

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.

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



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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 (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

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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.

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.**

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.

- 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.**

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

Partnership in Public Policy

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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