

xShare-Powered Personal Digital Twins: End of Privacy or Key to Precision Health?

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Abstract. The proliferation of health data available in real-time and the availability of low-cost computation are powering a new research area: Digital Twins. In the context of the European Health Data Space (EHDS), an enabler for personal Digital Twins is the xShare “Yellow” Button that aims to empower individuals to share their data, one time, or for a period with applications of their choice. This paper presents different use cases that are made possible by the personal health twins and reflects on relevant challenges and opportunities, debating whether ethical and privacy concerns can overcome the benefits of personalized precision medicine powered with the dynamic real-time feedback to digital twins.

Keywords. Health data spaces, interoperability, Electronic Health Record, health literacy, privacy, participatory personalized precision health, patient summary

1. Introduction

One of the most fascinating and challenging trends in modern healthcare is the advancement and effective implementation of participatory personalized precision medicine [1]. The traditional one-size-fits-all treatment is gradually replaced with innovative personalized treatments tailored to the unique characteristics of individual patients. Instead of prescribing medications and dosage appropriate for the average patient, medication and dosage options will be tested on digital twins using Gen-AI methods and treatment options are discussed with the patient. It is widely recognized that individuals can respond very differently to the same drug, influenced by factors such as genetics, lifestyle, and underlying health conditions. Given this variability, a crucial question arises: for a specific person battling a particular illness, which drug offers the most benefits, matching personal health goals and lifestyle, while minimizing risks?

While clinical trials have historically been the gold standard for evaluating the safety and efficacy of treatments, their findings are generally designed to apply to the “average” patient and frequently face diversity and bias concerns. At best, clinical trials provide insights into specific demographic or clinical subgroups, but they rarely, if ever, account for the intricate differences among individuals, a task left for real world evidence. This gap leaves us wondering: wouldn't it be transformative to predict how a particular drug would work for a single, unique patient, rather than rely solely on data for the average

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person? Although this vision may seem daunting, recent advancements in digital health technologies, particularly the development of Personal Digital Twins (PDTs), are bringing these goals within reach [2]. PDTs are sophisticated virtual models that simulate an individual's biology and health profile, enabling researchers and clinicians to predict how an individual will respond to a particular treatment. However, instead of being a one-off model, PDTs may be continuously updated with medical and health data as they become available, from the patients themselves, who may also provide patient reported outcomes (PROMs) and experience (PREMs) related to treatment. A few years ago, organizations like the Society for Participatory Medicine and platforms such as "PatientsLikeMe" revolutionized the way patients experience their health journeys [3]. By enabling individuals to connect with others facing similar medical conditions, these services offered valuable insights into the trajectory of diseases and potential treatment regimes. By leveraging foundational AI models, we can integrate a wealth of personal health data—including genetic profiles, medical history, lifestyle factors, and current health conditions, along with PROMs, to create a highly detailed and dynamic PDT.

In this rapidly evolving landscape of personalized healthcare delivery and continuous health monitoring, our work with the xShare "yellow button" is emerging as a powerful enabler in the creation and utilization of PDTs [4]. This innovative tool allows patients to seamlessly and securely share their health data, paving the way toward patient empowerment, and effective collaboration of patients with their care team. By leveraging the xShare button, patients can continuously feed their PDTs with up-to-date health information, including vital signs, medical history, and other personal metrics. This ongoing flow of data enhances the accuracy and relevance of PDTs, creating more effective tools for predictive analytics and tailored healthcare interventions. Patients can now discuss with their PDTs and gain insights from their health data. The concept of the xShare Button originates from the Blue Button that was quite famous in the United States during the days of Meaningful Use era [5]. While the Blue Button concentrates in claims data, the xShare button empowers patients not only to receive personalized care, but also to connect with communities of individuals, who share similar health conditions or experiences. These connections foster a sense of support and enable the exchange of valuable insights, contributing to an engaging participatory and informed healthcare experience. This seamless integration of real-time data sharing, personalized insights, and community engagement represents a significant step forward in the realm of precision medicine. By enabling the development and application of PDTs, the xShare xShare button is helping redefine what is possible in patient-centered care, ultimately driving better health outcomes and improved quality of life. The next section explores in the literature the degree to which the xShare Button can support use cases and at what cost. In the results, priority use cases and challenges are identified with a future workplan.

2. Methods

We opportunistically searched google scholar, Pubmed, and scopus for recent research papers using keywords such as "Personal Digital Twin", "Health Digital Twin" and "healthcare" and "challenges". The research area of digital twins has exploded during the last 3 years, partly due to Gen-AI. We selected review papers from different disciplines and articles referring to diverse applications of PDTs. We made an inventory and classification of the use cases that can benefit from patient empowerment as manifested with the xShare Button. We organized research challenges and privacy

threats presented with mitigation factors offered. The ultimate aim is to develop a strategy for protecting individuals that use the xShare Button, while enhancing patient/health team interactions. Use cases allow organizations to run table-top exercises exploring the impact of implanting the xShare Button and PDTs as part of their strategy.

3. Results

PDTs are changing the landscape so that some people talk about a “revolution” in healthcare [6]. PDTs can be part of digital health services offered in virtual environments (metaverse), as for example in remote consultation, or telemonitoring, and help people productively engage with their care plan, in collaboration with the health team [7-10]. PDTs are also used in remote health education [11], in emotion recognition [12], and in many diseases and associated procedures [13-15]. We identified research papers in more than 20 medical disciplines ranging from cardiovascular, cancer, migraines, neurological disorders, dementia, dentistry, rehabilitation, and surgery planning. Keystone groups of use cases that present the multidisciplinary nature of PDTs are presented below.

