PARTNERS IN PRACTICE

PARTNERS IN CARE

PARTNERS IN ACTION

PATIENTEXPERIENCEROADMAP 2018–2021

BC Children's and BC Women's Hospitals

Meaningful engagement leads to improved patient experience that contributes to better patient outcomes

Provincial Health Services Authority
Province-wide solutions. Better health.

BC Children's Hospital
An agency of the Provincial Health Services Authority

SunnyHill HEALTH CENTRE FOR CHILDREN
A program of BC Children's Hospital

BC WOMEN'S HOSPITAL+ HEALTH CENTRE
An agency of the Provincial Health Services Authority

Contents

1. Definition

Patient Experience is the sum of all interactions shaped by an organization's culture, and that culture influences patients' perceptions across the continuum of care (Beryl Institute). BC Children's and BC Women's are committing to a healthy, engaged workforce by building capacity for effective partnerships with patients, families and patient supporters and taking an equity based approach. Guided by the Mission, Vision and Values, and strategic directions of the Provincial Health Services Authority (PHSA), improved patient experience is a priority and a responsibility shared by everyone at PHSA. As such, the requirement to continuously partner with patients and their supporters, providers and staff on quality and safety and improvements is inherent in all aspects of BC Children's and BC Women's Hospitals.

2. Principles

The principles we follow are people-centric and adapted from the BC Patient Voices Network:

- We engage in mutually-beneficial partnerships
- We value opportunities to co-create and learn from each other
- We support partnerships that enable participants to add value and have meaningful impact on decisions
- We build trust and respect through a culture of openness, accountability and inclusion
- We are guided by diverse voices of our partners and adapt to their evolving needs and efforts to improve quality of care
- We challenge the status quo and embrace new ways of thinking to support improvement

3. Stakeholder Consultation

Following six (6) months of varied engagement with patients, families, supporters, partners, staff and providers on patient experience, the road map emerged. Feedback was secured in person, electronically and by telephone and we engaged over three hundred (300) stakeholders. Settings included world cafes, facilitated sessions, unit and program visits, linked with patient and family councils, networks and advisories and donor events. Draft content on health literacy, patient engagement and how practice could improve was socialized and feedback secured.

Participant Feedback:

- *I feel this session was invaluable -starting a much-needed dialogue. Excellent communication and follow up with patients and families is essential. ...I felt included and my opinion mattered.*
- *Hearing about healthcare experiences directly from patients and families is incredibly powerful.*
- *I like giving my ideas on how they could implement even little things to make a difference.*
- *We want to be involved in care decisions like using apps instead of paper.*

The collation of the extensive feedback has identified themes of work each connected to patient and workplace experience, opportunities for continuous quality improvement, safety and enriched partnerships. As a result, our mandate is to ensure patients and their families are offered authentic partnerships, co-design and engagement opportunities, are active participants in managing their care, and are activated as decision-makers and collaborators with staff and providers who have the capacity to improve their practice as patient and family-centric.

4. Purpose of Document and Intended Audience

The purpose of this document is to provide a strategic direction that defines and supports initiatives to improve patient experience and continue with the movement of the organization to a culture of authentic and safe partnerships with patients and their supporters. This document is for all stakeholders: patients, families, volunteers, donors and BC Children's and BC Women's Hospitals' workforce. The document will be housed on inter and intranet Patient Experience webpages at http://www.bcchildrens.ca/about/accountability/patient-experience and http://www.bcwomens.ca/about/accountability/patientexperience or a copy may be requested at patientexperience@cw.bc.ca or by toll free at 1-844-874-3267

5. Themes of Work

Partners in Practice
BC Children's and BC Women's Hospitals' are committing to build capacity with staff and providers on effective patient/supporter partnerships, patient and family-centric communication, and afford opportunities to develop reflective practice strategies, cultural safety and humility and incorporate principles of trauma-informed care.

Partners in Care
Building health literacy skills inclusive of system navigation, including self-managed care and patient activation strategies, using plain language, utilizing multiple tools and channels, promoting peer support, and delivering innovative and responsive approaches across the continuum of care.

