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Project Synergy: co-designing technology-enabled solutions for Australian mental health services reform



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Project Synergy: co-designing technology-enabled solutions for Australian mental health services reform

Ian B Hickie¹, Tracey A Davenport¹, Jane M Burns²

Summary

- Project Synergy aims to test the potential of new and emerging technologies to enhance the quality of mental health care provided by traditional face-to-face services. Specifically, it seeks to ensure that consumers get the right care, first time (delivery of effective mental health care early in the course of illness).
- Using co-design with affected individuals, Project Synergy has built, implemented and evaluated an online platform to assist the assessment, feedback, management and monitoring of people with mental disorders. It also promotes the maintenance of wellbeing by collating health and social information from consumers, their supportive others and health professionals. This information is reported back openly to consumers and their service providers to promote genuine collaborative care.
- The online platform does not provide stand-alone medical or health advice, risk assessment, clinical diagnosis or treatment; instead, it supports users to decide what may be suitable care options.
- Using an iterative cycle of research and development, the first four studies of Project Synergy (2014–2016) involved the development of different types of online prototypes for young people (i) attending university; (ii) in three disadvantaged communities in New South Wales; (iii) at risk of suicide; and (iv) attending five headspace centres. These contributed valuable information concerning the co-design, build, user testing and evaluation of prototypes, as well as staff experiences during development and service quality improvements following implementation.
- Through ongoing research and development (2017–2020), these prototypes underpin one online platform that aims to support better multidimensional mental health outcomes for consumers; more efficient, effective and appropriate use of health professional knowledge and clinical skills; and quality improvements in mental health service delivery.

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Monitoring and evaluation: The Social Policy Research Centre at the University of New South Wales has been contracted to independently monitor and evaluate the outcomes of Project Synergy (2017–2020), including the return on investment associated with the funding as well as the progress made toward achieving technology-enabled mental health services reform.

Competing interests: Professor Ian Hickie is the Scientific Advisor to, and an equity shareholder in, InnoWell Pty Ltd. Professor Jane Burns sits on the Board of Directors of, and is also an equity shareholder in, InnoWell.

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Chapter 1

Overview of Project Synergy: building an online platform to deliver right care, first time

Ian B Hickie¹, Tracey A Davenport¹, Jane M Burns²

In Australia, and globally, the need for mental health services far exceeds the current capacity of health systems to provide care.^{1–6} In Australia, 3.9 million people experienced a mental disorder in the past 12 months,⁷ but only 1.8 million (46%) accessed treatment.⁸ Many experience significant barriers to accessing mental health care — particularly if they are young people, older people, Aboriginal or Torres Strait Islander people, from a non-English speaking background, homeless, live in areas with poorer socio-economic conditions, or live in rural and remote areas.^{1,9–15}

Limited access to high quality services is notable for young people as it is well established that 75% of serious mental illness and alcohol or other substance misuse emerge before 25 years of age.¹⁶ When young people do seek and receive help, timely and evidence-based treatments are only received by a minority.¹⁷ For young people, stigmatising attitudes and embarrassment are often cited as prominent barriers to help-seeking.¹⁸ Other barriers include concerns around confidentiality and trust,¹⁹ difficulty identifying the symptoms of mental illness, undue reliance on self-help (ie, not wanting professional help), limited knowledge about mental health services, and a lack of accessibility (eg, transport, geographical location, cost).¹⁸ Lack of actual availability of high quality services and trained health professionals is another significant barrier.^{10,19–22}

Increasing access to care alone is not sufficient to ensure good outcomes for people with mental illness. Additionally, access to evidence-based treatments is critical to achieving good outcomes.⁸ 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 issues.²³ While there is conflicting evidence as to whether some parts of the internet, specifically social networking sites, may be associated with mental health issues,²⁴ the internet in general is also increasingly recognised as a critical setting to promote youth mental health and wellbeing.²⁵ The World Health Organization²⁶ advocates engaging young people in the environments where they interact, and using the tools and networks with which they are familiar. In Australia, almost all young people aged 16–25 years are online (99%), with 60% using the internet to find information related to mental health.²⁷

To date, the most common drivers for developing and promoting online support have been economic and access based. That is, the cheapest way to reach more people is via the internet.^{26,28} However, the evidence base now also suggests that integrating online health information technologies with face-to-face services can:

- promote universal access to services, regardless of location, vulnerability or socio-economic status;^{29,30}

- increase disclosure to facilitate a stepped approach to help-seeking;³¹
- reduce burden on the face-to-face system by using technologies to promote self-management and prevention where possible;³²
- increase effectiveness of face-to-face services by augmenting traditional mental health support with technologies that promote shared management;^{33,34}
- improve the identification of people at risk of suicide by using online assessment before face-to-face appointments to enable an appropriate and timely response from service providers;³⁵ and
- facilitate rapid identification of individuals at risk of progressing to more severe mental illness.³⁶

An integrated system would also provide a unique opportunity to improve the management, coordination and delivery of appropriate services, better matched to need and personal circumstance.³⁷ This may be addressed through an increased emphasis on prevention, early intervention and general health and wellbeing (thereby also developing a more mentally healthy population), and reduced pressure on current mental health services (by providing targeted, high quality and more efficient services tailored to those most in need).³⁸ In a stratified care delivery system, spreading the reach of technology to provide support to people with milder needs could reduce demand for face-to-face services and may also enable higher intensity services and better tracking of multidimensional (ie, health and social) outcomes for those with more complex needs.^{39,40}

In 2014, the Young and Well Cooperative Research Centre (CRC) was invited by the National Mental Health Commission (NMHC) to provide advice about new and emerging technologies in e-mental health.⁴¹ In summary, the Young and Well CRC briefing paper argued that new and emerging technologies were available to build an integrated system that entwines both online and face-to-face models of mental health care. Further, it recommended that a re-imagined mental health care system should be oriented around the user, promote self-managed care, ensure individuals can control their own data, and allow mass customisation.

The Young and Well CRC briefing paper⁴¹ resulted in a direct recommendation by the NMHC that new and emerging technologies should be considered a cornerstone of major mental health services reform in Australia.¹⁰ Further, the NMHC, in its 2014 Report of the National Review of Mental Health Programmes and Services, called for an overhaul of the mental health system, including an integration of e-mental health with face-to-face services.^{10,38}

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Description of the online platform as it is listed on the Australian Register of Therapeutic Goods (software as a medical device, class 1, ARTG ID 315030)

- The online platform is a customisable digital tool that assists assessment, monitoring and management of mental health issues, and maintenance of wellbeing.
- It does this by collecting personal and health information from consumers and their service providers. This information is stored, scored and reported back to consumers and their health professionals to promote collaborative care.
- The clinical content is determined in collaboration with the service provider who invited the consumer to use the platform. The platform does not provide stand-alone medical or health advice, diagnosis or treatment. Instead, it guides and supports (but does not direct) consumers and their health professionals to decide what may be suitable care options. Importantly, all care aligns with the existing clinical governance (eg, policies and procedures) of the service provider.

Over the past decade, while a growing number of efficacy trials have shown strong outcomes for use of health information technologies in mental health treatments, there are only a few examples of successful integration into services.⁴² In response to these findings and the NMHC recommendations, Project Synergy was commissioned in 2014 by the Australian Government Department of Health and conducted by the Young and Well CRC in partnership with the University of Sydney's Brain and Mind Centre.

Project Synergy

The broad aim of Project Synergy is to harness new and emerging technologies to enhance the quality of mental health care provided by traditional face-to-face and online mental health services. More specifically, Project Synergy aims to co-design, build, implement and evaluate an online platform (ie, group of technologies that are used as a base upon which to customise and configure service-specific digital solutions) to ensure consumers get the right care, first time (delivery of effective mental health care early in the course of illness). This care can encompass the entire spectrum of health and wellbeing. Individuals, ranging from those who simply want support to achieve specific mental health goals to those requiring care for serious mental health problems, can gain value from this solution.

Given the ongoing nature of Project Synergy, two phases have been identified:

- Phase 1 (2014–2016): the primary objective was to use new and emerging technologies to transform the provision of mental health services for all young people across Australia, by co-designing and building prototypes as well as implementing and evaluating the impact of the prototypes for all users (specifically including young people and their supportive others, health professionals and service providers).
- Phase 2 (2017–2020): the primary objective is to use the research and development cycle (co-design workshops, user testing, implementation and feasibility testing) from Phase 1 to iterate the prototypes to one online platform (Box). This platform can then be embedded into traditional mental health services as a means to deliver right care, first time across all age groups and populations.

Through the first four studies of Project Synergy (2014–2016) with young people, described in this Supplement (Chapters 3–6), valuable information concerning the co-design, build, implementation and evaluation of online prototypes in different

settings and for different purposes was derived. Bringing these together within one online platform means consumers can access support through many doors, and only ever have to tell their story once. Additional learnings also related to:

- the need for the online platform to be configurable, including for content, population and locality;
- how best to achieve successful integration and interoperability of external partner organisation apps and e-tools;
- enhancing specific functionality of the online platform relating to usability and reliability;
- identifying key clinical content in the online platform that improves timely care provision, such as rapid assessment of suicidal thoughts and behaviours and other at-risk mental states; and
- recognising the barriers and facilitators that lead to the successful adoption of these co-designed technologies in traditional mental health service settings.

Differentiating the online platform

While there are many forms of health information technology available for use in health and mental health service settings, these technologies vary greatly in terms of key features, evaluation, maturity and depth. The range of features available includes multidimensional (self-report or clinician-aided) assessment, (self-administered or clinician-guided) evidence-based interventions, shared decision making between consumers and health professionals, teletherapies, and routine outcome monitoring.

A number of other health information technologies offer various features and solutions that overlap with our aim to use digital technologies to support timely and ongoing mental health care. For example, the Monsenso mHealth solution for mental illnesses has been designed to collect self-report and sensor data (eg, physical activity, mobility and phone usage), trigger notifications in response to warning signs, and provide insights into the associations between behavioural patterns and mental ill health;⁴³ and Recovery Record is an mHealth app for eating disorders that allows individuals to log their meals, thoughts and feelings.⁴⁴ Logged information can then be overseen by a health professional to monitor progress and identify triggers to improve care. By contrast, consumer-focused apps and online programs such as headspace, Big White Wall and Moodpath offer wellbeing tracking, information and advice, personal goal setting as well as self-management tools, techniques and programs.⁴⁵ Notably, within this person-focused (direct-to-consumer) market, many competitors provide similar solutions. There are also a vast number of digital applications for wellbeing-focused strategies that do not directly assess mental health status or provide mental health interventions.

