Patient engagement in health education curriculum: A scoping review

Scoping Review

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Prepared By:
Sears, K.[1], Belbin, S.[2], Ermel, D[3], Skrapek, C. [3], Richan, B.[4], Ross-White, A. [1,5], & Godfrey, C. [1]

1. JBI Queen's Collaboration for Health Care Quality, School of Nursing, Queen's University, Kingston, Ontario, Canada
2. British Columbia Institute of Technology, School of Health Sciences, School of Nursing, Burnaby, British Columbia, Canada
3. Saskatchewan Centre for Patient-Oriented Research, Patient Advisors Network, University of Saskatchewan, Regina, Saskatchewan, Canada
4. School of Nursing, Queen's University, Kingston, Ontario, Canada
5. Bracken Health Sciences Library, Queen's University, Kingston, Ontario, Canada

Contact:
Dr. Kim Sears

Email: searsk@queensu.ca

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SPOR Evidence Alliance operates from the St. Michael's Hospital, Unity Health Toronto which is located on the traditional land of the Huron-Wendat, the Seneca, and the Mississauga's of the Credit. Today, this meeting place continues to be home to many Indigenous Peoples from across Turtle Island.

We are grateful to have the opportunity to work on these lands.

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Project Contributors

Dr. Kim Sears, JBI Queen's Collaboration for Health Care Quality, School of Nursing, Queen's University, Kingston, Ontario, Canada, Co-*Principal Investigator*

Sam Belbin, British Columbia Institute of Technology, School of Health Sciences, School of Nursing, Burnaby, British Columbia, Canada, *Patient Partner and Co-Investigator*

Candace Skrapek, Saskatchewan Centre for Patient-Oriented Research, Saskatchewan Health Authority, University of Saskatchewan, Saskatoon, Saskatchewan, Canada, *Patient Partner,* Co-*Principal Investigator*

Diana Ermel, Saskatchewan Centre for Patient-Oriented Research, Patient Advisors Network, University of Saskatchewan, Regina, Saskatchewan, Canada, *Patient Partner,* Co-*Principal Investigator*

Beth Richan, School of Nursing, Queen's University, Kingston, Ontario, Canada, *Co-Investigator*

Amanda Ross-White, Bracken Health Sciences Library, Queen's University, Kingston, Ontario, Canada, *Library Scientist*

Dr. Christina Godfrey, JBI Queen's Collaboration for Health Care Quality, School of Nursing, Queen's University, Kingston, Ontario, Canada, *Methodologist*

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Abbreviations and Definitions

Key Definitions

Patient Partners: people with lived expertise, or experience, of a health condition.[1]

Abstract

Objective: In 2015, following an international conference, The Vancouver Statement was issued identifying nine priorities for action to "embed patient involvement in the education and health and social care professionals".[2] This scoping review, initiated by patient partners, was undertaken to reveal why the call to action to "embed patient involvement in the education and health and social care professionals" has not been widely implemented. *Inclusion Criteria*: This review focused on patient partners which are defined as people with lived expertise, or experience, of a health condition.[1] Existing patient partner engagement in curriculum planning, implementation, and evaluation of patient-centered care education and health curriculum delivery. Studies from all countries were included in the search strategy to ensure a broad focus. *Methods*: The scoping review was conducted in accordance with the JBI methodology for scoping reviews.[3] An initial search approach was employed to locate published studies. A preliminary search was conducted in Ovid MEDLINE and reviewed by the whole team. From this initial search, a more comprehensive search was developed for Ovid MEDLINE and translated to Ovid Embase, Ovid EBM Reviews for Cochrane Central Register of Controlled Trials (CENTRAL), Scopus and CINAHL (EbscoHost). *Results*: One hundred and thirty-eight papers were included from 21 countries. These studies were published between 1978 and 2025 with 61% of studies published in the last 10 years and 91% within the last 20 years. The review showed the need for a recommitment to intentional strategies to overcome systemic barriers, institutional initiatives led by champions in the academic community, adequate resources, and fostering respectful, collaborative relationships. *Conclusion*: The inclusion of patient partners as co-educators enriches health education curricula but a conscious recommitment to the nine priorities for action is required to fully embed patients and families in the academic processes.

Executive Summary

Objectives: This scoping review was undertaken to understand the issues involved in the engaging of patients in the education of health and social care professionals.[2] The question driving the review was: What are the governance structures and processes needed to ensure that patients, families and communities are engaged as partners in the co-design, implementation, and evaluation of health education curricula? The sub-questions are: (1) What are the attitudinal barriers and how can they be overcome; (2) What are the facilitators that support engagement, and (3) How can a cultural shift of healthcare and education towards patient-centered care be supported?

Design: A scoping review was used to determine the existing research related to patient partner engagement in health education curriculum planning, implementation, and evaluation. Studies from all countries were included in the search strategy to ensure a broad focus.

Method: The scoping review was conducted in accordance with the JBI methodology for scoping reviews.[3] An initial search was conducted in Ovid MEDLINE and reviewed by the whole team. From this initial search, a more comprehensive search was developed for Ovid MEDLINE and translated to Ovid Embase, Ovid EBM Reviews for Cochrane Central Register of Controlled Trials (CENTRAL), Scopus and CINAHL (EbscoHost).