Partners in Action
Enabling purposeful partnerships with patients, families and patient supporters through the expansion of patient and family networks, advisories, barrier-reduced volunteer opportunities and the co-development of standards of engagement practice that inform all aspects of care and service delivery.

6. Related Definitions and Research:

Creating a Climate for Change
Creating a Climate for Change is based on the commitment of all provincial health care partners to do better when it comes to culturally safe and humble care for First Nations and Aboriginal people. BC First Nations Health Authority guides Provincial Health Services Authority agencies through resources that names the problem, offers definitions of key concepts, offers testimony from clients about racism in the health system, and provides a high level overview of the Declaration of Commitment to Cultural Safety and Humility.

Cultural Safety

Cultural safety is an outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the healthcare system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care.

Cultural Humility
Cultural humility is a process of self-reflection to understand personal and systemic biases and to develop and maintain respectful processes and relationships based on mutual trust. Cultural humility involves humbly acknowledging oneself as a learner when it comes to understanding another's experience.

Reflective Practice
Reflective practice is a process of continuous learning by which you stop and reflect on your practice, consciously analyse your decision-making, draw on theory and relate it to what you do in practice.

Reflective practice has achieved wide uptake in health care such that the benefits of being a reflective practitioner are well-evidenced in several health care fields including pharmacy (Owen & Stupans, 2009), medicine (Walker, 1996; Mamede, et al., 2008) and, most prominently, nursing (Atkins & Murphy, 1993; Walker, 1996; Wilkinson, 1999; Esterhuizen & Freshwater, 2008).

Continual critical thinking and reflection can close the gap between theory and practice, improve quality of care and stimulate personal and professional development (Argyris & Schön, 1978; Schon, 1983; Schon, 1987; Boud & Walker, 1998; Epstein & Hundert, 2002). Indeed, it has been suggested that reflecting from professional experiences, rather than learning from formal teaching, may be the most important source of personal professional development and improvement (Jasper, 2003).

In *Experts by experience*, educators providing feedback on medical students' work-based assessments (Excton, 2007) and *Nurse Education Today* (retrieved May 29, 2017) note that reflection are the examination of personal thoughts and actions. For staff and providers this means focusing on how they interact with their colleagues and with patients/patient supporters. Reflective practice is a process by which practitioners can better understand themselves in order to build on existing strengths and take appropriate future action. When routinely engaged in reflective practice, staff and providers are in a continuous improvement cycle.

Advances in Health Sciences Education, Theory and Practice (2014, pp. 595-621) identifies the act of reflection as a great way to increase confidence, improve empathy and become more proactive and engaging. Reflective practice deepens relationships, which will contribute to improved communication and quality of care, reduce care-related conflict and improve patient safety.

Utilizing methods to incorporate reflective practice, such as in facilitated practice sessions or less formal huddles, creates a safe, structured group setting where staff can be open about their experiences, patient stories and work. Increased staff disclosure increases the available information about patients and thereby improves team understanding. This in turn makes joint formulations easier. It also improves morale and reduces staff burnout.

Trauma-Informed Practice (TIP)
In TIP, trauma is thought of as experiences that overwhelm a person's capacity to cope. Experiences can be from early childhood or later in life, and can involve one incident or repeated exposure to emotional or physical traumatic events. TIP recognizes and understands the potential impact of trauma and builds in this recognition, through practical strategies when providing care at all levels. The following four principles provide a framework for how to incorporate trauma-informed care into practice and interactions with patients and families: 1. Understanding of trauma and how it can relate to physical and mental health. 2. An emphasis on building relationships and environments that promote trust and physical, emotional, and cultural safety. 3. Recognizing the importance of reparative opportunity, ensuring patients and families have choices, feel connected, and work in collaboration with treatment providers. 4. Working with patients and families in ways that identifies and builds upon their strengths, resiliency and coping skills.
Reference: BC Provincial Mental Health and Substance Use Planning.

