CONSUMER INVOLVEMENT IN HEALTH SERVICES

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QUESTION

In health services or hospitals, what evidence supports the implementation of consumer involvement and/or consumer advisors at a service-wide level?

RESULTS

ONLINE RESOURCES

AUSTRALIAN HEALTH SERVICES

Monash Health Centre for Clinical Effectiveness. (2019). **Consumer participation and engagement framework in health services**. Web link.

- Previous literature review conducted on articles from 2015-2018.

UK HEALTH SERVICES

NHS England. (2025). **Policy on working in partnership with people and communities.** Web link.

- Sets out how NHS England meets commitments to working in partnership with people and communities, including through roles such as patient and public voice (PPV) partners.

INTERNATIONAL GUIDANCE

OECD. (2021). **Health for the People, by the People: Building People-centred Health Systems.** Web link.

- Part of the OECD economics of patient safety series, exploring how patient engagement can improve safety across healthcare settings, including system-level recommendations.

OECD. (2023). **Patient engagement for patient safety.** Web link.

- Distinguishes levels of engagement (inform, consult, involve, partner/co-produce) across system levels and governance.

WHO. (2016). **Framework on integrated, people-centred health services.** Web link.

- A global framework advocating for health systems that deliver care centred on people and communities, promoting consumer participation in planning, decision-making and system integration.

PEER-REVIEWED JOURNAL ARTICLES – MOST RECENT FIRST

Articles are grouped by theme:

- Developing and Implementing Consumer Involvement
- New Models and Tools
- Cultural Sensitivity
- Healthcare Workers' Experiences with Consumer Involvement
- Barriers to Implementing Consumer Involvement

Each article summary contains excerpts from the abstract and an online link.

DEVELOPING AND IMPLEMENTING CONSUMER INVOLVEMENT

Nixon, J., et al. (2024). **The Symphony of Consumer Partnering and Clinical Governance: An Organizational Review Using the RE-AIM Framework**. *Health expectations : an international journal of public participation in health care and health policy, 27*(6): e70095. Link to full text.

Partnering with Consumers in healthcare systems is now widely accepted and mandated in many countries. Despite this acceptance, there is minimal information regarding the best practice of how to successfully establish systems to embed this practice into healthcare systems. This article described how an Australian Health Service embedded a Consumer Partnering Team into a Clinical Governance Unit to ensure that partnering became business as usual practice. Enablers, barriers, and unintended consequences can be used as learnings for other organizations to develop a similar approach. Two Consumer Partners with lived experience of the health service, and members of the organizations committee structures are part of the evaluation team. As team members, the consumers participated as equal contributors in evaluation design, analysis of the focus group and interview data, and contribution to the writing and review of the manuscript. Two Consumer Partners with lived experience of the health service, and members of the committee structures participated in the focus groups and the interviews.

Chen, Y., et al. (2023). **Digital technology and patient and public involvement (PPI) in routine care and clinical research-A pilot study**. *PloS one, 18*(2): e0278260. Link to full text.

Patient and public involvement (PPI) has growing impact on the design of clinical care and research studies. There remains underreporting of formal PPI events including views related to using digital tools. This study aimed to assess the feasibility of hosting a hybrid PPI event to gather views on the use of digital tools in clinical care and research. A hybrid PPI event is feasible and offers a flexible format to capture the views of patients. The overall enthusiasm for digital tools amongst patients in routine care and clinical research is high, though further work and standardised, systematic reporting of PPI events is required.

Baines, R., et al. (2022). **Meaningful patient and public involvement in digital health innovation, implementation and evaluation: A systematic review**. *Health expectations : an international journal of public participation in health care and health policy, 25*(4): 1232-1245. Link to full text.

