

Digitized minds: Designing digital mental health tools with culturally diverse parents and young people

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Abstract

Background: Approximately 39% of young people (16-24 years) experience mental ill-health, but only 23% seek professional help. Early intervention is essential for reducing the impacts of mental illness, but young people, particularly those from culturally diverse communities, report experiencing shame and stigma, reducing face-to-face service engagement. Digital mental health tools (DMH tools) promise to increase access, but there is a lack of literature exploring the suitability of DMH tools for culturally diverse populations.

Objective: The project was conducted in partnership with a large-scale national digital mental health organization that promotes evidence-based early intervention, treatment and support of mental health in young people and their families. The organization wanted to develop a self-directed online platform for parents and young people that integrates psychological assessments and intervention pathways via an online 'check in' tool. Our project explored culturally diverse parent's and young people's views of opportunities and barriers to engagement with an online digital mental health screening tool.

Methods: We conducted a two-phase qualitative study aiming to identify potential issues faced by culturally diverse communities when engaging with DMH tools designed for the Australian public. We worked with culturally diverse parents (n=8) and young people (n=10) in a series of design-led workshops drawing on methods from speculative design and user experience to understand the opportunities and barriers that organizations might face when implementing population-level DMH tools with culturally diverse communities. NVivo was used to conduct thematic analyses of the audio-taped and transcribed workshops.

Results: Five themes were constructed from the workshops: (1) Trust in the use and application of a DMH tool, (2) Data management and sharing, (3) Socio-cultural influences on mental health, (4) Generational differences in mental health and digital literacy, and (5) Stigma and cultural-based discrimination in mental health support.

Conclusions: The emerging themes have important considerations for researchers wishing to develop more inclusive DMH tools in the future. The study found that healthy parent-child relationships will increase engagement in mental health support for young persons from diverse backgrounds. Barriers to engagement with DMH tools included cultural-based discrimination, the influence of cultural on mental health support, and how a diagnostic label may impact the likelihood of engaging in help-seeking. The study's findings suggest a need for culturally safe psychoeducation for culturally diverse end users that fosters self-determination with tailored resources. They also highlight important key challenges when working with diverse populations. Clinical Trial: NA

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Original Manuscript

Original Paper

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ABSTRACT

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Five themes were constructed from the workshops: (1) Trust in the use and application of a DMH tool, (2) Data management and sharing, (3) Socio-cultural influences on mental health, (4) Generational differences in mental health and digital literacy, and (5) Stigma and cultural-based discrimination in mental health support.

Conclusions:

The emerging themes have important considerations for researchers wishing to develop more inclusive DMH tools in the future. The study found that healthy parent-child relationships will increase engagement in mental health support for young persons from diverse backgrounds. Barriers to engagement with DMH tools included cultural-based discrimination, the influence of cultural on mental health support, and how a diagnostic label may impact the likelihood of engaging in help-seeking. The study's findings suggest a need for culturally safe psychoeducation for culturally diverse end users that fosters self-determination with tailored resources. They also highlight important key challenges when working with diverse populations.

Keywords:

Digital mental health; Young people; Cultural diversity; Web-based and mobile health interventions; Qualitative methods; User-centered design; Human Computer Interaction

1 INTRODUCTION

It is thought that around 13% of the global population living with mental health problems are young people (aged 16-24 years) (1). Young people with mental health disorders also experience higher rates of morbidity and mortality risk than the general population, leading to a 10-20 year reduction in life expectancy (2, 3). These rates were compounded during the COVID-19 pandemic, where globally 1 in 4 youths were found to experience clinically elevated levels of depression, and 1 in 5 experienced clinically elevated levels of anxiety (4). Yet, during this period, there was no concurrent increase in uptake for mental health support (5). For young people, untreated mental health problems can have long-lasting impacts due to the important social, emotional, and cognitive developmental changes that are being experienced simultaneously (6).

1.1 Cultural diversity in the context of Australia

Australia is a culturally diverse society, with over 27.6% of Australians born overseas (1). This diversity spans across differences in cultural identity, language, country of birth, religion, heritage, and national origin (7). Through a legacy of colonialism, racial inequality has shaped Australia and its relationship with non-white immigrants (8) and the first nations people (9).

Studies have identified higher rates of mental ill-health for culturally diverse groups compared to the Australian population (10, 11). This is, in part, due to mental health risk factors such as language, cultural adjustment, loss of family connection, and an inability to use knowledge and occupational skills to attain meaningful employment, which create barriers for people from diverse backgrounds to actively participate in society (12). Young people from culturally diverse backgrounds tend to be the most reluctant to seek help, and if they do, it is usually through informal sources such as talking to their family, friends and elders (13, 14). Of those who have sought professional support, they report that the types of support they received were either inaccessible, culturally inappropriate, or lacking cultural relevance (15-17).

Common barriers for diverse communities accessing mental health care include lack of information and knowledge about available health care, language barriers or cultural conceptions of mental health, and lengthy waitlists (18-22). Discrimination can be experienced throughout a person's mental health journey, with studies finding that culturally diverse people are far less likely to engage in mental health visits or seek specialist care than white ethnic groups (23). Research

found that clinicians are less likely to involve culturally diverse patients in friendly discussion or include them in the treatment decision making process (24). Instead, people from diverse backgrounds tend to access mental health services through clinical emergency services during an acute crisis rather than accessing early interventions before the problem is severe, hindering their prospect of recovery (25, 26). Culturally diverse people in Australia also experience more involuntary hospital admissions for their mental health (16).

1.2 Current landscape of digital mental health tools and opportunities

Digital mental health tools (DMH tools) (e.g. apps, online services) delivered through smartphones (27-31), computers (32, 33), and wearables (34, 35) promise to overcome many of these barriers (36). DMH tools can include self-directed online interventions (37, 38), mental health screening or 'check ins' to assess mental health status (39), digital health apps allowing for real-time monitoring of mental health (40, 41), chatbots to support help-seeking (42), and even interventions on specialist technologies such as virtual reality headsets (43, 44). Studies have shown that young people and parents prefer digital over face to face treatment (45, 46). DMH tools promise easily accessible, low-cost services to address common mental health problems (47, 48). Self-directed DMH tools may offer alternative or complimentary services to face-to-face clinical care, with the potential to provide support to people on waitlists for clinical care in remote locations, or those who may not have financial means to seek face-to-face treatment (43). An interest in designing culturally sensitive DMH tools is increasing (17, 49) with DMH apps and online platforms being designed especially for ethnically diverse groups (50). However, examples are limited and diversity, equity and inclusion factors are rarely included in their design or evaluation (51).

Online self-screening tools provide useful information about self-reported mental health symptoms, supplying clinical cut-offs that indicate further assessment or support is needed, as well as offering resources for support. They also allow anonymous pathways for disclosing mental health symptoms and offer digital interventions (4, 52, 53), which have been shown to be fundamental for a diverse user's mental health journey as digital interventions and resources are more likely to reach diverse populations who may not have access, or are not yet engaging in mental health support (54). Large-scale digital mental health platforms, incorporating screening, access to online clinicians, self-directed resources, and suites of trusted apps, are growing within public health organizations across Western contexts (e.g. UK National Health Service's Talking Therapies program) (48). However, whilst these public facing DMH tools are intended for use by all of society, they tend to be designed by and for the dominant Western culture (55).

In addition, DMH tools hold the potential for supporting mental health beyond traditional one-to-one contexts. Online health oriented communities offer benefits such as peer support networks (e.g. Headspace and Orygen both offer online youth mental health support in Australia). Similarly, social media groups centered on mental health have been shown to be significant for rural end users where geographical location limits access to mental health service providers (56), for guided online therapy (57), skills building (58), symptom monitoring (59), and social support (60, 61). However, for culturally diverse communities, where English can be a second language, willingness to engage in these types of peer support offerings tend to be lower (50).

