

Submission to National Digital Mental Health Framework December 2020

This submission responds to the questions set out in the Commonwealth Department of Health's Scoping and development of a National Digital Mental Health Framework: Consultation Paper (November 2020), prepared by PricewaterhouseCoopers.

Comments are focused on the needs and experiences of people affected by eating disorders and body image concerns, including families and carers.

3.1 Demand for and use of digital mental health services

- **What are peoples' preferences for blended models of care and treatment modalities? What are some enablers and barriers to these preferences?**

Response:

Blended models of care can be beneficial for people with eating disorders and body image concerns with online/self-help/other digital formats being used for prevention/early intervention style services, and an opportunity to create "warm" referrals post triage/self-help intervention.

One barrier is that the digital platform not being able to facilitate warm referral due to insufficient information about the treatment provider waitlist.

An enabler is that technology can be used to track/update service providers' availability and make referrals based on up-to-date knowledge as opposed to sending people away with a list of services (all of which might have closed books). Technology which allows for the coordination of a multi-disciplinary team would also be beneficial.

Blended models of care would be beneficial when the intervention provided via digital platforms is not sufficient for the level of care that an individual needs. To ensure that there is sufficient continuity of care, warm referral pathways into services would enable people to get the help they need, and they are not "lost" in the system.

- **How can vulnerable and at-risk cohorts be better supported via digital tools and platforms as part of a blended model of care?**

Response:

Online tools form part of an interactive and dynamic part of treatment plan for people with eating disorders. Digitally acquired data is used in real time to track and inform clinician practice. If digital tools can be used effectively, they can increase self-efficacy and empower clients thus potentially better engaging vulnerable and at-risk cohorts. Clinicians use data to provide feedback on progress/patterns to clients and teach them skills to do this themselves. This might lead to higher levels of engagement because weekly/fortnightly sessions are often not sufficient to properly engage vulnerable clients.

Online tools such as chatbots can also function as a gateway to service access, with demand from mental health organisations on the rise in recent years.

In relation to body image concerns and initial help-seeking, Butterfly Foundation has recently released a chatbot, known as "KIT". A world-first in relation to body image, the objective of KIT is to educate and provide information for those seeking help. Powered by conversational intelligence platform, Iris, KIT has been designed to provide users with general information on body image issues and eating disorders as well as teaching coping mechanisms to help make the social media experience a more positive one. It was developed in recognition of the fact that seeking in-person support can be a big first step, and that usually a period of pre-contemplation and contemplation precedes an approach to a mental health service.

KIT was developed by a team of mental health researchers, clinicians and IT experts at Monash University and Swinburne University of Technology, in partnership with conversational AI specialists and Iris developers, Proxima. Housed on Butterfly's website and fully integrated with Facebook Messenger, KIT provides psychoeducation, including a range of information and resources and evidence-based strategies, including cognitive behavioural therapy skills and mindfulness.

The chatbot is also button-activated to help reduce risk of people disclosing personal health information.

An organisational objective of the chatbot is assistance with managing and responding to the enormous increase in demand through the Butterfly National Helpline as a result of COVID-19. While chatbots are not a substitute for speaking with a trained counsellor, KIT is available 24/7, is anonymous and confidential, and has specific advice on coping with COVID-19-related stressors. For people wanting further support, KIT can connect them with Butterfly's National Helpline, ED HOPE.

KIT will be continually evaluated as part of research at Monash University and will be updated to ensure it is best supporting users. As KIT develops, researchers will be able to learn more from the way people engage with the bot and refine the options within a real world setting.

- **How important is preserving anonymity, privacy and confidentiality for people accessing digital mental health support and is there an acceptable approach to enable data sharing (with consent) if it produces a better outcome and experience? What else is needed to support this?**

Response:

Preserving anonymity is of paramount importance for people with eating disorders – without this, clients are unlikely to engage in a digital service.

