

Co-Architecting Healthcare Transformation

How Leading Health Systems Put Patients
and Families at the Forefront of Design

2018 RESEARCH REPORT

Research study by the Experience Innovation Network, part of Vocera, examining how hospitals and health systems engage patients and families as partners in designing and developing the future of caring.

Executive Summary

As healthcare enters a new era of consumerism, more and more systems are working to embrace principles of patient- and family-centered care. Many are working hand-in-hand with patient-family improvement partners to shape their transformation. The Experience Innovation Network conducted research to examine how leaders at hospitals, clinics, and health systems are engaging patients and families in improvement and transformation efforts, and how patients and families perceive those efforts' effectiveness.

Through our research, we found a fair amount of variation in the integration of patient-family perspective, influence, and advocacy into healthcare transformation. While most systems today receive patient-family feedback in the form of surveys and advisory councils, only an elite few have integrated patients and families as true co-architects of transformation. Those that have are embracing key principles of patient-family partnership:

- **Engage patient-family partners across the spectrum from strategy to operations.** Rather than keeping patient-family partners in silos, leading systems embed them in all of their work—from setting system strategy and designing care systems to observing daily work and participating in continuous improvement efforts.
- **Let patient-family partners influence both the what and the how of transformation.** Many patient-family partners lamented that they get more say on how to design improvements than on what areas need improvement. Leading systems have patient-family partners that guide priorities and influence areas of focus.
- **Prepare both patient-family partners and team members for effective collaboration.** Patient-family partners and care team members see healthcare from very different perspectives—which is part of why partnership is so important for effective transformation. But it also takes effort and preparation for both sides to build constructive working relationships and achieve optimal outcomes.
- **Create intentional strategies to include under-represented partners.** While most system leaders recognize the need for greater diversity of patient-family partners they work with, most lack a specific strategy to improve representation. Leading systems go beyond advisory councils and meet patients where they are with novel access pathways to build inclusion.
- **Value patient-family partnership appropriately.** Budgets to support patient-family partnerships are small (25% of respondents have no budget), and system leaders struggle to quantify the value that patient and family resources bring. Leading systems will find ways to build a better business case—and they'll share benefits with patient-family partners.

Looking ahead, system leaders and patient-family partners envision a future where all stakeholders work together to co-architect an optimal healing health system.

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“

I often say higher education was the most inflexible space I've ever been in—until I got to healthcare. It's a systems problem—it's not the people. We need to get people together from very different backgrounds—people who see things in a different way to truly disrupt healthcare. Together, we can ask better questions and get better answers. As a patient wanting to improve things, you have to have this delicate balance between being the patient pain-in-the-ass advocate who gets tolerated, and saying this is an issue I have to stand up for because it matters to me—and it should matter to you.

”

J. Greg Merritt, PhD

Founder and CEO, PatientisPartner, LLC



“

Health systems too often bring patients and families in to the transformation process too late or just to 'check the box' on patient participation. To build the humanized health system of the future, health systems need to flip the design process on its head and have patient partners co-lead the design process. Patients should identify the areas needed for innovation and should be deeply embedded in the organization as co-architects, shaping all aspects of care redesign.

”

M. Bridget Duffy, M.D.

Chief Medical Officer
Vocera Communications

Methodology

The Process

We began by isolating next practices and thought leadership from the status quo through a series of expert interviews combined with a thorough literature review of best practices.

Health System Leaders

Quantitative (n=103)

Invitation-only survey completed by 103 system leaders representing hospitals, clinics, and health systems across the US and Canada.

28%

Director

25%

VP/C-Suite

24%

Manager/Leader

22%

Frontline/Other

Qualitative (n=44)

In-depth interviews with 44 select health system executives, academics, and thought leaders focused on elevating the role of the patient and family to one of co-architect of change.

Patient-Family Improvement Partners

Quantitative (n=54)

Invitation-only survey completed by 54 patient and family improvement partners identified by WEGO Health, the Society for Participatory Medicine, PFCC partners, and Experience Innovation Network members.

34%

caregiver for a loved one with a condition or illness

66%

patients with a condition or illness

Qualitative (n=20)

In-depth interviews with 20 patient-family partners referred by Experience Innovation Network members and by self-referral during the patient-family survey.

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**Patient
Partnership Has
Yet to Achieve
“Always” Status**

**Only
1 in 5**

system respondents say their system “Always” includes patient-family improvement partners in strategic decision making.

A Patient Partner Driving Strategic Change



Cancer treatment was grueling. The only way I survived was by cobbling together a support system of integrative therapies—nutrition, exercise, guided visualization, and

the like. These therapies helped me endure the physical and emotional challenges of treatment; there's no way I could have finished without this support. Afterwards, I thought it was crazy that I had to piece everything together myself, so I approached my oncologist and the hospital and convinced them to hire me to build a comprehensive integrative medicine program.

My background is consumer marketing. I lived and breathed “customer-centricity” and “customer engagement”

for years with brands such as Harley-Davidson, Gap, and Williams-Sonoma. I have a visceral understanding of what “brand loyalty” means—after all, people love the Harley-Davidson brand so much they literally tattoo it on their bodies! So I'm thrilled the healthcare industry is beginning to focus on “patient-centricity,” but I cringe when the examples I hear are things consumer brands were doing 40 or 50 years ago. Patients deserve better than this!

There was a lot I didn't know about healthcare when I started the Center for Integrative Health & Wellness (CIHW): Joint Commission, Commission on Cancer, CPT codes—these were all new to me. I quickly realized the power certain organizations have and I became more aware of the constraints healthcare organizations face. But I have a strong vision for what patients

need and I was determined to bring that patient perspective to life, so I sometimes chose to ignore the constraints and just plow forward.

I encountered tremendous resistance at times. Many people were skeptical that I didn't have a traditional healthcare background and yet was delivering patient services. Others saw my naiveté as an advantage, though – I wasn't hindered by a “that's not how things work here” mentality nor any desire to maintain the status quo.

In the end, I was successful in building CIHW because I had the support of very respected physicians who care deeply

about helping their patients heal more fully and I had the backing of my hospital's top administrators. We need more brave leaders willing to break the paradigm, for when the mandate, support, and vision come from the top, change is both possible and accelerated.



Julie Wheelan, MBA
CEO and Founder,
Navius Health

Health Systems Are a Long Way from Always Involving Patients and Families in Transformation

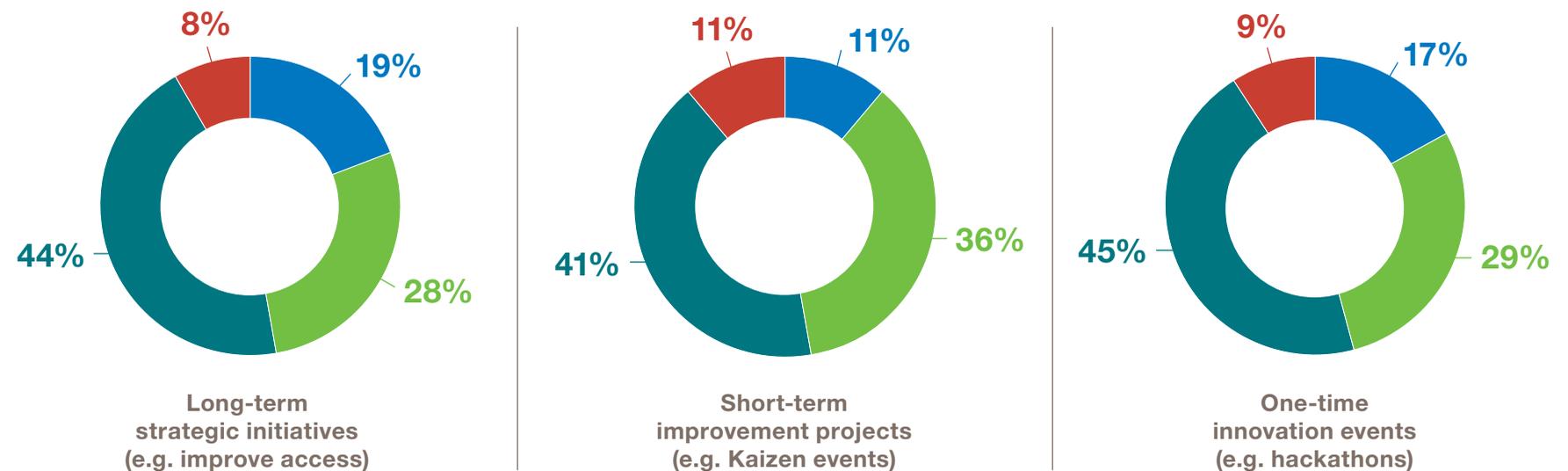
Most system respondents involve patient-family partners “sometimes”

We asked system respondents what kind of improvement programs they involve patients and families in—strategic initiatives, short-term improvement projects, and one-time innovation events. While only a small percent of respondents said they never involve patients and families in these change efforts, the largest proportion for each type of opportunity, indicated that they only involve patients and families ‘sometimes.’

Based on our interviews, the most likely explanation for this inconsistency is that there are pockets of both acceptance and resistance to inviting patients and families into the inner workings of health system processes and transformation. Only when a senior leader insists on making patient-family input an essential part of decision-making do organizations get to “always.”

For what kinds of improvement opportunities do you engage patient-family improvement partners?

n = 72



Numbers may not total 100 due to rounding

Most Systems View Patient-Family Input in Decisions as Optional

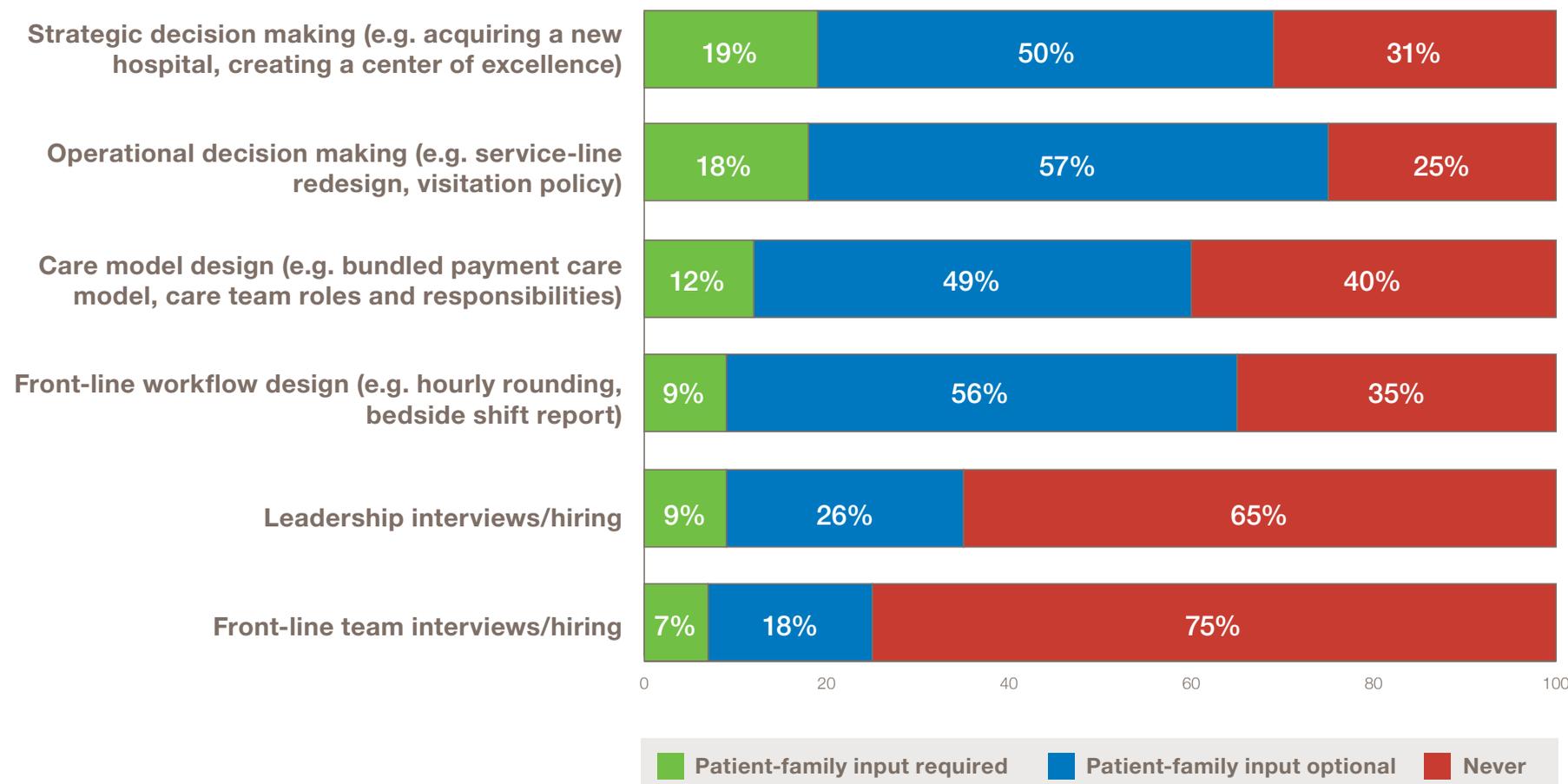
Strategic decisions are most likely to require patient-family involvement

We asked system respondents whether they involve patients and families in key decision processes, and whether patient-family inclusion is optional or required. Almost one in five respondents indicated that their system requires patient-family input into strategic decisions such as acquiring a new hospital or opening a new facility.

But across the board, patient-family involvement in decision process was much more likely to be reported as optional rather than required, and for processes such as hiring, the majority reported they never involve patients and families. Interestingly, systems are more likely to involve patients and families in the hiring of leaders than in front-line team members.

In which, if any, of the following decision processes do you involve patient-family improvement partners?

n = 68



Numbers may not total 100 due to rounding

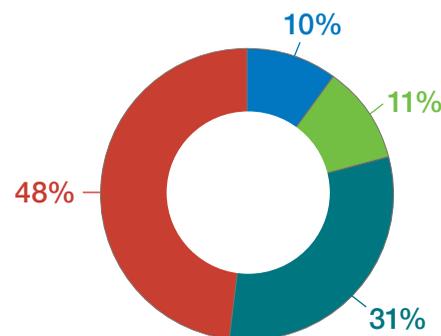
Patient-Family Partners Have Limited Involvement in Day-to-Day Operations

Root-cause analysis is most likely to include patient-family partners

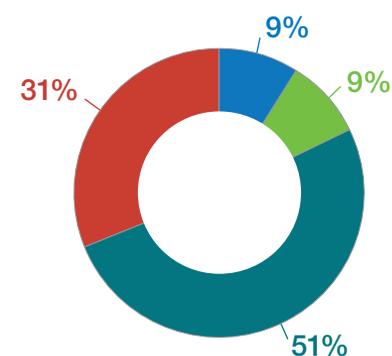
As health systems adopt continuous improvement models such as Lean, more and more improvement decisions are made through daily operations processes such as rounds, huddles, and event analysis. While only a few respondents said that patient-family improvement partners are always involved in these operational improvements, there are some glimmers where patient-family involvement is beginning to occur. Almost a quarter of respondents said they “usually” or “always” involve patient-family partners in front-line leader rounds. And more than two-thirds of respondents said that patients and families are involved in root cause analysis for quality/safety events at least some of the time.

In which, if any, of the following ways do you involve patient-family improvement partners in day-to-day operations?

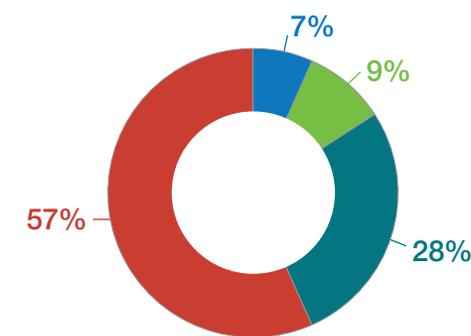
n = 65



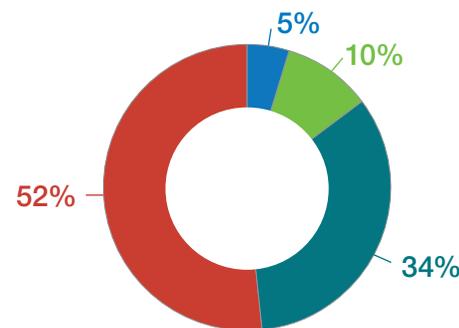
Partners involved in front-line leader rounds



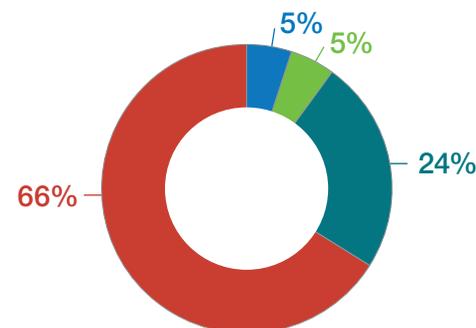
Partners involved in root cause analysis for quality/safety



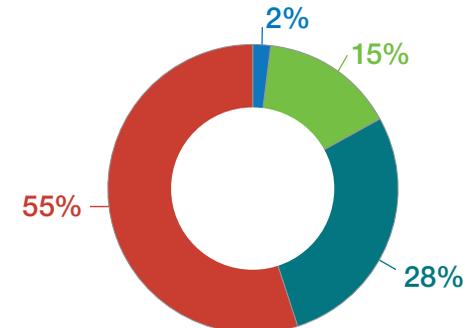
Partners involved in executive leader rounds



Partners involved in team huddles



Partners involved in morbidity/mortality conferences



Partners conduct their own rounds with current patients/families



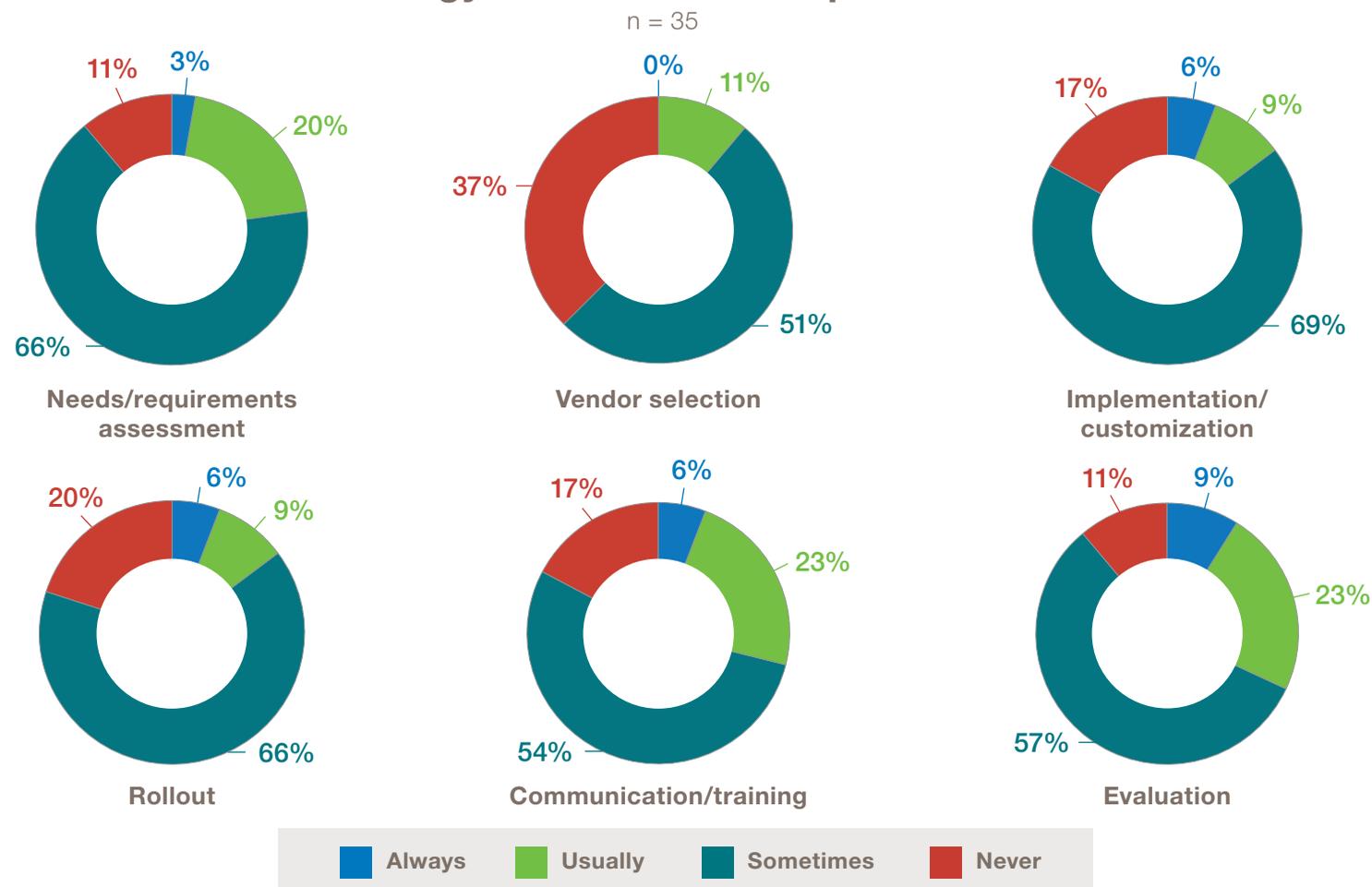
Numbers may not total 100 due to rounding

Patients and Families “Sometimes” Get a Say in Technology Decisions

Vendor selection has the lowest likelihood of patient-family input

Technology is ubiquitous in healthcare—from clinical systems such as MRI machines and surgical tools, to information systems that form the basis for data management and communication. And while only some technologies have a patient- or family-facing component, nearly all have an impact on the way that care is organized, delivered, or paid for. Still, patients and families are only “sometimes” involved in most technology decisions and implementations—and respondents said their organizations “usually” involve patients and families most often in the later stages of implementation, after technologies have been evaluated and implemented.