The importance of meaningfully involving patients and the public in digital health innovation is widely acknowledged, but often poorly understood. This review, therefore, sought to explore how patients and the public are involved in digital health innovation and to identify factors that support and inhibit meaningful patient and public involvement (PPI) in digital health innovation, implementation and evaluation. Searches were undertaken from 2010 to July 2020 in the electronic databases MEDLINE, EMBASE, PsycINFO, CINAHL, Scopus and ACM Digital Library. Grey literature searches were also undertaken using the Patient Experience Library database and Google Scholar. PPI is largely viewed as valuable and essential in digital health innovation, but rarely practised. Several barriers exist for both innovators and patients, which currently limits the quality, frequency and duration of PPI in digital health innovation, although improvements have been made in the past decade. Some reported barriers and enablers such as the importance of data privacy and security appear to be unique to PPI in digital innovation. Greater efforts should be made to support innovators and patients to become meaningfully involved in digital health innovations from the outset, given its reported benefits and impacts. Stakeholder consensus on the principles that underpin meaningful PPI in digital health innovation would be helpful in providing evidence-based guidance on how to achieve this. This review has received extensive patient and public contributions with a representative from the Patient Experience Library involved throughout the review's conception, from design (including suggested revisions to the search strategy) through to article production and dissemination. Other areas of patient and public contributor involvement include contributing to the inductive thematic analysis process, refining the thematic framework and finalizing theme wording, helping to ensure relevance, value and meaning from a patient perspective. Findings from this review have also been presented to a variety of stakeholders including patients, patient advocates and clinicians through a series of focus groups and webinars. Given their extensive involvement, the representative from the Patient Experience Library is rightly included as an author of this review.

Bryant, E. A., et al. (2022). **Patient and public involvement in the development of clinical practice guidelines: a scoping review**. *BMJ Open, 12*(9): e055428. Link to full text.

Organisations that develop clinical practice guidelines (CPGs) encourage involvement of patients and the publics in their development, however, there are no standard methodologies for doing so. To examine how CPGs report patient and public involvement (PPI), we conducted a scoping review of the evidence addressing the following four questions: (1) who are the patients and publics involved in developing the CPG?; (2) from where and how are the patients and publics recruited?; (3) at what stage in the CPG development process are the patients and publics involved? and (4) how do the patients and publics contribute their views? Our scoping review has revealed knowledge gaps to inform future research in several ways: replication, terminology and inclusion. First, no standard approach to PPI in CPG development could be inferred from the research. Second, inconsistent terminology to describe patients and publics reduces clarity around which patients and publics have been involved in developing CPGs. Finally, the under-representation of research describing PPI in the development of screening, as opposed to treatment, CPGs warrants further attention.

Cluley, V., et al. (2022). **Mapping the role of patient and public involvement during the different stages of healthcare innovation: A scoping review**. *Health expectations : an international journal of public participation in health care and health policy, 25*(3): 840-855. Link to full text.

Patient and public involvement (PPI) has become increasingly important in the development, delivery and improvement of healthcare. PPI is used in healthcare innovation; yet, how it is used has been under-reported. The aim of this scoping review is to identify and map the current available empirical evidence on the role of PPI during different stages of healthcare innovation. Healthcare innovation tends to be a lengthy process. Yet, our study highlights that PPI is more common across earlier stages of innovation and focuses mostly on service innovation. Stronger PPI in later stages could support the adoption and diffusion of innovation. One of the coauthors of the paper (S. S.) is a service user with extensive experience in PPI research. S. S. supported the analysis and writing up of the paper.

Ramsey, L., et al. (2022). **Patient and Family Involvement in Serious Incident Investigations From the Perspectives of Key Stakeholders: A Review of the Qualitative Evidence**. *Journal of patient safety, 18*(8): e1203-e1210. Link to full text.

Investigations of healthcare harm often overlook the valuable insights of patients and families. Our review aimed to explore the perspectives of key stakeholders when patients and families were involved in serious incident investigations. Our review provides insights to ensure patient and family involvement in serious incident investigations considers both clinical and emotional aspects of care, is meaningful for all key stakeholders, and avoids compounding harm. However, significant gaps in the literature remain.

Rowland, P., et al. (2021). **Metaphors of organizations in patient involvement programs: connections and contradictions**. *Journal of health organization and management, ahead-of-print*(ahead-of-print): 177-194. Link to full text.

In this paper, we contribute to the theorizing of patient involvement in organizational improvement by exploring concepts of "learning from patients" as mechanisms of organizational change. Using the concept of metaphor as a theoretical bridge, we analyse interview data (n = 20) from participants in patient engagement activities from two case study organizations in Ontario, Canada. Inspired by classic organizational scholars, we ask "what is the organization that it might learn from patients?” Through our analysis, we interpret a range of metaphors of the organization, including organizations as (1) power and politics, (2) systems and (3) narratives. Through these metaphors, we display a range of possibilities for interpreting how organizations might learn from patients and associated implications for organizational change.This analysis has implications for how the framing of the organization matters for concepts of learning in patient engagement activities and how misalignments might stymie engagement efforts. We argue that the concept and commitment to "learning from patients" would be enriched by further engagement with the sociology of knowledge and critical concepts from theories of organizational learning.

