as the availability of appropriate services; cost of services and accessibility of services (Jansen & Rieh, 2010). This model takes into account the barriers that may hinder help-seeking but is not specific to a particular behaviour.

The Theory of Planned Behaviour (TPD) has been widely applied to understand and influence health behaviours and in some cases help-seeking behaviours (Bohon et al., 2016; Zorrilla et al., 2019). Despite this, it is widely criticized for having poor generalisability and interventions based on this theory have showed limited success (Gollwitzer & Oettingen, 2015; Noar & Zimmerman, 2005). Additionally, it has been widely criticized for being too cognitive and not taking into account the effect of strong emotions on behaviours (Conner et al., 2013; Conner & Armitage, 1998). Furthermore, it does not take into account the effect behaviour has on cognition and how this influences future behaviour (Jokonya, 2017; Sniehotta et al., 2014). Evidence suggests that the efficacy of using the Theory of Planned Behaviour to predict helpseeking remains unclear (Tomczyk et al., 2020) and for this reason has not been applied in this thesis.

#### 2.6.2 Rickwood's et al.'s Theory of Help-Seeking

Rickwood et al. (2005) identified a number of areas within the field of helpseeking that lacked a cohesive approach and understanding, one of which being a unifying theory of help-seeking. As opposed to previous theories, they developed a theory that looked at the micro-level factors that would either promote or hinder the help-seeking process. Rickwood et al. (2005) put forward a process model which is based on the understanding that help-seeking is a deeply personal journey, moving from the intrapersonal to interpersonal in an attempt by the person to address their personal or emotional concerns.







The process is initiated when the young person becomes aware that there are symptoms or difficulties that are causing them concern; they then make the appraisal whether these concerns might require intervention. The next step requires the young person to have the skills or ability to express their difficulty in a way that is understandable to others. The third step in the process requires that there be sources of help available that suit the young person's needs and the final step requires the young person to be willing to approach these sources of help and disclose their concerns. There are factors at each of these steps that can either facilitate or hinder the process. For example, if the young person has low levels of mental health literacy they might not be able to appraise their difficulties correctly and will not move forward with the process.

Applying Rickwood's Model to Online Help-Seeking. Whilst this model was originally developed to understand when young people accessed formal services at a youth mental health charity (Headspace) in Australia, it has also been applied to understand help-seeking in the online context (Kauer, Buhagiar, & Sanci, 2017; O'Dea et al., 2019). This thesis further explores the potential of this model when applied to online help-seeking, focusing on how Internet and technology provide opportunities to at each step of the process. The researcher proposes that online resources can improve mental health literacy (awareness); decrease stigma through providing anonymity (willingness) and can offer additional pathways through which to access mental health services (availability). Rickwood's help-seeking model is applied throughout this thesis in order to conceptualise and understand the online help-seeking process and how it compares to the offline context.

#### 2.6.3 Self-Determination Theory

Self-Determination Theory (SDT) is a macro theory of motivation and wellbeing (Deci & Ryan, 2008; Ryan & Deci, 2017). It is concerned with the degree to which behaviour is self-determined and motivated. Self-determination theory is based on the principle that each person has an innate drive towards growth and development and will pursue activities that promote a sense of mastery (Ryan & Deci, 2000, 2017).

**Motivation.** In SDT, motivation is understood as the psychological energy directed towards a certain task and emphasizes that the quality of motivation is as important as the amount of motivation (Deci & Ryan, 2000). It asserts that the quality of motivation is a likely predicter of important outcomes such as health and wellbeing, performance and learning. The quality of motivation is represented on the continuum below:



Figure 2.4 Self-Determination Theory's Taxonomy of Motivation

Note. From the Center for Self-Determination Theory © 2017. Reprinted with permission.

SDT differentiates between two types of overall motivation, autonomous and controlled (Deci & Ryan, 2008). Autonomous motivation comprises of both intrinsic and types of extrinsic motivation. The types of extrinsic motivation included in autonomous motivation are characterised by instances when an individual can identify with an activity's value and integrate it into their sense of self i.e. introjection, identification and integration seen in the continuum above. Autonomous motivation is more likely to lead to psychological health, improved performance and long-term persistence (Deci & Ryan, 2000). Controlled motivation on the other hand are behaviours that are driven or pressured by intra- or inter-personal factors or external regulation but still energize and direct behaviour (Deci & Ryan, 2008).

Three Basic Psychological Needs. This theory asserts that each person has three basic, innate psychological needs: autonomy, competence and relatedness. These needs play a key role in supporting effective functioning and psychological growth (Ryan, 1995; Ryan & Deci, 2017). Additionally, when these psychological needs are satisfied, individuals are moved through the continuum of motivation described above towards autonomous motivation. Ryan and Deci assert that these needs are applicable at all developmental stages, including emerging adulthood, as well as across all cultural contexts (Chen et al., 2015). Although each need might not be equally valued across all cultures and socioeconomic status, if any need is not met, the individual will experience negative psychological consequences. This implies that if digital environments and tools are designed to meet these needs then they contribute
to the person's overall wellbeing. SDT recognises that personal and contextual factors such as biology, education and socio-political structures will impact on the individual's wellness.

**SDT in eHealth.** SDT is commonly applied to the technology context as the needs can easily be operationalised into digital features. These three needs, their description and examples of how they can be operationalised in the context of technology is illustrated in Table 2.1 below:

Psychological Needs	Description	Example of Operationalisation in technology
Autonomy	Acting in accord with one's own volition.	Having a set of meaningful choices in weight management app, that allows the user to set their goal and select a preferred strategy
Competence	Feeling effective; mastery; expression of one's capacities and talents	Gradual increase in difficulty of levels in video games
Relatedness	Feeling a sense of belonging and connection to others	Wall posts, likes and comments on social media

 Table 2.1 SDT Psychological Needs and their Operationalisation in Technology

Migliorini, Cardinali and Rania (2019) highlight the important role SDT can play in innovation in health care. Its impact is twofold. Firstly, it has been found to support improved health outcomes when utilized in health interventions and secondly, it has been found to positively contribute to user engagement in interventions. A common hurdle faced by many eHealth interventions and tools is sustained engagement. It is proposed that if Self-Determination Theory principles are applied throughout the design, construction and evaluation processes of these interventions, it will result in sustained engagement as well as assist users to achieve and maintain their health goals.

SDT outlines some of the features of environments and contexts that promote and satisfy the three basic psychological needs (Ryan & Deci, 2018). For example, competence can be satisfied by providing adjustable challenges paired with positive feedback and rewards. This promotes feelings of mastery which in turn predicts intrinsic motivation. These features can be applied in virtual environments, as most often seen in video games but also in health interventions. Peters et al. (2017) emphasize that SDT as a framework, easily lends itself to the design and evaluation of technology. It has been successfully applied in the design of smoking cessation apps (Blok et al., 2019; Choi et al., 2014) and an Asthma Self-Management App in young people (Peters et al., 2017). Experiences of autonomy, competence and relatedness have been found to predict improved wellbeing outcomes and future use of these kinds of eHealth tools.

Applying SDT to Online Help-Seeking. Motivation and more specifically internal motivation are important factors when considering help-seeking, engagement with help-seeking sources and mental health outcomes. When a young person engages in help-seeking, a willingness and readiness to address the mental health concern is needed. Whilst not yet applied to online help-seeking, this thesis proposes that Self-Determination Theory is a useful framework through which to examine the factors that influence young people's help-seeking for mental health concerns. Autonomy can be met by providing meaningful health related choices. It can be further facilitated by providing opportunities for young people to choose their pathway to care and determining their own help-seeking journey. However, some young people may delay help-seeking as a means of retaining autonomy. The offline context requires interpersonal exchanges in help-seeking. Although the person may be engaging in a social exchange, their needs for relatedness might not necessarily be being met, as this exchange would have to foster connection and make the help-seeker feel valued. Finally, competence plays a key role in help-seeking as it requires a knowledge of self, an awareness of available resources and knowing how to communicate one's difficulties to sources of help, both formal and informal. A key concept in SDT is that the satisfaction of the basic psychological needs leads to persistence at important activities and towards goals, this becomes even more important when help-seeking for a mental health difficulty.

In the context of this thesis, SDT will act as a lens through which to understand young people's online help-seeking behaviours and how technology can be used to assist young people to achieve their help-seeking goals. When considering online help-seeking in terms of SDT, the online environment can provide need satisfaction with an immediacy and density that is unparallel to the offline context and therefore it is an important area of investigation.

#### 2.7 Conclusion

This chapter began by providing an overview of competing paradigms in the conceptualisation and understanding of mental health and mental illness. The aim was to clarify to the reader why a contextual approach to mental health has been taken throughout the thesis and in the design of subsequent studies. The importance of addressing youth mental health and its impact on societal wellbeing was then discussed. This chapter also presented important theoretical frameworks that can be used to understand the help-seeking process and how they might be useful in the context of online help-seeking. Chapter 3 will present the methodological approach used to address the research questions presented in Chapter 1.

## Chapter 3: Methodological Approach

#### **3.1 Introduction**

Innovations in technology and digital tools are shifting modes of health service delivery. Chapter 2 provided a brief overview of the role technology and the Internet can play in mental health service delivery as well as facilitating help-seeking behaviour. This chapter provides an overview of the role eHealth and eMental Health can play in evolving societal health care needs and how this can be accomplished through Human-Centred Design. The remainder the chapter will focus on the methodological approach, the CeHRes roadmap, taken to guide the design and planning of the studies discussed in this thesis. An overview of how each study fits into this roadmap is provided.

#### 3.2 Opportunities in eHealth and eMental Health

#### 3.2.1 Introducing eHealth

The field of eHealth has grown rapidly over recent years, applied to a variety of health concerns with the aim of improving overall health and wellbeing. It encompasses the whole healthcare continuum, from prevention to treatment, creating new opportunities to facilitate healthcare and better meet patient's needs (Whitehouse & Wilson, 2014).

The World Health Organisation defines eHealth as "the use of information and communication technologies (ICT) for health." (eHealth at WHO section, paragraph 1). The term was supposedly coined by industry, in line with other "e-words", as the Internet and developments in technology created new opportunities to address health care challenges (Eysenbach, 2001). Whilst the concept and its definition are often debated, a commonly cited definition of eHealth by Eysenbach (2001) highlights that this is a field that is very broad and encompasses whole healthcare systems and problems:

e-Health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or

enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-ofmind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve healthcare locally, regionally, and worldwide by using information and communication technology. (Eysenbach, 2001, p.1)

Fundamental to this definition of eHealth is the pursuit to improve healthcare using technology (van Gemert-Pijnen, Kelders, Kip, & Sanderman, 2018). Concerns that current healthcare system structures are unsustainable and far too expensive to maintain have prompted calls to redesign and relook at these structures. eHealth has been lauded as one approach through which to do this and has shown important benefits in doing so, including higher quality of care, reduced costs, increased efficiency and improved reach (Fitzpatrick & Ellingsen, 2013; Li et al., 2013).

Despite the many advantages and opportunities within eHealth, adherence to eHealth interventions and their efficacy seem to be dependent on a number of factors including user demographics; level of motivation and engagement of users; technology literacy; providing ongoing support and perceived trust of eHealth services (Hardiker & Grant, 2011; Kelders et al., 2011). van Gemert-Pijnen et al. (2018) highlight that eHealth has the capability to take into account the whole person as well as their context. When designing and implementing eHealth technologies, irrespective of where it falls on the continuum, it is important to prioritise an understanding of the intended user in their context. Contexts are always evolving but technology provides the flexibility in order to adapt alongside these evolutions. To remedy the difficulties to engagement and efficacy listed above, a focus on the user and their context is paramount.

#### 3.2.2 eMental Health

Traditional mental health care systems are facing a number of difficulties in meeting the needs of a growing society and treatment gaps have become evident globally (Hollis et al., 2015). The urgency with which this needs to be addressed has been highlighted by numerous authors and it is the key concern of many mental health researchers (Lal, 2019; McGinty et al., 2006; Schmidt & Wykes, 2012). eMental Health has been highlighted as one of the approaches through which to address some of these gaps.

eMental Health as a term originates from eHealth discussed above. Christensen and colleagues (2002) defined e-mental health as "mental health services and information delivered or enhanced through the Internet and related technologies" Whilst a theme issue in the Journal of Medical Internet Research (JMIR) defined it as:

The use of information and communication technology (ICT) –in particular the many technologies related to the Internet –when these technologies are used to support and improve mental health conditions and mental health care, including care for people with substance use and comorbid disorders. (Riper et al., 2010, p.1)

Lal & Adair (2014) found that across the field, definitions for eMental healthcare can either be quite broad or narrow. This is an indication of the growing nature of this area of research. One review indicated that there are four main areas of application within eMental Health research: information provision; screening, assessment and monitoring; intervention; and social support (Lal, 2019; Lal & Adair, 2014). A systematic review of HCI research in affective health indicated that much of the research in the field concentrates on diagnosis, self-tracking and structured interventions (Sanches et al., 2019). Despite the growing popularity of mental health research.

Some examples of the research being done in the areas of screening and assessment include studies investigating ecological momentary assessment (EMA) as well as digital phenotyping (Bernardos et al., 2019; Chan et al., 2018; Rooksby et al., 2019; Saha et al., 2017; Torous & Keshavan, 2018). The measurement of mood and emotion are key components when assessing an individual's mental state and fluctuations in these can be indicative of mental ill-health. Historically, EMA was often dependent on the self-report practices of users, however advances in smartphones, sensors and other technology have allowed for more passive methods to monitor mood, emotion and other indicators of mental health. As Rooksby (2019) illustrates, this allows for a multitude of opportunities in the design and delivery of mental health interventions, however careful consideration needs to be given to user's concerns over privacy, data protection and the potential for harm.

Interventions can include teletherapy, computerised therapies, and selfmanagement tools all of which can be delivered using a diverse set of technologies,

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including websites and mobile phone applications. Sanches et al. (2019) found that many studies within HCI focus on the use of Cognitive Behavioural Therapy (CBT) as the therapeutic model of choice. CBT has been applied in various ways, including through the use of computer games, virtual reality and online platforms (Coyle et al., 2011; Doherty et al., 2012; Van Rooij et al., 2016).

The Acceptability of eMental Health Interventions. The eMental Health field has become increasingly popular recently due the benefits associated with it. eMental Health strategies have been identified as a means through which to address gaps in service delivery as it has the potential to improve access; reduce wait lists; provide services to those who live remotely or in rural areas; or for those who would normally be hesitant to access care due to stigma (Lauder et al., 2007). An example of a mental health service that has capitalised on these benefits is 'eHeadspace' (https://headspace.org.au/eheadspace/), an online counselling service provided to Australian young people. Users of this service have been found in the earlier stages of illness and tend to be those who wouldn't regularly seek out in-person help (Rickwood et al., 2016).

eMental Health interventions are seen as acceptable augmentations to traditional services as technology has the ability to be flexible and offer more in terms of personalisation (Lal & Adair, 2014). Many eHealth interventions can be tailored to particular users and are easily updated when improvements are identified (Musiat et al., 2014). Technology offers the potential to address some of the conventional barriers to care faced by traditional services without aiming to replace those services.

Due to the proliferation of the eMental Health technologies, the field has been criticised for a lack of evidence and quality control, many pointing to the abundance of mental health related apps that can be found in app stores (Neary & Schueller, 2018; Torous et al., 2018, 2019). In response to this, initiatives such as Psyberguide (psyberguide.org), a project that seeks to evaluate mobile applications for mental health, have grown in importance (Lipczynska, 2019). Psyberguide uses expert reviewers to review applications in terms of three criteria: credibility, user experience and transparency. Similar concerns have been raised about the amount of resources and information regarding mental health that are available on the Internet.

There is some reluctance on the part of health professionals to adopt or integrate technologies into their everyday practice (Schueller et al., 2016). Despite this, a recent study found that many practitioners expressed a readiness to introduce

technology into their work but did not support technologies that aimed to replace faceto-face services or that were poorly designed (Clarke et al., 2017). Similarly, a study by Musiat et al. (2014) found that despite users valuing anonymity, convenience and low cost when accessing mental health services, they still preferred face-to-face services over a web based application. Additional barriers to the use of eMental health strategies have also been noted including: that it may not always be suitable to those with low literacy levels, more severe illness or may further disenfranchise those with physical and financial limitations (Lal, 2019; Schmidt & Wykes, 2012). This is reflected in findings that show those with higher levels of education and higher household income showed a greater likelihood to use eMental Health services (Apolinário-Hagen et al., 2017).

However, there is an openness in the public to use these interventions. A systematic review investigating the acceptability of eHealth interventions for people with severe mental health problems found that acceptability was quite high especially when these interventions met certain criteria. These criteria included remote online support; an engaging and appealing delivery format as well as the inclusion of peer support (Berry et al., 2016). Another scoping review also found that eMental Health services were more acceptable when they included a therapist-assisted component (Apolinário-Hagen et al., 2017). A study by Stawarz et al. (2020) found that whilst patients were open to the use of an integrated platform for the delivery of a CBT intervention, initial face-to-face sessions played a valuable role in establishing a therapeutic relationship with therapists. This highlights the importance of seeing eMental Health services as an adjunct to normal services and not as replacements of traditional services.

#### 3.3 Human-Centred Design and its appropriateness to e-Mental Health

Human Computer Interaction (HCI) has long recognised the importance of bringing together numerous fields. Human-Centred Design (HCD) is a frame of reference that can be applied within HCI. HCI allows researchers to ask the important questions, questions focusing on gender, sustainability, health and wellbeing and social change (Bardzell & Bardzell, 2015; Harrison et al., 2007), whilst HCD is a problem-solving approach that provides the methods to provide solutions to these

problems (IDEO.org, 2015; Steen, 2011). According to the 2019 standard ISO 9241-210:2019, the ISO defines HCD as the following:

Human-centred design is an approach to interactive systems development that aims to make systems usable and useful by focusing on the users, their needs and requirements, and by applying human factors/ergonomics, and usability knowledge and techniques. This approach enhances effectiveness and efficiency, improves human well-being, user satisfaction, accessibility and sustainability; and counteracts possible adverse effects of use on human health, safety and performance. (ISO, 2019, p.2)

HCD is characterised by an unrelenting focus on understanding the problem from the perspective of the user and their needs throughout the design process (Giacomin, 2014). Designers are more likely to conduct research "in the wild," in the context of the people using the technology in order to understand the user's needs in the user's context (Bødker, 2015). This often necessitates the use of ethnographic methods to try to capture the complexities of the human experience (Steen, 2011). The key aim here is to design technology that matches the needs and context of users and stakeholders. As outlined in Chapter 2, the context impacts upon a young person's mental health in a variety of ways, thus a contextual understanding is especially important when designing technological solutions for this population.

HCD developed out of fields such as ergonomics, computer science and artificial intelligence, and it is often characterised by its adoption of multidisciplinary skills and perspectives (Giacomin, 2014). It takes a holistic approach to design, incorporating the views not only of end users but also stakeholders who will be influenced by the design of a new technology. It encourages partnerships between stakeholders, users and designers to achieve the best possible outcome. The empirical studies in this thesis have often be done in collaboration with youth mental health charities operating in the Irish context. The survey (Chapter 5) was done in collaboration with ReachOut Ireland, whilst the co-design study (Chapter 6) was facilitated in partnership with staff members from Jigsaw.

When designing and testing, various cycles of iterations are characteristic of HCD, this ensures that the design matches the needs of the users effectively (Burns, 2018; Maguire, 2001). HCD works incrementally, often using prototyping as a means

through which to gain insights from users (Bazzano et al., 2017). These prototypes often go through many iterations and is considered necessary in order to develop novel solutions.

In the design of any technology, it is important that the needs of as many people as possible are met and therefore generalizability is important, but it is very difficult to achieve (Harrison, Tatar, & Sengers, 2007). HCD values universal design in order to make technologies as accessible as possible for various groups (Harte et al., 2017), a key consideration when working within the field of mental health. Designers working within the HCD paradigm are likely to design from requirements gathered directly from users, but the opportunity also exists for designers to design in such a way that they inform the user's requirements. This is an important consideration when considering the role mental health literacy can play in facilitating help-seeking. It can be assumed a system that is designed with the goal of facilitating help-seeking, may improve mental health literacy by providing appropriate referrals which in turn will have a positive impact on help-seeking intentions.

Current emerging adults are seen as digital natives. These are individuals who do not know a world without technology or personal computers and thus it is intrinsic to the way in which they make meaning of the world. Their identities are now developed, expressed and captured through technology. HCD enables designers to consider not only the requirements of these digital natives but also work in collaboration with them (Harrison et al., 2007). This allows a wide variety of design opportunities (Harrison et al., 2007; Kannabiran et al., 2012). This opportunity was prioritized throughout this research project and young people were actively involved in the design of the survey in Chapter 5 and through the co-design study in Chapter 6.

HCD is an integral approach applied the Centre for eHealth Research Roadmap (CeHRes Roadmap) which is detailed below. Within the field of eHealth research, a number of methods and frameworks have evolved including Research through Design (Zimmerman et al., 2007), Value Sensitive design (Friedman & Hendry, 2019) and the Medical Research Council's guidance on developing and evaluating complex frameworks (Skivington et al., 2018); however, the CeHRes Roadmap was applied in this thesis.

#### 3.4 Methodological Approach: CehRes Roadmap

van Gemert-Pijnen et al. (2011) have put forward the Centre for eHealth Research Roadmap (CeHRes Roadmap) as a holistic design framework for the creation and design of eHealth tools. This framework incorporates human-centred design principles; a participatory design approach; persuasive design and business modelling into its theoretical underpinnings (van Gemert-Pijnen et al., 2018). This framework is differentiated from other frameworks in that it recognises that eHealth technologies need to acknowledge and work with the interdependencies that exist within the context of the healthcare system it is trying to improve (van Gemert-Pijnen et al., 2011). The CeHRes roadmap is a useful framework to use for the planning, coordination and execution of a eHealth tool and has been applied widely to different types of mental health interventions (Kelders et al., 2013; Kip et al., 2019; Lambert et al., 2017; Reblin et al., 2017). A key principle of this framework is that technology should fit the culture, processes and demands of the specific health context. It asserts the holistic development process is more likely to increase successful adoption and engagement in the intended setting and with intended users.

This framework was selected as appropriate for this research project as it acknowledges that the context, users and technology are all interdependent and will impact upon one another. The importance of context and its impact upon mental health was highlighted in Chapter 2. This framework was also deemed appropriate because of its focus on human centred design principles and participatory design.

It is intended to be used in an interdisciplinary setting, clearly communicating findings from the contextual inquiry and value specification phases in a design document. Cycles are interrelated through formative evaluation throughout the process to ensure that the stakeholder perspective is maintained throughout and outcomes from previous phases are taken forward.

This framework is intended to be flexible and iterative. Sequential models of development are often seen as reductive and can lose the nuance of complex situations and does not take into account that behaviour is influenced at multiple levels in a person's context.

This framework emphasises good, clear research questions at every phase of the development process. Research questions operationalise the goals and vision of the project. It is important to reflect and ensure that the appropriate research methods are applied at each phase in relation to the research questions posed.



Figure 3.1 The Center for eHealth and Disease Management Roadmap

Note: Copyright 2011 by the Centre for eHealth and Disease Management

This framework has been applied successfully in the development of other eHealth interventions, including the development of a web-based intervention to promote physical activity in those with depression (Lambert et al., 2017). It's application to this intervention was found to be highly useful because of this framework's focus on development and fit between the technology and the context. The development of this particular engagement prioritised patient consultation, a practice prioritised by the CeHRes Roadmap.

## 3.4.1 Contextual Enquiry

As stated in Chapter 1, whilst in HCI research 'contextual enquiry' often refers to a research method, it is understood as a phase in the CeHRes Roadmap. The priority at the beginning of the process is to understand the context of use as deeply as possible. This phase is also often referred to as 'requirements gathering' in other user-centred models. The requirements gathered during this phase will form the foundation of the design and future phases and should therefore be given special attention. The contextual enquiry enables researchers to create an in-depth understanding of the intended users, their context and the processes within their context that affect their health outcomes. Some of the key activities in this phase include identifying the stakeholders; tasks and roles of those stakeholders; the current situation; and its strengths and weaknesses. This is done in order to assess in what way eHealth can fit into and strengthen the situation. eHealth interventions should fit the needs and processes of the stakeholders, as highlighted previously without this these interventions are likely to have poor engagement and uptake which will not positively affect the healthcare system as intended.

The first two studies discussed in this thesis form part of the contextual enquiry. These studies include a systematic literature review and a large-scale online survey. Kip and van Gemert-Pijnen (2018) state that literature reviews can play an important role in identifying stakeholders and the current state of the situation. They assert that various methods should be combined in order to get an in-depth and comprehensive understanding of the current context. In order to achieve this, the results of the systematic literature review were supplemented by the online survey, discussed in Chapter 5.

The outcomes from this phase should identify areas in which the intended intervention can add value and positively contribute to the situation. Information from this phase must be used to inform decisions at each of the next phases. This ensures that the technology remains a good fit between the stakeholders and their context.

#### 3.4.2 Value Specification

This phase of the design process takes the findings from the contextual enquiry and then elaborates on them. To do this, researchers often consult with stakeholders again to verify these findings. In this thesis, this was achieved through the co-design study detailed in Chapter 6. Researchers and designers use these findings to determine what would specifically be needed from a technology in order to meet the needs identified in the contextual enquiry. This is why a co-design study proved useful at this stage. The key task here is to determine what added value the technology will bring to the context. Finally, an important goal of this phase is to specify the technological requirements that the technology should encompass, the co-design study proved useful in narrowing these requirements. A discussion is provided at the end of Chapter 6.

When technologies are being designed for commercial purposes, it would also be during this phase that the business modelling would be initiated which was not the case in this project.

#### 3.4.3 Design

This phase is characterised as iterative and collaborative. It focuses on producing many high and low fidelity prototypes in collaboration with stakeholders. It is also common for usability tests to be conducted in this phase. It is also during this phase that researchers and designers think about including persuasive elements into the prospective technology. In the case of this thesis, this includes applying Self-Determination Theory. It is common for personas to be used in this phase in order to communicate the design needs and prompt further iterations. The main outcome from this phase is to have a first version of the technology that can be used by stakeholders. It's important that it still reflects findings from the contextual enquiry and the values outlined in the value specification. An early, low-fidelity prototype was implemented during this phase, the process and findings of which are discussed in Chapter 7. Whilst further iterations would be conducted at this phase, it was outside of the scope of this thesis to do so and is deemed as valuable future work.

#### 3.4.4 Operationalization

Although this research project has not proceeded to the operationalization phase, this thesis provides design guidelines that would enable future operationalization of the technology and contribute to the success of this phase. The operationalization phase is characterised by the planning necessary to implement the technology in the intended context. This phase builds on each of the previous phases. It is assumed if stakeholders have been consulted throughout and their input prioritised, it will positively contribute to overall adoption and implementation of the technology. The business model plays an important role in guiding the implementation plan and the roll out of the technology.

#### 3.4.5 Summative Evaluation

Evaluation is a key step in the scientific method, with traditional evaluation methods in HCI focusing on measuring usability and embedded within that, efficiency (Harrison, Tatar, & Sengers, 2007). However, when designs have to take into account complex phenomenological elements, evaluation becomes more complex. Evaluation ultimately asks, is the design successful. However, correlational evidence is far more likely than causal evidence. In most cases, researchers evaluate technology in relation to the original goal of the technology (Dix, 2010). Evaluation also needs to take in

account the spin-off effects that may have been difficult to predict at the beginning of the design process. The study by O'Kane (2014) serves as a useful example; discusses designing mobile medical devices that measure blood glucose levels for type I diabetes. The evaluation for measuring success would be how accurately the device is in measuring blood glucose levels. Nonetheless, because the device is within the personal space of the user constantly, the fact that user may find the device cumbersome or invasive, deters the use of the device; and therefore, effectiveness of the device in measuring blood glucose levels becomes irrelevant (Sengers et al., 2009). The iterative process of design research allows repeated evaluations of eHealth tools which allows the constant improving of the technology.

#### 3.5 Applying the CehRes Roadmap to this Thesis

The CehRes roadmap is not prescriptive in terms of the methods used at each phase as it asserts that the methods used need to fit the research question. However, Kip and van Gemert-Pijnen (2018) do make suggestions for appropriate methods and activities for each phase. These suggested activities are outlined below in Table 3.1 as are the methods that were implemented in this thesis.

In addition, an outline for the thesis is provided in Figure 3.2 and Table 3.2 below. It details each study according to its corresponding phase in the CehRes Roadmap. The table includes research questions in relation to the overall thesis as well as to each particular study and its objectives.

Phase	Aim	Suggested	Methods	
		activities at this	employed in this.	
		phase	thesis	
Contextual enquiry	• To gain an	Literature.	Systematic	
	understanding	reviews	Literature	
	of prospective	Focus groups	review	
	users and their	<ul> <li>Interviews</li> </ul>	(Chapter 4)	
	context.		Online survey	
	• To uncover the		(Chapter 5)	
	strong and			
	weak of points			
	the system.			
Value Specification	• To translate	Interviews	Co-design	
	users' needs	Questionnaires	workshops	
	and wishes into	• Idea	(Chapter 6)	
	user	generation:		
	requirements.	prototyping		
Design	• Use the	Prototyping lo-fi	• User study	
	requirements	and hi-fi	(Chapter 7)	
	from the	prototypes		
	previous phase	Usability tests		
	to prototype	Add persuasive		
	versions of the	elements		
	technology			
Operationalization	• To complete	• Finalise the	This phase was not	
	the planning	business model	reached during this	
	necessary for	• Finalise the	PhD	
	the	plan to		
	implementation	implement the		
	of the	technology into		
	technology in			

 Table 3.1 Phases of the CehRes Roadmap and Corresponding Activities

		its	inter	nded		its i	nter	nded	
		contex	ĸt.			context			
Summative	•	To eva	aluate	e the	•	Determ	ine	the	This phase was not
Evaluation		techno	ology.			uptake	of	the	reached during this
		Key o	quest	tions		technol	ogy		PhD
		include how it is		•	Determ	ine			
		being	used	and		impact	of	the	
		its e	ffect	on		technol	ogy	on	
		patient	ts	and		the con	text		
		health	care.						

Figure 3.2 CehRes Roadmap and Corresponding Studies



Table 3.2 CeHRes Roadmap as Applied to the Thesis Outline

CeHRes	Chapter	Main Activities	Research Questions
roadmap phase			
Contextual 4 <u>STUDY 1:</u> Inquiry Systematic Literature Review	PhD RQ Answered RQ1. How do young people who are experiencing mental health concerns seek help online? RQ2. What are the benefits and limitations of the current technologies that young people use wher seeking help online from mental health resources?		
			<ul> <li><u>RQ's specific to study</u></li> <li>A. How do young people seek help online for mental health issues?</li> <li>B. What are young people's experiences of online help-seeking?</li> <li>C. What are the benefits of young people's use of online mental health resources for help-seeking?</li> <li>D. What are the limitations of young people's use of online mental health resources for help-seeking?</li> </ul>
	5	STUDY 2: Online help- seeking survey with young people aged 18 – 25	PhD RQ Answered RQ1. How do young people who are experiencing mental health concerns seek help online? RQ2. What are the benefits and limitations of the current technologies that young people use wher seeking help online from mental health resources?

			<ul> <li><u>RQ'S specific to research study</u></li> <li>A. What are the personal and emotional concerns that impact on young people's mental health and wellbeing?</li> <li>B. What are the online help-seeking experiences of young people aged 18-25?</li> </ul>
Value Specification		Requirement Analysis	<ol> <li>What are the values, attributes and requirements identified by stakeholders in the contextual enquiry phase?</li> <li>What are priority requirements?</li> </ol>
	6	STUDY 3: Co-design workshops	PhD RQ Answered RQ3. What are the critical design factors that will facilitate the development of more effective technologies?
			RQ'S specific to research study A. Which design features facilitate different types of help-seekers to achieve their help-seeking goal?
Design	7	<u>STUDY 4:</u> Develop and user test low fidelity prototype	PhD RQ Answered RQ4. Do help-seeking technologies that embody the design factors identified in Study 3 above support more effective help seeking?
			<u>RQ'S specific to research study</u> Is the prototype useful in assisting the online help seeking process?

#### 3.6 Conclusion

This chapter provided an overview of eHealth and eMental Health as this project falls within these domains. It emphasized the consideration that these domains give to context and the inclusion of users in the development process. This philosophy aligns with the overall approach taken throughout this thesis. This was the same motivation for applying the CehRes Roadmap to guide the design of the overall research project and to achieve its aims. This chapter also outlined how the studies in this thesis align with each phase of the CehRes Roadmap and the research questions addressed by each. The next chapter will report on the findings from a narrative systematic review, conducted as a key activity in the contextual enquiry phase.

# **Chapter 4:** Exploring Young People's Online Help-Seeking and Mental Health Difficulties using a Systematic Narrative Review

#### 4.1 Introduction

Whilst the facilitators and barriers to help-seeking in the offline context are well documented, a synthesis of these factors in the online context was not yet available. This chapter reports the findings of a narrative systematic review, conducted as part of the contextual enquiry phase of this research. The objective of the systematic review was to examine young people's online help-seeking behaviours for mental health concerns. It aimed to summarise young people's experiences and identify the benefits and limitations of online help-seeking for this cohort. It also applies Rickwood's help-seeking model and Self-Determination Theory as lens through which to conceptualise online help-seeking. This study has been published in the Journal of Internet Medical Research (JMIR) (Pretorius, Chambers, & Coyle, 2019). This chapter differs from the published version in that it discusses help-seeking in an offline context and its associated barriers and facilitators.

#### 4.1.1 Background

Help-seeking in the offline context has been widely studied, identifying patterns in young people's preferences and help-seeking behaviours. It has been found that certain types of personal and emotional concerns are more likely to prompt helpseeking than others. Furthermore, young people assign different sources of help in relation to the problem they're experiencing. Two main types of help-seeking sources have been identified – formal and informal. Formal help-seeking can be understood as seeking assistance from any professional who has a recognised and legitimate role in providing support. Informal help-seeking is understood as pursuing assistance from informal social supports with whom the individual may or may not share a personal relationship (Rickwood et al., 2005). Research shows that most young people have a preference for self-reliance when experiencing personal and emotional concerns and are more likely to make use of informal help sources than formal help sources when and if they do reach out (Rickwood et al., 2005). Young men are especially more likely to reach out to family and other informal sources.

Many barriers to help-seeking in an offline context exist, the most prominent of which is stigma (Gulliver et al., 2010). Stigma has been found to be a significant deterrent to help-seeking, prompting young people to seek help from sources they designate as confidential and trustworthy (Aguirre Velasco et al., 2020). Embarrassment around mental health difficulties often prevent young people from reaching out especially in rural, remote communities where seeking help anonymously can be more difficult (Rickwood et al., 2005). Remote, rural areas are further complicated as factors of accessibility come into play. However, accessibility is not limited to those living in rural areas. Accessibility includes constraints of time, finances and transport (Radez et al., 2020). Young people are often still financially dependent on their parents or caregivers or living with them, making it more difficult to access services confidentially. Mental health literacy, or lack thereof, also serves as significant barrier to help-seeking. The lack of mental health literacy is evident in two areas, lack of knowledge of self and lack of knowledge about help sources. Many young people have difficulty identifying symptoms of mental ill health; they are likely to be aware of their distress however they are likely to downplay their concern and its impact upon their wellbeing (Salaheddin & Mason, 2016). Rickwood et al. (2005) found that young people with poor emotional competence (a poor ability to describe and manage emotions) were more likely to have had less successful help-seeking experiences. Poor mental health literacy also influences young people's knowledge about mental health services. Few young people accept that their GP can be the first step on their help-seeking journey. Many young people also have critical attitudes towards professionals. Many believe that seeking help from a professional is futile or would only worsen the problem. Furthermore, young people's evaluation of the characteristics of the professional, such as their perceived credibility and ability, are also likely to influence their help-seeking intentions (Radez et al., 2020).

However, having positive previous experiences with help-seeking is more likely to encourage future help-seeking (Mitchell et al., 2017). Successful help-seeking is likely to improve mental health literacy and reduces fears about the unknown. Positive experiences of other young people also filter into social influences. If a young person knows of someone who has successfully sought help they are more likely to seek help in the future. In addition to this, social encouragement plays an important role. If family members, partners and peers express positive attitudes towards help-seeking, this positively influences the young person's help-seeking intentions. This is especially true of young men, who are most influenced by close and trusted relationships (Rickwood, 2005).

Most recently, computer mediated technologies have begun to influence the help-seeking process. The Internet offers another pathway to access care and help when young people are experiencing mental health concerns. Young people use the Internet as their main source of information for all of their daily needs – accordingly, this logically extends to accessing information regarding their physical and mental health (Best et al., 2016; Gowen, 2013; Subramaniam et al., 2015). Various formal online services are readily available, as are informal resources such as discussion boards and social media (Collin et al., 2011). Information gained from these sources could facilitate the help-seeking process to the next stage and could influence the way in which individuals form their help-seeking attitudes. The Internet also offers unique benefits in the form of anonymity, access and user control that can interfere with the offline help-seeking process as discussed above (Burns et al., 2016). The availability of high-quality mental health information and online resources could have a significant impact on the health outcomes of a young person (Kauer, Mangan, & Sanci, 2014).

#### 4.2 Methods

#### 4.2.1 Objectives

Whilst the potential benefits of online mental health resources have been acknowledged there are also some concerns. For example, there is the worry that online help-seeking may delay access to formal help sources (Gowen, 2013). Previous systematic reviews have been conducted in this area with a focus on how young people search for health-related information on the Internet (Park & Kwon, 2018) and the effectiveness of online mental health services to improve help-seeking (Kauer et al., 2014). However, this review sought to understand the process and experiences of young people with regard to their online help-seeking experiences. The objectives were to conduct a systematic analysis of the research on this topic and use the research to identify future opportunities for research and design that can improve the

online help-seeking experiences of young people. The specific aims of this systematic review were as follows:

1. To examine the strategies employed by young people to search for help online for mental health difficulties.

2. To describe young people's experiences of online help-seeking for mental health difficulties.

3. To identify the benefits of young people's use of online mental health resources for help-seeking.

4. To identify the limitations of young people's use of online mental health resources for help-seeking.

#### 4.2.2 Search Overview

This review was conducted adhering to the PRISMA guidelines (www.prismastatement.org) and was registered on the PROSPERO database (PROSPERO registration number: CRD42017072487). Based on the aims of the study, inclusion and exclusion criteria were established to guide the subsequent search process.

#### 4.2.3 Search Strategy

The following six databases were searched from database inception: PsychInfo, CINAHL, PubMed, Cochrane Library, ACM Digital Library and IEEE Xplore during August 2017. Additionally, the reference lists of all the included studies were scanned for relevant articles. The search terms aimed to represent the primary concepts of 'online help-seeking,' 'mental health' and 'young people.' Keywords were generated for each of these concepts by examining the terminology used in review papers in the help-seeking literature and the authors sought the guidance of a trained librarian in the formation of the search string. The search strings are included in Appendix B | Chapter 4 Supplementary Material. In keeping with the emerging youth mental health paradigm as described in the International Declaration on Youth Mental Health (ACAMH Special Interest Group in Youth Mental Health, 2013), the studies were restricted to young people aged 25 years and younger. Only English-language studies were included. All studies identified in the database search were exported to a reference managing software (EndNote) and duplicate records were deleted.

The initial search identified 1890 published English-language abstracts. After duplicates were removed, 1300 papers remained. These articles were then reviewed

by title and abstract to determine whether they met the inclusion criteria, resulting in 93 potentially relevant studies. At this stage, the full texts of these studies were then obtained to confirm whether the inclusion and exclusion criteria listed below were met, resulting in 65 studies being excluded. The remaining 28 studies were included.

A random sample of 10% of the articles were re-examined at three stages (screening by title and abstract; screening by full text and validity assessment) of the process by the researcher's supervisors, Dr David Coyle (from here forth referred to DCUCD) and Derek Chambers (referred to as DCHSE in this chapter). A few discrepancies were noted and those were resolved by discussion and subsequent double-checking to ensure consistency.

Figure 4.1 The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRIMSA) Flow Diagram Illustrating the Screening Process of Papers



## 4.2.4 Eligibility Criteria

The inclusion and exclusion criteria are shown below:

## Inclusion Criteria:

1.Young people not older than 25

2. Participants who present with psychological distress; self-selected general population samples and those who have received a diagnosis from a healthcare practitioner.

3. Studies designed to investigate and document the online help-seeking intentions and behaviours of young people.

4. Studies that included intervention/s designed to improve help-seeking attitudes or increase help-seeking intentions or help-seeking behaviours of young people

- 5. Web-based help-seeking interventions
- 6. Online mental health resources
- 7. Informal and formal help-seeking

### Exclusion Criteria:

- 1. Studies focused on a third party seeking help for the young person
- 2.Not mental health related
- 3. Not web or mobile application based

4. Unrelated technology e.g. computer games and their impact on mental health; social media and forums that are not specifically focused on mental health related topics

5. Studies focused on online treatment methodologies and interventions e.g. cCBT or online counselling

6. A review paper

#### 4.2.5 Data Extraction

Each article was read by the researcher (from here on referred to as CP) and relevant details were extracted into a Microsoft Excel spreadsheet. There were a number of different protocol details that were examined and recorded for each article. The coding scheme was used to help identify the components relevant to the study design and to address the research questions. The coding scheme included the year of publication, purpose of the study, country, number of participants, participants' characteristics (e.g. medical conditions and age), theoretical framework, research design, sampling, data collection methods, instruments (including reliability and validity), data analysis, help-seeking model employed, strategies found to be used by young people to seek help online, young people's experiences of online help-seeking, facilitators, barriers, major findings, and study limitations.

#### 4.2.6 Analysis Synthesis

Quality assessment of included studies was conducted using the Critical Appraisal Skills Program (CASP) checklists (www.casp-uk), as there are quantitative and qualitative versions available to allow appraisal across different study designs. The CASP checklists enable the assessment of trustworthiness, relevance and results of published papers and are divided into three sections to assess internal validity, the results and relevance to practice. Quality criteria for surveys included sections on: research question and design, sampling framework and participant understanding; instrument metrics, response rate, coding and analysis; and result presentation (Critical Appraisal Skills Programme, 2019; Ponto, 2015; Rolls et al., 2016).

These sections are assessed by questions that can be answered with 'yes', 'no' or 'can't tell.' Based on the ratings, each study received an overall rating of either 'strong', 'moderate', or 'weak', based on the number of questions scored as 'yes'. Studies had to be scored as 'yes' on majority of the questions to be rated 'strong' overall (see Appendix B | Chapter 4 Supplementary Material for details, as criteria differed by study design).

CP performed all of the quality assessments, with a 10% sample being given to her supervisor, DCUCD to compare. Following the quality assessment stage, the inclusion of studies and extraction of key findings was finalised. Extracted data were entered into a table of study characteristics including the quality assessments ratings for each study. The decision was made to use narrative synthesis as it provides a broad overview of relevant information through a textual approach and is appropriate when it is expected that the studies will be heterogenous. Due to the nature of the review questions it was expected that the studies included would investigate help-seeking differently, make use of different research questions and use different criteria to investigate help-seeking behaviours thus it would not be appropriate to make use of statistical synthesis techniques. The Guidance on the Conduct of Narrative Synthesis in Systematic Reviews (Popay et al., 2006) informed the data synthesis process in order to ensure that results and analysis were reported accurately. All the data extracted from the articles are presented narratively in text and summary tables which can be found in Appendix B | Chapter 4 Supplementary Material.

#### 4.3 Results

#### 4.3.1 Study Characteristics

A total of 28 studies met the inclusion criteria (see Appendix B), of which the majority (n=16) were conducted in Australia. Others were conducted in the United Kingdom (n=4), Canada (n=4), the United States (n=2), Ireland (n=1), and the Netherlands (n=1). The studies were published between 2010 and 2017.

The research methodologies of the studies were varied. Only four of the 28 included studies mentioned whether a help-seeking model was employed to inform the study design (Best et al., 2014b; Collin et al., 2011; Cunningham et al., 2014; Kauer, Buhagiar, & Sanci, 2017). These models were limited to Rickwood's help-seeking model and the theory of planned behaviour. Survey research was the most widely employed research design; overall 11 studies (Bell et al., 2018; Ellis et al., 2013; Feng & Campbell, 2011; Frost et al., 2016; Frost & Casey, 2016; Horgan & Sweeney, 2010; Ruppel & McKinley, 2015; Spears et al., 2015) made use of an online survey and 4 studies (Birnbaum, Garrett, et al., 2017; Bradford & Rickwood, 2014; Mars et al., 2015; O'Dea & Campbell, 2011) administered the survey in person to collect data from participants. Survey questions included standardized measures such as the General Help-Seeking Questionnaire (Wilson et al., 2005) and mental well-being scales such as the Kessler Psychological Distress Scale (Kessler et al., 2002), but questions regarding technology and Internet use varied and no standardized scales seemed to be available. Areas explored in these sections of the surveys included the

Internet and social media use, use of online mental health resources, perceived usefulness of these resources, and preference regarding these resources. Other study designs included one randomized controlled trial (Sanci et al., 2017), one feasibility study (Kauer, Buhagiar, Blake, et al., 2017), two comparative studies (Haner & Pepler, 2016; Rickwood et al., 2015), and four qualitative studies (Best et al., 2016; Greidanus & Everall, 2010; Havas et al., 2011; Mar et al., 2014). These studies aimed to assess the intention to seek help from different help sources, previous help-seeking behaviours from different help sources, level of psychological distress, and preferred modes of delivery of online mental health services.

The number of participants in studies ranged from 23 to 3946. Their ages ranged from 12 to 25 years. The majority of studies had gender-mixed samples; however, three studies looked specifically at the online help-seeking behaviour of males (Best et al., 2016; Ellis et al., 2013; Lohan et al., 2015). In all, nine studies recruited participants who were students at a university or high school (Best et al., 2014b, 2016; Bradford & Rickwood, 2014; Feng & Campbell, 2011; Havas et al., 2011; Horgan & Sweeney, 2010; O'Dea & Campbell, 2011; Ruppel & McKinley, 2015), whereas six studies (Ellis et al., 2012, 2013; Frost et al., 2016; Frost & Casey, 2016; Spears et al., 2015; Wetterlin et al., 2014) used online recruitment strategies. Most studies (n=22) were conducted with samples not selected on the basis of mental health status. However, five studies focused on participants who had reported experiencing self-harm and suicidal ideation (Bell et al., 2018; Frost et al., 2016; Mar et al., 2014; Mars et al., 2015; Mok et al., 2016), and one study specifically recruited participants who had been diagnosed with psychosis and nonpsychotic mood disorders (Birnbaum et al., 2016).

#### 4.3.2 Methodological Evaluation

Many of the studies achieved a strong or moderate rating on the various CASP checklists. However, some limitations were identified. The survey studies showed poor adherence or failed to report that they had indeed piloted the survey with a small number of young people before administering the surveys (Best, Manktelow &Taylor, (2016), Birnbaum et al. (2017), Burns et al., (2010), Ellis et al., (2013), Ellis et al. (2021), Feng & Campbell, (2011), Frost & Casey, (2016), Horgan & Sweeney, (2010), Mars et al., (2015), Mok, Jorm & Pirkis, (2016), O'Dea & Campbell, (2011), Ruppel & McKinley (2015). Furthermore, randomized controlled trials showed small treatment

effects, and there was poor evidence of rigorous data synthesis methods in the qualitative studies.

#### 4.3.3 How Young People Seek Help Online

Six studies found that young people made use of text-based queries using search engines to find mental health related information rather than accessing a specific website (Best et al., 2016; Burns et al., 2010; Feng & Campbell, 2011; Mar et al., 2014; Mars et al., 2015; O'Dea & Campbell, 2011). Information seeking about symptoms and forms of treatment are common goals when searching online (Wetterlin et al., 2014) The study by Birnbaum et al. (Birnbaum, Rizvi, et al., 2017) showed that type of mental illness (mood disorder versus psychotic disorder) influenced what young people searched for. In this case, young people experiencing a mood disorder were more likely to search for how to stop symptoms whereas those with a psychotic disorder preferred to understand why their symptoms had come about. When investigating the terms used by young people to search for mental health help, there was frequent use of "mental health", "mental health problems", "depression", or "symptoms of...." and "treatment of ..." (Horgan & Sweeney, 2010; Mar et al., 2014; O'Dea & Campbell, 2011). A common theme in the studies is the search for symptoms and treatment for the mental health concern the young person is currently facing (Wetterlin et al., 2014). The other types of content accessed that were identified by the studies include YouTube videos, factsheets, personal stories and forums (Wetterlin et al., 2014).

Three studies found that young people had used social media to locate mental health information (Best et al., 2014a; Birnbaum, Rizvi, et al., 2017; Feng & Campbell, 2011). The use of mental health or government websites varied from study to study. A study by Burns et al. (2010) found that less than 44.4% sourced information from mental health websites, similarly the study by Feng et al. (2011) found that only 26% of their sample had made use of information sites. Conversely, in a more recent study by Wetterlin et al. (2014), 82.9% of the sample indicated that they would be "somewhat likely" or "very likely" to use an information based website. The study by Best et al. (2016) found that less of a quarter of their sample would make use of a government website.

Despite the lack of preference for formal mental health or government websites, a number of studies found that young people valued online services run by mental health professionals (Best et al., 2016; Birnbaum, Rizvi, et al., 2017; Frost et al., 2016). The study by Birnbaum et al. (2017), found that young people expressed an interest in obtaining help from mental health professionals through social media whilst the study by Best et al. (2016) found that young people valued online services run by mental health professionals despite not wanting to use government websites. Haner & Pepler. (2016), found that the more distress the young person was experiencing the more likely they were to access the 'Live Chat' option with a website providing mental health support to young people. Similarly, Frost, Casey & Rando (2016), found that young people who self-harm would prefer an online service that allowed them to directly link with a mental health professional via instant messaging when in crisis.

