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Community Perspectives on Advanced Primary Care

New York City Population Health Improvement Program

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INTRODUCTION

In January 2015, the New York City Population Health Improvement Program (NYC PHIP) was launched as a collaboration between the Fund for Public Health in New York, the New York City Department of Health and Mental Hygiene (NYCDOHMH), the United Hospital Fund (UHF), and The New York Academy of Medicine (The Academy). The NYC PHIP, one of 11 such bodies around the state, is funded by the State Department of Health and tasked with aligning various health reform activities to support population health and to promote the Triple Aim of better care, lower health care costs and better health outcomes for New Yorkers.

Objectives for the first two program years include promotion of increased multi-sector investment in interventions that prevent disease and improve health equity in NYC, specifically by (1) developing a PHIP Steering Committee to promote engagement in and support for population health interventions; (2) engaging the community in advancing the City's strategic health agenda; and (3) generating recommendations and analyses that inform stakeholders about actions they can take to support population health improvement.

Objectives also include the support of a local transition to value-based health care, and development of a plan for expansion of Advanced Primary Care (APC) in New York State (NYS). This report supports those objectives by presenting community perspectives on primary care, particularly in those communities identified as having significant need. The findings described in this report are intended to provide the PHIP Steering Committee and its Advanced Primary Care Workgroup with patient perspectives to inform ongoing development and implementation of the APC model.

METHODS

Findings presented in this report are based on data from five focus groups, specifically addressing the topic of Advanced Primary Care, convened in NYC between November 2015 and January 2016 (N=64). The Academy partnered with the NYCDOHMH and UHF to select a priority neighborhood in each borough. These were: Jamaica, Queens; Port Richmond, Staten Island; Brownsville, Brooklyn; East Harlem, Manhattan; and Hunts Point, Bronx (see focus group implementation details in Figure 1). The Academy then conducted outreach to community organizations in each neighborhood, requesting that they host a group and recruit participants. Focus groups included ten to fifteen participants, ages 18 years or older.

Focus groups were facilitated by two Academy staff and lasted for approximately 90 minutes. They were conducted in English (n = 4)¹ or Spanish (n = 1). A semi-structured guide was used for the focus groups (see Appendix), which covered topics including participant experiences with and perspectives on primary care services, both generally and as related to characteristics of the APC model, as well as participant recommendations. Participants were asked to complete a brief questionnaire in order to gather basic sociodemographic and health information. The focus group guide and brief questionnaires were translated into Spanish for the Spanish language group.²

Focus groups were recorded. English language groups were professionally transcribed. The recording of the Spanish language group was summarized with literal translations of relevant passages. Transcripts and summaries were managed and coded using NVivo, a software package for qualitative data analysis. A coding scheme (with definitions) was developed that included pre-identified and emergent themes. All transcripts were coded and analyzed using an iterative process that allowed for identification of salient findings.

¹ A number of participants in the focus group conducted in the Nepali community had limited English language skills. A staff member remained on site during the group, interpreting for those participants.

² The project protocol and all instruments were reviewed under expedited procedures and approved by the Academy's Institutional Review Board. All participants received an information sheet and were asked to provide verbal consent. Participants were informed that their involvement in the research was completely voluntary and that they could refuse to answer questions or leave the focus group at any time. They were told that their responses would be kept confidential and would be reported in such a way that individuals could not be identified. Brief demographic questionnaires were completed anonymously. All data were stored on password protected drives at the Academy. Participants received a \$25 incentive.

FIGURE 1. FOCUS GROUP IMPLEMENTATION OVERVIEW

BOROUGH	NEIGHBORHOOD	COMMUNITY-BASED PARTNER	DATE OF GROUP	NUMBER OF PARTICIPANTS
MANHATTAN	East Harlem	LSA Family Health Services	November 13, 2015	11
STATEN ISLAND	Port Richmond	Make the Road New York (Spanish)	November 24, 2015	13
BRONX	Hunts Point	The Point	December 3, 2015	10
QUEENS	Woodside/ Jackson Heights	Adhikaar	December 6, 2015	15
BROOKLYN	Brownsville	BMS Family Health Center	January 14, 2016	15

TABLE 1. CHARACTERISTICS OF FOCUS GROUP PARTICIPANTS (N=64)

	N	%
AGE		
18 - 35	17	28%
36 - 45	12	20%
46 - 55	14	23%
56 - 64	11	18%
65 and older	7	11%
EDUCATION		
Some/Did not attend HS	29	45%
HS grad/Technical + vocational training	11	17%
Some college but no degree	15	23%
Associates/Bachelor/Advanced degree	9	14%
GENDER		
Female	46	74%
Male	16	26%
RACE/ETHNICITY*		
Hispanic/Latino	26	41%
Black/African American	23	36%
Asian	16	25%
White	5	8%
Other	13	20%
WORK STATUS		
Employed full time	9	14%
Employed part time	17	27%
Not working	32	50%
Retired	3	5%
Student	2	3%
MAIN LANGUAGE SPOKEN AT HOME		
English	24	38%
Spanish/Spanish and English	22	34%
Nepali/Nepali and English/Tibetan	13	20%

