

THE ROADMAP TO CONSUMER CLARITY IN HEALTH CARE DECISION MAKING

Making Person-Centered Care a Reality



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The Patient Advocate Foundation
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■ INTRODUCTION AND OVERVIEW

THE ROADMAP FOR CONSUMER CLARITY

INTRODUCTION

The primary goal of the Roadmap for Consumer Clarity in Health Care Decision Making is to propose actionable models to drive person-centered care at key “decision milestones” in the health care system. Achieving this goal requires making changes to the ways health care providers and patients interact with each other at pivotal moments during the illness experience.

These changes include:

- Greater consumer engagement on the part of patients and caregivers
- More transparency in providing information about care and treatment options and discussing their respective benefits, risks and costs
- Improved education and training for patients, caregivers and providers in skills that improve communication and facilitate shared decision making
- Better use of innovative tools and platforms that help both patients and providers access and utilize information
- More systematic measurement of the utilization and effectiveness of person-centered interventions and activities, including incorporation of patient-reported data into the process.

Implementing a truly person-centered system will improve communication between health care consumers and their providers, facilitate shared decision making, improve care planning, enhance overall measurement of the value of care, and improve quality of life.

Patients play a key role in driving the systematic changes that make this type of quality care possible. This begins with effective self-advocacy and extends to active efforts to educate other patients, providers and policy makers on the benefits of person-centered care. Patients and those who advocate for them should take steps to help assure that they, and their caregivers as appropriate, have the tools and opportunities to engage in shared decision making at every critical point during their care.

Designing a person-centered system is neither exclusively a clinical activity, nor a primary burden for the patient. It is a collaborative effort in which patients are part of the change process, not simply the objects of that change. The ultimate goal is to have patients and their providers co-create health care plans that meet clinical objectives while honoring individual values.

“This document is about health, dignity and compassion. Despite all the terms that are used today, these are the essence of value-based care. What we know, and what our focus groups told us, is that quality health care comes down to ‘health and caring,’ and we need to learn how to do that better, heart by heart.”

Meg Gaines, J.D. LLM

A growing emphasis on finding transformative ways to improve quality of care while lowering costs affords a compelling opportunity to address value in health care across the full spectrum of delivery venues and populations. The Roadmap seeks to build on the substantial work that has been done in this critical arena by proposing models that are evidence-based, skills-driven and evaluable. To make a difference, it is essential that these models work at key points in the patient experience with illness and acknowledge that patients will vary significantly in their interest and

ability to engage in shared decision making. Replicable models must also be actionable in a wide range of clinical and community settings without increasing the already substantial demands on provider time and resources. The Roadmap creates an integrated framework for linking together what are now mostly discreet activities to create an information system for incorporating patient goals and preferences that allows for a scalable approach to customization that can be replicated throughout the system.

While those goals sound broad and formidable, the time is right for creating clarity in health care decision making through person-centered care that treats the whole person in addition to the disease. In 2012, a group of leading health care executives identified patient-centeredness and empowerment as top strategies for creating better value, defined as high quality at lower cost. They pointed to patient-centered care as a means of allowing health systems to be effective, efficient and continuously improving.¹ In 2013, an Institute of Medicine roundtable concluded that “prepared engaged patients are fundamental to high-quality care, lower costs and better outcomes.”²

OVERVIEW

Section 1 of this report focuses on Consumer Engagement in Health Care and the Role of Information in developing key skills, facilitating communication and improving shared decision making.

Section 2 discusses Opportunities to Deliver Person-Centered Care with a focus on the critical components of shared decision making and the tools that are available and necessary to make this process successful.

Section 3 presents an integrated systems model for linking together the action steps for Building a Person-centric System for Consumer Engagement in Health Care.

The Patient Advocate Foundation (PAF) thanks the many people who contributed to this project, including

patients, advocates, the stakeholder advisory group and the thought leaders who gave their time, wisdom and insight to this effort.

PERSON-CENTERED CARE

Person-centered care provides opportunities for patients to interact with the health care delivery system to make critical choices about their treatment and care. It does this by—

- Asking or assessing what matters to patients and caregivers at key points during the illness experience
- Capturing and documenting their goals and priorities

- Continually monitoring these goals as they evolve and change over the course of the illness
- Honoring the patients' and caregivers' perspectives about what is important and contributes to their quality of life and wellbeing throughout the care continuum

Person-centered care reflects the importance that people place on personal choice and control as priorities. The 2001 Institute of Medicine report, *Crossing the Quality Chasm: A New Health System for the 21st Century* provided perhaps the most widely used definition of patient-centered care: "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions." It cuts to the very essence of good medicine and the crucial elements of delivering value in health care services.

High-quality, effective health care requires expert attention to physical and psychological symptoms,

plus communication and coordination. Patients rarely experience their symptoms as one isolated problem. Distress, for example, may lead to physical symptoms related to the patient's emotional and social concerns or physical impairments may lead to distress. Yet, our health system's disease-centric and highly segmented structure often metes out care in distinct silos with little incentive or opportunity for discrete disciplines to come together in a coordinated model for delivering services that matter most to the patient. "Physicians who are not patient-centered (i.e., have poor relationships or communication, or lack empathy) order more tests, hospitalizations, prescriptions and referrals."³ Determining what patients and their families consider most important and then aligning those preferences against the benefits, risks, and costs of various care options over the course of the patient's journey provides the bedrock for a person-centered health care system. Improving person-centered care in the health care marketplace must involve building skills for patients, caregivers and their providers.

FIVE KEY FINDINGS FROM THE VALUE FOCUS GROUPS

As part of the Roadmap project, PAF conducted four focus groups with diverse sets of participants who produced a number of key, shared themes for patients:

- "Value" means having a patient/provider relationship in which the physician shows respect, interest, care and compassion, and is accessible and responsive. This "value" definition holds true across patient groups, regardless of age, disease type, cultural and ethnic background, health literacy and insurance status.
- Patients attach great importance to the provider-patient relationship. They want physicians who acknowledge them as individuals, are open and honest and are good listeners. They also respond to truthful and empathic communications, even on difficult topics.
- While the physician remains at the center of the relationship, patients value relationships with their entire treatment team. Many members of this team play key roles in providing person-centered care. Their contributions, demeanor, and knowledge are very important.
- The provider-patient relationship has an important impact on health care outcomes, affecting key areas such as adherence and decisions about treatment options.
- Both direct and indirect costs play a key role in decision making and need to be incorporated into communications between providers and patients.

The full Focus Group report is attached in the Appendix.

KEY TRENDS DRIVING PERSON-CENTERED CARE

Several rapidly emerging forces open the doors to shifting the health care system to make patients more informed, involved, empowered and engaged in all aspects of their care:

- Precision medicine and the evolution of individually-based treatments provide more opportunity for value-based care and shared decision making related to specific benefits and risks of treatment.
- Consumer-driven benefit designs increase the amount of “skin in the game” on the part of consumers, while other efforts also bring market-oriented approaches to the health care system. Costs are increasingly shifting to individuals in the form of higher deductibles, copays and coinsurance. These new approaches are intended to transform patients from passive, often poorly informed recipients of care to more active, cost-conscious consumers.
- Increased emphasis on patient-reported outcomes and engagement across the spectrum of health care planning and implementation.
- Significant efforts are focused on shifting payment models from volume to value. These efforts focus on paying for care based on its ability to deliver quality and value rather than volume or utilization. The care delivery tools and models associated with these payment strategies emphasize evidence-based treatment and care, shared decision making, care planning and care coordination.^{1,2}
- Advancements in personal technology make it possible to engineer complex customer service platforms into elegant, but simple user interfaces. These include personal health records as well as mobile applications, patient-oriented websites and real-time interactive communications among patients and providers driven by smartphones and tablets.³

The Roadmap draws on the existing literature, best practices, quantitative and qualitative market research and emerging technologies to synthesize a model that will prioritize the development of these skills, as well as providing the tools to optimize them. It also recalibrates the system to reinforce the importance of person-centered data to guide and improve policies and practices related to care planning and decision making.

KEY ASSUMPTIONS AND STEPS FOR DEVELOPING THE ROADMAP

The Roadmap Project builds on a growing body of knowledge that seeks to understand what matters most to people who are experiencing health care, as well as what makes them feel respected and supported as they move through the stages of their diagnosis, treatment and the resolution of their condition, whether it be

recovery, living with a chronic condition or progressive disease at the end of life.

In creating this roadmap, the choice was made to focus on specific populations and spheres within the health system, primarily on the types of serious and life-threatening chronic conditions requiring ongoing care that impose consistent costs on the patient, their family and the system. The goal is to develop a process model that can be applied to the consumer experience beginning around the time of diagnosis all the way through the full continuum of care. The basic model proposed and the opportunities for action can be applied to a full range of disease areas as well as other aspects of the health system, such as prevention.

No distinction is made between consumers and patients, but rather, the diagnosed patient is defined as a consumer. For purposes of this project, the terms “patient-centered” and “person-centered” are used

interchangeably, with the full knowledge that individuals are “persons” throughout their lives and “patients” for a distinct period of that life. The goals and values that drive shared decision making apply throughout a person’s entire life span, and “person-centered” care reinforces that quality care delivery involves treating the person beyond the disease.

The Roadmap also acknowledges that patients do not all have the same access to resources or the ability to make choices about their care. Fewer resources often mean fewer choices. Patients find their options limited by many factors, including costs, health literacy, cultural barriers and geography. A patient, for example, who has to travel a hundred miles to see a specialist may have fewer options than one who lives in a city in which there are multiple facilities and physicians available. Health equity is a critical issue in assuring that the Roadmap can become a reality for every person facing a serious illness.

“Fewer resources often mean fewer or no options for patients. Access and availability are not just disparity issues. Geography can play a major role as can logistics like child care or lost job time.”

Thomas Workman, PhD

The content of this project and its recommendations were informed by the following activities:

The Patient Advocate Foundation

- **Convened** a stakeholder advisory group comprised of a diverse group of experts on person-centric care who contributed substantive input and feedback to the project over the course of a year. See page 82 for a list of participants.
- **Conducted** a comprehensive market and opinion survey effort that reached more than 1,600 patients, collected findings from 35 people in four settings with an emphasis on those who are vulnerable or underserved, and conducted qualitative interviews with 15 patients and caregivers. A copy of the focus group report starts on page 52.

- **Reviewed** existing models and literature that represent either actual or potential best practices in relevant areas, incorporating them into the Roadmap findings and recommendations.
- **Leveraged** its own extensive experience in providing case management services to primarily low-income patients coping with serious illnesses who need immediate assistance with a financial, logistical, or coverage problem related to their health care.

The Roadmap serves as a framework to create a person-centered system that helps patients, caregivers and their health care providers navigate through multiple decision points along a common path to arrive at a destination each defines as important. While acknowledging the obstacles, our focus is on actionable solutions that will make a difference in the patient, caregiver and provider experience. Our analysis indicates that many existing models and tools can be applied to and adapted for diverse clinical settings to affect positive change without being disruptive or adding significantly to the cost or time required to deliver quality care. Opportunities also exist to develop innovative approaches that take advantage of emerging technology and platforms that both provide people with and gather key information about costs, benefits and risks to personalize access to health care information, care planning, and measurement.

DELIVERING CARE THAT MATTERS TO PATIENTS

Delivering Care that Matters to Patients is the Benchmark for 21st Century Health Care. The 2001 IOM committee charged with charting a 21st century health care system outlined several key steps grounded in the fundamental notion that care should be customized according to patient values and needs. A number of key requirements were identified in the report:

- Patients should receive care whenever they need it, with access to care provided in person, but also over the Internet, by telephone, and by other means.

- Patients should have unfettered access to their own medical information and to clinical knowledge; and decision making should be evidence-based.
- Transparent information that enables patients to make informed decisions including safety data, evidence-based practice, and patient satisfaction is critical.⁴

While implementing consumer-oriented strategies grounded in person-centered care may be a complex undertaking, the driving principle is simple and universal: Mutual respect lies at the heart of all health care that addresses the physical as well as the psychological, social, and spiritual issues that influence quality of life. Respect for the patient’s values, preferences, and expressed needs should be considered a core indicator of quality and safety⁵ and the primary starting point for consumer engagement.⁶

The Roadmap puts forth recommendations based on what matters to patients and their caregivers around value, cost, benefits and risks of care. It defines pivotal opportunities and platforms in which providing information will make a difference in the quality of care and the value of the health care experience. The seriously ill person needs to be the focal point around which the health system is transformed to deliver and pay for value. As the well-known economist, Michael Porter, explained, “Value should always be defined around the customer, and in a well-functioning health care system, the creation of value for patients should determine the rewards for all other actors in the system.”⁷

CASE HISTORY
Shannon: Advocating for Clinical Trials

Shannon was a healthy woman with a family, a busy career as a physician’s assistant and strong interest in outdoor activities. At age 53, she was diagnosed with stage IV cancer of the thymus, a disease with traditionally few treatment options and a poor prognosis. After progressing on standard treatment, and being told to “get her affairs in order,” Shannon demanded and got genomic testing which revealed

a targetable mutation. She left home for a cancer center in a different city and clinical trial that gave her 10 months of quality life. Once she relapsed, she worked with her team to get a referral to an immunotherapy trial in another center. She had three disease-free years on the trial, was able to return to work and travel, before her disease progressed. As of the date of this publication, she is seeking a new clinical trial, and remains both determined and optimistic.

“I think doctors have to know their patients, and learn who that patient is as a person. I know it’s hard in a short period of time, but I think one way to do this is to find out a little about that person’s life. Where do they live? What do they do? It’s really important because looking down the road it helps doctors present alternatives and it helps people make decisions that are more in keeping with their lifestyle and their thought process.”

**BASIC ROADMAP ARCHITECTURE:
THE INPUT OUTPUT MODEL**

A “super highway” of information is needed to create transparency, capacity and choice for patients. Information alone, however, is not the engine that drives consumer behavior. The manner and timing with which that information is presented to patients and how it is used to shape decisions is just as critical.⁸ Widespread, meaningful clarity in health care decision making for patients and their caregivers requires an information system based on an Input-Process-Output (IPO) model inherently designed for responsiveness to patient preferences.

Table 1. Roadmap Architecture

1	Creating clarity requires an information system, not just information
2	The system must be engineered using an IPO model that includes feedback loops for rapid learning and continuous quality improvement
3	The system must be responsive to patient preferences to allow for custom configuration

The Encyclopedia Britannica defines an Information System as “an integrated set of components for collecting, storing, and processing data and for providing information, knowledge, and digital products.”⁹ If the goal of providing information to patients is to make them more active and engaged consumers, then the Information System (IS) that supplies that knowledge must be built for the patient

both in its design and its application. An Input-Process-Output (IPO) model is a common means by which to conceptualize the structure of an information system.¹⁰

In the case of health care decision making, the input is information about benefits, risks, and cost. The output is the actual impact of care in terms of costs, benefits and risks and the extent to which the care received aligns with the values, goals and preferences that shaped the selection process. The end product’s quality and its alignment with the user’s expectations are then captured in the form of patient-reported outcomes data. These real-world experiences have the potential to generate a feedback loop that can inform the ongoing process of care for that same patient or help inform the decision of similar patients who are weighing various options in the context of their own personal values.

TABLE 2: BASIC IPO MODEL COMPONENTS FOR HEALTH CARE DECISION MAKING

The goal of the Roadmap is to create an information system centered on the health care consumer. The Roadmap uses the IPO model as the basis for building a person-centered system of care, which is delineated in Section 3.

Input	information about benefits, risks and costs used to customize the identification and assessment of care options
Process	decision-making activities and execution of a goal-concordant care plan
Output	the actual impact of care in terms of costs, benefits and risks

The elements of the information system must be configured and integrated to produce a customizable output. To be useful, this output must also account for variation in consumer practice and preference.

Production models are typically broken down into two types:¹¹

- Efficiency models generally are built for speed of execution and standardization of both process and product.
- Responsiveness models, by contrast, are adaptable to inherent variances in consumer product preferences so the product or process or both can be adjusted for customization.

These two approaches to creating a product or service can be combined such that parts of the process are standardized to maximize efficiency but still allow for customization of end products that are “configurable to order.” This approach, known as custom-configuration, allows for “multiple (potentially unlimited) configurations of the finished product on a unique platform according to the end consumer’s needs.”¹²

Decisions about health care are extremely personal. What’s important in terms of patient goals and preferences related to benefits, risks, and costs will vary, as will the tradeoffs a patient is willing to make between them. These values and choices change over a person’s illness experience and lifetime.

A custom-configured approach in the health care information system must accommodate variation in patient goals and values, while also recognizing that standardizing the process by which the information is customized to the individual can optimize efficiencies needed for time and scale. The optimal approach is customization coupled with appropriate standardization.

CASE HISTORY

Amanda: A Focus on Quality of Life and Honest Communications

Amanda's father was 48 when he was diagnosed with stage IV lung cancer. Amanda, a college student at the time, left school and quit her job to come home and care for him. Although initially his doctors presented an optimistic picture of the prospects for treatment, Amanda's father rapidly became more ill and died eight months after his diagnosis. Amanda's experience inspired her to return to school and become a nurse.

"The doctors held up four pictures of the lung cancers in my father, and said although it was pretty significant, it would be treatable, giving us maybe some false hopes that this was something he could beat. They did allow us to ask some questions, but it took some time to process, and so we weren't entirely sure what questions to ask. But they certainly didn't ask us any questions as to what or how we were feeling.

I sort of wish that things were offered to us as far as expectations. We weren't told about side effects of chemo and how treatments vary in different people. We didn't talk about quality of life expectations. You know, what we could do to make things better for him, and for us, instead of having to figure it out as we go.

I think with the doctors there was not really much balance as far as quality of life. They were very concerned with curing—that it was his cancer they wanted to treat and not him. The nurses, they saw my dad. And they saw a family who was grieving and needed help.

I think that with this type of cancer, the hope may change with time as mine did, as ours did as a family—from hoping for a cure to hoping that dad would be comfortable. I think it is very important for everybody to be honest with families, to tell you what is going to happen, and this is how you can prepare. Then your hope can change along with the circumstances."

■ SECTION 1

CREATING INFORMATION AND CONVERSATIONS THAT MATTER TO PATIENTS

Simply stated, three critical factors are necessary to design and implement person-centered information systems that improve decision making:

1. Availability: Is the information available? Do patients have input data on key areas such as the benefits, risks and costs of treatment?
2. Context: Is the information understandable, timely and accessible? Is it presented in ways that are personally meaningful, related to the care plan and actually helpful in choosing between options?
3. Feedback: Is there a feedback loop that allows patients and providers to evaluate the outcomes of their decisions and share their knowledge and experiences with others?

In recent years, the “patient voice” and patient-reported outcomes have become increasingly important in the rallying cry to improve the US health care system. Patient participation on advisory boards, panels and in the design and implementation of clinical trials is growing increasingly substantive—and in many circumstances, required. The old model in which patients and caregivers are the passive recipients of care is being replaced by one in which they are active, informed participants, or partners, in their health care.

In fact, when patients were asked as part of the market research for this project how they would like to approach making decisions about medical treatment, almost 55% of the respondents indicated that they like to partner with their doctor to make treatment decisions together as a team.

“The consumer experience should be very different from what it is today. We need something that pulls all the pieces together. To do what is right for patients, we fundamentally need to figure out what people want.”

