



Delaware Center for
Health Innovation

Achieving Meaningful Patient and Consumer Engagement

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Introduction

The patient/consumer, who will be defined and distinguished later in this paper, is at the center of Delaware's health care innovation efforts. Delaware's broad aims are improving the health of Delawareans, improving the quality of care and the patient experience, and reducing health care cost growth. Achievement of these aims will require individuals to meaningfully engage in their health and wellness to realize their greatest potential, underscoring both the opportunities and the challenges in designing and implementing a system of "patient-centered care."

The charge of the Patient and Consumer Advisory Committee (the Committee) is to ensure that the patient/consumer perspective is reflected in all of the work of the Delaware Center for Health Innovation (DCHI) and to promote outreach and education to Delawareans about how Delaware's health transformation efforts support and empower patients and consumers. Specifically, the Committee has four primary responsibilities:

1. Gather input from Delawareans and represent their voices
2. Lead and coordinate patient engagement programming
3. Raise awareness about the State Health Care Innovation Plan and the improvements it will bring
4. Encourage and empower Delawareans to manage their own health and their healthcare through education and outreach, including the use of technology

Since its initial convening, the Committee has been actively soliciting information from a broad array of "stakeholders" which include health care providers, patients, payers, policymakers, taxpayers and others, to better understand the various approaches to meaningful patient and consumer engagement and to extract lessons learned relative to the healthcare innovation work. Representatives from healthcare systems, community-based organizations, professional associations, State agencies and others have shared presentations, reports, marketing materials and other information with the Committee highlighting their successes, best practices and lessons learned. Much of the information gained through this process has been synthesized by the Committee and adapted for inclusion in this paper.

The purpose of this consensus paper is to identify for the DCHI board and other interested stakeholders, including the public, the Committee's overarching vision for patient and consumer engagement within the health innovation work and to

highlight those principles and strategies essential to driving productive and meaningful engagement. Because patient and consumer engagement is central to the work of each of the DCHI's five committees, this paper is intended to offer insights and recommendations to be considered by the other committees as they execute their respective efforts toward achieving the Triple Aim Plus One: better health, improved health care quality and patient experience, lower growth in per capita health care costs and an enhanced provider experience that promotes patient-centered engagement.

DELAWARE HEALTH CARE INNOVATION PLAN

The passage of the Affordable Care Act (ACA) in 2010 set the stage for the development and implementation of Delaware's health care innovation plan. Section 3021 of the ACA authorized the creation of the Centers for Medicare and Medicaid Innovation (CMMI) to test "innovative health care payment and service delivery models with the potential to improve the quality of care and reduce Medicare, Medicaid, and CHIP expenditures." CMMI is currently focused on the following priorities:

- Testing new payment and service delivery models
- Evaluating results and advancing best practices
- Engaging a broad range of stakeholder to develop additional models for testing

As Delaware aspires to be a national leader on each dimension of the Triple Aim Plus One, in 2013, the Delaware Health Care Commission (DHCC) convened stakeholders across the state – including consumers, providers, physicians, payers, community organizations, academic institutions and state agencies – to work together to build a strategy to achieve these goals. That work culminated in Delaware's State Health Care Innovation Plan representing Delaware's road map for achieving our broad aspirations for improved health, health care quality and experience, and affordability for all Delawareans. In 2014, Delaware was awarded a four-year, \$35 million State Innovation Model (SIM) Testing Grant from CMMI to support implementation of the plan.

Combined with additional investments by purchasers, payers, and providers of care in Delaware, grant funds are intended to support changes in health care delivery to create more than \$1 billion in value through 2020.

The DCHI is a non-profit organization established in the summer of 2014 with the mission of achieving the vision outlined in Delaware's Innovation Plan.

Collectively, with the DHCC and the Delaware Health Information Network (DHIN), DCHI guides and tracks statewide progress related to the SIM grant.

