

Challenges in Supporting Social Practices Around Personal Data for Long-Term Mental Health Management

Lucy Van Kleunen

University of Colorado Boulder
lucy.vankleunen@colorado.edu

Stephen Volda

University of Colorado Boulder
svolda@colorado.edu

ABSTRACT

We discuss the importance of designing self-tracking technologies for serious mental illness (SMI) that allow individuals with SMI to collect, share, and sense-make over data with a dynamic set of support system members. Our collaborative work with individuals diagnosed with bipolar disorder has suggested the following design and technical challenges for supporting social practices around personal data in long-term mental health management: allowing for fine-grained control over data disclosure by individuals with SMI, supporting dynamism in relationships and roles over long-term use of a system, and allowing individuals flexibility in the variables that they self-track. We discuss these challenges and how they relate to the goals of predictive modelling and intervention in mental health personal informatics systems.

CCS CONCEPTS

• **Human-centered computing** → **Ubiquitous and mobile computing**.

KEYWORDS

Personal Informatics, Serious Mental Illness

ACM Reference Format:

Lucy Van Kleunen and Stephen Volda. 2019. Challenges in Supporting Social Practices Around Personal Data for Long-Term Mental Health Management. In *Adjunct Proceedings of the 2019 ACM International Joint Conference on Pervasive and Ubiquitous Computing and the 2019 International Symposium on Wearable Computers (UbiComp/ISWC '19 Adjunct)*, September 9–13, 2019, London, United Kingdom. ACM, New York, NY, USA, 5 pages. <https://doi.org/10.1145/3341162.3346273>

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).

UbiComp/ISWC '19 Adjunct, September 9–13, 2019, London, United Kingdom

© 2019 Copyright held by the owner/author(s).

ACM ISBN 978-1-4503-6869-8/19/09.

<https://doi.org/10.1145/3341162.3346273>

1 INTRODUCTION

Personal informatics (PI) systems have largely been designed to help individuals collect and explore data about themselves [14]. However, an individual's health data is often engaged with by groups of stakeholders or even aggregated at the community level, resulting in *social PI practices* [20, 21]. These practices are particularly relevant in the domain of serious mental illness (SMI), where the notion of “relational recovery” acknowledges the role that family, friends, antagonists, and even organizations and cultures play in coping and long-term management of SMI [22]. Our collaborative research with individuals diagnosed with bipolar disorder (BD) who self-track as a way of managing their condition has established that existing PI interfaces, data representations, and digital infrastructures fail to support the collective data capture and sense-making practices that many individuals with BD and members of their support networks are developing on their own [16, 17, 21, 24].

In light of this work, we propose the following challenges for discussion at this year's workshop:

- How can we design interfaces and infrastructures that support *fine-grained management of data disclosure* between individuals with SMI and members of their support system?
- How can we design interfaces and infrastructures to support *dynamism in relationships and roles* expected with long-term use of a social PI system?
- How can we allow individuals *flexibility in the variables that they self-track* to more accurately represent their lived experience of serious mental illness?
- How can we support the above goals while still maintaining necessary sophistication of data collection such that the data is relevant for *predictive modelling*?

2 RELATED WORK

Personal informatics and bipolar disorder

Recent research on behavior-based interventions has shown that tracking and stabilizing everyday activities such as light exposure, sleep-wake routines, and social rhythms can

result in pronounced functional improvements and minimized symptom severity for people with BD [7, 18]. Clinical guidelines therefore encourage incorporating daily self-monitoring into condition management [10]. Furthermore, self-tracking can provide a sense of agency for people whose disorder makes them feel out of control [19] and can help individuals establish and maintain a sense of identity as their condition evolves [9].

Conceptual models of healthcare ecologies

In contrast to a “single-loop” approach to personal health informatics that focuses on self-tracking, self-reflection, and self-improvement, chiefly from the perspective of the individual, recent work has advocated for a “double-loop” model involving both the patient and the clinician in tandem [1].

Still necessary, however, is accommodating the broader network of relations potentially involved in an individual’s health management in various implicit and explicit capacities. Partners, relatives, and professional caregivers are commonly identified as stakeholders [6] who could benefit from shared health information spaces. However, research specifically focusing on the context of SMI care has identified additional stakeholder groups including organizational entities such as patient associations and home care services [2]. Appropriate disclosure and communication about experiences with SMI amongst these stakeholders can help build stronger social support networks for individuals managing SMI [8].

