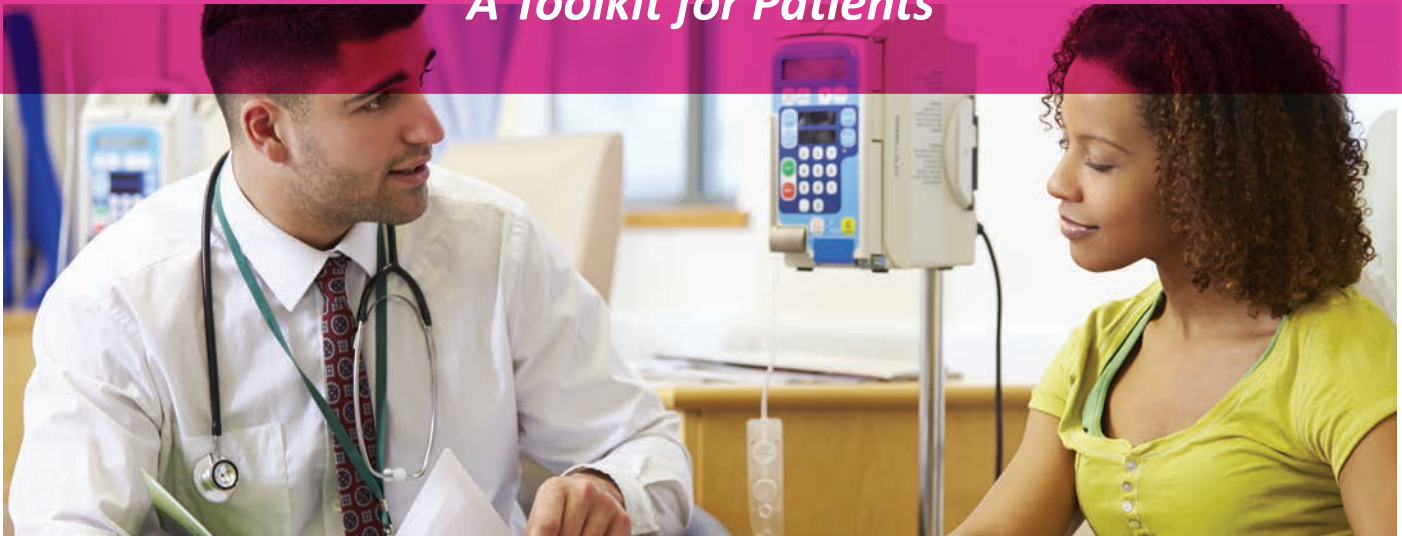


BUILDING TRUST WITH YOUR HEALTHCARE TEAM THROUGH SELF - ADVOCACY

A Toolkit for Patients



CREATED WITH YOU IN MIND

We see you. We hear you. We've got you covered.

We have witnessed, heard and personally experienced racial challenges specifically for Black women due to systematic racism within healthcare. For these reasons we've carefully crafted this toolkit with you in mind. The goal of this toolkit is to:



1. Equip you with the right tools to build trusting relationships with your health care providers, based on mutual respect, understanding and empathy



2. Give you information on what you can do if you feel like you're not being heard or adequately cared for.

Racism in medicine is an unfortunate reality that no one should suffer the consequences of, and we hope that this toolkit can help you navigate interactions with your providers, advocate for yourself and seek the best care that you are entitled to. You are your own best advocate, so let's make sure that you have the tools you need to do what is best for *you*.



WHY TRUST IS IMPORTANT

Medical distrust is prevalent in the Black community: for example, Black Americans are far less likely than white Americans to trust their physician. This distrust stems from both negative experiences and a place of trauma caused by very real historical events - with the Tuskegee study and the theft and commercialization of HeLa cells from Henrietta Lacks, being the most infamous examples. Trust is earned, and a history of bias and discrimination has given people of color reasons to distrust providers.

At Tigerlily, we believe that trust can be repaired, and that the 'trust gap' can be bridged through practices that foster mutual respect and understanding. You deserve to be cared for by providers who respect and understand you. Next to access to care, the relationship between a patient and healthcare provider is one of the most important aspects of patients' rights.

Ultimately, the care team should serve both as your treatment team AND your cheerleaders. And research shows that there is a positive correlation between a positive patient/provider relationship and health outcomes.