Lewis Sandy, MD

In this emerging era of consumer engagement, patients express their goals, preferences and values surrounding their treatment to their care team. These discussions are the core of shared decision making as well as the primary means by which appropriate supportive services needs are identified to accompany disease-directed treatment. A growing body of evidence suggests that this approach leads to both better outcomes and lower costs.¹

CASE HISTORY

Kate: Value is What Works Best for Me

Kate was diagnosed with relapsing remitting MS at age 35. She was single, a successful woman who wanted a central relationship in her life. Initially she feared that her illness would make that impossible and was deeply concerned about life as a disabled person. She has since learned to live with her MS and to use her skills as a video producer and writer to become an advocate for other people facing serious illnesses. She developed

and runs a special website, My Counterpane (<http://www.mycounterpane.com>) in which patients can tell and share their stories — and she has married and had children. In the course of her treatment, she has undergone both conventional and alternative therapies.

“I think value for me is really seeking to understand what works best for me. It’s this whole sense of finding what feels good and knowing what works for me may not work for other people. If you give people the right channels to explore their own power, I think there is tremendous value in that, that has nothing to do with the health care system.

“I’m really hopeful that this holistic space is beginning to open and I know it is in the MS space. That can mean opening up a position for a nutritionist or being able to listen to things that don’t necessarily fall into your clinical training. I just feel so passionate about people being holistic towards their healing and clinicians acting that way too.”

“We need to set expectations from the first visit, and gain some understanding of how [people] want to participate in the decision making about their care. That has to be balanced with not overwhelming them with too much information. We have four questions, literally attached to our ID badge, that we ask every time we see a patient. What are you hoping for? What is it important to you? What are you most worried about? What brings you joy? That tells you a lot about the patient.”

Lillie Shockney, M.A.S.

KEY THEMES FROM ROADMAP IN-DEPTH INTERVIEWS

For this project, 15 people who have experienced serious illness as either patients or caregivers responded to interview questions designed to elicit their views about what constitutes effective communication with the health care team, and to identify factors which contribute to a person-centered experience. Many of these individuals are also active patient advocates and thought leaders. Key themes that emerged from these conversations included the following commentary:

- “Good” experiences are those in which the medical team includes discussion of what is important to the patient at every stage of care.
- While patients want a coordinated team approach and value their interactions with members of that team, having one doctor who is at the center of their care and with whom they have a trusted relationship is very important.
- Numerous critical decision-making points occur throughout the course of the illness, but the most vulnerable and difficult often come at the point of diagnosis and during early decisions about treatment.
- When care is truly person-centered, it can result in a positive experience even when the prognosis or medical outcomes are poor.
- Advocating for person-centered care requires skills. For many people, these skills are acquired during and as a result of their illness experience—and improve with the length and depth of that experience.
- Caregivers are critical to person-centered care, but are often neglected in terms of both their role and providing support to them.
- Palliative care is essential and must be integrated into the treatment plan from the beginning. Both patients and providers need better understanding of its meaning and value.

THE PATIENT AS ENGAGED CONSUMER

A paradigm shift has moved patient decision making closer to that of other consumer-based transactions in which consumer engagement is both an approach and a process. It involves a buyer who takes an active role in gathering “product” information in order to make a choice aligned with perceived needs and wants.² Ideally, that buyer has access to and utilizes a reasonable amount of information about the cost, benefits and potential risks of the product as the basis for making a selection. Engaged consumers actively seek to understand this information and use the knowledge to compare various options against personal goals and preferences.

When asked to what extent they felt prepared with enough information about the impact of their selected treatment option on their out-of-pocket expenses, more than 50% of respondents in this project’s opinion survey indicated that they were sufficiently or extremely well informed of the anticipated impact.

Consumers also have the ability to share information and experiences with others who are making similar decisions. Individuals who have been through similar experiences provide feedback on their experiences, which in turn proves useful to others in gauging costs, benefits and risks. The result of this engagement process should be a voluntary choice to buy a product or use a service in which consumers feel confident that their preferences are reflected in the final decision. It is this model of consumer engagement that forms the foundation for and drives person-centered health care.

Health care has traditionally deviated from these guideposts in that the “buyers” are often unaware and disconnected from the direct and indirect costs of their care, do not have usable, actionable information about the benefits and risks of their treatments and are not given the opportunity to integrate their values and life goals into the decision-making process.

One out of every four respondents in this project’s opinion survey stated that this opportunity to glean valuable information around what was important to them in regards to making treatment plans was

completely absent from the discussion they had with their doctor.

Much can be learned from the ways in which other market sectors orient their entire business around the customer, but it would be a mistake not to recognize the many ways in which health care is different.³ Most patients are only paying a portion of the cost of the care out of their own pocket, with the majority of the cost spread out amongst others through their insurance coverage. Thus, it is reasonable to expect patients to concede a portion of their decision-making authority to their health care team. A patient’s potential options are also constrained to some extent by scientific evidence, clinical judgment, and fiscal prudence as it relates to managing a global budget for a group of insured lives.

“For person-centered care, we need to recognize the asymmetry gap in information. Physicians know the clinical information. Patients know everything about their lives and their values. Bridging this gap so that real conversations occur requires training, on both sides. It’s not a natural process for anybody.”

Lewis Sandy, MD

Today, numerous consumer-driven strategies are being implemented in the health care system. Health savings accounts, for example, are meant to provide consumers with more control over their health care dollars and, presumably, more awareness of what things cost when they use those dollars.⁴ The creation of specialty pricing tiers that often dramatically increase the out-of-pocket payments associated with predominantly high-cost medication is another approach designed in part to encourage consumers to be more sensitive to the cost of medications and explore cheaper alternatives when appropriate. However, using “price signals” alone to steer patients towards or away from a therapy or service is not in and of itself a consumer engagement strategy.⁵

When asked about making a decision around treatment for their disease, a third of the respondents in this project's opinion survey stated that they wanted the most medically beneficial option, regardless of the treatment cost.

"I think that asking these questions up front and understanding how patients want to get information saves time. Rather than starting from the beginning each time, going through a trial and error process, you know that this person likes charts and data, or this one wants to ask a lot of questions, or this one doesn't want as much detail."

Lillie Shockney, M.A.S.

DISTINGUISHING COST FROM VALUE

In conversations about what matter to patients, information about costs and price signals offered in isolation are not sufficient to help patients make decisions about their care. The critical distinction is between "value" and cost. Patients can't compare the "value" or benefits of two different treatments with only information about the cost because they have no basis upon which to compare cost to benefit.⁶ Consumer strategies that focus entirely on the cost component may actually run counter to the fundamental goal of trying to improve the patient's health, as indicated by a comprehensive literature review of 160 articles on the topic which concluded that increasing the price signal with regard to medication actually decreased adherence and health outcomes.⁷

At the very least, information or consumer signals about cost must be provided alongside information about the quality of the benefits and the nature of the risks in order to provide an opportunity for patients to construct a care plan they believe will provide the greatest value based on what matters most to them.^{8, 9} Some researchers have even concluded that consumers are more interested in the quality of health care than in its cost.¹⁰ **When asked about the out-of-pocket costs**

for treatment versus the benefits experienced or gained, 3 out of every 4 respondents stated that improvements to their overall health were worth the costs of the treatment or procedure. Others have documented an aversion to or unwillingness on the part of some patients to consider cost as a factor in decision making.¹¹ A 2012 IOM report issued the following recommendations: "Health care delivery organizations, clinicians, and payers should increase the availability of information about the quality, price, and outcomes of care, and professional specialty societies should encourage transparency in the information provided by their members. Consumer and patient organizations should disseminate this information to spur conversations and promote informed decision making."¹²

PROVIDING CLARITY AND CONTEXT FOR DECISION MAKING

Simply serving up to consumers a plethora of data regarding benefits and risks alongside cost in an effort to create transparency is not sufficient. Patients need more than just transparency to be engaged consumers. Information systems must provide clarity and context to inform preference-sensitive decision making. Benefits, cost, and risk information must be understandable, relevant, and specific to the patient.¹³

This information, for example, must include the impact that a treatment or procedure may have on the patient's ability to continue working during or after an intended therapy selection. When chronically ill patients, who were either currently in treatment or recently treated for their disease, were asked in this project's opinion survey about their employment status in the last 12 months 17% either lost their job or had to retire prematurely and an additional 12% who were unemployed stated that their condition made it difficult to find a new position.

Patient preference research, for example, indicates that patients want cost data that reflect their own out-of-pocket expenses for an entire episode of care, not for individual procedures and services.¹⁴ Information

about cost should also incorporate the practical circumstances that may contribute to a patient's substantial financial burdens, such as transportation, childcare and absenteeism. While they are very real to the health care consumer, they are not subject to, nor counted towards, out-of-pocket maximums delineated in the benefit design. Context requires that patients evaluate the benefits, costs, risks through the personal lens of their goals and what is important to them to provide a personal value framework against which to make meaningful comparisons across these various domains.¹⁵

When asked about their ability to express their goals, needs and preferences related to costs, side effects and other impacts related to treatment options with their medical providers, more than 50% of respondents in this project's opinion survey felt they were well equipped to have these types of conversations and 80% felt that it was important for all patients to have this ability.

In addition to cost considerations, limitations on the number of options may actually be beneficial to consumer engagement. Too many choices can make it difficult for many health care consumers to make a decision, especially when the choices are complex with multiple tradeoffs. Having a narrow range of personalized, evidence-based choices presented in the simplest way possible is likely to be more empowering to most patients.

A systematic review of the literature in this area by Kurtzman and Greene concluded that: "Consumers better understand and make more informed choices when the information display is less complex. Simplification can be achieved by reducing the quantity of choices, displaying results in a positive direction, using non-technical language and evaluative elements, and situating results in common contexts."¹⁶

Individual patient goals and preferences related to their health care will vary from person to person based on a variety of factors including type of disease, stage of disease, stage of life, race/ethnicity, and income. **When patients were asked in this project's opinion survey to identify and indicate their level of importance for multiple treatment considerations, including cost,**

avoidance of treatment complications and impacts on quality of life, the results of this question provided no clear answer pattern, supporting the theme that each patient's journey is unique. True consumer engagement allows the patient to have the opportunity to weigh benefits, risks, and costs and arrive at a decision that reflects a balance between these three dimensions. The trade-off between competing values represents a "consumer-driven" approach to care that in many ways mirrors other market-based delivery systems.

One method that patients use is to compare the anticipated side effects vs. the benefit they hope to receive. When asked about these tradeoffs with respect to the treatment they choose to address their chronic illness, over 50% of the respondents in this project's opinion survey indicated that the medical benefit they received from the treatment was worth the side effects they experienced during the treatment process.

Engaging consumers requires personalizing the options, not maximizing them. The criteria used to narrow potential options are at least in part reflective of what patients have identified as important to them and not just reflective of what the doctor or the insurer has determined *a priori* should be most important. Decision support tools (DSTs), for example, should enable personalization of appropriate choices rather than deny patients an opportunity to personalize their care. This can be accomplished in ways that are completely appropriate and evidence-based (see Section 2 for further details about DSTs). Carman et al. found that patients viewed the discussion of evidence as an essential role for their doctors, and that doctors act as a trusted source for how the evidence applied to the patient's individual case.¹⁷ In person-centered care, however, efforts should be taken to empower patients to play an active role in narrowing options, and then comparing those options using variables they (as opposed to the physician) have defined as important.

The processes by which the health care system defines and limits options based on medical evidence and insurance viability are fairly well established and applied. What the system lacks is the ability to systematically and routinely capture the preference-

sensitive information needed from the patient to help make sure input at the individual level also shapes the available options. We need far deeper and broader understanding of how individual patients think about these dimensions, and how and why it varies.

A number of key factors influence the process and outcomes of understanding what matters most to patients. These include recognition of the following circumstances:

- What matters most will vary from patient to patient. These differences will stem from subjective/situational factors such as personal preferences, age, health status, social status, cultural and family issues and external factors such as insurance coverage and clinical setting.¹⁸
- What matters most will change throughout the treatment process and needs to be reassessed on a regular basis. Determining core decision-making points is a key driver in developing collaborative/cooperative care models.
- Finding out what matters most requires that patients and caregivers have timely, usable information about the costs, benefits and risks of their care.
- Understanding what matters most requires both hearing the individual patient voice in patient provider interactions and the collective one through data collection and analysis.
- Decisions often have significant downstream impact.
- All patients, regardless of their health, social status, or health literacy are capable of making shared decisions about their care.
- All patients expect and deserve respect and benefit from a collaborative, cooperative relationship that includes open communication.

CASE HISTORY

Shonta: Changing Roles and Needs Over Time

Shonta's mother was diagnosed with progressive multiple sclerosis in the early 1980s when Shonta was in high school. Shonta has served as her primary caregiver since the early '90s. In the years immediately after her diagnosis, her mother didn't tell Shonta she had MS, wanting to protect her daughter from the knowledge of her illness. As her mother's disease worsened, Shonta became more involved, began to ask questions and educate herself about MS. Shonta continues to raise her sons, and pursues a very active career, but her role as a caregiver has increased and become a "dominant" part of her life.

"In the last few years, I have really transitioned from my mother's child to her caregiver. It's been gradual. With the progression of her condition, she has more cognitive dysfunction. Her physical impairment has gotten worse. So, she is less able to take care of many things that she used to do, and with that my role as caregiver has become more important. I try, as much as possible, to make sure she is involved and active in her own care. Her doctor has always been aggressive in treating her disease, but about two years ago we had to make a decision. There was a new drug that might be less effective in preserving her function but have fewer side effects. The question was does this provide the best quality of life for her. Her doctor asked her how she felt about things. They have a relationship and he knew that for her, it's about preserving quality of life. To her, that means spending time with her grandkids. We decided to go with the new drug. It's really about having a health care provider that really listens, actively listens. It is so important. Not just hears, but really listens."

■ SECTION 2

KEY OPPORTUNITIES IN THE HEALTH CARE SYSTEM TO CREATE CLARITY IN DECISION MAKING

Patient decision making is a merger of skills and science, a point at which clinical knowledge and patient preferences and values come together. The process for integrating the various components that comprise patient decision making is of equal importance to the information itself. The Roadmap to Consumer Clarity requires a clearly defined set of specific activities and tools that support the decision-making process and optimize the opportunities for person-centered care.

Most of the processes and activities necessary to maximize consumer engagement within the clinical workflow already exist, but in many cases, the information is not presented or utilized in ways that facilitate communications on key issues at critical decision-making points. To be effective, those activities must be reoriented to ensure that the information is personalized to the patient and reflects social, emotional, spiritual and physical dimensions as well as the clinical aspects of decision making.

The goals are to:

- Provide usable, understandable information about the relative costs, benefits and risks of treatment throughout the care and treatment process
- Provide the patient and family with a foundation for making decisions based on individual values, goals and preferences
- Link to a clear and detailed goal-concordant plan for the delivery of services that support these decisions

- Provide tools for making and assessing decisions that align with stated values and goals
- Provide navigation support, both in person and through use of digital tools
- Take action that is consistent with evidence-based treatment and care
- Link patient preferences to measurable outcomes

The following activities in the health care system represent the most important opportunities to provide or use information about cost, benefits, and risks in ways that can truly personalize the care experience and ideally also optimize the lived experience. They are grouped into two general categories: 1) those processes that generate or process data created by patient action; and 2) those that use data to inform or trigger actions.

Activities That Generate or Process Data Created by Action	Activities That Turn Data Into Action
Utilizing decision support and decision support tools (DST)	Shared decision making (SDM)
Generating patient-reported outcomes (PRO)	Care planning and communication
Conducting ongoing quality measurement (QM)	Care navigation and coordination

These activities are the Roadmap's basic building blocks, providing the means to use data to inform decision making, and to create data to inform future decision making. They must all be present to some degree in the life cycle of the patient's decision-making journey, and they must come together in an integrated fashion to create a person-centered system of care (see Section 3).

The Roadmap project seeks to assure that these critical components of person-centered care are present in the system in ways that are customized to meet the patient's needs.

SHARED DECISION MAKING

Shared decision making is a key component of person-centered health care. It is a process in which clinicians and patients work together to make decisions and select tests, treatments, care plans and supportive services based on clinical evidence that balances risks and expected outcomes with patient preferences and values.

When asked if their doctor spoke with them about how they would like to receive medical information and to what level they would like to be involved in making health care related decisions, 59% of respondents in this project's opinion survey indicated that their doctor initiated this conversation during their visit and 55% want to be a partner in making decisions with their provider.

Shared decision making is perhaps the most important opportunity for the consumer to engage as partners with the provider in a process that brings clarity to the various care options, and allows the patient to make an informed choice. This approach is critical because patients weigh options differently based on "preference sensitive filters." These individual goals or values lead them to choose or not choose "particular treatments, or to be treated at all, depending on their own feelings about the risks versus the benefits of treatment, their ability to live well with their conditions, or other factors."¹

Most health care providers practice, or at least try to, shared decision making to some degree. This process

is critical in allowing patients and providers to match preferences and goals related to benefits, risks, and costs with clinically appropriate care options. The conversation about treatment choices is a highly personal, important moment for patients during which they seek information and analysis to provide them with insights about tradeoffs between potential options.² The chances of the "right decision" being made are greater when both the patient and provider contribute to the information that shapes the decision.³

"Fewer than half of patients believe their clinicians understand their goals and concerns, and many people who are seriously ill say their medical care is not aligned with their preferences. Nearly half of the time when doctors say they discussed prognosis and likely outcomes with patients, their patients say there was no such conversation."

Dhruv Khullar, MD
New York Times
September 16, 2016

No clear standard or process exists for how shared decision making should occur. Too often, the focus is on the obstacles, rather than the opportunities. Commonly cited barriers to implementing shared decision making are overworked physicians, time constraints, insufficient provider training, and clinical information systems that do not track patients throughout the decision-making process.^{4,5} Numerous steps can and should be taken to create a meaningful process for patients, providers and health systems to overcome these and other barriers. Skills building and system modifications that prioritize communication and enhance the shared decision making discussion include:

- Better preparation and training for patients. Patients and caregivers often receive little or no preparation on how to be part of the decision-making process.⁶ Decision making requires access to information about the process itself, knowledge about how to differentiate and discuss options, and in some

instances, education about how to be an effective self-advocate. **These needs are reflected in the response to a question about how best to enable or help other patients when it comes to the ability to self-advocate for treatment: 86% of respondents in this project's opinion survey felt that learning or knowing how to express their goals, needs and preferences was very or extremely important.**

- Training for clinicians and health care team members. Physicians receive little training in how to discuss treatment options and quality of life priorities in the setting of serious illness, or how to involve their patients in decisions. While other members of the team may have more training and time for these discussions, the physician remains a central figure in a successful shared decision making process. Evidence-based communication skills training programs and resources for health professionals are available in multiple formats, including through an innovative “VITALtalk” platform (www.vitaltalk.org) recommended in two recent Institute of Medicine consensus reports that offer online talking and teaching maps and curricula, smartphone apps, and in-person advanced communication skills courses and faculty training sessions.⁷
- Normalizing conversations between patients and care teams about personal priorities. Discussions about what matters to people should become part of the workflow process of treating them.
- Shared decision making requires adequate time and skilled communication to have a meaningful conversation. Better preparation, more effective use of technology and skills development training can make the process more efficient, but time remains a critical component. Physicians and other clinicians are often overscheduled, lack communication skills training, and have little flexibility to extend time to cover all the needed ground in clinical conversations with patients. Effective shared decision-making models need to recognize this barrier and build approaches that improve efficiencies through training, technology and advance preparation without sacrificing the quality of the engagement.
- More effective use of non-physician members of the health care team to support engaged conversations with patients and caregivers about their individual preferences, goals, values and life factors that affect their decision making.
- Clinical data systems that track patient decision making throughout the treatment process. Most electronic medical records are not a viable solution for dynamic patient interaction as they were built around providers and the transactional service and payment environment.
- They were not designed to specifically track the decision-making process or changes that may occur during care transitions, and their inherent limitations around interoperability do not provide a platform for continuity of patient engagement. They were not designed to specifically track the decision-making process or changes that may occur during care transitions, and their inherent limitations around interoperability do not provide a platform for continuity of patient engagement.
- More direct discussion of cost and financial factors. Costs are increasingly critical to patients in assessing their options and making choices. Many physicians are neither prepared nor able to incorporate that conversation into their patient interactions. Resources need to be identified and created that increase transparency about costs of care to support these conversations. The discussion needs to include anticipated out-of-pocket costs as well as indirect costs, such as lost job time, childcare and transportation needs that may influence choices about treatment options.
- Improved standardization and evaluation of the shared decision-making process. Attempts to standardize key elements of care to reduce variability using tools such as process measurement and clinical pathways are commonplace in the clinical setting. Patient-reported outcomes are one key method of capturing both common issues and concerns and identifying areas in which individual preferences or values are more important. New and better development of person-centered quality measures must be tied to identifying and honoring

patient preferences, and clinicians must utilize those person-centered quality measures in the shared decision-making process.

