

Participatory Design to Support Serious Mental Illness

Jaime Snyder, MFA, PhD, Information School, University of Washington

1 COMMUNITY ENGAGEMENT

Over the last decade, our team has explored the potential for technology to help manage chronic health conditions. Specifically, we have studied serious mental illnesses (SMIs), such as bipolar disorder. Recognized as one of the ten most debilitating illnesses worldwide (Murray & Lopez, 1996), it is often characterized by difficult-to-predict cycles that vary between manic and depressive episodes (Soreca, Frank, & Kupfer, 2009) as well as disruptions to biological and behavioral rhythms, notably sleep and physical activity (Gonzalez, 2014). A number of therapeutic approaches to the treatment of bipolar disorder encourage patients to track their behaviors and emotions as a means of identifying triggers and other patterns associated with mood episodes and to cultivate a sense of agency (Frank et al., 2005; Martin, 2007).

As the number of consumer products for tracking health and wellness activities has grown (e.g., FitBit, Apple Watch), they have played an increasingly central role in these therapeutic practices (Matthews, Murnane, Snyder, et al., 2017; Matthews, Murnane, & Snyder, 2017; Murnane, Matthews, & Gay, 2016). The ways in which self-tracking data are visually represented can be critical to support healthy self-reflection, a sense of agency, and effective communication with care providers. Our previous research has shown that standard charts and graphs used to display data collected by these consumer products are not always ideal for users like those managing bipolar disorder because they rely on problematic ideas of what is “normal,” “ideal,” or even what is “achievable” in terms of personal goals (Murnane et al., under review; Snyder, Murnane & Voida, under review).

In order to improve the display and usability of self-tracking data for people living with SMI, we decided to try something different. From the beginning of the design process, we chose to include the population we were trying to help: people who have been diagnosed with bipolar disorder. Technology design often starts in the lab, where engineers and computer scientists plan and build prototypes that are then tested with target users. Instead, we used *participatory design* (Ehn, 1993; Muller, 2007; Simonsen & Robertson, 2012), a human-centered (as opposed to computer- or technology-centered) approach that recognizes the deep expertise of users, viewing them as *collaborators* rather than mere *consumers*.

We worked with fourteen individuals (5 male, 9 female; 20 to 64 years old with average age 45.9), all of whom self-reported that they: (1) were over the age of 18, (2) had an existing diagnosis of bipolar disorder, and (3) had not been hospitalized for mental health issues in the last six months (i.e., were stable at the time of interviews). Participants were recruited via campus and local community organizations that included National Alliance for Mental Illness (NAMI) local chapter, the Depression and Bipolar Support Alliance (DBSA), the Institute of Translational Health Sciences (ITHS) patient recruitment service, and materials distributed through campus health care clinics and email listservs. We also invited participants to share information about the study with their personal social networks. Each participant joined us for a series of interviews and design activities that helped us learn more about their experiences with bipolar disorder.

We highlight three aspects of our work with and for vulnerable populations:

1. Deploying participatory design techniques
2. Articulating specific vulnerabilities of the population
3. Viewing participants as having deep expertise

2 CO-DESIGNING SOLUTIONS

2.1 Co-creating narrative timelines

We began interviews by asking participants to talk about their experience with bipolar, starting from either the first appearance of symptoms, or from their formal diagnosis. We prompted them to share how

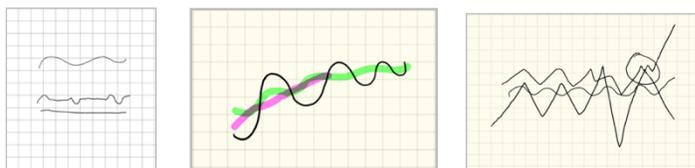
they check in with themselves over time, how they know if they are doing O.K., and what triggers they watch out for. We also asked about whether they tended to share these observations with anyone; if so, how they decide with whom to share information about their mental health; and if their sharing preferences or practices have changed over time.

Next, we began the collaborative design process. Through a series of simple activities, we oriented participants to the Apple iPad Pro tablet, Apple Pencil stylus and GoodNotes (<http://www.goodnotes.com/>) digital drawing application that were used for drawing activities. When the participant was comfortable working with the tablet, we started recording the iPad session. We used QuickTime recording software, which ran on a laptop connected to the tablet. This allowed us to capture video of drawing activities on the iPad, along with audio from the laptop's internal microphone.

