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Technology Ecosystems: Rethinking Resources for Mental Health

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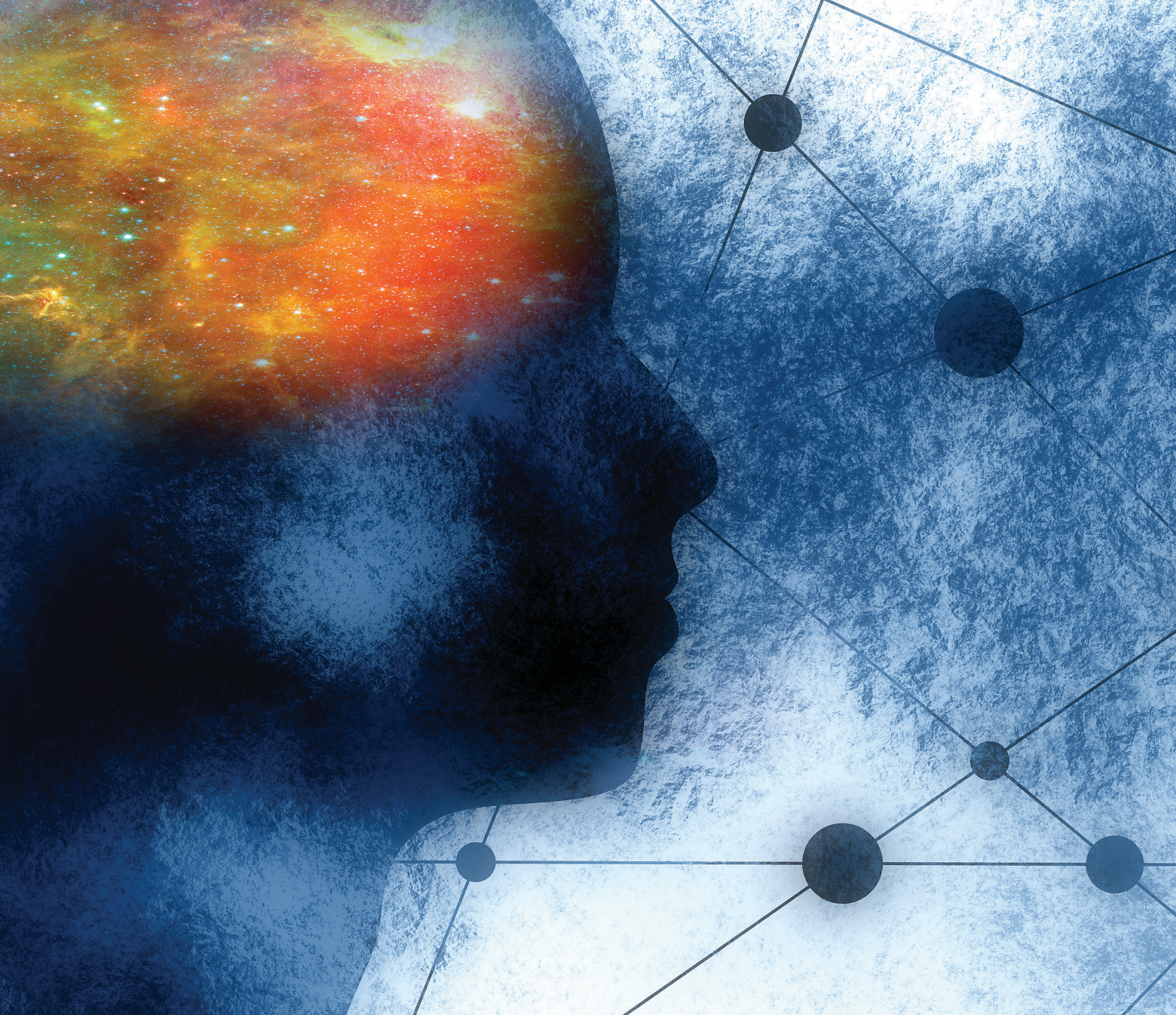# Technology Ecosystems: Rethinking Resources for Mental Health

Insights

→ Understanding tools used in technology ecosystems can lead to mental health resources that leverage existing opportunities rather than create new demands.

→ Mixed method, multidisciplinary approaches can capture the complexity of technology ecosystems.

→ Foregrounding ethical considerations highlights the needs of people with mental illness including potential and inadvertent consequences of systems designed with good intentions.

