Visually Encoding Personal Data for Vulnerable Populations
Jaime Snyder
Assistant Professor
Information School
University of Washington

"How well did I sleep last night? How relaxed am I right now? Will I feel better or worse tomorrow?" The expectation that questions about personal health and wellness can be answered with data is characteristic of the digital age (Berson, 2015). Recent work in Personal Informatics (PI) has improved the instruments, methods, and algorithms that support autonomous and semi-autonomous self-tracking, strengthening connections between self-knowledge and pervasive personal data. These advances have coincided with an increased demand by the public to see and understand their own data in order to make informed health decisions. Personal visualizations are playing a critical role in this process (Cuttone, Petersen, & Larsen, 2014), driven by the notion that by simply making data visible we also make it more accessible, and in many cases more social.

Visual representations of personal data support the interpretation and use of what can be a dizzying amount of information by people not necessarily trained in data science or statistics (Carpendale, Tory, & Tang, 2014; Huang et al., 2015; Leung, Tomitsch, & Vande Moere, 2011; Wang, Tanahashi, Leaf, & Ma, 2015). Personal visualizations can offer "substantial opportunities to help individuals gain insight and knowledge about themselves and their communities, ranging from health and fitness information, to energy consumption, to records of their interactions with others through social media" (Tory & Carpendale, 2015, p. 26). But as visual and media studies research demonstrates, there is still much to learn about biases inherent in some visualization conventions (Fyfe & Law, 1988; Kennedy, Hill, Aiello, & Allen, 2016; Kostelnick & Hassett, 2003; Kress & van Leeuwen, 1996). Design choices in the visual encoding of personal data can strongly influence how data-driven self-knowledge is shaped and how effective data sharing via visualizations can be.

Our recent work designing PI for people who self-track to manage serious mental illness (SMI) shows that standard visualization conventions applied to personal data can reflect problematic assumptions associated with normative assessment of progress and medicalized interpretation of biometric data. In these contexts, highly individualized (and at times idiosyncratic) personal data is forced to be reconciled with collective standards related to social and culturally determined expectations about health and wellness. In working with people with bipolar disorder (BD) who use self-tracking as a form of therapy, we discovered misalignments between common data visualization conventions (i.e. use of statistical smoothing, normative baselines, continuous temporal models) and the idiosyncratic and often disjointed ways that individuals with BD describe lived experiences of change over time (i.e., rapid and disassociated transitions, distorted comparisons, discontinuous timelines) (Snyder et al., under review)

Another common challenge described by participants related to the representation of personal data involved reconciling an internal version of themselves (i.e., how the biochemistry of BD makes them feel) with external reflections of their behavior and actions in social contexts (i.e., how their actions are perceived by others). During participatory design sessions, individuals created persistent, material representations of their experiences—either through drawing or photo elicitation—that served as concrete points of reference from which personal experiences could be probed and clarified (Snyder, 2014). This enabled more specific conversations about connections between personal data across time, magnitude of episodes, and complexities of interdependencies. Cultivating opportunities

to clarify and confirm representations of self is critical for supporting vulnerable individuals who, like our participants, may have experienced doubt, scorn, or distrust from society over the course of their lives.

Future work will focus on the following questions: 1) How are social and cultural practices of identity formation and self-knowledge influenced by data-driven representations of personhood? (2) How do normative visualization conventions driven by data science and statistics map to lived experiences of personal data? (3) How best can information and data scientists identify and leverage the situated expertise expressed through non-expert practices which might diverge from disciplinary best practices? We plan to expand our inquiry by exploring the visual encoding of personal data for other populations particularly vulnerable to discriminatory and biased technology. Specifically we plan to engage two groups who face social vulnerabilities related to stigma, ableist perspectives, and life-long health risks: (1) transgender, intersex, and gender nonconforming young adults who are at high risk for serious mental illness (Haas et al., 2010) and are coming of age in an era of binary data systems that reinforce normative notions of identity (Hoffmann, 2017; Spade, 2015); and (2) autistic young adults who often struggle to reconcile internal experiences of emotion with external social cues and for whom some researchers advocate using affective computing systems to help bridge this gap (Bagatell, 2003; Picard, 2009). The goal of this work is to design more inclusive approaches to visualizing personal data in order to support the many ways that diverse groups, especially those using PI to manage serious mental illness and chronic health conditions, track and share information about themselves.