Self-Managed Care
The Canadian Research Network for Care in the Community defines self-managed care as "having the appropriate knowledge, skills and opportunity to be an active and effective partner in one's health with adequate supports from health and social service providers, health educators and health policy planners" (p. 1).[3] Spalding et al. further emphasize that individual agency and choice are the defining principles of self-managed care.[2]

Patient Activation

Activated patients are defined as "patients who have the motivation, knowledge, skills and confidence to make effective decisions to manage their health."[1] Patient activation is a component of patient engagement, putting the patient at the centre of care and ensuring patients are partners with health care providers.[6] Bryant-Lukosius et al. describe patient activation as the degree to which an individual understands the important role they play in managing their health and health care and the extent to which they feel ready and able to take on this role. Patient activation is a core requirement for effective self-management. Activated patients are empowered. They have the motivation, information, skills and confidence necessary to effectively make decisions about and manage their health.

Health Literacy

Health literacy is "the ability to access, comprehend, evaluate and communicate information to promote, maintain and improve health in a variety of settings across the life-course."[8]

Health literacy can be viewed as a supporting skillset to patient activation and self-managed care. Many patients have the desire to be more engaged in their health care and have access to an overwhelming amount of information to make decisions.[3] With 60% of adults and 88% of older adults in Canada not being health literate, support is required from the health care system to build patients' skills in finding quality, understandable information and using it safely.[3, 4] "People who are motivated and confident in their ability to use their knowledge and skills are more likely to be active participants in maintaining and improving health."[7]

These concepts work in tandem to recognize the individuality of a patient and the range of options available for care. While self-managed care requires patients to be proactive, the goal is to engage patients as partners, not to "offload."[3] Meeting a patient where they are naturally leads to increased patient activation and the ability to self-manage care.[1] when health literacy is embedded within organizational culture and health care providers tailor services to individual patient skills and abilities, patients are empowered and health care outcomes are improved.

British Columbia is viewed as a leader in self-managed care and has adopted the Expanded Chronic Care Model to "achieve better health outcomes, resulting in healthier patients."[1, 5] Self-management strives for preventive measures and has been empirically shown to improve quality of life, decrease pain, enhance day-to-day living and reduce hospital admissions.[3]

Several domestic and international studies have found that patient activation initiatives, such as educating patients to be proactive during interactions with health care providers, also leads to improved health outcomes strongly based on preventive measures.[1, 6]

Patients with high activation levels are more likely to have better clinical indicators and less likely to be hospitalized or to have used the emergency department.[1]

The Patient Activation Measure (PAM), the leading survey used in patient activation studies, has proven "to be reliable and valid across different languages, cultures, demographic groups, and health statuses."[6] Studies show that patients less activated according to PAM are three times as likely to have untreated health care needs, and twice as likely to delay care.[6] Patients more activated according to PAM are twice as likely to prepare questions for medical visits, seek medical information and have positive health care experiences. In one study using PAM, the Courage Center in Minnesota increased their patients' PAM scores by 7 points (out of PAM's 100 point scale) on average over 12 months and reduced hospital days by 71%.[6]

Though these findings are largely representative of patients with a range of health conditions and backgrounds, results indicate especially significant benefit to supporting activation among low socioeconomic patients.[1, 6] "The strong associations of health literacy and patient activation with socioeconomic status suggest individual and public health approaches that address these issues may concomitantly reduce health disparities in health and healthcare."[7]

Patients as Partners
Patients and families are partners in health care, supported and encouraged to participate in their own care, in decision making about that care, in choosing their level of participation in decision-making, in quality improvements, and in health care redesign.

Patient Engagement
Carman et al. (2013) define patient engagement as "patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care" (p. 244).

Patient Experience
The Beryl Institute (2016a) defines patient experience as "the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care."