PATIENT CONSIDERATIONS:

What you should expect from your health care provider

Clear Understanding

Health care providers should try and make an effort to speak to you using words that you understand. Your provider should take into account your culture and religious beliefs as well. If language is ever a barrier, you have a right to an interpreter; many hospitals have multi-lingual staff and if they don't, telephone-based interpreters are available for free at treatment centers, some insurance companies as well as non-profit organizations.

Additionally, it's OK to ask questions, no matter how silly or embarrassing you think it might be. Many times we are afraid to ask our health care providers embarrassing questions out of fear of being judged, but as doctors, they have heard it all before. Patients know that their health care provider is (or should be) a safe space and if it concerns their health, it concerns their provider. Vulnerability is a great way to show a doctor that you are open, receptive and ready to build a relationship based on honesty.



Comfortability

In collaboration with you, health care providers are responsible for your health. Health care providers should offer a non-judgmental environment and ask motivational questions (often open-ended and affirmational, rather than accusatory) to ensure you feel comfortable sharing any issues impacting your health. You will be interacting with your provider for some time, so you want to ensure that you are comfortable sharing truthfully and openly.



Honesty

Health care providers should be honest, collaborative and transparent with you. Your doctor should be willing to hear you out and take your concerns seriously. Be willing to discuss ALL aspects of your treatment and health plan with them.



Compassion

Your health care provider should offer compassion and understanding. This is often displayed in their ability to listen, reflect your concerns, respect your opinions and feedback, and always keeping your quality of life in mind.





PATIENT CONSIDERATIONS: What you can do to help build trust

The relationship with your HCP is a two-way street, that requires effort on both sides. Patients can absolutely help build the trust in this relationship. Here are some ways to do so:

Ask Questions

It's OK to ask questions, no matter how silly or embarrassing you think it might be - so many times we are afraid to ask our health care providers embarrassing questions out of fear of being judged, but they're doctors and they have probably heard it all before. Patients know that their health care provider is (or should be) a safe space and if it concerns their health, it concerns their provider. Vulnerability is a great way to show a doctor that you are open, receptive and ready to build a relationship based on honesty.

Additionally, do not fear challenging your provider. When presented with a particular treatment, ask *"why is it better than x"*. You should always understand why the proposed treatment is the best one for you.

Mindset

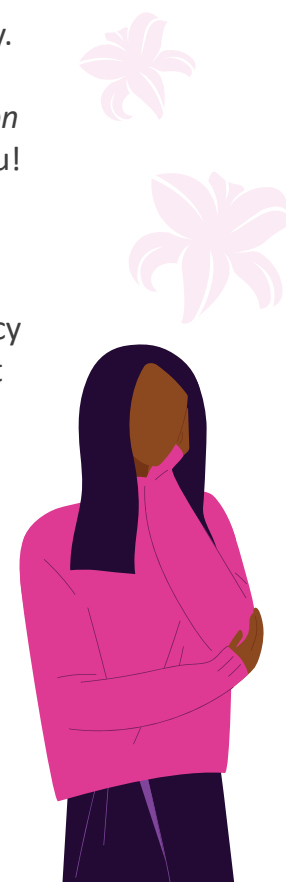
Being open-minded and going in with a sense of curiosity can help open the pathway. We do understand this is not a regular annual check-up; it's cancer and it's serious. But try to go into this relationship with your provider with the mindset of, *"this person is on MY team, they work for me"* they are there to help and kick cancer's butt with you!

Honesty

Be honest. Being honest with your provider can possibly save your life. Full transparency about your lifestyle habits, diet, living situation, etc is so important. In some cultures, it could be considered prodding or being nosy, but health care providers need to know that information - it is vital and crucial.

Additional Support

Don't let nerves impact your relationship with your provider. It is completely normal to be nervous during these interactions. If you are, that's totally ok - practice writing down some questions ahead of time, or have a trusted friend, family member or caregiver come along for your appointments.





What you can do if trust is not there

What if you have a provider who is simply not a good fit? Or worse, one who doesn't take your concerns seriously or is disrespectful towards you?

