

Consumer Engagement Taskforce Final Report

Background

In January 2014, the Health Services Cost Review Commission (HSCRC) implemented a new hospital reimbursement system that promises to slow spending at rates lower than the national average by incentivizing institutions to implement models of care that simultaneously promote health, improve patient experience, and contain costs. Maryland's New All-Payer Model (NAPM) has adopted the prevailing theme in healthcare--the Triple Aim—to fulfill the terms of this new “waiver”. To achieve the Triple Aim goals of improving health outcomes, enhancing quality, and reducing costs, Maryland's hospitals have been charged with identifying efficiencies in internal practices, and forging non-traditional partnerships to implement prevention and population health interventions.

As the regulating body for the state's hospital industry, the HSCRC believes that collaboration among healthcare providers and active engagement of the consumer community are critical to identifying impactful, sustainable approaches to fulfilling the aspirations of the NAPM. The HSCRC's position is consistent with a growing trend in the movement to modernize health care, which prioritizes engaging consumers in planning, implementation, and evaluation of health services to assure that they are reflective of the needs and desires of the community and supportive of consumers' ability to be involved and influential in their own care.

The NAPM joins the field of local and national initiatives that endeavor to contribute to reforming the nation's health care system. The emerging system is characterized by innovative models of care and technology that are person-oriented, coordinated, collaborative, and integrated. The Maryland Health Benefits Exchange is one such example of technology enabling consumers to be more self-directed in their pursuit of health services. In this case, technology and information have combined to allow the public to select a health insurance plan based on their own needs.

A robust, integrated, statewide information technology system is critical to support transformation efforts, particularly as it relates to consumers' access to their health information. Health information systems that optimize the manner in which health information is stored, shared, analyzed, and communicated across providers and communities facilitate the efficiency and integration that must be the hallmark of a truly modernized system. In Maryland, CRISP offers promise of an eventual IT infrastructure where institutions can track patients across systems and communities.

Nationally, the patient-centered medical home (PCMH) has become a prominent example of person-centered approaches. This model of care, which places the patient in the center of a team-based, multi-disciplinary approach, combines the triple aim and consumer engagement principles. PMCH research has been informative to consumer engagement efforts, particularly as they relate to the potential to positively impact health outcomes, quality, and costs.

The HSCRC Consumer Engagement Taskforce

In January 2015, the HSCRC convened a Consumer Engagement Workgroup to provide the Commission guidance and recommendations to ensure that health care consumers have access to the necessary information, tools, and mechanisms to play a critical role in discussions and decision-making related to advancing the goals of the NAPM.

To achieve this multi-faceted deliverable, the Workgroup was divided into two taskforces: the Consumer Engagement Taskforce and the Consumer Outreach Taskforce. The rationale was that these groups would perform distinct yet complementary activities to gather the information and insight needed to provide reports to the Commission that, together, would provide a complete picture and clear guidance for creating a consumer engagement strategy.

The Consumer Engagement Taskforce was comprised of representatives from consumer advocacy groups, professional associations, local public health, community-based organizations, and health service providers. A complete listing of the members is provided in Appendix X. The Commission issued two charges for the Consumer Engagement Taskforce:

- Charge #1** Provide a rationale for health literacy and consumer engagement, with core principles and, from that, define the audiences, identify the messages, and based upon that, propose education and communication strategies as appropriate. This work should reflect the outcomes from both the Communications & Community Outreach taskforce and other workgroups, principally Care Coordination.
- Charge #2** Address avenues/strategies to provide consumers with ways to: (i) engage with decision makers, regulators, etc. on the impact on individual and/or community health issues of the design and implementation of the reform initiatives and principally the NAPM; and (ii) ensure an appropriate and consumer-friendly communications process for those directly impacted by the NAPM's goals.

