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Health Coverage that Works for New Yorkers

Health Care For All New York's 2012 Statewide Listening Tour

by Carrie Tracy, JD & Arianne Slagle, MPA

The Community Service Society of New York (CSS) is an informed, independent, and unwavering voice for positive action representing low-income New Yorkers. CSS addresses the root causes of economic disparity through research, advocacy, and innovative program models that strengthen and benefit all New Yorkers. For more information visit www.cssny.org.

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Health Care for All New York (HCFANY) is a statewide coalition of over 150 organizations dedicated to winning quality, affordable health coverage for all New Yorkers. We strive to bring consumer voices to the policy conversation, ensuring that the concerns of real New Yorkers are heard and reflected. We also provide expert policy analysis, advocacy, and education on important health policy and coverage issues that affect New Yorkers around the state. For more information on HCFANY, visit us on the web at www.hcfany.org.

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Introduction

Health Care For All New York (HCFANY) is a statewide coalition of over 150 consumer advocacy organizations dedicated to securing access to affordable, comprehensive, and high quality health care for all. Together, we work to advance the concerns of everyday New Yorkers and help devise concrete health policy solutions in the interest of consumers and small businesses.

In March 2010, President Obama signed the Affordable Care Act (ACA) into law to significantly improve the availability, affordability, and quality of health insurance nationwide.[1] New Yorkers have already benefited from many of the law's new consumer protections. However, the major expansion of coverage promised by the law is yet to come: the opening of the New York Health Benefit Exchange, a new insurance "marketplace," in October 2013.

The ACA sets forth health insurance exchanges as a mechanism to provide consumers and small businesses with a new, simplified means to purchase and enroll into health insurance through a consumer-friendly website. Help is also available to those who need it via a number of different outlets, including a telephone hotline and in-person enrollment help from community-based organizations. This will allow people to:

- screen eligibility for and enroll into public health insurance programs;
- easily compare private health insurance plans on an "apples to apples" basis, including covered benefits, costs, and consumer satisfaction ratings;
- purchase and enroll into private health plans; and
- apply for federal tax credits and subsidies to help pay for private health insurance.

While the majority of states have elected to have an Exchange for their consumers and small businesses that is run by the federal government, roughly 17 states—including New York—have elected to operate their own "state-based" Exchange. These states have considerable discretion in the design and implementation of their Exchanges so as to best meet the diverse needs of their own population.

The New York Health Benefit Exchange is well underway to begin open enrollment in October 2013. The state began laying groundwork for this in late 2010, securing millions in federal funding and engaging experts to study the most important Exchange design questions. In April 2012, Governor Cuomo issued an Executive Order establishing the New York Health Benefit Exchange in the Department of Health.[2] In September 2012, the Exchange convened five Regional Advisory Committees with over 200 stakeholders around the state to further weigh in on some of the design questions. In October 2012, New York submitted its Exchange implementation plan to HHS, which was approved in December.[3] Consumers and small businesses will be able to start shopping for affordable health coverage on October 1st and apply for coverage that will begin on January 1, 2014.

The success of the Exchange in meeting its enrollment goals will rely heavily on its final design. As many as one million New Yorkers are expected to gain coverage through the new Health Benefit Exchange. This many potential users from the many different and diverse corners of the state will only be able to enroll successfully if the Exchange is equally accessible to all, easy to use, and designed in a consumer-friendly way.

With this in mind, HCFANY began talking to consumers, advocates, and decision-makers around the state about the need for a strong, consumer-friendly Health Insurance Exchange in New York. HCFANY developed five principles to help guide decisions about the design of the Exchange and ensure that it is consumer-friendly:

1. One statewide Exchange for all.
2. An Exchange that offers quality and affordable benefit packages.
3. An Exchange that is easy to navigate and represents the voice of consumers.
4. An Exchange that builds on the success of New York's public health coverage programs, including Medicaid, Family Health Plus, and Child Health Plus.
5. An Exchange that supports principles of health equity.

During the spring of 2012, as HCFANY discussed the development of New York's Exchange with its membership, allies, and other key stakeholders, we determined that many New Yorkers still did not know much about it. But time was running out; key federal deadlines for critical state Exchange staff decisions that would affect New York's readiness for open enrollment on October 1, 2013 were quickly approaching.

HCFANY decided to launch a Listening Tour and a series of Roundtable events in the summer of 2012 with three main goals: (1) explain some of the most important decisions of the Exchange's design to diverse consumers around the state; (2) get feedback from these consumers about what they think the outcomes of these decisions should be; and (3) give these educated consumers a chance to talk to decision-makers in their community about how the Exchange should work for consumers.

This report provides a major overview of HCFANY's 2012 Listening Tour activities and findings and presents a series of recommendations for policymakers to use in the Exchange design process.

The Tour and Roundtables

Before beginning our Listening Tour, HCFANY created a slideshow presentation that explained several issues (cost, quality and accessibility) that will affect how well the Exchange will serve consumers and small businesses. HCFANY also created a survey form for consumers to complete and an accompanying guide. The survey questions can be found in Appendix 2. HCFANY organizations used these materials to lead qualitative conversations with consumers around the state and record their feedback.

Listening Tour conversations took place around the state between May and September 2012, with consumers representing the great diversity of New Yorkers, including race, gender, sexual orientation, age, insurance status, and disability status. In some cases, Listening Tour sessions were one-on-one conversations between a HCFANY representative and a consumer or advocate during which the participant filled out a survey form. In other cases, HCFANY members hosted an informal focus group after which conversation leaders wrote a report summarizing the conversation.

In October 2012, HCFANY invited consumers who participated in the Listening Tour to join one of a series of Roundtables—events where they could meet with decision-makers and community leaders and explain their hopes for the New York Health Benefit Exchange. In total, there were nine Roundtables held: in Binghamton, the Bronx, Brooklyn, Buffalo, Long Island, Lower Manhattan, Staten Island, Upper Manhattan, and Westchester County. Two additional Roundtable events were scheduled in Queens and Syracuse, but were cancelled due to Hurricane Sandy. As a substitute, HCFANY held in-depth interviews with consumers and small business owners in Syracuse and Queens to add their input to this report. A list of the Roundtable events and participants can be found in Appendix 1.

As a result of these activities, HCFANY:

- Collected 259 surveys.
- Held 28 Listening Tour sessions with diverse participants, including:
  - Moderate- and low-income people
  - Staff of social service agencies serving people of color, people with disabilities, and seniors
  - Seniors
  - People with disabilities, including people with visual impairments, deaf people, amputees, people who use wheelchairs, and people with cognitive and mental conditions
  - Urban and rural residents
  - People living with HIV
  - LGBT people including Latinos, immigrants, and formerly homeless young adults
  - Women's health activists
  - Leaders of diverse faith communities
  - Consumers with public and private insurance and uninsured consumers
  - Residents of diverse regions of the state, including New York City, Long Island, Western New York, and the Southern Tier
  - Immigrants

- Held nine roundtables, with 125 participants, including:
  - State Senators, Assembly members and their staff
  - Local elected officials
  - Members of Exchange Regional Advisory Committees
  - Local, State, and Federal administration representatives
  - Consumer advocates and community members
  - Small businesses and small business advocates
  - Community health care providers
  - Leaders of diverse faith communities
  - Labor representatives

Findings

This reports organizes the findings from HCFANY's listening tour and survey into five areas:

1. a baseline assessment of participants' views of the current health insurance system;
2. affordability of coverage and an exploration of the ACA's Basic Health Option;
3. accessibility of the system and consumer assistance;
4. quality of coverage, including health equity, active purchasing and the essential health benefit package; and
5. public participation in the Exchange development.

The results of HCFANY's findings in these five areas are described below.

1 ASSESSMENT OF THE CURRENT HEALTH INSURANCE SYSTEM

Designing a consumer-friendly Exchange requires a good understanding of the ways in which the existing health insurance system meets, or fails to meet, consumer needs. So, as an ice-breaker, HCFANY urged participants to describe their current experience with the health insurance system. Specifically, we asked participants what kinds of problems they, their close friends, and family faced under our current system of health coverage. The survey included a list of common issues, and left room for participants to write in other problems. In response, the consumers and small businesses we met with voiced many concerns.

Findings:

Lack of affordability, poor quality of plans, and difficulty of use were the three main concerns participants identified with our existing system. The word cloud below shows the words that came up most frequently in participants' written answers to this survey question in relation to these three main concerns. Figure 1 shows how participants identified with the list of common issues we provided.

