



Table of Contents

PART I: Structural Racism in the US Healthcare System

- o6 How To Use This Resource Guide
- 08 Brief Timeline

PART II: Real-Life Examples for Personal Reflection

- 12 Topic: Patient Care
- 14 Topic: Medical Devices
- 16 Topic: Research
- 18 Topic: Telehealth
- 20 Call to Action

PART III: Advocacy Tools for Patients

- 24 Health & Safety Tips
- 26 Be Ready for Your Next Appointment
- 27 Changes to Discuss
- 30 Questions to Consider in Your Doctor's Appointment
- 32 Your Health Information Privacy (HIPAA) Rights
- The Harms of Being Labeled a Difficult or Non-Compliant Patient
- 36 Screening Guides for Infants, Children, Teenagers, & Adults
- 39 Vaccinations
- 42 Helpful Resources
- 44 Additional Readings

PART IV: Advocacy Tools for Providers

- 48 8 Reasons Patients Don't Take Their Medications
- How Using the Term "Non-Compliant" Keeps Providers From Partnering with Patients
- Health Literacy: A Prescription to End Confusion
- To Boost Outcomes, First Unlock the Power of Health Literacy
- Advancing Health Equity by Avoiding Judgmentalism and Contextualizing Care
- 54 Consider Culture, Customs, and Beliefs
- 56 Communicate Clearly
- 58 Use the Teach-Back Method
- 61 Follow-Up With Patients
- 63 Address Language Differences
- 66 | Speak Cards
- 68 Encourage Questions

Resources

- 72 Additional Readings
- 74 Additional References
- 76 Contributors





PART I: Structural Racism in the US Healthcare System

Structural racism in the US Healthcare System has deep historical roots and is ongoing, negatively affecting millions of Americans as patients and providers. This resource guide can help you advocate for health equity by guiding patient-provider relationships for improved health outcomes.

Part I serves as an introduction, defines common language, and offers a timeline of key events exploring the connection between racism and health in the US.

How To Use This Resource Guide



What is this Resource Guide?

This is an educational resource for patients and providers to help navigate the barriers resulting from structural racism in the US Healthcare System.



Who is this Resource Guide for?

This resource guide is for patients, family members, advocates, US healthcare administrators and providers, and medical school professors and students.



How can Patients use this Resource Guide?

Use this as a guide to support stronger relationships between you and your healthcare team as you work toward optimal health outcomes.



How can Providers use this Resource Guide?

Use this as a training tool to increase awareness and support improved patient-provider relationships for improved health outcomes. This can also serve as a guide when developing workplace policies and educational tools for medical students, providers, hospital administrators, and other staff.



"The story of public health in America wouldn't make any sense if you didn't understand the story of race in America."

- Dr. Ashish K. Jha, Brown University School of Public Health

COMMON LANGUAGE

Structural Racism

Historical and current policies, practices, and norms that create and maintain White supremacy. Racial and ethnic minorities are offered limited or no access to opportunities for upward mobility. This limits access to quality education, housing, health care, and equal treatment in the criminal justice system.

Equality versus Equity

Equality: Everyone gets the same thing, but not what they need. Equity: Everyone gets what they need.

Health Equity

Exists when everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health, such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care (Robert Wood Johnson Foundation).

Implicit Bias

A negative attitude against a specific social group, which can be intentional or not.

Minority versus Minoritized

Minority traditionally means a smaller number of people compared to a majority. It usually refers to Black/African Americans and other people of color compared to White people. We believe minoritized is a better term to use because it suggests that minoritized communities (Black/African Americans and other people of color) have much less economic and social power than White people due to racism and discrimination.

Racial Equity

The process of eliminating racial disparities and improving people's lives. It is the continued practice of changing policies, practices, systems, and structures by prioritizing positive change in the lives of people of color (<u>Race Forward</u>).

Social-Ecological Framework

A model to understand our society's multiple, overlapping levels that influence behavior

White Supremacy

An ideology that White people and the ideas, thoughts, beliefs, and actions of White people are superior. This informs a political system where White people enjoy advantages and rights that other racial and ethnic groups do not.

Brief Timeline

1950 HENRIETTA LACKS Medical Progress Uses a Black Woman's Cells Without Her Consent





JAMES MARION SIMS AND THE
CONTROVERSIAL BEGINNING
OF MODERN GYNECOLOGY
The Abuse of Black Bodies as
Medical Test Subjects

1900 1950

1920s-1980s
MISSISSIPPI APPENDECTOMY
Involuntary Sterilization of Poor, Black
Women Deemed "Unfit" to Reproduce



1932-1972
TUSKEGEE EXPERIMENT:
DECEPTION THAT CONTRIBUTED TO
ONGOING HISTORICAL MISTRUST
Treatment Withheld from Men with Syphilis







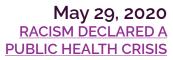
2020 - Present
COVID-19 WORSENS
HEALTH COVERAGE
5 Million Black and
Hispanic People
Projected to Lose
Health Insurance



July 30, 1965
LAUNCH OF MEDICARE
AND MEDICAID
Addressed Limited Access

Addressed Limited Access to Healthcare

2000



Racism Attacks People's Physical and Mental Health





1981 - Present
AIDS EPIDEMIC
Lack of Empathy to Provide
Necessary Prevention and Health
Care for Underserved Communities





PART II: Real-Life Examples for Personal Reflection

Advocacy starts with awareness and education. The following pages have case studies, which are examples of real-life projects or events. Each case study focuses on one of four areas: **patient care, medical devices, research,** and **telehealth**.

Take some time to read each case study, either on your own or with others you know. Reflect on similar experiences you've had as a patient and/or provider. Think of ways the lessons learned in these studies can help progress health equity.

Patient Care



EXAMPLE ONE

A Multi-Faceted Intervention Aimed at Black-White Disparities in the Treatment of Early Stage Cancers: The Accure Pragmatic Quality Improvement Trial

Cykert, S. et al. (2020). A multi-faceted intervention aimed at Black-White disparities in the treatment of early stage cancers: The ACCURE pragmatic quality improvement trial. Journal of the National Medical Association, 112(5), pp. 468-477.

Summary

NIH funded a five-year intervention, Accountability for Cancer Care through Undoing Racism and Equity (ACCURE). ACCURE was the first study to show racial disparities in health care can be eliminated. It used a community-based participatory research approach and racial equity lens.

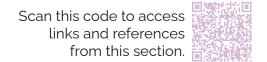
The study consisted of early-stage breast and lung cancer patients at two cancer centers, a community hospital in Greensboro, NC, and a university hospital in Pittsburgh, Pennsylvania. The ACCURE study also showed when racial disparities are eliminated, all patients benefit, regardless of race.



Reflective Question

What proven approach can be taken to eliminate racial disparities across healthcare systems in the United States?

EXAMPLE TWO



Structural Racism— A 60-Year-Old Black Woman with Breast Cancer

Pallok, K., S. B., De Maio, F., Ansell, D. A. (2019). Structural racism—A 60-year-old Black woman with breast cancer. The New England Journal of Medicine, 380(16), 1489-1493.

Summary

A group of physicians, community leaders, and public health advocates led a task force to address the growing disparity between Black and White women in breast cancer-related mortality in Chicago. This gap had nothing to do with biological differences but instead with access to mammography and gaps in the quality of breast cancer diagnosis.

Quality improvement efforts, such as nurse navigators and operational process improvements, are one of the many ways to reduce or even close the racial disparity gap between Black and White patients.

Reflective Question (7)



How might implicit biases, based on incorrect beliefs regarding biological differences, reinforce racial disparities and health inequities?





Medical Devices



EXAMPLE ONE

Racial and Ethnic Discrepancy in Pulse Oximetry and Delayed Identification of Treatment Eligibility Among Patients with COVID-19

Fawzy, A., Wu, T. D., & Wang, K. (2022). Racial and ethnic discrepancy in pulse oximetry and delayed identification of treatment eligibility among patients with COVID-19. JAMA Internal Medicine, 182(7), 730-738.

Summary

The consistent use of common medical devices, like the pulse oximeter, plays an import role in the daily healthcare treatment of patients. A pulse oximeter is a non-invasive tool that measures the amount of oxygen in your blood.

During the pandemic, oxygen levels were used to determine if and when COVID-19 therapy should be given. Researchers looked at data collected from five hospitals. They found some racial and ethnic minorities were either considered not eligible for treatment or delayed treatment based on inaccurate estimates of oxygen levels by pulse oximeters.



Reflective Question

How can healthcare providers become more aware of disparities when using medical devices? What steps should be taken in clinic/patient visits?



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The Fight to Fix a Racist Medical Gadget

Zukerman, W. (Executive Producer). (2022, September 22). The fight to fix a racist medical gadget [Audio podcast episode]. In Science vs. Gimlet. https://gimletmedia.com/shows/science-vs/8whnlz7/the-fight-to-fix-a-racist-medical-gadget

Summary

An electroencephalogram (EEG) is a medical device that records the brain's electrical activity. EEG machines attach to a person's scalp, which can be an issue if your hair is really coily or curly. These machines also have a hard time attaching to weaves or dreadlocks. This podcast episode speaks with a team of young Black scientists who partnered with hairdressers and transformed the EEG to attach more easily to hair textures typically associated with Black / African American people.

Reflective Question



How can you make sure your healthcare team is able to make needed medical device adjustments?

TOPIC: Research

EXAMPLE ONE

Enrollment of Racial Minorities in Clinical Trials: Old Problem Assumes New Urgency in the Age of Immunotherapy

Nazha, B., Mishra, M., Pentz, R., & Owonikoko, T. K. (2019). Enrollment of racial minorities in clinical trials: Old problem assumes new urgency in the age of immunotherapy. American Society of Clinical Oncology Educational Book, 39, 3-10.

Summary

According to the National Institutes of Health (NIH), cancer is the second leading cause of death in the United States, even though many new cancer treatments, like immunotherapy, have emerged because of clinical trials. However, minoritized communities are underrepresented in the research for various reasons. As a result, there is limited data available on the impact of treatment on minoritized ethnic groups.



