



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

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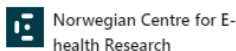
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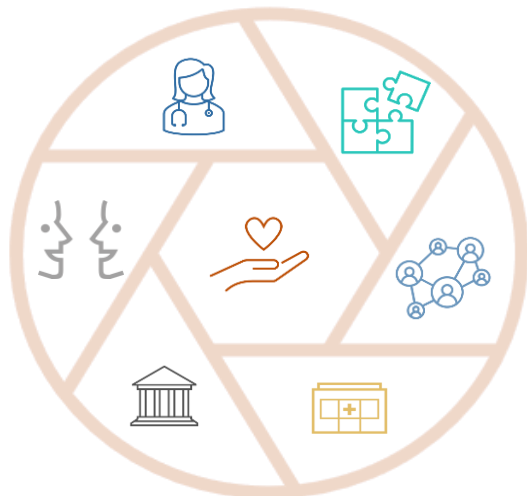
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The Voice of the Patient in Learning Health Systems



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INTRODUCTION

Definition
VLP: A patient's perspective, experience and preferences regarding their care journey, treatment outcomes, and healthcare system.

Benefits
Enhanced trial process, Empowering patients and improving the quality of care.

Problem and goal
Need to better understand 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 explore an approach to meet these challenges.

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ENABLERS

Patient Participation
Provide various ways patients can participate in coordination, implementation, such as patient advisory boards for self-experiment.

Patient partnership
Develop new skills and research methods to aid patients, boost their confidence and maximize efficiency, engagement, results, understand and benefit from the research the VLP represents.

Clinical framework
Develop an ethical framework for action involving patients and build capacity for implementation, understanding and managing patient needs and experiences.

Measurable outcomes
Clearly define the benefits and how the VLP could influence cost, delivery, efficiency and so on. For example, VLP is a cost reduction and it is financial incentives for doing so.

Technology
Utilize new sources of VLP such as mobile health, wearables, and social media. To achieve this data set it can be easily collected, organized and shared throughout the LHS.

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FINDINGS

Patient participation
VLP was included directly in research projects (70%), mostly at a single point in time. However, plans, needs, and experiences of patients' involvement increases the number of activities patients were consulted before and after completion to provide better patient.

Measurement outcomes
LHS or implementation outcomes, such as implementation of VLP or patient participation, were not measured. Only cultural and structural enablers were assessed.

Partnership
Lack of time, partnership, the VLP was considered as a barrier to patient participation, providing a critical input in evaluating an implementation strategy. Patients participating in research projects, such as patient advisory boards, were not measured.

Technology
Implementation outcomes (implementation outcomes) were not measured. Only cultural and structural enablers were assessed.

Effect
The evidence shows patient participation is a barrier to the culture of implementation. Some health systems (e.g., NHS) or regions (e.g., NHS) have implemented the use of health systems.

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SUMMARY

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

Conclusion
The use of VLP in research is a challenge. Implementation of VLP, especially across multiple health systems, could help the research results.



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 Lack 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 implemented 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



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

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.

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

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

- Utilize new sources of VoP, such as health, wearables, and social media.
- Integrate 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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