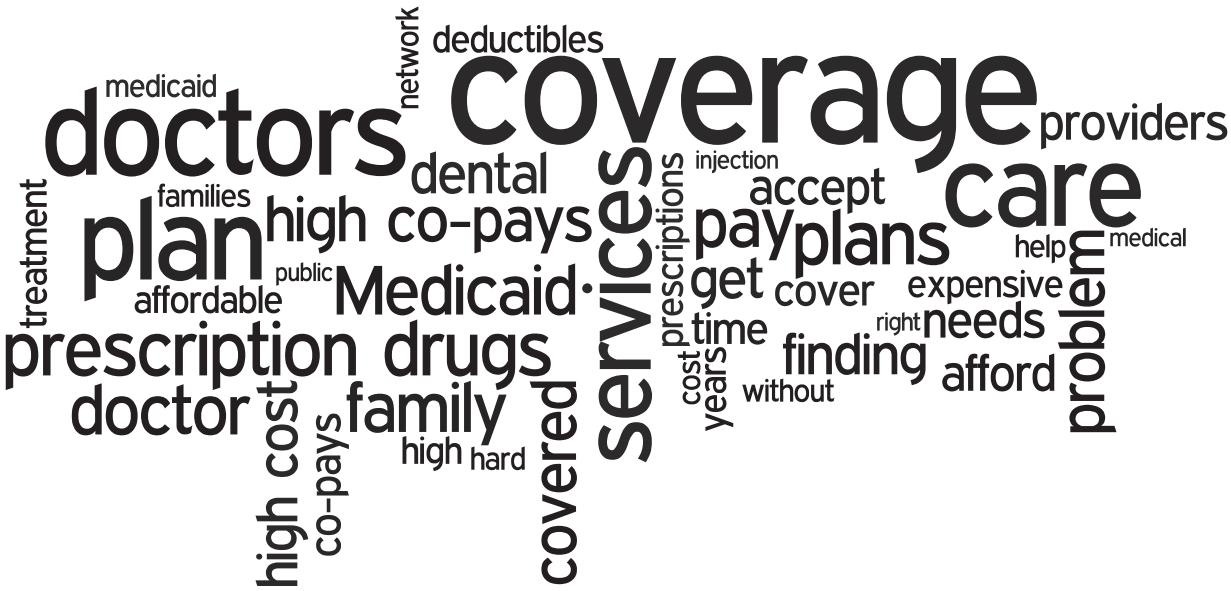
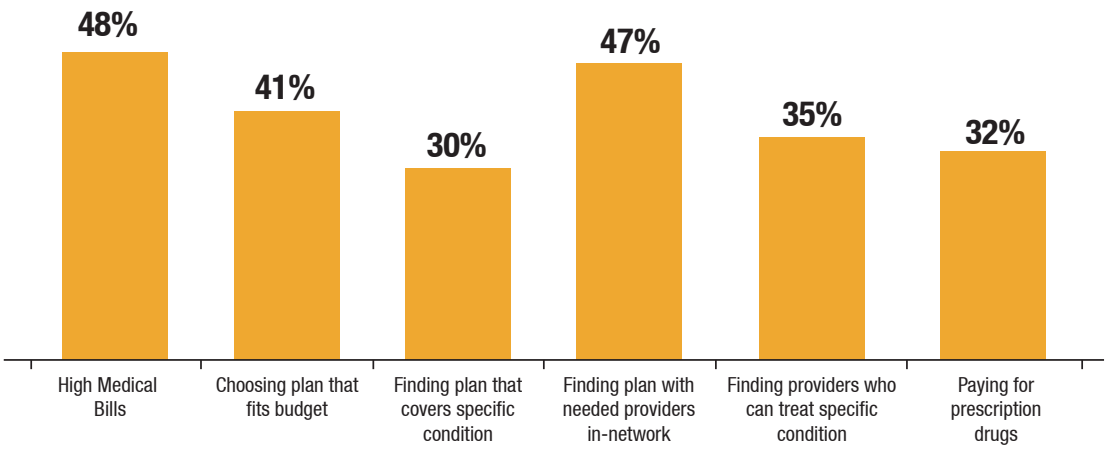


FIGURE 1:
What kinds of problems have you or close friends or family faced with health insurance coverage?



Field Survey Results, n=166

Consistent with extensive national and state-based research, cost was a major concern for many participants. Forty-one percent of those we spoke to reported having trouble finding a plan that fits their budget. Even consumers with coverage said they have trouble paying for premiums, co-pays, or services (and providers) not covered by their policy. Others wrote in that there were no affordable insurance options available at all. Often this coincided with being over the income level for public insurance eligibility. Similarly, 32 percent of participants voiced concern over the cost of prescription drugs. Forty-eight percent said they had problems with high medical bills.

Plan quality in relation to limited provider networks and limited benefits covered also topped the list of concerns. Forty-seven percent of participants indicated they had problems accessing their preferred or needed providers because they did not belong to their plan's provider network. Many wrote in that their preferred providers did not accept Medicaid. Thirty-five percent said they had trouble finding doctors who could treat their specific condition. Thirty percent said they had problems finding a plan that would cover their specific condition. Others spoke about not having coverage for needed benefits or high-quality services. For example, a survey respondent from the town of Kenmore in Western New York said that her insurance required her to pay high co-pays for each of the radiation treatments, blood-work, and other procedures she needed to treat her cancer. A patient without the money for those co-pays, she worried, would be forced to choose surgery instead, a less-effective treatment option. Similarly, others had plans that did not include access to other needed benefits, like dental care, durable medical equipment, or hearing aids.

Finally, ease of use was of great concern to many participants. Most said that the current system is much too confusing and difficult for the average consumer to navigate. Many did not understand their plan benefits or how costs were calculated. Others said they had trouble finding doctors that spoke their language.

The following sections look at each of these issues identified—affordability, quality of plans, and ease of use—in depth and provide recommendations on each.

Latesha Richards, a 34-year-old Brooklyn resident, is one of the one million New Yorkers who may gain insurance coverage through the New York Health Benefit Exchange in 2014. Latesha has not had insurance since 2007, when she left a job that provided coverage. The job she moved to did not work out, and the part-time jobs she found during the recession paid too little for her to purchase insurance on her own. She is interning and volunteering now to build skills and make connections as she looks for paid work in marketing in the health care field.

Latesha counts herself lucky to be healthy, and takes advantage of free health screenings at health fairs when she can. "In general everything is fine, but I am concerned that—God forbid—anything serious should happen, that I would not be able to afford proper healthcare," Latesha said. "The thing is, I am collecting unemployment so I can't get Medicaid, and the health insurance policies are unaffordable. I am still looking for more affordable options." Latesha will be able to find those affordable options on the Exchange starting October 1st.

2 AFFORDABILITY

One of the most common concerns consumers talked about regarding the existing insurance market was affordability. This included high insurance premiums, high cost-sharing requirements, and high bills for services that are not covered by their insurance. One solution available to make health insurance more affordable for low-income New Yorkers, which HCFANY discussed with participants, was the option for the state to create a Basic Health Plan through the Exchange.[4]

The Basic Health Plan Option

The ACA addresses affordability issues in three ways: by mandating individuals to have coverage (which lowers cost by spreading insurance risk over a greater population), by offering premium tax credits and subsidies to make the purchase of coverage affordable, and by permitting states to establish a Basic Health Plan (BHP) for low-income residents.

A BHP is a state coverage option for people who earn too much to qualify for Medicaid, but still have incomes low enough to have trouble paying for private coverage even with subsidies available through the Exchange. Even with subsidies, the annual premium for a low-income family of three in the Exchange can range between $780 and $2,330 a year. Consumer advocates have argued and public opinion surveys have found that these premium levels are more than many families can afford.[5] If adopted by a state, a BHP would cover individuals between the Medicaid eligibility cutoff of 138 percent and 200 percent of the Federal Poverty Level (FPL) (between $26,000 and $39,000 for a family of three).[6] Lawful immigrants who do not qualify for federally-matched Medicaid because of their immigration status would also be covered below the Medicaid threshold of 138 percent of FPL.

The benefits of a BHP are twofold: it would lower costs for the state, and provide quality, affordable coverage to low-income New Yorkers. Experts agree that the BHP would be paid for entirely with federal funding, saving New York State between $500 million and $1 billion a year.[7] Consumers who sign up for the BHP are also guaranteed to get coverage that is at least as affordable and comprehensive as that offered by private plans in the Exchange.[8] However, there are potential downsides to having a BHP. For example, consumers might have fewer plan choices in a BHP than they would in the Exchange market.

Susan Rumack, a 62-year-old Buffalo resident, is hoping that New York creates a Basic Health Plan (BHP). Susan is unemployed and hasn't had insurance since her last job ended. She lives on a small amount of income from shrinking investments, but that small income makes her ineligible for Medicaid. Susan explored all of the options available now, from Healthy New York to the New York Bridge plan, but cannot afford any of them. So, she visits a doctor only in emergencies and does her best to manage her diabetes on her own. Susan's brother-in-law died of diabetes, so she knows how dangerous it is to neglect care for the condition. "I'm waiting for the Exchange and hoping that it includes a BHP," Susan said. "I think it's my best hope for quality health care that I can really afford."

HCFANY asked consumers whether New York should offer a BHP.

Findings:

HCFANY found overwhelming support for a BHP in New York. Participants across the board recognized that low-income New Yorkers would have trouble meeting out-of-pocket costs for coverage on the Exchange, even with federal subsidies. Eman Rimawi, a freelancer in Brooklyn, explained at the Brooklyn Roundtable, "the problem is that when people have low incomes, they do not really have any disposable income. When I think about having to pay another $100 a month, it is kind of difficult."

For most participants, the BHP seemed to be a clear win-win solution for New York. As Carmina Bernardo of Planned Parenthood of New York City said at the Upper Manhattan Roundtable, "Not only would the BHP allow people who are not Medicaid-eligible to have access to comprehensive coverage, but the Federal government is paying for it. What is the challenge in doing this?"

There were, however, three concerns about a BHP that the Exchange would have to address. Providers worried that provider reimbursement rates through a BHP would not be high enough to attract strong networks. Some consumers also mistakenly assumed that the name "Basic Health Plan" meant that the BHP would offer very limited benefits. And a few participants did not like the idea that consumers who qualify for the BHP would not be able to purchase Exchange-based coverage with subsidies.