Reflective Question

What steps can clinical and public health professionals take to build trust with minoritized populations to increase clinical trial participation?



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EXAMPLE ONE

Counter the Weaponization of Genetics Research by Extremists

Carlson, J., Henn, B. M., Al-Hindi, D. R., & Ramachandran, S. (2022). Counter the weaponization of genetics research by extremists. Nature, 610, 444-447.

Summary

Genetics research—the study of human DNA to discover what genes and environmental factors contribute to diseases—is being misinterpreted and misused by White nationalists to support their racist ideologies. The scientific community is attempting to prevent this by diversifying their research participants, being more responsible when sharing their data, and calling out extremists who misuse their work. All scientists should consider the potential harm of their research and how it could be interpreted.

Reflective Question



How do you know the data you see in articles and social media are accurate?



TOPIC: Telehealth

EXAMPLE ONE

Racial and Ethnic Differences in Self-Reported Telehealth Use During the COVID-19 Pandemic: A Secondary Analysis of a US Survey of Internet Users from Late March

Campos-Castillo, C., & Anthony, D. (2021). Racial and ethnic differences in self-reported telehealth use during the COVID-19 pandemic: A secondary analysis of a US survey of internet users from late March. Journal of the American Medical Informatics Association, 28(1), 119-125.

Summary

The COVID-19 pandemic led to a widespread need for technology to help provide safe, quality care. Telehealth services became crucial to address access issues. Although telehealth has mostly been seen as positive, the rapid uptake of telehealth has widened gaps in disparities for minoritized and marginalized populations.



Reflective Question

How can we make sure that marginalized people have proper access and are included in the advancement of telehealth?



Scan this code to access links and references from this section.





Telemental Health Through a Racial Justice and Health Equity Lens

Carrington, S., & Driskell, J. (2021). Telemental health through a racial justice and health equity lens. Carrington, Scune and Driskell, Jeff, Telemental Health Through a Racial Justice and Health Equity Lens (October 9, 2021). Available at SSRN: https://ssrn.com/abstract=3960052 or http://dx.doi.org/10.2139/ssrn.3960052

Summary

COVID-19 worsened the many inequities, barriers, and challenges that marginalized communities face due to systemic racism. The pandemic increased mental health issues, increasing the need for mental health support using telehealth services. However, there were many barriers/challenges that reflect continued inequities for racial and ethnic minorities.

Reflective Question



How can access to telehealth be improved to provide equitable mental health services?

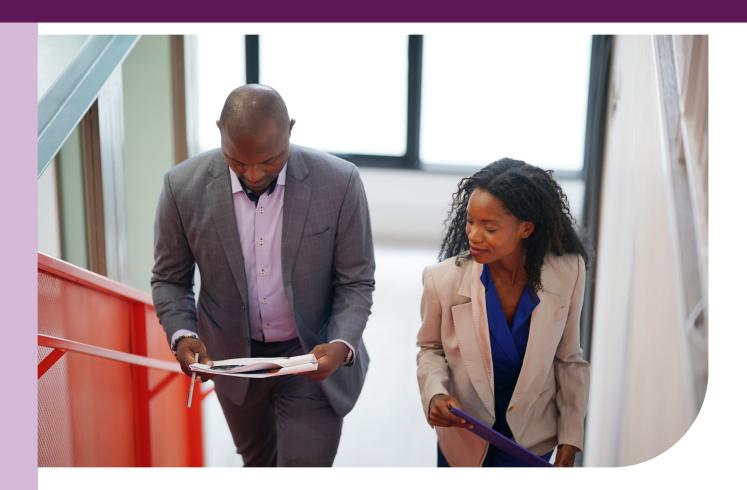
Call to Action

The US Healthcare System is working as designed. Our flawed healthcare system contributes to racial and health disparities, from the design of medical devices to the participants we recruit for research studies.



"Racism is a longstanding systemic structure in this country that must be dismantled through brutally honest conversations, policy changes, and practices."

- Georges Benjamin, MD, American Public Health Association (APHA) Executive Director



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What Can We Do?

It is crucial that we think, talk, and take action against structural racism. You are not alone in this fight. You can start by doing the following:



Educate yourself and reflect on your personal experiences



Have conversations with family, friends, and community members about their experiences receiving healthcare



Speak up when you feel discriminatory or neglectful behavior directed towards you by healthcare members



Listen, acknowledge, and accept the experiences of others



Call your elected representatives and express your concerns over policies and laws that may contribute to structural racism



Volunteer in community organizing campaigns that address unfair healthcare practices and treatment





PART III: Advocacy Tools for Patients

Change begins with you. Navigating the healthcare system can be overwhelming, so we want to provide tools to help prepare you for upcoming visits.

Use these tools and resources to help advocate for yourself and others.

Health & Safety Tips

from The Cleveland Clinic and the Agency for Healthcare Research and Quality



Take an Active Role in Your Care and Safety

You are the best advocate for yourself and your family. You and your healthcare providers are a team. Remember these tips for you and your family to help ensure everyone's health and safety.

Tip #1:

Be involved in your healthcare. You are the leader of your team.

- · Be a part of all your treatment choices.
- Complete your <u>advance directives</u> and provide a copy to your healthcare provider.
- · Share any special needs you have.
- Ask a trusted family member or friend to go with you to your doctor's visit if you are too sick or stressed to be an active part of the visit.

Tip #2:

Speak up if you have any questions or concerns.

- You have a right to ask questions.
- Write down your questions to make sure you get all of the information you need.

Tip #3:

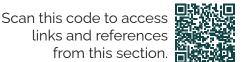
Identify yourself.

- Be sure the healthcare professional asks for your name and birthdate.
- Don't hesitate to speak up if you think they have confused you with another person.

Tip #4:

Know the plan.

 Ask healthcare workers to tell you what they plan to do before you agree to any procedure.



Tip #5:

Bring a list of your medications and mention any allergies you have.

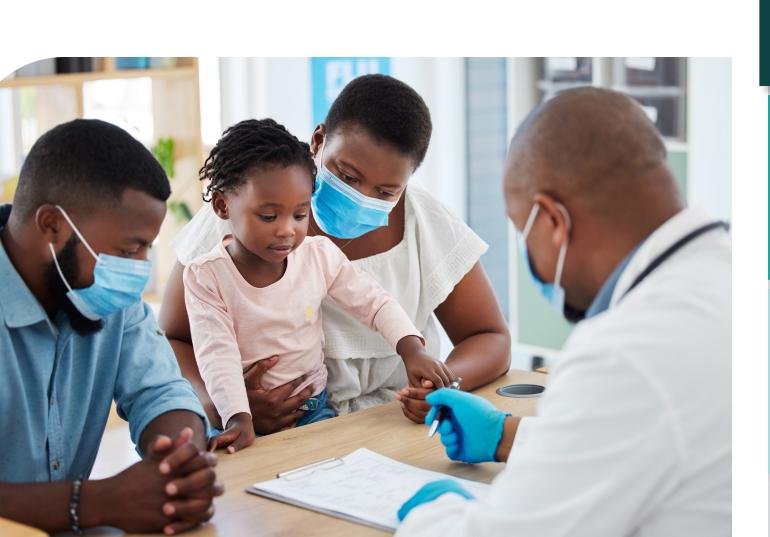
- Include all over-the-counter (OTC) medicines (*i.e. Tylenol®*, *Benadryl®*, *etc.*), home remedies, and herbal medicines like tea, vitamins, and weight gain or loss products (*like shakes*, *pills*, *or bars*). Sometimes they can be dangerous when you take them with other medicines.
- Know what medicines you are taking, why you are taking them, and their potential side effects.
- Let the doctor and nurse know about any allergies you have and the type of reaction or side effects you have.
- · Ask questions about the medicines you are prescribed during your appointment.

Tip #6:

Ask healthcare workers to wash their hands before any direct contact.

 Handwashing is an important way to stop the spread of infection. Make sure your doctor or nurse washes their hands before having any direct contact with you or your family members.
 Healthcare workers may also use hand sanitizer.

Information adapted from The Cleveland Clinic and the Agency for Healthcare Research and Quality.



Be Ready for Your Next Appointment

For some people, doctor's visits can be stressful. Being prepared for your appointment can help make the visit go a little smoother.

Here is a list of things to think through before your next doctor's visit:

APPOINT	MENT INFORMATION:
Doctor's N	Name:
Type of D	octor:
Appointm	nent Date: Appointment Time:
Office Add	dress:
BEFORE A	APPOINTMENT CHECKLIST:
☐ Me	dicine (take your medicine bottles, including vitamins and supplements)
☐ Wri	ite down any changes in your health (see Changes to Discuss checklist)
☐ Wri	ite down any questions you have
Gat	ther any documents you need to bring (test results, paperwork, etc.)
IF YOU AF	RE SEEING A NEW DOCTOR, MAKE SURE TO TAKE:
Pho	oto ID
☐ Inst	urance Card
For	ms you were asked to bring
☐ Pha	armacy name and address or phone number
List	of medical conditions

Changes to Discuss

Tell your doctor about any changes in your life since your last visit.

The list below can help you think of changes to mention. Take a minute to think about the changes and write down when you first noticed the change and any other information that can help your doctor. This list doesn't include everything and may not apply for every visit.

