ADDRESSING CONSUMER PRIORITIES IN VALUE-BASED CARE

Guiding Principles and Key Questions

A CONSENSUS FRAMEWORK FROM THE HEALTH CARE TRANSFORMATION TASK FORCE
Introduction

The Health Care Transformation Task Force (Task Force) is an industry consortium that brings together patients, payers, providers, and purchasers to align private and public sector efforts to clear the way for a sweeping transformation of the U.S. health care system. Each Task Force member commits to rapid, measurable change, both for their organization and the country. Our payer and provider members also aspire to having 75 percent of their respective business operating under Triple Aim value-based payment arrangements by 2020.

To effectively achieve this goal, the Task Force believes the interests of consumers/patients must be considered during all aspects of health care delivery transformation—the developing, implementing, and assessing value-based care models. As such, the Task Force developed this consensus framework on how we believe consumer priorities should be addressed and accounted for in value-based care models.

The Task Force’s work in this area is complementary to the value-based care transformation being undertaken in the public sector. Public sector efforts are being driven by new laws, economic incentives, and technologies. Implementation of the historic Patient Protection and Affordable Care Act (ACA) is driving rapid adoption of new value-based care contracts to better serve Medicare beneficiaries across the country, while also providing important new rights, benefits, and protections for health care consumers. While the Medicare program’s value-based transformation is very visible and widely discussed, private payers and state Medicaid programs are also increasingly implementing their own value-based reimbursement programs. These programs are creating significant new financial opportunities for innovative health delivery organizations.

Technologically, new information processing and medical technologies including the continuing move to interoperability, online access to health records, use of smart phones, and new “big data and analytics” capabilities are creating many new opportunities to improve health care services for consumers and the organizations which serve them. Combined, these forces, are opening the door to a new era of person-centered, value-driven care where individual preferences can increasingly influence the delivery of health care services both through private and public sector initiatives.

However, many challenges remain on the path to a person-centered, value-driven U.S. health care system. New policies, practices, and tools need to be researched, designed, developed, and deployed by groups of collaborating stakeholders. The Task Force’s intent in producing this consensus framework is to help ensure that consumer priorities remain front and center for consideration during all phases of the transformation to a value-based care system.

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1 A note about terminology. This document uses consumer as an umbrella term to represent an individual or their authorized representative, such as a parent of a minor or a child of an aging parent, who interacts with the health care system. A consumer may also be referred to as an individual, person, patient, member, beneficiary, caregiver, or resident. The terms patient and care are also used in certain contexts. To some, these terms could imply a focus on episodes of illness and exclusive dependency on professionals. However, any effort to improve engagement of patients and those who support their care (such as family, friends, and community-based caregivers) must include the use of terminology that also resonates with numerous consumer perspectives not adequately reflected by medical model terminology. For example, people with disabilities frequently refer to themselves as “consumers” or merely “persons” (rather than patients). Similarly, the health care community uses the terminology “caregivers” and “care plans,” while the independent living movement may refer to “peer support” and “integrated person-centered planning.” The term authorized caregivers is used in certain contexts to refer to patient-authorized individuals involved in providing care or decision-making support for a consumer/patient. Authorized caregivers may include family members, friends, authorized representatives, community-based supporters, or others authorized by the patient to support them in their care.
Gaps in Policy and Practice

The Task Force decided to pursue this project after identifying an important set of gaps in the current knowledge base regarding how best to address consumer priorities in health care system redesign and patient care delivery. Open questions in this area include:

**Systems Level**
- What structures and mechanisms are in place to solicit consumer input into delivery system design?
- How can consumers be best represented in the governance of health plans, providers, and other health services organizations?
- How effective are different methods and structures for engaging consumers in system design and care management?
- What structures and processes work best for engaging different population subsets?
- How can sufficiently detailed datasets and subsets of consumer data be identified and developed to support valid measurements of the effects of policies and practices on specific sub-groups?
- What are the best ways to proactively use value-based policies and practices to reduce health disparities?

