Patient and Family Engagement: A Partnership for Culture Change

A Report of the NCIOM Task Force on Patient and Family Engagement

July 2015

North Carolina Institute of Medicine

In partnership with North Carolina Quality Center of the North Carolina Hospital Association, Community Care of North Carolina, North Carolina Medical Society, and Foundation for Nursing Excellence

Funded by The Duke Endowment

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The North Carolina Institute of Medicine (NCIOM) is a nonpolitical source of analysis and advice on important health issues facing the state. The NCIOM convenes stakeholders and other interested people from across the state to study these complex issues and develop workable solutions to improve health, health care access, and quality of health care in North Carolina.

The full text of this report is available online at **http://www.nciom.org**

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Suggested citation
North Carolina Institute of Medicine. Patient and Family Engagement: A Partnership for Culture Change. A Report of the NCIOM Task Force on Patient and Family Engagement. Morrisville, NC: North Carolina Institute of Medicine; 2015.

In partnership with North Carolina Quality Center of the North Carolina Hospital Association, Community Care of North Carolina, North Carolina Medical Society, and Foundation for Nursing Excellence. Funded by the The Duke Endowment.

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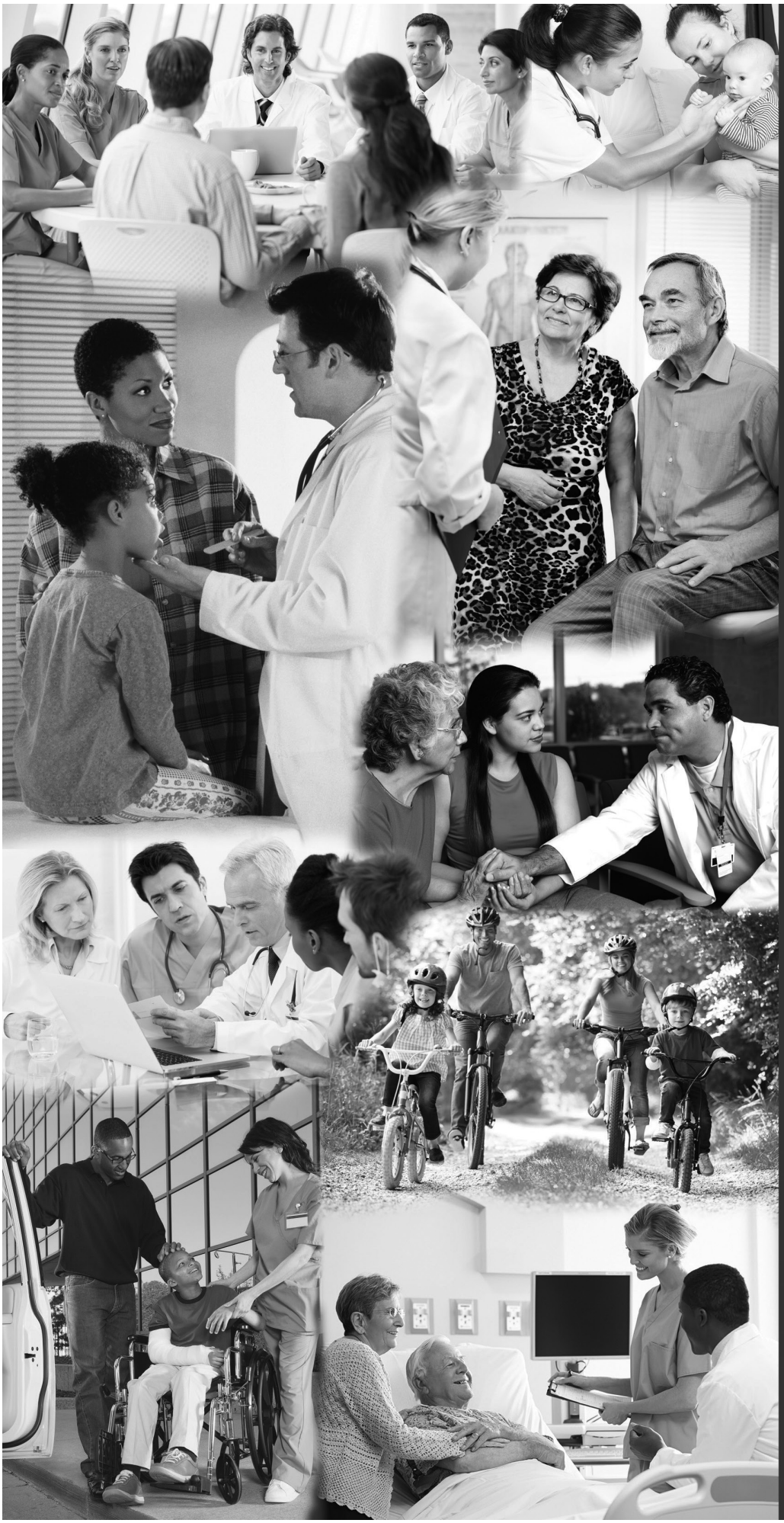

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Acknowledgements

The North Carolina Institute of Medicine (NCIOM) Task Force on Patient and Family Engagement was convened in 2014 in partnership with North Carolina Quality Center of the North Carolina Hospital Association, Community Care of North Carolina, North Carolina Medical Society, and Foundation for Nursing Excellence. The Task Force was funded by The Duke Endowment.

The Task Force was chaired by Kimly Blanton, patient family advisor, Vidant Health; Melanie Bush, MPAff, assistant director of policy and regulatory affairs, Division of Medical Assistance North Carolina Department of Health and Human Services; and Warren Newton, MD, MPH, director, North Carolina AHEC Program, William B. Aycock professor and chair, Department of Family Medicine University of North Carolina School of Medicine. The Task Force's work would not have been possible without their leadership. The NCIOM also wants to thank the members of the Task Force and Steering Committee who gave freely of their time and expertise to address this important issue over the past year and a half. The Steering Committee members provided expert knowledge and guidance, helped develop meeting agendas, and identified expert speakers. For a complete list of Task Force and Steering Committee members, please see pages 7-9 of this report.

The NCIOM Task Force on Patient and Family Engagement heard presentations from multiple experts throughout the course of the project. We would like to thank the following people for sharing their expertise and experiences with the Task Force: Brent Anthony, family caregiver; Val Atkinson, patient family advocate, patient advisory council member, UNC Family Medicine; Kimly Blanton, MIS, MLS, patient advocate, Vidant Health; James H. Bundy, member of peer support group, Alzheimer's North Carolina; Melanie Bush, MPAff, assistant director of policy and regulatory affairs, Division of Medical Assistance, North Carolina Department of Health and Human Services; Anthony J. Caprio, MD, Department of Family Medicine, Carolinas Healthcare System; Brian Caveney, MD, JD, MPH, vice president & medical director, Healthcare Division, Blue Cross and Blue Shield of North Carolina; Peter W. Chauncey, FACHE, president, Carolinas Market, Aetna; Robert Childs, MPH, executive director, North Carolina Harm Reduction Coalition; Sue Collier, MSN, RN, FABC, performance improvement specialist, Patient-Family Engagement, North Carolina Quality Center/North Carolina Hospital Association; Earl M. Craig, Jr., state certified peer support specialist, National Alliance for the Mentally Ill (NAMI-North Carolina Chapter); Pam Dardess, principal researcher, American Institutes of Research; Darren DeWalt, MD, MPH, assistant professor of medicine, Division of General Medicine, University of North Carolina at Chapel Hill; Deborah L. Dokken, MPA, family advocate/consultant, Institute for Patient- and Family-Centered Care; Sharon Elliot-Bynum, PhD, MA, RN, BSN, executive director, CAARE, Inc.; Edwin Fisher, professor, Gillings School of Global Public Health, University of North Carolina at Chapel Hill; Linda Griffin, RN, BSN, CCM, lead nurse care manager, Community Care Partners of Greater Mecklenburg; Gayle B. Harris, BSN, MPH, RN, public health director, Durham County Department of Public Health; Martin J. Hatlie, JD, chief executive officer, Project Patient Care, president, The Partnership for Patient Safety; Thomas J. Hoerger, PhD, senior fellow, Health Economics and Financing, RTI International; Amy Jones, administrator, Office of Patient and Family Experience, Vidant Health; Joanna Kaufman, RN, MS, program/information specialist, Institute for Patient- and Family-Centered Care; Hannah Klaus, youth

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In addition to the above individuals, the staff of the North Carolina Institute of Medicine contributed to the Task Force's work and the development of this report. Adam Zolotor, MD, DrPH, president and chief executive officer, guided the work of the Task Force and helped author the report. Kimberly Alexander-Bratcher, former project director, served as the project director for the Task Force. Liz Chen, MPH candidate, Michelle Ries, MPH, project director, Elena Rivera, MPH candidate, and Berkeley Yorkery, MPP, project director, also helped author this report.

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Task Force on Patient and Family Engagement

Executive Summary

Patients who are actively involved in their health and health care tend to have better outcomes and care experiences and, in some cases, lower costs.[1-3] Implementing patient and family engagement strategies has led to fewer hospital-acquired infections, reduced medical errors, reduced serious safety events, and increased patient satisfaction scores.[3-5] Because of the potential for improved health outcomes and patient satisfaction, patient and family engagement has emerged as a critical strategy for improving the performance of our health care system. The American Institutes for Research defines patient and family engagement as "patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system to improve health and health care."[6]

Patients who are actively involved in their health and health care tend to have better outcomes and care experiences.

Patient and family engagement strategies have shown such promise that they have been incorporated into many recent efforts to improve health care quality.[7-12] Research shows that patients who are more engaged in their care have lower medical costs, fewer hospital admissions, and improved health outcomes, such as a healthier diet, increased levels of physical activity, and weight loss for patients with diet-related chronic diseases.[12,13] However, a recent survey of American health care consumers found that one in three consumers is disengaged in their care.[14]

Nationally and locally, many efforts are underway to increase patient and family engagement. In North Carolina, Community Care of North Carolina (CCNC), the Medicaid program's primary care case management contractor, and the North Carolina Quality Center (NCQC) have been at the forefront of patient and family engagement efforts. The North Carolina Institute of Medicine (NCIOM) received grant support from The Duke Endowment to convene a task force on patient and family engagement in order to build upon current efforts in North Carolina. The NCIOM Task Force on Patient and Family Engagement was created in collaboration with the NCQC within the North Carolina Hospital Association, CCNC, the North Carolina Medical Society, and the Foundation for Nursing Excellence. The Task Force was charged with identifying and examining evidence-based, evidence-informed, and promising strategies for increasing patient and family engagement.

The Task Force was chaired by Kimly Blanton, a patient family advisor with Vidant Health; Melanie Bush, assistant director of policy and regulatory affairs with the Division of Medical Assistance in the North Carolina Department of Health and Human Services; and Dr. Warren Newton, director of the North Carolina Area Health Education Centers Program and professor and chair of the Department of Family Medicine at the University of North Carolina at Chapel Hill School of Medicine. The Task Force included 46 additional task force and steering committee members representing patients and family members, youth, caregivers, providers, insurers, health systems, community-based organizations,

local health agencies, and several divisions within the North Carolina Department of Health and Human Services. The Task Force met monthly from February 2014 to January 2015 for a total of 12 meetings.

After reviewing best practices and evidence-based strategies for increasing patient and family engagement in direct care settings, hospitals, health systems, the community, and through policy, the Task Force developed and refined a set of 17 recommendations that will catalyze patient and family engagement and improve health and health care systems in North Carolina.

Patient and Family Preparation

At all levels of engagement, patients and families must be educated, prepared, and empowered to engage effectively in their own health and health care. To engage patients and families, it is necessary to provide them with the skills, knowledge, and confidence to be effective partners in their care.

Recommendation 3.1: Educate and Train Patients and Families about Partnering and Engaging (PRIORITY RECOMMENDATION)

North Carolina Area Health Education Centers should lead a collaboration of state agencies, community organizations, faith-based organizations, and payers to identify and implement model curricula and tools for educating and training patients and family members about partnering and engaging with their health care providers.

Most of the time, patients and families are managing their health and wellness on their own. Peer support—which refers to linking a patient with another individual who has some level of training and knowledge from personal experience with a condition—coupled with education and training, can provide additional resources to strengthen the individual and family and better prepare them to engage more fully in their health care.[15,16]

Recommendation 3.2: Increase Availability of Peer Support

Organizations that provide care management services should encourage health care systems and payers to recognize the critical aspect of peer support, build peer support into their systems, and facilitate linkages to existing peer support groups, online networks and resources, and condition-specific support groups.

Clinician and Leadership Preparation

In order for the benefits of patient and family engagement strategies to be realized, health care providers and health care leadership must understand the key concepts of patient and family engagement, utilize engagement strategies, and understand how to support and encourage the cultural transformation that patient and family engagement requires. Providers and health care system administrators need to understand not only the concept and importance of patient and family engagement, but also how to effectively engage patients and families. However, few providers receive training on patient and family engagement.

Recommendation 4.1: Incorporate Patient and Family Engagement Techniques into Health Professional Training (PRIORITY RECOMMENDATION)

Health education programs, both pre-service and in-service, should educate health care providers on how to provide patient- and family-centered care and how to engage patients and families in their care. Patients and families should be included in designing and implementing these trainings.

Recommendation 4.2: Amend Health Professional Licensure and Certification Requirements to Include Patient and Family Engagement Skills as a Core Competency

Health professional licensing boards and associations should consider incorporating concepts and skills for patient- and family-centered care and patient and family engagement as a core competency that is included in initial licensure requirements, as well as maintenance of ongoing certification requirements.

Care and System Redesign

Redesigning system processes, policies, and structures to provide opportunities for and support of partnerships between patients, families, and the health care team is necessary to facilitate patient engagement. In order to redesign care and systems, it is important to implement communication mechanisms that help clinicians elicit, understand, and respect patient perspectives and concerns. Redesign may also include structuring care processes to support and value shared decision-making, involving patients and families in care planning and self-management, sharing information, and providing specific engagement opportunities.

Recommendation 5.1: Make Patient and Family Engagement a Goal of Health Care Systems

The North Carolina Hospital Association and all health care systems in North Carolina should encourage and support patient and family engagement at all levels of health care systems by making patient and family engagement one of the goals of their organizations, implementing evidence-based strategies to enhance patient and family engagement, and assessing the impact of patient and family engagement strategies.

Recommendation 5.2: Support Patient and Family Engagement through Health Care Organization Policies and Processes (PRIORITY RECOMMENDATION)

The North Carolina Medical Society, the North Carolina Hospital Association, the North Carolina Community Health Center Association, and other partners should promote policies and processes that support and encourage patient and family engagement including welcoming and supporting patients and families and establishing policies and procedures that promote patient and family engagement in all aspects of their health care experience.

Family caregivers are an important member of a patient's health care team and should be recognized as such by health care providers. Almost half of family caregivers perform medical tasks such as wound care and operating complex medical equipment.[17] Many of these family caregivers are not trained in these tasks prior to the patient needing their support. These caregivers need training and skills to facilitate their engagement.

Recommendation 5.3: Recognize Caregivers as Members of the Health Care Team

Health care organizations should adopt policies that recognize the role of caregivers as members of the health care team including documenting family caregivers, acknowledging their role as part of the care team, and identifying caregiver support resources.

Organizational Partnership

When fully realized, patient and family engagement extends beyond the direct care experience and influences all aspects of health care organizations. There are many ways health care organizations can integrate patient and family perspectives and experiences into their governance structure and organizational decision-making. Creating opportunities throughout health care organizations for patients and family members to influence decisions can help ensure health care organizations are meeting the needs of the communities they serve.

Recommendation 6.1: Include Patients and Families on Health Care Organization Boards and Committees

Health care organizations should appoint a minimum of two patients (or family members) to boards and advisory committees within their organizations. To the extent possible and practical, patients (or family members) should represent the diversity of the community served by the health care system. Patients (or family members) should receive training and mentoring to help prepare them to be productive board and committee members.

Creating a patient and family advisory council (PFAC) is another strategy to ensure the needs and concerns of patients and families are heard and used to inform decision making. PFACs are teams of patients and families working with providers and staff to provide an opportunity to engage patient perspectives in the planning, implementation, and evaluation of health care services and programs.[18]

Recommendation 6.2: Engage Patients and Families in the Governance and Operation of Health Care Organizations (PRIORITY RECOMMENDATION)

Health care organizations should develop patient and family advisory councils (PFACs) to provide input into the governance and operation of health care at all levels. PFACs should represent the community that the agency or health care organization serves.

Measurement, Research, Transparency, and Accountability

Data can be used to inform patients and families about the success of efforts by health care providers to embrace patient and family engagement, and can drive consumer decision making. A key strategy to increasing patient and family engagement is for an organization to create measures and conduct research to improve care, facilitate changes in processes, and assess the relationships among engagement, experiences, and outcomes.[6]

Recommendation 7.1: Measure the Impact of Patient and Family Engagement

The North Carolina Hospital Association, in partnership with the North Carolina Medical Society and organizations that provide care management services, should work with patients and families to develop patient and family engagement measures, and collect and disseminate data in hospitals and ambulatory settings across the state.

