



IssueBrief

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More than a nice idea

Engaging patients leads to better care and better outcomes: Here's how

You'd be hard-pressed to find someone who objects to the concept of patient engagement. But putting the concept into practice has proved surprisingly difficult.

"Strengthening patients and families as partners in their care is more than just a good idea," says MaryBeth Kurland, chief executive officer of the Commission for Case Manager Certification. "It's a foundational principle."

She points out that it's recognized by the Department of Health and Human Services as "a critical factor in achieving improvements in the quality and safety of care." The Joint Principles of the Patient-Centered Medical Home cite patient engagement as a mark of quality.

And yet, true engagement happens only in a few exceptional organizations. For patient and family engagement to gain traction, it must be integrated into an organization's training and culture, and become an everyday part of care delivery.

And there's the rub.

"How do we convert it from aspirational aim to executable strategy?" asks Sara Guastello, the director of knowledge management for Planetree International. "What will it take to create a health care culture of patient

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CEO, COMMISSION FOR
CASE MANAGER CERTIFICATION

and family engagement? We know it takes more than the will to engage patients and families.”

She identifies three things that need to be in place to move from aspiration to actuality:

1. **A framework.** One of the most significant barriers to putting the idea of patient engagement into practice is a lack of understanding of what it would look like in practice, she explains. That’s why there’s a need for a framework.
2. **Evidence.** Many health care professionals and organizations—even patients—have been skeptical about efforts to more fully engage patients. They may like the *idea*, but they don’t have a reason to stop doing business as usual. But now, there’s a robust evidence base that ties engagement of patients and families to measurable outcomes.
3. **Actionable strategies.** Finally, these approaches must be viable in the real world, not just on

paper—so that when we apply them in the field, they work. “We need field-tested practices and approaches that truly facilitate the shift from the patients being passive recipients of care to becoming active members of their own care team,” says Guastello. Strategies are also needed to help staff members make the shift, she adds.

Framework, evidence and actionable strategies—that’s what Planetree and the National Academy of Medicine (NAM, formerly, the Institute of Medicine) address in a recent discussion paper. It introduces a logical framework for creating a culture of patient and family engagement, an annotated bibliography of the supporting research and real-life, evidence-based actionable strategies.

The National Academy of Medicine/Planetree paper—*Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care*—“represents, in my opinion, a major step forward in building the knowledge base and strategy,” she says.

It also changes the very definition of engagement. Back in 2001, it involved building care *around* the patient, in consideration of the patient’s needs:

“Patient centered care is providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all

clinical decisions.”—Institute of Medicine, *Crossing the Quality Chasm*, 2001

That was a good start, Guastello says. The NAM/Planetree paper makes the definition more robust:

Patient and family engaged care is care planned, delivered, managed, and continuously improved in active partnership with patients and their families (or care partners as defined by the patient) to ensure integration of their health and health care goals, preferences, and values. It includes explicit and partnered determination of goals and care options, and it requires ongoing assessment of the care match with patient goals.

This, Guastello explains, represents a move beyond discrete practices to a more sustained, holistic approach. The goal of the framework team is to develop a common understanding of the essential elements for creating and sustaining a patient- and family-engaged culture.

See how the framework pulls it together in Figure 1 (next page).

From evidence to action

“The evidence shows us that patient and family engagement is good for patients and family members, *and* it yields better outcomes,” Guastello says.

