

INTEGRATING PERSON-CENTERED CARE & EVIDENCE-BASED RESEARCH

A Road Map for Essential Hospitals



ESSENTIAL
HOSPITALS
INSTITUTE

ABOUT AMERICA'S ESSENTIAL HOSPITALS

America's Essential Hospitals is the leading champion for hospitals and health systems dedicated to high-quality care for all, including the most vulnerable. We support our 325 members with advocacy, policy development, research, and education. Communities depend on essential hospitals to provide specialized, lifesaving services; train the health care workforce; advance public health and health equity; and coordinate care. Essential hospitals innovate and adapt to lead the way to more effective and efficient care. Learn more at essentialhospitals.org.

ABOUT ESSENTIAL HOSPITALS INSTITUTE

Essential Hospitals Institute is the research and quality arm of America's Essential Hospitals. The Institute supports the nation's essential hospitals as they provide high-quality, equitable, and affordable care to their communities. Working with members of America's Essential Hospitals, we identify promising practices from the field, conduct research, disseminate innovative strategies, and help our members improve their organizational performance. We do all of this with an eye toward improving individual and population health, especially for vulnerable people.

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INTRODUCTION

Over the past two decades, the values and practices of patient-centered care have increasingly supplemented traditional care delivery. For example, through patient-centered approaches, patients have been encouraged and empowered to take a more active role in their care. Given national reforms toward value-based care and population health, these methods have broadened to encompass more holistic approaches, putting more emphasis on the “whole person” and giving rise to the term “person-centered care.”

At the same time, evidence-based research has become increasingly integrated into health care practice. For example, the establishment of the Patient-Centered Outcomes Research Institute (PCORI) in 2010 provided a platform and funding mechanism for researchers and health care providers to conduct and use evidence-based research. Specifically, as subsets of evidence-based research, PCORI encourages and supports comparative-effectiveness research and patient-centered outcomes research, as both play important roles in generating evidence that helps clinicians better understand the unique needs and values of all patients.

There is a strong intersection in everyday health care practice between person-centered care and evidence-based research. While these two disciplines have historically remained siloed, they serve as complementary strategies for improving patient experience and outcomes. For example, evidence-based research strives to investigate what is most important to patients, caregivers, and communities and includes them as research partners. Person-centered care strives to include patients and families in their own care and respond to what’s most important to them during clinical visits and in making treatment decisions. When implemented simultaneously, these two approaches can benefit one another as well as larger goals of better care delivery.

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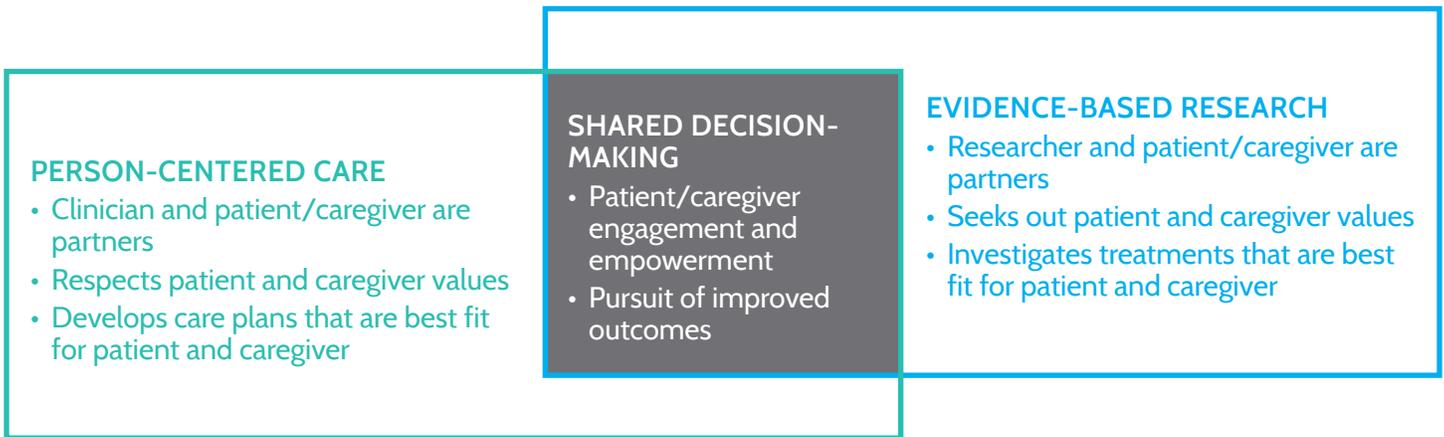
THE HEALTH RESEARCH SPECTRUM



