Consumer Voices for Innovation

Grant Program Evaluation
Year 1 - Interim Report

Prepared by the Institute for Community Health
for the Center for Consumer Engagement in Health Innovation

June 2018

CENTER FOR CONSUMER ENGAGEMENT
in health innovation
A better way to better health. For everyone.

Prepared by the **Institute for Community Health**.

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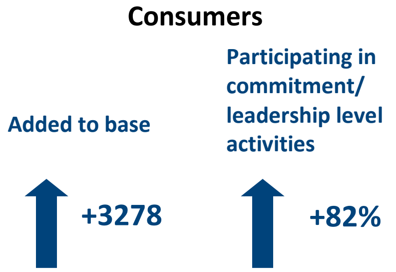
EXECUTIVE SUMMARY

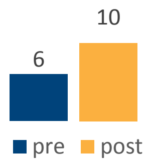
Increasingly, policy and health system leaders recognize the importance of engaging consumers in health care system design and implementation.[1] Despite emerging consensus on the evidence, there remains uncertainty about the best strategies to accomplish this.[2] To better understand the most effective strategies for engagement, in 2017 Community Catalyst launched the Consumer Voices for Innovation (CVI) Grant program, which funded 6 state health advocacy organizations to catalyze grassroots organizing and base building in health system transformation (HST). The program focused on consumers who have presented particular challenges for engagement: people from low-income communities, people of color, and/or older adults. Grantees used a wide variety of strategies to engage consumers, including broad-reaching techniques (e.g., advertising in local media), smaller-scale strategies (e.g., house parties) and outreach via service provision (e.g., providing care coordination). Each grantee also received technical assistance (TA), mentorship and group learning opportunities.



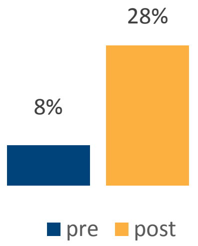
The Institute for Community Health (ICH) conducted a mixed methods evaluation, using grantee surveys and interviews, a consumer survey, conversations with CVI staff, and review of quarterly reports and TA tracking. The evaluation provides evidence that the CVI program is making progress toward increasing grantee capacity to build an engaged consumer base. Grantees made progress in developing capacities for mobilizing and organizing at the grassroots level, gaining visibility, recruiting volunteers, establishing credibility and training leaders. Over 3,200 consumers were added to the base. The number of consumers participating in activities consistent with participation, and commitment/ leadership increased. Consumers also reported increases in their leadership skills and their sense of their own power to be involved in HST.

Although grantees reported starting with high levels of engagement with decision-makers, there was evidence that engagement with decision-makers further increased over the course of the grant, and that decision-makers increased their incorporation of consumer experience into health policies and practice. While it is too early to understand the full impacts of this effort, grantees reported a range of positive impacts, from increased consumer and grantee influence at the state and local level, to legislative wins or changes in state processes, to helping defend the ACA and Medicaid.

Top 2 decision-makers meeting grantees ≥ every 2 months (n=10)



Target communities for which grantees report 'Very Strong' capacity to mobilize base



Overall, the evaluation findings are promising, and highlight a range of positive outcomes. The evaluation data also suggest areas for focus of the technical assistance and supports for the second grant year. Grantees will benefit from support in understanding how to most effectively build relationships with consumers, and how to connect individual consumers' experience to the bigger policy picture, in order to get consumers more meaningfully engaged, particularly as leaders. Continued supports to help grantees best leverage connections with individuals of relevant professional backgrounds and points of contact with decision-makers will maximize impact. Finally, the evaluation data point to the need for continued investment and ongoing support for engaging consumers in HST. The evaluation of the second year will be an opportunity to build upon the findings presented here, with the ultimate aim of creating a deep and nuanced understanding of how best to support consumer advocacy organizations in engaging consumers in HST efforts.

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[1] Jacobs LM *et al*. Journal for Health Care Quality; 2018. http://europepmc.org/abstract/med/28786845.

[2] Frampton SB, *et al*: National Academy of Medicine; 2017. https://nam.edu/wp-content/uploads/2017/01/Harnessing-Evidence-and-Experience-to-Change-Culture-A-Guiding-Framework-for-Patient-and-Family-Engaged-Care.pdf

BACKGROUND

Increasingly, policy and health system leaders recognize the importance of engaging consumers in health care system design and implementation.[3] Despite emerging consensus on the evidence, there remains uncertainty about the best strategies for engagement,[4] particularly for engaging consumers from low-income communities, communities of color and/or older adults. To better understand the most effective strategies for engagement, Community Catalyst's Center for Consumer Engagement in Health Innovation (hereafter, 'Center') launched the Consumer Voices for Innovation (CVI) Grant program in 2017.

The CVI program is an innovative effort to catalyze grassroots organizing and base building in health system transformation (HST). The goal of the program is to support organizations' state or regional efforts to build an engaged base of consumers in order to permanently strengthen their capacity to engage consumers in HST. Over the long term, the goal is to foster consumer activism in health advocacy, especially in low-income communities, communities of color, and/or communities of older adults. The initial year, the first of two one-year cycles, coincided with a significant shift in politics in the United States, with multiple national efforts to repeal, reduce or defund the Affordable Care Act (ACA).

Table 1. Consumer Voices for Innovation 2017 grantees

Grantee	Program objectives
Maryland Citizens' Health Initiative Education Fund	Working to expand the Faith Health Network which uses lay leaders to help support fellow congregants' needs during hospitalizations and post-discharge.
The TakeAction Minnesota Education Fund	Organizing grassroots consumers and advocacy organizations around defending and improving the transparency and effectiveness of Minnesota's successful Medicaid innovations to better reflect the needs of consumers.
Make the Road New York (MRNY)	Organizing grassroots participation in a Performing Provider System to be more responsive to community needs and to increase the role of community health workers.
Oregon State Public Interest Group (OSPIRG) - Unite Oregon - Oregon Latino Health Coalition (OLHC)	Organizing grassroots participation in Coordinated Care Organizations (CCOs) in southern Oregon and aiming to increase the influence of consumers and focus on addressing social determinants of health in the CCO.
Pennsylvania Health Access Network (PHAN)	Organizing consumers affected by the rollout of managed long-term services and supports in Pennsylvania's Medicaid program, with a focus on mobilizing seniors.
Rhode Island Organizing Project (RIOP)	Working to engage dual eligible individuals in the Rhode Island duals demonstration by advocating for more person-centered approaches, working to increase consumer engagement in the demonstration and improving transportation for low-income consumers.

CVI funded 6 grantees across the United States (Table 1). Each grantee was also supported by the Center through ongoing technical assistance, the Leadership in Action program and group learning opportunities. Technical assistance targeted six capacity areas: campaign development, communications, policy analysis and advocacy, resource development, coalition and stakeholder alliances, and grassroots organizing. In the Leadership in Action program, the Center matched each grantee with a Senior Leader, recruited for their experience in a specific aspect of HST (such as knowledge of health plan finance, hospital operations, or policy). Finally, the Center provided group learning activities (such as learning community calls and in-person meetings with other grantees). The six

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[3] Jacobs LM *et al*. Journal for Health Care Quality; 2018. http://europepmc.org/abstract/med/28786845.

[4] Frampton SB, *et al*: National Academy of Medicine; 2017. https://nam.edu/wp-content/uploads/2017/01/Harnessing-Evidence-and-Experience-to-Change-Culture-A-Guiding-Framework-for-Patient-and-Family-Engaged-Care.pdf

grantees started at different stages of organizing for HST; while some had significant experience with HST organizing, some were embarking on organizing for HST for the first time.

EVALUATION OVERVIEW

The Institute for Community Health (ICH) was the evaluation partner for the grant program. ICH began by reviewing relevant background documents, and proceeded to collaboratively develop a framework for the evaluation through the creation of a logic model (Appendix A). This framework reflects the Center's approach to consumer engagement, understood as a pyramid of five dynamic levels of engagement.[5]

These formative activities led to the following key evaluation questions:

- How many consumers (particularly from low-income communities, communities of color, and older adults) were engaged through grantee initiatives?
- Did consumers become more meaningfully engaged as a result of grantee initiatives?
- What aspects of the consumer engagement strategy were most effective at encouraging and supporting consumer engagement?
- How did policies, programs, or practices change in some states as a result of consumer engagement and action?

To answer these questions, ICH engaged in four broad evaluation activities as outlined in Table 2.[6]

Table 2. Overview of evaluation activities

Activity*	Goal	Participants
Grantee survey (baseline and 1-year follow-up)	Assess changes in the size of the consumer base, depth of consumer engagement, grantee capacity, relationship with decision-makers, and grantee perceptions of changes in decision-maker understanding	5 grantees
Stakeholder interviews	Deepen understanding of grantees' grassroots organizing efforts, successes, challenges and lessons learned	1-2 staff members from each grantee (10 individuals)
Consumer survey	Understand activities consumers participated in; identify best practices for effective engagement strategies from the consumers' perspective	Consumers from each state (112 consumers)
Review of grantees' quarterly reports and Centers' technical assistance tracking	Summarize key points about grantees' progress and impacts; understand program implementation activities such as types of technical assistance provided	Grantees, Center staff

** Tools are available in the appendix.*

FINDINGS: PROGRAM IMPLEMENTATION

Understanding of the program's implementation draws upon learning from Center staff (e.g., technical assistance tracking) and grantee descriptions in reporting, surveys and interviews. We focus on the two key activities of the program - technical assistance (TA) and Leadership in Action – as well as key activities undertaken by grantees.