NEW MODELS AND TOOLS

Barbara, R., et al. (2025). **Lived Experience Advisor Program initiative: harnessing consumer leadership for best care**. *Australian health review : a publication of the Australian Hospital Association, 49*(9gc, 8214381). Link to full text.

The Lived Experience Advisor Program (LEAP), introduced at Western Health in January 2023, is an innovative approach to consumer engagement in mainstream health care, integrating lived experience perspectives into organisational decision-making, research, and quality improvement. As health care has increasingly embraced consumer involvement at both direct care and governance levels, the LEAP was implemented to expand the role of health consumers beyond traditional volunteer positions, recognising lived experience as a valuable form of expertise. Through employment of Lived Experience Advisors (LEAs) across a range of clinical and operational projects, this program has enhanced service planning and health literacy for diverse communities. The impact of the LEAP has extended beyond individual projects, influencing organisational culture, and enhancing staff capabilities in consumer partnership. The case study offers practical insights for other healthcare organisations aiming to integrate lived experience roles, emphasising the potential for consumer-led initiatives to drive transformative change in healthcare delivery and policy.

Subasinghe, A. K., et al. (2025). **Consumer-Led Codesign of an Effective Online Consumer and Community Involvement Audit Tool**. *Health expectations : an international journal of public participation in health care and health policy, 28*(2): e70249. [Link to full text.]()

There is evidence that consumer and community involvement (CCI) improves the quality and outcomes of health research. However, there is currently limited support for organisations to plan, implement and evaluate CCI activity. We aimed to codesign an audit tool that will enable organisations, researchers, community members and funders to measure the extent and nature of CCI in their respective settings. The tool was based on the Western Australian Health Translation Network's CCI Handbook. Overall participants had a positive response to the audit tool and believed it had value in quantifying direct implementation of CCI in their workplaces. Gaps identified included the need to address health and research literacy of community members, culturally responsive approaches when working with community members from migrant backgrounds and an identified need for visual and digital resources., Application of the tool enabled participants to identify their respective CCI strengths, weakness and opportunities for improving the meaningful involvement of community members and community in their research activities and to support equity in these processes. The public participated in workshops providing feedback on the general structure of the audit tool as well as testing it within their research projects.

Newton, L. and T. L. Dimopoulos-Bick (2024). **Assessing early feasibility of a novel innovation to increase consumer partnership capability within an Australian health innovation organisation using a mixed-method approach**. *BMJ Open, 14*(5): e080495. [Link to full text.]()

Engagement-capable health organisations recognise that consumer engagement (also known as patient engagement, consumer engagement, patient and public involvement) must occur at every level of the organisation if it is to be meaningful and genuine. Despite this aspiration, health organisations struggle to adopt, implement, and embody consumer engagement capability in a way that has yielded impact. The Partner Ring (PR) is an embedded model for building staff capability for consumer partnerships. It is hosted by an employed Patient Partner. PR was implemented at the Agency for Clinical Innovation in New South Wales, Australia. The aim of this study was to assess the feasibility (acceptability, demand and practicality) of this innovation to increase consumer engagement capability. The PR is feasible and likely to be an acceptable innovation for building staff capability and consumer engagement skills across a large health system or organisation. It could be adopted or adapted by other jurisdictions.

Lantz, A.-C. H., et al. (2023). **Evaluation of patient participation in relation to the implementation of a person-centered nursing shift handover**. *Worldviews on evidence-based nursing, 20*(4): 330-338. [Link to full text.]()

It has been suggested that nursing shift-to-shift handover should be a more team-based dialogue with and for the patient rather than about a patient., AIM: The aim of this study was to evaluate patient participation in relation to the implementation of the person-centered handover (PCH). Most patients want to be present at PCH. Therefore, nurses should ask for the patients' preferences regarding PCH and act accordingly. Not inviting patients who want PCH could contribute to insufficient patient participation. Further studies are needed to capture what assistance nurses would want in identifying and acting in alignment with patient preferences.

Knowles, S. E., et al. (2022). **Participatory codesign of patient involvement in a Learning Health System: How can data-driven care be patient-driven care?**. *Health expectations : an international journal of public participation in health care and health policy, 25*(1): 103-115. Link to full text.

A Learning Health System (LHS) is a model of how routinely collected health data can be used to improve care, creating 'virtuous cycles' between data and improvement. This requires the active involvement of health service stakeholders, including patients themselves. However, to date, research has explored the acceptability of being 'data donors' rather than considering patients as active contributors. The study aimed to understand how patients should be actively involved in an LHS. Patient involvement in an LHS should be 'with and by' patients, not 'about or for'. This requires systems to actively work with and respond to patient feedback, as demonstrated within the study itself by the adaptive approach to responding to contributor questions, to work in partnership with patients to create a 'virtuous alliance' to achieve change. Public contributors were active partners throughout, and co-authored the paper.