Comparative-effectiveness research is designed to compare the effectiveness of different interventions by examining the risks and benefits of several treatment interventions. **Patient-centered outcomes research** is a specific type of comparative-effectiveness research that also takes into consideration the needs, preferences, and outcomes of greatest value to those receiving care. Both types of research produce evidence-based findings that can support shared decision-making and improve care delivery.

Adapted from Alberti, AAMC, 2015

INTERSECTION BETWEEN PERSON-CENTERED CARE AND EVIDENCE-BASED RESEARCH



OUR RESEARCH

In support of its member hospitals, and through a contract with PCORI, Essential Hospitals Institute developed this road map to encourage and facilitate the integration of person-centered care and evidence-based research among essential hospitals and health systems. Each strategy included in this document stems from the findings of these research tasks and from stakeholder input:

- **Advisory Groups:** The Institute convened three advisory groups to provide guidance on all project activities. These included a Patient Advisory Group, a Clinician Advisory Group, and a Chief Medical/Chief Quality Officer Advisory Group. There were 21 advisers across the three groups.
- **Landscape Review:** A landscape review was conducted to gather information about the current state of person-centered care and evidence-based research among hospitals and health systems. This included a review of academic and grey literature and eight interviews with leaders from America's Essential Hospitals member institutions.
- **Hospital Survey:** The Institute developed, tested, and administered an electronic survey for chief quality officers and chief medical officers of America's Essential Hospitals members. The survey asked specific questions about hospitals' practices related to evidence-based research and person-centered care. Thirty-four surveys were returned, a 22 percent response rate.
- **Patient/Caregiver Interviews:** The Institute conducted six interviews with 15 patients and caregivers, in groups of two or three, to collect additional information about patient/caregiver perceptions of person-centered care and evidence-based research.
- **Deliberative Summit:** On April 19, the Institute and The MetroHealth System in Cleveland hosted a summit to deliberate on the draft contents of this road map. Attendees included five members of the Patient Advisory Group (as well as two caregivers/travel companions), four members of the Clinician Advisory Group, one member of the Chief Medical/Chief Quality Officer Advisory Group, and three staff members from America's Essential Hospitals.

HOW TO USE THIS ROAD MAP

There are four main sections to this road map. The first is a value proposition. Implementing changes to hospital policies or practices requires a clear understanding of the value the changes will bring. This section aims to communicate the benefits of integrating person-centered care and evidence-based research to facilitate buy-in and sustainability.

Then, the road map covers three operational objectives, which target critical catalysts for integrating person-centered care and evidence-based research. These include establishing a person-centered culture, participating in evidence-based research, and integrating person-centered care and evidence-based research into everyday practice.

This road map is intended for administrators, researchers, clinical providers, and other key stakeholders directly involved with integrating person-centered care and evidence-based research in hospitals. It is inclusive of all levels of experience and expertise. The road map should not be viewed as a strict rulebook, but rather a menu of strategies that should be applied within a hospital or health system's individual context.



DEMONSTRATING VALUE

The topics of person-centered care and evidence-based research are especially pertinent to vulnerable populations, which are often under-represented in research and may require special considerations due to complexities stemming from multiple chronic conditions and/or limiting socioeconomic situations. As the primary providers for vulnerable patients across the nation, it is critical for essential hospitals to engage in the integration of person-centered care and evidence-based research. However, competing priorities, as well as time and resource restrictions, can hinder this process. As a first step to mitigating such barriers, it is important to understand the direct and indirect benefits that come with integrating person-centered care and evidence-based research.

