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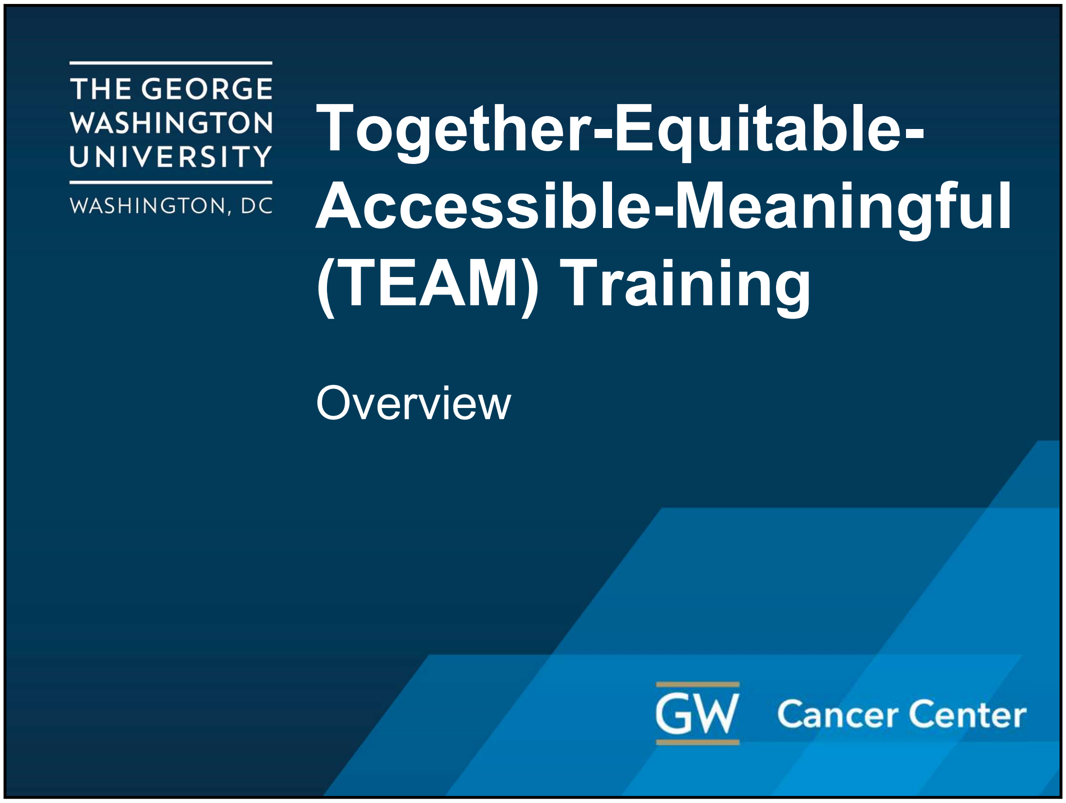

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Together-Equitable-Accessible-Meaningful (TEAM) Training

Overview

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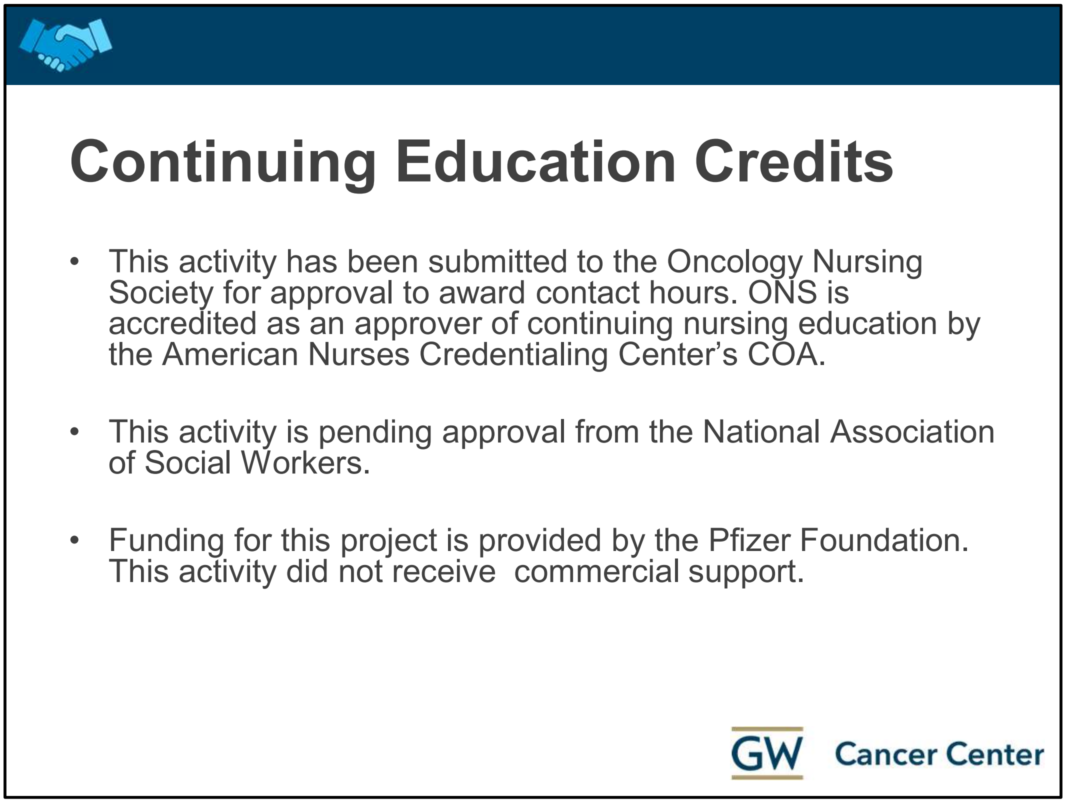
Welcome to the Together-Equitable-Accessible-Meaningful (TEAM) Training. This introduction will cover the goals of the training, define common terms used throughout and provide an overview of the training so you can know what to expect as you move through the lessons.



Continuing Education Credits

- This activity has been submitted to the Oncology Nursing Society for approval to award contact hours. ONS is accredited as an approver of continuing nursing education by the American Nurses Credentialing Center's COA.
- This activity is pending approval from the National Association of Social Workers.
- Funding for this project is provided by the Pfizer Foundation. This activity did not receive commercial support.

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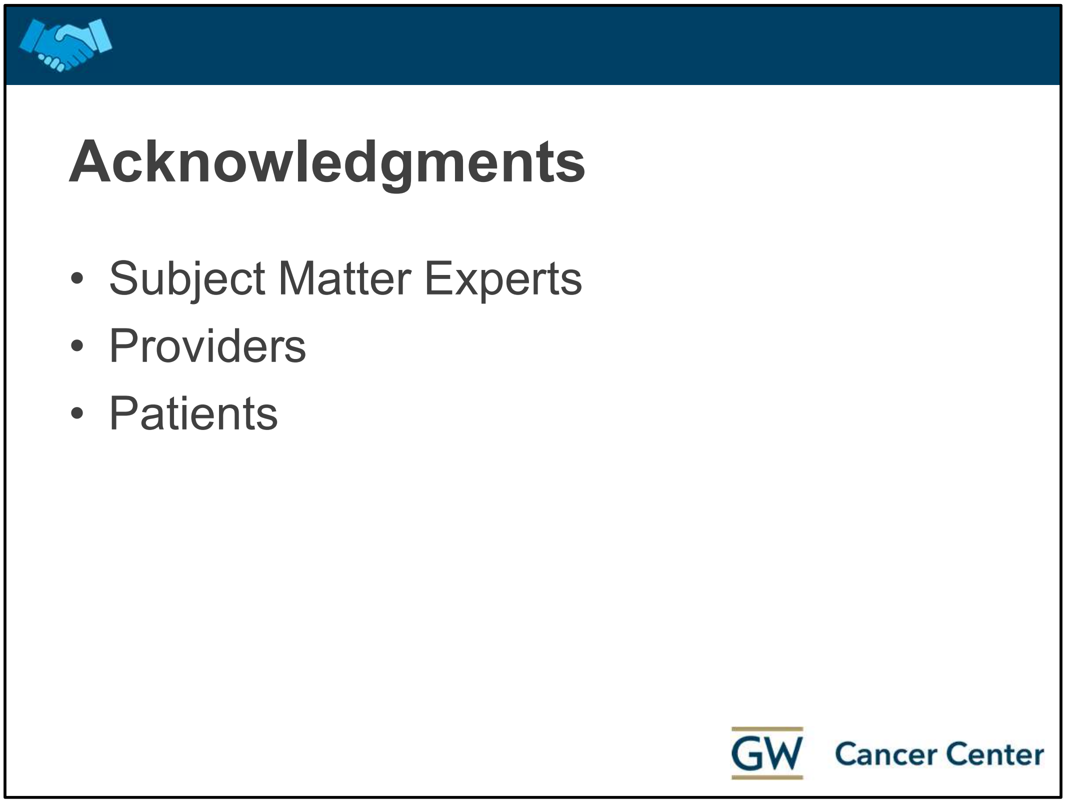
CE language will go here—about credits offered, funding (Pfizer) and any disclosures, etc.
Once you complete all required components of the training, the Claiming Continuing Education Credit or Certificate of Completion Module will open with instructions on how to claim credit. If you are not eligible to claim continuing education credit there is a certificate of completion available for your records.



Acknowledgments

- Subject Matter Experts
- Providers
- Patients

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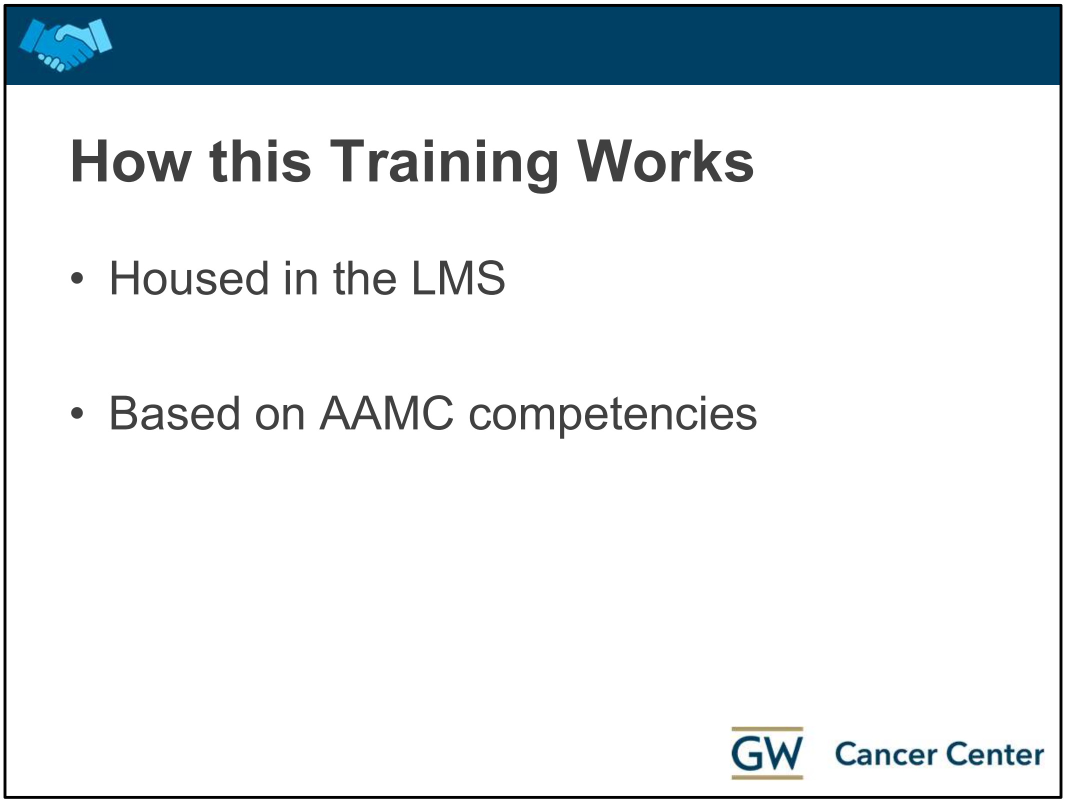
We would also like to thank our subject matter experts for their thoughtful review of and contributions to our lessons, as well as the health care professionals who participated in the National Cancer Care TEAM Survey and patients who participated in the National Cancer Care TEAM Study to inform the development of this training.



How this Training Works

- Housed in the LMS
- Based on AAMC competencies

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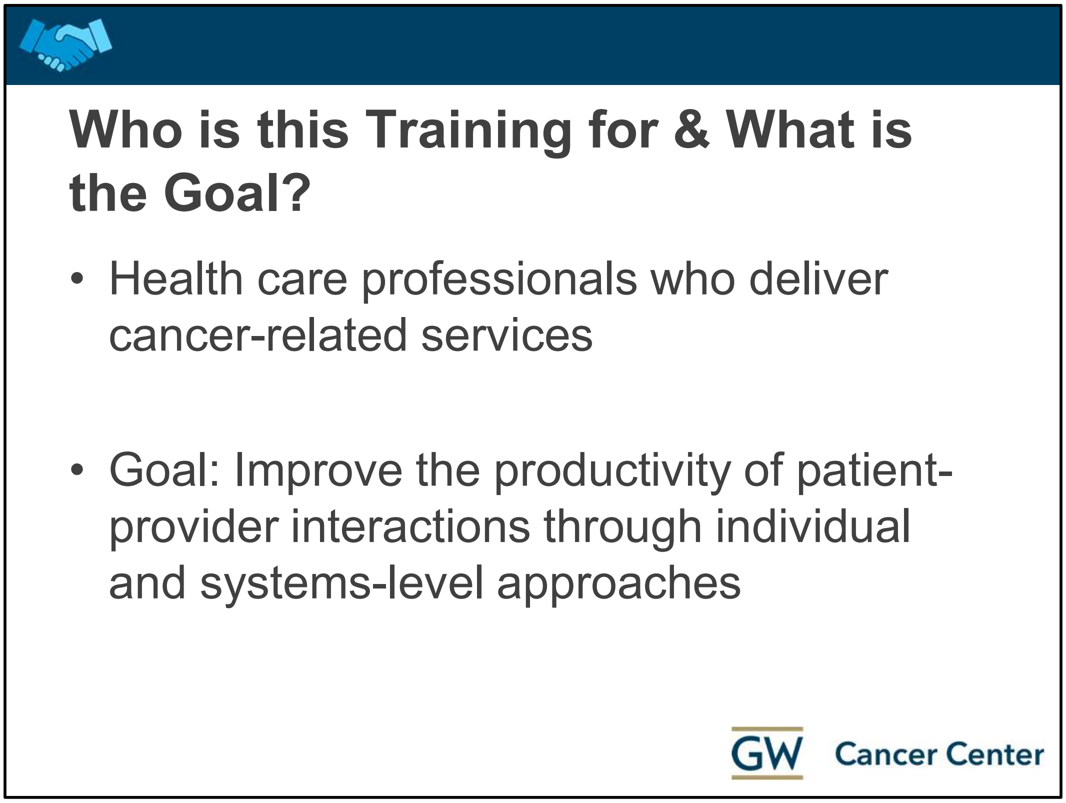
Before we begin, let’s take a moment to go over how to access and complete the training. The TEAM training is hosted on The George Washington University’s Learning Management System (or the LMS). Through the LMS, you can complete the training at your own pace. You will only be able to proceed to the next lesson once you have completed all aspects of the lesson you are currently taking.

The competencies of this training are based on the Association of American Medical Colleges’ report, titled *Implementing Curricular and Institutional Climate Changes to Improve Health Care for Individuals who are LGBT, Gender Non-Conforming, or Born with DSD: A Resource for Medical Educators.*



Who is this Training for & What is the Goal?