Harris, K. and S. Russ (2021). **Patient-completed safety checklists as an empowerment tool for patient involvement in patient safety: concepts, considerations and recommendations**. *Future healthcare journal, 8*(3): e567-e573. Link to full text.

The application of safety checklists to healthcare settings to help systematise routines and improve communication between healthcare professionals has proven to be effective in reducing errors, complications, mortality and hospitalisation time. There is a new call to extend the checklist concept to develop safety checklists that can be used by patients to help empower their involvement in safety practices. Only a handful of studies around patient-completed checklists exist, but those that do indicate a positive impact on patient empowerment and involvement in safety-related behaviours. In this article, we present the concept of patient-completed checklists and provide a review of the existing evidence, highlighting important design and implementation considerations, and making recommendations for future research and development.

CULTURAL SENSITIVITY

Kelly, J. T., et al. (2025). **'Don't Assume, Ask': A Collaboration With Consumers, Interpreters, Clinicians and Health Service Staff to Increase Video Telehealth in Culturally and Linguistically Diverse Groups**. *Health expectations : an international journal of public participation in health care and health policy, 28*(2): e70232. Link to full text.

We aimed to understand gaps in telehealth use across culturally and linguistically diverse (CALD) populations in a metropolitan Australian setting and elicit solutions to support inclusive telehealth-delivered care. Our collaboration highlighted the need for more education and reinforcement to promote equitable and efficient processes for accessing telehealth appointments for CALD consumers requiring an interpreter., PATIENT OR PUBLIC CONTRIBUTION: Patients, caregivers, and interpreters from culturally and linguistic diverse backgrounds were workshop participants and co-developers of solutions to address telehealth access gaps. Final research outputs were also circulated to participants for feedback before being disseminated.

Roberts, N., et al. (2023). **How can we meet the needs of patients, their families and their communities? A qualitative study including clinicians, consumer representatives, patients, and community members**. *BMC Health Services Research, 23*(1): 809. Link to full text.

The Diversity Working Group was formed in response to Australian Quality and Safety Health Care Standards that require organisations plan service delivery that incorporates information about the diversity of consumers, and those at higher risk of harm. Taking a person-centred approach can potentially better understand the needs of patients and communities so that this information can be incorporated into health service delivery. Resources are needed to support patients and their families at times of transition care, particularly when care is unplanned.

Bartlett, R., et al. (2022). **Empathy and journey mapping the healthcare experience: a community-based participatory approach to exploring women's access to primary health services within Melbourne's Arabic-speaking refugee communities**. *Ethnicity & health, 27*(3): 584-600. Request the full text.

This community-based participatory research focused on physical and social barriers to healthcare for refugee women in Melbourne, Australia. Women from non-English speaking backgrounds explored the meaning and impact of their health journeys through group surveys, Photovoice and GIS go-alongs. This empathy-building research also explored acceptability, desirability and feasibility of mHealth solutions to improve access to primary healthcare services. Refugee women reported low utilisation of preventive healthcare services including limited awareness of cervical or breast screening. Phone ownership and health information searches online indicate mHealth solutions are feasible and acceptable to improve healthcare access, literacy and autonomy within this population.

Fraser, S. L., et al. (2021). **On the move: exploring Inuit and non-Inuit health service providers' perspectives about youth, family and community participation in care in Nunavik**. *BMC Health Services Research, 21*(1): 94. Link to full text.

Literature about participation in health and social services suggests that youth, and more specifically Indigenous youth, are difficult to engage within health and social services. Youth are less likely to access services or to actively participate in decision-making regarding their personal care. Service providers play a crucial role in engaging youth based on the ways in which they seek, establish, and maintain relationships with youth and their families. The way in which providers engage with youth will depend on various factors including their own perceptions of the roles and relationships of the various people involved in youth's lives. In this article, we analyze health and social service providers' perspectives, experiences and expectations regarding the roles of Indigenous youth, families and community in care settings in Nunavik, Quebec. We adopt a critical lens to reflect on the key findings in order to tease out points of tension and paradoxes that might hinder the participation of youth and families, specifically in a social context of decolonization and self-governance of services.

Ocloo, J., et al. (2021). **Exploring the theory, barriers and enablers for patient and public involvement across health, social care and patient safety: a systematic review of reviews**. *Health research policy and systems, 19*(1): 8. Link to full text.