Activities related to the decision-making process currently receive relatively minor attention from payers and professional societies in terms of standardization and evaluation. A robust and properly structured shared decision-making process provides a basis for standardizing both the process and outcomes while allowing for appropriate variability. It also can reduce cost. For example, a study by David Veroff found that patients who received enhanced decision-making assistance had 12.5% fewer hospital admissions and 20.9% fewer heart surgeries, which contributed to overall medical costs that were 5.3% lower than for those receiving only the usual support.⁸

CASE HISTORY

Blyth: The Value of Anticipatory Guidance in Decision Making

Blyth's daughter, Cameron, was diagnosed with Tay-Sachs disease, a fatal, genetic condition that results in progressive disability, seizures and death, usually in early childhood. Blyth and her husband had no illusions about the prognosis, and in fact, were familiar with Tay-Sachs because their nephew had been diagnosed with the same condition a year before Cameron. Blyth was able to work closely with Cameron's pediatrician, who served as the primary care provider and coordinated her care. Together they made decisions about Cameron's care including the most difficult ones related to when to stop actively treating her. Shared decision making and palliative care from the beginning of the process were critical in helping Blyth and her husband cope with this illness, its progression, and Cameron's eventual death.

"We always knew we were focused on quality of life. I mean, honestly, with her diagnosis, there was no treatment and no cure, so it was only about quality of life. We had to decide what quality of life means to us, what we think it means to her, and does quality of life

equate with length of life. There were choices we made that were not just about comfort care, that were about duration of life.

"The most important component (of the relationship with the doctor) was one of trust. Just absolute and total trust in him and his respect for us. We trusted him to guide us and listen to us. He understands disease and symptom management in a way we do not. At the same time, we were the ones who were in control of what defines quality of life for our daughter.

"Anticipatory guidance is really helpful. We knew all the bad things that were coming. We weren't living in fear of the other shoe dropping because we knew that eventually seizures were going to happen. We knew that she would get pneumonia, that we would have to decide about putting a feeding tube in. It's unpleasant to wait for the seizures to start, but at least you know what to expect and I think that was very helpful.

"Through my creation of Courageous Parents Network (www.courageousparentsnetwork.org) I have become an advocate for parents of seriously ill children. I tell them they want to have a doctor or care team that they trust, that listens to them and communicates honestly. I tell them they want to find a community of others who can help them feel less alone, which is typically other parents. And, I recommend that early in their child's illness, they get a good palliative care team in place to provide an extra layer of support as a lifeline to quality of life."

RECOGNIZING AND MANAGING VARIABILITY IN DECISION MAKING

Every person confronting a serious illness wants to have some level of understanding about that condition, the treatment options and the impact on quality of life, including the implications of the illness for their entire family. The ways in which people engage the health care system to get information and make decisions vary significantly. These differences result from multiple factors including age, gender, overall health status, health literacy and information-seeking preferences,

personality and cultural issues that influence patient provider relationships. The decision-making process also evolves with the duration and severity of the illness experience. Patients often express one set of goals at the point of diagnosis and the early stages of treatment but may change as a condition becomes more chronic, improves or worsens. Many patients who are overwhelmed at the beginning of an illness experience develop better communications, coping and self-advocacy skills as they move through the process. They may also build more trusted, established relationships with health care providers over time that enhance communications, connections and shared decision making.

Patients and caregivers also differ in terms of how much information they want and the extent to which they want to be involved in the decision-making process. Not every patient wants the decision-making process to be shared.

In fact, 10% of respondents to this project's opinion survey wanted to be in complete charge of their health care decisions and 2% wanted their medical team to make the decision for them.

Some people feel more comfortable with their doctor telling them what they should do while others opt to make a decision with limited input from their physician. Others are aggressive seekers of information and expect to be full partners in the decision-making process. Patients also will vary in how much weight they give to the level of scientific evidence regarding benefits, side effects or quality of life implications. They may also differ in how sensitive they are regarding cost.

37% of respondents to this project's opinion survey wanted to consider the cost benefit ratio to determine the best treatment fit for their financial situation, while 33% responded that they want to use the most medically beneficial treatment regardless of the cost.

These preferences are often not fixed and are likely to shift over time as the patient progresses through the care journey. In every case, it is important for clinicians to specifically ask patients and their caregivers about their preferences on how they would like to get information about their condition and their care.

Medical decision making is increasingly evidence-based, but for many patients, data are just one component of the shared decision-making process. Individual values and preferences and the patient physician relationship play key roles as well. After interviewing nearly 1,000 participants, the Community Forum Deliberative Methods Demonstration project concluded that “although participants perceived evidence as being essential to high-quality care, they also believed that personal choice or clinical judgment could trump evidence. They viewed doctors as central figures in discussing evidence with patients and key arbiters of whether to follow evidence in individual cases.”⁹

Providers also bring very different skill sets, personalities and perspectives, and sometimes biases, to the decision-making process. The goal is not to homogenize the provider-patient relationship, but rather to develop models that allow for a standardized approach that accounts for this variability. This requires better definition of the shared decision-making process as well as training for clinicians in how to create an experience in which the patient feels that he/she is making informed choices aligned with personal preferences.

Shared decision making is not a bi-modal phenomenon—one that either occurs or does not. Variability on the part of health care providers and patients creates a continuum with a significant range of patient decision-making power. Carman et al. described two extremes of patient engagement in decision making:

“At the continuum’s lower end, patients are involved but have limited power or decision-making authority. Providers, organizations, and systems define their own agendas and then seek patients’ input. At the continuum’s higher end, engagement is characterized by shared power and responsibility, with patients being active partners in defining agendas and making decisions. Information flows bi-directionally throughout the process of engagement, and decision-making responsibility is shared.”¹⁰

The goal of the Roadmap is to engineer a decision-making support system predicated on this higher end of engagement that acknowledges and embraces the natural complexity of this process. The system should create processes that allow for variation and uncertainty in patient preferences to be aligned against the most appropriate care options.¹¹

DEVELOPING A STANDARDIZED APPROACH

While shared decision making involves a high degree of variability for both patients and providers, the system can also be designed to assure appropriate standardization. To some extent, this balance requires a reconceptualization and retooling of the interaction between the health care team and the patient. These systems revisions represent a significant step in the direction of person-centered care, but the actual processes required are not that complicated. They begin with better preparation on the part of both the health care team and the patient to assure that the information is available and understood and that the time is well used. Digital tools can play a key role in this preparation, helping to focus patients and their caregivers on key issues and minimizing the time investment for all parties. Preparation for shared decision requires groundwork:

- Prior to a shared decision-making engagement, patients should be provided with an explanation of the process and the patient's role in it. This should include discussion about what role the patient wants others to play in the process, including both members of the health care team as well as caregivers, family and friends.
- The initial explanation should be followed by an assessment of the patient's readiness and preferences related to shared decision making.
- Feedback from this pre-shared decision-making work needs to be communicated to the provider so he or she knows beforehand some key information about what the patient's attitudes and goals are related to the process.

Once initiated, a standard set of question prompts should guide the shared decision-making discussions. It is critical that these be tailored to accommodate different diseases and different cultures.¹² The key is to allow preferences related to benefits and risks into the decision-making process in a standardized manner.¹³ Routinely asking patients about their understanding of their illness situation at the current time can also elicit helpful information that providers can use to guide these conversations and help support informed and shared decisions.

A routine set of questions asked at each visit allows the patient to walk into the appointment feeling prepared and provides the clinician with a metric that can be tracked and evaluated over time. The Consumer Based Cancer Care Value Index was able to capture this concept by asking patients how often their care team asked them about side effect management over the past 12 months.¹⁴ Almost half (47%) indicated that they were always asked this question, and an additional 20% stated they were almost always asked this question.

A range of different care and support options need to be part of any shared decision-making process to include "prognosis, treatment benefits and harms, palliative care, psychosocial support, and estimates of the total and out-of-pocket costs."¹⁵ The information provided should be personalized as much as possible based on the best available evidence through the use of decision support tools.¹⁶ The provider can then filter the different options using the preferences expressed through the decision aid and explain the degree to which various options align with those preferences.

When asked if they would feel comfortable telling their doctor that they would like to discuss what is important to them in terms of their quality of life, 41% of respondents to this project's opinion survey indicated that they would be open to initiating this conversation.

CASE STUDY

The Share Approach Workshop

The **SHARE Approach Workshop Curriculum** is designed and promoted by the Agency for Health Care Research and Quality (AHRQ) to foster health decisions that take into consideration evidence-based information about options, provider knowledge, and the patient's values and preferences.

Two commonly cited barriers to this shared decision-making (SDM) model are over-worked physicians and insufficient provider training. The SHARE Approach addresses both of these barriers through curriculum materials which facilitate a team-based approach to shared decision making in person-centered care during the clinical encounter, with emphasis on the provider's five essential steps to SDM:

1. Seek the patient's participation
2. Help the patient explore and compare treatment options
3. Assess the patient's values and preferences
4. Reach a decision with the patient
5. Evaluate the patient's decision

The one-day training program, available online and free of charge, provides support for organizing clinical practice to effectively engage patients in meaningful dialogue. Four content modules include detailed downloadable facilitator guides, training tips, webinars on topics related to implementation of SDM, a toolkit of reinforcing materials, checklists for implementation, forums for sharing experiences, and success stories to model effective implementation. Quick reference guides present a compendium of information to:

- Identify points at which patient-centered outcomes research resources can be introduced
- Provide sample dialogue
- Identify signs of decisional conflicts
- Offer tips for overcoming communications and literacy barriers
- Explain how to convey meaningful numbers and understandable risk information
- Highlight the value of teach-back techniques; and
- Offer assessment tools for measuring the health organization's cultural and linguistic competencies.

In addition to its emphasis on preparing the entire medical team to engage with the patient as the center of SDM, the SHARE Approach also offers support for helping patients to clarify their own values and preferences, and for understanding why those preferences are especially critical when evidence-based assessments of treatment options don't identify one clearly superior treatment.

Patients make decisions at multiple points in their journey through the health care system, so it is possible to apply the same basic structure and process repeatedly at each of these points. Key decision points for a cancer patient, for example, include "the time of initial diagnosis, when patients experience cancer progression or recurrence, following treatment, or when the goals of care or patient preferences change."¹⁷ For an individual with MS, diagnosis, relapse, remission and progressive disease could be potential key points.

THE AHRQ SHARE MODEL



To be effective, a standardized, common process for patient engagement in decision making needs to be engineered into every aspect of a patient's health care journey where an important decision is made. The ultimate goal, as the IOM noted in 2013, is to create a process that listens carefully to patient and caregiver voices at every level of decision making.¹⁸ While basic elements of the process would be standardized, the information conveyed during this process should be personalized and "patient specific" to take into account their culture, language, health literacy, gender, age, and emotional needs."^{19,20}

Health IT can play an important role in this process by providing a platform that helps the patient and provider prepare for the shared decision-making process as well as facilitating a standardized process that still enables customization.

CASE HISTORY

Rachel: Changing Needs and Decision Making for Chronic Illness

Rachel's mother has been ill for her entire adult life. She was diagnosed with Lyme disease when Rachel was a senior in high school. Her condition has deteriorated over years and has been complicated by a life-long struggle with depression. Rachel and her brother have provided physical care and emotional support for their mother for over 30 years, combining their roles as caregivers with their own lives as they finished their educations, married, raised their children and pursued their own careers.

"I want to be clear about the difference between the sort of emotional connection around her, her needs and her illness and the sort of executive function of partnering with her. I mean she is completely compos mentis, but she struggles with depression. So those are the kinds of things we're thinking about. We're figuring out what we can and can't help her with and what that partnership looks like.

"I think that the key is always remembering that it's a real person in front of you and not a case. That's

something that many clinicians still struggle with in some way, which is why it is so rare to find a specialist that has a specific kind of technical depth that you need in terms of their expertise, but can still treat someone as a person.

"In terms of what is important to her, I have not heard them ask that exactly, but I have heard them get to know her and understand a bit about what makes her tick and what's important to her. I guess indirectly. I think they could really be asking questions like "What do you want your health for?" That would help her caregivers and her clinicians understand her a little better."

DECISION SUPPORT TOOLS

Decision support tools (DST - also known as decision aids) are intended to help providers and patients understand various care options and engage more effectively in shared decision making.²¹ For example, clinical pathways are a common DST used in the physician practice setting. Consumers use online tools like WebMD to search for information by symptom or disease. Studies show the use of patient decision aids for a range of preference-sensitive decisions lead to:

- Increased knowledge
- More accurate risk perceptions
- A greater number of decisions consistent with patients' values
- A reduced level of internal decisional conflict for patients
- Fewer patients remaining passive or undecided.²²

When combined with shared decision making, a robust DST can help address the problems of overdiagnosis and overtreatment. For example, the use of patient decision aids in shared decision making for preference-sensitive conditions has been shown to reduce patients' selection of major elective invasive surgery in favor of more conservative treatment options.²³

“We are all in favor of shared decision making. The question is how do we do that. What are the evidence-based tools for teaching physicians how to have these conversations? How do you prime the patient population to use the available information? What tools exist out there that have been vetted and demonstrated to work?”

Kathleen Foley, PhD

A sophisticated digital platform can also incorporate interactive and dynamic decision support tools into the shared decision-making process. These tools should be designed to help a patient and provider match the best scientific evidence with the patient’s preferences related to benefits, risk and costs in part based on real world data about the experience of patients who have selected different care options. This approach is analogous to the way a hotel search engine can find hotels that match specific criteria determined by the user while giving the decision makers ratings based on the experience of previous hotel guests.

Ironically, some of the tools created by payers and providers to help reduce potentially inappropriate variability in treatment decisions, such as clinical pathways, do so by making predetermined decisions about the best option for a patient based on the application of very general eligibility criteria (e.g., type and stage of disease). When applied rigidly, these are attempts to engineer a predetermined treatment option limit or eliminate customization by circumventing the shared decision-making process. This approach makes it difficult to incorporate key attributes of the care decision that may be meaningful, relevant, and appropriate for optimizing care options unique to the individual patient.

The ideal DST would have the following characteristics:

- Be easy to use and provide accurate information.
- Allow consumers to understand their share of cost, the total cost, and their spending and utilization to date.

- Identify preference-sensitive care options aligned with evidence.
- Adjust for certain variables that may impact care selection including race/ethnicity, transportation, genetics, and financial toxicity.
- Help navigate discussions about uncertainty.
- Show quality ratings and feedback that are credible and matter to consumers.
- Allow consumers to compare price and quality easily and side-by-side.
- Help consumers identify and understand likely benefits and risks.
- Contain information on pharmacy and ancillary services, as well as other information designed in particular to assist the elderly and chronically-ill.
- Help consumers avoid unneeded care and identify less expensive but still appropriate care options.
- Easily customize and integrate smoothly with other platforms and products.
- Give employers reports on utilization and savings, and involve them in continuous quality improvement activities.
- Include support for determining the right social support services.
- Identify evidence-based quality measures that could be used to help track and score the success of the care plan.

Decision aids can be especially helpful when multiple scientifically valid options exist and each has different pros and cons depending upon the patient’s preferences. Every care option will vary in its level of likely benefits and side effects as well as cost. Similarly, patients are likely to vary in terms of their preferences in each of those areas and the tradeoffs they are willing to make between them.

While many decision aids are currently being used in clinical settings, there is a clear need for more research to evaluate their effectiveness and efficiency, especially with specific patient populations. This includes work to evaluate:

- Adherence with the chosen option
- Associated costs
- Use with patients who have more limited reading skills
- The level of detail needed in a decision aid.²⁴

In addition, patients need to be trained in some basic skill sets in order to use a robust DST including “understanding probabilistic risks and benefits; ability to identify personal values and preferences and self-efficacy for Ask Share Know questions to engage in SDM during health care interactions.”²⁵

GOAL-CONCORDANT CARE PLAN

The logical outcome of using decision aids in shared decision making is to create a care plan that outlines the goals of care, and documents diagnosis, prognosis, the planned path of care, and who is responsible for each portion of that care.²⁶ Ideally, the plan should be “goal concordant” to reflect the patient’s personal needs, values, and preferences regarding tradeoffs between benefits, risks, and costs spanning treatment, palliative care and psychosocial support.²⁷ The care plan must be captured digitally in a dynamic way so patients can track their progress, provide data and feedback related to their care goals, and interact with their care team.

In addition, the plan must be readily understood and digestible by the patient. For example in the CCCVI study, patients were asked if their medical team explained things in ways that were easy to understand (Always 54%) and if they understood the next step in their treatment process (Always 51%).²⁸

A 2013 IOM committee identified thirteen key elements that should comprise a person-centered care plan for people diagnosed with cancer:²⁹

- Patient information (e.g., name, date of birth, medication list, and allergies)
- Diagnosis, including specific tissue information, relevant biomarkers, and stage
- Prognosis
- Treatment goals (curative, life-prolonging, symptom control, palliative care)

- Initial plan for treatment and proposed duration, including specific chemotherapy drug names, doses, and schedule as well as surgery and radiation therapy (if applicable)
- Expected response to treatment
- Treatment benefits and harms, including common and rare toxicities and how to manage these toxicities, as well as short-term and late effects of treatment
- Information on quality of life and a patient’s likely experience with treatment
- Who will take responsibility for specific aspects of a patient’s care (e.g., the cancer care team, the primary care/geriatrics care team, or other care teams)
- Advance care plans, including advanced directives and other legal documents
- Estimated total and out-of-pocket costs of cancer treatment
- A plan for addressing a patient’s psychosocial health needs, including psychological, vocational, disability, legal, or financial concerns and their management
- Survivorship plan, including a summary of treatment and information on recommended follow-up activities and surveillance, as well as risk reduction and health

Only 55% of respondents to this project’s opinion survey said that after the disease diagnosis, their clinician asked them about what they consider important in regards to making plans for their treatment.

CARE COORDINATION AND NAVIGATION SUPPORT

Health care is a complicated ecosystem, medically, financially, and logistically. A care plan provides an essential platform for care coordination and navigation by consolidating key information about the patient into one place that can be viewed by all the relevant clinicians likely to be involved in the care plan’s execution.³⁰

Care coordination improves the patient experience and also can save money for both the patient and the system by minimizing unnecessary duplication of tests

and procedures as well as avoiding potential safety concerns created by unknown or unsafe drug or other treatment combinations.³¹ While the clinical care team must work together to coordinate medical care for the patient, the missing element is often a navigation element focused on the patient's logistical, financial, and psychosocial support needs. A navigator who represents the consumer's best interest is a common feature in other markets with similar complexity like real estate, law, investments, and mountaineering.

Health care systems are moving towards this model. When queried about the use and accessibility of an advocate/navigator during their time at a cancer treatment center, 54% of respondents to this project's opinion survey indicated using this resource with an additional 18.5% stating that they wish a navigator had been available to them.