Globally, the World Health Organization (WHO) estimates that 450 million individuals suffer from mental and neurological disorders. In the U.S. alone, in a given year, 44 million adults experience mental illness, including anxiety, depression, eating disorders, and schizophrenia. Individuals living with mental illness navigate disclosures of their experience and self-management as well as interactions with clinical care as part of their everyday lives. Activities to manage mental health needs may be broad reaching and dispersed, including in-person conversations, therapy, and interactions online and through mobile applications. A growing body of research in HCI suggests that people do not rely on only one resource or

technology to manage their mental health. Frequently, individuals use a variety—or an *ecosystem* [1]—of technologies to share their experiences, connect with others, and manage aspects of care.

In recent years, digital resources to support mental health have proliferated. While there have been some approaches to categorize and characterize resources, such as One Mind PsyberGuide (https://onemindpsyberguide.org/) for mobile apps, we have limited understanding of the breadth of tools, services, and other approaches for mental health support and the best practices of their use. While HCI researchers have examined the role(s) of technologies for individuals living with mental illness, much of this

work focuses on specific platforms or applications, rather than on the entirety of an individual's technology ecosystem. Here, we begin to explore the ways in which individuals use an ecosystem of resources to support mental health self-management. As we consider the impact of the Covid-19 pandemic on mental health and the disruption of mental health services, we need to examine more closely how we can design, implement, and sustain digital mental health support. In this article, we share themes from our 2020 CHI workshop, Technology Ecosystems: Rethinking Resources for Mental Health (mhtechecosystems. wordpress.com), which was held virtually in April 2020.

Drawing on presentations from two keynote speakers, a Covid-19 and Mental Health panel, and 14 small-group discussions [2], we present four main themes that cut across the presentations and discussions: 1) technology ecosystems for mental health support, 2) research methods to study technology ecosystems, 3) Covid-19 implications for mental health management and research, and 4) ethical issues in mental health research.

TECHNOLOGY ECOSYSTEMS FOR MENTAL HEALTH SUPPORT

Many researchers have investigated the benefits and challenges of technologies for supporting mental health. However, the scope of analysis for the majority of these studies is often a single technology tool or service. For example, researchers have examined how to support mental health through mobile apps, online communities, and social media. What is missing, however, is a broader view that can account for the combination and diversity of technology resources that people use in their everyday lives. We wondered: Could a *technology ecosystems* [1] approach help us to identify gaps in how we are creating mental health resources? Could we use this concept to inform how we think about designing for and with multiple stakeholders? Could a technology-ecosystem approach help us to consider the unique challenges of underserved groups and their mental health needs? These questions guided this workshop.

First, we considered the variety of tools and services used in the

technology ecosystems of individuals managing their mental health. A technology ecosystem may include mental health apps (e.g., Headspace), telemedicine services, social media platforms, online communities (e.g., Facebook, Reddit), texting, phone calls, music, and games, among many other tools and services [3]. Second, technology ecosystems are inextricably intertwined with individuals' social relations. Many technologies are inherently social (e.g., social media), so it is important to understand technology ecosystems through the perspectives of a variety of stakeholders. For instance, people not only manage their mental health individually but also turn to others for support [4]. Individuals also engage in sensitive disclosure of their stigmatizing experiences as a way to find common ground and validation from their social audiences (e.g., on social media apps like Instagram [5]).

While designers strive to include users as a part of the design process, much of the user-centered design research has so far focused on single stakeholders such as patients or clinicians. However, it is important to provide a broader picture of stakeholders involved in a technology ecosystem. Depending on the user and the type of intervention, stakeholders might include: therapists, psychiatrists, primary care doctors, users managing one or multiple illnesses, families and friends of the users, coaches, designers, and nonprofit organizations. Some questions here include: *How do we incorporate various stakeholders and users in the design process* and *how do we include features that incorporate the social aspects of mental health support and management?* For instance, caregivers may themselves suffer from mental health issues in addition to the person whom they are supporting. Understanding the set of stakeholders of a potential tool or service is essential in order to design within people's current workflows both at the individual and system levels.

To begin to do this multistakeholder work and to bridge communities in our research and practice, this workshop brought together participants from a range of interdisciplinary backgrounds (Figure 1) to talk about our experiences in studying issues of mental health and technology.

