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Knowledge User Engagement for Digital Health Data in Suicide Prevention: Lessons Learned for a Multinational Data Governance Framework

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Abstract. Digital health data is being increasingly collected and used in the field of suicide prevention and care, but the extent to which knowledge users are engaged in these initiatives is unclear. We build on previous work by conducting a secondary analysis of rapid review data, to describe knowledge user perspectives, the level of engagement and resulting outputs.

Keywords. Knowledge user engagement, suicide prevention, data governance

1. Introduction

In recent years, digital tools for suicide prevention have proliferated, including apps, websites, wearables for ecological momentary assessment, and predictive analytics like machine learning algorithms applied to electronic health record (EHR) data [1]. The data collected via these tools can be used to determine suicide risk and guide follow-up care. However, it is unclear to what extent knowledge users are involved in the development of these initiatives [2]. Incorporating diverse perspectives while developing and implementing these tools improves transparency, builds trust, and increases acceptance of these data-driven approaches [3]. Thus, to examine how and to what extent knowledge users were engaged in digital health initiatives in the context of suicide prevention and care, we conducted a secondary analysis of a rapid review [4]. This approach allows for a more focused analysis of a subset of the data [5]. We defined three new research questions for this secondary analysis: a) How can we characterize the type of knowledge user engagement [6]? b) What key insights emerge from this engagement process? c) What are the key outputs from this engagement, particularly in terms of policy, design, or data governance changes?

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2. Methods

This secondary analysis is a part of a larger study informing the data governance framework and strategy for a new multinational suicide prevention mobile health (mHealth) initiative. Previously, we conducted a rapid review to understand the extant literature and knowledge gaps in using digital health data for suicide prevention and care. Full details about the review methodology are reported elsewhere [4.] This paper presents the findings from a secondary analysis of the review to identify key insights learned from knowledge user engagement in these studies [4]. For this analysis, we identified papers that reported knowledge user engagement as a main objective [6]. Fourteen of the 70 (20%) articles fulfilled the criteria. In this secondary analysis, we applied a systematic coding process to extract key themes related to the type of knowledge user engagement and knowledge user perspectives on the use of digital health data for suicide prevention and care. We also assessed the type of engagement, categorizing it from consultation to collaboration Our goal was to examine to what extent knowledge users were involved in decision-making across the studies and to assess how this might impact data governance frameworks and organizational policies.

3. Results

3.1. Type of engagement

Most (n=9) of the knowledge user engagement can be classified under the ‘consult’ and ‘involve’ categories [6, 7], where knowledge users share their ideas and provide feedback on the project [8–16]. In a smaller number of studies, (n=5) knowledge users collaborated as equal partners with shared-decision making power, helping set priorities for future research and policy [17–20]. Another consideration for the level of engagement is the types of knowledge user groups engaged [7]. While most of the studies engaged only one kind of knowledge user (e.g., people with lived experience of suicidal ideation), five of the studies engaged multiple types of knowledge users, including service users, clinicians, family members, researchers, health system administrators, bioethicists and data scientists [17–21].

3.2. Insights: Knowledge users’ perspectives on data collection/use

Knowledge users were engaged for a variety of suicide prevention tools, ranging from mobile apps to predictive analytics applied to EHR data. Five of the studies reported on the *acceptability* of relying on digital tools to collect data for suicide prevention. In general, most knowledge users were positive about using suicide prevention apps and their related features [8, 11, 12, 16]; the use of EHR data to identify those at risk of suicidal behavior [17]; and about providers asking about suicide in a primary care visit [14]. The degree of acceptability was mediated by three key factors: *privacy, transparency and digital health equity.*

Privacy. Knowledge users had mixed opinions about the privacy of their information. Some knowledge users noted concerns about sharing their location and information about ideation on suicide prevention apps [12, 21], requested password protection and a non-stigmatizing app name and that psychometric test results from an app being shared with providers might potentially affect their care [16, 21]. Whereas others reported not being concerned about the security of their data in general [12]. In one study, patients reported concerns with privacy of suicide risk information and preferences for which clinicians should have access to this information [17], whereas in another study, most knowledge users felt their privacy would be respected if they were identified by a predictive algorithm applied to EHR data [10].

