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Digital Sensing for Mental Health

Title

Workgroup 4 - **User Perspective** *Recommendations from the Digital Sensing Workshop held at UCLA Feb 28-March 2, 2023*

Permalink

https://escholarship.org/uc/item/0p39q718

Author

Digital Sensing Workshop Participants (https://ucla.box.com/v/dig-sensing-wkshp-pubroster)

Publication Date

2023-05-20

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USER PERSPECTIVES

Integrating Diverse User Perspectives into the Development and Testing of Digital Sensors for Mental Health

WORKGROUP #4 – COMPILED RECOMMENDATIONS

These recommendations were compiled as an output of the Advancing the Utility of Digital Sensing Tools for Mental Health Research workshop ("Digital Sensing Workshop") sponsored by the UCLA Depression Grand Challenge, Wellcome Trust and NIMH. Workshop participant roster may be found at: https://ucla.box.com/v/dig-sensing-wkshp-pubroster.

Please submit feedback at https://bit.ly/dig-sensing-report-feedback by August 31, 2023.

Integrating Diverse User Perspectives into the Development and Testing of Digital Sensors for Mental Health

Realizing the ultimate promise and positive impact of digital sensing technologies in real world settings requires the integration of diverse user perspectives starting at the research and development stages. This report outlines key factors related to trust and relevance, considering cultural and socioeconomic diversity, and broadly increasing representation into research on digital sensors for mental health.

Trust and Relevance

One key factor in broadening the reach to diverse users is increasing trust and relevance of research in digital sensing. In order to increase trust and relevance across diverse populations in the development and testing of digital sensing technologies for mental health, it is important to involve the community and acknowledge the historical and systemic factors that have negatively impacted trust. This includes making clear statements acknowledging past harms that can help to build trust (APA, 2021). One of the key approaches to uplift this goal is participatory action research (PAR), where the community is viewed as research partners and works closely together to define the problem, create solutions, test hypotheses, and provide constant feedback. To further dive into the process, a Needs Assessment Playbook could be created, which would help manage expectations and set realistic goals.

It is important to acknowledge the lack of trust that exists and why it exists, as well as the historical trauma and past experiences in research that have negatively impacted trust, such as the Tuskegee Experiment and others that have caused harm. Hard conversations need to be had, and trust can be built by demonstrating consistency, meeting people where they are, and going to where the community already is, such as schools or community centers. The power imbalance needs to be acknowledged, and co-created commitments need to be established to address it. This can include upstream feedback and a constant feedback loop.

It is also important to articulate the mission statement and objectives, and work with the community to identify common ground while being transparent about the limitations of the work. This helps to manage expectations and mitigate unintended consequences and mission creep. The community should be asked how they want to be involved, positioning them as equal partners in the process. Internal and external sponsors, or "champions," should be identified to help build trust and relevance. Community liaisons can also be identified to help with cultural understandings and build trust.

Consistency is key in building trust, and researchers and clinicians should meet people where they are, using layperson's terms and speaking the language of clients, community, and stakeholders. Culturally adapted translations should also be included to ensure that everyone can understand and participate.

The Needs Assessment Playbook could include benchmarking and a literature review on the target population, identifying cultural liaisons, creating an advisory board of external and internal partners, and community engagement and outreach strategies. By involving the community and acknowledging historical and systemic factors, trust and relevance can be increased across diverse populations in the development and testing of digital sensing technologies for mental health. The Needs Assessment Playbook would be an essential tool in the process of increasing trust and relevance across diverse populations. The following is a high-level outline of the playbook:

Benchmarking and Literature Review: Conduct a thorough analysis of the target population, including a zip code analysis of needs, historical trauma, and cultural factors that affect the community's trust in research. This information will guide the research team in the development of the research question and hypothesis.

Identifying Cultural Liaisons: Identify and engage with cultural liaisons who can help the research team understand cultural factors that affect the community's perceptions of research. This will involve identifying individuals who have deep roots in the community and are trusted by community members.

Creating an Advisory Board: Create an advisory board that includes both internal and external partners. Internal partners should be individuals with authority who are committed to building trust and relevance, such as the Chief of Diversity, Equity, and Inclusion (DEI) within a leading organization. External partners should be community organizers or local NGOs who are already viewed as trusted parties.

