



WE THOUGHT YOU'D NEVER ASK!

LEARNING FROM BOSTON'S BLACK COMMUNITY WHAT SUPPORTS ITS HEALTH, RESILIENCE & WELLBEING

A Report of Key Findings, Voices that Informed those Findings, & Powerful Stories Shared by Boston's Black Community

REPORT RELEASED BY



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INTRODUCTION



“When I think about what could bring increased wellness to Black people, I think about the importance and power of a community that loves and sustains us. If we love and trust and support each other, we can save each other’s lives.”

The Black Boston COVID-19 Coalition and Fenway Health began conversations in fall 2020 about the urgent need for health care institutions in Boston to better serve the Black community to address the devastating impacts of two deadly pandemics: COVID-19 and generations of systemic racism that preceded COVID and have made it worse. The two organizations agreed it was essential to engage the Black community as an authentic partner to both understand and address these urgent issues. They also agreed that for Fenway Health to effectively partner with the Black community to address these issues, Fenway Health would need to commit to addressing systemic racism and building a culture that centers racial equity within its own organization, its leadership, and its work.

BBCC and Fenway Health agreed to work toward achieving the following broad goals:

- Understand and improve the health and wellbeing of Boston’s Black community during the current and evolving pandemic and its impacts as well as longer term.
- Understand how systemic racism has undermined these outcomes, develop a plan to address the systemic racism they find, and then take action to address it.
- Help Fenway Health become an anti-racist organization and build a race equity culture in order to effectively serve the Black community.
- Collect, share widely, and continuously improve data and metrics that tell the truth about the health and wellbeing of Boston’s Black community.

- Develop a case study of what we learn through our partnership. Share it with others in Boston and around the country in order to challenge, inspire, and better equip them to improve the health and wellbeing of, and partnership with, Black communities everywhere.

BBCC appointed its member, Jacqui Lindsay, as project consultant. Ms. Lindsay, of Innovation by Design, worked with Fenway Health and BBCC to create a steering committee (SC) in spring 2021 to set direction for, oversee, and guide planning for the first phase of their partnership.

The SC agreed on a project plan and to use what it learned from implementing it to make recommendations for how to move forward. The SC was fully aware from BBCC’s own compelling data that Boston’s Black community was hit especially hard by COVID-19. While data about community needs and challenges was, and continues to be, essential to figuring out what needs to be done to save lives in the Black community, the SC knew that there was another important story that was not being told: a story about what strengths and assets were supporting and sustaining the community to address these challenges—a story just as essential to saving lives, not only during the evolving pandemic but longer term. So the SC decided to undertake community research to learn more about what works to improve the health care, health, resilience, and wellbeing of Boston’s Black community, and what more needs to be done to further strengthen these outcomes.

To help achieve this goal, the SC decided that it was important to learn from the Black community itself the following:

- What it values and trusts – in the health care system and beyond
- What works to support its health and wellbeing
- What doesn't work: what hinders or undermines its health and wellbeing
- What priorities need to be addressed to overcome these gaps and barriers
- Which organizations BBCC and Fenway Health should work with to address priorities important to the Black community for advancing its health and wellbeing.

The project conducted research in August 2021 through focus groups and street surveys. Eight virtual focus groups, of about 8-10 people each, were held with different parts of the Black community, oversampling for the Black LGBTQIA+ community because it is underrepresented in the population that both Fenway Health and BBCC currently serve. The other parts of the Black community who participated in the focus groups were elders, women, men, young adults, and African community leaders. Within these groups, there were people from the health care system, the education system, the social services system, the faith community, and running groups. Street surveys were conducted at many BBCC mobile vaccination sites in August that were in different neighborhoods in the Black community. A total of 169 surveys were collected.

The surveys were important for three reasons:

1. To help the project hear from individual community residents
2. To see if survey findings surfaced anything different than focus group findings
3. To learn from a larger and more random pool of people whether they get health care.

Nothing was mentioned in the surveys that wasn't captured, and captured in greater depth, in the focus groups. The key finding about who gets health care is reported on below in the Key Findings section of this report.

The report is organized in a section of key findings that begins with an executive summary of key themes, followed by key findings regarding the central questions posed to focus group and survey participants. The report concludes with an appendix that includes three things: powerful stories of assessment participants, the names of organizations who hosted focus groups, and a glossary that includes a few words or terms used in this report that may be unfamiliar to some readers, or are widely used but may mean different things to different people. We've provided definitions to let people know how our project understands the words.

As we prepare to share this report with the Boston community, the steering committee for this project issues this challenge and invitation to all of us who want to see race no longer be a predictor of life outcomes for Black people – or any community: How can we make sure that this report, with all the meaningful contributions that have shaped it, leads to real action instead of becoming one more piece of research that gets shoved into a drawer? How do we make sure that this report gets the attention of those who can make a difference?

We welcome your thoughts about this challenge—and this report—and we invite you to join us in addressing it.

KEY FINDINGS



Executive Summary: Key Themes



WHAT BLACK PEOPLE SAY HEALTH AND WELLBEING LOOK LIKE

- A worldview and shared values that guide us to value each other's humanity, respond to and support each other when we're in need, prevent further suffering, and support individuals and communities to become whole
- Comprehensive health care, equitable health care, and equitable access to health care, i.e., non-discriminatory services
- Cultural humility and respect for Black people within healthcare and other systems that impact their health and wellbeing
- **Safety:**
 - Having safe spaces to unwind from and process the discrimination they face, and to recharge to face possible discrimination all over again
 - Having safe access to their spiritual practices and their spiritual leaders, and, as a spiritual community, not having to worry about discrimination
 - Feeling safe around state authority
- Supportive relationships and community to withstand the ongoing impacts of racism as well as to imagine and build the lives, community, and world they want
- Access to healthy fresh food and cultural food that are affordable, information about healthy eating and its impact on our bodies, developing healthy habits to support a healthy lifestyle
- Physical health and regular physical activity
- Peace of mind and mental health
- Financial/ economic security
- **Self-determination and independence:** the ability to do what they want because they're in good health; having control over their decisions; and the freedom to do what they want without monitoring, supervision, or restriction. Acknowledgement that there are different ways of knowing, other cultural practices that people can incorporate to make decisions about their health, and that they can do that in ways they feel are safe and are not limited because of the color of their skin, their income, or the language they speak.
- Health facilities and providers that meet their needs, and that they can communicate and connect with

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WHAT BLACK PEOPLE TRUST IN THE HEALTH CARE SYSTEM

- **Walking in a space of shared humanity with their doctors:** i.e., they trust doctors who take the time to get to know their patients and make a human connection, respect them, create a safe space to be open about everything, listen to, learn from, and take their patients seriously, are open to their questions and finding answers to them, are honest with them and thorough, treat their patients as a partner in decision making about their health care, and advocate for them within the health care system to ensure they get the tests and services they need in a timely fashion.
- Having the option to choose their primary care doctor
- The opportunity to connect with and be cared for by Black health care professionals, including primary care doctors, nurses, and specialists; and seeing Black men and women in leadership roles of health care institutions
- Being able to have people they trust accompany them on visits to the doctor, as advocates

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WHAT BLACK PEOPLE DON'T TRUST IN THE HEALTH CARE SYSTEM

- Health care providers who DON'T recognize the humanity of Black patients or their family members or community – and don't treat them with respect. Patients feel that instead of recognizing their humanity, these providers only see and respond to people's race, class, and gender.
- Health care providers who are not culturally sensitive to Black people, whether born here or immigrants, or to people from the LGBTQIA+ community
- Doctors who don't trust that their patients know something about their own bodies
- A physician who doesn't listen to or follow through on their patients' questions and concerns, who doesn't look into them to explore what's happening and why, who doesn't explain things so patients understand their situation, what they need to do, and and what they should be looking out for, i.e., a physician who prepares patients to understand how to support their health
- Doctors who don't inform their patients up front about what costs the patient is responsible for regarding any procedure the doctor recommends, so that the patient has the option of choosing. The result can be a big bill the patient did not expect and cannot afford to pay.
- Having to wait forever to get an appointment

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WHO GETS HEALTH CARE

- The overwhelming majority of people who participated in all focus groups reported that they get health care and use it.
- **Regarding survey participants:**
 - 97% (164 out of 169) say they get health care.
 - 3% (5 out of 169) say they do not get health care.

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BESIDES HEALTH CARE, WHAT ELSE BLACK PEOPLE DO TO SUPPORT THEIR HEALTH AND WELLBEING

- They stay up to date regarding what's important regarding their health, and they learn to advocate for themselves within health care and other systems.
- They get mental health support.
- They prioritize self care and try to keep their homes as peaceful places to unwind.
- They engage in physical activity, sports, spiritual practices, meditation, and yoga - to support their physical and their mental health. Many experience running as an activity that brings both physical and spiritual benefits.
- They try to surround themselves with positive energy and relationships, people who love and trust each other and support each other's healthy lifestyle, development, growth, and agency.
- They maintain their social life.
- They keep up with current events and continue to be active in their community and society.

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WHAT WOULD BRING INCREASED WELLNESS TO THE BLACK COMMUNITY

- Counteracting stigma and stereotypes—around race, culture, gender, and HIV—within health care, other systems, and the broader community
- Understanding that the Black community has assets that can be built on to strengthen its health and wellbeing: what the Black community already knows, what it's already doing, and how it operates.
- Developing a more human-centered approach to health care. Health care providers would have relationships with their patients that go beyond an awareness of their needs. There would be real awareness of who their patients are as human beings and what they bring.
- Adding more healthcare professionals who are Black and people of color, because they know how to identify, how to talk to people, and they know the frustrations of people of color. Also developing community members professionally to be able to take on those roles.
- Understanding within the health care system that wellness is not just about health care: it's about addressing a person's basic needs. It's about their housing, their employment, their mental health, and whether they've eaten today, i.e., the social determinants of their health. Because racism can make it difficult for Black people to secure these resources, cultural competence within health care and other social systems in this country is needed to help Black people gain access to the basic resources they need.
- Reaching and empowering people not currently served by our health care system to gain access to key resources they need to protect their health. We'd connect with people living in poverty, people who don't really go to the clinic, people who don't get checked, people who don't have health insurance.
- Having community health centers expand their footprint by using health vans to bring key services, like blood pressure testing and wellness education, especially to the poorest parts of their community where people may not have access to health care.
- Healthy eating, widespread community education about healthy eating and how it impacts our bodies, and the availability of healthy, fresh, affordable food in our neighborhoods, and a thriving food culture in our community
- Having lots more people, including seniors, engage in activities that support and promote physical, mental, and community health

- Ensure that people, including seniors, have caring personal networks and supportive relationships to help improve the quality of their lives and their mental health.
- If health and wellbeing were fully present in the Black community you'd see increased mental health, support for it, and overcoming the stigma of it. Black people would seek therapy and seek support when they need help. They'd unlearn toxic behaviors and learn self care. But they'd have to overcome two big barriers to get there: their distrust of the health care system because of how it has mistreated them, and their resistance against acknowledging that they need help when they are struggling emotionally. To overcome the Black community's current distrust of the health care system, there would have to be mental health professionals Black people trust: therapists who listen to them, are culturally competent, and best of all, are from the Black community.
- Widely distributing information throughout our community to help people make the connection between their behaviors and their health and their wellbeing
- Black people participating in a healthy economy inside their community as well as in the wider world. As a result, You'd see parents able to support their families at a threshold level of wellbeing because they receive a life supporting wage. You'd see the creation of new businesses by Black people.
- Black people would have access to high quality health care in their neighborhoods, and cultural competence and cultural humility would be widely practiced in health care institutions in our neighborhoods and across the city. All of these institutions would partner with the Black community to figure out how to improve the health outcomes of Black people in Boston—so that race no longer becomes a predictor of Black people's health. Instead, the authentic engagement, partnership, and leadership of the Black community would become a key predictor of the health and wellbeing of Black people, communities, and the institutions and systems that serve them to improve health and the social determinants that impact health and wellbeing.

“If people had housing, enough food to eat, things like that, I think it would support them to be healthier by stopping them from getting sick in the first place. Not having these basic things causes people to get sick. Having these basic things helps make people and communities healthier.”

Black Young Adult



KEY BARRIERS TO THE HEALTH AND WELLBEING OF THE BLACK COMMUNITY - AND WHAT'S NEEDED TO OVERCOME THEM

- Racism is systemic within health care and other systems and needs systemic solutions to overcome it to support increased health, well being, and self-determination among Black people, their families, and their communities.
- Many Black people live in poverty, which is reinforced by multiple systems that have failed them over time, keep them poor, and undermine their health and wellbeing. They lack access to and cannot afford health care and other resources they need to support and sustain the health and wellbeing of themselves, their families, and their community. We need systems that see the humanity of Black people, including those who are poor and immigrants, and target their resources to improve the lives of those most in need.

“The greatest barrier is systemic racism in the health care system and in all the other systems that impact our lives and community. We lack access to employment to support and sustain our families, to healthy food and food security, to quality and affordable health care, housing, and education, and to the tables that make decisions for all these systems. In short, we lack access to the social, economic, and political resources we need to support and sustain the health and wellbeing of our families and the Black community. Being impacted by systemic racism in all these areas and across generations leads to entrenched poverty, which creates even higher barriers, for people and communities trapped by them, to the hope and resilience needed to overcome them. Which is why we must work together and not abandon the Black community to the job of removing barriers of systemic racism that keep it trapped, barriers it did not create.”

- Key barriers within the health care system:

Interpersonal Barriers in Health Care

- Being/feeling judged by health providers, which can lead patients not to be open
- Assumed to be like all other Black people (lack of providers' ability to see the individual)
- Feeling surveilled or inappropriately monitored
- Health care providers who are not sensitive to LGBTQIA+ issues or to cultural practices
- Providers who don't take the time to listen, answer questions, or believe patients' knowledge of their own bodies
- Mistrust from bad experiences in health care being carried forward into new settings and with new providers
- Generational mistrust of the medical system and providers, particularly re mental health
- Self-isolation and loss of social contact and outlets, especially as one gets older

Institutional/Systemic Barriers in Health Care

- Poverty, high cost of health care
 - Lack of accurate information
 - Lack of services for immigrants
 - Not seeing leaders in health care positions who look like them
 - Location and hours of health care services
 - Lack of access to healthy food
 - Language barriers for those who do not speak English
- **Health care and other systems need to do their own work internally and externally to identify and remove interpersonal, institutional, and systemic barriers, including:**
 - Have Black people and leaders working throughout their systems.
 - Take responsibility for ensuring that ALL of their employees, leaders, and partners are trained and held accountable for being culturally sensitive and competent.
 - Work in authentic partnership with the Black community to make sure that it is effectively served and its health outcomes improved.

- Racism’s mental health impact is widespread and support is needed to overcome it.
- Wellness education and access to healthy, fresh, affordable food is needed throughout the Black community to support healthy foods and healthy eating over a lifetime.
- Regular exercise is essential to health and wellbeing, along with green spaces and gyms to support physical fitness.
- Positive outlets—clubs, organizations, and groups—that can keep us on track and help us navigate the very tough situations we face.
- **Black people need personal, social, and spiritual safe spaces, as individuals and communities, to unwind from racism’s impact, and to communicate, connect with, and support each other to:**
 - Understand the generational traumas Black people have experienced from systemic racism and are still wrestling with, and their impact on Black people as individuals and as a community.
 - Know our worth and how to advocate for ourselves within systems that are not listening to us or effectively serving us. Challenge the interpersonal, institutional, and systemic barriers within health care and other systems.
 - Get the support needed to heal from the impact of systemic racism, grow to build healthy identities and become our best selves, as well as build healthy communities for Black children and future generations.