Recommendations:

Under new federal guidance, New York has the option to launch a BHP beginning January 1, 2015 and additional federal guidance is expected shortly.[9] But the design and launch of a BHP takes significant state planning and also requires authorization from the Legislature. In 2013, the legislature authorized a workgroup to study this issue. Based on the feedback of participants in the Listening Tours, we recommend that:

- The Exchange should offer BHP plans beginning in 2015.
- These BHP plans should have adequate provider networks.
- Consumer education materials and product marketing and branding should make it clear that the BHP offers comprehensive coverage, not just "basic" benefits.

"I hear from many uninsured families who are facing serious struggles while health care costs keep rising. I'm happy that relief is on the way. An Exchange will give hundreds of thousands of New Yorkers a far stronger sense of security. A Basic Health Plan will give people that have been uninsured for lengthy periods of time the opportunity to secure a quality health insurance plan and the ability to maintain their health."

- Senator Tim Kennedy, Buffalo, NY

3 MAKING HEALTH INSURANCE COVERAGE EASY TO ENROLL IN AND USE

Participants agreed that the health insurance system today is extremely complex, and can be very difficult for the average person to navigate. We explored one solution to this problem, the creation of robust Consumer Assistance and Navigator programs.

Consumer Assistance and Navigators

Health insurance plans are complicated. Consumers and small employers often are faced with a dizzying array of plan offerings with confusing terms. Consumers regularly have difficulties finding their preferred providers in their plan's network, taking advantage of new rights and benefits under the ACA, and resolving issues with insurance companies and providers.

Congress anticipated these problems and included funding for state-based Consumer Assistance Programs in the ACA to help consumers understand their new rights and enrollment options under the ACA. New York's Consumer Assistance Program, Community Health Advocates (CHA), has helped resolve over 100,000 cases for New Yorkers since November 2010. CHA provides health care and health insurance information, advice, and navigational assistance to uninsured and insured consumers and small businesses through a toll-free helpline and through a network of trained and trusted health advocates in communities throughout the state. New Yorkers can also get help signing up for public programs from Facilitated Enrollers, and small businesses can turn to brokers and organizations like the Chamber of Commerce for help enrolling in commercial coverage.

Congress also anticipated that consumers will need help understanding and enrolling into their new coverage options through the Exchanges. In addition to providing customer services through a website and phone assistance, each Exchange must set up a Navigator program to provide community-based outreach and enrollment assistance.[10] To do so, the Exchange will contract with entities around the state that have existing relationships with consumers and small businesses. Navigators can be groups like consumer-focused nonprofits, trade and industry groups, Chambers of Commerce, and other public and private entities.[11]

We asked consumers what this assistance should look like—would phone assistance and Internet access be enough, or would consumers need "hands-on" assistance from individuals to lead them through the process? We asked them where they would prefer to get information: from a community group or a government agency? Through these questions, and others, we were able to explore their preferred format for Consumer Assistance and the state's future Navigator program.

Findings:

Participants recognized that many New Yorkers will need help enrolling in coverage through the Exchange. Many participants worried that some consumers might not be able to navigate the Exchange website due to low literacy levels, lack of experience using computers, or difficulty accessing the internet because of lack of familiarity

with it or because they live in rural areas with limited connections. Consumers and advocates for people with disabilities raised concerns about the accessibility of the Exchange website. "Many websites are not accessible to blind, cognitive, or physically disabled readers," explained Mel Tanzman of Westchester Disabled on the Move at the Westchester Roundtable. "Disability experts should look at the website before it goes live."

Participants also worried that a call center might not be able to serve everyone effectively. They felt that a consumer with limited English proficiency, low literacy, or a disability might have trouble getting help through a call center. "The people [answering calls for the Exchange] have to speak the kind of Spanish that a person without a college education will understand," said Samantha Paz of the Hispanic Federation, Manhattan.

For these reasons, participants agreed, the Exchange must design Exchange customer services, including the website and telephone support, in active consultation with consumers, small businesses, and advocates for the disabled, immigrants, and other underserved communities.

Participants also spoke about the need for enrollment assisters and consumer assistance based in the community. HCFANY heard over and over again about the need for "hands on" help in the community. In response to our question about the best way to provide this assistance, some participants favored government agencies because they are considered highly credible and responsible purveyors of independent information. But others recounted bad experiences when trying to get help from a local social services office. These participants favored help

"Phone and Internet not are enough—especially in the beginning. There needs to be face-to-face. I believe a nonprofit would do better than a government agency, but a nonprofit would need funding to provide service."

- Survey response from participant in a listening session at the Center for Disability Rights in Rochester.

available through trusted community-based organizations (CBOs). All agreed that staff members at government agencies or CBOs should be thoroughly trained. The word cloud on the previous page shows the words that came up most frequently in participants' written answers to this survey question.

Recommendations:

Regardless of how consumer-friendly the Exchange is designed to be, some consumers and small businesses will need more in-depth help. Some will need help choosing coverage on the Exchange and figuring out whether they qualify for tax credits. Others will have coverage for the first time and will need help understanding how to use their new coverage, find a primary care doctor, and deal with paperwork. HCFANY heard from participants that they want to be able to turn to someone in their own community who can explain their options in plain language. Based on these conversations, HCFANY recommends that:

- The Exchange should provide significant funding to ensure that there is enough community-based, one-on-one assistance to serve all of the consumers and small businesses who require help.
- Consumer assistors, based in CBOs or government agencies, should be thoroughly trained and monitored on public and private coverage, as well as linguistic and cultural competency.
- Community-based entities should be diverse, to reach all of New York's diverse consumers.
- The Exchange website and telephone assistance should be accessible to consumers with low literacy, limited English, and disabilities.

4 QUALITY

HCFANY found that quality proved to be as important to participants as affordability. Consumers and small employers alike were frustrated by the perception that they are paying for coverage that does not cover the services they need. Others had trouble finding needed providers through their plan networks.

We explored three areas related to the availability of high quality, comprehensive coverage on the Exchange for consumers and small businesses: (1) addressing health equity; (2) negotiating or setting quality standards with health plans; and (3) the essential health benefit package.

Addressing Health Equity

As part of the listening sessions, HCFANY asked participants how the Exchange might address health equity. Studies show that racial and ethnic minorities, women, people with disabilities, and lesbian, gay, bisexual and transgender (LGBT) people often receive a lower level of care and have poorer health outcomes than others. For example:

- African American and Hispanic New Yorkers die prematurely at rates nearly twice that of whites;[12]
- People with mental illness tend to die on average 25 years earlier than the general population; [12]
- LGBT people are more prone to experience depression and anxiety, which seems to be linked to stigma and bias-related violence. [14]

In some cases, these disparities can be compounded by several factors. For example, women of color are affected by disparities related to both gender and race, like high rates of maternal mortality and morbidity.

HCFANY asked Listening Tour participants if they were aware of health disparities. We also asked them to think about different ways that the Exchange could reduce disparities. We explored some concrete examples, including: targeting enrollment efforts to communities with high rates of uninsurance; allowing the Exchange to enroll people in all public health programs; requiring

insurance companies and hospitals to collect data on health outcomes by race, gender, primary language, disability status, sexual orientation, and other factors; ensuring that the Exchange has adequate language services and bilingual staff; and requiring cultural competency training for health care providers and consumer assistance staff. Many of these tactics were recommended in a recent report prepared for the New York State Department of Health Exchange by the Center for Popular Democracy on how the Exchange can help reduce health disparities.[15] We also asked participants to suggest other solutions.

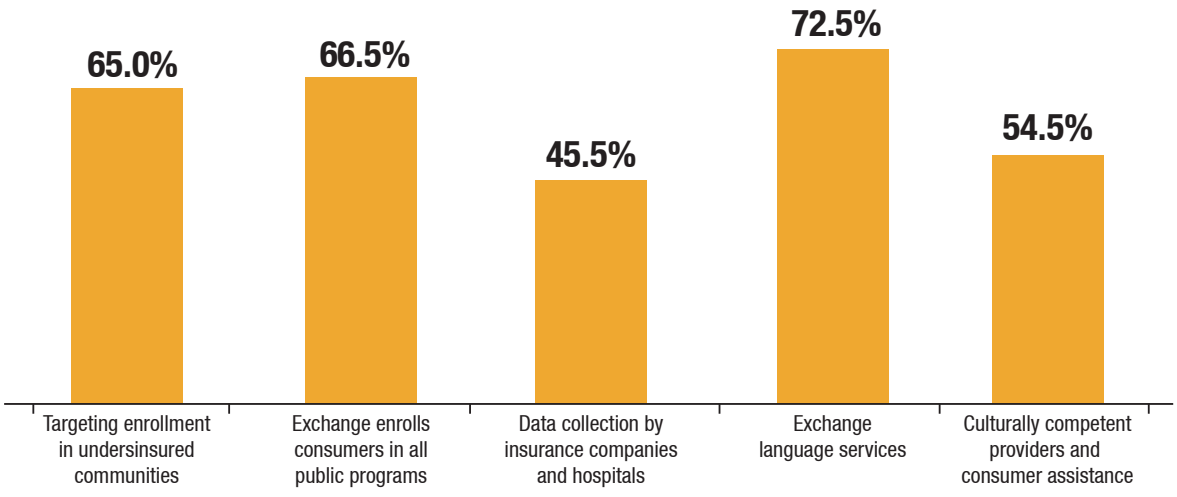
Findings:

Participants were very much aware of the existence of health disparities related to race, gender, sexual identity, and disability. We heard broad support for Exchange measures to reduce these disparities.