Ecological systems theory model for SMI

To construct design requirements for a social PI system in the domain of SMI, we have previously explored the connections and bonds between individuals with SMI and the social relations that surround them [21]. We completed a series of one-on-one interviews with individuals with SMI ($N = 14$) as well as focus groups involving both individuals with SMI and individuals that they identified as being close to them and providing assistance in some way around management of their illness ($N = 8$).

We structured our analysis of the resulting data using an adaptation of Bronfenbrenner’s Ecological Systems Theory (EST), which captures the breadth of influences on an individual’s life across various degrees of proximity [5]. Our adaptation of the model also more explicitly considered how technology mediates layers of the social ecology.

At the center of our model (Figure 1) is the individual managing SMI, annotated with their identifying attributes. The *microlayer* involves individuals with close relationships to the central individual who are directly involved in monitoring and facilitating their healthcare. The microlayer typically involves professional caregivers such as clinicians and nurses, as well as an inner social circle of family and friends. The *exolayer* involves wider institutional entities that impact how

the individual manages their conditions: workplaces, schools, community organizations, and health insurers. Finally, the *macrolayer* refers to an individual’s larger social context—the ideologies, cultures, and societal attitudes around mental illness, as well as economic trends and government policies that influence healthcare availability and affordability.

Temporal patterns and traditions, as well as socio-historical events, cut across these social layers. In particular, transitional experiences such as changing doctors, switching medications, death or traumatic loss, divorce, losing or gaining friends, and moving locations or jobs were often mentioned by participants as impacting or being impacted by their BD through the course of long term illness management.

We saw that personal data could act as a relational entity, bridging relationships between the individual at the center and people and institutions at varying levels of the social ecology. We also saw that these relationships differed in terms of *valence* (degree to which they were positive or negative), *intensity* (degree to which they were weak or strong), *directionality* (who was influencing whom, or whether the relationship was uni-, bi-, or multi-directional), and *dynamism* (degree to which relationships were stable or unstable).

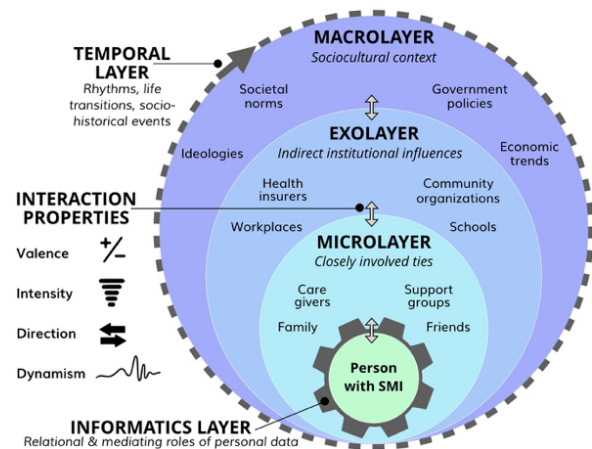


Figure 1: Our ecological model of the social and personal informatics entities that influence and are influenced by serious mental illness (SMI) [21]

Here, we discuss in more detail a number of design and technical challenges arising from this work. These challenges are motivated by an interest in building self-tracking applications that support long-term mental health management and related social practices around personal data.

3 DATA DISCLOSURE

Our prior work revealed many instances of individuals with BD intentionally sharing personal data with individuals in their microlayer. This sharing was motivated by a desire to

build mutual awareness and empathy around the experience with BD and to improve loved ones' ability to notice lapses in effective condition management or crisis warning signs. Respondents shared data with clinicians primarily in order to aide in decision making related to their treatment.

However, many individuals were concerned about unintentional disclosure of personal data. In some cases, they did not want to unnecessarily worry their loved ones or burden them with information about their condition. In more extreme cases, they worried that details of their condition might be exposed to unsympathetic employers or individuals from their past with whom they had negative or abusive relationships. Possible negative consequences of leaking sensitive health data were the most common reasons noted by individuals for avoiding self-tracking altogether.

