Community Listening Sessions on Primary Care

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About the Project

Health Equity Solutions (HES), a 501(c)(3) organization in the state of Connecticut, was contracted by the Office of Health Strategy (OHS) to develop materials and conduct outreach sessions that engaged consumers in discussions about primary care payment and delivery reforms. These system-level changes would enable primary care providers to expand and diversify their care teams; offer flexible, non-visit-based methods for patient care; and help to address needs associated with social determinants of health. This report summarizes the findings shared and collected during the facilitated consumer sessions.

Background

In the United States, 54.5% of doctor's office visits are made with primary care physicians.[1] Yet, the US spends almost 2.5 times more on specialty care compared to primary care indicating an imbalance in resources and investment.[2,3] Research also shows that a person's social determinants of health account for 80 – 90% of their health outcomes while the remaining 10 – 20% is based on care received in the medical setting.[4,5] The State Innovation Model (SIM) within the Connecticut Office of Health Strategy identified the rising cost of health care and related barriers to health access, quality, and patient satisfaction as critical to advancing equitable patient and population health outcomes. In response, SIM developed a novel care model predicated on promoting health care delivery in the primary care setting. The goals of the model were to improve access, patient experience, and quality while positively impacting health equity. The aim was to advance patient-centered health care through delivery and payment reforms that focused on value over volume. In order to increase the capacity for primary care in Connecticut, the model proposed the following features summarized in Table 1.

[1] Rui P, Okeyode T. National Ambulatory Medical Care Survey: 2016 National Summary Tables..
[2] U.S. Department of Health and Human Services. Agency for Healthcare Research and Quality. Medical Expenditure Panel Survey (MEPS), 2014.
[3] Petterson S, McNellis R, Klink K, Meyers D, Bazemore A. The State of Primary Care in the United States: A Chartbook of Facts and Statistics. January 2018.
[4] Hood, C. M., K. P. Gennuso, G. R. Swain, and B. B. Catlin. 2016. County health rankings: Relationships between determinant factors and health outcomes. American Journal of Preventive Medicine 50(2):129-135.
[5] Bradley, E. H., B. R. Elkins, J. Herrin, and B. Elbel. 2011. Health and social services expenditures: Associations with health outcomes. BMJ Quality and Safety in Health Care 20(10):826-831.

Table 1: Primary Care Innovation Features

Core integrated features	Elective features
• Diverse care teams • Behavioral health integration • eConsultations & Co-management • Alternative communication via email, text, phone and video visits • Remote patient monitoring • Specialized care for older adults with complex needs and adults and children with disabilities • Paint management & addiction treatment • Community integration to address social determinants of health	• Oral health integration • Community Purchasing Partnerships • Shared medical appointments

Methods

Between June 2019 and December 2019, Health Equity Solutions conducted 8 listening sessions in English that engaged a total of 52 participants from various geographies and community populations in Connecticut. HES developed a standard presentation based on health literacy principles that was used as a tool to guide discussions. Sessions ranged from 45 minutes to over 2 hours and were recorded with participant consent. Throughout the sessions, participants shared their personal experiences with primary care and provided feedback, questions, and reactions to the SIM model. The table below provides a summary of consumer sessions.

Table 2: Consumer Listening Sessions

Date	Session Location	City
6/17/2019	iCAN Conference Behavioral Health Partnership	Rocky Hill
9/11/2019	George Washington Carver Community Room New London Housing Authority	New London
9/11/2019	Williams Park Community Room New London Housing Authority	New London
9/26/2019	iCAN Conference Behavioral Health Partnership breakout I	Hartford
9/26/2019	iCAN Conference Behavioral Health Partnership breakout II	Hartford
11/4/2019	Newington Senior & Disabled Center	Newington
12/6/2019	CT Hospital Association	Wallingford
12/16/2019	Zoom webinar	Meriden

This report is segmented by overarching themes that emerged across sessions. Each section summarizes general consumer experiences of health care received within the primary care setting followed by specific consumer feedback in response to the SIM model, including recommendations and proposals. Callout boxes containing direct quotes from session attendees are integrated throughout the report to relay the experiences and thoughts voiced by consumers. The report concludes with a section on limitations and future considerations.

Findings & Feedback

Expectations of Primary Care Providers:

Consumers' expectations of their primary care provider (PCP) was central to their experiences of health care in the primary care setting. Multiple consumers shared a desire for their PCP to have a comprehensive understanding of their health and be able to function as an aggregator, synthesizing their various medical conditions and social factors and identifying issues or inconsistencies that a specialist might overlook.

"My primary care provider is my manager. He's certainly my partner, but I make sure that there are no gaps when I see a specialist. Between what's going on with the specialist and what my primary care provider knows. Because I want him to have the whole picture" - Mary

"Unlike a specialist who's looking at your gallbladder or your liver or whatever or your bones. Ideally, but not always, the primary care doctor has feedback from all of the specialties that you see and really has a whole picture and therefore can recognize anything that might fall through the cracks from all of the different specialists who are communicating with each other." - Jillian

"I have a nurse practitioner as my primary care provider and I count on her to manage my routine health, you know, my cardiovascular standards, my cholesterol, blood pressure, all the stuff that the specialists don't look at and kind of will fall through the cracks if I just see a specialist. So, I see her a minimum of once a year and I count on her for that basic, you know, looking at the big picture, making sure I'm maintaining my basic health." - Bernice

That said, one consumer noted that not everyone has a PCP, nor does everyone understand the important role that a PCP can play in maintaining overall health. She recalled how she learned about PCPs when trying to access care for her child and noted that after being assigned a PCP the stability of having a single provider made a difference in her experience of the health care system.