As Figure 2 shows, survey respondents supported every example of health equity measures we presented. Providing effective language services, targeting enrollment measures in underinsured communities, and screening Exchange applicants for all public programs were the most popular recommendations. These three tactics in particular would ensure the greatest enrollment take-up by underserved communities who may not be proficient in English or aware of the opportunities available to them. More than half of participants also prioritized cultural competence training for providers and consumer assistance available through the Exchange. Data collection, which was perceived as a less urgent matter, ranked the lowest. However, it was still prioritized by just under half of participants.

One barrier to reducing health disparities that many participants identified is the lack of information to help consumers decide which plans address disparities that may affect them. "There are no ratings on LGBT health, or gay-friendly providers. It just doesn't exist. There are ratings on women's health, on adolescent health; there are no ratings on LGBT health," said Liz Pantino of Callen-Lorde Community Health Center, at the Upper Manhattan Roundtable. "When people ask which health plan is good for them, we don't have an answer for them.

FIGURE 2:
Health Equity–What kinds of steps do you think the Exchange could undertake?



Field Survey Results, n=200

There is no data for them to actually do the research on their own."

Others spoke of the need for culturally competent providers with front-line staff who treat patients with respect, regardless of factors like race, income, sexual identity, or insurance type. "If you are a person of color, and you are asked 'how many kids you have?' rather than 'what kind of reproductive care do you need?' that stigmatizes people," said Reverend Dominique Atchison of Brown Memorial Baptist Church at the Bronx Roundtable. "So does assuming all heavy people have high blood pressure or assuming the person has asthma rather than allergies. Also, people at the front desk can be rude."

Participants also discussed the need to eliminate barriers that prevent immigrants from accessing coverage and care. "As an immigrant myself, sometimes it is difficult to find services where our needs and experiences are understood," explained Cesar Palomeque of Queens. "Sometimes people in my community are scared that their child won't qualify for insurance because the parent is undocumented, or think that if they apply for their children it will affect their immigration status." Cesar suggested that funding and training CBOs in the immigrant community to provide consumer assistance could help reduce some of this confusion.

Recommendations:

The Exchange has many opportunities to improve health equity. Listening Tour and Roundtable participants supported the following proposals:

- Provide effective language assistance though multilingual staff, interpreters, translated materials, and materials in formats accessible to people with disabilities. The Exchange should also require Navigators to provide language services.
- Target enrollment efforts to reach underserved communities with high numbers of uninsured members.
- Allow consumers to screen for and enroll in all public programs through the Exchange, including SNAP assistance, hospital charity care, and Emergency Medicaid.
- Provide access to coverage or care to all immigrant residents of New York, regardless of their immigration status. Ensure effective outreach to immigrant communities through community-based organizations so residents understand how to apply.
- Collect demographic data that allows the state to track and analyze progress in reducing health disparities.
- Require plans, providers, and Navigators to participate in cultural and disability competency training.
- Set standards for plans sold through the Exchange that address disparities, including: nondiscrimination requirements; diverse provider networks, including providers who speak languages other than English; and meeting health equity quality measures. This data should be regularly reported and updated to allow consumers to make better informed plan choices.

Negotiating for Quality

Currently, consumers who buy coverage on the individual market and small businesses have much less bargaining power than a large employer buying coverage for hundreds of workers. As a result, large employers generally get a better deal on insurance than individuals and small businesses. Small businesses who do not employ human resources staff can also be overwhelmed by the roughly 15,000 different plan offerings in New York, which make it a daunting process to find and choose a plan.[16] However, beginning in 2014, the state has the option to ensure that only the highest quality, most affordable coverage is offered through the Exchange.

Under the ACA, New York could potentially use the bargaining power of the one million consumers slated to get coverage through the Exchange to negotiate better

deals with insurance companies than any one consumer could do on her own. The New York Exchange could also set quality standards and only sell insurance that meets those high standards. This is called "active purchasing" or "selective contracting." For example, California's Exchange will be pursued an "active purchaser" model when it selected the plans to be offered to Californians.

However, active purchasing does have some potential drawbacks. Selecting only the plans that bid to meet the lowest prices or the highest quality standards might mean that some consumers would have fewer—or even no—choices. This could be particularly detrimental to the many parts of the state where there are just a few (or even one or two) plans that serve that region of the state. Additionally, if too few plans are selected, there may not be enough capacity to serve the volume of enrollees expected to acquire coverage through the Exchange.

An alternative to a pure "active purchasing" model would be to use the Exchange as a vehicle to standardize the market. In fact, New York State appears to be pursuing a hybrid approach to procurement which will force standardization of the products offered in the individual and small group market.[17]

We asked consumers two questions about this issue. First, we asked whether they thought that: (1) all plans meeting basic standards should be allowed in the Exchange (prioritizing choice); or (2) only the highest quality plans should be allowed (prioritizing quality). Next, we asked consumers what standards the Exchange should look at. We provided some possible answers, including: broad provider networks; provider networks that meet the needs of specific communities; a range of specialists; strong consumer assistance; and affordability. Consumers were also asked to suggest other standards.

Findings:

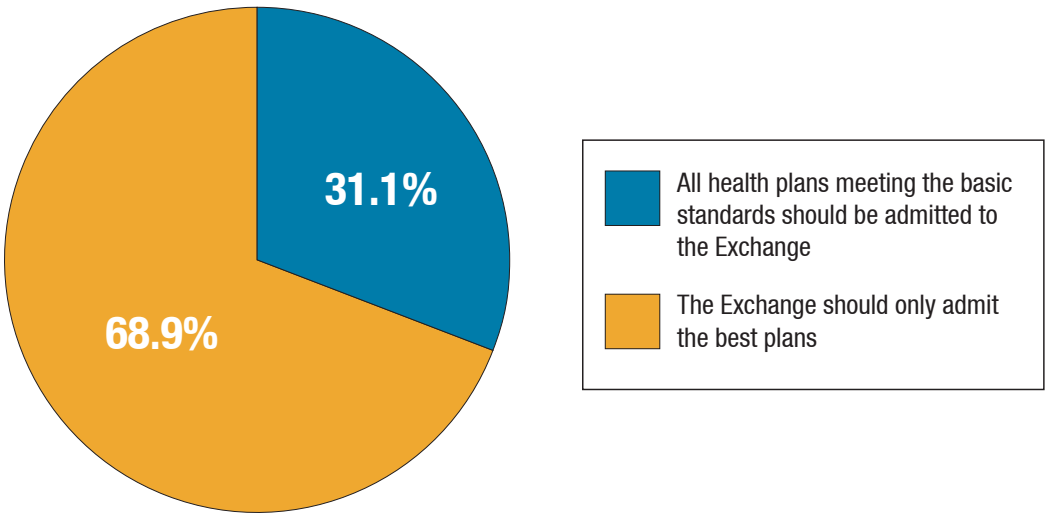
Most participants said that the Exchange should use its negotiating power to hold participating plans to higher standards. Almost 70 percent of survey respondents said that the Exchange should select the highest quality plans for consumers (see Figure 3).

Many were willing to let the Exchange help sort out the highest quality plans, even if it meant that there would be fewer insurance plans available on the Exchange. One survey participant from the Bronx explained, "It is better to have fewer but better quality plan choices. This way, there is a set standard for choices, then it is the consumer's choice to decide which plan to participate in."

Some participants said they would like to have all available choices, even lower-quality plans, because they might be more affordable. These participants emphasized that the Exchange should provide enough information to allow consumers to make educated choices between plans, and strong consumer assistance. For example, a Manhattan survey respondent said, "The key for me is education and information. The consumer should be given all the facts in order to make the best choice. There should be independent, objective people to answer their questions and help them find a plan that suits their needs."

Participants supported all of the five examples of standards for Exchange-offered plans that we presented (broad networks; networks that meet the needs of specific communities; a range of specialists; strong consumer assistance; and affordability). Suggestions for standards made by participants included: standards related to health outcomes; an easy-to-deal-with payment system; and compliance with offered plan benefits.

FIGURE 3:
The Exchange as an Active Purchaser or Active Negotiator–
Which of the following most closely fits your personal views?



Field Survey Results, n=225

Recommendations:

New York's Exchange released its invitation for plans to participate in the NYS Health Benefit Exchange in late January 2013, which included the standards that plans must meet in order to participate in the Exchange as a Qualified Health Plan.[18] HCFANY was glad to see that the Exchange set relatively high standards for plans that wish to participate in the Exchange, including standards to ensure network adequacy, non-discrimination, consumer assistance and customer service, accessibility, and decertification for plans that fail to comply. Notably, plans who wish to participate must also include a quality strategy to address health disparities. Further, this move to standardize health plans via the Health Benefit Exchange puts the state in prime position to take on an active purchasing role in the future.

Essential Health Benefits

A measure of quality that resonated with consumers around the state is whether their insurance covers the services that they and their families need. This includes both basic services like preventive care, and more comprehensive services, like cancer treatments and mental health services.

The ACA addresses this issue with a requirement that plans offered inside and outside the Exchange must cover a benefit package called the "essential health benefits" (EHB) package starting in 2014.[19] Each state had the opportunity in 2012 to decide on a unique EHB package for its residents based on federal regulations. To do so, each state selected a "benchmark" plan from a list of ten state-based plans; the benefits included in that selected plan will serve as the list of essential health benefits for the state through 2015.[20] The ten benchmark plan options included: (1) the three largest small group insurance products in the state's small group market; (2) the three largest state employee health benefit plans; (3) the three largest national federal employee health plan options; or (4) the largest Health Maintenance Organization (HMO) in the state.

We asked Listening Tour participants which of the four types of benchmark plans they would prefer for the EHB. We also asked them to name specific benefits that they and their family members need coverage for.

