The Path to a People-Centered Health System

Next Generation Consumer Health Advocacy

Because we all should have a say in decisions that affect our health

COMMUNITY CATALYST

Mission

Community Catalyst's mission is to organize and sustain a powerful consumer voice to ensure that all individuals and communities can influence the local, state and national decisions that affect their health.

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Executive Summary

BACKGROUND

Despite its challenges and flaws, the Affordable Care Act (ACA) represents a monumental leap forward in access to health coverage and care for millions of Americans. But, while consumer advocates continue the important work of ensuring full implementation of that law, they must also now pivot to a significant and growing challenge: the rapid transformation already underway in our health care financing and delivery system.

The impetus for health system transformation, from our perspective, is two-fold. First, our current levels of health spending pose a threat to the sustainability of the ACA and Medicare and Medicaid. We spend almost twice as much per capita on health care than any other western democracy. Second, our health status and outcomes are generally poorer than those of our peer nations despite all of this spending. Our system is notable not only for its excessive prices but also for its variable quality, inefficiency, fragmentation, health inequities and lack of people-centeredness. Quite simply, we are not getting enough "bang for our buck."

There is general agreement that the status quo is not acceptable, but there is a concern among consumer advocates and their allies that the proposed "fixes" will focus primarily on the spending aspect. They fear it will be easier for policymakers and others – both conceptually and in practice – to shift costs to consumers through higher premiums and co-pays, benefit cutbacks and reduced eligibility. To counter these negative approaches and promote those that will actually benefit consumers, advocates must become fully engaged in this work – and do so very quickly.

The ultimate goal for all stakeholders should be a health care system that operates effectively and efficiently to ensure all people get the care they need and that invests in keeping them healthy. Closing the gap between the current system and this goal will require a fundamental alteration of the way health care is currently financed and delivered. It will also

compel re-thinking how we define health and the factors that influence it, with particular attention to the disproportionate impact those factors have on certain groups. Most importantly though, it will require creating a system that incorporates structures – at all levels – that enable consumers to highlight problematic health care delivery and financing experiences and that can act on systemic issues revealed through those experiences.

As with any paradigm shift, this will be no quick and easy task. Educating consumers about how the system could better meet their needs is a key aspect. Mobilizing public support will likely be hampered by the number and complexity of issues to be addressed. Industry stakeholder and interest group dynamics – including dynamics within the advocacy communities – will also be complicated, not least because there will be economic and policy winners and losers. And overlaying it all are the politics. The partisan fights around solutions – driven by both ideology and money – will likely persist, creating impediments to federal and state government testing of new models and approaches.

Are consumers and their advocates up to the task? History suggests they are, but they will need significant support to take on this challenge. Even though they are at the center of the health system, consumers have been the least empowered of all stakeholders. The government, in its payer role, wields tremendous power, but so do the many well-financed industry groups that use their resources to protect and expand their own turf. Nevertheless, consumers and their advocates have been key participants in successful federal and state health access and coverage initiatives for decades. There is also a long tradition of consumer involvement in altering certain structural and care delivery aspects of the health system over the same period. Advocates for women's health, HIV/AIDS activists, and parents of children with special needs have fought – and won – battles at both the policy and system levels to improve the approach to and quality of care for these populations.

In this new phase of work, advocates – and consumers – must be prepared to operate on three levels:

- Policy advocacy: Many of the transformation-related proposals will arise in the federal and state policy arenas. Medicare, Medicaid, and federal and state budgets, will likely be principal vehicles for such activity, but policy issues may also arise in local government contexts. Indeed, this community level may well be where many of the upstream factors that affect health are best addressed. Advocates will have to operate within both legislative and executive branches at all levels.

- System-level advocacy: Many transformation-related activities will occur at the implementation/operational level, i.e., within the hospital systems, health plans, Accountable Care Organizations, etc. Therefore, consumers and their advocates must be able to engage with the delivery system itself. This is necessary to ensure that providers and health plans operate in ways that place priority on the needs of consumers relative to those of other stakeholders, and also to ensure that system players contribute to population and community health.

- Individual-level advocacy: Consumers must also, where possible, become active, engaged and knowledgeable participants in their own health and health care, and advocates must promote changes that facilitate such participation. Consumers will need quality information and support from policymakers and the health system that enables them to build their understanding of health system transformation issues and make sound and informed choices on their health and health care options. There is a growing body of evidence which demonstrates that patients who are more engaged in their own health care have better health outcomes and care experiences. Consumers must also be prepared to share the consumer/patient experience within the permanent structures we envision to ensure that "course corrections" are directly responsive to consumer experiences – whether positive or problematic.

KEY OBSERVATIONS

We wanted to understand what kinds of challenges consumer advocates will face as they become more fully engaged in this new phase of work, and what types of support will maximize their effectiveness. To do this, we consulted with consumer advocates from more than 40 states and a diverse group of other system stakeholders. Key observations are:

- While there is consensus on the general direction for health system transformation, i.e., pay for value, people-centered, etc., there is little clarity as to what that means in practice or how to achieve it.

- Consumer advocates are already engaging on some transformation-related issues, and, at least with respect to health equity topics (e.g., language access, cultural competency and data collection), are often leading the work in their respective states.

- Building and sustaining effective coalitions is expected to be a challenge. Compared to access campaigns, advocates see health system transformation as a broad, diffuse and often technical topic. Moreover, the "wins" aren't clearly defined or immediately evident. There may also be reluctance on the part of some key partner and ally organizations and constituencies to support certain common features of delivery system change because of funder relationships or unique constituency needs or preferences.

- Consumer advocates need help building their capacity to conduct legal and policy research and analysis on complex financing and delivery system issues. They also cite an urgent need for assistance and/or tools to help them assess their political and market environments, identify openings for action, understand and prioritize the various "handles/levers" for health system transformation and set realistic priorities for transformation-related work. Assistance must be tailored to the particular political, policy and delivery system environment.

- Building a grassroots base of support and developing new consumer leaders may also be a challenge. Understanding what individuals and families experience in the health system is key to establishing a consumer agenda. Ensuring there are mechanisms in place to capture these experiences is critical. Additionally, providing coaching and support to prepare consumers to play meaningful roles on boards, councils and advisory committees will require new resources.

- Consumer advocates anticipate needing advice and support to develop effective working relationships with other system stakeholders. In contrast to coverage campaigns, there may be fewer points of intersection between consumer interests and those of other key players, but these relationships are viewed as critical to advocates' success because consumers can't reshape the system on their own.

- Advocates need resources – at least initially – to address these challenges. While many see the potential to institutionalize support for consumer assistance and participation in the future, effective engagement now will require an investment in capacity strengthening.

RECOMMENDATIONS

Health system transformation is a long-term undertaking, and the needs of consumers and their advocates may shift over time. What we offer here are the building blocks for a durable foundation that will serve this work both now and into the future.

Recommendation 1: Articulate a proactive vision and framework for a transformed health system. An initial task for consumer advocates is to articulate a positive, unified vision of what health system transformation would look like. National groups must come together, along with state and local community advocates, to shape that vision, which will serve as the basis for development of federal, state and local agendas.

Recommendation 2: Strengthen and expand coalition building at the state and local levels. Although federal law and regulations set parameters for many of the changes underway, much of the development and implementation of new models occurs at the state, local and institutional level. A shared vision and strategy that is responsive to each state's local market and policy dynamics will be critical to developing an effective consumer voice to shape the changes underway. State advocates should consider establishing a table of consumer groups around the vision of transformation, seeking agreement on a basic framework, with transparency and thoughtful exchange about specific differences. There should be focused outreach to those groups that represent or work with vulnerable populations, and to advocates that work on "upstream" issues, such as housing, community planning and youth development.

Recommendation 3: Build policy and delivery system expertise. Consumer advocates face a significant learning curve with regard to transformation-related policy content, both in terms of the breadth of issues involved and the technical depth required. This is further complicated by the significant variation in local health care markets and state health policy environments, so effective policy interventions will vary from place to place. But transformation will also require advocates (and consumers) to engage at the delivery system level, so in addition to building policy knowledge, advocates must also immerse themselves in developing delivery system expertise.

Recommendation 4: Build – or strengthen existing – grassroots engagement and leadership development work. Giving voice to consumer experience and needs is fundamental to the paradigm shift we seek. The capacity to identify problems, analyze individual experiences, find patterns and express ways to improve the system is critical. An initial task will be to elicit consumer concerns and offer opportunities to learn some health system basics. This process will help identify potential public and private policy targets and also serve as an organizing tool.

Recommendation 5: Build – or strengthen existing – stakeholder alliances. Transforming the health system to put the individual patient/family and the community at the center will require new kinds of working relationships with other system stakeholders. Consumer groups by themselves do not have enough power to drive system change, so they will need these alliances. This may range from finding common ground with employers and private payers around a shared interest in reducing low-value care, to working with health plans and providers to design new and more effective ways of both delivering care and supporting people and communities to better manage their own care.

Recommendation 6: Build a communications program for use at all levels of advocacy that generates public support for health system transformation. Framing and communicating health system transformation issues will be a long-term process that starts with building public knowledge and moves to building public and political will for change. It will take an investment in public education to better inform and engage the public in conversations around challenges with the system and potential approaches to addressing them.

Methodology

This report launches a new phase of work for Community Catalyst – a phase that is focused on building and supporting consumer advocacy and engagement in transforming the health system. Preparation of the report entailed three modes of information gathering:

- "Desk" research, which involved a literature review on topics including national and international health care expenditures and health outcomes, and the drivers of health care costs. We also reviewed recent public opinion research on health care costs, health care delivery and public attitudes about the health care system in general. Finally, we reviewed information on the issue and advocacy agendas of a number of national consumer health-focused organizations.

- An online survey of consumer health advocacy coalition members from 40 states, and several small group meetings and focus groups with state-based consumer health advocacy leaders representing states with both progressive and conservative political environments. The purpose was to understand what health system transformation issues they are – or anticipate – working on in their respective states, and the types of technical assistance or other support they will need to fully engage on transformation-related issues.

- Telephone interviews with a diverse group of other system stakeholders and experts (e.g., purchasers, health policy experts, state officials, organized labor, health care quality experts, and state-based health foundations). The individuals interviewed were selected because of their familiarity with the health care environment in general, and with the substance and range of their constituencies' work in particular.

- An internal project team met regularly to review and analyze the information, identify common themes, and propose a framework for moving forward. Drafts of this paper were then circulated to outside readers with expertise in health policy, politics, and advocacy, and their feedback was incorporated. We anticipate future work products that will build off of this report as consumer advocates become more engaged in transformation-related issues.

Introduction

The Affordable Care Act (ACA) represents a monumental leap forward in access to health coverage and care for millions of Americans. The elimination of common insurance industry barriers, the expansion of Medicaid and the availability of premium subsidies will together provide a degree of health and financial security for individuals and families that was previously unavailable. But, while they continue the important work of ensuring full implementation of that law, consumer advocates must also now pivot to a significant and growing challenge: the rapid transformation of our health care financing and delivery system.

The impetus for health system transformation, from our perspective, is two-fold. First, our current levels of health spending pose a threat to the sustainability of the ACA, as well as Medicare and Medicaid. We spend almost twice as much per capita on health care than any other western democracy. Second, our health status and outcomes are generally poorer than those of our peer nations despite all of this spending. Our system is notable not only for its excessive prices but also for its variable quality, inefficiency, fragmentation, health inequities and lack of people-centeredness. Quite simply, we do not get enough "bang for our buck."

There is general agreement that the status quo is not acceptable, but there is a concern among consumer advocates and their allies that the proposed "fixes" will focus primarily on the spending aspect. It seems easier – both conceptually and in practice – to shift costs to consumers and justify that approach with simplistic premises like: "Health care costs are high because consumers don't have enough skin in the game." Unless the value aspect – that is, the "bang for the buck" – of our spending problem also receives concerted attention, the results will be problematic.

Many of the system shifts we are witnessing today were already well underway before the ACA's passage, but provisions of that law have accelerated them. To date, the consumer voice has been largely muted, especially relative to that of other well-resourced and powerful system stakeholders. However, our research suggests there is growing awareness among consumer advocates that they must "up their game" now for two principal reasons:

> *"Cost reduction without regard to the outcomes achieved is dangerous and self-defeating, leading to false 'savings' and potentially limiting effective care."*[1]
>
> *– Michael Porter*

- Many of the changes currently underway in the financing and delivery system – in particular, the shift to more integrated provider systems with more accountability for the cost of care – are not inherently good or bad for consumers in general, or for vulnerable populations in particular. Whether they have a positive or negative impact will depend on how they are implemented. It will be largely up to consumers and their advocates to ensure the impact is positive.

- Even though health care spending growth has moderated significantly in the last several years, it is safe to assume there will be ongoing pressure to cut back on both public benefits and the scope of private coverage. Consumers must be prepared to fend off proposals that may lower costs for business and government, but will drive up costs to individuals, while doing nothing to improve quality or health equity.[2] It won't be possible to fend off these cuts by just saying "no." Rather, consumers and their advocates will need to develop and promote a pro-consumer value agenda to counter those efforts.

The ultimate goal for all stakeholders should be a health care system that operates effectively and efficiently to ensure all people get the care they need and that invests in keeping them healthy. Closing the gap between the current system and this goal will require

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1   Porter, Michael E. "What Is Value in Health Care?" The New England Journal of Medicine (2010): 363:2477-2481.
2   Ibid.

a fundamental alteration of the way health care is currently financed and delivered. It will also compel re-thinking how we define health and the factors that influence it, with particular attention to the disproportionate impact those factors have on certain groups. Most importantly though, it will require creating a system with structures – at all levels – that enable consumers to highlight problematic health care delivery and financing experiences and that can act on systemic issues revealed by consumers.

In essence, we are talking about a paradigm shift, and, as with any fundamental re-ordering, this will be no quick and easy task. Educating consumers about how the system could better meet their needs is a key aspect. Mobilizing public support will likely be hampered by the number and complexity of issues to be addressed. Industry stakeholder and interest group dynamics – including dynamics within the advocacy communities – will also be complicated, because there will be economic and policy winners and losers. And overlaying it all are the politics. The partisan fights around solutions – driven by both ideology and money – will likely persist, creating impediments to federal and state government testing of new models and approaches.

The purpose of this initial report, which is intended primarily for consumer advocates, their allies and supporters, is:

- to offer our assessment of the health system status quo.

- to share our perspective on the forces driving health transformation challenges.

- to provide an overview of where consumers and their advocates are with respect to their thinking and their work related to transformation and the challenges they face.

- to suggest an analytical framework advocates can use to identify and evaluate transformation opportunities and threats in different political environments.

- to offer a set of recommendations for moving forward with the work.

The Status Quo

Advocates are well aware that health care spending is a persistent source of public and private fiscal concern and are already engaged, or preparing to engage, in conversations to address these concerns. At the federal level, many policymakers view health spending as the principal cause of budget deficits and long-term federal debt. At the state level, many governors and legislators see Medicaid expenditures as a persistent drain on resources. And, although the evidence is weak, many in the private sector maintain that health care costs have a negative impact on business's ability to compete in a global economy. Consumers, for their part, are seeing a steady increase in their out-of-pocket health-related expenses, a trend they identify as a major challenge to their personal financial security.[3][4]

3   Health Care Cost Institute. *2012 Health Care Cost and Utilization Report*. Rep. N.p., Sept. 2013.
4   Keckley, Paul H., PHD and Sheryl Coughlin, PHD. *Deloitte 2012 Survey of U.S. Health Care Consumers: The Performance of the Health Care System and Health Care Reform*. Issue brief. The Deloitte Center for Health Solutions.

The dimensions of the health spending challenge are particularly stark when the U.S. is compared to other Organization for Economic Cooperation and Development (OECD) member countries. The rate and level of our health spending – in most categories – is substantially higher, a difference that cannot be attributed to an aging population, higher income or greater use of health services.[5] And, in contrast to the U. S., most of those countries have had universal coverage for years. Examples of the variances include:[6]

- Health care spending per capita in the United States – at almost $8,000 in 2009 – is twice as much on average, as that in 12 OECD comparison countries.

- Total U.S. health spending represented more than 17 percent of Gross Domestic Product (GDP) compared to 12 percent or less in the comparison countries.

Despite the fact that we spend more on health care than any peer country, our outcomes in a number of critical measures are mediocre at best.