- Health care professionals who deliver cancer-related services
- Goal: Improve the productivity of patient-provider interactions through individual and systems-level approaches

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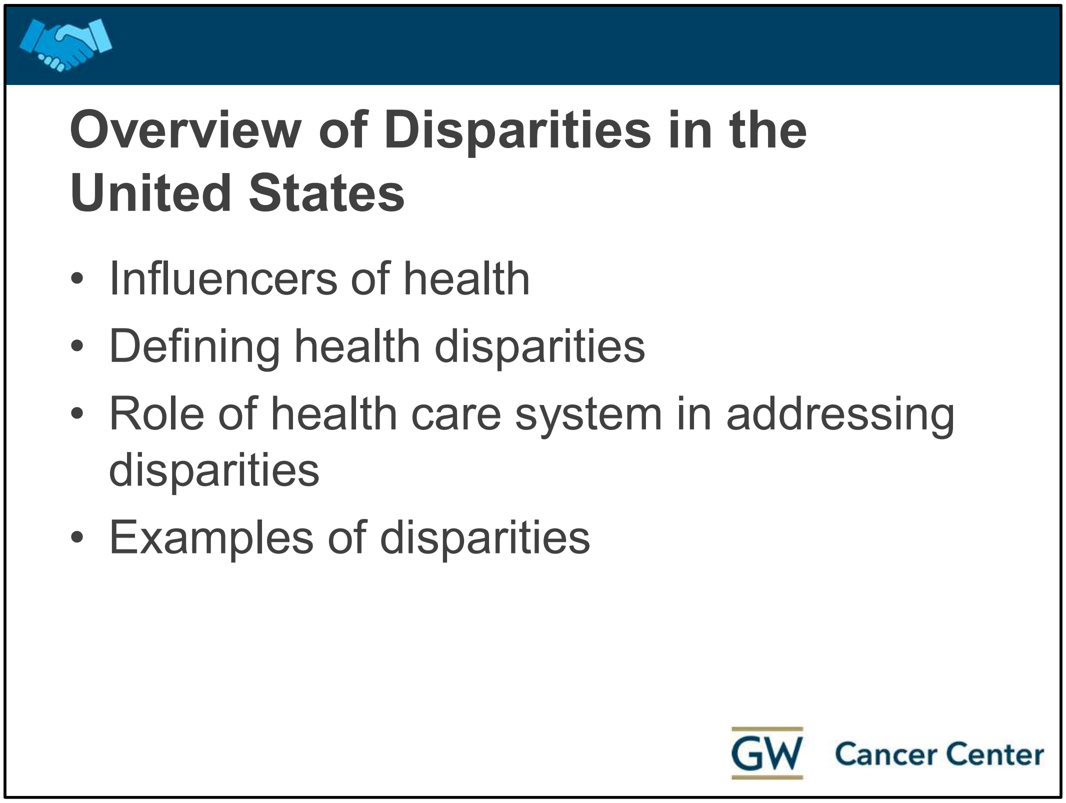
This training is designed for all health care professionals who deliver cancer-related services to patients across the care continuum, including those who work in administrative, supportive, clinical, research or community capacities.

The training seeks to provide health care professionals with additional knowledge and strategies to support your efforts as you engage with patients, their caregivers and families in patient-provider communication and employ culturally competent practices.

By doing this, the training will advance its ultimate goal, which is to improve the productivity of patient-provider interactions through individual and systems-level approaches. This, in turn, will lead to more equitable, patient-centered care, decrease cancer disparities and improve health outcomes for those impacted by cancer.

In order for this training to be most effective, it is recommended that you and your colleagues, who work in different capacities across your organization, take the training over the same period of time.



Overview of Disparities in the United States

- Influencers of health
- Defining health disparities
- Role of health care system in addressing disparities
- Examples of disparities

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There are a number of sociodemographic factors that influence a person's health—some examples of influencers of health, often referred to as social determinants of health, include where a person lives, works and how they are identified by society—such as by race, ethnicity, sexual orientation and physical ability.

These factors contribute to health disparities, which the Centers for Disease Control and Prevention defines as "...preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations." (https://www.cdc.gov/mmwr/preview/mmwrhtml/su6203a2.htm?s_cid=su6203a2_w) You may also be familiar with the term health inequalities, which is also used to describe health disparities.

The term health inequities is used to describe "…a subset of health inequalities that are modifiable, associated with social disadvantage, and considered ethically unfair." (https://www.cdc.gov/mmwr/pdf/other/su6001.pdf)

It is recognized there must be a multi-sector, systems-level approach in order to reduce disparities in the United States. Strides are being made in many areas, including health care. In 2003 the Institute of Medicine, now the National Academy of Medicine, released an important report: *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. The report states:

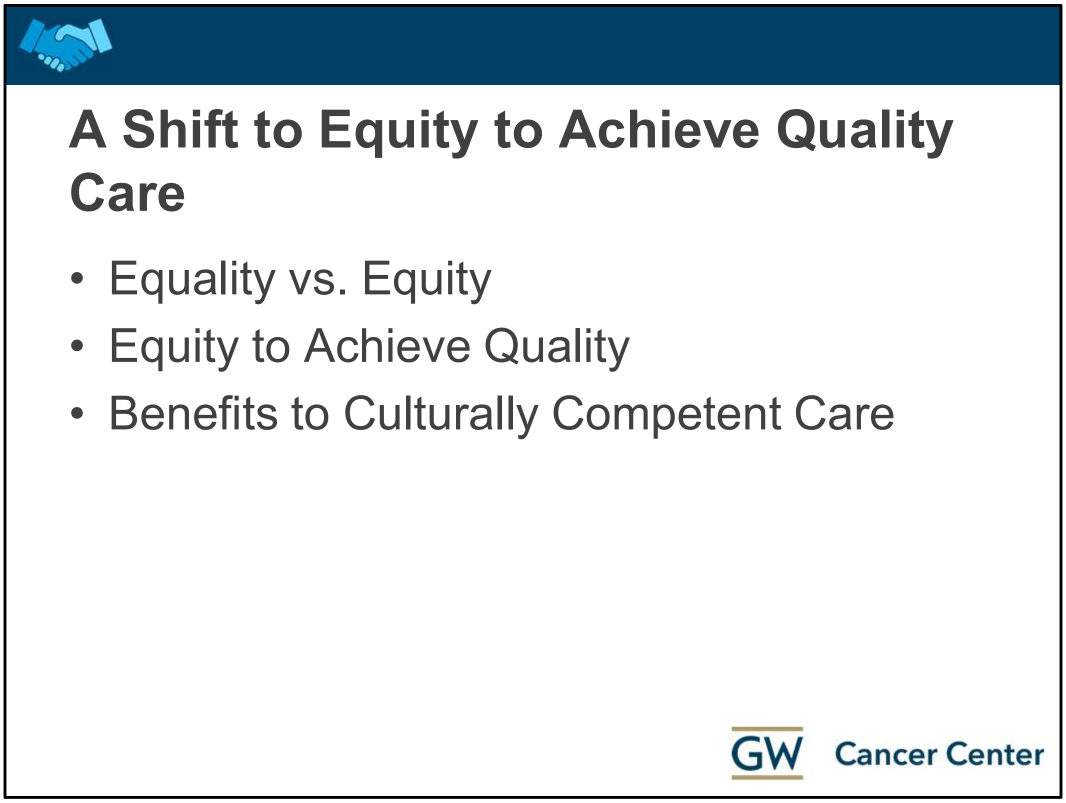
Racial and ethnic minorities tend to receive a lower quality of healthcare than non-minorities, even when access-related factors, such as patients' insurance status and income, are controlled. The sources of these disparities are complex, are rooted in historic and contemporary inequities, and involve many participants at several levels, including health systems, their administrative and bureaucratic processes, utilization managers, healthcare professionals, and patients…. Minorities may experience a range of other barriers to accessing care, even when insured at the same level as whites, including barriers of language, geography, and cultural familiarity. Further, financial and institutional arrangements of health systems, as well as the legal, regulatory, and policy environment in which they operate, may have disparate and negative effects on minorities' ability to attain quality care…. Broad sectors—including healthcare providers, their patients, payors, health plan purchasers, and society at large—should be made aware of the healthcare gap between racial and ethnic groups in the United States.

Two examples of cancer disparities include:

Racial and ethnic minority survivors are more likely to experience barriers to follow-up care and surveillance, indicate poorer patient provider communication, indicate not being prepared for side effects after treatment, report more unmet needs, not have access to culturally and linguistically appropriate resources and report lower quality of life (Palmer et al., 2015; Salz, Woo, Starr, Jandorf & DuHamel, 2012; Alanee et al., 2016; Palmer et al., 2014; Torres, Dixon & Richman, 2016; Haynes-Maslow, Allicock & Johnson, 2016; Le et al., 2015; McNutly, Kim, Thurston, Kim & Larkey, 2016; Wen, Fang & Ma, 2014; Yanez, Thompson & Stanton, 2011, Pinherio et al., 2016).

Rural cancer survivors are more likely to smoke, be less physically active, have health-related unemployment and report poorer physical and mental health and may be less likely to receive follow-up care recommendations from their provider and forgo medical care compared to cancer survivors who do not live in a rural setting (Weaver, Palmer, Lu, Case & Geiger, 2013; Schootman, Homan, Weaver, Jeffe & Yun, 2013; Palmer, Geiger, Lu, Case & Weaver, 2013; Burris & Andrykowski, 2010; Andrykowski, Steffens, Bush & Tucker, 2014; Sowden, Vacek & Geller, 2014).

Confronting the fact that not everyone receives the same care may be uncomfortable. We recognize that health care professionals and organizations want to provide high quality care to all patients, yet data indicate that not all patients in the United States receive the same care. Therefore, it is important for both health care professionals and organizations to assess and examine their current practices and then take steps to address issues they may identify, which will ultimately improve the quality of care for all patients and reduce disparities.



A Shift to Equity to Achieve Quality Care

- Equality vs. Equity
- Equity to Achieve Quality
- Benefits to Culturally Competent Care

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Traditionally, it has been a widely accepted practice in health care to provide equal treatment – or the same care to all patients, regardless of their background. Delivering equitable care, on the other hand, requires that a health care professional provide care that identifies and addresses the unique needs of each person, instead of providing the same level and type of care to all. This care will differ based on factors such as an individual’s age, racial or ethnic background, sexual orientation or gender identity and other sociodemographic factors. It is important to acknowledge the difference between providing equal care and equitable care when focusing on quality improvement.

The Agency for Healthcare Research and Quality described quality care as “doing the right thing for the right patient, at the right time, in the right way to achieve the best possible results”. In other words, high quality health care should be both equitable and patient-centered. This aligns with the National Academy of Medicine’s report *Crossing the Quality Chasm: A New Health System for the 21st Century*, which includes equitable and patient-centered care as two of the six domains for quality care improvements.

Patient-centered care is care that is respectful of patients’ culture, social context and specific needs and ensures that patients’ values guide all clinical decisions. Cultural competence is a key component of providing patient-centered care. Cultural competence in health care is “the ability of systems to provide care to patients with diverse values, beliefs and behaviors, including tailoring delivery to meet patients’ social, cultural, and linguistic needs.”

There are a number of benefits to creating an environment where culturally competent care is the norm. This can be thought of in three categories: social benefits, health benefits and business benefits. These benefits include increased respect and mutual understanding from patients, increased participation from the local community, increased preventive care by patients, reduced number of missed medical visits, and Traditionally, it has been a widely accepted practice in health care to provide equal treatment – or the same care to all patients, regardless of their background. Delivering equitable care, on the other hand, requires that a health care professional provide care that identifies and addresses the unique needs of each person, instead of providing the same level and type of care to all. This care will differ based on factors such as an individual's age, racial or ethnic background, sexual orientation or gender identity and other sociodemographic factors. It is important to acknowledge the difference between providing equal care and equitable care when focusing on quality improvement.

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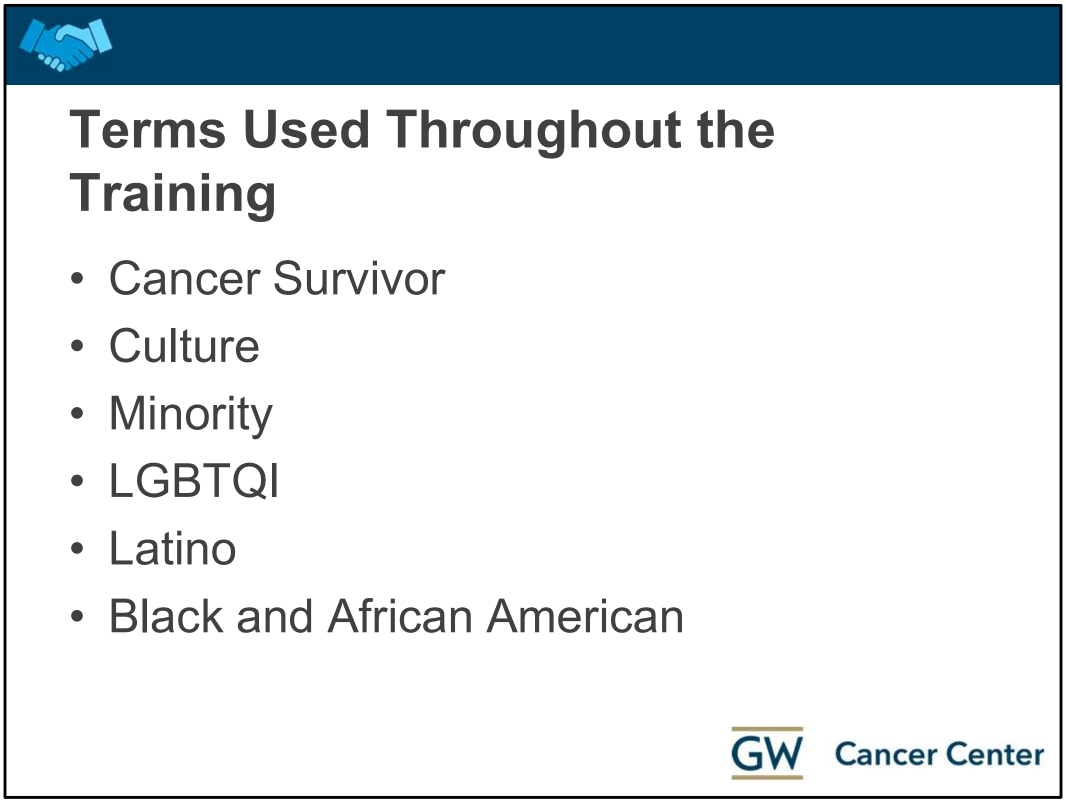

Terms Used Throughout the Training

- Cancer Survivor
- Culture
- Minority
- LGBTQI
- Latino
- Black and African American

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Now that we have discussed the goals and need for this training, let’s discuss some of the specific terms we will be using throughout the training. These terms will be important to understand many of the concepts we will be cover.

There are many terms used to describe individuals affected by cancer. For this training, we will use the term cancer survivor, which means “anyone who has been diagnosed with cancer, from the time of diagnosis through the balance of his or her life.” At other times, we will use the term “cancer patient” when discussing the interactions between individuals and health care professionals in the clinical setting. Finally, we say “people living with cancer” or “people affected by cancer” to emphasize that these individuals are not just patients, but rather people with experiences and needs outside of the clinical setting. That said, we recognize that a person may identify with these terms differently, use a different term or choose not be labeled at all based on their personal experience with cancer.

Culture here refers to “the sum of attitudes, customs, and beliefs that distinguishes one group of people from one another.” Culture is dynamic and constantly shifting; it is based on geographic, historical, social and political factors; and it provides individuals with a framework to attribute meaning to the world around them. In research or in care, we often use factors to indirectly describe or assess an individual’s culture – like race, ethnicity, national origin, language used at home or other demographics. It is important to note, however, that a person’s culture is not the same as their race, ethnicity, national origin, sexual orientation, gender identity, etc.

Throughout the training, we will also highlight the specific cancer care needs for many underserved populations. During the training, we may use the term “minority” to refer these individuals or populations. This is for continuity purposes, as the term “minority” is commonly used in research and literature. That said, it is important to understand the multiple definitions of the term “minority” and recognize the implications of its use.