Direct benefits include supporting other hospital initiatives in a way that is efficient and not duplicative. For example, many essential hospitals own and operate patient-centered medical homes (PCMHs). The National Committee for Quality Assurance's standards for recognizing PCMHs foster practices around involving patients and families in governance or stakeholder committees, implementing clinical decision supports that follow evidence-based guidelines, and adopting shared decision-making aids. Integrating such strategies into everyday practice beyond the medical home can not only serve to improve all clinical visits; it can also streamline meeting PCMH certification requirements.

Likewise, there are strict quality metrics for Medicare accountable care organizations (ACOs) that include Consumer Assessment of Healthcare Providers and Systems (CAHPS) measures to evaluate provider communication and mechanisms for shared decision-making. Integrating strategies related to person-centered care and evidence-based research can support these practices and, in turn, improve quality scores and shared savings. What's more, improving CAHPS scores regardless of ACO quality measures can lead to better hospital ratings and value-based purchasing reimbursement.

Indirect benefits, at least in the short term, relate to patient retention. Implementing new practices related to person-centered care and evidence-based research arguably can create new opportunities for positive patient and family engagement, potentially producing happier health care consumers who are more likely to return. Over time, utilization data can be used to identify trends toward increased patient retention, which ultimately supports a hospital's or health system's financial stability. Most important, this type of utilization and retention—which remains grounded in streamlined care delivery that incorporates patient and caregiver priorities—does not compromise larger goals to move toward value-based care.

It is important for hospital executives to discuss the value of integrating person-centered care and evidence-based research as it pertains to their hospital or health system, especially before taking any of the steps outlined in the road map. This process should include systemwide representatives, as integrating person-centered care and evidence-based research has systemwide implications. Key stakeholders in these discussions include chief executive officers, chief operations officers, and chief financial officers. Other entities and partners, such as pharmacy and therapeutics committees, quality-improvement teams, and academic affiliates, may also have important insights to offer.

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ESTABLISH A PERSON-CENTERED CULTURE

Establishing an organizational culture around person-centered care can naturally create a space and role for evidence-based research. For example, person-centered care can foster evidence-based research through patient and family engagement and activation. Organizational culture is complex, however, and is built not only by leadership but also by clinicians, patients, and families. Creating a person-centered culture will require the involvement of all these groups. To accomplish this objective, hospital leaders can review organizational priorities, implement systemwide training, identify and foster champions, and/or establish patient and family advisory councils.

REVIEW ORGANIZATIONAL PRIORITIES

Hospital leaders should spend time reviewing—and, when appropriate, amending—organizational priorities to better facilitate a person-centered culture that embraces evidence-based research. Many health care providers already embed patient engagement and person-centered care into their mission, vision, and values statements, and this trickles down to guiding principles, strategies, and processes. A new element for consideration is how evidence-based research can support existing goals and strategies as part of a new and complementary approach to bolstering the patient experience.

A gap analysis can help with developing more in-depth priorities by systematically identifying assets, needs, and barriers around person-centered care. Additionally, patients, caregivers, clinicians, and administrators can provide input to further guide the priority-setting process and establish metrics for measuring success. From here, organizational priorities can be communicated to staff, patients and families, and the larger community and demonstrated through allocation of resources, changes to policies and practices, and stakeholder engagement.

IMPLEMENT SYSTEMWIDE TRAINING

Education and training is a crucial step for translating organizational priorities to on-the-ground culture. Training can underscore the importance of person-centered care and evidence-based research and give executives, clinicians, and

Strategy: Normalizing Research

Hospital leaders might seek to set priorities that normalize the term and concept of “research.” In some communities, often those served by essential hospitals, “research” has negative connotations and acts as a barrier to engaging patients. Taking steps to normalize the term and communicate its value through organizational priorities and statements can facilitate additional activities as part of integrating person-centered care and evidence-based research.

In the Field: Henry Ford Health System

Henry Ford Health System, in Detroit, established four core areas at the system level—Patient Engagement, PCOR Methodology, Data Analysis, and Dissemination—which include their evidence-based research efforts. As part of the Patient Engagement Core, patient advisers are put through a standardized training program to become familiar with concepts in patient engagement and research, as well as receive training in active listening and effective communication skills. As of mid-2018, Henry Ford Health System has trained more than 350 patient advisers who serve on research and operational projects.

patients greater understanding of the background and value of these disciplines. Training also prepares staff for changes in policies, procedures, and job functions.

