Participatory Health and Artificial Intelligence: A Literature Review

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Abstract. *Introduction*: Participatory Health (PH) emerges as a consequence of the
rise of the internet, which has led to a patient-centered approach. Participatory
Health Informatics (PHI) uses information technologies and evaluates the use of
tools. The emergence of new Artificial Intelligence (AI) techniques represents a
great advance for PH. The objective of this article is to study the facilitators and
opportunities that AI offers to PH, but also the challenges and barriers it faces.
Methods: A literature review on barriers and facilitators of AI in PH was conducted,
including articles published in the last 10 years. *Results:* 38 articles were eventually
selected for review. Several aspects and applications of AI in PH were identified,
including health domains and types of participation; types of AI used; reported
barriers and challenges; facilitators and opportunities; impact on participatory
health; and ethical, legal and patient safety considerations. *Discussion and
conclusion*: 6 main thematic areas of interaction between AI and PHI were
identified. There is a wide variety of applications, with special impact on predictive
analysis, the management of healthcare data and conversational agents. Legal and
privacy issues are seen as the main barriers for the use of AI in PHI, whereas
improving diagnostic accuracy, optimizing patient flow, and patient empowerment
are considered the main opportunities.

Keywords. Participatory Health, Participatory Health Informatics, Artificial
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1.   Introduction

The rise of internet, social media and mobile technologies have enabled a paradigm shift in healthcare towards a person-centered approach, known as Participatory Health (PH), where people become proactive in all matters related to the health of an individual [1]. Using technologies, people are more engaged and empowered in their health conditions enabling their participation in the shared decision-making process. The role of technology in PH is essential and has led to the development of a new discipline, Participatory Health Informatics (PHI): "PHI is a multidisciplinary field that is applied to medical conditions, uses information technology, and studies the effects of the use of tools. PHI provides resources and delivers tools supporting active participation, and focuses on individual-centered care, individual-centered self-management, and individual-centered decision making. PHI also assesses accessibility, usability, individuals' technology acceptance, experience, and satisfaction, and tool appropriateness and quality" [2]. Artificial Intelligence (AI) techniques have been used for years in healthcare, with special emphasis on areas such as pattern recognition, management of medical records or analysis of the effectiveness of interventions. As of today, AI is used in a wide variety of health-related disciplines, from clinical decision support to self-care of chronic conditions at home [3]. AI can offer great advantages in PH, and its role was studied in Denecke et al.'s review [4]. The progress of technology has enabled the rise of Big Data, Large Language Models or Artificial Intelligence of Things, which has led to new technical, ethical and legal challenges [5-7].

The objective of this article is to study how AI is currently being used in participatory health, identifying barriers and challenges and trying to take advantage of facilitators and opportunities. We also analyze the impact of AI in participatory health, as well as the different ethical and legal considerations.

2.   Methods

To gain an overview of the articles published in the last 10 years on barriers and facilitators of AI in PH, we conducted a literature review. The search was performed on August 1st, 2024, across PubMed, IEEE Xplore, and Cochrane Reviews. We looked for publications that included terms related to "participatory health" and "artificial intelligence" in their titles or abstracts, as well as terms related to "barriers" and "facilitators" in the title. The identified references were uploaded to EndNote 20.6 and Rayyan for evaluation. Two authors assessed the eligibility of the publications based on the following criteria. **Inclusion criteria**: 1) The publication explicitly addresses any form of PH, where patients, users, healthcare professionals, or other stakeholders are actively involved in a health-related activity; and 2) The publication mentions any AI used in the context of PH-related activities. **Exclusion criteria**: 1) Publications that do not meet the inclusion criteria; 2) Abstracts or documents where the full text is inaccessible; 3) Publications in languages other than English, Spanish, or German; 4) Publications from 2013 or earlier.

Three authors extracted the following data from the selected articles: health domain; type of participatory health; type of AI; reported barriers and facilitators. Detailed information about this study can be found in a repository [8].

3. Results

In total, our database search yielded 608 results. After discarding duplicate records and reading the abstracts, 570 were excluded from this list. Overall, 38 articles were used for literature review. We identified a wide range of studies exploring various aspects and applications of AI in PH. Below is a detailed description of the key findings, categorized into thematic areas.

Health domains and types of participation: 50% of the studies addressed applications in general healthcare settings, while 30% focused on specific chronic diseases such as diabetes. The remaining 20% covered areas such as mental health and specialized fields such as urology and radiotherapy. Patient participation and the involvement of other healthcare actors vary significantly. Some studies focus on patient education and empowerment through self-management and AI-based tools such as conversational agents and virtual assistants. Others emphasize shared decision-making processes between patients and healthcare providers. In the area of telemedicine, AI has shown promise in improving operational efficiency and communication. Conversational agents can offer support in the management of stress and anxiety in older adults, showing an improvement in satisfaction and perceived quality [9]. The integration of AI in remote monitoring of chronic pathologies also shows encouraging results as it allows doctors to detect abnormal patterns and make quick decisions, improving the management of these diseases. However, Castelyn et al. (2021) report that, while algorithms have been effective in predicting chronic disease-related events, there is a lack of evidence on their overall impact [10].