(continued on P7)

HEALTH INSURANCE*		
Medicaid	37	58%
Medicare	14	22%
Private/Commercial insurance	4	6%
Other	4	6%
Uninsured	10	16%
HAD MONEY CONCERNS REGARDING FOOD/HOUSING IN PAST YEAR		
Always/Sometimes	46	72%
Rarely/Never	15	23%
CURRENT HEALTH CONCERNS*		
Asthma	17	27%
High blood pressure	17	27%
Depression or anxiety	15	23%
Chronic pain	12	19%
LOCATION OF USUAL HEALTH CARE*		
Doctor's office	31	48%
Hospital-based clinic	20	31%
Community/Family health center	13	20%
Emergency room/Urgent care	15	23%
Other	3	5%
No usual source of care	4	6%

* Multiple responses permitted

As shown in Table 1, close to three-quarters (74%) of participants were female. The majority were African American (36%) or Latino (41%); 25% were Asian. Approximately 50% spoke a language other than English at home. Forty-five percent did not graduate from high school; approximately 40% were working either full or part time. The majority of participants were low income: approximately 72% reported that they had concerns about food or housing in the last year and 60% were insured through Medicaid. The most commonly reported health conditions were asthma (27%), hypertension (27%), depression and/or anxiety (23%), and chronic pain (19%). Close to half of participants (48%) reported that their usual source of care was a doctor's office, 31% received care in a hospital-based clinic, and 20% in a community/family health center. Other sources of care included the emergency department (13%) and urgent care center (11%). Six percent of participants reported that they had no usual source of care.

FINDINGS

The findings described in this report detail participant experiences and perspectives on primary care. To the extent possible, the report is organized according to categories consistent with the relevant main components of the APC model. These categories include: 1) patient satisfaction, 2) access to care, 3) health promotion and education, 4) broader determinants of health, 5) care coordination, and 6) health information technology. Each section aims to highlight patient experiences in these areas, as well as their perspectives on value and quality with respect to each.

In keeping with the aims of the PHIP, this study focused on New Yorkers living in areas of greatest need and therefore represents the perspectives of mainly low income, minority residents. Notably, many saw their experiences with primary care through the lens of their experience of inequity, as evidenced by comments such as those below.

I notice the difference between private and all the hospital facilities and clinics. You get treated different, and you get treated with all the best benefits of seeing a doctor when you're paying for it, as going to a private doctor. When you go to medical facilities around the clinics or the hospital, you don't get the same benefits as [when] paying for it with a private doctor. (Bronx)

But my whole thing, my point is, we make doctor's appointments and we think that we're going to get one that month, in the next two weeks or so. Oh, you know – and it's like a month away. From what I know it's only in the poor neighborhoods that we're being treated this way. (Brooklyn)

Patient Satisfaction

Patients have a right, even though you're not paying for the care, and I'm poor. I still have a right to be treated with dignity. (Bronx)

A main theme across focus groups was patient satisfaction and the quality of care received from primary care providers. Participants reported that respect and compassion were important provider qualities. Examples of positive experiences

often centered on patient–provider interactions that demonstrated a patient–centered approach, where patients felt their needs were valued and prioritized.

I am satisfied with [my provider] because she is very caring. And if I have high blood pressure, she's over here and she'll see me regularly and stuff like that. And she gave me all the medication that I need and always advises me if I need to have a diet. She's always there telling me. So I'm satisfied with her. (Manhattan)

I had asthma from a young age, and he used to call my mother, make sure I'm okay, my sister, too... And he is more compassionate. He cares about all his patients ... I used to be bigger, almost 300 pounds probably. And he gave me diet regimens. He really cared about me to make sure I was okay and stuff. And when I go to [the hospital] he calls [there] to make sure there's nothing going on. (Brooklyn)

Counter examples were also provided. Among the clearest were those that emphasized a lack of time and attention to the patient.

Whenever I go [to see my children's physician], I feel like the doctor is a businessman more than a doctor. That's what I feel. Maybe I'm wrong, but she wants to see the patient quickly ... I feel every time I go there. (Queens)

Where they just write your prescription, don't fully check you, I was getting that too much so I transferred [providers]. (Brooklyn)

I went to this guy, and he never took my [blood pressure]. But he said, "I know you have high blood pressure." And I'm like, "How do you even know that? How do you even—you just looked at me like he was a cyborg and just checked me out." And it's like he goes, "Men of your age blah, blah, blah ..." He gave me kind of like a spiel about like, "You're Spanish, you're 30." (Bronx)

Patient–Provider Interaction: Culturally and Linguistically Appropriate Services (CLAS) and Other Communication Issues

Patient–provider communication was described as an important factor in care and one they felt reflected how providers valued them. The manner in which providers spoke to patients affected multiple components of the interaction. A few participants described alarming experiences with provider insensitivity—two shared stories in which providers referred to them as “fat,” another received unsolicited advice to have children, because she was “getting old.” These experiences were described as insulting to patients, leaving them distrustful, dissatisfied and reluctant to return to that particular provider.

