The 360|Report

Blue Cross and Blue Shield of Minnesota –
"Pledge to Listen" Fall Sessions
Engage! Healthcare

Facilitated by MTI

Events: 17 November 2020, 19 November 2020, 1 December 2020

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The Pledge to Listen: Engage! Healthcare Twin Cities – The Fall Sessions
Blue Cross and Blue Shield of Minnesota
17 November 2020, 19 November 2020, 1 December 2020

The 360 | Demographics[1]

Total Guests | 150 across all events – 47 (November 17), 47 (November 19), 56 (December 1)

Indigenous or Other People of Color | Approx. 87 (58%)
Youth/Under 24 | Approx. 21 (14%)

Human Survey Results | Self-indicated by participants via two voluntary online polls held during the events. Not all questions were asked at all events in accordance with the principals of emergent, responsive design. *First Poll: N = 127 participants* | *85% response rate. Second Poll*[2]*: N = 67* | *65% response rate.*

- If needed healthcare/insurance, knows where to go to get started**: N = 69 (67%)**
- Currently insured: **N = 66 (64%)**
- Has a regular healthcare provider: **N = 78 (76%)**
- Had opportunity to share something with BCBSMN that would improve personal/family health: **n = 83 (82%)**
- Learned something they didn't know before about BCBSMN: **n = 58 (57%)**
- Wants to come again: **n = 92 (91%)**
- Would invite someone: **n = 91 (90%)**
- Interested in joining an advisory board, if community recommended it: **n = 72 (71%)** (An additional **6%** said "Maybe")

Table 1. Overview of Key Themes from Fall Mindstorm Listening Sessions:
"More on trust: How can we trust doctors who don't value or respect our existence?"

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[1] **Note:** Percentages above have been rounded up to the nearest whole percent and therefore represent close approximations.

[2] Due to technical and logistical adjustments to the program, the second poll was not presented to participants of the first event on November 17th, altering the denominator of the response rate. Of 103 participants who received the opportunity to take this poll, 67 submitted responses, resulting in a response rate of 65%. All 150 participants received the opportunity to take the first poll, making the denominator for that poll's response rate 150, with a numerator of 127 and a response rate of 85%.

Theme: *Disparities in clinical settings, treatment and health outcomes by race, gender, sexuality, or culture of origin.*

Highlights:

- **Poor or under-treatment of Black women and other community members of color** in clinical settings; providers not taking their pain seriously, experiences of microaggressions (and macroaggressions) based on race (such as the assumption of a drug problem in the absence of indications to that effect) and **Black and brown participants' personal stories of receiving insufficient, inappropriate or "a less sophisticated level of care"** in hospitals and clinics.
- Persistence and severity of **prejudice toward trans men, trans women, and gender nonconforming individuals in clinical and other healthcare environments**; inability to access needed care.
- Perception that many are unwilling to discuss disparities in treatment and outcomes by race and gender under Covid-19, and the practical realities faced by Black and brown, trans and LGBTQIA+ community members seeking care, sense that providers and insurance representatives can be dismissive of concerns when raised.

Related/supporting theme(s): *Lack of institutional and provider trust among Black patients in relationship to historical traumas such as the Tuskegee experiments in which Black patients were famously sterilized and subject to experimentation without their knowledge or consent or the history of biases and undertreatment of Black pain in clinical settings and the cultural context of such experiences – impact of these traumas and the resulting lack of trust upon Black community members anxieties about the Covid-19 vaccine and when or whether to take the vaccine.*

Theme: *Affordability and accessibility of insurance and medical care – difference between having insurance and being able to use it/access the care one requires.*

Highlights:

- **Gaps by generation/access to technology and the internet** in context of **telemedicine offerings** (for elders, those without reliable internet access or suitable devices, etc.).
- Need for **quality care that is affordable and accessible**, personal stories of having to leave the country (or considering such a move) to receive adequate and/or affordable care – with and without insurance.
- Patients reporting needing treatments at critical moments in their lives and health and finding them unexpectedly not covered.
- Positive perceptions of **universal healthcare.**

Related/supporting theme(s): Difficulties finding affordable dental care, especially for low-income households and individuals, immigrants; insufficiency of existing resources.

Theme: *Need for more culturally appropriate care options and culturally competent providers as well as more medical and healthcare professionals who "look like [patients]" (i.e., culturally, racially, ethnically and linguistically diverse providers a valued and important resource that needs to be made visible and accessible beyond hiring practices alone).*

Highlights:

- Deep interest in having **culturally appropriate care,** sensitivity to the needs and experiences of trans and queer community members, and more options and choices for providers and holistic care needs.
- Need for common treatments and services critical to **trans health to be included in insurance policies and coverage.**
- Address stigma against LGBTQIA+ community members and **disparities in treatment and care** as well as life outcomes.
- Interest in **user-friendly interfaces and opportunities to read and post reviews of provider experiences** and costs of common services up-front.

Theme: *Role of institutional obstacles, stigma and trust in seeking and receiving health care, advocating for loved ones; experiences seeking health care and attempting to navigate the system so distressing that it creates or triggers mental health crises including suicidal ideation; general desire to be treated as fully human, whole human beings – rather than one's SES, gender, race or other elements of identity.*

Highlights:

- **Bureaucracy and delays** are a problem across systems/regions, but experiences vary in different states; perception that policies have been designed for the convenience of companies, clinics and providers, rather than patients and families.
- Medical **providers are not always knowledgeable about how to navigate insurance and pricing** from the patient perspective, too much pressure on doctors and nurses.
- Need for **critical culturally specific services and programs** to be continued and/or **expanded during the Covid-19 crisis.**
- Challenges and **obstacles to self-advocacy or advocacy for the care of others**; self-advocacy not always enough to ensure appropriate care and treatment; need for more supports for family members responsible for coordination of a loved one's care.
- **Stigma and experiences of discrimination are an active barrier to seeking treatment and care** subsequently, being shamed by providers over body weight in ways that discourage seeking care later on – or, being misdiagnosed due to weight stigma and biases.

The 360 | Executive Summary, Event(s) Overview

Over the course of three virtual events hosted via the videoconferencing platform Zoom, Marnita's Table and Blue Cross and Blue Shield of Minnesota brought together 150 community members across the Twin Cities Greater Metropolitan Area to reflect and provide feedback on community needs and priorities since the police killing of George Floyd in Minneapolis on May 25th 2020 in conversation with the Blue Cross and Blue Shield of Minnesota team. All conversations were open to the community and featured a feast appropriate for all dietary needs from vegan to carnivore, prepared by local caterers and small-business vendors. Meals were provided for participating households and delivered in accordance with public health guidelines for food delivery during the ongoing Covid-19 pandemic[3]. Families and other household groups were invited to participate in the conversation together over dinner utilizing either a single shared device or separate personal devices.

Participants discussed their experiences seeking and receiving healthcare, challenges navigating insurance and the medical and dental care systems, as well as their concerns and priorities around holistic

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[3] For participants who were either unable or unwilling to receive delivery at their home or other location from which they participated in the virtual conversation, gift cards were provided for a meal of their choice.

wellness, racial justice, queer and LGBTQIA+ care and other topics via the mechanism of a guided conversation which placed the discussion in the context of community participants' experiences and personal perspectives. Significant themes emerging in the qualitative content analysis of the small group discussion notes included the need to ensure access to comprehensive affordable, high-quality and culturally appropriate care for all, and emphasized the need for holistic options, trust-building among providers and patients, redress of persistent inequities, and elimination of stigma. Participants also expressed interest in seeing the development of more supports and resources for family healthcare advocates, highlighting the importance of providing information in Spanish and other languages and ensuring that competent and well-trained interpreters be made available to patients and family members. Additional themes include the problem of historic traumas like the Tuskegee syphilis experiments in which unsuspecting Black patients were sterilized and experimented upon without their consent or knowledge, and the importance of technical support and computer literacy training for elders and others, especially those in need of telemedicine services, though some point out that a lack of appropriate devices and reliable internet connection are also barriers to the accessibility of existing online resources.

The Minneapolis and Greater Twin Cities-based events represent a set of conversations conducted in November and December of 2020 in support of Blue Cross and Blue Shield of Minnesota's 2020 Pledge to Listen and learn from community feedback in a relational and participatory process. The series was co-hosted by President and CEO Dr. Craig E. Sammit and members of the Blue Cross and Blue Shield of Minnesota team, with facilitation provided by Marnita and the Marnita's Table team in the model of Intentional Social Interaction (IZI). Project coordination, logistics and outreach were led by senior project director Sammie Ardito Rivera with support from outreach specialist and Spanish language coordination lead Marlene Rojas Lara and training director Lauren Williams. Materials design, research, evaluation and analysis were conducted under the supervision of research director Elexis Trinity with support from operations and evaluation manager Lars Goldstein and other members of the MTI team.

Each gathering concluded with a ritual Circle Share-in session in which participants were asked to share one hope they hold for the future of health and wellbeing. Comments from participants drawn from this session were transcribed by members of the MTI research team during each event and can be found at the conclusion of this report. The following report consists of qualitative discussion data collected from the above activities and the thematic analysis of their results conducted by the Marnita's Table research team.

Blue Cross and Blue Shield of Minnesota
Engage! Healthcare Twin Cities – The Fall Sessions
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Mindstorm

Directions: Identify someone to write down what is discussed. Read the questions and decide together which ones you think are most important to answer. Then discuss those questions as a small group. Start with the most important question! Freely enter and exit groups. Remember to listen and give everyone a chance to speak. Speak from your own personal point of view.

Questions for Discussion: *10-15 minutes per question. Begin with the question(s) your discussion group finds most important.*

1. **Have you ever encountered barriers to receiving the healthcare that you needed?** If so, what obstacles did you face? Is there anything that would have helped you to overcome those barriers? Have you ever had a bad experience seeking healthcare due to your disability or citizenship status, culture of origin, class, race/ethnicity, gender, sexuality or other aspect of your identity?

2. **Has the Covid-19 pandemic changed the way you seek or receive care?** If so, how have you been managing those challenges? What role, if any, has technology played in your ability to access the healthcare (or other wellness resources) that you need?

3. **Have you ever encountered challenges seeking therapy for mental or behavioral healthcare for yourself or a loved one?** Is there anything that would support your mental health and wellbeing needs that an insurance company or healthcare provider could make available?

4. **Are you able to find culturally appropriate care?** Are there any cultural or holistic practices for health and wellbeing that you'd like for insurance or healthcare providers to cover/provide? Do you have any experience with healthcare systems outside of the U.S.? Locally? What have those experiences been like? Is there anything that worked well for you? Is there anything that could have been improved?

5. **Do you have a trusted source of information about seeking, receiving and/or paying for healthcare?** If so, what are those sources? Do you feel that you have the information you need to take care of your healthcare needs? Why or why not? Are there resources for health and wellbeing in the community that everyone should know about? Please share.

6. **Is there anything that we didn't ask that we should have?** What isn't here that you would like to see? Are there any questions you have for Blue Cross and Blue Shield of Minnesota? Please share your question(s), and any answers that your group discusses.

For Scribes:

- Write down your first name and the first names of the others in your group.
- Take notes about things your group thinks important to note in the space provided.
- Please write legibly or ask someone who writes legibly to write the notes.
- Be prepared to share your findings with the larger group.
- Please turn your notes over to Marnita's Table staff at the end of the evening.

The 360 Report | Mindstorm Themes & Analysis

Blue Cross and Blue Shield of Minnesota
Engage! Twin Cities
The Fall Listening Sessions
17 November 2020, 19 November 2020, 1 December 2020

Overview & Methodology:

The following is a summary and analysis of the discussion notes submitted by small-group conversation facilitators during the virtual Mindstorm sessions hosted during the events of November 17th, November 19th and December 1st, 2020. This focused conversation was undertaken by a total of 150 participants[4] of the three-part initial series of fall community engagement, dialogue and listening series *Engage! Healthcare Twin Cities* hosted virtually over the Zoom videoconferencing platform in Minneapolis and the Greater Twin Cities Metropolitan Area. In total, nineteen (19) small groups submitted notes from their conversations. The responses and discussion themes emerging from the small-group sessions have subsequently been aggregated and made anonymous for the purposes of this analysis. The full text of the submitted notes is available on page 22 of this report, while a facsimile of the Mindstorm packet distributed during these conversations, including instructions and questions, has also been included *(see: page 8 for more details).*

Because of the free-flowing nature of the hour-long small group discussions which were guided in an intentionally non-rigid manner in order to allow for flexibility, participant choice, and community-based responsiveness in accordance with the model of Intentional Social Interaction, many of the themes emerging during these conversations occur across individual discussion questions and overlap with topics raised by participants. Accordingly, the thematic content of this Mindstorm has been analyzed holistically with care and attention to both the substance and the context of participant discussions, and every attempt made to render topical linkages apparent and to highlight the many instances where themes overlap and participant stories and comments reference previous discussion themes or insights. The key themes emerging across both events have been summarized and outlined below in Table 1.

Table 1. Overview of Key Themes from Fall Mindstorm Listening Sessions: "More on trust: How can we trust doctors who don't value or respect our existence?"
Theme: *Disparities in clinical settings, treatment and health outcomes by race, gender, sexuality, or culture of origin.*

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[4] Our research team reported 47 participants of the initial session (November 17th) with 6 discussion groups submitting notes from their conversations, another 47 participants at the second session (November 19th) with 5 discussion groups submitting notes, and 56 participants of the final session (December 1st) with 7 discussion groups submitting 8 sets of notes (one group had two scribes submit separate notes) – a sum total of 150 participants and 19 discussion groups across all events. All participants received the same instructions and discussion questions. Transcriptions of the orally reported highlights and key observations from these discussions as summarized by participants during the event can be found on page 19 of this report.

Highlights:

- **Poor or under-treatment of Black women and other community members of color** in clinical settings; providers not taking their pain seriously, experiences of microaggressions (and macroaggressions) based on race (such as the assumption of a drug problem in the absence of indications to that effect) and **Black and brown participants' personal stories of receiving insufficient, inappropriate or "a less sophisticated level of care"** in hospitals and clinics;
- Persistence and severity of **prejudice toward trans men, trans women, and gender nonconforming individuals in clinical and other healthcare environments**; inability to access needed care.
- Perception that many are unwilling to discuss disparities in treatment and outcomes by race and gender under Covid-19, and the practical realities faced by Black and brown, trans and LGBTQIA+ community members seeking care, sense that providers and insurance representatives can be dismissive of concerns when raised.