1.4 Designing with diverse populations

Designing digital services tailored for culturally diverse populations is becoming more widely recognized, through responsive and inclusive design processes. Many researchers and designers in this space have adopted participatory research and user-centered approaches wherein members of the community are involved in the design process to identify their unique needs, goals, and concerns and to ensure that these are considered and accommodated for in the final service design (62-67). Technologies developed for underserved communities are most impactful when designed with members of the community (68). The use of user-centered approaches is shown to improve

acceptability, effectiveness, and contextual relevance of novel technologies for community (55). Engaging members of the community in a design process often requires creative methods and tools to ensure that it is safe, beneficial, and easy for them to participate. Some studies have used creative tool kits, personas, and vignettes to scaffold design thinking (69, 70).

User-centered design approaches are also increasingly recognized among mental health researchers and practitioners, including government agencies, that recommend the inclusion of meaningful engagement with consumers and carers in the service design (71). Research interest in culturally sensitive design through participatory research and user-centered design methods is mounting (72-74). However, despite the political and cultural shift, there is still only a small, yet growing, body of work, in the field of human computer interaction (HCI) that explores the needs of culturally diverse populations in the area of digital mental health services (17, 49, 75, 76). While these studies provide useful insights, they tend to focus on one community or culture and offer specific, rather than generalized interventions. While there are steps being made to engage diverse communities in technology design across various fields of research, there are still various mental health factors that could impact the uptake of novel DMH tools (e.g. cultural concepts of mental health, stigma around mental health). As such it is vital that we aim to better understand how to design tools that account for these factors and enhance service engagement for diverse communities. For the successful implementation of clinical innovations at a public scale, novel digital solutions need to be designed *with* diverse populations to ensure that they meet their needs (17, 77). Engagement with marginalized groups' perspectives and with those outside the Western traditional norms will help ensure DMH tools are more inclusively designed (78, 79).

To address this gap, we worked with culturally diverse young people and parents to design a national digital self-directed mental health check-in tool, called *Growing Minds Check-In (GMCI)*, for the Australian public. The GMCI aims to provide an assessment of mental health and wellbeing symptoms and recommendations to tailored online mental health services and information. This study engaged with user-centered design due to the restrictions on the level of involvement the participants would have on the final production of the GMCI. Due to the narrow development timelines, the participants in this study were able to contribute to the design process but did not have decision-making powers, but instead they were involved in appropriate ways throughout the development of the GMCI (80). We conducted a two-phase study aiming to identify potential issues faced by culturally diverse communities when engaging with DMH tools, such as the Growing Minds Check-In. The purpose of this study is to describe the attitudes, barriers and benefits of culturally diverse parents and young people to engagement with DMH tools. This information is likely to be relevant to DMH interventions for parenting and child wellbeing, but may also be relevant to other online programs, especially those delivered as universal public health interventions. We propose a set of design strategies for the future development of public facing DMH tools and provide reflections on our own design process, and the challenges we faced engaging diverse communities in research.

2 METHODS

2.1 Study Context

The project was conducted in partnership with the Growing Minds Australia Clinical Trials Network (GMA-CTN), Australia's first clinical trials network for child and youth mental health research (81). The project forms part of the first phase of design for the GMA-CTN flagship trial, the Growing Minds Check-In (GMCI): a national online platform for parents and young people that integrates a mental health and wellbeing 'check-in' with personalized feedback and suggestions for online mental health services and resources. We came into the project with the aim of focusing enquiry on how the future-facing platform could be designed more inclusively to ensure that it is relevant and accessible for diverse communities. We used a speculative digital mental health 'app' that contained features

similar to those proposed by digital phenotyping software, that could collect both passive and active data.

The study comprised two phases to engage groups of parents and young people with lived experience of mental health from culturally diverse backgrounds. The first was a scoping phase employing user-centered design methods with diverse populations that employed speculative DMH tools to tease out the benefits, concerns, and trade-offs they offer. The second was a prototype exploration phase, whereby a proposed nationwide mental health screening tool was used as an artefact for participants to determine possible challenges and ethical issues that culturally diverse populations may face when engaging in DMH tools. This included a facilitated emotional walkthrough of the screening tool using a workbook (see Figures 3 and 4), followed by a data consolidation workshop that reflected on participants' experiences of using the tool. We hoped to identify potential benefits and possible challenges of a large-scale online 'check in' service, and to take these insights and incorporate them into a more inclusive design for future DMH technologies. The Design Justice framework was applied to the design of the research questions, the activity schedule, and the analysis of the findings as this lens promotes the exploration of how benefits and burdens are distributed between varying groups, challenging the inequalities that are often reproduced in design by applying an intersectional approach that considers race, gender, sexual orientation, and culture (82, 83). This framework incorporates participatory and user-centered design methods that promote the prioritization of community needs and encourages researchers to consider how power can shape participation in the design processes (82).



Figure 1.

Visualization of study design

2.2 Ethics and Recruitment

Our study received ethical approvals through Monash University (ID 31138). All participants were provided with an explanatory statement detailing the project and were asked to read and sign a consent form prior to the sessions. The explanatory statement and consent form were provided to participants prior to the workshops. Participant consent and demographic information (e.g. country and culture they identify with, how many years they had lived in Australia, and the languages they

spoke at home) was collected prior to the workshops (see Table 1). Participants across all phases of the study were remunerated AUD\$40p/h for their time.

We partnered with a multicultural community mental health organization to recruit and facilitate the workshops, utilizing their advertising streams to recruit participants who were involved as volunteers with their organization and were likely to be mental health literate. As part of the screening process, we asked that the participants have a high school level of spoken English, in order to participate in the workshops due to time limitations and budget restrictions that did not allow for the inclusion of translators. Calls for participation in the workshops were advertised through flyers distributed via the community organization. For inclusion in the study, participants needed to identify as either having lived experience with mental health problems or children with lived experience. These workshops were conducted in person and therefore limited to communities living in Victoria, Australia. A majority of participants were from South or East Asia, which is consistent with the Australian population (1). In phase 2, we involved one Anglo-Australian participant (P8) who was put forward as a research participant by the mental health organization. We decided to include them despite not being from a culturally diverse background because they were an experienced peer support worker with multicultural populations. This participant had lived experience of complex mental health and was a parent.

Table 1. Phase 1 and 2 participant demographics.

Phase 1

Name	Age	Parent or Young Person	Years in Australia	Identified Culture	Languages spoken at home
P1	65	Parent	35	Indian	English, Tamil, Hindi
P2	57	Parent	35	Indian	English and Tamil
P3	53	Parent	23	Indian	Tamil
P4	67	Parent	50	German	German and English
P5	48	Parent	48	Italian	Italian and English
P6	58	Parent	41	Indian	Hindi, Punjabi and English
P7	67	Parent	67	Australian and German	English and German
YP1	22	Young person	3.5	Turkish	Turkish
YP2	16	Young person	7	German and Indian	German and English
YP3	22	Young person	11	Malaysian	Cantonese and English
YP4	21	Young person	4	Indian	Hindi
YP5	23	Young person	21	Han Chinese	Mandarin Chinese
YP6	22	Young person	12	Australian-Chinese	Mandarin Chinese
YP7	18	Young person	17	Malaysian	English
YP8	24	Young person	5	South African	Zulu
YP9	24	Young person	11	Malaysian-Chinese	Cantonese, Mandarin, Bahasa Melayu
YP10	21	Young person	20	Indian or Hindu	English and Tamil

Phase 2

Name	Age	Parent or Young Person	Years in Australia	Identified Culture	Languages spoken at home
P1	65	Parent	35	Indian	English, Tamil, Hindi
P2	57	Parent	35	Indian	English and Tamil
P3	53	Parent	23	India	Tamil
YP3	22	Young person	11	Malaysian	Cantonese and English
YP4	21	Young person	4	India	Hindi
YP10	21	Young person	20	India or Hindu	English and Tamil
P7	67	Parent	67	Australian and German	English and German
P8	47	Parent	47	Australian	English

2.3 Phase 1: Contextual Enquiry Through User-centered Design

We conducted two user-centered design workshops: one with young people (n=10: 7 female, 3 male; aged 16-25;) and another workshop with parents of young people (n=8: 4 female, 4 male; aged 21-67). Each workshop included a researcher facilitator and a co-facilitator provided by the mental health organization who assisted with recruitment. Power imbalances were mitigated by conducting the workshops at the multicultural organization's office space that participants were affiliated and felt comfortable. The workshops ran for 3 hours with a 20-minute refreshment break. We included three broad research questions:

- 1.) How do diverse end users value data about mental health, whom would they share their mental health data with and how may their data differ in the future?
- 2.) How is screening information communicated and understood, and to what impact would this have on therapeutic relationships?
- 3.) What are the social factors that influence the likely use and application of digital mental health technologies, and are diverse users concerned about third-party use of their data?