So I went in the doctor’s office one day. And, again, I wasn’t feeling well. And the doctor came in, took one look at me, and said, “Wow, I know what your problem is.” ... So I said, “Oh, okay. Well, what’s the problem?” He didn’t listen to my chest, didn’t check my pressure. He said: “You are fat.”
(Manhattan)

I never said I’m a size 2. I’m a size 22. This is what the doctor said to me, and I wanted to hit her, but I had to humble myself. She said, “Oh, I’m not going to be able to heal the cyst because you’re too fat.” (Brooklyn)

[My gynecologist] basically told me if you want to have children, you better get started because your eggs are getting old. And you better find a husband and a lot of stuff. And the men now want younger women because they know that—Just so insulting. And at the time, and I still don’t have children, and I’m 44 years old. So I’m seeing that window of biological motherhood possibly closing on me. And I’m dealing with what that means for me. So when she said this, when I was beginning to deal with that biological clock and our freaking cultural expectations and stuff, it had me leave her office in tears. I was hysterically crying. (Bronx)

Thoughtful interpersonal interactions and communication were viewed as part of good quality care that could lead to positive outcomes. One participant shared an unusual, but noteworthy story demonstrating how a positive relationship with a provider led to improved care. In this case, friendly conversation during a provider visit allowed her

doctor to see a picture of the mold in her home, leading him to reassess and improve his approach to her care.

I went to the doctor because I was having really bad pains in my legs and I'm not diabetic. ... And the doctor was going to send me for all of these other tests. And we got off subject talking about something else. And I went to show him pictures [of something I made] on my phone. ... He said, "Wait a minute. What is that?" I had pictures I had taken of the mold in my apartment. ... He said, "Oh, all these tests I was sending you for, you don't need them. This is what the situation is. ... If he didn't see what was going on in my home, and we changed the conversation to my home, I wouldn't have gotten the services that I did need. (Manhattan)

Provider communication skills relevant to health issues and disease management were also of particular importance to participants. They expressed an interest in having access to comprehensible information regarding their treatment and health conditions, although actual experience varied. While some had providers who took the time to explain, or to print specific information, others found that doctors put little effort into communication and spoke in unfamiliar terms, or did not bother to share information and test results at all.

They give you examples. Sometimes, they give you examples of it. They give it to you again: "And it's this, and now do you get it?" They just say it again. (Manhattan)

Don't talk doctor talk to me. Speak to me human. That's how you learned in school, but we need to know how our body is doing on the inside. Don't say whatever your doctor terms are to me, because then I'm not understanding. ... Speak English to me. (Brooklyn)

I want someone who'll explain to me when and what time am I supposed to take the medicines, not just give me medicines. And make sure the medicine is right, and ask me where is the pain and everything in details. (Queens)

For those with limited English proficiency, a language concordant provider—and office—was important. Some said they were able to find providers who spoke their language, while most described relying on ad hoc interpretation by office staff or family members to interpret during a visit, or they went without language services.

Professional interpreters were described as available in hospitals, but generally not in community settings.

The fact that they understand your language, and you understand theirs. Or if they don't understand your language, can they get someone who can understand your language? That's very important. (Spanish speaker, Manhattan)

Well, my mother only speaks Spanish. So either I go with her or my aunt. I'm basically the translator because ... at the front desk, she'll be bilingual. Once you get to the doctor, some doctors maybe [speak Spanish], some doctors no. (Bronx)

So far, I have my family and my two daughters with me, so it's not a problem. But if I go alone, then I don't think they will explain that in my language. (Nepali speaker, Queens)

Although many participants were accepting of this kind of ad hoc interpretation, explaining that it is important for family members to know about health concerns, a few articulated the ways in which a lack of integrated language services has negatively impacted their care. The consequences described include greater inconvenience, loss of confidentiality, and reduced quality of communication.

So I have to take my son, and every time when I fill the forms, that they have questions about menstruation, which I don't feel comfortable sharing with my son. (Nepali speaker, Queens)

Sometimes in the hospital they tell you to speak English, "Oh well, there isn't anyone who speaks Spanish, so wait until someone walks by who speaks Spanish or someone we can call." And so you have to wait for a translator. I went one time and I was in pain and came crying by myself, and they made me wait with the pain for an hour because no one spoke Spanish. They just looked at me and asked if I was okay. "No." And, finally there was a doctor who spoke Spanish, and I said, "Thank God." (Spanish speaker, Staten Island)

But the people that translate for you ... they're just regular staff. And they come up to you and try to translate, but then your business is elsewhere. Because that person that just translated for you knows somebody that you know. And they're like, "She came here, and she told me this."