- *Participatory Personalized Precision Medicine.* For any given illness, there is often a spectrum of medications available, each with varying levels of efficacy and side effects. Patients may respond differently to the same set of drugs/dosage, influenced by factors such as genetics, lifestyle, and underlying health conditions. Getting detailed information on medication treatment and adherence helps collect real world data on drug efficacy. The xShare button enables patients to share their health data on a continuous basis with their PDTs. PDTs simulate the patient’s physiological responses, enabling researchers and clinicians to test and validate treatment options, educating and empowering patients. Here’s how this process may work: the physician creates a cohort of PDTs based on EHR and patient generated sensor data; then administers different drugs, dosages, or treatment regimens to each PDT. By observing how each PDT responds, the physician can identify with the patient the most effective drug-dosage combination the patient is comfortable with and observe it in action. By leveraging continuous data sharing and advanced simulations, patients and their health team are empowered to make data-driven decisions that cater to the unique needs of the patient, setting a new standard for safe, effective, and personalized care [16].
- *Personalized Therapy and Treatment Planning.* Consider a complex disease like cancer that often involves a combination of surgery and chemotherapy. Each tumor is as unique as the individual it affects, and its response to a given therapeutic protocol can vary widely based on factors such as the tumor’s genetic profile, location, and stage, as well as the patient’s overall health and mindset. PDTs present an innovative and highly promising approach to modeling this problem. By creating a PDT, including models of organs with the solid tumor, experts can simulate various surgical and chemotherapy protocols. This allows us to observe how the tumor responds to different treatments prior to the actual intervention. Afterwards, the xShare Button can help follow long term effects and care plans with the survivorship passport.
- *“Yellow” Button to empower Patient Communities advancing health data spaces.* Connecting with others who share similar disease experiences offers patients

emotional and practical benefits. Sharing stories, challenges, and successes fosters a sense of belonging, alleviates isolation, and builds supportive communities. Beyond emotional relief, these interactions provide insights into treatments, coping strategies, and outcomes, empowering patients to make informed healthcare decisions and actively participate in their care. However, finding patients with closely aligned experiences can be difficult, especially for those with rare diseases or from underrepresented groups. The xShare Button addresses this problem by allowing patients to securely share their health data anonymously to identify others with similar conditions. Using PDT technology, the platform matches patients based on symptoms, treatments, and outcomes, enabling virtual communities that transcend geographic and demographic barriers. These communities offer spaces for sharing knowledge, support, and collaboration. The xShare button empowers patients and families with actionable data and connects them with peers in trust and privacy, fostering an ecosystem of mutual learning and encouragement.

4. End of Privacy or Key to Participatory Personalized Precision Health?

While PDTs represent a groundbreaking innovation in personalized healthcare, they also demand high computing power, and introduce significant ethical, privacy and security challenges that must be carefully addressed to ensure ethical and trusted implementation:

(i) *Sensitive Data Protection.* PDTs depend on repositories of highly sensitive information, including electronic health records, genetic data, biometric markers, and detailed medical histories. Their exposure can impact on the patient's livelihood.

(ii) *Privacy Implications for Family Members.* The privacy concerns of PDTs extend beyond the individual to their family members. Because genetic data is shared among relatives, one person's genetic information may inadvertently reveal sensitive data about their family, especially when correlated with other personal data.

(iii) *The Right to Destroy a Digital Twin.* While PDTs offer immense benefits, individuals should retain full control over their digital replicas, including the right to delete or "destroy" them if desired. However, ensuring complete erasure poses significant challenges. First, PDTs may be shared with multiple healthcare providers, researchers, and institutions: tracing and permanently deleting every copy becomes a complex task. Second, there are legal obligations: Hospitals and medical institutions are often required by law to retain patient records, including PDT data, for a specified period. This legal requirement may conflict with an individual's desire to erase their data, raising questions on how to balance privacy rights with regulatory compliance. Legislators can address PDT governance under EHDS, perhaps adapting GDPR "*right to be forgotten*."

While PDTs hold immense potential in revolutionizing personalized healthcare, several limitations were identified that can serve as areas of future work. First, there is the challenge of *Incomplete Data*: PDTs rely on comprehensive, high-quality datasets, but gaps in patient data or missing health records can lead to incomplete or inaccurate models. Second, there is *Data standardization and quality management*: Health data is often fragmented across various formats and systems, challenging integration and use in AI. Harmonization in national and global AI policies and programs is needed. EEHRxF and the EHDS data utility label are drivers for standardization research in this area. Last, there are *Real-Time Updates and regulation*: Maintaining trust in PDTs requires real-time updates from wearables, sensors, and medical systems, addressing also verification, validation, and uncertainty quantification, in pathways to regulatory approval [17].

5. Conclusions

PDTs represent a groundbreaking development in health informatics, harnessing the confluence of vast health data availability, affordable computational power, and the transformative energy of Gen-AI prompts. This emerging field is poised to revolutionize personalized medicine by creating digital replicas of individuals that simulate at all scales and predict health outcomes based on comprehensive, real-time data inputs and feedback. PDTs and enabling tools like the xShare Button are ushering in a new era of participatory, personalized, and precision healthcare, fundamentally reshaping how individuals engage with their health and care. This transformative approach not only empowers patients, but also enhances the effectiveness of healthcare systems globally. The jury on whether PDTs signal the end of privacy or form an essential element of future health is still out. In the meantime, PDTs research is on-going their success dependent on thoroughly tested algorithms and high-quality standardized data checked against diversity and bias. Standards and professional organizations have a vital role to play in preparing our society to adjust responsibly to the new reality, while we learn how to create and use PDTs, while protecting our privacy and that of those around us.

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