RESEARCH METHODS TO STUDY TECHNOLOGY ECOSYSTEMS

A recurring theme in the workshop was the need for mixed-method approaches to capture the complexity of technology ecosystems. Researchers have used a variety of methods including surveys, interviews, focus groups, participatory design, and computational methods to study digital technologies for mental health support. While each methodology has its unique benefits and challenges, no single method can tackle all the research questions around technology ecosystems. On the one hand, interviews can generate rich, contextual data that provides insight into people's appropriation and meaning making of technologies. For instance, through in-depth interviews, we can learn how individuals managing depression may appropriate calendar applications to schedule social interactions, making sure they have some but not an overwhelming number of social engagements every week [3]. System usage data, on the other hand, passively and automatically captures the use of and engagement with technologies over an extended period of time. Using this data in the context of calendar use, we might learn how often people conducted this behavior, how many social events people scheduled per week on average, what type of social events people scheduled, and so on. Thus, mixed-method research has the potential to provide a holistic picture of the use and efficacy of technologies for supporting mental health. HCI has often adopted a qualitative approach, whereas clinical psychology is primarily rooted in quantitative methods; we are able to combine these traditions by conducting mixed-methods work.

Second, we need to focus on temporal issues when studying technology ecosystems. Notably, much HCI research on technology use has been cross-sectional, with data collected at a specific point in time. However, this does not allow for an assessment of causality or change over time. Specifically, how might we understand technology ecosystems longitudinally, knowing that people will use different technologies over time for different tasks? More longitudinal studies are needed to depict how individuals' personal technology ecosystems change over time. Longitudinal studies may also enable researchers to investigate factors that may determine or influence the use of certain technologies. In particular, within the context of mental health management, experience sampling methods (ESM) or ecological momentary assessments (EMA) promise to be effective methods to examine technology use in specific social contexts. EMAs allow researchers to study how the ebbs and flows of one's emotional state might influence the use of different technologies. When coupled with system use data, EMA can help delineate the temporal dynamics of technology ecosystems and how temporality is associated with one's mental health and other health status [6].

COVID-19 IMPLICATIONS FOR MENTAL HEALTH MANAGEMENT AND RESEARCH

The theme of Covid-19 disruptions and social distancing's effects on mental health was a major thread of discussion throughout the virtual workshop. Our panelists discussed how the communities they research and interact with have experienced the pandemic. Panelists recognized the unprecedented use of technology-mediated communication such as social media and videoconferencing, and they reflected on the implications of increased screen time and digital well-being. Kelechi Ubozoh, a nonfiction author and mental health advocate, described the impacts of stress and fear on mental health and the importance of peer support and connectivity as a mitigation strategy. Mary Czerwinski of Microsoft Research echoed this, noting that her research team is seeing increased emotional exhaustion and loneliness during this difficult time. Adrian Aguilera (UC Berkeley) described how Maslow's hierarchy of needs has intensified in importance because many people have lost their jobs and economic stability. He also described how we can view the pandemic as a

moderator, magnifying both new and previous issues. Regarding interventions to support individuals in need, Gavin Doherty (Trinity College Dublin) discussed how his team prioritizes elements such as having a human in the loop, emphasizing social connectedness, and maintaining some relationship with the user even at a large scale. By discussing these intersecting issues, the panelists concluded with a call to action for researchers to learn about people's changing needs and to find ways to support individuals and communities using sociotechnical approaches during these difficult times.

At the same time, Covid-19 has also deeply affected both clinical practice and mental health research, moving both toward remote interactions. Individuals within mental health service delivery have been forced to quickly adopt technology. In Kaiser Permanente Washington, mental health visits changed from 10 percent virtual to 95 percent virtual in a period of two weeks [7]. Providers have had to learn how to use digital tools, and consumers have had to grow comfortable relying on these tools for mental health services. Similarly, researchers, especially those who do design work, face unprecedented challenges as they transition to remote research methods such as technology-mediated interviews, remote focus groups, and remote participatory design activities. Aspects such as recruitment and building rapport with participants can be challenging. For example, while social media and crowdsourcing platforms such as Amazon Mechanical Turk can enable the fast recruitment of participants, recruitment for longer or more engaged studies often lags. Additionally, without in-person interactions with participants, researchers may find it difficult to build rapport and hold participants accountable. Some researchers have had higher attrition rates and more last-minute rescheduling requests from participants compared to research conducted face to face. Potential solutions discussed include increasing incentives, sending reminders, and stressing the importance of research commitment.