YOUR PHYSICAL HEALTH

Recent emergency or hospital visits	Date: Notes:
Bone pain, joint pain, or stiffness	Date: Notes:
Bowel or bladder problems	Date: Notes:
Headaches	Date: Notes:
Feeling dizzy or lightheaded	Date: Notes:
Vision or hearing changes	Date: Notes:
Skin changes (rash, changes in color, etc.)	Date: Notes:

YOUR MEDICINES AND LIFESTYLE

Alcohol use	Date: Notes:
Weight changes	Date: Notes:
Diet or appetite changes	Date: Notes:
Medicines	Date: Notes:
Tobacco use	Date: Notes:
YOUR MENTAL HEALTH,	THOUGHTS, AND FEELINGS
Feeling lonely or isolated	Date: Notes:
Feeling sad, down, or blue	Date: Notes:
Problems with	Date:
memory or thinking	Notes:

EVERYDAY LIVING

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Accidents, injuries, or falls	Notes:
Daily activities	Date: Notes:
Exercise	Date: Notes:
Problems with intimacy or sexual activity	Date: Notes:
Driving, transportation, or mobility	Date: Notes:
Advance directives	Date: Notes:
Living situation	Date: Notes:
Other	Date: Notes:
Other	Date: Notes:

Questions to Consider

in Your Doctor's Appointment

Have you ever walked out of a doctor's appointment and thought of 2 or 3 questions you wish you had asked? You are not alone. The questions usually come after you've had time to think about what the doctor said. It's good to be prepared, and it is important to ask your healthcare provider questions. They are there to help you, and they can do that if you let them know what you need or don't understand.

Here are a few questions to consider for your next visit:

LABWORK OR TEST

- Why is the test being done?
- · What does the test involve?
- How should I get ready?
- Are there any dangers or side effects?
- How will I find out the results?
- How long will it take to get the results?
- What will the test tell us?
- · Can I eat or drink before the test?

DIAGNOSIS

- · What may have caused this?
- Will I have this my entire life?
- · How will this affect my home and work life?
- How is this condition treated or managed?
- How can I learn more about my condition?
- What symptoms should I look for?
- · Will I need more medical tests?
- Do I need a follow-up visit? When?
- Do I need to take precautions to avoid infecting others?
- How do I protect myself and others?

TREATMENT

- What are my treatment options?
- How long will the treatment take?
- What is the cost of the treatment?
- Which treatment is most common for my disease or condition?
- Is there a generic form of my treatment?
 - Is it as effective?
- · Are there side effects?
 - What side effects can I expect?
 - What should I do if I have side effects?
- What risks and benefits are associated with the treatment?
- What would happen if I didn't have any treatment?
- What would happen if I delay my treatment?
- Is there anything I should avoid during treatment?
- How will I know if the treatment is working?
- Will my job or daily life be affected?
- What should I expect in the short-term?
- What should I expect in the long-term?



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MEDICINE

Ask your Doctor...

- What is the name of the medicine?
 (ask them to spell it if you aren't sure)
- · Why do I need to take this medicine?
- Is there a less expensive option?
- What does this medicine treat?
- When should I expect the medicine to start working?
- How will I know if it is working? How will I know it is not working?
- What side effects should I expect, if any?
 - What should I do if I have serious side effects (this includes minor side effects that affect your quality of life)?
- Will this medicine cause problems with my other medicines, vitamins, or supplements?
- What should I do if I want to stop taking this medicine?
 - Is it safe to stop suddenly?
 - What should I do if I want to take less of this medicine?
- If I need a refill, do I need to schedule an appointment or call your office?

Ask Your Pharmacist...

- Is it safe for me to drive while taking this medicine?
- Should I take the medicine with food?
 - Is there anything I should not eat or drink when taking this medicine?
- How much medicine should I take?
- How many times a day should I take it?
 - At what time(s)? (Ex. If the bottle says to take "four times a day," does that mean four times in 24 hours or four times when I am awake?)
- What does "as needed" mean?
- If I forget to take my medicine, what should I do?
- What is the difference between the brand name and the generic version of this medicine?

SURGERY

- Why do I need surgery?
- What surgical procedure are you recommending?
- Is there more than one way to do this surgery?
- Are there other options besides surgery?
- How much will surgery cost?
- What are the benefits of having surgery?
- · What are the risks of having surgery?
- · What if I don't have this surgery?
- · Where can I get a second opinion?
- · What kind of anesthesia will I need?
- How long will it take me to recover?
- Have you done this surgery before?
- Will I need to be in the hospital?
 - If so, how long will I be in the hospital?
- Will I need someone to take care of me at home?
 - If so, how long?
- What is the latest time I can eat or drink before surgery?

NEXT STEPS

- What happens next?
- When will I hear back from your office about the appointment with the specialist?
- · What do I need to take to the appointment?
- Why am I seeing the specialist?
- When do I need to see you again?
- How often should I see you?
- Who should I call if I need help?
- Who should I call if I have questions?
- · What symptoms do I need to call you about?

RESOURCES

Are there services that can help me?

- If I can't afford my medicine?
- If I don't have transportation?
- If I need supplies?





YOUR HEALTH INFORMATION **PRIVACY RIGHTS**

Most of us feel that our health information is private and should be protected. That is why there is a federal law that sets rules for health care providers and health insurance companies about who can look at and receive our health information. This law, called the Health Insurance Portability and Accountability Act of 1996 (HIPAA), gives you rights over your health information, including the right to get a copy of your information, make sure it is correct, and know who has seen it.

Get It.

You can ask to see or get a copy of your medical record and other health information. If you want a copy, you may have to put your request in writing and pay for the cost of copying and mailing. In most cases, your copies must be given to you within 30 days.

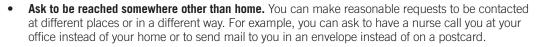
Check It.

You can ask to change any wrong information in your file or add information to your file if you think something is missing or incomplete. For example, if you and your hospital agree that your file has the wrong result for a test, the hospital must change it. Even if the hospital believes the test result is correct, you still have the right to have your disagreement noted in your file. In most cases, the file should be updated within 60 days.

Know Who Has Seen It.

By law, your health information can be used and shared for specific reasons not directly related to your care, like making sure doctors give good care, making sure nursing homes are clean and safe, reporting when the flu is in your area, or reporting as required by state or federal law. In many of these cases, you can find out who has seen your health information. You can:

- Learn how your health information is used and shared by your doctor or health insurer. Generally, your health information cannot be used for purposes not directly related to your care without your permission. For example, your doctor cannot give it to your employer, or share it for things like marketing and advertising, without your written authorization. You probably received a notice telling you how your health information may be used on your first visit to a new health care provider or when you got new health insurance, but you can ask for another copy anytime.
- Let your providers or health insurance companies know if there is information you do not want to share. You can ask that your health information not be shared with certain people, groups, or companies. If you go to a clinic, for example, you can ask the doctor not to share your medical records with other doctors or nurses at the clinic. You can ask for other kinds of restrictions, but they do not always have to agree to do what you ask, particularly if it could affect your care. Finally, you can also ask your health care provider or pharmacy not to tell your health insurance company about care you receive or drugs you take, if you pay for the care or drugs in full and the provider or pharmacy does not need to get paid by your insurance company.



If you think your rights are being denied or your health information is not being protected, you have the right to file a complaint with your provider, health insurer, or the U.S. Department of Health and Human Services.

To learn more, visit www.hhs.gov/ocr/privacy/.



U.S. Department of Health & Human Services Office for Civil Rights



The Harms of Being Labeled

a Difficult or Non-Compliant Patient



"To some, a difficult patient is one who makes irrational choices that would be harmful to [their] own health. Another physician may think of a patient that [they] can't cure or satisfy as difficult. In some circumstances, it may boil down to a clash of personalities between a patient and physician. At other times, the difficulties arise as a result of something more fundamental such as patients' beliefs and values that run counter to the physician's own,"

- Dr. Audiey Kao, MD, Ph.D.

(Kao, 2003) The Harms of Being Labeled a Difficult Patient



TERMS & LABELS

Common Negative Terms and Labels Found In Medical Records:

- Non-Compliant
- Angry
- Aggressive

- Challenging
- Exaggerate
- Difficult

It is very important to request a copy of your medical records on a regular basis.

You want to make sure the information in your record is correct. But just as important, you want to make sure there aren't labels in your medical record that can affect you in other ways. Negative terms and labels can follow a patient forever. Negative labels can make it harder to get unbiased care.

A Few Consequences Associated with Negative Labels:

- · Symptoms are more likely to be dismissed
- Less likely to receive aggressive pain management
- Less likely to receive regular screenings for serious diseases
- May be denied services or benefits (i.e., disability, social security, life insurance, etc.)
- You may begin to doubt yourself or ignore serious symptoms

What You Can Do:

- · Bring a friend or family member to advocate for you
- Check your medical records regularly
- Talk with your doctor or choose another doctor
- Ask to have it removed from your record

Learn more about bias in electronic medical records through these <u>Health Affairs</u> and <u>JAMA</u> articles.

Information adapted from The Harms of Being Labeled a Difficult Patient.

Screening Guides

for Infants, Children, Teenagers, & Adults

Risk is based on family and medical history. Talk with your doctor to see if you are at risk for a specific health condition.

INFANTS	Birth			10-12 months	13-18 months		19-24 months	
Physical Exam	ysical Exam Regularly		ly	Regularly	ularly Regula		Regularly	
Dental Exam					Every 6 months		Every 6 months	
Heel Prick & Hearing	1-2 days old							
Lead				At 12 months			At 24 months	
Iron				Once by 12 months				
Tuberculosis (TB)	If at risk	If at risk		If at risk	If at risk		If at risk	
Fluoride	-	If at risk		If at risk	If at risk		If at risk	
CHILDREN	2	3-4		5-6	7-8		9-10	
Physical Exam	Regularly			Yearly	Yearly Ye		Yearly	
Dental Exam	Every 6 months	Every 6 months		Every 6 months	Every 6 months		Every 6 months	
Cholesterol							Test once	
Lead	_ead If at risk		k	If at risk	If at risk		If at risk	
Iron							Once by 12	
Tuberculosis (TB)	If at risk	If at risk		If at risk	If at risk		If at risk	
Fluoride	If at risk	If at ris	isk If at risk		If at risk		If at risk	
Urine	-	-			Yearly if sexually active		Yearly if sexually active	
TEENAGERS	11-12		13-	-14		15-18		
Physical Exam	Yearly	y		Yearly			Yearly	
Dental Exam	Dental Exam Every 6 mo		Every 6 months		Every 6 months		y 6 months	
Cholestrol	If at risk		If at risk		If at risk			
Iron	Yearly if menstruating		Yearly if menstruating		Yearly if menstruating			
STIs + STDs (Chlamydia, Gonorrhea, HIV, Syphilis)	Yearly if sexually active		Yearly if sexually active		Yearly if sexually active			
Tuberculosis (TB)	If at risk		If at risk		If at risk			



Scan this code to access links and references from this section.