“The Black community, then and now, doesn’t have the basic options and resources to be human. Structural and systemic racism absolutely needs to be addressed if our community is ever to experience health and wellbeing...it comes down to the ability to provide enough options for unique individuals in all our communities to realize their unique individual selves. The role of all members of our society is to work together to make that happen for all of us.”

Addressing systemic racism within and across our institutions and systems is critical to building a social determinants of health (SDoH) ecosystem in our city and state that strengthens health and wellbeing in the Black community rather than continues to undermine it.

Systemic racism and poverty or access to health care, employment, housing, education, healthy food, and a supportive community reinforce each other to either undermine or strengthen the Black community's health. This is true whether Black people in Boston were born in this country or immigrated to it. The role of SDoH is either to deny or to provide Black people with the services, support, and resources they need to survive, be respected in our society, and lead self-determined lives that also give back to others. We must work together to remove the barriers of systemic racism—in health care and other systems as well as in our hearts—that have been created across generations and kept the Black community trapped. Removing these barriers will not only finally provide Black people with the social, economic, and political resources they need to support and sustain the health and wellbeing of their families and communities. It will also allow us all – as individuals, communities, and as a society – to grow in our humanity. We need to put caring for each other at the center of our work together to truly connect as human beings and to reimagine and co-create the city and state we want to live in. By acknowledging our shared humanity and re-aligning our institutions, systems, and resources to support it, we can choose to make our city, state, and future generations truly better for all. We can become a community with the heart, the courage, and the commitment to shape a shared future we all want to live in, and to get there together.

**What does health and wellbeing
look like to you?**



FEEDBACK FROM MEMBERS OF THE BLACK LGBTQIA+ COMMUNITY

Members of the Black LGBTQIA+ community say they are often looked down upon and can face discrimination almost every day. There is broad agreement among them that having safe spaces as individuals and as a community is what health and well being most mean to them:

- **Safe spaces at home to take care of themselves:** to unwind from the day, deconstruct whatever they've had to deal with, and prioritize and center their mental wellbeing so they can recharge to face possible discrimination all over again the next day
- **Safe spaces as a community where they don't have to worry about the pressures of discrimination they experience in society:** places where they feel they won't be judged, where they can relax, let things out, and make connections as human beings.

“What health and wellbeing look like to me is the ability to wind down and be able to completely leave the bullshit outside the door. Right now in our world over the past year, when we as people of color have been literally faced with is so much systemic racism, including deaths from COVID, just the ability to have a safe space to call home and separate myself from a crazy world is really important for my mental and physical health.”



FEEDBACK FROM BLACK ELDERS

Black elders say that the following are essential to their health, wellbeing, and state of mind:

- **A supportive personal network** to help us realize we need to get help, and to help us get the help we need
- **Financial security, especially Social Security and Medicare**, or other health insurance—and knowing where we can go to get it
- **Health facilities and providers that meet our needs:** especially important is having a primary care physician you communicate and connect with: one who respects you, listens to and learns from you, treats you as a partner in decision making about your health care, and advocates for you within the health care system to ensure you get the tests and services you need in a timely fashion.
- **High quality information to support our health**, so that we can become both informed consumers of health care as well as informed and empowered partners with our doctors in making decisions about our health and health care. It's also important to have access to this information in advance so that we can be proactive in maintaining our health and preventing illness, instead of only finding out about key information when we have to address health issues as they pop up.
- **Healthy fresh food that's affordable, and information about healthy eating:** understanding that there's a relationship between nutrition and health, and also understanding the connection between what you put in your body, how your body reacts to it, and that that relationship changes over time
- **Exercise**
- **High quality information about how to support our health and healthy eating is widely shared with the Black community** and disseminated to places where we can access it and through networks we trust: for example, health clinics, schools, Black churches, supermarkets, restaurants, barbershops, and hairdressers.

“Waiting until we become seniors to be dealing with these issues is, to me, too late. I think what supports our health and wellbeing - as individuals, families, and communities - is being educated as early as possible about healthy eating, exercise, supportive relationships, and financial security as part of lifestyle planning to support and sustain health over time.”



FEEDBACK FROM BLACK WOMEN WHO RUN

Black women who run say that regular exercise is foundational to their health and wellbeing.

- **They describe running as a holistic experience and agree that its benefits are physical, mental, and spiritual.** They say they feel most connected to themselves in this holistic way when they exercise.
- **Regular exercise keeps them clear, centered, peaceful, and energized to continue to accomplish more than they thought they could,** a practice that has helped them realize they have the capacity to accomplish much more not only in running but in other areas of their lives.
- **Exercise helps them deal with the “onslaught of isms”—i.e.,** discrimination based on their race, ethnicity, color, class, gender identity, and age—they encounter and have to navigate every day. They say that regular movement and their mental health are aligned: that they experience health and wellness through the power of movement, and that they experience movement as power.
- **They want to be as preventive as possible: to develop healthy habits—of exercise and healthy eating—that can not only save their own lives, but that they can pass on to their children, their community, and possibly future generations.**

“One of the things I’ve learned from running is that I can go further, I’m capable of doing anything and everything. The mind is a powerful thing. Running has allowed me to see just how powerful the mind is. For me, it’s not just about my physical ability. it’s about the mental ability to do it. I’ve always thought of running as more of a spiritual experience because I feel most connected when I’m doing it. The high you get from running is like God giving you the positivity to feel you can conquer anything. When you realize you have this capacity, you start asking yourself how you can bring this capacity to other areas of your life.”




FEEDBACK FROM BLACK MEN WHO RUN

Black men who run say that while their continued physical ability is a big part of what health and wellbeing look like to them, what supports them most is their brotherhood. They not only run together but support each other as human beings—emotionally, spiritually, socially, and professionally—to become the best version of themselves as individuals and as role models for their community. This support helps them withstand the ongoing impacts of racism as well as reimagine and build the lives, community, and world they want.

- **Physical health and physical activity are very important to them.** They try to stay active and engage in some form of activity—walking, running, working out at home or in the gym every day. They do this as part of a plan to stay healthy and have quality of life for a long time.
- **They all agree that physical activity helps them maintain their mental health.** It's both a great stress reliever after a long day at work, and also an outlet, a way to let out the anger that can build up inside from the ongoing racism they experience as Black men in this society, a racism that doesn't recognize their humanity, respect their individuality, or give them the space to just be, to bring their full selves to the table. Daily exercise helps them release the impact of all the ways their humanity is undermined on a daily basis. They also agree that continuing to push the bounds of their bodies, pushes them mentally, helps improve my lives both physically and mentally, and keeps them centered and balanced.
- **They pay attention to what they eat and to developing habits to support a healthy lifestyle:** fresh healthy food, natural products and services, and high quality information.
- **They encourage and support each other to think about and have a plan for how to sustain their health and wellbeing over time so they can live a long and fulfilling life with the resources they need to support it.**


“My health and wellbeing are very, very important to me and I do a lot of things to support it. Running to maintain my physical mobility is at the top of my list because at the end of the day, I need to be able to maintain my life at the quality level that I’ve set for myself. Cardio is key.”



“Sports give me energy and allow me to release emotions that upset me. They allow me to remain an open vessel, so that if anything comes around, it’s all right, it’s cool. I take it as it comes and the next day I work out. That helps me release whatever I need to to maintain my mental health. Also, it’s so awesome to connect with these brothers, this community of runners.”

“Physical ability is a big part of what health and wellbeing look like to me, and the ability to engage in it over time. It has also always played a role in my social health, helping me create spaces where I can connect with others. Black Men Run is a community of brothers who’ve given me a sense of self, a sense of purpose, even a sense of shared purpose regarding how I fit into this larger world.”

“What do health and wellbeing look like to me? It looks like great energy. It looks like commitment to myself and to my brothers. When I think about health, I see Black men running. To me they are the embodiment of what healthy looks like, and they are the embodiment of what will be.”



“When I think about what health and wellbeing look like to me, I think first of mental health. If you don’t have an outlet, a way to check in with your emotions and express them, then no matter how much you exercise, you might still die from a cardiac event. We know that 24% of Black men over the age of 20 are going to die this year because of some cardiac condition. And it’s not always because they don’t have a good diet or because there’s some history of heart disease. Stress will kill you. That’s a fact. As a Black man in this country, I do not have the privilege to not be able to articulate my emotions and what drives them. If I don’t articulate them, what builds up and comes out is anger. So for me, healthy emotional expression is probably the highest level of well being, and I can’t get there if I don’t have a support system to help me check myself and ask whether I’m actually keeping it real. I need to have a community that loves me enough to pay attention and help me keep it real.”



FEEDBACK FROM BLACK YOUNG ADULTS

Black young adults say that what health and wellbeing means to them is:


- **The freedom to do basic human things**—to eat, work, do school work, walk around freely—**without monitoring, supervision, or restriction by anyone**. They say that health and wellbeing means that we’re able to do what we want to do because we are in great health.
- **Taking care of your body**: getting enough exercise, drinking water, eating the right foods
- **The whole body**—mental health as well as physical health



FEEDBACK FROM AFRICAN COMMUNITY LEADERS


African community leaders talked about the challenges that members of their communities face, especially those who are immigrants and not U.S. citizens. They do not have access to the kinds of social services and support that U.S. citizens receive, especially if they are white. These leaders say that the immigration status of these members of their communities puts them outside the circle of our society's awareness, understanding, or human concern. To address the critical needs and human suffering of these members of their communities, these leaders say we need to focus on the following to support their health and wellbeing:

- A worldview and shared values that guide us to value each other's humanity, respond to and support each other when we're in need, prevent further suffering, and support individuals and communities to become whole.
- Comprehensive health care, equitable health care, and equitable access to health care, i.e., non-discriminatory services. When members of their communities get sick, they need to have easy access to what they need.
- Strategies that support their physical, mental, emotional, and social wellness, because the challenges these community members face are multi-layered.
- **Self-determination is key to health and wellbeing:**
 - **Being able to be self-sufficient, to have control over decisions** about how they want to live, what they need to feel safe and respected, including the kind of health care they receive
 - Acknowledgement that there are **different ways of knowing, other cultural practices** that people can incorporate to make decisions about their health, and that they can do that in ways they feel are safe and are not limited because of the color of their skin, their income, or the language they speak
 - The ability to have **equal access** to healthy food, cultural food, and food that's **not too expensive**
 - People having **safe access to their spiritual practices and their spiritual leaders**, and, as a spiritual community, not having to be hyper vigilant about their lives while trying to worship
 - **People feeling safe around state authority**



“I see it as part of the holistic gospel we believe in to preach access to the support people need to address their needs and prevent further suffering. How do we create this access and provide people the support they need? What kind of community do we have to build to both recognize these very real human needs and challenges as well as respond to them, to support individuals and communities to become whole?”

“Being able to be healthy means that I am able to incorporate all the ways of knowing, make decisions about my health, and do that in ways I feel safe and I’m not limited because of the color of my skin or because of my income.”



Do you get health care?
If so, where? Do you trust it?



FEEDBACK FROM MEMBERS OF THE BLACK LGBTQIA+ COMMUNITY

Three focus groups were held with the Black LGBTQIA+ community members. Two were hosted by **Boston LesBiGay Urban Foundation** and one was hosted by **Men of Melanin Magic**. Almost all participants in these focus groups say they get health care. More than half of them get their care from **Fenway Health**.

- **The overwhelming majority of those who receive care at Fenway Health trust it for the following reasons:**

- It's easy talking to doctors at Fenway about being trans: they are friendly, open, respectful of pronouns, and great for people of the LGBTQIA+ community. Fenway providers really relate to their patients.
- Fenway Health's approach to health care—many patients would like to see it adopted by health care institutions across the city, that serve neighborhoods as well as Greater Boston, so that they all learn to provide the quality of care and respect that the LGBTQIA+ community has experienced at Fenway Health.

- **People say that Fenway Health can improve its care in the following ways:**

- Make it easier to get an appointment. COVID has made it even harder to get one.
- If Fenway Health is really committed to partnering with and better serving the Black community to help improve its health outcomes, it needs to put Black gay men and Black gay women in leadership roles—on Fenway's board, in upper management, on their planning committees, and in their operational space—so that from their positions of leadership, Black people can continue to push Fenway to better serve the Black community. Several focus group participants shared their belief that the Fenway we see today, an institution publicly committed to advancing racial equity, is partially the result of all the pushing that the Black community did five years ago.

The rest of assessment participants from the Black LGBTQIA+ community also reported that they get health care, and receive it from various institutions across the city.

• **Most are not satisfied with the health care they receive or have received at these institutions, and gave the following reasons:**

- A few assessment participants said they grew up without health coverage, never had a primary care doctor or regular checkups, and, when they needed medical care, they ended up in the emergency room. As a result, they've never been taught about healthcare or its benefits.
- Health care providers at many health institutions in Boston are not culturally sensitive to the LGBTQIA+ community: they did not understand how to communicate, connect with, or serve them.
- They've encountered systemic racism and now want to be served by Black health care providers, doctors and nurses who recognize and respect the humanity of Black people and can understand their culture, the racism they face, and their other life experiences at a deeper level.
- When patients bring something to the doctor that concerns them, the doctor brushes it off and doesn't look into it or do tests to learn more.
- As a result of not trusting their doctors, a number of people say they haven't let their doctors know anything about their sexuality.

“If I feel the least bit uncomfortable with what my healthcare professional just said or how it was said, I let them know and that they need to fix it. I’ll give them one shot at it. But if it happens again, I’m outta there because I need them to believe what I’m telling them and to respond. I get to the point. I think we, as a community, have to be unafraid to challenge healthcare professionals and to be unafraid to make a change in our health care providers when it’s necessary. We need healthcare providers who are more mindful about the people and communities they serve. If you feel uncomfortable with your healthcare provider, you have choices: there are bunches of healthcare professionals who will want your money just as much as the next one. And I don’t let them rush me either.”

- **The few who say they are satisfied gave the following reasons:**

- Having a primary care physician who is kind and understanding and has conversations outside of healthcare to get to know their patients and make a human connection
- Feeling respected, listened to, taken seriously, and responded to
- Having people of color as their doctors
- Having a doctor who is very thorough

“What I trust in a healthcare professional is someone who listens to me, learns from me, and builds a relationship with me so that we can function as partners in my health care. I happen to have a very good healthcare professional. My primary care physician is a straight white female, but she’s on the money and she doesn’t play when it comes to anything I tell her. She explores it. She doesn’t just give it a pass and say check back with me in a couple of weeks and see how you feel. She refers me to others when we need to get more information to better understand and solve the problem. At my age, it’s everything to feel like my healthcare professional has my back. Yeah, it’s everything.”



FEEDBACK FROM BLACK ELDERS

Elder Health Care Disparities Coalition hosted the focus group for seniors. Everyone in the focus group gets health care, and from various institutions across the city.