Overall, we saw that individuals with BD have diverse perspectives regarding disclosure and complex criteria when determining which data will be shared, with whom, and how. Supporting social PI practices in the SMI domain will likely require more nuanced design and engineering solutions than simply enabling multi-user account access in self-tracking apps or enabling social media-based personal data sharing.

A possible way to mitigate some of the risks of unintentional disclosure is to allow data sharing within a sandboxed PI application rather than via integration with general-purpose social media platforms. In our current work, we are beginning to explore how to design interfaces and infrastructures to support intentional data disclosure and curation for this context [12].

For example, a social PI system might allow users to choose between an approach of “always on” streaming of personal data and a model of manual data requests and pushes. The first approach prioritizes continuous monitoring and reduces the burden on the individual with SMI to remember to share data. The second approach prioritizes control over data disclosure. A request-and-push approach would allow users to view and adjust data before sending it, perhaps filling in missing pieces, obscuring sensitive data points, and configuring the level of aggregation or fuzzing with which it was shared. Allowing secondary users to request data might have the additional benefit of fostering dialogue around data. A hybrid approach might maintain continuous data streaming, but also allow individuals to configure the level of aggregation or fuzzing applied to their data in others' views.

Diversity in preferences around data disclosure also suggests that a system should support data sharing configurations based on multiple criteria, including the receiving user's identity, role, the data type being shared, and even the content of individual data points. For example, an individual might want the system to automatically send weekly summaries of their self-reported mood data to a specific member of their inner circle. They may prefer a request-and-push

model for sharing data with their clinician. Before each appointment, they could curate recent more finely-grained data across a number of data types, including from mobile and wearable sensors, before pushing this composite data record to their clinician.

While these solutions mitigate some of the risks of unintentional disclosure, they also come with their own risks. We want to give users agency over their data, but we also want to reduce the up-front burden on users to configure data disclosure with this level of detail if it is not needed or desired. We also want to make sure that the system always accurately reports high-level summaries or predictive metrics representing an individual's state to secondary users. There are also risks with these solutions specific to BD mood fluctuations: *What if a user wants to use a request-and-push model for sharing data but is unable to respond to requests during a depressive episode? What if they obscure or misrepresent their data during a manic episode?* These concerns suggest that such a system may also need mechanisms for overriding or preventing certain actions based on a user's detected state; perhaps these too can be pre-configured by users in collaboration with members of their support network.

4 DYNAMIC RELATIONSHIPS AND ROLES

Changes to an individual's social support system—even those that seem “permanent,” like family relations—are inevitable, and will need to be handled by self-tracking systems for SMI intended for long-term use. To support this sort of dynamism, infrastructures must be set up such that users are not cast into permanent “roles” within the system.

Social dynamism also impacts how historical data within the system is shared. We must assume that new individuals, such as new clinicians or friends, will be added to the system while it is already in use and afford for appropriately sharing historical data or trends. We must also assume that some social ties will be broken, and afford for appropriate obscuring of historical data that has already been shared.

There may also be co-tracking scenarios in which the individual with BD is not the only one collecting data. In some cases, a member of the individual's inner circle might assume the role of data collection proxy and take over logging duties, particularly during manic or depressive episodes.

There are also opportunities for other individuals to simultaneously track data with the individual with BD. The unpredictable mood swings that characterize BD can be difficult to recognize and self-assess by the person experiencing them, resulting in warning signs going un-noted and unrecorded [13]. Systems like MoodRhythm [15] and MONARCA [1] have therefore explored passive data collection and symptom detection as a way to relieve some of the burdens and limitations of purely manual tracking. Comparing self-assessment with peer-assessment might be another way to allow for

some triangulation within the system and improve the system's ability to detect inaccurate reporting.

In these co-tracking scenarios, the traditional PI paradigm is challenged, as the user submitting the data is not the same user being tracked. As a result, data collection interfaces and infrastructures should be extended to enable proxy or co-tracking scenarios and include the ability to work with data based on its provenance or reporting source.

5 FLEXIBLE VARIABLES

Prior research has identified that individuals managing SMI are particularly vulnerable to feeling judged, flawed, and isolated when confronted with normative PI measurement scales that do not align with their own mental models that they use to gauge and make sense of their condition [16]. For example, it might be challenging for someone with SMI to understand how to self-assess mood on a numerical scale.

