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Project Proposal: Creating a Data Mural to Identify Ethical Concerns in Mental Health Research Using Data Science

Data Science in Mental Health Research and its Ethical Considerations

Feelings of stress at work and school are common, but when the effects of stress begin to interfere with your daily functioning, it may be a sign of a greater affliction. A survey conducted by the Anxiety Disorders Association of America in 2006 highlights that 40% of participants reported experiencing "persistent stress or excessive anxiety in their daily lives," but only 9% of them reported having been diagnosed with an anxiety disorder.[1] This mental disorder is one of many that affect tens of millions of people each year,[2] but why has a stressful work-life relationship become the norm? People are not receiving appropriate help. Although therapy is used to diagnose and treat many mental health conditions, the effectiveness of treatment varies considerably depending on multiple factors, like the therapist's adherence to protocol[3], collection of patient data throughout and after therapy[4], and most importantly, the patient's unique mental health--a complex composition of lived experiences, relationships, and values.

Currently, data science-based methods are not widely used in the mental health industry, but this rapidly evolving field presents new opportunities to incorporate real-world complexity in mental health analysis through techniques like deep learning computational processes and collecting more patient data. Researchers and professionals believe that data science may be a promising tool for identifying mental illnesses earlier in patients' lives and for properly treating their diagnoses through personalized care, advancements that would revolutionize mental health care.

While research is underway, it is important that researchers consider the ethical concerns at stake when collecting and reframing personal data of patients with mental disabilities. Most importantly, I want to highlight ethical considerations around representation of the patient in data and research: what data is used to measure a person's mental self, how is it constructed, and does this data accurately represent the individual? At stake in this research is not only the patient's physical wellbeing but also their sense of identity and value in relation to their world and the influence of their persona on those around them; therefore, data science researchers in this field

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[1] "Highlights: Workplace Stress & Anxiety Disorders Survey." ADAA
[2] "Facts & Statistics: Anxiety and Depression Association of America, ADAA." ADAA
[3] de Jong, Kim. "Why are some therapists 'better' than others?"
[4] Brenner, Brad. "Data-Driven Therapy: The Future of Mental Health Care."

must strive to create a precise representation of the individual's mental self through direct input from the patient and careful consideration of all its nuances, like the patient's sense of identity, interaction with the world, and relationships with people of varying importance.

I propose that a community-designed data mural--a mural that visualizes collected data--is an impactful and effective strategy to raise public awareness of these ethical questions. Participants in creating the mural should be volunteers that come from diverse backgrounds so that the message conveyed through the mural is holistic and representative of all the individuals who are affected in any degree by the data science research. Examples of potential volunteers include individuals who struggle with some form of mental illness, especially mental illnesses being studied through data science research; people who are connected with individuals suffering from these afflictions like partners, family and friends; researchers in the field of mental illnesses, particularly those utilizing data science methods; mental health professionals like therapists and psychiatrists; and students studying the intersection of mental illness and data science. This project should be inclusive, collaborative, and equitable, where everyone participating is heard, valued, and actively included in data collection, analysis and storytelling through the mural itself. I hope that researchers and clinicians can incorporate this data mural exercise into their practice to engage with patients and community members in conversations on the ethical concerns of their research and to recognize the individual voices at play in their practice.

Enhancing Mental Health Data Science Research Through Community-Designed Data Murals

Data murals are designs painted for public spaces that encourage the creators to engage with their own data to find a meaningful story or message.[5] They allow for widespread data literacy amongst the mural producers and those interacting with the mural within the community that is independent of computational skills or knowledge. Examples of three diverse data murals are included in the Appendix. They highlight the various stories that could be told through data, the people involved in developing the mural, and the mural's accessibility. As seen in the examples listed in the Appendix, the first step in creating the mural is "story-finding" where group members analyze their personal and group backgrounds, such as demographics, education,

[5] Bhargava, Rahul. "Data Murals:," 198.

or satisfaction survey reports, depending on the project. They then collectively decide on a single story to tell based on the data they find most valuable. The next step is collectively creating the visual design; this procedure consists of various group exercises that may inspire ways of representing their data-informed story, such as building activities with legos, word web creations, and collaborative drawing. The visual representation ideas that resonate the most with the group are then combined and transformed into a design for the mural. The final mural is painted together as a community, typically extending beyond those who constructed the mural design to include local neighborhoods and organizations; this is seen in Data Mural Examples 1 and 2 in the Appendix. Finally, the data mural may be painted onto visible, public spaces or banners that could be moved around and displayed at various locations.

