

**Language Translation, Cultural and Contextual Adaptation of Health
Information Technologies to Transform Mental Health Care in Low- and Middle-
Income Countries: An Example of a Prototypic Mental Health eClinic for Colombia**

*It's not just about better access to care, but also better quality care, facilitated by these
technologies to bridge inequalities in our health systems*

A thesis submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy

Laura Ospina Pinillos

Brain and Mind Centre

Faculty of Medicine and Health

The University of Sydney

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Declaration of Originality

To the best of my knowledge, this thesis contains no copy or paraphrase of work published by another person, except where duly acknowledged in the text. This thesis contains no material which has been presented for a degree at the University of Sydney or any other University. Details of contents are on the next page.

Laura Ospina Pinillos

Date: 27st September, 2019

Authorship Attribution Statement

This thesis principally represents the work of Laura Ospina Pinillos. The data forming the basis of the empirical studies was collected under protocol conceptualised and designed by Prof. Ian B. Hickie, Ms Tracey Davenport, Ms Cristina Ricci, A/Prof Elizabeth M. Scott and Ms Ospina Pinillos. Ms Ospina Pinillos has also performed data collection throughout the candidature, and was primarily responsible for all data analyses, interpretation, and preparation of manuscripts presented in this thesis. Assistance with data collection and interpretation across the studies presented here was provided by Ms Tracey Davenport, Dr Frank Iorfino, Dr Ashleigh Tickell, Dr Shane Cross and Dr Antonio Mendoza Diaz. Each author provided comments on manuscript drafts and approved the final versions of papers on which they are listed as co-authors.

As supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statements above are correct.

Prof. Ian Hickie

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Publications Presented for Examination

The following papers form the basis of this thesis:

1. Ospina-Pinillos, L., Davenport, T. A., Ricci, C. S., Milton, A. C., Scott, E. M., & Hickie, I. B. (2018). Developing a mental health eClinic to improve access to and quality of mental health care for young people: using participatory design as research methodologies. *Journal of medical Internet research*, 20(5), e188.

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2. Ospina-Pinillos, L., Davenport, T., Iorfino, F., Tickell, A., Cross, S., Scott, E. M., & Hickie, I. B. (2018). Using new and innovative technologies to assess clinical stage in early intervention youth mental health services: Evaluation study. *Journal of medical Internet research*, 20(9), e259.

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3. Ospina-Pinillos, L., Davenport, T., Diaz, A. M., Navarro-Mancilla, A., Scott, E. M., & Hickie, I. B. (2019). Using Participatory Design Methodologies to Co-Design and Culturally Adapt the Spanish Version of the Mental Health eClinic: Qualitative Study. *Journal of medical Internet research*, 21(8), e14127.

Presented in *Chapter 4* of this thesis.

4. Ospina-Pinillos, L., Davenport, T., Navarro-Mancilla, A., Cheng, V. W. S., Cardozo Alarcon, A.C., Rangel, A. M., Rueda Jaimes, G. E., Gomez Restrepo, C., Hickie, I. B. Involving End Users in Adapting the Spanish Version of the Mental Health eClinic for Young People in Colombia: A Pilot Study Using Participatory Design Methodologies. *JMIR Ment Health* (forthcoming). doi:10.2196/15914

Presented in *Chapter 5* of this thesis.

Additional Relevant Peer-Reviewed Publications

A substantial contribution was also made to the following papers, as part of research studies, which were complementary to the thesis. The outcomes of these studies helped to inform the theoretical framework and interpretations of the data reported in the thesis.

(Appendix 1)

1. Hussain, M. S., Li, J., Ellis, L. A., **Ospina-Pinillos, L.**, Davenport, T. A., Calvo, R. A., & Hickie, I. B. (2015). Moderator assistant: A natural language generation-based intervention to support mental health via social media. *Journal of Technology in Human Services*, 33(4), 304-329.
2. Iorfino, F., Davenport, T. A., **Ospina-Pinillos, L.**, Hermens, D. F., Cross, S., Burns, J., & Hickie, I. B. (2017). Using new and emerging technologies to identify and respond to suicidality among help-seeking young people: a cross-sectional study. *Journal of medical internet research*, 19(7), e247.
3. Tickell, A. M., Scott, E. M., Davenport, T., Iorfino, F., **Ospina-Pinillos, L.**, Harel, K., ... & Hermens, D. F. (2019). Neurocognitive clusters: A pilot study of young people with affective disorders in an inpatient facility. *Journal of affective disorders*, 242, 80-86.
4. Tickell, A. M., Scott, E. M., Davenport, T., Iorfino, F., **Ospina-Pinillos, L.**, White, D., ... & Hermens, D. F. (2019). Developing neurocognitive standard clinical care: A study of young adult inpatients. *Psychiatry research*, 276, 232-238.

5. Specific contents of the supplement of the Medical Journal of Australia:

Hickie, I. B., Davenport, T. A., Burns, J. M., Milton, A. C., **Ospina-Pinillos, L.**, Whittle, L., ... & Piper, S. E. (2019). Project Synergy: co-designing technology-enabled solutions for Australian mental health services reform. *Medical Journal of Australia*, 211, S3-S39.

- A. Davenport, T. A., Milton A., **Ospina-Pinillos, L.**, Whittle, L., Ricci, C.S., Burns, J.M., Hickie, I.B. (2019). Project Synergy research and development cycle: iterative processes of participatory design, user testing, implementation and feasibility testing. *Medical Journal of Australia*, 211, S38-S11.
- B. Davenport, T. A., **Ospina-Pinillos, L.**, Ricci, C.S., Milton A., Burns, J.M., Hickie, I.B. (2019). Study 1: Fit Uni Life to thrive: an online health and wellbeing prototype for young people. *Medical Journal of Australia*, 211, S12-S16.
- C. Davenport, T. A., Whittle, L., **Ospina-Pinillos, L.**, Milton A., Burns, J.M., Hickie, I.B. (2019). Study 2: Evaluating engagement with a prototypic online platform to improve the mental health and wellbeing of young people living in disadvantaged communities. *Medical Journal of Australia*, 211, S17-S23.
- D. Davenport, T. A., Milton A., Whittle, L., McLoughlin, L., **Ospina-Pinillos, L.**, Mendoza, J., Burns, J.M., Hickie, I.B. (2019). Study 3: Co-designing, user testing and evaluating digital suicide prevention functionality. *Medical Journal of Australia*, 211, S24-S29.

- E. Cross, S., Piper, S., Davenport, T. A., Milton A., Iorfino, F., Ricci, C.S., **Ospina-Pinillos, L.**, Whittle, L., Hickie, I.B. (2019). Study 4: Implementation study of a prototypic e-clinic being integrated into youth mental health services: staff experiences and reported service quality improvements. *Medical Journal of Australia*, 211, S30-S36.
6. Milton A., Stewart, E., Davenport, T. A., **Ospina-Pinillos, L.**, Hickie, I.B. (2019). Participatory design of an activities based collective mentoring program in after school care settings: The Connect Promote and Protect Program (CP3). *International Journal of Early Childhood*. Manuscript submitted for publication.

Other Peer-Reviewed Work Relevant for this Thesis

As part of this research process a grant proposal was presented to the The National Health and Medical Research Council to the Global Alliance for Chronic Diseases in the 2017 Mental Health Call. Although, the grant was not successful the research exercise was valuable and help to inform the future directions of this thesis. (Appendix 2)

Conference Presentations During Candidature

- Ospina-Pinillos, L. (2015, July). *The e-Mental Health Clinic: Jumping Barriers for Traditional Mental Health Care*. Paper presented at the National Suicide Prevention Conference, Hobart, Australia.
- Ospina-Pinillos, L. (2016, August). *Designing and developing online systems to improve young people's health and wellbeing: The Spanish adaptation*. Paper presented at the Autonomous University of Bucaramanga, XIII International Congress of the Faculty of Health Sciences, Bucaramanga, Colombia.
- Ospina-Pinillos, L. (2016, September). *Configuring the Mental Health eClinic (MHeC) to Time and Place*. Paper presented at the Faculty of Child and Adolescent Psychiatry Conference, Hobart, Australia.
- Ospina-Pinillos, L. (2016, September). *Development of the eMental Health Clinic (MHeC-S) (Spanish Version)*. Paper presented at the Research and Innovation alliances between Australia and Ibero-America, Sydney, Australia.
- Ospina-Pinillos, L. (2016, October). *The Mental Health eClinic: Breaking Down Traditional Mental Health Care Barriers by Utilising New and Emerging Technologies*. Poster presented at the Early Intervention in Mental Health, Milan, Italy.
- Ospina-Pinillos, L. (2016, November). *The Mental Health eClinic (MHeC) a Configurable System to Enhance Access to Mental Health Care*. Paper presented at the World Psychiatric Association Conference, Cape Town, South Africa.

- Ospina-Pinillos, L. (2017, May). *Improving the Mental Wealth of Adolescents and Young People*. Paper presented at the Improving Student Learning Through Well-being Conference Children's Hospital Education Research Institute, Sydney, Australia.
- Ospina-Pinillos, L. (2017, September). *Development and Validation of an Online Clinical Staging Model for Use in Early Intervention Youth Mental Health Service*. Poster presented at the 4th International Conference on Youth Mental Health, Dublin, Ireland.
- Ospina-Pinillos, L. (2017, October). *Developing Transdiagnostic Services for Implementation in Colombia*. Paper presented at the World Psychiatric Association Conference, Berlin, Germany.
- Ospina-Pinillos, L. (2017, October). *The Mental Health eClinic (MHeC) Connecting Young People to the Right Services at the Tight Time*. Paper presented at the World Psychiatric Association Conference, Berlin, Germany.
- Ospina-Pinillos, L. (2017, October). *Web Programs as Add-on and Alternative to Conventional Care?*. Paper presented at the World Psychiatric Association Conference, Berlin, Germany.
- Ospina-Pinillos, L. (2017, December). *Increasing Cross-cultural Mental Health (e)Care: Lessons from the Development of the Spanish Version of the Mental Health eClinic*. Paper presented at the Society of Mental Health Research Conference, Canberra, Australia.
- Ospina-Pinillos, L. (2018, February). *Reducing the gap in cross-cultural mental health: Lessons from the development of the Spanish version of the Mental Health eClinic*. Poster presented at the World Psychiatric Association Thematic Congress, Melbourne, Australia.

- Ospina-Pinillos, L. (2019, February). *Current Solutions for Online Trauma Support*. Workshop presented at the E-Mental Health Conference, Vancouver, Canada.
- Ospina-Pinillos, L. (2019, February). *Project Synergy – A Connecting Platform for Different Solutions Through EMH*. Paper presented at the E-Mental Health Conference, Vancouver, Canada.
- Ospina-Pinillos, L. (2019, June). *Development of user-centered Health Informational Technology*. Paper presented at the Pontificia Universidad Javeriana, Psychiatry Current Topics 2019 Symposium., Bogota, Colombia.
- Ospina-Pinillos, L. (2019, August). *The Potential of Web-Based Care for Poor Countries*. Paper presented at the World Psychiatric Association Conference, Lisbon, Portugal.

List of Common abbreviations

GDP: Gross domestic product

HIT: Health information technology

KT: Knowledge translation

MHeC: Mental Health eClinic

MHeC-C: Colombia version of the Mental Health eClinic

MHeC-S: Spanish version of the Mental Health eClinic

NMHS: Colombian National Mental Health Survey

PD: Participatory design

PTSD: Posttraumatic stress disorder

R&D: Research and development

LMIC: Low-and middle-income countries

Abstract

Globally, there is increasing recognition that new strategies are required to reduce disability due to common mental health problems. This scenario is particularly discouraging for children and adolescents living in low- and middle-income countries (LMIC) which are typified by a scarcity of youth health professionals, community services and infrastructure, as well as specific policies for this population. With 90% of young people globally living in LMIC, and just 20% of the world's mental health resources being invested in these countries, there is an urgent need to provide readily accessible and affordable care. When considering how to provide such care at scale, health information technologies (HIT) show promise in augmenting traditional face-to-face services. Despite the spread of such HITs in high-income countries, these HITs have slow uptake and implementation by LMIC. People living in these parts of the world are at risk of experiencing not only physical and social but also technological inequalities in health.

The overall aim of this thesis was to present a case example of how a co-designed and developed HIT in an industrialized country (i.e. Australia) can be translated, culturally-sensitised and context-adapted for a LMIC (i.e. Colombia). The first paper of the thesis uses participatory design (PD) techniques as research methodologies with end users (including, young people aged between 16 and 25 years as well as health professionals) to develop the Mental Health eClinic (MHeC; a Web-based mental health clinic) that has the potential to improve timely access to, and better quality of, mental health care for young people across Australia. The second paper of the thesis, tested the prototypic MHeC in a real-world setting (i.e. two youth primary mental health services). This research more specifically demonstrated the comparison of online self-report assessments with traditional face-to-face clinical assessment in a cohort of young people newly presenting for mental health care. The paper

also evaluates how online self-report assessments identify key features such as initially-suggested clinical stage (a method of categorising the severity, complexity and chronicity of mental ill health), lifetime trajectories, and recognition of comorbidities while also managing suicidality and responding to more complex cases (i.e. psychosis or comorbidities).

Once the MHeC had been co-designed, developed, user-tested and trialled in an Australian real world-setting, the process of translating, culturally-sensitizing and context-adapting began – broadly to the Spanish language and then more specifically Colombia. The third paper of this thesis, used PD research methodologies in an adapted version of an established research and development cycle (R&D cycle) to co-design the Spanish version of the MHeC (MHeC-S) with and for a Spanish-speaking young person population currently living in Australia. Here, the initial prototype was further developed and user-tested, and the online self-report assessment was translated (and back translated), culturally-adapted and face-validated in Spanish. The next step was to adapt the MHeC-S to a Colombian young person population, the findings of which constitute the fourth paper of this thesis. Important findings from this research demonstrated that a Colombian adaptation of the MHeC-S (MHeC-C) should not only be culturally sensitive but also be adapted to the different contexts and needs of young people living in such a diverse country.

The overall findings of this thesis can be divided into three areas. First, there is an urgent need to provide scalable interventions to young people across the world, but especially to those in LMIC who are currently at risk of additionally experiencing technological inequities in health. A possible solution to bridge this gap is to make use of the already available (and successful) HITs that are rapidly being developed in other countries. Secondly, in order to make these HITs accessible to culturally, linguistically and geographically diverse

communities, it is necessary to tailor them beyond just language but to also consider them within a culturally and contextually appropriate framework. Thirdly, this framework should also incorporate the use of PD research methodologies that involve stakeholders and end users early in the co-design, development and adaptation of these HITs. The R&D cycle that we employed in this PhD should be considered an optimal process to engage, retain, and work more efficiently with hard-to-reach populations.

A systematic use of such methodologies would finally result in the development of evidence-based, culturally-sensitive, context-adapted HITs that are relevant, appropriate, and usable over time and into the future. The adaptation of successful HITs represents a low-cost and scalable alternative for LMIC to provide young people with accessible, available, affordable mental health care at the *right time, first time*. The health system potential of this approach not only means better mental health outcomes for young people but potentially more efficient, effective and appropriate use of scarce health professional knowledge and clinical skills, as well as quality improvements in mental health service delivery.

Chapter 1: Introduction

1.1 Young People's Mental Health in Low and Middle Income Countries

Globally, there is increasing recognition that new strategies are required to reduce disability due to common mental health problems such as anxiety, depression, and comorbid substance misuse. As public awareness increases, the demand for mental health care far outstrips the capacity of health systems to provide access to quality care (Alegria, Nakash, & NeMoyer, 2018). To achieve a meaningful reduction in population-level burden of disease, there is a need to provide both prevention and early intervention strategies at scale. As 75% of mental health and substance use disorders emerge during the teenage or early adulthood years (Gore et al., 2011), these strategies need to be readily accessible to young people.

Notwithstanding that, LMIC host 80% of the population worldwide, and 90% of the population aged between 10 to 24 years (Gupta et al., 2014); and just 20% of the mental health resources are invested in these countries (Sweetland et al., 2014). There is an enormous treatment gap (number of people with a mental health condition who need treatment, but who do not get it (Kale, 2002)) that in some LMIC could be as high as 90% (Patel et al., 2010). The low levels of expenditure, lack of awareness, scarcity of human resources, and failures and delays in treatment seeking are obstacles to effective treatment delivery, that in some developing countries could be as low as 2% (Eaton et al., 2011). The disparity between the need and the access to evidence-based mental health care in Latin American countries is not any different from other LMIC (Rodríguez, Kohn, & Aguilar-Gaxiola, 2009); mental health disorders account for 22% of the entire burden of disease in this region (Rodríguez et al., 2009). In 1990 with the Caracas Declaration (advocates for the reform of mental health care services based on scientific evidence, respect for human rights),

Latin American countries committed to reduce the mortality and burden disease associated with mental health disorders and to strengthen mental health policies in the following years. Additionally, it recognized the need to move from a hospital-centred delivery of care to a decentralized, community-based care model with greater emphasis on prevention and continuity of care. Almost 30 years after the Caracas Declaration, numerous advances have been documented, but there is still a significant unmet need.

It has been calculated that 10 to 20% of young people experience some kind of mental health condition (Organization, 2018), yet only one in four receives professional help (Libby et al., 2007; Slade, Johnston, Oakley Browne, Andrews, & Whiteford, 2009). Of those who do receive help, only a small proportion receives timely and evidence-based treatments (Libby et al., 2007). The current psychiatric classification systems remain limited for young people (Hickie, Scott, Hermens, et al., 2013) and, as interventions are often guided by diagnosis, young people experiencing subthreshold symptomatology do not always receive appropriate or any type of care (Cross et al., 2014). In most countries, young people are less likely to receive effective mental health care as a consequence of financial, attitudinal, and health system literacy factors (Gulliver, Griffiths, & Christensen, 2010; McLaughlin, 2004).

For young people, there is typically a prolonged delay between the onset of first symptoms and initial treatment contact (Wang, Berglund, Olfson, & Kessler, 2004). By the time most young people present to health services, they already have significant functional impairment, are psychologically distressed, or have some degree of established comorbidity (Iorfino et al., 2018; McGorry & van Os, 2013). This scenario is particularly discouraging for children and adolescents as LMIC have greater shortages of youth mental health professionals, community services and infrastructure as specific policies related to the

provision of mental health services for this population are also scarce (Juengsiragulwit, 2015). There is a shortage of child and adolescent psychiatrists around the world (in high income countries 1.19 per 100,000 youth); however appallingly, in LMIC, where the majority of young people are located, the ratio is 0.1 per 100,000 young people (Skokauskas et al., 2019). Sadly, policy in some areas ignore or do not reflect accurately this problem; the 2017 World Health Organization (WHO) Mental Health Atlas identified that just 46% of the responding countries have indicated they have a plan or strategy for child and adolescent mental health (World Health Organization, 2018). Education is another area requiring increased awareness and reform; in most LMIC, general practitioners play a bigger role in mental health care, however this is not reflected in the outdated undergraduate medical curriculums (Rodríguez et al., 2009), leaving medical doctors with limited knowledge about mental health.

The need for mental health services far outweighs the capacity of service providers all over the world (World Health Organization, 2018). Access to quality mental health care is also limited for many populations, but particularly for vulnerable groups such as the elderly and youth populations, racial and ethnic minorities, the socioeconomically disadvantaged, and rural populations (Clarke & Yarborough, 2013). For example, several studies have shown increased rates of mental health problems in migrant populations (Bhugra, 2004; Lee, Maria, Estanislao, & Rodriguez, 2013; Suh, van Nuenen, & Rice, 2017). Individuals who do not speak English but live in English-speaking countries are less likely to receive mental health care (Ohtani, Suzuki, Takeuchi, & Uchida, 2015). Language proficiency has been identified as a true barrier for migrant men when using services (Kelaher, Williams, & Manderson, 1999). Young migrants from LMIC living in countries with a different native language are, therefore, at particular risk of experiencing health inequalities.

Since the 2007 publication of the Global Mental Health series in *The Lancet*, the awareness of improving mental health and well-being in LMIC and scaling up services has increased with international organisations committed to join efforts and bridge gaps in mental health care. The WHO Mental Health Action Plan 2013-2030 (World Health Organization, 2013) aims to “...*promote mental well-being, prevent mental disorders, provide care, enhance recovery, promote human rights and reduce the mortality, morbidity and disability for persons with mental disorders*” (p.9). This initiative embraces a life-course approach (including infants, children and adolescents) for the implementation of services, plans and policies according to need and builds upon the Mental Health Gap Action Programme that aims to scale up services for mental, neurological and substance use disorders (especially in LMIC), by integrating into primary health care and general medical services evidence-based packages to be delivered by non-specialists (World Health Organization, 2008). Furthermore, in 2012, the United Nations (UN) adopted a resolution on universal health coverage (United Nations, 2012) which has become one of the main activities of the WHO by supporting countries to develop health systems to achieve and sustain universal access and monitor progress (World Health Organization, 2019).

The World Psychiatry Association (WPA) Action Plan 2017-2020 intends to improve mental health for people globally by promoting equitable access and quality care. This plan specifically targets young people who face adversity or disadvantage (Herrman, 2017). The strategy strongly advocates to enhance the community orientation to psychiatry, promotes psychiatrists to use their expertise in enabling the work of non-specialists and calls for international cooperation (Herrman, 2017, 2019). In the same line of the Lancet Global Mental Health series, both the WHO and the WPA, put a great focus on the task-shifting of

mental health interventions to non-specialists as a way to scale up services and reduce the treatment gap. A 2013 Cochrane review showed that non-specialist health worker interventions can reduce symptoms of depression, anxiety, PTSD, dementia, alcohol and perinatal depression. However, data was insufficient to draw conclusions about the cost-effectiveness and adverse effects (self-sufficiency, distress and client expectations) of these interventions and more importantly, it's effects are not clear in the younger populations (Van Ginneken et al., 2013).

Despite international efforts, a recent study has just shown that mental and substance use disorders are still the largest contributors to disability in young adults (GBD 2016 Disease and Injury Incidence and Prevalence Collaborators, 2017). It is well known that early prevention strategies are more cost effective than remediation and are associated with higher levels of productivity. In contrast, the lack of availability of these interventions is associated to long-term negative effects such as chronic disability, poor educational outcomes and loss of productivity (Kieling et al., 2011). Additionally, mortality associated with these disorders still remains high, accounting for 8 million deaths each year (Walker, McGee, & Druss, 2015). The burden in this population feeds into the complex negative cycle between social inequality, poverty and mental ill-health, where poverty increases the risk of mental health disorders, and having a mental health disorder increases the odds of living in poverty; therefore, directly threatening the economy and growth of nations (Allen, Balfour, Bell, & Marmot, 2014; McLeod & Shanahan, 1993).

1.2 The Potential of Health Information Technologies to Transform Mental Health Care

This year the World Economic Forum (WEF) encouraged the "...use (of) technology to promote broad and equal access to treatment, thus combatting rather than exacerbating the

digital divide and promoting equality” (World Economic Forum, 2019). As a consequence, the same institution makes a call for stepping up actions that allow governments, policy-makers, business leaders and practitioners to effectively reduce the obstacles that prevent people from getting appropriate mental health care by developing regulations and addressing ethical considerations (in terms of data use and confidentiality) of HIT use. Additionally, the WEF advocates for imbedding evidence-based clinical interventions into the technologies and adopting a “test and learn” approach which facilitates the continuous assessments and improvement of HIT in real life settings.

The Internet and emerging technologies have long been identified as having the potential to reach a wide geographic area via remote delivery of care (Judd et al., 2001); decrease costs in delivering self-help and social networking interventions, and allow for relatively rapid and centralized scaling up of interventions to a public health dissemination level (Blaya, Fraser, & Holt, 2010). Over the past decade, evidence suggests that the Internet is considered not only a major source of information about health (including mental health) and well-being (Eysenbach, Powell, Kuss, & Sa, 2002; Kauer, Mangan, & Sanci, 2014; Wood, Benson, LaCroix, Siegel, & Fariss, 2005) but also HIT mental health interventions have proven to be effective at all stages of care (Burns, Davenport, & Christensen, 2013; Griffiths, Farrer, & Christensen, 2010; Oh, Jorm, & Wright, 2009), from self-screening and referral (Kim, Coumar, Lober, & Kim, 2011), to reducing symptoms, increasing self-care and delivering treatment for major mental health disorders (Hoek et al., 2011). A number of studies, including randomized controlled trials, have also demonstrated the effectiveness of various Internet-delivered interventions, such as psychotherapy and psychoeducation (van der Zanden, Kramer, Gerrits, & Cuijpers, 2012), treating problematic health behaviours (Tait & Christensen, 2010), and delivering prevention and treatment programs (Calear & Christensen,

2010). Other population-based studies have reported that HITs can enhance the delivery of mental health care in primary care settings (Hunkeler et al., 2000) and support training and supervision for providers (Epstein et al., 2011).

While there are concerns about a potential lack of accountability in the mHealth (mobile health is the use of mobile and wireless technologies to enhance health) field and that online communications could miss nonverbal cues that can ultimately impact empathy and patient satisfaction (Miller & Derse, 2002), it is also evident that HIT programs can facilitate disclosure (Bradford & Rickwood, 2015) and such online interventions are as effective and even more efficient than traditional interventions in mental health (Bashshur, Shannon, Bashshur, & Yellowlees, 2015; Bouchard et al., 2017). Furthermore, evidence shows that telepsychiatry is as accurate as in-person psychiatry, and online users experience the same degree of satisfaction as face-to-face users (Hyler, Gangure, & Batchelder, 2005).

Young people today, are leading the digital economy, with 70% of people aged 15 to 24 years being connected to the Internet (94% in developed countries vs 30 to 67% in LMIC) (International Telecommunication Union, 2017). With the expansion of mobile-broadband services and the ever-increasing availability and use of technology, the potential to reach young people is especially promising (Burns et al., 2013; International Telecommunication Union, 2017). The number of Internet-based treatment approaches for a range of mental health problems in adults and adolescents is growing rapidly (Andersson & Cuijpers, 2009; Griffiths et al., 2010; Naslund, Marsch, McHugo, & Bartels, 2015; Tate, Finkelstein, Khavjou, & Gustafson, 2009) (Mitchell, Vella-Brodrick, & Klein, 2010). Although positive results are seen from the use of self-directed electronic health interventions, increased effectiveness has been reported if they are used as part of a stepped-care model (van Straten,

Seekles, van't Veer-Tazelaar, Beekman, & Cuijpers, 2010), with the support of a trained health professional (Perini, Titov, & Andrews, 2009) or as an adjunct to face-to-face treatment (Saulsberry et al., 2013).

For adolescents and young people that present with sub-threshold and non-specific symptoms, HIT platforms are also being used to deliver real-time stepped care services (Cross & Hickie, 2017), providing information and low-intensity treatment for those in the early stages of help-seeking, with the capacity to increase scope and intensity of treatments as illnesses progresses (Kauer et al., 2014). Most of the developments focus on providing solutions to specific problems (World Economic Forum, 2019), with far less focusing on comprehensive HITs (e.g. platforms or ecosystems) or systems that integrate real-time web-based stepped-care support in mental health services (Faurholt-Jepsen et al., 2014; Frost, Okun, Vaughan, Heywood, & Wicks, 2011). What is missing is a web-based mental health clinic that includes access to all the components and services necessary to meet the needs of all young people (those between the ages of 16 and 25 years), regardless of where they are on the spectrum of mental health or ill-health.

Despite the growth of such HITs in high-income countries, these HITs are still lacking in LMIC (Martinez, Rojas, Martinez, Lara, & Perez, 2018). Traditional telemedicine has supported the cooperation between developed and developing countries to deliver care across borders by linking professionals rather than providing direct connection between professionals and patients (Saliba et al., 2012). Telepsychiatry has been used to deliver mental health care to individuals requiring attention, not only locally (Barrera-Valencia, Benito-Devia, Velez-Alvarez, Figueroa-Barrera, & Franco-Idarraga, 2017; Castro, Larrain, Fritsch, & Rojas, 2012; Moreno, Chong, Dumbauld, Humke, & Byreddy, 2012), but also

internationally, as a means to deliver care to Spanish-speaking individuals residing in a different country (Baker-Ericzen et al., 2012; Mucic, 2008; Saliba et al., 2012). This type of care is a more efficient alternative, as it does not require the use of interpreters and is culturally sensitive (Yellowlees et al., 2013). Although Spanish is the second most common language spoken worldwide and some successful Spanish-language HIT interventions have been applied in several fields, such as cancer, diabetes, and child, infant, or maternal health (Chaet, Morshedi, Wells, Barnes, & Valdez, 2016); HITs available for mental health care are scarce. Initial reports have demonstrated their potential utility in the screening of mental health problems (Ferrari, Ahmad, Shakya, Ledwos, & McKenzie, 2016), as well as in the treatment of depression (Aguilera, Bruehlman-Senecal, Demasi, & Avila, 2017; Martinez et al., 2018; Romero-Sanchiz et al., 2017), anxiety (Ramos, Cortes, Wilson, Kunik, & Stanley, 2017), and substance use disorders (Muroff et al., 2017).

At present, LMIC have slowly started to develop HITs, however, costs, lack of expertise and limited human resources act as barriers for these countries to keep up with the expansion seen in the developed world. It has been calculated that the development of an average mHealth app costs 425 K USD from development to launch (Research2Guidance, 2018), and this does not include implementation and/or maintenance costs. As an example, the adoption of an electronic medical record in the first 60 days could cost around 170 K USD in a solo practice (O'Neill Hayes, 2015). At the same time, building capacity by training health professionals (the costs in Colombia for training physicians are 81 K USD at a private university and 55 K USD at a public university; (Gil-Rojas et al., 2018) and building health infrastructure (in Colombia the estimated cost of a third level hospital is 1.4 K USD per square meter (Daza, Andrade, Bedoya, Barreneche, & Saldarriaga, 2017)) is also a slow and expensive pathway (Health Canada, 2008; Daza et al., 2017; Gil-Rojas et al., 2018).

As a consequence, people living in these areas are at risk of experiencing not only physical but also technological social health inequalities (Latulippe, Hamel, & Giroux, 2017). Despite HITs show potential being cost-efficient in the long-run (Blaya et al., 2010; De La Torre-Díez, López-Coronado, Vaca, Aguado, & de Castro, 2015); the development of them is also a demanding and expensive process.

The “Principles for Digital Development” provide guidance to individuals or organisations to successfully apply digital technologies to development programs for international development and cooperation. Many international organizations (e.g. United Nations Children’s Fund [UNICEF], WEF, WHO, the Bill and Melinda Gates Foundation, etc.) endorse these nine principles: i) design with the user; ii) understand the existing ecosystem; iii) design for scale; iv) build for sustainability; v) be data driven; vi) use open standards, open data, open source, and open innovation; vii) reuse and improve; viii) address privacy and security; and ix) be collaborative (Principles for Digital Development, 2019). In order to provide a solution to the scarcity of HITs in LMIC, the “reuse and improve” principle should be a guideline as it encourages not to start from scratch but to look for what is possible to adapt and improve existing HITs. In the same line, previous research has highlighted the need to tailor HITs beyond content and language, by including culture (Chaet et al., 2016) – this thesis illustrates how a HIT can be adapted for use in LMIC and more specifically in Colombia.

1.3 Developing Usable HITs, from Participation to Empowerment

In a systematic review of mental health HIT for young people, limited uptake, engagement, adherence, and dropout rates have been identified as significant problems

(Clarke, Kuosmanen, & Barry, 2015; Doherty, Coyle, & Sharry, 2012). These phenomena can be explained by Eysenbach's attrition law (Eysenbach, 2005), which postulates that a substantial proportion of end users lose interest or experience some difficulties whilst using the technological intervention and, in turn, stop using it. This might be due to the perception that the intervention is not creating any benefit, that it is responding to an overly specific need, or that it has usability problems (Eysenbach, 2005). Although academia-led HIT interventions have the strength of incorporating evidence-based and best clinical practices into their design, it is common to sacrifice the intervention's usability over content due to limited funding (Cheng et al., 2018; Fleming et al., 2016). For researchers, it is hard to compete with commercial products that provide highly intuitive and engaging experiences in their products, despite having unknown evidence-based or clinical value (Cheng et al., 2018; Fleming et al., 2016).

In order to ensure that end users of HIT interventions can derive maximum value from these interventions, it is important to involve them in the design and development of such interventions, and to strike a balance between best clinical practice and user experience (including usability). PD methodologies represent one such solution (Bjerkkan, Hedlund, & Hellesø, 2015; Ospina-Pinillos et al., 2018; Zhang & Ying, 2019).

PD methodologies, which were developed in the late 1960s and early 1970s, emphasize the importance of involving all stakeholders (including end users, developers, and researchers) during the development of products to help ensure the end product meets everyone's needs; has good usability, and ultimately increases engagement with end users (Bjerkkan et al., 2015; Peters et al., 2017; Rothgangel, Braun, Smeets, & Beurskens, 2017). The process involves iterative design cycles in which end users and researchers contribute to

knowledge production and the development of the end product (Muller & Kuhn, 1993; Orłowski et al., 2015). Importantly, end users should participate in all stages of development (Sjöberg & Timpka, 1998), not as consultants or controllers of the process, but sharing equal responsibility with the research team for the outcomes (Orłowski et al., 2015). Some researchers (Hagen et al., 2012) consider PD as key research methodologies that overtly put the end user at the centre of research (Sullivan, 1989) and could lead to better engagement and outcomes (Bilsbury & Richman, 2002; Lyles et al., 2016; Orłowski et al., 2015).

The use of PD is expanding in the development of HIT-based mental health and well-being interventions for young people. In 2015, a systematic review (Orłowski et al., 2015) described the development of these interventions in areas such as prevention, screening (Gordon, Henderson, Holmes, Wolters, & Bennett, 2015), and treatment programs (Monshat, Vella-Brodrick, Burns, & Herrman, 2012). In the majority of cases, however, end users assumed more of a consultative role. Despite the fact that uptake of PD in the development of HIT-based mental health and well-being interventions has increased, evidence is still needed to assess the impact of these research methodologies in the outcomes of these interventions (Orłowski et al., 2015).

As consumers have the opportunity to share their preferences before the development of expensive, and potentially helpful systems, the rationale behind the use of PD in the development of mental health HITs could mean that an active engagement of end users could reduce the 17-year gap in translational research (Morris, Wooding, & Grant, 2011).

Although the development of HITs in Spanish is recent, their usability and retainability among end users is of concern (Martinez et al., 2018). A close collaboration with

end users ensures the appropriateness of these systems for culturally and linguistically diverse populations (Ginossar & Nelson, 2010). Therefore, incorporating PD research methodologies that puts end users at the centre of the design and development process is greatly needed for Spanish-language-based HITs. To the best of our knowledge, there has been no research to date incorporating PD methodologies into the development of Spanish-language HITs for mental health care.

1.4 A Colombian Example

According to the World Bank, Colombia is defined as a LMIC with a Gross Domestic Product (GDP) of 314 B USD (World Bank, 2019) and is one of the most economically unequal countries in the world (Gross National Income per capita of 6.2 K USD (World Bank, 2019a)], 14.5K USD in purchasing power parity (World Bank, 2019b)). It has an estimated population of 48.3 million inhabitants, with 77% of the population living in urban areas and the remaining 23% in rural areas (National Department Administrative of Statistics, 2018). Furthermore, 40% of the Colombian population (approximately 18 million inhabitants) is younger than 25 years of age, with 18% of the population (approximately 8 million inhabitants) aged between 15 and 24 years specifically (National Department Administrative of Statistics, 2018). In relation to Colombia's health expenditure, it has been calculated that the country has spent 7% of its GDP over the last 15 years in the health sector (World Health Organization, 2015). According to the WHO, expenditure on mental health treatment in Colombia is just 0.08% of the total health budget, the least of all South American countries (World Health Organization, 2005).

Regarding the health workforce, in 2015 there were approximately 19.4 physicians for every 10,000 inhabitants (Pan American Health Organization, 2018). Although Colombia has a high level of nationwide health coverage (approximately 95%) (Colombian Ministry of

Health and Social Protection, 2019), this health coverage is still relatively difficult to access for ethnic minorities and by those living in Colombia's poorest regions. Additionally, as the Colombian health system is disease-centred, the continuity and the quality of service is an important challenge in mostly rural areas due to the difficulty of attracting qualified specialists (Colombian Ministry of Health and Social Protection, 2018). Therefore, demand for appropriate mental health care in these regions is significantly higher than the health professionals available to service these regions. In 2017, it was estimated that there were just 1,003 psychiatrists in Colombia (Colombian Ministry of Health and Social Protection, 2018) and that 80% of psychiatrists were situated within major cities, resulting in a treatment gap of more than 50% (Colombian Ministry of Health and Social Protection, 2015). Furthermore, there are only a small number of specialized child and adolescent psychiatrists in the country, most of them located in urban areas. Mental health services for young populations (outpatient and inpatient) occur in the context of adults' facilities, creating additional barriers to getting help.

According to the most recent Colombian National Mental Health Survey (NMHS) (2015), the lifetime prevalence rates of mental health disorders for adolescents aged 12 to 17 years was 7% (any disorder) and the rate of suicide attempts for this age group was 3% (Colombian Ministry of Health and Social Protection, 2015). This survey grouped adults between 18 to 44 years of age, and hence the lifetime prevalence of these disorders in young adults is not clear. In a survey conducted in Medellin in 2012 (Torres de Galvis et al., 2012), the lifetime prevalence for young people aged 13 to 29 years of age were depression - 7%, any anxiety disorder - 13%, and post-traumatic stress disorder - 4%. Among university students in Colombia, the prevalence of mental health disorders is estimated to vary between 11% and 75% (Arrieta Vergara, Díaz Cárdenas, & González Martínez, 2014; Cáceres,

Salazar, Varela, & Tovar, 2006; Erazo Caicedo & Jiménez Ruiz, 2012; Gutiérrez Rodas et al., 2010). In one study, it was found that 20% of college students had suffered from a mental health problem in the past year, where anxiety, mood and substance use disorders were the most prevalent; and only 16% of students received any health care treatment for their mental disorders in the preceding 12 months (Torres de Galvis et al., 2012).

One of the most important problems in the country is the exposure to violence. Colombia has experienced one of the longest lasting internal conflicts in the world (more than 50 years) which has resulted in a significant number of lives lost, internal displacement and crime. The impact of the conflict has also extended to detriments in the social fabric and generation of a vast burden for society and the economy as a whole (Tamayo-Agudelo & Bell, 2019). A recent study has revealed that the Colombian populations that have been exposed to violence, regardless of the intensity and the constancy of the conflict had a higher prevalence of mood and anxiety disorders as well as suicide, substance use and post-traumatic stress disorders (Chaskel et al., 2015; Gómez-Restrepo et al., 2016; Tamayo-Agudelo & Bell, 2019). Although the full impact on children and adolescents is not entirely understood, research has shown that past trauma is a strong predictor of meeting criteria (DSM V) for a psychiatric diagnosis (odds ratio: 4.2; 95% CI: 2.3–7.8) (Tamayo-Agudelo & Bell, 2019).

In late 2016, a peace deal with the Revolutionary Armed Forces of Colombia (the largest and oldest rebel group) was achieved (Economist, 2016; Paz, 2016) and many people have become optimistic about how peace could transform the social and economic prospects of Colombia, including improving the right to health by increasing access in rural areas, delivering psychosocial rehabilitation to victims, providing strategies of promotion and

prevention to vulnerable communities, and reducing substance use disorders (Colombian Ministry of Health and Social Protection, 2016). International recognition has been placed in Colombia due to its transformation, and the former Colombian President (Mr Juan Manuel Santos Calderon) was awarded the Nobel Peace Prize in 2016. Additionally, international stakeholders like the United Nations have invested their efforts to contribute to the transformation of the country (United Nations, 2019).

Today, Colombia has universal Internet access meaning that all its municipalities have a reliable (broadband, satellite or microwave) Internet connection (Ministry of Information and Communications Technology, 2014). A recent Information and Communications Technology use survey revealed that 64% of the households have access to the Internet and that 72% of the households have at least one smartphone. Moreover, there are more than 1,500 free WIFI zones located in major community spots of the territory. In the case of adolescents, research has also reported that their most preferred device for using the Internet were mobile phones (75%) (TigoUne & EAFIT, 2018). Importantly, 75% of adolescents reported accessing Internet in their own bedrooms without parental supervision (TigoUne & EAFIT, 2018).

According to the WHO, telemedicine is defined as “... *The delivery of health care services, where distance is a critical factor, by all health care professionals using information and communication technologies for the exchange of valid information for diagnosis, treatment and prevention of disease and injuries, research and evaluation, and for the continuing education of health care providers, all in the interests of advancing the health of individuals and their communities*” (p.9) (World Health Organization, 2010). Colombia was one of the first countries in Latin America to propose a specific telehealth legislation

(Law 1419 of 2010). Its main aim is to integrate HITs to the local health system in order to provide health services across all levels: promotion, prevention, diagnosis, treatment, rehabilitation and health education (Jiménez Barbosa & Acuña Gómez, 2015).

Telemedicine in Colombia has been successfully operating since 1998 (Cáceres-Méndez, Castro-Díaz, Gómez-Restrepo, & Puyana, 2011), and it has been calculated that the country has about 2,500 registered telemedicine service centres, which are located in the major cities and towns (Protection, 2016a). The number of these centres is constantly growing as some of the most important academic institutions and hospitals (public and private) are committed to delivering clinical assessments (including most of the medical specialties) to rural areas and marginalized populations (Jiménez Barbosa & Acuña Gómez, 2015; Colombian Ministry of Health and Social Protection, 2016; Rey-Moreno, Reigadas, Villalba, Vinagre, & Fernández, 2010). In 2010, records showed that more than half a million individuals have been assessed thanks to synchronic telemedicine (real-time videoconferencing) (Rey-Moreno et al., 2010).

Asynchronous telemedicine, which involves delivering end users text messages (more commonly containing questions) to experts (teleconsultation) via website or apps, has experienced great growth in the country in the past years (Lopez et al., 2014). With more than 83 million inquiries (IDOC3, 2019; Solve, 2018; Valenzuela, Lopez, Guzman, & Fajardo, 2010), this type of communication has been postulated as an effective method for providing reliable health information and open dialogue about sensitive topics such as sexuality, drug use or health concerns (Lopez et al., 2014; Valenzuela et al., 2010). Although HITs in Colombia seem to have a positive impact, most of the projects still require rigorous evaluation (Rey-Moreno et al., 2010).

Despite these advances, several barriers have been identified in the practice. It has been described that there is still a certain degree of scepticism in the general population to trust their health care being delivered in this way, and health professionals still have limited knowledge on how to work effectively with technology (Correa-Díaz, 2017; Jiménez Barbosa & Acuña Gómez, 2015). Notwithstanding the progress in the legislation, the current law still restricts the use of telemedicine in rural populations, limiting its use in medium and small towns and as a tool only when the face-to-face contact is not available (Cáceres-Méndez et al., 2011; Correa-Díaz, 2017; Jiménez Barbosa & Acuña Gómez, 2015). Other legal limitations include the need for health professionals to be on both sides of the assessment (institution of remission and institution of reference), meaning that an individual cannot directly connect with the health professional or connect directly with foreign institutions; and there are also ethical concerns related to privacy and security (Correa-Díaz, 2017; Jiménez Barbosa & Acuña Gómez, 2015). In Colombia, innovative uses of HITs such as mHealth and uHealth (ubiquitous health is information technology combined with medical technology to support health) are still unregulated.

The Colombian context is complex as it has several challenges that could impact on its population's mental health and delivery of care. Despite economic growth, inequality continues to be a great issue for the country as people still live in poverty and in some places still struggle to satisfy basic needs (National Department Administrative of Statistics, 2016). One quarter of its population live in rural settings with low numbers of health professionals, limited infrastructure (Chaskel et al., 2015), and high levels of violence following the 50 years of internal conflict. This results in a high level of challenge for individuals, health professionals, service providers and decision-makers to change the delivery model as well as

treatment standards. Web-based health solutions mark a paradigm shift beyond traditional models of health-care delivery. Integrating physical resources with HITs would capitalise on Colombia's heavy investment in telecommunications and could enable the Colombian population to access new resources, make better use of expertise and provide better access for individuals, peers and families. This should be done through collaborative interdisciplinary work with ongoing international support to capitalize on global medical knowledge and find new solutions, leading to quicker innovations in health service delivery.

The overall aim of this thesis was to present a case example of how a co-designed and developed HIT in an industrialized country (i.e. Australia) can be translated, culturally-sensitised and context-adapted for a LMIC (i.e. Colombia). The first paper of the thesis uses participatory design (PD) techniques as research methodologies with end users (including, young people aged between 16 and 25 years as well as health professionals) to develop the Mental Health eClinic (MHeC; a Web-based mental health clinic) that has the potential to improve timely access to, and better quality of, mental health care for young people across Australia. The second paper of the thesis, tested the prototypic MHeC in a real-world setting (i.e. two youth primary mental health services). This research more specifically demonstrated the comparison of online self-report assessments with traditional face-to-face clinical assessment in a cohort of young people newly presenting for mental health care. The paper also evaluates how online self-report assessments identify key features such as initially-suggested clinical stage (a method of categorising the severity, complexity and chronicity of mental ill health), lifetime trajectories, and recognition of comorbidities while also managing suicidality and responding to more complex cases (i.e. psychosis or comorbidities).

Once the MHeC had been co-designed, developed, user-tested and trialled in an Australian real world-setting, the process of translating, culturally-sensitizing and context-adapting began – broadly to the Spanish language and then more specifically Colombia. The third paper of this thesis, used PD research methodologies in an adapted version of an established research and development cycle (R&D cycle) to co-design the Spanish version of the MHeC (MHeC-S) with and for a Spanish-speaking young person population currently living in Australia. Here, the initial prototype was further developed and user-tested, and the online self-report assessment was translated (and back translated), culturally-adapted and face-validated in Spanish. The next step was to adapt the MHeC-S to a Colombian young person population, the findings of which constitute the fourth paper of this thesis. Important findings from this research demonstrated that a Colombian adaptation of the MHeC-S (MHeC-C) should not only be culturally sensitive but also be adapted to the different contexts and needs of young people living in such a diverse country.

Chapter 2: Designing and developing a Mental Health eClinic

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Original Paper

Developing a Mental Health eClinic to Improve Access to and Quality of Mental Health Care for Young People: Using Participatory Design as Research Methodologies

Laura Ospina-Pinillos¹, MD; Tracey A Davenport¹, BA (Hons), eMBA; Cristina S Ricci¹, BSc (Hons), LLB, BEd, MEd; Alyssa C Milton¹, BSc (Psych), MAppSc (Health Psychology), PhD; Elizabeth M Scott², MD, FRANZCP; Ian B Hickie¹, AM, MD, FRANZCP, FASSA

¹Brain and Mind Centre, The University of Sydney, Sydney, Australia

²School of Medicine, University of Notre Dame, Sydney, Australia

Corresponding Author:

Laura Ospina-Pinillos, MD

Brain and Mind Centre

The University of Sydney

94 Mallett Street, Camperdown

Sydney, 2050

Australia

Phone: 61 0286276946

Email: laura.ospinapinillos@sydney.edu.au

Abstract

Background: Each year, many young Australians aged between 16 and 25 years experience a mental health disorder, yet only a small proportion access services and even fewer receive timely and evidence-based treatments. Today, with ever-increasing access to the Internet and use of technology, the potential to provide all young people with access (24 hours a day, 7 days a week) to the support they require to improve their mental health and well-being is promising.

Objective: The aim of this study was to use participatory design (PD) as research methodologies with end users (young people aged between 16 and 25 years and youth health professionals) and our research team to develop the Mental Health eClinic (a Web-based mental health clinic) to improve timely access to, and better quality, mental health care for young people across Australia.

Methods: A research and development (R&D) cycle for the codesign and build of the Mental Health eClinic included several iterative PD phases: PD workshops; translation of knowledge and ideas generated during workshops to produce mockups of webpages either as hand-drawn sketches or as wireframes (simple layout of a webpage before visual design and content is added); rapid prototyping; and one-on-one consultations with end users to assess the usability of the alpha build of the Mental Health eClinic.

Results: Four PD workshops were held with 28 end users (young people n=18, youth health professionals n=10) and our research team (n=8). Each PD workshop was followed by a knowledge translation session. At the conclusion of this cycle, the alpha prototype was built, and one round of one-on-one end user consultation sessions was conducted (n=6; all new participants, young people n=4, youth health professionals n=2). The R&D cycle revealed the importance of five key components for the Mental Health eClinic: a home page with a visible triage system for those requiring urgent help; a comprehensive online physical and mental health assessment; a detailed dashboard of results; a booking and videoconferencing system to enable video visits; and the generation of a personalized well-being plan that includes links to evidence-based, and health professional–recommended, apps and e-tools.

Conclusions: The Mental Health eClinic provides health promotion, triage protocols, screening, assessment, a video visit system, the development of personalized well-being plans, and self-directed mental health support for young people. It presents a technologically advanced and clinically efficient system that can be adapted to suit a variety of settings in which there is an opportunity to connect with young people. This will enable all young people, and especially those currently not able or willing to connect with face-to-face services, to receive best practice clinical services by breaking down traditional barriers to care and making health care more personalized, accessible, affordable, and available.

KEYWORDS

mental health; community-based participatory research; eHealth

Introduction

Background

The Internet and emerging technologies have long been identified as having the potential to significantly expand the reach of quality mental health care by addressing geographical, economical, and human resource barriers [1,2]. Over the past decade, evidence suggests that the Internet is considered not only a major source of information about health (including mental health) and well-being [3-5], but that it is also useful for mental health promotion, screening, prevention, early intervention, and referral processes [6-9]. Web-based platforms are also being used to deliver real-time stepped care services [10], providing information and low-intensity treatment for those in the early stages of help-seeking, with the capacity to increase scope and intensity of treatments as illnesses progress [11].

In Australia, new and emerging mental health technologies are urgently needed as 1 in 5 young Australians aged between 16 and 24 years experience a mental health disorder each year, yet only 1 in 4 receives professional help [12]. Of those who do receive help, only a small proportion receives timely and evidence-based treatments [13]. Access to quality care is especially difficult for disadvantaged and vulnerable populations, including children; Aboriginal and Torres Strait Islander young peoples; young people from culturally and linguistically diverse backgrounds; and young people living in regional, rural, and remote areas [14,15].

Today, with ever-increasing availability and use of technology, the potential to reach young people is especially promising [7]. For example, in 2014-15, 85% of people aged 15 years and over in Australia were Internet users, and young people in the age group of 15 to 17 years had the highest proportion of use (99%) [16]. Importantly, there is also a growing body of literature supporting the use of Internet-based treatment approaches for a range of mental health problems in adults and adolescents [6,17-19]. Although there is far less research focusing on systems that integrate real-time Web-based stepped care support in mental health services [20], some research examining comprehensive Web-based support systems is starting to emerge [21,22].

Web-Based Health Information

Young people are increasingly relying on the Internet to find answers about their health concerns. For example, in Australia, a national survey in 2012-13 revealed that 53% of young people aged between 16 and 25 years with moderate and very high levels of psychological distress sought Web-based information related to a mental health and/or alcohol or other substance use problem; the majority found this information to be helpful [23]. In other surveys, young people reported feeling comfortable accessing Web-based mental health tools because they felt they were anonymous, welcoming, less stigmatizing, and, for the

most part, trustworthy [24]. Similarly, in the United States, a survey in 2013 found that 59% of patients had gone online to look for health information in the previous year and 35% had gone online to self-diagnose or diagnose someone else's condition. Of the "online diagnosers," 46% concluded that they needed to see a health professional, whereas 38% preferred a self-management option [25].

Similarly, a small pilot study evaluating an online triage platform also found that, for every user requiring a general practitioner response through an e-consultation, 5 users required online self-help only (WebGP, 2014) [26,27]. The Internet, therefore, offers people seeking information with a useful and easy gateway to answers and solutions that respond to their needs.

Internet-Based Screening

Individuals often show a preference for computerized screening over face-to-face interviews when the subject matter is sensitive in nature [28-32]. Importantly, Internet-based screening for common mental health problems has been shown to be reliable and effective [9,33,34]. In relation to screening for suicidal ideation, it is argued that the implementation of standardized, self-reported, computer-based assessments (with stringent suicide response protocols) may be a strategy that is both accurate and viable if followed up with health professional support [20,35]. In general, there is, however, the potential that symptom, Web-based assessment tools may increase demand on services as the tools are often risk averse (due to medico-legal concerns), recommending professional care when self-management is an appropriate alternative [36,37].

Videoconferencing

The provision of mental health services through videoconference systems have been widely used since the 1960s [38]. Videoconferencing is viewed as more advantageous than telephone support as the health professional can gauge important visual cues to inform their assessment such as appearance, facial expression, motor activity, movements, and mannerisms [39]. Supportive Web-based conversations with a health professional and referral to appropriate resources have also been found to negate risky behaviors, such as suicide and violence, in highly distressed people [40]. Importantly, videoconferencing has been found to be as reliable as face-to-face assessments, and more cost-effective [41].

In Australia, telepsychiatry (videoconferencing) has been practiced since the 1990s and its benefits have been translated into a wide range of populations including rural populations, Indigenous communities [42], the defense force [43], and children and adolescents [44]. Surprisingly, despite the reliability and benefits of videoconferencing, use of videoconference systems remains low in the different settings [45]. Embedding videoconferencing in comprehensive Web-based support systems would enable a more systematic use of this technology and a greater number of people to access mental health services.

Comprehensive Web-Based Mental Health Care

The augmentation of traditional videoconferencing with online self-reported health questionnaires or screening results has now emerged in the research literature [20,46]. In a study conducted by Williams and colleagues, participants who screened positive for major depression or suicidality were given the opportunity to schedule a videoconference via Skype with a psychiatrist within a 2-week period [46]. In a recent study conducted by our team, an initial Web-based clinical assessment (with an embedded suicidality escalation protocol) was completed as a routine part of the assessment process (either before a video or face-to-face visit with a health professional) for a subset of participants. After the assessment was completed, the severity of mental illness was determined using a clinical staging model [47], and those who were considered to be high-risk (according to the suicidality escalation protocol) were escalated to the youth health service, bringing forward their initial face-to-face appointment [20].

Mental Health Interventions for Young People

In a systematic review of Web-based mental health interventions for young people, however, limited uptake, engagement, adherence, and dropout rates have been identified as significant problems [48,49]. Some researchers, including ourselves, believe that the involvement of young people and youth health professionals in the design, development, and delivery of youth services could lead to better engagement and outcomes [50-52].

Participatory Design and Technology-Based Mental Health Interventions

Participatory design (PD) methodologies, which were developed in the late 1960s and early 1970s, emphasize the importance of involving all stakeholders (including end users, developers, and researchers) during the development of products to help ensure the end product meets everyone's needs; improve usability; and increase engagement of users [53-55]. The process involves iterative design cycles in which end users and researchers contribute to knowledge production and the development of the end product [50,56]. Importantly, end users should participate in all stages of development [57], not as consultants or controllers of the process, but sharing equal responsibility with the research team for the outcomes [50]. Some researchers [58], including us, consider PD as key research methodologies that overtly put the end user at the center of research and here, the development of the MHeC [59].

The use of PD is expanding in the development of technology-based mental health and well-being interventions for young people. In 2015, a systematic review [50] described the development of these interventions in areas such as prevention, screening [60], and treatment programs [61]. In the majority of cases, however, end users assumed more of a consultative role. Despite the fact that uptake of PD in the development of technology-based mental health and well-being interventions has increased, evidence is still needed to assess the impact of these research methodologies in the outcomes of these interventions [50].

As consumers have the opportunity to share their preferences before the development of expensive, and potentially helpful,

systems, the rationale behind the use of PD in the development of mental health technologies could mean that an active engagement of end users could reduce the 17-year gap in translational research [62].

This Study

In Australia, Web-based mental health services include health promotion, self-directed, and low intensity mental health support (eg, ReachOut! [63]; beyondblue [64,65]); national online counseling services (eg, eheadspace [66]); structured self-directed online therapy (eg, MoodGYM [67]); and those offering a combination of assessment and structured online therapy, including additional therapist support (eg, MindSpot Clinic [68]).

What is missing is a Web-based mental health clinic that includes access to all the components and services necessary to meet the needs of all young people (those between the ages of 16 and 25 years), regardless of where they are on the spectrum of mental health or ill-health, or where they reside in Australia.

The aim of this study was to use PD with end users (young people and youth health professionals) and our research team to codesign and build a Mental Health eClinic (MHeC) to improve timely access to, and better quality, mental health care for young people across Australia.

Methods

Participants

Participants included young people attending *headspace* Camperdown and *headspace* Campbelltown, and youth health professionals from both *headspace* Camperdown and *headspace* Campbelltown (*headspace* is the national youth mental health foundation dedicated to improving the well-being of young Australians; Camperdown and Campbelltown are two different sociodemographic areas of Sydney).

The University of Sydney's Human Research Ethics Committee approved the study (Protocol No. 2014/689). For all phases, participants (young people aged between 16 and 25 years and youth health professionals) who expressed an interest to participate in the study were provided with the participant information statement and participant consent form before providing consent and participating in the study. Parental consent was also obtained for participants aged between 16 and 17 years. At the conclusion of each PD workshop and one-on-one end user consultation, each young person was provided with a gift voucher to thank them for their participation and sharing their expertise; young people were also reimbursed for any travel-related expenses to attend the workshop or session. Youth health professionals were not provided with gift vouchers as they participated in stages 1 and 3 during work time. All workshops were catered.

Recruitment Strategy

Recruitment strategies for young people included the posting of flyers at each *headspace* center inviting young people to be involved in the study, and informing youth health professionals and reception staff at each *headspace* center about the study so they too could assist with recruitment. All young people

belonging to *headspace* Camperdown and *headspace* Campbelltown Youth Reference Group were also invited to participate in the study. Inclusion criteria for the study were as follows: young person attending either *headspace* Camperdown or *headspace* Campbelltown; aged between 16 and 25 years; and with access to the Internet through a mobile phone, tablet, desktop, or laptop.

In relation to the recruitment of youth health professionals, senior management at *headspace* Camperdown and *headspace* Campbelltown informed all staff about the study and called for expressions of interest to participate.

Research and Development Cycle

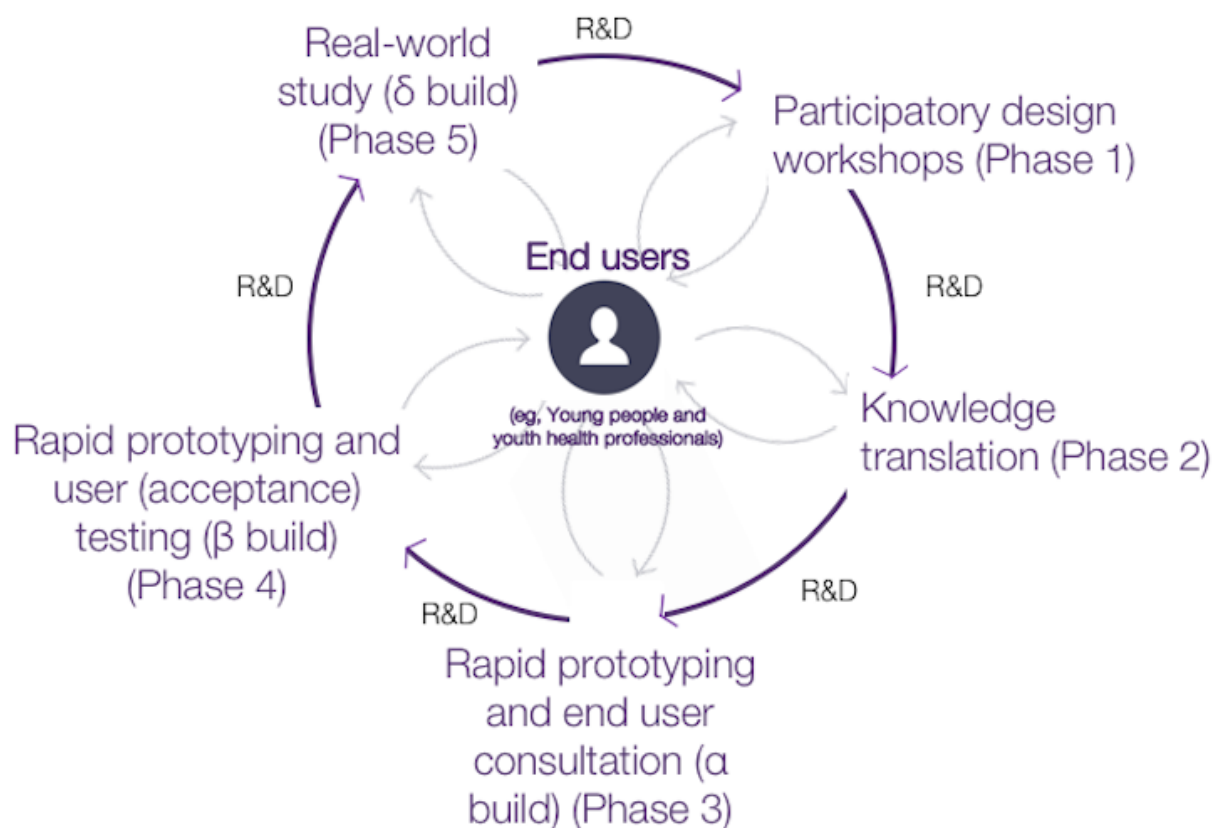
The research and development (R&D) cycle for the codesign and build of the MHeC included several iterative PD phases (Figure 1): PD workshops (phase 1); translation of knowledge and ideas generated during workshops (“knowledge translation”; KT) to produce mockups of webpages (either hand-drawn sketches or wireframes; phase 2); and rapid prototyping and one-on-one consultations with end users, including assessing the usability of the online alpha build of the MHeC (phase 3). The remaining phases of PD for the MHeC (rapid prototyping and user [acceptance] testing of the beta build [phase 4], and real-world study of the delta build [phase 5]) are currently underway and will be reported separately.

Participatory Design Workshops (Phase 1)

The PD employed in this study was informed by the research methodologies developed by the Young and Well Cooperative Research Centre for the development of evidence-based online youth mental health promotion, intervention, and treatment [58]. PD workshops were developed to accommodate a maximum of 12 participants per workshop. The same group of researchers facilitated all PD workshops. Importantly, a mental health professional was present on-site for the duration of all workshops involving young people in case anyone experienced psychological distress as a result of the subject matter. A scribe was present to take hand written notes at each workshop.

PD workshops were held in two stages with young people and youth health professionals attending separate workshops (stage 1) or a combined workshop (stage 2; Textbox 1). Following each workshop, the knowledge and ideas generated during the workshop were translated to produce mockups of webpages, either as hand-drawn sketches or wireframes produced using Balsamiq (Balsamiq Solutions, LLC, Sacramento, California, United States: a rapid wireframing tool that reproduces the experience of sketching on a whiteboard but using a computer) [69]. The mockups were then presented at the next workshop, enabling content and broad design ideas to be discussed, critically analyzed, and further developed.

Figure 1. PD research methodologies used during the design and build of the MHeC where end users participate in all stages of development, are at the center of the R&D cycle, and share equal responsibility with the research team for the outcomes. PD: participatory design; MHeC: Mental Health eClinic; R&D: research and development.



Textbox 1. Phases 1 and 2 workflow.

- Phase 1, stage 1 (young people only, Camperdown): One 1-day participatory design (PD) workshop with young people attending *headspace* Camperdown; workshop held in *headspace* Camperdown

Knowledge translation for young people only (phase 2)

- Phase 1, stage 1 (young people only, Campbelltown): One 1-day PD workshop with young people attending *headspace* Campbelltown; workshop held in *headspace* Campbelltown.

Knowledge translation for youth health professionals only (phase 2)

- Phase 1, stage 1 (youth health professionals only): One 1-day PD workshop with youth health professionals from *headspace* Camperdown and *headspace* Campbelltown; workshop held in *headspace* Campbelltown.

Knowledge translation combined workshop (phase 2)

- Phase 1, stage 2 (young people and youth health professionals combined): One half-day PD workshop with both young people and youth health professionals from *headspace* Camperdown and *headspace* Campbelltown (all participants must have previously participated in a stage 1 workshop); workshop held in *headspace* Camperdown.

Topics for stages 1 and 2 workshops included the MHeC home page; important website functions; look and feel of the website; online physical and mental health assessment; provision of assessment results online (including consideration of a dashboard of results); a video visit system (utilizing live interactive videoconferencing); and the development of personalized well-being plans based on assessment results. Importantly, technology was not used in any PD workshop; instead, several artifacts and design activities (Figure 2) were used in each workshop to facilitate discussions and the design process. The activities included:

- The use of propositions to explore and communicate the concept of the MHeC
- End user sketching [70] (hand-drawn sketches by young people and youth health professionals, either individually or in groups) to enhance the feedback process and generation of new ideas
- Analysis of mockups of webpages (hand-drawn sketches and wireframes) to test designs and provide feedback about the look, feel, content, and behavior of the MHeC.

Knowledge Translation (Phase 2)

At the conclusion of each workshop, the transcript and all visual artifacts were independently analyzed by a KT Team (three 2nd- and 3rd-year psychology students [AI, ML, and ED], all females aged between 20 and 23 years) who were interns at the time at The University of Sydney's Brain and Mind Centre). Observations were tallied, and those observations with three or more tallies were considered for inclusion in the next generation of wireframes for discussion and analysis at the following workshop. Information was compiled until saturation point was reached (defined as the point where no new information was attained) [71].

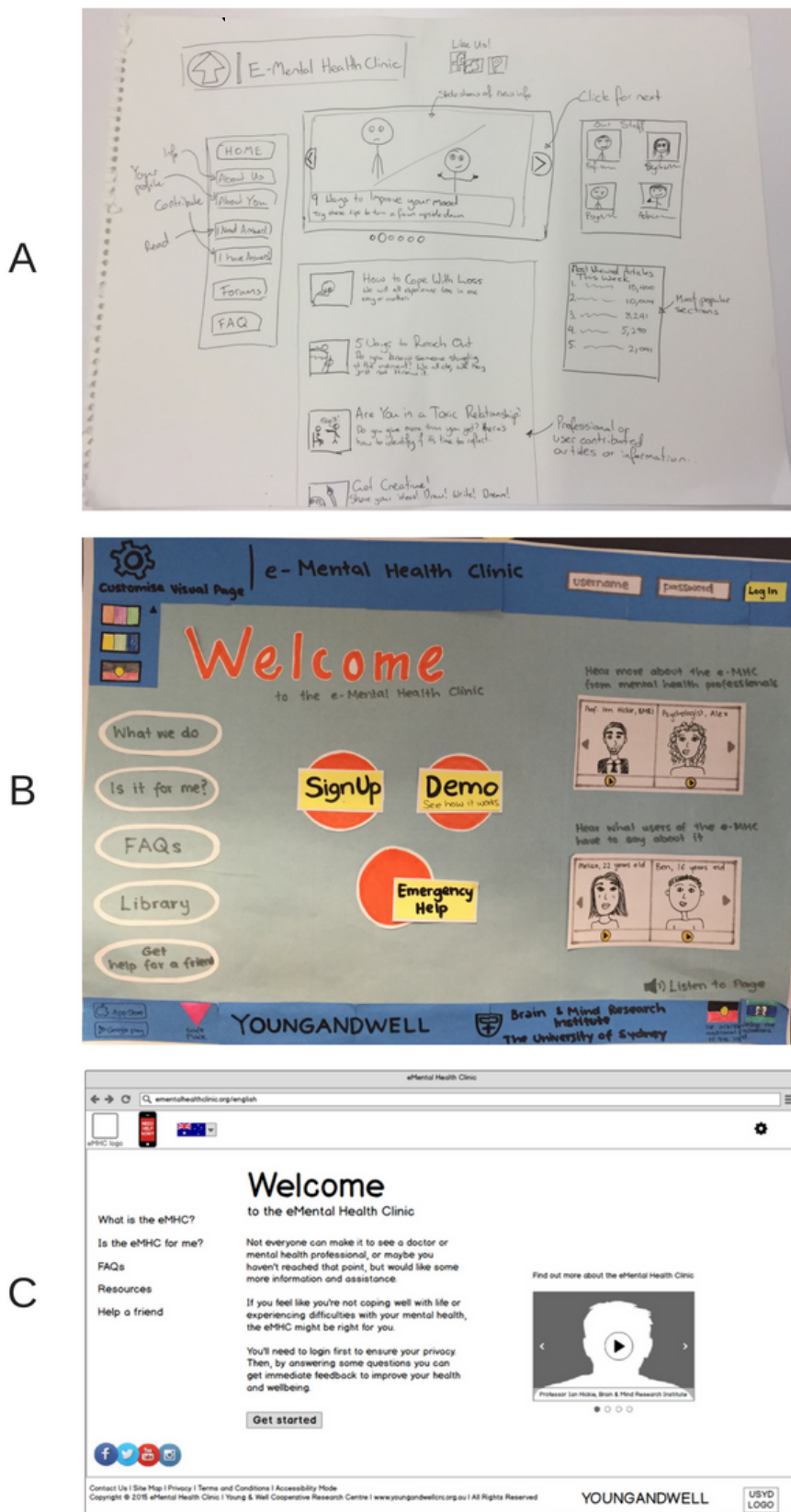
One-on-One Consultations With End Users, Including Assessing the Usability of the Alpha Build of the Mental Health eClinic (Phase 3)

Phase 3 involved in-depth one-on-one consultations with new end users (young people and youth health professionals who had not participated in Phase 1). The inclusion of new participants aimed to reduce biased responses due to habituation or familiarity with the topic as a result of prior participation in the study. In each 90-min one-on-one end user consultation, a researcher was paired with a participant (end user) and an observer took notes. Sessions involved the use of laptops where participants had access to the alpha build of the MHeC website. Employing a think-aloud protocol [72], participants were observed as they navigated the MHeC and responded to questions posed by the researcher about the main components of the MHeC; responses were recorded by the observer. The initial effectiveness of the system was then assessed by asking participants to complete 3 usability tasks: (1) create an account and login; (2) find the "need help now" button; and (3) book an appointment. Task completion time was recorded to assess the efficiency of the system. No instructions or clues were provided, and comments in relation to navigation were recorded.

Data Analysis

Qualitative data were interpreted using thematic analysis techniques [73] according to the following themes: general elements of the MHeC; general look and feel; privacy and data sharing; and interaction of the MHeC with social networks. Records of all tallies obtained in Phases 1-3 were then grouped and interpreted by a team of researchers (LOP, TD, and 2nd- and 3rd-year psychology students [AH and FY] who were interns at the time at The University of Sydney's Brain and Mind Centre). Each theme and associated content was discussed by the group, and differences of opinion were discussed until consensus was reached.

Figure 2. Samples of visual artefacts. (A) Hand-drawn sketch by end users during a PD workshop; (B) Hand-drawn sketch of a webpage generated following a KT session; and (C) Wireframe generated using Balsamiq following a KT session. PD: participatory design; KT: knowledge translation.



Results

A total of 4 PD workshops, 4 knowledge translation sessions, and 1 round of one-on-one end user consultation sessions were conducted between October 2014 and June 2015 (Figure 3).

Participant Characteristics

PD workshops were held with young people attending *headspace* Camperdown (n=7) and *headspace* Campbelltown (n=11), and youth health professionals working at those services (*headspace* Camperdown n=5; *headspace* Campbelltown n=5). A total of 18 young participants participated in stage 1 (young people only) PD workshops: there was equal gender participation, and 78% (14/18) were aged between 18 and 25 years. Ten youth health professionals participated in stage 1 (youth health professionals only) PD workshop: the majority of these participants were female (70%, 7/10) and aged between 20 and 30 years (70%, 7/10). The group comprised 4 psychologists, 2 occupational therapists, 1 medical student, 1 general practitioner, 1 social worker, and 1 Aboriginal youth worker.

Nine participants participated in stage 2 (young people and youth health professionals combined): young people (n=5) and youth health professionals (n=4). The majority of the participants were male (56%, 5/9); the youth health professional's group included 3 psychologists and 1 occupational therapist.

Six people participated in Phase 3 (consultation with end users, including usability assessment of the online alpha build). The majority of these participants were female (67%, 4/6). The group contained 1 clinical psychologist, 1 psychology student, and 4 young people.

Main Components of the Alpha Build of the Mental Health eClinic

The iterative R&D cycle revealed the importance of five main components of the MHeC. These informed the alpha build of the MHeC (Figure 4-8): a welcoming home page with a visible triage system; a comprehensive physical and mental health assessment; a detailed dashboard of results; a booking and a video visit system; and the generation of a personalized well-being plan that includes links to evidence-based, and health professional-recommended, apps and etools. The five components will have different functionalities depending on whether the user is a young person or a health professional.

Element 1: Home Page and Triage

Young people suggested the home page should be a “welcoming space,” where young people can feel “comfortable,” without compromising the authenticity and professionalism of the site. As such they indicated a banner with the institutional logos should be visible at all times at the footer of the home page. Young people also wanted the following features to be included on the home page: testimonials from young people about their experiences with the MHeC (“a young person explaining why they are there and how to use it”); reliable mental health information (resources); information about how to help a friend; frequently asked questions; and a brief explanation about how the MHeC works. Young people also suggested that as this information would be of interest to a wide range of people, the home page needs to be available to everyone, even if they have not signed up for the MHeC. Youth health professionals and young people suggested that, before any login process, a triage system needs to be in place to ensure that young people in distress can access immediate care and a “need help now” button should be clearly visible for those in crisis.

Figure 3. Study Gantt chart. KT: knowledge translation; MHeC: Mental Health eClinic.

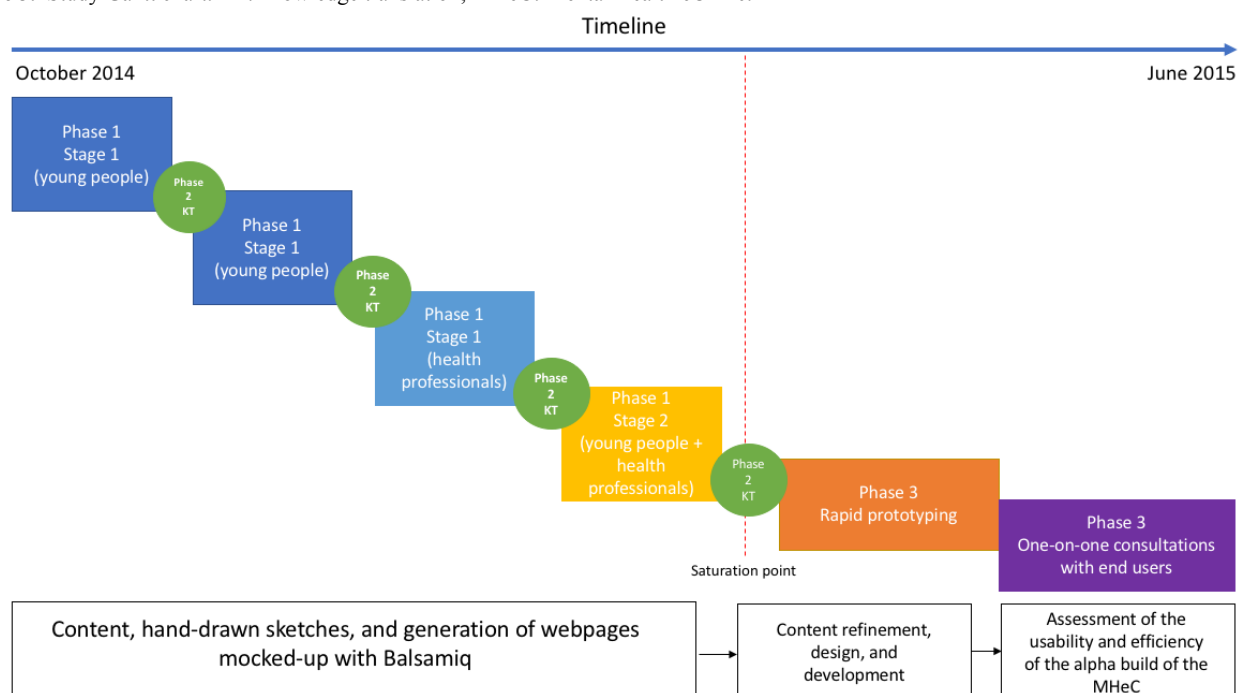


Figure 4. Home page with a clearly visible triage system for those requiring urgent help.

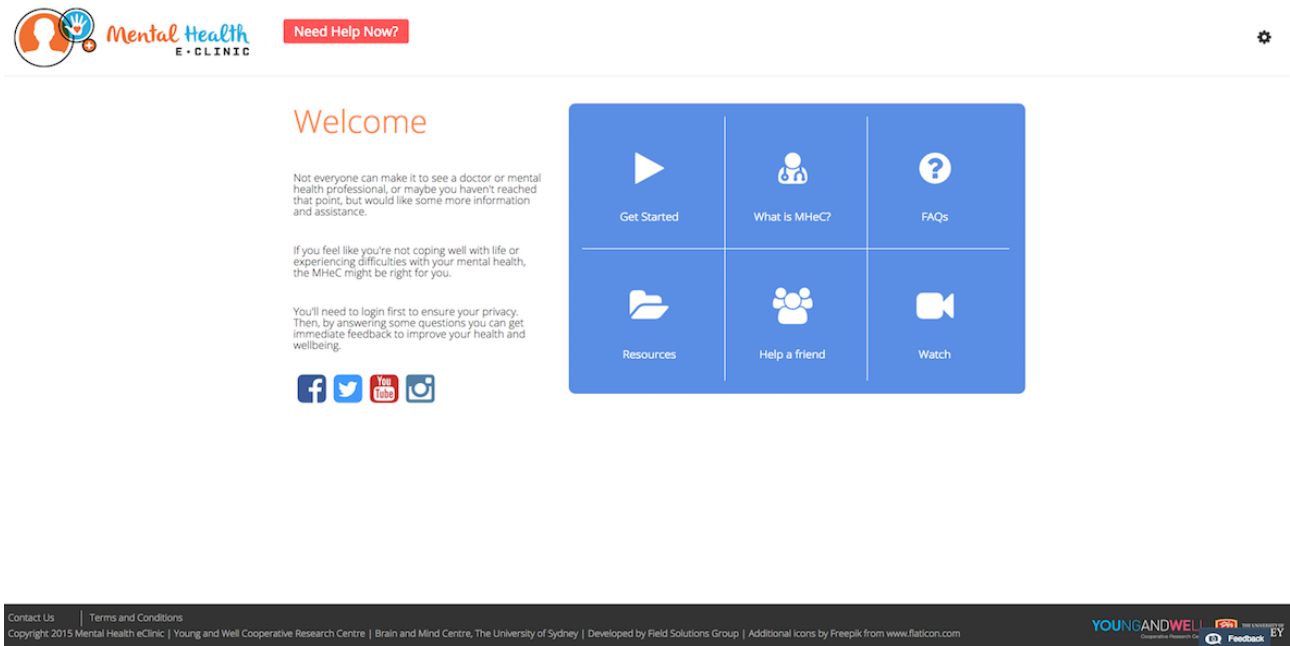


Figure 5. Comprehensive online physical and mental health assessment.

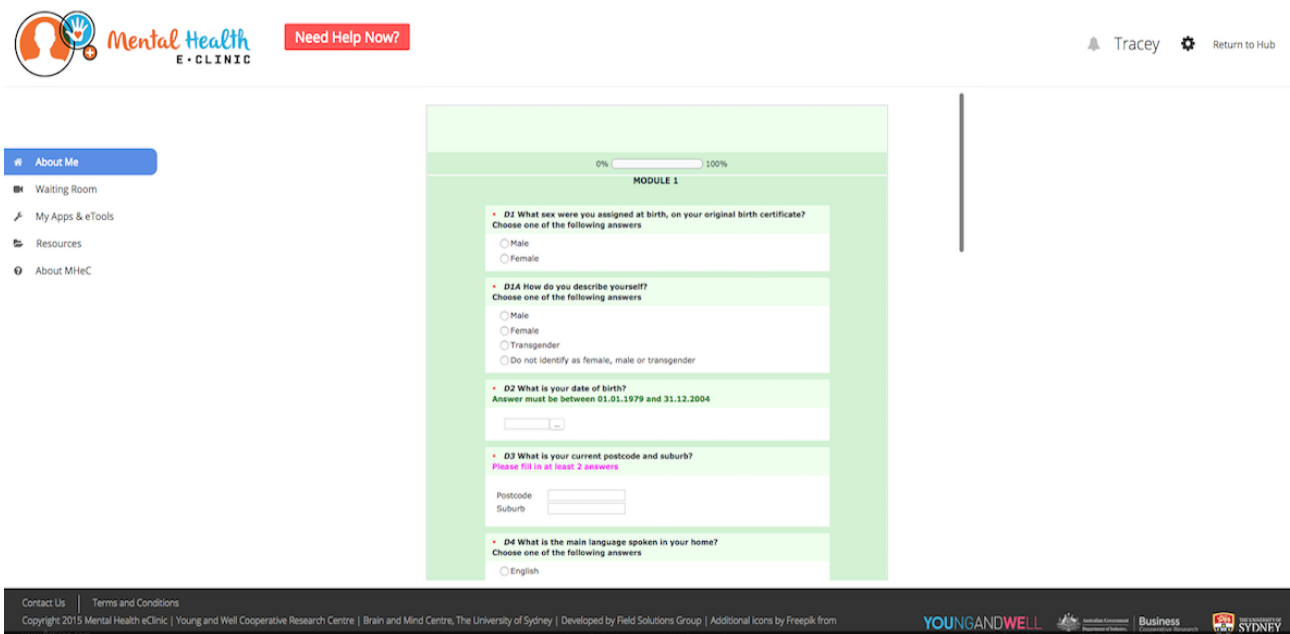


Figure 6. Dashboard of results and progress report.

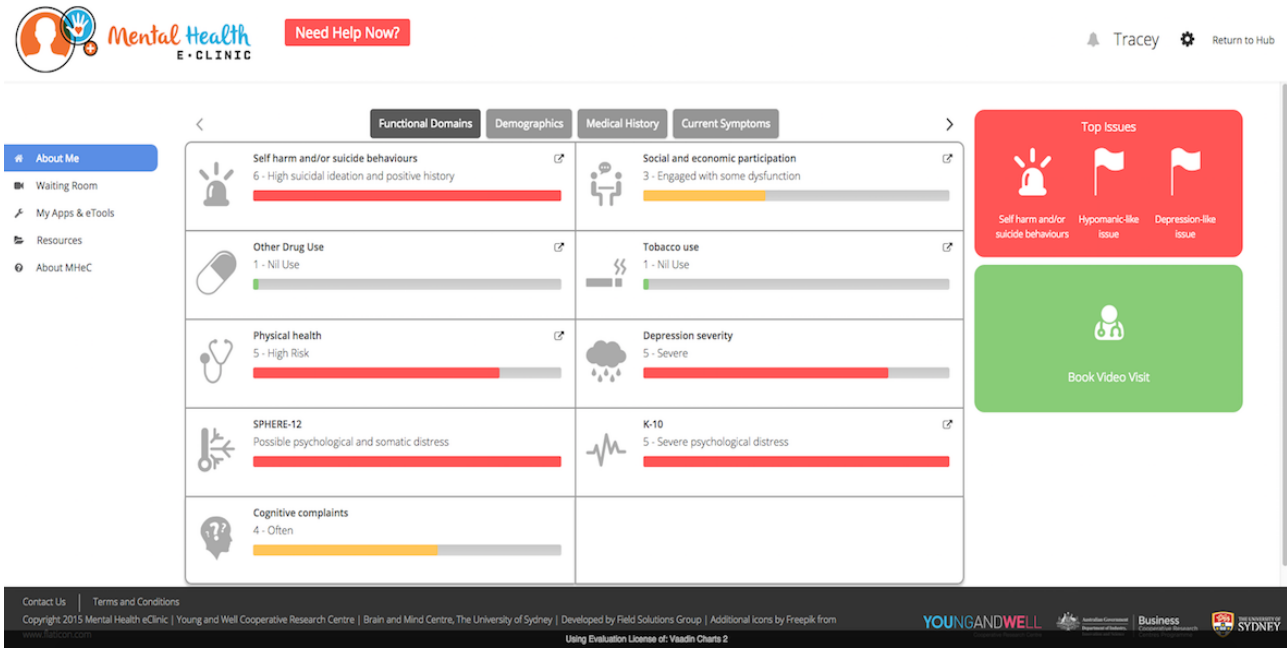


Figure 7. Booking and video visit system.

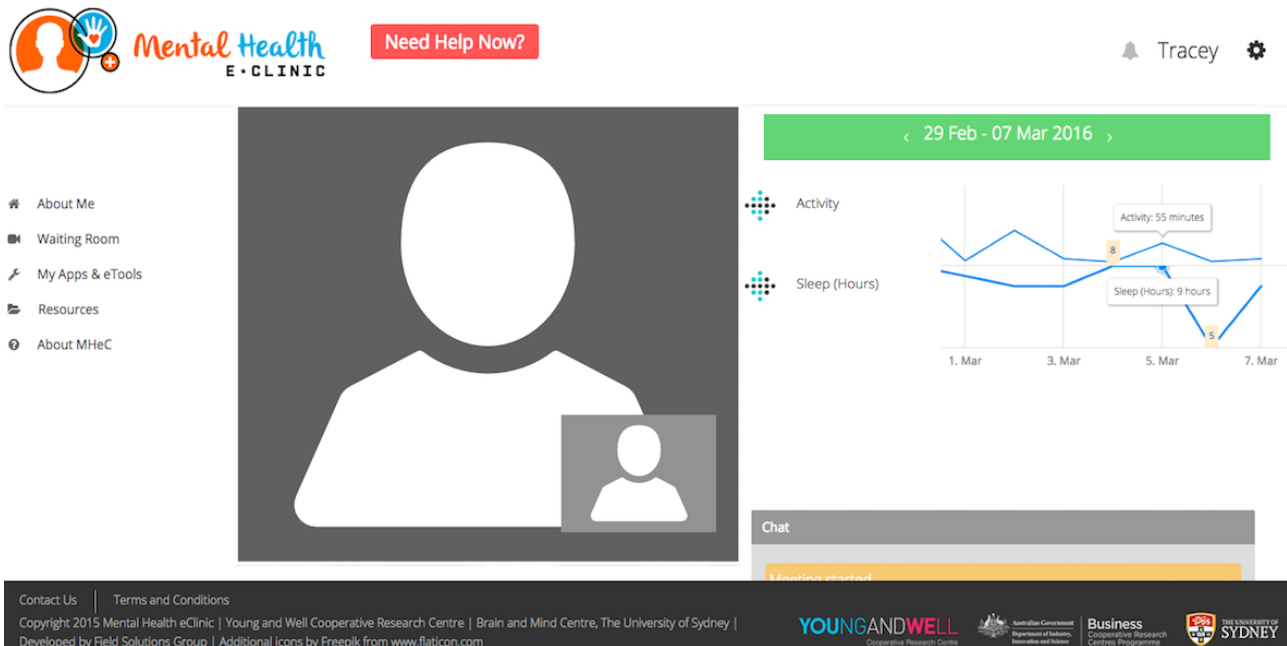


Figure 8. Personalized well-being plan, including recommended apps and etools.