We were curious to explore both the inclusion of diverse communities in the design of a digital platform, but equally to consider the impact of future data use and where an end users' sensitive data may be later used. Given the propensity for alternative data use by third parties, we wanted to better understand the degree to which diverse end users worried about how their data may be used and whether they felt it would have future implications.

The sessions were guided by a semi-structured activity guide that was developed by the authors and reviewed by colleagues independent of the study. See Appendix for details. We began each session with an icebreaker activity and initiated a group discussion to set the context for the following activities. Using a whiteboard and markers, we asked participants about their understanding of mental health and what makes for good and poor mental health. This activity was intended to provide insight into participant's mental health literacy. We then provided participants

with a speculative design probe, the ‘mental health vault’ (see figure 2), to unpack abstract conceptions of sensitive digital health data. The vault included 3 layers to indicate varying levels of personal information that may be uncovered by DMH tools: 1) a locked safe using a metal box (most personal); 2) an inner layer using a thick metal chain; and 3) an outer layer using a thin rope (least personal). The activity schedule contained 4 activities and were categorized as: 1) *Digital Vault*, 2) *Blank Keys*, 3) *Data Sharing*, and 4) *Future Forecasting*. These activities were centered on an imagined DMH tool that could actively and passively collect data on an end user, which differs from the GMCI’s intended use and functionality as a web-based tool that provides personalized feedback and suggestions for online mental health services and information matched to need.

Activity 1: Digital Vault. The aim of this activity was to address RQ 1 by gauging participants’ level of understanding of mental health data, how personal they viewed it, and with whom they would want to share it. We provided stimuli picture cards of potential mental health data points to scaffold their thinking (i.e. a diary, a phone, GPS data, survey test results, social media data, etc.) and asked participants to place the card, depending on how secure they felt each data point was, within the different layers of the vault (i.e., inside the metal box, inside the chain, and the outer thin-rope layer). The most private was inside the metal box and the least private was in the outer layer of the rope. After asking them to place the cards according to their preferences, we then asked them to describe what each layer meant for them and why they placed the data point within each (e.g., why they would be okay with sharing their social media data publicly and not their survey test results).



Figure 2. Image

activity in Phase 1.

capturing the ‘digital vault’

Activity 2: Blank Keys. The aim of this activity was to understand who the participants were willing to share their data with and their reasons why to address RQ 1. Using an inductive approach, we used this component of the activity to leverage and broaden the discussion to generate ideas on new “trusted” or “non-trusted” people that the participants may think of on their own, without being probed or prompted by the researcher’s own suggestions. We gave participants 6 blank paper keys and asked them to write who they would be willing to provide access to the vault (e.g. their Imam, family member, or teacher) that they then placed the keys within the inner layer they were most comfortable with them accessing. We then asked participants to use these blank keys to write down who they thought might rob the vault and then place the newly labelled keys into the layer of the vault they felt the ‘data robber’ might access. An example of the activity schedule script included: ‘Now let’s imagine digital bank robbers broke into your vault. What is the worst thing that can happen? Who might the robbers be? Why would they want your data? Which specific area of the

vault would they be most interested in?’

Activity 3: Data Sharing. Building on the digital vault scenario, we introduced a ‘digital vault manager’ who has access to the data contained in the digital vault and use it to identify mental health issues. This activity addressed RQ 2 and RQ 3. We then probed the participants on whether they would want anyone to know about the prediction, and if so, who they would share it with. This activity was designed to get participants thinking about their individual perspectives as well as how others may feel about having their personal data shared with the intention of helping individuals or their community (e.g. whether a school or current employer should be notified).

Activity 4: Future Forecasting. This activity examined how screening information is likely to be communicated, understood, and applied in face-to-face sessions with a clinician. This activity addressed RQ2 and RQ3. We asked participants to imagine that the digital vault had been passively collecting data that predicted their mental health for 20 years. Firstly, we gathered emotional reactions to the prediction using cut-out emoji faces and by asking participants to indicate how they felt about having predictions made about them. Then, through a discussion-based activity, we explored how their prediction influenced trust, empowerment and agency, and how the prediction would best be communicated, and by whom. An example of activity schedule script included: *Do you feel empowered knowing this prediction in advance so you can seek help? Do you trust its accuracy? Would you prefer your GP or mental health clinician had told you? Would you trust it more if your GP told you? Are you concerned about who else is accessing this digital vault from some years ago?*

Findings from the future facing DMH tool discussion in phase 1 were used to frame the emotional walk-through activity and focus groups with parents and young people in phase 2. We considered the benefits, burdens and trade-offs diverse participants discussed in these workshops and wove them into the emotional walkthrough activity in an attempt to establish challenges with an existing system that could then feed into a future design. This activity series was designed to address RQ 1-3.

2.4 Phase 2: Emotional Walk-through

Incorporating a user experience (UX) technique traditionally referred to as a cognitive walkthrough, we wanted to explore the emotional responses that arose for the participants as they engaged in the interface (84, 85). We adapted a walkthrough user testing methodology (86) and created a 6-page emotional walk-through booklet that was distributed to participants along with a link to a prototype of the online mental health screening platform intended for national deployment in the near future (see Figures 3 and 4). This was a written task that was designed to help facilitate discussion and ideas about the issues we intended to explore in the prototype testing workshop. The completed booklets were then used in the session as a mnemonic reminder of participant’s thoughts and experiences. Participants were then invited to take part in a joint consolidation workshop (parents and young people) to discuss their thoughts in further detail. We supplied participants with the workbooks 2 weeks before the workshop to allow participants time in their daily schedule to complete the workbook and GMCI prototype. Six participants agreed to participate (3 parents and 3 young people; 3 female and 3 male). The aim was to elicit thoughts and feelings about digital mental health data as participants completed the online mental health check-in journey. The workbook surveyed a range of questions gauging emotional reactions and rating scales as participants used the online screening platform. We included a number of ethical considerations within each section of the workbook and encouraged participants to consider the social impact of the DMH tools, including their understanding of mental health, how their community understands mental health, views on data privacy and management, how they would like to receive feedback about their mental health, and whether they felt they could challenge a mental health outcome. Participants then took part in a

consolidation workshop to discuss their experience of using the prototype and to consolidate their ideas and expectations of engaging with an online mental health screening service. The session was broken down into four parts; 1) *What are the motivations, benefits, and challenges accessing a tool like this*, 2) *Discussion on where the data they entered online may go*, 3) *How well did the participants understand the feedback supplied and did it resonate with their cultural background*, and, 4) *Do's and Don'ts – participants were asked for suggestions to make a tool like this more accepted within their specific community*.

Part Three: the feedback

Now that you've completed the survey you will have received some feedback.

How well did you understand this feedback? Use the star stickers to indicate

1 2 3 4 5

How would you like to receive this kind of information (i.e. with a health professional, as a print out)? Would you trust it more if it was delivered by a health care professional?

Of course, it would feel more trustworthy if coming directly from a health care professional. However, most users should understand that this is an initial screening tool.

How would you feel if you thought that the information was inaccurate or challenging?

It would raise doubts, and I'd be more likely to dismiss it. But if it raised concerns, I would seek further opinions from a doctor etc.

Part Three: the feedback continues

Take a moment to review the recommendations. Who might you share with feedback with? Please circle those you might tell in the box below

What kind of resources (i.e. extra support, mental health care plan or referral to health professional) might you need access too now that you've received this feedback? Please respond in the box below

MHCP → Psychologist / Psychiatrist
extra support from family / friends / community
support from school counsellor?

Figure 3. Image of completed Emotional Walkthrough booklet in Phase 2.1

Part Two: the survey

As you browse the options for various social, emotional, and behavioural problems, take a moment to consider how you relate to these diagnostic terms.

