



Scientific Advisory Panel on the Evidence Base for Patient and Family Engaged Care

NAM SAP Goals

- Support NAM's aim to facilitate the advancement of patient and family engaged care by building and disseminating the evidence base for the tools, strategies, and culture required,
- Identify research/researchers who can contribute to the evidence base for this work,
- Develop a common understanding of essential elements for creating and sustaining patient and family engaged culture,
- Establish a process for sharing and compiling existing and emerging research in support of these essential elements.

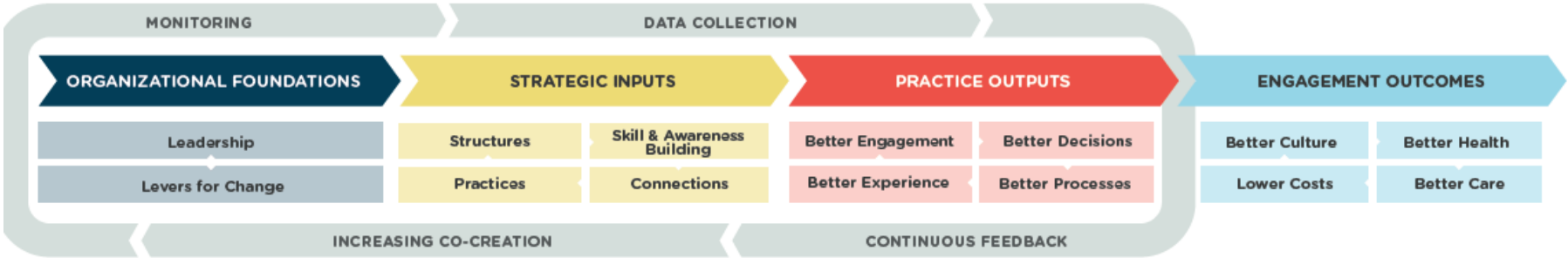


Scientific Advisory Panel for Patient and Family Engaged Care

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Deliverable #1: Guiding Framework for Patient and Family Engaged Care



- Leadership**
- Commitment to change
 - Leadership vision and behaviors aligned with PFEC
 - PFEC as strategic priority

- Levers for Change**
- Assessment of current state
 - Change champions
 - Industry, business, policy and payer incentives for PFEC

- Structures**
- Shared governance
 - Promoting transparency, visibility & inclusion among personnel and patients/families
 - Fostering dialogue between clinical researchers and patients/families
 - Interdisciplinary and cross-sector teams
 - Cross-continuum collaboration
 - PFEC-aligned personnel management practices
 - Built environment that facilitates PFEC

- Skills and Awareness Building**
- Training to expand partnership capabilities of healthcare personnel and patients/families
 - Development, sharing, translation of research

- Connections**
- Connection of skill-building for personnel and patients/families
 - Experiential learning
 - Connection to purpose

- Practices**
- Promoting patient and family engagement
 - Attending to the emotional, social and spiritual needs of patients/families and personnel
 - Engaging patients/families in research activities

- Better Engagement**
- Patient/family activation
 - Increased family presence
 - Increased feelings of autonomy

- Better Decisions**
- Improved health confidence
 - Improved decision quality

- Better Processes**
- Improved care coordination
 - Culture of safety

- Better Experience**
- Improved sleep
 - Reduced stress
 - Improved communication
 - Decreased grievances and malpractice claims

- Better Culture**
- Joy in practice
 - Increased compassion
 - Improved staff experience
 - Improved staff retention
 - Reduced burnout/stress

- Better Health**
- Improved patient-defined outcomes
 - Increased patient self-management
 - Improved quality of life
 - Reduced illness burden

- Better Care**
- Care plans match patient goals
 - Improved symptom management
 - Improved safety
 - Improved transitions
 - Decreased readmissions
 - Improved patient experience

- Lower Costs**
- Decreased utilization and length of stay
 - Improved efficiency
 - Lower healthcare costs
 - Better value for patients and families