The screenshot displays the 'Mental Health e-Clinic' interface. At the top left is the clinic logo and a 'Need Help Now?' button. A user profile 'laura' is visible in the top right. The main content area features a dropdown menu for 'App Category' with options: '<All>', 'Depression and Anxiety', 'Bipolar disorder', 'Psychosis', 'Alcohol and other drugs', and 'Support for parents'. Below this, a list of recommended apps and eTools is shown:

| App/ETool | Status | Action |
|-----------|---------------|----------|
| Recharge | Not Connected | More ... |
| UBWell | Not Connected | More ... |

The footer contains contact information, terms and conditions, and logos for Young and Well, CSIRO, and Feedback.

Element 2: Online Physical and Mental Health Assessment

Young people said they felt comfortable about completing an online physical and mental health assessment and receiving immediate feedback of their results. The majority also initially reported that they preferred short questionnaires (approximately 15 min in duration). After an explanation was provided, however, about the number and types of questionnaires that would be included to fully assess their physical and mental health (including the range of standardized assessments that are currently being used in *headspace* centers and completed using paper and pencil or iPad) and that a comprehensive assessment would enable a detailed dashboard of results and well-being plan to be generated (including recommended apps and etools), young people understood the need to complete a more comprehensive assessment (up to 1-hour duration). Young people suggested that a pause and “resume later” feature would be helpful with a longer questionnaire to ensure completion. In addition, young people reported that they preferred Likert-scale questions (typically a 5-, 7-, or 9-point agreement scale), two-way close-ended question (no/yes) or multiple-choice questions rather than free-response (“enter text”) questions. The MHeC’s assessment includes medical history, physical health, mental health symptomatology, and health behaviors. For youth health professionals, the questionnaire functionality enables them to write notes or complete/add additional information for relevant questions in relation to their young person’s progress or specific clinical observations (eg, provide a score in the Social and Occupational Functioning Assessment Scale [74] or allocate participants to a clinical stage [47]).

Element 3: Dashboard of Results and Progress

Young people reported that after completing the assessment, immediate feedback about their results was essential. They also reported that knowing this would occur would improve motivation to respond as best as possible and answer all

questions. Young people said they wanted accurate feedback about their results and for this to be represented in a detailed dashboard (“visual concept”), with the option of printing or saving the file as a PDF for their records, or to share with a health professional in the future. Simple bar graphs, colored icons, and traffic light representations were seen as the most acceptable and understandable options for the presentation of results. Line graphs were the preferred option to represent changes over time and to track progress. Young people also suggested the availability of a “customize option” would be useful to enable individuals to select multiple variables of interest to explore if, and how, they influence another. Youth health professionals would have access to a young person’s results and progress as they reported that a dashboard of results would help guide care before and during video and face-to-face visits.

Element 4: Waiting Room, Booking System, and Video Visit System

Young people requested that a booking system be available to make timely appointments with youth health professionals attached to the clinic. Young people also suggested a “waiting room” be included in the MHeC where individuals wait for their video visit to begin. While on this page, young people suggested various activities could be available, for example, breathing exercises or watching selected videos until the video visit icon changes color, signaling their video visit is about to commence. In relation to the youth health professionals’ functionality of this component, they suggested that it would be important to have access to a booking system (“to add or cancel a booking as well as block timeslots”).

Acknowledging cultural preferences, and that some people do not feel comfortable seeing their image (“seeing myself distracts me, I would be looking at myself”), it was suggested by some young people that at the moment of booking an appointment the option of hiding their image should be available. It was also

suggested that in the event of communication cut-offs or a young person wanting to say something sensitive, a chat box would allow a fluid conversation. All participants agreed that the video visit system needs to be embedded in the MHeC as “it would be secure.” As it happens in regular practice, the youth health professionals are in charge of inviting a young person to come to their office; therefore, in the MHeC, the youth health professional has the possibility to start and end the video visit. Importantly, this video visit system includes a “share” functionality, where relevant information can be shared and made visible on a young person’s screen (eg, “explain their dashboard of results during the session”).

Element 5: Personalized Well-Being Plan That Includes Links to Evidence-Based, and Health Professional–Recommended, Apps and Etools

All participants reported that they would like to be provided with a personalized well-being plan (generated from their assessment results) that included tailored automatic recommendations on how to improve their health and well-being. Young people believe that apps and etools targeting their main concerns/issues would be beneficial. However, young people believe that “health professional recommended” and free apps/etools are more likely to be downloaded over apps/etools that have to be purchased or that are not recommended by health professionals. The areas of main interest to young people were apps/etools that help them with their sleep; improve their memory; assist with mood tracking; and help with tracking their progress over time. Ideally, apps and wearable devices should be integrated with the MHeC. Youth health professionals felt confident about the MHeC suggesting apps and etools to young people “only if they are from a reputable source” and had greater confidence in those that had been independently rated using the Mobile App Rating Scale [75]. In terms of functionality, all end users suggested that the MHeC should have a list of apps sorted by categories such as sleep, mood, anxiety, and physical health, among others. Participants suggested that each app should have an Apple Store and Google Play link to facilitate the download process.

User Interface

In relation to the look and feel of the MHeC, young people and youth health professionals agree that the system should be “clean and tidy,” displaying short and concise information and making good use of space. Most of the participants preferred to have icons instead of text and preferred to self-explore the system rather than having lengthy instructions. The use of stereotyped photos with “happy” or “sad people” was highly discouraged by young people. The participants wanted to see videos about how to use the system, but indicated that these should be short (no more than 30 s) and not auto-play due to data download size concerns and privacy issues (eg, a video commencing while sitting in a public space). Soothing colors were preferred for the background and brighter colors for the functionalities, suggesting combinations such as blue and orange for consideration. Young people also suggested the possibility of a “customizing” option to enable users to choose between two to three text types and background color options.

Privacy and Data Sharing

Young males were more concerned about privacy issues than young females. For example, young male participants said “sharing data is OK, but it must say it's confidential” or “I wouldn't share my location with the system.” On the other hand, young female participants said, for example, “I have no privacy concerns specifically if going to a clinician.” All young people, however, said they would share their data as they believe the MHeC would be a professional and trustworthy site and this would enable them “to get most help.” Young people, however, emphasized that they want to be informed about how the data will be handled before giving permission for data sharing and to have the opportunity to withdraw this permission at any time.

Integration With Social Networks

Young people believe that the MHeC should be part of social networks as they would like to be able to share the MHeC in their profile or with a friend through a private message. Moreover, they wanted to be able to like the MHeC or write a comment on it. One of the suggested preferred features of the MHeC was “tips” and for these to be displayed throughout all components of the MHeC. Young people also thought it would be valuable if they were able to share these tips via their social networks.

Usability

Information about the efficiency and effectiveness of the alpha build of the MHeC was obtained during the one-on-one consultation sessions. All participants (n=6) completed usability tasks. All participants found that “creating a MHeC account” and “login” were relatively simple processes. Half of the participants thought that giving the option of login with their social media details (single sign on) was a good idea as it would speed up this process (“super easy”). The other half were against social media login as they were concerned about the MHeC sharing information with their friends (“I don't want my friends seeing this information”). Finding the “need help now” button was a simple task; all participants found it in less than 5 s. Booking an appointment was a straightforward task as well, and participants were able to navigate the MHeC and complete the process almost immediately.

Discussion

Principal Findings

Our study utilized an innovative approach to the development of a Web-based mental health clinic for young people (the MHeC). The PD employed ensured that end users (young people and youth health professionals) had an active and equal involvement in all phases of the design and development process. By engaging these stakeholders, we attempted to respond to end users' expectations about the MHeC and what was achievable in terms of technology and what has been proven to be effective in the mental health field. The use of several design activities (propositions, hand-drawn sketches, and mockups) and the combination of different PD methodologies (workshops and one-on-one consultations with end users, including assessing usability of the online alpha build of the MHeC) enhanced feedback processes and the generation of new

ideas. This combination of research methodologies also accelerated the refinement of the MHeC to achieve the build of the alpha prototype.

In the past decades, the development and use of eHealth solutions in mental health care have expanded; however, these solutions have been developed to address specific problems or to replace different components of the traditional health care system. As an example, the majority of self-triage tools rely on people actively searching for these tools on the Internet; however, some health services provide self-triage tools on their websites, particularly when booking appointments online [26]. Telepsychiatry (videoconferencing), as another example, has also been a particularly effective way of providing support as it allows real-time interaction while negating barriers such as cost, geographical location, and stigma concerns associated with face-to-face support [46]. To the best of our knowledge, our MHeC is one of a kind as it integrates triage, online assessments, online provision of results with easy-to-interpret graphic representations (a dashboard), enables video visits with youth health professionals, provides a personalized well-being plan with immediate interventions, and tracks progress. We believe this is more sophisticated and technologically advanced than traditional telemedicine.

One of the strengths of our system is that it integrates new and emerging technologies with the traditional face-to-face process. Several studies emphasize that screening alone is insufficient for connecting end users with the necessary resources for effective treatment [9,76-78]. Instead, it is argued that online screening should supplement, and be integrated when necessary, with additional support and assessment, which can include face-to-face or online assessments with health professionals within mental health services [9,78]. In line with these recommendations, Internet-based clinical assessments have been implemented and trialed in various Web-based clinics as a means of rapid assessment and referral to appropriate online interventions [79,80] and integrated with face-to-face and online support [20].

Important considerations need to be made in relation to an end user's health literacy as it is argued that Web-based health care communication demands a higher level of health literacy from end users, including the knowledge and skills that enable them to navigate the health system [81]. National datasets report that 60% of Australians have health literacy scores at the lowest two levels of proficiency (scoring 1 or 2), whereas only 6% attain the highest two levels (scoring 4 or 5) [82]. Furthermore, if an end user is experiencing active psychosis or is in crisis, for example, the ability to accurately read or reflect upon information may prove challenging [83,84].

Video visits (as provided in the MHeC with "share" functionality), and face-to-face support provided by health professionals, may provide end users with the support they need to help them navigate the online physical and mental health assessment, dashboard of results, and the health system. These noted challenges highlight the need for health professionals to remain involved in some capacity in the online assessment process, particularly to prevent the unnecessary funneling of end users into the health system.

In 2017, it was estimated 95% of young people in Australia had access to a mobile phone [85,86], making Internet access more widely available to individuals. Mobile phones also provide individuals with higher levels of privacy (compared with shared computers) when participating in a video visit or completing assessments. Consequently, these devices could serve as great facilitators of health care provision, playing a crucial role in health reform.

Implications

In 2014, the Australian Government asked the National Mental Health Commission (NMHC) to review existing mental health services and programs and "...assess the efficiency and effectiveness of programs and services in supporting individuals experiencing mental ill health and their families and other support people to lead a contributing life and to engage productively in the community" [87]. Similar to previous reviews, the NMHC, called for an overhaul of the Australian mental health system, including an integration of e-mental health with face-to-face services. Innovations in the use of technology during the assessment process hold potential as they can go some way to addressing documented youth service capacity issues [84,88].

In alignment with the NMHC's three key components (person-centered design principles; new system architecture; and shifting funding to more efficient and effective "upstream" of services and supports), we envisage that the MHeC will result in a usable system, with high engagement rates, and could finally improve access for all young people requiring assistance across Australia. We see the MHeC as a real-time primary care clinic integrated with current face-to-face services, offering end users at a minimum immediate online clinical assessment; immediate generation of a dashboard of results and personalized well-being plan with tailored interventions; and inbuilt triage and escalation protocols to accurately respond to severe and risky cases. The MHeC offers timely support and interventions through the development of an individual and health professional shared treatment plan. It also provides an opportunity for young people to have a video visit with a health professional despite their current geographical location. Although developed for Australian settings, the MHeC has the potential to be customized for use in developed and developing countries (and especially in those countries where Internet connectivity is high).

Information obtained from this alpha build (more specifically it's screening and triage protocols; online physical and mental health assessment, video visit system; and self-directed mental health support features) are now informing the development and build of the Synergy Online System (Synergy). Synergy is a Web-based modular platform that links integrated and interoperable resources (eg, apps, etools, data sharing, and access to online and in-clinic health services). Synergy operates through existing health providers to promote access to high-quality and cost-effective mental health services. This system does not deliver services or compete with existing service providers; rather, it aims to complement them by linking with other services. In addition, it enables real-time health and social outcomes tracking, thus providing high-quality and personalized service recommendations to the person seeking help. Synergy

has been configured to permit the transfer of individual-level data (allowing for other ethical, consent, governance, and privacy considerations) between it and other existing record systems. The actual capacity to do this in any specific service setting depends on the ways in which existing service systems are configured and governed. Synergy aims to enable Australian mental health service transformation for better outcomes for individual users, their families and supportive others, health professionals, and service providers.

Currently, a series of collaborative research trials are planned to evaluate the use of Synergy across the lifespan. This research is funded by a 3-year agreement (2017-20) between the Australian Government Department of Health and InnoWell Pty Ltd (a joint venture between The University of Sydney and PricewaterhouseCoopers) to the value of Aus \$30 M. Results from this research will be reported separately.

Limitations

Our sample size in Phase 3 (one-on-one consultation with end users) was in the lower range of the average numbers for this type of study (between 6 and 12 participants) [89]. However, our sample size still enabled us to collect sufficient information for analysis in the framework and reach a saturation point. Further research is needed to understand the acceptability and usability of the system, as well as to validate all the components in real-world settings.

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Conflicts of Interest

LOP, TAD, CSR, and ACM have no conflicts of interest to declare. EMS is the Medical Director of the Young Adult Mental Health Unit, St Vincent's Hospital, Darlinghurst; Discipline Leader of Adult Mental Health, School of Medicine, University of Notre Dame; Research Affiliate, The University of Sydney; and Consultant Psychiatrist. She has received honoraria for educational seminars related to the clinical management of depressive disorders supported by Servier and Eli-Lilly pharmaceuticals. She has participated in a national advisory board for the antidepressant compound Pristiq, manufactured by Pfizer. She was the National Coordinator of an antidepressant trial sponsored by Servier. IBH has been a Mental Health Commissioner at the National Mental Health Commission since 2012. He is the Co-Director, Health and Policy at the Brain and Mind Centre (BMC), University of Sydney. The BMC operates an early-intervention youth service at Camperdown under contract to *headspace*. IBH has previously led community-based and pharmaceutical industry-supported (Wyeth, Eli Lilly, Servier, Pfizer, AstraZeneca) projects focused on the identification and better management of anxiety and depression. He is a member of the Medical Advisory Panel for Medibank Private, a Board Member of Psychosis Australia Trust, and a member of the Department of Veterans' Affairs Veterans Mental Health Clinical Reference Group. He is the Chief Scientific Advisor to, and an equity shareholder in, Innowell Pty Ltd. Innowell has been formed by The University of Sydney and PricewaterhouseCoopers (PwC) to deliver the Aus \$30 M Australian Government-funded "Project Synergy." Project Synergy is a 3-year program for the transformation of mental health services through the use of innovative technologies.

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Abbreviations

- KT:** knowledge translation
- MHeC:** Mental Health eClinic
- NMHC:** National Mental Health Commission
- PD:** participatory design
- R&D:** research and development

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Chapter 3: Real World Trialling the MHeC: Assessing Clinical Stage in Early Intervention Youth Mental Health Services Using MHeC

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Original Paper

Using New and Innovative Technologies to Assess Clinical Stage in Early Intervention Youth Mental Health Services: Evaluation Study

Laura Ospina-Pinillos¹, MD; Tracey Davenport¹, BA (Hons), EMBA; Frank Iorfino¹, BSc (Psych), MBMSc; Ashleigh Tickell¹, BSc (Psych); Shane Cross¹, BPsych (Hons), MPsych (Clin), PhD; Elizabeth M Scott², MBBS, FRANZCP; Ian B Hickie¹, MD, FRANZCP

¹Brain and Mind Centre, The University of Sydney, Sydney, Australia

²University of Notre Dame Australia, Sydney, Australia

Corresponding Author:

Laura Ospina-Pinillos, MD

Brain and Mind Centre

The University of Sydney

Shops 1-3, 66-70 Parramatta Road

Camperdown

Sydney,

Australia

Phone: 61 028 627 6946

Email: laura.ospinapinillos@sydney.edu.au

Abstract

Background: Globally there is increasing recognition that new strategies are required to reduce disability due to common mental health problems. As 75% of mental health and substance use disorders emerge during the teenage or early adulthood years, these strategies need to be readily accessible to young people. When considering how to provide such services at scale, new and innovative technologies show promise in augmenting traditional clinic-based services.

Objective: The aim of this study was to test new and innovative technologies to assess clinical stage in early intervention youth mental health services using a prototypic online system known as the Mental Health eClinic (MHeC).

Methods: The online assessment within the MHeC was compared directly against traditional clinician assessment within 2 Sydney-based youth-specific mental health services (*headspace* Camperdown and *headspace* Campbelltown). A total of 204 young people were recruited to the study. Eligible participants completed both face-to-face and online assessments, which were randomly allocated and counterbalanced at a 1-to-3 ratio. These assessments were (1) a traditional 45- to 60-minute *headspace* face-to-face assessment performed by a Youth Access Clinician and (2) an approximate 60-minute online assessment (including a self-report Web-based survey, immediate dashboard of results, and a video visit with a clinician). All assessments were completed within a 2-week timeframe from initial presentation.

Results: Of the 72 participants who completed the study, 71% (51/72) were female and the mean age was 20.4 years (aged 16 to 25 years); 68% (49/72) of participants were recruited from *headspace* Camperdown and the remaining 32% (23/72) from *headspace* Campbelltown. Interrater agreement of participants' stage, as determined after face-to-face assessment or online assessment, demonstrated fair agreement ($\kappa=.39$, $P<.001$) with concordance in 68% of cases (49/72). Among the discordant cases, those who were allocated to a higher stage by online raters were more likely to report a past history of mental health disorders ($P=.001$), previous suicide planning ($P=.002$), and current cannabis misuse ($P=.03$) compared to those allocated to a lower stage.

Conclusions: The MHeC presents a new and innovative method for determining key clinical service parameters. It has the potential to be adapted to varied settings in which young people are connected with traditional clinical services and assist in providing the right care at the right time.

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KEYWORDS

staging model; mental health; primary health care; telemedicine; symptom assessment health service reform

Introduction

Globally, there is increasing recognition that new strategies are required to reduce disability due to common mental health problems such as anxiety, depression, and comorbid substance misuse. As public awareness increases, the demand for mental health care far outstrips the capacity of health systems to provide access to quality care [1]. To achieve a meaningful reduction in population-level burden of disease, there is a need to provide both prevention and early intervention strategies at scale. As 75% of mental health and substance use disorders emerge during the teenage or early adulthood years [2], these strategies need to be readily accessible to young people. In most countries, however, young people are less likely to receive effective mental health care as a consequence of financial, attitudinal, and health system literacy factors [3,4].

For young people, there is typically still a prolonged delay between the onset of first symptoms and initial treatment contact [5]. By the time most young people present to health services, they already have significant functional impairment, are psychologically distressed, or have some degree of established comorbidity [6]. For these young people, the current psychiatric classification systems remain limited [7] and, as interventions are often guided by diagnosis, young people experiencing subthreshold symptomatology do not always receive appropriate care [8].

When considering how to provide such services at scale, eHealth (electronic health is a relatively recent health care practice that is supported by internet and/or other technologies) [9] and more recently mHealth (mobile health is the use of mobile and wireless technologies to enhance health) [10] and uHealth (ubiquitous health is information technology combined with medical technology to support health) [11] technologies show promise in augmenting traditional services and can be adapted potentially to all aspects of care [12]. A consistent theme is that such technologies can also address poor youth engagement with mental health services [13]. In these services, for example, innovations in the use of such technologies that allow the assessment process to be brought online could improve current wait times and provide a wider reach for young people who physically (or emotionally) struggle to access face-to-face clinical care [14].

While there are concerns about potential lack of accountability in the mHealth field and that online communications could miss nonverbal cues that can ultimately impact empathy and patient

satisfaction [15], it is also evident that Web-based programs can facilitate disclosure [16] and such online interventions are as effective and even more efficient than traditional interventions in mental health [17,18]. Furthermore, evidence shows that telepsychiatry is as accurate as in-person psychiatry, and online users experience the same degree of satisfaction as face-to-face users [19].

Imported from general medicine, the concept and application of clinical staging to mental health disorders seeks to redefine traditional diagnostic systems by placing individuals on a spectrum from early identification of nonspecific or mixed forms of mental symptoms through to more discrete disorders and then recurrent and persistent forms of illness [20]. Transdiagnostic staging models have been employed in youth mental health settings and have demonstrated utility [8,21] (Textbox 1). To date, research among youth-focused primary mental health care services has shown that 33% to 41% of young people presenting to early intervention youth mental health services are assigned to stage 1a, 38% to 40% to stage 1b, 11% to 14% to stage 2 and 7% to 8% to stages 3 and 4 [8].

As the staging framework recognizes the continuum of illness progression, it also encourages more personalized and responsive care at each point of the spectrum [20]. This framework supports the promotion of self-help and encourages easier navigation for stepping up through the mental health system [22]. Stepped (or clinically staged) care aims to provide evidence-based, less intensive, low-risk, and low-cost interventions to the less severe cases while prioritizing more intensive or prolonged interventions for more complex cases [7,23-26].

The process for determining stages has been outlined previously by Cross and colleagues [8]. To briefly summarize the procedure, allocation of an individual to a particular stage is undertaken at regular multidisciplinary clinical consensus meetings involving senior mental health professionals (consultant psychiatrists or senior clinical psychologists) aided by objective symptom and functional measures (including paper and pencil questionnaires and surveys administered by tablets) and cross-referencing the staging framework set out by Hickie and colleagues [7]. Converting these methodologies to an online assessment (including a self-report Web-based survey, an immediate dashboard of results, and a video visit with a clinician) has the genuine potential to increase engagement with young people for many reasons. First, the internet is so widely used it is now the preferred mode of communication for youth [27,28].

Textbox 1. Clinical staging model for mental health disorders.

- Stage 0 : no symptoms; person at risk of disorder
- Stage 1a: help-seeking; person with mild symptoms and mild functional impacts
- Stage 1b: attenuated syndrome; person with mixed or ambiguous symptoms and moderate to severe functional impacts
- Stage 2 : discrete disorders such as clear episodes of psychotic, manic, or severe depressive disorders
- Stage 3 : recurrent or persistent disorder
- Stage 4 : severe, persistent, and unremitting illness

Second, the assessment offers the possibility of immediate recommendations, support, and interventions anytime, anywhere, through a personalized dashboard of results (an easy-to-read clinical report with infographics) upon completion of the online assessment. Third, the assessment breaks down traditional geographical and socioeconomic barriers by increasing access to any care but specifically to more specialized assessment.

The aim of this study was to test new and innovative technologies to assess clinical stage in youth-specific mental health services using a prototypic online system known as the Mental Health eClinic (MHeC) [29]. Specifically, we tested how online assessments compared with traditional face-to-face assessments in a cohort of young people seeking mental health care. We report how online assessments perform in identifying key features such as stage allocation, lifetime trajectories, and recognition of comorbidities while also managing risk (suicidality) and responding to the more complex cases. The study compares the online assessment within the MHeC (including a self-report Web-based survey, an immediate dashboard of results, and video visit with a clinician) to standard face-to-face assessment as provided through 2 Sydney-based *headspace* services.

Methods

Participants

Participants were recruited from 2 youth-specific mental health services (*headspace* Camperdown and *headspace* Campbelltown) located in inner and outer metropolitan Sydney, Australia, respectively. *headspace* services are specialized, primary care early intervention mental health services for young people aged 12 to 25 years [30]. They provide services such as care coordination and support by allied health professionals; general medical services by general practitioners (primary care physicians); more specialized mental health services delivered by clinical psychologists and psychiatrists; and education, employment, and other social supports delivered by colocated specialist services. A key aspect of *headspace* is the direct connection and ease of access to secondary care specialists such as early psychosis services.

Within these *headspace* services, all young people who met inclusion criteria between the period of July 2015 to August 2016 were invited to participate in the study. Inclusion criteria included young people who (1) were aged 16 to 25 years, (2) were newly registered with *headspace*, (3) had regular access to the internet, and (4) had regular access to a webcam. Young

people were reimbursed (voucher equivalent to Aus \$20 [US \$15]) for their participation.

Ethics

The University of Sydney's Human Research Ethics Committee approved the study (protocol number 2014/689). All participants were provided with information about the study prior to participating and consenting. Parental consent was also obtained for participants aged 16 and 17 years.

Procedure

In order to test the online assessment within the MHeC, all eligible participants were invited to complete both the online assessment and standard assessment in face-to-face services. Participants were randomly allocated and counterbalanced by a 1-to-3 ratio to either undertake the face-to-face assessment or online assessment first. Considering the online assessment was a new method of assessment, an unequal randomization was preferred in order to minimize the impact of learning effects [31]. A condition of the study was that both assessments had to be completed within a 2-week timeframe from the first evaluation (the maximum interval of time in which symptomatology would not considerably differ between assessments).

The face-to-face assessment included completion of the *headspace* National Minimum Dataset (a very brief, 5- to 7-minute demographic and service activity questionnaire; data from this tool was not analyzed in this study) as collected through a survey administered via a tablet (smart skip rules are not available) upon entry to the service and then a 45- to 60-minute face-to-face psychosocial assessment with a Youth Access Clinician that is an adaptation of the HEEADSSS (Home, Education and Employment, Eating, Activities, Drugs and Alcohol, Sexuality, Suicide and Depression, Safety) [32] semistructured interview for *headspace*. This interview collects narrative information by assessing the young person's home and environment and then progressively moves through the domains of education and/or employment, activities, drugs and alcohol, relationships and sexuality, conduct difficulties and risk taking, anxiety, eating, depression and suicide, and psychosis and mania [33-34] (Textbox 2).

The online assessment was based on the staging model as developed and adapted for early intervention youth mental health services. This assessment included 3 components (Textbox 3): a self-report Web-based survey, an immediate dashboard of results, and a video visit with a clinician. The self-report Web-based survey of the MHeC was designed and developed by our clinical research team to collect both demographic and

clinical data. It is specifically ordered to reflect a best practice clinical interview [35] and includes 10 modules. Participants complete general questions about their demographics and medical history followed by questions assessing their current physical and mental health status. Questions are guided by smart skip rules that enable the self-report Web-based survey to be personally tailored to each young person (eg, if screening

questions are positive, a more in-depth assessment will be triggered) and takes the minimum time to complete for each individual based on how they respond. Sensitive items (eg, suicidality and self-harm behaviors) are only asked once trust in the system has been generated and the young person is familiarized with the module's topic and type of questions (ie, when rapport has been established).

Textbox 2. Face-to-face assessment.

- *headspace* psychosocial assessment
 - Domain 1: home and environment
 - Domain 2: education and/or employment
 - Domain 3: activities
 - Domain 4: drugs and alcohol
 - Domain 5: relationships and sexuality
 - Domain 6: conduct difficulties and risk-taking
 - Domain 7: anxiety
 - Domain 8: eating
 - Domain 9: depression and suicide
 - Domain 10: psychosis and mania
- Face-to-face consultation with a clinician

Textbox 3. Online assessment.

- Self-report Web-based survey
 - Module 1: collects demographic information
 - Module 2: assesses medical history
 - Module 3: screens for prevalent mental health conditions [36]
 - Module 4:
 - Screens for hypomanic symptoms (items derived from the Altman Self-Rating Mania Scale [37])
 - Screens for psychotic symptoms (items derived from the Community Assessment of Psychotic Experiences Positive Symptoms Scale [38])
 - Measures psychological distress with the 10-item Kessler Psychological Distress Scale [39]
 - Measures somatic distress with the Somatic and Psychological Health Report [40]
 - Module 5: Assesses self-harm behaviors and suicidality using the Suicidal Ideation Attributes Scale [41]
 - Module 6: Assesses tobacco, alcohol and substance use—items derived from the Alcohol Use Disorders Identification Test [42], the Alcohol, Smoking and Substance Involvement Screening Test [43], the Drinking Motives Measure [44], the Fagerstrom Nicotine Dependence Test [45], and select items from the National Household Drug Survey [46]
 - Module 7: Measures physical activity using the International Physical Activity Questionnaire [47]
 - Module 8: Assesses sleep behaviors using 4 sleep-related items from the Quick Inventory of Depressive Symptomatology [48]
 - Module 9: Assesses eating behaviors with items derived from the Eating Disorder Examination [49]
 - Module 10: Measures social connectedness—items derived from the Perceived Social Support/Conflict Measure [50] plus 5 items measuring relationship with peers [51]
- Immediate dashboard of results
- Video visit with a clinician

The video visit of the online assessment included a brief, semistructured interview ([Multimedia Appendix 1](#)) with clinicians (LOP, a psychiatrist and mental health researcher, and AT, a research psychologist) trained in the application of clinical staging [7] for young people presenting to *headspace* service. Importantly, the video visit was guided by the automatically generated results of the self-report Web-based survey as shown in the dashboard of results.

At the conclusion of each face-to-face session and video visit, all clinicians determined stage. These results were then collapsed into 2 groups: stage 1a or stage 1b and above (stage 1b+). Participants in stage 1a were help-seeking with mild symptoms and mild functional impairment while those in stage 1b+ were experiencing more severe symptoms and functional impairment. This key differentiation is predictive of clinical course and can be used to allocate service resources preferentially to those in greater need. Clinicians also completed the Social and Occupational Functioning Assessment Scale (SOFAS), which measures an individual's functional status not directly related to the severity of their psychological symptoms [52], and the Clinical Global Impression Scale-Severity (CGI-S), a 7-point illness severity scale subjective to clinician's past experience with other individuals with the same illness [53].

Interrater Agreement Between the Online Clinicians

In order to validate online assessment and staging classification, 2 trained clinicians (LOP and AT) were present during all video visits until such time their interrater agreement was considered reliable; that is, LOP (rater A) and AT (rater B) conducted alternating video visits while the other was present but not in view of the webcam (as per ethics approval and consent obtained from the young person). Raters A and B then determined stage independently, and once substantial concordance was sufficiently reached, LOP and AT conducted any remaining video visits with or without the other present.

Statistical Analyses

All statistical analyses were performed using SPSS Statistics for Mac 22.0 (IBM Corp). Group differences in demographic, functional, and clinical variables were assessed using nonparametric Kruskal–Wallis test (H) or chi-square test (χ^2) at a 95% level of confidence (when the expected count was less than 5, a Fisher exact test [FET] was employed). Medians were reported due to sample size. Post hoc analyses (Mann–Whitney test [U], χ^2 , or FET) were performed in variables that showed significant differences between groups, using Bonferroni correction and adjusted alphas dependent on number of groups ($n=3$). P values less than .01 considered to be significant.

Interrater analyses determined degree of agreement of staging results between face-to-face and online clinicians as well as the 2 individual online clinicians (ie, rater A vs rater B). Cohen kappa statistic [54] was calculated and followed the interpretation criteria of Viera et al [55]: kappa=.01 to .20, slight agreement; kappa=.21 to .40, fair agreement; kappa=.41 to .60, moderate agreement; kappa=.61 to .80, substantial agreement; and kappa=.81 to .99, almost perfect agreement. For the continuous variables (SOFAS and CGI-S), the intraclass correlation coefficient (ICC) was used to calculate agreement

between offline and online clinicians [56], and interpretations were based on a 95% confidence interval where estimates less than .50 reflect poor agreement; ICC=.50 to .75, moderate agreement; ICC=.75 to .90, good agreement; and greater than .90, excellent agreement [57].

Results

Recruitment and Participation

A total of 204 young people were identified as eligible to participate in the study. Based on a 1-to-3 random allocation counterbalancing ratio, 54 participants were invited to undertake standard face-to-face assessment first and 150 participants were invited to undertake the online assessment first; 125 participants were from *headspace* Camperdown and 79 from *headspace* Campbelltown. All were aged 16 to 25 years, and 71.6% (146/204) were female.

As shown in [Multimedia Appendix 2](#), a total of 24% (13/54) of participants allocated to receive standard face-to-face assessment first completed both assessments, 46% (25/54) completed the standard face-to-face clinical assessment only, 19% (10/54) failed to complete either assessment, and the remainder withdrew from the study or were lost to follow-up. Conversely, 39.3% (59/150) of participants allocated to complete the online assessment first completed both assessments, 5.3% (8/150) completed the online assessment only, 49.3% (74/150) failed to complete either assessment, and the remainder withdrew from the study or were lost to follow-up. Overall, 72 participants completed the entire study protocol of which 68% (49/72) were recruited from *headspace* Camperdown and the remainder (23/72, 32%) from *headspace* Campbelltown. The average time to completion of the online assessment was 60 minutes including approximately 45 minutes (median 51 minutes) for the self-report Web-based survey and approximately 12 minutes (median 15 minutes) for the video visit.

Sample Characteristics

The mean age of all participants was 20.35 (SD 2.63, range 16 to 25) years, 71% (51/72) were female, and 51% (37/72) had completed or partially completed tertiary education. Participants reported moderate distress levels (10-item Kessler Psychological Distress Scale mean 28.93, SD 8.42, range 10 to 50) with almost three-quarters (53/72, 74%) of the sample currently experiencing anxious and/or depressive symptoms. Nearly one-third (21/72, 29%) of participants screened positive for hypomanic symptoms, and one-third (24/72, 33%) screened positive for psychotic-like symptoms.

Almost half (35/72, 49%) of participants reported self-harm. Using our digitally smart Suicidality Escalation Protocol [58], the online assessment was able to detect and triage young people at risk in real time. In total, 18% (13/72) of participants reported high suicidality (Suicidal Ideation Attributes Scale [SIDAS] score $\geq 21/50$), of which more than half (7/13, 54%) were escalated by the online clinicians to one of the *headspace* services as they considered current wait times for face-to-face care too long.

Interrater Agreement Between Online Clinicians

In order to validate the online assessment and staging classification, the trained clinicians were both present in 14 video visits until agreement was measured as substantial ($\kappa=.76$, $P=.003$) with concordance at 93% (13/14). All subsequent video visits were assessed by the raters according to their availability. The online interrater agreement was determined for 59% (48/82) of participants who completed the online assessment (self-report Web-based survey, immediate

dashboard of results, and video visit with a clinician). As shown in [Table 1](#), participants were entered into a 2-by-2 comparison of stage assigned (stage 1a vs stage 1b+) and type of online rater who assigned that stage: online rater A and online rater B. Overall agreement between online raters was measured as substantial ($\kappa=.77$, $P<.001$) with concordance at 90% (43/48) upon completion of all online assessments; 82% (14/17) were classified by both online raters as stage 1a and 94% (29/31) as stage 1b+.

Table 1. Interrater agreement between online rater A and online rater B by assignment of clinical stage.

| Online rater B | Online rater A | |
|-------------------------|------------------------|-------------------------|
| | Stage 1a (n=16), n (%) | Stage 1b+ (n=32), n (%) |
| Stage 1a (n=17), n (%) | 14 (29) | 3 (6) |
| Stage 1b+ (n=31), n (%) | 2 (4) | 29 (61) |

Table 2. Interrater agreement between face-to-face and online clinicians by allocation to clinical stage.

| Face-to-face clinical assessment | Online assessment | |
|----------------------------------|------------------------|-------------------------|
| | Stage 1a (n=27), n (%) | Stage 1b+ (n=45), n (%) |
| Stage 1a (n=42), n (%) | 23 (32) | 19 (26) |
| Stage 1b+ (n=30), n (%) | 4 (6) | 26 (36) |

Face-to-Face Versus Online interrater Agreement

To calculate interrater agreement for assigning stage, participants were entered into a 2-by-2 comparison of stage assigned (stage 1a vs stage 1b+) and type of clinician who assigned that stage: face-to-face clinician versus online clinician ([Table 2](#)). Interrater agreement of stage between face-to-face and online clinicians demonstrated fair agreement ($\kappa=.39$, $P<.001$), with concordance in 68% (49/72) of participants; here, clinicians identified 55% (23/42) stage 1a (agree) (staged as stage 1a by online and face-to-face clinicians) and 87% (26/30) stage 1b+ (agree) (staged as stage 1b by online and face-to-face clinicians). Of note, 1 participant was assigned stage 2 following face-to-face clinical care, and 3 participants were assigned stage 2 following the online assessment. In this study, no participants were assigned to the more severe stages (ie, stages 3 or 4). There was moderate interrater reliability in the SOFAS score between face-to-face and online clinicians ($ICC=.73$) and poor interrater reliability in the CGI-S allocation ($ICC=.49$) for all participants.

Comparison of Self-Reported Measures Where There Was a Disagreement Between Face-to-Face Clinical Assessment and Online Assessment

[Table 3](#) shows the main self-reported clinical characteristics across the 3 groups: stage 1a (agree); stage 1b+ (agree); and stage 1b+ (disagree). Stage 1b+ (disagree) refers to participants who were staged 1b+ by online clinicians but assessed as stage 1a by face-to-face clinicians.

Stage 1a (Agree) Versus Stage 1b+ (Disagree)

Comparing stage 1b+ (disagree) with those participants determined as stage 1a (agree) by both clinician types, post hoc analyses showed that almost all young people in stage 1b+ (disagree) reported a previous history of mental health problems

($\chi^2_1=10.71$, $P=.001$), and more than a third (7/19, 37%) reported they had a history of developing a suicide plan ($P=.002$; FET). With regard to current symptomatology, there were no significant differences in psychological distress or suicidal ideation. However, weekly cannabis use was higher in stage 1b+ (disagree) ($P=.03$; FET). Although both groups' SOFAS ([Table 4](#)) scores were located within the same range (71 to 80: no more than a slight impairment in social, occupational, or school functioning), participants allocated to stage 1b+ (disagree) were consistently scored with lower levels of functioning ($U=117$, $z=-2.58$, $P=.01$) compared to those in stage 1a (agree).

There was also a major discrepancy between the face-to-face and the online clinicians in categorizing the symptom severity for the participants allocated to stage 1b+ (disagree) group; face-to-face clinicians considered this group as normal (not at all ill) whereas online clinicians assigned a mildly ill classification. Among the online observations, the symptomatology of this group was considered to be significantly more pronounced compared to the stage 1a (agree) participants (CGI-S median rating of borderline ill; $U=68$, $z=-4.08$, $P<.001$).

Stage 1b+ (Agree) Versus Stage 1b+ (Disagree)

When comparing stage 1b+ (disagree) with those in stage 1b+ (agree), post hoc analysis showed that participants assessed as stage 1b+ (agree) had significantly higher levels of suicidal ideation on the SIDAS ($U=133.50$, $z=-2.64$, $P=.008$) and lifetime self-harm behavior ($\chi^2_1=7.35$, $P=.007$). According to online clinicians ([Table 4](#)), young people allocated to stage 1b+ (agree) had lower functioning levels on the SOFAS when compared with the stage 1b+ (disagree) group ($U=121$, $z=-2.93$, $P=.003$). However, the stage 1b+ (agree) group was classified by both assessment modes as more unwell on the CGI-S when

compared with the stage 1b+ (disagree) group (face-to-face clinical care, $U=55.5$, $z=-4.54$, $P<.001$; online assessment, $U=149$, $z=-2.48$, $P=.01$). Previous mental health history, distress levels, alcohol and/or other substance use disorders, or comorbidities did not differ between these groups.

Post hoc analysis with stage 1a (disagree) (stage 1a by online clinicians but assessed as stage 1b+ by face-to-face clinicians) participants was not conducted due to insufficient cell size.

Table 3. Median scores and significance test results for self-reported variables among groups.

| Characteristics | Stage 1a (agree) ^a (n=23), n (%) | Stage 1b+ (agree) ^b (n=26), n (%) | Stage 1b+ (disagree) ^c (n=19), n (%) | Significance test H^d or FET ^e (P) | Post hoc P values | |
|--|--|---|--|--|-------------------|--------|
| | | | | | a vs c | b vs c |
| Demographics | | | | | | |
| Female, n (%) | 15 (65) | 18 (69) | 14 (74) | 1.70 ^e (.72) | — ^f | — |
| Age in years, median (IQR) ^g | 20.00 (4) | 20.50 (4) | 21.00 (4) | 0.78 ^d (.86) | — | — |
| Education | | | | 1.58 ^e (.71) | | |
| Secondary, n (%) | 12 (52) | 14 (54) | 8 (42) | — | — | — |
| Tertiary, n (%) | 11 (48) | 12 (46) | 11 (58) | — | — | — |
| Clinical characteristics | | | | | | |
| K-10 ^h , median (IQR) | 25 (13) | 32.0 (9) | 28.0 (13) | 5.51 ^d (.14) | — | — |
| Depression/anxiety (current), n (%) | 16 (70) | 22 (85) | 14 (74) | 6.03 ^e (.09) | — | — |
| Hypomanic-like issue (current), n (%) | 5 (22) | 10 (38) | 6 (32) | 2.91 ^e (.38) | — | — |
| Psychotic-like issue (current), n (%) | 5 (22) | 12 (46) | 7 (37) | 4.92 ^e (.15) | — | — |
| Mental health history, n (%) | 11 (48) | 20 (77) | 18 (95) | 11.83 ^e (.005) | .001 | .21 |
| Lifetime self-harm, n (%) | 7 (30) | 20 (77) | 7 (37) | 13.28 ^e (.003) | .67 | .007 |
| Suicidality | | | | | | |
| SIDAS ⁱ , median (IQR) | 1 (4) | 9.5 (24) | 1 (5) | 12.59 ^d (.006) | .71 | .008 |
| Suicide planning history, n (%) | 0 (0) | 12 (46) | 7 (37) | 17.75 ^e (<.001) | .002 | .53 |
| Suicide attempt history, n (%) | 0 (0) | 6 (23) | 1 (5) | 6.98 ^e (.04) | .45 | .21 |
| Alcohol and/or other substance misuse | | | | | | |
| Lifetime substance misuse, n (%) | 17 (74) | 18 (69) | 14 (74) | 0.36 ^e (.98) | — | — |
| Cannabis weekly, n (%) | 1 (4) | 8 (31) | 6 (32) | 7.60 ^e (.04) | .03 | .95 |
| Substances to cope with emotions, n (%) | 6 (26) | 18 (69) | 8 (42) | 10.85 ^e (.009) | .24 | .07 |

^aStage 1a by online and face-to-face clinicians.

^bStage 1b+ by online and face-to-face clinicians.

^cStage 1b+ by online clinicians but assessed as Stage 1a by face-to-face clinicians.

^dKruskal–Wallis test, 2-tailed.

^eFET: Fisher exact test, 2-tailed.

^fNot applicable.

^gIQR: Interquartile range.

^hK-10: 10-item Kessler Psychological Distress Scale.

ⁱSIDAS: Suicidal Ideation Attributes Scale.

Table 4. Median scores and significance test results for clinician-reported variables among groups.

| Tests | Stage 1a (agree) ^a (n=23), n (%) | Stage 1b+ (agree) ^b (n=26), n (%) | Stage 1b+ (disagree) ^c (n=19), n (%) | Significance test <i>H</i> ^d (<i>P</i>) | Post hoc <i>P</i> values | |
|---|--|---|--|---|--------------------------|--------|
| | | | | | a vs c | b vs c |
| CGI-S^e | | | | | | |
| Face-to-face, median (IQR) ^f | 2.0 (1) | 3.0 (2) | 1.0 (1) | 37.04 (<.001) | .83 | <.001 |
| Online, median (IQR) | 2.0 (1) | 4.0 (1) | 3.0 (1) | 35.29 (<.001) | <.001 | .01 |
| SOFAS^g | | | | | | |
| Face-to-face, median (IQR) | 75.0 (9) | 69.0 (15) | 75.0 (5) | 12.17 (.007) | .10 | .08 |
| Online, median (IQR) | 75.0 (9) | 60.0 (10) | 71.0 (10) | 25.33 (<.001) | .01 | .003 |

^aStage 1a by online and face-to-face clinicians.

^bStage 1b+ by online and face-to-face clinicians.

^cStage 1b+ by online clinicians but assessed as stage 1a by face-to-face clinicians.

^dKruskal–Wallis test, 2-tailed.

^eCGI-S: Clinical Global Impression Scale–Severity.

^fIQR: Interquartile range.

^gSOFAS: Social and Occupational Functioning Assessment Scale.

Discussion

Principal Findings

The MHeC presents a new and innovative method for determining key clinical service parameters. While there was fair agreement between the staging classifications after both online and face-to-face assessment in the majority of cases (68%, kappa=.39), an important area of difference did emerge. During face-to-face assessments, clinicians tended to rate stage more conservatively compared to clinicians acting with the assistance of the MHeC.

Among the discordant cases, in 26% of cases face-to-face assessment appeared to place less emphasis on lifetime history of mental health problems. By contrast, the online assessment placed greater focus on past history of mental health problems ($P=.001$), as well as any previous suicide planning ($P=.002$) and current comorbidity with cannabis misuse ($P=.03$) as indicators of progression of disease. It appears the online assessment process was a more efficient way of detecting lifetime severity by holistically evaluating these young participants' current and previous mental health status.

There are a range of possible explanations for this important difference between the face-to-face and online assessments, including (1) face-to-face assessment places greater emphasis on current symptomatology, (2) online clinicians made specific use of more extensive data collection about past as well as current symptomatology that was collected prior to the video visit (and as a consequence, their clinical assessment used all available data relevant to assign stage), and/or (3) face-to-face clinicians may be more influenced by the consequences of their clinical assessment for allocating service resources—that is, higher stage ratings are reserved preferentially for those who are perceived to be in need of more intensive or prolonged care.

Assessing the mental health of young people and their need for immediate or ongoing health care is a real challenge for clinicians and youth mental health services. Specifically, this

includes being able to distinguish normative emotional development and brief stress-related responses from emerging mental disorders [59,60] as well as obtaining accurate information from young people who may be apprehensive or hostile toward their clinician. Further, building rapport can take longer in this population [61], and clinician training is often based on the recognition of symptomatology leading to specific diagnostic (eg, *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition*, or *International Classification of Diseases and Related Health Problems, 10th Revision*) constructs [62]. However, such categories do not accurately represent the most common admixtures of symptoms in young people presenting for mental health care. Clinicians working with the staging model are using a framework that proposes that once a person has reached a defined stage, it is not possible to return to an earlier stage, and as mental disorders are typically cyclical, complexity lies in understanding the variability of presentations over time. Therefore, clinicians would greatly benefit from accurate methods of collecting relevant staging information. The *headspace* psychosocial assessment used in practice predominantly focuses on the current symptomatology of young people and, as a result, misses relevant lifetime information that is crucial for staging.

By entering information online, young people can complete a self-report Web-based survey in their own time whenever and wherever they prefer. This provides greater choice at the forefront of mental health care by directly and immediately responding to young people's needs [29]. For clinicians, this provides reliable information about the individual (current and lifetime) prior to a face-to-face assessment that can be used for staging, enabling clinicians to move away from traditional evaluations to more detailed data-driven assessments. This could translate into a more efficient way of assessment and improve the 1-on-1 time (face-to-face or video visit), enabling clinicians to expand and refine the information collected and deliver interventions that match a young person's unique needs. Over time this online assessment process could be augmented by

continuous data tracking and more detailed online assessments to help clinicians recognize patterns of symptoms in the data. Additionally, future systems could develop more complex algorithms through big data analyses and machine learning processes that can better inform young people, clinicians, and services.

As community-based and outpatient mental health care is limited, all services struggle with high demand pressures [63]. Consequently, users face long waiting lists that may have an adverse impact on their engagement with the service and ultimately increase the risk of hospitalizations, functional deterioration, self-harm, or suicidal behavior [64]. Additionally, clinicians and services face substantial demands to reduce waiting times while providing appropriate clinical care. Typically, service systems respond by prioritizing assessment, limiting the number of intervention sessions available and giving priority to more urgent cases [65]. We suggest that the difference in staging by face-to-face clinicians might also be contributed to by their practical awareness of such service constraints.

A systematic clinician bias toward underrating young people to stage 1a could have deleterious effects on service users. Our previous research has shown that 15% of people in stage 1b transition to stage 2 within 1 year [7], people in stage 1a receive different, shorter, and less intensive treatment compared with those in stage 1b [21], and young people in stage 1b tend to remain impaired and distressed over time [21]. The presence of past mental health and suicidal thoughts and/or behaviors indicates that this group of young people require a more personalized treatment that not only covers their current needs but responds appropriately to the higher stage they have reached over the course of their illness. An online assessment like the one proposed in the MHeC could assist to immediately identify young people who might benefit from seeing a more experienced clinician as soon as they enter a service for care. Consequently, such online assessment has the potential of transforming youth mental health services as it streamlines internal processes such as triage and evaluation, increases clinician capacity by providing immediate results, and matches the right clinician and intervention to the young person's needs, thus ensuring the right care is provided at the right time.

Finally, one of the most obvious advantages of the online assessment addresses geographical barriers. In this trial, 10% (8/82) of the video visits were completed with 1 of our clinicians online while she was overseas (LOP traveled overseas due to work commitments) using secure videoconference software. This positions online assessment as an efficient solution connecting young people not only with care but with the right clinician regardless of their location, potentially saving time and money for young people, clinicians, and services.

Limitations

One limitation of this study is the sample size because the face-to-face arm suffered from greater participant attrition. It

is possible that participants who had already completed the face-to-face assessment felt that completing a second assessment online was an unnecessary use of time. Additionally, this study required people to complete all of the 4 main components (tablet questionnaire, face-to-face interview, Web-based survey, and video visit) within 2 weeks of the first interview, and the majority of attrition in both study arms was accounted for by this stringent protocol. Although the unequal randomization (1-to-3) favored the analysis with the reduction of the impacts of the learning curve, it compromised the power of the study. Future research is needed with a 1-to-1 randomization, increasing the power of the comparison.

Our study revealed poor interrater reliability on CGI-S allocation between face-to-face and online clinicians. There are 2 possible explanations for this disagreement. Face-to-face clinicians do not use the CGI-S in their daily practice and therefore are less familiar with its application, while online clinicians had used this tool in other research studies and were consequently more familiar with its application. Additionally, due to the CGI-S's instruction ("Considering your total clinical experience with this particular population, how mentally ill is the patient at this time?"), it has been acknowledged that clinician experience could explain the variability in the CGI-S scoring [66]. It is important to note that our study used varying levels of clinicians (eg, psychiatrists vs less experienced Youth Access Clinicians) that could also act as confounding factors when scoring. Furthermore, this study reveals a difference between face-to-face and online clinicians, despite all clinicians having been trained in using the clinical staging framework as set out by Hickie and colleagues [7]. This suggests a need for an ongoing education and training program.

Future research is needed to evaluate the engagement, efficacy, and effectiveness of MHeC's online assessment within real-world service environments. It would also include formal validation of the online assessment against gold standard assessment and testing the effectiveness of any education and training program that might be developed to supplement these new and innovative technological solutions for the delivery of better mental health care.

Conclusions

This study highlights the use of new and innovative technologies to assess clinical stage in early intervention youth mental health services through an online MHeC. It promotes systematic assessment of lifetime severity and complexity of clinical presentations while concurrently addressing risk assessment in a shorter period of time. The MHeC has the potential to be adapted to varied settings in which young people are connecting with traditional clinical services and assist in providing the right care at the right time.

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Conflicts of Interest

IBH was an inaugural commissioner on Australia's National Mental Health Commission (2012-2018). He is the Co-Director, Health and Policy at the Brain and Mind Centre (BMC), University of Sydney. The BMC operates an early-intervention youth service at Camperdown under contract to *headspace*. IBH has previously led community-based and pharmaceutical industry-supported (Wyeth, Eli Lilly, Servier, Pfizer, AstraZeneca) projects focused on the identification and better management of anxiety and depression. He was a member of the Medical Advisory Panel for Medibank Private until October 2017 and a board member of Psychosis Australia Trust and a member of Veterans Mental Health Clinical Reference group. He is the Chief Scientific Advisor to, and an equity shareholder in, Innowell. Innowell has been formed by the University of Sydney and PricewaterhouseCoopers to deliver the \$30 million Australian Government-funded Project Synergy, a 3-year program for the transformation of mental health services through the use of innovative technologies. EMS is the Medical Director of the Young Adult Mental Health Unit, St Vincent's Hospital, Darlinghurst; Discipline Leader of Adult Mental Health, School of Medicine, University of Notre Dame; Research Affiliate, The University of Sydney; and a consultant psychiatrist. She has received honoraria for educational seminars related to the clinical management of depressive disorders supported by Servier and Eli Lilly. She has participated in a national advisory board for the antidepressant compound Pristiq, manufactured by Pfizer. She was the national coordinator of an antidepressant trial sponsored by Servier. LOP, TD, FI, AT, and SC have no conflicts of interest to declare.

Multimedia Appendix 1

Video visit semistructured interview.

[PDF File (Adobe PDF File), 26KB - [jmir_v20i9e259_app1.pdf](#)]

Multimedia Appendix 2

Consolidated Standards of Reporting Trials diagram indicating the flow of participants through the study.

[PDF File (Adobe PDF File), 34KB - [jmir_v20i9e259_app2.pdf](#)]

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Abbreviations

CGI-S: Clinical Global Impression Scale-Severity

FET: Fisher exact test

H: Kruskal–Willis test

HEEADSSS: Home, Education and Employment, Eating, Activities, Drugs and Alcohol, Sexuality, Suicide and Depression, Safety

ICC: intraclass correlation coefficient

IQR: interquartile range

MHeC: Mental Health eClinic

SIDAS: Suicidal Ideation Attributes Scale

SOFAS: Social and Occupational Functioning Assessment Scale

U: Mann–Whitney test

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Chapter 4: Translating and Culturally Adapting Mental Health eClinic for a Spanish-Speaking Population

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Original Paper

Using Participatory Design Methodologies to Co-Design and Culturally Adapt the Spanish Version of the Mental Health eClinic: Qualitative Study

Laura Ospina-Pinillos^{1,2}, MD; Tracey Davenport¹, BA (Hons), EMBA; Antonio Mendoza Diaz³, BPsych, PhD; Alvaro Navarro-Mancilla⁴, MPH, MD; Elizabeth M Scott⁵, MBBS, FRANZCP; Ian B Hickie¹, MD, FRANZCP

¹Brain and Mind Centre, The University of Sydney, Sydney, NSW, Australia

²Department of Psychiatry and Mental Health, Pontifical Javeriana University, Bogota, Colombia

³School of Psychiatry, Department of Medicine, University of New South Wales, Sydney, NSW, Australia

⁴Neuropsychiatry Research Group, Autonomous University of Bucaramanga, Bucaramanga, Colombia

⁵School of Medicine, University of Notre Dame Australia, Sydney, NSW, Australia

Corresponding Author:

Laura Ospina-Pinillos, MD

Brain and Mind Centre

The University of Sydney

Shops 1-3, 66-70 Parramatta Road

Sydney, NSW, 2051

Australia

Phone: 61 028 627 6946

Email: laura.ospinapinillos@sydney.edu.au

Abstract

Background: Populations who do not speak English and reside in English-speaking countries are less likely to receive mental health care. In Australia, international students have been identified as disadvantaged compared with their peers; have weaker social support networks; and have higher rates of psychological distress. This scenario is acquiring significant relevance as Spanish-speaking migration is rapidly growing in Australia, and the mental health services for culturally and linguistically diverse populations are limited. Having a Spanish version (MHeC-S) of the Mental Health eClinic (MHeC) would greatly benefit these students.

Objective: We used participatory design methodologies with users (young people aged 16-30 years, supportive others, and health professionals) to (1) conduct workshops with users to co-design and culturally adapt the MHeC; (2) inform the development of the MHeC-S alpha prototype; (3) test the usability of the MHeC-S alpha prototype; (4) translate, culturally adapt, and face-validate the MHeC-S self-report assessment; and (5) collect information to inform its beta prototype.

Methods: A research and development cycle included several participatory design phases: co-design workshops; knowledge translation; language translation and cultural adaptation; and rapid prototyping and user testing of the MHeC-S alpha prototype.

Results: We held 2 co-design workshops with 17 users (10 young people, 7 health professionals). A total of 15 participated in the one-on-one user testing sessions (7 young people, 5 health professionals, 3 supportive others). We collected 225 source documents, and thematic analysis resulted in 5 main themes (help-seeking barriers, technology platform, functionality, content, and user interface). A random sample of 106 source documents analyzed by 2 independent raters revealed almost perfect agreement for functionality ($\kappa=.86$; $P<.001$) and content ($\kappa=.92$; $P<.001$) and substantial agreement for the user interface ($\kappa=.785$; $P<.001$). In this random sample, no annotations were coded for help-seeking barriers or the technology platform. Language was identified as the main barrier to getting medical or psychological services, and smartphones were the most-used device to access the internet. Acceptability was adequate for the prototype's 5 main elements: home page and triage system, self-report assessment, dashboard of results, booking and video visit system, and personalized well-being plan. The data also revealed gaps in the alpha prototype, such as the need for tailored assessment tools and a greater integration with Spanish-speaking services and communities. Spanish-language apps and e-tools, as well as online mental health information, were lacking.

Conclusions: Through a research and development process, we co-designed and culturally adapted, developed and user tested, and evaluated the MHeC-S. By translating and culturally adapting the MHeC to Spanish, we aimed to increase accessibility and

availability of e-mental health care in the developing world, and assist vulnerable populations that have migrated to English-speaking countries.

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KEYWORDS

telemedicine; medical informatics; eHealth; mental health; cultural characteristics; cultural competency; ethnic groups; transients and migrants; quality of health care; international students; Hispanics; Latinos; community-based participatory research; primary health care; patient participation; patient preference; patient satisfaction; consumer health information

Introduction

Background

The need for mental health services far outweighs the capacity of service providers all over the world [1]. Access to adequate-quality mental health care is also limited for many populations but is particularly limited for vulnerable groups such as the elderly and youth populations, racial and ethnic minorities, the socioeconomically disadvantaged, and rural populations [2]. Limited access to services is of particular concern for young people, as it is well established that 75% of the serious mental diseases and substance use problems emerge before 25 years of age [3]. When young people do seek and receive help, timely and evidence-based treatments are encountered by only a small proportion; in some low- and middle-income countries, the treatment gap can be as high as 90% [4].

Populations who do not speak English in English-speaking countries are less likely to receive mental health care [5]. In Latino populations with mental health problems, the lack of English proficiency is one of the biggest barriers when accessing services [6]. In Australia, non-English-speaking migrant populations struggle to access and understand the local health care system [7]. Language proficiency has been identified as a true barrier for migrant men when using services [8].

International Students

Australia is a popular study destination for students around the world. Most of Australia's international students are enrolled in the higher education sector (44%), followed by the vocational education and training sector (27%), and English-language intensive courses for overseas students (19%) [9]. Studying abroad can be one of the most remarkable and rewarding experiences, but it can also be a source of great distress. The way migration is experienced by each individual highly depends on the push and pull factors that precipitated the migration [10]. In the case of international students, a high motivation to study in a different country can act as a protective factor, but the cultural distance of the host country, the lack of social support, and academic pressure can be powerful stressors. Consequently, several studies have shown increased rates of mental health problems in this population [10-12].

In Australia, international students have been identified to be disadvantaged compared with their peers; have weaker social support networks; have higher rates of psychological distress [13]; and are at higher risk of experiencing an adjustment disorder or other mental health problems [14]. The "International Student Welfare in Australia" report suggested that Australia

does not adequately protect international students' human rights and highlights mental health as a key area of concern [15]. Recently, awareness of these issues has been covered by Australian mass media due to 27 suicides in the international student population between 2009 and 2015; sadly, all were reportedly associated with low help-seeking behaviors (22%) [16]. As international students are less likely to receive mental health care, the previously mentioned report encourages institutions to provide information, including available services and increased research in this area. However, most of the research has been focused on tertiary education students and none or very little has been dedicated to language students.

This scenario is acquiring a significant relevance in Australia, where the Spanish-speaking (including Latino) international student migration is rapidly growing. In 2016-2017, language student visa grants (subclass 570) increased by 16.8%, where 3 Spanish-speaking countries (Colombia, Spain, and Chile) were situated in the top 10 countries of applications logged outside Australia [17].

Health Information Technologies

The internet and new and emerging technologies hold enormous promise for significantly expanding the reach of adequate-quality mental health care by addressing several barriers [18]. Interventions delivered through these technologies have the potential to reach a wide geographic area via remote delivery of care [19]; decrease costs in delivering self-help and social networking interventions; and allow for relatively rapid, centralized scaling up of interventions to a public health dissemination level [20]. English-language, Web-based mental health interventions have proven to be effective for self-screening and referral [6], reducing symptoms and delivering effective treatment for major mental health disorders [21]. A large number of studies, including randomized controlled trials, have also demonstrated the effectiveness of various internet-delivered interventions, such as psychotherapy and psychoeducation [22], treating problematic health behaviors [23], and delivering prevention and treatment programs [24]. Other population-based studies have reported that Web-based tools can enhance the delivery of mental health care in primary care settings [25] and support training and supervision for providers [26]. The number of programs available is growing rapidly [27]. Although positive results are seen from the use of self-directed electronic health interventions, increased effectiveness has been reported if they are used as part of a stepped-care model [28], with the support of a trained health professional [29] or as an adjunct to face-to-face treatment [30].

Despite the growth of such technologies in high-income countries, these technologies are still lacking in low- and middle-income countries and, more specifically, in the Spanish language [31]. Traditional telemedicine has supported the cooperation between developed and developing countries to deliver care across borders by linking professionals rather than providing direct connection between professionals and patients [32]. Telepsychiatry has been used to deliver mental health care to individuals requiring attention, not only locally [33-35], but also internationally, as a means to deliver care to Spanish-speaking individuals residing in a different country [32,36,37]. This type of care is a more efficient alternative, as it doesn't require the use of interpreters and is culturally sensitive [38]. Successful Spanish-language health information technology (HIT) interventions have been applied in several fields, such as cancer; diabetes; and child, infant, or maternal health [39]. Despite this, the HITs available for mental health are scarce. Initial reports have demonstrated their potential utility in the screening of mental health problems [40], as well as in the treatment of depression [31,41,42], anxiety [43], and substance use disorders [44].

Although the development of HITs in Spanish is recent, their usability and retainability among users is of concern [31]. Experience in other languages (mostly English) has demonstrated that participatory design research methodologies that involve stakeholders and end users in the design and development of these systems at all stages could finally increase user engagement and system usability [45-48]. A close collaboration with end users ensures the appropriateness of these systems for culturally and linguistically diverse populations [49]. Therefore, incorporating participatory design research methodologies that puts end users at the center of the design and development process is greatly needed for Spanish-language-based HITs.

Objectives

The University of Sydney's Brain and Mind Centre (Sydney, Australia) is a leader in the development of youth-specific mental health services [50,51] and evidence-based electronic health technologies to engage young people in their own care [52]. The Mental Health eClinic (MHeC) [48,53] was a prototypic Web-based tool designed and developed through a partnership between the Young and Well Cooperative Research Centre and the Brain and Mind Centre. The MHeC aimed to deliver best-practice clinical services to young people experiencing mental health problems by making clinical care accessible, affordable, and available to young people whenever and wherever they need it most. The original MHeC had 5 main elements: a home page with a visible triage system for those requiring urgent help; a comprehensive online physical and mental health self-report assessment; a detailed dashboard of results; a booking and videoconferencing system to enable video visits; and the generation of a personalized well-being plan that included links to evidence-based, young person-suggested, health professional-recommended apps and e-tools [53]. We hypothesized that having a Spanish version of the MHeC (MHeC-S) could greatly benefit young people who are native Spanish speakers living in Australia and who are actively seeking help.

Using a research and development cycle (including several participatory design phases) with end users (young people aged 16 to 30 years, supportive others [such as family, friends, caregivers, coaches, teachers, or community members], and health professionals) as a framework, in this study we aimed to (1) conduct co-design workshops with end users to co-design and culturally adapt the MHeC for Spanish-speaking young people based in Australia; (2) inform the development of the alpha prototype of the MHeC-S; (3) test the usability of the alpha prototype of the MHeC-S; (4) translate, culturally adapt, and face-validate the self-report assessment to a Spanish-speaking population based in Australia; and (5) collect information to inform the beta prototype of the MHeC-S.

Methods

Participants

Participants included community-based young people aged 16 to 30 years; native Spanish speakers living in Australia; and native Spanish-speaking young people attending headspace Camperdown and headspace Campbelltown (headspace Australia's National Youth Mental Health Foundation provides early intervention mental health services and assistance in enhancing young peoples' [aged 12-25 years] well-being; Camperdown and Campbelltown are 2 sociodemographic areas of Sydney, Australia). Additionally, native Spanish-speaking health professionals and supportive others participated. Participants were required to have regular access to a smartphone (with the iOS or Android operating system) and the internet.

The University of Sydney's Human Research Ethics Committee approved the study (Protocol No. 2014/689 for the co-design workshops and Protocol No. 2016/487 for the user testing sessions). Participants were provided with the relevant information about the study (participant information statement) before providing their consent and participating in the study. We also obtained parental consent for participants under 18 years of age. Young people received gift vouchers to thank them for their time and expertise when they attended the co-design workshops and the user testing sessions.

The recruitment strategy included the identification of potential participants through headspace Camperdown and headspace Campbelltown; poster and postcard advertisements displayed in community organizations; Facebook advertisements and a study-specific Facebook page; use of organizational social media channels; universities, institutes of technical and further education, language schools, and vocational and training institutes; and cooperation with Spanish-speaking consulates in Australia.

Procedure

We based the participatory design research methodology on the Young and Well Cooperative Research Centre's guide *Participatory Design of Evidence-Based Online Youth Mental Health Promotion, Intervention and Treatment* [54]. The research and development cycle used our previously established phases for co-design and build of the original version of the prototypic MHeC [53]. The process encompasses several

participatory design phases: co-design workshops (phase 1); knowledge translation (phase 2); language translation and cultural adaptation (phase 3); rapid prototyping of the alpha prototype and user testing (phase 4); rapid prototyping and user (acceptance) testing of the beta prototype (phase 5); and real-world trialing of the final prototype (phase 6). This paper reports the initial 4 phases; we will report phase 5 and phase 6 separately (Figure 1).

Phase 1: Co-Design Workshops

We held co-design workshops in 2 stages with a maximum of 10 participants per workshop; we ran these with young people and health professionals separately. We did not use technology

in the workshops; instead, we conducted the following design activities to facilitate the process: we used design testing using mockups and end user sketching (Figure 2) to obtain information for the content, functionality, and the look and feel of the prototype.

The topics covered in each workshop included defining the advantages and disadvantages of having a Spanish version of the MHeC; defining the barriers of having an MHeC-S; assessing the 5 main elements of the MHeC; and defining the functionality and the user interface. At the end of each workshop, the knowledge translation team analyzed and synthesized the information.

Figure 1. Research and development cycle of the Spanish version of the Mental Health eClinic.

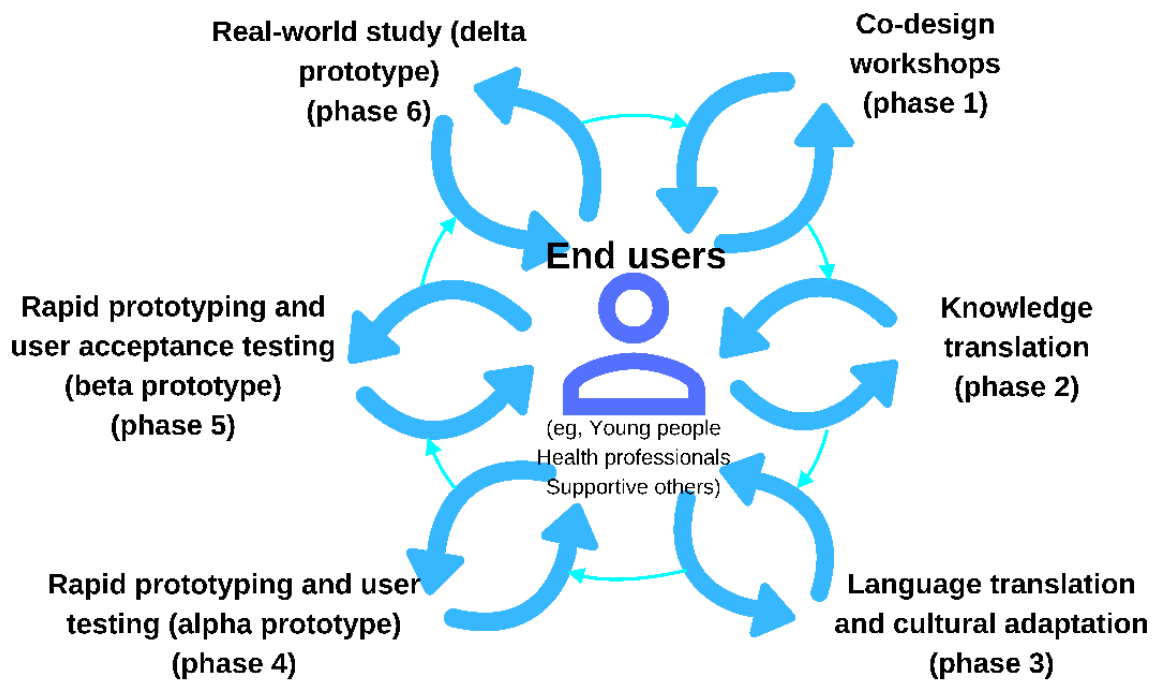
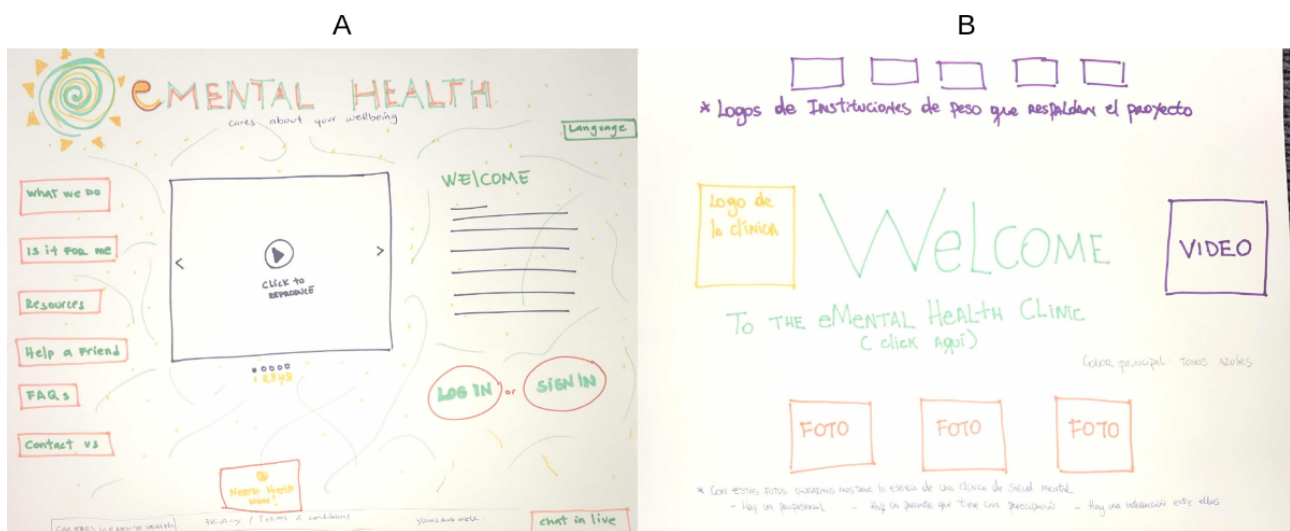


Figure 2. Samples of end user sketches made during a co-design workshop. (A) Hand-drawn sketch by a young person. (B) Hand-drawn sketch by a health professional.



Phase 2: Knowledge Translation

The knowledge translation team independently analyzed the diagrams and notes taken from the previous phase (or workshop), then compared and discussed observations until they reached an agreement. They then synthesized the information by creating wireframes that would be used in the subsequent phase.

Phase 3: Language Translation and Cultural Adaptation

Language of the Prototype

For all of the prototype's language, a native Spanish-born psychiatrist (LOP) performed a simple translation. Then, for general-content items, 2 Spanish-born psychologists (not involved in the publication of this paper) reviewed the translations. A second Spanish-born psychiatrist (ANM) also reviewed specific mental health content or sensitive content such as the dashboard of results and psychoeducational factsheets. Discrepancies between the translations were resolved by consensus in the group.

Translation and Cultural Adaptation of the Self-Report Assessment

Understanding the great need for health professionals and researchers to have available, reliable, and valid measures across different languages and populations, we aimed to translate, back-translate, culturally adapt, and face-validate the Australian self-report assessment using a modified version of the "user-friendly guideline for the translation, adaptation and validation of instruments or scales for cross-cultural health care research" developed by Sousa and Rojjanasrirat [55].

Two Spanish bilingual health professionals (LOP and ANM) independently translated all (health-related) items from English to colloquial Spanish, with the exception of standardized surveys already available in Spanish. A third native Spanish-born psychologist (AMD) reviewed the translated versions and the original English versions. Then, in group discussions, we ensured that all items were linguistically and culturally appropriate by assessing the face-validity of each item in the self-report assessment, as well as assessing the readability and grammatical consistency of the entire assessment. All items were then back-translated to English by one Australian adult (not involved in the publication of this paper) who is fluent in colloquial Spanish and is based in Colombia, has extensive research experience and tertiary qualifications in health, and is accredited to teach English to adults. Discrepancies between the original and back-translated versions were resolved in group sessions between the translators and back-translator.

A literature review was undertaken (by LOP) to identify relevant measures for this population, as well as those instruments already translated and validated into Spanish. The review included both published (identified via PubMed, Google Scholar, SciELO, and LILACS) and gray literature (identified via Google Advanced search) in both English and Spanish. Understanding that some questionnaires might have several translations or versions, we established the following process to select the instruments: first, we selected official translations; if these were

unavailable, we selected versions of the published translation and psychometric processes. When more than 1 version or source was available, the 2 previously mentioned health professionals (LOP and ANM) by consensus selected the most appropriate to be included.

Phase 4: Rapid Prototyping and Usability Testing of the Alpha Prototype

Phase 4 involved user testing with end users: young people, health professionals, and supportive others. Sessions used laptops, tablets, and smartphones (with the iOS or Android operating system), where participants had access to the alpha prototype of the MHeC-S. In each 90-minute one-on-one user testing session, a researcher was paired with an end user. Using a think-aloud protocol [56], participants were observed as they navigated the prototype and responses were recorded to questions posed by the researcher about the main elements of the MHeC-S. A total of 4 usability tasks were completed in the session: (1) create an account and log in, (2) find the Need Help Now button, (3) explore the dashboard of results, and (4) book an appointment. Task completion (yes/no) and task difficulty were measured using the Single Ease Question (SEQ; responses ranged from "very difficult" to "very easy," rated from 1 to 7) [57]. User testing also explored the prototype's utility and the users' inclination to use the MHeC-S, overall comments, and naming of the prototype. Interviews and observations were transcribed. No instructions or clues were provided, and all responses and observations (eg, nonverbal cues) were transcribed.

Data Analysis

We simultaneously collected and analyzed data at the end of each phase in order to facilitate the process. Hence, we explored preliminary findings in the following phase. We determined interrater reliability and analyzed task difficulty using IBM SPSS Statistics for Mac 22.0 (IBM Corporation). We uploaded and analyzed source documents (workshop discussion notes, artifacts [mockups and end user sketches] and user testing notes) using thematic analysis techniques [58] in NVivo 11 for Mac (QSR International) [59]. The thematic analysis framework involved both inductive and deductive coding. Acknowledging that one of the biggest challenges in this project was the translation and cultural adaptation of the MHeC-S, in the deductive code framework we considered the adaptation of the prototype in 4 dimensions: technology platform, functionality, content, and user interface. As defined by Valdez et al in their culturally informed design framework [60], "technology platform" refers to the different types of hardware, "functionality" indicates the actions that can be performed, "content" refers to the message that is transmitted, and "user interface (design)" refers to the visual presentation of the content and functionality. We also enriched this type of coding with our previously established [53] codes (general elements of the MHeC; general look and feel; privacy and data sharing; and interaction of the MHeC with social networks).

Data collection and qualitative analysis were done in Spanish. To facilitate reporting, we provide quotes translated from the original data. [Multimedia Appendix 1](#) shows the original quotes in Spanish.

One researcher coded all the material (coder A: LOP) and a second coder (coder B: not involved in the publication of this paper) reviewed half of the collected documents in order to assess the reliability, assess consistency, and reduce potential bias [61]. We calculated interrater agreement for each theme using the Cohen kappa statistic on a binomial distribution (category present vs category not present) for each of the themes [62] and interpreted the obtained values using Viera and Garrett's criteria: kappa range .01 to .20 indicates slight agreement, kappa range .21 to .40 indicates fair agreement, kappa range .41 to .60 indicates moderate agreement, kappa range .61 to .80 indicates substantial agreement, and kappa range .81 to .99 indicates almost perfect agreement [63].

Results

Workshops and Sessions

In May 2015, we conducted 1 full-day co-design workshop with Spanish-speaking young people based in Australia and 1 full-day co-design workshop with Spanish-speaking health professionals based in Australia. In total, we conducted 3 knowledge translation sessions immediately after each workshop and at the end of the usability testing. The general-content translation process started in June 2015, and the self-report assessment literature review and translation process started in January 2016 and lasted until the end of the same year. We conducted 15 one-on-one user testing sessions between March and November 2017.

Participant Characteristics

A total of 10 young people participated in the co-design workshops; 8 were female and their ages ranged from 17 to 29 years (median age 24 years). Of the young participants, 8 were Colombian and 2 were Chilean. A total of 7 health professionals participated in the workshops; 6 were female and their ages ranged from 22 to 24 years (median age 28 years). Of the health professionals, 3 were from Colombia, 2 were from Chile, and 2 were from Spain.

A total of 15 participants participated in the one-on-one user testing sessions: 7 young people with ages ranging from 19 to 30 years (median age 26 years); 5 health professionals with ages ranging from 27 to 74 years (median age 35 years); and 3 supportive others with ages ranging from 30 to 57 years (median age 30 years). Of these participants, 10 were female and 12 were Colombian, while the rest were from Argentina, Spain, and Venezuela.

Thematic Analysis

We collected and analyzed a total of 225 source documents (2 workshop discussion notes and 208 artifacts produced by participants were collected in the co-design workshops plus 15 user testing notes) during the entire process.

Coding Interrater Reliability

Using inductive coding, 1 new main theme emerged (help-seeking barriers) and, from the deductive coding framework, 4 main themes were reiterated (technology platform, functionality, content, and user interface). Of the 225 source documents, 106 (47.1%) were analyzed by both raters. A total

of 378 annotations were recoded from both coders (coder A and coder B). Interrater agreement of functionality theme between coder A and coder B was "almost perfect" ($\kappa=.86$; $P<.001$), with concordance in a total of 93.7% (354/378) of the annotations. Similarly, we obtained an "almost perfect" agreement ($\kappa=.92$; $P<.001$) between raters in relation to the content theme, with 97.6% (369/378) of total concordance. In relation to interface, interrater agreement between coders was "substantial" ($\kappa=.785$; $P<.001$), with concordance in a total of 90.0% (340/378) of the annotations. In this random sample, no annotations were coded for help-seeking barriers or technology platform themes.

Help-Seeking Barriers

Within this domain, participant perceptions of the help-seeking barriers fell into 3 categories: the language barrier, problems recognizing symptoms or poor mental health literacy, and the availability and accessibility of sources of help.

Language Barrier

All participants (32/32, 100%) highlighted language as the main barrier to getting medical or psychological services ([Multimedia Appendix 1](#)):

...even if I needed to call 000, I wouldn't be sure if they understand what I'm saying... [Young person, quote A]

I don't think that I would be able to explain my feelings to someone in English... [Young person, quote B]

As the aim for most of these students was to learn English (or improve their English level), their communication skills were, in general, limited. This was a source of distress, as they felt limited in their day-to-day living:

...it's very hard to arrive here (Australia) and not understand what is happening... [Young person, quote C]

...understanding simple instructions—like where is the train stop—is very difficult... [Young person, quote D]

For some, the language barrier could have a very negative impact on their confidence:

...it's like in English I'm a different person; sometimes I feel people think I'm dumb... [Young person, quote E]

...the impact on their [international students] confidence is huge. Sometimes I have to remind him [international student] what he is capable of... [Health professional, quote F]

Problems Recognizing Symptoms or Poor Mental Health Literacy

International students face different issues during migration that could have an impact on their well-being. Participants felt concerned for those who have recently arrived in Australia, as they are perceived as being more vulnerable. According to these participants, a great majority experienced some degree of cultural shock upon their arrival; getting used to regular things

such as food, climate, and transport can be relevant stressors among students.

...it is hard to try to fit, and try to understand how things work here... [Young person, quote G]

As Australia's cost of living is high, all participants reported economic concerns (32/32, 100%), whereas some (17/32, 53%) experienced difficulties with housing, getting a job (or a job with fair work conditions), or establishing relationships with peers. All these factors put the students at a higher risk of adaptational problems, which are often unnoticed.

Additionally, the conditions of migration greatly affect individuals' experience in a new country. Some common negative factors were visiting another country for the first time, travelling alone, and not having family members or friends already residing in that country. Most international students need to work to pay their expenses; however, the jobs they find to support their stay are often not related to their already acquired skills, as a young person explained:

...the majority [of] us have Bachelor degrees in our home countries...so when we arrive in Australia, the jobs we find are very different from what we have been trained in—most of us have to work cleaning, or as a waitress or in construction [Young person, quote H]

For many young people, reconciling this discrepancy is challenging.

Availability and Accessibility of Sources of Help

All 12 health professionals and all 3 supportive others believed that international students have a great need for Spanish-language-based mental health services in Australia. They perceived that the cases of young people requiring help are increasing, as a supportive other explained:

...possibly one international student dies by suicide every year here, and more frequently we have to provide assistance to students that are hospitalized for a mental health concern... [Supportive other, quote I]

Young people believed that having an MHeC-S would be of great utility, as they struggle to understand Australia's health system and are not aware of their Overseas Student Health Cover benefits. All young participants (17/17, 100%) knew Australia's national emergency phone number (000). However, just a few (7/17, 41%) of them understood where to go if they needed nonurgent medical care, and all of them stated that they didn't know where to get psychological assistance.

All 17 young people said they would use a system like the MHeC-S, as they felt it would be a tool to increase mental health awareness and access to sources of help. Additionally, students believed they would be more inclined to use the MHeC-S if they knew about it beforehand, perhaps in the information they receive before arriving in Australia. All 12 health professionals imagined the prototype acting as a bridge between established services and centers in Australia such as the Transcultural Mental Health Centre; New South Wales (NSW) Service for

the Treatment and Rehabilitation of Torture and Trauma Survivors; Translating and Interpreting Service; NSW Spanish and Latin American Association for Social Assistance; other relevant cultural associations; and diplomatic missions.

In relation to online sources of help, participants stated that Google was their main source for getting information about their health symptoms. However, they did not necessarily trust all the information they obtained. Participants agreed that there is a shortage of Spanish-language online information (from reputable sources such as universities and organizations) and, more specifically, trustworthy apps and e-tools.

Technology Platform

All participants (32/32, 100%) reported that they had constant access to the internet via mobile data plans or Wi-Fi networks. The most commonly used device to access the internet was a smartphone (32/32, 100%), followed by a laptop. All participants agreed that the MHeC-S needs to be accessible via a mobile device in order to really respond to this population's needs, as some of the students did not have a desktop, laptop, or tablet. All 17 young people reported that mobile phones and the internet were necessary tools in this period of their life, as they used them to communicate with English-speaking people and keep in contact with family and friends overseas. Additionally, they used them in their daily activities (eg, a global positioning system feature), or as a way to find a job or accommodation. As a consequence, they highlighted the importance of the MHeC-S having a responsive Web design, where the prototype needs to work on mobile devices; otherwise, access would be jeopardized.

Functionality

There was adequate acceptability of the 5 main elements of the MHeC-S: a home page with a visible triage system for those requiring urgent help; a comprehensive online physical and mental health self-report assessment; a detailed dashboard of results; a booking and videoconferencing system to enable video visits; and the generation of a personalized well-being plan that includes links to evidence-based, young person-suggested, health professional-recommended apps and e-tools.

Element 1: Home Page and Triage System

When shown the home page, participants (15/32, 47%) suggested that the MHeC-S webpage's domain should be ".com" or ".org," as this would increase the website's credibility. At the same time, they wanted the home page to display all relevant logos of affiliated organizations such as the logo of the University of Sydney and relevant Latin American or Spanish universities associated with the MHeC-S. In this space, they wanted to find a simple description of "...what the MHeC-S has to offer..." (young person, quote J) and perhaps a series of short videos that explain more about the MHeC-S and also contained testimonials. As language might be a concern, participants suggested adding a settings cog on the home page so they could choose their language and, consequently, relevant content would also be prompted. The triage system was widely accepted, as all users understood the need for screening for urgent services and for rapid referral of users (Figure 3).

Figure 3. Home page and triage system.