Results: In this review there were 138 papers included from 21 countries. Publication years for these studies ranged from 1978 to 2025, with 61% of studies published in the last 10 years and 91% within the last 20 years. There were many perspectives found in the papers, with the majority coming from patient partners themselves (n=49), researchers (n=70), and academic institution decision-makers (n=45). The engagement of patients and communities primarily occurs within post-secondary educational institutions (n=99), reinforcing the central role of academic environments in formalizing patient partnerships. In terms of curriculum development stages, most studies involved developing new materials (n=56) and redesigning old materials (n=41), demonstrating a focus on iterative improvement and innovation. Co-design approaches such as co-developing new courses (n=9) and co-redesigning existing courses (n=3) were less common, suggesting that while engagement exists, full co-production remains limited. Only five articles described fully embedded patient engagement (n=5), indicating that sustained, institutionalized governance structures for co-design are still emerging. The literature identifies a range of structural barriers that impede meaningful engagement of patients, families, and communities in the co-design, implementation, and evaluation of health education curricula. These barriers span systemic, institutional, and interpersonal levels and highlight both practical and attitudinal challenges to sustained collaboration. Despite a variety of barriers to patient, family, and community engagement in health education, the literature overwhelmingly highlights support systems as the most critical facilitator. However, limited attention to other potential enablers, such as policy, cultural factors, or environment, points to missed opportunities for strengthening engagement through a more holistic and strategic approach.

Conclusion: This scoping review compiled information related to the facilitators and barriers to the authentic engagement of patient partners in healthcare education. The inclusion of patient partners as co-educators enriches health education curricula but there needs to be a recommitment to the nine priorities of the Vancouver Statement of 2015. Action is required to engage patients and families in academic processes. This includes intentional strategies to overcome systemic barriers, institutional commitment led by champions in the academic community, adequate resources, and fostering respectful, collaborative relationships.

Introduction

Authentic engagement of patients and families as equal collaborators in patient-provider interactions and across all levels of a healthcare organization is essential for better health outcomes, improved care experiences, and controlled healthcare costs. In 2015, following an international conference, The Vancouver Statement was issued identifying nine priorities for action to “embed patient involvement in the education of health and social care professionals”.[2] The statement highlights the vital role of incorporating patients' lived experiences into healthcare education, emphasizing that this approach is key to preparing professionals to deliver patient-centered care. The priorities related to policy were believed to be most critical to bring about real change that would see patient-oriented programs that will provide future practitioners with the ability to provide genuine patient-centered care.[2]

Despite this call to action, health education curricula continue to lack mechanisms to engage providers, patients, and families in the co-design, implementation, and evaluation of health education curricula. Currently, health education programs primarily teach patient- and family-centered care without involving patients as partners, missing valuable perspectives.

A scoping review was undertaken. To reveal why these calls to action have not been widely implemented.

Review Question

The review question guiding this review was: What are the governance structures and processes needed to ensure that patients, families, and communities are engaged as partners in the co-design, implementation, and evaluation of health education curricula? The sub-questions are: (1) What are the attitudinal barriers and how can they be overcome; (2) What are the facilitators that support engagement, and (3) How can a cultural shift of healthcare and education towards patient-centered care be supported?

Inclusion Criteria

Participants: This review focused on patient partners who are defined as people with lived expertise or experience of a health condition.[1]

Concept: Existing patient partner engagement in curriculum planning, implementation, and evaluation of patient-centered care education and delivery.

Context: Studies from all countries were included in the search strategy to ensure a broad focus.

Types of Sources: This scoping review considered both experimental and quasi-experimental study designs including randomized controlled trials, non-randomized controlled trials, before and after studies, and interrupted time-series studies. In addition, analytical observational studies, including prospective and retrospective cohort studies, case-control studies and analytical cross-sectional studies, were considered for inclusion. This review also considered descriptive observational study designs, including case series, individual case reports and descriptive cross-sectional studies for inclusion. In addition, systematic reviews that met the inclusion criteria were also considered, depending on the research question. Text and opinion papers were also considered for inclusion in this scoping review.

Methods

The scoping review was conducted in accordance with the JBI methodology for scoping reviews.[3] An initial search approach was employed to locate published studies. A preliminary search was conducted in Ovid MEDLINE and reviewed by the whole team. From this initial search, a more comprehensive search was developed for Ovid MEDLINE and translated to Ovid Embase, Ovid

EBM Reviews for Cochrane Central Register of Controlled Trials (CENTRAL), Scopus and CINAHL (EbscoHost). All databases were searched from inception to February 2025, and no language or date restrictions were applied.

Results

Article summary

The number of search results from all databases and information sources searched was 4613. The number of records after removing duplicates in Covidence systematic review software was 3576. The total number of records identified for each database and information source is provided in Appendix 1. Search strategies for each database and information source searched are presented in Appendix 2. The final set of included studies comprised 138 studies. The PRIMSA chart can be found in Appendix 3. Data was extracted from papers included in the scoping review by two or more independent reviewers using a data extraction tool developed by the reviewers (Appendix 4).

There were 138 papers included that met the inclusion criteria.[8-145] Most studies in this review were qualitative (n=52), text and opinion (n=13), systematic reviews (n=12), and literature reviews (n=12). Within the set of 47 quantitative studies, the range of study designs included: randomized control trials (n=9), cross sectional (n=6), case control (n=5), descriptive (n=5), program evaluations (n=5), mixed methods (n=4), non-randomized experimental (n=4), analyses (n=3), pilot (n=2), observational (n=1), delphi technique experiment (n=1), and unspecified (n=4).

A total of 21 countries were found as study locations. In descending order, the number of countries are as follows: United Kingdom (n=49), Canada (n=28), United States of America (n=26), Australia (n=6), Netherlands (n=6), Ireland (n=5), France (n=2), New Zealand (n=2), Switzerland (n=2), Brazil (n=1), Denmark (n=1), Germany (n=1), Italy (n=1), Malaysia (n=1), Norway (n=1), the Philippines (n=1), South Africa (n=1), Spain (n=1), Sweden (n=1), Syria (n=1), and Uganda (n=1). Publication dates of the studies included in this review range from 1978 to 2025 with 61% of studies published in the last 10 years and 91% within the last 20 years.