Patient experience is an integral part to providing patient-centred care. It is holistic and complex, extending far beyond the clinical experience.[1, 4, 14, 15] essentially, patient experience is about how patients feel.[1, 9, 14] When patients feel comfortable and empowered, it

produces a snowball effect. Positive emotions lead to increased reception to new information and change, which can lead to lower readmission rates, which can lead to overall better quality of life and so on.[1, 4, 5, 7, 8, 9, 11, 14]

Patient engagement is a critical component to patient experience.[7, 8, 11, 15] Studies have shown that patient engagement initiatives, especially those involving health literacy and shared decision-making, lead to better health outcomes and higher levels of satisfaction.[7, 8, 11, 16] Broken down further, patient engagement includes benefits that directly contribute to successful patient experience, such as higher levels of trust, patient safety and a better understanding of relevant health information.[11, 16]

While broad in nature, it is essential to clearly define patient experience in order to establish its importance and embed it within organizational culture.[2, 3, 7, 8, 9] For patient experience to be successful, organizations must focus not only on patient engagement but on staff engagement as well.[6, 8] Both patients and staff must see the direct value in engagement in order for significant change to occur.[8, 9, 10, 13] Simply presenting data is not enough, and more meaningful initiatives such as storytelling are particularly powerful.[9] In turn, patient engagement benefits not only patients but also staff and health care organizations from a business standpoint. Studies have shown that increased patient participation could potentially result in significant budget savings and increased staff time, along with staff satisfaction and provision of service.[4, 11]

In BC, patient- and family-centred care is a shared priority with the BC Ministry of Health, the Provincial Health Services Authority and the associated agencies that include BC Children's and Women's Hospitals (C&W). A strategic priority is to improve the patient experience along every step of their journey. Evidence in the literature confirms that patient engagement is a critical component of patient experience.

Studies have shown that patient engagement initiatives, especially those involving health literacy and shared decision-making, lead to better health outcomes and higher levels of satisfaction. Engaging patients as partners includes benefits that directly contribute to successful patient experience, such as higher levels of trust, patient safety and a better understanding of relevant health information.

Patient Input

Patient input for improvement with qualitative and quantitative approaches is essential for continuous quality improvements. Input mechanisms vary from:

- Real-time questions on what matters

- Bedside observations to focus groups
- Patient storytelling and journey mapping

Input opportunities should be accessible, consistent and transparent for informing care and service delivery that will be equally meaningful to clinicians and patients which may be collected and responded to at three (3) levels:

1. **Individual:** Improve quality of care by informing care planning and management.
2. **Service:** Identify what's working well and areas for improvement.
3. **System:** Evaluate system of integration and outcomes.

Finding repeated links between patient experience and clinical safety (Doyle, Lennox & Bell, 2013), their review of fifty-five (55) studies found the following key messages: Patient experience is consistently positively associated with patient safety and clinical effectiveness. Patient experience is positively associated with self-related and objectively measured health outcomes, adherence to recommended treatments, preventative care and an impact on primary care such as the use of screening services and immunization. Their extensive study demonstrated the links and supported the notion that patient experience, clinical effectiveness and patient safety are linked and should be considered as a collective.

7. Next Steps

The Patient Experience Roadmap applies a broad lens and proposed consolidated direction for work being planned, implemented and evaluated that focuses on patient experiences at BC Children's Hospital and Women's Hospital and Health Centre. Next steps involve aligning the three themes to three working groups. These working groups will be led by and consist of internal and external members with subject matter and content expertise. The working groups will further define each theme of work; create theme specific work plans that include milestones and deliverables that are meaningful to our campus community. Researchers interested in this work will come together to help promote new knowledge and innovation.

Governance will be established to support the vision for this work. A matrix relationship will be established with PHSA Patient Experience leadership with the goal of informing each other's' work aligning to the provincial direction for exceptional patient experiences in health care.