Element 2: Online Physical and Mental Health Self-Report Assessment

When shown the assessment (via questionnaire) (Figure 4), participants liked that the online physical and mental health assessment used rule-based decision algorithms that enable personalization of the assessment to the young person's needs (eg, sex-specific questions or in-depth assessments according to positive screening responses) and inform the dashboard of results. They also accepted the established features of pausing and resuming later, as they would give participants more flexibility to complete the assessment where and when they prefer. Additionally, participants approved the type of questions (eg, Likert-type scale questions and 2-way closed-ended questions) contained in this assessment. However, health professionals (12/12, 100%) suggested including 1 open-text question at the beginning of the assessment with the aim of assessing the reason for accessing the MHeC-S that day, as one clinician explained:

I would like to know the reason [why the young person was] visiting the MHeC-S...as we do in practice assessing the presenting or chief complaint...
[Clinician, quote K]

Element 3: Dashboard of Results and Progress

All 32 participants agreed that after completion of the online self-report assessment a dashboard of results should be displayed immediately (Figure 5). Participants accepted the simple bar and line graphs, colored icons, and traffic light representations, and reported that they were easy to understand. Health

professionals (12/12, 100%) believed that the assessment and the dashboard of results were useful tools to inform their practice, not only in their first assessment but also as an ongoing form of care. In relation to the dashboard's language, participants preferred the use of lay terms instead of medical terminology. When medical jargon is needed (eg, psychosis or hypomania), participants proposed that the prototype should display a simple explanation of the term when they click on the word or hover over it.

Element 4: Booking System and Video Visit System

All participants agreed that the booking and video visit system embedded in the MHeC-S (Figure 6) was a secure way of protecting privacy. Due to the limited numbers of Spanish-speaking health professionals in Australia, participants believed that having a video visit with a Spanish-speaking health professional would be an effective way of screening and assessment, as well as providing (and receiving) advice, treatment, and therapy. Importantly, they acknowledged that video visits would be more efficient, as this would save them time and money, as a young person explained:

...we will know exactly where to go and not to waste time going from one place to another, searching for someone that understands me... [Young person, quote L]

Furthermore, the prototype provided them with security, as a health professional explained:

...they can always know where to go, like a secure base... [Health professional, quote M]

Figure 4. Online physical and mental health self-report assessment.

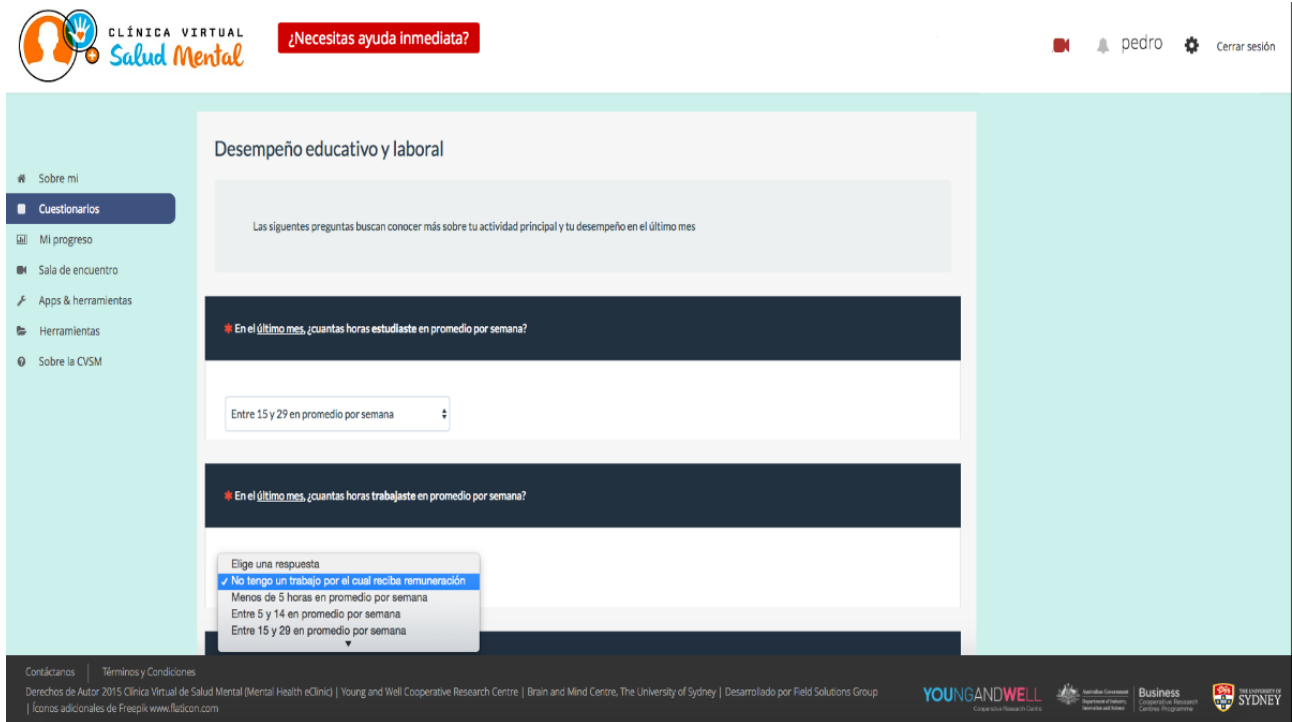


Figure 5. Dashboard of results and progress.

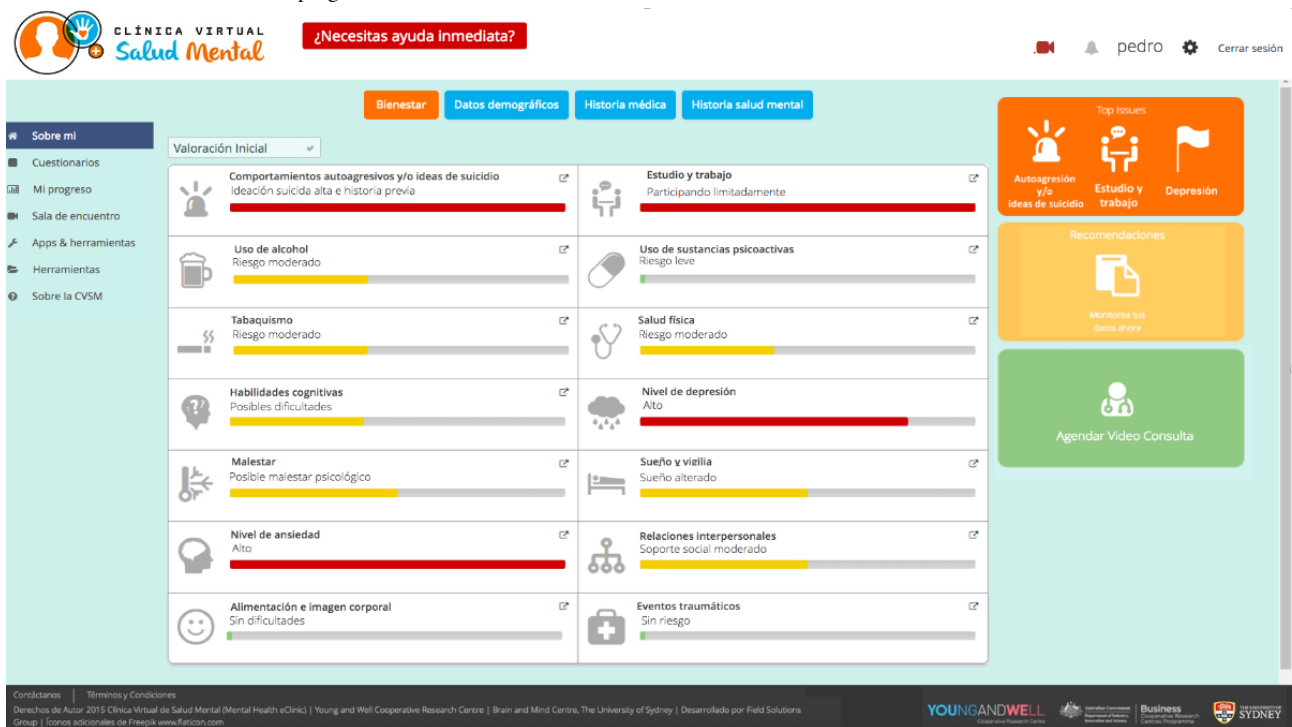
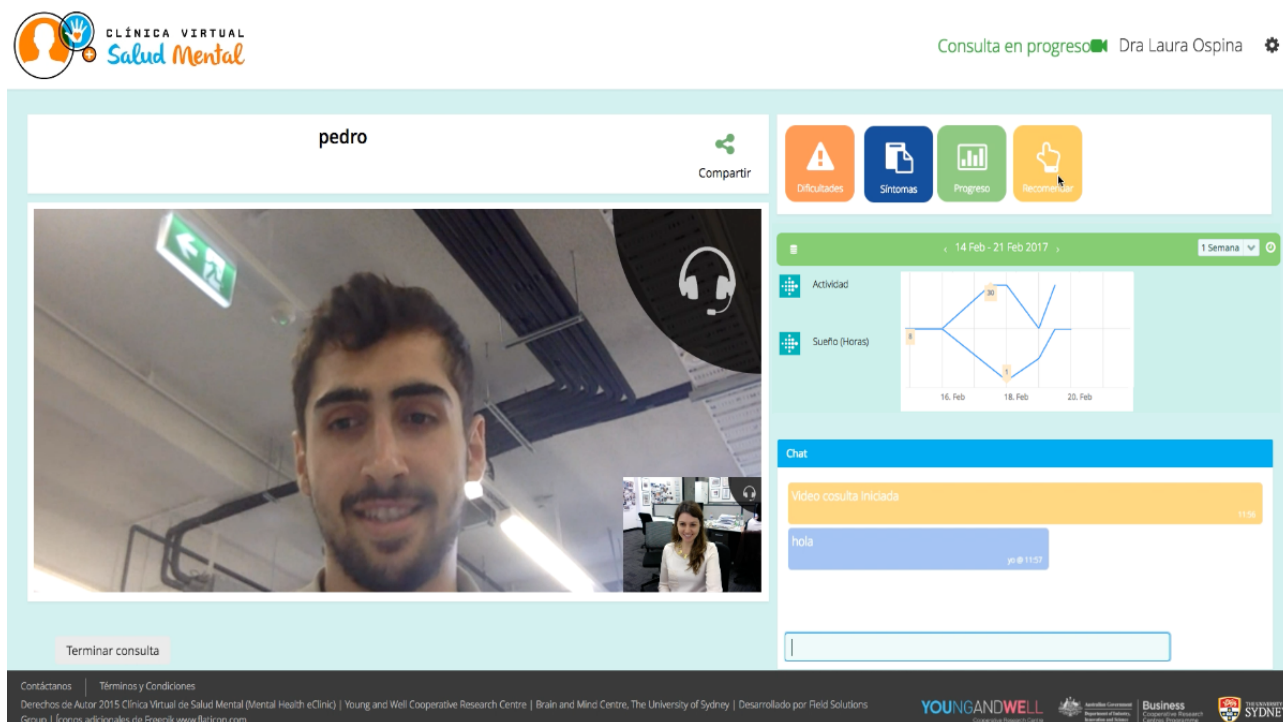


Figure 6. Booking system and video visit system.

Element 5: Personalized Well-Being Plan That Includes Links to Evidence-Based, Young Person–Suggested, Health Professional–Recommended Apps and E-Tools

The idea of having a tailored plan and recommendations immediately after the completion of the self-report assessment was widely accepted by participants (32/32, 100%) (Figure 7). Young people (17/17, 100%) said that they would be likely to download and use the recommended apps and e-tools if those matched with their needs. However, most of the participants (29/32, 91%) highlighted a lack of Spanish-language apps and e-tools. Young people (17/17, 100%) said that they would try to use an app in English, but they also recognized that their experience and the benefit would be limited, especially for those apps that have audio resources, as one young person explained:

I would try to use it as much as I can, but I think there are going to be many things I don't understand—for example, the mindfulness audios... [Young person, quote N.]

As potential solutions, participants proposed the creation of videos that contain general information, as well as relaxation and breathing exercises; a detailed directory that describes available English apps and e-tools; and, ideally, the development of several Spanish-language apps, e-tools, and Spanish adaptations of the best evidence-based resources.

Content: Translation and Cultural Adaptation of the Self-Report Assessment

The self-report assessment included 16 modules (Table 1 [64-89]) with smart skips built in so that it was tailored to each

individual and took a minimum amount of time to complete (approximately 45 minutes).

The self-report assessment translation process started in early 2016, with the literature review. We found 8 Spanish-translated versions of measures from the original source: the 2-step method to measure transgender identity [90], 10-item Kessler Psychological Distress Scale [91], Quick Inventory of Depressive Symptomatology [92,93], Community Assessment of Psychic Experiences [94,95], Alcohol Use Disorders Identification Test [96], Alcohol, Smoking and Substance Involvement Screening Test [97], International Physical Activity Questionnaire [98,99], and the Spanish version of the World Mental Health Composite International Diagnostic Interview used in the National Comorbidity Survey Replication Adolescent Supplement [100,101]. We selected 5 because we found their translation and psychometric properties in the academic literature: the Primary Care Posttraumatic Stress Disorder (PTSD) Screen [102], PTSD Checklist-Civilian Version [103], Altman Self-Rating Mania Scale [104], the Cutting down, Annoyance by criticism, Guilty feeling, and Eye-openers questionnaire (which has been widely used in several Spanish-speaking studies and several versions are available online [105,106]; we used the Colombian version for its methods [107]), and the Fagerström Test for Nicotine Dependence [108]. Although we didn't find any versions of the empathy quotient scale in the academic literature, we found a Spanish version provided by the Autism Research Centre of the University of Cambridge [109].

Figure 7. Personalized well-being plan that includes links to evidence-based, young person–suggested, health professional–recommended apps and e-tools.

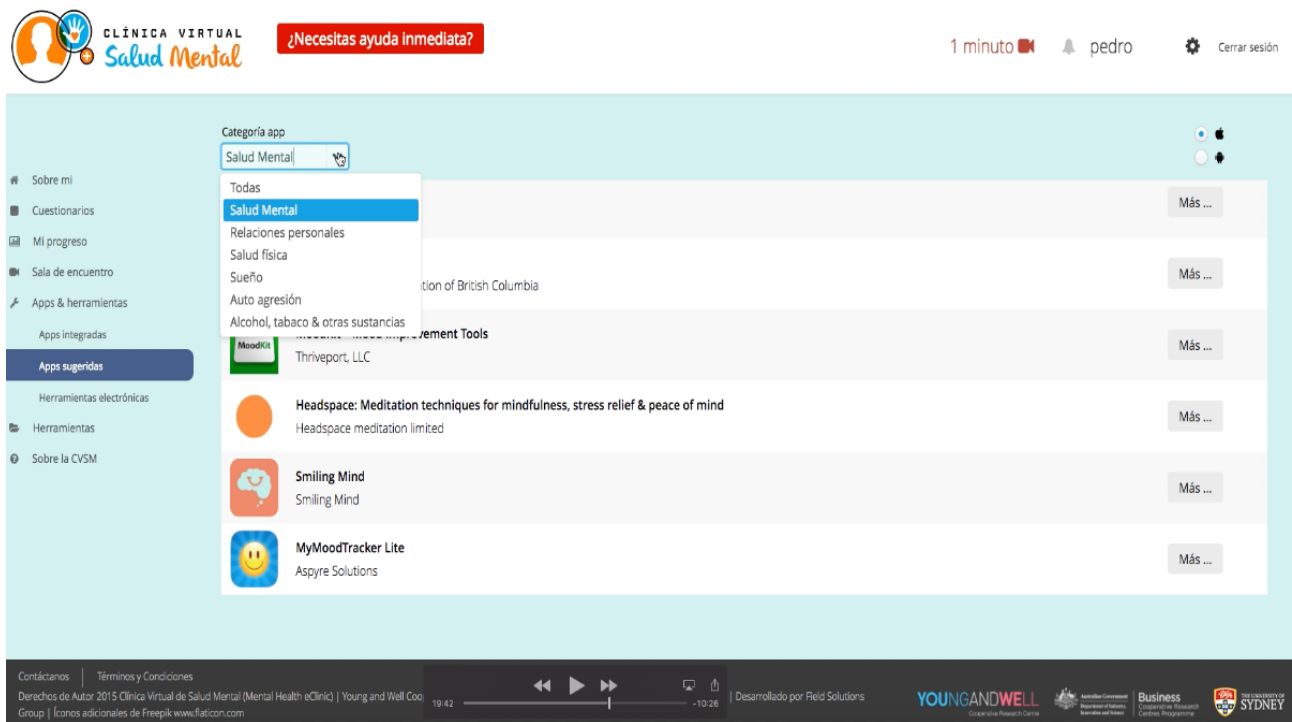


Table 1. Self-report assessments in each of the 19 modules.

| Module | Questionnaires |
|---|--|
| 1. Main reason for visiting the MHeC-S ^a | Short open-text question |
| 2. General demographics | Items derived from the Second Australian Young and Well National Survey [64] and the 2-step method to measure transgender identity [65] |
| 3. Social and occupational function | Modified versions of the Brief Disability Questionnaire [66] and the self-report version of the Social and Occupational Functioning Assessment Scale [67] |
| 4. Psychological distress | 10-item Kessler Psychological Distress Scale [68] |
| 5. Depressed mood | Quick Inventory of Depressive Symptomatology (QIDS-SR-16) [69] |
| 6. Anxiety | Overall Anxiety Severity and Impairment Scale [70] |
| 7. Mania-like experiences | Items derived from the Altman Self-Rating Mania Scale [71] |
| 8. Psychosis-like experiences | Items derived from the Community Assessment of Psychic Experiences-Positive Symptoms Scale [72] |
| 9. Traumatic experiences | Primary Care PTSD ^b Screen [73] and the PTSD Checklist-Civilian Version [74] |
| 10. Self-harm behaviors and suicidal ideation | Suicidal Ideation Attributes Scale [75] |
| 11. Tobacco, alcohol, and substance use | Items adapted from the Alcohol Use Disorders Identification Test [76], the Alcohol, Smoking and Substance Involvement Screening Test [77], the Cutting down, Annoyance by criticism, Guilty feeling, and Eye-openers questionnaire [78], the Drinking Motives Questionnaire [79], the Fagerström Test for Nicotine Dependence [80], and selected items from the National Drug Strategy Household Survey [81] |
| 12. Physical activity | International Physical Activity Questionnaire [82] |
| 13. Sleep behaviors | Sleep-related items from the QIDS-SR-16 |
| 14. General mental health conditions | National Comorbidity Survey Replication Adolescent Supplement [83] |
| 15. Overall health and somatic distress | Somatic and Psychological Health Report [84], self-perceived health status, and general body measurements |
| 16. Medical, mental health, and family history | Multiple-choice questions |
| 17. Cognitive concerns and empathy | Derived from the Subjective Scale to Investigate Cognition in Schizophrenia [85] and the empathy quotient [86] |
| 18. Eating behaviors and body image | Derived from the Eating Disorder Examination [87] |
| 19. Social connectedness and support | Derived from the Perceived Social Support/Conflict Measure [88] plus 5 items measuring relationships with peers [89] |

^aMHeC-S: Spanish version of the Mental Health eClinic.

^bPTSD: posttraumatic stress disorder.

We didn't find any Spanish versions of the items assessing disability, suicide ideation, and anxiety rating. Considering their relevance in overall assessment and potential medicolegal repercussions, we decided to find Spanish-speaking analogs to these measures. We replaced the Brief Disability Questionnaire with the World Health Organization Disability Assessment Schedule 2.0, which has an official translation available [110]. We replaced the Suicidal Ideation Attributes Scale with the Suicide Behaviors Questionnaire-Revised [111] and we replaced the Overall Anxiety Severity and Impairment Scale with the 7-item Generalized Anxiety Disorder scale [112], both of which have their translation process and psychometric properties published.

In July 2016, the rest of the items were carefully translated into 3 individual sessions of colloquial Spanish, and we conducted 1 round of translation and cultural adaptation for Spanish-speaking populations living in Australia. At this stage, we adapted 3 questions in the demographics sections: country

of origin; language spoken at home, enriched with relevant dialects from Spanish-speaking regions, such as Quichuan and Catalan; and the ethnicity question, modified to the indigenous populations in Latin America.

To reach agreement, 2 individual sessions of back-translations were performed, followed by 1 round of discussion between the translators and back-translators.

User Interface

All participants accepted the Spanish version of the original MHeC's logo (Figure 8). However, young people preferred a name that they could associate more with general well-being than with mental health, as some of them believed that this would have a wider reach among students.

In relation to language, participants expressed different preferences for the linguistic form in which to address the users (interlocutors); Colombian participants (20/32, 63%) favored the use of formal pronouns (usted), as they considered that the

delivery of online health services should follow the same conventions as face-to-face services:

In Colombia, the doctor-patient relationship is always treated in a formal way... [Health professional, quote O]

Participants of other nationalities (12/32, 38%) preferred the prototype to use the colloquial or familiar pronouns (tú, vos), as the formal pronoun seemed excessively formal in an online context. Considering this discrepancy, all participants agreed that the prototype would use the colloquial or familiar form of the second person singular pronoun (tú), as the target of the MHeC-S is young people from different nationalities. Additionally, participants suggested the possibility of a customizing option to choose to see the prototype (1) completely in Spanish (including menus, links, call-to-action buttons, instructions, videos, apps, and e-tools), (2) in a bilingual version

(which would display menus, call-to-action buttons, and instructions in English, but the most relevant content in Spanish, such as the physical and mental health self-report assessment and video visit; or a mix of Spanish and English apps, e-tools, and resources), or (3) completely in English (which would look more like the original MHeC but with relevant information for this population).

Participants in the one-on-one user testing sessions (n=15) assessed the interface in the prototype. These participants approved the MHeC-S's font, color palette (light blue, orange, and green), and the tile-shaped buttons (15/15, 100%). Despite this, young people (7/15, 47%) thought that the Get Started call-to-action button needed to be different (bolder, bigger, brighter, or in a different shape) to get the participants to sign up. In relation to the menus, horizontal or hamburger displays were preferred over the current vertical presentation.

Figure 8. Original Mental Health eClinic logo and its Spanish adaptation. Created by Mandarin Creative



Usability

A total of 15 participants completed 4 usability tasks: (1) create an account and log in, (2) find the Need Help Now button, (3) explore the dashboard of results, and (4) book an appointment. Mean SEQ scores for the tasks were 7 (SD 0); 6.93 (SD 0.26); 5.07 (SD 1.49); 5.80 (1.66) respectively, range 1 to 7. All 15 participants did not report problems completing tasks 1 and 2. In relation to task 3, participants said that exploring all of the dashboard tabs was slightly complicated, as they were not evident at first glance. They had slight difficulty in completing an appointment booking, as the action button was located on the bottom right corner of the site, so this task wasn't intuitive for some participants.

Discussion

Principal Findings

Our study used a comprehensive research and development approach to co-design and culturally adapt a prototypic

Web-based mental health clinic (MHeC) for Spanish-speaking young people based in Australia (MHeC-S). Thematic analysis resulted in adequate acceptability of the 5 main elements of the alpha prototype (a home page and triage system; a comprehensive online physical and mental health self-report assessment; a dashboard of results and progress report; a booking and videoconferencing system to enable video visits; and the generation of a personalized well-being plan that includes links to evidence-based, young person-suggested, health professional-recommended apps and e-tools). The data also revealed gaps in the alpha prototype, such as the need for tailored assessment tools and a greater integration with Spanish-speaking services and communities; a lack of Spanish-language apps and e-tools, and of online mental health information was noted. As a consequence, the development of new features included the addition of cultural adjustment items in the online self-report assessment, creation of specific algorithms, and development of several videos and factsheets ([Multimedia Appendix 2](#)). In the future, the beta prototype should additionally include refinements of language;

explanations of specific medical terminology; and minor changes in layout and navigation.

Migrants and newly arrived residents have been identified as populations who are difficult to recruit, and then to involve and maintain in research [113], yet this is a population in critical need of support. The research and development cycle that we employed in this study is an optimal methodology to engage, retain, and work more efficiently with hard-to-reach populations. We selected various participatory design methodologies to enhance the generation of new ideas and improve the feedback process. The nature of the research and development cycle and the use of diverse methodologies enabled the research to be conducted and completed in a time-efficient manner.

Previous research has highlighted the need to tailor HIT interventions beyond content and language, by including culture [39]. One of the strengths of this study was the incorporation of the cultural framework as a cornerstone of the research and development cycle. As a consequence, we obtained information about the participants' cultural preferences for the prototype's interface and functionality, as well as the development of culturally appropriate content and features. Performing data collection and analysis in the original language reduced the risk of losing relevant information (or meaning), and decreased research time and costs [114]. Other advantages of this study were the variety of origin of participants (Argentina, Chile, Colombia, Spain, and Venezuela) and the research team (Australia, Chile, Colombia, and Venezuela). Furthermore, this research united all relevant stakeholders (young people, supportive others, and health professionals) in a common goal of adapting this prototype to a population in need.

Although Spanish is the second most common language spoken worldwide and HIT is a growing field, Spanish-speaking populations (including migrants and those residing in low- and middle-income countries) are at risk of experiencing not only physical but also technological social health inequalities [115]. This body of research aims to breach this gap by creating a widely available MHeC-S that works across devices. The participation of end users in the design process ensured that the prototype was accessible to individuals of varying literacy levels with a range of cultural differences. Furthermore, the MHeC-S has the potential to be configured and adapted for use in Spanish-speaking countries and in other multicultural countries with Spanish-speaking migrant populations.

Implications

International education in Australia has grown dramatically and is its third largest export industry, contributing Aus \$32.4 billion to the Australian economy [116]. It highlights a significant bilateral exchange (Aus \$755 million in 2012) between Latin

America and Australia, which is increasingly recognized as an important destination for the English education of Latin Americans [117]. In 2017, the Latin American Spanish-speaking international student population had reportedly increased to more than 21,000 [17]. Our study highlighted a critical concern in the community in relation to a shortage of mental health services targeting the well-being of these students. This is vital, as these students are at higher risk of developing adaptational problems and being socially and linguistically isolated [118]. Participants generally expressed a lack of understanding of the Australian health system, particularly service providers and insurance agencies, resulting in an important barrier for students' help-seeking process. Even for those who do know how to navigate the health system, a reduced English competence could impair the care they do obtain. Protecting, caring for, and enhancing positive experiences for international students is Australia's best strategy to protect and grow this industry.

New and emerging technologies present a solution, as they have changed the way young people communicate, connect, and engage with each other and with society. With the introduction of smartphones, information, services, and resources provided online or via mobile apps can be accessed privately and at any time. This can be empowering for individuals who are marginalized or geographically or socially isolated. It could also help to address the need for Spanish-speaking mental health professionals and interpreters. Having an MHeC-S could greatly benefit young people who are native Spanish speakers living in Australia and who are actively seeking help. This study is the first step toward providing a technology-enabled solution to improve this population's mental health and well-being in Australia. To the best of our knowledge, there has been no research to date in this field.

Conclusion

Further research is needed to understand the psychometric properties of the online self-report assessment (eg, criterion validity) and the integration of the MHeC-S with other apps or e-tools. Importantly, additional steps are needed to evaluate the engagement, efficacy, and effectiveness of the MHeC-S in real-world settings. The MHeC-S shares the same elements and functionality of the original version of the MHeC. Its main difference relies on interaction with face-to-face services. The original MHeC was designed to work with primary care mental health services; however, in the case of the MHeC-S, in Australia it could be used additionally by language schools and Overseas Student Health Cover providers. To the best of our knowledge, this study is the first to explore mental health care barriers and facilitators, and potential technology solutions in a language student population; additional research is needed to expand the knowledge on this topic.

Acknowledgments

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back-translation process; and Ms Abigail Escobar for coding the data. This project was funded by the Young and Well Cooperative Research Centre (Western Sydney University, Penrith, Australia; 2014-2016), which was led by Professor Jane Burns.

Conflicts of Interest

IBH was an inaugural Commissioner on Australia's National Mental Health Commission (2012-18). He is the Co-Director, Health and Policy at the Brain and Mind Centre (BMC) University of Sydney. The BMC operates early-intervention youth services at Camperdown under contract to headspace. IBH is the Chief Scientific Advisor to, and a 5% equity shareholder in, InnoWell Pty Ltd. InnoWell was formed by the University of Sydney (45% equity) and PwC (Australia; 45% equity) to deliver the \$30 M Australian Government Department of Health-funded Project Synergy (2017-20); a three-year program for the transformation of mental health services) and to lead transformation of mental health services internationally through the use of innovative technologies

Multimedia Appendix 1

Original quotes in Spanish.

[[PDF File \(Adobe PDF File\), 47KB - jmir_v21i7e14127_app1.pdf](#)]

Multimedia Appendix 2

Development of new features during the rapid prototyping phase.

[[PDF File \(Adobe PDF File\), 30KB - jmir_v21i7e14127_app2.pdf](#)]

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Abbreviations

HIT: health information technology

MHeC: Mental Health eClinic

MHeC-S: Spanish version of the Mental Health eClinic

NSW: New South Wales

PTSD: posttraumatic stress disorder

SEQ: Single Ease Question

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Chapter 5: Translating, Culturally and Context Adapting a Mental Health eClinic for Colombia

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Original Paper

Involving end users in adapting the Spanish version of the Mental Health eClinic for young people in Colombia: A pilot study using participatory design methodologies

Authors: Laura Ospina-Pinillos^{1,2}, Tracey A Davenport¹, Alvaro Andres Navarro-Mancilla³, Vanessa Wan Sze Cheng¹, Andres Cardozo², Andres Mauricio Rangel Martinez-Villalba⁴, German Rueda-Jaimes³, Carlos Gomez-Restrepo², Ian B Hickie¹

Institution/s:

1. The University of Sydney, Brain and Mind Centre, Sydney, NSW, Australia
2. Department of Psychiatry and Mental Health, Pontificia Universidad Javeriana, Bogotá, Colombia
3. Mental Health Department, Universidad Autonoma de Bucaramanga, Bucaramanga, Colombia
4. E-Health Living Lab, Faculty of Medicine, Universidad de Antioquia, Medellin, Colombia

*Corresponding author:

Laura Ospina-Pinillos

Address: The University of Sydney, Brain and Mind Centre, 94 Mallett Street, Camperdown, NSW 2050, Australia

Email: laura.ospinapinillos@sydney.edu.au

Telephone: +61 2 8627 6946

Abstract

Background

Health information technologies (HIT) hold enormous promise for improving access to, and better quality, mental health care. However, despite rapid spread of such technologies in high-income countries, they have not yet been commonly adopted in low-and middle-income countries. People living in these parts of the world are at risk of experiencing not only physical but also technological and social health inequalities. One possible solution is to utilise already available (and successfully implemented) HITs developed in other countries.

Objective

Using participatory design methodologies with Colombian end users (young people, their supportive others, health professionals), this study aimed to: conduct co-design workshops to culturally adapt an online mental health clinic (MHeC) for young people; perform one-on-one user testing sessions to evaluate an alpha prototype of a Spanish version of the MHeC, and adapt it to the Colombian context; and, inform the development of a skeletal framework and alpha prototype for a Colombian version of the MHeC (MHeC-C).

Methods

Utilisation of a research and development (R&D) cycle including four iterative phases: co-design workshops; knowledge translation; tailoring to language, culture and place (or context); rapid prototyping; and then, one-on-one user testing sessions.

Results

Two co-design workshops were held with 18 users (young people n=7, health professionals n=11). A total of 10 participated in one-on-one user-testing sessions (young people n=5, supportive others n=2, health professionals n=3). 203 source documents were collected and 605 annotations were coded. A thematic analysis resulted in six main themes (i.e. opinions about the MHeC-C, Colombian context, functionality, content, user interface and technology platforms). Participants liked the idea of having a MHeC specially designed and adapted for Colombian young people and its five key elements were acceptable in this context (home page and triage system, self-report assessment, dashboard of results, booking and video visit system and personalized well-being plan). However, to be relevant in Colombia, participants stressed the need to develop some additional functionality (eg. phone network backup, chat, geolocation, and integration with electronic medical records, apps or e-tools) as well as adaptation of the self-report assessment. Importantly, the latter not only included language but also culture and context.

Conclusions

The application of an iterative R&D cycle that also included processes for adaptation to Colombia (language, culture, context), resulted in the development of an evidence-based, language-appropriate, culturally-sensitive, context-adapted HIT that is relevant, applicable, engaging and usable in both the short- and longer-term. The resultant R&D cycle allowed for the adaptation of an already available HIT (i.e. MHeC) to the MHeC-C – a low-cost and scalable technology solution for low-and middle-income countries such as Colombia, which has the potential to provide young people with accessible, available, affordable and integrated mental health care at the right time.

Keywords

Colombia; telemedicine; medical informatics; eHealth; mental health; cultural characteristics; cultural competency; ethnic groups; quality of health care; community-based participatory research; primary health care; patient participation; patient preference; patient satisfaction; consumer health information; methods; research design.

Introduction

Background

According to the World Bank, Colombia (48 M inhabitants [1]) is defined as a low-to-middle income country (Gross Domestic Product (GDP) of US\$314 B [2]), however, its one of the most unequal countries in the world (with a 2017 GINI index of 49.7[3]). While the country has spent 7% of its GDP on health over the past 15 years [4], only 0.08% of that spending has gone to mental health – the lowest of all South American countries [5]. Furthermore, although the country has a high level of nationwide health coverage (95%) [6], this is still difficult to access for ethnic minorities and Colombia's poorest regions. This is particularly the case for rural regions, where 15% of the population lives [1]. As the Colombian health system is disease-centered, the continuity and the quality of care is jeopardized in these areas due to the difficulty of attracting qualified specialists [7]. In 2017, it was estimated that there were just 1,003 psychiatrists in Colombia [7] and that 80% of psychiatrists were situated within major cities, resulting in a treatment gap of more than 50% [8].

Colombia has a very young population (40% of the population is aged below 25 years and 18% of the population is aged between 15 and 24 years of age) [9]. According to the most recent Colombian National Mental Health Survey (NMHS) (2015), the lifetime prevalence rates of mental health disorders for adolescents aged 12 to 17 years was 7% (any disorder) and the rate of suicide attempts for this age group was 3% [8]. This survey grouped adults between 18 to 44 years of age, and hence the lifetime prevalence of these disorders in young adults is not clear. In a survey conducted in Medellin in 2012, the lifetime prevalence for young people aged 13 to 29 years of age were: depression 7%; any anxiety disorder 13% and post-traumatic stress disorder 4% [10]. However, there are only a small number of specialized child and adolescent psychiatrists in the country; most of them located in urban areas [11, 12]. Many Colombian adolescents access mental health services (outpatient and inpatient) through adult facilities, which may not be fully equipped to meet their unique needs (appropriate to the stage of illness and developmental period, youth-friendly, stigma-free, preventative, positive, flexible accessible, affordable, etc) which results in more alienation for this young population [13].

Given the nature of the Colombian health system and its geography, the Internet holds promise in bypassing barriers to accessing mental health care for the country's population. This is particularly the case as Colombia has universal Internet access (broadband, satellite or microwave) [14]. A recent information and communications technology use survey revealed that 64% of the households have access to the Internet and that 72% of the households have at least one smartphone. Further, there are more than 1,500 free WIFI hotspots located in major public places of the country. Colombia was one of the first countries in Latin America to propose a specific telehealth legislation (law 1419 of 2010). Its main aim is to integrate health information technology (HIT) interventions into the local health system in order to provide health services across all levels: promotion, prevention, diagnostic, treatment, rehabilitation and health education [15].

Telemedicine in Colombia has been successfully operating since 1998 [16]; today the country has more than 2,500 registered telemedicine service centers, which are located in the major cities and towns [17]. The number of these centers is constantly growing as some of the most important academic institutions and hospitals (public and private) are committed to delivering clinical assessments (including most of the medical specialties) to rural areas and marginalized populations [15, 17, 18]. The delivery of asynchronous telemedicine, which involves delivering end users text messages (more commonly containing questions) to experts (teleconsultation)

has been postulated as an effective method for providing reliable health information and open dialogue about sensitive topics such as sexuality, drug use or health concerns in the country [19-22]. Although HITs in Colombia seem to have a positive impact, most of the interventions still require rigorous evaluation [18].

However, while telemedicine has seen success in Colombia, there are a number of barriers to its further and more integrated implementation into the Colombian health system. There is still a certain degree of skepticism in the general population towards delivering their health care in this way, and health professionals still have limited knowledge on how to work effectively with technology [15, 23]. Notwithstanding the progress in the legislation, the current law still restricts the use of telemedicine in rural populations (therefore limiting its use in medium and small towns) and limits the use of telemedicine as a tool to only when face-to-face contact is not available [15, 16, 23]. Other legal limitations include the need for health professionals to be on both sides of the assessment (institution of remission and institution of reference), meaning that an individual cannot directly connect with local or international health professionals; and some concerns related to security, privacy, data sharing and data integrity [15, 23]. Innovative uses of HITs such as eHealth, mHealth and uHealth are still unregulated.

These barriers contribute to lack of uptake, engagement, and adherence, as well as high drop-out rates. These phenomena can be explained by Eysenbach's attrition law [24], which postulates that a substantial proportion of end users lose interest or experience some difficulties whilst using the technological intervention and will stop using it. This might be due to the perception that the intervention is not creating any benefit, that it is responding to an overly specific need, or that it has usability problems [24]. Although academia-led HITs have the strength of incorporating evidence-based and best clinical practices into their design, it is common to sacrifice the intervention's usability over content due to limited funding [12, 25]. For researchers, it is hard to compete with commercial products that provide highly intuitive and engaging experiences in their products, despite having unknown evidence-based or clinical value [12, 25].

In order to ensure that end users of HITs can derive maximum value from such interventions, it is critically important to involve them in their design and development, and to strike a balance between best clinical practice and user experience (including usability). Participatory design (PD) methodologies represent one such solution [26-28]. The process involves engaging end users and other stakeholders at all stages (from conception to completion) of the design, development and testing of these technologies [27],[29, 30]. Through several iterative phases the prototype is co-designed, co-developed and refined until it has value to the end users, meets their needs, and is appealing, engaging, acceptable and usable[31] [27, 32]. As end users share equal responsibility with the researchers for the outcomes, the rationale behind the use of PD methodologies could result in better products that are more functional in real-life settings, hence closing the translational research gap [27]. In recent years, it is more common to see the use of these methodologies in the development of mental health interventions in English-speaking countries [27-29, 31, 33]. However, to our knowledge these methodologies have yet to be used in Colombia, or any other Latin American country, in this field.

The University of Sydney's Brain and Mind Centre is a leader in development of evidence-based eHealth technologies [12, 27, 34-39]. Through a partnership with the Young and Well Cooperative Research Centre (2014-16) the prototypic version of the Mental Health eClinic (MHeC) [27, 37] was designed and developed. This web-based tool aimed to deliver best practice clinical services to people experiencing mental health problems making clinical care

accessible, affordable and available to young people whenever and wherever they need it most. The original MHeC was then co-designed and culturally-adapted, developed and user tested (2015-17) with Spanish-speaking young people currently living in Australia, resulting in the Spanish version of the Mental Health eClinic (MHeC-S) [32].

The original MHeC consisted of five key elements: a home page with a visible triage system for those requiring urgent help, a comprehensive online physical and mental health self-report assessment, a detailed dashboard of results (with colored icons and traffic light representations of results), a booking and videoconferencing system to enable video visits and the generation of a personalized well-being plan that includes links to evidence-based apps and e-tools recommended by health professionals and suggested by young people [27]. These elements were well accepted by Spanish-speaking young people living in Australia [32]. Considering the potential of the MHeC-S to be configured and adapted for use in Spanish-speaking countries and in other multicultural countries with Spanish-speaking migrant populations, as well as Colombia's health and Internet characteristics described above, we envisioned that a Colombian version of the MHeC (MHeC-C) could greatly benefit young Colombians who are actively seeking help.

Aims

Using a modified version of our already established research and development cycle [27, 32] with Colombian end users (young people aged 16 to 30 years, supportive others and health professionals) as a framework, the aims of this study were to: (1) conduct co-design workshops with end users to culturally adapt the MHeC for young people in Colombia; (2) perform one-on-one user testing sessions with end users to evaluate the alpha prototype of the MHeC-S and how to adapt it to the Colombian context; and (3) inform the development of the skeletal framework and alpha prototype of the MHeC-C.

Methods

Participants

Participants included community-based young people aged 16 to 30 years, health professionals and supportive others with regular access to a mobile phone (iPhone or Android) and the Internet. The recruitment strategy included the identification of potential participants through the reference groups and youth reference groups of our Colombian partner institutions (Pontificia Universidad Javeriana, Universidad de Antioquia and Universidad Autónoma de Bucaramanga), poster and postcard advertisements displayed in common areas where the reference groups meet, Facebook advertisements and a study-specific Facebook page.

The University of Sydney's Human Research Ethics Committee approved this study (Protocol No. 2014/689 for the co-design workshops and Protocol No. 2016/487 for the user testing sessions); however, as requested by the HREC, local (Colombian) approvals were also obtained in order to ensure the study complied with all local regulations on research with humans. Participants were provided with the relevant information about the study (participant information statement) before consenting and participating in the study. Young people received gift vouchers to thank them for their time and expertise when they attended the co-design workshops and the user testing sessions.

Research and Development Cycle (R&D)

The PD methodologies employed in this study were based on the guidelines provided by the Young and Well Cooperative Research Centre [40]. The R&D cycle implemented in this study

has been demonstrated to be an efficient method to obtain the most information from end users by engaging them in different activities. For this pilot study, we conducted a modified version of our previously established R&D cycle [27, 32]. This study consisted of four concurrently running phases: co-design workshops (Phase 1), knowledge translation (Phase 2), content tailoring (Phase 3) and one-on-one user testing sessions (Phase 4). Considering that language and culture are the key aspects in the process of adaptation, we decided to incorporate language and culture as part of the framework the R&D cycle based on. With that in mind, Phase 3 (Language translation and cultural adaptation) [32] of our previous MHeC-S's R&D cycle moved to be the cornerstone of the cycle used in this study, and Phase 3 in this study refers to the content tailoring process only. Phases 4: rapid prototyping and user testing (alpha [a preliminary version that can be interacted with for user testing purposes] and beta [a more refined version of the prototype that is much closer to the final product] prototypes) and 5 (real-world study [with a delta prototype that can be used directly by end users for feasibility testing]) would be the subject of future research.

Phase 1: Co-design workshops

We held two co-design workshops, one with young people and the other one with health professionals. The workshops were conducted in Bogota, Colombia, in 2015. The aim of these workshops was to identify how best to co-design the MHeC-C's alpha prototype; and, more broadly, how to adapt the MHeC to a Colombian setting and population. The half-day (4 hour) workshops consisted of three stages: discovery; evaluation; and prototyping. At the end of each workshop the information was analyzed and synthesized by a knowledge translation team (consisting of two interns at The University of Sydney's Brain and Mind Centre) for design testing in subsequent workshops. Digital technology was not used in any stage of the workshops.

Discovery

Workshop moderators facilitated participant discussion in relation to the following topics: defining the advantages and disadvantages of having a MHeC-C, defining the barriers of having a MHeC-C and how a prototype like this should look and function in order to meet young persons' needs in the Colombian context. Handwritten notes were taken during the entire workshop.

Evaluation

Participants were then presented with screenshots of existing mental health websites and wireframes or mockups of the early versions of the MHeC and the MHeC-S for their critical evaluation. These items contained a variety of features of interest such as the five key elements of the MHeC and other relevant apps and e-tools related to mental health or well-being. Marker pens were provided for participants to annotate their observations.

Prototyping

Finally, participants were asked to hand-draw their ideas, specifications and requirements for a MHeC-C. Sketchbooks and marker pens were provided for this activity.

Phase 2: Knowledge translation process

The knowledge translation process consisted of analyzing the visual artifacts (mockups and end user sketches) produced in the design testing and sketching stages and tallying requested MHeC-C features from the notes taken in Phase 1 (co-design workshops). Observations that were repeated three or more times were considered for inclusion in Phase 4 or in the

development of wireframes. Discrepancies that arose during this process were discussed between the knowledge translation team and two mental health researchers and Colombian psychiatrists (LOP and ANM) until reaching consensus.

Phase 3: Content tailoring

LOP and ANM reviewed the general content of the MHeC-S alpha prototype in order to detect language subtleties. A literature review of published (identified via PubMed, Google Scholar, SciELO, and LILACS) and gray literature (identified via Google Advanced search) was undertaken by LOP to identify relevant measures for this population, as well as those instruments already translated, validated and used in Colombia. Recognizing that some questionnaires might have several versions, the following process was established to select instruments: (1) selection of official and published translations; and (2) selection of published Colombian versions of the official translations. When more than one version or source was available, the two Colombian psychiatrists (LOP and ANM) selected the most appropriate to be included through discussion and consensus. If questionnaires were not publically available or there were no self-report versions for the topics to be assessed, expert recommendation (discussion and consensus between three Colombian psychiatrists LOP, ANM, and AC) was utilised.

Phase 4: Remote one-on-one user testing sessions

Phase 4 involved in-depth one-on-one user testing sessions with new end users (young people, health professionals and supportive others). Sessions were held remotely using GoToMeeting and its shared screen capacity (GoToMeeting by LogMeIn, Boston, Massachusetts, United States, is a screen sharing software that allows users to display the entire screen, multiple monitors or specific applications at any time) [41] using laptops, tablets and mobile phones. In each 90-minute one-on-one user testing session, a researcher guided an end user into the already available alpha prototype of the MHeC-S. Using a think-aloud protocol [42] participants provided their observations as they were shown the navigation through the prototype. These sessions also explored the utility and the end users' inclination to use a MHeC in Colombia, overall comments, and naming of the prototype. Handwritten notes were taken during all sessions.

Data analysis

All source documents (Phase 1 – co-design workshop notes and artifacts, Phase 4 – user testing notes) were uploaded to NVivo 11 for Mac (QSR International) and analyzed using thematic analysis techniques [43, 44]. Importantly, source documents were analyzed at the end of each phase in order to explore preliminary findings and inform subsequent phases. The thematic analysis framework involved both inductive and deductive coding, with the deductive codes being five previously identified themes [32]: help-seeking barriers; technology platform; functionality; content; and user interface [27]. Two researchers (LOP and ANM) coded the material (LOP) and one researcher analyzed the information (LOP). Data collection and qualitative analysis were done in Spanish by LOP and ANM. To facilitate reporting of results, translated quotes from the source documents are included below and Multimedia Appendix 1 lists the original quotes in Spanish.

Results

Co-design workshops and user testing sessions

In June 2015, we conducted one half-day co-design workshop with young people in Colombia and one half-day co-design workshop with Colombian health professionals. In total, we conducted two knowledge translation sessions: one after the co-design workshops (Phase 1) and the other at the end of the one-on-one user testing sessions (Phase 4). We conducted 10 remote one-on-one user testing sessions in August 2017. The language and cultural adaptation process started in June 2015 and finished in November 2017.

Participant characteristics

A total of seven young people participated in the co-design workshops; five were female and their ages ranged from 18 to 22 years (median age 19.5 years). A total of 11 health professionals participated in the workshops; five were female and their ages ranged from 20 to 29 years (median age 27 years). Of the health professionals, two were medical students and the rest were psychiatry registrars.

A total of 10 participants participated in the one-on-one user testing sessions: five young people with ages ranging from 17 to 24 years (median age 22 years); three health professionals with ages ranging from 29 to 36 years (median age 29 years, all of them psychiatrists); and two supportive others with ages ranging from 19 to 24 years (median age 21.5 years). Of these participants, seven were female.

Coding framework

During the co-design workshops a total of 193 source documents were developed and analyzed (two sets of workshop notes and 192 artifacts produced by participants). A total of 312 annotations were coded: 106 annotations in the content theme, 151 annotations in the functionality theme and 47 in the user interface theme. Two new themes emerged in this phase: opinions about the MHeC-C (4 annotations) and Colombian context considerations (4 annotations). There were no annotations in the help-seeking or the technology platform themes in this stage.

During the one-on-one user testing sessions, 10 sets of notes were generated. A total of 293 annotations were coded: 132 annotations in the functionality theme, 58 in the user interface theme, 42 annotations in the content theme, 23 annotations in the opinions about the MHeC-C theme, 20 annotations in the Colombian context considerations theme and 18 annotations in the technology platform theme. There were no annotations in the help-seeking theme, as a consequence it was removed from the coding framework analysis.

For the purposes of this paper, we report the data aggregated from the co-design workshops and the one-on-one user testing sessions, specifying in which session the information was collected where relevant.

Opinions about the MHeC-C

All participants (28/28) liked the idea of having a MHeC specially designed and adapted for a Colombian context. As possible advantages they suggested it would reduce costs; even if initially the investment would be considerable, in the long-run individuals would save time and money and the need of physical infrastructure would be less. All young people (12/12), all health professionals (14/14), and supportive others (2/2) agreed a prototype like this would expand access to health professionals (especially in rural areas), facilitate monitoring

and reduce loss to follow-up. This would ultimately increase satisfaction, convenience and engagement with the health system, as individuals would have more flexibility with their time and no location barriers. Additionally, all health professionals (14/14) felt the prototype would improve the health service network as it would provide specialized assessments regardless of the individuals' location and support for rural professionals. Integrating the MHeC-C with electronic medical records, laboratory results and pharmacological records would increase treatment adherence and provide more objective information that would translate in better monitoring and health outcomes. Some health professionals from the co-design workshops (7/11) also believed that this prototype could be safer in cases of assessing individuals with violent behaviours, whilst the rest (6/11) believe they would feel safer if the MHeC-C was part of the already established health network.

However, regarding disadvantages and barriers, all participants (28/28) mentioned that in some places the Internet connection is not reliable so the prototype needs to be backed up with a phone network. Among barriers of using a MHeC-C, all young people (12/12) mentioned difficulties accessing the Internet, as most young people don't pay for mobile data and therefore require Internet access in their homes, schools or free WIFI networks. All health professionals (14/14) recognized that the MHeC-C could have limited utility in acute cases or in cases where performing physical (neurological) assessments would be required.

Colombian context considerations

Overall, health professionals (14/14) believed the MHeC-C should be led by a partnership between a university and a health service provider and have strong networks with the community and other relevant organisations. Partnership with local governments and stakeholders would be necessary but especially relevant in rural settings to increase trust in the prototype. In order for people to use the MHeC-C it needs to be recommended by clinicians, health services, and school and university well-being centres, which should be complemented with publicity and media coverage (e.g. radio, television, social networks, magazines, newspapers, etc). As most young people are not economically independent it would be important that the MHeC-C would be embedded in the public healthcare system.

In relation to the branding and name of the MHeC-C, young participants (12/12) considered that the combination of terms "mental health" and "clinic" would be less appealing for them as they might feel the MHeC-C deals only with severe cases and might not be appropriate for them and that it would, as a consequence, be more stigmatizing.

Functionality

As defined by Valdez et al in their culturally-informed design framework [45], functionality indicates the actions that can be performed in the prototype. All participants (28/28) agreed that the five key elements of the MHeC-C were acceptable in this context. In general, participants agreed the MHeC-C should be compliant with international cybersecurity standards to ensure privacy and data protection.

Element 1: Home page and triage system

All participants (28/28) agreed that in order to gain trust and increase credibility, the MHeC-C webpage's domain should be ".com", ".co", or ".org". Alternatively, the MHeC-C could be imbedded in universities' official websites, as they believe universities should have a lead role in the development and maintenance of this kind of prototype. Logos of the principal institutions as well as partner organisations should be displayed at this stage. Participants also agreed with providing a small description of the MHeC-C, delivered with images, videos and

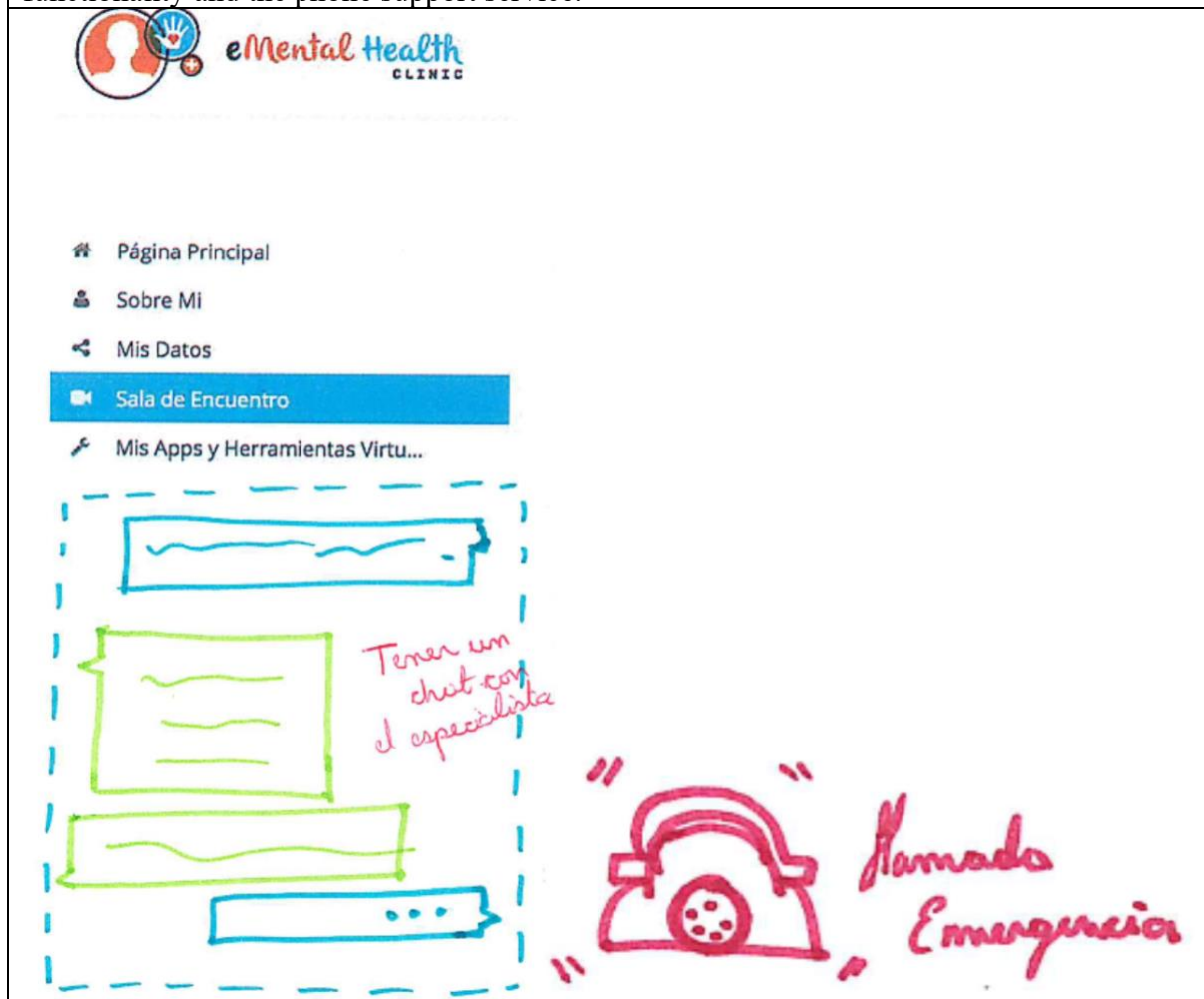
testimonials from young people and health professionals. Both young people and health professionals agreed the initial home page could be the same for both groups; however, after registration and logging in processes, the prototype would change in order to address both user types' different needs.

All participants liked the triage functionality and recognized the importance of referring someone to emergency help services promptly. In the same line, the 'Need Help Now' button was identified as an important resource for people in crisis that didn't know the emergency lines. Participants highlighted the importance of this button to be associated with a geolocation system, as in Colombia emergency (psychological) numbers change according to their location. As one health professional explained:

"...the general emergency line is the same 123, but the psychological emergency line changes, for example in Bogota it is 106 and in Cartagena it is 125... [health professional, quote A]

As online services are scarce in Colombia it was proposed to have an 24/7 moderated online chat that would provide support and counselling to individuals seeking help. For young people, this functionality would be situated under the 'Need Help Now' button. Health professionals believed a functionality like this would also be useful for them to provide guidance and supervision to other less experienced health professionals (e.g. general practitioners in their social compulsory service) or to those located in rural areas. The chat functionality for health professionals would work only for health services and professionals attached to the MHeC-C. In case the Internet connection is intermittent or lost, the chat functionality should also have a phone support service that would be enabled to continue with the conversation (Figure 1).

Figure 1. Hand-drawn sketch by end users during a PD workshop representing the chat functionality and the phone support service.



Participants acknowledged the difficulty of having health professionals available at all times to chat, so they proposed the chat to work only during extended hours (from 6 am to 12 am) and in off-time hours, have the possibility to leave a question to be answered later. At the same time, young people recognized the importance of having carefully moderated blogs, forums or group chats with a selection of helpful topics to find support and learn from other people's experiences. Figures 2 and 3 represent the proposed home page for future developments.

Figure 2. Hand-drawn sketch by end users during a PD workshop representing the home page

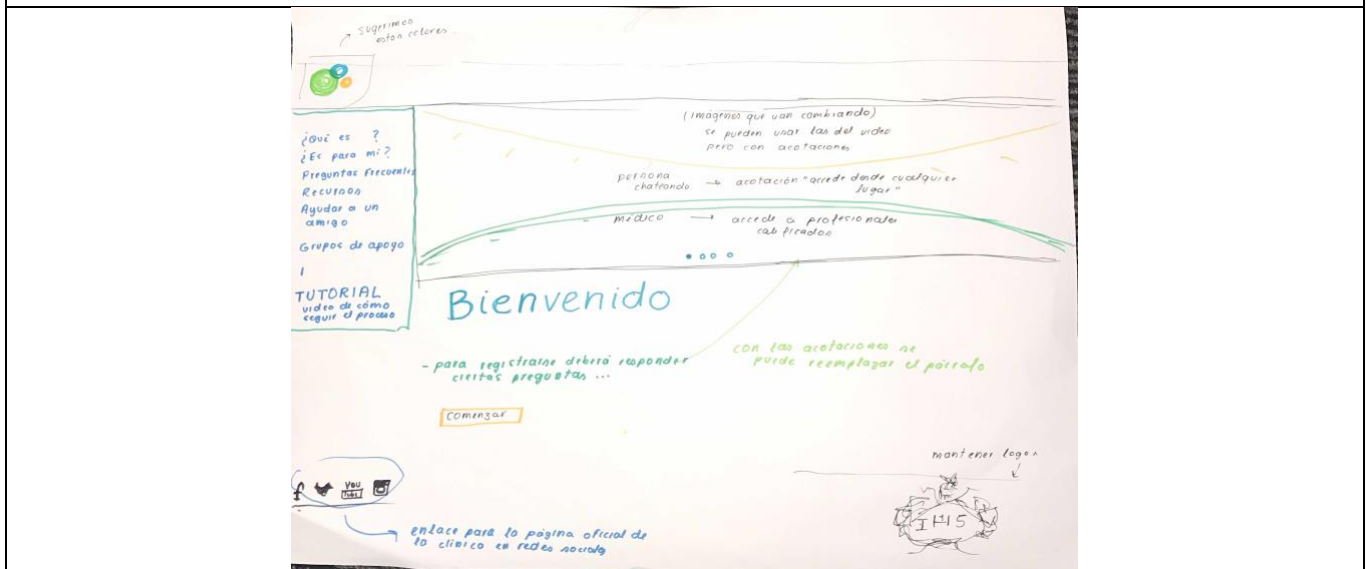


Figure 3. Skeletal framework of the home page of the MHeC-C



Element 2: Online physical and mental health self-report assessment

All participants agreed with the need to assess young people's physical and mental health. The already established features of this element were accepted among the end users: modular display of question sets, capacity of pausing and resuming later, and rule-based decision algorithms that enable personalized assessment of the young person. Again, participants mentioned the possibility of using geolocation in order to automatically collect data about the participants and personalize the assessment. As one health professional explained:

"...it would be very useful to geolocate the person, this means the prototype would be able to know where they are so they don't have to waste time filling their addresses. Also, as Colombia is so diverse, we know that the regions have different needs so the questions could be specific to those needs. For example, in regions affected with violence, assessing this topic in-depth would be crucial. Another example would be

assessing thoroughly the social determinants of health if the person lives in a poor area or is identified with a low socioeconomic status... [Health professional, quote B]”

The type of questions in the prototype (Likert-type scale questions and two-way closed-ended) were also acceptable to participants. However, health professionals (11/14) suggested adding visual responses such as the pain visual analogue scale [46] and including one open-text question with the aim of assessing the individuals’s reason for accessing the MHeC-C over traditional face-to-face services.

Element 3: Dashboard of results and progress report

There was a discrepancy in end users’ opinion on the immediate display of the dashboard of results after completion of the online self-report assessment. All young people (12/12) and some of the health professionals (6/14) agreed the prototype should display the results immediately. Other health professionals (8/14) were concerned with the pertinence of the results as a young person could potentially experience some distress facing their results, especially for those living in rural areas. As a potential solution to this, participants suggested giving individual’s the option to pick if they want to see their results immediately or wait to review their results with a health professional.

Participants agreed with the traffic light representations and colored icons. Simple bar and line graphs were preferred to represent progress and track data over time. Health professionals considered that the dashboard of results was useful to inform their practice, making the assessments more efficient and specific as well as enabling them to deliver interventions earlier and monitor the individual’s progress over time. Additionally, health professionals believed that the results of the assessment and the dashboard were useful research tools. In relation to the dashboard’s language, lay terms were preferred over medical terminology. The option of displaying a simple explanation of the term (only when medical terms are needed) when they click on the word or hover over it was widely accepted among the participants.

Element 4: Booking system and video visit

Before booking a video visit, participants wanted to see the profiles of the health professionals attached to the MHeC-C so they could choose the professional they want to see. As a young person explained:

“...I would like to know more who I’m going to see, so I can decide if I see a man or a woman or see what are their areas of expertise...[young person, quote C]”

Additionally, it was proposed to have calendar functionality so young people could book appointments according to health professionals’ availability. This functionality should also reflect other relevant calendars such as the health professional’s calendar and the administrative staff so they can use it for other purposes such as billing.

Health professionals preferred that the video visit could also be a useful tool to provide supervision, training and consultation to colleagues located in rural areas. As a health professional explained:

“...doctors in their social compulsory service (located in rural areas) might need support from specialists, it would be very useful to use the video visit system to help them assessing difficult cases or to provide supervision...[health professional, quote D]”

Additionally, as some health services still have paper-based medical records, having an electronic medical record attached to the MHeC-C would be ideal so all individual's information would be stored in the same place.

Given that health professionals would have detailed and accurate self-report information before the video visit (dashboard of results) all participants agreed that around 20 minutes would be enough time to assess a young person and provide recommendations. Health professionals would also like the possibility to extend video visit time with complex cases. Should a video visit appointment run late, health professionals also suggested that the MHeC-C should send a notification to people waiting for subsequent appointments.

Element 5: Personalized well-being plan includes links to evidence-based, young person-suggested and health professional-recommended apps and e-tools

Participants accepted the activation of a personalized well-being plan and recommendations according to their results. Young people and health professionals believed these recommendations could be delivered as: apps, videos, or printable material. Health professionals suggested the MHeC-C to be connected to the website “mental punto de apoyo” (<https://www.javeriana.edu.co/mentalpuntodeapoyo/>) [47, 48] as this informational website has a wide variety of information, psychoeducational material and community blogs for individuals, carers and health professionals.

The shortage of Spanish-language apps and e-tools was also raised. Health professionals believed that developing such apps to track variables such as mood, sleep, physical activity and nutrition, as well as interventional apps that contain cognitive behavioral therapy strategies and mindfulness, would be necessary. In general, participants believed these apps and e-tools need to be in Spanish as the chances of using an English-based app are minimal. The need to create videos with general information, as well as relaxation and breathing exercises, was also mentioned.

Content

General content

Content refers to the message that is transmitted [45]. Participants from the one-on-one user testing sessions had the opportunity to explore the alpha prototype of the MHeC-S. These participants (10/10) found that some pieces of general content already available were relevant for them but needed minor tweaks to fit the context such as: general information about the MHeC-S, breathing exercises, frequently asked questions and how to help a friend. Other content including: health services information, terms and conditions and information about partner organisations needed major changes to be relevant to Colombia. Again, the scarcity of Spanish-language apps and e-tools was highlighted as they are the cornerstone of the personalized well-being plan.

Cultural adaptation of the self-report assessment

The original Spanish-language self-report assessment included 20 modules (Table 1) with smart skips built in so that it was tailored to each individual and took the minimum possible amount of time to complete (approximately 45 minutes) [32]. Of the 20 modules, 19 modules were considered relevant by the participants and one module (cultural adaptation and adjustment disorder) was considered unnecessary. Health professionals (3/3) and supportive others (2/2) from the one-on-one user testing sessions suggested including further topics to be

assessed. As 'family' is very important in Colombian culture, it was suggested to assess family structure and support network. Religion and spirituality were also considered important factors to be assessed as they might influence an individual's mental health, act as support or define some treatments. Due to the country's characteristics it was also considered necessary to evaluate social risk by screening economic stability, neighborhood and physical environment, food security and access to the healthcare system [49]. As Colombia has been severely affected by violence, participants also suggested to evaluate violence exposure, trauma and resilience.

The cultural adaptation of the self-report assessment started in November 2016, with the literature review. We found six questionnaires that could be integrated to the MHeC-C in order to address the already mentioned needs. In order to assess family structure and support network, we selected the family APGAR that has been widely used in Colombia [50, 51]. In order to assess social risk we selected items assessing socioeconomical status, food insecurity, sanitation, access to drinking water, electricity, housing, assets and healthcare from the National Mental Health Survey (NMHS, 2015) [51]. Items regarding attitudes and experiences to violence (domestic violence, organized crime, displacement and armed conflict) from the NMHS were also included. Selected items from the Adverse Childhood Experiences questionnaire were selected to enrich the trauma component [52]. In relation to resilience we found three scales validated in the Colombian context –Adolescent Resilience Scale [53], Child and Youth Resilience Measure 12-item [54], and Connor-Davidson Resilience Scale (CD-RISC 10) [55]. All of these scales assess resilience's internal resources [56], however, the last two assess external resources as well. We selected the CD-RISC 10 as it has been widely used in the country and for its length. Religion and spirituality were also assessed with selected items from the NMHS. Table 1 represents the proposed self-report assessment for the MHeC-C.

Table 1 Self-report assessments in each the MHeC-S and the MHeC-C

| Self-report assessments of the MHeC-S ^a | | Self-report assessments of the MHeC-C ^b | |
|--|--|--|--|
| Module | Questionnaires | Module | Questionnaires |
| 1. Main reason for visiting the MHeC-S | | 1. Main reason for visiting the MHeC-C | |
| | Short open-text question | | Short open-text question |
| 2. General demographics | | 2. General demographics | |
| | Items adapted to Spanish from the Second Australian Young and Well National Survey [57] and the two-step method to measure transgender identity [58]. | | Items adapted to Spanish from the Second Australian Young and Well National Survey [57] and the two-step method to measure transgender identity [58]. Religion, spirituality socioeconomic status, food insecurity, sanitation, access to drinking water, electricity, housing, assets and healthcare selected items from the NMHS [51]. |
| 3. Social and occupational function | | 3. Social and occupational function | |
| | World Health Organization Disability Assessment Schedule 2.0 [59], and an adapted version of the self-report version of the Social and Occupational Functioning Assessment Scale [60]. | | World Health Organization Disability Assessment Schedule 2.0 [59], and an adapted version of the self-report version of the Social and Occupational Functioning Assessment Scale [60]. |
| 4. Psychological distress | | 4. Psychological distress | |
| | 10-item Kessler Psychological Distress Scale [61]. | | 10-item Kessler Psychological Distress Scale [61]. |
| 5. Depressed mood | | 5. Depressed mood | |
| | Quick Inventory of Depressive Symptomatology (QIDS-SR-16) [62, 63]. | | Quick Inventory of Depressive Symptomatology (QIDS-SR-16) [62, 63]. |
| 6. Anxiety | | 6. Anxiety | |

| | | | | |
|---|--|--|--|--|
| | | Generalized Anxiety Disorder Assessment (GAD-7) [64]. | | Generalized Anxiety Disorder Assessment (GAD-7) [64]. |
| 7. Mania-like experiences | | Items derived from the Altman Self-Rating Mania Scale [65]. | 7. Mania-like experiences | Items derived from the Altman Self-Rating Mania Scale [65]. |
| 8. Psychosis-like experiences | | Items derived from the Community Assessment of Psychic Experiences-Positive Symptoms Scale [66, 67]. | 8. Psychosis-like experiences | Items derived from the Community Assessment of Psychic Experiences-Positive Symptoms Scale [66, 67]. |
| 9. Traumatic experiences | | Primary Care PTSD Screen [68] and the PTSD Checklist-Civilian Version [69]. | 9. Violence exposure and traumatic experiences | Attitudes and experiences to violence (domestic violence, organized crime, displacement and armed conflict) form the NMHS. Selected items from the Adverse Childhood Experiences [52]. Primary Care PTSD Screen [68] and the PTSD Checklist-Civilian Version [69]. |
| 10. Self-harm behaviors and suicidal ideation | | Suicide Behaviors Questionnaire-Revised (SBQ-R) [70]. | 10. Self-harm behaviors and suicidal ideation | Suicide Behaviors Questionnaire-Revised (SBQ-R) [70]. |
| 11. Tobacco, alcohol, and substance use | | | 11. Tobacco, alcohol, and substance use | |

| | | | |
|--|--|--|--|
| | Items adapted from Alcohol Use Disorders Identification Test [71]; Alcohol, Smoking and Substance Involvement Screening Test [72]; and Cutting down, Annoyance by criticism, Guilty feeling, and Eye-openers questionnaire [73]. Items adapted to Spanish from the Drinking Motives Questionnaire [74], Fagerström Test for Nicotine Dependence [75], and selected items adapted to Spanish from the National Drug Strategy Household Survey [76]. | | Items adapted from the Alcohol Use Disorders Identification Test [71]; Alcohol, Smoking and Substance Involvement Screening Test [72], and Cutting down, Annoyance by criticism, Guilty feeling, and Eye-openers questionnaire [73]. Items adapted to Spanish from the Drinking Motives Questionnaire [74], Fagerström Test for Nicotine Dependence [75], and selected items adapted to Spanish from the National Drug Strategy Household Survey [76]. |
| 12. Physical activity | International Physical Activity Questionnaire [77, 78]. | 12. Physical activity | International Physical Activity Questionnaire [77, 78]. |
| 13. Sleep behaviors | Sleep-related items from the QIDS-SR-16. | 13. Sleep behaviors | Sleep-related items from the QIDS-SR-16. |
| 14. General mental health conditions | Spanish version of the World Mental Health Composite International Diagnostic Interview used in the National Comorbidity Survey Replication Adolescent Supplement [79, 80]. | 14. General mental health conditions | Spanish version of the World Mental Health Composite International Diagnostic Interview used in the National Comorbidity Survey Replication Adolescent Supplement [79, 80]. |
| 15. Overall health and somatic distress | Items adapted to Spanish from the Somatic and Psychological Health Report [81], self-perceived health status, and general body measurements. | 15. Overall health and somatic distress | Items adapted to Spanish from the Somatic and Psychological Health Report [81], self-perceived health status, and general body measurements. |
| 16. Medical, mental health, and family history | Multiple-choice questions | 16. Medical, mental health, and family history | Multiple-choice questions |

| | | | |
|---|--|--|---|
| 17. Cognitive concerns and empathy | | 17. Cognitive concerns and empathy | |
| | Items derived from the Subjective Scale to Investigate Cognition in Schizophrenia [82] adapted to Spanish and the empathy quotient [83]. | | Items derived from the Subjective Scale to Investigate Cognition in Schizophrenia [82] adapted to Spanish and the empathy quotient [83]. |
| 18. Eating behaviors and body image | | 18. Eating behaviors and body image | |
| | Items derived from the Eating Disorder Examination [84] adapted to Spanish. | | Items derived from the Eating Disorder Examination [84] adapted to Spanish. |
| 19. Social connectedness and support | | 19. Social connectedness, support and family structure | |
| | Items derived from the Perceived Social Support/Conflict Measure [85] plus five items measuring relationships with peers [86] adapted to Spanish. | | Items derived from the Perceived Social Support/Conflict Measure [85] plus five items measuring relationships with peers [86] adapted to Spanish and family APGAR [50, 51]. |
| 20. Cultural adaptation and adjustment disorder | | 20. Resilience | |
| | Adaptation Scale (BSAS), Brief Psychological Adaptation Scale (BPAS), Brief Perceived Cultural Distance Scale (BPCCDS), and Brief Acculturation Orientation Scale (BAOS) [87]. | | Connor-Davidson Resilience Scale (CD-RISC 10) [55] |
| | | 21. Cultural adaptation and adjustment disorder | |

| | | | | |
|--|--|--|--|--|
| | | | (Optional, Consider in case of migrant populations) | Adaptation Scale (BSAS), the Brief Psychological, Adaptation Scale (BPAS), the Brief Perceived Cultural Distance Scale (BPCDS) and the Brief Acculturation Orientation Scale (BAOS) [87] |
| | | | | |

^aMHeC-S: Spanish version of the Mental Health eClinic.

^bMHeC-C: Colombian version of the Mental Health eClinic.

^cPTSD: posttraumatic stress disorder

User interface

User interface refers to the visual presentation of content and functionality [45]. When shown the homepage, participants agreed that the website should look professional but also be appealing and engaging for a young person. Horizontal menus were preferred over vertical menus in a laptop interface, but hamburger and vertical menus were the preference in tablets or mobiles. Young people (12/12) preferred to have less text and more visual content. Health professionals (14/14) and supportive others (2/2) also recognized the importance of visual content as they believed young people tend to read just the minimum amount of text and that information could be lost. Participants preferred to have on the home page pictures of young people interacting with the MHeC-C with a light background or calming landscape.

The colour palette suggested in the co-design workshops was blue-greens complemented with yellow-oranges. However, participants from the one-on-one user testing sessions liked the orange colour. The MHeC-S logo was rejected by participants in the one-on-one user testing sessions as they did not find any representation of mental health on it and did not find the colour appealing. Most participants (24/28) suggested a logo depicting a brain or a head (Figure 4):

“...It reminds me of orange uniforms of the Colombian Civil Defense... [young person, quote E]”

“...I might be wrong but the logo needed to include a brain or a head or something like that... [health professional, quote F]”

Figure 4. Hand-drawn sketch by end users during a PD workshop representing the MHeC-C's logo



Participants felt that the ‘Need Help Now’ button needed to draw individuals’ attention, and suggested making this button bigger or brighter and perhaps adding an icon that represented help such as a ringing phone, a Christian cross or a SOS acronym. Participants also felt that ‘Need Help Now’ should provide chat functionality as well as information about local emergency phone lines.

In relation to the interface’s language (regarding formal and informal pronoun usage), all end user groups agreed that the preference to use a particular pronoun was not an issue; however, they highlighted the importance of using the pronouns consistently. As a health professional explained:

“...the country is so diverse that there are regions that use formal pronouns and others informal pronouns, the most important thing is to use it consistently... [health professional, quote G]”

As a possible solution to reconcile this discrepancy it was proposed that the prototype used the colloquial or familiar form of the second person singular pronoun (tú) as it was targeting young people.

Technology platform

Technology platform refers to the different types of hardware [45] the prototype should work on. Unanimously, participants agreed that mobile phones were the most important device to increase the reach of young people. However, health professionals also suggested it should work on desktops, laptops and tablets – which are their preferred devices in the workplace.

Discussion

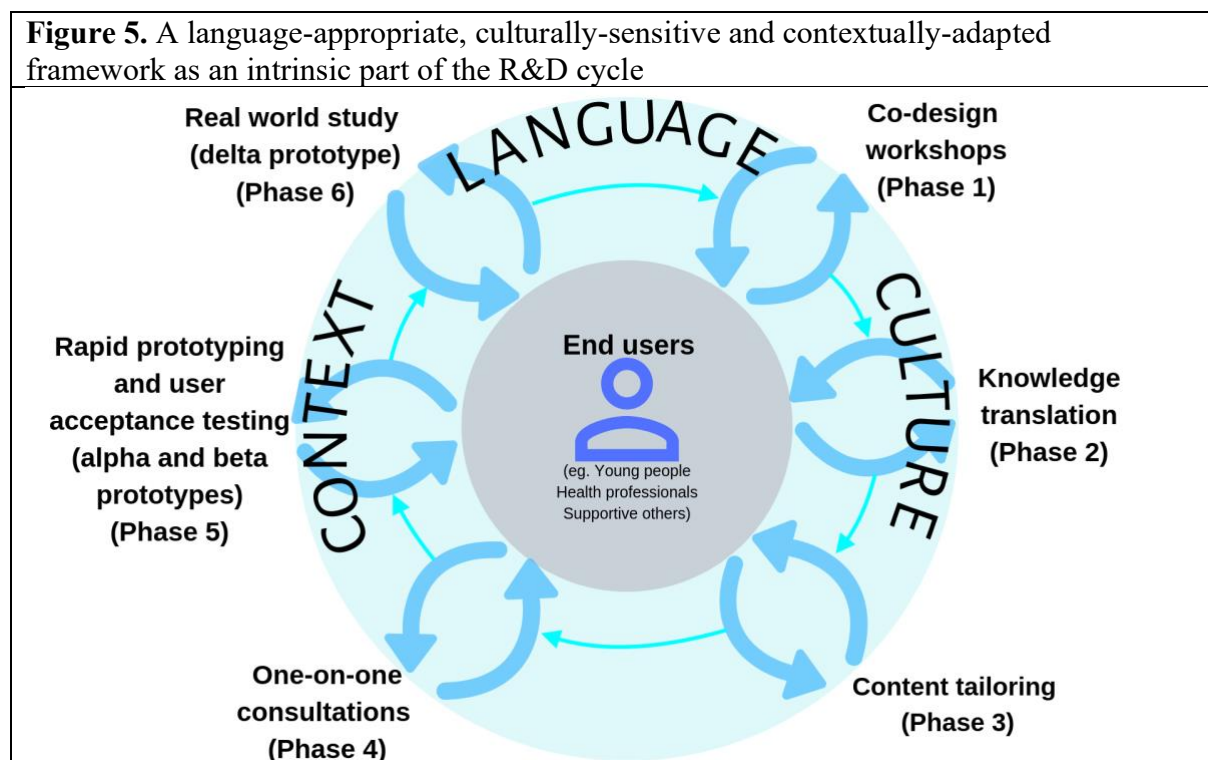
Principal findings

This pilot study used a modified version of our previously established R&D cycle to co-design and culturally-adapt a prototypic Spanish-language version of a Web-based mental health clinic (MHeC-S) into a Colombian version for young people in Colombia (MHeC-C). Thematic analysis resulted in adequate acceptability of the functionality of the five key elements of the prototype (a home page and triage system; a comprehensive online physical and mental health self-report assessment; a dashboard of results and progress report; a booking and videoconferencing system to enable video visits; and the generation of a personalized well-being plan that includes links to evidence-based, young person-suggested, health professional-recommended apps and e-tools). However, in order for these elements to be relevant in Colombia, participants stress the need to develop additional functionalities such as backing up the system with a phone network, a chat system, a geolocation system, and wide integration with electronic medical records and other already available apps and e-tools. Participants stated that in order to make the MHeC-C appropriate to the (Colombian) context, it needed to operate in alliance with academic institutions, health providers (at all levels) and other community organizations. Due to the unique Colombian context, the self-report assessment needed to include items evaluating (including the creation of specific algorithms) the social determinants of health, attitudes towards and experiences of violence, resilience and extending the trauma module to assess childhood adverse experiences. In relation to the future build of the MHeC-C, it needed to include refinements to the interface such as: changing the color palette, designing a logo that makes reference to mental health, and further modifications in language.

While the MHeC-S was comprehensible to our Colombian participants, many changes were requested. In agreement with other authors [88] we strongly advocate for the need to adapt HITs beyond language by considering cultural variations. The same authors suggest adapting or designing HITs to acknowledge cultural differences in four main dimensions: content, functionality, technology platform and user interface [45]. However, the methodology needed to achieve this has not been conceptualized. Continuing with our previous research [32], we aimed to adapt our prototype using a modified version of our previously established research and development approach [31] within a framework composed of two dimensions (language and culture). During this study a new theme emerged which added the missing piece of the methodology, the contextual adaptation. As a result, it was possible to obtain culturally and contextually appropriate information about what is required in terms of content and functionality, as well as preferences for the prototype's interface and the technology platform. All of this was done in a participative, collaborative and time-efficient manner. The

approach enabled us to collect information, define the needs and find solutions on how the MHeC-C would respond to them.

In order to make these HITs available in other languages, cultures and places, it is necessary to tailor them beyond just language. In other words, it is important to consider them within a culturally and contextually appropriate framework. This framework should also incorporate the use of participatory design methodologies that involve stakeholders and end users from the beginning in the co-design, development and adaptation of these HITs (Figure 5). To our knowledge, this paper reports the first body of research that proposes a methodology researchers can replicate and use to adapt HITs. A systematic use of such methodologies would finally result in the development of evidence-based, culturally-sensitive, contextually-adapted HITs that are relevant, appropriate, engaging and usable in the short- and longer-term.



Data shows that people living in rural areas receive less mental health treatment than those residing in metropolitan areas [89]. As almost one quarter of the Colombian population lives in rural areas, the systematic adaptation process used in this study allowed us to thoroughly identify the potential specific requirements for rural populations such as the chat functionality to support local general practitioners (including those health professionals completing their social compulsory service), a geolocation system that will help tailor helplines and services available around them and necessary adaptations of the content of the MHeC-C's self-report assessment to reflect rural needs. Despite the proposed benefit, it is important to consider the barriers and challenges to implement the MHeC-C in real settings. Mental health and digital literacy levels are common obstacles in the implementation of HITs; it is well known that many people around the globe are unable to recognize mental disorders [90, 91] and that this lack of knowledge associated with stigma could prevent people from seeking help and providing treatment to those in need. These problems are a particular concern in low-and middle-income countries where health services are already limited [92].

Health professionals in our study showed some degree of apprehensiveness in relation to the aptitudes required for, and the pertinence of, an automatic display of the dashboard of results for young people. Paternalistic attitudes are no longer desirable as they increase the asymmetry in the relationship and finally lead individuals to agree with the health professional's decisions [93, 94]. The patient-centred approach and shared-decision making encouraged by the MHeC-C gives individuals more control and promotes mutual participation; and, research has shown that this type of care translates to better health outcomes and a more efficient health system [95, 96]. Increasing the individuals' power, strengthening critical thinking and empowering more informed and autonomous decisions are key concepts in HITs as they act as digital companions by providing individuals greater participation in the decision making process [97]. HITs also assist health professionals in presenting their advice in a respectful manner that includes the individual's singularity and complexity [98]. The proposed elements (dashboard of results and personalised well-being plan) of the MHeC-C could enhance young people's understanding of their health status, assist them in the decision making process, build their sense of agency and promote their functional empowerment.

Another challenge would be the integration of the MHeC-C with the current Colombian health system and benefit schedule which is under the administration of several public and private institutions (that use regulated government funds) [99]. As there are many institutions involved in provision of services, the MHeC-C would need to integrate with all of them in order to avoid perpetuating health inequities. The final goal of developing HITs is to actually develop a prototype that has great value for all end users even if the set of functionalities are different. For example, while a young person would use the MHeC-C to improve their health and wellbeing, track their progress, and stay connected to their health professionals, health professionals would use the system to inform their day-to-day practice, access support and training, and facilitate communication with those under their care. By building an appealing, usable prototype that responds to these specific needs based on end user type, we aim to surpass the attrition law and sustain usage over time.

Our strategic partnerships made it possible for a native Colombian team of researchers to conduct all the phases (including data collection and analysis) in the Spanish language. This approach reduced the risk of losing information (or meaning), and increased research efficiency by decreasing time and costs [100]. Additionally, through working closely with end users, the adapted R&D cycle allowed constant iteration of the MHeC-C in response to technological advances and end user needs. Effective engagement with local stakeholders, the use of local capacities and systems, and measuring relevant results for the community have been identified as strategies to promote translational research in low-and middle-income countries [101].

Implications

Countries like Colombia, which have limited resources allocated to health (7% of its GDP), struggle to make decisions regarding where to invest in order to have the best outcomes. HITs show promise in reducing costs and being cost-efficient in the long-run [102, 103]; however, the development (from conception to implementation and sustainability) is an expensive and arduous process [104, 105]. At the same time, building up capacity by training health professionals and increasing infrastructure is also a slow and pricey pathway [106-108]. As a solution, we proposed a rigorous methodology to adapt already available (and evidence-based) HITs along three main pillars: language, culture and context. A systematic use of this approach has the potential to reduce costs and to increase the number of HITs

available (in different languages and cultures) in a time-efficient manner. HITs that show value in terms of content and appropriateness to context could integrate with already available health systems and finally help to breach not only physical, but also technological and social health inequalities [109], making health care more accessible, affordable and available.

The Colombian context is complex as despite economic growth, it continues to be one of the most unequal countries in the world [110]. One quarter of its population live in rural settings with low numbers of health professionals, limited infrastructure [11], and high levels of violence following five decades of internal conflict. This results in a high level of challenge for individuals, health professionals, health providers and decision-makers to change the delivery model as well as treatment standards. Web-based solutions mark a paradigm shift beyond traditional models of health-care delivery. Integrating physical resources with HITs would capitalise on Colombia's heavy investment in telecommunications and could enable the Colombian population to access new resources, make better use of expertise and provide better access for individuals, peers and families. This should be done through collaborative interdisciplinary work with ongoing international support to capitalise on global medical knowledge and find new solutions, leading to quicker innovations in health service delivery.

Limitations and future research

While the importance of adapting HITs appropriately to the local context cannot be overstated, it must also be acknowledged that contexts are in constant change. For example, Colombia's population makeup has changed since 2015 (when the workshops were conducted) due to recent migration from Venezuela. In the past year, more than 350,000 people have migrated from Venezuela [1], and at the beginning of 2019 it was calculated that there were more than 1 M Venezuelans residing in the country. Migrant populations have been identified to be at greater risk of psychological distress or common mental disorders, and host countries must respond to this effectively. A pressing future need of the MHeC-C would be to include migrant populations; therefore, a new cycle of adaptation would be required. As an initial proposal and capitalizing from our previous research [32] the new version of the MHeC-C would include the cultural-adaptation and adjustment disorder (available from the MHeC-S) items as the addition of the assessment of other risk factors such as: conditions of the migration process, level of acculturation, family reunification, perceived discrimination, and the length of time of the residence in the host country [111]. Further research is also needed to develop the MHeC-C and test its engagement, efficacy, and effectiveness of the MHeC-C in real-world settings.