For clarity in reporting results, articles will be classified under the research question and sub-questions posed to guide the scoping review.

***Question 1**: What are the governance structures and processes needed to ensure that patients, families and communities are engaged as partners in the co-design, implementation, and evaluation of health education curricula?*

1. Who are the patient partners?

The literature demonstrates a broad spectrum of patient partners engaged in health education curriculum processes. Most commonly, patients themselves were involved (n=43) [8, 9, 11-13, 15, 18, 19, 26, 28, 30, 35, 40, 45, 46, 54, 57, 61, 62, 65, 67, 68, 70, 77, 79, 80, 92, 93, 95, 110, 117, 120, 125, 128, 131, 132, 135, 136, 138, 139-141, 145], suggesting a growing emphasis on integrating lived experiences directly into curriculum development. Followed by individuals with lived experience which might have involved families and others (n=28) [10, 16, 24, 34, 36, 42, 43, 56, 63, 69, 74, 75, 83, 91, 98, 102, 104, 107-109, 111, 113, 115, 118, 123, 130, 137, 144] and patient educators (n=24) [21, 23, 25, 27, 29, 31-33, 37, 48, 49, 52, 60, 64, 71, 76, 86, 96, 97, 99-101, 112, 126], indicating that both formal and informal patient roles contribute to educational reform. Notably absent were patient family members, citizen engagement, and patient community collaborators, highlighting a gap in inclusive governance that could integrate broader community and familial perspectives. The presence of "other" categories (n=43) [14, 17, 20, 22, 39, 41, 44, 47, 50, 51, 53, 55, 58, 60, 66, 72, 73, 78, 81, 82, 84, 85, 87-90, 94, 103, 105, 106, 114, 116, 119, 121, 122, 124, 127, 129, 133, 134, 142, 143] in the literature underscores diversity in partner roles, possibly including advocates, community representatives, or nonidentified contributors. This signals an emerging need for clearer role definitions and structures for engagement across the patient-family-community spectrum.

2. What types of health program educators and professionals are involved?

Governance for patient and community engagement in curriculum design is shaped by a multidimensional academic and clinical team. Academic educators (n=73) [9, 10, 12-14, 16, 18, 20, 21, 23, 25-28, 31-34, 36-38, 40, 42, 43, 51-53, 55, 56, 58, 61-64, 66, 67, 71-73, 75, 76, 78, 80-82, 84, 87-92, 94, 96, 97, 100, 102, 106, 107, 111, 114, 116, 118, 119, 121-124, 126-128, 134, 135, 144, 145] were more frequently involved than clinical educators (n=43) [11, 22, 24, 29, 30, 35, 39, 45, 46, 49, 54, 57, 59, 60, 65, 68-70, 76, 77, 83, 85, 93, 95, 99, 101, 103-105, 108, 112, 115, 117, 131, 133, 136, 137, 139, 140, 142, 144], with some instances of joint academic-clinical collaboration (n=13) [17, 41, 47, 50, 86, 98, 113, 120, 125, 129, 130, 141, 143]. This indicates that although co-design is rooted in educational settings, bridging to clinical practice remains essential.

From a professional perspective, physicians (n=42) [8, 15, 23, 26, 33-35, 39, 41, 46, 47, 50, 52, 58-60, 65, 68, 71, 72, 76, 80, 83, 87, 90, 93, 96, 100, 101, 104, 110, 114, 116, 120, 131, 133, 136, 137, 139-141, 144] were most represented among health professionals, suggesting leadership roles in curriculum governance. In contrast, nurses (n=8) [16, 43, 54, 69, 82, 84, 85, 125] and therapists (n=0) were underrepresented, pointing to a possible discipline-specific imbalance in governance inclusion. A large contingent of "other" health professionals (n=88) [9-14, 17-22, 24, 25, 27-32, 36-38, 40, 42, 44, 45, 48, 49, 51, 53, 55-57, 61-64, 66, 67, 70, 73-75, 77-79, 81, 86, 88, 89, 91, 92, 94, 95, 97-99, 103, 105-109, 111-113, 115, 117-119, 121-124, 126-130, 132, 134, 135, 138, 142, 143, 145] were involved, reflecting interprofessional engagement and potential for broad collaboration when governance models are inclusive.

Moreover, researchers (n=70) [8, 10-12, 14-18, 22, 23, 24, 26, 28, 32, 35, 38, 41-45, 47, 49-51, 53, 56, 58-60, 62, 64-67, 69, 70, 72-74, 82-85, 88, 89, 92, 93, 97, 104, 105, 109, 110, 114, 116-118, 123-126, 128, 129, 131, 133-135, 138-140, 145] and academic institution decision-makers (n=45) [9, 13, 20, 21, 25, 29, 30, 31, 36, 39, 46, 52, 54, 55, 63, 68, 71, 75, 77, 78, 80, 81, 86, 87, 90, 94-96, 103, 106, 107, 111, 112, 115, 119, 120, 127, 132, 136, 141-144] played key roles, indicating that curriculum governance structures often include individuals with institutional authority and research expertise. However, representation from professional regulatory bodies (n=5) [19,34,61,108,113] and other stakeholders (n=18) [27, 33, 37, 40, 48, 57, 76, 79, 91, 98-102, 121, 122, 130, 137] was limited, suggesting an area for improvement in policy-level and systemic stakeholder inclusion to ensure sustained, accountable co-design efforts.

