

# NQP Action Team to Co-Design Patient-Centered Health Systems

**Patients, families, and caregivers are often missing from key conversations and decisions around healthcare delivery, quality, and safety initiatives. While many healthcare organizations have emphasized improving patient, family, and caregiver involvement and engagement in direct care experiences, involving these critical stakeholders as partners in health system co-design remains an ongoing effort.<sup>1</sup>**

Patient-centered co-design—defined as the act of collaborating with patients, families, and caregivers as equal partners in designing healthcare activities that affect quality of care and experience—is an opportunity to expand our view of what aspects of care matter most to patients. By engaging a diverse cross-section of the people who utilize healthcare in the co-design of the system itself, leaders and stakeholders can continuously improve patient experience, staff engagement, and the quality, safety, equity and value of care.<sup>2,3</sup>

Engaging patients, families, and caregivers as partners in both direct care experiences and health system improvement efforts is imperative to achieving patient-centered healthcare. Patients, families, and caregivers have critical information and lived experience to share, and they offer a valuable and essential perspective that illuminates the needs of the diverse patient populations served by the organization. Building patient, family, and caregiver engagement into a health system's practices and policies can help improve patient outcomes and patient experience while reducing unnecessary use of medical services.<sup>4</sup> Over the past decade, the increased focus on patient centeredness has led to increased development and use of patient-driven experience measures for quality improvement, accreditation, certification, payment, public-reporting, research, and recognition within health systems.<sup>5</sup> Standardized surveys can be a starting point, but fall short of the purposeful collaboration that defines co-design. Surveys provide initial insight into untapped perspectives, but for a culture of co-design to emerge, it is essential to complement data collection with structured methods to actively engage patients, families, and caregivers in designing improvements. Organizations can build partnerships in

co-design and quality improvement by incorporating a variety of these methods, such as inviting patients, family members, and caregivers to sit on safety committees and task forces, educating consumers and staff on design thinking, and reserving voting seats on governance boards for people who utilize the health system. A variety of methods can also be used to seek feedback from patients, families, and caregivers, such as creating patient and family advisory councils, holding focus groups, and actively engaging patients through social media.

**Despite the evidence that co-design leads to improved quality and safety,<sup>6</sup> healthcare organizations still face numerous challenges that make it difficult to create a true culture of co-design. Buy-in, leadership involvement, and support from all healthcare stakeholders are critical to cultivating and supporting purposeful partnerships with patients, families, and caregivers, and are essential drivers of high quality, high value patient-centered care.<sup>5</sup>**

To amplify the need to share best practices and recommendations to improve the engagement, safety, and health outcomes of patients, the National Quality Forum (NQF) convened the National Quality Partners™ (NQP) Action Team to Co-Design Patient-Centered Health Systems in December 2019. The NQP Action Team brought together 29 of NQF's member organizations that represent multistakeholder groups including patient and caregiver partners, health systems, quality improvement organizations, professional societies, payers, research organizations, and federal agencies. The NQP Action Team is committed to identifying and sharing actionable strategies and practices that organizations can use to create and advance a culture that embraces co-design in quality and safety initiatives.

**The NQP Action Team identified the following set of priority challenges for stakeholders to assess and address in the pursuit of co-designing patient-centered health systems:**

- **Misaligned organizational culture and commitment, and limited buy-in and support from key stakeholders** across the spectrum of care, limits the ability for organizations to embed co-design within their cultures
- **Competing priorities and inadequate resource allocation** results in limited support for co-design
- **Reluctance and uncertainty about how to effectively engage patients, families, and caregivers in new ways** leads to a lack of transparency, resistance to change, and the continuation of an unsatisfactory status quo
- **Inadequate communication and outreach among diverse populations and representative patients** interferes with meaningful engagement and building trust with patients, family members, caregivers, peer advocates, and community-based organizations
- **Insufficient organizational educational plans, including not co-designing the education initiatives themselves,** hinder promotion of patient participation in co-design activities and perpetuate a lack of organizational understanding of what patients, families, and caregivers want and need
- **Difficulty of demonstrating impact** because organizations do not know how to measure specific outcomes of co-design makes it challenging to show value to funders, leadership, staff, and other key stakeholders

Patient-centered co-design is integral to an effective quality and safety program. Patient-centered co-design should be an organizational priority that centers around the importance and value of partnering with patients, families, and caregivers as key stakeholders. Leaders and organizations can demonstrate their commitment to building this partnership by actively prioritizing co-design and allocating resources.