Conclusions

In low-and middle-income countries, the potential to utilise already developed HITS for improved access to, and better quality, mental health services is enormous. This would result in not only better mental health outcomes for young people but also more efficient, effective and appropriate use of scarce health professional knowledge and clinical skills, as well as quality improvements in mental health service delivery. Here, an adapted R&D cycle resulted in a technology solution acceptable for use by Colombian young people (and their supportive others) experiencing mental health problems as well as health professionals delivering care. This methodology should now be applied to other HITs as a means to bridge the digital and health care gaps not only in Colombia and the developing world; but also globally to other

communities or settings where resources are scarce, culture matters and/or geography presents a challenge.

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Abbreviations

GDP: Gross domestic product

HIT: Health information technology

KT: Knowledge translation

MHeC: Mental Health eClinic

MHeC-C: Colombia version of the Mental Health eClinic

MHeC-S: Spanish version of the Mental Health eClinic

NMHS: Colombian National Mental Health Survey

PD: Participatory design

PTSD: Posttraumatic stress disorder

R&D: Research and development

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Appendix 1

Quote A: “...the general emergency line is the same 123, but the psychological emergency line changes, for example in Bogota it is 106 and in Cartagena it is 125...”:

La línea general de emergencias es 123, pero las líneas de atención psicológica cambia por ejemplo en Bogotá es 106 pero en Cartagena es 125

Quote B: “...it would be very useful to geolocate the person, this means the prototype would be able to know where they are so they don't have to waste time filling their addresses. Also, as Colombia is so diverse, we know that the regions have different needs so the questions could be specific to those needs. For example, in regions affected with violence, assessing this topic in-depth would be crucial. Another example would be assessing thoroughly the social determinants of health if the person lives in a poor area or is identified with a low socioeconomic status...”:

Sería muy útil geolocalizar a la persona. Esto nos ayudaría a que el sistema supiera donde se encuentran y así los pacientes no tienen que perder tiempo llenando donde viven. Además, cómo vivimos en un país tan diverso en sus necesidades sería una buena idea que las preguntas reflejaran esto. Por ejemplo, en las regiones más afectadas por la violencia pudiéramos evaluar este tema en profundidad. Otro ejemplo sería en regiones más pobres o de bajo estrato socioeconómico valorar bien los determinantes de la salud...”

Quote C: “...I would like to know more who I'm going to see, so I can decide if I see a man or a woman or see what are their areas of expertise...”:

Me gustaría saber quien me va a atender, elegir entre un hombre o una mujer o saber quien es experto en las áreas que me interesan.

Quote D: “...doctors in their social compulsory service (located in rural areas) might need support from specialists, it would be very useful to use the video visit system to help them assessing difficult cases or to provide supervision...”:

Los rurales pueden necesitar ayuda de los especialistas con los casos difíciles, el Sistema de videoconferencia sería útil en estos casos para ayudarles con las valoraciones o supervisarlos

Quote E: “...It reminds me of orange uniforms of the Colombian Civil Defense...”: Me hace pensar en los uniformes anaranjados de la Defensa Civil Colombiana

Quote F: “...I might be wrong but the logo needed to include a brain or a head or something like that...”: Puede que esté equivocado pero creo que el logo debería incluir un cerebro o una cabeza, algo así.

Quote G: “the country is so diverse that there are regions that use formal pronouns and others informal pronouns, the most important thing is to use it consistently...”: El país es tan diverso, que hay regiones que usan los pronombres formales y otras los informales, creo que lo más importante es ser consistente

Chapter 6: Discussion

The work presented in this thesis had two key aims. The first was to co-design a MHeC for young people and test its acceptability in real-world settings. The second was to describe how this MHeC could be translated into Spanish and culturally and contextually adapted to two different populations. The results from individual studies have been discussed in their respective discussion sections (see Chapters 2 to 5). The first section of this chapter summarizes the principal findings of these studies in relation to the aims of this thesis. The sections that follow discuss the broader implications of these studies in the context of the current literature. The final sections of this discussion address the overall limitations and future directions of this research, finalizing with concluding remarks.

6.1 Summary of Findings

Chapters 1 and 2 address the first aim of this thesis and generate new insights into PD methodologies and the kind of HITs required to provide available, affordable and accessible mental health care for young people. Chapter 2 demonstrates the process of using PD techniques as research methodologies with end users (including young people aged between 16 and 25 years as well as health professionals) to develop the MHeC; and, to potentially improve timely access to, and better quality of, mental health care for young people across Australia. There are two important findings from this study. First, to the best of our knowledge, it was the first time that a Web-based clinic has been conceptualized and co-designed through an iterative R&D cycle with end users. The close collaboration between all different stakeholders has the potential to effectively increase accessibility to mental health services for young people and the quality of care provided to young people, as well as increase engagement with, and usability of the final product. The second result of this study was the development of an integrated MHeC. This means that the main components of this

system ensure that young people seeking help can find what they need within one system. As presented in Chapter 2, the MHeC was one of a kind as it integrated triage, online assessments, online provision of results with easy-to-interpret graphic representations (a dashboard), enabled video visits with an appropriate health professional, provided a personalized well-being plan with immediate interventions, and tracked progress. The MHeC reconciled the fragmentation of available HITs at that moment (separated systems providing promotion, support, counselling, online therapy and teleconsultations) and promoted the participation of end users.

The study contained in Chapter 3 tested the prototypic MHeC in a real-world setting and compared online self-report assessments with traditional face-to-face clinical assessment in a cohort of young people newly presenting for mental health care. The chapter highlights the efficiency of the MHeC in identifying key features such as initially-suggested clinical stage (a method of categorising the severity, complexity and chronicity of mental ill health), lifetime trajectories, and recognition of comorbidities while also managing suicidality and responding to more complex cases. While some health professionals might still be hesitant about the role of technology, this chapter highlights the benefits of incorporating the MHeC in a clinical practice as it provides reliable information about the individual prior to a face-to-face assessment that can be used for staging, thus enabling health professionals to move away from traditional evaluations to more detailed data-driven assessments. This could translate into a more efficient way of assessment and improve one-on-one time, enabling health professionals to expand and refine the information collected and more effectively deliver interventions that match need.

Chapters 4 and 5 address the second aim of this thesis, provide further information about adaptation of HITs for different languages, populations, cultures and contexts, and finally, describe a new methodology that can be easily replicated in order to develop (adapt) evidence-based, language-appropriate, culturally-sensitive, context-adapted HITs that are relevant, appropriate, engageable and usable over time and into the future. Chapter 4 presents the process of translating and culturally adapting the MHeC to Spanish, while also highlighting the need to develop HITs for migrant populations that could provide a solution to address their unmet mental health needs more effectively. International students are at higher risk of presenting with mental health problems and having weaker support networks. This is particularly relevant for Australia as the Spanish-speaking international student migration is rapidly growing and international education represents the third largest export industry in Australia. Through a R&D cycle, the Spanish version of the MHeC (MHeC-S) was co-designed and culturally adapted, developed and user tested, and evaluated. By translating and culturally adapting the MHeC to Spanish, we contributed to increase accessibility and availability of e-mental health care for vulnerable populations that have migrated to English-speaking countries. Importantly, this blueprint MHeC-S could easily be adapted to any Spanish-speaking country or Spanish-speaking population (e.g. Latino populations in North America) around the world.

Finally, Chapter 5 takes this MHeC-S blueprint to Colombia, delineates the steps required and proposes a thorough and replicable methodology. This study resulted in a HIT solution, the Colombian version of the MHeC (MHeC-C), that is acceptable for use by Colombian young people (and their supportive others) experiencing mental health problems as well as health professionals delivering care. The application of an iterative R&D cycle that also included processes for adaptation to Colombia (language, culture, context), resulted in

the development of an evidence-based, language-appropriate, culturally-sensitive, context-adapted HIT that is relevant, applicable, engaging and usable in both the short- and longer-term. Countries around the world where health professionals are scarce and the use of technology is rapidly growing, have the potential to use the adapted MHeC with the proposed methodology to overcome entrenched geographical and infrastructural barriers to provide appropriate mental health care to young people.

6.2 Raising the Bar: Envisioning Better Mental Health Care for LMIC

Globally, there is increasing recognition that new strategies are required to reduce disability due to common mental health problems. This scenario is particularly challenging for children and adolescents living in LMIC which are typified by a scarcity of youth-specific health and community services, health professionals and relevant infrastructure, as well as specific policies for this population. With 90% of young people globally living in LMIC, and just 20% of the world's mental health resources being invested in these countries, there is an urgent need to develop new, accessible and affordable care systems.

Despite efforts made in the past decade by international organizations such as the WHO, WPA and other stakeholders, the global burden of these disorders has risen in not only LMIC but in almost all countries (Patel et al., 2018), demonstrating that the actions in place are certainly not enough. As a consequence, the most recent Lancet Commission (2018) on global mental health and sustainable development, recognizes the need to move the focus from reducing the treatment gap to improving the populations' mental health around the world (with greater emphasis on younger populations) and as such, decrease the burden of disease. This statement has two different implications for LMIC – the first one is conflicting in nature as most of the actions and initiatives in place are structured to address the treatment gap by mainly addressing the access problem. The WHO's universal health coverage

initiative promotes the inclusion of essential and quality services across the health spectrum (promotion to prevention, treatment, rehabilitation, and palliative care), while enabling access to services that address the most prevalent causes of disease and death, placing a strong focus on primary health care. In the same line, the WHO's Mental Health Action Plan and the Mental Health Gap Action Programme, as well as the WPA Action Plan, reinforce the need to expand access and strengthen primary care, but also emphasize in task-sharing and non-specialist roles. Although, these are well-intentioned initiatives which genuinely aim to improve peoples' mental health, their translation into real-world settings and especially in LMIC could result in more unequal and unequitable mental health care.

As previously described, LMIC not only have greater failures and delays in treatment seeking (Wang et al., 2004), but also these countries face complex issues (poverty, unmet basic needs, violence, complex trauma, disrupted support networks, lower levels of education, stigma discrimination, human rights violations, etc) that complicate clinical practice (assessment, evaluation, case formulation) and treatment delivery. Consequently, actions (or initiatives) guided to provide minimum viable or simple care options to countries that require more complex interventions due to its intrinsic complexities are just unacceptable. The idea that improving access to mental health care by strengthening primary care and training non-specialists to deliver an important proportion of the care will solve the problem, means that most of the problems are going to be detected but not properly treated. To simplify this point further, for people with more severe or persisting and disabling disorders (like psychotic or bipolar disorders), the analogy with cancer would mean that people are going to get their cancer detected, but in order to get treatment, they have to rely on primary care treatments or treatments delivered by non-specialists.

The second implication to the Lancet Commission on global mental health and sustainable development statement provides new hope and supports the idea that there is still a great need to develop new solutions that provide personalized care and treatments. In order to improve people's mental health, it is crucial to increase well-being, but also to take care of those who have more complex cases and require more care, and finally, if not properly treated, would result in greater disabilities and reduced productivity. There is still also a need to provide equity in mental health care, to eliminate health inequities within and between countries and to increase global mental health that "...*transcends national borders, class, race, gender, ethnicity and culture...*" (Collins et al., 2011; National Institute of Mental Health, 2011). As a starting point to achieve these goals, mental health care and associated initiatives and policies should be planned and envisioned to provide timely and evidence-based mental health care with a broad rather than a narrow approach (which is the case of the current actions that provide the minimum necessary care for LMIC).

In 2001, the United States' Institute of Medicine (IOM) (Institute of Medicine Committee on Quality of Health Care in America, 2001) outlined six aims of high quality health care (to be safe, effective, patient-centred, timely, efficient and equitable) that should be applied to all mental health services, regardless of their location, and as such, reduce the treatment gap but also and more importantly, the quality gap. With increased interest in, and awareness of, the importance of mental health around the world, this gives LMIC the opportunity to step-up and advocate for (and demand to have) real, innovative, effective and equitable solutions to their mental health needs, shifting away from the deeply-rooted face-to-face care provision systems.

6.3 HITs Enable the Provision and Delivery of 21st Century Mental Health Care

When considering how to provide mental health care at scale, HITs show promise in two main areas: through a direct deployment to those in need as well as via augmentation of traditional face-to-face services. The past decade has provided a great development and expansion of HITs and eHealth solutions in mental health care, however, most of these solutions have been developed to address specific problems (e.g. mindfulness apps) or to replace different components of the traditional health care system. As an example, the majority of self-triage tools rely on people actively searching for these tools on the Internet; however, some health services provide self-triage tools on their websites, particularly when booking appointments online (Imison, Castle-Clarke, Watson, & Edwards, 2016). Telepsychiatry (videoconferencing), as another example, has also been a particularly effective way of providing support as it allows real-time interaction while negating barriers such as cost, geographical location, and stigma concerns associated with face-to-face support (Kauer et al., 2014; Wong, Bonn, Tam, & Wong, 2018). Several studies emphasize that online interventions should augment, and be integrated when necessary, with additional support and assessment, which can include face-to-face or online assessments with health professionals within mental health services (Gilbody, Sheldon, & House, 2008; Kim et al., 2011).

In addition to the digital revolution in health care, new ways to conceptualize mental health have been described, which are currently transforming the delivery of care (Hickie et al., 2019). The staging model recognizes the continuum of illness progression, advocating for more personalized and responsive care at each point of the spectrum (Hickie, Scott, & McGorry, 2013). This framework supports the promotion of self-help and encourages easier navigation for stepping up or down through the mental health system (Hickie, 2015). A staged-based stepped-care model aims to provide evidence-based, less intensive, low-risk,

and low-cost interventions to the less severe cases while prioritizing more intensive or prolonged interventions for more complex cases (Cross, Hermens, Scott, Salvador-Carulla, & Hickie, 2017; Cross, Scott, Hermens, & Hickie, 2018; Hickie, Naismith, Norrie, & Scott, 2009; Hickie, Scott, Hermens, et al., 2013), as well as monitoring for outcomes that might require an increase or decrease in service provision (Iorfino et al., 2019).

As exemplified in this thesis, the increase in availability of these digital interventions, devices and services has been associated with an effective improvement in the delivery of mental health care for both individuals and health professionals (Hickie et al., 2019; Ospina-Pinillos et al., 2018) (see Appendix 1 complementary papers presented in this thesis as the author has made a substantial contribution, paper #5E. Complementary papers presented in this thesis as the author has made a substantial contribution), and have started to shift the health systems, by decentralizing care delivery models. This move has started to displace high-cost gatekeepers and to generate more educated users – these changes are democratising the health care systems. As consumers are starting to demand more personalized data and outcome-driven mental health services, the development and provision of simple (or parts of) systems (e.g. apps) that respond/ address single or specific needs is outdated. Integrated, interoperable platforms and ecosystems that make use of new and emerging technologies (e.g. artificial intelligence (Hussain et al., 2015)see Appendix 1, paper # 1. Complementary papers presented in this thesis as the author has made a substantial contribution] or big data analyses), embedded in current face-to-face services, are positioned to be the real and innovative solutions.

Nowadays, technology gives us the opportunity to enhance traditional face-to-face care, while also addressing the barriers of care (e.g. regional, rural and remote locations,

health conditions that obstruct care). Additionally, the increasing availability and the real-time nature of technology generate consumer empowerment as they can have access to the information and manage their own health data, as well as effective data-driven health professionals. The digitalisation of the components of the provision of care (access/ intake, assessment, treatment planning, delivering of interventions, progress monitoring and exit/referral) based on the staged-based stepped-care model (see Chapter 3) and integrated with the current face-to-face services provides personalized, appropriate and responsive care to individuals – taking into consideration function, symptoms and level of severity – meaning young people can get the right care at the right level and thus right service at the right time. The effective implementation of this kind of (smart 21st century) HIT is like “*having all shops in the one location*” where young people get the *right care, first time* including prevention, maintenance of well-being, primary, secondary or tertiary care, or even rehabilitation (see Appendix 1, paper #3-4) regardless of their physical location.

This type of cutting-edge HIT, also allows services to have a constant evaluation of the quality of their services and ensures they are complying with the IOM 21st century health care system expectations. While it has been almost 20 years since the publication of the “Crossing the Quality Chasm” report which delineated the six aims of high quality health care and recognized the key role of HITs in reshaping health systems (Institute of Medicine Committee on Quality of Health Care in America, 2001), few advances have been translated into the provision of mental health care in real practice, especially those located in LMIC. One of the reasons why this might have happened was that in 2001 there had been little progress in integrating technology in the mental health field. However, nowadays with the current advances and the support of international organisations such as the WEF (World Economic Forum, 2019), technology might just be the game changer in the provision of

accessible, affordable, equitable and quality mental health care to all populations, as it has clearly been demonstrated by the work through this thesis. The red shadow of Figure 1 represents the reach of mental health care related to current policies and services, while Figure 2 represents the reach of such care, policies and services enhanced by this type of “smart” HIT.

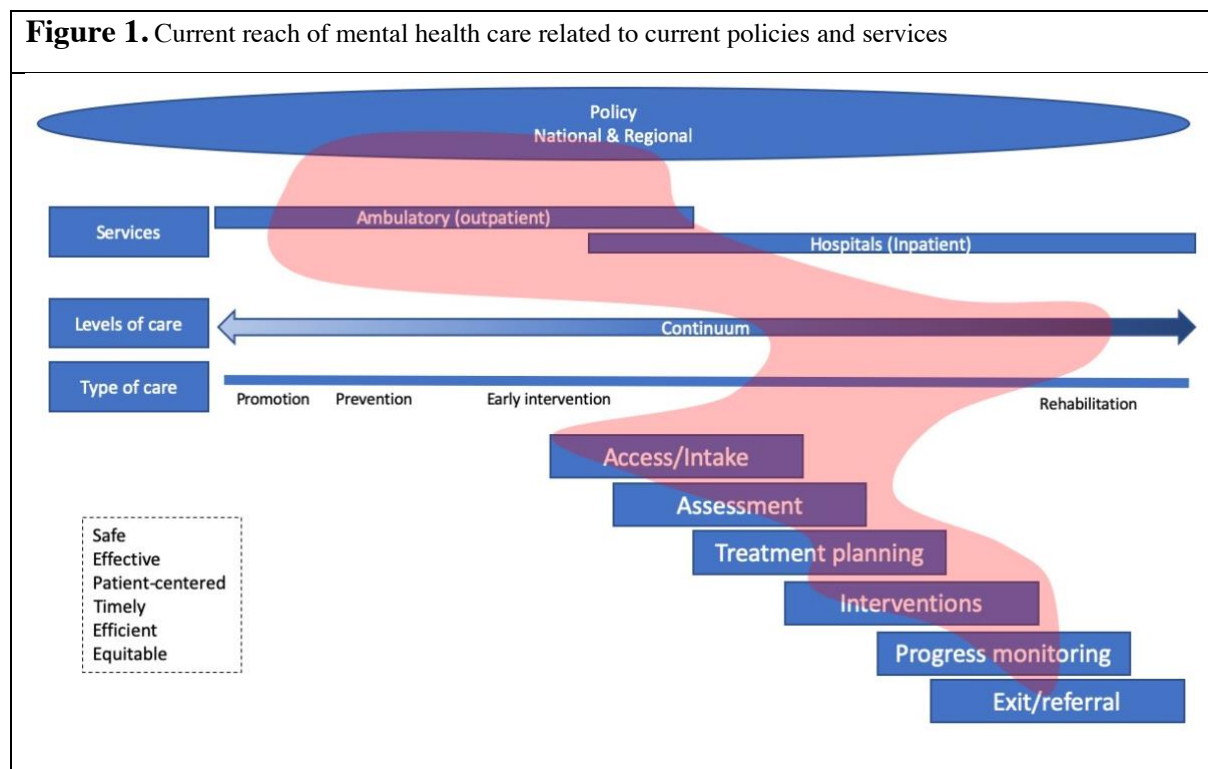
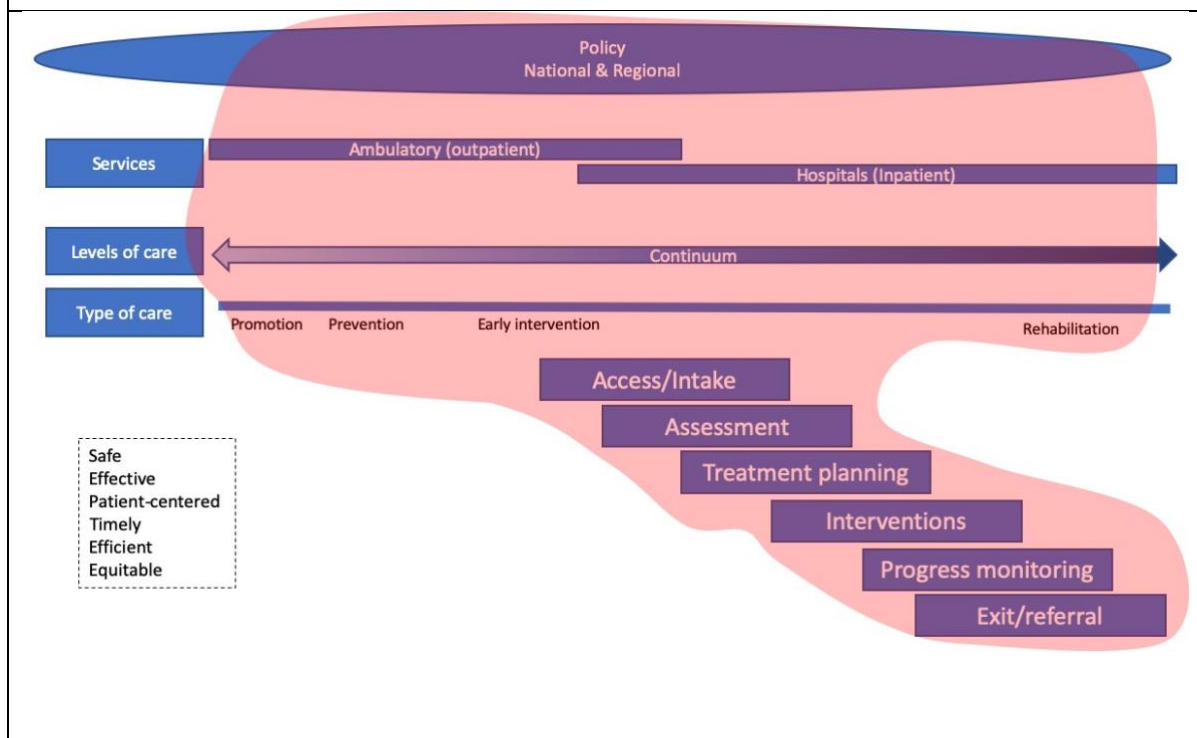


Figure 2. Potential reach of mental health care related to policies and services enhanced by smart HITs



The prototype (MHeC) and the related work presented in this thesis is positioned to be one-of-a-kind as it has eight major strengths: i) was co-designed with end users, ii) assembles all the different components of care (e.g. access/ intake, assessment, treatment planning, delivering of interventions, progress monitoring and exit/ referral), iii) is integrated with new and emerging technologies, iv) built on a staged-based stepped-care framework, v) augments face-to-face services, vi) complies with 21st century standards of quality care (Institute of Medicine Committee on Quality of Health Care in America, 2001) (see Table 1 for details); vii) complies with all the “Principles of Digital Development” (Development, 2019) (see Table 2 for details), and viii) informs data supported policy-making.

| Table 1. Examination of the work presented in this thesis within the context of IOM's 21st century aims of high quality health care | |
|---|--|
| 1. <i>Safe</i> — avoid injuries to people from the care that is proposed to help them | <ul style="list-style-type: none"> • Development of the Suicide Escalation Protocol: Facilitated a systematic assessment and detection of help-seeking young people presenting with suicidality. The protocol empowered the young person by suggesting pathways to care that were based on their current needs. The protocol also enabled an appropriate and timely response from service providers for young people reporting high suicidality that was associated with additional comorbid issues, including psychosis-like symptoms, and a history of suicide plans and attempts (see Appendix 1 paper #2). • Co-design of the digital suicide prevention functionality: enabled risk assessment and supported active suicide prevention strategies (see Appendix 1 paper #5D). |
| 2. <i>Effective</i> — provide evidence-based care to all individuals that could benefit, and refrain from providing it to those who are not likely to benefit | <ul style="list-style-type: none"> • Matching a young person's needs to a health professional's knowledge and clinical skills: the online assessment could assist to immediately identify young people who might benefit from seeing a more experienced health professional as soon as they enter a service for care (see Chapter 3). |
| 3. <i>Patient-centred</i> | <ul style="list-style-type: none"> • The PD research methodologies and the R&D cycle overtly put the end user at the centre of research and the development of all the prototypes of this thesis |

| | |
|---|---|
| | (see Chapters 2, 4 and 5) (see Appendix 1, paper #5[A-E]-6). |
| 4. <i>Timely</i> — reduce wait and delays for both individuals and health professionals | <ul style="list-style-type: none"> • Moderator assistant: Though natural language recognition and natural language generation, a system like Moderator Assistant could be used to generate appropriate and relevant interventions for mental health support via social media (see Appendix 1 paper #1). • Real-time assessment feedback and immediate provision of clinical resources: relevant resources were made available to the young person as soon as the online assessment was completed (see Chapter 2-4 and 5) (see Appendix 1, paper #5E). |
| 5. <i>Efficient</i> — avoid waste | <ul style="list-style-type: none"> • Reduction in duration of assessments: by having an accurate dashboard before their initial or ongoing assessment (face-to-face or video visit) represents a reduction in overall assessment time and maximising the quality of one-on-one care (see Chapter 3) (see Appendix 1, paper #5E). • Reuse and improve: Instead of starting from scratch (which would incur high costs and extended timelines), evidence-based HITs can be adapted to be used in other settings and countries. The development of the MHeC and its adaptation to the MHeC-S and the latter MHeC-C demonstrate this point (see Chapters 2, 4 and 5). |
| 6. <i>Equitable</i> — providing quality care does not vary because of individual's | <ul style="list-style-type: none"> • At a local level and international level: Special considerations need to be made to bring appropriate mental health care through technology to disadvantaged, vulnerable, and culturally and |

| | |
|--|--|
| characteristics (gender, ethnicity, location, or socioeconomic status) | linguistically diverse populations (see Chapters 4 and 5) (see Appendix 1, paper #5C). |
|--|--|

Table 2. Examination of the work presented in this thesis within the context of the “Principles of Digital Development”

| | |
|--|---|
| <i>Design with the user</i> | <ul style="list-style-type: none"> • The MHeC, MHeC-S and the MHeC-C were co-designed with end users (see Chapters 2, 4 and 5) (see Appendix 1, paper #5A). • End users were also at the centre of the development of Fit Uni Life to thrive (see Appendix 1, paper #5B) and the digital suicide prevention functionality (see Appendix 1, paper #5D) and the Connect Promote and Protect Program (see Appendix 1, paper #6). |
| <i>Understand the existing ecosystem</i> | <ul style="list-style-type: none"> • The end user’s constant engagement in the R&D cycle as well as the proposed methodology for the adaptation of HITs employed in this thesis provided constant and updated information of the needs, tools and strategies to be used in different contexts (see Chapters 2, 4 and 5) (see Appendix 1, paper #5[A-E]-6). |
| <i>Design for scale</i> | <ul style="list-style-type: none"> • Special attention is required to develop HITs that can be replicable and usable around the world (see Chapters 4 and 5). |
| <i>Build for sustainability</i> | <ul style="list-style-type: none"> • Participation of end users and all relevant stakeholders including local policy makers is crucial to guarantee sustainability over time. (see Chapters 2, 4 and 5) (see Appendix 1, paper #5[A-E]-6). |

| | |
|--|--|
| | |
| <i>Be data driven</i> | <ul style="list-style-type: none"> • Real time data tracking informs better outcomes (see Appendix 1, paper #5B) and policy making. |
| <i>Use open standards, open data, open source, and open innovation</i> | <ul style="list-style-type: none"> • The integration with evidence-based apps and etools (with open application programming interface) is an essential feature of the MHeC's functionality (see Chapter 2). |
| <i>Reuse and improve</i> | <ul style="list-style-type: none"> • This thesis proposes a solution to bridge the digital health gap by making use of the already available, evidence-based and successful HITs developed in other countries and to implement them in LMIC (see Chapter 6, Section 6.4). |
| <i>Address privacy and security</i> | <ul style="list-style-type: none"> • The MHeC has been configured to permit the transfer of individual-level data (allowing for other ethical, consent, governance and privacy considerations) between it and other record systems (see Chapter 2). |
| <i>Be collaborative</i> | <ul style="list-style-type: none"> • International collaboration, effective engagement of local stakeholders and development of local leadership are essential actions to ensure HITs sustainability (see Chapters 4 and 5). |

In congruence with the WEF's call, this thesis strongly advocates for governments and policy-makers to build governance structures and develop regulation that enable innovation and effective incorporation of technology in health care systems – not only would

this allow young people to get better access to care as well as better quality care, but “smart” HITs would also help to bridge the inequalities in our health systems. As a consequence, countries like Colombia (that have high Internet connectivity) should start: delineating policies that integrate and expand online care to already available health systems as well as developing strategies designed to increase IT literacy in both individuals and health professionals; strengthening digital support networks and other types of care delivered by peers, family, educators and other relevant members of the community; and developing psychoeducational material in a wide range of digital forms.

6.4 No Need to Reinvent the Wheel: Reuse and Improve

Despite the spread of HITs in high-income countries, HITs have a slow uptake and implementation in LMIC. People living in these parts of the world are at risk of experiencing not only physical and social inequalities in health but also increasingly technological inequalities in health. Countries like Colombia, which have limited resources allocated to health (7% of its GDP), struggle to make decisions regarding where to invest in order to have the best outcomes. HITs show promise in reducing costs and being cost-efficient in the long-run (Blaya et al., 2010; De La Torre-Díez et al., 2015), however, the development (from conception to implementation and sustainability) is an expensive and arduous process (O'Neill Hayes, 2015; Research2Guidance, 2018). At the same time, building capacity by training health professionals and increasing infrastructure is also a slow and pricey pathway (Health Canada, 2008; Daza et al., 2017; Gil-Rojas et al., 2018).

As a solution to bridge this gap, this thesis proposes to make use of the already available, evidence-based and successful HITs developed in other countries. While this seems like a simple and straight forward solution, the process of adapting these HITs to other languages and places should not be as simple as copying and pasting. As part of the real

change in health systems, HITs need to deliver equitable health care, which means to be responsive to cultural and contextual differences. Since 2003, the IOM, (Institute of Medicine Committee on Understanding Eliminating Racial Ethnic Disparities in Health Care, 2003) has highlighted the need to provide initiatives to enhance cultural appropriateness in health care systems (Valdez, Gibbons, Siegel, Kukafka, & Brennan, 2012). Initially, the focus was on enhancing cross-cultural sensitivity and competencies at the individual-interpersonal level by augmenting language diversity and cultural sensitivity that would finally result in a better relationship between the individual and the providers of health care services (Chin, Walters, Cook, & Huang, 2007; Horvat, Horey, Romios, & Kis-Rigo, 2014). Nowadays, the focus has extended to an organizational-systemic level, where the systems, processes and policies need to be tailored to be inclusive and responsive (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003; Truong, Paradies, & Priest, 2014). The process occurring in services also need to be reflected in HIT adaptation.

With the constant increase of HITs, it is crucial to start thinking about how these technologies incorporate into health systems. As a consequence, there is an urgent need to consider how HITs are built, and what are the cultural assumptions behind them are (Shah, 2013; Valdez et al., 2012). While many people around the world use platforms that might work, regardless of the difference of culture or contexts (e.g. Facebook, Uber, Google, Gmail, etc), this is not the case for HITs. The debate around standardization versus localization in software design and use is still ongoing. While some might argue there is a homogeneous online culture due to the nature of the Internet, HITs have important implications and repercussions (e.g. medico-legal considerations and impact in health outcomes) which means that ethically the adaptation or development of them should cautiously consider the end users' culture and context. Valdez and collaborators (Chaet et al.,

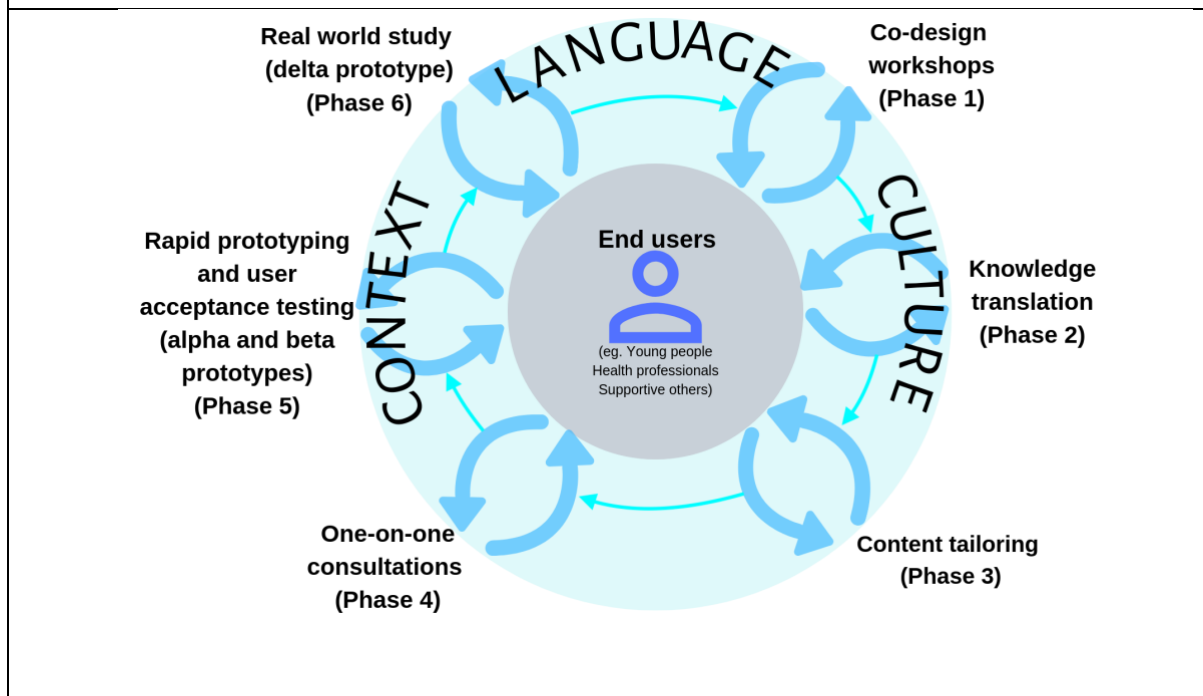
2016; Valdez et al., 2012) have postulated a culturally-informed design framework as a guideline for developers to design appropriate HITs in four main domains: content (refers to the message that is transmitted); functionality (indicates the actions that can be performed), user interface (refers to the visual presentation of the content and functionality) and technology platform (different types of hardware).

Despite this awareness, a 2016 systematic review of Spanish-language consumer HITs revealed the most common cultural adaptation from existing English-based HITs were at the content level, while the other three dimensions (functionality, technology platform and user interface) were barely considered (Chaet et al., 2016). HIT adaptation needs to move beyond straight language and content translation to recognize differences in practice, aptitude, values and belief systems that could act as barriers or facilitators to enter, use or ongoingly engage with them. This body of research advocates for the need to adapt all the relevant aspects of the technology, paying special consideration of not only the culture but also the context in which HITs are going to be deployed. Although there is certain clarity in the theory and the requirements, the methodology needed to achieve this has not been conceptualized. Importantly, this body of research is the first to provide a methodology that other researchers can use to adapt any HIT to any language, culture and context.

The proposed methodology uses PD methodologies based on the guidelines provided by the Young and Well Cooperative Research Centre (Hagen et al., 2012) and involves stakeholders and end users from the beginning in the co-design, development and adaptation of these HITs (Figure 3). The R&D cycle implemented in this methodology has been demonstrated to be an efficient method to obtain the most information from end users by engaging them in different activities. This cycle comprised of six concurrently running

phases: co-design workshops (Phase 1), knowledge translation (Phase 2), content tailoring (Phase 3), one-on-one user testing sessions (Phase 4), rapid prototyping and user testing of the alpha (a preliminary version that can be interacted with for user testing purposes) and beta (a more refined version of the prototype that is much closer to the final product) prototypes (Phase 5), and real-world trialing with a delta prototype that can be used directly by end users for feasibility testing (Phase 6). This R&D cycle has been adapted based on a framework that considers language, culture and context in all the relevant aspects of the HITs design, development or adaptation: content, functionality, user interface and the technology platform. A systematic use of this methodology would finally result in the development of evidence-based, culturally-sensitive, contextually-adapted HITs that are relevant, appropriate, engaging and usable in the short and longer term.

Figure 3. A language-appropriate, culturally-sensitive and contextually-adapted framework as an intrinsic part of an R&D cycle



More specifically to the language translation and adaptation processes, the methodology also recommends consideration at two levels: first the translation of the general language within the system (e.g. login, set up an account, frequently asked questions, etc.) and second the translation of the self-reported assessments (if required). In relation to the first level, the proposed process involves the translation of a native speaker with extensive knowledge in that particular field (the HITs purpose[s]) to perform a simple translation. Then, two (different) native speakers with extensive knowledge in that particular field review the translations. Discrepancies between the translations are resolved by consensus in the group. Special attention is needed to identify subtle differences of a language, including regional differences, jargon and literacy levels.

The second layer, the translation of the self-reported assessments, would only be applicable to HITs that contain assessments of specific conditions (e.g. triage, symptom severity, etc.). In this layer, it is suggested to implement the widely described processes of translation, back-translation, cultural adaptation, validation of assessments using the “...*user-friendly guideline for the translation, adaptation and validation of instruments or scales for cross-cultural health care research...*” (p.1) developed by Sousa and Rojjanasrirat (Sousa & Rojjanasrirat, 2011)

6.5 Limitations of This Research

This body of research has several limitations. First, our prototype was co-designed with young people, supportive others and health professionals in the general population who had an interest in the subject matter. Although recruitment of individuals was chiefly through mental health service channels, not all the young people who participated would have had a lived experience of mental health problems. While these preliminary results show

acceptability of the MHeC, the MHeC-S and the MHeC-C, their generalisability to broader communities cannot be guaranteed.

Second, despite relatively small sample sizes, information collected was sufficient for analysis and did reach a saturation point. Further research however, with larger sample sizes, is needed to understand the acceptability and usability of the prototypes, as well as to validate all the components in real-world settings.

Third, securing funding to keep HITs technically updated and thus sustainable over time, is an essential requirement to consider before starting the processes of development and adaptation. LMIC are at great risk of investing considerable amounts of time and efforts to obtain usable HITs within their contexts, but due to lack of expertise or ongoing funds these HITs could likely stop being used by end users as they are no longer compatible with the latest operating systems.

6.6 Future Directions

The MHeC prototype and the work in this thesis have informed the development of the InnoWell Platform, a Web-based platform that supports the prevention, early intervention, treatment, and continuous monitoring of mental ill health and maintenance of well-being of all age ranges (Davenport et al., 2019). The Platform is embedded in existing mental health services and used to provide individuals with access to evidence-based assessments, intervention options, and outcome monitoring. It collects, stores, scores and reports personal and health information back to individuals and their health professionals and promotes a person-centred and shared-decision making approach. Through Project Synergy (2016-2020; an Australian Government Department of Health-funded initiative that aims to transform mental health services through the use of new and emerging technologies) (Hickie,

Davenport, & Burns, 2019), the InnoWell Platform will be tested with individuals aged 2 years and older presenting to nominated mental health care services, and includes “...*persons from the veteran community, Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, the lesbian, gay, bisexual, transgender, and intersex community, and those from broader education and workforce sectors, as well as people with disabilities, lived experience of comorbidity, complex disorders, and suicidality*” (p.1) (Davenport et al., 2019).

As previously mentioned, a key area for future research should be to continue to co-design the beta and delta prototypes of the MHeC-S and the MHeC-C and to evaluate them in real-world settings. More specifically, for the MHeC-S the next step would be to naturalistically evaluate the engagement, efficacy and effectiveness in an Australian-based Spanish-speaking population of young people (trial already approved by The University of Sydney’s Human Research Ethics Committee Project No: 2016/487). In relation to the MHeC-C (Appendix 2), a suitable starting point would be to further develop the MHeC-C through the well-established R&D cycle and use a stepped-wedge model to implement and trial the MHeC-C through three large universities (this body of research has also resulted in the development of alliances with the Universidad de Antioquia [Medellin, Colombia] and Autonomous University of Bucaramanga [Bucaramanga, Colombia] which were cemented in late 2016 through a Memorandum of Understanding). Additionally, we have an active framework of research cooperation with the Pontifical Javeriana University in Bogota (Bogota, Colombia) via student Well-being Centres and associated primary health care services in metropolitan and rural areas and more broadly into a wider range of health care services across Colombia. Implementation of the MHeC-C includes physical integration of the HIT (i.e. installation) as well as a structured training program for health professionals

comprising Colombia-specific clinical, service, digital and suicide prevention modules. As noted above, trialling will encompass a detailed evaluation strategy including engagement, efficacy, effectiveness and cost-benefit analyses such as social and economic return on investment.

Although this thesis justifies the need to adapt HITs in LMIC, it is important to note that the MHeC and the proposed methodology would be applicable and relevant to all parts of the world where there is a chance to connect with young people. In agreement with the 2018 Lancet Commission in terms of mental health, all countries are developing countries in the context of mental health. Rural areas, disadvantaged communities, and culturally and linguistically diverse populations experience similar barriers to get access to and effective treatment of mental health conditions. Regardless of a country's wealth, high income countries still have at least one area where mental health resources are scarce and as such, an underserved population. Thinking about regionality and considering any region's strengths and difficulties (which are not just financial), provides a frame to formulate innovative solutions like the one proposed in this thesis – by being responsive to contextual differences the provision of equitable care within and between countries is actually achievable.

In countries like Colombia where resources for youth mental health care are limited, effective actions are required to create a solid foundation for better youth mental health care. This cannot be done without international collaboration and supportive local leadership. International organisations and wealthy countries should support the build of sustainable and scalable products that could be replicated and maintained in less resourced settings. Supporting local leadership, sharing expertise and advise, and sustaining a collaborative framework are all essential actions for less resourced settings to avoid replicating the same

errors of what wealthier countries have made in the past – creating dysfunctional structures and wasting resources.

As the provision of mental health care building upon the idea of ever expanding infrastructure fails, HITs offer an opportunity to do things differently, in places where resources are currently scarce – here, they can start again and build from scratch. These places can now plan for a functional solution, learn from international experiences of what strategies have been successful (and which have not) with the final goal of creating a youth mental health system that integrates efficient and effective technology with face-to-face services, provides staged-based stepped-care, provides 21st century quality care and more importantly empowers individuals.

6.7 Concluding Remarks

There is an urgent need to provide scalable interventions to young people across the world, but especially to those in LMIC who are currently at risk of additionally experiencing technological inequities in health. A possible solution to bridge this gap is to make use of the already available (and successful) HITs that are rapidly being developed in other countries. In order to make these HITs accessible to culturally, linguistically and geographically diverse communities, it is necessary to tailor them beyond just language – and to also consider these HITs within a culturally and contextually appropriate framework.

The methodology employed in this thesis resulted in the development of evidence-based, culturally-sensitive, context-adapted HITs that are relevant, appropriate, and usable over time and into the future. The adaptation of successful HITs represents a low-cost and scalable alternative for LMIC to provide young people with accessible, available, affordable

mental health care at the *right time, first time*. The health system potential of this approach not only means better mental health outcomes for young people but potentially more efficient, effective and appropriate use of scarce health professional knowledge and clinical skills, as well as quality improvements in mental health service delivery in any region of the world.

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M. Sazzad Hussain, Juchen Li, Louise A. Ellis, Laura Ospina-Pinillos, Tracey A. Davenport, Rafael A. Calvo & Ian B. Hickie

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Moderator Assistant: A Natural Language Generation-Based Intervention to Support Mental Health via Social Media

M. SAZZAD HUSSAIN

School of Electrical and Information Engineering, The University of Sydney, Sydney, NSW, Australia; Health and Biosecurity, CSIRO, Epping, Sydney, NSW, Australia

JUCHEN LI

School of Electrical and Information Engineering, The University of Sydney, Sydney, NSW, Australia

LOUISE A. ELLIS, LAURA OSPINA-PINILLOS, and
TRACEY A. DAVENPORT

Faculty of Medicine, The University of Sydney, Sydney, NSW, Australia

RAFAEL A. CALVO

School of Electrical and Information Engineering, The University of Sydney, Sydney, NSW, Australia

IAN B. HICKIE

Faculty of Medicine, The University of Sydney, Sydney, NSW, Australia

As online mental health support groups become increasingly popular, they require more support from volunteers and trained moderators who help their users through “interventions” (i.e., responding to questions and providing support). We present a system that supports such human interventions using Natural Language Generation (NLG) techniques. The system generates draft responses aimed at reducing moderators’ workload, and improving their efficacy. NLG and human interventions were compared through the ratings of 35 psychology interns. The NLG-based system was capable of generating messages that are grammatically correct with clear language. The system needs improvement, however, moderators can already use it as draft responses.

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Address correspondence to M. Sazzad Hussain, School of Electrical and Information Engineering, The University of Sydney, Bldg. J03, Maze Crescent, Darlington Campus, NSW 2006, Sydney, Australia. E-mail: sazzad.hussain@sydney.edu.au

KEYWORDS interventions, mental health, NLG, online support groups, social media

INTRODUCTION

Mental health problems are known to cause disability, decrease productivity, and reduce overall quality of life (WHO, 2003). The World Health Report (WHO, 2001) states that one in four people worldwide will meet criteria for a mental disorder at some point during their life. According to the Australian Bureau of Statistics (2007), almost half (45%) of Australians age 16 to 85 years, experience a mental disorder at some stage. Anxiety and mood disorders are the most prevalent mental illness in Australia and elsewhere (Demyttenaere et al., 2004). Depression alone is predicted to be one of the world's largest health problems by 2020 (Murray & Lopez, 1996). Despite high prevalence rates, the diagnosis and treatment of mental disorders has long been neglected, especially in rural populations where access to quality care is limited (Burns, Davenport, Durkin, Luscombe, & Hickie, 2010; Clarke & Yarborough, 2013; Strecher, 2007). Moreover, people are often reluctant to seek help, with only 13% of males and 31% of females age 16 to 24 years with a mental health problem in Australia accessing a clinical service (Slade, Johnston, Browne, Andrews, & Whiteford, 2009). In many cases, the lack of available trained mental health professionals, as well as the intensive time and cost needed for treatments, allow for only a minority of people experiencing problems to be treated and supported (Doherty, Coyle, & Sharry, 2012; WHO, 2008, 2011). Strong stigmatizing attitudes and beliefs toward mental health disorders are other key factors that have resulted in a wide treatment gap and reluctance in the help-seeking process across the globe (Clarke & Yarborough, 2013; Corrigan, 2004; Henderson, Evans-Lacko, & Thornicroft, 2013).

Internet-based interventions have the potential to jump many of the traditional barriers when accessing and receiving mental health treatment (Ospina-Pinillos, Davenport, Burns, & Hickie, 2015). The anonymous nature of Internet-based interventions has been found to increase participant's utilization of self-help options (Berger, Wagner, & Baker, 2005; Ybarra & Eaton, 2005). Furthermore, web-based interventions provide an alternative to face-to-face patient care (Currell, Urquhart, Wainwright, & Lewis, 2000) while also eliminating travel and treatment waiting times, increasing treatment accessibility and flexibility, reducing overall cost, and, perhaps most importantly, increasing access to mental healthcare (Doherty et al., 2012; Kazdin & Rabbitt, 2013). This has allowed structured interventions models, such as computerized/Internet-based cognitive behavior therapy (CBT) to receive a lot of attention over the past decade (Christensen, Griffiths, & Jorm, 2004; Spek et al., 2007). A number of randomized studies have particularly

investigated the effects of Internet-based interventions on depression and anxiety related disorders (Spek et al., 2007). The Internet-based CBT approaches have proven to be effective at several levels, especially with a therapist involved (Postel, de Haan, & De Jong, 2008).

One of the most promising aspects of Internet-based tools and interventions is the widespread availability of online communities and peer support groups enabling people in distress to identify with others with similar needs and problems, share feelings and information, provide and receive advice, and develop a sense of community (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). Online peer support groups are becoming increasingly popular on social networking websites such as Facebook as well as for organizations such as ReachOut.com in Australia. Some of these support groups are moderated by trained young people or allied mental health staff (e.g., ReachOut.com), giving people the opportunity to receive help from professionals and use resources developed by experts. However, as such communities keep growing, the amount of work required of the moderators continues to increase, ultimately making quality support unsustainable (Liu, Calvo, Davenport, & Hickie, 2013).

One way to address this problem would be to automate the generation of interventions (e.g., posts or e-mail responses) using computer programs. This would require detecting a problem (i.e., a mental health related concern) and generating an appropriate text that would be useful to the help-seeking individual. Although it is technically demanding to generate human-quality feedback even in the simplest application, this challenge may be insurmountable in the context of complex mental health issues. A possible solution would be to augment the abilities of human moderators, helping them reach out to more people (i.e., help-seekers), more effectively and efficiently (Calvo & Peters, 2014). This could be done using Natural Language Processing and Generation tools that filter, sort posts, and generate draft responses that the moderators could then use and subsequently track the impact of their feedback.

Currently, templates are used to generate standardized responses; however, their value is limited as the content tends to be simplistic, static, rigid, repetitive, and only partially appropriate for the target user. Within the health domain, personalization has been considered critical to patient-centered care and a number of studies have used Natural Language Generation (NLG) (DiMarco et al., 2007). NLG is a subfield of artificial intelligence and computational linguistics which primarily focuses on producing human-like text from nonlinguistic data with specific communicative goals (Reiter & Dale, 2000). To date, NLG has generally been used for the authoring and personalization of webpages containing patient education materials. DiMarco and colleagues (2007) called this *Information Therapy* describing a system with personalized preoperative information, including resources that would typically be presented in a series of brochures discussing various surgical procedures. The system had a collection of reusable texts, each annotated with linguistic and

formatting information that the NLG tools automatically drew from to select, assemble, and tailor the reader-specific pieces of text. The studies described later have shown that NLG systems are able to produce dynamic human-like, individualized sentence structures suitable to various contexts (further examples can be found in proceedings of the International Natural Language Generation Conference). Moreover, NLG systems can generate tailored and meaningful interventions by combining psychological strategies (Van Bilsen, 2013; Wiemer-Hastings, Janit, Wiemer-Hastings, Cromer, & Kinser, 2004) and techniques applied by moderators in peer support groups.

The aim of this project is to develop a Natural Language Generation Service (NLGS) that will create draft responses (i.e., interventions) to social media posts using input from a mental health knowledge base. The interventions can then be edited by moderators and delivered to individuals through social networks or online support groups.

A first step in this project involved generating interventions in response to posts related to two mental health conditions: *depression* and *anxiety*. These conditions were chosen, as they are the most prevalent in Australia and elsewhere. A sample of posts ($n = 25$) collected from various mental health support groups/forums were used as the basis for generating interventions. These reflect the typical posts received by moderators of online support groups. We then asked a senior moderator from a youth mental health organization in Australia, and three mental health professionals to write responses (i.e., interventions) for the same posts. Finally, both human and system interventions were rated by university psychology students/interns ($n = 35$) using quality measures designed specifically for the study. In this article we evaluate the following in detail:

1. The quality of NLGS interventions as responses to posts on depression, anxiety or both.
2. The quality of NLGS compared to human-generated interventions.

Our study contributes the first evaluation of a NLG system in a mental health application. The system is novel in that it is being developed to support human moderators by providing a draft intervention, rather than fully automating the response process. This approach, where the technology augments human capabilities, is particularly useful in contexts where those providing feedback might not have expertise in clinical psychology (something the system can help with) but have useful personal experiences they can share (something the computer cannot).

NATURAL LANGUAGE GENERATION

The Internet helps deliver early interventions to at risk, help-seeking individuals and brings together people with shared health problems.

Internet-based interventions can help large populations with minimal time, effort, and cost through self-help programs (e.g., web-based) and minimal-contact therapy settings (e.g., e-mails, phone calls) (Barak, Hen, Boniel-Nissim, & Shapira, 2008; Doherty et al., 2012; Spaulding, Belz, DeLurgio, & Williams, 2010). The field has grown and some structured frameworks and taxonomies for research of computer-mediated and Internet-based interventions have been developed (Barak & Grohol, 2011; Barak, Klein, & Proudfoot, 2009). Computerized interventions using different modalities such as online chat (Dowling & Rickwood, 2013), relational agents (Bickmore & Gruber, 2010), and interactive graphical exercises (Coyle, Doherty, Matthews, & Sharry, 2007; Doherty et al., 2012) have been investigated. These approaches can be suitable for engaging users through human–human or human–computer dialogue and interactivity.

Text-based interventions, such as those employed in this study can be used in synchronous communication (e.g., online chat) or asynchronous communication (e.g., e-mails and discussion forums), providing supportive messages with suggested activities or resources based on the problem(s) identified. Text-based interventions can be in the form of fixed responses targeting the overall community (e.g., via web pages), but a more nuanced and dynamic approach is to generate personalized text interventions to provide ad hoc messages in human-like natural language structure (Reiter & Dale, 2000). Text generation approaches in the form of natural language have been used in a variety of applications each focusing on a particular problem. Back in the 1960s, the system called ELIZA (Weizenbaum, 1966) was one of the first that emulated a Rogerian psychologist through dialogue and certain types of conversation (e.g., psychological issues). ELIZA was an early development but was a source of inspiration for programmers and developer in artificial intelligence that attempted such type of human–computer interaction.

New developments in human–computer interaction nowadays allow for much more sophisticated interfaces. In particular, *Affective Computing* (Picard, 1997) can make text generation systems more natural (Dockrey, 2007). For example, automated conversational coaches (Hoque, Courgeon, Martin, Mutlu, & Picard, 2013) and robots (Breazeal, 2003) have been developed that aim to provide a variety of proto-social responses (e.g., simulating affects) by detecting natural social cues (e.g., speech, gaze, posture, facial expressions, etc.). Some applications have aimed to help crisis counselors by analyzing psychological and emotional patterns through text-based platforms (e.g., chat, SMS). For example, Fathom (Dinakar, Chen, Lieberman, Picard, & Filbin, 2015) is a natural language interface that makes use of machine learning approaches and probabilistic graphical models to extract and visualize psychological and emotional patterns in patients (e.g., during calls with counselor). The statistics and visualization then allows the counselor to respond accordingly. As for text generation, NLG-based systems like

PyschoGen (Dockrey, 2007) have been proposed that generates responses based on emulated mental/emotional states.

By considering the psychological and emotional factors, NLG approaches would be suitable for automatically generating interventions that express empathy and compassion along with the client-centric health information and resources. This can be ideal for mental health clinicians, where information about a specific patient can be presented in the form of a report or as part of structured interventions. For moderators in online support groups, such information that can be used for quickly customizing and replying would greatly reduce their workload.

Even though the concept of text generation was developed much earlier (Appelt, 1985; McKeown, 1992), the field of NLG only started to mature in the late 1990s when new comprehensive structures of NLG systems suitable for real-word applications were proposed (Reiter, 1999; Reiter & Dale, 2000). Following this, several NLG systems were developed for a growing number of applications (Gatt & Reiter, 2009; Reiter, 1999; Vargas et al., 2012). At the end of 1990s, Reiter and Dale (2000) wrote “Building Natural Language Generation Systems,” the first book to provide a comprehensive overview of the tasks involved in building a NLG system.

A number of NLG frameworks that facilitate the development of new systems have been created, including SimpleNLG (Gatt & Reiter, 2009). Others focus on a single application, like SemScribe (Vargas et al., 2012) which produces clinical reports from medical observations entered into a structured entry form, and BabyTalk (Portet, Reiter, Hunter, & Sripada, 2007), which provides support to medical professionals to make decisions based on large amounts of information. In recent years, researchers have started to apply NLG techniques to provide personalized health information for individual patients (DiMarco et al., 2007). For example, some attempts have been made to generate letters tailored for smokers using a NLG system called STOP (Reiter & Dale, 2000; Reiter, Robertson, & Osman, 2003). However, these first steps aiming to offer personalized interventions in physical health have yet to be achieved in mental health applications.

Tailored Information Systems Using NLG

Tailored patient information systems produce personalized medical information and/or advice (Reiter & Osman, 1997). The information can be patient centric by providing information about an individual’s health condition or diagnosis, or doctor centric by providing patient reports to doctors. Tailored systems provide more appropriate information relevant to each individual and, therefore, are more effective (Bental, Cawsey, & Jones, 1999). Evaluations of tailored information systems provide evidence that they may improve the quality and effectiveness of personalized texts.

SemScribe (Varges et al., 2012) is a system that automates the process of generating medical reports (particularly in cardiology), in natural language based on individual medical observations. By using NLG for a fully automatic mapping between nonlinguistic input and linguistic output, it enables the doctor to get the corresponding medical report immediately after they enter observations (Faulstich et al., 2011).

The Baby Talk project (Portet et al., 2007) was developed to present clear summaries of medical data about sick babies in a neonatal intensive care unit. The data included physiological signals (e.g., heart rate, blood pressure), patient related notes, and laboratory test results. BT-45, the first Baby Talk system was able to generate written summaries of 45 min of clinical data by combining techniques from intelligent signal processing and NLG. An experiment showed that BT-45 texts were as effective for decision support as conventional visualizations (Portet et al., 2007).

Not all studies have shown improvements. STOP (Reiter & Dale, 2000) is another NLG system that generates short tailored smoking cessation letters based on users' responses to a four-page smoking questionnaire. A clinical trial showed that STOP was not effective as recipients of a tailored letter were less likely to stop smoking compared to recipients of a nontailored letter (Reiter et al., 2003).

Generic Architecture for NLG

There are several possible architectures for NLG systems, but the one proposed by Reiter and Dale (Reiter & Dale, 2000) is broadly compatible with most applications. In this architecture, three components are connected together into a pipeline. More specifically, a *Document Planner* determines the content and structure of a document. A *Microplanner* decides how to communicate the content and structure chosen by the Document Planner. This involves choosing words and syntactic structures. A *Surface Realizer* maps the abstract representations used by the Microplanner into an actual text. *Message*, *Document Plan*, and *Text Specification* represent the input and output of each component.

MODERATOR ASSISTANT: NLG SERVICE FOR MENTAL HEALTH INTERVENTIONS

We have adopted the Reiter and Dale (2000) architecture as part of our mental health intervention module for the Moderator Assistant (MA) system (Liu et al., 2013). The MA system is able to retrieve all incoming posts from nominated social media groups/forums using their Application Programming Interface (API). A triage module of the MA system, which implements a text classifier using Natural Language Processing (NLP) and machine learning techniques, is responsible for identifying mental health categories (e.g., depression,

anxiety) from social media posts. This module also retrieves the timestamp of the post, name of the person, and other details that can be used as input by the NLG component. The interventions generated by NLG can then be administered by moderator and posted back as comments to corresponding posts using the API. The overview of our NLG architecture is shown in Figure 1.

The first step in this architecture is *Content Determination* where Messages are instantiated. Each Message represents a chunk of data that can be grouped together to express a specific meaning. The second step is *Document Structuring*, where the Messages are combined into Document Plan using schema and heuristic algorithms in order to group different kinds of Messages together in a logical order. This represents a tree structure with Messages as terminal nodes and *Discourse Relation* as internal nodes.

Although Document Plan groups Messages together, it does not specify how the information inside a Message should be structured. Therefore, the domain model expressed inside Messages need to be mapped into words that make sense. The third step is *Lexicalization and Aggregation*, where words and syntactic structures are chosen to communicate the information in the Document Plan. This is a very important part of providing mental health intervention through this NLG architecture. The meaning of the information needs to be expressed correctly as inappropriate feedback may have a negative impact on the user.

Templates were used in Content Determination, which were retrieved from mental health professionals as well as by extracting some common

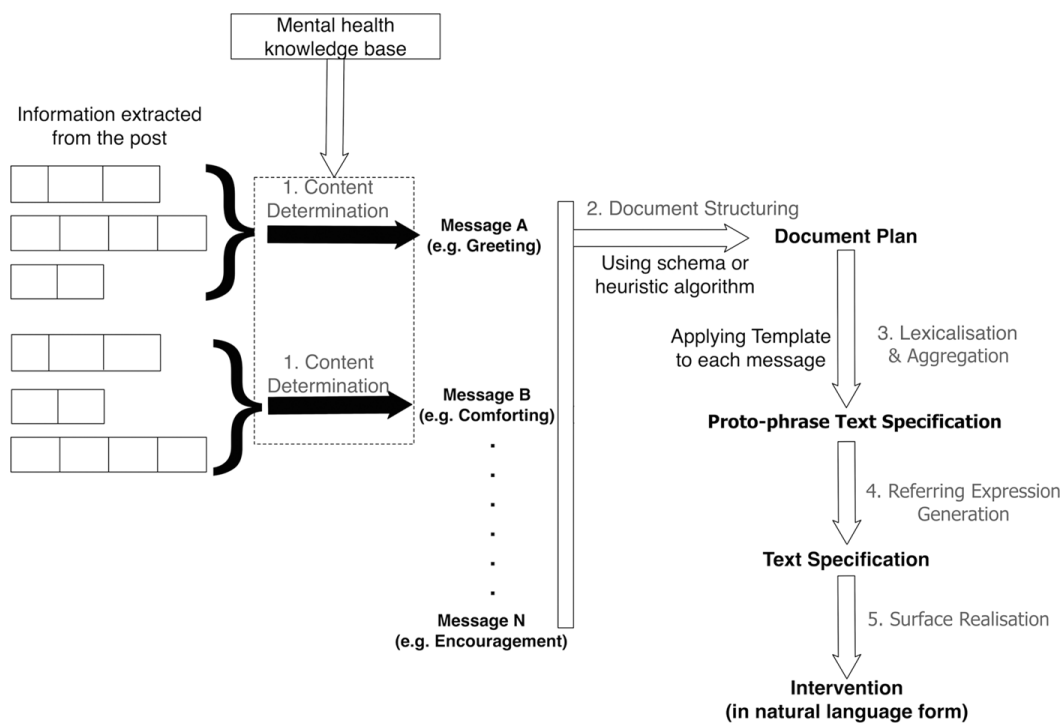


FIGURE 1 Overview of the NLG architecture for mental health interventions.

feedback/comments from *Livejournal*, *Facebook*, and *ReachOut.com* posts. These templates are mostly formed in complete sentences; therefore, the resulting Messages also consist of well-structured sentences. Only the other Messages, such as greetings with name, need to be refined in the Lexicalization and Aggregation stage. The resulting document from this step is a *Proto-phrase Text Specification*.

The Proto-phrase Text Specification can be used as the input to the *Surface Realization* directly. It can also be refined in step four, *Referring Expression Generation*, where the symbolic names of entities are replaced by the semantic content of noun phrase referring expressions. The output of this stage is the Text Specification, which contains all information needed, as well as the message structure and the sentence structure.

The Lexicalization and Aggregation and Referring Expression Generation steps do not affect the NLG process for this version of the NLGS architecture because the Text Specification has exactly the same structure as the Document Plan. Therefore, the Lexicalization and Aggregation and Referring Expression Generation steps are not implemented in this version of the NLGS architecture. The Text Specification contains all the necessary information, which is then passed to Surface Realizer. This converts the Text Specification into real text from the abstract representations. The system will then produce the intended feedback. The following sections give the details of different parts of the NLGS architecture.

Defining Messages

A Message is essentially a form of particular configuration of domain elements, and it may contain different levels of information for each particular system (Reiter & Dale, 2000). In order to define the message, we need to analyze the indented output that is to be generated as part of the intervention. Analyzing several examples of real-world interventions from our dataset, we identified the following four types of messages that appear in social media interventions for mental health:

- greeting the person posting (*Greeting Message*),
- comforting the person experiencing mental health problems (*Comforting Message*),
- suggestions to the person experiencing mental health problems (*Suggestion Message*), and
- encouragement to the person experiencing mental health problems (*Encouragement Message*).

Four types of messages were constructed for the intervention. Figure 2 shows how messages from the four types are grouped together to form an intervention.

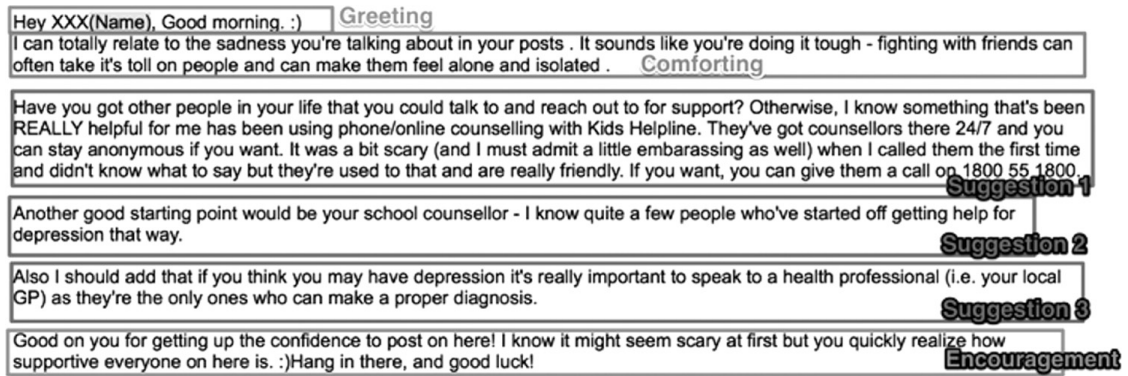


FIGURE 2 Example intervention divided into messages.

Content Determination

In the Content Determination phrase, the system instantiates Messages designed in the previous section using postrelated (e.g., mental health category) information extracted from social media posts and other information (e.g., current time). The NLGS system implements the content determination logic inside a group of “Feedback Generator” classes using the *generateFeedback* method. The “Intervention Generator” class handles the overall NLG generation tasks, including the content determination task (Figure 3). According to the figure, the Greeting Message is generated based on current timestamp. The *generalFeedbackGenerator* generates the Message that is suitable for any type of mental health categories whereas the specific mental health category feedback generators (e.g., *DepressionFeedbackGenerator*, *AnxietyFeedbackGenerator*) create Messages based on the mental health categories detected in the social media post. If no mental health category can be identified from the post then the *unknowCategoryFeedbackGenerator* is triggered. Finally, the Messages are combined into a List<Message> object. Currently, these feedback generators cannot

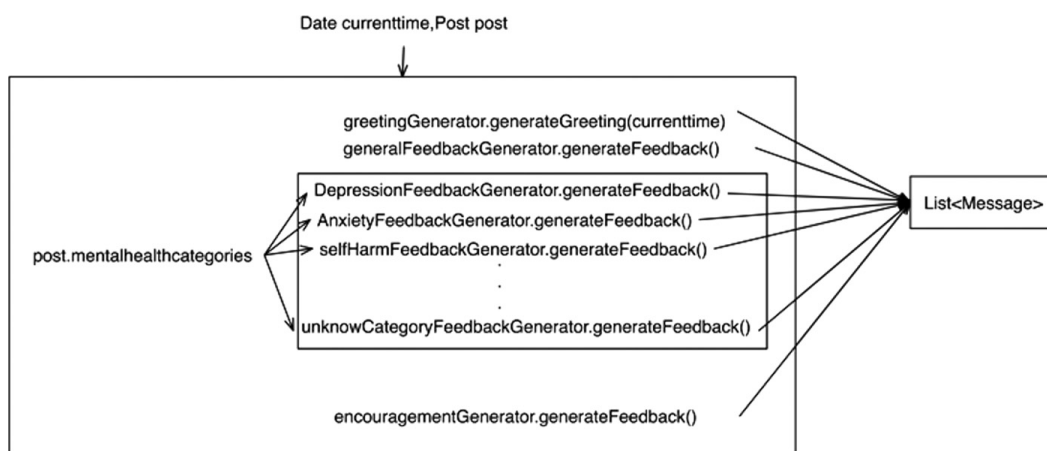


FIGURE 3 Overview of Content Determination logic.

TABLE 1 Greeting Based on the Current Time

| Current time | Greeting |
|-----------------|----------------|
| 0 a.m.–6 a.m. | Hi |
| 6 a.m.–12 noon | Good morning |
| 12 noon–18 p.m. | Good afternoon |
| 18 p.m.–24 p.m. | Good evening |

generate a more personalized feedback Message due to the limitations of the information extracted from posts.

GREETING GENERATOR

The greeting contains two parts, the first part is generated using the current timestamp (Table 1), and the second part is generated randomly (Table 2). These two are then combined to form the output Greeting Message.

GENERAL FEEDBACK GENERATOR

The general feedback does not relate to a specific mental health problem. It contains text suitable for any type of mental health category. It can generate random Comforting Messages, Suggestion Messages, and Encouragement Messages based on the templates (i.e., knowledge base) provided by mental health professionals. Other than that, it also contains feedback providing suggestions based on the posting behavior (e.g., the time when the post was submitted). For example, it will generate feedback similar to the following if the person posted late at night:

It seems that you post really late; Healthy sleep habits can make a big difference in your quality of life. Make whatever adjustments you need to sleep 7–8 hours/night. Respect your need for sleep, and trust me, many other things will just fall in place.

DEPRESSION AND ANXIETY FEEDBACK GENERATOR

This feedback generator produces feedback suitable for a specific mental health issue (e.g., depression, anxiety). It can generate random Comforting

TABLE 2 Random Greeting

| |
|---|
| Random |
| How are you? |
| How are you doing? |
| How is everything? |
| How's everything going? |
| Thanks for letting us know how things went. |

Messages, Suggestion Messages, and Encouragement Messages under its mental health category based on the template provided by mental health professionals. As the MA system (Liu et al., 2013) builds on the NLP component, which is responsible for extracting personalized information from the original post, the feedback generator can be improved with new data or features about the user or post.

Document Plan, Document Structuring and Realizer

All the Messages are retrieved from the Content Determination and then separated into different Message lists according to the Message type (i.e., Greeting, Comforting, Suggestion, Encouragement).

Each Document Plan is a node in a tree structure, containing a parent (also a Document Plan), a topic (the information carrying document plan), and constituents. The constituents contains the children document plans and the discourse relationship (e.g., Sequence, Contrast, Elaboration) between them. Each node in the tree contains a complete Document Plan for each Message that are already in the form of surface text.

In order to instantiate the Document Plan, both schema and heuristic algorithms are used in the Document Structuring phrase. In this process, all Document Plans that contain same types of Messages are grouped together into a higher level Document Plan. Finally, according to the order of different types of Messages, the final Document Plan is constructed.

The Realizer constructs the final intervention by traversing the Document Plan tree using postorder traversal. This is achieved by combining all the Document Plan contents (i.e., the node of the tree) together.

DESIGN AND METHODS

Evaluation Study

Augmentation is the process of supporting the moderator, as opposed to automation where the computer accomplishes tasks normally done by the human. The quality of the augmentation is related to the quality of the texts automatically generated, which we evaluate by measuring the variation of the output texts and their appropriateness in relation to the corresponding mental health problem and post. This section details the process of selecting sample posts, assessing variation (Jaccard distance) in the NLGS-generated texts, the quality measures, the ratings, and the evaluation process.

Pilot Evaluation

As a way of testing the system and the quality of text generation, we performed a pilot evaluation for NLGS in the context of responding to *depression*

and *anxiety* posts, where three mental health professionals rated the NLGS interventions along with the human interventions (Hussain et al., 2015). Both sources of interventions were randomized and then presented for the rating procedure. Despite variations in rating scores, results showed that the quality of the interventions generated by NLGS for depression and anxiety were satisfactory in relation to the early development and nature of the application. As part of an extended evaluation, 35 University psychology students/interns rated the NLGS in order to provide a broader sense of quality of the interventions. The following section describes the extended evaluation.

Main Evaluation

This section presents the main evaluation for NLGS in the context of *depression* and *anxiety*. In order to evaluate the performance of NLGS, 25 social network posts related to depression and anxiety were chosen. These two categories were chosen because the end user organization (i.e., ReachOut) found them the most critical categories in a triage system.

With those 25 posts as input, we generated 25 corresponding interventions using NLGS. Three clinicians (two psychologists, one psychiatrist) and a trained moderator separately wrote responses (i.e., interventions) for the 25 posts. The clinicians are experts in the field of mental health and are collaborating closely with the project. The moderator is a senior staff in ReachOut who has a lot of experience in supporting young people through their forums. We hypothesized that the two groups (clinicians vs. moderator) would generate two different types of interventions each with their own qualities. In order to simulate the environment in which they may be responding to users, the original posts were presented to the clinicians and the moderator with the respective categories using Google Blogger and interventions were collected as comments.

All the interventions were rated by participants as described in section “Rating Interventions.” The project was approved by The University of Sydney Human Research Ethics Committee.

SELECTING POSTS FOR INTERVENTION

We collected sample posts from two online peer-supported groups (Livejournal, Facebook) as well as one online, moderated health support group (ReachOut.com). The author’s name (i.e., username) and identifying information were removed from each post. Initially two psychologists and a psychiatrist selected 90 posts out of 4,583 that were classified under depression, anxiety, and 14 other mental health related categories (e.g., self-harm, suicide, drug/alcohol use, bullying, violence, medication/treatment, psychosis, bipolar, eating disorder, personality disorder, sleep, accessing help, positive emotion, self-care, etc.) These posts were used as gold standards for training

the participants and were assumed to be best examples of the total 4,583 posts. Of the 90 posts, a total of 25 related to depression and anxiety or both were randomly selected. The final distribution was: seven of depression, eight of anxiety and 10 combined (contained both depression and anxiety) posts. The clinicians and the moderator had to read the individual posts and write corresponding responses as part of the human interventions; hence the total number of 25 posts allowed a reasonable workload for this task.

NLGS INTERVENTIONS AND MEASURE OF VARIATIONS

The sample 25 posts were used as input for NLGS to generate 25 matching interventions. The NLGS interventions are intended to be dynamic; therefore, it is useful to evaluate the variation of the output text to avoid the repetitious nature of the interventions such as when responding to posts indicating similar mental health problems to the same recipient within a short period. By measuring the dissimilarity between interventions that NLGS generated, using the Jaccard distance (Niwattanakul, Singthongchai, Naenudorn, & Wanapu, 2013), we are able to identify the variation in the 25 NLGS interventions. Jaccard distance is obtained by subtracting the Jaccard similarity coefficient from 1. In this context, the dissimilarity is defined as the difference in the number of the union and the intersection of words in sentences divided by the number of the union of the words in the sentences. For example, the two NLGS interventions in Table 3 have the intersection ($|A \cap B|$) value of 25 and union ($|A \cup B|$) value of 136, which gives the Jaccard distance ($1 - |A \cap B|/|A \cup B|$) of 0.82. Here, the high value of the Jaccard distance represents a strong dissimilarity between the two texts.

TABLE 3 Sample NLGS Interventions for Calculating Jaccard Distance

Sample NLGS Interventions

Intervention: A

“How’s everything going? You’re feeling out of it and frustrated. That’s understandable. It’s really important that you keep yourself safe. Do you have a support network who you can contact when things are bad? A counsellor, a doctor? There are ALWAYS people out there who are willing to listen, sometimes we just need to make the first step in asking for help. Are you at school? Do you have a school counsellor? There is also eheadspace, which is another great service. check them out here: <http://www.eheadspace.org.au>. You get well soon, dear friend.”

Intervention: B

“Good afternoon. When we’re sad, it’s really hard to see the positive side of life. Also I should add that if you think you may have depression it’s really important to speak to a health professional (i.e., your local GP) as they’re the only ones who can make a proper diagnosis. I know something that’s been REALLY helpful for me has been using phone/online counseling with Kids Helpline: <http://www.kidshelpline.com.au>. They’ve got counsellors there 24/7 and you can stay anonymous if you want. It was a bit scary (and I must admit a little embarrassing as well) when I called them the first time and didn’t know what to say but they’re used to that and are really friendly. If you want, you can give them a call on 1800 55 1800.”

The NLGS interventions have an average of 0.69 Jaccard dissimilarity, which indicates that the system is able to generate interventions with good variation. With that being said, since the interventions all relate to a specific mental health topic, the variation is not extremely high as some keywords repeatedly appeared under the same topics. The average Jaccard dissimilarity for the seven depression interventions, eight anxiety interventions, and 10 combined interventions are 0.71, 0.67, and 0.68, respectively.

QUALITY MEASURES

In order to rate the interventions, quality measure questions were developed specifically for the project by research staff at the Brain and Mind Research Institute, The University of Sydney. These measures were then used to rate the 75 interventions (25 NLGS interventions, 25 moderator interventions, and 25 mental health professional interventions). The questions in Table 4 were asked to measure quality of the interventions.

RATING INTERVENTIONS

The participants who rated the interventions (human and NLGS) were aged from 18 to 27 years and were mostly undergraduate students from first year to fourth year pursuing Psychology or an equivalent university degree. The cohort of raters was considered informed and interested enough in mental

TABLE 4 Quality Measure Questions and Response Type

| Questions | Response type |
|---|---|
| The intervention is grammatically correct (Grammatical). | Likert scales: 1 (<i>strongly disagree</i>), 2 (<i>disagree</i>), 3 (<i>neither</i>), 4 (<i>agree</i>), 5 (<i>strongly agree</i>) |
| The language used in the intervention is clear and unambiguous (Clarity). | Likert scales: 1 (<i>strongly disagree</i>), 2 (<i>disagree</i>), 3 (<i>neither</i>), 4 (<i>agree</i>), 5 (<i>strongly agree</i>) |
| The intervention is appropriate (Appropriateness). | Likert scales: 1 (<i>strongly disagree</i>), 2 (<i>disagree</i>), 3 (<i>neither</i>), 4 (<i>agree</i>), 5 (<i>strongly agree</i>) |
| The intervention provides the recipient with useful advice (Usefulness). | Likert scales: 1 (<i>strongly disagree</i>), 2 (<i>disagree</i>), 3 (<i>neither</i>), 4 (<i>agree</i>), 5 (<i>strongly agree</i>) |
| The intervention is likely to encourage the recipient to take positive steps toward enhancing their mental health and wellbeing (Positive Reinforcement). | Likert scales: 1 (<i>strongly disagree</i>), 2 (<i>disagree</i>), 3 (<i>neither</i>), 4 (<i>agree</i>), 5 (<i>strongly agree</i>) |
| What is your overall rating of the intervention (Overall)? | Likert scales: 1 (<i>very poor</i>), 2 (<i>poor</i>), 3 (<i>average</i>), 4 (<i>good</i>), 5 (<i>excellent</i>) |
| In your opinion, was this intervention machine-generated? | Discrete: yes, no, don't know |
| Do you have any comments regarding this intervention? | Comment box |

TABLE 5 Grouping for Intervention for Rating

| Group | First part Interventions (25) | Second part Interventions (25) | Num. of rats |
|-------|----------------------------------|-----------------------------------|--------------|
| CM | Clinician | NLGS | 9 |
| RM | ReachOut | NLGS | 11 |
| MC | NLGS | Clinician | 8 |
| MR | NLGS | ReachOut | 7 |

health issues, yet not expert psychologists. This is a representative sample of the human moderators who do this job, both in age, interest, and prior knowledge of mental health first aid.

A total of 44 psychology students from a variety of universities in Australia were recruited and allocated the rating task; however, only 35 interns completed the task. In order to facilitate the rating process, a rating system was developed in-house and was explained to the raters before they started the task. The rating system presented a form for collecting demographic information followed by the rating task. Each participant rated a total of 50 interventions (i.e., 25 NLGS interventions and 25 human interventions). A comprehensive face-to-face training was provided by a psychiatrist who described the experiment and the rating procedure. Participants were asked to complete as many ratings as possible during the training and all issues (e.g., questions and confusions) were resolved through discussion. They completed the remaining task over a period of 1 week.

To explore if the order of presentation had an effect on the results, the participants were randomly allocated to one of four groups. Each group either started with human interventions (trained professional moderator or mental health professional) or the NLGS ones. In the second stage they rated the other type: NLGS for the former and either trained professional moderator (ReachOut) or mental health professional (Clinician), for the latter (see Table 5). Initially, all 44 interns were divided into the four groups equally. The participants were not informed about the groups allocated to them as well as the order of presentation.

HYPOTHESES

We hypothesized that rating scores change over time and that the quality of interventions would be perceived as good initially but drop toward the end. We believed that when raters see many of the system-generated interventions in a short period of time, they may start to find them less interesting.

While comparing NLGS ratings with human ratings, we hypothesized that rating scores would change based on the order of presentation. More specifically, we propose that the system-generated interventions would be rated higher if the raters saw the human intervention responses after the NLGS interventions and vice versa. We believe that when raters see the

human interventions in the first order, they may find the NLGS interventions less appealing.

DATA ANALYSES

The Likert scale for first six questions in Table 4 was converted to 1.00–5.00 values. Then the average and standard deviation (SD) scores were calculated for the NLGS and human interventions over all participants ($n = 35$). The scores of the individual categories (depression, anxiety, and combined) are reported as part of the NLGS analysis. The percentage of NLGS that received rating above 2.00 and 3.00 were calculated individually for the three categories and for the overall, over all participants. This is used to report the proportion of the interventions receiving high rating scores (above 2.00 and 3.00).

The performance of the NLGS interventions were compared with the human-generated ones by considering the overall ratings (average and SD scores) of the three categories. The one-tailed t -test ($p < 0.05$) was conducted for reporting significant differences in the rating scores for these two intervention types and the order of presentation for NLGS.

RESULTS

This section presents the outcome of the NLGS interventions using the rating scores. The results are presented for the following: (a) the quality of NLGS interventions, and (b) the quality of NLGS in comparison to human-generated interventions.

Overall Quality of NLGS Interventions

Firstly, we report the quality of NLGS interventions (Figure 4) based on the average and standard deviation (SD) for three types of intervention cate-

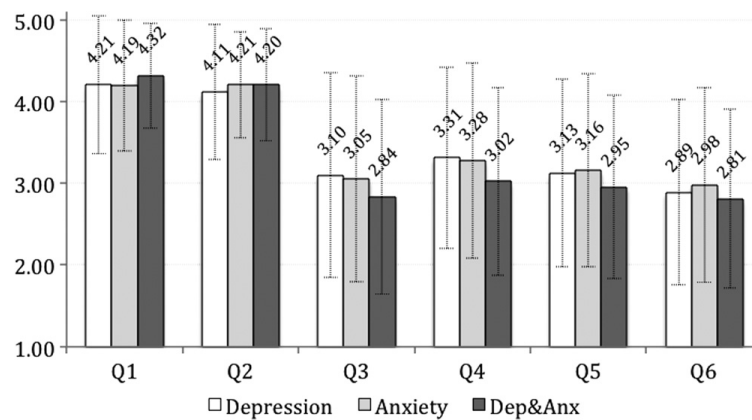


FIGURE 4 Average and SD rating scores for system interventions.

gories: *Depression*, *Anxiety*, and both (*Dep&Anx*). *Grammatical* and *Clarity* (Q1 and Q2) received average scores slightly above 4.00 for all three types of intervention categories. Both *Depression* and *Anxiety* for *Appropriateness* (Q3), *Positive Reinforcement* (Q5) and *Dep&Anx* for *Usefulness* (Q4) received average scores slightly above 3.00. As for all other cases the average score was slightly below 3.00. This indicates that the interventions were grammatically correct and clear, but average in relation to delivering interventions that are appropriate to the corresponding post, providing useful resources, and offering advice to improve general wellbeing. The SD is lower for *Grammatical* and *Clarity* compared to the other questions for the three categories, indicating that the raters had more agreement in scoring *Grammatical* and *Clarity*, whereas opinions were more varied in relation to other questions.

The majority of the NLGS interventions received ratings above 2.00 (Table 6). Over 90% of the ratings scored above 2.00 for *Grammatical* and *Clarity* (Q1 and Q2), whereas the remaining questions scored 60%–70%. The result is similar for achieving ratings above 3.00 for *Grammatical* and *Clarity* (Q1 and Q2), however, only 30%–50% for *Appropriateness* (Q3), *Usefulness* (Q4), *Positive Reinforcement* (Q5), and *Overall* (Q6) ratings (Table 7).

In Figure 5, we present the average scores for the first, middle, and last proportion of the interventions in the time-series over all raters for the three categories. According to the results the first and middle five interventions received higher rating scores compared to the last five interventions for *Appropriateness* (Q3), *Usefulness* (Q4), *Positive Reinforcement* (Q5), and *Overall* (Q6). The ratings for *Grammatical* and *Clarity* were consistent for the first, middle, and last five interventions.

TABLE 6 Proportion of NLGS Interventions Receiving Rating Above Disagree (2.00)

| | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 |
|------------|------|------|------|------|------|------|
| Depression | 0.93 | 0.93 | 0.63 | 0.73 | 0.66 | 0.60 |
| Anxiety | 0.95 | 0.98 | 0.63 | 0.71 | 0.68 | 0.63 |
| Dep&Anx | 0.98 | 0.97 | 0.56 | 0.63 | 0.61 | 0.58 |
| Overall | 0.96 | 0.96 | 0.60 | 0.68 | 0.65 | 0.60 |

TABLE 7 Proportion of NLGS Interventions Receiving Rating Above Neutral (3.00)

| | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 |
|------------|------|------|------|------|------|------|
| Depression | 0.89 | 0.87 | 0.47 | 0.52 | 0.44 | 0.30 |
| Anxiety | 0.89 | 0.91 | 0.45 | 0.54 | 0.46 | 0.40 |
| Dep&Anx | 0.96 | 0.91 | 0.35 | 0.39 | 0.36 | 0.29 |
| Overall | 0.92 | 0.90 | 0.42 | 0.48 | 0.41 | 0.33 |

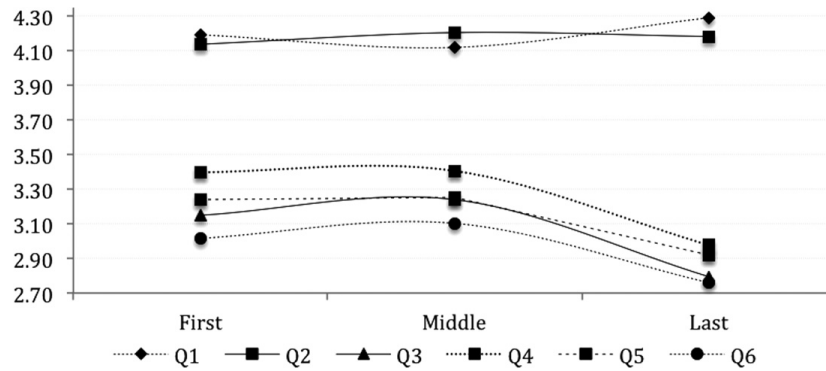


FIGURE 5 Average score for first, middle, and last portion of system interventions.