Time and Provider Constraints:

Consumers consistently brought up time as a barrier to receiving quality care and a reason for dissatisfaction. Consumers also linked the scarcity of appointments and short office visit times to the shortage of primary care providers.

Long Wait Times. Multiple consumers described facing lengthy wait times when attempting to schedule office visits with their primary care provider and felt that this was a significant factor contributing to their frustration with the current health care delivery landscape. As a result of long wait times, consumers experienced discontinuities of care, particularly with routine treatment or prescriptions, which put a strain on their physical health and caused significant anxiety.

"Wait time is really an issue when you can't get in for 3 - 4 months and it leaves you dangling without care." - Mary

In addition to waiting to get into a provider's office, some consumers discussed their frustration with the extended amounts of time they spent in clinic waiting rooms when a provider was "off schedule." One consumer found the lack of notice and unexpected delays on the day of her appointment to be even more challenging because there was little accountability or care for how that would impact her day.

"I've been in the examining room waiting for the doctor to come in for like a half hour to 45 minutes. So that messes up their 15 minutes a patient. And they don't think anything of it." - Carmen

The experiences shared by Connecticut consumers align with evidence from the *9th Annual Vitals Index* that included one survey in which 84% of respondents agreed that reasonable wait times played a somewhat or very important role in their patient satisfaction ratings.[6] From an equity perspective, evidence also demonstrates that long wait times disproportionately impact patients experiencing the greatest barriers to accessing health care, with 53% of self-reported patients experiencing poor health care access citing long wait times as their reason for walking out of an appointment[7].

Conversely, not all consumers felt negatively towards their PCP for running behind schedule, with one consumer commenting:

"If they took extra time [for someone else], they'll take extra time with you." – Marsha

Consumer Feedback. Another consumer who had a PCP that was consistently running behind schedule would call her provider's office before leaving for her appointment to ask about the status of the day's schedule. Being informed about the timeliness of her appointment allowed her to plan childcare accordingly. Consumers in this session agreed with a suggestion of a formal system providing real-time status updates about clinic wait times for scheduled appointments with their PCP.

Short Appointment Times. Across sessions, consumers agreed that being a patient in the current system that only allots 10 – 15 minutes of time with their PCP was highly challenging. Specifically, not having enough time was a factor preventing consumers from having a meaningful and trusting relationship with their PCP.

"How can you really connect over such a short time? It's like speed dating." - Layla

[6] Business Wire. 9th Annual Vitals Wait Time Report Release. 2018. Available at: https://www.businesswire.com/news/home/20180322005683/en/ 9th-Annual-Vitals-Wait-Time-Report-Released. Accessed January 23, 2020.
[7] Ibid.

In addition, consumers did not feel fully seen or heard, especially when dealing with multiple complex medical issues, due to having to pick and choose their priorities in the face of a ticking clock.

> "There's not enough doctors to see the patients. They can't spend enough time delving into problems to strategize with you and try and find what's going on with you." - Bob

Overall, consumers wanted to see a transformation in payment and delivery that supported more time for authentic provider-patient interactions and less time "dangling between care" and sitting in waiting rooms.

Scarcity of Primary Care Providers. Consumers perceived the lack of primary care providers, specifically physicians, as a common factor contributing to long wait times and short interactions during appointments. There was consensus among participants that physicians practicing in a primary care setting were overburdened, undercompensated, and working in conditions that led to "physician churn" or "burnout." Consumers did not feel that primary care physicians were being adequately supported to accomplish their work during regular clinical hours. The providers who went above and beyond their allotted patient time did so to the detriment of their work-life balance. Consumers discussed examples of providers working around the clock during their scheduled days off. These consumers were sympathetic to provider conditions even though they were simultaneously benefitting by receiving additional attention and services from their provider in a timely manner.

> "Come on, who wants to work 20 hours a day and get paid $85,000? Nobody. Well, yeah, especially with the amount of training that they have to pay for." - Donna
>
> "[PCPs are] in there like 5, 10 minutes at most, right? If you have a really, really sick patient or someone who has extra questions it throws [the provider] off for the rest of the day and [they are] there until 6:00, 7:00, or 8:00 at night." - Corey

An elderly couple noted that they have seen three different primary care physicians over the past seven years. They expressed disappointment in a system that neither prioritized the needs of patients nor providers leading to their experience of high provider turnover, which, in turn, challenged their feelings of stability and security with the health care that they received.

