# 4<sup>th</sup> Symposium on Computing and Mental Health: Designing Ethical eMentalHealth Services

# **John Torous**

Division of Digital Psychiatry, Department of Psychiatry, Beth Israel Deaconness Medical Center, Harvard Medical School Boston, MA, USA jtorous@bidmc.harvard.edu

# **Greg Wadley**

Interaction Design Lab, School of Computing and Information Systems, University of Melbourne
Parkville, Vic, Australia
greg.wadley@unimelb.edu.au

# Maria K. Wolters

Centre for Design Informatics, University of Edinburgh Edinburgh, UK Alan Turing Institute London, UK maria.wolters@ed.ac.uk

## Rafael A. Calvo

Positive Computing Lab, School of Electrical and Information Engineering, University of Sydney
Sydney, NSW, Australia
rafael.calvo@sydney.edu.au

#### **ABSTRACT**

With psychiatric conditions like depression now the leading global causing of disability, the need for innovative solutions is apparent. The promise of mental health care delivered through technology (eMentalHealth) to provide personalized care offers a promising solution that has galvanized interest worldwide. However, in order to ensure that eMentalHealth is scalable and sustainable, service delivery

Permission to make digital or hard copies of part or all of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for third-party components of this work must be honored. For all other uses, contact the owner/author(s).

CHI'19 Extended Abstracts, May 4–9, 2019, Glasgow, Scotland, UK
© 2019 Copyright held by the owner/author(s).
ACM ISBN 978-1-4503-5971-9/19/05.
https://doi.org/10.1145/3290607.3298997

and health and social care policies need to be integrated into the design of technology interventions. This will require new forms of interdisciplinary collaborations that we hope to foster in this symposium. Thus, in this fourth in our series of Symposia on Computing and Mental Health, the focus will be on the intersection of the communities innovating in this space: patients, designers, data scientists, clinicians, researchers, computer scientists, developers, and entrepreneurs guided by core medical ethical principles including respect for persons, beneficence, and justice. Our aim is thus to enable the vision of better mental health through ethical innovation powered by the right collaborations

#### **CCS CONCEPTS**

Human-centered computing → Empirical studies in HCI; Interactive systems and tools;
 Empirical studies in HCI; • Applied computing → Health informatics.

## **KEYWORDS**

Mental Health; Positive Computing; eHealth; Service Design.

#### **ACM Reference Format:**

John Torous, Maria K. Wolters, Greg Wadley, and Rafael A. Calvo. 2019. 4<sup>th</sup> Symposium on Computing and Mental Health: Designing Ethical eMentalHealth Services. In *CHI Conference on Human Factors in Computing Systems Extended Abstracts (CHI'19 Extended Abstracts), May 4–9, 2019, Glasgow, Scotland, UK.* ACM, New York, NY, USA, 9 pages. https://doi.org/10.1145/3290607.3298997

#### **BACKGROUND**

The Human-Computer Interaction community remains at the forefront of creating new mobile health apps, wellness programs, online tools, methods, and novel devices that help people stay well and patients recover quickly. The evidence for these new innovations in mental health continues to support their efficacy with positive results for apps in depression [6], anxiety [7], and schizophrenia [1, 2].

Continued innovation in device-based care such as virtual and augmented reality also continues to offer promising results for mental health [9]. Wearable devices like smartwatches and other custom devices able to record information on heart rate, skin conductance, and more continue to make advances in mental health conditions [12]. This wealth of new data about mental health and the ability to now quantify the lived experience of those suffering from these conditions is simply unprecedented.

As the potential of e-MentalHealth interventions increases and such interventions become pervasive, so does the need for a strong theoretical grounding on how they are designed to be fair and inclusive, maximize wellbeing and maintain the rhythm of innovation. This is the fourth in a series of symposia [4]. The  $1^{st}$  Symposium contributed a taxonomy of the work being done across HCI and the Mental Health communities [5] while the  $2^{nd}$  focused on bringing the different disciplines

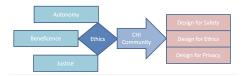


Figure 1: Core ethical principles can be utilized by the CHI community to guide new design principles for digital mental health solutions.

together [3]. The  $3^{rd}$  focused on approaches to "understanding and engaging users" [15]. This  $4^{th}$  workshop aims to catalyze interdisciplinary conversation on the ethical challenges of how this could be done. As has been the tradition for the previous symposia, all topics at the intersection of HCI, technology innovation and mental health will be covered, but preference will be given to articles that contribute to the year's focus.