TOTAL HEALTH SPENDING PER CAPITA

Source: OECD Health Data 2011
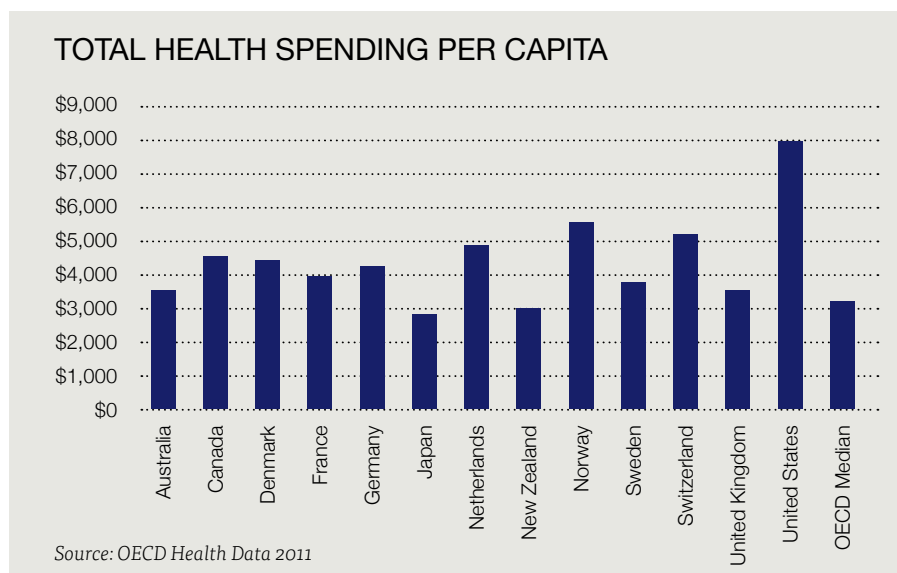
Some of our measures are even worse than those in countries that are far less developed. Life expectancy in the state of Georgia, for example, is lower than in Morocco or Libya, and in some of that state's counties, it's even lower than in El Salvador or Gaza.[7]

TOTAL HEALTH SPENDING AS A PERCENT OF GDP

Source: OECD Health Data 2011

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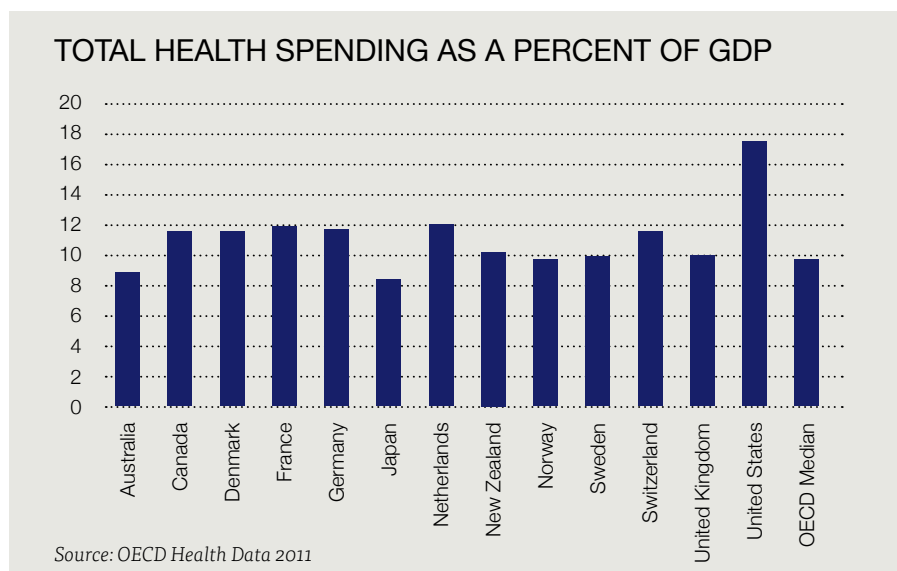
5   Squires, David A. Explaining High Health Care Spending in the United States: An International Comparison of Supply, Utilization, Prices, and Quality. Publication no. 1595. Ed. Deborah Lorber. The Commonwealth Fund, May 2012. Web.
6   Ibid.
7   Hataway, J. (2010, August 23). Georgia has Life Expectancy Lower Than Some Third World Countries. *Like the Dew - A Journal of Southern Culture & Politics*.

These quality gaps affect Americans at all socioeconomic levels. But the burden of our system's deficiencies falls disproportionately on lower-income populations, racial and ethnic minorities, and individuals with disabilities and/or chronic illnesses – even after controlling for insurance status. Examples of quality gaps include:

- Mortality from cardiovascular diseases: The U.S. ranks 25th in mortality from cardiovascular diseases compared with the other 34 OECD nations,[8] and within the U.S., as of 2007, African American men were 30 percent more likely to die from cardiovascular disease than were non-Hispanic white men.[9]

- Access barriers: Denial of health care and multiple barriers to care are commonplace in the lives of transgender and gender-nonconforming people. Subjects in a major federal study report they were denied equal treatment in doctor's offices and hospitals (24 percent), in emergency rooms (13 percent), in mental health clinics (11 percent), by emergency medical technicians (5 percent), and in drug treatment programs (3 percent).[10]

- Life expectancy: The United States ranks 27th out of the 34 OECD countries in terms of life expectancy, and, in the United States[11], life expectancy is 3.8 years greater for whites than for blacks.[12]

- High rates of hospital readmissions: One in eight Medicare beneficiaries is readmitted to the hospital within 30 days of being released after surgery, and one in six returns to the hospital within a month of discharge. While some readmissions are predictable and others are unplanned and difficult to prevent, many readmissions are a result of a fragmented system and can be prevented.[13]

- In 2011 there were an estimated 722,000 health care-associated infections in U.S. acute care hospitals, and approximately 75,000 hospital patients with these types of infections died during their hospitalizations.[14]

Consumers with insurance coverage also register high levels of dissatisfaction with the system. While they may like their own providers, they often report finding their care-seeking experiences confounding in terms of understanding what care is available, what services are covered, how to access those services, and who – if anyone – is coordinating their care. When they do finally access services, they may also face high out-of-pocket costs. As a consequence, many forego the care they or their family members need, or they accumulate medical debt.[15]

8   OECD Health Statistics 2014 How Does the United States Compare? Issue brief. The Organisation for Economic Co-operation and Development, 2014.
9   U.S. Centers for Disease Control and Prevention. The Million Hearts Initiative. About Heart Disease & Stroke. N.p., n.d. Web.
10   U.S. Agency for Healthcare Research and Quality. Chapter 10. Priority Populations (continued): National Healthcare Disparities Report. By Rockville. N.p., Apr. 2012.
11   See Supra Note 8.
12   U.S. Centers for Disease Control and Prevention. Division of Vital Statistics. Death: Preliminary Data for 2011. By Donna L. Hoyert and Jiaquan Xu. National Vital Statistics Reports, 10 Oct. 2012.
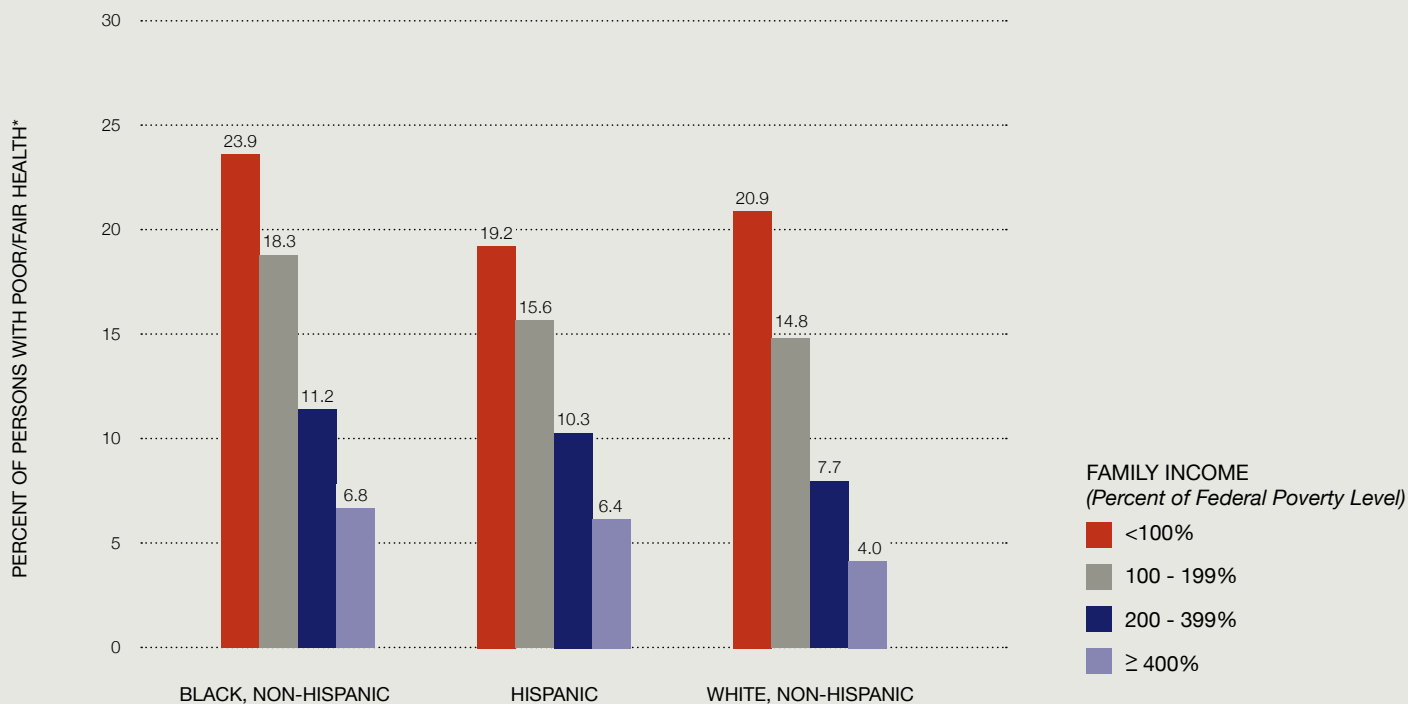13   Dartmouth Atlas Project, and Perry Undem Research & Communitcations. The Revolving Door: A Report on U.S. Hospital Read-missions. Rep. Robert Wood Johnson Foundation, Feb. 2013.
14   U.S. Centers for Disease Control and Prevention. NCEZID and DHQP. Healthcare-associated Infections (HAIs). N.p., 15 Sept. 2014.
15   Dig Deep: Impacts and Implications of Rising Out-of-pocket Health Care Costs. Rep. Deloitte Center for Health Solutions, n.d.

INCOME IS LINKED WITH HEALTH ACROSS RACIAL OR ETHNIC GROUPS

Differences in health status by income do not simply reflect differences by race or ethnicity; differences in health by income can be seen within each racial or ethnic group. Both income and racial or ethnic group matter for health.

PERCENT OF PERSONS WITH POOR/FAIR HEALTH*

	BLACK, NON-HISPANIC	HISPANIC	WHITE, NON-HISPANIC
<100%	23.9	19.2	20.9
100 - 199%	18.3	15.6	14.8
200 - 399%	11.2	10.3	7.7
≥ 400%	6.8	6.4	4.0

FAMILY INCOME
(Percent of Federal Poverty Level)

- <100%
- 100 - 199%
- 200 - 399%
- ≥ 400%

Source: CDC/NCHS. National Health Interview Survey 2010, Family Core And Sample Adult Questionnaire. Published in National Center for Health Statistics. Health, United States 2011: With Special Feature on Socioeconomic Status and Health. Hyattsville, MD: 2012. www.cdc.gov/nchs/data/hus/2011/056.pdf. Accessed November 29, 2012.
** Age-adjusted. Based on self-report and measured as poor, fair, good, very good, or excellent.*

LIFE EXPECTANCY AT BIRTH VARIES ACROSS RACIAL OR ETHNIC GROUPS

Blacks have the shortest average life expectancy at birth among the racial or ethnic groups for which these statistics are frequently reported. On average, a black baby can expect to live seven years less than a Hispanic baby and nearly five years less than a white baby.

RACIAL OR ETHNIC GROUP

- Black, non-Hispanic
- Hispanic
- White, non-Hispanic

LIFE EXPECTANCY AT BIRTH*

Black, non-Hispanic	Hispanic	White, non-Hispanic
73.7	81.0	78.4
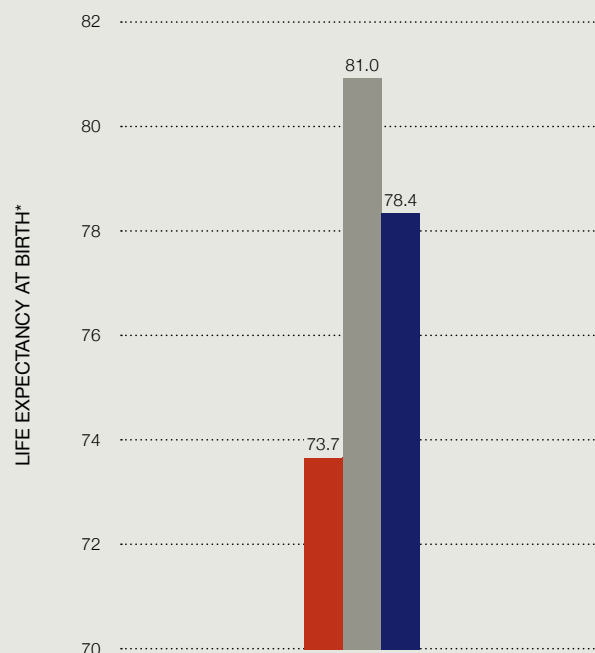
Source: Arias E. United States Life Tables, 2008. National Vital Statistics Reports; vol 61 no 3. Hyattsville, MD: Centers for Disease Control and Prevention, National Center for Health Statistics; 2012.
* Age-adjusted

This value gap is primarily attributable to four factors: high prices for health care services; administrative waste; poor quality of care; and poor population health.

1. High prices. Health care prices are the primary contributor to higher health spending in the U.S.[16] Comparative studies show that prices for many health services in the U.S. are significantly higher than in 12 other OECD study countries.[17] For example, prices for the 30 most commonly prescribed drugs are one-third higher in the U.S. than in Canada and Germany, and more than double the prices in Australia, France, the Netherlands and the United Kingdom.[18] Similar variances are evident in prices for primary care office visits and orthopedic surgeon fees for hip replacements. With regard to hospitalizations, the U.S. has shorter lengths of stay for acute care and fewer discharges per capita than the OECD median, but the spending per discharge in the U.S. was $18,000 compared with less than $10,000 in Sweden, France and Germany.[19]

2. Aministrative expenses. The Institute of Medicine estimates that more than $190 billion a year is spent in the U.S. on administrative inefficiencies related to the demands of multiple insurers with differing paperwork related to care documentation.[20] Its overall estimate of waste in the system from various sources is $765 billion. Therefore, administrative expenses account for almost 25 percent of system waste.

3. Third, poor quality of care. The failure to provide the right care, which includes the right amount of care, at the right time is one of the biggest sources of low-value and excess spending. We noted above the number of hospital readmissions and health care-acquired infections. Medication errors are also a significant problem. Nationally, serious preventable medication errors occur in 3.8 million inpatient admissions and 3.3 million outpatient visits each year. In its report "To Err Is Human," the Institute of Medicine estimated 7,000 deaths in the U.S. each year are due to these errors.[21] And some populations bear a disproportionate burden of poor care quality. For example, elderly black patients in the U.S. have higher 30-day readmission rates than white patients for heart attacks, congestive heart failure and pneumonia.[22]

4. Poor population health. Health care expenditures tied to preventable illnesses and diseases like obesity, type 2 diabetes, and hypertension exceed hundreds of billions of dollars each year.[23] Investments in programs that enable healthier behavior and safer environments have the potential to not only save lives, but also to bring down health care costs.[24] Furthermore, population health initiatives aim to address major population health

16 Lorenzoni, Luca, MSc, and Annalisa Belloni, MSc. "Health-care Expenditure and Health Policy in the USA versus Other High-spending OECD Countries." The Lancet 384.9937 (2014): 83-92.
17 See supra note 5.
18 See supra note 5.
19 See supra note 5.
20 Institute of Medicine. Best Care at Lowest Cost. The Path to Continuously Learning Health Care in America. Ed. Mark Smith, Robert Saunders, Leigh Stuckhardt, and J. Michael McGinnis. Washington, D.C.: n.p., 2013. The National Academies Press.
21 To Err Is Human: Building a Safer Health System. Rep. N.p.: n.p., 1999. Institute of Medicine.
22 Joynt, K. E., E. J. Orav, and A. K. Jha. "Thirty-Day Readmission Rates for Medicare Beneficiaries by Race and Site of Care." JAMA: The Journal of the American Medical Association 305.7 (2011): 675-81.
23 Waidmann, Timothy A., Barbara A. Ormond, and Randall R. Bovbjerg. Rep. The Urban Institute Health Policy Center, n.d.
24 Milstein, Bobby, Jack Homer, Peter Briss, Deron Burton, and Terry Pachacek. "Why Behavioral And Environmental Interventions Are Needed To Improve Health At Lower Cost." Health Affairs 30.5 (2011): 823-32.

determinants beyond health care, such as education, the built environment and housing[25], along with the distribution of health outcomes within a group of individuals.[26]

COUNTY HEALTH RANKINGS MODEL
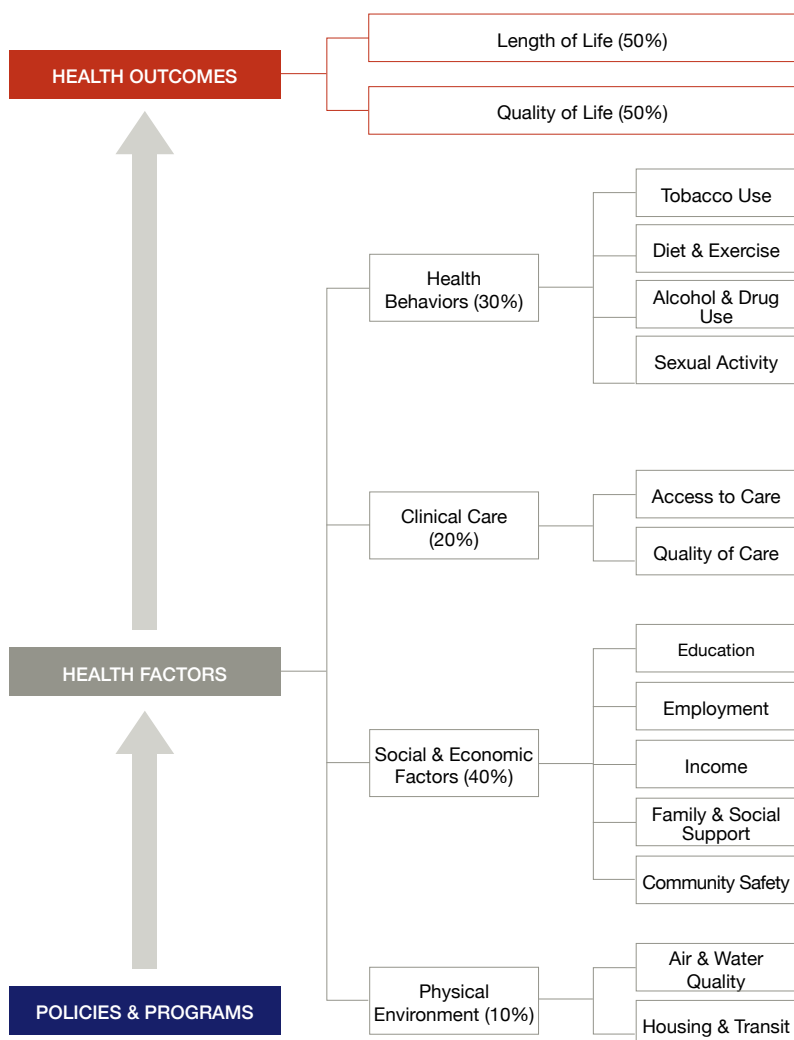
County Health Rankings model © 2014 UWPHI

> *Leading hospitals, Federally Qualified Health Centers (FQHCs), housing developers and homeless service providers are collaborating to improve health outcomes for chronically homeless patients – a population recognized as "high-utilizers" of the health care system. The integration of care management and supportive housing for the high-risk homeless population has resulted in dramatically improved health outcomes and decreased costs due to reductions in emergency department use, inpatient admissions and hospital days, detox use and psychiatric inpatient admission.[28]*

Concepts of population health fall along a spectrum, with a focus on health outcomes in populations defined by geography or similar factors at one extreme and accountability for health outcomes in populations defined by health care delivery systems such as health plans or Accountable Care Organizations (ACO) at the other extreme.[27]

25 Williams, David R. et al. "Moving Upstream: How Interventions That Address the Social Determinants of Health Can Improve Health and Reduce Disparities." *Journal of Public Health Management and Practice* : JPHMP 14.Suppl (2008): S8–17. PMC. Web. 23 Dec. 2014.

