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Exploration of the Voice of the Patient in Learning Health Systems: A Socio-Technical Perspective

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Abstract. Despite learning health systems' focus on including the patients in improving healthcare services, research shows they are still considered participants, not partners. This article aims to provide practical guidance for recognizing and including the Voice of the Patient (VoP) as data in a continuous LHS by describing how the VoP can present itself, how it can be incorporated into the LHS and the barriers and enablers for doing so. Five key domains were identified to consider when including the patient perspective. The use of technology could be a facilitator for patients to provide their perspectives. However, there is a risk of increased health inequity by reducing the VoP of patients with low health or digital literacy.

Keywords. Learning health systems, patient voice, health equity, co-design

1. Introduction

A growing body of literature recognizes that including the patient perspective in developing healthcare services, the Voice of the Patient (VoP), can lead to increased effectiveness, patient-perceived quality of care, and reduced hospital admission [1]. Conventionally, the VoP has been interpreted within a biomedical framework, where the patient's illness is defined by symptoms [2]. Today, the patient perspective is recognized as providing an opinion when a healthcare service is developed and as a resource to guide patient-provider interaction [1]. However, some patients' voices are less influential in healthcare service development due to issues related to equality, such as gender, culture, income, or the nature of their impairments [3].

A healthcare improvement model, Learning Health Systems (LHS), has been considered particularly well-suited for including the VoP in healthcare service design. An LHS can collect, analyze, and present health data for various purposes, enabling more informed decision-making and long-term learning [4]. At a macro level, including the VoP across disciplines and healthcare organizations can provide the potential for policy changes. At a meso level, the VoP can be included in multiple data sources to

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develop shared knowledge and new praxis. At a micro level, including the VoP as knowledge when improving healthcare services can support the empowerment of patients and improve the quality of care [5].

Limited literature has explored the barriers and enablers to engaging patients in an LHS, even though low levels of participation can hamper the transformational potential [7]. There seems to be a lack of practical guidance for recognizing and including VoP as data in a continuous LHS or evaluating the effect [8]. This study reviews existing research to 1) identify and examine how the patient voice is incorporated in LHS research, 2) identify barriers and enablers for including the patient voice, and 3) suggest an approach to meet these challenges.

2. Methods

A literature review was conducted to examine the breadth and depth of available literature in the field of LHS. The academic databases PubMed, Scopus, and Web of Science were searched from 2012 to 2022 in title and abstract. All searches included variations of the term "Learning health system", "implementation", "patient", and "participation" to ensure the results included patient-centric, implemented LHS. The Scopus search string was: (TITLE-ABS-KEY ("learning health*") AND TITLE-ABS-KEY (implement*) OR TITLE-ABS-KEY ("case study") AND TITLE-ABS-KEY (multi-organizational) OR TITLE-ABS-KEY (inter-organizational) OR TITLE-ABS-KEY (cross-sectoral) OR TITLE-ABS-KEY (integrat*) AND (patient) AND PUBYEAR > 2011). Search strings for PubMed and WoS were in accordance.

3. Results

The search returned 140 journal articles. The few studies of implemented LHSs led to the inclusion of planned and historical implementations. A total of 118 articles were excluded due to lack of patient involvement or not being in English. Of the remaining 22 articles, 10 discussed conceptual ideas for including the VoP in developing LHSs, and 12 referred to actual implementations. The findings were organized into five domains, patient voice, outcomes, partnership, technology, and ethics.

The patient perspective was addressed using various sources. A total of 17 articles (77%) included the VoP directly, commonly through patient-reported outcomes or experience measures (PROMs and PREMs) at a single point in time [4,9-24]. The VoP was also presented indirectly through patient advocates, clinical data from care visits or clinical registries, where five studies (23%) relied on historical data without direct patient engagement [25-29]. Two articles (9%) emphasized the need for an analytical discussion about the content of patient-centric «health data» [19, 21].