It is very important to ensure individuals provide consent before they are referred on. If someone is not ready to access face to face service, provided that there is no imminent risk of harm, their autonomy must be respected. But for those who are ready to access face to face services, the system should allow for seamless transfer of care (e.g. via a different waitlist).

Centralised referrals forms/systems might enable data sharing – but more importantly, services need to have an easy way to gather information from each other. Can we better utilise online collaborative tools that are easy to use, time & cost efficient and reduce burden on busy clinicians? Email/fax is an archaic way of sharing information and a lot gets lost, so there is plenty of scope to improve.

- **What opportunities exist to enhance referral pathways so that people receive connected care across all stages of the care continuum?**

Response:

The current system has many gaps in referral pathways leading to delays in accessing appropriate treatment. Mental health service users are often faced with long waitlists and shoulder the burden of having to make multiple contacts with services prior to accessing care. In complex presentations, such as eating disorders, delays in being able to access appropriate treatment in a timely manner can lead to poor prognosis and outcomes. Significant opportunities exist through using technology to provide connected care. This includes: being able to access waitlist information online; warm referrals to specific services at the end of low-cost digital interventions; better communication between the digital care provider and the face to face team; and centralised systems that allow ease of clinician communication. An opportunity exists with current technology platforms to enable communication between MDTs. This should allow for data transfer (e.g. medical status) to be vastly improved from the outdated use of facsimile technology.

3.2 Integrating the lived experience perspective in service design and delivery

- **How can lived experience perspective be better integrated into the design and delivery of digital mental health services?**

Response:

People with a lived experience offer a unique perspective in terms of what they will find helpful or unhelpful in the design and delivery of digital mental health services. It is imperative to draw on the knowledge held by people with lived experience in order to ensure that their services being developed are meeting the needs and expectations of users. It is critical to consult meaningfully with people with complex mental health conditions such as eating disorders because their needs will likely differ significantly to those with generalised conditions.

Ideally lived experience perspectives should be incorporated at every stage in the development of services, including ideation, testing, development, implementation and evaluation. Multiple engagement methods should be used, with lived experience knowledge valued in the same way as other forms of knowledge, including via payment. Tokenistic approached to engagement will likely result in wasted effort as services will not sufficiently meet the needs of beneficiaries.

4.1 Mental health workforce implications

Workforce

- **What are possible financial and non-financial incentives (professional standards, training, monetary incentives) to encourage health practitioners to adopt digital mental health services into “business as usual”?**

Response:

Lack of training can impact uptake, so it would be imperative to provide appropriate training an ongoing supervision in the delivery of digital mental health services. Lack of time is also a factor for practitioners, especially within services which are experiencing increased demand, such has been the case for several services in the context of COVID-19. Many GP practice management software solutions (e.g. Medical Director, Best Practice) remain server based. It is critical that these transition to cloud-based options that would enable better cross service communication and data sharing.

- **Should there be standardisation of triage and treatment protocols, treatment and referral pathways used by digital services etc. and which elements would be most useful?**

Response:

While standardisation can be very beneficial, it is also important to ensure that clinicians within any specific digital service are able to work to the needs of their own consumer base. For example, treatment of eating disorders will have different treatment protocols to treatment of some other mental health conditions. Hence the process can be standardised but the content will need to be developed based on the knowledge skills and experience off the specific provider delivering the service.

- **What and where are the gaps in our existing workforce to support a blended delivery model where digital mental health services are used in conjunction with face to face services? E.g. do we need more care navigators, peer-support workers etc. and what considerations need to be made to support this model?**

Response:

In the area of eating disorders, we need more care navigators, peer support workers and a much broader skilled workforce in order to meet the needs of people with eating disorders and their families and carers. Clear understanding of the various aspects and responsibilities of members of the multidisciplinary team is also important and hence this delineation of roles and responsibilities should be a focus in professional training as well as ongoing supervision.