Screening tests and immunization recommendations vary according to age, sex, medical history, and family history. Guidelines are based on nationally validated recommendations including those from the U.S. Preventive Services Task Force and the Advisory Committee on Immunization Practices.

ADULT FEMALE (1)	18-39	40-49	50-64	65-74	75+
Mammogram	If at risk	Yearly	Every 1-2 years	Every 2 years	If at risk
Pap Smear (Cervical & HPV)	Every 3 years	Every 5 years*	Every 5 years*	Every 5 years*	Ask your doctor
Pelvic Exam (Ovarian Cancer)	Yearly	Yearly	Yearly	Yearly	Yearly
Clinical Breast Exam	Every 1-3 years	Yearly	Yearly	Yearly	Yearly
Bone Health	If at risk	If at risk	If at risk	Every 2 years*	Every 2 years*
ADULT MALE (2)	18-39	40-49	50-64	65-74	75+
Prostate Exam		If at risk	Ask your doctor	Ask your doctor	Ask your doctor
Testicular Exam	Yearly	Yearly	Yearly	Yearly	Ask your doctor
Abdominal Aortic Aneurysm	Ask your doctor	Ask your doctor	Ask your doctor	Ask your doctor	Ask your doctor
ALL ADULTS	18-39	40-49	50-64 Every 10	65-74 Every 10	75* Every 10
Colonoscopy (FOBT, FIT, Cologuard) Cholesterol	Every 5	Every 5	yeárs Every 5	yeárs Every 5	yeárs Every 5
	years Ask your	years Aşk your	years Aşk your	years Ask your	years Ask your
Blood Sugar	doctor	doctor	doctor	doctor	doctor
HIV Infection	If at risk	If at risk	If at risk		
Lung Cancer			Check if history of smoking	Check if history of smoking	Check if history of smoking
Hepatitis C			Check if born between 1945-1965	Check if born between 1945-1965	Check if born between 1945-1965
Skin Cancer	If at risk	If at risk	If at risk	If at risk	If at risk
Physical Exam (Foot, Urine, BP, A1C)	Every 1-2 years	Yearly	Yearly	Yearly	Yearly
Dental Exam	Every 6 months	Every 6 months	Every 6 months	Every 6 months	Every 6 months
Eye Exam with Dilation		Yearly	Yearly	Every 1-2 years	Every 1-2 years
Hemoglobin A1C	If at risk	Baseline test at 45 years	Every 2 years	Every 2 years	Every 2 years
ТВ	If at risk	If at risk	If at risk	If at risk	If at risk

^{*} Dependent on screening history

⁽¹⁾ Assigned female at birth

Additional Notes on Screenings

Did You Know...

Besides a colonoscopy, you have other options for colorectal cancer screenings such as a Sigmoidoscopy (*every five years*) or a Virtual Colonoscopy (*every five years*). Talk with your doctor about which test is right for you. The following tests can be done at home:

- High-Sensitivity Fecal Occult Blood Test (FOBT)
- Fecal Immunochemical Test (FIT)
- Stool DNA Test (Coloquard) (every three years or as recommended by your doctor)

Guidelines for People with Coronary Artery Disease and Diabetes

There are a few additional tests to help manage the disease and prevent complications. Talk with your doctor about which tests are right for you.

Coronary Artery Disease

At least once per year, you should:

- · Get a fasting cholesterol lab
- Discuss your medicine regimen with your doctor (aspirin, ACE, ARB, beta blocker)

Diabetes

You need a base line test if you are 45 years old or older <u>or</u> less than 45 years old, overweight, and have one or more risk factors for pre-diabetes or type 2 diabetes. At routine health visits, you should have the following checked:

- A1C test at least twice a year (blood sugar)
- Blood pressure (BP) at least once a year
- Eye exam with dilation
- · Urine test for proteins to check kidney functioning
- Foot exam

Talk with your child's doctor about the following

Infants

- · Safe sleep
- Injury prevention
- Help to guit smoking
- Feeling sad or anxious
- Feeding, including breastfeeding

Children

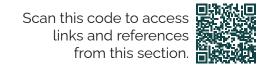
- Healthy eating and sleeping habits
- Safety and injury prevention
- Concerns about behavioral or brain development
- Healthy relationships
- Emotional and physical changes
- Problems at school or bullying



Teenagers

- Concerns about feeling down or anxious
- Trouble sleeping
- · Healthy body weight and body image
- Safe and healthy relationships
- Protection from sexually transmitted infections (STIs) and pregnancy
- · Tobacco or substance use

Vaccinations



Vaccines have helped eliminate or reduce the number of diseases that used to harm or kill. Protection from some vaccines can fade over time so you may need to get a booster to maintain protection. Staying up-to-date on your vaccines is important.

Guidelines are based on nationally validated recommendations, including those from the U.S. Preventive Services Task Force and the Advisory Committee on Immunization Practices. Screening tests and immunization recommendations vary according to age, gender, medical, and family history. These vaccines can be given during the specified age ranges.

COVID-19

COVID-19 vaccines have been added to the CDC's recommended immunization schedule and should be added to your personal vaccination regimen. This tool is intended to help you make decisions about getting COVID-19 vaccinations. As with other vaccine-preventable diseases, you are protected best from COVID-19 when you stay up to date with the recommended vaccinations, including recommended boosters.

COVID-19 vaccination timelines, the number of doses, and the interval between doses depend on the following:

- Past infection history
- Brand of vaccination
- Weakened immune system (immunocompromised)
- · Other medical conditions
- Age

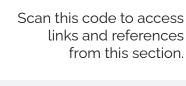
To view a complete and updated COVID-19 vaccine schedule based on age, medical conditions, and vaccine composition, **please visit the CDC website here.**



To learn more about the vaccines you need, complete this <u>quiz on the CDC website</u>.

The following vaccination schedules are adapted from CDC and CDPHP guidelines.







COVID-19: Protects against serious illness, hospitalization, & death if infected with COVID-19.

VACCINATION INFO

DTaP: Protects young children and infants against <u>Diphtheria</u>, Tetanus (*lockjaw*), and Pertussis (*whooping cough*). Diphtheria can lead to difficulty breathing, heart problems, and/or death.

Hepatitis A (Hep A): Protects against <u>Hepatitis A</u> which can cause liver infection.

Hepatitis B (Hep B): Protects against <u>Hepatitis B</u> which can cause liver infection.

Hib: Haemophilus Influenzae Type B protects against brain, spinal cord, & blood infections.

HPV: Helps prevent many cancers (*cervical*, *vaginal*, *vulvar*, & *anal*) caused by human papillomavirus.

Influenza (Flu): Protects against <u>flu</u> which can cause serious respiratory problems.

Lead Screening: Detects raised blood lead levels, possible signs of <u>lead poisoning</u>.

Meningococcal: Protects against four most common types of bacterial meningococcal disease including blood, brain, & spinal cord infections.

MMR: Protects against Measles, Mumps, and Rubella (German measles).

PCV: <u>Pneumococcal conjugate</u> protects against serious infections (*ear and sinus, pneumonia, & blood*).

Polio: Inactivated vaccine (IPV) protects against polio which can infect the spinal cord and cause <u>paralysis</u>.

RV: Protects against <u>Rotavirus</u> which can cause severe diarrhea and vomiting in infants and children.

RZV: Recombinant Zoster helps prevent shingles.

Tdap: Same protection as <u>DTaP</u>; given to children and adults 7 years old and older.

Varicella (VAR): Varicella zoster vaccine protects against chickenpox.

Helpful Resources



Fair Health Consumer

<u>FAIR Health</u> is an independent, non-profit organization whose mission is to help you understand your healthcare costs and health coverage. Get an estimate of the cost for medical, hospital, and dental services. Also learn basic information to help you better understand insurance coverage.



Cost Plus Drugs

<u>Cost Plus Drugs</u> fills and delivers prescriptions at cost plus a fixed 15% margin. They ship prescriptions to patients nationwide.

You can buy your medicine from them directly or through one of their <u>employer-sponsored</u> <u>programs</u>. Learn more about this program and the medicines available for purchase at Cost Plus Drugs.



211 Hotline

Call or go to the website to access resources for mental health, food, utility bills, immigration paper work, assistance, etc. Types of resources vary based on your area.

Call 211 or go to 211.org to find resources in your local area.



Scan this code to access links and references from this section.



Talking Prescription Labels

ScripTalk provides specially programmed labels that can be read aloud using the ScripTalk app or a ScripTalk Station. This is a great option for you or family members that have trouble reading prescription labels.

Your pharmacist enters all your prescription information: drug name, dosage, instructions, warnings, pharmacy information, doctor name, prescription number, and date on a small electronic label. You can then place your medicine on the *ScripTalk Station* or scan the label with the *Scriptalk App (App Store or Google Play)* to have it read aloud. This is a free service.

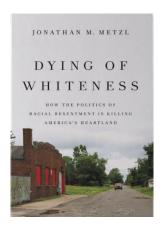
Learn more about <u>ScripTalk</u> and find a pharmacy near you that carries <u>ScripTalk Talking Labels</u>. If you would like to become a ScripTalk advocate for your community, Call 1-800-890-1180 to request more information.



Additional Readings

Just as it's important to equip yourself with the tools and skills needed to navigate the healthcare system, it is also important to learn more about past and current influences on today's healthcare system. There are so many books and articles which explore these topics. Here are just a few to consider as you continue on your advocacy journey.