[Spanish speaker, Manhattan]

I have to bring my daughter with me so that she can interpret, but it takes too long. She has to take a day off in order for me to go to the health care services. [Nepali speaker, Queens]

In addition to language, provider cultural competency was described as important. Many reported that they had not had negative experiences, although some from different cultural and ethnic groups shared stories of being stereotyped or treated with cultural insensitivity, with negative effect. One participant said she specifically sought out providers of color because she felt she would be better understood by them.

Stop stereotyping us when we come into these doctor's offices, acting like we're not educated, we don't know nothing, we ain't got the sense God gave us. We got more sense than some of these doctors. ... Excuse me. Just because the health care don't fit in our budget, don't stereotype our intellect.

[Brooklyn]

When my primary care doctor wasn't available they assigned me to someone else and it was a different culture and they were so nasty. I didn't understand what they were saying. And they act like they didn't understand what I was saying. So that put me in full rage. [Brooklyn]

So I also feel more comfortable with a doctor of color ... I want to be able to know that I can have a conversation with my doctor, and he not only understands but have the doctor understand me and where I'm coming from. [Bronx]

Access to Care

Access was a key consideration for participants when seeking primary care. Proximity and provider hours (including availability outside regular work hours) were among the factors first considered when choosing a provider, and participants felt that increased accessibility in this regard positively affected their ability to get care. A reasonable wait time was another aspect of accessibility that was emphasized by participants. Many described long waits on the day of a visit that limited their ability to fulfill other important responsibilities; some reported switching providers as a result of extended delays.

I would go for an appointment like after school at 2:30 or 3:00, I wouldn't get out until 6:30 or 7:00. So when you're a working parent, still got homework, still got to cook, that's an inconvenience. That's three hours that you don't want to be there, especially when your child hasn't even done their homework.
(Bronx)

Participants valued having a provider that could be contacted or seen quickly, in case of an urgent health problem or a prescription renewal, although few reported having this kind of relationship with their provider. One participant detailed her concerns when deciding where to get care, which included the need for an effective system for coverage and referral when her provider was unavailable. Participants that were not able to see their providers when needed used urgent care centers or emergency departments as back-up providers.

I like the fact I can call my doctor and say, "You know what? There's been a couple of days I didn't take my blood pressure medicine. Now, I ran out of it." And I don't want to track all over the world to get a prescription. "Don't worry about it, Ms. Harris." And Rite Aid calls me and tells me to come pick up [my] prescription. (Manhattan)

Will you fit me in for the day, or are you going to tell me, "Tomorrow," when I just told you my child has a fever? Stuff like that, to me, is important. Basically, I want to have the accessibility to the doctor whenever I need the doctor. If I can't get in touch with you, then do you have somebody that I can call? And they can send me somewhere else where you're going to be able to get the record and keep that together for my child, which is what I get when I go out of the Bronx. (Bronx)

Sometimes with a primary, you have to make an appointment. So, then I'll either go to the emergency room—or going to an urgent care that I found, that's pretty convenient because you don't have to wait the time at the emergency room. And you're kind of seen and your needs are taken care of.
[Bronx]

Health Promotion and Education

Participant experience with health education in a primary care setting varied, although many said they had received some of these services. For several participants, it was specifically because they were overweight, had been diagnosed with high blood pressure, or had another health condition. For others, health education was more proactive and preventative in focus. Examples included health and nutrition counseling by providers during a visit and pamphlets and health-related television programming available in provider waiting rooms. A small number were offered more in-depth health information, including workshops on topics such as diabetes prevention.

My sugar level was little high, so my doctor told me to eat more vegetables, exercise in the morning. [Queens]

And there's a TV, and it shows you when you're diabetic what to do and what to eat. ... And you sit there while you wait for the doctor, all of these interesting things about health. I like to watch that. [Manhattan]

I've seen [information about classes] posted inside of the clinic. It's totally up to you and sometimes the doctor will tell you, "Well, this is available and this class is coming up or this research thing is coming up. It's totally up to you to participate." But I've seen them posted and if it's directed for me, the doctor will say, "Well, this is available for you on this day. Do you want to go? Do you want me to sign you up or anything like that?" [Brooklyn]

In one notable instance, a young participant described the value of an asthma education coordinator who joined his primary care practice. Not only did his asthma knowledge and medication adherence improve, the educator provided information on other health topics, like nutrition and sexual health.

I feel as though, lately, they have been [providing health education], but before, not really, because I never really knew much about my asthma up until like two years ago when they probably hired somebody new ... He was an asthma education coordinator, and he actually told me what the pump is, how to use it. I never knew that you actually had to hold it in. It's just all this other information. He's even [covered] nutrition and even sexual education. He does all of it. (Bronx)

Participants in all of the focus groups said they felt that health education in a primary care setting was important and expressed a desire to receive information if they were not already. In the Queens group, one participant articulated a particular need among the Nepali immigrant community, which he felt was specifically lacking in basic knowledge regarding health and healthcare.