- **What they say they trust:**

- A physician who takes the time to get to know their patients and works with them proactively
- A doctor who's honest with them, treats them with respect, sees them as a partner in making decisions about their own health care, is not threatened by the patient asking questions to better understand their situation, and is open to finding out whether a particular medication impacts Black people differently than other populations
- The opportunity to connect with and be cared for by Black health care professionals, including primary care doctors, nurses, and specialists
- A doctor who advocates for the patient within the health system, including getting necessary tests and procedures done
- Being able to have people they trust accompany them on visits to the doctor, as advocates to help the patient get their needs met: to ask the questions they have, get them answered, understand what is being said, and take notes on the meeting so that the patient has their own record of the meeting and can use it to decide what's best for their own health.
- Having a doctor who accepts that the patient will be a full partner in advocating for their own health

“My doctor and I are coming up on our 25th anniversary. I’m still going to my guy. And until he locks up the door and takes away his shingle. I’m still going to my guy, because we have a long-term relationship of trust and I trust him with my life.”

- **What they say they don't trust:**

- A physician who doesn't listen to or follow through on their concerns, who doesn't explain things to them so they understand their situation, what they need to do, and what they should be looking out for, i.e., a physician who prepares patients to understand how to support their health

“I’m always ready to question my healthcare provider if I do not get a response that I feel comfortable with. A key factor that impacts whether I trust the health care I’m getting is having a doctor who accepts that I will be a full partner in advocating for my own health. Listening to and learning from each other to do our best to support and sustain my health and wellbeing has to be at the center of that relationship. I will not be a silent partner. Because what’s at stake is my life.”



FEEDBACK FROM BLACK WOMEN WHO RUN

TrailblazHERS hosted this focus group. Everyone in the focus group gets health care, and from various health institutions across the city.

• **What they say they trust:**

- Being welcomed and treated and spoken to with respect and human warmth
- Health care providers who listen to their patients and respect their wishes
- Primary care physicians who give their patients options and make a referral right away if it's something the doctor can't take care of
- The opportunity to connect with and be cared for by Black health care professionals, including primary care doctors, nurses, and specialists

• **What they say they don't trust:**

- Health care providers who don't acknowledge the humanity of their patients or treat them with respect, and who ignore their questions
- Doctors who don't trust that their patients know something about their own bodies
- Doctors who dismiss their patients' concerns instead of listening to them, taking them seriously, and looking into them to explore what's happening and why
- Doctors who don't inform their patients up front about what costs the patient is responsible for regarding any procedure the doctor recommends, so that the patient has the option of choosing. The result can be a big bill the patient did not expect and cannot afford to pay.
- Having to wait forever to get an appointment
- Getting health care from the same health care organization where patients work causes concern among some patients about their privacy.

“I had this nurse. She came three or four times asking me if I wanted pain meds. I said no, she came back, and I said no. She asked me so many times that she felt like she was being pushy. I just felt like I wasn’t being heard. I knew what I wanted for myself and I repeatedly let her know. I didn’t like that. It’s with me till this day. I think about it all the time. Why would a nurse push a patient like that for something the patient doesn’t want? I never went any further with it, but I felt she crossed a line.”

“I don’t want to feel defensive about the place I go to for help, but I’ve felt my issues were not being taken care of, that I was not being listened to, and that my feelings were not being acknowledged – so I stood up for myself. But It took me a while to advocate for myself. Throughout this whole time, I continued to communicate to my doctors that I was experiencing severe pain: I couldn’t even walk. But they still were not hearing me: it was as if they didn’t believe me.”

“What is the benefit of all that innovation if you’re not putting it into practice? They’re bringing in the innovation but falling down on the care. As a Black woman and a patient who’s experienced that first hand, it doesn’t feel like world class health care to me. They have a lot of work to do. To improve their performance, they need to begin by listening to their patients, being attentive to their needs, and trusting that their patients know something about their own bodies. They need to trust the validity of their patients’ experience, and they need to work with their patients rather engaging in a power dynamic as the health care professional who knows all. The goal should be to provide the best care possible for the patient, and that can only be achieved by respecting the patient as a full partner in the process. The doctor and the patient need to learn from each other if quality care is to be achieved.”



FEEDBACK FROM BLACK MEN WHO RUN

Black Men Run hosted the focus group. Everyone in this focus group gets health care, and from various health institutions across the city.


- **What they say they trust:**

- The support they get from their personal support network, including their doctor but also their family and friends as well as their running group, sports trainers, and life coaches, and therapists
- They can tell their doctor anything: she creates a safe space to be open about everything.

- **What they say they don't trust:**

- Doctors who don't connect with you and respect you as a human being
- Doctors who are intimidated by Black men
- Doctors who don't acknowledge your feelings, who ignore your symptoms, aren't clear in their explanations of what your symptoms are, don't give you clear answers, and don't speak to you with confidence and assurance


“Yes, I have access to healthcare and I use it when I need it. I've been with the same primary care physician since I was a freshman in college. I do trust him. I trust that he did his work to earn his position and has more knowledge than I do in that space. I trust him but I don't have blind faith in him, because I recognize the challenges in our healthcare system and also the benefit of being able to educate myself. So I make sure that I double check, triple check, and verify or disconfirm what his recommendations are. I don't have blind faith because I know that it's not a perfect health care system, and that my health care resides within that imperfect system. I make it a point to be assertive and exercise a lot of agency, a trait I share with my Black brothers in my running group. We all have and support each other to have a healthy sense of identity. All the brothers have a healthy sense of pride in being Black. As a result, all have a healthy sense of value and self worth, which gets expressed in their self care to support their health and wellbeing as well as their advocacy for themselves within the health care system.”



“No, I don’t trust them, because when I do go to the doctors, there’s often a mentality they have. When you get to be my age, you get to understand exactly the subtle body language that says I don’t respect you, I don’t believe you, and I really don’t think that you’re really going through what you say you are. This is how the violence to our humanity happens, especially if you’re not highly educated and didn’t learn big words. I get angry and then end up not going back into the healthcare system because the last time I went, the doctor talked to me like I didn’t know what was going in my own body.”

“I couldn’t tell whether he underestimated my ability to understand the science behind the symptoms I was experiencing, or whether he was intimidated by me because I insisted on his giving me a real answer. So I left that doctor and found one who would explain things to me.”

“People I trust help keep me relaxed, focused on my self care, and balanced and centered. As a Black man, having this support system is key because most of the time, I never feel like I get a chance to pause and just be myself. I’m always having to react to other people’s assumptions or expectations of who I should be. But with people I trust, I know they genuinely see and care about me. I can just be myself: relax, restore my balance, and walk in my own power and my own being. That’s been really good for me. Being around them is healing.”





FEEDBACK FROM BLACK YOUNG ADULTS

Greatest MINDS hosted this focus group. Everyone in the focus group has access to health care, though one person doesn't remember using it. They get it from various health institutions across the city. Some have been going for years, since they were kids, to the same health care provider as part of their family's health plan.

- **What they say they trust:**

- It's very friendly. My doctor and other people who attend to me show concern. I'm very satisfied with it.
- I get health care from my school and I also go to see my doctor in a health care center. They're very kind.
- I have the option to choose my own primary doctor.
- I like that it's relatively inexpensive.

- **What they say they don't trust:**

- I don't like the doctor's office or hospitals at all. I've never been comfortable there.
- I don't remember the last time I went to the doctor's office. I don't like it because I feel like it's kind of a waste of time. Since our bodies are going to heal over time, I don't like going to places like that. I've been that way since I was a kid.

- **What could make it better:**

- I do get health care and just started this year. I was with another health insurance company connected to my job, but I got laid off from my job so I ended up signing up myself to the health care I get now. I'm still relatively new at it. I haven't really used it that much. I haven't actually been to the doctor at all this year. I'm about to go for my physical next month. But what would make it better - and I've been talking about this for a long time with people - I don't understand why we can't get it together and have universal health care that is free. That would make it better because I believe health care should be free. It should be something that everyone has access to when they need it, without having to pay.
- A lot of people don't really have the option, the freedom to choose their own doctor and choose the medical facility they go to. I think everyone having the option to choose would make health care better.



FEEDBACK FROM AFRICAN COMMUNITY LEADERS

A focus group of **African Community Leaders** was hosted by Chioma Nnaji, a Nigerian American who does community organizing and works with diverse African communities in Greater Boston. Two members of the focus group say they receive health care. The other members of the focus group did not share whether or not they do.

•What they say they trust:

- Health care providers who recognize my humanity and respect and treat me as a human being
- Providers who are women of color because, in my personal experience, they are the only people who've listened

• What they say they don't trust:

- How brainwashing the steps to becoming a doctor, a nurse, or other health provider, can be
- Health care providers who DON'T recognize my humanity and, the humanity of others—my family and members of my community—and, instead, only see my race, my class, and my gender

“I trust it to some extent, but something happened to me two or three years ago that was both painful and disturbing. I needed surgery on my eye and just as it was about to begin, the team realized they didn't have a key product they needed to perform the surgery, so they decided to perform the surgery an old way, using materials that left my eye in pain for a long, long time. I've asked myself regarding what happened to me in that hospital, would this have happened to me if I weren't Black? Was what happened because of racism? But another question, just as disturbing, also comes up for me: Was what happened to me a one off, or are there other instances of practices in that hospital where they show up for something like a surgery and they're not prepared? What do they go through to make sure that everything is in order before they even start? I don't know what they do. This is an important question to ask because it's not about me. What about people who don't have the opportunity, as I do, to get my healthcare elsewhere? What happens to them?”

“My trust of the health care system is really determined by how I see them treat me, or when I had an accident, how they responded to that, or when I see them speak to my family who still have their accents, how they respond to that. It’s almost like testing somebody you’re going to dinner with by seeing how they treat the wait staff. Do you respect me as a human being? Do you recognize my humanity - or instead not recognize it because of my race, my class, my gender? That is more telling to me than how well you’ve memorized several medical textbooks. Healthcare providers are not trained by institutions to help them see and respect our humanity. I want to trust them, but what I pay attention to and respond to is their behavior. If their behavior is not respectful, I don’t trust them.”

Besides receiving health care, assessment participants reported that they do other things to support their health, resilience, and wellbeing:

- Spiritual practices to support health and healing
- Meditation and yoga
- Employing coping mechanisms whenever I have anxious thoughts or experience stress
- Prioritizing self care
- Keeping my home space peaceful
- Running groups and other sports clubs
- The visual and performing arts, including writing, acting, music, dancing, and clubs
- Maintaining my social life: through relationships, social interaction, social outings, spending time with friends
- Circles of support: individuals you trust who support each other, understand your experience because they come from it, and support your development, growth, and agency.
- Community groups, like the LGBTQ Elders of Color
- Mentoring others
- Learning to advocate for myself
- Staying up to date regarding what’s important regarding my health
- Keeping up with current events and continuing to be active in society: participating in online forums and community conversations to figure out how we can come together to strengthen our community and this city so that they are better for all. We need to talk about how to breakthrough to a better life for all.

What would your community look like if health and wellbeing were fully present to support you and your family? What would bring increased wellness to your community? What resources do you wish were available?



FEEDBACK FROM MEMBERS OF THE BLACK LGBTQIA+ COMMUNITY

I think more acceptance or just loving people. I've found that sometimes it's hard to be in my community because a lot of people constantly judge each other and focus especially on the way people look.

I would like to see a community that has eliminated stigma around gender, and less focused on our sexual habits. What's up with that? Currently, once people identify you as being gay or lesbian, they want to know about your sexual health, about your sex life. I don't ask you about your sex life. We need to eliminate stigma about many things: culture, gender, and HIV. These are the kinds of things that continue to push our community members away from getting the good health that they need.

Adding more healthcare professionals who are people of color would bring increased wellness to our community in a big way, because they know how to identify, they know how to talk to people, and they know our frustrations. Often, by the time we finally get in front of a healthcare professional, it's not always about what is actually ailing us. It may be a whole bunch of other stuff. Your doctor may ask you, well, how come you're not taking your pills? How about your doctor asking about what is going on in your life to better understand what needs to be addressed? The healthcare professional would have more of a holistic approach to healthcare, and it would give them a way to see and address more of your personal issues, i.e., address what is going on around you and what is going on outside of their office. I think that would go a long way to improve the health and wellbeing of our community.

I agree. I think we need to employ people who look like us in these healthcare positions, but it's not just about putting Black people in those roles. It's about how do we develop community members professionally to be able to take on those roles, AND it's about developing a more human-centered approach to health care. What I've heard from everyone on our call today is that our doctors, our nurses speak to us like we don't know ourselves, like we don't know our bodies, and like we don't know our needs. If we could just break down that barrier and walk in a space of shared humanity with our doctors, as well as transparency and honesty with our doctors, and eliminate their current "All I have is 15 minutes to deal with you on what you need" approach, I think that would bring increased wellness to our community.

So let's make this more about addressing the needs of a person than just about pricking someone's finger or drawing their blood and finding out if they have HIV or not. It's about their housing. It's about their employment, it's about their mental health, and it's about, did they fucking eat today? That's something we need to address when we're talking to the Black community and our clients about what's needed to increase their health and wellbeing. Yeah.

We'd have strategies that reach and empower people not currently served by our health care system to gain access to key resources they need to protect their health. We'd have ways to connect with people living in poverty, people who don't really go to the clinic, people who don't get checked, people who don't have health insurance. You have to understand that the majority of the people who aren't going to the hospital, the majority of the people who aren't getting the mental health they need, the majority of the people who aren't getting tested are the ones we need to reach through the clubs. A club can gather 800 people in a room on a weekend. How can we ensure that our health care organizations have placement in these places?

When we used to have the balls, the people that didn't have jobs and didn't have money, they came, and when they came, they got an HIV test and we gave out information and other free things to protect their health. Then they got to go in for free. They got to ball, somebody bought them a drink, but, most importantly for their health, they got tested. There are people in our community who are not taking advantage of whatever health resources might be out there to keep themselves healthy, like getting vaccinated against COVID-19. What we need to do is meet them where they are: go to the events they will show up for, provide incentives they like, and make sure that they get tested and get information about resources they can access to protect themselves and get their health care needs met. These kinds of strategies support physical, mental, social, and community health.



FEEDBACK FROM BLACK ELDERS

What we've learned in the last year under COVID is, it seems like every time you turn around some community health center has a pop up testing site beyond their campus in their surrounding area. To bring increased wellness to our community, I'd love to see that expand beyond just COVID testing. I would love to see pop up blood pressure testing. We've got health vans going around, but they don't go around to all the neighborhoods. So I would challenge community health centers, like the Harvard Street Neighborhood Health Center, to go beyond just the parking lot and go down the street to Academy Homes and into Martha Elliot right into projects. I challenge them to expand their footprint, so that the people who live near them, across the street from them, not only know about their services but can access their services without having to walk through their doors. I'm a strong advocate of bringing the services to the community especially if you're in the community.

If health and wellbeing were more fully present, we'd see widespread education about food and the availability of fresh, affordable food. We assume people understand not only the value of it but what is good about it. I think if people – families, kids, and communities—were more educated about the value of healthy eating and how it impacts their bodies, and actually began to change their eating habits, it could support and sustain their wellbeing over a lifetime.

We'd see lots more people, including seniors, engaging in activities that support and promote physical, mental, and community health: getting a physical every year to understand the condition of your health, discover if anything needs to be addressed, and, if so, to take action early; participating in the arts; learning new things; joining others in strengthening our civic life; and exercising. As a sidebar to that, people would not presume that you have to go to the gym every day to be more physically fit to protect your health. We'd see people getting exercise in many other ways and places that are free, including walking and running in our parks.

We'd see the prevalence and equitable distribution of green spaces supporting the health and wellbeing of our communities. Boston does this better in some neighborhoods than others. We'd see green spaces that are there for us to use, for people to experience and have full access to—and not there just for decoration.