For example, although “minority” is typically used to modify people of a racial or ethnic background, the term may also be used to reference people who identify as lesbian, gay, bisexual, transgender, queer or intersex; people with physical or mental disabilities; people who follow a certain faith or religion; or live in a certain geographic area. In addition to being an ambiguous term, minority is often used in ways to make a person feel as an “other” and obscure the existence of their multiple intersecting identities. The concept of multiple intersecting identities is referred to as intersectionality, and its frequent omission from conversations about underserved or underrepresented communities is one of the reasons why this training was developed.

The theory of intersectionality is a framework for understanding how multiple identities such as race, gender, sexual orientation, socioeconomic status and disability intersect at the micro level of individual experience to reflect interlocking systems of privilege and oppression (such as racism, sexism, heterosexism, classism) at the macro social-structural level. This training will include discussions of many underserved communities , but it will provide a specific focus on individuals who identify as Black and African American, Latino, lesbian, gay, bisexual, transgender, queer or intersex. Intersectionality will be particularly important during our discussions as we further explore cancer disparities, barriers to care and areas of resiliency among these individuals.

As we discuss the needs and experiences of lesbian, gay, bisexual, transgender, queer and intersex (or LGBTQI) individuals and communities, it is important to recognize that this includes all individuals who are sexual or gender minorities, or those whose sexual orientation, gender identity and expressions or reproductive development varies from traditional, societal, cultural or physiological norms. The acronym LGBTQI is an umbrella term that contains descriptions from two separate categories: sexual orientation and gender identity. Keep in mind that these are very different terms. For example, knowing someone’s gender identity gives no indication about sexual orientation and vice versa.

Sexual orientation refers to the primary sexual, romantic and relational ties that an individual holds to other individuals.
The term **lesbian** refers to the identity of women who have primary sexual, romantic and relational ties to other women;

The term **gay** refers to the identity of men who have primary sexual, romantic and relational ties to other men; and
The term **bisexual** refers to the identity of individuals who have sexual, romantic and relational ties to people of the same gender and different genders .

Individuals who do not identify as a sexual minority are referred to as **heterosexual**, which means that this individual is only attracted to individuals of the opposite gender.

Gender identity is an individual's internal sense of being a male, a female, a blend of both or neither. In other words, gender identity describes how individuals perceive themselves and what they call themselves; and this may be the same or different from their sex assigned at birth. Individuals who identify as **transgender** have a gender identity that does not align with the sex they were assigned at birth. In contrast to transgender individuals, individuals who identify as **cisgender** have a gender identity that aligns with their sex assigned at birth.

The term **intersex** refers to people who have differences in anatomy (reproductive or sexual) that do not fit into our typical definitions of female and male.

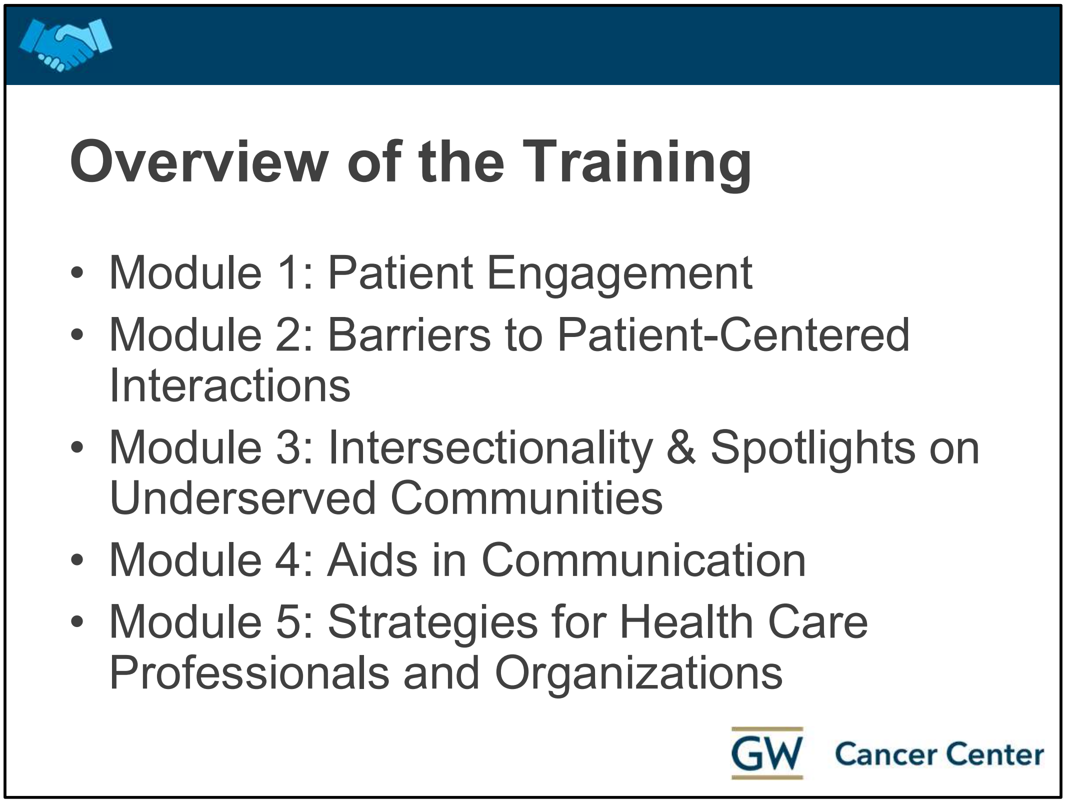
The terms **queer** and **genderqueer** may be used by individuals in reference to their sexual orientation or gender identity as a fluid construct. In addition, some individuals use "queer" as a reclaimed term for those who identify as not heterosexual or not cisgender.

It is important to keep in mind that these terms are constantly evolving. Also, people often have other ways of describing themselves. You do not have to remember all of the ways people identify themselves – just pay attention to the words that patients use and reflect those words. We use LGBTQI to be inclusive, but often organizations will use LGBT, and you may see that reflected here when discussing others' work.

The term "Latino" is used throughout the training to refer to individuals or communities of various Latin American origins or descent. We purposefully use this term because it is that which is most widely accepted and adopted by individuals in these communities. At times, we also use specific gendered terms ("Latino" for men or "Latina" for women) when appropriate. However, it is worth noting that the term "Latinx" is increasingly being embraced by some in communities of Latin American descent, particularly sexual and gender minorities within these communities as a gender-neutral alternative. The term is used to acknowledge the idea that a person is not necessarily either male or female.

We use the term Black and African American in this training to refer to the myriad of people who reside in the United States and self-identify as members of either of these groups. For example, there are African, Haitian, Afro-Caribbean and Afro-Latino individuals who all may identify as Black or are identified by data systems as Black. The U.S. Census has designated a number of racial and ethnic categories - all of which may not be consistent with how groups that reside in the United States and its territories self-identify. While we use the term Black and African American, we do acknowledge the differences in the histories, races, cultures and ethnicities between individuals for whom we use this term.

Finally, while we highlight the needs and experiences of underserved communities throughout the training, these discussions are simply meant to serve as diverse examples for learners to consider. While these discussions often draw upon real experiences, they are in no way intended to be generalizations about particular communities or individuals. It is important to remember in all encounters with patients, their caregivers and families; each person is unique and has different needs, beliefs and values.



Overview of the Training

- Module 1: Patient Engagement
- Module 2: Barriers to Patient-Centered Interactions
- Module 3: Intersectionality & Spotlights on Underserved Communities
- Module 4: Aids in Communication
- Module 5: Strategies for Health Care Professionals and Organizations

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Now that we've discussed terms we will use, let's conclude with a brief look at how the training will unfold. Again, the goal of the TEAM training is to improve the productivity of patient-provider interactions through individual and systems-level approaches in order to improve quality of care by providing equitable, accessible and patient-centered care that decreases disparities and improves health outcomes for those impacted by cancer.

Module 1 describes patient engagement and the ways it can be implemented in both the research and clinical care settings. This module sets up the rest of the course by explaining where we're trying to go – to inform and encourage health care professionals to work in partnership with patients to create care and research that responds to their needs and incorporates the contributions of patients, their caregivers and families and community members .

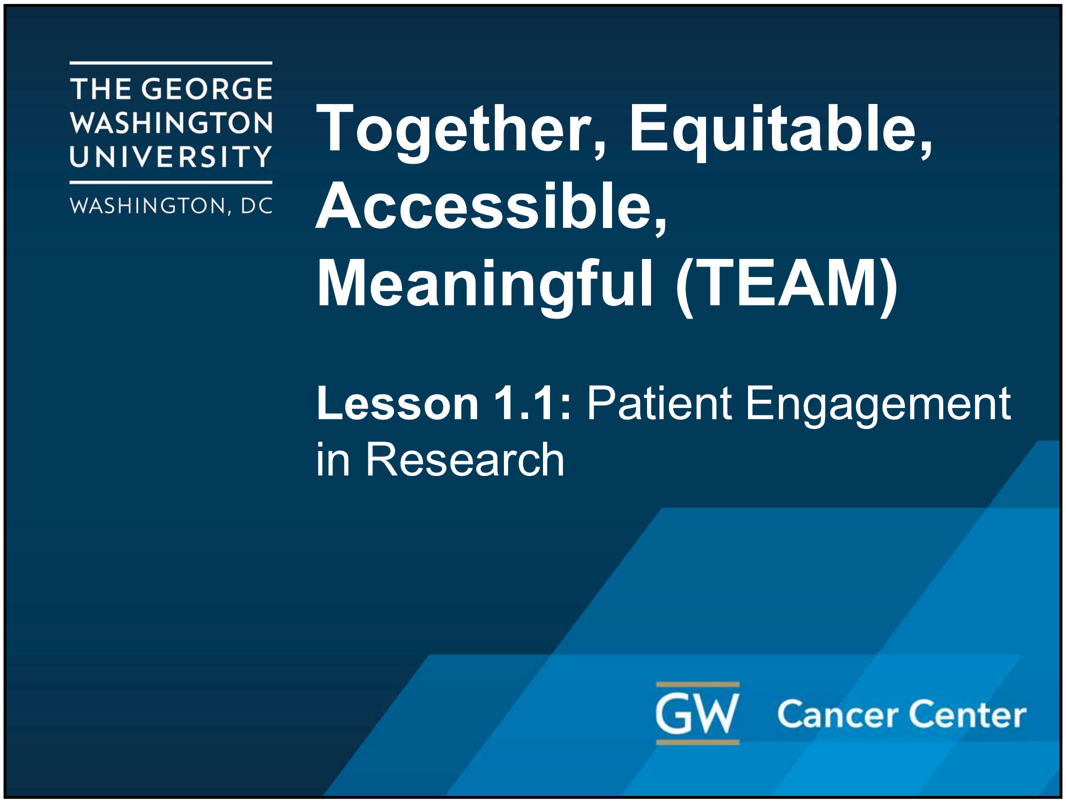
Module 2 addresses barriers to these types of patient-centered interactions. This includes systemic and interpersonal barriers.

In Module 3, we examine what impact these barriers have on health and care, particularly for underserved populations disproportionately affected by cancer. The first lesson of Module 3 covers intersectionality in depth. We then shine spotlights on various disparities, experiences with the health care system and cancer care needs for individuals who identify as LGBTQI, Black and African American or Latino.

Module 4 moves from the discussion of barriers to a review of communication strategies that health care professionals and organizations can use to support patient-centered care.

Finally, Module 5 takes all the information previously presented in the course and channels it into strategies that health care professionals can use on their own or as part of an organization to provide more equitable, accessible and patient-centered care and services.

We're glad you've chosen to participate in this training and hope that it benefits you, your organization and those you serve.



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Together, Equitable, Accessible, Meaningful (TEAM)

Lesson 1.1: Patient Engagement in Research

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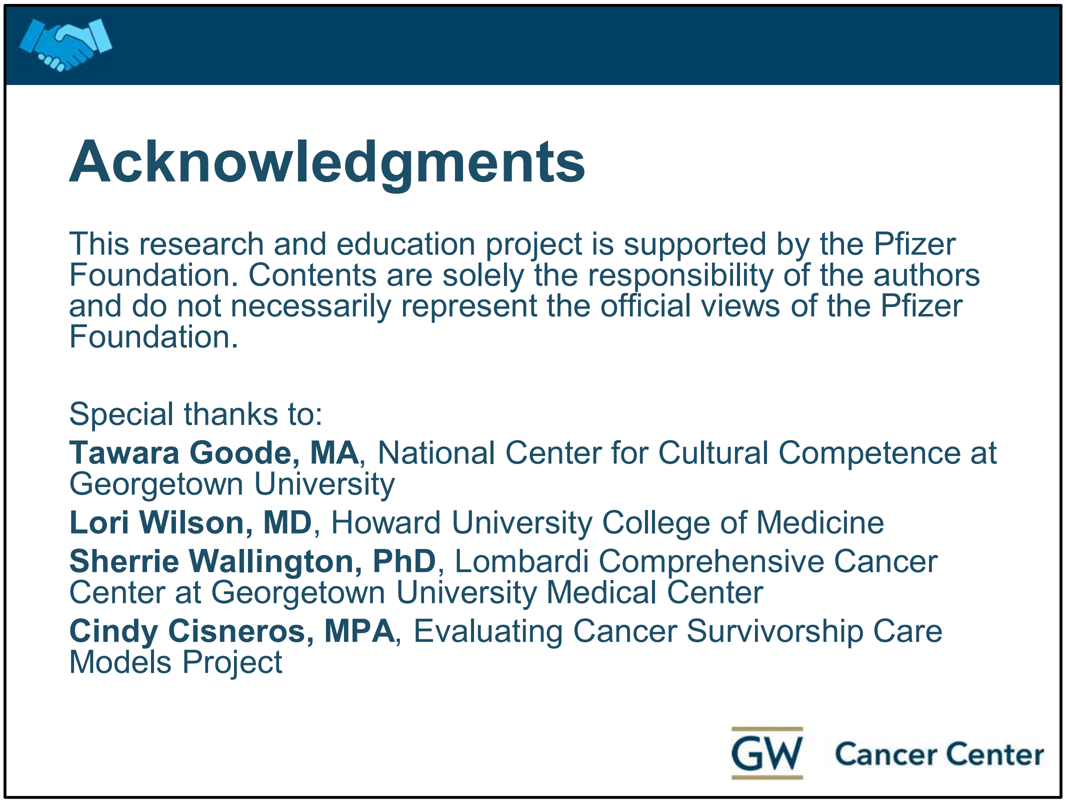
Welcome to Module 1, Lesson 1: Patient Engagement in Research



Acknowledgments

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Cindy Cisneros, MPA, Evaluating Cancer Survivorship Care Models Project

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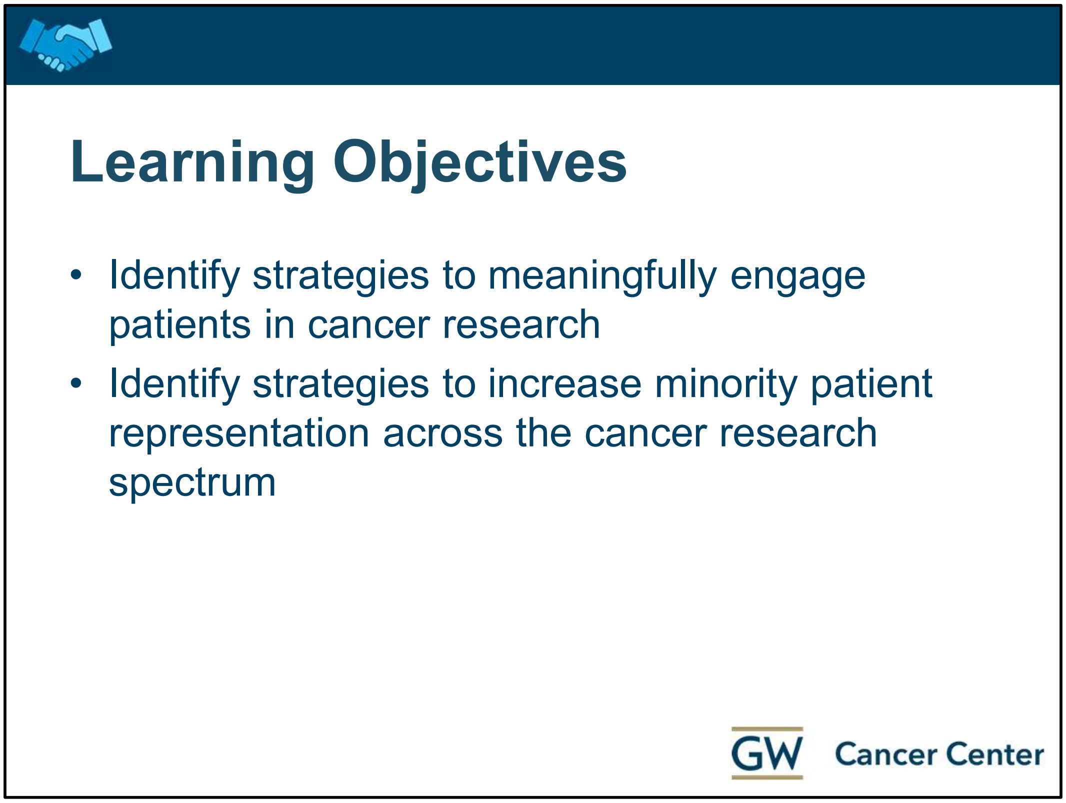
We would like to acknowledge the Pfizer Foundation for supporting this work. We would also like to thank our subject matter experts for their review of and contributions to this lesson.