They could do more prevention and give talks. I think that's really missing. For example, when you're in the waiting room, I've never seen anyone say, look, here's a pamphlet, read it. They don't give you any information to prevent certain diseases or problems that can happen. (Staten Island)

It is good if [doctors provide health education] because most of us, we don't have much education or knowledge about health. We came here, we little bit knowing slowly, but it is good if the doctor gives information about health. It's good if you get information. (Queens)

Many participants, although not all, reported receiving health care screenings and, occasionally, reminders for visits and vaccines from their providers. Some said that they were reminded in person by their primary care doctor during a visit. Others said they received communication by mail or by telephone reminding them to get screenings. When reminders were provided, participants reported that they were appreciative.

Normally I get my screenings when I go for the physical and he'll see that it's time for this specific test or if I'm old enough for this test. So normally when I go for my physical examination, I'm told I need this screening. (Brooklyn)

A few exceptional approaches to prevention were described. In the Bronx, participants were effusive about a particular Urban Health Plan initiative and their work to coordinate health events, which included screenings for the community, and vouchers that could be used to buy fresh fruits and vegetables at the farmer's market. In Brooklyn, Healthfirst members praised the insurer for reaching out to patients regarding needed screenings—even incentivizing them with gift cards.

At Urban Health Plan, what they do, every Wednesday, you could go buy vegetables. They give out tickets, like I think a \$5.00 or \$2.00 voucher. And every Wednesday, they go to each clinic, and they gather people, and they take them to the market. And they could use the coupons to buy the vegetables and stuff. They do that a lot. They have pamphlets about health. They're very big on getting the community healthy and eating right because this area definitely needs it. (Bronx)

Healthfirst is the main one that will definitely call you to remind you you're due for a physical, the preventive programs for the asthma treatment, and everything. And a lot of the screening and stuff. (Brooklyn)

Another participant went on to say about Healthfirst:

They also make sure that we get rewards, like if you're a diabetic and they do certain tests and stuff they'll send you—and you call them back and let them know you did the test, they'll send you \$25. (Brooklyn)

Broader Determinants of Health

Most participants reported that their primary care setting did not address the broader determinants of health, such as income or housing security. In most focus groups, participants felt it would be helpful for their primary care providers to ask about non-medical aspects of their lives, such as their ability to afford healthy food and about their housing conditions. Many felt that these issues were relevant to their health and as long as the purpose of these questions was made clear—to connect them to needed services or appropriately tailor recommendations, and not simply to pry into their lives—the questions were welcome.

If we'll be realistic, a salad costs you \$9.50. Meanwhile, McDonald's, you got the dollar menu for a cheeseburger. So with a \$1.00, you have yourself burgers, fries, and a drink, and you're good to go. And that's when the problem comes. Also, income, as she mentioned with the co-pays, that's a problem because some people would prefer saving that money to do something else than going to the doctor and paying a co-payment. (Manhattan)

You never get asked those questions from your primary care doctor. But I think it would be great if they do ... and if they could help or refer you to some place or somebody who can help, an agency, it would be great. ... But just out of random to ask a person, "What's your income?" and then not really explain why you are asking ... I think that's more of a personal thing. If they're going to explain why exactly they're asking the questions, then I think anybody would be open to help if they can get it. (Bronx)

However, the Staten Island focus group, which largely consisted of Spanish speaking immigrants, differed from the other groups with respect to questions regarding non-medical issues. They were skeptical of provider motivation for questions related to patient income and speculated that this information might be used to identify patients who are unable pay for services and then deny them care.

First they ask if you have money. If I say, "Yes, I make money, I have a job." They will take care of you. But if I say, "No," they may not take care of you. If you have money, welcome. If you don't ... (Staten Island)

Participants with providers that asked about the non-medical aspects of their lives, primarily housing and mental health, reported that they appreciated the concern, although questions were most likely to lead to referrals, rather than concrete assistance. In the Brooklyn group, for example, several participants lamented the fact that even when doctors asked about housing, there was a limit to what they could do, given inadequate affordable housing in NYC.

Since I've been going to the Brookdale Clinic, he'll ask how is your housing situation, are you depressed, do you need to see a therapist or is there anything that you need to tell me where I can help you? ... If it's not onsite, he's going to refer us to someone else that can help us. (Brooklyn)

They suggest where to go, but they don't help you get the help. So they're like, "You can just go to this office. They will be able to help you." But why don't you tell me or call them for me and tell me that this is an appointment for you to go there. (Manhattan)

Coordination of Care

Many focus group members described being referred by their primary care physicians to specialists, or to other providers for testing and screening services. Most often participants had to go outside of their primary care setting for these services. Co-location was largely restricted to providers that were part of large networks and hospital-affiliated clinic settings, where the resources of the system were available to patients, and records were easy to transfer between doctors.