How, if at all, do you involve patient-family improvement partners in technology decisions and implementation?



Numbers may not total 100 due to rounding

[This question was only asked of respondents who responded “Patient input required” (10%) or “Patient input optional” (44%) for “Technology selection/implementation.”]

Kingston General Hospital Engages Patients as True Partners in All Decision Processes



Daryl Bell, M. Div., R.P.
Professional Practice Leader,
Spiritual Healthcare, Lead, Patient-
and Family-Centered Care



In 2009, Kingston General Hospital (KGH) was struggling with finances, clinical quality, and experience. The organization committed to “engage patients in all aspects of our quality, safety, and service improvement.”

Daryl Bell currently spearheads patient engagement. He described KGH’s work to ensure patients and families have a meaningful say in the hospital’s strategy and operations. “We have advisors on every program council to encourage joint learning and collaboration. We have patients and families on hiring interviews for all external hires and management positions. They speak before the CEO in orientation. When new residents start on July 1, patients speak before the chief of staff. We have patients and families on the board—they’re involved in finance, governance and people, quality/safety. Every new policy we create or which is up for renewal requires the patient’s perspective to be included. Patient engagement is in our job descriptions and employee evaluations. We include patient partners on our accreditation walkabouts.”

KGH currently has 220 opportunities on committees, working groups and projects where patients and families are partnering with staff. An essential component of success, according to Mr. Bell, is having a senior leader who is willing to stop any program or proposal that comes before the executive committee without clear input and influence from patient advisors.

Since 2009, **KGH has seen dramatic improvements in its finances, quality, safety, clinical efficiency, patient experience, and employee engagement.** “Some people say you have to rate the effectiveness of patients and family participation, which is interesting since we don’t rate the effectiveness of say, a physician at the table. It’s not just that patients and families have a vested interest, they bring value,” said Mr. Bell. “It takes time for staff to see that they are making better decisions by including the patient perspective. It took about one-and-a-half years to begin to see the culture changing.”

PATIENT-CENTERED LEADERSHIP CHECKLIST

See

Do you see patients as people beyond the numbers?

If you see a 0.08% improvement in infection rates, how many people are still leaving the hospital with an infection? Is that acceptable?

Include

Have you included patients and families today?

Can you demonstrate that patient-family perspective was included in every decision? Input can be in person, virtual, or via data.

Learn

What have you learned from a patient today?

Have you been out and talked to patients and families? If not, how can you spend your time differently to make sure you are connecting with patients and families?

Share

How do you share what you’ve learned?

As a leader, are you helping to amplify the impact of patient-family voices? And have you shared stories of other team members who effectively partner?

Providence Health and Services Invites Advisors to Inform Strategic Priorities



Chantell Fitz-Amado, BA
Program Coordinator
Providence Medical Group



When Providence Medical Group at Providence Health and Services (PHS) in Oregon created its strategic plan for 2018, senior leaders wanted to make sure the strategy was centered around what patients value most as the organization shifted from ‘patient centered’ to ‘patient driven’. Unlike many systems that focus patient-family advisory work on hospital experience and operations, PHS Oregon Region has built a strong advisory program for its medical group, managed out of its Innovation department. The program includes a virtual advisory board 540 patients strong.

PHS leaders identified six strategic priorities for their 2018 plan: experience, engagement, quality, utilization, access, and cost. They then invited patients to weigh in, and gathered patient and family input on what it would look like for PHS to deliver on those priorities. “We asked them what was important to them and what direction we should be going,” said Chantell-Fitz-Amado.

Patient input on strategic priorities is both the what and the how of PHS’s Providence Medical Group’s services. For example, patients made it clear that access is about getting in to see doctors where they most need them. So PHS has built on-demand services through clinics at Walgreens, as well as offering video visits with patients’ doctors. To support cost containment, they offer standalone express care clinics with fixed-price services. “For 2018, based on patient feedback, on-demand services ranked among the top four priorities,” Ms. Fitz-Amado reported.

To make sure that patients continue to have a voice in clinic and system priorities, Ms. Fitz-Amado connects continually with clinic leaders to learn where they are interested in getting patient feedback while facilitating the sharing of best practices across clinics. “Clinic leadership has to be on board for a successful and engaged PFAC,” she stressed.

Strategic Priority	Patient-Informed Value
Experience	Deliver care with ease and unforgettable compassion
Engagement	Enable sustainably engaged providers and caregivers
Quality	Provide clinically excellent, comprehensive and coordinated care
Utilization	Right care, right time, right place
Access	Provide exceptional access and continuity of care
Cost	Bridge the value chasm

Patients and Family Members Have the Power to Drive Strategic Innovation



I was once on a PFAC. They had us design a lobby. We should have a lobby, but we can help with so much more—fundamental care design, access to data, patient partnership, communication. We're already changing what it looks like to be a patient. There's so much we could do to transform healthcare. I see hospitals being the place people want to go, with Internet access and a place to play. They can become the hub of the community if they change how they talk to patients.

– Regina Holliday
Artist and Patient Activist

Our leadership pays a lot of attention to what the people on our PFAC think and what they think the priorities should be. There's a lens that patients and families have that staff doesn't. They are held in high regard. They influence the prioritization of our goals.

– Patricia Stahl
PFAC Staff Liaison and Manager of Volunteer
Programs and Services
Dana-Farber Cancer Institute

I was on the committee to evaluate candidates for the CEO and COO position at my health system. My opinion was given the same weight as everyone else there. I was treated just like everyone else on the committee. I think we made a very good choice.

– Michael Asip
Patient Improvement Partner

Innovation Opportunity: Commit to Patient-Family Transformation Partnership—Always

Include patients and family members in:

Strategic Decision Making

- ✓ Annual strategic planning
- ✓ Merger and acquisition decisions
- ✓ Hiring decisions
- ✓ Technology decision making
- ✓ Service line or process (re)design
- ✓ Care transition (re)design
- ✓ Communication planning and training
- ✓ Policy creation, updates, sunseting

Patient-family partners for strategic decision making may draw from PFACs or governance committees, or systems may choose to hire patient-family partners with specific experience or expertise.

Daily Operations

- ✓ Leader rounds
- ✓ Visual management boards (e.g. “ideas in motion”)
- ✓ Daily huddles
- ✓ Root-cause analysis
- ✓ Peer navigators
- ✓ Peer rounds

Patient-family partners for daily operations may draw from PFACs or governance committees, or systems may choose to engage people actively receiving services who are well enough and interested in contributing.

Getting to Always

Make a rule: If a change involves more than three people or three process steps, patient input is required.

Patient-Family Involvement Structures Reinforce a Lack of Strategic Involvement

81%

of system respondents have at least one patient-family advisory council (PFAC)

But

only 33%

have a patient or family representative on their board of directors

Hospital-Level Patient-Family Advisory Committees are Common

Less than half of system respondents have clinic-level PFACs

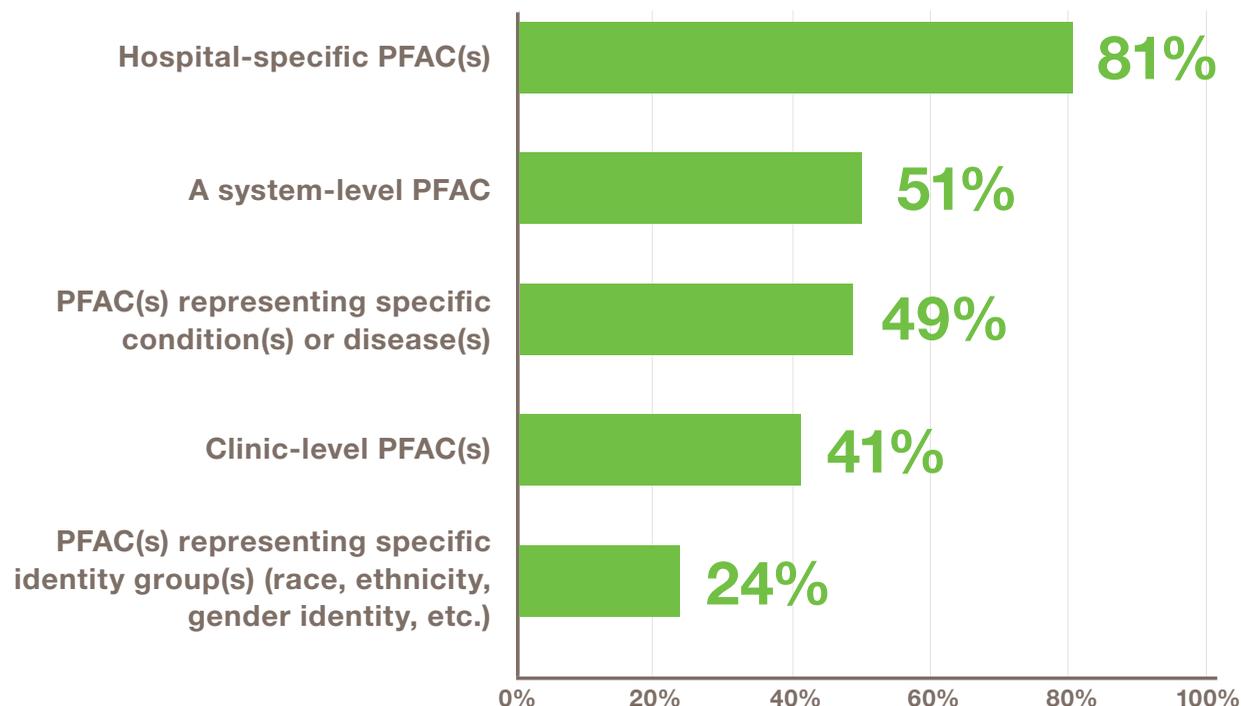
Eighty-one percent of system respondents indicated that their organization has at least one hospital-level, patient-family advisory council (PFAC). Based on our interviews, PFACs are among the most ubiquitous ways to assemble patient and family partners to weigh in on issues, offer feedback, and engage in health system, hospital, or clinic business in an ongoing way. Some U.S. states, such as Massachusetts, have passed legislation mandating PFACs, which may explain, at least in part, their popularity.

Almost twice as many respondents have hospital-level PFACs as have clinic-level representation. With continued pressure to shift care to outpatient settings, plus PFA requirements for [CPC+](#) clinic designation in the U.S., we expect to see the creation of formal mechanisms for patients to influence clinic transformation.

Please indicate whether you have any of the following type of patient-family advisory committees (PFACs):

(multiple responses accepted)

n = 79



Patient-Family Partners Report a Variety of Experience

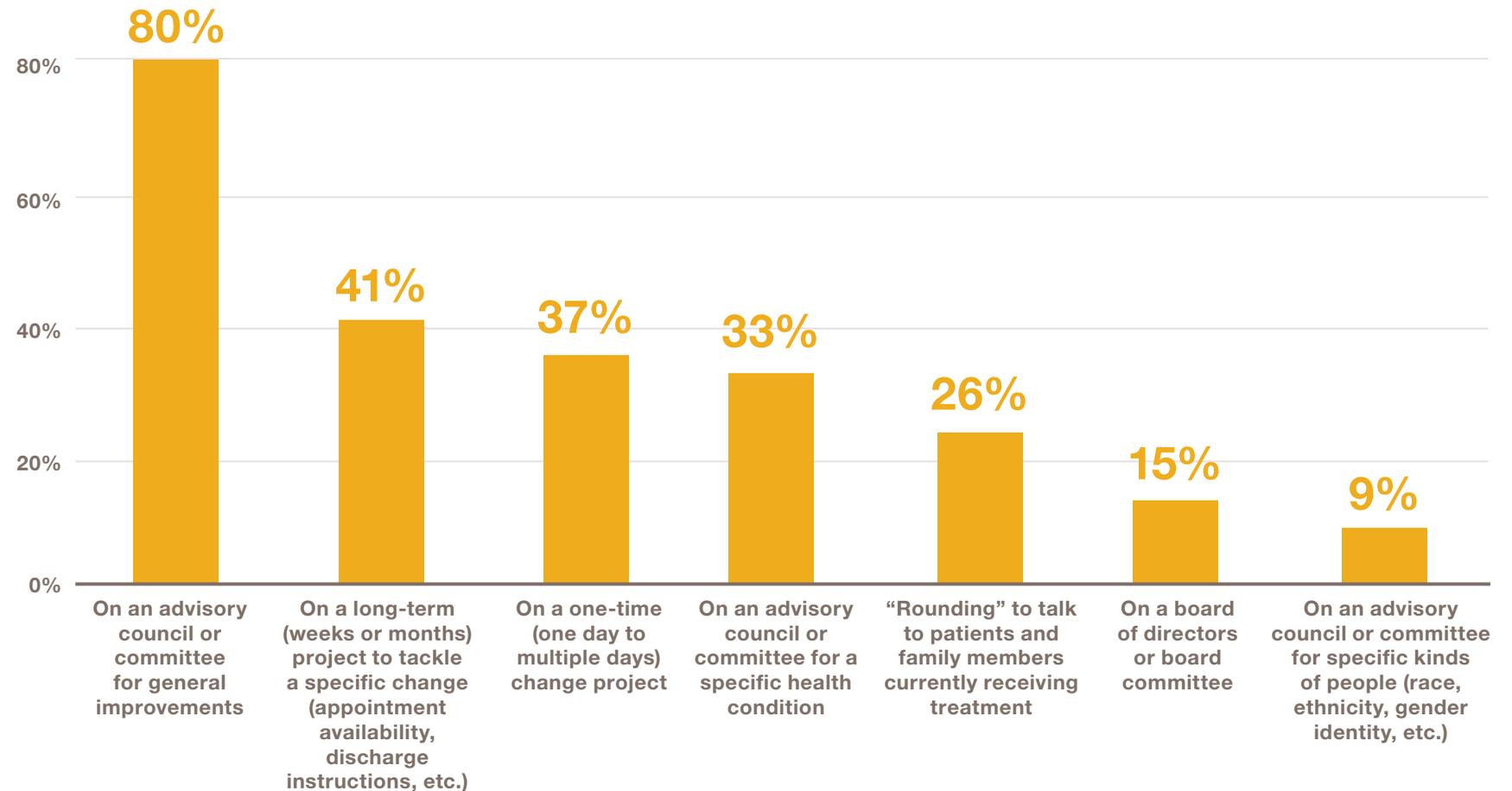
Advisory committees are more common than focused project work

The patient-family partners we surveyed reported a variety of different ways they participate in health system improvement. Most have worked on advisory committees for general improvement (80%), and 33% have experience on a committee for a specific health condition. Fifteen percent have been involved in a committee of the board. Only 9% have been involved in a committee that focused on specific kinds of people (race, ethnicity, gender identity, etc.).

Project work is less common than committee work, but 41% have engaged in a long-term improvement project, and 37% have been involved in a shorter-term innovation project.

How have you worked with health systems to drive improvement? (Please select all that apply.)

n = 54



■ denotes patient-family partner survey data

Patients and Families are Gaining Board-Level Representation

Quality/safety committees have the highest likelihood of patient-family representation

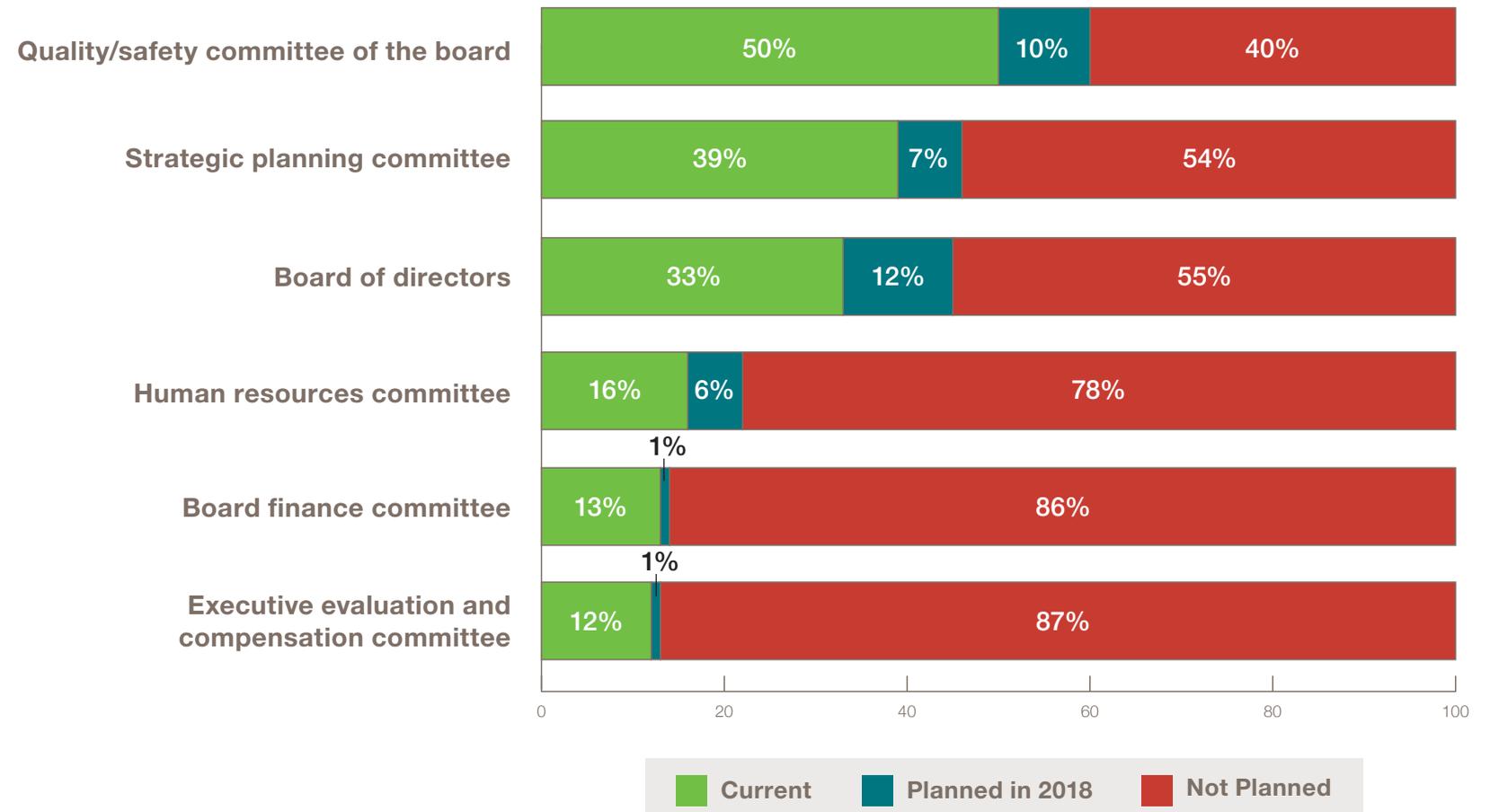
Fifty percent of system survey respondents indicated that patients and families are part of the quality/safety committees of their boards, with another 10% planning to add patient-family representatives in 2018.