Community Engagement and Outreach Strategies: Develop and implement community engagement and outreach strategies that meet the community where they are. This will involve going to where people congregate, such as schools or community centers, and using layperson's terms to communicate with clients and stakeholders. The research team should also consider providing culturally adapted translations of all materials.

Prioritizing and Aligning Objectives: Work with the community to identify common ground and set realistic expectations by articulating the mission statement and objectives of the research. This will help to manage expectations and mitigate unintended consequences and mission creep.

Hypothesis and Prototype Development: Use feedback from the community to develop a hypothesis and prototype that meet their needs and address the research question. This will involve creating upstream feedback loops and constantly engaging with the community to ensure the research stays on track.

Testing and Evaluation: Test the hypothesis and prototype with the community and evaluate the effectiveness of the research. This will involve a constant feedback loop to ensure that the research remains relevant to the community's needs and concerns.

Overall, the Needs Assessment Playbook will be an essential tool for increasing trust and relevance across diverse populations when engaging in digital sensing research. By involving the community in every step of the research process, acknowledging the historical and systemic factors that affect the community's perceptions of research, and demonstrating consistency, the research team can build trust and create meaningful change.
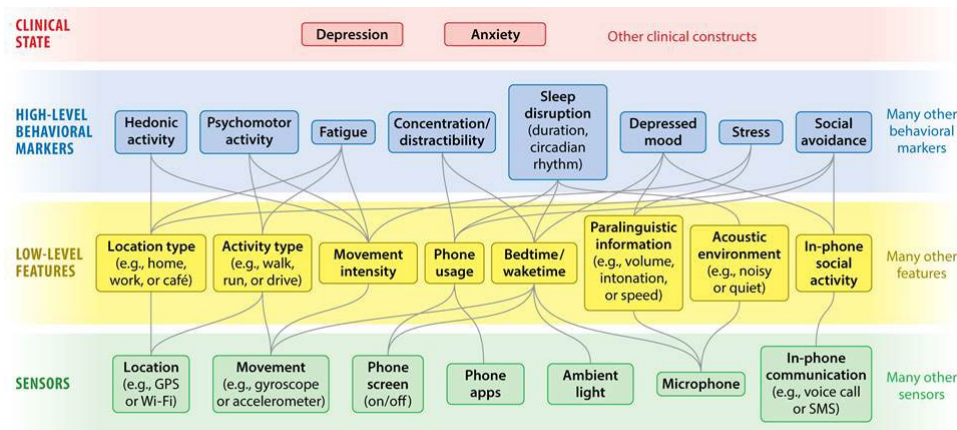
Integrating cultural differences

Cultural Difference in Measurement is a crucial aspect that needs to be considered while researching sensing devices and collecting data. Norms of behavior and emotions vary across cultures and, therefore, affect the usage of devices, the data collected, and meaning-making. Meaning-making refers to how people understand the purpose of using sensors, how sensing devices work, and how the research process works. However, this understanding may not align with the researcher's objective and values. Thus, it is crucial to understand cultural differences to ensure good science and external validity.

Culture plays a significant role in determining what is considered "healthy" and what it means to be a "good" person. For instance, in a collectivist culture, being an integral member of a social network may be considered relatively more healthy than the individual achievement and focus in other cultural contexts. A concrete example is postpartum social norms - postpartum in China implies staying at home, whereas Spain involves going out for new parents. Many studies in the US have considered a lack of leaving home a marker of poor mental health. Therefore, cultural differences can affect how people use sensors and participate in research, as well as what the data means. Researchers need to be aware of these differences to ensure sound science.

Moreover, cultural differences also affect social communication norms, text, phone screens, microphones, and other sensors that feed into higher level endophenotypes and clinical states. For example, who uses the phone, phone usage, activity (vary by culture and neighborhood), physical activity in the home versus outside, facial recognition, body habitus, and device type (e.g., operating systems, processor speed,

RAM, space required to install sensing app) are affected by cultural differences. Additionally, low-level features such as form of communication (verbal vs. non-verbal), texting vs. calling, and others are also influenced by culture.