26 Kindig, David, and Greg Stoddart. "What Is Population Health?" *American Journal of Public Health* 93.3 (2003): 380–383. Print.

27 Stoto, Michael A., Ph.D. *Population Health in the Affordable Care Act Era*. Rep. N.p.: n.p., 2013. Academy Health.

28 The Business Case for Collaboration: Care Management Linked to Supportive Housing for Chronically Homeless Patients. June 2012.

Current Health Care Marketplace Dynamics

We noted earlier that changes in health care financing and delivery are already underway in response to the spending and value concerns described above. The question is: will these changes actually reduce spending and/or improve value? The jury is still out. And, even if changes improve value, whether they are compatible with consumer priorities and needs remains an open question. Certain trends are readily discernible though, and they are important to reference here because they will, to a large extent, affect the direction of consumer advocacy for the foreseeable future. The two most visible and pervasive trends are the consolidation of system stakeholders, especially among payers and providers, and the integration of clinical services.[29]

Experts suggest that two factors are driving consolidation: the desire to achieve economies of scale and the desire to gain negotiating over the other interests. If the economies of scale truly stabilize or lower costs, and if those lower costs are actually passed through to consumers, then consolidation could be a positive thing. However, it is more likely that the consolidation of hospitals and medical practices into ever-larger systems allows those entities to command higher payment rates from insurers resulting in higher premiums. Consolidation among payers, particularly in areas with few competitors, gives them the upper hand in negotiations with providers, and lessens the need to compete for business on premiums. There is little evidence to date that consolidation improves quality or increases consumer choice. There is evidence though – at least in hospital-owned physician practices – that it increases costs.[30] [31]

The second trend – integration of clinical services – may foster provider consolidation as a by-product, but also has the potential to improve quality and lower costs if it results in better coordination across the full spectrum of care. Medical costs are driven overwhelmingly by chronic illness among every age cohort, and many of these costs are attributable to fragmentation of care.[32] When clinical services are integrated, the costly "slippage" that occurs when providers don't communicate with each other, or when substance use disorder treatment services are outsourced, or when the long-term supports and services that can maintain individuals in the community aren't available, can be significantly reduced.

A number of ACA initiatives are specifically designed to support better care integration and

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29 Moses H, III, Matheson DM, Dorsey E, George BP, Sadoff D, Yoshimura S. The Anatomy of Health Care in the United States. *JAMA*. 2013;310(18):1947-1964.

30 Ibid.

31 Robinson JC, Miller K. Total Expenditures per Patient in Hospital-Owned and Physician-Owned Physician Organizations in California. *JAMA*. 2014;312(16):1663-1669.

32 *Clinical Integration – The Key to Real Reform*. Issue brief. N.p.: American Hospital Association, 2010. Print. TrendWatch.

coordination in both the Medicare and Medicaid programs. For example, Medicare is experimenting with paying for outcomes. It is also supporting a number of demonstration projects, including those that provide coordinated care for individuals who are dually eligible for Medicare and Medicaid, and those that facilitate development of Accountable Care Organizations (ACO) and Patient-Centered Medical Homes (PCMH). A particularly positive feature of these new care delivery and financing models – and an intervention point for consumers and their advocates – is the requirement that they actively solicit consumer input. While there are some early indications that the PCMH model in particular is facilitating a transformation of primary care delivery, it will be some time before a comprehensive evaluation of the model's ability to stabilize costs and improve quality is possible.[33]

Federal law and regulations set the parameters for many of the changes, but the impact of these new models will play out at the health care delivery system level. For example, Blue Cross and Blue Shield of Massachusetts (BCBSMA) introduced an "alternative quality contract" (AQC) for many of its providers four years ago. The contract uses a global payment model that combines a fixed per-patient payment (adjusted annually for health status and inflation) with substantial performance incentive payments that are tied to nationally accepted measures of quality, effectiveness and patient experience. A recent evaluation of that approach shows that it has had a positive impact on both costs and the quality of patient care and has lowered costs since it was implemented.[36] It is important to note that BCBSMA controls the largest percentage of the state's commercial insurance market (49 percent). Eighty-five percent of its HMO network is subject to the AQC. This relatively deep penetration suggests that the model is gaining real traction in the marketplace, and it's reasonable to expect that it will migrate to other payers.

> *Missouri implemented a Medicaid health home for people with behavioral health problems using the state's community mental health centers. The model combines behavioral health services with primary care, care coordination and self-care management. Preliminary results show improvements in physical health and decreased hospitalizations, reducing costs for high-need Medicaid beneficiaries by $4.2 million.[34] [35]*

Because there is significant variation among health care markets across the country, advocates' starting points will differ depending on local or regional conditions. For example, there may be a single dominant insurer in some markets, or a provider community composed primarily of solo or small group medical practices, or a region that is dominated by a large health system. The structure of any particular market is important for advocates to understand because it affects political power and the type of policy approach advocates might employ.

33 Crimm, Allan, and Don Liss. "Patient-Centered Medical Home Evaluations: Let's Keep Them All In Context." Web log post. *Health Affairs Blog*. N.p., 21 May 2014.

34 Nardone, Mike, Sherry Snyder, and Julia Paradise. *Integrating Physical and Behavioral Health Care: Promising Medicaid Models*. Issue brief. N.p.: Kaiser Commission on Medicaid and the Uninsured, 2014.

35 Sherry, Mike. "'Health Home' Initiative Shows $4.2M Savings in First Year." *Kansas Health Institute*. N.p., 25 June 2013.

36 Song, Z., D. G. Safran, B. E. Landon, M. B. Landrum, Y. He, R. E. Mechanic, M. P. Day, and M. E. Chernew. "The 'Alternative Quality Contract,' Based On A Global Budget, Lowered Medical Spending And Improved Quality." Health Affairs 31.8 (2012): 1885-894.

To date, consumers have had little input in – or impact on – many of these market shifts. The principal participants in these public and private market shifts have been providers and payers, and consumers have, at times, been caught in the middle.

These shifts show no sign of abating, and appear to be accelerating. Consumers are at significant risk if they remain on the sidelines. The fundamental question is – are they up to the challenge?

The Consumer Role in Health System Transformation

The answer is "yes," with the right kinds of support. Consumers are, in some sense, at the center of the health system, but they generally have been the least empowered of all stakeholders. The government, in its payer role, wields tremendous power, but so do the well-financed industry groups that can use their resources to protect and expand their turf. This is not a new situation, but it elevates the challenge where health system transformation is concerned because it touches every aspect of the system. We've already articulated reasons that consumers and their advocates must become actively engaged in the health system's transformation. We also recognize that this represents new – and relatively uncharted – terrain for them. However, there is a foundation on which to build.

Consumers and their advocates have been key participants in health access and coverage debates for decades. Prior to passage of the ACA, consumers and their advocates played a significant role in all of the major federal laws to expand access to health coverage (e.g., the Children's Health Insurance Program (CHIP), Medicare Part D). They also spearheaded a number of successful state initiatives, including those in Maryland, Massachusetts and Minnesota that expanded and improved coverage for millions. Even in challenging political environments, advocates have played critical roles. In Alabama, advocates were instrumental in the design and implementation of the first Children's Health Insurance Program (CHIP).[37] In North Carolina, advocates were engaged in the implementation of Community Care of North Carolina, a systemic care management intervention program that has been successfully providing person-centered care to Medicaid recipients throughout North Carolina, while

Each year, Timothy and Diane Young select a Medicare Advantage plan for Diane's 81-year-old mother. Each year, the result of that process is the same: They pick a Highmark plan, because Diane's mother likes her Blue Cross Blue Shield coverage.

This year? "We've been on the phone all day," Ms. Young said Tuesday.

The Youngs are in thick company, as seniors — and adult children who are helping them — are collectively trying to determine whether their primary care physicians and specialists are among the 700 UPMC doctors who, for now, have been fully removed from Highmark's provider network.

That means neither under-65 commercial customers nor over-65 Medicare Advantage patients will be able to see those doctors, even though both Highmark and UPMC have promised for years that seniors wouldn't be affected by the break-up of the two Pittsburgh health giants.

By Bill Toland / Pittsburgh Post-Gazette, November 26, 2014.

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37 Fillmore, Herbert, C. Annette Dubard, Grant A. Ritter, and Carlos T. Jackson. "Health Care Savings with the Patient-Centered Medical Home: Community Care of North Carolina's Experience." Population Health Management (2013): 141-48.

improving quality and reducing costs.[38]   More recently, advocates played a pivotal role in the ACA campaign, and have been key players in outreach and enrollment work, which continues to be a priority for many.

In addition to active participation in coverage and access campaigns, there is a long tradition of consumer involvement in altering certain structural and care delivery aspects of the health system. For example, advocates for women's health, HIV/AIDS activists, and parents of children with special needs have fought – and won – battles at both the policy and system levels to improve the approach to and quality of care for these populations. In the 1990s, both consumers and providers rebelled when the market was flooded with so-called managed care plans that focused less on providing comprehensive, coordinated care than on obtaining price concessions from providers and creating administrative barriers to care.[39] Enrollment in both Medicare and commercial managed care plans dropped significantly for a number of years, and some of the features that characterized an early generation of managed care organizations, such as narrow networks and vertical integration, are only now starting to make a comeback, albeit in a more flexible form but one that is more costly to the consumer.

This history demonstrates that it is possible to energize consumers and that they can be effective in altering the status quo. However, the health system transformation we envision will require something more organized, systematic, and broad-based than those earlier efforts. Our research indicates that consumer advocates at both the state and federal level are already engaged in a variety of transformation-related efforts, but, as described in a subsequent section, it also shows that a range of vital supports would increase their effectiveness in this new chapter of work.

Health System Transformation and the Consumer Advocacy Community Today

A principal purpose of this report was to gather baseline information on state-based consumer health advocates' understanding of and engagement in efforts to transform the health system. In order to obtain a comprehensive overview of the consumer advocacy environment, we also interviewed a number of other individuals, including funders, state agency officials, health policy experts, a representative from organized labor, and individuals with expertise in health care quality. Finally, we reviewed recent public opinion polling, focus group and survey data to understand how individual consumers view their own health care and the current health system in general.

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38 Cosway, Robert, Chris Girod, and Barbara Abbott. *Analysis of Community Care of North Carolina Cost Savings*. Rep. Milliman Client Report, 15 Dec. 2011.

39 Oberlander, J., and J. White. "Public Attitudes Toward Health Care Spending Aren't The Problem; Prices Are." *Health Affairs* 28.5 (2009): 1285-293.

Where are state-based consumer health advocates?

The following findings are derived from our online survey of state-based consumer advocacy coalition members, and small group meetings and focus groups with state consumer advocacy leaders:

There is an urgent need for a framework, proactive guiding principles and a vision for health system transformation work. All research participants share a view that the sheer number and technical nature of many of the issues involved pose real challenges for advocates and individual consumers. There is a critical need to articulate a vision for a transformed system that makes sense to consumers because it addresses things they care about, in language that is universally understood. This vision would be the basis for an overarching framework for payment and delivery reform from a consumer advocacy perspective. However, there was acknowledgment that there have been tensions in the past in developing a shared approach to various policy issues, so it may take some work to reach broad agreement around transformation.

Advocates are already engaging on some transformation-related issues. Despite the fact that state-level ACA outreach, enrollment and Medicaid-related implementation issues continue to claim much of the consumer health advocacy community's attention, advocates are already engaged to some degree with transformation-related issues. Advocates calibrated their choice of issue focus and policy vehicles to what is feasible within a state's particular political environment. For example, in states with political leadership that is less supportive of the ACA, like Virginia, New Hampshire, Arkansas, Nebraska and Alabama, health system transformation opportunities are occurring in the context of Medicaid restructuring/"privatization" initiatives through federal waivers of Medicaid rules. In other states, especially those that have already expanded Medicaid and implemented other provisions of the ACA, policymakers are ready to move on to broader system-wide efforts to curb costs, increase quality, and improve health outcomes. Policymakers in Oregon and Alabama are exploring models to coordinate all care – including behavioral health – for their Medicaid populations. Taking a different approach, Maryland policymakers are exploring payment reform through global budgeting.
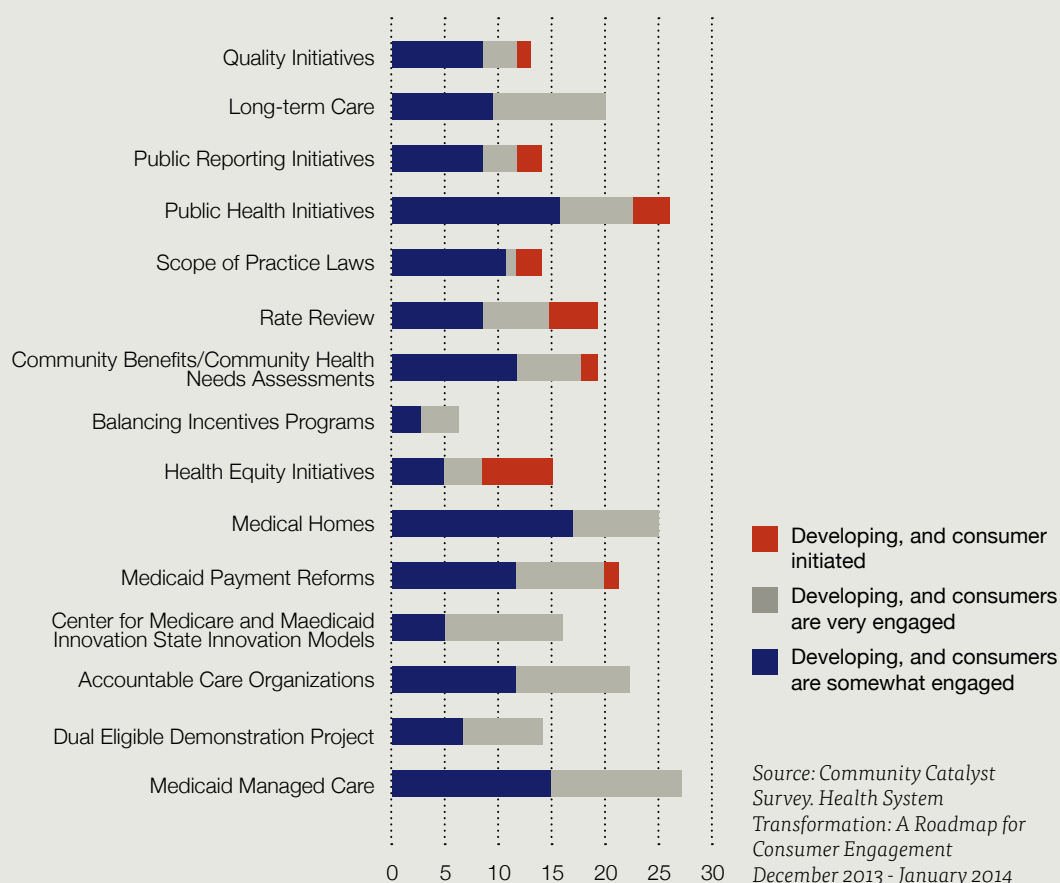
> *"Delivery reform can be a code word for many things. The mantra is better care for less money. Better care needs to be the bigger part of the equation."*
>
> *– Consumer Health Advocate, Community Catalyst Focus Group*

Oregon's Coordinated Care Organizations (CCO) recruit community members to serve on Community Advisory Councils that advise and make recommendations to the CCO board on the strategic direction of the organization. Similarly, Alabama is creating Regional Care Organizations (RCOs) to move to "provider-based, community-led" managed care for Medicaid beneficiaries in five regions. The state has also created RCO Citizens' Advisory Committees and governing boards that provide consumer input into the direction of Medicaid transformation in Alabama.