> "[Primary care physicians] are leaving the practice because they are stressed out. We had one who left week and a half ago. She was a young female physician with small children. She said when she got home, [after] the whole day of seeing patients, she had no time to look at test results coming in on all of her patients. She had to do this after hours at home, which meant when she got home, she had no personal time. So, the system seems overloaded. Now, with a system like that, if you want the primary

care physician to take on more, you need more primary care physicians, or you've got to do something. Because primary care physicians are not staying." – Linda

"If primary care doctors weren't so pressed for time and had a lower patient load. I recognize that there's a shortage of primary care doctors, so that's a big thing to be addressed and that gets into complexities that are way beyond the scope of this, like help them get through med school and be able to afford to pay it back." - Marsha

This theme of provider scarcity highlighted consumers' desire to have consistent and continual relationship with their PCPs in a system that prioritizes high impact, relationship-based care, invests in the training and working conditions of primary care providers, and is not incentivized by a large patient panel.

Consumer Feedback. The SIM model proposed diverse care teams as one way to address the time and provider constraints discussed above. Consumers had mixed feelings about this feature. They appreciated the idea of being supported by more than one person who would help connect them to care. They were also in favor of having a team of people who would enable them to have more time with their PCP and receive timely follow up. In particular, the care coordinator role in the primary care setting was perceived as adding the most value to address some of the barriers impeding access to adequate care.

"I think it would be great to have a person who could coordinate care and then refer and communicate with the other specialists. That would be a very valuable team member. Sort of like a social worker would be in a hospital, setting up your aftercare within the primary care setting. That would be great." - Marsha

Furthermore, consumers recognized the importance of patient advocacy and positive impact that diverse care teams would have on increasing accessibility to advocates. A few consumers shared how they were able to play an advocate role for themselves or their loved ones and the significant amount of time and effort that this required. For example, one consumer recounted a challenging series of encounters with her son's insurance company as she struggled to identify in-network providers who were accepting new patients.

[My son] didn't have the time to make the kind of phone calls that I had to make because he works 10 hours a day. So, yeah, I don't know what he would've done, but it's not good…Somebody has to know. Someone has to speak up if they don't know. I mean, I'm very proactive. Most people with complications develop this skill because you have to…" - Carolyn

Multiple consumers also noted that while not every person has the same ability or time to advocate for themselves, everyone should have an advocate available to them

if wanted or needed. For these reasons, the advocacy aspect of having access to a community health worker found broad appeal across listening sessions.

Some consumers also stated that they would be open to a diverse care team; however, they wanted to know more about the degree of choice that would be available to those who already had an existing team of providers across health care settings. Namely, consumers with complex diseases expressed their desire to maintain their autonomy by having a say in who was on their care team. For example, one consumer felt that the risk of not matching with a specific provider on the care team made the prospect of receiving care from a diverse care team model unappealing.

> "People with complex needs and complex care going in there and getting six, seven minutes of quality time feel kind of ripped off. So, you know, there's a time factor. There's a communication factor that I think are two huge issues. I'd rather see that than a diverse care team in there, to be honest with you. I'd rather see 10 primary care providers than have to worry about getting a mental health provider I match with in the office." – Deborah
>
> "I think I wouldn't object to that because there will be people who have none of these resources. So, having somebody [else] there is good, but I wouldn't want it to be limited like programs where you have to go to that center and you only have your choice of this team. I would like it to also include the ability to be referred out." – Tina

Consumers were also concerned with the potential restrictions of a diverse care team model, particularly their ability to be referred to a different team member if the relationship between consumer and provider does not fit. Furthermore, they wanted the option to personalize their care team by maintaining a standing relationship with an independent care provider, such as a behavioral health specialists or nutritionist.

A segment of consumers was still wary about diverse care teams because they preferred their current relationship with their PCP and felt that their ability to see their primary care physician would be adversely impacted.

> "It seems to me it's just getting more people involved. I mean, I like the old-fashioned way you go, and you talk to your doctor." - Betty

Therefore, including an accessible way for consumer preferences to be recorded and respected will be a crucial aspect to consider when determining how exactly diverse care teams will be created and operationalized.

Barriers to Health Care Access:

Consumers identified transportation and difficulty finding providers accepting Medicaid (HUSKY) insurance as top barriers to accessing health care in the primary care setting.

Quality of Non-Emergency Medical Transportation Services. Across all sessions, consumers brought up transportation as a challenge to accessing health care and social services. Non-Emergency medical transportation services were not well regarded, particularly among consumers with HUSKY. Consumers expressed significant anxiety and frustration about missing appointments due to unreliable transportation, which often resulted in delayed care. Furthermore, consumers felt unsatisfied because they did not have a meaningful way to file complaints and secure alternative options for transportation services. Overall, challenges in securing consistent transportation impacted consumers' access to health care, particularly when compounded by the scarcity of appointment times and the logistics of setting up another transportation service.

> "I don't trust the ride." -Tom
>
> "Yesterday I was sitting with a group of women. They all had their medical ride not show up at all. At all." - Beth
>
> "They have a doctor's appointment at 9:00 o'clock. The cab is nowhere to be seen. They had to cancel their appointment and then make another appointment and pray that that the car will be there." - Richard

Consumers also mentioned experiencing uncoordinated transportation services that included sharing rides with people who had appointments in different locations that were significant distances apart. This meant consumers had to spend even more time in transit. Similarly, shared transportation services often led to consumers being stranded in a clinic for an extended amount of time while waiting for other patients to finish their appointments.