The emergence of patient and public involvement (PPI) in healthcare in the UK can be traced as far back as the 1970s. More recently, campaigns by harmed patients have led to a renewed focus on strengthening PPI. There is a growing awareness of the benefits of PPI in research as well as a need to address power inequities and a lack of diversity and inclusion. This review was undertaken to look at evidence for theories, barriers and enablers in PPI across health, social care and patient safety that could be used to strengthen PPI and address a perceived knowledge and theory gap with PPI in patient safety. The review findings suggest that a commitment to PPI and partnership working is dependent on taking a whole system approach. This needs to consider the complex individual and organisational enablers and constraints to this process and address imbalances of power experienced by different groups. Addressing equality and diversity and use of a theory-driven approach to guide PPI are neglected areas. The long tradition of involvement across health and social care can provide considerable expertise in thinking about ways to strengthen approaches to PPI. This is especially important in patient safety, with a much newer tradition of developing PPI than other areas of healthcare.

HEALTHCARE WORKERS' EXPERIENCES WITH CONSUMER INVOLVEMENT

Bardach, S. H., et al. (2025). **Evaluation of the Patient Innovation Partner Role: Perceived Benefits, Structures, Supports, and Recommendations for Lived Experience Engagement in Healthcare Innovation Teams**. *Health expectations : an international journal of public participation in health care and health policy, 28*(2): e70194. Link to full text.

Patient engagement plays a valuable role in health research and quality improvement. While prior research highlights some principles and key considerations for patient involvement in these efforts, there is a limited understanding of how best to structure and support this engagement, especially from the patient perspective and for healthcare innovation projects. These findings highlight the importance of recognizing the bidirectional benefits of patient engagement within project teams. Taking opportunities to check in with patients throughout the project period, both formally and informally, regarding their preferences for involvement and experiences on the team would enable real-time feedback and adjustments to optimize patient partner engagement. Since its inception, the Susan and Richard Levy Healthcare Delivery Incubator has incorporated patient and public involvement into the design and operations of its healthcare innovation projects. While the conceptualization of this analysis did not engage patients or the public, patients and individuals with lived experience provided the data. Further, three patient partners were engaged in the review of the findings, two of whom also actively contributed to the preparation of the manuscript by reviewing drafts, adding content, and making revisions.

Fernandez, N. and J. P. Sturmberg (2025). **Fostering Physician-Patient Partnerships: The Importance of Embracing the Ontological and Epistemological Understandings of Knowledge**. *Health Expectations, 28*(6): e70484. Link to full text.

Healthcare is becoming substantially complex in part due to greater multimorbidity, climate-related health issues, and problems related to access to care. While patient partnership is widely advocated as a strategy to adapt medical practice to the complexity, significant barriers persist. We sought to shed light on the ontological and epistemological 'tensions' generated by the implementation, sometimes by imposition, of the concept of physician-patient partnership in medical practice. This exploration into the complex nature of physician-patient partnerships provides insights about avenues for strengthening them and making them fulfil their promise to enhance health care access and outcomes for all. Patient Contribution: The first author is a kidney transplant recipient (2008) and has been actively involved in patient partnership within health research and medical education since 2010. This paper reflects his accumulated insights and observations regarding the barriers that hinder the development of effective partnerships in health care.

Modigh, A., et al. (2021). **The impact of patient and public involvement in health research versus healthcare: A scoping review of reviews**. *Health policy (Amsterdam, Netherlands), 125*(9): 1208-1221. Link to full text.

Many policies promote patient and public involvement (PPI) in health research and healthcare provision. However, research points to uncertainties about its impact. The aim of the article was to compare what types of impact have been reported in reviews of PPI in health research and healthcare, respectively, and to map differences and similarities between the review studies. A review of reviews was undertaken with a search strategy based on the PCC mnemonic for scoping reviews. Four online databases were searched. Studies published in English between the years 2000-2020, using a review-based method and aiming to demonstrate impact of PPI were included, resulting in sixty-one articles. More reviews of PPI impact in healthcare than in health research were found, although the latter included a larger number of empirical studies. Systematic reviews, quality assessment and quantitative studies were less common in health research. Many original studies were from the United Kingdom. In health research, reported impacts most often related to research design and delivery, while in healthcare the most commonly reported impacts were individual health outcomes/clinical outcomes. However, there is still uncertainty about the strength of evidence for PPI, in particular when it comes to collective involvement in healthcare, that is in policymaking and service improvement initiatives at hospitals or the like.