ENGAGEMENT AMONG CONSUMER HEALTH ADVOCATES IN HEALTH SYSTEM TRANSFORMATION ISSUES

Quality Initiatives
Long-term Care
Public Reporting Initiatives
Public Health Initiatives
Scope of Practice Laws
Rate Review
Community Benefits/Community Health Needs Assessments
Balancing Incentives Programs
Health Equity Initiatives
Medical Homes
Medicaid Payment Reforms
Center for Medicare and Maedicaid Innovation State Innovation Models
Accountable Care Organizations
Dual Eligible Demonstration Project
Medicaid Managed Care

0 5 10 15 20 25 30

■ Developing, and consumer initiated
■ Developing, and consumers are very engaged
■ Developing, and consumers are somewhat engaged

Source: Community Catalyst Survey. Health System Transformation: A Roadmap for Consumer Engagement December 2013 - January 2014

Health equity issues are a high priority on state consumer advocates' health system transformation agendas.

All survey and focus group participants are engaged to some degree on health equity issues, and consumer advocates note that, to date, they are leaders within their states in developing – and engaging consumers on – those issues.

Examples of issues advocates are currently working on to advance health equity include:

- Network adequacy
- Data collection
- Language access standards for providers and/or health plans
- Cultural competence standards for providers and/or health plans
- Non-discrimination provisions
- Requiring diverse consumer advisory boards for health plans

> *"In thinking about health equity we need to make sure we don't forget that not everyone accesses the health care system in the same way."*
>
> *– Consumer Health Advocate, Community Catalyst Focus Group*

ENGAGEMENT AMONG CONSUMER HEALTH ADVOCATES IN HEALTH SYSTEM TRANSFORMATION INITIATIVES THAT ADVANCE HEALTH EQUITY
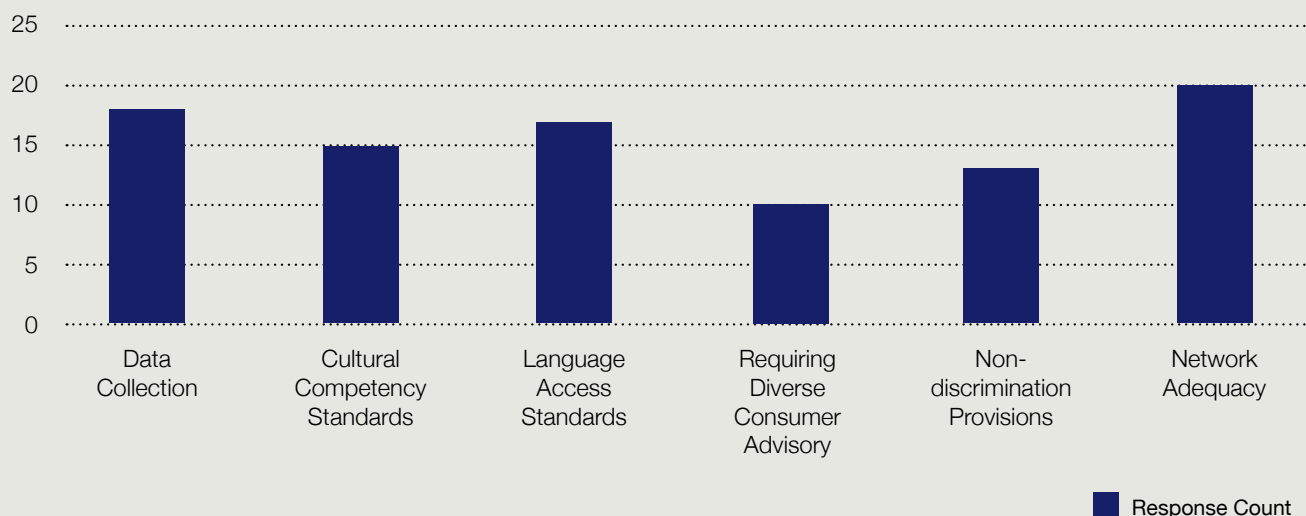
■ Response Count

Source: Community Catalyst Survey. Health System Transformation: A Roadmap for Consumer Engagement December 2013 - January 2014

Advocates would like help building their policy capacity on health system transformation issues.

With respect to their capacity to conduct legal and policy research and analysis and develop feasible policy alternatives, advocates seek assistance on a range of topics, including payment reform (e.g., provider payment arrangements, risk adjustment), quality measures, private insurance reform and various approaches to Medicaid managed care.

Advocates also report they require assistance and/or tools that will help them assess their political and market environments, identify openings for action, understand and prioritize the various "handles/levers" for health system transformation, and set realistic priorities for transformation-related work. Assistance must be tailored to the particular political, policy and delivery system environment.

Advocates would also like a catalogue of best practices to help them develop and shape their work. They note that policy and best practice information would also support the consumer engagement process, as would a mechanism for sharing that information across states (or regions). Advocates especially need evidence-informed examples to bring to their constituencies and to decision-making tables that typically are filled with health professionals and other perceived experts.

Data collection requirements are a good entry point for advocacy on health equity issues. In Minnesota, consumer advocates worked with legislators to pass a bill that would strengthen data collection practices to include information about race, ethnicity and language. In Ohio, advocates are working with the Ohio Commission on Minority Health to include health equity-related data collection in various delivery reform initiatives.

Building and sustaining coalitions will be a challenge.
Despite the fact that advocates in many states strengthened their connections to a broad array of statewide and community-based organizations as a result of their work on ACA outreach, education and enrollment activities, building new – or sustaining existing – coalitions is expected to be a challenge. The most reliable allies over time have been disability groups, children's groups, legal services, and senior groups. But health system transformation is different because it is a broad, diffuse and often technical topic. Advocates understand that organizations might have different visions, and it will take some work to understand disagreements and build unity.

Some interviewees also noted that it might be a challenge to connect many of the transformation-related policy issues to their "pay off" for individual consumers – especially those who don't have serious or ongoing health issues – in a clear and accessible way. As a result, it may be difficult for advocates to make a compelling case to consumers to take on an issue. An exception may be those activists who have – or work with individuals who have – serious, chronic health problems, and, as a result, are more likely than others to be interested and engageable in transformation efforts.

Another challenge in coalition building can be reluctance on the part of some organizations to support certain common features of delivery system change. One example might be the increasingly common adoption by health plans of step therapy (or "fail first") policies in pharmacy benefit design. These policies restrict coverage of expensive therapies unless patients have already failed treatment with a lower-cost alternative. Some organizations that represent populations with specialized needs, particularly organizations that advocate for those with mental illness, have resisted these policies arguing that they pay insufficient attention to the unique needs of individuals.

A somewhat related challenge is presented by advocacy groups that rely on industry and allied stakeholders for financial support. Hospitals, the pharmaceutical industry and providers often give funds to advocacy organizations, which could affect an organization's stance on a particular issue the funder is interested in. Advocates acknowledge that this type of challenge may be difficult to navigate, but they also understand that these other organizations may have few alternatives from a funding perspective. In some instances, unions must balance potentially competing pressures around keeping jobs in the health care industry against cost pressures that reconfigure how and where care is provided.

Ensuring effective consumer representation in different advisory venues is also a challenge.
Many advocates report being very successful in creating roles for consumers on advisory councils and in other representative bodies, particularly since passage of the ACA. In more challenging environments, there has been resistance to any consumer representation and every

"The wins were clearly defined in our ACA advocacy. People either had coverage or they didn't. Reducing costs and improving quality are on a spectrum."

– Consumer Health Advocate, Community Catalyst Focus Group

"If the issue is reshaping a program for their particular constituency, the group is there, but otherwise, not so much."

– Consumer Health Advocate, Community Catalyst Focus Group

"In 2003 our legislature eliminated all statewide advisory committees, most of which had seats for consumer representatives."

– Consumer Health Advocate, Community Catalyst Focus Group

consumer seat must be fought for. Even where there are concrete opportunities for participation, it can be a challenge to fill those slots with consumers (as opposed to consumer advocates). Consumers need both substantive knowledge (or a source that can readily provide it) and support to develop the skills that will enable them to question, challenge and otherwise represent the consumer experience – as distinct from their individual needs – in the venue.

Advocates note that because the ACA built consumer input requirements into so many models and new programs (e.g., the dual eligible demonstration projects, Accountable Care Organizations), providers should also have an interest in training and supporting consumers in those roles. Advocates identified the need to develop tools and models to help health plans and providers structure meaningful consumer engagement. A persistent challenge, though, is to ensure that, wherever there are provisions for consumer representation, those roles are actually substantive and not just window-dressing. The structure of these bodies can pose a challenge, especially if consumers represent only a small minority of members or participants.

Building a grassroots base of support also presents unique challenges. Advocates observe that consumers, in general, think about the health care system through the prism of their own – and their families' – experiences. But advocates believe that to be effective, they must build an authentic consumer voice in policy and delivery system advocacy. Figuring out how to do that is essential to their ultimate success. Many advocates report having created a strong foundation for this aspect of the work through their involvement with diverse community organizations and individual consumers in their ACA outreach, education and enrollment work. Building on this foundation will require that there be mechanisms for consumers to talk about what they experience within the system and what is important to them as a key input to develop a system change agenda. To the extent engagement is possible, it will be important to connect potential policy changes to things consumers value. A few advocates cited insurance premiums and the cost of health care as having the potential to energize consumers.

Another important point raised by several interviewees is that consumers are not monolithic. Their own experiences – or those of their families – will affect their view of what is desirable. Using pharmaceuticals as an example again, some individuals will not want any limitations on access, while others are willing to accept what they feel are reasonable limits in exchange for lower premiums. It may be a challenge for some advocates to find common ground with their natural constituents.

Advocates identified the following resources as being most helpful to building grassroots engagement on health system transformation issues: additional grassroots organizing capacity within the organization;

> *"How do you develop and train consumer representatives so they open their mouth at a table with doctors and providers? How do you bring together a citizen advisory council that can advise in meaningful way?"*
>
> *– Consumer Health Advocate, Community Catalyst Focus Group*

> *"We've been working on a campaign for consumer-focused insurance rate view, and we were able to develop a petition that boils the issue down really simply to a few key issues. To date we have 30,000 signatures."*
>
> *– Consumer Health Advocate, Community Catalyst Focus Group*

leadership development curricula; constituency-specific materials and talking points; and story-banking around delivery reform. Perhaps most important is the observation of a number of focus group participants that if organizations want to build an authentic consumer voice, it will be important to provide logistical and tangible support to participating consumers, such as transportation, child care, stipends and/or expense reimbursement.

In contrast to ACA advocacy around coverage, advocates anticipate difficulties engaging with some system stakeholders on transformation issues.
Advocates recognize that they will need to collaborate with providers, health plans and other stakeholders, and that this will be critical to transformation at both the policy and delivery system levels. It is also an area in which advocates would like support. For the most part, consumer advocates, the provider community and the insurance industry were on the same side during the ACA debate with respect to expanding coverage (although there were significant differences around other important issues like market regulation and inclusion of a public option). Health system transformation presents a challenge, as many of the policy proposals could result in reduced provider reimbursement, limits on insurer expenditures, and other restrictions. Advocates from a number of states note that work on cost containment already is perceived as being antagonistic toward the hospital, insurance and medical establishments.

> *"We're having some success building relationships with geriatrics experts and others involved in patient-centered primary care."*
>
> *– Consumer Health Advocate, Community Catalyst Focus Group*

Nevertheless, some consumer advocates are developing strategies to address the challenge. For example, stakeholder trade associations/societies are viewed as taking positions that represent the broadest spectrum of their membership, but there often are more progressive individuals or subgroups within those organizations that are open to engaging with advocates. For example, safety-net hospitals, community health centers and pediatricians, among others, have demonstrated a notable willingness to work with consumer advocates. Other advocates have had some success connecting with insurers around Medicaid managed care. And, beyond health care industry stakeholders, advocates report having periodic/issue specific relationships with employers, public health officials, and other government officials and agencies. A number also report having formal collaborations with organized labor.

Survey respondents identified the following four principal challenges to building and maintaining stakeholder alliances on health system transformation issues:

- Time and capacity to build and maintain relationships,

- Lack of policy and operational knowledge/expertise to be at stakeholder tables,

- Inability to bring a consumer constituency into the dialogue, and

- Overcoming a history of differing positions.

Generating resources to engage in health system transformation work is difficult.
The majority of those interviewed report they do not have funding specifically earmarked for

health system transformation work. Some have been able to work on discrete aspects as part of their other funded activity or through general operating support, and a few have resources to do some consumer engagement work and policy research on delivery and payment system reform. In every case though, they report the funding is insufficient for the workload.

A few advocates have seen their funding efforts for health system transformation gain traction, especially if they are able to frame the work through a health equity lens or through a focus on vulnerable populations that funders also care about. In addition, advocates have also found that relationship-building with local provider groups has led to more funding through smaller community-based grants to engage in local health system transformation efforts. And since we conducted our survey of consumer advocates, there are signs of growing funder interest in supporting consumer advocacy in health system transformation.[40]

Observations of other system stakeholders and experts

Our research also involved interviewing a number of individuals who have an organizational connection to transformation work and/or are able to observe transformation-related activity from a broad vantage point. They included purchasers, health policy experts, state officials and state-based health foundations, among others. The purpose of these interviews was to obtain some additional insight and, potentially, some corroboration of the views of state health advocates. Findings include the following:

To date there does not appear to be a comprehensive, proactive health system transformation agenda among the national consumer advocacy community.
While some work has been done on specific aspects of health system transformation,[41] there is currently no agenda that encompasses the full range of issues that must be addressed to create the people-centered system that is the goal. Observers attribute this primarily to two things: access and coverage issues have consumed the bulk of advocates' resources, focus and political capital up to this point; and, health system transformation encompasses so many – and such varied – issues that advocacy expertise tends to be narrowly focused and spread over a broad substantive terrain.

In addition to working collaboratively on the ACA's access and coverage provisions, many national consumer advocacy groups were at the table working to insert health system

40 Community Catalyst's Affordable Care Act Implementation Fund (ACAIF) included health system transformation in its 2014 grant making priorities funding four sites for this work. http://www.communitycatalyst.org/initiatives-and-issues/initiatives/ aca-implementation-fund/body/2014-Grant-Making-Strategies-for-ACA-implementation-fund.pdf. The Robert Wood Johnson Foundation (RWJF) recently announced a new Value Advocacy Program to support state consumer health advocacy on health system transformation in up to six sites. Community Catalyst will manage and provide technical assistance through the program. Simultaneously, Consumers Union received RWJF support to establish a policy hub on this topic for state consumer health advocates. http://www.rwjf.org/en/grants/grant-records/2014/10/supporting-consumer-health-advocates-in-influenc- ing-the-shape-of.html.The Atlantic Philanthropies is supporting state consumer engagement in the development and imple- mentation of the dual eligible demonstration projects in five states through the Voices for Better Health Project. http://www. communitycatalyst.org/initiatives-and-issues/initiatives/voices-for-better-health.The John A. Hartford Foundation supports new partnerships between these state advocates and geriatric providers. http://www.jhartfound.org/blog/raise-your-voices-for- better-health/

41 Carman KL, Dardess P, Maurer ME, Workman T, Ganachari D, Pathak-Sen E. A Roadmap for Patient and Family Engagement in Healthcare Practice and Research. (Prepared by the American Institutes for Research under a grant from the Gordon and Betty Moore Foundation, Dominick Frosch, Project Officer and Fellow; Susan Baade, Program Officer.) Gordon and Betty Moore Foun- dation: Palo Alto, CA; September 2014. www.patientfamilyengagement.org.

transformation provisions into the ACA on issues of concern to their particular constituencies. They have continued to be focused/engaged on their particular issues, but to a much lesser extent on the broader work.

While there is agreement that the health system should shift to one that is shaped around value and population health, there is not a consensus on how to get there.
Many stakeholder activities are focused on quality measurement and payment reform. Interviewees noted that current transformation efforts are occurring in the context of demonstrations and other federally funded models, and bringing those projects that are successful to scale will be a challenge. While most of those interviewed do not work directly in the states, they note that there is significant variation across the country in terms of interest and capacity for change.

The interest in a stronger consumer voice in transformation issues is balanced by a general concern that consumer groups are not currently equipped to engage effectively with experts and industry stakeholders.
A strong consumer voice and presence is seen as important on a number of specific policy issues, including system consolidation, payment reform, safety-net providers, Medicaid managed care, and specialized health plans and delivery models such as dual eligibles plans and patient-centered medical homes. Several interviewees noted that working to ensure the consumer voice is actually connected to – and representative of – an authentic consumer base will also be important.

"We need folks who can go toe-to-toe with special interest groups to represent the consumer point of view."

– Funder

Current quality-focused activities were cited by several interviewees as a good example of the challenge consumers face. Several national entities (e.g., National Quality Forum, National Committee on Quality Assurance) are charged with developing quality measures, but they are highly technical, led by professionals, and move slowly. There is a concern that they don't always focus on the issues that matter most to consumers. The consumer presence has been welcome at the quality measures "table," but consumers are not perceived as having much power there.

Another source of concern is that consumer advocates may have a hard time taking positions that challenge other stakeholders who previously have been allies or benefactors on some issues. For example, advocates may be uncomfortable challenging a hospital consolidation if the affected hospitals have provided support – financial, in-kind, etc. – to the advocacy organization. Similarly, concerns about a possible loss of jobs if spending is reduced can raise concerns.

"...There's been more consumer inclusion than in the past, but mainly on a 'country cousin' basis."

– National Consumer Health Advocate

Where is the public?

A review of public opinion surveys and other research undertaken from 2010 to date reveals some interesting but contradictory views among the participants.