Online communities and discussion forums also serve as a platform young people use to seek help. In the analysis of an online community, Greidanus & Everall (2010), found that help-seekers would come to the forum to post messages seeking help for personal distress, looking for input from other users of the online community. The use of discussion boards or online support groups was reported by 11% of the sample in the study by Feng & Campbell (2011) and 48.6% of the sample in a study by Frost, Casey & Rando (2016).

#### 4.3.4 Motivating Factors for Young People to Seek Help Online

The studies identified by this review indicated that many young people were going online to look for a space where they could share their feelings without fear of judgement or labelling but at the same time, it was important that these spaces protected their privacy (Horgan & Sweeney, 2010; Mar et al., 2014; Wetterlin et al., 2014).

Many studies found that there is an association between high levels of psychological distress and engaging in help-seeking online (Barker et al., 2017; Best et al., 2014b; Collin et al., 2011; Haner & Pepler, 2016; Mars et al., 2015). Majority of this help-seeking tends to take place after 11pm at night (Best et al., 2014b; Burns et al., 2010). The study by Best et al. (2016) found that a preferred online service would be one run by professionals, available 24 hours a day. The need for services run and recommended by professionals is a recurrent theme throughout all of the studies (Ellis et al., 2013; Frost et al., 2016; Greidanus & Everall, 2010). Findings from Wetterlin et al. (2014) found that 83.9% of participants reported that it was important to them to have human contact within an online mental health resource. This need for human

contact also includes the need or desire to connect to peers online who can support the online help-seeking process, this is especially true of users of online support communities (Greidanus & Everall, 2010; Horgan & Sweeney, 2010; Mar et al., 2014; O'Dea & Campbell, 2011; Rickwood et al., 2015; Wetterlin et al., 2014).

There seems to be a sentiment that there is more help available to young people online than offline, and that young people from minority groups and those with higher levels of psychological distress, were more likely to disclose their current difficulties online rather than offline (Bradford & Rickwood, 2014; Spears et al., 2015). A study by Frost, Casey & Rando (2016) indicated that this may be due to many young people finding online spaces to be less judgemental and the support they received was non-stigmatizing. This is especially important because a number of studies found that those young people with increased levels of psychological distress were likely to access mental health content online but not seek help from offline sources (Burns et al., 2016; Frost & Casey, 2016; Frost et al., 2016; Rickwood et al., 2015; Ruppel & McKinley, 2015).

#### 4.3.5 Young People's Experiences of Online Help-Seeking

The findings regarding the perceived helpfulness of online resources were variable. Ellis et al. (2012) found that 81.9% of females in their sample found that talking online had helped and that they were either satisfied or very satisfied with the process. Similarly, 54.9% males had talked about their problems online and 81.3% of men found that it had 'helped' and were satisfied with the help they had received. The study by Feng & Campbell (2011) found more mixed results with 59% of this sample indicating that the online resources they had made use of "didn't make things better or worse" and 40% reported that they had "helped a little." Ruppel & McKinley (2015) investigated social anxiety and levels of social support in relation to the perceived usefulness of online resources, they found that participants with higher levels of social anxiety and also those with high levels of social support both found online support groups to be very useful. The analysis of an online community by Greidanus & Everall (2010) found that young people had experienced the online communities (a community message board) as understanding and affirming, this sentiment was especially strong for users who felt misunderstood offline. Overall, the comments indicated that users had found their engagement on the site to be a positive experience.

Table 4.1 Findings Identified in Studies: What Are Young People's Experiences of Seeking Help Online?

Authors	Findings related to young people's experiences online
(year)	
Ellis et al. (2013)	<ul> <li>Most females said that talking online <i>helped</i> (81.9%), and that they were <i>satisfied</i> or <i>very satisfied</i> with the online help they received. More than half of all male respondents reported that they had talked about their problems online (54.9%).</li> <li>Most said that talking online <i>helped</i> (81.3%), and that they were <i>satisfied</i> or</li> </ul>
<u> </u>	very satisfied with the online help they received (82.9%).
Feng and Campbell (2011)	<ul> <li>In total, 59% of participants reported that online resources that they had used <i>didn't make things better or worse</i>, 40% reported <i>they helped a little</i>, and only 1% of participants reported <i>they helped a lot</i>.</li> <li>Although there is a preference for text-based search engines and information sites, the current sample does not seem to find them to be efficacious.</li> </ul>
Frost and Casey (2016)	<ul> <li>Over half of these online help seekers perceived that they had more support available to them online than offline.</li> </ul>
Frost et al. (2016)	• Young people identifying the need for a non-judgmental (n=68) and safe (n=14) environment and interactions. Many young people used the term non-judgmental, whereas others indicated that they needed support in a way that was not stigmatizing, did not stereotype them, blame them, or label them as an attention seeker.
	<ul> <li>Safety in online services for self-injury centred around the need for moderation, warnings about triggering content, and the risks of self-injury becoming competitive.</li> </ul>
	<ul> <li>Young people with a previous experience of online help seeking were more likely to endorse the importance of reduced isolation and a supportive online culture.</li> </ul>
Greidanus & Everall	<ul> <li>Most messages written by the trained volunteers took the form of an affirmation of some aspect of the help seeker's character.</li> </ul>
(2010)	<ul> <li>A strong sense of community was indicated in several of the threads when help seekers stated they felt their experiences were understood and shared by other members. This sense appeared to be especially strong for those help seekers who felt misunderstood by those in their offline lives.</li> </ul>
	<ul> <li>Most of the community members authored a number of threads themselves and posted in threads of other members, occasionally making reference to the content of other threads.</li> </ul>
	<ul> <li>Participant comments often indicated they found engagement on the site to be a positive experience and provided a place to express feelings, receive support, and obtain referrals.</li> </ul>
Mars et al. (2015)	Almost a quarter of the sample had come across a site that discussed self-harm or suicide.
Ruppel and McKinley (2015)	<ul> <li>Participants with higher social support perceived websites and online support groups as more useful.</li> <li>The perceived usefulness of online support groups was highest among participants who had high levels of social anxiety and high levels of social support.</li> </ul>
Wetterlin et al. (2014)	<ul> <li>Most participants (87.7%) rated their privacy as a user as very important.</li> </ul>

#### 4.3.6 Benefits of Online Help-Seeking

Online help-seeking offers a number of benefits to young people experiencing personal and emotional difficulties. A total of 14 studies identified benefits of online help-seeking. These benefits could be grouped into eight overarching categories which have been included in Table 4.2.

#	Benefit	No of studies	Studies:
1.	Anonymity and privacy	8	Best et al. (2016); Bradford and Rickwood, (2014); Burns et al. (2016); Ellis et al. (2013); Frost, Casey & Rando (2016); Greidanus & Everall, (2010); Horgan & Sweeney (2010); Mar et al. (2014)
2.	Ease of access and immediacy	7	Bell et al. (2018); Best et al. (2016); Bradford and Rickwood, (2014); Burns et al. (2016); Burns et al. (2010); Greidanus & Everall, (2010); Horgan & Sweeney (2010);
3.	Connecting with others with similar experiences	7	Bell et al. (2018); Bradford and Rickwood, (2014); Burns et al. (2016); Frost, Casey & Rando (2016); Greidanus & Everall, (2010); Horgan & Sweeney (2010); Mar et al. (2014)
4.	Acts as a gateway to further help- seeking	5	Birnbaum, Rizv, Correll, Kane and Confino (2017); Collin et al. (2011); Frost & Casey (2016); Frost, Casey & Rando (2016); Mar et al. (2014)
5.	Increased perceived control of help-seeking journey	3	Best et al. (2016); Frost, Casey & Rando (2016); Mar et al. (2014)
6.	Meets the needs of those with a preference for self- reliance	2	Ellis et al. (2013); Mar et al. (2014);
7.	Early access	2	Birnbaum, Rizvi, Correll, Kane and Confino (2017); Frost, Casey & Rando (2016)
8.	Inclusiveness of different SES/cultures/gend ers	1	Best, Manktelow, & Taylor (2016);

Table 4.2 Benefits of Seeking Help Online by Study

Eight studies found that the anonymity provided by the Internet was an important facilitator to online help-seeking (Best et al., 2016; Bradford & Rickwood, 2014; Ellis et al., 2013; Greidanus & Everall, 2010; Horgan & Sweeney, 2010; O'Dea & Campbell, 2011). Similarly ease of access and the immediacy of the Internet plays an important role in its attractiveness to young people (Best et al., 2016; Bradford & Rickwood, 2014; Burns & Birrell, 2014; Collin et al., 2011; Frost et al., 2016; Frost & Casey, 2016; Horgan & Sweeney, 2010). The non-stigmatising nature of Internet help-seeking makes it an attractive option for marginalised groups as seen in the study by

Haner et al. (2016). These groups include migrants and members of the LGBT+ community who may be fearful of disclosing personal concerns to their informal networks (Haner & Pepler, 2016). Similarly, a study by Best, Manktelow & Taylor (2014b) found that online help-seeking was not affected by socio-economic status or educational attainment.

Young people are finding a sense of community online and are able connect with others who have similar experiences to their own (Bell et al., 2018; Birnbaum et al., 2016; Mar et al., 2014). They feel they are able to communicate with this community without fear of judgment and more importantly they can control their level of disclosure (Best et al., 2016; Frost et al., 2016). Two studies indicate that young people who had previously gone online to seek help for self-injury or suicide related issues were significantly less likely to have disclosed to someone offline (Bell et al., 2018; Frost et al., 2016).

Online help-seeking seems to act as a gateway behaviour to further helpseeking. It enables young people to access information about their mental health difficulties and therefore decide whether there is a need to seek professional help (Best et al., 2014a, 2016; Birnbaum et al., 2016; Collin et al., 2011; Frost et al., 2016). The Internet provides alternative routes to access mental health professionals, for instance, Birnbaum et al. (2017) found that young people would be willing to access opportunities to connect with clinicians over social media. Collin et al. (2011) investigated the role of an online youth mental health website, ReachOut.com, in promoting young people's help-seeking behaviour. Users of the website (43.3% of those surveyed) indicated that using the website had helped them to acquire the skills and confidence to seek help if they needed it. Online resources could have a role to play in early intervention as the information found online could help early identification of concerning symptoms but also assist in reaching out to mental health professionals.

The Internet also provides access to the information and tools that may assist those young people who have a preference for self-reliance or for informal sources of help (Ellis et al., 2013; Greidanus & Everall, 2010). In the study by Mar et al. (2014), participants indicated that they used the Internet to search for active coping strategies such as journaling to assist them to cope with their current difficulties.
#### 4.4.7 Limitations to Online Help-Seeking

Limitations to online help-seeking were discussed by 14 studies with six common categories of limitations found across all the studies (see Table 4.3).

#	Limitation	No of studies	Studies:
1.	Uncertainty about trustworthiness of	5	Best et al. (2016); Horgan &
	resources		Sweeney (2010); Kauer et al.
			(2017); Horgan & Sweeney
_			(2010); Kauer et al. (2017);
2.	Lack of mental health literacy	5	Bell et al. (2018); Best et al.
			(2016); Feng & Campbell (2011);
			Mar et al. (2014); Ruppel &
			McKinley (2015)
3.	Reinforcing treatment avoidance	4	Birnbaum et al. (2017); Mars et al.
			(2015); Rickwood et al. (2015);
4.	Concerns about privacy and	3	Best et al. (2016); Horgan &
	confidentiality		Sweeney (2010); Mar et al. (2014)
5.	Triggering negative behaviour	2	Bell et al. (2018); Mars et al.
			(2015);
6.	Difficulty in providing an emergency	1	Mar et al. (2014)
	response		

Table 4.3 Themes Identified in Studies: Limitations of Seeking Help Online

Young people are motivated to look for help online, however their ability to access reliable, helpful information is influenced by their lack of mental health literacy and a lack of knowledge of which resources to search for (Best et al., 2014a; Feng & Campbell, 2011; Mar et al., 2014; Ruppel & McKinley, 2015). In the context of help-seeking, mental health literacy can be understood as knowledge and understanding of mental health problems which aids their recognition and management (Jorm et al., 1997). Formal online services are limited and would need to be familiar to the help-seeker in order to be accessed (Best et al., 2016). A key concern raised by young people across three studies is that they were uncertain whether certain sources are reliable or not and lack an understanding of the indicators of quality (Best et al., 2016; Horgan & Sweeney, 2010; Kauer, Buhagiar, & Sanci, 2017). It appears that young people attribute quality based on superficial characteristics such as rank on Google search results, design and layout of websites (Best et al., 2016).

Treatment avoidance is a real risk associated with online help-seeking. Content exists online that can be stigmatising, triggering or that may reinforce harmful behaviours and thoughts (Bell et al., 2018; Frost et al., 2016). Certain communities

may also perpetuate the stigma surrounding mental health and psychiatric treatment options which may contribute to a reluctance to seek help from offline, professional services (Birnbaum, Rizvi, et al., 2017; Burns et al., 2016). The usual protective measures are not present in unmoderated communities and it is concerning that risky content may not be removed (Bell et al., 2018). This risk is exacerbated as young people may incorrectly attribute certain sources as 'helpful' when in fact they are dangerous (Best et al., 2016; Birnbaum, Rizvi, et al., 2017; Horgan & Sweeney, 2010; Mars et al., 2015). Rickwood, Mazzer & Telford (2015) expand on this by emphasizing the self-reliance afforded by online help-seeking may have limited young people's access to the appropriate help source at the appropriate time, due to limits of their own mental health literacy.

Finally, young people are concerned about the implications of making use of online help-seeking. These include fears over protection of privacy; that it may be too impersonal and that the help found there would be unreliable and untrustworthy (Horgan & Sweeney, 2010; Kauer, Buhagiar, Blake, et al., 2017; Mar et al., 2014). Mar et al. (2014) found that young people's concerns regarding their privacy centred around fears that family and friends would somehow find out about their mental health concern. A concern many of them also have about offline help-seeking.

#### 4.4 Discussion

#### 4.4.1 Principle Findings

This review aimed to extend understanding of how young people use online resources to seek help for their mental health concerns. A total of 28 studies were identified. Only four studies explicitly identified a theoretical framework of help-seeking that guided the study design. Moving forward, the development of such theoretical frameworks represents a key challenge. Results suggest that the Internet serves three functions to help-seekers: (1) as a gateway to further information and knowledge acquisition around their symptomology; (2) as a way to connect with others, professional or peer, around the topic of their mental health difficulties; and (3) as an alternative option to offline help-seeking for those who are most at risk. A text-based query via an Internet search engine was the most commonly identified help-seeking approach. But social media, government or charity websites, live chat, instant messaging, and online communities and discussion forums are also used. The

perceived benefits of online help-seeking include anonymity and privacy, ease of access, inclusivity, and the ability to connect with others and share experiences. Online help-seeking may also increase young peoples' sense of control over their help-seeking journey; meet the needs of those with a preference for self-reliance; or act as a gateway to further help-seeking. In contrast, significant limitations were also identified. A lack of mental health literacy can act as a barrier to effective help-seeking, as can concerns about privacy and confidentiality, and uncertainty about the trustworthiness of online resources. There is a concern that online help-seeking can reinforce treatment avoidance or trigger negative behaviour.

#### 4.4.2 Theoretical Frameworks in Online Help-Seeking

This review highlights the limited use of theoretical frameworks to help conceptualize online help-seeking and guide the development of improved resources. Whilst a framework is proposed in Chapter 8, two potential starting points for such a framework: Rickwood et al.'s help-seeking model (2005) and Self-Determination Theory (SDT) are explored here. In each case, the existing theory is used as a lens through which to analyse the benefits and limitations of online help-seeking identified in this review and how they can either support or frustrate the help-seeking process.

The Help-Seeking Model. The help-seeking model of Rickwood et al. (2005) provides a stage-based model to understand traditional help-seeking behaviours. It was applied by two studies in this review and was detailed in Chapter 1 of this thesis. Best et al. (2016) have proposed a pathways-based extension of this theory through their pathways to online help-seeking model, which seeks to predict people's help-seeking decisions on the basis of their mental health literacy and perception of stigma.

Table 4.4 demonstrates another approach to applying the help-seeking model. It outlines one way in which the benefits and limitations identified in this review can be mapped to stages of the help-seeking model. Through such a mapping, one can begin to identify and think about important issues that impact different stages of an online help-seeking process. For example, early access and the potential of online services to act as a gateway to further help-seeking may offer significant benefit at the awareness stage of a help-seeking process. This is offset by the lack of mental health literacy many young people will have at this stage of the process. Similarly, a lack of literacy is also likely to impact the expression stage. However, while young people may struggle to recognize or express their symptoms using formal clinical language,

they might benefit from reading the stories of other young people, whose experiences they might relate to, potentially helping them to understand their own symptoms in a more accessible manner, and thus enabling expression.

As shown in Table 4.4, this approach can also be applied at the availability and willingness stages. In each case the approach provides a structured way to think about benefits that might be maximized, while also highlighting limitations that need to be addressed. Such an analysis can guide the design of more effective online help-seeking services. It is also important to note that do the mapping presented here is not seen as exclusive or exhaustive. It is recognized that other mappings are possible. The intention is to demonstrate how consideration of distinct benefits and limitations at each stage of a help-seeking model can shed light on key challenges and opportunities in the design of online help-seeking services.

Store	٨	waranaaa	<b>E</b> \	recorden	~	voilobility	Willingnooo
Stage	A	wareness		kpression	A	valiability	winingness
Process	В	ecoming aware of	E>	pressing the	lo	dentify sources of	Willingness of the
	S	ymptoms,	sy	rmptoms	h	elp that are	help-seeker to
	a	ppraising the	ex	perienced and	а	vailable and	disclose difficulties
	a	ssistance required	th	at they are in	а	ccessible	to the selected,
			ne	ed of help or			available source
			su	ipport			
Benefit /	٠	Early access	٠	Connecting with	•	Ease of access	<ul> <li>Anonymity and</li> </ul>
Support	•	Acts as a		others with		and immediacy	privacy
	g fi	nateway to	similar experiences	Inclusiveness		Control of help-	
		further help-			seekina journev		
		sooking			•	Meets the needs	Connecting with
		Seeking				of those with a	others with similar
						preference for	
						self-reliance	experiences
Limitation /	٠	Lack of mental	٠	Lack of mental	•	Lack of	<ul> <li>Concerns about</li> </ul>
Frustration		health literacy		health literacy		immediate, crisis	privacy and
		-				support	confidentiality
							Treatment
							avoidance
							<ul> <li>Triggering</li> </ul>
							negative behaviour

Table 4.4 A Mapping of the Benefits and Limitations to Online Help-Seeking Based on the Stages of the Rickwood et al. Help-Seeking Model

**Self-Determination Theory.** As discussed in Chapter 2, Self-Determination Theory (SDT) is a theory of motivation that has been applied across many settings in education and healthcare in order to understand and predict psychological wellbeing

(Deci & Ryan, 2008; Ryan & Deci, 2017). In recent years it has also been applied in the design of digital technologies that can support mental health and wellbeing (Calvo & Peters, 2014; Peters et al., 2018). To date it has not been applied to online help-seeking.

This section considers how SDT can be applied to conceptualise motivation in online help-seeking. In Table 4.5 the benefits and limitations of online help-seeking identified in this review are clustered in terms of their impact on autonomy, competence and relatedness as consistent with SDT. In online help-seeking the goal might vary from person-to-person, however those specific goals could be understood within the broad themes of achieving growth and wellbeing. One could therefore argue that online searches and resources that are designed to support these basic psychological needs will be better able to support young people when they engage in help-seeking.

	Autonomy	Competence	Relatedness
Benefit / Support	<ul> <li>Anonymity and privacy</li> <li>Ease of access and immediacy</li> <li>Control of help-seeking journey</li> <li>Meets the needs of those with a preference for self-reliance</li> </ul>	<ul> <li>Acts as a gateway to further help-seeking</li> <li>Early access</li> </ul>	<ul> <li>Connecting with others with similar experiences</li> <li>Inclusiveness</li> </ul>
Limitation / Frustration	<ul> <li>Concerns about privacy and confidentiality</li> <li>Treatment avoidance</li> </ul>	<ul> <li>Lack of mental health literacy</li> </ul>	<ul> <li>Lack of immediate, crisis support</li> <li>Triggering negative behaviour</li> </ul>

Table 4.5 A Clustering of the Benefits and Limitations to Online Help-Seeking Based on the Primary Psychological Needs Identified in Self-Determination Theory

The evidence from this review suggests that there were mixed responses with regard to young people's satisfaction with their experiences when looking for help online. This mixed response could be attributed to online resources not fully meeting the needs for autonomy, competence, and relatedness, or these needs only being partially met. An example of this could be the use of a text-based search engine, which facilitates the need for autonomy, but leads to an abundance and variety of search results that could overwhelm the young person, frustrating their need for competence.

The mapping also shows how a lack of mental health literacy can be thought of as an issue of competence. Addressing this competence may increase overall motivation for help-seeking. Similarly, the decision to avoid treatment may be a negatively focused expression of autonomy. In such a conceptualization, it might be predicted that systems which support alternative forms of autonomy, for example, by making control of the journey more explicit, will reduce the likelihood of treatment avoidance.

The importance of connecting with another online, whether professional or peer, is emphasized by participants in many of the reviewed studies, indicating the importance for a human element in both formal and informal online help sources. Previous research has also shown that knowing someone who has sought help for a mental health difficulty has a positive effect on one's attitude toward help-seeking (Kearns et al., 2015; Rickwood et al., 2005; Vogel et al., 2009). Viewed through the lens of SDT, engaging with people online or with content that shares the stories of other's help-seeking journeys helps to provide relatedness and improve mental health literacy. As such the Internet may play an important bridging role between different stages of a help-seeking process, first facilitating informal contact, but also increasing motivation towards formal help-seeking.

#### 4.4.3 Tensions and Opportunities in Online Help-Seeking

Evidence suggests that the Internet has the potential to serve as an inclusive gateway that assists all young people in accessing help, especially those from minority groups and groups who experience a great deal of stigma. It provides immediacy of access and allows people to connect with others, while also preserving the option to remain anonymous and control how much information they reveal, thereby supporting relatedness and also meeting the need for autonomy. However, many young people may feel forced to limit what they reveal or how they search due to concerns around privacy and confidentiality, now limiting their autonomy. This highlights a tension between the potential benefit of human contact versus the need for confidentiality. Relatedly, there is a tension between the preference of some young people for selfreliance versus the benefits of disclosure to formal sources of help.

Rickwood et al.'s model emphasizes the importance of the social transactions implicit in traditional offline help-seeking (2005). However, online help-seeking changes the nature of and need for social transactions with others. This review has found that while some online help-seekers prefer online mental health resources that

offer the opportunity to connect with others, others prefer to navigate the process on their own and rely on self-help strategies, removing the need for a social transaction. The different types of content on the Internet mean that the nature of social transactions have also changed: a help-seeker can now read content regarding another young person's personal experiences of mental health difficulties without ever directly engaging with the original writer of the content. The writer of the content can still have a profound effect on the help-seeker, not only improving their mental health literacy, but also providing an example of someone who has also sought help for a mental health difficulty. In this way, help-seekers become the consumers as well as the creators of help-seeking content online.

Online help-seeking can facilitate young people's autonomy by allowing them to control their help-seeking journey. However, as noted, young people have differing preferences for which online resources they access and which resources they find useful. These preferences are not just different from person to person. They may also differ for any given person, depending on their immediate circumstances. A key challenge for future research lies in providing tailored and appropriate online resources for different preferences and groups that meet all three psychological needs. Addressing all three needs in an online resource currently appears to be lacking. For example, young people are accessing resources where they can read and share personal stories, which meets their need for relatedness but it is unlikely that they would meet their needs for competence (is this information trustworthy?) and autonomy (is my privacy ensured?) through these resources.

This analysis suggests that young peoples' online help-seeking may trigger key tensions between supporting and frustrating the 3 basic psychological needs outlined in SDT; simultaneously, the Internet and online resources have the opportunity and capability to address these needs through careful and considered design. Managing these tensions will be important if we are to realize the full potential of systems that support online help-seeking.

#### 4.5 Limitations

#### 4.5.1 Limitations of the Studies Include In this Review

All of the studies included some notable limitations which indicate specific gaps in the literature and findings that may not be generalisable to other populations. Many of the

studies reported having participants where the majority were female (Bradford & Rickwood, 2014; Feng & Campbell, 2011; Frost et al., 2016; Frost & Casey, 2016; Haner & Pepler, 2016; Horgan & Sweeney, 2010; Mok et al., 2016; Ruppel & McKinley, 2015; Wetterlin et al., 2014). Although some studies focused specifically on males, it must be considered that much of the evidence in this area is from a female perspective. Many of the studies were based in Australia, where there is a great deal of investment in youth mental health services compared to other countries in the world. Additionally, many of the studies recruited from a university population only (Bell et al., 2018; Feng & Campbell, 2011; Horgan & Sweeney, 2010; Mar et al., 2014; Ruppel & McKinley, 2015), who are not representative of young people in general. Finally, many of the studies were cross-sectional or retrospective studies (Bell et al., 2018; Birnbaum, Rizvi, et al., 2017; Collin et al., 2011; Frost & Casey, 2016; Mars et al., 2015), these types of studies include recall bias and do not accurately account for actual future behaviours.

#### 4.5.2 Limitations of this Review

This review has several limitations. Although a number of databases have been included, the choice of keywords may have resulted in missing relevant research. Owing to the exploratory nature of this review, the decision was made to include a wide range of study designs, and the review will ultimately be limited by the design of the studies included. Although strategies to limit bias were included through consultation with the second and third reviewer, the possibility of subjectivity in analysing the findings is acknowledged. Additionally, the measures used in the studies were varied and samples were heterogenous, making it a challenge to compare outcomes across studies. It is also evident from the studies included in this review that further investigation is needed into the online help-seeking behaviours of young people from populations other than those included in these studies. These data are representative of a mostly female, university student sample, often living in Australia. These findings may not translate well onto other populations such as those young people living in Europe, Asia, or Africa, young men and those young people who have not accessed tertiary education.

#### **4.6 Conclusions**

A key concern for researchers in this area should be the development of a model or framework in which to explain the motivations and benefits of online help-seeking and how it fits in with the overall help-seeking process for young people. The conceptualization of such a model would contribute to the cross-validation of findings and provide the ability to determine patterns. This review has considered the help-seeking model and SDT as valuable starting points for such a theory. It would allow research questions to be framed within the SDT constructs and theories, allowing for comparison and validation.

# **Chapter 5:** A Cross-Sectional Survey Study Investigating Young People's Online Help-Seeking

# **5.1 Introduction**

Online help-seeking may offer an additional domain where young people can seek help for mental health difficulties, yet the current understanding of how young people seek help online is limited. This chapter details Study Two and the second study of the contextual enquiry phase. This was an exploratory study which aimed to investigate the online help-seeking behaviours and preferences of young people. The findings from the survey are reported in JMIR Mental Health which can be found in Appendix F | Publications (Pretorius, Chambers, Cowan, et al., 2019). This chapter differs from the published versions in that it reports the findings from the question on the General Help-Seeking Questionnaire which have not previously been published.

# 5.1.1 Background

As highlighted in previous chapters, computer-mediated technologies and webbased resources have changed the nature of help-seeking. A study by Dooley & Fitzgerald (2012) indicated that 77% of young people were likely to use the Internet to find information or support for a mental health concern. The increased role of alternative sources of help such as YouTube, Bloggers/Influencers, self-help websites and discussion forums has to be taken into account (Sun et al., 2017). Building on the findings from the systematic review reported in the previous chapter, a need to investigate young people's current online help-seeking behaviours in more detail was identified.

Although a large number of web-based information resources and interventions are available, they are of variable quality (Moock, 2014). A study by Feng et al. (2011) found that whilst there are many online resources available, this does not necessarily result in user engagement, or that their use is necessarily helpful to the help-seeking process. The amount of evidence regarding the helpfulness of online resources in facilitating the help-seeking process is a notable gap in the literature (Kauer et al., 2014).

The systematic review reported in Chapter 4 indicated that surveys, especially online surveys, were a popular and efficient means through which to conduct research with young people when investigating their help-seeking behaviours. Surveys have been found useful to describe large populations, whilst allowing the use of both qualitative and quantitative methods (Ponto, 2015). A survey was deemed appropriate as it allowed potential access to a broad sample of young people from across Ireland to address some of the population gaps identified by the systematic review. A survey also allowed the comparison of Irish young people's experiences of online helpseeking to those themes and patterns identified in the systematic review.

#### 5.2 Methods

Ethics approval for this research was provided by the University College Dublin (UCD) Office of Research Ethics (LS-17-116-Pretorious-Coyle). All data was collected through an anonymous online survey.

#### 5.2.1 Objectives

As with offline help-seeking, each young person has their own preferences for online help-seeking sources and preferred pathways in order to cope with their mental health difficulties and concerns (Reavley et al., 2011). The need to identify these sources and why they are attractive to young people is important. The aim of this study was to investigate and better understand the current online help-seeking behaviours and preferences of young people. This was achieved through an online survey addressing several key issues: current areas of concern; intentions to seek help; preferred online resources; credibility of online resources and finally the current wellbeing of this sample.

#### 5.2.2 Survey Development

This survey was undertaken with the support of a youth mental health charity, ReachOut Ireland. ReachOut Ireland is the sister organisation of ReachOut Australia. ReachOut is a mental health service that offers online mental health resources specifically for young people. Additionally, ReachOut runs a youth participation programme that ensures young people's involvement through all of their work. Prior to the survey going live, the survey was piloted with five young people from the ReachOut Ireland youth panel in order to hear their thoughts on the survey and its acceptability. This survey was developed iteratively, informed by research in the area (Burns et al., 2010; Ellis et al., 2012; Frost et al., 2016; Younes et al., 2015); input and previous research from ReachOut Ireland (ReachOut Ireland, 2017); and the commentary from the youth panel in order to make it as accessible and nonthreatening to as many young people as possible. In adhering to this input from the youth panel, the final survey did not refer specifically to symptoms such as feeling anxious or having low mood. Instead the survey asked young people about the personal concerns that were causing them the most stress or worry. The term personal or emotional concern was selected as the authors wanted to use non-medicalised language throughout the survey. These concerns addressed in the survey also represent the most frequently expressed concerns on the ReachOut Ireland website.

#### 5.2.3 Survey Procedure

This study made use of a survey link to direct participants to the survey. This link was made available through various online sources: youth mental health-related websites (ReachOut Ireland, SpunOut, and BodyWhys) and targeted advertisements posted on Facebook and Twitter. The adverts consisted of a short title, an image and the survey link. The Facebook and Twitter advertisements were specifically targeted to appear on the feeds of Irish users between the ages of 18 and 25. The survey was hosted on LimeSurvey on a local server to ensure compliance with GDPR. The first component of the survey consisted of the information page which included information regarding purposes of the study, how the data would be used, anonymity, confidentiality and data protection. Participants were then asked to provide consent and confirm that they were aged between 18-25 years old and living in Ireland if they wished to continue with the survey. Information on mental health supports was provided on the landing page of the survey as well as on the survey termination page. The survey consisted of 22 questions, over 6 screens and took between 15 and 20 minutes to complete (See Appendix C | Chapter 5 Supplementary Material for the survey questions). Multiple responses from the same user were prevented through the use of cookies. No incentive was offered. Participants were permitted to skip any question they were unwilling to answer during the course of the survey. In total, 2352 people began the survey but a total of 1308 participants successfully completed the entire questionnaire. Data from uncompleted surveys was not used as withdrawal from the survey indicated withdrawal of consent.

#### 5.2.4 Survey Measures

The survey consisted of both quantitative and qualitative questions to assess: (1) demographics, (2) young people's technology use, (3) propensity to seek help from different sources as measured by the General Help-Seeking Questionnaire (GHSQ) [23], (4) current personal and emotional concerns, (5) preferred online resources, (6) credibility of online resources, (7) facilitators and barriers to online help-seeking, and (8) wellbeing of participants measured by the Short Warwick–Edinburgh Mental Wellbeing Scale (SWEMWBS) (Haver et al., 2015). Findings from (3) and (8) has been included under the description of the survey participants.

#### 5.2.5 Data Analysis

The survey data were analysed using IBM's Statistical Packages for the Social Sciences (SPSS, Version 24) primarily using descriptive statistics. Only completed surveys were analysed. Open response questions were analysed using thematic analysis (Braun & Clarke, 2006).

#### 5.3 Results

#### 5.3.1 Survey Participants

A total of 1308 participants were examined in this study, of which 78.52% (n = 1027/1308) were female, 18.50% (n= 242/1308) were male, 1.68% (n=22/1308) were non-binary and 0.84% (n=11/1308) identified as transgender. The mean age of the population was 20.68 (SD = 2.22), with a minimum and maximum age of 18 and 25 respectively. The survey had good national coverage with respondents from all Irish counties. Of the whole sample, 67.13% (n=878/1308) reported that they were currently living in a city or town. Most of the sample reported their current level of education to be undergraduate (59.17%, n = 774/1308). A majority of the sample accessed the survey link through Twitter (68.88%, n=901/1308) and Facebook (24.08%, n=315/1308). The results from the GHSQ were similar to findings from previous studies, the propensity to not seek help at all was very high (45.2%; n=591/1308). Informal sources of help were preferred over formal sources. Only 18.5% of the sample indicated that they would be 'likely' or 'extremely likely' to seek help from a mental health professional whereas 53.3% (n=697/1308) of the sample were 'likely' or 'extremely likely' to seek help from an intimate partner. The SWEMWBS has good

internal consistency, with a Cronbach Alpha coefficient reported of 0.84. In the current study, the Cronbach Alpha coefficient was 0.835. This sample mean (mean =19.0362, SD = 3.522) is one standard deviation lower than the normative group (mean = 23.6093, SD = 3.90264). Scores on the SWEMWBS can range from 7 to 35 and higher scores on the SWEMWBS indicate higher positive mental well-being.

#### 5.3.2 Young People's Technology Use

The majority of respondents owned a mobile phone (99.62%, n=1303/1308) and a laptop/computer (92.35%, n=1208/1308), with fewer owning a tablet (38.91%, 509/1308) or game console (34.10%, n=446/1308). Mobile phones were the preferred device to use the Internet in order to look for help online (80.66%, n=1055/1308), with only 32.65% (n=427/1308) of the sample indicating that they would use their laptop/computer. A negligible proportion of the sample used a tablet or game console to access the Internet or to look for help.

#### 5.3.3 Areas of Personal and Emotional Concern and Online Help-Seeking

The closed response questions indicated that school/college was a source of personal concern for a majority of the sample, with 87.08% (n=1139/1308) indicating that it had recently caused them stress. This was followed by concern caused by body image (73.01%, n=955/1308) and exams (72.02%, n=942/1308). These results are similar to ReachOut's previous findings which also found exams, school and body image to be major stressors for young people (ReachOut Ireland, 2017). Table 5.1 lists the other triggers of stress responded to by respondents.

In the open response section of these questions, 100 respondents provided additional data. These concerns were grouped into the following themes: mental health, work, finances, harm from others, housing, sports, identity, interpersonal difficulties, parenting, physical health, transitional challenges and societal concerns. Table 5.2 below outlines each theme with quote taken from the survey as example for each.

Stressor	Caused significant stress (yes) %(n)	Looked online for help with(yes) %(n)
School/College	87.08% (1139)	85.32% (1116)
Body Image	73.01% (955)	70.41% (921)
Exams	72.02% (942)	71.25% (932)
Family	69.11% (904)	51.83% (678)
Money	67.89% (888)	55.58% (727)
Deciding on a career	65.67% (859)	85.78% (1122)
Relationships	63.46% (830)	64.07% (838)
Friends	61.77% (808)	58.33% (763)
Social Media	40.06% (524)	37.08% (485)
Illness of family member or friend	39.22% (513)	60.93% (797)
Local or World News	30.58% (400)	62.31% (815)
Personal Illness	28.29% (370)	65.60% (858)
Bullying	28.06% (367)	23.85% (312)
Sexuality	23.85% (312)	38.40% (502)

Table 5.1 Areas of Personal or Emotional Concern

Theme	Quote
Mental Health	"Just mental health, specially general anxiety" P1011
Finances	"Unemployment after 4 years in college." P1926
Work	"Participating in a work environment, ie: an office or the service industry" P622
Housing	"Living in rented accommodation- cost, relations with house mates" P1242
Sports	"Competitive sport" P1812
Identity	"Developing a sense of identity, trying to be the best" P1097
Interpersonal Difficulties	"an ability to understand people, the fear of not accepted as a member of a group or have actual friends, fear of trust due to let downs." P938
Parenting	"Being a parent" P203
Physical Health	"Physical health (no diagnosed illness)." P2109
Transitional Challenges	"The process of finishing college and transitioning from a world where others organised so much of my life to having to find a job and be the only one with the responsibility to progress my life." P732
Societal Concerns	"Guilt about seeing world atrocities such as the homelessness crisis and racism/sectarianism and not being able to do much about it" P376

# Table 5.2 Personal or Emotional Concerns Qualitative Responses

This question was followed by a question asking whether young people had gone online to look for help for these concerns. To this question, 85.32% (n=1116) of the sample had gone online to look for help with their stress caused by school/college and 70.41% (n=921) had gone online to look for help with concerns over body image and 71.25% (n=932) looked for help with exams. Majority of the respondents, 85.78% (n=1122) had also gone online to look for help with deciding on a career.

Respondents were asked if they had ever gone online to look for help for a family member or friend. 68.43% (n=895/1308) indicated that they had gone online to look for help/information for a friend, whilst 55.58% (n=727/1308) indicated they had searched for help for a family member.

#### 5.3.4 Young People's Propensity to Seek Help

Respondents were asked to complete the General Help-Seeking Questionnaire. This questionnaire asks respondents to rate the likelihood on a 5-point Likert scale that they would approach a mentioned source of help when experiencing a personal or emotional difficulty. Results from this question indicate that young people are most likely to seek help from an intimate partner (mean=3.37, SD=1.37), followed by from a friend (mean=3.17, SD=1.24). The propensity for self-reliance was quite high in this sample (mean=3.15, SD=1.25). The propensity to seek help from a blogger or influencer was quite low (mean=1.33, SD=0.71).

Help source	Mean	Std. Deviation
Likely seek help from a friend	3.17	1.24
Likely to seek help from a parent	2.58	1.32
Likely to seek help from another relative/family member	1.93	1.08
Likely to seek help from Intimate partner (e.g. girlfriend, boyfriend, partner, husband, wife)	3.37	1.37
		0.94
Likely to seek help from GP / family doctor	1.77	
Likely to seek help mental health professional (e.g. psychologist, social worker, counsellor)	2.08	1.19
Likely to seek help from Teacher / school counsellor	1.65	0.92
Likely to seek help from Minister or religious leader (e.g. priest, rabbi, chaplain)	1.15	0.45
Likely to seek help from a Phone helpline (e.g. Samaritans)	1.51	0.81
Likely to seek help from I would not seek help from anyone	3.15	1.25
Likely to seek help from Online counselling service (e.g. Niteline)	1.71	0.98
Likely to seek help from A person I know who has had their own experiences of emotional/mental health difficulties	2.82	1.24
Likely to seek help from Blogger / influencer	1.33	0.71

Table 5.3 Means (M) and Standard Deviations (SD) of Help-Seeking Intentions(GHSQ) for Personal-Emotional Problems and Different Sources of Help (N=1308)

### 5.3.5 Young People's Preferred Online Resources

Respondents were asked which online sources they use to gain more information for personal or emotional concerns; 82.57% (n=1080/1308) indicated that they would make use of an Internet search, whilst 57.03% (n=746/1308) indicated that they would use a health website and 32.26% (n=422/1308) would make use of a forum or discussion board. Fewer (12.16%, n = 159/1308) would use a mental health app or a social media blogger/influencer (8.18%, n=107/1308). An Internet search is widely

used across all gender groups whilst the use of a blogger/influencer was low across all groups.

In the open response section of this question, other preferred sources of information identified by the respondents could be grouped in the following ways: formal offline source, informal offline source, formal online source and informal online source. Examples of formal online resources included SpunOut.ie and ReachOut Ireland, whilst informal online sources included Reddit, YouTube and Tumblr.

In the subsequent question, respondents were asked how satisfied they were with their experiences of these sources if they had used them. The previous question indicated that the most preferred online resource by young people was the Internet search and this question indicated that 36.94% (n=399/1080) were 'satisfied' or 'very satisfied' with an Internet search. The second most used online resource was a health website, in this question 49.33% (n=368/746) indicated that they were 'satisfied' or 'very satisfied' with this resource (see Table 5.4).

	Not sure	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied
	% (n)	% (n)	% (n)	% (n)	% (n)	% (n)
Health website	7,1% (53/746)	0.54% (4/746)	9.92% (74/746)	33.11% (247/746 )	46.11% (344/746)	3.22% (24/746)
Mental Health App	11,95% (19/159)	2.52% (4/159)	13.84% (22/159)	34.59% (55/159)	32.7% (52/159)	4,4% (7/159)
Internet Search	9.63% (104/1080)	1.11% (12/1080)	11.57% (125/1080)	40.74% (440/108 0)	34.26% (370/1080)	2.69% (29/1080)
Influencer /blogger	8.41% (9/107)	2.8% (3/107)	1.87% (2/107)	28.97% (31/107)	46.72% (50/107)	11.21% (12/107)
Forums / discussion board	4.97% (21/422)	0.71% (3/422)	8.06% (34/422)	44.08% (186/422 )	36.73% (155/422)	5.45% (23/422)
Websites already used	7.35% (10/136)	1.47% (2/136)	12.5% (17/136)	45.59% (62/136)	27.94% (38/136)	5.15% (7/136)

Table 5.4 Levels of Satisfaction with Online Resources

#### 5.3.6 Credibility of Online Sources

Respondents were asked how they would rate the trustworthiness of the above online resources. The previous section of the survey had identified health websites and Internet search as the most frequently used online resources. Health websites were found to be the most trustworthy with 39.45% (n=516/1308) indicating that found them to 'trustworthy' or 'very trustworthy'. Respondents did not rate 'Internet search' as very trustworthy, with 47.09% (n=616/1308) of the respondents saying that it was 'not trustworthy' or 'slightly trustworthy'. Overall, none of the online sources listed were rated as 'trustworthy' or 'very trustworthy' by the majority of respondents (see Table 5.5). Following on from this question, respondents were asked which elements of an online resource would make it more credible. The vast majority (82.95%, n= 1085/1308) indicated that a health service logo was an important indicator of credibility, similarly an endorsement by schools and colleges (54.97%, n=719/1308) or the presence of another government logo (57.57%, n=753/1308) played an important role (see Table 5.6). The majority of respondents, 80.43% (n=1052/1308), indicated that references to scientific data and authors was a key indicator of credibility in an online resource. These indicators were followed by an open response question that asked: "Is there anything not listed above that makes an online resource trustworthy/reliable?" In this section, respondents indicated that online security was important; citing elements such as the green padlock in the Internet browser as well as the lack of ads on webpages. Other themes identified in this open response section included: written/informed by a reputable person/organisation; links to local support services; grounded in research; design and layout; guality of content; the ability to rank or comment on content; and ability to contact someone directly through the source. Participants also mentioned cross checking sources with other sources to ensure reliability and credibility of that source, as stated by one participant "If it's consistent with other online resources. If 3 or 4 sites say the same thing, they I begin to trust it" with another participant suggesting that sources could make this cross-checking process easier by providing hyperlinks to related work.

	Not Trustworthy	Slightly Trustworthy	lt's OK	Trustworthy	Very Trustworthy	Don't know
N=1308	% (n)	% (n)	% (n)	% (n)	% (n)	% (n)
Health website	1.61% (21)	18.88% (247)	33.72 % (441)	32.34% (423)	7.11% (93)	6.35% (83)
Mental Health App	1.45% (19)	10.32% (135)	23.09 % (302)	22.55% (295)	3.29% (43)	39.30% (514)
Internet Search	12.46% (163)	34.71% (453)	36.85 % (482)	9.40% (123)	0.23% (3)	6.42% (84)
Influencer / Blogger	35.63% (466)	23.78% (311)	10.47 % (137)	5.43% (71)	0.69% (9)	24.01% (314)
Forums / discussion board	16.97% (222)	30.20% (395)	21.79 % (285)	9.63% (126)	0.99% (13)	20.41% (267)
Website already used	32.26% (422)	22.55% (295)	13.15 % (172)	5.28% (69)	0.15% (2)	26.22% (348)

Table 5.5 Trustworthiness of Online Resources

N=1308	Disagree	Not sure	Agree
	% (N)	% (N)	% (N)
Links to Social Media	53.36% (698)	36.70% (480)	9.94% (130)
Government Logo	19.42% (254)	23.01% (301)	57.57% (753)
Health Service Logo	6.27% (82)	10.78% (141)	82.95% (1085)
Good Design and Layout	33.18% (434)	25.6% (334)	41.3% (540)
Top of Google search results	35.2% (460)	25.54% (331)	39.53% (517)
College or School Endorsement	14.53% (190)	30.50% (399)	54.97% (719)
References to scientific data and authors	4.89% (64)	14.68% (192)	80.43% (1052)
A quiz or assessment	47.25 (618)	36.24% (474)	16.51% (216)
Contains personal stories/experiences	13.53% (177)	33.10% (433)	53.36% (698)

Table 5.6 *Elements that Indicate Credibility* 

#### 5.3.7 Facilitators and Barriers to Seeking Help Online

Respondents were asked which factors would encourage them to seek help online or through an online resource if they were facing a personal or emotional concern. Young people affirmed that anonymity and confidentiality offered by the Internet was an important motivating factor when deciding to search for help online with 80.00% of the sample indicating that it influenced their decision 'a lot' or 'quite a lot'. Similarly, the low monetary cost of using the Internet was also an important motivator in selecting the Internet, with 84.41% indicating it encouraged them to seek help online ''a lot' or 'quite a lot'. Some of the important barriers highlighted by young people included being unsure if information is reliable as well as wanting to solve problems on their own. Even though the Internet offers more anonymity than offline pathways, young people are still concerned about others finding out that they are experiencing a difficulty.

Facilitator	Mean (SD)	Not at all	A little	A lot	Quite a
N=1308		%(N)	%(N)	%(N)	10t %(n)
It's free	3.31(0.81)	3.29% (43)	12.23% (160)	34.56% (452)	49.85% (652)
Anonymous & confidential	3.26(0.89)	5.12% (67)	14.91% (195)	28.90% (378)	51.07% (668)
Can take it at own pace	3.16 (0.82)	3.59% (47)	15.67% (205)	41.82% (547)	38.91% (509)
Abundance of information	3.12(0.80)	2.91% (38)	17.66% (231)	43.88% (574)	35.55% (465)
Others like me	3.10 (0.91)	5.66% (74)	19.65% (257)	33.41% (437)	41.28% (540)
Access any time of day	3.01 (0.88)	4.82% (63)	23.32% (305)	37.77% (494)	34.10% (446)
Unsure if I'm unwell enough	2.75(1.09)	17.58% (230)	22.25% (291)	28.06% (367)	32.11% (420)
Too unwell to reach local support services	2.20(1.04)	31.27% (409)	32.19% (421)	21.48% (281)	15.06% (197)
There are no other options available	2.13(1.04)	34.17% (447)	33.33% (436)	18.20% (238)	14.30% (187)

Table 5.7 Facilitators to Online Help-Seeking

Barriers	Mean (SD)	Not at all	A little	A lot	Quite a lot
N=1308		%(n)	%(n)	%(n)	%(n)
Unsure if information is reliable	2.70(0.91)	8.49% (111)	35.55% (465)	33.64% (440)	22.32% (292)
Solve problems on my own	2.58(1.09)	21.18% (277)	26.15% (342)	26.30% (344)	26.38% (345)
Concerns others might find out	2.36(1.17)	31.88% (417)	25.15% (329)	17.58% (230)	25.38% (332)
Thinking I don't have a problem	2.34(1.04)	24.77% (324)	34.10% (446)	23.47% (307)	17.66% (231)
Unsure what to search for	2.13(0.92)	26.61% (348)	43.58% (570)	19.95% (261)	9.86% (129)
Not sure of my privacy and anonymity	2.10(1.05)	36.09% (472)	31.80% (416)	17.97% (235)	14.14% (185)
Prefer alternative forms of help	1.88(0.94)	42.43% (555)	34.63% (453)	15.06% (197)	7.87% (103)
Having no one help navigate options	1.84(0.97)	48.17% (630)	27.91% (365)	15.67% (205)	8.26% (108)
Being too unwell to look for help	1.73(0.94)	53.75% (703)	26.83% (351)	11.85% (155)	7.59% (99)
Having previous bad experiences	1.61(0.88)	60.09% (786)	24.46% (320)	9.56% (125)	5.89% (77)

#### Table 5.8 Barriers to Online Help-Seeking

In the open response section, respondents were asked 'Is there anything not listed above that would encourage you to seek help online for a personal or emotional concern?'. One hundred and twenty-four respondents provided answers. These answers were grouped together in themes, for example: anonymity; reduced stigma; validation of experiences; current situation in the health service and ease of access (see Table 5.9 below). Respondents also highlighted barriers to online help-seeking in this space: the cost of some online services; unsure of credibility of some online resources; not finding personalised information and a lack of mental health literacy which impacted on their ability to find the right online resource.