NOTE: linear placement of each bucket is not meant to suggest order or hierarchy

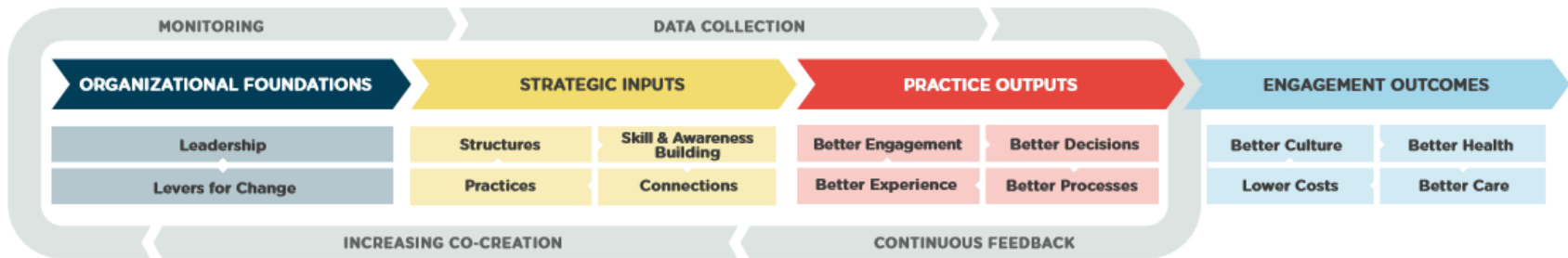


From High Level

Broad overview of the framework with core elements of each transformational stage delineated



Delineation of core elements of each transformational stage



To a more detailed implementation plan



NOTE: linear placement of each bucket is not meant to suggest order or hierarchy



Deliverable #2: NAM Perspectives discussion paper and supporting literature

DISCUSSION PAPER

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Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care

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ABSTRACT | Patient and family engaged care (PFEC) is care that is planned, managed, and continuously improved in partnership with patients and their families (as defined by the patient) in a way that respects their preferences, values, and desired health outcomes. PFEC represents a shift in the role patients and families play in their care decisions, as well as in ongoing quality improvement and care delivery efforts. PFEC also represents an important shift from focusing solely on the processes to aligning those processes to best address the health outcomes that matter to patients. In a culture of PFEC, patients are not merely subjects or spectators of their care; they are active participants whose voices are honored. Patients' (and their families') expertise about their bodies, lifestyles, and priorities is incorporated into care planning. Their care experience is valued and incorporated into improvement efforts.

A prevalent and persistent challenge to a system-wide transformation to PFEC is uncertainty about whether the resource investment required will lead to better results. There is also a lack of clarity about how, practically speaking, to make it happen.

To address these barriers, the National Academy of Medicine's Leadership Consortium for a Value & Science-Driven Health System convened a Scientific Advisory Panel (SAP) to compile and disseminate important insights on culture change strategies. The SAP's focus was on evidence-based strategies that facilitate patient and family engagement and are tied to research findings revealing improved patient care and outcomes. To achieve this goal, the SAP drew on both the scientific evidence and the lived experiences of patients, families, practitioners, and leaders to develop a comprehensive framework that explicitly identifies specific

high-impact elements necessary to create and sustain a culture of PFEC. Research in support of the various elements of the model was then compiled into a selected bibliography. This paper introduces the framework and associated evidence, along with practical examples of elements of the model applied in the "real world," with the goal of supporting action that will pave the way for PFEC to become the norm in health care.

Introduction

Patient and family centered care (PFCC) has been identified as a cornerstone of the national strategy for delivering better care and achieving better patient experiences at lower cost. Until fairly recently, efforts to promote PFCC have focused primarily on changing behaviors of patients (and, increasingly, families). These endeavors simultaneously treated patients as

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IN DEVELOPMENT



Opportunities

- Widely accepted definition of Patient/Family Engagement remains fairly narrow
- Limitations of traditional scales for rating the quality of research
 - Opportunity to elevate the credibility of experience-based research closely aligned with the priorities and experiences of patients/families
- Need for greater inclusion and proactive engagement of underserved, “hard-to-reach,” and “complex” patients and their caregivers
- Need for further exploration of opportunities to strengthen and expand the evidence-base focused on:
 - Effectiveness of training to expand partnership capabilities of patients and families
 - Effectiveness of patient engagement in large-scale healthcare quality improvement efforts, i.e. relationships between outcomes and degree of co-design
 - Extent to which experiential learning creates sustained changes in behavior of healthcare team members