One possible solution is to allow individuals to add self-tracking variables representing personalized aspects of their life and condition. The ability to add custom variables of various data types has already been explored in general-purpose self-tracking systems [11]. There may also be opportunities to allow individuals to customize how they self-assess subjective states (e.g., mood) by creating their own scale or allowing for a custom set of choices, free text notes, photo, or drawing uploads in place of quantification.

In the context of long-term use, it is also reasonable to assume that individuals may want to change the way they track over time by adding new variables or ceasing to actively track certain variables. They may also want to adjust with what granularity they are actively tracking certain variables or opting in or out of tracking these variables passively using mobile or wearable sensors (e.g., [4]).

6 MOOD PREDICTION AND INTERVENTION

There has been much recent interest in building systems that infer depressive or manic symptom severity from mobile sensor data [3, 23]. One concern with our proposed approach is that allowing individuals with SMI to configure data disclosure, distributed tracking responsibilities, or customize how they track variables may conflict with the goal of providing algorithms with all of the variables that are most predictive of clinical assessments of mania and depression.

This is another instance in which passive data collection can be beneficial. Prior research has shown that some sensor-based metrics related to location and social activity show promise in predicting depressive and manic states [23]. If predictive models are effective without relying on self-assessment data, this might reduce the requirements for self-assessment variables to be standardized on particular scales.

If an individual should choose to disable collection of passively sensed data, such as location, due to privacy concerns,

there may be other signals available to an application built on our adapted EST model that can be used as inputs in mood prediction models. Meta-information related to the presence or timing of gaps in data collection, initiation of co-tracking data arrangements, adjustments in variables collected, or the addition or removal of support system members or clinicians all indicate shifts that may be relevant to illness trajectory. Trace data of app usage, particularly around social communication and data sharing, might be integrated into proxies of social activity already used in many mood prediction models.

This type of application also creates new opportunities for when and how interventions are delivered by the system during times of crisis. Many of our interviewees described accountability and intervention systems that they have already set up with loved ones, such as protocols in which their family members bring them to the hospital if they observe certain behaviors. If the system suspects that an individual is in crisis, perhaps it could enact such a preset plan—for example, automatically alerting specific members of the individual's support system.

7 AIMS FOR THE WORKSHOP

The long-term aim for our research is to enable effective collective sense-making over personal data to support long-term mental health management. This involves presenting data visualizations to various stakeholders that are sensitive to each of their perspectives and needs, the disclosure preferences of the central individual with SMI, and the appropriateness of various visual metaphors for conveying experience with SMI [24]. Accomplishing this goal will require building a flexible data infrastructure that inherently accounts for long-term dynamism in stakeholders, roles, variables, and passive or active tracking approaches, as well as appropriate interfaces to allow individuals to configure and adjust these preferences. Our primary aim for this workshop is to discuss and unpack the above challenges in building such infrastructures and interfaces with other researchers working in the space of mental health sensing and intervention.

8 AUTHORS' BACKGROUND

Lucy Van Kleunen (lucy.vankleunen@colorado.edu) is a second-year PhD student in Computer Science at the University of Colorado Boulder working with the Too Much Information (TMI) research group. She has an A.B. from Brown University in Computer Science and Public Policy.

Stephen Voida (svoida@colorado.edu) is an Assistant Professor and founding faculty member of Information Science at the University of Colorado Boulder. He directs the Too Much Information (TMI) research group, where he and his students study personal information management, personal and group informatics, health informatics technologies, and ubiquitous computing.

ACKNOWLEDGMENTS

We would like thank our colleagues Jaime Snyder, Mark Matthews, Liz Murnane, Caitie Lustig, and Justin Petelka for their involvement in the empirical work and contributions to the ideas presented in this challenge paper. We would like to acknowledge their ongoing role as active collaborators in our SMI technology design efforts.