We'd see the quality of life and mental health of everyone, including seniors, being improved through caring personal networks and supportive relationships in all areas of our lives: personally, professionally, at school, as a community that supports each other, and in the healthcare system. Specifically, with our health care providers, we'd see relationships that go beyond an awareness of our needs. There would be real awareness of who we are and what we bring. There's something called our social identity map, which includes many things like our citizenship, our place of birth, our gender, and our family heritage. A multiplicity of things determines who we are and how we see ourselves in the world and how others see us in the world.

If health and wellbeing were fully present in our community, we'd see information widely distributed throughout our community about the connection between all the things we're talking about – information that shows seniors the connection between being physically active, eating well, and the importance of caring personal networks and social connection for preventing isolation and loneliness and supporting and sustaining their physical and mental health. This would help people make the connection between their behaviors and their health and their wellbeing. Black churches would be key partners in helping us get the word out. Seniors who never used computers before COVID would continue to do so, so that they can stay connected both socially and to support their health. We'd see them attending forums on diabetes, high blood pressure, exercise, how preventing and addressing prostate cancer can improve our sex lives, and other things important to sustaining their wellness. We'd see them using the internet to find guidance on their rights and how to advocate for themselves within the healthcare system (and other systems), including how to change their doctors or their health care institutions if they're unhappy with the care they're getting, and how to assess where and how to find something new.

Seniors need to know things like:

- 1. All hospitals in this city and state have patient advocates, so seniors can put in a formal complaint if they have one, or they can ask the patient advocate to help them understand how to switch their doctor or their health care facility;*
- 2. If seniors have straight Medicare, not Medicare Advantage, they can refer themselves. They do not need a referral or anyone's permission. The only time they need someone's permission is when they have insurance other than Medicare as their as their primary insurance. All they have to do is call up or go online;*
- 3. If seniors are using the internet, switching is fairly easy online, no matter what insurance seniors have. They can look up the kind of doctor they want and check to see whether or not that doctor, or a particular health care facility they want, is taking on new patients. While switching is fairly easy online, finding out who's really effective is harder. I would encourage Black seniors to ask for recommendations from trusted sources in their own personal networks.*

To bring increased wellness to our community, we'd see information like this being conveyed to Black seniors in ways they can identify with and in a language that connects—so that seniors are not just receptive to information shared with them, but can actively use it and engage with others who share their values and interests, including the policy advocacy community focused on improving the health care system for all. I've noticed that the Mayor's Office and other senior centers are actually offering daily sessions that people, including seniors, can access just by clicking into Zoom and being connected. So we know that social connection and getting high quality information to support their health and wellbeing are priorities for seniors, and that they're willing to learn new behaviors to address their priorities.

If health and wellness were fully present in our community, Black people, including seniors, would have access to high quality health care in our neighborhoods and we'd see cultural competence and cultural humility widely practiced in health care institutions in our neighborhoods and across the city. Health care institutions would know something about Black culture and understand that the Black people they serve bring knowledge and experience that must be invited, respected, and used to inform the health care they receive. Black people would feel welcomed, affirmed, and effectively cared for in all these institutions. It would be normal to see Black people leading these institutions, on their boards and as their top managers. It would be routine for Black people and everyone else to have Black doctors as their primary care physicians and specialists.

All of these institutions would partner with the Black community to figure out how to improve the health outcomes of Black people in Boston—so that race no longer becomes a predictor of Black people's health, and the authentic engagement, partnership, and leadership of the Black community becomes a key predictor of the health and wellbeing of Black people, communities, and the institutions and systems that serve them to improve health and the social determinants that impact health and wellbeing.



FEEDBACK FROM BLACK WOMEN

If health and wellbeing were fully present in my community, we'd see peace of mind. I feel like we are stressful beings. Racism has been put on us for generations and generations and we're still fighting to find a piece of mind. What's needed in our community to produce peace of mind is communication with each other about how we can be better, as a group, as a community. I feel like there's such a huge disconnect and because of that disconnect we are where we are. We have to find a way to come back together.

What would bring increased wellness within the Black community is mental health—and overcoming the stigma of it within the Black community. We'd seek therapy and seek support when we need help. But we'd have to overcome two big barriers to get there: our distrust of the health care system because of how it has mistreated us, and our resistance against acknowledging that we need help when we are struggling emotionally. To overcome our current distrust of the health care system, we need mental health professionals we can trust: people who listen to us and are culturally competent, and best of all, are from our community.

When Black people don't feel heard or respected by their primary care physician, that can translate into a distrust of other health care professionals like therapists. To feel comfortable seeking their help, people need to feel they can have trust and rapport with their therapist, a healthy relationship. I think that would play a big part in increasing health and wellness in our community. If you don't trust your doctor who's checking your blood pressure, you might not also trust the therapist, who's been referred by that same doctor. There are layers within that medical team, and lack of trust can be spread around. That's why it's important to have mental health professionals who are culturally responsive and do their due diligence to work with our community, and to support our community. I also think that Black people have a complicated relationship with resilience. We've been taught and raised for so long that we've got to be strong, that we we have to push through. But at the same time, we need support. We need support when we're struggling with something. In my view, seeking help is not a weakness. It's really a strength to advocate for yourself and change the narrative. So, to me, seeking help is empowering and helpful and can lead to an overall better circumstance.

I want to see peace of mind in our community, too. I think what it will take is very layered, because we're talking about decades and centuries of trauma and fear and pain and disillusion that all has to come into play when we're talking about peace of mind.

I believe that Black people, of all people, need to see a therapist. We're dealing with so much generational trauma that we don't even know how it manifests in our lives, like why we do the things that we do. I come from an African family. We're highly religious, highly Christian. For a long time, I was not able to tell my family members that I was depressed and dealing with anxiety. If I tried to share what was going on with me, their responses were always the same: to ask me if I was praying enough, to tell me I needed to find a good church, and to tell me I needed to talk to God. Don't get me wrong. I think God is great, and we definitely need to have our own relationship with God. But that's not necessarily taking care of your mental health, unlearning toxic behaviors and learning about self care.

What it will take to being about peace of mind in our community is a deep question. And there can be multiple answers. While running and other forms of exercise can bring tremendous health, wellness, and peace to us as individuals, we also have to be aware of how history across generations can affect the health of individuals and their community. The impact of that history and the trauma that history has to be addressed: first by acknowledging that history and its impact, and then by supporting a community to heal from the impact. We have to name the deepest sources of why we don't have peace of mind, and then we have to do something about it: we have to talk about and reimagine the kind of society we want to live in, and then work together to make it happen.

When I think of what it takes to have peace of mind, I think you have to have a healthy sense of your identity, especially regarding race. That's extremely important here in the States because it's history, culture, and current society are so steeped in systemic racism. You need a strong healthy identity so you don't internalize the racist messages this country sends constantly. I emphasize this because I work with children and see how they internalize all these negative messages about themselves. You need to have a healthy sense of yourself your racial identity, which is very hard to cultivate when from the time you're young, you've been shown and heard negative images of yourself and your counterparts. You're constantly bombarded with these images. How can you actually know who you are versus what you've been told about who you are? When you actually know who you are, you reject those messages, images, and assumptions. You say that's not me and that's not my culture.

Supporting our children to know who they really are requires that our community take responsibility for it. That's generational work that needs to be done. You have to first have a generation that can see and acknowledge what's happened and then make corrections. For example, I've already said that because of my experiences, I don't have a good relationship with the healthcare system. I've acknowledged that and I know the reasons for that. My children don't necessarily need to have the same relationship that I do, I'm not expecting that they would necessarily trust the health care system, but that they can move differently through it if we do the work to change it.

As a result, I want them to know more than I did about how to advocate for themselves and their community as they navigate their use of the health care system to meet their needs and goals. I want to get them to the next step. I don't want to see them or Black people always in a survival mode. I want to see us thinking ahead—ten, twenty, and thirty years down the line - about what we need to support peace of mind for ourselves, our community, and future generations of Black people. We need to start thinking that way and we need to start talking together with each other as a community, and healing as a community, because we can't do this work by ourselves. We have to do it together: it has to be shared. And it doesn't even have to be everybody, but it has to be enough of us, where we're coming together and creating this critical mass of our people who want to see peace of mind prevail in our community, who are willing to talk about what stops us from having peace of mind, what gets in the way, and what we need to start putting in place so that we can literally start creating not only a healthier environment for ourselves, but a healthier environment and possibilities for our children. We need to connect and learn from our past and present and define what's needed to create the future we want: a future of health, well being, and peace of mind for our kids and our community. We have to do it.

Getting rid of food deserts is essential for bringing increased wellness to our community. Obesity has been directly linked to poverty. When you're on a limited budget, you can only buy inexpensive things, things that last longer, to feed your kids. Things that spoil faster, like fresh fruits and vegetables, are things you can't afford. The result is obesity. Even when the stores in our neighborhoods do sell fruits and vegetables, they don't look fresh. Why do we still have to get like the bottom of the barrel? Why do I have to go all the way to JP to Whole Foods to get my fruits and vegetables? We need to be able to get fresh, healthy food we can afford in our own neighborhoods. This is essential to building health and wellbeing in the Black community.

What we need to bring increased wellness to the Black community is to strengthen relationships within our community and across communities that want to see improved health, resilience, and wellbeing for all in our city. And as we do this relationship and community building, we need to create safe, welcoming spaces where people feel comfortable to be and bring themselves fully. We need to create a culture in these spaces that's very organic in the way we build community, inviting people to join us who will do the work to support themselves, each other, and the community to deepen their own health and well being.



FEEDBACK FROM BLACK MEN

The products available in Black communities are mostly dangerous to your health. On almost every corner you see a liquor store, and the food isn't healthy or fresh in the places where you can buy it. To get healthy, fresh food you have to go a white community—but we don't have to get used to junk food and liquor stores in our community! What would bring increased wellness to the Black community is the ability to get healthy, fresh food and natural products in our own neighborhoods. It's essential to support health and wellness. We'd see fewer liquor stores and fast food chains in our community, and more chains like Whole Foods that sell healthy, fresh food—but it would have to be at an affordable price. We'd also see more farmer's markets as well as locally owned businesses, like restaurants and take out shops, that sell fresh, healthy food from different cultures that now live in Boston. You'd see a thriving food culture flourishing in our community, which would not only attract the Black people who live there, but people from across Greater Boston who love food from different cultures and also want it made with healthy, fresh ingredients. Our different cultures know how to make food taste good, but because of systemic racism and poverty, including segregating our communities and cutting them off from basic resources they need to be healthy, our community has not had access to healthy, fresh food - and you see the impact of that on our health across generations.

What we now have the opportunity to do is reverse that by waging a campaign in our community to combine healthy, fresh food with what we know best: how to make it taste good! I'd like to see us wage this campaign and target our homes, our schools, our nursing homes, our supermarkets, our restaurants, and our streets. I believe this kind of campaign would help improve our health, strengthen the economic development of our neighborhoods, and engage members of our community in working together to improve and sustain their own health as well as that of their families and friends across generations.

What would bring increased wellness to my community is more groups like Black Men Run—an amazing group that connects exercising with building healthy relationships with each other and a healthy community. I really needed this and so do many others in our community. I'd been looking for a group like this for a long time. I'd been going through a phase of not being too motivated about exercising or doing things to improve my life. I'd just go to work, come home, and that's about it. Until I met Black Men Run. Now my Saturday mornings, to run with and connect with this group, are very, very important. I now also work out during the week. I've been motivated to make this shift because of all the encouragement they've given me. The group provides space for us to talk about all kinds of things, from what's going on in the wider world to what's going on in our lives personally, and how we can support one another. We share a kind of vulnerability that you don't often see with Black men. We talk a lot about wellness and well being

and prioritize it. We learn lessons from each other. When I first attended this group, it became clear to me that this group is about more than just running when we had our opening circle and each of us shared what was going on. I said to myself, okay, this is different. It's just not a running group. We take the time to talk with one another and share. That's the reason I love this group.

If health and wellbeing were more fully present in our community, it would look like a bigger version of Black Men Run. I think one of the most important pieces to this is the ability to control our narrative, our own story of who we are. I think that's really important when we speak about the health care system and how it's based on structural racism. To be able to tell our own story and speak from our authentic voice, and not be trapped by performance—expected behaviors we engage in to be included and accepted by others, and out of fear of being rejected—is very important because for too long, Black people have been told who we are by other entities that don't value us, and a lot of us have been believing that. So it's important that we start writing our own narrative, and controlling that narrative in the healthcare system so that we can make more empowered decisions about who we are, what we want, and what needs to be done to achieve our goals.

It's important not to fall to the trap of performance, because it's not who we really are. It's important for us to be authentic and stay centered in and true to who we really are. Since the health of the Black community is impacted by the health care system as well as other systems, it's important to bring about change across all these systems: i.e., to change the narrative, the practice, and the accountability of these systems for producing results that help improve the Black community's health.

What the Black community would look like if health and wellbeing were fully present? First and foremost, you'd see people investing in themselves, their own self care, as well as the health and wellbeing of their families and friends. I think this is essential for building a healthy community. And I feel this group, Black Men Run, can help bring about that change. As we run on Saturday mornings, we hear people cheering us on, shouting praise to us, and asking about our group. We stand out, first and foremost, because there are no other Black running groups for men. But I think there's another reason we attract attention: showing up like this, modeling this behavior, showing our community what we as a community can be, is a way of being leaders, being recognized, being seen—and being a reflection of what we want this community to look like.

I think when we run, people see our positive spirit, a positive outlook that Black men can bring to our community, which challenges the negative images they hear or see in the media. So positive Black men, that's what this group's about. It's just not the running aspect. It's the positive mental aspect as well, and being able to share our experiences comfortably with one another and talk about those things in the group. I was a member of

a different running group beforehand, and it was nothing like this. I can count on one hand how many Black people are in that or other running groups. That was always something that didn't sit right with me. The other group was a nice group but it wasn't what I was really looking for. So when I discovered Black Men Run and saw the opportunity to join it, I jumped all over it—and I haven't looked back. I've been so grateful for being part of it.

If health and well being were fully present, what you'd see in our community is a kind of social, spiritual, communal connection—a love—that allows and supports people to be and creates the space for them to grow and become their best selves. You'd see people supporting each other, caring for each other, working together from a space of love and from standards of integrity, inclusion, and civility.

Another thing you'd see—and that we need to bring increased wellness to the Black community—is Black people participating in a healthy economy inside their community as well as in the wider world. The barriers that currently keep them from participating would be removed and allow them full access to the resources they need to grow and become their best selves. You'd see parents able to support their families at a threshold level of wellbeing because they receive a life supporting wage. You'd see the creation of new businesses by Black people, inside as well as beyond the Black community, including those that focus on and support health and wellness: farmer's markets that sell fresh, healthy, and affordable fruits and vegetables; holistic stores where people can buy herbs, grains, nuts, and other natural products; and high quality trusted information to support individual and community self care.

What it would look like if health and wellbeing were fully present in our community is that our community would have all the elements that exist in the suburbs or in affluent communities that generate better health outcomes. That's what our communities needs. In fact, if we had those elements, our community would be even better than suburban or affluent communities because we have a lot more the diversity, a lot more swag. We'd also replace things that are hurting our communities with things that would help our community. For example, we'd replace liquor stores as well as fast food stores and mom and pop shops that don't provide healthy food options with things that help improve our health outcomes.