The DCHI is led by a diverse Board of Directors representing Delaware's major providers, payers, state agencies, community organizations, and the business community. DCHI represents a partnership between the public and private sectors with a shared vision of providing all Delawareans with accessible, effective, and well-coordinated care that supports the Triple Aim Plus One.

Vision for Patient and Consumer Engagement within Delaware's Health Care Innovation Work

Delaware's State Health Care Innovation Plan includes goals to make Delaware one of the five healthiest states in the nation and to put it in the top ten percent of states in health care quality and patient experience. Achieving these ambitious goals will require active engagement by patients and consumers across the state: patients to more fully participate in management of their health and health care decision making, and consumers to become more educated buyers of health care goods and services that best meet the needs of them and their families.

The vision of the Patient and Consumer Advisory Committee is for the vast majority of patients and consumers in Delaware to understand how health care transformation efforts can impact them and improve the quality and cost of care in the state; to actively participate in re-shaping the system into one that better meets the needs of Delawareans; and to engage as fully as possible in the management of their own health and the healthcare that they receive. In order to facilitate accomplishment of this goal, the Committee is dedicated to supporting the provision and awareness of knowledge and engagement tools designed to support engagement and informed decision-making.

Patient vs. Consumer

In articulating this vision, it is important to note that the terms patient and consumer are not synonymous. Patient generally refers to a person who is under the care of a physician or other healthcare provider, possibly related to a particular disease or condition. Consumer, on the other hand, generally describes someone who purchases goods and services, which may include health insurance and healthcare-related goods and services.

Many articles have been written describing the patient-consumer connection and the importance of distinguishing between the two. Some suggest that the use of the term 'patient' indicates a level of passivity at a time when there is increasing emphasis on the importance of individuals making active, informed decisions about their own healthcare and choosing how to spend their healthcare dollars accordingly. On the other hand, some have taken issue with the increasing use of the term 'consumer' in discussions about health care policy decisions, suggesting that use of the term is an effort to reduce complex medical considerations regarding individual lives into transactional, financial terms. Hence, while the work of this Committee is focused on both the patient and consumer, we do not

take it for granted that the terms are interchangeable and are careful to use them as such only where appropriate. We also acknowledge that sometimes caregivers are consumers helping patients with decision making and care coordination, especially when patients struggle to manage wellness on their own. In order to advance innovation, all aspects need to be integrated with this approach.

Intersection with Other SIM Committees

As noted in the Introduction to this paper, the work of the Patient and Consumer Advisory Committee intersects significantly with that of the other DCHI committees because of the importance of representing the perspective of the patient and consumer in all aspects of healthcare transformation efforts. Examples of Committee efforts that directly impact other committees and broader DCHI efforts include:

- Providing input and feedback for the development of the choosehealthde.com website, specifically related to making the site user friendly and accessible for patients and consumers
- Reviewing and providing feedback on the draft agenda, format and content of community forums across Delaware intended to inform the public about healthcare innovation efforts and solicit feedback and questions from them
- Supporting the development of a promotional campaign regarding innovation efforts including review of draft marketing materials and outreach plans
- Assisting the Healthy Neighborhoods committee with its rollout strategy in nine selected communities across Delaware, where on the ground activities will engage the public at large
- Collaborating with the Delaware Health Information Network (DHIN) and other technology-related entities on the development of consumer-focused technology and patient engagement tools that will enable consumers to more directly access and manage their personal healthcare information and thus better manage their health.

The Committee will continue to collaborate with the other DCHI Committees to share our findings and best practices and to learn from their experiences related to patient and consumer engagement.