Learning Objectives

- Identify strategies to meaningfully engage patients in cancer research
- Identify strategies to increase minority patient representation across the cancer research spectrum

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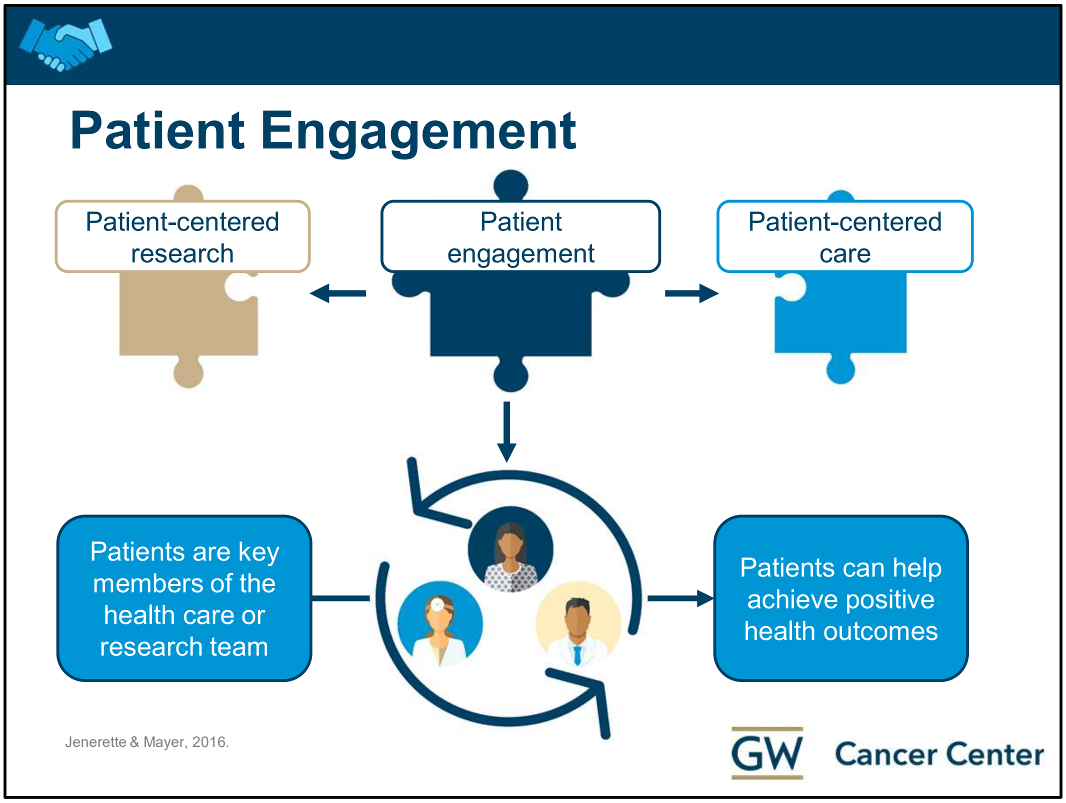
After completing this lesson, you will be able to:

- Identify strategies to meaningfully engage patients in cancer research
- Identify strategies to increase minority patient representation across the cancer research spectrum



Patient Engagement

Patient-centered research

Patient engagement

Patient-centered care

Patients are key members of the health care or research team

Patients can help achieve positive health outcomes

Jenerette & Mayer, 2016.

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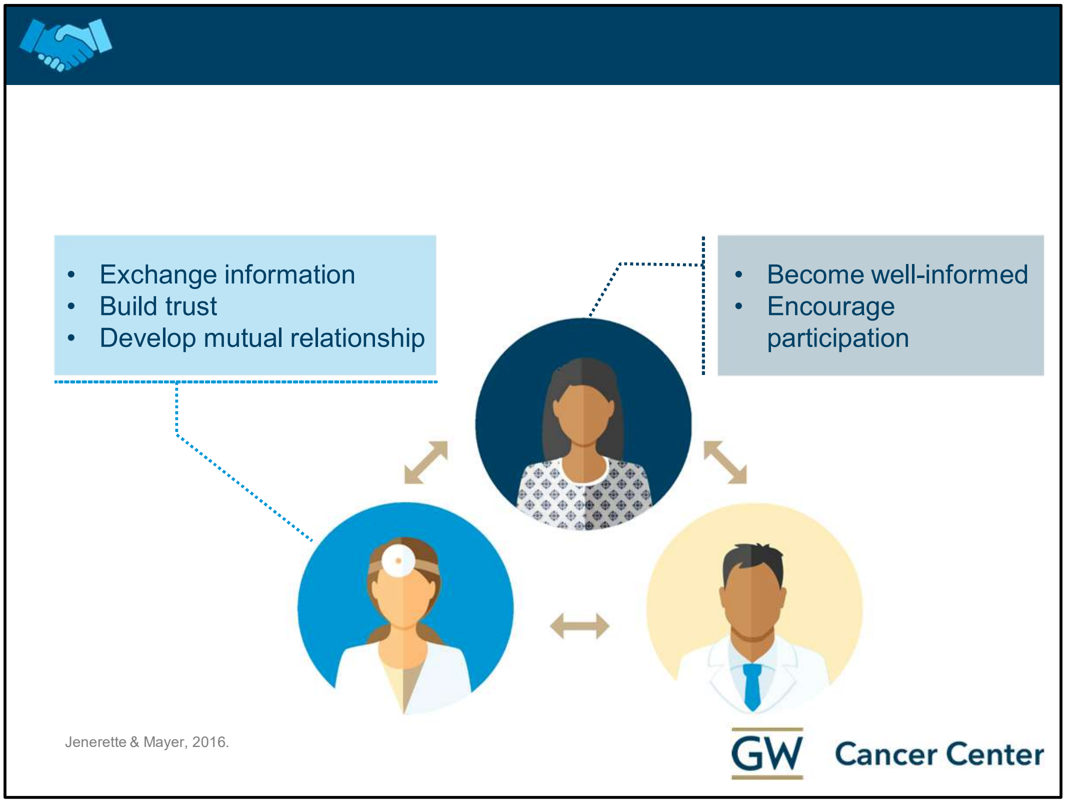
The TEAM course emphasizes the importance of patient engagement to fully realize the goal of patient-centered cancer care and research. A person affected by cancer can become capable of managing their health, understanding their care or participating in research. They are also a key member of the health care or research team working to help achieve desired health outcomes – whether at the individual, community or societal level.

Patients can increase their level of engagement if they are well-informed and actively encouraged to participate in care or research. Health care professionals and organizations play an important role in this. Through exchanging information and interacting with patients to build trust and develop a mutual relationship.



- Exchange information
- Build trust
- Develop mutual relationship

- Become well-informed
- Encourage participation

Jenerette & Mayer, 2016.

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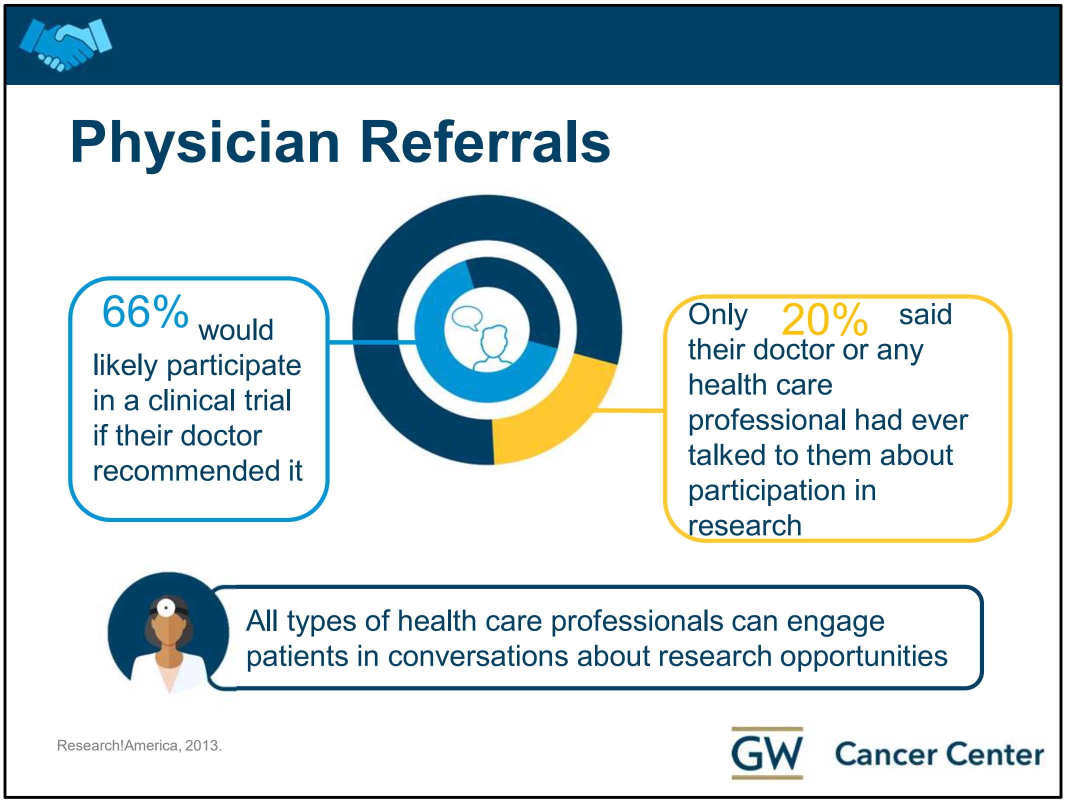

Physician Referrals

66% would likely participate in a clinical trial if their doctor recommended it

Only 20% said their doctor or any health care professional had ever talked to them about participation in research

All types of health care professionals can engage patients in conversations about research opportunities

Research!America, 2013.

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In addition to building trust, perhaps one of the most prominent barriers to participation in one form of research, clinical trials, is the lack of physician referrals.

While more than 66 percent of individuals in a national survey reported they would likely participate in a clinical trial if their doctor recommended it, only 20 percent said their doctor or any other health care professional had ever talked to them about participation in research. Therefore, clinicians– whether involved in research or not – can play a role in enhancing the representation in research by engaging patients in conversations about research opportunities.

Without research, we would not have continual advances in health or health care delivery. People with cancer (and communities more broadly) play and have played a vital role in contributing to cancer research. Yet, it is important to note that how research has been conducted has set the tone for how many patients approach the heath care system and research today.

Patient Involvement in Research

Patients and communities play a vital role in contributing to research and the research process

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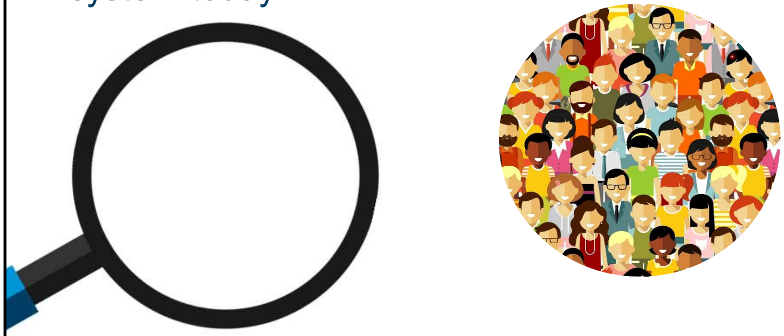
Negative experiences have set the tone for how many patients interact with and approach the health care system today.



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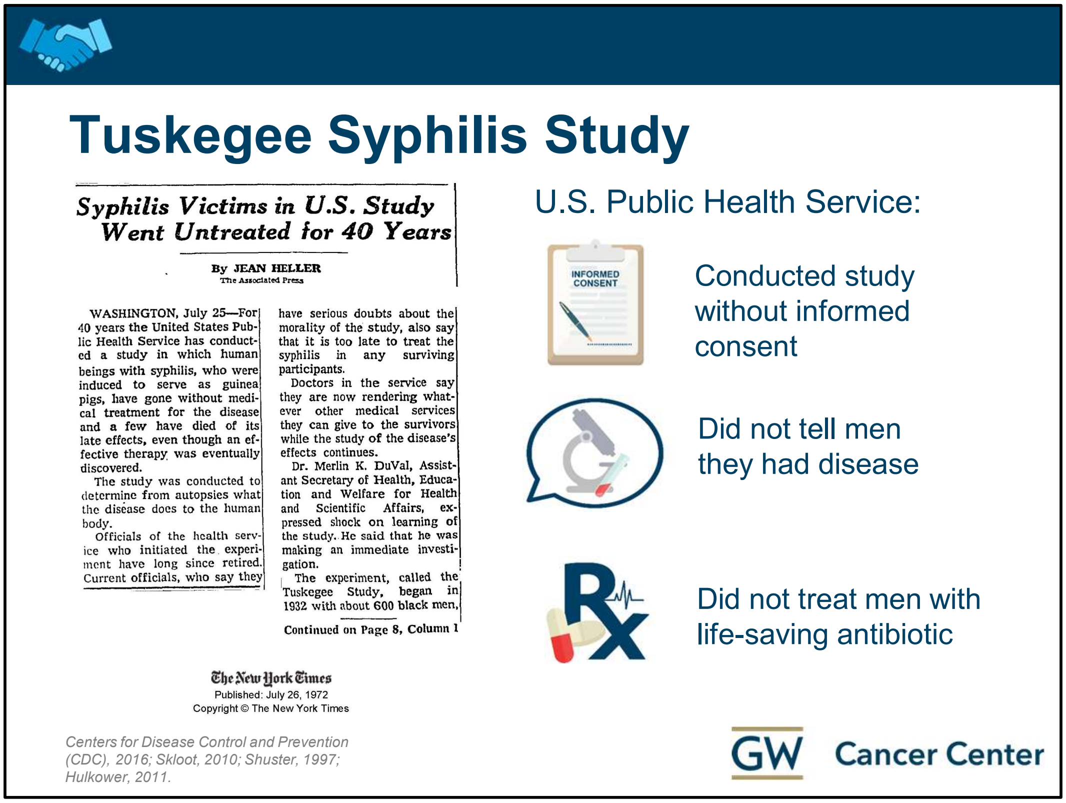


Tuskegee Syphilis Study

Syphilis Victims in U.S. Study Went Untreated for 40 Years

By JEAN HELLER
The Associated Press

WASHINGTON, July 25—For 40 years the United States Public Health Service has conducted a study in which human beings with syphilis, who were induced to serve as guinea pigs, have gone without medical treatment for the disease and a few have died of its late effects, even though an effective therapy was eventually discovered.