Patient and family engagement in health care will ultimately require improved access to information. Some patients want information such as the cost of care, how often a doctor or hospital performs a certain type of procedure, or the complication rate. Such data is collected by both health care providers and payers (insurers) and may be available for the most common procedures, but may also be difficult to access, as well as not always easy to understand. As patients become responsible for more out of pocket costs, patients have shown more readiness to partner in their care, use available tools, and find ways to lower their costs.[19] While taking care to use principles of health literacy and shared decision-making, efforts should be made to provide patients with more information about costs of health care, which will help them select higher value care that better meets their needs.[20]

Recommendation 7.2: Encourage Health Care System Transparency (PRIORITY RECOMMENDATION)

All health care systems and providers should ensure information on services, cost, and quality is easily accessible to consumers in print and electronic formats.

Recommendation 7.3: Encourage Health Care Payer Transparency

Payers should provide, on their websites and in their written materials, information that is easily understood by consumers on covered providers and common procedures, including data on costs, quality, safety, and patient experiences.

Recommendation 7.4: Provide Health Care Cost Information to the Public

The North Carolina General Assembly should collaborate with the North Carolina Department of Insurance, health care systems, and insurers to create a statewide, mandatory data reporting system to enhance pricing transparency for medical care

and health care services. This collaborative effort should include input from additional stakeholders on database use and access. Participating stakeholders should include employers, health care providers, academic and industry researchers, and patient and family advocacy groups.

Transparency around quality and costs is one method to help consumers make more informed choices about their health care. Another potential method is collaborative documentation or charting. Collaborative charting refers to a spectrum of shared medical record keeping between the health care provider and the patient. Collaborative documentation is a promising technique for engaging patients and families in care.

Recommendation 7.5: Increase Collaborative Documentation

Health care organizations should examine opportunities to increase collaborative documentation aimed at increasing patient and family engagement. The North Carolina Quality Center and the North Carolina Hospital Association should continue to provide consultative support to health care organizations implementing collaborative documentation.

Legislation, Regulation, and Partnership in Public Policy

There is significant opportunity in health care to align legislation, regulation, and public policies with the principles of patient and family engagement, while improving health outcomes and quality of care. Payers of health care services wield enormous influence over available health care services based on reimbursement policies. There are many opportunities for health care payers, employers and other organizations to promote and support patient and family engagement through member education, reimbursement policies, and health care plan design.

Recommendation 8.1: Advance Patient and Family Engagement through Payer Policies (PRIORITY RECOMMENDATION)

Payers (insurers) should consider changes to health plans and policies that support patient and family engagement. Those changes may include creating new payment options, developing member advisory committees, and providing more accessible information to consumers.

Health care organizations are leaders in their communities, employ large numbers of people, and have a unique perspective on the importance of maintaining a healthy workforce, all of which make them well suited to implementing comprehensive worksite wellness programs. Worksite wellness programs are an evidence-based approach to engage employees in their health care.

Recommendation 8.2: Implement Comprehensive Worksite Wellness Programs that Include Patient and Family Engagement Support (PRIORITY RECOMMENDATION)

Health care organizations should, with employee input, develop and implement comprehensive worksite wellness programs that include employee engagement strategies. They should encourage other community employers to as well.

There is an opportunity for broader patient and family engagement at the policy making level. Just as health care organization policies benefit from the active involvement of patients and families, federal, state, and local health policies benefit from the involvement of patients and families in the policy making process. Including patient representatives in public decision-making can improve trust and confidence in the health system as a whole. In addition, inclusion of patient experiences in creating organizational and public policies may lead to higher-quality and more effective decisions.

Recommendation 8.3: Ensure Patient and Family Representation on Boards with Broad Policy Making Power (PRIORITY RECOMMENDATION)

Local boards of health, health professional and licensure boards, health insurance companies, mental health managed care organizations, and administrative units and entities in state government that execute state health-related policies should include, at a minimum, at least two trained patient and family representatives on their boards.

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Introduction

Chapter 1

The United States health care system is the most expensive per capita health care system in the world.[1] However, when compared with other developed countries on indicators such as health outcomes, quality, and efficiency, the United States ranks last. With rising health care costs and suboptimal performance on health care measures, there is increasing interest and urgency to address this paradox. One promising pathway toward improvement is the field of patient and family engagement.

Patient and family engagement strategies have shown such promise that they have been incorporated into the majority of recent efforts to improve health care quality. The National Strategy for Quality Improvement in Health Care, established as part of the Affordable Care Act, focuses on patient-centered care, "ensuring that each person and family is engaged as partners in their care" in order to advance health care quality improvement goals.[2] The Centers for Medicare and Medicaid Services describe patients and their families as "essential partners in the effort to improve the quality and safety of health care."[3] The American Institutes for Research (AIR) defines patient and family engagement as "patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system to improve health and health care."[4] Other organizations have different definitions of patient and family engagement; however the key concepts are similar.[5] All definitions emphasize that specific action must be taken by patients, providers, and others in health care systems to create collaborative partnerships to improve both individuals' health and the health care system.

Patients and families are essential partners in the effort to improve the quality and safety of health care.

It is important to remember that engaging patients and families requires more than a series of simple steps or a checklist of activities. Meaningful patient and family engagement necessitates a shift in the traditional culture of health care. It is about creating a partnership culture within health care. Though it is a significant undertaking, with leadership, collaboration, and perseverance, health systems can create cultures centered on patients and families, with the goals of improving patient experience, improving quality of care, and decreasing cost.

The Need for Patient and Family Engagement

Patients have much to gain when patients and families provide input and when the responsibility for health is shared.[6] Research shows that patients who are more engaged in their care have lower medical costs, fewer hospital admissions, and improved health outcomes, such as a healthier diet, increased levels of physical activity, and weight loss for patients with diet-related chronic diseases.[7,8] However, a recent survey of American health care consumers found that one in three consumers is disengaged in their care. These individuals report a lower need for care, take less preventive action, have lower interest in resources, and are less financially prepared than consumers who are more engaged.[9]

There are many factors that can contribute to lower levels of engagement. In the recent economic recession, many families had fewer resources to focus on health care.[10] Although the economy has recovered, many families are still experiencing economic hardship. Some families must choose to prioritize other needs like food and shelter. When individuals work more than one job to make ends meet, time off of work for health care visits may not be feasible. In addition to socioeconomic factors, there are also cultural barriers to patient engagement. Some racial and ethnic cultures have a history of mistrust with medicine and health care.[11] Others may practice traditional healing, prayer, meditation, or herbal supplementation they feel will not be supported by health care providers.[11] Patient and family engagement can be viewed as a means of health equity, with providers and systems focused on patient-centered care, and patients and families prepared to partner in a way they choose.

One in three consumers is disengaged in their care.

Research shows that patients and providers support engagement and believe that increased involvement in health care by patients and families can lead to improved experiences and outcomes.[12] In 2012, 63% of health care consumers were dissatisfied with the United States health care system, giving it a report card grade of C, D, or F. Health care organizations interested in boosting their scores should consider the benefits of patient and family engagement. One study found that patients who are highly engaged are 10 times more likely to report high patient satisfaction scores when compared to patients who are less engaged.[13] Increasing levels of patient and family engagement may lead to gains in patient satisfaction and experience of care scores.

In addition to becoming more involved in their own care and well-being, patients and families can also be involved in the governance and oversight of health care organizations and systems. Health care systems implementing patient engagement efforts have seen reductions in medical errors, hospital-acquired infections, and other serious safety events.[14-16]

Increasing Patient and Family Engagement

Patient engagement can occur at multiple levels of the health care system.[14,15] In direct patient care, providers can include patients as partners in the care process, tailoring health decisions to their preferences and values, and communicating as a partner with patients and families. At the organizational level, hospitals, practices, and other provider organizations can include patients as advisors in the strategy and management of their organizations so that the delivery of care is informed by patient experiences. Practices, hospitals, and health systems can be designed to maximize communication and partnership with patients and families at every point in the care continuum. At the policy level, health policymakers can work with consumers in the development and implementation of policies and regulations that pertain to their care, and state and federal policies as well as private payer policies can provide incentives to practices that engage patients and families.[4]

Engagement can be present at every level in health care, on a continuum ranging from consultation all the way to true partnership and shared leadership.[4] Providers and systems must examine current engagement efforts and focus on strategies for improving patient engagement at all levels. Nationally, the Agency for Healthcare Research and Quality, AIR, Institute for Healthcare Improvement, the Institute for Patient- and Family-Centered Care, and the National Association for Healthcare Quality are all working to help health care providers and systems increase their engagement with patients and families. In North Carolina, Community Care of North Carolina (CCNC), North Carolina's Medicaid program's primary care case management contractor, takes a community and patient-centered approach to health care and seeks to engage patients in their care. Additionally, the North Carolina Quality Center (NCQC) has been at the forefront of patient and family engagement efforts in hospitals since its creation in 2004.[17]

Engagement can be present at every level in health care, on a continuum ranging from consultation all the way to true partnership and shared leadership.

NCIOM Task Force on Patient and Family Engagement

The North Carolina Institute of Medicine (NCIOM) received grant support from The Duke Endowment to convene a task force on patient and family engagement in order to build upon current efforts in North Carolina. The NCIOM Task Force on Patient and Family Engagement was created in collaboration with CCNC, the North Carolina Division of Public Health within the Department of Health and Human Services, the NCQC of the North Carolina Hospital Association, the North Carolina Medical Society, and the Foundation for Nursing Excellence. The Task Force was charged with identifying and examining evidence-based, evidence-informed, and promising practices and strategies for increasing patient and family engagement.

The Task Force was chaired by Kimly Blanton, a patient family advisor with Vidant Health; Melanie Bush, assistant director of policy and regulatory affairs with the Division of Medical Assistance in the North Carolina Department of Health and Human Services; and Dr. Warren Newton, director of the North Carolina Area Health Education Centers Program and professor and chair of the Department of Family Medicine at the University of North Carolina at Chapel Hill School of Medicine.

In addition to the chairs, the Task Force was comprised of 41 members. The group included patients and family members, youth, caregivers, providers, insurers, and representatives from various health systems, community-based organizations, local health agencies, and several divisions within the North Carolina Department of Health and Human Services. There was a specific focus on ensuring the Task Force was representative of the state, including diversity of age, race, ethnicity, socioeconomic status, and region of the state. The Task Force met monthly from February 2014 to January 2015 for a total of 12 meetings.

After reviewing best practices and evidence-based strategies for increasing patient and family engagement in direct care settings, hospitals, health systems, the community, and in policy, the Task Force developed and refined a set of recommendations that will catalyze patient and family engagement and improve health and health care systems in North Carolina.

This report contains nine chapters, the first being this brief introduction. The second chapter discusses the vision and mission of patient and family engagement through the framework and roadmap developed AIR. Subsequent chapters expand on change strategies of the AIR patient and family engagement roadmap.

The Task Force developed a set of recommendations that will catalyze patient and family engagement and improve health and health care systems in North Carolina.

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Overview of Patient and Family Engagement

Chapter 2

Patients who are actively involved in their health and health care tend to have better outcomes and care experiences, and, in some cases, lower costs.[1-3] Implementing patient and family engagement strategies has led to fewer hospital-acquired infections, reduced medical errors, reduced serious safety events, and increased patient satisfaction scores.[4-6] Because of the potential for improved health outcomes and patient satisfaction, patient and family engagement has emerged as a critical strategy for improving the performance of our health care system. The United States health care system is one of the most costly in the world, yet without health outcomes to show for it.[7] One strategy that the United States is using to address this paradox is to focus on improving population health, improving patients' experience of care, and reducing per capita costs, also known as the Triple Aim.[8] Patient engagement is a pathway to helping achieve the Triple Aim.[1-3,9] As one health care executive described it, "We will never create an efficient, affordable, effective, and high quality health care delivery system unless we leverage all the assets at our disposal. The knowledge, insight, and clarity that patients and families offer are badly under-leveraged."[10] The partnerships between patients, providers, and health systems can help each meet its goals.

The patient and family are important partners in care.

The core of patient and family engagement lies in welcoming the patient and family as important partners in care. The Institute of Medicine of the National Academies (IOM) describes patient and family engagement as a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences. The IOM further states that patients should receive the education and support that they need to make decisions and participate in their own care.[11] For patient and family engagement to work, patients must have, or be given, the knowledge, skills, and confidence to manage their health and health care.[12] In addition, health care at every level needs to be patient and family centered. The Institute for Patient- and Family-Centered Care defines patient- and family-centered care as "an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families."[13] The Institute describes the foundations for patient and family engagement as dignity, respect, information sharing, participation, and collaboration.

According to a recent survey of American health care consumers, one in three consumers is disengaged in their care.[14] These individuals report less need for care, take fewer preventive actions, have less interest in resources, and are financially less prepared than consumers who are more engaged.[14] Both patients and providers support engagement and believe that increased involvement in health care by patients and families can lead to improved experiences and outcomes.[15] These positive attitudes and support for increased engagement are critical to affecting change.

Some providers and systems have already begun to engage patients as partners or have created a culture in which patients are partners. However, many providers and systems have focused their energy on other goals and have yet to prioritize patient and family engagement. This report highlights evidence-based strategies, best practices, and various examples of successful models for organizations to measure their efforts, assess gaps, and connect to resources that support patient and family engagement.

Current Efforts

The theme of patient and family engagement is central throughout the Patient Protection and Affordable Care Act (ACA), passed in 2010. Several provisions of the ACA directly promote patient engagement and patient-centeredness, including support of primary care medical homes, medication management, community health assessments, and incentives for chronic disease prevention under Medicaid.[a]

Patient and family engagement has emerged as a critical strategy for improving the performance of our health care system.

Nationally, many efforts are underway to increase patient and family engagement. The Agency for Healthcare Research and Quality, the Institute for Healthcare Improvement, the Institute for Patient- and Family-Centered Care, and the National Association for Healthcare Quality, are all working to increase and improve patient and family engagement. Several important partnerships and networks have been created with the goal of promoting patient and family engagement through research, collaboration, and shared learning. In 2011, the Centers for Medicare and Medicaid Services created Partnership for Patients to improve patient safety and quality. The Partnership worked to identify, disseminate, and expand patient and family engagement best practices to more than 3,700 hospitals that were members of its Hospital Engagement Network through 2014. Another Partnership aim was to increase collaboration between patients, families, providers, and caregivers to improve care transitions and reduce readmissions through its Community-Based Care Transitions Program.[16] The American Institutes for Research (AIR) created a Center for Patient and Consumer Engagement, which conducts research and spearheads engagement efforts such as increasing health literacy, improving communication between patients and providers, working in communities to promote engagement, and providing technical support for patient and family engagement work throughout the country.[17]

Many organizations in North Carolina are working to implement patient and family engagement strategies around our state. For example, Community Care of North Carolina (CCNC), the North Carolina Medicaid program's primary care case management contractor, takes a community and patient-centered approach to health care and seeks to engage patients in their care.[18] CCNC care managers collaborate with patients to develop patient-centered, self-management care plans that are focused on patient-centered goals, self-management education,

a Patient Protection and Affordable Care Act, Pub L.

and contact information for community resources. The North Carolina Quality Center (NCQC), which was created by the North Carolina Hospital Association (NCHA) in 2004, has been at the forefront of patient and family engagement efforts across the state. Charged with leading the state's hospitals to become the safest and highest quality in the country, the NCQC most recently launched a Patient-Family Engagement Learning Network. Between April 2014 and April 2015, the Learning Network met to share best practices and evidence-based strategies and to provide support for developing and implementing a patient and family engagement plan for hospitals throughout North Carolina. The NCQC also monitors, evaluates, and reports on the processes and outcomes of its work.[19] In addition to the work of NCQC, the NCHA is also driving patient engagement through its own activities. In May of 2013, the NCHA Board declared patient and family engagement one of its Patient Safety Goals and since then has been collaborating with various hospitals throughout the state to identify leaders and guide the planning, implementation, and evaluation of patient engagement initiatives.[20]

The knowledge, insight, and clarity that patients and families offer are badly under-leveraged.