**To support the development of patient-centered co-design in health systems, the NQP Action Team recommends that healthcare organizations, community stakeholders, and patients, families, and caregivers must partner together to:**

## 1 PRIORITIZE AND INVEST IN CO-DESIGN

- Make an organizational commitment to prioritize the insights and expertise of patients, families, and caregivers and their role as equal partners in designing safety, quality, and care initiatives
- Embed co-design into the goals, vision, mission, values, policies, and procedures of the organization
- Dedicate adequate funds within the organization's budget for co-design initiatives
- Identify innovative ways to partner with other organizations and funders to financially support co-design initiatives when resources are limited

## 2 EDUCATE AND EXPAND AWARENESS TO FOSTER SUCCESSFUL AND SUSTAINABLE CO-DESIGN INITIATIVES

- Involve all levels of health system staff—including executives, direct care providers, and indirect care providers—in co-design initiatives that demonstrate value and promote the impact of patient partners
- Ensure patients, families, and caregivers participate in co-designing educational and experiential initiatives
- Support patients, families, and caregivers in developing storytelling skills, and empower them to share their stories openly in ways that connect to the priorities of the organization
- Encourage the sharing of co-design experiences with organizational leadership and staff to increase comfort in engaging patients, families, and caregivers and create lasting cultural change
- Include other healthcare stakeholders, such as payers, as valuable partners in understanding how patients navigate the complex healthcare system and identifying opportunities for co-design

## 3 RECRUIT AND INCLUDE DIVERSE, REPRESENTATIVE PATIENT VOICES

- Strive for co-design teams with diverse participation representative of the population the organization serves, recognizing that one patient does not equal all patients

- Address social determinants of health and other barriers to participation by assessing the needs of individual patient, family, and caregiver partners and asking how the health system can support their participation, rather than making assumptions about their needs and circumstances
- Offer compensation for patients, families, and caregivers as a mechanism to both reinforce the value of their contributed expertise and help overcome barriers that limit participation, particularly for underrepresented populations
- Build trust by involving respected community leaders and community-based organizations to garner support in recruiting partners in co-design

- Measure return-on-investment of co-design initiatives by analyzing patient, family, and caregiver experience, cost avoidance, and outcome measures associated with processes and settings that utilize co-design
- Create and participate in collaboratives to share data on the impact of co-design initiatives across organizations

Creating meaningful and inclusive partnerships with patients, families, and caregivers is paramount to the success of quality, safety, research, and care initiatives. Patient-centered co-design to improve quality of care does not exist without this active partnership. Health systems must prioritize and invest in co-design, educate and expand awareness to foster successful and sustainable initiatives, recruit and include diverse and representative patient voices, and measure and share the impact of co-design on quality and safety. Health systems can create new opportunities to partner with patients, families, and caregivers by engaging a diverse cross-section of the communities they serve in initiatives focused on quality and safety. Health systems that commit to co-design will improve both organizational health and the future of healthcare.

## 4 MEASURE AND SHARE ORGANIZATIONAL IMPACTS OF CO-DESIGN

- Begin with simple measurement approaches, and assessment and evaluation metrics, to understand if co-design is occurring
- Use a combination of process, structure, and outcome measures to understand the impact of co-design, especially in a field of evolving measurement science

## NQP ACTION TEAM TO CO-DESIGN PATIENT-CENTERED HEALTH SYSTEMS

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## ENDNOTES

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