We recognized that for some participants thinking in images would be a natural way of describing their condition. For others, articulating these associations might be more challenging. We designed activities to be easy to perform; to encourage participants to expand on their experiences; and to probe visual associations with bipolar disorder (Gaver, Boucher, Pennington, & Walker, 2004; Snyder et al., 2014). Activities did not require any special artistic skills or abilities and were intended to be fun and thought-provoking. We explicitly reassured participants that there was no “wrong” way of responding to any of our prompts and that they could start over or revise their responses whenever they wanted. In cases where participants appeared uncomfortable drawing or making marks on the tablet, we also offered to do the drawing for or with them, following their instructions.

First, we asked participants to draw a line that represents their journey or experience with bipolar, in a way that reflected their own perspective (i.e., *not* how they might think their therapist or family might represent things). As participants drew, we typically asked clarifying questions, including: 1) whether the line represented a specific time period or series of events, and 2) whether specific visual features of the line had particular meaning (i.e., “I see this part of the line as really bumpy, but straightens out over here. Does that represent a specific event or experience? When you drew it that way were you thinking about a specific feeling that you associate with that time?”). This often prompted participants to augment, correct, add to, or delete portions of the line in order to refine their image. How, why, and when they changed the line was often as interesting to us as their initial drawing.

Next, we asked participants to add a second line to their drawing that represented the presence of someone who was or continues to be close to them during the time represented by the first line. This could be a family member, a friend, a therapist or clinician, or even a pet. Again, we asked for clarifications regarding the ways in which participants chose to encode the presence and experience of the additional person. Finally, we asked participants to add a third line that represented what they considered to be an ideal state during that same period. Few participants drew a flat line in response to this prompt. For most, an ideal state did not equate to a lack of variation, just moderated (or “manageable”) amounts of variation. Examples of output from this activity are shown in Figures 1a-c.



Figures 1a (left), 1b (center), 1c (right). Examples of output from the first visual elicitation activity Interview 1.

For the second drawing activity, we asked participants to create a more detailed timeline. Participants used a range of visual metaphors, some departing from linear representations entirely (Figures 2a-c). We continued to learn about individual experiences with bipolar by referencing these timeline drawings as we reflected back what we thought we had heard and seen as the participant shared their stories. We added annotations using a different colored digital ink, documenting specific intended meanings and clarifying

potential ambiguities (Figures 3a-b). This process often inspired collaboration between researcher and participant as the visual representation was clarified, refined, expanded, or re-created altogether.

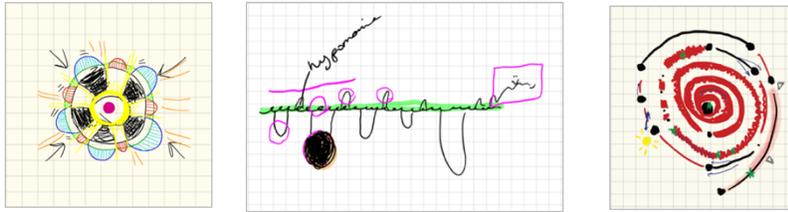


Figure 2a (left), 2b (center), 2c (right).
Variations on detailed timeline activity.

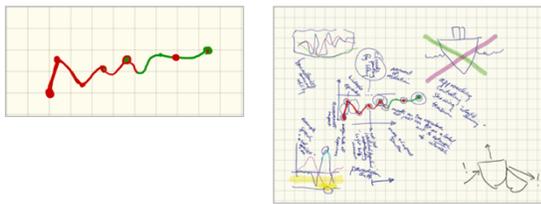


Figure 3a (left) and 3b (right).
Example of original and annotated timeline.

2.2 Finding images that resonate

We also asked participants to use Google Image Search to find existing online images that resonated with their experiences of bipolar. For this task, we adapted a traditional photo elicitation interview (Collier & Collier, 1986; Mitchell, 2011; Pink, 2012). We started with words and phrases used by the participant as they talked about their experiences. For example, “boundaries,” “split road,” “fireflies,” “ocean,” “penguins huddling,” “bear hibernating,” and “white noise” were all phrases used to begin searching. The participant was then asked to consider which of the images returned in the search results (if any) most closely aligned with their experiences (see Figures 4a-c for examples). In most cases, search terms were refined, revised, abandoned, and introduced reflecting the stream of consciousness of the participant. This activity provided yet another way for us to learn more about bipolar experiences and to help us understand nuances of those experiences. Images that were either particularly resonant or notably dissonant were downloaded for future analysis.