Consumers think the cost of health care is a significant problem.
Consumers overwhelmingly characterize the U.S. health care system as expensive.[42] This perception applies primarily to their own out-of-pocket costs, and only minimally to system-wide costs. With regard to personal expenses, they express considerable concern that they won't be able to sustain additional increases in their out-of-pocket health care expenses. They do not have strong confidence that over the next 10 years they will be able to get the care they need, have enough provider choices, or be able to afford health care without financial hardship.[43] [44]

> *"There is some concern that consumers won't be able to make hard decisions that go against the interests of big players like hospitals or unions."*
>
> *— Health Plan Leader*

With regard to system-wide costs, they have only a general sense of how broader system costs are paid.[45] In one series of focus groups, consumers were presented with a set of prices for various procedures performed at different hospitals. They were surprised at the magnitude of variations among facilities. Nevertheless, they identify the pharmaceutical industry, insurance company administrative expenses, fraud and hospital pricing as the principal "culprits" of high and escalating spending. However, they do not see public spending on health care (especially on the Medicare program) as a major contributor to the federal deficit.[46]

Consumers view health care through a very personal lens with respect to their providers and the care they receive.
Consumers report being generally satisfied with their own providers and the health care they receive. They appear to focus on the "softer" side of a medical practice, including the communication style of staff they interact with, attention to medical details and office wait time.[47]

While generally satisfied with their own care, consumers believe there is room for improvement in the health care system's overall performance.
When asked about what types of reforms they would favor, there was support for:

- Price negotiations between payers – public and private – with pharmaceutical and medical device companies, and negotiations with hospitals and doctors.

- Information about the costs of care they will be responsible for prior to receiving care.[48]

- Information about the quality of care provided by different providers and hospitals.

42 *Talking about Health Care Payment Reform with U.S. Consumers: Key Communications Findings from Focus Groups*. Rep. N.p.: Aligning Forces for Quality, 2011.
43 *Consumer Attitudes on Health Care Costs: Insights from Focus Groups in Four U.S. Cities Anger and Confusion as Rising Premiums and High Deductibles Claim a Bigger Share of Household Budgets*. Rep. N.p.: Robert Wood Johnson Foundation, 2013.
44 See supra note 4.
45 Quincy, Lynn. *Engaging Consumers On Health Care Cost and Value Issues*. Rep. N.p.: Consumers Union, 2014.
46 See supra note 43.
47 See supra note 45.
48 Stremikis, Kristof, Cathy Schoen, and Ashley-Kay Fryer. *A Call for Change: The 2011 Commonwealth Fund Survey of Public Views of the U.S. Health System*. Issue brief. N.p.: Commonwealth Fund, 2011.

- Having one place or provider responsible for their care, and ensuring that all of their providers have access to their medical records.[49]
- Alternatives to fee-for-service financing, e.g., payment to providers of a comprehensive fee that covers all care.

On this last point, consumers see the comprehensive fee approach as a way to constrain costs, reduce overtreatment, and improve patient care. However, there is some concern that the approach might lead providers to ration care.

Other observations about quality.
Consumers recognize that quality of care varies widely across hospitals and types of physicians. There is a persistent view among many, in at least one survey, that specialists and high-profile hospitals (e.g., academic medical centers) provide care that is superior to that provided by primary care providers and community/non-teaching hospitals. On the other hand, consumers in a series of focus groups did not think higher prices were tied to higher quality.

The role of government in the health system.
There is some concern about "government intrusion" in the health care system around both health care spending and delivery, but there seems to be agreement that government regulation has to play some role in addressing rising costs.[50] [51]

What consumers can do
In the series of focus groups, consumers indicated they did not know what they could do to lower the cost of care other than not get sick. Living a healthier lifestyle and requesting generic drugs were the two principal actions they felt they could take in that regard. Their focus was very much on what they could do to save their own money, and not on how reducing spending could help the economy or otherwise help the broader community.

49 Ibid.
50 Schleifer, David, Carolin Hagelskamp, and Christopher DiStasi. Curbing Health Care Costs: Are Citizens Ready to Wrestle with Tough Choices? Rep. Ed. Ilse Tebbetts. Public Agenda and the Kettering Foundation, 2014.
51 See Supra Note 45.

Hospital charges bring a backlash

PATIENTS' COSTS SKYROCKET; *Specialists' Incomes Soar*

BITTER PILL: WHY MEDICAL BILLS ARE KILLING US

Where is the Media?

As an additional means of understanding the context in which these reforms are underway, we also undertook a high-level review of traditional media coverage to see what transformation-related topics are part of the public conversation, and what language is being used around them.

Most national coverage addresses health care system changes within discussions of the ACA.
National reporters also focus on specific reform issues rather than on the wider system and where the consumer fits in. The most pervasive topics related to health system transformation issues appear to be health care prices, care coordination, unnecessary medical spending, hospital funding, physician compensation, personal medical costs, ineffective treatments, and transparency around quality and prices. The highest-profile journalism in the last two years had to do with hospital prices. An investigative series in the *New York Times* ("Paying Till it Hurts") by Elisabeth Rosenthal in the *New York Times* and an extensive piece by Stephen Brill in *TIME* ("Bitter Pill: Why Medical Bills Are Killing Us") provided the most comprehensive examinations of the byzantine world of health care and hospital pricing, told through consumers' accounts of their struggles to pay their hospital bills. Both pieces garnered significant public attention, generating hundreds of reader comments.

For example, an April 2014 story in the New York Times economy section, "Acceleration Is Forecast for Spending on Health," explored the wastefulness of medical spending and ways to curb it. It highlighted that our current fee-for-service system lacks incentives to limit spending.[52]

National and state news outlets rarely use terms such as "delivery system reform" to refer to the whole health care system.
Trade publications use the term more frequently, but there is no clear consensus among any of the media on what the phrase encompasses. On the rare occasions when news outlets do use the term "delivery system reform," they highlight opportunities to provide quality care at lower costs and reduce unnecessary spending.

State and local radio and print media stories focus both on broad topics and issues of local interest, and only the occasional convergence of the two.
General topics most frequently covered include the high cost of health care, affordability of care for consumers, the affordability of coverage for businesses, and transparency around

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52 Porter, Eduardo. "Acceleration Is Forecast for Spending on Health." The New York Times. The New York Times, 22 Apr. 2014.

health care costs and quality.[53] These issues often play out at the local level around such things as funding sources for local hospitals,[54] the impact of health funding on the state budget, and the cost and quality of local providers.

Health trade publications use broader aspirational phrases when referring to health system transformation issues.
They do not, however, describe the different pieces that make up the full system or propose a clear solution to the system's shortcomings. Trade media use the following terms or phrases in conversations about delivery system reform:

- Improving outcomes and saving money

- Designing health care and payment systems to improve quality and efficiency

- Creating a higher value health system

- Transforming primary care practices

- Enhancing physician satisfaction and practice sustainability

For example, a New Hampshire paper recently published a story examining doctor salaries and highlighted how difficult it is for consumers to identify the best place to get quality, cost-effective care.[55]

There is a relatively small conversation about delivery system reform on Twitter.
Our review found only a few thousand mentions related to terms such as "health care price transparency," "doc fix," "physician satisfaction," "delivery system reform" and "health care outcomes." Among these issues, "doc fix" and "health care price transparency" have generated the largest discussions. There are few conversations around terms that encompass the whole system, such as "delivery system reform" and "health care outcomes." Within these conversations, the focus is on accountability and incentives for quality, cost-effective care; price transparency; and the efficiency of health care technology and databases.

There is more conversation in other social media formats, but it is typically directed to non-consumer audiences.
A wide variety of people and organizations are discussing delivery system reform issues in other social media formats. They include bloggers, physicians, advocates, health care financial management organizations, medical associations and health care information technology companies.

53 Kowalczyk, Liz. "Lahey Clinic Charges Hospital Fees to Patient." The Boston Globe, 27 Jan. 2013.
54 Frost, Mary. "Brooklyn Hospitals Hear from State about Applying for Medicaid Waiver Funds." Brooklyn Daily Eagle, 17 Apr. 2014.
55 "Medicare Database Reveals Top-paid Doctors." Fosters.com, 20 Apr. 2014.

Developing a Vision and an Agenda

From our perspective, advocates and consumers – must be prepared to operate on three distinct levels:

- **Policy advocacy:** Many of the transformation-related proposals will arise in the federal and state policy arenas. Medicare and Medicaid and federal and state budgets will likely be principal vehicles for such activity, but policy issues may also arise in local government contexts. Indeed, this community level may well be where many of the upstream factors that affect health are best addressed. Advocates will have to operate within both legislative and executive branches at all levels.

- **System-level advocacy:** Many transformation-related activities will occur at the implementation/operational level, i.e., within the hospital systems, health plans, Accountable Care Organizations, etc. As a result, consumers and their advocates must be able to engage with the delivery system itself. This is necessary to ensure that providers and health plans operate in ways that place priority on the needs of consumers relative to those of other stakeholders, and also to ensure that system players contribute to population and community health.

  - **Individual-level advocacy:** Consumers must also, where possible, become active, engaged and knowledgeable participants in their own health and health care, and advocates must promote changes that facilitate such participation. Consumers will need quality information and support from policymakers and the health system that will enable them to build their understanding of health system transformation issues and make sound and informed choices in regard to their health and health care options. There is a growing body of evidence to demonstrate that patients who are more engaged in their own health care have better health outcomes and care experiences. Consumers must also be prepared to share the consumer/patient experience within the permanent structures we envision to ensure that "course corrections" are directly responsive to consumer experiences – whether positive or problematic.
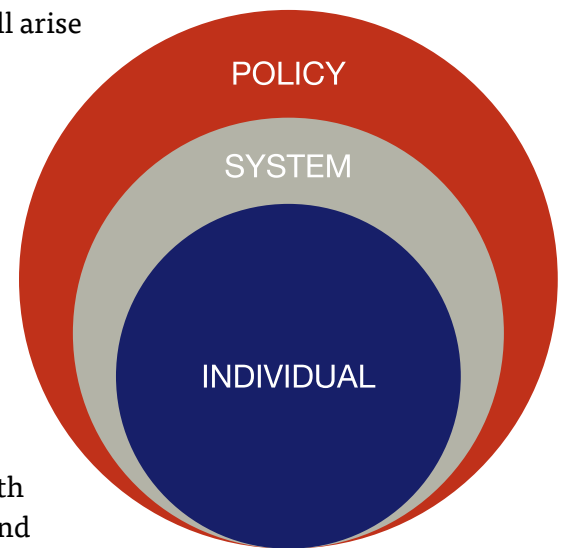
Health care organizations across the country, including Kaiser Permanente, Boston's Dana Farber Cancer Institute, and Cincinnati Children's Hospital Medical Center are creating roles for patients in the delivery system decision-making process as members of patient/family advisory councils. Council participants serve as advisors to enhance quality and safety, redesign systems of care and educate health care providers about the consumer experience.[56]

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56 Partnering with Patients and Families to Enhance Safety and Quality. A Mini Toolkit. Institute for Patient- and Family-Centered Care, n.d.

A principal finding in our research was that even though there is consensus among consumer-focused interests on the general direction for health system transformation, i.e., pay for value, patient-centered, etc., there is little clarity on what that means in practice, or how to achieve it. Moreover, consumer organizations at the national and state levels have only just begun to think about a framework and to develop issue expertise, messaging or strategies to move very far in that direction. Therefore, an initial challenge consumer health advocates face is how to articulate a vision of what a consumer-focused, transformed health system would look like, both for individual consumers, and for society more broadly. We offer the following "wish list" as a starting point:

More highly engaged individuals are significantly more likely to engage in healthy behavior such as eating a healthy diet and getting regular exercise, and to avoid health-damaging behavior such as smoking and illegal drug use. [57]

HEALTH SYSTEM TRANSFORMATION VISION

A transformed health system would be people-centered, effective, timely, efficient, safe and equitable. It would proactively address health disparities. It would use evidence-based policies by applying what we know works to achieve the desired outcome – not what we think or hope will work. The system would incorporate quality reporting that provides meaningful information to patients and afford due process rights to protect consumers from arbitrary or inappropriate coverage decisions. A transformed system would be one in which payment reflects appropriate risk sharing/risk mitigation and incentivizes positive outcomes. Equally important, a transformed system would be one that invests in health and not just health care. This means a system that would address the multiple factors and determinants that have a far greater impact on health status and life expectancy than clinical care. Finally, a transformed health system would incorporate an organized, independent, influential and permanent consumer voice at the policy, system and individual/community levels to ensure it truly works for the people that justify its existence.

Others – consumer advocates, their constituents, and their partners and allies – may have different or additional thoughts, so a first task in building up the work would be to test these initial thoughts with others.

When it comes to developing an agenda for transformation work, we know from our survey that the sheer number and technical nature of the issues is daunting. To help advocates focus their time and resources in the areas and on the issues that offer the best opportunity for positive change, we offer these criteria to help set priorities:

▶ **Advocacy efforts should focus on proposals that actually tackle one or more of the four principal drivers of poor value.**

57 Hibbard, J. H., and J. Greene. "What The Evidence Shows About Patient Activation: Better Health Outcomes And Care Experiences; Fewer Data On Costs." Health Affairs 32.2 (2013): 207-14.

ADMINISTRATIVE WASTE	HIGH PRICES	POOR QUALITY CARE	POOR POPULATION HEALTH
Medical loss ratios	Negotiate prices for Medicare Part D	Don't pay for avoidable bad outcomes	Tax sugar-sweetened beverages
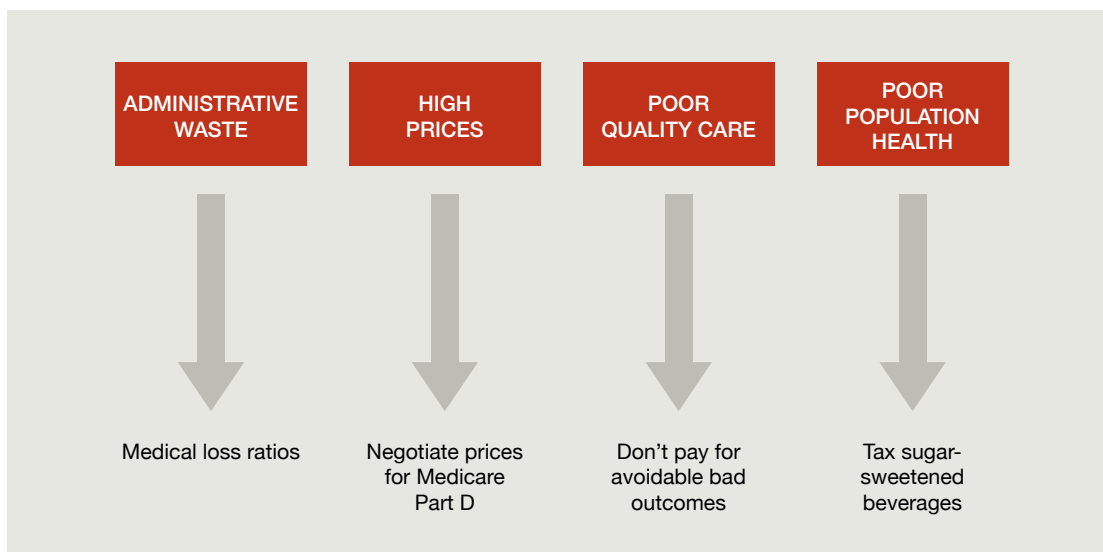
We have identified the four principal drivers of poor value in our health care system: high prices, poor quality, administrative inefficiency and poor population health. In developing their own proposals or approaches, advocates should ensure they tackle one or more of these drivers. In assessing the proposals and/or approaches of others, they should look for this linkage and also demand that the "authors" articulate it.

▶ **In general, advocacy efforts must be about improving value, not just reducing spending.**

There are lots of ways to lower costs/spending. One example might be the adoption of a narrow provider network. If network selection is based primarily on which providers offer the best contract terms, then there is cause for concern on the value front, especially on behalf of individuals with special needs that can't be adequately met within the narrow network. However, if the selection is made on the basis of high – and meaningful – practice quality indicators and there are appropriate "safety valves" when specialty care is needed, then the approach meets the value test. It is important to note that there may also be reductions in costs/spending that have a neutral impact on consumers, and neither improves nor harms quality. Finally, there are also ways to improve value that don't reduce cost and may actually increase it in some cases. These approaches should never be ruled out, especially if consumers can make a strong business case.

"An example of the "neutral" impact would be increasing a statutory medical loss ratio requirement. This would affect health plans (rather than individuals) by increasing the percent of any premium dollar they must spend on health care/ services and reducing the percent they can spend on administrative expenses."

– Health Policy Expert

> *Sometimes savings can only be achieved in the long term with investments up front.[58] The Commonwealth Care Alliance invests millions of dollars each year through their Senior Care Options program to support multidisciplinary team models of care that promote home medical management, continuity of care and the ability to substitute home and community services for hospital and nursing home care. The enhanced financial resources going to primary care infrastructure, care coordination, and home and community long-term care services can be financed from savings achieved by reducing hospitalizations and nursing home placements. The strategic resource allocations are deliberate cost-effective service substitutions and do not come from overpayments by government payers and are not a result of "rationing,"[59]*

We acknowledge that assessing any particular proposal may be challenging. To use a familiar

REFRAME THE DEBATE: IMPROVING VALUE

HEALTH OUTCOMES

		WORSE	SAME	BETTER
COSTS	HIGHER	**No**	No	Depends
	SAME	No	What's the point	Yes
	LOWER	No	Yes	**Yes**

58 Verdier, James M., Melanie Au, and Jessica Gillooly. *Managing the Care of Dual Eligible Beneficiaries: A Review of Selected State Programs and Special Needs Plans*. Rep. N.p.: n.p., 2010. A report by staff from Mathematica Policy Research, Inc. for the Medicare Payment Advisory Commission.

59 Commonwealth Care Alliance. Senior Care Options Program Factsheet. August 2011.

phrase, "it's complicated." The matrix below offers a visual representation of this criterion.