But patients and families still lack representation at the highest level of the board—where votes and decision authority often rest. Only 33% of respondents said there are patients and families on their board of directors. Only slightly more (39%) said they have patients and families on their strategic planning committees.

Patients and families are also notably absent from board committees responsible for executive evaluation and compensation, human resources, and finance.

For each of the following boards and board committees, please indicate whether patient-family improvement partners are members of the committee:

n = 101



Building a System-Level Advisory Group at Ascension

Ascension is undergoing an ambitious transition from a system of systems to an integrated health ministry. The strategic shift involves setting strategy at the system level, as well as sourcing and spreading best practices consistently to local regions and ministries.

While many local ministries had robust and effective patient-family advisory councils, system leaders felt strongly that tapping into the voices of those they served to inform the national strategy would be essential. “Truly listening to the voice of those we serve allows us to better deliver on our Ascension promise to provide compassionate, personalized care,” said Marie Judd, MBA, FACHE, SPHR, CPXP. “As we continue to evolve as a national system, we need new ways to listen to our persons/patients, families, associates, and providers to take meaningful action.”

The national person and family engagement team, led by Ms. Judd, has

invited advisors who have contributed effectively in their local ministries to participate in the national advisory council. The council will “meet” in a lot of different ways (phone, email, in-person) to accommodate both geographic spread and diversity. “Building a diverse and inclusive person and family advisory council allows us to live our mission, eliminate disparities in care, and honor our promise by understanding what matters most to those we serve,” said Ms. Judd.

The system-level advisory council, facilitated by April Tinsley, RN, MBA, NE-BC, CPXP, is being co-created with its founding members. “We co-created a vision, and now we’re doing process checking to make sure we’re meeting it,” reported Ms. Judd. “We ask, ‘Are we living up to this vision? Where are our gaps? How can this group add the most value?’ Every six months we go through a stop-start-stay evaluation. We’re asking our advisors for feedback on process and logistics as well as strategy.”



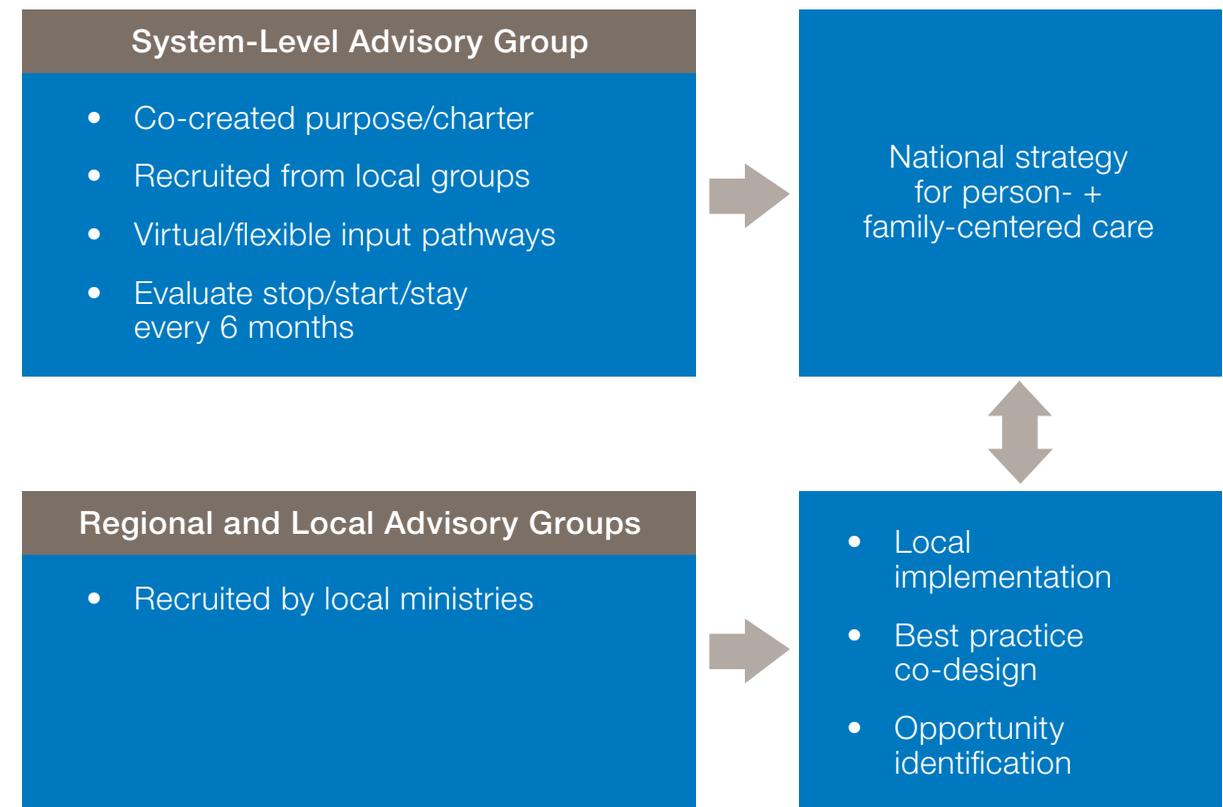
Marie Judd
MBA, FACHE, SPHR, CPXP
Senior Director, Care Excellence



April Tinsley
RN, MBA, NE-BC, CPXP
Director, Care Excellence



Ascension



Hackensack Meridian *Health* Engages Patients from Input to Advocacy

Like many health systems, Hackensack Meridian *Health* (HMH) is the product of mergers and acquisitions across several legacy systems and hospitals. The system's goal is to take a unified approach to all aspects of the quadruple aim (quality/safety, cost, patient-family experience, and joy in work) through a unified governance structure consisting of system-level executive oversight, a system-level Human Experience Steering Committee, hospital-specific Quadruple Aim Councils, and unit- or department-level dyad leadership teams.

While building out their governance structure, HMH devised a voice-of-the-patient strategy that embeds patients and family members into ongoing governance, targeted improvement projects, innovation selection, and one-off input opportunities. To make sure patient-family partners and team members are clear on responsibilities and expectations, HMH has devised clear and distinct roles that allow patients and their care partners to participate in defined ways at the system and facility levels.

► **Advisors** provide feedback on specific solutions, such as the design of an application to support breast cancer patients, or helping to select which innovation proposals will receive funding at one of the system's Experience Innovation Café events.

► **Designers** participate in Patient-Family Design Teams (PFDTs) to assist with targeted projects with measurable results and a reasonable timeframe. PFDTs are typically convened by the Quadruple Aim Councils or local dyads to tackle a known issue.

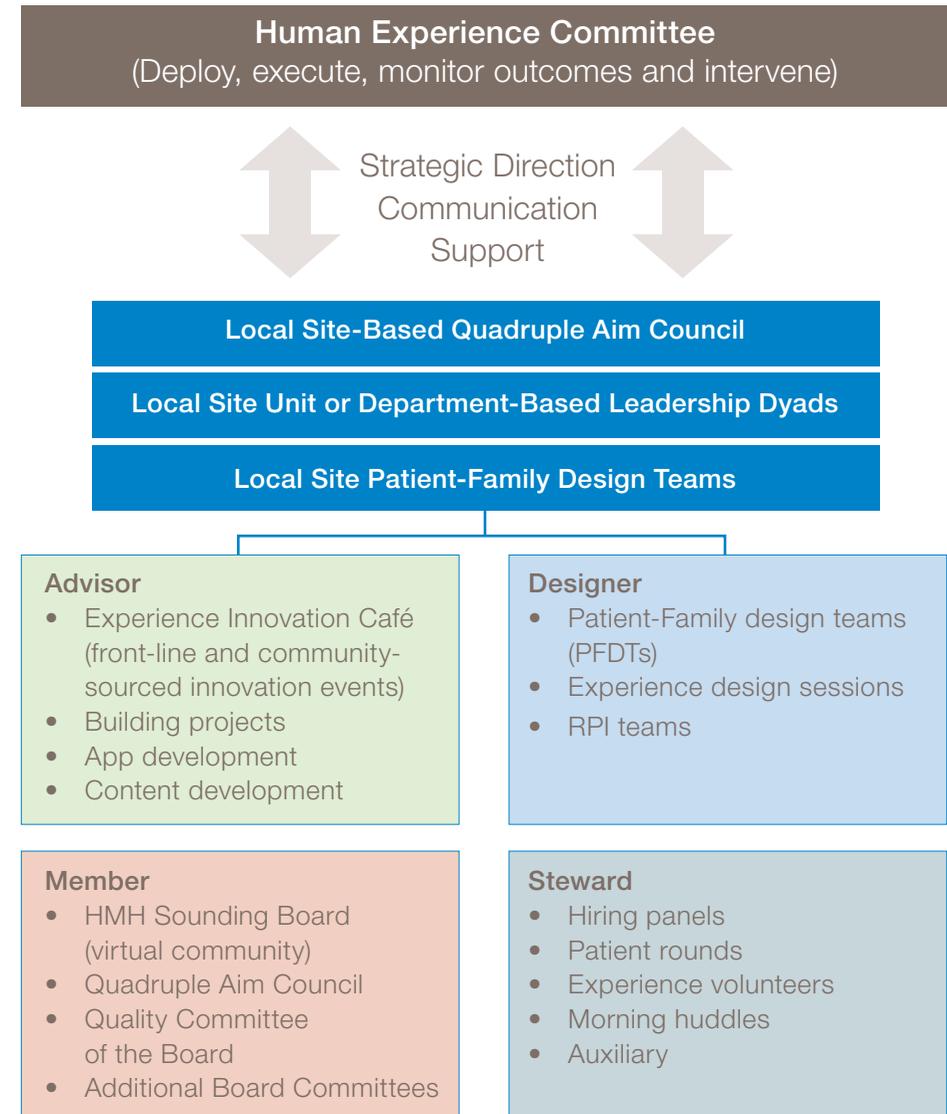
► **Members** sit on board committees and other governance councils to provide ongoing input into strategy and priorities. They also join the HMH Sounding Board, a technology platform with 4,000 volunteers who have consented to share personal information and provide on-demand input either virtually or in person.

► **Stewards** are selected based on previous work with the system to participate in daily operational activities such as hiring panels, patient rounds, and morning huddles.

"We're invested in this approach," said Tria Deibert. "We're building a database of all the patients and family members we've worked with, including what made them unique and what they helped us with. It allows us to recruit the right people for the right roles."



Tria Deibert
Vice President
Experience Marketing

True Partnership with Patients and Families Takes an Intentional Effort



Good partnerships with patients and families for improvement don't happen by accident. Organizations have to have some level of infrastructure, similar to other major aims. If you're serious about it, there has to be the time, energy, and infrastructure to do it.

– Barbara Balik, EdD, MS, RN
Institute for Healthcare Improvement Senior Faculty
Common Fire Healthcare Consulting

My primary job is supporting the patient-family advisors for our medical group. It's very unusual for an organization to dedicate someone to a position like this, but it lets me really focus on building relationships and making sure there is as much value for our advisors and for us as possible.

– Chantell Fitz-Amado, BA
Program Coordinator
Providence Medical Group

We were very intentional when we set up our patient-family partnership program. We worked with patients, staff, and leaders to design every aspect of it. It's a lot of work to keep it going—a lot of hand holding, calling, emailing, and sending letters home so everyone can stay engaged. It's about knowing our partners, knowing what's important to them, and helping them contribute in a constructive way.

– Phuong Hathaway, MS, CTRS
Chair of Patient and Family Advisory Council
San Mateo Medical Center

Innovation Opportunity: Embed Patient-Family Partners in All Aspects of Governance

Board of Directors

- ✓ 1-2 patient-family partners required on the board
- ✓ 1-2 patient-family partners required on each committee of the board (quality/safety, finance, compensation, HR, etc.)
- ✓ 2-4 year terms of service. Limit: 2 terms

Operational Governance

- ✓ 1-2 patient-family partners required on each governance committee with decision authority
- ✓ Patient-family partners optional but encouraged for governance committees without decision authority
- ✓ 2-3 year terms of service. Limit: 1 term per committee

Ongoing Improvement

- ✓ 1-2 patient-family partners required on each improvement project
- ✓ Patient and family input required for improvement proposals
- ✓ Terms of service limited to length of project or program. Unlimited participation, based on partners' interest

Community of patient partners who contribute virtually and/or in person on a continuous basis.
Organized by geography/facility and affinity (condition, expertise, background, demographics, condition, etc.).
Reflective of the full diversity of the service area.

Patient-Family Partner for Governance Groups

Make a rule: A person who identifies **first and foremost** as a patient or caregiver, not just someone who has received care at a your facility.

Expanding Patient-Family Voice
from the 'How' to the 'What'

Patient-Family Partners Get More Say in the 'How' than the 'What' of Improvement

only
42%

of patient-family respondents
said they get a say in what
problems to address

82%

of system respondents
involve patient-family
partners in brainstorming
solutions to problems

Versus

61%

who engage patient-family
partners to decide what
problems need to be addressed

Patient-Family Partners Have More than Feedback to Offer



I was completely healthy until I was 41 years old. Then I got incredibly ill and was in the ICU and the hospital for nearly a year. I'm well now—I have a regimen and still

see my doctors. And I work with my health system on their advisory committee for the ICU. I love the people at my hospital. **When they interviewed me for the PFAC they made it clear, 'We have a list of things we want to accomplish, and we don't want to deviate. We appreciate your opinions, but aren't looking for our advisors to bring your own agenda to these meetings.'**

We've worked on some good things such as rewriting a letter for patients leaving the ICU. It started with a statement that felt like "congratulations"—but nobody wants to move out of the ICU once you're there. You've had two people dedicated to you, and now you're going to a floor where the nurse will have six patients. It's terrifying. We rewrote the letter. We also did a project on the waiting room and I hope I saved them money. They wanted to change things that really don't matter to patients—like the floor.

One of the biggest ways I made an impact was doing a role-play for intakes. I got in a bed with a johnny on and shared my exact symptoms to an intern and then offered constructive criticism. The first question she asked me was if I had an end of life plan and a health care proxy. I know she needed answers to

both questions, but if I had been asked that when I first entered ICU, I would have been petrified and thought that they must know something serious I don't. My suggestion was to put context around the question and say something like, "Nancy, we have to ask you a couple of questions today—as we do for everyone who comes through these doors. I don't want you to be alarmed, but I do need to ask them. May I go ahead?" I would have thought that this was normal operating procedure if they had been a set-up like that. I felt like it was an eye opener for her and that she appreciated the feedback.

It really would be different if the patients were setting at least part of the agenda. I'd encourage them to focus on things I remember from my ICU stay, like getting woken up in the middle of the night for blood draws when I needed sleep to

heal. Or how important hope is—one of my nurses, Erin, gave me hope just by telling me I was going to get better. Another let me go outside against protocol so I could feel the sun on my skin. That piece of hope was so healing. That's what I would tell them to focus on.



Nancy Michaels
Speaker and
Author on effectively
communicating
with key customers
Author of *Patient Speak*,
*7 Communication Practices
to Improve Patient and
Family Experience*

Patient-Family-Led Innovation



Fifteen years ago, I was stricken with a chronic pain condition. It took 10 years to find the right diagnosis, treatment, and cure. During that period, I became profoundly

aware that my health trajectory and my stamina for enduring were completely tied into my relationship with my primary family caregiver—my husband. Our relationship was as important to my ultimate recovery as was any doctor. He and I not only made all medical decisions together, he provided hope and practical help so that I could bear the day-to-day until I found providers who helped me get better.

I became very interested in and researched the ways patient/caregiver relationships can affect health outcomes. I wrote a book (*Love in the Time of Chronic Illness: How to Fight the Sickness, Not Each Other*) and started working with health systems to help providers support (and not inadvertently harm) that vital connection between patient and caregiver, at a time when they are most vulnerable, as part of providers' day-to-day work.

The caregiving relationship has a profound impact on health and treatment follow through. One story I heard repeatedly in my research: The doctor prescribes a new medicine to the wife. The husband says, "What? Why do you need another medicine?" She stops taking the medicine and doesn't tell her doctor. Some health systems are already patient-centered, and some are aware

of how illness impacts the caregiver. Neither one of those is sufficient. The missing element is not the patient alone or the caregiver alone; it's the two of them together – how they make health decisions and sustain each other during an illness experience.

I work with a large health system to create and deliver a course for care team members based on my book. We teach it in three modules. The first module is about the caregiver—what they do and the challenges they encounter. The second describes the ways illness affects the patient/caregiver relationship and the tools providers can use to strengthen that relationship. In the third module, we talk about the research that shows that including the caregiver and paying attention to the patient/caregiver relationship lead to better outcomes.

I'm grateful for opportunities to share what I've learned about the centrality of the patient/caregiver relationship to resilience and health outcome. It's a powerful dynamic that's easy to overlook, until you've lived it.



Barbara Kivowitz, MSW

Healthcare Consultant,
Author, *Patient-Family Advisor*
Author, *Love in the Time of Chronic Illness*

Patients and Families Are Most Often Asked to Weigh in on System-Identified Issues

Improvement partners don't often get to identify which problems are a priority

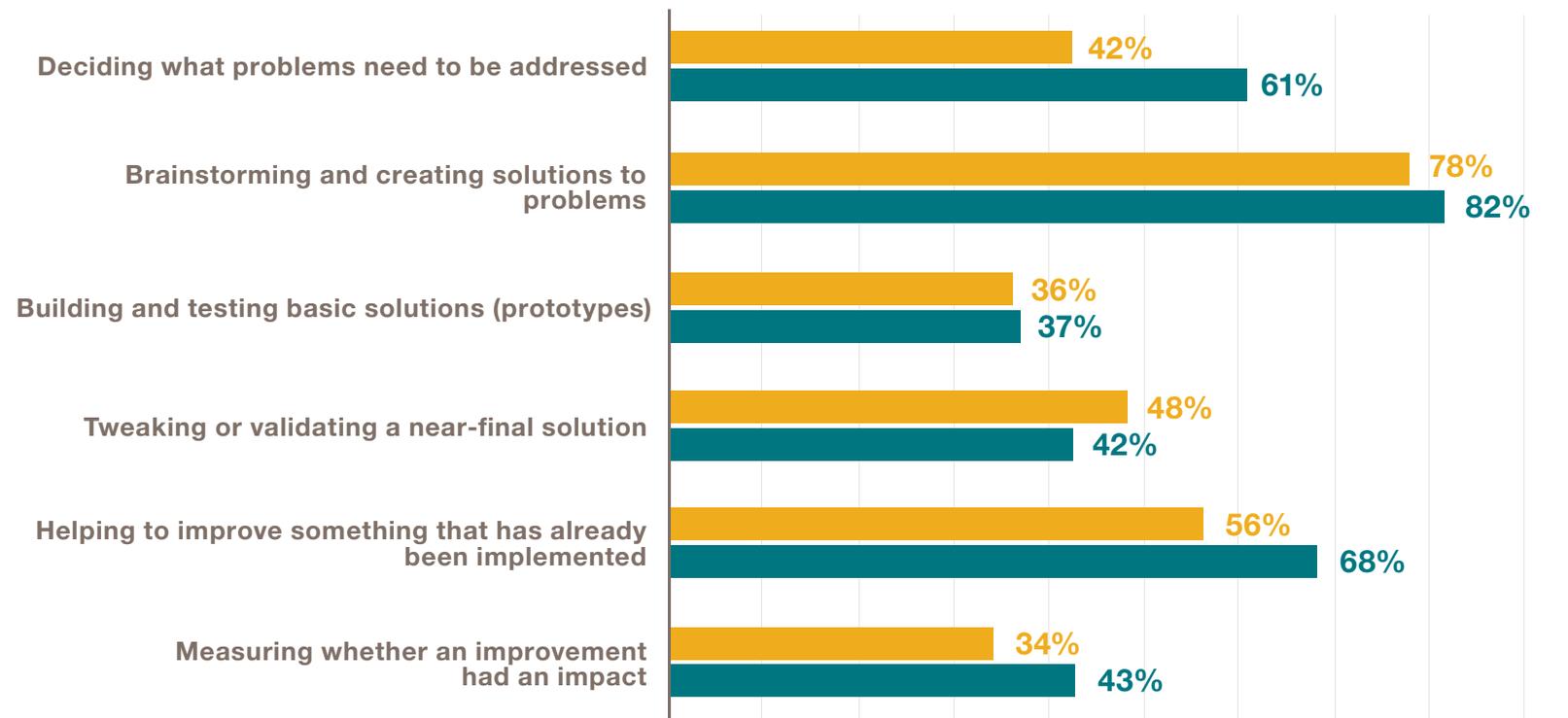
Although 61% of system respondents reported that patient-family improvement partners are involved in deciding what problems need to be addressed, only 42% of patient-family respondents agreed. Both patient-family and system respondents indicated that patient-family improvement partners are most commonly involved in brainstorming and creating solutions to problems. While this is a crucial component of co-design, many patients and family members expressed frustration in both the survey and interviews that they don't get more of a say in deciding what issues are most important to address. Said one survey respondent, "I think hospitals would get more real value by asking patients what they think needs to be focused on as well. It's always surprising to see how much impact we have on issues (correspondence, etc.) that they are almost ready to send out."