This collaborative process of creating a data mural addresses two important concepts: the power of ubiquitous data in bringing people together and the use of art to "engage with, and reframe, people's relationships to power structures in everyday life." [6] When looking at data murals from this perspective, it is clear that data empowers individuals to develop informed messages advocating for change and that public art serves as the medium to share that story. Based on this reasoning, creating a data mural to address ethical concerns in mental health research with data science may help redefine the patient's relationship to the daunting power structures they engage with, such as researchers and medical professionals. The participants in creating this mural which were previously described--patients, their concerned loved ones, professionals and students--will be the artists and will develop their data literacy pertaining to mental health. The participants involved with collecting and analyzing data in the process of "story-finding" should primarily be the patients, who may be handling and understanding their data and place in research conducted on their behalf for the first time. Through this approach, patients with mental health disabilities can help us understand how they see themselves through their data. With the power to choose their own representation in data, we also get a glimpse of how much their mental health illness influences their personal sense of self. The goal of this approach is to emphasize the importance of accurately representing the individual in mental health research with data science since the work conducted does not influence just one facet of their lives but their entire sense of self. The data that would be collected and analyzed would primarily consist of clinical information or standard mental health statistics pertaining to the

[6] Bhargava, Rahul. "Data Murals:," 199.

patients with mental health illnesses; however, this limited description of their illnesses, symptoms, and lives through a clinical lense is bound to lead to a limited analysis of their mental health profile. The next phase in creating the data mural, visual design, addresses this shortcoming and is a key difference in how this data is currently interpreted and seen. Patients would be encouraged to create representations of their data in the ways they feel most comfortable expressing themselves while keeping in mind the differences in how they express their illnesses to a doctor versus a loved one; in this mural process, it is important to acknowledge that there may be discrepancies in how a patient communicates their needs and illnesses to a professional versus someone familiar or comforting. Different forms of expression for patients may include visual art, music, spoken word, or casual dialogue, for example. Patients' loved ones, community allies, and medical professionals may all have a role in helping patients translate their expressions of their data into one collective data mural, but patients must ultimately have the leading voice in the design process. Finally, everyone is encouraged to engage with the physical creation of the mural through painting and conversing about what is being told through the art.

At the end of this process, patients would have better recognition of their position, value, and own mental self, allowing them to communicate their needs more effectively; this simultaneously enhances data science research in the field of mental health since it would lead to more informed and holistic patient data. In addition to these developments, a data mural used in public outreach initiatives by researchers and clinicians accomplishes the following: reminds researchers to consider the individual in large datasets and opens the conversation of data science usage for mental health research. While data murals may allow patients to communicate who they are and their concerns to researchers in this field, research institutions must also be prepared to incorporate this feedback into their practice.

Examples of Using Creative Media to Better Understand Mental Health

Similar to how a data mural equips patients with the tools to translate their "needs, affordances, history and context" [7] to mental health researchers, the Rorschach test created by psychiatrist Hermann Rorschach relies on the patient's perception of a series of carefully crafted

[7] Bhargava, Rahul. "Data Murals:," 199.

paintings resembling inkblots to get a better understanding of the patient's inner self.[8] The overlapping issue that a data mural and the Rorschach images address is the challenge of creating an external representation of a patient's mental self in a conventional clinical or research setting. Patient information that cannot be translated into words or numbers is omitted from traditional mental health data collection, but this missing insight still contributes towards creating the identity of the individual and should be accounted for in data science research. In the case of the Rorschach test, professionals may interpret the patient's unconscious self that is revealed through their observation of the "inkblot" images to create a more holistic representation of the patient's actions and personalities.[9] Ultimately, what the historic example of the Rorschach test and the data mural both emphasize and corroborate is that the patient's inner self is best revealed through interpretation of creative media and that this information is vital for developing an accurate representation of the patient in mental health research.