▶ **Advocates must be aware of the differential impact policies have on different populations, and should place a high priority on proactively developing and engaging on policy solutions that increase health equity.**

When we use the term "health equity," we envision a society in which everyone has a fair opportunity to achieve their full health potential, regardless of the individual or population group's race, color, religion, national or ethnic origin, immigration status, class, age, disability, veteran status, sexual orientation, gender, or gender identity or expression. We need to be concerned about the differential impact policies may have on different populations and be particularly sensitive to potential harms to people with greater – or different – health care needs and/or lower incomes, and to members of racial and ethnic minorities. Some policies may lower costs for some system participants while raising them for others, or they may have a negative health impact on some but not on others. This leads to the question of "improving value…for whom?" As a key piece of their work, consumer advocates need to be proactive in elevating the interests of the poorest and sickest, and especially those from communities of color or other populations that experience disproportionately poor health outcomes.

▶ **Advocates should promote policies that empower consumers and link individual engagement to policy and systems engagement.**

Advocates should assess whether a particular policy proposal empowers consumers, patients, and communities to help solve the problem. Despite the fact that they are the health care system's ultimate end-users, consumers too often have been given short shrift – deliberately or not – when it comes to having a say in public or institutional policies, program operations or their own health decision-making. Thus, advocates should be prepared to develop – or promote – policies that "bake in" substantive roles for consumers. In addition to securing consumer positions on boards, councils and panels, advocates should demand the incorporation of organized, systematic opportunities for consumers to share their experiences, address problematic ones and proactively help shape solutions.

We recognize that while our approach seems fairly straightforward in concept, it is not so simple in practice. The "devil is often in the details," and the actual effect of policies may be quite different from their initial presentation. For example, policies to promote integrated care may be advanced under the guise of improving quality and efficiency, but their actual effect could be to enable integrated delivery systems to extract monopoly prices. Furthermore, what is desirable from a consumer point of view (and consumers may differ on what is desirable) may not be achievable in the short run in a given environment, so policy and systems change agendas will have to adapt to variations in both political and market conditions. With this in mind, we have included Appendix B which applies this screen to a selection of current issues.

Recommendations

These recommendations have been crafted to reflect the current state of consumer health advocacy around health system transformation and to anticipate the evolving needs of those advocates as the policy and market environments respond to quality and cost pressures. The complex and highly technical nature of health system transformation, and its long-term trajectory are key factors that inform the work that lies ahead. Most of the demonstrations, pilots and other innovation supports contained in the ACA are underway, but it is unlikely that a reliable assessment of their impact and outcomes will be available for several years. The same is true of much of the market restructuring that has been – and will be – ongoing over at least the next decade. Thus, it is likely that advocates' issue focus and strategies will shift in response to new information and changing circumstances.

In an earlier publication, we identified six capacities that are key to a consumer health advocacy organization's ability to influence state-level policymaking.[60] They are:

- the ability to analyze complex legal and policy issues.

- the ability to use media and other communications strategies to build timely public and political support.

- the ability to build a strong grassroots base of support.

- the ability to build and sustain strong, broad-based coalitions and maintain strategic alliances with other stakeholders.

- the ability to generate resources from diverse sources to support the work.

- the ability to organize and strategically deploy these abilities/capacities.

COMMUNITY CATALYST SYSTEM OF ADVOCACY

60 *Consumer Health Advocacy: A View from 16 States*. Rep. N.p.: Community Catalyst, 2006.

Because these capacities are unlikely to exist within a single organization, we also noted that policy victories are more achievable when consumer advocates build collaborations and partnerships with organizations that share similar policy goals and that bring expertise in one or more of the needed capacities. This "system of advocacy" approach has been tested, refined and validated in the eight years that have elapsed since its development.[61] It was a major factor in the adoption of an array of state health reforms, and it was pivotal in the passage and implementation of the ACA. We believe it is uniquely suited to tackling health system transformation at the national, state and local levels.

While the basic advocacy structure should remain the same, health system transformation work places a number of new demands on advocates and their organizations. The legal and policy issues, communications framing and content, grassroots engagement strategies, and the stakeholders and other coalition partner and ally relationships will likely differ from those developed in connection with coverage and access expansion work. Therefore, it will be necessary for advocates to develop new skills and expertise to meet these challenges. Building on the work that has come before, the recommendations we offer here address three strategic imperatives:

- the need to ensure effective consumer advocacy leadership that develops and promotes a positive vision for health system transformation and ensures coordination of local-, state- and federal-level advocacy

- the need to strengthen the organizational capacity of state and local consumer advocates to fully participate in this critical new phase of work

- the need to educate and engage individual consumers on three levels – participation in their own health care, engagement at the system/institutional level, and participation in policy advocacy – and to link these three levels of engagement

We offer the following recommendations:

RECOMMENDATION 1: Articulate a proactive vision and framework for a transformed health system.

An initial task for consumer advocates is to articulate a positive vision of what a transformed health system would look like. National groups must come together along with state and local community advocates to shape this vision, which in turn will serve as the basis for development of federal, state and local agendas.

During the ACA debate and implementation work, state and national advocates developed productive coordination structures. National advocates consulted closely with state advocates around development of the federal implementation framework, ensuring that their suggestions and concerns reached both federal legislators and agency officials. Similarly, national organizations served as a resource to state-based advocates when federal

61 Strong, D., D. Lipson, T. Honeycutt, and J. Kim. "Foundation's Consumer Advocacy Health Reform Initiative Strengthened Groups' Effectiveness." *Health Affairs* 30.9 (2011): 1799-803.

regulations or guidance needed to be clarified. For several reasons, a similar type of coordination will be important during the long haul to health system transformation. First, Medicare and Medicaid will be integral factors in the transformation process and regulation of private sector coverage will also impact quality and cost. The mix of federal and state programs and regulation, and the potential cascade effect of decisions in one venue having unintended – and potentially negative – consequences in another, requires the creation of a forum or other setting where policies can be developed or assessed by those with the knowledge and expertise to understand their implications.

A second reason coordination is necessary is that there inevitably will be disagreements among national groups – that may also be reflected among some state-based coalitions – on both policy and strategy. Agreement on the basics though, with transparency and thoughtful exchange about specific differences, will further the interests of all.

Urgent initial tasks are as follows:
- Consumer groups must come together to create a vision, framework and proactive guiding principles for people-centered health system transformation in order to move beyond addressing issues in an ad hoc and opportunistic manner, to developing a more organized, comprehensive and strategic agenda. Building off the expertise of pioneers in disability rights, women's health and health equity efforts, the vision, framework and principles must address and/or incorporate the following:
  - The guarantees of Medicare and Medicaid must be at the core of the vision.
  - Health disparities must be addressed head on.
  - Population health must be fully integrated.
  - Meaningful consumer voice must be institutionalized at all levels of the system.
  - The consumer experience "on the ground" must be an integral part of the information that informs strategy.
  - Vulnerable populations and representatives from those constituencies – seniors, people with disabilities, communities of color, etc. – must be key participants in the development of the vision, framework and principles. Health care leaders and innovators who already are demonstrating what transformation can be must be welcomed into the development process.
  - The public sector must set the "rules of the game" to assure that consumer interests are protected and promoted.

- Existing mechanisms for knowledge transfer between state and national consumer health advocates must be reviewed and strengthened. Where necessary, advocates must collaborate with each other to enhance systems to coordinate information sharing, identify issue priorities, and collaborate on the development of policy approaches for some of the more challenging transformation-related issues.

RECOMMENDATION 2: Strengthen and expand coalition building at the state and local levels

Although federal law and regulations set parameters for many of the changes underway, much of the development and implementation of new models occurs at the state, local and institutional levels. A shared vision and strategy that is responsive to each state's local market and policy dynamics will be critical to ensure an effective consumer voice in shaping the changes underway. We propose the following steps:

State groups should consider:
- Establishing a state table of consumer groups around the transformation vision, seeking agreement on a basic framework and committing to transparency and thoughtful exchange about specific differences.

- Reaching out to health plans and providers with a track record of supporting meaningful consumer engagement.

- Developing alliances with other issue advocates, e.g., housing, community development, environmental activism, etc., because they focus on many of the upstream issues that affect individual and community health.

- Using economic, market and political assessment tools to establish strategic priorities for a state consumer health system transformation agenda.

National groups should consider:
- Providing tools and technical assistance that facilitate coalition building and offer strategies to navigate policy/issue differences, including approaches used successfully in different states.

Funders – national, state, and local – should consider:
- Providing grants and technical assistance to undertake individual state environmental assessments.

- Supporting and facilitating the state/local convening and planning process.

- Supporting coalition coordination and infrastructure.

- Assisting in the development of sustainability approaches for the infrastructure

- Connecting advocates with local subject matter and policy experts.

RECOMMENDATION 3: Build policy and delivery system expertise

Consumer advocates face a steep learning curve with regard to transformation-related policy content, both in terms of the breadth of issues involved and the technical depth required. This is further complicated by the significant variation in local health care markets and state health policy environments, so effective policy interventions will vary from place to place. And, because transformation will also require advocates (and consumers) to engage

at the delivery system level, advocates must immerse themselves in gaining delivery system expertise. For example, there is a growing body of "best delivery system practices" advocates should be aware of, both to ensure that those practices actually address consumer needs/concerns and, where they do, to promote them more broadly as models.

State groups should consider:
- Developing internal capacity to analyze new policy and delivery system intervention models.

- Building working partnerships with state and local policy experts and health care innovators.

- Incorporating a strong population health policy agenda into state and local policy advocacy.

National groups should consider:
- Developing tools and providing technical assistance to state and local advocates to assess their political, economic, policy, and market environments as a strategy to identify the most important and promising opportunities for health system transformation.

- Creating a clearinghouse of current policy information on health system transformation and current delivery system best practices.

- Providing tailored technical policy support on specific issues in real time (including access to subject matter experts on complex financing and delivery system issues).

National and state groups – working together – should consider:
- Developing a shared federal agenda and bringing a united voice to federal policymaking that will shape state and local delivery system reform.

- Bringing state experiences and voice to the national level dialogue.

- Collaborating to analyze new models and refine their agendas, as necessary.

- Building a robust learning community across states around policy, advocacy strategies and organizing approaches.

Funders should consider:
- Supporting – or continuing to support, in the case of many national and some state funders – relevant and timely research on health system transformation issues and, with incremental investment, translating the research into lay language to ensure it reaches the ground.

- Supporting national and state-based convenings/learning communities.

- Supporting evaluation of new models of consumer participation.

RECOMMENDATION 4: Build – or strengthen existing – grassroots engagement and leadership development work

Fundamental to the paradigm shift we seek is the importance of giving voice to consumer experiences and needs. Advocates' capacity to identify problems, analyze individual experiences, find patterns, and give voice to ways to improve the system is critical. Grassroots organizing strategies will vary with different populations. For example, dual eligibles and their caregivers are likely to have many interactions with the health system and will be invested in specific issues, such as medical care coordination and long-term supports and services (LTSS). For low-income families with children that are generally healthy, health system issues may not be a high priority, but a "healthy homes" program for a child with asthma, or a program that enables a trusted member of the community[62] to help a middle-aged diabetic manage his or her own care may resonate.

The following are some first steps:

State groups should consider:

- Developing listening mechanisms that consumer advocates can employ to understand consumers' systemic concerns. This information is fundamental to informing advocates' issue priorities and strategies. It is important to note that the work done – and the connections made – by advocates involved in ACA outreach and enrollment efforts has already laid a foundation for these mechanisms.

- Creating and testing education and leadership development models – informed by the listening mechanisms – that address topics of concern, such as proven best practices/ model programs, a basic overview of the health care system, patient confidence tools, etc.

- Developing or identifying ways to insert authentic consumer representation into the three levels of engagement.

- Developing specialized tools and coaching support mechanisms that build both knowledge and skills that will help consumers serve effectively on boards, councils and in other advisory capacities.

- Seeking partnerships with community-based organizations, social service providers, and substance use disorder organizations around educating consumers and identifying issues.

- Building consumer assistance and ombuds functions that can address consumer needs, document consumer experiences and identify systemic issues.

State and national groups working together should consider:

- Providing a clearinghouse of best practices for consumer engagement, leadership development and evaluation tools.

- Developing and disseminating evaluation tools and approaches for use in the field in order to continually refine and improve consumer engagement and leadership development approaches.

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62 *Community Health Workers Evidence-Based Models Toolbox*. Rep. N.p.: U.S. Department of Health and Human Services Health Resources and Services Administration, 2011.

**COMMUNITY CATALYST
PYRAMID OF ENGAGEMENT**

LEADERSHIP
Serves as a
decision-maker
or thought leader and/
or engages and/or leads
others in the work

COMMITMENT
Fully invested in the mission & success of
the organization, a program or campaign

PARTICIPATION
Contributes time & financial or social capital to the
organization, a program or campaign

INTEREST
Understands the cause and is interested in learning more and
possibly participating or increasing commitment

AWARENESS
Has knowledge of an issue or cause

- Collaborating with state and local advocates to develop new education and training tools in response to needs identified on the ground.

Funders should consider:

- Supporting recruitment and training of consumers.

- Supporting community-based organizations and direct service providers to recruit and engage consumers in new roles.

- Facilitating dialogue and collaboration between consumer advocates and health providers.

- Supporting development of formal feedback loops such as consumer assistance services, helplines, surveys and focus groups.

- Supporting evaluation of consumer engagement tools and outcomes.

RECOMMENDATION 5: Build – or strengthen existing – stakeholder relationships and alliances

Transforming the health system to put the individual patient/family and community at the center will require new kinds of working relationships with other system stakeholders. Consumer groups by themselves do not have enough power to drive system change so they will need these alliances. This may range from finding common ground with employers and private payers around a shared interest in reducing low-value care, to working with health plans and providers to design new and more effective ways of both delivering care and supporting people and communities to better manage their own care. Some highly technical – but absolutely critical – issues will never engage a lot of people, but informed advocates will need to be at the table with other interests to negotiate.

State groups should consider:
- Identifying and building relationships with innovative health plans and provider groups, and developing opportunities for collaboration at all three levels of engagement.

- Establishing or building deeper relationships with a broad range of providers such as behavioral health, social workers, community health workers and others.

- Fostering dialogue with both payer and provider trade associations, and with individual association members.

State and national groups working together should consider:
- Documenting and disseminating case studies of successful collaborations.

Funders should consider:
- Supporting consumer/stakeholder dialogues on specific priority issues.

- Facilitating new partnerships between innovative leaders and consumer advocates.

RECOMMENDATION 6: Build a communications program for use at all levels of advocacy that generates public support for health system transformation.

Framing and communicating health system transformation issues will be a long-term process that starts with building public knowledge and moves to building public and political will for change. It will take an investment in education to engage the public in conversations around challenges with the system and potential approaches to addressing them. A recurring theme in some of the public opinion research is that consumers want to be engaged in reform conversations, and consumer advocates can play an important facilitation role.[63]

Because consumers mostly view health system transformation issues through the lens of their own experiences, they don't have an expectation or aspiration with respect to what the overall health system should be. Issue framing and messaging backed by polling and focus

63 See Supra Note 45.

group research is necessary to craft and test a vision and to frame policy solutions in a way that resonates with consumers and other key audiences. This research could also help inform policy priorities by identifying the most salient issues. Lastly, advocates will need to identify and prioritize key audiences, map out the decision makers, influencers and messengers for each audience, and identify potential opposition.

State and national groups working together should consider:
- Commissioning new public opinion research at the state level to help advocates prioritize issues and develop message platforms. Research could address:
    o Which specific aspects of delivery system reform/issues motivate our audiences?
    o Which message frames describe these issues to different audiences in a compelling way?
    o Where are specific audiences on proposed solutions?
    o Who are opponents and how are they framing the issues?
    o What do people value the most about health coverage?

- Providing tailored technical assistance to develop state communications plans, including messaging for state issue campaigns.

- Elevating health system transformation issues and policy solutions with the media to generate awareness and build public and political will for change.

- Creating and deploying story-banking operations to put a human face on the issues.

National groups should consider:
- Coordinating across organizations to carry out an ongoing program of public opinion research that can inform public education and issue framing for national and state agendas.

- Serving as a clearinghouse for current public opinion research.

- Developing an overarching message platform that supports a positive vision for the health system and can be incorporated into issue-based message platforms for state-specific campaigns.

Funders should consider:
- Supporting public opinion research, including state-specific research tied to active policy initiatives.

- Supporting communications planning and capacity building, including story-banking and media relations.

RECOMMENDATION 7: Develop and implement campaigns around key health system transformation issues.

Campaign development requires deployment of all the key capacities, and each campaign builds on the learning, relationships and power of previous ones.

In contrast to coverage and access work, campaigns around health system transformation may be more challenging to mount because the topic is so much more complex. To the extent they are feasible, it is likely they will be more narrowly focused with respect to both issue and target, at least at the outset. An example might be a campaign around a large local health system that consistently fails to meet the unique health care needs of individuals with physical disabilities. While some issues, especially technical ones, may not lend themselves to campaigns, it is important for advocates to identify issues that are suited to campaigns and to maintain their capacity to implement strategic campaigns.

State groups should consider:
- Identifying and prioritizing issues that offer the potential to mobilize consumers.

- Closely tracking the health market environment, the policy process, and the consumer feedback loop for intervention opportunities, then move quickly to take advantage of them.

- Assessing the strategic value of a particular campaign relative to the necessary resources, e.g., will it achieve a policy goal? Will it educate/mobilize people? Will it raise the profile and credibility of the coalition?

- Providing mutual aid and support to the campaigns of partners and allies, as appropriate.

- Orchestrating the involvement of campaign partners and allies so they do the right thing at the right time in decision-making processes

Funders should consider:
- Providing financial or in-kind support to the campaign planning and mobilization process.

- Facilitating connections/negotiations, where appropriate, between advocacy organizations and campaign targets.