This function spans a variety of areas currently covered to varying degrees by different staff depending upon the resources a health system can dedicate to such activities. These include nurses, social workers, financial counselors, hospital navigators, and community health workers. The increasing prevalence of these types of positions reflects the complex interplay that exists between the patient's clinical journey and the everyday issues related to work, emotional wellbeing, childcare, transportation, food, and housing. Life elements have important, substantial costs and benefits that can influence a patient's adherence to care both positively and negatively.

These factors need to be evaluated and incorporated into the decision-making process. Without them, a patient could, for example, select a treatment

PALLIATIVE CARE AS A PERSON-CENTERED MODEL FOR SHARED DECISION MAKING AND MAXIMIZING QUALITY OF LIFE

Palliative care is an interdisciplinary, team-based model of care devoted to improving the quality of life by prioritizing and aligning services that relieve pain, symptoms, and distress while providing skilled communication about what matters most to patients and their families and well-coordinated and communicated care over the course of a serious illness. It is delivered at the same time as curative or disease-directed treatments as an extra layer of support for any age and any disease stage. Eligibility is based on patient and family need and not on prognosis.

Palliative care has been shown to reduce symptoms and enhance quality of life, improve doctor-patient-family satisfaction with care, enhance efficiency and effectiveness of hospital services, reduce health care costs, and in cancer patients, improve survival.^{1,2,3,4} Despite being a relatively new field, palliative care has become one of the fastest-growing medical specialties, with more than 95% of all mid- to large-size hospitals

in the US now having palliative care teams and models of palliative care delivery being rapidly created and disseminated in non-hospital care settings.⁵

This expansion is in direct response to the increasing numbers and needs of adults and children living with serious, complex and chronic illnesses, and the realities of the care responsibilities faced by their families. Forward-thinking hospitals, health systems, health plans, and health professionals are increasingly recognizing the importance of palliative care's contributions to care coordination, pain and symptom management, shared decision making and person-centered goal setting as important complements to disease-directed treatments that help improve the lived experience for seriously ill adults, children and their families throughout the care continuum.

Unfortunately, most patients and families who could benefit from palliative care do not know of its existence or equate palliative care with end-of-life care or hospice and thus cannot or do not request palliative care

option in which the transportation and absenteeism demands jeopardize his or her ability to adhere to treatment, when other appropriate options exist that don't require as much time away from work and/or as much travel.

Even when these factors are carefully considered during the shared decision-making process, most patients are going to experience unforeseen problems and challenges as they implement their care plan. The system needs to allow for opportunities to identify and intervene as these issues arise.

Currently, patients are often offered assistance with the many pitfalls they can encounter reactively rather than proactively, especially when it comes to managing their emotional, physical and social support needs. Efforts to address non-clinical or unanticipated issues

are often fragmented and uncoordinated. In addition, these services are often tied closely to only one aspect of the patient's journey, such as time spent in the hospital or clinic associated with a specific service like surgery or chemotherapy.

The spectrum of navigation functions need to be centralized and coordinated to maximize the likelihood that the financial, social, physical, and emotional goals imbedded in the patient's care plan are realized. These functions should not be limited only to the "four walls" of a particular institution. Patients spend most of their time outside hospitals and clinics so the tools that support their care plan and navigation needs should be readily accessible to them in their homes, work places and communities.

when they can most benefit from it – early and throughout the course of a serious illness. Recent market research revealed, however, that once people are made aware of palliative care and its benefits, they overwhelmingly (92%) report they would want it as an extra layer of support during serious illness for themselves or their loved ones.⁶ Similarly, many physicians have misperceptions about palliative care, particularly those trained before palliative medicine became a board-certified subspecialty about 10 years ago, because they received little to no training in the core knowledge and skills of palliative care and had no exposure to modern palliative care teams during their educational training. Moreover, the number of palliative care specialists falls far short of what is necessary to serve the current population in need.

Ensuring reliable and equitable access for all adults and children needing palliative care to optimize their quality of life will require these key action steps in the context of the Roadmap:

- Patient and provider education to increase awareness of palliative care's benefits.
- Primary palliative care skills core competencies training for all clinicians in all hospital and community care settings to equip them with basic skills in pain and symptom management and person-centered communication.
- Workforce initiatives to ensure sufficient numbers of palliative care specialists to teach health care trainees and practicing clinicians in the core knowledge and skills of palliative care, conduct the needed research to enhance the evidence base, and provide appropriate care for the most complex populations of seriously ill patients and their families.
- Research support to augment the current inadequate evidence base guiding clinical care.

Appropriately constructed digital platforms can address these issues and simultaneously provide solutions. A dynamic, interactive digital interface should be a primary means of delivering most navigation services to most patients. Just like DST can be linked to data sets and algorithms that help identify and filter various care options, so too can navigation support tools help automate, centralize, and coordinate a navigation function for key supportive services.

Navigation functionality should be imbedded in the IT platform that supports the care plan. A more IT-driven approach will allow social support and other navigation services to be scaled while making sure that “live” support and “in-person” services are used in a targeted, prioritized manner. If patients are providing data to the IT system related to their level of financial or emotional distress or key side effects like depression, pain, nausea, and neuropathy, then certain thresholds can automatically trigger notifications to the appropriate member of the care or social support team to take action based on patient-reported outcomes.

CASE STUDY

AHQR's Patient Question Builder

AHRQ's **Patient Question Builder** recognizes that “a simple question can reveal as much as a test.” When patients are engaged with their provider, they are asking questions that lead to improved health outcomes. These outcomes include not only increased capacity to comply with treatment recommendations, but also increased opportunity to express preferences and reveal values that impact the care process and treatment decisions. When patients ask questions, they are revealing their most important health concerns; and when patients prepare in advance for their medical appointments, they are more likely to come away with the information they need.

However, patients often hesitate to ask questions, even when they have serious conditions. They may not

know what questions they want to ask in advance of the appointment, and provider time constraints during most medical appointments do not allow for exploration which elicits those questions and values. Where there is limited health literacy, lack of medical knowledge, or high emotion, a patient's ability to formulate those questions in the medical setting is further curtailed. When complex decisions must be made, extended time for reflection and investigation of patient concerns and options is a critical element to effective person-centered and shared decision-making.

The Patient Question Builder helps patients to prepare in advance for a variety of medical appointments by selecting and prioritizing questions for four categories of medical appointments to 1) talk about a health condition; 2) get or change a medicine; 3) get medical tests; or 4) talk about surgery.

The interactive tool first asks patients to choose the kind of appointment they need, and then provides a list of questions which would apply to that category. For example, for an appointment to “talk about a health problem,” the user can check as many questions as apply from the following options:

- What is my diagnosis?
- Will I need any more tests?
- What are my treatment options?
- How soon do I need to make a decision about treatment?
- How much does this treatment cost?
- Are there any side effects?
- What happens if I choose to not have treatment?
- What is the outlook for my future (prognosis)?
- Will I need special help at home?

The subsequent pages rank the patient's selected questions, in order of importance to the patient. With this form in hand, patients are more likely to ask the questions that are important to them; providers who share the preparation platform with the patient can be sure to answer the questions which are most important to the patient.

The Question Builder is supplemented by a series of 2-minute videos of both providers and patients in different kinds of situations which model “How to start the conversation,” which demonstrate how questions can reveal barriers to care, and increase patient involvement in treatment and decisions; these videos recognize and address the discomfort some patients feel in asking a question. A 7-minute Waiting Room video features patients and clinicians discussing the importance of asking questions and sharing information.

CASE HISTORY

Ann: Making Decisions When Goals and Outcomes are Not Clear

Ann was initially diagnosed with complex regional pain syndrome in her mid 40s. She went from being an active mother, wife, educator and tennis player to a person in constant pain, unable to get out of bed for more than a few minutes. Through a combination of strong self-advocacy and alternative medical care, Ann recovered and resumed her life. Then, two years ago, the condition recurred. Since then, she has struggled with pain, serious eating problems and disability. She is slowly recovering, but the process has been agonizing at times, uncertain and slow. Ann accepts that her condition is chronic but is determined to regain as much of her life as possible. Her relations with her many doctors have been characterized by lack of knowledge on the provider’s part of her condition, skepticism about the reality of her symptoms and frustration—both on Ann’s part and that of her physicians.

“I can’t specifically say that (my doctor) has asked me what my goals are, but I think it’s pretty clear because she asks me about my life, that my goal is not to be in such agony. It’s a very simple goal. We aren’t even looking at long-term goals. It’s like, how do I not spend hours a day in bed crying? Let’s start with that. What can we do to make it so I am not non-functional?”

“People like me who deal with a disease by getting educated and reading and becoming analytic want to discuss that with their doctor. They don’t want to

be shut down or feel that their doctor is threatened by the fact that they are looking up articles. Maybe those articles are wrong. Maybe the internet doesn’t know what it is talking about, but I want to be able to discuss it.

“I wasn’t in such a great state. I’m sure I wasn’t super cheerful and happy. I sure I may have come across as combative. When you’re in pain and you’re upset, you are constantly trying not to come across as difficult. When you are with doctors, it’s even harder because you have anxiety on top of all these other things going on.”

PATIENT-REPORTED OUTCOMES

Patients are often best qualified to assess whether a treatment plan is meeting their goals. Self-reported patient outcomes are an important complement to clinical measures, diagnostic tests, and physical examination.³² They provide “standardized assessments of how patients function or feel, fueling conversations between patients and providers that lead to shared decision making and individualized care, as well as improved safety and effectiveness.”³³ “Patients must generate these data as they document the outcomes of their decision paths related to key areas like symptoms, quality of life, and functioning, values and preferences, and goals for health care.”³⁴

The outcomes measured should be related either directly or indirectly to the goals most relevant to patients and span a period long enough to encompass the ultimate results of care.³⁵ Data about the benefits, risks, and cost will help patients track their progress, problems and pitfalls along their journey, trigger care coordination and navigation interventions, and inform future decision-making activities. **For instance, when asked about their satisfaction level in regards to the benefit they received from their oral treatment, 79% of respondents to this project’s opinion survey were moderately or extremely satisfied with their outcome, and 75% would recommend their treatment to a friend with the same condition.** Patient reported outcomes (PROs) need to be shared

among clinicians, patients, and families, and should be used to inform shared decision making with patients.

This level of data sharing also facilitates engagement between patients and providers in ways that maximize the impact and efficiency of the brief periods of time patients spend face-to-face with members of their care team.³⁶

Patients can also contribute real-world data to help measure the total patient costs over an entire care cycle including those not included in the traditional out-of-pocket structure for insurance coverage, such as transportation, lodging and absenteeism. The likelihood of structural cost reduction is greatly enhanced when patients are provided the opportunity to measure their costs against the outcomes most important to them, and to view how other patients rate their satisfaction with various aspects of their care journey.³⁷

When asked about costs that contributed to their financial struggle, among respondents to this project's opinion survey, oral prescription drugs ranked the highest (11%), followed by transportation/travel costs (9%), visits to specialists (8%), and loss of income due to my or my caregiver's inability to work (7%).

When patients contribute data relevant to their own care, they also contribute to a body of information that helps bring clarity to the decision-making process for others facing similar circumstances. PROs can serve as the raw material for conversations between patients and providers that lead to shared decision-making and individualized care, as well as improved safety and effectiveness.³⁸

CASE HISTORY

Amy: Aligning Choices with Personal Goals

In 2010, Amy, a nurse, was diagnosed with stage IV inflammatory breast cancer. Amy knows that her breast cancer is not curable and had been a strong self-advocate for aligning her treatment choices with her personal goals and values. She is now on her third line of therapy and feels well. Amy is committed to enjoying whatever time she has with her family,

traveling and trying new things. Since her diagnosis, she has gotten the dog she always wanted and gone swimming with the Polar Bear Club on New Year's Day.

"You know I ask questions. I have no problem saying, 'Listen, I don't understand what you are trying to tell me. Explain it in terms I will understand.' If we want to get care that fits with our goals and needs, we have to have basic information not just about the diagnosis, but about the path. What's it going to feel like to be on these medications? What will it cost? What's it going to do to me?"

"Right after I was diagnosed, I went to an expert and he said this is what we are going to do—chemotherapy, mastectomy, radiation, then more chemotherapy, the most intense my body could handle. He didn't ask a thing about what was important to me, nothing. And for me, the question was how am I going to live because this is not a disease you're cured of, so what is the way I am going to approach this illness to live the best life. Everything I have done is to support that and you know, to maximize the quality of my life."

CASE STUDY

Patient Priority Care

Patient Priority Care has been further defined through CareAlign, a collaborative project funded by the Patient Centered Outcomes Research Institute (PCORI) Eugene Washington Engagement Award. Focused on the development of aligned, patient goals-directed care for older adults with multiple chronic conditions (MCC), Patient Priority Care occurs when three key actions take place: The patient's goals and care preferences are elicited and shared, clinicians translate those goals into care options, and care is aligned with patient's goals within the context of care preferences.

Patient priority care requires a shared team focus on the specific and measurable outcome goals identified by the patient, across the health span; it is not disease-specific, and not specific to advanced illness or setting.

When providers are willing to give over authority to patients in a shared decision-making process to identify options that will be the most valuable to the patient, care improves; and when care incorporates patient feedback in ways that shape key processes across the health care continuum, outcomes which matter to the patient improve. PCORI's CareAlign team outlined the central domains for care preferences:

- Health care utilization (number of visits, hospitalizations, clinicians, diagnostics)
- Medication management (complexity, adverse effects, monitoring)
- Self-management tasks (diet, exercise, check weights, blood pressure, glucose)
- Procedures (time, discomfort, anxiety, complications, time to recover)

These domains are considered within the context of the patient's daily activities, the likely consequences of treatment choices, and the patient's willingness and ability to tolerate those consequences to achieve his or her desired outcomes.

Incorporating patient health priorities into clinical practice is appropriate for everyone, but may be most helpful to patients with MCC, where the applicability of evidence-based guidelines is

uncertain due to life expectancy, complexity and/or the number and severity of conditions, or impaired function. For example, an 83-year-old man with diabetes, hypertension, heart failure, osteoporosis, and depression, was receiving care from a cardiologist, endocrinologist, psychiatrist and primary care physician. Each caretaker had separate recommendations, resulting in over 20 provider visits a month, the prescription of 12 medications, and the patient's increasing fatigue, weakness, and decreasing appetite. When the patient's preferences were considered (fewer medications and side-effects and less time involved in health care) his outcomes improved: He had less fatigue and weakness and was able to do things which mattered to his quality of life—specifically, to be able to walk to a friend's house and to a babysit a grandson once a week.

QUALITY MEASURES

Numerous quality measures have been established over the years to assess various aspects of health care. A very rigorous and arduous process exists for moving a quality measure from development and validation to endorsement and utilization. The current quality measurement landscape tends to be very clinically oriented, often with little meaningful involvement from patients and patient advocacy organizations.

FEDERAL AND STATE POLICY RECOMMENDATIONS

- Encourage and work with the Center for Medicare and Medicaid Innovation to promote the use of decision support tools that can improve patients' understanding of their options.
- Encourage PCORI to focus more funding on research that will assist patients, caregivers, clinicians, payers, and policy makers in making informed health decisions.
- Adopt a measurement of patients' level of activation as an intermediate measure for ACOs, patient-centered medical homes, and other new and emerging delivery and payment structures as recommended by Hibbard and her coauthors.
- Require that to be certified by the state, ACOs and medical homes must include shared decision making.
- Require that organizations wishing to be certified as patient-centered medical homes, for example, must undertake surveys of patients that ask about whether clinicians engage them in shared decision making or provide support for them to manage their conditions.

The importance of quality measures has increased dramatically with the passage of the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) and the emergence of new payment models tied to value rather than volume. Physician and hospital reimbursements are increasingly likely to be tied to performance against certain quality measures and generating savings rather than the volume of the services delivered.

While basic consumer theory asserts that paying for value requires measuring what actually matters to patients, most current quality metrics refer only to professional standards without reflecting what individuals want.³⁹ As the well-known economist Michael Porter noted: “Value should always be defined around the customer, and in a well-functioning health care system, the creation of value for patients should determine the rewards for all other actors in the system.”⁴⁰ This gap results in a natural disconnect between what a patient might define as a good measure of quality versus what payers and clinicians might measure.

Most attempts to establish patient-oriented quality measures have centered on patient satisfaction with various aspects of their clinical experience or quality of life. The need to focus on outcomes-based measures in addition to process-driven measures has been well established.⁴¹ The latter comprise the overwhelming majority of widely used and endorsed measures. Process measures are a great means by which to assess and promote high-quality care when there is significant confidence that simply following a process will lead to or maximize the likelihood of an important health outcome.⁴² In terms of delivering person-centered care, multiple opportunities exist to measure the quality of the process from a patient’s perspective. Specifically, the shared decision-making process, the utilization of decision support tools, and the effectiveness of the care plan are well suited for a process measurement approach. Some measures already exist in these areas.

The bigger challenge is how best to use certain patient-reported outcomes as quality measures, and thus as a basis for payment. The Patient-Reported

Outcomes Measurement Information System (PROMIS) is the source of the most widely used and rigorously validated set of measures in this area. This collection of cross-sectional measures is designed to evaluate and monitor patient satisfaction with various aspects of physical, mental, and social health. The focus is predominantly on issues related to quality of life rather than clinical benefit or cost. This limitation is notable because “the proper unit for measuring value should encompass all services or activities that jointly determine success in meeting a set of patient needs.”⁴³ PROMIS does, however, cover a wide array of potential disease and treatment-related side effects spanning numerous domains.

The other general problem with quality measurement currently is that individual patients play no role in selecting the measurements used to evaluate their care, and thus there is no relationship between the measurement activities and what matters most to a particular patient in terms of quality. In other words, the process of selecting the quality measurement protocol is done with no input from the individual patient whose care is going to be the source of the quality measurement data.

A “one-size fits all” approach to establishing a standardized measure set is likely to have little to no relevance to individual patients and their care plans if the measures do not reflect to some extent their values and preferences. A person-centered approach to quality measurement requires a process by which the patient selects, through consultation with their care team as part of the shared decision making, at least some of the outcome measures based on those most aligned with individual preferences and care goals. This approach would allow the patient to see a direct connection between the personalized goals contained in their care plan, the surveys they will be asked to complete, and the data they provide.

From the patient perspective, this approach should change the role of data collection so it is seen as something intrinsically valuable and relevant to his/her care plan and not just information submitted to an impersonal black box for others to use. As part of the care-planning process, patients should be offered a menu of various quality measure options related

to the goals and preferences documented in the plan. The quality measures they select would be incorporated into the care plan along with the data the patient is responsible for providing to populate those quality measures.

Personalizing quality measurement would align what the patient says matters regarding benefits, risks, and costs against specific quality measures that most accurately reflect the attributes across those domains. It shifts the focus from its current overemphasis on standardization, which is premised on every patient having the same goal.

Such standardization forces the care team to try to measure that goal in the same way for every patient without regard to the significance of that standardized measure to the individual patient. A more person-centered approach would allow the specific measures deployed to depend in part of the patient's individual preferences. As a result, the quality measurement would assess the degree to which satisfaction was achieved in the delivery of those domains selected by the patient. Provided that the scale for measuring satisfaction was

standardized across all the possible domains, the scores could be aggregated across different measures.