Engaging Consumers: An Emerging Consideration

Consumer Engagement is an evolving concept in US health care. The limited, yet growing, body of work on this topic falls short of arriving at a standard definition for “consumer” or offering a common distinction between “patient” and “consumer”. For the purposes of this report, “patient” will be defined as a person who directly is interacting with health care providers and services about personal health concerns, while “consumers” will be defined as people who use, or are potential users, of health services.¹ Consumers may be those who make decisions about accessing health care for themselves or loved ones, including choosing among health plans, services, and health care providers.

While the term “consumer engagement” began appearing in the literature a little more than a decade ago, only recently has the concept consistently been included in discussions about transforming the health care system. Meanwhile, Australia has emerged as a global leader in consumer engagement in

¹ Health Consumers Queensland. *Consumer and Community Engagement Framework*

health care, availing evidence-based guidance to efforts seeking to implement a more person-centered, integrated approach to modernizing health care.

In its 2012 report, *Consumer and Community Engagement Framework*, Health Consumers Queensland discusses the value of engaging consumers in designing health care systems and offers specific ways consumers can be included in this effort. The report asserts that:

“Effective engagement is embedded in an organisation’s [sic] culture and practice. It informs health service organisations about the needs of the people who use their services and people who may be potential users of services who may, for different reasons, experience barriers to access. It is a mechanism that can enable health service organisations to better plan, design and deliver services that meet the needs of the people who use them, to gather feedback about initiatives and reforms that will impact upon service delivery and to monitor the quality and safety of providers to deliver improved services for consumers, their families and carers [sic].”

Generally, there are two schools of thought in the consumer engagement arena. One focuses on activities aimed at influencing behavior change in individuals to increase their level of “activation” in managing their health and health care. Given the context in which this exploration was solicited, the Taskforce chose the second framework, which focuses on identifying structural and procedural enhancements that can create an environment where consumers have ready access information, support, and resources that enable them to be actively involved in their own health and health care.

Categories of Consumer Engagement

In this emerging field, three categories of engagement routinely are considered as ways to meaningfully engage consumers in optimizing and reforming health care. They include:

- **Information and Education** – This refers to creating and making accessible to consumers information that they understand and upon which they can act to make informed health care decisions for themselves or an individual for whom they are caring.
- **Advisory** – This type of engagement entails enlisting consumers in an advisory capacity to provide input on programs and services. In this role, consumers may influence decision-making.
- **Feedback Process** – This category of engagement formally secures feedback from consumers about experiences as a patient or caregiver. This solicited or unsolicited information can be used to refine or create programs and services.

Benefits of Consumer Engagement

There is an emerging consensus in the health policy community that informed and engaged consumers have a vital role in improving the quality of care that the US health system delivers to patients. The expectation is that when consumers are armed with the right information, they will demand high-quality services from their providers, choose treatment options wisely, and become active participants and self-managers of their own health and health care.²

There is a paucity of research that quantifies the impact of consumer engagement. However, as the field continues to expand, the Taskforce anticipates more research results similar to a 2012 study of Medicaid beneficiaries that found that patients who lack the skills to manage their health care incur

² Academy Health Care. Improving Quality Health Care: The Role of Consumer Engagement

costs 8% to 12% higher than those who are highly-engaged in their care, even after adjusting for health status and other factors.³ These findings are corroborated by enumerable anecdotal reports on the benefits individuals and the health care system realize as a result of consumer involvement.

Benefits to Consumers and the Community

Engaging consumers in health care design and decision-making can produce substantial, enduring benefits for the individual, community, and the health care system. Individuals who have the resources and mechanisms to be engaged may experience:

- Improved understanding about their health condition and how to access the appropriate services to manage their health
- Improved relationships with health care providers
- Improved quality of health care
- A more responsive, better informed, efficient health care system
- Personal sense of value, ownership, and influence in health care decision-making

Benefits to Health Care Providers and Institutions

Because person-centered systems must be created and, presumably, funded by institutions, it is imperative that they appreciate the potential benefit to their operation and commit to consumer engagement processes. Institutions that meaningfully engage the consumer can experience:

- Greater confidence that their programming meets the needs of consumers and the community, particularly those with unique needs
- Improved relationships with the individuals and communities they serve
- A better structure to accept and apply information and insight gained from the community
- More efficient use of health services by informed, empowered consumers

Taskforce Methodology

During preliminary planning of the approach to fulfill its responsibility to the Commission, the Taskforce learned that the recent growing interest in engaging the consumer has outpaced the body of literature that can be referenced by groups interested in researching or implementing consumer engagement initiatives. Consequently, the Taskforce largely relied on anecdotal information, findings extrapolated from consumer advocacy or patient engagement research, and lessons learned from local and international consumer engagement efforts.