Driving principles for the working groups:

- **Focused:** we consciously adopt the perspective of what matters most to Child/Youth/Women/Families.
- **Inclusive**: membership reflects the campus diversity and reflective of those who serve and those served.
- **Interdisciplinary**: membership is strengthened by engaging the collective wisdom from various disciplines, care and service areas.
- **Research Driven:** groups maintain an eye to evaluative opportunities; they build on or integrate evidence and the ongoing pursuit of patient centric quality improvements.
- **Goal Oriented:** work plans support targeted timelines and deliverables.
- **Exceptional:** work demonstrates a commitment to creating, living and sustaining exceptional care experiences and environments.
- **Innovative**: our work fosters a spirit of inquiry and innovation that drives authentic patient experiences.

8. References

Adams, et al. (2013). British Columbia Provincial Mental Health and Substance Use: Trauma-Informed Practice Guide. Retrieved from: http://bccewh.bc.ca/wp-content/uploads/2012/05/2013_TIP-Guide.pdf

Argryis, C. (1997). *Increasing Professional Effectiveness*. Jossey Bass. Retrieved from: http://www.alps-cetl.ac.uk/documents/Reflection_BAA_article_submission.pdf

Argyris C. & Schön, D. (1978). *Organization learning: A theory of action perspective*. Reading, Massachusetts: Addison Wesley.

Atkins, S. & Murphy, C. (1993). *Reflection: A review of the literature*. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3555667/

Benner P. (1984). *From novice to expert: Excellence and power in clinical nursing practice*. Addison-Wesley. Menlo Park, CA: Addison-Wesley.

Bryant-Lukosius, Hibbard, & Mahoney. (2013). *Building Academic Practice*. MacColl Institute.

Doyle, et al. (2014). *A systemic review of evidence on the link between patient experience and clinical safety and effectiveness.* Retrieved from: http://bmjopen.bmj.com/content/3/1/e001570

Canadian Public Health Association. (2008). *A Vision for a Health Literate Canada: Report of the Expert Panel on Health Literacy*. Ottawa, ON: Rootman, I., et al. Retrieved from: http://www.cpha.ca/uploads/portals/h-l/report_e.pdf

Epstein R. M. & Hundert E. M. (2002). *Defining and assessing professional competence*. *JAMA, 287*, 226-235. Retrieved from: http://jamanetwork.com/journals/jama/article-abstract/194554/

Boud D. (2000). *Sustainable assessment: Rethinking assessment for the learning society*. *Studies in Continuing Education, 22*, 151-167. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3555667/

Greene, J., & Hibbard, J. H. (2012). Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *Journal of General Internal Medicine, 27*(5), 520-526. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3326094/

Haddock, J. & Bassett. (1997). Nurses' perceptions of reflective practice. *Nursing Standard, 11*(32), 39-41. Retrieved from: https://rcni.com/nursing-standard/evidence-and-practice/cpd-articles

Hibbard, J.H., & Greene, J. (2013). What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs. *Health Affairs, 32*(2), 207-214. Retrieved from: http://content.healthaffairs.org/content/32/2/207.short

Home and Continuing Care Unit of the Health Care Policy Directorate, Health Canada. (2006). *Self-Managed Care Programs in Canada: A Report to Health Canada*. Toronto, ON: Spalding, K., et al. Retrieved from: https://www.canada.ca/en/health-canada/services/publications/health-system-services/self-managed-care-programs-canada-report-to-health-canada.html

Lum, J. M., et al. (2010). Supporting Self-Managed Care. *In-Focus Backgrounders: The Canadian Research Network for Care in the Community*, Feb. 2010. Retrieved from: http://www.ryerson.ca/content/dam/crncc/knowledge/infocus/factsheets/Self_Managed_Care_In_Focus_Feb_2010.pdf

Mamedew, A., et al (2014). *Advances in Health Sciences Education and Theory Practice.* Retrieved from: http://jamanetwork.com/journals/jama/article-abstract/194554

Ministry of Health. (2014). *Expanded Chronic Care Model*. Retrieved from http://www.primaryhealthcarebc.ca

Owens & Francis. (1997). Risks and Rewards of Reflective Practice. James Cook University, Townsville. Retrieved from:

> https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3555667/

Public Health Agency of Canada. (2014). *Health Literacy*. Retrieved from: http://www.phac-aspc.gc.ca/cd-mc/hl-ls/index-eng.php

Shon, D. A. (2002). *The reflective practitioner* (2nd ed.). Jossey Bass, San Francisco. Retrieved from: https://graysreadinggroup.wordpress.com/2012/12/18/the-reflective-

> practitioner-by-donald-schon/

Smith, S.G., et al. (2013). Skill set or mind set? Associations Between Health Literacy, Patient Activation and Health. *PLoS One, 8*(9), 1-7.