Which of the following best describes when you are typically asked to offer input into improvement opportunities?
(Please select all that apply.)

n = 50

Thinking about the typical kind of request for input your patient-family improvement partners receive, at which parts of the process is their input requested?
(Please select all that apply.)

n = 76



■ denotes system leaders survey data

■ denotes patient-family survey data

Patient-Family Improvement Partners Value Full Partnership in Transformation Efforts

Improvement partners' best experiences involve respect and results

When we asked patient-family survey respondents to describe the positive attributes of their best experience working with a health system on improvement, a key theme across almost half of responses was that they felt respected, their opinion was valued, and that the system partners they worked with really listened to what they had to say. Another one in five said they appreciated when they could see the impact of their efforts through immediate change.

Thinking about the BEST experience you've had working with a health system on improvement, what made it particularly good? (results aggregated from open-ended responses)

n = 54



■ denotes patient-family partner survey data

“ I felt heard, and was a full partner in the design of my care.

- Patient-Family Partner Survey Respondent

The work we did translated into demonstrable changes that affected all patients for better health care.”

- Patient-Family Partner Survey Respondent

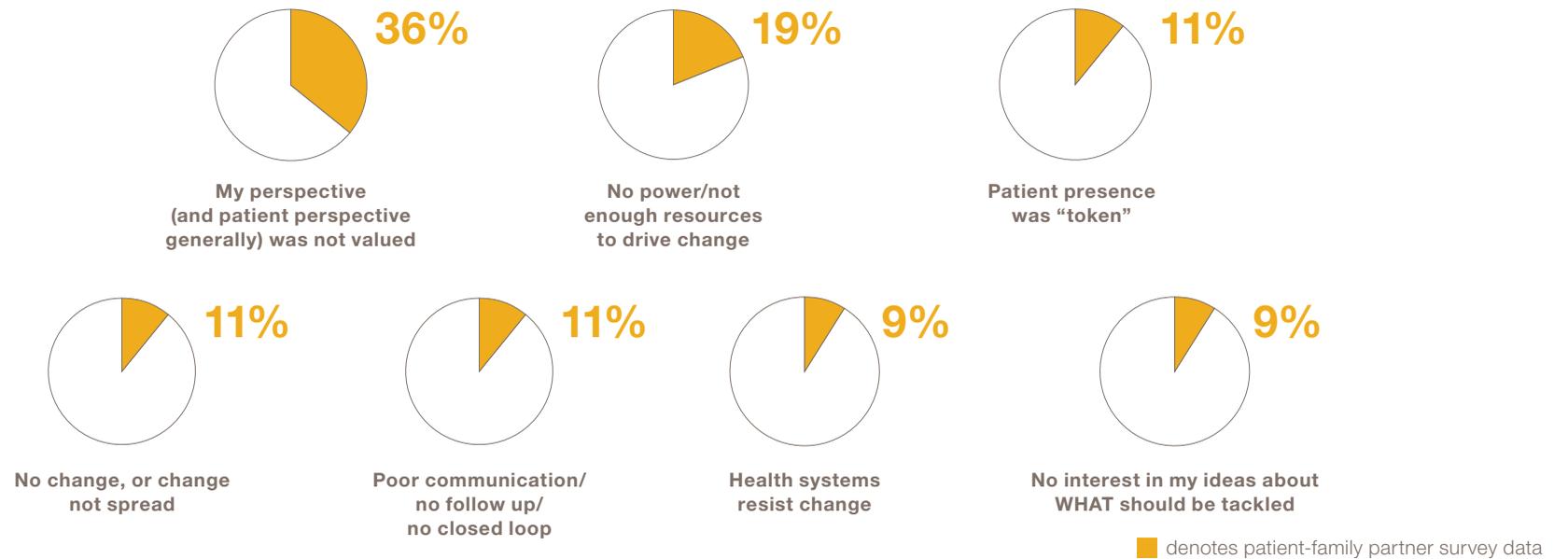
Patient-Family Partners Know When Their Perspective Isn't Valued

Improvement partners cited not feeling heard and not having power to create change as their worst experiences

When we asked patient-family improvement partners about their worst experiences working with health systems, more than a third said it was when their perspectives weren't valued as much as other participants in the process. Another 11% described feeling like they were included as "token" patients, and that the organizations they worked with weren't really on board with including patients as partners in transformation.

Thinking about the WORST experience you've had working with a health system on improvement, what made it particularly bad? (results aggregated from open-ended responses)

n = 53



When it seemed like I was only being asked what I thought as a stamp of approval.

- Patient-Family Partner Survey Respondent

Not getting any follow-up on ideas. Were they implemented? What happened?

- Patient-Family Partner Survey Respondent

Very strong cultural resistance to innovation and change.

- Patient-Family Partner Survey Respondent



MU Health Care Engages Issue-Oriented Advocates to Solve Focused Problems



Kevin Gwin

Chief Patient Experience Officer



In many of our interviews, system leaders responsible for coordinating patient-family improvement partners talked about steering clear of people with a specific “axe to grind”—an issue that was of high importance to them —because they would not be able to set aside their single issue focus and contribute productively to the ongoing and multi-faceted work of a PFAC.

But at University of Missouri Health Care, Kevin Gwin seeks out patients and family members who have signaled interest in a particular issue. Using data from a variety of sources (grievances, compliments and complaints, survey data, social media, and open-ended feedback), Mr. Gwin and his team identify issues that are detracting from the patient-family experience or resulting in diminished care outcomes. “Then, I use our data to identify people who have struggled or recognized us for great work related to the issue we want to improve on,” reported Mr. Gwin. “We put them together for a specific purpose they care about, and they do their thing.

They create ideas and they let us go.”

The first step in Mr. Gwin’s strategy was to eliminate anonymous surveys in favor of results that can be tied back to patients’ medical records and revenue cycle information. “We reach out to patients who give us a low score so we can understand how to improve,” said Mr. Gwin. “Not once has a patient complained when we follow up—mostly they appreciate it.” In cases of grievances, Mr. Gwin and his team work to resolve the grievance first. “That’s helpful—it lets us understand if it’s a systemic issue that affects a lot of people, or just a one-time misstep.”

Working with targeted, project-focused teams brings a different kind of energy to improvement. “When I choose mini groups, I’m bringing people with an agenda to the table. It’s a different type of activation than from the PFAC,” reported Mr. Gwin. “I can also use the data to make sure I’m getting a diverse set of voices.”

Intersect patient experience data with medical record and revenue cycle data to uncover focus areas.

Use patient comments from those focus area surveys, as well as grievances, complaints, compliments and ideas (again specific to those areas) to identify specific patients to join improvement efforts.

Reach out to patients and families to participate in the improvement project or, if not, to dig deeper into focus area.

Assemble patients and families to work with targeted, time-limited improvement projects.

Recognize participants for their contribution.

Kaiser Permanente Evolves to Ubiquitous Patient-Family Voice



Jonathan Bullock
Principal Consultant



KAISER PERMANENTE®

Kaiser Permanente started down the path to partnering with patients for improvement more than a decade ago. In the initial stages, leaders had the typical fears: Will they come? Will they be demanding? Will they be unrealistic? “We found out patients were much more sophisticated about health and healthcare than we’d given them credit for,” reported Jonathan Bullock.

A series of successful collaborations and quick wins spread by word of mouth among managers, leading to a growing acceptance of patient-family partnership as the best approach to improvement work. The program has grown significantly, but there are still some hurdles to overcome. “The argument now is that it’s something nice to have, just not nice to have right now. Our push is to view patient partnership as a must have, and must have right now,” said Mr. Bullock.

As the work has evolved, the organization has built closer collaboration with patient-family partners, beyond the original PFAC

structure. “We’re embedding patients into our internal structures because it’s more effective,” explained Mr. Bullock. “At the same time we’re targeting patients with conditions or journeys that need improving and embedding them from conception to conclusion in co-design.”

In one example, Mr. Bullock and his team worked with transgender patients, recruited from across the community, to create a clinic designed to meet their needs. “Patients came in from the start, told stories, said what’s important to them. We had working groups to test ideas, build on them, build prototypes, and then roll out in the clinic. That clinic is now very successful. The satisfaction scores reflect that what patients get is what they want and need.”

Mr. Bullock’s vision for patient-family partnership is bold. “We are building out the steps to take crowdsourcing even broader—using virtual platforms, social media, texting, etc. I’d love to make it almost imperative for every patient to sign up at some level.”

Early 2000s	
<ul style="list-style-type: none"> • 10 partners ID’d by ombudsman • Focus on issue resolution 	<ul style="list-style-type: none"> • Fear and skepticism common among leaders
Today	
<ul style="list-style-type: none"> • 800+ partners • 75 councils (focused on cancer, transgender, autism, etc.) • 100 partners embedded in internal workgroups/committees • Partners on regional leadership committees 	<ul style="list-style-type: none"> • Focus on co-design • Patients recruit peers (for diversity) • Multiple pathways for inclusion • Limited skepticism; some inertia
Future	
<ul style="list-style-type: none"> • All patients contribute • Every touchpoint (portal, social, texting, in-person, etc.) is a pathway for feedback and co-design • All team members solicit patient input 	<ul style="list-style-type: none"> • Patient-family centered care principles married with improvement work • Patient-family partners integrated in operations

Patient-Family Partners Have a Passion for Driving Meaningful Change



We have recently welcomed a patient advisor who came to us with a passion to create a better experience for victims of violence. We are partnering with her and redesigning that process with better connections to community resources. We figured out a way to put in place what we could, including clothing, blanket, and a journal. It was because of her initiative and drive that we're making these improvements.

– CJ Merrill, MSN, CPXP, CPHQ
Patient Experience Officer
Mission Health System

Patients can help craft patient centered policies/processes. Include us from the beginning. We can bring new perspectives and ideas that will help improve healthcare. Often we are asked to sign off on a fully developed plan. It would be much more beneficial to include us in the planning to keep the patient focus. How can you plan something for patients without our input?

– Patient-Family Partner Survey Respondent

We have patient-family advisors on 14 or 15 different committees, including the Quality Committee, Patient Safety Committee, and Ethics Committee. Getting advisors on board committees lets them influence higher-level strategic decisions. It also helps leaders get comfortable with the idea of having a patient or family member at the table with them, listening, learning, and sharing their opinions. That comfort increases the level of trust and opens up other opportunities for partnership.

– Marilyn Potgiesser, BS, RNC
System Manager, Patient and Family-Centered Care
Bronson Healthcare Group

Innovation Opportunity: Patient-Led Design



- Patient-family partners contribute to the priorities and identify challenges to focus on
- Patient-family partners take part in surveys, interviews, and observations to understand the current state

- Patient-family partners co-define scope, focus, and success metrics
- Patient-family partners co-define problem statements

- Patient-family partners brainstorm solutions, drawing on expertise from their healthcare and non-healthcare experience and expertise

- Patient-family partners help create prototype solutions (processes, communication, technology, etc.)
- Patient-family partners help refine solutions until a viable prototype is created

- Patient-family partners help collect feedback and refine solutions
- Patient-family partners help collect success metrics
- Patient-family partners help spread and scale successful ideas



If you want to fix your vacation scheduling, find a patient from FedEx that has worked logistics her whole career—not a doctor who thinks they know how to fix scheduling.

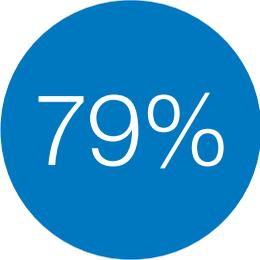
- J. Greg Merritt, PhD, Founder and CEO, PatientisPartner

I think people who have spent years in healthcare are numb to the multiple touchpoints in a typical patient experience that are not customer-centric, from public signage announcing meetings for “How to Move the Obese Patient” to ridiculous hospital gowns to the naming of hospital floors. For a patient, being sent to the “Cancer Center” or “4th Floor-Oncology” is terrifying! My vision is to pull together a cross-section of top talent from highly customer-centered brands to walk through a hospital and point out all the little things that are the antithesis of “patient-centric.”

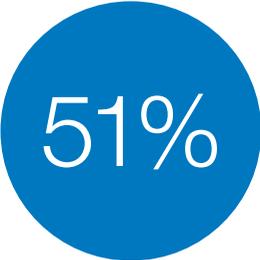
- Julie Wheelan, MBA, Founder and CEO, Navius



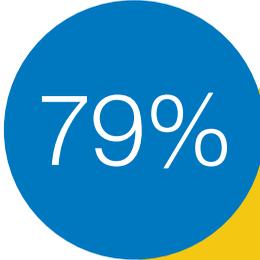
Patient-Family Partners Often Receive Little Preparation for their Roles



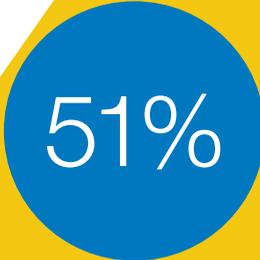
of system respondents say training for patient-family partners is 'Extremely Important' or 'Important.'



of system respondents offer only standard volunteer orientation or no training for patient-family partners



of system respondents say training team members to work with patient-family partners is 'Extremely Important' or 'Important'



of system respondents offer limited or no training for team members working with patient-family partners

A Patient-Network Building Transformation Skills



In 2016, a group of patient advisors in Canada got together and decided to form a network. We hammered out a manifesto and formed a community of practice with the

goal of giving patient advisors the tools they need to be effective collaborators. Now we have more than 100 members across the country.

We want to help other people raise their capacity to be involved. Our website has resources in the public area about things like storytelling—then there’s a members-only section that has more tools and ways for people to connect. We try to

pair people up where you have an experienced patient and a naïve patient going to an event. The naïve patient gets their feet wet, and the experienced patient helps support them. We also help connect patient advisors with the right opportunities. Just because I can talk about the patient perspective on innovation, it doesn’t follow that I can talk about value-based procurement! Help from fellow members is welcome.

If you don’t know how to participate, you can’t have the full impact you want. If you ask a new patient to create slides and they’ve never done that, it’s intimidating.

The hard part in becoming a patient advisor who is involved and active is developing the confidence to give your opinion. You need the conviction that the patient voice is valuable and deserves to be there. I gained confidence from a design thinking challenge at MedicineX. I think I’ve taken all the courses available in patient involvement in research. The Partners in Research course is a good one, in its fourth iteration, and they’re continuing to involve advisors. I’m co-presenting now with the researcher/doctor who is involved in the course.

Ultimately, patients and the public are supporting the whole healthcare system—through taxation, insurance, etc. Everyone is supported except patients. There should be funds to support patient

groups that are not disease-based. Patients also need to have formal and informal ways to network.



Annette McKinnon
Patient Advisor
Founding Member
Patient Advisor’s Network

www.patientadvisors.ca

System Respondents Value Role Descriptions and Recruitment Over Charter and Governance

System leaders focus on getting the right patient-family partners in the role

When we asked system respondents to rate the importance of different elements to the effectiveness of their patient-family improvement partnerships, they rated clear role descriptions and effective recruitment and selection processes in the top two slots. While 60% and 56% rated role descriptions and recruitment as extremely important, respectively, only 39% gave the same weight to having a clear charter and governance guidelines—the tools that define what partners are responsible for and how they will tap into organizational power structures to get things done.

For each of the following, please rate its importance to the effectiveness of your patient-family improvement partnerships:

n = 62

	Extremely important	Important	Somewhat important	Not at all important	We don't have
Clear role descriptions for patient-family partners	60%	26%	0%	0%	15%
Recruitment processes and patient-family selection	56%	29%	0%	0%	15%
Training of patients and family members in how to be effective partners	52%	27%	5%	0%	16%
Training of healthcare team members in how to be effective facilitators and partners	50%	29%	6%	0%	15%
Clear charter/governance guidelines	39%	32%	13%	2%	15%
“Term limits” or other clear limits to the length of engagement	29%	24%	18%	10%	19%

Numbers may not total 100 due to rounding

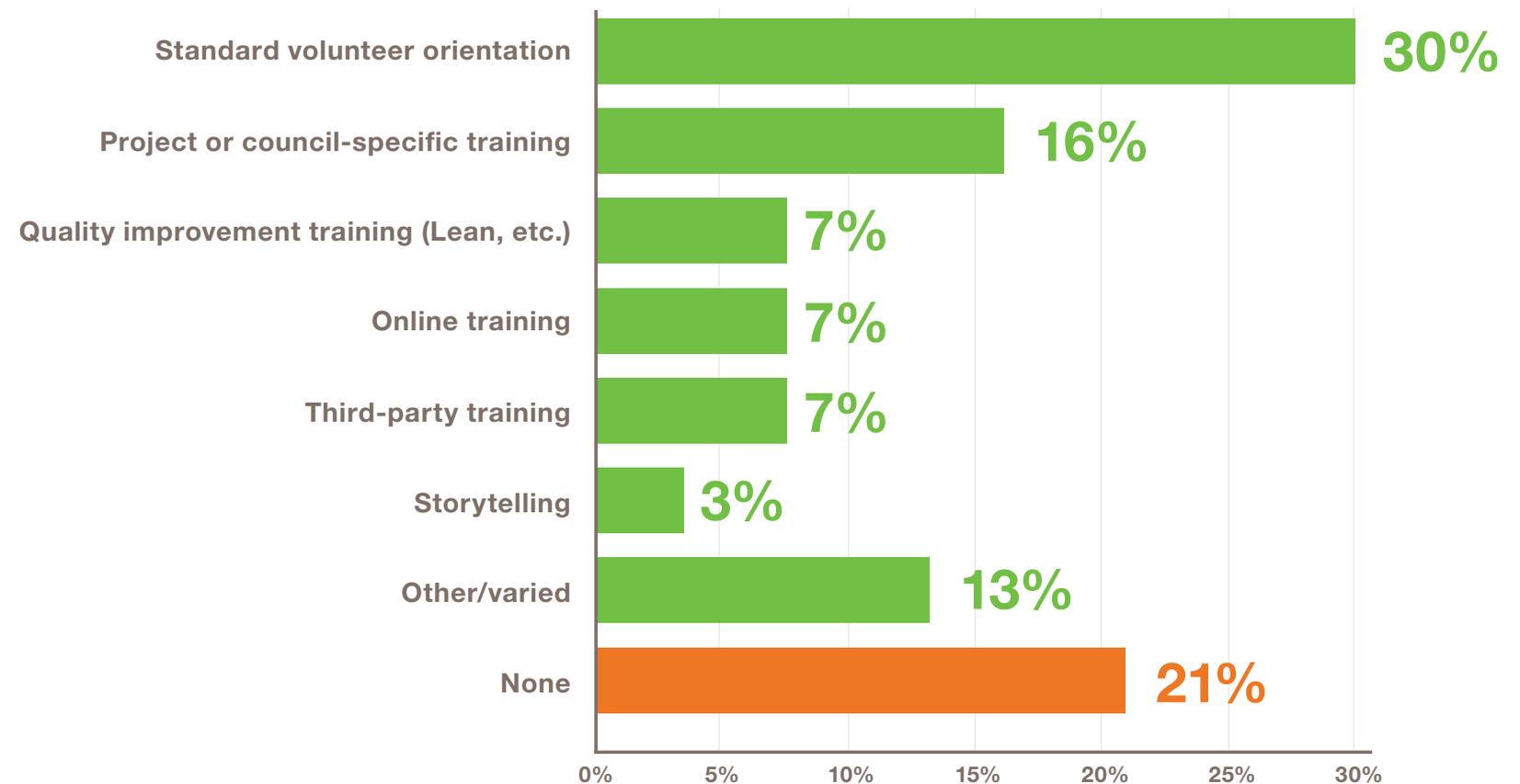
Most Patient-Family Improvement Partners Receive Limited or No Training to Help Them Succeed

Standard volunteer training is the most common approach

Despite the fact that 52% of system respondents said that training for patient-family improvement partners is extremely important and another 27% said it's important to the success of patient-family improvement partnerships—when we asked what training systems provide, slightly more than half said either none, or just the standard volunteer orientation (which typically includes system history, mission, values, and confidentiality requirements). Only 16% said they provide training related to the specific project or council the patient or family partner will support, and another 7% provide quality improvement training.