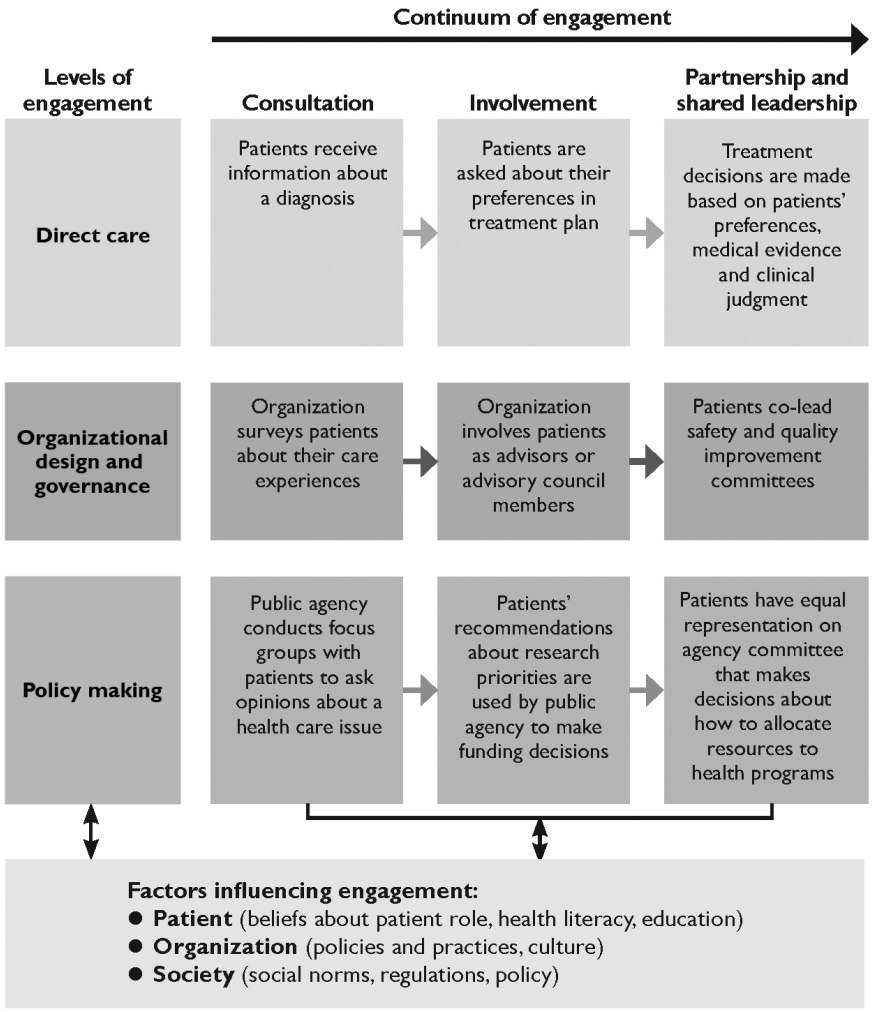
Patient and Family Engagement Framework

In an effort to learn more about the field of patient and family engagement, the Task Force identified several options for organizing its work. While the Task Force has not endorsed a particular group's approach, the Task Force chose to use the Framework for Patient and Family Engagement to help guide its evidence gathering and the formation of its recommendations. The Framework was developed by researchers at AIR and others to help create these changes in health care. (See Figure 2.1.) AIR defines patient and family engagement as "patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system to improve health and health care."[10] The Framework includes patients, family (as defined by the patient), friends, clinicians, health care providers, health care organizations and systems, and public policies and culture as participants in patient and family engagement.

The Framework demonstrates that patient and family engagement exists in multiple forms along the continuum of engagement. Traditionally, the patient-provider interaction has taken place on the lower end of the continuum of engagement, with patients having direct care consultations with their providers. Moving along the direct care continuum, patient input and shared decision-making increases to involvement and, finally, to partnership and shared leadership. The partnership and shared leadership at the higher end of the continuum has communication moving in both directions between patients and providers, and responsibility for decision making is shared. Moving along either the level of engagement or the continuum of engagement axis requires culture change that consists of support and commitment of leadership and providers, patient education, and potential changes to workflow, policies, and procedures.

Patient and family engagement exists in multiple forms along the continuum of engagement.

Figure 2.1
A Multidimensional Framework for Patient and Family Engagement in Health and Health Care



SOURCE Kristin L. Carman, Pam Dardess, Maureen Maurer, Shoshanna Sofaer, Karen Adams, Christine Bechtel, and Jennifer Sweeney, "Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies," *Health Affairs* 32, no. 2 (2013): 223-31. **NOTE** Movement to the right on the continuum of engagement denotes increasing patient participation and collaboration.

The Framework also highlights the fact that engagement is not confined to individual health behavior or direct care interactions, but includes organizational design, governance, and policy making. Patients may interact in a variety of organizational settings, including community-based organizations, faith-based organizations, home health services, clinics, and hospitals. Patient and family needs, desires, and preferences can be included in each of these settings along the continuum of engagement. At the policy level, patients and families can provide input into setting agendas that ensure engagement of and responsiveness to

patients and families. Multiple factors influence patients' engagement (such as beliefs about their role, faith, health literacy, and education), the organization (such as policies, practice, and culture), and society (such as social norms, regulations, and policy).

The Roadmap for Patient and Family Engagement in Healthcare Practice and Research

The Roadmap for Patient and Family Engagement in Healthcare Practice and Research provides guidance for both practice and research, with practical steps that can begin immediately.[10] The Roadmap includes a vision for patient and family engagement in health care, eight change strategies to drive action towards increased patient and family engagement, and actions that various stakeholder groups can begin today.

Patients and families must be educated, prepared, and empowered to engage effectively in their own health and health care.

Each of the eight strategies identifies a priority action area with significant opportunities for growth and change. The strategies include: patient and family preparation; clinician and leadership preparation; care and system redesign; organizational partnership; measurement and research; transparency and accountability; legislation and regulation; and partnership in public policy. For each strategy, the Roadmap includes a description, tactics or examples of translated actions, and milestones to help assess progress toward the ultimate goal of true patient and family engagement. Rather than assign specific organizations the responsibility for strategies and tactics, the Roadmap encourages partnership among stakeholders. The Roadmap provides strategies to help gauge the stakeholder's current efforts and opportunities to improve engagement, emphasize action across the levels of engagement, and illustrate how this work is interrelated. The strategies are described in detail below.[10]

Patient and Family Preparation

At all levels of engagement, patients and families must be educated, prepared, and empowered to engage effectively in their own health and health care. If patients and families are prepared, they will believe that engaging in their care and partnering with providers and organizations will help improve the quality and safety of care, which will help enable them to partner effectively across the levels of engagement. Therefore, it is necessary to provide them with the skills, knowledge, and confidence to do so effectively. Patients and families are unique, and not all will choose the same level of engagement. Thus, it is important to help prepare patients and families for the level of engagement that they want to achieve and with which they are comfortable. The Roadmap includes tactics to drive the change strategy at the levels of direct care, organization, and policy.

Tactics at the direct care level may focus on educating patients and families about their health and health care and supporting and encouraging them to take an active role both within and outside the context of a specific care encounter. Other direct care tactics include implementing patient-centered tools for patients and clinicians to support shared decision-making. At the organizational level, tactics prepare patients and families to partner with health care organizations,

systems, and researchers in designing and conducting research studies. The policy level tactics help to prepare patient and family representatives to partner with other stakeholders in local, state, and national policy and programmatic decisions. The Roadmap also includes five relevant actions individuals can perform immediately to support and advance patient and family engagement. These include: providing feedback on their experiences; reviewing information to help them understand their health and health condition; preparing for their next health care visit; tracking and organizing their medical information; and volunteering to be a patient and family advisor.

Educating, preparing and empowering clinicians and health care leaders to partner effectively with patients and families is also necessary.

Clinician and Leadership Preparation

Educating, preparing and empowering clinicians and health care leaders to partner effectively with patients and families is also necessary to facilitate patient and family engagement. This includes educating and training clinicians about patient and family engagement; preparing clinicians and staff to partner with patients and families at the health care organization and system level; and establishing organization and system level expectations for patient and family engagement. To be successful at clinician and leadership preparation, clinicians and health care leaders must believe that patient and family engagement is an essential component of improving care quality and safety. Further, clinicians must be willing and prepared to engage effectively with patients and families during clinical encounters. Health care leaders must be willing and prepared to partner with patients and families on issues of organizational design and governance.

Care and System Redesign

Redesigning system processes, policies, and structures to provide opportunities for and support of partnerships between patients, families, and the health care team is necessary to facilitate patient engagement. In order to redesign care and systems, it is important to implement communication mechanisms that help clinicians elicit, understand, and respect patient perspectives and concerns. Redesign may also include structuring care processes to support and value shared decision-making, involving patients and families in care planning and self-management, and sharing information and providing specific engagement opportunities. Facilitating care coordination across different settings and supporting the ability of clinicians to care compassionately for patients can also help support systems redesign. Successful implementation of this strategy may result in family members (as defined by the patient) welcomed into the care team; patients, families, and clinicians developing care plans and making health care decisions jointly; patients and families establishing positive, meaningful relationships with their clinicians; and seamless care coordination.

Organizational Partnership

Organizations can be designed or redesigned with patients and families included in the governance structure. The perspective of patients and families should be included when developing policies and procedures related to health and health

care. Similar to clinician and leadership preparation, organizational redesign includes preparing clinicians, staff, and health care leaders to partner with patients and families at the organization and system level. Tactics to achieve organizational partnership involve creating roles for patients and families such as advisory councils and representation on boards.

Measurement and Research

A key strategy to increasing patient and family engagement is for an organization to create measures and conduct research to improve care, facilitate changes in processes, and assess the relationships among engagement, experiences, and outcomes.[10] The tactics include developing measures of patient level experiences, goals, and outcomes as well as measures that assess the process of patient and family engagement—how and to what extent engagement occurs. Measures can be used to assess progress (or lack thereof), provide feedback to clinicians and organizations, and drive organizational change. Health care providers should also consider conducting research on how engagement leads to improved health, higher quality, reduced costs, and/or improved staff satisfaction.

The perspective of patients and families should be included when developing policies and procedures related to health and health care.

Transparency and Accountability

This strategy for change involves making data and information transparent to promote organizational accountability for quality and safety, and enabling patients and families to be more active in their health and health care. Tactics may include giving patients access to their medical records; giving patients the ability to contribute to their medical records; providing transparent information about risks, benefits, costs of care, and treatment options; and publicly reporting cost, quality, and safety information. The milestones of a more transparent and accountable system include providing patients and their families clear and usable information about the risks, benefits, costs, and lifestyle implications of different care and treatment options.

Legislation and Regulation

Regulation and legislation can motivate individual and organizational behavior change. The development and alignment of mandates and incentives can encourage patients, families, clinicians, health care leaders, and health care organizations and systems to change in ways that promote and support patient and family engagement as well as other key objectives. Tactics include providing recognition and rewards for care that fully incorporates patient and family engagement, and aligning incentives and penalties to support patient and family engagement. Requiring patient and family engagement competencies for certification or accreditation, and advancing patient and family participation through legislation are other strategies that would more strongly encourage support for patient and family engagement.

Partnership in Public Policy

Tactics for partnership in public policy include creating opportunities for patient and family representatives to serve on local, state, and national committees focused on health or health care which allow for the public to contribute to

health and health care policy decisions. An additional tactic is to prepare patient and family representatives to partner with other stakeholders in local, state, and national policy and programmatic decisions. This tactic allows for stakeholders and policymakers to partner with patient and family representatives in shaping public policy.

The eight key strategies for change and their tactics and milestones have been individually described. However, they are all connected and interrelated. Tactics from one strategy may help facilitate many of the others. The tactics are suggestions to bring the strategies into action, but several additional action steps can be taken.

Subsequent chapters of this report will describe the recommendations from the NCIOM Task Force on Patient and Family Engagement in each of the eight change strategies of the Roadmap.

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Overview of Patient and Family Preparation

Chapter 3

Patients and families must be educated, prepared, and empowered in order to engage effectively in their own health and health care.[1] Patients and families can engage at all levels (i.e. direct care, organizational design and governance, and policy making), but must have the skills, knowledge, and confidence to do so effectively. A change in culture is necessary for patients, families, and providers to build partnerships and share responsibility for health. Increasing health literacy, education, and training on how to fully engage in one's health care, as well as the issue of peer support, are important tools to prepare patients and families.[1] Prepared and empowered patients and families benefit from better experiences of care, while the larger community benefits from improved population health and potentially reduced costs.[2]

The New Patient Role

Historically, the health care system in the United States has been a paternalistic system with the doctor or other health professional providing knowledge and expertise and the patient being fairly passive in the diagnosis and treatment of whatever ails them.[3] At the heart of patient and family engagement is the redefinition of the patient as a key player in their health and health care and a redefinition of the patient-provider relationship.[4] The role of health care provider and patient can vary widely—at one end of the spectrum is the traditional paternalistic model where the health provider makes decisions on behalf of the patient without considering the patient's preferences. At the other end is informed decision making—where the health provider diagnoses the patient and then details all treatment options and their implications so the patient can make the decision based on their own preferences.[5] The goal of patient and family engagement is for patients and their families to be active participants in their health and health care.

At the heart of patient and family engagement is the redefinition of the patient as a key player in their health and health care.

However, it is important to note that willingness to accept this new patient role varies greatly.[3-5] A representative survey of American adults found that while 96% of Americans want to be offered choices by their health provider and asked their opinions, only 48% wanted to make the final decision on their care.[3] Furthermore, age, gender, education level, race/ethnicity, and health status all influence the degree to which individuals want to engage in their own health care decision making.[3,4]

Patients and families will not all choose or be able to have the same level of engagement. Thus, it is essential to help patients and families prepare for the level of engagement they desire and to move them up the ladder to higher levels of engagement and partnership when appropriate. Preparing patients and families is not only the responsibility of those individuals, but also health care providers, health care systems, and the community as a whole.

Health Literacy

Patients and Families

One way to increase patient and family engagement is to improve the health literacy of patients and families. Health literacy is the ability to obtain and understand basic health information as well as services needed in order to make appropriate health decisions. Literacy—or the ability to read—is not the same as health literacy. Many who can read without difficulty may have difficulties understanding complex medical or insurance terminology. Some groups of people, including older adults, people with less education, those who are cognitively impaired, racial and ethnic minorities, and people with low incomes are more likely to have problems with health literacy.[6] Health literacy skills include the ability to interpret documents, read and write prose (print literacy), use quantitative information (numeracy), and speak and listen effectively (oral literacy).[7,8] These skills are important for patients and family to fully engage in their own care. According to the National Institutes for Health (NIH), more than one in three adults in the United States have difficulties understanding and acting upon health information.[8] Recent studies have demonstrated that health care interventions, such as disease management programs paired with educational materials, can have a positive effect on health outcomes for individuals with low health literacy.[9,10]

More than one in three adults in the United States have difficulties understanding and acting upon health information.

Provider Efforts

Health care providers may use a number of approaches to overcome low health literacy among patients and their families. The NIH recommends that written materials used to communicate health information to patients be kept between the 6th and 7th grade reading levels.[11] During patient encounters, providers can relay medical and health related information into language that is easy to understand.[1] Providers can also use the teach-back method to ensure the he or she has explained the information clearly and the patient has understood what the provider has explained.[12]

Health Literacy Efforts

A number of organizations across North Carolina have been devoted to improving health literacy for many years. In 2007, the North Carolina Institute of Medicine Task Force on Health Literacy released its report, "Just *What* Did the Doctor Order? Addressing Low Health Literacy in North Carolina,"[6] which included 14 recommendations for improving health literacy. In 2010, a review of the recommendations found that 79% of the recommendations had been partially or fully implemented.[13] These included educating health providers about how to use effective communication strategies; enhancing the role of pharmacists as medication counselors; increasing the readability of materials provided by health providers, the Department of Health and Human Services, and insurers; and improving health communications practices at all levels of patient interactions.[13]

The University of North Carolina (UNC) at Chapel Hill Program on Health Literacy—a joint initiative between several UNC professional and graduate schools, UNC Greensboro, Duke University, and other universities, community groups, and state agencies—fosters collaboration throughout the academic community to advance health literacy research and improve practice. The Program on Health Literacy provides resources and expertise to help organizations interested in promoting health literacy in practice and research.[14] They have also developed toolkits to help providers assess their practice, raise awareness, and take steps to increase patients' health literacy.[12]

Training and Education

The skills and knowledge patients and families need varies greatly based on their backgrounds, community resources, diagnoses, and the form and level of engagement they desire.[3,4] At the direct care level, patients and families may need skills on how to engage effectively with their health care team as well as more knowledge specific to their health needs. Various strategies can be used to prepare patients and families to engage more fully in their care. There are many educational models and tools that community-based organizations, health care providers, and others can utilize to increase patients' skills, knowledge, and confidence to meaningfully engage. Well known models include the Engagement Behavior Framework, the Chronic Disease Self-Management Program, and the Collaborative Care Model.

Various strategies can be used to prepare patients and families to engage more fully in their care.

Engagement Behavior Framework

The Engagement Behavior Framework focuses on actions that patients and families can take to support their health and benefit from health care.[15] The Framework provides a comprehensive list of 10 steps, each with measurable actions, that individuals and/or their caregivers can perform in order to maximally benefit from the health care available to them. In specifying the 10 steps, the Framework emphasizes the challenges people face in finding and using quality health care.[16] The 10 steps include: find quality health care, communicate with health care providers, organize health care, pay for health care, make good treatment decisions, participate in treatment, promote health, obtain preventive health care services, plan for end-of-life care, and seek knowledge about their health care needs.

The Framework provides examples of the actions needed to accomplish each step; however, many individuals will not have the skills or knowledge needed to complete the steps without additional guidance and training. Patients and families with low levels of health literacy may find the steps particularly challenging without assistance. Thus the Framework can also be used by health systems, community organizations, and other partners to assess the types of information, education, and support that patients and families may need.