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[5] Community Catalyst Pyramid of Engagement. https://www.communitycatalyst.org/resources/tools/pyramid-of-engagement

[6] One grantee was not expected to continue into the second year; during the first year, this grantee submitted quarterly reports and participated in the qualitative interviews, however, they did not complete the follow-up grantee survey or administer the consumer survey.

Technical Assistance: The Center's State Advocacy Managers (SAMs) conducted regular TA check-ins with grantees at least once per month and more frequently upon request, mostly by telephone, and tracked capacity areas addressed during these calls. Overall, the most frequently addressed capacity area was policy analysis and advocacy, which was addressed in 43/55 contacts. This is followed by grassroots organizing, addressed in 33/55 contacts, and coalition and stakeholder alliance, addressed in 21/55 contacts. Specific topics addressed varied widely according to the specific needs of the grantee.

Table 3. Capacity areas addressed (n=55)

Capacity Area	Example	Number / %
Policy analysis & advocacy	Updates on the larger legislative picture, particularly the national legislative context, and lessons from other states attempting similar delivery reform initiatives	43/ 78%
Grassroots organizing	Developing questions for a consumer focus group on HST	33/ 60%
Coalition & stakeholder alliance	Strategies for working in coalition with other organizations, including approaches and troubleshooting of relationships.	21/ 38%
Resource development	Provided insight on foundation funder priorities	16/ 29%
Communications	Messaging, testimony, and "asks" in advocacy work	8/ 15%
Campaign	Discussion of bigger-picture organizing strategy	8/ 15%
Other (e.g., evaluation, organizational development)	Provided guidance on accessing and improving training programs	8/ 15%

Grantees found this TA to be helpful. For example, one grantee commented: "*Honestly, [the Center] does a great job supporting us now. Continuing to share best practices, policy updates and information relevant to our work, and gentle reminders about deadlines are always helpful.*"

Leadership in Action: Although we did not query specifically about LIA mentors, several grantees volunteered that this program was "very helpful". These mentors provided various forms of assistance to grantees, including strategic introductions to particular power brokers; knowledge of specific policies, standards, or contracts and their implications; help with messaging and crafting specific messages such as requests for funds; and even serving as a speaker at one grantee event.

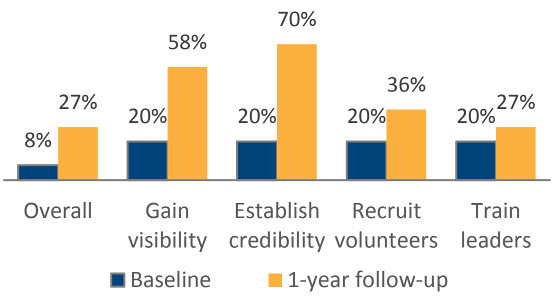
Grantee Activities: Over the course of the first grant year, grantees conducted a wide variety of activities as they attempted to reach out to consumers, engage consumers around HST issues, deepen consumers' engagement, and develop consumers' leadership skills around these issues. Beginning with the most broad-reaching techniques, grantees conducted outreach using local, trusted media sources, organized large events such as educational forums, spoke at events organized by others such as conferences or religious gatherings, and tabled in places frequented by the populations of interest. Smaller-scale but more intensive strategies included holding workshops, meetings and house parties. Several grantees were able to do outreach via service provision, such as outreach through community health workers, assisting individuals in struggles with their personal health care coordination, and organizing a network connecting religious organizations with their congregants upon hospitalizations. Grantees also organized consumers to participate in direct actions, including making advocacy trips to Washington D.C. and state capitals, and attending hearings and rallies. For some grantees, unexpected and urgent efforts to defend the ACA and Medicaid diverted attention away from developing and mobilizing a consumer base around HST issues.

FINDINGS: PROGRAM IMPACT

CONSUMER ENGAGEMENT CAPACITY

At both baseline and the end of the first grant year, grantees reported on their self-assessed capacity within the following domains for each target community: (1) overall capacity for mobilizing and organizing a strong grassroots base of support for HST; (2) gaining visibility; (3) establishing credibility; (4) recruiting volunteers and (5) training leaders. For each capacity, we created a summary measure by summing the number of communities for which grantees reported very strong capacity and dividing that by the number of communities served (range of 10-13), thus giving us the proportion of communities for which grantees report having very strong capacity.

Figure 1. Grantees reporting Very Strong capacity to do the following in the target communities

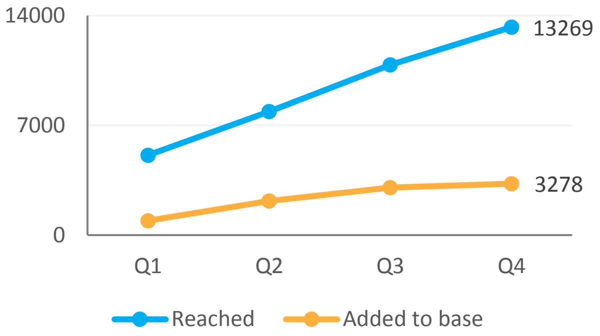


During the grant year, the proportion of communities for which grantees reported having very strong capacity increased across all capacity measures (Figure 1). Grantees reported the highest increases in their capacity to establish credibility and gain visibility. It should be noted that at baseline, grantees may have overestimated their capacity, as many had not yet started their HST efforts. In other words, before getting started, grantees may not have "known what they didn't know." This would lead us to underestimate the true effect of the program. In addition, one grantee reported a change from strong to very strong capacity across all measures; while much of the increase is attributable to this grantee, this grantee does not account for all of the increase seen.

CHANGES IN CONSUMER BASE: SIZE OF BASE, DEPTH OF ENGAGEMENT AND CONSUMER LEADERSHIP SKILLS

Increased capacity was expected to lead to (1) an increased *size* of the consumer base, (2) increased numbers of consumers at every stage of engagement ('*depth of engagement*') and (3) increased *consumer leadership skills and power* to be involved in health policy and systems change.

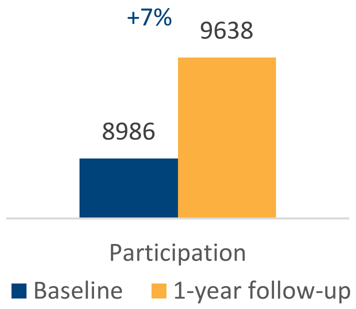
Figure 2. Number of consumers reached and added to the base



Increasing the size of the consumer base, particularly for target communities, was a key goal of this program. During the year, grantees reported making contact with a total of 13,269 new people during the grant year (for example via phone banking and knocking on the door) (Figure 2). As a result of this outreach, 3,278 consumers were added to the base (i.e., grantees obtained contact information and put that information in their database), as reported on grantee quarterly reports (Figure 2). This growth in consumer base was driven in large part by one grantee that added 37% (n=1233) of the consumers to the total base (range: 200-1233).

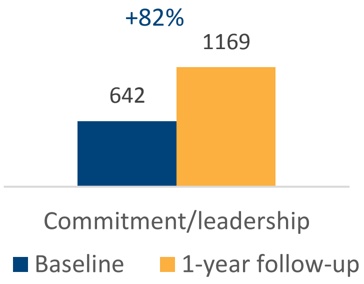
A separate data source, the consumer survey, provided evidence that grantees reached individuals in the target communities. Of survey respondents (n=112), 76% were a member of at least one of the target communities; 40% were non-White, 33% were very low income (defined as food insecure, homeless or unstably housed, and/or at risk of losing utilities such as electric, gas, water or oil), and 24% were 65+ years old.

Figure 3A. Number of consumers engaged at the stage of participation



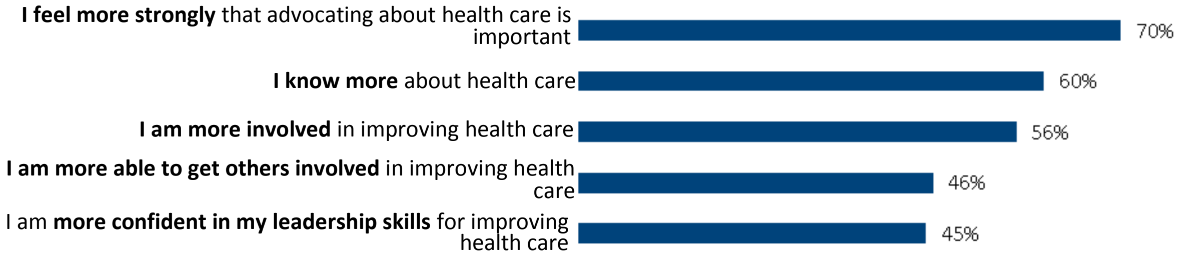
Depth of engagement is understood as five categories of increasing engagement from awareness, interest, participation, commitment to leadership.[7] Because increasing awareness and interest were not key goals of this program, we did not measure changes in awareness (i.e., having knowledge of an issue or cause) or interest (i.e., understanding the cause and being interested in learning more and perhaps participating**).** Reflecting the fact that in the initial year, the focus was to create a pipeline for leadership, we combined commitment and leadership for the purposes of our analysis. Changes in participation and commitment/leadership were measured by asking grantees to report the number of participants participating in activities that reflected the different stages of engagement at baseline and follow-up (see Appendix for individual questions). Grantees reported increases in the numbers of consumers engaging in activities consistent with participation (7% increase, Figure 3A), and commitment/leadership (82% increase, Figure 3B). The results of the consumer survey appeared to corroborate the observation that grantees were engaging consumers in a variety of activities that spanned all levels of engagement (see Figure 6 below).