The pace of innovation in quality measurement must keep pace with the e-innovations occurring in the areas of payment, medical technology, and clinical delivery. "There is wide agreement that even more could be done to measure how and how well health care organizations engage patients, and help to realize individuals' full potential to maintain and improve their health."⁴⁴ Thus, advancing the science of quality measurement is critical to creating the next generation of measures "that comprehensively assess patient outcomes and functional status, care coordination and transitions, patient-centeredness and equity, and efficiency and resource use."⁴⁵ HHS is working in collaboration with multiple stakeholders to determine the best approaches for developing the infrastructure required for the capture and use of clinically rich, patient-reported data that will form the basis of outcomes-oriented measure sets for new payment models based on value.⁴⁶

■ SECTION 3

THE MODEL FOR CONSUMER-DRIVEN DECISION MAKING IN HEALTH CARE

This section offers a systematic model for consumer-driven decision making in health care. The Roadmap merges the need to deliver information on benefits, risks and costs outlined in Section 1 with the key mechanisms to deliver that information described in Section 2 into an integrated delivery model for consumer engagement that can be applied across the health care continuum. The goal is to create a usable, cohesive system that allows for a balance between customization and standardization.

The system must be personalized to acknowledge the complexity and variability of the individual illness experience, and address the multiple decision-making milestones that people with serious, chronic and life-threatening conditions encounter. The system must standardize the delivery of the right care, to the right patient at the right time on a scalable basis. The goal is to capture, monitor, and assess patients' perspectives and use those insights to improve care. This goal involves specific actions identified in Section 2, such as establishing decision support tools that facilitate data sharing among clinicians, patients, and families and making high-quality tools available for shared decision making with patients.¹

To be effective, the system must 1) create and support the patient's goal-concordant care plan; 2) measure outcomes and quality in ways that matter to patients related to that plan; and 3) generate and use a stream of actionable, real-world data that creates essential feedback loops that track progress of the individual patient and then can be aggregated with other data to inform decision-making processes for future patients.

For the system to be truly person-centered, each element must:

- Emphasize focus around the patient
 - Take into account patient preferences and values
 - Allow those preferences and values to impact the system in ways that are meaningful and tangible to the patient
 - Generate measurable data that inform care outcomes and choices for current and future patients
-

BUILDING BLOCKS OF CHANGE

The essential building block for change is a standardized, but still customizable model for shared decision making that aligns choices about intervention options with personalized goals, needs, and preferences, ultimately leading to a goal-concordant plan for care.²

A personalized shared decision-making process should generate a similarly personalized care plan that includes identification of social support, navigation, and other needs that the patient instantly recognizes as concordant with his or her goals. This goal-concordant care plan should incorporate the myriad of interventions that a person with a complex condition is likely to need from diagnosis through acute care, chronic disease and end-of-life care. Decision support tools can be used to help filter different care options and psychosocial

support services against the patient's unique attributes and personal preferences for benefits, risk, and costs. These tools are critical to identify the evidence-based options that best fit those parameters and provide clarity about the trade-offs and lack of certainty that frequently arises in the process of decision making.

For example, for a survey conducted by PAF in 2016 with a cohort of respondents receiving treatment for chronic disease, patients were asked about what types of treatment or services they had received in the past 12 months. The majority of respondents indicated that they had received oral therapy (33%), infused therapy (21%) and to a lesser extent radiation (9%) and/or surgery (10%). Additional treatments included pain management (8%), hormonal therapy (5.5%) or homeopathic remedies (3%).

The graphic visualization of this part of the model, depicted in Graph 3.1, demonstrates how the shared decision making and care plan process should be interconnected across the key decision milestones for all the episodes associated with a single care plan.

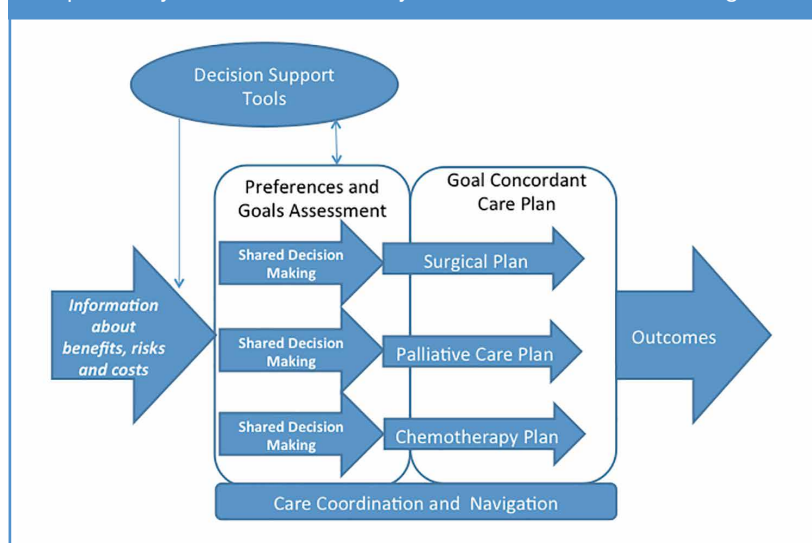
Throughout the patient's journey, doctors, patients and caregivers make key decisions about tests, surgery, radiation, medications, palliative care, rehabilitation services, and others. Each of these different episodes of care (like chapters in the same book) should be mapped and logged using the same common platform. This approach allows the patient to visualize and review each episode of care in one accessible location, establishes links between different outcomes at each step in the dynamic care process, and informs the next choice. At various points, as the patient's care plan is assessed and reevaluated, the process begins anew.

Health care is complicated. There are often numerous providers involved in care, and their roles change. Patients' needs and circumstances evolve over time. Because identifying and accessing appropriate resources is challenging for even the savviest health care consumers, care coordination and navigation are essential model components. Care coordination provides the platform upon which different "streams of care" can be considered as a whole. A common group

of people, or treatment team, tracks the patient's needs and actions throughout the process. Depending on the decision point, these roles may be specific and can evolve or change. This coordinated approach allows the patient to serve as the common denominator around which all the key health care staff responsible for the care plan must communicate.

A navigator who represents the consumer's best interest is a common feature in other markets with similar complexity like real estate, law, investments, and even mountaineering; however, a robust health IT platform that facilitates and automates the care coordination activity is the most likely means by which to scale the coordination of care efficiently and effectively. The same holds true for the role of navigation in supporting the patient through the care plan. The IT platform and navigation functions can support and complement each other. A comprehensive and interactive Health IT platform can automate some of the navigation functions so that deployment of human navigation can be conducted in the most targeted and cost-effective ways.

Graph 3.1 "Systems Model for Clarity in Health Care Decision Making"



The core of the person-centered care experience maximizes consumer engagement through shared decision making that leads to a documented care plan supported by care coordination and navigation.

FEEDBACK LOOPS

Another key component of the model, as depicted in Graph 3.2 below, is an information feedback loop that provides users with information about their actions in real time (or something close to it) and allows patients, the care team, and navigators an opportunity to take action or make a decision in response to those data. To create a feedback loop, at least four different stages are required spanning data development, translation, delivery, and use:³

1. **Evidence:** The raw data generated by an action must be measured, captured, and stored. It is important that the specific data collected be meaningful and relevant to the patient in terms of tracking the progress toward the activity's goal.
2. **Relevance:** Information is useless if the user doesn't know what it means and how it relates to his or her individual situation. Thus, the information must be delivered back to the individual, the care team, and navigators in a context that resonates emotionally and practically rather than simply as raw data.
3. **Consequence:** The information must be used to identify one or more paths for consideration and choice. Decision support tools can play a role in this process of helping to align meaningful and relevant

data with personal preferences and characteristics to provide a range of options that can both guide and personalize shared decision-making discussions based on a variety of clinical and real-world data.

4. **Action:** A clear moment must exist when the individual can recalibrate a behavior, make a choice, and act. That action then creates more raw data and the feedback loop can begin anew. The key action steps in the model are shared decision making and the consequent development and execution of a care plan.

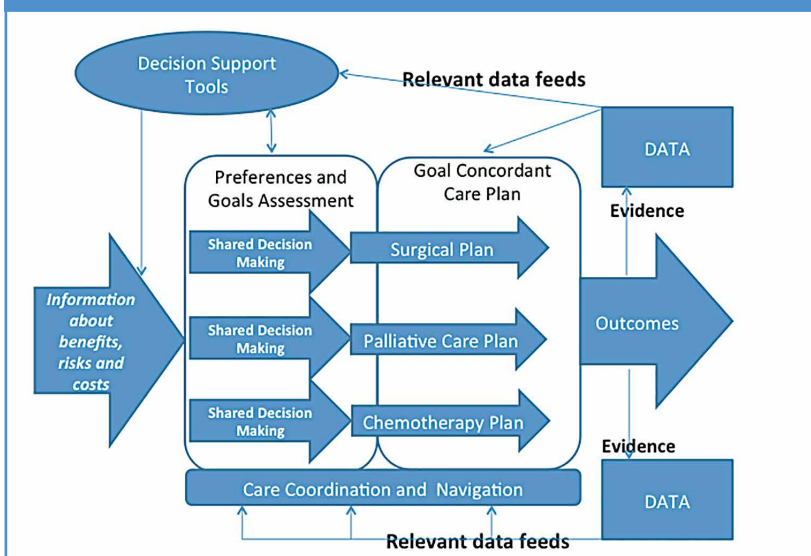
The goal is to combine the shared decision making and care planning with the data feedback described above. The system then generates the necessary data and facilitates its use to create a rapid learning environment for the individual patients and others facing similar circumstances.

As a patient implements the care plan, there are consequences and outcomes that naturally follow. These include costs, side effects and benefits. The real-world reporting of these outcomes is the raw evidence that must be captured to drive the rapid learning environment (described in more detail below). These data must reflect those which the patient identifies as most meaningful to the care plan to ensure that he or she has a vested interest in tracking and reporting data relevant to measuring its success.

Bandura observed that giving individuals a clear goal and a means by which to evaluate their progress toward that goal greatly increased the likelihood that they would achieve it.⁴ Patient-reported data can provide a means by which the patient and the care team can track progress against the care plan and create signals that trigger action or early warning signs related to benefits, costs, and risks. For example, regular tracking of a patient's experience with financial challenges or absenteeism at work could trigger an intervention from a financial counselor to help the patient avoid significant pitfalls.

Beyond the benefit to the individual of documenting his or her experiences and outcomes, these individual data sets can be combined to create real world evidence about benefits, costs, and risk. When properly distilled, and analyzed, this information can help guide the

Graph 3.2 "Systems Model for Clarity in Health Care Decision Making with Information Feedback Loop"



decision-making process of others. Decision support tools can be used to translate this real-world data into actionable information filtered by the individual patient's preferences to pinpoint the most appropriate options from which to make a personalized decision. A process designed to solicit knowledge about the patient, "including life situation, home environment, personal preferences, and caregiver status," will lead to more realistic care recommendations to which patients are more likely to adhere.⁵

THE DIGITAL PLATFORM

Ideally, all or most of the functions of this system would be delivered on a single digital platform that integrates and interfaces with the decision support tools, the shared decision-making process, the care plan, and the data capture and analytics aspects. In short, the IT platform provides the means by which to customize the system in a manner that is both scalable and efficient. The IT system captures and filters the data stream that serves as the engine for a feedback loop that feeds information back into the system. Its user interface must be simple and intuitive enough to be incorporated into diverse clinical settings and work with the full range of patients and caregivers.

The ultimate goal is to create the digital platform to support a rapid learning health care system (RLHS), described as follows:

"...one that uses advances in information technology to continually and automatically collect and compile from clinical practice, disease registries, clinical trials, and other sources of information, the evidence needed to deliver the best, most up-to-date care that is personalized for each patient. That evidence is made available as rapidly as possible to users of a RLHS, which include patients, physicians, academic institutions, hospitals, insurers, and public health

*agencies. A RLHS ensures that this data-rich system learns routinely and iteratively by analyzing captured data, generating evidence, and implementing new insights into subsequent care."*⁶

A highly-sophisticated IT platform must exist to 1) standardize the process and link the different steps in the care plan process, 2) create the ability to personalize the data inputs and outputs that inform the unique decision making, planning, and measurement activities for the individual patient, and 3) provide the means by which to capture the real-world data that can serve as a rapid learning environment.

The IT component also allows for the mobility required for the system to meet patients where they are. Most of the patient's life happens in the community, outside the four walls of the hospital or clinic. Thus, the patients' ability to interact with a care plan, input and access actionable data, and navigate to important social and emotional support services must literally be at their fingertips.

CASE STUDY

Mayo Clinic: iPad "Breast Cancer Surgical Decision Support Tool"

Technology has the potential to allow greater personalization in how health care information is communicated between provider and patient. A team of specialists at Mayo Clinic, led by Dr. Sandhya Pruthi, have leveraged technology to develop a personalized decision support tool for breast cancer patients housed on patient iPads currently being implemented in their practice.

Patients access an application that delivers information about their specific diagnosis and cancer, allowing them to view content that is efficient and personalized. Dr. Sandhya and colleagues enter details of each patient case into the application, channeling the vast and overwhelming amount of information on breast cancer into what is specific to the patient's own type of cancer

and with direct links to their own care team. Because the tool is portable, patients can view and respond on their own time and when they are best able.

This personalization offers the ability to engage the patient in a series of questions and options that return to the surgical and treatment team so that they can view the patient's input on a surgical dashboard. Patients are able to view surgical, non-surgical and medical options, the details of their own case, the details of their care team, and what to expect related to risk, side effects and recovery. They are then engaged in a value survey that allows them to define value and confidence in surgical decisions to communicate what is most important to them back to their care team. The application even allows for patient-defined data to be captured and shared that best reflect variables the patient feels are critical to their care. The "Breast Cancer Surgical Decision Support Tool" standardizes process while personalizing information, to empower patients to participate in the decision process and inform treatment decisions.

STANDARDIZATION VS. CUSTOMIZATION

How do you reduce the risk that customization could actually produce inappropriate variations? Homogenous standardization is often the primary means by which the delivery of a service or product is thought to be scalable in a way that minimizes unnecessary variation. However, standardization can be a blunt instrument when applied in the wrong setting with no room for appropriate or desirable variation.⁷ Customization, by contrast, can produce desirable variations at scale, but only when the basic processes and steps are standardized to allow for predictable variations to be delivered from the same process infrastructure.

More importantly, both patients and providers value the ability to engage in a manner that allows for customization. Providers often refer to this as clinical judgment. For patients, it is about personalization. In both cases, both parties must have reasonable autonomy to make the best choice for the individual patient based on unique circumstances. In some cases, these circumstances may suggest a standard approach

while in other cases a less common approach may be more appropriate.

When asked about the importance of receiving a personalized treatment regimen, 83% of respondents to this project's opinion survey said it was very or extremely important for treatment to be highly personalized to their characteristics.

The problem is that the freedom to personalize in the absence of a logical and replicable process that allows for appropriate variation could lead to unnecessary or unexplainable variation that potentially results in poor patient care. Custom configured delivery models create a replicable process for explainable variations that lead to a more desirable product for the consumer because they allow for outcomes that more closely match personal preferences.⁸

A systematic alignment between shared decision making, personalized care planning, and data feedback could provide a greater role for patients in the quality measurement process. Until recently, patients have largely been unaware of and uninvolved in this process. In fact, in the system outlined here, it would actually be critical to use quality measures to assess and compare patient satisfaction with the system's ability to create a meaningful shared decision-making experience that leads to a personalized care plan. Patients could also be provided a menu of quality measures from which they could select the ones most appropriate to the success of their care plan, including both process measures and outcome measures. If quality measures are meant to help focus the system on performing those tasks most closely aligned with value, then at least some of the measures should be personalized to reflect the patient's preferences and goals.

CASE STUDY

PREPARE: Helping Patients and Families Identify Their Personal Priorities for Living

PREPARE (www.prepareforyourcare.org) is an online, interactive care-planning decision aid developed in 2012 by researchers at the University of California San

Francisco and the Veterans Health Research Institute. This decision-making tool extends beyond the advance directive to include surrogate selection, specific questions which help users to identify their own values and preferences, and models for how to communicate those preferences to providers and family or other caregivers.

The PREPARE learning module's custom-configured approach accommodates variation in patient experiences, skills, goals, and values. Plain language written on a fifth-grade reading level is intended to meet the needs of underserved populations and those with limited reading or computer literacy and/or visual or hearing impairment. English and Spanish text with audio voice-over demonstrates a 5-step process for deciding not only how to make medical decisions, but also how to make other decisions which impact treatment and quality of life outcomes. These include identifying values, recalling previous experiences with serious illness, identifying health situations which would be intolerable (where death would be preferable over treatment), considering how values change over time, and deciding how much decision-making flexibility to allow a surrogate.


Multiple scenarios depicted through video enactments provide viewers with a variety of scripts which may apply to their own situation and feelings. Video demonstration also provides patients with models for how to ask questions about benefits, risks, treatment options and effects. PREPARE's interactive features also allow users to develop an action plan, and to print and store a recorded summary of preferences which

can be shared with caregivers and providers and/ or accessed from the website at a later date.

FUNDAMENTAL SYSTEM FEATURES

Essential features that must be considered and incorporated into the system:

- Include a proactive, consistent, two-way discussion of patient values, listening to what is important to the individual.
- Avoid adding significantly to the time involved in the patient/physician interaction. Many models depend on asking a few key questions that elicit critical information about patient values and goals. Evidence suggests that these questions in many cases do not add to the length of the patient interaction, and may actually shorten it by improving communication between patient and physician.
- Utilize information sources to help patients understand the benefits, costs and risks of their treatment that enhance or supplement discussions with health care providers. These sources can be traditional, such as print or video, or take advantage of new digital and mobile platforms.
- Help to shape the treatment decisions once the patient identifies what is important.
- Be integrated into all core decision-making points of the diagnostic, treatment, and care process and include defined opportunities for patients and caregivers to align their goals and preferences with treatment decisions by providing usable, accessible, timely information.
- Be linked to delivery of services or appropriate support based on patient values.
- Address emotional, social, financial issues, symptom control and care planning.
- Respect the individual, regardless of social, economic or literacy status.
- Create meaningful, measurable change.
- Include and involve caregivers and support systems.

**PREPARE**
for your care

Learn more about PREPARE for Your Care

PREPARE helps you make informed decisions and get the care that is right for you.

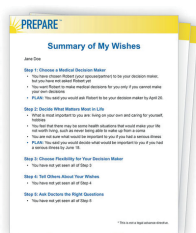
It is OK if you are not ready to make these decisions right now. PREPARE can help you get started.

PREPARE walks you through an easy, **5-step process** with video stories and questions to help you decide what matters most.

Each step takes about 10 minutes.

After doing any step in the program, PREPARE creates a "Summary of My Wishes" form. [Click here](#) to learn more about the Summary.

Start Using PREPARE



PREPARE
Summary of My Wishes

Step 1: Choose a Medical Decision Maker
• You must choose someone to make decisions for you if you cannot make them for yourself.
• You must choose someone who is at least 18 years old.
• You must choose someone who is not your spouse or partner if you are married or in a domestic partnership.
• You must choose someone who is not your child or grandchild.
• You must choose someone who is not your sibling or parent-in-law.
• You must choose someone who is not your friend or neighbor.
• You must choose someone who is not your employer or someone who works for you.
• You must choose someone who is not your doctor or healthcare provider.
• You must choose someone who is not your religious leader or spiritual advisor.
• You must choose someone who is not your lawyer or accountant.
• You must choose someone who is not your insurance agent or broker.
• You must choose someone who is not your real estate agent or broker.
• You must choose someone who is not your mortgage lender or servicer.
• You must choose someone who is not your landlord or tenant.
• You must choose someone who is not your neighbor or community member.
• You must choose someone who is not your fellow resident or tenant.
• You must choose someone who is not your fellow employee or coworker.
• You must choose someone who is not your fellow student or classmate.
• You must choose someone who is not your fellow member or associate of a club, organization, or association.
• You must choose someone who is not your fellow member or associate of a religious, spiritual, or ethnic group.
• You must choose someone who is not your fellow member or associate of a political party or organization.
• You must choose someone who is not your fellow member or associate of a labor union or other group.
• You must choose someone who is not your fellow member or associate of a professional association or guild.
• You must choose someone who is not your fellow member or associate of a trade or industry association.
• You must choose someone who is not your fellow member or associate of a sports team or league.
• You must choose someone who is not your fellow member or associate of a hobby or interest group.
• You must choose someone who is not your fellow member or associate of a social or recreational group.
• You must choose someone who is not your fellow member or associate of a religious, spiritual, or ethnic group.
• You must choose someone who is not your fellow member or associate of a political party or organization.
• You must choose someone who is not your fellow member or associate of a labor union or other group.
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• You must choose someone who is not your fellow member or associate of a trade or industry association.
• You must choose someone who is not your fellow member or associate of a sports team or league.
• You must choose someone who is not your fellow member or associate of a hobby or interest group.
• You must choose someone who is not your fellow member or associate of a social or recreational group.

