

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.



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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 organization, 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									
<p>Recommendation 5.1: Make Patient and Family Engagement a Goal of Health Care Systems</p> <p>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.</p>					✓	✓			
<p>Recommendation 5.2: Support Patient and Family Engagement through Health Care Organization Policies and Processes (PRIORITY RECOMMENDATION)</p> <p>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.</p>				✓					NCMS, NCCHCA, and professional associations
<p>Recommendation 5.3: Recognize Caregivers as Members of the Health Care Team</p> <p>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.</p>						✓	✓		

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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

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<p>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.</p>						✓	✓		
<p>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.</p>								✓	
<p>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.</p>	✓	✓				✓		✓	NCDOI
<p>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.</p>				✓			✓		NCQC

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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

References

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