Maria Morales owns a restaurant, Los Potrillos, on Staten Island. She has not been able to get insurance yet for herself and her three employees because the available plans are too expensive. When she needs health care, she travels to Mexico for more affordable care.

"I work every day, sometimes up to one hundred hours a week for my business and my clients, and I'm proud of what I've done for the community," Maria said. "But I would like to have health insurance."

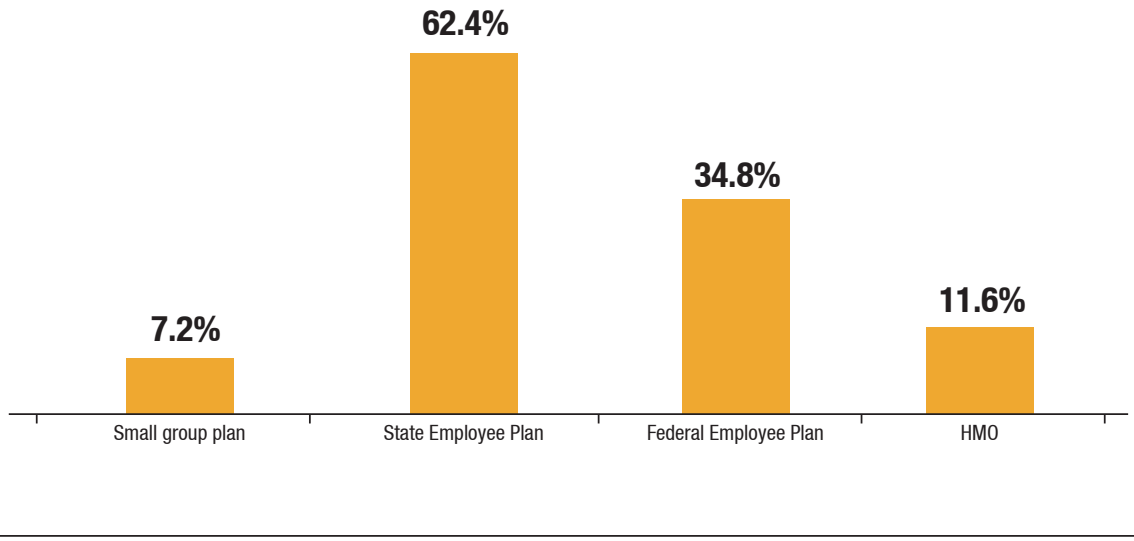
Maria plans to get coverage for her business on the Exchange in 2014, and she wants the Exchange to use its bargaining power to ensure that there are good options available for small businesses like hers. "I want there to be affordable insurance—low cost and good quality," she explained. "Sometimes, small businesses are tempted to buy the cheapest plan to save money. But if the plan does not cover the services needed or if you have to pay a large deductible, we will end up owing even more money."

Findings:

Participants overwhelmingly spoke in favor of selecting a more comprehensive EHB benchmark plan. Out of the options available, survey respondents as a whole preferred the federal or state employee benefit plans, which cover the most comprehensive range of benefits (see Figure 4).

We also asked participants which specific benefits were most important to them and their families. Dental care, prescription drugs, vision, preventive care, and hospital care were the most frequently mentioned. One survey respondent in Brooklyn said, "It is important to have care that will cover you if you become majorly hurt

FIGURE 4:
Essential Health Benefits–Which of these options would you prefer?



Field Survey Results, n=181

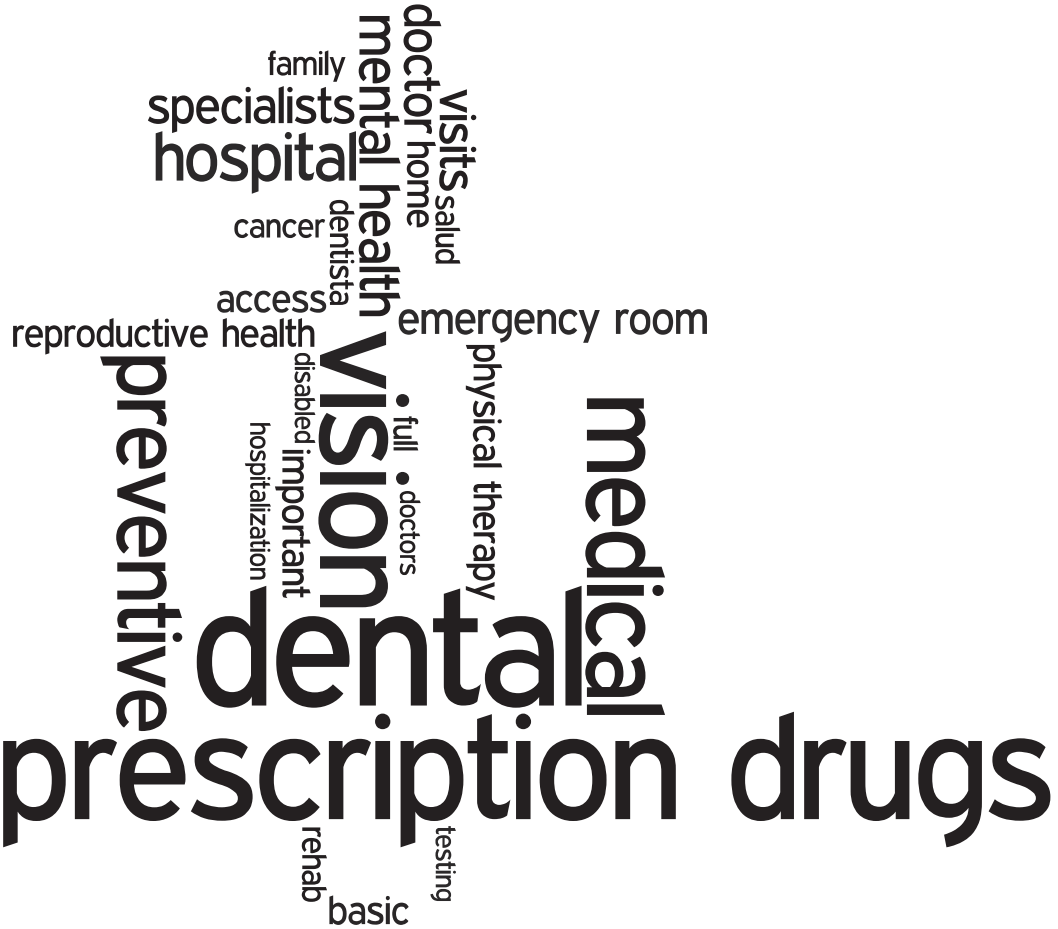
or disabled. Basic annual checkups and reproductive health are necessary." Many respondents discussed the importance of covering preventive care to avert more costly care. Others spoke of the need to cover emergencies and health crises like a cancer diagnosis. The word cloud below shows the most common terms people used in the written surveys in response to this question.

Recommendations:

In New York, the benchmark decision ultimately came down to a choice between two plans: the largest small group plan (an Oxford plan) or the Empire Plan, a New York State employee plan. The Empire plan was more generous, but would cost about $16 per member per month more than the Oxford plan.[21]

Consumer advocates argued for the adoption of the Empire Plan, which had more generous benefits, despite the higher cost. But business groups and insurance companies preferred the Oxford plan, which they believed still had generous benefits, but would be more affordable for their constituents. The State Exchange staff ultimately selected the Oxford plan.[22] New York will have another opportunity to revisit this decision in 2015.

Consumers spoke out strongly in favor of a more comprehensive benefit package—despite the higher cost—in our conversations. Moving forward, we recommend that the Exchange collect feedback from consumers about how well the Oxford EHB benchmark that was selected meets the needs of consumers and small businesses. The Exchange should also carefully study the effect of any benefit substitutions that plans are allowed to implement to ensure that these benefit choices help consumers.



Laura McLoughlin, a 32 year-old Brooklyn resident, spoke of the need for comprehensive benefit packages that cover the services people really need. Laura spent six years paying off dental bills incurred while she had employer-based insurance coverage that did not cover dental services.

"Thank God the dentist allowed me to pay him 50 dollars a month," she said. "Not everyone will let you do that."

Later, waitressing to pay her way through graduate school, Laura went without health insurance. When she needed dental care, she went to a dental clinic that offered discounted care by dental students. "I was grateful for that service but they ended up breaking my tooth so they just had to pull it out. I don't think I got the best care because I had to go wherever I could get care affordably."

5 PUBLIC PARTICIPATION

Listening Tour participants, many of whom were learning about the Exchange for the first time, agreed that New York's Exchange should actively reach out to consumers and small businesses to teach them about the new coverage options and get feedback about the best ways to serve them. As of the publication of this report, New York has offered limited opportunities for stakeholders to weigh in on the design of the Exchange. Most of these opportunities have been focused on experts and professional advocates, rather than the average consumer or small business owner.

Currently, the primary means of stakeholder input on the New York Exchange is through the state's Regional Advisory Committees (RAC). The RACs divide the state into five regions: Western; Central/Finger Lakes; Capital District/Mid-Hudson/Northern; New York City/Metro; and Long Island. The RACs include representatives for consumers, small businesses, health care providers, insurance companies, agents and brokers, labor organizations, and others. In September 2012, Exchange staff briefed each RAC on issues and asked for feedback. A limited number of non-RAC members were able to attend the meetings, which were broadcast live, and recordings of the meetings are now posted on the Exchange website. A second set of RAC meetings were held in May 2013.