The study was conducted to determine from autopsies what the disease does to the human body.

Officials of the health service who initiated the experiment have long since retired. Current officials, who say they have serious doubts about the morality of the study, also say that it is too late to treat the syphilis in any surviving participants.

Doctors in the service say they are now rendering whatever other medical services they can give to the survivors while the study of the disease's effects continues.

Dr. Merlin K. DuVal, Assistant Secretary of Health, Education and Welfare for Health and Scientific Affairs, expressed shock on learning of the study. He said that he was making an immediate investigation.

The experiment, called the Tuskegee Study, began in 1932 with about 600 black men,

Continued on Page 8, Column 1

The New York Times
Published: July 26, 1972

U.S. Public Health Service:

- Conducted study without informed consent
- Did not tell men they had disease
- Did not treat men with life-saving antibiotic

Centers for Disease Control and Prevention (CDC), 2016; Skloot, 2010; Shuster, 1997; Hulkower, 2011.

Historically, there has not been full transparency or accountability to patients in health research. Vulnerable communities have been exploited for centuries. Let's take a moment to reflect on a few examples of a long history of exploitation of vulnerable communities in research. By doing so we can better understand the challenges researchers and health professionals face in engaging communities, but these examples do not fully depict the extensive nature of discrimination and exploitation of vulnerable communities .

In the Middle Ages, those who were executed were sometimes used for public dissections. Anatomical dissections were associated with dishonor, so government officials used the threat of dissection as a way to stop people from doing crimes.

Later in the 18th and 19th centuries, grave robbing became a common way of making money. People dug up buried bodies to sell to medical schools that needed cadavers for medical student dissection. These grave robbers were known as "Night doctors" or "body snatchers." Sometimes people who wanted quick money even murdered someone to sell the body to anatomy labs. Most often, the graves that were dug up were those of unprotected members of society, like black and African American individuals.

To curb these crimes, Massachusetts became the first state in 1830 to allow bodies unclaimed in hospitals, prisons, and asylums to be given to state medical schools. This led to a more socially-approved way of obtaining cadavers, but dissection was still linked with poverty. Poor people without families were the ones whose bodies were sent to medical schools. Not until the 1968 Uniform Anatomical Gift Act did body donation start to become voluntary, and eventually, a mark of privilege in giving back to society.

The most infamous case of harm performed on vulnerable citizens through research in the U.S. was the Tuskegee Syphilis Study. In this study the U.S. Public Health Service looked at the effects of untreated syphilis in Black men in Alabama from 1932 to 1972. The study was conducted without any of the infected men being told they had the disease. Furthermore, none were treated with penicillin even after it was proven to be a life-saving treatment for syphilis.

In the field of cancer research, in 1951, researchers used cells from Henrietta Lacks, an African American woman whose cervical cancer cells were biopsied and replicated. This was done without her knowledge or consent. At that time, doctors routinely obtained samples without consent from their patients, particularly among those who could not pay for medical care. Henrietta Lack's cells (commonly known as HeLa cells, named from the first two letters of her first name followed by the first two letters of her last name) have been distributed broadly around the world.

The practice of experimenting on patients without consent went largely unquestioned until three Jewish doctors refused to follow instructions from their supervisor to inject patients with Henrietta's cancer cells, citing the Nuremberg Code that mandates that "the voluntary consent of the human subject is absolutely essential." The Nuremberg Code was established in 1947 as a result of torturous research and murders performed on human prisoners by Nazi doctors. This Code was a watershed moment, leading to important human protections in research.

Those who were institutionalized were also subjected to great research abuse prior to human subjects protections. For example, prisoners were asked to volunteer for research that injected HeLa cells into their arms, giving them tumors. Some participants said they agreed to the research as a way to try to make up for their crimes to society.

Such exploitations are not limited to the African American community, the institutionalized, nor to the distant past. Just over a decade ago, the Havasupai tribe filed a lawsuit in Arizona against a university for misusing DNA samples. The samples were first taken with permission as a part of one study. However, the samples were then used in unrelated studies without the participants' permission. These other studies dealt with issues that are taboo to the Havasupai tribe, including schizophrenia, migration and inbreeding.

As a result, scientists and health professionals face challenges in engaging a number of minority communities including African Americans, Latinos, Pacific Islanders and others in research studies.

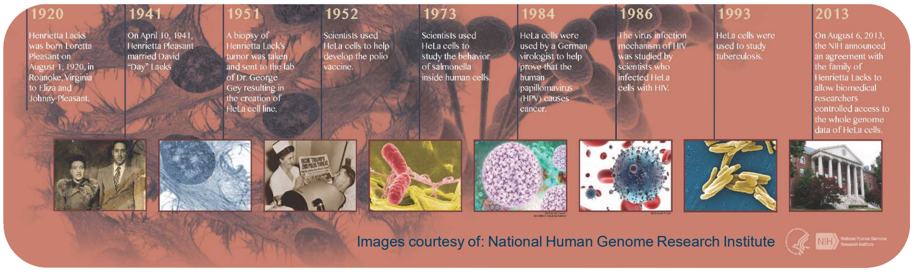
A key barrier shared across all groups was mistrust. This mistrust stemmed not only from documented instances of research exploitation, but also because of experiences of continual systematic discrimination, concerns that research will only benefit white people and fear of being treated as a “guinea pig.” It is important to remember that these fears are founded on a true, well-established and compelling history of research abuse.

Henrietta Lacks

African American woman whose cervical cancer cells were removed and replicated without her consent

Over the last 60 years, HeLa cells have been used in research across the world to:

- Investigate the nature of cancer
- Develop drugs to fight diseases like leukemia
- Identify the chromosomal composition of human cells



1920
Henrietta Lacks was born Loretta Pleasant on August 1, 1920, in Roanoke, Virginia to Eliza and Johnny Pleasant.

1941
On April 10, 1941, Henrietta Pleasant married David "Day" Lacks

1951
A biopsy of Henrietta Lack's tumor was taken and sent to the lab of Dr. George Gey resulting in the creation of HeLa cell line.

1952
Scientists used HeLa cells to help develop the polio vaccine.

1973
Scientists used HeLa cells to study the behavior of salmonella inside human cells.

1984
HeLa cells were used by a German virologist to help prove that the human papillomavirus (HPV) causes cancer.

1986
The virus infection mechanism of HIV was studied by scientists who infected HeLa cells with HIV.

1993
HeLa cells were used to study tuberculosis.

2013
On August 6, 2013, the NIH announced an agreement with the family of Henrietta Lacks to allow biomedical researchers controlled access to the whole genome data of HeLa cells.

Images courtesy of: National Human Genome Research Institute

Daulton, 2014.
Images courtesy of the National Human Genome Research Institute.

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Exploitations are Widespread

Exploitations aren't limited to the African American community or the past


The New York Times

U.S.

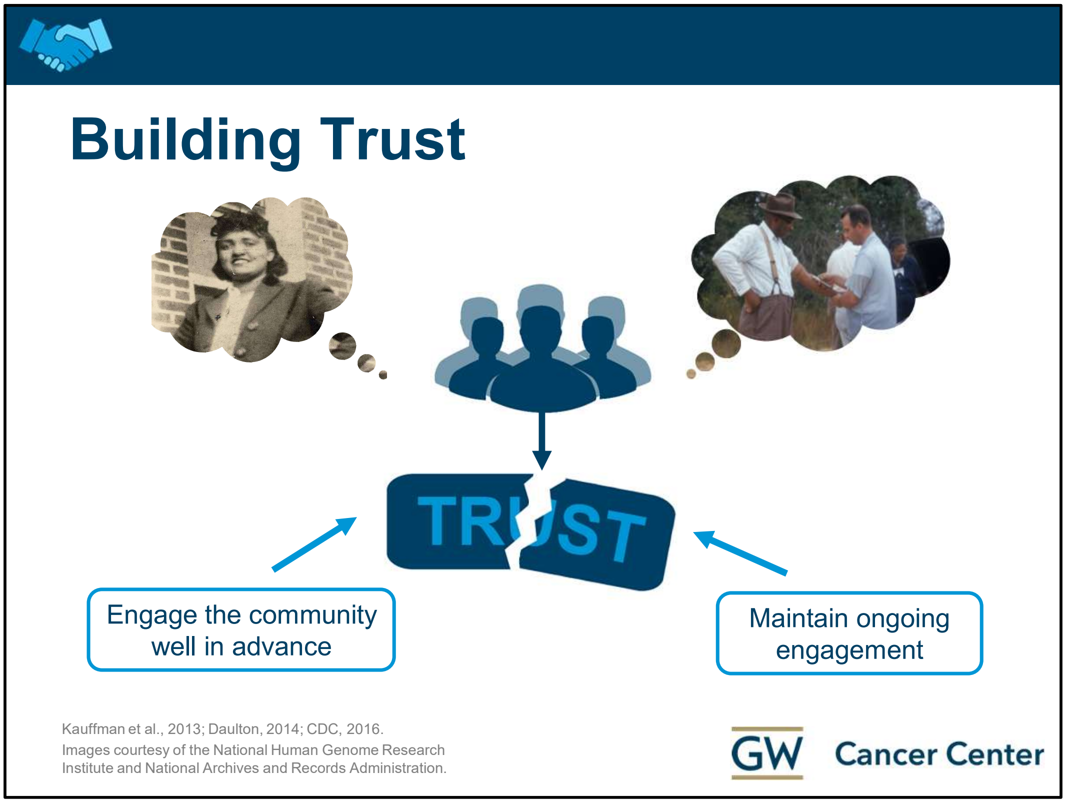
Havasupai Case Highlights Risks in DNA Research

By AMY HARMON APRIL 21, 2010

Scientists used DNA samples from the Havasupai tribe in unrelated studies without participants' consent

Scientists face challenges engaging various minority communities in research due to mistrust

National Congress of American Indians, n.d.; George, Duran, & Norris, 2014.



Building Trust

Engage the community well in advance

Maintain ongoing engagement

Kauffman et al., 2013; Daulton, 2014; CDC, 2016.
Images courtesy of the National Human Genome Research Institute and National Archives and Records Administration.

With this in mind, building and maintaining trust with communities that have historically been the subject of discrimination and abuse, whether in a research or clinical setting, is crucial. Researchers build trust by engaging the community well in advance of approaching community members about participating in a specific trial or project. Trust is maintained through ongoing engagement with participants, as well as the greater community.

This ongoing and meaningful process of engagement is often referred to as community-based participatory research (or CBPR).

Community-Based Participatory Research

A "collaborative approach to research that **equitably involves all partners in the research process** and recognizes the unique strengths that each brings.

CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities."

Faridi, Grunbaum, Gray, Franks, & Simoes, 2007.

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CBPR is a "collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities."

Benefits of patient engagement through CBPR include improved participant recruitment among underrepresented populations and enhanced relevance of the intervention and findings. Patients or community members also help anticipate and address study logistical challenges and increase participation through their communication channels and tailored messaging.

A main component of patient or community involvement in research is the building of reciprocal relationships and co-learning. This involves the respect of each other’s contributions and mutual transfer of knowledge and skills. For instance, researchers train community members in research methodology and community members train researchers in cultural practices and beliefs.

In CBPR, community members should be involved in all stages of research. This can include funding decisions and research question determination, execution, study design, review of recruitment methods and materials, data collection and analysis, and interpretation and dissemination of findings.

Other methods of patient engagement in research can include advisory groups, focus groups, interviews or surveys to provide feedback and pilot test approaches. Patients, caregivers and community members can be important members of the research team. Formal agreements surrounding patient engagement in research can also be an important component of successful partnerships, such as clarifying roles and expectations as well as authorship considerations and other forms of recognition.

True research collaboration with communities is the ideal. Yet, at the very least, communities need to be *represented* in research in order to reflect their health needs and guide the planning of appropriate and effective interventions.

Benefits of CBPR:

Improves participation

Enhances relevance of findings

←

Community communication channels

Tailored messages

Hubbard, Kidd, & Donaghy, 2008; Ellis & Kass, 2017;
Thompson, Bissell, Cooper, Armitage, & Barber, 2012.

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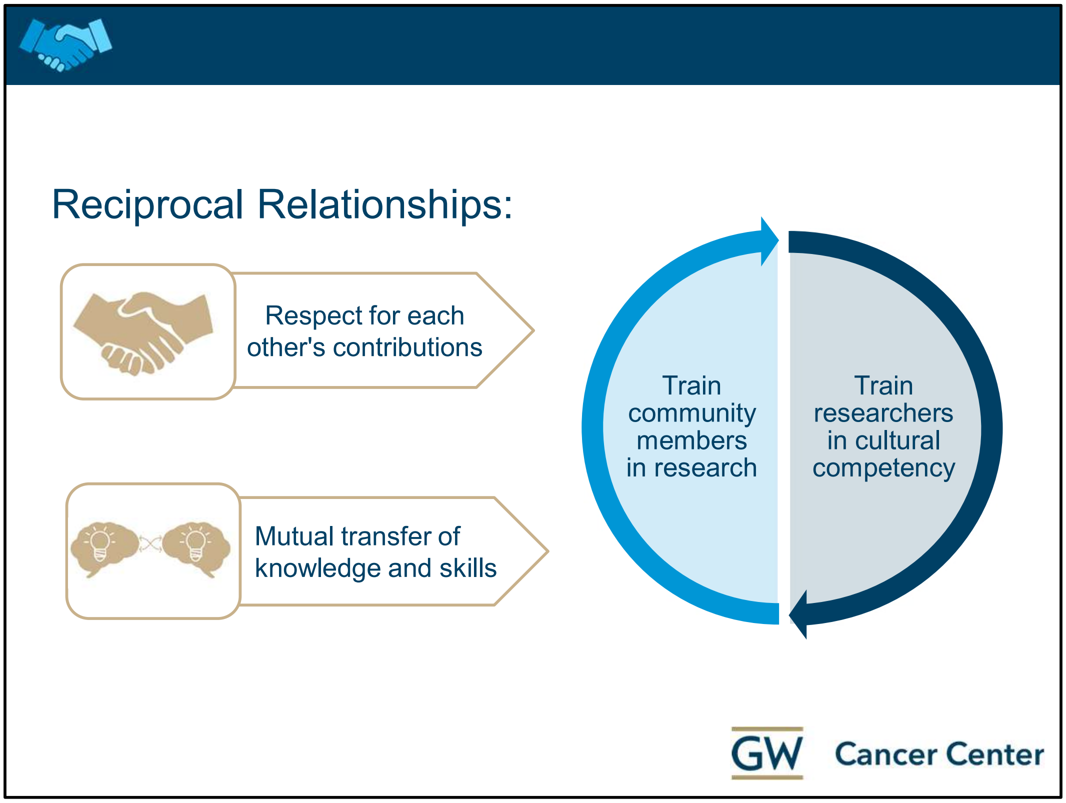

Reciprocal Relationships:

Respect for each other's contributions

Mutual transfer of knowledge and skills

Train community members in research

Train researchers in cultural competency

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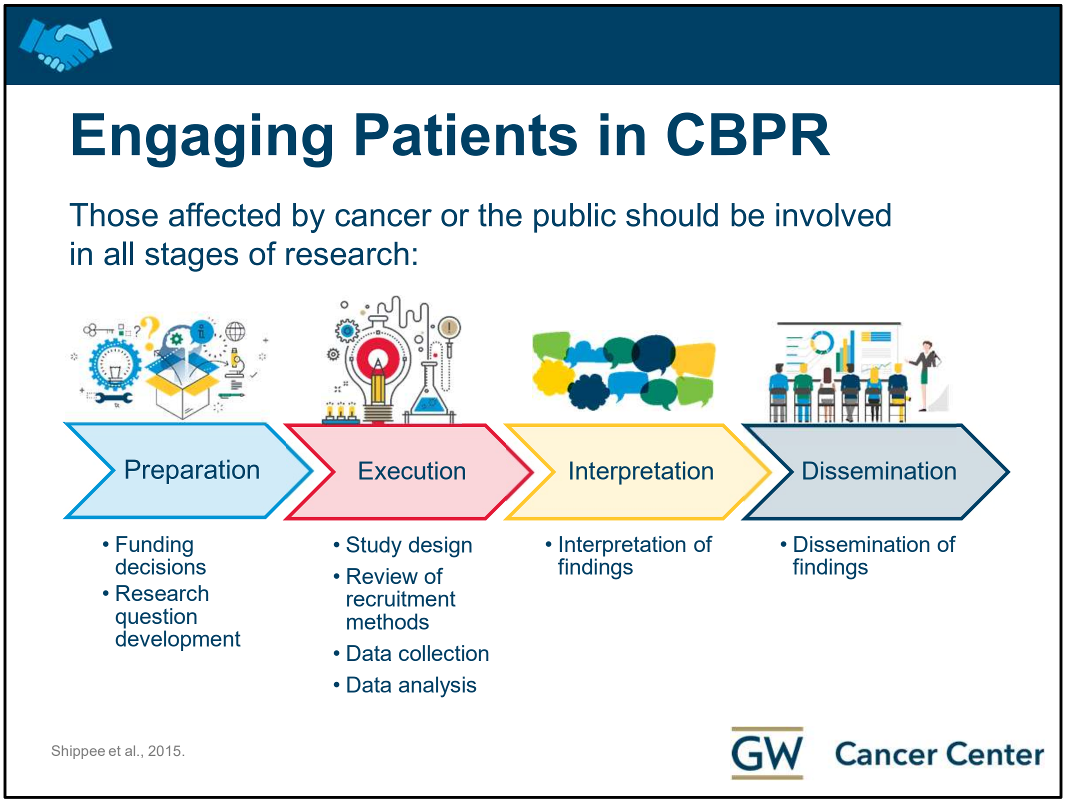

Engaging Patients in CBPR

Those affected by cancer or the public should be involved in all stages of research:

Preparation
- Funding decisions
- Research question development

Execution
- Study design
- Review of recruitment methods
- Data collection
- Data analysis

Interpretation
- Interpretation of findings

Dissemination
- Dissemination of findings

Shippee et al., 2015.

