

Developing a Prototype for Patient-Centric Digital Health Advisor for Patients with Complex Needs

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Abstract:

This study aims to outline the essential features of a comprehensive digital health advisor tailored for frail elderly individuals and patients with multiple chronic conditions, along with their caregivers. Through in-depth interviews, personas, and use cases were developed, leading to the creation of a low-fidelity prototype. Feedback from participants, developers, investors, regulators, and health system leaders underscored the feasibility of such a tool. Key functions identified include tracking and insights, advice and information, holistic patient overview, and facilitating coordination and communication. However, to advance its development, clarifying the business case and addressing policy, organizational, and cultural barriers is crucial.

Keywords —Patient-centered design, Chronic disease.

I. INTRODUCTION

Twenty years ago, Peter Szolovits and his colleagues introduced the concept of a digital "Guardian Angel," suggesting a shift in focus from serving health institutions to empowering individual patients [1]. This digital health advisor would collect patient data, monitor health conditions, interpret health information, assist in customizing treatment plans, facilitate information sharing with the care team, and provide medication and appointment reminders. Despite recent technological advancements making the creation of a digital health advisor feasible, it has yet to materialize. One obstacle to its development may be the absence of a clear set of requirements to guide its design. While there are various tools that perform related functions and some studies covering certain needs, they have not been presented in a manner actionable for developers [2].

The Commonwealth Fund, a foundation dedicated to improving healthcare access, has been investigating this opportunity through its program on IT-enabled consumer healthcare. The fund is particularly interested in care models for high-need, high-cost (HNHC) patients, and in enhancing

coordination, patient, and caregiver engagement [3]. Our aim was to identify how digital tools could address the concerns of HNHC patients and their caregivers, and to communicate this to the stakeholders responsible for developing and distributing these tools. This paper outlines our strategy, emphasizing the use of persona development and an illustrative prototype to engage key stakeholders and encourage the creation of a digital health advisor tailored to those who stand to benefit the most.

II. METHODS

A. Solutions to Enhance Care for High-Need, High-Cost Patients

Information and communication technologies (ICTs) have revolutionized numerous industries by reorienting services around consumer needs. However, the healthcare sector has been slower to adapt. Many current consumer-facing applications primarily target relatively healthy individuals [4]. There has been a noticeable gap in addressing the needs of the 5% of the population responsible for nearly 50% of all healthcare costs in the United States and other regions [5]. These high-need, high-cost (HNHC) individuals often suffer from multiple

chronic conditions and are more likely to have lower incomes, as well as face housing and food insecurity [6-9]. They are poorly served by a healthcare system primarily focused on diseases and institutions, resulting in fragmented and sometimes conflicting care [10,11]. Among different population segments, the frail elderly represent the largest subgroup (46.2%) of high-cost patients, followed by adults under 65 years with disabilities and adults with major complex chronic diseases [12]. These individuals engage in various activities to manage their health [13,14], and digital technologies have the potential to assist them. Seniors, the largest subgroup, are increasingly adopting technology, with 76% using cell phones, 64% using computers, 43% using the internet, and 40% using email and texting [15]. They are already exploring new healthcare approaches: 16% of seniors search the internet for health information, 8% examined a range of HNHC patients, and none were to fill prescriptions, 7% to contact physicians, and 5% focused on designing a general tool to help patients achieve their goals, such as the digital health advisor. However, despite the availability of over 165,000 health apps, a 2016 review revealed that most digital tools for chronic diseases are fragmented, offer limited functionality, and fail to address the needs of patients with complex chronic conditions [4,16]. Furthermore, a review of app evaluations for conditions associated with higher needs found that most studies were small, and few assessed process or outcome measures [17]. Another review compiled proposed functions from different studies, emphasizing the importance of developing tools with user needs in mind [2].

B. Understanding and Communicating User Needs

Human-centered design (HCD) has been instrumental in developing many transformative ICT solutions and is increasingly applied in healthcare [10,18-29]. HCD, a problem-focused method originating from industrial design and more recently software development, allows for a rapid understanding of user needs and effective communication of those needs in emotionally engaging and actionable ways. This approach often involves interviews, observation, and immersion in a user's context to develop user personas, or archetypes, and use cases [22,27]. A persona is a

detailed description of a fictional person, often a composite of real individuals, used to communicate the key motivations, concerns, and interests of a user group [10,26,27]. Related to the persona is a use case or user story, which is a narrative describing the actions and decisions of a user in a particular context [26,27]. These representations help designers foster empathy, better understand user needs, and develop new service options and tools [26]. Although persona development has been employed in various studies, they have mostly focused on specific chronic conditions (e.g., older adults with diabetes [31], heart disease [32,33], or multiple sclerosis [34]) or specific groups such as high users of the emergency department [35]. One study created personas of the "oldest old" but primarily focused on implications for the design of computer interfaces [27]. None of these studies achieved their goals, such as the digital health advisor.