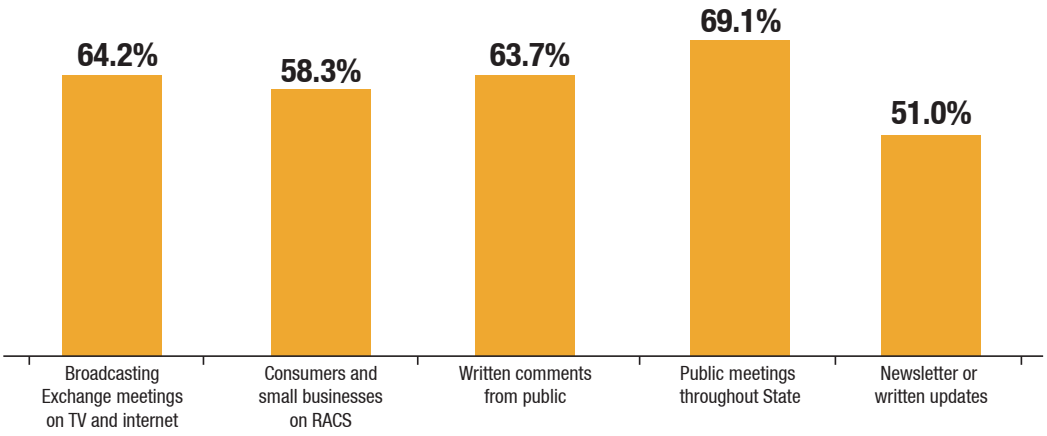
Each avenue for stakeholder input so far has required a very high level of background knowledge about health coverage issues. The average consumer would not have been able to drop into a RAC meeting and follow the conversation that took place. So, HCFANY asked consumers how they thought the Exchange should share information with and solicit feedback from the general public.

We suggested five possible methods of public engagement: (1) broadcasting Exchange meetings on public television or the internet; (2) including consumer and small business representatives on the RACs; (3) allowing written comments; (4) holding public meetings around the state; and (5) sending out a newsletter.

Findings:

Participants agreed that the state should utilize all possible routes of public education and engagement and voiced strong support for each of the 5 methods we suggested (see Figure 5). Participants also had many different ideas about the best ways to inform members of

FIGURE 5:
What are the best ways of informing the public and getting public input?



Field Survey Results, n=204

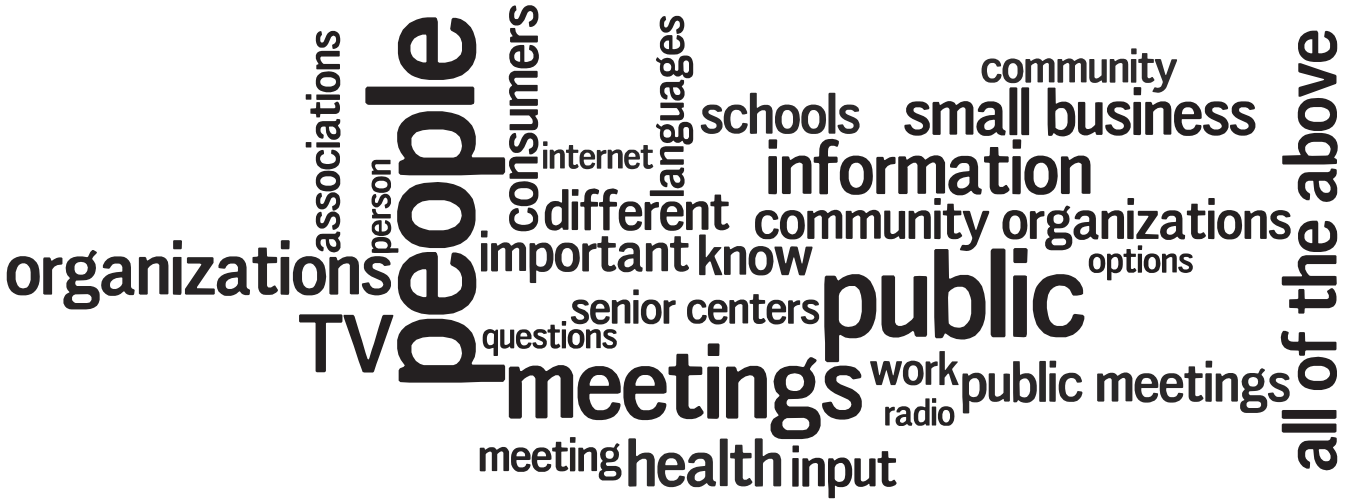
their communities about the Exchange. In addition to the five suggestions we provided, participants suggested the following ideas:

- Bus shelter ads
- Ads on ethnic radio and television stations
- Workplace information sessions
- Outreach workers in grocery stores and other public places
- Door-to-door canvassing
- Social media like Facebook and LinkedIn
- Health fairs
- Meetings at schools, community centers, senior centers, Independent Living Centers, and public housing

Participants agreed on the importance of engaging community-based organizations that have strong relationships with community members. Some participants suggested that faith-based organizations will be a critical resource, because many consumers belong to faith communities, and faith leaders are trusted messengers.

Many participants also supported the idea of holding public forums in communities around the state. One participant pointed out that the meetings should be held at different times of the day, so that community members with different work schedules could attend.

Participants said that the Exchange should ensure that consumers and small businesses get information in a language they can understand. Participants stressed the importance of providing all communications, from written materials to speakers at events, in the languages commonly spoken in New York. Further, as some pointed out, there is more work to be done just to break down these complex policy issues into plain English. The most commonly used terms in written survey responses are shown in the word cloud on the following page.



Legislators who attended Roundtable events urged participants to contact their elected officials about the importance of these issues. At the Bronx Roundtable, Senator Ruth Hassell-Thompson recommended that community members organize and bring health care issues to the attention of their legislators. On Staten Island, Assembly Member Matthew Titone suggested that participants contact their elected officials. If community members can not get a meeting with an elected official, he recommended that they collect and send in letters from their neighbors.

Recommendations:

We heard from participants that the Exchange should use a wide variety of methods to reach out to every community in New York, and particularly communities with high rates of uninsurance. One of the most common written responses to our question about what methods to use was "all of the above." We recommend that the Exchange adopt this "all of the above" approach to public participation in the Exchange:

- The Exchange should implement a robust and coordinated public education campaign to inform consumers about the new coverage available in 2014. The Exchange should get design input from community stakeholders, including consumer groups and small business representatives.
- The Exchange should take this education campaign into the community through a variety of venues including: schools, senior centers, houses of worship, door-to-door canvassing, and other examples listed above.
- The Exchange should utilize ethnic and local media, social media, television and radio, and other media resources.
- The Exchange should mobilize community-based organizations (CBOs) that reach into New York's diverse communities. These CBOs are the most effective way to get the word out to consumers.
- The Exchange should engage consumer and small business representatives to the RACs, keeping them well-informed about the issues and providing timely and meaningful opportunities for them to consult with their constituents and weigh in on critical decisions.

Conclusions

In the years to come, New York's Exchange will serve millions of consumers and small businesses that need help finding and using affordable, high quality health coverage. In this respect, consumers and small businesses are the real experts when it comes to identifying what the Exchange must provide to be consumer-friendly. Yet, many New Yorkers do not know anything about the Exchanges or other benefits available to them under the Affordable Care Act. They need to know more about their options, and they need more opportunities to weigh in on Exchange design.

The recommendations provided in this report merely scratch the surface of the level of public engagement needed to inform the design process for a successful Exchange. A strong information and feedback loop for consumers and small businesses must be incorporated into the Exchange design and operational processes moving forward to ensure that consumers secure the promise of the Affordable Care Act: affordable, quality health coverage for all.

ENDNOTES

[1] Patient Protection and Affordable Care Act of 2010 (ACA), Pub. L. No. 111-148.

[2] Executive Order 42, April 12, 2012, available at http://www.governor.ny.gov/press/04122012-EO-42.

[3] December 14, 2012 letter from Secretary of Health and Human Services (HHS) Kathleen Sebelius to Governor Andrew Cuomo, available at http://www.cciio.cms.gov/resources/files/Files2/ny-blueprint-exchange-letter-12-14-2012.pdf.

[4] After the Roundtable discussions were completed, HHS announced that the Basic Health Plan option will not be available to states until 2015. See "Questions and Answers: Medicaid and the Affordable Care Act," Centers for Medicare and Medicaid Services, February 2013, available at http://www.medicaid.gov/State-Resource-Center/Frequently-Asked-Questions/Downloads/ACA-FAQ-BHP.pdf.

[5] E. Benjamin and A. Slagle, "Bridging the Gap: Exploring the Basic Health Insurance Option for New York," Community Service Society, January 2012. http://www.healthcarereform.ny.gov/research_and_resources/docs/bridging_the_gap_exploring_basic_health_insurance_option.pdf.

[6] A BHP would also cover lawfully present immigrants who are ineligible for federal Medicaid funding. Under welfare reform legislation passed in 1996, Medicaid applies a limited definition of "qualified aliens" that excludes some lawfully present immigrants who will qualify for exchange subsidies in states that do not implement BHP. Under a court case called Aliessa v. Novella, 730 N.Y.S.2d 1 (2001), New York covers hundreds of thousands of immigrants with state-only Medicaid funding.

[7] *Supra* n 5. See also S. Dorn, "The Basic Health Program Option under Federal Health Reform: Issues for Consumers and States," The Urban Institute, March 2011. Available at http://www.urban.org/UploadedPDF/412322-Basic-Health-Program-Option.pdf.