Theme	Quote
Facilitators	
Affordability	"Not having enough money to afford counselling in person." P889
Anonymity	"Some issues can feel embarrassing to talk about. The anonymity online cancels this out" P617
Ease of Access	"Its mostly just the speed of it that helps me out. In my case I can find so much info. on social anxiety with just one click rather than driving 30 minutes from my college to speak to the college counsellor." P1412
Validation of Experience	"Thinking that you are making up the illness in your head and that it isn't real, and you are putting it on for attention.". P1018
Reduced Stigma	"I often go online because I know there is something wrong, but I don't want to tell anyone in my real life for fear that they will judge me or they won't care and ill just be bothering them. Online help can help me deal with my problem alone so I will not have to tell anyone." P470
Privacy	"It provides a level of privacy and I feel like I can control my own feelings."P392
Response to negative life events	"A huge trauma maybe" P33

Table 5.9 Qualitative Responses Indicating Facilitators and Barriers to Online Help-Seeking

Theme	Quote
Barriers	
Affordability	"Hard to find a free option for when times are really bad." P1401
Lack of personalisation	"It's not personal: all the information out there already exists and is not tailored for me" P132
Lack of mental health literacy	"Being unsure what to search/look for online instead of searching for hours for a website that I am comfortable with" P242
Unsure of credibility	"Something to reassure me that the content I am viewing is reliable and trustworthy and having a person to discuss issues with." P863

The Importance of Connecting with Someone Online. At the end of the section covering barriers and facilitators, a qualitative question asked respondents "Is being able to connect to another person online important to you when seeking help online? If yes, why?" 536 of the participants answered this question. The data was inductively coded using thematic analysis following Braun & Clarke's methodology (Braun & Clarke, 2006).

Analysis of this question revealed three key groupings which represent different types of online help-seekers. These groupings were primarily characterised based on their objectives when engaging in online help-seeking behaviour.

The *information-seeker* values independence, their objective is to browse information regarding their mental health query without the intervention or interference of another person, online or offline. This type of help-seeker wants a confidential experience that allows them to access well-written, credible information. This is evidenced through comments such as "I prefer to be independent" and "I like to gather the information myself, without talking to others".

In contrast, other help-seekers are **person-centred**. They are looking for an affirming and empathetic experience. This help-seeker wants to validate their own experiences and would like to make use of an online guide. This could be due to feelings of uncertainty, "Sometimes it can be hard to identify what the problem is" as well as wanting a personalised experience:

I think a lot of information is very general and can seem cold and clinical. If you can talk to someone about your personal and specific experience, information can be tailored and make the person feel more important.

Finally, people seek help online when they are facing *a crisis situation*. This helpseeker wants to connect with another person, either online of offline, because they are in severe distress and need assistance, "Sometimes, in very severe situations I want to talk to a real person..."

Often a crisis help-seeker is looking for immediate relief ("it is immediate"), but when they are looking for help and a personal connection, it is often outside of typical office hours ("I find this especially true at night time, and this is the time when all of the usual go-to help are not available").

The data suggests that many online help-seekers will fall into one of three groupings identified above. However, it is also clear that people cannot, and should not, be referenced as a single static type of help seeker. Rather, young people seek different types of help at different times in their lives, depending on their needs and goals. For example: "It can be useful during times of crisis and extreme emotional stress, but with average emotional stress I prefer to do my own research."

There cannot be a one-size-fits-all approach. It therefore makes sense to design online mental health resources that can address the needs of different types of helpseekers.

#### **5.4 Discussion**

#### 5.4.1 Principle Findings

The results of this survey clearly indicate that the Internet has a major role to play in the help-seeking process for young people. The survey has highlighted that young people are already going online to look for help for issues that are causing them distress and are engaging different online sources for their help-seeking needs. Given the proportion of young people who encounter mental health difficulties and turn to the Internet to meet some of their mental health needs, it is important that researchers and service providers have an accurate and holistic understanding of what these needs encompass.

Help-seeking is a complicated process and young people use different online mental health resources based on their needs. Rickwood's model (Rickwood et al., 2005) of help-seeking refers to 4 stages of help-seeking: (1) becoming aware of and appraising the problem; (2) expressing the need for support; (3) knowledge of available and accessible sources of help; and (4) being willing to disclose personal information. This model acknowledges that there are several barriers that may impede help-seeking at any stage. It can be hypothesized that different online mental health resources are used at different stages of the help-seeking process. The greater part of the sample, 82.6%, indicated that they would make use of an Internet search to locate information when experiencing a personal or emotional difficulty. The Internet search could be conceptualized as playing a role in both the expression and availability stages of the process. However, only 37% of the sample indicated that they were satisfied with this mode of finding help. This could indicate that Internet search is being used due to its easily accessible nature and the anonymity it offers, however it appears insufficient to meet the mental health needs of the present sample. For these reasons, it is possible that an Internet search could act as both a facilitator and a barrier to further help-seeking.

Similar to findings in a study by Reavley, Cvetkovski & Jorm (Reavley et al., 2011), health websites and discussion boards/forums seem to play an important role in meeting young people's mental health needs. This may be due to varied reasons. A health website is likely to provide more accurate information substantiated by research and written by subject experts whilst forums allow users to engage with peers who are similar to them and have lived experience. Comparably, a study by Lal, Nguyen & Theriault (Lal et al., 2018) indicated that young people value resources that allow them to access the personal stories of peers with lived experience and that gives them the opportunity to process the information at their own pace. The current study found that other popular online resources include formal youth mental health websites such as ReachOut Ireland and informal sites such as YouTube. It is worth noting that these sources are likely to change with time and new/other platforms grow in popularity.

Young people are often described as digital natives (Prensky, 2001). This includes the assumption that young people can effectively identify and locate credible resources in the online space (Best et al., 2014a). A study by Montagni et al. (2016), found that half of their sample trusted what they found on the Internet, however their

sample identified one of the disadvantages of using the Internet was its unreliability. This survey also indicates that assigning online credibility can be confusing but young people have developed different strategies to determine the reliability of an online resource. Some of these strategies include checking multiple sources and cross-checking information. The results from this survey has shown endorsements from reputable and known government bodies and educational institutions can play an important role in helping young people to identify credible and reliable online resources. It is evident though that the sources young people were surveyed on, apart from health websites, are not deemed to be very credible or reliable by young people. This disparity between a plethora of online sources available and their perceived lack of credibility could have a jarring effect on the help-seeking process of the young person and this needs to be investigated.

There are a multitude of facilitators and barriers associated with online helpseeking. Many studies have found that the ease of access of the Internet plays an important role in helping young people, a finding that this study supports (Best et al., 2016; Bradford & Rickwood, 2015; Ellis et al., 2013; Frost et al., 2016). Particularly, a study by Birnbaum et al. (2017), highlighted that the Internet plays an important role in early intervention and in young people's further help-seeking. Young people are drawn to the Internet because of the wealth of free resources available but further help-seeking, such as talking to a professional, may be too costly for this demographic. A systematic review by Kauer, Mangan & Sanci (2014) confirmed that online helpseeking is attractive to many young people because of its confidentiality and anonymity. This survey found that concerns about anonymity and privacy remain, and although it seems that the anonymity offered by the Internet does go a long way in circumventing the stigma associated with mental health help-seeking, young people are still concerned about others finding out. It may be for this reason that majority of the sample indicated that they would use their mobile phone to search for help online.

#### 5.4.2 Considerations for Design

The findings from the survey suggest four broad categories of design features that can either meet or frustrate an online help-seeker's needs.

**Content**. The spectrum of help-seeking needs is broad and thus the types of content provided by an online resource should cater for this. The survey found that young people do make use of information pages containing factual information about

symptoms and treatment. Less formal information was also favoured and can be provided through the use of personal stories detailing the lived experiences of other young people. To address the objectives of different types of help-seekers, young people indicated that reliable information regarding self-help strategies should be included in online resources. These strategies need to be supported by research, and references to research should be included. Content should be tailored so that it is applicable to both people searching for themselves and those searching for others.

Interactive Features. The survey highlighted that reading is not the only activity engaged in by online help-seekers. There is a need to enable them to interact and engage with the content they find online. Users suggested that this could be done through comments sections at the bottom of information pages with the ability to upvote certain comments, similar to platforms such as Reddit. Depending on the needs of the help-seeker, the need to connect with another person online whilst help-seeking was highlighted. This can be with a peer or a professional. Finally, any resource needs to be designed for mobile. Good design needs to create a comfortable environment for online content and provide features that are easily accessed through mobile technology.

**Support Credibility**. Concerns over credibility are likely to become a barrier to further help-seeking in the future. Helping young people to assign credibility to online resources also has the potential to play an important role in developing their mental health literacy. The findings from the survey indicate that young people value information that is backed by research and written by experts in the field. Young people's online information-gathering behaviours can be facilitated by including hyperlinks to other online resources that can complement the help-seeking journey. Online resources can indicate their credibility by working in partnership with governmental health services and local schools or colleges.

Support Different Help-Seeking Pathways and Different Kinds of Help-Seekers. Online help-seeking pathways for different help-seekers need to be considered. Existing online resources are predominantly guided by mental health difficulty, diagnoses and symptoms. This has the risk of pathologizing normal emotional responses to everyday life events and stressors which may negatively impact help-seekers experience, deterring future help-seeking when in need.

#### 5.5 Limitations

The survey findings were based on self-reported data from the respondents. The results might not be generalizable; given that recruitment of participants happened through online platforms, this sample is limited to young people who access Facebook, Twitter and other charity websites. The survey may not have captured the views of help-seekers who access alternative resources on the Internet. Future studies should include alternative recruitment strategies targeting low help-seekers, particularly men, and help-seekers who may not access mainstream social media platforms or charity websites. A large majority of the participants were female and undergraduate students, which also limits the generalizability of the results. This survey focuses on emotional concerns that cause participants significant distress and for which they might go online to look for help and did not ask about search for symptoms such as 'feeling depressed' or 'feeling anxious' and thus cannot comment on the types of mental health symptoms participants might seek help for online. This consideration should be taken into account in future work. Finally, the list of online resources offered was not extensive and future studies should investigate further the preference between online and offline sources and whether there are potential differences between preference for informal and formal online resources.

#### **5.6 Conclusions**

The findings of this study indicate that young people are engaging in helpseeking behaviour online to look for help for personal and emotional concerns that are causing them distress. Levels of satisfaction with regard to different online resources are varied and web-based mental health resources need to ensure that they meet the needs of online help-seekers in providing support. Young people have established strategies to assign credibility online, however the availability of credible, online resources needs to be addressed. Steps should also be taken to help governmental organisations and educational bodies identify and support trustworthy and reliable online resources. As with traditional offline help-seeking, a number of barriers exist to deter help-seeking, however the Internet circumvents some of these through its offering of privacy and confidentiality. The findings from the survey indicate that young people have different goals when going online to seek help for the personal and emotional concerns and these goals influence their needs from online sources. These goals and considerations for design will be further explored through Study 3, detailed in Chapter 6.

# **Chapter 6:** Co-Designing an Online Help-Seeking Resource with Young People

## 6.1.1 Introduction

This chapter describes a co-design study that was undertaken as part of the value specification phase of the CehRes Roadmap. The co-design study was undertaken to further explore and verify findings from the systematic review and survey discussed in Chapters 4 and 5. Using the survey data from Chapter 5, personas were developed to represent different help-seekers - each characterised by a particular help-seeking scenario. The personas were then used in the co-design workshops to facilitate further exploration of help-seeking needs. Four key design considerations were identified: connectedness. accessible information. personalisation, and immediacy. Based on these findings, this chapter discusses design recommendations that are grounded in existing theories of help-seeking. The findings from this study was accepted for publication in the Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems. This chapter differs from the published version in that it includes more images of workshop artefacts and certain sections of the methodology section have been elaborated.

### 6.1.2 Background

The systematic review and online survey presented in this thesis have established that the Internet is being used by young people, in a variety of different ways to find support for their mental health difficulties. Many young people are making use of search engines and specific mental health resource websites to meet their needs. A study by Birnbaum et al. (2017) included in the systematic review discussed in Chapter 4, found that the search terms used by young people vary depending on the mental health difficulty faced. Those with psychotic disorders were more likely to search why their symptoms had started, whereas those with mood disorders were more likely to search for how to stop their symptoms. The systematic review also found that young people most at risk, those experiencing self-harm or suicidal intent, were more likely to access the Internet than reach out to someone offline (Frost & Casey, 2016). A slightly larger proportion of these young people are accessing resources that are helpful but there is still a proportion accessing potentially harmful sites (Mars et al., 2015). Whilst a number of online mental health resources exist, very few studies investigate how online help-seeking technologies or online mental health resources can be designed to better meet young people's help-seeking needs.

It is common for HCI research in healthcare to use co-design with specific diagnostic populations in order to ensure that user needs are met (Hetrick et al., 2018; Simm et al., 2016). However, this research sought to gain the perspective of young people who fall into the general population and might not fall into any clinical categories, as would be the case for many young people searching for help online. Co-design methods investigating design needs with young people in relation to mental health have been found to be very useful in the past (Kauhondamwa et al., 2018; Nicholas et al., 2012). They provide a medium to build a shared understanding based on research findings; but can also help to gain the perspective of potential users in a non-intimidating manner (Hagen et al., 2012). Previous HCI research has demonstrated that the use of personas is an acceptable way to facilitate empathy and help to focus design sessions (Marsden et al., 2017; Matthews et al., 2012; Nielsen, 2013b). The use of personas in this study was integral to the methodology used and will be elaborated on in the methods section of this chapter.

#### 6.2 Methods

#### 6.2.1 Objectives

A key task of the design specification phase is to confirm and elaborate findings from the contextual enquiry. To do this, co-design methods were utilised. The survey discussed in Chapter 5, identified three distinct categories of help-seeker: the information-seeker, the person-centred help-seeker and the crisis help-seeker. These categories of help-seeker were translated into personas. These personas were used in co-design workshops reported in this chapter to gain further insight into online helpseeking journeys and young people's design needs. The survey reported four design considerations that needed further exploration and confirmation.

#### 6.3.2 Persona Development

The survey allowed the collection of data from a large number of young people but relied on online survey methods. In this study, co-design methods were applied to engage more directly with young people. As mental health is a sensitive subject and co-design involved group workshops, it was deemed that it would be inappropriate for the participants to speak directly to their own mental health experiences. Instead, data from the survey was used to develop empirically informed personas for young people seeking help for mental health difficulties. Each persona was characterised by one of three goals: to find information; to connect with others, and to find immediate help in times of crisis.

#### Figure 6.1 Jane, the Information-Seeker Persona



Persona development was informed by Nielsen's description of engaging personas (Nielsen, 2004). Engaging personas make use of stories to provide an understanding of the whole person and avoid seeing the user as a stereotype (Nielsen, 2004, 2013b). Engaging personas also take into consideration the emotions and backgrounds of the user. This perspective emphasizes the narratives of the user and how stories can engage and bring personas to life. Nielsen (Nielsen, 2004, 2013a, 2013b) outlines a ten-step process to create these personas which can be

summarised by four main sections: data collection and analysis; persona descriptions; scenarios for problem analysis and idea development; and finally, acceptance from the organisation and involvement of the design teams. In the first three steps, quantitative data (in this case, the survey data) was used to determine who the users are and what they do with the current systems. A hypothesis was then formed to describe different user groups. These hypotheses are then verified. For this study, qualitative data from the survey study and previous systematic review of the literature was used to accomplish this (Pretorius, Chambers, & Coyle, 2019). As part of step four, it was decided to create one persona per grouping identified in the survey. Once the number of personas were decided, steps 5 and 6 included describing these personas and preparing scenarios for each persona. These were again informed by the results of the survey. Throughout the process, designs were discussed among collaborators and field experts (stakeholders from Jigsaw Mental Health Services and Derek Chambers from Connecting for Life in the Health Service Executive (HSE)), to ensure they were valid and representative of the data and actual users.

Step	Description	
1. Data is collected	Data was collected about potential users using the	
	systematic literature review as well as the online	
	survey.	
2. Form a hypothesis	Three types of help-seeker categories were identified	
	from the two previous studies: the information-seeker;	
	the crisis-help-seeker and the person-centered help-	
	seeker. It was hypothesized that all online help-seekers	
	fall into one of these categories.	
3. Everyone accepts the	In order to validate the above suggested help-seeker	
hypothesis	categories, the researcher invited two secondary	
	reviewers to review the codes and their	
	categorisations.	
4. Establish a number	It was decided it would be best create one persona per	
	user category.	

Table 6.1: Nielsen's Engaging Personas Applied to this Study
5. Describe the personas	The personas can be found can be found in Appendix
	D
6. Prepare scenarios for	Scenarios included: details on the character; time; the
the personas	problem the persona is facing and their setting.
	Scenarios are told from the narrator's perspective.
7. Obtain approval	Personas and scenarios were checked with
	collaborators from Jigsaw Youth Mental Health and the
	HSE to ensure validity.
8. Disseminate knowledge	Personas were used in co-design workshops with
	young people.

Figure 6.1 shows one of the final personas. All three personas are included in Appendix D | Chapter 6 Supplementary Material. Beyond the scope of this study, the personas may be useful to other researchers working in this field. They are empirically derived and can help to inform both design processes and decisions.

# 6.2.3 Workshop Procedure

Four separate, two-hour co-design workshops took place over a one-month period with four different groups in different urban and rural locations. Two of the workshops took place with students from local vocational colleges, with the final two workshops taking place with young people from a charity youth advisory panel (from Jigsaw Mental Health Services). All recruitment was facilitated by the youth mental health charity Jigsaw Mental Health Services. There was a total of 35 (Female=20, Male=15) participants across all workshops. The co-design process consisted of three distinct activity phases and the format was informed by the work of Blake et al. (Blake et al., 2016). The workshop protocol is provided in Appendix D | Chapter 6 Supplementary Material. Data was collected in the form of audio recordings of group interactions and artefacts created by groups during the workshops. Artefacts were later photographed, and audio recordings transcribed. Co-design study participants were not asked about their personal experience of mental health services, due to concerns that confidentiality might be compromised in a group setting. Ethics permission for this study was provided by University College Dublin Office of Research Ethics (LS-19-20-Pretorius-Coyle).

Activity One: Persona Immersion. The three personas were used to provide representative illustrations of online help-seekers, according to the groupings described earlier. Participants were divided into groups of two or three, with each group assigned one persona. The intent was to allow participants to become immersed with the user and allow them to think of the help-seeking journey from their perspective. To facilitate this, groups were asked to work through the scenario from the point of view of the persona. Participants were asked to complete an empathy map to elicit empathy and understanding (Dam & Siang, 2020). Empathy maps in association with the use of personas, are powerful tools when using a user-centred approach to understand the scenario from the perspective of the user and to see the world through their eyes. It allows others to understand a user's needs and reveal opportunities (Ferreira et al., 2015, 2016). The personas and empathy maps allowed participants to explore a sensitive topic from the perspective of another young person.



# Figure 6. 2 Empathy Map for the Jane Persona

Activity Two: Mapping the Help-Seeking Journey. In the same small groups, participants were then asked to map the help-seeking journey for each persona using the scenarios (Howard & Tharon, 2014). The groups were asked to execute the steps the persona might take to achieve their personal help-seeking objectives and to record these steps. Participants were asked how the person would feel at different points in the process; where they may feel their needs are met and where that particular persona might feel frustrated.



Figure 6.3 Blank and Complete Journey Maps

Activity Three: Brainstorming Features for an Online Mental Health Resource. The brainstorming section of the workshop consisted of two parts. The participants were first asked to brainstorm as many features and qualities they thought were relevant for an online mental health resource for their persona. They completed this brainstorming activity on their own and then discussed their ideas in their groups and grouped similar ideas together. Once this was completed, participants were then asked to sketch their most preferred features. To conclude, participants discussed their sketches in groups and identified the most important features overall.

Activity Four: Designing the Online Experience. Each small group was asked to design the ideal online mental health resource that would facilitate the help-seeking of their persona and which incorporated the features they had identified in the brainstorming process. Participants used A1-sized paper and markers to illustrate their designs. See Figure 6.4 below for an example.



Figure 6.4 Final Design of Ideal Online Resource from One of the Co-Design Workshops

# 6.2.4 Data Analysis

A directed content analysis approach was used on the qualitative data (Hsieh & Shannon, 2005). All workshop artefacts were photographed and uploaded to NVivo. Three parties participated in coding, Claudette Pretorius (CP), Dr David Coyle (DCUCD) and Darragh McCashin (DM). CP coded all workshop data using open and closed coding. An *a priori* list of codes were derived from the Rickwood's help-seeking model, Self-Determination Theory, known facilitators and barriers to help-seeking, and categories of features that would inform design. Data that could not be coded to the predetermined codes were identified and analysed to determine whether they represented a new category or sub-category. The two remaining coders used the same approach, with DM coding 75% of the data and DCUCD coding 25% of the data. Thereafter, codes were compared, and any disagreements were discussed until consensus was reached. Using this qualitative approach, each artefact could be coded for multiple codes. Once coding was completed, codes from facilitator and barrier categories, as well as from feature categories, were analysed for overall themes.

#### 6.3 Results

Collectively, the overall dataset clustered into four key themes that described important design needs for young people throughout their help-seeking journey.

#### 6.3.1 Chat and Relatedness

Participants repeatedly described chat features as an important component to helpseeking and expressed a clear wish for relatedness. This was described in a variety of formats, including virtual reality, chatbot-driven, 24/7 real-time interactions, community forums, options for chat with both peers and professionals, in addition to preferences for anonymous chat. Across all workshop designs, participants included a chat option within a broader interface that addressed various help-seeking pathways. The chat function was also highlighted by some of the participants as a useful way to assist those who were in crisis.

"The only thing about a live chat, if it's 24/7, it would have to be like, you can feel bad at any time in the day like, you know what I mean? Maybe like you could have an emergency contact thing, where it's like, if you go on at two in the morning, like someone, like you could go on a call or something."

Links to social media were also a minor theme within the data. Participants used social media as a means to connect to a broader community as well as means to learn about online mental health resources.

#### 6.3.2 Information and Competence

The second key theme was a desire for information regarding mental health issues, noting also the impact that too much information could have on a person's sense of competence. Participants showed strong preferences for traditional information page content including articles and FAQs. Many groups named formal websites (such as Healthline or the National Health Service in the UK). They were also clear in expressing their wish for diverse formats of information - videos, podcasts, links to other sources, and personal stories were all seen as helpful.

Connected to the drive for information was the need for accessible layouts and design, and this was seen as integral to both the credibility and usability of the online

resources. Furthermore, participants indicated that credibility could be promoted by referencing scientific research and mental health professionals.

The issue of competence was most clear when participants discussed strategies of searching for information. Activity two asked all groups to execute the steps their persona might take to achieve their personal help-seeking objectives. In the workshops, all groups, irrespective of the persona assigned, began with an Internet search – typically via Google. However, the content of the search was variable, some groups searched specifically for mental health conditions such as depression or anxiety. Others inserted symptom-related queries such as "heavy feeling in my body." Some groups reported being unsure of what to search for: "But she probably doesn't have a full understanding of what she has, I think like when she's searching, she's guessing."

Also, all participants were aware of limitations associated with search results, "...if there's nothing on the first page, you're screwed."

A common frustration in groups was to feel overwhelmed by the amount of results that a search returned ("Because a lot of people would feel that there's too much"). It is also worth noting that many final designs viewed an online search as a first step in seeking offline solutions (such as accessing traditional formal services).

#### 6.3.3 Personalisation of Resources and Autonomy

There was a strong preference for online resources to provide both content and features that were personalised to young people. When groups browsed articles and information pages to learn more about the difficulty their persona was experiencing, they frequently indicated the need for tailored information and tools to suit the preference of the persona ("Not enough information. It just didn't do it for me. Not enough, not personal enough").

Personalisation was often achieved through a questionnaire or psychometric to help the young person address their current concerns. Participant's designs often included 'quizzes' to redirect users to personalised features. Importantly, personalisation included activities specific to their local area, books and documentaries relevant to their needs, and personal testimonies applicable to their challenges. The use of apps, diaries and mood-tracking technologies were also seen as part of an online resource that could be personally tailored to suit differing help-seeking needs of young people. Supporting the young person's autonomy and avoidance of medicalized labels were also identified as important in supporting personalization:

"The quiz doesn't diagnose you with depression or anxiety or anything, obviously, but it just sees where you're at. Then it would match you up a counsellor based on your results."

As noted above, relatedness was an important theme across all of the designs irrespective of the persona used. The importance of autonomy was again evident in this context. Anonymity was included across different design features, and was seen as important in personalized resources:

"Think the anonymous aspect of it, where you don't need to give all of your information to get a diagnosis, where you can keep the app, but not have to give your name, your age, your location or anything like that unless you want to give your location. I think that makes people feel safer, without having to give personal details."

# 6.3.4 Immediacy

In addition to chat, information, and personable features of online resources, participants also emphasized the need for help that could be acted upon immediately. In some instances, this took the form of practical activities that could be completed in times of stress, including guided meditation and breathing. Other features included daily challenges, inspirational quotes, and tips and tricks for self-help. One participant stated:

Maybe in the app, just having suggestions of things someone could do, just tips and tricks if they're feeling anxious or something. I don't know, something they could do at that moment, just to make them feel calmer.

It appears that some of the resources outlined so far – such as static information pages – fail to provide an additional step for online help-seekers, in that few offered suggestions for actions that could be taken in the moment to relieve immediate distress. Continuously, participants also mentioned games, guided relaxation, music, podcasts, and VR-led features as sources of instant activities.

#### 6.4 Discussion

#### 6.4.1 Applying Theory to Understand Online Help-Seeker's Needs

The study outlined in this chapter aimed to provide insight into how young people can be supported in their online help-seeking through the appropriate design of online mental health resources. This discussion reflects on the findings via Rickwood's help-seeking theory and Self-Determination theory, to highlight challenges and opportunities for design. It builds on the discussion provided in Chapter 4. Specifically, it discusses how the features and characteristics of online mental health resources can either facilitate or impede help-seeking. Rickwood's model is considered first and how it can be applied to understand the online help-seeking process.

Rickwood's Help-Seeking Model. Online help-seeking appears to circumvent the necessity for the process to move from the intrapersonal to the interpersonal. Young people can engage in the entire help-seeking process, and successfully find help, without having to interact with another person should they choose not to. The Internet seems to offer options to support young people's preference for self-reliance. In mapping online help-seeking to Rickwood's model, one can assume that the young person is exercising the expression stage by completing an online search. Search results inform the availability stage, whilst assessing and pursuing certain resources speaks to the willingness stage. This process can happen again once the young person has accessed an online resource, but perhaps in a different order. As the young person accesses different available resources, they are expressing their symptoms and identifying available sources of help. But they may also improve their mental health literacy through these actions, which in turn may facilitate increased awareness of their symptoms and difficulties. As young people build their mental health literacy, they also have on-going and progressive options on the degree to which they disclose their difficulty (i.e. willingness). This might involve a transition from informal to formal sources of help. But equally it may mean remaining anonymous.

There are a number of features and characteristics that can be included in online resources to either facilitate or hinder online help-seeking in terms of this model. Table 6.1 outlines concrete examples. For example, while online search can facilitate expression, a lack of mental health literacy may act as a barrier to young people's

ability to identify appropriate search terms. Structured questionnaires may help to overcome this barrier. Online resources that are designed to maximise the facilitators identified in Table 6.1 and overcome the listed barriers, have the potential to provide young people with a more satisfactory online help-seeking experience.

	Facilitator	Barrier
Awareness	Personal stories, articles and FAQ's	Difficulty in accessing relevant personalised content
Expression	Search, psychometric assessments, trackers, and questionnaires.	Lack of mental health literacy in order to input appropriate search terms
Availability	Ease of access and instantaneity	Overwhelming number of options of variable quality available and difficulty in choosing an appropriate option
Willingness	Anonymity	Lack of live, immediate support

Table 6.2 Applying Rickwood's Model to Design Strategies That Can Either Facilitate or Impede the Help-Seeking Process

**Self-Determination Theory.** Self-Determination Theory is also proposed as a useful framework to apply to conceptualise online help-seeking and meet the design requirements of young people. Many of the features and characteristics identified in this study can be thought of as meeting one of the three basic psychological needs. However, it is more likely that they will have an impact across multiple needs. Frustrating these needs can hinder help-seeking; much like satisfying these psychological needs can facilitate the process. Table 6.2 again outlines concrete examples of how these needs can be met or, alternatively, frustrated in the online context.

Systems will work best when the three psychological needs are met, work together in harmony and facilitate one another. If not, the experience is more likely to be frustrating and not meet the help-seeker's needs. Our synthesised data consistently highlighted the need to effectively balance young people's needs for both competence and autonomy. To go online for help in the first instance can be theoretically understood as an autonomous act, leading to the exploration of resources that can build competencies, often in tandem with relatedness. However, while information pages can facilitate competency, information overload can reduce a young person's sense of competence. Participants indicated that information pages should have different sections, including facts and information that can be quickly consumed; longer, more detailed sections; video; stories and images. Online help-seeking also meets the need for relatedness through a variety of different means (i.e. personal stories, discussion boards, chat). Providing choice within information pages and relatedness channels can help to support autonomy.

	Facilitator	Barrier
Autonomy	Anonymity	Difficulty in accessing
		relevant personalised content
Competence	Search, psychometric	Lack of mental health literacy
	assessments, trackers, and	In order to input appropriate
	questionnaires.	search terms
Relatedness	Ease of access and	Overwhelming number of
	instantaneity	options of variable quality
		available and difficulty in
		cnoosing an appropriate
		option

Table 6.3 Applying Self-Determination Theory to Design Strategies That Can Either Facilitate or Impede Basic Psychological Needs

When considering the dominant theories of help-seeking, what is novel about online help-seeking in this study is that numerous needs and stages become realised through different individual features, sometimes simultaneously. For example, the preference for live anonymous chat with a professional can be seen as autonomously engaging in a competency-building activity with a human who can offer help. According to the presented theories, this would represent a propensity for both informal and formal sources, expression (Rickwood's help-seeking model) and a need for relatedness (SDT). However, the need for anonymity and the preference for this activity to *only* occur online directly challenges traditional ideas of relatedness. It raises the question: to what extent are young people seeking relatedness when favouring anonymised interventions online? Systems that use Rickwood's help-seeking model or Self-Determination Theory to guide their design should consider tensions such as those highlighted in this section.

#### 6.5 Limitations

The personas in this study represent three different help-seeking scenarios but should not be considered an exhaustive list - future research is likely to provide further detail and may identify other important help-seeking scenarios relevant to the online space. Additionally, while the scenarios and personas are applicable to differing helpseeking needs of a young person at various timepoints, it is not yet known how and why a young person might shift between help-seeking pathways. For example, a young person might only seek information online to self-educate; but they may also shift into preferring person-centred resources that provide relatedness or experience a crisis situation. The exact reasons for shifting between these scenarios and preferences warrants further investigation.

This study approached the issue of online help-seeking for mental health via the lens of help-seeking theory. In elaborating and refining the understanding of help seekers and scenarios, it will also be interesting to apply an Information Science perspective (Fisher et al., 2005; Fisher & Julien, 2009).

This was beyond the scope of the current study, but future work would provide alternative and complementary theories on how people seek, manage and use information. Longer-term research to synthesise theories of help-seeking and Information Science is likely to provide valuable insights on how young people use online resources to address mental health concerns. For example, application of Rieh's work on the judgement of information quality could provide greater understanding of how young people assign credibility to online mental health resources (Rieh, 2002).

Finally, these findings should be considered in light of the fact that, to the best of the researcher's knowledge, the sample was non-clinical. Therefore, it is not known if the results are applicable to clinical populations. As the study took place in Ireland this data is most representative of a western European demographic. Whilst the codesign study contained a near gender balance, the survey was disproportionately female. Future work should investigate if there are any gender differences regarding the help-seeking process of young people online.

# 6.6 Design Recommendations when Considering Findings from both the Survey and the Co-Design Study

Consistent findings from both the survey and co-design study imply that online resources need to fulfil two practical roles, providing both referral tools and help sources. Irrespective of the help-seeker, and with a view to fulfilling these two needs, four key design recommendations are proposed: provide opportunities for connectedness; provide credible and accessible information; provide personalisation, but also respect anonymity; and, finally provide "just-in-time" support options. These recommendations are both theoretically informed and based on the data.

#### 6.6.1 Provide Opportunities for Connectedness

Young people require online resources that offer opportunities to connect with others, peers and professionals, and feel part of a community. This can be achieved through various means including chat, forums and personal stories. Dependant on the stage of help-seeking the young person is at, connectedness will entail different types of activities. Previous work has shown the importance of providing structured, safe peer support channels for those seeking mental health support and the benefit this can have on young people's overall wellbeing (Nagshbandi et al., 2016; O'Leary et al., 2018). There is value in providing opportunities for young people to discuss and ask questions from peers and professionals anonymously. Mental health concerns remain a very stigmatised topic and the preference for anonymous help-seeking online is understandable. This is also more likely to help young people move forward through the stages of help-seeking. Previous literature has confirmed that opportunities to find support online are now as important as traditional sources of support, both formal and informal (Park, 2018). The opportunity to feel part of a community online or engage with others in similar situations is an important need for young people when seeking help online. If this is designed correctly, help-seeker's need for relatedness and competence are met concurrently. Simultaneously, it also needs to be recognized that, for some help-seekers, there will be preferences to experience that connectedness in an offline context, but they will need assistance in finding appropriate offline opportunities. It is recommended that online resources include tools and mediums through which young people can experience connectedness in meaningful ways, including links to appropriate and, critically, local offline supports.

#### 6.6.2 Provide Credible and Accessible Information

Findings from both studies have shown that online resources have to offer more than text-based mental health articles. Information needs to be offered in the form of different mediums including video, audio, short as well as long articles, and quicker to access FAQ sections. In this way, content can cater for various levels of mental health literacy and different online help-seeking goals. These findings reflect similar results to a study by Cunningham et al. (2014), which found that young people had different mental health information strategies. Mental health literacy has been found to be a significant barrier to help-seeking (Daine et al., 2013; Gulliver et al., 2012; Wilson et al., 2005) and technology offers opportunities to address this by providing content that suits different information preferences. In meeting varying informational preferences, online resources can also facilitate young people through the stages of help-seeking, whilst helping to meet their needs for competence and autonomy.

#### 6.6.3 Provide Personalisation, but also Respect Anonymity

Young people are currently frustrated by the difficulty in accessing tailored and appropriate content relative to their needs. They feel overwhelmed by the abundance of choice and information that search results offer that do not speak to their online help-seeking goals. Their need for autonomy and competence are being frustrated. Other research has also shown that personalisation is an important factor for consideration when designing digital mental health technologies (Hollis et al., 2015). However, personalisation needs to take into account that anonymity is an important facilitator to help-seeking. This resonates with findings that in the case of search, as opposed to use of social media, users do not face the same temptations to self-censor (Zaman et al., 2019). Young people face a great deal of stigma regarding their mental health and when anonymity is included in the design of an online resource, users are likely to feel safer and more autonomous in disclosing their difficulties.

Finally, personalisation needs to recognize that different help-seekers will have different preferences for further support; how the need for relatedness is met will look different for different young people. Some help-seekers will prefer to have their entire help-seeking experience online, whilst others will go online with offline intent - for example, using a website to self-diagnose so as to make an online appointment with an appropriate local professional. Online resources that provide credible, tailored content are more likely to provide a positive help-seeking experience and designers

of online mental health resources should endeavour to create personalised pathways for their target users.

#### 6.6.4 Provide 'just-in-time' Support Options

Online mental health resources have an important role to play in facilitating young people's help-seeking and ensuring that they access the appropriate help at the right time. In order to do this successfully, online resources need to have options that provide both immediate and long-term solutions. A study by de Alva and colleagues (2015) investigating user's opinions of mental health apps found that users were often left feeling unsupported by mental health apps in times of distress. Similarly, O'Leary et al. (2017) found people who experience mental illnesses are often looking for "just-in-time" support when experiencing crisis. Participants in the co-design workshops indicated that providing online services and tools that are available and that are executable 24/7 and that can relieve distress in the moment. The co-design workshops indicated that these might include chat with a professional in times of crisis or grounding techniques, but further investigation is needed into what types of exercises, activities and services would effectively meet this need.

#### 6.7 Conclusions

The findings from the survey and the co-design study indicate that young people have concerns when looking for help online and that these concerns could be addressed through considered and purposeful design. The findings from both these studies proposes that online mental health resources can facilitate the help-seeking process by providing (1) opportunities for connectedness (2) credible and accessible information (3) personalisation, but also respect autonomy and (4) "just-in-time" support options. This study provided an understanding of how young people use the Internet to engage in online help-seeking behaviour and the recognition of specific design opportunities to positively facilitate online help-seeking. Offline help-seeking faces a number of barriers, including stigma, the opportunity now exists to address these in an online context.

# **Chapter 7**- A User Study to Evaluate Design Guidelines for Online Help-Seeking Technologies

# 7.1 Introduction

Using the findings from the previous three studies, detailed in Chapters 4 to 6, design recommendations were proposed for the development of online help-seeking technologies and online mental health resources. To investigate whether these recommendations were valid, a user study was designed to explore how a technology enabling these recommendations compared to other help-seeking technologies. Two prototypes were created, one in the form of a website and another using a chat interface. These prototypes were compared to Google, the HSE website and the ReachOut Australia Next Step tool. A think-aloud approach was used, with participants completing a TENS-Interface questionnaire after using each technology and a short semi-structured interview at the end of the session. The procedure and findings from this study are reported in this chapter. Using the findings and insights gained from this study, the design recommendations are then refined and updated.

# 7.1.1 Background

There is a substantial body of work investigating the health information search behaviours of different populations as users experience similar difficulties in locating information and resources for their health concerns (Wang et al., 2020). Various approaches are being investigated in order to understand how best to facilitate user's online health information-seeking behaviours. One such case is of Pang and colleagues (2015) who developed the system, 'the Better Health Explorer', to support exploratory search within websites for health information. This system relies on users to find a specific but widely accessed health website using a search engine but once they land on the page, their search is facilitated by the Better Health Explorer tool. This tool makes recommendations for further exploration related to the health topic using a series of sliders to widen or narrow results. Other studies have investigated tailoring recommendations to match different audiences in terms of language complexity, this includes making different health website recommendations for clinicians versus patients (Alfano et al., 2019). The use of Health Recommender Systems to facilitate online health seeker's goals is also being explored, although studies evaluating their use and success are still in the early stages of investigation (Schäfer et al., 2017).

Even fewer studies investigating help-seeking technologies for mental health can be found, although a few exist from Canada and Australia. The Thought Spot platform (<u>https://mythoughtspot.ca/</u>) in Canada presents a collaboration between researchers and young people to design a tool to facilitate young people's access to and navigation of mental health services (Van Heerwaarden et al., 2018; Wiljer et al., 2016, 2017). It works as an online mapping platform that can be used through the Internet on mobile devices. It also allows users to select services based on various preferences and their locations.

Another example of a help-seeking technology for mental health can be found in Australia in the form of the ReachOut Next Step tool on the ReachOut Australia website (Kauer, Buhagiar, & Sanci, 2017; Sanci et al., 2017). This tool was developed using co-design methods with young people, with the aim to develop a tool that would refer young people to appropriate online mental health resources. This tool is further discussed in the 'Methods' section below.

#### 7.2 The Design Phase of CeHRes Roadmap

A key task of this phase is to use the blueprint provided by the contextual enquiry and value specification phases to develop a design that meets the user's needs (van Gemert-Pijnen et al., 2018). The design of the technology evolves through the development of low- and high-fidelity prototypes that are tested with end-users and other stakeholders. This enables the researchers to ensure that the technology fits the needs of the users and is in line with their preferences. In the case of this research, the two previous phases found that for young people seeking help online; the design of the technology should address their needs for information, connectedness and support. This chapter reports on the findings from a user study of a prototype designed to represent the design recommendations identified through previous studies.

# 7.3 Methods

# 7.3.1 Objectives

This study builds on the findings from the three previous studies. Findings outlined in Chapter 6 identified four key design recommendations that should be included in the design of online mental health resources in order to facilitate young people's online help-seeking. These four key design recommendations are: provide opportunities for connectedness; provide credible and accessible information; provide personalisation but also respect anonymity; and provide "just-in-time" support options. This study investigates these four design features in more detail.

#### **Research Questions:**

1. Do help-seeking technologies that embody the design factors identified support effective help seeking?

2. How do help-seeking technologies that embody the identified design factors compare with currently used help-seeking technologies?

#### **Objectives:**

1. To operationalise the design factors identified through the use of different technologies

2. To reveal unanticipated difficulties or needs not addressed by the identified design factors

# 7.3.2 Procedure

This study compares the online help-seeking process across five platforms in order to test whether help-seeking technologies that embody design factors identified in Chapter 6 support more effective help-seeking. Two of the platforms were prototypes designed by the researcher and informed by the key design factors identified in previous studies. The first was a chat interface and the second a directorybased search system. The final three platforms included for comparison were: Google search, the Irish national Health Service Executive website, and a youth mental health charity website (ReachOut Australia). Participants were asked to look for help using each of the platforms from the perspective of a particular persona. The persona represented a help-seeker who is struggling with symptoms of depression. The persona was written using gender neutral language to avoid bias. Each participant began with a Google search, after which the order with which they used each platform was randomised. All participants used all five platforms. A 'think-aloud' protocol/method was used to gather data. This requires participants to speak their thoughts aloud (think aloud) whilst performing tasks, i.e. they say what comes to mind as they perform tasks. This is a well-established method for evaluating interactive computing systems (Eccles & Arsal, 2017). After the use of each platform, participants were asked to complete a brief 12-item questionnaire called the TENS-Interface. More detail on this measure is provided below (Peters, Calvo & Ryan, 2018). Once participants had used all of the platforms, a short semi-structured interview was conducted. Each session lasted about one hour and was audio-recorded. Ethics permission for this study was provided by University College Dublin Office of Research Ethics (LS-20-03-Pretorius-Coyle).

# 7.3.3 Platforms

**Google.** Google was selected as findings from the previous studies indicated that this is currently the most commonly used platform to locate online mental health resources (Best et al., 2016; Pretorius, Chambers, & Coyle, 2019; Pretorius, Chambers, Cowan, et al., 2019). This was especially evident in the help-seeking journey maps from the co-design study reported in Chapter 6. Other studies have found similar trends (Best et al., 2016; Mar et al., 2014; Mars et al., 2015).

**ReachOut Australia Next Step Tool.** The ReachOut Australia 'Next Step' Tool is integrated into the homepage of the ReachOut Australia website<sup>1</sup>. ReachOut Australia is an online mental health organisation aimed at young people, offering tools and information in order to support mental health. The 'Next Step' tool was developed to address the low rates of formal services accessed by young people. The tool aims to assist young people to navigate available mental health services by recommending personalised supports, based on how significantly their symptoms are affecting them. The tool has gone through a number of iterations, a participatory design process and has been evaluated using a randomised control trial (Blake et al., 2016; Kauer, Buhagiar, & Sanci, 2017; Sanci et al., 2017). This tool was selected for comparison as it is one of the few online help-seeking tools available specifically for young people, which has been subjected to detailed academic research. It entails a three-step process which asks the user to select issues that may be bothering them, how severely

<sup>&</sup>lt;sup>1</sup> /web/20200728113333/https://au.reachout.com/

it's affecting them and then offering a number of online and offline resources in relation to this. Most of the online resources recommended are within the ReachOut services. Figure 7.1 below, shows screens from the tool.



Figure 7.1 ReachOut Australia 'Next Step' Tool

**HSE**. The Health Service Executive (HSE) is Ireland's national health service, similar to the NHS found in the United Kingdom. Prior to 2019, the HSE had a separate mental health website, titled yourmentahealth.ie. A dedicated HSE website for mental health still exists but it has now been incorporated into the new, updated HSE website. The Mental Health homepage consists of three sections. The first offers 6 broad categories for users to choose from. The second section entitled "What's on your mind?" offers specific areas of concern to choose from including anxiety, depression and Schizophrenia. It also offers a drop-down menu to locate results according to 'issue', age group and location. The third and final section includes links and excerpts to a mental health blog. This platform was selected for inclusion as findings from the systematic review and the online survey demonstrated that governmental organisations and health bodies are often trusted sources of online mental health information for young people. Figure 7.2 below shows some of the screens from the HSE.

# Figure 7.2 Section 1 of HSE Mental Health Website



# Figure 7.3 Section 2 of the HSE Website



**Website Directory.** A prototype was created to represent the design guidelines identified in Study 3 (Pretorius et al., 2020). Rough sketches were used to ideate and illustrate design ideas. The researcher then consulted with her supervisor and other collaborators on these sketches. These sketches were then amended and iterated

based on the feedback from collaborators. The digital version of the prototype was built using the website builder Wix and was hosted on a local server. To test the prototypes, the study setting was then simulated with volunteers from the Insight Centre for Data Analytics. These volunteers were asked to role-play study participants using the system. Difficulties were identified and then remedied before simulating with other volunteers.

The final version of the prototype offered four categories within which to make a selection for the type of mental health resource they were looking for. These categories included: 'Information'; 'Connect'; 'Relevant to Me'; and 'Something to do'. The choices represented in each category were informed by elements identified in previous studies as important as well as by what was available on the destination resources. As items were selected, relevant resources appeared below. All resources linked to Irish-based charities or mental health services. As such the destination resources provided by this website are similar to those provided by the HSE, but the way in which the resources are accessed are different. Instead of a structure based on clinical conditions the resources are structured based on elements identified in previous studies, namely information, opportunities to connect, personalisation and just-in-time support options. This approach emphasises a non-clinical approach to finding help-seeking resources. See Figure 7.4 below for the design and layout of the website directory.

# Figure 7.4 Directory Tool

# Looking for mental health help online?

There are many resources online and we know how tough it can be to find the right one. Use our directory to find what you're looking for.

> We have listed different types of online mental health resources that might be useful to you. Please select what you're looking for today, you do not have to make a selection from each category:



Chat Directory. Chat was highlighted by young people in Study 3 as a potential means through which find online mental health resources. The directory above was duplicated but in chat. A Wizard of Oz approach was used. Wizard of Oz simulations allow designers and researchers to investigate designs, content and developing technology with the intended users (Steinfeld et al., 2008). A Wizard of Oz approach uses a human to simulate an interaction with technology where normally that interaction would be facilitated by a technology (Dahlbäck et al., 1993). A member of the research team, Darragh McCashin (DM), acted as the 'wizard' and would respond to participants using a script. In order to prepare for the study, aspects of the Wizard's behaviour were agreed upon before the study commenced. This included: the wizard would not deviate from the script; the Wizard would respond as quickly as possible; the Wizard would only be revealed if participants asked directly about its nature; and the researcher who was with the participant would direct participants how to use the chat system. The Wizard was given the opportunity train by simulating the study setting with 2 different volunteers who roleplayed as study participants. This was done to standardize the experience across participants. Participants were offered the same four categories as above. Participants were prompted by the researcher to make one

selection each time. After their final selection they would be provided with a recommendation of two resources with links. A copy of the script is included in Appendix E | Chapter 7 Supplementary Material. Whilst participants were not told outright that they were interacting with another person, they were told this if they enquired.

#### 7.3.4 Data Collection Methods

**TENS-Interface.** Peters, Calvo & Ryan (2018) propose that through deliberate and considered design, designers can incorporate the three basic psychological needs of SDT through the functions, features and contents of technology. This should in turn positively influence wellbeing, motivation and user experience. In order to evaluate how well a technology enables these three basic psychological needs they have developed a number of psychometric measures, including the TENS-Interface (Peters et al., 2018). The TENS-Interface (Technology-based Experience of Need Satisfaction-Interface) measures the extent to which engagement with technologyinterface supports psychological need satisfaction. The measure requires respondents to rate their level of agreement using a 5-point Likert scale (1=Not Agree, 5=Strongly Agree). All items are weighted equally, and the measure includes some reversescored items. Scores can then be summed and compared for each psychological need. Research has reported satisfactory internal consistency (alphas of 0.67 (autonomy), 0.75 (relatedness) and 0.79 (competence)) and satisfactory validity (Peters et al., 2018). A basic stem phrase is provided that can be adapted to suit the purpose and task of the technology being investigated. The measure consisted of 14 items and can be found in Appendix E | Chapter 7 Supplementary Material.

Think-Aloud Method. This method asks users to speak their thoughts out loud whilst completing a task assigned by the researcher (Eccles & Arsal, 2017; L. van Gemert-Pijnen et al., 2018). The premise being that the thoughts reflected whilst performing the task are a valid reflection of a subset of thoughts associated with that task (Eccles & Arsal, 2017). The think-aloud method is often used in usability testing and is useful in finding recurring problems in a system (L. van Gemert-Pijnen et al., 2018). Burns in van Gemert-Pijnen et al. (2018) states that when a suitable scenario with the right participant cohort is used, five to eight participants will provide valuable insights, whilst 15 participants are likely to yield more stable results.

**Semi-Structured Interview.** The Semi-structured interview was conducted at the end of the session once the participants had used all of the platforms. Kip & van Gemert-Pijnen (2018) recommend an interview is done in conjunction with the thinkaloud method to gather further information about general impressions of using the prototypes. The topic guide (included in Appendix E) consisted of 10 questions which focused on participant's experiences of using the different platforms; how they could be improved and which platforms they preferred and why.

#### 7.3.5 Participants

The initial sampled was intended to be 24 participants, 12 females and 12 males. However, due to COVID-19 and the subsequent lockdown, the study had to be terminated before data collection was finalised. The final total number of participants was 12, six females and six males. All participants were university students and were recruited from the UCD community using posters and flyers. While it would have been preferable to have 24 participants, 12 participants still represent a suitable number for a study of this type. It reduces the potential for statistically significant findings in the TENS scores, but this was not the primary motivation for the study, and a large amount of qualitative data was also collected. The analysis and insights provided through this qualitative data collection was the primary focus of the study.