> http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0074373

Walker, S. (1996). Reflective practice in the accident and emergency setting. *Accident and Emergency Nursing, 4*, 27-30. Retrieved from: http://www.alps-

> cetl.ac.uk/documents/Reflection_BAA_article_submission.pdf

9. Annotated Bibliography

1. Barello, S., et al. (2016, January 8). eHealth for Patient Engagement: A Systematic Review. *Frontiers in Psychology*. https://doi.org/10.3389/fpsyg.2015.02013

In their review, authors found that patient engagement initiatives are often limited in aspect. A more holistic view of patient needs is required to gain positive outcomes. The authors believe patient engagement comprises three key components:

> 1. *A Behavioral dimension* (What the patient *does):* connected to all the activities the patient acts out to face the disease and the treatments.

> 2. *A Cognitive dimension* (What the patient *thinks* and *knows*): connected to what the patient knows, understands and how he/she makes sense of the disease, its treatments, its possible developments, its monitoring.

> 3. *An Emotional dimension* (What the patient *feels*): connected to the psychological and emotional reactions the patient experiences when adjusting to (and elaborating) the onset of the disease and new life condition linked to it.

The emotional dimension is especially crucial in order to bridge the disconnect between clinical effectiveness and positive patient care experience. Asking what a patient feels when taking part in health care interventions may lead to positive self-perception and increase openness to new information and change.

2. The Beryl Institute. (2016a). Defining Patient Experience. Retrieved from: http://www.theberylinstitute.org/?page=definingpatientexp

The Beryl Institute developed their definition of patient experience via a working group of patient experience leaders. The group recognized that patient experience is extremely broad in its scope and intend this definition to be a starting point for further conversations.

3. The Beryl Institute. (2016b). Guiding Principles for Patient Experience Excellence. Dallas, TX: Wolf, J. A., & Palmer, S.

Defining patient experience within an organization is essential for demonstrating its importance and initiating meaningful change. Recommended strategies include: placing prominence on a patient experience leadership role, defining patient experience, defining a process for ongoing input and engagement (for example, advisory councils),

involving voices beyond patient experience staff and patients, looking beyond the clinical experience and providing opportunities within the community opportunities to learn, connect and engage.

4. The Beryl Institute (2013). Voices of Patients and Families: Partners in Improving Patient Experience. Dallas, TX: Wolf, J. A.

The authors collected more than 450 pages of transcripts of interviews with contributors and found that engaging patients to make their voices heard leads to positive patient experience. This benefits not only patients but everyone within a health care organization. For example, a positive patient experience generally leads to lower readmission rates. Lower readmission rates means staff have more time and resources, which leads to less demand on budget, which benefits the organization as a business.

Two important themes arose from the transcripts. First, offer compensation and childcare when recruiting patients or membership may be skewed. Second, engage staff in cultural/emotional competency training before implementing new patient engagement initiatives.

5. Camden, C., et al. (2015). Engaging stakeholders in rehabilitation research: A scoping review of strategies used in partnerships and evaluation of impacts. *Disability and Rehabilitation, 37*(15), 1390-1400. doi: 10.3109/09638288.2014.963705

In this review, authors identified a number of factors that organizations can overcome to improve patient engagement. These include: providing financial compensation to acknowledge the substantial time commitment, allowing stakeholders a voice to determine their own roles and expectations and how they would like to be engaged, providing stakeholders with more responsibility, such as setting meeting agendas, and improving marketing and awareness of patient engagement opportunities.