Principles of Meaningful Patient and Consumer Engagement in Large Scale Public Health Initiatives

In executing its charge, the Patient and Consumer Advisory Committee has leveraged the experience and expertise of many other patient and consumer engagement programs active in Delaware to cull information about strategies and best practices that have applications to the healthcare innovation work. Through these efforts, the Committee has identified several key themes related to effective patient and consumer engagement that have yielded positive impacts around health care initiatives and outcomes. These include:

- *Involving a variety of stakeholders* with different perspectives, abilities and resources allows issues to be addressed holistically and from multiple angles
- *Engaging dedicated community and organizational leaders* is instrumental to ensuring broader engagement and ‘buy-in’ among all parties
- *Linguistic, cultural and literacy awareness and sensitivity* are critical to ensuring that the message connects to and resonates with its intended audience, which must include the most vulnerable and disengaged health care consumers. For many of these individuals, English is not their first language and they may also have limitations reading and writing. These individuals are often high volume users of health care and/or depend on financial programs and supports to access services – including if they are undocumented - and need to be successfully engaged in order for the State’s transformation efforts to yield the desired results.
- *Simplification of messaging* increases the likelihood that it will be received and understood by a wide audience
- *Articulating proposed changes, intended benefits and potential costs* can increase the willingness of the target audience to participate in new programs and initiatives
- *Identifying and articulating goals and challenges* from the outset lays a strong foundation for working through barriers and achieving intended outcomes
- *Consumer empowerment through tools and information* enables the consumer to play a more active role in his or her healthcare and healthcare

decision making to and seek the care and resources that support personal needs and preferences. Consumers – and often their loved ones - may feel overwhelmed by the volume of information they are expected to track and manage relative to their health. Care coordination within practices can and often does play a critical role in supporting consumers in this regard.

- *Customizing information and resources* for different audiences involved in the same initiative (e.g. patients and providers) increases engagement by making the information relatable and emphasizing the benefits of participation as it relates to that specific party
- *Leveraging lessons learned and best practices* from organizations and others who have undertaken similar efforts may pave the way to success by minimizing pitfalls previously experienced by others and investing in those practices that are proven to promote positive outcomes.
- *Partnering and supporting existing organizations working toward similar goals* increases collaboration and may yield a more cohesive, widespread consumer engagement effort.

In developing these key themes, the Committee considered numerous examples of successful programs from diverse entities across Delaware. Notable among these is the Health Insurance Marketplace and related ChooseHealth Delaware initiative, a statewide outreach and education campaign to help Delawareans understand health insurance options and benefits and enroll in affordable healthcare coverage. The initiative, which has resulted in over 38,000 Delawareans newly enrolled in coverage since 2014, utilized many of the practices and tools outlined in this paper and the ChooseHealth Delaware brand has been expanded to encompass Delaware's health care innovation work.

Key Strategies to Promote Meaningful Patient and Consumer Engagement

Through its wide-ranging research and information gathering activities, the Patient and Consumer Advisory Committee has compiled an extensive body of knowledge related to effective strategies and methods for meaningful patient and consumer engagement. The key themes identified in the previous section of this consensus paper lay the groundwork for designing strategies that can be employed to effectively increase patient and consumer engagement and participation in health care-related initiatives. Below is a detailed explanation of key strategies identified that are currently guiding the work of the Committee and are herein formally suggested for consideration by the broader stakeholder community.

Use a variety of communication mediums and resources to reach different audiences and reinforce messaging. Individual learning styles, literacy levels and communication preferences necessitate the use of different mediums to effectively engage a broad representation of information recipients. While one person may prefer to receive information face-to-face, another may be satisfied with reviewing content online through a computer or mobile device. With this in mind, making content available in multiple and accessible formats that may include in-person sessions, printed materials, web content, mobile applications, video and/or audio recordings, etc. increases the likelihood that it will reach and be absorbed by the greatest possible number of recipients. Further, the use of visual displays and graphics to explain or further highlight information in favor of or in addition to text/narrative may be effective in increasing comprehension by the intended audience.