References

Bagatell, N. (2003). Constructing identities in social worlds: Stories of four adults with autism (Ph.D.). University of Southern California, United States -- California. Retrieved from http://search.proquest.com.offcampus.lib.washington.edu/docview/305307552/abstract/334275C86DC3490FPQ/2

Berson, J. (2015). Computable Bodies: Instrumented Life and the Human Somatic Niche. Bloomsbury Publishing.

Carpendale, S., Tory, M., & Tang, A. (2014). A Personal Perspective on Visualization and Visual Analytics. In Proceedings of the 2014 Companion Publication on Designing Interactive Systems (pp. 223–225). New York, NY, USA: ACM. https://doi.org/10.1145/2598784.2598806

Cuttone, A., Petersen, M. K., & Larsen, J. E. (2014). Four Data Visualization Heuristics to Facilitate Reflection in Personal Informatics. In C. Stephanidis & M. Antona (Eds.), Universal Access in Human-Computer Interaction. Design for All and Accessibility Practice (pp. 541–552). Springer International Publishing. https://doi.org/10.1007/978-3-319-07509-9_51

Fyfe, G., & Law, J. (1988). Picturing power: visual depiction and social relations. Routledge.

Haas, A. P., Eliason, M., Mays, V. M., Mathy, R. M., Cochran, S. D. P., D'Augelli, A. R., ... Clayton, P. J. (2010). Suicide and Suicide Risk in Lesbian, Gay, Bisexual, and Transgender Populations: Review and Recommendations. Journal of Homosexuality, 58(1), 10–51. https://doi.org/10.1080/00918369.2011.534038

Hoffmann, A. L. (2017). Data, Technology, and Gender : Thinking About (and From) Trans Lives. In J. C. Pitt & A. Shew (Eds.), Spaces for the Future (pp. 3–13). https://doi.org/10.4324/9780203735657-1

Huang, D., Tory, M., Aseniero, B. A., Bartram, L., Bateman, S., Carpendale, S., ... Woodbury, R. (2015). Personal Visualization and Personal Visual Analytics. IEEE Transactions on Visualization and Computer Graphics, 21(3), 420–433. https://doi.org/10.1109/TVCG.2014.2359887

Kennedy, H., Hill, R. L., Aiello, G., & Allen, W. (2016). The work that visualisation conventions do. Information, Communication & Society, 19(6), 715–735. https://doi.org/10.1080/1369118X.2016.1153126

Kostelnick, C., & Hassett, M. (2003). Shaping Information: The Rhetoric of Visual Conventions. Carbondale, IL: Southern Illinois University Press.

Kress, G., & van Leeuwen, T. (1996). Reading Images: The Grammar of Visual Design. New York: Routledge.

Leung, M., Tomitsch, M., & Vande Moere, A. (2011). Designing a Personal Visualization Projection of Online Social Identity. In CHI '11 Extended Abstracts on Human Factors in Computing Systems (pp. 1843–1848). New York, NY, USA: ACM. https://doi.org/10.1145/1979742.1979882

Picard, R. W. (2009). Future Affective Technology for Autism and Emotion Communication. Philosophical Transactions: Biological Sciences, 364(1535), 3575–3584.

Snyder, J. (2014). Visual Representation of Information as Communicative practice. Journal of the American Society for Information Science and Technology (JASIST), 65(11), 2233–2247.

Snyder, J., Murnane, E., Lustig, C., and Voida, S. (under revoew). Visually Encoding the Lived Experience of Bipolar Disorder. CHI'19.

Spade, D. (2015). Normal Life: Administrative Violence, Critical Trans Politics, and the Limits of Law. Duke University Press.

Tory, M., & Carpendale, S. (2015). Personal Visualization and Personal Visual Analytics [Guest editors' introduction]. IEEE Computer Graphics and Applications, 35(4), 26–27. https://doi.org/10.1109/MCG.2015.88

Wang, S., Tanahashi, Y., Leaf, N., & Ma, K. L. (2015). Design and Effects of Personal Visualizations. IEEE Computer Graphics and Applications, 35(4), 82–93. https://doi.org/10.1109/MCG.2015.74