- Be incorporated into existing care delivery systems and settings.
- Take advantage of new technology and personalized platforms for obtaining information and planning care.
- Include members of the clinical team who often have more time to interact with patients and caregivers, including nurses, nurse practitioners and social workers.
- Be understood and supported by all team members.
- Be reliably and easily accessible to providers, and include training in the essential elements of understanding what matters most to patients and incorporating these into shared decision making. Person-centered, empathic communication is a learned skill that can and must be trained, practiced, and measured.
- Include built-in accountability/feedback mechanisms and provide real-time data as part of the routine of health care delivery.
- Include outcomes and quality measures that will help other people facing similar issues shape their decisions.

“Half of getting to the goals of this Roadmap lies in getting people to stop working in isolation. There are lots of excellent initiatives out there, but they are like separate islands. We need to bring these different perspectives together, to become of one mind and see everyone’s pieces begin to merge into a land mass. We need to have a central vision that drives the individual efforts.”

Thomas Workman, PhD

Many of the thoughtful patient preference and engagement tools that exist today are applicable only to one event or institutional silo and do not “meet the

patients where they are.” This fragmentation exists because tools are often created by or for a singular stakeholder for use within their “closed” infrastructure and/or for a singular event in the system. Many PHR systems, for example, are physician-oriented, and do not include patient-oriented functionalities.⁹

CASE STUDY

The GIST Life Raft Group Patient Registry

The GIST Patient Registry illustrates a comprehensive strategy for executing multiple roadmap recommendations for a specific patient population, including increased consumer engagement, transparency in providing information about benefits and risks of treatments as identified by patients, improved education for patients to facilitate more effective communication, use of innovative platforms to collect and share information, and systematic measurement and utilization of patient-reported data.

Created by the Life Raft Group, the GIST Patient Registry serves as a connector and source of information for gastrointestinal stromal tumor (GIST) patients, caregivers and both the clinical and research communities. All information in the registry comes directly from patients or caregivers and is returned to patients with the understanding that timely knowledge and information is key to achieving better care and quality of life. The registry contains over 15 years of self-reported and clinical data encompassing 35 years of patient history crossing institutional boundaries. The Patient Registry has 1,703 patients from 67 countries with the youngest patient diagnosed at 5 and the oldest at 92 and represents 12 different mutational types.

Components of the GIST Patient Registry that achieve roadmap recommendations include:

- **Patient Registry Team.** Patients and caregivers are part of a team inclusive of staff and volunteer navigators. The team approach facilitates one-on-one discussion of treatment options, side effects management and dietary advice, assistance for the

patient in preparation for medical appointments and direct connection to others through GIST Patient Match Program.

- **Care Management.** Offers a portable record to track care history, provides access to care resources including specialists and clinical trials, and allows comparative data of individual patient data to the larger GIST community to inform individual care decisions.
- **Education and Training.** Team members are offered online patient training courses, specialized webinars and content driven by patient-reported data, all tools to empower team members to become their own advocates and drive shared decision making.
- **Research and Consultation.** Offers a GIST collaborative tumor bank for facilitation of patient contribution to research and a virtual GIST Tumor Board for experts to discuss eligible patient cases with treating physicians to drive better communication and care.

The data collected is used to examine questions that are not being answered quickly enough by current trials or that are not being evaluated in clinical trials and to monitor the latest treatments for early indications of a response. Examination of these trends lead to outputs and offers real world evidence to patients on questions that can inform decisions, including how many patients are treated with the brand or generic form of a drug, to the average number of tissue samples donated per patient for research.

This patient-powered medical registry enables patients and caregivers with tools to improve their own care, contribute to research, and improve clinical understanding and communication about their rare disease on a broad scale.

CONCLUSION

A Roadmap is only a beginning. The journey to person-centered care and shared decision making is a complex undertaking that requires understanding, commitment and action from a wide range of stakeholders. It is a process that demands change—at many levels—ranging from how we educate providers, how we develop and use tools, how we pay for the time required to provide this care, to how we evaluate its impact and effectiveness across the spectrum. Large questions need to be addressed and answered about ways in which person-centered care can be made a reality in diverse clinical and community settings, and with people who bring vastly different levels of health literacy, and interest in the process, to the discussion.

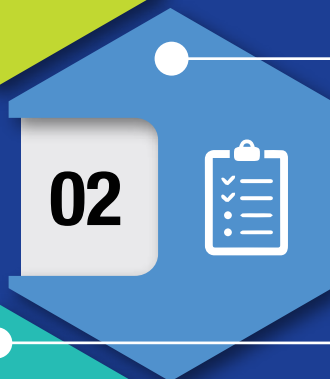
There are also critical, complicated areas in which we must acknowledge that not all decisions are really based on patient preference. Some are driven by cost, or the availability of specific treatments, or by sheer logistics. In other circumstances, there are tradeoffs, often not clear cut, between the quality of life and the length of life.

The goal of creating this Roadmap is to provide the framework for reforms that put people at the heart of health care through delivery of person-centered care. It provides stakeholders with a starting point, a basis on which to decide what specific role each can play, and what specific actions will have the greatest impact in the setting in which they work. It is our intention to carry this forward, in multiple settings and with many partners to advance our shared goals for making person-centered care an integral part of the health care delivery system.

THE ROADMAP



BUILDING THE FOUNDATION
Skills Building and Education



PLANNING THE TRIP
Preparing for
Person-Centered Care



STARTING THE JOURNEY
The Initial Appointment



**MORE STOPS
ON THE JOURNEY**
The Changing Landscape
of Chronic or Serious Illness



MOVING THE FIELD FORWARD
Changing Practice and Policy

01



02



03



04



05



- Incorporate communications skills development training into educational curricula for physicians and all members of the health care team that provides essential scaffolding for care goals and shared decision-making discussions.
- Develop education and clinical practice models and materials for patient-based care, including core questions and decision aids for both professionals and patients. These should include

both standardized questions and questions customized to the specific disease or condition and utilize innovative digital platforms when possible.

- Require communications skills training and proficiency in person-centered care in continuing medical education training for practicing physicians and other health care professionals.

- Educate the public about the value of person-centered care through media outreach programs.
- Educate advocates about specific issues and skills related to person-centered care and communications with the health care team.

- Provide every patient diagnosed with a serious or chronic illness with information and assessment materials prior to the first appointment, including:
 - ♦ Basic information on the condition.
 - ♦ Core questions to assess areas of concern, treatment goals, life issues that will impact decision making and basic attitudes and needs

related to the shared decision-making process. This can be done digitally.

- ♦ Basic information on self-advocacy and how best to communicate with the health care team on issues related to serious illness and quality of life.

- Provide the health care team with the results of the assessment process prior to the appointment.
- Add sections to patient portals that address key decision-making points, quality of life, patient preference and include feedback from both patients and providers.

- Allow sufficient time in the first appointments to have a discussion on treatment options and the shared decision-making process.
- Introduce members of the health care team who will be involved in patient care and explain their roles.
- Identify members of the patient's support and caregiving team.

- Ask core questions, based on the pre-appointment assessment, about what is important to the patient in making key treatment choices.
- Assess needs related to social, emotional and financial aspects of treatment as well as symptom management.
- Provide a summary of decisions made to the patient that forms the basis for an ongoing

personalized care plan. Document these decisions on the patient portal when possible.

- Provide patients and caregivers with an opportunity to evaluate the process and outcomes of the appointment. This can be done digitally with a few standardized questions.

- Identify key decision-making points for specific conditions and individual patients.
- Build relationships that allow providers to know their patients and understand their goals and values. While physicians need to play a central role in this process, other providers, including nurse practitioners, nurses and social workers are critical to establishing and nurturing these relationships with patients and caregivers.

- Reassess patient goals and preferences at each key decision point using standardized core questions as well as discussion personalized to the individual patient. Document outcomes using standardized platforms.
- Review and update the personalized care plan at each critical step or decision point.
- Provide patients with ongoing opportunities to assess their experience and improve

communications with their health care team. This can be done through short digital assessments, patient portals, navigators and when indicated, discussions with providers.

- Develop feedback loops and triggers to alert health care providers to issues that require intervention or additional discussion.

- Develop and utilize standardized measures for assessing both the process and outcomes of person-centered care and shared decision making.
- Identify and share best practices and models for person-centered care.

- Use quantitative and qualitative data to continuously improve decision-making tools, skills training and assessment of the person-centered shared decision-making process.

- Use data from person-centered care to drive policy and payment reform and improve education of health care providers.
- Continue educating the public, patients and the advocacy community on person-centered care.

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■ APPENDIX

FOCUS GROUP REPORT

Value in Care Focus Groups



FINAL OUTCOMES REPORT

February 10, 2017

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EXECUTIVE SUMMARY

Background. This report summarizes findings of focus groups conducted by Strategic Management Services, LLC (SMS) on behalf of the Patient Advocate Foundation as a part of a grant awarded by the Robert Wood Johnson Foundation to build and design a framework that supports the inclusion of both the patient's voice and the patient's value. The focus groups sought to explore patient's experiences with providers and learn how patients define and perceive "value" in healthcare and treatment. Findings outlined in this report are based on focus groups conducted in January 2017 for African-American and Latina Patients/Survivors of Breast and Gynecological (GYN) Cancers, persons identifying as LGBTQ living with HIV/AIDS and persons identifying as Heterosexual living with HIV/AIDS.

Methodology. A total of four focus groups were conducted on January 27, 28 and 30, 2017. Trusted community-based organizations and "gate-keepers" were engaged to assist with participant recruitment. Interested participants completed an online registration form via the EventBrite platform and were asked to complete a brief, one-page demographic survey that included questions on age, ethnicity, educational attainment and level of income among others. A total of 35 individuals participated in the four focus group. Each focus group was led by a trained facilitator and was recorded on audiotape to ensure the thoughts, opinions, and ideas presented by the group were accurately captured and represented in the final report. Questions explored during the focus groups sought to uncover patient's perceptions of "value" and what is important with regards to their treatment and care from providers.

Key Findings. Qualitative data analysis revealed five overarching themes across the four focus groups. An expanded explanation and discussion of the findings, demographics, the focus group questions, and informed consent documents can be found in the appendices.

- THEME 1.** Value means having a relationship with your physician where the physician shows respect, interest, care and compassion and is accessible and responsive.
- THEME 2.** The provider-patient relationship is extremely important. Patients' want physicians that are respectful, knowledgeable, open and honest, good listeners and positive.
- THEME 3.** Patients' interactions with their physician and the ENTIRE care team (nurses, case workers, front desk staff, etc.) are extremely important.
- THEME 4.** The provider-patient relationship affects a patient's health outcome. A provider's character and demeanor are VERY important.
- THEME 5.** Participants across all groups expressed that cost plays a role in the quality of the care received by patients.

Conclusion. Participants expressed their will to live and having a physician who they trusted and believed was willing to help them fight to live was of most value to them. As such, it can be concluded that "value" to all participants did not equate to cost, rather was viewed in non-monetary terms to include **respect, consideration, care, competence and compassion** showed to them by their health care provider(s) and health care team.



Recommendations. While respect, consideration, care and compassion cannot necessarily be taught they can be assessed. One way to address this concern would be to have physicians undergo “mock” encounters and have their behaviors assessed by a team to include other medical professionals and individuals living with the illnesses those physicians will treat. Additionally, during each of the four focus groups, participants expressed their desires regarding information they wish they had or feelings, thoughts or emotions they would have like conveyed from their physician and health care team. Participants across all four groups agreed they wish they had the following:

- An orientation, communication and information (facts) about what is going on and what is going to happen with regards to their treatment and care; and
- An explanation of the payment system and the costs involved for their treatment and care.

Both of the aforementioned items can be easily incorporated into a patient’s visit and could help alleviate some of the stress and anxiety patients and their families may feel which in turn can help them feel more “valued”.



INTRODUCTION

Engaging stakeholders often leads to the generation of diverse perspectives, ideas and outcomes that, when combined, highlight patterns and factors impacting successes and challenges of an organization's initiatives. Once uncovered, these factors can be further examined and used to initiate conversations with stakeholders internally and externally around solutions to address gaps through additional resources and strengthen programmatic and governance components. This approach will be effective at developing a complete and in-depth view of how and what a patient views as valuable and create momentum for subsequent phases of work.

In December 2016, Strategic Management Services, LLC (SMS) was contracted by the Patient Advocate Foundation to develop, recruit for and execute a series of four focus groups to explore and uncover patient's perceptions and estimated values in different care delivery settings. This report summarizes findings of focus groups conducted by Strategic Management Services, LLC (SMS) on behalf of the Patient Advocate Foundation (PAF) as a part of a grant awarded by the Robert Wood Johnson Foundation (RWJF) to build and design a framework that supports the inclusion of both the patient's voice and the patient's value. The findings summarized in this report are based on a series of four focus groups conducted January 27, 28 and 30, 2017.

The focus groups sought to explore patient's experiences with their providers and learn how patients define and perceive "value" in healthcare and treatment. Questions explored during the focus groups sought to uncover patient's perceptions and estimated values in different care delivery settings. The qualitative data and findings obtained from the focus groups will be used to infuse the patient into the center of the RWJF framework to ensure that their voice is paramount in the discussions regarding their health and healthcare.

METHODOLOGY & APPROACH

2.1 Target Population and Participant Recruitment

The target population for the focus groups included persons of color living with or survivors of the following diseases: breast cancer, cervical cancer, and HIV/AIDS. The ideal sample size for the focus groups was 8-10 participants per group for a total of 32-40 participants. The parameters for the breast and gynecological (GYN) cancers focus group was set at African-American and Latina women regardless of other social determinants such as age, income, race or employment status. To ensure a diversity of perspectives and input, it was decided that the focus group for Latina breast and GYN cancers would be conducted in Spanish. Parameters for the HIV/AIDS focus group were open as well however to ensure diversity of perspectives, recruitment for one the groups was heavily focused on the Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQ) population.



To secure participants for the focus groups several trusted organizations and known community “gatekeepers” within the Washington, D.C. Metropolitan-area (DC, MD and Northern VA) were engaged to first, build awareness of the purpose and intentions of the focus groups and second, to secure their endorsement. Securing the endorsement from organizations and “gatekeepers” was key to validating the focus groups as an “approved” activity that was safe for community members to participate in. Once endorsement was obtained, advice was sought on recruitment strategy, dates and times, and language for promotional materials for the focus groups.

2.2 Times & Venues

To ensure a diverse representation of perspectives, it was important that the focus groups be scheduled at times that support attendance for people who work during the weekdays and have non-traditional work schedules. Additionally, sites for the focus groups were selected with the convenience of the participants in mind. Two of the focus groups, the Latina Breast and GYN Patients/Survivors and LGBTQ HIV/AIDS groups, were held at service organizations in the community that were familiar to participants as noted in the table below.

Table 1. Focus Group Times & Venues

FOCUS GROUP	DATE	TIME	VENUE
Focus Group #1: <i>African-American Breast & GYN Cancer Survivors</i>	January 30, 2017	4:30 PM - 6:00 PM	Lofts at 600 F Street (Downtown)
Focus Group #2: <i>Persons Living with HIV/AIDS</i>	January 30, 2017	7:00 PM - 8:30 PM	Lofts at 600 F Street (Downtown)
Focus Group #3: <i>Latina Breast & GYN Cancer Survivors</i>	January 28, 2017	10:30 AM - 12:00 PM	The Smith Center for Healing and the Arts
Focus Group #4: <i>LGBTQ Person Living with HIV/AIDS</i>	January 27, 2017	4:30 PM - 6:00 PM	DC Center for the LGBT Community

2.3 Registration

The EventBrite (www.eventbrite.com) platform was the mechanism used to register and track participants. This platform had several features that enabled us to limit the number of participants that registered, allow participants to join the “wait-list” if the group they selected was full, pull participants from the wait-list and invite them to register within a defined time frame and include demographic questions for participants to complete as part of the registration process. Demographic questions included questions on age, ethnicity, educational attainment and income level among others.

Registered participants were called and emailed two days before each group to confirm their participation and to answer any questions they may have had about the groups. Registration and attendance figures for all four groups are detailed in **Table 2** below.



Table 2. Focus Group Attendance

FOCUS GROUP	GOAL	REGISTERED	ATTENDED
Focus Group #1: African-American Breast & GYN Cancer Survivors	10 participants	10 RSVPs, 3 WL (Wait List)	7 Participants
Focus Group #2: Persons Living with HIV/AIDS	10 participants	10 RSVPs, 2 WL	10 Participants
Focus Group #3: Latina Breast & GYN Cancer Survivors	10 participants	10 RSVPs, 2 WL	8 Participants
Focus Group #4: LGBTQ Person Living with HIV/AIDS	10 participants	10 RSVPs, 2 WL	10 Participants
TOTALS	40 participants	40 RSVPs, 9 WL	35 Participants

2.4 Structure and Format

A Discussion Guide (**Appendix A**) containing the focus group questions along with scripted roles for staff was developed to aid the facilitator during the focus group sessions. The questions in the Discussion Guide were developed to solicit patients' perceptions pertaining to what they feel is important during diagnosis in a physician's office; what's important in the hospital during and after treatment; continuity of care; the provider-patient relationship; and the perceived effect their relationship with their provider has on their health outcome. The discussion guide for the Latina group was translated into Spanish and the questions amended to ensure appropriate terminology and context.

The four focus groups were conducted in three different settings across three separate dates as outlined in **Table 1** above. A meal was provided appropriate to the time of day the focus group was being held in consultation with the organizations/gatekeepers. Each group was scheduled for a 90-minute time slot with the first 30 minutes including 15 minutes to allow participants to obtain food and drinks and settled in, and 15 minutes for introductions, overview of project, review of ground rules, project team introductions, and signing of consent forms. The actual facilitated session lasted approximately 60 minutes for each group and was audio recorded. Each focus group discussion started with the facilitator engaging participants in an icebreaker. Participants were asked to state their name/name they preferred to be called, what interested them about participating in the focus group, and their favorite dessert. With the Latina focus group, country of origin was also asked.

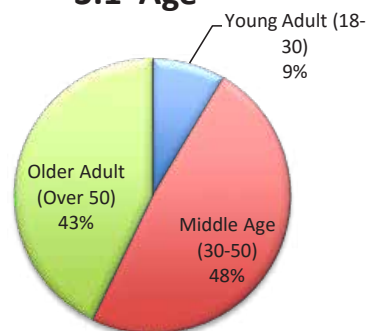
A series of 14 questions with subsequent probing questions were outlined in the Discussion Guide. Going into the focus groups, it was understood that all questions may not get asked directly depending on the flow of conversation, however each topic would get addressed. Participants were provided with pens and blank sheets of paper and instructed to jot down any thoughts they may have about questions asked that they did not feel comfortable expressing in the group setting. Additionally, when closing out each group, participants were instructed to use the blank sheets of paper to write their response. Each group closed with thanking the participants for their participation and the distribution of a \$50 gift card incentive.