For consumer focused tools and resources, seek to design from the consumer perspective anticipating needs, preferences and challenges to the greatest extent possible. Designing materials that are truly consumer-friendly requires multiple layers of scrutiny and feedback to determine whether the information is likely to draw in and resonate with its intended reader/viewer. In addition to soliciting feedback from consumers that fit the profile of the target audience, it may be helpful to ask certain questions when developing and reviewing draft materials. The following are questions suggested for consideration by Christiana Care Health System's Learning Institute:

- What message(s) will resonate with consumers?
- For what segments would this be appropriate?
- Does the message contain the right information?
- What elements are unclear? For those elements, how can we improve or simplify messaging?
- Are graphics and visuals effective? How might they be improved?

Developing a checklist to ask these and other questions may go a long way toward ensuring that the end product is relatable and inclusive of all consumers and reflects their particular interests and concerns.

Consider the linguistic and cultural attributes and preferences of the intended audience and ensure that information and materials are inclusive to these items. This item is especially critical to effective patient and consumer engagement because failure to implement presents an upfront barrier to the individual and often results in immediate and sometimes permanent disengagement from the initiative. This can also be especially difficult to implement when the entity responsible for developing content does not adequately reflect the demographics of the target audience and therefore may not fully understand or appreciate the concerns and culture of diverse populations. In this case, it is particularly important that the material development process involves stakeholders representing the communities identified for outreach and that additional feedback is solicited from stakeholders prior to widespread release of materials.

Some of the major factors to consider in this regard are health and general literacy, language preferences (particularly for non-English speakers), physical impairments or disabilities that may require alternative communication formats and issues related to gender and sexuality. Materials should also be compliant with requirements outlined in the Americans with Disabilities Act (ADA.) Delaware has many examples of programs and resources whose design has successfully addressed cultural competency needs in each of these areas and that have resulted in meaningful engagement of the intended audience. Examples include eight Delaware hospitals receiving Healthcare Equality Index Leader Designation in 2016, the University of Delaware Cooperative Extension's Smart Choice Health Insurance Program and the Delaware Hispanic Commission's Cultural and Linguistic Statewide Study.

Develop tools to capture regular feedback over the lifetime of the initiative.

Instituting a regular feedback loop offers a valuable opportunity to understand the real-time needs and concerns of the target audience. This is especially useful during a large-scale, multi-year initiative since it is likely that participants will experience changes in understanding, preferences, values, favorability ratings, etc. over the course of time that will require adjustments to content and strategy on the part of the implementer. The type of information collected may range from qualitative feedback about the format and content of materials to quantitative, statistical information such as comprehension levels and favorability ratings.

An example of a program that has effectively utilized the feedback loop is Nemours' "Navigating Healthcare from an Adolescent Perspective" program, which was piloted over a year with teachers, students and schools across Delaware. During that time, the program conducted multiple surveys and trainings to collect feedback that was used to develop and refine future trainings and resources, thereby increasing their impact and applicability to the target audience.

Consider the whole array of patient and consumer barriers to accessing healthcare and seek to collaborate with established partners and organizations that can address these barriers. When considering barriers that may prevent individuals from accessing care, the issue that frequently comes to mind is cost and/or lack of insurance, which is generally related to cost. Of course, a number of other issues may prevent consumers from accessing care including cultural and linguistic barriers, limited health literacy, mistrust of providers and transportation challenges, among others. In order to encourage individuals to formally engage with the healthcare system, acknowledging the various barriers and seeking solutions to them is vitally important. Further, because it is extremely unlikely that any single provider or agency could address all of the barriers individuals face, collaboration with established community partners and agencies that can collectively address individuals' needs can often enable them to access needed care where otherwise they may not have done so. This level of collaboration needs to occur at a macro level - as being executed by the Healthy Neighborhoods work in communities - and micro level on a team-based approach to an individual's care. Also, working through trusted entities such as these often makes the difference in terms of an individual's willingness to consider and accept the benefits and importance of seeking care, particularly if he or she has been disengaged from the healthcare system for a long time. The important role of care

coordination in addressing barriers to access through engagement of patients, consumers, caregivers and a host of other stakeholders must also be noted.