Quality of NLGS Interventions vs. Human Interventions

We also compare the rating scores (i.e., performance) of NLGS intervention with human intervention. Table 8 gives the average and SD scores over all raters for the NLGS and human interventions. Grammatical (Q1) and Clarity (Q2) have similar rating scores for both NLGS and human interventions, however the average rating is above 4.00 for all questions for human interventions. The standard deviations indicate higher variations in ratings for NLGS (except of Grammatical and Clarity). The difference in the scores of NLGS and human interventions were significant ($p < 0.05$) for all questions except Grammatical (one-tailed $t(1748) = 1.19, p = 0.12$).

The authorship (i.e., human or system) was recognizable as shown in the answers to Q7, “in your opinion, was this intervention machine-generated?” We find that 76% of the NLGS interventions were correctly recognized by raters to be machine generated. Table 9 gives the percentage scores for the individual intervention types. As for the human interventions, 82% were assumed by raters to be generated by humans.

TABLE 8 Comparing Interventions Average (SD) Ratings (NLGS vs. Human)

| | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 |
|-------|-------------|-------------|-------------|-------------|-------------|-------------|
| NLGS | 4.25 (0.76) | 4.18 (0.72) | 2.98 (1.24) | 3.19 (1.16) | 3.07 (1.15) | 2.89 (1.14) |
| Human | 4.29 (0.93) | 4.47 (0.64) | 4.33 (0.77) | 4.31 (0.75) | 4.18 (0.83) | 4.14 (0.85) |

TABLE 9 Opinion About Q7 (Is Machine Generated?)

| NLGS | Q7 |
|------------|-----|
| Depression | 80% |
| Anxiety | 71% |
| Dep&Anx | 79% |
| Overall | 76% |

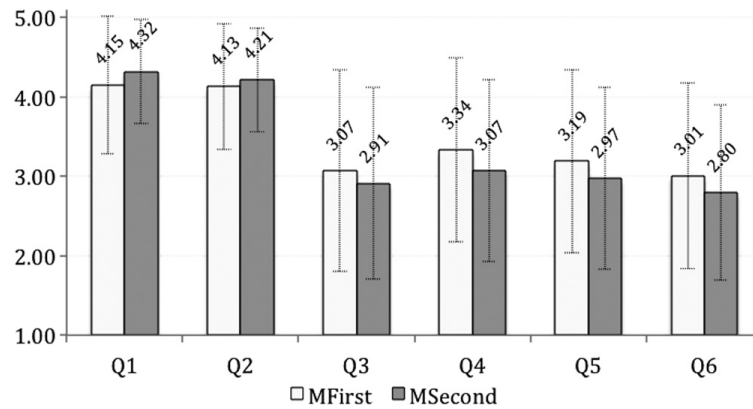


FIGURE 6 Average and SD rating scores for NLGS based on presentation order (machine vs. human).

TABLE 10 *t*-test (One-tailed) for Evaluating Difference in MFirst and MSecond

| Question | <i>t</i> -test score |
|-----------------------------|---------------------------|
| Grammatical (Q1) | $t(873) = 3.31, p < 0.05$ |
| Clarity (Q2) | $t(873) = 1.65, p = 0.05$ |
| Appropriateness (Q3) | $t(873) = 1.87, p < 0.05$ |
| Usefulness (Q4) | $t(873) = 3.35, p < 0.05$ |
| Positive Reinforcement (Q5) | $t(873) = 2.78, p < 0.05$ |
| Overall (Q6) | $t(873) = 2.78, p < 0.05$ |

In Figure 6, we present data for the average (and SD) scores for the NLGS interventions based on the order of presentation. *MFirst* represents when raters were presented with the NLGS interventions first and then human ratings and *MSecond* represents the opposite. According to the results MFirst received slightly higher average rating scores compared to MSecond for Appropriateness (Q3), Usefulness (Q4), Positive Reinforcement (Q5), and Overall (Q6). The ratings for Grammatical and Clarity (Q1 and Q2) were opposite. This indicates that for Grammatical and Clarity the ratings were good for NLGS due to having rich text contents generated by the system. However, the raters have a slightly lower perception of the quality of NLGS interventions after seeing human interventions that were tailored for the user as well as providing support and other useful resources. The difference in the scores of MFirst and MSecond were significant (Table 10).

DISCUSSION AND CONCLUSIONS

This article presented NLGS, an NLG-based system for generating interventions for supporting mental health. Despite the work on NLG-based implementations in other domains (Portet et al., 2007; Reiter, 1999; Vargas et al., 2012), its use in mental health, particularly for interventions, is still very

novel. Previous work, such as PsychoGen (Dockrey, 2007) have attempted NLG approaches in the mental health domain but are limited in terms of generating long/complicated natural language output and lacks a proper evaluation of its quality.

The positive findings of our study suggest that the system is capable of generating natural language interventions for mental health support. More specifically, the NLGS produced intervention-based responses that were clear and grammatically correct. The system is also capable of producing interventions with good variation in the text, something that moderators consider important for uptake of the tools. However, the results suggest that improvements are needed in the appropriateness and quality of information included in the text.

As hypothesized, the results showed that the rating scores changed over time in terms of appropriateness, usefulness, and positive reinforcement. In all cases the quality of the NLGS interventions were perceived to be lower toward the end of the rating process. This effect might be important when the intervention is made public, for example, in forums where one user (i.e., help-seeking individual) can read the responses to someone else's question (i.e., posts). We expect the effect not be as important when the intervention is provided privately, for example, in a direct message. Moreover, users are less likely to receive too many responses consecutively in a short period of time, as in the case of the evaluation. The effect of the order in which a person reads the interventions was also observed when comparing the NLGS rating with human rating. In this case, the quality of the system-generated interventions were perceived to be lower when presented after human interventions. This type of scenario is also less likely in practice.

When asked about the authorship of the interventions, the majority of them were recognizable. Overall, 76% of the NLGS interventions and 82% of the human interventions were recognizable. This is expected for this version of the NLGS and due to the factors hypothesized and discussed earlier. Improving the quality of the NLGS interventions in terms of appropriateness and tailoring them for individuals should make the system interventions appear more humanlike.

Although the aim of NLGS is not to replace a human moderator, this system could potentially be very useful for providing moderators with draft responses, which would reduce their workload, even if those responses require editing, and allow them to meet increasing demand. While questions remain as to the ability of the NLGS in relation to the generation of personalized messages, in practice and in the context of a sensitive area such as mental health, personalized messages are always encouraged to come from humans.

The Moderator Assistant system (including the NLGS component) is being deployed in an Australian mental health organization, and we are evaluating time saving and other benefits that moderators may find. One approach in the real world is to automate the process of detection concerning contents and generating corresponding responses. Despite this being a

very cost and time effective solution, it is unsuitable for sensitive issues like mental health and its support. Instead, human moderators can administer contents detected (e.g., keyword-based, NLP) and generated (e.g., NLG) by machines. For example, the moderators in ReachOut.com have to ensure that they collect, read, and understand the contents posted by the community and then respond with resources (e.g., links) and personal experiences related to the concerns. The Moderator Assistant system aims to help detect some of the issues the moderators listen out for and provide template responses for the corresponding concerns for them to administer and use. The NLGS will provide the support for the later.

Limitations

This study has two important limitations. The first, related to its ecological validity, is that the way moderators and end users perceive the quality of posts (both human or NLG generated) would be different in a real life situation to what we have been able to do here. Second, we have not attempted to evaluate the impact that the interventions have on health outcomes. The differences in perceived quality may or may not have significant impact on the way the interventions help end users. This is a common problem, the health impact of human-generated interventions in peer-support groups are often not measured directly.

As part of future work, other mental health categories (e.g., self-harm, suicide) and personalized information (e.g., age, sentiment, cognitive processing, etc.) from social media posts will be extracted for the NLGS input in order to address a broader range of mental health problems and to improve the quality of the personalized messages. Furthermore, the current system only uses the mental health categories (e.g., depression, anxiety) for individual posts to generate the interventions. Any previous responses or dialogue between the moderator and the help-seeker would be considered as part of future work by storing historical information/keywords in the NLG knowledge base.

As for evaluating the quality of interventions, the procedure presented in this article is based on a small sample size (i.e., raters) with quality measure questions developed specifically for this study. The questions can be revised in future studies for reporting the quality of interventions as the enhancement of NLGS progresses. Despite the limitations, the evaluation presented in this article provides good insight into the capability of the NLGS for generating natural language responses in the mental health domain.

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Original Paper

Using New and Emerging Technologies to Identify and Respond to Suicidality Among Help-Seeking Young People: A Cross-Sectional Study

Frank Iorfino, BSc (Psych), MBMSc; Tracey A Davenport, BA (Hons), eMBA; Laura Ospina-Pinillos, MD; Daniel F Hermens, PhD; Shane Cross, BPsy (Hons), MPsych (Clinical), PhD; Jane Burns, PhD; Ian B Hickie, AM, MD, FRANZCP, FASSA

Brain and Mind Centre, The University of Sydney, Sydney, Australia

Corresponding Author:

Frank Iorfino, BSc (Psych), MBMSc
Brain and Mind Centre
The University of Sydney
94 Mallett St, Camperdown
Sydney, 2050
Australia
Phone: 61 02 9351 0827
Email: frank.iorfino@sydney.edu.au

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Abstract

Background: Suicidal thoughts are common among young people presenting to face-to-face and online mental health services. The early detection and rapid response to these suicidal thoughts and other suicidal behaviors is a priority for suicide prevention and early intervention efforts internationally. Establishing how best to use new and emerging technologies to facilitate person-centered systematic assessment and early intervention for suicidality is crucial to these efforts.

Objective: The aim of this study was to examine the use of a suicidality escalation protocol to respond to suicidality among help-seeking young people.

Methods: A total of 232 young people in the age range of 16-25 years were recruited from either a primary mental health care service or online in the community. Each young person used the Synergy Online System and completed an initial clinical assessment online before their face-to-face or online clinical appointment. A suicidality escalation protocol was used to identify and respond to current and previous suicidal thoughts and behaviors.

Results: A total of 153 young people (66%, 153/232) reported some degree of suicidality and were provided with a real-time alert online. Further levels of escalation (email or phone contact and clinical review) were initiated for the 35 young people (15%, 35/232) reporting high suicidality. Higher levels of psychological distress ($P<.001$) and a current alcohol or substance use problem ($P=.02$) predicted any level of suicidality compared with no suicidality. Furthermore, predictors of high suicidality compared with low suicidality were higher levels of psychological distress ($P=.01$), psychosis-like symptoms in the last 12 months ($P=.01$), a previous mental health problem ($P=.01$), and a history of suicide planning or attempts ($P=.001$).

Conclusions: This study demonstrates the use of new and emerging technologies to facilitate the systematic assessment and detection of help-seeking young people presenting with suicidality. This protocol empowered the young person by suggesting pathways to care that were based on their current needs. The protocol also enabled an appropriate and timely response from service providers for young people reporting high suicidality that was associated with additional comorbid issues, including psychosis-like symptoms, and a history of suicide plans and attempts.

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KEYWORDS

suicidal ideation; mental health; primary health care; telemedicine; health services

Introduction

Suicidal thoughts are common among young people presenting to traditional face-to-face mental health services and engaging with online mental health services [1,2]. Young people presenting to such services are also more likely to engage in suicidal behaviors (such as planning or attempts), which are among the strongest predictors of completed suicide [3-6]. Suicidal thoughts and behaviors are also associated with complex comorbid mental health problems [7], alcohol, or other substance use problems [8], as well as social and economic difficulties that contribute to greater disability [9]. Together, this highlights the need for suicide prevention and early intervention strategies that facilitate the early detection and rapid response to suicidality for those help-seeking young people [10,11].

This is a particularly pertinent issue given that almost half of those who have died by suicide had contact with a primary care provider within one month of the suicide [12], and one-quarter of those with depression who die by suicide are likely to have been in active engagement with mental health services at the time of death [13-16]. This emphasizes the challenge mental health professionals and services face when trying to identify and respond to those at high risk of engaging in harmful suicidal behaviors. This may be influenced by the relatively limited

exposure to acutely suicidal patients in a clinician's daily work and a lack of systematic or organizational processes that directly address suicidal thoughts and behaviors [17].

New and emerging technologies (eg, mobile and Internet-based apps and e-tools) may be able to improve the systematic assessment and response to suicidality at a service and individual level so that those at risk can receive the appropriate care sooner [18,19]. Evidence indicates that online assessments are preferred and accurate for identifying suicidal thoughts and behaviors and other sensitive information [20,21], and online screening has demonstrated utility for facilitating access to treatment, especially when integrated with professional services [22-24]. The integration of these technologies with traditional services is crucial, and understanding how best to utilize the benefits of new and emerging technologies in terms of accessibility is an important goal for the ongoing development of effective early intervention strategies that target suicidal thoughts and behaviors.

The aim of this study was to examine the use of a suicidality escalation protocol embedded within the Synergy Online System (Textbox 1) that identifies and responds to suicidal thoughts and behaviors experienced by young people (aged 16-25 years) seeking help through primary mental health care and community settings and to identify specific predictors of suicidality.

Textbox 1. Synergy Online System.

The Synergy Online System is a personalized Internet-based resource designed to help people manage their physical, mental, and social wellbeing using a mixture of evidence-based apps, e-tools, and online and face-to-face services. One of the cornerstone principles of the Synergy Online System is a focus on the entire spectrum of health and well-being, from those who simply want to achieve goals to improve their daily habits, to those experiencing serious mental health problems. A key feature of the Synergy Online System is that it's configurable (ie, can rearrange or turn on or off different components within the system as well as tailor content), which allows it to easily adapt and thus meet the needs of end users. The System aims to transform the provision of mental health services by delivering readily accessible, affordable, and equitable mental health care through an increased focus on prevention and early intervention and improving the management of mental disorders across settings.

Methods**Participants**

Participants in this study included young people aged 16-25 years who had access to the Internet and were either seeking help through primary mental health care services (*headspace*) or online in the community for the first time. Participants were recruited into one of three groups as follows:

Primary care sample 1: Participants were recruited from a group of young people presenting for the first time to *headspace* Camperdown or *headspace* Campbelltown (both in Sydney, Australia) from July 2015 to July 2016. These participants were recruited for the initial "proof of concept" trial of the Mental health eClinic (MHEC) of the Synergy Online System.

Primary care sample 2: Participants were recruited from a group of young people presenting for the first time to any *headspace* service in the Central and Eastern Sydney Primary Health Network (ie, Ashfield, Bondi Junction, Camperdown, Hurstville, and Miranda) from September 2016 to February 2017. These

participants were recruited for a trial of the MHEC of the Synergy Online System embedded with primary mental health care services (*headspace*).

Community sample: Participants were recruited from three urban, regional, and rural communities in New South Wales that have a number of geographical, social, and economic vulnerabilities (ie, Central Coast, Western Sydney, and the Far West). Participants were recruited through targeted advertising in each of these communities (including posters and postcards in local businesses, paid Facebook advertisements, and advertisements on organizational social media channels) from March 2016 to June 2016. Young people were invited to participate in the study if they were currently living in one of these communities and had regular access to a mobile phone and the Internet.

Ethics

The University of Sydney Human Research Ethics Committees approved these studies and all participants gave written or online informed consent when they first accessed the Synergy Online System and before completing the initial clinical assessment.

Measures

All participants were invited to complete an initial clinical assessment (accessed via the MHeC of the Synergy Online System). Participants from primary care sample 1 were provided with a URL to the alpha version of the MHeC and asked to complete the initial clinical assessment online before either a video visit or face-to-face appointment with a clinician. Participants from primary care sample 2 were provided with a URL to the beta version of the MHeC (with the video visit “turned off”) and asked to complete the initial assessment before their scheduled face-to-face appointment with a clinician. Participants from the community sample either navigated themselves to the MHeC or were automatically directed (via an e-tool embedded within the Synergy Online System) to the beta version of the MHeC (with the video visit “turned on”) if they were expressing psychological distress. For all participants using the MHeC, a “need help now” button was always displayed to provide the details of relevant emergency and helpline services for those who sought immediate help.

The initial clinical assessment assesses a range of mental health outcomes, as well as comorbid and associated risk factors. Being administered online and using smart skips, the full assessment takes approximately 45 min to complete (median, 47.5 min) and includes 14 modules (in the following order): demographics; current education and employment participation; mental health concerns; self-harm and suicidal behaviors; tobacco, alcohol, and other substance use; physical activity; sleep-wake behaviors; lifetime disorders; physical and mental health history; cognition; eating behaviors and body image; social connectedness; and puberty. Participants completed all modules. For the purposes of this study, the following measures were specifically selected and included for analysis.

Demographics

Participants’ age, gender, highest level of education, and current education, employment, and training status (used to determine not in education, employment or training [NEET] status).

Mental Health

Current psychological distress was assessed using the Kessler-10 (K10) questionnaire [25] that is a well-validated measure of general psychological symptoms and distress widely used in adult and adolescent populations in both clinical and community settings. Hypomania-like symptoms over the last 12 months were assessed using a screener derived from the Altman self-rating scale [26]. Psychosis-like symptoms over the last 12 months were assessed using a screener derived from Community Assessment of Psychotic Experiences-Positive Symptoms scale [27]. Participants were also asked “Have you ever experienced a major mental health or behavioral problem that has affected your everyday life?” and this was used as a proxy for a previous mental health problem.

Suicidality

The Suicide Ideation Attributes Scale (SIDAS) is a 5-item scale assessing suicidal ideation over the past month [28]. The scale assesses frequency, controllability, closeness to attempt, distress, and interference with daily activities on a 10-point Likert scale. A score of 0 corresponds to “no current ideation”, a score of 1

to 20 corresponds to “low current suicidal ideation”, and a score of 21 to 50 corresponds to “high current suicidal ideation”. The scale has strong internal reliability (Cronbach alpha=.91). Lifetime suicidal thoughts and behaviors (ideation, planning, and attempts) were assessed by three questions from the Youth Risk Behaviors Survey [29,30]; (1) “Have you ever seriously thought about killing yourself?” (2) (1) “Have you ever seriously thought about killing yourself?” (2) “Have you ever made a plan about how you would kill yourself?” and (3) “How many times have you actually tried to kill yourself?”.

Functioning

An item from the Brief Disability Questionnaire (BDQ) was used to assess participant’s inability to carry out daily tasks over the previous month [31]. Specifically, participants were asked “Over the past month, how many days in total were you unable to carry out your usual daily activities fully?” This enabled a calculation of “days out of role in the past month.”

Alcohol and Substance Use

Two questions about alcohol and substance use were used to assess the presence of a current comorbid alcohol or substance use problem. Specifically, participants were asked “Have you recently thought that you should cut down on alcohol or other addictive drugs?” (derived from the CAGE questionnaire; [32]) and “Have you recently had a friend, relative or doctor suggest that you should cut down on alcohol or other addictive drugs?” (derived from the Alcohol Use Disorders Identification Test; [33]). Participants who answered “no” to one or both of these questions were categorized as “no problem”, and participants who answered “yes” to both questions were categorized as “likely problem” [34].

Statistical Analyses

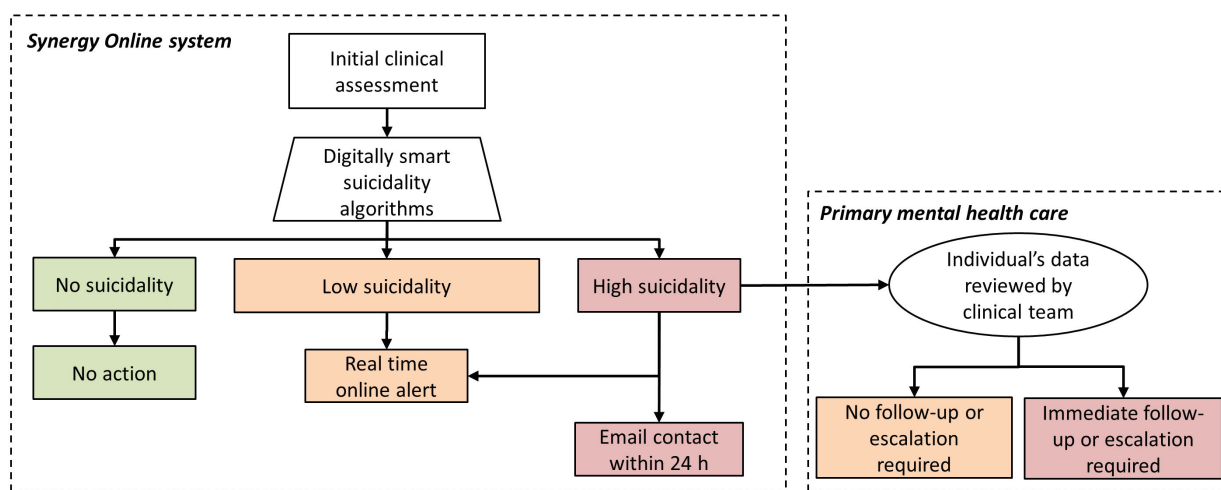
All statistical analyses were performed using Statistical Package for the Social Sciences (SPSS 22.0 for Windows). Group differences between the three sample groups (primary care sample 1, primary care sample 2, and community sample) were assessed using the Kruskal-Wallis H test for continuous variables and the chi-square test for categorical variables. The sample was then split by suicidality group (see Textbox 2; “no suicidality”, “low suicidality”, and “high suicidality”) to assess group differences using the Kruskal-Wallis H test for continuous variables and the chi-square test for categorical variables. To examine the independent predictors of suicidality, two separate logistic regressions were conducted. The first model compares the “no suicidality” group with the “any suicidality” group (low and high suicidality groups combined). The second model compares the “low suicidality” and “high suicidality” groups. For both models, variables were entered using a forward forced-entry method with demographic variables (age, gender, education, and NEET status) entered in the first block, current mental health variables (K10, hypomania-like symptoms, psychosis-like symptoms, and alcohol or substance use) entered in the second block, mental health history variables (previous mental health problem, suicide plans or attempts history) entered in the third block, and functioning (days out of role) entered in the final block. To control for sample groups in the analyses, “sample” was also entered in the final block. Only models with

nonsignificant Hosmer-Lemeshow goodness of fit tests were included.

Textbox 2. Suicidality escalation protocol.

The suicidality escalation protocol involves multiple levels of action, dependent on the participants' responses to the initial assessment (Figure 1). Every young person completes the initial clinical assessment, and at the end of the suicidality module the digitally smart algorithms assess current and past suicidality. The algorithm assigns them to one of the three groups: "no suicidality" (SIDAS score of 0 and no lifetime suicidal behaviors), "low suicidality" (SIDAS score of 1-20 and/or lifetime suicidal behaviors), and "high suicidality" (SIDAS score of 21 to 50). For the "no suicidality" group, no action is taken. For those in the "low suicidality" or "high suicidality" groups, an automatic real-time alert is immediately presented on the young person's screen. The alert displays information regarding both crisis and non-crisis services so the young person can access immediate support if needed. For those in the "high suicidality" group, two additional actions are initiated. First, a notification is sent to the clinical research team who initiate email contact with the participant within 24 h. This email aims to provide further information that encourages the young person to seek help and requests they inform the clinical research team how they are going by replying to the email or calling. Second, for those currently in contact with a service, the young person's data is forwarded to the clinical service for review, and a decision is made regarding further follow-up or escalation. Further follow-up or escalation involves one or more of the following: contact over the phone, rescheduling the young person's appointment or an online "video visit" within the subsequent 72 h. Importantly, this suicidality escalation protocol is designed to respond in real-time to the suicidality expressed by the young person and is not used to determine suicide risk. Formal suicide risk is determined by a health professional or a multidisciplinary team after making contact with the young person and reviewing the young person's data.

Figure 1. Suicidality escalation protocol.



Results

Sample Characteristics

The demographic and behavioral characteristics for each sample are presented in Tables 1 and 2. A total of 232 participants were included in the analyses (95 from primary care sample 1, 105 from primary care sample 2, and 32 from the community sample). The mean age of the entire sample was 20.44 years (standard deviation [SD]=2.59; median=21 years), 69% (160/232) were female, and 37% (87/232) were classified as NEET. Across all three samples, the mean K10 score was in the severe range of psychological distress (\bar{x} =28.99, SD=8.86; median=30); 17% (40/232) reported no psychological distress, 13% (31/232) reported mild psychological distress, 19% (43/232) reported moderate psychological distress, and 51% (118/232) reported severe psychological distress. The mean SIDAS score was 8.25 (SD=11.52; median=2); 39% (90/232) reported no current suicidal ideation, 46% (107/232) reported low current suicidal ideation, and 15% (35/232) reported high current suicidal ideation. The only statistically significant differences identified between the three sample groups were for "days out of role" over the past month ($\chi^2_2=16.2, P<.001$).

Suicidality Escalation in Primary Care—A Proof of Concept

The first use of the suicidality escalation protocol in a primary mental health care setting occurred at *headspace* Camperdown and *headspace* Campbelltown and was rolled out entirely by the clinical research team. Of the entire primary care sample 1, 33% (31/95) were identified as "no suicidality" and so no action was initiated, 51% (49/95) were identified as "low suicidality" and were presented with a real-time alert only, and 16% (15/95) were identified as "high suicidality," which initiated the real-time alert and an additional two escalation actions. All 15 individuals were contacted via email by the clinical research team and had their data reviewed. Of these 15, 7 had their entry into clinical care escalated (ie, their initial clinical assessment appointment was brought forward). Clinicians reported that the decision to escalate an individual was influenced by the following: (1) concerns over specific suicidal ideation attributes such as little of control over suicidal thoughts (5/7 participants) and closeness to making an attempt (5/7 participants), (2) concerns over the presence of hypomania or psychosis-like symptoms (1/7 participants), (3) recent plans to make an attempt that were identified upon follow-up (1/7 participants), (4) few protective factors identified upon follow-up (1/7 participants), (5) few protective factors identified at follow-up (1/7

participants), and (6) recent self-harm (1/7 participants). All 7 participants were escalated due to one or more of these factors being present, and the clinician decided that their initial appointment for care was too long to wait. The remaining 8 participants did not have the initial assessment appointment

brought forward due to most, or all of the above, factors being absent or because their clinical appointment was scheduled within a few days (range=0-5 days), which was deemed to be sufficient by the reviewing clinician.

Table 1. Demographic characteristics by sample group (N=232).

| Characteristics | Primary care 1 (n=95) | Primary care 2 (n=105) | Community (n=32) | P value |
|---------------------------------------|--------------------------|---------------------------|---------------------|---------|
| Age, mean (SD ^a) | 20.39 (2.56) | 20.41 (2.53) | 20.66 (2.90) | .88 |
| Gender, n (%) | | | | .76 |
| Female | 68 (72) | 71 (68) | 21 (66) | |
| Male | 27 (28) | 34 (32) | 11 (34) | |
| Education^b, n (%) | | | | .70 |
| Secondary | 44 (46) | 49 (48) | 16 (55) | |
| Tertiary | 51 (54) | 54 (52) | 13 (45) | |
| NEET^c status, n (%) | | | | .12 |
| Non-NEET | 62 (65) | 59 (56) | 24 (75) | |
| NEET | 33 (35) | 46 (44) | 8 (25) | |

^aSD: standard deviation.

^b“no formal education” and “primary education” groups were left out due to insufficient cell counts (n=5 cases missing).

^cNEET: not in education, employment or training.

Suicidality Escalation Scaled Up for Use in Primary Care

The suicidality escalation protocol was scaled up and rolled out across all *headspace* services in the Central and Eastern Sydney Primary Health Network. Of the entire primary care sample 2, 34% (36/105) were identified as “no suicidality” and so no action was initiated, 55% (57/105) were identified as “low suicidality” and were presented with a real-time alert only, and 11% (12/105) were identified as “high suicidality,” which initiated the real-time alert and an additional two escalation actions. All 12 individuals were contacted via email by the

clinical research team and had their data forwarded for review to the clinical service responsible so that specific service protocols could be initiated.

Of the entire community sample, 37.5% (12/32) young people were identified as “no suicidality” and so no action was initiated, 37.5% (12/32) were identified as “low suicidality” and were presented with a real-time alert, and 25% (8/32) were identified as “high suicidality”, which initiated the real-time alert and an additional two escalation actions. All 8 individuals were contacted via email by the clinical research team, and had their data reviewed.

Table 2. Behavioral characteristics by sample group (N=232).

| Characteristics | Primary care 1 (n=95) | Primary care 2 (n=105) | Community (n=32) | P value |
|---|--------------------------|---------------------------|---------------------|---------|
| K10 ^a score, mean (SD ^b) | 29.28 (8.16) | 29.75 (8.28) | 25.59 (11.76) | .11 |
| K10 category, n (%) | | | | .08 |
| No | 13 (14) | 15 (14) | 12 (38) | |
| Mild | 15 (16) | 13 (13) | 3 (9) | |
| Moderate | 18 (19) | 20 (19) | 5 (16) | |
| Severe | 49 (51) | 57 (54) | 12 (37) | |
| SIDAS ^c score, mean (SD) | 7.93 (11.50) | 7.52 (9.71) | 11.59 (16.05) | .87 |
| SIDAS category, n (%) | | | | .34 |
| No ideation | 37 (39) | 40 (38) | 13 (41) | |
| Low ideation | 43 (45) | 53 (51) | 11 (34) | |
| High ideation | 15 (16) | 12 (11) | 8 (25) | |
| Hypomania-like symptoms, last 12 months, n (%) | | | | .06 |
| No | 68 (72) | 88 (84) | 22 (69) | |
| Yes | 27 (28) | 17 (16) | 10 (31) | |
| Psychosis-like symptoms, last 12 months, n (%) | | | | .51 |
| No | 65 (68) | 71 (68) | 25 (78) | |
| Yes | 30 (32) | 34 (32) | 7 (22) | |
| Days out of role in past month, mean (SD) | 7.53 (7.22) | 8.04 (8.47) | 2.34 (2.66) | <.001 |
| Alcohol and substance use, current, n (%) | | | | .22 |
| No problem | 60 (73) | 87 (83) | 25 (78) | |
| Likely problem | 26 (27) | 18 (17) | 7 (22) | |
| Previous mental health problem, ever, n (%) | | | | .24 |
| No | 27 (28) | 31 (29) | 14 (44) | |
| Yes | 68 (72) | 74 (71) | 18 (56) | |
| Suicide plans or attempts, ever, n (%) | | | | .18 |
| No | 67 (71) | 66 (63) | 17 (53) | |
| Yes | 28 (29) | 39 (37) | 15 (47) | |

^aK10: Kessler-10.

^bSD: standard deviation.

^cSIDAS: Suicide Ideation Attributes Scale.

Predictors of Suicidality

The overall sample was split according to “no suicidality”, “low suicidality”, and “high suicidality” to examine the demographic and behavioral differences between these groups (Tables 3 and 4). No differences were identified between the sample groups ($P=.33$) or for the demographic variables; age ($P=.08$), gender ($P=.74$), or NEET status ($P=.29$); however, significant differences were identified for highest level of education ($\chi^2=8.6$, $P=.01$). In terms of behavioral characteristics, no differences were identified for days out of role ($P=.09$);

however, significant differences were identified between the three suicidality groups for psychological distress ($\chi^2=48.5$, $P<.001$), hypomania-like symptoms in the last 12 months ($\chi^2=12.9$, $P=.002$), psychosis-like symptoms in the last 12 months ($\chi^2=29.2$, $P<.001$), alcohol or substance use ($\chi^2=8.3$, $P=.02$), and previous mental health problem ($\chi^2=15.8$, $P<.001$). Significant differences between the “low suicidality” and “high suicidality” groups were also identified for history of suicide plans or attempts ($\chi^2=22.3$, $P<.001$).

Table 3. Demographic characteristics by suicidality group (N=232).

| Characteristics | Suicidality | | | P value |
|---------------------------------------|--------------|----------------|----------------|---------|
| | No (n=79) | Low (n=118) | High (n=35) | |
| Sample, n (%) | | | | .33 |
| Primary care 1 | 31 (39) | 49 (42) | 15 (43) | |
| Primary care 2 | 36 (46) | 57 (48) | 12 (34) | |
| Community | 12 (15) | 12 (10) | 8 (23) | |
| Age, mean (SD) ^a | 20.32 (2.66) | 20.75 (2.52) | 19.66 (2.53) | .08 |
| Gender, n (%) | | | | .74 |
| Female | 57 (72) | 79 (67) | 24 (69) | |
| Male | 22 (28) | 39 (33) | 11 (31) | |
| Education^b, n (%) | | | | .01 |
| Secondary | 32 (41) | 53 (46) | 24 (71) | |
| Tertiary | 46 (59) | 62 (54) | 10 (29) | |
| NEET^c status, n (%) | | | | .29 |
| Non-NEET | 48 (61) | 71 (60) | 26 (74) | |
| NEET | 31 (39) | 47 (40) | 9 (26) | |

^aSD: standard deviation.

^b“no formal education” and “primary education” groups were left out due to insufficient cell counts (n=5 cases missing).

^cNEET: not in education, employment or training.

Table 4. Behavioral characteristics by suicidality group (N=232).

| Characteristics | Suicidality | | | P value |
|---|--------------|----------------|----------------|--------------------|
| | No (n=79) | Low (n=118) | High (n=35) | |
| Sample, n (%) | | | | .33 |
| Primary care 1 | 31 (39) | 49 (42) | 15 (43) | |
| Primary care 2 | 36 (46) | 57 (48) | 12 (34) | |
| Community | 12 (15) | 12 (10) | 8 (23) | |
| K10 ^a score, mean (SD) ^b | 24.30 (8.04) | 29.92 (8.22) | 36.43 (6.41) | <.001 |
| K10 category, n (%) | | | | <.001 |
| No | 26 (33) | 14 (12) | 0 (0) | |
| Mild | 14 (18) | 16 (14) | 1 (3) | |
| Moderate | 17 (21) | 22 (18) | 4 (11) | |
| Severe | 22 (28) | 66 (56) | 30 (86) | |
| Hypomania-like symptoms, last 12 months, n (%) | | | | .002 |
| No | 67 (85) | 92 (78) | 19 (54) | |
| Yes | 12 (15) | 26 (22) | 16 (46) | |
| Psychosis-like symptoms, last 12 months, n (%) | | | | <.001 |
| No | 67 (85) | 82 (70) | 12 (34) | |
| Yes | 12 (15) | 36 (30) | 23 (66) | |
| Days out of role in past month, mean (SD) | 6.22 (7.63) | 7.18 (7.69) | 8.46 (7.35) | .09 |
| Alcohol and substance use, current, n (%) | | | | .02 |
| No problem | 70 (89) | 87 (74) | 24 (69) | |
| Likely problem | 9 (11) | 31 (26) | 11 (31) | |
| Previous mental health problem, ever, n (%) | | | | <.001 |
| No | 34 (43) | 36 (30) | 2 (6) | |
| Yes | 45 (57) | 82 (70) | 33 (94) | |
| Suicide plans or attempts, ever, n (%) | | | | <.001 ^c |
| No | 79 (100) | 67 (57) | 4 (11) | |
| Yes | 0 (0) | 51 (43) | 31 (89) | |

^aK10: Kessler-10.

^bSD: standard deviation.

^cThis P value refers to the 2x2 comparison between the low and high groups. By definition the “no suicidality” group has 0 “yes” responses.

Further analyses using logistic regression were conducted to (1) identify predictors of “no suicidality” compared with “any suicidality” (low and high suicidality groups combined) (Model 1, Table 5), and (2) to identify predictors of “low suicidality” compared with “high suicidality” (Model 2, Table 5). Model 1 identified that higher psychological distress and a current alcohol or substance use problem were predictors of “any suicidality”

compared with “no suicidality” ($\chi^2_{12}=57.7, P<.001, R^2=0.22$). Model 2 identified that higher psychological distress, any psychosis-like symptoms in the last 12 months, a previous mental health problem, and a history of suicide plans or attempts were all predictors of “high suicidality” compared with “low suicidality” ($\chi^2_{13}=67.0, P<.001, R^2=0.36$).

Table 5. Logistic regression models showing predictors of suicidality (N=232).

| | No suicidality versus any suicidality ^a | | | Low suicidality versus high suicidality ^b | | |
|--|--|------------------|---------|--|--------------------|---------|
| | Beta (SE ^c) | OR (95% CI) | P value | Beta (SE) | OR (95% CI) | P value |
| Age | .05 (0.07) | 1.05 (0.91-1.22) | .47 | -.17 (0.15) | 0.84 (0.63-1.13) | .26 |
| Gender | | | | | | |
| Female | | 1.00 | | | 1.00 | |
| Male | .65 (0.38) | 1.92 (0.92-4.02) | .08 | .66 (0.64) | 1.94 (0.55-6.81) | .30 |
| Education^d | | | | | | |
| Secondary | | 1.00 | | | 1.00 | |
| Tertiary | -.22 (0.39) | 0.81 (0.37-1.75) | .58 | -.91 (0.69) | 0.40 (0.10-1.57) | .19 |
| NEET^e status | | | | | | |
| NEET | | 1.00 | | | 1.00 | |
| Non-NEET | .30 (0.35) | 1.35 (0.68-2.67) | .39 | .92 (0.68) | 2.50 (0.66-9.51) | .18 |
| K10 ^f score | .11 (0.02) | 1.12 (1.07-1.17) | <.001 | .11 (0.04) | 1.12 (1.03-1.21) | .01 |
| Hypomania-like symptoms, last 12 months | | | | | | |
| No | | 1.00 | | | 1.00 | |
| Yes | .14 (0.45) | 1.16 (0.48-2.76) | .75 | .41 (0.60) | 1.50 (0.47-4.84) | .50 |
| Psychosis-like symptoms, last 12 months | | | | | | |
| No | | 1.00 | | | 1.00 | |
| Yes | .80 (0.41) | 2.22 (1.00-4.95) | .05 | 1.54 (0.58) | 4.68 (1.51-14.53) | .01 |
| Alcohol and substance use, current | | | | | | |
| No problem | | 1.00 | | | 1.00 | |
| Likely problem | 1.04 (0.46) | 2.84 (1.15-7.05) | .02 | -.12 (0.63) | 0.89 (0.26-3.04) | .85 |
| Previous mental health problem | | | | | | |
| No | | 1.00 | | | 1.00 | |
| Yes | .42 (0.35) | 1.52 (0.77-3.03) | .23 | 2.43 (0.99) | 11.34 (1.64-78.30) | .01 |
| Suicide plans or attempts, ever | | | | | | |
| No | | | | | 1.00 | |
| Yes | N/A ^g | N/A | N/A | 2.34 (0.70) | 10.41 (2.65-40.83) | .001 |
| Days out of role, past month | -.02 (0.02) | 0.98 (0.94-1.03) | .42 | .01 (0.04) | 1.00 (0.92-1.09) | .93 |
| Sample | | | | | | |
| Community | | 1.00 | | | 1.00 | |
| Primary care 1 | -.22 (.57) | 0.80 (0.26-2.43) | .69 | .25 (0.86) | 1.28 (0.24-6.83) | .77 |
| Primary care 2 | -.27 (.57) | 0.76 (0.25-2.30) | .63 | -.51 (0.92) | 0.60 (0.10-3.67) | .58 |

^aModel 1 : $R^2=0.22$ (Cox and Snell), 0.31 (Nagelkerke). Model $\chi^2_{12}=57.7$, $P<.001$.

^bModel 2 : $R^2=0.36$ (Cox and Snell), 0.55 (Nagelkerke). Model $\chi^2_{13}=67.0$, $P<.001$.

^cSE: standard error.

^d“no formal education” and “primary education” groups were left out due to insufficient cell counts (n=5 cases missing).

^eNEET: not in education, employment or training.

^fK10: Kessler-10.

^gN/A: Not applicable, this comparison is invalid since the “no suicidality” group, by definition, has no history of suicide plans or attempts and therefore was left out of the model.

Discussion

Principal Findings

We identified that two-thirds of help-seeking young people reported some degree of suicidality, and the protocol provided these young people with a real-time alert online. Further levels of escalation (email or phone contact and clinical review) were initiated for the 15% (35/232) of young people who reported high suicidality. Higher levels of psychological distress and a current alcohol or substance use problem predicted any level of suicidality (compared with no suicidality). In addition to higher levels of psychological distress, psychosis-like symptoms in the last 12 months, a previous mental health problem, and a history of suicide plans or attempts were specific predictors of high suicidality (compared with low suicidality). These results support the use of new and emerging technologies to facilitate the systematic assessment and detection of young people experiencing suicidal thoughts with additional comorbidities and enable an appropriate and timely response from service providers.

The use of the suicidality escalation protocol of the Synergy Online System as an adjunct to traditional primary mental health care services assisted clinical decision-making about suicide risk and the need for care among those young people reporting higher levels of suicidality. Of the young people in primary care, 13.5% (27/200) had their case escalated to clinical review by a clinician or clinical team before their entry into care. Importantly, none of these young people were referred to crisis services but instead had their entry into care facilitated due to a clinically perceived higher need for immediate care. This escalation process ensured that individuals presenting to primary care services with increased suicidality were not delayed by a service waitlist, which commonly arises from a mismatch between service demand and capacity [35]. Instead, the Synergy Online System was able to deploy many immediate actions to ensure the suicidality risk is addressed in a timely and efficient manner. The use of this System has already had major implications on actual health service practices for the youth mental health services that have adopted Synergy; specifically, improving patient and workforce management through systematic assessment, automatic escalation of an individual's data, and assisting clinical team review and decision-making processes.

Importantly, the results here also highlight the benefits of offering online services to young people by allowing mental health care and the service to be brought to the young person when they need it, wherever they live, rather than relying on young people to present initially to a face-to-face service which has many barriers to overcome [36]. Notably, there were comparable levels of suicidal ideation in the community sample compared with those presenting to primary mental health care. These young people may never have presented to a face-to-face service either because of common barriers to help-seeking or because a service was not available locally [37,38]. The use of the online service meant that a service could "come to them" when they needed it and in a manner that is preferable to some young people [39]. The use of new and emerging technologies

as reported in this paper is critical in reaching the high numbers of at-risk youth in the community who are not presenting to traditional face-to-face services. Importantly, with the rapid increase in new and emerging technologies for mental health care, there is a significant need for effective suicide escalation protocols that can appropriately and efficiently manage risk. A real-time mapping system to (local) mental health services might be useful for those in the community who seek help online to ensure the system effectively facilitates help-seeking behavior, which is a crucial unresolved issue for online assessment and feedback systems [40-42]. Similarly, further follow-up through partnerships with specific local or national suicide prevention organizations may be needed to increase help-seeking behavior for those identified as at-risk or in need of care in the community.

Psychological distress differentiated between each level of suicidality identified, which is consistent with the established relationship between distress and suicidality [43,44]. The only other predictor that differentiated between no suicidality and any suicidality was a current alcohol or substance use problem. This reflects the common relationship between alcohol and substance use and suicidal thoughts and behaviors, particularly among young people with mental health problems [45]. Young people reporting high suicidality were also more likely to report psychosis-like symptoms in the last 12 months, a previous mental health problem, and a history of suicide plans or attempts. Together, this confirms the significant comorbidity that help-seeking young people initially present with and reiterates the need for services to be equipped to respond to the differing individual needs a young person has when they first present to care.

The ongoing development of the Synergy Online System would benefit from employing methodologies that utilize longitudinal outcomes to improve the existing algorithms accuracy for identifying individual cases of suicidality that should be escalated and followed up immediately by a clinician and service. Machine learning methodologies are increasingly used in psychiatric research as they facilitate individual-level prediction of unseen observations, which makes them suitable for the development of clinically useful digital tools [46]. Recent evidence has demonstrated the use of these algorithms to utilize clinical and demographic variables to predict suicide attempters among a group of mood disorder patients with accuracy comparable with most breast cancer prediction algorithms [47,48], whereas another study demonstrated the utility of such algorithms to differentiate between suicidal and nonsuicidal patients [49]. Employing these approaches could improve the personalization of care beyond simple cut-off scores and include key risk factors specific to a particular individual. Similar approaches have been employed by Facebook who have developed an online tool that uses machine learning to identify users at risk of suicide by assessing their posts and comments and provides the user with a number of options for how to get help [50]. These semiautomated approaches require rigorous evaluation and validation using qualitative person-centered approaches such as user acceptance testing, in addition to more traditional quantitative methods to determine whether they are appropriate and effective. This is important for the development

of clinically useful and scalable suicide prevention and early intervention efforts that are integrated with existing services and practices.

Limitations

For the future development of the protocol, some limitations need to be addressed. First, the initiation of the suicidality escalation protocol is dependent on when the young person completes the online assessment. So young people at-risk who don't complete the online assessment immediately cannot be identified and spend a longer period under distress and not in care. Second, the outcome for those who had their entry into care escalated is unclear, so it is difficult to determine the impact of the suicidality escalation protocol on their clinical outcome. This was beyond the scope of this particular study, but it is an important focus for future research to establish the long term impact of this protocol on engagement with services and clinical trajectory. Another key focus for this work would be to determine whether the protocol missed individuals who would become high risk or later engage in suicidal behaviors. Third,

the relatively small sample size of the community sample, compared with the two primary care sample groups, means that the sample characteristics were somewhat biased toward the primary care groups and limits the generalizability of these results to young people in the community who seek help online. Finally, the use of the K10 as a measure of general psychological distress may be limited primarily to depression and anxiety symptoms and less useful for other mental health problems common in adolescence.

Conclusions

This study contributes to the research and knowledge about the use of new and emerging technologies to identify and respond to increased suicidality among help-seeking young people. Young people with increased suicidality were more likely to present with a number of comorbid issues including psychosis-like symptoms and a history of plans or attempts, which emphasizes the need for these young people to receive appropriate and timely care.

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Conflicts of Interest

Professor Ian Hickie has been a commissioner in Australia's National Mental Health Commission since 2012. He is the co-director, Health and Policy at The University of Sydney's Brain and Mind Centre. The Brain and Mind Centre operates an early-intervention youth services at Camperdown under contract to headspace. Professor Hickie has previously led community-based and pharmaceutical industry-supported (Wyeth, Eli Lilly, Servier, Pfizer, AstraZeneca) projects focused on the identification and better management of anxiety and depression. He is a member of the Medical Advisory Panel for Medibank Private, a board member of Psychosis Australia Trust, and a member of Veterans Mental Health Clinical Reference group. He is the chief scientific advisor to, and an equity shareholder in, Innowell. Innowell has been formed by The University of Sydney and PricewaterhouseCoopers (PwC) to deliver the \$30m Australian Government-funded "Project Synergy." Project Synergy is a 3- year program for the transformation of mental health services through the use of new and innovative technologies. Professor Jane Burns is the CEO of, and an equity shareholder in, Innowell.

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Abbreviations

BDQ: Brief Disability Questionnaire

K10: Kessler-10 Questionnaire

MHeC: Mental health eClinic

NEET: Not in Educational, Employment or Training

SIDAS: Suicide Ideation Attributes Scale

SPSS: Statistical Package for the Social Sciences

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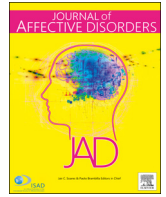
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Research paper

Neurocognitive clusters: A pilot study of young people with affective disorders in an inpatient facility



Ashleigh M. Tickell^{a,*}, Elizabeth M. Scott^b, Tracey Davenport^a, Frank Iorfino^a,
Laura Ospina- Pinillos^a, Kate Harel^b, Lisa Parker^b, Ian B. Hickie^a, Daniel F. Hermens^{a,c}

^a Clinical Research Unit, Brain and Mind Centre, University of Sydney, 100 Mallett Street, Camperdown, NSW 2050, Australia

^b Young Adult Mental Health Unit, Uspace, St Vincent's Private Hospital, Australia

^c Sunshine Coast Mind and Neuroscience Thompson Institute, University of the Sunshine Coast, Birtinya, QLD, Australia

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ABSTRACT

Background: There is growing evidence to support the need for personalised intervention in the early stages of a major psychiatric illness, as well as the clear delineation of subgroups in psychiatric disorders based on cognitive impairment. Affective disorders are often accompanied by neurocognitive deficits; however a lack of research among young adult inpatients highlights the need to assess the utility of cognitive testing in this population.

Methods: A computerised cognitive battery was administered to 50 current inpatient young adults (16–30 years; 75% female) with an affective disorder. Patients also completed a computerised self-report questionnaire (to measure demographics and clinical features) that included items evaluating subjective impressions of their cognition.

Results: Hierarchical cluster analysis determined two neurocognitive subgroups: cluster 1 ($n = 16$) showed more severe impairments in sustained attention and memory as well as higher anxiety levels, compared to their peers in cluster 2 ($n = 30$) who showed the most impaired attentional switching. Across the sample, poor sustained attention was significantly correlated with higher levels of current anxiety and depressive symptoms, whereas poor verbal memory was significantly associated with increased psychological distress.

Limitations: This study has a relatively small sample size (due to it being a pilot/feasibility study). Furthermore, future studies should aim to assess inpatient samples compared to community care samples, as well as healthy controls, on a larger scale.

Conclusions: The findings suggest neurocognitive profiles are important in understanding phenotypes within young people with severe affective disorders. With clear subgroups based on cognitive impairment being demonstrated, the clinical utility and use of new and emerging technologies is warranted in such inpatient facilities. This pilot/feasibility study has strengthened the utility of cognitive screening as standard clinical care in an inpatient unit.

1. Introduction

Affective disorders are characterised by disturbances in mood and emotional state (i.e. episodes of depression, mania and/or anxiety). Early stages of affective disorders may also be accompanied by functional impairment and neuropsychological changes such as difficulties in mental flexibility (Hermens et al., 2011), attention (Thompson et al., 2005), memory (Thompson et al., 2005) and executive function (Sweeney et al., 2000). Furthermore, studies have shown that patients' neuropsychological (or 'neurocognitive') course is one of the best predictors of long-term function, over and above current affective

symptoms (Lee et al., 2015).

To our knowledge there are very few studies that have specifically examined neurocognition in inpatients with affective disorders. Sweeney et al., (2000) utilised a computerised cognitive battery assessing working memory, set-shifting, visual learning and short term memory. A total of 93 inpatients (58 non-bipolar major depression ($M = 32$ years of age) and 35 bipolar ($M = 31$ years of age)) were compared to 51 healthy controls ($M = 36$ years of age) (Sweeney et al., 2000). This study found more severe deficits in neuropsychological profiles of patients experiencing a manic/mixed illness phase (including deficits in executive function, episodic and working memory),

* Corresponding author.

E-mail address: ashleigh.tickell@sydney.edu.au (A.M. Tickell).

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compared to patients during a more depressive illness phase (less severe deficits in episodic memory only) (Sweeney et al., 2000). Another study by Levy and Weiss (2010) examining inpatients with bipolar disorder ($n = 59$, $M = 37$ years of age) used a computerised cognitive battery assessing attention and working memory, visual and verbal memory, and executive function. This study found more severe neurocognitive deficits in verbal memory and executive function in inpatients with psychotic symptoms, compared to those without psychotic symptoms (Levy and Weiss, 2010). The results of both of these studies (Levy and Weiss, 2010; Sweeney et al., 2000) suggest potential markers for neurocognitive impairment based on the presence or absence of certain symptoms and/or severity of illness. However, given the age of the patients in these studies these findings may also be due to differences in illness chronicity.

Whilst various literature shows the associations between neurocognitive performance and longitudinal outcomes (Lee et al., 2015, 2013), the strength of neurocognitive performance beyond diagnostic course (Lee et al., 2015), and the clear delineation of cluster phenotypes based on neurocognitive measures including sustained attention and verbal learning (Lee et al., 2015); there is a paucity of research and general lack of information in regards to young adult inpatients with affective disorders, and more specifically in relation to their neurocognitive profiles and associated symptom management. Historically, neurocognitive performance (or deficits for instance) has been able to explain variations in functional abilities in psychiatric disorders (Alden et al., 2015), furthermore cognitive subgroups have been found in patients with bipolar disorder suggesting phenotypes that allow for more targeted and personalised assessment (Burdick et al., 2014). Research shows that acute psychiatric symptoms can affect cognitive performance (David et al., 2008) (which would be expected to be especially evident in an inpatient sample), therefore the association between acute symptoms and cognitive performance is another key factor to explore. Burdick et al., (2014) examined the utility of a cognitive battery in 136 outpatients with bipolar disorder ($M = 40$ years of age) using a hierarchical cluster analysis. Three distinct subgroups were found, including; (i) a cluster with intact cognitive performance comparable to healthy controls; (ii) a cluster with moderate impairments in four of the seven cognitive domains (selective impairment); and (iii) a cluster with global impairment across all cognitive domains (Burdick et al., 2014). The presence of cognitive subgroups has also been demonstrated in early stages of affective disorders specifically. Our group previously examined the neuropsychological profiles of 109 help-seeking young adult outpatients ($M = 20$ years of age) by also using a hierarchical cluster analysis (Hermens et al., 2011). In this study of outpatients we also found three distinct cluster profiles characterised by (i) poor memory; (ii) poor mental flexibility; or (iii) more global impairments (Hermens et al., 2011). Such literature therefore suggests that young adults with acute affective disorders are differentiated by patterns of neurocognitive impairment, and more importantly there appears to be a tendency to form distinct neurocognitive subgroups, despite diagnostic or symptomatic similarities. The clinical importance of these neurocognitive subgroups may lie in their ability to allow for more targeted assessment (Burdick et al., 2014), likewise there may be an indication of early affective disorders being characterised by different cognitive profiles and severity of illness (Hermens et al., 2011). In particular, these two studies (Burdick et al., 2014; Hermens et al., 2011) support the notion of further research into the neurocognitive profiles of more severe cohorts such as inpatient young adults with affective disorders (Burdick et al., 2014). Whilst a lot of research into cognitive clustering has been undertaken in community and outpatient samples, there is also, as noted above, examples of inpatient samples. There is an argument that acute psychopathology in community samples of people with mental illness, is less likely to impact neurocognitive test performance compared to a more severe inpatient sample, thus suggesting the potential impact of illness severity on the accuracy of assessment and current neurocognitive ability. However, it is important

to assess neurocognitive ability, and the extent of impairments and deficits (e.g. reduced attention and concentration, and the impact of encoding and consolidation of memory) in more severe cohorts to facilitate a more personalised approach to mental health care. Furthermore, neurocognitive testing has the potential to be impacted by various factors including sleep, mood, or the time said testing was completed (i.e. morning or afternoon), however these are factors that need to be taken in consideration based on each individual case. In addition to this, the previous studies above have shown the clear delineation of neurocognitive clusters in regards to illness severity and differences in symptoms (Hermens et al., 2011; Levy and Weiss, 2010; Sweeney et al., 2000), which suggests research into cognitive clusters is of clinical importance.

The current aim of this study therefore was to determine whether there are neurocognitive cluster profiles within such patients. We hypothesised that inpatients would show impaired neuropsychological profiles, and that one cluster would be distinguished by global impairment.

2. Methods

2.1. Patients and design

To examine whether neurocognitive profiles of admitted young adults with acute affective disorders differ, this paper reports on a cross-sectional analysis of neurocognitive and clinical data collected as part of a pilot study examining the feasibility of using computer-assisted neurocognitive assessment. The inclusion criteria are comprised of: (i) patients currently admitted to the Young Adult Mental Health Unit (U-space); and (ii) current presentation of a severe affective episode (i.e. depressive, manic, anxiety; including those with psychotic features). Exclusion criteria for this study were: (i) insufficient fluency in the English language to participate in the cognitive testing; (ii) unable to consent due to intellectual impairment (for example, $IQ < 70$) or severity of mental illness (as determined by the treating psychiatrist/psychologist); and (iii) refusal to provide informed consent. Comorbid or pre-existing childhood-onset conditions (e.g., Attention Deficit Hyperactivity Disorder (ADHD) and conduct disorder), as well as alcohol or other substance misuse or autistic spectrum disorders were not exclusion criteria. We conducted a pilot study of 50 young people, aged 16–30 years, who were current inpatients at the Young Adult Mental Health Unit ('U-space'), St Vincent's Private Hospital Sydney, Australia for the assessment of mental health problems. Active recruitment of patients was between May and December 2016. A total of 68 patients were approached to participate in the pilot study (73.5% consented to participate and completed the full protocol). The remaining non-consenting patients did not want to participate due to: (i) 'not feeling they were in a good enough headspace' ($n = 9$); (ii) feeling the study did not appeal to them ($n = 1$); and/or (iii) disruptive symptomatology (e.g., high anxiety and nervousness surrounding possible performance, participation and/or results) ($n = 2$). Several patients were also unable to be followed up for the informed consent process due to being discharged early, or being transferred to a different hospital due to medical reasons ($n = 6$). Patients were determined to have a primary diagnosis of major depressive disorder, anxiety disorder, or bipolar disorder through consensus diagnosis; that is, via multidisciplinary clinical assessment (by psychiatrists, psychologists and allied health professionals) at U-space, St Vincent's Private Hospital. Primary diagnosis for patients ($n = 50$) were as follows: $n = 41$ with a depressive disorder [major depressive disorder (MDD) ($n = 41$)]; $n = 4$ with an anxiety disorder (AD) [obsessive-compulsive disorder (OCD) ($n = 2$); generalised anxiety disorder (GAD) ($n = 2$)]; $n = 5$ with a bipolar disorder [bipolar disorder I (BD I) ($n = 2$); bipolar disorder II (BD II) ($n = 3$)].

2.2. Setting and procedure

The University of Sydney Human Research Ethics Committee and St Vincent's Hospital Sydney Human Research Ethics Committee approved this study. Mental health clinicians confirmed patients as having the mental and intellectual capacity to give written informed consent prior to participation. Following a complete description of the study to patients (and parents/guardians if under the age of 18), written consent was obtained.

Uspace, St Vincent's Private Hospital Sydney, Australia, is a private mental health service, targeted to the needs of young adults (16–30 years of age). Patients are referred for the assessment of mental health problems; with a mission to promote recovery and psychological well being of young adults with severe and emerging mental health problems.

Cognitive testing and self-report assessments were completed on 50 young inpatients. On average, patients were in hospital for 19 days (range: 4–51 days), and neurocognitive screening was completed 3.6 days (range: 2–18 days) following admission. Through consecutive referral, patients who were newly admitted to Uspace were given a Participant Information Sheet and Consent Form (PICF), and followed-up by the researcher (AT) for informed consent, no less than 24 h later. Following informed, written consent (and parent or guardian written consent for patients under the age of 18), patients were booked in to complete neurocognitive testing and self-report questionnaires. Patient availability and booking schedule was based around their own routine appointments and groups as inpatients, with most patients being booked within 4 days of admission. Neurocognitive testing (CANTAB) was completed on an iPad, taking between 35 and 45 min to complete. Self-report questionnaire completion was completed the day after neurocognitive testing, taking 45–60 min, and depending on the patient. Once both the neurocognitive testing, and questionnaire were completed, a feedback report was generated (within 7 days of completion).

2.3. Measures

2.3.1. Self-report questionnaire

Patients completed self-report questionnaires on a touchscreen tablet (iPad), as part of the Mental Health e-Clinic (Iorfino et al., 2017), Brain & Mind Centre (BMC), University of Sydney. Initial questions obtain key demographic and clinical information, focusing on critical illness course variables (e.g., onset of symptoms, hospitalisations, age of first help seeking). Standardised questionnaires included the 10-item Kessler Psychological Distress Scale (K-10) (Kessler et al., 2002) to detect psychological distress, with scores ranging between 10 and 50 (a score over 30 representing a likely severe mental disorder); Quick Inventory of Depressive Symptomatology (QIDS-16) (Rush et al., 2003) to assess severity of depressive symptoms, with scores ranging between 1 and 27 (a higher score representing greater severity of depression); Overall Anxiety Severity and Impairment Scale (OASIS), a 5-item measure for assessment of severity and impairment in regards to anxiety symptoms (Norman et al., 2006), with scores ranging between 0 and 20 (a higher score representing a higher frequency and severity of anxiety [across anxiety disorders]); Psychosis Screener derived from Community Assessment of Psychic Experiences (CAPE) (Stefanis et al., 2002), a positive symptoms scale and psychosis screener, developed to measure the lifetime prevalence of psychotic-like experiences in the general population; Hypomania Screener derived from the Altman Self-Rating Mania Scale (ASRM) (Altman et al., 1997), a 5-item self rating scale to assess the severity of manic symptoms, a higher score (five or more) indicating a high probability of a manic or hypomanic condition; Suicidal Ideation Attributes Scale (SIDAS) (van Spijker et al., 2014), a 5-item scale to screen participants for suicidal thoughts and severity of these thoughts, with scores ranging between 0 and 50 (a higher score representing more severe suicidal thoughts (a score over 21 being in the

high risk category)); the Somatic and Psychological Health Report (SPHERE-12) (Hickie et al., 2001), a 12-item measure to screen for current depression and/or anxiety-like symptoms (a score of two or more on the psychological subscale and a score of three or more on the somatic subscale indicating current depression and/or anxiety-like symptoms). Self-reported, non-structured, standardised questions in regards to the patient's own sense of cognition was assessed prior to testing (e.g., changes in everyday thinking skills and neurocognitive abilities).

All electronic data files were retained in a secured SQL eResearch platform (and database) hosted by the BMC, University of Sydney. Once completed, the data from the self-report assessment is collated, and displays a detailed and immediate dashboard of results. This information is available to the trained research psychologist (AT) immediately upon the patient's completion of the self-report assessment.

2.3.2. Neurocognitive screening

A trained research psychologist (AT) conducted the cognitive testing battery, which included computerised assessments. First, premorbid intellectual functioning ('predicted IQ') was estimated on the basis of performance on the Wechsler Test of Adult Reading (Wechsler, 2001). This test compares individual performance on an irregular word reading task with an age-matched normative sample to provide a standardised estimate of full scale IQ for which 100 is the normative mean performance. Following this, patients completed tests from the Cambridge Neuropsychological Test Automated Battery (CANTAB) (Sahakian and Owen, 1992). The CANTAB tests have the advantage of being largely non-verbal (i.e. language-independent, culture-free) and have been described in detail elsewhere (Hermens et al., 2011; Sahakian and Owen, 1992; Sweeney et al., 2000). Five tasks were included in this study: an introductory task to prepare patients for testing (i.e. not included in overall results), induction of sensorimotor and comprehension of tasks measured by the Motor Screening Task (MOT); 'verbal memory and new learning' as measured by the Verbal Recognition Memory task (VRM immediate and recall/delayed), indexed by the encoding and subsequent retrieval of verbal information scores; 'mental flexibility' as measured by the Attention Switching Task (AST) and indexed by the total adjusted score; 'visuo-spatial learning and memory' as measured using the Paired Association Learning task (PAL) and indexed by the total adjusted errors score; and, 'sustained attention', as measured by the Rapid Visual Processing task (RVP) and indexed by the RVP A prime (sensitivity to the target). These cognitive measures were chosen as they are representative of a more broad neurocognitive domain appropriate for a routine cognitive screen.

Patients' individual, normed results were calculated by a trained research psychologist (AT) within two to three days of completion of the cognitive testing battery, with calculation of CANTAB z-scores were completed for each patient. To control for the effects of age, cognitive variable raw scores were converted to 'demographically corrected' standardised scores (z-scores) using a normative database of healthy controls (<http://www.cambridgecognition.com>). Each patient's predicted IQ score was used to evaluate where we would expect a patient's neurocognitive performance to be based on age and education. Impairment is defined as 1.5 standard deviations below the normative mean. All outliers (e.g. beyond ± 3.0) were confirmed to be statistical sample outliers (i.e. not artifacts). Each patient's predicted IQ is assessed in the cognitive screener to examine whether their current neurocognitive test performance as measured via the demographically- and normative-adjusted standardised scores (<http://www.cambridgecognition.com>), is consistent with their expected level of intellectual capability as measured via the WTAR. Neurocognitive screening results do not specifically test intelligence; they reflect current cognitive skills, which may change overtime.

2.4. Statistical analyses

Statistical analyses were performed using Statistical Package for the Social Sciences Version 24.0 (SPSS). A hierarchical cluster analysis utilising Wards method of minimum variance with a squared Euclidean distance measure was conducted to identify patterns of impairment across four key neuropsychological variables. Cluster analysis techniques were based on previous similar studies (Delano-Wood et al., 2009; Goldstein, 1990; Hermann et al., 2007, 2011) and statistical recommendations (Norris, 2010). The agglomerative hierarchical method was used as it does impose preconceived notions regarding the number of clusters. Change in agglomeration coefficients was used to determine a demarcation point. Unlike other statistical techniques (e.g., factor analysis), cluster analysis does not identify a particular statistical model (Norris, 2010); that is, a classification technique for forming homogeneous groups within complex data sets (Borgen, 1987). Whilst there are no specific rules about the number of cases (and the corresponding number of variables) required for cluster analysis, hierarchical clustering is recommended for smaller data sets (Norris, 2010); the type and number of variables are typically chosen on theoretical grounds (Delano-Wood et al., 2009; Goldstein, 1990). Ideally, a good cluster solution is when the data segregates into theoretically meaningful subsets (Delano-Wood et al., 2009) and this is usually achieved by examining cluster characteristics at consecutive steps until a reasonable number of relatively homogenous groups is obtained (Norris, 2010).

Pearson's correlations were used to examine associations between functional/clinical variables (K-10, QIDS-16, OASIS, Psychosis screener, Hypomania screener, and SPHERE) and key neuropsychological variables (AST, RVP, PAL and VRM) for the entire sample of subjects.

One-way between-subject analysis of variance (ANOVA) was used to assess differences in demographic, clinical and functional, and neuropsychological variables among cluster groups. The chi-square test was used to compare the ratio of females to males across cluster groups. Significance levels were set at $p < .05$. Based on a similar methodology (Delano-Wood et al., 2009) we also conducted a confirmatory (standard) discriminant function analysis (DFA) to determine which combinations of the neuropsychological variables best distinguishes the cluster groups and whether these combinations could reliably predict cluster-group membership.

3. Results

For the overall sample, the average age was 18.8 ± 3 years (75% female). The average \pm SD predicted IQ was 104.3 ± 8.5 (standard deviation being the measure of sample variability), as well as 32% of patients not being in current education, employment or training (NEET status).

3.1. Cluster characteristics

Agglomeration coefficients generated by cluster analysis revealed a demarcation point between two cluster solutions; this was confirmed by inspection of the dendrogram. Thus, the two groups were made up of $n = 16$ (cluster 1) and $n = 30$ (cluster 2) patients, with four patients being excluded due to at least one neuropsychological variable being missing (i.e. due to the patient being unable to complete a given test). ANOVA determined statistical significance of 'cluster group' for each neurocognitive variable, as well as the demographic and clinical variables (see Table 1 for means and standard deviations). The cluster groups differed significantly in all four neuropsychological variables ($p > .05$), whereas among the demographic and clinical variables (Table 1), the cluster groups differed only in one variable; that is, OASIS total score. Here, cluster 1 showed higher levels of anxiety and impairment compared to their peers in cluster 2. There were no significant

differences among the remaining demographic and self-reported measures.

Table 1 shows medication categories were relatively well distributed across the two cluster groups. Chi-square analysis revealed there were no significant differences between the clusters ($p > .05$) in regards to medication status. Chi-square analysis further showed no statistical differences based on diagnosis between clusters (i.e. Cluster 1 diagnoses including: 87.5% ($n = 14$) MDD; 6.3% ($n = 1$) BD; and, 6.3% ($n = 1$) AD. Cluster 2 diagnoses including: 80.0% ($n = 24$) MDD; 13.3% ($n = 4$) BD; and, 6.7% ($n = 2$) AD).

3.2. Neurocognitive cluster profile

Both clusters are characterised by poor performance ($p > .05$) across all measures. The proportion of inpatients meeting neurocognitive impairment criteria (i.e. a score below -1.5) was 86% in attention switching, 24% in visual memory, 72% in sustained attention, and 56% in verbal memory. Furthermore, all patients showed impairment on at least one neurocognitive task. Fig. 1 depicts the profile of cluster 1 being categorised by more severe impairments in sustained attention and memory, compared to their peers in cluster 2. In contrast, Fig. 1 also shows cluster 2's profile had the most impaired attentional switching.

3.2.1. Discriminant function analysis

Discriminant function analysis (DFA) confirmed a single function accounting for all (100%) of the variance among the clusters [Wilks' $\lambda = 0.228$, $p < .001$] and the structure matrix revealed a clear delineation for sustained attention (RVP; $r = 0.655$) and learned associations (PAL; $r = 0.570$), with the remaining two variables having low loadings (< 0.3). The DFA showed an overall correct classification result of 97.8%; that is, 93.8% of cluster 1 cases were correctly classified, and 100% of cluster 2 cases were correctly classified. Cross-validation confirmed the stability of these classification results with the same overall correct classification as the original grouped cases (i.e., 97.8%).

3.2.2. Correlations between neuropsychological performance and self-reported symptoms

Table 2 shows the correlation coefficients for the four neuropsychological scores and clinical variables for the entire sample. Three significant ($p < 0.05$) correlations were revealed: RVP-A was associated with both QIDS ($r = -0.336$) and OASIS ($r = -0.386$), while VRM correlated with K-10 ($r = -0.299$). The strongest of these correlations is depicted in Fig. 2. Here, higher anxiety and impairment scores (OASIS) are associated with poorer performance in sustained attention (RVP-A). Importantly, this scatterplot shows a segregation of the two cluster groups, whereby cluster 1 individuals appear at the worst end of this spectrum (see Fig. 2).

4. Discussion

As expected, all inpatients in this study demonstrated impaired performance on at least one neurocognitive task, which also suggests a possible marked reduction in their current neurocognitive performance when compared with their predicted IQ (which was generally within the average range). However, two distinct neurocognitive profiles of young adult, current inpatients were revealed by the cluster analysis. Cluster 1 was characterised by more severe neurocognitive impairments in sustained attention and memory, compared to their peers in cluster 2 who showed the most impaired attentional switching. Across clusters, higher scores of anxiety correlated with greater impairment in sustained attention, with cluster 1 showing the highest levels of both sustained attention impairment and anxiety compared to their peers in cluster 2. Overall, the results of this study are in line with previous studies demonstrating the value of neuropsychological profiling, as well as the importance of neurocognitive assessment as a critical tool to aid

Table 1

Mean scores (± standard deviation) for demographic and clinical variables, and medication status (%) across clusters; between group differences were tested by chi-square or ANOVA.

| | Cluster 1 (N = 16) | Cluster 2 (N = 30) | Significance test [p] |
|---------------------|--------------------|--------------------|------------------------------|
| Sex (m/f) | 2/14 | 11/19 | $\chi^2(1, 46) = 3.0$ [.083] |
| Age, years | 18.6 ± 3.1 | 19.7 ± 3.1 | F(1, 44) = 1.3 [.254] |
| Predicted IQ | 100.86 ± 5.08 | 105.75 ± 9.28 | F(1, 40) = 3.4 [.074] |
| K-10 Total | 38.4 ± 5.7 | 35.3 ± 5.5 | F(1, 41) = 3.0 [.089] |
| QIDS-16 Total | 17.7 ± 4.6 | 16.2 ± 5.5 | F(1, 41) = 0.8 [.389] |
| OASIS Total | 12.8 ± 3.2 | 10.5 ± 3.2 | F(1, 38) = 4.5 [.041] |
| Psychosis Screener | 1.8 ± 1.8 | 1.9 ± 1.9 | F(1, 40) = 0.0 [.893] |
| Hypomania Screener | 1.8 ± 2.3 | 2.7 ± 2.0 | F(1, 41) = 1.8 [.188] |
| SIDAS | 28.4 ± 16.0 | 24.8 ± 18.2 | F(1, 41) = 0.4 [.535] |
| SPHERE Psyc | 8.5 ± 2.4 | 6.3 ± 3.4 | F(1, 38) = 4.0 [.051] |
| SPHERE Soma | 6.4 ± 3.1 | 6.2 ± 2.9 | F(1, 41) = 0.1 [.794] |
| Nil medication (%) | 6.3% | 10% | $\chi^2(1, 46) = 0.2$ [.667] |
| Antidepressant (%) | 68.8% | 70.0% | $\chi^2(1, 46) = 0.8$ [.930] |
| Antipsychotic (%) | 56.3% | 40.0% | $\chi^2(1, 46) = 1.1$ [.292] |
| Mood Stabiliser (%) | 31.3% | 36.7% | $\chi^2(1, 46) = 0.1$ [.713] |

Abbreviations: K10 = Kessler Psychological Distress Scale; OASIS = Overall Anxiety Severity and Impairment Scale; QIDS-16 = Quick Inventory of Depressive Symptomatology; SIDAS = Suicidal Ideation Attributes Scale; SPHERE = Somatic and Psychological Health Report.

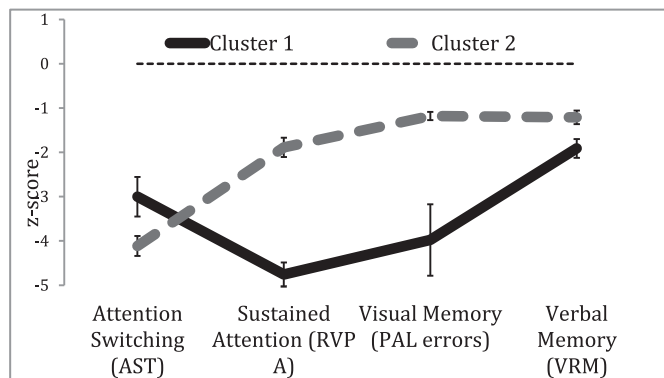


Fig. 1. Profile (n = 46) of mean z-scores (with standard error bars and dashed line representing the standardized norm (equivalent of 0 z-score)) for neuropsychological measures across cluster groups: cluster 1 (n = 16) and cluster 2 (n = 30).

Table 2

Pearsons correlation coefficients (* denotes p < 0.05) between functional/clinical versus key neuropsychological variables for the entire sample of subjects.

| | AST | RVP A | PAL | VRM |
|--------------------|--------|---------|--------|---------|
| K-10 Total | 0.087 | -0.250 | -0.230 | -0.299* |
| QIDS-16 Total | 0.016 | -0.336* | -0.112 | -0.096 |
| OASIS Total | 0.262 | -0.386* | -0.176 | -0.287 |
| Psychosis Screener | 0.296 | 0.002 | 0.070 | -0.077 |
| Hypomania Screener | 0.116 | 0.096 | 0.002 | 0.153 |
| SIDAS | -0.097 | -0.268 | -0.053 | -0.075 |
| SPHERE Psyc | 0.115 | -0.300 | -0.101 | -0.150 |
| SPHERE Soma | -0.072 | -0.086 | -0.152 | -0.269 |

Abbreviations: AST = Attention Switching Task; PAL = Paired Associations Learning Task; RVP = Rapid Visual Processing Task; VRM = Verbal Recognition Memory; All clinical variable abbreviations, see Table 1.

Note: the four cognitive tests (VRM, AST, PAL, RVP) were all performed via touchscreen computer (CANTAB); standardised scores are presented.

clinical evaluation (Hermens et al., 2013, 2010; Lee et al., 2015). The evidence here of a differential pattern of acute anxiety in this inpatient cohort according to neurocognitive cluster group (specifically, higher anxiety levels in Cluster 1 compared to Cluster 2) suggests there are also different outcome measures in terms of treatment and symptom resolution. For example, Cluster 1 has greater anxiety and poorer sustained attention, thus the possibility of greater motivational support

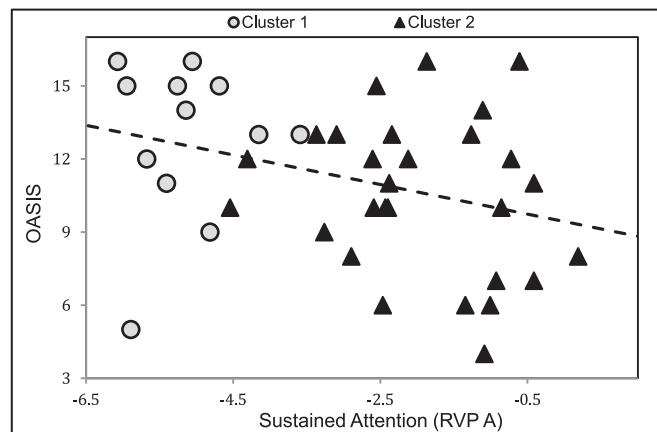


Fig. 2. Scatterplot of inpatients showing the association (r = -0.386) between Overall Anxiety Severity and Impairment Scale (OASIS) and Sustained Attention (RVP A) between cluster 1 (n = 16) and cluster 2 (n = 30).

when engaging in potentially challenging cognitive tasks, or greater external compensatory approaches during treatment. On the other hand, Cluster 2 may be better situated with more explicit emphasis on concrete explanations during therapy sessions. The information based on cluster analysis neurocognitive performance is also clinically relevant in showing the extent of subjective neurocognitive deficits in inpatients on an individual level. It also further supports the need for inpatient psychiatry clinicians to be sensitive to and compensate for particular neurocognitive impairments with their patients, as well as taking into consideration the changes in predicted IQ, likely exacerbated by symptom acuity.

Critically, the two distinct neurocognitive profiles in this study appear despite any demographic/clinical differences between clusters (with the exception of current anxiety symptoms). This strengthens the notion of neurocognitive profiles being important in understanding phenotypes within otherwise similar clinical samples (Lee et al., 2015). Although this study did not include a healthy control group, the profiles (of demographically-corrected standardised scores) shown here are in the impaired range (i.e. 3–4 standard deviations below established norms). As expected, cluster 1 presented a more globally impaired neurocognitive profile compared to cluster 2. Importantly, this also shows that neurocognitive profiles and clusters are clinically meaningful, in the identification of cognitive deficit patterns, and in the future, more preventative and early intervention type strategies (Burdick et al., 2014). Furthermore, it should be noted that

performance across all four neurocognitive tasks was substantially below the estimated 'average' level of premorbid intellectual ability (as indexed by WTAR) in both cluster groups. This is important as it suggests that in the acute illness phase, neurocognitive performance is not only impaired relative to a normative sample, but also lower than what would be expected for these young people in terms of their premorbid intellectual ability.

Neurocognitive profiles are important in their aptitude to identify patterns to guide understanding and treatment, as well as its relation and interaction with each individual's mood state and functioning levels. Mood fluctuations have always been an important aspect of clinical care; however, it is becoming increasingly important that cognition (Lee et al., 2015) and thus current functioning is assessed (O'Dea et al., 2016). Neurocognitive profiling has great value in its ability to distinguish patients who would otherwise appear to be similar (i.e. the same symptomatology, similar diagnoses, and demographics). Yet distinct subgroups have been demonstrated in this data-driven cluster analysis, and in previous literature (Burdick et al., 2014; Lee et al., 2015), on the basis of patients' cognitive profiles. This is what impacts treatment, makes the intervention personalised, and is important for both young adults, and clinicians.

There are some limitations worth mentioning in regards to this study. The first limitation is in the relatively small sample size ($n = 50$), given the cross-sectional design and clinical heterogeneity. Future studies with larger sample sizes should assess potential differences across diagnoses; e.g., among those with unipolar versus bipolar depression. The sample also predominately contained young adults with a diagnosis of MDD, and only a small number with anxiety ($n = 4$) and bipolar disorder ($n = 5$). The breakdown of diagnoses in this study is representative of young adults presenting to the mental health inpatient unit (Uspace) specifically (a heterogeneous sample). Therefore it can be argued that patterns of clustering may be altered if only patients with MDD were included (i.e. the highest presented diagnosis). There were no patients who performed well on the cognitive battery; that is, there were no examples of patients with 'average' (or higher) capabilities in their thinking or neurocognitive skills. In addition to this, poor performance is assumed based on a theoretical norm, however this should be interpreted with caution since a healthy control group was not included in this study. The majority of these patients were also medicated, which can have an impact on their neurocognitive abilities and profiles. It may therefore be helpful for future research to examine, within a similar inpatient cohort, how representative testing is and whether different symptom presentations and diagnosis result in the same observed clustering. Future studies should also aim to directly compare inpatient and outpatient samples as a means to determine differences based on illness severity, which would better facilitate common early intervention approaches across services. The final limitation worth mentioning is the application of only four facets of neurocognitive measures being examined in the cognitive screening battery, whereby clusters may differ based on measured cognitive domains. However, it is also important to note the clinical application and logistics behind the implementation of this battery, as standard clinical care was one of the main considerations, as well as attempting to cover a broad range of cognitive domains within a 40-minute time frame. It is also important to note the differences and similarities between the CANTAB battery utilised here and other commonly used batteries such as the Brief Assessment of Cognition in Affective Disorders (BAC-A) (Keefe et al., 2008) which covers a slightly different range of cognitive domains in approximately the same time frame. Future studies comparing these batteries across touch-screen versus pencil-and-paper formats would be helpful in establishing clinical utility in younger affective disorder samples.

Despite these limitations, this is an important study as it is the first to show an in-depth, inclusive (heterogeneous group), inpatient cohort's neurocognitive profile. The findings of this study suggest that neurocognitive profiles are important in understanding phenotypes within

young people with severe affective disorders. Furthermore, individually tailored cognitive assessment and interventions are warranted in such inpatient facilities. This pilot study has been successful in terms of feasibility to assess patient experience in the study protocol, as well as the inner workings and logistics of the protocol in an everyday clinical setting (i.e. inpatient facility). One example of this was a fair amount of patients incorrectly interpreting their cognitive results being representative of their intelligence. Some patients internalised certain information and felt that weaknesses in cognitive areas meant they were not 'smart'. This resulted in more information being included in the cognitive screener report itself, explaining performance as being a reflection of current cognitive skills and not intelligence, and that neurocognition may change overtime. Additionally, we incorporated cognitive psychoeducation groups (run by researcher AT) into the inpatient program. This was a way for patients to better understand cognition and changes in cognitive performance (i.e. how this relates to symptoms and functioning).

Outside of a research setting (i.e. clinical care), we found each case needs to be personalised based on the patient's symptomatology of thinking and behaviour. In terms of future directions, this pilot data has led to changes in the protocol (already being implemented in a current confirmatory study, including for example, having feedback sessions that are based more on the patient's current mood, symptoms, and cognitive cluster type). Moreover, this feasibility study has strengthened the application of this protocol and cognitive screening as standard clinical care at the Young Adult Mental health Unit, Uspace.

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Contributors

D.F.H. and I.B.H. contributed to the conception of the study; A.M.T. managed study, completed all data collection and study completion, analysis, data processing and statistical analysis; D.F.H. contributed to early editing stages; A.M.T. wrote the first draft of the manuscript; E.M.S. contributed to diagnostic, clinical and medication discussion and confirmation. T.D., F.I. and L.O.P. contributed to online technology design and assistance; F.I. further assisted with syntax and technology analysis; K.H. and L.P. managed patient unit participation and supervision. All authors contributed to data interpretation, discussion, and have approved the final manuscript.

Conflict of interest

The authors have no conflict of interest.

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Developing neurocognitive standard clinical care: A study of young adult inpatients



Ashleigh M. Tickell^{a,*}, Elizabeth M. Scott^b, Tracey Davenport^a, Frank Iorfino^a,
Laura Ospina-Pinillos^a, Django White^a, Kate Harel^b, Lisa Parker^b, Ian B. Hickie^a,
Daniel F. Hermens^{a,c}

^a Clinical Research Unit, Brain and Mind Centre, University of Sydney, 100 Mallett Street, Camperdown, NSW 2050, Australia

^b Young Adult Mental Health Unit, Uospace, St Vincent's Private Hospital, Australia

^c Sunshine Coast Mind and Neuroscience Thompson Institute, University of the Sunshine Coast, Birtinya, QLD, Australia

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ABSTRACT

Neuropsychological assessments have provided the field of psychiatry with important information about patients. As an assessment tool, a neuropsychological battery can be useful in a clinical setting; however, implementation as standard clinical care in an inpatient unit has not been extensively evaluated. A computerized cognitive battery was administered to 103 current young adult inpatients (19.2 ± 3.1 years; 72% female) with affective disorder. Neurocognitive tasks included Verbal Recognition Memory (VRM), Attention Switching (AST), Paired Association Learning (PAL), and Rapid Visual Processing (RVP). Patients also completed a computerized self-report questionnaire evaluating subjective impressions of their cognition. Hierarchical cluster analysis determined three neurocognitive subgroups: cluster 1 ($n = 17$) showed a more impaired neurocognitive profile on three of the four variables compared to their peers in cluster 2 ($n = 59$), and cluster 3 ($n = 27$), who had the most impaired attentional shifting. Two of the four neurocognitive variables were significantly different between all three cluster groups (verbal learning and sustained attention). Overall group results showed an association between poorer sustained attention and increased suicidal ideation. These findings strengthen the idea that neurocognitive profiles may play an important role in better understanding the severity of illness in young inpatients with major psychiatric disorders.

1. Introduction

Psychiatric illness (including affective disorders such as depression and bipolar) typically emerges during adolescence and young adulthood and has been shown to impact long-term social and functional outcomes over a lifetime for at-risk people. Along with negative mood symptoms and mood instability, cognitive (and thus functional) impairment is a major concern for patients and their clinicians alike.

Historically, neuropsychological functioning has been a main consideration in both research and medical settings in regard to confirmation, management and treatment of major brain injuries, and

neurological and developmental disorders (Allott et al., 2013; Johnstone et al., 1997). In recent years, however, the utility of neuropsychological assessment has been increasingly seen as useful in psychology and psychiatry. This includes early classification of cognitive deficits and their potentially predictive nature (Lee et al., 2015), markers for specific disorders such as bipolar disorder (Cosway et al., 2000; Lee et al., 2014), and serious clinical symptoms such as suicidal ideation (Gorlyn et al., 2015; Marzuk et al., 2005; Westheide et al., 2008).