CLINICAL STATE: Depression | Anxiety | Other clinical constructs

HIGH-LEVEL BEHAVIORAL MARKERS: Hedonic activity | Psychomotor activity | Fatigue | Concentration/distractibility | Sleep disruption (duration, circadian rhythm) | Depressed mood | Stress | Social avoidance | Many other behavioral markers

LOW-LEVEL FEATURES: Location type (e.g., home, work, or café) | Activity type (e.g., walk, run, or drive) | Movement intensity | Phone usage | Bedtime/waketime | Paralinguistic information (e.g., volume, intonation, or speed) | Acoustic environment (e.g., noisy or quiet) | In-phone social activity | Many other features

SENSORS: Location (e.g., GPS or Wi-Fi) | Movement (e.g., gyroscope or accelerometer) | Phone screen (on/off) | Phone apps | Ambient light | Microphone | In-phone communication (e.g., voice call or SMS) | Many other sensors

Mohr DC, et al. 2017.
Annu. Rev. Clin. Psychol. 13:23–47

To address the issue of Cultural Difference in Measurement, it is essential to engage people from other fields such as cultural psychology, HCI, anthropology, and others. For example, Kohrt's work on Qualitative Cultural Assessment of Passive Data Collection Technology (QualCAPDT) (2019) provides a valuable framework for selecting digital sensing technologies for passive data collection with children and their caregivers. It involves qualitative cultural assessment in South Africa and Nepal to understand cultural differences.

To ensure good science, researchers need to develop guidelines for considering cultural differences in measurement and interpretation of data. At a minimum, researchers need to develop a list of considerations and protocols to test assumptions about how a set of sensors will work in the population they plan to study. Achieving measurement invariance is crucial as it assesses a construct's (psychometric) equivalence across groups or measurement occasions and demonstrates that a construct has the same meaning to those groups or across repeated measurements. Additionally, researchers should consider qualitative feedback and take appropriate action if one group is not as engaged or adherent. Cultural differences should be considered in the development of research questions to accurately assess whether the constructs of interest are adequately being studied.

Representation

The use of digital sensing technology in mental health has grown significantly over the past few years. It offers a unique opportunity to understand and treat mental health

conditions through the collection of continuous and objective data. However, there is a lack of broad representation of groups that are impacted by mental health issues in the development and use of digital sensing technology. Diversity refers to the quantitative aspect of representation, meaning the presence of people from various demographic backgrounds. Equity, on the other hand, refers to the goal of equal outcomes for all individuals, regardless of their demographic background. Inclusion refers to the qualitative and quantitative efforts to create an environment where everyone feels valued and supported. In the context of digital sensing for mental health, representation means ensuring that the people who are most impacted by mental health issues are involved in the development and use of digital sensing technology.

The problem of a lack of representation in digital sensing for mental health is multifaceted. Groups that are most impacted by mental health issues and have the least access to effective interventions, such as marginalized communities, are often underrepresented in research and development processes. This lack of representation can lead to biased and incomplete data, which can negatively impact the effectiveness of digital sensing technology in treating mental health issues. The root causes of this problem include funding and systems, research equity, device and tech equity, and accountability, regulation, and oversight.

To address these challenges, it is important to integrate representation into research processes, including funding and process. The National Academies of Sciences recommends several actions to improve representation in clinical trials and research, including the creation of a grant proposal process that prioritizes underrepresented communities, the implementation of research, device, and tech equity, and the improvement of data access and reporting.

Increasing representation in digital sensing for mental health is essential to ensure that the technology is effective and accessible for all individuals, regardless of their demographic background. By integrating representation into research processes, creating partnerships with relevant organizations, and exploring successful strategies, we can work towards a more equitable and inclusive future in digital sensing for mental health.

Socioeconomic Status

Socioeconomic status intersects with other identities previously addressed including racial and cultural diversity. Addressing social and environmental factors is crucial in the area of digital sensing for mental health. Key factors to consider are education, language, and socio-economic status (SES) as they impact access and digital literacy. A person's educational background, language proficiency, and SES can affect their ability to access and understand digital health resources, including mental health apps

and sensor-based technologies. To address this issue, it is important to ensure that digital health interventions are designed with these factors in mind, such as incorporating various language options and creating accessible educational materials that are written at around 5th grade reading levels whenever possible.

In addition to individual level SES, research into digital sensing for mental health should consider the general conditions of the local environment. This includes transportation, access to resources, and other environmental factors that can affect a person's ability to use and benefit from digital sensing for mental health. For example, if a person lives in a remote area with limited internet connectivity, access to digital health resources may be limited. To address this issue, it is important to consider the environmental factors of the area and to design digital health interventions that can overcome these barriers.