Importantly, our online platform is differentiated from many health information technologies in that it is focused on supporting existing health services to deliver more effective care, at scale. It is not primarily focused on providing specific online interventions for any particular mental disorder, but rather collating the necessary personal and social information to support the user and the health professional towards achieving highly personalised and measurement-based care options. Such care options may be delivered online or by traditional face-to-face methods. The online platform is also backed by ongoing and

iterative research and development. Through its transparent use of information, it puts the person at the centre of their own care and is data-driven and

delivered immediately (ie, in real-time), thereby facilitating right care, first time. This approach is designed to lead to better mental health outcomes for consumers;

more efficient, effective and appropriate use of health professional knowledge and clinical skills; and quality improvements in mental health service delivery.

- 1 Australian Bureau of Statistics. National Survey of Mental Health and Wellbeing: summary of results, 2007 (ABS Cat. No. 4326.0). Canberra: ABS, 2008. <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4326.0> (viewed Aug 2019).
- 2 Australian Bureau of Statistics. National Survey of Mental Health and Wellbeing: profile of adults, 1997 (ABS Cat. No. 4326.0). Canberra: ABS, 1998. <http://www.abs.gov.au/ausstats/abs@.nsf/ProductsbyReleaseDate/DSA0AC778746378FCA2574EA00122887> (viewed Aug 2019).
- 3 Health Workforce Australia. Australia's Health Workforce Series: Psychologists in focus. Adelaide: HWA, 2014. http://iaha.com.au/wp-content/uploads/2014/03/HWA_Australia-Health-Workforce-Series_Psychologists-in-focus_vF_LR.pdf (viewed Aug 2019).
- 4 World Health Organization. Investing in mental health: evidence for action. Geneva: WHO, 2013. http://www.who.int/iris/bitstream/10665/87232/1/9789241564618_eng.pdf?ua=1 (viewed Aug 2019).
- 5 World Health Organization. Mental health action plan 2013–2020. Geneva: WHO, 2013. http://www.who.int/iris/bitstream/10665/89966/1/9789241506021_eng.pdf?ua=1 (viewed Aug 2019).
- 6 Saxena S, Thornicroft G, Knapp M, Whiteford H. Resources for mental health: scarcity, inequity, and inefficiency. *Lancet* 2007; 370: 878–889.
- 7 Australian Institute of Health and Welfare. Mental health services in Australia [web report]. <https://www.aihw.gov.au/reports/mental-health-services/mental-health-services-in-australia/report-contents/summary/prevalence-and-policies> (viewed Aug 2019).
- 8 Whiteford HA, Buckingham WJ, Harris MG, et al. Estimating treatment rates for mental disorders in Australia. *Aust Health Rev* 2014; 38: 80–85.
- 9 Australian Institute of Health and Welfare. Young Australians: their health and wellbeing 2011 (Cat. No. PHE 140). Canberra: AIHW, 2011. <https://www.aihw.gov.au/getmedia/14eed34e-2e0f-441d-88cb-ef376196f587/12750.pdf.aspx?inline=true> (viewed Aug 2019).
- 10 National Mental Health Commission. Contributing lives, thriving communities. Report of the national review of mental health programmes and services. Sydney: NMHC, 2014. <http://www.mentalhealthcommission.gov.au/media/119905/Vol%201%20-%20Main%20Paper%20-%20Final.pdf> (viewed Aug 2019).
- 11 Muir-Cochrane E, O'Kane D, Barkway P, et al. Service provision for older people with mental health problems in a rural area of Australia. *Aging Ment Health* 2014; 18: 759–766.
- 12 van Gaans D, Dent E. Issues of accessibility to health services by older Australians: a review. *Public Health Rev* 2018; 39: 20.
- 13 Costello L, Thomson M, Jones K. Mental health and homelessness: final report. AHURI Research Synthesis Report for the Mental Health Commission of NSW. Melbourne: Australian Housing and Urban Research Institute, 2013. <https://nswmentalhealthcommission.com.au/sites/default/files/publication-documents/Final%20Report%20-%20AHURI%20-%20Men> <http://www.mentalhealthcommission.gov.au/media/119905/Vol%201%20-%20Main%20Paper%20-%20Final.pdf> (viewed Aug 2019).
- 14 Vinson T, Rawsthorne M, Beavis A, Ericson M. Dropping off the edge 2015: persistent communal disadvantage in Australia. Melbourne: Jesuit Social Services and Catholic Social Services Australia, 2015. http://k46cs13u1432b9asz49wnhcx-wpengine.netdna-ssl.com/wp-content/uploads/0001_dote_2015.pdf (viewed Aug 2019).
- 15 Hassett A, George K, Harrigan S. Admissions of elderly patients from English-speaking and non-English-speaking backgrounds to an inpatient psychogeriatric unit. *Aust N Z J Psychiatry* 1999; 33: 576–582.
- 16 Gore FM, Bloem PJ, Patton GC, et al. Global burden of disease in young people aged 10–24 years: a systematic analysis. *Lancet* 2011; 377: 2093–2102.
- 17 Libby AM, Brent DA, Morrato EH, et al. Decline in treatment of pediatric depression after FDA advisory on risk of suicidality with SSRIs. *Am J Psychiatry* 2007; 164: 884–891.
- 18 Gulliver A, Griffiths KM, Christensen H. Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review. *BMC Psychiatry* 2010; 10: 113.
- 19 Torous J, Roberts L. Needed innovation in digital health and smartphone applications for mental health. *JAMA Psychiatry* 2017; 74: 437–438.
- 20 Bendall S, Phelps A, Browne V, et al. Trauma and young people. Moving toward trauma-informed services and systems. Melbourne: Orygen, The National Centre of Excellence in Youth Mental Health, 2018. https://www.orygen.org.au/Policy-Advocacy/Policy-Reports/Trauma-and-young-people-Moving-toward-trauma-info/Orygen_trauma_and_young_people_policy_report.aspx?text (viewed Aug 2019).
- 21 Sawyer SM, Patton GC. Why are so many more adolescents presenting to our emergency departments with mental health problems? *Med J Aust* 2018; 208: 339–340. <https://www.mja.com.au/journal/2018/208/8/why-are-so-many-more-adolescents-presenting-our-emergency-departments-mental>
- 22 Ivancic L, Cairns K, Shuttleworth L, et al. Lifting the weight: understanding young people's mental health and service needs in regional and remote Australia. Sydney: ReachOut Australia and Mission Australia, 2018. <http://about.au.reachout.com/wp-content/uploads/2018/06/ReachOut-Australia-Mission-Australia-Lifting-the-Weight-2018.pdf> (viewed Aug 2019).
- 23 Burns JM, Davenport TA, Durkin LA, et al. The internet as a setting for mental health service utilisation by young people. *Med J Aust* 2010; 192 (11 Suppl): S22–S26. <https://www.mja.com.au/journal/2010/192/11/internet-setting-mental-health-service-utilisation-young-people>
- 24 Pantic I. Online social networking and mental health. *Cyberpsychol Behav Soc Netw* 2014; 17: 652–657.
- 25 World Health Organization Secretariat. Global health promotion scaling up for 2015: a brief review of major impacts and developments over the past 20 years and challenges for 2015. Background document for the Sixth Global Conference on Health Promotion; 2005 Aug 7–11; Bangkok, Thailand. http://www.who.int/healthpromotion/conferences/6gchp/hpr_conference_background.pdf?ua=1 (viewed Aug 2019).
- 26 Clarke G, Yarrowborough BJ. Evaluating the promise of health IT to enhance/expand the reach of mental health services. *Gen Hosp Psychiatry* 2013; 35: 339–344.
- 27 Burns JM, Davenport TA, Christensen H, et al. Game on: exploring the impact of technologies on young men's mental health and wellbeing. Findings from the first Young and Well National Survey. Melbourne: Young and Well Cooperative Research Centre, 2013. <https://cdn.movember.com/uploads/files/Our%20Work/game-on-movember-foundation.pdf> (viewed Aug 2019).
- 28 Muñoz RF. Using evidence-based internet interventions to reduce health disparities worldwide. *J Med Internet Res* 2010; 12: e60.
- 29 Griffiths KM, Christensen H. Internet-based mental health programs: a powerful tool in the rural medical kit. *Aust J Rural Health* 2007; 15: 81–87.
- 30 Lal S, Adair CE. E-mental health: a rapid review of the literature. *Psychiatr Serv* 2014; 65: 24–32.
- 31 Bradford S, Rickwood D. Acceptability and utility of an electronic psychosocial assessment (myAssessment) to increase self-disclosure in youth mental healthcare: a quasi-experimental study. *BMC Psychiatry* 2015; 15: 305–317.
- 32 Clarke AM, Kuosmanen T, Barry MM. A systematic review of online youth mental health promotion and prevention interventions. *J Youth Adolesc* 2015; 44: 90–113.
- 33 Palen TE, Ross C, Powers JD, Xu S. Association of online patient access to clinicians and medical records with use of clinical services. *JAMA* 2012; 308: 2012–2019.
- 34 Wentzel J, van der Vaart R, Bohlmeijer ET, van Gemert-Pijnen JEW. Mixing online and face-to-face therapy: how to benefit from blended care in mental health care. *JMIR Ment Health* 2016; 3: e9.
- 35 Iorfino F, Davenport TA, Ospina-Pinillos L, et al. Using new and emerging technologies to identify and respond to suicidality among help-seeking young people: a cross-sectional study. *J Med Internet Res* 2017; 19: e310.
- 36 Ospina-Pinillos L, Davenport TA, Iorfino F, et al. Using new and innovative technologies to assess clinical stage in early intervention youth mental health services: Evaluation study. *J Med Internet Res* 2018; 20: e259.
- 37 Zwar N, Harris M, Griffiths R, et al. A systematic review of chronic disease management. Australian Primary Health Care Research Institute, School of Public Health and Community Medicine, University of New South Wales, 2006. https://openresearch-repository.anu.edu.au/bitstream/1885/119226/3/final_25_zwar.pdf_85791.pdf (viewed Aug 2019).
- 38 Patel V, Saxena S, Lund C, et al. The Lancet Commission on global mental health and sustainable development. *Lancet* 2018; 392: 1553–1598.