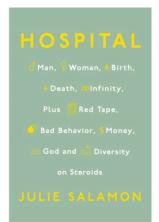
A Few Good Books



Dying of Whiteness: How The Politics of Racial Resentment is Killing America's Heartland

By Jonathan M. Metzl

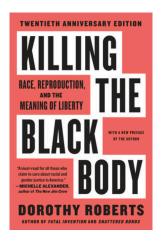
"Physician and sociologist Jonathan M. Metzl travels across America's heartland seeking to better understand the politics of racial resentment and its impact on public health. Interviewing a range of Americans, he uncovers how racial anxieties led to the repeal of gun control laws in Missouri, stymied the Affordable Care Act in Tennessee, and fueled massive cuts to schools and social services in Kansas. Although such measures promised to restore greatness to white America, Metzl's systematic analysis of health data dramatically reveals they did just the opposite: these policies made life sicker, harder, and shorter in the very populations they purported to aid. Thus, white gun suicides soared, life expectancies fell, and school dropout rates rose. Powerful, searing, and sobering, Dying of Whiteness ultimately demonstrates just how much white America would benefit by emphasizing cooperation, rather than by chasing false promises of supremacy." (dyingofwhiteness.com)



Hospital: Man, Woman, Birth, Death, Infinity, Plus Red Tape, Bad Behavior, Money, God, and Diversity on Steroids

By Julie Salamon

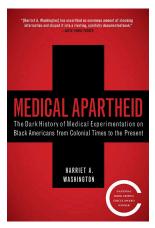
"Hospital follows a year in the life of Maimonides Medical Center in Brooklyn, which serves a diverse multicultural demographic. Salamon tracks the individuals who make this complex hospital run-from doctors, patients, and administrators to nurses, ambulance drivers, cooks, and cleaners. Drawing on her skills as an award-winning interviewer, observer, and social critic, Salamon reveals the dynamic universe of small and large concerns and personalities that determine the nature of care in America." (Amazon)



Killing the Black Body: Race, Reproduction, and the Meaning of Liberty

By Dorothy Roberts

"In 1997, this groundbreaking book made a powerful entrance into the national conversation on race. In a media landscape dominated by racially biased images of welfare queens and crack babies, Killing the Black Body exposed America's systemic abuse of Black women's bodies. From [enslavers'] economic stake in bonded women's fertility to government programs that coerced thousands of poor Black women into being sterilized as late as the 1970s, these abuses pointed to the degradation of Black motherhood—and the exclusion of Black women's reproductive needs in mainstream feminist and civil rights agendas." (Penguin Random House)



Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present

By Harriet A. Washington

"Medical Apartheid details the ways both lenslaved peoplel and freedmen were used in hospitals for experiments conducted without their knowledge—a tradition that continues today within some Black populations. It provides the fullest possible context for comprehending the behavioral fallout that has caused Black Americans to view researchers—and indeed the whole medical establishment—with such deep distrust." (Amazon)



The Racial Divide American Medicine Black Physicians and the Struggle for Justice in Health Care

Edited by Richard D. deShazo, MD, MACP

The Racial Divide in American Medicine: Black Physicians and the Struggle for Justice in Health Care

Edited by Richard deShazo, MD, MACP

"Dr. deShazo has assembled an accurate account of the lives and experiences of Black physicians in Mississippi, one that gives full credit to the actions of these pioneers. Dr. deShazo's introduction and the essays address ongoing isolation and distrust among Black and White colleagues. Contributors reveal details of individual physicians' journeys for recognition both as African Americans and as professionals in Mississippi. Despite discrimination by their White colleagues and threats of violence, a small but fearless group of African American physicians fought for desegregation of American medicine and society." (University Press of Mississippi)



Under the Skin: The Hidden Toll of Racism on American Lives and on the Health of Our Nation

By Linda Villarosa

"In Under the Skin, Linda Villarosa lays bare the forces in the American health-care system and in American society that cause Black people to 'live sicker and die quicker' compared to their white counterparts. Today's medical texts and instruments still carry deceptive slavery-era assumptions that Black bodies are fundamentally different from white bodies. Study after study of medical settings show worse treatment and outcomes for Black patients. Black people live in dirtier, more polluted communities due to environmental racism and neglect from all levels of government. And, most powerfully, Villarosa describes the new understanding that coping with the daily scourge of racism ages Black people prematurely. Anchored by unforgettable human stories and offering incontrovertible proof, Under the Skin is dramatic, tragic, and necessary reading." (African American Literature Book Club)





PART IV: Advocacy Tools for Providers

Just as patients must advocate for their health care, providers also have an obligation to improve their relationships with patients and work to improve health care for everyone.

Providers can do this through workplace interventions, policy reviews, and listening and believing patients.

8 Reasons

Patients Don't Take Their Medications

Medication nonadherence—when patients don't take their medications as prescribed—is unfortunately fairly common, with <u>research showing that patients don't take their medications as prescribed about half the time</u>. The phenomenon has added consequences for patients with chronic diseases. When this is the case, it is important for physicians and other health professionals to understand why patients don't take their medications. This will help teams identify and improve patient's adherence to their medications.

If you don't have a true picture of a patient's medication-taking behavior, you may needlessly escalate their treatment, resulting in potential harm to the patient, unnecessary work for the practice and increased costs overall.

Most nonadherence is intentional, with patients making a rational decision not to take their medicine based on their knowledge, experience, and beliefs. These are eight common reasons for intentional non-adherence.



1. Fear

Patients may be frightened of potential side effects. They may have also experienced previous side effects with the same or similar medicine.

Additionally, patients report not taking their medication because they may have witnessed side effects experienced by a friend or family member who was taking the same or similar medication. From seeing those side effects experienced by someone else, it may have led them to believe the medication caused those problems.



2. Cost

A major barrier to adherence is often the cost of the medicine prescribed to the patient. The high cost may lead to patients not filling their medications in the first place. They may even ration what they do fill in order to extend their supply. To overcome this, check that the drug you're prescribing is on the patient's insurance formulary.

Selecting and prescribing a medication known to be on a discount list can decrease the cost regardless of insurance.



3. Misunderstanding

Nonadherence can also happen when a patient does not understand the need for the medicine, the nature of side effects, or the time it takes to see results. This is especially true for patients with chronic illness—taking a medication every day to reduce the risk of something bad happening can be confusing.



4. Too Many Medicines

When a patient has several different medicines prescribed with higher dosing frequency, the chances that they are nonadherent increase. Physicians can try to simplify a patient's dosing schedule by adjusting medicines so they can be taken at the same time of day. Choosing long-acting drugs can also help if the dosing burden is too complex.

Additionally, if possible, consolidate medicines by using combination products.



5. Lack of Symptoms

As stated before, nonadherence might occur when there is a lack of symptoms. Patients who don't feel any different when they start or stop their medicine might see no reason to take it. Additionally, once a patient's condition is controlled, they may think the problem has been resolved and may discontinue using the medication.

It is important to inform your patient that they may need to take the medicine for a long time.



6. Mistrust

There has been news coverage of marketing efforts by pharmaceutical companies influencing physician prescribing patterns. This ongoing mistrust can cause patients to be suspicious of their doctor's motives for prescribing certain medications.

Learn how building patient trust can support medication adherence.



7. Worry

If a patient is concerned about becoming dependent on a medicine, it can also lead to nonadherence. One way to overcome this is to improve patient-physician communication. Inadequate communication can account for 55% of medication nonadherence, making it important to understand the patient's rationale for nonadherence.



8. Depression

Patients who are depressed are less likely to take their medications as prescribed. Physicians and other health professionals may be able to uncover this by sharing issues and asking if the patient can relate to them.

To reduce embarrassment, express that many patients experience similar challenges.

Additional Study



NON-COMPLIANCE

How Using the Term "Non-Compliant" Keeps Providers From Partnering with Patients

Sinkfield-Morey, T. (2018). How using the term "non-compliant' keeps providers from partnering with patients. Creative Nursing, 24(3), 178-185.

Abstract

This article aims to offer an alternate perspective for nurses to consider when assigning the label "non-compliant" to a patient. This article features four peoples' experiences after being labeled non-compliant. Three were thought of as problems, and one's autonomy was respected.

The unintended negative consequences of labeling people as non-compliant are examined through the lens of three ethical principles: (a) respect for autonomy, (b) beneficence, and (c) non-maleficence.

Excerpt

"Health-care professionals who use the term non-compliant to refer to patients and families who appear to be disregarding a recommended plan of care have an ethical obligation to examine the consequences of their use of this word. The term non-compliant indicates a wanton disregard for a suggested path to well-being but fails to acknowledge the mistrust, disruption, inaccessibility, and even the marginalization that sometimes perpetuates a person's need to deviate from a health professional's care plan..." Read More



Health Literacy: A Prescription to End Confusion

National Academy of Sciences. (2004). Health literacy: A prescription to end confusion. https://www.ncbi.nlm.nih.gov/books/NBK216032/pdf/Bookshelf_NBK216032.pdf

Abstract

As the US becomes more diverse, the context of culture in our understanding of health literacy has become even more important. The 2000 US Census identified 19 ethnic and cultural groups, outside of those of European descent, living in America. Many of these populations have differing beliefs about health and illness that affect how people think and feel about their health, seek health care, and respond to providers' recommendations.

Culture and health literacy both influence the guidance and outcomes of healthcare encounters. Health literacy not only involves communication and mutual understanding between patients and the healthcare team but also involves family members. A definition of health literacy that does not recognize the potential effect of cultural differences on the communication and understanding of health information would miss much of the deeper meaning and purpose of literacy for people.