Chronic Disease Self-Management Program

Stanford University has developed a series of internationally recognized, evidence-based patient and family education and engagement programs

collectively referred to as the Chronic Disease Self-Management Program. In North Carolina, the implementation of the Chronic Disease Self-Management Program occurs under the program name Living Healthy, and is offered statewide through all 16 Area Agencies on Aging and/or their partner organizations.[a,b] Living Healthy consists of a series of weekly workshops, lasting 2.5 hours each, for 6 to7 weeks, in community settings such as senior centers, churches, libraries, and hospitals.[17] Many of these classes are provided at no charge to patients and families. Individuals with various chronic health problems attend together, as the workshops focus on topics that relate to the individual's responsibility for managing their own specific health condition, rather than on the condition itself. Caregivers also benefit from attending the program with the person for whom they care or as an individual participant. Workshops are facilitated by two trained leaders, one or both of whom are non-health professionals with chronic diseases themselves. Classes are highly participatory, where mutual support and success build the participants' confidence in their ability to manage their health and maintain active and fulfilling lives. In addition to the Chronic Disease Self-Management Program for all health conditions, North Carolina agencies offer the Diabetes Self-Management Program, the Positive Self-Management Program for HIV/AIDS, and the Chronic Pain Self-Management Program in English and in Spanish.

Collaborative Care Model

Collaborative care is a multi-component, health care system level intervention using case managers to link primary care providers, patients, and specialists. The Collaborative Care Model is designed to improve clinical and community support for active patient engagement, improve routine screening and diagnosis of health problems, and increase provider use of evidence-based protocols for proactive management of diagnosed disorders. The Collaborative Care Model is recommended by the US Preventive Services Task Force in the clinical setting.[18] In North Carolina, Community Care of North Carolina (CCNC) uses a model similar to the Collaborative Care Model.[19] CCNC uses coordinated care to help meet its goals of patient education, case and disease management, and ongoing relationships building with patients and families.[20,21] For example, in the initial encounter with patients, care managers identify the patient's personal goals which act as a foundation on which to build relationships and collaboration around the patient's health care needs and behaviors. Health care notebooks are provided to patients as practical tools for organizing health care information, learning to proactively manage all facets of their health care, and as a strategy to communicate with providers at any point in the health care system. Patient-centered, self-management care plans are also developed in collaboration with patients and are focused on patient-centered goals, self-management education,

a Miller, Nicolle. Chronic Disease Self-Management Education/Living Healthy Coordinator, Division of Aging and Adult Services, North Carolina Department of Health and Human Services. Personal (email) communication. Thursday January 29, 2015

b CCNC networks and local health departments are also major providers of these programs, but it varies among regions.

and contact information for community resources. CNCC has also worked with multiple adult and pediatric practices to teach patient-centered care, which includes the development of low health literacy teaching tools and the use of motivational interviewing techniques.

Increasing Training and Education in North Carolina

As discussed, a variety of community-based organizations across North Carolina, including Area Agencies on Aging, CCNC networks, local health departments, faith-based organizations, and free clinics offer a wide array of services that can support patient and family engagement in direct care. Many offer training and technical assistance to patients and families that could be enhanced to include strategies supporting patient and family engagement. Offering proven models of engagement, such as the Engagement Behavior Framework and Living Healthy, and partnering with patients and families can help prepare them to more fully engage in their health and health care. The Task Force recognized the importance of preparing patients and families to engage, therefore, the Task Force recommends:

Recommendation 3.1: Educate and Train Patients and Families about Partnering and Engaging (PRIORITY RECOMMENDATION)

North Carolina Area Health Education Centers should lead a collaboration of state agencies, community and faith-based organizations, and payers to identify and implement model curricula and tools for educating and training patients and family members about partnering and engaging with their health care providers.

a) Trainings should be delivered in a variety of settings to various stakeholder groups including, but not limited to, peer support networks, lay health advisors, advocacy groups, caregivers, community and faith-based organizations, school nurses, social workers, agencies serving the older population, and youth councils or youth-focused health groups.

b) Trainings should include information on navigating and overcoming challenges in the health care system, working with health care providers, patient and family-centered care, serving on patient and family advisory councils, shared decision-making tools, peer support, improving health literacy, health insurance literacy, and advocating for one's own health.

c) Community and faith-based organizations should tailor and adapt trainings and their content to their community's priorities, including those of local patients and families.

d) Organizations should consider regular evaluation of trainings to assess knowledge, attitude, and behavior change.

Peer Support

Health and well-being are fundamentally correlated with social connectedness and support.[22] People are more effective and happier when they have someone who cares about them who they can talk to about personal matters, and who is available to help them when needed.[23] Health care providers typically spend just a few hours with a patient during the year; for the majority of the time, patients and families are managing their health and wellness on their own.[24] Peer support, coupled with education and training, can provide additional resources to strengthen the individual and family and better prepare them to engage more fully in their health care.[24]

Health and well-being are fundamentally correlated with social connectedness and support.

Peer support refers to linking a patient with another individual who has some level of training and knowledge from their own experiences with a condition.[25] Peer support includes four core functions: assistance in daily management; social and emotional support; linkages to clinical care and community resources; and ongoing support that is extended over time. For example, linking a patient newly diagnosed with a chronic condition with another patient with that same condition who can share knowledge and experience, including some that may not be shared by health professionals. Peer support can complement and enhance other health care services by creating emotional, social, and practical assistance for managing the disease and staying healthy.[25]

Peer support can provide additional resources to strengthen the individual and family and better prepare them to engage more fully in their health care.

Research overwhelmingly shows the positive impact of social and peer support on health, well-being, and engagement.[26] Overall, studies have found that social support decreases morbidity and mortality rates and increases life expectancy.[27] Peer support increases knowledge of a disease, improves self-care skills, including medication adherence, and reduces the use of emergency services. Peer support provides emotional and social support, but also helps people cope with the stress that often accompanies illness and disease.[28] Peer support can build individual and community capacity for understanding health problems, promoting ways of addressing those health problems, and advocating for patients, families, and their communities.[29]

Peer support may vary by location and setting. In chronic disease management, there are several models of peer support. They include professionally led group visits with peer exchange, peer-led, face-to-face self-management groups, peer coaches, community health workers, support groups, telephone-based peer support, and web and email-based programs.[28] Alcoholics Anonymous is a long-standing, well-known example of peer support for a chronic disease. In some locations, peer supporters are called lay health workers, community health workers, or promotoras. Group peer support may be based on diagnosis, age, ethnicity, gender, or other demographic characteristics. Peer support can also be used to provide support to patients' family members; for example, it may focus on parenting a child with a chronic disease, caregiving for older adults, or other challenges families may be facing in caregiving. Peer support may also be used to help individuals

facing specific life circumstances such as divorce, death of a spouse or child, or recovering from an abusive relationship. It is important to take into account the local, regional, and cultural influences when implementing peer support programs for patients and families.[30]

In addition to benefits for patients and families, peer support offers benefits to health care providers, organizations, and systems that provide health care services, when peer support is linked to clinical services and care management. Peer support can be a strategy for culturally sensitive outreach and follow-up that enhances the link between patients and provider teams.[31] Peer support can also help providers recognize and promote appropriate care for psychosocial issues and provide an outlet for the patient and family, which then allows the provider to focus on clinical care. Integrating peer support into their care models can also help health providers, organizations, and systems meet the National Committee on Quality Assurance's Patient-Centered Medical Home standards.[32]

Peer support increases knowledge of a disease, improves self-care skills, and reduces the use of emergency services.

Peer support is generally not reimbursed by insurers. Insurance companies may understand the importance of peer support but stop short of seeing this as the responsibility of the insurer rather than the family or community. However, with mounting evidence for both the effectiveness and cost-effectiveness of peer support, this may change. Particularly as insurance practices move towards pay-for-value models (such as accountable care organizations) and away from fee-for-service, models that include peer support may be particularly effective at improving population health while reducing cost. One reason reimbursement for peer support is limited or nonexistent is due to licensing issues. It is challenging for a health insurer to reimburse for a health service delivered by an unlicensed health professional. This issue is currently under examination by the North Carolina Division of Public Health.

Peer support can provide benefits for patients, families, and providers; therefore the Task Force recommends:

Recommendation 3.2: Increase Availability of Peer Support

Organizations that provide care management services should encourage health care systems and payers to recognize the critical aspect of peer support, build peer support into their systems, and facilitate linkages to existing peer support groups, online networks and resources, and condition-specific support groups.

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Clinician and Leadership Preparation **Chapter 4**

In order to realize the benefits of patient and family engagement, health care providers and those in health care leadership must understand the key concepts of patient and family engagement, utilize engagement strategies, and understand how to support and encourage the cultural transformation that patient and family engagement requires. However, few providers receive training on patient and family engagement. Preparing health care providers and leaders to partner with patients and families begins with academic training and continues through practice and continuing education. Learning how to effectively engage patients and their families in their health care is important for all health care practitioners, as well as those in leadership and administrative roles within health care organizations.

It is important to prepare health care providers and leaders to partner with patients and their families.

There are numerous methods that providers can implement to increase patient and family engagement, some of which are discussed in other chapters. The Task Force did not study all patient and family engagement methods. Instead, the Task Force chose to highlight three evidence-based strategies for increasing providers' knowledge and skills around patient and family engagement that are currently being used by health care organizations in North Carolina.

Methods of Engagement

Assessing Patient Readiness

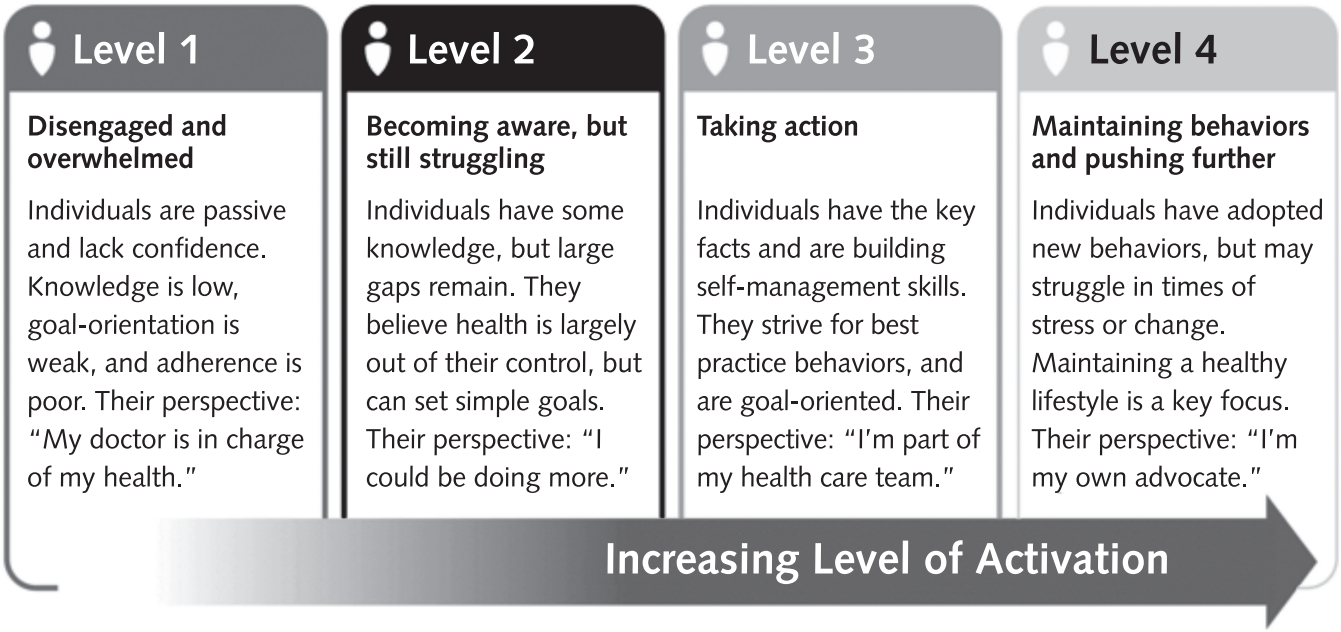
Because self-management is such a significant part of individual health, providers often need to be able to assess a patient's preparation to manage his or her own conditions. One tool health care providers can use is the Patient Activation Measure (PAM).[1] The PAM measures the extent to which patients know how to manage their condition; have the skills and behavioral repertoire to manage their condition; and have the confidence to collaborate with their health providers, maintain functioning, and access appropriate and high quality care.[2] Research has demonstrated PAM's ability to effectively measure activation and predict health-related behaviors and outcomes including medication adherence, emergency room utilization, and hospitalization.[3,4] Providers can administer the assessment, collect the information, and categorize patients into one of the following four levels.[1]

Knowing a patient's PAM level can help providers match the patient's individual care plan to their level of activation.[1] The PAM includes tools for individualized coaching based on a patient's level of readiness to move along the continuum of activation.

Motivational Interviewing

Motivational interviewing (MI) is a set of techniques providers can use to improve patient engagement. Motivational interviewing is a patient-centered, goal-oriented method of communication for enhancing patients' motivation to change by exploring and resolving ambivalence or reluctance to change.[5]

Figure 4.1
The Patient Activation Measure



Source: Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. Health Aff (Millwood). 2013;32(2):207-214.

MI can be used to assess patients' readiness to adopt behaviors to manage care and improve health, and find ways to motivate patients to participate in these processes. MI relies on four principles to help providers encourage patients: expressing empathy with patients; emphasizing differences between patients' current behavior and healthier behaviors; minimizing conflict between providers and patients; and supporting the patients' ability to change health behaviors.[5] In the past, MI was primarily used to address substance abuse, but providers today have expanded the use of MI to impact a wide array of health behaviors including diet and exercise, smoking, chronic disease management, and oral health. The patient is the expert on himself/herself. Providers can serve as partners by using their technical expertise to help the patient establish and meet goals for improving health. MI may also allow for a shift in power in the provider/patient relationship, wherein the patient becomes a more equal partner in determining how to achieve health behavior change. Ideally, MI is a partnership between experts.

The spirit of motivational interviewing is collaborative. Without MI, providers may identify a problem and offer patients a solution to fix it, which may have nothing to do with—or may even conflict with—the patient's desires or needs. For example, a provider may identify an unhealthy condition (e.g. obesity) and readily offer a plan for behavior change (e.g. diet and exercise) as the obvious solution. A provider may prescribe behavior change, but fail to consider how the patient feels about this prescription, which can often lead to resistance from the patient instead of change. By contrast, MI is a set of techniques that allows the

patient, rather than the provider, to make the arguments for change.[6] Providers learn specific skills for talking about the patient's own motivations for change in order to construct an action plan for meeting health and behavior goals. With providers working with patients to explore ambivalence or reluctance, patients will be more likely to take effective action toward improving their lifestyle.[7]

MI started as a technique used by mental health professionals. As such, many organizations that provide training and education for mental health professionals in North Carolina also offer MI training. For example, the North Carolina Council of Community Programs, an organization supporting the coordination, reform, and growth of the North Carolina mental health, intellectual/developmental disabilities, and substance abuse system, offers a 13-hour online training course on MI for mental health professionals. MI has more recently been incorporated as a technique used by a broader range of health professionals. In North Carolina, Community Care of North Carolina (CCNC) has embraced MI as a key component of care.[8] All CCNC care managers have received extensive training, coaching, and technical assistance on MI. All new hires receive a full day of MI training during orientation. Throughout CCNC, MI Champions serve as mentors for education and practice, and have created a Motivational Interviewing Resource Guide that reinforces the concepts taught during orientation. CCNC's long-term goal is to support MI at the individual practice level for both physicians and their staff to further enhance communication and improve the overall health system.[8]

Learning how to effectively engage patients and their families in their health care is important for all health care practitioners.

Shared Decision Making

Shared decision making is another strategy that can better prepare providers to increase patient and family engagement. Shared decision making (SDM) is a particular process of joint patient-provider decision making by which an individual: understands the risks or seriousness of the disease to be prevented or managed; understands screening and/or diagnostic tests (including the benefits, risks, alternatives, and uncertainties); has weighed his or her values regarding the potential benefits and harms; and has made a decision or deferred a decision.[9,10] SDM is an important tool for patient and family engagement because it is patient-centered, improves health outcomes, reduces costs, and increases patient satisfaction, psychological and physical well-being, and adherence to treatment.[11-13]

While there are various clinical models to practice shared decision making, they often rest on supporting a process of deliberation and understanding that decisions should be influenced by exploring and respecting what matters most to patients and their families. This exploration, in turn, depends on patients developing informed preferences. While there are different models, the required SDM steps include three steps: choice talk, option talk, and decision talk.[14]

Choice talk refers to the process of making sure the patient knows that reasonable options are available. This does not need to be performed during in-person visits. An email, letter, or telephone call can be sufficiently effective to initiate

this planning step. Option talk refers to providing more detailed information about available options for treatment or management of a condition. During this step, providers should supply patient decision support tools, if applicable.[a] These tools may include decision support interventions, such as exercises that allow patients to clarify their preferences, brief text or diagrams, or patient decision aids.[15] Lastly, decision talk refers to supporting the work of considering patients' preferences and deciding what is best for the patient and the patient's family. The entire process of deliberation begins as soon as options have been described during option talk. The deliberation process is both recurrent and frequent and it may take place, in part, outside of the clinical encounter.

Educating Health Care Providers and Leaders

Training and continuing education are critical to develop a workforce of health care providers and leaders who encourage and embrace patient and family engagement.

Developing a workforce of health care providers and leaders who encourage and embrace patient and family engagement begins with academic education and training and continues through practice and continuing education. Health care providers and leaders within health care systems must learn the theory and benefits of patient and family engagement as well as the skills necessary to fully engage with patients and families.