Related/supporting theme(s): *Lack of institutional and provider trust among Black patients in relationship to historical traumas such as the Tuskegee experiments in which Black patients were famously sterilized and subject to experimentation without their knowledge or consent or the history of biases and undertreatment of Black pain in clinical settings and the cultural context of such experiences – impact of these traumas and the resulting lack of trust upon Black community members anxieties about the Covid-19 vaccine and when or whether to take the vaccine.*

Theme: *Affordability and accessibility of insurance and medical care – difference between having insurance and being able to use it/access the care one requires.*

Highlights:

- **Gaps by generation/access to technology and the internet** in context of **telemedicine offerings** (for elders, those without reliable internet access or suitable devices, etc.).
- Need for **quality care that is affordable and accessible**, personal stories of having to leave the country (or considering such a move) to receive adequate and/or affordable care – with and without insurance.
- Patients reporting needing treatments at critical moments in their lives and health and finding them unexpectedly not covered.
- Positive perceptions of **universal healthcare.**

Related/supporting theme(s): Difficulties finding affordable dental care, especially for low-income households and individuals, immigrants; insufficiency of existing resources.

Theme: *Need for more culturally appropriate care options and culturally competent providers as well as more medical and healthcare professionals who "look like [patients]" (i.e., culturally, racially, ethnically and linguistically diverse providers a valued and important resource that needs to be made visible and accessible beyond hiring practices alone).*

Highlights:

- Deep interest in having **culturally appropriate care,** sensitivity to the needs and experiences of trans and queer community members, and more options and choices for providers and holistic care needs.

- Need for common treatments and services critical to **trans health to be included in insurance policies and coverage.**
- Address stigma against LGBTQIA+ community members and **disparities in treatment and care** as well as life outcomes.
- Interest in **user-friendly interfaces and opportunities to read and post reviews of provider experiences** and costs of common services up-front.

Theme: *Role of institutional obstacles, stigma and trust in seeking and receiving health care, advocating for loved ones; experiences seeking health care and attempting to navigate the system so distressing that it creates or triggers mental health crises including suicidal ideation; general desire to be treated as fully human, whole human beings – rather than one's SES, gender, race or other elements of identity.*

Highlights:

- **Bureaucracy and delays** are a problem across systems/regions, but experiences vary in different states; perception that policies have been designed for the convenience of companies, clinics and providers, rather than patients and families.
- Medical **providers not always knowledgeable about how to navigate insurance and pricing** from the patient perspective, too much pressure on doctors and nurses.
- Need for **critical and culturally specific services and programs** to be continued and/or **expanded during the Covid-19 crisis.**
- Challenges and **obstacles to self-advocacy or advocacy for the care of others**; self-advocacy not always enough to ensure appropriate care and treatment; need for more supports for family members responsible for coordination of a loved one's care.
- **Stigma and experiences of discrimination an active barrier to seeking treatment and care** subsequently, being shamed by providers over body weight in ways that discourage seeking care later on – or, being misdiagnosed due to weight stigma and biases.

Themes & Analysis: Summary

Question Set One:

We asked: *Have you ever encountered barriers to receiving the healthcare that you needed? If so, what obstacles did you face? Is there anything that would have helped you to overcome those barriers? Have you ever had a bad experience seeking healthcare due to your disability or citizenship status, culture of origin, class, race/ethnicity, gender, sexuality or other aspect of your identity?*

Of the nineteen total discussion groups submitting notes during the fall events hosted virtually in Minneapolis and the Twin Cities, ten submitted comments addressing this topic including one group whose facilitators submitted two sets of notes taken by different scribes during their conversations. However, it is significant that personal stories and reflections upon experienced or observed obstacles facing Black, brown, LGBTQIA+ and immigrant community members in particular when seeking and/or receiving care remain a prominent theme throughout the discussion notes and conversation topics included in the guide. While disparities in treatment and health outcomes by race, gender, sexuality and culture of origin is most significant in the notes submitted in this section, groups also introduced notions of intersectionality into their discussions, considering the unique difficulties encountered by Black and trans women, for example.

A number of Black participants (and a few others of color) shared their stories of receiving insufficient, inappropriate or "a less sophisticated level of care," especially around pain management. Participants described the impact of micro-aggressions, rudeness and racialized stereotypes upon care and clinical experiences, such as the assumption of a drug problem in the absence of indications to that effect – an experience shared by several participants of different discussion groups and event dates and appearing multiple times in the notes – resulting in undertreatment or outright failure to treat pain and other symptoms experienced by Black, Indigenous and other patients of color at clinics and hospitals. What's more, the persistence and severity of prejudice toward trans men and women – and even the refusal to provide urgently needed services and failure of insurance companies to cover common procedures and treatments critical to trans health – is highlighted as a major ongoing obstacle to receiving care. This is underscored elsewhere in the Mindstorm notes where prejudice in general is indicated in the comments of several groups to be a major institutional barrier to seeking, accessing and ultimately receiving quality care for a number of marginalized communities – including IBPOC, LGBTQIA+, immigrants, English language learners and sometimes family advocates and elders.

The following excerpts illustrate some of the ways guests framed their comments on these themes:

> I feel like I have [experienced obstacles to receiving the care I needed related to prejudice]. About a year or so ago I was having some pain – I went to my doctor, [saw] recommended physicians – and no one was able to tell me what was wrong. I felt like they kept brushing me off and not taking my pain seriously. The only answer they had for me was that they've done; I feel like I was doing the best I could to advocate for myself, but I feel like there's this presence of bias, microaggressions. As a Black woman, I didn't feel like my pain was taken at face value. I didn't feel like I mattered in that space. I didn't feel like best practices were pursued on my behalf.
>
> I had an experience similar to that actually earlier this year – and not necessarily getting diagnosed properly, getting the care I needed. I was in an accident recently and had a concussion that went undiagnosed for a long time. I'm lucky that I'm educated, I have a lot of resources at my disposal – I had lawyers and family to advocate for me, but I think there's this real hesitancy to dig deeper into some of the experiences and health related issues that people might be encountering as a result of Covid-19 and other things. I think it's important that providers take more care in performing their screenings and assessments.
>
> I'll piggyback off of what you're saying – related to Covid and how I have been reading about the inequities and which doctors will administer [less competent] treatment to black and brown patients than they will for white patients, which results in higher mortality rates, because of the level of care they receive – a less sophisticated level of care.
>
> Being employed full time, I have been fortunate to have access to good healthcare when needed. However, with my partner (who is a green card holder) I have seen how racism has affected his healthcare, and how it is different to mine, both in care and cost. Plus, the social/cultural stigma of mental issues is affecting my ability to get him to seek help.
>
> My ex is a green card carrier too. He has dental care he needs but the cost is so high that I don't think he'll get it done…

In addition to barriers related to discrimination and prejudicial treatment, another central theme – of this section and of the discussions more broadly – involved affordability and accessibility of care alongside other institutional and systemic barriers. Comments focused upon the need for affordable and accessible insurance and medical care often pointed to the difference between having insurance and being able to use it to access the care one requires and included consideration of gaps by generation and/or access to technology in context of telemedicine offerings (for elders, those without reliable internet access or suitable devices, etc.). Indeed, insurance itself is positioned very much as a thicket of barriers including those with and without some form of it.

> I think there's healthcare and having insurance – and then there's how people access it. I think with Covid interrupting so many things – from infrastructure to how people access things – we have to talk about the way technology has changed this. A lot of people, like I think of people in my family, and because of the way that they struggle with technology, they're not able to access the care and resources they need now that so much has moved online. I want

> to know how we can close that gap around technology and access to information and health care – and in a way that is realistic about how people actually use information and access systems, culturally and personally. There's the self-selection and the technology gap that is creating huge barriers. A lot of people don't have the technology to even hop on Zoom or a Skype call online.
>
> I think of elders in my family and they are really engrained in their in-person connections and they just don't really engage in an online context. So, with their usual clinics closed to in-person visits, they've just gone basically a year without seeing their regular primary care doctors. So, how do we ensure people are getting the care they need if they are unable or uncomfortable using technology or accessing telemedicine? How do we meet people in their communities, start to educate people? How do we begin addressing some of those barriers you are sharing so that we can continue to do better?

Relatedly, several discussion groups touched upon institutional barriers and lived experiences seeking healthcare and attempting to navigate a system so complex and distressing, that the process itself creates or triggers mental health crises including suicidal ideation, according to participant comments. In general, the discussion notes highlight a desire to be treated as fully human, whole human beings – rather than one's socio-economic status, gender, race or other elements of identity. To a lesser extent, some shared experiences being shamed by providers over body weight in ways that discourage seeking care later on – or, being misdiagnosed due to weight stigma and biases.

> I've been very blessed, and I've been with the same clinic since I was 16 – and I'm 44 now. I've stayed with them because it's personal. I know the nurses, I know the blood clinics and knowing them, I speak with everyone and I'm thankful for everything. I lived in Los Angeles for five years and it was night and day difference. I had doctors while I was pregnant [who] didn't know who I was. I would sit in waiting rooms for hours. I felt like I was in a cattle call. I would get in the doctor and they would treat me like I don't go to the clinic. We decided to move back to Minnesota to have my daughter. I was on medical assistance I would not wish that on anyone. I felt like a number. I never experienced that in my life – and it caused a barrier to my healthcare, it caused stress and I was being treated specialty because of my age. When I got home, I went back to the clinic, it was night and day, finally I was coming home. I'm thankful for the care I received. I know that that's not everyone the experience I received.
>
> It seems like doctors are a lot better these days. When I started to go to the doctor on my own, I could feel a lot of shaming… now I have a doctor that doesn't shame me for my weight but there were YEARS that I didn't go to the doctor (like 10) and the only time I went was when I had to go to the hospital because I would wait so long to seek care. Now I have a family practice practitioner and they aren't rude. I don't know If things are getting better as a whole in the medical community or it's just me.
>
> I had a diagnosis that was ignored because of my lack of weight…
>
> I moved here in 2016, after living in Nigeria. Prior to that I lived in England, [so] the way I've been used to healthcare provision – in England or the whole of UK – it's a social program and everyone pays into it. And [you pay into that system and receive care] regardless if you are a citizen or not. Now [for] some specialist care you might be required to pay for extra services. Well, I moved here in 2016, and in 2017 I had a stress related ailment. I wasn't diagnosed with anything; it was just stress. At the time I didn't have [insurance] coverage from my job and all the doctors just couldn't figure out what was going on. Some thought I was doing drugs, [even though] I don't drink or smoke. I finally went to three or four doctors before [encountering] the last doctor, who was a black person and he said to me, "what exactly is going on with your personal life?" I haven't been working – all of this stuff, from what you have told me, I think it's stress related and you need to rest and take your mind away. True enough, by that time [they] shut down everything for two weeks. And I felt better. What was missing was support of mental care. I could have easily killed myself from that experience from that state of mind. I didn't have any family there at the time and not having any kind of support system. And talking to doctors and not being able to figure out things. I've changed significantly since then, but I don't wish it on anyone.

Question Set Two

We asked: *Has the Covid-19 pandemic changed the way you seek or receive care? If so, how have you been managing those challenges? What role, if any, has technology played in your ability to access the healthcare (or other wellness resources) that you need?*

Eight of nineteen total discussion groups submitted notes in this section, including one group whose facilitators submitted notes taken by two different scribes. Building upon the central themes of the previous section, discussion notes on this theme suggest the prevalence of a perception that many – both within and outside of clinical healthcare environments – are unwilling or resistant to discussing disparities in treatment and outcomes by race and gender under Covid-19, and the practical realities faced by Black and brown, trans and genderqueer community members seeking care. Several groups raised the issue of bureaucracy and delays, generally considered a problem across systems/regions, but with experiences varying in different states per the comments. Some participants expressed the perception that policies have been designed for the convenience of companies, clinics and providers, rather than patients and families, with many urging need to ensure that critical and culturally specific services and programs are continued and/or expanded during the Covid-19 crisis.

> I feel like providers are dismissive, I went to Allina, and they would just give me a different doctor, and I was able to finally find a doctor that I could connect with and I'm now doing more preventative care.
>
> I didn't have medical [insurance], I had Blue Shield in California and I wouldn't get in until noon. Has anyone ever been to the doctor and get a bill like 4 years [later] for a service?
>
> I'm from California. I moved here a year ago. I have Lupus, [and] the care I received there was so different [from the care I receive here].
>
> It's going to take me a ton of loops [to get the care I need]. I have to do things for a year to get on a waiting list and then there's another year and a half. There's a lack of providers right now. And I have to be completely ready to do [all these things] and then wait for a year. The policy that makes it easier on the provider[s], but they also delay it because they don't see the urgency. It shows how little the lived experiences of Trans people matter. Part of it is understanding that calling necessary [care and treatment for the purposes of] insurance "cosmetic," and that comes from the standards of care that was last updated in 2011 – and allowing access. When you're Trans, you need medical care, you need hormones and having access to insurance [makes a huge difference], and [given that we are] having 47% of Trans people attempt suicide, this is timely and important stuff. It feels hopeless sometimes. I work full time and I'm in grad school fulltime and it's tiring to try and do things. I work in a school district where I'm the first Trans person in the history of my department.
>
> The combination with the medical services and insurance is hard for a lot of people. We put so much on doctors…. I go to the doctor and they say that I need to have a medical procedure done and then when I go to get the procedure done, they tell me that it isn't covered. You would think the doctor would know that it might not be covered for me, before giving me the advice. How can we let people know in advance?

Question Set Three

We asked: *Have you ever encountered challenges seeking therapy for mental or behavioral healthcare for yourself or a loved one? Is there anything that would support your mental health and wellbeing needs that an insurance company or healthcare provider could make available?*

Seven of nineteen discussion groups elected to submit notes on this topic, in which participants reflected upon the prohibitive cost and stigma of seeking mental or behavioral healthcare, the needs of children, youth and disabled community members, and challenges dealing with the intersection of over-policing, underfunding of mental and behavioral healthcare and lack of resources for educators and counselors. Here, as noted elsewhere, lived experiences of prejudice, lack of understanding and compassion across identity differences (including all those mentioned so far in this report, but also for those who have experienced one or more mental illnesses and those recovering from a substance use disorder) emerges as a central obstacle to receiving needed care, suggesting a barrier that is as much cultural as it is institutional in its systemic impacts. Participants spoke of language barriers and institutional challenges and obstacles to self-advocacy or advocacy for the care of others, with some emphasizing that self-advocacy not always enough to ensure appropriate care and treatment. Participants underscored the need for more information, resources and navigational supports for family members responsible for coordination of a loved one's care, though sensitive to the challenges of privacy and information security that often complicate family-health-advocate arrangements. Technology appears as an obstacle to seeking the support of a therapist, especially for those living in rural areas or who otherwise are without reliable internet service and/or appropriate devices. The added strain of Covid-19 and high demand for psychiatric and psychological services during this time also appears as a barrier in the notes for this section.