The opportunities created by new devices, data, and connectivity are broad and range on the spectrum from wellness to illness and prevention to emergency care. As raised by the capability approach of Sen [13], such opportunities to help crucially depend on the capabilities to benefit of those being targeted. Not all users are equal, and their different ways of being and doing needs to be considered by designers. Ethics considerations have become increasingly important in the design of technologies for vulnerable or marginalized participants, such as those living with (or at risk) of mental illness [10]. One way that this has been addressed in HCI is through participatory and user centred approaches, increasingly common in the design of mental health applications and services [14, 16]. In addition, we want to build on the work on value-sensitive design [8], bringing in awareness of our own preconceptions on issues such as privacy, surveillance, safety and the conceptions of wellbeing itself [11], and link findings from HCI with the ongoing debates in public health.

#### TOWARDS SOLUTIONS AND THIS YEAR'S SYMPOSIUM

One thread that will be especially emphasized this year is ethics. In the last two years there have been an increasing number of concerning examples of how lack of regard for ethics can jeopardize the entire potential of innovation in mental health. The Cambridge Analytica privacy scandal which began with a mental health related personality test online, the increases in live streaming of suicide via various social media platforms, and rising concerns about invasive monitoring from smartphones, sensors, and social media data, are just some of the ethical concerns that have captured the public attention. Core medical ethical principles including respect for persons, beneficence, and justice are often lacking in this space.

But fortunately, the CHI community and members of this workshop have the skills and opportunity to build tools and systems that truly embody ethics by design (see Figure 1). It is time to shift the focus of the eMental Health community from usability to user experience, and investigate how we can build wellness and flourishing into our methods, tools, and apps. An important part of this is usable security and privacy, in particular better user controls over personal mental health' data. Following the CHI 2019 theme, we will use this workshop to weave solutions from the different disciplines, cultures, sectors, communities, backgrounds of those in attendance.

To support the needs of the mental health space, theme of the conference, and interests of those partaking—we will again feature a journal special edition where submitted and peer reviewed papers that are accepted will be published in the open access journal JMIR Mental Health. Given that nearly 100 submissions were received for last year's special edition, this year we will require that inclusion in the special edition is subject to at least one author from that paper attending the workshop. Attendance at prior workshops has been high—72 in 2017 and 65 in 2018. To maintain the interactive and collaboration-fostering environment of prior workshops, we will cap attendance at 100. However, for those not able to attend this year we will seek to offer a live blog, live tweeting, and video clips (as permitted) of talks to ensure all have access to the content and ideas discussed.

While the core structure of the workshop will continue to build off the success from the prior three years, this year will feature several new additions.

First, we will work to better engage the community before the meeting. All attendees will be encouraged to post a profile on an open blog post on the workshop's Wordpress website after registration order to foster introductions before the workshop itself. Based on the past two years, we expect this symposium to attract a large number of attendees. Most participants will be researchers, developers and mental health professionals, and will not give presentations, but will benefit from networking opportunities

Second, we will introduce a new design session to the agenda that features the theme of 'ethics by design' where we ask those in attendance to propose design solution to ethical challenges in the digital mental health space.

Third, we will upload all papers associated with posters, the posters themselves, and all social papers to the workshop website before the meeting itself to ensure maximal exposure and allow all attendees to preview them before the meeting itself. All accepted submissions will be tagged for easier navigation.

Finally, to support new collaborations, this year, we will assign workshop participants to tables to foster diversity among attendees and formation of new bonds.

#### **ORGANIZERS**

Our team of four organizers, working in the Asia-Pacific European and North American regions, represent a range of relevant backgrounds and interests.