Brener, L., et al. (2022). **Establishing the impact of consumer participation in alcohol and other drug treatment settings in Australia**. *Health & social care in the community, 30*(4): e1183-e1193. Link to full text.

It is generally recognised that engaging consumers to participate in policy making, programming, and practice is fundamental to effective alcohol and other drug (AOD) treatment, however, literature continues to document challenges and barriers to its implementation in AOD settings. This study reports on an evaluation of the Consumer Participation Project implemented in key non-government AOD services in Australia. Consumers discussed the significance of being actively involved in their AOD treatment service while stressing the importance of proper training and support for those engaging in consumer participation. This research highlights the benefits of consumer participation in AOD treatment and suggests that most consumer participation activities undertaken at present are "low" level involvement concerned with providing and receiving information from consumers. Importantly, however, our study did demonstrate some support for "high" level involvement activities and service providers being open to doing more to encourage consumer participation.

Codsi, M.-P., et al. (2021). **Changing relationships: how does patient involvement transform professional identity? An ethnographic study**. *BMJ Open, 11*(7): e045520. Link to full text.

To understand identity tensions experienced by health professionals when patient partners join a quality improvement committee. Qualitative ethnographic study based on participatory observation. An interdisciplinary quality improvement committee of a Canadian urban academic family medicine clinic with little previous experience in patient partnership. This research provides a new perspective on understanding how working in partnership with patients transform health professionals' identity. When they are called to work with patients outside of a simple therapeutic relationship, health professionals may feel tensions between their identity as caregivers and their identity as colleague. This allows us to better understand some underlying tensions elicited by the arrival of different patient engagement initiatives (eg, professionals' resistance to working with patients, patients' status and remuneration, professionals' concerns toward patient 'representativeness'). Partnership with patients imply the construction of a new relational framework, flexible and dynamic, that takes into account this coexistence of identities.

BARRIERS TO IMPLEMENTING CONSUMER INVOLVEMENT

Arthur, M., et al. (2023). **Community participation and stakeholder engagement in determining health service coverage: A systematic review and framework synthesis to assess effectiveness**. *Journal of global health, 13*(101578780): 04034. Link to full text.

Community and stakeholder involvement in decision-making to determine publicly-funded health services and interventions is advocated to fulfil citizens' rights and improve health outcomes. The inclusion of public actors, particularly disadvantaged populations, in priority setting for universal health coverage (UHC) is also enshrined in guidance from the World Health Organization (WHO). However, challenges remain in operationalising this policy aim and ensuring that these approaches are effective and equitable. This study aimed to synthesise published evidence on the role of community and stakeholder participation in determining health service coverage. This systematic review identifies key gaps and opportunities in the literature and practice related to effective and equitable community and stakeholder participation in determining health service coverage. It offers essential considerations for planning and executing inclusive approaches to priority setting for publicly-funded health services and interventions and defining health benefit packages for UHC.

Hatfield, D., et al. (2023). **'It is still coming from the centre and coming out': The material conditions adding to over-bureaucratised patient and public involvement for commissioning health and care in England**. *Health expectations : an international journal of public participation in health care and health policy, 26*(4): 1636-1647. Link to full text.

To understand how materiality affects patient and public involvement (PPI) for commissioning and leading health and care services in the English National Health Service (NHS) context. From April 2013 groups of general practitioners (GPs) became members of NHS clinical commissioning groups (CCGs) to assess needs and procure core health services for and with local communities. Since July 2022, integrated care systems (ICSs) have subsumed this responsibility. NHS reorganisations have been driven by the promise of more effective and efficient health care and have led to a long history of PPI on economic, political, and moral grounds. Few studies researching PPI in clinical commissioning exist and fewer still have explored a more agentic understanding of materiality and its impact on PPI. System leaders in ICSs should consider the significance of materiality in centrally driven processes involved in PPI commissioning to reduce barriers and ensure meaningful partnerships within local communities. The study design ensured PPI throughout the research process in keeping with contemporary research practice guidance. The project steering committee included service users with current or recent PPI clinical commissioning experience outside of the study sites. There was PPI involvement in the original study proposal and its development including the bid for doctoral funds on which this study is based. All were involved in assessing the rigour of the data collection, interpretation of the findings and ensuring the project remained true to the aims of the study. Two members have also participated in presentation of the study findings.

Lee-Foon, N. K., et al. (2023). **Positioning patients to partner: exploring ways to better integrate patient involvement in the learning health systems**. *Research involvement and engagement, 9*(1): 51. Link to full text.