Question Set Four

We asked: *Are you able to find culturally appropriate care? Are there any cultural or holistic practices for health and wellbeing that you'd like for insurance or healthcare providers to cover/provide? Do you have any experience with healthcare systems outside of the U.S.? Locally? What have those experiences been like? Is there anything that worked well for you? Is there anything that could have been improved?*

Of nineteen total discussion groups, four submitted notes for question set four. Participants in this section indeed confirmed their interest in traditional, holistic and culturally appropriate care modalities, as well as, in general, a desire for a greater breadth and diversity of choices among providers, insurers and care alternatives. In particular, participants expressed the difficulty of finding culturally competent care and lamented the underrepresentation of providers of color. The community-specific needs of trans men and women were again highlighted here, as participants pointed out the unique challenges trans patients face spanning stigma, bigotry and mistreatment, lack of insurance coverage for critical healthcare services, and encounters with doctors who are poorly informed about trans identity and trans healthcare needs. Comments indicate a general need for more culturally appropriate care options and culturally competent providers as well as more medical and healthcare professionals who "look like [patients]," which is to say that diverse providers are a valued and important resource that needs to be made visible and accessible beyond hiring practices alone. Others stress that it is equally important to ensure that holistic, integrative, culturally-specific and traditional healthcare options need to be included in insurance coverage – especially in cases where research findings and relevant evidence demonstrates efficacy for treatment. Long-term, broad-scale investments in providing access to those working in racial justice-informed healing practices is identified as a key strategy for those working within healthcare and insurance systems.

> The diverse population of providers, doctors that could refer people or have that option when you call into your healthcare provider. To piggyback off your story when you talked to a doctor of color they could relate to your whole story. When I call in, I'm looking for a dentist. To have more culturally specific options. You know what you're experiencing in your body. And they're very dismissive, and they look at you like you're another Black girl, it's like you don't matter. It's something a health care provider, incorporating more…
>
> Seeking [and finding] providers that are culturally competent is a challenge.
>
> A few years ago, I was dealing with a cultural issue… I dealt with white women practitioners that shamed me. I was previously with a Latina provider for 8 years and then I had to stop seeing her… with BCBS, for whatever reason, I couldn't see her anymore. Eventually, I was able to find another Latina provider and I had to go through a long process.
>
> More IBPOC to be healthcare providers! It's important!
>
> [It's about] access, [we need more people of color to] become a provider and have cultural influence.
>
> Thinking about the birth outcome disparities here in Minnesota for Black and Indigenous women, we know because of Dr. Hardemann at the University of Minnesota that the support and relationship that doulas provide to birthing mothers is really important and effective – but they're not covered under health insurance plans. We need them to be covered – then it comes down to who can afford a doula. There are also disparities around close-door negotiations about medicate – Edina gets more money for state insurance than HCMC does, for example – and

> because it's closed-door, you don't know why, and you can't *do* anything about it. I think there's a lot we could do with analysis and assessment.
>
> This resonated with me for sure. I've been disappointed at times when I'm seeking holistic care. I'll get referrals and recommendations from people in my community about specialists who can heal in culturally appropriate ways and they're often just not covered in insurance. We're seeing more chiropractors covered, but other homeopathic providers and holistic professionals in my community are still not covered. I've also encountered a lot of predominantly white providers, so I'm looking forward to seeing a shift toward more Black and Indigenous and Latinx – and other practitioners of color.
>
> When I first started doing system work around racial justice in the hospitals – I would tell people that I was experiencing secondary racism, seeing it over and over at the workplace – and so I had to find a resource to manage, so I found – her name is Marie Michaels and she does racial justice healing work, but she's not considered a provider – even though she's a provider to me. She helps me keep from shutting down when I witness racism in the workplace. I'm Anishinaabe and I live in the city, but I had never been around so much racism in my life until I started working at the hospital. I learned from her that you could use your awareness to pinpoint the stress and anxiety in your body and get through it with breathing and breath work. But she doesn't get paid what she's worth.
>
> The biggest challenge I see is that the therapies that help us (BIPOC community members) to heal aren't necessarily just found in people who studied psychiatry. If I had my way, I would train the aunties and grandmas in our community to do the healing work of body workers – breathing and getting into your body – and I would pay them to do it. It's the work they are already doing. Honestly, if you think about it, it doesn't make any sense to pay colonizers to teach us how to heal from colonization. I'm actually getting the cultural care that I need, but she can't get paid like these other providers – I have to pay her like I'd pay someone for doing my nails.
>
> It's just in recent years that insurers would even cover acupuncture – despite it being a centuries old practice – or chiropractors. Those kinds of services were considered – you had to have Jesus Christ and all his disciples to certify that it was needed.

In addition to more options, participants again raise the issue of affordability and accessibility in this section, sharing personal stories of seeking care in another country and/or having to leave the country (or considering such a move) to receive adequate and affordable care – with and without insurance, and reported needing treatments at critical moments in their lives and health and finding them unexpectedly not covered (as in the case of one trans participant who spoke of experiences seeking medical care in the face of institutional barriers, bias and discriminatory treatment, or another participant living with diabetes during pregnancy and seeking endocrinological care not covered by her insurance provider).

> Part of me wants to opt out of our medical system. To your point, I want to do more holistic care and try not to go into big pharma. There's a history of so many of my family members taking medications and there are more side effects than there are benefits for the medication. Diabetes, heart disease etc. Culturally, the generation before me, what have they done in terms of healing? I would love to see some of our providers make it easier to do acupuncture, crystals, energy work – those Black and Indigenous people aren't even paid or covered by a lot of our health care providers. I used to have Blue Shield and now I don't, and it's frustrating. I intentionally seek out providers who are women or femmes and people of color. It is hard to come by a Black woman doctor. My practitioner is a Latina. I told her I specifically found you online because you are the only woman of color that I found. This summer, I had uterine fibroid tumors that were equivalent to me being pregnant. The white women kept saying I needed to get rid of my uterus... but I don't have children – and I just think – had I not had the courage to advocate for myself or had the education… who knows. I had two aunts have the same experience themselves 30 years ago and they didn't know they had options to not get rid of their uterus which is disheartening. We know in this country that there are doctors that are doing hysterectomies on Latina women without their permission. Also, the Tuskegee experiments… so we don't always trust a system rooted in White Supremacy.
>
> **[Another participant, in response:]** I, too, have had 4 aunts have a hysterectomy for less dire situations…
>
> About two years ago, I didn't have insurance and I couldn't afford it through my job and the state was saying I made too much to not get insurance. And I got sick twice and I was hospitalized twice. And I had to get insurance and I had a blood disorder called ITP and the total for everything was $60,000 and I didn't know what to do and I got really stressed and depressed. I was able to get a lot of financial help through the hospitals, and I'm still on the payment plan with $3,000 left out of $5,000. Just making it more affordable for people. It's a lot to take out. Then the state tells you that you make too much to get insurance [support]."

Universal healthcare is mentioned favorably, with comments indicating interest in user-friendly interfaces and opportunities to read and post reviews of provider experiences and costs of common services up-front for greater transparency and more patient-driven decision-making processes.

> I would love to shop for healthcare like I shop in Amazon. I would love reviews and I would get to see how much it would cost.
>
> [We should have] Universal healthcare, so you don't have to worry about costs.
>
> What does it do if people [who] are providers are competing for you?
>
> I asked the front desk staff, and they recommended the doctor I ended up connecting with.
>
> In my case I didn't have that choice, I went down the pecking order of doctors, Doctor XYZ, Doctor ABC. I think the other thing, I wish our jobs could give us multiple options. I work for US Bank and they use United Healthcare. I would like to know what other options you could have.

Question Set Five

We asked: *Do you have a trusted source of information about seeking, receiving and/or paying for healthcare? If so, what are those sources? Do you feel that you have the information you need to take care of your healthcare needs? Why or why not? Are there resources for health and wellbeing in the community that everyone should know about? Please share.*

Five of nineteen discussion groups submitted notes in this section. Participants addressing this theme spoke repeatedly of a marked lack of institutional and provider trust in relationship to historical traumas such as the Tuskegee experiments in which unsuspecting Black patients were famously sterilized and subject to experimentation without their knowledge or consent and the history of biases and undertreatment of Black pain in clinical settings and the cultural context of such experiences. Several discussion groups raise the impact of these traumas upon contemporary public health problems, such as concerns about whether pharmaceutical companies, medical professionals and institutions may be trusted to produce a safe vaccine under the circumstances of the Covid-19 pandemic, and the resulting lack of trust upon Black community members and anxieties about whether and when to take a vaccine that becomes more generally available.

Relatedly, comments in this section – and supporting themes from the notes for other sections – point to the obstacles to seeking and receiving competent mental and behavioral healthcare services that provider biases and institutional trust barriers related to historic traumas create. Some discussion group participants express the perception that insurance companies and policies play a key role in perpetuating racism, while others intimate a need for intersectional considerations of race and economic inequities. A few also point to the need for more research that is inclusive of Black and other people of color in order to ensure equitable health outcomes and address research disparities, but stress the tension created by existing trust barriers that prevent many community members from feeling safe participating in such research.

> I think another barrier related to that, culturally – and I'm a mental health therapist – is that many times people – in my culture, many Black people are not trusting of the mental health system and when they do seek care, they're looking for therapists who look like them. And there's a lack – in terms of being able to find them, in terms of training and credentialing. I was told several times that "there are enough" [Black mental and behavioral health providers]. There are actually many, many Black therapists out there, but they're often not credentialed through these big credentialing institutions, so they don't show up in insurance coverage.
>
> Even though we're the leading victims of so many major cancers and diseases, the Black community is very under-represented in research. It means that we can't really receive equal care, because we're not represented in the research and clinical studies.

> I want to go back to trust – I know trust is a big thing in the black community. Being a social worker in these school and working with people who look like me, and so many people are suspicious of the vaccine because of trust issues – I'm talking about educated people, professional people. They want to see another culture take it first – they don't want to see another Tuskegee [experiment/violation of human rights and ethical standards in medical research]. Black folks have a right to be suspicious of medicine and clinical testing – just look at the history.
>
> It's as if they treat the disease and not the person – they don't look past the disease to see who we are as people, our cultures and racial and ethnic backgrounds. To me that just breaks down the trust and continues that cycle. I've been experiencing it more recently in the stigma around substance issues and mental health – there's so much stigma in that too.
>
> Insurance companies are a big part of perpetuating racism. It continues – the cost of healthcare, people of color are still at the bottom of the rung, not being able to afford the care we need as a human being? My question is, what are we going to do about this? Just continue on for the next few decades like this? I want to know what the insurance companies are going to actually do.

A major gap in accessible, affordable healthcare emerging in this section is the need for dental insurance coverage and quality dental care, especially for low-income households and immigrants, with an emphasis on the insufficiency of existing resources, even for those who do have some form of dental insurance.

> The main barrier is surrounding dentists, I get low-income healthcare, I pay a small amount, whatever their formula is per month in copays for visits and prescriptions. It's so hard, we can't get emergency dental services – recently I had issues with my teeth, [and] calling around finding specialists and health care providers is a struggle. The dentist thing is such a mess in my experience.
>
> I have the same situation – it's been very frustrating. I have an outstanding bill of over $1000 that I can't pay, and it keeps escalating. The place that I've had probably – I went to the University of Minnesota [clinic], but [even though] I was able to get good care, it was still expensive. I don't understand why they can't come up with something that is more inclusive of dental.
>
> Being an immigrant, when I first got here, I didn't know where to go to the dentist and what to pay.
>
> My ex is a green card carrier... He has dental care he needs but the cost is so high that I don't think he'll get it done…

Finally, a few comments point out that medical providers and insurance professionals are themselves not always knowledgeable about how to navigate complex systems of insurance and pricing from the patient perspective, placing too much pressure on doctors and nurses. Such notes echo themes emerging in other sections focused upon institutional barriers and hopes for more transparent, patient-focused and user-friendly platforms for navigating insurance, provider selection, care management and payment processes. These ideas are illustrated in the comments below.

> Actually, I just got a new insurance card and I have no idea how to find a dentist who is in my network. They didn't really send any information with it, so I'm not sure where to begin.
>
> In most of our systems – whether you use google maps for driving or grub hub for ordering food – you can make things more visual, make it clearer how to navigate. I work for Blue Cross and Blue Shield, and when I speak with families, they often talk about how hard it is to find the info that they need [to find a dentist or other provider], and when I explain to them, they say, well – how would I know that?
>
> I think it's important to note that health insurance itself is not healthcare – there are other steps in there, and people who have means can figure out how it works, whereas the rest of us might take months to figure out the system – and then the first question is can I afford it. But that's not the elephant in the room – it's the whale in the room.
>
> Yeah, there's a lot that's really confusing. I called a clinic, and they wouldn't tell me if they were even taking new patients until they found out what kind of insurance I had.

What else should we know?

What else should we know*? Is there anything that we didn't ask that we should have? What isn't here that you would like to see? Are there any questions you have for Blue Cross and Blue Shield of Minnesota? Please share your question(s), and any answers that your group discusses.*

These two sections of the Mindstorm provide an opportunity in their framing for participants to propose their own directions for discussion not already provided for in previous questions. Eight groups submitted notes in this section, including four who used this section to submit unstructured notes from their conversations in lieu of organizing their discussion notes under the questions included in the Mindstorm guide. Notes in this section largely track with the major themes explored elsewhere in this report, however the emphasis across the notes here upon the desire of patients to be viewed holistically, as whole people, by providers and to have the opportunity to interact with providers educated about and sensitive to inequalities and historic traumas underscore the general key themes particularly well. One group used this section to propose the question: How is Blue Cross Blue Shield using this engagement – and how are they harvesting it? The notes for that group indicate that the question was answered directly by Blue Cross and Blue Shield of Minnesota professionals who participated in the listening session and engaged transparently with participants about their experiences. One group submitted a brief miscellaneous note, while the remaining notes revisit the need for a diversity of providers and emphasize, again, participant interest in a transparent, online interface for gathering and sharing information and making informed decisions about healthcare, similar to marketplace applications such as Amazon or Yelp (In the words of one commenter, "Shopping is easy for every other aspect of life – why is healthcare so different?").

Mindstorm: Oral Report Notes

About These Notes

The below notes were taken by members of our research team during the oral report-out from the Mindstorm small-group focused conversations during the virtual engagement events of November 17th and 19th and December 1st of 2020 hosted in Minneapolis and the Greater Twin Cities area. During this activity, participating discussion groups nominate a representative from their table to share with the larger group a few key themes emerging from their conversations. Groups have been numbered according to the order in which they presented.

17 November 2020 | Session #1

Group 1: The two issues that were paramount for us as African Americans are trust – we don't trust the healthcare industry and medical experiments. If you look at [the] Tuskegee [experiments] and all of the black people who died because of the unethical experimenting conducted. So, we don't really trust this idea of testing the vaccine on the Black community, even though we are suffering from it the worst. The other issue is as it relates to systemic racism and how insurance companies perpetuate it – in that the cost is exorbitant for us, so people of color are not afforded the healthcare that should be provided to people of all races. So, we wanted to know what insurance companies are going to do about it? Are we going to continue to perpetuate these disparities in the United States – the wealthiest country in the world?

Group 2: Some of the main things we talked about is white body supremacy and how it infiltrates all of our systems, including systems of care, for people of color. We also talked about the importance of having a provider who looks like you – and how important it is to have providers of color.

Group 3: So, we had a lot of great conversations, but two things that really stuck out to me is how Covid has impacted appointments and how we get to see our health providers. Another one that stood out is how there aren't enough providers to support transgender community members and how we need more representation among providers and more resources.