Through this exploration, the Taskforce agreed to a definition of consumer engagement, collected data and information on the current state of consumer engagement infrastructure in Maryland, identify strategies to implement consumer-centric communication strategy, and devise metrics that can be used to measure the impact of these consumer engagement activities.

The Taskforce met at least monthly to expand their knowledge about consumer engagement and monitor progress towards their two charges. A subgroup, comprised of members and interested

³ Institute for Patient- and Family-Centered Care, Individual and Family Engagement in the Medicaid Population: Emerging Best Practices and Recommendations, 2014.

professionals, met more frequently to collaborate on more involved activities of the workgroup. Finally, a few members from the Taskforce were represented on a subgroup that also included representatives from the Consumer Outreach Taskforce. It was the role of this combined group to ensure alignment between the individual taskforces.

The Taskforce responded to the limited evidence-based on consumer engagement by seeking information and insight from individuals and organizations that had expertise or experience in related areas. These entities presented at Taskforce and subgroup meetings and participated in email discussions and one-on-one conversations. Below are the areas for which the subject matter experts and independent research provided the Taskforce insight and guidance.

Expertise and Perspectives Explored

- Consumer Advocacy
- Care Coordination
- Population Health Management
- Health Care Quality Report
- Consumer Engagement in Total Patient Revenue (TPR) environment
- Geographic Targeting
- Patient/Consumer Engagement Infrastructures in Hospital Settings
- Disposition of Consumer Complaints by Hospital and Government Entities
- Online Resources to Support
- Performance Measures to Assess Consumer/Patient Engagement
- Consumers

*A complete list of presentations and subject matter experts is provided in Appendix X.

Emerging Consumer Engagement Themes

Through these discussions several overarching themes, concepts, and guidance emerged:

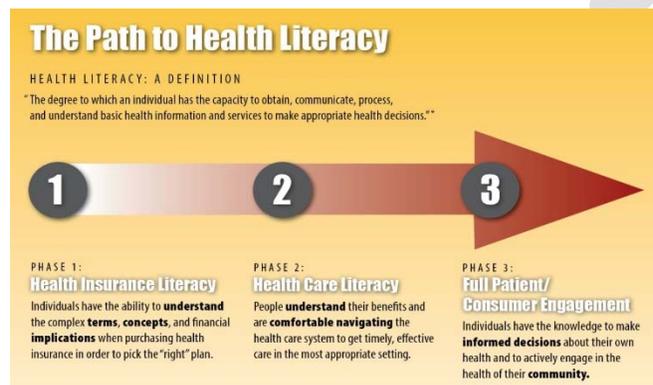
- Consumer engagement efforts must offer a clear call to action
- Emotion motivates consumers to become engaged in their health care
- Health care information should be disseminated and consumer engagement activities should be led by sources that consumers trust.
- Consumer engagement requires extraordinary commitment from health care leadership
- Consumers should be engaged at the point of contact in the health care system.
- A more robust consumer complaint system is needed.
- End-of-life planning and life-sustaining treatments are necessary, yet delicate discussions in the consumer engagement arena.
- Avoid describing the nuances of the NAPM, instead focusing on what's new and that hospitals are incentivized to work with others to keep consumers healthy.
- Privacy concerns should be addressed and are top-of-mind issues for consumers.
- Consumers appreciate the enhanced care coordination aspect of the NAPM.