Transparency was a key theme with interwoven attributes: explainability and informed consent. Knowledge users- specifically clinicians - expressed a need to know why an algorithm flagged certain individuals as being at risk of suicide and reported that specific risk factors can influence their follow-up decision-making more than others (e.g., explainability) [9,13]. Other studies noted that most existing data infrastructures and digital health tools are not capable of meeting these transparency requirements due to technical or resource limitations (e.g., underlying digital infrastructure limitations) [9,19]. Although sparse, discussions about informed consent around automated suicide risk prediction suggests that patients want the option to opt-in to the use of their EHR data for risk identification and the use of predictive algorithms applied to their data [17, 10].

Digital health equity. Despite a general sense of acceptability for these tools, there were caveats. Knowledge users were wary about the health equity implications of digital health data. Knowledge users had concerns about automatic suicide risk identification resulting in harm and amplifying inequities in health care by underestimating suicide risk for underserved populations [17, 19]. In some studies, suicide prevention apps were compatible for specific smartphone models (IPhones v/s Androids only), which limited the pool of knowledge users who could provide their feedback [8,15]. While some studies engaged knowledge users from underserved populations [9, 12, 14]; others noted a lack of diversity in the sample of knowledge users recruited, which could impact generalizability of results [11, 17].

3.3. Outputs

We extracted a wide range of outputs from knowledge user engagement. In two studies, researchers developed *study procedures* with knowledge users [11, 17]. A number of studies *co-designed* digital tools such as a suicide prevention app with knowledge users [16] or refined *features* on the next iteration of a suicide prevention apps based on knowledge user feedback [12, 21]. Another study *implemented* a predictive algorithm to flag suicide risk [9]. In one study, researchers developed *consensus-based recommendations* for implementing predictive models [19] while another c*onsensus guidelines* for the assessment of suicidal ideation/behavior in clinical trial data [20]. In one study, researchers continuously engaged a variety of knowledge users and developed an *ethical framework* to guide the implementation of suicide risk prediction models [18].

4. Lessons Learned

The type of knowledge user engagement varies widely. Our study found that knowledge user engagement ranged from consultation to active collaboration, with only a minority of studies involving knowledge users as partners in decision-making. This highlights the importance of more collaborative engagement to ensure that the tools developed reflect the needs and priorities of those affected by suicide risk. In particular, inputs from a wider range of perspectives, such as data scientists, health system administrators, providers, and people with lived experience, helped identify needs and preferences specific to each group, as well as potential blindspots or biases that are missed if only one group is engaged.

Privacy, Transparency and Digital Health Equity are Key to Acceptability. Knowledge users generally supported the use of digital tools for suicide prevention but raised concerns about transparency (e.g., explainable AI), privacy and equity. Users wanted control over how their data is used, clarity on why certain individuals are flagged as high risk, and assurances that these tools would not amplify health inequities. This suggests that addressing these concerns in the development and governance of digital health tools is crucial to acceptance and success.

Engagement Leads to Concrete Outputs and Policy Change. Knowledge user engagement in these studies resulted in tangible outputs, such as co-designed tools, refined features in suicide prevention apps, and the development of ethical frameworks. This demonstrates that involving knowledge users not only improves the design of digital health initiatives but can also lead to meaningful policy, design and data governance changes, making these initiatives more responsive and effective. Responsiveness is critical as new data collection and use practices emerge alongside advances in Artificial Intelligence (e.g., predictive algorithms), introducing new risks alongside new opportunities to enhance suicide prevention and care with digital health data.

5. Limitations

Standards for patient engagement and evaluating patient engagement continue to emerge and be updated. In addition, concepts related to knowledge user/engagement/perceptions were not searched in our original rapid review. These factors could have resulted in us missing papers with the primary aim of engaging knowledge users about their data collection and use in suicide prevention and care. Despite these limitations, our analysis highlights the critical insights gained from engaging a diverse range of knowledge users.

6. Conclusions

To ensure that digital health tools, such as those used for suicide prevention, are developed and implemented effectively, it is essential to establish clear policies and frameworks that prioritize knowledge user engagement at every stage. Multidimensional inputs sought early and consistently can ensure the real-world acceptability and utility of digital health tools. By incorporating diverse perspectives, leadership can guide the ethical and equitable development of these tools, ensuring they meet the needs of all users and address potential risks. Future research should explore best practices for knowledge user engagement, particularly with equity-deserving groups. Additionally, research should focus on how to integrate engagement into data governance frameworks. Embedding engagement into organizational policies and multinational initiatives can help standardize patient involvement, ensuring consistent, transparent and accountable governance throughout the lifecycle of digital health initiatives.

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