Previous reviews have suggested that research into cognitive deficits and neuropsychological profiles is not always consistent and these

Abbreviations: ADD, attention deficit disorder; ADHD, attention deficit hyperactivity disorder; AST, attention switching task; APS, attenuated psychosis syndrome; CANTAB, Cambridge neuropsychological test automated battery; DSM-IV, diagnostic and statistical manual of mental disorders; EDNOS, eating disorder not otherwise specified; GAD, generalized anxiety disorder; K10, Kessler psychological distress scale; MDD, major depressive disorder; MOT, motor screening task; NA, not applicable; NEET, not in education, employment or training; OASIS, overall anxiety severity and impairment scale; PAL, paired associations learning task; QIDS-16, quick inventory of depressive symptomatology; RVP, rapid visual processing task; SIDAS, suicidal ideation attributes scale; SPHERE, somatic and psychological health report; VRM, verbal recognition memory

* Corresponding author.

E-mail address: ashleigh.tickell@sydney.edu.au (A.M. Tickell).

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deficits are more prevalent in wider age ranges than in specifically young cohorts (Castaneda et al., 2008). Neuropsychological assessments have often been used to objectively determine or verify current cognitive deficits objectively, yet they are typically used on an as-needed basis as opposed to a routine assessment for all inpatients. While it is extensive and comprehensive, it can also be expensive, time consuming (approximately 3–4 h overall) (Thomas Gualtieri, 2004), and come later in diagnostic planning and treatment of a patient rather than earlier.

Thomas Gualtieri (2004) examined the employment of computerized neurocognitive testing (in psychiatry) for its usefulness in psychiatry using repeated administration and at more frequent time points. This study (Thomas Gualtieri, 2004) concluded that cognitive assessment should be routine in initial psychiatric evaluation. Furthermore, Keefe (1995) noted the importance of having objective data available in mental illness diagnosis and assessment of symptoms (Keefe, 1995). Importantly, pilot studies have previously demonstrated the usefulness of routine cognitive screening for a small sample size of inpatients with affective disorders (Tickell et al., 2019), suggesting further examination in a larger sample size would be prudent.

Neuropsychological subgroups and clusters have been assessed in previous studies (Hermens et al., 2011; Lee et al., 2013; Tickell et al., 2019) and proven to be helpful in prediction of functional outcomes (Lee et al., 2013), as well as clearly distinguishing neuropsychological impairments and their relationship to symptoms and diagnoses (Hermens et al., 2011). In regard to symptoms, research has demonstrated a potential relationship between cognitive impairments and suicidal ideation in patients with affective disorder diagnoses (i.e. major depressive disorder (MDD)) (Gorlyn et al., 2015; Marzuk et al., 2005; Westheide et al., 2008). Unfortunately, the literature does not specifically examine this association in a clearly defined young adult cohort. Furthermore, as noted by Westheide et al. (2008), these studies use relatively small sample sizes (Gorlyn et al., 2015; Marzuk et al., 2005; Westheide et al., 2008).

We believe further examination of neurocognitive performance and clinical outcomes is necessary. Previous studies have demonstrated research into cognitive clusters and profiles is of clinical importance due to the clear delineation of said profiles in regard to illness severity and differences in symptoms (Hermens et al., 2011; Levy and Weiss, 2010; Sweeney et al., 2000). Thus, the argument in support of an initial neurocognitive assessment (i.e. screener) in a young adult inpatient cohort (i.e. comparatively more severe than a community sample) as standard practice is strong.

The purpose of this study is to expand on a previous smaller sample pilot study (Tickell et al., 2019) and to further demonstrate the feasibility of routine neurocognitive screening as standard clinical care in an inpatient unit. It further aims to explore the cognitive and clinical profiles of a current inpatient sample, as well as assess whether a clustering model is meaningful when assessed against external validators. Considering various literature stating the strength in prediction of social and vocational outcomes (Lee et al., 2015; Metzler et al., 2014), we expect that neurocognitive profiles and socio-occupational functioning will be especially helpful predictors in a younger age inpatient facility, providing excellent information on appropriate immediate interventions. We also hypothesize a potential link, in accordance with previous literature, between cognitive dysfunction and more severe negative clinical outcomes (such as suicidal ideation).

2. Methods

This study was approved by the University of Sydney and St Vincent's Hospital Human Research Ethics Committees. Following confirmation that potential participants were of mental and intellectual capacity to give informed consent, a complete description of the study was discussed and, those under the age of 18 having their parent or guardian also consent, written consent was obtained.

2.1. Patients and design

Inclusion criteria comprised of: (i) patients currently admitted to the Young Adult Mental Health Unit (Uospace); and (ii) current presentation of a severe affective episode (i.e. depressive, manic, anxiety; including those with psychotic features). Exclusion criteria for this study were: (i) insufficient fluency in the English language to participate in the cognitive testing; (ii) unable to consent due to intellectual impairment (for example, IQ < 70) or severity of mental illness (as determined by the treating psychiatrist/psychologist); and (iii) refusal to provide informed consent. Comorbid or pre-existing childhood-onset conditions (for example Attention Deficit Hyperactivity Disorder (ADHD) and conduct disorder), as well as alcohol or other substance misuse or autistic spectrum disorders were not exclusion criteria. The sampling used in this project is consistent with the 'Research Domain Criteria' (RDoC) approach (Casey et al., 2013) as a means of classifying mental disorders based on neurobiological (in this case, cognitive) measures. Furthermore, this study utilizes a subject sample (i.e. across the inpatient unit) with the appropriate variance as advocated by proponents of the RDoC approach (Casey et al., 2013).

2.1.1. Patient cohort

Active recruitment of patients was between May 2016 and December 2017. Primary diagnosis for patients ($n = 103$) were as follows: $n = 88$ with a depressive disorder [MDD ($n = 86$); MDD with psychotic features ($n = 2$)]; $n = 8$ with an anxiety disorder (AD) [obsessive compulsive disorder (OCD) ($n = 3$); generalized anxiety disorder (GAD) ($n = 5$)]; $n = 7$ with a bipolar disorder [bipolar disorder I (BD I) ($n = 2$); bipolar disorder II (BD II) ($n = 5$)].

2.2. Settings, and cognitive screen

The Young Adult Mental Health Unit (Uospace), St Vincent's Private Hospital Sydney, Australia is a voluntary private mental health service, targeted to the needs of young adults (16–30 years of age). Patients are referred for the assessment of mental health problems; with a mission to promote recovery and psychological well-being of young adults with severe and emerging mental health problems. Patients were determined to have a primary diagnosis of an affective disorder. At Uospace, these included depressive disorder, anxiety disorder, or bipolar disorder through consensus diagnosis; that is, via multidisciplinary clinical assessment (by psychiatrists, psychologists and allied health professionals) St Vincent's Private Hospital. A total of 149 patients were approached to participate (69% consented to participate and completed the full protocol). The remaining non-consenting patients did not want to participate for the following reasons: (i) 'not feeling they were in a good enough headspace' ($n = 9$); (ii) feeling the study did not appeal to them ($n = 19$); (iii) disruptive symptomatology (e.g., high anxiety and nervousness surrounding possible performance, participation and/or results) ($n = 2$); (iv) did not get parent/guardian to sign consent form/forgetting to sign consent form themselves ($n = 4$); and/or (v) 'embarrassed' or concerned about potential results due to mental illness or felt they wouldn't be able to complete testing due to current symptoms ($n = 4$). Several patients were also unable to be followed up for the informed consent process due to being discharged early or being transferred to a different hospital due to medical reasons ($n = 7$).

Cognitive testing and self-report assessments were completed on 103 young inpatients. On average, patients were in hospital for 17 days, and neurocognitive screening was completed 2 days following admission.

2.3. Measures

2.3.1. Self-report questionnaire

Patients completed self-report questionnaires, on a touchscreen tablet (iPad), as part of the Mental Health e-Clinic (Iorfino et al., 2017),

Brain & Mind Centre (BMC), University of Sydney. Initial questions obtain key demographic and clinical information, focusing on critical illness course variables (for example, onset of symptoms, hospitalizations, age of first help seeking). Standardized questionnaires included the 10-item Kessler Psychological Distress Scale (K-10) (Kessler et al., 2002) to detect psychological distress, with scores ranging between 10 and 50 (a score over 30 representing a likely severe mental disorder); Quick Inventory of Depressive Symptomatology (QIDS-16) (Rush et al., 2003) to assess severity of depressive symptoms, with scores ranging between 1 and 27 (a higher score representing greater severity of depression); Overall Anxiety Severity and Impairment Scale (OASIS), a 5-item measure for assessment of severity and impairment in regard to anxiety symptoms (Norman et al., 2006), with scores ranging between 0 and 20 (a higher score representing a higher frequency and severity of anxiety (across anxiety disorders)); Psychosis Screener derived from Community Assessment of Psychic Experiences (CAPE) (Stefanis et al., 2002), a positive symptoms scale and psychosis screener, developed to measure the lifetime prevalence of psychotic-like experiences in the general population; Hypomania Screener derived from the Altman Self-Rating Mania Scale (ASRM) (Altman et al., 1997), a 5-item self-rating scale to assess the severity of manic symptoms, a higher score (five or more) indicating a high probability of a manic or hypomanic condition; Suicidal Ideation Attributes Scale (SIDAS) (van Spijker et al., 2014), a 5-item scale to screen participants for suicidal thoughts and severity of these thoughts, with scores ranging between 0 and 50 (a higher score representing more severe suicidal thoughts (a score over 21 being in the high risk category)); and, the Somatic and Psychological Health Report (SPHERE-12) (Hickie et al., 2001), a 12-item measure to screen for current depression and/or anxiety-like symptoms (a score of two or more on the psychological subscale and a score of three or more on the somatic subscale indicating current depression and/or anxiety-like symptoms). Self-reported, non-structured, standardized questions in regard to the patient's own sense of cognition was assessed prior to testing (for example, changes in everyday thinking skills and neurocognitive abilities).

All electronic data files were retained in a secured SQL eResearch platform (and database) hosted by the BMC, University of Sydney. Once completed, the data from the self-report assessment is collated, and displays a detailed and immediate dashboard of results. This information is available to the trained research psychologist (AT) immediately upon the patients' completion of the self-report assessment.

2.3.2. Neurocognitive screening

A trained research psychologist (AT) conducted the cognitive testing battery, which included computerized assessments. First, premorbid intellectual functioning ('predicted IQ') was estimated on the basis of performance on the Wechsler Test of Adult Reading (Wechsler, 2001). Following this, patients completed tests from the Cambridge Neuropsychological Test Automated Battery (CANTAB) (Sahakian and Owen, 1992). CANTAB tests have the advantage of being largely non-verbal (i.e. language-independent, culture-free) and have been described in detail elsewhere (Hermens et al., 2011; Sahakian and Owen, 1992; Sweeney et al., 2000). Five tasks were included in this study: the Motor Screening Task (MOT), an introductory task to prepare patients for testing (i.e. not included in overall results) using induction of sensorimotor and comprehension; the Verbal Recognition Memory task (VRM immediate and recall/delayed) assessing 'verbal memory and new learning' indexed by the encoding and subsequent retrieval of verbal information scores; the Attention Switching Task (AST) assessing 'mental flexibility' and indexed by the total adjusted score; the Paired Association Learning task (PAL) assessing 'visuo-spatial learning and memory' indexed by the total adjusted errors score from; and, the Rapid Visual Processing task (RVP) assessing 'sustained attention' and indexed by the RVP A prime (sensitivity to the target).

Patients' individual, normed results were calculated by a trained research psychologist (AT) within two to three days of completion of

cognitive testing battery. Calculation of CANTAB z-scores were completed for each patient. While each patient's predicted IQ is assessed in the cognitive screener, this is specifically to personalize results based on each patient's age, education and background, compared to 'demographically corrected' standardized scores (z-scores) using an internal normative database of healthy controls (<http://www.camocog.com>).

2.4. Procedure

Through consecutive referral, patients (16–30 years of age) who were newly admitted to Uspace were given a Participant Information Sheet and Consent Form and followed-up by the researcher (AT) for informed consent, no less than 24 h later. Following informed, written consent (and parent or guardian written consent for patients under the age of 18), patients were booked in to complete neurocognitive testing and self-report questionnaires. Patients availability and booking schedule was based around their own routine appointments and groups as inpatients, with most patients being booked within four days of admission. Neurocognitive testing (CANTAB) was completed on an iPad, taking between 35 and 45 min. The self-report questionnaire was completed the day after neurocognitive testing, taking 45–60 min, and depending on the patient.

2.5. Statistical analyses

Statistical analyses were performed using Statistical Package for the Social Sciences Version 24.0 (SPSS). To control for the effects of age, cognitive variable raw scores were converted to 'demographically corrected' standardized scores (z-scores) using an internal normative database of healthy controls (<http://www.camocog.com>), and each patient's predicted IQ score. Any deviation from instruction, distraction or refusal to complete any one task during CANTAB testing was invalid for that specific variable. Prior to analyses, while all outliers were confirmed to be statistical (i.e. not artifacts), outliers beyond ± 4.0 z-scores for each neuropsychological variable were curtailed to values of +4.0 or -4.0. As this is a hospitalized sample of current patients, we believe curtailing of +4.0 or -4.0 more appropriately captures the severity of impairment, compared to the usual +3.0 or -3.0 curtailing. There were no more than 7% of cases in any group with a z-score of beyond ± 4.0 across variables.

A hierarchical cluster analysis utilising Ward's method of minimum variance with a squared Euclidean distance measure was conducted to identify patterns of impairment across four key neuropsychological variables (i.e. AST, RVPA, PAL and VRM). Cluster analysis was used for this study due to its ability to assess natural groupings within data, and the heterogeneous class of this inpatient cohort. The rationale being, the importance of examining distinctive and clear differences in an inpatient sample based on meaningful grouping. Furthermore, of the clustering techniques and algorithms, hierarchical clustering offers a more informative and structured analysis. Cluster analysis techniques were based on previous similar studies (Delano-Wood et al., 2009; Goldstein, 1990; Hermann et al., 2007; Hermens et al., 2011) and statistical recommendations (Norusis, 2010). The agglomerative hierarchical method was used as it does not impose preconceived notions regarding the number of clusters. Changes in agglomeration coefficients were used to determine a demarcation point. Unlike other statistical techniques (e.g., factor analysis), cluster analysis does not identify a particular statistical model (Norusis, 2010); that is, a classification technique for forming homogeneous groups within complex data sets (Borgen and Barnett, 1987). While there are no specific rules about the number of cases (and the corresponding number of variables) required for cluster analysis, hierarchical clustering is recommended for smaller data sets (Norusis, 2010); the type and number of variables are typically chosen on theoretical grounds (Delano-Wood et al., 2009; Goldstein, 1990). Ideally, a good cluster solution is when the data segregates into theoretically meaningful subsets (Delano-Wood et al., 2009) and this is

usually achieved by examining cluster characteristics at consecutive steps until a reasonable number of relatively homogenous groups is obtained (Norusis, 2010).

Pearson's correlations were used to examine associations between functional/clinical variables (K-10, QIDS-16, OASIS, Psychosis screener, Hypomania screener, and SPHERE) and key neuropsychological variables (AST, RVPA, PAL and VRM) for the entire sample of subjects. Given the number of correlations conducted (32), and to further minimize the likelihood of type 1 errors, only correlations at $p < .01$ were considered to be significant.

One-way between-subject analysis of variance (ANOVA) was used to assess differences in demographic, clinical and functional, and neuropsychological variables among cluster groups. Scheffé's tests were used to determine post-hoc pair-wise comparisons. The chi-square test was used to compare the ratio of females to males across cluster groups. Significance levels were set at $p < .05$. Based on a similar methodology (Delano-Wood et al., 2009) we also conducted a confirmatory (standard) discriminant function analysis (DFA) to determine which combinations of the neuropsychological variables best distinguishes the cluster groups and whether these combinations could reliably predict cluster-group membership (Hermens et al., 2015, 2011).

3. Results

The average age of the cohort ($n = 103$) was 19.2 ± 3.1 years (72% female). The average predicted IQ was 105.5 ± 7.7 , as well as 41.5% of patients not being in current education, employment or training (NEET status).

Due to technical difficulties there is missing self-report data worth noting (18.4%). A total of 78 patients (75%) had fully completed self-report data with a further 6 patients (5.8%) partially completed. Therefore, a total of 84 patients (81.6%) had some quantity self-report data.

3.1. Cluster characteristics ($n = 103$)

Agglomeration coefficients generated by cluster analysis revealed a demarcation point between three cluster solutions; this was confirmed by inspection of the dendrogram. Thus, the three groups were made up of $n = 17$ (cluster 1), $n = 59$ (cluster 2), and $n = 27$ (cluster 3) patients. Six patients were missing at least one neuropsychological variable (i.e. due to the patient being distracted during testing); their scores were replaced with averages of the specific group variable. ANOVA determined statistical significance of 'cluster group' for two neurocognitive variables (PAL and RVP), as well as one clinical variable (SIDAS).

Table 1 shows medication categories were relatively well distributed across the three cluster groups. According to chi-square analysis the three clusters did not significantly differ ($p > .05$) in regard to medication status. Chi-square and post-hoc Scheffé's analysis further showed no statistical differences based on diagnosis between the three clusters.

3.2. Cluster profiles ($n = 103$)

Fig. 1 demonstrates all three clusters were characterized by poor

Table 1

Cross-tabulation of cluster by medication category of Uspace sample (%), as tested by chi-square.

| Current medication | Cluster 1 (N = 17) | Cluster 2 (N = 59) | Cluster 3 (N = 27) | Significance test (χ^2) |
|---------------------|--------------------|--------------------|--------------------|----------------------------------|
| Nil (%) | 17.6% | 13.6% | 0% | $\chi^2(1, 103) = 4.606 [1.100]$ |
| Antidepressant (%) | 64.7% | 74.6% | 85.2% | $\chi^2(1, 103) = 2.480 [2.289]$ |
| Antipsychotic (%) | 41.2% | 30.5% | 37.0% | $\chi^2(1, 103) = 0.822 [6.663]$ |
| Mood stabilizer (%) | 23.5% | 27.1% | 25.9% | $\chi^2(1, 103) = 0.089 [9.956]$ |

Abbreviations: AST = attention switching task; PAL = paired associations learning task; RVP = rapid visual processing task; VRM = verbal recognition memory.

performance; however, of the four neurocognitive variables, two were found to be significantly different between the three clusters. As seen in Table 2, PAL and RVP were both significant ($p < .05$). Due to adjustments of predicted IQ scores in CANTAB testing, corresponding ANCOVAs controlling for predicted IQ demonstrated that the same significant differences for both PAL and RVP remained. Post-hoc comparisons using the Tukey HSD (honestly significant difference) test indicated the mean scores for PAL variables significantly differed between all cluster solutions (i.e. 1, 2 and 3), confirmed further by Scheffé's test with RVPA between cluster 1 and 2 showing no statistical significance. Tukey DSH tests showed RVP variables were significantly different between cluster 1 and 3, and cluster 2 and 3. Significance was found between three cluster groups in one clinical variable only (SIDAS), as shown in Table 3; post-hoc Scheffé's test confirming this significant between clusters 2 and 3. Significant differences were found between clusters in age and predicted IQ, with cluster 1 having the lowest predicted IQ scores, and cluster 3 being the eldest (by almost 2 years).

Discriminant function analysis (DFA) confirmed a single function accounting all (100%) of the variance among the two significant clusters [Wilk's $\lambda = 0.062, p < .000$]. Furthermore, the structure matrix revealed a clear delineation for verbal learning (PAL, $r = 0.936$), and sustained attention (RVP; $r = 0.707$), with the two remaining variables not significant. The DFA showed an overall correct classification result of 99.0%; that is, 100% of cluster 1, 98.3% of cluster 2 cases, and 100% of cluster 3 cases were correctly classified. Cross-validation confirmed the stability of these classification results with the same overall correct classification as the original grouped cases (i.e., 98.1%).

3.3. Correlations between neuropsychological performance and self-reported symptoms ($n = 103$)

Table 4 shows the correlation coefficients for the four neuropsychological scores and clinical variables for the entire sample. One significant ($p < 0.01$) correlation was revealed: RVP-A was associated with SIDAS ($r = -0.297$). Importantly, a scatterplot of this significant correlation showed a segregation of the three cluster groups, whereby cluster 1 individuals appear at the lower end of this spectrum.

4. Discussion

As expected, this inpatient sample ($n = 103$) showed varying levels of cognitive deficits, with three neurocognitive profiles being revealed. Cluster 1 was characterized by a more impaired neurocognitive profile overall (except for attention shifting), followed by Cluster 2, and Cluster 3 having the least impaired neurocognitive profile comparatively, but showing the most impairment in attention switching. There was a significant statistical difference between the three clusters in two of the four neurocognitive variables; verbal learning (PAL) showed the most differences between clusters (i.e. cluster 1 having the most impaired scores, and cluster 3 with the best scores, with cluster 2 being intermediate), followed by sustained attention (RVP); with clusters 1 and 2 (both compared separately to cluster 3) showing the most impairment. Of note, suicidal ideation was found to be the only clinical variable that was significantly different between clusters, with cluster 1

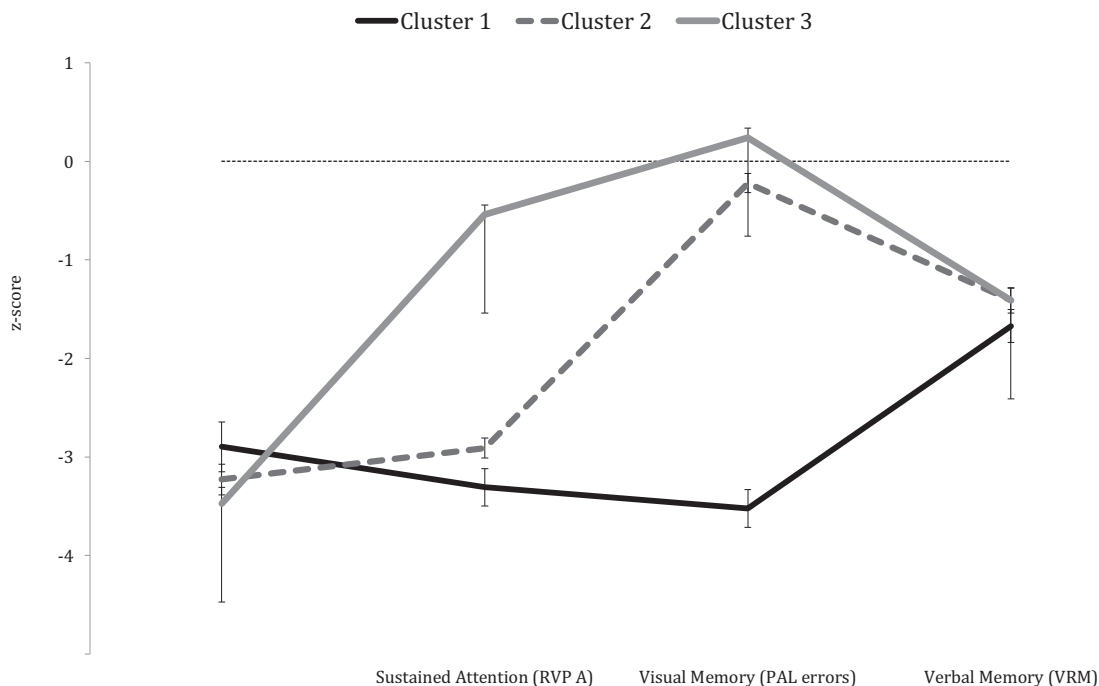


Fig. 1. Profile (n = 103) of mean z-scores (with standard error bars and dashed line representing the standardized norm (equivalent of 0 z-score)) for neurocognitive measures across cluster groups: cluster 1 (n = 17), cluster 2 (n = 59), and cluster 3 (n = 27).

Table 2

Mean z-scores (± standard deviation) for neurocognitive variables across the three clusters with corresponding results for ANOVA.

| | Cluster 1 (N = 17) | Cluster 2 (N = 59) | Cluster3 (N = 27) | Significance Test [p] | Post-Hoc 1v2 | 1v3 | 2v3 |
|------|--------------------|--------------------|-------------------|---------------------------|-----------------|-----|-----|
| AST | -2.90 ± 1.04 | -3.23 ± 1.20 | -3.47 ± 0.85 | F (2, 102) = 1.4 [.242] | | | |
| PAL | -3.52 ± 0.77 | -0.22 ± 0.75 | 0.24 ± 0.50 | F (2, 102) = 176.1 [.000] | * | * | * |
| RVPA | -3.31 ± 0.78 | -2.91 ± 0.78 | -0.54 ± 0.52 | F (2, 102) = 117.3 [.000] | | * | * |
| VRM | -1.67 ± 0.69 | -1.41 ± 0.98 | -1.41 ± 0.64 | F (2, 102) = 0.7 [.524] | | | |

Abbreviations: AST = attention switching task; PAL = paired associations learning task; RVP = rapid visual processing task; VRM = verbal recognition memory. Note: the four cognitive tests (VRM, AST, PAL, RVP) were all performed via touchscreen computer (CANTAB); standardized scores are presented. Note: Significance levels for each Scheffé’s post-hoc comparison is depicted by: *p < .05.

Table 3

Mean scores (± standard deviation) for demographic and clinical variables across the three clusters; between group differences were tested by chi-square or ANOVA.

| | Cluster 1 (N = 17) | Cluster 2 (N = 59) | Cluster 3 (N = 27) | Significance Test [p] | Post-Hoc 1v2 | 1v3 | 2v3 |
|--------------------|--------------------|--------------------|--------------------|--|-----------------|-----|-----|
| Sex (f) | 15 (83.2%) | 42 (71.2%) | 18 (66.7%) | χ ² (1, 103) = 2.637 [.268] | | | |
| Age, years | 19.5 ± 3.3 | 18.6 ± 2.8 | 20.4 ± 3.2 | F (2, 102) = 3.5 [.034] | | | * |
| Predicted IQ | 100.9 ± 6.8 | 105.9 ± 8.0 | 107.4 ± 7.5 | F (2, 95) = 3.5 [.034] | | * | |
| K-10 Total | 39.1 ± 5.3 | 36.1 ± 6.1 | 35.7 ± 7.2 | F (2, 76) = 1.3 [.288] | | | |
| QIDS-16 Total | 19.2 ± 4.6 | 17.7 ± 4.7 | 15.4 ± 5.7 | F (2, 68) = 2.6 [.082] | | | |
| OASIS Total | 13.2 ± 3.5 | 11.5 ± 3.5 | 10.5 ± 4.1 | F (2, 59) = 1.6 [.201] | | | |
| Psychosis Screener | 1.6 ± 1.6 | 2.7 ± 2.6 | 1.7 ± 1.9 | F (2, 73) = 1.8 [.167] | | | |
| Hypomania Screener | 2.4 ± 2.3 | 2.8 ± 2.1 | 1.7 ± 2.0 | F (2, 72) = 1.9 [.157] | | | |
| SIDAS | 29.3 ± 15.7 | 28.0 ± 15.5 | 17.0 ± 17.7 | F (2, 74) = 3.9 [.025] | | | * |
| SPHERE Psyc | 8.0 ± 2.5 | 6.6 ± 3.6 | 5.9 ± 3.2 | F (2, 66) = 1.2 [.317] | | | |
| SPHERE Soma | 6.5 ± 2.7 | 5.9 ± 3.1 | 5.8 ± 2.9 | F (2, 72) = 0.2 [.837] | | | |

Abbreviations: AST = attention switching task; PAL = paired associations learning task; RVP = rapid visual processing task; VRM = verbal recognition memory. Note: the four cognitive tests (VRM, AST, PAL, RVP) were all performed via touchscreen computer (CANTAB); standardized scores are presented. Note: Significance levels for each Scheffé’s post-hoc comparison is depicted by: *p < .05.

having the highest scores, suggesting more severe suicidal ideation, and both clusters 1 and 2 averaging in the ‘high risk’ category (i.e. a score over 21).

In this current study we have found an association between cognition and suicidal ideation, which is in accordance with previous studies examining cognition and suicidal ideation in MDD. Pu et al. (2017)

examined cognitive deficits and suicidal ideation (with or without) using a neuropsychological battery in 233 outpatients, aged between 17 and 76 years of age, with a diagnosis of MDD. While this study used a specific brief cognitive measure of schizophrenia, it is one of the first studies to suggest an association between neurocognitive performance and suicidal ideation in patients with MDD (Pu et al., 2017). Overall,

Table 4
Pearsons correlation coefficients ($p < .01$) between functional/clinical versus key neurocognitive variables for the entire Uspace sample ($N = 103$).

| | AST | RVP A | PAL | VRM |
|--------------------|--------|---------|--------|--------|
| K-10 Total | −0.035 | −0.090 | −0.208 | −0.252 |
| QIDS-16 Total | −0.017 | −0.211 | −0.112 | −0.126 |
| OASIS Total | 0.121 | −0.126 | −0.178 | −0.242 |
| Psychosis Screener | 0.046 | −0.031 | 0.087 | 0.015 |
| Hypomania Screener | −0.006 | −0.092 | −0.043 | 0.144 |
| SIDAS | −0.039 | −0.297* | −0.151 | −0.132 |
| SPHERE Psyc | 0.062 | −0.136 | −0.136 | −0.151 |
| SPHERE Soma | 0.024 | −0.077 | −0.077 | −0.288 |

Abbreviations: AST = attention switching task; PAL = paired associations learning task; RVP = rapid visual processing task; VRM = verbal recognition memory.

* $p < .01$

outpatients with suicidal ideation (i.e. 59% of the 233 sample) demonstrated significantly more severe cognitive deficits (i.e. performed worse on the neuropsychological battery), compared to outpatients without suicidal ideation; furthermore, executive function was a main player in this association (Pu et al., 2017). Previous studies have demonstrated a strong link between cognitive dysfunction and the presence of suicidal ideation in patients with MDD (compared to those without suicidal ideation), with neurocognitive deficits (or rigidity) being referred to as a possible risk factor for suicidal ideation and behavior (Gorlyn et al., 2015; Marzuk et al., 2005; Westheide et al., 2008). Marzuk et al. (2005) examined 33 current MDD inpatients (5 with suicidal ideation, and 28 without) (Marzuk et al., 2005). While the small sample size and uneven groups need to be taken into consideration, this study demonstrated current inpatients with suicidal ideation performed significantly worse in executive function, and also showed more global impairments, compared to those inpatients without suicidal ideation (Marzuk et al., 2005). Likewise, Westheide et al. (2008) compared inpatient groups with MDD based on suicidal ideation (mean age of 34.3 years with suicidal ideation, and 40.4 years without suicidal ideation), and found impaired executive function in those inpatients with suicidal ideation, compared to those without (Westheide et al., 2008). The studies from Pu et al. (2017), Marzuk et al. (2005) and Westheide et al. (2008) as well as this current study, further validate the importance of cognitive function, and value of cognitive testing and modelling (Stip et al., 2017) in regard to collaborative, integrated, and personalized care. Clinically speaking, neurocognitive dysfunction could be helpful in establishing contributing factors to certain clinical domains, in this instance, suicidal ideation. Importantly, we have gained further knowledge in regard to the logistics of neurocognitive testing as standard clinical care in an inpatient facility, as well as capturing a representative, albeit heterogeneous, sample of patients in an inpatient unit. Importantly, the literature in this area is not always clear and sometimes studies combine suicidal ideation and suicidal attempt status. Despite this, Richard-Devantoy et al's (Richard-Devantoy et al., 2012) meta-analysis of suicidal behaviours (i.e. inclusive of both ideation and/or attempts) in affective disordered patients demonstrated eight out of nine analysed studies found a link between cognitive dysfunction and suicide attempt (Richard-Devantoy et al., 2012). While the large age ranges across the studies included (i.e. 18 to 86 years) may be a limitation in terms of younger cohorts, this study does not make a clear distinction between suicidal ideation and attempt. Suicidal behaviour is examined as a symptom including both ideation and attempt (as opposed to separate states) and linked to executive function and depression. On the other hand, some literature has suggested that cognitive deficits are associated with suicide attempt and not suicidal ideation (Keilp et al., 2013). Clearly, future studies in young patients with affective disorders need to differentiate suicidal ideation from suicide attempts and examine their unique relationships with cognition.

There are some limitations worth mentioning in this study. Firstly, there has been disagreement surrounding the potential effects of acute psychiatric symptoms' impact on cognitive testing performance. However, there are various factors that have the ability to influence cognitive performance, for example quality and quantity of sleep, and time of testing (i.e. morning or evening). Various factors need to be taken into consideration in order for this assessment to be representative of personalized care (i.e. catering to an individual). Secondly, this study relies heavily on technology. While it is true the CANTAB program itself initially relies on an internet connection, this is only to switch the device to being offline active; this means, while testing is commencing there is no reliance on internet connection (i.e. drop outs do not impact testing). The self-report questionnaire, however, is reliant on a persistent internet connection, and unfortunately, due to technical problems with the hospital setting itself, 45% of patients were unable to access and complete all modules of the self-report questionnaire. Lastly, due to the heterogeneous nature of this sample a hierarchical cluster analysis was employed in order to examine inpatient cohort groupings. However, a model-based approach such as mixture modeling or examining measures as a set of potential predictor variables, may also be an option for future research.

We believe this study is novel in its aims of assessing a younger, more severe cohort of current inpatients and the utility of technology and neurocognitive testing as standard clinical care in an inpatient unit. Future directions of this work as standard clinical care at Uspace have seen updates in protocol, and further discussion in regard to a neurocognitive battery that fits the needs of the unit (i.e. time, usability and automatic report generation), and the addition of a psychoeducational group as part of the inpatient hospital program. On a more general scale, this study of an inpatient cohort shows clear neurocognitive clusters, which further strengthens the idea of neurocognitive screening being useful in intervention, care and management.

Disclosure statement

The authors report no conflicts of interest.

Availability of data and material

The dataset generated and/or analysed during the current study are not publicly available due to individual privacy, and the nature of the studies, but are available from the corresponding author on reasonable request.

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CRedit authorship contribution statement

Ashleigh M. Tickell: Data curation, Formal analysis, Writing - review & editing, Investigation, Validation, Writing - original draft, Formal analysis. **Elizabeth M. Scott:** Writing - review & editing, Data curation, Formal analysis, Validation. **Tracey Davenport:** Writing - review & editing, Data curation, Formal analysis. **Frank Iorfino:** Writing - review & editing, Data curation, Formal analysis. **Laura Ospina-Pinillos:** Writing - review & editing, Data curation, Formal analysis. **Django White:** Writing - review & editing, Data curation, Formal analysis. **Kate Harel:** Writing - review & editing, Data curation, Formal analysis. **Lisa Parker:** Writing - review & editing, Formal analysis. **Ian B. Hickie:** Conceptualization, Writing - review & editing, Data curation, Formal analysis. **Daniel F. Hermens:** Conceptualization, Writing - review & editing, Data curation, Formal analysis.

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Compliance with ethical standards

Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent: Informed consent was obtained from all individual participants included in the study.

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Chapter 2

Project Synergy research and development cycle: iterative processes of participatory design, user testing, implementation and feasibility testing

Tracey A Davenport¹, Alyssa C Milton¹, Laura Ospina-Pinillos^{1,2}, Lisa Whittle¹, Cristina S Ricci¹, Jane M Burns³, Ian B Hickie¹

In Australia, one in four young people aged 16–24 years experiences a mental illness every year.¹ A compounding challenge is that young people are often reluctant to seek help, with data from the second National Survey of Child and Adolescent Mental Health and Wellbeing indicating that only 21% of young men and 22% of young women with emotional or behavioural problems accessed any form of mental health care in 2013–2014.² Technology-based mental health resources and interventions have been highlighted as a key part of the solution for better access to, and quality of, mental health services.^{3,4} Not only do online health and wellbeing technologies address traditional geographical, economic and human resource barriers,^{5–7} they can also provide a valuable platform for screening, prevention, early intervention and referral processes.^{8–10}

There has been rapid growth in the availability of online health information technologies for young people who report feeling comfortable accessing mental health tools online.¹¹ Most research in this field has focused on testing the effectiveness of health information technologies; however, engagement and dropout rates have been identified as significant problems.^{12,13} To address this, involvement of users from the outset is now viewed as best practice.¹⁴ Meaningful involvement of young people in the design and development of health information technologies from the start is an important step in improving engagement and potential impact as it maximises the value of the technology to the user.

Ultimately, engagement of users from the outset, and in all design and development processes, is more likely to result in technology that is far more personalised and responsive to their needs. However, a recent systematic review of the design and development of technology-based youth mental health and wellbeing interventions reported that youth participation is variable, with 70% of projects being predominantly consultative in nature, and only 30% collaborative.¹⁵

Co-designing solutions

Utilising strategies to enhance community and consumer participation is now a national priority for 2020 in the health, medical and research sectors.^{3,16} Participatory design (also referred to as co-design) methodologies are one way of achieving this. As co-design positions users at the centre of the design process,¹⁷ the user's role is not only as a consultant or tester of technology solutions but also as a co-designer who has involvement from conception to completion of the project.¹⁸ Co-design as a principle is not new. It was developed in the 1960s in relation to technical communication, and its importance has been advocated for more than two decades.¹⁹ It was not until recently, however, that these methodologies have

been applied to design and develop health and wellbeing technologies such as telemedicine services,²⁰ e-health solutions for women with perinatal depression,²¹ information systems in health care,¹⁷ web-based integrated care plans,¹⁴ and mindfulness programs.²²

Three principles of participatory design

In 2012, the Young and Well Cooperative Research Centre (CRC) created a guide for using participatory design for the development of evidence-based online youth mental health promotion, intervention and treatment programs.¹⁸ These guidelines outlined three principles. The first is that young people are active participants throughout the entire design process, from problem setting to problem solving. This principle is vital — in a recent systematic review of participatory development of technology-based interventions, Orłowski and colleagues¹⁵ reported that they did not identify any projects which had actively involved young consumers in the project planning stage, with project aims and goals unreflective of their input. The second principle is that of co-design where young people are design partners — they contribute to the project by participating in idea generation, creating solutions and giving feedback on existing design concepts. The third principle involves an iterative process in which the acceptability of the proposed technology is continually evaluated from the perspective of young people to determine if it is relevant, meaningful and engaging. This also includes considering the potential for positive and negative impacts on mental health and wellbeing outcomes.

Adhering to these principles, the Project Synergy research and development (R&D) cycle explicitly positions users as empowered participants in all stages of design, development, implementation and feasibility testing.

Methods of participatory design

Across our studies which involved young people in four groups — those attending university, those in three disadvantaged communities in NSW, those at risk of suicide and those attending five headspace centres — the Project Synergy R&D cycle was underpinned by three phases: co-design workshops, user testing, and implementation and feasibility testing. Co-design workshops enabled representatives from all user groups (young people, supportive others, health professionals), researchers, academics and technology developers to co-design alpha prototypes (a version of the technology that allows users to interact with and test the proposed solution). Importantly, supportive others are considered a user group as it has been consistently found that young people (with or without mental health problems) report that the top sources of help they would go to are friends, parents,

¹ Brain and Mind Centre, University of Sydney, Sydney, NSW. ² Department of Psychiatry and Mental Health, School of Medicine, Pontificia Universidad Javeriana, Bogota, Colombia.

³ Swinburne Research, Swinburne University of Technology, Melbourne, VIC.

relatives and other family friends.^{1,2,8} Further, supportive others (or carers) are commonly consulted in mental health settings to develop interventions.²³ User testing refers to the process of evaluating the degree to which the alpha prototype meets specific usability criteria, with evaluation by all user groups. Through implementation and feasibility testing, the beta prototype (a more polished version of the prototype that can be used directly by users for feasibility testing) is tested to determine engagement and potential impact of the final technology solution. The phases of the R&D cycle are conducted sequentially; however, time frames for each phase are dependent on the needs of each unique user group within the various target communities.

The development of the R&D cycle was overseen by a multidisciplinary team including users, researchers, academics, health professionals and technologists. Knowledge translation teams (comprising people who can implement research findings into practice) assisted with the knowledge translation and rapid prototyping during Phase 1 (co-design workshops).

Phase 1: Co-design workshops

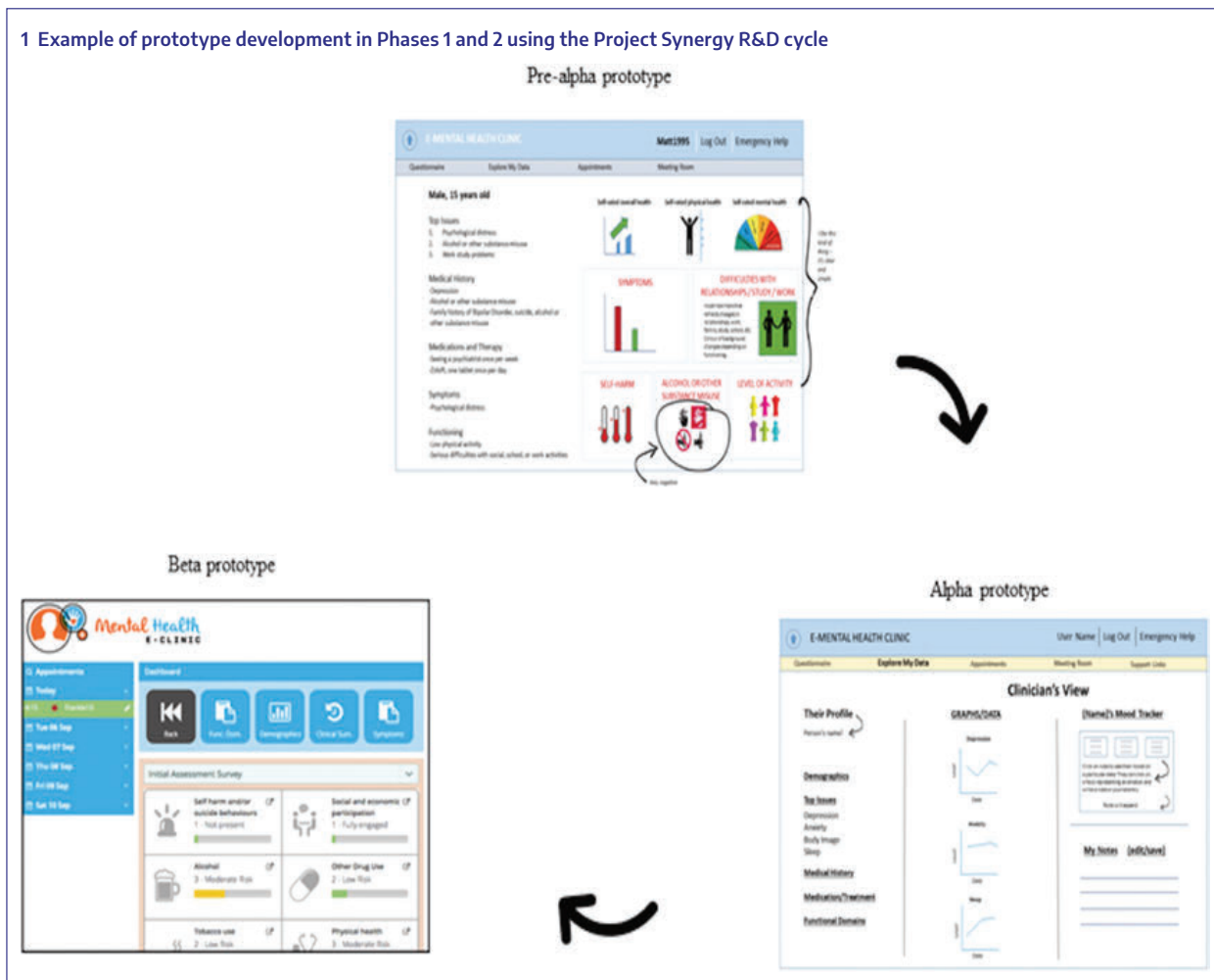
Co-design workshops for each of the four research studies were facilitated by the R&D team with users including young people, supportive others and health professionals (see the studies outlined in Chapters 3–6 for details of participant recruitment strategies and

additional methodologies). The purpose of these workshops was to determine user needs to inform prototype designs.

Each co-design workshop had at least one facilitator, and a health professional available for the duration of the workshop as a requirement of the University of Sydney Human Research Ethics Committee to ensure duty of care requirements could be met in the event that any of the workshop participants experienced distress during an activity.

For each study, a series of co-design workshops was conducted as rapidly as possible to maintain the momentum of idea creation, continuing until theme saturation had been reached and no new insights were identified. Each individual workshop was undertaken by participants over a 3-hour period using an agenda consisting of three stages: discovery, evaluation and prototyping. An important component of this methodology was that no digital technology was used during the workshops. Research has shown that a paper-based approach to co-design results in a greater number of ideas and design solutions being generated within a session, compared with workshops that use digital technology.²⁴ Data from the workshops were collected through three main sources: gathering written comments made by co-designers relating to previous real-life examples; hand-drawn mock-ups; and transcribing detailed qualitative notes of the comments made throughout the workshops.

1 Example of prototype development in Phases 1 and 2 using the Project Synergy R&D cycle



Phase 2: User testing

The aim of this phase was to assess the usability of alpha prototypes from the perspective of users, and to understand their views on the prototype's impact. People who were identified as target users participated in one-on-one interviews, lasting about 90 minutes. Within these sessions, participants engaged with the alpha prototype and were guided through various tasks by a facilitator. The user testing process allowed facilitators to understand how users experience the technology and consequently to identify errors within the software. As participants were guided through the alpha prototype by a facilitator, they provided verbal feedback on usability, experience and personal acceptance of the software. Facilitators used a detailed guide which applied "think aloud" methodology (a qualitative research method in which participants speak aloud any words on their mind as they complete a task, for the purpose of making their thought processes explicit and improving feedback about the testing process) and observations of a participant's online behaviour. A scribe was also present to note all comments made by participants as well as discussion between a facilitator and participants. In relation to fulfilling duty of care requirements, where relevant, the facilitator was also a health professional. Where the facilitator was not a health professional, a health professional was on standby.

The qualitative data from user testing were collated and rapid prototyping took place based on this feedback. During rapid prototyping, research and development were conducted as parallel processes. Each prototype, which may or may not evolve into the final version of the technology, was created and tested by users.²⁵ This was carried out through an iterative process until agreement was reached for the beta version of the prototypes.

Phase 3: Implementation and feasibility testing of beta prototypes

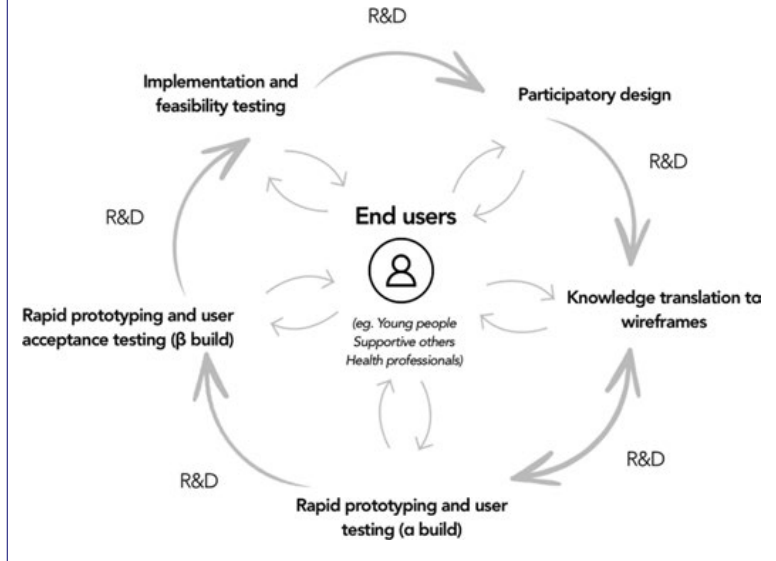
Through implementation and feasibility testing, beta prototypes were tested to determine engagement and impact of technology solutions. Engagement measures how users interact with the prototypes. For example, this can include frequency and length of session, when the prototype is used and on what device, what pages are visited, what apps and e-tools are integrated, and how users exit a prototype. Data concerning the acceptability and usability of prototypes were also collected to determine, for example, user satisfaction with the product. These data may also include personal impacts on users, such as determining changes in their social, health and wellbeing outcomes.

During implementation and feasibility testing, users were given access to the technology solution for a set period of time. Data were collected directly through the prototypes, from online analytic tools as well as evaluation surveys, to provide feedback on engagement and potential impact.

Outcomes of participatory design

To ensure all users had the opportunity to independently explore and voice their needs to inform alpha prototype designs, the first round of co-design workshops for each study grouped

2 Final Project Synergy R&D cycle



participants according to user category (ie, young people, supportive others, health professionals, service providers). This helped each user group to explore their needs within a safe environment and, for many participants, helped build their confidence in voicing their opinions. Once the initial round of single user type co-design workshops was completed, all subsequent co-design workshops involved co-attendance and participation by multiple user types. This ensured robust discussion and exploration of ideas from multiple perspectives, often resulting in a combined view being suggested for consideration.

At the end of the participatory design stage, knowledge translation teams independently collated and analysed the visual data as well as transcripts generated from the workshops. Their contribution to the R&D cycle was a key point of difference from the many diverse participatory design processes described in the literature. A form of inductive qualitative analysis was then carried out by thematically coding the workshop materials using a standard approach commonly used in mental health settings.²⁶ Using all the available workshop artefacts (ie, data), common themes that captured important ideas and patterns of responses were identified. Knowledge translation team members used wireframing software to independently develop wireframes (hand-drawn diagrams representing the skeletal framework of a website), which formed pre-alpha prototypes. Feedback on pre-alpha prototypes was elicited through an iterative process until agreement was reached.²⁷ The resulting alpha version provides the initial prototype of any technology solution which can then be user tested in the next stage of the R&D cycle.

User testing specifically assessed whether participants were able to complete specified tasks successfully; how long it took to complete these specified tasks; participants' satisfaction with how the prototypes operated; changes required to improve user performance; and whether the performance of prototypes met usability objectives.

An example of Phases 1 and 2 of the R&D cycle is provided in Box 1. Additionally, the population and participation details for each of these phases for the four studies are presented in Supporting Information, chapter 2, table 1. Findings from Phase 3 implementation and feasibility testing are described in detail

in Chapters 5 and 6, and the final Project Synergy R&D cycle is illustrated in Box 2. Specifically, Box 2 shows how users are placed at the centre of the co-design process, as they help inform the continuous development of the technology solution through the iterative use of participatory design (or co-design), knowledge translation, rapid prototyping and user testing methodologies, as well as implementation and feasibility testing.

Discussion

Through four studies, the development of an iterative Project Synergy R&D cycle of co-design workshops, user testing, implementation and feasibility testing has been refined. This cycle will continue to be applied to future Project Synergy research studies, and may be used as a model for other disciplines to apply when researching and developing the application of new technology solutions.

Ultimately, this iterative R&D cycle addresses a key challenge in creating new and innovative technology solutions. While it takes 17 years on average for original research to be sequentially integrated into clinical practice,²⁸ by using the R&D cycle, each of the studies went from design to development to implementation and feasibility testing within a 12-month period. Importantly, this was enabled by the rapid, iterative and continuous nature of the cycle. This rapid turnaround is crucial because new evidence-based innovations are continuously being developed and they must keep pace with the rapid rate of new and emerging technologies being released on a daily basis.

The agility required for co-design, development, and implementation and feasibility testing poses a challenge for the Australian health system. However, we believe that the innovative methods outlined in the Project Synergy R&D cycle provide a framework for developing technology-enabled solutions for mental health services reform.

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Supporting Information

Additional Supporting Information is included with the online version of this article.

Chapter 3

Study 1: Fit Uni Life to thrive: an online health and wellbeing prototype for young people

Tracey A Davenport¹, Laura Ospina-Pinillos^{1,2}, Cristina S Ricci¹, Alyssa C Milton¹, Jane M Burns³, Ian B Hickie¹

The late adolescent and young adult years are a prime time to promote healthy behaviour and develop wellbeing skills, particularly as young people transition from secondary school to post-school education, training or employment. Entering post-school education requires young people to face multiple new challenges (eg, changes in living arrangements, academic environments, and family, friendship and social networks) while adapting to greater independence and responsibility for their own health and wellbeing. Although most young people negotiate this transition successfully, a significant proportion will experience short or long term physical or mental health problems, misuse alcohol or other substances, or be affected by social isolation.¹

Concurrently, there is also a high dropout rate for young people from their first year of university (ranging from 10% to 24%) at a significant cost to students, their families and higher education institutions (average cost of \$36 million per institution per year).² Dropout rates have also been linked to groups of students who are perceived to be less prepared for the challenges of university³ and those with emerging mental health difficulties. The first year of post-school education is therefore a crucial time to provide young people with tools that may assist them to develop personal and social skills to manage their health and wellbeing and social connectedness. The overall goal is ongoing and productive participation in higher education.

Wellbeing and technology

Broadly, wellbeing can be viewed as a construct concerned with optimal experience and functioning.⁴ Optimal wellbeing can be considered to be in place when an individual has the physical, psychological and social resources to meet their needs and goals.⁵ Subjective wellbeing is associated with greater success in quality-of-life domains, including health, relationships and work.^{6,7}

Important determinants of wellbeing include good physical health (which has added benefits of reducing mortality risk, and improving mental health and other social outcomes)^{8,9} and higher levels of social connectedness. An increasing body of review evidence suggests that loneliness predicts higher rates of morbidity and mortality.^{10–14}

With advances in digital technology, and the near universal availability of smartphones, there is great opportunity for personal wellbeing apps and e-tools to provide support for multiple components of wellbeing — including physical, mental and social dimensions.¹⁵ Recent research conducted by the Australian Communications and Media Authority and the Office of the

Children's eSafety Commissioner¹⁶ highlighted that 99% of young people have access to the internet; 86% of young people aged 14–17 years have a home internet connection; 88% of teen users went online more than once a day; 83% access the internet three or more times a day; 89% have a mobile phone (80% have a smartphone); and 65% use their mobile phone to access the internet.

Core features for inclusion in an online health and wellbeing system

Based on published research findings and commentary, several core features should be considered when developing an online health and wellbeing system for young people. These include:

- A rapid but comprehensive self-rating system that examines a range of health and wellbeing domains. By contrast, most existing systems focus on only one specific health dimension, such as weight loss¹⁷ or smoking cessation.¹⁸
- Specific goal-setting functions. To establish goals that effectively help an individual alter their behaviour, goals should be personally relevant, challenging but realistic and achievable, and sufficiently specific so that outcomes can be measured.¹⁹
- Real-time tracking of actions to achieve self-determined goals. As smartphones can be linked with powerful technology that can track and monitor geographic, personal and social information,¹⁵ sensor data can be used individually or triangulated to track user activities and wellbeing. Ideally, individuals would use aggregated behavioural data to improve their habits and behaviour. Behaviour change research has long demonstrated that the combination of goals plus feedback is more effective than goal setting alone.^{20,21}

Most existing systems, however, only focus on one of these features rather than providing a comprehensive and integrated system of support. The objective of this study, therefore, was to co-design an online health and wellbeing system for young people that also included social connectedness, plus participation and engagement in post-school education.

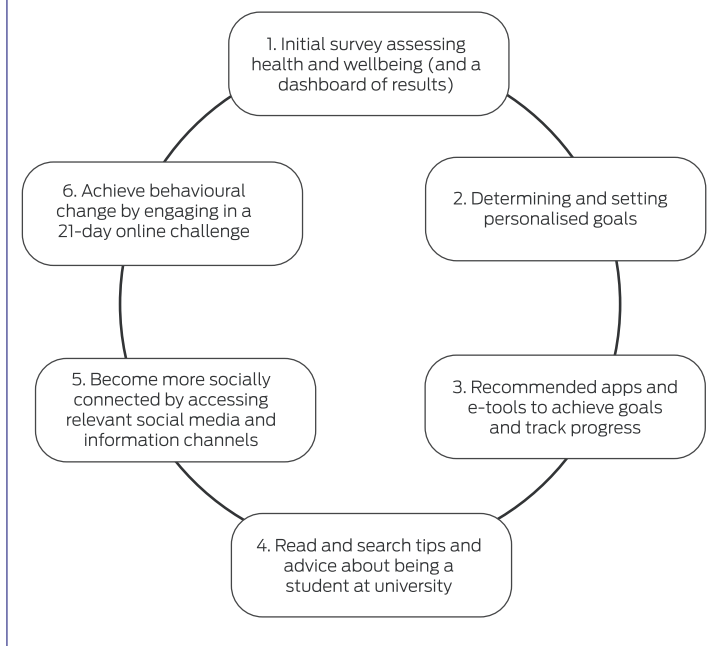
Methods

Using Project Synergy's research and development cycle, co-design workshops and knowledge translation were carried out at the University of Sydney between July 2014 and January 2015.

Participants were recruited using a university-wide multi-pronged approach, which included: posters displayed on student and staff noticeboards; an organic study-specific (snowball) Facebook page; and existing university social media channels.

¹ Brain and Mind Centre, University of Sydney, Sydney, NSW. ² Department of Psychiatry and Mental Health, School of Medicine, Pontificia Universidad Javeriana, Bogota, Colombia. ³ Swinburne Research, Swinburne University of Technology, Melbourne, VIC.

1 Key features of the co-designed online health and wellbeing prototype



wellbeing, social connectedness, participation and engagement at university, and academic outcomes — all of which were included as workshop topics. Other topics included: developing personalised wellbeing plans; assessing current health and wellbeing online; setting goals; providing results online (summary of results); selecting apps and e-tools; collecting and monitoring personal data (including data from apps and e-tools); opting to share data with the university; and generating progress reports.

Results

Through participant idea generation and feedback, the co-design and knowledge translation processes resulted in a unique and integrated solution for the prototype (Box 1). The prototype included three core features: (i) an initial survey to assess current health and wellbeing, and the subsequent development of a personalised plan and selection of goals to achieve this plan; (ii) links to an integrated set of quality assured apps and e-tools that match the chosen goals; and (iii) provision of real-time feedback, permitting young people to monitor their own progress, make changes that suit them best (in line with their goals), and consider what is and isn't working.

Students and staff participated in the co-design workshops and co-developed user journeys for the prototype (user journeys are diagrams of the steps or processes for a scenario in which a user may interact with the content of an online tool). After each workshop, findings were translated by a knowledge translation team into draft wireframes, which were later refined and used to build the prototype (see Chapter 2 for a detailed description of these phases and explanations of the terminology used in this chapter).

All participants received a voucher to thank them for sharing their knowledge and expertise. The value of the voucher varied depending on the activity type and duration. The study was approved by the University of Sydney Human Research Ethics Committee (Protocol No. 2014/82).

Co-design workshops

Three co-design workshops for this prototype were held on campus at the University of Sydney and informed by guidelines created by the Young and Well Cooperative Research Centre.²² Each workshop had different groups of participants and addressed different research questions.

The first workshop was held with 18–24-year-olds ($n = 15$; eight women, seven men). The focus of the workshop was to explore internet use and hardware use (eg, smartphone *v* tablet *v* PC or laptop). Use (or potential use) of online e-tools to improve general health, wellbeing and social connectedness was also explored. Participants then helped develop designs for a new e-tool (ie, the prototype), including how it might look and function.

The second workshop was held with first-year university students ($n = 16$; eight women, eight men) to determine their specific needs and wants for the prototype and further inform the design. The third workshop was held with university staff from a diverse range of faculties ($n = 15$). These two workshops focused on exploring the requirements of university students and staff, to ensure the prototype met the aims of improving health,

Assessment of health and wellbeing

Participants recommended that three broad health and wellbeing domains be assessed: health, social connectedness, and functioning and engagement. Our research group subsequently selected measures that represented these domains:

- Health was measured by items including overall health, overall mental health, overall physical health, resilience, misuse of alcohol or other substances, sleep,²³ somatic concern (Somatic and Psychological HEalth REport),²⁴ and physical activity (International Physical Activity Questionnaire).²⁵
- Social connectedness was measured by items including time spent socialising,²³ satisfaction with personal relationships, and satisfaction with support from personal relationships (adapted from the World Health Organization Quality of Life scale).²⁶
- Functioning and engagement were measured by items including time spent engaged in education, work or volunteering,²³ general functioning (self-rated and adapted from the Social and Occupational Functioning Assessment Scale),²⁷ days out of role (Brief Disability Questionnaire),²⁸ and work–life balance.²³

2 Domains of the Mobile App Rating Scale and what they assess²⁹

| Domain | Criteria assessed |
|---------------------|--|
| Engagement | Entertainment, interest, customisation, interactivity, target group |
| Functionality | Performance, ease of use, navigation, gestural design |
| Aesthetics | Layout, graphics, visual appeal |
| Information quality | Accuracy of app description in app store, goals, quality of information, quantity of information, visual information, credibility, evidence base |

3 Co-designed user journey of “Jake” (a hypothetical first-year university student) using the online health and wellbeing prototype*

FIRST YEAR UNIVERSITY STUDENT USER JOURNEY

Jake

Jake (19), living independently for the first time after moving to Sydney to start University, experiences a break up, and begins to develop difficulties with sleep, mood, and motivation.

GOALS:

- Improve Mindfulness
- Improve Sleep
- Improve Mood
- Improve Relationships

DEVICES: iPhone 7

BACKGROUND

Jake has just moved to Sydney from Orange to start his Electrical Engineering degree at University. Jake is living out of his home for the first time with a group of flatmates he does not know. He has left behind his mum, dad and three younger siblings as well as his long-term girlfriend but plans to drive home every weekend to see them. Jake has great mates in Orange but most of them are staying to work or are attending different universities. Jake has always been pretty level-headed, loves his sport and a beer at the pub after a footy game.

WEEK 0 ORIENTATION WEEK

Jake attends Orientation Week at University where he keeps hearing about FitUniLife to thrive and what it can do for him in his first year at University. Jake does not really get stressed and is not too worried about his relationship, but likes the idea of trying mindfulness and especially likes the idea that he can monitor his sleep and physical activity to see what impact they have on his mood.

After signing up to FitUniLife to thrive, Jake is taken through a series of short questions about what he hopes to achieve at university in his first year and his responses result in a customised 'health and wellbeing plan' (including recommended goals) and three new apps that he can download which focus on mindfulness, sleep and mood. Jake also sees an app that helps with healthy eating and downloads that too.

WEEK 4 (EASTER BREAK)

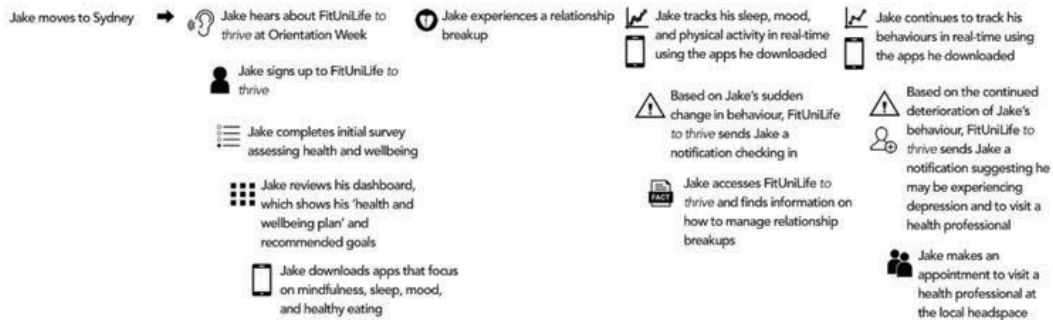
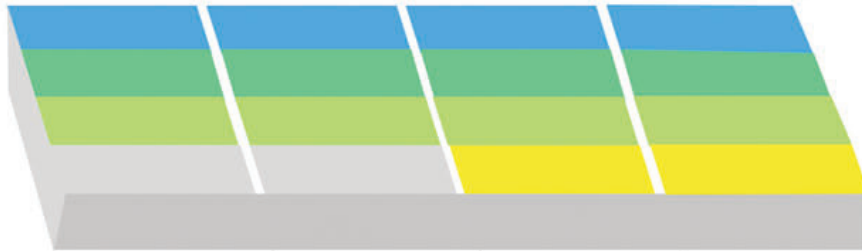
During Easter break, Jake's girlfriend tells him that she has met a local winemaker through her family vineyard and that the long distance has made the relationship too tough to manage. Jake, devastated and heartbroken, returns to Sydney.

WEEK 5 (BACK TO UNI)

Jake's first week back at University after the breakup is tough, and he spends most nights tossing and turning wondering what he could have done differently. Jake's mood does not improve and he feels really down, flat and miserable. He is missing more sleep and finding that he cannot concentrate in class during the day. He is so exhausted and cannot find any motivation to exercise. Based on his sudden change in behaviour (poor sleep, low mood, no physical activity), FitUniLife to thrive sends him a notification checking in. Jake goes back into the system and finds some information on how to manage relationship breakups.

WEEK 7

Another two weeks pass and Jake is still sad, is not sleeping or exercising and feels that it is impossible to get out of bed. FitUniLife to thrive again sends him a notification and this time suggests that he may be experiencing depression and suggests he visit ReachOut.com, beyondblue or headspace (Project Synergy partner organisations) to learn more. Jake takes the advice and makes an appointment to visit a health professional at the local headspace service.



Potential app & etool recommendations for Jake

| | | | |
|----------------------------|----------------------|---------------------|------------------------------|
| | | | |
| Mind Shift | Daylio | Mood Mission | Chats For Life |
| | | | |
| Headspace | Smiling Mind | Recharge | Sleep Better |
| | | | |
| Mind Shift | myCompass | Love Smart | Mind Max |
| Improve Mindfulness | Improve Sleep | Improve Mood | Improve Relationships |

Other suggested apps

| | | | |
|--------------|-----------------|--------|--------------------|
| | | | |
| Music eScape | SPINRIT | Strava | Nike Training Club |
| | | | |
| Distress | Physical Health | Fitbit | MyFitness Pal |

* A user journey is a diagram of the steps or processes for a scenario in which a user may interact with the content of an online tool. ◆

Goals, apps and e-tools

To assist young people to achieve their personalised goals, the prototype recommended apps and e-tools that were quality assured using the Mobile App Rating Scale (MARS) (Box 2).²⁹ This is a tool that assesses app and e-tool quality on four key domains: engagement, functionality, aesthetics and information quality. MARS rates these dimensions using a five-point scale: 1 for inadequate, 2 for poor, 3 for acceptable, 4 for good, 5 for excellent.²⁹

The prototype also provided a detailed breakdown of how recommended apps and e-tools can aid a young person's health and wellbeing based on the PERMA model of flourishing.³⁰ The PERMA model categorises subjective wellbeing into five domains: positive emotions (P), engagement (E), relationships (R), meaning (M) and accomplishment (A). These constructs share multiple elements with other common models of wellbeing.^{31–34} By highlighting the different subjective wellbeing domains that each recommended app or e-tool promotes, the user gains a greater understanding of the areas of subjective wellbeing they may be improving by using these software programs. This also enables the user to differentiate between various programs that may target the same goal and enable them to decide which apps or e-tools better suit their individual needs and goals.

The prototype was interoperable with real-time tracking wearables and apps, such as Fitbit, Strava, Recharge and UBwell. Using aggregated data from these devices, the prototype was able to generate tailored progress reports for each user. These reports provided a holistic picture of the user and their progress across several health and wellbeing domains (eg, physical activity, sleep, mood, anxiety, energy, substance use, functional engagement, healthy eating and weight). Enabling such diversity of tracking domains has been advocated in research publications.¹⁵

Both the co-design and knowledge translation processes acknowledged engagement and user retention problems, which have been increasingly documented.^{35,36} These problems were addressed by developing a tips-and-advice feature, integrating the prototype with university social media channels and including a 21-day online challenge (Box 1). The ability to tailor the prototype to the context in which it would be used was also considered very important, so the prototype was designed to be configurable (or rebranded). The University of Sydney participants named their version of the prototype "Fit Uni Life to thrive".

Finally, to contextualise the prototype, participants iteratively developed a hypothetical user journey over the three workshops (Box 3). It was shown on a timeline, as this makes it easier to understand changes in context, and understand user motivations,

problems and needs. The user journey helps technology developers understand why and how young people want to use the co-designed prototype. It also guides them in building a user experience that is easy to understand, efficient to use, and will ensure that young people return.

Discussion

An online health and wellbeing system was co-designed for young people within a post-school education setting. The prototype comprised an integrated suite of features, including assessment, planning and goal setting, recommended apps and e-tools, real-time feedback, and functions dedicated to connecting young people to their university community (the tips-and-advice feature, social media channels and 21-day online challenge).

The initial survey to assess current health and wellbeing resulted in a personalised plan, as well as goals to achieve this plan. By personalising goals, it is more likely that young people will view them as relevant and achievable, which are both key features of goal setting.¹⁹

The prototype also included an integrated set of quality assured apps and e-tools that were categorised using the PERMA model of flourishing.³⁰ By categorising the apps and e-tools, young people would gain a greater understanding of the areas of subjective wellbeing that they were targeting.

Another important feature of Fit Uni Life to thrive was its whole system focus on social connection, which is critically important to a young person's health and wellbeing. People aged 16–24 years are particularly vulnerable to loneliness and a lack of social connection,³⁷ and age appropriate co-designed interventions to address this have been called for in the mental health literature.³⁸ We argue that early intervention and preventive digital tools focused on enhancing social connection are therefore vital, particularly as this age group is at the greatest risk of the emergence of mental ill health. Thus, a multifaceted approach to assisting young people with their social connection underpins the entire Fit Uni Life to thrive prototype.

Effective ways for universities to promote and support good mental health within their communities are multifaceted.³⁹ One of the key areas for investment when working towards better health and wellbeing of both students and staff is developing, evaluating and promoting evidence-based health information technologies. Strategically, these are ideal in settings such as universities — they can reach large numbers of staff and students, and they can ultimately form part of a solution to promoting good health and wellbeing in the 21st century.

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Chapter 4

Study 2: Evaluating engagement with a prototypic online platform to improve the mental health and wellbeing of young people living in disadvantaged communities

Tracey A Davenport¹, Lisa Whittle¹, Laura Ospina-Pinillos^{1,2}, Alyssa C Milton¹, Jane M Burns³, Ian B Hickie¹

Disadvantaged communities experience marked social and health inequalities compared with the general population.¹⁻³ These can include reduced educational and employment opportunities; lower income; poorer access to and use of health services; higher levels of disease risk factors and illness; and higher rates of suicide. In Australia, people living in regional, rural and remote areas as well as Aboriginal and Torres Strait Islander peoples have been identified as groups that are likely to experience persistent disadvantage.^{1,6}

While no marked difference has been found in the overall prevalence of mental illness between people living in metropolitan areas and those living in regional, rural and remote areas (about 20%),⁷⁻⁹ dramatic differences have been found in the acuity of mental illness for people living in regional, rural and remote areas owing to: poor access to primary and acute care; limited numbers of mental health services and mental health professionals; distance from and cost of mental health services; concerns about stigma; cultural barriers relating to service access; and reluctance to seek help.^{7,8} Rates of suicide and self-harm have also been found to increase with remoteness (compared with cities, rates are 40% higher in rural areas and almost double in remote areas).⁸ It is estimated that people living in remote areas are only able to access mental health services at a fifth of the rate of their metropolitan counterparts.⁸ Disparity also exists in the quality and outcomes of mental health care for those who access services.^{2,10}

For Aboriginal and Torres Strait Islander peoples, rates of serious mental illness and of mental health problems associated with social disadvantage are higher than for non-Indigenous Australians.^{2,11} Furthermore, the disadvantage is even greater for those living in regional, rural and remote areas.² Suicide also accounts for a greater proportion of all deaths of Aboriginal and Torres Strait Islander peoples compared with deaths of non-Indigenous Australians (6% *v* 2%, respectively).¹²

In relation to the mental health and wellbeing of all young people living in regional, rural and remote areas, the suicide rate for young men aged 15–29 years is almost twice as high as it is in major cities.⁸ For Aboriginal and Torres Strait Islander peoples aged 15–34 years, intentional self-harm was the leading cause of death between 2013 and 2017.¹² A sense of pessimism about future prospects, unemployment, loneliness and pressure to conform to locally accepted patterns of behaviour may exacerbate the risk of mental health problems for young people living in these areas.⁸ For lesbian, gay and bisexual (LGB) individuals,

minority stress and less LGB community connectedness are additional risk factors for psychiatric morbidity.¹³

The use of health information technologies, however, holds promise in terms of augmenting health service delivery and reducing marginalisation for all disadvantaged communities across Australia, and for young people in particular. Research findings suggest that internet use among children and young people does not differ significantly between metropolitan and remote or very remote areas of Australia.¹⁴ Furthermore, it has been highlighted that youth in rural areas may stand to benefit the most from technology-supported services.¹⁵ This is, at least partially, because these young people experience structural barriers to help seeking, such as a lack of specialist services, out-of-hours support and reliable transport.^{16,17} Young people in rural areas also experience contextual barriers, such as reduced anonymity associated with rural communities, which may exacerbate fear of gossip, stigma and social exclusion.^{16,17}

The primary objective of this study was to evaluate the engagement of young people living in disadvantaged communities in three areas of New South Wales with a prototypic online platform with features as previously described (see the Box in Chapter 1) and observe any changes in health and wellbeing in this group when using the prototype. A secondary objective was to further inform the co-design and development of the prototypic online platform.

Methods

Design and setting

The study was conducted online with participants from the Central Coast, Western Sydney and Far West NSW between February and September 2016. Participants residing in these areas were given access to the prototypic online platform for 90 days. Within this period, they could navigate the prototype at their own pace, and engage with its functionality and that of recommended apps, e-tools and other resources.

The Central Coast, Western Sydney and Far West NSW were chosen as they each include towns or communities listed in the top ten most disadvantaged Statistical Local Areas in NSW or the top ten most disadvantaged Statistical Local Areas in Greater Sydney (according to the Index of Relative Socio-economic Advantage and Disadvantage).^{1,9}

The Central Coast is a peri-urban region in NSW and part of Greater Sydney that has a population of about 320 000 people.

¹ Brain and Mind Centre, University of Sydney, Sydney, NSW. ² Department of Psychiatry and Mental Health, School of Medicine, Pontificia Universidad Javeriana, Bogota, Colombia.

³ Swinburne Research, Swinburne University of Technology, Melbourne, VIC.

Supplement

1 Median responses for all mental health and wellbeing items for participants who completed questionnaires across time points, with comparisons using the Friedman test for non-parametric related samples*

| | Time point | | | | | P |
|---|------------|--------|--------|--------|--------|-------------------|
| | Baseline | Day 15 | Day 30 | Day 60 | Day 90 | |
| Number of participants | 259 | 171 | 165 | 148 | 133 | |
| Mental health and wellbeing items | | | | | | |
| 10-item Kessler Psychological Distress Scale score (psychological distress) | | | | | | |
| Median | 17.0 | 16.0 | 16.0 | 15.0 | 14.0 | < 0.001 |
| IQR | 13.0 | 13.0 | 11.0 | 12.0 | 11.0 | |
| 5-item Psychiatric Frequency Symptom Scale (suicidal ideation or acts) | | | | | | |
| Median [†] | 1.0 | 1.0 | 1.0 | 1.0 | 1.0 | 0.66 |
| IQR | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | |
| 14-item Mental Health Continuum Short Form (positive mental health status) [‡] | | | | | | |
| Median (category) [§] | 2.0 | 1.0 | 1.0 | 2.0 | 2.0 | 0.43 |
| IQR (category) | 1.0 | 1.0 | 1.0 | 1.0 | 1.0 | |
| Overall health rating | | | | | | |
| Median [¶] | 4.0 | 4.0 | 4.0 | 4.0 | 4.0 | 0.006 |
| IQR | 1.0 | 1.0 | 2.0 | 1.0 | 2.0 | |
| Overall mental health rating | | | | | | |
| Median [§] | 4.0 | 4.0 | 4.0 | 4.0 | 4.0 | 0.01 |
| IQR | 1.0 | 1.0 | 2.0 | 2.0 | 1.0 | |
| Oxford Happiness Questionnaire – short scale (happiness) | | | | | | |
| Median | 18.0 | 17.0 | 17.0 | 17.0 | 18.0 | 0.28 |
| IQR | 6.0 | 7.0 | 5.0 | 5.0 | 7.0 | |
| Personal concern items | | | | | | |
| Alcohol | | | | | | |
| Median** | 1.0 | 1.0 | 1.0 | 1.0 | 1.0 | 0.45 |
| IQR | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | |
| Body image | | | | | | |
| Median** | 3.0 | 2.0 | 2.0 | 2.0 | 1.8 | < 0.001 |
| IQR | 2.0 | 2.0 | 2.0 | 2.0 | 0.9 | |
| Bullying or emotional abuse | | | | | | |
| Median** | 1.0 | 1.0 | 1.0 | 1.0 | 1.0 | 0.10 |
| IQR | 0.0 | 1.0 | 1.0 | 1.0 | 0.0 | |
| Coping with stress | | | | | | |
| Median** | 3.0 | 2.0 | 2.0 | 2.0 | 2.0 | < 0.001 |
| IQR | 2.0 | 2.0 | 2.0 | 2.0 | 1.0 | |
| Depression | | | | | | |
| Median** | 1.0 | 1.0 | 1.0 | 1.0 | 1.0 | 0.004 |
| IQR | 2.0 | 1.0 | 1.0 | 1.0 | 1.0 | |
| Drugs | | | | | | |
| Median** | 1.0 | 1.0 | 1.0 | 1.0 | 1.0 | 0.43 |
| IQR | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | |
| Self-harm | | | | | | |
| Median** | 1.0 | 1.0 | 1.0 | 1.0 | 1.0 | 0.32 |
| IQR | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | |

IQR = interquartile range. Significant P values are bolded. *Includes participants who provided responses for any of the questionnaires at any time point. †Psychiatric Frequency Symptom Scale presented median 1 "no suicidal ideation or acts". ‡Three-category diagnosis of positive mental health. §Mental Health Continuum Short Form medians were 1 "moderate" or 2 "flourishing"; P value calculated from total scale score. ¶Overall health and overall mental health median was 4 "good". **Personal concern medians were 1 "none of the time", 2 "a little of the time" and 3 "some of the time". ◆

Western Sydney is a major urban district of Sydney with a population of about 1.7 million people and a large population of people from culturally and linguistically diverse backgrounds. Far West NSW includes the towns of Broken Hill, Wilcannia and Menindee — isolated mining towns in the outback of NSW with a combined population of about 30 000 people, including Aboriginal and Torres Strait Islander peoples (10% of the combined population).

The key inclusion criteria for the study were: age 16–25 years; residing in one of the three areas as specified by postcode; and having regular access to a smartphone (iPhone or Android) and the internet.

Co-design and user testing

Using Project Synergy's research and development cycle, preliminary work to locally configure the prototypic online platform was carried out in the three selected areas of NSW in early 2016. Young people, supportive others and health professionals were engaged in co-design workshops, and then three cycles of user testing were conducted. Later in 2016, we evaluated engagement with the configured prototype that had been developed during the co-design process.

In this study, the prototypic online platform brought together a general health and wellbeing prototype (Chapter 3) with a more specialised mental health e-clinic prototype^{18,19} (Chapter 6). Subsequent integration of these two prototypes onto one online platform also required the development of single sign-on (a user authentication service that allows users to access multiple applications with one set of login credentials [eg, email and password]) and interoperability of data between the two prototypes.

Ethics approval

The co-design workshops and user testing sessions were approved by the University of Sydney Human Research Ethics Committee (Protocol No. 2015/417), and the same committee separately approved the protocol for the study evaluating engagement with the configured prototype (Protocol No. 2015/946). The study also received approval from the State Education Research Applications Process to conduct the research in NSW public schools (SERAP No. 2015729).

Recruitment procedures

Participants were recruited using a community-wide multi-pronged approach including: posters displayed at businesses and community organisations; paid (targeted) Facebook advertisements; an organic study-specific (snowball) Facebook page; and existing social media channels of associated organisations (eg, the University of Sydney's Brain and Mind Centre, the Young and Well Cooperative Research Centre and the Mental Health Commission of NSW). In addition, owing to specific ideas generated during the co-design workshops, several novel recruitment strategies were employed, which aimed to embed the research in each of the communities and thus increase participation in the study. These included: community events focused on young people (Supporting Information, chapter 4, figures 1–5); approaching local media channels; and employing researchers who lived and worked in each of the communities. All participants, regardless of recruitment strategy, were directed to the prototypic online platform.

Potential participants were screened online for eligibility and, if eligible, were provided with a study information sheet and consent form. After providing consent, participants were given access to the prototype through a secure login. During the study, all data gathered from participants were collected in the prototype's secure database, which was hosted by the Brain and Mind Centre. In addition, participants were sent an email inviting them to participate in an online survey comprising a series of questionnaires at baseline (Day 0), and at various time points thereafter (Day 15, Day 30, Day 60 and Day 90). Participants were provided with a \$10 gift voucher after submitting each questionnaire. Questionnaires were hosted online and fed back into the prototype's database using straight-through processing methods.

Data collected in online survey

Participant demographics were collected at baseline only. Changes in the health and wellbeing of participants when using the prototype over time were measured. This involved use of: two separate items for overall health and overall mental health that were rated on a five-point Likert scale (1 for "very bad" to 5 for "very good");²⁰ current levels of psychological distress via the 10-item Kessler Psychological Distress Scale (K10);²¹ suicidal ideation and acts from the five-item Psychiatric Frequency Symptom Scale;²² positive mental health status using the 14-item Mental Health Continuum Short Form (MHC-SF);²³ happiness status using four items from the Oxford Happiness Questionnaire – short scale;²⁴ and data about personal concerns relating to seven specific issues (alcohol, body image, bullying or emotional abuse, coping with stress, depression, drugs and self-harm) were rated on a five-point Likert scale (1 for "none of the time" to 5 for "all of the time"). Engagement with the prototype was measured at Day 90 by an adapted version of the 10-item System Usability Scale rated on a five-point Likert scale (1 for "strongly disagree" to 5 for "strongly agree"),^{25,26} and by 14 quantitative and four qualitative items concerning its use and acceptability, including frequency of use, session length and devices used to access the prototype (Supporting Information, chapter 4, table 1).

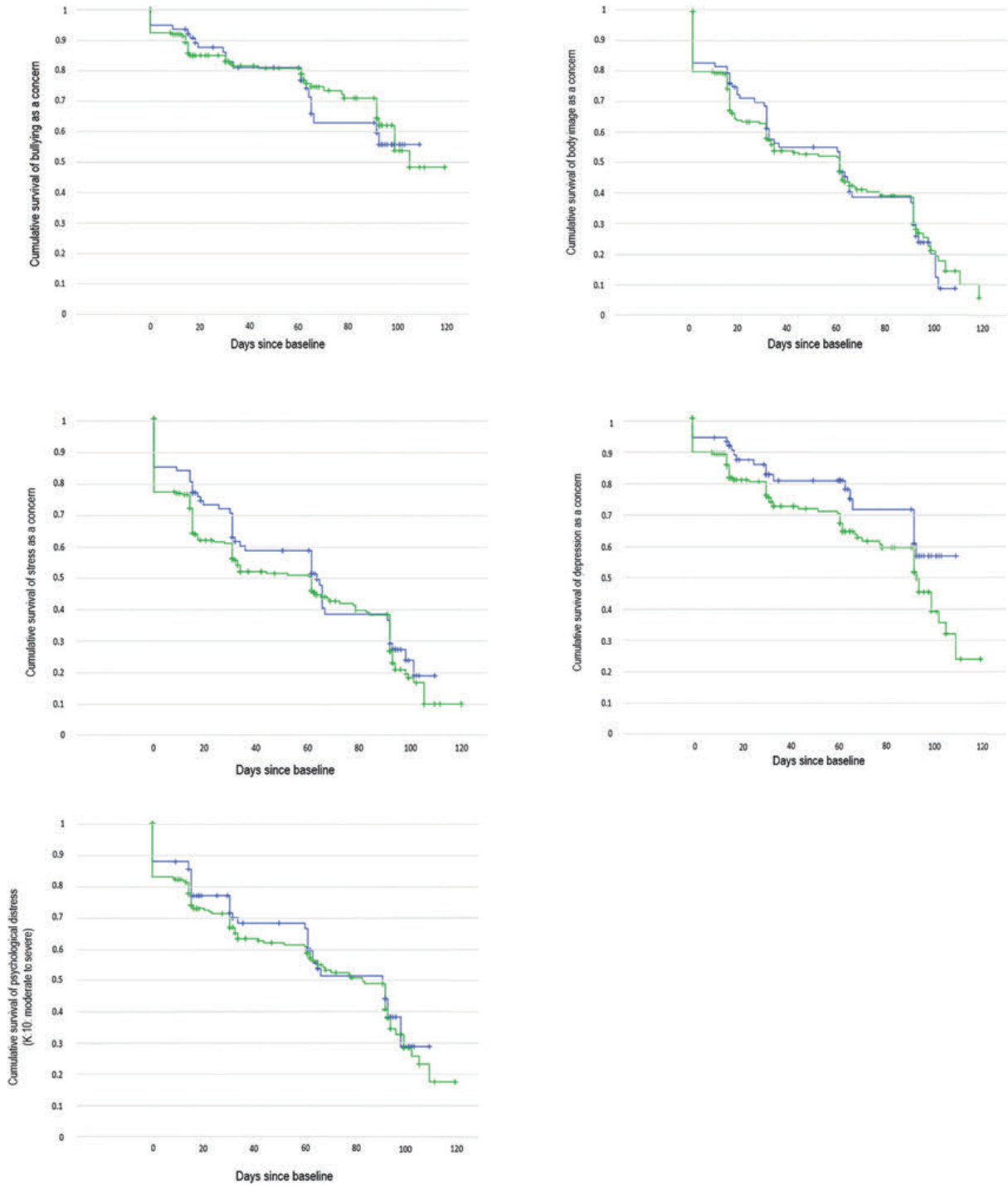
Analysis

All statistical analyses were conducted using SPSS, version 22 (IBM Corporation). Descriptive and frequency data were prepared for all participants at each time point. Differences in the baseline demographics of participants who dropped out compared with those who remained in the study were undertaken using χ^2 analysis. Baseline and post-test change scores for each measure were compared for participants who completed the questionnaire at each of the five time points. As the measures yielded data on the ordinal level or were skewed in nature, non-parametric statistical methods were considered the most appropriate. Consequently, comparison of the repeated measures was performed using a Friedman χ^2 test for K-related samples,²⁷ set at a 95% level of confidence.