> "They'll pick me up out here at 7:30am. My appointment is usually always for 9:00am or 9:15am. We came down here around eight 8:30am. I go to my appointment. I'm done by 9:15am and I have to sit there and wait until the last person comes in. I've been down there as late as 2:15pm in the afternoon… That's a long day." - Benjamin

Public Transportation Availability. Accessing public transportation was also cited as a significant challenge because not all neighborhoods or towns have comprehensive transportation services, particularly in rural areas. Some consumers liked the idea of more decentralized services that included smaller medical homes in proximity to patients, which would allow them to receive primary care services closer to home.

Consumer Feedback. Overall, consumers wanted to see streamlined transportation services integrated into the primary care model. They wanted to see the model include more detailed features and solutions that would respond to consumers' transportation needs and provide accountability to ensure the quality of existing transportation services. To address this barrier, consumers were in favor of having access to someone like a community health worker who was dedicated to helping patients identify and secure reliable transportation options. Other suggestions

related to addressing transportation included possible partnerships with commercial ride services like Uber or Lyft, which already have accountability mechanism embedded into their systems.

Low Acceptance of HUSKY. Multiple consumers shared that they were unable to access care near their homes because not enough providers were willing to accept HUSKY. As a result, consumers had to travel long distances for care that met their needs, receive less satisfactory care, or go without care. For example, one consumer was only able to identify one naturopathic physician who accepted HUSKY C in Connecticut. This barrier was exacerbated in non-urban areas and by factors such as practices not offering evening or weekend hours.

"There are a bunch of [doctors] around here, but none of them take HUSKY…I have had to call every one of them." - Jim

"This place [New London}, in this area here is so difficult. As opposed to Hartford or New Haven for doctors." – Benjamin

Across multiple sessions, consumers supported payment reforms that would ensure that HUSKY members had equitable access to providers in the primary care setting.

Alternative Communication:

Consumers had mixed reactions to the integration of phone, text, email, and telemedicine capabilities in the delivery of primary care. Some consumers found alternatives to office visits appealing for certain services, because they would save time, money, and the hassle of securing reliable transportation. One consumer shared that her physician was an early adopter of such forms of communication. For example, she was able to send him a picture and have him refer her husband to a dermatologist for Lyme disease without going into the office. Another consumer shared that she and her PCP were able to discuss and address concerns about her chronic medical condition via email so that she only needed to see him twice a year.

Technology Adoption. Discussions with older consumers about alternative forms of communications brought up issues of technology literacy and how these capabilities may be difficult for some older adults due to limited access to devices such as smart phones or computers as well as limited experience or physical ability to use these technologies.

"Because of the rapid movement into the Internet over all functions of life, there's a whole segment of people that you're talking about that are left out because they can't afford it. They don't want it or whatever other reasons that it's creating some issue. I think, not only older people. I think that the whole segment of people in general out there that would fit that." – Sue Ann

"I'm saying that I think in five or 10 years, this might work because people are becoming more familiar with computers. But now they don't have them, they don't want to know. It's too soon to bring this up."- Ellen

"[It's] different for the older people who don't have access…who don't know how to use computers. Having alternatives. Not everyone has a computer or a smart phone." - Lydia

Consumer Feedback. Some consumers also thought that some of the alternative communication features proposed in the model were "too soon" given that they felt accessing a physician on the phone was already a challenge. There were also questions on how payment would be structured so that telemedicine would not pose an unintended consequence of keeping people from physical office visits, when that was their preference.

"How are they going to be compensated? They have to be compensated properly. How are they going to fit that in if they're going to add 50% of telemedicine that's trying to screen out 40% of office visits? Where do you get the time?"- Betty

While, consumers were excited about the inclusiveness that alternative communication would provide, this discussion highlighted consumer interest in payment reform, variable understanding of value-based care, and the continued need for information and education to increase consumer literacy in this area. Some consumers felt that this feature of the model would better respond to consumer circumstances and preferences, particularly for younger patients.

Although, certain consumers were in favor of alternative communication or visit methods, multiple consumers voiced concerns that alternative communication had the potential to exclude segments of the population and perpetuate existing barriers to care. The hesitancy expressed across sessions demonstrates the need for delivery reform to be flexible and inclusive of various communities' needs and preferences.

Siloed Information and Data System Infrastructure:

In reflecting on primary care experiences, consumers across all groups shared their desire for alignment among information systems and shared personal challenges related to being a part of multiple systems and networks that did not easily 'talk' to each other. Consumers perceived that the lack of interoperability between systems contributed to poor intra-provider communication and follow up and inconsistent medical data collection that adversely impacted their health care experiences and outcomes.

Poor data sharing infrastructure between providers. Consumers detailed challenges they experienced as a result of their PCP and various specialists not

having access to information sharing capabilities. This was the case for providers working within the same health system:

> "They do not link up under their own umbrella. Even different systems within a larger parent system." - Franklin

Similar problems were apparent for consumers who received care from providers in multiple systems:

> "My PCP is under St. Francis. My cardiologist is under Hartford, so never the two shall meet." - Jim
>
> "I have a real problem with information sharing because I have maybe eight or nine specialists and one PCP that I go to twice a year for visits. They're not all on the same computer system. And [my PCP has] got stuff from two doctors and nobody else. It drives me insane." – Mary

Consumer Feedback. Consumers found the co-management and eConsultation capabilities of the model appealing because they addressed some of the structural barriers with information systems while enhancing consumer access to a greater array of specialists. One consumer was excited about how these capabilities would facilitate getting a second opinion on a diagnosis. Another consumer mentioned a service, Best Doctors, that bundled her medical records and sent them out to actively practicing world specialists, which was important given her rare disease. The service made disease co-management easier. She felt that expanding consumer access to this type of capability would be beneficial for patient and provider outcomes.