John Torous, MD (main contact) is director of the digital psychiatry division Beth Israel Deaconess Medical Center, a Harvard Medical School affiliated teaching hospital. He has a background in electrical engineering and computer sciences and received an undergraduate degree in the field from UC Berkeley before attending medical school at UC San Diego. He completed his psychiatry residency and clinical informatics fellowship at Harvard. Dr. Torous is active in investigating the potential of mobile mental health technologies for psychiatry, developing smartphone tools for clinical research, leading clinical studies of smartphone apps for diverse mental illnesses, and publishing on the research, ethical, and patient perspectives of digital psychiatry. He serves as editor-in-chief for JMIR Mental Health and currently leads the American Psychiatric Association's work group on the evaluation of smartphone apps.

Rafael A. Calvo is Professor at the University of Sydney, and ARC Future Fellow. He worked at the Language Technology Institute in Carnegie Mellon University, Universidad Nacional de Rosario (Argentina) and on sabbaticals at the University of Cambridge and the University of Memphis. Rafael also has worked as an Internet consultant for projects in the US, Australia, Brasil, and Argentina. He is the author of two books and over 200 publications in the fields of learning technologies, affective computing and computational intelligence. Rafael is Associate Editor of the Journal of Medical Internet Research Human Factors (JMIR-HF), co-Editor of the Oxford Handbook of Affective Computing, and co-author of Positive Computing (MIT Press) with Dorian Peters.

Maria K. Wolters is Reader in Design Informatics at the University of Edinburgh, and a Faculty Fellow of the Alan Turing Institute for Data Science and Artificial Intelligence, London, UK. She received her PhD from the University of Bonn, Germany, in Communication Research and Phonetics and worked as a speech synthesis development engineer and clinical phonetician at Rhetorical Systems (now Nuance), the University of Newcastle, and Queen Margaret University before joining the University of Edinburgh. She is the author of over 80 peer-reviewed papers on accessibility, telehealth, mental health, computational linguistics, and speech science and has a long track record of interdisciplinary collaboration with psychologists, psychiatrists, and neurologists.

**Greg Wadley** is a Senior Lecturer in the School of Computing and Information Systems at the University of Melbourne, Australia. His research involves the design and evaluation of technologies for health and wellbeing, including collaborative projects in the areas of mental health, social connectedness, hospitalized children, smoking cessation, chronic pain and addiction. He holds degrees in computer science (Queensland), cognitive science (Melbourne), and human-computer interaction

Table 1: Preliminary Schedule.

09:00-09:30	Welcome and Introductions
09:30-10:15	Invited Speaker 1
10:15-11:15	Coffee and Posters
11:15-12:00	Invited Speaker 2
12:00-13:30	Group Lunch
13:30-14:30	Presentations of Accepted JMIR Papers
14:30-15:30	Panel: Designing for Ethics
15:30-16:00	Coffee and Posters
16:00-17:00	eMentalHealth in Practice: Guided Discussion

(Melbourne). Since 2009 a major focus has been collaboration with an Australian youth mental health clinic to design and trial online social therapies for young people and their carers.

# **WEBSITE**

We have an established website at http://mentalhealth.media.mit.edu that stores the proceedings from 2016 through 2018 and has facilities for hosting blog posts and the call for papers. We will use this again in 2019.

EasyChair will be used to manage poster and social paper submissions. Long papers will be selected from those accepted for publication in JMIR Mental Health, which is a high ranking journal in medical informatics. All posters and social papers will be published on the symposium website at least one week before the event itself.

## **WORKSHOP STRUCTURE**

The overall preliminary schedule of the workshop can be found in Table 1

# **Speakers and Panelists**

Each of the earlier Symposia on Computing and Mental Health has invited prominent researchers from a range of disciplines to give keynote presentations and take part in discussions. This year's symposium will feature three speakers chosen to represent different mental health research communities, including local voices and a focus on interdisciplinary publishing. We have confirmed participation by the following distinguished speakers:

**Professor Dame Til Wykes** is a Professor of Clinical Psychology and Rehabilitation at King's College London and NIHR Senior Investigator. She is also editor of the Journal of Mental Health and Vice Dean of Psychology and System Sciences at the Institute of Psychiatry, Psychology and Neuroscience. Her work focuses on the development on novel treatments for people with a diagnosis of schizophrenia, her studies on cognitive remediation therapy have redefined the concept of recovery in schizophrenia. Professor Dame Til Wykes currently leads several projects investigating computerized cognitive remediation as well as smartphone and sensor based monitoring in serious mental illnesses. A strong advocate for patients, she has been an early advocate of patient-centric and ethical technology use in mental health.