Another challenge is maintaining participant engagement with research

Disciplinary Background of Workshop Attendees

77%

10%

- ■ Human-computer interaction (HCI) or UX researcher
- ■ (Clinical) psychology researcher
- ■ Health informatics and HCI researcher
- ■ Data scientist and researcher in digital mental health intervention
- ■ Human development (interdisciplinary including developmental and social psychology, education, health disparities)
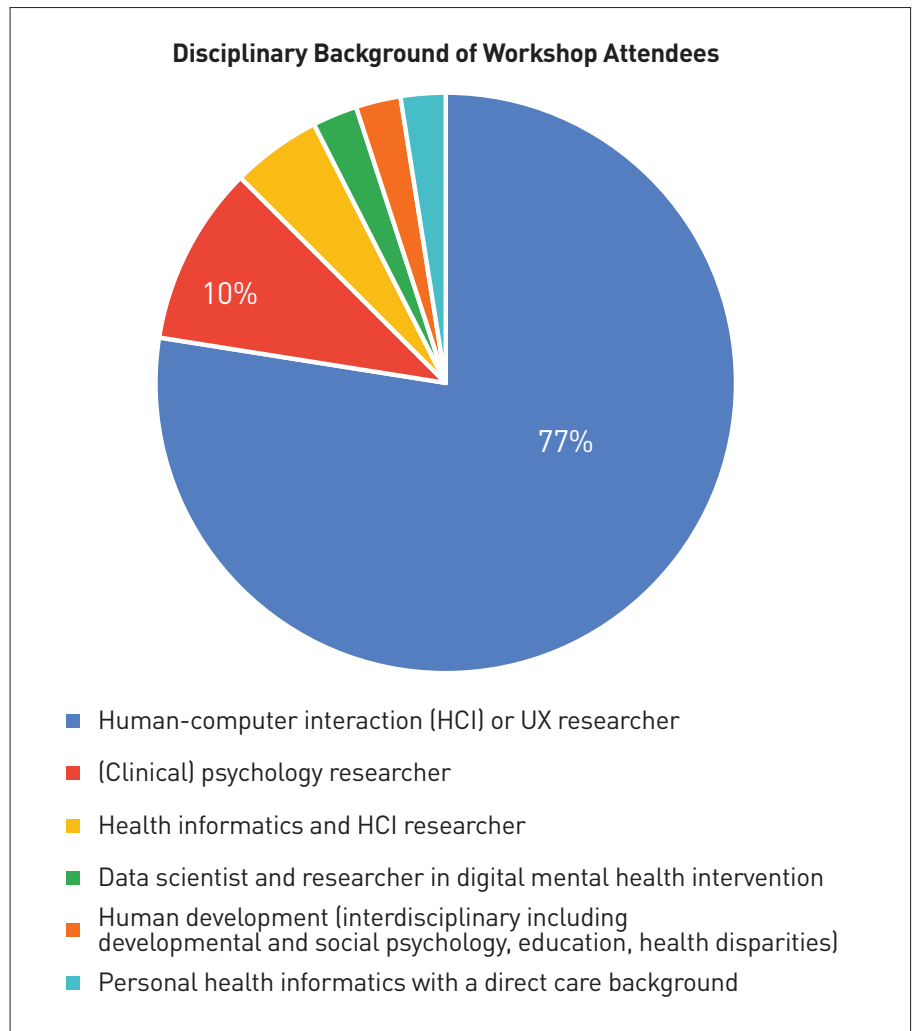- ■ Personal health informatics with a direct care background

Figure 1. "What is your disciplinary background?" question for workshop attendees.

activities. Attention span tends to be short in online settings. This is compounded by stay-at-home orders. People can be easily distracted by their surroundings: kids crying, dogs barking, and phones pinging. Thus, researchers need to think creatively about ways to boost engagement while accepting the fact that participants may not be as engaged as we would like during this stressful time. Examples of innovative remote methods include the asynchronous remote communities (ARC) method and graphical tools for collaborative design work such as Aww App and Lucidchart. Additionally, it is imperative to pay attention to who gets left out when we proceed with remote studies, such as people who have limited access to the Internet and those who have low digital literacy. Creative methodological approaches and potential biases regarding online recruitment and sampling should be well documented.

ADDRESSING ETHICS IN MENTAL HEALTH RESEARCH

Ethical concerns, including consent, bias, and privacy, are integral to how we approach the design and provision of mental health support resources and interventions. Given the stigma associated with mental illness and the marginalized status that often accompanies it, researchers should be attentive and engaged when working with people managing mental illness. During the workshop, we discussed three key challenges regarding ethical engagement with members of our research population(s): 1) How do we know when an intervention is working right and when is it not? 2) Should we attempt to engage individuals who are not actively seeking support? and 3) What should be our ethical considerations in research that uses available public data to develop mental health support systems, and how should these tools be developed in a way that does not

undermine people's needs, values, and experiences? We present these challenges to promote conversations regarding how researchers can approach these ethical dilemmas within their own specific contexts of study.