We also continue to see the benefits of incorporating creative media to address the ethical concern of patient representation in mental health research during recent events. In the same way that a data mural aims to bridge conversation between the community, mental health patients and researchers, the online project Pause for a Poem under the overarching MindReading project during the COVID-19 pandemic brought community members, patients and medical professionals together under a common creative discourse. Clinicians and patients were encouraged to use poetry as a form of coping by finding a moment of calm within their day to listen to poems read aloud by healthcare professionals. Creators Dr. Elizabeth Barrett and Dr. Melissa Dickson developed MindReading to explore how both literature and clinical medicine cover issues surrounding "subjective identity, selfhood, and social and cultural determinants of health and well-being."[10] By unpacking patient experience through literature and personal narrative, the project aims to inform self care, patient-centered care, and practice.[11]

Building upon this example, the collaborative process of creating a data mural as previously described may enhance mental health research with data science while establishing ethical standards that include patient input; aside from accurately representing patients' identities and mental selves through their data, other ethical considerations may include secure handling

[8] Johnson, Carolyn Y. "What the Rorschach Tells Us."
[9] Johnson, Carolyn Y. "What the Rorschach Tells Us."
[10] Barrett, Elizabeth, et al. "Storytelling and Poetry,".
[11] Barrett, Elizabeth, et al. "Mind Reading."

and storing of patients' data and transparency in how patient data is being used. The data mural would offer unique insight into the patients' mental selves while creating the opportunity for personal growth amongst all participants; moreover, a data mural would instigate greater patient participation and inclusion for improvement and accountability within mental health data science research that outlives the mural itself.

Reframing Ethical Challenges in Mental Health Data Science Research Through Data Murals

With these artistic approaches to patient-researcher relationships in mind, it is important to establish how a data mural may help overcome ethical challenges that arise in current research institutions pioneering data science applications for mental health diagnosis. The Alan Turing Institute, for example, uses multi-model data to produce AI tools that can be used to personalize mental health profiles and improve the precision of early diagnosis and treatment.[12] Their work paves the way for more efficient clinical assessment tools that are scalable for widespread implementation.[13] Dr. Peter Schofield, a research fellow at King's College London, remarks that in light of the large volume of mental health data, researchers must value what their work informs them of the individual patient; it comes down to "understanding the human story behind how the data were created, having the analytical skills to best interpret the data, and being transparent in the way results are reported." [14] The Alan Turing Institute has been proactive in voicing the importance of ethical considerations in data science projects by enforcing a comprehensive code of conduct with overarching principles of transparency, accountability, and fairness for members working directly or indirectly with data in the public sector. [15] However, an initiative for translating their AI systems to the people affected by their decisions is still in development.[16] A patient-led data mural addresses this divide between researchers, patients, and the public by bringing these communities into direct conversation, allowing all parties to voice their views on the ethical concerns at stake while simultaneously creating a new foundation for

[12] "AI for Precision Mental Health." The Alan Turing Institute. Please refer to this site for more information on the project science, aims, applications, updates and contributors.
[13] "AI for Precision Mental Health." The Alan Turing Institute.
[14] Schofield, Peter. "Big Data in Mental Health,".
[15] "Data Ethics Framework." GOV.UK. Please refer to this pdf for a breakdown of how the Data Ethics Framework is implemented: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/923108/Data_Ethics_Framework_2020.pdf
[16] "Developing an Ethical Framework for Explaining Algorithmic Decision-Making." The Alan Turing Institute.

the institution's ethical standards. Furthermore, this collaborative data mural would encourage developers to enforce practices and designs that are patient-driven, transparent, and ethical.