Have you ever been told by a doctor or other health professional that Test 13 has any of the following social, emotional, behavioural and/or development problem(s)? Please select all that apply.

- ☐ No - I have not been told by a doctor or other health professional that Test 13 has any of the following social, emotional, behavioural and/or development problem(s)
- ☐ Don't know
- ☐ Partner not diagnosed
- ☐ Separation Anxiety Disorder
- ☐ Social Anxiety Disorder
- ☐ Generalised Anxiety Disorder
- ☐ Obsessive Compulsive Disorder (OCD)

How would you feel about your parents filling out this screening on your behalf?

I would be okay with that, because that means that they are just concerned about me and they want the best for me.

How does your community understand mental health?

"Mental Health" term itself is still a taboo in India. We give importance to family connection & bonding (wellbeing strategy) but always have learnt to support and be there for one another

Part Two: the survey continues

As you're submitting your responses to the prompts, let's consider where these responses may be stored. Do you have any concerns about where your data may be kept? Or whom may use it? Or if it will be used again?

Yes, in a digitally, fast-paced world data storage online can feel a little concerning for anyone. If it was a anonymous survey it would be alright. In this case, there is no too much personal information, so it's 50-50 for me.

As you move through the prompts on the survey, have you noticed any additional thoughts or concerns about the use of a tool like this. Please briefly list any other wonderings in the space below

Figure 4. Image of completed Emotional Walkthrough booklet in Phase 2.1

2.5 Positionality Statement

The authorship team for this project come from a variety of different cultural backgrounds and bring a range of perspectives on the topic based on our own experiences. We took part in this research as we personally believe that there is great importance in fostering equal opportunities to access mental health services for diverse end users. The breakdown of the authorship team is as follows: 5 females with European, Anglo-Celtic and Irish heritage and 3 males with Anglo-Celtic, Anglo-Australian and Pilipino heritage. Three of the authors are first-generation migrants to Australia. Four of the authors identify as parents and three work with young people, parents, caregivers and families. The authorship team consists of clinical and registered psychologists, a neuroscientist and bioethicist, an HCI and design practitioner, and researchers working in digital mental health and responsible innovation. The authors were committed to extending their own knowledge and understanding of diverse research practice to empathise and engage with culturally diverse parents and young people in this work, and this has informed our approach to the study design and data analysis.

2.6 Data Analysis

All three face-to-face workshops (phase 1: n=2; phase 2: n=1) were audio recorded, transcribed and thematically analyzed using NVivo software. Inductive thematic analysis was conducted on all of the transcriptions, without a pre-existing coding framework, to explore the interpretation of themes and subthemes (87). Initial codes were generated by IB to organize the data from phase 1 into potential items of interest. Three additional researchers (AC, RM, JS) familiarized themselves with the data from phase 1 and reviewed the initial codes. Iterative coding was then completed by IB and 21 subthemes were generated that informed the design of the emotional walkthrough. Three additional research members (AC, RM, JS) cross-coded themes from the emotional walkthrough booklets and transcript from the consolidation workshop. The codes were reviewed to ensure the themes were clear and descriptive. The coded data from both phases were combined for analysis with a total of 5 themes. In each workshop, an activity schedule was used to scaffold free flowing discussion between participants. Variations in participant opinions were coded and contrasted to develop the subthemes. Participants were collaborative and brought diverse and unique experiences, offering rich anecdotes in each session

3 RESULTS

Five major themes were developed from the analysis of the data collected from both phases: 1) Trust in the use and application of a DMH tool, 2) Data management and sharing, 3) Socio-cultural influences on mental health, 4) Generational differences in mental health and digital literacy, and 5) Stigma and cultural-based discrimination in mental health support.

3.1 The impact on interpersonal relationships and therapeutic relationships DMH tools may have

The discussions around how the creation of DMH tools may impact the therapeutic relationship with their current or future clinician varied; however, both groups reported trusting a clinician in a face-to-face setting more than in a digital tool. Participants in both groups also agreed that they would be more likely to trust a mental health recommendation or diagnosis taken from a DMH tool if a clinician was involved at some point:

“I feel like I would still and then like accept whatever the app tells me, but it will be very helpful if the psychiatrist or psychologist are linked with this app. Like they sort of like, acknowledge that this app is useful or something like that.” (YP5).

Participants in Phase 2 acknowledged they would seek advice from a digital mental health platform if a clinician was hard to access or as a first step in help seeking. However, participants felt it was hard to know where to search, and that they would use DMH tools as a screening tool, but would seek help from a trusted health professional, such as a general practitioner, psychiatrist, or psychologist, about information provided by a DMH tools (YP10, YP7, YP5, P2). Conversely, other participants found face-to-face interactions to be ‘*embarrassing*’ (YP10), ‘*confronting*’ (P8) or rushed:

“I feel like because GPs usually see patients 15 minutes per block, it feels that it's quite rushed and sometimes GPs wouldn't take the time to go over time [...] it will make us feel that we're not as like important.” (YP9).

Once they received the recommendation or treatment suggestion from DMH tools, participants in both groups expressed an eagerness to have the opportunity to process it on their own first (P6, YP5, P3). *“I would want to see the information first and then several steps down the road, consulting with a specialist might be an option”* (P3). Once coming to a point of acceptance there was variability in whom they would share this data with, with disclosures to family, friends and practitioners varying within both groups. Parents preferred to be given the recommendation prior to sharing with their children (P1, P2, P3), two of the younger participants (YP2, YP5) were happy to share with their parents and siblings, whilst many of the other young person group members identified that they would prefer to share with a trusted contact or friend over their parents and siblings (YP1, YP3, YP8, YP9, YP10), who they believed would help put them in touch with a professional or assist in accessing further resources.

One young person suggested having the ability to choose to download feedback from a DMH tool depending on the severity of the user’s mental health problems (YP3). Another young person suggested:

‘If you delete it, they ask you, “Are you sure?” or like, “Are like are you too busy?” “Is it distracting?” Like it ask you the reasons why you are downloading it. Have you met your match? [similar to a dating app] I think the same should be with the app. Like if you don't like the app, but you still, you downloaded this, but you still feel like you need someone to talk to, call these numbers. And it shouldn't be triple zero, because why would I call triple zero in my, like I don't...maybe triple zero can be like the last thing, but like call this person or locate the nearest center or psychologist, or locate your nearest person or something else’ (YP8).

Suggestions were made in regard to having a trusted contact who would receive a notification about a user who might be at high risk of poor mental health determined, and an understanding that the trusted person wasn’t obligated to take on this responsibility. Two parents emphasized the importance of a DMH tool’s recommendation or resource that offered peer support networks (P7, P8). Another suggestion was that the user should pre-determine a lower threshold for a risk notification if they were at risk of increased suicidality in order to intervene earlier:

“There's blurred lines to it, but at least like... having an accountability system, ... accepting, declining... being able to be there, or if I'm not, if I can be an emergency contact, but I'll accept, just going through this with you. Like, being there with you but I will not be your emergency contact. Like, I can share experience. In the case where it is an emergency, I don't want to be an emergency contact, but I can maybe assist you in contacting your emergency contact or something.” (YP8).

Participants agreed that DMH tools should offer further resources and alternative options

once initiating a screening or check in, such as “resources to learn more about what I might be going through” (YP4). Both parents and young people emphasized the importance of healthy relationships, including parent-to-parent and child-to-parent, before completing a screening on behalf of their child. One parent elaborated:

“Obviously we agree to disagree on a lot of topics, but you know, after a certain years, you know your child very well. And... It depends on the relationship between the father and the mother as well.” (P2).

The closeness between parent and child would be a significant factor in the quality of input into a DMH tool’s screening, which would then impact the meaningfulness of any subsequent recommendation or prediction.

“It'd be a case of if you could offer it as a dual package. So if the child was up to do it with their parents as one option, then you'd have, so you'd have three options, you'd have an adult, you'd have the youth separate, and then you'd have a child and a youth and a parent combo ... there's something to suit everyone depending on their communication space with their family members and how open they are to their mental health.” (P10).