Figures 4a-d (left to right). Examples of Google Image Search results.

2.3 Enriching the technology design process

While reporting detailed findings from our study is outside the scope of this paper, we believe it is helpful to share examples of what can be achieved through this type of participatory design process. In analyzing our collaborative design sessions, we identified *visual motifs* that seemed to show up with some frequency in people’s narratives. Here we highlight two: *water* (e.g., tidal currents, feeling submerged, distortions and parallax, etc.) and *ropes* (feeling bound, frayed, twisted, in tension, etc.). We enlisted the help of a graphic artist who is familiar with the bipolar community to create a series of design concepts based on these motifs (examples shown in Figures 5a-b). They serve as the inspiration for data visualizations that can better reflect the lived experiences of individuals diagnosed with bipolar disorder. Sketches like these are in the process of being vetted by participants and will be used in future system prototypes. Future work will integrate visuals like these in digital tools that support individuals managing

SMI through therapeutic self-tracking. We are also using these participatory design techniques with other vulnerable communities facing similar challenges as a result of chronic health problems.

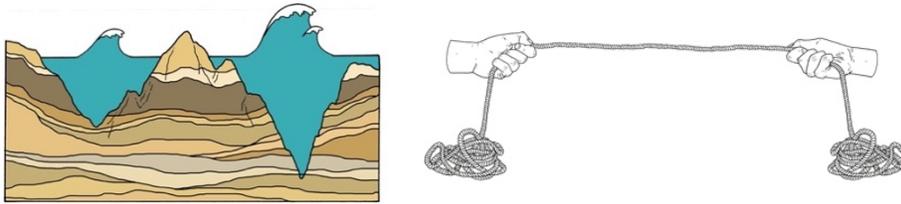


Figure 5a (left), 5b (right).
Design concepts.

3 ADDRESSING SYSTEMATIC INEQUALITIES

3.1 Recognizing participant vulnerabilities

Within the context of research interviews and collaborative design sessions, bipolar participants might, on any given day, cycle through manic, hypomanic, or depressive states. This cycling might not be overtly observable—especially as we work mainly with people who self-report as being stable—but many participants share that they maintain a constant vigilance toward swings and shifts of mood and other markers of impending manic or depressive episodes. Maintaining this control can be exhausting. Research interviews with new settings and perceived pressure to perform can cause added stress. Further, the side effects of medications and medical interventions like electroconvulsive therapy (ECT or shock therapy) used to treat bipolar disorder can include short- and long-term memory loss. We are observant to both verbal and non-verbal indicators of emotional fatigue, check-in regularly with participants to make sure they are comfortable proceeding, and schedule interviews around ECT treatments or changes in medication as cognitive difficulties in the week or so after these events.

It is common for individuals with bipolar disorder to struggle with social anxiety (Cosoff & Hafner, 2002; Simon et al., 2004). This can result in anxiety during interviews, including fidgeting and lack of eye contact. Participants in our study who self-identified as having social anxiety were more likely to mention feeling frustrated or irritated during the interview. We noted a higher frequency of cancelled or rescheduled appointments for these individuals as well. Noting these patterns, we made a point of explicitly recognizing the burden being placed on these participants and worked with them to do what we could to reduce that load. For example, one participant requested that we hold interviews in a location that was more familiar to them. In other cases, we made it clear that appointments could easily be rescheduled in the event that the participant was having a bad day.

Many individuals with bipolar disorder also suffer from PTSD or other forms of trauma (Kennedy et al., 2002). During our screening interview, we asked participants if they had experienced significant trauma and whether they felt that might make it difficult for them to describe and reflect on their experiences with bipolar disorder. During interviews we explicitly informed participants that they were entirely in control of what they shared (a notable difference from the experiences they may have had in clinical settings). We did not specifically ask about any traumatic experiences unless they introduced the topic, and then only to inform the narrative of their experience with bipolar disorder. Within this framing, many willingly shared information about mental and physical abuse, rape, addiction, homelessness, and attempted suicide.