**Patient Care Level**
- How can the effectiveness of new care and payment delivery models designed to meet patients’ and patient-authorized caregivers’ needs be best assessed?
- What is the most appropriate way to measure patient engagement and experience, particularly for vulnerable populations?
- How can health information technology (Health IT) be leveraged to facilitate effective and meaningful patient, consumer, family, and community engagement in health decision-making?
- What are the most efficient ways to capture patient goals, values, and preferences in the payment and delivery model measurements?
- How can providers respond effectively to patient goals, values, and preferences?
- What consumer protections are necessary to adequately inform consumers about their care and safeguard their access to high-quality and affordable care?
Purpose

This paper focuses on providing a set of questions to facilitate consideration of consumer priorities in the development of person-centered, value-based care policies and practices for improving U.S. health care. Our purpose is both aspirational and practical. The paper does not seek to provide definitive answers to questions of how to modify policy and practice to better account for consumer priorities. Instead, it strives to provide a framework— a set of guiding principles and key questions that stakeholders involved in developing new policies and practices for improving health care can use, and find useful, in their work.
Guiding Principles for Addressing Consumer Priorities in Value-Based Care Policies and Practices are presented in summary form (below). A detailed discussion of each principle along with key questions follows the summary.

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Overarching Question about Patient Responsibility

In developing these principles and key questions, an overarching question of broad interest to Task Force members was carefully considered: how best to engage patients/consumers in taking shared responsibility for their health and care. Principles and key questions presented in this document reflect the following recommendation for addressing the important question of patient responsibility:

Shared Responsibility Based on Shared-Care Planning Models

- Are shared-care planning models used?
- Are responsibilities of providers and patients/consumers driven by shared understandings and agreements about treatment goals and plans?
- Are shared-care conversations and plans sensitive to the preferences, capacities, limitations, and social and economic contexts of patients and their support networks?
Guiding Principle 1

Person-centered, value-driven health care delivery includes patients/consumers as partners in all aspects of decision-making about their health and care.

A. Decision-making partnerships are seen as key to successful transformation of health care payment and delivery.
B. Partnerships between health services organizations and patients/consumers exist not only at the level of individual health care decision-making; instead, they take place at all levels of care delivery, including at point-of-care, in the design and redesign of clinical care models, in policy and governance, and in the community.
C. Consumer input meaningfully shapes the design, implementation, and evaluation of all value-based care delivery programs.

Key Questions

1. Are patients/consumers meaningfully engaged in governance and oversight?
   a. Does the effort include structures and practices within health services organizations for meaningful consumer engagement, such as patient participation on boards and committees, patient and family advisory councils, or patient involvement in quality improvement efforts?
   b. Do governance and oversight boards include commitments to improve ability to personalize care by addressing the unique needs of the individual patient and family members?

2. Are consumers meaningfully included in program design and implementation?
   a. Does the effort offer multiple, ongoing opportunities for consumers to meaningfully participate in design, implementation, and continuous improvement of the program?
   b. Is a "patient-centered" design process that includes consumers in the process of design and implementation in place?

3. Are person-centered performance measures included?
   a. Does the effort incorporate the use of patient-generated data, including patient experience measures and patient reported outcome measures (PROMs)?
   b. Are those measures available and transparent to consumers?
4. Is leadership committed to supporting and cultivating changes in culture required to foster true partnerships with patients at all level of care?
   a. Is there executive support for engaging patients/consumers as decision-making partners at every level?
   b. Is the “consumer as a partner” principle reflected in writing in the vision/mission statement of the organization or program?
   c. Are mechanisms in place for educating employees and patients about this principle and its implications for improving practice?
   d. Are mechanisms in place to measure the degree to which the principle is applied in practice?

5. Does the system’s design strengthen consumer engagement in their own health and wellness decision-making?
   a. Does the design support patient engagement in shared care planning?
   b. Does it support evidence-based self-management programs?
   c. Does it support use of digital tools and apps for engaging consumers?
   d. Does it encourage providers to ask patients to engage in the care process?

6. Are appropriate mechanisms for helping consumers take responsibility for their care considered?
Guiding Principle 2

Delivery of person-centered care is a cornerstone of value-based health care delivery systems.