> "[The specialists co-managing my condition] confirm the diagnosis. And I continued treatment with my [primary] doctor. You know, he was on the same page as the specialists. It is kind of nice." - Maria

Several participants in sessions were veterans and asked how TRICARE was being engaged in the conversation of statewide data sharing, as the existing infrastructure posed an additional barrier to navigating care.

> "Like, if I go to my PCP on the outside, I have to request him to make sure that information gets pushed to the V.A. and from the V.A. back to the PCP… Because I just had an instance where the PCP at the V.A. wouldn't discuss my problems until she got information from both my PCP and my cardiologist [outside of the system]."
> - Harry

Another consumer was interested in understanding how community care settings, specifically school-based health centers would be integrated into primary care reform efforts, indicating a desire for greater coordination and data sharing with systems that have been traditionally carved out from standard delivery of primary care.

Overreliance on patients to provide medical history. Because data is not easily shared among providers, consumers described feeling the onus was put on the patient to remember and be responsible for their own medical history. This posed an additional burden for consumers having to navigating an already complex medical system.

> "There are good physicians within all of [the health systems], but to start navigating all...it was a burden on [me], the patient. And, you know...I am very computer literate. Not a problem there, but it takes a lot of time to really stay on top of this and to get what you really need for yourself. I'm [my husband's] advocate also. So, I do it for me and for him. I can spend hours trying to do this." - Lydia

While there are existing programs or features that attempt to facilitate the aggregation of patient records, consumers noted that they are not easily accessible and required them to spend significant time and effort reentering data.

> "Like in *Mychart* it says, you know, connect your records in one place or whatever and you know, you probably have half a day that the patience of a saint to try to follow them. They are so complicated, but it will only work with other EPIC institutions." - Melinda

As mentioned previously, consumers acutely felt the scarcity of time during their clinical interactions in the primary care setting. The challenges related to siloed information systems contributed to consumers' feelings of being shortchanged during provider visits.

> "I gotta go to my PCP and spend 9 of the 10 minutes bringing her up to date. It's ridiculous." - Bryan

Consumer Feedback. Many consumers liked the idea of a common electronic health record or virtual patient record (VPR). Having one portal to facilitate the consent process needed to share their medical information across providers would address the lack of alignment between various EHRs and the current reality of portal sprawl that necessitates navigating multiple disparate patient portals. Consumers also liked the possibility of having portal access through a secure app on their phones. Additional suggestions about a central portal for patients included having a graphic-based interface to account for consumers with low health literacy or non-native English speakers. One consumer suggested building a feature that would enable patients to have their own folders on the VPR. This would allow consumers to securely upload files that then could be "sanitized" and opened by any provider with whom they consented to share their information.

As necessary as consumers found data sharing to be to improve the experience and quality of health care they received, they also raised several concerns about data

privacy and governance. Media coverage of serious data breaches have informed consumers' reticence towards information sharing. For example:

> "Those who are worried about their information being shared. We have good reason to be because there are enough reports of information breaches and data breaches and stuff." - Betty

As innovation in data systems and information technology advance in Connecticut, awareness campaigns regarding consumer data rights and privacy safeguards will be required in order to allay consumer concerns.

Provider willingness to bridge information gaps. Consumers experienced a wide variation in the willingness of their providers to follow up and actively share information with other providers. While some consumers felt cynical, other consumers enthusiastically expressed deep appreciation of providers who went above and beyond the status quo to ensure their data was shared in a timely way.

> "[Specialists] don't pick up the phone and call your primary care provider to give them an update. You're lucky if they send a note." – Kia
>
> "[My specialist] is very good about sending letters, detailed letters back to my primary care provider. Because that's who he is, and he works in a teaching hospital and he's a researcher and he appreciates the value of that communication." - Mary

Consumer Feedback. Overall, consumers wanted a system that supported the seamless flow of information between their providers. Consumers desired a feedback loop mechanism that would provide a confirmation that their information had been transferred from system A to system B. They felt this to be a necessary feature to enable them to keep track of information gaps between providers. This feature would also support consumers in building and sustaining trust with providers across primary and specialty care settings, particularly when dealing with complex conditions.

> "I don't expect my primary care person to be very knowledgeable about rare disease because that's not their thing. But I do expect her to get the name of it right and at least to maybe look it up once when I start going there or something. And, you know, I don't feel like [my PCP] is well versed in my disorders. So, you know, that's a little bit of a concern to me. And she does seem to be good enough to send me off somewhere when I when it's outside of her purview. I think if there was more of a feedback loop and she was getting constant updates from my endocrinologist or other doctors, she'd probably learn a little more because she'd get that feedback." – Deborah

Participants also mentioned consumer education as a key aspect to consider when introducing technology innovations that would change the patient experience. It will

be important to identify effective ways to educate consumers about technology innovation, while continuing to consider the segments of consumers who may not benefit from such technological advances.