3. What environments and stages of curriculum development are involved?

The engagement of patients and communities primarily occurs within post-secondary educational institutions (n=99) [8-10, 12, 13, 16, 18, 20, 21, 23, 24, 26-34, 36, 37, 39, 42-44, 46-49, 51, 53, 55, 56, 59, 61, 63-76, 78, 80-82, 84-102, 104-109, 111, 114, 115, 119, 121, 123, 124, 126-129, 131, 132, 134-136, 141-145], reinforcing the central role of academic environments in formalizing patient partnerships. Engagement in hospitals (n=15) [11,14, 22, 35, 50, 52, 54, 62, 103, 112, 116, 117, 120, 125, 138] and other settings (n=24) [15, 17, 19, 25, 38, 40, 41, 45, 57, 58, 60, 77, 79, 83, 98, 110, 113, 118, 122, 130, 133, 137, 139, 140] such as community spaces or professional associations was less frequent, implying opportunities to extend co-design practices beyond academic walls into care delivery and community spheres.

In terms of curriculum development stages, most studies involved developing new materials (n=56) [10, 13-15, 19, 21-23, 25, 31, 32, 37, 38, 41, 43, 46-48, 51, 52, 55, 63, 65, 76, 82, 83, 87, 88, 93, 94, 99-103, 106, 108, 115-118, 120, 122, 124-127, 129, 131, 134, 135, 137, 139, 141, 143, 144] and redesigning old materials (n=41) [8, 11, 12, 16-18, 34, 35, 39, 40, 42, 53, 54, 56, 57, 61, 62, 68, 70-74, 78, 81, 86, 92, 95-98, 104, 105, 107, 109, 113, 123, 128, 132, 136, 138], demonstrating a focus on iterative improvement and innovation. Co-design approaches such as co-developing new courses (n=9) [24, 26, 58, 69, 75, 85, 91, 133, 140] and co-redesigning existing courses (n=3) [66, 90, 119] were less common, suggesting that while engagement exists, co-production remains limited. Only five articles described fully embedded patient engagement (n=5) [29, 33, 50, 60, 64], indicating that sustained, institutionalized governance structures for co-design are still emerging.

The "other" category with regard to environment and stages of curriculum development (n=22) [9, 20, 27, 28, 30, 36, 44, 45, 49, 59, 67, 77, 79, 80, 84, 89, 110-112, 114, 130, 142] and not identified (n=2) [121, 145] suggest a lack of clarity in the research or reporting on these topics. In some studies, there is a pointing to the need for standardized frameworks for documenting patient and community engagement in education.

Sub-Question 1*: What are the attitudinal barriers and how can they be overcome?*

The literature identifies a range of attitudinal barriers that impede meaningful engagement of patients, families, and communities in the co-design, implementation, and evaluation of health education curricula. These barriers span systemic, institutional, and interpersonal levels and highlight both practical and attitudinal challenges to sustained collaboration.

1. Lack of Awareness and Support Systems

The most reported barriers were lack of awareness (n=49) [14, 20, 22, 24, 25, 29, 30, 35, 37, 40, 43, 44, 47, 48, 50-52, 56, 66, 71, 74, 81-85, 87, 88, 90, 91, 93, 94, 99-101, 103, 104, 106-110, 113, 114, 116, 118, 120, 125, 128] and lack of a support system (n=37) [9, 10, 13, 15, 16, 19, 21, 26, 28, 31-33, 42, 46, 55, 60, 70, 72, 73, 75, 76, 78, 89, 95, 117, 119, 121, 126, 130, 132-135, 138-141]. Lack of awareness refers to insufficient understanding among educators and institutions about the value, methods, and outcomes of involving patients and community members in curriculum development. This barrier may result in tokenistic involvement or complete omission of community voices.

Closely linked is the absence of institutional support structures, such as clear engagement frameworks, mentorship for patient partners, or dedicated roles and resources to facilitate participation. Without these mechanisms, patient involvement can become inconsistent, burdensome, or ineffective.

Overcoming these barriers requires:

- Formal training and orientation for educators and institutional staff on patient and community engagement.
- Establishment of governance frameworks that institutionalize engagement as a core function.
- Ongoing capacity-building for patient partners, including mentorship and compensation.
- Inclusion of engagement expectations in accreditation or program evaluation standards.

2. Cultural Barriers and Stigma

Cultural barriers (n=4) [34, 67, 92, 127] and stigma or negative attitudes (n=2) [38, 69] were also reported, though less frequently. These barriers may stem from differences in values, communication styles, or educational backgrounds between institutional actors and community partners. For marginalized populations, such as racialized or Indigenous communities, cultural disconnects and stigma can amplify feelings of exclusion or tokenism.

Strategies to address cultural and attitudinal barriers include:

- Incorporating cultural safety and humility training for academic and clinical staff.
- Co-developing engagement approaches with community leaders to ensure cultural relevance.
- Addressing unconscious bias through reflection, dialogue, and accountability mechanisms.

3. Financial and Resource Barriers

Financial constraints (n=2) [36, 53] were identified as a barrier to engagement, particularly where patients or community members are expected to participate without appropriate compensation.

This underlines systemic inequity in how knowledge and time are valued, especially when academic contributors are compensated while patient voices are treated as voluntary or ancillary.

Solutions include:

- Providing honoraria or salaries for patient and community collaborators.
- Securing dedicated funding lines within education budgets to support engagement.
- Advocating for engagement costs to be recognized as essential, not optional, in project planning.