DMH tools as a complementary support alongside a clinician was suggested in both workshops. Additional affordances from the use of DMH tool, included setting reminders or nudges to promote health activity such as going for a walk or engaging in a mindfulness meditation. A participant in the young person workshop also suggested DMH tools could be useful for users with acute mental health challenges:

‘I think it would be good for Bipolar Disorder. For example, if you were able to get a new notification about your hyper episode, then you would be able, you wouldn't be able to change your episodes like change your, arrange your calendar according to that’ (YP1).

In relation to the technology, one young person identified enjoying how music apps and YouTube tailored to her mood:

‘So I relate how I'm feeling, even if it's like a chronic like mental illness, like how I'm feeling is through my algorithm of my music. So like I'd be on YouTube and I'd probably right now I'm, like... I just figured out I had ADHD so like I'm like constantly watching things that have to do with that. So like I feel like different platforms can algorithmize my personal experience.’ (YP8).

Another young person echoed this, and suggested:

“I think technology in essence should be supporting humans and human work, rather than trying to replace it. Um if my GP or my psychologist fails to diagnose or intervene with me early, I recognize that everything they know about me is what I've told them, and those people are human. It's people they might miss things. So I'll be more than happy for this sort of data to assist in diagnosing me. Um, and together it will be more valid than just one source or the other.” (YP7).

In summary, when considering how results are communicated and what impact on clinical practice DMH tools may have, diverse end users wanted to process a recommendation or prediction on their own first, preferred digital mental health as complimentary to face to face clinical intervention and were open to having a trusted contact to share a recommendation or prediction with.

3.2 Data management and sharing

Conversations in both phases established that participants had a moderate level of understanding about their personal data and how to manage it, acknowledging they were aware of daily data collection via Internet searches and app use, and that it can be outsourced to different countries and third parties through data harvesting (P3, YP10, P2, P7, YP7, YP8, YP5). One participant in the young person's workshop suggested that some data has to be shared in order to build more accurate and personalized apps: *"I feel like data collection should be a two-way street. If you, I mean, like it should be mutual benefit, right?"* (YP7).

Data breaches by governments, concerns after experiences of surveillance measures during Covid-19 pandemic and the recent government health data breaches, and identity theft were participants' key concerns (P8, P7, P2, YP9, P6, P5):

"It could be mental health related or something else related. And then that information goes to your doctor, you consult a specialist or a GP or someone. And then it goes back to your insurance provider. And the insurance provider knows about it and straight away your premium goes up because they classify you as a high risk." (P3).

In contrast, young people were more open to having their data tracked or shared, having grown up with much of their information already available online and accessible by others. However, one young person acknowledged the challenging bind of accepting data collection in order to have a more personalized online experience but described that it is as a 'grey area' for broader reaching data collection, stating:

"When they click 'Accept All', that gives a warrant basically, and that's nothing that you can do because the website can just say, 'You said, 'Accept All' and continue. That's the warrant for me to say... to collect all your data and personalize it for you. And I feel like it's, it's quite a grey area basically." (YP7).

Another described uncertainty in a preference for certain data points to be collected or tracked by specific services:

"I would want my location to be tracked by medical services. Say, for example, I get hurt and then, um, my phone... like my watch has this thing where it says, 'Accident Detected,' But I think about who gets access to what data and what they do with it and I think that's also really hard to track so it depends." (YP2).

In summary, diverse mental health users valued data about mental health, with variation in openness to data sharing and how the data may be shared in future.

3.3 Socio-cultural influences on mental health

Participant's experiences with mental health were grounded in socio-cultural complexities, with variations in cultural understandings of mental health, help seeking, parental influence, community and spiritual support, and migration status, all playing a role in diverse communities' engagement with digital mental health support.

Many of the participants identified as having lived experience with mental ill-health and discussed the importance of self-understanding when it came to mental wellbeing (YP7, YP1, YP8, P8). Parents, in particular, recognized the importance of acceptance and education around mental health:

"Probably because nobody wants to tell anyone, I'm going through not a very nice day or I'm going through mental health issues, so basically we have to come out of that state so we have to

educate ourselves there's no point in just keeping everything to yourself.” (P2).

Outside of the family unit, participants agreed that their ethnic communities placed more importance on family connection and bonding, than mental health specifically. This was highlighted when written by a young person in the emotional walkthrough booklet:

“The ‘Mental health’ term itself was still a taboo in India. We give importance to family connection and bonding (as a wellbeing strategy) but always have learnt to support and be there for one another” (YP4).

In addition, several participants discussed the reliance that their communities placed on religious leaders to provide mental health support, rather than accessing formal care (P1, P7, YP4). However, the dominant cultural lens within a household impacted whether mental health was openly discussed. As one parent explained:

“I would say it’s very culturally influenced. From my perspective, the culture which we’re connected to, you know. For everything there is a step up process for you to understand, you know, why this is done, why it is not done. The reasons behind it. So where we grew up in our culture, we explain to them why we are doing this, to keep them on track. To keep you calm. It will protect you. The faith base.” (P1).

Migration and differences in the availability of support depending on visa status was also significant.

“When I came from Turkey to here, one of the biggest surprises I have come across was the, how common suicide was among younger generations of Turkish people here. I was shocked, I lived in Turkey for 19 years, and I’d never even heard of someone who has heard of someone else’s suicide. Like, never even came across it from the third degree or fourth degree. Many here, I spoke to a family member of someone who was a victim to suicide. The mother told me about her son’s suicide, and I was so shocked. And then I heard the same story from multiple other people as well, and it just made me realize how widespread it was here, in younger generations of Turkish people.” (YP1).

In summary, socio-cultural factors influenced the use and application of DMH tools, with diverse end users describing how their culture informed their understanding of mental health and help seeking.

3.4 Generational differences in mental health and digital literacy

There were notable differences between the two generations across both study phases, particularly in terms of accessing mental health professionals, digital literacy, and whether participants were first- or second-generation migrants. Language barriers were identified with one parent stating: *“That support is lacking. So you can imagine for some of these cultural communities, English might be a barrier, language might be a very big barrier” (P6).*

Parents preferred confiding in a close friend and face-to-face interactions over digital therapies (P6, P2, P8, P3). In contrast, young people appeared more willing to share their mental health experiences (YP8, YP10, YP3 and P8). One young person stated: *“I know that like when I was a young teenager, going through my rebellious phase in an ethnic household where I didn’t feel like it was safe to open up to my parents, the online anonymous aspect was what made online like, Tumblr, a safe place for me to, I guess, voice my mental health concerns about myself...” (YP5).* Some parents also believed that young people were also more mentally healthy and digitally literate:

“I think teenagers today are really, because they do things like that in school now, they understand about self care, they do mindfulness, they do all that sort of thing as teenagers now in high schools and things. I think that, the word self care is so synonymous now, everyone knows what that means. There's depths of it, of course, but to a teenager even knowing, and they know how much time they spend, too much time on social media, they know they need to get more sleep, but you know, when they do all those things and they know they shouldn't eat McDonald's every day, they're not silly, these kids are smart.” (P8).

As a first-generation migrant, one parent felt it was important not to impose her own cultural rules on her Australian born children:

“Because they're going to be Indian Australians, or Indian whatever it is. Deep down, they're Indian, they grew up as Australian children. They're more Australian than Indian sometimes. So we don't, um, there's no hard and fast rules. We can't tell them, you have to get up at 5 o'clock and pray.” (P2).

The discrepancy between how young people perceived mental health challenges compared to their parents was regularly raised, with one young person elaborating:

“I think another aspect of like, immigrant parents on things about mental health, gender identity, sexuality that's a big thing that, I know people, who are even single parents, who come from the immigrant background, they don't understand what their young child is going through with gender identity and all that stuff, because it's ... it wasn't really a thing when they were growing up, and, suddenly it's become something now, and they don't know how to deal with it.” (YP10).

In summary, generational differences were a central social factor that influenced the use and application of DMH tools.

