

The Tubman Center for Health & Freedom

WELL US STUDY

Wellness Equity by Lifting-up Local Under-reported Solutions



THE TUBMAN CENTER
FOR HEALTH AND FREEDOM

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TABLE OF CONTENTS

Executive Summary of <i>WELL US</i>	4
Introduction	6
About this Study	8
Part I: Community	9
Part II: The Survey	18
Part III: The Findings	21
Part IV: Recommendations	28
References	30



EXECUTIVE SUMMARY OF WELL US

Despite robust public health infrastructure and liberal ideals, **marginalized communities across the Puget Sound region face significant barriers when attempting to access mainstream medicine.** Both the qualitative and quantitative segments of this mixed-methods study point to clear obstacles to accessing quality healthcare. Top 5 commonly reported responses were: 1.) finances/costs, 2.) racism/harassment, 3.) fear of discrimination, 4.) inability to find a provider and 5.) language barriers.

Members of marginalized communities do have preferred methods of care and healthcare modalities that are utilized. Many people from these communities come from cultural backgrounds that prioritize communal care networks where relationships are the center/root. **This underscores the importance of having providers that come from the communities being served.** Oftentimes, members of these communities have previously had

poor experiences within mainstream medical systems. Prior research has also indicated that people who have experienced discrimination in mainstream healthcare systems often prefer the high level of autonomous medical decision-making that is often associated with what is considered “Complimentary or Alternative Medicine (CAM).” While the causal pathway was not within the scope of this study, the correlation of these factors should not be overlooked. The stereotype that CAM therapies are exclusively used by wealthy White women seeking “self-care” was found to be untrue. **Astonishingly, 100% of survey respondents who carry one or more marginalized identities indicated using at least one modalities or care model that mainstream medical models and insurers refer to as “CAM”** such as massage, acupuncture, herbal medicine, or traditional/indigenous medicine.

Insurer’s coverage for modalities and methods of care preferred by members of marginalized

communities is grossly inadequate. By refusing to cover costs associated with the types of healthcare that our communities consume, both private payor and managed care plans shift healthcare costs to the patients and created barriers to accessing the types of medical care utilized by members of marginalized communities. The most frequently stated barrier to care reported in this study was healthcare costs. **The lack of coverage for these preferred modalities and methods is a blatant example of systemic racism/oppression** and may be further perpetuating health disparities.

Concrete interventions to address this inequity will change insurance and managed care plans' practices to ensure access to the type of healthcare services that members of marginalized communities most rely upon. This includes:

1. All insurance plans, including managed care plans offered through the state, should be required to follow Washington State's Every Category of Provider Law.
2. Provider networks should be expanded to increase the number of available in-network providers to improve patient access and choice.
3. Providers who care for marginalized communities, often those with the most complex medical cases, should be incentivized by receiving premium reimbursement for their services. Thereby improving patient access and choice.
4. Health insurance benefits should cover the cost of vitamins and medicinal herbs.
5. Indigenous and ancestral medicine should be covered by insurance payors.



INTRODUCTION





This report is the culmination of **WELL US**, a one-year community directed exploratory sequential mixed methods research study. The study was conducted by the Tubman Center for Health & Freedom (TCHF) in partnership with Byrd Barr Place and several community-based organizations. These partners were interested in examining the ways in which the communities that are most often marginalized by the mainstream medical system tend to and care for the health and wellness of themselves and their family members.

Public health literature has no shortage of data illustrating the barriers that Black, Indigenous and other people of color face when attempting to access healthcare. While there is less data for Disabled, Immigrant and LGBTQIA+ communities, the existing data conclusively indicates that these communities also face structural and discriminatory barriers when attempting to access healthcare.

The academically trained researchers leading this study (Jefferson-Abye, D.; Nuguse, R.; Tamngin, R.; Brooks, P.) are deeply entrenched in their community networks and carry many of the identifiers of the surveyed populations. The community research team's corresponding representation allowed for an added layer of scientific accountability and reliability necessary when conducting health justice research. Because of this representation among researchers and the study populations, our research was conducted in a way that honored community, culture, our strengths, and resilience. In the **WELL US** study, we were not interested in continuing the deficit narrative frequently assigned to our communities in public health. Alternatively, we wanted to learn the ways in which people who have been marginalized from mainstream medicine tend to and care for themselves, the types of healthcare that they prefer as well as some of the motivations behind their preferences for care.

TCHF is building a medical model that centers the needs and desires of marginalized community members. This model stands in contrast to reform efforts have largely been focused on finding ways to force-fit marginalized peoples into existing models that have largely been shown to be ineffective for our care. Our research will inform the design of TCHF

and will hopefully be of beneficial use to our partner organizations. We held four objectives for this report:

1. Inform the design of TCHF.
2. Provide useful data to Community Partners in their work to improve the health of marginalized community members.
3. Inspire further research into how to redesign healthcare and insurance payment models to truly meet the needs and desires of the people.
4. The community-centered research methodologies used in this study will inspire future public health research to center community and health justice in research methodologies and practices. Recognizing that researchers come from the communities that are being analyzed is a best practice. Community participatory research is not synonymous with community directed or community-based research.

Communities, their organizations, and their leadership will have access to de-identified data from the Community Partners' input and from the community survey findings. TCHF, the lead and coordinating community organization, plans to use these data to help in the design of TCHF Medical Center (anticipated to open in 2025). TCHF is also interested in using findings to identify health policy opportunities, contribute to the research literature on health and marginalized communities, and make targeted recommendations for healthcare improvements.

Funding for this study came from a TCHF contract with Byrd Barr Place, based on grants received by Kaiser Permanente and Premera. In addition to the communities' involvement, several academic volunteers and the lead researcher's faculty advisor at the University of Washington (UW) gave input to the study's design. The UW Institutional Review Board (IRB) reviewed the study's methodology and determined that this study was exempt from UW's IRB review. Community Partners have read, critiqued, and approved this report. De-identified data are retained by TCHF and communities have access to these de-identified data. A special thanks to Dr. Pauline Brooks, Dr. Patricia Karimi, and Dr. Barbara Baquero for their contributions and support.



ABOUT THIS STUDY

This exploratory sequential study used community-based qualitative research methods to inform and direct the quantitative research portion of this mixed methods study. Section I covers the activities and findings from the qualitative portion of the *WELL US* study. *WELL US* was the first community survey conducted by communities that have been pushed to the margins (e.g., Black, Brown, LGBTQIA+, Immigrant, and Disabled) in the Puget Sound area of Washington State in partnership with the Tubman Center for Health & Freedom (TCHF). These communities have long voiced concern about the unacceptable levels of disparity in all areas of health treatment, outcomes, and prevention. Community activists and leaders (referred to here as Community Partners) from these underserved and marginalized Puget Sound communities came together to discuss, design, revise, and implement a survey about current health conditions in their communities.



PART I: COMMUNITY

There are four parts to the complete **WELL US** report: PART I covers the role of community in the study, including the issues that Community Partners and other community members identified and described as health concerns among marginalized communities in the Puget Sound area. Some of these issues appear as questions on the **WELL US** community survey. PART II covers the methodology used for the quantitative research survey. PART III presents data from the survey, with brief analyses, and connects select issues and findings raised by the Community Partners and the survey to existing research literature. PART IV provides a set of opportunities and recommendations for applying the research findings. The Executive Summary of **WELL US** covers PARTS I–IV.