- 39 Cross S, Hermens D, Scott E, et al. A clinical staging model for early intervention youth mental health services. *Psychiatr Serv* 2014; 65: 939–943.
- 40 Cross SP, Hickie I. Transdiagnostic stepped care in mental health. *Public Health Res Pract* 2017; 27(2): pii: 2721712.
- 41 Burns J, Liacos G, Green F, et al. Advice on innovative technologies in e-mental health: briefing paper for the National Mental Health Commission. Melbourne: Young and Well Cooperative Research Centre, 2014. <https://www.mentalhealthcommission.gov.au/media/119671/Innovative%20technologies%20in%20e-mental%20health%20-%20Young%20and%20Well%20CRC.pdf> (viewed Aug 2019).
- 42 Mohr DC, Lyon AR, Lattie EG, et al. Accelerating digital mental health research from early design and creation to successful implementation and sustainment. *J Med Internet Res* 2017; 19(5): e153.
- 43 Monsenso. The Monsenso mHealth solution for mental illnesses. Product sheet. December 2017. https://www.monsenso.com/wp-content/uploads/2018/02/171220.Monsenso.Product.EN_.pdf (viewed Aug 2019).
- 44 Lindgreen P, Lomborg K, Clausen L. Patient experiences using a self-monitoring app in eating disorder treatment: qualitative study. *JMIR Mhealth Uhealth* 2018; 6(6): e10253.
- 45 Mani M, Kavanagh DJ, Hides L, Stoyanov SR. Review and evaluation of mindfulness-based iPhone apps. *JMIR Mhealth Uhealth* 2015; 19(3): e82. ■

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, Orlowski 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,

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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

Pre-alpha prototype



Beta prototype



Alpha prototype



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

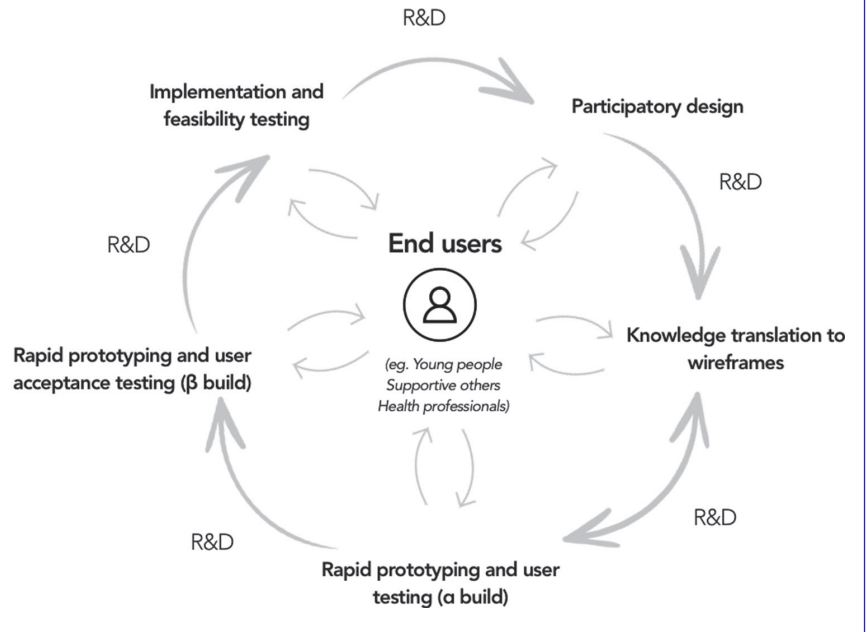
Through implementation and feasibility testing, beta prototypes were tested to determine engagement and impact of technology solutions. Engagement measures how users interact with the prototypes. For example, this can include frequency and length of session, when the prototype is used and on what device, 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 transcriptions 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.

- 1 Australian Bureau of Statistics. National Survey of Mental Health and Wellbeing: summary of results, 2007 (ABS Cat. No. 4326.0). Canberra: ABS, 2008. <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4326.0> (viewed Aug 2019).
- 2 Lawrence D, Johnson S, Hafekost J, et al. The mental health of children and adolescents: report on the second Australian child and adolescent survey of mental health and wellbeing. Canberra: Commonwealth of Australia, 2015. [https://www.health.gov.au/internet/main/publishing.nsf/Content/9DA8CA21306FE6EDCA257E2700016945/\\$File/child2.pdf](https://www.health.gov.au/internet/main/publishing.nsf/Content/9DA8CA21306FE6EDCA257E2700016945/$File/child2.pdf) (viewed Aug 2019).
- 3 Australian Government Department of Health and Ageing. E-mental health strategy for Australia. Canberra: DoHA, 2012. [http://www.health.gov.au/internet/main/publishing.nsf/Content/7C7B0BFEB985D0EBCA257BF001BBOA6/\\$File/emstrat.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/7C7B0BFEB985D0EBCA257BF001BBOA6/$File/emstrat.pdf) (viewed Aug 2019).
- 4 Torous J, Roberts L. Needed innovation in digital health and smartphone applications for mental health. *JAMA Psychiatry* 2017; 74: 437–438.
- 5 Jackson CL, Janamian T, Booth M, Watson D. Creating health care value together: a means to an important end. *Med J Aust* 2016; 204 (7 Suppl): S3–S4. <https://www.mja.com.au/journal/2016/204/7/creating-health-care-value-together-means-important-end>.
- 6 Judd FK, Jackson H, Davis J, et al. Improving access for rural Australians to treatment for anxiety and depression: the University of Melbourne Depression and Anxiety Research and Treatment Group–Bendigo Health Care Group initiative. *Aust J Rural Health* 2001; 9: 92–97.
- 7 McHugh RK, Barlow DH. The dissemination and implementation of evidence-based psychological treatments: a review of current efforts. *Am Psychol* 2010; 65: 73–84.
- 8 Burns JM, Davenport TA, Christensen H, et al. Game on: exploring the impact of technologies on young men's mental health and wellbeing. Findings from the first Young and Well National Survey. Melbourne: Young and Well Cooperative Research Centre, 2013. <https://cdn.movember.com/uploads/files/Our%20Work/game-on-movember-foundation.pdf> (viewed Aug 2019).
- 9 Oh E, Jorm AF, Wright A. Perceived helpfulness of websites for mental health information: a national survey of young Australians. *Soc Psychiatry Psychiatr Epidemiol* 2009; 44: 293–299.
- 10 Kim EH, Coumar A, Lober WB, Kim Y. Addressing mental health epidemic among university students via web-based, self-screening, and referral system: a preliminary study. *IEEE Trans Inf Technol Biomed* 2011; 15: 301–307.
- 11 Powell J, Clarke A. Investigating internet use by mental health service users: interview study. *Stud Health Technol Inform* 2007; 129 (Pt2): 1112–1116.
- 12 Clarke AM, Kuosmanen T, Barry MM. A systematic review of online youth mental health promotion and prevention interventions. *J Youth Adolesc* 2015; 44: 90–113.
- 13 Doherty G, Coyle D, Sharry J. Engagement with online mental health interventions: an exploratory clinical study of a treatment for depression. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems; 2012 May 05–10; Austin, Texas, USA. New York: ACM, 2012: 1421–1430.
- 14 Bjerkan J, Hedlund M, Hellesø R. Patients' contribution to the development of a web-based plan for integrated care - a participatory design study. *Inform Health Soc Care* 2015; 40: 167–184.
- 15 Orlowski SK, Lawn S, Venning A, et al. Participatory research as one piece of the puzzle: a systematic review of consumer involvement in design of technology-based youth mental health and well-being interventions. *JMIR Hum Factors* 2015; 2: e12.
- 16 Australian Government Department of Health. Review of health and medical research in Australia: terms of reference. <https://www.ans.org.au/images/pdf/83.pdf> (viewed Aug 2019).
- 17 Sjöberg C, Timpka T. Participatory design of information systems in health care. *J Am Med Inform Assoc* 1998; 5: 177–183.
- 18 Hagen P, Collin P, Metcalf A, et al. Participatory design of evidence-based online youth mental health promotion, intervention and treatment. Melbourne: Young and Well Cooperative Research Centre, 2012. <https://researchdi.uct.westernsydney.edu.au/islandora/object/uws%3A18814/datastream/PDF/view> (viewed Aug 2019).
- 19 Sullivan P. Beyond a narrow conception of usability testing. *IEEE Trans Prof Commun* 1989; 32: 256–264.
- 20 Larsen SB, Sørensen NS, Petersen MG, Kjeldsen GF. Towards a shared service centre for telemedicine: telemedicine in Denmark, and a possible way forward. *Health Informatics J* 2016; 22: 815–827.
- 21 Gordon M, Henderson R, Holmes JH, et al. Participatory design of ehealth solutions for women from vulnerable populations with perinatal depression. *J Am Med Inform Assoc* 2016; 23: 105–109.
- 22 Monshat K, Vella-Brodrick D, Burns J, Herrman H. Mental health promotion in the Internet age: a consultation with Australian young people to inform the design of an online mindfulness training programme. *Health Promot Int* 2012; 27: 177–186.
- 23 Milton A, Lloyd-Evans B, Fullarton K, et al. Development of a peer-supported, self-management intervention for people following mental health crisis. *BMC Res Notes* 2017; 10: 588.
- 24 Heintz M, Law ELC, Soleimani S. Paper or pixel? Comparing paper and tool-based participatory design approaches. In: Abascal J, Barbosa S, Fetter M, et al, editors. Human-Computer Interaction – INTERACT 2015. Lecture Notes in Computer Science (Vol 9298). Proceedings of IFIP TC 13 Conference on Human-Computer Interaction (INTERACT); 2015 Sept 14–18; Bramberg, Germany. Cham, Switzerland: Springer, 2015: 501–517.
- 25 Tripp SD, Bichelmeyer B. Rapid prototyping: an alternative instructional design strategy. *Educ Technol Res Dev* 1990; 38: 31–44.
- 26 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101.
- 27 Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field methods* 2006; 18: 59–82.
- 28 Morris ZS, Wooding S, Grant J. The answer is 17 years, what is the question: understanding time lags in translational research. *J R Soc Med* 2011; 104: 510–520. ■

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

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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

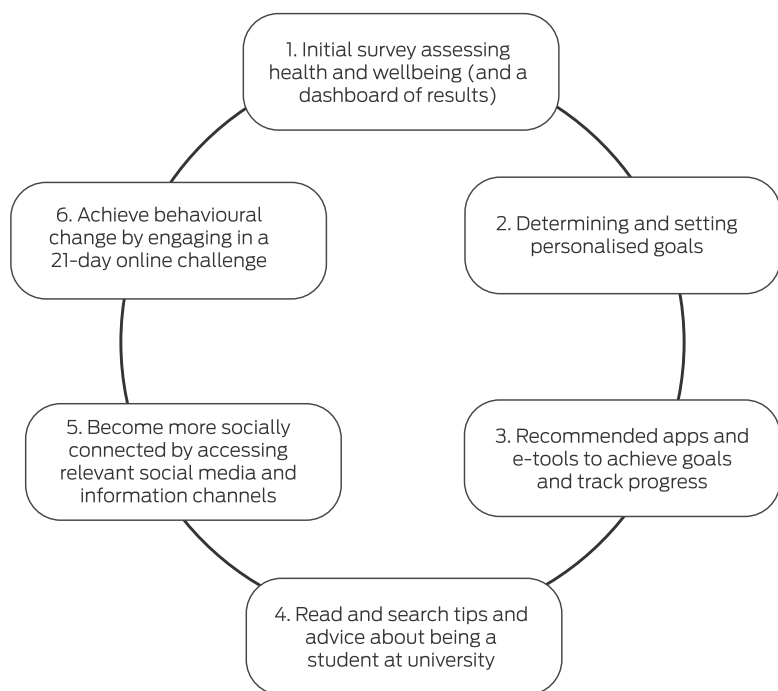
Using Project Synergy's research and development cycle, co-design workshops and knowledge translation were carried out at the University of Sydney between July 2014 and January 2015.