Black men are not a monolith. Some of us have grown up in families that were able to support us, and some of us have not. I don't come from money at all. I come from a very, very low income household. My mom and my dad struggled with substance abuse, so my older brother and I had to raise ourselves from a very young age. I remember looking through our couch for change to buy food. What helped me overcome those very significant barriers was having access to play and utilizing play as my outlet. It was very therapeutic for me to overcome the barriers I faced. The support I wasn't receiving at home, I was receiving in the streets: learning how to recognize right from wrong and not get involved in things that a lot of my

peers would encourage me to do. I just focused on playing and having fun with friends I loved and trusted. That's what saved my life. If I use that logic to think about what could be added to our communities today to bring greater health and wellness, I would add access to resources that would allow our people to have positive outlets: positive clubs, organizations, and groups like Black Men Run that can keep us on track and help us navigate the very tough situations we face. We need to make sure that our people have access to things that can keep them from stepping on landmines that are all over our communities. Black Men Run provides that for me: it has been a continuum of what I had access to growing up, something that saved my life: being part of a community that loves, trusts, and sustains me. So when I think about what could bring increased wellness to Black people, I think about the importance and power of a community that loves and sustains us. If we love and trust and support each other, we can save each other's lives. I'd like to see us figure out how to spread what we've learned to do in Black Men Run with and for each other. I'd like to see every member of the Black community have access to this kind of care and support.

It's taken me 40 years on this earth to be able to name and own my humanity. My grandfather's grandparents were enslaved. My mother's mother was a sharecropper who had to run from violence, only to find more violence in Chicago. I did not have a lot of support growing up. My parents were doing the best they could to try to figure things out. The Black community, then and now, doesn't have the basic options and resources to be human. Structural racism absolutely needs to be addressed if our community is ever to experience health and wellbeing. There's a statistic that sticks in my head and my heart that I can't shake: an adult living in Roxbury has a life expectancy of 58 years, but if you move three miles north into Back Bay, an adult can live to 91 years old.

If I boil it down, for me, it comes to the ability to provide enough options for unique individuals in all our communities to realize their unique individual selves. The role of all members of our society is to work together to make that happen for all of us. That's what would bring increased health and wellbeing to the Black community and every community. In the mean time while we are working toward that goal, we, as African Americans have to do what we've always done: put our arms around each other as we continue to affirm and be inspired by our humanity, fight for our human rights, and fight for full access to the resources we need to realize both the potential of our communities as well as the promise of our unique individual selves.



FEEDBACK FROM BLACK YOUNG ADULTS

That's a question I never really thought about, other than what I said previously: being able to see in our community free access to health care for people. That's what's important to me.

I think what could bring increased wellness to everyone is getting people the support and resources they need to be able to take care of their bodies: to be able to have clean drinking water, to eat fresh food, to feel mentally supported in their emotional and psychological health. We need supermarkets with fresh produce in our communities. We need fitness centers and gyms: we need to have more places where people can get physically fit. In our community it's a detriment that people don't really have access to these types of resources which are available in other communities.

We need resources to educate people about the food they eat, how it impacts their bodies, and to encourage them to eat more natural foods. That's way better than most of this artificial stuff. Having this kind of information could be a solution for people. It could be a life changer, a big game changer.

If people in my community had health and wellbeing, there would be fewer people on the streets asking for money. There would be fewer people who are starving. And they would have homes and somewhere to go eat, and they wouldn't have to beg for it. If people had housing, enough food to eat, things like that, I think it would support them to be healthier by stopping them from getting sick in the first place. Not having these basic things causes people to get sick. Having these basic things helps make people and communities healthier.



FEEDBACK FROM AFRICAN COMMUNITY LEADERS

If health and wellness were fully present in our community what would be there is self determination for ourselves, our families and our communities. This is important because so much of what we have to endure puts us in situations where we don't have a choice. My family didn't have a choice but to immigrate here. Most of my family's here under asylum. It's kind of hard to picture a healthy community and a healthy African community specifically while in a place that's not our homeland. We can make it our home, we can build communities, but it's not our ancestral homeland. It's not where we belong, and that might not be true for everyone, but it is true for how I've felt my entire life and how I've experienced the United States since I've come here. So a healthy self determining community might not have been one that chose to immigrate here. it's very difficult to imagine a healthy community in the United States because for me, self determination for the future of ourselves is so important to help me determine where we get our food from, where and how we can practice our religions, and who we get our health care from. It's very difficult to imagine that here.

I agree that healthy self determination for individuals and communities is crucial to having health and well being fully present in a community, not only because of the history they experienced that led them to migrate here, but what they experience here in the United States. It feels as central to health and well being in a community as what was named earlier: having a worldview of wholeness. Those two things combined feel like they give a community the sense of connection, solidarity, and power to advocate for what that community needs, even if that community finds itself in a context that is not it's original home. When you've got healthy self determination along with a spiritual world view of wholeness, that feels like an engine for transformation.

I agree. And then the engine needs gas: the community needs resources to add to the mix to create the conditions, the access, and everything else that it needs to be healthy. It needs access to healthy food, clean water, and basic human necessities. Racism can make it difficult to secure these resources, so cultural competence within health care and other social systems in this country are also needed for our community to access them. And because people need money to live, our community needs access to jobs to support their families.

Regarding the questions of what would bring increased wellness to our community, I think what's missing is understanding that communities have assets. I think this goes to a lot of what people are saying about there's a missing link regarding understanding who people and their community really are. Without this understanding, we're not in a position to be able to build on what our community already knows, what our communities are already doing, and how they operate. And so even though we have in the health care system a pastor who works at a hospital, we're not able to have services that make sense for our community. What would it mean to place health services actually in community? When I say in community, I don't mean that since a lot of Africans live in Dorchester we're going to put a health center in Dorchester, that's not what I mean. I mean, what does it look like to place services at the church that's on the corner that is led by the Nigerian pastor? Or what does it mean to put services at the tropical food store that everybody goes to? What would it mean to place health services in places that people trust and are familiar with, and that incorporate our own practices along with biomedicine? What would it mean to place those services where people feel comfortable in terms of their spiritual practices, outside of the fact that they're located on Blue Hill Avenue.

One thing I want to bring up. I'm probably the only one on this call that identifies as a Nigerian American, meaning that I was born here and my family's Nigerian, versus individuals who were born on the continent and immigrated here, so I believe immigration status needs to be part of our conversation because, some people might have immigration status that gives them access to health care, and some people might not. I work with people who don't have that right and they might be doing exactly what one of you shared you are doing: piecing together health care because you're not able to get health insurance because you don't have the right immigration status or you're not able to or you don't feel comfortable going to the health care center because you don't know if you're going to get picked up by a police officer. We need to bring all these issues into play when we consider what it really means—and why might it be essential—to provide health services in the community, by the community. What's needed may not necessarily be a community health center. There might be other outlets.

I was trying to ask: for people who are not legally here, who do not have their immigration status, how do they get access to quality service? The question of whether the individual's status is right or not, I think that needs to be addressed. What about fairness? She mentioned something about the tropical food store: this is where you see many immigrants, especially of African descent. They come there to buy. This is a trusted place for them. What kind of resources do we have around this place that are accessible, accessible to people like these irrespective of their backgrounds, their social status, economic status, or immigration status? These are questions on my mind. How do we help people like this, because they are part of the community? I'm a big fan of taking an inclusive and holistic approach to serving our community.

What do you see as the greatest barriers to the health and wellbeing of the Black community—regarding COVID and longer term?



FEEDBACK FROM ALL SEGMENTS OF THE BLACK COMMUNITY

- **The greatest barrier is systemic racism in the health care system and in all the other systems that impact our lives and community.** We lack access to employment to support and sustain our families, to healthy food and food security, to quality and affordable health care, housing, and education, and to the tables that make decisions for all these systems. In short, we lack access to the social, economic, and political resources we need to support and sustain the health and wellbeing of our families and the Black community. Being impacted by systemic racism in all these areas and across generations leads to entrenched poverty, which creates even higher barriers for people and communities trapped by them to the hope and resilience needed to overcome them. Which is why we must work together and not abandon the Black community to the job of removing barriers of systemic racism that keep it trapped, barriers it did not create.
- **We don't see the doctor as often as we should because we can't afford it.** And when we can afford it, it's hard to see the doctor in a timely fashion. We have to wait months before we can get an appointment. So lack of access and affordability affect our health and wellbeing.
- **Lack of communication, community education, and community building are big barriers to supporting our health and wellbeing. We need to focus on and address:**
 - **The generational traumas we've experienced from systemic racism and are still wrestling with, and their impact on us as individuals and as a community.** We need to share this information within our community to build shared understanding about our own story: our history, reality, and the future we want. Then we need to use our shared understanding to do two things: heal from the traumas we've experienced, and work together to respond to our reality and create the future we want. How we respond matters. How we, each as individuals, every single day, how we show up in the world, not just for ourselves but for each other, and for all of the little kids who are out there every single day watching what we do, what we eat, and how we move, matters. We need to keep our focus on what we need to do to ensure the next generation is in a different place. We must not just think about ourselves as individuals, we must think about our community and how we keep it connected to continue to heal ourselves, strengthen ourselves, and create the healthy future we want for our kids and our community.

- **Knowing our worth and how to advocate for ourselves** within systems that are not listening to us or effectively serving us. I think, for the most part, that when we're talking to our doctor or professionals in other systems, we know things but we don't speak up. The question I always ask myself is what am I pretending not to know when I actually do know? It's so easy to think that people who are more educated than us are going to bring up what matters to us, so we don't have to. I believe that getting educated about how to advocate for ourselves can open so many doors and make us feel good and increase our confidence and our ability to stand up for ourselves in health care and other systems that have failed to serve us effectively because of systemic racism.
- **Nutrition:** healthy foods and healthy eating over a lifetime. This includes understanding how different foods impact our health, as well as understanding the importance of and greater nutritional value of eating foods in season, instead of eating foods grown in a laboratory.
- **As we get older, self isolation becomes an issue and our elders need more social contact and social outlets.** COVID has interrupted all of that and probably exacerbated isolation.



FEEDBACK FROM THE BLACK LGBTQIA+ COMMUNITY

- Health disparities that exist because of systemic racism
- Lack of access to somebody like me to talk to, i.e., an LGBTQIA+ practitioner
- Everybody's not always honest with their doctors. A lot of people are not comfortable telling their doctors certain things because they feel they will be judged. But doctors have to make decisions about the healthcare they provide us based on what we tell them. If we don't tell them, they can't make informed decisions.
- Things I wasn't taught growing up, like how to take care of myself by going to the doctor, or how to support my mental health as well as my physical health. I'm now raising myself and learning those things as an adult.
- Not a lot of information about what health and other social resources are available to support our health and wellbeing is taught to lower income communities and people who live in the projects. The health of these communities is not just shaped by the health care system but by the social determinants of health.
- Many African-Americans fear the doctor, fear health issues, and fear finding out about things as a whole. I feel like our people think if we just don't even address our health issues, or don't even acknowledge them, then we don't have to worry about them. it's just easier to deal with not knowing than going to the doctor. Fear plays a big part the health of our community.
- Mental health isn't taken seriously in the Haitian community.
- Lots of doctors don't want to administer pain medication the way they used to because this country has an opioid crisis.
- We, as a Black LGBTQIA+ community, are disjointed and divided instead of helping each other survive this pandemic. Our lack of connection makes us even more vulnerable.



FEEDBACK FROM AFRICAN COMMUNITY LEADERS

- **Systemic and structural racism**—and a worldview that limits access to accurate and empowering information, resources, and opportunity
- The African community lives at the intersection of racism and xenophobia. Massachusetts has the largest population of African immigrants.
- **Language barriers:** When you go to the hospital or anywhere, there's always a translator for a Spanish-speaking person or someone who speaks Chinese, but rarely is there one for our language, unless you have a child who speaks English. This makes it hard for us to speak to them or for them to speak to and understand us. Sometimes the language barrier feels like a kind of set back to our community. In New York, they have a place where they can call for a translator for any language that they need, but in Massachusetts, I don't think we have that yet for African languages.
- Fear of the unknown
- **Lots of misinformation:** we need to provide accurate information and dispel misinformation but also understand that many fears are justified.
- People are bringing expectations of certainty to something that is new, still evolving, while they're still learning. As a society, we need frameworks for different contexts we're in.

What top priorities would you like to see addressed to remove these barriers and prevent them, to help strengthen the health, resilience, and wellbeing of the Black community?



FEEDBACK FROM THE BLACK LGBTQIA+ COMMUNITY

- Having safe spaces to be able to be myself
- Having accessibility to more queer doctors and Black doctors and not feeling judged
- The Black LGBTQIA+ community needs to come together and overcome its divisions so it can figure out ways to intersect, connect, support each other, and work together to strengthen its health, is mental health, and to save each other's lives.

I think that it's mental health. I think that we have to prioritize the mental health of our communities for us to be able to be effective. I'm just going to say something that is personal. Back when Trayvon Martin died, I would never forget it. This is before I started getting therapy. This was before all of that. And, I remember watching the news and literally watching the video on repeat. And then people started going into the streets. They started protesting in the streets to burn shit down. Then I'm on social media and I see and hear the same thing. I couldn't figure out where to place the frustration I was having. So I turned to sex. For me at that moment, I will never forget that night. Had I had the tools at that time to really address what I was feeling, or what I was thinking, and how this was impacting my body, I would not have needed a coping response of needing to engage in a level of pain to numb my frustration. Having the tools, or having access to someone with those tools, would have definitely helped me in that moment. We have to break down the barrier to access to mental health in order to truly address the real issues that we're facing. So I'd make mental health, access to it when we need it, and centering that in our work my top priority.

I agree that mental health must be a top priority to support the health and wellbeing of our Black queer community, I feel like most queer trans people in our community deal with self-harm because we don't get those resources to address our mental health issues when we get rejected. To numb the pain, we self-medicate by engaging in sex or other things we don't want to do, but what we really need in those moments is to be connected with someone, to feel like someone's listening, and to feel comforted by someone. The key factor is to get to the mental health first because, without it, you can't move. I had pause moments where I was just numb. So I agree that mental health and access to it must be a top priority for our community.

I couldn't agree more. Right now our community is divided. A big part of our mental illness, and a big part of the things we're going through is because we don't have each other's big hearts. If I can't call somebody who I feel like is in the same space as me and not feel judged, that's a problem. I feel like we need to bring ballroom back. I would just have color. I need ballroom. We need to bring ballrooms of Boston, the real ballroom. There needs to be a category for everybody. I feel like we're so divided and there's nothing that brings us together so right as ballroom. We need to bring it back to bring our community together.

In addition to ballroom, what are other inclusive things we could do to rebuild our community? We need to start doing more events together. We need to start making them more noticeable for him and her. The more we start to connect, the more we start to get together. Then, and only then, will the mental illness start to go down a little bit because we'll have each other: we'll have people who understand what we're going through. And this will also help address the loneliness we feel going through all these issues alone. COVID has just exacerbated our isolation, loneliness, and divisions in our community. We need to reconnect and rebuild our community—and work together to figure out how to do this, because addressing our mental health is a big deal, and strengthening our community is key to strengthening our mental health, our health, and our wellbeing. (To hear more stories about this - the need for mental health plus building community as a key strategy for strengthening mental and physical health—please see the Appendix.)

I want to get high quality health care that meets my needs in my own community. I think that is where we need to put our energy and push our work. I want to see Fenway Health work with us to get health care institutions across this city to learn from us and from Fenway how to better serve our community—so that we can get quality health care in our own neighborhoods as well as at the big health care institutions that serve the city. We've got to hold them accountable in all these places. We have to step into it in a way where we're not sugarcoating it. We need to make clear what we want, and that we're not taking anything less. We want to normalize people's being able to get high quality health care where they live, so they don't have to leave their community to get it. This would not only help improve health outcomes for the Black community, it would improve health outcomes and the healthcare system for the entire city.