4. Unspecified or Multifaceted Barriers

A significant number of articles (n=43) [8, 11, 12, 17, 18, 23, 27,39, 41, 45, 49, 54, 57-59, 61-65, 68, 77, 79, 80, 86, 96-98, 102, 105, 111, 112, 115, 122-124, 129, 131, 136, 137, 142-144] cited "other" barriers, which were not always clearly categorized but likely include issues such as unclear role expectations, power imbalances, language barriers, and bureaucratic complexity. The high frequency of these unspecified barriers suggests a need for better documentation and analysis of engagement challenges across contexts.

Overcoming these multifaceted challenges involves:

- Establishing clear role definitions and expectations at the outset of co-design efforts;
- Building trust through transparent decision-making and shared leadership;
- Engaging in ongoing evaluation and feedback with patient partners to identify and address emergent issues.[8, 11, 12, 17, 18, 23, 27,39, 41, 45, 49, 54, 57-59, 61-65, 68, 77, 79, 80, 86, 96-98, 102, 105, 111, 112, 115, 122-124, 129, 131, 136, 137, 142-144]

5. Gaps in Reporting

Interestingly, no articles cited policy, trauma, location, human resources, or context/environment as barriers, which may reflect underreporting or a lack of attention to these factors in the literature. These omissions suggest the need for more comprehensive frameworks and future research that considers broader social determinants and system-level constraints that may impact patient and community engagement.

***Sub-Question 2**: What are the facilitators that support engagement?*

Despite a variety of barriers to patient, family, and community engagement in health education, the literature overwhelmingly highlights support systems (n=122)[8-13, 15-21, 23-32, 34-36, 39-43, 45-57, 60-63, 65-76, 78-87, 89-109, 111-115, 117-119, 121-138, 140-145] as the most critical facilitator. However, limited attention to other potential enablers, such as policy, cultural factors, or environment, points to missed opportunities for strengthening engagement through a more holistic and strategic approach. The facilitating potential of financial support was noted in one paper (n=1)[120].

1. Support Systems as the Primary Facilitator

The most dominant facilitator identified across the literature was the presence of a support system (n=122)[8-13, 15-21, 23-32, 34-36, 39-43, 45-57, 60-63, 65-76, 78-87, 89-109, 111-115, 117-119, 121-138, 140-145]. Support systems refer to institutional structures, processes, and interpersonal practices that enable meaningful, consistent, and effective participation of patients and communities in health curriculum co-design. These systems include dedicated staff, clear engagement protocols, logistical and administrative support, ongoing communication, and training for both patient partners and academic staff.

Key characteristics of effective support systems include:

- Dedicated roles and liaison personnel to manage engagement logistics and maintain continuity.

- Training and capacity-building for all stakeholders, ensuring patients understand the academic environment and educators understand community knowledge systems.
- Ongoing mentorship and feedback mechanisms to strengthen relationships and foster trust.
- Accessible materials and inclusive communication methods, such as plain language and translation services.

To leverage these support systems, institutions could:

- Embed patient engagement infrastructure into program governance (e.g., advisory councils, co-leads, evaluation frameworks).
- Ensure engagement activities are adequately resourced and sustained over time.
- Develop institutional cultures that prioritize relational and inclusive approaches to co-production.

2. Financial Support

Financial support was identified as a facilitator in one article (n=1)[120], yet its significance cannot be underestimated. Compensation validates the time, expertise, and contributions of patient and community partners and reduces the risk of exclusion based on socioeconomic status.

To enhance this facilitator, institutions could:

- Standardize compensation policies and include engagement costs in budgets from the outset.
- Promote financial transparency and involve patient partners in setting fair remuneration standards.

3. Other Facilitators

Fifteen articles cited "other" facilitators (n=15)[14, 22, 33, 37, 38, 44, 58, 59, 64, 77, 88, 110, 116, 139], which may include elements such as strong leadership, shared goals, community-driven research partnerships, and flexible curriculum structures. Though not detailed in the dataset, these factors likely contributed to the success of engagement initiatives by fostering innovation and shared accountability.

To capitalize on these less formal facilitators, academic programs could:

- Support distributed leadership models that include patients in decision-making.
- Align engagement activities with broader community goals or health equity mandates.
- Enable adaptive processes that can evolve in response to partner input.

Sub-Question 3: How can a cultural shift of healthcare and education towards patient-centered care be supported?

A cultural shift toward patient-centered care in healthcare and education can be supported by embedding patients and individuals with lived experience directly into the design and delivery of health professional curricula. The data underscores how authentic patient engagement transforms not only the content of health education but the mindset and values of learners. This transformation is driven by emotional connection, experiential insight, and the deconstruction of professional hierarchies.

1. Fostering Emotional and Empathic Engagement

Patient narratives and direct interaction evoke powerful emotional responses among learners, which help build empathy and deepen understanding of the human experience of illness. One participant noted the emotional impact of hearing a patient's story of sudden disability:

"It was quite emotional... everything changes completely..." (page 123). [13]

These moments of vulnerability and insight can shift students' focus from disease to person, enabling a more humane, compassionate approach to care. Such emotional engagement is often described by learners as one of the most effective and lasting educational experiences.

2. Facilitating Experiential and Reflective Learning

Learners consistently report that hearing firsthand accounts from patients offers deeper and more memorable insights than traditional instruction. As one student expressed:

"Meeting a patient and hearing about experiences helped a lot. Very moving and in my view the most effective way of gaining an insight into how the patient feels." (page 97). [28]

These real-world encounters facilitate reflection, perspective-taking, and a shift from theoretical knowledge to applied, person-centered practice. Patient inclusion helps bridge the gap between classroom learning and the lived realities of healthcare delivery.