In addition to the three strategies discussed above, there are other evidence-based strategies for increasing providers' knowledge and skills around patient and family engagement. Regardless of the strategies chosen, it is important for organizations providing education and training to incorporate a diverse range of teaching techniques when working toward changing providers' ingrained ways of doing their jobs. Research has demonstrated that classroom-type, theory-based training alone is an ineffective means for stimulating and maintaining behavior change. However, when traditional training is supplemented with active and ongoing practice-based coaching and consultation, the vast majority of participants are able to successfully implement new skills or behaviors in their workplace.[16] Coaching and consultation activities include supervision, teaching while engaged in practice activities, assessment and feedback, and the provision of emotional support. Coaching and consultation are important because they allow staff to get on-the-job feedback and encouragement as they learn new skills and practices.[16]

Our general understanding of the relationship between patient and family engagement, health outcomes, and care experiences is relatively new. Thus, both seasoned providers and many recent graduates are limited in their training on how to effectively engage patients and their families. Providers and health care system administrators need to understand not only the concept and importance of patient and family engagement, but also how to effectively engage patients and families. Therefore, the Task Force recommends:

a A decision aid is a multimedia tool for patients with a particular disease or condition that provides information, values clarification, and coaching in deliberation and communication.

Recommendation 4.1: Incorporate Patient and Family Engagement Techniques into Health Professional Training (PRIORITY RECOMMENDATION)

a) **The North Carolina Community College System, the University of North Carolina system, and private colleges and universities that prepare members of the health care team should train students to provide patient- and family-centered care. Training should include evidence-based patient and families engagement strategies including motivational interviewing, the Patient Activation Measure (or other tools to gauge readiness to engage), peer support, shared decision-making tools, and health literacy strategies. Education should also include strategies for incorporating caregivers as members of the health care team.**

b) **North Carolina Area Health Education Centers programs, organizations that provide care management services, and associations including, but not limited to, the North Carolina Medical Society, North Carolina Dental Society, North Carolina Nurses Association, North Carolina Academy of Physician Assistants, and the Council for Allied Health in North Carolina should offer continuing education on evidence-based patient and family engagement strategies including motivational interviewing, the Patient Activation Measure (or other tools to gauge readiness to engage), peer support, shared decision-making tools, and health literacy strategies. Education should also include strategies for incorporating caregivers as members of the health care team.**

   1) **Training should be offered in multiple settings, with opportunities for more intensive trainings for those who will become champions of patient and family engagement methods and help other staff in the practice to learn engagement skills and techniques.**

   2) **Patients and families should be included in planning and implementing these trainings.**

Recommendation 4.2: Amend Health Professional Licensure and Certification Requirements to Include Patient and Family Engagement Skills as a Core Competency

Health professional licensing boards and associations should consider incorporating concepts and skills for patient- and family-centered care and patient and family engagement as a core competency that is included in initial licensure requirements, as well as maintenance of ongoing certification requirements.

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Care and System Redesign

Chapter 5

In addition to preparing patients, families, health care providers, and leadership to engage patients and families, our health care organizations must be designed to create environments where engagement is expected, welcomed, and facilitated.[1] Such environments provide concrete opportunities for patients and families to engage in their care; support and encourage the partnership between providers, patients, and families; and implement processes that allow patients' and families' voices to be heard. Creating such environments will require dedicated work on the part of health care providers and organizations. Necessary changes may include implementing communication mechanisms that help clinicians elicit and understand patient perspectives and concerns; structuring care processes to support and value patient and family engagement; and providing specific engagement opportunities. These changes in care and system design support patient and family engagement and the goals of better population health, better quality, and, potentially, reduced costs.[2]

Our health care organizations must be designed to create environments where engagement is expected, welcomed, and facilitated.

Culture change

An organization's culture is a combination of the organization's implicit and explicit goals and a shared set of values and beliefs that characterize how people work together to achieve these goals. Health care providers and systems have many potential goals (e.g. to improve the health of patients, to be a leading academic health center, to be the leading regional health care provider, to meet the health care needs of the community, to meet the needs of the patient) and values (e.g. excellence, safety, quality, respect, caring, teamwork).[3-8] Changing an organization's culture often requires revising existing mission, vision, and values statements. During this process of change, leadership must provide incentives and drive behaviors to align with the new mission, vision, and values.[1]

In studying several health care organizations known for improving patient engagement, researchers identified several facilitators and barriers to promoting a culture supportive of patient engagement. Facilitating factors included strong committed senior leadership, clear communication of strategic vision, active engagement of patients and families throughout the institution, sustained focus on staff satisfaction, active measurement and feedback reporting of patient experiences, and culture strongly supportive of change and learning.[9] Barriers identified included resistance to changing the culture from "provider focus" to "patient focus" and the length of time for transition or change.[9] Changing health care culture to encourage patient and family engagement at all levels is challenging and requires commitment from leadership, a strategic vision, planning, and participation of all stakeholders.[1]

Developing Processes to Support Patient and Family Engagement

Leadership is needed to drive culture change for the redesign of health care systems and care models. In addition to aligning mission, values, and vision statements to embrace patient and family engagement, the American Institutes

for Research's *Roadmap for Patient and Family Engagement in Healthcare Practice and Research* outlines a number of tactics that leadership should consider as they work to focus their organizations on patient and family engagement. The first tactic is the implementation of communication mechanisms that help elicit, understand, and respect patient and family perspectives and concerns.[1] As discussed in Chapter 4, motivational interviewing and shared decision making are strategies that health care providers and system leaders can use to engage patients and families. Other tactics include creating universal advance directives, conducting advanced care planning with patients and families, and having a point person on staff with whom patients and families can contact with any concerns.[1]

Health care systems can incorporate strategies that welcome patients and families as active and participating members of the health care team.

Health care systems can also develop processes to involve patients and families in care planning and support them in self-care. With the right tools, health care providers can document patients' health goals in their medical records, help identify strategies for reaching those goals, and provide support for patients. This may require staff training and coaching, additional time during visits, new tools to measure implementation, and/or technology to support implementation.[10,11] In order to implement such methods, health care systems must develop processes to support and enable the use of these strategies across the health care continuum. Additionally, health care systems can incorporate strategies that welcome patients and families as active and participating members of the health care team through messaging in their facilities. A strategy that is easy to implement is using posters and other forms of media which invite patients to prepare for and engage in the health visit. For example, the Ask Me 3 strategy uses a visual cue to encourage a patient or caregiver in thinking about what he or she hopes to accomplish before the visit.[12]

Family engagement cannot occur if the family, as defined by the patient, is not welcomed as a partner in the patient's care. Currently, many hospitals across the state have restrictive visiting policies, especially in intensive care and other higher level inpatient units.[13] Often the reasons for such policies include concerns about confidentiality, infection control, patient safety, security, patient and family needs, and the impact on staff.[14] These reasons are based on tradition rather than science.[14] Research shows that isolating patients from the people who know them best during their most vulnerable times places them at risk for medical error, emotional harm, inconsistencies in care, and unnecessary care.[15,16] For example, family presence in adult critical care decreases anxiety, increases satisfaction for patients and families, and is not associated with increased infection rates.[17,18] Families are usually more aware of changes in cognitive function than hospital staff, and therefore are a valuable resource during hospitalization. Families should be respected as part of the care team—never viewed as visitors—in all types of health care encounters.[14] This means that families should be welcomed during outpatient visits, inpatient visits (including around-the-clock access), bedside change of shift, physician

rounding, resuscitation, and other times at the discretion of the patient and family. Health care systems can facilitate family engagement through developing family presence policies that encourage families to take part in care visits and participate as active members of the health care team.[1] Additional tactics may include conducting bedside shift change reports with patients and families as part of the team and implementing patient- and family-centered discharge planning.[1]

One North Carolina Hospital System Has Embraced Family Engagement

Vidant Health System, based in Greenville, North Carolina is one of the Better Together campaign's exemplar hospital systems, profiled for its work in family engagement.[19] Although successful efforts to advance patient- and family-centered care began at the system's Children's Hospital and Regional Rehabilitation Center in the late 1990s, these efforts did not automatically advance throughout the health system. A defining moment with senior leadership occurred when a hospital employee and her family shared their experience of being treated as visitors and the adverse effects that experience had on them. From there, the leadership implemented new family friendly systems and processes. Leadership listened and engaged with staff. Workgroups with patients, families, and staff from every department mapped out steps needed to become a health care system that fully embraced patients' families.[19]

The Task Force reviewed strategies for health care system process redesign and recommended mechanisms and processes to support patient and family engagement. To fully engage patients and families, health care systems must implement processes to encourage and support patient and family engagement throughout the health care continuum. Therefore, the Task Force recommends:

Recommendation 5.1: Make Patient and Family Engagement a Goal of Health Care Systems

The North Carolina Hospital Association and all health care systems in North Carolina should encourage and support patient and family engagement at all levels of their systems by:

a) Incorporating patient and family engagement as a leading goal of their organizations.

b) Implementing evidence-based strategies with fidelity, to enhance patient and family engagement at multiple levels within the organization.

c) **Assessing how patient and family engagement strategies impact patient experience and outcomes, costs, and staff morale, using both qualitative and quantitative evidence.**

d) **Convening a stakeholder forum to share best practices among health systems.**

e) **Identifying a leader for patient and family engagement within their organization who can serve as a point of contact and a resource for patients, families, and the community.**

Recommendation 5.2: Support Patient and Family Engagement through Health Care Organization Policies and Processes (PRIORITY RECOMMENDATION)

The North Carolina Medical Society, the North Carolina Hospital Association, the North Carolina Community Health Center Association, and other partners should promote policies and processes that support and encourage patient and family engagement including:

a) **Welcoming and supporting patients and families as partners in care through communication and messaging. Patients and families should be involved in the design and implementation of patient engagement communications planning.**

b) **Examining and revising policies and procedures to promote patient and family engagement throughout the health care experience. Such policies and procedures may include those impacting access, coordination of care across multiple sites, organizational transitions, bedside rounding, family presence and visitation policies, shared decision making, care coordination, care transitions, and end of life planning.**

c) **The health care team should develop care plans based on patient and family goals, with patient and family input.**

d) **Fostering a work culture that supports increased empathy and improved listening and communication skills on the part health care providers.**

Recognizing and Supporting Family Caregivers

In addition to ensuring that families are welcomed throughout a patient's health care experience, health care providers should recognize, acknowledge, and support family members who provide direct care support to patients. In 2012, there were approximately 65 million family caregivers in the United States providing care for family members across the lifespan.[20] Almost half of family caregivers perform medical tasks, such as wound care and operating complex medical equipment.[20] Many of these family caregivers are not trained in these tasks prior to the patient needing their support. These caregivers need training and skills to facilitate their engagement. Family caregivers are an important member of the patient's health care team, and, as such, should be recognized by health care providers.

Health care providers should recognize, acknowledge, and support family members who provide direct care support to patients.

Family caregivers have a unique relationship with the patient. To ensure the best care for patients, health care providers need to recognize and support this relationship. Many health care organizations and systems, however, are not designed to support the relationship with family caregivers. Family caregivers are typically welcomed at health care visits and some information about the patients' care and needs is often shared, however, this is not always the case. Health care systems should develop policies that specify families as important members of the health care team and ensure families are welcomed during patient visits.[1] The family caregiver may not have access to the patient's medical record, even when the patient would like that information shared. Some families have managed to gain access to medical records, through the Health Insurance Portability and Accountability Act (HIPPA), with appropriate legal paperwork (power of attorney). However, many families continue to need help in navigating access to medical records.

Several organizations nationally and in North Carolina provide training and support to family caregivers. AARP, the Red Cross, and many local organizations such as county cooperative extension offices and area health education centers offer trainings for individuals caring for older family members.[21] AARP and Area Agencies on Aging offer the Power Tools for Caregivers course at no cost. Power Tools for Caregivers is an evidence-based program of 2.5 hours sessions for 6 weeks that improves self-care behaviors, management of emotions, confidence in coping with caregiving demands, and utilization of community resources. It has shown a positive impact on caregiver health for a diverse group of caregivers, including those in rural areas, ethnic minorities, adult children of aging parents, spouses/partners, and caregivers at differing stages in their caregiving roles, living situations, financial status, and educational backgrounds. In addition, the North Carolina Division of Aging and Adult Services offers the Family Caregiver Support Program and many hospital systems in North Carolina also provide support groups for families of patients with various medical conditions.[22]

The Task Force acknowledged the value of family caregivers, and recommended strategies to facilitate their partnership with the health care team.

Recommendation 5.3: Recognize Caregivers as Members of the Health Care Team

Health care organizations should adopt policies that recognize the role of caregivers as members of the health care team including:

a) The health care team should document the primary (family) caregiver, when applicable, in the medical record and ensure that designated family caregivers have access to the medical record in accordance with applicable (HIPPA) law.

b) The health care team should recognize the role of the caregiver and include them as a member of the health care team.

c) The health care team should treat patients with multiple chronic conditions and their family caregivers as a unit.

d) The health care team should encourage caregiver self-care, and provide assistance with identifying support resources and respite care.

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Organizational Partnership

Chapter 6

Comprehensive patient engagement across the health care continuum is a challenging task for health systems. Welcoming, encouraging, and supporting patient and family engagement in direct care, as discussed in Chapter Five, is the first level of engagement for patients, families, and organizations according to the Framework for Patient Engagement.[1] Moving to the next level of engagement requires patients and families to be involved in organizational design and governance.[1] Creating opportunities and roles for patients and families to influence the design and governance of health care organizations is critical to ensure their voices are heard and that health care organizations and systems are responsive to their needs.

Comprehensive patient engagement across the health care continuum is a challenging task for health systems.

Involving Patients and Families in Organizational Decision Making

There are many ways health care organizations can integrate patient and family perspectives and experiences into their organizational decision making.[1] Patient and family representatives serving on governing boards and advisory committees within the health care system can share their perspectives on how policies and processes affect those served by the health care system. Including patients on the governing board can also help ensure that the health care organization is responsive to the community's health care needs and experiences. For this reason, federally qualified health centers have a federal mandate that the majority of their board members be individuals served by their centers.[a] Health care organizations often have numerous advisory committees, some of which focus on system wide issues like safety while others focus on specific services within the system like cancer or women's health.[1] Vidant Health, a regional health system serving 29 counties in eastern North Carolina, has prioritized including patients and family members on committees, interview teams, facility design and renovation teams, the development team for the electronic medical record patient portal, and editorial review committees for patient and family education.[2] Creating opportunities throughout health care organizations for patients and family members to influence decisions can help ensure health care organizations are meeting the needs of the communities they serve. Therefore, the Task Force recommends:

Recommendation 6.1: Include Patients and Families on Health Care Organization Boards and Committees

Health care organizations should appoint a minimum of two patients (or family members) to boards and advisory committees within their organizations. To the extent possible and practical, patients (or family members) should represent the diversity of the community served by the health care system. Patients (or family members) should

a Section 330 of the Public Health Act (42 U.S.C. §254b).

receive training and mentoring to help prepare them to be productive board and committee members.

See also Recommendation 8.3.

Creating opportunities and roles for patients and families to influence the design and governance of health care organizations is critical.

Patient and Family Advisory Councils

Creating a patient and family advisory council (PFAC) is another strategy to ensure the needs and concerns of patients and families are heard and used to inform decision making. PFACs are teams of patients and families working with providers and staff to provide an opportunity to engage patient perspectives in the planning, implementation, and evaluation of health care services and programs.[3] Patient and family advisors serve as consumer representatives and provide an important perspective to the design and delivery of health care systems and help ensure the focus of health care is centered on the patient and the family.[3] PFACs provide an opportunity to improve understanding and cooperation, and promote meaningful partnership among patients, families, providers, staff, and health care organizations.[3] PFACs also provide an efficient and effective approach to elicit the unique perspectives of patients on issues that impact their care. Patient and family advisors benefit from their participation in PFACs because participation in a PFAC allows them to learn skills that may be new to them, including facilitation and listening skills. Participation in a PFAC gives patients and families an opportunity to enhance their understanding of the health care system, while providing a means to advocate for patient and family-centered health care in their communities. PFACs also provide the opportunity for patients and families to give back to their communities and build relationships.

Health systems have engaged patient and family advisors in many key roles such as quality and safety initiatives, facility planning, staff education, patient/family education, and staff hiring.[2,4,5] Health care systems across North Carolina, including UNC Health System, Duke University Health System, Wake Forest Baptist Medical Center, Vidant Health, and many regional hospitals, have PFACs addressing various issues. For example, Onslow Memorial Hospital's PFAC has provided recommendations that have led to improved signage throughout the hospital, making the lobby more welcoming, changing the hospital's visitation policy so that patients define their family, and revising patient education literature. Involving patients at the organizational level has resulted in positive outcomes including improved patient satisfaction, efficient facility design, and improved health system reputation.[6] Although many health systems that have established PFACs report positive qualitative outcomes, there is less documentation of key quantitative indicators such as reduced costs or improved patient outcomes.