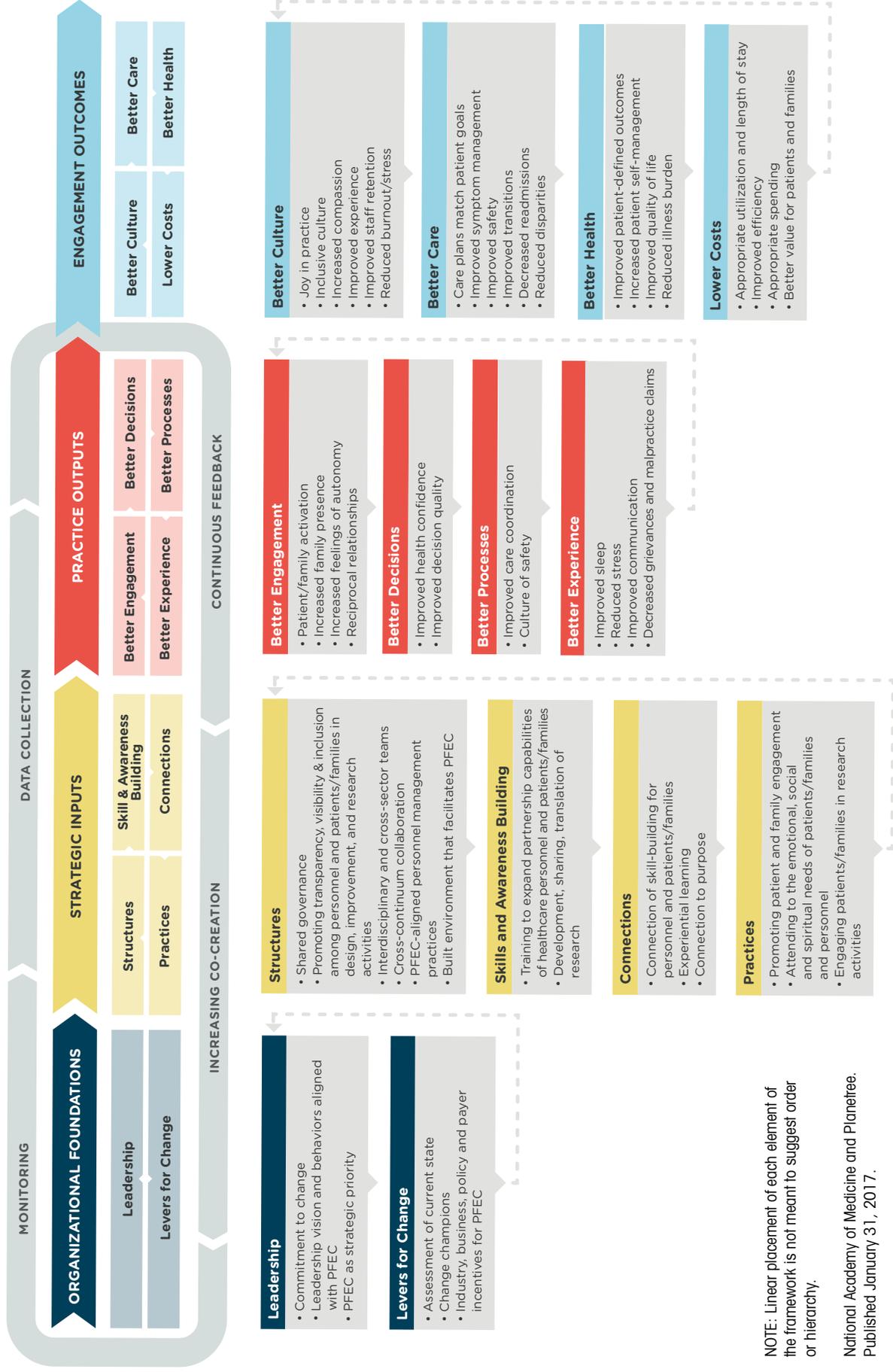
Among the evidence reported in the paper: Engagement of a

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DIRECTOR OF KNOWLEDGE
MANAGEMENT
PLANETREE

FIGURE 1

Patient and Family Engaged Care: A Guiding Framework



NOTE: Linear placement of each element of the framework is not meant to suggest order or hierarchy.

National Academy of Medicine and Planetree. Published January 31, 2017.

hospitalized patient's family in care activities and coordination improves patient outcomes, including better pain management, improved sleep, increased health literacy and improved health confidence—plus smoother transitions and fewer readmissions.^{1,2,3}

But what's especially important, say both Kurland and Guastello, is that these aren't just academic or aspirational findings. They have been road-tested in hospitals and health systems around the country.

Now that patient and family engagement are confirmed in research and practice as the best approach for better health and better care, how do case managers make that happen? Guastello points to several evidence-based⁴ opportunities.

- **Ask patients to identify a care partner.** The very act of doing this honors the role of the family member or friend and allows for greater collaboration. One of the strategies the paper explores is a formal care partner program. That program formally engages family caregivers as members of the care team, making them partners with the

¹ Meyers TA, et al. Family presence during invasive procedures. *Am J Nurs.* 2000;100(2):32-42.

² Jabre P, et al. Family presence during cardiopulmonary resuscitation. *N Engl J Med.* 2013;368(11):1008-1018.

³ American Geriatrics Society, (2001). Guideline for the prevention of falls in older persons. *Journal of the American Geriatrics Society*, 49

⁴ Frampton SB, Guastello S, Hoy L, Naylor M, Sheridan S, Johnston-Fleece M. *Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care.* Discussion Paper. National Academy of Medicine, 2016

When setting goals and developing care plans, ask patients what matters most to them. Most are motivated by meaningful goals rather than an abstract indicator. Case managers should appeal to what truly motivates the client, whether it's running a 5K or playing with grandchildren.

staff as part of the patient's support network. They are thus involved in care planning, and even provide hands-on care where appropriate.

Although the paper looks at this approach in terms of hospitalized patients, it needn't be limited to that, Guastello says. The evidence, she says, should change the question from "Why should we engage family members?" to "Why wouldn't we engage family members?"

- **Engage in collaborative goal setting.** When setting goals and developing care plans, ask patients what matters most to them. Most are motivated by meaningful goals rather than an abstract indicator. Case managers should appeal to what truly motivates the client, whether it's running a 5K or playing with grandchildren.

Related to this is **shared decision making**, interacting with patients who wish to be involved in arriving at an informed, values-based choice among two or more medically reasonable alternatives.

- **Use teach-back and reflective listening.** Teach-back is a

technique for validating patients' comprehension of the information you've just conveyed. You simply ask the patient to restate, in his or her own words, what they heard from you. In reflective listening, you share your understanding of what the client said. Using both techniques together creates a back-and-forth partnership.