METHODOLOGY:

COMMUNITY PARTNERS

TCHF reached out by email and/or phone to 38 individuals associated with 31 different community-based organizations in the Puget Sound area. These are organizations and individuals from Black, Indigenous, POC, Disabled, LGBTQIA+, and Immigrant groups/populations that have experience of and knowledge about inequitable health treatment and outcomes in their respective communities.

Including TCHF, 12 community organizations participated in this study. In total, 17 individuals attended one or more of the community meetings/discussions. (Some organizations had multiple members in attendance, and two individuals reportedly were not affiliated with any organization at the time of their participation.) The participating community-based organizations were:

1. API Chaya
2. Alphabet Alliance of Color
3. Onion Carillo De Norman (Individual—community activist)*
4. Chief Seattle Club
5. Open Arms
6. Nile's Edge
7. Somali Health Board
8. Byrd Barr Place
9. Pacific Islander Health Board
10. Equity Alliance of WA
11. Decolonizing Naturopathic Medicine Collective, Bastyr University
12. Patricia Karimi-Taleghani, ABD (Individual—African American historian)*
13. Pauline E Brooks Consulting, LLC (Evaluation)
14. Tubman Center for Health and Freedom (TCHF)

* Independent individuals reportedly not officially affiliated with an organization at the time of this study

TIME FRAME

The first formal Community Partners meeting was held in February 2021 on Zoom. The second formal meeting of the Community Partners occurred two months later, in April 2021. Discussion content from both meetings were used to identify and shape items for the community survey. In May 2021, after several versions, TCHF emailed a draft survey to the Community Partners, soliciting further revisions, including input on how to shorten the survey. At that time, there were also efforts to identify which organizations would help get information about the survey out to communities, which included ensuring organizations could assist community members with accessing the survey.

COMMUNITY DIRECTED APPROACH

TCHF was a relatively new non-profit. However, its founding members were well known and had been active, some for decades, in the communities that were the foci of the **WELL US** study. Many community leaders and activists were already engaged in discussions about health disparities in their communities. The **WELL US** study recognized and acknowledged this, and further built upon this prior work by Black, Indigenous, People of Color, Disabled, LGBTQIA+, and Immigrant community leadership. These are the people who know the conditions within their respective communities and know many of the areas of health that need to be researched. Throughout the process, the effort was made for Community Partners to have ownership in the **WELL US** study.

TCHF (a non-profit community-based organization) took the lead in identifying several broad initial health topics, namely: discrimination and other barriers to accessing quality healthcare, health insurance, and exploring what marginalized people do outside of formal mainstream healthcare to heal and stay healthy. TCHF secured the funding for the study, convened the meetings, and made and retained records of community discussions. Because of the COVID-19 pandemic, the bulk of interactions among the different Community Partners and TCHF for this project were electronic, not in-person.

The rough timeline of events, the proposed initial health topics, and the formal scheduled community meetings served as a skeleton structure for community methods. Within that structure, however, there was also back-and-forth, cyclical, tangential, and additional community inputs, suggestions, and offers of help. This took the form of myriad phone, text, Zoom, in-person, email and other communications among TCHF, Community Partners, and a wider set of other concerned community individuals.

Throughout the period of this study (February–August, 2021), these community organizations and individuals did a lot of volunteer work. They were generous in giving their time, thought, and resources. They provided rich qualitative content in their discussions and gave insightful thought to shaping and administering the survey.

Behind the scenes, other community members and organizations stepped forward to help get information about the survey out into marginalized Puget Sound communities. Throughout their participation, Community Partners did not request portions of the money that had been set aside to assist their participation. TCHF had not made the common mainstream assumption that community organizations should be volunteering their time, energy, and resources, even while others on the research project are being paid. TCHF had budgeted funds in advance to help support Community Partners' work. This was announced at the Community Partners' meetings; partners, however, continued to volunteer their participation and resources.¹

Through these Community Partners and other community participants, Puget Sound's marginalized communities had voice: They had a voice in influencing and determining issues to be explored. They influenced how questions would be best asked: For instance, the question, "What gender do you identify with?" offered six options, instead of the usual question, "Gender," with two

"I would say that I have more anxiety about doctors commenting on my weight more than anything. That has only happened once, but that stuff sticks"

—SURVEY RESPONDENT

¹ From an evaluation perspective, this can be interpreted as an indication of their concern, commitment, and ownership of this work.



options. In addition to English, the survey was translated into Chinese, Vietnamese, Amharic, Spanish, and Somali. The consensus among Community Partners was that because communication and language are such key factors in accessing health and health information, offering multiple languages would expand potential participation and help reach more deeply and broadly into these underserved, marginalized communities.

Community Partners played active roles in facilitating community awareness of the survey. They also provided information about known and trusted websites through which communities could access information and complete the survey. Voice also meant being in a knowledgeable position to recommend this study to marginalized Puget Sound communities as something safe. Community Partners could confidently say that communities' participation in this study would be used to help, not harm, their communities—there is a long history of research on marginalized communities being used to the detriment, not benefit, of these communities.

Collectively, the work of the Community Partners—their activities and methods, both formal and informal—generated important information (qualitative data) about health concerns within Puget Sound's marginalized communities. All of this and more formed the “community methodology,” with TCHF serving in

the roles of coordinator, convener, documenter, and implementer of the study.

COMMUNITY PARTNER DISCUSSIONS: BARRIERS AND CHALLENGES TO ACCESSING QUALITY HEALTHCARE

People want to go where they feel safe and comfortable. They want to be heard, valued, appropriately cared for, and feel that they can trust their care providers to promote their wellness. For marginalized individuals and communities, many things often get in the way of these kinds of positive, desirable experiences.

The following lists summarize some of the points raised in Community Partner discussions. Items on the lists are in no particular order; items are not prioritized. Though presented only briefly here, Community Partner discussions point to areas in mainstream healthcare where people from different marginalized communities often feel that their family's and/or their community's health is minimized, de-valued, not considered, not cared about and/or not well served. The following lists (Lists 1–5) give concrete examples of why communities may feel this way.

LIST

1

Discrimination in Mainstream Healthcare as Experienced by Marginalized Communities in Puget Sound

- When people of African ancestry and other people of color speak up, it is often taken as aggression—things often do not go well after that
- Negative experiences: e.g., providers do not explain or thoroughly investigate our health concerns; not being heard, believed, or respected in medical settings; sent home repeatedly without proper medical attention; having to get second opinions; being marginalized by all aspects of the health system; having to navigate multiple systems to get access to care; providers attributing diseases to racial/ethnic factors instead of the actual causes, which are so often systemic racism, lack of access, and other sociopolitical causes
- All forms of racism: lack of representation/diversity in healthcare facilities; our family sees a different white provider each time—parents and children need a trusted home to talk about their family's health; we need providers that match race and ethnicity as clients, not only in looks but by dialect and