**Dr. Victoria Betton** is the mHealth Programme Director (Mental Health and Long Term Conditions) at Leeds and York Partnership NHS Foundation Trust and Leeds Community Healthcare NHS Trust. She holds a PhD on the theme of online social networks and mental health. Victoria explores the social media platform for learning, sharing and networking on a professional basis. She founded mHabitat in 2014 to support people-centered digital innovation in health and care and recently published a book on youth mental health in the digital age.

### POST-WORKSHOP PLANS

Our 3rd special issue of JMIR will be published in time for the anticipated 2020 symposium and will consist of full versions of papers presented at the 2019 symposium.

We will engage with members of the public by writing a summary of the symposium for the popular press. We have created a LinkedIn group to support an ongoing interdisciplinary community. We will discuss with participants their desires regarding further symposia. We anticipate that the symposium will continue to run in 2020.

#### 250-WORD CALL FOR PARTICIPATION

The World Health Organization predicts that by the year 2030, mental illnesses will be the leading disease burden globally. If mental health technologies are to be successful at supporting those who experience mental distress to succeed, human-centered design of technology and services is essential.

This 4<sup>th</sup> Symposium on Computing and Mental Health will provide an opportunity for researchers to meet under the auspices of CHI 2019. It follows three successful symposia at CHI 2016, 2017 and 2018.

In convening at CHI, we are especially interested in work that seeks to understand users and contexts of use. Our particular focus is on people who are difficult to reach, and who may be socially or digitally excluded, because these people may be less likely to seek and receive help.

Three kinds of submission are invited:

**Long papers** should be submitted straight to JMIR. Authors of JMIR papers must register at the workshop for inclusion in the special issue associated with the symposium. Authors of papers that have been submitted and accepted by April 13 will be invited to give a brief presentation.

**Posters** describe work-in-progress and must include both a user study / empirical data and clearly relate to technology. They could also include industry presentations of new products. Submissions consist of the final poster in PDF format; file size should not exceed 20MB.

**Social papers** are maximum one page in length and act as a CV for networking. They can also include existing publications.

Poster and social papers submissions will be managed via EasyChair and made available via the symposium website. Our earlier special issue of JMIR is available at http://www.jmir.org/themes/461. For more details please see: http://MentalHealth.media.mit.edu/.

Important Dates:

- Submission deadline for posters and social papers: 12 February 2019
- Submission window for long papers: December 2019—10 June 2019
- Acceptance notifications for posters and social papers: 26 February 2019
- Symposium: 4 May 2019Special issue: Spring 2020

#### **ACKNOWLEDGMENTS**

Maria Wolters' work is supported by the Alan Turing Institute (EPSRC; #EP/N510129/1).

#### REFERENCES

- [1] Mario Alvarez-Jimenez, MA Alcazar-Corcoles, Cesar Gonzalez-Blanch, Sarah Bendall, PD McGorry, and JF Gleeson. 2014. Online, social media and mobile technologies for psychosis treatment: a systematic review on novel user-led interventions. *Schizophrenia research* 156, 1 (2014), 96–106.
- [2] Dror Ben-Zeev, Rachel M. Brian, Geneva Jonathan, Lisa Razzano, Nicole Pashka, Elizabeth Carpenter-Song, Robert E. Drake, and Emily A. Scherer. 2018. Mobile Health (mHealth) Versus Clinic-Based Group Intervention for People With Serious Mental Illness: A Randomized Controlled Trial. *Psychiatric Services (Washington, D.C.)* 69, 9 (Sept. 2018), 978–985. https://doi.org/10.1176/appi.ps.201800063
- [3] Rafael Calvo, Karthik Dinakar, Rosalind Picard, and John Torous. 2017. 2Nd Symposia on Computing and Mental Health. In Proceedings of the 2017 CHI Conference Extended Abstracts on Human Factors in Computing Systems (CHI EA '17). ACM, New York, NY, USA, 3073–3080. https://doi.org/10.1145/3027063.3108902
- [4] Rafael Alejandro Calvo, Karthik Dinakar, Rosalind Picard, Helen Christensen, and John Torous. 2018. Toward Impactful Collaborations on Computing and Mental Health. *Journal of Medical Internet Research* 20, 2 (Feb. 2018), e49. https://doi.org/10.2196/jmir.9021
- [5] Rafael A. Calvo, Karthik Dinakar, Rosalind Picard, and Pattie Maes. 2016. Computing in Mental Health. In Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems (CHI EA '16). ACM, New York, NY, USA, 3438–3445. https://doi.org/10.1145/2851581.2856463