6. Canadian Institutes of Health Research. (2014). Strategy for Patient-Oriented Research: Patient Engagement Framework. Retrieved from: http://www.cihr-irsc.gc.ca/e/48413.html

The Canadian Institutes of Health Research (CIHR) developed Canada's Strategy for Patient-Oriented Research (SPOR) in collaboration with patient representatives and patient engagement experts. This paper explores patient engagement framework to ensure ongoing successful collaborations. "Engaging patients requires a climate in which staff understands the value of involvement and patients see the value of these interactions." CIHR recommends that organizations provide an inclusive environment and support, including financial compensation. Additionally, organizations need to push boundaries on engagement and giving increased power and responsibility to patients.

7. Carman, K. L., et al. (2013). Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies. Health Affairs. 32(2), 223-231. Retrieved from: http://content.healthaffairs.org/content/32/2/223

The authors constructed a patient engagement framework as a guided pathway towards safe and quality health care and improved population health. Although in its infancy, patient engagement is taking place and achieving positive results. As one example, a direct correlation was found showing that patients who experienced shared decision-making chose far less invasive treatments than those who did not.

Organizations must demonstrate the importance of patient engagement in order to engage staff. "Interventions often focus on changing patient factors without addressing organizational and societal barriers."

8. Coulter, A. (2012). Patient engagement – what works? *Journal of Ambulatory Care Management, 35*(2), 80-89. doi: 10.1097/JAC.0b013e318249e0fd

This systematic review found that although the path to implementing patient engagement initiatives varies greatly from organization to organization, patient engagement is consistently influenced by three factors: health literacy, shared decision-making, and quality improvement. Additionally, patient engagement must be embedded in organizational culture, and staff must be trained and engaged themselves in order to drive change.

Patient engagement may very well lead to improved patient satisfaction, confidence, health outcomes and quality of life, but more evidence-based research is required. One evidence-based conclusion is that providing feedback to patients on outcome measures can increase patient participation in consultations, improve their diagnosis, and improve the self-management of their conditions, emphasizing the importance that simply gathering data isn't enough.

9. Guler, P.H. (2017). Patient experience: A critical indicator of healthcare performance. *Frontiers of Health Services Management, 33*(3), 17-29. doi: 10.1097/HAP.0000000000000003

Award-winning health organization found that patients are less anxious and more empowered when they feel connected and informed. Their practice found success in the following:

Entrench patient experience within organizational culture. Sharing patient experience stories particularly effective at connecting staff with the importance of patient engagement.

Engage physicians. It's a trend in organizations to develop patient engagement courses taught by physicians to colleagues.

Be consistent. Implement standards using a cross-coordinated approach. Build up the organizational culture first and then implement initiatives over time.

Use data meaningfully to drive change. Adventist Health System surveyed inpatients. Patients who answered yes that a nurse always visited hourly during the day scored nurse communication as 86.9%. Those who answered no to the hourly rounds questions scored nurse communication "always" only 59.3% of time.

10. INVOLVE. (2017). Lessons from Involving Children and Young People in Service Improvement. London, UK: Ghaye, T. Retrieved from: http://www.invo.org.uk/lessons-from-involving-children-and-young-people-in-service-improvement/

This article debriefs REDY (Real-time Evaluation Device for Youth), which gathers information on youth using touch-screen technology. Staff involved concluded that improving patient experience, especially when involving children and youth, is dependent on looking beyond engagement. "More than consulting, engaging, participating with and involving children and young people. It is about creating 'communication friendly spaces.'" The authors also highlighted the positive effect of showing data in real-time so that patients can see their contribution.

11. National Health Service England. (2013). Transforming Participation in Health and Care: "The NHS Belongs to Us All." Patients and Information Directorate.

This article provides guidance and data about the effects of shared decision-making within health care. When patients are involved in decisions, they are more likely to have better outcomes, follow drug treatments, avoid over-treatment and are less likely to be hospitalized. One study referenced estimated that 4.4 billion could potentially be saved in the UK through increased patient engagement; another American study estimated a 21% reduction in health care costs in the US.