We need a strategy to ensure that we are all speaking the same language and saying the same thing about what's important to accomplish to improve the health of our community, and then empowering people from our community to work together and with health care and other institutions to help achieve our goals.



FEEDBACK FROM ALL SEGMENTS OF THE BLACK COMMUNITY

- Cultural humility, cultural competence, and respect for Black people in our health care system and institutions
- The availability and understanding of doctors who can relate to us, i.e., form authentic relationships with us: it's about really joining with the patient to provide the best care that's available for them.

Have more ways of sharing information about clinicians of color by gender: primary care physicians, mental health practitioners, and other specialists. This is information about good people that we can share with others. I think that would be beneficial especially during and after COVID, when people are really hurting and feeling the isolation deeply. I already have a list that we can build on. I'll share it once I fact check it and make sure they're still seeing clients.

Related to this priority is another. Over the years I've met some incredible young Black doctors who have left the city because they didn't feel welcomed. We need to find a way to reverse this trend so that we build up a pool of Black doctors, in primary care as well as specialties, who can effectively connect with, serve, and improve the health of our community as well as the city. We need to create an environment in this city, where Black doctors and other professionals would want to stay. We've mentored them but they've left, they've not wanted to stay. That's a problem. I've had conversations with a number of them to try to understand why they left. What they said was that they enjoyed being in Boston but I didn't feel that Boston enjoyed having them here. The hospitals do a really good job of recruiting these young doctors out of medical school and setting them up, but they don't provide them with a social network. If these young doctors don't come with a partner or a husband or a wife, they're on their own. I can remember Harvard Medical School. When the residents showed up, they were told what neighborhoods not to go to. They were steered away from neighborhoods that were predominantly of color. One of the things I'm involved with is trying to build a network for young Black and Latino doctors of color, so that when they come here to do their residency, we as the community embrace them and make them feel wanted, because the reality is when they walk out of their clinic and are off the clock, they're on their own. We have to embrace them and show them who we are as a welcoming community—our churches, arts and cultures, diverse foods and neighborhoods, our sports clubs, and our community parks and recreational spaces—so they don't feel alone and can imagine themselves making Boston their home.

Educating our community as early as we can about health and about how important it is to understand our family history—regarding what we eat, regarding other behaviors that can affect us long term, and regarding diseases that previous generations of our family members may have had. For example, my sister was diagnosed with autism and suffered for years. I’m trying to understand what was going on with her body and how to treat her. One day she asked the question: Did anybody in our family ever suffer with autism? Well, it turns out that my great great grandmother did, but none of us never knew that. I’m just learning things that she was troubled with and how she took care of herself. It would have been helpful to know all that much earlier so that my sister might not have suffered all those years. Educating our community about all these things is important because we have a pattern of rejecting the changes we need to make in our behavior—regarding eating differently, how we conduct ourselves, or even being able to advocate for ourselves with our doctors. How do I say to my doctor I don’t agree with that, or can I have a second opinion? I see a lot of the elders who are afraid to ask their doctor, “Is there another way you can treat me, or is there another way I can get that medicine?” It’s always the fear that they will be rejected or that they will suffer dire consequences. I think conversations about how to advocate for ourselves, our family members, and our community should happen earlier in life. We need to begin to disseminate as soon as possible information that can help us stand up for what we need: from our doctors, from the health care system, and to bring greater wellness to our community. The words we use to educate our community about this really matter. Sometimes our language is too ambiguous. It needs to be simpler to connect with the communities we serve.

I’m seeing how COVID affects the mental health of people in my community: I see changes in people’s personalities. I see how, pre-COVID, people used to have a very active social life: they went out, they went on vacations. And now because of COVID, I notice that people in our community are not as social as they once were. A lot of things we used to do in our everyday lives have been taken away from us, like going to school, going to work from nine to five each and every day, and going to the supermarket and shopping mall – just about anything that people would normally do as part of their daily routine. Now we’re all in the house all the time, and have been for more than a year. At first, when the vaccines came out, I thought we would get back to some type of normalcy. But once the Delta virus hit us, I feel we may not be making the forward progress we all wanted to see. COVID really has done some things to people. The mental health impact is what I see. This is an important priority I’d like to see addressed to improve the health of my community.

I think addressing COVID should be a priority, too, because I’m seeing people not get vaccinated. My friends are vaccinated but my barber is not. He said he caught it, got through it okay, and doesn’t have it any more. He says he doesn’t trust the vaccine at all: he has a lot of distrust for it and won’t get vaccinated. But my friends are all vaccinated, tired of COVID, and want to get past it and move forward. But we’re stuck because it’s still not safe. We’re just at home, but we want to be at school having fun and learning.

Because I'm fully vaccinated, I'm not going to criticize anybody who chooses not to get vaccinated because that's their choice. But I think that given the things I've seen on the media so far, one of the reasons why there is so much distrust with regards to the vaccine is because we're not getting actual clear answers from the medical community about the benefits of the vaccine. The only thing the medical community is telling us is to get vaccinated, and that will prevent chances of getting COVID 19. But we know that people have gotten vaccinated and still gotten the virus. The medical community also initially told us that if we're fully vaccinated, we don't have to wear a mask. So a lot of people who are fully vaccinated stopped wearing their mask, and many of them got COVID. I think so much conflicting information from the medical community makes people distrustful of the vaccines. As a result, people are unsure of what to do. I think the problem is that not enough people in the medical community are on the same page regarding the vaccine and its effectiveness.

The main thing I'd like to see is a better networking system to get information out to our people. In my view, getting high quality information to the Black community should be a top priority. What I think is most important is being able to formalize how we're going to get this information out there. We've got a lot of tools we can use. We've got technology, word of mouth, and going through organizational partners. Somehow we need to be able to come up with a way that we're going to do this so that the information gets out there. We also have a big resource that other communities may not have, and that's the Black church. We should also reach out to HBCIs (Historically Black Colleges and Universities) so that this information is shared with every young person who goes to an HBCU. So that's what's most important to me: to agree on how we're going to use these tools in a uniform way so that information gets out there, and so that information from different sources gets incorporated so that it all comes from one place.

To support and improve the health and wellbeing of our communities, the social determinants of health need to be taken very, very seriously because the presence or absence of these social supports makes all the difference in the world. For these systems to be healthy, they have to center and operate from a worldview of wholeness, otherwise the services they provide will not be healing or bridge gaps. They have to see the people they serve as part of the human community the social systems are committed to. This is a spiritual perspective that deeply centers human beings. It's got to be a central part of any solution we come up with. It's got to be the centerpiece. If it's present, you can then work out from there. If it's not present, almost anything else that is present is not going to be effective. It's clear to me that if you want to improve health and well being, you've got to center this worldview in our health care system and all the other social systems that impact our communities.

**Possible Next Steps: Including,
Which organizations would you like
to see us work with to help address
priorities most important to you?**



RECOMMENDATIONS FROM THE PROJECT STEERING COMMITTEE

- **Share this report widely:** with partners, other health care institutions, organizations that contributed to this research, the Black community, and the broader public.
- **Brief and engage other institutions and systems**—including those that are part of our social determinants of health ecosystem—to join us in working together to:
 - Learn from and address the issues, barriers, and priorities identified in this report.
 - Advance racial equity within their own institutions and systems to improve the health outcomes of the Black community.
 - Advance racial equity to support systemic change more broadly within and across other institutions and systems—the social determinants of health—that impact the health of the Black community. Throughout our history and until today, systemic racism has been reinforced by this ecosystem which has consistently failed to support the health and wellbeing of Black people and communities. We need to address the systemic racism and systemic failures that permeate this ecosystem, so that race no longer becomes a predictor of the health and wellbeing of the Black community.
- The feedback we get from sharing the report and inviting others to join us in a shared commitment to improve health outcomes for Boston's Black community could be used to develop a shared framework and catalyst for change for advancing racial equity and improving the health outcomes of Boston's Black community.
- Next steps are still TBD by the partners, BBCC and Fenway Health, but could include activities such as sharing this report with the city—i.e., with the Black community, institutions, systems, and the public:
 - To support them to learn from the report
 - To invite them to join us in a shared and public commitment to work within our institutions and together to improve the health outcomes of Boston's Black community
 - To use the report to define and take action to drive internal and external systemic change, i.e., to:
 - Advance racial equity within their institutions and systems.
 - Improve health outcomes of Boston's Black community.



QUESTIONS THAT NEED FURTHER EXPLORATION

- What are health care institutions doing to educate/empower people in their care? What can they do more of or better?
- How can providers be supported to provide care without bias?
- Who's providing mental health care and doing it well in the Black community?
- What is Fenway's role in support of programs already happening—e.g., offering space, resources?



FOR FUTURE ROUNDS OF RESEARCH, WE SHOULD CONTINUE TO DEFINE WHO THE BOSTON BLACK COMMUNITY IS

Our current research process relied on engaging and learning from existing organizations, which means we learned from subsets of the Black community that have organizations. What about other subsets of the Black community that don't yet have organizations to represent them—e.g., Spanish-speaking Blacks. This leads to logical “what's next” questions for our research, i.e., how to expand the next round of our research to include who's emerging.

APPENDIX



STORIES OF ASSESSMENT PARTICIPANTS: In Their Own Words

From the Black LGBTQIA+ Community

From Black Elders

From Black Women

From Black Men

From Black Young Adults

From African Community Leaders

FROM THE BLACK LGBTQIA+ COMMUNITY

The need for mental health plus building community as a key strategy for strengthening mental, physical, and community health

STORY 1

I was a young man when I left Boston, I was born and raised in Boston and left when I was almost 30. I went to New York and stayed for over 30 years. But I came back because my mental health was screwed up. I was all caught up in and deeply impacted by 9/11. I lived and worked in ground zero. I was a shattered mess. By the time I came back to Massachusetts, I had to get some mental health care from a mental health professional. And not just seek it out, but really get treatment. The mental health care I received got me back to my senses.

I think we all need to have some therapy, but especially Black people and people of color, because of what this country has subjected us to for generations. For my entire life, I was told that the only thing we ever needed to survive all these challenges was family church. If you had God, that was it. I was raised to believe that if you just relied on God, you'd come out of whatever you're going through and you'd be all right. But you're never really all right, because you never have an opportunity to talk about those things that impact you personally, that you're afraid to share with other people.

With the support of therapy, I had a lot of breakthrough moments with stuff that I was just carrying, never even knew I was carrying, but there were things I would carry that I just never shared with other people. So mental health, or our well-being, is significantly impacted by a mentor. And I suggest that anybody struggling with issues, who hasn't talked to a therapist, get their way to see one quick. I'm just saying it helped me, my mental state, and it might help you. It can help keep us from living in our own heads.

Oftentimes that's where the conflict is—living in our own heads. Getting support can take care of some of the loneliness. Yeah. You feel like you need to be connected with other people. I've felt this before: there was a time when I experienced Boston as a very connected and very healthy, hearty, Black gay community. Everybody supported everybody. We were always doing something with somebody, and if somebody needed something, we took up collections and all to help somebody out. That was just stuff that we did to support each other as a community, and there were older folks who were my mentors. We would connect in this way and be part of each other's lives. I wanted to be part of this when I came back to Boston but I was struggling with mental health issues and disconnected from the community.

Now that I've received mental health care, I realize that when we see members of our community disconnecting as I did, we need to really be mindful of each other and be more mindful that we can help each other.

STORY 2

I think that we have to prioritize the mental health of our communities for us to be able to be effective. I'm going to say something that is personal. Back when Trayvon Martin died, I would never forget it. This is before I started getting therapy. I remember watching the news and literally watching the video on repeat. And then people started going into the streets. They started protesting in the streets, burning shit down. Then I'm on social media. It's the same thing. I couldn't figure out where to place the frustration I was having. So I turned to sex. And for me at that moment, I will never forget that

night. I didn't have the tools at that time to really address what I was feeling or what I was thinking and how this was impacting my body. Because I didn't have the tools, sex was my coping response to numb the pain. The right tools would have definitely helped me in that moment. If we could find a way to truly prioritize mental health and center that in our work, I think that would be important. And getting an appointment to see a mental health provider when you need to is key. Before COVID there was a six-month wait. Now with tele-medicine, getting an appointment is

much faster. We have to break down the barriers to access to mental health care in order to truly address the real issues we're facing. Queer trans people in our community deal with self-harm because we don't get the resources to address our mental health issues when we need to. You've got to get to mental health first because without it, you can't move. I had moments where I was just numb. So I would say mental health and access to it is essential. The need for it is great in our community, point blank period.

FROM BLACK ELDERS

The importance of supportive relationships, eating healthy food, advocating for ourselves, and addressing systemic racism within our health care system

STORY 1

My father worked in construction. And I remember him coming home many, many a night literally bloodied and bruised from things that happened on the work site. When my mother would ask him if he was okay, his answer would always be, I'm fine: I'm just going to take some aspirin and lie down. She had to drag him to the hospital.

A few years ago, I contracted a virus. It really wiped me out. But I kept going to work, kept doing what I had to do. And one morning my partner woke me up and looked at me and said "You've been shivering all night long. Put on your clothes, I'm taking you to the hospital." If she hadn't done that I would have had kidney failure. Overnight I had become my dad. I remember seeing my mom physically throw my dad in the car and take him to the hospital because he wouldn't take himself: when that happened to me, I realized I'm not unique. And I'm going to be specific, since we're talking about the Black community. It's amazing to me how many Black men, older and younger, end up dying because we don't have a personal network that includes

somebody who loves and cares about us enough to throw us into a car and take us to the hospital. And it's irrelevant whether or not they have health insurance. It's irrelevant whether or not they have a primary care physician. It's irrelevant whether or not they even know where the hospital is. I live literally a 15-minute walk from my hospital. I know because I go by it whenever I walk my dog. And yet, it took this woman who loved me to throw my butt in a car and drive me that 15 minutes—to save my life.

STORY 2

Waiting until we become seniors to be dealing with the issue of learning to eat healthy food or taking care of ourselves in other ways to support our health and wellness is, to me, too late. For example, I've seen young children who refused to eat a sandwich because they didn't like tomatoes. Instead of taking the tomatoes off the sandwich, they threw their whole sandwiches away. That's what they carried through their lives: that it's alright to get rid of healthy food. Another example: a couple of years ago, my son had pain in his chest. He felt a lump. He took himself to

the doctor because I had always said to him that his body is not supposed to have pain and that whenever it does, that's telling him something. He went to the doctor and learned he had breast cancer. He was able to say to his children, Nana always said, when I was growing up, if something hurts, come to her or Dad, and that as an adult, I was to seek attention and not wait, because if you wait, it may be too late.

I live in senior housing and have listened to seniors talk about the reasons they will not go to the doctor, or the fact that it's hard to get healthy food when, in fact, almost all senior housing has a food program that includes healthy food. They might not like the food, but if they think about, and can remember their own parents talking to them about the Depression, then they will eat. We need to change our way of thinking.