What, if any, training do you do for patients and family members who want to engage as improvement partners?
(results aggregated from open-ended responses)

n = 61



Most Team Members Get No Training in How to Work Effectively with Patient-Family Improvement Partners

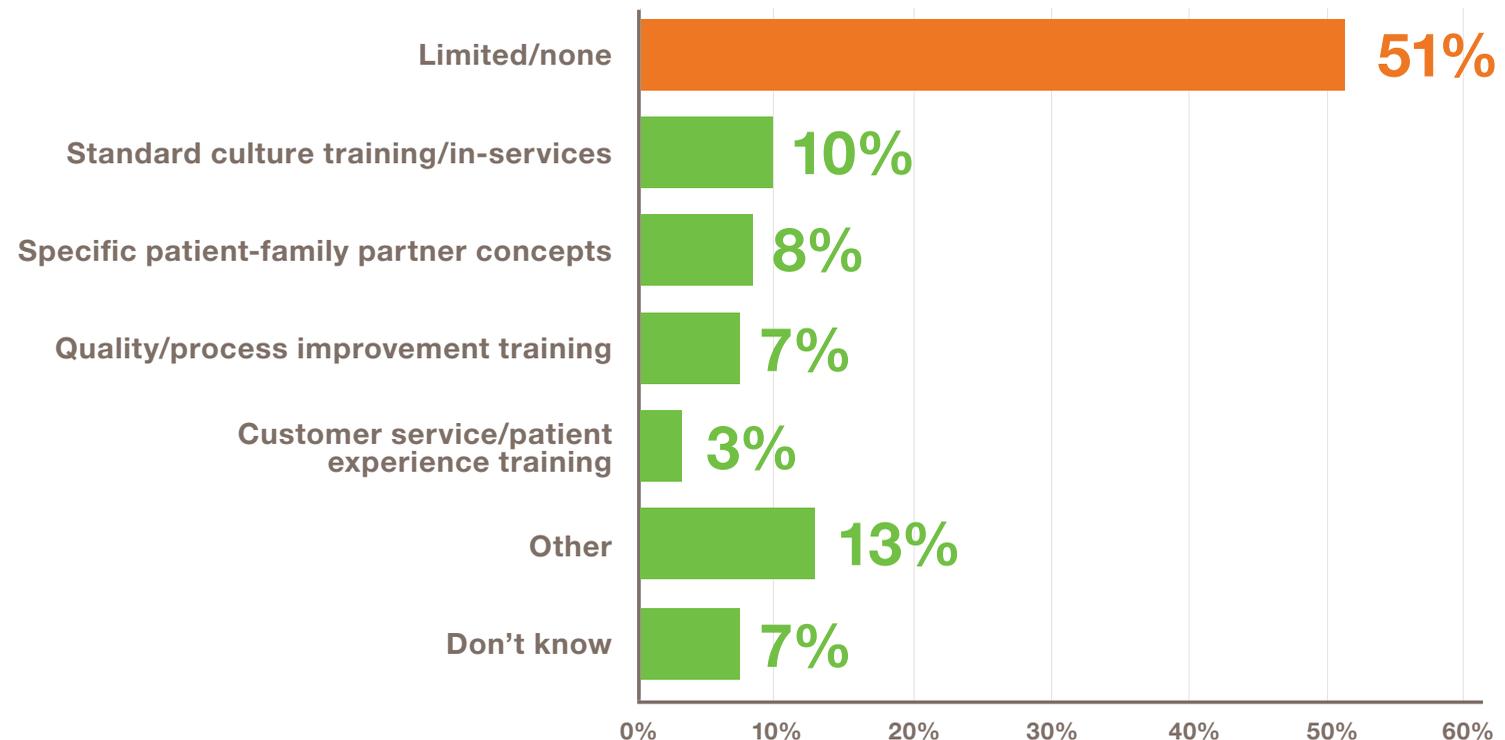
Only eight percent of system respondents provide specific training for team members

Similar to training for patient-family improvement partners, 50% of system survey respondents indicated that training for team members on how to work effectively with patient-family improvement partners is “extremely important” to success, and another 29% rated it “important.” However, 51% of respondents said they offer limited or no training for team members, and only 8% offer training specifically geared toward helping team members work most effectively with patient-family partners.

In our interviews, we heard stories about team members questioning the credentials and value of patient-family partners, or dismissing their ideas outright—sometimes to their faces. This suggests that training in both the how and why of effectively including patient-family improvement partners is warranted.

**What, if any, training do you do with team members to help them work effectively with patient-family improvement partners?
(results aggregated from open-ended responses)**

n = 61



Bronson Healthcare Involves Patient-Family Partners in Learning Opportunities



Marilyn Potgiesser, BS, RNC
System Manager
Patient & Family Centered Care



Bronson Healthcare began its journey to build patient-family partnerships in 2006. By 2007, the organization had made it a strategic initiative with board-level support. In 2008, they hired Marilyn Potgiesser, BS, RNC, to lead their patient-family centered care efforts. “Having leadership—from the board to the CEO and the executive team—really embrace this has been key to our success,” said Ms. Potgiesser.

Ms. Potgiesser and her team of patient-family advisors are involved with improvement across the organization. They join nursing huddles, participate in employee events, and have seats (often more than one) on most key committees including the Quality Oversight Committee of the Board of Directors for the entire Bronson system.

Ms. Potgiesser has been instrumental in bringing patient-family advisors to meetings and events that are usually reserved for “professional” attendees. “I take patients to the Michigan Health and Hospital Association, Person and Family Engagement Council meetings. We go

to MHA safety and quality conferences every year. At first, I was one of the only leaders who would bring patient-family advisors to those conferences. At our state level, we have a board for safety and quality at Michigan Health and Hospital Association called the Keystone Board. They invited one of the advisors I brought to be on their board.”

In addition to educating and supporting patient-family partners, Ms. Potgiesser and her team work with leaders and team members to make sure that they understand the organization’s commitment to patient-family centered care, and what it means to embrace patients and families as true partners.

“You can’t expect patient-family advisors to be involved unless you make an effort to take them to these events, make them feel comfortable, prepare them, coach them, help them learn, and involve them,” said Ms. Potgiesser. “It’s not a competition when it comes to patient safety and patient experience. We should all be sharing and learning from each other.”

Leader and Team Member Preparation

Board of Directors

- Patient-family advisors share stories
- Twice annual reports on recruitment, open positions, accomplishments, meeting hours, and activity hours for patient-family partners

New hire orientation

- Commitment to patient-family-centered care (PFCC)
- Patient advisors share their stories and why they are involved in improvement

Introducing advisors to a committee or team

- Meet with chair and staff coordinator
- Share guidelines and resource sheets on involving patient-family partners
- Advisors fill out quarterly feedback sheets
- Advisors report out to PFAC on committee work

A Boston-Based Hospital Built a Cadre of Research Partners



**Maureen Fagan, DNP, MHA,
FNP-BC, FAAN**

Former Executive Director of the Center for Patients and Families, Boston-Based Hospital, current Chief Experience Officer at UMiami Health System

Maureen Fagan, DNP, MHA, FNP-BC, FAAN, was used to managing a robust set of operationally-focused patient-family advisory councils. But after the launch of the Patient-Centered Outcomes Research Institute (PCORI), she began getting a new set of requests for patient input—from researchers.

PCORI was established to fund research that can help patients and those who care for them make better-informed decisions about the healthcare choices they face every day, guided by those who will use that information. Its grants require that researchers include patient advisors in their process, which is what prompted the requests Dr. Fagan received. “Initially, the researchers were coming to me right before they were going to put in the grant,” Dr. Fagan reported. “But the patients and I recognized there was an opportunity for deeper engagement.”

Dr. Fagan and her team built a process to empower patients to shape the research (from aims and methodology to analysis, results, and dissemination)

that would, in turn, shape their care. In the process, she found that both patients and researchers needed preparation to work together effectively. Patients and family members needed to understand the scientific process and how to build a valid study. “Once they understood, patients took it as a serious responsibility to advance the science,” said Dr. Fagan. Researchers, in turn, needed to understand that patients could participate in all parts of the research process. “Researchers have a tendency to try to protect patients’ time, not wanting to bother them. But it’s no bother. Patients want to help!”

Preparation on both sides paid off in a better research process. “In each grant, there’s a moment where the authentic relationship begins,” explained Dr. Fagan. “There’s ROI for the scientists, the caregivers, the patients, and the disease state. The research is asking and answering the questions patients most care about—often questions that are completely different from those researchers would devise on their own.”

Researcher preparation

- Understand the importance of patient-family participation
- Training in how to talk with patient partners as peers (plain language, tone, etc.)

Patient-Family preparation

- Understand the research process (aims, methodology, peer review, scientific method, etc.)
- Learn basic statistical analysis (how to read results in tables, descriptive statistics, statistical validity, etc.)

Value of training to collaboration

- Patients participate as true peers to advance the science
- Patients combine lived experience of disease or condition with understanding of scientific rigor of research
- Researchers gain greater respect for patient perspectives

Learn more about patient-researcher partnership: [Implementing a pragmatic framework for authentic patient-researcher partnerships in clinical research](#)

A Good Partnership Takes Skills and Preparation on Both Sides of the Table



If you're going to invite new patients to work with you on a committee or an advisory board, don't just say "welcome," change everything about how you run the meeting. You don't invite people to your house, and shout from the couch "come on in, help yourself to whatever's in the fridge."

There are rules of etiquette on both sides that people need to follow. You clean up and prepare for their arrival, and they honor your hospitality, and respect your home.

– Meg Gaines, J.D.
Founder, Director
Center for Patient Partnerships

More than half of our advisors have gone through root cause analysis training. Now they're involved regularly in critical incident review. It helps ensure that we're seeing it from all sides.

– CJ Merril, MSN, CPXP, CPHQ
Patient Experience Officer
Mission Health System

When we built our new hospital, we required all of the project staff and all people involved with building planning to spend time in a local First Nations community and to take cultural competency courses so they could work with First Nations partners to understand what they needed. Workers from all over the world did this—architects, designers, everyone.

– John Fitzgerald
Director Occupational Health & Safety
Vancouver Island Health Authority

All of our staff go through Core Concepts training on how to listen and communicate, how to build teamwork, and how to give and receive stories.

– Doug Eby, M.D., MPH, Vice President
Southcentral Foundation

Innovation Opportunity: Equip Patient-Family Partners and Team Members to Lead

Align training with needs and responsibilities

Patient-Family Partner Training

- ✓ **Basic**
 - Healthcare business basics
 - Storytelling
 - Position-specific (as needed)
 - Policy creation, updates, sunseting

- ✓ **Advanced**
 - Design thinking
 - Change management
 - Root-cause analysis
 - Business analysis
 - Facilitation/mediation

Team Member/Leader Training

- ✓ **Basic**
 - The value of co-architecture
 - Active listening
 - Change management
 - Design thinking

- ✓ **Advanced**
 - Patient-family mentoring
 - Facilitation/mediation
 - Ethnography

Patient-Family Fellowship

Engage patient-family partners to co-architect a curriculum and training pathways that give partners the skills they need to lead transformation.

Systems Need Access and Accommodation Strategies to Promote Diversity in Patient-Family Partnerships

19
of 30

organizations interviewed
acknowledged needing to
do more to boost diversity
in patient-family partnerships

25%

of system respondents
have no specific strategies
to promote diversity in
patient-family partnerships

Advocating for Better Cross-Race Understanding – at the Patient and System Level



As a retired African American with a background in immunology and community nutrition, I now volunteer in the community as an advocate for fellow ethnic

minority patients who are distrustful of the medical community's discriminatory policies. I also volunteer as an Improvement Partner with my local health system, where I voice the patient (consumer) perspective, striving to analyze and improve health care procedures for staff and patients. Lastly, I am active in my local health system's Disparity Committee activities, working towards improving health outcomes for all patients in the system.

Years ago, I lived and worked abroad. My socio-cultural experiences while

living there and traveling about Europe inspired in me confidence and renewed sensitivity to the health needs of ethnic minorities. I committed to try to affect change, in some small way, upon my return to the USA.

In some settings I feel that my role in advocating for patients is welcomed and valued in affecting some change. Participating alongside hospital staff members in the Disparity Committee, for instance, I see progress toward improving and equalizing health outcomes for the hospital's ethnically-diverse groups of patients.

In other settings, however, cross-race fluency is woefully inadequate. In general community medical venues, for instance, when advocating on behalf of a specific patient, I have too often encountered resistance when seeking a better or more aggressive

treatment plan. Unequal treatment for such patients is often a function of subconscious biases and, thus, difficult to successfully confront. This is so, despite national statistics that clearly indicate the underserved health status of ethnic minorities today.

Unequal health care and treatment is not an archaic (1700s – 1900s) issue. Unhealthy—sometimes frankly rude or even dangerous incidents—are still visited upon ethnic minority patients today. It is a complicated exercise to challenge medical providers (one at a time) who feel that they have “no skin in the game.”

To do this work, one must learn to graciously accept uncomfortable

situations. One must be patient—and persistent—in the face of resentful denial by some providers. Indeed, such is a reflection of our greater society's unwillingness to tackle the long-standing issue of racial bias. Health systems and individual medical providers hold much power over peoples' well-being and, thus, have a profound opportunity to lead this country toward greater cross-racial and cross-cultural understanding. In doing so, unbiased, consistent health care and treatment, with better outcomes and at lower overall cost, can be delivered to all patients in an equitable manner.



Jeri L. Hill, PhD
Patient Improvement Partner

Supporting a Diverse Range of Patient Voices Remains a Challenge for Most Systems

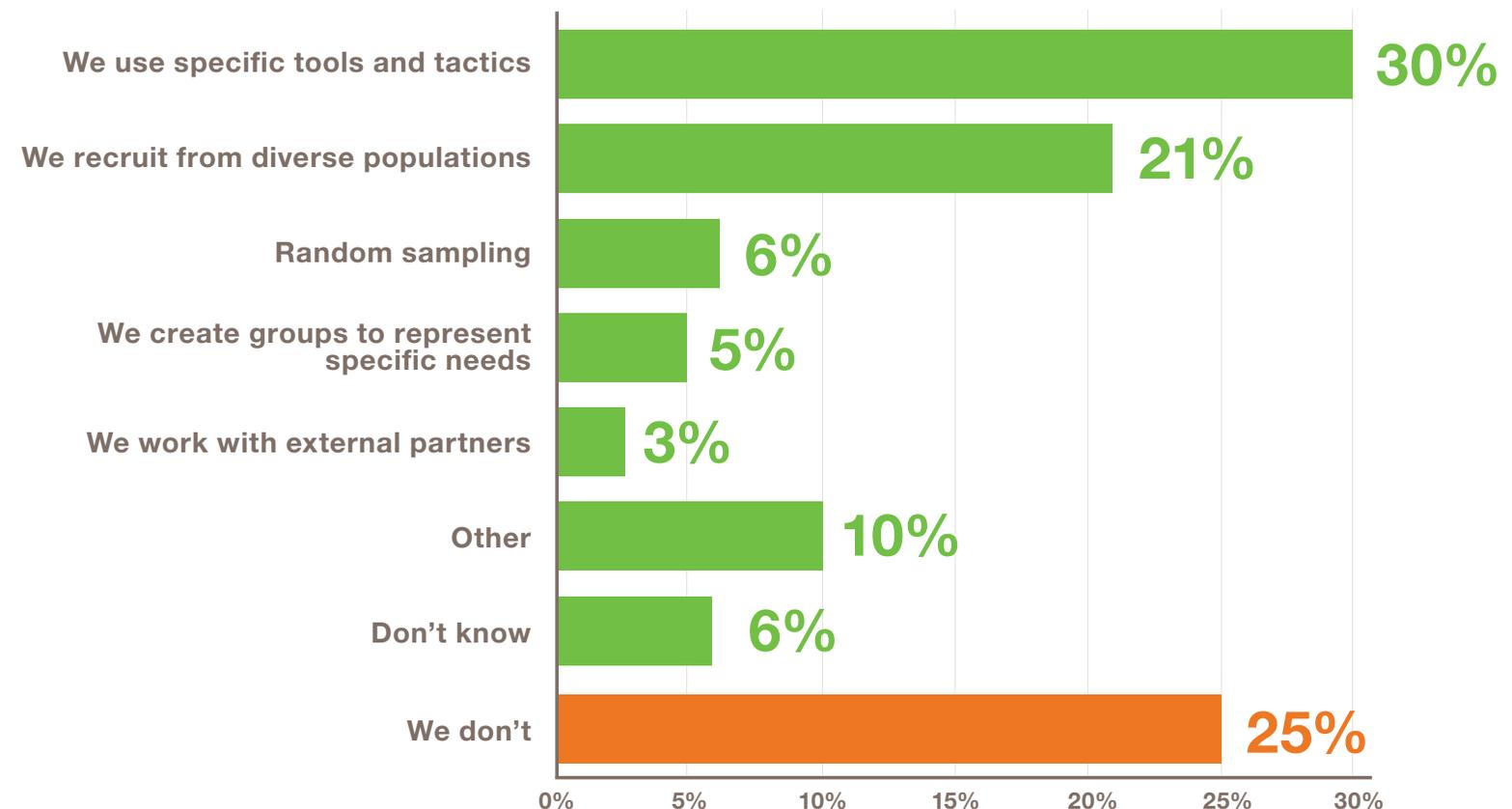
One quarter of system respondents lack an approach to ensure diversity

Only 30% of system respondents described specific diversity recruiting tactics such as reaching out to under-represented populations or engaging advocates to connect with hard-to-reach communities. Five percent said they create specific groups to represent key voices. But one quarter have no strategy for diversity and inclusion, and 21% said that because their patients are diverse, their improvement partners naturally evolve to represent diversity.

In our interviews, most system leaders acknowledged that they can and should do more to ensure that all voices are represented. They also admitted the formats such as PFACs—which often meet during business hours and require travel and a fixed time commitment—tend to exclude poorer patients, younger patients, and some minority patients who don't trust that the system is ready to listen.