A. Patients and their authorized caregivers (including family, friends, authorized representatives, community-based supporters, and others) are at the center of the care team.

B. Health care decisions are informed by the preferences of patients/consumers and their authorized caregivers.

C. Evidence-based clinical care models are used that:
   - Support effective coordination of care across the patient’s care network;
   - Address the full continuum of care, including behavioral health;
   - Address social determinants of health and non-clinical factors that contribute to health and well-being; and,
   - Can be tailored to the needs of the patients being served.

D. Care delivery models couple innovations with adequate consumer protections and safeguards tailored to specific care models.

E. Organizations enable patients to be actively involved in all aspects of their care by providing full access to information on covered plan benefits, provider network availability and limitations, and cost and quality of treatment.

F. Alternative payment and care delivery models are implemented in ways that don’t outpace the capacity to provide care to consumers in a safe, effective, coordinated, and comprehensive manner.

G. Narrow networks that harm ability for patients to access quality, affordable care are not used.

Key Questions

1. Is a clear and accessible point of contact available to support patients in health-related decision-making no matter where they go for care?
   a. Does the effort foster a strong foundation of primary care – such as a patient-centered medical home – to coordinate care across the care spectrum?
   b. Does the effort promote the use of care teams that include diverse providers who can understand the needs and preferences of the patient and their authorized caregivers?
   c. Does the effort incentivize safe, seamless, and person-centered transitions across providers and care settings, including, for example, transition from active treatment to survivorship/maintenance for cancer patients?
2. Are individualized care plans for patients supported?
   a. Does the model encourage using a shared care planning model to engage patients and their authorized caregivers in treatment discussions and decisions?
   b. Can patients and their authorized caregivers access the care plan?
   c. Does the effort support the following:
      i. Addressing patient-specific values, preferences, and goals in care plan development?
      ii. Granting patients and their authorized caregivers the ability to participate in care decisions?
      iii. Using timely, comprehensive health risk assessments that collect functional status information, cultural and linguistic preferences, and information about caregiver roles in order to create an individualized plan of care?

3. Are evidence-based clinical care models used that support:
   a. Effective care coordination across the patient’s care network?
   b. Care across the full continuum of care, including behavioral health?
   c. Consideration of social determinants of health and non-clinical factors that contribute to health and well-being?
   d. Services tailored to the personalized needs of the patients being served?

4. Are patient-centered workflows supported?
   a. Does the effort support development and use of patient-centered processes that work across the spectrum of care for each patient?

5. Are appropriate consumer disclosure and transparency mechanisms supported?
   a. Does the effort support providing patients with clear, easy-to-understand information on aspects of their treatment including covered benefits, limitations to this coverage, whether providers are in network, and patient out-of-pocket costs for treatments (including prescription drugs)?
   b. Does the effort encourage providers to be transparent with their outcomes directly to patients?

6. Is the capacity to provide care to consumers in a safe, effective, coordinated, and comprehensive manner being put at risk?
   a. Has a risk assessment for the model been done?
   b. Is the model safe for patients/consumers?
   c. Is the model being implemented in a way that is safe and effective?

7. Are patients protected from “narrow network” limitations?
   a. Is the network of care broad enough to support delivery of quality care services across the spectrum of care the patient requires?
Guiding Principle 3

Person-centered, value-driven health services networks use alternative payment models (APMs) that benefit consumers.

A. APMs offer appropriate financial incentives that encourage savings only through improvements in health outcomes and health care quality, and also ensure beneficiary rights and protections.

B. While cost-savings are an important consideration, delivery of high-quality care appropriate to the patient’s needs, goals, and preferences is the highest priority.

C. In APMs, gain-sharing is contingent upon performance on quality measures in addition to cost-savings.

D. APMs include strong consumer protections, including but not limited to:
   - Choice in enrollment and provider selection;
   - Data-sharing notifications;
   - Basic education, notices, and tools developed in partnership with consumers and their representatives;
   - Fair appeals and grievance processes;
   - Sufficient oversight to protect against discriminatory treatment for sub-populations;
   - Adequately trained and resourced ombudsman programs or other tracking mechanisms for consumer complaints and questions;
   - Assumptions tied to specific measures based on specific guidelines for that specific group of payments; and
   - Transparency regarding provider incentives and quality performance.

