Using participatory design to engage young people in the development of a new online tool to increase help-seeking

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Participatory design methods were used to engage end users in the development of an online tool designed to increase help-seeking for mental health issues among young adults aged 18 to 25. The research found that the help-seeking journey for young people can be overwhelming, non-linear and often reliant on a young person's ability to find appropriate help and supports. This situation may be mitigated by the development of a tool based on a three-step process that supports young people to 'explore and reflect', 'accept' and 'act'.

As many as one in four young Australians aged 16 to 24 years are currently living with a mental health difficulty (Australian Bureau of Statistics (ABS) 2008). Timely and appropriate help-seeking can reduce the long-term health, social and economic impact of many of these mental health problems (Rickwood et al. 2005), yet studies repeatedly show that the majority of people experiencing a mental illness do not get the professional help they need (McLennan 1998). Recent national survey data suggests that rates of help-seeking have increased in the last 10 years with 65% of “in need” 12- to 17-year-olds seeking help (Lawrence et al. 2015). This increase is most likely due to the recent investment in service delivery and promotion in Australia (Hickie & McGorry 2007). Nevertheless, at least 35% of young people are not getting the help they need. Young adults (18- to 25-year-olds) who can no longer access school services,
and may have less parental involvement in their health care than younger cohorts, may experience more barriers to seeking help. Furthermore, this survey found that 65% of those who had sought help found the care they received did not meet or only partially met their needs (Lawrence et al. 2015). Left untreated, mental health problems can not only become more severe, but also often lead to other difficulties including social withdrawal, breakdown of family and personal relationships as well as poorer education and employment outcomes and overrepresentation in the justice system (Meadows et al. 2015; NSW Mental Health Commission 2015).

There are several well-established barriers that prevent young people from seeking professional help for mental health problems, these include: lack of knowledge of where to go for help; limited access to and availability of services; the stigma associated with accessing a service; poor mental health literacy; a desire for autonomy and self-efficacy; being unsure whether their symptoms warrant support or are “normal”; negative past experiences with health services and clinicians; and the help negation effect wherein increasing levels of distress or suicidal ideation decrease young people’s intention to seek help (Wilson & Deane 2012; Gulliver, Griffiths & Christiensen 2010; Wilson et al. 2010; Wilson & Deane 2001; Wood et al. 2005). Stigma often manifests as young people being embarrassed about seeking help, and fearing what others, including friends, family and the clinician, might think (Gulliver, Griffiths & Christiensen 2010; Barney et al. 2008).

Interventions or services that increase young people’s willingness or readiness to seek help are needed in order to increase the number of young people who seek professional care and thereby improve their mental health outcomes (Haller et al. 2009). The theory and development underlining such interventions, particularly online interventions, are rarely evaluated or published (Hegarty et al. 2008). Without a sound theoretical basis, interventions may lack the mechanisms required to affect young people’s service willingness, or readiness to seek help (Bilardi et al. 2009; Craig et al. 2008). The concepts within the theory of planned behaviour (Azjen 1991) and the help-seeking model (Rickwood et al. 2005) are closely linked, but not necessarily in a linear manner. Together, they provide a useful conceptual framework for designing tools and interventions to improve help-seeking, including relevant theoretical constructs such as: increasing awareness of symptoms and services; improving attitudes towards help-seeking; decreasing self- and social-stigma; and increasing young people’s control of access to mental health services (Kauer, Buhagiar & Sanci 2016).
Using online technology to design a solution

The internet provides a unique opportunity to reach young people in spaces where they already interact, and to overcome or reduce barriers to help-seeking. Over 95% of Australian young people aged 16 to 25 access the internet daily (Ewing, Thomas & Schiessl 2008), with many using multiple devices in a day (EY Sweeney 2016). A study by EY Sweeney, found 79% of 18- to 34-year-olds check their mobile devices as soon as they wake up and spend more time on their devices than they do sleeping, with an average of seven hours and 20 minutes sleep and 10 hours on devices (2016).

Young people use the internet for a combination of entertainment (including streaming videos and audio, online gaming), communication (including social networking), research and browsing (Australian Communications & Media Authority 2016). The internet has been shown to be accessible, anonymous, engaging and informative, and to provide a space in which young people can feel empowered and confident to talk about sensitive issues (Burns et al. 2010; Gould et al. 2002).