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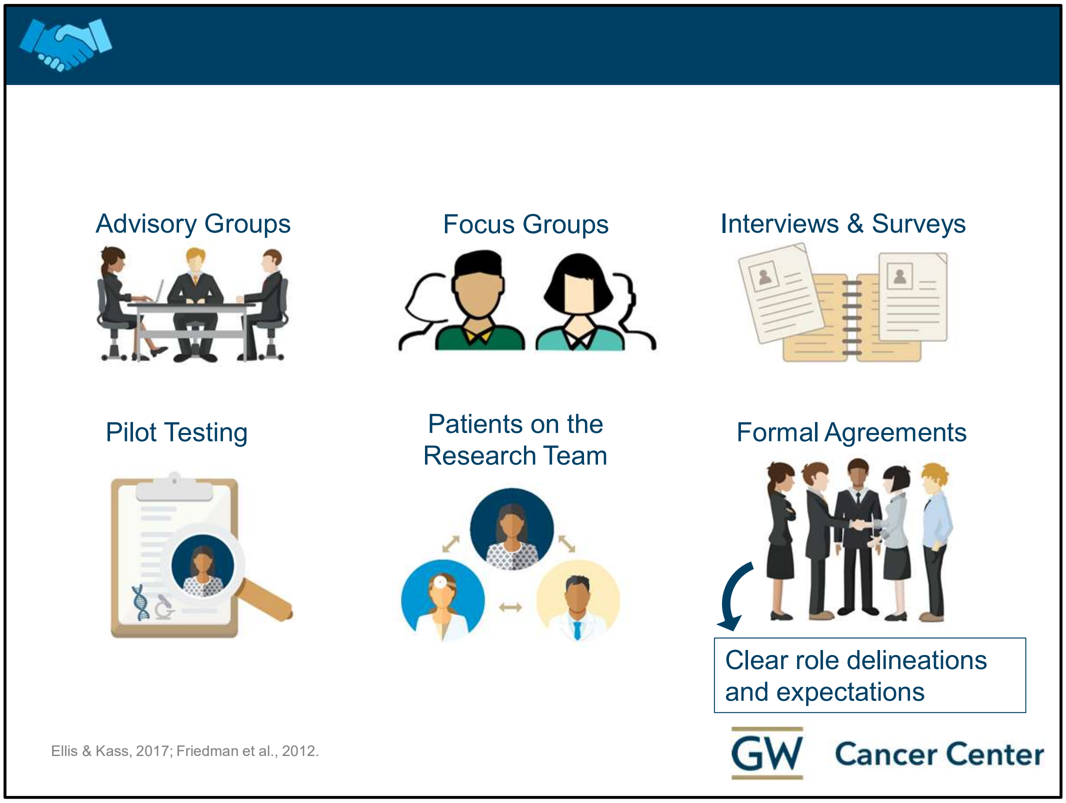

Advisory Groups

Focus Groups

Interviews & Surveys

Pilot Testing

Patients on the Research Team

Formal Agreements

Clear role delineations and expectations

Ellis & Kass, 2017; Friedman et al., 2012.

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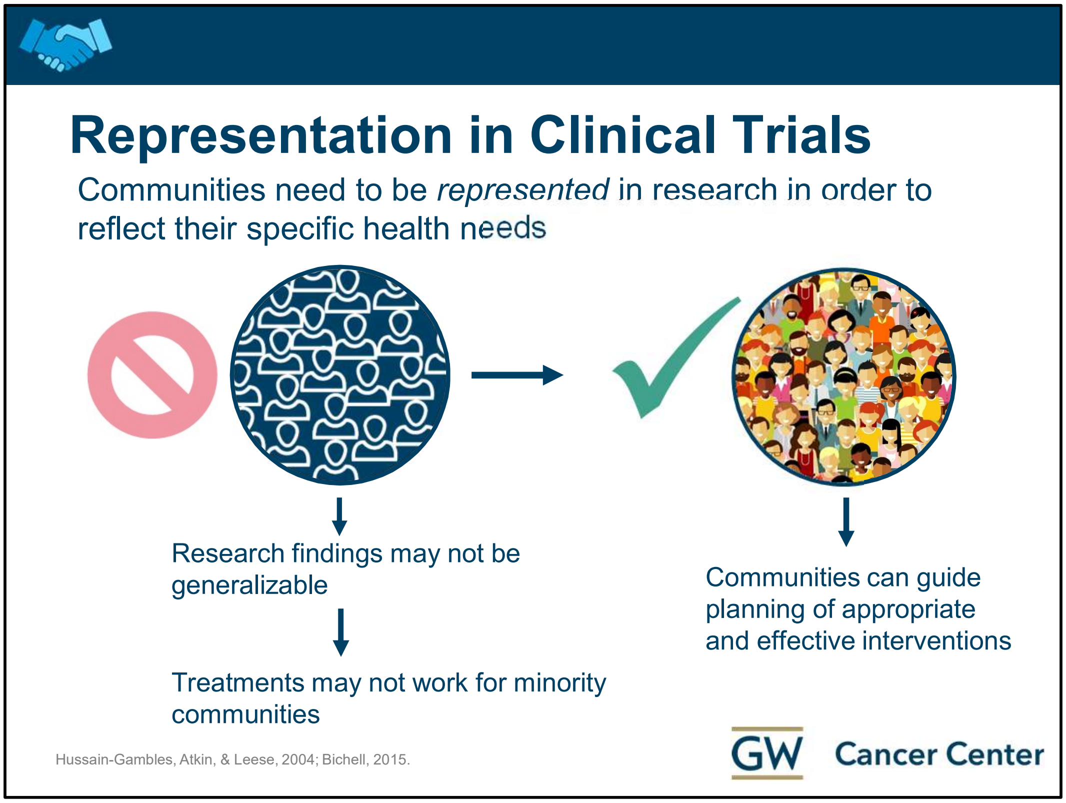

Representation in Clinical Trials

Communities need to be *represented* in research in order to reflect their specific health needs

Research findings may not be generalizable

Treatments may not work for minority communities

Communities can guide planning of appropriate and effective interventions

Hussain-Gambles, Atkin, & Leese, 2004; Bichell, 2015.

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In looking at clinical trials, we can see how important inclusion of diverse patient populations is. Without strong representation of minority communities (including racial, ethnic, sexual and gender minorities), research findings run the risk of not being generalizable. Treatments developed based on these findings may not work for individuals in minority communities.

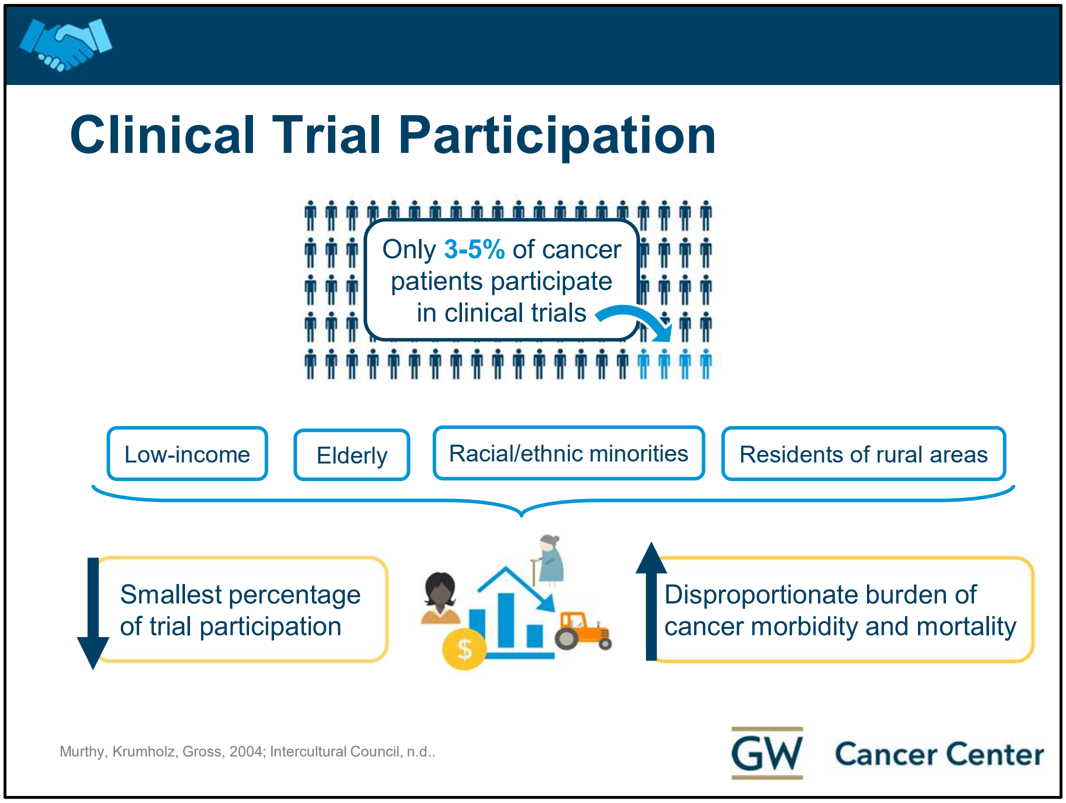
Only about three to five percent of cancer patients participate in clinical trials. However, people who are low-income, elderly, racial/ethnic minorities or residents of rural areas have the smallest percentage of clinical trial participation. Yet, they bear a greater burden of cancer morbidity and mortality. For instance, while racial and ethnic minorities constitute almost 40 percent of the U.S. population, only 17 percent are included in Phase III cancer clinical trials.

Also less than 2 percent of cancer clinical trials funded by The National Cancer Institute (NCI) focus primarily on ensuring ample representation of racial and ethnic minorities.

Because effective cancer prevention and treatment techniques are based on clinical trial results, low participation in cancer clinical trials by minorities may contribute to existing cancer survival and mortality rate disparities.

In addition, research that evaluates interventions to promote or manage health must represent diverse communities, for example, people of color are significantly underrepresented in the growing field of internet-based intervention studies.

Strategies mentioned in our discussion of CPBR can be used to more effectively engage patients and community members in these types of studies.



Clinical Trial Participation

Only **3-5%** of cancer patients participate in clinical trials

Low-income

Elderly

Racial/ethnic minorities

Residents of rural areas

Smallest percentage of trial participation

Disproportionate burden of cancer morbidity and mortality

Murthy, Krumholz, Gross, 2004; Intercultural Council, n.d..

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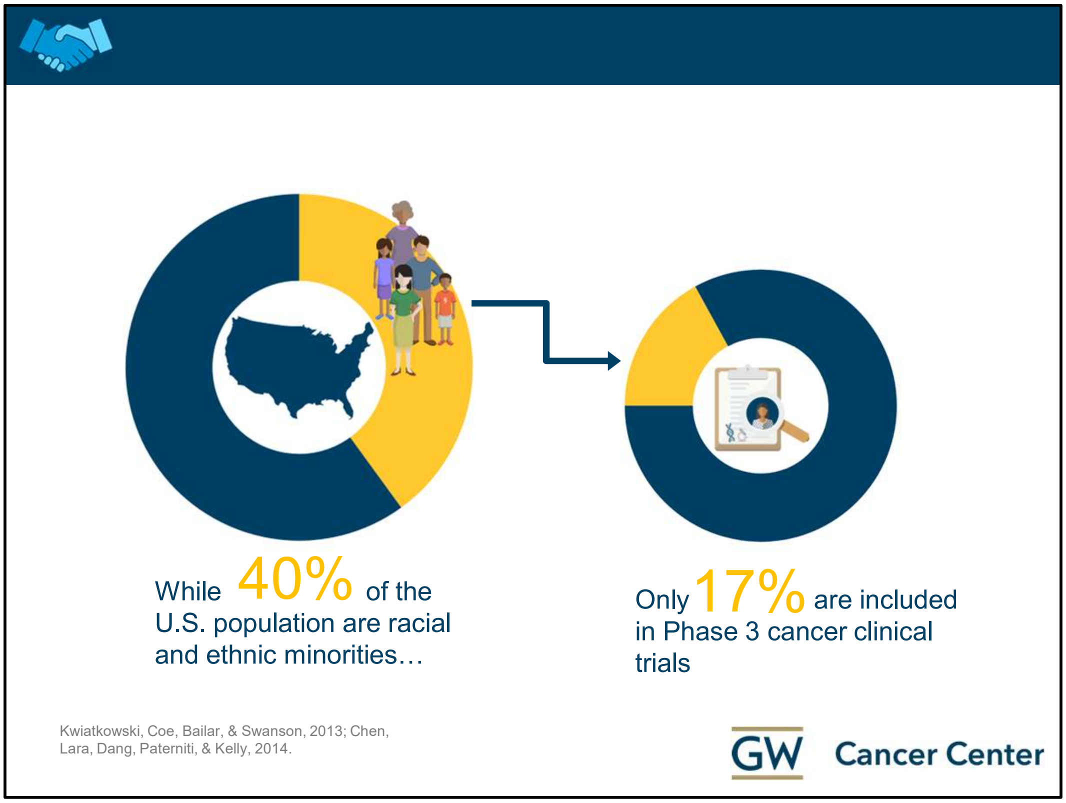

While 40% of the U.S. population are racial and ethnic minorities…

Only 17% are included in Phase 3 cancer clinical trials

Kwiatkowski, Coe, Bailar, & Swanson, 2013; Chen, Lara, Dang, Paterniti, & Kelly, 2014.