E. Ultimately, APM financial incentives do not reduce access to needed health care services; consumers are also protected from discrimination.

Key Questions

1. Do consumers benefit?
   a. Does the program benefit consumers by delivering better care, better quality, improved patient experience, lower patient cost, and other relevant measures?
2. Are consumers’ rights safeguarded and disclosed?
   a. Are consumer risks and rights – clinical and payment related – defined and explained in clear, consumer-accessible language?
   b. Are consumer risks and rights routinely disclosed to patients?
   c. Are consumers protected from quality problems associated with unduly narrow network design?
   d. Does the model support appeals, exceptions, and grievance processes that are fair, accessible to the consumer, and explained clearly?

3. Are vulnerable populations protected?
   a. Does the model address potential risks to access, treatment, and payment for vulnerable populations?
   b. Does the model consider provide risk-adjusted payments or other payment mechanisms tied to socioeconomic status (SES) to protect access to quality care for vulnerable populations?

4. Do high-priority populations benefit greatly?
   a. Does the payment reform initiative tie financial incentives directly to improvements in outcomes with a particular focus on improving care for high-need/high-cost populations?

5. Do consumers have choice?
   a. Does the payment model allow the patient choice in enrollment and/or choice in providers?
   b. Does the model require disclosure of provider incentives and data-sharing?
   c. Do patients participating in the model have access to innovative care, including clinical trials?

6. Is transparent quality performance data accessible to consumers for evaluation?
   a. Does the program appropriately support transparent reporting of results accessible to consumers through the web?
Guiding Principle 4

Continuous quality improvement drives the development and success of person-centered, value-driven health services.

A. Organizations involved in health care transformation drive continuous quality improvement informed by greater transparency of quality, performance, price, and patient experience data.
B. New models of payment and care delivery hold providers accountable to a high-quality performance threshold.
C. Patient-reported outcomes and patient-experience measures are essential components of any measure set applied to a new payment or delivery model.
D. Quality performance and price data are transparent and informed by consumer input.
E. Quality performance and price data including retail charges, negotiated rates, out-of-pocket costs for consumers, and, where appropriate, provider costs, are easily accessible by consumers and are presented in a consumer-friendly manner.
F. Quality measures are continually improved by retiring topped-out measures, adding new measures, and standardizing and simplifying measures as appropriate.

Key Questions

1. Are patients and their authorized caregivers meaningfully engaged in quality improvement efforts?
   a. Do patients and their authorized caregivers have access to quality ratings?
   b. Do patient and their authorized caregivers (such as family, friends, or community-based advocates) provide quality improvement evaluations?
   c. Are the quality ratings transparent, meaningful, and actionable for patients/consumers?

2. Have all the types of data needed to evaluate efficacy for consumers been considered?
   a. Are patient cost, quality, outcome, and patient experience measures used?
   b. Are consumer-centered quality metrics used, i.e. those that measure whether care is delivered in a way that is consistent with patient’s goals, values, and preferences?
   c. Are patient-generated data from apps, devices and self-reporting used?
   d. Are patient-reported outcomes data, such as functional status and pain assessments, used?
   e. Are mechanisms in place for stratifying quality metric data by age, race, ethnicity, location, primary language, gender identity and sexual orientation, self-reported health, mental health and clinical condition?
   f. Does the effort offer providers and other participants appropriate access to both adjusted and non-adjusted data so they can use it for payment and population health purposes?
3. Are quality improvement structures and processes supported?
   a. Are quality improvement structures and processes in place to:
      i. Assess and improve overall quality?
      ii. Evaluate patient and authorized caregiver experience survey results?
      iii. Drive improvements to care practices/delivery based on feedback from patients and families supported?
   b. Are appropriate evidence-based methodologies used for quality reporting?
   c. Is segmentation by demographics and type of illness supported?
   d. Does the system support understanding of how needs differ based on population segments?

