



YOU DESERVE PATIENT-CENTERED, RESPECTFUL, HEALTHCARE YOU CAN TRUST:

A Guide for People of Color



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Note: the terms “people of color and “Black” are used interchangeably in this guide



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Introduction

The purpose of this guide is to help all people, but particularly people of color, develop a better understanding of patient-centered care and how it can help to improve their healthcare experience. This guide was also written to show how patient-centered care can improve trust in healthcare providers and improve personal health and wellness outcomes.



Important Disclaimer: This guide does not replace any information provided to you by your physician or other healthcare providers responsible for your care. You should not consider any information in this guide as medical advice.

About the Author



James P. Young, Jr., Ph.D

My Experience With Racial Disparities in Healthcare

My journey through the healthcare system spans forty years. I was blessed to have opportunities to work directly with patients and healthcare providers for most of my time in healthcare. As a medical device consultant and business owner, I was often asked to explain to patients how medical devices worked to help their hearts. I also worked with physicians before, during, and after surgery and in their offices during patient visits for device follow-up. For patients who have pacemakers or defibrillators, you know how much you interact with pacemaker representatives in the hospital and doctors' offices.

I observed healthcare providers who had excellent skills interacting with people of color and others I would not trust with my worst enemy, regardless of color. I also watched White pacemaker representatives treat patients of color condescendingly and disrespectfully. I got in one rep's face so

bad; we almost went to blows. You see, he wore gloves when touching a Black patient's skin but did not wear gloves when touching a White patient's skin. Our discussion wasn't pretty.

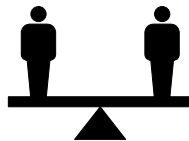
In one extreme case, a White physician made an error in surgery, requiring the patient to return to surgery the next day. He and his White nurse treated that Black man so rudely at his bedside that he begged me to find him another physician at another hospital to correct the problem. As hard as I tried to convince him to let the physician correct the problem, he was adamant about leaving AMA (Against Medical Advice), even though he was in the early stage of congestive heart failure.

I reached out to the best Black physician I knew who took his case, corrected the problem, and when the brother was leaving the hospital, he felt so good he wanted to show me his "pimp walk."

On the other hand, I have worked with very dedicated providers from different cultures to help them with behaviors that could improve Black patients' interactions. One example was the use of "Ma'am" and "Sir" when addressing an older Black person. I told the providers that these were terms Black people had to use in the south when addressing White people, and White people often responded by calling them "Boy" or by their first name (for Black women).

I remember showing a team of physicians how this worked. While checking an elderly Black female's device, I kept saying yes or no, ma'am, each time she asked a question. After the check, her response was, "thank you son, you're a good boy." Lesson learned.

Through these experiences and my research, I became interested in patient-centered care and Patient-Centered Medical Homes to improve health equity and treatment. These care models offer people of color the best chance of receiving healthcare services in an equitable, respectful manner and consistent with our culture, values, and goals.



What COVID-19 Revealed About Disparities in Healthcare

The 2020 COVID-19 has helped the world see how Black people experience racial disparities in diseases and treatment. It also caused people to raise questions about why there was a difference in how health care providers and hospitals treated people of color.

The COVID-19 Virus also helped the world better understand the amount of mistrust people of color have for healthcare. When the FDA and CDC approved a vaccine for the Virus, surveys showed that

many people of color were reluctant to get a shot because of mistrust and mistreatment. This mistrust was stronger than the benefits of getting the shot and was often tied to the Tuskegee Experiment, where Black men thought they were being treated for syphilis but were given shots that did not contain medicine to treat them. Instead, the “Experiment” was actually designed to see how the disease progressed in the body until death. However, the Tuskegee Experiment was part of a much larger system of racism in healthcare that has had a long-lasting effect on Black people and their mistrust of healthcare systems and providers. COVID-19 was merely successful in “uncovering” a problem that healthcare providers and systems hid in plain sight.

Now there is a scramble to address “systemic racism” and better understand racial disparities in healthcare. Better late than never.

What is Patient-Centered Care?