Current State of Consumer Engagement

The Taskforce's independent research and insights gained from the various subject matter experts revealed that Maryland's health care system lacks the infrastructure to support a statewide consumer engagement effort. However, the Taskforce was encouraged to find elements and attitudes that might be leveraged to serve as the foundation for the eventual creation of this vital infrastructure.

Health Literacy

The Institute of Medicine defines health literacy as "The degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions." The field of health literacy and the pivotal role it plays in person-centered systems has gained increased visibility in recent years. There is heightened awareness that a person's ability to understand and act on health information is critical in optimizing their appropriate use of health services.



This graphic depicts "The Path to Health Literacy", suggesting that it is a process that begins with understanding health insurance and ending with full engagement in the management of one's own care.

Source: Maryland Women's Health Coalition

Increasingly, health care institutions are moving towards implementing standards for considering health literacy in their programming and services. However, the Taskforce did not find evidence of a mandatory policy in any institution that addressed minimum reading levels of written products or a prominent commitment about CLAS standards, which assist health and health care organizations in implementing culturally and linguistically appropriate services. .

Patient and Family Councils, Patient Rights, Complaint Process

Patient and Family Advisory Councils (PFAC), Patients' Rights, and a formal and publicized complaint process are prominent mechanisms in engaging health care consumers.

Comprised of patients, family members, clinicians, staff, and administrators, PFACs provide a structure for receiving and responding to consumer input. The Agency for Healthcare Research and Quality (AHRQ) asserts that they are one of the most effective strategies for involving families and patients in the design of care. While PFACs do not exercise fiduciary or ultimate decision-making over an institution, they can provide valuable input into areas such as program development, implementation, and evaluation, capital projects, staff selection and clinical tools and practices.

A review of the websites of Maryland’s acute care hospitals was conducted to learn the status of key consumer engagement elements statewide. The table below summarizes the findings.

Consumer Engagement Infrastructure on Institutions’ Websites (as of Date)	
Consumer Engagement Elements	Number of Institutions
Patient Rights	39
Formal Complaint and Response Process	27
Patient Advisory Council	7
Possess All Three	5

Need to add info about complaints process

Consumer Engagement in a Total Patient Revenue (TPR) Environment

Prior to the NAPM, several Maryland hospitals were operating under a similar reimbursement model called Total Patient Revenue (TPR). Although the TPR arrangements did not contain the same NAPM directives, many institutions chose community partnerships and consumer engagement to achieve their goals. Presentations and conversations with hospital and public health staff found that there are thriving programs and collaboratives around that state that embody consumer engagement elements.

CETF Guiding Principles

As a result of extensive discussion and exploration, the Taskforce devised the guiding principles for the Consumer Engagement initiative that should inform and influence the activities of the HSCRC as they endeavor to implement the recommendations outlined in this report.

Vision

A fully coordinated, integrated healthcare system in which all Marylanders can achieve optimal health.

Mission

Foster a health care system driven by a culture of robust and meaningful consumer engagement that addresses the Triple Aim, as evidenced by:

- Ongoing consumer participation in system decisions
- Improved individual and population health
- Improved experiences with the health care system
- Efficient use of healthcare resources and reduced costs

Principles

- **Participation** - People and communities participate and are involved in decision-making about the health care system.
- **Person-centered** - Engagement strategies and processes are centered on people and communities.
- **Accessible and Inclusive** - The needs of people and communities, particularly those who may experience barriers to effective engagement, are considered when determining steps to enhance accessibility and inclusion.
- **Partnership** - People, including health care providers, community and health-related organizations work in partnership.
- **Diversity** - The engagement process values and supports the diversity of people and communities.
- **Mutual Respect and Value** - Engagement is undertaken with mutual respect and the valuing of other's experiences and contributions.
- **Support** - People and communities are provided with the support and opportunities they need to engage in a meaningful way with the health care system.
- **Influence** - Consumer and community engagement influences health policy, planning and system reform, and feedback is provided about how the engagement has influenced outcomes.
- **Continuous Improvement** - The engagement of people and communities are reviewed on an on-going basis and evaluated to drive continuous improvement.