3.2 Honoring the expertise of participants

The situated expertise shared by participants in our study (Moran, 2002; Wakkary & Maestri, 2007) spanned domains including the diagnosis and treatment of bipolar; risks and side effects of pharmaceutical interventions; evaluation of therapeutic interventions; restrictions and policies related to federal, state, and local health care and medical services; policies and procedures related to unemployment and disability programs; and social and economic inequities often disproportionately experienced by individuals suffering from SMI.

We learned that it was not only ethically imperative to identify ourselves as technologists and not clinicians, but that we also needed to convey to participants that we valued their perspectives outside of a clinical or diagnostic context. It was critical to clarify that we wanted to learn more about what it has been like for them to manage their bipolar disorder and that hearing about their experiences would help us design better technologies to support individuals facing similar challenges. It is worth noting that many responded by saying that no one had ever asked them to share their experiences in this way.

We also recognized through our previous work that participants were able with some prompting to describe their experiences in ways that provided compelling inspirations for visual representations of their personal data. We recently conducted a large survey of technology use by individuals with bipolar disorder. In addition to a series of questions targeted to learning about attitudes and practices related to technology use in general, we also asked and received insightful responses to the questions: (1) "What are some of the ways you have described your experience of your bipolar disorder to other people?" and (2) "Please describe any imagery or metaphors you associate with bipolar disorder, either generally or during manic or depressive episodes."

Responses reflected descriptive imagery that was deeply personal and highly complex. One participant shared that manic experiences of bipolar disorder are like "jumping rope while using the treadmill set at 20mph and getting frustrated that the thing can't keep up with me." Another person described manic episodes as "like being on cloud nine until it becomes out of control, and then it's like trying to stop a speeding car and realizing the brakes are broken." Depression was described by one individual as being like "tar pits, sinkholes, and undertows, with limbs/eyelids weighted down... or a dissociative-like automaton or someone else moving my body, directing my actions." In addition to idiosyncratic and evocative descriptive imagery, a number of respondents offered variations of the statement, "I don't describe my experience to others. No one would understand." This not only hinted at the significant social isolation respondents faced, but also the importance of developing representations that more effectively reflect their lived experiences and have a greater capacity to cultivate empathy.

4 CONCLUSIONS

Challenges, Obstacles and Missteps. This was a pilot study, meaning our team had never before asked participants to perform tasks like the ones we have described here. Early on, we underestimated the emotional burden of revisiting past trauma through these activities, especially for those with PTSD. We quickly learned to be more explicit about screening for this. As mentioned above, we also learned that sessions could be fatiguing and stressful, provoking irritability, headaches, and fear of doing something wrong. Lastly, we discovered that scheduling, running interviews, and working with the very rich data from these sessions all took much longer than anticipated. We often radically underestimated how long it would be between contacts with participants. This caused unnecessary confusion, frustration, and some participants expressed concern about being dropped from the study. As we made corrections to our language, the pacing of interviews, and more "check-ins" during sessions (to make sure participants were ok proceeding), we recovered from such errors. These experiences will help us to run similar studies with other vulnerable communities more smoothly.

Hope in the Future. We were fortunate to work with individuals who had a range of experiences—from those who had only recently been diagnosed to those who have successfully managed their mental illness for decades. While we were impressed with the candor, resilience, and reflections of all the people we worked with, a few of the young adults really stood out. They described their experiences with SMI as an integral and important part of their identities. They also spoke passionately about trying to make things better not only for themselves but for others facing similar challenges. These individuals have inspired us to expand our work related to the display and usability of personal data to other groups of young people facing mental health challenges.