Types of AI used. Various AI technologies are being used in PH: conversational agents, machine and deep learning used for predictive analysis and treatment personalization [11], natural language processing implemented in communication and diagnostic tools [12], big data analysis and automation of clinical tasks with the reduction of administrative burden and optimization of clinical workflow [13].

Reported barriers and challenges. Implementing AI in participatory health poses several challenges with resistance to change by healthcare professionals due to lack of familiarity and fear of being replaced as one of the biggest. 55% of studies highlighted technical issues, such as lack of interoperability between AI systems and existing healthcare infrastructures. The fragmentation of health data across multiple platforms and formats makes it difficult to consolidate the information needed for AI to work effectively. Developing and deploying AI systems can be expensive, limiting their adoption in resource-constrained environments. Furthermore, the technological infrastructure necessary to support these tools is not available in all regions, exacerbating differences in access to health. Using large volumes of data to train AI models is crucial, but poses challenges related to data quality, privacy, and equity [9]. Ethical concerns, including data privacy and the risk of AI systems breaching patient confidentiality, were reported in 60% of studies. Conversational agents and self-assessment tools can change the relationship between patients and care providers [14].

Facilitators and opportunities. Several enablers that could improve the adoption and effectiveness of AI in PH were identified. Educational initiatives aimed at improving digital literacy among health professionals were suggested in 50% of the studies as a fundamental step towards a successful integration of AI, through specific training programs for health professionals in the use of AI. At this point, continued education about the benefits and limitations of AI is crucial to encourage broader adoption. Additionally, 40% of studies recommended improvements in data security and

blockchain technology was cited as a promising solution to address privacy concerns. Another key opportunity lies in the development of easy-to-use AI tools that are compatible with existing clinical workflows (35% of the studies). Furthermore, empowering patients through education and active participation in health decision-making can drive the adoption of AI technologies. Informed and engaged patients are more likely to adopt and trust AI-based solutions.

Impact on participatory health. The application of AI in participatory health shows considerable potential to transform interactions between patients and providers and improve health outcomes. For example, studies show that AI tools can significantly improve doctor-patient communication, improving the accuracy and effectiveness of communication, reducing errors, and optimizing clinical time [14]. Approximately 40% of studies report decision support by facilitating shared decisions based on personalized data [15], resulting in improvements in patient participation and adherence to treatment plans. In chronic disease management, AI-powered predictive analytics has been shown to reduce hospital readmission rates by up to 25%, as noted in 30% of studies.

Ethical, legal and patient safety considerations. There are some ethical challenges, including privacy and equity in access [5]. The use of AI in personalized medicine and shared decision-making raises questions about transparency and informed consent [16]. Safe implementation of AI is critical to avoid risks associated with algorithm errors and automated decisions [17]. 25% of studies expressed concerns that AI could exacerbate health disparities, especially in underserved populations where access to the technology may be limited.

4.   Discussion and Conclusions

From the results of our analyses, 6 main thematic areas representing the interaction of AI and PH were identified. Our results showed that patient and other healthcare workforce involvement and participation shows a great variability due to the broad landscape of areas where AI is being developed and applied. This aspect is also reflected in the diversity of the AI technologies that are being applied where 70% of them are focused on predictive analysis and the management of healthcare data whereas conversational agents represent the remaining 30% and are closer to the patient involvement.

The main barriers for the implementation of AI are related with resistance of the workforce to change technical issues and infrastructure and ethical access and management of data. Those aspects are also identified with some of the ethical considerations identified which covered privacy and disparities which included technology accessibility. Safety is also an essential aspect of such technologies due to potential negative effects or harm. Issues such as the accuracy of data and outputs, performance, and bias of data or algorithms need to be carefully considered. Legal liability in the use of AI in health remains a controversial issue. The assignment of responsibility in cases of diagnostic errors or inadequate treatments is not clearly defined, which could discourage the adoption of these technologies by health professionals.

On the other hand, the training of health professionals is identified as an opportunity and facilitator for the successful use of AI. The use of AI with personalized data was identified as a contributor to the improvement patient participation which was an aspect also identified as an opportunity. AI has the potential to revolutionize healthcare by improving diagnostic accuracy, optimizing patient flow, and patient empowerment. To

fully realize these benefits, it is essential to address the technical, ethical and social challenges associated to AI. However, the analysis also reveals the need for more research to evaluate the long-term impact of AI technologies on PH, particularly about their effectiveness, equity, and potential unintended consequences of adoption.

In conclusion, despite some technical and ethical barriers and challenges that are being addressed, AI is already a major player in the development of novel PH solutions and it is expected that its contribution to the field will keep growing in the future.

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