Taskforce Goals and Objectives

Goal #1

Establish a consumer-centered health care delivery system with an ongoing role for consumers to participate in the design and implementation of policies and procedures at all levels.

Objective 1.1 Create connections among government, hospitals, health care providers, community-based organizations, and individuals in the development of policies, procedures, and programs that will improve health outcomes, and patient satisfaction while lowering system costs.

Objective 1.2 Engage, educate, and activate people who use hospital services in health policy, planning, service delivery and evaluation at service and agency levels to ensure ongoing consumer support of and participation in Health System decisions.

Goal #2

Engage, educate, and activate people who use or are potential users of hospital services in their own health care in order to promote efficient and effective use of the health care system.

Objective 2.1 Provide people who use or are potential users of hospital services with the information and resources needed to become health care aware consumers who are actively engaged in their own health care.

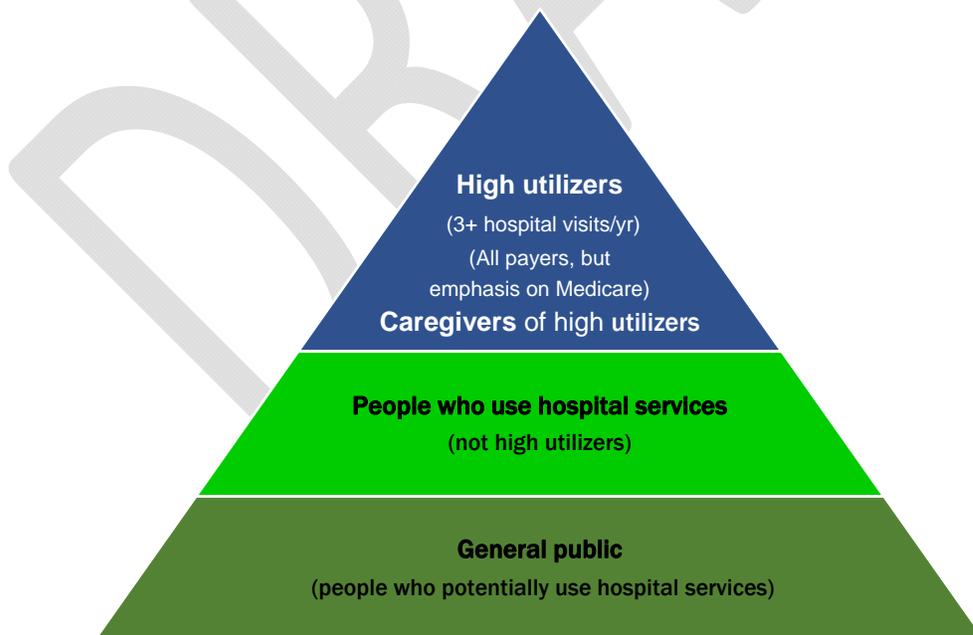
- Objective 2.2 Support consumers' decision-making by providing clear, culturally and linguistically appropriate, and actionable information and opportunities for effective interactions with health care professionals.
- Objective 2.3 Educate consumers about the most appropriate settings to receive care.
- Objective 2.4. Support consumers in the appropriate use of care planning and self-management tools.

Communication Strategy

A substantial portion of the Taskforce's work has been summarized in a Communication Strategy that provides comprehensive guidance on targeting audience for messaging related to the NAPM. The strategy stratifies the population by priority and health status, offers approaches for disseminating information, and provides concepts that can be developed into messages to inform the public about the NAPM. Excerpts from the strategy are provided in this section. The full documents can be found in Appendix X.

Segmenting and Prioritizing the Population

The graphic below shows segmentation of target audiences into three audience groups. The messaging framework builds upon itself and funnels messages to audiences based on their priority. For example, primary audiences will be exposed to the general messages designed for all audiences *as well as* more specific messages focused on the behaviors we want to encourage specifically within our primary target audiences.



The table below summarizes the messengers and distribution channels for information about the NAPM.