Figure 3B. Number of consumers engaged at the stage of commitment/leadership



Consumers' leadership skills and empowerment to be involved in health policy and systems change was assessed by asking consumers if, compared to one year ago, they (1) knew more about health care, (2) felt more strongly that advocating about health care was important, (3) were more involved in improving health care, (4) were more able to get others involved in improving health care and (5) were more confident in their leadership skills. Forty-five to 70% of consumers reported they felt 'a lot more' able to perform these functions, with the highest gains in confidence in leadership skills for improving health care and ability to get others involved in health care. (Figure 4)

Figure 4. Consumers reporting that compared to one year ago they felt the following had changed "A lot more" (N=112)



DECISION-MAKER ENGAGEMENT AND UNDERSTANDING

We assessed changes in (1) engagement between grantees and decision-makers and (2) decision-makers' understanding of and incorporation of consumer perspectives in their work. In order to assess these outcomes, we asked grantees to answer questions about the top two decision-makers or decision-making groups (hereafter 'decision-maker') they were targeting. Grantees reported working with a broad range of decision-makers including leaders from state executive branches (n=4), health care systems (n=4), as well as state (n=1) and federal (n=1) legislative branches. In some cases, these were particular elected representatives; in others, they were organizations, such as a hospital association, a particular department within the state department of health, or a body that is in charge of implementation of Medicaid waivers. Notably, for several grantees, the identified decision-makers changed over the course of the year.

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[7] Community Catalyst Pyramid of Engagement. https://www.communitycatalyst.org/resources/tools/pyramid-of-engagement

Engagement between grantees and decision-makers was assessed by asking grantees to describe how often they had different types of interactions with decision-makers, including having meetings or phone calls, being contacted by decision-makers, and having decision-makers attend events. Reflecting the fact that many grantees were already engaged in HST work at the start of the grant, at baseline the majority (six of 10) reported meeting with or having phone calls with decision-makers at least every 2 months. Nonetheless, this contact increased during the course of the grant, with all grantees reporting these contacts at least every 2 months at follow-up.

There was no clear pattern of change in how often decision-makers contacted grantees. Being contacted by decision-makers likely reflects a later stage of engagement in which the grantee is seen as a go-to expert. At this stage of the grant, grantees were not yet expected to be go-to experts. Further, this may reflect the fact that at follow-up, several grantees were focusing on newer relationships with policy-makers, and may have not yet built trust to that degree.

The number of decision-makers attending grantee events at least every 2 months decreased from 4 to 2. The decrease in decision-makers attending events may be explained by grantees' decreased emphasis on large events at which a decision-maker's presence might be appropriate, as they increasingly understood that smaller-scale, high-touch strategies for consumer engagement were ultimately more successful when working in the HST space. Additionally, again, because several grantees changed the decision-makers they were focusing on and new decision-makers would be expected to be at an earlier stage in their relationships with grantees, decision-makers may have been less likely to attend events at the time of the 1-year follow-up survey.


Photo courtesy of Rhode Island Organizing Project

Decision-makers' understanding of and incorporation of consumer engagement were assessed by asking grantees how well they felt decision-makers (1) understood the goals of the grantees' work, (2) understood the importance of consumer engagement in HST and (3) incorporated consumer experience into health system policies and practice. At the beginning of the grant period, grantees reported that 7/10 decision-makers understood the goal of the grantees' work and 6/10 understood the importance of consumer engagement 'very well', leaving little room for improvement; indeed there was no clear pattern of change at 1-year follow-up.

In contrast, there was a modest pattern of increase in the way decision-makers incorporated consumer experience into health systems policies and practice. At baseline, grantees reported only 2/10 decision-makers incorporated consumer experience 'very well' and reported that 2/10 decision-makers incorporated consumer experience 'not at all'. At follow-up, 9/10 grantees reported decision-makers incorporated consumer experience at least 'poorly' and 3/10 reported this was occurring 'very well'. The modest nature of this change may reflect the early stage of the grant, and the time it may take to move decision-makers toward incorporating consumer experience into decision-making. Again, it may also reflect the fact that several grantees were focusing on new relationships with decision-makers.

BEST PRACTICES

CONSUMER OUTREACH AND ENGAGEMENT

A broad range of lessons learned emerged regarding best practices for consumer outreach and engagement. These lessons learned were gleaned from both the successes and challenges the grantees experienced.

Figure 5. Best practices for consumer outreach and engagement

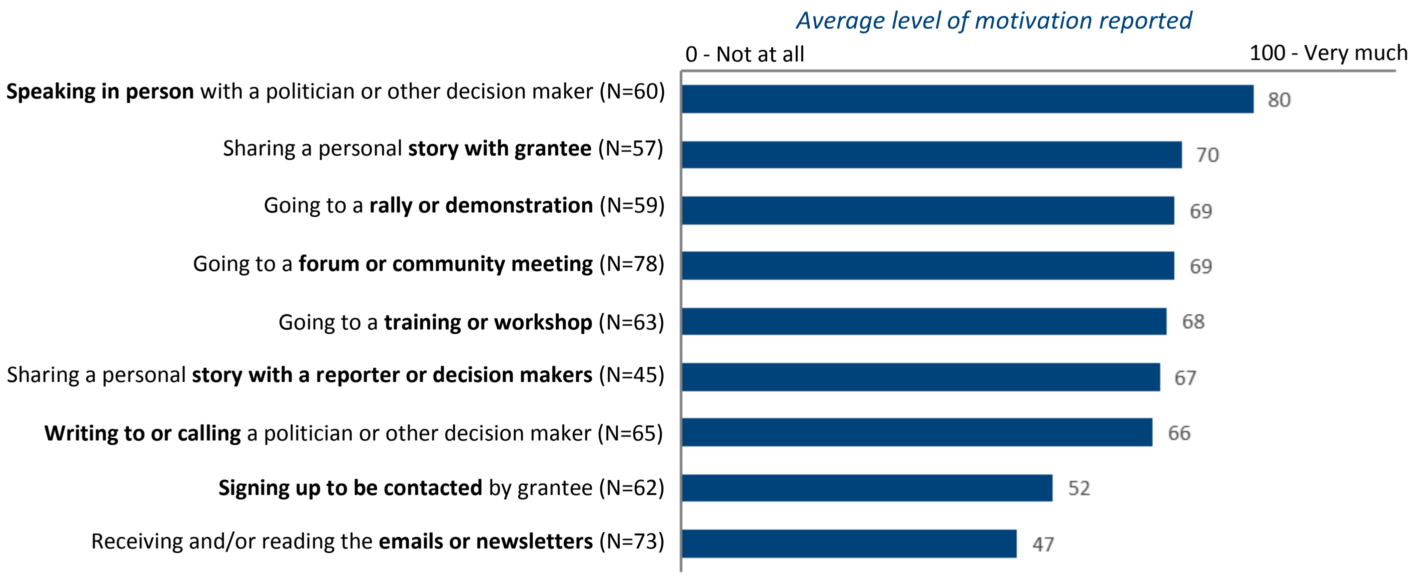
Focus on relationships and trust	• Partner with organizations that have trust and moral authority • Engage respected and trusted community leaders and members • Nurture individual relationships (work with consumers one-on-one)
Invest time and patience	• Health system transformation and policy takes time • Working with individuals takes time • Resources are needed to make these investments (time = money)
Build a bridge from individual experience to bigger picture	• Connect individual experience to bigger policy goals • Address concrete needs
Details and preparation are critical	• Prepare consumers prior to meetings • Ensure events incorporate consumers' perspectives and contributions • Address location, translation, meals, childcare, transportation

Focus on relationships and trust: One of the most frequently mentioned lessons learned was the importance of relationships and trust in consumer outreach and engagement – a lesson shared by grantees both in the interviews and in the 1-year follow-up survey. Grantees discussed the importance of partnering with organizations that have trust and "moral authority" in the target communities. For one grantee, "*partnering with organizations like the NAACP, churches, senior centers, and other institutions that serve and are trusted by each specific community*" was critical to engaging people from the target communities. Another important tactic was working with individuals who were already respected leaders in the target communities. Grantees used a mix of strategies for working with these individuals, including hiring them to be outreach workers and ensuring they attended community meetings. As one grantee noted, *"Recruiting respected, paid outreach consultants [organizers] from the target communities was very helpful."* This strategy helped grantees to expand their reach through using these individuals' personal networks to identify potential consumer advocates and other community leaders, and personalizing their recruitment strategy.

The importance of using strategies based on relationships and personal connections was echoed by consumers' responses to the consumer survey. Among the 112 consumer survey participants, the most common ways that people heard about the grantees were through personal interactions: either a friend or family member told them (n=21), or at a community meeting (n=22). The next most common was social media (n=10), email (n=10), or "someone talking to me in public" (n=10). Impersonal means of learning about the grantees were much less common: newspaper, radio or TV (n=6), website or newsletter (n=3), and phone call (n=1). In addition, consumers were asked to share the degree to which the activities they participated in motivated them to get more involved in improving health care. Among the most commonly attended activities, the most motivating activities were ones that provided the opportunity for speaking to, meeting with or sharing stories with others (Figure 6). In contrast, the least motivating activities conferred no personal contact with others (e.g., reading newsletters or emails).

> "*Working through trusted organizations and media sources, and, as we engage new leaders of color, new leaders who have lower incomes, and new older adult leaders, we ask them to help us deepen and make new connections in their community*" – 1-year follow-up survey respondent

Figure 6. Consumer report of level of motivation to get more involved in HST associated with participating in activities



Over the course of the grant period, grantees were increasingly appreciative of the importance of nurturing relationships. At baseline, grantees were asked “What activity or activities was / were most successful in adding to your base?” Responses focused on specific outreach strategies such as canvassing, clip-boarding, phone banks, meetings, and forums. At follow-up, grantees were asked to share successful strategies for finding and engaging the target communities. In contrast to their responses at baseline, grantees responses showed a strong focus on relationships with members of the target communities. Grantees found that meeting with consumers one-on-one was a high impact strategy. For example, one grantee highlighted the importance of *“Being accessible and investing the time in each individual relationship.”* That is, although grantees found that they could reach large numbers of people through big events or through canvassing, this relatively impersonal method made it more difficult to move to the next step and engage these people. Grantees learned that a much more effective way to do this is to draw people in by understanding an individual’s story and their complex motivations for becoming involved.