Training should target areas identified in gap analysis to address knowledge, skills, and resource challenges. These areas might include foundations of person-centered care, methodology of evidence-based research, interpreting evidence to support decision-making, educating patients as part of decision-making, effective dissemination and implementation of research findings, statistical analysis, or use of IT resources.

IDENTIFY AND FOSTER CHAMPIONS

Champions play an important role in sustaining commitments to person-centered care and evidence-based research at a hospital or health system. Champions function as advocates, role models, and accountability partners and are defined by their actions, knowledge, and dedication. Anyone can serve as a champion, including patients, caregivers, physicians, nurses, and administrators.

Often these champions are already present within the hospital or health system but may need to be identified. As essential hospitals strive to facilitate a culture that supports evidence-based research as part of person-centered care, it is important to consistently identify, encourage, and support champions to maintain continued commitment irrespective of leadership changes or staff turnover.

ESTABLISH PATIENT AND FAMILY ADVISORY COUNCILS

Patient and family advisory councils play an important role in guiding broader organizational priorities and activities. These councils can comprise patients, caregivers, community members, and hospital staff who are champions of improving hospital operations and patient experiences.

Establishing these councils can serve as a foundational strategy for other activities that may require patient or caregiver partners. For example, their experience in developing recommendations and guiding activities can be utilized during implementation of any new practices or policies related to integrating person-centered care and evidence-based research.

Strategy: Patient and Caregiver Training

Training and education will most likely be needed to familiarize patients and caregiver partners with the concepts of evidence-based research. This type of training can help improve comprehension; support understanding of basic research models and protection of human subjects' principles; and prepare patients and caregivers for participation as research partners.

In the Field: The MetroHealth System

The MetroHealth System, in Cleveland, has a thriving Patient and Family Advisory Program as part of its Office of Patient Experience. Created more than four years ago, with patients serving on the development team, the program places one or two patients on committees throughout the organization. Patient and family advisers serve or have served on MetroHealth trustees' committees, quality teams, design groups for new construction, the arts-advisory board for the system's Arts in Medicine department, and in many other capacities. In every case, they are full members of the committee with decision-making and leadership roles. Almost every new team or committee that is formed in the health system now requests a dedicated Patient and Family Advisory Group.

PARTICIPATE IN EVIDENCE-BASED RESEARCH

Essential hospitals can not only use findings from evidence-based research; they can participate in the research process as well. Doing so can strengthen other strategies for integrating person-centered care and evidence-based research, such as engaging patients and families in new ways and supporting shared decision-making with relevant, evidence-based information. Such participation can also make an important contribution to the field by increasing research that includes underserved and underrepresented populations. Strategies to accomplish this objective can be tailored to a given hospital's individual circumstances; they might include serving as a community research anchor, leveraging research collaboratives, and/or building a foundation to conduct research.

SERVE AS A COMMUNITY RESEARCH ANCHOR

Essential hospitals often serve as anchor institutions in their communities, providing much more than health care alone. This role can be extended to evidence-based research. As trusted members of the community, essential hospitals can facilitate patient, family, and community participation in evidence-based research studies conducted by the hospital itself or by a partner institution.

As a foundational step—and one central to achieving the goal of integrating person-centered care and evidence-based research—patients and caregivers should be included as partners in the research process, possibly as co-investigators or research advisers. Doing so can help hospitals:

- steer research efforts to topics of high priority to patients and caregivers;
- develop and implement person-centered research methods;
- produce outcomes most important to patients and caregivers; and
- more effectively synthesize and disseminate research results.

Essential hospitals can facilitate recruitment of patients and caregivers to serve in these advisory roles, or to participate directly in research studies, by advertising research opportunities—reaching out to members of existing patient and family advisory councils, for example, or using community leaders as liaisons.

Additionally, essential hospitals can facilitate the sharing of research findings with all stakeholders, including staff, providers, research participants, patients and caregivers, and the community at large. Hospitals can, for example, turn to patient and caregiver advisers to test research materials and ensure that these

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Strategy: Defining Approach and Roles

Hospitals can develop formal frameworks that give patient and caregiver partners, researchers, and providers a clear and agreed-upon understanding of expectations for a patient's or caregiver's role in the research process, specifically around transparency, accessibility, cultural appropriateness, privacy, and incentives. For example, frameworks should clearly define types of patient and family engagement; provide a period of education and trust-building prior to larger research engagement; and outline expectations, risks, and benefits of participation.