- language—these and other cultural barriers are a big deal, especially when dealing with medical language
- There is a need for anxiety-free safe places/spaces for undocumented people to receive quality physical and mental healthcare and health insurance
 - Ageism, especially with people of color being told that they are experiencing a certain ailment because of age; accessing care through computers may exclude many elders
 - Ignorance and hostility towards non-Eurocentric care that BIPOC and/or other marginalized groups may use; marginalization, diminishment, and/or fear of BIPOC cultural health concepts and practices; inaccurate/ill-informed assumptions about BIPOC cultural care; tribal knowledge and cultural approaches move native people to tribal and reservation providers
 - Treating women of color poorly and not listening or taking their healthcare issues seriously; obstetrical violence (e.g., maternal and infant mortality and morbidity)
 - Classism and political status influence quantity and quality of care
 - Size-ism/weightism: e.g., assuming that all of one's health issues are caused by or related to being "overweight"
 - Islamophobia and the dismissal of religious and cultural practices. There's a general lack of understanding and prevalence of assumptions associated with Islam—especially for Muslim women in hijab
 - Lack of providers of color and/or people with necessary language, cultural, disability backgrounds and experiences to effectively work with mental health issues
 - Not everyone has health insurance. And, even when they do, marginalized people often face additional challenges to accessing quality and timely healthcare

LIST 2

Barriers for Disabled Persons Accessing Healthcare in Puget Sound

- Lack of physical infrastructure to allow people with different abilities to enter health facilities
- Problems with wheelchair accessibility for practitioners working out of smaller, more affordable locations
- Defining people entirely by their disability
- Assuming that someone with a physical disability must also have mental/intellectual or other impairments
- Sometimes you must "prove" your disability to the state before qualifying for resources
- Many times, folks with disabilities are denied—making access to proper care unaffordable
- Occupational injuries may leave someone without work, but that person may not be able to prove disability
- Work requirements for some benefits, including healthcare, may exclude Disabled people
- Mental health problems aren't seriously considered a disability, so people aren't supported in finding providers to help
- Ableism: defining people entirely by their disability; assumption that someone with physical disabilities also has mental/intellectual impairments



LIST 3

Barriers for LGBTQIA+ Persons Accessing Healthcare in Puget Sound

- Finding good providers who practice Transgender medicine
- Provider ignorance of, open hostility, fear, and/or a complete lack of education about LGBTQ+ communities, people perceived to be other than heterosexual or binary male/female, and especially Transgender people; mis-gendering in a million settings (especially sexual/reproductive healthcare, but also mental health, etc.); assumptions about promiscuity, and that anyone who is other than heterosexual is defined entirely by their gender identity or sexual orientation
- Intake forms that only give options of male or female as gender identity
- Lack of insurance coverage for gender-affirming procedures

LIST 4

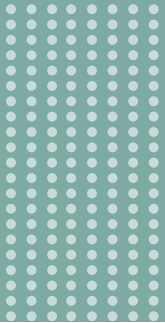
Insurance Barriers as Experienced by Marginalized Communities in Puget Sound

- No health insurance or limited/inadequate health insurance; a lot of people are forced to pay out of pocket and don't have the money
- Undocumented people may not have access to health insurance, leading to lack of access to mental and physical healthcare
- Switching insurance frequently (e.g., changing jobs, losing jobs, etc.) leads to switching providers/ doctors; eligibility expires per status; this is even more difficult for communities where rapport and relationship building are important in order to build trusting relations with healthcare providers
- BIPOC do not have access to policymakers or lobbying representation to help shape health policy
- Not clear what the insurance plan offers and what is or is not covered—very complicated language and terminology
- Culturally appropriate care is often not covered by insurance (e.g., traditional herbs, some supplements, etc.); high-level mainstream decision-makers tend not to understand the contexts and barriers experienced by BIPOC
- Paying into insurance only to find out the things you need are not “approved” or not in the insurance plan's network
- Lack of covered care for Transgender community
- Often excludes Natural Medicine practitioners
- Low rates of reimbursement to providers at all levels
- Malpractice insurance helps doctors, not patients; there should be some kind of restorative justice on behalf of patients
- Racist, sexist, ableist, homophobic, etc., healthcare is largely not considered malpractice—it should be
- There is a need to include home visits
- Discrimination (racist, sexist, ableist, homophobic, etc.) barriers get in the way of BIPOC having full use of insurance even when they have “good” insurance

LIST 5

Communication Barriers to Quality Healthcare as Experienced by Marginalized Communities in Puget Sound

- Complicated language, especially concerning medical information as well as what insurance plans cover and don't cover
- "I find my immigrant parents never understand what the Dr.'s diagnosis is or what medicine they take."
- Failure to not only explain, but failure to truly investigate our health concerns
- Having to rely upon kids as translators
- If English is not your first language, or if you can't speak it at all, there is an assumption that you are ignorant or uneducated
- Not understanding that many people from Central America do not speak Spanish: there are many Mayan-speaking populations in Washington and Oregon, and there are many Mayan languages and dialects
- Lack of proper interpretation
- Immigrants, especially non- or limited English speaking, experience the healthcare here as confusing and very different from that in their countries of origin
- Weaknesses in medical community's abilities to effectively, knowledgeably, sensitively, and thoroughly communicate with and provide quality care (including reproductive healthcare) for patients that are LGBTQIA+, and especially for Transgender patients



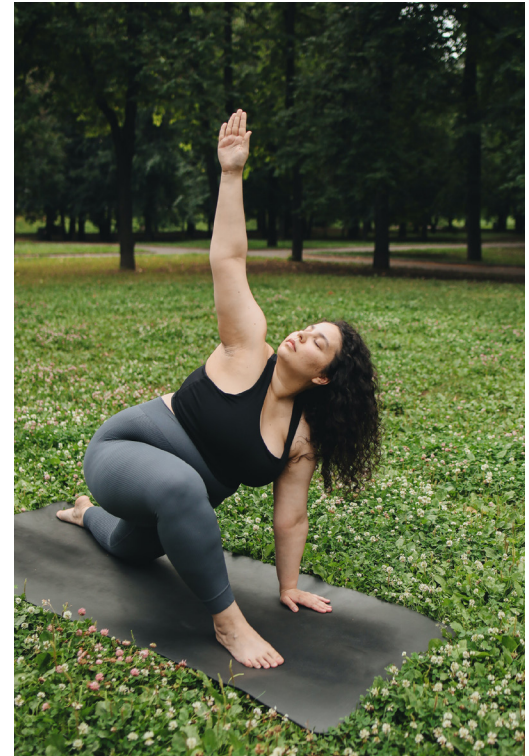
Given the nature and amount of the barriers in Lists 1–5, the question naturally arises: What is it that people in these communities do to care for their physical, mental and emotional health and well-being independent of mainstream healthcare? List 6 captures the Community Partners' exploration of this question. List 6 identifies efforts, activities, and strategies that members of marginalized communities in the Puget Sound area use to heal and keep themselves well.