Pre-existing mental health difficulties were not considered as an exclusion condition for this study; however, it was emphasised that young people should be well and not currently experiencing any significant distress or active symptomology at the time of the study.

# 7.3.6 Data Analysis

**TENS-Interface.** Descriptive statistics were used to analyse the results from the TENS-Task.

Think-Aloud and Semi-Structured Interviews. Audio-recordings were transcribed verbatim and data was were entered into Nvivo 12. Data was then coded using Braun and Clarke's six phases of thematic analysis which is outlined in Table 7.1 below. Phase 1 began with the researcher (CP) reviewing the data and noting ideas for initial codes. Two additional researchers, Darragh McCashin (DM) and Dr David Coyle (DC) assisted with Phase 2 of the process. This process involved CP, DM and DC each coding three transcripts and comparing codes. A final codebook was

then agreed upon by all three researchers. CP recoded the entire dataset whilst, DM coded three different transcripts. CP and DM then completed a coding comparison for agreement. Codes were then organised into themes and then reviewed themes in relation to coded extracts by one researcher. Themes were then agreed upon by DM, DC and CP.

Table 7.1	Qualitative	Analysis	Process	using	Braun	and	Clarke's	Six	Phases	s of
Thematic	Analysis									

Phase	Description	Activity
1	Familiarising yourself with the data	CP goes through entire data set and notes preliminary codes
2	Generating initial codes	<ul> <li>i. CP codes the entire data set with initial codes</li> <li>ii. DC (3) + DM (3) code a portion of the data set</li> <li>iii. Compare codes and generate final code book</li> <li>iv. CP recodes entire data set</li> <li>v. DM recodes a portion (3) of the data set</li> <li>vi. Coding comparison, DC to resolve disagreements</li> </ul>
3	Searching for themes	CP + DC to organise codes according to themes
4	Reviewing themes	CP reviews themes in relation to coded extracts
5	Defining and naming themes	CP + DC + DM to finalise themes, agreeing on definitions and names for each
6	Producing report	CP write up study - select extracts for examples, relating analysis back to research question and other data from the study

# 7.4 Results

# 7.4.1 TENS-Interface Results

The TENS-Interface indicated that both the Directory Tool and Chat Tool performed well overall in terms of facilitating the three basic psychological needs, with the overall highest means scores of 54.42 and 53.25 respectively. A one-way ANOVA test revealed no significant differences between any of the platforms (p=0.05) see Table 7.4 below. No significant differences were found on the Competence, Autonomy and Relatedness Scales (p=0.05). The ANOVAS are reported in Tables 7.13 to Table 7.15 in Appendix E. A broad overview of the results per scale are presented in Table 7.2 below. As noted above the reduction in final numbers from 24 to 12 limited the potential for statistically significant results in the TENS analysis.

		Google	ReachOut	Directory	Chat	HSE
Competence	Mean	16.67	18.25	20.67	18.58	18.83
	Median	17	20.5	20	18.5	20.5
	Range	15	20	12	15	16
Autonomy	Mean	19.167	19.83	21.167	20.9167	21
	Median	20	20	22	21	20.5
	Range	8	10	12	11	8
Relatedness	Mean	9.67	11.5	12.583	13.75	10.083
	Median	8	11.5	12	15.5	10
	Range	13	14	12	11	12
Overall	Mean	45.5	49.58	54.4167	53.25	49.9167
	Median	47	50.5	55.5	53.5	53.5
	Range	26	35	24	31	29

Table 7.2 Results of the TENS-Interface According to Scale

Table 7.3 Mean and Std. Deviations of Overall Scores of the TENS-Interface

Platform	Ν	Mean	Std. Dev.	Std. Error
Google	12	45.5	8.4261	2.4324
ReachOut	12	49.5833	9.5295	2.7509
Directory	12	54.4167	7.077	2.0429
Chat	12	53.25	11.498	3.3192
HSE	12	49.9167	8.9388	2.5804

Table 7.4 Analysis of Variance Results for Overall Scores on the TENS-Interface

	Sum of	DF	Mean	F	Sig.
	Squares		Square		
Between	588.9367	4	157.2342	1.7362	0.1552
Groups					
Within	4664.0067	55	84.8001		
Groups					
Total:	5252.9434	59			

# 7.4.2 Feedback on Different Platforms

**Google.** All participants started with a Google search. Some entered specific statements related to situation the persona was experiencing like "exam stress" and "feeling overwhelmed." Other participants inserted questions to understand the symptoms the persona was experiencing "why am I finding it hard to sleep?" One

participant stated, "I would be a hypochondriac, I'd be Googling my symptoms." Some participants wanted to understand the causes behind the symptoms the persona was experiencing and how to address them, one participant stated "I guess the first thing I would do is look like how to sleep better. Or... what would I type in? Yes, not sleeping at night. Maybe the causes." Only one participant used Google to find a specific resource they already had in mind. This particular participant directly looked up UCD Counselling Services. After browsing their site and not finding what she was looking for, the participant then went to other known UCD support services, including student advisors and peer mentors. Some of the quotes detailing participant's search terms are outlined in Table 7.5 below. The search terms used by participants have been grouped into three categories as all the search terms used fell into one of these three categories.

Symptoms	"exam stress" – P001
	"I can't sleep" P012
Causes	Why are bad things happening to me?" P005
	"What causes stress?" P006
	"Can stress cause sleep deprivation" P006
	"What causes sleep deprivation" P010
	"Why am I stressed?" P011
Solutions	"ways to make myself happy" P005
	"how to make myself cheerful" P006
	"how to sleep better" P009
	"methods to alleviate pressure" P010

Table 7.5 Categories of Search Terms by Participants

Whilst many participants indicated that using Google would be the first tool they would use when using the Internet to understand their mental health concerns ("Yes, I think whenever anything I'm looking for, I just Google it.."-P002), they often expressed frustration with the results they were presented with ("Google was helpless"-P007). Frustrations centred around results that were irrelevant, ("you were typing into the search bar feeling pressured and it would bring back high blood pressure and whatever else, things that aren't really related, which was frustrating"-P010) or results that felt overwhelming. There was an assumption that they were never sure what kind of results they were going to get ("Yes, Google gave you lots of good stuff, but also lots of completely irrelevant stuff, or stuff that might look good and then you're not so sure. There's the weird PDF I got into."-P002).

Participants did appreciate the autonomy Google provided them in being able to access numerous sources at once (Yes, open up like 20 tabs and be quick to be like, no, this isn't it, this isn't it, just keep exiting out of tabs"-P002) but also being able to repeatedly and quickly, search different terms to understand the situation ("Google, I like the fact that I could go question after question. If I had a question from a previous article, I could resolve it immediately."-P006). The familiarity of Google offered them the immediacy and speed they were looking for when trying to understand the situation.

**ReachOut Australia 'Next Step' Tool.** There was some frustration with the Next Step tool. While the tool is featured on the website, it is optimized for mobile use and the navigation did not work as well on a laptop ("Yes, at least it has the little dots to click through. Okay, yes, I wish there was a better way of scrolling through all of those options."-P002). This frustration with use of the tool caused some participants to dislike the tool irrespective of the recommendations made ("I have to say, in the first one, still, was a mess. I don't think the problem is before on the filters, also how the information is displayed."-P011).

Respondents rated the way in which results were presented according to categories favourably ("It gives you different options based on what you've selected? There are forums, apps, chat, face-to-face, info. That's pretty good. It's given different options, whereas, the other one just gave a singular option"-P001) and appreciated being given a choice of different options ("as I mentioned before, they give you options in terms of just a good overview of different choices, so I don't need to actually consciously type it out"-P002).

Some participants appreciated the use of emoticons to rate the severity of their problem, whilst some respondents found it unhelpful and difficult to gauge (I think that's a bit ridiculous. That kind of trivialises how I'm feeling a bit.-P012).

**HSE.** For some of the participants the HSE provided results that they deemed too extreme or over-medicalised, "Here, it's saying for her to go to her GP, but she may not necessarily feel that it's bad enough to go to her GP yet. Yes, like talking about medication and behavioural therapy."-P001. Another respondent stated "the top bit wasn't great; it was a bit severe. The bottom bit was sure enough, there were all of the severe options, but the fact that anxiety was there and the fact that stress was there"-P007.

There was, however, an overarching sense of trust in the information and results provided by the HSE as the recognised national health service ("The HSE one, I think they're probably is very good information in there."-P001 and "but just seeing that all of this info is here and on a site that I trust is good to see"-P002).

Participants indicated that the site could be improved by offering more tailored results and information - "They didn't narrow down things at all. They just put it all up on the site" - P002. However, they were happy that all the information could be found on the HSE website with some searching and clicking through links – "everything together, a cure, remedy, understanding, chat because they gave me not only one link, multiple links to go through and to see which is relevant for me"-P006.

**Website Directory.** Participants suggested that the directory could be improved by adding filters that allowed them to indicate the issues they were currently struggling with, "I couldn't really specify what issues I was dealing with; I just could specify how I wanted to get content"-P002.

In general, participants valued being able to select resources according to what they were looking for and found the four categories meaningful, "I like this much better already. This is kind of what I thought it should be. First of all, you can pick what kind of information you want. I actually really like this."-P012.

This suggests that a balance is needed between providing support for concernbased search and the type of content/services help-seekers are looking for.

Participants showed an interest in selecting different items from different categories to see which different resources would come up and which ones came up repeatedly, "I'd just be clicking on these at random to see what popped up and see what kinds of things are out there."- P012.

**Chat Directory**. Similar to the Directory, participants indicated that the chat could be improved by allowing the option to indicate the issues they were concerned about.

However, they did find the chat more personal but without the same autonomy that the directory offered, "This one, the chat, it is good, but it needs to still be modified. Rather than giving these options, it can search for the keyword, what people are typing with. For example, if it's stressful or something, it would be specifying on the stress. It is the keyword"-P008. They felt that having an anonymous chat was important and made it less intimidating, "I think when it comes to asking my questions, or having that relatable talk, I think chat would be better"-P006.

Many participants enquired whether the chat was automated or being facilitated by 'a real person' and this distinction was important to them. Participants expressed less trust in a bot and stated that talking with a 'real' person was important when experiencing personal and emotional concerns.

# 7.4.3 Preferred Platform

The preferred resource differed for all respondents, but each participant had one or two preferred platforms. Some participants also expressed strong feelings of dislike towards some of the platforms. Table 7.6 below demonstrates some of the participants opinions regarding their preferred platforms.

Table 7.6 Quotes from Participants Indicating Their Platform Preference

Participant	Preferred Platform	Quote
P001	Chat Directory	"I would recommend the chat function one. Now, just because it was easy to use and it's that bit more personal. It was very tailored."
P002	HSE	"Probably the HSE. I think just having a source that you know it's well-vetted and trustworthy is kind of the most important part for me. I would probably just default there."
P003	ReachOut Next Step Tool	"Well, let me think, if I had to recommend one, I would recommend the Australian one, just because of the variety of choices and how straightforward the interface is."
P004	Chat Directory	"I think this one, last one. This one was the chat, right?Yes, this one, yes. I hope it's not a robot there, yes, but it always asks you the question. How much of the technology has grown, it's always better talking to a human person who has feeling when you talk to that person, it always directs you to it. I always go for these usually."
P005	HSE	"I would recommend this HSE"
P006	A combination of platforms	"Maybe a combination of the platforms would be a better option, like Google this one and the chat would be like I could go around asking, altogether, put together, maybe as an amazing experience, but only one platform will not be the answer."
P007	ReachOut Next Step Tool	"The blue one there."
P008	ReachOut Next Step Tool	Participant: "Yes, first, I would recommend this one." Interviewer: "The reach out one."
P010	Website Directory	"No, I think that last one ( <i>directory</i> ) was bang on what was needed, because it's just very straight to the point, has those options that you can select more than one and it puts out the information that could be useful to Joe very quickly. It's just very clean and simple and straightforward to use."
P011	Chat Directory	"Okay. I really liked the chat. It would have been great I think if this would have been, I imagine it is stuff that I have to click and write, I would have not done that. I like how the stuff was going on. Maybe it would have been great to do stuff as option."
P012	Website Directory	"Whereas, this second one ( <i>directory</i> ), I like because it's all in front of you and then it's up to you to whittle it down. It does give you information and you can pick what kind of information even you like. I would probably go for one of those,"

One participant felt that none of the platforms fully met his needs and would have preferred a combination or elements from all of the platforms.

"Maybe a combination of the platforms would be a better option, like Google this one and the chat would be like I could go around asking, altogether, put together, maybe as an amazing experience, but only one platform will not be the answer." – P006

#### 7.4.4 Needs in Online Help-Seeking Themes:

This section discusses overall themes that were identified during the thematic analysis process conducted using Braun and Clarke's methodology detailed above. These themes reflect participant's needs when seeking help online.

**Meaningful, Relevant Choices**. This theme indicated a need for platforms to offer participants meaningful and relevant options when using them to locate resources to meet their help-seeking needs. The platform should offer a choice of resources that offer different types of support (information, activities, connecting with someone), however there should not be too many options as this results in help-seekers feeling overwhelmed. Participants often indicated the results presented by Google often felt overwhelming and they would select one of the top results out of habit or default behaviour as opposed to its relevance.

Participants expressed frustration when the choices offered to them by the platform was not tailored to their needs or requirements, or in line with what they were looking for. Many indicated that tailoring should include elements that made results issue, age and type of resource specific.

Recommending relevant resources would include recommending resources already known to participants. Many participants often indicated when a resource/organisation/website, such as the NHS, was familiar to them and this inspired some level of trust. They would be more likely to click into these resources.

Table 7.7 outlines the codes that formed this theme, with some quotes from each code illustrating participant's needs.

Theme	Subcodes	Quotes
Meaningful, relevant choices	Having choice available	"I think it's actually really good because I like the way they give you all of these options, especially apps and stuff, that's what people do these days. If they're up to date on what people use, that's good." P009
		"I liked that it gave you quite a range of options even within each category of chat or phone or text. I thought that was really good because it could literally be a case of you not liking the layout or someone not being available in one of them. I thought actually that was good."-P012
	Relevance	"I think for me, yes, but not for other people because it's trying to cater to everyone. I'm going into it very understandably. Like, I don't have alcohol and drug problems, but I'll get to where I need to eventually." -P003
		"I don't want to know what stress is, I know what stress is. I want to know what a remedy is for stress. Like, when I typed what causes stress, I don't need the first thing to be, what is stress?"-P006
	Tailoring	"the chat seemed like it was just completely random whether I was going to get what I wanted or not, because I couldn't say what issue I was dealing with, I could just say how I wanted, like, what I wanted the content to look like"-P002
		"I think it can start with the age group, asking the age group because that will filter and narrow it down a lot. Then maybe ask what kinds of issues they're helping, so it could be multiple, like educational problems, work related problems, financial issues, issues with friends, relationship issues, things like that. I think starting with age will be better because it filters down, brings it down."-P004
	Overwhelming amount of choice	"Yes, I feel quite a bit overwhelming as well. There's a lot of stuff there to take in on the first go" -P001
		"Now, I don't think, sometimes even on the Australian one I think it was and even in Google, you're presented with too much information and it can feel very overwhelming,"-P010

Table 7.7 Sub-Codes and Quotes for the Theme of 'Meaningful, Relevant choices'

**Immediacy.** Participants indicated that when using a platform, they wanted to find the appropriate resources quickly. Google often met the need for immediacy in that it offered a number of options fairly instantaneously and could easily be reset, "Google, I like the fact that I could go question after question. If I had a question from a previous article, I could resolve it immediately."-P006.

This need for immediacy was also reflected in participant's frustration with having to follow numerous links in order to find the resource which was appropriate to their need, "I think I don't like the idea of a really long journey and I have to click one thing and then I have to click the next.....It was just that I don't like these long processes. I would just prefer to find something quickly."-P003.

Similarly, when looking for information, the format of the information had to provide the required information, quickly and clearly. Participants did not want to browse for long periods of time, to find the information relevant to their concern, "I have a lot going on and I don't have time to sit and browse through a website, because I might have a part-time work coming up or an assignment, which I have to do. I want quick answers. The same time to the point."-P006.

Chat was seen as having the capability to meet this need for immediacy, especially if that chat was with another 'live' person, "I felt like in the chat if you said that you needed support, you needed chat, so I think they would have had that immediately so that you could get the help you need."-P004.

Theme	Sub-codes	Quotes
Immediacy	Immediacy	"Google, I like the fact that I could go question after question. If I had a question from a previous article, I could resolve it immediately."-P006.
		"I think that people or Joe or in general maybe in these types of situations need to find help fast. Find what they need quickly or else they'll lose faith in the tech and they'll just end up staying in the place that they are."-P010

Table 7.8 Sub-Codes and Quotes for the Theme of 'Immediacy'

**Search Facilitates Insight**. A predominant code throughout all of the transcripts was 'Uncertainty about what the problem is.' Initially, many participants struggled to determine what the most appropriate search terms would be. Many indicated that the person portrayed in the persona might find it difficult to know what the problem and how to express their difficulty, "Yes, actually, quite difficult to really – I suppose putting it into words is quite difficult"-P010.

It's likely that online help-seeking helps young people to gain more clarity around the difficulties they're facing before taking next steps on their help-seeking journey, including talking to others, "I don't know, I'd want to get more info and figure things out for myself before I want to go chat to people"-P002.

A number of features were mentioned as ways to facilitate awareness of the problem, including personal stories, symptom checkers and chat. Some participants preferred personal stories and symptom checkers before speaking with someone, "I would like to be able to access information in that way to be able to maybe read someone else's stories, so that can better understand what's going on with me if I were to be Joe"-P003. Symptom checkers seemed to be preferable when the participant found it difficult to verbalise what the persona was experiencing, "The answers are there, aren't they? The questions are there. Chances are, it might be multiple choice, like you can engage a bit easier, do you know that kind of way?"-P007.

Theme	Sub-codes	Quotes
Search Facilitates Insight	Uncertainty about what the problem is.	"At least even we'll get a clarity when they ask you, is it that, is it this? When someone asks you point to point, you'll be like, you can think, is that affecting you? I think that narrows it down to a point. Self-reflection, as well" – P004
		"If you didn't really understand how you're feeling, it might be hard to choose which one."-P009

Table 7.9 Sub-Codes and Quotes for the Theme of 'Search facilitates insight'

Matching Current Level of Need of the Help-Seeker. This theme describes the extent to which a resource matched the level of need of the help-seeker and whether it was too superficial or too extreme. It also describes the degree to which the resource matched the needs of the stage of help-seeking the participant was currently at.

Throughout all of the sessions, many participants indicated discomfort with 'extreme' results they were presented with, especially when using Google. These extreme results often also resulted in participants questioning whether the persona might be experiencing a mental illness. Simultaneously, it also resulted in a lot of frustration, "They just know there's something up and then they go on and they're looking, depression, depression, you're like, okay, maybe I'm ill. You're not, you're just feeling a bit down or something. That kind of way"-P007.
In trying to cater for as many readers as possible, many resources provided generic information. This generic information was often found across numerous resources and was at times described as 'repetitive'. The result was often participants felt that resources and the information they provided weren't suited to their needs or to their stage of the help-seeking journey.

Some participants expressed frustration when a resource would force them down a certain path, essentially forcing them to the next stage of their help-seeking journey, before they felt they were ready. One participant described this experience as "controlling" and feeling "forced."

Theme	Sub-codes	Quotes	
Matching Current Level of Need of the Help-Seeker	Trade-off between general and specific	"so I think some of the platforms that just broad info right away and then platforms that got into specific tips were good."-P002	
		"They're more for giving a general remedy. Like, just breathe and go out, take fresh air. It's like they don't have a particular person or a personalised touch."-P005	
	Directive and non- directive	"The first thing they tried to send me to was their forums. If that was the first place I landed and it tried to send me to a forum to discuss my issues before I even had a good idea of what was going on, or if what I was dealing with was something everyone else is dealing with. It seemed like the wrong first step."-P002	
		"I think it was just that you're put down a very specific – you're put down in a very specific journey, where you have to go one link to the other. Then another one. Then you get to three which meant that I felt forced to have to go through a really long process, rather than just get to what I need, in terms of just an article maybe would have been helpful."-P003	
	Extreme results	"I feel like if I searched a feeling overwhelmed and saw depression there, I'd actually get a fright."-P009 "you see one about mental health issues, but Joe	
		probably mightn't see themselves as having mental health issues. Like, in general, they seem quite okay with just down periods and responses that you might expect to stress and stuff. I don't know if I would see myself as having a mental health issue."-P012	

Table 7.10 Sub-Codes and Quotes for the Theme of 'Matching Current Level of Need of the Help-Seeker

The Need to Connect with Someone Occurs on a Continuum. Participants expressed different needs in terms of connecting with someone online. Some participants did not want any contact online and wanted to find resources anonymously. Other participants expressed that connecting with someone online might be helpful if that person could direct them to useful and relevant resources. Some participants expressed wanting to connect with a mental health professional both online and offline to assist with the difficulty the persona was facing.

Theme	Sub-codes	Quotes
The Need to	Preference for in-	"I think for her face-to-face might be good here
Connect with	person	because from what she's suffering and her age, I
Someone		think she should talk it out with someone face-to-
Happens on a		face and be comfortable with whatever it is."-
Continuum		P004
		"I'm the kind of person that I would rather talk to someone straight away and someone that I knew as qualified for sure. Yes, if it was me, I know I would probably go for in-person counselling or look up someone in my institution, like I like practical help"-P012
	Preference for a professional	"I know there are psychologists too to call, so if I need some help immediately, then I'll go to this one."-P006
		"Then it's just trained mental health professionals, that sounds good. Then this one, offer support, these are trained counsellors, so they might just be a little bit more laid back. It might be just a bit easier to talk to kind of job."-P007
	Direct contact with	"I'm not a person who shares it with anyone. I'd
	another person online	keep it to myself. For me, the only remedy is the online, whatever I get online" -P005
		"Yes, that's better. I think that's better. It's a bit more there's talking to someone. It's more what is it? Proactive, that kind of way." -P007

Table 7.11 Sub-Codes and Quotes for the Theme 'The Need to Connect with Someone Happens on a Continuum'

**Good, Clear Design.** Whilst not surprising, the design of platforms and the subsequent resources to which they referred were often commented on by participants. Poor design and usability were often the source of frustration and would

negatively influence the participant's perceptions of the platform and/resource. Overall, participants favoured a 'less is more' approach, in terms of the presentation of information. They preferred content laid out in bullet points instead of lengthy paragraphs. Similarly, when platforms were not intuitive to navigate to the participant, this caused frustration and created a negative perception of the platform.

Theme	Sub-codes	Quotes
Good, Clean Design	Ease of use	"Yes, it seems like each different thing that I'm dealing with is on this site and pretty easy to get to." -P002
		"This site is very user-friendly because everything is right in front of my face. I like this site."-P006
	Design	"Yes, a bit awkward to use at the start. I never did know how to use that, but apart from that, it seems good." -P001
		"Yes, I like all of them. The only thing I don't like about it is the actual layout of the website. Like, it's too wordy."-P009

Table 7.12 Sub-Codes and Quotes for the Theme 'Good, Clean Design'

# 7.5 Discussion

This study investigated whether help-seeking tools that embody the design factors identified in Chapter 6 support effective help-seeking and how help-seeking tools that embody these factors compare to other help-seeking technologies. This section discusses considerations for future iterations of the design of both the directory and the chat tool. The design recommendations previously identified in Chapter 6 are then re-examined in the context of the findings of this study.

# 7.5.1 Future Iterations of the Directory and the Chat Tool

Both the Directory and Chat tool compared comparatively well to the other platforms in terms of facilitating the help-seeking process. Both platforms also compared comparatively well on the TENS-Interface, indicating that they facilitated the basic psychological needs to a similar extent as the other platforms.

Both the Directory and the Chat Tool recommended resources based on the type of content the participant was looking for, with four categories to choose from: information, connect, relevant to me and something to do. These categories were informed by the design guidelines outlined in Chapter 6. However, it was difficult to

find online mental health resources for all the choices within a category and only a few online resources could match numerous choices and/or categories. The categories and choices that are presented in an online help-seeking technology are only meaningful if there are online mental health resources to refer to. The lack of online mental health resources that meet young people's needs in terms of these categories will limit the help-seeker's autonomy which in turn will affect the autonomy the tool can provide. This also highlights the need for online mental health resources to be carefully examined and redesigned to ensure that they are meeting the needs of young people who are engaging in online help-seeking.

The directory tool received a high score on the autonomy scale of the TENS-Interface. This can be attributed to participant's ability to control the resources that would appear in relation to the choices they selected. However, the relevance of the results offered to help-seekers can be improved by including an 'issues' section in addition to the four categories. Incorporating a similar structure to that found in 'Section 2 on the HSE's website as additional filters would likely positively contribute to improved relevance of the options shown.

A key critique of the chat platform was the lack of autonomy it offered participants in stating what they were looking for and the issues they were looking for more information on. Participants indicated that being able to insert free text would meet their needs for autonomy more appropriately. Participants valued the potential for relatedness the chat platform offered, however communicating with a 'real' person over a chatbot was preferred. The potential role of chat in mental health prevention and treatment interventions needs to be considered in order to make mental health services more accessible. A recent systematic review indicated that synchronous chat interventions compared favourably with wait-list or treatment-as-usual conditions and were often preferred over telephone interactions by participants (Hoermann et al., 2017). A study by Nagshbandi et al. (2016) investigated the use of a peer-supported chat system for early help-seekers and found that this approach was appropriate in supporting help-seeker's autonomy and allowed peer moderators to develop a sense of competence. Other research has also indicated positive results when utilising peer support technologies in supporting young people's mental health (O'Leary et al., 2018).

This does however pose a problem for the feasibility of the future of such a tool as an online help-seeking platform, in terms of the cost and resources needed. A potential solution to this could be the use of artificial intelligence which could detect the use of specific terms, to identify the issue and type of content relevant to the helpseeker. When comparing the search terms used in Google by participants, it appears help-seekers often search for three clusters of terms, including causes of symptoms, what do clusters of symptoms mean (diagnosis) and how to address or alleviate symptoms. The use of different search terms by participants indicate different needs amongst help-seekers and a platform using artificial intelligence would need to take this into consideration. Whilst, many new mental health applications are starting to make use of artificial intelligence, chatbots and conversational agents, including therapeutic interventions such Woebot and Koko (Morris et al., 2018), none have explored the use of these technologies with regard to help-seeking. However, they must be considered as some AI and chatbots interventions have reported to contribute towards positive clinical outcomes. A recent study indicated that participants who interacted with a chatbot who encouraged self-disclosure were more likely to later report increased self-disclosing behaviour when meeting with a mental health professional (Lee et al., 2020). Studies investigating the effectiveness of using fully automated conversational agents to address mental health concerns have reported improved psychological wellbeing and decreased depressive symptoms (Ausman, 2019; Fitzpatrick et al., 2017; Ly et al., 2017). However, other studies indicate that users still rate chatbots less favourably than a peer (Morris et al., 2018), similar to the results reported in this study.

# 7.5.2 Design Recommendations

The co-design study outlined in Chapter 6 identified 4 key design recommendations: provide opportunities for connectedness; provide credible and accessible information; provide personalisation, but also respect anonymity; and, finally provide "just-in-time" support options. This study identified additional needs that should be considered in the design of help-seeking technologies, some of which support and expand on the existing recommendations whilst others can be classified as additional recommendations.

**Provide Opportunities for Connectedness.** "The Need to Connect with Someone occurs on a continuum" theme emphasized that connectedness online will take different forms for different help-seekers. Connectedness for some help-seekers will happen through reading personal stories whilst completely avoiding interpersonal interaction both online and offline. The inclusion of an online guide or moderator into a help-seeking technology could play a significant role in facilitating help-seeking for some help-seekers. Research has shown that including human interactions in the design of online mental health services play an important role in users engagement and treatments outcomes (Lederman et al., 2014; Mohr et al., 2011; Schueller et al., 2017; Yardley et al., 2016). Our findings suggest that preference for peer or professional vary from help-seeker to help-seeker and is likely dependant on the severity of the mental health concern faced and at which stage of the help-seeking journey the help-seeker finds themselves. However, a study by Hartzler and Pratt (2011) suggests that service users valued both the support from peers and professionals, throughout the treatment seeking process.

The role of online communities has been found to play an important role in patient's acceptance and understanding of their conditions. Individuals use the experiences of others with a similar condition to make sense of their own health difficulties (Johansen et al., 2012; Ziebland & Wyke, 2012). Providing for different types of connection online could play an important role in facilitating help-seekers insight into their difficulty and facilitating their help-seeking to the next stage.

Provide Credible and Accessible Information. Search plays an important role in facilitating online help-seeker's mental health literacy. It facilitates awareness of the personal or emotional concern they're facing. Information and content that is presented in an accessible manner can facilitate a help-seeker's competence to navigate the help-seeking process. Resources providing information and services online need to encourage trust. Research has found that ease of use, content and interactive features play an important role in encouraging trust in online health resources (Sbaffi & Rowley, 2017). Online help-seeking technologies can play an important role in referring to trusted resources where normally the help-seeker might not be sure how to locate these. An important consideration when compiling these resources is to be wary of when to recommend resources that are overly medicalized, as these can adversely affect the help-seeking process. Many participants in this study simply scrolled past resources they deemed too 'extreme' or diagnostic for their needs irrespective of whether these resources had relevant or useful content.

**Provide Personalisation, but also Respect Anonymity**. The findings from this study reaffirmed young people's frustration when having difficulty in accessing relevant and meaningful content. It is clear that help-seeker's autonomy is facilitated

when they have a range of meaningful choices of resources available to them but in turn their autonomy can be frustrated when there are too many choices, or the choices offered are not relevant or do not match their level of need. SDT proposes that when autonomy is facilitated through offering opportunities for meaningful choice, intrinsic motivation is facilitated (Ryan & Deci, 2006). Help-seeking technologies that aim to recommend mental health resources to young people do not need to aim to duplicate Google but rather should aim to offer curated and vetted recommendations which are more likely to facilitate the help-seeking process.

**Provide 'Just-in-time' Support Options.** A recurring theme from previous studies, immediacy was again highlighted as an important requirement to online help-seekers. In this study, it was characterised by finding information relevant to their query very quickly. This applied not only to how quickly a platform could provide results but how quickly relevant content/activities could be found within a resource. This highlights that resources not only have to provide activities that could be done in the moment to relieve distress but should also include information and support options that can be found easily and quickly relative to the help-seeker's needs. The findings from the systematic review reported in this thesis found that the immediacy offered by the Internet is one key benefit it offers young people in their help-seeking journey.

**Provide Clear, Professional Design.** Whilst this is not a novel or unexpected finding, it's importance cannot be underestimated. Poor design of any online tool will negatively influence its use, despite whether it makes meaningful and appropriate resource recommendations. Peters, Calvo & Ryan (2018) propose that it is helpful to think about four different spheres of experience when interacting with a technology at which need satisfaction can either be met or frustrated. The first of these spheres is how the person interacts with the technology through its interface. If the interface is poorly designed, it will ultimately impact need satisfaction within the other spheres.

# 7.6 Limitations

This study initially intended to test the platforms with 24 participants. This would have provided a larger data set, which would have provided more robust descriptive statistics. Future work could investigate future iterations of both these prototypes with a larger sample of young people.

This work demonstrates insights from low-fidelity prototypes which allowed the operationalisation of the design recommendations. However, these prototypes were used in comparison to establish, professionally designed platforms. This may have skewed participant's impressions and opinion of these platforms. However, when analysing both the quantitative and qualitative data, these platforms appeared to have performed comparably to the others.

# 7.7 Conclusions

This chapter detailed a user study using two prototypes to operationalise and evaluate the design guidelines proposed in Chapter 6. The findings from this study indicated that a help-seeking technology should facilitate a help-seeker's autonomy by offering options to filter results by preference of content required as well as according to the difficulty being faced. It also highlighted a non-medicalised approach is preferred by most participants. In order to meet help-seeker's needs, help-seeking technologies and online mental health resources need to collaborate in order to provide positive online help-seeking experiences and facilitate their needs for autonomy, relatedness and competence.

# **Chapter 8:** Discussion, Limitations and Future Work

# 8.1 Introduction

This concluding chapter discusses the theoretical and empirical contributions of this PhD thesis. The application of Rickwood's Help-Seeking Model and Self-Determination Theory are discussed, with a conceptualisation provided of how these theories can be used to understand the online help-seeking for young people. Following from this, design recommendations for both help-seeking technologies and online mental health resources are presented. Finally, the limitations and suggestions for future work are outlined.

# 8.2 Applying Theory to Understand Young People's Online Help-seeking

In Chapter 2, Rickwood's Help-seeking Model and Self-Determination Theory were proposed as possible theories through which to understand the online help-seeking behaviours of young people. These theories were applied throughout the studies included in this thesis and were found to be useful theories through which to conceptualise online help-seeking.

# 8.2.1 Extending Rickwood's Help-Seeking Model

Rickwood et al. (2005) proposed a four-step process model through which to understand the help-seeking of young people. The model represents the personal process a young person undergoes as they work to address their personal or emotional concern. This process includes four stages: awareness, expression, availability and willingness. A key feature of this model is that the young person is moved from dealing with the concern in an intrapersonal domain to an interpersonal domain.

The studies in this thesis have found this model a useful lens through which to understand online help-seeking, however the process may not be as linear in an online context as it is offline. For young people the initial awareness stage still takes place intrapersonally. The help-seeking process then moves online at the expression stage. This stage requires the young person to take an active step by going online to learn more about the personal or emotional concern they're currently experiencing. For many young people, this involves making use of a search engine such as Google to run a keyword search. Depending on their level of insight and mental health literacy, this search may start quite broad and be very explorative. The search results inform the availability stage.

The availability stage can to some degree be facilitated by carefully considered design. If the resources that are presented are relevant and appropriate to the young person's level of need, they are then more likely to move towards the willingness stage and investigate the results offered to them. Design and technology are still limited here by the availability of resources that meet the young person's preferences. As highlighted in Study 4, whilst young people might prefer certain types of content or means in which to view content, these options do not always exist.

The willingness stage can also be facilitated through design and the application of the design guidelines outlined in this thesis. If an online resource is able to meet the young person's help-seeking needs, young people are more likely to find that resource engaging which will in turn increase their willingness to persist in finding the help they need.

An important opportunity for collaboration exists between research and practice at this junction. Designers and researchers need to work together with health services, charities and mental health service providers in order to ensure that the help-seeking needs of young people can be met.

As young people progress through these steps, and if the help-seeking technology is well designed, it is likely that their mental health literacy and insight into their concern will be improved. This in turn will prompt further awareness of the problem and its symptoms, which would restart the help-seeking process.

A key difference in the online context, is that the young person may never move to an interpersonal domain when addressing their personal or emotional concern. The studies in this thesis have found that the need to connect with someone when helpseeking takes place on a continuum, ranging from no or very little interpersonal interaction to online or offline, in-person help-seeking. Examples include scanning information pages independently (little or no interpersonal interaction) to engaging with others through discussion boards to making appointments to see health professionals in an offline setting (increased interpersonal interaction).

The preference for self-reliance young people have when facing a personal or emotional concern has been found in numerous studies (Radez et al., 2020; Rickwood et al., 2005; Salaheddin & Mason, 2016). The online context offers the opportunity to provide young people with the skills and self-help tools they need if this is their preference. Among the three help-seeking types identified in Study 2, the information-seeker highlighted that some young people prefer an anonymous, independent online experience, where they can peruse resources in their own time without the interference from others. These resources can include information pages but also activities that could assist in relieving distress in the moment or other self-help techniques that assist with emotional regulation.

# 8.2.2 Self-Determination Theory

Self-Determination Theory is a macro theory of motivation and wellbeing consisting of a number of sub-theories. One of these sub-theories, Basic Psychological Needs Theory, proposes that each human being has three basic psychological needs: competence, relatedness and autonomy; and when these needs are satisfied, individuals are moved towards wellbeing and sustained motivation (Deci & Ryan, 2008). This theory states that when these needs are met, individuals are more likely to be motivated to pursue their goals (Ryan & Deci, 2000). SDT has successfully been applied to development of various technologies and designing to satisfy these needs can be linked to improved engagement and sustained motivation towards goals (Peters et al., 2018). This is an important consideration when designing to promote and encourage continued help-seeking. Technologies that aim to promote and support help-seeking, need to be designed in order to facilitate these needs instead of frustrating them. The online mental health resources to which help-seeking technologies refer, also need to be designed to meet these needs.

The guidelines provided in Chapter 7 provide concrete recommendations for the design of help-seeking technologies that can meet these three basic needs. A technology that is designed well and is easy to use, will facilitate the help-seeker's need for competence. The manner in which mental health information is presented will also impact upon help-seeker's sense of competence. Information that is overly medicalised or presented in an academic format is unlikely to meet the average helpseeker's need for competence or positively contribute to their mental health literacy. Participants in Study 3 and 4, indicated that textual information should include bullet points and long blocks of text should be avoided. Alternative formats of presenting mental health information should be considered: using videos, podcasts and other media formats young people regularly engage with.

The technology needs to offer choices in terms of content, opportunities to connect and activities to relieve distress, in order to produce search results that are meaningful and relevant. This will meet the help-seeker's need for autonomy. Help-seekers often expressed frustration when presented with an abundance of search results that did not seem to be relevant to them. Similarly, their autonomy would be frustrated if the technology did not present enough resources to choose from.

Including content with personal stories or resources that provide the opportunity to connect, create the opportunity to meet help-seeker's need for relatedness. As mentioned previously, the need for interpersonal interaction takes place on a continuum, with some help-seeker's requiring more interpersonal interaction than others. For those requiring more interpersonal interaction, the need for relatedness can be met through online chat, discussion forums or email. For help-seekers who require less interpersonal interaction, their need for relatedness can be met through elements such as personal stories presented in videos, blogs or interviews.

However, certain design choices may simultaneously meet and frustrate a need. For example, anonymity has been highlighted by participants as an important requirement in facilitating their autonomy. However, anonymity can potentially limit the degree to which results and content suggested is personally relevant. Certain demographic details, such as age or location, are needed from online help-seekers in order to provide tailored resource recommendations. When a technology is unable to provide tailored resource recommendations, help-seeker's need to for autonomy will be frustrated.

8.2.3 A Conceptual Model to Understand Online Help-seeking for Mental Health in Young People

Online help-seeking plays an important role in facilitating young people's insight into the personal or emotional concern they're experiencing. The act of search and finding different mental health resources are key actions in their sense-making process.

Two different search behaviours have been identified in health informationseekers, namely exploratory and focused search (Pang, Chang, Verspoor, & Pearce, 2016; Pang et al., 2015; Pang, Chang, Pearce, & Verspoor, 2014). In exploratory search, health seekers prefer to read as much information around the health issue as possible as they are unfamiliar with the domain. They often have an unclear search goal and therefore have a far wider search scope which may result in irrelevant results. Focused health searchers on the other hand concentrate on a smaller range of information. These help-seekers have a better understanding of the health condition they're investigating and have specific search goals in mind. However, for these health-seekers, their search might be frustrated when they do not use the correct terminology or cannot express their concern correctly. Both search strategies are dependent on health literacy (Pang et al., 2014).

The results of this thesis provides evidence that young people engaging in online help-seeking can successfully progress through Rickwood's help-seeking stages, if their basic psychological needs, as outlined by SDT, are met at each stage by the design of the technology and the online resources. If this is achieved, it is proposed that the help-seeker's insight into their difficulty is improved as is their mental health literacy. Help-seekers are likely to first engage in exploratory search and then move towards a more focused search as they gain insight into their difficulty. Figure 8.1 below illustrates the online help-seeking process as interpreted through the lenses of Rickwood's help-seeking model and SDT simultaneously

Figure 8.1 The Online Help-Seeking Process Interpreted Using Rickwood's Help-Seeking Model and



# 8.3 Design Recommendation for Help-Seeking Technologies and Online Resources

Building on the results of Studies 1 and 2 and based on the empirical findings from Studies 3 and 4, the following design recommendations are provided to support the design of online help-seeking technologies and online mental health resources. Online mental health resources, often in the form of mental health services such as ReachOut, the HSE, SpunOut, will be the referral targets of a help-seeking technology. Whilst the help-seeking technology can offer meaningful choices to the help-seeker to tailor their search results, these choices are only possible if resources for each of these choices exist. This requires the careful evaluation of existing online resources to determine to which extent they meet help-seeker's needs in terms of the following 5 design recommendations. An opportunity exists between research and practice to inform the design of online mental health resources for young people. Table 8.1 below outlines how these design guidelines can be applied to both online help-seeking technologies and online mental health resources.

Design Guideline	Applied to Help-Seeking	Applied to Online Mental
	Technologies	Health Resources
Provide Opportunities for Connectedness	<ul> <li>Provide opportunities to connect with an 'online guide' to find relevant online resources</li> <li>Provide referrals to online resources that offer a variety of ways to connect</li> </ul>	<ul> <li>Opportunities to connect through personal stories, forums, online chat with peers and professionals</li> </ul>
Provide Credible and Accessible Information	<ul> <li>Provide curated referrals that are endorsed by research, a health service or professional body</li> <li>Make it clear that resources have been vetted and what criteria was used</li> </ul>	<ul> <li>Information presented in videos, podcasts, infographics and narrative formats</li> <li>Provide references where appropriate</li> <li>Make clear government, health service or statutory body's endorsement</li> </ul>
Provide Personalisation, but also Respect Anonymity	<ul> <li>Provide ability to tailor results according to issue, location, age, and type of content and support required</li> <li>Make use of symptom checker or quiz feature to assist in identifying concern</li> </ul>	<ul> <li>Provide infrastructure that makes content and resources easy to find i.e. link to relevant pages on resource from within a current page</li> <li>Include a 'search bar' on the resource</li> <li>Provide tools to find relevant content</li> </ul>
Provide Just-in-time Support Options	<ul> <li>Link to relevant pages/content/Activities on target MH resources</li> <li>Link to crisis support services, with 24 hours availability</li> <li>Provide referrals that can offer activities and strategies that can relieve distress in the moment</li> </ul>	<ul> <li>Provide activities and strategies that relieve distress in the moment</li> <li>Provide activities, strategies and resources that provide long term solutions</li> <li>Provide links to local resources that are easily accessible</li> <li>Provide resources/links to connect with a trained peer or professional in times of crisis, especially after hours</li> </ul>
Clear, Professional Design	-Easy to navigate -Ensure navigation is intuitive	<ul><li>Easy to navigate</li><li>Bullet points</li></ul>

Table 8.1 Recommendations for the Design of Help-Seeking Technologies andOnline Mental Health Resources

8.4 The Use of Personas in Investigating Online Help-Seeking with Young People

Personas are widely used to help design teams gain insight into their users. They allow designers to document and represent a wide variety of potential users of a technology (Nielsen, 2013a). Personas were used in both Study 3 and 4 in order to gain young people's insights into online help-seeking but also in order to provide an unthreatening manner for them to do so.

Study 2 indicated that different help-seekers have different needs from online resources in different scenarios, and this affects which online resources may be relevant to them. Mental health help-seekers do not follow one type of help-seeking. Instead, they may change between types based on the urgency of the issue affecting them, personal preferences and prior help-seeking experiences. There cannot be a one-size-fits-all approach. To investigate these different types of help-seekers further and to elicit their design needs, personas were created to represent these help-seekers. These personas were presented to young people in Study 3 and were used as prompts in order to design their ideal online mental health resources. In Study 4, a persona was used to help guide participant's online help-seeking and evaluation of different help-seeking platforms. This persona was also empirically derived, using data from the previous three studies.

In both studies, the use of personas allowed participants to share their insights into the sensitive topic of mental health. A similar tool, called vignettes, is often used in social science research and has been found to be a useful medium through which to explore issues that participants might find difficult discussing (Hughes & Huby, 2004; Kandemir & Budd, 2018). Personas were used in a similar manner in this thesis. Similarly, to vignettes, personas were empirically developed using findings from previous studies in the research project. Participants were able to project their thoughts, opinions and design needs onto the persona without being made to feel vulnerable or that they were revealing too much about their own mental health status. This method was also helpful in allowing participants to share their insights in a group context in Study 3. It also provides participants with the ability to share their views on a topic they might not think they had personal experience with.

Whilst the use of personas and vignette like methods are common in HCI research (Andalibi & Forte, 2018), the use of personas in this way for mental health research in HCI research provides an opportunity to explore sensitive topics with target

groups, including young men, who may be hesitant to discuss topics related to mental health or who may not be aware that they have relevant experiences with regard to mental health.

#### 8.5 Limitations and Future Work

#### 8.5.1 Limitations

Whilst Study 3 and 4 were equally representative of males and females; females were over-represented in the studies included in the systematic literature review and in the online survey in Chapter 5. In order to deliver effective mental health services to this group, new and innovative strategies are required to recruit and engage with young men on topics of mental health. Whist, previous research suggests that there are gender differences for certain mental health disorders, these conclusions are based on the assumptions that the samples investigated were representative of the broader population (Ellis et al., 2014). Young men are underrepresented in their accessing of mental health services, their involvement in clinical trials and in providing feedback on the design of mental health services (Ellis et al., 2014). There is much speculation about the reasons why men don't participate in mental health research including mental health stigma, fears about confidentiality, inconvenience, and lack of financial reward (Rickwood et al., 2005). Ellis et al. (2014) suggest that elements such as study design, the presentation of promotional materials and participant reimbursement also influence young men's willingness to participate in research. It has been suggested that using the Internet to recruit young men might be the solution to some of the recruitment difficulties faced. However, the experiences of recruitment in this research has found using known networks, such as those in the Jigsaw Youth Mental Health Services and in schools, were most successful in recruiting representative samples. Future research should consider using recruitment strategies that collaborate with networks and groups to which young men already belong, these could include sports clubs and other extra mural groups.

Whilst recruitment through Jigsaw in Study 3, yielded a more representative sample both the survey and the user study, were over representative of those young people who attended third level institutions and were users of social media. The experience of recruitment throughout all of the studies has highlighted the need for a strong youth participatory approach throughout the research process. Although it is time and labour intensive, young people, representative of the population, should be included at every stage of research, including in the design of studies, promotional materials as well as in the analysis and write up of these studies. This would not only work towards ensuring that research is more representative of the general population but would simultaneously involve young people in research that impacts upon their experiences of mental health and mental health technologies.

# 8.5.2 Future Work

**Continued Application of the CeHRes Roadmap**. Whilst it was beyond the scope of this thesis, the next steps according the CeHRes Roadmap would include more iterations of the directory and the chat tool, together with other novel prototypes, with further tests with users until an approved version was created. The next phase, which is the operationalization phase, includes the launch and marketing of the technology. A help-seeking technology would be best placed on a website or resource already commonly used by young people. It would be beneficial to consider partnering with the health service, educational institutions or other bodies that are already known to young people. This would encourage trust but also improve potential reach in the amount of young people assisted by the technology.

The final phase, summative evaluation, aims to explore how the technology is being used now that it has been implemented and what are its effects on users and stakeholders. The objective of the evaluation for a help-seeking technology would have to determine how well the technology facilitated the user towards their helpseeking goal; recognising that for some help-seekers, the goal is not to seek formal or in-person help. The ReachOut Next Step discussed in this thesis, used a randomized control trial to evaluate the effectiveness of the tool versus alternative help-seeking strategies. To determine the effectiveness of the tool, scores on scales measuring both positive and negative affect; quality of life, and barriers to help-seeking were compared. No qualitative data was collected. Help-seeking technologies such as the ReachOut Next Step Tool and the help-seeking directory presented in Chapter 7, could be evaluated using a mixed-methods approach, combining both psychometric scales and qualitative questions to determine the extent to which these tools facilitate help-seekers towards their goals and have an effect on their mental wellbeing.

**Collaboration for Effective Help-Seeking Technologies**. The findings from this thesis suggest that in order for a help-seeking technology to have real-world

impact, a collaboration between researchers, designers and service providers is necessary. Chapter 2 of this thesis highlighted the importance of context in terms of a young person's mental health. Equally context needs to be considered when designing to improve help-seeking experiences. A young person's online help-seeking journey includes many stakeholders which includes designers, content creators, peers, mental health experts, mental health service providers. Help-seeking technologies need to take into consideration the context of young people and the roles of various stakeholders. Future work needs to concentrate on fostering collaboration between various stakeholders in order to meet the needs of young people in their help-seeking journey.

# 8.6 Closing Remarks

Young people's mental health is of key concern at a global level. Whilst previous research and interventions have focused on the treatment of mental health difficulties, investigation into help-seeking technologies requires further attention. Research has shown that help-seeking plays an important role in improved health outcomes and future help-seeking intentions. Technology can play a significant role in addressing some of the traditional barriers to help-seeking, whilst also meeting young people's help-seeking needs in a manner that cannot be done offline. The ways in which technology can meet the help-seeking needs of young people, is an area of research that requires further exploration and investigation. This thesis has utilised two theories in order to understand online help-seeking behaviours and how these theories can be applied to meet the design needs of young people.

Another key contribution of this thesis includes design recommendations that can be implemented by help-seeking technologies and online mental health resources in order to better meet the help-seeking needs of young people.

This thesis has provided a foundation from which online help-seeking can investigated but also provides practical guidelines to inform the design of online mental health resources.

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# Appendices

## Appendix A | Chapter 2 Supplementary Material

A.1 The International Declaration on Youth Mental Health 10 Year Targets

1. Suicide rates for young people aged 12–25 years will have reduced by a minimum of 50% over the next ten years. This minimum target means that we do not accept that the death of any young person by suicide is inevitable.