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.

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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)

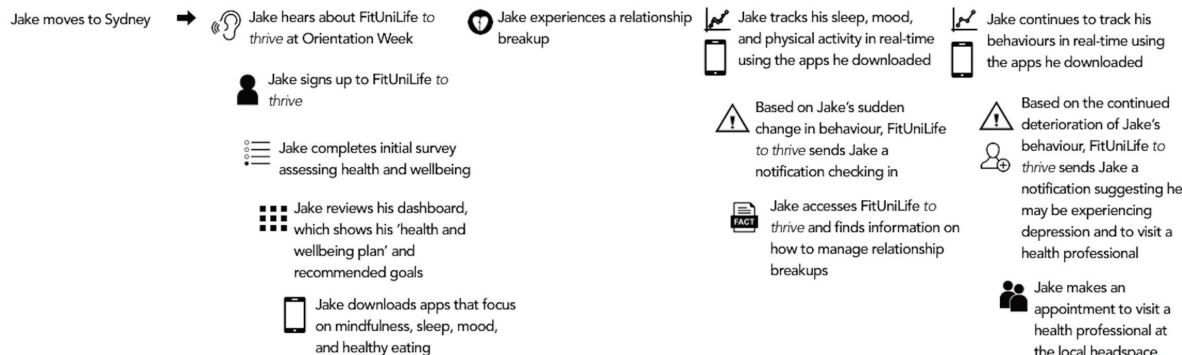
During Easter break, Jake's girlfriend tells him that she has met a local winemaker through her family vineyard and that the long distance has made the relationship too tough to manage. Jake, devastated and heartbroken, returns to Sydney.

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

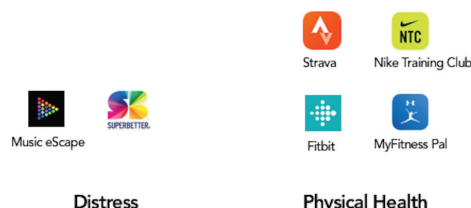
Another two weeks pass and Jake is still sad, is not sleeping or exercising and feels that it is impossible to get out of bed. FitUniLife to thrive again sends him a notification and this time suggests that he may be experiencing depression and suggests he visit ReachOut.com, beyondblue or headspace (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



Other suggested apps



* 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 promote good health and wellbeing in the 21st century.

1 Pittman LD, Richmond A. University belonging, friendship quality, and psychological adjustment during the transition to college. *J Exp Educ* 2008; 76: 343–362.

2 Hare J. High university drop-out rates cost \$1.4bn. *The Australian* 2010; 19 Oct. <https://www.theaustralian.com.au/higher-education/high-university-drop-out-rates-cost-14bn/news-story/3ab0e494787389df9b0a8a892bba2242> (viewed Aug 2019).

3 Hobsons. The good universities guide 2015. Melbourne: Hobsons, 2014. <http://downloads.realviewtechnologies.com/Hobsons/Good%20Universities%20Guide/The%20Good%20Uni>

versities%20Guide%202015.pdf (viewed Aug 2019).

4 Ryan RM, Deci EL. On happiness and human potentials: a review of research on hedonic and eudaimonic well-being. *Annu Rev Psychol* 2001; 52: 141–166.

5 Kloep M, Hendry LB, Saunders D. A new perspective on human development. *Conf Int J Arts Sci* 2009; 1: 332–343. <https://pdfs.semanticscholar.org/9f30/4cc2ec19dfa4f88c29e6e8c9843511673010.pdf> (viewed Aug 2019).

6 Lyubomirsky S, Sheldon KM, Schkade D. Pursuing happiness: the architecture of

sustainable change. *Rev Gen Psychol* 2005; 9: 111–131.

7 Lyubomirsky S, King L, Diener E. The benefits of frequent positive affect: does happiness lead to success? *Psychol Bull* 2005; 131: 803–855.

8 Bauman A, Merom D, Bull FC, et al. Updating the evidence for physical activity: summative reviews of the epidemiological evidence, prevalence, and interventions to promote "active aging". *Gerontologist* 2016; 56 Suppl 2: S268–S280.

9 Mammen G, Faulkner G. Physical activity and the prevention of depression: a systematic review

- of prospective studies. *Am J Prev Med* 2013; 45: 649–657.
- 10 de Jong-Gierveld J. A review of loneliness: concepts and definitions, determinants and consequences. *Rev Clin Gerontol* 1998; 8: 73–80.
 - 11 Hawkey LC, Cacioppo JT. Loneliness matters: a theoretical and empirical review of consequences and mechanisms. *Ann Behav Med* 2010; 40: 218–227.
 - 12 Heinrich LM, Gullone E. The clinical significance of loneliness: a literature review. *Clin Psychol Rev* 2006; 26: 695–718.
 - 13 Holt-Lunstad J, Smith TB, Baker M, et al. Loneliness and social isolation as risk factors for mortality: a meta-analytic review. *Perspect Psychol Sci* 2015; 10: 227–237.
 - 14 McWhirter BT. Loneliness: a review of current literature, with implications for counselling and research. *J Couns Dev* 1990; 68: 417–422.
 - 15 Lane ND, Mohammad M, Lin M, et al. BeWell: a smartphone application to monitor, model and promote wellbeing. Proceedings of the 5th International ICST Conference on Pervasive Computing Technologies for Healthcare, May 23–26, 2011. Dublin: IEEE Press, 2011: pp 23–26.
 - 16 Australian Communications and Media Authority and the Office of the Children's eSafety Commissioner. Aussie teens and kids online. Canberra: Australian Communications and Media Authority, 2016. <https://www.acma.gov.au/theACMA/engage-blogs/engage-blogs/Research-snapshots/Aussie-teens-and-kids-online> (viewed Aug 2019).
 - 17 Pagoto S, Schneider K, Jovic M, et al. Evidence-based strategies in weight-loss mobile apps. *Am J Prev Med* 2013; 45: 576–582.
 - 18 Abrams LC, Lee Westmaas J, Bontemps-Jones J, et al. A content analysis of popular smartphone apps for smoking cessation. *Am J Prev Med* 2013; 45: 732–736.
 - 19 Schmidt RA, Wrisberg WA. Motor learning and performance: a situation-based learning approach. 4th ed. Champaign, Ill: Human Kinetics, 2008.
 - 20 Bandura A, Cervone D. Self-evaluative and self-efficacy mechanisms governing the motivational effects of goal systems. *J Pers Soc Psychol* 1983; 45: 1017–1028.
 - 21 Becker LJ. Joint effect of feedback and goal setting on performance: a field study of residential energy conservation. *J Appl Psychol* 1978; 63: 428–433.
 - 22 Hagen P, Collin P, Metcalf A, et al. Participatory design of evidence-based online youth mental health promotion, intervention and treatment. Melbourne: Young and Well Cooperative Research Centre, 2012. <https://researchdirect.westernsydney.edu.au/islandora/object/uws%3A18814/datastream/PDF/view> (viewed Aug 2019).
 - 23 Burns JM, Davenport TA, Christensen H, et al. Game on: exploring the impact of technologies on young men's mental health and wellbeing. Findings from the first Young and Well National Survey. Melbourne: Young and Well Cooperative Research Centre, 2013. <https://cdn.movember.com/uploads/files/Our%20Work/game-on-movember-foundation.pdf> (viewed Aug 2019).
 - 24 Hickie IB, Davenport TA, Hadzi-Pavlovic D, et al. Development of a simple screening tool for common mental disorders in general practice. *Med J Aust* 2001; 175: S10–S17. <https://onlinelibrary.wiley.com/doi/abs/10.5694/j.1326-5377.2001.tb143784.x?sid=nlm%3Apubmed>
 - 25 Craig CL, Marshall AL, Sjöström M, et al. International physical activity questionnaire: 12-country reliability and validity. *Med Sci Sports Exerc* 2003; 35: 1381–1395.
 - 26 The WHOQOL Group. Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychol Med* 1998; 28: 551–558.
 - 27 Morosini PL, Magliano L, Brambilla L, et al. Development, reliability and acceptability of a new version of the DSM-IV Social and Occupational Functioning Assessment Scale (SOFAS) to assess routine social functioning. *Acta Psychiatr Scand* 2000; 101: 323–329.
 - 28 Von Korff M, Ustun TB, Ormel J, et al. Self-report disability in an international primary care study of psychological illness. *J Clin Epidemiol* 1996; 49: 297–303.
 - 29 Stoyanov SR, Hides L, Kavanagh DJ, et al. Mobile app rating scale: a new tool for assessing the quality of health mobile apps. *JMIR Mhealth Uhealth* 2015; 3: e27.
 - 30 Seligman MEP. Flourish: a visionary new understanding of happiness and well-being. New York City, NY: Free Press, 2011.
 - 31 Keyes CL. Mental illness and/or mental health? Investigating axioms of the complete state model of health. *J Consult Clin Psychol* 2005; 73: 539–548.
 - 32 Huppert FA, So TTC. Flourishing across Europe: application of a new conceptual framework for defining well-being. *Soc Indic Res* 2013; 110: 837–861.
 - 33 Maslow AH. A theory of human motivation. *Psychol Rev* 1943; 50: 370–396.
 - 34 Ryff CD. Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *J Pers Soc Psychol* 1989; 57: 1069–1081.
 - 35 Cheng VWS, Davenport TA, Johnson D, et al. An app that incorporates gamification, mini-games, and social connection to improve men's mental health and wellbeing (MindMax): participatory design process. *JMIR Mental Health* 2018; 5: e11068.
 - 36 Cheng VWS, Davenport TA, Johnson D, et al. Gamification in apps and technologies for improving mental health and well-being: systematic review. *JMIR Ment Health* 2019; 6: e13717.
 - 37 Lasgaard M, Friis K, Shevlin M. "Where are all the lonely people?" A population-based study of high-risk groups across the life span. *Soc Psychiatry Psychiatr Epidemiol* 2016; 51: 1373–1384.
 - 38 Pitman A, Mann F, Johnson S. Advancing our understanding of loneliness and mental health problems in young people. *Lancet Psychiatry* 2018; 5: 955–956.
 - 39 Fernandez A, Howse E, Rubio-Valera M, et al. Setting-based interventions to promote mental health at the university: a systematic review. *Int J Public Health* 2016; 61: 797–807. ■

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

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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.