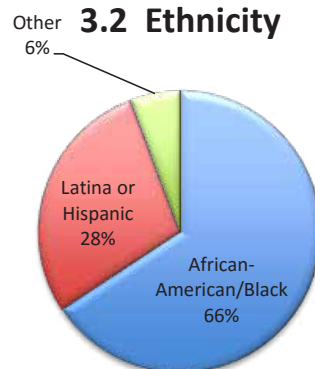
PARTICIPANT DEMOGRAPHICS

Recruited participants were asked to complete a 10 question Demographic Questionnaire (**Appendix B**) prior to participation in the focus group. Participants were asked to complete the Demographic Questionnaire as a part of the registration process online. Two participants were unable to complete the questionnaire online due to lack of access to a computer/internet and were contacted via phone to provide their responses verbally. Additionally, several participants that registered were unable to attend and those on the wait-listed were subsequently registered. Individuals that were moved from the wait-list were asked to complete the Demographic Questionnaire onsite. A breakdown of demographics across all four focus groups is outlined below.

3.1 Age

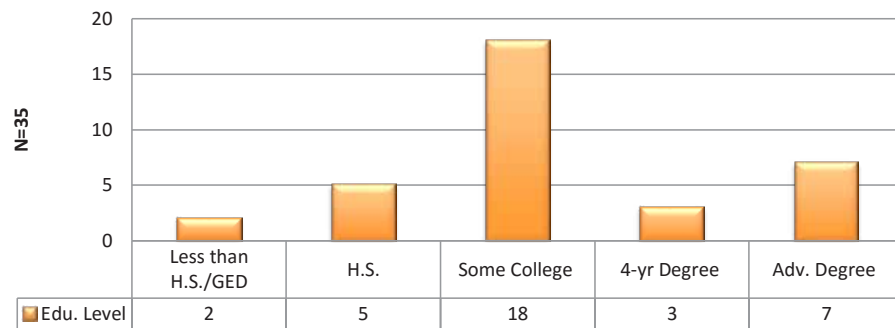


3.2 Ethnicity

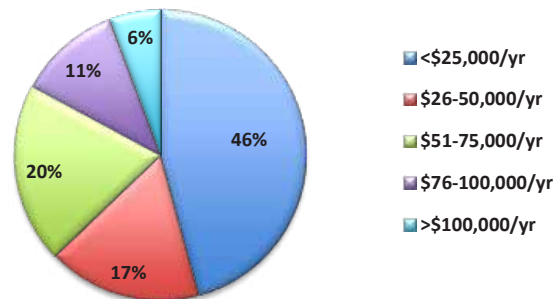




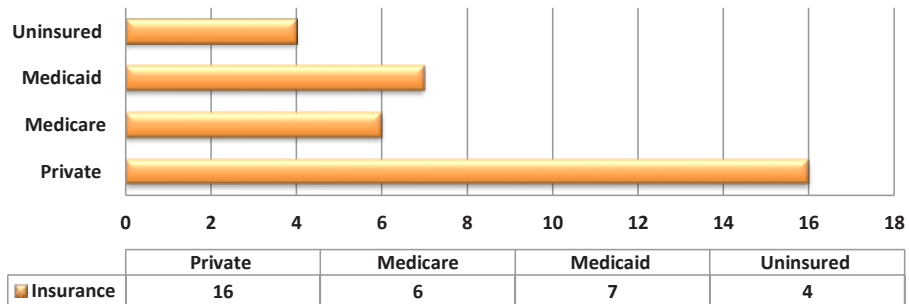
3.3 Educational Attainment



3.4 Household Income

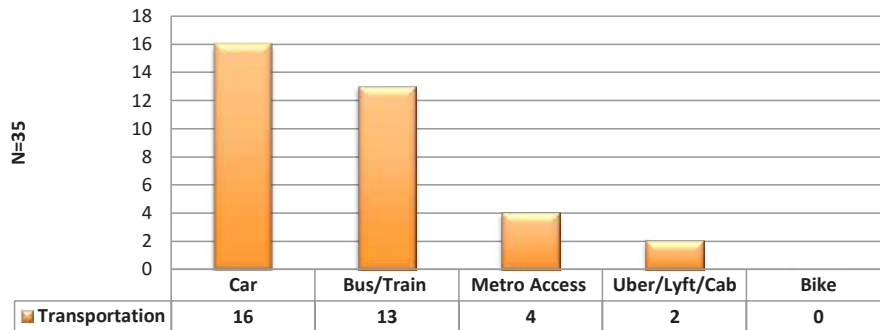


3.5 Insurance Status



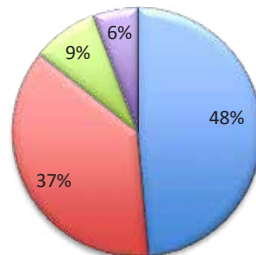


3.6 Primary Mode of Transportation

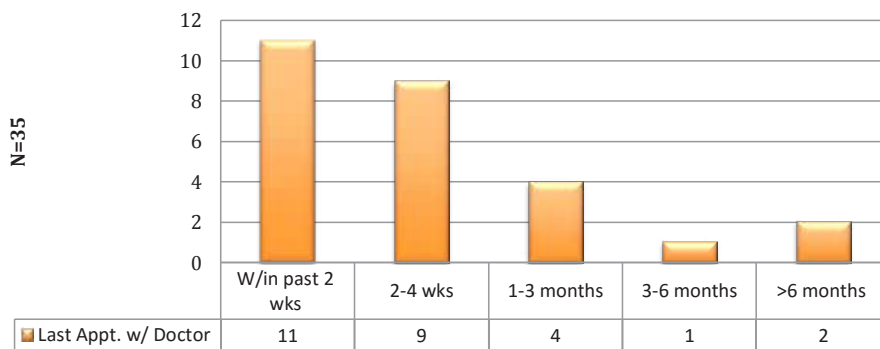


3.7 Distance Traveled to See Doctor

■ <5 miles ■ 5-10 miles ■ 10-20 miles ■ 20-30 miles

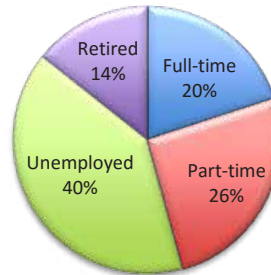


3.8 Last Appointment with Doctor

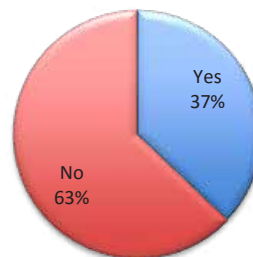




3.9 Employment Status



3.10 Participants with Other Chronic Health Conditions



OVERARCHING THEMES & DISCUSSION

5.1 Common Overarching Themes Across All Four Focus Groups

The following represents the overarching themes from qualitative data generated during the four focus groups. Focus group questions (see Discussion Guide), informed consent documents, and demographics for each focus group can be found in the **Appendices (A, C, and D)**. These themes include:

THEME 1. Value means having a relationship with your physician where the physician shows respect, interest, care and compassion and is accessible and responsive.

THEME 2. The provider-patient relationship is extremely important. Patients' want physicians that are respectful, knowledgeable, open and honest, good listeners and positive.



THEME 3. Patient's interactions with their physician and the ENTIRE care team (nurses, case workers, front desk staff, etc.) are extremely important.

THEME 4. The provider-patient relationship affects a patient's health outcome. A provider's character and demeanor are VERY important.

THEME 5. Participants across all groups expressed that costs plays a role in the quality of the care received by patients.

Each theme below includes a bulleted list of direct quotes and excerpts of participants' perceptions and experiences from across all four focus groups discussions that fell under that theme. While focus group participants may have stated their experiences and opinions in different words, the quotes selected represent statements expressed by a majority of participants across all four groups.

Theme #1: Value means having a relationship with your physician where the physician:

- **Shows respect, interest, care and compassion.**

- "My physician expressing care and concern about me as a whole person, not just my disease"
- "They need to know your name, your children, your family, etc. It makes a big difference, makes you feel important."
- "Don't rush through the exam, spend time."
- "Shows interest in my care, describe what's going on and understand that my life is important."
- "Understand and be compassionate about what I'm going through."

"I once saw a neurologist and a knee doctor for issues with my knees and when they found out I was HIV positive – they only took into account the HIV. They didn't even bother to examine me. Everything that was wrong with me was solely because I had HIV."

- **Is accessible and responsive.**

- "Responsive to my needs and treats me like I am the only one that matters."
- "I can reach and communicate with my doctors directly and don't have to go through people."
- "Follow-up, call and let me know what's going on with my health and what I am doing right."

Theme #2: The provider-patient relationship is extremely important. Patients' want physicians who are:

- **Respectful**

- "Respect and appreciate my time." "Don't make me wait long." "Consider all I have to go through to get to an appointment."
- "Don't be dismissive and cold."
- "Providing equal treatment regardless of what type of insurance I have or my financial status."
- "Not judging me on my lifestyle when I disclose things I do with you."
- "Making eye to eye contact."



- **Knowledgeable and competent.**
 - “Efficiency and competency is important.”
 - “There’s a difference between a physician versus a resident especially at a teaching hospital. It’s important for staff to identify who they are and what role they play.
 - “Physicians that wear gloves anytime they touch you versus only when they take blood.”
 - “Reviewing my charts before my visit, sharing information with my other doctors so I don’t have to repeat myself and everyone knows what’s going on.”
- **Open and honest.**
 - “Explain the process, procedures, effects of medicines and treatment and be specific about what I need to do.”
 - “Seek feedback from me on what they say.”
 - “Ask me instead of assuming.”
- **Good listeners.**
 - “Talking “to” and not “at” me.”
 - “Use a language, words and terms that I understand.”
- **Positive.**
 - “My physician having a positive attitude is very important.”
 - “My physician was hopeful which gave me hope.”

Theme #3: Patient’s interactions with their physician and the ENTIRE care team (nurses, case workers, front desk staff, etc.) are extremely important.

- “Social workers and case managers can negatively impact your health.”
- “It would be much better if social workers worked in conjunction more with physicians.”
- “The front desk staff is important. When they greet me and know my name, it makes me feel special.”

Theme #4: The provider-patient relationship affects a patient’s health outcome. A provider’s character and demeanor are VERY important.

- “It’s important for my physician to have a good character, be sensitive (character is IMPORTANT)”
- “Being treated like an individual (not being treated like all “gay men are drug addicts and all are the same”).”



Theme #5: Participants across all groups expressed that cost plays a role in the quality of the care received by patients.

- “Cost means everything that’s involved with treatment and care... access to the doctors, the cost of treatment, co-pays, medicine, personal costs (rent/mortgage, food), etc.”
- “Cost means having to make tough decisions... rent or medicine, food or doctor.”
- “Cost means anger and frustration.”
- “Type of insurance makes a HUGE difference!”
- “DC Medicaid – difference in the value that you get, most doctors are turning it down. A lot of the good physicians would rather not go with DC Medicaid.”
- “DC Medicaid is good for when a patient has an acute emergency (something bad) because they know they can bill.”
- “Specialty physicians don’t like to deal with Medicaid and appointments can be 3-6 months out.”
- “Specialty physicians do not get paid right away – the way the system is set up is part of the problem.”

“I once went to the hospital – thought I needed my appendix removed but it was a bowel obstruction. The hospital ran 25 tests just because they knew they could get reimbursed quickly (through DC Medicaid) ”

In addition to the aforementioned themes, similarities also existed amongst participants with regard to good and bad health care experiences. Those experiences are highlighted in **Table 3** below.

Table 3. Participant Examples of Good and Bad Experiences

BAD EXPERIENCES VS. GOOD HEALTHCARE EXPERIENCES	
BAD EXPERIENCES	GOOD EXPERIENCES
<ul style="list-style-type: none">▪ Doctor told me “you’re going to expire” or “you’re going to die.”▪ Doctor’s candor...acting like it’s trivial or nothing.▪ Doctor didn’t tell me “you will be ok”.▪ “Going to the pharmacy and finding that I can’t take the medication the doctor prescribed because I can’t afford it.”▪ Lack of confidentiality... medical team spoke loudly about my condition in front of others.▪ Talking to you like you’ve had this diagnosis for years, not compassionate or empathetic.	<ul style="list-style-type: none">▪ Doctor explained what was going on with me.▪ Doctor involved me in the decisions about my care.▪ Doctor made me feel that I was the only one that mattered.▪ Got connected to a support group.▪ Case manager that loved and cared on me.▪ Got connected to a good clinic.▪ Doctor told me “you’re going to be ok.”▪ My family received the same education and support as I did.



5.2 Deviating Themes Across All Four Groups

While there were many common themes amongst participants across all four focus groups, there were some interesting themes that surfaced specific to the focus group based on type. Areas of deviating themes revolved around:

- Sources of stress and strength;
- Good and bad health care experience; and
- Social and/or cultural details/features that influence their decisions to go to a certain physician or health care facility.

Participant perspectives regarding sources of stress and strength differed based on type of illness faced however both groups listed “dying/death” as a source of fear. However, interestingly both HIV/AIDS groups listed “fear of dying” as their primary source of stress and strength. For these participants, the thought of dying elicited fear but also was something they used as a source of motivation and strength. This fear motivated them to keep up with their therapeutic medication regimen; see their physicians; and do everything they could to prevent dying. Alternatively, for both cancer groups, “family, children and the future” served as sources of stress and strength. Additionally, all participants in the African-American Breast and GYN Cancer group shared that their “spirituality” served as a huge source of strength. Additional sources of stress and strength are summarized in the **Table 4** below.

Table 4. Participant Sources of Stress and Strength

SOURCES OF STRESS AND STRENGTH	
HIV/AIDS Groups (#3 & 4)	Cancer Groups (#1 & 2)
<ul style="list-style-type: none">▪ Dying/Death (Stress)▪ Rejection... stigmas especially family (<i>Heterosexual HIV/AIDS group</i>) (Stress)▪ Relationships... no one’s going to want me (<i>Heterosexual HIV/AIDS group</i>) (Stress)▪ Pregnancy... making sure baby is born negative and healthy (<i>Heterosexual HIV/AIDS group</i>) (Stress)▪ Insurance coverage for treatment and medication (Stress)▪ Fear of dying= double-edged sword... source of stress and source of strength (Stress) & (Strength)	<ul style="list-style-type: none">▪ Family, children, and the future? (Stress) & (Strength)▪ The medicine and everything you have to do. (Stress)▪ The process and living a new life with the disease. (Stress)▪ Spirituality (<i>African-American Group</i>) (Strength)▪ Dying/Death (Stress)

Another interesting deviating theme centered on the importance of social and/or cultural details/features that influence choice of a certain physician or health care facility. For Focus Groups #1, 2 and 3, race/ethnicity and gender were not important factors that influenced patronage with a certain physicians or health care facility. **Focus Group #1: African-American Breast and GYN Patients** resounding preferred a physician that was spiritual or respectful of their spirituality and beliefs. Race/ethnicity or gender was not a critical factor. Participants in **Focus Group #2: Latina Breast and GYN Cancer** all agreed that the most important feature was



that the physician/health care team spoke their language (Spanish) regardless of race/ethnicity or gender. The participants in **Focus Group #3: HIV/AIDS**, only preference was that the physician was knowledgeable and compassionate. Participants in **Focus Group #4: LGBTQ HIV/AIDS** were very specific regarding criteria important to them when selecting a health care provider. These include:

- All except one participant preferred not to see a white male or white straight male physician. For a therapist, all ten participants state that they would only see a black gay man because “he would know/understand their plight”.
- A majority of the group also expressed that due to past experiences being abused as a child, they preferred not to have a African-American, straight male physician.
- All but one participant stated that they were “afraid” of Caucasians. Several expressed that this fear was taught to them growing up.

CONCLUSION

While the cost of care was mentioned as a source of stress/anxiety, when making decisions about care and treatment, what was most important to participants was that they had a physician that they trusted to have their best interest at heart and who respected who they were as a whole person beyond the illness they were confronting. In the end, participants expressed their will to live and have a physician who they trusted and believed was willing to help them fight to live was of most value to them. As such, it can be concluded that “value” to all participants did not equate to cost rather was viewed in non-monetary terms to include **respect, consideration, care, and compassion** showed to them by their health care provider(s) and health care team. Also, having a provider that was competent was extremely important.

The patient-provider relationship was viewed as critically important to each participant’s health outcomes. As such, building a good report and establishing trust with not only their provider, but also the entire health care team to include front desk staff and allied health professionals was extremely important. Additionally, participants across all four groups believed cost plays a huge role in the type of care they receive. Interestingly, despite acknowledging that cost plays a huge role in the type of care received, participants still advocated for the best care and refused to accept bad treatment because of the type of insurance they had.

RECOMMENDATIONS

While respect, consideration, care and compassion cannot necessarily be taught; they can be assessed. Participants across all groups wished the physicians with whom they had negative encounters with had undergone empathy or compassion classes so they could improve their bedside manner. One way to address this concern would be to have physicians undergo semi-annual assessments during which physicians’ encounters with patients get assessed by a team



to include other medical professionals with high competencies and patients living with the illnesses those physicians treat. Additionally, during each of the four focus groups, participants expressed their desires regarding information they wish they had or feelings, thoughts or emotions they would have like conveyed from their physician and health care team. One of the questions specifically asked included “what information/ support do you wish you had prior to having to make a tough decision their care?” Participants across all four groups agreed they wish they had the following:

- An orientation, communication and information (facts) about what is going on and what is going to happen with regards to their treatment and care; and
- An explanation of the payment system and the costs involved for their treatment and care.

Both of the aforementioned items can be easily incorporated into a patient’s visit and could help alleviate some of the stress and anxiety patients and their families may feel which in turn can help them feel more “valued”.



APPENDICES

Appendix A: Discussion Guide

Appendix B: Demographic Questionnaire

Appendix C: Informed Consent Form

Appendix D: Focus Group Demographics

APPENDIX A

Prepared for:



FOCUS GROUP DISCUSSION GUIDE

AGENDA OUTLINE

- I. Welcome, staff introductions housekeeping, and ground rules
- II. Review confidentiality and have participants sign forms
- III. Overview of Value Project (*why we're here and what will be done with the information*)
- IV. Warm-up & ice breaker
- V. Introductory Question
- VI. Guiding Questions
- VII. Concluding Question/Last thoughts
- VIII. Wrap-up & Thank you.

WELCOME, STAFF INTRODUCTIONS, HOUSEKEEPING & GROUND RULES

Tasha: *Good evening and thank you for volunteering your time to join us for this discussion on value and healthcare. My name is Tasha Moses and I will be the facilitator for this discussion. Your have been asked to participate because your opinions, feedback and point of view is important to us. Before we get started I'd just like to first briefly introduce our team and review some housekeeping and rules.*

<<<Begin team introductions (Name/Organization) in the following order: Shonta Chambers (PAF) Christine Wilson (PAF) – Rachel Landefeld (SMS) –>>>

Housekeeping:

- Focus group will last about one hour.
- Point out bathrooms and exits.
- Encourage participants to grab refreshments.

Ground Rules:

- Please turn off your cell phone.
- The most important rule is that only one person speaks at a time. Everyone's voice is important and it is important to us to obtain ALL views.

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APPENDIX A

Ground Rules (cont'd):

- There are no right or wrong answers. We truly just want to know how your thoughts, feelings and perspective.
- Also, you do not have to agree with the views of other people in the group however we will ask you to agree to disagree.
- You do not have to speak in any particular order. Just please be respectful of one person speaking at a time.
- When you do have something to say, please do so. This is your time to share your thoughts on this particular topic.