Participant and Researcher Stakeholders:

When developing digital sensors for mental health, it is important to consider the needs of both participants and research stakeholders. These needs may be aligned or may conflict with each other. For instance, stakeholders may have conflicting needs regarding the scope of descriptive data collected, real-time access to data collected by digital tools, and final expectations for the use of the results. However, stakeholders' needs may also be aligned, such as ensuring data security and analytical validation of the digital tool.

Collaboration and co-creation should occur throughout the research process to address these differing needs. This can include involving patient representatives or advocacy groups during the design phase, conducting qualitative or mixed methods research to understand needs, and conducting pilot studies to allow for patient feedback. During the research process, it is essential to capture adherence data and develop plans to address any issues. After the study, researchers should consider how the community can benefit from the study findings and whether the community has access to the digital tool or intervention beyond the study.

Engagement considerations should be made for patients/participants, advocacy groups, community agents of health, qualitative research experts, research funders, device/tech manufacturers, healthcare systems/payers, and other stakeholders to ensure that the budget is sufficient to cover engagement, the digital tool meets the identified needs, and the incentives are aligned.

Existing frameworks

Two existing frameworks that can be helpful in guiding the integration of diverse users are the Digital Health Equity Framework (DHEF) (Richardson et al., 2022) and the

Digital Health Social Justice Guide (DHSJG) (Figueroa et al, 2022). The DHEF expands on the National Institute for Minority Health and Health Disparities research framework that considers the multilevel influence of individual, interpersonal, community and societal factors. The digital environment and sensing research also needs to consider the influence of these various factors to understand the ability of people to engage in the research based on factors from the individual (e.g. digital literacy and access) to the community level (e.g. community tech norms) to the societal (e.g. social norms and algorithmic bias).

Domains of Influence (Over the Lifecourse)	Levels of Influence*			
	Individual	Interpersonal	Community	Societal
Biological	Biological Vulnerability and Mechanisms	Caregiver–Child Interaction Family Microbiome	Community Illness Exposure Herd Immunity	Sanitation Immunization Pathogen Exposure
Behavioral	Health Behaviors Coping Strategies	Family Functioning School/Work Functioning	Community Functioning	Policies and Laws
Physical/Built Environment	Personal Environment	Household Environment School/Work Environment	Community Environment Community Resources	Societal Structure
Digital Environment	Digital Literacy, Digital Self-Efficacy, Technology Access, Attitudes Towards Use	Implicit Tech Bias, Interdependence (e.g. shared devices), Patient-Tech-Clinician Relationship	Community Infrastructure, Healthcare Infrastructure, Community Tech Norms, Community Partners	Tech Policy, Data Standards, Design Standards, Social Norms & Ideologies, Algorithmic Bias
Sociocultural Environment	Sociodemographics Limited English Cultural Identity Response to Discrimination	Social Networks Family/Peer Norms Interpersonal Discrimination	Community Norms Local Structural Discrimination	Social Norms Societal Structural Discrimination
Health Care System	Insurance Coverage Health Literacy Treatment Preferences	Patient–Clinician Relationship Medical Decision-Making	Availability of Services Safety Net Services	Quality of Care Health Care Policies
Health Outcomes	Individual Health	Family/ Organizational Health	Community Health	Population Health

The DHSJG outlines 5 key areas to address in the development of digital tools, which includes digital sensing technologies. The framework considers equitable distribution and design which has been mentioned extensively in this report. In addition, privacy and data return are key factors in maintaining trust with diverse communities. Lastly, the framework recommends considering whether research is aggravating bias, which is a documented concern when developing artificial intelligence algorithms. Lastly, research should consider the context structural and societal racism as it relates to the mental health outcomes of interest. If possible, efforts should be made to address structural factors but at minimum, these factors can be acknowledged, as was mentioned previously in this report.

Conclusions

Integrating diverse users and their broader societal context can serve to make digital sensing research more contextually aware and in turn more impactful to addressing real public mental health needs that ensure benefit to a broad swath rather than the fortunate few with easier access to resources. This work requires sustained effort by individual researchers but also structures that are supported by research institutions and funders that make the consideration of broad context and the goals of equity central to the work.