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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

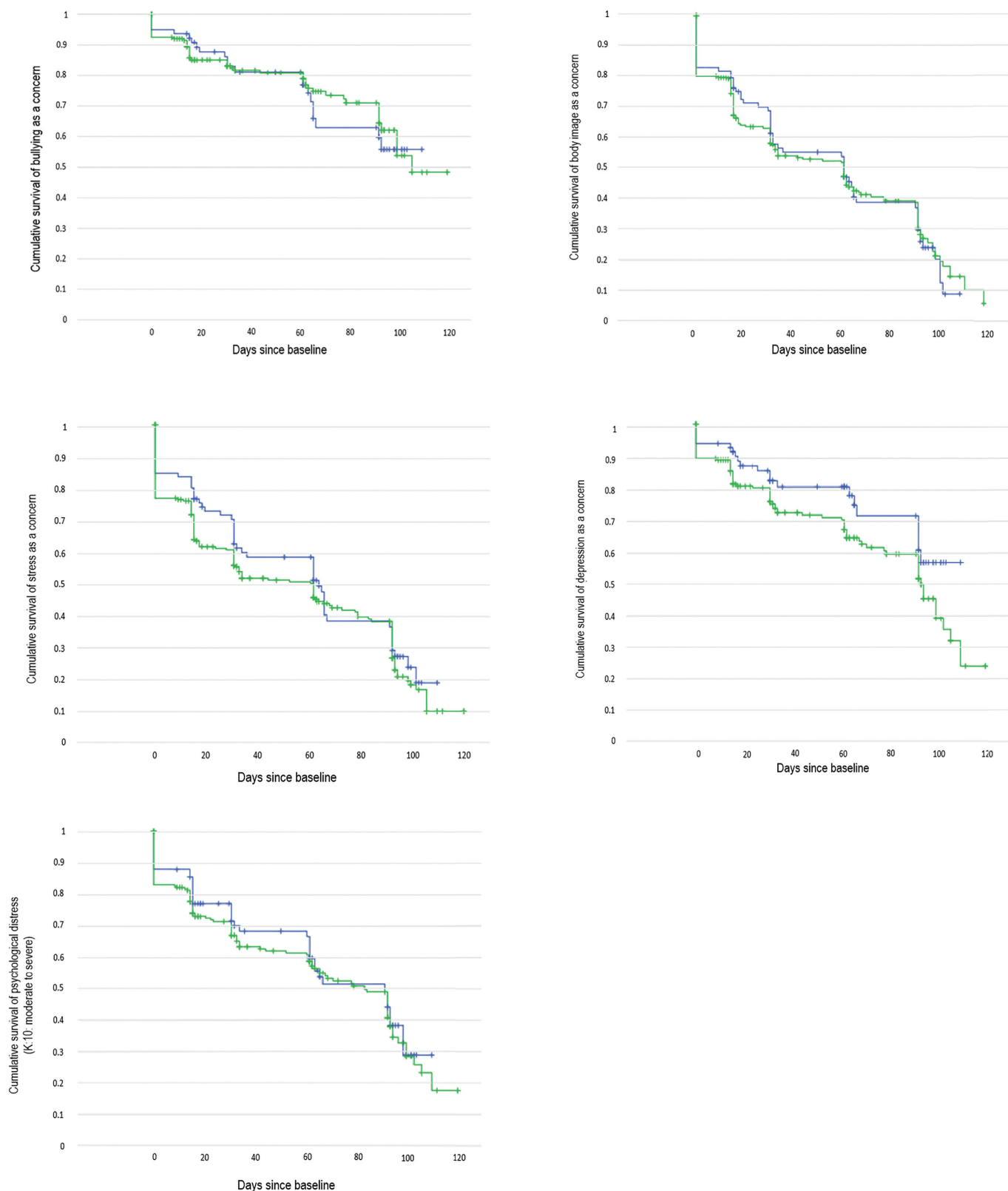
Participant demographics were collected at baseline only. Changes in the health and wellbeing of participants when using the prototype over time were measured. This involved use of: two separate items for overall health and overall mental health that were rated on a five-point Likert scale (1 for "very 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

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”.²⁹ 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.

- Vinson T, Rawsthorne M, Beavis A, Ericson M. Dropping off the edge 2015: persistent communal disadvantage in Australia. Richmond: Jesuit Social Services and Catholic Social Services Australia, 2015. http://k46cs13u1432b9asz49wnhcx-wpengine.netdna-ssl.com/wp-content/uploads/0001_dote_2015.pdf (viewed Aug 2019).
- Hunter E. Disadvantage and discontent: a review of issues relevant to the mental health of rural and remote Indigenous Australians. *Aust J Rural Health* 2007; 15: 88–93.
- Australian Bureau of Statistics. National Survey of Mental Health and Wellbeing: summary of results, 2007 (ABS Cat. No. 4326.0). Canberra: ABS, 2008. <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4326.0> (viewed Aug 2019).
- Australian Institute of Health and Welfare. Rural and remote health [web report]. Canberra: AIHW, 2017. <https://www.aihw.gov.au/reports/rural-health/rural-remote-health/contents/rural-health> (viewed Aug 2019).
- Australian Institute of Health and Welfare. Health and illness. In: Australia's health 2014 (AIHW Cat. No. AUS 178; Australia's Health Series No. 14). Canberra: AIHW, 2014. https://www.aihw.gov.au/getmedia/fc2c053f-7707-437e-90b3-227818bba0a5/1_1-health-illness.pdf.aspx (viewed Aug 2019).
- McLachlan R, Gilfillan G, Gordon J. Deep and persistent disadvantage in Australia. Productivity Commission staff working paper. Canberra: Productivity Commission, 2013. <https://www.pc.gov.au/research/supporting/deep-persistent-disadvantage/deep-persistent-disadvantage.pdf> (viewed Aug 2019).
- Bishop L, Ransom A, Laverty M, Gale L. Mental health in remote and rural communities. Canberra: Royal Flying Doctor Service of Australia, 2017. https://www.flyingdoctor.org.au/assets/documents/RN031_Mental_Health_D5.pdf (viewed Aug 2019).
- National Rural Health Alliance. Mental health in rural and remote Australia [fact sheet]. <http://ruralhealth.org.au/sites/default/files/publications/nrha-mental-health-factsheet-dec-2017.pdf> (viewed Aug 2019).
- Australian Bureau of Statistics. ABS releases measures of socio-economic advantage and disadvantage [media release]. 26 Mar 2008. <http://www.abs.gov.au/ausstats/abs@.nsf/mediareleasesbyReleaseDate/AC5B967F97D4902ECA257B3B001AF670> (viewed Aug 2019).
- Cheek C, Bridgman H, Fleming T, et al. Views of young people in rural Australia on SPARX, a fantasy world developed for New Zealand youth with depression. *JMIR Serious Games* 2014; 2: e3.
- Australian Indigenous HealthInfoNet. Social and emotional wellbeing. <https://healthinonet.ecu.edu.au>

- edu.au/learn/health-topics/social-and-emotional-wellbeing (viewed Aug 2019).
- 12 Australian Bureau of Statistics. Intentional self-harm, key characteristics. In: Causes of death, Australia, 2017 (ABS Cat. No. 3303.0). Canberra: ABS, 2018. <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/3303.0~2017~Main%20Features~Intentional%20self-harm,%20key%20characteristics~3> (viewed Dec 2019).
 - 13 Morandini JS, Blaszczyński A, Dar-Nimrod I, Ross MW. Minority stress and community connectedness among gay, lesbian and bisexual Australians: a comparison of rural and metropolitan localities. *Aust N Z J Public Health* 2015; 39: 260–266.
 - 14 Australian Bureau of Statistics. Internet and mobile phones. In: Children's participation in cultural and leisure activities, Australia, Apr 2012 (ABS Cat. No. 4901.0). Canberra: ABS 2013. <https://www.abs.gov.au/ausstats/abs@.nsf/Products/4901.0~Apr+2012~Main+Features~Internet+and+mobile+phones?OpenDocument> (viewed Aug 2019).
 - 15 Orlowski S, Lawn S, Antezana G, et al. A rural youth consumer perspective of technology to enhance face-to-face mental health services. *J Child Fam Stud* 2016; 25: 3066–3075.
 - 16 Aisbett DL, Boyd CP, Francis KJ, et al. Understanding barriers to mental health service utilization for adolescents in rural Australia. *Rural Remote Health* 2007; 7: 624–633.
 - 17 Boyd C, Francis K, Aisbett D, et al. Australian rural adolescents' experiences of accessing psychological help for a mental health problem. *Aust J Rural Health* 2007; 15: 196–200.
 - 18 Ospina-Pinillos L, Davenport TA, Ricci CS, et al. Developing a Mental Health eClinic to improve access to and quality of mental health care for young people: using participatory design as research methodologies. *J Med Internet Res* 2018; 20: e188.
 - 19 Ospina-Pinillos L, Davenport T, Mendoza Diaz A, et al. Using participatory design methodologies to co-design and culturally adapt the Spanish version of the Mental Health eClinic: qualitative study. *J Med Internet Res* 2019; 21: e14127.
 - 20 Blanchard M, Morris J, Birrell E, et al. National young people and asthma survey: issues and opportunities in supporting the health and wellbeing of young people living with asthma. Melbourne: Young and Well Cooperative Research Centre, 2014. <https://protect-au.mimecast.com/s/EsVPCxnMRvtogOyPT8gLJv?domain=asthmaaustralia.org.au> (viewed Aug 2019).
 - 21 Kessler RC, Andrews G, Colpe LJ, et al. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychol Med* 2002; 32: 959–976.
 - 22 Lindelow M, Hardy R, Rodgers B. Development of a scale to measure symptoms of anxiety and depression in the general UK population: the psychiatric symptom frequency scale. *J Epidemiol Community Health* 1997; 51: 549–557.
 - 23 Keyes CL. Mental health in adolescence: is America's youth flourishing? *Am J Orthopsychiatry* 2006; 76: 395–402.
 - 24 Hills P, Argyle M. The Oxford Happiness Questionnaire: a compact scale for the measurement of psychological well-being. *Pers Individ Dif* 2002; 33: 1073–1082.
 - 25 Brooke J. SUS: a retrospective. *J Usability Stud* 2013; 8: 29–40.
 - 26 Brooke J. SUS: a “quick and dirty” usability scale. In: Jordan PW, Thomas B, Weerdmeester BA, McClelland IL, editors. Usability evaluation in industry. London: Taylor & Francis, 1996: pp. 189–194.
 - 27 Siegel S, Castellan NJ. Nonparametric statistics for the behavioral sciences. 2nd ed. New York: McGraw-Hill, 1988.
 - 28 Kaplan EL, Meier P. Nonparametric estimation from incomplete observations. *J Am Stat Assoc* 1958; 53: 457–481.
 - 29 Bangor A, Kortum P, Miller J. Determining what individual SUS scores mean: adding an adjective rating scale. *J Usability Stud* 2009; 4: 114–123.
 - 30 Newman L, Biedrzycki K, Baum F. Digital technology use among disadvantaged Australians: implications for equitable consumer participation in digitally-mediated communication and information exchange with health services. *Aust Health Rev* 2012; 36: 125–129.
 - 31 Baum F, Fisher M. Why behavioural health promotion endures despite its failure to reduce health inequities. *Social Health Illn* 2014; 36: 213–225. ■