Young people increasingly look to the internet as a source of support and information for issues such as depression (Griffiths & Christensen 2007), sexuality (Suzuki & Calzo 2004) and physical activity and nutrition (Spittaels & De Bourdeaudhuij 2006). In addition, the internet offers low-cost, 24/7 access for young people while reducing costs for content providers (Hosie et al. 2015). Most importantly, young people report feeling comfortable accessing information about mental health issues online, and the anonymity of online interventions has the potential to engage young people who avoid face-to-face services because of the stigma associated with mental illness (Oh, Jorm & Wright 2008).

Burns et al. (2010) found that young people's first step in sourcing information about mental health and wellbeing online was consistently a search engine such as Google. Due to the vast amounts of information available it can be difficult for a young person to discern which information is trustworthy. Based on ReachOut Australia’s qualitative research with young people and service providers, as well as an audit of existing services in Australia and overseas, the need was identified for a self-directed online tool that could help young people make sense of the plethora of information and services available and improve their timely access to support (Kauer, Mangan & Sanci 2014). ReachOut works in partnership with young people to understand their needs and perspectives on mental health and wellbeing, and to design and deliver relevant online services with those young people. Along with the University of Melbourne, ReachOut
Australia was funded by the Young and Well Cooperative Research Centre to design an online tool to facilitate help-seeking among young people.

Participatory design methods were used (Hagan et al. 2012) to involve end users in the design of the tool. In participatory design, the end users of a service are considered experts in their own lives and partners in the design and development process (Sanders 2013). The research is conducted in partnership with individuals or a community of interest in order to ensure the end design is useful and engaging for them, thereby increasing uptake (Orlowski et al. 2015). As such, young people are involved at every stage of the design process, from defining the central problem or need, designing the tool and evaluating its usefulness. This paper outlines the first stage of the participatory design process – defining the requirements of the online tool.

The study: Designing an online tool with young people

Objective
Participatory design methods were used to define the requirements for the development of an online tool to support help-seeking in young adults aged 18 to 25. Specifically, the research sought to understand a typical help-seeking journey for young people in Australia, what factors inhibit and facilitate help-seeking online and offline, and the design features that are important to young people in order for the tool to be useful and engaging.

Recruitment
Participants were recruited through advertisements distributed by mental health organisations via their social media profiles (Twitter and Facebook) and email lists, and through university bulletins. Advertisements described participation in the project as an opportunity “help build a new national online health and wellbeing service for young people”.

Participants were eligible if they were 18 to 25 years of age, lived in Australia, and had sought some form of support (phone, face-to-face or online) for mental health difficulties, either for themselves or a friend, in the previous 12 to 24 months. Young people who had prior knowledge of the mental health system were selected as they could share their experiences of help-seeking, what worked well and what could be improved. Participants were provided with a $100 voucher for electronic store JB HiFi as an incentive to participate.
Participants
A total of 23 young adults (7 males and 16 females) aged 18 to 25 years participated in the research. The participants were recruited from around Australia, with six participants from regional Australia. The majority of participants were studying at university.

Procedure
Two workshops were conducted a week apart; the first included 11 participants and the second included 12 participants. A facilitator guided participants through three main activities, which are described below.

Method one: Persona immersion
Personas are a well-documented participatory design method (Bødker 2000; Blythe & Wright 2006), which involves introducing participants to “ personas” – fictional characters or archetypes that represent potential users of a service (Miaskiewicz & Kozar 2011). These personas allow participants to talk about and give their opinion about sensitive issues like mental health, without disclosing their personal experiences. They also enable participants to build empathy with the future users of whatever they are designing (Nicholas et al. 2012). The personas used were developed on the basis of field research conducted by ReachOut and by utilising the concepts of the help-seeking model (Rickwood et al. 2005) and Theory of Planned Behaviour (Ajzen 1991), wherein different personas had different awareness of their symptoms, stigma about mental illness, exposure to others who had sought help, and barriers to accessing care.

Five personas were designed to represent a relevant mix of gender, age, mental health symptoms and risk factors. Participants worked in small groups of two and three, each of which was assigned a persona. In order to build empathy with their persona, each group undertook an immersion activity. They were provided with a template and instructed to create the Facebook page for their persona. The template included sections for their persona’s interests, photos, friends, recent conversations etc. (Figure 1).
Figure 1: Persona immersion: Snapshot of Facebook page designed by participants

**Method two: Mapping the help-seeking journey**

Within the same small groups, participants were instructed to map the pathway and steps that their persona might take from their current situation to a point where they were feeling more in control of their mental health, including how they might connect with and use mental health information and services. Participants were prompted to map the steps involved, how the persona would feel at different points in the journey and the enablers and barriers to getting help along the way.