I think it works pretty well, as long as they're affiliated. If they're not affiliated, that's when it becomes a problem, because they're going to have to ... take your personal medical record or maybe even take it yourself. Because, if you leave it to the office, they might take forever to send it over. ... With Fidelis you can make sure that the doctor you pick is affiliated with a hospital that you want to go to. So when anything happens after hours, during hours, whatever, you have that cross communication between them. (Bronx)

When I go to see my doctor, I can see my counselor, Chris. While I wait, I see her. And then when we finish, I see the doctor, and when I finish with the doctor, I come back to her. And then she also gave me a referral. (Manhattan)

Participants appreciated when communication between providers worked well and did not require extra effort on their part. In cases where coordination was poor, participants said they were responsible for making sure that a comprehensive health record was available to all their providers. They also felt that poor coordination between providers meant they had to give the same information to multiple doctors, even if there was a referral relationship between them.

[My provider] sent me with a referral to [the hospital] to get my GI test ... and it seemed like they have no information here, and I'm trying to figure why. If all my referrals came from here to these doctors, why would I sit before these doctors in here, [and] they act like I'm speaking French. (Brooklyn)

So my thing is if I'm a doctor, if I'm a physician, I send a referral to you, your job is once you take care of my client, you're just supposed to automatically have someone send that information back to the doctors. Why do we always got to go back or either the doctor's got to keep calling from here, the primary doctor and a lot of times they never still send it. (Brooklyn)

One participant from Staten Island described how, as an hourly worker, poor coordination between providers meant that she lost both time and money when she had to travel between doctors' offices. Another in the same group, with limited English proficiency, said that it was particularly problematic when her doctors did not speak directly to each other, because her English was not strong enough to communicate her health care information effectively.

It takes time and money ... you have to pay for transportation to get there, you have to ask for time off from your job. And the time is important—to go somewhere for specialist services you need at least a half a day—transportation plus the time you're waiting ... and if you care about your health, you're going to do it, but a day that you don't work is a day that you don't get paid. (Staten Island)

[Coordination between providers] is important because they use various medical terms that you don't understand. So even if they tell you your test results and that you have to go back and tell your doctor ... you don't understand the words in English. And because they're doctors, they understand each other better, so it would be good for them to always coordinate between themselves. (Spanish speaker, Staten Island)

Access to Mental Health Services

In several of the groups, integration or coordination of mental health services, either within their primary care setting or as the result of a referral from a primary care doctor, was described. These connections to mental health care were often described as the result of direct conversation with primary care providers about feeling depressed. Participants were generally positive about being connected to services through their primary care doctors and were seemingly unconcerned about stigmatization or disclosure that might result.³ One participant described a positive experience in which a discussion with a primary care provider after the death of her father helped her to begin counseling.

When my father passed away I was very depressed because I was a daddy's girl. I went in [to see my primary care doctor] and ... he was like, "I'm sorry about your father. How are you doing?" Before I even got to say anything he said, "How are you dealing with it?"... He was like, "You're not dealing with it." He says, "So here. This is where you're going to go."... I was so angry and the doctor saw it. ... And now that I speak to somebody about it, [I'm] much better.
(Brooklyn)

Health Information Technology

Many participants said their providers used technology in caring for patients, either for record keeping and information sharing or for logistical purposes, such as appointment making. Participants generally held positive views about electronic health records (EHRs) and most did not feel that provider use of a computer was disruptive to their care. Many felt EHRs improved the patient experience and should be used to promote efficiency and care coordination. Several described how they had benefitted from an electronic health records system that was shared between their primary care doctor and specialists, allowing for helpful coordination of services between providers.

It's much easier now that the electronic system is up to date. We don't have to worry about, "I'm going to lose this paper taking it back to my doctor." The doctor logs in the system, sees your chart, and everything is there.
(Manhattan)

³ Those who described mental health issues in a focus group setting may represent a biased sample who are less concerned with stigmatization or privacy issues than other participants.

I think [electronic health records are] good, because if you're sick, all of your information is right there and they can see what's been going on with you in the computer. (Staten Island)

A few participants also described use of a patient portal, which allowed them to schedule or cancel appointments and access their own or their children's health records. Those who had access to such services framed them positively.

I was surprised. I had one doctor that actually did it. She put all my information, and then I just put my email. Now, I can just look up any results from any test, whatever it is, MRI, you name it. (Manhattan)

Still, participants felt that EHRs were not being used to their maximum potential. Several described situations in which providers had used electronic health records to take notes during a visit, but seemingly failed to send those records to a second provider. This resulted in frustration on the part of participants, who resented having to report the same information to multiple providers.

They have the technology, but they're not using it. You got to bring paperwork. This doctor should already know. Once you refer me to him, he should already have all of my information, "What's wrong with me?" And then all he should be doing is worrying about the solution of how to fix whatever the situation I'm having. But they don't have that. You got to go sit down, then they question you. They go in the computer. I'm like, "I thought you read this. It's all in the computer. It's been sent to you, but you feel like you've got to ask me the same exact question that was sent to you. And that gets me irritated because you're not reading what's going on." Why do I have to repeat the same thing I told my primary care doctor to the doctor that was referred to me? (Bronx)

I'm quite sure they put all this in the system. ... So now when a new doctor comes, they should be able to pull me up in the system and see what's going on there, but they don't do that. You sit down in front of them and they say, "Okay, what's your problem?" (Brooklyn)

A small number of participants did express skepticism about the use of electronic health records. One feared a computer crash and the loss of medical records. Another felt that her provider focused too much on the computer and not enough on her physical exam. A third feared that confidential health information was less secure stored in electronic form.