First, it is imperative to consider the consequences of mental health interventions. Despite good intentions and positive outcomes, interventions can engender negative effects, including concerns around data privacy and security, reminders of illness, frustration, obsessive logging, and coercion. Thus, it is critical in mental health research to understand the potential consequences and harms produced by well-intended interventions. To this end, researchers must engage people with mental illness in their scholarship and the design of interventions. This involves striking an artful balance between the potential for burdening and exploiting members of a marginalized group and inviting individuals to contribute their experiences, knowledge, and sensibilities.

Second, when is it appropriate to engage individuals who are not actively seeking support, for instance, for the purposes of intervention or providing mental health resources? This question has become pertinent to conversations about developing technology ecosystems powered by people's data. Ernala et al. [8] have shown that, despite considerable efforts to detect certain mental illness content online (such as individuals' diagnosis of schizophrenia), there are several methodological issues regarding prediction accuracy, construct validity, and clinical utility that limit their feasibility of practical use. The stigma surrounding mental illness can also prevent people from connecting with formalized care, prompting them to seek peer support online. Therefore, an ongoing question here is: *What are ethical strategies to engage these individuals online, who may not be seeking formalized mental health care?* In

other instances, some people post on social media rather than going to the hospital because of traumatic experiences in the hospital, both their own or stemming from collective, generational trauma. Receiving suggestions that direct them back to places they consider traumatizing may make people feel uncomfortable or even resistant. One way to understand these intricate issues is to conduct in-depth interviews with participants to understand their struggles and aspirations rather than solely relying on their digital trace data online.

Third, when it comes to using public data (e.g., social media data) to develop mental health support systems, important questions arise about data ownership, consent, monetization, and practical translation. In recent years, scholars have begun to discuss these issues at length. For example, Chancellor et al. [9] presented a three-prong taxonomy to analyze ethical issues including: ethics committees and the gap of social media research; questions of validity, data, and machine learning; and implications of this research for key stakeholders. Similarly, Benton et al. [10] suggested guidelines to inform institutional review boards (IRBs) of the unique challenges that mental health research presents. There have also been concerns about using public data without an individual's explicit consent, and also about the unintelligible privacy terms of mental health apps [11]. It is important for researchers to break down what kind of data is being used and to consider how to enable people to opt out with plain language. In addition, the expansion of machine learning algorithms has enabled business models relying on the monetization of behavioral data. Thus, users may be exploited by companies that sell their data to third-party companies to generate revenue. How can we make more fair exchange and

clear ownership of data? Perhaps we need different business models where people own their data [12].

CONCLUSION: WAYS TO MOVE FORWARD

In this workshop, we asked: *How can applying a technology ecosystem lens to the breadth of mental health resources help us to identify gaps and motivate future resource design?* We began to explore this, but we believe that this workshop was only a first step in bringing a diverse group together to start working on these issues. Using the technology ecosystem perspective, we can take a high-level view of the breadth of tools and services that individuals are using. Moving forward, we advocate for supporting reflective processes for users (perhaps in collaboration with their healthcare providers) across the range of tools that they use day to day. To encourage further conceptualization and utility in exploring these concepts, participants generated open dimensions of technology ecosystems relevant for conceptualizing and designing within these technology ecosystems:

• *User goals.* Within the ecosystem of accessible technologies that people select from, how and why do people pick the tools they use? Are there dependencies in their assemblages of tools and services? Are these choices based on accessibility?

• *Life stage.* How might technology ecosystems change over the course of an individual's life? What transitions do people make between tools and services over time? How might the technology ecosystems used by young people differ or be similar to ecosystems used by older people?

• *Health management journey.* For individuals managing illness, how do their tool and service journeys interact with what researchers conceptualize as chronic condition journeys (e.g., the experience of being diagnosed and living with a chronic condition)?

• *Scale.* Should we investigate technology ecosystems at the level used by an individual, or should we consider larger units of analysis? For instance, what if we looked at the ecosystems of potential apps for Android versus iPhone users? How about the technology ecosystems of a neighborhood? A city?