Table X. Disseminating NAPM Information to Consumers by Segment Type		
	Messenger	Distribution Channel
Primary	<ul style="list-style-type: none"> • High utilizers • Caregivers/Guardians 	<ul style="list-style-type: none"> • Hospitals • Payers • Community health clinics • Faith and other community-based organizations • Pharmacists • Primary care physicians • Caregiver support groups • Social workers/case managers • Long-term care facilities/providers • Behavioral health providers • DHMH/Local Health Departments • Department of Aging
Secondary	<ul style="list-style-type: none"> • People who use hospital services 	<p>All of the above plus:</p> <ul style="list-style-type: none"> • Consumer advocacy groups • ER waiting rooms
All	<ul style="list-style-type: none"> • General public 	<p>All of the above plus:</p> <ul style="list-style-type: none"> • News media • MHBE/Connector Entities & Partner Organizations • Members of town and county councils • Local community activists

A Consumer-Centered Approach to Materials Development

In the Communication Strategy, the Taskforce offers recommendations for developing written materials so that they appeal to a broad audience. The standards below should ensure (1) cultural/linguistic appropriateness materials, (2) accessibility of the materials, and (3) efficacy of the messages and materials provided.

Minimum Considerations

- Consumer representatives are involved in developing materials
- Surveys and/or focus groups are used to solicit consumer feedback on the design, format, and final language of materials prior to mass production

- Materials reflect the cultural and linguistic diversity of the populations served
- Health literacy experts are involved in the development of materials to ensure that basic health literacy and CLAS standards were followed in the development of materials
- Materials for consumers are written at or below a 6th grade reading level
- All electronic materials are Section 508 compliant
- All information is available in at least one format that is appropriate for all ability types
- All information is available in at least one format that is appropriate for all literacy levels (audio and video recordings or reading assistance for people who cannot read)
- All information is available in print, online, and mobile formats allowing each consumer to select the format that is most helpful to him/her

Strategies and Tactics

Just as effective consumer engagement requires that individuals *own* their health and health care, the HSCRC must take ownership of a pro-active consumer engagement plan that supports its commitment to a person-centered health care system. Therefore, it is imperative that the Commission embraces the principles and strategies outlined in these recommendations and assumes a leadership role in implementing the communication strategy.

For All Stakeholders

- Develop a statewide public education campaign to promote health and wellness

For Policy Makers

- Foster a consumer-centered health care system with policies and procedures informed by stakeholder involvement

For Hospitals and Providers

- Incentivize hospitals to support patients' and caregivers' ability to manage their own care, including access to community based health care resources.

For Consumers

- Provide consumers (patients, caregivers, etc.) with the information and resources they need to make wise decisions and better manage their care.
- Create a sense of ownership and involvement in the NAPM for the prime audiences by educating Marylanders about the NAPM and instilling pride and excitement that Maryland is creating a unique model of delivery system transformation
- Engage local and regional news media to distribute frequent updates about the NAPM to their audiences

Evaluating Consumer Engagement

As previously acknowledged, the field of consumer engagement is emerging. Consequently, the Taskforce was unable to identify metrics of validated tools that could specifically and directly evaluate the impact of consumer engagement on health outcomes, patient experience or satisfaction, provider satisfaction, improved program design or decision-making, or access or utilization.

As a result, the taskforce offered existing measures from Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) and Communication Climate Assessment Toolkit (C-CAT) to evaluate progress towards the goals and objectives outlined in this report.

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Conclusions

Summarize conclusions here

Recommendations

1. Implement a statewide communication campaign using the Taskforce's Communication Strategy as the foundation.
2. Allow a meaningful, ongoing role for consumers at the HSCRC, to include:
 - a. Standing Advisory Committee – composed of consumers, payers,
 - b. Consumer spot on commission
3. Continue to expand consumer engagement efforts.
4. Include life-sustaining treatments and end-of-life-care in discussions about consumer engagement and educating consumers.
5. Establish health literacy standards for information disseminated to health institutions
6. Establish a standard for institutions to have all three things in place