Social Issues in Personal Informatics: Design, Data, and Infrastructure

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Abstract

An abundance of digital tools exist for tracking various aspects of one's life, body, health, and activities. These personal informatics (PI) and quantified self (QS) technologies are designed to help users capture, reflect on, and get actionable feedback about personal information. In the past (and still in many cases), the design of such systems emphasized an individual-centric vantage point that focused on supporting an individual's self-tracking, self-knowledge, and self-management activities. Over time, however, a growing number of researchers are recognizing that such practices are socially motivated, collaboratively conducted, and embedded in interpersonal contexts, in ways that extend well beyond single-user use cases and requirements. This is resulting in the appearance of a host of new theories, methods, and frameworks for considering social contexts and practices within PI literature and design spaces. This one-day workshop will bring together researchers interested in better understanding and designing for PI at its intersection with social computing. Activities will provide participants with opportunities to share insights, exchange approaches, foster collaborations, and strengthen our connections.

Author Keywords

Personal Informatics; Quantified Self; Collective Engagement; Collaborative Sensemaking; Data Representation

ACM Classification Keywords

[Human-centered computing]: Human computer interaction (HCI); HCI design & evaluation methods; Collaborative & social computing; Computer supported cooperative work

Introduction

Driven by advances in pervasive and ubiquitous computing, the field of Personal Informatics (PI) is seeing an expansion of tools for tracking health, productivity, and participation in real-world social support networks. In parallel, data practices previously conceptualized as "personal" are increasingly becoming (or coming to be recognized as) *inter*-personal in nature — influenced by and interacting with a variety of social factors [11]. Data that represents a single individual can lead to group or community engagement in many different ways, under different circumstances [21]. For example, recent work has identified common collective activities such as socially sharing personal data, tracking on someone's behalf, and pooling communal data [1, 4, 7, 12, 13, 16, 17, 18, 19].

Collective engagement with personal data can be seen in contexts ranging from the long-term management of serious mental illnesses (SMI) like bipolar disorder [15] and post-traumatic stress disorder (PTSD) [20] to emerging practices related to personal genomics and customized medical interventions [2, 5, 10]. Socially-driven personal data practices even raise possibilities in speculative contexts such as crisis informatics and the modeling of human experiences during and after disasters [14]. The range of these use cases highlights a diversity of issues that require further attention including challenges of: representing data for disparate stakeholders; managing brokerage, ownership, permissions, and privacy; and modeling collective decision making in socially complex and dynamic contexts. Such topics are central to CSCW research.

This one-day workshop will focus on synthesizing across the growing body of research that seeks to better understand and support such collective personal informatics practices. This event will strengthen and expand conversations among PI researchers seeking to move beyond ego-centric paradigms through theory building and design research. Strengthening ties across PI researchers interested in collective engagement has the potential to result in systems that:

- Provide a range of different types of stakeholders with appropriate access to personal data records;

- Scaffold existing social relations at multiple levels within support networks that, for example, have been shown to play important roles in the management of chronic health conditions;

- Respond to dynamic changes in social relations and contexts over time, recognizing that longitudinal use is inevitably accompanied by reconfigurations of trust and agency; and

- Standardize platforms for collective and collaborative practices of gathering, validating, and interpreting behavioral trace data (including contextually sensitive data models, automated and semi-automated tracking tools, and visualizations that more closely align with the lived experiences of users).

Achieving these gains will require multidisciplinary teams and coordinated efforts. Connections established through this workshop will enable our diverse community to tackle challenges related to:

- Modeling complex and dynamic privacy scenarios that will require both technical innovation and ethical oversight (e.g., [3]).

- Studying the potential impacts of PI on the interpersonal contexts of CSCW work — for instance, investigating how data-driven practices enable, enhance, impede, change, and/or reinforce new and old dynamics related to decision-making, responsibilities, and roles in domains ranging from healthcare, wellness, and fitness to business intelligence.

- Developing new data literacies about how individuals capture, interpret, and define what qualifies as data, as well as what kinds of questions are being asked of that data, who is asking, and who benefits from the discoveries made (e.g., [6, 8, 9]).

- Unpacking the biopolitics of self-quantification, including questions and policy implications around data as a private vs. public asset and PI commodification.

- Understanding and mitigating the impacts of potentially discriminatory practices in the representation, modeling, and presentation of personal data for different audiences, especially those groups who face disproportionate social vulnerabilities and marginalization.

This workshop will bring together CSCW researchers interested in identifying and addressing such challenges by exploring novel theoretical frameworks, methodologies, and design techniques in order to study, support, and responsibly design and develop for the social ecologies of personal data practices.