The non-parametric estimate of the survival curve using the Kaplan–Meier method²⁸ was used to analyse survival probabilities as a function of time over the five time points. Here we examined survival curves of symptoms and concerns relating to bullying, body image, coping with stress and depression ("a little of the time" to "all of the time"); and psychological distress case ("moderate", "high" or "very high") for participants with low system engagement (one use) compared with those with

Supplement

2 Survival curves for symptoms and concerns relating to bullying, body image, coping with stress and depression,* and psychological distress† for participants with low engagement (one use of the prototype; blue line) and multiple engagements (more than one use of the prototype; green line)‡



* Coping with stress and depression was rated from "a little of the time" to "all of the time". † Psychological distress was rated "moderate", "high" or "very high". ‡ Only includes participants who provided responses for every questionnaire at every time point. ◆

multiple system engagements (more than one use). Mantel–Cox, Breslow and Tarone–Ware tests were used to determine equality across groups.

A System Usability Scale (SUS) score was calculated for each participant by summing scores for the ten individual SUS items, and then multiplying the sum by two to convert the original scores of 0–50 to a SUS score of 0–100. For each open-ended question, basic qualitative coding was carried out using NVivo 10 software (QSR International) by grouping responses into positive, mixed and negative comments.

Results

Participant characteristics

A total of 449 young people enrolled to participate in the study (Central Coast, $n = 226$; Western Sydney, $n = 125$; Far West, $n = 98$) and 58% fully completed all the questionnaires at baseline (259/449). Of the baseline participants, 63% were women (164/259), 36% were men (92/259) and 1% identified with another gender group (3/259). Thirteen percent of the sample identified as being of Aboriginal or Torres Strait Islander origin (34/259) and 8% spoke a language other than English (21/259). Seventeen percent identified as LGB (45/259). Forty-two percent of the sample were at school, TAFE or university (108/259), 22% were employed full-time (30 or more hours per week; 57/259), 11% were employed part-time (fewer than 30 hours per week; 29/259), and 23% were unemployed or not in paid employment for various other reasons (59/259). Across the other time points, the numbers of participants who fully completed all the questionnaires were 129 at Day 15, 92 at Day 30, 76 at Day 60, and 73 at Day 90. The numbers of participants who partially completed the questionnaires at the time points were 42 at Day 15, 73 at Day 30, 72 at Day 60, and 60 at Day 90.

Friedman χ^2 analysis showed there were no significant differences between participants who completed the survey at all time points, compared with those who did not, in terms of gender identity ($P = 0.09$), sexual identity ($P = 0.16$), employment, education or training status ($P = 0.49$), Aboriginal or Torres Strait Islander origin ($P = 0.81$) or speaking English as a first language ($P = 0.42$).

Engagement

At Day 90, nearly one in five participants reported using the prototype every day or weekly (18% [13/73]), with the remainder reporting use once or twice a month or less often (82% [60/73]) (Supporting Information, chapter 4, table 1). About three in four participants used the prototype at least two to five times in total (73% [53/73]). The greatest proportion of participants estimated that their sessions lasted, on average, 1–10 minutes (74% [54/73]). Participants chiefly reported using their smartphone to access the prototype (63% [46/73]), with access peaking during mid-afternoon (22% [16/73]) and evening (34% [25/73]).

Health and wellbeing over time

At baseline, a third of participants reported “high” to “very high” psychological distress on the K10 (34% [87/259]), with the remainder reporting “moderate” (23% [60/259]) or “low” distress (43% [112/259]). About one in ten (13% [33/259]) reported experiencing suicidal ideation or acts during the previous 12 months. As rated by the MHC-SF scale, at baseline just over half

the participants reported that they were “flourishing” (56% [119/214]), 36% considered their mental health was “moderate” (77/214) and only 8% reported that they were “languishing” (18/214). In terms of overall health ratings, most participants rated their health as “good” or “very good” (69% [175/255]), a quarter rated their health as “moderate” (24% [61/255]) and 7% (19/255) rated their health as “bad” or “very bad”. At baseline, participants also reported some personal concern with alcohol (18% [46/259]), body image (66% [171/259]), bullying (25% [66/259]), depression (34% [88/259]), drugs (7% [18/259]) and self-harm (12% [30/259]).

Box 1 presents median responses for all mental health and wellbeing items for participants who completed any of the questionnaires at any time point, with comparisons made using the Friedman test for non-parametric related samples. Participants reported a significant reduction in psychological distress scores (K10) over time ($P < 0.001$). The mean scores of overall health and overall mental health also showed significant improvement over time ($P = 0.006$ and $P = 0.01$, respectively) (data not shown), although their median scores did not change. There were also significant reductions in participants’ personal concerns relating to body image ($P < 0.001$), coping with stress ($P < 0.001$) and depression ($P = 0.004$). No other variables demonstrated significant changes.

Box 2 presents the resolution of symptoms or concerns (“a little” to “all the time”) for body image, bullying, coping with stress, depression and psychological distress cases (“moderate”, “high” or “very high” distress) over time, by prototype engagement, using survival functions. It only includes participants who provided responses for every questionnaire at every time point. Participants with low engagement and those with multiple engagements showed a decline in symptoms or concerns over time, with most resolving by the end of the study (except for bullying for both users with low engagement and users with multiple engagements, and alcohol and depression for users with low engagement). Participants with multiple engagements with the prototype had greater resolution of symptoms or concerns, but this was only found to be significant (when testing for equality across groups) for concerns about depression (Mantel–Cox $\chi^2 = 3.9$, $df = 1$, $P = 0.048$; Breslow $\chi^2 = 3.6$, $df = 1$, $P = 0.06$; Tarone–Ware $\chi^2 = 3.8$, $df = 1$, $P = 0.05$). The Mantel–Cox test demonstrated that there was not equality across groups, but this must be interpreted with caution as the Breslow and Tarone–Ware tests indicated that there was no difference between groups.

Prototype acceptability and usability

At Day 90, the System Usability Scale score, a measure of the quality of a user’s experience when using a technology, was 68.2 (SD = 12.3, $n = 151$), which is considered average²⁵ and falls into the “high marginal” acceptability range. On an objective scale, this is equivalent to “okay” or “good”.²⁶ In addition, when asked “Do you think [the prototype] is useful/helpful for young people with mental health concerns?”, most participants responded “yes” (53% [74/140]) or “maybe” (42% [59/140]), and only seven responded “no” (5% [7/140]). Participants were also asked “Do you like [the prototype]?” Again, most responded “yes” (61% [85/140]) or “maybe” (34% [48/140]), and only seven participants responded “no” (5% [7/140]). Basic qualitative coding of the question “What were your first impressions of [the prototype]?” resulted in comments coded as positive (56% [79/128]), mixed (24% [34/128]) and negative (11% [15/128]). Selected illustrative examples of the positive, mixed and negative qualitative feedback are presented in Supporting Information, chapter 4, table 2.

Discussion

These results show that a prototypic online platform holds promise in terms of acceptability and having an impact on some aspects of mental health and wellbeing over time. Although these are preliminary findings, they provide important evidence for understanding the potential of the prototype in supporting young people's mental health and wellbeing in disadvantaged communities. More research is needed to understand how such online tools could break the cycle of poor health by increasing access and augmenting health service delivery, thus reducing marginalisation.

The results showed that although acceptability of the prototype was "okay" or "good", self-reported access was low. Most participants accessed the prototype only once or twice per month, or less often, and for 10 minutes or less. This was in contrast to what might be expected given the reductions in psychological distress and multiple health concerns reported by the participants. It may be that those who were more engaged with the prototype were more likely to benefit in terms of their mental health and wellbeing outcomes, which was demonstrated in the survival functions (Box 2). Variations in access may have been for several reasons, including participants' needs for the prototype, its usability and design, a lack of guidance to participants on how often they should access the prototype due to the study's design, and reliability of internet access. In relation to the latter, it has been highlighted that many young people still do not have unlimited access to the internet or related technologies, particularly in rural and remote areas.³⁰ This can be due to reasons such as having challenges with network connectivity or a limited download capacity, which can be because of financial situations or geography. This was particularly the case for Far West NSW, so we paid for an aerial and donated it to the community to provide better access to the internet, and thus improved access to the prototype. These technology-related challenges, which were also cited in the preliminary co-design workshops, may explain some of the low use. Ultimately, however, the technological challenges that disadvantaged communities face can reinforce the cycle of disadvantage.^{15,31} Going forward, it is particularly important that this issue is addressed because online access to services, support and information will become progressively more commonplace.

Limitations

While these preliminary results show some influence on young people's health and wellbeing over time in a few settings, their

generalisability to other disadvantaged communities cannot be guaranteed. The results were also somewhat mixed, with some improvements across time points being reported for certain health and wellbeing items (psychological distress, overall health, overall mental health, body image, coping with stress and depression) but not others (suicidal thoughts and behaviour, positive mental health, happiness, alcohol and drug use, and bullying). Sample attrition across time was an issue, with just over a quarter (28%) of the full sample completing questionnaires at all five time points. Consequently, results may reflect that those who were highly engaged with the prototype experienced better mental health and wellbeing outcomes. Also, it is possible that the reduction in sample size over time meant we were not able to detect significant change. These results might also be due to low reporting of issues such as alcohol, drug use and self-harm as personal concerns. Ultimately, as the study was not randomised or controlled, cause-effect relationships cannot be determined. For example, we cannot determine whether the changes in distress simply reflect the effect of time. In addition, we did not have access to information on important external factors such as whether participants were also accessing other mental health and wellbeing services. Finally, reliance on self-reporting may have resulted in issues relating to participant recall and response accuracy, particularly for items assessing engagement with the prototype over the study. Overall, this research must be considered preliminary, so further evidence from more rigorous studies is needed.

Strengths

Despite its limitations, a strength of this study was that it was naturalistic, meaning that data were collected outside of a controlled environment. This enabled it to evaluate engagement with the configured prototype in real-world disadvantaged communities, and thus achieve maximum external validity in a pragmatic and cost-effective manner. A further strength of the study was that it aggregated data from three diverse locations, rather than relying on one community only.

Conclusion

We believe the results of this study contribute valuable information about the potential of our prototype to provide mental health and wellbeing support to young people living in disadvantaged communities.

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Supporting Information

Additional Supporting Information is included with the online version of this article.

Chapter 5

Study 3: Co-designing, user testing and evaluating digital suicide prevention functionality

Tracey A Davenport¹, Alyssa C Milton¹, Lisa Whittle¹, Larisa T McLoughlin⁴, Laura Ospina-Pinillos^{1,3}, John Mendoza^{1,5}, Jane M Burns², Ian B Hickie¹

Suicide is the leading cause of death for Australians aged 15–44 years.¹ National rates of suicide increased between 2008 and 2017, and the number of deaths from suicide increased by 9% between 2016 and 2017. In 2015 and again in 2017, the number of deaths from suicide was recorded at 12.6 deaths per 100 000 population — the highest recorded rate in 10 years.¹ Given the importance of this issue, the National Mental Health Commission (NMHC) National Review of Mental Health Programmes and Services report, published in 2014, recommended a coordinated nationwide introduction of sustainable, comprehensive, whole-of-community approaches to suicide prevention; a greater focus on suicide prevention for people attending health and mental health services; and, specifically, better integration of e-mental health services.² Similarly, the World Health Organization (WHO) has recognised that mobile devices are an important option for providing support and therapy to people at risk of suicide.³

Digital tools are particularly appealing in mental health care as they provide new pathways for reaching more people, while also addressing a range of other social and community challenges (such as social isolation and poor physical health).^{4–8} Typically, these tools have been developed for young people, particularly those born after the widespread adoption of technology.⁷ A recent systematic review on technology and suicide prevention highlighted the promise of mobile, computer or web-based apps in improving young people's outcomes,⁹ however, the scarcity of evidence on online and mobile interventions for suicide prevention in young people was also noted. Suicide prevention apps and e-tools can range from useful and engaging to poorly designed and ineffective.⁷ Other general population research identified 123 apps in the marketplace that were related to suicide.¹⁰ Of these, 10% contained what was considered potentially harmful content, 25% had obvious technical faults or reliability issues, and fewer than half (41%) were developed by academics or health care institutions. One reason for these problems may be that most design of digital content is structured around positive user journeys (steps or processes by which a user may interact with the content), and that more consideration of people who are in crisis is needed when designing the structure of the content.¹¹ Our own user experience designer and researcher reviewed available Australian mental health websites and found varying levels of success in designing user experience for crisis (Eric Fitzgerald, Creative Director, InnoWell, Sydney, personal communication, 2018). Very few offered more than a simple (often red) call button or urgent help button with a long and static list of services. Only one site was found that offered three levels of immediate support (via a “need help now” option) on the homepage; the three support options were “call us”, “crisis

support chat” and “help resources”. A more recent initiative of the Department of Health is Australia's digital mental health gateway known as Head to Health (<https://headtohealth.gov.au>). This site was developed in collaboration with the community and the mental health sector, and it includes a more refined “need help now” feature. This functionality has a short list of recommendations that are, importantly, guided by a set of rules developed by users. These rules include that recommendations must be local to Australia, provide 24-hour access to support, have multiple modes of communication (ie, telephone and web chat) and be sensitive to cultural diversity.

Much work in Australia in suicide prevention over the past two decades has focused on community-level initiatives rather than active engagement of general health and mental health services as key agents in any large-scale response to this major health challenge. However, some novel applications are starting to emerge; for example, our research group has used new and emerging technologies to identify and respond to suicidality among help-seeking young people.¹²

By contrast, considerable international effort has been directed to developing and evaluating health system-level strategies¹³ (eg, Towards Zero Suicide). The NMHC report specifically highlighted the need for Australian health services to actively adopt a “zero suicide in care” philosophy and develop policies and procedures to support this approach.²

The objectives of this study were to explore with participants (young people, supportive others and health professionals) how best to assess risk and support active suicide prevention strategies; co-design digital suicide prevention functionality for potential integration with a prototypic online platform; and conduct a national online evaluation of the digital solution.

Methods

Participants

For the co-design workshops and user testing sessions, people aged 16–30 years, supportive others and health professionals were initially recruited to participate in this study from the general patient populations of Primary Health Networks (PHNs) in four regions of Australia: Central and Eastern Sydney; Murrumbidgee; Central Queensland, Wide Bay and Sunshine Coast; and Country Western Australia. For the online evaluation study, the same groups (ie, people aged 16–30 years, supportive others and health professionals) were recruited more widely from the general Australian population, as described below. All research was conducted between August and December 2016.

¹ Brain and Mind Centre, University of Sydney, Sydney, NSW. ² Sunshine Coast Mind and Neuroscience – Thompson Institute, University of the Sunshine Coast, Birtinya, QLD. ³ Department of Psychiatry and Mental Health, School of Medicine, Pontificia Universidad Javeriana, Bogota, Colombia. ⁴ ConNetica, Caloundra, QLD. ⁵ Swinburne Research, Swinburne University of Technology, Melbourne, VIC.

Design and procedures

Following Project Synergy's research and development cycle, the co-design, user testing and evaluation of the digital suicide prevention functionality were carried out in sequential phases (see Chapter 2 for a detailed description of each phase and the terminology used):

- Phase 1 – co-design workshops with participants from the four PHN regions; after each workshop, findings were translated into draft wireframes by a knowledge translation team (see below) to inform generation of subsequent wireframes and build of the functionality;
- Phase 2 – one-on-one 90-minute user testing sessions of the functionality; and
- Phase 3 – a national online evaluation study which involved giving participants 7 days of unlimited access to view the functionality (but not use it) and then having them complete a 10-minute survey.

Participants were recruited for each phase via posters and postcards displayed at services within the PHNs and using existing social media channels of the University of Sydney's Brain and Mind Centre and ConNetica (a mental health and suicide prevention consulting practice). After reading a detailed study information sheet, online informed consent was obtained from participants. Importantly, a health professional was present at all co-design workshops and user testing sessions in case the subject matter caused participant distress.

The knowledge translation team was recruited, using local services, from the Central and Eastern Sydney PHN. All participants received a voucher to thank them for sharing their knowledge and expertise. The value of the voucher varied depending on the activity type and duration.

This research was approved by the University of Sydney Human Research Ethics Committee (Protocol No. 2016/529).

Measures

The online survey used in Phase 3 collected demographic information including: sex, age, postcode, and whether the participant was a young person, supportive other and/or health professional. Technology and internet use were assessed with two items. The first asked participants to indicate the device(s) they used to access the functionality, with multiple responses being provided such as iPhone, PC or Mac computer. The second assessed participants' internet connection quality on a five-point Likert scale (1 for "poor" to 5 for "great"). Feedback on the likeability of various components of the functionality was subsequently provided by participants. This was done by asking respondents to indicate the best liked and least liked features of the digital solution, including: a mapping system to find local or closest mental health services; recommended apps and e-tools; a "rant" feature (space for users to privately express their feelings or experiences); simple clean design; and colour scheme. Participants were also asked to give the functionality a star rating on a five-point Likert scale (one to five stars) and to rate it on an adapted version of the 10-item System Usability Scale (SUS)¹⁴ provided on a five-point Likert scale (1 for "strongly disagree" to 5 for "strongly agree"). Participants were then asked: "Do you think this functionality is useful/helpful for young people with mental health concerns?" (response options: no, maybe and yes); "If you were experiencing distress, how likely would you be to use this functionality?" (answered on a five-point Likert scale; 1 for "not at all" to 5 for "very likely"); and "If

a friend or family member was experiencing distress, how likely would you be to refer them to this functionality?" (answered on a five-point Likert scale; 1 for "not at all" to 5 for "very likely"). At the end of the questionnaire, open-ended qualitative feedback was gathered from participants using questions such as "What were your first impressions of the functionality?".

Analysis

Details describing the process of knowledge translation and user testing in Phases 1 and 2 are provided in Chapter 2. For Phase 3, all statistical analyses were conducted using SPSS, version 22 (IBM Corporation). No missing values were imputed. A SUS score was calculated for each participant by summing scores for the ten individual SUS items, and then multiplying the sum by two to convert the original scores of 0–50 to a SUS score of 0–100. Two comparison groups were created, with the first group being all young people aged 30 years or younger, and the second group being supportive others or health professionals who were over 30 years of age. For each questionnaire item, descriptive and frequency data were analysed. In addition, a two-tailed *t*-test (set at a 95% level of confidence) was conducted to test whether there was a significant difference between the SUS ratings of the two comparison groups. Basic qualitative coding of the question "What were your first impressions of the functionality?" was also carried out using NVivo 10 software (QSR International).

Results

For Phase 1, ten co-design workshops were run with young people, supportive others and health professionals across the four PHNs, with 80 participants in total (15 from Central and Eastern Sydney, 20 from Murrumbidgee, 21 from Central Queensland, Wide Bay and Sunshine Coast, and 24 from Country WA). Of these Phase 1 workshops, 42 participants attended the five workshops that were targeting young people.

For Phase 2, 23 new participants (young people, supportive others and health professionals) completed one-on-one 90-minute user testing sessions across the four PHNs (five from Central and Eastern Sydney, seven from Murrumbidgee, five from Central Queensland, Wide Bay and Sunshine Coast, and six from Country WA). Participants could identify with more than one group, with equal numbers of young people ($n = 13$) and health professionals ($n = 13$) taking part, and a smaller number of supportive others ($n = 5$).

For Phase 3, 101 people participated in the online survey across Australia. Again, participants could identify with more than one group, with the largest group being young people ($n = 54$), followed by health professionals ($n = 47$) and then supportive others ($n = 9$).

Phases 1 and 2: Co-design workshops and user testing sessions

Through participant idea generation and feedback, the co-design workshops resulted in development of the digital suicide prevention functionality, which enhanced traditional "need help now" buttons. The co-designed solution, which was consolidated by the knowledge translation team, included:

- three levels of user response options to address different levels of suicide prevention needs (Services, Talk and !Help);
- recommended apps, e-tools and other types of online resources;

- machine learning which would use artificial intelligence to provide the prototypic online platform with the ability to learn and respond to users without being explicitly programmed (details of how machine learning would be applied to the rant feature are provided as an example below); and
- a mapping system to indicate local mental health services, or the closest services available, to users.

The co-design workshops and user testing sessions emphasised the need for digital content to be personalised, appealing for young people in terms of content and style, accessible and non-stigmatising. Participants also emphasised that the functionality should consolidate and provide links with other online services, face-to-face services, and options for support and information (covering the full spectrum of young people's needs, ranging from prevention and early intervention stages to the crisis stage). Illustrative quotes regarding important features of the digital suicide prevention functionality collected during user testing are presented in Supporting Information, chapter 5, box 1.

Creation of three levels of support

Feedback from young people, supportive others and health professionals during the co-design workshops demonstrated a clear need for any digital solution to be interactive and to provide a greater breadth of options, catering for different individuals' needs, rather than traditional static information-based "need help now" functionality. In response to this, the co-designed digital suicide prevention functionality included three levels of user options – Services, Talk and !Help. These three levels of support were designed based on a traffic light rating system: Services (yellow), Talk (amber) and !Help (red).

The Services level of support (highlighted in yellow) was co-designed to provide information about support services that are available online or nearby (within close physical proximity). The page that lists online services allows users to select from a range of apps, e-tools and other online resources that were quality assured using the Mobile App Rating Scale¹⁵ (see Chapter 3 for further detail), including: apps available in the App Store and Google Play (eg, BeyondNow, My3, Conversations for Life and MYPLAN), e-tools (eg, Mental Health eClinic) and other online resources (eg, Lifeline, Kids Helpline, Beyond Blue, eheadspace, ReachOut). The page that lists nearby services includes integration of an interactive digital atlas for mental health, whereby a user can select service attributes via tags (eg, open now or walk-in) and using smartphone GPS functionality or a postcode to be automatically directed to local mental health services (an example is shown in Box 1, illustrating this feature at the initial knowledge translation phase and the final prototype stage).

The Talk level of support (highlighted in amber) was co-designed to provide additional supportive connections for young people using the functionality when they were not in an immediate emergency but wanted to connect with others to talk about their situation. This includes call, online chat and rant options. The call page enables users to select and be directed to a real-time telephone service to speak with someone. The online chat page is where users can select and be directed to an online chat

service and converse with someone by text. The rant page provides a space for users to privately express their feelings or experiences by typing or voice recording how they feel.¹⁶ The rant text or voice recording can then be saved to the user's personal built-in mood journal or deleted in a visually appealing way. The rant feature would be supported by machine learning using natural language processing and generation tools¹⁷ that filter rant content, sort rants and escalate concerning content so that human moderators can respond efficiently and appropriately.

Finally, the !Help level of support was co-designed to be highlighted in red to reflect the need for immediate emergency support. This feature provides an instant clickable link to talk with emergency services (Triple Zero [000]) and other 24-hour services including Lifeline, Suicide Call Back Service and Kids Helpline. This feature is shown in Box 2, at the initial knowledge translation phase and the final prototype stage.

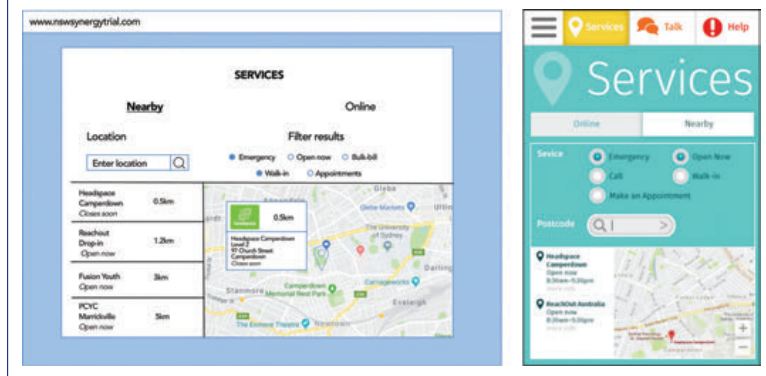
Phase 3: National online evaluation study

A total of 101 participants (56 young people [56%], nine supportive others [9%] and 36 health professionals [36%]) enrolled to participate in the online evaluation study. Their demographic characteristics and data on their technology use are shown in Box 3. The median age band was 20–24 years for young people, 35 years and older for supportive others and 30–34 years for health professionals. Most participants were women (78%). Almost half of the participants were from the Sydney region (49%), close to a quarter were from Western Australia (24%), and the remainder were residing in other regions across Australia (27%). Most participants used either a PC or Mac computer, whereas smaller numbers used an iPhone or other smartphone, and most had an average or better than average internet connection.

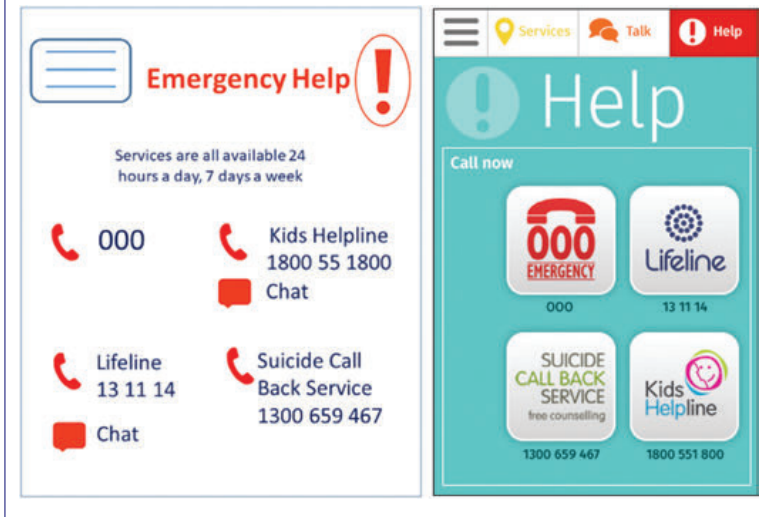
Engagement

Data on engagement of young people, supportive others and health professionals with the functionality are presented in Supporting Information, chapter 5, table 1. The components that were liked the most by participants included: the mapping system (young people, 64%; supportive others and health professionals, 49%); recommended apps and e-tools (young people, 53%; supportive others and health professionals, 42%); and the simple and clean design of the functionality (young people, 42%; supportive others and health professionals, 53%). The rant component was one of the best liked for a large proportion of participants, particularly young people (young people, 58%;

1 Wireframe for the nearby services page at the knowledge translation phase (left) and the final prototypic functionality design (right)



2 Wireframe for the !Help page at the knowledge translation phase (left) and the final prototypic functionality design (right)



supportive others and health professionals, 36%). However, it was also the most divisive component, with the largest proportion of participants rating it as the least liked component (young people, 16%; supportive others and health professionals, 22%) outside of a “don’t know” response. Importantly, the vast majority agreed that the functionality was designed appropriately for young people (young people, 93%; supportive others and health professionals, 93%) and, to a lesser extent, there was agreement that it was designed appropriately for adults (young people, 44%; supportive others and health professionals, 42%).

Acceptability and usability

The acceptability and usability of the functionality as rated by all participants (young people, supportive others and health professionals) is presented in Box 4. When participants were asked whether they thought the functionality would be useful or helpful for young people with mental health concerns, all said either “yes” or “maybe”. Young people were slightly more likely to endorse the functionality as useful or helpful than supportive others and health professionals (96% *v* 87%). In total, only 2% indicated they would not be likely to use the functionality if they were experiencing distress, whereas 60% of young people and 42% of supportive others and health professionals reported being likely or very likely to use it. Furthermore, only 3% of participants indicated that they would not recommend this solution to a friend or family member experiencing distress, whereas 78% of young people and 80% of supportive others and health professionals reported being likely or very likely to recommend it.

On a star rating scale of 1 to 5, the functionality achieved a median rating of 4 stars (60%). Overall, 82% of young people and 85% of supportive others and health professionals rated it as 4 or 5 stars.

Participant views on usability were measured using SUS scores, a measure of the quality of a user’s experience when using a technology. The overall mean SUS score was 84.4 (SD, 11.7) for all participants, which is considered acceptable.¹⁸ Young people’s SUS ratings (mean, 84.9; SD, 10.5) were slightly higher than those of supportive others and health professionals (mean, 83.8; SD, 12.8); however

this difference was not significant ($t(73) = -0.5$; $P = 0.06$). The overall SUS score on usability was in the top quartile, which equates to a “B grade” and falls between objective ratings of “good” and “excellent”.

Basic qualitative coding was carried out for the open-ended question “What were your first impressions of the functionality?”. Most comments were positive (63%) and the remainder were mixed (23%), negative (10%) or deemed not applicable as feedback (4%). Illustrative positive, mixed and negative comments are presented in Supporting Information, chapter 5, box 2. Positive quotes centred around the clean and simple design, the accessibility of the functionality for young people, the layered and tailored nature of the support options provided, and the “one stop shop” of information and support. Mixed quotes often provided suggestions for additional functionalities. For example, suggestions included use of an avatar, and inclusion of additional resources such as referrals to different national and international health services, treatment, information or sup-

port. There were only nine negative comments, and these all related to the design, such as the colour scheme or a need for more visual features in the system.

Discussion

Previous reviews have highlighted the need for digital suicide prevention tools to provide an interactive experience for users.¹⁰ Similarly, in our series of co-design workshops, participants identified the need for, and then co-developed, a digital solution which provides an interactive experience. This co-design process progressed the traditionally static and information-based “need help now” functionality to an interactive tiered system of support (Service *v* Talk *v* !Help) that allows users to engage with each tier based on their self-identified level of need. This was, however, only a prototype of a digital solution. Further testing is required to understand how users navigate and interact with the functionality before it can be integrated into any online platform.

An important advantage of potentially integrating this functionality into our prototypic online platform is that the platform provides a centralised place where other evidence-based apps and e-tools can also be recommended. This empowers young people to choose from apps and e-tools that are high quality and suitable for their needs and goals. Importantly, many of the digital tools that are recommended by the platform are already available in the marketplace, so the platform does not endeavour to reinvent or compete with these products. Instead, the platform provides a pathway to established evidence-based tools, and will continue to do this as new material becomes available. Furthermore, as part of the platform’s quality assurance process, the quality of these apps and e-tools is ensured by use of tools such as the Mobile App Rating Scale.¹⁵ Such quality assurance processes are in turn important for the digital suicide prevention functionality as it is well recognised that these tools need to be high quality, reliable and free from harmful content.¹⁰

Limitations

This study had several limitations. First, our prototype was co-designed with young people, supportive others and health

3 Participants' demographic characteristics and use of technology

| Item | Number (%)* |
|---|-------------|
| Demographics | |
| Sex | |
| Female | 77 (78%) |
| Male | 22 (22%) |
| Age band | |
| 15–19 years | 16 (16%) |
| 20–24 years | 27 (27%) |
| 25–29 years | 17 (17%) |
| 30–34 years | 15 (15%) |
| 35 years and older | 24 (24%) |
| Group | |
| Young person (30 years or younger) | 43 (43%) |
| Supportive other (over 30 years) | 9 (9%) |
| Health professional (30 years or younger) | 11 (11%) |
| Health professional (over 30 years) | 36 (36%) |
| Region | |
| Sydney (Central Eastern, Western, South Western, North) | 48 (49%) |
| Western Australia (Perth South, Perth North, Country WA) | 24 (24%) |
| Far West NSW and Murrumbidgee | 9 (9%) |
| Eastern NSW and ACT (Hunter New England, Nepean Blue Mountains, North Coast, South Eastern NSW, ACT) | 6 (6%) |
| Queensland (Central Queensland, Wide Bay, Sunshine Coast, Gold Coast, Brisbane North, Brisbane South) | 5 (5%) |
| Victoria (North West Melbourne, South Eastern Melbourne) | 4 (4%) |
| South Australia (Adelaide, Country SA) | 3 (3%) |
| Technology and internet use — device(s) used | |
| PC | 54 (54%) |
| Mac computer | 22 (22%) |
| iPhone | 14 (14%) |
| Other smartphone (Samsung, Android, Windows) | 11 (11%) |

Percentages may not add up to 100 due to rounding. ◆

professionals in the general population who had an interest in the subject matter. Although recruitment of individuals was chiefly through mental health service channels, not all the young people who participated would have had a lived experience of suicide-related thoughts or behaviour, either personally or as a supportive other. We did not directly ask participants about these experiences at any stage of the study, which we acknowledge could have provided another level of validity to the digital suicide prevention functionality.

Second, the Phase 3 national online evaluation was only designed to assess acceptability and gather basic feedback on usability. We know the functionality was liked, but we did not

4 Participant feedback relating to acceptability and usability of the digital suicide prevention functionality*

| Item | Number (%) | | |
|--|--------------|---|----------|
| | Young people | Supportive other or health professional | Total† |
| Number of participants | 45 | 45 | 87 |
| Do you think this functionality is useful/helpful for young people with mental health concerns? | | | |
| No | 0 | 0 | 0 |
| Maybe | 2 (4%) | 6 (13%) | 8 (9%) |
| Yes | 43 (96%) | 39 (87%) | 79 (91%) |
| Median | Yes | Yes | Yes |
| If you were experiencing distress, how likely would you be to use this functionality? (overall median = 4) | | | |
| 1 — not at all | 0 | 2 (4%) | 2 (2%) |
| 2 | 1 (2%) | 1 (2%) | 2 (2%) |
| 3 — maybe | 17 (38%) | 23 (51%) | 39 (45%) |
| 4 | 17 (38%) | 10 (22%) | 26 (30%) |
| 5 — very likely | 10 (22%) | 9 (20%) | 18 (21%) |
| Median | 4 | 3 | 4 |
| And, if a friend or family member was experiencing distress, how likely would you be to refer them to this functionality? (overall median = 4) | | | |
| 1 — not at all | 0 | 0 | 0 |
| 2 | 0 | 2 (4%) | 3 (3%) |
| 3 — maybe | 10 (22%) | 7 (16%) | 15 (17%) |
| 4 | 14 (31%) | 15 (33%) | 28 (32%) |
| 5 — very likely | 21 (47%) | 21 (47%) | 41 (47%) |
| Median | 4 | 4 | 4 |
| Star rating (overall median = 4) | | | |
| 1 star — one of the worst tools I've used | 0 | 0 | 0 |
| 2 stars | 0 | 0 | 0 |
| 3 stars — average | 8 (18%) | 6 (13%) | 14 (16%) |
| 4 stars | 23 (51%) | 31 (69%) | 52 (60%) |
| 5 stars — one of the best tools I've used | 14 (31%) | 7 (16%) | 21 (24%) |
| Median | 4 | 4 | 4 |

* Data are number (%) unless otherwise indicated. † Participants could belong to more than one group (ie, young person, supportive other or health professional). ◆

test whether any measurable changes resulted from its use. Indeed, participants only had access to the functionality for viewing and feedback purposes, so they could not directly trial its use. Larger scale studies are needed to understand more about the efficacy of the co-designed digital suicide

prevention functionality, in both community settings and mental health service settings.

Finally, the rant feature (which was co-designed by participants) was the most divisive component. It was more popular with young people than with supportive others and health professionals. Further exploration of this feature's efficacy and safety is needed before it can potentially be included as part of the digital suicide prevention functionality. While the idea would be to support the rant feature with machine learning using natural language processing and generation tools,¹⁷ another study by our research group that was focused on systematic assessment has demonstrated how the use of new and emerging technologies

employing escalation algorithms can facilitate access to mental health services for help-seeking young people presenting with suicidality.¹²

Conclusion

Ultimately, our co-designed digital suicide prevention functionality was rated as highly acceptable and usable by end users. The high acceptability demonstrates the value of involving users (in this case, young people, supportive others and health professionals) from project conception, and supports recommendations that such involvement constitutes best practice.¹⁹

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Supporting Information

Additional Supporting Information is included with the online version of this article.

Chapter 6

Study 4: Implementation study of a prototypic e-clinic being integrated into youth mental health services: staff experiences and reported service quality improvements

Shane P Cross¹, Sarah E Piper¹, Tracey A Davenport¹, Alyssa C Milton¹, Frank Iorfino¹, Cristina S Ricci¹, Laura Ospina-Pinillos^{1,2}, Lisa Whittle¹, Ian B Hickie¹

Improving access to, and the quality of, mental health services through the use of health information technologies was highlighted as a key strategic recommendation in the 2014 report of the National Review of Mental Health Programmes and Services by the National Mental Health Commission.¹ More specifically, the Commission called for an overhaul of the Australian mental health system, including an integration of e-mental health into face-to-face services.

While an enormous body of literature regarding digital mental health services exists, both nationally (eg, eheadspace, Mental Health Online, MindSpot Clinic) and internationally (eg, Babylon, PlusGuidance, BetterHelp, Talkspace), these services are almost all stand-alone clinics.² The successful implementation of health information technologies into face-to-face services, however, has the potential to vastly improve traditional service quality.³ For example, the use of health information technologies before initial clinical assessment may reduce service entry wait times, especially for those with complex needs,⁴ and can go some way to addressing youth mental health service capacity constraints.⁵ Although access to these services is rising,^{5,6} many young people enter care for the first time with significant functional disability and symptomatic distress,^{7,8} and those with higher needs at entry tend to have poorer outcomes at exit.^{7,9} Health information technologies hold promise to improve clinical outcomes by enhancing access to more appropriate and timely care for those with chronic and enduring health conditions.³

While research regarding the engagement, efficacy and effectiveness of health information technologies is growing, there is currently little research into the implementation of technology-enabled solutions into existing mental health care settings.¹⁰ As with general health care settings, it is crucial that research aims to recognise and understand barriers to and facilitators of implementation. Research must also aim to devise strategies for improving widespread and effective uptake of health information technologies, and promoting their ongoing use.¹¹ Broadly, implementation barriers can be split into clinician (or health professional) factors and service factors.

Clinician factors

Research has shown that almost all young Australians aged 16–24 years (99%) are online, with 60% using the internet to find

information relating to mental health.¹² In contrast, use of online services in mental health clinics has been acknowledged as a challenge to the professional attitudes and values of some health professionals. For example, health professionals may feel unable to trust online service capability,^{13,14} they have questioned the effects of technology on establishing and maintaining therapeutic relationships,¹⁵ and they have raised concerns about being able to manage or allay consumer confidentiality and privacy concerns.^{14,16}

Recently, a review of the youth mental health workforce found that health professionals consider the assessment and management of risk and safety issues to be critically important and expressed concerns regarding the ability of technology to accurately assess, interpret or communicate such issues back to consumers.^{13,17} In situations where doubts about the appropriateness of technology have been expressed by health professionals (eg, regarding the clinical applicability and utility of technology), this influences their engagement with the technology.¹⁷ Consumer factors such as age, personal attitudes and prior use of technology also influence health professionals' perceptions regarding use of technology in service.¹³ Education and training of staff that addresses such concerns and perceptions, and emphasises the benefits and utility for consumers and clinicians, is therefore an important component of implementation.¹⁷

Service factors

Several service-level implementation barriers have been identified. These include an increase in financial and time constraints, the divergent needs of multiple stakeholders and the level of local leadership.^{14,16} Leadership has been recognised as important in creating the culture and climate for implementing service innovation and evidence-based practice.^{18,19} Advocates have been referred to as "champions", and their key role in supporting implementation has been highlighted.¹⁴ More broadly, congruence of strategy across multiple organisational levels of leadership (corporate, government and unit level) has been cited as a facilitator of implementation.²⁰ Barriers related to a lack of organisational support and official expectations regarding use of technology have also been highlighted as key influences on implementation in practice.¹⁷ In addition, the importance of building relationships and effective communication in supporting partnerships between health professionals and researchers has been emphasised.²¹

¹ Brain and Mind Centre, University of Sydney, Sydney, NSW. ² Department of Psychiatry and Mental Health, School of Medicine, Pontificia Universidad Javeriana, Bogota, Colombia.

Prototypic mental health e-clinic

A prototypic mental health e-clinic was co-designed with young people, health professionals and researchers.^{22,23} It aimed to deliver best practice clinical services online to young people experiencing mental health problems. The content (including the questionnaires used) and initial testing of its assessment functionality has been reported previously.²⁴ In summary, the prototype offers an online self-report assessment across a range of health domains (eg, overall health, mental health, everyday function, suicidal thoughts and behaviour, and social connectedness) that can be completed at any time on any smart device (including computers). The results of the assessment are summarised and made immediately available via a “dashboard of results” to both the young person and their health professional(s) via the service provider. The dashboard provides a multidimensional profile of the young person’s health and wellbeing that in turn facilitates person-centred care, self-management, early intervention, shared decision making and routine outcome monitoring.²⁵ Importantly, the online dashboard is based on a clinical staging model which has been validated in a youth mental health service setting.^{24,26} Clinical staging is a refinement to traditional diagnostic practice which allows health professionals to provide more personalised and responsive care for consumers who present with mild, sub-threshold or full-threshold severe disorders.^{7,27}

The aim of this study was to identify health professional and service-level facilitators of and barriers to implementation of the prototypic mental health e-clinic integrated into five youth mental health services. It also reviewed service quality improvements as reported by staff and observed by researchers during implementation into existing service models and clinical pathways.

Methods

Setting

The prototype was integrated into five headspace centres in the Central and Eastern Sydney Primary Health Network: Ashfield, Bondi Junction, Camperdown, Hurstville and Miranda. Formerly known as the National Youth Mental Health Foundation, headspace provides early intervention mental health services to 12–25-year-olds in Australia, along with assistance relating to employment and education, use of alcohol and other substances, and physical health.²⁸

Sampling strategy

Staff from the five headspace centres were invited to participate in the study, and those who gave consent for participation were provided with a comprehensive education and training program that included modules on how to use the prototype plus the clinical and service elements of the prototype (Supporting Information, chapter 6, table 1). Two implementation officers were employed to provide regular and ongoing “on-the-ground” support to each headspace centre, to address implementation concerns and to collect in-situ feedback on the use of the prototype during attendance at multidisciplinary team review meetings and staff workshops.

Participating staff invited young people to use the prototype when they first entered the service. Young people who gave consent for participation were sent an invitation to the prototype, where they created an account and completed the online assessment. As described above, their results were then immediately available via a dashboard of results.

This research was approved by the Sydney Local Health District Human Research Ethics Committee (Protocol No. X16-0297; HREC/16/RPAH/380).

Participants

Forty staff across the five centres participated, including youth access clinicians (allied health professionals), mental health nurses, psychiatrists, general practitioners, service managers, and reception and administration staff. With regards to young people, 671 consented to participate, of whom 549 used the prototype as part of their care.

Data collection

Quantitative data collected consisted of demographic, clinical and behavioural characteristics of the young people who used the prototype. Responses to staff surveys about the usefulness and accuracy of the dashboard of results were also collected.

Qualitative data relating to implementation experience were also collected. These included quotes and feedback from participating staff during initial and ongoing education and training sessions, multidisciplinary team review meetings and staff workshops, as well as observations made by implementation officers when they were providing on-the-ground support.

Data analysis

Descriptive and frequency data were prepared for all quantitative data using SPSS, version 22 (IBM Corporation). Basic qualitative coding was carried out using NVivo 10 software (QSR International). For the qualitative analysis, a form of inductive and thematic coding²⁹ was applied to a variety of resources such as notes from education and training sessions and staff workshops, as well as implementation officer observations of clinical processes. Coders reviewed resources and noted relevant concepts in the applicable individual’s own words. Key concepts were then reviewed across all resources and an initial coding framework was developed. The information was coded in NVivo 10 using this framework. Importantly, the coding followed an iterative process of reading, coding, and discussing the patterns and content of coded data. Similarities and differences in opinion were examined, and differences were discussed until consensus was reached, which is a common analysis method in mental health qualitative service evaluation research.^{30,31}

Results

Quantitative data

The mean age of young people using the prototype was 20 years (SD, 2.6 years), and two-thirds (67% [366 participants]) were female. Most (57% [313]) reported severe levels of psychological distress on the Kessler Psychological Distress Scale,³² and 40% (219) had moderate or greater psychosocial impairment on the self-report Social and Occupational Functioning Assessment Scale.³³ More than half (51% [280]) completed the online assessment outside of service opening hours (5pm–9am), with the mean time to complete it being 42 minutes (SD, 12.8 minutes).

Staff evaluation ratings of the prototype’s dashboard of results showed that most agreed that it was useful and accurate. Specifically, results from 117 separate surveys from staff indicated that 52% (57 staff) “agreed” or “strongly agreed” that the

dashboard was useful, while 27% (32) “neither agreed or disagreed”, 19% (21) “disagreed” or “strongly disagreed”, and the remaining 6% (7) did not answer the question. In addition, 64% of staff (70) “agreed” or “strongly agreed” that the dashboard was an accurate representation of their young person consumer at the time of completion, while 19% (23) “neither agreed or disagreed”, 16% (17) “disagreed” or “strongly disagreed”, and the remaining 6% (7) did not answer the question.

Qualitative data

Implementation facilitators and barriers. Implementing a prototypic mental health e-clinic into existing service models and clinical pathways at participating headspace centres provided an opportunity to understand the factors that acted as facilitators and barriers. Facilitators, which ultimately aided the implementation of the prototype into each centre, related to the organisational approach to implementation and the factors which supported this process (Box). Nearly twice as many facilitators of implementation were reported compared with barriers to implementation. The barriers theme did not include recommendations of suggested improvements to the mental health e-clinic prototype, which we collated elsewhere – rather, the facilitator and barrier themes focused on service implementation.

Service quality improvements. Several observed service quality improvements were reported as a result of the implementation: reduction in duration of face-to-face assessment; earlier response to risk; efficiency of senior health professional-supported treatment planning; and real-time assessment feedback and immediate provision of clinical resources. Qualitative data collected while implementation officers were providing on-the-ground support were gathered from centre staff. Summaries are presented here according to each observed service quality improvement.

Reduction in duration of face-to-face assessment. Staff who engaged with a young person’s dashboard before their initial face-to-face assessment reported a reduction in overall assessment time. They reported that the dashboard provided a “guide” or “enhancement” to their face-to-face assessment and enabled them to quickly provide basic intervention strategies for issues that the dashboard had categorised as being of possible or probable concern. However, trust was an important factor in this process, and this was particularly evident in the early phases of implementation. For example, it was reported in the early stages of implementation that some staff were “still doing a full face-to-face assessment, due to their distrust of the dashboard” (source: headspace centre meeting notes, February 2017).

Earlier response to risk. Online assessment identified risk and safety issues earlier, and the use of our suicide escalation protocol³⁴ enabled staff to respond to identified risk faster. Every dashboard generated by a young person completing the online assessment that indicated high suicidality (≥ 21 on the Suicidal Ideation Attributes Scale)³⁵ was escalated and reviewed by staff before the young person’s face-to-face appointment. Escalation due to reporting of high suicidality in the online assessment occurred for 82 young people (16%). Access to the young person’s dashboard before their face-to-face assessment with a health professional enabled earlier detection of suicidality and follow-up. Staff subsequently liaised internally to determine an appropriate response via a follow-up phone call or by bringing forward the young person’s face-to-face appointment. Further, the dashboard was generated immediately after the young person completed the online assessment, so it provided the young

person with suggestions of face-to-face, online and telephone resources to support their identified needs. The introduction of our suicide escalation protocol,³⁴ and the subsequent changes in processes made by services to respond to risk, was reported by staff as enabling faster and more efficient responses to young people at risk of suicide.

Efficiency of senior health professional-supported treatment planning. In one headspace centre, dashboards were used regularly in multidisciplinary team review meetings. The summary results for each young person were projected onto a screen to enable discussion with senior health professionals. Previous team-based review processes relied on verbal summaries provided by youth access clinicians. Several occasions were observed whereby a senior health professional provided clinical advice to a youth access clinician to take more immediate action regarding features of risk or acuity. Although there was one occasion where staff suggested that young people may “under-report online” (source: implementation officer feedback), there were more frequent occasions where young people disclosed information in their online assessment that they did not disclose in their face-to-face assessment. In the latter cases, the online disclosure facilitated further discussion with health professionals. The staff who were fully using the prototype to complement their clinical review process reported that it resulted in more thorough and accurate decision making that was based on data and combined with clinical expertise, thus minimising variability in the provision of care. Headspace centres that had greater trust in the prototypic mental health e-clinic, and had a more evident culture of innovation stemming from their leadership team, were earlier adopters of this method of combining data to inform decision making.

Real-time assessment feedback and immediate provision of clinical resources. The dashboard and recommended resources were made available to the young person as soon as the online assessment was completed, which was often 2–4 weeks before their first face-to-face appointment with a health professional. In addition to the in-centre care provided, the provision of online resources (apps, e-tools, fact sheets, breathing and mindfulness videos, tips and advice) and the dashboard of results offered more immediate support, particularly outside of service opening hours. Staff reported that some young people felt empowered by receiving their dashboard and the online resources, and subsequently requested no additional care from the service. At one headspace centre, a health professional reported that a young person who had recently completed an online assessment felt “empowered by the assessment and was able to make some changes in their life in accordance with the information they received in their dashboard”. Further, after discussing results from the dashboard in their initial face-to-face assessment, the young person “reported not to need further counselling after that due to being able to make the changes necessary for their wellness”. Applied more broadly, such instances may result in a reduction in wait times, and provide those with milder concerns the option of receiving appropriate care outside the restrictions of a face-to-face service. However, it is important to acknowledge that this implementation process took time to integrate into the centres due to the prototypic nature of the mental health e-clinic. The iterative co-design processes allowed for continuous improvement of the prototype. For example, multiple health professionals reported that the early version of the initial assessment was “too long” for some young people (source: implementation officer feedback). This feedback led to streamlining of the initial assessment.

Observed facilitators of and barriers to implementation of a prototypic mental health e-clinic into headspace centres

| | Illustrative quote | Sub-themes |
|---|---|---|
| Observed facilitators | | |
| Leadership support | "Leadership presence within clinical meetings helped with the utilisation of the [prototype]" (source: implementation officer log, January 2017) | <ul style="list-style-type: none"> High-level endorsement and coordination support by the Central and Eastern Sydney Primary Health Network Leadership present during initial education and training General commitment, support and advocacy by leadership in all meetings Presence and engagement by leadership to assist staff to solve clinical and implementation challenges Effective communication and engagement between leadership and implementation officers to support the implementation |
| Co-design | "The feedback received from headspace clinicians regarding the dashboard has been valuable, and each piece of feedback has been documented to further improve and inform the build of the [prototype]" (source: headspace centre communication circular, October 2017) | <ul style="list-style-type: none"> Staff were involved in the co-design of the prototype and resultant service model and clinical pathway changes from the outset Ongoing feedback from staff regarding prototype improvements that resulted in tangible changes to the technology |
| Technology-implemented service models and clinical pathways | "We did implement a staging model, we used to do reviews ourselves. Bring young people in every three months and meet with clinician. Did it every three months, but there was a lot of paperwork, following ... chasing ... Most of the time you weren't getting everyone there every three months. If it was all technology based, it would take away that clunkiness, it would allow for better indicators as to whether a person has improved or they are deteriorating. If we can get something that can do that, that would reduce a hell of a lot of time. And get us to do our other clinical work." (source: staff feedback, January 2017) | <ul style="list-style-type: none"> Online self-report assessment was introduced to each young person as an option at first contact before a face-to-face clinical assessment Young person's dashboard of results was used before and during the initial intake appointment Young person's initial dashboard of results was reviewed in multidisciplinary team review meetings, to assist with triage, shared decision making and routine outcome monitoring Service models and clinical pathways were altered to allow for the benefits of the prototype to be realised |
| Culture of innovation | "When the research culture is supported by the leadership team it is helping the engagement with the study, but if there is a lack of clarity regarding the centre's research capacity it is resulting in a less clear integration of the [prototype]" (source: implementation officer log, January 2017) | <ul style="list-style-type: none"> Culture of research and desire for quality improvement evident in the service and reinforced by leadership team |
| On-the-ground support | "Discussed ideas with the team about how to assist with this, and decided ... [implementation officer] to attend a clinical review meeting once/fortnight." (source: headspace centre meeting notes, February 2017) | <ul style="list-style-type: none"> Implementation officers employed to provide firsthand on-the-ground support at each centre, including: provision of education and training; collection of quantitative and qualitative staff feedback; and problem solving to address centre-specific issues |
| Centre-specific education and training | "Follow up training focus is on centre-specific aspects of delivery... we are working with clinical staff to respond to centre-specific issues" (source: implementation officer log, January 2017) | <ul style="list-style-type: none"> Education and training provided in relation to digital, clinical and service elements of the prototype to optimise effective engagement with all stakeholders at each centre with follow-up centre-specific and/or needs-based sessions provided as necessary (eg, due to staff turnover) Centre-specific education and training resources tailored to centre needs, including handbooks and online demonstration videos |
| Recognition of benefit of prototype | "Treatment is an hour a week, what happens rest of the time? Having technology helps them throughout the rest of their life. If you can stay connected to service, without having to be engaged in full on therapy, it improves the outcome" (source: staff feedback, January 2017) | <ul style="list-style-type: none"> Leadership and staff recognised the benefit of technology-enabled assessment and follow-up for young people Endorsement of technology-enabled assessment by health professionals, with prior experience of using technology in clinical practice |
| Observed barriers | | |
| Limited service capacity | "Well established headspace centres appeared more able to integrate the [prototype]" (source: implementation officer log, January 2017) | <ul style="list-style-type: none"> Limited staff numbers and high staff turnover (especially of those performing intake functions), affected young person recruitment numbers and capacity to maintain the implementation Staff experienced tension between already established work demands and the introduction of new technology-related processes and tasks |

Continues

Continued

| | Illustrative quote | Sub-themes |
|--|---|--|
| Variation in timing of offering an online self-report assessment | "Centres that offer the study prior to intake (vs after a phone intake) have higher recruitment. This might be because there is more incentive for the young person to engage with it. Especially as longer waiting lists means that the [prototype] is used by a young person during this interim." (source: implementation officer log, January 2017) "You have a limited number of sessions ... Having the ability to access information from home, rather than them having to travel 30 mins to an hour on the bus" (source: staff feedback, January 2017) | <ul style="list-style-type: none"> • Introduction of the option to complete an online self-report assessment after a young person had undertaken an intake assessment (over the phone or face-to-face) resulted in lower recruitment numbers compared with introducing the prototype before an intake assessment |
| Perceptions and beliefs of technology | "Clinicians are looking at the dashboard, but are still doing a full face-to-face assessment, due to their distrust of the dashboard" (source: headspace centre meeting notes, February 2017) | <ul style="list-style-type: none"> • Staff with expectations of the functionality and capacity of the prototype in a clinical setting beyond its current capability, and related misunderstanding of the limitations (cost and time) of technology design and development • Staff with negative attitudes towards incorporating the prototype into their practice • Concerns about technology replacing clinical care • Staff with a distrust of the prototype's accuracy were less likely to engage with the technology |

Discussion

This study provided initial evidence on factors supporting successful implementation of health information technologies in youth mental health services, as well as the effects on service quality for young people accessing these services. Consistent with findings from previous implementation research,²⁰ engagement of both levels of leadership (local service level and higher commissioning level at the Primary Health Network) and their involvement in co-design greatly facilitated successful implementation into established service models and clinical pathways. Where service leaders and staff engaged early and actively in the implementation of the prototypic mental health e-clinic at their centre (including active communication with on-the-ground implementation officers), greater service integration occurred, and higher levels of centre-specific recruitment were observed. However, two key barriers to implementation were observed — a lack of internal organisational support and direction regarding use of the prototype in service delivery, and variation in the ability of leaders at various levels to promote and integrate the prototype into existing service models and clinical pathways. In addition, under-staffing and high staff turnover resulted in broader service disruption, which had flow-on effects relating to how the prototype was implemented.

The importance of ongoing co-design with young people and health professionals, as well as supportive others and service staff, was evident. Our research process allowed for such feedback to inform the continued co-development of the prototype, and progressive changes to the technology were made based on this iterative process. Negative feedback about the usefulness and accuracy of the prototype that was obtained at the beginning of the study was used to improve the technology. These improvements included: replacing clinical language with consumer-friendly plain language; adding to and clarifying existing clinical information to improve usability; and transferring critical clinical information into the service's electronic medical records.

The importance of leadership support for implementation was also highlighted in the study. Leadership support is essential for the successful implementation of technology into services and can enable a culture and climate of service innovation.^{18–20}

Leaders are required to take an active role in the process by engaging with staff and maintaining a consistent and integrated service approach to using the technology. Strategies for future implementation must include emphasis on a top-down approach with service management at initial implementation (primarily to engage and drive change from a senior level) in parallel with a bottom-up approach that involves staff and consumers at each stage of the process.

Ongoing education and training of all staff, and a culture of continuous staff feedback regarding prototype improvements, was also observed to be critical to implementation success. A mix of team-based learning and feedback, individual health professional support and feedback from implementation officers proved to be beneficial. In addition to the initial education and training provided, it was clear that ongoing education and training at group and individual levels was vitally important for successful implementation. Where common needs were identified, group-level education and training was provided. Where individual-level concerns were uncovered (eg, individual health professionals lacking familiarity with technology in general or holding negative beliefs about the prototype), these were often best addressed through one-on-one support sessions. Follow-up staff workshops also served as an opportunity to demonstrate that previously reported feedback about the prototype was prioritised and resulted in tangible changes to the technology.

These preliminary findings indicate that health information technologies can have a positive effect on mental health service delivery. Broadly, the prototype appeared to have positive effects on service efficiency, access to service, response to risk and collaborative care. Safety was greatly enhanced via the use of a suicide escalation protocol,³⁴ collaboration was improved via technology-enabled team-based treatment planning, and greater efficiencies were observed in terms of quicker access to assessment feedback for young people and more effective use of time in face-to-face intake assessments.

The most positive effect of implementing the prototype appeared to be its impact on access to care. Despite adhering to one overarching framework for youth mental health service delivery,²⁸ significant variations in service models and clinical pathways existed between the five headspace centres. In some centres, access

to care was facilitated quickly by well trained reception staff who directly booked an initial appointment with a health professional, whereas other services required young people to engage in multiple phone calls and assessments before accessing face-to-face care. The time taken and the number of discrete steps, between seeking help and receiving a clinically informed treatment plan, varied significantly between centres. There was preliminary evidence that use of the prototype, as close as possible to a young person's request for help, resulted in reduced wait times and fewer transactional steps for the young person to obtain an initial treatment plan. Resource limitations may continue to result in considerable wait times for face-to-face mental health services. However, the study showed that innovative health information technologies can go some way to improving efficiency for young people, health professionals and youth mental health services.

Limitations

The study was limited by its use of qualitative rather than quantitative data to report on service quality improvements.

The qualitative feedback was collected through multiple channels and, although we applied standard qualitative analytic techniques, the data collection process was not in the form of a structured qualitative interview. Future research should seek to quantify metrics of service quality (Chapter 7) and compare them with a control condition to assess the direct impact of health information technologies on service quality. The findings are also limited to staff and young people who consented to participate in the study. We are yet to see how these findings would generalise to all staff and young people in a full implementation.

Conclusion

Future research should aim to use these significant implementation and service quality improvement findings, and apply them more broadly to other settings and populations. It should focus on how health information technologies can be used to improve service quality for all consumers.

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Supplement

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Supporting Information

Additional Supporting Information is included with the online version of this article.

Participatory design of an activities based collective mentoring program in after school care settings: The Connect Promote and Protect Program (CP3)

Alyssa C Milton^{1*}, Elizabeth Stewart¹, Laura Ospina Pinillos¹, Tracey A Davenport¹, Ian B Hickie¹

¹ Brain and Mind Centre, The University of Sydney, NSW, Australia.

*Corresponding Author

Address: Brain and Mind Centre, The University of Sydney, 88 Mallet Street, Camperdown, NSW 2050, Australia

Email: alyssa.milton@sydney.edu.au

Telephone: +61 2 86276947

ORCID: [0000-0002-4326-0123](https://orcid.org/0000-0002-4326-0123)

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Abstract

Out of school hours care (OSHC) services provide a unique opportunity to deliver early-intervention programs to enhance primary-school age children's social, emotional, physical and cognitive wellbeing, yet such programs are currently lacking. The study employed methods of participatory design, user (acceptance) testing and iterative knowledge translation to develop a novel wellbeing program framework – the Connect, Promote and Protect Program (CP3) – with key stakeholders (e.g. OSHC staff, volunteers, families, clinicians, educators and researchers). Thematic techniques were used to interpret and translate qualitative information obtained during the research and design cycle. The co-design process generated the CP3 model, which comprises a group-based mentoring approach to facilitate enhanced activities in OSHC settings. Activities are underpinned by four key principles of program delivery: (1) *Build Wellbeing & Resilience*; (2) *Broaden Horizons*; (3) *Inspire & Engage*; and (4) *Connect Communities*. To our knowledge, the CP3 program is the first co-designed wellbeing program developed specifically for OSHC services.

Background

In the most recent report by the Australian Early Development Census (AEDC), an alarming 22% of primary school age children were found to be vulnerable to experiencing a developmental delay in one or more areas of functioning (Department of Education and Training, 2016). This included delays in social competence, emotional maturity, language and cognitive skills, communication and general knowledge, and/or physical health and wellbeing (Department of Education and Training, 2016). These concerning rates of developmental vulnerability are reflected in other Organisation for Economic Co-operation and Development (OECD) countries, and have sparked international discussions into how governments, educators, individuals and communities can work together to minimize risk of developmental vulnerability, and maximize the likelihood that all children have the best chance of a positive early start (OECD, 2017). A key focus area that has arisen is the importance of utilizing existing educational structures to optimize the environments in which children learn and grow (OECD, 2017). This includes broadening the scope of educational curriculums to include programs that target children's health and wellbeing, and importantly, delivering programs not only in formal school hours but also in before and after school care (OECD, 2011).

Out of school hours care (OSHC) services offer a safe and supervised environment for primary school aged children before and after school. These centres provide a vital service for many families by enabling parents/ caregivers to achieve a balance between childcare, social responsibilities and work (Hand & Baxter, 2013). In addition to their practical benefits, OSHC offers a unique opportunity to implement programs designed to enhance children's health and wellbeing in a multi-dimensional way – including socially, emotionally, physically and cognitively (Winefield et al., 2011). Despite their potential, OSHCs too often function as supervised childcare facilities, resulting in a missed opportunity to implement prevention and early intervention programs (Blau & Currie, 2006). As such, there has been increased attention from researchers, educators, government, and the broader community into how out-of-hours school time can be better utilized to support children's learning and growth.

There is currently a dearth of literature into how health and wellbeing programs for primary school age children can be developed, implemented and evaluated in OSHC settings. While numerous programs have been developed to target adolescent groups (Britner & Randall, 2014), far less research has been conducted examining health and wellbeing programs to support children in the primary school years (aged 5-11 years),

aptly named the ‘in-betweeners’ as they fall in between the toddler and post-pubertal groups (Jung Jr, 1967). Programs developed for these ‘in-betweeners’ have been overwhelmingly skewed towards physical health and nutrition (Spittle, O’Meara, Garnham, & Kerr, 2008; Thompson, Cooper, Flanagan, Crawford, & Worsley, 2006), and while interventions targeting healthy eating and physical activity are undoubtedly beneficial, they fail to consider children’s health more holistically. Moreover, many existing programs have tended to be highly specific and non-generalisable, providing limited scope beyond implementation of the program itself (Kien & Chiodo, 2003; Story et al., 2003). Such programs at this age are critical as experiences from early to middle childhood, including a child’s environment and relationships, shape their brain development and lay the foundations for their future social, emotional, cognitive and physical wellbeing (Berry & O’Connor, 2010; Farah et al., 2006; McHale, Dariotis, & Kauh, 2003). Disruptions in this developmental process can have long-term impacts, affecting the way children learn and interact with others (Humphreys & Zeanah, 2015).

In OSHC services, the provision of high-quality programming, characterized by positive staff–child relationships, a variety of enrichment activities, and student choice and input into program activities has been positively associated with children’s engagement and motivation (Eccles & Gootman, 2002; Grossman, Campbell, & Raley, 2007; Mahoney, Parente, & Lord, 2007), as well as their cognitive and social outcomes (Vandell et al., 2005). The presence of appropriately trained staff and out-of-school coordinators to assist with professional development and networking are other factors that have been related to OSHC quality (Simoncini & Lasen, 2012). Given that OSHC services differ in geographic location, expertise of staff, and the characteristics and number of children who attend, programs that are suitable for one OSHC service may not be feasible or appropriate for another. As such, providing a model that allows OSHC programs to be individually tailored to meet the needs and preferences of children and their families, the skillset of staff, and broader ethos and goals of the community is critical.

At present, there are no clear models in the literature detailing how wellbeing-focused programs, including appropriate mentorship and program development, can be developed and delivered in OSHC settings. As such, there is an urgent need to develop an evidence-based framework to guide staff, educators, community members and other key stakeholders who are responsible for the delivery of wellbeing-focused programs to children in the primary school years. In order to develop a program framework that best meets the needs of the community and service, the involvement of key stakeholders (e.g. children, parents/ caregivers, staff, volunteers,

educators, clinicians, community members) in the co-design and evaluation of the intervention is critical (Winefield et al., 2011).

One way to develop this above-mentioned model is through the use of participatory design (PD), also known as co-design, research methods, in which stakeholders are placed at the centre of the design process (Ospina-Pinillos et al., 2018; Sjöberg & Timpka, 1998). Often used in designing digital technologies, PD is part of a paradigm shift towards collaborative bottom-up engagement, whereby stakeholders jointly explore and create solutions to program design and service delivery. The PD process involves a series of iterative design cycles in which all stakeholders contribute their knowledge to produce a program model (Muller & Kuhn, 1993; Ospina-Pinillos et al., 2018). The ideas generated within each cycle are discussed, evaluated and built-upon during subsequent design stages. Importantly, all stakeholders participate in each development cycle (Sjöberg & Timpka, 1998), as they share equal responsibility with the research team for outcomes (Orlowski et al., 2015). This iterative research design cycle of development, feasibility, evaluation and implementation follows the Medical Research Council guidelines for developing complex interventions (Craig et al., 2008).

The primary aim of this study was to utilise a multidisciplinary collaboration between members of an OSHC community (e.g. staff, volunteers, parents/ caregivers), local community members (e.g. youth workers from local organisations, clinicians, educators) and researchers, to co-design a wellbeing program model for delivery in OSHC settings. The program has been termed the Connect, Promote and Protect Program (CP3).

Methods

This research was approved by the University of Sydney's Human Research Ethics Committee (Protocol Numbers: 2017/509 AND 2018/832).

Study Design

The study employed a prospective observational design including participatory design and user (acceptance) testing methodologies. The research and development (R&D) cycle was conducted in a series of stages, based on previously established processes by our research group (Mitchell et al., 2017; Ospina-Pinillos et al., 2018). The co-design and build of CP3 included several iterative stages that build upon each other (Figure 1). Stage 1 involved PD workshops and knowledge translation, whereby knowledge and ideas generated

during workshops were translated to produce an overarching CP3 program model (α model). In Stage 2, iterative user (acceptance) testing, via a naturalistic formative service evaluation of implementation, and further PD workshops were used to refine ideas generated in Stage 1 with a wider group of stakeholders associated with the OSHC (i.e. both adults and children); knowledge translation was then used to develop a comprehensive CP3 model (β model). Finally, in Stage 3 (which is not reported in this paper) a real world cluster randomized controlled trial (RCT) will be carried out. This paper focuses on Stages 1 and 2 with adult participants only, which took place prior to Stage 2 co-design with children who access the OSHC service and the Stage 3 program implementation.

[INSERT FIGURE 1 ABOUT HERE]

Participants

Adult participants were recruited from a community sample in the Illawarra NSW region between July 2017 to September 2018. Electronic and paper-based advertising materials were used to notify potential participants of the study. Passive snowballing through the networks of identified participants was also used to increase the participant pool (See (Biernacki & Waldorf, 1981)). Stage 1 participants comprised three main stakeholder groups: (1) parents/ guardians/ primary carers of primary school children; (2) volunteers or employees of the non-government organisation establishing the OSHC; and, (3) stakeholders such as local community members, supportive others, academics, educators and school personnel from the Illawarra region of NSW (where the program was to be established). Inclusion criteria were as follows: (i) identify as part of one of the main stakeholder groups; (ii) be able to participate in English; and (iii) provide written informed consent to participate in the research. In Stage 2, participation was extended to include children (aged 5 – 11 years old) accessing the OSHC service, in addition to the groups included in Stage 1, however, the data being generated with children is ongoing and will be reported elsewhere. Participants did not receive any compensation or reward for taking part in the workshops.

Participatory Design (PD) Workshops

A total of four, three-hour PD workshops were held at the OSHC where the program was to be established. The workshops were facilitated by a psychologist (AM), with support from a researcher with either experience in the OSHC sector or youth mental health (LOP, SP, RA, NA). A scribe was also present to take

detailed notes. Within each workshop, adult stakeholder backgrounds were intentionally mixed – meaning that parents/ guardians, volunteers or employees, and other community stakeholders all participated together. This mixed participant approach enriches the workshop discussion by drawing on a range of participant experiences, ultimately enhancing the overall program design solution. The workshop program consisted of a three phase agenda including discovery, evaluation and prototyping. In the discovery phase, stakeholders were involved in the design process by identifying local needs and issues and defining research objectives, strategies and goals. These discussions help to identify key issues and shape creative concepts and ideas for the program development and implementation. In the evaluation phase, stakeholders worked together to evaluate program ideas (whether they are ideas from external sources such as other programs or those generated in previous workshops) to understand how they might be improved and refined to fit the local program needs. In the prototyping phase, stakeholders collaborated to develop and refine content and work through implementation strategies to determine the optimal program design.

Workshop sessions applied an iterative knowledge translation process, so that preliminary ideas generated within earlier workshops were further developed (and fed back on) by participants in later workshops.

Data Analysis

Qualitative data sources (artefacts) from PD workshops included detailed notes from the scribe and notes written by participants on handouts, worksheets and surveys. All data were uploaded onto NVivo (version 11) software. Qualitative data were interpreted using previously established thematic techniques (Braun & Clarke, 2006) by two researchers (AM and NA). All qualitative data sources from the workshops and feedback surveys were reviewed by noting relevant points. Key concepts were subsequently analysed across all participants to develop an initial coding framework. Notes were then coded in NVivo (version 11) software (QSR International Pty Ltd., 2016) using this framework by two researchers per transcript. The coding followed an iterative process of reading, coding, and discussing the pattern and content of coded data. Similarities and differences in opinion were discussed until consensus was reached. An initial report was written for the knowledge translation team, who then established the CP3 model for user acceptance testing and evaluation. The knowledge translation process involves researchers working with stakeholders to synthesise, exchange, and apply knowledge to enhance systems and improve outcomes (Pablos-Mendez & Shademani, 2006).

Results

Sample Characteristics

In total, 28 participants took part across the initial three Stage 1 workshops during the August and September 2017 period, and a further six adult participants took part during 2018 (commencement of Stage 2). Demographic characteristics of participants are presented in Table 1 (See Supplementary File 1 for a full breakdown of participant characteristics for individual workshops).

[INSERT TABLE 1 ABOUT HERE]

CP3 Principles

Discovery of CP3 Principles

In the discovery phase, which focused on creating CP3 Principles, stakeholders chiefly identified program goals. Four key themes were generated, which related to: (1) enhancing wellbeing (*Build Wellbeing & Resilience*); (2) creating opportunities for development and growth (*Broaden Horizons*); (3) meaningfully engaging children (*Inspire & Engage*); and (4) promoting social and community connectedness (*Connect Communities*).

Workshop participants emphasized that CP3 should aim to enhance children's wellbeing in a multi-dimensional and holistic way. The multiple ideas generated relating to improving wellbeing were categorised into four key domains – social, emotional, physical and cognitive wellbeing (See Figure 2). Enhancing the child's social wellbeing was the most frequently referenced domain, followed by emotional wellbeing, cognitive wellbeing then physical wellbeing. Social wellbeing items included building communication and social skills, enhancing citizenship behaviours, promoting positive and supportive relationships, and feeling connected to the local community. The focus of emotional wellbeing related to building self-esteem, confidence, happiness, emotional health, resilience and coping skills. Cognitive wellbeing items chiefly related to problem solving and decision-making. Physical wellbeing items predominately focused on healthy eating, undertaking physical activity (indoor and outdoor), connecting with the environment, and understanding the benefits of healthy lifestyles.

[INSERT FIGURE 2 ABOUT HERE]

The theme relating to broadening the child's opportunities and skills by providing a diverse range of experiences that children might not generally have access to in their day-to-day lives was highlighted in all workshops. Participants emphasised that the activities on offer in CP3 should be enriching in that they help students broaden their horizons, develop new skills and contribute to their personal and social development.

The theme relating to meaningfully engaging children had a number of different areas of focus. Consistent themes raised in the workshops relating to the best approach to facilitating CP3 chiefly centred around flexibility and choice for the children. "...giving the children some freedom to choose what activities they enjoy" (OSHC Manager, Workshop 2) was viewed as important as it was reported to be "...nearly impossible to expect all children to engage in a controlled activity after a long day at school, especially if they are not interested in it" (OSHC Manager, Workshop 2). This flexibility included the children helping to provide input and co-design into what the activities program would look like.

"It would be great if the activities could be tailored to the child as much as possible and be child-led. Child input and choice is important as is flexibility in programming" (Community Member, Workshop 3).

Although the importance of social connection was also raised as part of the wellbeing component, participants in all workshops emphasised that enhancing social connectedness would be an important focus for CP3 as a distinct principle – not only for children accessing CP3, but also families connected to CP3, staff and volunteers delivering CP3, and the wider community. It was hypothesised that if the program could build social connectedness, it would also create more awareness, tolerance and understanding in the local communities through contact with others. The program would need to establish firm pathways to community resources (including people, organisations and online resources) for children, their families and the staff and volunteers delivering CP3. These community resources could range, for example, from skill development to mental health resources and services (such as counseling).

Prototyping the CP3 Principles

The prototyping stage led to the full formation of four key CP3 Principles and the definitions (presented in Table 2), which are underpinned by the existing the *My time Our Place Framework* (Department

of Education and Training, 2011) and the *National Quality Standards* (Department of Education and Training, 2009), which are described in detail Figure 5.

[INSERT TABLE 2 ABOUT HERE]

CP3 Core Program Features

Discovery

In the discovery phase relating to program design, stakeholders chiefly identified two key features of CP3: (1) group-based (collective) mentoring; and (2) the provision of enhanced activities.

Evaluation

In the iterative evaluation stage, the provision of a mentoring component forming part of CP3 was viewed as highly acceptable across all workshops. A number of participants also highlighted that the key differentiation between CP3 and regular OSHC programming would be this mentoring component, which would require considerable focus to establish and sustain into the future.

“The real point of difference of the program is the mentoring component, [we] need to capitalise on this and ensure that the program doesn’t just turn into another OSHC.” (Community Worker, Workshop 3)

The value of mentoring was also highlighted throughout the workshops.

“Including the mentoring component in the program might have positive impacts for the wider community, as it plants the seed for growth and can broaden perspectives.” (Community Member, Workshop 2)

The mentoring component was not only seen as beneficial to the children accessing the OSHC, but also was viewed as giving the mentors themselves skills, confidence, social connection and *“A feeling of ‘giving back’” (Mentoring benefits artefact, Workshop 3).*

Concerns were raised about child protection and an emphasis was placed on the need to ensure that the program uses *“...the right people in the right capacity” (Mentoring mind map artefact, Workshop 3).* It was the

prevailing view that such issues could be addressed through rigorous mentor recruitment, training, supervision, policies and procedures.

In all workshops, the suggestions generated by participants highlighted that the OSHC activities on offer in CP3 should be enriched and enhanced, especially when compared to regular OSHC services. The term created for this component by participants in early workshops was “*enhanced activities*” as they are “...*more than just extracurricular activities*” (Parent and community worker, Workshop 1), which was subsequently accepted and adopted in the later workshops. Enhanced activities were viewed as the vehicle for carrying out the CP3 Principle of *Broaden Horizons* – as the activities would be enriched, allow children to develop new skills, and contribute to their personal and social development. Some participants viewed this program component as particularly beneficial for the more vulnerable children who might access CP3.

“Enhanced activities would be wonderful. Especially as they can be completely out of reach for some young people.” (Parent and community worker, Workshop 1)

Enhanced activities were viewed as needing to be stimulating to ensure children were engaged and motivated to take part. This was directly related to the CP3 Principle of *inspire and engage* and went hand-in-hand with the mentoring component.

“The mentoring and activities should create a spark for the child.” (School Teacher, Workshop 3)

The overarching iterative feedback generated during the workshops were chiefly positive.

“This type of program could have huge benefits for wider community change as it sets out to make positive community connections – this can be powerful on a large scale and be a catalyst for huge community change.” (Community Worker, Workshop 3)

Prototyping

When prototyping the mentoring component design, participants developed a plan for group-based (collective) mentoring, otherwise defined as collective mentoring. Collective mentoring of children in group settings was viewed as more beneficial in an OSHC environment, as compared to one on one mentoring, as it addressed concerns relating to program acceptability, matching children with mentors, mentor recruitment and turnover, and this could easily run alongside general OSHC activities.

To enhance mentoring options for the children accessing OSHC, and ensure CP3 was not a “*..blanket one size fits all program...*” (*School Teacher, Workshop 3*), a three-level approach to mentoring was generated during workshop discussions. This included skill-based mentoring, CP3 mentoring and peer-to-peer mentoring. Skill-based mentoring meant that mentors with special skills would facilitate activities in their area of expertise. It was highlighted that these “*...mentors should be passionate about what they are teaching...*” (*School Teacher, Workshop 3*) to motivate, inspire and engage children in CP3. The second type of mentor identified was a “CP3 mentor”, trained in CP3 principles, and could provide support to the enhanced group-based activities as well as the OSHC’s day-to-day running. Peer-to-peer mentoring was also proposed as an additional avenue for CP3 to engage OSHC students to take on a leadership role – which reflected the *Inspire & Engage* CP3 Principle.

Specialised CP3 training – designed for both staff and volunteer mentors – was seen as crucial to the delivery of CP3. Prototyped areas of training included: vision and mission of CP3; mentoring processes and relationships; building emotional literacy; child development; working with special needs; managing challenging behaviours and situations; referral pathways and support; and, risk management and safety.

When prototyping the enhanced activity component, participants highlighted that implementation needed to avoid activities being delivered in a “*..piecemeal manner...*” (*Teacher, Workshop 1*). That is, there needed to be a coherent structure to the program, where activities link together to form a greater purpose of working towards the CP3 principles.

“The building blocks system or foundation as part of the program – where it’s not just one lesson and then move on will be important. It needs a framework that everyone is privy to.” (*Educator, Workshop 1*)

Based on this feedback, a CP3 Activity Development Guide was prototyped. This is a tool for selecting and designing the enhanced activities. It ensures that the staff and children think purposefully about programming so that it provides every opportunity to enhance the experience in terms of the CP3 Principles, the *My Time Our Place Framework* and the *National Quality Standards*. The tool also supports reflective practice and sharing of ideas. An example summary page from the CP3 Activity Development Guide is provided in Figure 3.

[INSERT FIGURE 3 ABOUT HERE]

Additional Program Features

Discovery

Two additional features of CP3 were identified which included the provision of one-on-one wellbeing support for children with greater needs and involving families meaningfully.

Evaluation and Prototyping

The idea generated by participants that CP3 could provide additional one-on-one psychological support for children with additional biopsychosocial needs, such as “*...if there was a grief issue or if there was a diagnosis that required further support...*” (Teacher, Workshop 1), received positive feedback when iteratively evaluated. Participants emphasised that if additional support were offered it would need to be carried out by a registered psychologist or other qualified health professional. The provision of such additional support was seen as particularly beneficial for prevention and early intervention of social, emotional, physical or cognitive difficulties.

Participants also recommended that “*...there needs to be a whole family approach...*” (Workshop 3, community member) for CP3 implementation. Ideas generated included CP3 “*...build[ing] the capacity of parents...*” (Parent and community worker, Workshop 1) which included developing a resource kit for parents, providing support pathways and “*...link[ing] parents with counselling services...*” (Community Worker, Workshop 2), “*...resources to support their children effectively...*” (Teacher, Workshop 3), such as “*...active parenting programs...*” (Teacher, Workshop 3), “*...positive parenting programs or circles of security...*” (Parent, Workshop 2). Providing clear communication channels such as a “*...feedback cycle between the child, families*

and school...” (CP3 Mindmap Artefact, Workshop 3), finding out “*..positives about their children through feedback from the program...*” (Parent program outcomes artefact, Workshop 2), telling parents “*..about the focus of the learnings...for example, we are going to talk about character and strength this week...*” (Community Member, Workshop 3) and creating a CP3 newsletter or social media page (eg. Facebook). Thirdly, building sense of community for parents such as providing a “*..chance to meet and interact with others of similar interests, problems etc. ...*” (Parent program outcomes artefact, Workshop 2) and having an “*...open day...*” (Community worker, Workshop 3).

Knowledge Translation

A staged approach to implementation was raised as a possibility in the workshops for the development and evaluation of CP3. In the knowledge translation stage, this idea was refined to three stages: CP3 Lite, CP3, and CP3 Plus (outlined in Figure 4). These stages are now being iteratively developed, delivered and evaluated through a formative evaluation process.

[INSERT FIGURE 4 ABOUT HERE]

CP3 Lite is the minimal viable product of CP3 (α build). This stage provides enhanced activities underpinned by the CP3 Principles (1. *Build Wellbeing & Resilience*; 2. *Broaden Horizons*; 3. *Inspire & Engage*, and; 4. *Connect Communities*) using the CP3 Activity Development Guide. This component is facilitated by OSHC educators and qualified community experts. Example excerpts from the CP3 activity planning process, which led to the establishment of the CP3 Activity Development Guide for training and trialing are presented in Figure 5.

[INSERT FIGURE 5 ABOUT HERE]

The next stage, which is currently under development, is the implementation of CP3 (see Figure 6) which is underpinned by the existing *My Time Our Place Framework* and the *National Quality Standards* that is used in OSHC services. When implemented, CP3 will include the facilitation of enhanced activities plus a fully developed collective mentoring component. This stage may also include a peer-to-peer support component, dependent on service evaluation outcomes and resourcing. This would initially include the development of a training package for CP3 volunteers to aid staff in facilitating CP3. The final stage, CP3 Plus, would provide enhanced activities and collective mentoring plus the additional family resource package and one-on-one support. Again, the development of this stage will be dependent on service evaluation outcomes and resourcing.

[INSERT FIGURE 6 ABOUT HERE]

Discussion

In this study, we used participatory design (or co-design) research methods to develop a novel health and wellbeing program for primary school aged children (5 to 12 years old) to be delivered in out of school hours care (OSHC): the Connect, Promote and Protect Program (CP3). To our knowledge, CP3 is the first health and wellbeing program model designed specifically for OSHC settings that allows tailored interventions to be developed depending on the unique needs and preferences of the end-users, including children, their parents/guardians, staff, volunteers and the broader community. CP3 adopts a holistic, community-focused approach, encouraging active participation of community members, peer-to-peer and adult-led mentoring, and interventions that not only focus on physical development, but also foster social, emotional and cognitive wellbeing. In this way, CP3 addresses the goals and objectives of the AEDC (2016) and OECD (2017) for early childhood education and care, which focus on building supportive environments and developing strengths-based programs to build children's competencies during the primary school years.

CP3 addresses a major gap in the literature and in the delivery of universal health and wellbeing programs in educational settings. Unlike existing OSHC programs, which have tended to be prescriptive, narrowly-focused and non-generalisable, CP3 offers a framework for flexible program development and delivery, while ensuring that a high standard of program development will be maintained. The four CP3 Principles co-designed during PD workshops (i.e. *Build Wellbeing & Resilience*; *Broaden Horizons*; *Inspire & Engage*; *Connect Communities*) ensure that goals of CP3 interventions can be clearly delineated. This is critical,

as one of the pitfalls in the implementation of new wellbeing programs is that they often fail to adhere to the core components of best practice and frequently do not utilise a program model (Rhodes, 2002; Sipe, 2002). Moreover, as highlighted in the MRC guidelines for developing complex interventions, the first step to developing novel interventions is identification or development of a theoretical model, which the current study has achieved (Craig et al., 2006). In addition, CP3 provides more specific guidance on essential program features, namely collective mentoring and enhanced activities. The involvement of mentors is a key point of difference between CP3 and existing OSHC programs, and promotes the CP3 Principle of *Connect Communities*. Currently, the available evidence in the literature indicates that for a program to be effective, it is necessary to follow best practices in recruiting, training, and providing ongoing support and supervision to mentors (DuBois, Holloway, Valentine, & Cooper, 2002; Sipe, 2002). These views were generated by participants in the PD workshops, particularly due to the importance of child protection when delivering the program. Such support for the mentors may also assist them to build and sustain their relationship with the OSHC over an extended time, as high staff turnover can negatively impact engagement (Cross, Gottfredson, Wilson, Rorie, & Connell, 2009).

CP3 has been designed to ensure universal access to a health and wellbeing focused program for all children, meaning equal opportunities and adequate fit regardless of socio-economic background, geographic location, community resources, goals and expertise of service providers, and preferences and needs of the community. One of the major advantages of CP3 is therefore its appropriateness and ability to be adapted for disadvantaged and vulnerable groups, such as children from low socio-economic backgrounds, geographically-isolated communities, Aboriginal and/or Torres Strait Islander people, and people from culturally and linguistically diverse groups. By placing communities at the centre of the design and development process, CP3 ensures that interventions will be culturally sensitive and relevant, will respect local knowledge and meaning, and will empower communities to take action by taking matters into their own hands. This community-based approach transitions power back to local communities, and is central to allowing communities, and subsequently their young people, to thrive.

Despite the goal of universal access and participation, research has shown that the simple introduction of a universal program does not in itself guarantee equal access or equal participation (Jones, 1992). Therefore, one of the mandates of the CP3 coordinator role is to assist families and communities with greater socio-

economic challenges to actively participate in both the design of the program and utilising OSHC services. This is important as research and evaluations of OSHC programs have found greater positive effects on outcomes for at-risk populations compared with more heterogeneous samples (Marshall et al., 1997; Scott-Little, Hamann, & Jurs, 2002). The success of the universal program approach to design and delivery will be further evaluated during the full program evaluation, which will take account of both service specific and external factors such as the Australian Government changes to parent activity testing and childcare subsidies introduced in 2018 (Department of Education and Training, 2018).