LIST 6

How Do We Care for Our Health

- Movement healing (walking, dancing, yoga, tai chi, traditional dances like Aztec dance or Ballet Folklórico)
- Reaching out to family and peers for direction, information, and support
- Traditional and family remedies: foods, salves, liquids, herbs, spiritual practices: e.g., medicinal soups, broths, teas; garlic for antibiotic; mint tea and warm compresses for menstrual pain; cloves for toothache; traditional self-care and lodge medicines and teas at fireplace; healers and root workers; sweat lodge and seeking ancestral connection and guidance; storefront curanderas or community clinics; Sobanderas (traditional massage with different medicines), these people do home visits and get paid basically by donations
- Spas, soaks/steam/saunas
- Doulas (specializing in birth, death, and/or illness), midwives, community health workers
- Facebook Live events, group shares, mutual aid groups, and other online platforms
- Routinely checking in on one another, especially checking in on elders
- Professional group therapy/support groups/counseling
- Text message chains about locations/events offering care for undocumented folks
- Sweatlodges: allows for people to pray for each other and reveal the depth of healthy relationships for each other; bonding by working together
- Traditions especially for women: gatherings (baby showers or bridal showers) allow safe female space for women to talk about sex, parenting and healthy relationships, coping skills; traditional dances
- Prayer and praying over each other
- Go to pharmacy or ER
- School-based access points and grassroots resource drives
- Waiting until it's a dramatic emergency then going to urgent care where people know they won't be denied
- Acupuncture, complementary/alternative medicine
- Self-medicating based on self-study
- Massage





DISCUSSION

Community Partner discussions also identified several barriers that impact health at a population level, such as the need for increased supports in areas like maternity and paternity leave; home birth, natural birth, and breastfeeding; and accommodating the challenges experienced by families when they go to the doctor (e.g., the need for child care, money for transportation, time off from work, etc.). Community Partners also emphasized the need to make the healthcare setting safe, non-judgmental, caring, and competent so as not to further compound the many other barriers interfering with underserved and marginalized communities accessing quality and timely healthcare.

Throughout, there was clear intention for this study to be culturally appropriate, inclusive, and community-led, and to focus on areas of healthcare that are meaningful to the communities. What this study focused on and the way it operated promoted health justice. It served to open opportunities. These opportunities include:

1. Disenfranchised voices to be heard concerning health
2. Community organizations to work and plan together collectively
3. Collecting data from the perspectives of and with benefits for the diverse marginalized communities
4. Gaining increased insights into the needs of specific marginalized communities
5. Identifying and naming particular barriers that need to be removed and particular clinical care that needs to be improved
6. Identifying pressing issues for future health policy work



The Community Partners pointed to barriers that were far more than accidental mistakes, one-time bad practices, or a few bad apples. They pointed to patterns. These were patterns like racism, ableism, classism, and homophobia. They spoke of intersections of some of these patterns. They spoke of ignorance, fear, hostility, lack of concern and care, and sometimes simply not taking people's health concerns seriously.

One way of interpreting the content generated by the Community Partners (in Lists 1–6) is that there are significant problems when mainstream healthcare engages with marginalized communities. These include:

1. Healthcare providers and healthcare designers fundamentally not seeing, not paying attention to, or simply neglecting people's needs, especially given the historical and present-day contexts of people's (patients') environments, situations, and options (e.g., medical staff not taking the time to make sure that all patients are clear about their diagnoses, the medicines that they are to take, and why and how the medicines will work in their body)
2. Conscious, unconscious, and dysconscious discrimination that shows up as racist, sexist, classist, ableist, etc. ideas, attitudes, beliefs, orientations and normalized practices within and across the different systems of healthcare (e.g., when people of African ancestry speak up, it is almost immediately taken as aggression/threat, and healthcare help easily goes awry at that point)
3. Lack of information/education, cultural and professional blind spots, inexperience, mis-education including stereotypes, myths, pseudoscience, false beliefs, etc. concerning people and communities that have been pushed to the margins (e.g., hesitancy, fear, incompetence, or acting as if anyone who is Disabled or not cis-gendered or heterosexual is entirely defined by their gender identification, sexual orientation or disability)
4. The actual arrangements and practices of the many systems of healthcare are problematic by design (e.g., healthcare treated as a commodity, onus on patient not the system, volume-based medicine, over-emphasizing cost savings, lack of coordinated care, exclusive medical training)

The preceding four points can be thought of not so much as concrete categories, but more like four active streams (or forces) of undesirable health experiences and outcomes. These four streams may run parallel to one another but also intersect. However, they all flow toward outcomes of marginalized people and communities not getting the full quantity and quality of physical, mental, and emotional healthcare that they need.

People in Puget Sound's marginalized communities do things on their own to take care of their health. Social, spiritual, and cultural ways have importance. People sometimes use cultural dancing. They engage in cultural remedies that include foods, teas, and herbs. They explore acupuncture and meditation. They do spa treatments, massage, and yoga. People turn to family members and friends for health information, assistance, and to do health activities together. They use traditional medicine, which often incorporates

prayer for themselves and for others, in their efforts to heal. Some people regularly check in on one another and check in on the elderly. They use online sources to participate in virtual health communities and do self-study and self-medication. Their health burden is compounded by the presence of racism, sexism, ableism, anti-gender non-conforming attitudes, Islamophobia and so much more in environments that have often been degraded.

This study focused on personal and community solutions to the healthcare problems imposed upon marginalized communities. For future efforts, it will be important to expand this kind of community-led work. Such work can scrutinize healthcare structures, policies, and processes that create and permit the large-scale inequities in treatment, outcomes, and prevention that exist for these communities. It also provides a roadmap for community directed systems change.



PART II: THE SURVEY

QUANTITATIVE METHODOLOGY

To retain a community driven and focused study, the research team began by connecting with community organizations in the Puget Sound area that are dedicated to serving their respective communities. It is not uncommon for community organizations to compete for funding resources, so this study served as an opportunity for several organizations to collaborate in collecting pertinent information from their respective constituency groups regarding relationships to mainstream healthcare treatment, insurance, and alternative healthcare treatments and models of care. The **WELL US** research team leveraged the deep knowledge and wisdom that resides in the leaders and community members of our Community Partners to create and develop a survey that was both culturally appropriate and inclusive to all the constituency groups we were seeking information from.

THE SURVEY TOOL

The research team began creating the survey by drafting a list of questions that encompassed the expectations and concerns brought up by Community Partners in the first meeting. This draft initially included over 20 questions. The research team aimed to limit the number of survey questions to 15 to avoid respondent fatigue. By the second Community Partner meeting, the research team had revised and edited the survey to meet expectations. It was in this meeting that the research team collected more input and feedback to

fine-tune the survey further. After adding these edits, the research team presented the final draft **WELL US** survey to Community Partners for approval. The tool was considered validated because it was developed and tested by a diverse representative set of community members.

This version was subsequently translated into Chinese, Vietnamese, Amharic, Spanish, and Somali and uploaded to Qualtrics, where the survey could be formatted accordingly. All six languages were accessible on the Tubman Center for Health & Freedom website and made available from June 16, 2021 through July 30, 2021.

SURVEY DISTRIBUTION

Throughout the approximate month and a half that it was available, the research team continuously advertised and pushed the survey out through social media, in-person events and vaccination clinics, and Community Partner networks. The research team distributed a toolkit that consisted of flyers, email templates, videos, and blog and newsletter templates that contained all the information regarding the purpose, duration, and details of the **WELL US** study.

LITERATURE REVIEW

Along with the distribution of the **WELL US** survey, the research team simultaneously conducted a literature review. The research team developed three focus topics based on conversations from previous Community Partner meetings. These three topics of focus are



as follows: 1) *Types of insurance and how type of insurance determines the level of care individuals and their families receive*; 2) *Accessibility of various types of care, cultural connections, and alternative medicine use*; and 3) *Patient-provider relationships and how these relationships or interactions affect the type of care that is provided as it pertains to gender, race, and identity*. The research team determined that these topics of inquiry provided rooting context to aid in survey analysis and recommendations. Furthermore, it identified opportunities for further research.