2. Every young person will be educated in ways to stay mentally healthy, will be able to recognise signs of mental health difficulties and will know how to access mental health support if they need it

3. Youth mental health training will be a standard curriculum component of all health, youth and social care training programmes

4. All primary care services will use youth mental health assessment and intervention protocols

5. All young people and their families or carers will be able to access specialist mental health assessment and intervention in youth-friendly locations

6. Specialist assessment and intervention will be immediately accessible to every young person who urgently needs them

7. All young people aged 12–25 years who require specialist intervention will experience continuity of care as they move through the phases of adolescence and emerging adulthood. Transitions from one service to another will always involve a formal face-to-face transfer of care meeting involving the young person, his or her family/carers and each service involved in his or her care.

8. Two years after accessing specialist mental health support, 90% of young people will report being engaged in meaningful educational, vocational or social activity

9. Every newly developed specialist youth mental health service will demonstrate evidence of youth participation in the process of planning and developing those services

10. A minimum of 80% of young people will report satisfaction with their experience of mental health service provision

11. A minimum of 80% of families will report satisfaction that they felt respected and included as partners in care

# Appendix B | Chapter 4 Supplementary Material

## **B.1 Search Strings**

## **PsychINFO**

1. "Help seek\*" OR "Seek\* help" OR "Seek\* treat\*"

AND

2. "Web-base\*" OR Online OR e-health

### AND

3. Mental OR Depress\* OR Anxiety

### MySearch:

su(help seek\* OR seek\* help OR help seeking behaviour OR Health care seeking behaviour OR self-referral OR self help techniques) AND su(web-base\* OR online OR e-health OR Computer Applications OR mobile devices OR Internet OR Information Technology) AND su(mental health OR Mental Disorder OR Mental OR Depress\* OR Anxiety)

## PUBmed

1. Diagnostic Self Evaluation\* OR Self Assessment OR Information Seeking Behaviour OR Help Seek\* OR Seek help\* OR Self refer\*

## AND

Internet OR Cellular Phone OR Medical Informatics OR Software OR
 Web Base\* OR e-mental health OR Information Technology OR Website
 OR Online OR Computer Application

## AND

3. Mental Health OR Mental Disorders OR Mental OR Depress\* OR Anxiety

((("Diagnostic Self Evaluation\*" OR "Self Assessment" OR "Information Seeking Behaviour" OR "Help Seek\*" OR Seek help\* OR "Self refer\*")) AND (Internet OR "Cellular Phone" OR "Medical Informatics" OR Software OR "Web Base\*" OR "emental health" OR "Information Technology" OR Website OR Online OR "Computer Application")) AND ("Mental Health" OR "Mental Disorders" OR Mental OR Depress\* OR Anxiety)

## **Cochrane Library**

"Diagnostic Self Evaluation\*" OR "Self Assessment" OR "Information Seeking Behaviour" OR "Help Seek\*" OR Seek help\* OR "Self refer\*" AND Internet "Cellular Phone" or "Medical Informatics" or Software or "Web Base\*" or "e-mental health" or "Information Technology" or Website or Online or "Computer Application" and "Mental Health" OR "Mental Disorders" OR Mental OR Depress\* OR Anxiety

## SCOPUS

(TITLE-ABS-KEY ( "help-seek\*" OR "seek\* help" OR "seek\* treat\*" OR "help seeking behaviour" OR "Health care seeking behaviour" OR "self-referral" OR "self help techniques" ) AND TITLE-ABS-KEY ( "web base\*" OR online OR ehealth OR "Computer applications" OR "mobile devices" OR "Internet" OR "Information technology" ) AND TITLE-ABS-KEY ( "mental health" OR "mental disorder" OR mental OR depress\* OR anxiety ) )

## **B.2 Quality Assessment Tables**

### **Quality Assessment for qualitative studies**

1. Was there a clear statement of the aims of the research?

2. Is a qualitative methodology appropriate?

3. Was the research design appropriate to address the aims of the research?

4. Was the recruitment strategy appropriate to the aims of the research?

5. Was the data collected in a way that addressed the research issue?

6. Has the relationship between researcher and participants been adequately considered?

7. Have ethical issues been taken into consideration?

8. Was the data analysis sufficiently rigorous?

9. Is there a clear statement of findings?

Authors (year)	1	2	3	4	5	6	7	8	9	Rating
Best et al. (2016).	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Strong
Greidanus & Everall	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Strong
(2010).										
Havas et al. (2011).	Yes	Yes	Yes	Yes	Yes	Can't	Yes	Can't	Yes	Moderate
						Tell		Tell		
Mar et al. (2014).	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't	Yes	Strong
								Tell		

## **Quality Assessment for Survey/Questionnaire Studies**

1. Did study address a clearly focused issue?

2. Was a questionnaire the most appropriate research design for this question?

3. Was the sample recruited in an acceptable way?

4. What claims for reliability and validity have been made, and are these justified?

5. Were open-ended (qualitative) and closed-ended questions used appropriately?

6. Was a pilot version administered to participants representative of those in the sampling frame, and the instrument modified accordingly

7. What was the response rate and have non-responders been accounted for?

8. Was the analysis appropriate (eg statistical analysis for quantitative answers, qualitative analysis for open/ended questions) and the correct technique/s used?

- 9. Have all relevant results ('significant 'and 'non-significant')?
- 10. Do you believe the results?
- 11. Can results be more widely applied?

12. Do the results of this study fit with other available evidence

Authors (year)	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12/	Overall quality rating
Bell et (2018).	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Strong
Best, Manktelow, &	Yes	Yes	Yes	Yes	Yes	Not	Yes	Yes	Yes	Yes	Yes	Yes	Strong
Birnbaum et al. (2017),	Yes	Yes	Yes	Yes	Yes	Not sure	No	Yes	Yes	Yes	Yes	Yes	Moderate
Bradford.& Rickwood, (2014),	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Strong
Burns et al. (2016).	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Strong
Burns et al. (2010).	Yes	Yes	Yes	No	Yes	Not sure	No	Yes	Yes	Yes	Yes	Yes	Moderate
Ellis et al. (2013).	Yes	Yes	Yes	No	Yes	Not sure	No	Yes	Yes	Yes	Yes	Yes	Moderate
Ellis et al. (2012).	Yes	Yes	Yes	No	Yes	Not sure	Yes	Yes	Yes	Yes	Yes	Yes	Moderate
Feng, & Campbell (2011).	Yes	Yes	Yes	Yes	Yes	Not sure	Yes	Yes	Yes	Yes	Yes	Yes	Strong
Frost & Casey (2016)	Yes	Yes	Yes	Yes	Yes	Not sure	Yes	Yes	Yes	Yes	Yes	Yes	Strong
Horgan & Sweeney (2010).	Yes	Yes	Yes	Yes	Yes	Not sure	Yes	Yes	Yes	Yes	Yes	Yes	Strong
Mars et al. (2015).	Yes	Yes	Yes	Yes	Yes	Not sure	Yes	Yes	Yes	Yes	Yes	Yes	Strong
Mok, Jorm & Pirkis (2016)	Yes	Yes	Yes	Yes	yes	Not sure	No	Yes	Yes	Yes	Yes	Yes	Moderate
O'Dea & Campbell (2011).	Yes	Yes	Yes	No	Not sure	Not sure	Yes	Not sure	Not sure	Yes	Yes	Yes	Weak

## **Quality Assessment for Cohort Studies**

- 1. Did study address a clearly focused issue?
- 2. Cohort/ sample recruited in an acceptable way?
- 3. Exposure accurately measured to minimise bias?
- 4. Outcome accurately measured to minimise bias?
- 5. Have authors identified important confounding factors?
- 6. Have authors accounted for confounding factors in design and/or analysis?
- 7. Do you believe the results?
- 8. Can results be more widely applied?
- 9. Do the results of this study fit with other available evidence?

Authors (year)	1	2	3	4	5	6	7	8	9	Overall
										quality
										rating
Barker et al. (2017).	Yes	Not sure	Yes	Yes	No	No	Yes	Yes	Yes	Moderate
Haner & Pepler, D. (2016).	Yes	Yes	Yes	Yes	Yes	Not sure	Yes	Yes	Yes	Strong
Rickwood, Mazzer, & Telford (2015).	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Strong

#### **Quality Assessment Table for RCT Studies**

- 1. Did study address a clearly focused issue?
- 2. Was the assignment of participants to conditions randomised?
- 3. Were all of participants who entered the trial properly accounted for at its conclusion?
- 4.Were participants, health workers and study personal 'blind' to treatment?
- 5. Were the groups similar at the start of the trial?
- 6. Aside from the experimental intervention, were the groups treated equally?
- 7. How large was the treatment effect?

- 8. Will the results help locally?
- 9. Can the results be applied to the local population?
- 10. Were all clinically important outcomes considered?
- 11. Are the benefits worth the harms and costs?

Authors (year)	1	2	3	4	5	6	7	8	9	10	11	Overall quality rating
Kauer et al. (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Not large	Yes	Yes	Yes	Yes	Strong
Sanci, Kauer, & Buhagiar (2017)	Yes	Yes	Yes	Not Sure	Yes	Yes	Not large	Yes	Yes	Yes	Yes	Strong

B.3 Overview of Studies Included in Final Review.

Authors (year)	Location	Research methodology	Participants	Key findings		
Barker et al.	Australia	An online screen	Young people aged	Young peopl		
(2017)		consisting of the Alcohol	15-24 years;	being first tin		
		Use Disorders	(females =295,	An online too		
		Identification Test	males =245)	effective way		
		(AUDIT), Alcohol,		seekers.		
		Smoking, and Substance		• The online s		
		Involvement Screening		awareness a		
		Test (ASSIST), ASSIST],		suitable path		
		Kessler Psychological		offline.		
		Distress Scale(K10), and				
		Australian Treatment				
		Outcomes Profile (ATOP)				
Bell et a (2018)	United	Online survey	University students	Studies reve		
	Kingdom		aged 18-24 years	of suicide ris		
				suicide-relate		
				compared w		

							٠	Significantly
								reported that
								with their far
							•	Suicide-relat
								group who tu
								suicidal feeli
							•	The question
								depends on
							•	It is importar
								administrato
								unsupportive
								disruptive or
							•	A degree of
								assuming the
								about suicide
								effectivenes
								negative imp
Best	et al.	Northern	48-item	questionnaire:	High	school	•	Searching on
(2014)		Ireland	mental w	ell-being; social	students	, males		not associate
			networkin	g and Internet	aged 14	-15 years,		being among
					(N=527)			

		use; self-efficacy; online		Very few resp
		help seeking		likely to acces
				through gove
				Knowing that
				trusted sourc
				a trained prot
				importance fe
				services.
				Socioeconom
				level were no
				help-seeking
Best et al.	Northern	Modified photo-elicitation	High school	• The pathway
(2016)	Ireland	techniques were	students, males	conceptual m
		employed within 8	aged 14-15 years	Online inform
		semistructured focus	(N=56)	increased op
		group sessions		included loss
				Participants h
				online pathwa
Birnbaum et al.	United	Pathways to Care for	Participants	• A third of the
(2017)	States	Psychosis Questionnaire	recruited from	their primary
		(PCP-Q); the PCP-Q	clinical settings,	
				-

		consists of approximately	aged 12-21 years	health-re	lated
		70 open-ended and	(N=80; males =39,	the emerg	geno
		multiple-choice	females =41)	• The onlin	e en
		questions.		resource	regu
				of young	peo
				untreated	t illne
Bradford and	Australia	Self-report questionnaire	High school	Reason f	or pr
Rickwood			students (females	services i	inclu
(2014)			=139; males =92)	Internet; i	infor
				and that t	there
				who have	e bee
				Adolesce	ents a
				at all.	
Burns et al.	Australia	Telephone interview	Young people aged	Young pe	eople
(2016)			16-25 years (males	high leve	ls of
			=700; females	more like	ly to
			=700)	informatio	on al
				alcohol o	r suk
				with low p	osyc
			1		

					• You	ng female
					thar	n males to
					heal	lth inform
					• You	ng people
					leve	ls of psyc
					likel	y to use t
					thos	e with lov
					distr	ess.
					• The	Internet
					spei	nd time, c
					help	o for their
Burns	et al.	Australia	Telephone interview	Young people aged	• You	ng people
(2010)				12-25 years	for i	nformatio
				(n=2000, females	heal	lth proble
				=1000, males	had	a probler
				=1000)	• Less	s than ha
					mer	ntal health
					info	rmation fr
					gove	ernment v
					mec	lical journ

					research data
					websites.
					• Forums, bulle
					support group
					information.
Collin et	al.	Australia	Website statistics, user	2	The ReachOut v
(2011)			profiling survey, user-		gateway service
			generated content, and		identify that the
			interview and focus		help and then s
			groups		access appropria
Ellis et	al.	Australia	Online survey:	Young people aged	More than ha
(2012)			technology use; attitudes	16-24 years	psychologica
			and behaviors;	(N=1038, females	Internet for he
			psychological distress	=552, males =486	Significantly
			(K6), technology and		talked about
			mental health		<ul> <li>Majority of the</li> </ul>
					for their prob
Ellis et	al.	Australia	Online survey and focus	National online	Age was a sig
(2013)			groups	survey of 486	help online, v
				males (aged 16-24	

<sup>2</sup> Data not available

					years) and 17		likely to have
					focus groups		online than ol
					involving 118	•	Young men te
					males (aged 16-24)		friend to seek
							would require
							to start seekir
Feng a	nd	Australia	Online surv	ey:	First year university	•	Almost half of
Campbell			demographic items,	use	students (N=176,		they had use
(2011)			of e-mental he	alth	females =119,		time to learn
			information	and	males =57)		anxiety, sadn
			resources, Eyse	nck		•	No participan
			Personality				resources ma
			Questionnaire				worse.
						•	The sample h
							search engine
						•	Making e-me
							does not nec
Frost a	nd	Australia	Online surv	ey:	Young people	•	Online help s
Casey (2016)	)		psychological distr	ess	reporting a history		younger than
			(K10); self-injuri	ous	of self-injury (N=		online in relat
			behaviors (The Self-Ha	arm	679) were		

			Behavior [SHBQ]); s (SBQ-R); intentions	Questionnaire suicidal ideation help-seeking (GHSQ)	identified a larger (N=1463) e help (females males =71)	s part of study exploring seeking =513,	•	Young people relation to sel distressed an ideation. Those who has support in rela- belief that the them online. Online help s psychological self-injurious Young people
								relation to sel likely to have behavior to a
Frost (2016)	et al.	Australia	Online sur	vey	A sample of remained, v of these participants reporting a of self-injur	of 1463 with 679 s history ry. The	•	Online help s distressed, su degree of self did not seek h

			qualitative	•	Access relate
			question of		service with in
			relevance in the		support, from
			current paper was	•	A significantly
			completed by 457		who had prev
			(females =399)		in relation to
					the importanc
				•	Services deliv
					incorporate c
					peers to be m
Greidanus and	Canada	Analysis of records	_	•	In all cases, a
Everall (2010)		created on an online			experiences of
		community message			life stressors
		board			life events.
				•	Responding r
					all of the elen
					trained volunt
					these being e
					care/keep po

				Several of the
				support from
				writing to sup
Haner and	Canada	Comparative study:	232 phone clients	• There was a
Pepler (2016)		Counselling Client	(females =169,	heterosexual
		Questionnaire 2 +	males =53) and	than in the ph
		Objective Appraisal of	230 Live Chat	A significantly
		Risk Level	clients (females	sought help f
			=201, males =24)	mental illness
				Online chatte
				to have spoke
				helping profe
				therapists but
				ever had con
				service.
				Mental health
				were more fre
				those of calle
Havas et al.	The	Focus group interviews	High school	Participants r
(2011)	Netherlands		students aged 12-	search for he
		•		

				19 years (females	•	An ideal web
				=55, males =51)		self-tests, and
					•	Layout and d
						were related
Horgan	and	Ireland	Online survey: used the	University students	•	In total, 30.89
Sweeney			Internet, including	aged 18-24 years		Internet for m
(2010)			frequency, use of search	(N=922, females	•	It was sugges
			engines, use of social	=552, males =333)		access to cha
			networking sites, and			facility would
			information on how they			should includ
			use the Internet to search			the website s
			for general health		•	In all, 20.6%
			information.			would prefer
						face support.
Kauer et	al.	Australia	Feasibility study	Young people aged	•	One of the be
(2017)				18-25 years (N=51,		the qualitativ
				females =39,		increase in p
				males =12)		using the too
Mar et	al.	Canada	Qualitative interview	Young people aged	•	Participants h
(2014)				between 16 and 24		availability of
				years (N=23,		peer support,

			females =22,		was seen as
			males =1)		communication
				•	It was importa
					anonymous v
				•	Participants u
					seek help an
					to feelings of
				•	Users stated
					simple, look a
					and be easy
				•	Having a con
					feature for pa
Mars et al.	United	Quantitative	The questionnaire	•	A greater pro
(2015)	Kingdom		was sent to 8525		accessed site
			participants, of		support than
			whom 4110		information o
			(48.2%) responded	•	The risk of a
			and 3946 (46.3%)		harmful sites
			provided data on		among those
			their suicide/self-	•	The findings
			harm-related		suicide/self-h

				Internet use and	actually more
				previous self-harm	professional I
					thoughts than
					Females were
					suicide/self-h
					males in the
Mok et	al.	Australia	Online survey: Suicide	Young people aged	Suicide-relate
(2016)			Behaviors Questionnaire-	18-24 years	higher levels
			Revised; Patient Health	(N=205, females	suicidal ideat
			Questionnaire; Social	=156, males =45)	• Those who re
			Interaction Anxiety Scale;		ideation and
			General Help-Seeking		likelihood of f
			Questionnaire;		use the Interr
			Multidimensional scale of		Suicide-relate
			perceived social support;		likely to prefe
			suicide-related Internet		for future help
			use; barriers to help		
			seeking		
O'Dea	and	Australia	Cross-sectional survey	High school	• In total, 53%
Campbell				students (N=85,	the Internet to
(2011)				mean age =14.7	support.

			years, n=46	Participants b
			females)	sites could he
				problems.
Rickwood et al.	Australia	Comparative study: users	Young people aged	Self-initiation
(2015)		accessing face-to-face	12-25 years	help seeking
		Headspace and online e-	(females =48.7%,	• This was evid
		Headspace	males =51.3%)	with two-thirc
				group reporti
				the main influ
				• Friend influer
				the youngest
				environment,
				boys, it peak
				and then dec
				• The online er
				traditional in-
				this is the en
				navigating or
Ruppel and	United	Online survey focused on	University students	Individuals w
McKinley	States	the following measures:	(N=443, females	have a limite
(2015)		overall mental health;	=297, males =146)	available to th

				social support; so	cial			advantage of
				anxiety; usefulness	of			when necess
				online resourc	es;		•	Participants w
				previous use of on	line			benefits to on
				mental health resource	es			but do not ne
Sanci	et	al.	Australia	Randomized control	lled	Young people aged	Ar	n online referra
(2017)				trial		18-25 years	pr	ovides a positi
Spears	et	al.	Australia	Online survey		Young people aged	•	Young people
(2015)						12-18 years		category, in p
						(N=2338)		mental health
								connectednes
								and depression
							•	This group wa
								Internet after
								highly unlikely
								quarter seekii
							•	Online help se
								with the need
							•	More needs to
								online help so
								why some gro
1						1	1	

				seek help onl
				late at night v
				not be availal
Wetterlin et al.	Canada	Online survey: (1)	Young people aged	Most participa
(2014)		demographics, (2) mental	17-24 years	used the Inte
		health literacy, (3) online	(N=521, females	for the feeling
		and offline use of mental	=399, males =121)	The majority
		health resources, (4)		contact with a
		online and offline		therapist or c
		opinions about current		important or v
		mental health resources,		• Professional,
		and (5) preferences		involvement,
		regarding potential		important fea
		components of a mental		website.
		health website		• A mental hea
				information fr
				sources, inclu
				interventions
1				

Author (year)	Findings related to how young people seek help online
Best et al. (2016)	<ul> <li>In total, 57% of the sample used a text-based search engine</li> </ul>
	to locate information.
	<ul> <li>Overall, 48.9% used social media to locate mental health</li> </ul>
	information.
	<ul> <li>Less than quarter of the sample would access through a</li> </ul>
	government website, although they value mental health
	services run by trained professionals. However, these need to
	be available 24 hours a day.
Birnbaum et al.	Participants with non-psychotic mood disorders (NPMD)
(2017)	were primarily interested in obtaining information on how to
	stop symptoms.
	Participants with Psychotic Spectrum Disorders (PSD) were
	more commonly interested in what caused their symptoms.
	Young people are actively reaching out over social media
	and other online resources before they access professional
	care.
	Young people showed an interest in obtaining help/advice
	from professionals via social media.
Burns et al.	Young who are highly distressed were accessing the Internet
(2010)	after 11 pm at night.
	• A total of 21.4% of 12-17-year-olds and 93.3% of the sample
	used a search engine such as Google or Yahoo to find
	information rather than accessing a specific website.
	<ul> <li>In all, 33.9% of 18-25-year-olds reported that they had</li> </ul>
	specifically searched the Internet for mental health concerns.
	• Less than half, that is, 44.4% sourced information from
	mental health websites, whereas 50.7% sourced information
	from other websites.

B.4 Findings Identified in Studies: How Do Young People Seek Help Online?

Ellis et al. (2013)	Age, however, was a significant predictor for websites and church			
	leader, with younger males being more likely to recommend			
	websites than older males.			
Feng and	Overall, 44% reported they had used the Internet at some			
Campbell (2011)	point in time to learn about personal feelings of anxiety,			
	sadness, or confusion.			
	Participant usage rates of online resources for the purpose of			
	coping with feelings were distributed as follows: (1) 42%			
	used text-based search engines, (2) 26% used informational			
	sites, (c) 22% used Facebook or Myspace profiles, and (4)			
	11% used online support groups and discussion boards.			
Frost et al. (2016)	• The most popular suggestion was for "an online service with			
	direct links to professionals in real time via instant			
	messaging," which was endorsed by 54.1% of the young			
	people. Other highly endorsed online sources were peer			
	support such as online forums and chat rooms (48.6%),			
	online self-help programs (43.5%), and information provided			
	in text or fact sheets.			
	• A total of 13.8% the sample reported a desire for information			
	online that would help them to immediately talk to family,			
	friends, or a professional about their self-injurious behavior.			
	• In all, 45.7% of young people indicated a desire for advice or			
	help and support when seeking help online.			
	<ul> <li>Many young people specifically identified a need for</li> </ul>			
	information about self-injury, research, statistics, and fact			
	sheets and highlighted the importance of relevance and			
	reliability of such information.			
Greidanus and	• The roles of <i>help seeker</i> and <i>help provider</i> are dynamic,			
Everall (2010)	meaning that a single person may fill a role at different times			
	throughout the message boards. After posting messages			
	seeking help, help seekers wrote messages to encourage			
	each other and a community was developed that included			

	help seekers, help providers, and trained volunteers who			
	monitored the posts.			
	Each help seeker began the thread by posting a message			
	expressing personal distress that was often related to			
	suicidal feelings or concern that someone close to them was			
	suicidal.			
Haner and Pepler	When young people are extremely distressed, they seem to			
(2016)	access Live Chat options.			
Horgan and	. A total of 30.8% of participants used the Internet for mental			
Sweeney (2010)	health information.			
	2. The main information searched for was information on			
	depression, information for course work, general information on			
	mental health problems, and information on specific problems			
	they themselves or family or friends experienced.			
Mars et al. (2015)	A greater proportion of individuals had accessed sites			
	offering help, advice, or support than had accessed sites			
	offering information on how to hurt or kill yourself.			
	Almost half of those with suicidal self-harm had searched for			
	information about suicide and self-harm and 30.2% had used			
	the Internet to discuss suicidal feeling.			
	Many of the sample had looked for information about self-			
	harm or suicide using a search engine or used the Internet to			
	discuss self-harm or suicidal feelings.			
	Suicide/self-harm-related Internet use was particularly			
	prevalent among those who had self-harmed with suicidal			
	intent (70%).			
Mar et al. (2014)	The majority of the sample perceived it to be common and obvious			
	to google depression symptoms and/or depression treatment, and			
	searched for these phrases themselves.			
Wetterlin et al.	• A total of 52.4% of participants indicated that when using the			
(2014)	Internet for mental health information-seeking purposes, they			
	were looking for information about symptoms and 47.4%			
---	---			
	were looking for treatment options.			
•	Most (82.9%) participants were either somewhat likely or			
	very likely to use an information-based website with mainly			
	text. Slightly more than half of the participants were not at all			
	likely or somewhat unlikely to use online interactions such as			
	a group online chat session led by a psychologist (55.3%)			
	and chat rooms/support groups/discussion boards (56.6%).			
•	Only 10.6% said that they had used social media (eg,			
	Facebook and MySpace) to obtain help with problems such			
	as anxiety or depression. –			
•	Does not appear that this sample used social networking			
	sites when looking for help or support for problems such as			
	anxiety or depression.			

## Appendix C | Chapter 5 Supplementary Material

#### C1: Ethics Approval



UCD Office of Research Ethics Roebuck Castle University College Dublin Belfield, Dublin 4, Ireland T +353 1 716 8767 An Oifig Eitic Thaighde UCD Caisleán an Ruabhoic

An Coláiste Ollscoile, Baile Átha Cliath Belfield, Baile Átha Cliath 4, Éire hrec@ucd.ie www.ucd.iersearchethics

December 22<sup>nd</sup>, 2017

Ms Claudette Pretorius c/o Dr David Coyle The Insight Centre for Data Analytics UCD O'Brien Centre for Science Belfield Dublin 4

Re: LS-17-116-Pretorious-Coyle: A Survey of Online Help-Seeking in Young Adults

Dear Ms Pretorious

Thank you for your response to the Human Research Ethics Committee – Sciences (21/12/17). The Decision of the Committee is that approval is granted for this application which is subject to the conditions set out below.

Your request to access UCD students was also reviewed and granted. Please ensure that any additional permissions to access participants, whether internal (heads of Schools) or external are obtained before the recruitment of the participants is commenced.

Please note that public liability insurance for this study has been confirmed in accordance with our guidelines.  $^{I\!I}$ 

Please note that approval is for the work and the time period specified in the above protocol and is subject to the following:

- Any amendments or requests to extend the original approved study will need to be approved by the Committee. Therefore you will need to submit by email the Request to Amend/Extend Form;
- Any unexpected adverse events that occur during the conduct of your research should be notified to the Committee. Therefore you will need to Submit, by email, an Unexpected Adverse Events Report;
- You or your supervisor (if applicable) are required to submit a signed End of Study Report Form to the Committee upon the completion of your study;
- This approval is granted on condition that you ensure that, in compliance with the Data
  Protection Acts 1988 and 2003, all data will be managed in accordance with your
  application and that you will confirm this in your End of Study Report;
- Please note that further new submissions from you may not be reviewed until any End
  of Study Reports due have been submitted to the Office of Research Ethics. That is, any
  earlier study that you received ethical approval for from the UCD HRECs;
- You may require copies of submitted documentation relating to this approved application and therefore we advise that you retain copies for your own records;
- Please note that the granting of this ethical approval is premised on the assumption that the research will be carried out within the limits of the law;
- Please also note that approved applications and any subsequent amendments are subject to a Research Ethics Compliance Review.

The Committee wishes you well with your research and look forward to receiving your End of Study Report. All forms are available on the website <u>www.ucd.ie/researchethics</u> please ensure that you submit the latest version of the relevant form. If you have any queries regarding the above please contact the Office of Research Ethics and please quote your reference in all correspondence.

Yours sincerely,

John Dowel

Mr T. John O'Dowd Chairman, Human Research Ethics Committee - Sciences

<sup>[1]</sup> http://www.ucd.ie/researchethics/information\_for\_researchers/insurance

#### **C2: Informed Consent**

#### **Information Sheet**



Researcher: Ms. Claudette Pretorius

Supervisor: Dr David Coyle

Topic: Technology Enabled Mental Health for Young People.

Funder: European Union's Horizon 2020 research and innovation programme under the Marie Sklodowska-Curie Action grant number 722561

University College Dublin Belfield, Dublin 4, Ireland Email: Claudette.pretorius@ucdconnect.ie https://www.team-itn.eu

School of Computer Science

## Project Title: <u>A Survey of Online Help-Seeking in Young Adults</u>

This research is being conducted by Claudette Pretorius, a doctoral candidate in School of Computer Science at the University College of Dublin under the supervision of Dr. David Coyle. This research is part of the TEAM (Technology Enabled Youth Mental Health) consortium. Our focus is on the design and development of new technology-enabled mental health services.

We would like to invite you to take part in an online survey that looks at how young people look for information and help online for personal and emotional concerns. Before you decide whether to take part it is important that you understand why the research is being done and what it will involve. Please take time to read this information sheet carefully.

### What is this research about?

This research is interested in learning how young people look for help for personal and emotional concerns online and which factors influence this process. We are particularly interested in your views of e-mental health and using the Internet and technology for mental health information and support.

### Why are we doing this research?

We understand that it is sometimes difficult to find the right information online. By gathering information on young people's current online information and help-seeking behaviours, we hope by the end of the research project to develop an online tool that

can safely and accurately refer young people to online supports relative to their level of need.

## Why have you been invited to take part?

You have been invited to take part because you are a young person between the ages of 18 and 25. Your views and experiences are very important in helping us understand how young people look for support and information online for personal and emotional concerns.

## How will your data be used?

Results of the study may be presented at future academic or research conferences, or within research journals. Information from this study will also be included in a doctoral thesis. It won't be possible for any individual to be identified from these results.

With your permission, data related to your participation will be submitted to the Horizon 2020 open access repository. This data is completely anonymized. This process is integral to the research process as it allows other researchers to verify results and avoid duplicating research in the future.

### What will happen if you decide to take part in this research study?

If you wish to take part in the survey, you can click onto the next page. By completing the survey, you agree to take part in the research. The online survey will take approximately 15 minutes to complete.

## How will your privacy be protected?

This survey is anonymous in that we do not ask for your name or any identifying information. Your responses will be confidential and we do not collect identifying information such as your name, email address or IP address. Only those associated with this study will have access to these records which are secured by encryption and are password protected.

## What are the benefits of taking part in this research study?

Information from the survey will be used to guide the development of an online tool that will assist the online help-seeking process, hopefully making it simpler and more reliable. The information will also be used to inform the development and improvement of online mental health supports.

## What are the risks of taking part in this research study?

You may feel that some of the questions we ask are stressful or upsetting. If you should find any question to be invasive or offensive, you are free to omit answering or participating in that aspect of the study. If you do experience any distress from participation, please contact one of the mental health supports provided below:

### Samaritans:

<u>Phone</u>: 116 123 (Freephone, Republic of Ireland) <u>Email</u>: jo@samaritans.org 24 hours a day, 365 days a year

#### If you are in crisis:

- Contact your local doctor. To find yours, visit www.icgp.ie/go/find\_a\_gp
- Go to, or contact, the Accident and Emergency Department of your nearest general hospital
- Emergency services can be contacted at any time by dialling 999 or 112.

### Can you change your mind at any stage and withdraw from the study?

Participation in this research is voluntary. If you don't wish to take part, you don't have to. If you do consent to participate, you can withdraw from the survey at any time while you are answering the questions, however, once you have finished and submitted your answers, your data will be combined with that of other participants and will therefore no longer be identifiable. Accordingly, once your data have been submitted you will not be able to withdraw your participation.

# How will you find out what happens with this project and contact details for further information?

If you would like to be kept informed about the survey and the broader study, please contact Ms. Claudette Pretorius on <u>Claudette.pretorius@ucdconnect.ie</u>. You can also find more information general information about the TEAM project at this web address: <u>www.team-itn.eu</u>

## C3: Survey Questions

Secti	ion A: Consent Form		
A1.	I confirm that I am 18 years or older	Yes No	
A2.	I have read and understood the information sheet on the previous page	Yes No	
A3.	I understand that participation is voluntary and I can withdraw whilst taking the survey. I accept that once the survey is completed, I cannot withdraw due to the anonymous nature of the survey.	Yes No	
A4.	I agree my anonymised research data will be stored securely by the researcher up 5 years after the completion of the project at which time the information will be destroyed securely.	Yes No	
A5.	I consent to my anonymised data may be quoted in dissemination activities including but not limited to PhD thesis, scientific publication, conference proceedings and presentations	Yes No	
A6.	I agree that my anonymised data can be stored in an Open Access repository	Yes No	
<b>A</b> 7.	I understand that all information I provide for this study will be treated confidentially where normal limits of confidentiality apply.	Yes No	
A8.	I am aware that I can contact the researcher at any point to get further information or clarification about this research study.	Yes No	

A9.	I am aware that when the research study is complete, findings or results from this research study will be available from the researcher.	
	Yes	Ļ
	No	
A10.	If you do NOT wish to take part in the study you can click away from the survey now.	
	If you do wish to take part tic the box ''I consent to take part in the study'' and then click on.	
	I consent to take part in the study	
Sect: This sec	ion B: Demographics tion of the survey would like to determine some demographic details from you.	
B1.	Please indicate your gender	
	Male	Ļ
	Female	
	Transgender	ф —
	Non-binary	¢
	Prefer not to say	
<b>B</b> 2.	What is your current age?	
	18	Ļ
	19	<b></b>
	20	Ļ.
	21	¢
	22	Ċ.
	23	Ċ.
	24	Ċ
	25	

B3.	In which county do you live?	
	Carlow	П П
	Cavan	
	Clare	ф —
	Cork	ф —
	Donegal	ф —
	Dublin	Ċ.
	Galway	ф —
	Kerry	ф –
	Kildare	Ļ.
	Kilkenny	ф —
	Laois	ф —
	Leitrim	ф —
	Limerick	ф —
	Longford	ф —
	Louth	Ļ
	Мауо	ф —
	Meath	Ц –
	Monaghan	Ц.
	Offaly	Ļ
	Roscommon	ф —
	Sligo	ф —
	Tipperary	ф —
	Waterford	ф —
	Westmeath	ф —
	Wexford	Ļ
	Wicklow	
B4.	Do you live in a	
	City / Town	
	Rural area	

B5.	What is your current level of education?		
	5th Year	$\Box$	
	6th Year	¢	
	Undergraduate	¢	
	Postgraduate	¢	
	PhD	Ċ.	
	Apprenticeship	Ċ	
	Other		
	Other	•	
Sect	ion C: Areas of Stress		
C1.	Please indicate if any of the following have caused you a lot of stress	_	
	School / College		
	Family		
	Friends		
	Social Media		
	Money		
	Body Image		
	Exams		
	Relationships		
	Sexuality		
	Bullying		
	Local or world news		
	Deciding on a career		
	Personal Illness		
	Illness of a family member or friend		

C2.	Has anything that is not on the list above caused you stress or difficulty?	
C3.	Can you rank your top 3 causes of stress?	 -
	School / College	
	Family	
	Friends	]
	Social Media	]
	Money	]
	Body Image	]
	Exams	]
	Relationships	]
	Sexuality	]
	Bullying	]
	Local or world news	]
	Deciding on a career	]
	Personal Illness	]
	Illness of a family member or friend	]

Section D: Information and help-seeking	
D1. On an average day, if you were having a pers problem, how likely are you to seek help from Please mark the appropriate response	onal or emotional 1 the following people?
	Extremely Extremely
Friend (not related to you)	Unlikely Unlikely Neutral Likely likely
Parent	
Other relative/family member	
Intimate partner (e.g. girlfriend, boyfriend, partner, husband, wife)	
GP / family doctor	
Mental health professional (e.g. psychologist, social worker, counsellor)	
Teacher / school counsellor	
Minister or religious leader (e.g. priest, rabbi, chaplain)	
Phone helpline (e.g. Samaritans)	
Online counselling service (e.g. Niteline)	
A person I know has had their own experiences of emotional/mental health difficulties	
Blogger / influencer	
I would not seek help from anyone	
D2. Have you ever gone online to learn more about emotional problem you or someone close to you	it a personal or ou was experiencing?
	Yes Uncertain No Family member Friend Friend

D3.	Please indicate if you've ever gone online to look for help or information for any of the following?		
l	School / College	Yes Uncertain No	
	Family		
	Erianda		
	Social Media		
	Monar		
	Pal. Los		
	body image		
	Exams		
	Relationships		
	Sexuality		
	Bullying		
	Local or world news		
	Deciding on a career		
	Personal Illness		
	Illness of a family member or friend		
D4.	Please tick the appropriate responseDo you own any of the f devices?	ollowing	
		Smartphone	
		Tablet	
	La	ptop / Computer	
<b>D</b> .5		Games Console	
D5.	Please tick the appropriate response Which device do you use to access the internet?	e the most	
		Smartphone	
		Tablet	
	La	ptop / Computer	
		Games Console	

D6.	Please tick the appropriate responseWhich device would you use to access the internet to look for information/help for personal and emotional concerns?	
1	Smartphone	
	Tablet	
	Laptop / Computer	
	Games Console	
D7.	If you wanted more information about a personal or emotional problem concern, where would you find more information?	
	Health website	
	Mental Health App	
	Internet search	
	Social media@Blogger/ Influencer	
	Forums / discussion boards	
	Websites that you already use for other kinds of content e.g. Buzzfeed	
	Other	$\square$
	Other	
D8.	How satisfied were you with the information you found from this resource?	
	Very Not sure dissuisified Dissuisfied Neutral Satisfied	Very satisfied
	Health website	-
	Mental Health App	-
	Internet search	-
	Social media@Blogger/ Influencer	-
	Forums / discussion boards	-
Websit	es that you already use for other kinds of content e.g. Buzzfeed	-

D9.	Would you mind saying why? We would like to know why you experienced these online sources the way you did. What do they get right and what do they do wrong.	
Secti	on E: Credibility of Online resources	

# E1. How trustworthy / reliable do you find the information online from the following resources:



E2.	Which of these features makes an online resource trustworthy/reliable?		
l	Links to social media	Disagree Not sure Agree	I
	Government logo		
	HSE Logo		
	Good design and layout		
	At the top of a Google search results page		
	College or school endorsement		
	References to scientific data and authors		
	A quiz or assessment		
	Contains personal stories / experiences		
E3.	Is there anything not listed above that makes an online resort trustworthy/reliable?	urce	_

## Section F: Motivations for online help-seeking

#### F1. How likely are the following factors to encourage you to seek help online or through an online resource for a personal or emotional concern?

	Not at all	Alittle	A lot	lot
I can access information and support online any time of day	<u> </u>		-[]	-
Online help is mostly free	<u> </u>			-
Going online is anonymous and confidential				-
An abundance of information is readily available	<u> </u>			-
I can go through information and take action at my own pace				-
Knowing that there are others in the world who have gone through similar tough times			-[]	-
Being too unwell to reach out to my local support services				-
Being unsure if I am unwell enough to reach out to local support services				-
There are no other options available to me	<u> </u>			-

F2.	Have any of these issues ever stopped, delayed or discouraged you from seeking help online or through an online resource for a personal or emotional concern?				
		Quite a			
	Being unsure what to search for online				
	Wanting to solve the problem on my own				
	Preferring to get alternative forms of help	,			
	Being unsure if the information I find is reliable				
	Being too unwell to look for help	·[][]			
	Concern that others (family/friends) might find out	•			
	Having previous bad experiences with looking for help online	·[][][]			
	Thinking that I don't have a problem				
	Having no one who could help me navigate all the options online	; [][][]			
	Not being sure of my privacy and anonymity online				
F3.	Is there anything not listed above that would encou help online for a personal or emotional concern?	rage you to seek			
F4.	Is being able to connect to another person online in when seeking help online? If yes, why?	portant to you			

## Section G: Wellbeing

#### G1. Below are some statements about feelings and thoughts.

# Please tick the box that best describes your experience of each over the last 2 weeks.

"Short Warwick Edinburgh Mental Well-Being Scale (SWEMWBS) © NHS Health Scotland, University of Warwick and University of Edinburgh, 2008, all rights reserved."

	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	□		[]		
I've been feeling useful	<u> </u>				
I've been feeling relaxed	□		[]		
I've been dealing with problems well	□				
I've been thinking clearly	□				
I've been feeling close to people	□				
I've been able to make up my own mind about things	□		[]		

Thank you for taking the time to complete this survey!

If you would like to be kept informed about the survey and the broader study, please contact Ms. Claudette Pretorius on Claudette.Pretorius@ucdconnect.ie . You can also find more general information about the TEAM project at this web address: www.team-itn.eu

Support Services

The services listed below may be of benefit if you are looking for information or support.

Samaritans: Phone: 116 123 (Freephone, Republic of Ireland)

Email: jo@samaritans.org

24 hours a day, 365 days a year

If you are in crisis:

Contact your local doctor. To find yours, visit www.icgp.ie/go/find\_a\_gp Go to, or contact, the Accident and Emergency Department of your nearest general hospital Emergency services can be contacted at any time by dialling 999 or 112.

Mental health information and support services:

www.reachout.com - offers comprehensive information on all aspects of mental health and how to get help, and provides a safe space for engaging with a team of trained moderators and a panel of experts.

www.turn2me.org - provides a variety of support options, including online counselling, online support groups and live chat.

www.yourmentalhealth.ie – provides information on mental health, support services near you and the everyday #littlethings that can make a difference to your mental health and wellbeing.

www.bodywhys.ie – offers online support for eating disorder issues, including an online group counselling service.

www.drugs.ie – offers drug and alcohol information and support including a 'live helper' service that lets you chat to a staff member online.

## Appendix D | Chapter 6 Supplementary Material

#### D.1: Ethics Approval



UCD Office of Research Ethics Roebuck Castle University College Dublin Belfield, Dublin 4, Ireland T +353 1 716 8767 An Oifig Eitic Thaighde UCD

Caisleán an Ruabhoic An Coláiste Ollscoile, Baile Átha Cliath Belfield, Baile Átha Cliath 4, Éire hreo@uod.ie www.ucd.ie/researchethics

March 22nd, 2019

Ms Claudette Pretorious c/o Dr David Coyle UCD School of Computer Science Belfield Dublin 4

Re: LS-19-20-Pretorious-Coyle: Co-Designing an Online Help-Seeking Resource with Young People

Dear Ms Pretorious

Thank you for your response to the Human Research Ethics Committee – Sciences (21/03/19). The Decision of the Committee is that approval is granted for this application which is subject to the conditions set out below.

Please note that public liability insurance for this study has been confirmed in accordance with our guidelines.  $\ensuremath{^{\square}}$ 

Please note that approval is for the work and the time period specified in the above protocol and is subject to the following:

- Any amendments or requests to extend the original approved study will need to be approved by the Committee. Therefore you will need to submit by email the Request to Amend/Extend Form;
- Any unexpected adverse events that occur during the conduct of your research should be notified to the Committee. Therefore you will need to Submit, by email, an Unexpected Adverse Events Report;
- You or your supervisor (if applicable) are required to submit a signed End of Study Report Form to the Committee upon the completion of your study;
- This approval is granted on condition that you ensure that, in compliance with the Data
  Protection Acts 1988 and 2003, all data will be managed in accordance with your
  application and that you will confirm this in your End of Study Report;
- Please note that further new submissions from you may not be reviewed until any End
  of Study Reports due have been submitted to the Office of Research Ethics. That is, any
  earlier study that you received ethical approval for from the UCD HRECs;
- You may require copies of submitted documentation relating to this approved application and therefore we advise that you retain copies for your own records;
- Please note that the granting of this ethical approval is premised on the assumption that the research will be carried out within the limits of the law;
- Please also note that approved applications and any subsequent amendments are subject to a Research Ethics Compliance Review.

The Committee wishes you well with your research and look forward to receiving your End of Study Report. All forms are available on the website <u>www.ucd.ie/researchethics</u> please ensure that you submit the latest version of the relevant form. If you have any queries regarding the above please contact the Office of Research Ethics and please quote your reference in all correspondence.

Yours sincerely

John Dowel

Mr T. John O'Dowd Chairman, Human Research Ethics Committee - Sciences

[] http://www.ucd.ie/researchethics/information\_for\_researchers/insurance/

## D.2: Information Sheet and Informed Consent

S



Researcher:	Ms.	Claudette	School of Computer Science		
Pretorius					
Supervisor: Dr	David C	oyle	University College Dublin		
Topic: Tec	Technology	Enabled	Belfield, Dublin 4, Ireland		
Aental Health for Young People.			Email:		
under: Eu	European	Union's	Claudette.pretorius@ucdconnect.ie		
Horizon 2020	) resea pramme	arch and under the	https://www.team-itn.eu		
Aarie Sklodov	vska-Cu	rie Action			
grant number 7	22561				

# Project Title: Co-Designing an Online Help-Seeking Resource with Young People

This research is being conducted by Claudette Pretorius, a doctoral candidate in School of Computer Science at the University College of Dublin under the supervision of Dr. David Coyle. This research is part of the TEAM (Technology Enabled Youth Mental Health) consortium. Our focus is on the design and development of new technology-enabled mental health services.

We would like to invite you to take part in a co-design study that aims to identify the key design criteria for an online help-seeking tool for mental health difficulties. Before you decide whether to take part it is important that you understand why the research is being done and what it will involve. Please take time to read this information sheet carefully.

### What is this research about?

This research is interested in learning how young people look for help for personal and emotional concerns online and how an online tool could make this process easier. We are particularly interested in your thoughts regarding which design features that would be important to include in a tool of this nature. The format of this study is in the form of a co-design workshop. Co-design workshops use various interactive methods to learn more about user's (a user is the person who you intend to use resource) needs. In this study we use personas representing different types of help-seekers to do this. A persona is a fictional character that has been created using findings from previous research and represents a set of requirements we want to design for. It is not a real person.

#### Why are we doing this research?

We understand that it is sometimes difficult to find the right information online. By gathering information on young people's current online information and help-seeking behaviours, we hope by the end of the research project to develop a prototype of an online tool that can safely and accurately refer young people to online supports relative to their level of need. Co-design workshops allow us to work with the target audience for whom the tool is intended. We value your input and ideas regarding the design features of such a tool and how it should work.

### Why have you been invited to take part?

You have been invited to take part because you are a young person between the ages of 16 and 25. Your views and experiences are very important in helping us understand how young people look for support and information online for personal and emotional concerns and how a tool could facilitate this.

### How will your data be used?

Claudette Pretorius is a member of TEAM (Technology Enabled Mental Health for Young People) which has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No. 722561. Under Horizon 2020, beneficiaries should engage in dissemination activities which means sharing research results. Research results of the study may be presented at future academic or research conferences, or within research journals. Information from this study will also be included in a doctoral thesis as well as design guidelines to design online mental health resources. However, no individual participant will be identified in any publication or presentation and only anonymised quotes will be used in these reports and publications.

The information gathered in this study will be kept by the research team for a period of 5 years after the completion of the TEAM project. With your permission, data (photographs of artefacts and transcripts but not audio files) related to your participation will be submitted to the Horizon 2020 open access repository. This data is completely anonymised. This process is integral to the research process as it allows other researchers to verify results and avoid duplicating research in the future.

#### What will happen if you decide to take part in this research study?

If you wish to take part in the study, you can return a signed consent sheet to Claudette and you will be given the date to attend the workshop. If you are under the age of 18, you will require parental consent to take part in this study. Workshops will take place at Jigsaw Centers or in the Insight Center for Data Analytics at University College Dublin. Other young people from your local area or Youth Advisory Panel (YAP) will also be taking part in this workshop. The workshop will not have more than 9 participants at a time and will involve group work activities. The workshop will last for about 3 hours. The workshops will be facilitated by Claudette Pretorius and Naoise Kavanagh. The workshop will consist of 4 activities including a design activity. The workshops will make use of personas representing different types of help-seekers to facilitate these activities. The personas will be of a young person who is experiencing a personal or emotional problem and using the Internet to find help. The persona is not a real person; they are fictional characters that represent findings from previous research. You will be asked to design an online tool to assist the person in the persona. We will not ask you about your own personal or emotional concerns. However, in order to safeguard your wellbeing, if you are currently experiencing personal or emotional difficulties, or receiving psychological treatment or counselling, you will not be eligible to take part in this study. All group work exercises will be audio-recorded, and photographs will be taken of your design process and end-products (known as artefacts). No photographs will be taken of any of the participants.

#### How will your privacy be protected?

All of the information you provide will be kept confidential and anonymous, the only exception is where information is disclosed which indicates that there is a serious risk to you or to others. We will not report your name or anything that would make you personally identifiable in any outputs from the research. All participants will be given a pseudonym for the purposes of reporting, and any identifying information will be removed to ensure confidentiality. The group work conversations will be audio-recorded and once the workshop is completed, the recordings will immediately be transferred to an encrypted laptop and wiped from the recording device. Claudette will

be responsible for overseeing the transcription and the anonymity of the workshop proceedings. All audio-recordings will be destroyed after Claudette has completed her PhD. During the transcription process, all data will be anonymised in order to protect your identity. Your consent sheets will be kept in an encrypted file on a password protected computer, with only the researchers having access to it. All digital files, transcripts and summaries will be given codes and stored separately from any names or other direct identification of participants. Only those associated with this study will have access to the electronic records related to this study which are secured by encryption and are password protected.

#### What are the benefits of taking part in this research study?

Information from the workshops will be used to guide the development of an online tool that will assist the online help-seeking process, hopefully making it simpler and more reliable. The information will also be used to inform the development and improvement of online mental health supports.

### Will I be paid?

We will pay for any travel to and from the research site e.g. travelling to attend a workshop. Please keep all of your receipts.

### What are the risks of taking part in this research study?

You may feel that some of the topics discussed are stressful or upsetting. The researcher will be sensitive to this during the workshops and will encourage people to take a break or possibly withdraw from the activity if the circumstances become too stressful. If you are currently experiencing personal or emotional difficulties, or receiving psychological treatment or counselling, you will not be eligible to take part in this study.