Group 4: Our conversation was very interesting. One of the things we touched on is the need to have universal healthcare for everyone regardless of health or status. In the Latino community we know we have families of mixed status who aren't able to get health insurance and care – and people of color in general often can't access quality healthcare. So, universal healthcare for everyone regardless of ethnicity. We also discussed that whenever we go to the doctor and patients have a bad illness, they should be able to receive care even if they don't have insurance. We should be able to be treated as human beings. When my husband needed urgent surgery – they denied him the surgery because he didn't have insurance.

Group 5: We had a great conversation and touched on a lot of the topics already mentioned. We talked about how people are treated when seeking healthcare is usually different based on race. We talked a lot about the experience – it can be very transactional, cold, not welcoming. And the reason that is important is because it matters how the patient feels they were treated by the doctor – if they don't feel trust, like they're being treated like human beings, they won't listen to the provider. One person shared about how they were treated very differently [as a Black patient] once a doctor came by who knew the person personally. They had been told that they only needed eight stitches for a head injury, but it turned out that 21 stitches were really needed. So, in other words, you are treated totally different just because of race unless you have a personal connection.

19 November 2020 | Session #2

Group 1: The one thing that stood out to me was trust – as a Black and Native person, trusting science and medicine. –Yeah, and I as a queer and nonbinary person want to say that it's hard to trust if there's NOBODY on staff who can relate to me. We don't need someone who looks like us, but definitely someone who understands.

Group 2: We talked about how health insurance does not equal health care and the second one was that BCBS – or any organization engaged in healthcare shouldn't have diversity and inclusion as just one role or one department but woven throughout the whole organization so that it can be effective and sustainable.

Group 3: I also took away from a couple of our folks in the room about what providers go through and how it's a struggle still to navigate what benefits you have. A couple participants talked about the anxiety of having to face the hoard – folks on the other line who are going through so much and who may not be their best, who may be stressed out or unkind.

Group 4: So, I think we had a number of compelling stories. One that stood out: this person's partner is really educated and works in healthcare and even so, they are struggling to figure out how to navigate healthcare and insurance questions, to make those decisions. I really relate to that too. We also talked about how hard it is to find mental health practitioners and about the difficulty of helping relatives navigate the system and advocate for themselves when they need care.

Group 5: In our group we talked about how we need bilingual doctors and interpreters who speak our language. And at times there are many barriers to accessing healthcare in our communities…We need to trust health care – it's important to have providers who are culturally competent. When we go to the doctor, there are often not interpreters. We bring our kids to translate for the parents, but that is not right to put on kids who may not know how to translate everything correctly. Also, a lot of the times when families who are undocumented or who don't have insurance – they could qualify for a reduced rate or assistance, but they require so much (and such extensive/invasive) paperwork that people don't know or don't bother applying. Sometimes they apply and still never hear back – one woman shared about how she and her son applied for such benefits seven months ago and she still hasn't heard back. Just being able to go to the doctor without fear and know that you will be respected and treated with dignity – that is what we shared.

1 December 2020 | Session #3

Group 1: I'm really glad to be here tonight. We need to start action now. In communities of color, we're really struggling to find opportunities. We know that we're overqualified for jobs, but we're still not being selected for interviews or opportunities. The moment they find out you're African American, you don't get the job, they say it's closed or already filled all of a sudden. My daughter has been to law school, medical school and now a PhD and still struggles to get opportunities for which she is clearly overqualified. Also, when you talk about mental healthcare – it's so apparent that we need resources and support in the Black community. George Floyd was just the tip of the iceberg. It's time to say enough is enough. Discussions are wonderful, but now it's time for action.

Group 2: We talked about how your identity affects how you are treated by providers, how it's systemic. Many people spoke in our group about not having their pain believed, or about having doctors refuse to accept or discuss holistic and culturally appropriate interventions when they aren't the ones providing it. We also talked about the need for fresh air and the need to be able to be out in your community and how not everyone has equal access to natural resources, as well as about the ways that Covid has disrupted parenting and birthing and your choices about delivery support and providers. So, we talked about how do we make it so that patients are taken seriously and heard – not just "seen" – by the doctor or provider?

Group 3: What does healthcare look like if doctors work with sociologists, social workers and the community? We talk about the need to be open to medicine other outside of western health practice as such Eastern medicine. We need a community-based approach would allow us to be heard. We talked about young people accessing mental health. How do young people find mental healthcare when the adults don't know how to access healthcare? Why isn't healing a part of healthcare? Healthcare needs to address intersections of identities (i.e., woman, black, mother).

Group 4: We need healthcare to be culturally competent. There are so many barriers for BIPOC Communities accessing healthcare. We need to think about the providers, are they bringing culture competency to our community?

Group 5: We had a very important conversation. We talked about how the Latinx community faces problems when we need medical care or insurance. The staff is missing for translation or interpretation when you go to see a doctor. Sometimes it's so hard to get that kind of support when you go to the hospital or the doctor. They just say that they don't have an interpreter and then tell you the information in English. Even when we can understand English, medical terms are hard to understand in English. So, there is that fear that you will misunderstand something important. And it's so hard to explain your symptoms if you don't have the right vocabulary. Someone shared about how there was an accident and the first responder on the scene was actually making fun of her in her distress. There are so many inefficiencies in the medical system, but sadly, we seem to get the worst of it[5].

Group 6: There was an important discussion about how we need healthcare to be separate from employment. Also, less division between families and communities. There are many inequities exposed in the healthcare system, but we need fundamental changes even outside of that – like food, being able to access healthy foods and affordable housing. Also, we talked about how there should be customer service – the provision of a better customer experience in the healthcare field.

Group 7: So, mostly the same as what everybody said. We talked about the language barrier for our East African community, and how it's hard to trust the doctors. Especially under Covid, there's just no trust there with providers, especially when there are no providers who speak our language. A lot of the elders say, what if I go to the hospital now and I never come back? We also talked about the cultural barriers that exist – like how male nurses may not understand culturally why a woman in our culture wouldn't want a man in the room with them like that. They don't understand culturally.

Group 8: Again, much of what was said was also said in our room. A lot about how people are treated, and the assumptions made by medical staff and the different treatment you receive based on

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[5] Translated from Spanish by an interpreter.

those assumptions. We also talked about how we treat our elders. While things like HIPAA are supposed to protect our privacy, some of our elders are not getting the information they need. Like, I have to go through so much with my 93-year-old mother's doctors in order to make appointments for her, instead of having them reach out directly to her (when she isn't in a position to get medical help without support).

Mindstorm Notes | Raw Aggregate

Please note: While the small group discussion notes in this document have been organized by discussion question, ordered by date of the virtual events (bolded in the texts) and separated by discussion group (indicated by the following symbol: ***), not all groups submitted notes in response to every question. Additionally, some groups submitted notes that were not organized by question, but by theme. Where possible, such notes including clear responses to particular questions in the discussion notes have been reorganized under the relevant question and date. Where the conversation notes submitted appear to be too general or too broad to be broken out according to the Mindstorm questions, they have been included under the final section of this Mindstorm which allows participants to propose their own questions and/or organizational structure for their conversations. Personal stories appear often in the text of the notes and have generally been included here in the section under which they were submitted in order to avoid separating such comments from the context of the conversation in which they occurred, including in cases where themes overlap and/or the discussion in fact addresses several questions posed in the Mindstorm discussion guides.

Question 1: Have you ever encountered barriers to receiving the healthcare that you needed? If so, what obstacles did you face? Is there anything that would have helped you to overcome those barriers? Have you ever had a bad experience seeking healthcare due to your disability or citizenship status, culture of origin, class, race/ethnicity, gender, sexuality or other aspect of your identity?

17 November 2020

- I feel like I have. About a year or so ago I was having some pain – I went to my doctor, recommended physicians – and no one was able to tell me what was wrong. I felt like they kept brushing me off and not taking my pain seriously. The only answer they had for me was that they've done; I feel like I was doing the best I could to advocate for myself, but I feel like there's this presence of bias, microaggressions. As a Black woman I didn't feel like my pain was taken at face value. I didn't feel like I mattered in that space. I didn't feel like best practices weren't pursued on my behalf.
- I had an experience similar to that actually earlier this year – and not necessarily getting diagnosed properly, getting the care I needed. I was in an accident recently and had a concussion that went undiagnosed for a long time. I'm lucky that I'm educated, I have a lot of resources at my disposal – I had lawyers and family to advocate for me, but I think there's this real hesitancy to dig deeper into some of the experiences and health related issues that people might be encountering as a result of Covid-19 and other things. I think it's important that providers take more care in performing their screenings and assessments.
- I'll piggyback off of what you're saying – related to Covid and how I have been reading about the inequities and which doctors will administer treatment to Black and brown patients then they will for white patients, which results in higher mortality rates, because of the level of care they receive – a less sophisticated level of care.
- I think there's healthcare and having insurance and then there's how people access it. I think with Covid interrupting so many things – from infrastructure to how people access things – we have to talk about the way technology has changed this. A lot of people, like I think of people in my family, and because of the way that they struggle with technology, they're not able to access the care and resources they need now that so much has moved online. I want to know how we can close that gap around technology and access to information and health care – and in a way that is realistic about how people actually use information and access systems, culturally and personally. There's the self-selection and the technology gap that is creating huge barriers. A lot of people don't have the technology to even hop on zoom or a skype call online.

- I think of elders in my family and they are really engrained in their in-person connections and they just don't really engage in an online context. So, with their usual clinics closed to in-person visits, they've just gone basically a year without seeing their regular primary care doctors. So, how do we ensure people are getting the care they need if they are unable or uncomfortable using technology or accessing telemedicine? How do we meet people in their communities, start to educate people? How do we begin addressing some of those barriers you are sharing so that we can continue to do better?
- I think another barrier related to that, culturally – and I'm a mental health therapist – is that many times people – in my culture, many Black people are not trusting of the mental health system and when they do seek care, they're looking for therapists who look like them. And there's a lack – in terms of being able to find them, in terms of training and credentialing. I was told several times that "there are enough" [Black mental and behavioral health providers]. There are actually many, many Black therapists out there, but they're often not credentialed through these big credentialing institutions, so they don't show up in insurance coverage.
- Even though we're the leading victims of so many major cancers and diseases, the Black community is very under-represented in research. It means that we can't really receive equal care, because we're not represented in the research and clinical studies.
- I want to go back to trust – I know trust is a big thing in the Black community. Being a social worker in these school and working with people who look like me, and so many people are suspicious of the vaccine because of trust issues – I'm talking about educated people, professional people. They want to see another culture take it first – they don't want to see another Tuskegee [experiment/violation of human rights and ethical standards in medical research]. Black folks have a right to be suspicious of medicine and clinical testing – just look at the history.
- It's as if they treat the disease and not the person – they don't look past the disease to see who we are as people, our cultures and racial and ethnic backgrounds. To me that just breaks down the trust and continues that cycle. I've been experiencing it more recently in the stigma around substance issues and mental health – there's so much stigma in that too.
- Insurance companies are a big part of perpetuating racism. It continues – the cost of healthcare, people of color are still at the bottom of the rung, not being able to afford the care we need as a human being? My question is, what are we going to do about this? Just continue on for the next few decades like this? I want to know what the insurance companies are going to actually do.

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- The main barrier is surrounding dentists, I get low-income healthcare, I pay a small amount, whatever their formula is per month in copays for visits and prescriptions. It's so hard, we can get emergency dental services, recently I had issues with my teeth, calling around finding specialists and health care providers is a struggle. The dentist thing is such a mess in my experience.
- I have the same situation, it's been very frustrating, I have an outstanding bill of over $1000 that I can't pay, and it keeps escalating. The place that I've had probably, I went to the University of Minnesota, but I was able to get good care, it was still expensive. I don't understand why they can't come up with something that is more inclusive of dental.
- I've been fortunate to be healthy, I lost both of my parents and a brother and the challenge I struggled with was coordination of care. I know healthcare and I had trouble, and it's complicated healthcare to deal with. It's kind of a disaster.
- I moved here in 2016, after living in Nigeria, prior to that I lived in England, the way I've been used to healthcare provision, in England or the whole of UK it's a social program and everyone pays into it. And regardless if you are a citizen or not. Now some specialist care you might be

required to pay for extra services. When I moved here in 2016 and in 2017 I had a stress related ailment, I diagnosed with anything, it was just stress. At the time I didn't have coverage from my job and all the doctors just couldn't figure out what was going on. Some thought I was doing drugs, I don't drink or smoke. I finally went to 3 or doctors before the last doctor who was a Black person and he said to me, what exactly is going on with your personal life. I haven't been working, All of this stuff, from what you have told me, I think it's stress related and you need to rest and take your mind away. True enough by the time shut down everything for two weeks. And I felt better. What was missing was support of mental care. I could have easily killed myself from that experience from that state of mind. I didn't have any family there at the time and not having any kind of support system. And talking to doctors and not being able to figure out things. I've changed significantly since then, but I don't wish it on anyone.

- I had a situation where I needed knee surgery and for 20 years, I couldn't find any way to get it done without insurance and I couldn't find anything about how much it would cost and what the bill would cost. I considered going to a foreign country to get answers no matter what. I would ask if they could estimate it, and that was frustrating. And when I finally had insurance, I was able to get it.
- About two years ago I didn't have insurance and I couldn't afford it through my job and the state was saying I made too much to not get insurance. And I got sick twice and I was hospitalized twice. And I had to get insurance and I had a blood disorder called ITP, and the total for everything was $60,000 and I didn't know what to do and I got really stressed and depressed. I was able to get a lot of financial help through the hospitals and I'm still on the payment plan with $3,000 left out of $5,000. Just making it more affordable for people. It's a lot to take out. Then the state tells you that you make too much to get insurance.
- The diverse population of providers, doctors, that could refer people or have that option when you call into your healthcare provider. To piggyback off your story when you talked to a doctor of color they could relate to your whole story. When I call in, I'm looking for a dentist. To have more culturally specific options. You know what you're experiencing in your body. And they're very dismissive, and they look at you like you're another Black girl, it's like you don't matter. It's something a health care provider, incorporating more.
- I feel like providers are dismissive, I went to Allina, and they would just give me a different doctor, and I was able to finally find a doctor that I could connect with and I'm now doing more preventative care.
- I would love to shop for healthcare like I shop in Amazon. I would love reviews and I would get to see how much it would cost.
- Universal healthcare so you don't have to worry about costs.
- What does it do if people are providers are competing for you?
- I asked the front desk staff, and they recommended the doctor I ended up connecting with.
- In my case I didn't have that choice, I went down the pecking order of doctors, doctor xyz, doctor abc. I think the other thing, I wish our jobs could give us multiple options. I work for US Bank and they use United Healthcare. I would like to know what other options you could have.
- I've been very blessed and I've been with the same clinic since I was 16 and I'm 44 now. I've stayed with them because it's personal. I know the nurses, I know the blood clinics and knowing them. I speak with everyone and I'm thankful for everything. I lived in LA for 5 years and it was night and day difference, I had doctors, while I was pregnant didn't know who I was. I would sit in waiting rooms for hours. I felt like I was in a cattle call. I would get in the doctor and they would treat me like I don't go to the clinic. We decided to move back to Minnesota to have my daughter. I was on medical assistance I would not wish that on anyone. I felt like a number. I never experienced that in my life – and it caused a barrier to my healthcare, it caused stress and I was being treated specialty because of my age. When I got home, I went back to the clinic, it was night and day, finally I was coming home. I'm thankful for the care I received. I know that that's not everyone the experience I received.