3. Challenging Assumptions and Reframing Power Dynamics

Integrating patients into educational teams disrupts entrenched power structures in healthcare education. As one quote notes,

"The presence of a patient on the team called into question healthcare providers' preconceived notions..." (page 92). [30]

This presence shifts the traditional provider-patient dynamic and invites students to see patients as collaborators, not passive recipients. It fosters humility, openness to feedback, and recognition of diverse knowledge sources—all foundational to patient-centered care.

4. Highlighting Systemic Barriers and Promoting Advocacy

Patient involvement also exposes learners to systemic inequities and access barriers. In one example, a student reflected on how a home visit revealed the difficulties patients face navigating care systems:

- *"It was eye-opening... how difficult it could be for people to obtain even a moderate level of care..."* (page 7). [45]

These insights prompt learners to consider structural determinants of health and encourage advocacy for more equitable healthcare systems—key to sustaining patient-centered, justice-oriented care practices.

5. Reinforcing the Value of Relational and Attentive Care

Patient stories help students understand the value of presence, attention, and relational connection in clinical encounters. One learner recalled how meaningful it was for a patient to feel genuinely cared for by a nurse who was simply attentive:

"The speaker reminded me of how impactful it was for her nurse to have given her actual individual attention and made her feel cared for by simply being there." (page 3).[131]

This reinforces a shift away from task-oriented, biomedical care toward holistic, relational approaches—central tenets of patient-centeredness.

6. Supporting Systemic Change through Curriculum Co-Design

As noted in a synthesis of patient collaboration in education [26], engaging patients supports the development of essential competencies for future practitioners, including:

- Person-centered and relationship-based care
- Shared decision-making
- Self-care and resilience
- Communication and empathy
- Patient safety and quality improvement
- Equity, inclusion, and social justice

Embedding these competencies into curriculum through patient co-design ensures that the cultural shift toward patient-centered care is not left to chance—it becomes part of the professional identity formation process for all health learners.

Discussion

This review highlights the growing inclusion of patients and individuals with lived experience in the co-design and implementation of health education curricula. The findings underscore that effective engagement is contingent upon the presence of institutional support systems, which serve as the backbone for meaningful participation. These include dedicated roles, structured processes, training, and equitable recognition of patient contributions.

However, persistent barriers—including lack of awareness, insufficient support mechanisms, and cultural or attitudinal resistance—continue to limit the breadth and depth of engagement. Of particular concern is the underrepresentation of family members, community groups, and marginalized populations. It is interesting to note that the key barriers and facilitators to authentic engagement identified in the studies mirror those found in health research, healthcare, and quality improvement when related to meaningful patient engagement. This signals a need for more inclusive and equity-driven engagement frameworks in all sectors.

The data also reinforce the transformative potential of patient engagement on learners. Emotional connection, storytelling, and exposure to lived experience foster greater empathy, disrupt professional assumptions, and embed patient-centered values into health professional identities. These outcomes not only improve individual clinical practice but also support a broader cultural transformation in healthcare education toward inclusivity, partnership, and social justice.

While some examples of embedded engagement and co-production exist, they remain the exception. Transformation through changes to policy, funding, accreditation standards, and institutional culture is required to make engagement sustainable and impactful. The key barriers and facilitators identified in the studies within this report mirror those found in patient engagement in health research, healthcare, and quality improvement. With few exceptions, full embedding of patient partners in all aspects of health curriculum was not achieved.

As demonstrated by the Vancouver Statement, engaging with patients allows students to gain a deeper understanding of illness, disability, and the healthcare system, which in turn strengthens their empathy, communication skills, and clinical reasoning. The statement advocates for patient involvement at multiple levels, including classroom teaching, curriculum development, and institutional decision-making. However, it also acknowledges the challenges that can hinder meaningful participation, such as limited institutional support, funding constraints, and power dynamics between professionals and patients. Ultimately, the statement calls on healthcare leaders, educators, and clinicians to champion and model collaborative practices with patients throughout the educational journey.

Addressing Tokenism in Patient Engagement within Health Education Curriculum Development

A significant issue raised in the literature on patient engagement is the risk of *tokenism*—where one or very few patient partners are expected to represent the diverse experiences and needs of the entire patient population. Tokenism can be defined as "making a perfunctory or symbolic effort" to involve patients. It may also manifest through unequal power dynamics, limited influence of patient input, or engagement that primarily serves institutional goals rather than patient needs.[147]

For instance, in mental healthcare contexts, researchers have found that health professionals often select patient representatives who mirror their own views, using them as "tokens" rather than valuing authentic and varied perspectives:

"*They use me as a token a lot when they need a service user… the views… were not necessarily representative of service users in general*." (page 6) [148]

To mitigate tokenism and build genuine patient partnership, the literature emphasizes several key strategies:

- Longitudinal engagement and authentic relationship-building are critical to fostering trust and avoiding superficial involvement.[146]
- Addressing power imbalances is vital. One review highlights how resources and decision-making authority often remain concentrated among institutional actors, limiting patient partners' ability to meaningfully contribute.[149]
- Diverse and inclusive representation is essential. Engagement must include patients from seldom-heard and marginalized communities—those differing by race, socioeconomic status, disability, or other axes of inequity—to prevent exclusion or tokenism.[150]
- Structural support and organizational infrastructure help sustain meaningful patient involvement. Research from the National Institute for Health and Care Research (NIHR) initiative describes how funding, dedicated staff roles, and advisory groups can ensure patient partners move beyond being tick-box participants to valued contributors with real influence. [151]

Conclusion

This scoping review compiled information related to the facilitators and barriers to including patient partners in healthcare education. The inclusion of patient partners as co-educators enriches health education curricula but a conscious recommitment to the nine priorities for action of the 2015 Vancouver Statement is required to fully embed patients and families in academic processes. This includes intentional strategies to overcome systemic barriers, institutional commitment led by champions in the academic community, adequate resources, and fostering respectful, collaborative relationships.