Strengths and limitations of the research

In designing the CP3 model, an iterative PD approach was employed that placed key stakeholders at the centre of the design and development process. This process of co-design and development will continue to be used as CP3 is implemented and evaluated in stages 2 and 3. Indeed, these co-design research methodologies are also embedded in the program design itself in the continuous process of re-evaluation and re-responding to the community needs as children and their community grow and change over time. For instance, the CP3 principles of community collaboration (*Connect Communities*) and meaningfully engaging children in the decision-making process (*Inspire & Engage*) emphasise the importance of engaging end-users at all stages of the intervention development process. Children themselves form part of the co-design process, however this research is still underway as it forms part of the evaluation and thus will be reported elsewhere. This co-design and collaborative management means the OSHC can be delivered according to the communities strengths, while ensuring a level of program consistency is maintained. Despite these benefits, use of PD methods also carries challenges. PD takes considerable time and commitment from OSHC staff, researchers and the wider community. Academics simply designing a wellbeing program to be delivered and evaluated in an OSHC setting would certainly be less time-intensive; however, this would take away from the deep understanding and ability to respond to local community needs, which arguably leads to a better program.

Research suggests that health programs can take up to 17 years to move 14% of original research into actual service delivery (Balas & Boren, 2000). Here, however, the use of an ongoing formative evaluation process allows for the program design to be agile and actively respond to local needs as they arise over time. For example, when new opportunities arise (such as when mentors or staff with particular skills are recruited) additional enhanced activities can be designed using the CP3 Activity Development Guide that is guided by

CP3 Principles, the *My time Our Place Framework* (Department of Education and Training, 2011) and the *National Quality Standards* (Department of Education and Training, 2009). By using this approach the CP3 model can grow and be improved upon in real-time. This iterative design cycle of development, feasibility, evaluation and implementation follows recommendations by the MRC's newer guidelines for developing complex interventions (Craig et al., 2008).

Evaluation of CP3

The delivery and efficacy of CP3 is currently under evaluation. The evaluation stage of research is crucial as research suggests that many new mentoring programs are pursued without any supporting evidence from reliable or valid process or outcome evaluations (Rhodes, 2002; Sipe, 2002). Furthermore, research into what collective (group-based) mentoring with enhanced activities has not, to our knowledge, been investigated either within or outside of OSHC settings. Therefore, evaluation of outcomes will influence the proliferation of this type of program. Finally, one-on-one mentoring interventions that utilise evidence-based practices and provide the child with long-term, high quality relationships (as a stand alone one-on-one mentoring intervention or in combination with structured activities) can yield small but positive improvements on a range of psychosocial, health behavior and academic outcomes (DuBois, Portillo, Rhodes, Silverthorn, & Valentine, 2011; Rhodes, 2002; Sipe, 2002). However, lower quality one-on-one mentoring interventions can produce negative impacts on the child. Thus ensuring that CP3 applies high quality programming and has an evidence base is vital.

Formative evaluations of CP3 will occur during 2019 to 2020 and thus are yet to be fully reported. Further plans to measure the effectiveness of the CP3 model in a large-scale randomised controlled cluster trial are also being made. The major challenge is ensuring that engagement continues to be high when the research extends to new sites. As there is the possibility that the successful participatory design engagement is due to the nuances of the pilot OSHC community. For example, the pilot OSHC site was a brand new service, thus a focus on culture change to move away from a traditional OSHC model towards the CP3 was not required. The need for effective staff by-in and change management may be required when CP3 is introduced into already operational OSHC sites. Ultimately, the competence and capacity of the local facilitators will be crucial to successful implementation. This will be evaluated as CP3 is rolled-out further in already established OSHC sites.

Conclusions

To our knowledge, CP3 is the first co-designed health and wellbeing program to be delivered to primary-school age children in an OSHC setting. The co-design process is key to ensuring local community needs are met and that they are meaningfully and actively involved in all stages of the research and design process, from conception, to implementation, evaluation and continuous improvement. By providing a framework that encourages tailored interventions to be developed depending on the unique needs and preferences of the end-users (e.g. children and their families, staff, volunteers and the broader community), CP3 takes an important step forward towards achieving universal access to a holistic health and wellbeing program for all children. The CP3 model is currently under evaluation, and results will be used to determine the overall success and inform future re-development and implementation.

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Table 1. Basic participant demographics.

| Demographic item | n (%) |
|--|----------------------|
| Total N | 34 (100%) |
| Detailed participant type ^a | |
| <i>Parent/ guardian/ primary carer of a primary school student</i> | 8 (24%) |
| <i>Community volunteers</i> | 4 (12%) |
| <i>Supportive other of a primary school student</i> | 1 (3%) |
| <i>Potential future mentor of CP3</i> | 8 (24%) |
| <i>Researcher/ academic</i> | 1 (3%) |
| <i>Teacher/ educator</i> | 10 (29%) |
| <i>Local community member</i> | 19 (56%) |
| <i>Other child community organization</i> | 9 (26%) |
| Age range | |
| <i>16-24 years</i> | 3 (9%) |
| <i>25-34 years</i> | 2 (6%) |
| <i>35-44 years</i> | 6 (18%) |
| <i>45-54 years</i> | 6 (18%) |
| <i>55-64 years</i> | 6 (18%) |
| <i>65 years plus</i> | 4 (12%) |
| <i>Did not answer</i> | 7 (21%) |
| Gender | |
| <i>Male</i> | 11 (32%) |
| <i>Female</i> | 23 (68%) |

Language spoken at home^a

| | |
|-----------------------|----------|
| <i>English</i> | 27 (79%) |
| <i>Other</i> | 4 (12%) |
| <i>Did not answer</i> | 6 (18%) |

^a Multiple response options provided

Table 2. CP3 Principles.

| | |
|---|--|
| BUILD WELLBEING & RESILIENCE | Provide activities that seek to promote and enhance children’s social, emotional, cognitive and physical wellbeing. |
| BROADEN HORIZONS | Broaden opportunities and skills by providing a diverse range of experiences that children might not generally have access to in their day-to-day lives. |
| INSPIRE & ENGAGE | Focus on creating a ‘spark’ in children as the activity is interesting, motivating and fosters a growth mindset. Encourage meaningful involvement by promoting children’s leadership, decision-making and choice. |
| CONNECT COMMUNITIES | Promote connectedness, communication and belonging as children – and their families – forge strong links with local resources and their community. |

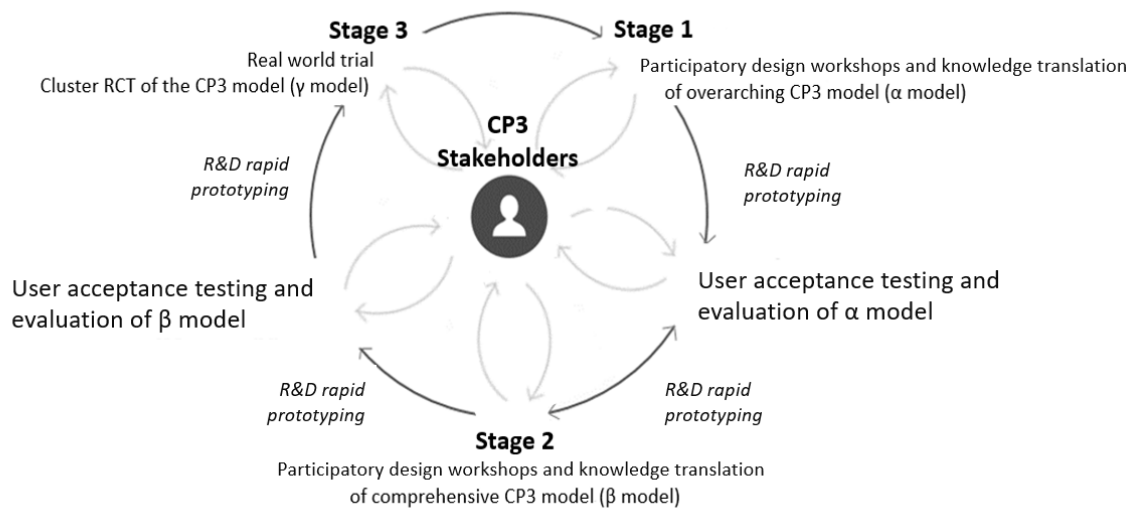


Figure 1. Connect, Promote and Protect Program (CP3) research and development (R&D) cycle.

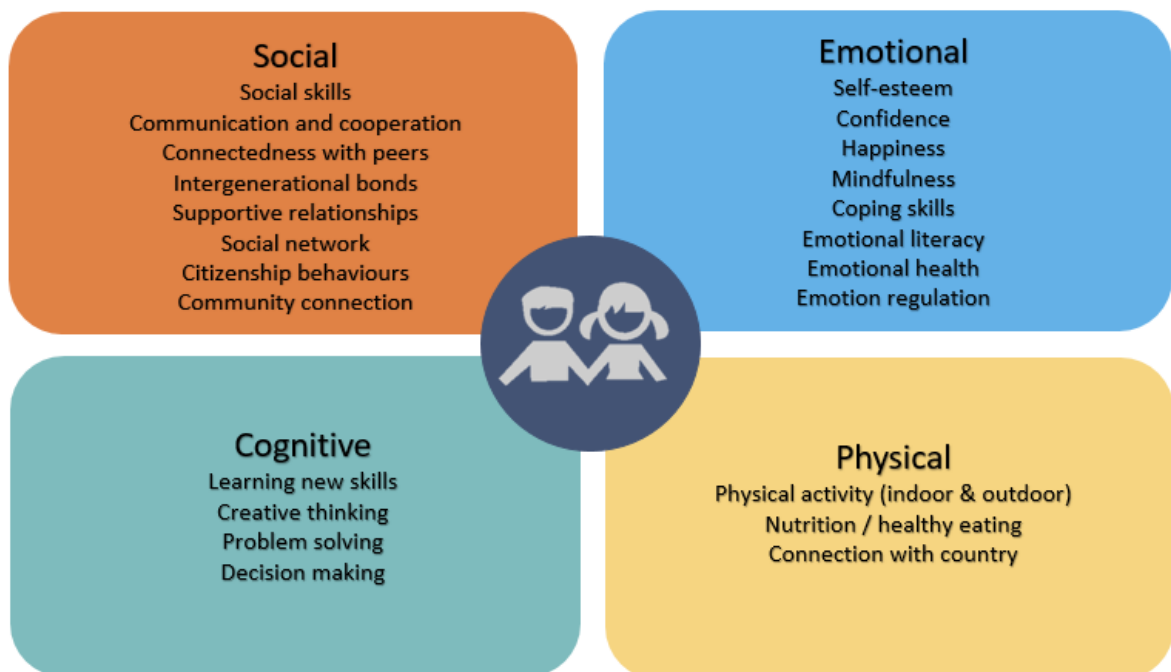


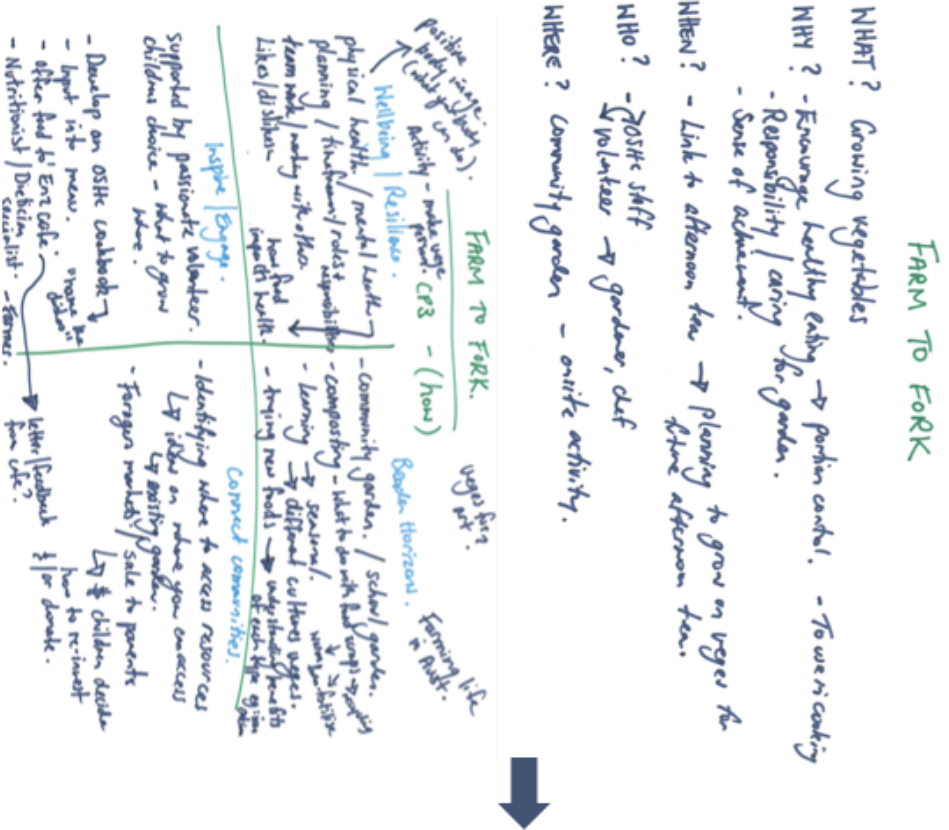
Figure 2. Children's wellbeing domains.



Figure 3. Example page from the CP3 Activity Development Guide after prototyping and knowledge translation.

| | CP3 Principles | Enhanced activities | CP3 collective mentoring package | Targeted 1:1 health professional support | Connected families resource package |
|-------------------|----------------|---------------------|----------------------------------|--|-------------------------------------|
| ① CP3 Lite | ✓ | ✓ | | | |
| ② CP3 | ✓ | ✓ | ✓ | | |
| ③ CP3 Plus | ✓ | ✓ | ✓ | ✓ | ✓ |
| Components | | | | | |

Figure 4. Components of CP3 stages.



| <h2>② Farm to Fork</h2> <p>Where community gardening and cooking meet as children learn to nourish their bodies and minds in fun and engaging ways. Here, children learn gardening skills whilst growing their own vegetables in the local community garden. These foods are then used in the kitchen where the focus is on cooking skills, healthy eating and nutrition to promote positive relationships with food. Children develop the menu and can share it with their peers at OSHC during afternoon tea. Children also create their own recipe books so they can take home their newly learnt skills to cook both local and international cuisine.</p> | |
|---|--|
| <p>BUILD WELLBEING & RESILIENCE?*</p> <p>Developing skills such as: sequencing, planning and numeracy (C), communication and cultural competence (S), the relationship between outdoors / good nutrition and mental health (E), nutrition, fine motor skills, and outdoor exercise (P).</p> | <p>BROADEN HORIZONS?</p> <p>Access to a community garden and kitchen. Learning about gardening, cooking and culture.</p> |
| <p>INSPIRE & ENGAGE?</p> <p>Child-led gardening and recipe planning. Facilitated by members of the CP3 team who are skilled and passionate gardeners and are inspired cooks.</p> | <p>CONNECT COMMUNITIES?</p> <p>Learning from people who are from various cultures. Child (and family) involvement in and use of a community garden within and outside of OSHC time. Connecting with local resources and groups such as farmers markets.</p> |

*Wellbeing domain key: C = cognitive wellbeing; S = social wellbeing; E = emotional wellbeing; P = physical wellbeing.

Figure 5. Example excerpts from CP3 enhanced activity planning.

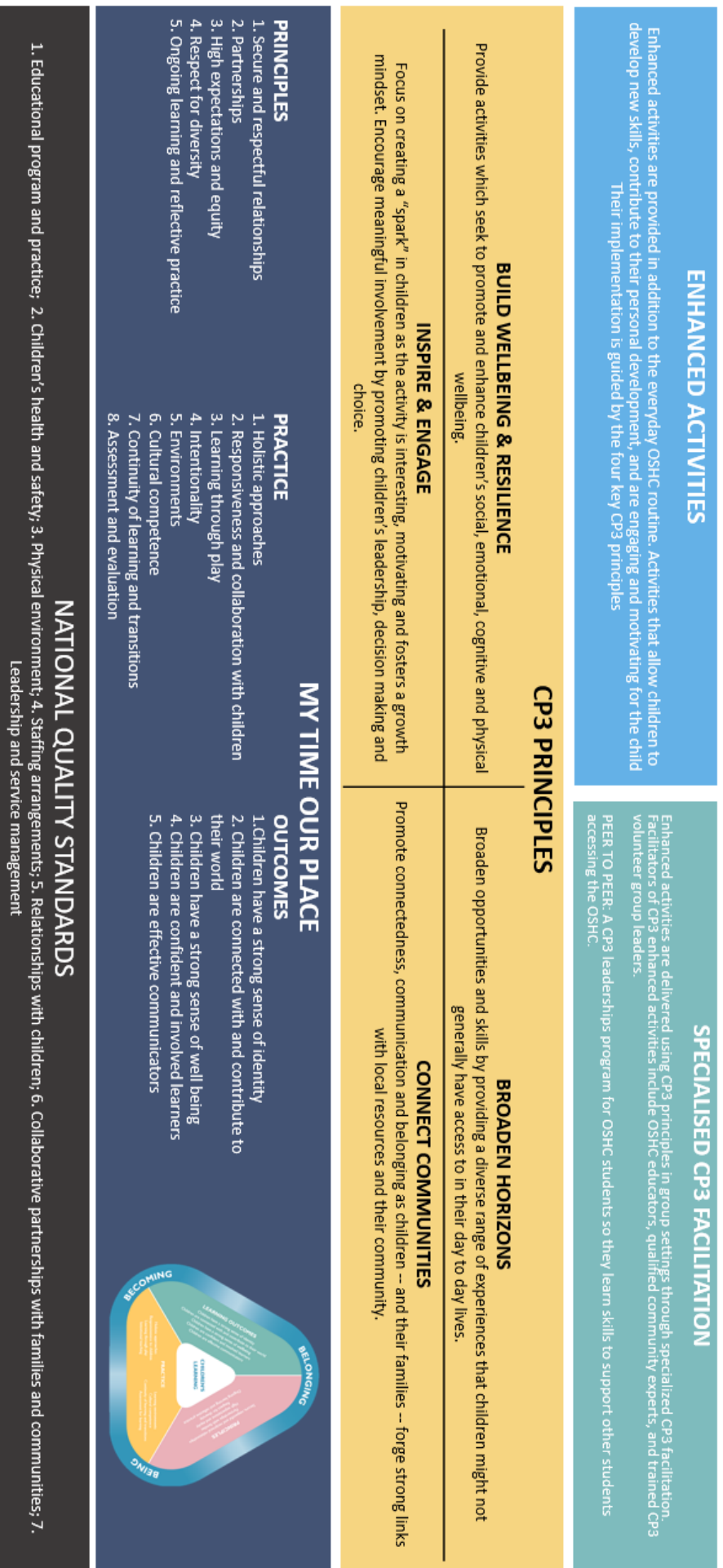


Figure 6. CP3 model underpinned by the existing *My Time Our Place Framework* and the *National Quality Standards*.

Supplementary Files

Table 1. Basic participant demographics.

| Workshop | Stage 1 | | | Stage 2 | Total |
|--|-----------|----------|----------|----------|-----------|
| | 1 | 2 | 3 | 4 | |
| | n(%) | n(%) | n(%) | n(%) | n(%) |
| Total N | 14 | 6 | 8 | 6 | 34 |
| Participant type ^a | | | | | |
| <i>Local community member</i> | 9 (82%) | 4 (80%) | 6 (86%) | 0 (0%) | 19 (56%) |
| <i>Parent/ guardian/ primary carer of a primary school student</i> | 3 (27%) | 1 (20%) | 2 (29%) | 2 (33%) | 8 (24%) |
| <i>Potential future mentor of CP3</i> | 1 (9%) | 2 (40%) | 1 (14%) | 4 (66%) | 8 (24%) |
| <i>Researcher / academic</i> | 1 (9%) | 0 (0%) | 0 (0%) | 0 (0%) | 1 (3%) |
| <i>Supportive other of a primary school student</i> | 0 (0%) | 0 (0%) | 1 (14%) | 0 (0%) | 1 (3%) |
| <i>Teacher/ educator</i> | 2 (18%) | 3 (60%) | 1 (14%) | 4 (66%) | 10 (29%) |
| <i>Community volunteer</i> | 3 (27%) | 0 (0%) | 1 (14%) | 0 (0%) | 4 (12%) |
| <i>Other child community organisation</i> | 4 (36%) | 0 (0%) | 3 (43%) | 2 (33%) | 9 (26%) |
| Age range | | | | | |
| <i>16-24 years</i> | 1 (7%) | 0 (0%) | 0 (0%) | 2 (33%) | 3 (9%) |
| <i>25-34 years</i> | 0 (0%) | 0 (0%) | 1 (13%) | 1 (17%) | 2 (6%) |
| <i>35-44 years</i> | 1 (7%) | 2 (33%) | 1 (13%) | 2 (33%) | 6 (18%) |
| <i>45-54 years</i> | 2 (14%) | 1 (17%) | 2 (25%) | 1 (17%) | 6 (18%) |
| <i>55-64 years</i> | 3 (21%) | 2 (33%) | 1 (13%) | 0 (0%) | 6 (18%) |
| <i>65 years plus</i> | 1 (7%) | 0 (0%) | 3 (38%) | 0 (0%) | 4 (12%) |
| <i>Did not answer</i> | 6 (43%) | 1 (17%) | 0 (0%) | 0 (0%) | 7 (21%) |
| Gender | | | | | |

| | | | | | |
|---------------|---------|---------|---------|----------|----------|
| <i>Male</i> | 5 (36%) | 3 (50%) | 3 (38%) | 0 (0%) | 11 (32%) |
| <i>Female</i> | 9 (64%) | 3 (50%) | 5 (62%) | 6 (100%) | 23 (68%) |

Language spoken at home

| | | | | | |
|-----------------------|---------|----------|----------|----------|----------|
| <i>English</i> | 8 (57%) | 5 (100%) | 8 (100%) | 6 (100%) | 27 (79%) |
| <i>Other</i> | 0 (0%) | 1 (17%) | 0 (0%) | 3 (50%) | 4 (12%) |
| <i>Did not answer</i> | 6 (43%) | 0 (0%) | 0 (0%) | 0 (0%) | 6 (18%) |

Multiple response options provided

Appendix 2

Grant proposal submitted to The National Health and Medical Research Council to the Global Alliance for Chronic Diseases in the 2017 Mental Health Call.

Title: Implementing and trialling a new and innovative online mental health system for use by young people in Colombia, a low-middle income country with 100% Internet connectivity

Cover Page (*1 page*)

Application ID: APP1147682

Title: Implementing and trialling a new and innovative online mental health system for use by young people in Colombia, a low-middle income country with 100% Internet connectivity

Chief Investigators:

CIA: Professor Ian Hickie

CIB: Dr Laura Ospina-Pinillos

CIC: Associate Professor Andres Rangel Martinez-Villalba

CID: Associate Professor German Rueda Jaimes

CIE: Professor Carlos Filizzola Donado

CIF: Associate Professor Elizabeth Scott

Research Proposal (9 pages)

This study will implement and naturalistically trial a new and innovative online mental health system for use by young people in Colombia. The Synergy Online System (SOS) is a personalised Internet-based resource designed to help young people manage their physical, mental and social wellbeing using a mixture of apps, etools, online and face-to-face services. SOS has the potential to transform the provision of mental health services as it is readily accessible, affordable and equitable, has an increased focus on prevention and early intervention, and improves the management of mental disorders across settings.

Importantly, SOS includes a Mental Health eClinic (MHeC) which is a real-time primary care online clinic that offers young people immediate self-report assessment, as well as timely support and programs, via a ‘video-visit’ with a health professional that results in a true share plan. By using the Internet, the MHeC aims to deliver best practice clinical services to young people with mental health problems. If needed, it also provides a seamless transition into web-based (or face-to-face) primary care.

AIMS

This study aims to:

1. Implement and naturalistically trial the Colombian version the Mental Health eClinic (MHeC-C) via SOS with young people aged 16 to 25 years in three large Colombian universities via their Wellbeing Centres and associated primary mental health care services in metropolitan and rural areas;
2. Implement the MHeC-C (via SOS) with young people aged 16 to 25 years in a broader range of health care services across Colombia;
3. Implement and naturalistically trial the structured training program that accompanies the MHeC-C for health professionals comprising Colombia-specific clinical, service, digital and suicide prevention modules;
4. Naturalistically evaluate the MHeC-C (via SOS) using measures of engagement, efficacy and effectiveness;
5. Inform the enterprise grade (or delta) build of the MHeC-C; and,
6. Measure the social and economic return on investment (SROI/ EROI) of the MHeC-C.

Colombia’s 100% Internet connectivity provides a strategic opportunity to test the MHeC-C (via SOS) and its ability to:

1. Address the large unmet need relating to mental health problems of young people aged 16 to 25 years living in low-middle income countries with high Internet connectivity;
2. Deliver person-centred care to psychologically-traumatised young people and communities in post-conflict countries; and,
3. Deliver a practical and targeted, technology-based solution to young people aged 16 to 25 years at any point along the entire spectrum of health and wellbeing, from those who simply want to achieve goals to improve their daily habits, to those experiencing serious mental health problems.

SOS, through its use of integration, interoperability, Tech Standards and Service (Privacy) Guidelines is the back-end technology solution that will provide the link between the evidence-based apps and etools, online and face-to-face services (i.e. MHeC-C) available across Colombia to the individual. This allows SOS to be built around the individual for the individual – wherever they are and whenever they need help, first time, every time.

BACKGROUND

The need for mental health services far outweighs the capacity of service providers all over the

world. Access to quality mental health care is also limited for many populations, but is particularly limited for vulnerable groups such as the elderly and youth populations, racial and ethnic minorities, the socio-economically disadvantaged and rural populations⁷. Limited access to services is of particular concern for young people, as it is well established that 75% of the serious mental diseases and substance use problems emerge before 25 years of age¹⁴ and when young people do seek and receive help, timely and evidence-based treatments are only encountered by a small proportion²⁷.

The University of Sydney's Brain and Mind Centre is a leader in development of youth-specific mental health services^{17,18} and evidence-based e-health technologies to engage young people in their own care⁶. Over the past decade, evidence suggests that the Internet is considered not only as an information resource, but a space where people feel confident to talk about their mental and physical health issues³. Today, online mental health services are considered to be readily accessible, available and low cost³⁶. Additional benefits include that such online mental health services are anonymous, welcoming, trustworthy and less stigmatising³. Most importantly, young people report feeling comfortable accessing online support, which ultimately increases the reach of these services to young people who would otherwise avoid seeking help³³.

Online mental health interventions for young people have proven to be effective for self-screening and referral²⁵, reducing symptoms and delivering effective treatment for major mental health disorders²¹. A large number of studies, including randomised controlled trials, have also demonstrated the effectiveness of various Internet-delivered interventions such as, psychotherapy and psychoeducation⁴³, treating problematic health behaviours⁴¹, and delivering prevention and treatment programs⁵. Other population-based studies have reported that online tools can enhance the delivery of mental health care in primary care settings²², improve mental health support in catastrophes⁴⁵, and support training and supervision for providers¹². The number of programs available is growing rapidly³⁰. Although positive results are seen from the use of self-directed e-health interventions, increased effectiveness has been reported if used as part of a stepped-care model⁴⁴, with the support of a trained health professional³⁴ or as an adjunct to face-to-face treatment³⁷.

As a result, The University of Sydney's Brain and Mind Centre in association with the Young and Well Cooperative Research Centre (2011-16) have developed SOS to transform the provision of health care services for young people across Australia. One of the cornerstone principles of SOS is a focus on the entire spectrum of health and wellbeing, from those who simply want to achieve goals to improve their daily habits, to those experiencing serious mental health problems. This means that the System is incredibly flexible and personalised, so that every user gets the right care at the right time, first time, every time. A core feature of SOS is that it's configurable, which allows it to easily adapt and meet the individual needs of young people and, as the health and wellbeing of an individual fluctuates over time. Further, with the MHeC focused on anxiety, depression, bipolar disorder, psychosis, eating disorder, suicidality, alcohol and other substance misuse, physical health and trauma, SOS is able to meet the many and varied current needs of its potential end-users. Clinical staging The MHeC is innovative in that it not only utilises new and emerging technologies but also incorporates the concept of clinical 'staging' of mental disorders to assist with prevention, early intervention, triaging and ensuring that young people get the assistance they require when interacting with SOS.

In Psychiatry, the current diagnostic systems such as DSM and ICD do not deal adequately with sub-syndromal and prodromal presentations. This weakness is relevant in young people because in the early stages of illness, they are often symptomatic, help-seeking, and experiencing psychosocial and role impairment, but do not yet meet specific criteria for any established disorder¹⁹. In response to this problem clinical staging has been developed²⁸.

The University of Sydney’s Brain and Mind Centre, in collaboration with other partners, have established comprehensive consensus criteria to incorporate a range of syndromes within the one clinical staging model (see Box 1). The real utility of this clinical staging model relies on whether we can identify any genuine transitions along the illness course, especially in the earlier Stages 1a and 1b¹⁹. Furthermore, three different pathophysiological pathways have been added to complete the initial model^{16,20}. This framework focuses on the underlying pathophysiological mechanisms of major psychiatric disorders^{26,31} to guide the delivery of specific treatments³⁹.

BOX 1: Summary of clinical staging model⁸

| | |
|----------|---|
| Stage 0 | No symptoms; person at risk of disorder |
| Stage 1a | Help-seeking; person with mild symptoms and mild functional impacts |
| Stage 1b | Attenuated syndrome; person with mixed or ambiguous symptoms and moderate/severe functional impacts |
| Stage 2 | Discrete disorders, such as clear episodes of psychotic, manic or severe depressive disorders |
| Stage 3 | Recurrent or persistent disorder |

When the staging model is applied in clinical settings, several studies have shown that more than half of the young people are assigned to the earlier stages¹⁹. Moreover, evidence suggests that even at these early stages young people have significant social and occupational dysfunction, which increases in severity through the latter stages^{19,38}. In total, 30% of the young people in earlier stages (Stages 1a and Stage 1b) transition to a later stage, and three quarters in Stage 1b transition within the first 12 months of initial service contact¹⁹.

New and emerging technologies New and emerging technologies have changed the way young people communicate, connect and engage with each other and with society; and, with the introduction of smartphones, information and services/ resources provided online or via mobile applications can be accessed privately and at any time. This can be empowering for individuals who are marginalised or geographically or socially-isolated. Therefore, it is important that we capitalise on these social and technological developments in ways that promote good health and wellbeing, including mental health.

New and emerging technologies (more recently known as the Internet of Things) hold enormous promise for significantly expanding the reach of quality mental health care by addressing several barriers²⁹. Such interventions have potential to reach a wide geographic area via remote delivery of care²³; to decrease the costs in delivering self-help and/or social networking interventions; and to allow for relatively rapid, centralised scaling up of interventions to a public-health dissemination level. Additionally it is known that technologies can be used effectively in improving mental health and wellbeing⁹ and emphasises the importance of e-health innovations for real mental health reform³⁵.

The MHeC via SOS Through the use of co-creation/ co-design (herein referred to as participatory design, PD) workshops with young people, supportive others and health professionals, we have been able to design and develop the MHeC so that such end-users feel comfortable using the System and so it meets their health care needs and wants. New research principles such as rapid prototyping and user (acceptance) testing has meant the System has moved beyond ‘telemedicine’. Instead, the MHeC is a user-driven etool that links every individual with the constantly evolving breadth of apps, etools and other online resources offered in-country and available through global partners, including Australia.

The MHeC (via SOS) includes multiple components:

1. Basic triage, initial assessment and more detailed clinical assessment via online surveying;
2. An initial and clinical dashboard of results;
3. Immediate recommendations in the form of goal setting that constitute a ‘wellbeing plan’ and/ or immediate recommendations in the form of online and clinical resources/ services that constitute a ‘share plan’;
4. Integrated and interoperable real-time data tracking capability (eg. FitBit);
5. Use of more specialised online mental health assessment and feedback (including ‘video-visits’) as an adjunct to face-to-face care; and,
6. Optimisation of digitally-smarter suicide prevention functionality to assist those who may be in crisis.

The initial questionnaire takes approximately five to 10 minutes to complete. If further assessment is required, the young person is recommended to complete the clinical questionnaire which currently includes 18 modules with smart skips built in so that the questionnaire is tailored to each individual and takes the minimum time to complete (approximately 45 minutes). The modules include the following measures: 1. Main reason for visiting service; 2. General demographics; 3. Social/ economic participation (eg. highest level of education, current education, employment and training status, everyday functioning) using a modified version of the Brief Disability Questionnaire (BDQ) and self-reported SOFAS; 4. Psychological distress using the 10-item Kessler Psychological Distress Scale as well as depression (Quick Inventory of Depressive Symptomatology, QIDS-SR-16) and anxiety (Overall Anxiety Severity and Impairment Scale, OASIS) symptoms; 5. Hypomania (derived from the Altman Self-Rating Scale) and psychosis symptoms (derived from the Community Assessment of Psychic Experiences (CAPE) – Positive Symptoms Scale); 6. Traumatic experiences using the Primary Care PTSD Screen (PC-PTSD) as well as the Post-traumatic Stress Disorder Checklist (PCL); 7. Self-harm behaviours and suicidal ideation over the past month with the Suicide Ideation Attributes Scale (SIDAS); 8. Tobacco, alcohol and substance use with items adapted from the Alcohol Use Disorders Identification Test (AUDIT), the Alcohol, Smoking And Substance Involvement Screening Test (ASSIST), the Drinking Motives Measure, the Fagerstrom Nicotine Dependence Test (FNDDT); 9. Physical activity with the International Physical Activity Questionnaires (IPAQ); 10. Sleep behaviours; 11. General mental health conditions (using the National Comorbidity Survey – Adolescent Supplement) that have a higher prevalence in young people; 12. Somatic distress using the Somatic and Psychological HEalth REport (SPHERE) as well as self-perceived health status and general body measurements; 13. Medical and mental health history; 14. Cognitive complaints and empathy; 15. Personality traits; 16. Eating behaviours and body image; 17. Social connectedness and support; and, 18. SROI/ EROI.

The Spanish version of the MHeC (MHeC-S) It has been widely identified that populations who do not speak English but reside in English-speaking countries, are less likely to receive mental health care; and in Latino populations specifically, a lack of English proficiency is one of the most significant barriers when accessing such services²⁵. This scenario is rapidly acquiring significant relevance in Australia, considering that Spanish is the second most widely spoken language in the world, and the Spanish-speaking (including Latino) migration (temporary or permanent) to Australia is constantly growing. In 2014-15 the Student Visa Grants to applicants from Colombia increased by 12% and it was calculated at June 2015 there were 6,592 Colombian students holding a Visa in Australia¹¹.

The National Mental Health Commission³², in their recent review of Mental Health Programmes and Services, has called for an overhaul of the mental health system, including an integration of e-mental health with face-to-face services. In Australia, non-English migrant populations struggle to access and understand the local health care system². Moreover, it has been identified that language proficiency is a true barrier for migrant men when utilising services²⁴. Taking into account Australia

is a multicultural/ multiracial country and the current increase in Spanish-speaking populations, having the MHeC-S would greatly benefit those young people who are Australian-based, native Spanish-speakers who are (or need to) actively seek help. A naturalistically controlled clinical trial aimed to evaluate the MHeC-S has already been approved by The University of Sydney's Human Research Ethics Committee and is due to start early March 2017 (see Figure 1).



Figure1: Landing page for the MHeC-S.

Over the past 12 months, the English version of the MHeC has been carefully translated into colloquial Spanish and culturally-adapted to Spanish-speaking populations currently living in Australia. With regards to translation, a Spanish-bilingual health professional translated all (health-related) items from English to colloquial Spanish, with the exception of standardised surveys already available in Spanish (i.e. QIDS, SBQ-R, K-10, WHODAS, IPAQ, NCS-A WHOASSIT, TIPI and SUS). Then two native-Spanish born adults with special mental health training (two psychiatrists of which one is also an experienced mental health researcher) reviewed the translations to ensure all items were linguistically and culturally appropriate by assessing the criterion validity of each item in the questionnaire, as well as assessing the readability and grammatical consistency of the entire questionnaire. All items were then back-translated to English by one Australian adult who is fluent in colloquial Spanish, has extensive research experience as well as tertiary qualifications in health and is accredited to teach English to adults. Discrepancies between the original and back-translated versions were resolved in several one-on-one sessions between the translator and back-translators.

With regards to cultural adaptation, CIB has to date run four PD workshops including two in Australia with Spanish-speaking populations (one with young people and supportive others, the other with health professionals) and two in Colombia (again, one with young people and supportive others, the other with health professionals), which specifically explored the cultural adaptation of the MHeC to both Australian-based Spanish speaking populations and Colombian population needs and wants.

Colombia: a World Bank defined low to middle income country Colombia has an estimated population of 49 M inhabitants¹⁰. The GDP is \$378 B¹⁵ and according to the World Bank the country has spent 7% of its GDP over the last 15 years in the health sector⁴⁷. Regarding the health workforce, during the period 2007-13 there were approximately 15 physicians for every 10,000 inhabitants¹. Although as stated, Colombia has 91% health coverage, it is still relatively low for ethnic minorities and the poorest regions. Additionally, as the Colombian health system is disease-centred the continuity and the quality of service is an important challenge in mostly rural areas due to the difficulty of attracting qualified specialists.

According to the WHO, expenditure on mental health treatment in Colombia is just 0.08% of the total health budget, the least of all South American Countries⁴⁶. Therefore, demand for appropriate

mental health care is significantly higher than the health professionals available. In 2013 it was estimated that there were just 1,250 psychiatrists in Colombia⁴⁰ and that 80% of psychiatrists are situated within major cities. Furthermore, there are only a small number of child and adolescent psychiatrists. The majority of the services for this population occur in the context of adults and patients with a chronic condition, creating additional barriers to getting help. During the past decade however, there has been an increase of mental health services in the university and college counselling centres.

In 2015 it was estimated that 36% of the Colombian population (17 M inhabitants) were aged 15 to 24 years. In that same year, lifetime prevalence rates of mental health disorders for adolescents aged 12 to 17 years was 7% (any disorder) and the rate of suicide attempts for this age group was 3%. In a survey conducted in Medellin in 2012, the lifetime prevalence for young people aged 13 to 29 years of age were: depression 7%; any anxiety disorder 13% and post-traumatic stress disorder 4%. Among university students in Colombia, the prevalence of mental health disorders is estimated to vary between 11% to as high as 75%. In one study, it was found that 20% of the college students had suffered from any mental health problem in the past year, where anxiety, mood and substance-related disorders were the most prevalent; and, only 16% of students with 12-month disorders received any health care treatment for their mental disorders in the preceding 12 months.

In 2013, eight out of 10 Colombians under the age of 55 years, regardless of where they lived, accessed the Internet⁴² and telemedicine has been operating since 1998 with legislation governing such activities is in place⁴. Today, Colombia has universal Internet access meaning that all young people have a reliable Internet connection. Colombia's very high Internet connectivity suggests that new emerging technologies could improve the availability, accessibility and affordability of mental health care for young people.

This is a pivotal moment for this country because it is just emerging from half a century of internal conflict, which has had its harshest effect on rural areas and the poor people of this population. In late 2016, a peace deal was achieved and many people are optimistic about how peace would transform the social and economic prospects of Colombia, improving the right to health. International recognition has been placed in Colombia due to its transformation, and the current Colombian President was awarded the Nobel Peace Prize in 2016. Additionally, international stakeholders like the United Nations have invested their efforts to contribute to the transformation of the country.

RESEARCH PLAN

In the first three years, the study will see the implementation of the MHeC-C (via SOS) in three University Wellbeing Centres (The University of Antioquia, Medellin; Javeriana University, Bogota; The University of Autonoma de Bucaramanga, Bucaramanga) as well as primary mental health care clinics associated with these universities. Implementation will include the integration of the latest MHeC-C technology as well as a structured online training program for health professionals comprising Colombia-specific clinical, service, digital and suicide prevention modules (the latter based on the recently developed Public Health Protocol of Surveillance of Suicide Attempts in Colombian) delivered by CIB, CIC, CID and CIE. Based on service implementation through these services, young person participants presenting for care will always be offered the MHeC-C as an online tool, but will have the opportunity to “opt-out” if they do not wish to participate in the study and/or use the technology. Using a stepped-wedge model (see Figure 2), the System will be trialled in consecutive years (Years 1, 2 and 3, respectively) through these universities and associated primary mental health care clinics thus allowing the MHeC-C to undergo a natural R&D cycle within each setting, before being released into the next setting where the R&D cycle begins again. In Year 4, it is expected an enterprise grade (or delta) version of the technology will be ready and available for full implementation (and ongoing trialling) into health

care services in cities and rural areas across Colombia. Importantly, each time the System is refined, all sites will be ‘updated’ thus having access to the latest version of the technology. By Year 4, a workforce of MHeC-C health professionals will have also been developed and it is these clinicians that will be the champions of training future health professionals in order to achieve full system implementation.

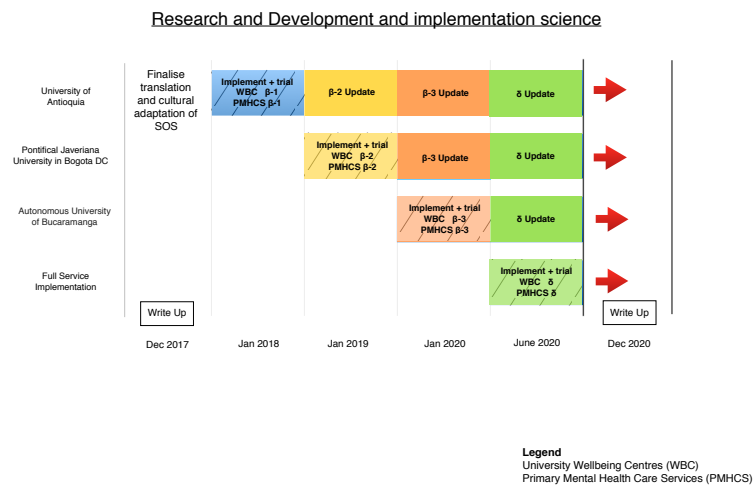


Figure 2: Stepped-wedge naturalistically controlled clinical trial – design.

Participatory design and user (acceptance) testing

In each University (and its associated primary mental health care clinics), the following R&D cycle will occur: PD workshops with 7-10 participants to configure the MHeC-C to the student population (Medellin, Bogota, Bucaramanga); rapid technology prototyping; one-on-one 90-minute user-experience testing with up to five participants per setting; more rapid technology prototyping; and finally, detailed one-on-one 90-minute user acceptance testing based on scenarios which are traditionally conducted just before release of any new technology ‘updates’ to ensure no system bugs exist. Only when 100% user acceptance is achieved with participants, will the System be rolled out to the University Wellbeing Centres and associated primary mental health care clinics at each site.

The stepped-wedge naturalistic controlled clinical trial Here potential participants (young people aged 16 to 25 years, with regular access to a smartphone [iPhone or Android] and the Internet) will be given unlimited access to the MHeC to use of their own accord. For those young people identified as Stage 1a we would expect use for a period of up to three months, for those identified as Stage 1b a period of up to 12 months and for those identified as Stage 2+, we would expect use for a period of around two to three years. Thus in addition to baseline assessment, follow-up timepoints will include 30 days, 60 days, 90 days, six months, 12 months, 18 months, 24 months and 36 months. Questionnaires at each timepoint will include items regarding engagement with, efficacy and effectiveness of, the MHeC-C. Logistically, participants who cease engagement with the System (before the first follow-up timepoint – 30 days) but remain in the study will be considered a control group which go on to receive standard care.

STATISTICAL ANALYSES AND POWER CALCULATION

For PD workshops, qualitative analyses will be in the form of knowledge translation to new wireframes that inform the initial MHeC-C (Beta 1) build and then iteratively the Beta 2, Beta 3 and Beta 4 builds over the three-year period. For user (acceptance) testing, qualitative analyses will be conducted in NVivo and explore themes related to general usability, different online behaviours and overall acceptance of the MHeC-C. Quantitative analyses on the System Usability Scale (SUS) and

Single Ease Questionnaire (SEQ) administered at the end of the 90-minute one-on-one sessions, will also be performed and involve simple descriptive statistics which reflect the technological development and improved user experience of the MHeC-C over the course of the study.

For the naturalistically controlled clinical trial, the MHeC-C (via SOS) will be evaluated by using a range of descriptive and multi-variate statistical analyses, which will essentially look at pre vs post longitudinal outcomes within group as well as and control vs experimental conditions. Engagement will be analysed by interrogating Google Analytics as well as SOS analytics; efficiency by assessing overall pre vs post longitudinal health outcomes; and effectiveness by a combination of engagement and efficacy as well as participant assessment of the actual System. For all quantitative statistical analyses, we conservatively assume a small effect size of 0.10 benefit in favour of those in the experimental condition. This assumption is based on current unknown impact of technology integrated into conventional clinical mental health care in Colombia. The proposed stepped-wedge design seeks to actively recruit at least n=2,000 young people to the experimental condition of which it is expected that 50% will move to the control group per year across each of the three university settings and associated primary mental health care clinics as well as an expected attrition rate of approximately 30% overtime (see Table 1). Total proposed experimental and control sample sizes (see Table 1) are therefore adequate given multiple repeat measure calculations (including within and between interactions), based on a small effect size of 0.10 for a one-sided test of 5% and 90% power, showing that approximately 791 participants are required at the 12-month timepoint. In addition, our proposed large samples for experimental and control conditions allow for the detection of Type I Error (i.e. at 5% n=791 and at 10% n=1,030); and, are beneficial for important subgroup analyses as a result of sampling heterogeneous clinical settings (eg. culturally and linguistically diverse communities, Aboriginal communities etc).

Table 1: Total proposed experimental and control sample sizes.

| Year | University | Condition | Questionnaire time point sample size (n) | | | | | | | |
|------|--|--------------|--|---------|---------|---------|----------|------------|-----------|-----------|
| | | | Baseline | 30 days | 60 days | 90 days | 6 months | 12 months* | 24 months | 36 months |
| 1 | The University of Antioquia, Medellin | Intervention | 2000 | 1000 | 925 | 850 | 775 | 700 | 650 | 600 |
| | | Control | NA | 1000 | 925 | 850 | 775 | 700 | 650 | 600 |
| 2 | Javeriana University, Bogota | Intervention | 2000 | 1000 | 925 | 850 | 775 | 700 | 650 | 600 |
| | | Control | NA | 1000 | 925 | 850 | 775 | 700 | 650 | 600 |
| 3 | The University of Autonoma de Bucaramanga, Bucaramanga | Intervention | 2000 | 1000 | 925 | 850 | 775 | 700 | 650 | 600 |
| | | Control | NA | 1000 | 925 | 850 | 775 | 700 | 650 | 600 |

* Reduced attrition rate (15%) expected after 12 months

Timeline The entire study will run for a total duration of four years.

Year 1: January 2018, Beta 1 version of the MHeC-C (via SOS) will be implemented and trialled through The University of Antioquia (Medellin) and its associated primary mental health care clinics.

Year 2: January 2019, Beta 2 version of the MHeC-C (via SOS) will be implemented and trialled through Javeriana University (Bogota) and its associated primary mental health care clinics.

Year 3: January 2020, Beta 3 version of the MHeC-C (via SOS) will be implemented and trialled through The University of Autonoma de Bucaramanga (Bucaramanga) and its associated primary mental health care clinics.

Year 4: January 2021, Delta version of the MHeC-C (via SOS) will be implemented in health care services in cities and rural areas across Colombia.

Year 4: June 2021, study wrap up and write up

Importantly, this study is only made possible through sound partnerships between The University of Sydney (CIA, CIB [Research Fellow for Project Synergy] and CIF) and The University of Antioquia (Medellin; CIB [Honorary Member of the School of Medicine] and CIC) and The University of Autonoma de Bucaramanga (Bucaramanga, CIB [Associate Researcher in Neuropsychiatry Research Group] and CID) which were cemented in late 2016 when Memorandum of Understanding's were signed in order to formalise these academic relationships. At the same time, a framework of cooperation was established with the Pontifical Javeriana University in Bogota (CIB [Associate Researcher of Mental Health Research Group] and CIE).

OUTCOMES AND SIGNIFICANCE

As a result of universal Internet access in Colombia and considering that Spanish is the second most common language spoken worldwide¹³, Colombia is an interesting and relevant country to measure the applicability of online interventions. If this application were successful, the research output potential is vast:

1. **LOCAL SERVICE IMPACT** – The iterative implementation and naturalistically controlled clinical trial means Colombia (a low-middle income country) will be in a position to transform local Colombian mental health services and address the large unmet need in its young people by allowing health professionals to more effectively and efficiently use their skills to help young people in that country.
2. **LOCAL IMPACT ON YOUNG PEOPLE** – The MHeC-C (via SOS) will provide its young people with a readily accessible, affordable and equitable online mental health system that is both adaptable and scalable allowing it to meet the needs of both small communities and the country as a whole; as well as deliver a practical and targeted, technology-based solution to significantly improve young people's mental health and wellbeing.
3. **INDIVIDUALLY TAILORED TECHNOLOGY** – Overtime, SOS would continue to grow as it learns more about the individual, through repeated assessment, real-time data tracking and more detailed further assessments and interventions, so that it can recommend goals, apps or etools, or assessments/ interventions that might be suitable for them at this point in time. The System would help the young person decide what app or etool might be useful for them to improve their sleep, or which face-to-face service might be suitable for them to see someone about their depression, or which online CBT program might help them address their anxiety. Importantly, SOS would move with the individual as they move in and out of good health and wellbeing, and in and out of different online and offline services.
4. **GLOBAL SCALABILITY AND REACH** – As Spanish is the second most spoken language in the world, a Spanish version of the MHeC would have far greater global reach for Spanish speakers across the world. Translations of the system are fundamental to providing more affordable and readily accessible mental health care to more people. This would also be a proof of concept that other languages could also be translated and culturally-adapted in to SOS.
5. **NATIONAL AND INTERNATIONAL HEALTH CARE REFORM**: Learnings from the study will (re)inform Australian and international mental health care reform. By making use of Australian innovative research techniques the MHeC, MHeC-S and MHeC-C will reduce the 17-year gap in translational research and subsequent implementation science.

CI Track Record, including top 5 publications in the last 5 years (2 pages per CI)**CIA PROFESSOR IAN HICKIE**

Prof Ian Hickie AM MD is an NHMRC Senior Principal Research Fellow (2013-17) and was previously an NHMRC Australian Research Fellow (2007-12). He is Co-Director, Health and Policy, of the Brain and Mind Centre, at The University of Sydney. He is a Fellow of the Australian Academy of Health and Medical Sciences and also the Academy of Social Sciences in Australia. From 2012 he has been a Commissioner of the Australian National Mental Health Commission (NMHC), with the major focus on improving outcome measurement and improved accountability for Australia's investments in mental health and linked social services.

Professor Hickie has participated in each of the major national advisory bodies on mental health to the Federal Health Minister or Prime Minister since 2007. In partnership with the Mental Health Council of Australia, the Human Rights and Equal Opportunities Commission, Orygen Youth Health, the Young & Well CRC and the National Mental Health Commission, he has authored major national reports on community experiences of mental health services.

The success of each of these national initiatives was recognised in the 2006-2011 COAG initiative in mental health, the 2011 Australian Budget investment of \$2.2 billion (over five years - including over \$400m to new youth services, prioritising e-health developments and establishing the NMHC). Consequently, Prof Hickie was a key participant in the development of the 2014 NMHC review of Mental Health Programmes and Services, which served as the template for the 2015 Turnbull Government initiatives in Mental Health Reform (total value \$190m), including specifically the \$30m Project Synergy investment in new technologies and the new \$90m investment in 12 large regional trials of suicide prevention.

Over the last decade much of his health service and clinical research effort has focused on continuous development and evaluation of new youth service initiatives – through development of new service models for Headspace-style services (largely in partnership with Professor Pat McGorry and Orygen Youth Health), as well as on-line clinics developed under the framework of the (\$35m) Young & Well CRC (in partnership with Professor Jane Burns).

Prof Hickie's long-standing commitment to enhanced mental health in Australia is onto evident in his research but also his: i) capacity to facilitate public engagement with mental health issues, notably through his initial CEO role with *beyondblue*; ii) engagement with major national mental health service reports over two decades (notably 2006, Not For Service Report with Human Rights and Equal Opportunities Commission) iii) continuous public commentary on contemporary mental health and suicide prevention issues; and; iv) role in implementation of substantive health services reform in Australia (e.g. Headspace and Young and Well CRC and now Project Synergy). In 2016 he has been nominated as a finalist for the inaugural Australian Mental Health Prize.

In the last five years Prof Hickie has led the NHMRC CRE on *Optimising personalised care for young people with emerging mood disorders* and been the CIB on the NHMRC CRE for Suicide Prevention (CIA: Helen Christensen), ensuring that the major policy outputs of these research investments are activated through the actions of the NHMRC and other linked agencies such as the NSW Mental Health Commission.

Top five publications in the last five years

1. McGorry P, Goldstone SD, Parker AG, Rickwood DJ, **Hickie I** (2014). Cultures for mental health care of young people: an Australian blueprint for reform. *Lancet Psychiatry*, 1(7): 559-68.

Critically outlines the case for a specific youth mental health stream and describe the innovative service reforms in youth mental health in Australia.

2. **Hickie IB.** (2015) Time to implement national mental health reform. *Medical Journal Commentary on the ways in which the recommendations of the 2014 NMHC Review of Mental Health Services and Suicide Prevention needed to be actioned by Gvernment.*

3. Rosenberg SP, **Hickie IB**, McGorry PD, Salvador-Carulla L, Burns J, Christensen H, Mendoza J, Rosen A, Russell LM, Sinclair S. (2015). Using accountability for mental health to drive reform. *Medical Journal of Australia*, 203(8):328-30.
Commentary on the priorities for setting outcome measures for new investments in mental health services and suicide prevention in Australia.
4. Scott J,...[22 others]..., **Hickie I** (2013). Adolescents and young adults who are not in employment, education, or training. *British Medical Journal*, 347: f5270.
Highlights the critical interplay between social functioning and mental health in young people.
5. Scott J, Leboyer M, **Hickie I**, Berk M, Kapczinski F, Frank E, Kupfer D, McGorry P (2013). Clinical staging in psychiatry: a cross-cutting model of diagnosis with heuristic and practical value. *British Journal of Psychiatry*, 202(4): 243-45.
Makes a case for transdiagnostic staging models that better reflects the developmental psychopathology and matches the complex longitudinal inter-relationships between subsyndromal and syndromal mood, psychotic and other disorders.

Overall track record in the last five years

Contributions to the field of research: (i) expansion of population-based mental health research and development of international mental health strategies; (ii) focused on using new technologies (structural/functional neuroimaging, immune markers, circadian measurements) to delineate pathophysiological pathways to mood disorders; (iii) developed a novel clinical staging framework for emerging and severe mental disorders in young people; and, (iv) established large clinical cohorts focused on the emerging mood disorders, as well as partnering with other national twin, epidemiological and longitudinal studies; International recognition for: (i) leadership of population-based approaches to changing attitudes to mental health; (ii) development of new e-health clinics; and (iii) increasing investments in new youth services.

Publications

- Published in top medical, psychological, psychiatric journals (e.g. *The Lancet*, *British Medical Journal*, *Psychological Medicine*, *Molecular Psychiatry*, *Biological Psychiatry*).
- Scopus H-factor, November 2016 = 66, 580 cited documents, Total citations=19,342

Grants and fellowships

- \$110+M funding since 2004; \$20M since 2010 including: NHMRC Australian Fellowship (2007-12); NHMRC CRE: “CRESP” (CIB: 2012-17); NHMRC CRE: “Optimizing treatments for emerging mood disorders (CIA: 2013-18), \$30M Project Synergy (Australian Government)

Invitations to speak

- International and National Plenary Talks including: American Psychiatric Association – Frontiers in Neuroscience, Hawaii (May, 2011); NIMH symposia, American College of Neuropsychopharmacology (ANCP), Florida (Dec, 2012); NIMH symposia, ACNP (Dec, 2013); International Society of Affective Disorders, Berlin (April 2014). IEPA, Plenary Address, Milan, 2016

Prizes, awards, honours

- Society of Mental Health Research, Founders Medal (2014); Australian Honours, Award of Member (AM, 2006); National Research Advocacy Award, Research Australia (2009).

CIB: Dr Laura Ospina-Pinillos

Dr Laura Ospina Pinillos is a psychiatrist with a special interest in child, adolescent and family psychiatry. In 2011 she became a consultant psychiatrist (similar to FRANZCP in Colombia) and from 2012-2013 she studied family therapy in Turin- Italy. Dr Ospina Pinillos is currently a PhD candidate at The University of Sydney and since 2014 has been a Research Associate at the Brain and Mind Centre, The University of Sydney. During her time in this Centre Dr Ospina Pinillos has been actively involved in the design, research and development of several technological solutions to better assist young people to manage their mental health and wellbeing. Her PhD focuses on the developing a Mental Health eClinic for Spanish-speaking young people and she has focuses her efforts on bringing this innovative system to Colombia. This work has built on her work in the development and validation of scales as well as culturally adapting tests to Colombia. In the past two years she has been instrumental in the development collaborative research partnerships between Australian and Colombian researchers. As a result in 2016, The Brain and Mind Research Centre established two Memorandum of Understandings with two Universities in Colombia: the University of Antioquia (Medellin, Colombia) and the University Autonomous of Bucaramanga (Bucaramanga, Colombia). Additionally, she has established the framework for a new Research Agreement with the Pontificia Universidad Javeriana (Bogotá, Colombia).

Top five publications in the last five years

1. Gómez-Restrepo, C., **Ospina, L.**, Castro-Díaz, S., Gil, F., & Villegas, C. A. A. (2011). Prevalencia del trastorno depresivo en pacientes que consultan un servicio de urgencias en Bogotá. *Revista Colombiana de Psiquiatría*, 40(1), 22-37.
This paper describes the prevalence of depressive disorders in people that attend to the emergency room for other causes not related to mental health problems in one University Hospital in Bogotá-Colombia.
2. Hussain, M. S., Li, J., Ellis, L. A., **Ospina-Pinillos, L.**, Davenport, T. A., Calvo, R. A., & Hickie, I. B. (2015). Moderator Assistant: A Natural Language Generation-Based Intervention to Support Mental Health via Social Media. *Journal of Technology in Human Services*, 33(4), 304-329.
This paper highlights how new and innovative technologies can assist support services.

Overall track record in the last five years

Contributions to the field of research: (i) Contributed to the research and design process of several mental health etools in Australia (including the Mental Health eClinic, Happiness Central Moderator assistant, UBWELL data tracker), using an end user design center approach; (ii) Designed, developed and culturally adapted the Mental Health eClinic into a Spanish-speaking population currently based in Australia and more broadly to Colombia; (iii) To the best of our knowledge Dr Ospina-Pinillos is a pioneer of the adaptation of mental health etools into Spanish; (iv) Liaising with top researchers across Australia and Colombia and establishing formal academic partnerships.

Grants and fellowships: Dr Ospina-Pinillos has received more than \$166,000 (AUD) from the Colombian Government and a Colombian non-profit foundation to support her PhD candidature. Additionally, she has been awarded with a University of Sydney Post-graduate Scholarship worth approximately \$100,000.

International standing: She presented on ‘The Mental Health eClinic (MHeC) a configurable system to enhance access to mental health care’ in 2016 at the International Congress World Psychiatric Association. The same year she was also an invited speaker to the XIII International Congress of the Faculty of Health Sciences and to the Autonomous University of Bucaramanga to

present how online systems can improve young people's health and wellbeing and the Spanish adaptation of e-tools. She was also an invited speaker at the conference entitled Research and Innovation alliances between Australia and Ibero-America at The University of Sydney. In 2014 she presented at the Bi-national Conference, The Faculty of Child and Adolescent Psychiatry a conference entitled 'Designing services for Colombian youth'.

Key collaborations: International collaborations in Colombia as an Honorary member of the School of medicine at the University of Antioquia. Associate researcher of the Neuropsychiatry Research Group. Universidad Autonoma de Bucaramanga. International collaboration with Prof Jan Scott (U Newcastle, UK).

Supervision and/or mentoring: 2016 auxiliary supervisor of a Master of Brain and Mind Sciences student. Clinical research mentor to a PhD Candidate at Brain and Mind Centre, the University of Sydney.

Professional involvement: Member of the IEPA Early Intervention in Mental Health

CIC: Andres Rangel Martinez-Villalba

Andrés Rangel Martínez-Villalba is an Associate Professor, consultant psychiatrist and Coordinator of the Clinical Epidemiology Department of the School of Medicine at the University of Antioquia (Medellin, Colombia). He has expertise in developing educational programs for people with mental problems, understanding the neurocognitive functioning in schizophrenia, and assessing and evaluating health services. Additionally he has wide experience in developing and validating psychometric tests for mood disorders, suicidal behaviours and eating disorders. Additionally, A/Prof Rangel is a lecturer for undergraduate and postgraduate programs in the University and leader in developing epidemiological methods for clinical research. A/Prof Rangel's clinical expertise has focused in the evaluation and treatment of mood and psychotic disorders in young people. He is also a private consultant at "Mente Plena" (private mental health service) that serves to urban and rural areas of the state of Antioquia, Colombia.

Top five publications on the last five years

1. **Rangel Martínez-Villalba AM**, Muñoz C, Ocampo M V, Quintero C, Escobar M, Botero S, et al. Subtipos neurocognitivos de esquizofrenia. *Actas españolas Psiquiatr. Actas Españolas de Psiquiatría*; 2015;43(3):80-90. *This paper explores the neurocognitive subtypes that aids in the identification of different endophenotypes.*
2. Quintero C, García J, Muñoz C, **Rangel Martínez-Villalba AM**, Palacio C, Ospina-Duque J, et al. Sensitivity in the Recognition of Facial Emotions as an Endophenotype for Schizophrenia. *Rev Colomb Psicol. Universidad Nacional de Colombia, Facultad de Ciencias Humanas, Departamento de Psicología*; 2015;24(1):113-27. *Compares the facial emotional recognition of patients with schizophrenia.*
3. Zapata Ospina JP, **Rangel Martínez-Villalba AM**, García Valecia J. Psychoeducation in schizophrenia. *Rev Colomb Psiquiatr. Asociacion Colombiana de Psiquiatría*; 2015;44(3):143-9. *Evaluates the scientific evidence of psychoeducation programs and identifies key points for the development of these interventions in Colombia.*
4. Rueda-Jaimes GE, Castro-Rueda VA, **Rangel-Martínez-Villalba AM**, Moreno-Quijano C, Martínez-Salazar GA, Camacho PA. Validation of the Beck Hopelessness Scale in patients with suicide risk. *Rev Psiquiatr Salud Ment (Barc.)*. 2016. DOI: 10.1016/j.rpsm.2016.09.004. *Assess the suicide risk in a Colombian sample.*
5. Rueda-Jaimes GE, Camacho López PA, Flórez SM, **Rangel Martínez-Villalba AM**. Validity and Reliability of Two Silhouette Scales to Assess the Body Image in Adolescent Students. *Rev Colomb Psiquiatr. Asociacion Colombiana de Psiquiatría*; 2012;41(1):101-10. *Evaluates the psychometric properties of two body image scales in a Colombian population.*

Overall track record (in the last 5 years)

Key contributions to research: (i) led the development of large psychoeducational program aimed to support people suffering from schizophrenia and their relatives; (ii) led the development of an integrated mental health service for medical students in the University of Antioquia; (iii) participated in the implementation of a state-wide telemedicine assistance program lead by the Medical School of the University of Antioquia.

Publications

- Published in the top journal of psychiatry in Colombia (Revista Colombiana de Psiquiatría) and recognized international medical journals (e.g. Atención Primaria, Weight and Eating Disorders, etc)
- A total of 17 peer-reviewed articles (2 as a first author)

Grants and Fellowships

- Two grants for clinical research given by the Colombian Association of Psychiatry for the development and evaluation of psychoeducational program for people suffering of schizophrenia and their relatives.
- National grant for epidemiological and clinical research given by the National Institute for Colombian Sciences (COLCIENCIAS) for the evaluation of attention program for mental disorders in university students of Antioquia's University.

Teaching

- Course lecturer, undergraduate and postgraduate. Medical School of the University of Antioquia.

Key Collaborations

- Prof Jenny García Valencia (University of Antioquia, Colombia), A/Prof German Rueda (Autonomous University of Bucaramanga, Colombia).

Professional involvement

- Fellow of the Colombian Association of Psychiatry.
- Associated member of the Research Ethics Committee of the Cancer Institute of Medellin.
- Regular peer-reviewer of the Colombian Psychiatry Association Journal (Revista Colombiana de Psiquiatría).

Supervision and Mentoring

- Research supervisor since 2014 for postgraduates students of the dermatology department and the allergy and immunology department.

Industry relevant expertise and output

- Speaker about health economics and care models in chronic diseases for Janssen Cilag S.A.

Community engagement and participation

- Active collaboration within the Universities and Associations aimed enhance the integration of epidemiological methods into mental health clinical research.

CID: German Rueda Jaimes

A/Prof German Rueda Jaimes is a consultant psychiatrist, Head of the Mental Health Department at the Universidad Autonoma de Bucaramanga (Bucaramanga, Colombia) and Director of the Neuropsychiatry Research Group. A/Prof Rueda Jaimes has an international reputation in the field of suicide prevention and risk management. In 2012 the Latin American Psychiatric Association recognized his work in the field. He is also internationally renown in the cross cultural field due to his vast contribution in validating questionnaires into Spanish, he has validated more than fifteen mental health scales such as the Center for Epidemiological Studies in Depression (CES-D), the Suicide Behaviors Questionnaire-Revised (SBQ-R), the Leyton Obsessional Inventory-Child version and the Conners Comprehensive Behavior Rating Scale (CBRS) among others. Currently, he is member of the Scientific Committee of the Colombian Journal of Psychiatry and member of the directive board of the Colombian Association of Psychiatry. From 2013 to 2015 he was appointed as Senior Researcher in Colciencias (the Administrative Department of Science, Technology and Innovation from Colombia). As the Head of the Mental Health Department at the School of Medicine he is responsible for the curriculum development, assessments, placements and supervision of medical students in their psychiatry rotation. Across his career he has published over 54 peer-reviewed papers, 25 of them as first author.

Top five publications in the last five years

1. **Rueda-Jaimes GE**, Castro-Rueda VA, Rangel-Martínez-Villalba AM, Moreno-Quijano C, Martínez-Salazar GA, Camacho PA. Validation of the Beck Hopelessness Scale in patients with suicide risk. *Rev Psiquiatr Salud Ment (Barc.)*. 2016. DOI: 10.1016/j.rpsm.2016.09.004.
This paper is a recent contribution to the cross-cultural and suicide fields as it validated the Beck Hopelessness Scale in Colombians with suicide risk.
2. **Rueda-Jaimes GE**, Pinto JL, Rangel-Martínez-Villalba AM, Camacho PA. Abuso de alcohol en niños y adolescentes escolarizados colombianos y factores asociados. *Rev Colom Psiquiatr* 2012; 41: 273-83.
This paper highlights the epidemiology and the associated factors of alcohol consumption in a young sample.
3. **Rueda-Jaimes GE**, Florez SM, Rangel-Martínez-Villalba AM, Camacho PA. Validez y confiabilidad de dos escalas de siluetas para valorar la imagen corporal en estudiantes adolescentes. *Rev Colom Psiquiatr* 2012; 41: 101-10.
Relevant research in the cross-cultural field as it validated two scales that measure body image in a adolescent sample.
4. **Rueda-Jaimes GE**, Díaz PA, Rangel-Martínez-Villalba AM, Castro-Rueda VA, Camacho PA. Diferencias de género en pacientes con suicidabilidad. *Rev Colom Psiquiatr* 2011; 40: 637-46.
Contribution to the suicide field, this paper analyses the gender differences in patients with suicidality.
5. Sánchez R, Navarro AA, **Rueda-Jaimes GE**, Gómez-Restrepo C. Desarrollo y validación de la versión II de la escala EMUN. *Rev Colom Psiquiatr* 2011; 40: 647-59.

This is an important contribution to Colombian research as it represents the development of one of the few Colombian psychometric tests. The paper shows the development and validation of a scale that measures manic symptoms.

Overall track record in the last five years

Key contributions to the field of research: A/Prof Rueda Jaimes has had an ongoing research track record in the field of suicide since 2008, including suicide prevention, suicide risk management, ambulatory treatment for suicidality and validation of suicide measures. Additionally, he has contributed in the validation of other questionnaires in different mental health areas.

Research support: Receives in kind support for research projects from the Universidad Autonoma de Bucaramanga.

Prizes, awards, honours: In 2012 A/Prof Rueda Jaimes was awarded with two national recognitions: The Pablo Pérez Upegui Prize for the best research project presented by a psychiatrist (Colombian Association of Psychiatry) and an honorific award for the best poster presented in the “LI Colombian Congress of Psychiatry”. In the same year he received an international prize by the Latin American Psychiatry Association for his work in the suicide field.

Collaborations: National collaborations with A/Prof Andres Mauricio Rangel Marinez-Villalba and Internationally with Dr Laura Ospina-Pinillos

Supervision and mentoring: Supervision of medical students in their psychiatry rotation from the Universidad Autonoma de Bucaramanga.

Professional involvement: Since 2010 he has been the Vice-president of the Colombian Association of Mood Disorders (ACTA) and in 2014 member of the directive board of the Colombian Association of Psychiatry. From 2011 to 2013 he was Director of the Scientific Committee of the Colombian Association of Psychiatry. In 2012 and 2013 he was appointed as President of the LI and the LII Colombian Congress of Psychiatry

Peer recognition: Since 2013 Senior Researcher in Colciencias

Peer review involvement: Peer reviewer, since 2010 member of the Scientific Committee of the Colombian Journal of Psychiatry.

CIE: Carlos Filizzola Donado

Professor Carlos Filizzola Donado is a consultant psychiatrist, psychoanalyst and currently Head of the Mental Health and Psychiatry Department in the School of Medicine of the Pontificia Universidad Javeriana (Bogota, Colombia). Prof Filizzola's Consultation and liaison expertise has provided him a wide experience in the treatment of the more complex and severe mentally ill cases; and currently he is the Director of the Mental Health High Complexity Unit at the Saint Ignacio Hospital. His areas of research cover dementia, neuropsychiatry, neuroimaging and comorbidity of mental disorders and physical conditions. Prof Filizzola is significantly involved in educational activities, currently leading the Colombia's largest psychiatry training program with more than 40 students (including registrars and fellows) at the Pontificia Universidad Javeriana. He is also a lecturer and supervisor of students for both undergraduate and postgraduate programs in the University. He has a extensive experience in psychotherapy and is the training coordinator of the Colombian Freudian Psychoanalytic Society. Prof Filizzola is an active member of the Colombian Association of Psychiatrists, where he is currently the Coordinator of the Scientific Committee.

Top five publications in the last five years

1. Martínez A., **Filizzola Donado C.**, Matallana D. L. Valoración de prosodia espontánea afectiva y análisis de discurso en pacientes con esquizofrenia y demencia frontotemporal (DFT) variante lingüística. Spontaneous speech prosody and discourse analysis in schizophrenia and Fronto Temporal Dementia (FTD) patients. *Revista Colombiana de Psiquiatría* 2015;44:13-9 ISBN
2. Matallana D, Reyes P, Santiago G, **Fillizola C**, Morillo A, Velasco S, Bermudez S. Simple task in fMRI for evaluating the perception of social interaction in patients with mild traumatic brain injury. *Universitas Psychologica* **Accepted for Publication.**
This publication is relevant due to its contribution to the head injury field and its relation with psychiatric symptoms.

Overall track record (in the last 5 years)

Key contributions to research: Prof Filizzola has contributed to the neuropsychiatry and neuroimaging field, more specifically regarding brain injury and dementia. Additionally he has made significant contributions in the area of comorbidity of mental disorders and physical conditions where he has explored several narratives of people with HIV. Prof Filizzola has also been involved in the development of brief mental health interventions for people with work related injuries.

Research support: Prof. Filizzola and his team were awarded with a competitive Colombian (Colciencias) grant number 697-2014 in the Phase 2 of the Primary Health Care Project, for approximately the equivalent to AUD 500,000. His role as a CI is for the development of brief mental health interventions with people with work related injuries.

Collaborations: Dr Diana Lucía Matallana Eslava in the Neuropsychiatry field. Mrs Mercedes Cecilia Escudero de Santacruz in the Primary Health Care Project.

Professional involvement: Prof Filizzola is currently the Coordinator of the Scientific Committee of the Colombian Association of Psychiatrists, and member of the Latin American Psychiatry Association. He is also a founding member of the Colombian College of

Neuropsychopharmacology, and Director of the Scientific program of the LIV Colombian Congress of Psychiatry.

International standing: Narratives, empathy concern and moral judgements in patients with HIV infection who decided not to tell about their diagnosis. Poster Accepted. The 25th European Congress of Psychiatry (EPA 2017)

Peer-review: Academic Peer for the Ministry of National Education -System of assurance of the Higher Education Quality

Teaching: Lecturer and Head of department of Psychiatry. Supervisor and Training Coordinator of the Colombian Freudian Psychoanalytic Society

Supervision and/or mentoring: As the Head of the Mental Health Department of the Pontifical Universidad Javeriana he is in charge and of the training, supervision, curriculum development, assessments and placements of 40 registrars and advanced fellows. It is important to mention that this University has the largest training program for psychiatrists in the country.

CIF ASSOCIATE PROFESSOR ELIZABETH SCOTT

Associate Professor Elizabeth Scott is consultant psychiatrist and clinical director of the *headspace* services (central Sydney and Campbelltown) of the Brain and Mind Centre, University of Sydney. She has expertise in youth mood disorders as well as sleep and circadian dysfunction and she is also the deputy director of the new inpatient services for young people with emerging psychiatric disorders (young adult mental health unit) at St Vincent's Private Hospital. A/Prof Scott is honorary lecturer at the Sydney Medical School, University of Sydney and discipline leader of Adult Mental Health, School of Medicine, University of Notre Dame. A/Prof Scott has substantial clinical expertise in the medical complications of psychiatric disorders, neuroimmunology and structural imaging in depressive and anxiety disorders. She also has extensive experience in developing and evaluating comprehensive assessment and management programs for young people with mental health problems through her work with the Brain & Mind Centre as well as the National Youth Mental Health Foundation (*headspace*) programs in Central and South West Sydney.

Top five publications in the last five years

1. **Scott E**, Hermens D, White D, Naismith S, Gehue J, Whitwell, Glozier N, Hickie I (2015) Body mass, cardiovascular risk and metabolic characteristics of young persons presenting for mental health care in Sydney, Australia. *BMJ Open*, 5: e007066.
This large-scale study evaluated the prevalence of risk factors to metabolic and cardiovascular disorders among 1005 young persons presenting for mental health care. Daily smoking was found to be the major risk factor and there was a lack of specificity with regards to diagnostic category.
2. **Scott E**, Hermens D, Naismith S, Guastella A, White D, Whitwell B, Lagopoulos J, Scott J, Hickie I (2013) Distress and disability in young adults presenting to clinical services with mood disorders. *International Journal of Bipolar Disorders*, 1:23.
Age, substance use and possibly gender are probably better predictors of distress/impairment sub-group than mood disorder sub-type in youth.
3. **Scott E**, Hermens D, Naismith S, Guastella A, De Regt T, White D, Lagopoulos J, Hickie I (2013) Distinguishing young people with emerging bipolar disorders from those with unipolar depression. *Journal of Affective Disorders*, 144: 208-15.
Subjects with bipolar disorders were best discriminated from those with unipolar depression by a family history of bipolar, psychotic or substance use disorders.
4. **Scott E**, Hermens D, Naismith S, White D, Whitwell B, Guastella A, Glozier N, Hickie I (2012) Thoughts of death or suicidal ideation are common in young people aged 12 to 30 years presenting for mental health care. *BMC Psychiatry*, 12: 234.
Feelings that life is not worth living, thoughts of death or suicidal ideation are common in young people seeking mental health care. These at-risk cognitions are evident before many of these individuals develop severe or persistent mental disorders.
5. **Scott E**, Hermens D, Glozier N, Naismith S, Guastella A, Hickie I (2012). Targeted primary care-based mental health services engage young Australians in treatment. *Medical Journal of Australia*, 196: 136-40.
This describes the first large dataset (n=1260) on the demographic, disability and illness stage characteristics of those attending the highly novel youth mental health services, and demonstrates how such services alter the nature of presentations in these critical periods.

Overall track record (in the last 5 years)

Key contributions to research: (i) led the development of the clinical service of the youth mental health service networks at the Brain and Mind Centre, and the process by which clinical research is translated into everyday practice; (ii) led the application of the innovative clinical staging model in the youth mental health service at the Brain and Mind Centre, a framework for choosing earlier,

safer and more effective interventions for psychiatric disorders; and (iii) first-authored a series of empirical papers detailing the demographic, clinical and functional characteristics of the first large cohort of young (12-25 years old) outpatients attending *headspace* services.

Publications

- Published in top-tiered (e.g. *Biological Psychiatry*, *American Journal of Psychiatry*, *British Journal of Psychiatry*) and specialist (e.g. *Journal of Affective Disorders*) journals.
- Published over 20 educational resource books for patients and clinicians.
- A total of 85 peer-reviewed articles (13 as first/senior author), with more than 2600 citations. Rapid increase in output in past 5 years: 50 papers.

Grants and fellowships

- \$1.3M career funding as CI, including two ARC linkages (both in 2011) examining: (i) social cognitive training in first episode psychosis; (ii) attentional mechanisms mediating anxiety.

Teaching

- Course convenor and lecturer, Postgraduate Brain and Mind Masters program (at Brain & Mind Centre).

Peer-review

- Oversees the service provision of the clinical neuropsychiatry practice and mentors medical students, psychiatry trainees and psychologists.

Research translation

- Developed, piloted and implemented a national education program for general practitioners in common mental health disorders. Importantly, this program has generated the largest ever data set (46,000 doctor/patient consultations) on mental health practice in primary care. This data (published in the *Medical Journal of Australia*) has been instrumental in formulating changes to education and practice in primary care in Australia. The project was awarded the Golden Medal Team Award for an outstanding contribution to theory, education or practice (A.N.Z. Mental Health Service Achievement Award, The MHS).

Key collaborations

- Prof Jan Scott (U Newcastle, UK); Prof Kathleen Merikangas (NIMH); Prof Pat McGorry (U Melb).

Professional activities

- Fellow of the Royal Australian and New Zealand College of Psychiatrists.
- Australasian Society for Psychiatric Research.

Community engagement and participation

- Regularly teaches within the field of neuropsychiatry.

Supervision and/or mentoring

- Mentorship for medical trainees in psychiatry and general practice to develop clinical research careers.
- Principally responsible for the training of all health service staff in the application of research methods in clinical research practice.
- PhD/MPhil clinical supervisor.

Team Quality and Capability relevant to this proposal (1 page)

Our team has the collective expertise to implement and trial the MHeC-C at-scale, as well as the capabilities provided to undertake the clinical, service and technological activities proposed. CIA has an outstanding track record in research, leadership and knowledge translation in youth mental health. He has also had a significant role over the last two decades in using clinical and health service data to drive enhanced primary care services, which includes the development and systematic evaluation of The University of Sydney sites delivering primary-care based youth mental health services (i.e. *headspace* with CIF), and more recently, the implementation and evaluation of SOS within five *headspace* sites located in the Central and Eastern Sydney Primary Healthcare Networks (with CIB and CIF). He played a key role in the National Review of Mental Health Programmes and Service Report (as a member of the National Mental Health Commission), which has been crucial for mental health service reform in Australia. CIB is a clinical research leader, with a key role in the development and validation of SOS. She is an international pioneer in the adaptation of mental health etools into Spanish, where she has led the design, development, translation and cultural-adaptation of the MHeC into the MHeC-S and in the future, MHeC-C. Her clinical research leadership is evident through the strong collaborative partnerships she has established across Australia (with CIA and CIF) and Colombia (with CIC, CID and CIE), which has laid sound foundations for the success of this study. CIC has expertise in clinical epidemiology, particularly in health service implementation and evaluation. His leadership in developing epidemiological methods for clinical research, specifically in the evaluation and treatment of mood and psychotic disorders in young people will be invaluable for the Colombian adaptation and statistical analyses of this study. CID is internationally renowned in the field of suicide prevention and risk management. He is also an expert in the cross-cultural psychiatry field due to his vast contribution in validating questionnaires into Spanish. His expertise in the area of suicide prevention and cultural adaption will be instrumental for both the suicide prevention and management components of SOS and the Colombian adaptation. CIE has extensive experience in educational activities, leading Colombia's largest psychiatry training program and coordinating the training for the Colombian Freudian Psychoanalytic Society. His expertise is vital for the training and educational component of the project. A major strength of the Colombian team assembled (which has an established history of collaboration as evidenced by past publications), will be led by CIB in collaboration with CIC, CID and CIE. This team is supported by the setting in which they are located including three schools of medicine, two with psychiatry training. CIF is a clinical services director previously at *headspace* Camperdown and now at USpace (a tertiary mental health care service operating through St Vincent's Private Hospital in Sydney), and for Project Synergy, whose work has focussed on the development and application of novel clinical models of care for early intervention youth mental health services (with CIA), and the integration of these models with new and emerging technologies (with CIA and CIB).

Benefit to Australia (*1/2 page*)

The learnings from this study will directly inform Australian and international mental health care reform. This ultimately has the potential to establish Australia as the world leader in the design, development and implementation of new and emerging technologies in delivering mental health care at-scale to culturally and linguistically diverse populations. The configurability and adaptation of the MHeC (via SOS) to specific populations in Australia is crucial to mental health reform, which aims to deliver the right care at the right time, every time, first time to all Australians. Culturally adapting and implementing the MHeC-C (via SOS) will lead to the further development of the technological capacity for such configurability and adaptation. This new and innovative technology lends itself to be configured and implemented in remote and rural Australian populations as well as for low-middle income populations who have the highest need for access to quality mental health care. Moreover, the adaptation of MHeC to colloquial Spanish, the second most spoken language in the world, will significantly contribute to meeting the mental health needs of Australian migrants, and has a huge potential to expand entirely to South and Central America as well as Spain. MHeC-C (via SOS) will be used to deliver personalised care to Colombia's post-war young person society, which will be highly relevant in informing Australian mental health research targeted at improving the management of trauma in the population. Specifically, among young people presenting to youth services in Australia, Australian war veterans, and in other migrant populations with complex trauma issues. In this globalisation era, it is crucial to establish new relations with other countries, and now this can be done with ease through the use of technology. This research will specifically strengthen the Pacific Alliance of which Australia is currently participating as an Observer State. This research partnership between Australia and Colombia will enhance academic collaboration as well as promote education and student exchange, enhancing Australia's Economy (with the fifth pillar of Australia's economy being education).

Consumer and Community Involvement, if applicable (1 page)

This study is only possible through partnership. Our team (CIA, CIB, CIF) has a proven track record using well-established methods of community and consumer engagement as demonstrated by our Australian Project Synergy work throughout 2014-16.

Project Synergy (2014-16) was conducted by the Young and Well Cooperative Research Centre in collaboration with The University of Sydney's Brain and Mind Centre along with other key partner organisations (including ConNetica, Central and Eastern Sydney Primary Healthcare Network, headspace, the Mental Health Commission of New South Wales, Orygen – The National Centre of Excellence in Youth Mental Health, Spark Strategy) who were all essential to the successful design and development, implementation and evaluation of four trials that originally prototyped SOS as an new and innovative Internet-based system of integrated and interoperable apps and etools designed to help end-users manage their health and wellbeing (including mental health). These partner organisations had a shared agenda to co-design/ co-develop, user-test and evaluate SOS in order to fully understand how new and emerging technologies enhance the health and wellbeing of end-users. For this future study (i.e. the current grant application), the groundwork of forging partnerships with Colombian Universities has already taken place and we will adapt these same key partnership principles learnt from previous Project Synergy trials in a culturally-appropriate way through the guidance of local collaborators (i.e. CIB, CIC, CID, CIE).

Perhaps the most important premise of Project Synergy is that collaboration begins with the end-user and ends with the end-user. A recent systematic review reported that end-user participation is variable in the development of mental health technology; with 70% of projects being predominantly consultative, and only 30% collaborative. Project Synergy's key to success is that it has always (and will always) work in partnership with the end-user to design, develop and redesign the technology solution through our now rigorously tested continuous and iterative co-design/ co-development, user-testing and evaluation methodologies. This ultimately results in a solution that is person-centred and configured to the many and varied populations (or communities) of end-users needs and wants that SOS can meet.

There are three key principles that underpin the Project Synergy co-design/ co-development methodology: (1) End-users are active participants from study commencement to conclusion; (2) End-users are design partners and contribute in terms of idea generation, solution creation, and providing feedback on existing design concepts; and, (3) The process is iterative, so that the proposed technology is understood and continually evaluated by end-users in terms of its relevance, meaningfulness and engagingness. Across all Project Synergy studies, the development process is underpinned by three key phases: (1) participatory co-design/ co-development and rapid prototyping through knowledge translation; (2) user (acceptance) testing; and (3) naturalistic trialling. Overall, this R&D Cycle (see Figure) has been refined during previous research and now forms a major part of the solution to increasing the capacity of implementation science to rapidly incorporate new evidence from health research fields and contemporary innovations in technology within mental health services in Australia and internationally.

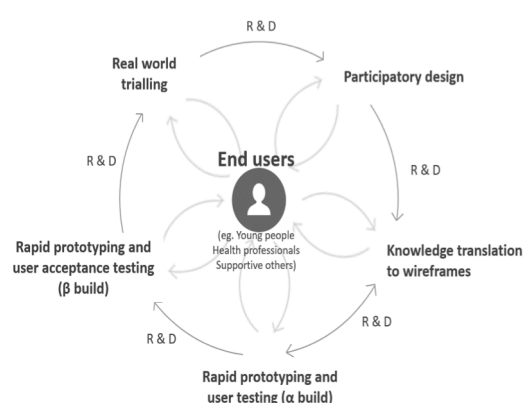


Figure: Project Synergy R&D Cycle, 2017.

Career Disruption, if applicable (*1 page per CI*)

Not applicable to any of the CI's

Relative to Opportunity, if applicable (*½ page per CI*)

Not applicable to any of the CI's

Indigenous Research Excellence Criteria, if applicable *(2 pages)*

Not applicable

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