What can AI do for me? - Facilitating participatory concept development with patients and clinicians

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Abstract: Ensuring participation and collaboration in digital health practices have been known to be inherently complex, especially when developing novel interventions. Existing knowledge and power asymmetries amongst different stakeholders have led to differing forms and modes of engagement, many of which are considered far from ideal. With the introduction of AI-based solutions into the mix, the challenges for HCI and PD researchers to incorporate diverse stakeholders into the digital health innovation process has become a considerable challenge. Through this short position paper, we examine the current state of participatory tools for AI-driven digital health, as well as discuss any limitations and opportunities contained therein.

CCS Concepts: • **Human-centered computing** → **Participatory design**; **Interaction design process and methods**.

Additional Key Words and Phrases: Digital health, Patient-centered, Artificial intelligence, Ideation

1 PARTICIPATORY DIGITAL HEALTH IN THE AGE OF AI

Patient-centricity and mutualistic approaches, such as shared decision-making, were introduced to ensure patient participation in healthcare, particularly to manage chronic conditions [1]. With the introduction of new technological tools such as wearable devices, patients were further equipped as experts of their own self-generated data, as well as their lived experiences, and encouraged to self-manage their own chronic conditions [2], in partnership with clinicians. The underlying assumption was that increasing patient participation in their healthcare would improve long-term health outcomes and reduce hospitalisation. This wave of sensors and wearables in digital health however brought its own challenges, viz. that of sensemaking, when dealing with large volumes of multiple, complex and dynamic data [11]. Following this trajectory, the next wave, of artificial intelligence (AI) based innovations, was seen as a way forward to make sense of this data deluge.

Despite any promises, the advent of AI in digital health has also been challenging, as new factors such as technological and AI literacy were added to the mix, affecting both patients and clinicians alike [18]. While an increasing potential to

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use AI in healthcare has been reported over the last years [6], rapid technological advancements also led to an "AI hype cocktail" which can make it difficult for patients, clinicians and other stakeholders to avoid falling into utopian and dystopian narratives and to understand how AI can be applied now and in the near future [21]. Continued participation through various means such as co-design or co-creation have been identified as one avenue to proceed. However, it is unclear how, when and where to include patients and doctors into the AI innovation process. In particular, as Delgado et al. aptly state, it is necessary to go beyond the seemingly simplistic notion to "add diverse stakeholders and stir" [7]!

2   AI LITERACY AND ITS LIMITS

Considering the increasing failure rates of AI projects (as high as 87 percent at times [5]) attributed to fundamental issues such as wrong 'problem selection and formulation' [23], HCI researchers proposed involving diverse stakeholders early in the innovation process. For example, when it comes to AI in digital health, this translates to the participation of patients and clinicians throughout the AI technology development process. Towards this goal, numerous AI literacy toolkits have been designed to introduce fundamental concepts to a nontechnical audience, enhancing involvement in co-design activities [20]. These toolkits were seen to encompass 4 themes (*Knowing and understanding*, *Using and applying*, *Creating and evaluating*, and *AI Ethics*) across projects and domains [15]. In digital health, many of these are primarily targeted towards clinicians, doctors and medical students [16]. Patient-centric solutions that address specific medical conditions or patient-clinician collaborations are yet to be widely designed, implemented or evaluated in real-world contexts.

From an HCI and PD perspective, '*Creating and evaluating*' are arguably the most important areas in AI innovation projects. Towards this, AI brainstorming toolkits that focus on communicating high-level AI capabilities to a wider audience have been developed by HCI researchers, for use in multiple domains. For instance, eight AI capabilities identified by Yildrim et al. are *Estimate*, *Forecast*, *Compare*, *Detect*, *Identify*, *Discover*, *Generate*, and *Act* [23]. Even though such brainstorming toolkits incorporate health and medical AI projects, amongst many other domains (as varied as stock markets and autonomous vehicles), they are not specifically built for use in digital health. Additionally, there is a need for patients to be aware of not just these high-level capabilities of AI systems (arguably a 'top-down' approach) but also incorporate key patient-facing factors such as digital tools and datasets, and how these are subsequently mapped on to AI models and capabilities, as part of an additional (and transparent) 'bottom-up' perspective. Hence there is a need to go beyond this one-size-fits-all approach to develop a toolkit specifically for the use of AI in digital health projects, that considers the needs and requirements of both patients and clinicians, enabling their participation in the innovation process alongside HCI researchers, product designers and technology developers, whilst acknowledging any inherent social, cultural or ethical concerns.