4. Are quality improvement requirements supported?
   a. Is there a requirement to gather and analyze important datasets to support continual improvement?
   b. Is there a requirement to publish process and outcomes data in consumer-accessible formats?

5. Are up-to-date quality measures being used?
   a. Are quality measures being used up to date?
   b. Are topped-out measures being used? If so, should they be retired?
   c. Do any new measures need to be added?
   d. Can any measures be standardized, combined, or simplified?
Principle 5. Accelerate Use of Person-Centered Health IT

Do alternative payment and care delivery models accelerate the effective use of person-centered Health IT?

Guiding Principle 5

Person-centered, value-driven health services networks use alternative payment and care delivery models that accelerate the effective use of person-centered health information technology (Health IT).

A. Person-centered Health IT:
   - Puts the consumer at the center of accessing, managing, and sharing their electronic health information wherever they receive care
   - Includes appropriate privacy and security safeguards for all parties
   - Provides patients and caregivers with access to comprehensive electronic health information needed to support effective health and wellness decision-making
   - Includes patient-generated information from apps, devices, and other sources
   - Anticipates the use of big-data driven “precision medicine” including genomics
   - Supports data collection and analysis for population health, public reporting, and research purposes
   - Supports population health data and analytics functions, including helping systems and the public to understand how new payment and care delivery models are impacting utilization and health outcomes, stratified by sub-populations/demographics
   - Supports innovation including new ways to deliver care – i.e., online or through apps

B. Health IT is used to improve coordination of care, increase accessibility of information for consumers, strengthen consumer engagement in managing their own health and health care, and strengthen communications with providers, among other functions.

C. New models of payment and care delivery encourage effective use of Health IT not only to enhance provider-to-provider information sharing and communications but to also encourage two-way provider-to-patient, consumer-to-consumer, and consumer-to-community interactions.

Key Questions

1. Is use of person-centered Health IT supported?
   a. Does the effort encourage patients and those who support them in the use of Health IT tools to improve their care?
   b. Does it help them learn more about the value of access to their digital health information?
   c. Does it support patient use of patient portals and apps to view, download, and transmit health information and engage in communications with providers?
2. Does the effort incorporate strong consumer health data access, privacy, and security provisions?
   a. Do patients have electronic, secure, and cost-free access to their health information?
   b. Are best-practice cyber-security protections supported?

3. Does the effort encourage interoperable health information exchange with all parties in the care network?
   a. Are all parties in the care network (including patients and their designated representatives, providers, mental and behavioral health practitioners, pharmacies, labs, community organizations, app providers, and any other organization involved in care delivery for the patient) able to access, store, and share relevant patient information through their EHRs, PHRs, apps and/or other systems?
   b. Are special protections in place for highly sensitive information including behavioral health?

4. Are all parties in the care network able to gather and share appropriate electronic health data for this effort with consumers and one another?
   a. Are providers and other organizations able to share data with one another and with consumers?
   b. Are consumers able to view, download, and transmit their own information from one provider to another?
   c. Are appropriate consumer-consent mechanisms in place for sharing sensitive data such as behavioral health?

5. Have all relevant types of data needed for this effort been considered?
   a. Care protocol data?
   b. Patient-generated health data from apps, devices, surveys, and other sources?
   c. Patient-reported outcomes measures?
   d. Patient experience measures?
   e. Genomics and other precision-medicine related data?
   f. Social and behavioral health data?
   g. Community services data?
   h. Big-data analytics results?
   i. Public health data such as immunizations and birth records?
   j. Advance directives? Does ownership of advance directives reside with patients and not within an electronic health record accessible only during a face-to-face visit with a physician?

6. Are consumers able to use patient portals, apps, and telemedicine systems to exchange information and communicate about the program?
   a. Can physician inquiries and questions be asked online or through an app?
   b. Can appointments be set online or through an app?
   c. Can lab results be viewed online or through an app?
   d. Are appropriate telemedicine solutions supported?
   e. Can patients securely exchange electronic messages with members of their care team?
   f. Do providers support consumer use of digital tools that leverage clinical health data?
Principle 6. Promote Health Equity for All

Does the health care delivery system and payment reform model promote health equity and seek to reduce disparities in access to care and in health outcomes for all?