Conclusion

We noted at the outset – and again, throughout this report – that health system transformation is an undertaking that is both long term and complex. It is also essential. The sustainability of Medicare, Medicaid and the ACA depend on it. The challenge for consumers, their advocates and allies is to make sure the outcome is driven by individual needs and preferences and not simply the business imperatives of the health sector.

We offer a series of recommendations for increasing consumer involvement and engagement in this work. At the heart of them, though, is the belief that transformation depends on embedding consumers in the structures that fundamentally shape the system. Consumers and their advocates have begun to acquire the knowledge base they need to operate effectively, and the existing consumer health advocacy infrastructure provides a solid foundation for moving forward. The right kinds of support will grow and strengthen this infrastructure. And just as it has been effective in expanding access, coverage and health equity over the years, the infrastructure will succeed in this new challenge.

Acknowledgments

Appendix A

INTERVENTION POINTS AND POLICY LEVERS FOR STATE CONSUMER ADVOCATES

A consumer health system transformation agenda can encompass a range of specific policies and institutional practices including but not limited to:

- Payment reforms linked to outcomes can promote integrated care and improved clinical practices as well as population health approaches
- Quality standards that encompass patient experience and patient activation
- Mechanisms for meaningful consumer feedback around policy and health systems
- Promotion of chronic disease self-management
- Stronger quality and access standards and reporting
- Network adequacy
- Establishing of independent consumer assistance programs
- Value-based insurance design
- Aligning public and private payment incentives

State and local advocates will need to prioritize which specific policies to pursue based on their constituents' needs and the political, market and policy environment. One element of this assessment process is to determine which specific intervention points or policy levers offer the best opportunity for moving an agenda, either because action is already taking place and/or there are allies with shared interest and/or the intervention point is most open to consumer interests.

Below is a list of intervention points with potential policy levers, categorized under state purchasing, private market oversight and provider/plan interventions.

STATE PURCHASING

State purchasing can be a major intervention point, depending on how reimbursement is structured and contract standards are set.

Levers include:

- Medicaid
- Medicaid waivers
- Medicaid/Medicare demonstration projects ("duals")
- State-based Marketplaces
- Public employee purchasing
- Mental health, corrections and other social service purchasing
- Transactions (i.e. mergers, acquisitions, affiliations, conversions) which might require some form of approval or license amendment

PRIVATE MARKET OVERSIGHT

State governments have historically had oversight over insurance, and the ACA provides new tools that states can use to establish access and quality standards and to foster payment approaches that integrate care and support patient engagement.

Levers include:

- Insurance regulation
- Rate review
- Essential Health Benefits
- All payer claims data base
- State-based Marketplaces
- State Innovation Models (federal grants to support state multi-payer delivery system and payment reforms that actively integrate public and private payers)

PROVIDER/PLAN INTERVENTIONS

There are increasing opportunities for consumer advocates to engage directly with health plans and providers. Consumer advocates can play a critical role in organizing and structuring consumer and community input by recruiting and training community members to share their experience and identify improvements. In the new payment environment, some health care leaders recognize the business case for connecting more fully with their community and those they serve in order to design better systems of care and to get feedback. There are also new requirements for consumer and community engagement under the ACA.

Levers include:

- Non-profit hospital community benefits. Provisions in the ACA address consumer protections in hospital billing and require that a Community Health Needs Assessment (CHNA) and implementation plan be completed every three years with annual reporting.

- The Center for Medicare and Medicaid Innovation (CMMI), which was created by the ACA to rapidly test, evaluate and replicate innovative models of care for those individuals who receive Medicare, Medicaid, or Children's Health Insurance Program (CHIP) benefits, is providing grants and technical assistance to providers and state governments to support health system transformation in hundreds of sites across the country. Many of these carry requirements for consumer and community engagement. Among the major initiatives with such requirements are:
  - o Duals Demonstration Programs
  - o CMMI State Innovation Model Initiatives (SIM)[1]
  - o Primary Care Medical Homes

- Transactions (i.e. mergers, acquisitions, affiliations, conversions) can serve as a focus for public corporate campaigns to get voluntary agreement about improved institutional policies and practices.

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1   Specific CMMI Levers Include: 1.Accountable Care; bundled payments for care improvement; primary care transformation; initiatives focused on the Medicaid and CHIP population; initiatives focused on the Medicare-Medicaid enrollees; initiatives to accelerate the adoption of best practices; and initiatives to accelerate the development and testing of new payment and service delivery models

Appendix B

EVALUATING HEALTH SYSTEM TRANSFORMATION POLICIES FROM A PRO-CONSUMER POINT OF VIEW

An initial challenge for consumer health advocates is how to sort through and prioritize the myriad transformation-related issues they are – and will be – confronted with. This will be necessary from a defensive perspective as well as a proactive one. We know from our survey that the sheer number and technical nature of those issues is daunting, but it is also clear from our research that consumers are an essential participant in public and private policymaking if the health care system is to evolve in a direction that meets their needs, interests and concerns.

In our paper we offer a set of criteria advocates might use in evaluating various public and private policy proposals as a means of setting priorities. Those criteria are:

- The policy should improve value rather than simply lower costs by shifting a greater burden onto patients.

- The policy should be scrutinized for the differential impact it may have on different populations, with a particular focus on potential harm to people with greater health care needs and/or lower incomes as well as to members of racial and ethnic minorities.

- The policy should actually tackle the root causes of one or more of the principal drivers of low value care -- high prices, poor quality, administrative inefficiency and poor population health.

- The policy should promote empowerment of consumers, patients and communities in helping to solve the problem.

What follows is an illustration of how this screen might be applied to a set of issues that are receiving some attention in both the public and private health care marketplaces. These policy examples below do not reflect any priority on our part but rather were chosen simply as illustrations.

Initiative: Price transparency for health care services

What it is: Making data on prices publicly available

Driver(s) it addresses: High prices

Consumer empowerment: Gives consumers more information to make health care decisions

Impact on vulnerable populations: No negative impact in and of itself, but it is often paired with proposals that seek to cut costs by increasing consumer cost-sharing. Increasing cost-sharing disproportionately burdens poorer and sicker populations.

1 Hostetter, Martha, and Sarah Klein. "Quality Matters." *Health Care Price Transparency: Can It Promote High-Value Care?* (Apr.-May 2012). The Commonwealth Fund.

What does the research say: There is some evidence that price information can work to lower costs with respect to some services like laboratory tests or imaging.[1]

Discussion: At the outset it should be noted that no other industrialized country relies on consumer price shopping to hold down the aggregate cost of care, and they all are more successful than U.S. with at least comparable quality. In short, the consumer shopping paradigm basically assumes weak payers as a given and dumps the problem in consumers' laps.

Consumers typically have no understand about how much a health care service costs. This may not matter if they don't have money at stake, but if they do (e.g. high plan deductibles or cost-sharing), knowing the cost of a service may allow them to choose more cost-effective options. The value "proposition" is that if consumers realize they can receive high quality services from lower cost providers, they will seek them out. This, in turn, could encourage competition among providers based on the value of care.[2]

A lot of the attention on price transparency is focused on hospital prices because there is a lot of price variation, much of which is not easily explained or justified. However, consumer-facing hospital price transparency, especially with a focus on "list price" is not a very promising tool. There are too many quality measurement challenges and too much uncertainty about what actually needs to be done especially for in-patient hospitalizations. Consumers also face many practical limits on hospital choice, which limit their ability to "shop".

Limitations of price transparency: Most health care spending is not "shoppable." Quality needs to be standardized and/or measured in a way that is both robust and readily intelligible/accessible. There is a potential for perverse effects--especially in the absence of strong data on comparative quality and tools to support consumer decision making—due —to the tendency of people to associate higher price with better quality.

Bottom line: Price transparency is not harmful in itself, but caution is in order because it is a necessary pre-condition for proposals that will increase patient cost-sharing as a cost control measure. To date evidence suggests there are limited savings from consumer- facing transparency.

To be successful, transparency initiatives should focus on areas that are actionable for consumers and where quality can be easily measured and compared. Imaging services are a good example. In some cases greater potential savings come from making data available to providers and payers than from giving consumers data with which to price shop.[3]

Initiative: Narrow networks

What it is: Allowing insurers to develop narrow provider networks to maximize their ability to get the best prices.[4]

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2 Ibid.
3 White, Chapin, Paul B. Ginsburg, Ha T. Tu, James D. Reschovsky, Joseph M. Smith, and Kristie Liao. *Healthcare Price Transparency: Policy Approaches and Estimated Impacts on Spending.* Rep. West Health Policy Center. May 2014.
4 Glaudmans, John, Michael Kolber, and Joel Ario. "Reference Pricing and Network Adequacy Standards: Conflict or Concord?" Weblog post. Health Affairs, 18 Sept. 2014.

Driver(s) it addresses: High prices and poor quality (if the network participants meet meaningful quality standards)

Consumer empowerment: No. Narrow networks constrain choice without offering any offsetting avenue in terms of empowerment. But meaningful consumer oversight could be made a precondition of granting approval for narrow network plans.[5]

Impact on vulnerable populations: There is a potential negative impact, especially on people with complex medical needs.

What does the research say: There is evidence that it can work, at least with respect to lowering costs. Premium increases in narrow networks have been significantly lower than those in broader network plans. It is a strategy that is being used in many of the Marketplace plans in a number of places. Its "sister" – reference pricing (see fn. 3) has also been shown to generate health plan savings in certain circumstances.[6]

Discussion: Compared with other countries, private payers in the United States are weak relative to providers. While Medicare and Medicaid are "price setters" (especially Medicare), private insurers are often unable to negotiate successfully with regionally dominant provider networks. By creating narrow networks, insurers can exclude the highest cost providers, which brings down insurance premiums and also puts pressure on higher cost providers to lower their prices in order retain patients. The value proposition is that because the narrow network has been vetted for quality, the only difference between it and dominant provider networks is the cost.

However, there is anecdotal evidence that suggests some networks may be assembled purely on price without consideration of quality. Lower prices without regard to quality do not necessarily improve value. Moreover, narrow networks can be used to exclude providers who specialize in treating the most complex cases, and as such they can be a back door way for insurers to discriminate against high-need populations, a practice that was supposedly barred by the ACA.

Limitations of narrow networks: Reliability of quality measures used in the provider contracting process is in question.

Potential difficulties and delays for consumers who need highly specialized out-of-network care (e.g. pediatric cancer treatment).

Bottom line: If the quality of a narrow network is truly equivalent to, or better than that of, higher-priced providers, then it may be a reasonable policy to support. There must, however, be a meaningful and timely way for consumers who require specialized care that is only available out of network to access it. And care must be taken to ensure that network development does not become a backdoor strategy for underwriting.

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5 *Hospital Networks: Configurations on the Exchanges and Their Impact on Premiums*. Issue brief. McKinsey Center for U.S. Health System Reform, Dec. 2013.
6 Lechner, Amanda E., Rebecca Gourevitch, and Paul B. Ginsburg. *The Potential of Reference Pricing to Generate Health Care Savings: Lessons from a California Pioneer*. Issue brief no. 30. Center for Studying Health System Change, Dec. 2013.

Initiative: Patient confidence

What it is Patient confidence is the extent to which patients feel like they understand and are able to manage their health conditions. It can be measured through survey research and strengthened through targeted interventions.

Driver(s): Poor quality, elimination of unnecessary care

Consumer empowerment: By definition this is an intervention that boosts consumer empowerment.

Impact on vulnerable populations: No adverse impact on vulnerable populations. Research tends to show that lower income and less well-educated patients tend to score lower on patient confidence measures. However, for that reason efforts to boost patient confidence, especially if targeted to vulnerable populations, hold out promise of improvement.[7]

What does the research say: There is growing body of literature that shows better outcomes/ lower cost when patients report they understand and feel confident they can manage their health.[8]

Discussion: One of the strengths of the intervention is that it can be applied across the whole range of delivery/financing systems including fee for service (FFS), accountable Care organizations (ACO), managed care organizations (MCO), etc. For example, primary care medical home (PCMH) certification standards could include a requirement to measure and report patient confidence using standardized tool. Similar requirement could be included in legislation or regulations pertaining to ACOs. SBMs could encourage or require plans to measure and report patient confidence and make information available on the state website.

Limitations: Although the available evidence supports both better outcomes and lower costs, the evidence for better outcomes is stronger.[9]

Bottom line: Integrating patient confidence into reformed delivery systems should be a priority goal for consumer advocates because it boosts consumer empowerment and makes the system more responsive to consumer needs while improving clinical outcomes and lowering costs.

Initiative: Pay for outcomes (P4O)

What it is: In contrast to "pay for performance" measures, that usually attach a financial incentive (reward and/or penalty) for specific processes such as percentage of patients getting a particular screening, pay for outcomes attaches financial incentives to achieving certain measurable outcomes such as rates of adverse events (e.g. falls in a nursing home or hospital acquired infections).

Drivers it addresses: Poor quality

7   James, Julia. *Patient Engagement*. Issue brief. Ed. Judith Hibbard. Health Affairs, 14 Feb. 2013.
8   Ibid.
9   Ibid.

Consumer empowerment: On the margin—public reporting of outcomes is a quality measure that can help consumers identify higher quality providers or plans, but pay for outcomes initiatives don't really build consumer power within the health care system.

Impact on vulnerable populations: If done correctly, P4O initiatives will not be harmful to vulnerable populations. The key is an appropriate risk adjustment mechanism that adjusts financial incentives to take into account both differences in clinical status and in socio-economic status that can affect utilization of health care services. In the absence of good risk adjustment, resources could be diverted away from providers or health plans that serve poorer or sicker patients. P4O also reduces perverse financial incentives that may encourage low value care.

What does the research say: Research has documented significant costs to the system of preventable readmissions, complications, hospital and nursing home admissions and emergency room visits. Early efforts under the ACA to curb readmissions seem to be having some effect and could serve as the foundation for broader efforts. Several states (NY, MD, TX) are also pursuing P4O strategies.[10]

Discussion: P4O reduces the incentives in the FFS for increasing service volume. For example, under a straight FFS system multiple providers (hospital, nursing home, ambulance service) may all have a financial incentive for frequent hospital admissions. A pay-for-outcomes approach could reduce or eliminate that incentive and instead give hospital and nursing home incentive to collaborate to provide better ambulatory and urgent care in the nursing facility. One strength of P4O is that it can be applied in a FFS setting, although it can be used more broadly in integrated systems.

Limitations: As noted above, risk adjustment is a critical element of this strategy. In addition, financial sanctions under a P4O program provide an incentive for providers to improve care, but for those that are severely resource constrained, may not provide the means. Consumer advocates should consider P4O strategies that devote a portion of any savings generated to targeted quality improvement efforts in low-performing providers.

Bottom line: Targets a critical driver of low value spending by focusing financial incentives to reduce utilization of services that can be prevented by providing better care to begin with.

Initiative: Value Based Insurance Design (VBID)

What it is: VBID differs from other price incentive strategies in that it isn't about increasing cost-sharing per se but about varying cost sharing to reduce utilization of low value care while removing financial barriers to accessing high value services, particularly to those necessary to manage chronic conditions.

Drivers it addresses: Poor quality by discouraging use of services with questionable or minimal clinical benefit while encouraging appropriate utilization.

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10 Miller, Michael, and Katherine Howitt. *Better Care at Lower Cost An Approach to Reduce Federal Health Spending by Paying for Outcomes*. Rep. Community Catalyst, Jan. 2013.

Impact on vulnerable populations: Potentially beneficial to people with chronic conditions. There is some evidence that, relative to more traditional cost-sharing, VBID can reduce health disparities. Depending on how cost-sharing is designed, financial barriers to those services deemed "low (or lower) value" could be substantial particularly for lower income populations.

Consumer empowerment: Pretty much neutral

What does the research say: Available evidence suggests that VBID can effectively reduce barriers to services needed to better manage chronic conditions. Its overall impact on cost is less clear.[11] At least in the context of prescription drugs, VBID has been shown to be most effective when it is targeted to people with chronic conditions and where there is a substantial reduction or elimination of cost sharing.

Discussion: VBID is a relatively new and rapidly evolving approach to insurance design. Most of the work done to date has focused on prescription drugs where cost-sharing reductions have been shown to improve medication adherence. A lot more work needs to be done in order to apply VBID concepts more broadly. It is also clear that not everything labeled "VBID" is equally effective (or equally benign).

Limitations: Within the framework of the ACA, in order for plans to remain within their actuarial tiers, reductions in cost sharing for some services must be offset with increases for others. Challenges remain in identifying those low-value services that should be subject to higher cost sharing.

Bottom line: VBID can be an attractive alternative to more "blunt instrument" cost-sharing approaches. The success of VBID initiatives offers a challenge to insurers who have tended to put medications for managing expensive conditions into the highest cost-sharing tiers. But because there is still much that we don't know about optimal benefit design, it is important to accompany VBID initiatives with strong oversight. Carriers that want to experiment with VBID should be required to submit benefit designs for a public hearing prior to approval for sale to give consumer advocates a chance to assess plans to ensure they are not imposing undue burdens on lower-income groups or advantaging certain groups while discriminating against others.

11 "Value-Based Insurance Design." National Conference of State Legislatures, Feb. 2014.

Appendix C

DISCUSSION GUIDE FOR FOCUS GROUPS WITH CONSUMER HEALTH ADVOCATES

1. What were your motivations for getting involved in health system transformation issues?

2. What are the challenges and opportunities of engaging constituencies that you are organizing in health system transformation issues?

3. What are the challenges or opportunities of engaging with other stakeholders?

4. What do you consider as "low hanging fruit" in advocacy work on health system transformation issues?

5. If you had funding, what would you actually do with it to move health system transformation forward from a consumer perspective?