In the Field: Bon Secours Health System

As part of a PCORI-funded contract to identify methods for including hard-to-reach patients in research, Bon Secours Health System, in Baltimore, collaborated with University of Maryland researchers and other parties to help recruit underrepresented groups, such as minority and low-income patients. The results from this research led to informed recommendations to facilitate comparative-effectiveness research and patient-centered outcomes research.

are culturally and linguistically appropriate and tailored to specific community audiences. They can also enlist patients, caregivers, or other community members to co-author papers or give presentations.

LEVERAGE RESEARCH COLLABORATIVES

Conducting complex, evidence-based research in-house may not be an option for most hospitals. Forming or joining research collaboratives can be an intermediary step that enables such hospitals to still contribute to evidence-based research.

For example, hospitals can form partnerships with an academic medical center or other research institution. Through such a partnership, a hospital can benefit from the increased availability of resources, such as staff and funding for research initiatives, while facilitating communication with patients and caregivers. This may include the inclusion of patient and caregiver partners in research; recruitment for studies; follow-up with research participants; and dissemination of results to patients, caregivers, and the community.

Another strategy to consider is forming or joining a data-sharing collaborative. Such groups can help a hospital access data from, or to use in, evidence-based research. Collaboratives can make evidence-based research more efficient, shift its focus toward patient and caregiver needs, and facilitate learning and improvement at health systems. One example of a data-sharing collaborative is a health-information exchange. There are also clinical data research networks (CDRNs), which offer large structures for conducting clinical-outcomes research. Several CDRNs have been formed through PCORI's PCORnet.

BUILD A FOUNDATION TO CONDUCT RESEARCH

Some essential hospitals may be able to conduct research with their current resources; others may be in the process of allocating resources to do so one day. In any case, if a hospital is going to be leading evidence-based studies, it is important to establish research priorities beforehand, to guide project topics and identify key research questions. The prioritization process should involve any stakeholders who will be involved in the research, including but not limited to patients, caregivers, clinicians, administrators, policymakers, and payers. Engaging relevant stakeholders to prioritize research topics and questions will help hospitals determine what topics are of greatest significance and will offer

Strategy: Partnerships

Academic medical centers are just one example of a research institution with which hospitals can partner. Most evidence-based research is housed within academic centers of a university: medical schools, nursing schools, and schools of public health. Similarly, non-academic research institutions might seek a clinical research partner, providing ample opportunity for essential hospitals to take a leading role in developing evidence-based research projects.

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In the Field: CaPriCORN

CAPriCORN, the Chicago Area Patient-Centered Outcomes Research Network, is a collaboration among health institutions that were able to overlook the barriers of competition for the purpose of sharing evidence-based research data. The alliance includes academic medical centers such as the Cook County Health and Hospitals System, University of Chicago Medicine, and the University of Illinois Hospital & Health Sciences System, as well as industry associations, patient-advocacy groups, insurers, government agencies, universities, and research institutes. CAPriCORN is designed to overcome the barriers of care fragmentation and limited resources to develop, test, and implement strategies to improve care for diverse populations and reduce health disparities.

the most value to end users of the research findings.

Developing a multidisciplinary research team is another critical strategy that supports the development of diverse research questions and mitigates potential barriers to implementation or dissemination. Such teams can and should include individuals from different departments across the organization. When possible, they also should include external researchers such as biostatisticians, epidemiologists, and health-services experts.

Dedicated resources can be set aside for this research team and other patient-engagement initiatives in a manner that potentially paves the way for a specific research department, center, or institute. Creating such a home for the team and its work can help establish organizational priorities and facilitate research efforts—but it should not become a silo, inaccessible to and disconnected from other operational teams. Clinical departments that are not a part of the research center should be routinely consulted and engaged in relevant aspects of the research, such as patient and caregiver recruitment.

Engaging relevant stakeholders to prioritize research topics and questions will help hospitals determine what topics are of greatest significance and will offer the most value to end users of the research findings.