Any questions?

CONFIDENTIALITY

Tasha: Now I will review confidentiality. You have a consent form in front of you because this conversation will be recorded via audiotape. I want to review how we will use the audio and will provide you time to ask questions. <<<read consent form aloud then review the following below>>>:

- No attendee will be identified by name. Your names and contact information will be removed from the demographic questions you responded to when you registered for the focus group.
- We are taping this conversation so that we can focus more on the discussion than note taking. Despite being taped, I would like to assure you that this discussion will be anonymous. Once we begin the tapes, we ask that you not refer to any participant by name rather by the number that is on their nametag. The tapes will be kept in a locked safe until they are transcribed, then they will be destroyed. The transcribed notes of the focus group will contain no information that would allow you to be linked to any specific statement.
- Lastly, we ask and would appreciate it if you would refrain from discussing the comments of other group members outside the focus group. If there are any questions or discussions that you do not wish to answer or participate in, you do not have to do so; however please try to answer and be as involved as possible.

Any questions? If there are no questions we ask that you please take a moment to review again and when you are ready, sign the document. Please hold it up when you are done and my colleague Rachel will collect.

Tasha: I will now turn it over to Shonta Chambers to explain why we're here and what we hope to learn from today's discussion.

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APPENDIX A

OVERVIEW OF VALUE PROJECT

Shonta: *Thank you for agreeing to participate in today's discussion. The Patient Advocate Foundation (PAF) was established in 1996. We offer assistance by providing professional case management services to patients living with chronic, life threatening and debilitating illnesses. PAF case managers serve as active liaisons between the patient and their insurer, employer and/or creditors to resolve insurance, employment issues and/or money crisis matters as they relate to their diagnosis.*

PAF was awarded a grant by the Robert Wood Johnson Foundation (RWJF) to build and design a framework that supports the inclusion of both the patient's voice and the patient's value. RWJF's interest in expanding patient engagement in decision-making dates back to at least 2007, when RWJF hosted a colloquium of health policy experts focused on "Improving Quality Health Care: The Role of Consumer Engagement." In the nine years since that first meeting and issue brief, the role of patient engagement in securing the triple aim— better health care, costs, and outcomes—has become increasingly vital.

With this focus group, we want you to help us better understand the patient experience and what about that experience you, as the patient value. The information we learn from you during this conversation will help us ensure that the patient's voice is paramount in discussions regarding their health and healthcare.

WARM UP & ICE BREAKER

Tasha: *Now we would like everyone to introduce them selves. Please tell us your name; what interested you about participating in the group; and your favorite dessert.*

<<<After participant introductions ask if anyone has any questions before we get started?>>>

INTRODUCTORY QUESTION

<<<Announce that the tape recorder will now be turned on.>>>

1. When you hear the word "value" in the context of health care or decisions that you may have to make about healthcare, what are the things that you think about?

GUIDING QUESTIONS

2. What social and cultural aspects influence you to go to a certain doctor or hospital
 - a. What influences you to stay with your doctor and health care provider?

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APPENDIX A

- 3. What have been your most significant source(s) of distress/worry and also strength/comfort in facing this illness?**
 - a. Has it been money, family, or employment?
 - b. What about these things caused you distress/worry?

- 4. Do you feel your health care provider/doctor has a role in reducing your burden of stress?**
 - a. If so, what do you feel that role should be and why?
 - b. Do you place importance on someone from the provider's office asking if there is a support system for you?
 - c. If you do not have assistance, how would you feel if a provider offered you assistance with creating a support plan?

- 5. What do you know now that you wish you had known earlier in the course of your illness and/or care?**

- 6. After your diagnosis, did your doctor ask you what is important to you as a part of making plans for your treatment?**
 - a. If yes, how did that make you feel?
 - b. If no, how would it have made you feel if they did ask?

- 7. How comfortable would you feel telling your doctor "I'd like to talk to you about what is important to me in terms of my quality of life?"**
 - a. If you would not feel comfortable, why not?
 - b. What would help you feel more comfortable with saying this to your doctor?

- 8. Have you ever had a conversation with your doctor about what matters to you?**
 - a. When you had a conversation with your doctor about what matters to you, did you feel your doctor took that information into account in making recommendations or plans about your treatment?
 - b. If you did not have that conversation, why not?
 - c. If you did not have that conversation, would you feel comfortable telling your doctors what matters to you?

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APPENDIX A

9. What do you feel makes a “bad” care experience—describe a time and the circumstances?

- a. What specifically about this experience was “bad”?
- b. How did it make you feel?
- c. Is there something you feel that the health care provider could have done differently to change the experience?

10. Describe a time and the circumstances when you feel you had a “good” health care?

- a. What specifically about this experience was “good”?
- b. How did it make you feel?

11. Describe an example/time when you felt your care team and you were on the same page.

- a. What specific factors contributed to you feeling that you were on the same page?
- b. How did this make you feel?

12. When you think about the word “cost” as it relates to healthcare or decisions you may have to make about health care, what are some words that come to mind?

- a. Describe what you think about when you hear cost and healthcare?
- b. What feelings do you associate with the words “costs” and “healthcare”?

13. Describe a time you faced a difficult decision about treatment—what information or support did you most want to know or wish you had?

- a. Was there something your healthcare provider could have said or provided?
- b. Was there information or resources that you wish you had? If so, what type of resources?

WRAP UP & THANK YOU

***Tasha:** That concludes our focus group. Thank you so much for coming and sharing your thoughts, feelings, stories and opinions with us. We have a short evaluation form that we would like you to fill out. If you have additional information that you did not get to say or feels comfortable saying in the focus group, please feel free to write it on this evaluation form. Thank you again and enjoy the rest of your evening!*

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APPENDIX B



Solving Insurance and Healthcare Access Issues | since 1996

Focus Group Demographic Questionnaire

Directions: Please check ☒ the box next to the answer that best describes how you identify.

1. Which of the following best describes your life phase?

- ☐ Young Adult
- ☐ Middle Age
- ☐ Older Adult

2. Which best describes your ethnicity? (Select all that apply.)

- ☐ African
- ☐ African-American/Black
- ☐ Asian
- ☐ Caucasian/ European Decent
- ☐ East Indian
- ☐ Latino/Latina or Hispanic
- ☐ Native American or Alaskan Native
- ☐ Pacific Islander
- ☐ Other _____

3. Which best describes your level of education?

- ☐ Less than high school education or GED
- ☐ High School
- ☐ Some College
- ☐ 4 year Degree
- ☐ Advanced Degree

4. Which best describes your household income?

- ☐ Less than \$25,000/yr
- ☐ \$26-50,000/yr
- ☐ \$51-75,000/yr
- ☐ \$76-100,000/yr
- ☐ Over \$100,000/yr

5. What type of insurance do you have?

- ☐ Private Insurance
- ☐ Medicare
- ☐ Medicaid
- ☐ I do not have insurance.

6. When was your last visit with your doctor?

- ☐ Within the past 2 weeks
- ☐ 2-4 weeks
- ☐ 1-3 months
- ☐ 3-6 months
- ☐ 6 months or more

7. On average, how far do you travel to see a doctor?

- ☐ Less than 5 miles
- ☐ 5-10 miles
- ☐ 10-20 miles
- ☐ 20-30 miles
- ☐ More than 30 miles

8. What is your primary means of transportation?

- ☐ Car
- ☐ Bus/Train
- ☐ Metro Access
- ☐ Uber/Lyft/Cab
- ☐ Bike

9. Which best describes your employment status?

- ☐ Employed Full-Time
- ☐ Employed Part-Time
- ☐ Unemployed
- ☐ Retired

10. In addition to cancer, do you have any other health conditions?

- ☐ Yes
- ☐ No

11. If yes, please write below:

APPENDIX C



CONSENT TO BE AUDIO RECORDED

You have been invited to participate in a focus group discussion with others on value and healthcare as it relates to management of your chronic disease/illness. Your participation will help health care providers to better understand how patients perceive and define “value” in health care and treatment. The focus group will last about 90 minutes. A trained leader will facilitate the discussion. The information obtained from the focus groups will be used to infuse the patient into the center of a Value Framework to ensure that their voice is paramount in the discussions regarding their health and healthcare. Your responses during this focus group will be unidentified and all information discussed will remain confidential.

We would like to record the focus group discussion on audiotape so that we can make sure to capture the thoughts, opinions, and ideas we hear from the group. No names will be attached to the focus groups and the tapes will be destroyed as soon as they are transcribed. A report on this discussion and the demographic information you provided will be prepared by Strategic Management Services, LLC, consultants for the Patient Advocate Foundation (PAF). In addition, a summary from today’s focus group might be shared with the public through various web-based materials and reports.

Only the project team will have access to the discussion notes and demographic information data. Anything you say during the discussion will be kept secure to the extent permitted by law. Your name will not be used in any reports or publications resulting from our discussion during the focus group. Information gathered from our discussion and the demographic information will be available to the project team during analysis and no names will be included. We also ask all participants to respect each other’s confidentiality. We understand how important it is that this information is kept private and confidential.

We do not foresee any risks to you from participating in this focus group. Your participation is completely voluntary and you do not have to answer any questions or discuss any issues that you do not want to discuss. You may stop participating at any time. This focus group is being conducted on behalf of the PAF with funding from the Robert Wood Johnson Foundation. If you have any questions or concerns about this project, please call Shonta Chambers, EVP Health Equity Initiatives and Community Engagement at the Patient Advocate Foundation at Shonta.Chambers@patientadvocate.org or at (757) 952-2533. We thank you for your time.

My signature verifies that I have read about the project and understand my rights as a participant. I agree to participate in today’s focus group discussion. I understand that the discussion will focus on how patients’ perceive and define “value” in health care and treatment. I agree to be observed and have my responses noted and recorded. I understand that only the people working on this project will be given access to the information collected. I understand that the Patient Advocate Foundation will not use my name or any other identifying information in any report or other products that may result from this focus group.

Print Name: _____

Signature: _____

Date _____

APPENDIX D

Focus Group Demographics

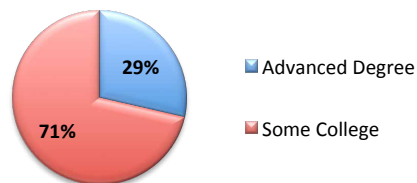
TABLE OF CONTENTS

<u>FOCUS GROUP #1: AFRICAN-AMERICAN BREAST AND GYNECOLOGICAL CANCERS</u>	<u>2</u>
<u>FOCUS GROUP#2: LATINA BREAST AND GYNECOLOGICAL CANCERS</u>	<u>3</u>
<u>FOCUS GROUP#3: HIV/AIDS</u>	<u>4</u>
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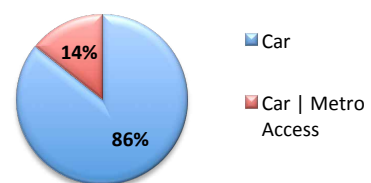
Focus Group #1:
African-American Breast and Gynecological Cancer Patients/Survivors (N=7)

- **Age:** 100% of participants identified as “older adult” (*age 50 or older*)
- **Ethnicity:** 100% of participants identified as African-American
- **Insurance Status:** 72% of participants have private insurance, 14% Medicaid, 14% Medicare
- **Other comorbidities amongst participants:** None of the participants had comorbidities.

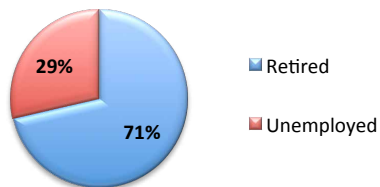
Level of Educational Attainment



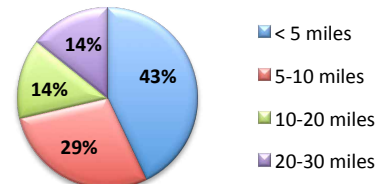
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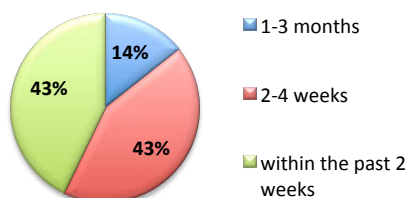
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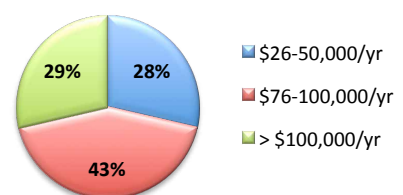
Distance Traveled to See a Doctor



Last Appointment with a Doctor



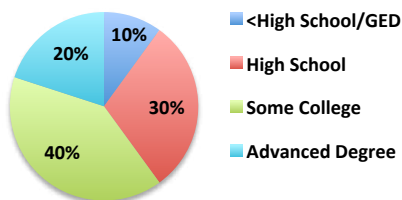
Household Income



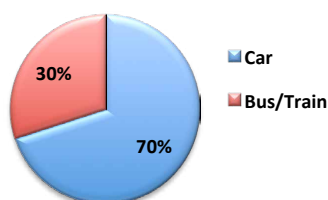
Focus Group #2:
Latina Breast and Gynecological Cancer Patients/Survivors (N=10)

- **Age:** 30% of participants identified as “young adult” (age 18-30), 30% identified as “middle age” (age 30-50), and 40% identified as “older adult” (age 50 and over)
- **Ethnicity:** 100% of participants identified as Latina
- **Insurance Status:** 40% of participants did not have insurance, 30% Medicaid, 10% Medicare and 20% Private Insurance
- **Other comorbidities amongst participants:** 60% of participants had comorbidities

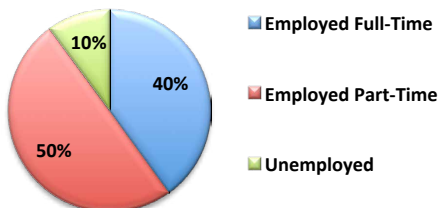
Level of Educational Attainment



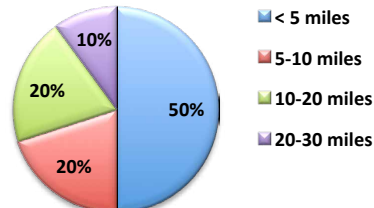
Primary Mode of Transportation



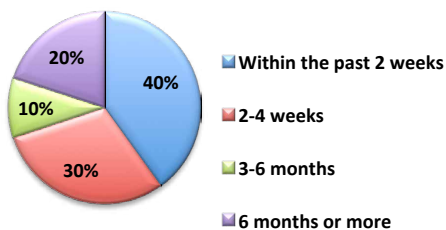
Employment Status



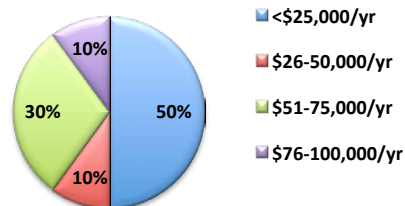
Distance Traveled to See a Doctor



Last Appointment with a Doctor



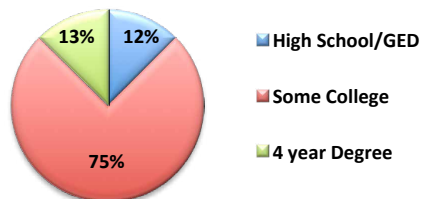
Household Income



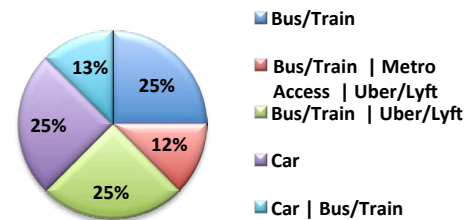
Focus Group #3: HIV/AIDS (N=8)

- **Age:** 90% of participants identified with being “middle age” (age 30-50), 10% identified as “young adult” (age 18-30)
- **Ethnicity:** 100% of participants identified as African-American
- **Insurance Status:** 80% of participants indicated they have Medicaid and Medicare, 10% Medicaid and 10% Private Insurance
- **Other comorbidities amongst participants:** 60% of participants had comorbidities

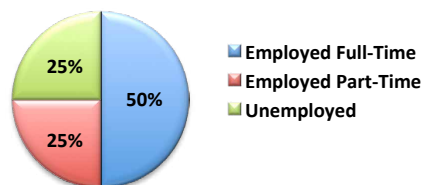
Level of Educational Attainment



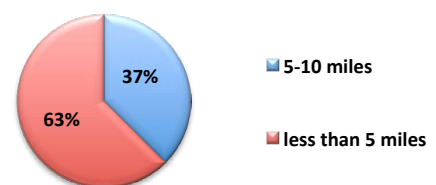
Primary Mode of Transportation



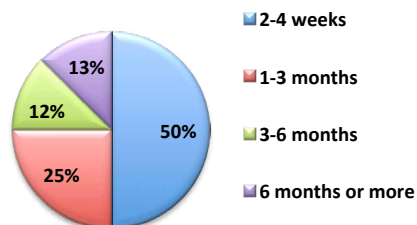
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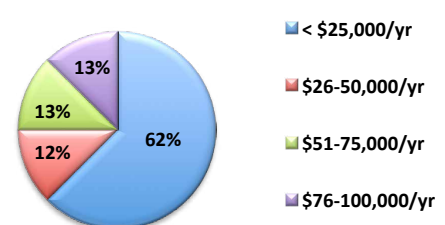
Distanced Traveled to See a Doctor



Last Appointment with a Doctor



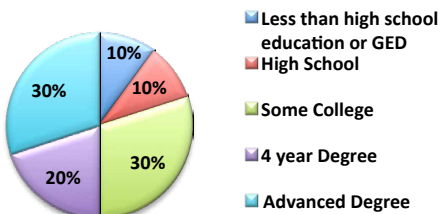
Household Income



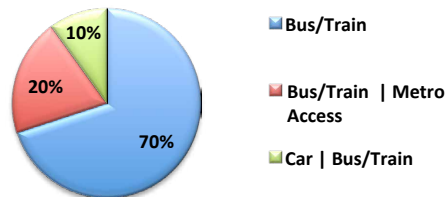
**Focus Group #4:
LGBTQ HIV/AIDS (N=10)**

- **Age:** 50% of participants identified with being “middle age” (30-50) and 50% “older adult”
- **Ethnicity:** 90% identified as being African-American, 10% of participants identified as “other”
- **Insurance Status:** 70% of participants had Medicaid, 20% had Medicare and 10% Private Insurance
- **Other comorbidities amongst participants:** 70% of participants had comorbidities

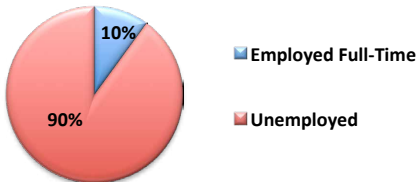
Level of Educational Attainment



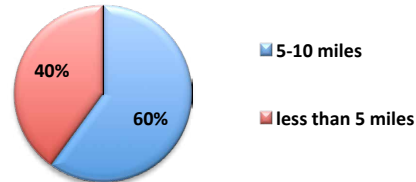
Primary Mode of Transportation



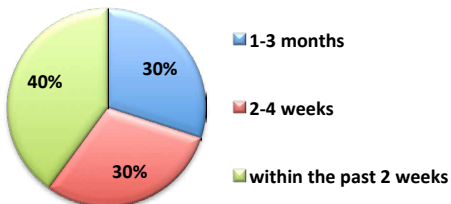
Employment Status



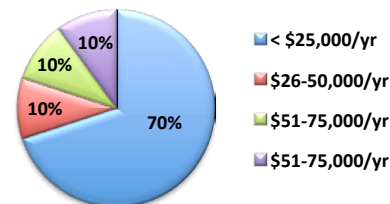
Distance Traveled to See a Doctor



Last Appointment with a Doctor



Household Income



■ APPENDIX

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■ APPENDIX

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