DATA CLEANING

Each of the languages were in separate data sets in Qualtrics, so the **WELL US** research team had to separately translate, clean, and combine the data sets. During this data collection process, it became

“As a young adult who entered adulthood without significant support from my parents or the older people in my life, navigating the healthcare system is overwhelming, intimidating, and discouraging.”

—SURVEY
RESPONDENT

clear that there were numerous bot responses and repeat responses. The **WELL US** research team consulted with a professional data analyst for recommendations on filtering out these responses. Based on the data measurements that Qualtrics provides for each response and the responses to the survey questions, a set of filters were created to remove bot and repeat

responses from the data. These filters are as follows:

1. Respondent did not finish the survey (Qualtrics measurement);
2. Responses that did not give consent or that were blank;
3. Respondent answered question 1 (regarding which marginalized identity one held) with “I do not identify with these groups”;
4. Responses under 4 minutes (240 seconds) in length;
5. Respondent identified only as BIPOC in question 1 and then subsequently identified as “White/Caucasian”;
6. Several responses to Question 34 were duplicated or did not follow the prompt of the survey question;
7. Several surveys having the same start and finish times and following a pattern that occurred several times throughout the collected data set;
8. Language of survey did not seemingly align with the identity of the respondent.

Of the total 2,032 responses collected from the **WELL US** survey, there were 1,596 English responses, 425 Chinese responses, 5 Vietnamese responses, 3 Amharic responses, 3 Spanish responses, and 0 Somali responses. After using the data cleaning filters described above, 350 responses were retained for the data analysis portion of this study. In other words, 17% of the collected data was used to inform the **WELL US** study.

Towards the end of the data cleaning process, the research team concluded that the **WELL US** study may

have experienced a malicious attack. There is record of other malicious attacks on studies asking questions perceived as liberal or progressive related to race, gender, and sexuality. These attacks are attempts to delegitimize studies.

DATA ANALYSIS

For data analysis we revisited the notes from the initial Community Partner meetings that took place at the beginning of the 2021 year. Compiling the questions from the survey and notes from our Community Partners, analysis questions that could be run through R Studio were developed. The research team primarily looked at how BIPOC, LGBTQIA+, Disabled, and

“Medical institutions are intimidating & processes sometimes seem daunting”

—SURVEY RESPONDENT

Immigrant communities experience mainstream healthcare, how they use their insurance, and how this relates to accessing alternative and/or traditional medicine and wellness. From this data set, the research team did a qualitative and quantitative analysis. As part of the **WELL US** survey, there was a question

providing the opportunity for survey respondents to provide written responses regarding their experiences with the healthcare system as well as a question asking permission to reach out to the respondent for an in-depth interview. The research team collected these written responses and spoke with a number of respondents who agreed to an interview providing us with a more detailed understanding of their lived experiences with healthcare. Some of the main topics that came from these interviews were around Transgender healthcare coverage, non-discrimination policy and accountability, quality of care, care coordination, bi-racial identity, Black maternal health, and insurance, among many others. These interviews were used for data analysis and recommendations and to identify future areas of research.

The qualitative and quantitative analyses of this study were imperative in providing a more complete and holistic understanding of the concerns and barriers

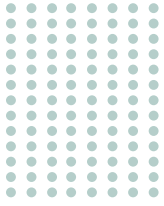
that BIPOC, LGBTQIA+, Disabled, and Immigrant communities in the Puget Sound area face in their efforts to improve their health. In order to create and establish a community clinic that properly serves the needs of these communities, the concerns and analysis from this data set must be taken seriously and used to drive future decisions.

REPORT OUT

At the end of August, after the data analysis was complete, the **WELL US** research team held another meeting with Community Partners to report on the outcomes of the study. This included the survey distribution process, data collection through Qualtrics, data cleaning, qualitative and quantitative data analysis, and additional questions that the community may want to be answered through this data set. Overall, the Community Partners were receptive and pleased with how the study was conducted. Understandably, there were questions around the malicious attacks and the data cleaning process, but ultimately the Community Partners agreed with the process used for preparing the data for analysis.

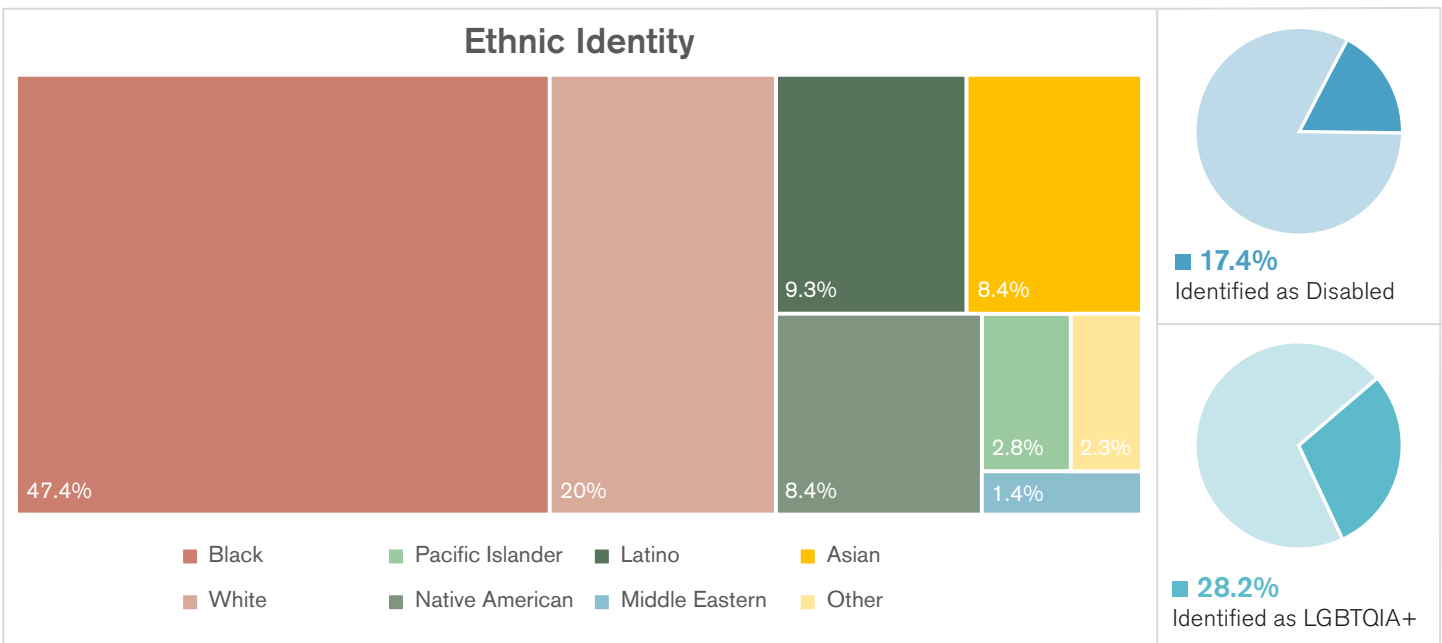
Once statistical analysis was completed using R Studio, data was once again shared with the community research team to obtain their thoughts and consideration and direction regarding additional correlations that should be examined. Researchers incorporated feedback and returned the draft final report for community approval.





PART III: THE FINDINGS

RESPONDENTS



I. Insurance does not always cover the preferred methods of healthcare

Our **WELL US** community survey found that even for participants who have insurance, their preferred methods of healthcare were not always covered.