In the Field: The Ohio State University Wexner Medical Center

To raise awareness about PCORI, The Ohio State University Wexner Medical Center, in Columbus, Ohio, holds two-hour informational sessions for staff, who learn how to apply for funding, share resources available to help investigators, and describe primary criteria for awarding grants. These sessions are promoted through daily medical center newsletters and on the hospital's intranet. The hospital encourages employees to participate in the PCORI workshop, cohosted by the Center for Clinical and Translational Science and the Office of Foundation Relations, a joint collaboration.



INTEGRATE PERSON-CENTERED CARE AND EVIDENCE-BASED RESEARCH INTO EVERYDAY PRACTICE

Person-centered care strategies and evidence-based research findings are most beneficial when used in everyday clinical practice. Standardizing their use as part of patient visits can promote shared decision-making, especially when they are integrated seamlessly into existing workflows. This empowers patients and caregivers, meets their demand for evidence-based information, and builds trust. To accomplish this objective, essential hospitals should aim to foster shared decision-making through person-centered care, create workflows that incorporate evidence into clinical visits, and/or use decision-making tools with patients and caregivers.

FOSTER SHARED DECISION-MAKING THROUGH PERSON-CENTERED CARE

Productive shared decision-making begins with a certain level of trust, engagement, and communication with the patient, which can be enhanced or compromised by a provider's actions and attitude. Clinicians should seek to create an environment that encourages shared decision-making—by, for example, demonstrating person-centered care, and including patients and caregivers in the decision-making team. This means having two-way conversations where the patient and caregiver feel comfortable asking questions, expressing their goals and values, raising concerns, and presenting information from other sources or providers. Fostering this type of environment for patient visits can greatly facilitate integration of evidence-based research findings into treatment decisions.

CREATE WORKFLOWS THAT INCORPORATE EVIDENCE INTO CLINICAL VISITS

Another beneficial strategy is to develop or enhance workflows that facilitate evidence-based conversations between physicians and patients/caregivers about treatment options. Such a workflow could start by asking about what a patient or caregiver has found on their own, so that both parties have a full picture of what is being considered. Subsequent steps can focus on proactively providing evidence-based information to offer additional context to the patient and caregiver and curating information that is most suitable for their circumstances. Where possible, electronic health records could ease and enhance workflow by embedding research findings relevant to a patient's diagnosis, prompting clinicians to review research findings, or linking to library facilities or repositories of evidence-based research.

USE DECISION-MAKING TOOLS WITH PATIENTS AND CAREGIVERS

Tools such as handouts and decision aids also can help patients, caregivers, and providers make informed treatment plans based on evidence. Hospitals can develop or use tools that incorporate findings from evidence-based research to guide decisions or provide comparative charts and data. Examples of these tools include outcomes data and statistics, condition- or population-specific data comparisons, and cost-benefit analyses. Such materials can support patient-provider interaction, enable patients to share information with families and caregivers, and ultimately help with care decisions.

Strategy: Addressing Complex Needs

As part of incorporating evidence-based research into shared decision-making, providers should remain aware of the unique or complex needs of their patient. For example, it may be necessary to address needs such as low health literacy, limited English proficiency, and social risk factors before starting conversations around research findings.

Strategy: Decision Aids

The most effective decision aids use accessible language, visuals, and user-friendly formatting. Patient/caregiver preferences for format (e.g., paper versus electronic) might vary, meaning providers ideally will offer multiple options. As health care becomes increasingly dependent on technology, essential hospitals may be able to incorporate evidence-based research information into patient portals to improve patient engagement and experience.

CLOSING

While integrating person-centered care and evidence-based research is an important process for essential hospitals, there still may be larger barriers to overcome. Specifically, evidence from comparative-effectiveness research, and even patient-centered outcomes research, that applies to the vulnerable patient populations essential hospitals serve may be lacking. To overcome this obstacle, it will be important for essential hospitals to get more involved in this area of research. By instilling these priorities into organizational culture, participating in research, and using findings in shared decision-making, essential hospitals can help ensure that the patients, families, and communities they serve have more representation and influence in evidence-based research studies. Moving in this direction can not only benefit care delivery and outcomes at essential hospitals but also create a new standard of practice for all health care providers across the country.