If you do experience any distress from participation, please contact one of the mental health supports provided below:

#### Samaritans:

<u>Phone</u>: 116 123 (Freephone, Republic of Ireland) <u>Email</u>: jo@samaritans.org 24 hours a day, 365 days a year

#### If you are in crisis:

- Contact your local doctor. To find yours, visit www.icgp.ie/go/find\_a\_gp
- Go to, or contact, the Accident and Emergency Department of your nearest general hospital
- Emergency services can be contacted at any time by dialling 999 or 112.

#### Can you change your mind at any stage and withdraw from the study?

Participation in this research is voluntary. If you don't wish to take part, you don't have to. If you do consent to participate, you can withdraw from the workshop at any time up until the point the transcripts have been anonymised, without giving a reason. Your decision not to participate in this study will not have any effect on your future involvement with the Jigsaw or the Jigsaw Youth Advisory Panel.

# How will you find out what happens with this project and contact details for further information?

If you would like to be kept informed about the co-design workshops and the broader study, please contact Ms. Claudette Pretorius on <u>Claudette.pretorius@ucdconnect.ie</u>. You can also find more information general information about the TEAM project at this web address: www.team-itn.eu



Supervisor: Dr David Coyle Topic: Technology Enabled Mental Health for Young People.

Funder: European Union's Horizon 2020 research and innovation programme under the Marie Sklodowska-Curie Action grant number 722561 University College Dublin Belfield, Dublin 4, Ireland Email: Claudette.pretorius@ucdconnect.ie https://www.team-itn.eu

Dear Participant,

After you have read the Participant Information Leaflet, please tick your response in the appropriate box.

# Title of Project: Co-Designing an Online Help-Seeking Resource with Young People

I have read and understood the information sheet		
	No 🗆	
I have been able to ask questions about the study (Note: you can	Yes□	
contact Claudette via email: claudette.pretorius@ucdconnect.ie)	No 🗆	
I have received satisfactory answers to all my questions, where I have	Yes□	
had a query	No 🗆	
I have received enough information about this study	Yes□	
	No 🗆	
I understand that I have to be between the ages of 16 and 25 to be	Yes□	
eligible to participate in this study and if I am under the age of 18, I		
require parental consent to participate in this study.		
I understand that to safeguard my own wellbeing, if I am currently	Yes□	
experiencing personal or emotional difficulties, and/or receiving	No 🗆	
psychological treatment or counselling I am ineligible to participate in		
this study.		

I understand that the products and designs (known as artefacts) will	Yes□		
be photographed during and after the workshop. No photographs will			
be taken of me.			
I understand that the workshop will be audio recorded.	Yes□		
	No 🗆		
I understand I am free to withdraw from the study up until the	Yes□		
transcripts have been anonymised.	No 🗆		
I agree my anonymised research data will be stored securely by the	Yes□		
researcher up 5 years after the completion of the TEAM project.	No 🗆		
I consent to the fact that my anonymised data may be quoted in	Yes□		
dissemination activities including but not limited to PhD thesis, design	No 🗆		
guidelines, scientific publication, conference proceedings and			
presentations.			
I agree that my anonymised data can be stored in an Open Access	Yes□		
repository	No 🗆		
I understand that all information I provide for this study will be treated	Yes□		
confidentially where normal limits of confidentiality apply.	No 🗆		
I am aware that I can contact the researcher at any point to get further	Yes□		
information or clarification about this research study.	No 🗆		
I am aware that when the research study is complete, findings or	Yes□		
results from this research study will be available from the researcher.	No 🗆		
I agree to take part in the study.	Yes□		
	No 🗆		

## Participant Consent

I have read this information sheet and have had time to consider whether to take part in this study. I understand that my participation is voluntary (it is my choice) and that I am free to withdraw from the research at any time without disadvantage.

Participant's	
signature:	
Date of Birth	
Date:	
Participant's	
name in Print:	
Contact email:	

**RETURNING THE CONSENT FORM:** We would ask you to please return the scanned consent form to Claudette before the workshops take place.

**CONTACT DETAILS:** You can contact Claudette:claudette.pretorius@ucdconnect.ie

## D.3: Workshop Protocol

### Equipment

- Blank paper
- Sticky notes
- Pens and coloured markers
- Printouts of Personas (A4), one for each group member
- Printouts of Empathy map (A3) (1 per group)
- Printouts of help-seeking journey mapping sheets (A3) (Multiple per group)
- Digital camera and 3 x digital audio recorders
- Portable router with data loaded
- Notebook for field notes

## 1. Introductions

### Key aims:

- To introduce the facilitators, the TEAM project and the aim of the overall research
- To explain that the session is interactive and will involve a lot of creativity.
- To explain that the aim of the session is to gather early ideas of what an online mental health referral resource would look like and how it would work
- To make sure participants understand that the session will be audio recorded in individual groups and that photos will taken of the artefacts created during the workshop but not of the participants themselves.
- To emphasize to participants that should they feel uncomfortable or distressed at any point, they can let the facilitators know and they can address it together
- To establish participants in their groups and set the tone for the session

### Script:

"Hi everyone, my name is Claudette Pretorius, a PhD student from University College Dublin, and this is Naoise Kavanagh, the eMental Health Programme Manager from Jigsaw, and we'll be guiding you through this session.

I'm part of a European funded project called TEAM which is interested in how technology can support young people's mental health. My specific research looks at

how young people use the Internet to find help for their personal and emotional concerns and how an online tool could make this process easier.

We've invited you here because we are really interested in hearing and seeing what you think a tool of this kind should do and what it should like in order to help different types of help-seekers. This workshop will be very interactive and will be very fast-paced. To help along your thinking and to keep things focused, we'll be making use of personas today. Personas are fictional characters that represent different types of people that might make use of the online tool. We've created these personas based on previous research and they are not a real person.

Because some of these personas are going through some tough times in the scenarios we'll put to you, some might find participating in this workshop upsetting. If you find yourself feeling upset, let either me or Naoise know. You are welcome to leave the workshop at any time should you feel the need to do so.

This is a confidential space and whilst we encourage you not to share any personal experiences regarding your own online help-seeking, please do respect your group members and avoid talking about things mentioned here, outside of this space.

Before we get started, we are going to divide you into 3 groups and then start our first activity"

#### Activity materials:

**ICEBREAKER:** For round one, challenge the groups to find two things they all have in common with one another. For round two, let the room know that the two things their group has in common is now their team name (i.e. Zombie Cats – one group found out that everyone liked zombie movies and cats). Give the groups five minutes to figure out how they will act out their team name. When time is up, have each group act out their team name to the entire room and have others guess the team's name.

#### <u>OR</u>

**ICEBREAKER:** Grandma, Tiger, Ninja - It's similar to *rock, paper, scissors*, except you act out each role with your entire body. For example, a Grandma would be hunched over, a tiger would leap up and go "rawr", and a ninja would strike a ready-to-attack pose.

- Ninja beats Tiger (since it's a Ninja)
- Tiger eats Grandma
- Grandma beats Ninja (since she's the Ninja's Mom)

Have each member of the group go up against each other until there is an overall winner. Then have the winners from each group go up against each other. Only one turn allowed per pairing in order to make this quick and challenging activity.

## 2. Introducing the Personas

#### Key aims:

To familiarise each group with their particular persona

 To allow groups to think about the scenarios from the perspective of the persona as opposed to from their own perspective

#### Script:

"We are now going to assign each group a persona at random. You'll be completing all the activities from this point forward from the perspective of the persona. To make this easier, we are going to start with an activity which should make it easier to see things through the eyes of the persona.

We're going to ask you to read through the personas on your own, then in your groups look at the empathy maps. There is scenario at the top of these sheets, explaining the tough time the persona is currently experiencing. In your groups, talk together about how this persona is feeling, what they're and saying, and what are they likely to do in this situation. Think about what their worries are right now in light of this scenario.

Note down all of your comments on the empathy maps provided. You'll have 20 minutes to complete this activity"

#### Activity materials:

I. Personas:

## Jane Smith



#### Bio

Jane is currently busy with her research masters degree in law. She is really interested in the arts and enjoys visiting the theatre with her friends. She's a very private person, who shares her concerns only with her closest friends and her older sister. She also enjoys spending time on her own, reading books or watching series on Netflix. Jane has experienced a number of 'lows' in the past but has never seen her GP or another health professional about this.

#### **A Typical Day**

Jane gets up at 6.30am in the morning. She has breakfast at home and takes the bus into college at 7.30 every morning. Her commute lasts around an hour. Depending on her schedule, Jane attends classes or works on her own from the library. Jane will grab a coffee mid-morning with one of her close friends before continuing with work and classes for the rest of the day. Jane will then travel home again by bus, before joining her family for dinner. After dinner she goes to her room where she finishes off some work from the day and then watches some Netflix before going to bed.

#### **Technology Use**

Jane own's her own laptop and mobile phone. She uses her laptop for her studies to conduct the majority of her research and work. Jane enjoys reading different forums such as Reddit and engaging in content there. Jane also streams Netflix from her laptop. She shares her Netflix account with her sisters. Jane takes her mobile phone with her everywhere she goes and often uses it to listens to podcasts on the bus when travelling into college.



#### To graduate at the end of this year cum laude and go on to work for an organisation such as the Irish Human Rights and Equality

Commission To take better care of her wellbeing, both physically and mentally, and hopes to achieve

more of a balance after college.

## Angela Kay

Privacy

Social Justice



to talk to someone about my troubles" AGE: 20

OCCUPATION: Receptionist FAMILY: Single, lives with two flatmates LOCATION: Cork

#### Values and Interests



#### Bio

Angela is currently working as a receptionist for a small advertising firm. She lives in shared apartment in Cork with two flatmates, lan and Lacey. Angela is a very personable and charming person but has few close friends although she has many acquaintances. She is not close to her family. She values her privacy and shares very little about her history with those around her. Angela has a history of depression and anxiety and has experienced at least 3 panic attacks in the past.

#### **A Typical Day**

Angela wakes up at 7am every morning. She gets coffee and croissant from her local coffee shop on her way to work. Her days at work are fairly busy. She takes a short lunch break to pop out to get something to eat. She chats to many of her colleagues throughout the day and often goes out for drinks or social events in the evening. Angela often gets home quite late and then spends time on social media. She often struggles to fall asleep.

#### **Technology** Use

Angela owns a mobile phone but no laptop. The apartment has a television and she'll sometimes watch something on there with her flatmates but it's very rare. Angela is very active on her social media accounts especially Instagram and Snapchat.

anton Uco	
Laptop Ose	
Social Netwo	orks
Mobile Apps	i

#### **Future Goals**

- To start saving some money, so she can take 6 months off work to go travel in South America
- To work towards managing her anxiety as she doesn't want a panic attack whilst abroad.

## Myles James



"Sometimes it can be hard to identify what the problem is when you're having a ough time and it helps to talk others ther

AGE: 19 OCCUPATION: College Student FAMILY: Girlfriend Kat, lives his mom and dad. LOCATION: Kildare

#### Values and Interests

#### Relationships



Bio

Myles is a student in his first year of college. His college is in Dublin, but he lives in a small town in county Kildare. He has been with his girlfriend, Kat, for two years and she is also currently studying in Dublin, where she moved to recently. Myles is finding the change from school to college challenging and misses having Kat around. He doesn't work during the semester but has a job as a waiter during the summer. Myles' loves playing rugby and he can be found at practice twice in the week and playing matches on Saturdays. He finds Dublin very busy and impersonal. He enjoys meeting people and making conversation but has found this to be quite daunting at college. Myles values relationships and often opens up to his girlfriend about things bothering him.

#### A Typical Day

Myles has to wake up at 5.30 in the morning in order to get to college by 9am for classes. He takes the train into Dublin and then takes the bus. He spends most of his day in classes. He has lunch with a small group of friends who have come to the same college as him. Myles has made a few new friends in classes and often has to decline offers for a pint after college as he has to get the train back home or be back home in time for rugby practice on certain days. Myles does lots of college work at night after dinner.

#### **Technology Use**

Myles owns a laptop which he got from his parents as a gift before starting college. He also has a mobile phone and PS4 console. Myles uses his phone to message and video call his girffriend; to watch videos on YouTube and listen to music. Myles is put off by the ads on websites. Myles doesn't use his PS4 as much as he used to but used to enjoy playing multi-player games online where he connects with other players across the world.

#### Mobile Phone Use

Laptop Use	
Social Networks	
Mohile Apps	

#### **Future Goals**

- To graduate from college in four years' time and then get a job closer to home.
- One day he'd like to be married but before that hopes he can travel with Kat.
- To keep playing rugby and feels that it will always be a part of his life.

## II. Empathy Maps





## 3. Mapping the help-seeking journey

Key aims:

- To simulate the online help-seeking pathway different types of help-seekers will take to meet their needs
- To identify whether different types of help-seekers take different online helpseeking journeys
- To identify pain points in the online help-seeker's journey
- To identify what's working successfully on the help-seeker's journey

#### Script:

"We're interested in how your persona would go about looking for help for their current situation using the Internet. If you feel comfortable, use one group member's phone, to carry out the tasks the persona would do in order to meet their help-seeking goals. We'd appreciate it if you could note down each step on the 'mapping sheets' provided. For each action taken, think about the questions, thoughts and feelings your persona would have and note them down under the action. You'll see there is also space to note down something is working well and when it isn't, note these down too when applicable. Not all the boxes on the table will be applicable for each action. You

can use as many of these as you need. We advise that if you're using an Internet browser that you do so in a 'private' or 'incognito' window. Please connect to the wifi network indicated with the password provided. You'll have 20 minutes to do this"

ACTIONS:			
QUESTIONS:			
THOUGHTS:			
FEELINGS:			
MOMENTS OF SATISFACTION:			
FRUSTRATIONS:			

#### Activity materials:

**GOAL:** 

### 4. Designing the Online Experience

Key aims:

- To design an online mental health referral resource for young people from the perspective of the persona
- To identify what the persona will need to overcome the pain points identified in the above exercise.

#### Script:

"We are now interested in seeing what an online tool that makes the online help-seeking process for your persona easier. Thinking of the previous exercise and thinking about which steps frustrated you, we want you and your group to design the ideal online experience through the use of a tool based online. We've given you lots
of markers, paper, and post-it notes to help and we'll help guide you through the process.

First each group member will come up with a bunch of ideas on their own in the following categories:

- 1. Features that have to be included for your persona
- 2. Format of the tool (webpage, web based app, online platform of some sort?)

No idea is too far-out, be as creative as you can. Try not share your ideas with your other group members until you are all done.

Next share, your ideas in these categories with your group members. Group similar ideas together and continue to elaborate on different ideas together.

Thirdly, each group member takes an A4 sheet and divides it into 8 sections. You'll have 8 minutes to sketch one idea on each rectangle. Share your sketches with your teammates, indicating how your idea would work, each of you gets a turn. Then using the small round dots on your tables, vote for the sketches you like most, you each get 3 votes. It's okay to vote for your own sketch.

Select the ideas your group thinks is the best and flesh out the sketch in a more detailed sketch of your online tool. Use multiple frames, pictures and words in your sketch. This will help communicate what you're trying to achieve. Some people might find it useful to show multiple screens or a storyboard. Find what works best for your group.

At the end we'll ask you to present your design to the whole group and walk us through it."

### Activity materials:

- Post-it notes
- Pens and Markers
- A4 blank sheets
- Newsprint
- Scissors
- Coloured card
- Storyboard example sheets
- Dot stickers

### 5. Reflection Exercise

Key aims:

- To summarise the session and bring it to a close
- To check in with all participants and see that they're OK

### Script:

"Before we close the session, we'd just like to ask you a few questions.

- 1. Which features or ideas stood out? Which are most intriguing and exciting?
- 2. What must-have's are we seeing?
- 3. What was a challenge? What conflicts emerged?
- 4. How did this feel for you as a participant?

Thank you for taking the time to participate today, your views, insights and creativity has been invaluable. If you'd like further information on this study please get in touch via the email address provided on your information leaflet."

### Appendix E | Chapter 7 Supplementary Material

#### E.1: Ethics Approval



UCD Office of Research Ethics Roebuck Castle University College Dublin Belfield, Dublin 4, Ireland T +353 1 716 8767 An Oifig Eitic Thaighde UCD

Caisleán an Ruabhoic An Coláiste Ollscoile, Baile Átha Cliath Belfield, Baile Átha Cliath 4, Éire hrec@uod.ie www.ucd.ie/researchethics

February 5th, 2020

Ms Claudette Pretorius c/o Dr David Coyle UCD School of Computer Science Belfield Dublin 4

Re: LS-20-03-Pretorius-Coyle: A User Study to Test Design Guidelines for Online Mental Health Resources

Dear Ms Pretorius

Thank you for your response to the Human Research Ethics Committee – Sciences (27/01/20). The Decision of the Committee is that approval is granted for this application which is subject to the conditions set out below.

Please note that public liability insurance for this study has been confirmed in accordance with our guidelines.  $\ensuremath{^\mathbb{I}}$ 

Please note that approval is for the work and the time period specified in the above protocol and is subject to the following:

- Any amendments or requests to extend the original approved study will need to be approved by the Committee. Therefore you will need to submit by email the Request to Amend/Extend Form;
- Any unexpected adverse events that occur during the conduct of your research should be notified to the Committee. Therefore you will need to Submit, by email, an Unexpected Adverse Events Report;
- You or your supervisor (if applicable) are required to submit a signed End of Study Report Form to the Committee upon the completion of your study;
- This approval is granted on condition that you ensure that, in compliance with the Data
  Protection Acts 1988 and 2003, all data will be managed in accordance with your
  application and that you will confirm this in your End of Study Report;
- Please note that further new submissions from you may not be reviewed until any End
  of Study Reports due have been submitted to the Office of Research Ethics. That is, any
  earlier study that you received ethical approval for from the UCD HRECs;
- You may require copies of submitted documentation relating to this approved application and therefore we advise that you retain copies for your own records;
- Please note that the granting of this ethical approval is premised on the assumption that the research will be carried out within the limits of the law;
- Please also note that approved applications and any subsequent amendments are subject to a Research Ethics Compliance Review.

The Committee wishes you well with your research and look forward to receiving your End of Study Report. All forms are available on the website <u>www.ucd.ie/researchethics</u> please ensure that you submit the latest version of the relevant form. If you have any queries regarding the above please contact the Office of Research Ethics and please quote your reference in all correspondence.

Yours sincerely

hina H Cover liona McGovern

Chair, Human Research Ethics Committee - Sciences

[9] http://www.ucd.ie/researchethics/information\_for\_researchers/insurance/

### E.2: Information Sheet and Consent Form





Supervisor: Dr David Coyle Topic: Technology Enabled Mental Health for Young People.

Researcher: Ms. Claudette Pretorius

Funder: European Union's Horizon 2020 research and innovation programme under the Marie Sklodowska-Curie Action grant number 722561 School of Computer Science University College Dublin Belfield, Dublin 4, Ireland Email: Claudette.pretorius@ucdconnect.ie https://www.team-itn.eu

#### Project Title: A User Study to Test Design Guidelines for Online Mental Health Resources

This research is being conducted by Claudette Pretorius, a doctoral candidate in School of Computer Science at the University College of Dublin under the supervision of Dr David Coyle. This research is part of the TEAM (Technology Enabled Youth Mental Health) consortium. Our focus is on the design and development of new technology-enabled mental health services.

We would like to invite you to take part in a user study that aims to evaluate the design criteria for an online help-seeking tool for mental health concerns. Before you decide whether to take part it is important that you understand why the research is being done and what it will involve. Please take time to read this information sheet carefully.

#### What is this research about?

This research is interested in learning how young people look for help for personal and emotional concerns online and how an online tool could make this process easier. We are particularly interested in your thoughts on different platforms that can be used to find online mental health resources. In this study we use personas representing different kinds of young people to do this. A persona is a fictional character that has been created using findings from previous research and represents a set of requirements we want to design for. It is not a real person. We'll ask you to look for information online about mental health for this persona using the pre-selected platforms. We'll then ask you opinion about these platforms as tools for young people.

#### Why are we doing this research?

We understand that it is sometimes difficult to find the right information online. By gathering information on young people's current online information and help-seeking behaviours, we hope by the end of the research project to develop validated guidelines for an online tool that can safely and accurately refer young people to online supports relative to their level of need. User studies allow us to work with the target audience for whom the tool is intended. We value your input and evaluation regarding the design of a few different versions of a tool such as this one.

#### Why have you been invited to take part?

You have been invited to take part because you are a young person between the ages of 18 and 25 and living in Dublin. Your views and experiences are very important in helping us understand how young people look for support and information online for personal and emotional concerns and how a tool could facilitate this.

#### How will your data be used?

Claudette Pretorius is a member of TEAM (Technology Enabled Mental Health for Young People) which has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No. 722561. Under Horizon 2020, beneficiaries should engage in dissemination activities which means sharing research results. Research results of the study may be presented at future academic or research conferences, or within research journals. Information from this study will also be included in a doctoral thesis. However, no individual participant will be identified in any publication or presentation and only anonymised quotes will be used in these reports and publications.

With your permission, data related to your participation will be submitted to the Horizon 2020 open access repository. This data is completely anonymized. This process is integral to the

research process as it allows other researchers to verify results and avoid duplicating research in the future.

#### What will happen if you decide to take part in this research study?

If you wish to take part in the study, you can return a signed consent sheet to Claudette and you will be given the date to attend the study. The study will take place at University College Dublin (UCD), in the Insight Centre for Data Analytics. It is for this reason that the study is open only to those living in Dublin. We'll ask you to travel to UCD and meet with Claudette, the researcher on this study. The study will last approximately one hour. The session will be audio-recorded using an audio device. The computer screen will also be recorded using screen recording software whilst you use the different platforms. It will not record your face. Your name will not be associated with of the recordings.

Audio recordings will be transferred via secure data transmission software to a professional transcriber who is fully based in Ireland and has been used by the researchers before. The data will temporarily be stored with this professional transcriber. They will temporarily hold the data on a password protected laptop and will be instructed to delete the data on the completion of the transcription.

In order to safeguard your wellbeing, <u>if you are currently experiencing personal or emotional</u> <u>difficulties</u>, or receiving psychological treatment or counselling, you will not be eligible to take <u>part in this study</u>. The entire session will be audio-recorded.

### How will your privacy be protected?

We will not report your name or anything that would make you personally identifiable in any outputs from the research and all best endeavours will be made to ensure that data in any publications is anonymised. All participants will be given a pseudonym for the purposes of reporting, and any identifying information will be removed to ensure confidentiality.

All audio-recordings will be destroyed after of 5 years after the study has been completed. During the transcription process, all data will be deidentified in order to protect your identity. Your consent sheets will be kept in an encrypted file on a password protected computer, with only the researchers having access to it. All digital files, transcripts and summaries will be given codes and stored separately from any names or other direct identification of participants. Only those associated with this study will have access to the electronic records related to this study which are secured by encryption and are password protected.

#### What are the benefits of taking part in this research study?

Information from this study will be used to guide the development of an online tool that will assist the online help-seeking process, hopefully making it simpler and more reliable. The information will also be used to inform the development and improvement of online mental health supports.

#### Will I be paid?

We will pay for any travel to and from the research site e.g. travelling to attend the study. Please keep all of your receipts. As a token of appreciation of your time, we would like to give you a €10 TESCO gift voucher.

#### What are the risks of taking part in this research study?

You may feel that some of the topics discussed are stressful or upsetting. The researcher will be sensitive to this during the study and will encourage you to take a break or possibly withdraw from the activity if the circumstances become too stressful. If you are currently experiencing personal or emotional difficulties, or receiving psychological treatment or counselling, you will not be eligible to take part in this study.

If you do experience any distress from participation, please contact one of the mental health supports provided below:

#### Samaritans:

<u>Phone</u>: 116 123 (Freephone, Republic of Ireland)
<u>Email</u>: jo@samaritans.org
24 hours a day, 365 days a year

### If you are in crisis:

- Contact your local doctor. To find yours, visit www.icgp.ie/go/find\_a\_gp
- Go to, or contact, the Accident and Emergency Department of your nearest general hospital
- Emergency services can be contacted at any time by dialling 999 or 112.

### Can you change your mind at any stage and withdraw from the study?

Participation in this research is voluntary. If you don't wish to take part, you don't have to. If you do consent to participate, you can withdraw from the study at any time without giving a reason.

# How will you find out what happens with this project and contact details for further information?

If you would like to be kept informed about the study and the broader study, please contact Ms. Claudette Pretorius on <u>Claudette.pretorius@ucdconnect.ie</u> . You can also find more information general information about the TEAM project at this web address: <u>www.team-itn.eu</u>

### E.3: Persona Jo

**Hard facts:** Jo lives with their family (mom, dad, sister and brother) in an estate in Dublin. Jo is 22 years old, in a relationship and studying at UCD. Jo has a small group of good friends, mostly from school that also go to UCD. Jo has experienced a one or two periods in the last few years, when they've felt quite low and overwhelmed by feelings of stress.

**Interests and values:** Jo enjoys college and the opportunity to meet new people there. However, in general, Jo is generally a private person but enjoys chatting to friends, and when experiencing concerns mostly shares with their best friend and older sister. Jo's hobbies include playing the guitar and reading. Jo tries to live a balanced life by going to gym regularly; taking time to read and play the guitar; spending time with friends and family; and working hard at college. It can be hard to maintain a balance especially when there's a lot of work to be done for college. Jo works in a retail job some weekends and over the summer to earn some extra money.

**Computer, Internet and mobile phone use:** Jo own their own laptop and mobile phone. Jo uses the laptop for college work and to stream Netflix. Jo shares their Netflix account with their siblings. Jo takes their mobile phone everywhere and often uses it to access social media including Instagram and snapchat.

**A Typical day:** Jo wakes up between 7am and 8am to get the bus into college in time for their first lecture. Jo spends most of their day at college, attending lectures and labs, working in the library and hanging out with friends. Three days a week, before taking the bus home, Jo goes to the gym for an hour with a close friend. Jo often uses the time on the bus to check social media and watch videos on YouTube. In the evenings, Jo has dinner with the family, before going to their room, to do some work and/or watch Netflix. On weekends, Jo goes out with friends, does one or two shifts at work and spends some time playing guitar.

### <u>Scenario</u>

Jo has been having a tough time for the last few weeks. They're struggling to concentrate during lectures and on their college work. Jo feels pressured by the upcoming exams. Jo is having a hard time falling asleep at night or when they do fall asleep, they wake up often and find it difficult to fall back asleep. Jo has been feeling sad a lot of the time lately and finds it hard to get excited about going out with friends or playing the guitar. Jo knows that something isn't quite right and wants to understand what has been going on and what they can do about it.

### E.4: Chat Directory Script

Welcome to the onlin	ne help guide! What ki	ind of resources are ye	ou looking for today?
Would you like			
Information?	To connect with	Tools that make	Something you can
	someone?	finding relevant	do right now?
		resources easier?	
After selecting one	of the options above	, provide one of the f	ollowing columns of
options			
Info pages	Phone helpline	For under 18's	Relaxation
			exercises
Personal stories	Text helpline	Search function	
Podcasts	Email helpline	Local location	
		finder	
Training and	Online chat		
courses			
	Online support		
	groups		
	Offline support		
	groups		
	Offline personal		
	counselling		
After respondent m	akes a selection, pro	ovide a list of resour	ces that match that
selection			

### E.5: TENS-Interface

Reflect on your experience on using this platform to find the mental health resources that might be helpful to your persona and rate your agreement with the following statements:

		Stron	gly		Stron	gly
		Disag	gree		Agre	e
	Statement	1	2	3	4	5
1	Using this platform, I feel very					
	capable and effective in finding					
	mental health resources.					
2	Using this platform, I feel confident					
	in my ability to find mental health					
	resources.					
3	Using this platform, it's easy to find					
	mental health resources.					
4	Using this platform, I find looking					
	for mental health resources too					
	challenging					
5	I find using this platform to find					
	mental health resources too					
	difficult to do regularly.					
6	The platform provides me with					
	useful options and choices.					
7	I can get the platform to do the					
	things I want.					
8	I feel pressured by the platform.					
9	The platform feels intrusive.					
10	The platform feels controlling.					
11	Using the platform helped me to					
	feel part of a larger community.					

### (1= Do not agree; 5= strongly agree)

12	The platform makes me feel					
	connected to other people.					
13	I don't feel close to others when I					
	engage in looking for mental health					
	resources on this platform.					
14	Using this platform, doesn't					
	support meaningful connections to					
	others					

### E.6: Interview Schedule

- 1. Describe your experience today of using different platforms to look for online mental health resources?
- 2. What aspects of the different platforms did you like and why?
- 3. Were there any parts of the different platforms that you found frustrating and why?
- 4. Sometimes when people are looking for help online, what they'd like is information, how did the platforms help your persona find the information they were looking for?
- 5. When people go online, they're looking for differing kinds of things, information, activities, linking in with groups or people, how did the different platforms help someone like Jo, find what they're looking for?
- 6. Which aspects of the different platforms allowed you to find personalised options?
- 7. Having tried all of the platforms, did you feel anything was missing from the platforms in order help a young person find the help and information they needed?
- 8. Did you find any filters were missing from the platforms when you were looking for resources?
- 9. If you were looking for resources online, what would you need to find them?
- 10. If you were advising a friend on which of these to use, which would you recommend and why?

### E.7: TENS-Interface ANOVA Results

	Sum of	DF	Mean	F	Sig.
	Squares		Square		
Between					
Squares	98.2333	4	24.5583	1.0294	0.4004
Within					
Groups	1312.165	55	23.8575		
Groups					
Total:	1410.398	59			

Table 7.13 ANOVA results for total scores on the Competence Scale

Table 7.14 ANOVA results for total scores on the Autonomy Scale

	Sum of	DF	Mean	F	Sig.
	Squares		Square		
Between					
Squares	36.6671	4	9.1668	0.7687	0.5503
Within					
Groups	655.918	55	11.9258		
Groups					
Total:	692.5851	59			

Table 7.15 ANOVA results of total scores on the Relatedness Scale

	Sum of	DF	Mean	F	Sig.
	Squares		Square		
Between	139.2321	4	34.808	2.2477	0.0756
Squares					
Within	851.7507	55	15.4864		
Groups					
Groups	990.9828	59			
Total:					

### Appendix F | Publications

#### **Review**

## Young People's Online Help-Seeking and Mental Health Difficulties: Systematic Narrative Review

Claudette Pretorius<sup>1</sup>, BSocSci, MA; Derek Chambers<sup>2</sup>, MA; David Coyle<sup>1</sup>, PhD

<sup>1</sup>School of Computer Science, University College Dublin, Dublin, Ireland <sup>2</sup>Connecting for Life, Health Service Executive, Cork, Ireland

**Corresponding Author:** Claudette Pretorius, BSocSci, MA School of Computer Science University College Dublin Belfield Dublin Ireland Phone: 353 017162818 Email: claudette.pretorius@ucdconnect.ie

### Abstract

**Background:** Young people frequently make use of the internet as part of their day-to-day activities, and this has extended to their help-seeking behavior. Offline help-seeking is known to be impeded by a number of barriers including stigma and a preference for self-reliance. Online help-seeking may offer an additional domain where young people can seek help for mental health difficulties without being encumbered by these same barriers.

**Objective:** The objective of this systematic literature review was to examine young peoples' online help-seeking behaviors for mental health concerns. It aimed to summarize young peoples' experiences and identify benefits and limitations of online help-seeking for this age group. It also examined the theoretical perspectives that have been applied to understand online help-seeking.

**Methods:** A systematic review of peer-reviewed research papers from the following major electronic databases was conducted: PsycINFO, Cumulative Index of Nursing and Allied Health Literature, PubMed, Cochrane Library, Association for Computing Machinery Digital Library, and Institute of Electrical and Electronics Engineers Xplore. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines were followed. The search was conducted in August 2017. The narrative synthesis approach to reviews was used to analyze the existing evidence to answer the review questions.

**Results:** Overall, 28 studies were included. The most common method of data collection was through the use of surveys. Study quality was moderate to strong. Text-based query via an internet search engine was the most commonly identified help-seeking approach. Social media, government or charity websites, live chat, instant messaging, and online communities were also used. Key benefits included anonymity and privacy, immediacy, ease of access, inclusivity, the ability to connect with others and share experiences, and a greater sense of control over the help-seeking journey. Online help-seeking has the potential to meet the needs of those with a preference for self-reliance or act as a gateway to further help-seeking. Barriers to help-seeking included a lack of mental health literacy, concerns about privacy and confidentiality, and uncertainty about the trustworthiness of online resources. Until now, there has been limited development and use of theoretical models to guide research on online help-seeking.

**Conclusions:** Approaches to improving help-seeking by young people should consider the role of the internet and online resources as an adjunct to offline help-seeking. This review identifies opportunities and challenges in this space. It highlights the limited use of theoretical frameworks to help conceptualize online help-seeking. *Self-determination theory* and the *help-seeking model* provide promising starting points for the development of online help-seeking theories. This review discusses the use of these theories to conceptualize online help-seeking and identify key motivations and tensions that may arise when young people seek help online.

#### (J Med Internet Res 2019;21(11):e13873) doi: 10.2196/13873

#### KEYWORDS

RenderX

internet; help-seeking behavior; youth; mental health; online behavior; self-determination theory; systematic review

http://www.jmir.org/2019/11/e13873/

#### Pretorius et al

#### Introduction

#### Background

Mental health is an important health concern for young people around the world, with the World Health Organization estimating that 10% to 20% of young people experience mental health disorders [1]. It is estimated that 50% of all adult mental disorders start in adolescence [2]. Yet, most young people are reluctant to seek help from formal mental health services [3-5]. The help-seeking process is difficult; it is complicated by personal and contextual factors, such as access, stigma, and mental health literacy [3,6,7]. It then becomes critically important to find alternative methods in which to target and assist young people who are not receiving help.

Figure 1. Rickwood's Help-seeking model.

Mental health help-seeking has been defined as "...an adaptive coping process that is the attempt to obtain external assistance to deal with a mental health concern" (p. 180) [8]. That external assistance can be from a wide array of sources. Rickwood et al [3] propose a conceptual model specifically taking into account the needs of young people (Figure 1). They describe help-seeking as a process that involves the following: (1) becoming aware of symptoms and making the appraisal that assistance might be required; (2) expressing the symptoms that they are experiencing and that they are in need of help or support; (3) the person should then be aware of sources of help that are available and accessible to them; and (4) the final step that depends on the willingness of the help-seeker to disclose their difficulties to the selected, available source [3].



Two main types of help-seeking sources have been identified: formal and informal. Formal help-seeking can be understood as seeking assistance from any professional who has a recognized and legitimate role in providing support. Informal help-seeking is understood as pursuing assistance from informal social supports with whom the individual may or may not share a personal relationship [3]. Research shows that most young people have a preference for self-reliance when experiencing personal and emotional concerns and are more likely to make use of informal help sources than formal help sources, when and if they do reach out [3].

Most recently, computer-mediated technologies have begun to influence the help-seeking process. The internet offers another pathway to access care and help when young people are experiencing mental health concerns. Young people use the internet as their main source of information for all of their daily needs; accordingly, this logically extends to accessing information regarding their physical and mental health [9-11]. Various formal online services are readily available, as are informal resources such as discussion boards and social media [12]. Information gained from these sources could facilitate the help-seeking process to the next stage and could influence the way in which individuals form their help-seeking attitudes. The internet also offers unique benefits in the form of anonymity, access, and user control that can sometimes interfere with the offline help-seeking process [13]. The availability of high-quality mental health information and online resources could have a significant impact on the health outcomes of a young person [14].

#### Objectives

Although the potential benefits of online mental health resources have been acknowledged, there are also some concerns. For example, there is a worry that online help-seeking may delay access to formal help sources [10]. It is important to understand how these online resources, both formal and informal, are viewed by young people. Systematic reviews have been conducted in this area with a focus on how young people search for health-related information on the internet [15] and the effectiveness of online mental health services to improve help-seeking [14]; however, this review sought to understand the process and experiences of young people with regard to their online help-seeking experiences. The objectives of this narrative review [16] were to conduct a systematic analysis of the research on this topic and use the research to identify future opportunities for research and design that can improve the online help-seeking experiences of young people. The specific aims of this systematic review were as follows:

- 1. To examine the strategies employed by young people to search for help online for mental health difficulties.
- 2. To describe young people's experiences of online help-seeking for mental health difficulties.
- 3. To identify the benefits of young people's use of online mental health resources for help-seeking.
- 4. To identify the limitations of young people's use of online mental health resources for help-seeking.

### Methods

#### Search Overview

This review was conducted adhering to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines and was registered on the PROSPERO database (PROSPERO registration number: CRD42017072487). On the basis of the aims of the study, inclusion and exclusion criteria were established to guide the subsequent search process.

#### Search Strategy

The following 6 databases were searched from database inception (no limits were placed on the publication date as the evidence base in this area is very recent and to the author's (CP, DCUCD, and DCHSE) knowledge, a systematic review of this nature has not been completed before): PsycINFO, Cumulative Index of Nursing and Allied Health Literature, PubMed, Cochrane Library, Association for Computing Machinery Digital Library, and Institute of Electrical and Electronics Engineers Xplore in August 2017. In addition, the reference lists of all the included studies were scanned for relevant papers. The search terms aimed to represent the primary concepts of *online help-seeking, mental health*, and *young people*. Keywords were generated for each of these concepts by examining the terminology used in review papers in the help-seeking literature,

and the authors sought the guidance of a trained librarian in the formation of the search string. The search strings are included in Multimedia Appendix 1. In keeping with the emerging youth mental health paradigm as described in the *International Declaration on Youth Mental Health* [17], the studies were restricted to young people aged 25 years and younger. Only English-language studies were included. All studies identified in the database search were exported to a reference managing software (EndNote X8 for Mac, Clarivate Analytics), and duplicate records were deleted.

The initial search identified 1890 published English-language abstracts (Figure 2). After removing the duplicates, 1300 papers remained. These papers were then reviewed by title and abstract to determine whether they met the inclusion criteria, resulting in 93 potentially relevant studies. At this stage, the full texts of these studies were obtained to confirm whether the inclusion and exclusion criteria listed below were met, resulting in 65 studies being excluded. The remaining 28 studies were included.

A random sample of 10% (130/1300, 10/93, 3/28) of the papers was re-examined at 3 stages (screening by title and abstract, screening by full text, and validity assessment) of the process by the other authors (DCUCD and DCHSE) of this paper. A few discrepancies were noted, and those were resolved by discussion and subsequent double checking to ensure consistency.

Figure 2. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRIMSA) flow diagram illustrating the screening process of papers.



#### **Data Extraction**

Each paper was read by CP and relevant details were extracted into a Microsoft Excel spreadsheet. There were a number of different protocol details that were examined and recorded for each paper. The coding scheme was used to help identify the components relevant to the study design and to address the research questions. The coding scheme included the year of publication, purpose of the study, country, number of participants, participants' characteristics (eg, medical conditions and age), theoretical framework, research design, sampling, data collection methods, instruments (including reliability and validity), data analysis, help-seeking model employed, strategies found to be used by young people to seek help online, young people's experiences of online help-seeking, facilitators, barriers, major findings, and study limitations.

#### **Analysis and Synthesis**

Quality assessment of included studies was conducted using the Critical Appraisal Skills Program (CASP) checklists [18] as there are quantitative and qualitative versions available to allow appraisal across different study designs. The CASP checklists enable the assessment of trustworthiness, relevance, and results of published papers and are divided into 3 sections to assess internal validity, results, and relevance to practice. Quality criteria for surveys included sections on research question and design, sampling framework and participant understanding, instrument metrics, response rate, coding and analysis, and result presentation [19-21].

These sections are assessed by questions that can be answered with *yes*, *no*, or *can't tell*. Each study received an overall rating

of either *strong*, *moderate*, or *weak*, based on the number of questions scored as *yes*. Studies had to be scored as *yes* on majority of the questions to be rated *strong* overall (see Multimedia Appendix 2 tables for details, as criteria differed by study design).

The first author (CP) performed all of the quality assessments, with a 10% sample being given to the second author (DCUCD) to compare. Following the quality assessment stage, the inclusion of studies and extraction of key findings were finalized. Extracted data were entered into a table of study characteristics, including the quality assessment ratings for each study.

The decision was made to use narrative synthesis as it provides a broad overview of relevant information through a textual approach and is appropriate when it is expected that the studies will be heterogenous. Owing to the nature of the review questions, it was expected that the studies included would investigate help-seeking differently, make use of different research questions, and use different criteria to investigate help-seeking behaviors; thus, it would not be appropriate to make use of statistical synthesis techniques. The Guidance on the Conduct of Narrative Synthesis in Systematic Reviews [16] informed the data synthesis process to ensure that results and analysis were reported accurately. All the data extracted from the papers are presented narratively in text and summary tables.

#### **Eligibility Criteria**

The inclusion and exclusion criteria are shown in Textbox 1.

Textbox 1. Inclusion and exclusion criteria.

Inclusion criteria

- Young people not older than 25 years;
- Participants who present with psychological distress, self-selected general population samples, and those who have received a diagnosis from a health care practitioner;
- Studies designed to investigate and document the online help-seeking intentions and behaviors of young people;
- Studies that included an intervention or interventions that were designed to improve help-seeking attitudes or increase help-seeking intentions or help-seeking behaviors of young people;
- Web-based help-seeking interventions;
- Online mental health resources;
- Informal and formal help-seeking.

#### Exclusion criteria

- Studies focused on a third party seeking help for the young person;
- Not mental health related;
- Not a Web or mobile app-based;
- Unrelated technology, for example, computer games and their impact on mental health and social media and forums that are not specifically focused on mental health-related topics;
- Studies focused on online treatment methodologies and interventions, for example, computerized cognitive behavioral therapy or online counselling;
- A review paper.

#### Results

#### **Study Characteristics**

A total of 28 studies met the inclusion criteria (see Multimedia Appendix 3), of which the majority (n=16) were conducted in Australia. Others were conducted in the United Kingdom (n=4), Canada (n=4), the United States (n=2), Ireland (n=1), and the Netherlands (n=1). The studies were published between 2010 and 2017.

The research methodologies of the studies were varied. Only 4 of the 28 included studies mentioned which help-seeking model they employed to inform their study design [6,12,22,23]. These models were limited to Rickwood's help-seeking model and the theory of planned behavior. Survey research was the most widely employed research design; overall 11 studies [24-33] made use of an online survey and 4 studies [34-37] administered the survey in person to collect data from participants. Survey questions included standardized measures such as the General Help-Seeking Questionnaire and mental well-being scales such as the Kessler Psychological Distress Scale, but questions regarding technology and internet use varied and no standardized scales seemed to be available. Areas explored in these sections of the surveys included the internet and social media use, use of online mental health resources, perceived usefulness of these resources, and preference regarding these resources. Other study designs included 1 randomized controlled trial [38], 1 feasibility study [39], 2 comparative studies [40,41], and 4 qualitative studies [9,42-44]. These studies aimed to assess the intention to seek help from different help sources, previous help-seeking behaviors from different help sources, level of psychological distress, and preferred modes of delivery of online mental health services.

The number of participants in each study ranged from 23 to 3946. Their ages ranged from 12 to 25 years. The majority of studies had gender-mixed samples; however, 3 studies looked specifically at the online help-seeking behavior of males [9,22,25]. In all, 9 studies recruited participants who were students university or high at school а [9,22,24,27,30,31,35,37,42], whereas studies 6 [25,26,28,29,32,33] used online recruitment strategies. Most studies (n=22) were conducted with samples not selected on the basis of mental health status. However, 5 studies focused on participants who had reported experiencing self-harm and suicidal ideation [24,28,36,43,45], and 1 study specifically recruited participants who had been diagnosed with psychosis and nonpsychotic mood disorders [46].

#### **Methodological Evaluation**

Many of the studies achieved a strong or moderate rating on the checklists. However, the survey studies showed poor adherence or failed to report that they had indeed piloted the survey with a small number of young people before administering the surveys. Furthermore, randomized controlled trials showed small treatment effects, and there was poor evidence of rigorous data synthesis methods in the qualitative studies. See Multimedia Appendix 2.

#### Limitations of the Studies

All of the studies included some notable limitations which indicate specific gaps in the literature and findings that may not be generalizable to other populations. Many of the studies reported having participants, where the majority were female [27-31,33,35,40,45]. Although some studies focused specifically on males, it must be considered that much of the evidence in this area is from a female perspective. Many of the studies were based in Australia, where there is a great deal of investment in youth mental health services compared with other countries in the world. In addition, many of the studies recruited from a university population only [24,27,30,31,43], who are not representative of young people in general. Finally, many of the studies were (12,24,29,36,47]; these types of studies include recall bias and do not accurately account for actual future behaviors.

#### How Young People Seek Help Online

In total, 6 studies found that young people made use of text-based queries using search engines to find mental health-related information rather than accessing a specific website [9,27,36,37,43,48] (see Multimedia Appendix 3). Information seeking about symptoms and forms of treatment are common goals when searching online [33]. The study by Birnbaum et al [47] showed that type of mental illness (mood disorder vs psychotic disorder) influenced what young people searched for. In this case, young people experiencing a mood disorder were more likely to search for how to stop symptoms, whereas those with a psychotic disorder preferred to understand why their symptoms had come about. When investigating the terms used by young people to search for mental health help, there was frequent use of mental health, mental health problems, depression, or symptoms of..., and treatment of... [30,37,43]. A common theme in the studies is the search for symptoms and treatment for the mental health concern the young person is currently facing [33]. The other types of content accessed that were identified by the studies include YouTube videos, factsheets, personal stories, and forums [33].

A total of 3 studies found that young people had used social media to locate mental health information [27,47,49]. The use of mental health or government websites varied from study to study. A study by Burns et al [48] found that less than 44.4% of the sample sourced information from mental health websites, similarly the study by Feng et al [27] found that only 26% of their sample had made use of information sites. Conversely, in a more recent study by Wetterlin et al [33], 82.9% of the sample indicated that they would be *somewhat likely* or *very likely* to use an information-based website. The study by Best et al [9] found that less of a quarter of their sample would make use of a government website.

Despite the lack of preference for formal mental health or government websites, a number of studies found that young people valued online services run by mental health professionals [9,28,47]. The study by Birnbaum et al [47] found that young people expressed an interest in obtaining help from mental health professionals through social media, whereas the study by Best et al [9] found that young people valued online services run by mental health professionals despite not wanting to use

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government websites. Haner and Pepler [40] found that the more distress the young person was experiencing the more likely they were to access the *Live Chat* option with a website providing mental health support to young people. Similarly, Frost et al [28] found that young people who self-harm would prefer an online service that allowed them to directly link with a mental health professional via instant messaging when in crisis.

Online communities and discussion forums also serve as a platform young people use to seek help. In the analysis of an online community, Greidanus and Everall [44] found that help-seekers would come to the forum to post messages seeking help for personal distress, looking for input from other users of the online community. The use of discussion boards or online support groups was reported by 11% of the sample in the study by Feng and Campbell [27] and 48.6% of the sample in a study by Frost et al [28].

#### Motivating Factors for Young People to Seek Help Online

The studies identified by this review indicated that many young people were going online to look for a space where they could share their feelings without fear of judgement or labelling but at the same time, it was important that these spaces protected their privacy [30,33,43].

Many studies found that there is an association between high levels of psychological distress and engaging in help-seeking online [12,22,36,40,50]. Majority of this help-seeking tends to take place after 11 pm at night [22,48]. The study by Best et al [9] found that a preferred online service would be one run by professionals, available 24 hours a day. The need for services run and recommended by professionals is a recurrent theme throughout all of the studies [25,28,44]. A study by Wetterlin et al [33] found that 83.9% of participants reported that it was important to them to have human contact within an online mental health resource. This need for human contact also includes the need or desire to connect to peers online who can support the online help-seeking process; this is especially true of users of online support communities [30,33,37,41,43,44].

There seems to be a sentiment that there is more help available to young people online than offline, and that young people from minority groups and those with higher levels of psychological distress were more likely to disclose their current difficulties online rather than offline [32,35]. A study by Frost et al [28] indicated that this may be due to many young people finding online spaces to be less judgmental, and the support they received was nonstigmatizing. This is especially important because a number of studies found that those young people with increased levels of psychological distress were likely to access mental health content online but not seek help from offline sources [13,28,29,31,41].

#### Young People's Experiences of Online Help-Seeking

The findings regarding the perceived helpfulness of online resources were variable (see Table 1). Ellis et al [26] found that 81.9% of females in their sample reported that talking online had helped, and that they were either satisfied or very satisfied with the process. Similarly, 54.9% males had talked about their problems online, and 81.3% of men found that it had helped and were satisfied with the help they had received. The study by Feng and Campbell [27] found more mixed results with 59% of this sample indicating that the online resources they had made use of didn't make things better or worse and 40% reported that they had *helped a little*. Ruppel and McKinley [31] investigated social anxiety and levels of social support in relation to the perceived usefulness of online resources; they found that participants with higher levels of social anxiety and also those with high levels of social support found online support groups to be very useful. The analysis of an online community by Greidanus and Everall [44] found that young people had experienced the online communities (a community message board) as understanding and affirming; this sentiment was especially strong for users who felt misunderstood offline. Overall, the comments indicated that users had found their engagement on the site to be a positive experience.