Invest time and patience: Grantees noted that change happens slowly, and that people attempting to do organizing work or creating change in policy should be prepared for “the long haul”. On the health system side, grantees observed that complex organizations like hospital systems change slowly, and that plans should be made accordingly. On the consumer side, engaging consumers requires being present in communities in the day-to-day interactions, approaching communities with an attitude of listening and learning (and not “barging in as the experts”), and in building relationships - which could span years. One grantee summarized the need for time by noting: *“Organizing is not a one-off thing. You can’t drop someone in for three months and expect to successfully build leadership in community relationships. It really does take a multi-year investment to do community organizing that actually leads to empowering communities to take on these issues.”* Grantees highlighted the need for ongoing investment of funds to support the investment of time needed for HST.

> *“…We have faith outreach consultants who will go and be there at the congregation, even though it can feel like an eternity sometimes, showing that level of commitment. And, you know, starting that relationship and doing that face-to-face, I think helps as you move forward.”*
> – Interview participant

Build a bridge from concrete needs to bigger-picture policy: Grantees described that HST is a relatively abstract, “wonky” topic around which to organize people. They found that they were able to be most successful when they were able to build a bridge between peoples’ concrete needs and the bigger policy picture.

> "*How can we give people a simple framework for understanding health system transformation issues that's kind of transferable to any of the subset of issues ... If you can switch on that HST light bulb, about what's that framework, how can we transfer this perspective to all of these different issues, I think that's really where the magic happens*." – Interview participant

"*Here's a service we can directly provide to you and your fellow congregants. And that gets people's attention… That opens the door to the liaisons being engaged in other things that we do. I think that that is really key*." – Interview participant

Grantees commonly made initial contact with people through helping them with their immediate needs. These needs included assistance to hospitalized congregants, health education and helping with casework issues (e.g. applications for services). While this strategy was an explicit part of some grantees' models, others came to employ this strategy over time as they recognized the importance of it. In addition to helping garner interest from consumers, this strategy helped teach the grantees about opportunities for advocacy.

> *"…we don't shy away from troubleshooting casework issues (helping people apply for LTSS, find Medicare counseling through APPRISE, work out an issue with their doctor, etc.) because they help build trust and teach us where systems are failing consumers."* –1-year follow-up survey

Finally, organizing around issues that feel urgent to consumers was a way to connect them with more policy-oriented work. During 2017, much activism energy was spent on resisting attempts to appeal the ACA. Some grantees experienced difficulty "channeling" that energy into further HST advocacy work, while others found that once people "came through the door" to resist the ACA repeals, they were able to get them engaged in HST work.

> *"…one of the things that has been really effective in organizing people around these issues, or at least getting people in the door to the point where they can start engaging with these issues, is actually the fight to defend the ACA and the kind of resistance to the federal agenda on health care. I think that's sparked a lot of grassroots interest and intensity that wouldn't necessarily have been there if we were in a different national environment… it has been a way of getting people to turn up for things"*
> – Interview participant

Details and preparation are critical: Grantees highlighted the importance of careful and deliberate planning in working with vulnerable populations. Preparing for events to fully incorporate consumers' contributions and experience was a challenge that grantees learned to be intentional around. As one grantee said:

> *"… figuring out what the best space is for [consumers] to come into, and how to elevate their voices in those spaces, and what needs to happen to really get them to be able to come to those spaces. From lots of small, logistical things including translation to larger things like making sure when meeting with them that they're prepared, that they understand the topic, to making sure the agenda's not too wonky, making sure we believe that one of our members' stories could set the tone for the event. Just really thinking through all of those things before just throwing someone into a meeting"* – Interview participant

Other grantees found that pre-event preparation and debriefing after the event were both important to supporting consumers. Finally, in working with vulnerable populations, the importance of logistical details was found to be magnified – holding events in non-English languages and in close proximity to the target communities, and providing language appropriate materials, childcare, a meal, or a transportation subsidy could all make a critical difference in the degree of consumer participation possible.

WORKING WITH DECISION-MAKERS

Though early in their work with decision-makers, grantees identified successful techniques they had used to help increase their influence with decision-makers. First, several found that serving on consumer advisory boards or other committees facilitated their contacts with decision-makers – they were able to find out about pending decisions in time to influence them, for example, and through the contacts made on these boards were invited to serve on other, more influential working groups. Second, grantees found that working closely with people with relevant professional backgrounds, either by hiring them or receiving mentorship from them, such as with the LIA mentors, helped facilitate their understanding of the relevant context and vocabulary of policy, and for getting introductions to influential people. Finally, one group found that co-sponsoring an event with an elected representative served their mutual interests – getting the representative more visibility and exposure, and getting the group some close contact with the representative.

IMPACTS


Photo courtesy of Make the Road New York

While it is too early to understand the full impacts of the CVI program, grantees reported a range of positive effects. These spanned a wide spectrum from increased consumer and grantee influence at the state and local level, to state legislative wins or changes in state processes, to helping defend the ACA and Medicaid. Increased consumer or grantee influence was exemplified by consumers joining meetings or workgroups, grantees receiving requests to help shape policies and regulations, and grantee representatives being appointed to serve on key decision-making boards and commissions. In most states, there were changes in state processes or laws. One state successfully defended and secured funding for a law providing free bus passes to 13,500 low-income seniors so that they would have access to transportation. A grantee in another state successfully advocated for a reduction in a budget cut. Other states noted changes in how workgroups functioned (e.g., agendas were newly made available to consumers ahead of time and time for consumer stories was newly created on agendas) or that workgroups included new members (e.g. one grantee was invited to join a state strategic advisory workgroup). Many of these impacts reflected an increased commitment by decision-makers to increase transparency and consumer education.

CONCLUSION

This evaluation utilized a range of data sources to examine CVI grantee experience with the TA and supports, as well as the impact of the program on a range of target outcomes. While there was variation among grantees in the type of TA needed, grantees found the TA and senior mentors through the Leadership in Action program to be very helpful.

Taken together, the outcomes data provide evidence that the CVI program has made progress toward building a base of engaged consumers, particularly from low-income communities, communities of color and older adults. Grantees made significant progress in developing capacities for mobilizing and organizing a strong grassroots base of support for HST, gaining visibility, recruiting volunteers, establishing credibility and training leaders. As a result of grantee activities, over 3,200 consumers were added to the base. Consumers became more meaningfully engaged in activities consistent with participation and commitment/leadership. At the same time, consumers who responded to a survey reported feeling that their leadership skills and power to be involved in health policy had increased, suggesting that grantees may be well poised to build leaders in the second year of the grant.

Although grantees reported starting with high levels of engagement with decision-makers, there was evidence that engagement with decision-makers increased over the course of the grant and that decision-makers increased their incorporation of consumer experience into health policies and practice. While it is too early to understand the full impacts of the program, grantees reported a range of positive effects that spanned a spectrum from increased consumer and grantee influence at the state and local level, to state legislative wins or changes in state processes, to helping defend the ACA and Medicaid. In fact, the full impact of the program on consumer engagement may not have been reached yet, given the effort many grantees diverted toward defending the ACA and Medicaid.


Photo courtesy of Pennsylvania Health Access Network

Overall, the combined quantitative and qualitative evaluation findings are promising, and highlight a range of positive outcomes that have been achieved over the grant period. In addition to these positive outcomes, the evaluation data suggest areas for focus of the TA and supports for the second year of the CVI program. In particular, grantees will benefit from support in understanding how to be most effective and efficient at building relationships and trust with consumers, and how to build connections from individual consumer experience to the bigger policy picture, in order to get consumers more meaningfully engaged and especially to build leaders. In addition, continued supports geared toward helping grantees to best leverage connections with individuals of relevant professional backgrounds (such as mentors in the Leadership in Action program) and points of contact with decision-makers will help maximize impact. Finally, the evaluation data point to the need for long-term investment and ongoing support for engaging consumers in HST.

The evaluation of the second year of the CVI program will be an opportunity to build upon the findings presented here, with the ultimate aim of creating a deep and nuanced understanding of how best to support consumer advocacy organizations in engaging consumers in health system transformation efforts.