The Institute for Patient-and-Family Centered Care defines patient-centered care as *“an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care by placing an emphasis on collaborating with people of all ages, at all levels of care, and in all health care settings. In patient- and family-centered care, patients and families define their “family” and determine how they will participate in care and decision-making. A key goal is to promote the health and well-being of individuals and families and to maintain their control.”*



This institute also added that patient-centered care includes:



What Makes Patient-Centered Care Work for People of Color?

The key to making patient-centered care work is knowledgeable and confident patients willing to interact with providers and become active in developing and adhering to their care plans. This need can be difficult for older patients of color because of their experience with racism and mistreatment by healthcare providers.

For the younger generations, this obstacle may also be challenging because of what they learned about racism in healthcare from older generations, especially people who lived in the south under Jim Crow Laws. White Southern Law Makers enacted Jim Crow Laws to legalize segregation under a separate but equal doctrine. And while “separate” was achieved, “equal” certainly was not, and mistreatment of people of color in healthcare was common and harmful.

This guide intends to show people of color that there are more resources to improve their knowledge of patient-centered care, where to find it, and how it can correct their past poor experiences with healthcare providers. This guide was also designed to help people of color see the benefits of being engaged with patient-centered providers who are skilled in developing culturally competent care plans that meet their needs and healthcare goals in a respectful and trustful manner.

How Does Patient-Centered Care Benefit Providers?

Thanks to President Obama, he was successful in getting the Affordable Care Act passed into law. What made the ACA a stroke of genius were the market forces he included that increased competition for Medicare and Medicaid dollars among providers. President Obama also had in the ACA financial incentives for improving patient-centered care for people with chronic conditions and underserved communities. He also included funds to help the government find ways to make more information about healthcare providers available to the public to help them make informed decisions about how providers performed regarding the quality of care and patient satisfaction with care.



Since the ACA's passage in 2010, the government and insurance companies have created more financial incentives to increase competition among providers. Now, healthcare providers who demonstrate that they can deliver patient-centered care can earn more money. The three things the government and insurance companies use to determine how well providers perform are healthcare and wellness outcomes, cost, and patient satisfaction. The term now used to define these measurements is *Value-Based Care*.

Under the old payment system, the government and insurance companies paid providers on **how much** they did. It was called *Fee for Service*. Hence, the more patient visits, procedures, prescriptions, examinations, and tests done, the more money healthcare providers made. Now, Value-Based Care and provider income are based on **how well** providers deliver care and how cost-efficient the care is delivered.



So, for the first time in medical history, provider income is tied to patient experience and behavior. For Black patients, we tend to have higher mistrust and lower satisfaction with providers and are less likely to engage with them, and when we do, we are less likely to follow their instructions (this is called compliance).

And for all patients, regardless of culture or race, low healthcare literacy is an added problem healthcare providers face in influencing patient behavior to make more money from delivering high-quality care. Health literacy is another consideration that patient-centered providers and Patient-Centered Medical Homes use for improving interactions and compliance with multicultural patient populations.



In September 2009, I enjoyed speaking to the Congressional Black Caucus Foundation in Tunica, Mississippi. The purpose of the meeting was to talk about healthcare reform ahead of the ACA vote in Congress. During my presentation, I emphasized the importance of including culturally competent care and healthcare literacy to improve trust and health equity for people of color in the bill. Without those provisions, I argued that the ACA would not produce the kind of change desired for Black patients.



Mississippi Congressman Bennie Thompson mentioned the following in his follow-up letter:

Dear Dr. Young

The policy session you presented in “Health Care Reform” was developed to further our purpose of educating our diverse group of participants and preparing them to return to their communities and make a change or at least view and act upon issues with a more learned perspective. Your presentation clearly met our intent.

Your approach and direction to educating our audience on a critical health issue which, in fact, many had probably not given due consideration to in the past was on-point. I sincerely wish there had been sufficient time for a more extensive presentation.

You will be pleased to know that there were many positive comments on you as a speaker and on the value of the information you imparted. In fact, one of our attendees told me what she learned from you was “life changing information”.