#### Table 1. Findings identified in studies: what are young people's experiences of seeking help online?

Authors (year)	Findings related to young people's experiences online
Ellis et al (2013) [25]	<ul> <li>Most females said that talking online <i>helped</i> (81.9%), and that they were <i>satisfied</i> or <i>very satisfied</i> with the online help they received. More than half of all male respondents reported that they had talked about their problems online (54.9%).</li> <li>Most said that talking online <i>helped</i> (81.3%), and that they were <i>satisfied</i> or <i>very satisfied</i> with the online help they received (82.9%).</li> </ul>
Feng and Campbell (2011) [27]	<ul> <li>In total, 59% of participants reported that online resources that they had used <i>didn't make things better</i> or worse, 40% reported <i>they helped a little</i>, and only 1% of participants reported <i>they helped a lot</i>.</li> <li>Although there is a preference for text-based search engines and information sites, the current sample does not seem to find them to be efficacious.</li> </ul>
Frost and Casey (2016) [29]	• Over half of these online help-seekers perceived that they had more support available to them online than offline.
Frost et al (2016) [28]	<ul> <li>Young people identifying the need for a nonjudgmental (n=68) and safe (n=14) environment and interactions. Many young people used the term nonjudgmental, whereas others indicated that they needed support in a way that was not stigmatizing, did not stereotype them, blame them, or label them as an attention seeker.</li> <li>Safety in online services for self-injury centered around the need for moderation, warnings about triggering content, and the risks of self-injury becoming competitive.</li> <li>Young people with a previous experience of online help-seeking were more likely to endorse the importance of reduced isolation and a supportive online culture.</li> </ul>
Greidanus and Everall (2010) [44]	<ul> <li>Most messages written by the trained volunteers took the form of an affirmation of some aspect of the help-seeker's character.</li> <li>A strong sense of community was indicated in several of the threads when help-seekers stated they felt their experiences were understood and shared by other members. This sense appeared to be especially strong for those help-seekers who felt misunderstood by those in their <i>affline</i> lives.</li> <li>Most of the community members authored a number of threads themselves and posted in threads of other members, occasionally making reference to the content of other threads.</li> <li>Participant comments often indicated they found engagement on the site to be a positive experience and provided a place to express feelings, receive support, and obtain referrals.</li> </ul>
Mars et al (2015) [36]	• Almost a quarter of the sample had come across a site that discussed self-harm or suicide.
Ruppel and McKinley (2015) [31]	<ul> <li>Participants with higher social support perceived websites and online support groups as more useful.</li> <li>The perceived usefulness of online support groups was highest among participants who had high levels of social anxiety and high levels of social support.</li> </ul>
Wetterlin et al (2014) [33]	• Most participants (87.7%) rated their privacy as a user as <i>very important</i> .

#### **Benefits of Online Help-Seeking**

Online help-seeking offers a number of benefits to young people experiencing personal and emotional difficulties. A total of 14 studies identified benefits of online help-seeking (see Table 2). These benefits could be grouped into 8 overarching categories which have been included in Table 3.

A total of 8 studies found that the anonymity provided by the internet was an important facilitator to online help-seeking [9,25,30,35,37,44]. Similarly ease of access and the immediacy of the internet plays an important role in its attractiveness to young people [9,12,28-30,35,51]. The nonstigmatizing nature of internet help-seeking makes it an attractive option for marginalized groups as seen in the study by Haner et al [40].

These groups include migrants and members of the LGBT+ community who may be fearful of disclosing personal concerns to their informal networks [40]. Similarly, a study by Best et al [22] found that online help-seeking was not affected by socioeconomic status or educational attainment.

Young people are finding a sense of community online and are able connect with others who have similar experiences to their own [24,43,46]. They feel they are able to communicate with this community without fear of judgment and, more importantly, they can control their level of disclosure [9,28]. In all, 2 studies indicated that young people who had previously gone online to seek help for self-injury or suicide-related issues were significantly less likely to have disclosed to someone offline [24,28].



 Table 2. Benefits of seeking help online by study

Authors (year)	Findings related to benefits of online help-seeking
Bell et al (2018) [24]	<ul> <li>Online help-seeking allows young people to communicate with others (social support but also reducing isolation).</li> <li>Information is readily available.</li> <li>Supportive sense of community and acceptance.</li> <li>Comfort and relief in realizing that they are not alone.</li> </ul>
Best et al (2016) [9]	<ul> <li>Anonymity</li> <li>Ease of access</li> <li>Immediacy</li> <li>Absence of judgement</li> <li>Can control level of disclosure</li> </ul>
Best et al (2014) [22]	<ul> <li>Some males may not disclose problems to others, but they are receiving some form of support through help-seeking practices online.</li> <li>Online help-seeking is not affected by Socio Economic Status or educational attainment.</li> <li>Online sources may be providing young males with an additional outlet to seek social support.</li> </ul>
Birnbaum et al (2017) [47]	<ul> <li>Opportunities for early intervention, as information found online can play an important role in the treatment-seeking decision-making process.</li> <li>Young people are fearful to talk to close others about their symptoms but are comfortable to use the internet for further understanding.</li> <li>Social media gives mental health clinicians the opportunity to engage and meaningfully interact with struggling youth at the earliest phases of illness potentially altering the trajectory to care.</li> <li>Online information seeking plays an important role in the initiation of help-seeking by influencing individual's understanding of symptoms and their decision to seek professional help.</li> </ul>
Bradford and Rickwood (2014) [35]	<ul> <li>Anonymity</li> <li>Information that is easily accessible</li> <li>Finding others who have similar experiences.</li> </ul>
Burns et al (2016) [13]	<ul> <li>Reasons for preference of online resources included the anonymity of the internet, that information was easily accessible, and that there are often people in chat rooms who have been through the same thing.</li> <li>Boys were shown to have a stronger preference for online resources compared with face-to-face help relative to girls.</li> </ul>
Burns et al (2010) [48]	• Access online mental health resources in crisis outside of working hours (after 11 pm).
Collin et al (2011) [12]	<ul> <li>Online help-seeking helps young people to be more willing to ask a professional for help.</li> <li>Upon having positive experience, help-seekers become advocates of help-seeking.</li> <li>Gateway services promote timeous help-seeking.</li> </ul>
Ellis et al (2013) [25]	<ul><li>Preference instead for self-help and action-oriented strategies.</li><li>The internet addresses their desire for anonymity and self-help.</li></ul>
Frost and Casey (2016) [29]	<ul> <li>Online help-seekers indicated a greater intention to seek help for self-injurious behavior in the future.</li> <li>A significant difference in help-seeking intentions from professionals emerged, with online help-seekers indicating significantly higher intentions to seek professional help compared with individuals who did not seek help online.</li> <li>The internet may have an important role to play in mitigating help negation in young people who self-injure.</li> <li>Young people who sought help online in relation to self-injury indicated a significantly greater intention to seek help for self-injurious behavior in the future, even after controlling for age, gender, and psychological distress.</li> </ul>
Frost et al (2016) [28]	<ul> <li>Over half of the sample indicated a desire to use the internet as a first step but to later gain support offline.</li> <li>The internet may provide a way of accessing support that is perceived as remaining private and within the control of the young person.</li> <li>Perceived sense of community and belonging for young people who self-iniure.</li> </ul>

Authors (year)	Findings related to benefits of online help-seeking
Greidanus and Everall (2010) [44]	<ul> <li>It is clear these help-seekers, who reported not feeling comfortable seeking help from professional <i>offline</i> services, were able to use internet-based communication to create a community where they found support and offered support to their peers.</li> <li>Children and adolescents who use alternative communication technologies find internet-based communications meaningful and personally relevant.</li> <li>Help-seekers identified anonymity, accessibility, and access to peers who understand their experiences as important aspects of online help.</li> <li>Help-seekers reported finding it easier to disclose some experiences online than offline.</li> </ul>
Horgan and Sweeney (2010) [30]	<ul> <li>Anonymity, privacy, and confidentiality.</li> <li>Accessibility, speed, and cost.</li> <li>Believed that they would not be judged and believed it would be a good place to get initial information.</li> <li>Easier to express themselves.</li> <li>Ability to communicate with others in similar situations to find out how they are coping.</li> <li>Young people indicated they are less likely to lie online.</li> <li>Young people are reluctant to access mainstream mental health services because of fear of judgement and because of the stigma that still exists in relation to mental health problems.</li> </ul>
Mar et al (2014) [43]	<ul> <li>Participants recounted using the internet to find others coping with similar problems, research their symptoms and prescribed medications, or understand their diagnosis.</li> <li>Participants also emphasized that knowing there is a community of others helps them to recognize that they are not alone with their problems.</li> <li>Participants sought a variety of e-mental health features, especially for engaging in active coping, such as journaling.</li> <li>Online services may afford them a level of privacy.</li> <li>E-mental health services may lessen the burden on providers or provide resources for patients waiting to access care.</li> <li>E-mental health services may help to treat those with mild symptoms or those who do not wish to seek professional support.</li> </ul>

• Online services may also help direct those in need to the traditional health care system.

Table 3. Key benefit themes and number of studies in which each theme is addressed.

Serial no	Benefit	Number of studies	Studies
1	Anonymity and privacy	8	Best et al (2016) [9]; Bradford and Rickwood (2014) [35]; Burns et al (2016) [13]; Ellis et al (2013) [25]; Frost et al (2016) [28]; Greidanus and Everall (2010) [44]; Horgan and Sweeney (2010) [30]; Mar et al (2014) [43]
2	Ease of access and immediacy	7	Bell et al (2018) [24]; Best et al (2016) [9]; Bradford and Rickwood (2014) [35]; Burns et al (2016) [13]; Burns et al (2010) [48]; Greidanus and Everall (2010) [44]; Horgan and Sweeney (2010) [30]
3	Connecting with others with similar experiences	7	Bell et al (2018) [24]; Bradford and Rickwood (2014) [35]; Burns et al (2016) [13]; Frost et al (2016) [28]; Greidanus and Everall (2010) [44]; Horgan and Sweeney (2010); Mar et al (2014) [43]
4	Acts as a gateway to further help-seeking	5	Birnbaum et al (2017) [47]; Collin et al (2011) [12]; Frost and Casey (2016) [29]; Frost et al (2016) [28]; Mar et al (2014) [43]
5	Increased perceived control of help-seeking journey	3	Best et al (2016) [9]; Frost et al (2016) [28]; Mar et al (2014) [43]
6	Meets the needs of those with a preference for self-reliance	2	Ellis et al (2013) [25]; Mar et al (2014) [43]
7	Early access	2	Birnbaum et al (2017) [47]; Frost et al (2016) [28]
8	Inclusiveness of different Social Economic Sta- tus/cultures/genders	1	Best et al (2016) [22]

Online help-seeking seems to act as a gateway behavior to further help-seeking. It enables young people to access information about their mental health difficulties and, therefore, decide whether there is a need to seek professional help [9,12,28,46,49]. The internet provides alternative routes to

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XSL•FO RenderX access mental health professionals; for instance, Birnbaum et al [47] found that young people would be willing to access opportunities to connect with clinicians over social media. Collin et al [12] investigated the role of an online youth mental health website, ReachOut.com, in promoting young people's

help-seeking behavior. Users of the website (43.3% of those surveyed) indicated that using the website had helped them to acquire the skills and confidence to seek help if they needed it. Online resources could have a role to play in early intervention as the information found online could help early identification of concerning symptoms but also assist in reaching out to mental health professionals.

The internet also provides access to the information and tools that may assist those young people who have a preference for self-reliance or for informal sources of help [25,44]. In the study by Mar et al [43] participants indicated that they used the internet to search for active coping strategies such as journaling to assist them to cope with their current difficulties.

#### Limitations to Online Help-Seeking

Limitations to online help-seeking were discussed by 14 studies with 6 common categories of limitations found across all the studies (see Tables 4 and 5).

Young people are motivated to look for help online; however, their ability to access reliable, helpful information is influenced by their lack of mental health literacy and a lack of knowledge of which resources to search for [27,31,43,49]. In the context of help-seeking, mental health literacy can be understood as knowledge and understanding of mental health problems which aid their recognition and management [52]. Formal online services are limited and would need to be familiar to the help-seeker to be accessed [9]. A key concern raised by young people across 3 studies is that they were uncertain whether certain sources are reliable or not and lack an understanding of

the indicators of quality [9,23,30]. It appears that young people attribute quality based on superficial characteristics such as rank on Google search results and design and layout of websites [9].

Treatment avoidance is a real risk associated with online help-seeking. Content exists online that can be stigmatizing, triggering, or that may reinforce harmful behaviors and thoughts [24,28]. Certain communities may also perpetuate the stigma surrounding mental health and psychiatric treatment options, which may contribute to a reluctance to seek help from offline, professional services [13,47]. The usual protective measures are not present in unmoderated communities, and it is concerning that risky content may not be removed [24]. This risk is exacerbated as young people may incorrectly attribute certain sources as *helpful* when in fact, they are dangerous [9,30,36,47]. Rickwood et al [41] expand on this by emphasizing that the self-reliance afforded by online help-seeking may have limited young people's access to the appropriate help source at the appropriate time because of limits of their own mental health literacy.

Finally, young people are concerned about the implications of making use of online help-seeking. These include fears over protection of privacy, that it may be too impersonal, and that the help found there would be unreliable and untrustworthy [30,39,43]. Mar et al [43] found that young people's concerns regarding their privacy centered around fears that family and friends would somehow find out about their mental health concern. A concern many of them also have about offline help-seeking.

 Table 4. Themes identified in studies: limitations of seeking help online.

No.	Limitation	Number of studies	Studies
1	Uncertainty about trustworthiness of re- sources	5	Best et al (2016) [9]; Kauer et al (2017) [39]; Horgan and Sweeney (2010) [30];
2	Lack of mental health literacy	5	Bell et al (2018) [24]; Best et al (2016) [9]; Feng and Campbell (2011) [27]; Mar et al (2014) [43]; Ruppel and McKinley (2015) [31]
3	Reinforcing treatment avoidance	4	Birnbaum et al (2017) [47]; Mars et al (2015) [36]; Rickwood et al (2015) [41]
4	Concerns about privacy and confidential- ity	3	Best et al (2016) [9]; Horgan and Sweeney (2010) [30]; Mar et al (2014) [43]
5	Triggering negative behavior	2	Bell et al (2018) [24]; Mars et al (2015) [36]
6	Difficulty in providing an emergency response	1	Mar et al (2014) [43]



Author (year)	Findings related to limitations of online help-seeking
Bell et al (2018) [24]	<ul> <li>The risk of triggering or reinforcing suicidal thoughts or behaviors.</li> <li>Unmoderated communities are risky as the fail-safe to remove risky content is not there.</li> </ul>
Best et al (2016) [9]	<ul> <li>Lack of understanding of indicators of quality.</li> <li>Lack of control of personal information once it is online.</li> <li>Lack of confidentiality when disclosing within your own social network.</li> <li>Lack of help-seekers' health literacy.</li> <li>Formal online resources are limited and need to be known to be accessed.</li> </ul>
Birnbaum et al (2017) [47]	• The online environment can be misleading and stigmatizing that reinforces pre-existing misconceptions about mental health and psychiatric treatment options, which may contribute to treatment avoidance.
Burns et al (2016) [13]	• There is still an overall orientation to not seek help, and barriers remain to all forms of help. This has concerning implications as it suggests that simply providing help through different means will not increase the likelihood that young people facing these barriers will actually use these new avenues of help.
Collin et al (2011) [12]	• Despite overall increased mental health literacy and intentions to seek help, ReachOut.com visitors remain reluctant to seek help from traditional and face-to-face sources.
Feng and Campbell (2011) [27]	• Young people are unaware of where to search for mental health concerns.
Frost et al (2016) [28]	<ul> <li>It is unclear whether online help-seeking was acting to replace offline help-seeking for these young people or whether the internet facilitates help-seeking in young people who otherwise would not disclose their self-injury to anyone. Similarly, it is unclear whether the failure of these young people to seek help offline may reflect a lack of linking to offline support in current forms of online support for self-injury.</li> <li>Young people in the current sample went beyond discussion of the positive aspects of online communities and online culture, expressing concerns about triggering content, unmoderated discussions, and the <i>glorification</i> of self-injury.</li> </ul>
Haner and Pepler (2016) [40]	• The possibility exists that the online counsellors can misinterpret neutral or positive typed communication with the presence of a vocal cue to suggest warmth of tone.
Horgan and Sweeney (2010) [30]	<ul> <li>A number of participants also reported that they believed it would be unreliable (15.1%), untrustworthy (5%), it lacks privacy (2.5%), is too impersonal (7.5%), and that insufficient support would be found (3.9%).</li> <li>A number of participants were concerned with the reliability of the information, highlighting that young people may be experiencing difficulty in determining the quality of information online.</li> </ul>
Kauer et al (2017) [39]	• Lack of trust in the accuracy of the information available on the internet was also a general concern for both the Link and comparison arms.
Mar et al (2014) [43]	<ul> <li>Two participants spoke of the importance of advertising the existence of online support offline, explaining that they felt it was not intuitive to look for help online.</li> <li>Participants' concerns over privacy generally linked back to the stigma of having friends or family find out about their mental health concern.</li> <li>Providers of e-mental health services for youth must appropriately address high suicide risk while maintaining a youth's privacy, which may need to be breached in emergency circumstances.</li> </ul>
Mars et al (2015) [36]	• Young people have difficulties in classifying sites as either <i>helpful</i> or <i>harmful</i> , as some offer concurrent suicide-promoting and help-promoting content.
Rickwood et al (2015) [41]	• Greater self-reliance online, with a slightly stronger peer influence, may be cause for concern, as young people and their friends may not be the best guides to appropriate mental health care.
Ruppel and McKinley (2015) [31]	• Limited mental health literacy and limited knowledge about which resources are available

### Discussion

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#### **Principal Findings**

This review aimed to extend understanding of how young people use online resources to seek help for their mental health concerns. A total of 28 studies were identified. Only 4 studies

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that guided the study design. Moving forward, the development of such theoretical frameworks represents a key challenge. Results suggest that the internet serves 3 functions to help-seekers: (1) as a gateway to further information and knowledge acquisition around their symptomology; (2) as a

way to connect with others, professional or peer, around the topic of their mental health difficulties; and (3) as an alternative option to offline help-seeking for those who are most at risk. A text-based query via an internet search engine was the most commonly identified help-seeking approach. But social media, government or charity websites, live chat, instant messaging, and online communities and discussion forums are also used. The perceived benefits of online help-seeking include anonymity and privacy, ease of access, inclusivity, and the ability to connect with others and share experiences. Online help-seeking may also increase young peoples' sense of control over their help-seeking journey; meet the needs of those with a preference for self-reliance; or act as a gateway to further help-seeking. In contrast, significant limitations were also identified. A lack of mental health literacy can act as a barrier to effective help-seeking, as can concerns about privacy and confidentiality, and uncertainty about the trustworthiness of online resources. There is a concern that online help-seeking can reinforce treatment avoidance or trigger negative behavior.

#### **Theoretical Frameworks in Online Help-Seeking**

This review highlights the limited use of theoretical frameworks to help conceptualize online help-seeking and guide the development of improved resources. The full development of such a theory is beyond the scope of this paper. However, we consider 2 potential starting points for such a theory: Rickwood et al's *help-seeking model* [3] and *self-determination theory* (SDT) [53]. In each case, we use the existing theory as a lens through which to analyze the benefits and limitations of online help-seeking identified in this review and how they can either support or frustrate the help-seeking process.

#### The Help-Seeking Model

Existing theories of help-seeking provide a valuable starting point for the development of online help-seeking theories. The *help-seeking model* of Rickwood et al [3] provides a stage-based model to understand traditional help-seeking behaviors. It was applied by 2 studies in this review. Best et al [9] have proposed a pathways-based extension of this theory through their *pathways to online help-seeking model*, which seeks to predict people's help-seeking decisions on the basis of their mental health literacy and perception of stigma.

Table 6 demonstrates another approach to applying the help-seeking model. It outlines 1 way in which the benefits and limitations identified in this review can be mapped to stages of the *help-seeking model*. Through such a mapping, we can begin to identify and think about important issues that impact different stages of an online help-seeking process. For example, early access and the potential of online services to act as a gateway to further help-seeking may offer significant benefit at the awareness stage of a help-seeking process. This is offset by the lack of mental health literacy many young people will have at this stage of the process. Similarly, a lack of literacy is also likely to impact the expression stage. However, while young people may struggle to recognize or express their symptoms using formal clinical language, they might benefit from reading the stories of other young people, whose experiences they might relate to, potentially helping them to understand their own symptoms in a more accessible manner, and thus enabling expression.

As shown in Table 6, this approach can also be applied at the availability and willingness stages. In each case the approach provides a structured way to think about benefits we might maximize, while also highlighting limitations that need to be addressed. Such an analysis can guide the design of more effective online help-seeking services. It is also important to note the we do not see the mapping presented here as exclusive. We recognize that other mappings are possible. Our intention is to demonstrate how consideration of distinct benefits and limitations at each stage of a help-seeking model can shed light on key challenges and opportunities in the design of online help-seeking services.

 Table 6. A mapping of the benefits and limitations to online help-seeking based on the stages of *help-seeking model* by Rickwood et al [3].

Stage	Awareness	Expression	Availability	Willingness
Process	Becoming aware of symptoms, appraising the assistance required	Expressing the symptoms ex- perienced and that they are in need of help or support	Identify sources of help that are available and accessible	Willingness of the help-seeker to disclose difficulties to the selected, available source
Benefit/support	<ul> <li>Early access</li> <li>Acts as a gateway to further help-seeking</li> </ul>	• Connecting with others with similar experiences	<ul> <li>Ease of access and immediacy</li> <li>Inclusiveness</li> <li>Meets the needs of those with a preference for self-reliance</li> </ul>	<ul> <li>Anonymity and privacy</li> <li>Control of help-seeking journey</li> <li>Connecting with others with similar experiences</li> </ul>
Limitation/frustration	• Lack of mental health literacy	• Lack of mental health literacy	• Lack of immediate, crisis support	<ul> <li>Concerns about privacy and confidentiality</li> <li>Treatment avoidance</li> <li>Triggering negative behavior</li> </ul>

#### Self-Determination Theory

SDT is a theory of motivation that has been applied across many settings in education and health care to understand and predict psychological well-being [53,54]. In recent years, it has also

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been applied in the design of digital technologies that can support mental health and well-being [55,56]. Until now, it has not been applied to online help-seeking.

SDT consists of a number of mini-theories; one of which is *cognitive evaluation theory* [53,54]. This theory proposes that there are 3 primary psychological needs for well-being and motivation: autonomy (to experience choice in line with one's own interests and values); competence (effectively interact with one's environment and express one's abilities); and relatedness (sense of belonging) [57]. SDT postulates that these basic 3 needs are essential for understanding how and why humans pursue certain goals. It asserts that the natural human trajectory is toward vitality, integration, and health [58] and argues that environments can support or frustrate these needs and thus influence well-being and motivation.

Here, we consider how SDT can be applied to conceptualize motivation in online help-seeking. In Table 7, the benefits and limitations of online help-seeking identified in this review are clustered in terms of their impact on autonomy, competence, and relatedness as consistent with SDT. In online help-seeking, the goal might vary from person to person; however, those specific goals could be understood within the broad themes of achieving growth and well-being. One could, therefore, argue that online searches and resources that are designed to support these basic psychological needs will be better able to support young people when they engage in help-seeking.

The evidence from this review suggests that there were mixed responses with regard to young people's satisfaction with their experiences when looking for help online. This mixed response could be attributed to online resources not fully meeting the needs for autonomy, competence, and relatedness, or these needs only being partially met. An example of this could be the use of a text-based search engine, which facilitates the need for autonomy, but leads to an abundance and variety of search results that could overwhelm the young person, frustrating their need for competence. The mapping also shows how a lack of mental health literacy can be thought of as an issue of competence. Addressing this competence may increase overall motivation for help-seeking. Similarly, the decision to avoid treatment may be a negatively focused expression of autonomy. In such a conceptualization, we might predict that systems which support alternative forms of autonomy, for example, by making control of the journey more explicit, will reduce the likelihood of treatment avoidance.

The importance of connecting with others online, whether professionals or peers, is emphasized by participants in many of the reviewed studies, indicating the importance for a human element in both formal and informal online help sources. Previous research has also shown that knowing someone who has sought help for a mental health difficulty has a positive effect on one's attitude toward help-seeking [3,53,54]. Viewed through the lens of SDT, engaging with people online or with content that shares the stories of other's help-seeking journeys helps to provide relatedness and improve mental health literacy. As such the internet may play an important bridging role between different stages of a help-seeking process, first facilitating informal contact, but also increasing motivation toward formal help-seeking.

Table 7. A clustering of the benefits and limitations to online help-seeking on the basis of the primary psychological needs identified in self-determination theory.

Benefits and Limitations	Autonomy	Competence	Relatedness
Benefit/support	<ul> <li>Anonymity and privacy</li> <li>Ease of access and immediacy</li> <li>Control of help-seeking journey</li> <li>Meets the needs of those with a preference for self-reliance</li> </ul>	<ul> <li>Acts as a gateway to further help-seeking</li> <li>Early access</li> </ul>	<ul> <li>Connecting with others with similar experiences</li> <li>Inclusiveness</li> </ul>
Limitation/frustration	<ul> <li>Concerns about privacy and confiden- tiality</li> <li>Treatment avoidance</li> </ul>	• Lack of mental health literacy	<ul> <li>Lack of immediate, crisis support</li> <li>Triggering negative behavior</li> </ul>

#### **Tensions and Opportunities in Online Help-Seeking**

Evidence suggests that the internet has the potential to serve as an inclusive gateway that assists all young people in accessing help, especially those from minority groups and groups who experience a great deal of stigma. It provides immediacy of access and allows people to connect with others, while also preserving the option to remain anonymous and control how much information they reveal, thereby supporting relatedness and also meeting the need for autonomy. However, many young people may feel forced to limit what they reveal or how they search due to concerns around privacy and confidentiality, now limiting their autonomy. This highlights a tension between the potential benefit of human contact versus the need for confidentiality. Relatedly, there is a tension between the preference of some young people for self-reliance versus the benefits of disclosure to formal sources of help.

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Rickwood et al's model emphasizes the importance of the social transactions implicit in traditional offline help-seeking [3]. However, online help-seeking changes the nature of and need for social transactions with others. This review has found that while some online help-seekers prefer online mental health resources that offer the opportunity to connect with others, others prefer to navigate the process on their own and rely on self-help strategies, removing the need for a social transaction. The different types of content on the internet mean that the nature of social transactions has also changed: a help-seeker can now read content regarding another young person's personal experiences of mental health difficulties without ever directly engaging with the original writer of the content. The writer of the content can still have a profound effect on the help-seeker, not only improving their mental health literacy but also providing an example of someone who has also sought help for

a mental health difficulty. In this way, help-seekers become the consumers as well as the creators of help-seeking content online.

Online help-seeking can facilitate young people's autonomy by allowing them to control their help-seeking journey. However, as noted, young people have differing preferences for which online resources they access and which resources they find useful. These preferences are not just different from person to person. They may also differ for any given person, depending on their immediate circumstances. A key challenge for future research lies in providing tailored and appropriate online resources for different preferences and groups that meet all 3 psychological needs. Addressing all 3 needs in an online resource currently appears to be lacking. For example, young people are accessing resources where they can read and share personal stories, which meets their need for relatedness but it is unlikely that they would meet their needs for competence (is this information trustworthy?) and autonomy (is my privacy ensured?) through these resources.

Our analysis suggests that young peoples' online help-seeking may trigger key tensions between supporting and frustrating the 3 basic psychological needs outlined in SDT; simultaneously, the internet and online resources have the opportunity and capability to address these needs through careful and considered design. Managing these tensions will be important if we are to realize the full potential of systems that support online help-seeking.

#### **Implications for Practice**

As the internet becomes increasingly a part of everyday life and is seen as an accessible tool for information, it is important to have an understanding of how young people use the internet to meet their mental health needs. A plethora of online resources exist, both good and bad, and we only have a limited understanding of the patterns and characteristics of young people's mental health–related internet use. Online help-seeking provides an added space for young people to access help sources; however, it is an addition to offline help-seeking and not a replacement. There remains a great need to educate young people to facilitate competent and appropriate help-seeking behavior, both online and offline. Online sources need to be designed with young people's needs in mind, specifically making services available after-hours and providing access to trained professionals and peers. To increase reach, offline service providers need to consider online/digital strategies to offer a continuum of services to address the mental health needs of young people. Similarly, those developing online resources for young people need to do so in collaboration with professionals and young people.

#### Limitations of This Review

This review has several limitations. Although a number of databases have been included, the choice of keywords may have resulted in missing relevant research. Owing to the exploratory nature of this review, the decision was made to include a wide range of study designs, and the review will ultimately be limited by the design of the studies included. Although strategies to limit bias were included through consultation with the second and third reviewer, the possibility of subjectivity in analyzing the findings is acknowledged. Additionally, the measures used in the studies were varied and samples were heterogenous, making it a challenge to compare outcomes across studies. It is also evident from the studies included in this review that further investigation is needed into the online help-seeking behaviors of young people from populations other than those included in these studies. These data are representative of a mostly female, university student sample, often living in Australia. These findings may not translate well onto other populations such as those young people living in Europe, Asia, or Africa, young men and those young people who have not accessed tertiary education.

#### Conclusions

A key concern for researchers in this area should be the development of a model or framework in which to explain the motivations and benefits of online help-seeking and how it fits in with the overall help-seeking process for young people. The conceptualization of such a model would contribute to the cross-validation of findings and provide the ability to determine patterns. This review has considered *the help-seeking model* and SDT as valuable starting points for such a theory. It would allow research questions to be framed within the SDT constructs and theories, allowing for comparison and validation.

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#### **Conflicts of Interest**

None declared.

#### Multimedia Appendix 1

Search Strings. [PDF File (Adobe PDF File), 71 KB-Multimedia Appendix 1]

#### Multimedia Appendix 2

Quality Checklists. [PDF File (Adobe PDF File), 129 KB-Multimedia Appendix 2]

#### Multimedia Appendix 3

Tables 1 and 2. [PDF File (Adobe PDF File), 153 KB-Multimedia Appendix 3]

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#### Abbreviations

**CASP:** Critical Appraisal Skills Program **SDT:** self-determination theory

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**Original Paper** 

# Young People Seeking Help Online for Mental Health: Cross-Sectional Survey Study

Claudette Pretorius<sup>1</sup>, MA; Derek Chambers<sup>2</sup>, MA; Benjamin Cowan<sup>3</sup>, PhD; David Coyle<sup>1</sup>, PhD

<sup>1</sup>School of Computer Science, University College Dublin, Dublin, Ireland

<sup>2</sup>Health Service Executive, Cork, Ireland

<sup>3</sup>School of Information and Communication Studies, University College Dublin, Dublin, Ireland

Corresponding Author: Claudette Pretorius, MA School of Computer Science University College Dublin Belfield Dublin, D04 V1W8 Ireland Phone: 353 017162818 Email: claudette.pretorius@ucdconnect.ie

### Abstract

**Background:** Young people are particularly vulnerable to experiencing mental health difficulties, but very few seek treatment or help during this time. Online help-seeking may offer an additional domain where young people can seek aid for mental health difficulties, yet our current understanding of how young people seek help online is limited.

**Objective:** This was an exploratory study which aimed to investigate the online help-seeking behaviors and preferences of young people.

**Methods:** This study made use of an anonymous online survey. Young people aged 18-25, living in Ireland, were recruited through social media ads on Twitter and Facebook and participated in the survey.

**Results:** A total of 1308 respondents completed the survey. Many of the respondents (80.66%; 1055/1308) indicated that they would use their mobile phone to look online for help for a personal or emotional concern. When looking for help online, 82.57% (1080/1308) of participants made use of an Internet search, while 57.03% (746/1308) made use of a health website. When asked about their satisfaction with these resources, 36.94% (399/1080) indicated that they were satisfied or very satisfied with an Internet search while 49.33% (368/746) indicated that they were satisfied or very satisfied with a health website. When asked about credibility, health websites were found to be the most trustworthy, with 39.45% (516/1308) indicating that they found them to be trustworthy or very trustworthy. Most of the respondents (82.95%; 1085/1308) indicated that a health service logo was an important indicator of credibility, as was an endorsement by schools and colleges (54.97%; 719/1308). Important facilitators of online help-seeking included the anonymity and confidentiality offered by the Internet, with 80% (1046/1308) of the sample indicating that it influenced their decision a lot or quite a lot. A noted barrier was being uncertain whether information on an online resource was reliable, with 55.96% (732/1308) of the respondents indicating that this influenced their decision a lot or quite a lot.

**Conclusions:** Findings from this survey suggest that young people are engaging with web-based mental health resources to assist them with their mental health concerns. However, levels of satisfaction with the available resources vary. Young people are engaging in strategies to assign credibility to web-based resources, however, uncertainty around their reliability is a significant barrier to online help-seeking.

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#### KEYWORDS

mental health; eHealth; mHealth; Internet; help-seeking behavior; health literacy; young adults; survey and questionnaires



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### Introduction

Globally, there is a growing recognition of the public health challenge associated with mental disorders [1-4]. Particularly, the mental health of young people is becoming of increasing concern [5,6]. It has been recognized that young people are especially vulnerable to experiencing mental health difficulties, with very few seeking treatment or help during this time [5,6]. A systematic review by Ibrahim et al [7] found that students, most of whom were between the ages of 18 to 25, experienced higher rates of depression than other age groups from the general population. This age group faces unique challenges and stressors as they transition into adulthood [8], as young people are expected to learn adult responsibilities, and many experience high levels of distress as they potentially make sense of numerous changes taking place in their lives [9]. The personal and emotional concerns associated with this stage of a young person's life, and how they seek help for these worries, are of critical concern.

Help-seeking for mental health difficulties is often understood to be an adaptive coping method where an individual engages in behavior that communicates their distress to others with the goal of getting help in the form of understanding, advice, information, treatment or general support [10,11]. Help-seeking is a complicated process influenced by a person's attitudes, preferences and goals. For this reason, many people make use of a multitude of sources of help [12-14]. Previous research has found that engaging in help-seeking behavior, both formal and informal, is an important protective factor for young people's mental health [15]. Despite this, evidence suggests that those experiencing higher levels of suicidal or self-harming thoughts and behaviors are less likely to seek help for their mental health difficulties [16].

Growing use of computer-mediated technologies and web-based resources have changed the nature of help-seeking, making it possible for users to engage in help-seeking behaviors without an interpersonal component [10]. While offline resources remain an important source of help to young people, the accessibility of the Internet has created an opportunity for more sources of help and information to become available [17,18]. A study by Dooley & Fitzgerald [15] indicated that 77% of young people were likely to use the Internet to find information or support for a mental health concern. The increased role of alternative sources of help, such as YouTube, bloggers or Influencers, self-help websites and discussion forums, have to be considered [12]. There is a need to investigate how young people use the Internet as part of their help-seeking strategies and how they can be supported in these strategies.

Although many web-based information resources and interventions are available, they are of varying quality [19]. A study by Feng et al [20] found that while there are many online resources available, this does not necessarily result in user engagement or show that their use is helpful to the help-seeking process. The amount of evidence regarding the usefulness of online resources in facilitating the help-seeking process is a notable gap in the literature [21].

As with offline help-seeking, each young person has their own preferences for both online sources and preferred pathways in order to cope with their mental health difficulties and concerns [22]. Thus, the need to identify these sources and why they are attractive to young people is important. The aim of this study was to investigate and better understand the online help-seeking behaviors of young people. This was achieved through an online survey addressing several key issues, including current areas of concern, intentions to seek help, preferred online resources, credibility of online resources, and finally the current wellbeing of this sample.

### Methods

#### Overview

Ethics approval for this research was provided by the University College Dublin Office of Research Ethics (LS-17-116-Pretorious-Coyle). All data was collected through an anonymous online survey.

#### **Survey Development**

This survey was undertaken with the support of a youth mental health charity, ReachOut Ireland, who are the sister organization of ReachOut Australia. ReachOut is a mental health service that offers online mental health resources specifically for young people, but they also run a youth participation program that ensures young people's involvement through all their work. Prior to the survey going live, it was piloted with five young people from the ReachOut Ireland youth panel to hear their thoughts on the survey and its acceptability. This survey was developed iteratively and informed by research in the area [13,17,23,24], and along with input and previous research from ReachOut Ireland [25] and the commentary from the youth panel, it was made as accessible and nonthreatening to as many young people as possible. In adhering to this input from the youth panel, the final survey did not refer specifically to symptoms such as feeling anxious or having a low mood and instead asked young people about the personal concerns that were causing them the most stress or worry. The term personal or emotional concern was selected, as the authors wanted to use nonmedicalized language throughout the survey. The concerns addressed in the survey also represent the most frequently expressed concerns on the ReachOut Ireland website.

#### **Survey Procedure**

This study made use of a survey link to direct participants to the survey. This link was made available through various online sources, such as youth mental health-related websites (ReachOut Ireland, SpunOut, and BodyWhys), and through targeted advertisements posted on Facebook and Twitter. The adverts consisted of a short title, an image, and the survey link. The Facebook and Twitter advertisements were specifically targeted to appear on the feeds of Irish users between the ages of 18 and 25. The survey was hosted on LimeSurvey on a local server. The first component of the survey consisted of the information page, which included information regarding the purposes of the study, how the data would be used, anonymity, confidentiality and data protection. Participants were then asked to provide consent and confirm that they were both between the ages of

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18-25 years old and living in Ireland, if they wished to continue with the survey. Information on mental health support was provided on the landing page of the survey as well as on the survey termination page. The survey consisted of 22 questions, over 6 screens, and took between 15 and 20 minutes to complete (see Multimedia Appendix 1 for the survey questions). Multiple responses from the same user were prevented by using cookies, and no incentive was offered. Participants were permitted to skip any question they were unwilling to answer during the survey. In total, 2352 people began the survey, but a total of only 1308 participants successfully completed the entire questionnaire. Data from uncompleted surveys was not used as withdrawal from the survey indicated withdrawal of consent.

#### **Survey Measures**

The survey consisted of both quantitative and qualitative questions to assess: (1) demographics; (2) young people's technology use; (3) propensity to seek help from different sources as measured by the General Help-Seeking Questionnaire (GHSQ) [23]; (4) current personal and emotional concerns; (5) preferred online resources; (6) credibility of online resources; (7) facilitators and barriers to online help-seeking; and (8) wellbeing of participants measured by the Short Warwick–Edinburgh Mental Well-being Scale (SWEMWBS) [24]. This paper will discuss findings from (2), (4), (5), (6), and (7) in detail, and findings from (3) and (8) are included under the description of the survey participants.

#### **Data Analysis**

The survey data were analyzed using IBM SPSS Statistics for Mac, Version 24, (IBM Corporation, Armonk, NY) primarily using descriptive statistics. Only completed surveys were analyzed. Open response questions were analyzed using thematic analysis [26].

### Results

#### **Survey Participants**

A total of 1308 participants were examined in this study, of which 78.52% (1027/1308) were female, 18.50% (242/1308) were male, 1.68% (22/1308) were non-binary and 0.84% (11/1308) identified as transgender. The mean age of the population was 20.68 (SD 2.22), with a minimum and maximum age of 18 and 25, respectively. The survey had good national coverage, with respondents from all Irish counties. Of the whole sample, 67.13% (878/1308) reported that they were currently living in a city or town, 59.17% (774/1308) reported their current level of education to be undergraduate, and most of the sample accessed the survey link through Twitter (68.88%; 901/1308) and Facebook (24.08%; 315/1308). The results from the GHSQ were like findings from previous studies, with a very high propensity for respondents to not seek help at all (45.2%; 591/1308). Informal sources of help were preferred over formal sources. Only 18.5% (242/1308) of the sample indicated that they would be likely or extremely likely to seek help from a mental health professional, whereas 53.3% (697/1308) of the

sample were likely or extremely likely to seek help from an intimate partner (see Multimedia Appendix 2). The SWEMWBS has good internal consistency, with a reported Cronbach alpha=0.84. In the current study, the Cronbach alpha=0.835. This sample mean (19.0362; SD 3.522) is one standard deviation lower than the normative group mean (23.6093; SD 3.90264). Scores on the SWEMWBS can range from 7 to 35, and higher scores on the SWEMWBS indicate higher positive mental well-being.

#### Young People's Technology Use

Most respondents owned a mobile phone (99.62%; 1303/1308) and a laptop or computer (92.35%; 1208/1308), with fewer owning a tablet (38.91%; 509/1308) or gaming console (34.10%; 446/1308). Mobile phones were the preferred device for using the Internet in order to look for help online (80.66%; 1055/1308), with only 32.65% (427/1308) of the sample indicating that they would use their laptop or computer. A negligible proportion of the sample used a tablet or games console to access the Internet or to look for help (see Multimedia Appendix 1).

#### Areas of Personal and Emotional Concern and Online Help-Seeking

The closed response questions indicated that school or college was a source of personal concern for most of the sample, with 87.08% (1139/1308) indicating that it had recently caused them stress. This was followed by concern caused by body image (73.01%; 955/1308) and exams (72.02%; 942/1308). These results are like ReachOut's previous findings, which also found exams, school and body image to be major stressors for young people [25]. Table 1 lists the other triggers of stress responded to by respondents.

In the open response section of these questions, 100 respondents provided additional data. These concerns were grouped into the following themes: mental health, work, finances, harm from others, housing, sports, identity, interpersonal difficulties, parenting, physical health, transitional challenges and societal concerns. Table 2 outlines each theme with a quote taken from the survey as an example for each.

This question was followed by a question asking whether young people had gone online to look for help for these concerns. For this question, 85.32% (1116/1308) of the sample had gone online to look for help with their stress caused by school or college, 70.41% (921/1308) had gone online to look for help with concerns over body image, and 71.25% (932/1308) had looked for help with exams. In addition, most of the respondents, 85.78% (1122/1308), had also gone online to look for help with deciding on a career.

Respondents were asked if they had ever gone online to look for help for a family member or friend. A total of 68.43% (895/1308) indicated that they had gone online to look for help or information for a friend, while 55.58% (727/1308) indicated they had searched for help for a family member.

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Table 1. Areas of personal or emotional concern (N=1308). All values are listed as n (%).

Stressor	Caused significant stress (yes)	Looked online for help (yes)
School or College	1139 (87.08)	1116 (85.32)
Body Image	955 (73.01)	921 (70.41)
Exams	942 (72.02)	932 (71.25)
Family	678 (51.83)	
Money	888 (67.89)	727 (55.58)
Deciding on a career	859 (65.67)	1122 (85.78)
Relationships	830 (63.46)	838 (64.07)
Friends	808 (61.77)	763 (58.33)
Social Media	524 (40.06)	485 (37.08)
Illness of family member or friend	513 (39.22)	797 (60.93)
Local or World News	400 (30.58)	815 (62.31)
Personal Illness	370 (28.29)	858 (65.60)
Bullying	367 (28.06)	312 (23.85)
Sexuality	312 (23.85)	502 (38.40)

Table 2.	Personal	or emotional	concerns	qualitative	responses.
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Theme	Illustrative Quote
Mental Health	Just mental health, specially general anxiety. [P1011]
Finances	Unemployment after 4 years in college. [P1926]
Work	Participating in a work environment, ie: an office or the service industry. [P622]
Housing	Living in rented accommodation- cost, relations with house mates. [P1242]
Sports	Competitive sport. [P1812]
Identity	Developing a sense of identity, trying to be the best. [P1097]
Interpersonal Difficulties	an ability to understand people, the fear of not accepted as a member of a group or have actual friends, fear of trust due to let downs. [P938]
Parenting	Being a parent. [P203]
Physical Health	Physical health (no diagnosed illness). [P2109]
Transitional Challenges	The process of finishing college and transitioning from a world where others organised so much of my life to having to find a job and be the only one with the responsibility to progress my life. [P732]
Societal Concerns	Guilt about seeing world atrocities such as the homelessness crisis and racism/sectarianism and not being able to do much about it. [P376]

# Young People's Preferred Online Resources

Respondents were asked which online sources they use to gain more information for personal or emotional concerns, and 82.57% (1080/1308) indicated that they would make use of an Internet search, 57.03% (746/1308) indicated that they would use a health website, and 32.26% (422/1308) indicated they would make use of a forum or discussion board. Fewer (12.16%; 159/1308) would use a mental health app or go to a social media blogger or influencer (8.18%; 107/1308). An Internet search was widely used across all gender groups, while the use of a blogger or influencer was low across all groups.

In the open response section of this question, other preferred sources of information identified by the respondents could be grouped in the following ways: formal offline source, informal

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offline source, formal online source and informal online source. Examples of formal online resources included SpunOut.ie and ReachOut Ireland, while informal online sources included Reddit, YouTube and Tumblr.

In the subsequent question, respondents were asked how satisfied they were with their experiences of these sources if they had used them. The previous question indicated that the most preferred online resource by young people was the Internet search, and this question indicated that 36.94% (399/1080) of respondents were satisfied or very satisfied with an Internet search. The second most used online resource was a health website, and in this question 49.33% of respondents (368/746) indicated that they were satisfied or very satisfied with this resource (Table 3).

Table 3. Levels of satisfaction with online resources. All values listed as n (%).

Resource	Not sure	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied
Health website (N=746)	53 (7.1)	4 (0.54)	74 (9.92)	247 (33.11)	344 (46.11)	24 (3.22)
Mental health app (N=159)	19 (11.95)	4 (2.52)	22 (13.84)	55 (34.59)	52 (32.7)	7 (4.4)
Internet search (N=1080)	104 (9.63)	12 (1.11)	125 (11.57)	440 (40.74)	370 (34.26)	29 (2.69)
Influencer or blogger (N=107)	9 (8.41)	3 (2.8)	2 (1.87)	31 (28.97)	50 (46.72)	12 (11.21)
Forums or discussion board (N=422)	21 (4.97)	3 (0.71)	34 (8.06)	186 (44.08)	155 (36.73)	23 (5.45)
Websites already used (N=136)	10 (7.35)	2 (1.47)	17 (12.5)	62 (45.59)	38 (27.94)	7 (5.15)

# **Credibility of Online Sources**

Respondents were also asked how they would rate the trustworthiness of the above online resources. Health websites were found to be the most trustworthy, with 39.45% (516/1308) of respondents indicating that they found them trustworthy or very trustworthy. Respondents did not rate an Internet search as very trustworthy, with 47.09% (616/1308) saying that it was not trustworthy or only slightly trustworthy. Overall, none of the online sources listed were rated as trustworthy or very trustworthy by a majority of the respondents (Table 4). Following on from this question, respondents were asked which elements of an online resource would make it more credible. The vast majority (82.95%; 1085/1308) indicated that a health service logo was an important indicator of credibility, but an endorsement by schools and colleges (54.97%; 719/1308) or the presence of another government logo (57.57%; 753/1308) also played important roles (Table 5). Many respondents, specifically 80.43% (1052/1308), indicated that references to scientific data and authors were a key indicator of credibility in an online resource.

These indicators were followed by an open response question that asked, "Is there anything not listed above that makes an online resource trustworthy/reliable?". In this section, respondents indicated that online security was important, citing elements such as the green padlock in the Internet browser as well as the lack of ads on webpages. Other themes identified in this open response section included: written or informed by a reputable person or organization, links to local support services, grounded in research, design and layout, quality of content, the ability to rank or comment on content, and the ability to contact someone directly through the source. Participants also mentioned cross-checking sources with other sources to ensure reliability and credibility of that source, as stated by one participant:

If its consistent with other online resources. If 3 or 4 sites say the same thing, they I begin to trust it.

Table 4.	Trustworthiness of	online resources	(N=1308). All	values listed as n (%).	
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Basauraa	Not tructure or the	Clightly transformerthy	It's OV	Transformerthy	Vom tmicticonthy	Don't know
Resource	Not trustworthy	Singhuy trustworthy		Trustwortny	very trustworthy	Don t know
Health website	21 (1.61)	247 (18.88)	441 (33.72)	423 (32.34)	93 (7.11)	83 (6.35)
Mental health app	19 (1.45)	135 (10.32)	302 (23.09)	295 (22.55)	43 (3.29)	514 (39.30)
Internet search	163 (12.46)	453 (34.71)	482 (36.85)	123 (9.40)	3 (0.23)	84 (6.42)
Influencer or blogger	466 (35.63)	311 (23.78)	137 (10.47)	71 (5.43)	9 (0.69)	314 (24.01)
Forums or discussion board	222 (16.97)	395 (30.20)	285 (21.79)	126 (9.63)	13 (0.99)	267 (20.41)
Website already used	422 (32.26)	295 (22.55)	172 (13.15)	69 (5.28)	2 (0.15%)	348 (26.22)

Table 5.	Elements	that in	ndicate	credibility	(N=1308)	. All	values are	listed as	n (9	%)
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Element	Disagree	Not sure	Agree
Links to social media	698 (53.36)	480 (36.70)	130 (9.94)
Government logo	254 (19.42)	301 (23.01)	753 (57.57)
Health service logo	82 (6.27)	141 (10.78)	1085 (82.95)
Good design and layout	434 (33.18)	334 (25.6)	540 (41.3)
Top of Google search results	460 (35.2)	331 (25.54)	517 (39.53)
College or school endorsement	190 (14.53)	399 (30.50)	719 (54.97)
References to scientific data and authors	64 (4.89)	192 (14.68)	1052 (80.43)
A quiz or assessment	618 (47.25)	474 (36.24)	216 (16.51)
Contains personal stories or experiences	177 (13.53)	433 (33.10)	698 (53.36)



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Another participant suggested that sources could make this cross-checking process easier by providing hyperlinks to related work.

# **Facilitators and Barriers to Seeking Help Online**

Respondents were asked which factors would encourage them to seek help online if they were facing a personal or emotional concern (Table 6). Young people affirmed that the anonymity and confidentiality offered by the Internet was an important motivating factor when deciding to search for help online, with 80% (1046/1308) of the sample indicating that it influenced their decision a lot or quite a lot. Similarly, the low monetary cost of using the Internet was also an important motivator in selecting the Internet, with 84.41% (1104/1308) indicating it encouraged them to seek help online a lot or quite a lot. Some of the important barriers highlighted by young people included being unsure if information was reliable, as well as wanting to

Table 6. Facilitators to online help-seeking (N=1308).

solve problems on their own (Table 7). Even though the Internet offers more anonymity than offline pathways, young people are still concerned about others finding out that they are experiencing a difficulty.