Excerpt

"Escorted by his teenage granddaughter, an elderly old Navajo grandfather was taken to the internal medicine clinic for an infection in his right leg. The granddaughter was fluent in English but had very limited Navajo speaking skills. Speaking in English, the doctor informed the man that the infection in his leg would get worse if he did not take his medication as prescribed. The granddaughter could not translate the scientific concept of infection into Navajo language. The doctor asked one of the nurses for help, and although the she tried as much as she could, she also was unsuccessful. The old man, becoming frustrated, just agreed that he understood everything that he had been told. He told the nurse he wanted to have a traditional ceremony performed for him within a couple of days, and for her to tell the doctor. The nurse translated this to the doctor, who restated the importance of taking the medicines. The grandfather insisted he understood, but in fact because he felt that he did not understand the physician's explanation, he decided to go to a traditional medicine man instead. The medicine man helped him the best he could, but the grandfather's leg had to be amputated, which the doctor ascribed to noncompliance..." Read More

Additional Study



HEALTH LITERACY

To Boost Outcomes, First Unlock the Power of Health Literacy

Copyright 1995 - 2021 American Medical Association. All rights reserved. https://www.ama-assn.org/delivering-care/health-equity/boost-outcomes-first-unlock-power-health-literacy

Abstract

One way to advance health equity is to improve health literacy, says one physician working to do just that—though she adds that low health literacy transcends social determinants of health such as education, income, and background.

Excerpt

"The way I think low health literacy is linked to health inequity is that, No. 1, if it's not recognized and addressed, it leads to poor outcomes," said Lisa Fitzpatrick, MD, MPH, MPA, an infectious disease specialist, epidemiologist and former Chief Medical Officer for the Washington, D.C., Medicaid program. "No. 2, people who have low health literacy that are also from under-resourced communities are already less likely to have the best outcomes," Dr. Fitzpatrick explained. "So if we're not addressing their health literacy needs, we can exacerbate health inequity just because people don't have access to the information they need to make a better health situation for themselves..." Read More



Advancing Health Equity by Avoiding Judgmentalism and Contextualizing Care



Weiner, S. J. (2021). Advancing health equity by avoiding judgmentalism and contextualizing care. AMA Journal of Ethics, 23(2) E91-96.

Abstract

This article examines the care of a Spanish-speaking woman with end-stage renal disease who repeatedly returns to the emergency department with complications related to missing hemodialysis. Her life circumstances suggest that she has been making difficult but rational decisions in an untenable situation, which is then readily resolved with the assistance of her care team. The case illustrates the pernicious effect of judgmentalism on patients from poor and marginalized communities, exacerbating health inequity and illuminating the ethical importance of contextualizing patients' care.

Excerpt

"What no one did, until the fourth admission, was to ask her why she kept missing her hemodialysis. All they'd documented in the medical record was that she was Inon-compliant]. Finally, during that admission, a member of the inpatient team—a fourth-year medical student—reached out through an interpreter and learned that [the patient] was responsible for a grandchild who had an unrelated chronic kidney condition and often needed to be seen in the medical center's pediatric nephrology clinic. This situation posed a logistical challenge for her, as the medical center was located about 7 miles north of her home and the site where she received her dialysis was located south of where she lived. The Medicaid transit van that she relied on to get to appointments could take her either to her dialysis site or to the medical center, but it couldn't take her from one facility to another. Hence, whenever her grandson needed medical care or hospitalization, she was forced to choose between his care and her own. She prioritized his needs..." Read More

Consider Culture, Customs, and Beliefs

<u>Religion, culture, beliefs, and ethnic customs</u> can influence how patients understand health concepts, how they take care of their health, and how they make decisions related to their health. Without proper training, clinicians may deliver medical advice without understanding how health beliefs and cultural practices influence the way that advice is received.

Asking about patients' religions, cultures, and ethnic customs can help clinicians engage patients so that, together, they can devise treatment plans that are consistent with the patients' values.



Tips

Here are some examples of how religion, culture, and ethnic customs can influence how your patients interact with you.

Health Beliefs: In some cultures, people believe that talking about a possible poor health outcome will cause that outcome to occur.

Health Customs: In some cultures, family members play a large role in health care decision making.

Ethnic Customs: Differing gendered roles of women and men in society may determine who makes decisions about accepting and following through with medical treatments.

Religious Beliefs: Religious faith and spiritual beliefs may affect healthcare-seeking behavior and people's willingness to accept specific treatments or behavior changes.

Dietary Customs: Disease-related dietary advice will be difficult to follow if it does not conform to the foods or cooking methods used by the patient.

Interpersonal Customs: Eye contact or physical touch will be expected in some cultures and inappropriate or offensive in others.

Learn From Patients

Respectfully ask patients about their health beliefs and customs, and note their responses in their medical records. Address patients' cultural values specifically in the context of their health care.

For example:

- "Is there anything I should know about your culture, beliefs, or religious practices that would help me take better care of you?"
- "Do you have any restrictions that we should consider as we develop a food plan to help you lose weight?"
- "Your condition is very serious. Some people like to know everything that is going on with their illness, where others may want to know what is most important but not necessarily all the details. How much do you want to know? Is there anyone else you would like me to talk to about your condition?"
- "What do you call your illness and what do you think caused it?"
- "Do any traditional healers advise you about your health?"

Avoid stereotyping based on religious or cultural background. Understand that each person is an individual and may or may not adhere to certain cultural beliefs or practices common in their culture. Asking patients about their beliefs and way of life is the best way to be sure you know how their values may impact their care.

Learn From Other Sources

High-quality online resources provide education about cultural competence, both as a general topic and as related to specific groups.

- Courses
 - Think Cultural Health offers several options for free continuing education credit.
- Websites
 - <u>EthnoMed</u> is a website containing information about cultural beliefs and medical issues of recent immigrants.
 - <u>Culture Clues</u> are one-page tip sheets that offer insight into the health care preferences and perceptions of patients from 10 different cultures and special needs groups (including the deaf and hard-of-hearing). The website also covers end-of-life issues.
 - <u>The Culture, Language, and Health Literacy</u> website provides an exhaustive list of resources regarding cultural competence issues for specific ethnicities, religions, and special populations.
- **Community Organizations** such as religious institutions and cultural organizations can often provide information and support to help make your practice more "culture-friendly."
 - Invite a member of a relevant cultural group to attend a staff meeting and share observations about how cultural beliefs may impact health care.
 - Invite an expert to conduct in-service training to educate staff about cultural competence.
- Integrate cultural competence into orientation and other training. Take advantage of opportunities to integrate cultural competence into all of your training activities.
- Use interpreters as cultural brokers. Interpreters can eliminate language barriers as well as help you and your patients avoid misunderstandings due to cultural differences. Go to <u>Tool 9: Address Language Differences</u> for more information about interpreters.

Help Staff Learn from Each Other.

To raise awareness about cultural competence among your staff, you could:

- Hire staff that reflects the demographics of your patient population. These staff members can
 help contribute to a comfortable environment for patients and can share insights with other staff
 regarding the customs of their religious or ethnic groups.
- Encourage staff to complete online cultural competence trainings and share what they learned with each other during a staff meeting.

Track Your Progress

Before implementing this Tool, count the number of staff members who have completed a cultural competence training session. Repeat after 2, 6, and 12 months.

On a regular basis, randomly select some medical records and see what percentage have notes on the patient's culture, customs, or health beliefs.

Consider Culture, Customs, and Beliefs: Tool #10. Content last reviewed September 2020. Agency for Healthcare Research and Quality, Rockville, MD. https://www.ahrq.gov/health-literacy/improve/precautions/tool10.html

Communicate Clearly

<u>Using clear oral communication strategies</u> can help your patients better understand health information. Communicating also allows patients to feel more involved in their health care and increases their likelihood of following through on their treatment plans.



"Patients misunderstand health communications more often than clinicians might think. For example, one practice shared a story of a clinician who told a patient that they could not use a local treatment to heal her wound. The patient thought she was going to have to travel to another city for care (instead of understanding that she could not use a topical treatment)."

– Family practice facility

USE THESE STRATEGIES FOR COMMUNICATING CLEARLY.

Greet patients warmly. Receive everyone with a welcoming smile and maintain a friendly attitude throughout the visit.

Make eye contact. Make culturally appropriate eye contact throughout the interaction. Refer to <u>Tool 10: Consider Culture</u>, <u>Customs</u>, and <u>Beliefs</u> for further guidance on eye contact and culture.

Listen carefully. Try not to interrupt patients when they are talking. Pay attention, and be responsive to the issues they raise and their questions.

Use plain, non-medical language. Don't use medical words. Use common words that you would use to explain medical information to your friends or family, such as stomach or belly instead of abdomen.

Use the patient's words. Take note of what words the patient uses to describe their illness and use them in your conversation.

Slow down. Speak clearly and at a moderate pace.

Limit and repeat content. Prioritize what needs to be discussed, and limit information to 3-5 keypoints and repeat them.

Be specific and concrete. Don't use vague and subjective terms that can be interpreted in different ways.

Show graphics. Draw pictures, use illustrations, or demonstrate with 3-D models. All pictures and models should be simple, designed to demonstrate only the important concepts, without detailed anatomy.

Demonstrate how it's done. Whether doing exercises or taking medicine, a demonstration of how to do something may be clearer than a verbal explanation. Confirm patients understand what they need to know and do by asking them to teach back important information, such as directions.

Invite patient participation. Encourage patients to ask questions and be involved in the conversation during visits and to be proactive in their health care.

Apply teach-back. Confirm patients understand what they need to know and do by asking them to teach back important information, such as directions. Refer to <u>Tool 5</u>: <u>Use the Teach-Back Method</u> for more guidance on how to use the teach-back method.

Help Staff Remember These Strategies. Review these strategies with staff during staff meetings, and hang the <u>Key Communication Strategies</u> poster in non-patient areas (e.g., kitchen or conference room) as a reminder.

Track Your Progress. Before implementing this Tool, ask all staff to complete the brief Communication Self-Assessment after a few patient encounters. Calculate the percentage of staff who completed the self-assessment. One month after beginning implementation, complete another round of self-assessments and look for changes.

Before and after Tool implementation, ask a respected individual to conduct observations of clinician/staff interactions with patients. Use the <u>Communication Observation Form</u> to assess communication quality. Provide feedback to staff. Repeat this process routinely. Calculate the percentage of staff who have been observed once and the percentage who have been observed more than once.