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

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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 develop and evaluate 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.

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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.

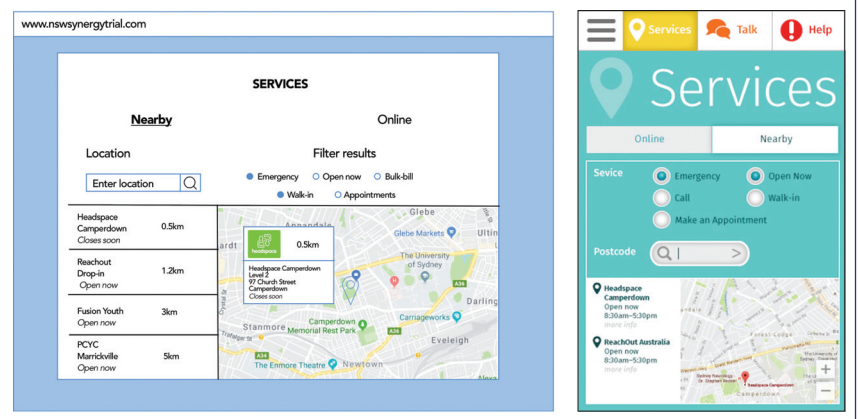
Phase 3: National online evaluation study

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.

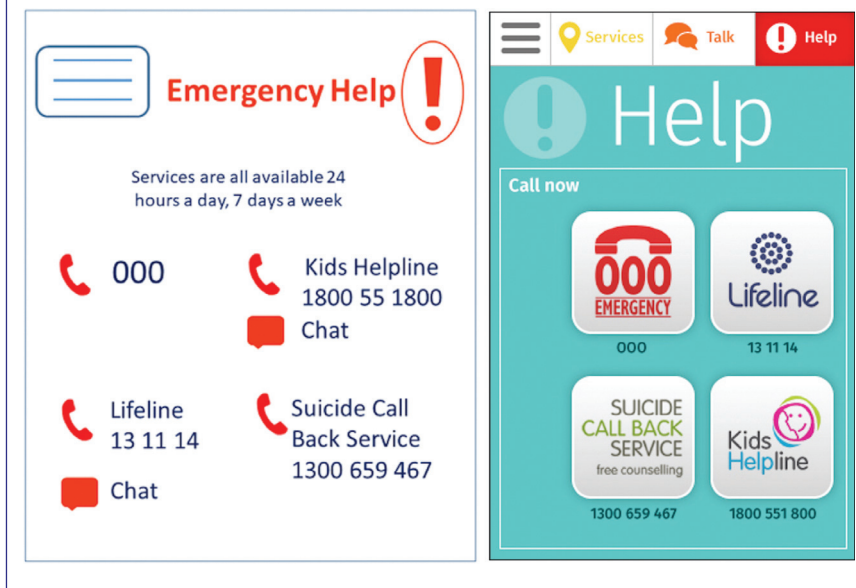
Engagement

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 support. 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

- 1 Australian Bureau of Statistics. Intentional self-harm, key characteristics. In: Causes of death, Australia, 2017 (ABS Cat. No. 3303.0). Canberra: ABS, 2018. <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/3303.0-2017-Main%20Features-Intentional%20self-harm,%20key%20characteristics-3> (viewed Aug 2019).
- 2 National Mental Health Commission. Contributing lives, thriving communities. Report of the national review of mental health programmes and services. Sydney: NMHC, 2014. <http://www.mentalhealthcommission.gov.au/media/119905/Vol%201%20-%20Main%20Paper%20-%20Final.pdf> (viewed Aug 2019).
- 3 World Health Organization. Preventing suicide: a global imperative. Geneva: WHO, 2014. http://apps.who.int/iris/bitstream/handle/10665/131056/9789241564779_eng.pdf;jsessionid=B219E73E07A304F0A00CBDCAS ECE2642?sequence=1 (viewed Aug 2019).
- 4 Patel V, Saxena S, Lund C, et al. The Lancet Commission on global mental health and sustainable development. *Lancet* 2018; 392: 1553–1598.
- 5 Ospina-Pinillos L, Davenport TA, Ricci CS, et al. Developing a mental health eClinic to improve access to and quality of mental health care for young people: using participatory design as research methodologies. *J Med Internet Res* 2018; 20: e188.
- 6 Ospina-Pinillos L, Davenport TA, Iorfino F, et al. Using new and innovative technologies to assess clinical stage in early intervention youth mental health services: evaluation study. *J Med Internet Res* 2018; 20: e259.
- 7 Aguirre RTP, McCoy MK, Roan M. Development guidelines from a study of suicide prevention mobile applications (apps). *J Technol Hum Serv* 2013; 31: 269–293.
- 8 Topham P. Making people appy. *AUCC* 2012 (Mar): 10–14. <http://eprints.uwe.ac.uk/16644/10/making%20people%20appy.pdf> (viewed Aug 2019).
- 9 Perry Y, Werner-Seidler A, Calear AL, Christensen H. Web-based and mobile suicide prevention interventions for young people: a systematic review. *J Can Acad Child Adolesc Psychiatry* 2016; 25: 73–79.
- 10 Larsen ME, Nicholas J, Christensen H. A systematic assessment of smartphone tools for suicide prevention. *PLoS One* 2016; 11: e0152285.
- 11 Lindberg O. Designing for crisis. *Net Magazine* 2016; 16 Sep. <https://medium.com/net-magazine/designing-for-crisis-9cab10b4c519> (viewed Aug 2019).
- 12 Iorfino F, Davenport TA, Ospina-Pinillos L, et al. Using new and emerging technologies to identify and respond to suicidality among help-seeking young people: a cross-sectional study. *J Med Internet Res* 2017; 19: e310.
- 13 While D, Bickley H, Roscoe A, et al. Implementation of mental health service recommendations in England and Wales and suicide rates, 1997–2006: a cross-sectional and before-and-after observational study. *Lancet* 2012; 379: 1005–1012.
- 14 Brooke J. SUS: a retrospective. *J Usability Stud* 2013; 8: 29–40.
- 15 Stoyanov SR, Hides L, Kavanagh DJ, et al. Mobile app rating scale: a new tool for assessing the quality of health mobile apps. *JMIR Mhealth Uhealth* 2015; 3: e27.
- 16 Buus N, Juel A, Haskelberg H, et al. User involvement in developing the MYPLAN mobile phone safety plan app: a case study. *JIMR Mental Health* 2019; 6: e11965.
- 17 Hussain MS, Li J, Ellis LA, et al. Moderator assistant: a natural language generation-based intervention to support mental health via social media. *J Technol Hum Serv* 2015; 33: 304–329.
- 18 Brooke J. SUS: a “quick and dirty” usability scale. In: Jordan PW, Thomas B, Weerdmeester BA, McClelland IL, editors. Usability evaluation in industry. London: Taylor & Francis, 1996: pp. 189–194.
- 19 Bjerkan J, Hedlund M, Hellesø R. Patients' contribution to the development of a web-based plan for integrated care - a participatory design study. *Inform Health Soc Care* 2015; 40: 167–184. ■

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

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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

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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

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.