- 42% of Disabled respondents on Medicaid indicated that they were less than satisfied with their insurance coverage.
- The most common response written into the survey's open-ended questions related to the desire to use these services, but the inability to pay for them because their insurance did not cover the costs.

Astonishingly, 100% of respondents reported using at least one modality that would be considered “alternative” or “complementary” care under insurance network plans. While modern medicine is rooted in the evolution of

knowledge originating from cultures around the world, the biomedical model is currently what is considered mainstream.⁴ Mainstream medicine has become detached from its integrative medicine roots, even though many community members have not, preferring methods of healthcare that are not solely biomedical. Culturally-based and traditional modalities are often considered “alternative” or “complementary” under insurance plan coverage.

Despite Washington’s “Every Category of Provider” law, which requires insurance companies doing business in Washington State to offer insurance coverage for “alternative” care providers as well as conventional medicine providers, there are limitations and loopholes that can make it difficult to receive one’s preferred methods of healthcare.⁵ Even when insurance covers some “alternative” options like acupuncture, they have limits on visits, a small and/or outdated list of network providers, or entirely exclude other forms of care like naturopathy.⁵ Preferred methods of healthcare continue to be difficult to access due to insurance companies prioritizing conventional, biomedical models of care, even though traditional medicine is valid and effective.

2. Cost of healthcare-related activities is a barrier

- ∴ 46% of Black, Indigenous and People of Color respondents found cost/finances a barrier to care.
- ∴ 47% of LGBTQIA+ respondents found cost/finances a barrier to care.
- ∴ 44% of Disabled respondents found cost/finances a barrier to care.

Participants frequently indicated that the cost of healthcare-related activities is a barrier. We found that indication of multiple marginalized identities increased the likelihood of not being able to afford medical care compared to those who indicated one marginalized identity. As previously discussed, 100% of respondents reported using at least one modality that would be considered “alternative” or “complementary” care under

insurance network plans. These preferred and highly used modalities often come with higher out of pocket costs, and in some instances they may not be covered under insurance plans at all.

Previous research on health disparities among local BIPOC, LGBTQIA+, and otherwise marginalized communities has found that these populations often face cost barriers when attempting to access primary and specialty care.¹⁻³ For instance, a 2018–2019 survey from the Consumer Voice Listening Project found that nearly a third (31.1%) of 2,860 King County participants reported cost as a reason for not seeking care during the past year.¹ One in five participants reported not having money to pay for the visit co-pay, and nearly one in five said they did not have insurance.¹ Overall, cost of care emerged as a barrier for each target community, including BIPOC and LGBTQIA+ respondents, limited English proficient respondents, respondents experiencing homelessness, and young adults.² Previous research also indicates a greater concern for cost in south King County compared to north King County.²





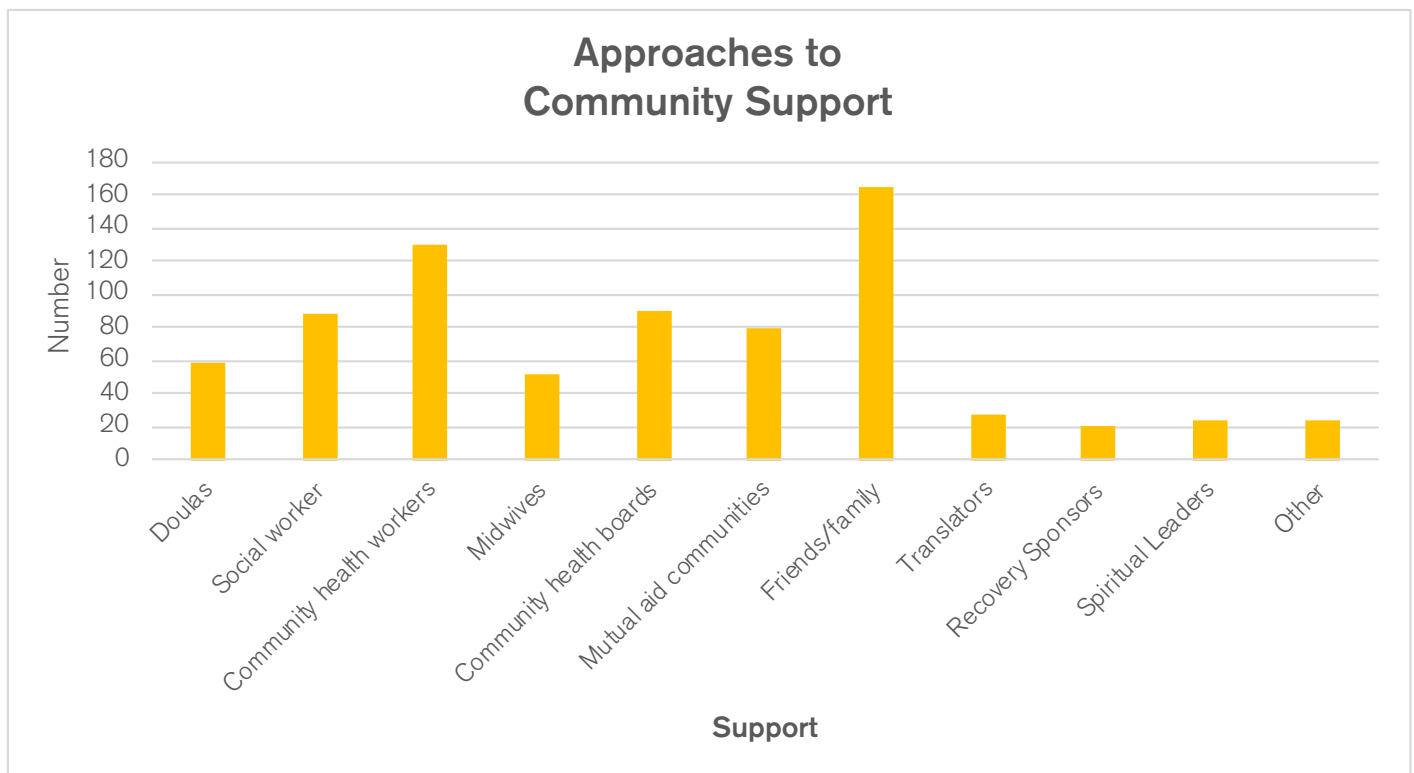
3. Marginalized people rely upon relationship networks to help navigate the healthcare system and remain healthy

- 61% of respondents that utilize doula care identified as Black.
- 91% of respondents rely upon friends and family to help navigate the healthcare system.
- Most commonly used supports for meeting healthcare needs were: friends and family, community health workers, mutual aid networks and social workers.

Another theme highlighted by our findings is that people who are marginalized by mainstream medicine rely upon relationship networks in order to navigate complex healthcare systems and remain healthy. From doula care to mutual aid networks, and with family members providing recommendations on where to go, who to see, and what to ask for, marginalized communities have a strong sense of community that supports them in their pursuit of health. Among other things, the COVID-19 pandemic has shed further light on the power of communal networks and mutual aid.⁶⁻⁷ By tapping into collective knowledge, power, and resources, communities who face ongoing systemic oppression and marginalization have responded to the COVID-19 pandemic in ways that are not often captured by popular media and literature.⁷ It is undeniable that community knows how to care for community. Community health workers are successful because of these relationships. Given that the system is so difficult to navigate, relationships have been essential to survival.