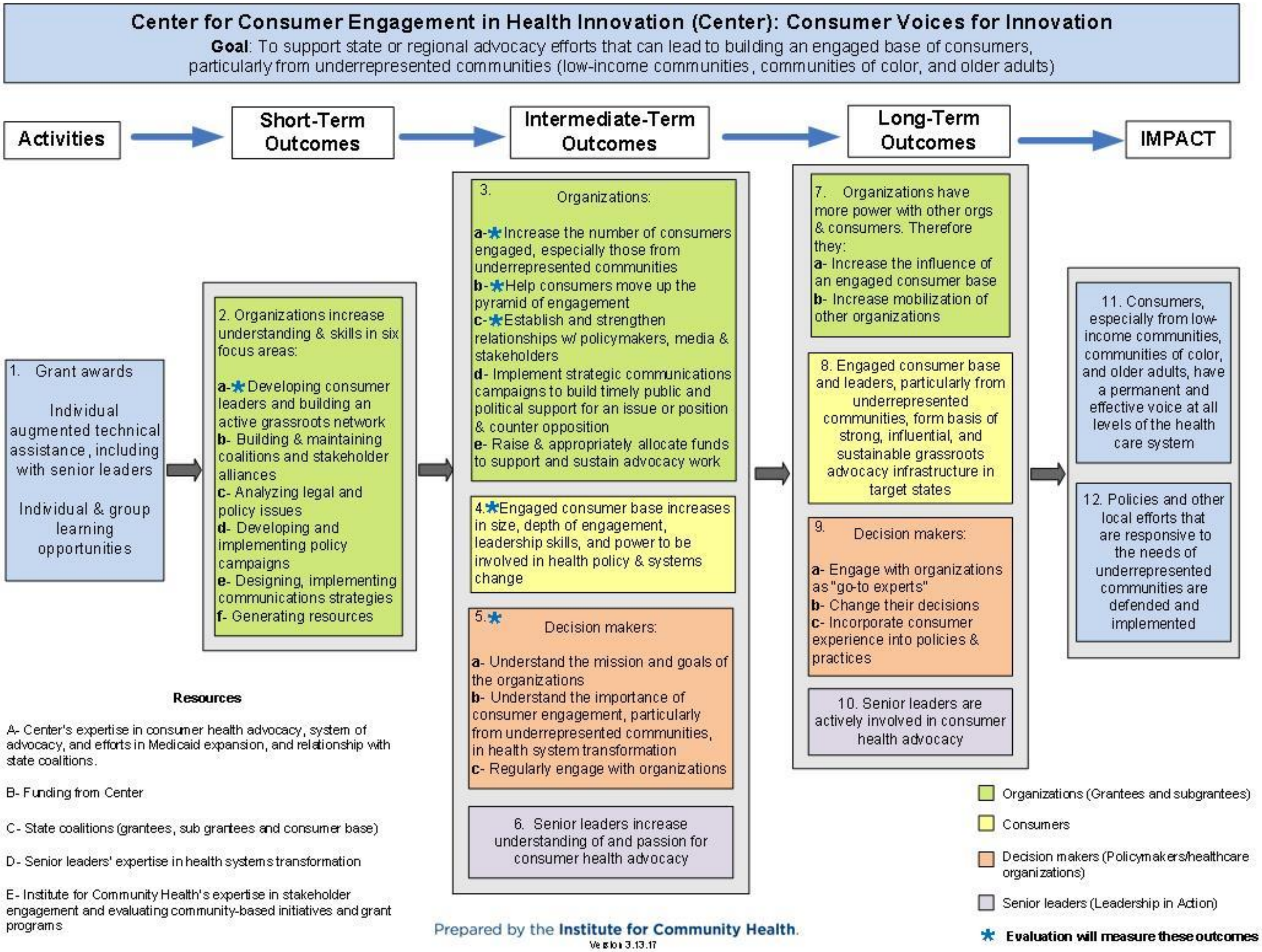
APPENDICES

Appendix A: Logic Model

Appendix B: Grantee Profiles

Appendix C: Data Collection Instruments

APPENDIX A - LOGIC MODEL



Center for Consumer Engagement in Health Innovation (Center): Consumer Voices for Innovation

Goal: To support state or regional advocacy efforts that can lead to building an engaged base of consumers, particularly from underrepresented communities (low-income communities, communities of color, and older adults)

Activities → **Short-Term Outcomes** → **Intermediate-Term Outcomes** → **Long-Term Outcomes** → **IMPACT**

Activities

1. Grant awards

Individual augmented technical assistance, including with senior leaders

Individual & group learning opportunities

Short-Term Outcomes

2. Organizations increase understanding & skills in six focus areas:

a-* Developing consumer leaders and building an active grassroots network
b- Building & maintaining coalitions and stakeholder alliances
c- Analyzing legal and policy issues
d- Developing and implementing policy campaigns
e- Designing, implementing communications strategies
f- Generating resources

Intermediate-Term Outcomes

3. Organizations:

a-* Increase the number of consumers engaged, especially those from underrepresented communities
b-* Help consumers move up the pyramid of engagement
c-* Establish and strengthen relationships w/ policymakers, media & stakeholders
d- Implement strategic communications campaigns to build timely public and political support for an issue or position & counter opposition
e- Raise & appropriately allocate funds to support and sustain advocacy work

4.* Engaged consumer base increases in size, depth of engagement, leadership skills, and power to be involved in health policy & systems change

5.* Decision makers:

a- Understand the mission and goals of the organizations
b- Understand the importance of consumer engagement, particularly from underrepresented communities, in health system transformation
c- Regularly engage with organizations

6. Senior leaders increase understanding of and passion for consumer health advocacy

Long-Term Outcomes

7. Organizations have more power with other orgs & consumers. Therefore they:
a- Increase the influence of an engaged consumer base
b- Increase mobilization of other organizations

8. Engaged consumer base and leaders, particularly from underrepresented communities, form basis of strong, influential, and sustainable grassroots advocacy infrastructure in target states

9. Decision makers:

a- Engage with organizations as "go-to experts"
b- Change their decisions
c- Incorporate consumer experience into policies & practices

10. Senior leaders are actively involved in consumer health advocacy

IMPACT

11. Consumers, especially from low-income communities, communities of color, and older adults, have a permanent and effective voice at all levels of the health care system

12. Policies and other local efforts that are responsive to the needs of underrepresented communities are defended and implemented

Resources

A- Center's expertise in consumer health advocacy, system of advocacy, and efforts in Medicaid expansion, and relationship with state coalitions.

B- Funding from Center

C- State coalitions (grantees, sub grantees and consumer base)

D- Senior leaders' expertise in health systems transformation

E- Institute for Community Health's expertise in stakeholder engagement and evaluating community-based initiatives and grant programs

🟩 Organizations (Grantees and subgrantees)
🟨 Consumers
🟧 Decision makers (Policymakers/healthcare organizations)
🟪 Senior leaders (Leadership in Action)
* **Evaluation will measure these outcomes**

Prepared by the **Institute for Community Health**.
Version 3.13.17

MARYLAND CITIZENS' HEALTH INITIATIVE EDUCATION FUND

Baltimore, Maryland

Target: communities of color, low-income communities, older adults

Overview

MCHI is the most influential health care consumer advocacy organization in Maryland. This grantee engaged stakeholders, particularly from the faith community, to drive health system transformation through a program called the Maryland Faith Health Network (MFHN) that creates infrastructure necessary for rural, suburban and urban hospitals to connect with faith communities when a congregant is hospitalized to both provide timely support and quickly address issues that may arise once the congregant is discharged. MCHI also invited congregations to engage in the organization's broader advocacy work independent from the MFHN in order to defend the ACA and Medicaid, and participate in relevant workgroups.

Key activities

- Expanded MFHN by recruiting hospitals, congregations and congregants to collaborate on HST
- Increased consumer engagement in public workgroups
- Trained MFHN liaisons who assist congregants who are hospitalized and provide feedback to hospitals on trends and patient experience
- Hosted public forums on HST and ACA/Medicaid defense for consumers to learn about these topics and share ideas and experiences
- Defended ACA and Medicaid by securing the creation of the Maryland Health Insurance Coverage Protection Commission, which is working to protect coverage gains made under the ACA

Outcomes and impacts

Consumer engagement

- Reached out to over 7300 consumers
- Added over 1200 consumers to base
- Saw reduced hospitalizations among MFHN members

HST promotion

- Stronger connection between hospitals and community-based caregivers
- MFHN gained recognition as a mutually beneficial mechanism to support consumers and bring health into faith communities, especially into communities of color
- MFHN is also the only non-provider organization in the state able to upload information about a person's valued social connections in the health information exchange
- State workgroups changed their practices to better support consumer engagements (e.g., agenda is available in advance; introductory materials and explanations are provided)
- MFHN is helping to ensure that patients' wishes are documented and honored through promoting completion of advance directives among MFHN partners

Lessons learned

- Advocacy organizations can play an important role in bringing together health systems and consumers to collaborate on HST. Organizations should give careful consideration about when to integrate this work with broader advocacy efforts and when to keep this work separate
- Faith communities bring tremendous professional expertise and deep moral commitment to ensuring that their members and the community at large get the best possible care

MAKE THE ROAD NEW YORK (MRNY)
New York City, New York
Target: communities of color, low-income communities

Overview

MRNY works in close partnership with community health workers (CHWs) to advocate for the inclusion of immigrant voices in HST and is actively involved in ACA defense work. MRNY aimed to improve grassroots participation in a Performing Provider System (PPS) in order to make it more responsive to community needs and to increase the role of community health workers.