Challenges with Accessing Prescription Medication:

Across listening sessions, consumers brought up challenges they faced receiving, refilling, and reconciling prescription medication. For routine refills, consumers discussed barriers that made visiting their PCP difficult, such as arranging transportation or taking time off from work. One participant's question: "Why do I physically have to go see my physician [for a refill]?" highlighted the ways in which a landscape that primarily incentivizes physical office visits does not account for consumers who have difficulty leaving their homes due to physical disabilities or as a result of their social determinants of health.

Managing Prescriptions. Accurately keeping track of prescriptions was another challenge brought up by several consumers. These participants cited how different prescriptions were in distinct systems, resulting in inconsistent records. In order to maintain up-to-date knowledge of their prescription medication lists, several consumers noted consistently asking for a printed record prior to leaving their provider's office. While this was seen as a solution among consumers, hard copies did not address the concerns that prescription medication summaries can be challenging to read and may not even be correct. One consumer who experienced immunodeficiency conditions reflected:

> "The patient at the end of the visit, gets a printout that lists the medicines. They're not in any order. Because it depends how the epic installation was originally done. It could be alphabetical. It could be the most recent prescription is first. It could be the oldest prescription is first. There is no rhyme or reason. The name of the drug is whatever the doctor wrote on the prescription. If there was a generic substitution made at the pharmacy, that will not be reflected on the drug list that gets printed out at the end of your visit." - Mary

The inconsistency between the prescription provided at the pharmacy versus the medications recorded on a patient's record indicates a need for improved flow of information within and between systems and types of providers, such as the PCP, the pharmacy, and the pharmacy benefits manager. While going over prescription lists is part of a PCP visit, time constraints and the need to prioritize other health concerns were often cited as factors limiting consumers' ability to reconcile their prescriptions.

Consumer Feedback. Features suggested by consumers included having a more formalized way to correct or ask questions, for example about a pill they are taking that is not reflected on the list. A related question arose in one session: "Where is Connecticut in pharmacy reconciliation?" This consumer shared a graphic mapping out her experience with prescriptions reconciliation versus her vision of the ideal process flow (Appendix A, Appendix B) and she followed up by saying, "This is the

level of disconnectedness that is just totally unknown by policymakers." For these reasons, consumers were in favor of having a pharmacist or another knowledgeable person on the care team to assist patients in having an accurate understanding of their prescriptions and ensuring that their records were correct. One consumer also expressed her appreciation for Surescripts, a tool that allows prescribers and members to access real-time information about their prescription benefits and costs as well as therapeutic alternatives that are available at lower costs.

Consumers also wanted a seamless information flow related to prescriptions that would prompt providers to follow up. One consumer provided an existing example of this:

> "I went to a walk-in clinic when I was in Denver for a UTI. And I came home [to Connecticut], and [my PCP] said, 'Oh, so I see you had another UTI and you got this prescription.' And I'm like, 'How do you know that?' I don't know how the information got transported, but I was pretty shocked."

Based on other experiences that consumers shared, this was an exception not the rule. However, replicating and scaling this type of follow up in the primary care setting is a part of what consumers felt was necessary to achieve patient-centered care.

Accessing Pain Management. Consumers noted the challenges they faced in receiving prescription pain medication amid the opioid epidemic. For example, one consumer shared that she received a prescription for only ibuprofen after having a knee replacement surgery. Another consumer disclosed that her provider had to go through three levels of prior authorization in order to prescribe oxycodone after an ankle reconstruction surgery. While this consumer did receive the medication, it was limited to a 5-day dose. This posed a challenge because of her limited mobility, causing her doctor to advocate on her behalf by asking: "How is she supposed to get to the pharmacy to get more?"

Although consumers acknowledged the importance of preventing the over-prescription of opioids, they felt that they were being inappropriately impacted in a way that decreased the quality of care they received.

Consumer Feedback. Many consumers were in favor of having expanded pain management at the primary care level because they felt that a trusting relationship with a PCP who knew their risks and behaviors was critical to receiving appropriate prescriptions and treatments. One consumer shared that she may need another surgery and had felt insecure about the pain management process until she spoke with her PCP:

"I said to my doctor, 'I'm really scared this time because with all of this cut back with pain medicine because of the opioid crisis, I'm scared to death that I'm going to be in a lot of pain.' And she said to me, 'I know you and don't worry, and that won't happen.' Well, what a relief… She's got my back now and she knows me well and I've been on and off them without issue, fortunately. So, she can assure me of that. That kind of relationship is priceless." -Rhea

Additionally, a few consumers mentioned that discrimination can factor into the likelihood of being prescribed an opioid. For example:

"We do know, and I think that everyone here would agree, that there is discrimination in terms of health care." – Jeanne

Racial inequities in pain management have been well documented in literature. Evidence shows that patients of color are less likely to receive an opioid or non-opioid prescription to manage their pain and more likely to report a greater severity of pain than their White counterparts[8]. Overall, consumer reactions affirmed the SIM model's prioritization of equity in the delivery of pain management and medication assisted treatment in the primary care setting[9].