Concluding Thoughts

Data science use in mental health research presents promising advancements for the precision of early diagnostics and AI that can create personalized treatment, as seen in work by the Alan Turing Institute; however, researchers must question if they are creating an accurate representation of the individual's mental self through their technology. Although this is one of many ethical concerns at stake in mental health research with data science-based methods, participatory creative projects may be a promising solution for addressing ethical challenges in this field. Introducing data mural projects to these research and clinical settings may be a pivotal first step towards inspiring civic participation in this conversation, establishing collaborative creation of ethical standards in this sector, and raising awareness within the general public and scientific community of ethical concerns in mental health research using data science

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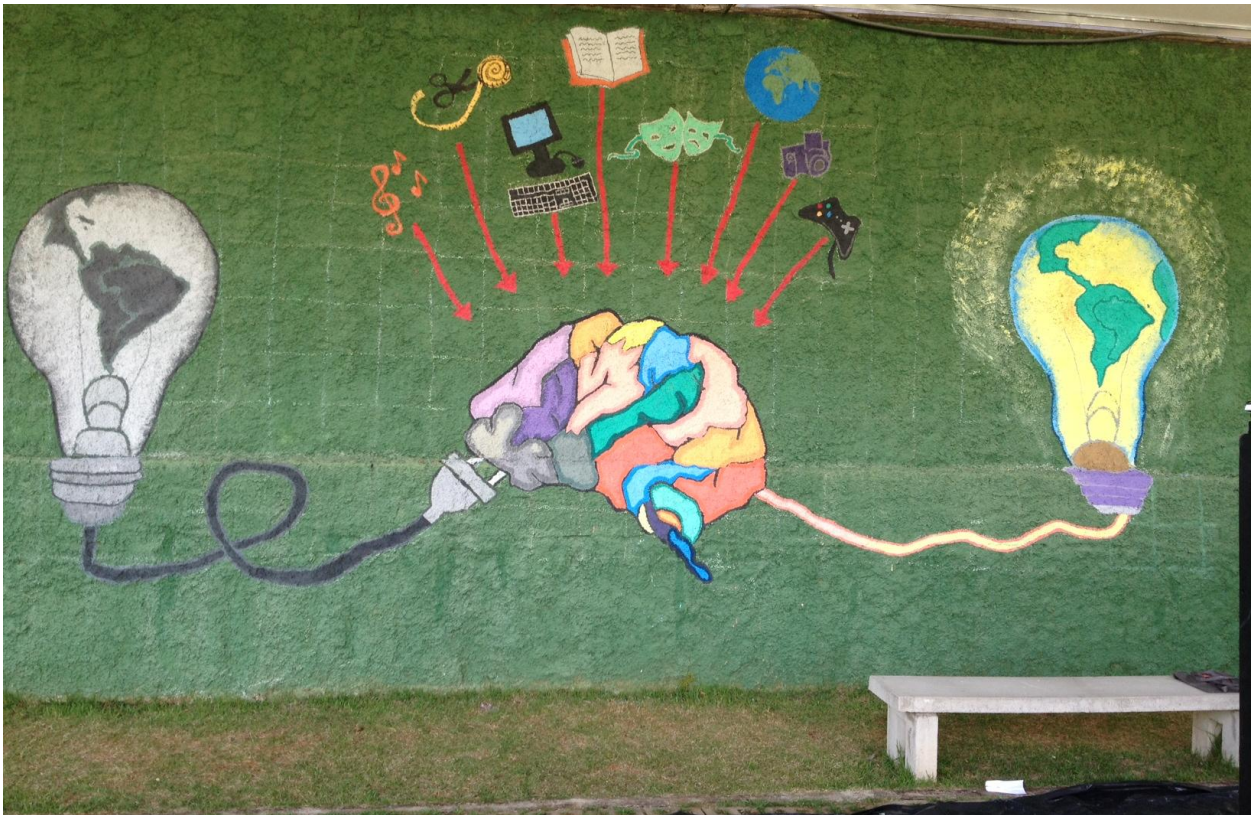
Appendix

Data Mural Example 1:



Data mural created by students at PlugMinas in Belo Horizonte, Brazil (March 2014).

The students at PlugMinas created a mural that portrays the process of transformation towards personal growth that they undergo at their school. They included the school's sub-centers that focus on particular enrichment topics--those depicted above the red arrows in the mural--to emphasize how students identify with these centers in relation to the school as a whole. The final mural was painted on campus by students and members of the school's neighborhood.