Guiding Principle 6

Person-centered, value-driven health services organizations promote health equity for all. They:

A. Promote health equity and work to reduce disparities in access to care and health outcomes.
B. Use payment and delivery models that do not reinforce disparities by creating incentives for providers to avoid serving populations that have more complex health needs.
C. Phase-in implementation of payment and delivery reforms for complex populations, such as persons with disabilities or individuals with multiple chronic conditions, to ensure that continuity of care can be achieved.
D. Incorporate connections to health care services with relevant community-based supports (housing, education, nutrition, etc.) in new models of care, to ensure that health care operates in concert with other drivers of health status including socioeconomic factors and social determinants of health.
E. View high standards of cultural competence and language access as necessary but not sufficient to help improve access for hard-to-reach communities.
F. Couple those high standards with active consumer engagement efforts, including partnerships with community-based organizations, to ensure that reform efforts improve the health of vulnerable communities.
G. Have mechanisms in place to closely monitor the effect of new models on access to care, particularly among vulnerable groups.
H. Monitor the appropriate use of resources to guard against fraud and abuse.
I. Use models that support risk adjustments in payment policies, where appropriate, based on socioeconomic status (SES) and demographic factors, while at the same time ensuring that non-risk-adjusted data is publically available to assess performance.

Key Questions

1. Does the effort support links to community based services and supports and other programs that address the social determinants of health, such as housing or food and nutrition programs?

2. Does the effort support the use of a diverse health care workforce, including the use of community health workers?
3. Does the effort support special health care services for at-risk populations, including:
   a. Patient translation services?
   b. Clinical and/or educational information in languages other than English?
   c. Targeted health literacy resources that are readable, accessible, and effective in helping individuals strengthen their health-related decision-making?
   d. Provision of health coaches and advocates to support care and decision-making?

4. Does the effort support access to data needed to assess health equity-related impacts?
   a. Is longitudinal clinical history supported?
   b. Are factors including age, race, ethnicity, citizenship, geography, primary language, gender identity, sexual orientation, education, ADA classifications, social status, and other social factors supported?

5. Does the effort support formal structures for identifying and addressing disparities?
   a. Is a formal structure such as a governance group or advisory board charged with identifying and addressing health disparities supported?

6. Does the model’s payment policy support risk adjustments, where appropriate, based on socioeconomic status (SES) and demographic factors, while at the same time ensuring that non-risk-adjusted data is publically available?
   a. Does the payment policy support risk adjustments based on SES and demographics?
   b. Does the model ensure that non-risk-adjusted data is publically available?
Conclusion

These guiding principles and key questions are designed to enable consideration of consumer priorities by health care stakeholders as they work together to develop policies, practices, and tools for person-centered, value-driven health care in the U.S.

The principles and questions provide a starting point for multi-stakeholder conversations. They will likely be updated and refined as the journey towards a person-centered, value-driven health care system continues.

The Task Force looks forward to working collaboratively with many others in advancing this important work.
Lee Sacks
EVP Chief Medical Officer
Advocate Health Care

Francis Soistman
Executive Vice President and President of Government Services
Aetna

Farzad Mostashari
Founder & CEO
Aledade, Inc.

Shawn Martin
Senior Vice President, Advocacy, Practice Advancement and Policy
American Academy of Family Physicians

Peter Leibold
Chief Advocacy Officer
Ascension

Emily Brower
Vice President, Population Health
Atrius Health

Jeffrey Hulburt
President and Chief Executive Officer
Beth Israel Deaconess Care Organization

Dana Gelb Safran, Sc.D.
Chief Performance Measurement & Improvement Officer and Senior Vice President, Enterprise Analytics
Performance Measurement & Improvement Blue Cross Blue Shield of Massachusetts

Joseph Hohner
Executive Vice President, Health Care Value
Blue Cross Blue Shield of Michigan

Kristen Miranda
Senior Vice President, Strategic Partnerships & Innovation
Blue Shield of California