Health systems that have PFACs have identified several challenges in fairly and effectively including consumers at the organizational level.[7] One of the most critical challenges is addressing the gap between consumer knowledge and health professional knowledge.[7] PFACs have also had difficulty identifying appropriate and diverse consumer participants, determining their roles, and establishing an equitable voice among advisory council members. Several strategies have been developed to more fully engage PFAC members including: designating a staff member of the organization for consumers to contact for regular concerns as well as for meeting briefings and debriefings; providing training and education for PFAC members; and creating a peer-to-peer exchange between organizations implementing PFACs.[7]

In North Carolina, the North Carolina Quality Center supports patient and family engagement efforts, including the creation and integration of PFACs, in hospitals around the state.[b] The Quality Center helps health organizations with PFACs overcome some of the challenges they face in integrating PFACs into their organization's decision making process. In 2015, the Quality Center plans to host a learning network of hospital patient engagement or experience staff.[b] The Quality Center also plans to invite patient and family advisors, hospital engagement or experience staff, and advocates to a summit to learn from each other and share best practices.[b] The Quality Center work on patient engagement will also continue within their other program areas of patient safety and quality.

The NCIOM Task Force on Patient and Family Engagement reviewed the research on PFACs' impact on patient engagement, and recommends:

Recommendation 6.2: Engage Patients and Families in the Governance and Operation of Health Care Organizations (PRIORITY RECOMMENDATION)

a) Health care organizations including, but not limited to, accountable care organizations, health systems, provider regional networks, and payers, should develop patient and family advisory councils (PFACS) to provide input into the governance and operation of health care at all levels. PFACs should represent the community that the agency or health care organization serves.

b) North Carolina Area Health Education Centers, in partnership with the North Carolina Hospital Association, should convene a statewide group of patients and families to help coordinate advocacy, capacity building, inventory, and support other PFACs.

b Koeble C. Executive Director, NC Quality Center, Senior Vice President, NC Hospital Association. Personal (telephone) communication. February 20, 2015.

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Measurement, Research, Transparency, and Accountability

Chapter 7

Data plays a dual role in patient and family engagement. Data can be used to inform patients and families about the success of efforts by health care providers to embrace patient and family engagement, and it can also drive consumer decision making. As health care systems and organizations engage in efforts to increase patient and family engagement, it is important to measure these efforts. Measurement is critical to conduct a successful evaluation, to determine if effort and costs yield benefits, to choose between strategies, and to develop a research base for future decision making.[1] Measurement results can be used to inform patients and families about the success of efforts by health care providers to embrace patient and family engagement. Additionally, to fully engage in and make informed decisions about their care, patients and families need access to clear and comprehensive information about cost, quality, treatment options, and their own health and health care needs.

As health care systems and organizations engage in efforts to increase patient and family engagement, it is important to measure these efforts.

Measuring Patient and Family Engagement

Several tools are available for providers and health systems to use in order to measure patient and family engagement.[2] However, the validity of these tools has not been clearly established.[3] In addition, the impact of positive and negative results of such measures has not been clearly associated with outcomes such as cost and quality.[4,5] Patient and family engagement can be measured by self-assessment or inventory, and by surveying patients. The most common tool to ask patients about their engagement experiences is a patient experience survey such as the Press Ganey survey.[6] This survey may do an excellent job in assessing some aspects of the patient experience, but a more developed and nuanced assessment of engagement is not a component of the Press Ganey survey.[7] One pilot study tested questions that could be included in a patient satisfaction survey and included the following dimensions: family participation in care, explanation of staff roles, staff supported family presence, and staff respected patients culture and spiritual beliefs.[8] This type of assessment could be easily incorporated into practice and health system assessments of patient experience, but would require new or redirected resources. Other strategies for directly involving patients in an assessment of patient engagement include the use of focus groups, interviews, and input from patient advisors and patient and family advisory committees, as well as newer methods including shadowing and guided tours.[2] These tools are useful for informing decision makers about a variety of perspectives but they are qualitative assessments and have not been validated.

In addition to patient-level assessments, health systems, hospitals, and practices can administer self-assessments of patient centeredness. Self-assessment tools are available for a variety of health units and can be used to assess the presence or absence of practices or policies, as well as the implementation of practices. These tools include an assessment of leadership commitment and culture. The Institute for Patient- and Family-Centered Care has a variety of specific tools available that can be used to assess various aspects patient centeredness.[9]

As part of the Centers for Medicare and Medicaid Partnership for Patients, the North Carolina Quality Center (NCQC), within the North Carolina Hospital Association (NCHA), has supported a Hospital Engagement Network in Virginia and North Carolina. The network has hosted over a 100 learning activities, including work to decrease complications, reduce readmissions, improve quality, and increase patient centeredness and engagement to aid in all of these goals.[10] Although the networks are no longer operating, NCQC will continue to serve as a resource for hospitals, health systems, and others concerned with patient engagement and patient-centeredness.

Payers have begun to use patient satisfaction as well as quality measures to tier reimbursement. An example of tiered reimbursement is the Blue Cross Blue Shield Blue of North Carolina Quality Physician Program. Practices and providers that adopt certain quality standards and take on training programs and modules are eligible for enhanced reimbursement. Recognition as a patient-centered medical home and trainings in cultural competency start to approach patient engagement, but more direct tools, practices, and measurement of patient engagement could be adapted into tiered reimbursement.[11] As research continues to demonstrate the value of patient and family engagement initiatives, it will be in the interest of health systems in value-based arrangements to embrace patient and family engagement programs. Evolving reimbursement models will be one of the most effective ways to ensure the adoption of practices to best support patient and family engagement. As research on patient and family centered care emerges, compelling data to support improved quality and decreased cost may drive health systems to more fully embrace this work, as accountable care organizations and shared risk/shared savings become more common in our health care delivery system.

Recommendation 7.1: Measure the Impact of Patient and Family Engagement

The North Carolina Hospital Association, in partnership with the North Carolina Medical Society and organizations that provide care management services, should work with patients and families to develop, collect, and disseminate patient and family engagement measures in hospitals and ambulatory settings across the state.

Transparency and Accountability

Patient and family engagement in health care will ultimately require improved access to information. Some patients want information such as the cost of care, how often a doctor or hospital performs a certain type of procedure, and the complication rate. If patients have more information about the cost of their health care, they may make more informed decisions about treatment. As they become responsible for more out of pocket costs, patient groups have shown

more readiness to partner in their care, use available tools, and find ways to lower their costs.[12] While adhering to principles of health literacy and shared decision-making, health systems and payers can provide patients with more information about costs of health care, helping them select higher value care that better meets their needs.[13]

Such data may be available for the most common procedures, but it may also be difficult to access and not always easy to understand. Further, putting insurance companies between patients and providers has made understanding data related to pricing difficult. Patients may be most interested in knowing their out of pocket cost—the cost of a unit of care after their insurance has negotiated a rate and paid the part for which the patient is not responsible. The cost of a particular unit of care to the provider varies by insurance provider and is not easily available, particularly in advance of treatment.[14] Patients are also motivated to understand the quality of a provider or a hospital for a given type of care or service, which is also not always readily available.[15,16] Complication rates are often correlated to provider experience and volume, but some types of care are provided so rarely that estimating complication rates may be unreliable predictors of quality. For example, estimating surgical quality with such data as procedure counts per year, rates of infections, and blood clots is relatively straightforward, although this data may still not be widely available. While there are now numerous measures of quality, agreeing upon the 'right' metrics for estimating quality has been more difficult.[17]

To fully engage in and make informed decisions about their care, patients and families need access to clear and comprehensive information about cost, quality, treatment options, and their own health and health care needs.

Information on facility and provider quality is increasingly available for resourceful patients with high health and computer literacy levels. The Centers for Medicare and Medicaid Services host and maintain several websites including: Hospital Compare, Physician Compare, Nursing Home Compare, Dialysis Facility Compare, and Home Health Compare.[18] One of the most complete of these websites is Hospital Compare. It includes 44 measures of hospital quality, patient experience, and cost.[19] However, data are still quite limited. It is not currently possible for an individual consumer with a particular insurance product to determine cost. Physician Compare currently contains virtually no information, except a physician's name, location, and whether or not he/she accepts Medicare. Available data for nursing homes, home health agencies, and dialysis centers are better than what is available for individual physicians, but not nearly as useful as hospital data.[18] It is also not yet clear whether or not patients use this kind of data when choosing a provider of care, or if choosing a care provider in this manner impacts quality and cost.[15,16]

Some states use a state run data system known as an all-payer claims database to report both cost and quality metrics to consumers.[20] A variety of proprietary sites disseminate information about health care quality and availability. With the exception of websites developed by commercial insurers, these generally disseminate the same publicly available information as that what is made available by the federal government, with the addition of feedback at an

individual level. Feedback such as customer reviews may be posted to the websites in a non-systematic way by individual clients.

Private payers have increasingly become more involved in sharing quality and cost information with their beneficiaries. However, private payers can only produce stable estimates of cost and quality where particular payers have a large market share, and for procedures that are commonly performed. Private payers, perhaps, have the greatest opportunity to contribute to public information sharing and transparency. Private payers have claims data available, which can be used to assess aspects of quality, and can also leverage practice and facility level audits of quality. Lastly, private payers have the final say on an individual patient's financial responsibility. Blue Cross Blue Shield of North Carolina has recently launched a website (http://www.bcbsnc.com/content/providersearch/treatments) to allow patients greater access to cost and quality data.[21] If this information is complete and patients understand how to use it, they can take advantage of this data to make more informed decisions about the choice of a health care provider. This information may have a powerful effect on their health care. However, only large insurers with a significant share of the market in an individual community will be able to aggregate data in a manner that is useful to consumers.

In 2013, the North Carolina General Assembly passed the Health Care Cost Reduction and Transparency Act requiring hospitals to post the prices of their most common diagnosis-related group (DRG) admissions and surgical procedures.[a] Lawmakers are interested in pricing transparency as one means of controlling health care costs. However, hospitals have found implementation of this law challenging because price, in and of itself, is not a meaningful measure. Should hospitals be posting the raw cost of the procedure, the average adjusted charge (or contractual rate with payers), the average charge to a patient without insurance, or the average amount for which a patient is responsible, after insurance pays its share? Ideally, information on pricing should be easily available and accessible to patients both with and without Internet access, and online searching skills, however, figuring out how and where to post information to meet these qualifications has been a challenge for hospitals. To help increase transparency in health care pricing, the Task Force recommends:

Recommendation 7.2: Encourage Health Care System Transparency (PRIORITY RECOMMENDATION)

All health care systems and providers should ensure information on services, cost, and quality is easily accessible to consumers in print and electronic formats.

a **NCGA § 131E-214.11—.14**

Recommendation 7.3: Encourage Health Care Payer Transparency

Payers should provide on their websites and in their written materials information that is easily understood by consumers on covered providers and common procedures, including data on costs, quality, safety, and patient experiences.

Several states have created all-payer claims data (APCD) systems to help provide the necessary state-level data that can improve price transparency. These claims data systems also support quality improvement activities, compare disease prevalence or utilization patterns across the state, identify successful cost containment measures, and evaluate health care reform efforts on costs, quality, and access. The data included in APCD systems generally consists of claims data from physicians, pharmacists, and dental care claims from public and private insurers, and includes payment information such as plan charges and member liabilities (e.g. co-pay, deductible payments, co-insurance).[22] As of 2014, 11 states had fully functional APCD systems, 6 states were in implementation, 20 states expressed strong interest, and 3 states had existing voluntary activities.[23] In 2012, the North Carolina Department of Health and Human Services created a workgroup to examine the possibility of creating a similar APCD or confederated data system to capture data from multiple existing data systems that could be used in North Carolina to examine population health, cost, and quality issues across the state. Such a system could provide important data on health care costs, including those for specific procedures, providers, or health systems. However, North Carolina's efforts are currently on hold while the state is implementing other major health information technology efforts, with several groups continuing to hold interest meetings regarding whether to move forward on APCD or a united data system.

Recommendation 7.4: Provide Health Care Cost Information to the Public

The North Carolina General Assembly should collaborate with the Department of Insurance, health care systems, and insurers to create a statewide, mandatory data reporting system to enhance pricing transparency for medical care and health care services. This collaborative effort should include input from additional stakeholders on database use and access, and participating stakeholders should include employers, health care providers, academic and industry researchers, and patient and family advocacy groups.

Collaborative Charting

Transparency around quality and costs is one method to help consumers make more informed choices about their health care; another potential method is collaborative documentation or charting. Collaborative charting refers to a spectrum of shared medical record keeping between the health care provider and the patient. Historically, patients' access to the information in their medical charts was quite limited until the the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA) which states that "patients must be able to see and get copies of their records, and request amendments."[b] The Institute of Medicine and others have suggested that allowing patients access to their medical records could reduce errors and improve quality.[24,25] This type of collaboration is not new, but the potential has exploded with the development of electronic medical records and patient portals.

What Could Collaborative Charting Look Like?
Imagine a patient walking into an exam room, noticing his medical chart on the door, and deciding to pick up the chart on the way into the exam room. Now imagine that patient has not only reviewed the chart, but made corrections and comments in the chart. This would be the essence of collaborative charting.

Historically, a patient's chart was a file folder full of their provider's documentation of their visits. Today it is more common for the chart to be electronic, which allows greater opportunities for collaboration. Under true collaborative charting a patient's medical record is about, for, and the property of the patient and they are encouraged to contribute to it and review it at will. Rather than owning the medical chart, the health care provider enters into a partnership with the patient that extends to record keeping to ensure accuracy and transparency in medical record keeping. While true collaborative charting is still quite rare, many health systems have begun to experiment with collaborative charting through the use of patient portals which allow patients access to some parts of their medical records online.

Skeptics of collaborative charting cite many reservations about its use.[25,26] Some providers consider the medical record to be a shorthand way of retaining key pieces of information about a patient, his or her health record, and for treatment planning. This information is primarily used for recall by the health care provider for ongoing care and for communication with other members of the care team. Other current uses of medical records include support of billing, in the event of an audit, and for legal protection in the event of a malpractice claim. Providers use a specialized jargon, and some fear open charting will make the process of charting more complicated and cumbersome. Other providers fear that open charting will expose them to increased litigation, with patients more readily pointing out medical errors in their care. Some providers are concerned that time will be wasted in correcting notes that are of minimal importance to caring for their patients. Still others fear that patients will be insulted by language or judgments rendered in chart—use of terms such as 'complains of' or 'denies' may seem unfair to some patients. More problematic still might be perceived diagnostic judgments such as 'drug seeker' or 'somatic disorder.'[25]

b Federal Health Insurance Portability and Accountability Act of 1996, Pub L. No 104 - 191

These concerns on the part of skeptics are important considerations in collaborative documentation. However, limited research to date has shown that collaborative charting is a mostly positive experience for both patients and health care providers. A study of Open Notes, a system for collaborative charting, demonstrated that most patients who used this system feel more in control of their health care, and have increased medication compliance.[27] Reports of collaborative charting show changes in the way providers document and/or required increased time for documentation. This system was tested in only three geographic areas and, given that the culture of medicine, expectations, and experiences of patients, and payment systems vary widely across the United States, further study of the spectrum of collaborative documentation will be important.[27]

While collaborative documentation is still relatively new, it holds promise as a technique for engaging patients and families in care. Therefore, the Task Force recommends:

Recommendation 7.5: Increase Collaborative Documentation

a) Health care organizations should examine opportunities to increase collaborative documentation aimed at increasing patient and family engagement including, but not limited to, patient portals, open charting, open notes, and other models.

b) The North Carolina Quality Center and the North Carolina Hospital Association should continue to provide consultative support to health care organizations implementing collaborative documentation.

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Legislation, Regulation, and Partnership in Public Policy

Chapter 8

There is significant opportunity within health care to align legislation, regulation, and public policies with the principles of patient and family engagement, with the goal of improving health outcomes and quality of care. Regulation and legislation can motivate both individual and organizational behavior change. Specific tactics for this strategy may include incentives and mandates that encourage or require patients, families, clinicians, health care leaders, health care organizations, and health care systems to change their behaviors in ways that promote and support patient and family engagement. Ideally, incentives should be aligned with performance measures on metrics such as patient-reported experience and outcomes, inclusion of patients and families in team-based care, and the extent of progress toward achieving patient-centered goals.

There is significant opportunity within health care to align legislation, regulation, and public policies with the principles of patient and family engagement.

Themes of patient and family engagement are central throughout the Patient Protection and Affordable Care Act. Several provisions directly address patient engagement and patient-centeredness, including support for primary care medical homes, medication management, community health assessments, and incentives for chronic disease prevention under Medicaid. Several additional provisions, while not solely focused on patient engagement, utilize its main principles and concepts. Provisions focused on quality reporting and quality measurement development, for example, require patient-centered assessments and similar tools.[1] The Centers for Medicare and Medicaid Services (CMS) has also emphasized patient and family engagement in its National Quality Strategy. This strategy highlights the importance of engaging patients and families "as informed, empowered partners in their care," and aims to incorporate patient and caregiver preferences, improve the experience of care, and promote self-management.[2]

Patient and Family Engagement Initiatives in North Carolina

The North Carolina Department of Health and Human Services' (NCDHHS) Division of Medical Assistance has aligned many themes of patient engagement in its work with care management programs through Community Care of North Carolina (CCNC). CCNC is a statewide medical home and care management system that includes regional networks of physicians, nurse practitioners, nurses, social workers, pharmacists, hospitals, health departments, social service agencies, and other community organizations. CCNC's main goals are improved care coordination and care management, as well as better outcomes.[3] As key components of their work, CCNC includes motivational interviewing, counseling, and referrals, as well as care management for patients with chronic diseases and complex health care needs.