Seek to execute new initiatives and resources with a sample group prior to widespread release. As noted above, testing new materials and strategies with a sample or small group prior to full release can be very effective in increasing the likelihood that the end product will resonate with its intended audience. This process enables the developing entity to gain feedback from the intended audience, make meaningful adjustments that may eliminate language or other content that may be off-putting and reframe information in a manner that is relatable to the desired end user. The review of marketing materials and the choosehealthde.com website with Committee members and a limited group of other stakeholders prior to full release is a good example of this strategy in action.

The phased approach to rolling out the Healthy Neighborhoods initiative is another good example of this type of execution. The first three Healthy Neighborhoods are being rolled out in 2016 and it is expected that the lessons learned from these three neighborhoods will be used to inform the rollout of the remaining six Healthy Neighborhoods, thereby increasing the efficiency of the process and the odds of widespread acceptance and integration of the initiative. Another example is the development of the Common Scorecard by the Clinical Committee, which was introduced to a limited group of providers to test for ease of use and to identify technical glitches and challenges so that any issues could be addressed and necessary updates made prior to putting the scorecard into wider circulation and use by the provider community.

Use available data and research to support assertions, inform the development of content and action steps and anticipate future needs. While patient and consumer engagement is heavily focused on qualitative considerations such as messaging and format that can impact receptivity, the strategic use of data and/or research to support these efforts can be very effective at increasing their impact and relevance. For example, examining demographic data can provide insight into current and future needs for linguistically and culturally appropriate materials. Data on the state's population of individuals with disabilities will also ensure materials are inclusive and accessible to diverse populations across the state. Data for Delaware suggests a steady increase in the population that identifies as Hispanic/Latino, which will likely necessitate the development of more Spanish language and culturally appropriate materials and services to adequately address

the needs of this population. Similarly, data that shows an increasing consumer preference for using web-based or mobile application tools in lieu of printed materials indicates the need to include these types of resources in an effective consumer engagement strategy.

Develop a set of Frequently Asked Questions that addresses important questions and concerns in a straightforward and easy to understand format.

Among the many tools identified as being effective in helping individuals to better understand important and often complex information about health-related issues, the Frequently Asked Questions (FAQ) tool was cited with particular regularity. FAQs can be particularly effective on many fronts. First, the creation of FAQs requires the author to consider what questions are likely to arise related to a particular topic or set of information, which creates opportunities to clarify information on the front end during that process. Second, FAQs can prevent user frustration by enabling users with a specific question or concern to forgo spending unnecessary time wading through information that may not be relevant in order to get to a particular answer. Often, clear statements related to the purpose or impacts of particular efforts are not easily articulated within a body of information, and an FAQ document provides a straightforward format in which to clarify such information. Finally, FAQs typically serve as living documents that can be regularly and easily updated to include new information and reflect changes in policies, features, requirements, etc. that are important for users to know.

Where possible, use meaningful incentives to encourage participants to fully and actively engage in programs and activities. It is common knowledge that the promise of a reward can be a powerful incentive to spur an individual to action; the same is true for patient and consumer engagement activities. The reward does not have to cost money or even come in the form of something tangible but can be as simple as a gesture that acknowledges progress on the part of the participant.

One recent example of this from Delaware is the Yes We Can Healthy Living Challenge, a University of Delaware initiative funded by a grant from the Division of Public Health to encourage healthier eating and increased physical activity. At the outset of the program, participants completed a questionnaire and were then encouraged to keep daily logs of activity and nutrition in order to earn rewards in the form of ‘points.’ Individuals created teams of 2 to 6 that provided motivational support and received newsletters and information and attended UD Cooperative

Extension educational programs that helped them increase knowledge about healthy food choices.

It is important to emphasize that the strategies noted above are part of an ongoing effort to engage patients and consumers rather than a one-time initiative. While each of these items is important to consider as part of the healthcare innovation work and related efforts, these tools and strategies are most effective when employed over the long term and relative to health care initiatives of all types.