How, if at all, do you ensure you have a diverse range of voices (age, gender, ethnicity, race, income, healthcare experience, etc.) represented across your patient-family improvement partners?
(results aggregated from open-ended responses)

n = 61



Technology-Based Platforms Provide More Flexible Access for Patient-Family Input

Almost half of system respondents use technology for patient-family input

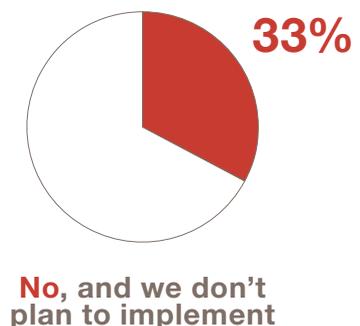
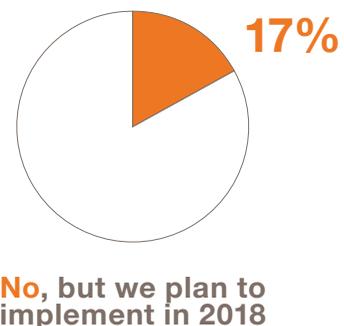
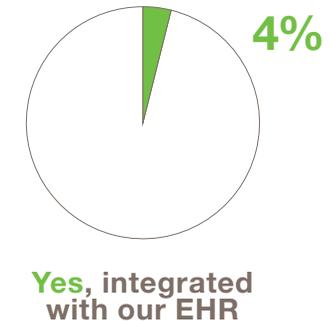
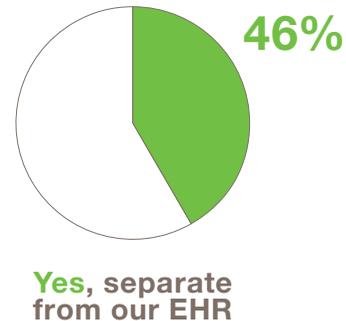
One strategy system leaders use to draw insights from a more diverse set of patients and families is a technology-based platform that allows them to reach out to participants who may not have time or inclination to join a PFAC. Forty-six percent of system respondents said they have a virtual or technology-based platform for patient input, and another 17% plan to implement something in the coming year.

Platforms range in sophistication from simple survey tools to virtual communities in which patient-family improvement partners offer input on multiple projects and programs over time.

While technology solves some of the challenges of access for patients with job and family obligations that preclude an in-person commitment, they still don't solve for inclusion of indigent or mistrustful patient-family perspectives.

Do you use a virtual/technology-based platform to solicit input from patient-family improvement partners?

n = 48



Note: Percentages are only of respondents who knew whether their system has a technology platform. Twenty-five percent responded, "I don't know."

PHSA Asked Community Members to Co-Create Engagement

When the Provincial Health Services Authority (PHSA) in British Columbia, Canada, set out to build a patient engagement policy and toolkit, leaders assumed they could create a draft and then get community members to weigh in, polish, and finalize the draft. They quickly learned that, if they wanted community members to buy into the end product, they needed to work with them to co-create the policy and toolkit as well as the process by which community members could offer input.

Early in the process, Shannon Griffin, MBA, explored the International Association for Public Participation's [public participation spectrum](#). She realized that success would hinge on an approach that was both collaborative and empowering. "The more inclusive our process was, the more legitimate it was viewed by our stakeholders: not only patients, and families, but also our workforce," she reported.

And so she, her team, and her patient partners shifted their approach. The team went out into the community to

talk with different stakeholders about their perceptions, preferences, cultural needs, and experiences with the system. Their listening and learning journey included 30 engagement sessions, involving over 340 individuals, in five cities across the province, during which they asked how stakeholders wanted to be involved and included in co-designing the health system. They had to face some unexpected truths, such as when First Nations participants told them that holding meetings in historically colonial buildings created a barrier to inclusion. "You're going to hear things you don't want to hear; be ready for it and be open," advised Elizabeth Edward, patient partner. "But you're also going to hear amazing stories of real care and compassion."

PHSA is now drafting its policy based on five months' worth of stakeholder engagement. The process cost roughly CAD\$100,000—an investment Ms. Griffin and her team are convinced will pay off as patients and family members work together to redesign and reimagine care in British Columbia.



Shannon Griffin, MBA
Corporate Director, Strategic Change and Improvement Chair of the PHSA Patient Experience Council



Elizabeth Edward
Patient Partner



Three Big Shifts in Patient and Family Engagement

Put Stakeholders in Charge of the Design Process

- Ask why. Why do we want to engage? What is the purpose? What is the gain?
- Leave the decision of how to engage up to influence by stakeholders.
- Build buy-in to the process, promote buy-in to the results.

Over-engage the Underrepresented and Hard-to-reach

- Go out to the places community members gather—don't ask them to come to you.
- Ask who in the community should be included—invite participants to invite their peers.
- Listen with empathy and without defensiveness.

Listen, Advocate, Be Open, Include

- Listen to patients, families, communities and your workforce—before the first draft begins.
- Senior leaders must be involved, comfortable, and ready and willing to advocate for stakeholder needs and preferences.
- Be open to the possibility that stakeholder input will change your scope—and your budget.
- Include everyone.

Santa Clara Valley Medical Center Strives for Inclusion



Taumaoe Gaoteote, EMPA, MBA
Customer Relations, Hospital Communication, Patient and Family Advisory Program Manager



As the second largest county health system in California, Santa Clara Valley Medical Center (SCVMC) serves patients and families across all walks of life. When leaders built their Patient-Family Advisory Program, they wanted to make sure their program was equally representative.

Taumaoe Gaoteote, EMPA, MBA, asked doctors and nurses to identify patients who might be interested. His team created banners and flyers that they posted at the hospital and clinics. Then they went a step further. “We went to community centers and senior citizens centers and gave them presentations and asked them to call if they were interested,” he explained. “We explained how important they were to helping us improve.”

Mr. Gaoteote wanted to build not just a team of advisors, but a program that would serve the needs of all patients the system serves, as well as building deeper relationships between patients

and staff members. “We recruited not only patients, but also staff,” he reported. “For all of our teams we recruit a staff member and a patient to be co-champions to communicate and work together.”

SCVMC has advisory teams at its hospital and clinics, as well as a virtual, web-based team. Patient-family advisors hold open houses several times a year to allow other patients to come share their ideas. The advisors also review comments left by patients and work to devise solutions.

All advisors are invited to an annual meeting with system executives where they present what they have accomplished in the previous year, as well as priorities for the coming year. “If you really want to make a change,” said Mr. Gaoteote, “patient voices should be everywhere.”

<p>Advisory Teams</p> <ul style="list-style-type: none"> • Hospital Advisory Team • Clinic-Level Advisory Teams • Homeless Patient Advisory Team 	<p>Additional Pathways</p> <ul style="list-style-type: none"> • Web-based virtual community • Advisor-led open houses • Comment boxes
<p>Recruitment</p> <ul style="list-style-type: none"> • Doctors, nurses, staff members • Banners, flyers, brochures • Community and senior centers 	<p>Diversity Considerations</p> <ul style="list-style-type: none"> • Race, ethnicity, age • Disease or condition • Ability • Language • Socioeconomic (e.g. homeless)
<p>Future Plans</p> <ul style="list-style-type: none"> • Language diversity strategies (Viet, Spanish, Cantonese, Mandarin) • Deeper integration of advisors on committees and other governance structures 	

Diversity and Inclusion Requires Intentional Shifts and Open Attitudes



Health systems aren't doing a good job working with hearing-impaired patients like me. The Americans with Disabilities Act is good in many ways, but it's still lacking. You have to accommodate people with hearing loss, but mostly if they're completely deaf. Forty-eight million people are diagnosed with hearing loss and we do so little for these people. My PFAC specifically invited me in because I understand things that other people don't about what it's like to be a patient AND have hearing loss.

– Rosemary Tuite, Patient Improvement Partner

Health systems need intentional, meaningful and targeted community involvement. Don't be afraid to say we have identified a deficiency with our x,y,z community and we are going to them and will work with them to resolve this deficiency. Be in the space of your patients. Feel what their discomfort feels like. Remember, when you come to me, you're showing you care.

– Patient-Family Partner Survey Respondent

If you have to work two jobs to support your family and you have a medically complex child, you can't entertain the possibility of volunteering. That's why I have virtual advisory council members. I have two Hispanic families who are virtual members, and I think they've only been to one meeting between the two of them. But they always respond to my emails. I send the agenda, minutes, questions—they often respond with a long commentary. I don't have an attendance policy—that's why.

– Darla Cohen, BS, MS Ed, CPXP
Coordinator Patient- and Family-Centered Care;
Program Coordinator Patient and Family Experience;
Riley Hospital for Children

Patients Perceive Trust and Power Dynamics as Another Barrier to Inclusion



I think there is a widespread perception in health systems that someone who is a patient or family member is not their equal and so our voices, insights—and even our intellect—is not as valued as it should be. Valuing the insight and real world knowledge that the patient or family member has gained through their medical journey would have a tremendous impact on the delivery of quality care.

– Patient-Family Partner Survey Respondent

Patient experts—those who have been through intense medical experiences, who often bring professional acumen to bear, and who have worked with many health systems and bring a greater depth of improvement expertise—are not recognized as peers. They're still viewed as lower level. Some patients lack experience, but some are true experts. Health systems will lose the opportunity to get critical insights from patients who have a broader understanding if they don't find a way to truly value their expertise.

– Kym Martin, MBA
President
360 Degree Insights LLC

The people who govern and manage large health care systems like the one where I serve on the PFAC are typically unusually wealthy and powerful individuals who remain fairly remote from the volunteer advisers. The volunteers, by comparison, typically are not wealthy or powerful. If the former truly seek and value decision-making input from the latter, I think they need to make an unusual effort to bridge this gap. If they do not, the volunteers may feel—and their input will likely be—marginalized.

– Patient-Family Partner Survey Respondent

Innovation Opportunity: Create Direct and Indirect Pathways for More Diverse Representation

Patient-Family Representation

Identify needs for thoughtful representation based on

- Demographics (age, sex, race, ethnicity, etc.)
- Socio-economic status (income, education, job, etc.)
- Access (rural, urban, housing, Internet access, etc.)
- Healthcare experience (patient, caregiver, condition, etc.)
- Underserved (ability, gender identity, etc.)

Direct Pathways

- ✓ Governance committees
- ✓ PFAC
 - Time/duration of meetings
 - Attendance requirements
 - Minutes/follow up
 - Reimbursement/compensation
- ✓ Web-based platform
- ✓ Projects and research partnerships
 - Reimbursement/compensation
- ✓ Listening tours
 - Over-represent the under-represented

Indirect Pathways

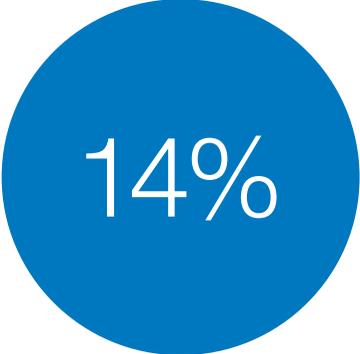
- ✓ Community outreach programs/community health workers
 - Invite feedback while providing service
- ✓ Community service centers, churches, recreation groups
 - Request access for feedback
- ✓ Social media patient-family experts
 - Access existing patient-family online communities

Recruit from Diversity

Invite people from every patient-facing role (billing, reception, housekeeping, etc.) to identify potential patient-family partners.

Recognizing Patient-Family Partner Value

Patient-Family Partners Want Recognition—and Sometimes Compensation—for Their Efforts



of patients surveyed say they've received a letter of recognition from an executive



say they would appreciate one

Patient Advocates Add Value; They Should Get Value



There's an assumption that patients will do work for free. Most institutions don't understand that patients really do truly want to help and be part of every

team. It may help when current leaders age out, and new leaders start to understand the gig economy.

There's a lot of benevolence around hospitals, and that's good. But it means that health system leaders often think they can control what people are involved in. But what people bring to the table is not something you can control.

A lot of hospital leaders are distanced from the realities of childcare and parents working. I brought it up in the PFAC I was part of. I told them, 'It's

a hardship for me to be part of this committee. You meet in the evening when I have to have childcare. I need to travel to get here. Every time I come to a meeting, it costs me \$50—to volunteer my time. Often the response is, 'We don't have buy in.' I was part of the committee for two years. All of the meetings were held during the day when they were being paid to be there. You get a lot of retirees who can pull it off. But for younger people or poorer people it's a real problem.

More phone meetings would be better. It would enable a wider range of people to participate. Or offer travel stipends. Part of the problem is the way leaders look at it. The thinking is, 'Most of our patients are old, so an older PFAC is representative.' If your goal is to come up with new solutions, having a wide range of thinkers is ideal for creating these solutions.

In the world of speaking, the traditional honorarium is \$500 because of U.S. tax law. If you pay someone less than \$600 you don't have to file a 1099. For most patients, speaking is a one off, so they don't mind. They're doing it a couple times kind of as a favor to an institution. A lot of institutions don't want to get into the world of contract employers. There are institutions that hire patients and put them in a role in the traditional institution. You have HIPAA requirements. You become a hospital patient advocate, not a patient advocate.

It's hard to hire someone for a short term. It's easier to funnel them off to the volunteer squad. You need a cheerleader within the organization. Often when I speak, the person at the organization who is advocating for me to come in started pitching for me four years ago.

Despite the obstacles, we're changing what it means to be a patient in healthcare. We research patterns and what's working in different communities, and we're spreading that change.



Regina Holliday
Artist and Activist
Founder, the Walking
Gallery of Healthcare

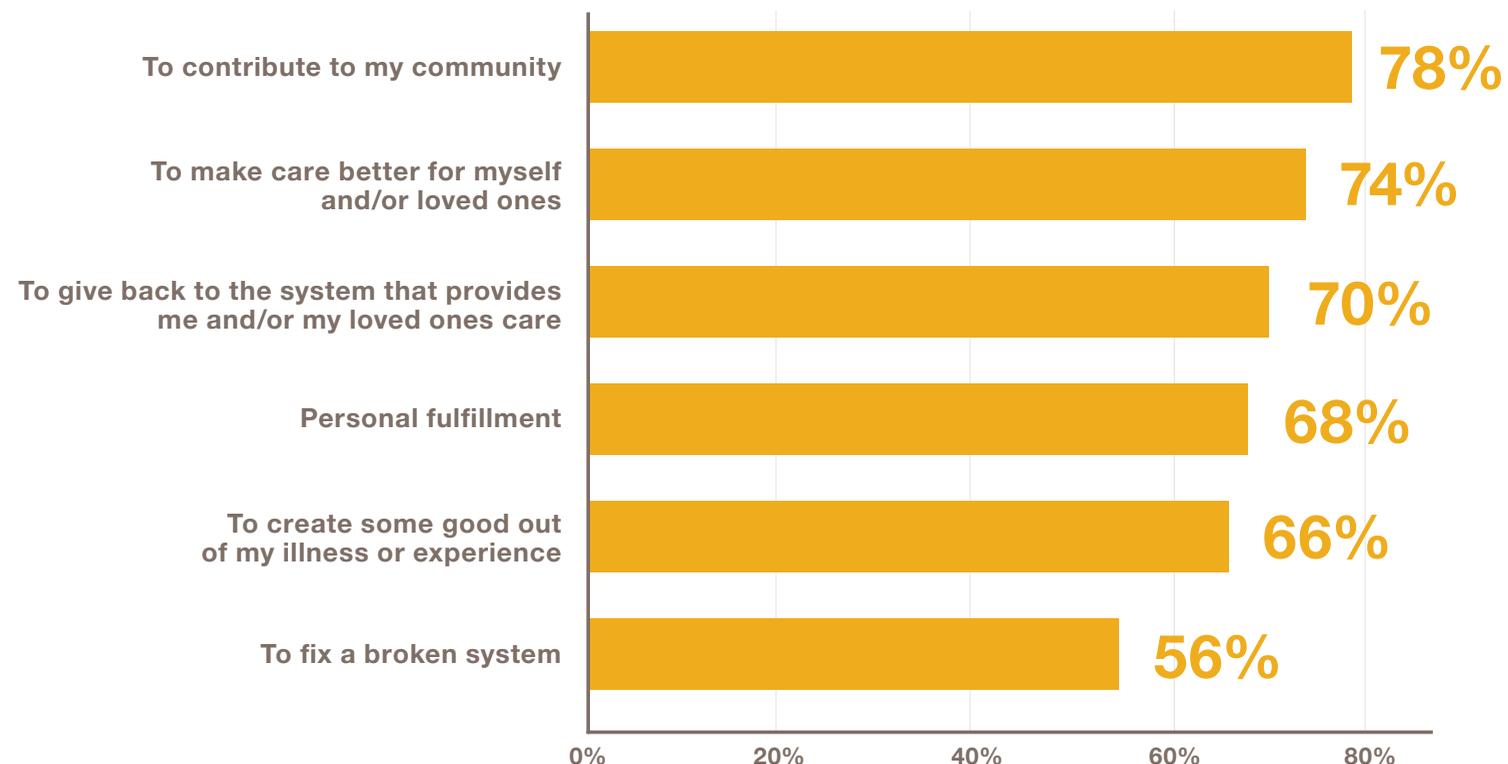
Patient-Family Improvement Partners Have Altruistic Motives for Helping

More than three quarters participate to contribute to their community

We asked patient-family respondents why they participate in health system improvement work. While more than half indicated that one motive was to fix a broken system, a greater majority said that contributing to their community or making care better for themselves and their loved ones was a bigger factor.

Why do you participate in health system improvement work? (Please select all that apply.)

n = 50



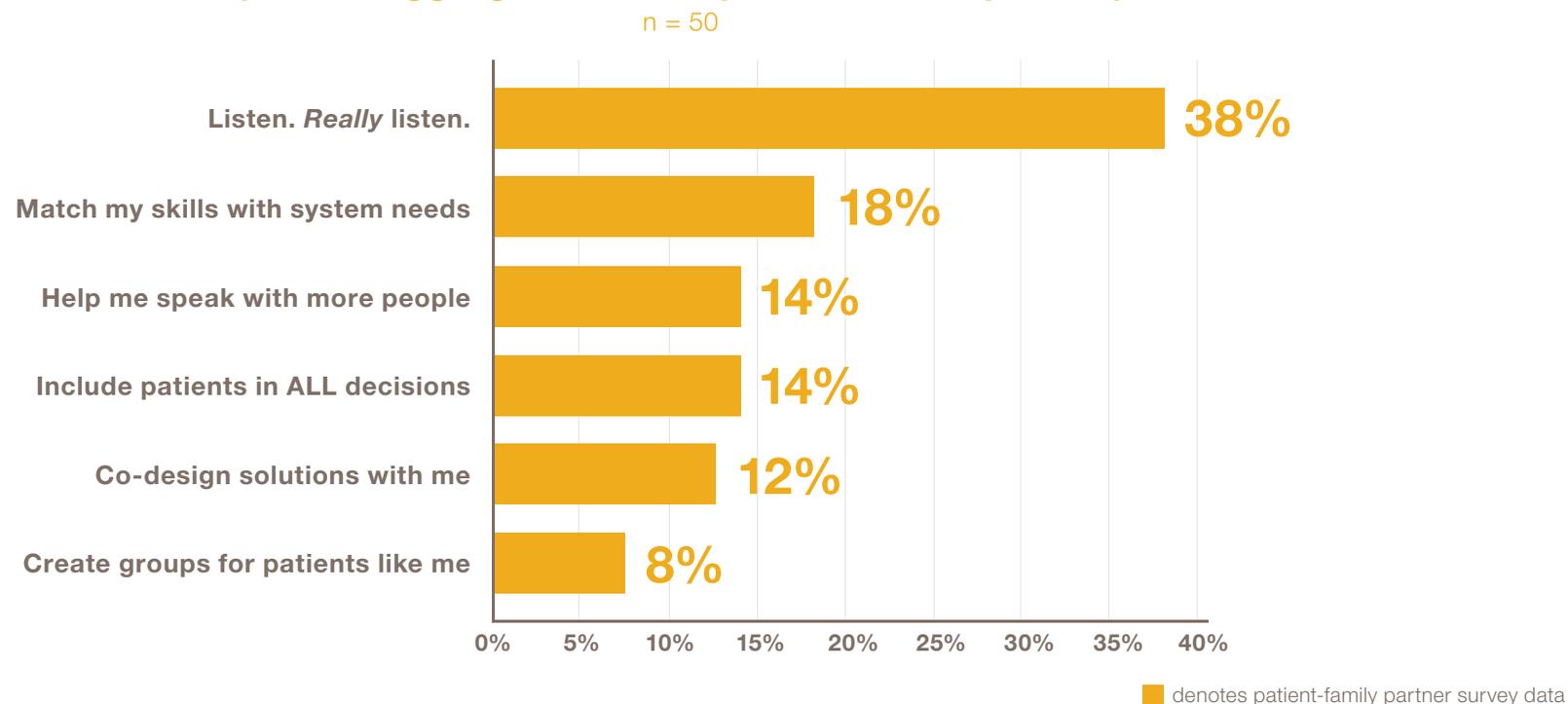
■ denotes patient-family partner survey data

Patient-Family Partners Care Most About Respect and Results

Patient-family partners say health systems would gain more from partnerships if they really listen

We gave patient-family respondents a chance to offer advice on how health systems could better tap into their experience and expertise. Thirty-eight percent of responses centered around the idea that health system leaders need to listen more closely to what patient-family partners are really saying—about what needs to be improved and how to improve it. Eighteen percent also saw an opportunity to more specifically align their skills and interests with system needs.