That is NEVER ok. No person should ever be made to feel that they are not being taken seriously or that their provider does not value them or their health. If that happens, here's what you can do:

- First, trust your instincts and don't doubt your experience. If you're feeling dismissed, don't hesitate to say so. Tell your provider that you feel like they're not listening to your concerns and/or giving you enough information. Here are a few pointers on how to make your point:
 - *"I'm worried that we aren't communicating well"*
 - *"I really want to understand more about X. Can we take some time to go over this?"*
 - *"Can you help me understand X?"*
 - *"I know my body, there is something wrong and I need to find out what it is going on"*
 - *"I appreciate your expertise, but I would like you to investigate this further"*
 - *"X is something that I have never experienced before and I really want us to do everything that is possible to understand what is causing it"*
 - *"Are there any more things X could be caused by? Have you investigated all possible options? Are there any more tests you could have me take?"*
- If you're unsatisfied with the care you are getting and your doctor is not listening, know that hospitals and health systems have patient advocates available. Ask to be connected to one.
- To help you, you can also seek out a caseworker (if you are on Medicaid), and/or the hospital's patient affairs office. Many hospitals also have a Patient Affairs Department, which acts as a liaison between patients, families and the facility's administration. They can provide you with more information and/or act as a mediator between your provider and you to help you reach a resolution. Whatever you do, document everything. Documenting and following up with the patient affairs contact can go a long way.
- If you're still not feeling heard or supported, you can (and should) get the care you deserve elsewhere. The relationship with your provider is just that – a relationship. If that's not a good one, you should get out of it. We understand that changing providers is not easy and that there are barriers that may limit your options, like insurance network limitations, or transportation challenges. But if you feel that the quality of your care depends on it, don't hesitate to take that step and get in touch with your insurance provider to see if you can see another doctor in your network/ close to your location. You have a right to see providers who listen and understand you.



WHAT THE LAW SAYS

If you want to go that route, you should know that as a patient, you have the right to report discriminatory or biased practices. There are many ways for you to do so, and people who can help you.

Patient Grievances

By law, all hospitals participating in Medicare and Medicaid programs (that is, the vast majority of hospitals) have a patient grievance process that allows patients to report concerns without fear of retaliation. Information on how to file a complaint should be provided to you as part of the hospital's Patient Bill of Rights.



The Joint Commission

Most hospitals are accredited by the Joint Commission, which is a private, non-profit group. The Joint Commission prohibits discrimination and will review any quality of care complaints. You can contact them at 1-800-994-6610 or via e-mail at patientsafetyreport@jointcommission.org. They also allow patients to file [online complaints](#).

The U.S. Department of Health and Human Services

Many state health departments will allow you to file a complaint with your hospital if you think they have violated state anti-discrimination laws. The U.S. Department of Health and Human Services has developed an [online resource](#) with website, phone, address, and e-mail contact information for your state health department.

United States Department of Health and Human Services' Office of Civil Rights

You may also file an [online complaint](#) with the United States Department of Health and Human Services' Office of Civil Rights if you feel that a provider or facility discriminated against you. You can also send your complaint via email to OCRComplaint@hhs.gov.

Title VI of the Civil Rights Act of 1964

Lastly, know that Title VI of the Civil Rights Act of 1964 not only prohibits intentional discrimination based on "race, color or national origin"; but also prohibits processes or criteria that may look neutral but unintentionally exclude people because of their nationality or race. If you feel like you've been the victim of discriminatory behaviors or 'unintentional' discrimination, you could seek legal intervention on those grounds.



TIGER TIPS

Be open and honest with providers: be fully transparent about your symptoms, habits, and lifestyle. No topic should be taboo. This is (and should be) a judgement-free zone. Also, be honest with your provider if you're not feeling heard by them: if you sense that there is a miscommunication, speak up.

Ask questions: Ask questions about anything that you do not understand, and do not be afraid to ask the question again if you don't understand the answer. Ask providers to clarify any medical term you're not familiar with. When it comes to your health, there are no stupid questions. To help you remember, you can also make notes about what you discuss so that you can refer to them as needed.

Tell providers your entire story, not just your symptoms: it is crucial to tell doctors what your symptoms are, but don't forget to put them in context by sharing your entire story: when did your symptoms start? When do they occur/how often? Are you experiencing any changes in your life that might be related in some way? This also comes down to being transparent.



Give feedback about the doctor's care and your office experience: if you feel like you're not getting the care you deserve, do reach out to a patient advocate/the hospital's patient affairs department. You have a right to be heard.

Ask for help/mediation: patient advocates and case managers can help you navigate the relationship with your providers. Don't hesitate to involve them; they're there to help you.

Trust yourself: if you feel you're being dismissed due to bias or discrimination, trust your instincts. The relationship with your provider should be one between equals, based on trust and understanding. If this understanding or respect isn't there, get the care you deserve elsewhere.



RESOURCES

At Tigerlily we are committed to providing you with the most up to date information along with resources to help you on your journey. We know that this is a challenging time and we want to provide you with resources not only Tigerlily offers, but also our partners. Check out our Toolkit page to find additional resources available to you.