Such an approach is especially important when providing support by phone, where there are no non-verbal cues to follow. Leave space for asking questions, and let patients know they are expected to ask them. It's a matter of changing your language, Guastello explains. Instead of "Do you have any questions?" ask "What questions do you have for me?"

- **Support a shared medical records policy.** The evidence supports allowing patients to access their real-time, in-progress personal health information at the point of care—for example, during a hospitalization and/or treatment. It flips the current paradigm and makes limited access the exception rather than the rule. Not only does this approach improve activation; it decreases

malpractice claims. Patients are also more likely to recommend a hospital that does this.⁵

Case managers can't always make this happen, but they can facilitate change. To learn how, read the March 2016 Commission issue brief, *P is for Portability: Want to engage patients? Help them obtain their own health data.*

Planetree provides an array of resources case managers can use to better deploy these approaches. (See sidebar for details.)

Although most of these practices are probably easiest to use in the in-patient or clinic setting, they can be adapted, Guastello says. So, in an emergent situation, you would

⁵ *Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care.* op. cit.

explain what's occurred, enlist a family member if possible, and provide the information the patient needs to move through the process. At the bare minimum, she says, "Don't step away from the patient, but engage the patient in the moment."

A call to case managers

For case managers, says Kurland, promoting patient and family engagement is second nature. "Case managers have a duty to step up to support their clients. And it's our responsibility to honor the wishes of patients, as well as to invite their family or other care partners to participate as important members of the team, too."

To make this work, there must be open, multi-directional communication, says Guastello. One of the NAM/Planetree findings is

that patients must be *actively encouraged* to participate, and told how they make a difference.

Kurland agrees, pointing out that sometimes patients don't always understand their role. "We know that patients and their family members should be the drivers when it comes to their own health care. But chronic health issues or an acute health crisis can put patients in uncertain territory; they may need gentle guidance to remind them it's *their* health, *their* lifestyle and *their* priorities that are most important."

Case managers are ideally suited to do just that. "It's the role of case managers, providers and health care organizations to help clients regain that confidence so they can become active players on the health care team," Kurland says. ■

Resources for Case Managers

Plain language summaries written by patient and family advisors:

- ***Harnessing Evidence and Experience to Change Culture***—Ideal for patients, families and laypeople to explain the evidence and best practices. Ideal to explain the evidence and best practices to patients and families.
- ***An Invitation to Engage***—A starting point to talk about engagement directly with family members and patients.

Other materials to share:

- ***Questions to Ask Your Hospital About Person-Centered Care***
- ***Questions to Ask Your Doctor About Person-Centered Care***
- ***Patient Preferences Passport***—A user-friendly, patient-owned tool that consolidates important patient information.

Toolkits and assessments

- **Shared Medical Record Quality Check**—10-question assessment tool designed to support organizations in assessing the quality of their shared medical record policy and execution of the practice. It also helps identify opportunities to strengthen partnerships with patients and family members for better engagement.
- **Patient-Directed Visitation Quality Check**—13-question assessment tool for inpatient care organizations to assess their patient-centered approach to visiting; it helps identify opportunities around welcoming the presence of family, and maximizing their potential as members of the care team.

Planetree provides these resources for download at planetree.org/resources

About the Experts



Sara Guastello
Director of Knowledge Management
Planetree

Sara Guastello is the director of knowledge management for Planetree, a not-for-profit advocacy and membership organization. Planetree works with health care provider organizations across the continuum of care to implement comprehensive patient- and person-centered models of care.

Guastello has developed a range of educational and implementation resources to guide organizations in their endeavors to deliver patient-centered care. She oversees the Patient-Centered Hospital Designation Program and the related Patient-Centered Merit Recognition Program, the only such program to recognize excellence in patient- and resident-centered care across the continuum. A frequent writer on patient-centered care, Guastello has contributed to numerous publications, and is also the co-editor of *The Putting Patients First Field Guide: Global Lessons in Designing and Implementing Patient-Centered Care*.



MaryBeth Kurland, CAE
CEO, Commission for
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MaryBeth Kurland leads and sets the Commission's strategic mission and vision. She manages relationships with likeminded Commission's and oversees business development as well as the organization's programs, products and services. She works directly with the Board of Commissioners, building its corps of volunteer and subject-matter experts who directly support and evaluate certification and related services. Prior to becoming CEO, Kurland served as the Commission's chief operations officer, and was staff lead for the development and launch of the Commission's signature conference, the CCMC New World Symposium.

Kurland brings extensive experience to her role, having served as executive director of organizations including the Association of Medical Media, Office Business Center Association International and the League of Professional System Administrators. She holds a bachelor of arts from the University of Delaware and is a member of the Institute for Credentialing Excellence, the American Society of Association Executives, and the Mid-Atlantic Society of Association Executives. In 2011, Kurland was recognized as Association TRENDS Young & Aspiring Association Professional.



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