Patient and community engagement in health education curricula is critical to shaping a healthcare workforce equipped to deliver compassionate, equitable, and collaborative care. To support this cultural shift, institutions must move beyond isolated efforts and commit to long-term, structural investment in engagement frameworks. By addressing barriers and scaling facilitators, especially support systems and experiential learning, health education can more fully reflect the values of patient-centered care and transform both teaching and clinical practice environments for the better.

The cultural shift toward patient-centered care is supported through direct, authentic involvement of patient partners in health education. By humanizing health experiences, fostering empathy, challenging norms, and embedding inclusive values, patient engagement shapes the attitudes, skills, and commitments of future healthcare professionals. This transformation is essential to building more compassionate, collaborative, and equitable healthcare systems.

Declaration of Conflict of Interest

None to report

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Appendix 1

Database Import	# Records Imported
Initial Medline Search (Feb 22, 2024)	1306
CINAHL	2067
Ovid Embase	2965
APA PsycInfo	343

Appendix 2

https://proxy.queensu.ca/login?url=http://ovidsp.ovid.com?T=JS&NEWS=N&PAGE=main&SHAREDSEARCHID=77QtBxVs0FKBd0IliZUSo4ue3OXD4zJVtPDSu4DIXVz41Jh7Ux15JBhOGYC1bHkNx

Ovid MEDLINE(R) ALL <1946 to February 15, 2024>

1 "Curriculum"/ 88799
2 exp Education, Professional/ 334961
3 curricul*.mp. 127669
4 Patient Participation/ 29777
5 (patient* adj1 (partner* or engag* or involv*)).mp. 28223
6 or/1-3 390389
7 4 or 5 54152
8 6 and 7 1306

https://proxy.queensu.ca/login?url=http://ovidsp.ovid.com?T=JS&NEWS=N&PAGE=main&SHAREDSEARCHID=2bjWIiQK1PkSKjDrkVePTcOVogGWIcRhI5zuLqOfNQgOhKWt6M8QeDxAQae12eXE6

Embase Classic+Embase <1947 to 2024 February 21>

1 "Curriculum"/ or curriculum development/ or curriculum/ or education/ or exp interdisciplinary education/ or interprofessional education/ or exp medical education/ or exp paramedical education/ 955247
2 exp Education, Professional/ 12829
3 curricul*.mp. 153988
4 patient engagement/ or patient participation/ 39959
5 (patient* adj1 (partner* or engag* or involv*)).mp. 44442
6 or/1-3 977941

7	4 or 5	76150
8	6 and 7	4718
9	limit 8 to (article in press or conference abstract or conference paper or letter or "preprint (unpublished, non-peer reviewed)")	1753
10	8 not 9	2965

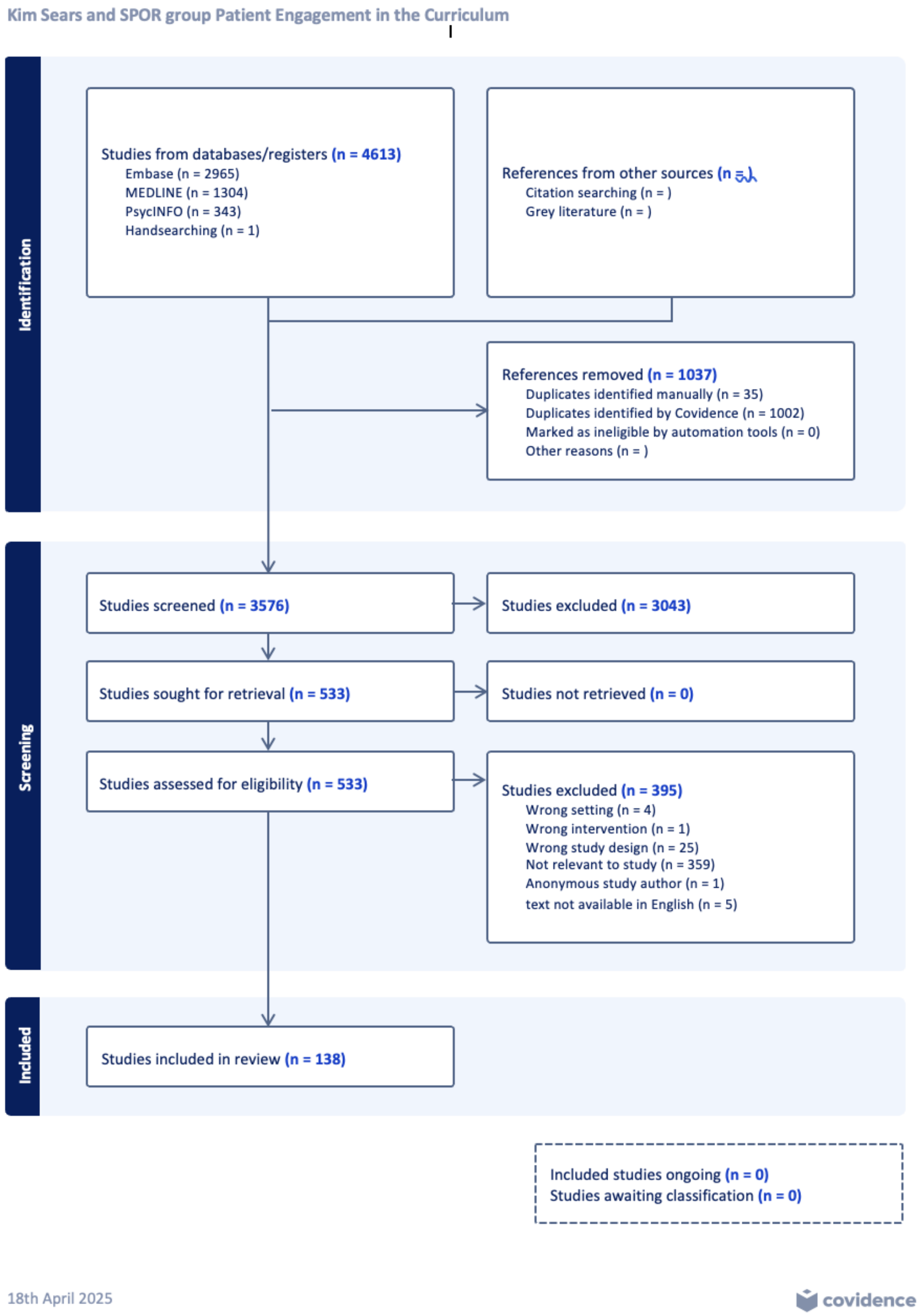
https://proxy.queensu.ca/login?url=http://ovidsp.ovid.com?T=JS&NEWS=N&PAGE=main&SHAREDSEARCHID=6xk6jLyG9Qw7sEPSq2o42xMksyJetZuwZ0kmlQy0pSwFdUXIAsaOF2GzcYMSIzVVy