Workshop Goals and Outcomes

A primary goal of the workshop is to forge an interdisciplinary network of researchers and practitioners who are interested in better supporting social and collective engagement with personal data. We are seeking participants with diverse perspectives, who work with and in a variety of methods and application areas; who are from academia, industry, startups, nonprofits, and government affiliations; and who represent a range of seniority levels from junior to more experienced researchers.

Through engagement at the workshop and beyond, we aim to develop and disseminate a greater understanding of social issues in personal informatics, as well as to identify key opportunities for future work in this space that spans disciplines and application areas. As with many workshops, our intention is to generate collaborative proposals, research projects, ideas for special issues of journals, and opportunities for students to engage with researchers across institutional boundaries. Additionally, we hope to take advantage of a full day of face-to-face interactions to establish a knowledge base and set of resources (i.e., people, literature, methods, etc.) for us all to draw from in our own future work. This will be accomplished through the creation of online repositories, communication channels, and a website. The website is available here: https://tmilab.colorado.edu/socialpi/.

We will also aim to identify fitting venues for discourse around computer-supported cooperative informatics such as other conferences, popular media, and journals — potentially determining next steps for organizing a special issue in a receptive journal such as *JCSCW* or *Human-Computer Interaction*.

We request interested attendees to submit a 2-page position paper (excluding references, no formatting requirements) that overviews the relevance of their work and/or interests to the goals of the workshop. From submissions, organizers will invite up to three attendees to deliver a short (~5-8 min) provocative talk designed to provide a micro-lesson on a topic relevant to workshop themes around social aspects of personal data. Submissions should note whether the applicant would be interested in being considered for one of these short presentations. We encourage submissions on topics including but not limited to:

- Data representation and presentation

- Role of computational models of social relationships and behaviors

- Infrastructure and architectures that support social engagement

- Collective use of data

- Understanding collective sensemaking

- Supporting communication, empathy, and collaborative decision-making

- Understanding stakeholders, motivations, and risks

- Ethical and privacy issues

- Requirements for specific subdomains (i.e., mental health, fitness, chronic illness, addiction management, client management, business intelligence, etc.)

The organizers will review each submission for relevance, originality, benefits that attendance will offer to the applicant, and the potential for the applicant's involvement to provoke generative, interdisciplinary interactions among workshop participants. Rather than technical submissions or reports on specific experimental findings, we are more interested in thought pieces, case studies, and speculative research visions that will prompt questions and discussions and generally expand our ways of thinking about the future for work in the space of collective informatics.

We will distribute our call through mailing lists, social media groups (e.g., CSCW Meta Facebook group, CHI Announcements mailing list, and the Personal Informatics Facebook group), and wider social networks, with an intention to reach scholars and practitioners in diverse fields spanning data science, design, HCI, information science, social semiotics, and visualization.

We will aim to accept 20–30 participants, in order to convene a broad collection of individuals while simultaneously fostering their active engagement, particularly for more junior scholars in attendance. To further support junior colleagues (PhD students and postdocs), we will 1) strive to match junior participants with senior mentors prior to the workshop through a pre-workshop survey that identifies interests and goals of attendees, 2) include junior participants in the spotlight presentations planned throughout the day, 3) balance the configuration of small groups to include a range of researchers from different fields and levels.

Workshop Structure and Schedule

To prompt engagement among workshop participants, we will structure the one-day workshop around short provocation presentations and group activities, including interactive panel discussions, a design session, and a planning forum. For equipment and supplies, we will need a projector as well as design materials (paper, pencils, pens, colored pencils and markers, collage materials, and scotch tape).

Our tentative schedule is as follows; we will adjust times to accommodate the overall conference schedule when it becomes available.

8:45–9am Organizer welcome and participant introductions
To give attendees visibility and voice from the start, all workshop participants will introduce themselves, their affiliation and background, and how their work connects to the theme and goals of the workshop.

9–9:10am Presentation on a topic related to the nature(s) of social engagement
We start with a short (~5–8 min) provocative talk — that is, aimed at provoking thoughts, questions, and discussion as opposed to detailing findings from previous research. The presenter will be selected from invited attendees based on 1) whether interest in giving a talk was expressed in the attendee's workshop submission, 2) how much we believe the talk will catalyze group engagement, and 3) how well the talk topic will have synergy with the other presentations. The goal of this session is to kick-off the day with a thought-provoking and interesting set of challenges and ideas.

9:10–10:50am Rotating-panel discussion on the many technical dimensions of social engagement
This energetic talk will be followed by a group discussion about the technical implications of designing for social engagement in the PI domain. A rotating panel format will provide all workshop participants with opportunities to ask and answer questions of the presenter and each other. Organizers will pose initial questions to seed discussion, and the panel configuration will start with 4–5 participants who specifically engaged with this topic in their position papers. As discussion progresses, panelists will invite others from the audience to swap places, sharing the spotlight and providing opportunities to hear new voices. Involvement from all attendees will be strongly encouraged but not required.