Other referenced studies have shown that patient engagement leads to improved quality of life, better recovery rates, patient safety and clinical effectiveness. The authors emphasized the holistic nature of patient experience and the effectiveness of providing feedback to patients, thereby increasing engagement.

12. Okrainec, K., et. al. (2017). Impact of patient-centred discharge tools: A systematic review. *Journal of Hospital Medicine. 12*(2), 110-117. doi: 10.12788/jhm.2692

Authors conducted a systematic review of studies that engage patients in the design/delivery of instructional discharge tools. The studies found that this had a positive effect on patients' comprehension of health information but that any effect beyond had not been formally studied. However, several studies referenced suggest that there are positive effects beyond three months. Additionally, more research is required on the level of involvement required for effective design since it varies widely from study to study.

13. Paediatric PROM&PREM Network. (2012). Patient Reported Outcome and Experience Measures (PROMs and PREMs): Service Users' Perspectives. London, UK: Tadic, V., et al.

The National Health Service encourages the use of Patient Reported Outcome and Experience measures (PROMs and PREMs) to assess patient health outcomes and experience. The authors held two focus groups comprised of young patients and family members, followed by a workshop involving professionals and family members, in order to effectively shape these measures.

The authors found that patients and parents are more willing to provide feedback to staff if they are informed of the value or purpose of gathering the information in return. Questionnaires are generally found to be too long and sterile and to oversimplify illnesses. Patients stressed the importance of reassurance of privacy, confidentiality, and impartiality as well as having the opportunity to report on their experience and views.

14. Palmen, M., & Kouri, P. (2012). Maternity clinic going online: Mothers' experiences of social media and online health information for parental support in finland. *Journal of Communication in Healthcare, 5*(3), 190-198. Retrieved from: http://dx.doi.org.ezproxy.library.ubc.ca/10.1179/1753807612Y.0000000013

In this study, a Finnish maternity clinic looked beyond the clinic experience and launched a pilot study offering social media tools and health information for parental support. To provide a positive patient experience, it is important to look at patients' lives in their everyday context, and research shows that women are the primary users of e-health resources. Additionally, social media is an ideal platform for patient engagement with new mothers as it is not bound to specific hours, and online health information has been shown to de-professionalize medicine, making content more approachable.

Overall, this study showed that social media coordinated by a health organization can effectively offer social support for parents with small children, which has been associated with a number of direct health benefits (for example, less postpartum depression).

15. Wolf, J.A., et al. (2014). Defining patient experience. *Patient Experience Journal, 1*(1), 7-19. Retrieved from: http://pxjournal.org/journal/vol1/iss1/3/.

Authors set out to define patient experience, as definitions vary extensively from organization to organization despite being of such emerging importance. Their literature review found that patient engagement is one of three critical components of overall patient experience (additional two factors: "need for person-centeredness and acknowledgement of the broad and integrated experience"). The authors also found that having a defined framework is essential to "provide clarity and reinforce applicability."

16. Prey, J.E., et al. (2014). Patient engagement in the inpatient setting: A systematic review. *Journal of the American Medical Informatics Association, 21*(4), 742-750. doi: 10.1136/amiajnl-2013-002141

Authors found that increased shared decision-making and patient participation leads to a myriad of benefits, including higher levels of satisfaction, improved health outcomes and increased patient-centred care.

10. Notable Sources:

Clinical Communication Deconstructed
 https://www.vocera.com/public/ein/research-studies/rs-clinical-communication-deconstructed-2017-ein.pdf

In Pursuit of Resilience, Well-Being, and Joy
 https://www.vocera.com/public/ein/research-studies/rs-pursuit-resilience-well-being-joy-2017-ein.pdf

BC First Nations Health Authority
 http://www.fnha.ca/documents/fnha-policy-statement-cultural-safety-and-humility.pdf