“As a black woman I have to alter my speech and coddle medical professionals.”

—SURVEY RESPONDENT



4. BIPOC, Disabled and LGBTQIA+ community members utilize significant amounts of what is considered “alternative” medicine

- Most utilized modality used by respondents was massage therapy
- People who identified as Middle Eastern, Asian, and Native American were most likely to use acupuncture.
- Nearly 1/3 of Black respondents also utilize acupuncture.

In our study, BIPOC and LGBTQIA+ community members commonly indicated that they use what is considered “alternative” medicine. Of respondents that identify as LGBTQIA+, 90.2% indicated that they utilize “acupuncture, massage, Ayurvedic medicine, chiropractic, or other” to benefit their health.

The finding that 100% of respondents from marginalized communities use one or more modality or treatment that would be considered “alternative” medicine is surprising in light of the prior literature. Studies have found that BIPOC and LGBTQIA+ people are likely to use complementary and alternative medicine (CAM), especially as a result of previous and/or anticipated discrimination.⁸⁻⁹ For LGBTQIA+ community members, CAM has been discussed as important given its support of holistic and emotional wellbeing.⁸ For Black community members, CAM has been discussed in the literature as a way of coping with barriers faced in institutional settings.⁹

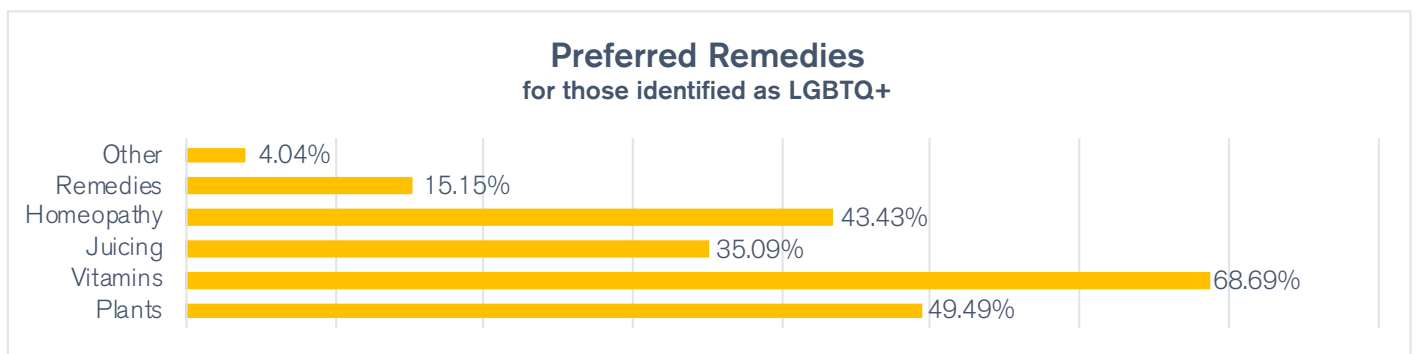
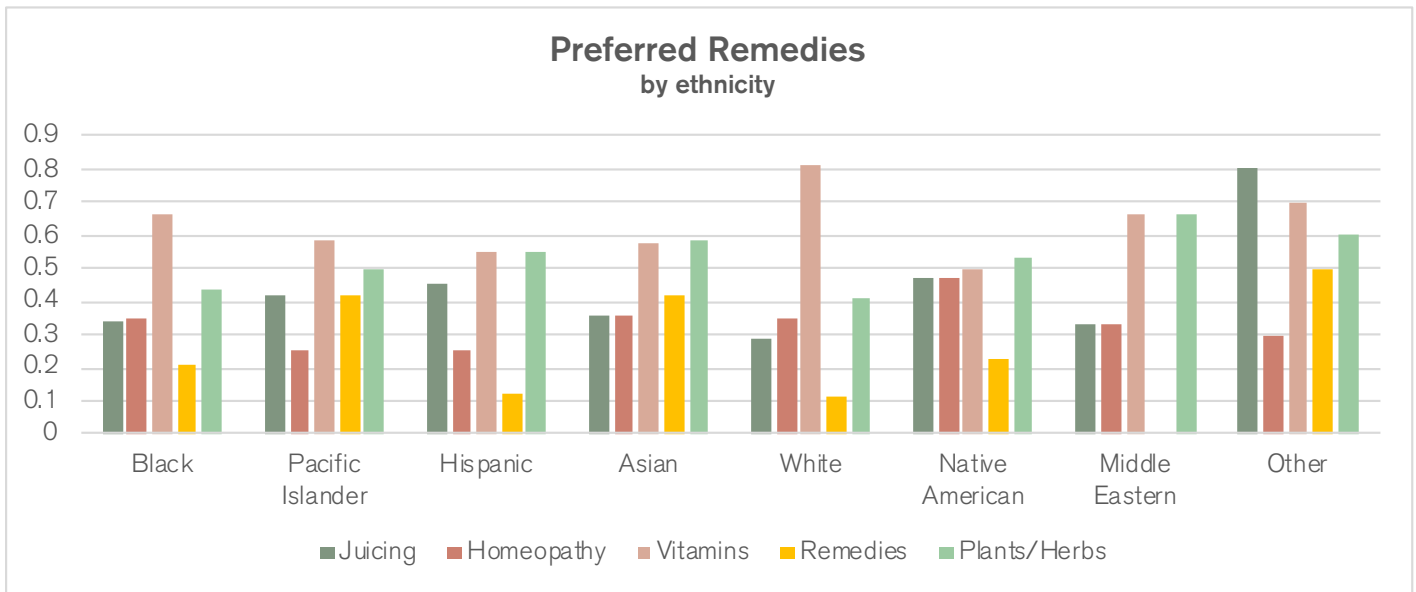
5. Vitamins and supplements are widely used to support health in marginalized communities

- 66% of Black respondents reported using vitamins.
- White LGBTQIA+ and Disabled respondents were least likely to use plants and herbs and most likely to use vitamins compared to Black, Indigenous, and other people of color.

Participants frequently cited the use of vitamins and supplements to support health. Those who identified as White were least likely to utilize plants and herbs for their health, compared to Black, Indigenous, and other people of color. Previous research suggests that African Americans are less likely to be prescribed medicine and instead tend to self-prescribe dietary supplements, herbs, and natural products.¹⁰ While a large body of research, including the 2002 Health and Diet Survey, confirms that the majority of U.S. adults use some form of dietary supplement, studies within the African American community show mixed findings.¹⁰ Our study contributes to evidence that marginalized communities use vitamins and supplements to support their health.

The number of respondents indicating use of homeopathy was much higher than anticipated. When this was shared with community members, one possible explanation offered was a misinterpretation of homeopathy to mean something along the lines of home remedies or treatments. Community members indicated that many people are unfamiliar with traditional homeopathic medicine but very familiar with similar sounding phrases such as “home remedies/treatments.”





6. Overall sense of dissatisfaction around health insurance coverage and processes

Overall, our participants expressed dissatisfaction around health insurance coverage and processes. In fact, 42% of respondents who identify as Disabled reported a lack of satisfaction with their health insurance. This is of particular significance, since many Disabled people are covered by Medicare insurance. Medicare is the leader and trend-setter in the health insurance market in the U.S. It's frequently said that "as goes Medicare, so goes all other insurance."