- I didn't have Medical, I had Blue Shield in CA and I wouldn't get in until noon. Has anyone ever been to the doctor and get a bill like 4 years [later] for a service?
- I'm from California I moved here a year ago, I have lupus, the care I received there was so different.
- I'm transgender, and the state of trans healthcare is very poor. There was a big survey and 27% of trans people in healthcare faced prejudice. And the way they classify services as nonessential. The waiting list for a therapist, and for pediatric therapy. I work in a pretty high-level job. I had to get a lawyer to get the coverage, I had the means to do that and a lot of trans people don't have that.
- A lot of the culturally specific groups cut services during the
- It's going to take me a ton of loops, I have to do things for a year to get on a waiting list and then there's another year and a half. There's a lack of providers right now. And I have to be completely ready to do and then wait for a year. The policy that makes it easier on the provider but they also delay it because they don't see the urgency. It shows how little the lived experiences of trans people matter. Part of it is understanding that calling necessary insurance as cosmetic, and that comes from the standards of care that was last updated in 2011 and allowing access, when you're trans you need medical care, you need hormones and having access to insurance and having 47% of trans people attempt suicide and this is timely and important stuff and there's It feels hopeless sometimes. I work full time and I'm in grad school fulltime and it's tiring to try and do things. I work in a school district where I'm the first trans person in the history of my department.
- I hear you and I see you, I'm not trans but I have trans fans, and I hear your frustration. I know someone that maybe I could connect you with.
- I still have friends that still have to describe what trans is to their own doctors.

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- Seeking providers that are culturally competent is a challenge
- When our first daughter was born, she didn't cry right away, so they drug tested her and me and when it came back clear the nurse was condescending. I wasn't able to hold her right away… I asked her if it could be because of the Zoloft… and that my doctor said it was okay. The nurse responded and asked why I didn't say anything before… then I asked the nurse if there were going to be any long-term impacts on my baby and the nurse just said well… I don't know in a very condescending tone. So, I was afraid. There is a lot of racism during that experience.
- As someone now in recovery, I am labeled as having an addiction… so now they assume that I am always looking for a drug every time I go to receive care.
- Being an immigrant, when I first got here, I didn't know where to go to the dentist and what to pay.
- As a diabetic and a pregnant person, we were denied… it wasn't medically necessary, so they didn't want to cover my endocrinology appointments. The clinic had never had any insurance deny a pregnant woman a service. They had to clear the invoice. That was with Blue Cross Blue Shield.
- Being employed full time, I have been fortunate to have access to good healthcare when needed. However, with my partner (who is a green card holder) I have seen how racism has affected his healthcare, and how it is different to mine, both in care and cost. Plus, the social/cultural stigma of mental issues is affecting my ability to get him to seek help.
- My ex is a green card carrier too. He has dental care he needs but the cost is so high that I don't think he'll get it done…
- It seems like doctors are a lot better these days. When I started to go to the doctor on my own I could feel a lot of shaming… now I have a doctor that doesn't shame me for my weight but

there were YEARS that I didn't go to the doctor (like 10) and the only time I went was when I had to go to the hospital because I would wait so long to seek care. Now I have a family practice practitioner and they aren't rude. I don't know If things are getting better as a whole in the medical community or it's just me.

- The combination with the medical services and insurance is hard for a lot of people. We put so much on doctors…. I go to the doctor and they say that I need to have a medical procedure done and then when I go to get the procedure done, they tell me that it isn't covered. You would think the doctor would know that it might not be covered for me, before giving me the advice. How can we let people know in advance?
- I had a diagnosis that was ignored because of my lack of weight…
- A few years ago, I was dealing with a cultural issue… I dealt with white women practitioners that shamed me. I was previously with a Latina provider for 8 years and then I had to stop seeing her… with BCBS, for whatever reason, I couldn't see her anymore. Eventually, I was able to find another Latina provider and I had to go through a long process.
- Parts of me wants to opt out of our medical system…. to your point, I want to do more holistic care and try not to go into big pharma. There's a history of so many of my family members taking medications and there are more side effects than there are benefits for the medication. Diabetes, Heart Disease etc. Culturally, the generation before me, what have they done in terms of healing? I would love to see some of our providers make it easier to do acupuncture, crystals, energy work… those Black and Indigenous people aren't even paid or covered by a lot of our health care providers. I used to have Blue Shield and now I don't and its frustrating … I intentionally seek out providers who are women or femmes and people of color. It is hard to come by a Black woman doctor. My practitioner is a Latina. I told her I specifically found you online because you are the only woman of color that I found… this summer I had uterine fibroid tumors that were equivalent to me being pregnant. The white women kept saying I needed to get rid of my uterus... but I don't have children… and I just think… had I not had the courage to advocate for myself or had the education… who knows. I had two aunts have the same experience themselves 30 years ago and they didn't know they had options to not get rid of their uterus which is disheartening. We know in this country that there are doctors that are doing hysterectomies on Latina women without their permission. Also, the Tuskegee experiments… so we don't always trust a system rooted in White Supremacy.
    - I, too, have had 4 aunts have a hysterectomy for less dire situations…
- More IBPOC to be healthcare providers! It's important!
- Access, become a provider and have cultural influence.

Facilitator's reframing [Spanish to English]: **What are the challenges that you have faced? Do you have stories to tell? We hope to take your stories to make changes in the health system because we know that there is institutional racism.**

- This year I haven't had issues with health care. I haven't been to the clinic in a long time because of COVID-19 and because I don't have medical insurance. I applied for insurance for my kids, but I haven't heard any response from the clinic. I don't go to the hospital or the clinic as often as I should because I don't have insurance.
- I had cancer. I came from Puerto Rico, what I would like to see in the future is medical insurance for everyone, including me, good checkups, good doctors. I can't pay the medical bill every time I go because it's too expensive. Everyone should have access to medical care. When I was diagnosed with cancer the only insurance that I qualified was Medical, private insurance didn't even consider me because I was already sick.

- My experience is not just Latinos get discriminated against in the medical field, all people of color get discriminated against. I feel like as of right now there is more discrimination going on in this county. I feel like part of it is coming from President Donald Trump. People face discrimination because you're not a citizen and that needs to change. Hopefully the new president makes medical care more accessible. I am happy that Biden won the election because that means we can change things in government for the benefit of everyone in this country and the world.
- There have been times I'm scared to go to the doctor because as a person that is not a citizen I'm scared of how high the medical bills are going to be. If I get sick or somebody in my family gets sick, we drink traditional remedies and eat healthy foods like "caldo de pollo" chicken soup.
- Last year, my husband had medical problems and the doctor said that he didn't need surgery. But I felt like he did need it. I feel like we were being discriminated against because he most likely needed the surgery but they didn't want to give it to him. The doctors just sent him home with pills hoping that it will go away. Part of me felt like they didn't want to do surgery because we didn't have insurance and they looked at us and probably said: "they won't be able to pay the surgery bill".
- My husband is getting better, the pain in his legs and ankle hasn't gone away yet. I been giving him herbs and massage, so he feels better.
- What I want to see/need is, to have affordable health care. I want to be able to go to the doctor without fear, feel respected and not worry about not having money to pay my medical bills.
- I just want doctors, nurses and medical insurance to see me as a human being.

19 November 2020

- So, kind of both on question one and two – my dad who I mentioned earlier is my world had Covid back in March and almost died. It was the first time that I came face to face with having to advocate for someone without being able to be present. Even though we're from Cuba and we've had to advocate for family members from a distance – there was always someone who was able to be there in person. So, my dad almost died – he was given a less than 10% chance of surviving. But there was a nurse who resisted giving him the medication that the doctor prescribed, she said she was worried he'd become aggressive – and when I asked her if she was worried about the drugs or worried about him because he's a Latino man? And she couldn't give me an answer. She doesn't work at the U [hospital] anymore because I reported her, and they investigated and found that there wasn't any reason other than bias for what she did – actions that risked my father's life. So, that's my first experience having to navigate advocating for my family without being able to be present for them.
    - I was told as he was going through all this that there's a learning curve with Covid, but our issues were with the bias that has been there way before Covid. So, I just said, let me help you with that learning curve there. My dad's bilingual, but I keep going back to that – if I'm having this struggle, as his medical proxy because my mother doesn't have strong enough English – think of what other immigrant families are going through? I didn't get to speak to a social worker until fifteen days into my dad's illness – that's fifteen days that he was suffering and had no one to advocate on his behalf.
- I work at a hospital and those experiences – we need families to know how to file a complaint so that others don't have to go through those things again. But the system is not set up to make that easy or to support that. Also, for most white folks we serve, they expect world class treatment – gold standard care – when they come in, whereas in my [Indigenous] community people just want to be left alone. There's no trust, and the expectations are so different – so much lower. We need communities and organizers to push for hospitals to do better. Every hospital has to do a community health assessment, and at the hospital that I work at, we have named racism as a public health issue and are partnering with community around that to put

structures underneath it. We're trying to capture racism in our research on patient experience by incorporating understandings about how racism feels like an offense against both your health and your dignity. Plus, if you don't have an advocate inside the institution – I mean, your access to resources depends upon how good your advocate is. Sometimes, for families – if the menu is all in English, patients don't even know that they have access to meals in the hospital. I just dealt with a case where a patient's family didn't speak any English and no one explained it to them, so the entire family went the whole weekend without food – without knowing that they should have had access to three meals every day. We need to start pushing institutions to do better. And I think that the way we start doing that from the community perspective is 1) to explicitly say that they're going to address racism and 2) that they put structures – actual policies – underneath this – and measure it! These institutions are really good at measuring things – we have been measuring distrust and mistreatment of American Indian community members in our research. But we can measure and measure and measure the existence of these biases, but until institutions like Blue Cross admit that they are contributing to this and need to do something about, nothing is going to change.

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- Has been in MN for over a year and hasn't used her insurance yet because she can't figure out how to get in. Trying to find a doctor. Half the country can't stand us. Looking at something in healthcare provider bios to indicate they care about Black people and want to work with them. It's too hard to find a doctor. If you're on Medicare, they may not want to see you. Her family is new here and she doesn't know who likes Black people. She hasn't found a doctor yet.

- MN has a race issue even though they are labelled progressive. MN Nice. White professionals associate Blackness with poverty and belligerence. Providers make assumptions of her way of life because of her Blackness. They assume you won't be a pleasant person to deal with because you are a person of color. At the mercy of your insurance – provider says they can't give you care because of your insurance.

- Provider perspective – if provider gives sliding fees or doesn't accept the co-pay, it's a barrier to care because the provider still needs to cover their bills. If someone has Medicare, the provider will get in trouble if they tell the person to just pay out of pocket. The provider gets worn down.

- Her mom with knee surgery was prescribed opiate medication and was really careful about taking meds. Her mom was with Health Partners. Her mom thinks the doctor (young white guy) thinks she is drug-seeking because she's Native. He wants to cut her off the medication she needs. Because there's opioid addiction in the Native community, he flagged her mom that way.

- Seeking care in this pandemic, expected to go to appointments alone. Go dressed up, go with a loved one to vouch for you, so cultural assumptions aren't made about you. Why is dependency seen as a moral failing by those in the healthcare system, when people really want to manage pain?

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- Notes: **Y——— –** Need emotional and mental health support while dealing with a health complication, language barrier, insurance not covering certain medication. **E——— –** Mental health support cut out during Covid pandemic. **F——— –** Not receiving proper care because of race, doctors not taking her seriously, #2, care got better during Covid because of virtual appointments and video being turned off. **M——— –** Had medical issues with stomach and felt like male doctor didn’t listen to them/doctor kept on arguing, went to a female doctor and felt heard and listened to. **S———** **–** Two different types of insurance denied medical surgery, cost was too high in state and had to travel to a different state, since the procedure wasn’t covered if something went wrong, they would have to pay for all of the follow up procedures, Non-binary care needs to improve.

- I have never felt discriminated against by the doctors but something that I want to see in the future is more Spanish-speaking doctors and more interpreters in the hospital. There are times that I have to translate for my mother and its not right because sometimes I don’t understand medical terminologies.
- All the time that I have been at the doctors’ office, they would attend to me well. But what I also want to see changed is more Spanish-speaking people at the hospital. Insurance should be free and accessible to everybody or at least for low-income families, kids that don't qualify for insurance should have resources and help for free insurance.
- I am undocumented and sometimes when I got to the doctor, doctors take too long to attend me. One time they made me to wait for 3 hours and the doctor and nurses forgot about me and the doctor left without seeing me. I remember nurses were kind of laughing at me because they couldn’t believe I was left there for hours. I don’t speak English, but I understand enough how I felt at that time. I felt humiliated and I cry on my way home. I felt shame for not been able to defend me. And I feel like I was discriminated.
- Medical bills need to be cheaper, especially for people that don't have the money to pay the bill. Insurance is a big problem right now in America because everybody is trying to get insurance and they don't qualify for it and when they go to the doctor, the bill or co-pays are too high too.
- There need to be more doctors that speak Spanish, because most of the time you have to wait a long time for the interpreters to arrive and you could have a bad medical emergency and will not be able to explain what’s happening to you.
- I always had good experiences at the doctor or going to the clinic for my checkups. I feel like why I don't get discriminated against is because I have insurance.
- We need more Spanish interpreters because every time I go to the doctor with my mom, I always interpret for her. It's not good for your kids to interpret sometimes because they don't know what to say or how to translate some words.
- I haven't applied for insurance, but I have for my kids because they are citizens, I live in Northfield and I go to the clinic and they don't have interpreters for me every time I go so they don't know what I'm saying.
- CLUES have a lot of good resources that would help people with their medical services that they need or help people pay their medical bills. I applied for my kids for insurance and they got it. I applied for me and my husband to get insurance, but we didn't qualify to get it.
- When I had COVID-19, Hennepin county helped me a lot. Hennepin county bringing me food and things that I needed so I can isolate at home. The only thing I didn't like about them is they took 7 days to let me know that I had COVID-19 and they didn't let me know sooner. I could have got other people infected.
- I have depression, anxiety and panic attacks. I didn’t want to see a doctor because I didn’t believe in mental health. I almost killed myself and my husband took me to the emergency room, there I understood that I was not okay and mental health is real and dangerous because you can try to commit, suicide, just like I did. I started to go to the doctor more regularly and see a psychologist but because of my status I don’t qualify for government insurance.
    - I bought a private insurance and every month I had to pay $230 out of my paycheck, that was a lot of money. I bought the insurance for one year but 3 months ago I had to

    - cancel it because I stopped working for the COVID-19 restrictions. I still have some meds, but I am not sure if I will be able to buy insurance again.
    - Some clinics and hospitals offer discounts for people like me, but if you need to seek specialized medical attention it is almost impossible.
    - Now I have to choose either to pay insurance or pay rent and buy food. It is a hard decision to make.
- We need more doctors and nurses who speak in Spanish, if there is no service in Spanish we have to wait until the doctors and interpreters arrive.
    - When my baby was about to be born, I didn't see interpreters. I alone guided myself to have the baby and my husband who was with me.
    - What helped me for the labor-work were the prenatal classes that I took.
    - The prenatal classes helped me prepare but not the doctors or nurses.
    - I knew what to do or my body knew what to do. It was hard but I am happy to know that my baby is healthy.
- I personally have had a good experience at the doctor, to renew my insurance is the most complicated.