Globally, health systems are increasingly striving to deliver evidence based care that improves patients', caregivers' and communities' health outcomes. To deliver this care, more systems are engaging these groups to help inform healthcare service design and delivery. Their lived experiences-experiences accessing and/or supporting someone who accesses healthcare services-are now viewed by many systems as expertise and an important part of understanding and improving care quality. Patients', caregivers' and communities' participation in health systems can range from healthcare organizational design to being members of research teams. Unfortunately, this involvement greatly varies and these groups are often sidelined to the start of research projects, with little to no role in later project stages. Additionally, some systems may forgo direct engagement, focusing solely on patient data collection and analysis. Given the benefits of active patient, caregiver and community participation in health systems on patient health outcomes, systems have begun identifying different approaches to studying and applying findings of patient, caregiver and community informed care initiatives in a rapid and consistent fashion. The learning health system (LHS) is one approach that can foster deeper and continuous engagement of these groups in health systems change. We conclude by recommending several factors health systems must consider in order to increase participation in their LHS. Systems must: (1) assess patients', caregivers and community understanding of how their feedback are used in the LHS and how collected data are used to inform patient care; (2) review the level and extent of these groups' participation in health system improvement activities; and (3) examine whether health systems have the workforce, capacity and infrastructure to nurture continuous and impactful engagement.

Abelson, J., et al. (2022). **Understanding patient partnership in health systems: lessons from the Canadian patient partner survey**. *BMJ Open, 12*(9): e061465. Link to full text.

To examine the sociodemographic characteristics, activities, motivations, experiences, skills and challenges of patient partners working across multiple health system settings in Canada. Online cross-sectional survey of self-identified patient partners. Patient partners in multiple jurisdictions and health system organisations. This survey is the first of its kind to examine at a population level, the characteristics, experiences and dynamics of a large sample of self-identified patient partners. Patient partners in this sample are a sociodemographically homogenous group, yet heterogeneous in the scope, intensity and longevity of roles. Our findings provide key insights at a critical time, to inform the future of patient partnership in health systems.

Ayton, D., et al. (2022). **Barriers and enablers to consumer and community involvement in research and healthcare improvement: Perspectives from consumer organisations, health services and researchers in Melbourne, Australia**. *Health & social care in the community, 30*(4): e1078-e1091. Link to full text.

Partnering with consumers and patients and the community and public is a research and healthcare improvement imperative. Consumer and community involvement (CCI) requires behaviour change at the individual (researcher, health professional, manager), organisational (health service, university, medical research institute) and system level (funding policies, collaboration between organisations). To understand the barriers and enablers to meaningful CCI, a qualitative descriptive study was undertaken with researchers, health professionals, representatives from consumer organisations, and health services and ethics committees in Melbourne, Australia. Twenty-eight semi-structured interviews and one focus group were conducted in May-August 2019. Ethics approval was obtained. Thematic analysis was guided by the Capability, Opportunity and Motivation and Behaviour model (COM-B). Training of researchers and health professionals in CCI, benefits and systems and processes to undertake CCI, alongside incorporating CCI as a requirement for funding were identified as enablers. Lack of time and resources for CCI, challenges in finding consumers for projects and a perceived lack of evidence of the impact of CCI were barriers. These identified barriers and enablers will inform strategies to build the capacity of CCI at the individual, organisation and system level within the Australian Health Research Alliance.

de Souza, A. D. Z., et al. (2022). **FACILITATORS AND BARRIERS OF PATIENT INVOLVEMENT IN HOSPITAL SERVICES: INTEGRATIVE REVIEW**. *Texto e Contexto Enfermagem, 31*(2022): e20200395. Link to full text.

To identify the facilitating factors and barriers that influence patient involvement in hospital services. Integrative review; search of articles published between January 2011 and December 2020, in the electronic databases PubMed, Web of Science, Cinahl, Lilacs and Scopus, using descriptors related to "patient involvement", Barriers, Facilitators, in English, Spanish and Portuguese. The analysis resulted in three categories of facilitating factors and barriers: communication, actors of involvement and organizational culture, allowing the elaboration of a theoretical model of patient involvement. This model shows that in the centrality of the process are the actors involved, that is, patients and professionals, inserted in an organizational context, being influenced by leadership, culture, environment, available resources and processes, where communication permeates as a basis for involvement. The facilitating factors and barriers identified in this review, synthesized in a theoretical model, allow transcending theoretical knowledge for practice. The complexity to operationalize this model requires patients, professionals, health services and society join forces to make this theoretical proposition a practice incorporated by the services.