Understanding the needs of target users is crucial for designing a comprehensive digital health advisor. However, to bring this vision to fruition, we must also address broader system and policy constraints that will impact its development. User-centered design can draw attention to solutions that are technically feasible but lack a sustainable business model and may not align with current regulations. It helps reframe problems and propose solutions that may operate independently of existing services or processes. In the realm of models of care for high-need, high-cost (HNHC) patients, the Commonwealth Fund has undertaken rigorous evaluations of new models, synthesized evidence from scientific literature, and developed a playbook for health systems to implement promising models and improve care for this group. Additionally, we have begun using design thinking as a tool to generate innovative solutions. We advance this forward-looking work through our role as a convener and advocate for improving access to care. Moving forward, in the realm of IT-enabled consumer healthcare, we must explore the collaboration required between stakeholders such as healthcare delivery organizations, patients, caregivers, technology companies, government

entities, and consumer advocacy groups. We also need to examine the incentives and business models necessary to attract entrepreneurs and developers to work in this area, as well as to encourage health systems to engage with consumer-facing IT tools. Given that system change is unlikely to originate from those currently within the system, the Commonwealth Fund is actively addressing policy and regulatory, business model, and cultural barriers to creating tools that prioritize patients and their goals at the center of the healthcare system. Furthermore, addressing the challenges of cloud migration for IP PBX (Internet Protocol Private Branch Exchange) systems in critical hospital environments is essential. Ensuring the seamless transition of communication systems to the cloud while maintaining reliability and security is vital for healthcare facilities. Critical hospital environments demand uninterrupted communication systems to ensure patient safety and efficient operations. Therefore, overcoming the challenges associated with cloud migration for IP PBX systems is crucial for the successful implementation of digital health solutions in healthcare settings [30].

C. Designing a Prototype for a Digital Health Advisor

The Commonwealth Fund aimed to develop a vision of a digital health advisor that could meet the needs of HNHC patients and encourage its development in the healthcare marketplace by developers, entrepreneurs, investors, health system providers, funders, and regulators. To achieve this, the Fund collaborated with the design firm gravitytank to identify the needs of HNHC patients and their caregivers and create a low-fidelity prototype. This prototype simulates key features of interest to this group without building out any specific functions [36,37]. The process involved interviews with experts, eight patient-caregiver pairs dealing with multiple chronic conditions or frailty among the elderly, and the mapping of the workflow of three care managers working with similar patients [36,37]. Based on the analysis of this data, a rough prototype of a digital health advisor was created and shared with patients and caregivers to gather feedback on usability and functionality. This feedback informed various

outputs aimed at making the insights more actionable.

III. RESULTS

First, we characterized the needs of patients with multiple chronic conditions and the frail elderly, along with their caregivers, focusing on the intersection of functional and emotional needs with medical and personal needs (refer to Figure 1). Patients expressed that a tool addressing functional needs could potentially improve health outcomes, but they emphasized that if a tool also addressed emotional needs, they would be more inclined to use it consistently. One critical link between functional and emotional needs was the ability of a tool to connect goals to functions and orient care to better manage their conditions, thus enhancing their ability to engage in meaningful activities. They highlighted challenges such as communicating with family members about end-of-life issues, sharing goals, navigating apps, and dealing with approval processes. Additionally, they expressed difficulty in understanding the wide range of uncoordinated advice they receive and following through on the subset of recommendations that address their specific needs. Based on these interviews, we developed four patient personas and two caregiver personas, along with four use cases. Finally, we created a low-fidelity prototype of a digital health advisor with several key features [38].

We presented the personas and prototypes of the digital health advisor to a diverse group including policymakers, regulators, clinicians, informatics experts, advertising professionals, health services experts, patient advocates, technology industry executives, and health system leaders. They generally agreed that most components are technically feasible using current technology, although they acknowledged the need for further development in decision support. Patients and participants from the advertising industry emphasized the importance of the tool being relatable and having a "stickiness" factor that makes it the first resource patients turn to when they have health-related questions. They stressed the need for a simple visual interface and opportunities for voice activation to benefit those with low literacy or cognitive challenges.