For more information, please visit:

www.media.mit.edu/publications/data-murals-using-the-arts-to-build-data-literacy/

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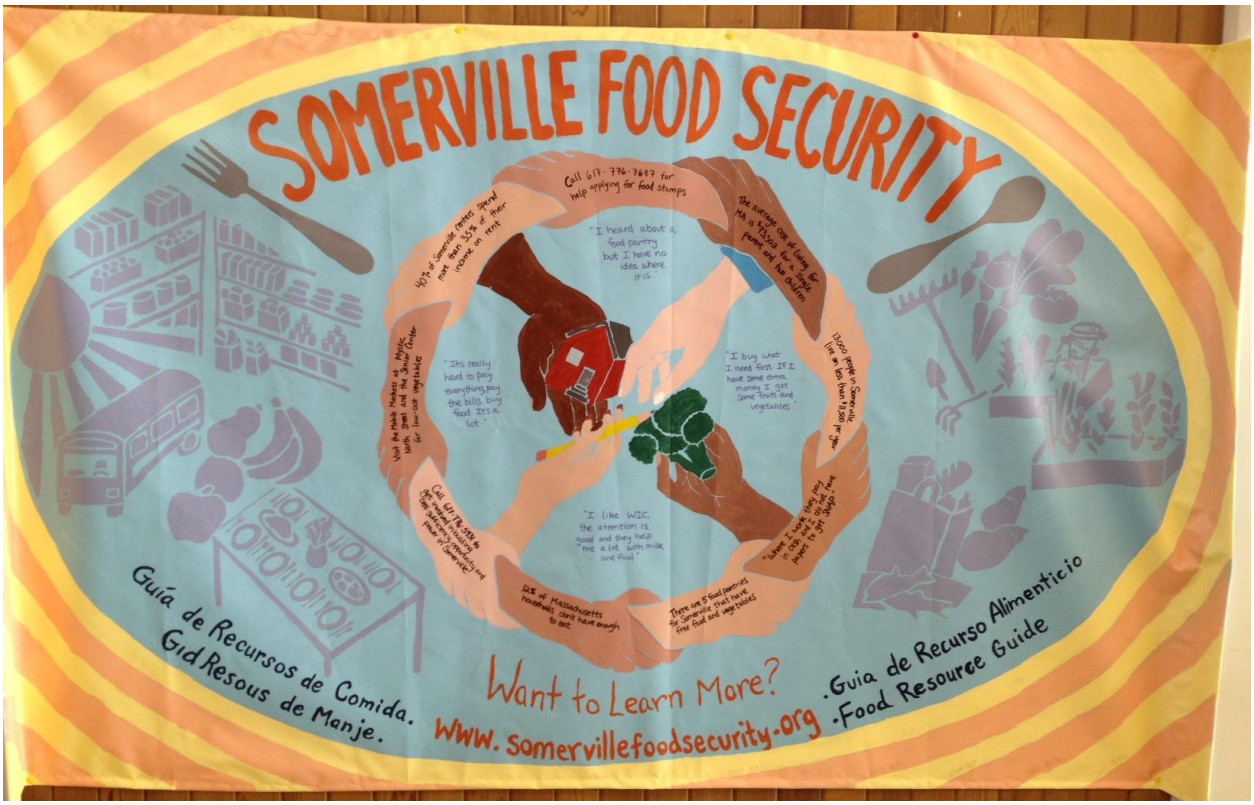
Data Mural Example 2:



The members of the Somerville Food Security Coalition wanted to highlight data that shows how food is not affordable or accessible for many people due to the high volume of people living in poverty or who are undocumented. They also wanted to share how there are helpful resources available to the community at their organization. The data mural was created by coalition members, partners from Tufts, and local high school students. It is on rotating display throughout the city for everyone to engage with and learn from.

For more information, please visit:

https://datatherapy.files.wordpress.com/2015/08/food-security-mural-handout-v1.pdf

Data Mural Example 3:

Clarion Alley Street Mural in San Francisco's Mission District (Photo by Oscar Perry Abello)

This mural portrays the San Francisco housing crisis through the lens of the people evicted from their homes and who now struggle with acquiring affordable housing. This muralist utilized geographical location data to highlight the areas of San Francisco that are most impacted by this housing crisis and to share the “narratives of displacement” of the individuals who resided in these areas. The muralist supports their story with statistics on evictions and displacement in a creative and personal manner, as seen on the left side of the mural. Finally, the public and semi-permanent location of this mural make the story and the resources painted onto the mural accessible to a wider audience.