APPENDIX

SEARCH METHODOLOGY

A systematic search was conducted for literature. The results were screened by librarians using Covidence.

SEARCH LIMITS

- English-language
- Published within the last 5 years
- Studies based in Australia, New Zealand, Canada, and the United Kingdom

DATABASES SEARCHED

- Medline – index of peer reviewed articles across health sciences and medicine.
- Embase – index of biomed and pharmacological peer reviewed journal articles.
- Emcare – index of nursing, allied health, critical-care medicine and more.
- Grey literature – Google, Google Scholar, Trip database, Biomed Central Proceedings.

MEDLINE SEARCH STRATEGY

This search strategy was conducted on 21/01/2026 and translated to other databases, as relevant. Searches in each database were conducted on the same day.

1 ((consumer* adj3 partner*) or (consumer* adj3 collaborat*) or (consumer* adj3 participat*) or (consumer adj3 perspective*) or (consumer* adj3 involve*) or (consumer* adj3 advocacy) or (patient* adj3 partner*) or (patient* adj3 collaborat*) or (patient* adj3 participat*) or (patient* adj3 involve*) or (patient* adj3 advocacy) or (carer* adj3 partner*) or (carer* adj3 collaborat*) or (carer* adj3 perspective*) or (carer* adj3 involve*) or (carer* adj3 advocacy) or (communit* adj3 partner*) or (communit* adj3 collaborat*) or (communit* adj3 participat*) or (communit* adj3 involve*) or (communit* adj3 advocacy)).ti. (16890)
2 ((Consumer advisor*) or (consumer representative*) or (consumer network* adj3 member*) or (consumer advocate*) or (consumer leadership) or (consumer committee*) or (consumer organi?ation*)).ti. (69)
3 (Health service* or hospital service* or healthcare service* or health care service* or patient service* or hospital network* or health network* or healthcare network* or health care network* or

health setting* or hospital setting* or healthcare setting* or health care setting* or health service-wide level or hospital service-wide level or healthcare service-wide level or health care service-wide level).ti,ab,kw. (277643)
4 exp Health Services/ (2615187)
5 exp Australia/ (187824)
6 (Australia* or Victoria* or Vic or Melbourne or New South Wales or NSW or Sydney or Queensland or QLD or Brisbane or Northern Territory or NT or Darwin or Western Australia* or WA or Perth or South Australia* or SA or Adelaide or Tasmania* or TAS or Hobart or Australian Capital Territory or Canberra or gold coast or cairns or newcastle or wollongong or geelong or townsville or ballarat or toowoomba or sunshine coast or bendigo or launceston or rockhampton or bunbury or mackay or bundaberg).mp. (452911)
7 exp Canada/ (196883)
8 (Canada* or Canadi* or Alberta* or Calgary* or Edmonton* or "British Columbia*" or Vancouver* or Victoria* or Manitoba* or Winnipeg* or "New Brunswick*" or Fredericton* or Moncton* or Newfoundland* or "New Foundland*" or Labrador* or "St John*" or "Saint John*" or "Northwest Territor*" or Yellowknife* or "Nova Scotia*" or Halifax* or Dalhousie* or Nunavut* or Igaluit* or Ontario* or Ontarian* or Toronto* or Ottawa* or Hamilton or Queen's or McMaster* or Kingston* or Sudbury* or "Prince Edward Island*" or Charlottetown* or Quebec* or Montreal* or McGill* or Laval* or Sherbrooke* or Nunavik* or Kuujjuaq* or Inukjuak* or Puvirnituq* or Saskatchewan* or Saskatoon* or Yukon* or Whitehorse*).mp. (408604)
9 New Zealand/ (47511)
10 (new zealand* or auckland or wellington or New Plymouth or Nelson or Canterbury or Otago).mp. (95786)
11 exp United Kingdom/ (410621)
12 (national health service* or nhs*).ti,ab,in. (333002)
13 (english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab. (157073)
14 (gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jw,in. (2758402)
15 (bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in. (2022973)

16 (bangor or "bangor's" or cardiff or "cardiff's;" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in. (82527)
17 (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or stirling or "stirling's").ti,ab,in. (295740)
18 (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in. (40288)
19 1 or 2 (16953)
20 3 or 4 (2781980)
21 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 (4312472)
22 19 and 20 and 21 (2178)
23 limit 22 to (english language and yr="2021 -Current") (620)

PRISMA CHART