I am a school nurse, and I have never met a more finicky group of children in terms of the way they eat today. The amount of food I see wasted in the garbage at the various school sites where I work is unreal. It doesn't make any difference whether the food comes from Whole Foods or Stop and Shop or Market Basket. What I see is a lot of waste. This is a health issue, an economic issue, and an environmental issue. To reverse this waste of healthy food, we need a lot of community education, and we need to start early, educating parents, kids, and the broader community about how to support and sustain the health and wellbeing of their families and our communities. This needs to include the diversity of our families, from different cultures, economic backgrounds, and speaking different languages. We have a garden where we raise vegetables that we use in our kitchen at school as well as send home to families: they're getting fresh food from us that the children help us grow. I don't know if families are eating this food or throwing it away.

I think the big picture issue here is the need to teach lifestyle planning that supports the health and wellbeing of our families, children, and communities.

STORY 3

I do trust my healthcare provider. However, I'm always ready to question my healthcare provider if I do not get a response that I feel comfortable with. I will give you an example: five years ago I was diagnosed with cancer. Three years before that I had started to lose weight and I went to my primary. I told him what was going on and that I felt like I was wasting away. He did a series of tests and said everything was okay, but three years later I was diagnosed with cancer. So although I'd been on top of my healthcare, this is what happened to me. So I'm even more vigilant at this point. While I'm comfortable with my healthcare provider, I'm not afraid to push back. And I have pushed back by walking out.

When I went to get feedback about what type of treatment I was going to get for my cancer, I knew I would be nervous. I'm good at taking notes but I took two people with me so that I could ask the questions and listen to what the doctors were telling me, and my friends could take notes. Also when you have witnesses in the room and a record of what was said, nobody can say you misunderstood them. I found this a powerful advocacy strategy. From the notes my friends took, I was able to better determine where I was going to get my health care. I chose to go to another provider, who was a better fit for me.

So, sometimes we have to be bold, but I do understand why some people don't do this because they're afraid of what their provider will do when asked questions. So sometimes we may need to have someone go with us to help give us the courage to be bold and ask the questions we have—and get our questions answered and our needs met so that we can decide what's best for our own health, including whether to stay with the provider we have or find someone else we feel is more comfortable working with us as the primary decision maker in our own health care. A key factor that impacts whether I trust the health care I'm getting is having a doctor who accepts that I will be a full partner in advocating for my

own health. Listening to and learning from each other to do our best to support and sustain my health and wellbeing has to be at the center of that relationship. I will not be a silent partner. Because what's at stake is my life.

STORY 4

As much as we may trust our health care provider, including at the most reputable institutions, we need to be advocates for our own health care, to be vigilant for the possibility of racism, and to speak up when we see it to make sure its addressed. We need to move from a position that lots of us were brought up to take, where doctors were on one level down from God—and always stand up for ourselves and take responsibility for asking whatever questions we have. Many years ago I served on a nonprofit board. At one of its meetings a gentleman introduced himself as a medical doctor, who was not in practice but worked in an organization set up by doctors to monitor the performance of their peers. We got into a discussion of his work and what it monitors and sees, and he said me, we know that most doctors didn't get A's, they didn't all go to Harvard. Some of them are doing drugs. Some of them are criminals.

That conversation reminded me of two experiences in my own family, first by me and then by my wife. I went to see my primary care physician about the results of a blood test that were out of range. She was almost in a state of panic and said she wanted me to see an oncologist. I went to see that doctor. He scrolled through my whole background and then asked me if I was from Haiti, the Dominican Republic, or Africa. I said, I'm from the Caribbean. Then he let me know there was a mistake in my test results because I had been mistakenly identified as a white, middle-aged white male whose blood cells were out of the norm. I happened to live in Swampscott, a predominantly white town where I was one of only four Black men in a town of 14,000 people. It seemed that the mistake occurred because the system assumed I was white because of where I lived, even though my records show me as self-identifying as Black. This experience really opened my eyes to the depth of

the ways that racism can operate to shape false assumptions about who we are. It reinforced for me why we need to stay vigilant and question the information we get from our doctors.

My second experience occurred when, shockingly, my wife was diagnosed with cancer and then died from it. The Lynn Item published an article about a study that had been done that compared the quality of health care delivered to women of different races in the neighboring towns of Swampscott and Lynn. In fact, our property borders the two towns. The study found that white women from Swampscott who were diagnosed with the same disease or ailments tended to live much longer than Black women from Lynn. My wife was Black, lived in Swampscott, and had the best medical insurance, but after her diagnosis she only lived as long as Black women from Lynn. Four or five months after the cancer returned, my wife was scheduled for a lung biopsy. Prior to the procedure, her doctor asked whether my wife was on a pain management program. We explained that my wife had been taking Tylenol, and the doctor said no, no, no! For what you have been experiencing the last year and a half, you should have been in a pain management program where you would have received much stronger medicine. I remember seeing his face. I saw this white man go from white to pink. My wife died three months later. All the insurance and medical service we have here on the North Shore did not save her from racism: she did not receive proper pain management and her life expectancy after her diagnosis matched the profile of Black women from Lynn rather than white women from Swampscott of the same economic status.

There is something systemically wrong here. Attention needs to be paid to this. We must look at the entrenched infrastructure and practices that perpetuate racism within the health care system. This needs to be fully researched and then widely shared and understood to change our health care administrative functions. There is an urgent need for holistic change. I hope our conversation today contributes to the wider understanding needed to drive systemic change.

STORY 5

My doctor and I are coming up on our 25th anniversary. I remember how we ended up together because 25 and some years ago I was assigned a doctor for my healthcare, and I remember I got tested for HIV because I worked in the industry. When I went to go get my test results, they gave me an envelope. I didn't understand what was written so I demanded to see a doctor who came out. I asked him to tell me what my test results meant because where I'm from negative is never a good thing. What he told me was you don't have it. And then he looked at me and said, I can tell you don't have it from the way you look. So I immediately fired him. Those of us who are old enough—I'm fighting being a senior kicking and screaming—remember that back in the day, they gave you the big book of doctors. This was before the internet and you had to pick a doctor. And so, I simply went looking for a doctor who practiced near where I lived. His first name is Mike so I don't forget it. That was all I was looking for

and that's how I met my doctor. Now, over the 25 years this man knows me well enough not to ask me any yes or no questions. Because he knows I'm going to be evasive, he's the one that scheduled my colonoscopy, and then called me and told me the scandal there. 10 years ago, in our annual checkup he looked at me and he said, what kind of life insurance do you have? He goes on to say, "You and I've been talking about you losing weight and if you don't lose weight, you're going to be dead in about 10 years, and I want to make sure your kids are taken care of. That's the relationship I've had with this man for 25 years now. We've also got an official agreement since I walked through the door. We've agreed to retire at the same time. If he reneges on it, I'm in trouble. He's got admitting rights at Faulkner Hospital and I work at the Brigham, so I have access to the whole Mass General Brigham network. But I'm still going to my guy. And until he locks up the door and takes away his shingle. I'm still going to my guy, because we have a long-term relationship of trust and I trust him with my life.

FROM BLACK WOMEN

The power of exercise to help us discover we can do more, physical movement essential to support a healthy lifespan, and the importance of having health care providers who respect our humanity, our experience of our own body, and listen to and learn from us as a full partner in guiding decisions about our health care

STORY 1

I'm a nurse. I run every week at least once a week. It helps clear my mind. I deal with a lot of patients every week and with things at home. Running allows me to clear my head. It also allows me to realize that I can do more than I think I can do. For the most part, I'm always in my mind before going out for a run. I set out to do three miles.

During this time, I run and I'm looking at my watch, thinking: how am I, where am I? But at the same time I think, well, I made it this far: I can go further, especially because I'm a scenic person. I hate running in the gym on a treadmill, but if I run outside, you can catch me in three or five different neighborhoods throughout Boston, as I go into a mental space where I say to myself, I've made it this far: I can go further. I use this time to

contemplate my life decisions. One of the things I've learned from running is that I can go further, i.e., I'm capable of doing anything and everything. The mind is a powerful thing. Running has allowed me to see just how powerful the mind is. I've even begun thinking about running marathons. For me, it's not just about my physical ability. It's about the mental ability to do it. I've always thought of running as more of a spiritual experience because I feel most connected when I'm doing it. The high you get from running is like God giving you the positivity to feel you can conquer anything. When you realize you have this capacity, you start asking yourself how you can bring this capacity to other areas of your life. So it's really great! I find that running is a practice that connects the physical, mental, and spiritual all in one. This is what health and wellbeing looks like and feels like to me.

STORY 2

Yes, I do get healthcare, from my employer, but I'll be honest with you: I don't use it that often. In general, I have a distrust of the healthcare system, so I try to avoid using it. My father, who was Black, passed away when I was very young. This happened in the 80s. He had pneumonia but they just assumed that he had HIV/AIDS. So he passed away from something that was totally curable and treatable. I've also had a death in my family recently that was related to COVID and which wasn't handled correctly. So I don't trust the healthcare system.

I think it's great on paper. I don't think the Hippocratic Oath means anything. I'm sorry if I sound very negative, but because of my negative experiences with the health care system, I tried to stay out of it.

There was a time when I had felt safe and comfortable. I went in for a very minor procedure, and I ended up seeing a healthcare provider that I recognized from high school, and I immediately felt at ease. I was very anxious going in, but seeing that familiar face, and the fact that she was a woman of color and knew me personally, made a very, very big difference in how I was treated and how I was spoken to. There was another time like when I had to go to an emergency clinic near my house. I know I had my health insurance card, but for some reason my health insurance wasn't captured by the clinic. I was hit with a bill

that I had to dispute. I showed them my health insurance, so I don't know why I was still billed, but the doctor who saw me was just very cold, very Cavalier, in the way he examined me. When I asked a clarifying question about the different types of pain killers he wanted me to take, his response was very cold. It made me feel very unwelcome.

I'm at the point in my life where I'm thinking about planning a family, and I have to get more involved with the health care system. I have to be more intentional and do research to find people that I will be comfortable with. That's a lot of work to do, but I feel it's necessary. I don't know where to start. I feel like I would love a list of recommendations of doctors of color.

STORY 3

I feel like I've had a very extensive relationship with my health care providers this year due to issues I've had with my foot and my back. I had to have surgery. I've also been in a lot of pain. Some moments I did feel I was being listened to and that my feelings were being acknowledged. Other times, I have not. There are moments where I feel I have to be an advocate for myself. I feel I shouldn't have to feel that way because I'm coming to doctors for healing. I expect them to have my best interests at heart. But as history has taught us, that's not always the case. I don't want to feel defensive about the place I go to for help. I've not had issues where I feel like I need to sue or anything, but I've felt my issues were not being taken care of, that I was not being listened to, and that my feelings were not being acknowledged—so I stood up for myself. But it took me a while to even advocate for myself.

I'm lucky because my cousin's a nurse. So I would talk to her and she'd let me know what the doctor should have done. Then I'd go back to the doctors and let them know. At one point I was going to have her come on an appointment with me because I just didn't feel they were hearing me. I just didn't feel like they were taking me seriously. I thought that maybe if they heard it from somebody else who was a practicing professional, that would help. What ended up happening was I spoke to my PCP, whom I actually met for the first time this year. She's been my PCP since 2012, but I'd never met her.

I've actually now been seeing her on a recurring basis. She's looped into the situation. I've shared all my concerns with her. Throughout this whole time, I continued to communicate to my doctors that I was experiencing severe pain: I couldn't even walk. But they still were not hearing me: it was as if they didn't believe me.

STORY 4

I get my health care through my job. The health care is supposed to be exceptional there, but as far as trusting it, I have concerns. The voices of Black women there and in the healthcare industry are often not listened to. I've had various experiences where I've expressed things to my primary care physician and to other healthcare professionals there, and their responses are dismissive: instead of taking my concerns seriously and looking into them to explore what's happening and why, they say it's not a big deal. I don't trust this behavior, and I've heard other Black women say they've had a similar experience. While my health care provider is a world class hospital that accomplishes all kinds of medical milestones in the health care industry, it would be great if the quality of their care

were as good as the quality of their technical innovation. They need to be more aligned. If all their new developments, which are wonderful, are not complemented with high quality of care that each and every patient deserves, no matter what they look like, then what is the benefit of all that innovation if you're not putting it into practice? They're bringing in the innovation but falling down on the care.

As a Black woman and a patient who's experienced that first hand, it doesn't feel like world class health care to me. They have a lot of work to do. To improve their performance, they need to begin by listening to their patients, being attentive to their needs, and trusting that their patients know something about their own bodies. They need to trust the validity of their patients' experience, and they need to work with their patients rather engaging in a power dynamic as the health care professional who knows all. The goal should be to provide the best care possible for the patient, and that can only be achieved by respecting the patient as a full partner in the process. The doctor and the patient need to learn from each other if quality care is to be achieved.

FROM BLACK MEN

The power and value of what we do comes from the community we build together to support each other to become the best version of ourselves—and to model this for others

STORY 1

Physical ability is a big part of what health and wellbeing look like to me. Since I was a kid, I remember always having thoughts about being my oldest self: the idea that one day I'm not going to physically be able to do the things I want to do is something that constantly sticks with me. That's part of why I got into running. It's an opportunity to be physically engaged in

a way that always affirms my physical ability. It's a constant goal that I try to maintain. Being able to be physically active makes a huge difference for me. It gives me an outlet for expression. It also has always played a role in my social health, helping me create spaces where I can connect with others, whether it's just running with this group, going to the park and playing basketball, or being able to connect as a brotherhood. It gives me a way to interact socially, and it gives

me a sense of self, a sense of purpose, even a sense of shared purpose in terms of my own identity and how I fit into this larger equation of the world.

STORY 2

Physical health and physical activity are very important to me. I try to be active, engage in some form of activity every day of the week, whether it's walking, running with my brothers, or just working out in my own basement. I look at it as something that's critical for me: to stay healthy and be active as I get older.

It also helps with my mental health. It's a great stress reliever for me to go out on runs, especially after a long day at work. I sit at a desk. So to get up and get active is very, very important to me, and I relieve a lot of stress after I take a run. It all goes away in that space, in that moment.

That's why exercising is so important to my physical health. Honestly, I want to live as long as I can and be active. I don't think you can do that without having some type of plan in place to stay active. One thing that stuck me when doing toad races during the pandemic is how many times I would see folk much older than me out there running. That's what I want to do when I reach that age, God willing. I want to be able to do that.

STORY 3

I think of health both mentally and physically. I have a great example: my grandmother, who lived to be 97 was a prime example of what health and wellbeing look like. She was fully aware until her last days. So when I think about health and wellness, a healthy life, I think about the ability to live a long life and to live a quality life. Do I have mental awareness, am I able to physically do what I need to do to live a fulfilling life, and what does it look like to live comfortably mentally and physically if any of those things need support?

I have access to resources that I can utilize, and there are very few barriers that get in the way of

my accessing what I need to live a healthy life. That leads to my having quality life and being able to have it for a long life. That's what health and wellbeing mean to me.

STORY 4

When I think about what health and wellbeing look like to me, I think first of mental health. If you don't have an outlet, a way to check in with your emotions and express them, then no matter how much you exercise, you might still die from a cardiac event. We know that 24% of Black men over the age of 20 are going to die this year because of some cardiac condition. And it's not always because they don't have a good diet or because there's some history of heart disease. Stress will kill you. That's a fact.

As a Black man in this country, I do not have the privilege if not being able to articulate my emotions and what drives them. If I don't articulate them, what builds up and comes out is anger. So for me, healthy emotional expression is probably the highest level of well being, and I can't get there if I don't have a support system to help me check myself and ask whether I'm just performing or actually keeping it real. I need to have a community that loves me enough to pay attention and help me keep it real.

