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

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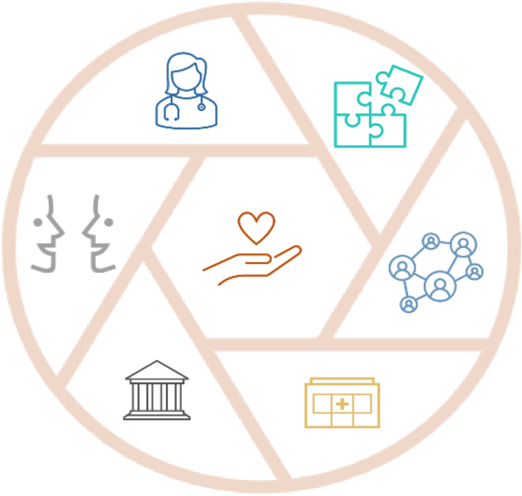
The Voice of the Patient in Learning Health Systems



Introduction

Definition

Benefits

Problem and goal

Findings

Enablers

Patient Participation

Measurable outcomes

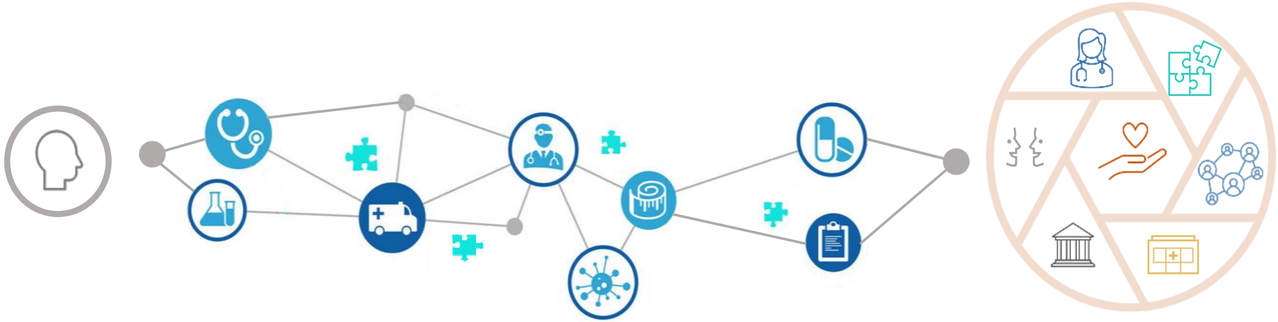
Ethical framework

Patient partnership

Technology

Summary

Introduction



Definition

VoP: A person's perspectives, experiences and preferences regarding their care journey, treatment outcomes, and healthcare system.
LHS: Learning health system integrates internal data and experience with external evidence and puts that knowledge into practice.

Benefits

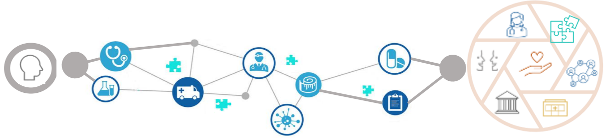
Individual level (micro): Empowering patients and improving the quality of care.
Organizational level (meso): Developing shared knowledge and new practices.
System level (macro): Uncovering systemic barriers to inform policy changes.

Problem and goal

There is limited research on how to include the patient voice in Learning Health Systems (LHS) or the barriers and enablers for doing so.

The goal of this study is to suggest an approach to meet these challenges

Findings



Patient participation

VoP was included directly in research projects (77%), mainly at a single point in time. However, illness, needs, and expectations evolve. Longitudinal participation increases the burden on vulnerable patients when continuously reporting and contributing to long-term learning processes.

Measurable outcomes

k of measurable outcomes, such as quantifiable metrics for patient participation and engagement to ensure patient-perceived value is added. Only 14% of the included studies used patient engagement metrics

Partnership

Lack of true partnership: the VoP was commonly represented by patient representatives providing initial input or evaluating an plemented service. Patients were rarely active research partners, deciding outcomes, co-designing and sustaining healthcare services (18%).

Technological

Unstructured data and fragmented electronic health record (EHR) systems hinder sharing and integrating the VoP across healthcare settings (77%). Technical solutions are not flexible enough to include emerging "new voices".

Ethical

Some patients' voices are less influential due to factors such as the nature of their impairments, lower health or digital literacy. 32% of studies addressed the risk of health disparities

Enablers

Patient Participation

Provide various ways patients can participate in continuous improvement, such as patient portals for self-reporting.

Ethical framework

Develop an ethical framework for actively involving patients and family members as collaborators, providing understanding and sensitivity regarding patient needs and expectations

Measurable outcomes

Clearly outline the benefits and how the
nhance care delivery. Encourage a
ding VoP in service improvement and
the financial incentives for doing so

Patient partnership

Develop new skills and research methods to aid patients, healthcare professionals and managers effectively recognize, include, understand and benefit from the resource the VoP represents.

Technology

Utilize new sources of VoP, such as
ealth, wearables, and social media.
VoP data so it can be easily collected, organized and
shared throughout the LHS.

Summary

- Simplify participation
- Quantify goals for patient engagement
- Engage patients throughout the research process
- Develop a culture for including the VoP
- Use multiple sources of VoP data and available technology for collection and sharing
- Be sensitive to patients' needs

Limitations
The lack of research on actual implementations of LHSs, especially across multiple healthcare levels, could bias the search results

Thank you!

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