Key activities

- Advocating with the PPS leaders for greater engagement with community based organizations
- Developed informational materials to educate consumers about HST
- Trained community health workers to better understand HST
- Well-developed base-building training for community health workers: “[they] have refined their training such that they really have it down to a science now…. They've got a good training program here that helps spark interest in delivery reform issues that can be used by other groups.” –TA tracker
- Collected consumer stories
- ACA and Medicaid defense through consumer stories collection, calls to elected officials, and public events

Outcomes and impacts

Consumer engagement

- Reached out to over 700 consumers
- Added 200 consumers to base

HST promotion

- Contributed to national efforts to block the passing of a legislation that would weaken the ACA by, among others, building a strong relationship with the representative of Staten Island and Governor Cuomo
- Selected to serve on strategic advisory workgroup organized by the PPS to advance HST
- Representative of Staten Island released a press statement confirming he would vote against the American Health Care Act (AHCA)
- Helped consumers participate in the first-ever bilingual NY Coverage For All; provided full logistical support to conveners and participants including facilitation of simultaneous interpretation, translation of materials and individual preparation for monolingual Spanish speakers to participate in the event

Lessons learned

- There is no need to work on HST as a whole; picking a piece of HST is more effective
- Working on building coalitions is important
- Building a base specifically or only around health system transformation is challenging
- “They've had a lot more success with low volume, intensive touch strategies, like training, or working through their navigators and CHWs, who have significant contact with consumers.” – SAM, TA tracker
- “Are finding that unless a person is coming in to talk about a recent/ongoing difficult experience they're having with the health system, it is difficult for people to pinpoint a story with any specificity. This adds to our knowledge about what works and doesn't around organizing in the HST space.” – SAM, TA tracker
- Mentorship from individuals with HST experience – the Senior Leader from the LIA program

OREGON STATE PUBLIC INTEREST GROUP (OSPIRG)

Unite Oregon & Oregon Latino Health Coalition (OLHC)

Portland, Oregon

Target: communities of color, low-income communities

Overview

OSPIRG works on policy development (legislative advocacy) and on-the-ground advocacy organizing. Along with their partners, Unite Oregon and OLHC, OSPIRG aimed to organize grassroots participation in Coordinated Care Organizations (CCOs) in southern Oregon and increase the influence of consumers and focus on addressing social determinants of health in the CCO.

Key activities

- Published press statements to illustrate potential negative impact of ACA repeal on consumers and state's HST efforts
- Engaged new Oregon Health Authority leadership to discuss next steps for the state's HST effort and the need for increased transparency and accountability for CCOs
- Organized community meetings on HST, Medicaid access and the threat of ACA repeal
- Attended meetings with stakeholders, such as the Community Advisory Councils of local CCOs, the steering committee for Southern Oregon Health Equity, and the county Perinatal Task Force
- Conducted lobby meetings with state legislators about HST, Medicaid access and health equity

Outcomes and impacts

Consumer engagement

- Reached out to over 2500 consumers
- Added over 600 consumers to base
- Established a new base of grassroots support for Unite Oregon in Josephine County

HST promotion

- Passed the state's first significant reform to the Medicaid CCO system since it was established
- At a CCO forum, the Chair of Oregon's House Health Care Committee announced publicly that he intends to make another effort at legislative reforms to advance transparency and accountability for CCOs in 2018
- Secured health care coverage for all Oregon children, many of whom were previously ineligible

Lessons learned

- Legislative advocacy can take up to a couple of 'failed' rounds before succeeding
- Consider how to integrate grassroots organizing with policy change goals, and how to target grassroots energy into the right place
- Organizing Medicaid consumers is extremely difficult, and "*It's absolutely critical, but you have to figure out how to do that in a way that's strategic and coordinated with other things that you're doing to try to amplify what that work can actually mean, so that you can show that it's really worth people's time to do it, if nothing else.*" - Interview participant

PENNSYLVANIA HEALTH ACCESS NETWORK (PHAN)

Philadelphia, Pennsylvania

Target: communities of color, low-income communities, older adults

Overview

PHAN is Pennsylvania's main consumer-led organization. PHAN's goal was to organize consumers affected by the rollout of managed long-term services and supports in Pennsylvania's Medicaid program, with a focus on mobilizing seniors who are eligible for both Medicaid and Medicare.

Key activities

- Held conversations and meetings with policymakers
- Conducted listening and education sessions (e.g., community conversations) about the new Medicaid managed care program, Community Health Choices (CHC)
- Produced simple, consumer-friendly educational materials
- Conducted trainings for potential consumer leaders: "Lift Up Your Voice!"
- Formed partnerships with community based organizations and religious groups to coordinate lobbying and outreach strategies, and to more widely disseminate consumer-facing materials
- Brought consumers to a lobbying event in Washington, DC
- Developed and administered a "consumer experience survey" to understand people's use of their new CHC managed care plans and the levels of support and service consumers are receiving

Outcomes and impacts

Consumer engagement

- Reached out to 700 consumers
- Added over 300 consumers to base

HST promotion

- Successfully lobbied the Office of Long-Term Living, which is managing the rollout and program design of CHC, to build consumer engagement and grievance processes into the metrics for success for the new CHC implementation process
- Successfully lobbied for and conducted observations of individual care planning sessions between consumers and CHC's service coordinator in order to lobby for consumers and provide feedback to CHC

Lessons learned

- Community organizing is a multi-year investment
- Conference calls are not an effective way to engage seniors
- "Crack[ing] the code" to make HST simple is important
- Leadership in Action mentor is an "incredible resource"
- Contacts made at events – both hosted and attended – lead to fruitful partnerships
- Well-targeted local earned media placements can result in successful outreach (an earned media event led to high attendance at an education event and increased calls after)

RHODE ISLAND ORGANIZING PROJECT (RIOP)
Providence, Rhode Island
Target: communities of color, low-income communities, older adults

Overview

RIOP works for social change through community organizing and empowerment. RIOP aimed to promote better health care outcomes through proper care coordination and increased home and community-based services, and improving access to transportation for low-income seniors.

Key activities

- Sponsored house meetings for consumers to learn about the ACA and other health care issues
- Invited consumers to participate in public hearings to share their stories about the impact of the bus fare on their lives
- Mentored consumer members of the Integrated Care Initiative (ICI) Implementation Council by helping them debrief the meetings
- Organized the "Lift Up Your Voice!" training for educating consumers about the health care system

Outcomes and impacts

Consumer engagement

- Reached out to over 600 consumers
- Added over 250 consumers to base
- Consumers now participate in and chair ICI Implementation Council meetings
- With the restoration of the No Fare Bus Pass, 13,500 consumers "have more disposable income, are less socially isolated, and are able to afford vital trips such as food shopping and medical visits" – RIOP quarterly report

HST promotion

- Restored the state public transit authority's (RIPTA) No Fare Bus Pass by having consumers provide testimonies and write support letters to public officials
- Built alliances with organizations that serve vulnerable adults dealing with homelessness, mental health issues, and disabilities, as well as the local branch of SEIU, the largest health care union in the US
- Joined the RIPTA planning committee to find a sustainable solution to keeping transportation free for seniors and people with disabilities

Lessons learned

- Flexibility and willingness to try out new things are key
- Meeting consumers where they are (e.g., senior center, recovery facility) is critical for working with seniors
- It can be hard to come up with a concrete, specific thing around health care since everybody has their own, personal experience with it
- House meetings are an effective format to identify new leaders, discuss with the community, and listen to their concerns
- Rallies and public hearings were helpful to identify potential leaders who can educate and motivate other consumers

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

INSTITUTE FOR
COMMUNITY
HEALTH

Consumer Survey

Greetings! We are working on improving issues that affect the health of people in *[insert name of state].* We ask you to fill out this survey because we want to improve advocacy for issues that affect health. Please answer the following questions honestly. We don't want to identify you in any way. We will only share your answers together with everyone else's. You don't have to answer any questions you are not comfortable with. Please contact *[insert name and email/phone number of grantee point person]* if you have any questions about this survey.

If you want to take this survey, we can enter your name in a lottery to win a gift card. Your contact info will be kept separately from your survey answers.

Thank you for your help!

1. **How long ago did you first get involved with [grantee]?**
   - ☐ Today is my first time
   - ☐ Today is not my first time, but it was less than 6 months ago
   - ☐ 6 months to less than 1 year ago
   - ☐ 1 year ago or more

2. **How much have these things changed for you in the last year?**	**NO CHANGE**	**A LITTLE MORE**	**A LOT MORE**
a. TODAY, **I know more about healthcare** than I did ONE YEAR AGO.	😐	🙂	😄
b. TODAY, I **feel more strongly that advocating about healthcare is important** than I did ONE YEAR AGO.	😐	🙂	😄
c. TODAY**, I am more involved in improving healthcare** than I was ONE YEAR AGO.	😐	🙂	😄
d. TODAY, I am **more able to get others involved** in improving health care than I was ONE YEAR AGO.	😐	🙂	😄
e. TODAY, **I am more confident in my leadership skills** for improving health care than I was ONE YEAR AGO.	😐	🙂	😄

3. **Where did you first hear about [grantee organization] and their work to improve things that affect peoples' health?** *(please select one)*

- ☐ Friend/family told me
- ☐ Community meeting
- ☐ Website or newsletter
- ☐ Newspaper, radio or TV
- ☐ Social media (like Facebook, Twitter, Instagram…)
- ☐ Email
- ☐ Place of worship
- ☐ Someone knocking on my door
- ☐ Someone talking to me in public
- ☐ Phone call
- ☐ School
- ☐ Other (please explain): ____

4. In the past year, how much did doing these things MOTIVATE YOU TO GET MORE INVOLVED in improving healthcare? *(please mark EITHER N/A OR X somewhere on the line)*	N/A (I did not do this)	
a. Receiving and/or reading the **emails or newsletters** about healthcare.	☐ N/A	Not at all Very much |---------|--------|--------|---------|
b. **Signing up to be contacted by** [organization] about healthcare.	☐ N/A	Not at all Very much |---------|--------|--------|---------|
c. Going to a **rally or demonstration** about health care.	☐ N/A	Not at all Very much |---------|--------|--------|---------|
d. Going to a **forum or community meeting** about health care.	☐ N/A	Not at all Very much |---------|--------|--------|---------|
e. Sharing a **personal health care story** with [organization].	☐ N/A	Not at all Very much |---------|--------|--------|---------|
f. **Sharing a personal health care story** with a reporter or decision-makers.	☐ N/A	Not at all Very much |---------|--------|--------|---------|
g. **Speaking in person** with a politician or other decision-maker about health care.	☐ N/A	Not at all Very much |---------|--------|--------|---------|
h. **Writing to or calling** a politician or other decision-maker about healthcare.	☐ N/A	Not at all Very much |---------|--------|--------|---------|
i. **Going to a training** or workshop about healthcare.	☐ N/A	Not at all Very much |---------|--------|--------|---------|
j. **Leading a training** about healthcare.	☐ N/A	Not at all Very much |---------|--------|--------|---------|
k. Serving **as a representative on committees or on workgroups** about healthcare.	☐ N/A	Not at all Very much |---------|--------|--------|---------|

5. Is there anything else you want to tell us?

Please answer the following questions about yourself. You don’t have to answer these questions if you don’t want to. You may skip any question you are not comfortable with. We do not want to identify you in any way. We will report this information to *[insert name of grantee]* only in general terms.