In the open response section, respondents were asked "Is there anything not listed above that would encourage you to seek help online for a personal or emotional concern?". A total of 124 respondents provided answers. These answers were grouped together in themes, including anonymity, reduced stigma, validation of experiences, current situation in the health service and ease of access (Table 8). Respondents also highlighted barriers to online help-seeking in this space, such as the cost of some online services, lack of surety of credibility of some online resources, not being able to find personalized information, and a lack of mental health literacy which impacted their ability to find the right online resource (Table 8).

Facilitator	Mean (SD)	Not at all, n (%)	A little, n (%)	A lot, n (%)	Quite a lot, n (%)
It's free	3.31 (0.81)	43 (3.29)	160 (12.23)	452 (34.56)	652 (49.85)
Anonymous and confidential	3.26 (0.89)	67 (5.12)	195 (14.91)	378 (28.90)	668 (51.07)
Can take it at own pace	3.16 (0.82)	47 (3.59)	205 (15.67)	547 (41.82)	509 (38.91)
Abundance of information	3.12 (0.80)	38 (2.91)	231 (17.66)	574 (43.88)	465 (35.55)
Others like me	3.10 (0.91)	74 (5.66)	257 (19.65)	437 (33.41)	540 (41.28)
Access any time of day	3.01 (0.88)	63 (4.82)	305 (23.32)	494 (37.77)	446 (34.10)
Unsure if I'm unwell enough	2.75 (1.09)	230 (17.58)	291 (22.25)	367 (28.06)	420 (32.11)
Too unwell to reach local support services	2.20 (1.04)	409 (31.27)	421 (32.19)	281 (21.48)	197 (15.06)
There are no other options available	2.13 (1.04)	447 (34.17)	436 (33.33)	238 (18.20)	187 (14.30)

#### Table 7. Barriers to online help-seeking (N=1308).

Barrier	Mean (SD)	Not at all, n (%)	A little, n (%)	A lot, n (%)	Quite a lot, n (%)
Unsure if information is reliable	2.70 (0.91)	111 (8.49)	465 (35.55)	440 (33.64)	292 (22.32)
Solve problems on my own	2.58 (1.09)	277 (21.18)	342 (26.15)	344 (26.30)	345 (26.38)
Concerns others might find out	2.36 (1.17)	417 (31.88)	329 (25.15)	230 (17.58)	332 (25.38)
Thinking I don't have a problem	2.34 (1.04)	324 (24.77)	446 (34.10)	307 (23.47)	231 (17.66)
Unsure what to search for	2.13 (0.92)	348 (26.61)	570 (43.58)	261 (19.95)	129 (9.86)
Not sure of my privacy and anonymity	2.10 (1.05)	472 (36.09)	416 (31.80)	235 (17.97)	185 (14.14)
Prefer alternative forms of help	1.88 (0.94)	555 (42.43)	453 (34.63)	197 (15.06)	103 (7.87)
Having no one help navigate options	1.84 (0.97)	630) 48.17%	365 (27.91)	205 (15.67)	108 (8.26)
Being too unwell to look for help	1.73 (0.94)	703 (53.75)	351 (26.83)	155 (11.85)	99 (7.59)
Having previous bad experiences	1.61 (0.88)	786 (60.09)	320 (24.46)	125 (9.56)	77 (5.89)



Table 8. Qualitative responses indicating facilitators and barriers to online help-seeking.

Theme	Quote
Facilitators	
Affordability	Not having enough money to afford counselling in person. [P889]
Anonymity	Some issues can feel embarrassing to talk about. The anonymity online cancels this out. [P617]
Ease of Access	Its mostly just the speed of it that helps me out. In my case I can find so much info. on social anxiety with just one click rather than driving 30 minutes from my college to speak to the college counsellor. [P1412]
Validation of Experience	Thinking that you are making up the illness in your head and that it isn't real and you are putting it on for attention. [P1018]
Reduced Stigma	I often go online because I know there is something wrong, but I don't want to tell anyone in my real life for fear that they will judge me or they won't care and ill just be bothering them. Online help can help me deal with my problem alone so I will not have to tell anyone. [P470]
Privacy	It provides a level of privacy and I feel like I can control my own feelings. [P392]
Response to negative life events	A huge trauma maybe. [P33]
Barriers	
Affordability	Hard to find a free option for when times are really bad. [P1401]
Lack of personalization	It's not personal: all the information out there already exists and is not tailored for me. [P132]
Lack of mental health literacy	Being unsure what to search/look for online instead of searching for hours for a website that I am comfortable with. [P242]
Unsure of credibility	Something to reassure me that the content I am viewing is reliable and trustworthy and having a person to discuss issues with. [P863]

# Discussion

# **Primary Findings**

The results of this survey clearly indicate that the Internet plays a major role in the help-seeking process for young people. The survey has highlighted that young people are already going online to look for help for issues that are causing them distress, and they are engaging with different online sources for their help-seeking needs. Given the proportion of young people who encounter mental health difficulties and turn to the Internet to meet some of their mental health needs, it is important that researchers and service providers have an accurate and holistic understanding of what these needs encompass.

Help-seeking is a complicated process, and young people use different online mental health resources based on their needs. Rickwood's model [27] of help-seeking refers to 4 stages of help-seeking: (1) becoming aware of and appraising the problem; (2) expressing the need for support; (3) knowledge of available and accessible sources of help; and (4) being willing to disclose personal information. This model acknowledges that there are several barriers that may impede help-seeking at any stage. It can be hypothesized that different online mental health resources are used at different stages of this process. Most of the sample, 82.6%, indicated that they would make use of an Internet search to locate information when experiencing a personal or emotional difficulty. The Internet search could be conceptualized as playing a role in both the expression and availability stages of the process. However, only 37% of the sample indicated that they were satisfied with this mode of finding help. This could indicate that the Internet search is being used due to its easily accessible nature and the anonymity it offers, but this appears insufficient to meet the mental health

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needs of the present sample. For these reasons, it is possible that an Internet search could act as both a facilitator and a barrier to further help-seeking.

Like findings in a study by Reavley, Cvetkovski & Jorm [22], health websites and discussion boards or forums seem to play an important role in meeting young people's mental health needs, which may be due to varied reasons. A health website is likely to provide more accurate information substantiated by research and written by subject experts, while forums allow users to engage with peers who are like them and have lived their same experiences. Comparably, a study by Lal, Nguyen & Theriault [28] indicated that young people value resources that allow them to access the personal stories of peers with lived experiences, which gives them the opportunity to process the information at their own pace. The current study found that other popular online resources include formal youth mental health websites, such as ReachOut Ireland, and informal sites such as YouTube. It is worth noting that these sources are likely to change with time and new or other platforms grow in popularity.

Young people are often described as digital natives [29]. This includes the assumption that young people can effectively identify and locate credible resources in the online space [30]. A study by Montagni et al [31] found that half of their sample trusted what they found on the Internet, but their sample identified one of the disadvantages of using the Internet was its unreliability. This survey also indicates that assigning online credibility can be confusing, but young people have developed different strategies to determine the reliability of an online resource. Some of these strategies include checking multiple sources and cross-checking information. The results from this survey have shown endorsements from reputable and known

government bodies and educational institutions can play an important role in helping young people to identify credible and reliable online resources. It is evident, though, that the sources young people were surveyed on, apart from health websites, are not deemed to be very credible or reliable. This disparity between a plethora of online sources being available and their perceived lack of credibility could have a jarring effect on the help-seeking process of the young person, so this needs to be investigated.

There are a multitude of facilitators and barriers associated with online help-seeking. Many studies have found that the ease of access of the Internet plays an important role in helping young people, a finding that this study supports [24,32-34]. Particularly, a study by Birnbaum et al [35], highlighted that the Internet plays an important role in early intervention and in young people's further help-seeking. Young people are drawn to the Internet because of the wealth of free resources available, but further help-seeking, such as talking to a professional, may be too costly for this demographic. A systematic review by Kauer, Mangan & Sanci [21] confirmed that online help-seeking is attractive to many young people because of its confidentiality and anonymity. This survey found that concerns about anonymity and privacy remain, and although it seems that the anonymity offered by the Internet does go a long way in circumventing the stigma associated with mental health help-seeking, young people are still concerned about others finding out. It may be for this reason that many of the sample indicated that they would use their mobile phone to search for help online.

# Limitations

The survey findings were based on self-reported data from the respondents, so the results might not be generalizable. Given that recruitment of participants happened through online platforms, this sample is limited to young people who access Facebook, Twitter and other charity websites. Thus, this survey may not have captured the views of help-seekers who access alternative resources on the Internet. Future studies should include alternative recruitment strategies targeting those who are less likely to seek help, particularly men, and help-seekers who may not access mainstream social media platforms or charity websites. In addition, a large majority of the participants were female and undergraduate students, which also limits the generalizability of the results. This survey focused on emotional concerns that cause participants significant distress for which they might go online to look for help but did not ask about searches for symptoms such as feeling depressed or feeling anxious. Thus, it cannot comment on the types of mental health symptoms participants might seek help for online. This should be taken into consideration in future work. Finally, the list of online resources offered was not extensive, so future studies should further investigate both the preferences between online and offline sources and whether there are potential differences between preferences for informal and formal online resources.

# Conclusion

The findings of this study indicate that young people are engaging in help-seeking behavior online to look for help for personal and emotional concerns that are causing them distress. Levels of satisfaction regarding different online resources are varied, so web-based mental health resources need to ensure that they meet the needs of online help-seekers in providing support. Young people have established strategies to assign credibility online, however, the availability of credible, online resources needs to be addressed. Steps should also be taken to help governmental organizations and educational bodies identify and support trustworthy and reliable online resources. Finally, as with traditional offline help-seeking, several barriers exist to deter help-seeking; however, the Internet circumvents some of these through its offering of privacy and confidentiality.

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# **Conflicts of Interest**

None declared.

# **Multimedia Appendix 1**

Survey Questions. [PDF File (Adobe PDF File), 4MB-Multimedia Appendix 1]

# Multimedia Appendix 2

Additional Tables. [PDF File (Adobe PDF File), 89KB-Multimedia Appendix 2]

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# Abbreviations

**GHSQ:** General Help-Seeking Questionnaire **SWEMWBS:** Short Warwick–Edinburgh Mental Well-being Scale

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# Searching for Mental Health: A Mixed Methods Study of Young People's Online Help-seeking

Claudette Pretorius<sup>1</sup> Darragh McCashin<sup>2</sup> Naoise Kavanagh<sup>3</sup> David Coyle<sup>1</sup>

<sup>1</sup> School of Computer Science. University College Dublin, Ireland

<sup>2</sup> School of Psychology, University College Dublin, Ireland

<sup>3</sup> Jigsaw, National Centre for Youth Mental Health, Dublin, Ireland

claudette.pretorius@ucdconnect.ie, {darragh.mccashin, d.covle}@ucd.ie, naoise.kavanagh@jigsaw.ie

### ABSTRACT

Seeking help is often an important step in addressing mental health difficulties. Evidence suggests that positive helpseeking experiences contribute to an increased likelihood of future help-seeking and achieving improved outcomes. However, help-seeking is a complex process. Alongside traditional sources, digital technologies offer many pathways to help. Using a mixed methods approach across two studies, this paper explores key design factors for online mental health resources that can support young people's helpseeking. First, a large online survey (n=1308) highlighted challenges and identified common help-seeking scenarios, including information-seeking, person-centred approaches and crisis situations. Using survey data, personas were developed to represent different help-seekers - each characterised by a particular help-seeking scenario. The personas were then used in co-design workshops to facilitate further exploration of help-seeking needs. Four key design considerations were identified: connectedness, accessible information, personalisation, and immediacy. Based on our findings, we provide design recommendations that are grounded in existing theories of help-seeking.

# **Author Keywords**

Mental health; help-seeking; search; young people; behaviour; co-design; personas; mixed methods

# **CSS** Concepts

#### •Human-centered computing~Human computer interaction (HCI);

# INTRODUCTION

The prevalence of mental health difficulties in the general population is well documented [12, 58], with the age of onset for most psychiatric disorders falling within the 14 - 25 age group [33]. Young people face a number of challenges that are unique to their developmental stage, including concerns about body image, education, and transitioning into

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independent living [29, 38]. As with many health-related concerns, there are barriers to accessing the appropriate help when necessary, including stigma around accessing mental health care, long waiting periods to see a mental health professional, financial constraints, and concerns around privacy and confidentiality [13, 14, 51]. Technology can and has played a role in addressing some of the traditional barriers young people can face when seeking help for mental health issues.

For many young people, particularly in developed countries, use of the Internet is embedded in their day-to-day lives. Evidence suggests young people are increasingly using the Internet to access mental health information [4, 20, 57]. They can do so anonymously, are not limited by geographical location, and a wide variety of information is readily available [9]. These factors can contribute to young people having increased access to resources, as well as increased control in meeting their own mental health needs [31]. Unfortunately, the quality of online mental health resources, both formal and informal, is inconsistent [37]. These resources can impact the psychological wellbeing of a young person and influence their likelihood of future help-seeking. It has been found that future help-seeking intentions are improved if previous help-seeking experiences have been positive [22]. Although some data exist about young people's online help-seeking preferences, little is known about young people's patterns of help-seeking online and how their needs can be appropriately met.

In this paper, we explore young people's online help-seeking practices. We begin by providing empirical evidence on how young people who are experiencing mental health concerns seek help online. Building on this, we worked directly with young people to explore how web-based technology can better meet their help-seeking needs. Two separate studies are presented. Study 1, a large online survey, explored young people's help-seeking preferences, patterns of Internet use for mental health, sources of information, in addition to satisfaction with content accessed online. The study identified three distinct scenarios or categories of helpseeker, which we subsequently translated into personas. In Study 2, these personas were used in co-design workshops with young people to gain further insight into online helpseeking journeys. Methodologically, personas proved

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valuable - allowing for engagement with sensitive topics in a group setting, without the need for direct personal disclosure.

This paper makes several distinct contributions. It provides empirical evidence of the approaches taken and challenges faced when young people use the Internet to seek help for mental health difficulties. Three key help-seeking scenarios are identified: self-directed information-seeking; personcentred approaches that emphasis relatedness and personal connections; and crisis situations. Building on this, personas provided a concrete means to investigate these help seeking scenarios, via co-design with young people. Four important considerations are identified that can help to support a positive help-seeking experience: connectedness; accessible information; personalization; and immediacy (i.e. options for immediate action). Based on our findings, we provide theoretically grounded recommendations to support the design of online help-seeking resources.

#### **RELATED WORK**

Within the mental health field, help-seeking has been defined as "an adaptive coping process that is the attempt to obtain external assistance to deal with a mental health concern" [52]. Help-seeking sources can be classified as either informal or formal [59]. In an offline context, informal sources are those sources such as peers, partners, friends and family. Formal sources are those sources with whom the person does not share a personal relationship and are usually from a professional, such as a general practitioner, psychologist or educator [59]. Historically, young people have shown a preference for seeking help from informal sources and a greater preference for self-reliance [55]. These same classifications can be applied to online resources, where health websites, online counselling services and charity websites would be considered to be formal online sources. Formal sources can also be accessed across various platforms including social media channels such as Instagram and Twitter. Similarly, informal sources can be accessed on these same platforms; as well as through unmoderated discussion forums, blogs and vlogs hosted by peers, and unclassified websites [50]. Traditionally, barriers to offline help-seeking would be fear of stigma, difficulty in accessing services and preferences for self-reliance [22]. Online helpseeking provides the opportunity to overcome these barriers [21, 31]. Previous research has found that help-seeking can be facilitated by having positive help-seeking experiences; having social support and encouragement from others, and improved mental health literacy [55]. Through thoughtful and critical design, online resources can support these facilitators and address the traditional barriers to help-seeking for mental health concerns.

In this paper we explore online help-seeking via the lens of existing offline help-seeking theory. We recognise that this issue could also be approached via an Information Science perspective, building on work by researchers such as Fisher et al. [17, 18] and Rieh [28, 53], but this was beyond the scope of the current paper. The potential to combine these

different theoretical perspectives is discussed further in our Limitations and Future Work section.

#### **Online Help-seeking Practices**

Previous research has focused on the content of social media posts and Google search-logs to predict mental health conditions or to be used as tools to assist with health assessment [11, 60]. More recently, research has begun to focus on how the Internet and social media is being used to find support for mental health difficulties. A study by Andalibi [3] found that Instagram was being used by people experiencing depressive symptoms to connect with others undergoing similar experiences and to seek support. Many young people are also making use of search engines and specific mental health resource websites to meet their needs. Individual search-logs can be particularly insightful of the difficulties currently being experienced. A study by Zaman et al [60] shows that individual search-logs can provide indicators that can identify those struggling with low selfesteem. Additionally, Birnbaum et al [5] found that the search terms used by young people vary depending on the mental health difficulty faced. Those with psychotic disorders were more likely to search why their symptoms had started, whereas those with mood disorders were more likely to search for how to stop their symptoms. Young people most at risk, those experiencing self-harm or suicidal intent, are more likely to access the Internet than reach out to someone offline [19]. A slightly larger proportion of these young people are accessing resources that are helpful but there is still a proportion accessing potentially harmful sites [34]. A systematic review by Kauer et al [31] investigating the effectiveness of online interventions on help-seeking behaviour found that, despite most studies reporting that young people were satisfied with online mental health resources, very few studies reported the effect of these online resources on facilitating young people's help-seeking.

# Theoretical Models of Help-seeking

Several existing theories provide conceptual frameworks to understand help-seeking. While each theory was developed in the context of offline help-seeking, they can provide valuable building blocks to also understand online helpseeking. The studies described below apply Rickwood's theory and Self Determination Theory (SDT). Rickwood's work has been widely applied to young people in offline contexts. It provides a stage-based approach to analysis. In contrast SDT focuses on basic psychological needs. Together they provided a means to investigate basic needs at different stages of an online help-seeking process. Rickwood's model and questionnaires are applied in the design of Study 1. Both theories are applied in the analysis of data in Studies 1 and 2. For completeness we also include a brief discussion of the Theory of Planned behaviour, although this specific theory was not applied in our work.

#### Rickwood's Help-seeking model

Rickwood's model is a stage-based model that reflects the interpersonal processes that take place when a young person seeks help [51]. It recognises the internal process that needs

to take place for help-seeking to move from an intention to a behaviour; from the intrapersonal to the interpersonal. These stages are: awareness and appraisal of problems; expression of symptoms and need for support; availability of sources of help; and willingness to seek out and disclose [59]. This model was specifically developed for help-seeking for mental health difficulties in a population age range of 14 - 24 years in the offline context. This model takes into account that help-seeking can be formal or informal but fails to take into account some of the external barriers that can hinder helpseeking [30].

# Theory of Planned Behaviour

Although not applied in this paper, this model proposes that behaviour is determined by behavioural intentions [1]. A person's behavioural intentions are informed by: their attitude toward the behaviour; their subjective norms around the execution of the behaviour; and their perceived behavioural control over the behaviour [1]. It has been suggested that, by changing a person's attitude towards helpseeking through improving their mental health literacy and changing their subjective norms (i.e. reducing the stigma), you can positively influence their intention to seek help [7]. However, the change from intention to behaviour is moderated by the individual's perceived behavioural control, which in the case of help-seeking are factors such as the availability of appropriate services; cost of services and accessibility of services [28]. This model takes into account the barriers that may hinder help-seeking but is not specific to a particular behaviour.

# Self-Determination Theory

Self-Determination Theory (SDT) is a theory of motivation and wellbeing [54]. Central to this theory is the concept of three basic psychological needs: competence, relatedness and autonomy; that when satisfied will promote wellbeing and sustained motivation [54]. It also asserts that goal pursuits can be understood through the satisfaction of these three psychological needs and that facilitators and barriers to a behaviour can be understood in terms of fulfilment of these needs [16]. SDT is being successfully applied to the development of technologies and is useful to apply when trying to understand user's design needs [10, 48]. A study by Naqshandi et al [39] investigating online peer supporter's design needs for a chat system with early mental health helpseekers, found that the themes from the data aligned with the three basic psychological needs outlined above. SDT can be used to understand motivation in online help-seeking, assuming that where all three needs are met, it could move an individual towards their intended help-seeking goal and enhance their wellbeing.

# A MIXED METHODS APPROACH

This research applies a mixed methods approach, including quantitative and qualitative data, and combining an initial online survey (Study 1) with later co-design workshops (Study 2). In designing and recruiting for our studies, we recognised that young people seeking help are often doing so in relation to everyday stressors. As a result, we deliberately It is common for HCI research in healthcare to use co-design with specific diagnostic populations in order to ensure that user needs are met [24, 56]. However, this research sought to gain the perspective of young people who fall into the general population and might not fall into any clinical categories, as would be the case for many young people searching for help online. Co-design methods investigating design needs with young people in relation to mental health have been found to be very useful in the past [32, 40]. They provide a medium to build a shared understanding based on research findings; but can also help to gain the perspective of potential users in a non-intimidating manner [23]. Previous HCI research has demonstrated that the use of personas is an acceptable way to facilitate empathy and help to focus design sessions [35, 36, 43].

# STUDY 1: ONLINE SURVEY

#### Procedure

This was an exploratory study which investigated the online help-seeking behaviours and preferences of young people aged 18-25, living in Ireland. We made use of an anonymous online survey hosted on LimeSurvey. Participants were recruited through social media ads on Twitter and Facebook. The survey consisted of both open and closed questions and addressed young people's technology use, their propensity to seek help from different sources, current personal and emotional concerns, preferred online resources, the credibility of online resources, and positive and negative experiences of online help-seeking. Quantitative data were analysed using descriptive statistics in IBM SPSS Statistics for Mac, Version 24; and qualitative data were analysed using QSR International's NVivo 12 software and was inductively coded using thematic analysis following Braun & Clarke's methodology [8]. All of the data was coded by the first author, with the second and fourth author coding a percentage of the data. Disagreements were discussed until consensus was reached.

The full quantitative results of this study are reported in [49]. Here we provide a brief summary to provide context for our qualitative work and subsequent discussion of our co-design study (Study 2). The qualitative results of this study have not been reported previously. Ethics permission for this study was provided by University College Dublin Office of Research Ethics (LS-17-116-Pretorius-Coyle).

# Results

#### Survey participants

A total of 1308 participants completed the online survey, of which 78.52% (n = 1027/1308) were female, 18.50% (n=

242)/1308 were male, 1.68% (n=22/1308) were non-binary and 0.84% (n=11/1308) identified as transgender. The mean age of the population was 20.68 (sd = 2.22), with a minimum and maximum age of 18 and 25 respectively. The survey had good national coverage. Of the whole sample, 67.13% (n=878/1308) reported that they were currently living in a city or town. Most of the sample reported their current level of education to be undergraduate (59.17%, n = 774/1308). A majority of the sample accessed the survey link through Twitter (68.88%, n=901/1308) and Facebook (24.08%, n=315/1308).

#### Quantitative Results

The survey showed that school/college (87%), body image (73%) and exams (72%) were personal concerns for the majority of the sample. The results further indicated that there was a correlation between these personal concerns and young people looking for help online. The survey demonstrated that the majority (82.6%) of the sample would make use of an Internet search to look for help online, however only 36.9% of the respondents were satisfied with their experience of using search. Other resources used by young people included health websites or discussion forums. Levels of satisfaction were higher for health websites, with 49.3% of the sample indicating that they were satisfied with this experience when help-seeking. Very few young people (12.2%) would make use of a mental health app. Open response questions in this survey indicated that other sources accessed when help-seeking could be classified in the following ways: formal offline source, informal offline source, formal online source and informal online source. When surveyed on the credibility of online resources, health websites were deemed trustworthy by 39.5% of the sample; with 47.1% indicating that they found an Internet search untrustworthy. Overall, none of the online sources listed were rated as 'trustworthy' or 'very trustworthy' by the majority of respondents. Respondents provided insight into which elements they deemed as important indicators of credibility online. This included: a health service logo; endorsement by a school or college; the presence of another governmental logo; and reference to scientific data or authors. In an open response question, young people indicated the following as playing a role in promoting credibility: links to local support services; grounded in research; design and layout; quality of content; the ability to rank or comment on content; and the ability to contact someone directly through the online resource.

When asked about facilitators and barriers to help-seeking, young people confirmed that anonymity and confidentiality played an important role in their motivation to use the Internet for help-seeking. Additionally, being able to connect with others with similar experiences was a significant facilitator. Some of the barriers included not knowing if information found online was reliable (55.9%) and a preference for self-reliance (52.7%). Respondents also had worries about their privacy and anonymity (32.1%) and concerns that others might find out (43%).

#### Qualitative Results

The qualitative sections of the survey focused on young people's experiences, in particular the barriers and facilitators they experience in seeking help online and their attitudes towards information-based help versus connection with another person. For example, participants were asked "Is being able to connect to another person important to you when seeking help online? If yes, why?" 536 participants answered this question.

Qualitative analysis identified affordability, anonymity, ease of access, validation of experience, reduced stigma, and privacy as key facilitators to online help-seeking. For example, a participant wrote:

I often go online because I know there is something wrong, but I don't want to tell anyone in my real life for fear that they will judge me or they won't care and i'll just be bothering them. Online help can help me deal with my problem alone so I will not have to tell anyone.

Affordability, lack or personalization, lack of mental health literacy and concerns about the credibility of online resources were key barriers to a positive experience. Participants comments included:

It's not personal: all the information out there already exists and is not tailored for me.

Being unsure what to search/look for online... searching for hours for a website that I am comfortable with.

Analysis of questions around help-seeking preferences revealed a number of key groupings. The *information-seeker* values independence, their objective is to browse information regarding their mental health query without the intervention or interference of another person, online or offline. This type of help-seeker wants a confidential experience that allows them to access well-written, credible information. This is evidenced through comments such as "I prefer to be independent" and "I like to gather the information myself, without talking to others".

In contrast, other help-seekers are *person-centred*. They are looking for an affirming and empathetic experience. This help-seeker wants to validate their own experiences and would like to make use of an online guide. This could be due to feelings of uncertainty, "*Sometimes it can be hard to identify what the problem is*," as well as wanting a personalised experience:

I think a lot of information is very general and can seem cold and clinical. If you can talk to someone about your personal and specific experience, information can be tailored and make the person feel more important.

Finally, people seek help online when they are facing *a crisis situation*. This help-seeker wants to connect with another person, either online of offline, because they are in severe distress and need assistance:

Sometimes, in very severe situations I want to talk to a real person...

Often a crisis help-seeker is looking for immediate relief ("*it is immediate*"). But when they are looking for help and a personal connection, it is often outside of typical office hours ("*I find this especially true at night time, and this is the time when all of the usual go-to help are not available*").

Our data suggests that many online help-seekers will fall into one of three groupings identified above. However, it is also clear that people cannot, and should not, be referenced as a single static type of help seeker. Rather, young people seek different types of help at different times in their lives, depending on their needs and goals. For example:

It can be useful during times of crisis and extreme emotional stress, but with average emotional stress I prefer to do my own research.

Finally, many young people indicated that when they seek help online, it is often in regard to the needs of another person, e.g. a friend or family member. The needs of the third-party help-seeker therefore also need to be considered.

#### Discussion

The findings from the survey suggest four broad categories of design features that can either meet or frustrate an online help-seeker's needs.

#### Content

The spectrum of help-seeking needs is broad and thus the types of content provided by an online resource should cater for this. The survey found that young people do make use of information pages containing factual information about symptoms and treatment. Less formal information was also favoured and can be provided through the use of personal stories detailing the lived experiences of other young people. To address the objectives of different types of help-seekers, young people indicated that reliable information regarding self-help strategies should be included in online resources. These strategies need to be supported by research, and references to research should be included. Content should be tailored so that it is applicable to both people searching for themselves and those searching for others.

#### Interactive Features

The survey highlighted that reading is not the only activity engaged in by online help-seekers. There is a need to enable them to interact and engage with the content they find online. Users suggested that this could be done through comments sections at the bottom of information pages with the ability to upvote certain comments, similar to platforms such as Reddit. Depending on the needs of the help-seeker, the need to connect with another person online whilst help-seeking was highlighted. This can be with a peer or a professional. Finally, any resource needs to be designed for mobile. Good design needs to create a comfortable environment for online content and provide features that are easily accessed through mobile technology.

#### Support Credibility

Concerns over credibility are likely to become a barrier to further help-seeking in the future. Helping young people to assign credibility to online resources also has the potential to play an important role in developing their mental health literacy. The findings from the survey indicate that young people value information that is backed by research and written by experts in the field. Young people's online information-gathering behaviours can be facilitated by including hyperlinks to other online resources that can complement the help-seeking journey. Online resources can indicate their credibility by working in partnership with governmental health services and local schools or colleges.

# Support Different Help-Seeking Pathways and Different Kinds of Help-Seekers

Online help-seeking pathways for different help-seekers need to be considered. Existing online resources are predominantly guided by mental health difficulty, diagnoses and symptoms. This has the risk of pathologizing normal emotional responses to everyday life events and stressors which may negatively impact help-seekers experience, deterring future help-seeking when in need.

#### PERSONA DEVELOPMENT

Study 1 allowed us to collect data from a large number of young people but relied on online survey methods. In Study 2, we applied co-design methods to engage more directly with young people. As mental health is a sensitive subject and co-design involved group workshops, we felt it would be inappropriate for the participants to speak directly to their own mental health experiences. Instead, data from Study 1 was used to develop empirically informed personas for young people seeking help for mental health difficulties. Each persona was characterised by one of three goals: to find information; to connect with others, and to find immediate help in times of crisis.

Persona development was informed by Nielsen's description of engaging personas [41]. Engaging personas make use of stories to provide an understanding of the whole person and avoid seeing the user as a stereotype [41, 43]. Engaging personas also take into consideration the emotions and backgrounds of the user. This perspective emphasizes the narratives of the user and how stories can engage and bring personas to life. Nielsen [41, 42, 43, 44] outlines a ten-step process to create these personas which can be summarised by four main sections: data collection and analysis; persona descriptions; scenarios for problem analysis and idea development; and finally, acceptance from the organisation and involvement of the design teams. In the first three steps, quantitative data (in this case, the survey data) was used to determine who the users are and what they do with the current systems. A hypothesis was then formed to describe different user groups. These hypotheses are then verified. For this study, qualitative data from the survey study and previous systematic review of the literature was used to accomplish this [50]. As part of step 4, it was decided to create one persona per grouping identified in Study 1. Once



Figure 1. Jane represents the Information Seeker.

the number of personas were decided, steps 5 and 6 included describing these personas and preparing scenarios for each persona. These were again informed by the results of the survey. Throughout the process, designs were discussed among team members and field experts, to ensure they were valid and representative of the data and actual users.

Figure 1 shows one of the final personas. All three personas are included as supplementary materials. Beyond the scope of this paper, the personas may be useful to other researchers working in this field. They are empirically derived and can help to inform both design processes and decisions.

#### STUDY 2: CO-DESIGN WORKSHOPS

#### Procedure

Four separate, two-hour co-design workshops took place over a one-month period with four different groups in different urban and rural locations. Two of the workshops took place with students from local vocational colleges, with the final two workshops taking place with young people from a charity youth advisory panel. All recruitment was facilitated by a youth mental health charity. There were a total of 35 (Female=20, Male=15) participants across all workshops. Co-design consisted of three distinct activity phases and the format was informed by the work of Blake et al [6]. Data was collected in the form of audio recordings of group interactions and artefacts created by groups during the workshops. Artefacts were later photographed, and audio recordings transcribed. Co-design study participants were not asked about their personal experience of mental health services, due to concerns that confidentiality might be compromised in a group setting. Ethics permission for this study was provided by University College Dublin Office of Research Ethics (LS-19-20-Pretorius-Coyle).

#### Activity One: Persona Immersion

The three personas were used to provide representative illustrations of online help-seekers, according to the groupings described earlier. Participants were divided into groups of two or three, with each group assigned one persona. The intent was to allow participants to become immersed with the user and allow them to think of the helpseeking journey from their perspective. To facilitate this, groups were asked to work through the scenario from the point of view of the persona. Participants were asked to complete an empathy map to elicit empathy and understanding [15]. The personas and empathy maps allowed participants to explore a sensitive topic from the perspective of another young person.

#### Activity Two: Mapping the help-seeking journey

In the same small groups, participants were then asked to map the help-seeking journey for each persona using the scenarios [26]. The groups were asked to execute the steps the persona might take to achieve their personal help-seeking objectives and to record these steps. Participants were asked how the person would feel at different points in the process; where they may feel their needs are met and where that particular persona might feel frustrated.

# Activity Three: Brainstorming features for an online mental health resource

The brainstorming section of the workshop consisted of two parts. The participants were first asked to brainstorm as many features and qualities they thought were relevant for an online mental health resource for their persona. They completed this brainstorming activity on their own and then discussed their ideas in their groups and grouped similar ideas together. Once this was completed, participants were then asked to sketch their most preferred features. To conclude, participants discussed their sketches in groups and identified the most important features overall.

#### Activity Four: Designing the online experience

Each small group was asked to design the ideal online mental health resource that would facilitate the help-seeking of their persona and which incorporated the features they had identified in the brainstorming process. Participants used A1sized paper and markers to illustrate their designs.

#### Data Analysis

A directed content analysis approach was used on the qualitative data [27]. All workshop artefacts were photographed and uploaded to NVivo. Three of the authors participated in coding. The first author coded all workshop data using open and closed coding. An a priori list of codes were derived from the Rickwood's help-seeking model, Self-Determination Theory, known facilitators and barriers to help-seeking, and categories of features that would inform design. Data that could not be coded to the predetermined codes were identified and analysed to determine whether they represented a new category or sub-category. The two remaining authors used the same approach, with the second author coding 75% of the data and the last author coding 25% of the data. Thereafter, codes were compared, and any disagreements were discussed until consensus was reached. Using this qualitative approach, each artefact could be coded for multiple codes. Once coding was completed, codes from facilitator and barrier categories, as well as from feature categories, were analysed for overall themes.

### Results

Collectively, the overall dataset clustered into four key themes that described important design needs for young people throughout their help-seeking journey.

#### Chat and relatedness

Participants repeatedly described chat features as an important component to help-seeking and expressed a clear wish for relatedness. This was described in a variety of formats, including virtual reality, chatbot-driven, 24/7 real-time interactions, community forums, options for chat with both peers and professionals, in addition to preferences for anonymous chat. Across all workshop designs, participants included a chat option within a broader interface that addressed various help-seeking pathways. The chat function was also highlighted by some of the participants as a useful way to assist those who were in crisis.

The only thing about a live chat, if it's 24/7, it would have to be like, you can feel bad at any time in the day like, you know what I mean? Maybe like you could have an emergency contact thing, where it's like, if you go on at two in the morning, like someone, like you could go on a call or something.

Links to social media were also a minor theme within the data. Participants used social media as a means to connect to a broader community as well as means to learn about online mental health resources.

#### Information and competence

The second key theme was a desire for information regarding mental health issues, noting also the impact that too much information could have on a person's sense of competence. Participants showed strong preferences for traditional information page content including articles and FAQs. Many groups named formal websites (such as Healthline or the National Health Service in the UK). They were also clear in expressing their wish for diverse formats of information videos, podcasts, links to other sources, and personal stories were all seen as helpful.

Connected to the drive for information was the need for accessible layouts and design, and this was seen as integral to both the credibility and usability of the online resources. Furthermore, participants indicated that credibility could be promoted by referencing scientific research and mental health professionals.

The issue of competence was most clear when participants discussed strategies of searching for information. Activity two asked all groups to execute the steps their persona might take to achieve their personal help-seeking objectives. In the workshops, all groups, irrespective of the persona assigned, began with an Internet search – typically via Google. However, the content of the search was variable, some groups searched specifically for mental health conditions such as depression or anxiety. Others inserted symptom-related queries such as "*heavy feeling in my body*." Some groups reported being unsure of what to search for:

But she probably doesn't have a full understanding of what she has, I think like when she's searching, she's guessing.

Also, all participants were aware of limitations associated with search results, "...*if there's nothing on the first page, you're screwed.*"

A common frustration in groups was to feel overwhelmed by the amount of results that a search returned ("*Because a lot of people would feel that there's too much*"). It is also worth noting that many final designs viewed an online search as a first step in seeking offline solutions (such as accessing traditional formal services).

## Personalisation of resources and autonomy

There was a strong preference for online resources to provide both content and features that were personalised to young people. When groups browsed articles and information pages to learn more about the difficulty their persona was experiencing, they frequently indicated the need for tailored information and tools to suit the preference of the persona.

Not enough information. It just didn't do it for me. Not enough, not personal enough.

Personalisation was often achieved through a questionnaire or psychometric to help the young person address their current concerns. Participant's designs often included 'quizzes' to redirect users to personalised features. Importantly, personalisation included activities specific to their local area, books and documentaries relevant to their needs, and personal testimonies applicable to their challenges. The use of apps, diaries and mood-tracking technologies were also seen as part of an online resource that could be personally tailored to suit differing help-seeking needs of young people.

Supporting the young person's autonomy and avoidance of medicalized labels were also identified as important in supporting personalization:

The quiz doesn't diagnose you with depression or anxiety or anything, obviously, but it just sees where you're at. Then it would match you up a counsellor based on your results.

As noted above, relatedness was an important theme across all of the designs irrespective of the persona used. The importance of autonomy was again evident in this context. Anonymity was included across different design features, and was seen as important in personalized resources:

Think the anonymous aspect of it, where you don't need to give all of your information to get a diagnosis, where you can keep the app, but not have to give your name, your age, your location or anything like that unless you want to give your location. I think that makes people feel safer, without having to give personal details.

#### Immediacy

In addition to chat, information, and personable features of online resources, participants also emphasized the need for help that could be acted upon immediately. In some instances, this took the form of practical activities that could be completed in times of stress, including guided meditation and breathing. Other features included daily challenges, inspirational quotes, and tips and tricks for self-help. One participant stated:

Maybe in the app, just having suggestions of things someone could do, just tips and tricks if they're feeling anxious or something. I don't know, something they could do at that moment, just to make them feel calmer.

It appears that some of the resources outlined so far – such as static information pages – fail to provide an additional step for online help-seekers, in that few offered suggestions for actions that could be taken in the moment to relieve immediate distress. Continuously, participants also mentioned games, guided relaxation, music, podcasts, and VR-led features as sources of instant activities.

# APPLYING THEORY TO UNDERSTAND ONLINE HELP-SEEKER'S NEEDS

The studies outlined in this paper aimed to provide insight into how young people can be supported in their online helpseeking through the appropriate design of online mental health resources. Here we reflect on our findings via existing help-seeking and psychological theory, to highlight challenges and opportunities for design. Specifically, we discuss how the features and characteristics of online mental health resources can either facilitate or impede help-seeking. We first consider Rickwood's model and how it can be applied to understand the online help-seeking process.

#### Rickwood's help-seeking model

Online help-seeking appears to circumvent the necessity for the process to move from the intrapersonal to the interpersonal. Young people can engage in the entire helpseeking process, and successfully find help, without having to interact with another person should they choose not to. The Internet seems to offer options to support young people's preference for self-reliance.

In mapping online help-seeking to Rickwood's model, we can assume that the young person is exercising the expression stage by completing an online search. Search results inform the availability stage, whilst assessing and pursuing certain resources speaks to the willingness stage. This process can happen again once the young person has accessed an online resource, but perhaps in a different order. As the young person accesses different available resources, they are expressing their symptoms and identifying available sources of help. But they may also improve their mental health literacy through these actions, which in turn may facilitate increased awareness of their symptoms and difficulties. As young people build their mental health literacy, they also have on-going and progressive options on the degree to which they disclose their difficulty (i.e.

	Facilitator	Barrier
Awareness	Personal stories, articles and FAQ's	Difficulty in accessing relevant personalised content
Expression	Search, psychometric assessments, trackers, and questionnaires.	Lack of mental health literacy in order to input appropriate search terms
Availability	Ease of access and instantaneity	Overwhelming number of options of variable quality available and difficulty in choosing an appropriate option
Willingness	Anonymity	Lack of live, immediate

# Table 1. Applying Rickwood's model to design strategies that can either facilitate or impede the help-seeking process.

willingness). This might involve a transition from informal to formal sources of help. But equally it may mean remaining anonymous.

There are a number of features and characteristics that can be included in online resources to either facilitate or hinder online help-seeking in terms of this model. Table 1 outlines concrete examples. For example, while online search can facilitate expression, a lack of mental health literacy may act as a barrier to young people's ability to identify appropriate search terms. Structured questionnaires may help to overcome this barrier. Online resources that are designed to maximise the facilitators identified in Table 1 and overcome the listed barriers, have the potential to provide young people with a more satisfactory online help-seeking experience.

# Self-Determination Theory

We have also proposed Self-Determination Theory as a useful framework to apply to conceptualise online helpseeking and meet the design requirements of young people. Many of the features and characteristics identified in this study can be thought of as meeting one of the three basic psychological needs. However, it is more likely that they will have an impact across multiple needs. Frustrating these needs can hinder help-seeking; much like satisfying these psychological needs can facilitate the process. In Table 2 we again outline concrete examples of how these needs can be met or, alternatively, frustrated in the online context.

Systems will work best when the three psychological needs are met, work together in harmony and facilitate one another. If not, the experience is more likely to be frustrating and not meet the help-seeker's needs. Our synthesised data consistently highlighted the need to effectively balance young people's needs for both competence and autonomy. To go online for help in the first instance can be theoretically understood as an autonomous act, leading to the exploration of resources that can build competencies, often in tandem with relatedness. However, while information pages can facilitate competency, information overload can reduce a young person's sense of competence. Participants indicated that information pages should have different sections, including facts and information that can be quickly

	Facilitator	Barrier
Autonomy	Anonymity	Lack of personalised content
Competency	Accessible information that can promote different activities.	Lack of suggestions for actions that can be completed in the moment to relieve distress
Relatedness	Live chat and personal stories	Unavailability of live formal support 24/7

#### Table 2. Applying Self Determination Theory to design strategies that can either facilitate or impede basic psychological needs.

consumed; longer, more detailed sections; video; stories and images. Online help-seeking also meets the need for relatedness through a variety of different means (i.e. personal stories, discussion boards, chat). Providing choice within information pages and relatedness channels can help to support autonomy.

When considering the dominant theories of help-seeking, what is novel about online help-seeking in this study is that numerous needs and stages become realised through different individual features, sometimes simultaneously. For example, the preference for live anonymous chat with a professional can be seen as autonomously engaging in a competencybuilding activity with a human who can offer help. According to the presented theories, this would represent a propensity for both informal and formal sources, expression (Rickwood's help-seeking model) and a need for relatedness (SDT). However, the need for anonymity and the preference for this activity to only occur online directly challenges traditional ideas of relatedness. It raises the question: to what extent are young people seeking relatedness when favouring anonymised interventions online? Systems that use Rickwood's help-seeking model or Self-Determination Theory to guide their design should consider tensions such as those highlighted in this section.

# **DESIGN RECOMMENDATIONS**

Consistent findings from both studies imply that online resources need to fulfil two practical roles, providing both referral tools and help sources. Irrespective of the helpseeker, and with a view to fulfilling these two needs, we propose four key recommendations: provide opportunities for connectedness; provide credible and accessible information; provide personalisation, but also respect anonymity; and, finally provide "just-in-time" support options. These recommendations are both theoretically informed and based on our data.

#### **Provide Opportunities for Connectedness**

Young people require online resources that offer opportunities to connect with others, peers and professionals, and feel part of a community. This can be achieved through various means including chat, forums and personal stories. Dependant on the stage of help-seeking the young person is at, connectedness will entail different types of activities. Previous work has shown the importance of providing structured, safe peer support channels for those seeking

mental health support and the benefit this can have on young people's overall wellbeing [39, 46]. There is value in providing opportunities for young people to discuss and ask questions from peers and professionals anonymously. Mental health concerns remain a very stigmatised topic and the preference for anonymous help-seeking online is understandable. This is also more likely to help young people move forward through the stages of help-seeking. Previous literature has confirmed that opportunities to find support online are now as important as traditional sources of support, both formal and informal [47]. The opportunity to feel part of a community online or engage with others in similar situations is an important need for young people when seeking help online. If this is designed correctly, helpseeker's need for relatedness and competence are met concurrently. Simultaneously, it also needs to be recognized that, for some help-seekers, there will be preferences to experience that connectedness in an offline context, but they will need assistance in finding appropriate offline opportunities. It is recommended that online resources include tools and mediums through which young people can experience connectedness in meaningful ways, including links to appropriate and, critically, local offline supports.

# Provide Credible and Accessible Information

Findings from both studies have shown that online resources have to offer more than text-based mental health articles. Information needs to be offered in the form of different mediums including video, audio, short as well as long articles, and quicker to access FAQ sections. In this way, content can cater for various levels of mental health literacy and different online help-seeking goals. These findings reflect similar results to a study by Cunningham et al [13], which found that young people had different mental health information strategies. Mental health literacy has been found to be a significant barrier to help-seeking [14, 22, 59] and technology offers opportunities to address this by providing content that suits different information preferences. In meeting varying informational preferences, online resources can also facilitate young people through the stages of helpseeking, whilst helping to meet their needs for competence and autonomy.

#### Provide Personalisation, but also Respect Anonymity

Young people are currently frustrated by the difficulty in accessing tailored and appropriate content relative to their needs. They feel overwhelmed by the abundance of choice and information that search results offer that do not speak to their online help-seeking goals. Their need for autonomy and competence are being frustrated. Other research has also shown that personalisation is an important factor for consideration when designing digital mental health technologies [25]. However, personalisation needs to take into account that anonymity is an important facilitator to help-seeking. This resonates with findings that in the case of search, as opposed to use of social media, users do not face the same temptations to self-censor [60]. Young people face a great deal of stigma regarding their mental health and when anonymity is included in the design of an online resource, users are likely to feel safer and more autonomous in disclosing their difficulties.

Finally, personalisation needs to recognize that different help-seekers will have different preferences for further support; how the need for relatedness is met will look different for different young people. Some help-seekers will prefer to have their entire help-seeking experience online, whilst others will go online with offline intent - for example, using a website to self-diagnose so as to make an online appointment with an appropriate local professional. Online resources that provide credible, tailored content are more likely to provide a positive help-seeking experience and designers of online mental health resources should endeavour to create personalised pathways for their target users.

## Provide "just-in-time" Support Options

Online mental health resources have an important role to play in facilitating young people's help-seeking and ensuring that they access the appropriate help at the right time. In order to do this successfully, online resources need to have options that provide both immediate and long-term solutions. A study by de Alva and colleagues [2] investigating user's opinions of mental health apps found that users were often left feeling unsupported by mental health apps in times of distress. Similarly, O'Leary et al [45] found people who experience mental illnesses are often looking for "just-in-time" support when experiencing crisis. Participants in the co-design workshops indicated that providing online services and tools that are available and that are executable 24/7 and that can relieve distress in the moment. The co-design workshops indicated that these might include chat with a professional in times of crisis or grounding techniques, but further investigation is needed into what types of exercises, activities and services would effectively meet this need.

#### LIMITATIONS AND FUTURE WORK

The personas in this paper represent three different helpseeking scenarios but should not be considered an exhaustive list - future research is likely to provide further detail and may identify other important help-seeking scenarios relevant to the online space. Additionally, while the scenarios and personas are applicable to differing help-seeking needs of a young person at various timepoints, it is not yet known how and why a young person might shift between help-seeking pathways. For example, a young person might only seek information online to self-educate; but they may also shift into preferring person-centred resources that provide relatedness or experience a crisis situation. The exact reasons for shifting between these scenarios and preferences warrants further investigation.

A noted in the related work section, this paper approached the issue of online help-seeking for mental health via the lens of help-seeking theory. In elaborating and refining our understanding of help seekers and scenarios, it will also be interesting to apply an Information Science perspective [17, 18, 28]. This was beyond the scope of the current paper but would provide alternative and complementary theories on how people seek, manage and use information. Longer-term research to synthesise theories of help-seeking and Information Science is likely to provide valuable insights on how young people use online resources to address mental health concerns. For example, application of Rieh's work on the judgement of information quality [53] could provide greater understanding of how young people assign credibility to online mental health resources.

Finally, our findings should be considered in light of the fact that, to the best of our knowledge, the sample was nonclinical. Therefore, it is not known if the results are applicable to clinical populations. As the study took place in Ireland our data is most representative of a western European demographic. Whilst the co-design study contained a near gender balance, the survey was disproportionately female. Future work should investigate if there are any gender differences regarding the help-seeking process of young people online.

#### CONCLUSIONS

Evidence suggests young people are increasingly using the Internet to access mental health information. The Internet allows them to access advice, help and support when they are experiencing distress and provides them with a wide variety of resources to choose from. The survey indicated that young people's goals varied when engaging in online help-seeking and the co-design study made use of personas to investigate these goals in terms of design needs. Both studies indicated that young people have concerns when looking for help online and that these concerns could be addressed through considered and purposeful design. Our research proposes that online mental health resources can facilitate the help-seeking process by providing (1) opportunities for connectedness (2) credible and accessible information (3) personalisation, but also respect autonomy and (4) "just-in-time" support options. The contributions of this work are an understanding of how young people use the Internet to engage in online helpseeking behaviour and the recognition of specific design opportunities to positively facilitate online help-seeking. Offline help-seeking faces a number of barriers, including stigma, the opportunity now exists to address these in an online context.

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