Health system leaders suggested that a dashboard displaying trends and current health status could make visits more efficient for people with complex conditions by reducing the time needed to collect this information, thereby leaving more time to discuss specific care goals. They also highlighted how a tool providing detailed but actionable information on goals, functional status, physiological parameters, and the current burden of treatment could facilitate difficult therapeutic decisions involving multiple providers. Representatives from healthcare delivery organizations emphasized the critical role they play in the development of a digital health advisor. They stressed the importance of fostering support in target communities, including patients, caregivers, families, and social networks. They highlighted the necessity for extensive collaboration to develop a robust digital health advisor, which should be an integrated suite of tools.

Furthermore, they emphasized that novel analytics alone are not sufficient; data must be made available in a usable format, and the necessary data for real-time decision-making (e.g., cost, quality, availability of services) are currently held by various groups in different formats. They suggested that a useful digital health advisor is more likely to emerge through partnerships with organizations focused on consumer needs, such as consumer advocacy groups and large retail companies. Moreover, they stressed the need for developing business cases and policy incentives to encourage broad data sharing among community, government, and commercial initiatives.

IV. DISCUSSION

A. Designing Tools and Systems to Meet Patient Needs

The concept of a comprehensive digital health advisor for patients, proposed over 20 years ago, is now technically feasible and appealing to high-need, high-cost (HNHC) patients in the United States. These patients highlight a variety of functional, emotional, medical, and personal needs that such a tool could address. They also identify several key functions such as tracking, providing advice, offering a holistic view of their health, and

facilitating coordination and communication. The use of human-centered design helps overcome the limitation that new healthcare designs are often created by providers to be easy to implement but may not be user-friendly for individuals who rarely use healthcare services and do not resemble the people they aim to help. Personas can enhance stakeholder engagement by providing detailed insights into patient needs and how a tool might address them, thereby making it easier to understand key functions, potential interactions with the healthcare system, data requirements, and potential regulatory concerns.

While some studies have used human-centered design to develop tools for patients with multiple chronic conditions [39,40], this approach is typically applied to specific populations (e.g., people with diabetes) [26,41,42] or specific purposes (e.g., communication, monitoring) [43,44]. Our work complements the findings of a recent review of mobile technologies for older adults, which summarized various design features from different articles, including graphs, notification systems, text and video messaging, scheduling, and aids for vision, hearing, and memory [2]. Despite the abundance of digital health tools on the market, few comprehensively address the needs of HNHC patients, and even those that do tend to focus primarily on medically defined needs rather than acting as general advisors. Bridging the gap between understanding needs and developing a functional tool that meets those needs within the context of someone's life is challenging and involves testing different use cases, functions, and target groups before finding an optimal fit. The personas and prototype we developed helped elicit specific feedback from providers, payers, regulators, developers, and investors by making the problems and options more tangible. This highlighted a range of challenges related to trust, adoption, integration with workflows, value proposition for different stakeholders, and potential business models, moving beyond a narrow focus on end-user needs and technological features.

The insights gained from this project about current HNHC patients could be applied to vulnerable populations at risk of becoming HNHC patients (another target group for the

Commonwealth Fund) and even the general public. We found that the highest users of the healthcare system are interested in tools that can help them manage their health challenges, but more importantly, they seek tools that help them live their lives to the fullest. This is likely to be true for all patients, who not only prioritize disease management but also view health as a means to identify and work toward their life goals. An individual's health is closely intertwined with their psychological, social, and economic context, and truly useful digital tools will help people manage their needs comprehensively and holistically rather than focusing on a disease or issue in isolation. While this has not been a primary goal for health systems or a major focus of quality improvement efforts, it could be supported by consumer-facing tools that engage and empower individuals.

V. CONCLUSION

Understanding the needs of target users is crucial for designing a comprehensive digital health advisor. However, to bring this vision to fruition, we must also address broader system and policy constraints that will impact its development. User-centered design can draw attention to solutions that are technically feasible but lack a sustainable business model and may not align with current regulations. It helps reframe problems and propose solutions that may operate independently of existing services or processes.

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Moving forward, in the realm of IT-enabled consumer healthcare, we must explore the collaboration required between stakeholders such as healthcare delivery organizations, patients, caregivers, technology companies, government entities, and consumer advocacy groups. We also

need to examine the incentives and business models necessary to attract entrepreneurs and developers to work in this area, as well as to encourage health systems to engage with consumer-facing IT tools.

Given that system change is unlikely to originate from those currently within the system, the Commonwealth Fund is actively addressing policy and regulatory, business model, and cultural barriers to creating tools that prioritize patients and their goals at the center of the healthcare system.

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