I see my doctor, as soon as I walk in the room she's typing. What is she typing? I have no idea, but she ain't touched me. So I don't know what she's putting in the system because my heart has not been checked. The nurse puts the pulse and the weight. ... But the whole visit is about her typing in. (Brooklyn)

Specific Patient Recommendations

When asked specifically for recommendations to improve primary care, not surprisingly, participants in almost all groups focused mainly on improving the accessibility of providers. They felt that primary care doctors should do more to reduce wait times on the day of a visit and try harder to be accessible to patients after hours.

I just think they should provide more doctors and more facilities in the facility so that we can have an easier time—a sensible timeframe of a waiting period. That is a big issue in East Harlem. It is a huge issue because everybody has things to do. People get picked up from school. And you shouldn't spend more than four hours in the emergency room or in the doctor's office because that always has been an issue. And that should be addressed more. (Manhattan)

Two participants made novel recommendations that do not represent consistent themes across groups, but are worth mention nonetheless. In Queens, one said he felt there should be a way to report poor quality doctors so they have an incentive to provide better care. Another suggested it would be helpful for primary care providers to employ staff who can help patients better understand their health care coverage.

My dentist, he didn't do good job with fixing my teeth, and I think he is not scared. I think he's not—he doesn't know that if he does a bad job, there is a consequence that he has to face. So I think they should know. (Queens)

They need to have somebody in that clinic there that knows what's going on with all the different plans they accept and be able to explain what's going on to you, because you don't know when you're going there what's going on. You don't know you can get your records. You don't know what you got to pay for, as opposed to this drug that they're prescribing and that. You don't know. They should have someone there to explain these things. (Bronx)

DISCUSSION

Participants described a range of experiences with primary care in New York City, both positive and negative. Findings indicate that patients desire care that is largely consistent with the Advanced Primary Care Model, suggesting that APC adaptations may improve patient experience of medical care.

Patient satisfaction hinged on several key factors including the degree to which care is responsive to patient needs, how much patients feel providers respect and care about them, and the effectiveness of provider communication regarding patient health and health care needs. Access was also described as important, and participants largely felt providers should be available to them at times that are convenient (i.e., outside regular work hours) and when assistance or care is needed most—such as in case of an urgent illness or when a prescription must be refilled.

Care coordination—another important attribute of Advanced Primary Care—was seen as most successful when patients were not responsible for transferring records or information between providers themselves, but instead could rely on their doctors to effectively communicate with one another. For patients whose providers were in large networks or were hospital-affiliated, co-location of services appeared to be more common. Participants described how hospital affiliation allowed for better access to a range of services as well as more coordinated record keeping and sharing. Notably, participants did not describe experiences with comprehensive care coordination; their experience was essentially limited to referrals and record sharing.

Electronic health records were viewed positively: participants were aware of the impact that use of such systems can have on patient experience and care delivery. However, they felt that existing systems were not being used to their potential. Information was being entered into the system, but—from their perspective—it was not being fully reviewed and utilized by a patient's other providers. It may be the case that providers have a rationale for repeating questions (e.g., to start a dialog, or hear about a problem in the patient's words). In such cases, an explanation may reduce patient frustration.

Both social service integration and health education and promotion were viewed positively by participants—they felt individual and community health could be improved by including these services and activities into primary care. Participants appeared to be open to discussing mental health issues with a primary care provider

and felt they benefited when their doctors were able to connect them to care. In the case of the broader determinants of health, many felt that it was important for providers to make clear to patients the rationale behind questions focused on issues like housing or income within the patient-provider interaction. Explanation for the reason behind such inquiry would reduce the perception that providers are prying into a patients' personal business and assuage fears that providers may refuse to treat those who cannot afford to pay.

In sum, the perspectives presented in this report indicate that patients are sensitive to and have expectations about the quality and type of primary care they receive. Some concerns raised by participants—that patients are sometimes asked to repeat the same information to different providers, or receive referrals instead of concrete assistance from doctors who ask about housing or income—may indicate that patient expectations are simply not in sync with the realities and limitations of the health care system. Communication around changes to medical practice could help address the disconnect between patient and provider expectations. The majority of issues raised by participants (e.g., accessibility, care coordination) relate to aspects of primary care that will be targeted for change within the APC model, suggesting that APC has the potential to significantly improve patient experiences of medical care. Understanding these specific concerns and priorities should be useful, as the model is translated into practice.

APPENDIX 1

THE NEW YORK ACADEMY OF MEDICINE PUBLIC HEALTH IMPROVEMENT PROGRAM

Focus Group Guide: Advanced Primary Care

Welcome and thank you for participating in this focus group. Today we are interested in talking with you about your experiences, needs and recommendations regarding primary health care—meaning the place people go for check-ups and care for more common health conditions. We work at The New York Academy of Medicine and are conducting this focus group in partnership with the New York City Department of Health and Mental Hygiene and the United Hospital Fund. These organizations are helping providers to improve primary care services, and would like community member input regarding changes that should be made.