3.5 Stigma and Cultural-based Discrimination

Challenges with mental health stigma was discussed in both phases, with participants explaining that different cultural beliefs informed alternative explanations of poor mental health, and concerns about further marginalization if a young person is given a mental health diagnosis, with fears it may ignite defensive barriers in community members and further ostracize. These experiences were centered on both internalized and externalized mental health stigma from family, friends, and extended cultural communities (P6, P3, P2, YP7, YP3).

When discussing a potential mental health diagnosis for a child or young person, one parent stated:

“It's denial first, thinking that nothing is wrong with your child [...] automatically you think, my child is fine, there's nothing wrong [...] So the acceptance [of poor mental health] is going to be very difficult.” (P2).

For a young person the experience of mental ill-health with culturally diverse parents was particularly challenging:

“When my parents found out that I had some mental health issues, [...] I noticed changes in their behaviors and in terms of my parents, and carers being from an ethnic environment, they're very judgmental. I just feel like my parents have zero understanding on mental health and mental illness so they wouldn't take any of that as a form of “I need help” They'll take it as I'm being

ungrateful.” (YP7).

One parent described how: *“mental illness ignites defensive barriers within people”* (P6), suggestive of an internalized resistance that may impact help seeking in a community. Another young person stated:

“It might also depend on the person and if they have internalized stigma. I think if an app has some sort of measure that can account for that [internalized stigma]. And that can frame the message depending on that, it would be really nice. So, even in ethnic communities, even if somebody is seeking help for example. Learning that you're depressed can be quite burdensome on your own mental health. The diagnosis might actually worsen your situation. Because the view of depressed people within your culture might always be these helpless people who cannot do anything basically” (YP1).

Regarding the diagnostic potential of DMH tools, parents were cautious about making their children *‘feel like they’re different’* (P8). One parent described how the diagnostic process could be enduring and punitive:

“You’re assuming the parent can put a diagnosis on a condition and that’s going to stick somehow. Because you’re sort of leading them down a particular path. I’m a great believer in diagnoses, but a diagnosis can be a sentence. Rather than a word, you know.” (P7).

There were concerns that a diagnosis can result in *‘life-long stigma for a child or young person’* (P7). As one parent put it: *“You know what, suddenly my kid gets this thing as a mental health patients, that's the end of their life. For the rest of their life they'll be on medication or for the rest of their life they'll be on this. They're branded like that.”* (P2). There was a perception among some parents that one would ‘lose face’ and be stigmatized in the eyes of their community if they or their child received a mental health diagnosis:

“When we talk about the ethnic communities, for them, their saving face becomes a very big issue. And you know, none of them want to lose face in the community in public and what have you. If somebody else doesn't even use their name then, for them, that stigma sort of stays, it's always going to take me years to rebuild that trust again.” (P6).

Participants in both phases raised concerns around cultural based discrimination when seeking mental health support, including an inequity in the availability of psychological assessments, screenings and support. Psychological assessments and mental health screening were identified as a form of systemic discrimination amongst the young participants, noting how most tools are only written in English with questions reflecting Western understandings of mental health. This results in people performing poorly due to an inability to understand the questions and being misdiagnosed. One young person described her lived experience of working in a Turkish speaking psychologist’s office in Australia and raised her concern at the limited number of bi-lingual psychologists,

“They were one of the few Turkish speaking psychologists we had, four or five months of wait lists. So, it was cheaper than private practitioners. Only 20% of the fee would be paid out-of-pocket. And it was impossible to get through. Even if you have, um, some sort of government supplement like Medicare or some sort of private insurance, it was just impossible to make an appointment with her. And the same thing was the case for our Bosnian psychologist and our other psychologist as well.” (YP1).

Difficulties accessing mental health support was raised across both groups, with participants discussing the challenges that migrants face when accessing mental health services, such as visa status, that can prohibit the ability to receive the same standard of support as other residents. This was particularly important to young international students waiting for permanent residency visas:

“But because they're still waiting for that process to get their PR [permanent residency visa]. They're [Asylum seekers] still in our schools. They go to private schools. They're living a good life. But because they're asylum seekers. We're international students. We don't have access to Medicare.” (YP2).

Discrimination from family members, friends, ethnic communities and third-party systems were voiced in both groups when receiving a mental health diagnosis (YP5, YP6, P6, YP1). Both groups identified concerns about future discrimination from third parties who may use their digital mental health diagnoses to withhold granting visa applications, have their identities stolen, or be charged higher insurance premiums (P1, P3, P5, P6, YP5, YP6). In summary, stigma and diagnostic barriers, cultural-based discrimination, and third-party access that may impact visa status and migration were central concerns.

Through this work we have explored the benefits, burdens and trade-offs of using DMH tools from the perspectives culturally diverse end-users. Grounded in these findings, we provide our provisional set of reflections regarding the future of culturally sensitive DMH tools.

4 DISCUSSION

The aim of the project was to explore culturally diverse parents' and young peoples' views of opportunities and barriers to engagement with an online digital mental health screening tool.

Consideration into parental influence based on their origin country, culture and level of mental health literacy, and how that is paired with raising a child who is growing up in Australia is complex. Young people were thought to have a higher level of general mental health and digital literacy, more aware of their mood, self-care routines and understanding of healthy diet and lifestyle routines, as well as being more willing to share about their mental health with others. These generational differences highlight the importance of accounting for perceived barriers such as the influence of culture on mental health support, cultural based discrimination in seeking mental health support, and who a diagnostic label may impact the likelihood of engaging in help seeking.

4.1 Leveraging family connectedness

We found that how our participants made sense of their mental health was centered on connection to family and parent-child relationships. Our findings suggest that family ties and family connectedness may influence the uptake of a mental health treatment or interventions, or whether and with whom DMH tool recommendations are shared. For culturally diverse youth, families provide an immediate social context (i.e. *The ‘Mental health’ term itself was still a taboo in India. We give importance to family connection and bonding (as a wellbeing strategy) but always have learnt to support and be there for one another*). Previous research found that the pace of cultural adaptation between parents and young people who resettle in Australia differs, with young people adapting faster but finding it hard to become independent from their family (16, 88).

Family connectedness has been linked with lower odds of significant stress and despair for youth during acculturation and may protect them from other risk factors. In fact, the quality of family relationships can have a positive effect on well-being (89-91). More research identifying positive family processes (e.g. closeness with mother and father) that build emotional-wellbeing in culturally diverse young people is needed (92). We found that familial influence informed young people's understanding of mental health, which according to some parents could be explained and managed

through religious practices or alternative methods. This is an important finding as it suggests future iterations of DMH tools should focus on increasing inclusion of culturally sensitive parental support and psychoeducation on mental health problems. It also highlights the importance of engaging community leaders, elders, religious leaders or advocates in different cultures and communities to gather their insights and explanations of wellbeing and mental health to ensure the technologies are culturally safe. We suggest culturally-appropriate and culturally-informed psycho-education with families is needed that encourages community buy-in in order to provide more effective DMH tools for diverse populations. This education would have to be offered thoughtfully, paired with data governance education to promote digital literacy and awareness of the (insufficiently) regulated data industry and unregulated practices that exist at current.

4.2 Cultural-based discrimination: Stigma, loss of face, and collectivist approaches to mental health

Barriers such as stigma, shame and perceived judgement from community members were regularly raised. Many parents voiced concern about losing face in their community. Collectivist cultures that share a collective identity, emotional dependence and shared duties and obligations, operate under a 'we' consciousness and are common in culture's outside of Western societies that prioritize the individual (93). The difference between individualism and collectivism ought to be considered when creating DMH tools, building an awareness that psychological support may be shared within a broad family network and that 'burden of results' may not be carried alone in collectivist communities. Individuals from many collectivist cultures may struggle to understand the typical individualistic approach to treatment, as they expect to be treated within their families (94).

Some may also have deeply held negative beliefs or attitudes toward those experiencing mental health challenges, making it important to design mental health services with informal avenues (e.g. friends and family) that individuals may rely on for support (95, 96). Loss of face is an important cultural factor in the Asian context and has been found to be a significant predictor of self-stigma and public-stigma that impacts attitudes toward help-seeking (97-99). Especially given that community belonging is a large contributing factor to migrant mental health (12).