The critical point in this part of the guide is that President Obama fought to change healthcare so that all people would have greater access to high-quality, equitable care. With providers' incomes now depending on how well they deliver care, we can benefit from increasing our knowledge of patient-centered care and how we can use it to work with providers who will perform well and help us achieve our healthcare and wellness goals in a caring and respectful manner.

There is one big problem, though. While providers adopt patient-centered care, understanding that it works better with knowledgeable and engaged patients, there are very few programs available to educate Black patients on patient-centered care and how it can benefit them. These problems are uniquely real with Black patients and communities where trust and satisfaction are low, chronic illnesses are high, and disparities are frequent.

What has become the foundation of patient-centered care is the Patient-Centered Medical Home. The healthcare industry often refers to Patient-Centered Medical Home as PCMH. Also, healthcare providers can earn additional money by transforming their practices into medical homes, which is not always easy.

What is a Patient-Centered Medical Home?



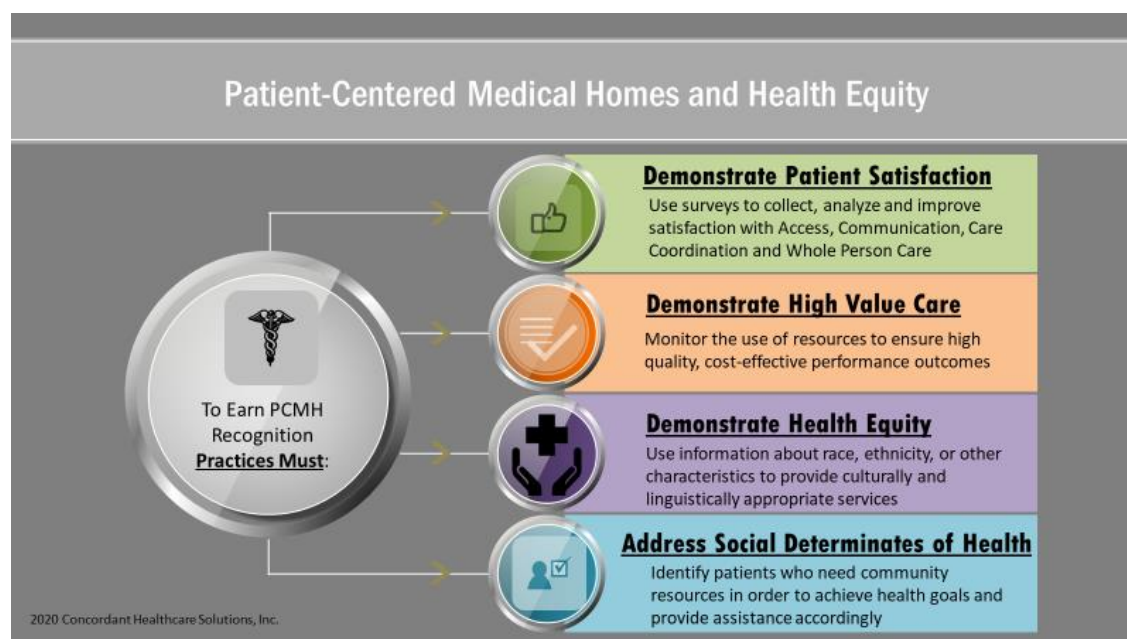
In December 2015, the National Academies Press defined the PCMH as:

A patient-centered medical home is essentially a relationship with a health care provider and health care team that knows a person's health issues and is accountable for taking care of that person. Patient-centered medical homes offer multiple opportunities to advance health equity.

“Taking care of that person” is an important thing to keep in mind as we take a journey through the Patient-Centered Medical Home Model because it has evolved into “whole-person care.”

The Patient-Centered Medical Homes featured in this guide are based on the National Committee for Quality Assurance (NCQA)*. This model has produced good results for patient-centered care in racially and culturally diverse communities and is frequently used by practices nationwide.