APA PsycInfo <1806 to February Week 3 2024>

1	education/ or nursing education/ or paraprofessional education/ or exp medical education/ or graduate education/ or dental education/ or rehabilitation education/	84531
2	curriculum/ or exp health education/ or curriculum development/	57811
3	curricul*.mp.	92590
4	patient engagement/ or patient participation/ or client participation/	3313
5	(patient* adj1 (partner* or engag* or involv*)).mp.	6619
6	or/1-3	180705
7	4 or 5	9114
8	6 and 7	343

#	Query	Results
S1	(MH "Curriculum") OR (MH "Curriculum Development") OR (MH "Integrated Curriculum")	39,404
S2	(MH "Education, Health Sciences+")	297,220
S3	TX curricul*	67,070
S4	S1 OR S2 OR S3	330,771
S5	(MH "Patient Participation")	154
S6	TX (patient* N1 (partner* or engag* or involv*))	28,188
S7	(MH "Patients+")	329,929
S8	TX (partner* or engag* or involv*)	630,903
S9	S7 AND S8	31,462
S10	S5 OR S6 OR S9	56,423
S11	S4 AND S10	2,067

Appendix 3


Kim Sears and SPOR group Patient Engagement in the Curriculum
Identification
Studies from databases/registers (n = 4613)
Embase (n = 2965)
MEDLINE (n = 1304)
PsycINFO (n = 343)
Handsearching (n = 1)
References from other sources (n =)
Citation searching (n =)
Grey literature (n =)
References removed (n = 1037)
Duplicates identified manually (n = 35)
Duplicates identified by Covidence (n = 1002)
Marked as ineligible by automation tools (n = 0)
Other reasons (n =)
Screening
Studies screened (n = 3576)
Studies excluded (n = 3043)
Studies sought for retrieval (n = 533)
Studies not retrieved (n = 0)
Studies assessed for eligibility (n = 533)
Studies excluded (n = 395)
Wrong setting (n = 4)
Wrong intervention (n = 1)
Wrong study design (n = 25)
Not relevant to study (n = 359)
Anonymous study author (n = 1)
text not available in English (n = 5)
Included
Studies included in review (n = 138)
Included studies ongoing (n = 0)
Studies awaiting classification (n = 0)
18th April 2025
covidence

Appendix 4

Table 1: General Information

Study ID #	
Article title	
First author	
Publication name	
Year of article publication	
Country where study was conducted	
Other relevant information not included above	

Table 2: Characteristics of Included Studies / Methods

Purpose of study	
Study design	
Sample size	
Other relevant information not included above	

Table 3: Participant Population

Patient partners (multiple choice)	Patient educators, patients, patient family, citizen engagement, people with lived experience, patient community collaborators, or other
Health program educators (multiple choice)	Academic, clinical, or other
Health professionals (multiple choice)	Physicians, nurses, therapists, or other
Researchers (multiple choice)	Researchers, academic institution decision-makers, professional regulatory bodies, or other
Environment (multiple choice)	Post-secondary educational institutions, Indigenous world views and knowledge in health professional education, hospital, or other
Curriculum (multiple choice)	Embedded, developing new materials, redesigning old material, co-developing new materials/courses, co-redesigning old materials/courses, or other
Other relevant information not included above	

Table 4: Barries, Facilitators, and Other Information

Barriers (multiple choice)	Financial, policy, trauma, lack of support system (patient partners, educators, students, health professionals, decision-makers, etc.), cultural, location, human resources, context/environment, stigma/attitude, lack of awareness (by health education programs, healthcare system, professional, etc.), or other
Facilitators (multiple choice)	Financial, policy, trauma, lack of support system (patient partners, educators, students, health professionals, decision-makers, etc.), cultural, location, human resources, context/environment,

	stigma/attitude, lack of awareness (by health education programs, healthcare system, professional, etc.), or other
Lived experience (describe if reported)	
Interesting quotes if relevant (with page numbers)	
Other relevant information not included above	