Before implementing the tool, collect patient feedback using the <u>Brief Patient Feedback Form</u> or the more comprehensive <u>Health Literacy Patient Survey</u> in <u>Tool 17</u>: <u>Get Patient Feedback</u>. Administer the questions 2, 6, and 12 months later to determine if there has been an improvement.

Resources. <u>Health Literacy and Patient Safety: Help Patients Understand</u>, by the American Medical Association, offers suggestions for improving oral communication and alternatives to complex medical words.

Communicate Clearly: Tool #4. Content last reviewed September 2020. Agency for Healthcare Research and Quality, Rockville, MD. https://www.ahrq.gov/health-literacy/improve/precautions/tool4.html

Use the Teach-Back Method

Regardless of a patient's health literacy level, it is important that staff ensure that patients understand the information they have been given. The teach-back method is a way of checking understanding by asking patients to state in their own words what they need to know or do about their health. It is a way to confirm that you have explained things in a manner your patients understand. The related show-me method allows staff to confirm that patients are able to follow specific instructions (e.g., how to use an inhaler).

The teach-back and show-me methods are valuable tools for everyone to use with each patient.

These Methods Can Help You:

- Improve patient understanding and adherence.
- Decrease callbacks and cancelled appointments.
- · Improve patient satisfaction and outcomes.

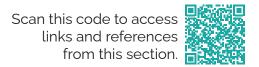


Fact

Studies have shown that 40-80% of the medical information patients are told during office visits is forgotten immediately, and nearly half of the information retained is incorrect.

Learn the Teach-Back Method

- The <u>Always Use Teach-Back!</u> Toolkit describes principles of plain language, teach-back, coaching, and system changes necessary to promote consistent use of teach-back. Its 45-minute Interactive Teach-Back Learning Module includes key content and videos of clinicians using teach-back. The module can be used by clinicians and staff members, in a group setting, or as a self-directed tutorial.
- <u>5-Minute Teach-Back Video</u>: This 5-minute video gives two examples for clinicians of how to use teach-back with medicine changes.
- <u>Health Literacy and Patient Safety:</u> *Help Patients Understand* is a 23-minute video from the American Medical Association that includes an example of a clinician using teach-back (see the last 5 minutes of the video).





Try the Teach-Back Method

Keep in mind this is not a test of the patient's knowledge. It is a test of how well you explained the concept.

Plan your approach. Think about how you will ask your patients to teach back the information. For example, "We covered a lot today and I want to make sure that I explained things clearly. So let's review what we discussed. Can you please describe the 3 things you agreed to do to help you control your diabetes?"

"Chunk and check." Don't wait until the end of a visit to initiate teach-back. Chunk information into small segments and have your patient teach it back. Repeat several times during a visit.

Clarify and check again. If teach-back uncovers a misunderstanding, explain things again using a different approach. Ask patients to teach-back again until they are able to correctly describe the information in their own words. If they parrot your words back to you, they may not have understood.

Start slowly and use consistently. At first, you may want to try teach-back with the last patient of the day. Once you are comfortable with the technique, use teach-back with everyone, every time!

Practice. It will take a little time, but once it is part of your routine, teach-back can be done without awkwardness and does not lengthen a visit.

Use the show-me method. When prescribing new medicines or changing a dose, research shows that even when patients correctly say when and how much medicine they'll take, many will make mistakes when asked to demonstrate the dose. You could say, for example, "I've noticed that many people have trouble remembering how to take their blood thinner. Can you show me how you are going to take it?"

Use handouts along with teach-back. Write down key information to help patients remember instructions at home. Point out important information by reviewing written materials to reinforce your patients' understanding. You can allow patients to refer to handouts, but make sure they use their own words and are not reading the material back verbatim. Refer to <u>Tool 12:</u> <u>Use Health Education Material Effectively</u> for more information.



"I decided to do teach-back on five patients. With one mother and her child, I concluded the visit by saying, 'so tell me what you are going to do when you get home?' She could not tell me what instructions I had just given her. I explained the instructions again, and then she could teach them back to me. I had no idea she did not understand. I was so wrapped up in delivering the message that I did not realize it wasn't being received."

-Pediatric Office

Promote the Use of Teach-Back

Train non-clinical staff. Non-clinical staff members who interact with patients should also use teach-back. For example, staff making appointments may use it to ensure the patients understand what is required of them at the next visit such as arrival time, insurance documentation, bringing medicines, fasting, and details about referrals to other clinicians.

Share teach-back stories. Ask one person at each staff meeting to share a teach-back "Aha!" moment. This serves as a reminder of the importance of using teach-back consistently.

Track Your Progress

The <u>Conviction and Confidence Scale</u> should be filled out before you start using teach-back and then 2, 6, and 12 months later to track your progress. Calculate the percentage of staff who have completed the scale at least twice in the past 12 months. The results can help you identify ways to build conviction and confidence in using teach-back.

The <u>Teach-Back Observation Tool</u> should be used by a designated observer as clinicians build their skills and confidence with teach-back. Use the findings to guide evaluation, coaching, additional learning, and establishment of consistent habits.

If you field questions from the <u>Health Literacy Patient Survey</u>, calculate what percentage of patients responded "Always" to question #12.

Use the Teach-Back Method: Tool #5. Content last reviewed September 2020. Agency for Healthcare Research and Quality, Rockville, MD. https://www.ahrq.gov/health-literacy/improve/precautions/tool5.html



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Follow-Up With Patients

<u>Follow-up</u> is the act of making contact with a patient or caregiver at a later, specified date to check on the patient's progress since their last appointment. Appropriate follow-up can help you to identify misunderstandings and answer questions, or make further assessments and adjust treatments. In addition, follow-up helps to promote a good working relationship between you and your patients.

Decide on the Reasons for Follow-Up

For example, you can follow up to:

- Monitor health.
- Reinforce knowledge and action plans.
- Confirm medicine regimens.

- · Schedule appointments.
- Verify follow-through on referrals.
- Share lab results.

Ask Patients to Record Information

- An excellent way to monitor health is to have patients track key clinical values and share that information with you between visits.
- For routine monitoring (e.g., blood sugar, blood pressure, weight), patients can record their values. This can be done using simple forms. The Follow-up Instruction Form is an example of a monitoring instruction sheet for a patient with diabetes to monitor treatment goals and blood sugar levels.
- Instructions to patients should include directions to contact the practice when their clinical values are of concern (e.g., blood pressure above 140/90, weight gain of more than 2 to 3 pounds in a day for heart failure patients).
- Be sure to thank patients for recording this information, highlighting how helpful it is, and providing clinical feedback (e.g., "It looks like you are doing a good job of keeping your blood sugar under control.").

Identify Who and How You Will Follow-Up with Patients

Who follows up depends on the purpose of the communication:

- **Primary Care Clinician:** If the follow-up is complex or sensitive, the primary care clinician may need to follow up.
- Nurse and Medical Assistant: Nurses and medical assistants have the training and expertise to
 follow up with patients to review things like blood pressure and blood glucose values. Nurses can
 also discuss and encourage specific health behaviors, review medicine adherence, and clarify lab
 results sent through the mail.
- **Pharmacist:** A pharmacist, if you have one on-site, is an ideal clinician to follow up with patients about their medicines.
- Other Office Staff: The front desk staff can follow up with patients to schedule appointments, confirm that patients have followed through with referrals, and provide patients with information about community resources.

Choose the ways your office will follow up.

- Phone. Talking on the phone allows patients to ask questions and staff to reiterate important points.
- **Secure Email.** Secure email is part of many patient portals and can be an effective way to communicate with patients. Make sure your emails are easy to understand (e.g., do not use medical jargon), and be sure to tell patients when and how often you check email. Sensitive health and personal information should not be sent through unsecured email.

- **Texting.** For patients who use text messaging, this approach can be effective for sending patient reminders and answering quick questions. Be sure that patients are willing to be contacted in this manner, as they may be charged for receiving texts from your office.
- Postal Mail. Postal mail can be used to share information, such as normal lab results and appointment reminders. This <u>Lab Results Letter</u> provides an example of an easy-to-read letter reporting test results.
- Automated Calling System. These types of systems can be used for reminders and to collect information from patients (e.g., blood pressure). You can type "automated calling system" into an Internet search window to find businesses that offer these services.

Initiate and Track Follow-Up

- Work with your clinical colleagues to identify the types of patients who would benefit from followup (e.g., patients recently prescribed blood thinners).
- · Identify the appropriate schedule for follow-up (e.g., after a dosage change).
- Establish systems for tracking follow-up through the electronic health record (EHR) or by using a computer-based calendar.
- Identify the staff members who will update these tracking systems.

Track Your Progress

Select the records of a sample of patients who should have received follow-up after a recent visit (e.g., patients with heart failure). Count the number of patients who received follow-up actions that were scheduled in your tracking system. Count the number of follow-up actions (e.g., phone calls, emails, letters, automated calls) that were performed within the desired time frame. Note what was achieved by the follow-up contacts: medicine changes, referrals made, and clarification of medicine regimens.



Follow Up with Patients: Tool #6. Content last reviewed September 2020. Agency for Healthcare Research and Quality, Rockville, MD. https://www.ahrq.gov/health-literacy/improve/precautions/tool6.html

Address Language Differences

Patients who do not speak English very well, including those who speak American or other sign language, often do not get the health information they need. Addressing language and sensory differences is an important part of addressing health literacy and is required by law. Practices participating in Medicare or Medicaid can be legally required to provide language assistance for patients who do not speak or understand English well. Failing to use acceptable forms of language assistance can expose a practice to liability.

Assess Language Preferences and Language Assistance Needs

- Ask all new patients what language they prefer to speak and read and if they would like an interpreter. Record patients' language assistance needs in their medical record.
- For patients who do not speak enough English to respond to questions about language preference, use <u>"I Speak" cards</u> (found on page 66) to identify their language.
- Match patients with qualified bilingual clinicians or staff members, or request an interpreter for patients who do not speak English very well or who appear to have difficulty understanding English.
- Display <u>Interpreter Services Posters</u> in your waiting and reception areas to make patients aware of the availability of free interpreter services.