***NCQA is a private, nonprofit organization dedicated to improving health care quality. NCQA accredits and certifies a wide range of health care organizations. It also recognizes clinicians and practices in key areas of performance. NCQA's Healthcare Effectiveness Data and Information Set (HEDIS®) is the most widely used performance measurement tool in health care. NCQA's website (ncqa.org) contains information to help consumers, employers, and others make informed health care choices.**



To become a Patient-Centered Medical Home, clinical practices must demonstrate that they have developed policies, procedures and use technology to guide the practice toward the kind of patient-





centered care that will satisfy patients, produce healthy outcomes and deliver care of the highest quality. The care provided should be evidence-based and supported by best practices as often as possible. Medical practices are required to submit policies, procedures, and data for review to determine if they meet all the requirements to deliver patient-centered care and encourage patients to develop healthcare plans that reflect their needs, values, culture, and healthcare goals.

Once a practice is approved, they must go through an annual review to demonstrate that they have followed the patient-centered policies and procedures they submitted for their initial evaluation.

Practices can also earn NCQA's Distinction in Multicultural Health Care, where they demonstrate skills in providing culturally competent care that improves patient satisfaction and reduces racial disparities. Earning this distinction is a rather lengthy process. Still, practices can use it to show their community that they are committed to providing respectful, trustful care that considers each patient's values, culture, goals, and needs.

Skills Required to Become a Patient-Centered Medical Home and How They Benefit People of Color



Skill	Benefits
<p>Care Team Delivery Format</p> <p>A care team is trained to develop care plans along with the patient and family or caregiver. They have specific roles to ensure that each team member is skilled in delivering patient-centered care for each patient who selects them.</p> 	<p>This kind of care allows you to take an active role in developing your care plan based on your needs, culture, health, and wellness goals. For Black patients, this kind of care helps establish trust in your care team and enable them to provide “whole-person care” for you and your family.</p> <p>To make this work, your care team should be skilled in communications and racially, culturally competent care and knows that your voice matters and your unique needs are satisfied with each decision.</p>

Skill	Benefits
<p>Knowing the Patients Who Trust You With Their Care</p> <p>Providers and care teams must demonstrate skills in delivering individualized care to patients from different races and cultures from the community served. Culturally Competent care is the formal term for this skill and helps support population or community health among diverse populations</p> 	<p>Your care team should help you with the challenges you face in achieving your health and wellness goals. These are called “Social Determinates of Health” and can include things like, food insecurity, transportation, safety, financial, shelter, etc. If you are experiencing stress-related racism or other social issues, you might want to discuss these with your team because stress can affect your health and well-being.</p> <p>The team should provide information that is easy for you to understand. The team should also offer you decision-making aids for treatment or other care options so that you can remain an active participant in the care team.</p> <p>The team should also keep track of disparities in care and improve to reduce them, so you are not treated differently than other races or cultures.</p>

Examples of Social Determinates of Health




<p>Economic Stability</p> <p>Low Employment, Low Income, High Expenses, High Debt, High Medical Bills, Poor Support</p>	<p>Physical Environment</p> <p>Housing, Transportation, Safety, Parks, Playgrounds, Walkability, Zip Code</p>	<p>Education</p> <p>Literacy, Language, Early Childhood Education, Vocational Training, Higher Education</p>
<p>Food</p> <p>Hunger, Access to Healthy Choices, Food Preparation, Food Safety</p>	<p>Previous Healthcare Experience</p> <p>Mistrust, Disrespect, Poor Communication, Poor Access, High Cost, Poor Outcome, Fear</p>	<p>Social</p> <p>Poor Support System, Discrimination, Racism, Stress</p>

Skill	Benefits
<p>Providing Enhance Access To Care</p> <p>Patient-Centered Medical Homes demonstrate skills providing services or information for routine and urgent care before, during, and after business hours. They must also establish and adhere to policies that require timely responses to patients throughout the 24 Hour day. Practices should also set access and response times based on the needs of the communities they serve.</p> 	<ul style="list-style-type: none"> • Same-day appointments • 24/7 access to care and information • Phone calls returned in a timely manner • Reduce unnecessary Emergency Room Use • Improves coordinated care between providers • Improves satisfaction with providers • Improves trust in the healthcare system • Reduces the risk of unequal treatment <p>These benefits can help people who have conditions and symptoms that do not require emergency room visits but require frequent contact with a medical team. Patients with diseases like asthma, diabetes, hypertension, or pain management can get help or information for non-emergent or routine care. Black patients are more likely to have illnesses like these and benefit from having around the clock support.</p> 