Measuring Effectiveness of Engagement Efforts

Once the strategies and best practices for encouraging meaningful patient and consumer engagement have been applied, the next challenge is how to gauge the impact and effectiveness of these efforts. This can be particularly elusive with regard to engagement efforts in that information may reach individuals through a variety of forums and sources that may not be easily trackable.

The Patient and Consumer Advisory Committee charter references three specific accountability targets to be considered in measuring the effectiveness of the Committee's efforts:

- **Consumer input:** Number of patients/consumers consulted on DCHI activities per year
- **Reach of messaging/Innovation:** Percent of Delawareans reached with messages about innovation activities
- **Reach of messaging/Patient and consumer tools:** Percent of Delawareans reached with messages about patient engagement tools
- **Consumer response from messaging efforts:** Number of unique patients/consumers who proactively respond to DCHI messaging. (e.g. sign up for an email distribution list, RSVP for an event, etc.)

As noted above, while each of the above is likely an accurate measure of impact, it may not be easily measured or recorded. For example, an individual who picks up and reads a brochure about healthcare innovation efforts at his or her doctor's office has been reached with messages about innovation activities but no method exists for tracking this activity. In light of this, the Committee has identified other potential avenues for capturing more tangible information about the reach of its engagement efforts including:

- **Choosehealthde.com website analytics:** The recently updated choosehealthde.com website is intended to be the go-to resource for consumers seeking information about innovation efforts in Delaware. The website has the ability to track figures and information regarding number of visitors and referral source and also offers consumers the ability to submit feedback and questions on the site. This information can offer insights into what organizations and websites are driving traffic to the site and whether particular outreach efforts appear to result in a spike in activity. Note that

the DCHI website (dehealthinnovation.org), while another key resource for information about innovation efforts, is more geared toward internal stakeholders and Committee members.

- **Patient and consumer feedback via surveys:** The use of survey tools can generate real-time and often detailed feedback regarding the reach and effectiveness of patient and consumer engagement efforts. The Committee recently helped design surveys for attendees of the community forums across Delaware. The survey includes both a pre- and post-forum section in order to gauge participant perceptions and awareness on key health issues and health-related performance prior to and following the session, which can be used to assess whether the information presented during the session is resonating with the audience and achieving its intended effect. The Committee will explore other opportunities for utilizing surveys to measure the level of patient and consumer engagement, gather perceptions about current efforts and identify potential areas for improvement.
- **Volume and scope of formal collaboration/partnerships:** One objective of the Committee is to increase awareness and promotion of healthcare innovation efforts through community partners who can take the message about these efforts to their clients, patients, members, employees and others. Messages delivered by trusted partners are more likely to be well received. Hence, another possible measure of the Committee's effectiveness is the number and scope of partnerships and collaborative efforts with entities including health systems, providers, community organizations, advocacy groups, universities and others whose role is to take the overarching message about healthcare innovation to their constituents and deliver it in a manner that is appropriate to them and addresses their particular interests.

Appendices

Appendix 1.

Listing of Patient and Consumer Advisory Committee Members

Rita Landgraf (Chair)
Delaware Department of Health and Social Services

Rosa Colon-Kolacko
Global Learning and Diversity Partners

Marianne Foard
Bayhealth Medical Center

Joann Hasse
League of Women Voters

Jim Lafferty
Mental Health Association in Delaware

Mary Kate Mouser
Nemours Health and Prevention Services

Brian Olson
La Red Health Center

Ann Phillips
Delaware Family Voices

Tim Rodden
Christiana Care Health System

Ronaldo Tello
Delaware Hispano Magazine

Thomas Weeks
New Destiny Fellowship (International)

In addition to its membership, the Patient and Consumer Advisory Committee benefits significantly from the participation of many involved stakeholders who regularly attend Committee meetings and events and provide thoughtful feedback on Committee and DCHI initiatives.

The Committee's work is also supported by input from the DCHI Board and other Committees. A full listing of DCHI Board and Committee members may be found on the DCHI website at www.dehealthinnovation.org.