Use Acceptable Language Assistance Services

Acceptable language assistance services include the following:

- Bilingual clinicians or staff members whose proficiency has been confirmed can communicate directly with patients in their preferred language.
- Staff who are trained as interpreters or on-site trained medical interpreters.
- Telephone or video medical interpreter services. Make sure you can access necessary equipment (e.g., dual handset phones) in all areas where patients interact with staff.

All clinicians, staff, and interpreters should understand the importance of using plain language. Go to <u>Tool 4: Communicate Clearly</u> for guidance on communicating clearly.

Do NOT use unacceptable language assistance services.

Individuals who are not trained to be an interpreter make more clinically significant mistakes. Unacceptable language assistance services include the following:

- Clinicians or staff who are **not** trained and/or certified as medical interpreters.
- The patient's family and friends. Using family or friends poses a problem with patient privacy. In
 addition, family or friends may provide you with their own views of what patients say or feel about
 their health problems. If a patient insists that a family member serve as interpreter, you should
 respect that request, but a qualified interpreter should also be present to assure that information is
 accurately relayed.
- · Minor children should never be used as interpreters.

Plan for Interpreter Services in Advance

- Use data about patients' language preferences to determine how to best meet their language assistance needs (e.g., hiring bilingual staff, hiring professional interpreters, training staff as interpreters).
- For practices with small populations of non-English-speaking patients, consider scheduling appointments and having call-in hours on specific days or times when appropriate interpreter services are available (e.g., Spanish interpreters available Thursdays 1-5 p.m.).

Provide Written Materials in Patients' Preferred Languages

- Do not assume that non-English speakers, including speakers of American Sign Language, will understand notes or other materials written in English.
- Decide what to translate, such as signs, forms, and instructions. Obtain multilingual health education materials. Go to the <u>List of Internet Resources</u> for a list of websites with a large selection of easy-to-read materials in several languages.
- When you can't obtain materials in patients' preferred languages, enlist the help of interpreters trained in sight translation.
 - Sight translation is reading a written document aloud in a different language from the one in which it is written.

Pursue Sources of Payment for Language Assistance Services

- Investigate whether insurers will pay for or have negotiated discounts with interpreters. Medicaid reimbursement is available in a number of states.
- Contact community organizations to see if they can provide volunteer-trained medical interpreters.
- Develop contracts with language assistance services that can be shared among several practices.
- Consider sharing language services with local hospitals.
- Apply for grants to support interpreter services.

Track Your Progress

Within a month of beginning implementation, ask staff to record all of the language assistance needs they encountered during a specified week and how these needs were met. Collect these notes and discuss them at the next Health Literacy Team meeting. Explore new approaches to address any weaknesses and do another evaluation in 2. 6. and 12 months.

Routinely conduct a review of medical records of patients with recent visits to ensure that language assistance needs are being assessed and recorded. Check that qualified individuals are giving language assistance.

Compile a list of the most common languages spoken by your patients. Compare that list with the languages used in the written materials you distribute. Repeat after 2, 6, and 12 months to see whether more non-English materials are available.

Address Language Differences: Tool #9. Content last reviewed September 2020. Agency for Healthcare Research and Quality, Rockville, MD. https://www.ahrq.gov/health-literacy/improve/precautions/tool9.html



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Language Resources



The Guide to Providing Effective Communication and Language Assistance Services from the U.S. Department of Health and Human Services provides comprehensive guidance on addressing language assistance services in health care settings.

The Office Guide to Communicating with Limited English Proficient Patients is a booklet by the American Medical Association that offers practical advice for addressing communication barriers in health care settings.

<u>Hablamos Juntos</u> has a number of resources for language services, including a toolkit on improving the quality of health care translation.

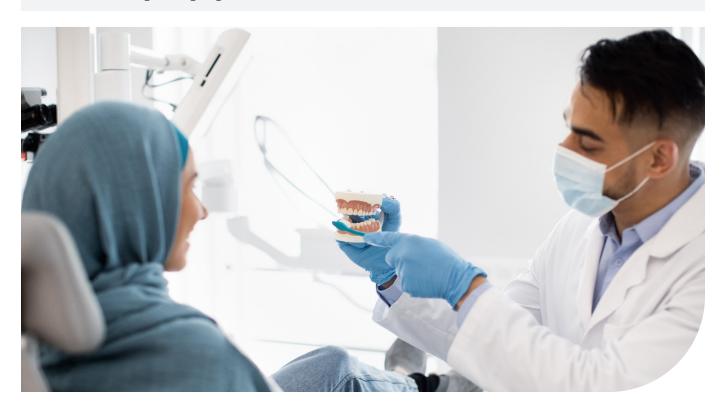
<u>Assessing Translation—A Manual for Requesters</u> provides a roadmap to help healthcare organizations improve the quality of their translated materials.

<u>LEP.gov</u> provides federal guidance in providing language access.

The American Translators Association allows you to search for local translators (for written materials) and interpreters (for verbal communication). The Certification Commission for Healthcare Interpreters has a searchable registry of certified interpreters, as does the National Board of Certification for Medical Interpreters.

Sources of multilingual easy-to-read materials:

- MedlinePlus by the National Institutes of Health.
- <u>Health Information Translations</u> provides materials in 18 different languages, including American Sign Language video.



I Speak Cards

Another great language assistance resource that is availble to you is the I Speak Cards.

This tool is a set of printable language identification flashcards featuring 38 different languages. They are easy for you to print, laminate, and keep in your practice as a helpful communication tool.

I Speak Cards are made by the U.S. Department of Commerce, Economics, and Statistics Administration and are available on their website:

https://www.lep.gov/sites/lep/files/resources/ISpeakCards2004.pdf





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Encourage Questions

Patients are sometimes embarrassed to ask questions and, in some cultures, deference to authority stifles questions. <u>Creating a shame-free environment</u> that encourages patients to ask questions is an important way to engage patients as active partners in their health care and is crucial in promoting patient safety and good health outcomes. It also can increase patient satisfaction and reduce the number of callbacks after a patient leaves.



"We decided to implement the 'Ask Me Three' program. As patients came in, I would give them a brochure and say, 'Every time you see your provider you should leave knowing the answers to these three questions.' I point to their brochure and hand them a pencil. When the nurse would take them back she would reinforce the pamphlet and encourage them to talk about their questions.

When the patient was ready to check out, I would ask them, 'Did you get your questions answered today?' Most of the responses were positive, but the more amazing thing was that fewer patients were stopping to ask questions or calling back in after their visit."

-Community Clinic

Invite Questions.

- Encouraging patients to ask questions can be as simple as saying, "What questions do you have?" This specific wording creates the expectation that they should ask questions.
- Do not ask patients, "Do you have any questions?" because most patients will respond to this wording by saying "no," even if they do have questions.
- · Ask patients what questions they have several times during an office visit.

Other Ways to Elicit Questions:

- "We discussed a lot of information. What can we review again?"
- "[Diagnosis] may be new to you, and I expect that you have some questions. What would you like to know more about?"

Use Body Language to Invite Questions.

- Sit, don't stand: Sit at the same level as your patient rather than stand.
- Look and listen: Look at patients when talking and listening, as opposed to looking at the chart or computer.
- Show that you have the time by being conscious about presenting yourself as having time and wanting to listen to their questions. Try not to interrupt.

Help Patients Prioritize Questions.

• If patients have a long list of questions, help them decide which ones are most important to address at this visit. Have them schedule another visit to address the rest of their questions.

Encourage Staff to Make Sure Questions are Asked and Answered

- Check-in and rooming staff can encourage patients to ask their clinicians any questions they have during the visit.
- Check-out staff can ask patients whether all of their questions were answered. Make sure you have a plan for how to respond if a patient says "no."

Remind Patients to Bring Questions with Them

- Appointment reminders can suggest patients bring a written list of questions with them.
- Check-out staff can suggest patients write down questions that occur to them after they leave so they can ask them at the next visit.

Encourage Patients to Ask Questions in Other Health Settings

For example, when giving a patient a new prescription, you might say, "Be sure to ask the pharmacist if you think of any additional questions about your medicine."

Track Your Progress

Over the course of a week, have check-out staff ask patients at the end of each visit, "Did you get a chance to ask all your questions today?" Record the number of patients who answered "yes" over time. Check before implementing this Tool and again after 2 months, 6 months, and 12 months.

Over the course of a week, record the percentage of patients who call the practice with questions within 48 hours after their office visit. Check before implementing this tool and again after 2 months, 6 months, and 12 months.

Before implementing this tool, collect patient feedback using the <u>Brief Patient Feedback Form</u>. Administer the questions 2, 6, and 12 months later to determine if there's been an improvement in response to the item on encouraging questions. If you field questions from the <u>Health Literacy Patient Survey</u>, calculate what percentage of patients responded "Always" to questions #7 and #8.

Resources

Practices found the following programs useful, especially when used in conjunction with <u>Tool 5: Use the Teach-Back Method</u>.

- Ask Me 3: The National Patient Safety Foundation's program encourages patients to ask three specific questions (and you to answer those questions even if they don't ask) at every visit.
- Questions Are the Answer: This resource, created by AHRQ, encourages patients to get more involved in their health care. It contains videos, handouts, and an online question builder.

Encourage Questions: Tool #14. Content last reviewed March 2022. Agency for Healthcare Research and Quality, Rockville, MD. https://www.ahrq.gov/health-literacy/improve/precautions/tool14.html





Resources

Scan this code to access links and references from this section.



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About RADx®

RADx® Underserved Populations (RADx-UP) represents a significant investment by the National Institutes of Health to address the COVID-19 pandemic and health equity in underserved populations. The RADx-UP consortium is a network of more than 137 community-engaged research project teams and mini-grant recipients across all 50 states, and U.S. territories and Tribal Nations. Each project is based at an academic institution and relies on the active partnership of community organizations and leaders.

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