The above dimensions are a start to encourage further thinking about technology ecosystems in our research

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It is critical in mental health research to understand the potential consequences and harms produced by well-intended interventions.

and design. Indeed, people may adapt their assemblages of tools and services over time to meet changing needs and goals. We need to understand how to assemble, study, and consider the ethics of technology ecosystems in order to design supportive solutions that connect with existing ecosystems and routines. This will require collaboration across disciplinary boundaries as well as rethinking the intersection of technology and mental health. The current moment demonstrates the critical need for mental health services as well as the potential of technologies to address this need. We have an important window of opportunity to design future technology ecosystems with mental health in mind.

ENDNOTES

1. DeVito, M.A., Walker, A.M., and Birnholtz, J. 'Too gay for Facebook': Presenting LGBTQ+ identity throughout the personal social media ecosystem. *Proc. ACM Hum.-Comput. Interact. 2*, CSCW (Nov. 2018), 44:1–44:23; https://doi.org/10.1145/3274313

2. Our workshop had two rounds of seven discussion groups based on the following topics: 1) Ethics of Mental Health Research and Intervention, 2) Technical Issues in the Design of Mental Health Resources, 3) Implications of Artificial Intelligence and Machine Learning, 4) Social Media and Social Support, 5) Research Methods for Technology Ecosystems, 6) Remote Mental Health Research Methods, and 7) Implementing and Evaluating Mental Health Resources.

3. Eschler, J., Burgess, E.R, Reddy, M.C., and Mohr, D.C. Emergent self-regulation practices in technology and social media use of individuals living with depression. *Proc. of the 2020 CHI Conference on Human Factors in Computing Systems Proceedings.* ACM, New York, 2020.

4. Burgess, E.R., Ringland, K.E., Nicholas, J., Knapp, A.A., Eschler, J., Mohr, D.C., and Reddy, M.C. 'I think people are powerful': The sociality of individuals managing depression. *Proc. of the ACM on Human-Computer Interaction 3*, CSCW (Nov. 2019), Article 41:29; https://doi.org/10.1145/3359143

5. Ernala, S.K., Labetoulle, T., Bane, F., Birnbaum, M.L., Rizvi, A.F., Kane, J.M., and De Choudhury, M. Characterizing audience engagement and assessing its impact on social media disclosures of mental illnesses. *Twelfth International AAAI Conference on Web and Social Media.* AAAI, 2018; https://aaai.org/ocs/index.php/ICWSM/ICWSM18/paper/view/17884

6. Schueller, S.M., Aguilera, A., and Mohr, D.C. Ecological momentary interventions for depression and anxiety. *Depression and Anxiety 34*, 6 (2017), 540–545; https://doi.org/10.1002/da.22649

7. Simon, G. Delivering on the real promise of virtual mental health care. Kaiser Permanente Washington Health Research Institute. May 19, 2020; https://www.kpwashingtonresearch.org/news-and-events/blog/2020/delivering-real-promise-virtual-mental-health-care

8. Ernala, S.K., Birnbaum, M.L., Candan, K.A., Rizvi, A.F., Sterling, W.A., Kane, J.M., and De Choudhury. M. Methodological gaps in predicting mental health states from social media: Triangulating diagnostic signals. *Proc. of the 2019 CHI Conference on Human Factors in Computing Systems.* ACM, New York, 2019, 1–16; https://doi.org/10.1145/3290605.3300364

9. Chancellor, S., Birnbaum, M.L., Caine, E.D., Silenzio, V.M.B., and De Choudhury, M. A taxonomy of ethical tensions in inferring mental health states from social media. *Proc. of the Conference on Fairness, Accountability, and Transparency.* ACM, New York, 2019, 79–88; https://doi.org/10.1145/3287560.3287587

10. Benton, A., Coppersmith, G., and Dredze, M. Ethical research protocols for social media health research. *Proc. of the First ACL Workshop on Ethics in Natural Language Processing.* Association for Computational Linguistics, 2017, 94–102; https://doi.org/10.18653/v1/W17-1612

11. Torous, J. et al. Towards a consensus around standards for smartphone apps and digital mental health. *World Psychiatry: Official Journal of the World Psychiatric Association (WPA) 18*, 1 (2019), 97–98; https://doi.org/10.1002/wps.20592

12. Martinez-Martin, N. Trusting the bot: Addressing the ethical challenges of consumer digital mental health therapy. *Ethical Dimensions of Commercial and DIY Neurotechnologies 3.* Elsevier, 2020, 63.

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