Mark McClellan
Director
Duke Margolis Center for Health Policy

Michael Rowan
President, Health System Delivery and Chief Operating Officer
Catholic Health Initiatives

Carlton Purvis
Director, Care Transformation
Centra Health

Wesley Curry
Chief Executive Officer
CEP America

Susan Sherry
Deputy Director
Community Catalyst

Robert Greene
Executive Vice President, Chief Population Health Management Officer
Dartmouth - Hitchcock

Elliot Fisher
Director for Health Policy & Clinical Practice
Dartmouth Institute for Health Policy and Clinical Practice

Shelly Schlenker
Vice President, Public Policy, Advocacy & Government Affairs
Dignity Health

Chris Dawe
Managing Director
Evolent Health

Ronald Kuerbitz
Chief Executive Officer
Fresenius Medical Care
Angelo Sinopoli, MD
Vice President, Clinical Integration & Chief Medical Officer
Greenville Health System

Stephen Ondra
Senior Vice President and Enterprise Chief Medical Officer
Health Care Service Corporation

Dr. Richard Merkin
President and Chief Executive Officer
Heritage Development Organization

Mark Wilson
Vice President, Health and Employment Policy, Chief Economist
HR Policy Association

Anne Nolon
President and Chief Executive Officer
HRHealthcare

Lynn Richmond
Executive Vice President
Montefiore

Leonardo Cuello
Director
National Health Law Program

Debra Ness
President
National Partnership for Women & Families

Martin Hickey
Chief Executive Officer
New Mexico Health Connections

Jay Cohen
Senior Vice President
Optum

Kevin Schoeplein
President and Chief Executive Officer
OSF HealthCare System

David Lansky
President and Chief Executive Officer
Pacific Business Group on Health

Timothy Ferris
Senior Vice President, Population Health Management
Partners HealthCare

Jay Desai
Founder and CEO
PatientPing

Blair Childs
Senior Vice President
Premier

Joel Gilbertson
Senior Vice President
Providence Health & Services

Steve Wiggins
Chairman
Remedy Partners

Kerry Kohnen
Senior Vice President, Population Health & Payer Contracting
SCL Health

Bill Thompson
President and Chief Executive Officer
SSM Health Care

Rick Gilfillan
President and Chief Executive Officer
Trinity Health

Judy Rich
President and Chief Executive Officer
Tucson Medical Center Healthcare

Dorothy Teeter
Director
Washington State Heath Care Authority
Special Thanks to the Advisory Group for Consumer Priorities

The Advisory Group for Consumer Priorities of the Health Care Transformation Task Force is comprised of thought leaders from leading U.S. health care consumer/patient advocacy organizations, providers and payers.

As part of the Health Care Transformation Task Force, we support the transition to value-based care by:

• Providing a reservoir of consumer voices to inform the Task Force, its workgroups, and all Task Force work products
• Bringing consumer perspectives and priorities to the Task Force and its work groups and ensuring their incorporation into Task Force work products
• Bringing questions and issues identified in other Task Force work groups back to the CP Subgroup for discussion, synthesis, and development of consensus recommendations
• Developing and providing specific guidance that other workgroups can use to ensure that consumer priorities are reflected in all Task Force work products
• Providing expertise about how execution of consumer priorities and partnership with consumers at all levels of care delivery can help enhance empowered consumer engagement in their own health and health care.

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• Stephanie Glover, Health Policy Analyst, National Partnership for Women & Families
• Lauren Birchfield Kennedy, Director of Health Policy. National Partnership for Women & Families
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• Susan Sherry, Deputy Director. Community Catalyst
• Jennifer Singleterry, Senior Analyst, Policy Analysis and Legislative Support, American Cancer Society, Cancer Action Network
• Judah Thornwill, CEO, GroupPlus LLC, Affiliate, Leavitt Partners, Assistant Professor (part-time), University of Louisville School of Public Health and Information Sciences
• Asha Tiwary, Director, Consumer Portal Operations, Trinity Health
• Chris Young, VP New Virtual Market Development & Incubations. Ascension Health
• Others who commented on drafts as it was developed.