- 1 National Mental Health Commission. Contributing lives, thriving communities. Report of the national review of mental health programmes and services. Sydney: NMHC, 2014. <http://www.mentalhealthcommission.gov.au/media/119905/Vol%201%20-%20Main%20Paper%20-%20Final.pdf> (viewed Aug 2019).
- 2 Rosenberg S, Hickie I. Online therapies can improve mental health, and there are no barriers to accessing them. *The Conversation* 2019; 5 Mar <http://theconversation.com/online-therapies-can-improve-mental-health-and-there-are-no-barriers-to-accessing-them-111357> (viewed Aug 2019).
- 3 Bauer AM, Thielke SM, Katon W, et al. Aligning health information technologies with effective service delivery models to improve chronic disease care. *Prev Med* 2014; 66: 167–172.
- 4 Cross SPM, Hickie I. Transdiagnostic stepped care in mental health. *Public Health Res Pract* 2017; 27: e2721712.
- 5 Hilferty F, Cassells R, Muir K, et al. Is headspace making a difference to young people's lives? Final report of the independent evaluation of the headspace program. Sydney: University of NSW, 2015. https://www.sprc.unsw.edu.au/media/SPRCFile/Evaluationofheadspaceprogram_published.pdf (viewed Aug 2019).
- 6 Rickwood D, Telford N, Parker A, et al. Headspace — Australia's innovation in youth mental health: who are the clients and why are they presenting. *Med J Aust* 2014; 200: 1–4. <https://www.mja.com.au/journal/2014/200/2/headspace-australias-innovation-youth-mental-health-who-are-clients-and-why-are>
- 7 Cross SP, Hermens DF, Hickie IB. Treatment patterns and short-term outcomes in an early intervention youth mental health service. *Early Interv Psychiatry* 2016; 10: 88–97.
- 8 Hamilton BA, Naismith SL, Scott EM, et al. Disability is already pronounced in young people with early stages of affective disorders: data from an early intervention service. *J Affect Disord* 2011; 131: 84–91.
- 9 Cross SP, Scott JL, Hermens DF, Hickie IB. Variability in clinical outcomes for youths treated for subthreshold severe mental disorders at an early intervention service. *Psychiatr Serv* 2018; 69: 555–561.
- 10 Mohr DC, Lyon AR, Lattie EG, et al. Accelerating digital mental health research from early design and creation to successful implementation and sustainment. *J Med Internet Res* 2017; 19: e153.
- 11 Ross J, Stevenson F, Lau R, Murray E. Exploring the challenges of implementing e-health: a protocol for an update of a systematic review of reviews. *BMJ Open* 2015; 5: e006773.
- 12 Burns JM, Davenport TA, Christensen H, et al. Game on: exploring the impact of technologies on young men's mental health and wellbeing. Findings from the first Young and Well National Survey. Melbourne: Young and Well Cooperative Research Centre, 2013. <https://cdn.movember.com/uploads/files/Our%20Work/game-on-movember-foundation.pdf> (viewed Aug 2019).
- 13 Orlowski S, Lawn S, Matthews B, et al. The promise and the reality: a mental health workforce perspective on technology-enhanced youth mental health service delivery. *BMC Health Serv Res* 2016; 16: 562.
- 14 Boswell JF, Kraus DR, Miller SD, Lambert MJ. Implementing routine outcome monitoring in clinical practice: Benefits, challenges, and solutions. *Psychother Res* 2015; 25: 6–19.
- 15 Lal S, Adair CE. E-mental health: a rapid review of the literature. *Psychiatr Serv* 2014; 65: 24–32.
- 16 Bradford S, Rickwood D. Electronic psychosocial assessment tool: Concept development and identification of barriers to successful implementation. *J Technol Hum Serv* 2014; 32: 275–296.
- 17 Kotte A, Hill KA, Mah AC, et al. Facilitators and barriers of implementing a measurement feedback system in public youth mental health. *Adm Policy Ment Health* 2016; 43: 861–878.
- 18 Aarons GA, Hurlburt M, Horwitz SM. Advancing a conceptual model of evidence-based practice implementation in public service sectors. *Adm Policy Ment Health* 2011; 38: 4–23.
- 19 Harvey G, Fitzgerald L, Fielden S, et al. The NIHR collaboration for leadership in applied health research and care (CLAHRC) for Greater Manchester: combining empirical, theoretical and experiential evidence to design and evaluate a large-scale implementation strategy. *Implement Sci* 2011; 6: 96.
- 20 Aarons GA, Ehrhart MG, Farahnak LR, Hurlburt MS. Leadership and organizational change for implementation (LOCI): a randomized mixed method pilot study of a leadership and organization development intervention for evidence-based practice implementation. *Implement Sci* 2015; 10: 11.
- 21 Kirchner JE, Kearney LK, Ritchie MJ, et al. Research & services partnerships: lessons learned through a national partnership between clinical leaders and researchers. *Psychiatr Serv* 2014; 65: 577–579.
- 22 Ospina-Pinillos L, Davenport TA, Ricci CS, et al. Developing a mental health eClinic to improve access to and quality of mental health care for young people: using participatory design as research methodologies. *J Med Internet Res* 2018; 20: e188.
- 23 Ospina-Pinillos L, Davenport T, Mendoza Diaz A, et al. Using participatory design methodologies to co-design and culturally adapt the Spanish version of the Mental Health eClinic: qualitative study. *J Med Internet Res* 2019; 21: e14127.
- 24 Ospina-Pinillos L, Davenport TA, Iorfino F, et al. Using new and innovative technologies to assess clinical stage in early intervention youth mental health services: evaluation study. *J Med Internet Res* 2018; 20: e259.
- 25 Davenport TA, LaMonica HM, Whittle L, et al. Validation of the InnoWell Platform: protocol for a clinical trial. *JMIR Res Protoc* 2019; 8: e13955.
- 26 Cross SP, Hermens DF, Scott EM, et al. A clinical staging model for early intervention youth mental health services. *Psychiatr Serv* 2014; 65: 939–943.
- 27 Hickie I, Scott J, McGorry P. Clinical staging for mental disorders: a new development in diagnostic practice in mental health. *Med J Aust* 2013; 198: 461–462. <https://www.mja.com.au/journal/2013/198/9/clinical-staging-mental-disorders-new-development-diagnostic-practice-mental>

- 28 McGorry P, Tanti C, Stokes R, et al. headspace: Australia's National Youth Mental Health Foundation – where young minds come first. *Med J Aust* 2007; 187: S68–S70. <https://www.mja.com.au/journal/2007/187/7/headspace-australias-national-youth-mental-health-foundation-where-young-minds>
- 29 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101.
- 30 Salzer MS, Shear SL. Identifying consumer-provider benefits in evaluations of consumer-delivered services. *Psychiatr Rehabil J* 2002; 25: 281–288.
- 31 Vaughn LM, Whetstone C, Boards A, et al. Partnering with insiders: a review of peer models across community-engaged research, education and social care. *Health Soc Care Community* 2018; 26: 769–786.
- 32 Kessler RC, Andrews G, Colpe LJ, et al. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychol Med* 2002; 32: 959–976.
- 33 Morosini PL, Magliano L, Brambilla L, et al. Development, reliability and acceptability of a new version of the DSM-IV Social and Occupational Functioning Assessment Scale (SOFAS) to assess routine social functioning. *Acta Psychiatr Scand* 2000; 101: 323–329.
- 34 Iorfino F, Davenport TA, Ospina-Pinillos L, et al. Using new and emerging technologies to identify and respond to suicidality among help-seeking young people: a cross-sectional study. *J Med Internet Res* 2017; 19: e310.
- 35 Spijker BA, Batterham PJ, Caelear AL, et al. The suicidal ideation attributes scale (SIDAS): community-based validation study of a new scale for the measurement of suicidal ideation. *Suicide Life Threat Behav* 2014; 44: 408–419. ■

Supporting Information

Additional Supporting Information is included with the online version of this article.

Chapter 7

Potential of real-time and integrated clinical data to drive continuous quality improvement in youth mental health services

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The 2014 Report of the National Review of Mental Health Programmes and Services by the National Mental Health Commission (NMHC) revealed fundamental shortcomings for mental health services across the lifespan.¹ Numerous other reports over the past 25 years have concluded that the quality of mental health care nationally^{2–5} and internationally^{6–8} is poor.

Service quality is an overarching concept that includes eight interrelated and internationally adopted domains,⁹ including:

- clinical safety (eg, how suicide risk is assessed and mitigated at service entry);
- accessibility and equity (eg, ease of access for high risk sub-populations);
- effectiveness and outcomes (eg, proportion of users who return to work or education);
- acceptability and satisfaction;
- efficiency, expenditure and cost;
- appropriateness (eg, matching service provision to clinical stage, which is an adjunct to mental health diagnosis that incorporates illness severity and risk of progression to facilitate appropriate treatment matching);
- continuity and coordination (eg, successful transitions from primary to secondary care); and
- workforce competence and capability (eg, assignment of skilled staff to specific interventions).

In recent years, there have been concerted attempts to collect and report consumer outcomes in Australian public sector mental health services.¹⁰ The National Mental Health Performance Framework¹¹ outlines clinical data capture across nine domains including effectiveness, efficiency, appropriateness, access, continuity, responsiveness, capability, safety and sustainability.

At present, there are major gaps in the data available (highlighted in an independent evaluation by headspace, Australia's Youth Mental Health Foundation);¹² 13 of the 24 identified National Mental Health Performance Framework data indicators remain undefined and require further development.¹¹ More recently, Primary Health Networks have been charged with commissioning regionally appropriate, community-based mental health services¹³ and have reported substantial challenges in accessing clinical data to assist them to fulfil their responsibilities.

These challenges arise in part from limitations associated with electronic medical record and minimum dataset systems, which

are typically divorced from the clinical data generated at the consumer–health professional level.^{14–18} Instead they rely heavily on measures of health system activity (in the case of minimum datasets) or have limited data extraction capability (in the case of electronic medical records). Neither are suitable for enabling continuous and real-time quality improvements in health care.^{14,15}

The mental health system trails behind the general health system in collecting and analysing standard health information for use at an individual treatment planning level and subsequently as aggregated data for quality monitoring at the service level.^{6,16,19,20}

Our approach has been to propose that co-designed, real-time and integrated health information technologies collecting and processing clinical data may prove to be the most powerful enabler of mental health services reform.

Through Phase 2 of Project Synergy, an online platform²¹ is now being further developed and trialled within face-to-face and online mental health services, with a focus on enabling quality improvements in service delivery. The further development of the online platform has been guided by three health system re-design principles outlined in two United States Institute of Medicine service quality reports.^{6,8} These principles are:

- care should be data-driven by utilising health information technologies to make the best scientific and clinical information available at the point of use (ie, real-time);
- care should be person-centred in that it respects the diversity of individuals and puts consumers in control of their own health; and
- care at the consumer level should also be service-minded, whereby broader coordination, integration and efficiency are key considerations.