3   A PATIENT-CENTERED PD TOOLKIT FOR DIGITAL HEALTH?

Ensuring transparency in AI development is essential for allowing healthcare professionals and other stakeholders not only to understand an output from an AI system but also the reasoning behind the exercise. This level of understanding is important for decision making within healthcare settings, showing the importance of transparency in AI development to derive at causality [10]. Explanations of AI processes are important for building trust and enabling usability of these systems [14]. For AI to be effectively integrated both into patient-centric care and clinical practice there is a need for collaboration among developers, healthcare professionals, patients and other relevant stakeholders, not only to meet the needs of these differing stakeholders, but also to ensure reliability of the system in the context of a healthcare setting.

Participatory design (PD) has been described as a process of mutual learning between participants/stakeholders and designers [19]. Facilitating spaces for PD within digital health comes with several challenges such as clinicians' time constraints or adapting methods to patients' needs without adding to their 'treatment burden', for instance, due to varying fatigue levels [13]. A fundamental question from a facilitator perspective is when to include which stakeholder, especially when aiming for better problem selection and formulation/conceptualisation, the bane of AI project failures. Recent models for PD collaboration in healthcare account for including patients at different stages of the process but prioritise them only at initial stages, e.g., when gathering information or developing first concepts [12, 17]. These models include clinicians and technology designers at later stages and, consequently, foster patient-centered concepts that are validated with/by other relevant stakeholders. Other researchers have started to adapt the previously mentioned AI brainstorming toolkit [23] to the digital health context in an ideation session with clinicians that focused on AI-based opportunities to mitigate increased workload [9]. However, PD AI projects need to go beyond mundane administrative or organizational tasks and better align patients' needs with AI capabilities to enhance patient-centered concept development for improved use of AI-based tools, and better health outcomes.

4   DISCUSSION AND NEXT STEPS

Delgado et al. analyzed 80 research articles that include PD methods in the context of AI and found that only four of them involved participants in discussions "whether and why the [AI based-] system should be built" and only eight involved them in the "overall design of [the] system (e.g. task specification) [8]. This is in contrast to the previously outlined principle of engaging participants early in the process, especially in concept development. The low level of initial engagement could stem from project management or political considerations, or from prevailing co-design practices that typically focus on involving participants in designing the user interface [8]. In other words, the decision of whether and why to develop a system could already be taken when establishing a collaboration or applying for funding, or, simply not be addressed even when opportunities exist. This raises the question whether the envisioned patient-centered AI capabilities toolkit could foster earlier participant involvement, and if so, how could its design and scope cover diverse types of data and technology. Extrapolating Bratteteig and Verne's provocative question here, does AI in digital health make PD obsolete, and is participation even feasible or possible? [3] And if yes, what are the limits, opportunities and challenges?

As a potential way forward, we propose to create first an adapted version of the more general AI capabilities toolkit [23] through a literature review covering existing AI-applications in the area of digital health. Ambiguity in understanding the various shapes and forms of AI remains a considerable challenge [4] especially in the health domain where the types of (i) medical conditions, (ii) available tools and technologies, (iii) relevant datasets from these varied sources (which may overlap or even differ from clinically relevant data), and hence (iv) AI / ML technologies developed or used, can vary widely [22]. This version should begin to encompass such factors, towards increased transparency and a better understanding of the possibilities and (more importantly) the limits of AI. Second, we suggest to discuss the adapted version with different stakeholders to explore how and where such a toolkit could be used. Considering the typically low participant engagement [8] in fundamental questions about the system design, there is the need to understand how a patient-centered artefact could be framed to not only facilitate a better understanding of what AI can do but also serve as a gateway for deeper involvement across diverse stakeholders. Finally, evaluating and iterating on the toolkit with patients and clinicians throughout different case studies would contribute to a better understanding of its value and usability before using it in concrete AI-based digital health innovation projects.

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