Appendix D

DISCUSSION GUIDE FOR INTERVIEWS TO ASSESS STAKEHOLDER DYNAMICS

1. What are your priorities for delivery reform and payment reform?
   a. What do you see as the current and developing trends in delivery reform and payment reform? Do you like them? If not, where should we be heading instead?
   b. Where would you like to see delivery reform and payment reform in the next 10 years?
   c. What are the barriers to moving your priorities forward?

2. In what ways are you allied with other stakeholders, both internal and external to your sector?

3. What is the capacity of federal and state governments to "step it up" on delivery reform and payment reform, and what are the critical politics at play?

4. Have consumer advocates been involved in delivery reform and payment reform?
   a. If so, how have they been helpful?
   b. If not, how would it be helpful to have them involved?

Appendix E

DISCUSSION GUIDE FOR INTERVIEWS WITH FOUNDATION STAFF AND POLICYMAKERS

1. What health system transformation initiatives are moving in X STATE?

2. Describe consumer involvement in health system transformation issues in X STATE.

3. What has been effective in regard to how consumers and communities get engaged? What has been challenging?

4. Looking forward – what role would you like to see consumers play, and what role do they need to play to move forward meaningful health system transformation?

5. What will consumers need to engage in Health System Transformation?

Appendix F

COMMUNITY CATALYST HEALTH SYSTEM TRANSFORMATION SURVEY TOOL

1. Survey Introduction

Community Catalyst is undertaking a project to gain an understanding of consumer engagement in health system transformation initiatives (delivery system reform, payment reform, and other initiatives that aim to improve the way health care is delivered and paid for). The information collected in this survey will be shared with participants and may be helpful in thinking about approaches for expanding and improving your health system transformation advocacy strategies.

This survey takes approximately 30-45 minutes. We are asking you to answer each question based on your understanding of how the "system of advocacy" in your state is engaging in these issues. In other words, we are asking you to answer, as best as you can, the questions as they pertain to your organization and the advocacy community. For example, we know that in many states, consumer advocacy organizations divide up participation among various state task forces/advisory groups and then collaborate to develop a shared position.

The survey will ask for your name, the name of your organization, and your state. Community Catalyst staff members are the only people that will have access to this information and no organization or individual will be identified in the study findings.

Instructions
A question with an asterisk next to it indicates that you must answer that question before the survey will allow you to proceed. We feel that the questions that require a response are essential for our understanding of consumer engagement in health system transformation initiatives.

Your responses for a page are saved when you move on to 'next' page; until you do that your responses for that page are not saved. If you cannot complete the survey in one sitting, you will be allowed to go back into the survey and pick up at the page you left off. Please do not clear your cookies. The link MUST be accessed on the same browser.

Once again, thank you for your time on this, and if you have any questions please contact Angela Jenkins at Community Catalyst (ajenkins@communitycatalyst.org)

2. Contact Information

Thank you for filling out the following information. We will be using this contact information for any follow-up and to send you the final report and survey results.

*1. Please provide your name, title and organizational contact information.

Name	
Organization	
Title	
State	
Phone Number	
E-mail	

3. Tell us about your organization and your collaborating partners

*2. What services does your organization provide? Check all that apply.

- ☐ Community Based Organizing/Mobilizing
- ☐ Direct Service
- ☐ Policy Advocacy/Lobbying
- ☐ Legal Services
- ☐ Research
- ☐ Other (please specify)

*3. Which of the following types of organizations are active collaborators in your health advocacy work, in general. Check all that apply.

- ☐ Faith-based
- ☐ LGBT
- ☐ AIDS/HIV
- ☐ Seniors
- ☐ Disability
- ☐ Children
- ☐ Communities of Color

- ☐ Behavioral Health/Substance Use Disorders
- ☐ Legal Services
- ☐ Community Health Centers
- ☐ Rural Organizations
- ☐ Public Health Advocates
- ☐ Public Health Departments
- ☐ Disease-Specific Organizations

Other (please specify)

4. Consumer Engagement in Health System Transformation

*4. What health system transformation initiatives (ie. policies or systems changes) are developing in your state, and how are consumers or consumer advocates engaged in each initiative?

	Not Developing	Developing, but consumers are not engaged	Developing, and consumers are somewhat engaged	Developing, and consumers are very engaged	Developing, and consumer-initiated	Don't Know
Medicaid Managed Care	○	○	○	○	○	○
Dual Eligible Demonstration Projects	○	○	○	○	○	○
Behavioral Health/Substance Use Disorders Reforms	○	○	○	○	○	○
Accountable Care Organizations	○	○	○	○	○	○
Center for Medicare and Medicaid Innovation State Innovation Models Initiative	○	○	○	○	○	○
Medicaid Payment Reforms	○	○	○	○	○	○
Medical Homes	○	○	○	○	○	○
Health Equity Initiatives (such as Race, Ethnicity, Language data collection)	○	○	○	○	○	○
Balancing Incentive Program	○	○	○	○	○	○
Community Benefits/Community Health Needs Assessments	○	○	○	○	○	○
Rate Review	○	○	○	○	○	○
Scope of Practice Laws	○	○	○	○	○	○
Statewide/county-wide Public Health Initiatives (obesity prevention, tobacco control, built environment, etc.)	○	○	○	○	○	○
Public Reporting Initiatives (quality)	○	○	○	○	○	○
Long-term Care (and caregiver) initiatives	○	○	○	○	○	○
Quality Initiatives Related to Health Information Exchanges	○	○	○	○	○	○

Please note if there are other policies or systems changes (such as any state-specific commissions, task forces, state-initiated restructuring such as Oregon's Coordinated Care Organizations) moving in your state and how you would classify consumer engagment on each issue.

5. Which, if any, of the following advisory or decision-making tables do you or your coalition partners sit on?

	Governance Boards	Advisory Groups	Regular Meetings	Periodic Meetings	Other (please specify below)
Medicaid	☐	☐	☐	☐	☐
Exchange	☐	☐	☐	☐	☐
Children's Health Insurance Program	☐	☐	☐	☐	☐
Centers for Medicare and Medicaid Innovation State Innovation Models	☐	☐	☐	☐	☐
Duals Demonstration Projects	☐	☐	☐	☐	☐
Health Equity Initiatives	☐	☐	☐	☐	☐
Health Departments	☐	☐	☐	☐	☐
Divisions of Insurance	☐	☐	☐	☐	☐
Medical Homes	☐	☐	☐	☐	☐

Other (please specify below)

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5. Advancing Health Equity

6. Are you or your coalition partners addressing any of the following health system transformation initiatives in your state as a way to advance health equity? Check all that apply.

☐ Data collection

☐ Cultural competence standards for providers and/or health plans

☐ Language access standards for providers and/or health plans

☐ Requiring diverse consumer advisory boards for plans

☐ Nondiscrimination provisions

☐ Network adequacy

Other (please specify)

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6. Policy Analysis and Avocacy

7. Which organizations do you currently rely on for support and/or information related to health system transformation issues? Check all that apply.

- [ ] AARP
- [ ] Center on Budget and Policy Priorities
- [ ] Center for Health Care Strategies
- [ ] Commonwealth Fund
- [ ] Community Catalyst
- [ ] Families USA
- [ ] Local Policy Expert (please specify in the comment section below)
- [ ] National Academy for State Health Policy
- [ ] National Program for Women and Families
- [ ] Robert Wood Johnson Foundation
- [ ] State Policy Institute (please specify in the comment section below)

Other (please specify)

[text field]

8. In which of the following policy areas do you need support? Choose your top three.

- [ ] Delivery System Reform
- [ ] Payment Reform
- [ ] Hospital Payment
- [ ] Prescription Drug
- [ ] Models of Care for the Dual Eligible Population
- [ ] Integrating behavioral health and substance use disorders
- [ ] Risk Adjustment
- [ ] Private Insurance Reforms
- [ ] Consumer Friendly Principles for transforming the health system
- [ ] Consumer approved digest for best practices for delivery reform
- [ ] Policy options for expanding population health initiatives
- [ ] Accountable Care Organizations
- [ ] Medicaid Managed Care
- [ ] Medical Homes

Other (please specify)

[text field]

8. In which of the following policy areas do you need support? Choose your top three.

- [ ] Delivery System Reform
- [ ] Payment Reform
- [ ] Hospital Payment
- [ ] Prescription Drug
- [ ] Models of Care for the Dual Eligible Population
- [ ] Integrating behavioral health and substance use disorders
- [ ] Risk Adjustment
- [ ] Private Insurance Reforms
- [ ] Consumer Friendly Principles for transforming the health system
- [ ] Consumer approved digest for best practices for delivery reform
- [ ] Policy options for expanding population health initiatives
- [ ] Accountable Care Organizations
- [ ] Medicaid Managed Care
- [ ] Medical Homes

Other (please specify)

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*9. What do you need to be effective in the policy advocacy areas you selected? Choose your top three.

- [ ] A training on or overview of health system transformation issues
- [ ] Consumer-friendly principles for transforming the health system
- [ ] Consumer-approved digest for best practices for health system transformation
- [ ] Issue briefs
- [ ] Talking points
- [ ] Strategies for building or strengthening stakeholder collaboration on health system transformation initiatives
- [ ] Ability to interact with advocates from other states working on similar issues

Other (please specify)

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7. Communications

*10. How frequently are health system transformation issues being covered in your local and state media outlets?

	Never	Rarely	Sometimes	Frequently	don't know
Blogs	○	○	○	○	○
Radio Stations	○	○	○	○	○
Social Media	○	○	○	○	○
Newspaper	○	○	○	○	○
Television News Stations	○	○	○	○	○

Other (please specify)

*11. Who is quoted on health system transformation issues in the media and how frequently?

	Never	Rarely	Sometimes	Frequently	Don't Know
Consumers	○	○	○	○	○
Hospitals	○	○	○	○	○
Doctors	○	○	○	○	○
Insurance Plans	○	○	○	○	○
Medicaid Directors	○	○	○	○	○
Executive Branch	○	○	○	○	○
Legislators	○	○	○	○	○
Business/employers	○	○	○	○	○
Labor Unions	○	○	○	○	○
LTSS Providers	○	○	○	○	○
Local, State or Federal Government	○	○	○	○	○
Don't Know	○	○	○	○	○

Other (please specify)

∗12. What are the top three substantive issues related to health system transformation that get discussed in state and local media coverage?

☐ High Costs

☐ Poor Quality of Care

☐ State Budget

☐ Affordability for consumers

☐ Affordability for business

☐ Innovation

☐ Creating efficiencies

☐ Waste

☐ Blaming consumers

☐ Don't know

Other (please specify)

[text box]
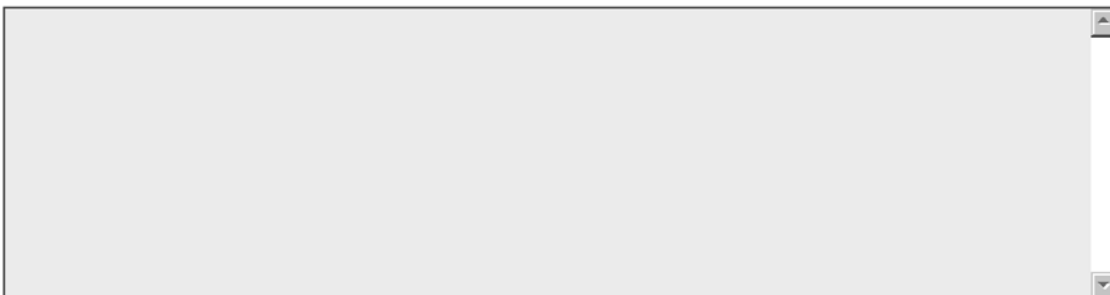
∗13. What are your top three needs around communicating the issue of health system transformation in local and state media?

☐ Research on how to talk to the public about these issues

☐ Messaging Strategies

☐ Constituency-specific messaging (ie. seniors, parents)

☐ Strategies to get media attention on this issues

☐ Strategies for the consumer voice to be recognized as valuable

☐ People need materials to use at the grassroots level and with advocacy organizations

☐ Storybanking around delivery reform

☐ Materials and talking points on good pro-consumer models

☐ Strategies for pushing back against bad ideas or cuts

☐ Research on how specific constituencies respond to health systems change that can inform messaging

Other (please specify)

[text box]

＊14. Which consumer advocacy groups have the expertise needed to work on health system transformation issues? Check all that apply.

- [ ] Faith-based organizing groups
- [ ] Legal Services
- [ ] Kids groups
- [ ] Senior groups
- [ ] Health Advocacy Groups
- [ ] Disability Groups
- [ ] Organizations of Color
- [ ] Disease groups
- [ ] AIDS/HIV groups
- [ ] Veterans
- [ ] Don't know

Other (please specify)

[text box]

＊15. What are the top three challenges for engaging in health system transformation initiatives for your consumer advocacy coalition?

- [ ] Political Environment
- [ ] Time
- [ ] Disagreements within consumer coalitions
- [ ] Lack of policy/technical knowledge
- [ ] Consumers not invited to the stakeholder table
- [ ] Policymakers don't understand the issue
- [ ] Lack of proactive agenda
- [ ] Need to defend against bad proposals
- [ ] Too difficult to mobilize people around
- [ ] Lack of dedicated funding for this work

Other (please specify)

[text box]

✱16. Do consumer advocates have any working relationships or funding arrangements with any of the following stakeholder groups on health system transformation? Check all that apply and select the level of collaboration?

	None	Periodic/issue specific	Ongoing, but informal partnership	Formal Collaboration	Don't Know
Health Centers	○	○	○	○	○
Nonprofit Medicaid Health Plans	○	○	○	○	○
Health Plans (in general)	○	○	○	○	○
Hospital Associations	○	○	○	○	○
Individual Hospitals	○	○	○	○	○
Behavioral Health (including Substance Use Disorders) Providers	○	○	○	○	○
Public Health Officials (local or state)	○	○	○	○	○
Medical Societies	○	○	○	○	○
Individual Practices or Physicians	○	○	○	○	○
Employers	○	○	○	○	○
State Employee Benefit Plans	○	○	○	○	○
Pharmaceutical Companies	○	○	○	○	○
Organized labor	○	○	○	○	○
LTSS providers	○	○	○	○	○
Medicaid directors	○	○	○	○	○
Legislators or legislative staff	○	○	○	○	○
Government officials or agencies	○	○	○	○	○
Other provider associations	○	○	○	○	○
Mid-level providers such as physician assistants, dental therapists, etc.	○	○	○	○	○
Employers	○	○	○	○	○

Other (please specify)

[text box]

✳17. What are the top three challenges for building and maintaining stakeholder alliances on health system transformation issues?

☐ Overcoming a history of differing positions

☐ Stakeholders don't see consumers as adding value

☐ Lack of knowledge on the advocacy side to be at stakeholder tables or engage in conversations

☐ Cannot bring a consumer constituency into the dialogue

☐ Time and capacity to build and maintain relationships

☐ Finding internal allies within stakeholder groups

Other (please specify)

[text box]

9. Grassroots Organizing

18. Which, if any, specific grassroots constituencies have been engaged in health system transformation and how?

	Governance boards	Hospital Community Benefits	Involvement in local ACOs or health plans	Sharing stories with media and/or policy makers	Other (please specify below)
Seniors	☐	☐	☐	☐	☐
Low-income seniors	☐	☐	☐	☐	☐
Low-income families	☐	☐	☐	☐	☐
People with disabilities	☐	☐	☐	☐	☐
People with specific chronic diseases	☐	☐	☐	☐	☐
People with mental health problems or substance use disorders	☐	☐	☐	☐	☐
Communities of Color	☐	☐	☐	☐	☐
Rural populations	☐	☐	☐	☐	☐
LGBT populations	☐	☐	☐	☐	☐
Faith-based communities	☐	☐	☐	☐	☐

Other (please specify)

[text box]

19. What are the barriers to engagement for those grassroots constituencies that have not been engaged in health system transformation?

*20. What resources would be most helpful to build grassroots engagement on health system transformation issues? Choose your top three.

☐ Training for consumer representatives in advisory roles

☐ Training on conducting listening sessions or focus groups

☐ Constituency-specific materials and talking points

☐ Tools and models to help plans and providers structure consumer engagement

☐ Storybanking around delivery reform

☐ Ladder of engagement/building community leadership

☐ Additional grassroots organizing capacity

Other (please specify)

10. Fundraising and Resource Development

*21. Have you and/or your consumer advocacy partners had (over the past two years) or do you currently have funding explicitly for health system transformation initiatives? If so, for what purposes?
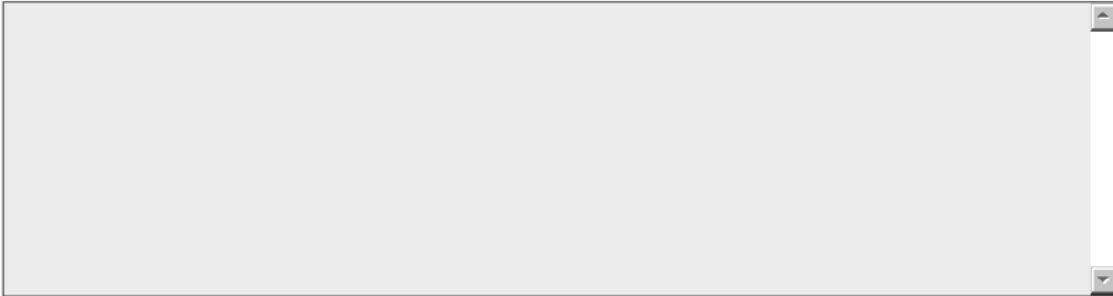
22. If you have tried to get funding for this work what have been the barriers? What have been the opportunities?

11. Closing

*23. What role, if any, do national groups/organizations play in influencing state policy-making related to health system transformation initiatives? Identify the strengths and weakness of those national influences?

24. Is there anything that you have not been asked in this survey that you would like to add?

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