REFERENCES

- Collier, J., & Collier, M. (1986). *Visual Anthropology: Photography as a Research Method*. UNM Press.
- Cosoff, S. J., & Hafner, R. J. (2002). The prevalence of comorbid anxiety in schizophrenia, schizoaffective disorder and bipolar disorder. *Australian and New Zealand Journal of Psychiatry*, 32(1), 67–72.
- Ehn, P. (1993). Scandinavian Design: Participation and Skill. In D. Schuler & A. Namioka (Eds.), *Participatory Design: Principles and Practices* (pp. 41–77). CRC Press.
- Frank, E., Kupfer, D. J., Thase, M. E., Mallinger, A. G., Swartz, H. A., Fagiolini, A. M., ... Monk, T. (2005). Two year outcomes for interpersonal and social rhythm therapy in individuals with bipolar I disorder. *Archives of General Psychiatry*, 62, 996–1004.
- Gaver, W. W., Boucher, A., Pennington, S., & Walker, B. (2004). Cultural Probes and the Value of Uncertainty. *Interactions*, 11(5), 53–56.
- Gonzalez, R. (2014). The relationship between bipolar disorder and biological rhythms. *J Clinical Psychiatry*, 75(4), 323–331.
- Kennedy, B. L., Dhaliwal, N., Pedley, L., Sahner, C., Greenberg, R., & Manshadi, M. S. (2002). Post-Traumatic Stress Disorder in subjects with schizophrenia and bipolar disorder. *J Kentucky Medical Association*, 100(9), 395–399.
- Martin, E. (2007). *Bipolar Expeditions: Mania and Depression in American Culture*. Princeton, N.J.: Princeton Univ. Press.
- Matthews, M., Murnane, E., & Snyder, J. (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), 413–446.
- Matthews, M., Murnane, E., Snyder, J., Guha, S., Chang, P., Doherty, G., & Gay, G. (2017). The double-edged sword: A mixed methods study of the interplay between bipolar disorder and technology use. *Computers in Human Behavior*, 75, 288–300.
- Mitchell, C. (2011). *Doing Visual Research*. Thousand Oaks, CA: Sage.
- Moran, T. P. (2002). Everyday adaptive design. In *Proceedings of the 4th Conference on Designing Interactive Systems: Processes, Practices, Methods, and Techniques* (pp. 13–14). ACM.
- Muller, M. J. (2007). Participatory Design: The Third Space in HCI. In Sears, Andrew & Jacko, Julie A. (Eds.), *The Human-Computer Interaction Handbook: Fundamentals, Evolving Technologies, and Emerging Applications* (pp. 1061–1081). New York: CRC Press.
- Murnane, E. L., Matthews, M., & Gay, G. (2016). Opportunities for Technology in the Self-management of Mental Health. In *Proceedings of the 18th International Conference on Human-Computer Interaction with Mobile Devices and Services Adjunct* (pp. 1093–1096). New York, NY, USA: ACM.
- Murnane, E. L., Walker, T., Tench, B., Volda, Stephen, & Snyder, J. (under review). Personal Informatics in Interpersonal Contexts: Towards the Design of Technology that Supports the Social Ecologies of Long-Term Mental Health Management. *Proceedings of SIGCHI Conference on Computer Supported Cooperative Work and Social Computing*: ACM.
- Murray, C. J. L., & Lopez, A. D. (1996). Evidence-based health policy – Lessons from the global burden of disease study. *Science*, 274(5288), 740–743.
- Pink, S. (2012). *Advances in Visual Methodology*. London: Sage Publications.
- Simon, N. M., Otto, M. W., Wisniewski, S. R., Fossey, M., Sagduyu, K., Frank, E., ... Pollack, M. H. (2004). Anxiety Disorder Comorbidity in Bipolar Disorder Patients: Data From the First 500 Participants in the Systematic Treatment Enhancement Program for Bipolar Disorder (STEP-BD). *Amer J Psychiatry*, 161(12), 2222–2229.
- Simonsen, J., & Robertson, T. (2012). *Routledge International Handbook of Participatory Design*. Routledge.
- Snyder, J., Baumer, E. P. S., Volda, S., Adams, P., Halpern, M., Choudhury, T., & Gay, G. (2014). Making Things Visible: Opportunities and Tensions in Visual Approaches for Design Research and Practice. *Human-Computer Interaction*, 29(5–6), 451–486.
- Snyder, J., Murnane, E.L., & Volda, S. (under review). Visual Materiality in Representations of Biological Rhythms. *Science, Technology, and Human Values*.
- Soreca, I., Frank, E., & Kupfer, D. J. (2009). The phenomenology of bipolar disorder: What drives the high rate of medical burden and determines long-term prognosis? *Depression and Anxiety*, 26(1), 73–82.
- Wakkary, R., & Maestri, L. (2007). The resourcefulness of everyday design. In *Proceedings of the 6th ACM SIGCHI Conference on Creativity & Cognition* (pp. 163–172). ACM.