
Privacy Concerns of Digital Phenotyping for Older Adults with Mental Health Issues

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Abstract

Despite well-known potential of digital phenotyping in prognosis and diagnosis of general mental health issues, use of digital phenotyping raises several privacy concerns (e.g., data collection, sharing and informed consent). In this work, we discuss digital phenotyping and potential privacy concerns of older adults with mental health issues (e.g., cognitive impairment, Alzheimer's Disease). We use findings and insights derived from the past studies to frame possible privacy concerns and difficulties in conducting a digital phenotyping research on older adults. We conclude by suggesting several research directions and outlook for future studies.

Author Keywords

Privacy; Digital Phenotyping; Older Adults; Mental Health

CCS Concepts

•**Security and privacy** → *Social aspects of security and privacy*; https://dl.acm.org/ccs/ccs_flat.cfm

Introduction

Digital phenotyping enables a collection of personal data through passive/unobtrusive wireless computing technologies (e.g., smartphones, wearable sensors) and data analytics to identify behavioral biomarkers (e.g., physical activity, social interaction, sleep behavior, mood) of an individual [6]. This approach can function as a risk indicator in clinical de-

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cision making based on a more nuanced and comprehensive understanding of one's state of physical (e.g., indicative of biological disease risk/onset/progression) and mental health (e.g., psychiatric disorders) [13].

Despite the promise of this new field, use of digital phenotyping also presents several privacy concerns. As collected data leads to unique source of information about an individual (e.g., user activity patterns & health, behavioral habits, environmental conditions), this may possibly create personal profile including sensitive information. Naturally, there is a concomitant need for discussions on privacy and use of the data (e.g., data collection/storage/sharing) in digital phenotyping. For example, Rooksby et al's recent study from CHI has illustrated university students' privacy concerns regarding data collection in digital phenotyping [16].

However, since "Diversity and Inclusion" has been one of the key mottoes in CHI community, we need to consider privacy concerns specifically targeted upon the "vulnerable population" (e.g., older adults with physical/mental illness, children). These subgroups may have a limited capacity to manage privacy risks successfully due to cognitive disability or lack of social/economic resources for effective protection, thus forced to resort to less effective coping strategies. Once we identify and secure privacy concerns of these subgroups, digital phenotyping may offer great potential with regard to the complementation of routine care of the vulnerable population in our society.

Among subgroups of the vulnerable population, several HCI studies from the past have paid attention to privacy concerns and perceptions of the older adults, especially with chronic health issues or those in need of assistive technologies for healthcare [11, 12, 18, 1]. However, we find that privacy concerns of the older adults in digital phenotyping are relatively unaddressed, as the concept was first introduced

in 2015 [8]. Some studies have also argued that relevant privacy concerns such as data sharing, ownership, and informed consent in digital phenotyping remain unsettled [6, 9].

As recent studies of digital phenotyping report its potential in mental health issues specific to older adults (e.g., detecting an early onset of Alzheimer's Disease (i.e., AD) [10, 6]), it is timely to explore privacy concerns of older adults with cognitive disability and ethical challenges that might arise from improving subject recruitment/compliance in digital phenotyping research. Thus, in this work, we review approaches to older adults with mental health issues (e.g., AD), introducing potential privacy concerns in conducting a digital phenotyping research. Then we provide several research directions and outlook on the future studies.

Types of Privacy Concerns and Challenges

Here, we present challenges with respect to three different types of potential privacy concerns in digital phenotyping research — *data sharing*, *data ownership*, and *informed consent* — and their relevance to older adults with mental health issues.

Data Sharing

Despite the fear of de-anonymization, past studies have showed that people generally agreed to share their data. According to mPower study on Parkinson's disease, 75% of participants were willing to share the collected data [3]. However, the story becomes different when it comes to mental health issues such as AD. Data sharing is not universal across AD research for a number of reasons. Since AD patients are readily identifiable based on their age or genetic profile, anonymity is not a strong protective measure [19]. Plus, people with mild AD symptoms and older adults with other types of cognitive disabilities have re-

ported concerns on social outings from their intimate boundaries due to data sharing [21, 6].