This finding supports previous research focusing on the role that insurance policies and features of managed care have in widening health inequities among marginalized peoples and language-based gaps in perceived quality of primary care. In one study of English-speaking Hispanic patients, perceptions of

quality of primary of care were more dissimilar from those of White patients when the policies of capitation or gatekeeping were used compared to when they were not used.¹¹ It is clear that patients from communities marginalized by mainstream medicine are dissatisfied with the insurance industry's coverage and processes that act as additional barrier.

7. Barriers to seeking medical attention

Top 5 commonly reported responses:

1. Finances/costs
2. Racism/harassment
3. Fear of discrimination
4. Inability to find a provider
5. Language barrier

Additional Qualitative Survey Responses:

“Insurance.”

“Mental health barriers.”

“PTSD from previous encounters with bad providers.”

“Fat shaming.”

“Traveling from home to office.”

“Systematic.”

“Not into traditional medicine.”

“Obesity; female; health condition not recognized by mainstream providers (chronic Lyme disease); being on Medicaid limits choice of providers and availability of appropriate care.”

“General tiredness of dealing with the health system.”

“Black and brown providers are harder to find.”

“Insurance doesn’t cover alternative treatment such as naturopath or chiropractor.”

“Waste of time (& increased running because physicians do not believe poor ppl, and being black poor people even less. So we are forced to wait until problems are so out of control that they are obvious (and often painful or debilitating) in order to get them addressed. As a black woman I have to alter my speech and coddle medical professionals.”

“Time, distrust, lack of respect for non-western medical philosophy.”

“The medical industry doesn’t make it easy to find primary care providers, ones that I identify with and ones that are easily accessible.”



“Comfort with provider.”

“Don’t like going to the doctor.”

“Sex work discrimination.”

“Feeling as though I won’t receive proper treatment and/or feeling as though they use my insurance for a bunch of tests that don’t do much towards my diagnosis.”

“Too busy.”

“My mom was isolated and murdered as part of the COVID count.”

“I was unable to see doctors for years due to finances and very unstable living conditions. Now, as an adult, I’m afraid to go to a doctor because I’ve been deeply shamed in the past for not being more on top of medical stuff. As a young adult who entered adulthood without significant support from my parents or the older people in my life, navigating the healthcare system is overwhelming, intimidating, and discouraging. I know I need to prioritize my health, but the fear of judgement (and experience with being judged by healthcare professionals) holds me back.”

“It’s more about not being listened to with my obvious issues.”

“I distrust doctors because they are highly biased and don’t see me.”

“Previous medical trauma.”

“Because of the limitation on office procedures when it comes to insurance.”

“Difficult to pay for parking and see a provider (UW Medicine facilities are expensive to park in) and public transportation often doesn’t work.”

“Fatigue.”

“Weight bias.”



PART IV: RECOMMENDATIONS

1. Insurers must cover the cost of healthcare our communities utilize

To reduce cost-related barriers and meet the needs of our communities, insurers must cover the cost of healthcare, including CAM. As our findings suggest, while our communities use and want CAM, insurance does not always cover these preferred methods of healthcare. Insurance policies such as gatekeeping and capitation have been found to widen racial and ethnic disparities in patients' evaluations of primary care.¹ For gender minority individuals, such as those who identify as Transgender or gender nonconforming, the cost of care and health insurance obstacles are commonly identified as barriers to accessing gender-affirming care or gender-appropriate screenings. In a previous study, gender minority individuals found that participants commonly cited insurance as an obstacle and expressed the need for gender-affirming care within the biomedical system.² Participants said that while CAM is preferred, particularly as it meets emotional health needs, financial barriers are a major concern because many CAM therapists are not covered by health insurance plans.² CAM use is prevalent and increasing among racial and ethnic minority populations in the U.S., and there is a growing body of literature investigating whether CAM can be used to reduce health disparities.^{3,4} Insurers must cover the methods of care our communities use so that cost and insurance practices no longer stand as barriers to the health-seeking behaviors of racial/ethnic and gender minorities, who already face other barriers including racism and discrimination.

2. “Alternative” medicine is not alternative for all communities

As evidenced in our findings, BIPOC and LGBTQIA+ community members frequently use what is commonly referred to as “alternative” medicine. By referring to CAM therapies as “alternative,” we are implying that the biomedical model used by mainstream medicine is the standard or default. It is imperative that CAM therapies are not always referred to as “alternative.” “Alternative medicine” is not alternative for all communities. These forms of medicine are oftentimes indigenous, ancestral or reflective of familial medicinal lineages that are familiar to many Black, Indigenous and other people of color. CAM is only referred to as “alternative” because mainstream medicine is a system into which our communities have been force-fit. We must recognize that the biomedical model is not superior to other ways of attaining and maintaining health and well-being. Our communities use CAM, and they have been using it for centuries. From the *botánica* for Latinos in the U.S.⁵ to Indian Ayurveda and yoga, massage and bodywork, to traditional Chinese medicine,⁶ acupuncture,⁶ and other indigenous methods of healing,⁷ centuries-old medicinal practices continue to be important and effective healthcare resources that are sometimes used interchangeably with or in lieu of conventional mainstream healthcare.⁸ Culturally-appropriate



and respectful medical care must come with the recognition that therapies and modalities that the global majority are familiar and comfortable with are not “alternative” but oftentimes primary, preferred methods of care.

3. Employ healthcare providers from the community

Our study participants indicated that building a trusting relationship with providers is important when navigating the healthcare system. This reinforces the importance of employing providers that are from the communities they are serving. Previous research has found that racial concordance between patients and providers improves health outcomes. For instance, a large study of 1.8 million hospital births in Florida between 1992 and 2015 found that newborn-physical racial concordance is associated with a reduction in mortality.⁹ Another study looked into racial/ethnic differences in pain reporting and treatment and found that Black patients reported better pain management when paired with a racially-concordant physician.¹⁰ Employing providers who are from the community they are serving, understand their patients (spoken language, daily life, culture, etc.), and are driven to build trusting relationships with patients would likely decrease the substantial necessity for and reliance upon personal networks to navigate healthcare systems and decision-making.

4. Incentivize providers who use the healthcare that marginalized communities prefer to use

Our communities have healthcare needs and preferences that go beyond what mainstream medicine provides. Given that marginalized communities are also most impacted by health disparities and are burdened most frequently with complex health cases, value-based payment structures and incentivizing culturally-appropriate care has the potential to reduce health disparities.¹¹⁻¹² This includes incentivizing not only reporting sociodemographic data,¹² but also resourcing providers with the tools necessary to address social determinants of health. The strategies to develop this work must be established by organizations and agencies that are embedded in the communities most impacted. Payers must also fairly reimburse for the care marginalized communities receive. Medicaid reimbursement rates must be increased.

5. Remove systemic barriers to care so that communities can access mainstream medicine without discrimination and that “alternative” medicine can be a chosen option

It is critical to the health of marginalized communities that systemic barriers to care such as cost and lack of insurance coverage and insufficient provider networks are removed. People should be able to make healthcare decisions based upon personal needs and preferences. Our study’s findings indicate that marginalized communities want to use “alternative” or culturally-based medicine, but are hindered due to the preference of the insurance industry for mainstream biomedical models of care. People from marginalized communities need to be able to access their preferred healthcare without barriers.

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