Do you have any questions before we start?

1. And before we begin, I also want to clarify what you think of as primary care. Can a few of you give me a description?

I'd like to start by asking you to talk about where you get primary health care.

2. Where do you regularly go for primary care, again by primary care we mean where you go for check-ups and care for more common health conditions?
 - a. How and why did you choose this place? How is it different than other providers you may have tried?
 - b. What factors were important to you when choosing this provider? (If needed, give example: location, reputation, hospital affiliation)
 - c. Do you always go to the same place for care? Why or why not?
3. Are there other places people in this community go for primary care (other than what's been mentioned)?
 - a. Why would people choose these other places—what are things they might consider?

4. [If not already clear] Do many people go outside the community for primary care?
 - a. Where do they go—and why?
5. [If not already clear] Does everyone use a primary care provider (for example, internal medicine doctor, family practice) for their primary care, or do some people only see specialists?
 - a. Why—what are the advantages of only seeing a specialist?

I'd like to switch topics a bit and ask about your experiences and feelings toward the primary care you receive.

6. To start, what kinds of services do you get from your primary care provider? Here we mean not just from the individual doctor you see, but from their practice setting as well. (prompt, if necessary: annual check-ups, chronic illnesses, other illness or injury)
 - a. Does anyone go to their primary care provider for counseling or other services of that kind?
 - b. Does anyone see their primary care provider for non-medical services, like signing up for entitlement programs or connecting to other social services? (request examples)
7. Are you satisfied with your primary care provider and their practice setting?
 - a. What are the positives? What do you like about the care you receive? (request examples)
 - b. How about the negative—what do you think should change? (request examples)
8. In your opinion, what are the most important qualities of a primary care provider and their practice setting? Why?
 - a. Does your current provider have those qualities? In what ways yes and in what ways no?

9. Besides the qualities of the provider, what qualities are important about the practice? These may include office hours, mix of providers in the practice, use of electronic health records, translation services, and availability of other services you might need such as x-rays or a pharmacy.
 - a. Does the practice have the qualities you think are important?
In what ways yes and in what ways no?

10. We are particularly interested in issues around culture, language, and sensitivity to other personal or community issues. Do you feel your provider (and the practice) has appropriate sensitivity to issues of this type?
 - a. Do they have materials or services targeted to different populations?
 - b. Where are the strengths? What are the gaps?

11. Another area of we're interested is communication in general. Do you feel that your provider takes the time to explain things to you?
 - a. Do you feel that she or he explains the information you need using language that's easy for you to understand?
 - b. Does anyone have examples of times when you didn't understand important information related to your health and health care?

Expectations of primary care providers have been changing in recent years. We'd next like to ask you if you've noticed any of these changes and what you think about them.

12. An increasingly important part of primary care is care coordination— or connecting and keeping track of all the services a person might need. Do your primary care providers do that? (request examples)
 - a. What kinds of providers or services do they coordinate with?
(e.g., other medical providers, social services)
 - b. How well does this coordination work? How does it make it easier for you to receive other medical and social services?
 - c. How important is it that you receive this coordinated care? Do you have any concerns about your primary care provider taking on this role?

13. Another important part of primary care is an emphasis on preventing health problems from occurring by providing reminders about screening. Do your providers do that regularly? (request examples)
 - a. How do you respond to the reminders?
 - b. How important is it to you that these services are provided?
 - c. Does your provider actively make referrals or appointments with other providers if you need them? (request explanation)

14. Does your primary care setting provide you with health information and education?
 - a. How do you respond to this?
 - b. How important is it to you that these services are provided?

15. Some primary care providers offer an increasingly diverse set of services—like they might have counseling or social workers on site?
 - a. Do your primary care providers offer more than one kind of service?
 - b. Can people talk about the advantages and disadvantages of having these other services on site?

16. To connect you to these services your provider may ask you about things that don't seem to relate to your health, like housing or your income. How do you feel about answering these kinds of questions?

I'd next like to ask about the structure—or administration of the primary care practice.

17. Are your primary care providers easily accessible?
 - a. Are they available nights and weekends? Are they available without an appointment?
 - b. To what extent is this important? Do you go to the doctor outside of regular business hours—or without an appointment? Why and when?

18. Does your primary care provider use electronic health records, as in, a computerized system to store your health information in place of a paper chart? Do you know what we mean by this?
- a. How do you feel about primary care providers using electronic health records?
 - b. Does it affect your interaction—either positively or negatively?
 - c. Can you log in to your medical records to make appointments, see test results, or otherwise communicate with your provider?
How often do you use this kind of service?

I'd like to finish by returning to more general questions:

19. Overall, do you have suggestions for changing primary care so it better meets your needs?
20. Is there anything else I didn't ask about that you'd like to share?

Thank you for participating... [continue with wrap up details and information.]

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