According to a study, surrogates or caregivers of older adults with mental health issues also showed concerns and inquiries on data sharing (e.g., operation of sensors, types of shared data, entities sharing data, monetization of data for profit) [6]. Such concerns are due to a lack of clarity regarding ownership of the data [6]. As participants or caregivers involved in a research are unsure of the final owner of the data, they are left perplexed while their level of privacy concerns arises. Thus, it is important to clarify data sharing policies and ownership issues prior to the process of informed consent, as misleading guidelines may cause further problems in one's understanding and agreement to an informed consent.

Data Ownership

Data ownership reflects an individual's perception of the degree of control over shared private information. It has been discussed through past studies that a lack of data ownership clarity leads to privacy concerns and challenges in conducting a digital phenotyping research [6, 9]. Serenko and Fan [17] recommend to healthcare providers, researchers and practitioners that creating a clear sense of ownership and authority to patients is the most critical factor that affects the overall privacy perceptions of patients in healthcare context, which may influence the degree of participation among patients.

Such statement is well corroborated through an eHealth technology study on older adults' with chronic health issues, as they desired to act as a gate-keeper over the collection, storage, release and use of their own personal data, but expressed frustration over a poorly explained data ownership, which makes them doubt the confidentiality of a research and reluctant to participate in a further process [20]. In line

with such concerns, a study has expressed difficulty in ensuring the ownership of the data in AD research [19], as the current state of 'Data Use Agreement' deployed in AD research seem to lack appropriate policies to ensure data privacy and unauthorized access to data.

One key mechanism suggested as a way to improve data ownership is to leverage a sense of "empowerment," which has been particularly effective strategy to older adults [5, 20]. Providing transparent and diverse channels of communication/medium to access their personal data made older adults feel a sense of achievement in their autonomy and increased self-efficacy [5].

Another practical measure to ensure data ownership is to create and scale data ownership platforms to systematically manage the data and make it possible for participants to fully own, know and manage their personal data. However, challenges still remain as suggested mechanisms may not be helpful to older adults with severe cognitive deterioration. Thus, networked discussions involving patients, caregivers and researchers to improve the status quo of data ownership are required.

Informed Consent

Digital phenotyping is currently used with an informed consent, but not much discussions have been made on providing context/subject specific informed consent in digital phenotyping research. Although past studies have argued that informed consent should be obtained despite cognitive impairments [4, 2], consenting to data collection and sharing from wearables and other passive/active sensors can be challenging for older adults with mental health issues, especially AD patients. According to an examination on scientific and ethical features of online tests for AD, given information were often complex, lengthy and lacked ethical norms that aim to protect participants' privacy [15]. Despite con-

tinuous debate on informed consent for AD patients, ethical discussions on cognitive deterioration and their capacity to consent have not been fully discussed [9].

To address this issue and inform future studies, Kim's study provided two ethical concepts —“Autonomy” and “Authenticity” [9]. Autonomous decisions are based on self-determination. If a patient is unable to make a decision, he or she is either excluded or participated upon surrogate's decision. Authenticity refers to a congruence between a patient's value and a surrogate's decision. These two concepts well reflect the ethical requirements of an informed consent: first, individuals should be treated as autonomous beings, and second, those with deteriorated autonomy are entitled to extra protection [7].

Discussion and Outlook

Below, we provide some potential design considerations to better reflect privacy concerns of the older adults in digital phenotyping context.

Design Space Exploration

A systematic review of existing privacy related issues and ethical challenges in digital phenotyping will be beneficial in future studies. Though a past study has provided a literature survey that covers ethics(e.g., privacy, autonomy) of using assistive technologies [21] for the older adults with AD, the study does not include phenotyping environment which involves multi-modal sensor streams. An integrative overview of such works will provide researchers an opportunity to broaden their contextual knowledge on older adults' privacy concerns and how to design/build more inclusive research. We can also expand our studies as comparative studies that investigate sensitivity of privacy concerns across different vulnerable population in an identical setting.

Facilitation and Extension of Ethical Framework

As suggested from a prior study [9], leveraging ethical concepts (e.g., Autonomous, Authenticity) as reference points will be helpful in future clinical trials of digital phenotyping. Robillard et al have suggested a term “ethical adoption,” which consists of five pillars — (1) include participatory design; (2) emotional alignment; (3) adoption modeling; (4) ethical standards assessment; (5) education and training — to be considered in using technology intervention for dementia care [14]. Facilitation or extension of such ethical concepts and framework to effectively assess and design privacy control will be helpful in conducting different clinical research on the older adults with mental health issues.

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