[8] S. Dorn, "The Basic Health Program Option under Federal Health Reform: Issues for Consumers and States," The Urban Institute, March 2011. Available at http://www.urban.org/UploadedPDF/412322-Basic-Health-Program-Option.pdf.

[9] "Questions and Answers: Medicaid and the Affordable Care Act," Centers for Medicare and Medicaid Services, February 2013, available at http://www.medicaid.gov/State-Resource-Center/Frequently-Asked-Questions/Downloads/ACA-FAQ-BHP.pdf.

[10] ACA, Pub. L. No. 111-148 §1311(i).

[11] Under the ACA, grants to Navigators must come from Exchange general funds, not federal Exchange Establishment grants. New York will also make grants to "In Person Assistors" using Exchange Establishment grant funds. The In Person Assistor program will be very similar to the Navigator program.

[12] NYS Department of Health, New York State Minority Health Surveillance Report 2012, p. 47, available at http://www.health.ny.gov/statistics/community/minority/docs/surveillance_report_2012.pdf.

[13] Craig W. Colton, PhD, Ronald W. Manderscheid, PhD "Congruencies in Increased Mortality Rates, Years of Potential Life Lost, and Causes of Death Among Public Mental Health Clients in Eight States," Preventing Chronic Disease, vol. 3 no. 2, April 2006.

[14] King, M., J. Semlyen, S. S. Tai, H. Killaspy, D. Osborn, D. Popelyuk, and I. Nazareth. 2008. A systematic review of mental disorder, suicide, and deliberate self-harm in lesbian, gay and bisexual people. BMC Psychiatry 8:70.

[15] Agarwal, N., "New York Health Benefit Exchange: Reducing Health Disparities, January 21, 2013, available at: http://www.healthbenefitexchange.ny.gov/resource/new-york-health-benefit-exchange-reducing-health-disparities.

[16] Wakely Consulting, Benefit Standardization Study for the State of New York, June 2012. Available at: http://www.healthcarereform.ny.gov/health_insurance_exchange/docs/wakely_benefit_standardization_study.pdf.

[17] New York State Department of Health, Office of the New York Health Benefit Exchange, Invitation for Health Insurer and Dental Plan Participation in the New York Health Benefit Exchange, January, 2013. Available at: http://www.healthbenefitexchange.ny.gov/sites/default/files/Invitation%20to%20Participate%20in%20NYHBE_0.pdf.

[18] *Ibid*

[19] ACA § 1302. Some plans are exempt from this rule: self-insured group health plans, health insurance coverage offered in the large group market, and grandfathered health plans.

[20] HHS will review the benchmark process for the year 2016 and beyond based on evaluation and feedback. The ACA requires that the EHB cover benefits in 10 categories: (1) ambulatory patient services, (2) emergency services (3) hospitalization, (4) maternity and newborn care, (5) mental health and substance use disorder services, including behavioral health treatment, (6) prescription drugs, (7) rehabilitative and habilitative services and devices, (8) laboratory services, (9) preventive and wellness services and chronic disease management, and (10) pediatric services, including oral and vision care. If a benchmark plan does not include any benefits from one of these categories, the State must supplement the EHB with benefits in that category. The State's largest small group plan is the default benchmark for any State that declines to choose one of the benchmark plans.

[21] New York State Health Benefit Exchange Staff Presentation to New York City Regional Advisory Council September 2012, http://www.healthbenefitexchange.ny.gov/sites/default/files/Sept%202012%20RAC%20Meetings%20Presentation_0.pdf.

[22] October 1, 2012 NYST letter to HHS to formally select a benchmark plan under the ACA, available at: http://www.healthcarereform.ny.gov/health_insurance_exchange/docs/ehb_letter_to_hhs_10-1-2012_final.pdf.

[23] Stakeholders have also been invited to presentations of the findings of reports produced for the Exchange by experts on Exchange development issues, and to submit written comments to the Exchange about the Essential Health Benefits benchmark plan selection.

APPENDIX 1 - ROUNDTABLE PARTICIPANTS

Binghamton Roundtable, October 12

Kevin McCabe, regional representative, Governor Cuomo

Assemblymember Donna Lupardo, 126th Assembly District

Donna Palmer, Mental Health Association

Doris Cheung, Mental Health Association, Cultural Competency Coordinator

Dana Brown, uninsured consumer

Lynne Theophanis, consumer

Tina Burns, consumer

Dr. Niru Anne, MD, FACS, Vice-President, Broome County Medical Society

A small business owner and her husband

Lenore Boris, Director of the Dr. Fattal Free Clinic; Member, Exchange Regional Advisory Committee member

Barbara Travis, Broome County Health Department, CASA Program Coordinator

Judy Arnold, consumer

Wanda Mead Campbell, consumer

Amy Fleming, Catholic Charities of Broome County

Cynthia Burger, Broome County Medical Society, Executive Director

Jane Long, Kate Griffith, Sue Ruff, Southern Tier Independence Center

Ingrid Husisian, Planned Parenthood of South Central New York , Director of Public Communications

Doris Reed

Dr. Erik Hiester

Westchester Roundtable, October 15

State Senator Andrea Stewart-Cousins, 35th Senate District

Assemblymember George S. Latimer, 91st Assembly District (since elected to the State Senate)

Assemblymember Shelley Mayer, 93rd Assembly District

Legislator Alfreda Williams, Westchester County Board of Legislators, District 8

Sherri Ehrlich, Director of Business Development & Account Management at Hudson Center for Health Equity and Quality

Diana Diaz Serafin, Director of Patient Services, Jansen Hospice and Palliative Care

Judith Dobrof, Executive Director, Cancer Support Team

Lucille Winton R.N. Coordinator of Patient and Family Services, Cancer Support Team.

Loretta Molinari, Visiting Nurse Services and Access to Care Coalition

Kristen Welton, Community Mission Manager, American Cancer Society

Brenda Spry, Labor Legal Representative, 1199, SEIU

Mel Tanzman, Executive Director, Westchester Disabled on the Move

Louis Bousche, Vice President, Yonkers Professional Firefighters, IAFF Local #628, Westchester Putnam Central Labor Body

Karen Bernbach, Lead Legislative Ambassador, American Cancer Society

Jean C. LePere, Manager, Network Community Programs, Memorial Sloan-Kettering Cancer Society

Judith Watson, Executive Director, Greenburgh Health Center

Catherine Lederer-Plaskett, President, WCLA-Choice Matters

Gina D'Andre Weatheop, Planned Parenthood Hudson Peconic

Dr. Robert G. Lerner, Professor of Medicine and Pathology, Vice Chairman, Department of Medicine New York Medical College, Chief of Hematology, Westchester Medical Center

Judy Farrell, Director, Government Affairs, Visiting Nurse Service of New York

Staten Island Roundtable, October 16

Assemblymember Matthew Titone, 61st Assembly District

Rev. Terry Troia, Project Hospitality, El Centro del Immigrante and the Coalition for Family Health of Staten Island

Mark Hannay, Metro New York Health Care for All Campaign, Exchange Regional Advisory Committee member

Alma Gonzalez, consumer

Marleny Porras, consumer

Martha Rivera, consumer

Romeo Moreno, consumer

Maria Morales, owner of restaurant in Port Richmond

Bronx Roundtable, October 16

State Senator Ruth Hassell-Thompson, 36th Senate District

Donna K. Drayton, Senior Executive Assistant, NYS Senator Ruth Hassell-Thompson

Melissa Cebollero, Director for Health and Human Services, Bronx Borough President

Nicole Hollingsworth, Senior Director for Community and Population Health, Montefiore Medical Center

Dr. William Jordan, Co-Director of Medical Student Education in the Department of Family and Social Medicine at Montefiore / Einstein, Community Health Center Family Doctor, Co-chair, Policy Committee of Public Health Association of NYC and Officer of National Physicians Alliance

Michael Lambert, Deputy Director, Mosholu Preservation Corporation

Reverend Dominique Atchison, Bronx resident and Associate Minister, Brown Memorial Baptist Church

Kathryn (Kate) Rose, Senior Director, Public Policy and Government Relations, Office of the President, Montefiore Medical Center

Elizabeth Guerra, Director of Community Mobilization, National Latina Institute for Reproductive Health

Roberto Garcia, CEO and Executive Director, Mosholu Preservation Corporation.