Measurable outcomes such as clinical outcomes and cost-effectiveness were found in nine articles (41%) [11,13,16,20,22,23,25,26,29]. Patient engagement metrics were included in three studies (14%) [11,22,26]. However, six articles (27%) emphasized incorporating metrics in future research [10,19,23,25,27,28]. Four studies (18%) discussed the need for research to demonstrate whether including VoP improves patient-perceived quality of care [9,19,23,25].

Most studies highlighted the importance of involving VoP in LHS research. In 18 (82%), the patient actively contributed data to design or evaluate LHS interventions or the LHS program [4,9,10,12-19,23-29]. Four studies (18%) engaged patients as research partners in co-designing health services [11,20-22]. Enablers for developing the patient-provider-researcher relationship included clearly outlining how the VoP could enhance care delivery, management support to foster a culture for including VoP in service improvement, financial incentives and training for healthcare professionals and patients on developing the LHS and utilizing VoP data. Three studies (14%) included inter-organizational LHSs [13,23,29]. In three studies (14%), the level of patient participation was identified as a limitation [9,10,12].

Seventeen studies (77%) emphasized technology's importance in collecting, organizing, and sharing VoP through LHS [4,9-11,13-15,17-24,26,27]. Patient portals were the most cited solutions for patients to self-report health status and care experiences. However, seven studies (32%) recognized technology's potential to exacerbate health disparities by reducing VoP of patients with low health or digital literacy [4,17-19,22,25,27]. Only one study explored using mobile health and wearables, such as smartwatches, as a new source for VoP data [24].

Five studies (23%) addressed the ethical implications of including VoP in LHSs [12,21,23,25,27], emphasizing diversity and acknowledging patient needs.

4. Discussion

The findings indicate that incorporating VoP into LHS research requires caution. All studies included "snapshots" of the patient perspective, which could be misleading as health conditions and experiences can change over time. However, continuously contributing to a long-term learning process could burden vulnerable patients.

As the ultimate objective of an LHS is to transform and improve healthcare, it is crucial to include quantified outputs to ensure actual value is added to patients. Including VoP is rare in LHS research, and the studies indicated the urgent need for such indicators in the future, as it would legitimize patient contributions.

Despite all articles recognizing the need for patient engagement, only a few studies included the patient in deciding outcomes, co-designing, learning, and sustaining health services. Human factors such as participation benefits and professional norms influence the patient-provider-researcher partnership in LHS research. Clinical and operational leaders play a vital role in building a culture that values the inclusion of the VoP in continuous learning, supports patient and clinician engagement and funds their participation. Additionally, new skills and research methods are needed to understand, recognize, include, and benefit from the resource the VoP represents.

Many studies emphasized exploring technology and improving data access as enablers to support the inclusion of VoP in LHS research. A structured format and system support for automatic data capturing were essential to present a broad spectrum of voices and actionable information to the right stakeholder at the right time, regardless of where or when it was generated, shortening the time from gathering data to creating new knowledge and changing praxis. Online patient portals were identified as cost-efficiently facilitators of broader patient participation, reducing health inequity, and providing high-quality patient-provided data for fact-based decisions. However, technical solutions must be flexible enough to include emerging "new voices".

Finally, the results highlight the need for an ethical framework that actively involves patients and families as collaborators, provides the necessary understanding and sensitivity regarding patient needs and expectations and guides learning activities.

5. Conclusions

This study provides novel insights into the ways the VoP can be expressed and the barriers and enablers for incorporating it in the continuous learning of an LHS. However, there is a risk for the lack of research on actual implementations of LHSs, especially across multiple healthcare levels, by biasing the literature search results.

In conclusion, patient engagement in LHS decision-making processes needs to be increased; however, it requires caution and considering patients' changing health conditions and experiences. Quantified outputs are necessary to ensure the actual value of providing the VoP is added for patients, and indicators to legitimize patient contributions are needed. At the same time, clinical and operational leaders play a vital role in developing a culture that supports patient and clinician engagement. Technical solutions and improved data access are essential to support the inclusion of the VoP, but must be flexible to include emerging "new voices". An ethical framework is also needed to guide collaboration and learning activities.

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