Medicaid reform in North Carolina will provide more opportunities to incentivize patient engagement amongst providers. In 2013, NCDHHS Secretary Wos and Governor Pat McCrory requested a federal waiver from CMS (Medicaid

waiver 1115) which would allow North Carolina to incorporate principles of patient engagement more thoroughly into the Medicaid program, and design changes to the state program that can be adapted to individual patient and family situations.[2,4] Patient and family engagement is a significant part of the second goal of the CMS National Quality Strategy to strengthen person and family engagement as partners in their care. The desired outcomes specifically include patients as partners at all levels of care; care and treatment that reflects the patient's personal values and goals; coordination and communication that occurs within and across care teams, including patients, families, and caregivers; and patient and family preferences as central in decision processes and implementation.[2] This is a part of the platform of Medicaid reform in North Carolina that is currently under debate in the General Assembly. Other potential upcoming changes to North Carolina's Medicaid program, including moving to an accountable care organization structure, may provide opportunity for improved care management and better patient outcomes.[5]

The North Carolina State Health Plan has also emphasized principles of patient and family engagement in recent plan changes. The State Health Plan provides health insurance coverage for approximately 630,000 North Carolina state employees and dependents, including teachers, state university faculty and staff, and lawmakers.[6] In 2009, the State Health Plan instituted a wellness plan under a mandate from the North Carolina General Assembly.[a] The wellness plan consists of options for smoking cessation treatment, wellness/health assessment, and reductions in co-pays for enrollees who designate their primary care providers. The State Health Plan also plans to focus on initiatives to improve health literacy among patients and has begun moving toward value-based insurance design, in which patients can choose from plans that offer financial incentives for actions taken to improve their health.[6,7] With value-based insurance design, insurers also encourage enrollees to use services or medications of higher value by reducing or eliminating the out-of-pocket cost sharing (for example, eliminating cost sharing for highly effective medications), or by increasing the cost sharing on services, procedures, or medications that are less cost effective.[8] Value-based insurance design products can also consist of offers for financial incentives for enrollees to encourage them to obtain care from high quality, lower cost health care providers.

Private payers have also implemented policies to enhance patient and family engagement. Blue Cross Blue Shield of North Carolina (BCBSNC) focuses on communication strategies to increase health literacy, primarily focusing on improving members' understanding of multiple plan choices to meet patients' needs. BCBSNC also provides incentives for patients who utilize higher quality health facilities. BCBSNC has implemented provider incentives for patient and family engagement, including increased reimbursement rates for providers

a North Carolina General Assembly § SL2009-16.

who participate in cultural competency trainings. Group purchaser incentives include discounts on renewal of employee plans if employees participate in the recommended preventive care. One example of incentives is the national Blue Distinction Center program, which identifies centers of excellence for non-emergent surgeries, based on generally recognized quality indicators such as post-operative complications and readmission rates. Another example is requiring a smaller copay for patients going to a designated patient-centered medical home to receive primary care. Self-funded plans have implemented a number of other creative ways to offer incentives to members who choose higher quality facilities and providers. Aetna has increased its focus on vulnerable populations, engaged healthy populations, and facilitated prevention by providing incentives for patients who complete health risk assessments and participate in health promotion and wellness programs.

Employers' and Payers' Support for Patient and Family Engagement

Employers and health care payers play significant roles in supporting patient and family engagement.

Employers and health care payers (i.e. insurance providers) play significant roles in supporting patient and family engagement. Employers offering health care coverage can support patient and family engagement by providing information about health care plans and options available to employees in easy to understand language. Employers can also provide additional education about the various plans and information on how employees can access the health care system. Employers can explore options for caregiver coverage for patient support and other services that save costs and resources for health care organizations and systems each year.

Health care payers can also support patient and family engagement through clear, easy to understand information on their insurance options. (See Chapter 3 for additional information on health literacy.) Health care payers can ensure their materials and communication are appropriate, using input and feedback from advisory committees members. Further, advisory committee members should be incorporated into the planning and governance structures of health care payers to ensure that concerns of patient and family representatives are heard and addressed. (See Chapter 6 for more information on patient and family advisory committees.)

There are many tactics health care payers can use to promote and support patient and family engagement through reimbursement policies and health care plan design. For example, payers can develop reimbursement policies that factor in patient satisfaction or the use of evidence-based practices that promote patient and family engagement. Tactics which promote patient and family engagement may include the use of motivational interviewing, peer support strategies, shared decision-making tools, and health literacy strategies. Embracing these strategies as part of reimbursement formulas will help prepare the health care team for the culture change of more engaged patients and families, as discussed in Chapter 3. Payers can also consider providing reimbursement for peer

support services (see Chapter 3) and valuing the work of family caregivers. For example, in the fields of mental health, developmental disabilities, and substance abuse services, peer support services are certified and credentialed through a training process that facilitates reimbursement. There are other state efforts to consider credentialing services for billing and reimbursement.

The Task Force examined the role employers and payers can play in promoting legislation and regulatory requirements, as well as corporate policies that support patients, families, and caregivers. The Task Force focused its recommendations on ways these partners can enhance patient and family engagement.

Recommendation 8.1: Advance Patient and Family Engagement through Payer Policies (PRIORITY RECOMMENDATION)

Payers should consider changes to health plans and policies that support patient and family engagement. Those changes may include, but are not limited to:

a) Offering payment options such as:

1) Factoring patient experiences of care, such as results of patient satisfaction surveys, into provider reimbursement rates.

2) Providing incentives to promote the use of evidence-based practices that engage patients and families in their own care (e.g. the Patient Activation Model, motivational interviewing, and decision support tools).

3) Providing reimbursement for certified peer support services.

4) Providing options for caregiver coverage in employer-based health plans/place caregiver reimbursement on menu of options available to payer.

5) Utilizing value-based insurance design.

b) Developing member advisory committees.

c) Using plain language in education and information about health insurance plans.

Engaging Employees in their Health and Well-Being

In addition to providing health care services for communities, health care organizations are employers. In many communities across North Carolina, health care organizations are among the largest employers. In 2008, the health care industry in North Carolina employed almost 500,000 people.[9] Employers are in a unique position to influence employees' health and well-being, both as

the place where employees spend many of their waking hours and as the provider of health insurance for many employees and their families. Employers greatly influence how their workers spend time at work, including how much exercise they get, the types of food they have access to, and opportunities for health education. As the provider of health insurance, employers have the opportunity to select health plans and wellness incentive programs, and to educate employees about their health plan and the options and services available to them. Health care organizations are leaders in their communities, employ large numbers of people, and have a unique perspective regarding the importance of maintaining a healthy workforce, all of which make them well suited to implement comprehensive worksite wellness programs. Additionally, in their roles as leaders in their communities and the providers of health services, hospitals can help influence other employers to implement worksite wellness programs as well.

Employers have the opportunity to select health plans and wellness incentive programs, and to educate employees about their health plan and the options and services available to them.

Worksite wellness programs are an evidence-based approach to engage employees in their health care. Comprehensive worksite wellness programs include health education programs; screening with appropriate follow-up and education; social and physical environmental supports and policies; linkages to safety and other employee benefits; and administrative, organizational, and structural support for wellness (such as staffing, resources, strategic planning efforts, and wellness committees).[10] Many comprehensive worksite wellness programs have demonstrated an ability to improve employee health, productivity, and employee morale, while reducing risk factors for chronic disease, and help control health care costs. While many of North Carolina's health care organizations engage in some level of worksite wellness, such as creating tobacco-free policies, comprehensive worksite wellness programs have not been widely implemented.[11]

In the workplace, patient and family engagement becomes employee engagement. Employee wellness committees help tailor health promotion programs to employees and to worksites and increase participation in health promotion programs.[10] Worksites with a wellness committee and coordinator are more likely to have environmental supports and policies for health and to have a comprehensive health promotion program.[10] Employee involvement in program development can enhance program benefits and increase the likelihood of wellness program sustainability.[10] Therefore, the Task Force recommends:

Recommendation 8.2: Implement Comprehensive Worksite Wellness Programs that Include Patient and Family Engagement Support (PRIORITY RECOMMENDATION)

a) Health care organizations should, with employee input, develop and implement comprehensive worksite wellness programs that include employee engagement strategies.

b) Health care organizations, in partnership with local health departments and local chambers of commerce, should invite and encourage other community employers, businesses, and government leaders to develop and implement, with employee input, comprehensive worksite wellness programs that include employee engagement strategies.

Partnership in Public Policy

Including patient representatives in public decision-making can improve trust and confidence in the health system as a whole.

There is an opportunity for broader patient and family engagement at the policymaking level. Just as health care organization policies benefit from the active involvement of patients and families, federal, state, and local health policies benefit from the involvement of patients and families in the policymaking process. On the continuum of engagement, patient involvement in policymaking can include consultation, in which patients are asked their opinions and experiences on health policy issues; involvement, in which patient experiences are directly used to guide funding decisions and research priorities; and partnership and shared leadership, in which patients have equal representation and authority on funding and policy decisions.[12] Engagement in policymaking may involve individual patients and family members, or may consist of organizational representatives of a specific patient constituency.[12]

There are a number of perceived barriers to partnering with patients or other partners in health care policymaking. One of these is a perceived lack of objectivity. A patient or family member may be perceived as only representing personal interests, and not those of a greater group. However, a well prepared patient or family representative serving on a health policy board or advisory board will seek to represent the views and interests of patients and families generally. Another perceived barrier may be that patients are not well informed about the policy process, or that their involvement may delay the process or make it less efficient. However, patient representatives should be considered experts in their own experiences and considered as valuable as any other content area expert whose ideas are critical to the policymaking process. By incorporating the voices of patients and families in the original policymaking process, policymakers can remove any objections regarding a lack of patient input, which may reduce delays later in the process.[13] As described in Chapter 6, appropriate preparation for patient participation in policymaking—for both patients and policymakers—can help facilitate the process.

Local county health departments and district health departments in North Carolina have made significant strides in community and patient representation in planning and policy. A survey of 53 local health department officials in North Carolina showed a wide variety of engagement with multiple stakeholder groups. The surveyed officials reported the lowest levels of engagement with patient representatives.[14] Additional research has indicated strong interest in increasing patient and public engagement; however, there is a notable lack

of research on how best to approach both the engagement process and the incorporation of patient input into policymaking.[15]

In North Carolina, the Durham County Department of Public Health provides an example of successful patient and community engagement in policymaking. The Centers for Disease Control and Prevention lists the mobilization of community partnerships as one of the 10 essential services for public health. Durham County utilizes a planning structure to enhance community engagement and partnerships. This structure includes invitations to community members to participate in the policymaking process, group conversations and meetings in various settings, group decision-making, and additional regular and ongoing contact through mailing lists and media contacts. The Health Department also manages several department/community collaborations, including the Partnership for a Healthy Durham, a coalition of Durham County community members, representatives of community organizations, and health department staff. They also run the Men's Health Advisory Group, a community group representing neighborhoods, community organizations, local government, and businesses. The strategy of engaging with the community in multiple ways facilitates the Department's ultimate goal of achieving shared decision-making with fully engaged community members.[16]

Partnership in Public Policy in Action at the County Level

In 2014, both Buncombe and Durham counties were nationally recognized by the Robert Wood Johnson Foundation with the Culture of Health Prize.[17] Both counties used extensive patient engagement in their community health assessment (CHA) process. Each county health department must complete a CHA at least every four years, as mandated by state statute, as well as being a required component of state accreditation.[b,c,18,] The health department must also compile a State of the County Health Report in each interim year. For the CHA, the counties collect health data including prevalence of chronic disease and injury, causes of death, health risk behaviors, access to care, access to exercise and healthy food, and citizen opinions on health issues.[19] This data is used to establish countywide public health priorities.

Durham County has broad community participation in the CHA process, including community listening sessions, with a total of nearly 300 community participants.[17] In fall 2014, the Durham County Health Department held several town hall meetings focused on the CHA health priorities. The meetings provided updates on the 2011 health priorities, and an opportunity for community members to provide feedback on upcoming proposed health department initiatives.

Buncombe County Health and Human Services convened the Public Health Advisory Council to bring together individuals, families, and local leaders to make Buncombe County a community where healthy choices are easy to make and are supported by the environment.[17] The leadership council includes an array of community stakeholders, including representatives of the YMCA of Western North Carolina, Asheville Area Chamber of Commerce, health care professionals, transportation experts, and representation from environmental organizations, among others. This broad-based group is assessing all aspects of life in the county in order to address the multitude of forces that impact health. The Council serves as a catalyst for providing leadership, support, and coordination to assist the community in achieving its health goals and spreading success into all areas of Western North Carolina. The Council has led and supported a number of initiatives, including the Innovative Approaches project, which is focused on bringing pediatricians, parents, and support agencies together to improve the quality of care for children with special health care needs.[17]

b G.S. 130A-34.1.

c The Affordable Care Act requires not-for-profit hospitals to complete community health assessments every three years. This is an opportunity for local health departments and not-for-profit hospitals to work together to complete their health assessments. Many communities have partnered to complete their community health assessments and meet the requirements of both health organizations.

Engaging Youth in Public Policy to Improve Community Health
Youth Empowered Solutions (YES!) uses the YES! Youth Empowerment Model to empower youth, in partnership with adults, to create community change.[20] The YES! model teaches youth skills to enable them to act as community advocates; helps youth obtain the information they need to analyze their communities' needs and become change agents; and provides opportunities for engagement in community change. Since 2008, YES! has empowered thousands of youth across North Carolina to advocate for healthier communities. YES! youth help faith communities create community gardens; garner funding and resources for school-based health centers; promote and support efforts for smoke-free ordinances across the state; lead efforts to increase access to healthy foods in all communities; and have created the North Carolina Youth Food Council.[20,21]

Including patient representatives in public decision-making can improve trust and confidence in the health system as a whole. In addition, inclusion of patient experiences in creating organizational and public policy may lead to higher quality and more effective decisions. Therefore, the Task Force recommends:

Recommendation 8.3: Ensure Patient and Family Representation on Boards with Broad Policymaking Power (PRIORITY RECOMMENDATION)

The following health care agencies and organizations should include, at a minimum, at least two trained patient and family representatives on their boards:

a) Local boards of health (or, if no board of health, County Commissioners should solicit trained patient input in county level health policies and priorities[d]);

b) Health professional and licensure boards;

c) Health insurance companies;

d) Mental health managed care organizations;

e) Administrative units and entities in state government that execute state health-related policies (including but not limited to Division of Medical Assistance, Division of Public Health, Division of Health Service Regulation, North Carolina State Health Coordinating Council, and the Department of Insurance).

Patient and family representatives should, inasmuch as possible, represent the diversity of communities served by their organizations.

d The Task Force recognized that local boards of health include community members. The focus of this recommendation is to include sufficiently prepared and trained patient and family representatives.

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Conclusion

Chapter 9

Patients who are actively involved in their health and health care tend to have better outcomes and care experiences and, in some cases, lower costs.[1-3] Implementing patient and family engagement strategies has led to fewer hospital-acquired infections, reduced medical errors, reduced serious safety events, and increased patient satisfaction scores.[3-5] Because of the potential for improved health outcomes and patient satisfaction, patient and family engagement has emerged as a critical strategy for improving the performance of our health care system. The American Institutes for Research defines patient and family engagement as "patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system to improve health and health care."[6]

Nationally and locally, many efforts are underway to increase patient and family engagement. In North Carolina, Community Care of North Carolina (CCNC), the Medicaid program's primary care case management contractor, and the North Carolina Quality Center (NCQC) have been at the forefront of patient and family engagement efforts. The North Carolina Institute of Medicine (NCIOM) received grant support from The Duke Endowment to convene a task force on patient and family engagement in order to build upon current efforts in North Carolina. The NCIOM Task Force on Patient and Family Engagement was created in collaboration with CCNC, the North Carolina Division of Public Health within the North Carolina Department of Health and Human Services, the NCQC within the North Carolina Hospital Association, the North Carolina Medical Society, and the Foundation for Nursing Excellence. The Task Force was charged with identifying and examining evidence-based, evidence-informed, and promising strategies for increasing patient and family engagement.

After reviewing best practices and evidence-based strategies for increasing patient and family engagement in direct care settings, hospitals, health systems, the community, and through policy, the Task Force developed and refined a set of 17 recommendations that will catalyze patient and family engagement and improve health and health care systems in North Carolina.

The Task Force developed and refined a set of recommendations that will catalyze patient and family engagement and improve health and health care systems in North Carolina.

