Engaging Older Consumers in Health Care Design and Delivery
Introduction

This paper grows out of a summit we held on February 9, 2012 in Washington, DC that brought together leaders in the health and aging professions who are graduates of our two foundation-supported programs -- the Health and Aging Policy Fellows and the Practice Change Fellows. We convened the meeting as part of our ongoing effort to explore the synergies between the two programs and to consider their future in light of the growing momentum for change in the way health care is delivered to vulnerable older adults.

Summit participants were selected for their demonstrated leadership in two specific models of reformed health care delivery for this vulnerable population – the medical home, and transitional care. They were joined by representatives of two leading advocacy organizations that are engaging consumers in health system reform, officials from the Center for Medicare and Medicaid Innovation at the Centers for Medicare and Medicaid Services who are implementing delivery innovations authorized by the Affordable Care Act, and project officers from foundations that support the leadership programs – The Atlantic Philanthropies and the John A. Hartford Foundation, as well as The SCAN Foundation.¹

The purpose of this summit was not to discuss delivery models per se, but rather to use participants’ experience in designing, implementing and promoting these models as a lens through which to consider the issue of consumer engagement in the design and delivery of health care – what it is, why it matters, the barriers that stand in its way, and practical and policy actions to overcome those barriers. From the rich discussion that took place, we have developed this paper with two audiences in mind:

- Leaders in the health and aging provider and consumer advocacy communities who are working to improve care for vulnerable older adults, and
- Foundations interested in supporting their efforts.

¹ See Appendix for description of the leadership programs and list of meeting participants.
Consumer Engagement – What It Is

The Centers for Medicare and Medicaid Services – the primary insurer of health care for frail and vulnerable older adults – has articulated a triple aim: better care for individuals, better health for populations, and lower cost. At the core of this triple aim lies the concept of patient-centered care -- care defined by the Institute of Medicine as “respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.” That can only be achieved with the full and active engagement of consumers in the design and delivery of care. Such engagement must occur at three levels:

1. The individual patient/provider relationship, where patients and their families define their life goals and preferences, share decisions with their provider about care based on those goals and preferences, and are activated to maximize their ability to manage their care.

2. The health care organization, where consumers are brought into the decision-making process in an organized fashion at every step in the design, delivery, and evaluation of care – moving beyond individual experiences to find common meaning and to search for solutions tailored to the needs of a wider community.

3. The policy level, where knowledgeable consumers and consumer groups participate in sufficient numbers to shape policy that aligns financial incentives and defines conditions of participation and accountability measures so as to advance person-centered care for vulnerable populations.

Who are we talking about? If the ultimate goal of health care is to meet the goals, needs and preferences of vulnerable populations, then individual patients and their families must be engaged in their own care. But that is not sufficient. We define the consumer broadly to include advocates for vulnerable older adults and their caregivers, as well as baby boomers and older adults who may not have serious medical conditions yet but have a stake in defining the care they will ultimately need.

Consumer Engagement – Why It Matters

Our meeting took place at a time of unprecedented momentum for health care payment and delivery reform – momentum driven by a number of factors:

- Mounting evidence that inappropriate and disjointed care for vulnerable older adults is causing medical errors, unnecessary and duplicative procedures, and avoidable hospitalization and nursing home placement – with poor outcomes for patients and unsustainable increases in health care costs;
- Growing recognition among consumer advocates of the importance of their engagement in payment and delivery issues, as well as health care access and affordability;

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Increased interest among health care organizations in new models of care that have been tested by leaders in the field and shown to improve outcomes and lower costs for this population;

Innovations put in place by the Affordable Care Act to promote these new models of care, penalize ineffective and inefficient care, and provide financial incentives for coordinated care;

Inevitable pressures for entitlement reform to control the growth of Medicare and Medicaid, which presents enormous risks for the most vulnerable older persons but also real opportunities for reform that results in better care at less cost.

Summit participants are convinced by their own experience and that of other health care innovators that consumer engagement is essential to assure that this momentum does in fact lead to better person-centered care for vulnerable older populations. They cited examples of the transformative impact of consumer engagement:

- At the individual patient/provider level, where initiatives like the Care Transitions Intervention\(^3\) and the Chronic Disease Self-Management Program\(^4\) that directly engage older persons and their families in their care have produced sustained reduction in emergency room visits, hospitalizations and readmissions, and outpatient visits, with positive outcomes and improved quality of life for patients and their family caregivers.

- At the organizational level, where providers have employed consumer engagement as a central strategy, included them on councils and quality and safety teams, and involved them in employee training and facility design, with a positive impact for both patients and providers as evidenced by shorter length of stays, reduced hospital readmissions, decreased staff vacancy rates, and lower malpractice expenses.\(^5\)\(^6\)

- At the policy level, where an organized coalition of over 130 consumer advocacy organizations has been instrumental in incorporating its principles for patient-centered care in the Affordable Care Act, along with requirements for consumer engagement in the design and implementation of new models of person-centered care for vulnerable older adults and in the performance measures for which those models will be held accountable.\(^7\)

While our summit participants see and understand the value of consumer engagement and are promoting it within their own circles of influence, they were quick to note that the concept has not been widely embraced by providers, health care organizations, patients, or the public. Evidence of its impact tends to circulate only within the community of providers and consumer advocates who are already persuaded. It has not been gathered, documented and disseminated in a way that persuades either providers or older persons not already engaged.