STORY 5

I've been an athlete the vast majority my life. I've been involved in sports since I was 14. For me, running and working out is very spiritual. It's an outlet for me. I'm angry a lot about certain things and physical activity allows me to let all that out. It also pushes me mentally. I've discovered that continuing to push the bounds of my own body, pushes me mentally. As an athlete, I've been raised with a competitive mindset.

Now as I get older, I'm really starting to focus on what I'm eating, what's going into my body. When I was growing up, because of sports, I could eat whatever I wanted. I didn't realize like how that affected my body. But now I realize that to stay mentally and physically healthy, I have to

put the right nutrients in my body, especially greens, and I have to make sure I'm cutting out a lot of sugars.

For me there's something about the energy, the excitement, that comes from the competition and the camaraderie. Sports give me energy and allow me to release emotions that upset me. They allow me to remain an open vessel, so that if anything comes up, it's all right, it's cool. I take it as it comes and the next day I work out. That helps me release whatever I need to in order to maintain my mental health. Also, it's been really awesome to connect with these brothers, this brotherhood of Black runners.

STORY 6

I get health care from different sources. First, I talk things out with my wife and with her brothers. Second, I've been involved with sports and had physical trainers or someone like that taking care of my body. Third, I trust the men in this running group with the things that I share with them, the things that I open up about. I feel taken care of by them and also by friends who are doctors and give me advice. If the science is out there I can find it. Fourth, if there's something medically wrong with me, I will go see my doctor, but for the most part, I keep myself in pretty good physical shape. Fifth, I recently got a life coach, which resonated a lot better for me than a therapist, because, as an athlete, I know and trust how coaches operate. My life coach has helped me clarify my goals, see how things are going on in my life, and guide me to focus on being more at ease. Her ability to help me shake anxiety and panic attacks has been huge.

So these five areas are key spaces and places that help me support and sustain my health and wellbeing. These are all people I trust who help keep me relaxed, focused on my self care, and balanced and centered. As a Black man, having this support system is key because most of the time, I never feel like I get a chance to pause and just be myself. I'm always having to react to other people's assumptions or expectations of who I should be. With this running group of

Black brothers, I can just be myself and walk in my own power and my own being. That's been really good for me. I know they genuinely see who I am and care about me. Being around them is healing because it helps me relax and restore my balance.

STORY 7

Black Men Run is a group I trust to help me support my health, resilience, and wellbeing. I have self health because I've become more and more reluctant to go to the doctors.

I'm narcoleptic. I got this diagnosis after college. I went through years of trying to figure out what was going on, and no one had answers. It was affecting my ability to work because I just didn't have any control: I didn't have physical ability or agency. My narcolepsy was a direct impediment to all of that. Then I began to see neurologists. They told me that they hadn't actually worked with anybody with my condition before but that they thought it was a neurological disorder. They said they actually didn't know why narcolepsy happens but they wanted to put me on medication. I don't have a medical degree but if you're telling me that you don't know what causes it, but you figure that by using these different medications it can help, I was like, wait a minute, that definitely takes a toll on my confidence in their recommendations.

I remember sharing this with our running group. One of the members of the group approached me with an idea to support my self care that I was really helpful, which I appreciated. I'm also an extrovert and need to be around folks. I might be one of the quietest people in the larger group, but I need to be around energy and draw energy and wisdom from the group so that I do not feel alone. So being part of this group has always been magnetic for me because of its the energy. It has helped me become very mindful about who I bring into my space. I feel like everybody in this group leads and the connections we've been able to build just keep cycling and growing. I've found this group to be exactly the self care I need.

STORY 8

I have access to healthcare and I use it when I need it. I've been with the same primary care physician since I was a freshman in college. I do trust him. I trust that he did his work to earn his position and has more knowledge than I do in that space. I trust him but I don't have blind faith in him, because I recognize the challenges in our healthcare system and also the benefit of being able to educate myself. So I make sure that I double check, triple check, and verify or disconfirm whatever his recommendations are. I don't have blind faith because I know that it's not a perfect health care system, and that my health care resides within that imperfect system.

I make it a point to be assertive and exercise a lot of agency, a trait I share with my Black brothers in my running group. We all have and support each other to have a healthy sense of identity, a sense of pride in being Black. As a result, we have a healthy sense of value and self worth, which gets expressed in our self care to support our health and wellbeing as well as in our advocacy for ourselves within the health care system. Our sense of self worth prompts us to be more direct, assertive, and diligent in looking for things that will support our health and wholeness. This is one of the reasons I'm part of the group. Their values and worldview complement mine. I appreciate our shared culture as Black men. Even though we come from different cultures and countries of origin, we feel a connection and are comfortable with each other. I appreciate everyone's work ethic, and the tools they have to understand and navigate the world. We learn a lot from each other, we support each other, and it's easy to be with each other and be fully ourselves with each other.

As Black men surrounded by racism in so many other areas of our lives, we need this kind of space to experience and express our full humanity. I knew that if I joined this group, because of

who was in it, that it was going to be a group of people I could connect with: because of their integrity and ethics, their cultural knowledge of the African Diaspora, their mutual support, and their energy, initiative, professional pride, and commitment to personal and community development.

Our group is new in Boston and new under the sun. Although our group is only a year old, many of our members have a long history with each other: the group is built on longstanding, trusted relationships and an approach to humanity that is a kind of masculine love that gives you security and hope. What we're creating as a consequence of coming together is much bigger than the running. We're not just a sports club. When I run with or just hang out with my brothers, I can be fully myself. That's really empowering for me and the most healing, affirming space anybody could hope to be in—especially when you're doing that inside of a society that's racist and hostile and oppressive in so many other ways.

Creating spaces for transformation is revolutionary in a racist society. These are spaces we create for each other to be, to discover, and to be affirmed and grow in our leadership. The culture we're building is inclusive, anchored in love, and holistic. It allows you to bring your full self to the space. Just the whole act of being able to be to exhale, to be able to breathe in what's around you, is affirming. We have shared purpose and values: to support each other and the Black community to build healthier, more resilient, and meaningful lives. There's something we are learning to do for ourselves and each other that feels important to share with healthcare institutions across this city who say they want to improve the health outcomes of the Black community. Our health care system needs to partner with and learn from Black and other communities how to support and invest in spreading health, not just addressing illness.

FROM THE BLACK YOUNG ADULTS

Health care for all—universal health care that is free and where people can choose the doctor and health center they go to—is key to improving the health of our community

STORY 1

I just started getting health care again this year. I was with another health insurance company connected to my job, but I got laid off from my job so I ended up signing up myself to the health care I get now. I'm still relatively new at it. I haven't really used it that much. I haven't actually been to the doctor at all this year. I'm about to go for my physical next month. It's relatively inexpensive. But what would make it better – and I've been talking about this for a long time with people – I don't understand why we can't

get it together and have universal health care that is free. That would make it better because I believe health care should be free. It should be something everyone has access to when they need it, without having to pay. Luckily I have the option to choose my own primary doctor that I've been seeing for two years and like. But a lot of people don't really have that option, the freedom to choose their own doctor and choose the medical facility they go to. I think everyone having the option to choose would make health care better.

FROM AFRICAN COMMUNITY LEADERS

We need to develop social systems, including health care, that recognize our shared humanity and our right to self-determination, and take an inclusive, holistic, and equitable approach to providing the resources needed to relieve human suffering and address the social determinants of our health and wellbeing

STORY 1

What do health and wellbeing mean to me? It means being guided by a worldview that's holistic and anchored by shared values from the Christian gospel, Matthew 25, which says, "When I was hungry, you gave me food to eat. When I was thirsty, you gave me drink. When I was in prison, you visited me." I see these values as part of the holistic gospel we preach, which guides

us to respond to and support each other when we're in need. How we respond plays a major role in either supporting the health and wellbeing of our people, or in deepening their suffering, which can result in psychological problems and other challenges. Each of these very real material conditions must be addressed to prevent continued and often greater suffering. I see it as part of the holistic gospel we believe in to preach access to the support people need to address

their needs and prevent further suffering. How do we create this access and provide people the support they need? What kind of community do we have to build to both recognize these very real human needs and challenges as well as respond to them, to support individuals and communities to become whole? These are important questions I believe we need to ask and answer together.

STORY 2

I get health care primarily through mutual aid, free clinics, and pop up clinics. My insurance status is not very stable. I'm a student, and getting health care depends on registration, which depends on complicated processes of paperwork. When I'm home in LA, I don't have insurance at all.

Do I trust it? I would like to. I trust it more when I'm dealing with providers who are women of color because, in my personal experience, those are the only people who've listened to me. But even then, I wish it could be an innocent until proven guilty situation, but that would be at the expense of my health and the health of people who look like me. And that's not something I'm willing to gamble.

I'm painfully aware of how brainwashing the steps to becoming a doctor, a nurse, or other health provider, can be. I wish I could trust them. I also wish it was more about their quality as a health professional. As a person who has the privilege of being relatively educated, I know what they're doing about half the time. And I wish my trust was determined by that, but it's really determined by how I see them treat me, or when I had an accident, how they responded to that, or when I see them speak to my family who still have their accents, how they respond to that. It's almost like testing somebody you're going to dinner with by seeing how they treat the wait staff. Do you respect me as a human being? Do you recognize my humanity – or instead not recognize it because of my race, my class, my gender? That is more telling to me than how well you've memorized several medical textbooks.

Healthcare providers are not trained by institutions that help them see and respect our humanity. I want to trust them, but what I pay attention to and respond to is their behavior. If their behavior is not respectful, I don't trust them.

STORY 3

I agree that health and wellbeing are about more than the individual and what decisions are being made about the individual. Sometimes decisions about our health, how we take care of ourselves, are outside of ourselves: they are made for us. So I think health and wellbeing also include being able to be self-sufficient, to have control over decisions about how we want to live and what we need to feel safe and respected, including the kind of health care we receive.

Health and wellbeing also means being able to access what you want to access without any kind of barriers. Right now access is too frequently determined by power, position, and money. Being able to erase all the ways in which we're not given access is critical.

Finally, I would add that health and wellbeing also means acknowledgement that there are different ways of knowing. This is important because we live in a society that highly values biomedicine. We forget that there are other ways of knowing, other cultural practices. Too often our health care system tells us to put those other practices and ways of knowing aside and just believe in the medication of our society. For me, being able to be healthy means that I am able to incorporate all the ways of knowing, make decisions about my health, and do that in ways I feel safe and am not limited because of the color of my skin or because of my income.

STORY 4

I've been in the healthcare industry for so many years. When COVID hit, I got involved in trying to set up different testing centers in and around Boston, using a mobile clinic everywhere. I knew

this would be important to support people who don't have transportation and don't have money to buy it, to be able to get tested for COVID. I was able to partner with a lot of community based organizations and churches to bring sites to their communities.

When the vaccines came out, I really saw what it means to be Black in America: I saw the inequitable distribution of health care to Black people and their communities. I saw our state government, led by our Governor, set up all these mass vaccinations centers in white neighborhoods like Gillette Stadium and Fenway Park. Many of us worked with the Black Boston COVID-19 Coalition (BBCC) to fight to get the first mass vaccination center in the Black community, in Roxbury. My husband is located in Dorchester, and Dorchester and Mattapan, both Black neighborhoods in Boston, have consistently had one of the lowest vaccination rates in the city. We shouldn't have to fight the government to make sure our people are safe and protected from COVID.

When I talk about health and wellbeing including equitable health care, this is what I'm talking about: making sure that Black people have equal access to the life saving health care we offer other communities. How many Black people have internet access to log into the internet and make an appointment? How many Black people have smartphones to do that?

COVID is a public health crisis. We need to make sure that every human being, including Black and Brown people, gets equitable access to the best health care we can offer. I believe this is essential for supporting the health and wellbeing for each of us and for all of us. Right now, from everything I've seen, Black people don't have access to these and other essential resources. While available to other communities, they have not been readily available to the Black community

STORY 5

I live in Newton, pastor a church in Dorchester, and work in one of Boston's major health care centers. So I see how the social determinants of health—which can support or hinder health—play out very differently in these different environments. I can imagine, even predict, that if anything goes wrong and I need health care, how long it will take for me to access health care in Dorchester as compared to accessing it in Newton. The economic resources and challenges in these two communities are significantly different: they determine the quality of and access to health care available in each community.

To support and improve the health and wellbeing of our communities, the social determinants of health need to be taken very, very seriously because the presence or absence of these social supports makes all the difference in the world. For these systems to be healthy, they have to center and operate from a worldview of wholeness, otherwise the services they provide will not be healing or bridge gaps. They have to see the people they serve as part of the human community the social systems are committed to.

This is a spiritual perspective that deeply centers human beings. It's got to be a central part of any solution we come up with. It's got to be the centerpiece. If it's present, you can then work out from there. If it's not present, almost anything else that is present is not going to be effective. It's clear to me that if you want to improve health and well being, you've got to center this worldview in our health care system and all the other social systems that impact our communities.

Organizations That Hosted Focus Groups

ORGANIZATIONS THAT HOSTED FOCUS GROUPS

1. AFRICAN COMMUNITY LEADERS

Hosted by Chioma Nnaji

2. BLACK MEN RUN

Hosted by Jeff Davis

3. BOSTON LESBIGAY URBAN FOUNDATION

Hosted by Curtis Santos (2 focus groups)

4. ELDER HEALTHCARE DISPARITIES COALITION—ROXBURY

Hosted by Ronald Lammy

5. GREATEST MINDS

Hosted by George Greenidge

6. LEAGUE OF WOMEN FOR COMMUNITY SERVICE

Hosted by Adrienne Benton

7. MEN OF MELANIN MAGIC

Hosted by Lambert Rahming

8. TRAILBLAZHERS

Hosted by Liz Rock

Glossary

GLOSSARY

Below are key words used in this report. We have included them in this glossary in case they are unfamiliar to some readers, or because they are widely used but may mean different things to different people. We've provided definitions to let people know how our project understands the words.

BLACK

Our project uses this term to include people of African descent who embrace this identity, whether born in the United States or who immigrated to this country.

ELDER

People 65 years or older. As one of our assessment participants said, he realized he was an elder when he received his Medicare card.

LGBTQIA+

This is an acronym that collectively represents people who identify as: lesbian, gay, bisexual, transgender, queer, intersex, or asexual

SOCIAL DETERMINANTS OF HEALTH (SDOH)

An array of normalized dynamics (historical, cultural, internalized, interpersonal, institutional) that produce inequitable outcomes over time and in an ongoing way. E.g., Poor communities have impoverished schools, reduced access to higher education and higher wage jobs and wealth. Wealthy communities have increased access to well-resourced schools, connections with high prestige colleges and higher paying jobs and wealth. Overwhelming and overrepresented number of depictions of people of color as criminals in mainstream media, which can influence how various institutions and individuals treat people of color with suspicion when traveling, shopping, seeking housing or employment. This report lifts up SDOH to highlight the impact that systems have in individual lives.

SYSTEMIC RACISM

Involves institutions and systems of power. These are the unfair policies and discriminatory practices of institutions (schools, workplaces, systems of health, etc.) that routinely produce inequitable outcomes for oppressed people and advantages for privileged people. The policy may never refer to any social identity group, but their effect is to create and sustain inequities. E.g., Limited representation (gender roles, identities, curricula); E.g., White students disproportionately underrepresented in disciplinary action.

WELLBEING

This terms means different things to different people, which is why we used our research to find out what it means to the Black people who participated in our research.