Lived experience workforce

- **What additional supports are needed to upskill the lived experience workforce in the use and delivery of digital mental health services and/or as digital inclusion champions?**

Response:

It is recommended that a tailored approach is taken when considering upskilling the lived experience workforce, particularly regarding different types of mental health conditions. People with an experience of an eating disorder represent a very diverse group of people, each with a unique experience and skill set. Some may benefit from additional training in digital applications whereas others may require additional support in managing the administrative tasks associated with this new way of working. More generally, ensuring that people with a lived experience of an eating disorder are included in the design process will help to create champions in the workforce. Eating disorders are highly complex in their presentation and treatment therefore it is imperative that lived experience insights are sought throughout the process to complement the digital delivery of more generalised mental health services.

With regard to the peer workforce, the Department of Health-funded National Eating Disorder Collaboration (NEDC) recently released a Peer Work Guide (<https://nedc.com.au/professional-development/peer-work/>) to promote and facilitate the implementation of evidence-based peer work in treatment and support services for people with eating disorders. The Guide includes an evidence review and organisational strategies to support safe and effective peer work initiatives.

- **What do people with lived experience need to support the building of trust, confidence, and ultimately, their uptake and use of digital mental health services?**

Response:

Several reports conducted by Butterfly find that stigma and discrimination from health professionals is common for people with an experience of an eating disorder. These experiences function as a barrier to seeking and continuing treatment. It is therefore vital that any mental health or general health practitioners

engaged to design or deliver digital services have adequate knowledge and skills in relation to eating disorders. Ensuring that the digital mental health framework is developed using language that is accessible and not stigmatising to people with an experience of an eating disorder will also go a long way to building trust and confidence.

When working with people with a lived experience it is imperative to take the time to ensure that they are valued in their engagement. This goes beyond seeking feedback solely for the purpose of the developing the service and includes ensuring that they are provided with opportunities to inform the work from inception to delivery. Providing lived experience participants with updates after delivery about when the service will be launched is also vital to building their trust will help to transform them from a subject matter expert to an advocate of any digital mental health service.

We note also that lived experience participants engaged as part of the Australian Commission on Safety and Quality in Health Care's recent webinar on the National Safety and Quality Digital Mental Health Standards said that privacy and security were the most critical elements of digital mental health care.

4.2 Integration of digital mental health services

- **How can digital mental health services better integrate into the stepped care framework?**

Response:

Digital mental health services can be useful in prevention and early intervention work as well as used in conjunction with face to face treatment in order to improve engagement and empower the client.

As noted above in relation to Butterfly's chatbot, digital interventions can be useful for people contemplating seeking support but who are not ready to call or speak to someone face to face.

- **What opportunities exist to create system interoperability to ensure digital mental health services can technologically connect and share information with other IT platforms and software?**

Response:

Depending on available technology and cost, central management of a system would be beneficial as this would relieve the burden on individual service providers. As with all digital interventions, management of data privacy and confidentiality would need to be prioritised if a shared platform was developed.

- **Where do broader general health and wellbeing applications and programs (e.g. FitBits) fit within the digital mental health services ecosystem and should there be separate governance mechanisms (e.g. accreditation of these products) to support these?**

Response:

There is a proliferation of for-profit fitness and 'wellness' apps on the market, many without any evidence of impact or testing to ensure their approach does not do harm to users. To take one example, in 2019 'WW' (previously known as Weight Watchers) released a weight loss app in the US called Kurbo for children aged 8-17 years. The app was part of the company's mission to increase memberships and grow revenue to more than \$2 billion. As dieting (especially calorie counting) and weight stigma are risk factors for the development of eating disorders in children, Butterfly advocated strongly against the release of this app in Australia.

There is a strong argument to be made to ensure that there is sufficient regulation of these products. For example, if a client with an eating disorder is using a Fitbit or meal planning app as a way to count their

calories, or activity and the application is providing encouragement for weight loss or excessive exercise, then this can be very detrimental to the individual.