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\(^3\) [http://www.caretransitions.org/](http://www.caretransitions.org/)


\(^7\) [http://www.nationalpartnership.org/site/PageNavigator/cbc_index](http://www.nationalpartnership.org/site/PageNavigator/cbc_index)
Barriers to Consumer Engagement

The meeting identified three sets of barriers to effective consumer engagement – attitudes of providers, patients, and the public; the way in which the system is organized and financed; and the politics and power that drive the discussion of health care.

**Attitudinal Barriers**

Deep-seated attitudes get in the way of true patient-centered care and consumer engagement. Providers have been conditioned to a mind set of “what we do for patients” rather than “what we do with them.” Training and competencies are geared toward a clinical “fix” of the presenting problem or a specific body part, not to the health and well being of the patient as a whole. Providers and health care administrators see consumer advocates as ill-informed adversaries rather than constructive partners and equal stakeholders. They do not see a business case for consumer engagement, nor do they understand how to engage consumers effectively.

 Patients commonly defer passively to providers. They lack the information on potential burdens, risks, and benefits of treatments that they need to make informed decisions, often over or underestimating the value of what can be done. The complexity of the system leaves them frustrated but feeling helpless – too ready to accept that “it’s just the way it is.” It is particularly difficult to engage the most vulnerable older adults (the target population) given their life circumstances – such as the loss of control that comes with multiple chronic conditions that cannot be cured, pressing non-medical needs that influence their health (e.g. lack of heat, transport and meals, social isolation, family dynamics, low income), and cognitive limits on their ability to participate in meaningful informed decisions.

 The public does not understand how broken the system is until they have actually experienced it. No one wants to be sick or frail. It is hard to engage people around something they do not want to be a part of, and that is exacerbated by more general fears and negative attitudes about aging. Reform is discussed in terms like “bundled payments,” or “accountable care” that do not resonate with people, making it all too easy for political opponents of reform to manipulate opinion through scare tactics like “rationing” and “death panels.”

**Health Financing and Delivery Barriers**

Providers see their patients in separate settings and silos of care without the infrastructure to share information and coordinate care according to a clear plan built around the patient’s goals and preferences. They are reimbursed for specific services and procedures – the more, the better in terms of payment – rather than for the time they need to spend with a vulnerable older person or the quality and outcome of the care they provide.

Provider performance is measured on condition- or disease-specific outcome measures that do not work for complex patients with multiple chronic conditions and functional limitations and may have little to do with their goals and preferences. There is no accountability for consumer engagement at either the individual patient or the organizational level.
While some shared decision-making tools are beginning to emerge, they are organized around treatment for a specific diagnosis. They are not designed to elicit patient goals and preferences in a way that would facilitate real informed decisions and enable assessment of whether those goals are being reached.

**Politics and Power Barriers**

Powerful well-financed stakeholder interests and industry lobbyists dominate the decision-making process at every level -- in legislatures and state and federal agencies, in the quality measure development process, and among providers and health care organizations. Consumers have not been at the right tables as equal, informed and empowered partners. Where patient advisory groups do exist, they are usually separate from decision-making bodies. So-called patients or patient representatives selected by providers to sit on such bodies are not necessarily representative of or connected to the broader community, nor sufficiently informed and supported to participate effectively as equal stakeholders.

Organized engaged groups of older adults that are focused on the needs of frail and vulnerable older persons are few and far between. Consumers are more likely to be organized around particular diseases and disabilities than around common overriding goals. Some patient advocacy groups are organized as fronts for industry rather than a true patient voice. Senior groups focus increasingly on younger seniors around issues like healthy aging, wellness, and financial security.

The artificial separation of health care, public health, and community-based aging services leaves providers operating in functional and too often oppositional silos, protecting their own place in the system rather than working together to figure out how to better serve the frail and vulnerable older adults for whom they share responsibility for care and support.
Action Steps

Participants recognize that fundamental change in the health care system will take time, but have confidence from their own experience that much can happen in the short term, especially given the levers created by the Affordable Care Act and by fiscal pressures to control costs. Change in payment and delivery is already happening and will inevitably accelerate. For this discussion, the central question is whether consumers will be engaged effectively in influencing that change in a way that results in better patient-centered care for vulnerable older adults and better health for an aging population. Evidence indicates that if we succeed in reaching these first two elements of the triple aim, we will achieve the third as well.

While leaders around the table at our summit can and do have much to say about how health care financing and delivery should be reformed to reach that triple aim, we limit our consideration of action steps here to those that health and aging practice and advocacy leaders can take to promote consumer engagement. The first set of action steps is designed to build and sustain momentum for consumer engagement. From that, we suggest a second set of action steps to institutionalize consumer engagement within the health care system.