Table 9.1 **Patient and Family Engagement Recommendations** RECOMMENDATION	Patients and Families	NCGA	AHEC	Medical Schools	NCHA	Health Care Systems	Health Care Organizations (e.g. Free Clinics, Community Health Centers)	Payers (Insurers)	Others
PATIENT AND FAMILY ENGAGEMENT									
Recommendation 3.1: Educate and Train Patients and Families about Partnering and Engaging (PRIORITY RECOMMENDATION) North Carolina Area Health Education Centers should lead a collaboration of state agencies, community organizations, faith-based organizations, and payers to identify and implement model curricula and tools for educating and training patients and family members about partnering and engaging with their health care providers.	✓		✓						Community and faith-based orgainzation, DMA, DPH, DMHDDSAS
Recommendation 3.2: Increase Availability of Peer Support Organizations that provide care management services should encourage health care systems and payers to recognize the critical aspect of peer support, build peer support into their systems, and facilitate linkages to existing peer support groups, online networks and resources, and condition-specific support groups.						✓		✓	CCNC, and organizations that provide care management
CLINICIAN AND LEADERSHIP PREPARATION									
Recommendation 4.1: Incorporate Patient and Family Engagement Techniques into Health Professional Training (PRIORITY RECOMMENDATION) Health education programs, both pre-service and in-service, should educate health care providers on how to provide patient- and family-centered care and how to engage patients and families in their care. Patients and families should be included in designing and implementing these trainings.			✓	✓					NCCCS, UNC System, private colleges and universities, CCNC and organizations that provide care management, NCMS, NCDS, NCNA, NCAPA, other professional organizations
Recommendation 4.2: Amend Health Professional Licensure and Certification Requirements to Include Patient and Family Engagement Skills as a Core Competency Health professional licensing boards and associations should consider incorporating concepts and skills									Health professional licensure boards and associations

RECOMMENDATION	Patients and Families	NCGA	AHEC	Medical Schools	NCHA	Health Care Systems	Health Care Organizations (e.g. Free Clinics, Community Health Centers)	Payers (Insurers)	Others
for patient- and family-centered care and patient and family engagement as a core competency that is included in initial licensure requirements, as well as maintenance of ongoing certification requirements.									
CARE AND SYSTEM REDESIGN									
Recommendation 5.1: Make Patient and Family Engagement a Goal of Health Care Systems The North Carolina Hospital Association and all health care systems in North Carolina should encourage and support patient and family engagement at all levels of health care systems by making patient and family engagement one of the goals of their organizations, implementing evidence-based strategies to enhance patient and family engagement, and assessing the impact of patient and family engagement strategies.					✓	✓			
Recommendation 5.2: Support Patient and Family Engagement through Health Care Organization Policies and Processes (PRIORITY RECOMMENDATION) The North Carolina Medical Society, the North Carolina Hospital Association, the North Carolina Community Health Center Association, and other partners should promote policies and processes that support and encourage patient and family engagement including welcoming and supporting patients and families and establishing policies and procedures that promote patient and family engagement in all aspects of their health care experience.					✓				NCMS, NCCHCA, and professional associations
Recommendation 5.3: Recognize Caregivers as Members of the Health Care Team Health care organizations should adopt policies that recognize the role of caregivers as members of the health care team including documenting family caregivers, acknowledging their role as part of the care team, and identifying caregiver support resources.						✓	✓		

Table 9.1 **Patient and Family Engagement Recommendations** RECOMMENDATION	Patients and Families	NCGA	AHEC	Medical Schools	NCHA	Health Care Systems	Health Care Organizations (e.g. Free Clinics, Community Health Centers)	Payers (Insurers)	Others
ORGANIZATIONAL PARTNERSHIP									
Recommendation 6.1: Include Patients and Families on Health Care Organization Boards and Committees Health care organizations should appoint a minimum of two patients (or family members) to boards and advisory committees within their organizations. To the extent possible and practical, patients (or family members) should represent the diversity of the community served by the health care system. Patients (or family members) should receive training and mentoring to help prepare them to be productive board and committee members.	✓					✓	✓		
Recommendation 6.2: Engage Patients and Families in the Governance and Operation of Health Care Organizations (PRIORITY RECOMMENDATION) Health care organizations should develop patient and family advisory councils (PFACs) to provide input into the governance and operation of health care at all levels. PFACs should represent the community that the agency or health care organization serves.	✓					✓	✓		
MEASUREMENT, RESEARCH, TRANSPARENCY, AND ACCOUNTABILITY									
Recommendation 7.1: Measure the Impact of Patient and Family Engagement The North Carolina Hospital Association, in partnership with the North Carolina Medical Society and organizations that provide care management services, should work with patients and families to develop patient and family engagement measures, and collect and disseminate data, in hospitals and ambulatory settings across the state.	✓				✓				CCNC, and organizations that provide care management, NCMS

RECOMMENDATION	Patients and Families	NCGA	AHEC	Medical Schools	NCHA	Health Care Systems	Health Care Organizations (e.g. Free Clinics, Community Health Centers)	Payers (Insurers)	Others
Recommendation 7.2: Encourage Health Care System Transparency (PRIORITY RECOMMENDATION) All health care systems and providers should ensure information on services, cost, and quality is easily accessible to consumers in print and electronic formats.						✓	✓		
Recommendation 7.3: Encourage Health Care Payer Transparency Payers should provide, on their websites and in their written materials, information that is easily understood by consumers on covered providers and common procedures, including data on costs, quality, safety, and patient experiences.								✓	
Recommendation 7.4: Provide Health Care Cost Information to the Public The North Carolina General Assembly should collaborate with the North Carolina Department of Insurance, health care systems, and insurers to create a statewide, mandatory data reporting system to enhance pricing transparency for medical care and health care services. This collaborative effort should include input from additional stakeholders on database use and access. Participating stakeholders should include employers, health care providers, academic and industry researchers, and patient and family advocacy groups.	✓	✓				✓		✓	NCDOI
Recommendation 7.5: Increase Collaborative Documentation Health care organizations should examine opportunities to increase collaborative documentation aimed at increasing patient and family engagement. The North Carolina Quality Center and the North Carolina Hospital Association should continue to provide consultative support to health care organizations implementing collaborative documentation.					✓		✓		NCQC

Table 9.1 **Patient and Family Engagement Recommendations** RECOMMENDATION	Patients and Families	NCGA	AHEC	Medical Schools	NCHA	Health Care Systems	Health Care Organizations (e.g. Free Clinics, Community Health Centers)	Payers (Insurers)	Others
LEGISLATION, REGULATION, AND PARTNERSHIP IN PUBLIC POLICY									
Recommendation 8.1: Advance Patient and Family Engagement through Payer Policies (PRIORITY RECOMMENDATION) Payers (insurers) should consider changes to health plans and policies that support patient and family engagement. Those changes may include creating new payment options, developing member advisory committees, and providing more accessible information to consumers.								✓	
Recommendation 8.2: Implement Comprehensive Worksite Wellness Programs that Include Patient and Family Engagement Support (PRIORITY RECOMMENDATION) Health care organizations should, with employee input, develop and implement comprehensive worksite wellness programs that include employee engagement strategies. They should encourage other community employers to as well.	✓						✓		Employers, Local Health Departments
Recommendation 8.3: Ensure Patient and Family Representation on Boards with Broad Policy Making Power (PRIORITY RECOMMENDATION) Local boards of health, health professional and licensure boards, health insurance companies, mental health managed care organizations, and administrative units and entities in state government that execute state health-related policies should include, at a minimum, at least two trained patient and family representatives on their boards.							✓	✓	Local boards of health, health professional and licensure boards, MCOs, DHHS

Glossary

AHEC:	Area Health Education Centers
CCNC:	Community Care of North Carolina
DMA:	Division of Medical Assistance, North Carolina Department of Health and Human Services
DMHDDSAS:	Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, North Carolina Department of Health and Human Services
DPH:	Division of Public Health, North Carolina Department of Health and Human Services
DHHS:	North Carolina Department of Health and Human Services
NCAPA:	North Carolina Academy of Physician Assistants
NCCCS:	North Carolina Community College System
NCCHCA:	North Carolina Community Health Center Association
NCDS:	North Carolina Dental Society
NCDOI:	North Carolina Department of Insurance
NCGA:	North Carolina General Assembly
NCHA:	North Carolina Hospital Association
NCMS:	North Carolina Medical Society
NCNA:	North Carolina Nurses Association
NCQC:	North Carolina Quality Center
MCO:	Managed Care Organizations

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Overview of Patient and Family Preparation

Recommendation 3.1: Educate and Train Patients and Families about Partnering and Engaging (PRIORITY RECOMMENDATION)

North Carolina Area Health Education Centers should lead a collaboration of state agencies, community and faith-based organizations, and payers to identify and implement model curricula and tools for educating and training patients and family members about partnering and engaging with their health care providers.

a) Trainings should be delivered in a variety of settings to various stakeholder groups including, but not limited to, peer support networks, lay health advisors, advocacy groups, caregivers, community and faith-based organizations, school nurses, social workers, agencies serving the older population, and youth councils or youth-focused health groups.

b) Trainings should include information on navigating and overcoming challenges in the health care system, working with health care providers, patient and family-centered care, serving on patient and family advisory councils, shared decision-making tools, peer support, improving health literacy, health insurance literacy, and advocating for one's own health.

c) Community and faith-based organizations should tailor and adapt trainings and their content to their community's priorities, including those of local patients and families.

d) Organizations should consider regular evaluation of trainings to assess knowledge, attitude, and behavior change.

Recommendation 3.2: Increase Availability of Peer Support

Organizations that provide care management services should encourage health care systems and payers to recognize the critical aspect of peer support, build peer support into their systems, and facilitate linkages to existing peer support groups, online networks and resources, and condition-specific support groups.

Clinician and Leadership Preparation

Recommendation 4.1: Incorporate Patient and Family Engagement Techniques into Health Professional Training (PRIORITY RECOMMENDATION)

a) **The North Carolina Community College System, the University of North Carolina system, and private colleges and universities that prepare members of the health care team should train students to provide patient- and family-centered care. Training should include evidence-based patient and families engagement strategies including motivational interviewing, the Patient Activation Measure (or other tools to gauge readiness to engage), peer support, shared decision-making tools, and health literacy strategies. Education should also include strategies for incorporating caregivers as members of the health care team.**

b) **North Carolina Area Health Education Centers programs, organizations that provide care management services, and associations including, but not limited to, the North Carolina Medical Society, North Carolina Dental Society, North Carolina Nurses Association, North Carolina Academy of Physician Assistants, and the Council for Allied Health in North Carolina should offer continuing education on evidence-based patient and family engagement strategies including motivational interviewing, the Patient Activation Measure (or other tools to gauge readiness to engage), peer support, shared decision-making tools, and health literacy strategies. Education should also include strategies for incorporating caregivers as members of the health care team.**

    1) **Training should be offered in multiple settings, with opportunities for more intensive trainings for those who will become champions of patient and family engagement methods and help other staff in the practice to learn engagement skills and techniques.**

    2) **Patients and families should be included in planning and implementing these trainings.**

Recommendation 4.2: Amend Health Professional Licensure and Certification Requirements to Include Patient and Family Engagement Skills as a Core Competency

Health professional licensing boards and associations should consider incorporating concepts and skills for patient- and family-centered care and patient and family engagement as a core competency that is included in initial licensure requirements, as well as maintenance of ongoing certification requirements.

Care and System Redesign

Recommendation 5.1: Make Patient and Family Engagement a Goal of Health Care Systems

The North Carolina Hospital Association and all health care systems in North Carolina should encourage and support patient and family engagement at all levels of their systems by:

a) Incorporating patient and family engagement as a leading goal of their organizations.

b) Implementing evidence-based strategies with fidelity, to enhance patient and family engagement at multiple levels within the organization.

c) Assessing how patient and family engagement strategies impact patient experience and outcomes, costs, and staff morale, using both qualitative and quantitative evidence.

d) Convening a stakeholder forum to share best practices among health systems.

e) Identifying a leader for patient and family engagement within their organization who can serve as a point of contact and a resource for patients, families, and the community.

Recommendation 5.2: Support Patient and Family Engagement through Health Care Organization Policies and Processes (PRIORITY RECOMMENDATION)

The North Carolina Medical Society, the North Carolina Hospital Association, the North Carolina Community Health Center Association, and other partners should promote policies and processes that support and encourage patient and family engagement including:

a) Welcoming and supporting patients and families as partners in care through communication and messaging. Patients and families should be involved in the design and implementation of patient engagement communications planning.

b) Examining and revising policies and procedures to promote patient and family engagement throughout the health care experience. Such policies and procedures may include those impacting access, coordination of care across multiple sites, organizational transitions, bedside rounding, family presence and visitation policies, shared decision making, care coordination, care transitions, and end of life planning.

c) The health care team should develop care plans based on patient and family goals, with patient and family input.

d) Fostering a work culture that supports increased empathy and improved listening and communication skills on the part health care providers.

Recommendation 5.3: Recognize Caregivers as Members of the Health Care Team

Health care organizations should adopt policies that recognize the role of caregivers as members of the health care team including:

a) The health care team should document the primary (family) caregiver, when applicable, in the medical record and ensure that designated family caregivers have access to the medical record in accordance with applicable (HIPPA) law.

b) The health care team should recognize the role of the caregiver and include them as a member of the health care team.

c) **The health care team should treat patients with multiple chronic conditions and their family caregivers as a unit.**

d) **The health care team should encourage caregiver self-care, and provide assistance with identifying support resources and respite care.**

Organizational Partnership

Recommendation 6.1: Include Patients and Families on Health Care Organization Boards and Committees

Health care organizations should appoint a minimum of two patients (or family members) to boards and advisory committees within their organizations. To the extent possible and practical, patients (or family members) should represent the diversity of the community served by the health care system. Patients (or family members) should receive training and mentoring to help prepare them to be productive board and committee members.

See also Recommendation 8.3.

Recommendation 6.2: Engage Patients and Families in the Governance and Operation of Health Care Organizations (PRIORITY RECOMMENDATION)

a) **Health care organizations including, but not limited to, accountable care organizations, health systems, provider regional networks, and payers, should develop patient and family advisory councils (PFACS) to provide input into the governance and operation of health care at all levels. PFACs should represent the community that the agency or health care organization serves.**

b) **North Carolina Area Health Education Centers, in partnership with the North Carolina Hospital Association, should convene a statewide group of patients and families to help coordinate advocacy, capacity building, inventory, and support other PFACs.**

Measurement, Research, Transparency, and Accountability

Recommendation 7.1: Measure the Impact of Patient and Family Engagement

The North Carolina Hospital Association, in partnership with the North Carolina Medical Society and organizations that provide care management services, should work with patients and families to develop, collect, and disseminate patient and family engagement measures in hospitals and ambulatory settings across the state.

Recommendation 7.2: Encourage Health Care System Transparency (PRIORITY RECOMMENDATION)

All health care systems and providers should ensure information on services, cost, and quality is easily accessible to consumers in print and electronic formats.

Recommendation 7.3: Encourage Health Care Payer Transparency

Payers should provide on their websites and in their written materials information that is easily understood by consumers on covered providers and common procedures, including data on costs, quality, safety, and patient experiences.

Recommendation 7.4: Provide Health Care Cost Information to the Public

The North Carolina General Assembly should collaborate with the Department of Insurance, health care systems, and insurers to create a statewide, mandatory data reporting system to enhance pricing transparency for medical care and health care services. This collaborative effort should include input from additional stakeholders on database use and access, and participating stakeholders should include employers, health care providers, academic and industry researchers, and patient and family advocacy groups.

Recommendation 7.5: Increase Collaborative Documentation

a) Health care organizations should examine opportunities to increase collaborative documentation aimed at increasing patient and family engagement including, but not limited to, patient portals, open charting, open notes, and other models.

b) The North Carolina Quality Center and the North Carolina Hospital Association should continue to provide consultative support to health care organizations implementing collaborative documentation.

Legislation, Regulation, and Partnership in Public Policy

Recommendation 8.1: Advance Patient and Family Engagement through Payer Policies (PRIORITY RECOMMENDATION)

Payers should consider changes to health plans and policies that support patient and family engagement. Those changes may include, but are not limited to:

a) Offering payment options such as:

   1) Factoring patient experiences of care, such as results of patient satisfaction surveys, into provider reimbursement rates.

   2) Providing incentives to promote the use of evidence-based practices that engage patients and families in their own care (e.g. the Patient Activation Model, motivational interviewing, and decision support tools).

   3) Providing reimbursement for certified peer support services.

   4) Providing options for caregiver coverage in employer-based health plans/place caregiver reimbursement on menu of options available to payer.

   5) Utilizing value-based insurance design.

b) Developing member advisory committees.

c) Using plain language in education and information about health insurance plans.

Recommendation 8.2: Implement Comprehensive Worksite Wellness Programs that Include Patient and Family Engagement Support (PRIORITY RECOMMENDATION)

a) Health care organizations should, with employee input, develop and implement comprehensive worksite wellness programs that include employee engagement strategies.

b) Health care organizations, in partnership with local health departments and local chambers of commerce, should invite and encourage other community employers, businesses, and government leaders to develop and implement, with employee input, comprehensive worksite wellness programs that include employee engagement strategies.

Recommendation 8.3: Ensure Patient and Family Representation on Boards with Broad Policymaking Power (PRIORITY RECOMMENDATION)

The following health care agencies and organizations should include, at a minimum, at least two trained patient and family representatives on their boards:

a) Local boards of health (or, if no board of health, County Commissioners should solicit trained patient input in county level health policies and priorities[a]);

b) Health professional and licensure boards;

c) Health insurance companies;

d) Mental health managed care organizations;

e) Administrative units and entities in state government that execute state health-related policies (including but not limited to Division of Medical Assistance, Division of Public Health, Division of Health Service Regulation, North Carolina State Health Coordinating Council, and the Department of Insurance).

a The Task Force recognized that local boards of health include community members. The focus of this recommendation is to include sufficiently prepared and trained patient and family representatives.

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