1 December 2020

- When I got out of college and started my job, I wanted to get off my parents' insurance, but I couldn't. I had difficulty getting off my parent's healthcare plan because my medication cost was so high.
- My experience with barriers was accessing dentalcare. At the time, I had insurance, but it would not cover deep cleaning. The dental office offered a credit payment, but I couldn't afford that either. My work hours were cut short, and I still have insurance, but it didn't matter. I still couldn't access healthcare.
- Before you come in, you are already labeled and judged. I went in for a shoulder pain. The nurse looked at me and asked what I was using. I told her I was using tree. She said the trees aren't label in Minnesota yet. I felt she judged me. She wanted to give me a shot that I couldn't afford and I didn't want any needles in, so I said no. I went home and took my tree, received massages and medicine from friends and got better. I didn't need that shot. This is the issue. How do you treat patients with the best care if you are prejudiced against them? How do they know what is best for us? Natural or unnatural, they always get to choose for us.
- That makes me think about what we consider as healthcare? We often don't care about dental as a problem. We also don't consider alternative medicines such as Eastern medicine or home treatment.
- I been homeless since 14. Healthcare wasn't a thing you did. It was an emergency room culture, only go in when things got real bad or you go to the school nurse. When I graduated from high school I had a pain on my leg. I was afraid to go to the doctor. I didn't know what insurance was. I didn't know if I had insurance. I didn't know how it worked. I let the situation get so bad that I had to go to the emergency room for surgery. I was 19 and on my own. I wanted a second opinion. But I didn't have anyone to ask. Now being more than 30 years old, I always wondered if I needed that surgery. Men of color never get authority in healthcare. How does the system treat you when they don't value your authority or opinion?
- I am a Black maternal health advocate. My job is making sure that Black mothers have equitable treatment. I have a daughter. She is two now. She has some problems resulted during my pregnancy. Similar to my aunt, when I was birthing, I told my doctor that I was in pain. No one was making that a priority. The doctor suggested "Tylenol!" My experience mirrors other women of color in my work where their opinion was not listened to. We have inherited a biased medical system. A system built on the experimentation of women of African descent. How do you do advocate for yourself when there's implicit bias? This is a matter of life and

death because it ends up being life or death. Black women are more like 3X to die than white women during childbirth. More Black women died today than during slavery giving birth. Our society has regressed.

- One of the biggest barriers in healthcare is a lack of trust between doctors and patients of color, which comes from the legacy of racism. My mom shared a story with me about her friend. Her friend was in the hospital and needed stitches. The doctor gave her 7 stitches. Then someone explained to the doctor that she's an important person. Then the doctor changed his mind and gave her 18 stiches instead. It's crazy how you are treated better or less based on your status.
- More on trust. How can we trust doctors who value or respect our existence? You end up having to trust yourself on life and death because you can't rely on the doctors. But you can't even do that. How do you ever trust yourself in these situations? Last year, I had a lump and went to see the doctor. The doctor said, "it was benign, so we are not going to do anything." I told the doctor, "If I come back in one year and if it got bigger, we gonna have a conversation." I drove home and cried and just hoped that I was going to be okay. I'm sure I need another scan. But I can't do anything about the doctor's decision. You're always at the mercy of how they said. I'm just grateful I am alive.

* * *

- "No one was believing what I was going through."
- "(I was treated differently) because of how I looked, of how I presented."
- "My personal methods can tell me what they can't." - in reference to one's own home care routine.
- "(Doctors) don't believe that I know myself."
- "(Doctors) don't understand unless I use their language/ don't speak in a way that I can understand."
- "I wasn't joking when I said that I need dentures... I can't get them, they're so expensive. And because of that, now I'm having problems with my stomach. Because I can't get help with my mouth, now my stomach is in terrible pain."
- "I have a hard time going to the doctor without reliving my past trauma."
- "The whole picture is made of little pictures, so if the little pictures don't make sense then the whole can't make sense either."
- "If I knew then what I know now, I would have had a different experience."
- "I'm trying to teach my 16-year-old daughter how to advocate for herself. There were too many things that I didn't know at that age.
- "But I want her to know, 'This is your body and your pain is real.' It's scary to leave your child with people you know are not going to advocate for her."
- "Even if I just had people who looked like me, even at the front desk, who maybe knew something about where I'm coming from, then I would feel safer."
- "We just need a more holistic healthcare system (laughter)."
- "I don't go to the doctor enough to have barriers."
- "Every form at every place is different. Each one is more complicated than the last one. They're confusing and take a lot of time and they want to trick you. I am a smart, college educated person. What if I wasn't? It would be so challenging that way."

[Second set of notes submitted by another scribe in the same group below:]

- Takwai moon ceremonies; no doctors and no therapists believed what I was going through; attempting suicide; doing so much and keeping the façade that I'm strong; not feeling safe to go to the doctor; you seem fine; if I didn't have insurance, they didn't check me until I get pregnant;

because of income level/access to health care insurance; look and how I presented; access was a barrier. Turned to alternative healthcare.

- **D——— –** single parent has done a lot of self-care; come across that at the professional level it's really unbalanced; I'm not believed that I know myself. As I try to communicate, I still have psychologists pushing medication on me. I needed something for anxiety. On assistance helps her raise her kids; very limited in services she receives; only get state MA; only gets certain services; she really needs dentures; now she has stomach issues; never went to the dentist because of severe sexual abuse and trauma; she's always gagging and no one wants to help her through this; it falls back to intersectional; relational; nuanced; for the individual to be heard and to be believed.
- Just because I don't know a word; personal experiences with saying the wrong or a cue word and doctors scold him for using the words he uses because it would change the diagnosis; 'manic'; yelled at me; other ways to communicate.
- **K——— –** had daughter at 21 just starting her career; treated with such assumptions; now that her daughter is 16 and having appointments independently; has to have conversations with her daughter about how to advocate for herself; she learned from her community; these are just people who read books; this is YOUR body; it feels so shitty for doctors to say my pain isn't real; the systems are systemically racist; barrier is having those conversations with folks; you deserve to get health care; you deserve to be heard and believed; your pain is real; if I walked into a place and saw people who look like me in the space; it would be so comforting; if I say I'm taking a crystals, tea, that's valid for me too; those are valid medicines for me; these are real healings; just because I want to use. We just need a more holistic health care.
- Disbelief when we know something is wrong. Starting from how we access health insurance so we can pay for health care; all of the forms to apply are different; all processes are different, all complex questions; are these questions really necessary? Are they really important to ask? And if you miss something that you're not going to get insurance or a doctor; costs for health care are being pushed on consumers; to pay high premiums and deductibles; these jobs that require people to help you get insurance means the system is really broken; the amount of time you have to spend on the phone; 4 months to get something covered; customer service doesn't have the power to address issues through to completion; we need to talk to people empowered to resolve these issues.

Question 2: Has the Covid-19 pandemic changed the way you seek or receive care? If so, how have you been managing those challenges? What role, if any, has technology played in your ability to access the healthcare (or other wellness resources) that you need?

17 November 2020

- Because of Covid we've done a lot of telemedicine and the clinic I go to is very strict on appointments, if you're late at all you have to reschedule. I guess it's on you, but it does kind of get to you sometimes. We were in a position where our primary physician wasn't available for a while. She was put into a rotation, so we just had to hope that whatever replacement they put us with is able to help us with our health issues.
- So, one of the things that I discovered – I have a lot of anxiety, and I was bringing a friend [who also has anxiety] to the clinic, but they wouldn't let me be there if I wasn't the one being seen? So, that was really hard – with my friend's anxiety, she really wanted me there to support her. It's hard to adapt to the way things have changed because of Covid.

- I was talking about how many specific LGBT care has been cut and the smaller your group the more your services are cut when there is a crisis like Covid.
- In my case I'm just so not ready to go into a hospital for anything, even with all the precautions. I know there are significant efforts to have telemedicine, but I'm not ready to take the chance.
- I'm not ready for a lot of things, even with the vaccine. I'm at the point if I need care, I'd be open to have a house call. The risk would be lower.
- The risk would be higher for that person, I guess with the other stuff. I haven't had my blood levels in 7 months, and I'm supposed to check every 3 months.

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- My healthcare hasn't changed. As a person who has been a caretaker for the majority of my family… Covid has changed my ability to advocate for my parents. My mom has a brain injury so right now she is going to all of my dad's appointments, but they need someone else because my mom can't attain the information… so that has been frustrating especially because in the past month my dad has been hospitalized twice and has a new pacemaker and coming appointments… so this for me has been a worrisome time. I feel like my access to what's going on with them has been curtailed. Could I be conferenced in? If I could be there virtually and be there to transcribe that would be great!

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- Improving mental health through exercise. Likes having therapy from home and not having to go to the gym setting to take a class. Likes being at home and hopes these distance participation activities can be normalized after COVID. Dislikes driving to places to participate.
- From St. Cloud (White Cloud) with 80% white folks. Delayed mammogram due to COVID. Finally went to get 2-D mammogram and then had to go back for a 3-D. She gets billed for the 3-D even though they messed up her 2-D which gave a false result of possible abnormality.
- Came from Singapore when she was 30 years old. Singapore has subsidized healthcare and people are treated as assets, so people need healthcare, transportation, etc. In US, people are not treated as assets. Racial health disparities are like genocide.

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- Notes **Y——— –** Covid has made everything more difficult from childcare/education to figuring out technology. **M——— –** Covid disproportionally affects women and caregivers since everything happens at home.

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- One thing I have noticed is that there is no privacy now when people are using virtual services, telemedicine or education.

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- I had a baby in Covid. Covid-19 changed my birthing experience. I couldn't get on the contraception that I wanted because they weren't seeing people. I have not done any other health services unless necessary. Healthcare is far more isolating when you can't have someone come with you. When I had to get my gallbladder out, my mom drove me to the hospital, but I was on my own after that. I got so anxious that my blood pressure shot up. The doctors did not know what was causing it.
- [Facilitator] What else could have been done to make you feel safer?

- It would've helped if doctors have a higher level of sensitivity and communication.
- One of the things that no one considered is the impact of being quarantined on people with mental health disorder. What happens when you cut off social interactions? I have a family member, who was greatly impacted by being home by themself. There are so much health benefits just by being outside and being with people. But now you can't. Who checks on people with mental health? I don't even want to go to the hospital now because that's where the diseases are at.
- Connection is so important for health.
- Minnesota is home to a huge network of sobriety, but so many people are relapsing right now because they don't have access to their sober network. Network and connect are important to being sober.
- There is a holistic issue that needs to be dealt with. The closing of art centers and community spaces, what does that do for community health?
- I have been very fortune that I didn't have to seek out care during Covid-19. However, there had been challenges with families with kids. Kids need access to constant care. The stressors for my family have been more with new norms and lack of comfort.
- Also, similar, I have been very privileged. I am managing my health by seeking friends and talking to my therapist through telehealth.

- "I'm paranoid."
- "I feel like I ask them too many questions. I don't want them to think that I don't think that they know how to do their jobs, but I need information."
- "I just deal with it. That's all I can really do."
- "I'm a cataloger in a digital world. I need and want things to be physical and in person, but I'm trying to get more comfortable with doing these things online."
- "I did a telehealth appointment for my daughter. It was just a dermatology appointment, she's sixteen, and that kind of stuff you can just take pictures. You download an app and do all this stuff and it was actually pretty easy." "Would you do it again?" "I wouldn't do it for all appointments, but for stuff like that yeah." "Would you do it again even after Covid?" "Yeah, I think so. It worked pretty well."
- "My employer has had a deal with people who do telehealth for a long time. When it works, it works very well, but sometimes when it doesn't work, it feels like it can be very dangerous."
- "I need a doctor who understands all the parts of me. I am not just Black or a woman or a mother. I am a Black woman with a 16-year-old daughter and all those needs need to be met. All these things are inside of me and all these things are true."

[Second set of notes submitted by another scribe in the same group below:]

- The pandemic has hit her hard; don't go anywhere; forget a lot of things; gets paranoid; going to the dentist; asks a million questions and feels like I'm questioning them; she needs information she has to get back to the eye doctor; stomach, etc. I just deal with it but am in continuous pain; just went to a virtual appt once.
- At times I feel that low-income individuals have to just settle with what they get and more often or not have to deal with poor quality health care.
- All the positive tests are so scary; I need things to be done in person; she felt safe with the dentist today so that was assuring.
- K—— likes the option for a virtual visit so that's a positive; she made sure it was HIPAA compliant. Telehealth has been accessible for her young people too. Would you do that even after COVID? Yes.

- A—— knows of a virtual health program that will go out and bring meds to your house.

Question 3: Have you ever encountered challenges seeking therapy for mental or behavioral healthcare for yourself or a loved one? Is there anything that would support your mental health and wellbeing needs that an insurance company or healthcare provider could make available?

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- It's almost impossible to find a therapist.
- Have an adult daughter when she was a sophomore in college, had a psychotic break; queer, BIPOC, …she lost her access to health care until ACA came along. She needed a BIPOC for both her therapist and psychiatrist; it took them 5 years to find a lesbian therapist and a Black therapist. "You don't get me. You don't get me." Just being able to search for therapists.
- Came out of foster care; 25% attempt suicide; this last year has been one of the hardest of her life. She was profiled in a park. Police had hands on weapons. It impacted her child who's gay and Black; it put him in a tailspin; 2 of his friends died of overdoses.
- Partner with dementia; profiled by white neighbor.
- I finally found a therapist of color. I worry for my son every day.
- Part of the mental health issue and policing; how is this happening in society; it does a lot to the brain. It changes something in you and not to the good. Society has to change. I'm really sad to hear this as an immigrant. We keep to ourselves a lot.
- NAMI advocate: got the police to do Crisis Intervention Training (CIT); I wish ALL police had CIT training. This is a part of the 'law and order' system that doesn't work for a lot of us (BIPOC, queer, immigrants, etc.) The police scare us.
- DMV story; questioning my name/status; can I get an extension? She was scrutinized behind closed doors by a white man. This is the dragnet of being undocumented. He then abused me. Getting a drivers' license renewed should not be a trauma. Not everybody has a mom who has the baby box of pictures, documents saved for you for these moments.
- Things that are easy for some people, aren't simple for me. When I travel internationally, I can't just go through.
- The relationship with health care personnel/nurses/they don't always see you as people. They are superior to you. It's not warm and welcoming especially in MN. This is multiplied in MN; don't feel like they need to be related to you. It's not trivial. There's a lot of research that says the way you feel about your doctor affects your probability to heal.
- I went to the dentist with my son and I was going with him and they stopped me. What are the rules that say I can't go with my son? There are so many ways to handle and communicate that. I brought it up to them and they were surprised. It's our responsibility to bring these things up.