How could health systems better tap into your experience and expertise? (results aggregated from open-ended responses)



By involving us in design and co-production of services. By REALLY listening. By taking on board what research we see as important. By acknowledging us as valued members of the care team. By consulting us as members of that team. By communicating better.

- Patient-Family Survey Respondent

Ask, listen and engage me, and then implement ideas of patients/caregivers who give novel ways to solve old, thorny problems.

- Patient-Family Survey Respondent



Patient-Family Partners Value Recognition from Senior Executives

Patient-family partners also appreciate expense payments

We asked patient-family respondents a similar question about compensation and recognition, this time asking not only what they have received, but what they value in return for their insights. Most indicated that they have received—and appreciate receiving—food and drink. Less than half have had expenses such as parking and transportation covered, and only 30% said this isn't important to me. In our interviews, several patient-family partners indicated that when expenses aren't covered it's as if they're having to pay to provide value to the hospital.

Where do systems have the biggest opportunity to recognize patient-family partners? Fifty-two percent said they'd appreciate a letter from an executive, though only 14% said they'd received one.

Some health systems offer compensation or recognition for patients and family members who participate as improvement partners. Which of the following types of compensation or recognition have you received? Which would you appreciate receiving?



Systems Most Often Provide Food and Drink and Offer Recognition in Return for Patient-Family Input

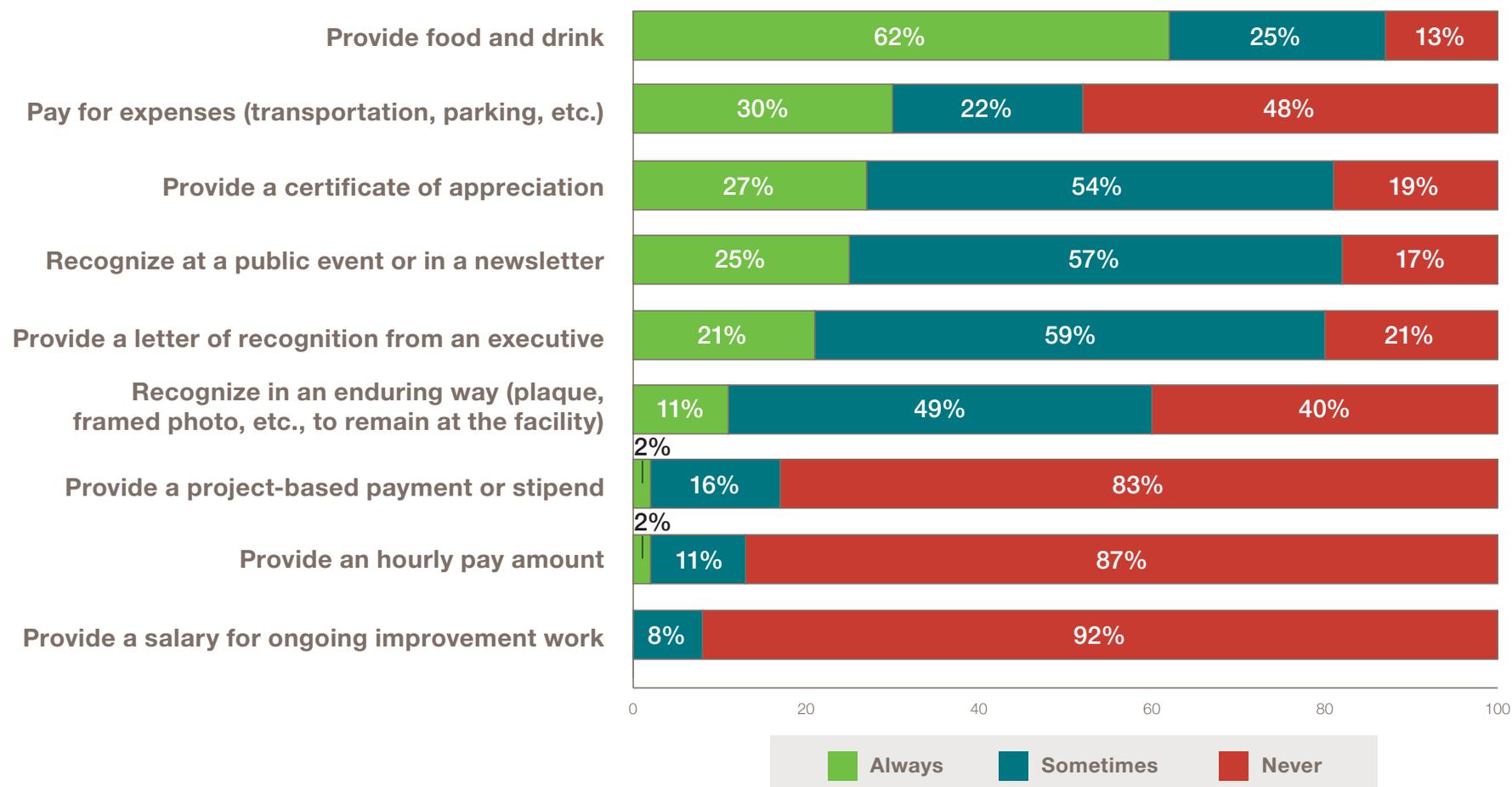
Just over half of system respondents compensate for expenses “always” or “sometimes”

Sixty-two percent of system respondents said they “always” offer food or drink to patient-family improvement partners, and another quarter do so at least some of the time. But from there, compensation dwindles, with less than a third “always” paying for expenses such as transportation or parking, and only 2% consistently providing hourly or project-based payments. This isn’t surprising, given Medicare rules limiting “incentives” that can be offered to patients, and median patient-family partnership budgets falling below \$50,000 (see page 63).

System respondents are more likely to offer recognition in the form of a plaque, letter, or at a public forum. However, these forms of recognition are somewhat inconsistent, with “sometimes” outnumbering “always” responses by a factor of two-to-three.

How, if at all, do you compensate or recognize patient-family improvement partners for their participation in improvement work?

n = 63



Numbers may not total 100 due to rounding

Patient-Family Improvement Partners and System Leaders Have Mixed Feelings on Compensation

For Compensation

Despite the fact that many people feel strongly about helping out of altruism, health systems should pay every patient who is asked to do work that others are getting paid for. You can give them the option of donating to charity or patient groups. If you rely solely on people who volunteer, you only get people who have the money and the time. You miss people whose voices are unrepresented.

– Annette McKinnon, Patient Advisor

Financial compensation would be helpful because every time I attend meetings I miss work, and lose income.

– Patient-Family Partner Survey Respondent

We all want to feel appreciated. It took me many years before I could or wanted to discuss my experience as a patient and I feel honored to contribute now, however, it is not always an easy thing to do. The work we do is comparable to what a consultant (with little or no patient experience has) so it's nice to be acknowledged, appreciated and compensated for our time and expertise.

– Patient-Family Partner Survey Respondent

I have done a lot of improvement work with health systems and organizations. I value the work, and I provide a lot of value when I'm involved. I'm usually working alongside people who are being paid, but I'm usually not paid at all or a very token amount. This makes me feel as if I am not valued or considered an equal. I'm having to re-examine my role in this work because I need to value myself and my time

– Hala Durrah, MTA, Patient-Family Engagement Expert

Opposed or Ambivalent about Compensation

If I need a job, I get a job. I don't think I should be paid for trying to help as a person that has free time. I am a volunteer for life.

– Rosemary Tuite, Patient Improvement Partner

The risk of paying patient-family advisors is that it fundamentally changes the “feel” of their role within the team. Finding ways to honor, acknowledge and appreciate the time and effort of advisors is key- short of a paycheck..

– Kristine White, RN, BSN, MBA, Co-Founder, Aefina Partners

I struggle with the role of paid patient advisors – I've observed that they can sometimes feel co-opted by the organization and lose their ‘outside patient view.’ It's so important, when partnering with patients and families, that we reach out to diverse populations and different perspectives, instead of relying on what's easiest for us.

– Shannon Griffin, MBA, Corporate Director, Strategic Change and Improvement and Chair of the PHSA Patient Experience Council, Provincial Health Services Authority

The reward for this work is seeing improvements based on your advice. Everyone on the panel feels the same way. We talk among ourselves and what we say is what gets done. That in itself is a reward. I have a debt to pay after my heart attack. My hospital team saved my life. Everyone on the committee has that same feeling.

– Michael Asip, Patient Partner

Innovation Opportunity: Create a Continuum of Patient-Family Partner Value

	Volunteers	Project Partners	Consultants	Employees
Contribution	<ul style="list-style-type: none"> Advisory council “Quick hit” feedback (virtual or in-person) Storytelling 	<ul style="list-style-type: none"> Focused, specific project with clear aims Short duration (2-5 days, or short bursts of input) Research partners 	<ul style="list-style-type: none"> Focused, specific project with clear aims and deliverables Longer duration (5+ days) Consultant is likely responsible for managing part of process 	<ul style="list-style-type: none"> Defined, patient-family-centered job responsibilities Long-term commitment
Compensation	<ul style="list-style-type: none"> Expenses covered Hand-written letter of appreciation Token gift Event or gathering to recognize collective contribution 	<ul style="list-style-type: none"> Expenses covered Project stipend or hourly pay Follow up on impact of project Recognition of contribution 	<ul style="list-style-type: none"> Expenses covered Contract payment aligned to value Clear statement of work, deliverables, and deadlines Recognition of contribution 	<ul style="list-style-type: none"> Salary + Benefits <p><small>*Note: bringing patient-family partners on board as employees is likely to change team member perception of their contribution</small></p>

← ALWAYS: Go to where patients and families already convene OR cover costs (parking, transportation, childcare, etc.)
 ALWAYS: Offer appreciation and recognition of contribution – especially from senior leaders →

What if they don't want it?

If patient-family partners prefer not to keep monetary compensation, create an anonymous mechanism by which they can donate their earnings to a fund ear-marked for patient-family-centered innovation.

Amplifying the Value of Patient-Family Partnerships

Patient and Family Partners Bring Immeasurable Value to Health System Improvement Efforts

Median annual budgets for patient family partnership

<\$50K

Getting it right the first time...

priceless

Tapping Into Patient Expertise to Drive Value



My background is in the education field. What I'm doing is taking what I know—the ways in which you build communities for 18 year-olds to live in residence halls—and say, how might we benefit from that work and apply it in healthcare?

I had a great experience with my health system's cardiac rehab center's advisory board. What I saw was a leadership willing to say, 'this is more than just a focus group where we've already decided what we'll do and we'll just get patients to sign off so we can tell the bosses.' They left it more open. Within the first year, we successfully

changed how they do cardiac rehab (CR) orientation. Originally, all of the orientation was individual. There was a big concern about people knowing each other's stuff. But if you're at CR, I know why you're there. It was an efficiency thing for them.

My experience with cardiac rehab wasn't good. I was freaked out. I was 46-years old and just died. Now I have to exercise. They threw a bunch of paper at me. I filled it out for an hour. I said, 'You're missing an opportunity!' I was building off of my experience with scared 18 year-olds living in a residence hall away from their parents for the first time. Instead of paperwork, have patients do it at home and start orientation with story. Let me realize that the person literally to my left

understands what I'm going through. We completely shifted and changed how they do it. Now, myself and another patient get there every Monday and we co-lead the session. We actually start the session as CR graduates. I've been in your shoes. I get it. Your care team will help you, but also partner with each other, build communities, create connections. That's my most successful improvement experience.

If a health center has a problem they're trying to solve, they should start with the people who see that as a problem—as broad a list as it can be: (registration folks to nurses to doctors). Then add a group of patients who have that illness/disease. Then reach out to some local college or university with an undergrad or graduate who likes problem solving.

I'd just as soon find a curious student than a specific skill set. Get them in a room. You create a trans-disciplinary conversation.



J. Greg Merritt, PhD
Founder and CEO
PatientisPartner, LLC

Patient-Family Partners Describe the Value They Deliver in Clear Terms

“How would you describe the value you provide to the health system(s) you work with?”

I understand my condition

“We provide the ‘lived experience’ of caregiving and have solutions to our own particular issues that if were made part of the design of healthcare policies, would alleviate huge stress and ultimately save time and money.”

I understand my treatment

“I have expertise like no one else in my care- I actually received the treatment in cardiac rehab after an SCA and MI.”

I remind you I’m a person, not an illness

“We are looking at the health systems not just as patients and caregivers but as humans first with a basic set of human needs that need to be met.”

I make it real

“[I am] firsthand, irrefutable proof of systemic quality issues.”

I’m not subject to your politics

“[I am] the voice of truth, urgency and honesty, unhampered by internal politics and paygrades.”

I have expertise beyond my patient experience

“[I have the] ability/willingness to look at non-traditional approaches that involve multiple disciplines’ expertise and patience to work with people with conflicting perspectives.”

I am persistent

“I strive to serve as a persistent, respectful vocal advocate for those issues that may be uncomfortable for committees that tackle ‘patient problems.’”

I get that we’re in this together

“I’m able to tell healthcare providers what the experience is like from my side, which is an incredibly valuable perspective to have when trying to improve the system - it needs to work for both providers AND patients to be a successful improvement.”

Systems Have Limited Budgets to Support Patient-Family Partnership

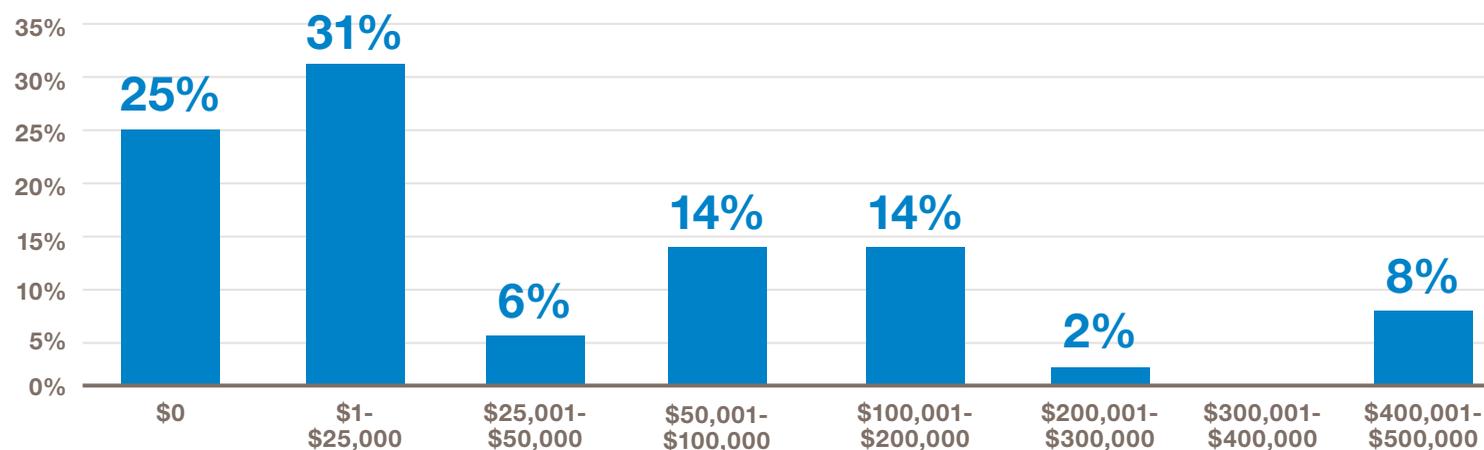
A quarter of respondents have no budget at all

We asked system respondents to estimate their budgets for patient-family partnership, inclusive of salaries and direct expenses, but excluding patient satisfaction survey vendor expenses. The budgets are generally meager, with the median budget falling below \$50,000. Twenty-five percent of respondents said they have no budget at all for this work.

In our interviews, system leaders indicated that lack of budget was a significant limiting factor. Leaders often lamented being a “department of one,” and indicated a desire to help cover more costs or provide greater financial incentive for patient-family participation, if they could get the budget.

What approximate range does your annual budget for patient-family partnership fall into? Please include salaries for leaders overseeing the work, technology platform expenses, food/parking expenses, payments to patient-family improvement partners, and other direct expenses. Please do NOT include patient satisfaction survey vendor expenses.

n = 51



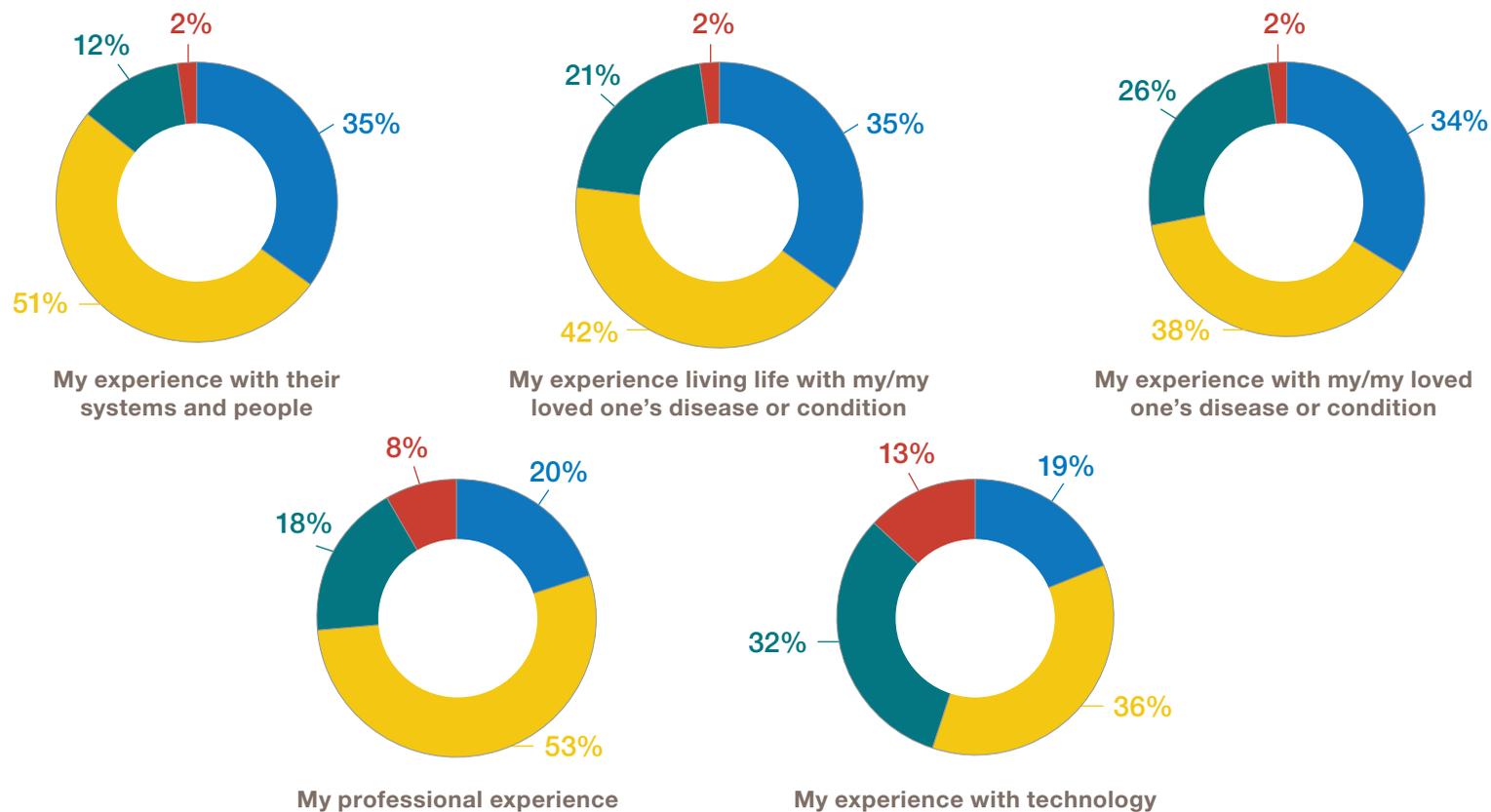
Patient-Family Partners Say Systems Value Health and Personal Expertise

Technology expertise is least valued

We asked patient-family respondents which aspects of their experience—system, condition, life, professional, and technology—health systems seem to value in their improvement work. Experience with systems and people received a slight edge, with 35% saying systems value this highly, and 51% saying systems value it. Professional expertise was viewed as less highly valued, at 20%, but 53% reported that systems find some value tapping into their professional experience. Experience with technology received the lowest marks, with 45% of patient-family respondents saying systems value this experience either slightly or not at all.