REFERENCES

- [1] Jakob E. Bardram, Mads Frost, Károly Szántó, Maria Faurholt-Jepsen, Maj Vinberg, and Lars Vedel Kessing. 2013. Designing Mobile Health Technology for Bipolar Disorder: A Field Trial of the Monarca System. In *Proc. CHI '13*. ACM, New York, 2627–2636. <https://doi.org/10.1145/2470654.2481364>
- [2] Joyce Bierbooms, Hans Van Oers, Jeroen Rijkers, and Inge Bongers. 2016. Development of a comprehensive model for stakeholder management in mental healthcare. *J Health Organization and Management* 30, 4 (2016), 630–647.
- [3] Luca Canzian and Mirco Musolesi. 2015. Trajectories of Depression: Unobtrusive Monitoring of Depressive States by Means of Smartphone Mobility Traces Analysis. In *Proc. UbiComp '15*. ACM, New York, 1293–1304. <https://doi.org/10.1145/2750858.2805845>
- [4] Eun Kyoung Choe, Saeed Abdullah, Mashfiqui Rabbi, Edison Thomaz, Daniel A. Epstein, Felicia Cordeiro, Matthew Kay, Gregory D. Abowd, Tanzeem Choudhury, James Fogarty, Bongshin Lee, Mark Matthews, and Julie A. Kientz. 2017. Semi-Automated Tracking: A Balanced Approach for Self-Monitoring Applications. *IEEE Pervasive Computing* 16, 1 (Jan. 2017), 74–84. <https://doi.org/10.1109/MPRV.2017.18>
- [5] Ellen P. Cook. 2015. *Understanding People in Context: The Ecological Perspective in Counseling*. American Counseling Assn, Alexandria, VA.
- [6] Stefan Rennick Egglestone, Lesley Axelrod, Thomas Nind, Ruth Turk, Anna Wilkinson, Jane Burridge, Geraldine Fitzpatrick, Sue Mawson, Zoe Robertson, Ann Marie Hughes, Kher Hui Ng, Will Pearson, Nour Shublaq, Penny Probert-Smith, Ian Ricketts, and Tom Rodden. 2009. A design framework for a home-based stroke rehabilitation system: Identifying the key components. In *Proc. PervasiveHealth 2009*. IEEE, Piscataway, NJ, 1–8.
- [7] Ellen Frank, Holly A Swartz, and Elaine Boland. 2007. Interpersonal and social rhythm therapy: an intervention addressing rhythm dysregulation in bipolar disorder. *Dialogues in Clinical Neuroscience* 9 (2007), 325–332. Issue 3. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3202498/>
- [8] Kathryn Greene, Valerian J Derlega, and Alicia Mathews. 2006. Self-disclosure in personal relationships. In *The Cambridge Handbook of Personal Relationships*, Anita L Angelisti and Daniel Perlman (Eds.). Cambridge University Press, Cambridge, UK, 409–427.
- [9] Maree L Inder, Marie T Crowe, Stephanie Moor, Suzanne E Luty, Janet D Carter, and Peter R Joyce. 2008. “I actually don’t know who I am”: The impact of bipolar disorder on the development of self. *Psychiatry: Interpersonal and Biological Processes* 71 (2008), 123–133. Issue 2.
- [10] David A Kahn, Gary S Sachs, David J Printz, Daniel Carpenter, John P Docherty, and Ruth Ross. 2000. Medication treatment of bipolar disorder 2000: a summary of the expert consensus guidelines. *J Psychiatric Practice* 6 (2000), 197–211. Issue 4.
- [11] Young-Ho Kim, Jae Ho Jeon, Bongshin Lee, Eun Kyoung Choe, and Jinwook Seo. 2017. OmniTrack: A Flexible Self-Tracking Approach Leveraging Semi-Automated Tracking. *Proc. ACM IMWUT* 1, 3, Article 67 (Sept. 2017), 28 pages. <https://doi.org/10.1145/3130930>
- [12] Lucy Van Kleunen and Stephen Volda. 2019. Controlling Disclosure of Personal Health Data. <https://privacy.shorensteincenter.org/controlling-disclosure>
- [13] David J Kupfer, Ellen Frank, Victoria J Grochocinski, Patricia A Cluss, Patricia R Houck, and Debra A Stapf. 2002. Demographic and clinical characteristics of individuals in a bipolar disorder case registry. *J Clin Psychiatry* 63 (Feb. 2002), 120–125. Issue 2. <https://www.ncbi.nlm.nih.gov/pubmed/11874212>