Skill	Benefits
<p>Patient-Guided Care</p> <p>The practice and care teams should demonstrate the ability to encourage patients to help develop care plans that reflect their goals, needs, culture, and values. The practice should also seek to understand the community's goals, needs, culture, and values and work to improve population health accordingly.</p>	<p>People of color tend to have low trust and satisfaction with healthcare providers.</p> <p>By inviting patients to take an active role in developing their care plans, they are more likely to follow the plan and trust their care team.</p> <p>By having a care team they trust, patients are more inclined to discuss barriers to following their care plan with their team. These discussions would allow the team to help the patient find support or resources to overcome the obstacles they might face following the care plan.</p>



Skill	Benefits
<p data-bbox="394 333 607 365">Coordinated Care</p> <p data-bbox="203 394 792 638">The practice and care teams have policies and skills to communicate and share patient information promptly. Test and Lab results are returned to the practice and shared with patients promptly. The practice and care teams keep track of turnaround times to ensure that they comply with their policies.</p> 	<p data-bbox="824 508 1344 609">People of color have higher rates of chronic conditions like diabetes, heart, and kidney disease.</p> <p data-bbox="824 638 1377 844">As a result, they are more likely to need care from specialists for these conditions. Having a healthcare team that includes primary care providers and specialists can improve the management of chronic diseases for people of color.</p> <p data-bbox="824 873 1364 974">Having a well-coordinated care team can also reduce hospitalizations and emergency room visits.</p> 

Skill	Benefits
<p data-bbox="293 338 708 369">Monitor Performance and Quality</p> <p data-bbox="203 394 797 604">The practice and care teams are skilled in setting up quality measurements to ensure that whole-person care is given to every patient and patient satisfaction is measured and monitored for improvement. The practice also includes patients on the quality and performance teams</p> 	<p data-bbox="824 338 1373 436">Collecting patient experience (satisfaction) information usually includes how patients feel about:</p> <ul data-bbox="873 468 1325 737" style="list-style-type: none">• Access to Care and Information• Care Coordination• Communication Skills of Providers• Office Staff Courtesy and Respect• Whole-person care <p data-bbox="824 762 1373 898">The survey used allows patient-centered practices to separate the information by race, which helps them compare races and improve any disparities they see.</p> <p data-bbox="824 930 1382 1098">Increasingly, the government and insurance companies require practices to submit their patient experience data for publication to help patients use the information to make informed decisions.</p>





Patient-Centered Care for Poor and Underserved Communities

One of the Social Determinates of Health for people of color is income and economic disparities. These obstacles can make it difficult for low income or underserved people to gain access to high quality, affordable healthcare. To address these issues, Congress established the Human Resources and Services Administration (HRSA) to support Federally Qualified Healthcare Centers (FQHCs), also known as Community Health Centers (CHCs).