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- Is a person of mixed heritage. When she was younger, she needed behavioral health care and saw different therapists in Twin Cities and Duluth. Not helpful to talk to therapists that have no way of talking about issues of race and without an understanding of what it's like to be mixed. White liberal guilt becomes centered and she ends up having to take care of the therapist. She doesn't know what culturally appropriate care would look like.
- Culturally appropriate therapists would be out of network or nowhere near where she lives.
- Owns a clinic for her job and has barriers to healthcare for her son. On the provider's end, they make more money and do less work if they work with people and issues that don't require being inclusive and aware as you possibly can. Provider sacrifices 95% of profit to serve the community, to serve people with barriers to insurance. Limitations around education and diversity of people who enter the profession, and there's bias that impacts people getting care.

- Need more diversity in the field. Using herself as an example, she is often told she should enter the field. She doesn't think it will be a good educational experience to go into the field. It's not a diverse field. She wouldn't get gratification going into the field – how will she get mentorship? Most areas are dominated by cis-white people. Even if she went that route, she would be discouraged going through the training.
- Special Ed teacher: Students go to day treatment programs, then the school will hear the therapist dismissed them because their care was too much for them. Why does the medical profession get to dismiss them, and it's accepted? What happens to the kids who need help working through their trauma? Her daughter got kicked out of day treatment because she hugged two people and touching wasn't allowed. Are they holding white kids to the same standards as kids of color?
- Funding is low for ESL, so kids get pushed into Special Needs. The child isn't Special Needs, just needs someone to teach them English. Parents are going home with the info of special needs when they just need more funding for ESL. Somali mothers formed Somali Action Alliance to bring attention to this.
- County community liaison for BCBS: She had to fight a system for $5.32. Fought with the clinic and insurance side about the billing. The system demeans her. They tell her it's her problem that she doesn't pay. Getting the stupid bills then having both sides tell her it her problem.
- Avoiding bill collectors for medical bills. Trying to get to the therapist 45 minutes away. Has ADD so would be late for the appointment and be charged $50 for being late. At work, she fainted, and company policy requires an ambulance. Being retroactively charged for a bill for something you were told was covered. She wouldn't have gotten the care if they had said it wasn't covered.
- Capitalism is a huge issue of healthcare. Needing to have a job to get care. For behavioral health problem, even having a job and having insurance won't cover the bills.

- Notes**: J——** In the D&I space and extremely hard to unplug. Needs someone to talk to with similar life experiences/looks likes me. All Black therapists are overbooked, being able to unplug is a luxury. **S——** Technology and internet connection. Only being able to book 2 appointments at a time but they're booked 3 months out. Difficulties complying with doctors and receiving notes. Too many doctors/specialists to keep track off. Needs a care coordinator. Shortage of medication due to Covid and can't get approved for other prescriptions, insurance not covering certain over-the-counter medications, If I didn't have medical literacy and energy to put in effort, I would receive no help. **C——** Agrees about the need for care coordinators, healthcare is overly complicated.

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- This sticks out to me because I'm a social worker, and I've worked in different capacities. Right now, I work as a school social worker and a social worker at an in-patient psychiatric center, so I think a lot about these issues and the challenges people face in finding culturally appropriate healthcare. Personally, I'm seeing some gaps in the conversations I've been having with my provider about health and nutrition – there needs to be a bridge for these gaps around culturally appropriate diets, nutrition and healthcare.
- Something similar happened to me where I had to change my diet very quickly, and there wasn't any room for talking about traditional foods or my cultural needs and how to do that in a healthy way.

- From my experience and other people, I know, accessing mental health care in rural areas is very challenging. There's [*sic*] just not enough resources. I had to wait three months to see someone. It's even more challenging getting to see or finding a new therapist.

- "A lot of psych practitioners are not taking new clients. They are so busy these days."
- "My insurance does like a 'three free sessions' kind of a deal, but it won't guarantee that you're going to be able to keep seeing the same person. Therapy is forever."
- "I would love a space."
- "Mental health is important. I see it on billboards. I hear it. It's on TV. But who is prioritizing that care? I'm told that it's important, but I can't find help when I ask for it."
- "What if insurance covered cultural healers? If they made it a priority like European medicine?"
- "I go to the Native American Health Community Clinic, and it's usually a lot of student care. A lot of the time, I've had to educate them."
- "I don't even know what's available."

[Second set of notes submitted by another scribe in the same group below:]

- The pandemic has hit the teenagers hard due to distance learning, not have extra-curricular activities, not having social events. It's really difficult to find mental health services in person and a lot doesn't have openings. That's not just COVID related; these providers in general are difficult to access. It's difficult to know how to start if you haven't had mental health insurance. Psychiatrist appts take 5 or 6 months.
- It's hard to know the ins and outs re: insurance for mental health; it's so expensive $200 a session. There is some mental health support connected through my work; but you get 3 sessions and then it's really not a therapist; you have a few choices; it's a push and pull. Would love a space for healers, doing this work for free. What if cultural healers were covered by insurance?
- Where does the care come from? Who's prioritizing this? Dedicating hours for those who can see folks who can't pay.
- It would be preferred if insurance could cover cultural healers….
- Advocating for her kids. How culturally diverse and culturally sensitive are they? And how trauma informed are they? My culture handles things differently; for me this works; it's really important (Indian Health Board) mental health services are provided by a lot of students vs. professionals; I have to navigate and educate them; there's so much IMBALANCE; Low-income individuals have to just settle for what they get; therefore, it's low-quality health care.

Question 4: Are you able to find culturally appropriate care? Are there any cultural or holistic practices for health and wellbeing that you'd like for insurance or healthcare providers to cover/provide? Do you have any experience with healthcare systems outside of the U.S.? Locally? What have those experiences been like? Is there anything that worked well for you? Is there anything that could have been improved?

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- It really is more related to Blue Cross Blue Shield and insurance companies. Just to share – I've had BCBS basically all my career. So, in retirement we thought okay, great – we'll just go with that. We had great coverage, a supplemental. WE were able to keep our doctors, they were in our network. And then all of a sudden, we were dropped. There was no explanation, there was no reason – we were just dropped. So now we have no insurance and we don't even know why. As a result, we had to rush to find another company. Only to get a letter maybe three months later saying we miss you! So, I had to get that out because it really left a sour taste in my mouth. Of course, the health insurance we're with now is good and we love it. But there's just that loss of trust. Being a senior, you know – it comes out of our account every month, so they were getting the money – it wasn't that. And I went through everything – is it because I'm Black? Because I'm a retired senior citizen?

- One time we ended up at the children's hospital at Buenos Aires. They asked us if we had insurance and we said no, and they just moved us to a different room for insurance…it was very different. Once you're insured in other countries you have good care and access then you're good to go.
- Holistic healing… I went to the clinic and I had to go online and make a bunch of calls to find out who was an acupuncturist… when you're already in pain it should be easy to find… other forms of medicine weren't updated on the website. How to find a provider and it wasn't updated.

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- When I first started doing system work around racial justice in the hospitals – I would tell people that I was experiencing secondary racism, seeing it over and over at the workplace – and so I had to find a resource to manage, so I found – her name is Marie Michaels and she does racial justice healing work, but she's not considered a provider – even though she's a provider to me. She helps me keep from shutting down when I witness racism in the workplace. I'm Anishinaabe and I live in the city, but I had never been around so much racism in my life until I started working at the hospital. I learned from her that you could use your awareness to pinpoint the stress and anxiety in your body and get through it with breathing and breath work. But she doesn't get paid what she's worth.
- The biggest challenge I see is that the therapies that help us (BIPOC community members) to heal aren't necessarily just found in people who studied psychiatry. If I had my way, I would train the aunties and grandmas in our community to do the healing work of body workers – breathing and getting into your body – and I would pay them to do it. It's the work they are already doing. Honestly, if you think about it, it doesn't make any sense to pay colonizers to teach us how to heal from colonization. I'm actually getting the cultural care that I need, but she can't get paid like these other providers – I have to pay her like I'd pay someone for doing my nails.
- It's just in recent years that insurers would even cover acupuncture – despite it being a centuries old practice – or chiropractors. Those kinds of services were considered – you had to have Jesus Christ and all his disciples to certify that it was needed.
- Yeah, I think that's been just in the last ten years.
- I guess I want to know why is diversity and inclusion always thought of as a separate thing, a separate unit [in the corporate structure]? Why is it that it's always put on one person's shoulders to bear that for an entire company or institution? One of the things that I've been thinking about is – if Blue Cross really wants to make some structure changes, they should integrate that department and have more people who can carry the burden – or carry the organization in such a way that the burden is not just on one person. If equity and diversity are so important, they shouldn't be relegated to the periphery, it should be something that is integrated where you have a whole thriving group of people doing that work. Most diversity and inclusion programs are just programs – there's no stair step to the director of the organization or department, sometimes it's not even a whole department. It's not even part of the pathway

to get to the CEO. If it's so important, I would think they'd want to make it an integral part of the organization and a pathway toward becoming the head of the organization as they move through their career.

- For me, in our diversity and inclusion efforts at the hospital I feel similarly. I wish it were integrated throughout the organization, because then everyone has to be engaged and accountable. People can just pass off responsibility on to some designated person. I work in the health equity department and was recently put up for a promotion, but because my background and experience is in Native peoples' issues and advocacy for indigenous communities, they said I needed experience with other people. And I just said – well hey, I have white grandparents and a Norwegian last name (laughs) – my people have been dealing with this forever, like – I've got a PhD in whiteness. If I had my way, every department would be led by people committed to equity, like-minded leadership across the whole institution. Because that's what it will take to make a change.
- I think a more integrated approach would make equity across a whole institution not dependent upon being lucky enough to have good leadership. Then, you don't have to worry that you will lose your progress when one great leader leaves – you're not dependent on the work of individuals who might leave.

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- This resonated with me for sure. I've been disappointed at times when I'm seeking holistic care. I'll get referrals and recommendations from people in my community about specialists who can heal in culturally appropriate ways and they're often just not covered in insurance. We're seeing more chiropractors covered, but other homeopathic providers and holistic professionals in my community are still not covered. I've also encountered a lot of predominantly white providers, so I'm looking forward to seeing a shift toward more Black and Indigenous and Latinx – and other practitioners of color.
- In the metro area there's a group – we call ourselves the Pan-Asian Voices for Equity – and we've been raising money and doing different virtual healing sessions for community members – yoga, diet and nutrition, singing bowls and centering yourself. We're not a nonprofit or anything, we're just a group of radicals. But we used to do this in person – we'd have sessions incorporating comedy and humor, centered on our Asian cultural heritage, and it was just such a healing space. I don't have that anywhere else. So that's a resource, but we self-raise the money. We try to get enough to give practitioners $250 for each session, because so many of them aren't covered by insurance, or even if they were, couldn't charge for what they do with us.
- I wonder what opportunities exist for someone of color who is highly qualified – has many degrees that are relevant and from a good university?
- That is an excellent question – so often we talk about recruiting as if there is a lack of qualified talent of color, but that's just not the case. In the metro area we have so many talented people with great qualifications. The talent is there.
- I work at BCBSMN, I've been there for five years and the only reason I got my position is because a Black woman at the organization advocated for me in the interest of taking diversity seriously. We have so much talent in the metro area – but even once you get here, there's a glass ceiling for people of color when it comes to advancing in the organization.
- At the Twin Cities Urban League Unity Ball, I'm receiving the relentless unapologetic advocate award. I'm going to continue to fight for people like me – we're educating our children, we're sending them to HBCUs, and they need and deserve opportunities for employment after their training. So, I'm going to really get out and deal with corporate America. It's time for us to stop pretending and really hit the ground running. So, I'm going to email the CEO and see if he'll have a conversation with me. I have a list of people I can send over who are highly qualified, and if we are going to commit to equity, then we need to act on it. We've talked and talked for almost

fifty years – it's time for us to take action. I am excited about this roundtable. We've been moving backward, and we need to address this. I have friends and others who will be on board with these efforts.

- I want to mention that NAMI also has some resources for multicultural mental health. They are a great resource – I've utilized it myself many times, and I know that because there aren't many resources for BIPOC, and their website is really helpful.
- Yeah, I've been to NAMI – I used to volunteer with them, and they have a very welcoming environment where you can go in and get some questions answered, they also have other resources and programs available.
- I work at an American Indian organization that serves the Indigenous communities here, so I'm here to listen and learn more about resources to hopefully be able to help the people that we work with, our clients.

Question 5: Do you have a trusted source of information about seeking, receiving and/or paying for healthcare? If so, what are those sources? Do you feel that you have the information you need to take care of your healthcare needs? Why or why not? Are there resources for health and wellbeing in the community that everyone should know about? Please share.

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- I'm an immigrant and I've been in the state for eight years and have worked in the healthcare industry for a long time, but when I moved here, I didn't know that urgent care existed – until my own daughter, who has asthma needed it. So, here was I, working in a hospital system, and yet – the assumption that you know – that you have access to the information that you need [is often misguided]. Can you imagine what would have happened if I'd just taken my daughter to the urgent care nearest my home – when actually she needed specialized care? We assume that because it exists, people should know about it. I think about back in 2006, how people assumed that I knew things I didn't about available resources because I worked in a hospital system.

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- Where do you go for trusted information? Is it your family? Online? Doctor?
- I had to call around my doctors, but this lady I call every time, and she pointed me on the way to getting help. But I had to call around to get help? One of my doctors referred her, she's connected to Fairview and she's an associate in woman's health. I heard it from word of mouth.
- Southside community clinic in Minneapolis. The one in St. Paul was Family Tree and they do a lot of LGBT and for trans people and they specifically advertise for it. At Pillsbury House they would get students together and you could come in to get chiropractic, massage, or speak to healthcare providers, acupuncture and I did it a lot for a few years. During Covid, I doubt they're doing it. They take insurance and the other place at Pillsbury House was free and you could get care for no cost.
- I use google. I try to call any available nurse line and I know there are people that help with co-pays like Salvation Army.

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- Actually, I just got a new insurance card and I have no idea how to find a dentist who is in my network. They didn't really send any information with it, so I'm not sure where to begin.
- In most of our systems – whether you use google maps for driving or grub hub for ordering food – you can make things more visual, make it clearer how to navigate. I work for Blue Cross and Blue Shield, and when I speak with families, they often talk about how hard it is to find the

info that they need [to find a dentist or other provider], and when I explain to them, they say, well – how would I know that?