Oral Health Integration:

Among the elective features presented in the primary care innovation model, consumers most frequently discussed oral health integration as the most critical feature. Consumers expressed their support for having their PCPs assess their oral health. They also were open to receiving care coordination in the primary care setting that included oral health in order to expand access to these services. In addition, one consumer suggested that dental cleanings be available more than once a year to adults on HUSKY.

"How about if at every primary care visit [your PCP] said, 'When was the last time you saw a dentist?' That needs to just be routine. And you need to plug them in to the navigator to hook them up with a dentist." – Mary

"My dentist performed an oral exam looking for cancer or things like that. I don't know that all dentists do, but it would be much better in a primary care setting. And then they can say, 'Go see the dentist," if there's a problem with your teeth that they can spot." - Carolyn

[8]Samuel, C. A., Corbie-Smith, G., & Cykert, S. (2019). Racial/Ethnic Disparities in Pain Burden and Pain Management in the Context of Opioid Overdose Risk. Current Epidemiology Reports, 6(2), 275-289.0

Bridging information between oral health and primary care providers. Like the gaps in information between PCPs and specialists, an existing challenge for consumers seeking oral health services was their responsibility for holding both their medical and dental history.

> "[The dentist] totally relies on you to give your own history, your own meds, your own everything." - Deborah

Consumer Feedback. Overall, many consumers saw oral health integration in primary care as important to bridging the divide between medical and dental services. Multiple consumers asked why oral health integration was an elective feature, which suggests that it should be considered a core capability of the model.

Consumers also noted that they wanted a way for their dental providers to be able to have access to their electronic medical record and vice versa for their PCPs having access to their dental records. One consumer asked if dental providers were being included in conversations about the statewide exchange of health information. She felt that this was a critical piece to ensuring coordination between oral and physical health.

Limitations & Recommended Next Steps

The qualitative data presented in this report represents a small sample size (n = 52) of consumers. While we have identified themes from across sessions, the findings are by no means comprehensive. Future consumer engagement that includes the collection of participants' basic demographic data and reaches a wider diversity of specific communities would be valuable to further contextualizing consumer observations of primary care and enabling a more detailed understanding of differences between consumer groups. Continued outreach and engagement with communities, particularly those experiencing the greatest barriers to achieving quality health, is necessary as efforts to reform health care delivery and payment move forward in Connecticut.