Goals of this session are 1) to begin to articulate and delineate challenges and opportunities in this domain and 2) to identify and coordinate the expertise in the room.

10-minute break
11–11:10am Presentation on data representation & display
This session focuses on another short (~7-10 min) provocation presentation by a willing workshop participant who has expertise in a topic related to visualization, interface designs, and representations of personal data. The goal of this session is to kick-off a discussion about the choices we make as system designers regarding what counts as personal data, how we provide access to users through visual and other types of representations of data, and how we consider multiple forms of literacies and the values of different types of stakeholders when we build tools.

11:10am–12:30pm Design activity: Visually representing social connections
To provide a focal point for discussing different roles, configurations, and relationships among social entities (and how we represent them), participants will be asked to create a series of sketches or collages that represent different aspects of social systems they encounter in their research and in their own lives. Attendees will be encouraged and coached in using simple graphic elements (i.e., lines, points, and color) to make tangible the ways in which we think about our own social support networks, how we conceptualize the social structures that influence participants in our research, and ideas we have for where, when, and why PI systems can intervene in and across these social systems. Resulting visual artifacts will be used to inform the sharing of different perspectives we bring to our work and to challenge preconceptions about the ways that social relations influence personal data practices.

12:30–2pm Lunch

2–2:10pm Presentation on topic related to ethics, privacy, brokerage, and sharing
This third and final short presentation will highlight a topic related to ethics and privacy concerns that stem from sharing personal data for collective sense-making.

2:10–3:50pm Rotating-panel discussion on ethics, privacy, and longitudinal use
Like the earlier rotating discussion, this panel will provide attendees with opportunity to discuss the many challenges related to who sees what data, when, and under what circumstances. An important aspect of this topic is the ways these factors can evolve, so this discussion will also provide the group with space to discuss the impacts of social change over time. The goal of this session is to round out discussions of technical challenges and issues of representation by addressing the ethical imperatives imbedded in building PI systems for collective engagement.

10-minute break
4–5pm Synthesis and planning
The workshop will conclude with participants identifying and discussing cross-cutting themes and takeaways from presentations, panels, and design activities. Organizers will specifically encourage participants to surface critical concerns, open questions, and otherwise complex issues relevant to the workshop's themes that may not be a common part of other discourses and formats within the CSCW program. In looking forward, we will also plan concrete next steps attendees can push on, including new collaborations, subsequent workshops at future CSCWs and/or other related conferences, and possible journal special issues.

5–5:15pm Closing remarks from organizers and call to action (next steps)

6pm Dinner (attendance optional but encouraged)

Organizers

Elizabeth Murnane is a postdoctoral scholar in Computer Science at Stanford University. Her research focuses on designing and developing interactive and ubiquitous technologies that support cognitive, physical, and psychological aspects of health and well-being. She has built assessment and intervention systems for personal and collective use, by populations ranging from children to older adults, in contexts such as cars, homes, hospitals, and workplaces.

Jaime Snyder is an Assistant Professor in the University of Washington's Information School where she co-leads the Critical Information and Data Studies research group and teaches visualization design. Her research focuses on the creation and use of visual representations of data and information to support collaboration and communication, ethics and values in the design of personal visualizations, and the role of visual representation in emerging data practices.

Stephen Voida is an Assistant Professor and founding faculty member of the Department 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 systems, health informatics technologies, and ubiquitous computing.

Matthew J. Bietz is an Assistant Research Professor at the University of California, Irvine. He has studied collaboration, data sharing, and the development of cyberinfrastructure in various scientific and engineering fields including HIV/AIDS research, genomics, oceanography, astronomy, software engineering, planetary science, and public health. A primary research interest is studying the negotiation and alignment work necessary to support large-scale data sharing.

Mark Matthews is the co-founder and CTO at Health Rhythms, a start-up focused on developing technology to support health and wellness. His research focuses on participatory approaches to the design of technology to support behavioral health.

Sean Munson is an Associate Professor in the Department of Human Centered Design & Engineering (HCDE) at the University of Washington and a member of the *dub* group. Working primarily in the domains of health and well-being and exposure to diverse information, Munson designs and evaluates techniques for helping people make sense of data about themselves and the world around them.

Laura Pina is an HCI researcher currently working in Privacy and Security in the Google Cloud Platform. She has designed and built technologies that address health needs and support wellness. In particular, her research has focused on family wellbeing, by supporting parents and children addressing and tracking their health together. She has worked on designing and helping families address sleep, supporting behavioral interventions, and stress. She completed her Ph.D. at the University of California at San Diego and was a postdoctoral scholar at the University of Washington with joint appointment in Computer Science and Engineering (CSE) and Human-Centered Design and Engineering (HCDE).

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