- I think it's important to note that health insurance itself is not healthcare – there are other steps in there, and people who have means can figure out how it works, whereas the rest of us might take months to figure out the system – and then the first question is can I afford it. But that's not the elephant in the room – it's the whale in the room.
- Yeah, there's a lot that's really confusing. I called a clinic, and they wouldn't tell me if they were even taking new patients until they found out what kind of insurance I had.
- I think healthcare companies are focused on sick care, and communities are focused on wellness. Thinking about the birth outcome disparities here in Minnesota for Black and Indigenous women, we know because of Dr. Hardemann at the University of Minnesota that the support and relationship that doulas provide to birthing mothers is really important and effective – but they're not covered under health insurance plans. We need them to be covered – then it comes down to who can afford a doula. There are also disparities around close-door negotiations about medicate – Edina gets more money for state insurance than HCMC does, for example – and because it's closed-door, you don't know why, and you can't *do* anything about it. I think there's a lot we could do with analysis and assessment.

1 December 2020

- I am a BCBSMN employee, but I worked in childcare for many years, and didn't have health or dental benefits, a 401K, until I was in my forties. But I had no idea how to use any of those programs – or where to find any information on that. Even now, I have all these benefits and I don't always know how things work. So, I went to see [redacted] at the retail store – not even because of where I work, but because I am the walking partner of a woman in her 60s who told me when I had questions that I ought to get down to the BCBS retail store. And [redacted] at the retail store in Roseville is just so good – really the best. At the retail stores they offer cooking and nutrition classes, yoga – but they also have a place where you can go to get any of your questions answered about insurance, your benefits, finding a provider. It's such a great resource. Everyone talks about how great [redacted] is – and he's bilingual!
- One thing I don't understand, is why would they put the retail centers in Roseville, Edina and St. Paul? Why wouldn't you put one where most of the people are?
- Yeah, why don't we have a retail center in Minneapolis? We should mention that when we report out.
- SEWA-AIF is a great resource for South Asian elders.
- Liberty Church in North Minneapolis is supporting healing for African American youth including healing foods and healing from trauma with African American mental health providers.
- One thing I'd like to raise is the question of trust with community members in the context of healthcare. When I think about the dentist I go to, it's the person my dad went to for years. His dentist does good work and because of that trust that is established, I have a reliable provider I know I can go to. What is BCBSMN doing to build trust with community members?

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- I often find that I don't have a trusted source of information. I am employed, educated and have insurance. However, whenever I have a question about the cost of a simple procedure, I can't find anyone to give me a straight answer, including the doctors and my insurance provider. They're all useless at giving me price range or accurate information. It's disappointing because they're supposed to be professional. Transparency on procedures and billing when talking with medical professionals is a real issue.

What else should we know? *Is there anything that we didn't ask that we should have? What isn't here that you would like to see? Are there any questions you have for Blue Cross and Blue Shield of Minnesota? Please share your question(s), and any answers that your group discusses.*

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- How is Blue Cross Blue Shield using this engagement – and how are they harvesting it? [Rosemond responds]

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- Being able to pick a doctor based on your demographic is something that never occurred to me. My wife just finished a PA program, and they don't train in cultural stuff.

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- I had an experience recently that makes me think that things are changing… over the last 6 months I've been doing a lot of consulting and work around the state… the counties are acknowledging the social determents of health… and it's the first time that I've seen the healthcare systems acknowledge the role of social determinants. I'm seeing it in policy, and they are acknowledging and trying to understand and realize that access to food and transportation need to be addressed, understood and assessed. State has rolled out more access to testing for Covid… they aren't asking for any payment or identification to have access to that testing… My heart goes out to the experiences you all are sharing…
- Where are the providers that deal with transgender issues or something specific that I may be dealing with … can we have an easier way to see who the providers are?
- Themes of the night:
  - ACCESS
  - Providers of color are important
  - Shame, whether weight or illnesses
- Chat Resources shared:
  - A great functional medicine doctor who is Black and recently moved from the Twin Cities to Georgia. She does holistic, whole person healing, including mental health. She also specializes in Black women's emotional health. Here is her website and info: https://www.imarahealthandwellness.com/
  - My mother couldn't care for me and so I went from household to household and was taken from my culture of origin. So I created MN Care Partner where we provide parent mentoring… it's holistic and culturally responsive. Includes doulas, parents mentoring, trauma-informed yoga and it's free and it we don't have to pathologize.
- There is a gap between the internal Blue Cross and Blue Shield of Minnesota team. How can they across the organization share information?
- When signing up for telehealth they don't ask you if you have a device… and they don't make sure you get one…

……

- It's important we ask how people FEEL when they go to their health care provider? This is an important question. We need to change HOW we treat everyone.
- How to create self-healing communities?
- Healthcare feels very transactional and cold. It doesn't feel friendly.
- Healing from Trauma; cultural appropriate integrated health and healing; African drumming; healers in the room, etc. "I actually felt like I belonged tonight; I feel healthier." Science says this really does improve health.

- Having a community who recognizes what you need to heal is so important.
- "How soon can I get in the water after this is done?" Wait, what is your name again? I became a person. You need 28 interlineated stiches. But when I was a Black woman, I was going to be given 5 stiches.
- Assuming we're 'drug seeking'.
- I get nervous going to the doctor. If they think I'm looking for drugs.
- "This is great news. You didn't waste our time. You did what you should do." It was my first time I wasn't treated like a criminal. He celebrated that I came to get help but it wasn't too serious.
- I had to have my white co-worker to make sure I was treated better. That's our life.
- I've been very lucky. Great family practice doctor. We're close in age and she never makes an assumption. Everyone I worked with was wonderful. I'm very fortunate.
- I concur with all the treatment of health care being non-white. We live in an oppressive medical community from dirty looks to assault. We receive service from a community that we've inherited that is oppressive. I was born in the East Coast, raised in PR. I've experience oppression and violence.
- I thought there's a DO NO HARM oath in the medical community!???
- Go back where I came from. I don't want to have to explain to anyone where I came from and I don't want my kids to do that either.
- Barriers are experienced in all 6 questions. American Descendant from Slavery, especially during COVID. We're not getting health care.
- Everyone I know gets the 'where are you from?" question.
- BC/BS could make it easier to get a hold of someone on the phone; the phone tree is so frustrating. 4 or 5 pages.
- **OUR CONVERSATION POINTS**
  - RACE INEQUALITY/OPPRESSION/VIOLENE – BEING MARGINALIZED "WHERE ARE YOU FROM?"
  - HAVING A RELATIONAL EXPERIENCE WITH YOUR PROVIDER
  - HAVING BETTER SERVICE FOR ELDERS AND IMMIGRANTS
  - SHOW YOUR PAPERS ISN'T ACCEPTABLE!

19 November 2020

- Notes **R———** I feel that we don't have Cultural Appropriate care for Indigenous ppl, in a Health care setting but out of a Building..
  #3~ its kinda hard as a Native person to seek or even understand Mental health.
  From **R———** to Me: (Privately) (7:08 PM)

  #2~ Yes.. cuz we did not have a Computer in the Beginning..
  #5~ No! I pay for Health Care but still do not understand the Coverage stuff (?) Stuff.. teehee.. but I would like a personal liaison to help me understand it.

- From **R———** to Me: (Privately) (7:14 PM)

  #6~Resources.: How can we get help understanding coverage.

  Thoughts on the vaccine – **C———** Won't take any vaccine that hasn't had multiple studies but will rather take the vaccine instead of the virus. I believe that the entire healthcare model and delivery system is going to change. Everyone needs to receive care differently and from someone they trust. **S———** will people have a choice of which vaccine we will get?

1 December 2020

- Idea of "sick care" should be looked at more broadly. Idea of wellness score captures his attention.
- Watching videos made her 'sick' to see that although it talks about equality, some of the reforms leave out disabled people.
- Struck by trade off when videos present solutions. There are positives but at the expense of a lot of negative aspects.
- Videos struck him the most when discussing potential of migration toward Minnesota.
- Appreciated the videos, struggles with imagining the future. made her think about the future more than she has in a while.
- 2020 pandemic has created an opportune time for restructuring healthcare and thought videos were helpful to bring out that conversation. also agrees scenario of migration toward states that are known to be xenophobic are a cause of concern. highlighted that the xenophobes are also people who have historically not valued true native peoples.
- Thinking about the positive side of things is the biggest hurdle given the strong sense of greed and self-interest that is inherent to the USA. Historically ingrained values that make it hard to get ideas that are transformational going forward.
- **Scribe Note:** The conversation then shifted to "one things you want to change or see in 2021"
- Wounds are cut open and put on display, wants to see real commitment - affirmative action- to offset imbalance of those historically cast aside.
- Health care should be separate from employment status - easy solution to help many people.
- Housing issue, wants to see more of it to decrease homelessness.
- Less division within political parties, within household. A covid vaccine - move on with our lives - no more loneliness, back to normal.
- So many inequities unrelated to health care exposed in the healthcare system. Public policy needed to create fundamental change, food security, involve multiple parties within society.
- Support the work of culture healers.
- Mental health stands out. Exposed issues in the time of covid. Financial perspective - costly to insurance. Better to treat holistically.
- Caregiver benefits to help navigate complex health condition is crucial to quality of life.
- Customer experience needs to be held accountable by insurance companies to ensure inclusive and culturally competent culture.
- People need to learn more about how to navigate insurance, what's covered, what's not? Not only when confronted with issue, but ahead of time.
- Young people uncertain of healthcare coverage after they are booted from parents insurance.
- A need for diversity and inclusivity in healthcare.

……

- I'm just grateful that BCBS is making an effort to listen. I'm glad they're improving. My husband who was undocumented for a long time had challenges with coverage. However, that has changed. His experience just speaks to access to care. You just have limited access to care when you're undocumented.

……

- Question: **Shopping is easy for every other aspect of life. Why is healthcare so different?**

    - "If I'm looking for a new doctor or healthcare provider, I also have to be thinking about how culturally educated they are. They gotta know their medical stuff but I want them to know how to culturally interact with me too."
    - "I want to see more community care. It's one thing to be educated but I want my caregivers to also stay proactive and sustain our community."

- Question: **Where do you go with these questions? Who do you turn to for help?**
    - "I would go to the Somali community, the elders who probably know more about it than I do. I dunno any agencies or anybody. I didn't know that was a thing."
    - "I would go to my family doctor. I don't have anyone else I could go to."
    - "Navigators or Care Coordinators. People whose job it is to know these kinds of things."
    - "I work at a clinic, so I have a good idea of what to do and where to go. If I didn't have that knowledge, I don't think I would know where to start."
    - "My sisters."
      "I had to learn it all by myself through lived experiences. I've had a lot of health problems and I had to figure it out all on my own."
    - "Luckily my mom was a care coordinator for several years. Otherwise, I don't think I would know anyone to even start asking about what I don't know."

- Question: **Do doctors know about all these services or do I have to find another caregiver to ask them?**
    - There was a brief discussion about how little communication there is between doctors and other services (such as social workers and other caregiving fields). If a person needs assistance from multiple areas of care, that's one person for each need which can quickly accumulate.

[Second set of notes submitted by another scribe in the same group below:]

- Continue to sustain productive participants in our community; ripple effect helps others; why is it so hard with the doctors to help us who isn't able to pay? Like dentures/implants – why doesn't insurance cover that? These are real valid questions.
- Mental health first thing comes to mind; BC/BS will you take state insurance? What are you doing for our community that serves mental health?
- Looking for help; navigation; we don't have a problem shopping in any other sector; but in health care, we don't know how to find what we need; **C——** had 3 times being caregiver for 2 sick parents/brother; when things got rough, I didn't know where to go for help; doctors weren't talking to other doctors' I didn't know who to ask for help or support
- Doctors know about ARMHS workers? No, they don't know; social workers or mental health or psychiatric nurse practitioner would know; any kind of a mental health social worker would be who to contact; that's a huge barrier!!
- Do doctors team with social workers??

- Question: **Where do you go for help??? Regarding healthcare; who would you trust most to get the most for health care?**
    - Go to friends; or Somali community; elders
    - Doctor for check-ups; don't really have anybody; home this semester
    - Navigators; coordinators; internet groups
    - Doctor really likes; work at a clinic
    - Two older sisters

  - **D——;** relationship building and networking; myself through lived experience; advice reach out to others with lived experience; older women in our community
  - Care Coordinators; talking with friends; Senior Linkage Line; Disability Linkage Line
  - Accessing an ARMHS worker
  - Accessing clearinghouses

- THEMES:
  - Health care professionals didn't think they know their bodies
  - Had to educate providers
  - Financial barriers
  - BALANCE
  - INTERDISCIPLINARY TEAMING WITH DOCTORS/NURSES/SOCIAL WORKERS/MENTAL HEALTH PRACTITIONERS

Blue Cross and Blue Shield of Minnesota
Engage! Twin Cities
The Fall Listening Sessions
17 November 2020, 19 November 2020, 1 December 2020

Circle Share-in Responses

The following notes were transcribed by members of the MTI research team during the virtual events of November 17th and 19th and December 1st. Organized by the date of the relevant virtual event, all comments included here were offered by participants in response to the same one sentence prompt (reproduced below). While it was not possible to capture all responses due to occasional challenges with audio during the video calls, three copies of the transcribed responses taken by different staff members have been compared against one another in order to provide the most complete transcription possible. Where relevant, comments contributed via the chat mechanism of the videoconferencing platform have been incorporated to allow for the inclusion of those who were not able to verbally share their answers.

One Sentence (Prompt): What is one hope you hold for the health and wellbeing of this community we've created tonight?

17 November 2020

- I hope for healing for everybody
- New information, new community!
- Healing
- Dignified healthcare
- Peace
- The ability to be
- More joy
- Access
- Equality
- Safety
- Wholeness
- Connection
- Learning
- Truth
- Community
- Unity
- Recognition and healing from trauma
- Growth
- Leisure
- New voices at the table
- Safety during Covid – mask up!
- Community, growth, healing and peace
- Open minds and open hearts

- Peace
- More love and more respect (in Spanish)
- A new friend
- More wiggles
- I hope that everyone gets a little bit of what they said they need to health and healing at the beginning of this call.
- Abundance
- Rest
- Joy, peace and hope
- Grounding
- A collective voice – paz (peace)
- Unconditional support and regard
- Money, love and peace (in Spanish)
- Amigos para siempre (friends forever)

19 November 2020

- I want everyone to be safe and healthy – just a little bit longer, and this too shall pass
- I would like to urge everyone here and at home with their families to take this seriously, to wear a mask – please take care of yourselves
- Please wear your masks for us to get back to our lives
- Health
- Serenity
- Joy
- I hope for more compassionate and ethical care for those healing through substance misuse

1 December 2020

- Peace
- Grace
- Equality
- Rest and renewal
- Grit
- Waa maxay hal rajo oo aad ka qabtid mustaqbalka qof walba oo caawa halkan jooga?
- Healthy skin and hair and bodies
- Linda noche ([a] beautiful night)
- Amor
- Music
- Amor
- Paz, amor, igualdad y mucha sanidad (peace, love, equality, and good health)
- Peace
- Rest
- Serenity
- Light
- Good health