- [6] Joseph Firth, John Torous, Jennifer Nicholas, Rebekah Carney, Abhishek Pratap, Simon Rosenbaum, and Jerome Sarris. 2017. The efficacy of smartphone-based mental health interventions for depressive symptoms: a meta-analysis of randomized controlled trials. World psychiatry: official journal of the World Psychiatric Association (WPA) 16, 3 (Oct. 2017), 287–298. https://doi.org/10.1002/wps.20472
- [7] Joseph Firth, John Torous, Jennifer Nicholas, Rebekah Carney, Simon Rosenbaum, and Jerome Sarris. 2017. Can smartphone mental health interventions reduce symptoms of anxiety? A meta-analysis of randomized controlled trials. *Journal of Affective Disorders* 218 (2017), 15–22. https://doi.org/10.1016/j.jad.2017.04.046
- [8] Batya Friedman. 1996. Value-sensitive Design. interactions 3, 6 (Dec. 1996), 16-23. https://doi.org/10.1145/242485.242493
- [9] Shaun W. Jerdan, Mark Grindle, Hugo C. van Woerden, and Maged N. Kamel Boulos. 2018. Head-Mounted Virtual Reality and Mental Health: Critical Review of Current Research. JMIR serious games 6, 3 (July 2018), e14. https://doi.org/10.2196/games.9226
- [10] Umashanthi Pavalanathan and Munmun De Choudhury. 2015. Identity Management and Mental Health Discourse in Social Media. In Proceedings of the 24th International Conference on World Wide Web (WWW '15 Companion). ACM, New York, NY, USA, 315–321. https://doi.org/10.1145/2740908.2743049
- [11] Dorian Peters, Mark Deady, Nick Glozier, Samuel Harvey, and Rafael A. Calvo. 2018. Worker Preferences for a Mental Health App Within Male-Dominated Industries: Participatory Study. *JMIR mental health* 5, 2 (April 2018), e30. https://doi.org/10.2196/mental.8999
- [12] Darius A. Rohani, Maria Faurholt-Jepsen, Lars Vedel Kessing, and Jakob E. Bardram. 2018. Correlations Between Objective Behavioral Features Collected From Mobile and Wearable Devices and Depressive Mood Symptoms in Patients With Affective Disorders: Systematic Review. JMIR mHealth and uHealth 6, 8 (Aug. 2018), e165. https://doi.org/10.2196/mhealth. 9691
- [13] Amartya Sen. 1993. Capability and Well-Being. In *The Quality of Life*, Nussbaum and Sen (Eds.). Clarendon Press, Clarendon Press, Oxford.
- [14] Malene Terp, Birgitte Schantz Laursen, Rikke Jørgensen, Jan Mainz, and Charlotte D Bjørnes. 2016. A room for design: Through participatory design young adults with schizophrenia become strong collaborators. *International journal of mental health nursing* 25, 6 (2016), 496–506.
- [15] Greg Wadley, Rafael Calvo, John Torous, and Mary Czerwinski. 2018. 3rd Symposium on Computing and Mental Health: Understanding, Engaging, and Delighting Users. In Extended Abstracts of the 2018 CHI Conference on Human Factors in Computing Systems (CHI EA '18). ACM, New York, NY, USA, Sym04:1–Sym04:8. https://doi.org/10.1145/3170427.3170665
- [16] Greg Wadley, Reeva Lederman, John Gleeson, and Mario Alvarez-Jimenez. 2013. Participatory design of an online therapy for youth mental health. In Proceedings of the 25th Australian Computer-Human Interaction Conference: Augmentation, Application, Innovation, Collaboration. ACM, 517–526.