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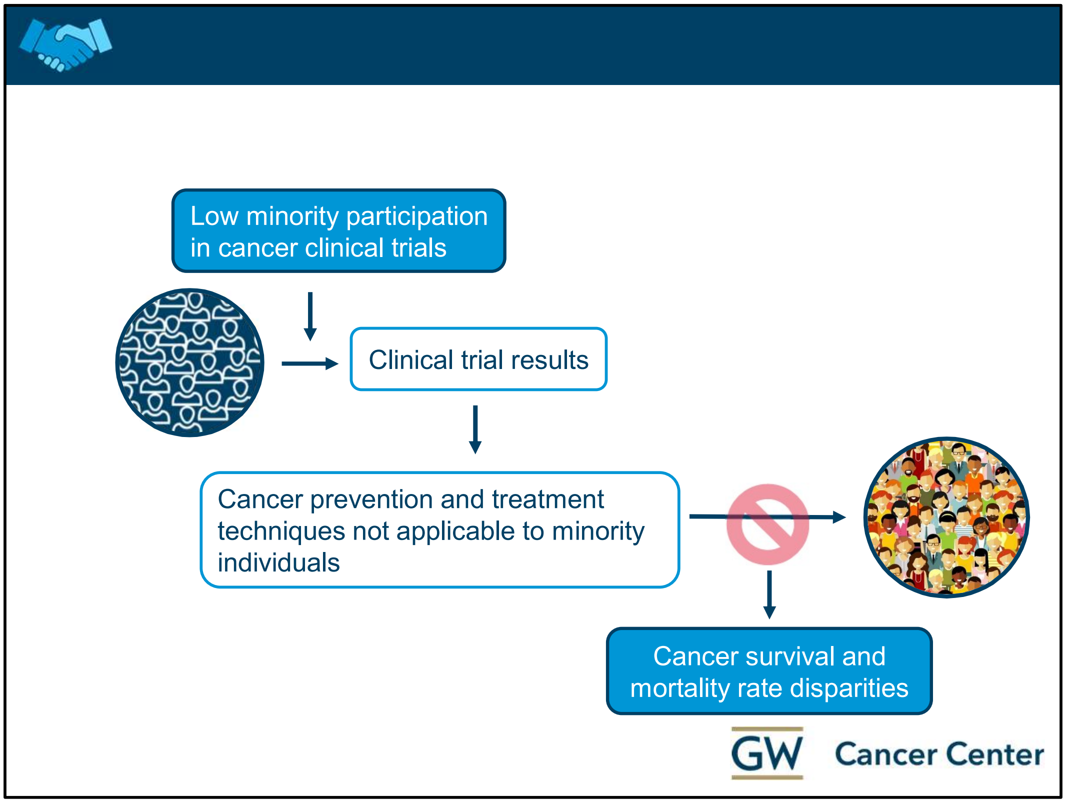

Low minority participation in cancer clinical trials

Clinical trial results

Cancer prevention and treatment techniques not applicable to minority individuals

Cancer survival and mortality rate disparities

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Evaluation Research

Research that evaluates interventions to promote or manage health needs to represent diverse communities

Example:

People of color are significantly underrepresented in internet-based intervention studies.

CBPR strategies can be used to engage patients and communities in these studies

Thompson et al, 2013.

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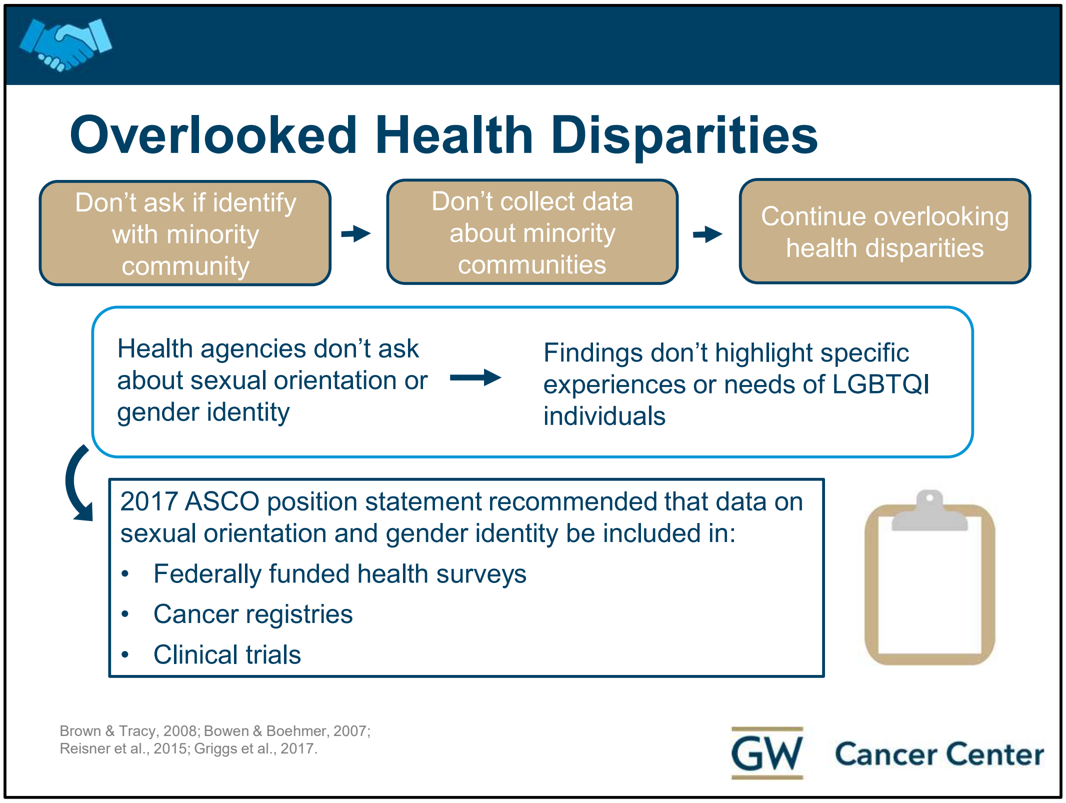

Overlooked Health Disparities

Don't ask if identify with minority community → Don't collect data about minority communities → Continue overlooking health disparities

Health agencies don't ask about sexual orientation or gender identity → Findings don't highlight specific experiences or needs of LGBTQI individuals

2017 ASCO position statement recommended that data on sexual orientation and gender identity be included in:

- Federally funded health surveys
- Cancer registries
- Clinical trials

Brown & Tracy, 2008; Bowen & Boehmer, 2007;
Reisner et al., 2015; Griggs et al., 2017.

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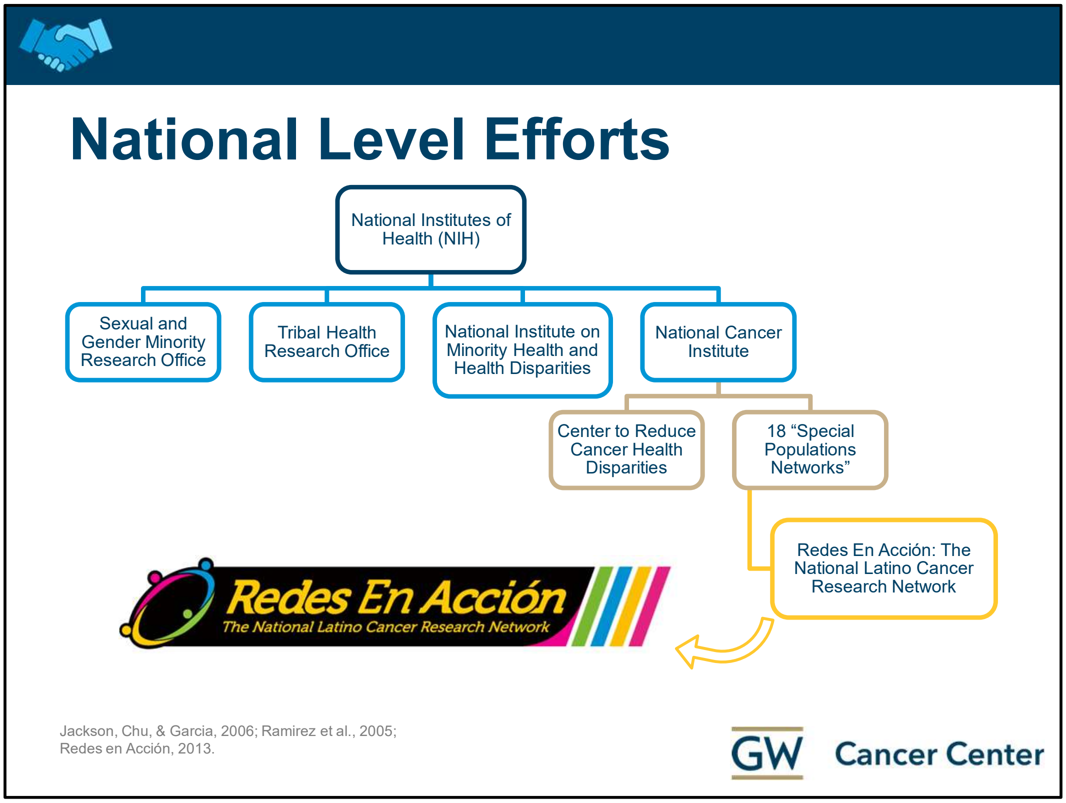
The research community also risks not fully uncovering health disparities when it does not collect data about minority populations.

This occurs when researchers do not ask individuals if they identify with a minority community or make assumptions about a person's race or ethnicity. For instance, health agencies generally do not ask questions about individuals' sexual orientation or gender identity in their data collection.

Therefore, findings cannot fully and accurately highlight the specific experiences of LGBTQI individuals compared with non-LGBTQI individuals. The result is that we have not yet been able to fully determine the cancer risk and incidence for people who identify as LGBTQI.

This consideration of individuals' sexual and gender minority status is also important because it should be considered alongside other important patient information—like socioeconomic experiences, race, ethnicity, geographic location and health literacy level. These factors, taken together, paint a more holistic picture of the U.S. population and their different health needs.

In response to this lack of data, the American Society of Clinical Oncology (ASCO) recommended in its 2017 position statement that data elements on minority status (in this case, sexual orientation and gender identity) be included in federally-funded health surveys, cancer registries and clinical trials.



National Level Efforts

- National Institutes of Health (NIH)
  - Sexual and Gender Minority Research Office
  - Tribal Health Research Office
  - National Institute on Minority Health and Health Disparities
  - National Cancer Institute
    - Center to Reduce Cancer Health Disparities
    - 18 “Special Populations Networks”
      - Redes En Acción: The National Latino Cancer Research Network

Redes En Acción
The National Latino Cancer Research Network

Jackson, Chu, & Garcia, 2006; Ramirez et al., 2005; Redes en Acción, 2013.

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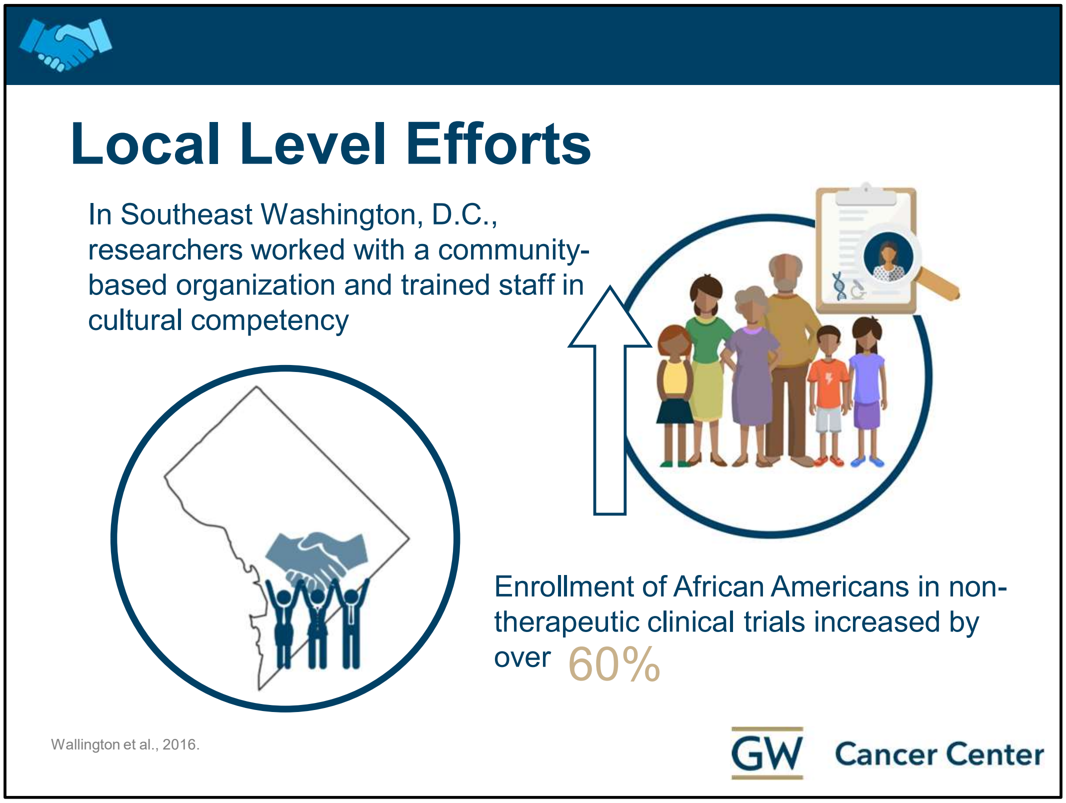
There is an improved focus on the need to increase minority representation in research which has led to the implementation of strategies at a variety of levels.

At the federal level, the National Institutes of Health (NIH) has established various offices committed to promoting research for underserved populations. These offices include the Sexual & Gender Minority Research Office, the Tribal Health Research Office, the National Institute on Minority Health and Health Disparities, and the National Cancer Institute Center to Reduce Cancer Health Disparities.

The NCI specifically funded 18 “Special Populations Networks” across the U.S. One goal is to increase CBPR among underserved populations.

Diversifying the research workforce to include more researchers from minority communities conducting cancer research is also an important endeavor. To this end, the network *Redes en Acción* partnered with the National Hispanic Medical Association to provide mentorship and professional development for Latino investigators to conduct NIH research.



Local Level Efforts

In Southeast Washington, D.C., researchers worked with a community-based organization and trained staff in cultural competency

Enrollment of African Americans in non-therapeutic clinical trials increased by over 60%

Wallington et al., 2016.

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At the local level, community-based organizations play a vital role in increasing minority communities' involvement in research.

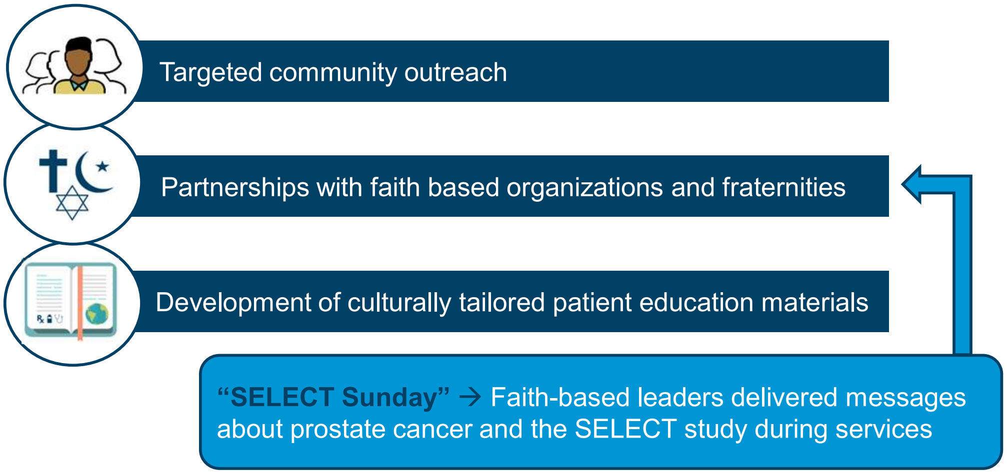
For example, in Southeast Washington, D.C., working with a community-based organization and training staff in cultural competency allowed researchers to increase enrollment of African American individuals in non-therapeutic clinical trials by over 60 percent.