Alyssa Aguilera, Community Organizer, Health Justice, New York Lawyers for the Public Interest

Pastor Robert Foley, Pastor, Cosmopolitan Church of the Lord Jesus Christ, Southwest Bronx

Long Island Roundtable, October 17

Gwen O'Shea, Health and Welfare Council of Long Island, Exchange Regional Advisory Committee member

Luis Valenzuela, Long Island Immigrant Alliance, Exchange Regional Advisory Committee member

Lisa Tyson, Long Island Progressive Coalition, Exchange Regional Advisory Committee member

Roger Clayman, Long Island Federation of Labor, Exchange Regional Advisory Committee member

Lara Kassel, Medicaid Matters NY, Exchange Regional Advisory Committee member

Danielle Asher, Long Island Progressive Coalition

Michelle Satriano, North Shore LIJ Hospital Council

Fritz Tavarez, Healthfirst

Phil Mickul, Family and Children's Association

Mary Dewar, Long Island Coalition for a National Health Plan; Long Island Council of Churches

David Nemiroff, Mental Health Association of Nassau

Michael Stoltz, Clubhouse of Suffolk, Suffolk County United Veterans

Rob Greenberger, FEGS Health and Human Services

Buffalo Roundtable, October 17

Assemblymember Robin Schimminger, 140th Assembly District

State Senator Tim Kennedy, 58th Senate District

John Craig Ph.D, Vice-President of Education, WNED Radio

Ellen Kennedy, member, State Board, Citizen Action of New York, Exchange Regional Advisory Committee member

Todd Tranum, Director of the Chautauqua County Chamber of Commerce, Exchange Regional Advisory Committee member

Marti Gorman, Buffalo small business owner and uninsured individual

Susan Rumack, uninsured consumer

Colleen Seminara, Director of Public Policy, Catholic Charities of Buffalo

Jan Ables-Register, Erie County School Counselor; member, Health Care Committee, Citizen Action of Western New York

Chris Caya, reporter, WBFO, Buffalo public radio

Upper Manhattan Roundtable, October 18

Dr. Jaime Torres, Regional Director of Region II (New York, New Jersey, Puerto Rico, U.S. Virgin Islands) for the U.S. Department of Health and Human Services

Marjorie Cadogan, Executive Deputy Commissioner of the Human Resources Administration, Office of Citywide Health Insurance Access (OCHIA)

Audrey Diop, Director of Public Health Insurance Initiatives, NYC Human Resources Administration, OCHIA

JoAnne Bailey, NYC Health Insurance Link project leader, NYC Human Resources Administration, OCHIA

Ian Hartman-O'Connell, Advisor for Health Policy, Office of the Deputy Mayor for Health & Human Services

Clara Wong, Consultant, National Council of Churches

Cecilia Gaston, Executive Director, Violence Intervention Program Inc, a Latina organization dedicated to ending violence in the lives of women

Alice Berger, Vice President of Health Care Planning at Planned Parenthood NYC, Exchange Regional Advisory Committee member

Heidi Siegfried, Director of Health Policy, Center for Independence of the Disabled, and Program Director, New Yorkers for Accessible Health Coverage

Liz Pantino, Manager of Facilitated Enrollment, Callen-Lorde Community Health Center

Social Worker, College and Community Fellowship

Mary Beth Morrissey, President of the Collaborative for Palliative Care, Inc., Exchange Regional Advisory Committee member

Carmina Bernardo, Director of Health Care Planning and Family Planning Benefit Program (FPBP) Training Coordinator at Planned Parenthood of NYC

Tai Geiger, Resident, True Colors Residence

Mildred Ramirez, Life Skills Coach, True Colors Residence

Kimberly Marshell, Program Director, True Colors Residence

Elizabeth Howell, Vice President of Development and Public Relations, Community Healthcare Network

Valentine Cruz, Women's Health Manager, Community Healthcare Network

Rhonda Patillo, consumer

Basya Schechter, consumer

Lower Manhattan Roundtable, October 19

Alice Fisher, Director Community Outreach at Office of NYS Senator Liz Krueger

A representative from the office of Assemblymember Richard Gottfried's

Suleika Cabrera Drinane, President and CEO, Institute for Puerto Rican/Hispanic Elderly

Mark Hannay, Metro New York Health Care for All Campaign, Exchange Regional Advisory Committee member

Pia Scarfo, Institute for Puerto Rican/Hispanic Elderly

Heidi Siegfried, Director of Health Policy, Center for Independence of the Disabled, and Program Director, New Yorkers for Accessible Health Coverage

Carlos Gaviria, Hispanic Senior Action Council

Linda Riera, Hispanic Senior Action Council

Brooklyn Roundtable, October 23

Dr. Jaime Torres, Regional Director for the U.S. Department of Health and Human Services

Tobi Jaiyesimi, Deputy Chief of Staff, Office of Assemblymember Hakeem Jeffries

Dynishal P. Gross, Chief of Staff, Office of Councilmember Albert Vann

State Senator Velmanette Montgomery and her community liaison, Joan M. Eastmond

Eman Rimawi, freelance writer, photographer, and political educator

Stephanie Friot, Program Coordinator, Medical Benefits Assistance, Diaspora Community Services

Guerline Lajoie, Program Assistant, Medical Benefits Assistance, Diaspora Community Services

Janna Zinzi, uninsured freelance communications consultant

Facilitated Enroller

Reverend Dominique Atchison, Associate Minister, Brown Memorial Baptist Church

Melissa Cross, Program Coordinator, Women's Health Department, Caribbean Women's Health Association, Inc.

Syracuse Roundtable Interviewees

Ann Tiffany, retired health care professional

Patricia Rector, health care outreach and education staffer

David Pasinski, consumer assistance staff, Syracuse Northeast Community Center

Cheryl Graves-Wright, health care consumer, former Certified Nurse Assistant (CNA)

Queens Roundtable Interviewees

Cesar Palomeque, Board of Directors, Make the Road New York

Blanca Palomeque, consumer

Bianey Garcia, organizer at PRYDE LGBTQ Justice Project

Juan, young adult consumer dedicated to ending violence in the lives of women

APPENDIX 2: LISTENING TOUR SURVEY QUESTIONS

Name: _____

Residence Address: _____

Phone # 1: (____)_____ Phone # 2: (____)_____

Fax: (____)_____ Email: _____ Gender _____Age _____ Sexual Orientation_____ Race_____ Disabled (Y or N) ____

Have health ins.? (Y or N) _____ Is your health ins. private or public? _____

1. What kinds of problems have you or your close friends or family faced with health insurance coverage, if any? Examples might be:

a. High medical bills

b. choosing a plan that was best for your financial needs and your family budget

c. finding a plan that covered your health condition or health need (please specify your condition or need on the comment lines)

d. finding the doctors and medical providers you needed in your health insurer's network and that are close enough to you

e. finding doctors, nurses and other providers than can take care of your health condition

f. paying for prescription drugs

2. The new federal health care law gives states the option of creating a "Basic Health Plan" for low and moderate income consumers that will have low or no premiums or out-of-pocket costs. If the State creates a Basic Health Plan, it would require low income individuals to choose from a more limited group of plans than those offered on the Exchange. The trade off is that the Basic Health Plan will cost much less for consumers. Basic Health Plans would still be required to offer a standard pre-set benefit package. Do you think New York should offer a BHP?

3. Which of the following statements most closely fits your personal views? Please feel free to explain your views in the comment lines provided.

_____ I believe that all health plans should be admitted into the Exchange provided they meet basic standards. Is it important for me to have the widest choice of health plans possible, even if the plans aren't of the highest standard.

_____ I believe the Exchange should make sure only the best plans are admitted into the Exchange. It's important that the plans available are of the highest standard, even if it means fewer choices.

4. If you selected the second choice, what types of standards do you think the Exchange should set for health plans? Here are a few examples:

a. enough providers like doctors and nurses that are available to consumers

b. adequate provider networks to meet the needs of particular groups of health consumers, such as women, people of color, rural consumers, people with disabilities, people with difficulty speaking English, and the LGBT community

c. a broad range of specialists for various health conditions

d. good consumer assistance programs and good customer service

e. more affordable health insurance

Are there any other standards we haven't mentioned that you think are important?

5. What kinds of assistance do you think are necessary to help consumers select, choose, enroll into, and use health insurance plans? For example, is quick phone assistance and good Internet information enough or do you think consumers need significant "hands on" help from an individual who can lead them through the process? Would you prefer that this "hands on" assistance be from trained non-profit

staff or the trained staff of a government agency like the Exchange?

6. Have you or someone you know ever had a dispute with a health insurer? If so, please discuss whether you had assistance from someone else to resolve the dispute (like an individual, not-for-profit, or government agency), how you learned about the assistance, and whether it helped you to resolve the problem and how. Is there anything you would have done differently?

7. New York will have to choose a benefits package for exchange coverage that is based on an existing plan. Here are the major options:

a. A typical health plan you would get from a small business, but that may not have fully comprehensive benefits if you get really sick or become disabled

b. A plan like the one New York State employees get, that offers pretty good benefits, but may not cover some things like eye exams or glasses

c. A plan like the one federal employees get, that has decent benefits, but may not cover certain kinds of reproductive health care services

d. An HMO plan that offers decent benefits and consumer protections, but doesn't provide fully comprehensive benefits

Which of these options would you prefer for yourself and your family and why?

8. What benefits are most important to you and your family, even if this means the state might to pay for this coverage with taxpayer funding?

9. What are the best ways of informing the public and getting public input into the decisions of the Exchange and why? Here are a few examples:

a. televising exchange meetings on public access television and/or broadcasting them on the Internet

b. ensuring that a significant number of consumers and small business representatives serve on committees that advise the Exchange

c. allowing the public to send in written comments through a web page, mail or fax

d. having the Exchange hold public regular meetings throughout the state on a regular basis (this could be as part of the regional advisory committee process created by the Governor's Executive Order)

e. having the Exchange send out a newsletter or written updates

10. What kinds of steps do you think the Exchange could undertake to reduce disparities in health care access and outcomes based on such factors as race, gender, disability, immigration status, and sexual orientation? Examples of reforms that have been proposed are:

a. targeting the enrollment efforts of the Exchange to communities where people of color, low-income people, immigrants and other communities where large numbers of people that lack health insurance live and work

b. making sure that the Exchange can enroll people in any public health coverage program, like Medicaid and Child Health Plus, in addition to private insurance programs

c. requiring health insurers and hospitals to collect data on health outcomes by race, gender, primary language, disability status, sexual orientation and other factors, and that this data is made easily available to the public at no charge

d. making sure that the Exchange has adequate language services and bilingual staff for enrollment and other exchange services

e. requiring that health providers and consumer assistance staff funded by the Exchange have "cultural competency" training

11. What other issues not addressed in the previous questions do you think are important for consumers and small businesses advocates to bring to the attention of state officials planning the state exchange?

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