Importantly, our online platform aligns with the National Mental Health Performance Framework¹¹ and Institute of Medicine^{6,8} service quality domains and captures associated performance indicators in real time (for examples, see Supporting Information, chapter 7, table 1). From a clinical data perspective, any consumer using the online platform is considered to be the foundational level, and their clinical data are obtained, with consent, at the time of collection, shared with their health professional(s), then integrated at the service level (eg, headspace) and potentially more broadly at the regional (eg, lead agency, Primary Health Network) or national (eg, government) level (Box). This integrated approach to service quality monitoring uses the rich

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Driving Australian mental health services reform through real-time use of multilevel measures of service performance indicator data



quantitative and transactional data obtained from users interacting with the online platform. For example, the online platform supports routine outcome monitoring at the consumer–health professional level (ie, both the consumer and their health professional can track and monitor clinical outcomes and change treatment as needed) to improve treatment outcomes; and these same clinical data are de-identified and collated with many others at the local, regional and national levels to allow analysis of between-service and between-region variation. There is also evidence that such information can guide evidence-based practice, performance management, accountability, clinical safety monitoring and resource allocation, as well as overall quality improvement.²² Indeed, high quality health services tend to employ management practices that focus on quality and use service metrics to set quality targets.²³

Discussion

Over the past 10 years, new youth mental health services in Australia (such as headspace²⁴ as well as Primary Health Network-administered youth intensive services) have been designed to improve access to various levels of care for young people aged 12–25 years. Concerns have been raised, however, about

the quality of these services in terms of outcomes, variability between centres and appropriateness of care provided.^{12,25–27} Specifically, ongoing challenges persist with excessive wait times, lack of timely intervention for illness acuity and suicidal thoughts and behaviours, appropriate treatment provision for those with complex needs, premature treatment drop-out, and ongoing functional impairment after treatment.^{28–31}

In Chapter 6 we showed that a co-designed, consumer-facing and clinically oriented health information technology can be used to collect clinical data based on real-time consumer–service interactions, and that these data can be used to monitor and improve some aspects of service quality in young people, including better monitoring of risk and safety issues, outcomes and efficiency. The deployment of the online platform and its relationships with potentially useful and specific benchmarks for a headspace-style service and a more specialised youth mental health service are also set out in Supporting Information, chapter 7, table 1.

The co-designed online platform developed through Project Synergy collects, stores, scores and reports clinical data back to the consumer and their health professional to promote person-centred care, self-management, early intervention, shared decision making and routine outcome monitoring (see the Box in Chapter 1).³² These core principles align with those of similar health information technologies aiming to help consumers access better mental health care (eg, Mosenso mHealth solution).³³ The aggregation of service-level quality performance indicator data, however, remains unique to our online platform. The e-clinic prototype is now being extended to more specialised youth services, particularly of the types supported by Primary Health Networks and other hubs of more specialised practice (as proposed in the Australian Government 2019–20 Budget).³⁴

A key research question for Phase 2 of Project Synergy (2017–2020) is how the online platform can be further developed and integrated into face-to-face and online mental health services across the lifespan. Used more broadly over time, we believe there is great potential for such co-designed health information technologies to support service providers, their funders and the commissioners of those services to drive true person-centred, service-level and system-wide mental health services reform and improved service quality in Australia.

- 1 National Mental Health Commission. Contributing lives, thriving communities. Report of the national review of mental health programmes and services. Sydney: NMHC, 2014. <http://www.mentalhealthcommission.gov.au/media/119905/Vol%201%20-%20Main%20Paper%20-%20Final.pdf> (viewed Aug 2019).
- 2 Groom G, Hickie I, Davenport T. 'Out of hospital, out of mind!' A report detailing mental health services in Australia in 2002 and community priorities for national mental health policy for 2003–2008. Canberra: National Mental Health Council of Australia, 2003. [https://mhaustralia.org/sites/default/files/imported/component/rsfiles/](https://mhaustralia.org/sites/default/files/imported/component/rsfiles/publications/Out_of_Hospital_Out_of_Mind.pdf)

publications/Out_of_Hospital_Out_of_Mind.pdf (viewed Aug 2019).

- 3 Hickie IB, Davenport TA, Luscombe GM, et al. Australian mental health reform: time for real outcomes. *Med J Aust* 2005; 182: 401–406. <https://www.mja.com.au/journal/2005/182/8/australian-mental-health-reform-time-real-outcomes>
- 4 Mental Health Council of Australia. Not for service: experiences of injustice and despair in mental health care in Australia. Canberra: Mental Health Council of Australia, 2005. https://www.humanrights.gov.au/sites/default/files/content/disability_rights/notforservice/documents/NFS_Finaldoc.pdf (viewed Aug 2019).

- 5 Griffiths KM, Mendoza J, Carron-Arthur B. Where to mental health reform in Australia: is anyone listening to our independent auditors? *Med J Aust* 2015; 202: 172–174. <https://www.mja.com.au/journal/2015/202/4/where-to-mental-health-reform-australia-anyone-listening-our-independent-auditors>
- 6 Institute of Medicine (US) Committee on Quality of Health Care in America. Crossing the quality chasm: a new health system for the 21st century. Washington, DC: National Academies Press, 2001.
- 7 World Health Organization. The World Health Report 2001. Mental health: new understanding, new hope. Geneva: WHO, 2001. <https://www.who.int/whr/2001/>

- who.int/whr/2001/en/whr01_en.pdf?ua=1 (viewed Aug 2019).
- 8 Institute of Medicine (US) Committee on Crossing the Quality Chasm: Adaptation to Mental Health and Addictive Disorders. Improving the quality of health care for mental and substance-use conditions: Quality Chasm Series. Washington, DC: National Academies Press, 2006.
 - 9 Lauriks S, Buster MC, de Wit MA, et al. Performance indicators for public mental healthcare: a systematic international inventory. *BMC Public Health* 2012; 12: 214.
 - 10 Brown P, Pirkis J. Mental health quality and outcome measurement and improvement in Australia. *Curr Opin Psychiatry* 2009; 22: 610–618.
 - 11 National Mental Health Performance Subcommittee. Key performance indicators for Australian public mental health services. 3rd ed. Canberra: Commonwealth of Australia, 2013. <https://www.aihw.gov.au/getmedia/f9bb1a07-a43b-458a-9b73-64ef19d8aedd/Key-Performance-Indicators-for-Australian-Public-Mental-Health-Services-Third-Edition.pdf.aspx> (viewed Aug 2019).
 - 12 Hilferty F, Cassells R, Muir K, et al. Is headspace making a difference to young people's lives? Final Report of the independent evaluation of the headspace program (SPRC Report 08/2015). Sydney: Social Policy Research Centre, UNSW Australia, 2015. <https://headspace.org.au/assets/Uploads/Evaluation-of-headspace-program.pdf> (viewed Aug 2019).
 - 13 Meurk C, Harris M, Wright E, et al. Systems levers for commissioning primary mental healthcare: a rapid review. *Aust J Prim Health* 2018; 24: 29–53.
 - 14 Berwick DM. A user's manual for the IOM's 'Quality Chasm' report. *Health Aff* 2002; 21: 80–90.
 - 15 Adler-Milstein J, Embi PJ, Middleton B, et al. Crossing the health IT chasm: considerations and policy recommendations to overcome current challenges and enable value-based care. *J Am Med Inform Assoc* 2017; 24: 1036–1043.
 - 16 Lora A, Lesage A, Pathare S, Levav I. Information for mental health systems: an instrument for policy-making and system service quality. *Epidemiol Psychiatr Sci* 2017; 26: 383–394.
 - 17 Rosenberg S, Hickie I, McGorry P, et al. Using accountability for mental health to drive reform. *Med J Aust* 2015; 203: 328–330. <https://www.mja.com.au/journal/2015/203/8/using-accountability-mental-health-drive-reform>
 - 18 Kilbourne AM, Beck K, Spaeth-Rublee B, et al. Measuring and improving the quality of mental health care: a global perspective. *World Psychiatry* 2018; 17: 30–38.
 - 19 Pincus HA, Page AE, Druss B, et al. Can psychiatry cross the quality chasm? Improving the quality of health care for mental and substance use conditions. *Am J Psychiatry* 2007; 164: 712–719.
 - 20 Rosenberg S, Hickie I. No gold medals: assessing Australia's international mental health performance. *Australas Psychiatry* 2019; 27: 36–40.
 - 21 Iorfino F, Cross SP, Davenport T, et al. A digital platform designed for youth mental health services to deliver personalized and measurement-based care. *Front Psychiatry* 2019; 10: 595.
 - 22 headspace, National Youth Mental Health Foundation. Increasing demand in youth mental health: a rising tide of need. April 2019. <https://headspace.org.au/assets/Uploads/Increasing-demand-in-youth-mental-h-a-rising-tide-of-need.pdf> (viewed Aug 2019).
 - 23 Tsai TC, Jha AK, Gawande AA, et al. Hospital board and management practices are strongly related to hospital performance on clinical quality metrics. *Health Aff* 2015; 34: 1304–1311.
 - 24 McGorry P, Tanti C, Stokes R, et al. headspace: Australia's National Youth Mental Health Foundation – where young minds come first. *Med J Aust* 2007; 187: S68–S70. <https://www.mja.com.au/journal/2007/187/7/headspace-australias-national-youth-mental-health-foundation-where-young-minds-come-first>
 - 25 Jorm AF. How effective are 'headspace' youth mental health services? *Aust N Z J Psychiatry* 2015; 49: 861–862.
 - 26 Cross SP, Hermens DF, Hickie IB. Treatment patterns and short-term outcomes in an early intervention youth mental health service. *Early Interv Psychiatry* 2016; 10: 88–97.
 - 27 Jorm A. Should we be protecting headspace youth mental health services? *Online Opinion* 2016; 27 June. <http://www.onlineopinion.com.au/view.asp?article=18332> (viewed Aug 2019).
 - 28 Cross S, Hermens D, Scott E, et al. A clinical staging model for early intervention youth mental health services. *Psychiatr Serv* 2014; 65: 939–943.
 - 29 Cross SP, Hermens DF, Hickie IB. Treatment patterns and short-term outcomes in an early intervention youth mental health service. *Early Interv Psychiatry* 2016; 10: 88–97.
 - 30 Cross SPM, Hermens DF, Scott J, Salvador-Carulla L, Hickie IB. Differential impact of current diagnosis and clinical stage on attendance at a youth mental health service. *Early Interv Psychiatry* 2017; 11: 255–262.
 - 31 Iorfino F, Hermens DF, Cross SPM, et al. Prior suicide attempts predict worse clinical and functional outcomes in young people attending a mental health service. *J Affect Disord* 2018; 238: 563–569.
 - 32 Davenport TA, LaMonica HM, Whittle L, et al. Validation of the InnoWell Platform: protocol for a clinical trial. *JMIR Res Protoc* 2019; 8: e13955.
 - 33 Monsenso. The Monsenso mHealth solution for mental illnesses. Product sheet. December 2017. https://www.monsenso.com/wp-content/uploads/2018/02/171220.Monsenso.Product.EN_.pdf (viewed Aug 2019).
 - 34 Australian Government. Budget 2019–20. <https://www.budget.gov.au/2019-20/content/services.htm#health> (viewed July 2019). ■

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