Community Health Center Services Can Include

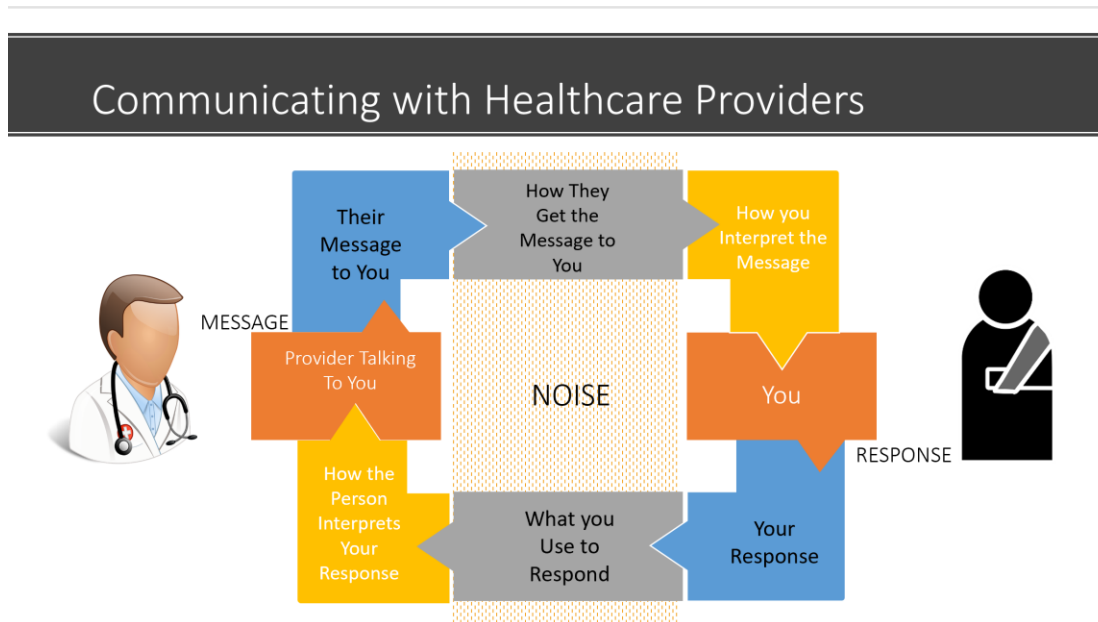


The government has given money to CHCs to help them transform into Patient-Centered Medical Homes to provide high-quality care to poor and underserved communities. CHCs are required to locate in underserved communities and must have a Board of Directors that includes patients from the community. They cannot deny healthcare services to anyone who cannot pay for care and offer a sliding scale for those who can pay for portions of their care.

Finally, CHCs are an essential part of President Biden's COVID-19 strategy as they will be primarily responsible for vaccinating poor and underserved communities, as well as communities at large. Here is an excerpt from Goal 6 of the President's Executive Order:

Expand access to high-quality health care. *The federal government will work to expand affordable coverage to increase access to care during this pandemic, and the Task Force will provide recommendations to align federal incentives with improved clinical outcomes. Specific actions include efforts to increase funding for community health centers, provide greater assistance to safety net institutions, strengthen home- and community-based services, expand mental health care, and support care and research on the effects of long COVID.*

Better Communications Between You and Providers



Seek First to Understand, Then To Be Understood

Stephen R. Covey

Communication with healthcare providers is often a challenge for anyone. It is particularly challenging for people of color due to distrust, low healthcare literacy, or the feeling of being disrespected during the communication process. The figure above represents a typical communication process. "Noise" is what occurs when the person talking does or says something that interrupts or distorts the message the listener is interpreting. Here are a few examples of noise.

Poor or no eye contact while speaking

Body language that says, "I will be glad when this is over."

Words or phrases that are difficult to understand (medical jargon)

Cutting off a person while they are speaking

Not addressing a person by their name

Asking a person if you can enter their space (may I come in)

Failure to verify that the person understands the message (talkback or teach-back)

Not inviting the person to ask questions before ending the conversation

Ignoring other family members in the room

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When the noise starts, understanding stops. I'm sure you can think of many more examples from your experience with healthcare providers. But help is here.

Good communications with patients is a frequent measurement for providers to earn more money from patient experience surveys. The survey most often used asks patients:

- How often did this provider explain things in a way that was easy to understand?
- How often did this provider listen carefully to you?
- How often did this provider give you easy to understand information about these health questions or concerns?
- How often did this provider seem to know the important information about your medical history?
- How often did this provider show respect for what you had to say?
- How often were clerks and receptionists at this provider's office as helpful as you thought they should be?
- How often did clerks and receptionists at this provider's office treat you with courtesy and respect?



These survey results are collected and used by the government and other payers to determine if providers and their staff have communication skills that patients find informative and respectful.

This communication measurement is one of the most critical components of culturally competent patient-centered care. It can influence the level of trust and satisfaction with providers for people of color.