Diverse communities may minimize the reporting of psychological symptoms or may be resistant to sharing personal health information because of a mistrust, perceived racism and a sense that the public mental health services do not accommodate or respect their cultural beliefs (100, 101). Culturally sensitive psycho-education within communities to combat stigma is needed. To do this, we suggest engaging with community and religious leaders and mental health advocates with lived experience of mental health challenges, given their influential reach to diverse end users, to promote community informed education, self determination and self-advocacy. Designs should offer transparent data collection policies, with tiered consent, to ensure the end user is still comfortable sharing their data, and this should be paired with digital navigators who were members of health care teams dedicated to help end users (102).

Young people in our study voiced concern that there was a lack of culturally and linguistically diverse clinicians and assessment tools, and that information were mostly communicated in English with a Western framework for assessing mental health. Research has found diagnostic assessments tend to not be sensitive for minority populations due to their exclusion from mental health research (103, 104). Furthermore, diverse community members are less likely to have satisfactory access to mental health support and are less likely to be diagnosed with a mental health condition (105, 106). If DMH tools are to be relevant, accessible and effective for diverse populations, future design and implementation must be written in languages other than English and allow for other cultural approaches to mental health. The very term *mental health* is a Western concept, and Western cultural traditions and understandings have informed much of the theory, practice and understandings of mental health, including within psychology and psychiatry, with a central focus on individual pathology instead of socio-cultural contexts and determinants (107, 108).

Furthermore, how patients from diverse backgrounds express their symptoms may vary, making it challenging to accurately diagnose or treat (104). Individualized models of care may not be appropriate for those who are accustomed to community or family-focused models of care (108). The British Psychology Society proposed the Power Threat Framework as a non-medicalized and non-diagnostic approach that instead describes how coping and survival mechanisms are adapted based on lived experiences, previous threats, and social context, accounting for cultural differences in experience and expression of distress with less emphasis placed on Western views (109).

We ought to consider how to design for cultural sensitivities that are informed by attitudes from diverse communities and encourage self-determination and cultural context within a well-being framework. One suggestion is for DMH tool developers to offer enhanced psycho-education that is culturally safe and fosters self-determination, with tailored psychological assessments and resources that account for language variations and barriers for users coming from collectivist cultures whose conceptions of mental health vary from the Western medicalized understanding.

4.3 Medicalization by design

Concerns were raised about making a child or young person feel different. Participants worried that “*a diagnosis may worsen your situation*” suggesting that a diagnostic label or detection of a mental health problem, and the diagnostic process itself, may further marginalize diverse communities through the medicalization of culturally appropriate cognitions or behaviors. Medicalization pathologizes behaviors according to a Western psychiatric framework, putting the responsibility back on the individual to stay healthy without considering other important social factors (110, 111). Online screening tools and mobile apps are being designed to promote wellbeing and provide psychological support, but they can also work to endorse ongoing surveillance (112) of mood and activity and set expectations about healthy behaviors and cognitions. A shift in how mental health is conceptualized and designed for in a way that accounts for cultural barriers that may narrow the engagement and usability for diverse end users of DMH tools is needed (109). Importantly we need to invest in community led practices that promote community leadership in the design and innovation of DMH tools (82) to avoid inbuilt discrimination that reproduce inequities due to normative or Western orientated assumptions about mental health (113). We suggest that when designing DMH tool outputs such as the communication of health information, recommendations for services and interventions, and referral pathways, that the reported symptoms entered by the end user are phrased in a way that avoids pathologization and diagnosis. Currently, DMH platforms tend to recommend resources on anxiety, depression and suicidal ideation, and eating disorders (39, 114), however we believe it is imperative that symptoms are spoken about in clusters, rather than specifying specific diagnostic criteria, that may then pigeonhole or ‘label’ an end-user without appropriate access to clinical care.

4.4 Attitudes toward data collection are a two-way street

When using DMH tools, participants felt there was less concern about privacy and data sharing when the data collected was more generalized. This is consistent with a recent study on diverse communities using mindLAMP, a digital mental health platform, where participants wanted their digital mental health apps to pull data from their current healthcare records in order for the app to be more personalized (115). Participants acknowledged that innovations and interventions require consent for collection of a substantial amount of data in order for it be tailored or for platforms to ‘*algorithmize my personal experiences*’; however, research has found that DMH tools are often not culturally tailored or responsive due to diverse or minority populations often not being considered in the development and evaluation of DMH tools (116, 117). Young people from culturally diverse communities recognized that they would need to provide access to personal digital health data to realize the benefits promoted by DMH tools. Critics have argued that young people may not comprehend the longevity and potential harms of a digital footprint, and that thoughtful education

and support around this is important for their future privacy (118). Whilst research has demonstrated an unwillingness from end users to share their sensitive health data with commercial organizations (23, 119-121), there was a sense in our findings that participants expected an 'algorithmized experience' which would require health data to be accessed as open data (122). Given the sensitive nature of mental health data, we suggest further education on data governance and potential re-use of big data is recommended for young people, given the nature of cross-sectoral data sharing. One approach may be incorporating speculative design approaches, like that suggested in (23), to engage young people in discussions around the digital futures, potential harms and misuse of their data.

In both phases the participants identified concerns about data breaches, including potential identity theft and the impact it could have on visa and migration status. These concerns are expressed in the literature, with one study finding nearly half of digital mental health apps surveyed didn't have a privacy policy despite healthcare apps commonly sharing their data points (i.e. age, contact information, username, passwords) with multiple third parties for commercial purposes (123, 124). Attempts have been made to move toward ethical standards of digital data gathered from DMH tools, including accounting for data breaches, which advise developers to account for hidden assumptions and unintended consequences (125). Attempts have been made to regulate data privacy such as through the General Data Protection Regulation (GDPR) in Europe with similar privacy acts being developed in Brazil, Chile, and Canada, but even the GDPR is limited in the context of emerging generative A.I innovations.

5 Reflections and limitations

This study sought to engage with diverse representatives in relation to cultural and lived experience of mental health. To do this, we approached an organization that was centered on multicultural mental health who advertised, recruited participants and supplied bi-cultural workers for our study. Whilst we were able to have meaningful discussions in our workshops, the participants were all affiliated with the organization, meaning it was not necessarily representative of a truly culturally diverse population given each participant was already mental health literate, able to communicate in English, and held a preconceived understanding of mental health, rather than being a layperson. The addition of an Anglo-Australian participant was also a limitation. Future research needs to engage with a broader range of culturally diverse participants including those with less digital and mental health literacy, and those who may be in a more contemplative stage of their mental health journey and possibly unaware of support services. Future research might consider recruiting through youth organizations or wellbeing counsellors who may have access to a more diverse range of participants that reflect a more diverse picture of mental health literacy and help seeking. Future research should also engage in participatory action research methods (e.g. codesign and coproduction) that allows end users to design research questions and study design. This can present additional challenges to building social capital and gaining trust to engage with diverse end users in a meaningful way that need to be factored into study timelines. Our study was bound to an innovation timeline, making recruitment of a truly diverse sample impossible. We were conscious that we did not invite the participants to review the data analysis or final manuscript, which could have reduced the power imbalances further by allowing the participants to join as co-researchers in the project from start to finish. Future iterations of this would benefit from inviting culturally diverse participants onboard as co-researchers, not just as a participant. We believe it is important that diverse community members voices must be embedded within the lifespan of a research project.

Most of our participants were from South-East Asia. Whilst this is an accurate reflection of the majority of culturally diverse Australians (1), it may not capture the views of minority cultures within Australia. We hoped to avoid essentializing all experiences as one, by including quotes from individuals, as we believe that diverse communities do not share a single common experience due to varying socio-political differences such as age, culture, and citizenship. The median age of the young people participants is quite high (one 16 year old, one 18 year old but the remaining were aged 20-

22). Our findings may not reflect the views of younger adolescents. Future endeavors should aim to apply the insights gained from this research in the development and pilot testing of DMH interventions and applications, by evaluating their effectiveness and refining them based on the outcomes.