Participants were asked to answer questions including: How would the persona feel at different moments along the journey? What would they be looking for online and offline at different stages? What would make them feel comfortable, at ease and reassured? How would they like information to be presented to them? When might they feel most frustrated or worried?

**Method three: Designing an online experience**

Following this, participants undertook an individual activity where they designed the ideal online experience for their persona using a future state vision of an online mental health tool designed specifically for young people. Participants described the different stages in the ideal experience and what their persona would need from the tool at these
different stages (e.g. on their first visit, after a few weeks etc.). They also listed some of
the features and information they thought the service should have in order to provide the
best experience for their persona.

Data transcription and analysis

The workshops were audio recorded and transcribed. Numerous visual artefacts were
also produced throughout the workshops including post-it notes, drawings, storyboards
and pathway designs, which also underwent analysis.

Thematic analysis of both the transcripts and the artefacts was undertaken by the
researchers in order to identify patterns in the data (Braun & Clarke 2006). Three
researchers individually coded the data and then came together to discuss the findings.
Themes were distilled into a set of “user goals” that described features necessary to
motivate and engage young people to use the online tool (Hagen et al. 2012). These
goals served as an important reference point for stakeholders (including researchers and
digital agencies) when designing the tool.

Results

This research found that a typical help-seeking journey for young people in Australia
can be overwhelming, non-linear and often reliant on a young person’s ability to find
appropriate help and supports. Participants indicated that an online tool designed to
increase help-seeking should simplify this process and make it easier to connect with
support services, validate the users’ feelings, provide hope and reassurance along the
way and be accessible on any device.

Visual and verbal data suggested three key stages in the help-seeking journey:
“exploring and reflecting”, “accepting”, and “acting”. These steps, described in detail
below, interrelate in an iterative cycle rather than a linear process.

Stage 1 – Exploring and reflecting

A common theme was the difficulty in knowing if help was needed and where to go in
order to start the process. One group commented that their persona might feel that
something is not quite right or be told that they “are not themselves”. Analysis indicated
that this exploratory stage is a time of growing awareness of symptoms and questioning
about whether to seek help and how to go about it. For many young people, this
exploring and reflecting stage can be quite informal, often learning from peers rather
than professionals. Participants gave the example that their persona may spend time browsing forums, blogs or video blogs (e.g. Tumblr or YouTube) and from there discover stories about other young people who have sought help and overcome mental health issues. They would also speak to friends, family and use search engines such as Google.

Participants felt that their personas may search online using Google for their symptoms (e.g. “how to get to sleep”, “how to get motivated” “balancing study and social life” “why do I wake up feeling crappy every morning?”), but suggested they might feel overwhelmed with the range and volume of information returned, and unsure where to go from there. They suggested that this experience can trigger feelings of fear, loneliness, uncertainty and anxiety for the young person. In describing their persona’s help-seeking journey, participants commented:

Challenging, she [the persona] may go through uncertainty ... get frustrated or worried ... being confronted with the information ... not knowing what to do next...

You need help with a place to start ... if you go into a situation you have never been to before you don’t know where to start and you’re just stuck ...

Assessing, she [the persona] would feel scared at this point, she doesn’t know what she can do, she’s already overwhelmed by her situation ...

Stage 2 – Accepting

Participants commented that once an issue or problem was identified, steps were needed to overcome the stigma of the problem, accept the issue and confirm that the issue was serious enough to seek help for. To assist with this, they suggested that the online tool should include a self-assessment style quiz or interactive questionnaire which could provide language to increase understanding and help young people make sense of what they may be experiencing. Participants felt that a quiz or questionnaire could help young people learn more about what feelings and symptoms need to be addressed. Participants also felt that such a tool could work to validate emotions and reassure young people that their experiences are important and warrant support. Participants suggested that any quiz or assessment used should be evidence-based and trustworthy; not overly clinical, and avoid jargon and technical language; relate to the symptoms young people may have; and be positive, reassuring and demonstrate that other people
experience similar symptoms. When describing the purpose of a quiz for their persona, one participant commented:

*Confirmation that something is wrong and lead him [the persona] to finding a GP... we [the group] thought he didn’t want to go ahead with too much because he didn’t know whether it was a legitimate reason to go looking for help. Being able to understand that it was okay ... online mood surveys, realising you may have some symptoms.*

**Stage 3 – Acting**

Participants identified that making contact with a recommended service was probably a step outside their comfort zone for many young people, and that taking this step may make them feel vulnerable and uncertain. Participants thought that questions young people asked themselves may prevent help-seeking, for example: “How can I explain what I’m feeling?” “What if I don’t like or relate to the counsellor?” “What will other people think about me seeing a counsellor?” “What if there’s nothing wrong with me?”