For example, when I finished checking a device, I would review the information with the physician, and they would go over it with the patient. I often observed the patient's face when the doctor quickly started talking medical jargon and was clueless that the patient did not understand a word they were saying. When this happened to Black patients, not only were they confused but angered by the disrespect they felt. On several occasions, Black patients would try to pull me aside to share how they felt and ask me to explain what they had heard... noise.

Conclusion

All people should be treated with respect in healthcare, and there are growing incentives for providers to demonstrate that they can achieve this goal. The more people of color learn about patient-centered care, the more they can select and work with providers to achieve health equity and care that is respectful, trustful, and is consistent with their culture and healthcare goals

The COVID-19 Virus and low trust in healthcare providers have illuminated systemic healthcare disparities that can increase the risk of harm and death among people of color. Patient-Centered care that includes team-based care and patient engagement can improve trust, satisfaction, and clinical outcomes among people of color.

If we keep in mind that healthcare is both a profession and a very profitable business, we can begin to appreciate our value as revenue-generating customers. Like the Montgomery Bus Boycott that succeeded because of Black revenue loss, healthcare cannot survive as a business without revenue from Black or White customers. The difference is that because the Black population tends to have more chronic and costly conditions, we tend to need more interactions with healthcare providers and systems and produce more revenue (even taking into account uncompensated care).

Under the new payment models for providers, they will earn more by treating people better. This guide was designed to help people of color understand their financial value and how they can work with patient-centered providers to develop care plans that will lead to a trustful, respectful, and mutually satisfying relationship.

Frequently Asked Questions



Can a practice deliver patient-centered, culturally competent care without being a Patient-Centered Medical Home?

Absolutely. Many practices deliver excellent patient-centered care without going through the formal process of becoming a Patient-Centered Medical Home.

Can specialists have a Patient-Centered Medical Home?

Yes. There are models specialists can use to demonstrate that they can deliver patient-centered care in coordination with primary care providers and facilities.

Does the size of the practice make any difference?

No. Any size practice can deliver patient-centered care or transform into a Patient-Centered Medical Home

Is it better to have a Black Provider than a provider of another race or culture?

While some studies demonstrate that Black Providers tend to deliver patient-centered care that is culturally competent for Black patients, providers from all races and cultures can develop skills to provide respectful, trustful, and patient-centered care.

What if I cannot find published quality or patient experience on a provider or practice?

In some cases, the practice may not have enough data to submit. But, you can still ask if there is data they can share with patients.

What if I love my primary care team but do not like the Specialist they refer me to.

Specialists rely on primary care providers for referrals and income. First, express your concern(s) with the Specialist and if you are not satisfied with the results, inform your primary care team so they can take appropriate action. Feel free to ask to see the Specialist's quality and patient experience data (or look them up).



Important Disclaimer: This guide does not replace any information provided to you by your physician or other healthcare providers responsible for your care. You should not consider any information in this guide as medical advice.

Resources

Here are a few links you can use to find information on healthcare providers and patient-centered care.

[About the National Committee for Quality Assurance \(NCQA\)](https://www.ncqa.org/)

<https://www.ncqa.org/>

[Culturally Competent Care](https://www.youtube.com/watch?v=ZsX0ha_rIBg)

https://www.youtube.com/watch?v=ZsX0ha_rIBg

[Guide For a Patient-Centered Care Plan](https://drive.google.com/file/d/1Xz1PRxSixYDAFhkR8580bMtNgloEuVfd/view)

<https://drive.google.com/file/d/1Xz1PRxSixYDAFhkR8580bMtNgloEuVfd/view>

[Here is an excellent video that explains the features of a Patient-Centered Medical Home](https://www.youtube.com/watch?v=CvroxEpoyNY)

<https://www.youtube.com/watch?v=CvroxEpoyNY>

[Compare Providers and Systems](https://www.medicare.gov/care-compare/?providerType=Physician&redirect=true)

<https://www.medicare.gov/care-compare/?providerType=Physician&redirect=true>

[Find a Patient-Centered Medical Home and Providers](https://reportcards.ncqa.org/#/practices/list)

<https://reportcards.ncqa.org/#/practices/list>

[Find a community health center](https://www.hrsa.gov/)

<https://www.hrsa.gov/>