- **Should parameters be set on the types of data that can be shared between different IT systems/tools and what are some implications, considering the use of shared data for outcomes monitoring and epidemiological surveillance?**

Response:

All data being utilised for non-clinical purposes should be deidentified and used with consent of the individual.

4.3 Importance of a data driven approach to enhance supply of services

- **What are the best ways to provide guidance around the use of data, client records, data sharing and consent processes for digital mental health service providers?**

Response: Nil

- **How important is epidemiological surveillance, data linkage and system outcomes in designing and evaluating digital mental health services and to what extent should they be considered?**

Response: Nil

5.1 Funding of digital mental health services

What alternative system-level funding models should be considered to enable better outcomes?

- **Is a blended (multi-modal) care model desirable and what are some ways to better incentivise this approach?**

Response: Nil

- **What mechanisms, if at all, could be considered to incentivise industry to develop digital technology solutions such as apps? What level of guidance is required by industry and developers? How should this be governed?**

Response:

Developers may need assurance of a “for purpose-for profit” model that clearly outlines how they can be enabled to use innovative business models to develop/build for a specific domain. Such business models would also need to allocate funds for ongoing review and development to keep in line with technological advances.

An accelerator fund to focus on and deliver such technology could be created to create space for specialisation so that frameworks are clearer understood by the key player(s) responsible for creating such technology.

Adequate seed funding/start-up capital would also be required for the development of prototypes and baseline technology.

A technical governance framework that is simple and easily adherable would enable providers to work towards certification (with frequent re-certification).

- **What tools, supports and implementation considerations are needed to enhance the digital literacy and inclusion of people with lived experience and health professionals?**

Response: Nil

- **At present few digital mental health services funded by the Australian Government are focused on culturally and linguistically diverse (CALD) people, Lesbian, Gay, Bisexual, Transgender and/or Intersex (LGBTI), Aboriginal and Torres Strait Islanders, and older cohorts – in what way could funding be designed and/or allocated to ensure digital services are available to these target groups?**

Response:

Understanding the needs of various cohorts is essential and should form part of any consultation and design process. This should include interrogating any assumptions about digital literacy and access to technology, along with consultation on needs and preferences.

Supporting universal access could include setting up a space where people can go to interact with technology if they don't have access at home. Developing sharing/library style models to enable those unable to purchase technology would be another way to improve access.

- **What are the governance considerations around payment models e.g. user-payment, co-payment and subsidised options to ensure the quality and safety of digital mental health services available to the public?**

Response:

Payment models should be developed with the principle of access and equity in mind ensuring that those who do not have the ability to pay are able to still access services.

- **How can additional funding for research and development, and monitoring and evaluation of digital mental health services, partnerships and relationships, warm-referral capacity etc. be built into service contracts? Should anything else be considered?**

Response:

In addition to federally funded or state/territory funded models, consideration could be given to innovative ways of raising funding including social impact investment bonds or collaborative partnerships with big technology companies within a corporate social responsibility framework.

- **What additional governance and/or guidance is needed around selection and implementation of technology, considering interoperability challenges now and into the future?**

Response: Nil

5.2 The legal and regulatory framework

- **What additional clinical governance and/or processes are required to support an optimum digital mental health ecosystem?**

Response:

Ongoing relationship between clinical and technical governance needs to be established so that care can be delivered in a safe and secure manner with clear lines of accountability and responsibility. While technology learns and develops, there is a need for active and ongoing collaboration between those

providing technical and clinical expertise in order to ensure the nuanced aspects of mental health care delivery are considered.

- **How can existing qualification programs be adapted to provide health practitioners with the skills and experience required to refer, deliver and integrate digital mental health services into their practice?**

Response:

Inclusion of mental health care assessment and treatment delivery in an online or digital manner can be incorporated as part of current training programs. Training around utilisation of technology in the assessment and development of treatment plans could be included as part of professional training programs.

- **What additional guidance or frameworks do service providers need to operate within the current regulatory environment?**

Response: Nil