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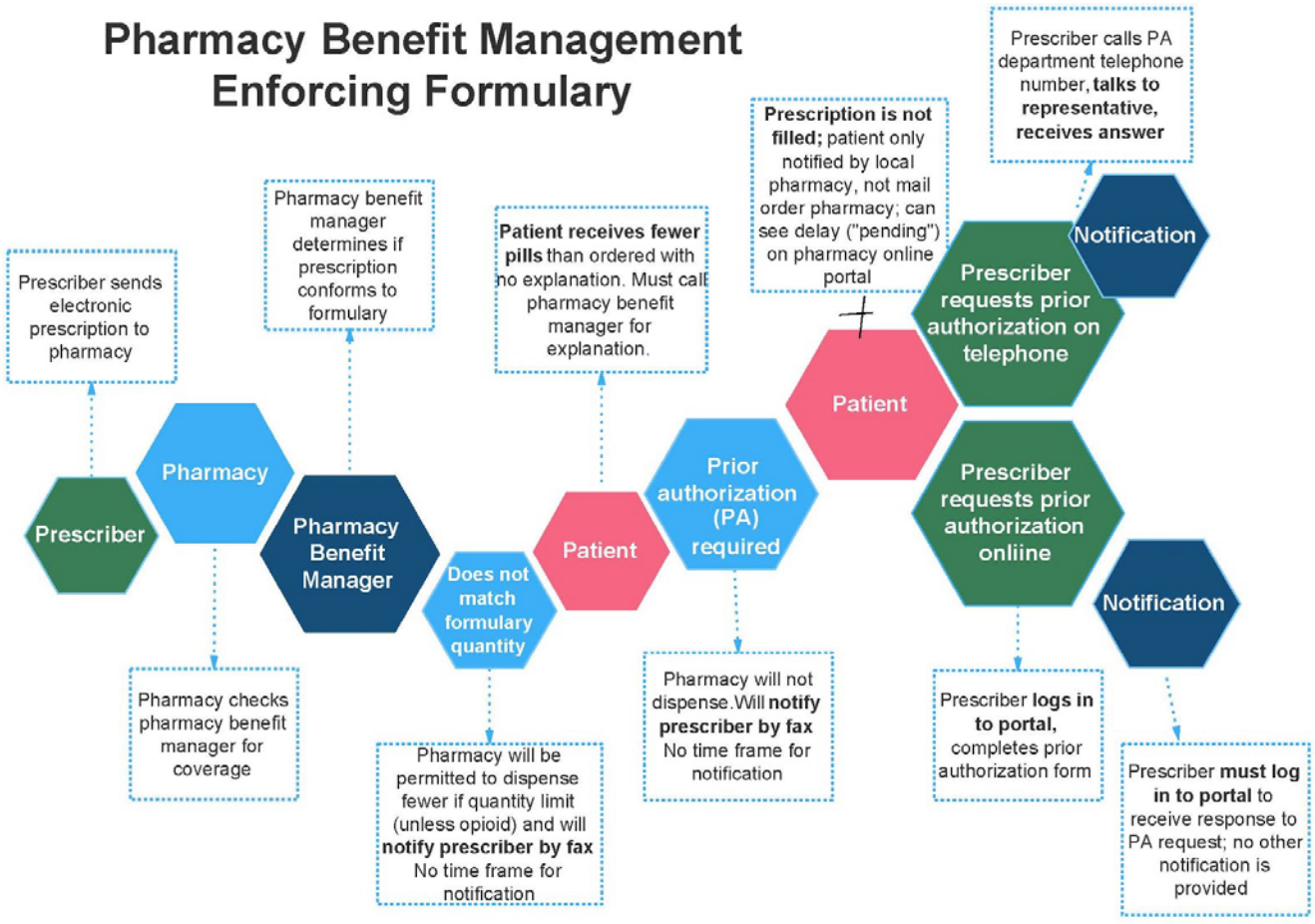
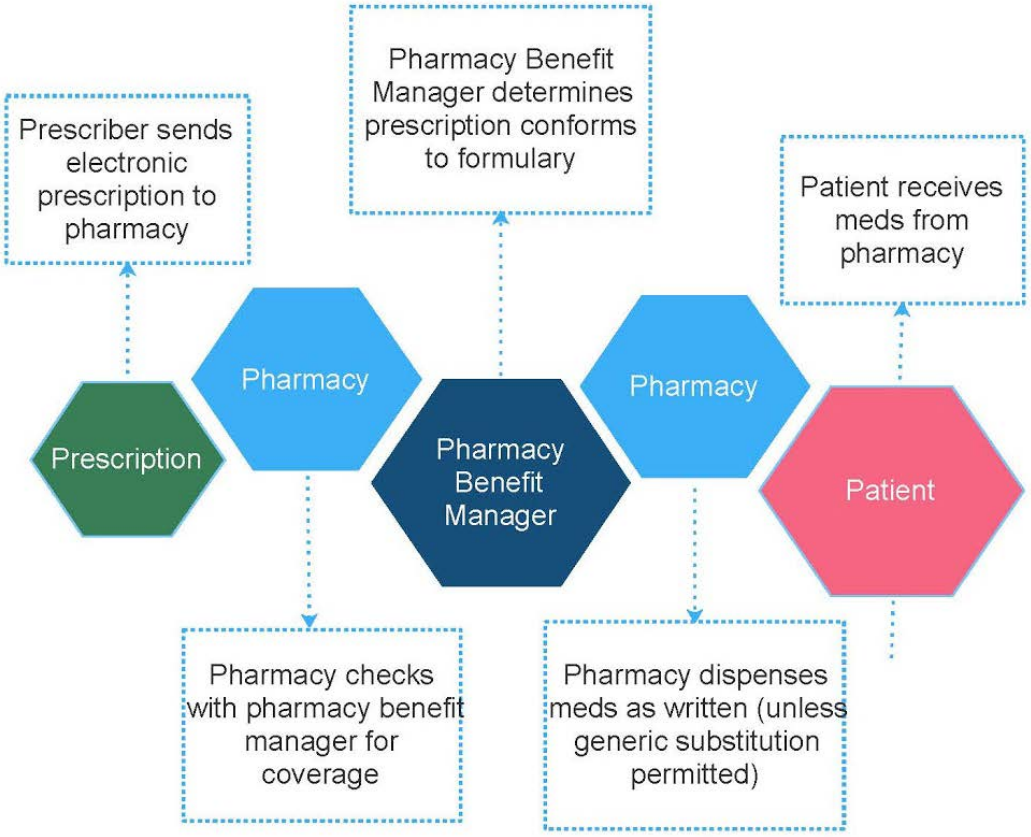
Appendix A: An existing consumer prescription experience



Source: Provided by consumer participant

Appendix B: An idea for prescription fulfillment



Source: Provided by consumer participant

Appendix C: Resources and services referenced by consumers

- **Best Doctors** https://bestdoctors.com/

  A service that enables consumers to receive expert medical opinions from specialty and subspecialty providers and work with their existing providers to assess diagnoses and modify treatment plans.

- **BrightMD** https://www.bright.md/

  A virtual, nonvideo-based telehealth care platform that enables patients to seek treatment for low-acuity conditions with an on-call provider.

- **Get Real Health** https://getrealhealth.com/

  A developer of digital health platforms and portals that enhance capacity for patient engagement.

- **Text4Baby** https://www.text4baby.org/

  A texting app that provides expecting mothers with best practices and resources during pregnancy and postpartum.

- **Surescripts** https://surescripts.com/enhance-prescribing/benefit-optimization/

  A provider of services enabling interoperability of prescription and clinical data between providers, pharmacy benefit managers, and pharmacies to enhance prescribing, optimize benefits through provision of real-time formulary information, and facilitate prior authorization processes.

- **VisualDX Plus DermExpert** https://www.visualdx.com/

  A support tool that aids primary care providers in accurately diagnosing skin conditions.