- [14] Ian Li, Anind Dey, and Jodi Forlizzi. 2010. A stage-based model of personal informatics systems. In *Proc. CHI '10*. ACM Press, New York, NY, 557–566. <https://doi.org/10.1145/1753326.1753409>
- [15] Mark Matthews, Saeed Abdullah, Elizabeth Murnane, Stephen Volda, Tanzeem Choudhury, Geri Gay, and Ellen Frank. 2016. Development and evaluation of a smartphone-based measure of social rhythms for bipolar disorder. *Assessment* 23, 4 (2016), 472–483.
- [16] Mark Matthews, Elizabeth Murnane, and Jaime Snyder. 2017. Quantifying the Changeable Self: The Role of Self-Tracking in Coming to Terms With and Managing Bipolar Disorder. *Human-Computer Interaction* 32, 5-6 (2017), 413–446. <https://doi.org/10.1080/07370024.2017.1294983>
- [17] Mark Matthews, Elizabeth Murnane, Jaime Snyder, Shion Guha, Pamara Chang, Gavin Doherty, and Geri Gay. 2017. The double-edged sword: A mixed methods study of the interplay between bipolar disorder and technology use. *Computers in Human Behavior* 75 (2017), 288–300. <https://doi.org/10.1016/j.chb.2017.05.009>
- [18] David J. Miklowitz, Michael W. Otto, Ellen Frank, Noreen A. Reilly-Harrington, Stephen R. Wisniewski, Jane N. Kogan, Andrew A. Nierenberg, Joseph R. Calabrese, Lauren B. Marangell, Laszlo Gyulai, Mako Araga, Jodi M. Gonzalez, Edwin R. Shirley, Michael E. Thase, and Gary S. Sachs. 2007. Psychosocial Treatments for Bipolar Depression: A 1-Year Randomized Trial From the Systematic Treatment Enhancement Program. *JAMA Psychiatry* 64, 4 (04 2007), 419–426. <https://doi.org/10.1001/archpsyc.64.4.419>
- [19] Elizabeth L Murnane, Dan Cosley, Pamara Chang, Shion Guha, Ellen Frank, Geri Gay, and Mark Matthews. 2016. Self-monitoring practices, attitudes, and needs of individuals with bipolar disorder: Implications for the design of technologies to manage mental health. *J American Medical Informatics Association* 23 (2016), 477–484. Issue 3.
- [20] Elizabeth L. Murnane, Jaime Snyder, Stephen Volda, Matthew J. Bietz, Mark Matthews, Sean Munson, and Laura R. Pina. 2018. Social Issues in Personal Informatics: Design, Data, and Infrastructure. In *Companion of the 2018 ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW '18)*. ACM, New York, 471–478. <https://doi.org/10.1145/3272973.3273016>
- [21] Elizabeth L. Murnane, Tara G. Walker, Beck Tench, Stephen Volda, and Jaime Snyder. 2018. Personal Informatics in Interpersonal Contexts: Towards the Design of Technology That Supports the Social Ecologies of Long-Term Mental Health Management. *Proc. ACM HCI 2, CSCW*, Article 127 (Nov. 2018), 27 pages. <https://doi.org/10.1145/3274396>
- [22] Rhys Price-Robertson, Angela Obradovic, and Brad Morgan. 2017. Relational recovery: beyond individualism in the recovery approach. *Advances in Mental Health* 15, 2 (2017), 108–120. <https://doi.org/10.1080/18387357.2016.1243014>
- [23] Jussi Seppälä, Ilaria De Vita, Timo Jämsä, Jouko Miettunen, Matti Isohanni, Katya Rubinstein, Yoram Feldman, Eva Grasa, Iluminada Corripio, Jesus Berdun, Enrico D’Amico, M-RESIST Group, and Maria Bulgheroni. 2019. Mobile Phone and Wearable Sensor-Based mHealth Approaches for Psychiatric Disorders and Symptoms: Systematic Review. *JMIR Mental Health* 6, 2 (2019), e9819. <https://doi.org/10.2196/mental.9819>
- [24] Jaime Snyder, Elizabeth Murnane, Caitie Lustig, and Stephen Volda. 2019. Visually Encoding the Lived Experience of Bipolar Disorder. In *Proc. CHI '19*. ACM, New York, Article 133, 14 pages. <https://doi.org/10.1145/3290605.3300363>