6. How did you get this survey?

☐ In the mail or by email
☐ At an event
☐ In a one-on-one meeting
☐ Over the phone
☐ Other

7. How old are you?

☐ ≤ 34 years old
☐ 35 to 64 years old
☐ 65+ years old
☐ I don’t want to answer

8. How do you identify your ethnicity / race? *(check all that apply)*

☐ American Indian or Alaska Native
☐ Asian
☐ Black or African American
☐ Hispanic/Latino
☐ Native Hawaiian or Other Pacific Islander
☐ White
☐ Some other race/ethnicity: ____________
☐ I don’t want to answer

9. In the past 12 months, have any of the following been true? *(check all that apply)*

☐ We worried whether our food would run out before we got money to buy more.
☐ We worried about losing housing or we were homeless.
☐ The electric, gas, water or oil company threatened to shut off services where we live.
☐ None of the above.
☐ I don’t want to answer.

Thank you very much!

Grantees/Sub grantees Baseline/Follow-up Survey

(Filled out by each grantee and each sub grantee)

Thank you for participating in this survey. Community Catalyst, and their external evaluators at ICH, are sending you this survey with the goal of collecting A) **[BASELINE]** baseline information on your organization's grassroots organizing efforts for health system transformation; B) **[FOLLOW-UP]** information on your organization's grassroots organizing efforts for health system transformation over the past year. **[BASELINE ONLY]** We understand that the some organizations are new to health system transformation and may therefore not have a lot of activities or organizing to report. That is OK! You will not be penalized for reporting low numbers, we want to learn collectively about what works and does not work in organizing and engaging community members in this issues area. Please just do your best to complete the survey as accurately as possible. We look forward to learning about this area with you. Thank you for your help!

[FOLLOW-UP ONLY] We want to understand both what went well and what has been difficult. Please feel free to share any challenges. You will not be penalized for what you report. We want to learn collectively about what works and does not work in organizing and engaging community members in this issues area. We look forward to learning about this area with you!

Your responses will be shared with Community Catalyst staff. Please do your best to complete the survey as accurately as possible. We estimate that this survey will take about 30 minutes to complete. If you have any questions or concerns, please reach out to your SAM, to Ann Hwang ahwang@communitycatalyst.org, or to Carolyn Fisher at cffisher@icommunityhealth.org. Thank you for your help!

[BASELINE, FOLLOW-UP]

1. ***What is the name of your organization?**
2. *What is the name of the person completing this survey?
3. *What is the role of the person completing this survey?
4. *[8]What is the best email address to reach the person completing this survey?

[BASELINE ONLY] We understand that some organizations are new to health system transformation and therefore may not yet have anyone in their database interested in health system transformation issues. Please answer the following questions as accurately as possible.

5. **[BASELINE]** Are you able to identify people in your contact database who are interested in health system transformation? ☐Yes ☐No (if no→ skips to #7)

   [FOLLOW-UP (reworded)] Among the people you have contact information for (e.g., in a database, Excel sheet, etc.), **are you able to identify** those who are interested *specifically* in health system transformation? ☐Yes ☐No (if no→ skips to #7)

6. **[BASELINE]** How many people in your contact database are interested in health system transformation? *Please write the number of people* (not percentage of people) _________

   [FOLLOW-UP (reworded)] How many of these people interested *specifically* in health system transformation do you have contact information for (e.g., in a database, Excel sheet, etc.)? *Please write the number of people (not percentage of people)* _________

---

[8] * = an answer is required

7. **[BASELINE ONLY]** People currently follow your organization's health system transformation efforts on:
    - ☐ Twitter
    - ☐ Facebook

7a. How many people currently follow your organization's health system transformation efforts on Twitter?
7b. How many people currently follow your organization's health system transformation efforts on Facebook?

[BASELINE ONLY] We understand that some organizations are new to health system transformation and therefore may not yet have engaged consumers in health system transformation.

[BASELINE, FOLLOW-UP]Please estimate the number of people in past year who . . .[9]

8a. signed up to receive emails, alerts, newsletters or blogs about health system transformation
8b. filled out a registration form or interest card for health system transformation
8c. attended an event such as a rally, community forum or other public event related to health system transformation (please add up the total attendance at all events)
8d. provided a personal health care story to your organization related to health system transformation
8e. spoke in person with a decision-maker (such as at a lobby day, through giving testimony, or attending a meeting with a decision-maker) about a health system transformation issue
8f. contacted a decision-maker (for example, by email, letter, post-card, or phone call) about a health system transformation issue
8g. shared a personal health care story with the media or legislators about a health system transformation issue
8h. attended a training or workshop related to health system transformation
8i. attended a train-the-trainer training or trained individuals in the community about a health system transformation issue
8j. regularly served as spokespeople for health system transformation issues
8k. Served on boards, committees, public workgroups, or regional partnerships relevant to health system transformation
8l. Is there another key health system transformation related activity that consumers participated in during the past year?

☐Yes (answer following Qs)
☐No (if no→ skips to #9)

Please briefly describe the activity: ______________________
Estimate the number of people who participated in this activity: _____

9. **[BASELINE, FOLLOW-UP]** Please describe the role of the top 2 decision-makers (or decision-making groups) that your organization is trying to influence. *For example, you may be trying to influence a senator, members of a Board of Trustees of a particular hospital, a healthcare advisor to the governor, or a particular oversight committee.*
    If you're trying to influence only 1 decision-maker, please leave "decision-maker #2" **blank**
    1. Decision-maker #1 role: _________________________________
    2. Decision-maker #2 role:_________________________________

10. **[BASELINE, FOLLOW-UP]** Thinking about the first decision-maker/decision-making group you described, approximately how many times in the past six months has…*(the following a,b,c asked as separate questions)*

---

[9] Questions 8a-8k ask about consumer participation in activities reflecting the following stages of engagement: interest (a, b); participation (c, d, f); commitment (e, g, h); leadership (i-k).

a. Your organization had meetings or phone calls with this decision-maker?
b. Your organization been contacted by this decision-maker (e.g., for information, meetings, stories)?
c. The decision-maker attended events such as rallies or community events planned by your organization?

☐ 0 times
☐ 1-2 times (every 3-6 months)
☐ 3-6 times (every 1-2 months)
☐ 7-24 times (more than once a month to weekly)
☐ 25 or more times (more than once a week)

11. **[BASELINE, FOLLOW-UP]** Thinking about the first decision-maker/decision-making group you described how well, in your opinion, does this decision-maker……*(the following a,b,c asked as separate questions)*
    a. Understand the goals of your organization's health system transformation work?
    b. Understand the importance of consumer engagement in health system transformation?
    c. Incorporate consumer experience into health system policies and practice?

☐ Not at all
☐ Poorly
☐ Somewhat well
☐ Very well
☐ I don't know

9B. **[BASELINE ONLY]** How many decision-makers/decision making groups is your organization trying to influence?

☐ 1 (→ skips to 14)
☐ 2

12. **[BASELINE, FOLLOW-UP]** Thinking about the second decision-maker/decision-making group you described, how often in the past six months has . . . .*(repeats question #10)*

13. **[BASELINE, FOLLOW-UP]** Thinking about the second decision-maker/decision-making group you described, how well does the decision-maker. . . *(repeats question #11)*

14. **[BASELINE, FOLLOW-UP]** How would you describe the overall capacity of your organization for mobilizing and organizing a strong grassroots base of support for health system transformation?

☐ No Capacity
☐ Little Capacity
☐ Some Capacity
☐ Strong Capacity
☐ Very Strong Capacity

15. **[BASELINE, FOLLOW-UP]** Which of the following communities is your organization trying to engage in health system transformation? *(check all that apply)*

☐ Communities of color
☐ Low-income communities
☐ Seniors

For each community, they will be asked the following questions. Thus, if they check all 3, they will get these questions 3 times; if they check only one, they will get the questions only once.

16. **[BASELINE, FOLLOW-UP]** How would you describe the capacity of your organization in each of the specific areas below?
    a. Organization's ability to **gain visibility** among [community]
    b. Organization's ability to **establish credibility** among [community]
    c. Organization's ability to **recruit volunteers to be consumer advocates** for health system transformation from [community]
    d. Organization's ability to **train consumer leaders** for health system transformation advocacy from [community]
    ☐ No Capacity
    ☐ Little Capacity
    ☐ Some Capacity
    ☐ Strong Capacity
    ☐ Very Strong Capacity

17. **[BASELINE ONLY]** What kind of activities, if any, has your organization conducted to specifically engage communities of color, low-income communities and seniors? _______
    a. How have these activities been tailored to these communities? ________
    b. Which activity or activities was/were most successful in adding to your base?
    c. Why do think these activities were successful in adding to your base?

18. **[FOLLOW-UP ONLY]** Please describe the kinds of activities your organization has conducted to *specifically* engage communities of color, low-income communities, and seniors, and any ways that they were tailored to these communities.