6 Conclusion

Inclusive design considerations for the future development of DMH tools that account for cultural-based discrimination, are culturally safe, consider family and cultural influence on mental health support, and are thoughtful in how mental health problems are detected and communicated to end users, would improve engagement in DMH tools and help seeking. We recommend encouraging culturally sensitive psycho-education, thoughtful non-pathologizing language that avoids providing a specific diagnosis, and the inclusive involvement of community leaders and advocates in the future design of DMH tools, to ensure they are designed to meet the needs of diverse end users.

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Conflicts of Interest

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Authors Contributions

The study was designed by IB, AC, RM, and JC. IB prepared the first draft of the manuscript. All authors contributed to and approved the final manuscript.

Abbreviations

DMH tools: digital mental health tools

HCI: human computer interaction

GMA-CTN: Growing Minds Australia Clinical Trials Network

GMCI: Growing Minds Check In

GDPR: General Data Protection Regulation

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Appendices

Digital Mental Health Co-design Workshop Schedule

Workshop aims:

- To identify the possible benefits, burdens, or trade-offs of how mental health data is collected, shared, and used.
- To examine how end-users value data about mental health and whom they will share their data with.
- To identify the social factors that influence the use and application of digital technologies, including third-party use.
- To examine how predictive information is communicated and understood, and to what impact on clinical practice this might have.

Duration	Exercise	Resources
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10am	Workshop Commencement	
10 mins	Welcome and introduction to the project S: explain session safety and etiquette I: explain overarching purpose of study Prompts: • Consent required? If so, sign forms • Cover study aims and workshop aims (slides) • In each of the activities we invite you to imagine yourself as a future user of digital mental health technology, it can be speculative and you don't have to discuss personal anecdotes if you don't feel safe to do so	- Consent forms - Information sheets - Pens - Audio recorders
10 mins	Persona Icebreaker: S: What is your understanding of mental health? What makes for good mental health? What makes for bad mental health? What can influence it? I: write down suggestions on sticky notes Group discussion to set the context for the following activities. This activity will help to get to know how participants understand mental health. Done via informal chat using a whiteboard to get to know different members of the group. Aim: To examine how end-users from priority groups perceive mental health and whom they will share their data with. Themes: mental health literacy and cultural fluency, social factors surrounding mental health	- Whiteboard - Marker pens - Flip chart paper
30 mins	Digital Vault: Aim: This activity is designed to gauge participants' level of understanding of MH data, how secure it is, different types of data, and who might share or access it.	- Large sheets of paper - Pens - Post-it notes - Stimuli: pictures of potential mental health data e.g.

	Themes: Understanding of MH data, privacy, access Instructions: 1. A physical box (representing the <i>digital vault</i> - <i>this vault will have 3 layers - the outer layer, an inner layer, and a chained safe</i>) will be placed at the centre of the room. 2. Set of pre-filled cards containing different forms of mental health data (e.g. social media apps, phone, diary, web-browser history) and blank ones that participants can write on to will be provided to each participant. 3. Ask participants to slot in the mental health data cards into specific areas of the vault they deem appropriate. 4. Probe why. I: read script S: help with arranging icons and keys within the vault, observing zoom participant and probing why Script: We will create a physical box to work as a vault. This digital vault or digital bank can store all of your mental health data safely. There is an outer vault, an inner vault, and a locked-up safe to contain important information about your mental health: - social medial interactions - the apps on your phone - your internet browser history - the tone of your voice from phone calls you've made What would you put in there? Why? What might you put right at the back of the vault, where it needs a key before it can be accessed? What don't you mind putting at the front where it might be somewhat visible? How do you feel about these data points passively tracking you? Why?	icons of social media apps, phone, diary, etc. - Cardboard box and piping - Set of cards, some prefilled some blank
30 mins	Blank Keys:	- Key cut outs - Pictures of

	Aim: This activity is designed to understand to whom the participants are willing to share their data with and their reasons why. Themes: understanding of MH data, privacy, access Instructions: 1. Give participants 6 key to the digital vault (i.e. post-it notes / key-shaped cut-outs); 2 keys for the inner vault, 2 keys for outer vault, 2 keys for the safe. 2. Ask the participants to write on to these blank keys the people they are willing to give access to the different areas of the digital vault. 3. Probe why. 4. Read the scenario about digital bank robbers and ask the probing questions. I: read script S: observe comments, probe and build on what participants raise Script: Who would you give the keys to the vault to? Your family, GP, spiritual leader, friends? Insert the keys into the vault in a position either on the inner or outer part of the vault depending how much you trust that person with the key. Why have you chosen this person? Why are they important to you? (15mins) Now let's imagine digital bank robbers broke into your vault. Who might the robbers be? Why would they want your data? Which specific area of the vault would they be most interested in? (15 mins)	robbers
	Leg Stretch Break 10 min	
45 mins	Data Sharing Aim: This activity is designed to get participants thinking about their individual perspectives as well as how others may feel about having their	- Pen - Post-it note - Picture prompts

personal data shared under the guise of helping them or the community.

To identify the social factors that influence the use and application of digital technologies, including third-party use and sharing.

Themes:

Data sharing, privacy, and control

Instructions:

1. For Sub activity 2: This is just a discussion based activity. Read the scenario and answer the probing questions.

I: read script

S: observe comments, probe and build on what participants raise

Script:

Sub-activity 1: YOU AS THE OWNER OF THE PREDICTION (25 mins)

Imagine your digital vault is now managed by a digital manager. This digital manager has worked out how to use the data points that were passively collected in your vault to predict mental health issues. The manager has indicated you are likely to have complex mental health (bi polar or schizophrenia).

Your digital vault has come back with a diagnosis/prediction you may have complex mental health condition. Would you want anyone to know about what was predicted from the digital vault? Who do you think the manager should share this information with? Who wouldn't they share this with?

A. Family:

- Do you think the manager should notify your partner or close friends? Why? Why not?

B. University:

- How would you feel if the university knew about your digital vault prediction? Who would you feel safe

	sharing this with at university? What would you be worried about? C. Current / Potential Employer: • How would you feel if your employer, knew about your digital vault prediction? Who would you tell? What would you be worried about? <i>Sub-activity 2: YOU AS A RECIPIENT OF OTHERS' PREDICTION (20 mins)</i> Imagine the vault manager has shared with you that your friend or colleague has a concerning outcome in their mental health prediction based on their digital vault data. What would you do with this information? Who would you share this with? Who wouldn't you share this with?	
	Lunch Break 15 mins	Lunch
30 mins	Future forecasting return of results data sharing: Aim: To examine how predictive information is communicated and understood, and to what impact on clinical practice this might have. This is a discussion-based activity to consider the modalities data donated today could be used in the future and whether digital mental health literacy and MH data counsellors are efficient. Themes: Privacy, safety, trust, informed consent, risk communication (triage officer), inherent uncertainty Instructions: 1. Co-facilitator to read the script about imagined future. 2. End with a discussion around information presentation of mental health predictions (sub-activity 2) I: read script S: observe comments, probe and build on what participants raise	- Post its - Pens or markers - Emoji icon cut outs

	Script: Imagine that in 20 years from now the uploads from your cloud storage have been combed continuously for analysis. Scientists have worked out a way to use your old cloud entries to predict possible signs of Parkinson's based on your data engagement, years and years before they are usually diagnosed. You're sipping a coffee at work one day when you receive an alert on your smart device. It's notifying you that there are important results in your digital inbox. You had forgotten about participating in this study and what you'd agreed to let the digital vault have secured, but the alert indicates it's about findings from a research study in 2022. The alert is a prediction that you're likely to have early-onset Parkinson's based on the data stored in your digital vault. I: read script Sub-activity 1: Emojis (15 mins) How do you feel about getting this result? [Anxious, relieved, glad, etc.]. Would you like to know this in advance? (Do you feel empowered knowing this prediction in advance? Do you trust its accuracy? Would you prefer your GP or mental health clinician had told you? Would you trust it more if your GP told you? Are you concerned about who else is accessing this digital vault from some years ago? (20 min) Sub-activity 2: Discussion (15 mins) Sarah: read script How would you like this prediction presented to you? How would this information be presented back to you in a way that you understand and is meaningful?	
5 mins	Wrap up and goodbye	