How well do you think health systems understand and value the experience you bring to improvement work in each of the following areas?

n = 51



Southcentral Foundation Built a System for Customer-Owners



Doug Eby, M.D., MPH
Vice President of Medical Services



Southcentral Foundation leaders don't just get patient-family feedback to improve existing systems; they have built a system that is premised on partnership with customer-OWNERS.

This belief has led to a fundamentally different care system. Southcentral Foundation primarily serves Alaska Native and American Indian people in Alaska, who comprise a majority of leadership and staff positions. Southcentral relies on a set of [Operational Principles](#) that were co-designed with members of the community to filter and guide innovation opportunities. These principles stress relationships, listening, and co-ownership; the foundation of the Nuka System of Care.

Southcentral Foundation has built co-ownership into its very fabric. "All of our processes are customer-owner-owned and -driven. It's real. It's structural. It's governance, change management, and feedback," explained Doug Eby, M.D., MPH. And much of it is based outside of the core institutional locations. "Co-

creation in most of healthcare still largely occurs within our construct, our confines, within the parameters of what we say is possible," said Dr. Eby. "This is not really listening, or co-creation. It's not responsive to what customers need. It's institutional and convenience-driven for the system."

By listening to and working with customer-owners, Southcentral Foundation has built a system that co-locates key services in a primary care center with multiple specialties aligned with patient relationships. Once relationships are established, two-thirds of services are virtual.

The results for the system are extraordinary. Since implementing the Nuka System of Care, Southcentral's total cost per person per year is down significantly, ER use dropped by 40 percent, and hospital use dropped 36 percent. "If you're going to do cost control, responsibility, and whole person care across time, this is the way to do it," said Dr. Eby.

Cultural Foundation	What Customer-Owners Want
<ul style="list-style-type: none"> • Customer-"owners," not patients • RELATIONSHIPS Operational Principles • Continuous feedback • Dig into "messy human" relationships 	<ul style="list-style-type: none"> • Companion model of care: coaching, advising, support • Two-thirds virtual (phone, text, video, email) • Whole person care = primary care center with a PCP, behaviorist, case management, pharmacist, midwife HIV specialist, psychologist, etc.
Co-Ownership	Results
<ul style="list-style-type: none"> • Dozens and dozens of customer-owner councils • iPad feedback throughout the care encounter • Senior executives spend 20-40% of their time listening • Leaders go to the community for feedback • Shared responsibility to align innovation with operating principles 	<ul style="list-style-type: none"> • Low total cost per patient • ER utilization down 40% • Hospital use down 36% (25th percentile with high-risk) • Staff turnover is low; satisfaction among highest in US • The only two-time Baldrige Award winner

Innovation Opportunity: Build the Business Case for Patient-Family Partnership

Capture Contribution

- ✓ Number of total partners
- ✓ Total hours contributed by partners (don't forget virtual!)
- ✓ Percent of committees with partners
- ✓ Number of projects involving patient-family partners
- ✓ Idea anecdotes
- ✓ Partner diversity
- ✓ Unique expertise (e.g. marketing expert, logistics expert)

Calculate Near-Miss Savings

Based on patient-family feedback:

- ✓ Facility redesigns NOT undertaken
- ✓ Videos, brochures, or other materials NOT produced
- ✓ Number of improvement projects "unstuck" (and results)

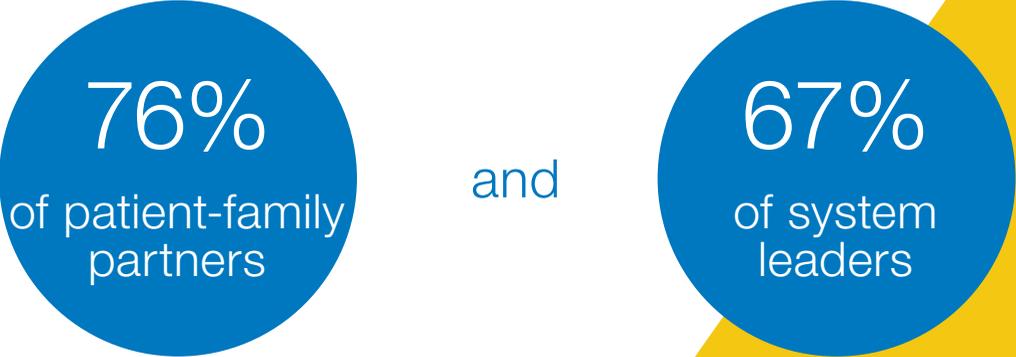
Measure Improvement Impact

- ✓ Improvements in quality, safety, efficiency, experience and other KPIs after patient-family partner-involved redesigns
- ✓ Reduction in voluntary turnover, patient, and staff experience when patients and families are involved in hiring

Open with a Story

Opening meetings with a story of patient care is becoming common; flip it and start with a story of the impact of patient-family partnership.

The Future of Patient-Family Partnership: Partners Get a Seat at Every Table



say patient-family partners need a seat on every decision-making team or committee

Patient-Family Partners Say More Power and Presence Would Lead to More Patient-Led Transformation

Patient-family partners need more power

We asked patient-family partners what it would take to create a future in which they are in charge of how healthcare change happens and which changes are implemented. Eighty percent indicated that PFACs and similar patient-family influence bodies would need more power, and 76% suggested that patients and family members would need a seat on every decision-making team or committee. Interestingly, almost as many indicated that system leaders would need to have more respect for patient-family perspectives.

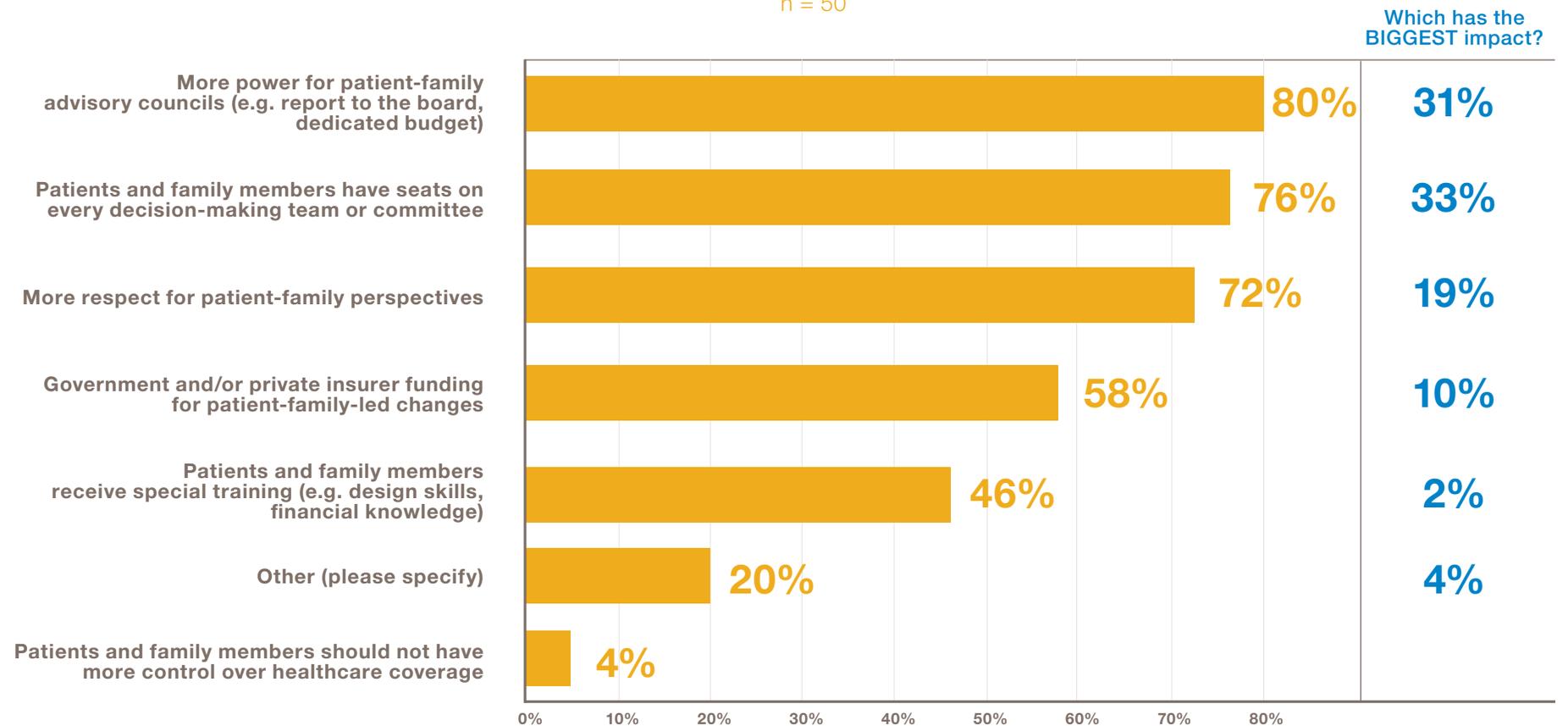
A few patient-family respondents cautioned that patients shouldn't take charge of healthcare transformation. Said one respondent, "I think patients and families should only have some degree of control—there needs to be control from the system's perspective about what is realistic, financially responsible, and good for the whole population."

Imagine a future in which patients and family members such as yourself are in charge of how healthcare change happens and what changes are put into action.

What would have to happen for that to take place?

(Please select all that apply.)

n = 50



■ denotes patient-family partner data

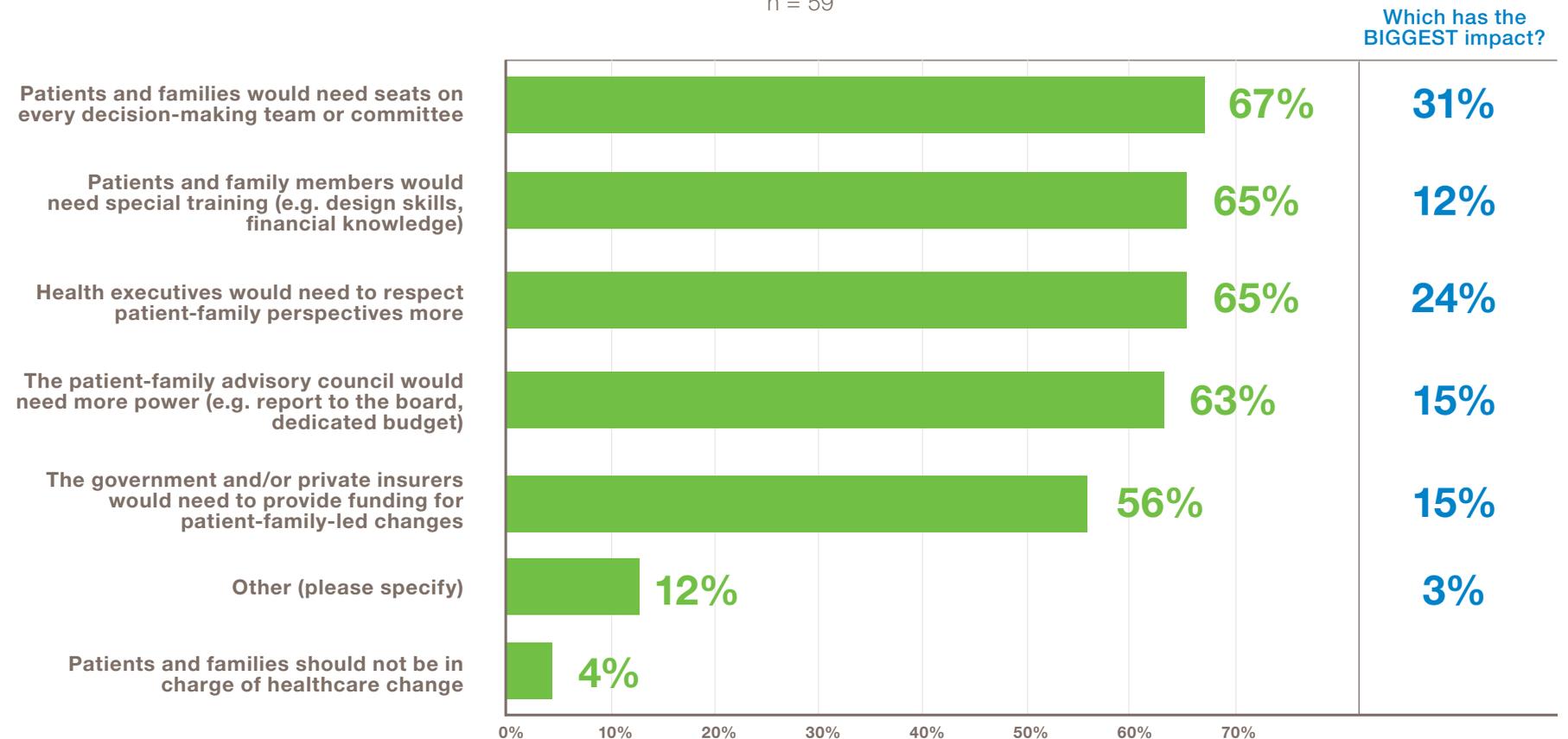
System Leaders are Largely Aligned with Patient-Family Perceptions

Two-thirds of system leader respondents say patient-family partners need seats on every decision-making team or committee

We asked system leaders the same question about how to create a future in which patients and family members are in charge of healthcare transformation. Their responses largely aligned with patients and families, though they were more likely to advocate for giving patients and family members skills training to support their involvement (65% of system leaders versus 46% of patients and families).

Imagine a future in which patients and family members are in charge of how healthcare change happens and what changes are put into action. What would have to happen for that to take place? (Please select all that apply.)

n = 59



The Future is Bright for Patient-Family Partnership



My vision is for the routine involvement of patients and families at all levels of our transformation efforts. We can do that by offering a variety of options for participation; making sure they're prepared (as much as we say we'll welcome them, if they don't know the language, it won't work); recognizing their contributions, which can be as simple as a certificate, a post on Facebook, or a faculty stipend. We can think big enough to solve this.

– Darla Cohen, BS, MS Ed, CPXP
Coordinator Patient- and Family-Centered Care;
Program Coordinator Patient and Family Experience;
Riley Hospital for Children

The key to our success for safe outcomes and high quality care is having strong patient and family involvement every step of the way. I've seen pockets of what it can look like when it works really well. We have this treasure right in front of us—we need to make sure we tap into it for every aspect of transformation. My future vision is that partnering with patients and families is woven into the fabric of our culture.

– Toni Millar, MS, CCLS
Vice President, Patient Centered Care for the
Regional Hospital Network,
NewYork- Presbyterian Hospital

Our vision is to have a membership program that lets patient-family partners engage at the level they want. We are building a database with information about all the patients and families who want to participate—their demographics, health experience, expertise, and how often they want to participate. Then, at any moment when the organization is working on something, we can reach out to patients and the community to bring in the voice of the customer.

– Mary Roderique, MHA
Experience Improvement and Innovation
Program Manager
University of Chicago Medicine

The background features a repeating geometric pattern of green and white triangles. The green triangles are arranged in a staggered, interlocking fashion, creating a dynamic, zig-zag visual effect. The white triangles fill the spaces between the green ones.

Co-Architecting Healthcare Transformation

Plan on a Page: Co-Architecting Healthcare Transformation Strategy Checklist

To reach a future where patients and families co-architect healthcare solutions that meet their needs in true partnership with system leaders, doctors, nurses, and other frontline team members, focus on the following checklist of opportunities:

"Always" Inclusion	Process Improvement	Training	Diversity & Access	Value/Compensation
<p>Strategic</p> <ul style="list-style-type: none"> <input type="checkbox"/> Strategy definition <input type="checkbox"/> Hiring <input type="checkbox"/> Boards <input type="checkbox"/> Improvement projects <input type="checkbox"/> Technology decisions <input type="checkbox"/> Market outreach <p>Operational</p> <ul style="list-style-type: none"> <input type="checkbox"/> Rounding <input type="checkbox"/> Huddles <input type="checkbox"/> Peer navigation 	<ul style="list-style-type: none"> <input type="checkbox"/> Identify opportunities <input type="checkbox"/> Define projects and scope <input type="checkbox"/> Ideate <input type="checkbox"/> Prototype <input type="checkbox"/> Implementation and testing <input type="checkbox"/> Spread and scale 	<p>Patients & Families</p> <ul style="list-style-type: none"> <input type="checkbox"/> Healthcare business basics <input type="checkbox"/> Storytelling <input type="checkbox"/> Design thinking <input type="checkbox"/> Position-specific (board bylaws, PDSA, research process, etc.) <p>Team Members</p> <ul style="list-style-type: none"> <input type="checkbox"/> The value of co-architecture <input type="checkbox"/> Active listening <input type="checkbox"/> Change management <input type="checkbox"/> Design thinking 	<p>Diversity</p> <ul style="list-style-type: none"> <input type="checkbox"/> Demographics <input type="checkbox"/> Socio-economic status <input type="checkbox"/> Access <input type="checkbox"/> Healthcare experience <input type="checkbox"/> Underserved <p>Access Pathways</p> <ul style="list-style-type: none"> <input type="checkbox"/> PFACs <input type="checkbox"/> Digital platforms <input type="checkbox"/> Listening tours <input type="checkbox"/> Community outreach <input type="checkbox"/> Social media 	<p>For Patient-Family Partners</p> <ul style="list-style-type: none"> <input type="checkbox"/> Executive appreciation <input type="checkbox"/> Feedback and results <input type="checkbox"/> Cost reimbursement <input type="checkbox"/> Program and training opportunities <input type="checkbox"/> Stipends <input type="checkbox"/> Consultant fees <p>For the System</p> <ul style="list-style-type: none"> <input type="checkbox"/> Capture inputs <input type="checkbox"/> Capture outcomes (quality, cost, experience)

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Gratitude for Patient-Family Partners

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A non-profit devoted to helping patients and healthcare professionals work together as partners as e-patients and empowered physicians.



Committed to building a community of healthcare providers, administrators and patients and families coming together in partnership to improve the quality, safety, experience and delivery of health care.



A mission-driven company connecting healthcare with the experience, skills and insights of Patient Leaders.

Experience Innovation Network members who connected us with their valued patient and family partners



About the Experience Innovation Network

The Experience Innovation Network, part of Vocera, works to restore the human connection to healthcare. We lead and accelerate the discovery, adoption, and execution of innovations that meet the quadruple aim of improving population health, elevating patient-centered care, and reducing costs while restoring joy to practice. Co-founded by Bridget Duffy, M.D., the first chief experience officer in healthcare, this global community of industry pioneers works to transform the healthcare experience.

For more information, visit www.vocera.com/EIN and follow us on Twitter at @EINHealth.

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Gratitude

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