Build and Maintain Momentum around Real Consumer Engagement

1. **Focus leadership programs** like the Practice Change Fellows and Health and Aging Policy Fellows on identifying and supporting those leaders within our communities who can function as true “boundary spanners” – breaking down the barriers to consumer engagement and true patient-centered care that exist within provider organizations, among practitioners caring for vulnerable older adults, and between providers and consumers. Consider expanding the existing leadership programs to include consumers, or create a parallel program to build and support a network of consumer leaders.

2. **Tell the story.** Document successful consumer engagement efforts and their impact for patients, providers, and costs and then identify what makes them work. From that evidence, develop a business case for health care providers and administrators. Implement a communications strategy that disseminates the story to multiple audiences – providers and provider organizations, patients and older adults, policy makers and the broader public. Create an expanding network that engages leadership program participants and graduates in that strategy.

3. Develop and disseminate tools and training that teach consumers, individual providers, and health care managers how to successfully engage consumers in the design, delivery, and evaluation of health care to vulnerable older adults.

4. Promote a culture change movement for consumer engagement within the provider community through the forums and sources providers and health care organizations look to for ideas, strategies, and recognition (e.g. provider trade associations, certification entities, centers of excellence.)
Institutionalize Consumer Engagement within the Health Care System

1. At the individual patient/provider level
   - Provide information for patients and families to help them understand what is acceptable and appropriate – so they know what to ask for, understand the range of feasible options, and can make informed decisions that further their goals and preferences.
   - Document patient goals and preferences -- in their own words -- in a medical record that follows the patient across providers and settings of care
   - Utilize the Patient Activation Measure to identify a patient’s level of engagement and to target intensive efforts on those least ready to engage. Develop the self-management skills of the patient and the family caregiver.
   - Engage the patient and family in case reviews, care team meetings, and hospital rounds at the bedside.

2. At the health care organization level
   - Recruit and support patients, families and true consumer representatives on decision-making bodies. Integrate consumer/family advisory bodies into organizational meetings, health systems and health plans, where decisions get made. Engage community leaders who are connected to real patients and vulnerable older persons.
   - Utilize patient experience of care measures, not just to provide essential feedback on operations but also to identify patients and families to engage in organizational efforts to improve care. Establish mechanisms to take individual complaints and develop organizational responses, involving patients with bad outcomes to address system change.
   - Develop partnerships with community providers that deliver non-medical services to vulnerable older persons.

3. At the national and state policy level, bring to the decision-making tables of policy makers consumer advocates who connect to vulnerable older adults and understand their experiences, needs, and preferences – in sufficient numbers and with the skill and training needed to balance powerful special interests and industry groups.

4. Develop and adopt performance measures on consumer engagement and hold providers accountable for them. This includes two types of measures: direct measures of patient engagement in their own care, and specific measures for consumer engagement at the organizational level.
Concluding Remarks

The health care system in the United States is at a critical juncture – providers, payers, employers, and policy makers are searching for ways to control the unsustainable projected increases in health care spending at a time when the number of vulnerable older adults with complex care needs continues to grow. Cost is only part of the equation, however – an equation that must also include better care for individuals and better health for populations. None of that will be achieved, however, unless the patient is at the center of any consideration of payment and delivery reform, and that will only occur if consumers are fully engaged in that consideration at every level where it occurs. Leaders in health and aging provider organizations, in consumer advocacy and in philanthropy have recognized responsibilities to improve care for vulnerable older adults and foster meaningful consumer engagement. Barriers can be overcome by moving forward on concrete actions that leverage the capacity and commitment of various stakeholders working together toward a common goal.
Descriptions of the Two Leadership Programs

The Practice Change Fellows Program (www.practicechangefellows.org)

The Practice Change Fellows program is a two-year opportunity for nurses, physicians, and social workers to develop leadership skills and content expertise in order to positively influence care for older adults. Fellows complete a project aimed at implementing a new geriatric program or service line integrated within their organization, allowing them to remain at their full time job throughout the two-year program.

The Practice Change Fellows program is designed to expand the number of health care leaders who can effectively promote high quality care to older adults in a wide range of health and health care organizations. Building a cadre of health care professionals who possess the essential leadership skills and understanding of promising innovations in care for older adults will ensure that this country will be prepared to meet the challenges of an expanding aged population.

The Health and Aging Policy Fellows Program (www.healthandagingpolicy.org)

The Health and Aging Policy Fellows Program is a unique opportunity for professionals in health and aging to receive the experience and skills necessary to make a positive contribution to the development and implementation of health policies that affect older Americans.

This Program, which is 9-12 months in length, offers fellows the opportunity to participate in a residential track or a non-residential track. The residential track allows fellows to participate in the policymaking process on either the Federal or state level as legislative assistants in Congress, professional staff members in executive agencies or policy organizations. The non-residential track allows fellows to work on a policy project and brief placement(s) throughout the year at relevant sites. Core program components focused on career development and professional enrichment are provided for fellows in both tracks. Fellows also have the opportunity to apply for second-year funding to continue components of their fellowship experience/project either at their placement sites, at the state/local levels, or with non-governmental organizations.

Acknowledgement

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