Participants also indicated that getting help was likely to take a long time and include many setbacks. When speaking about the process, one participant explained:

*He [the persona] goes to see his GP who is not overly helpful and then he goes to see a counsellor. His first counsellor sucks. He’s taken a few weeks to do that and then steps back ... it could take him up to three months to continue ... his initial thoughts would be stuff it. He needs to build up confidence.*

Participants suggested that the online tool should help young people feel prepared and confident to access a service by providing reassurance and explaining what to expect from the service. It should also act as a sanctuary or safe place to retreat, “... this is a safe way to express herself [the persona] away from that life over there ... the rest of the image she has portrayed on Facebook”.

Figure 2 is an example of a journey map created by one group for their persona. It shows the barriers the persona faces, including feeling overwhelmed, uncertain and vulnerable, and not knowing where to go.
General findings

Participants thought that it was very easy to lose motivation during the help-seeking journey. Just seeking information could leave them feeling overwhelmed and cause them to give up. For this reason, any language used throughout the tool needs to be accessible and relevant, and focused on signs and symptoms that young people may be experiencing rather than using diagnostic terms:

"Change the language so it’s a bit softer for young people ... do you feel fiddly, worthless — they’re really confronting words. It doesn’t have “do you have periods where you feel down” or “is it hard to get out of bed in the morning” ... if a young person doesn’t know anything about mental health and it says in the past four weeks how often did you feel depressed. They are not going to know, they won’t know what it means."

They also wanted to feel in control of their help-seeking journey:
I need to feel like I am always in control and provided with choices.

... there would be urgency going on “I need to take control of this and if you can’t help me straight away I’m going to look elsewhere”...

Figure 3 describes the user goals generated from the research.

**Figure 3: User goals**

User goals summarise the features the online tool needs in order to be useful and engaging for young people. They formed a basis for the development of the product.

Young people want the tool to:

- Validate my feelings
- Give me hope
- Give me a place to start and show me what’s next
- Enable access anytime on any device
- Make it easy to act/connect
- Walk me through the process
- Provide a safe place away from the pressure.

**Discussion**

The two participatory design workshops provided an understanding of what young people need and want from an online tool designed to facilitate help-seeking. The research revealed that young people experience help-seeking as a complex process that is non-linear and repetitive, which often takes place over months or years. Three iterative stages of help-seeking were identified and conceptualised as: “exploring and reflecting”, “accepting” and “acting”. The findings provide an in-depth description of the “lived” experience of help-seeking, which theory alone cannot articulate, most notably the significant period of exploration, questioning and uncertainty that characterises the help-seeking journey for many young people. This journey is overwhelming with many barriers along the way, which can hinder progression through the stages; a young person can get “stuck” at a certain point and give up, or they may come back after a year or two. Online tools need to consider these barriers and stages in order to increase timely access to support for young people.

These two participatory design workshops were part of a broader service design project which consulted end users at every stage of the development of the online tool through
co-design workshops, concept testing and prototype testing. Design elements were also mapped back to a theoretical framework for behaviour change, the Theory of Planned Behaviour (Azjen 1991); the detail for this process is described in a separate publication (Kauer, Buhagiar & Sanci 2016). A randomised controlled trial, reported in a separate publication, was also conducted to evaluate the tool’s impact on young people’s affect and help-seeking intentions and behaviour.

Limitations

A limitation of the study was that participants were not wholly representative of the intended audience of the online tool. It was difficult to recruit young men, meaning that only seven of the 23 participants were male. The majority of participants were attending university. Furthermore, participants were recruited through mental health service providers as it was important that they had experience of the mental health help-seeking process, what aspects worked well, and areas that were challenging. As such, the participants were already engaged with services and potentially were not representative of the target audience for the online tool, which is young people who are experiencing psychological distress but who are currently not seeking help for their distress. Future research will endeavour to include a more diverse sample of young people.

Conclusion

It is well accepted that many young people experiencing psychological distress do not readily seek help for their concerns (Gulliver, Griffiths & Christensen 2010). This research used participatory design methods to work with young people to understand their experience of the help-seeking process, the enablers and barriers, and their needs from an online tool. We found that the help-seeking journey for young people can be overwhelming, non-linear and often reliant on a young person’s self-efficacy to find appropriate help and supports. This may be mitigated by designing services that support young people to “explore and reflect”, “accept” and “act”.

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