19. **[FOLLOW-UP ONLY]** Which of these strategies were most successful in:
    a) Finding your target communities
    b) Engaging members of these target communities
    Why do you think they were successful?

20. **[FOLLOW-UP ONLY]** We understand that not every strategy will be successful, and we want to learn from your experiences. Please describe which strategies were LEAST successful in finding and engaging members of your target communities in Health Systems Transformation. Why do you feel this was?

21. **[BASELINE ONLY]** We would like to be prepared to support you in this work. Are there particular challenges or needs you anticipate in the next 6 -12 months?

22. **[FOLLOW-UP ONLY]** What can Community Catalyst do to better support you in your work in the next 6-12 months?

23. **[BASELINE, FOLLOW-UP]** Is there anything else you would like to share about your organization's grassroots organizing efforts in health system transformation?

Grantee Interview Guide

Hi, thank you for taking the time to participate in this interview. My name is ____ and I work for the Institute for Community Health (ICH), which is helping the Center for Consumer Engagement in Health Innovation evaluate the Consumer Voices for Innovation Initiative.

We wanted to spend the next 30-45 min reflecting back on the past year. Our goal is to identify common themes and lessons that we will share with the Center for Consumer Engagement in Health Innovation at a high level. You may recognize some of the questions as similar to your quarterly report; we hope that today we will dig deeper and learn from your perspective as on-the-ground organizer(s) of grassroots advocacy efforts, in hopes to better understand 1) how many consumers were engaged through grantee initiatives, 2) if consumers became more meaningfully engaged, 3) what was most effective at engaging them, and 4) policy changes. We know that not every project runs perfectly all the time. We want to hear about all types of experiences including things that went smoothly as well as things that were challenging.

We will summarize the themes from our interviews with grantees in our report to Community Catalyst's Center for Consumer Engagement in Health Innovation, but we will not directly quote your comments in a way that makes it possible for the Center to identify your organization. Moreover, the notes that we take will not be shared with anyone other than our staff and the Center's coordinator.

At some point, I may ask you to clarify some of the information you have provided in the quarterly report so that I can make sure that I can report back the information that you share with me today accurately.

While participating in evaluation activities is a requirement of the grant, you should feel free to decline to answer any given question that you don't feel comfortable with. We are recording these interviews so that we can make sure we accurately capture your experience. Is this OK with you?

Warm-up and context

1. Can you describe your involvement in the health system transformation efforts at your organization and in the Consumer Voices for Innovation Initiative?

2. The project has a number of **goals** including:
   a. Increasing the size of the consumer base and level of engagement among participating consumers - with a focus on low-income communities, communities of color and older adults,
   b. Building the leadership skills of participating consumers and
   c. Establishing and deepening relationships with decision-makers, media and stakeholders
   d. Achieve concrete, consumer-friendly policy changes

   Can you briefly describe your organization's efforts to achieve these goals as part of the Consumer Voices for Innovation Initiative?

Strengths / Successes

3. Reflecting back on the process of implementing your project over the past 9 months, what has **worked well in engaging consumers** - especially low-income, communities of color, and older adults - **in health advocacy**?

4. Were these the same strategies that your organization expected to be most effective? What surprises have you found?

Challenges

5. Reflecting back on the process of implementing your project over the past 9 months, can you describe the challenges you've found in **engaging consumers** - especially low-income, communities of color and older adults - **in health advocacy**?

6. It's not possible to foresee everything that comes up in the course of a project – can you talk about the UNFORSEEN challenges you faced?

7. What has been done (or could be done) to resolve some of the challenges you just described? How did (would) that help?

Impacts

8. Now let's think about the impact, both positive and not, of the project. What has changed (or will change) as a result of this program for:
    - <u>Your organization</u>?
    - The <u>community</u> that you serve?

Optional (if time allows)

9. What other recommendations can you offer to advocacy organizations starting new projects similar to yours? What about to other organizations like Community Catalyst that are interested in supporting consumer advocacy in health systems transformation?

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

Quarterly Report Template

State:
Organization:

[Q1-Q3] Please complete this status report on your health system transformation efforts (in no more than 5 pages) by [date]. This report should be submitted electronically to **HealthJusticeFund@communitycatalyst.org**.

[Q4] Please complete this status report on your health system transformation efforts (in no more than 7 pages) by [date]. This report should be submitted electronically to: **HealthJusticeFund@communitycatalyst.org.**

[Q1-Q3] Please attach up to three items of relevant media coverage, outreach materials, or products produced.

[Q1-Q4] Please use an asterisk to denote any activities where C(4) lobbying dollars were used.

[Q4] Please note there are two sections to this report: a section focusing specifically on fourth quarter activities, and a cumulative section focusing on the entire grant period. Please be aware that this report will be read both by your State Advocacy Manager as well as staff not as familiar with your work. **Please answer the questions thinking of a reader that might not be immersed in the details of your work.**

[Q1-Q3]
Report Date:

Reporting Period:

Report Completed by:

E-mail:

[Q4 ONLY]

Organization:

Summary of Quarterly Activities

[Q1-Q3] Provide a narrative summarizing your work during the past three months and describe the progress you've made toward the outcomes identified in your work plan. Please include a description of the strategies you've used to grow your base. Please also provide estimates for the following:

- How many new people did you reach out to as part of your project this quarter (e.g., they attended a community forum, or you phone banked them, or knocked on their door, etc.)?
- How many new people interested in health system transformation did you add to your base (i.e., you obtained contact information and put that information in your database) as part of this project this quarter?
- How many new grassroots leaders (e.g., people who would testify before decision-makers, speak to the press, lead others, etc.) did build as part of this project this quarter?

[Q4]

1. **Narrative:** Provide a brief narrative summarizing your activities during the past three months.
2. **Growing Your Base:** Please describe the specific strategies you've used to grow your base during this quarter.
    a. Please also provide estimates for the following questions. (Please note that your report will be considered incomplete without answers to these questions).
    - How many new people did you reach as part of your project this quarter (e.g., you phone banked them, or knocked on their door, etc.)?
    - How many new people interested in health system transformation did you add to your base (i.e., you obtained contact information and put that information in your database) as part of this project this quarter?
    - How many new grassroots leaders (e.g., people who would testify before decision-makers, speak to the press, lead others, etc.) did you build as part of this project this quarter?

Technical Assistance

[Q1-Q3] Over the last quarter, what technical assistance did your organization receive from the Center (e.g., messaging guidance for reaching your governor, strategizing about policy shifts away from block grants, best practices guidance about building a coalition, etc.) that was helpful? What additional technical assistance support would you like from the Center?

[Q4] Over the course of the grant period, what technical assistance did your organization receive from the Center or your Senior Leader that was most helpful? What technical assistance did you need but not receive? Please be as specific as possible in answering these questions.

[Q1-Q3] Deliverables

Provide a list of any deliverables developed during this reporting period.

[Q4] Deliverables: Please provide a list of up to three deliverables developed during this reporting period. If relevant, please either attach or include a link to up these items.

[Q1-Q3] Your Impact:

Please provide key examples from this reporting period of where you believe your work with these funds has had impact in the state. Please cite evidence of this impact. Impacts should not be a list of your activities. Rather, they should demonstrate the effect of your activities – they help you know that your activities moved you closer to achieving your project goals.

[Q1-Q3] Changes in Schedule

Describe any key activities that were either delayed or are ahead of schedule and why in this reporting period. Please explain the possible impact on your work, and plans for resolving any issues caused by the change in schedule. Describe any unforeseen circumstances that had an impact on your work.

[Q1-Q3] Issues/Opportunities/Contacts

Please describe any new challenges, opportunities (including, for example, new partnerships or relationships that you are planning to explore) or developments in the political environment that will change your strategy moving forward.

[Q1-Q3] Matching Funds

Please describe your efforts and progress toward obtaining matching funds. List all new or promising sources of funding and indicate funders who have not previously supported your organization. As a reminder, the match requirement for this grant is 50%.

[Q4] Matching Funds: Please provide a final report on your efforts and progress toward obtaining matching funds. As a reminder, the match requirement for this grant is 50%. Please include whether you met the match, and if so from whom. Please share any successes or challenges you had in achieving your match. Please note that your report cannot be considered complete without this information.

[Q1-Q3] Anything Else

Please use the space below to communicate anything else about this grant program or your project that you would like us to know

[Q4] Other: Please use this space to identify anything else about this grant program or project that you would like us to know.

[Q4 ONLY]

1. **Achievements:** What are the top three achievements that this grant made possible? Please indicate if these achievements were anticipated in your original proposal, or if these achievements were not anticipated at the time you wrote your original proposal but are nonetheless significant achievements of the project.

2. **Outcomes:** Please review the expected outcomes you identified in your original proposal and provide insight as to whether or not you achieved these. If not, please explain why not.

3. **Growing Your Base:** Over the course of the grant period, what were the three most successful strategies you used to grow your base. Please also identify any base building strategies you tried that were not successful.

    a. Please also answer the quantitative questions below <u>for the entire grant period</u>. (You may simply add the figures from your past quarterly reports to answer these questions. Please note that your report will be considered incomplete without answers to these questions).

        - How many new people did you reach as part of your project over the course of the grant period (e.g., you phone banked them, or knocked on their door, etc.)?
        - How many new people interested in health system transformation did you add to your

base (i.e., you obtained contact information and put that information in your database) as part of this project over the course of the grant period?

  - How many new grassroots leaders (e.g., people who would testify before decision-makers, speak to the press, lead others, etc.) did you build as part of this project over the course of the grant period?

4. **Challenges:** Please identify any significant internal or external challenges that the project encountered, including changes in schedule or unforeseen circumstances that had an impact on your work. Describe each challenge and the actions you undertook to address it.