Another example is the Selenium and Vitamin E Cancer Prevention Trial (or SELECT), which aimed to study the effect of Selenium and Vitamin E on the incidence of prostate cancer. SELECT conducted targeted community outreach, developed partnerships with faith-based organizations and fraternities and created culturally tailored patient education materials.

SELECT was then able to reach its recruitment goals for African American, Latino and Asian participants. For instance, "SELECT Sunday" involved faith-based leaders from local churches and mosques delivering messages about prostate cancer and the SELECT study during services.

Partnering with community-based organizations is key. But, it is important to engage in discussions with community members to understand barriers that individuals in the community face and identify strategies on how to reach individuals who may not be involved in organized groups.

Selenium and Vitamin E Cancer Prevention Trial (SELECT)



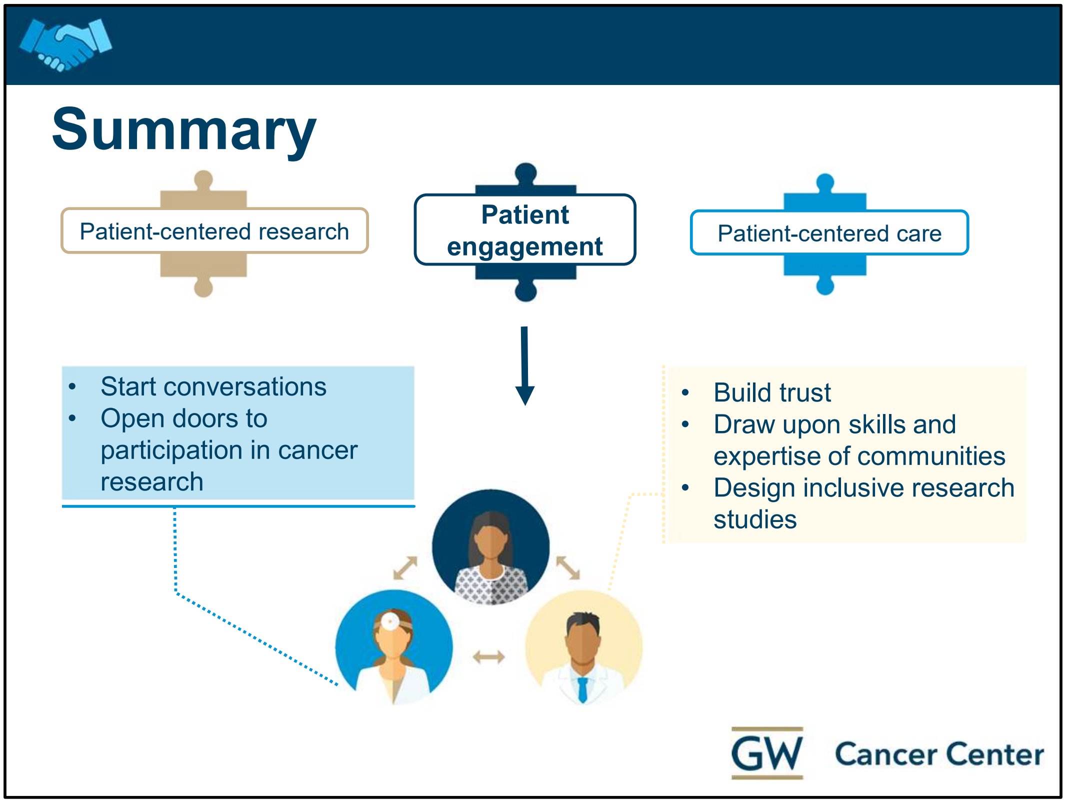
Targeted community outreach

Partnerships with faith based organizations and fraternities

Development of culturally tailored patient education materials

“SELECT Sunday” → Faith-based leaders delivered messages about prostate cancer and the SELECT study during services

Napoles, Cook, Ginossar, Knight, & Ford, 2017.



Summary

Patient-centered research

Patient engagement

Patient-centered care

- Start conversations
- Open doors to participation in cancer research

- Build trust
- Draw upon skills and expertise of communities
- Design inclusive research studies

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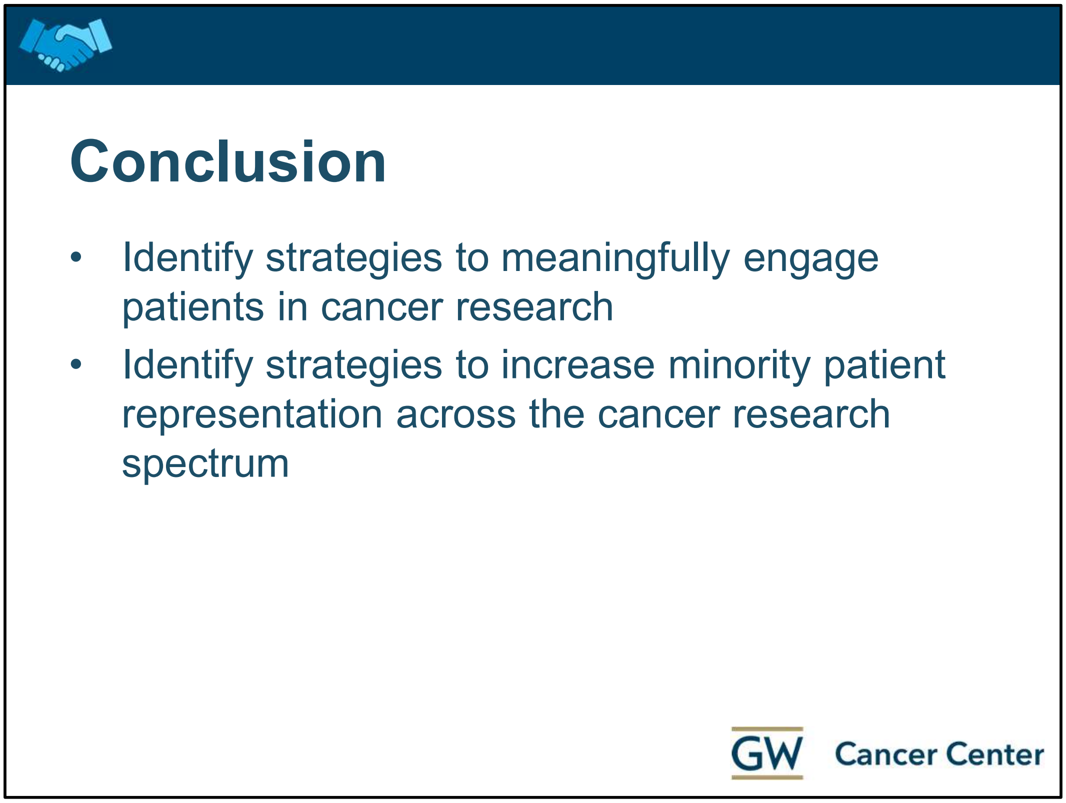
As we've discussed, patient engagement in research is crucial to the advancement of health and care of all communities.

Even if you are not directly involved in research, you have the opportunity to start conversations and open doors to cancer research participation.

If you are conducting research, we've highlighted the importance of building trust, drawing upon the skills and expertise of communities and designing inclusive research studies. In the next lesson, we will cover patient engagement in cancer care.

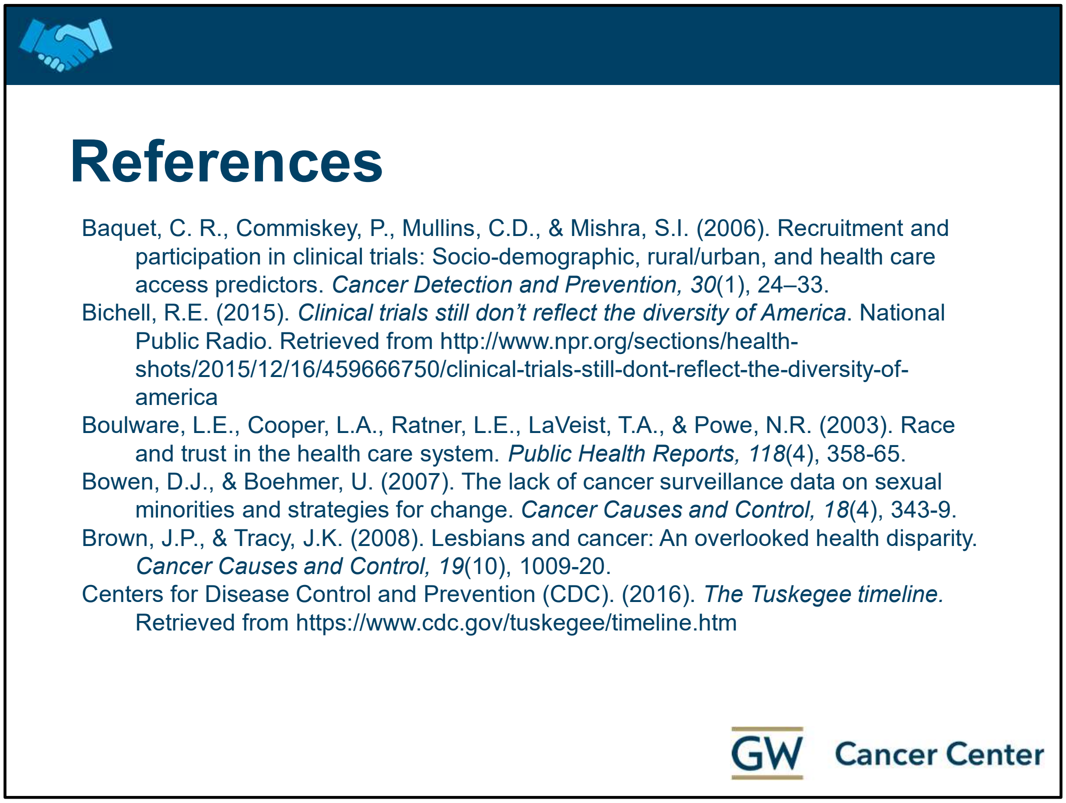


Conclusion

- Identify strategies to meaningfully engage patients in cancer research
- Identify strategies to increase minority patient representation across the cancer research spectrum

In this lesson, you learned to:

- Identify strategies to meaningfully engage patients in cancer research
- Identify strategies to increase minority patient representation across the cancer research spectrum



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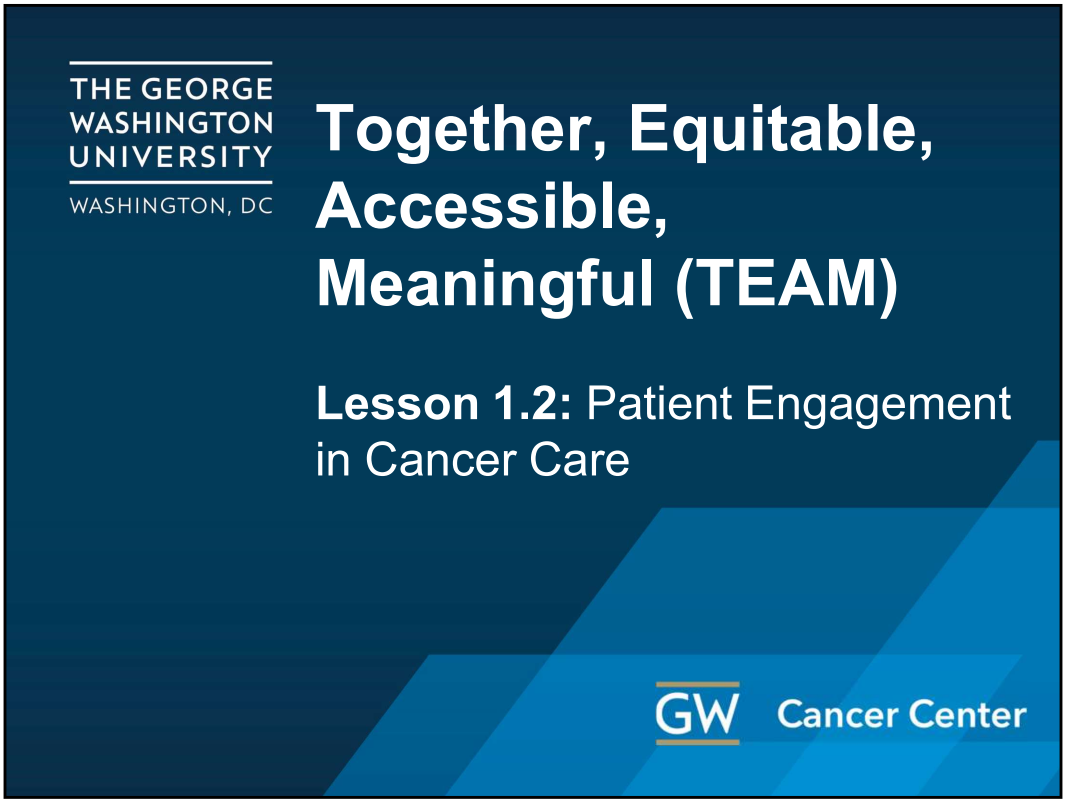

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Together, Equitable, Accessible, Meaningful (TEAM)

Lesson 1.2: Patient Engagement in Cancer Care

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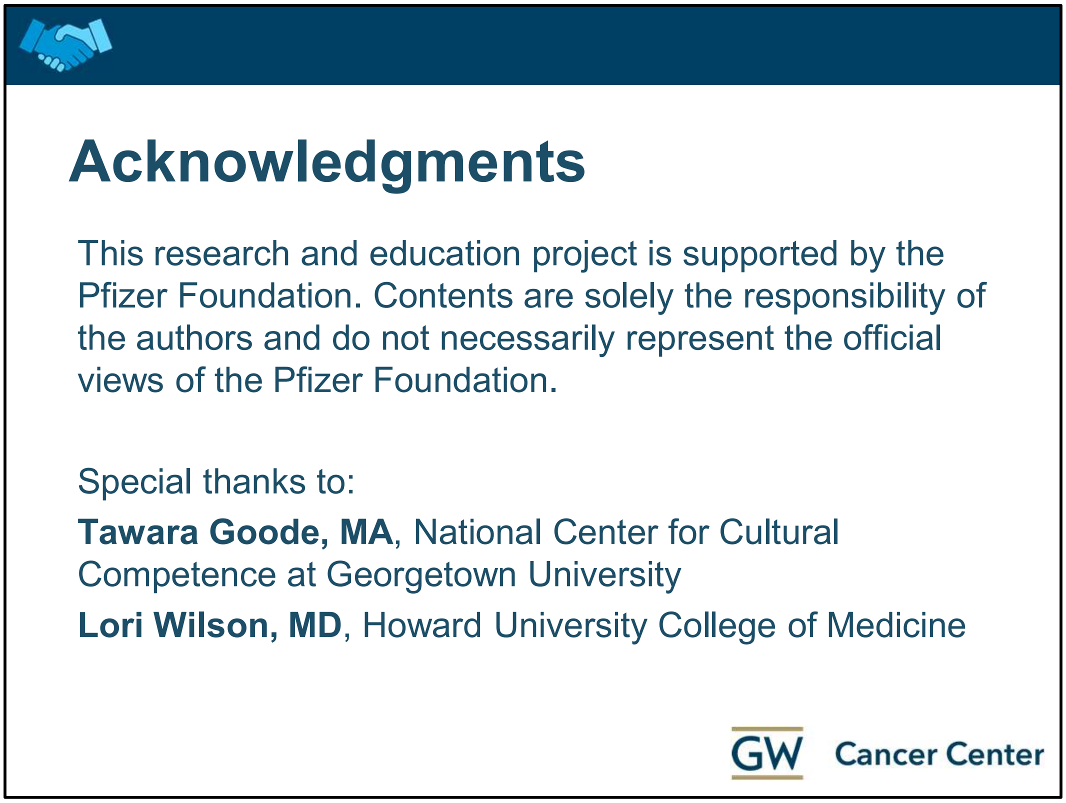
Welcome to Module 1, Lesson 2: Patient Engagement in Cancer Care



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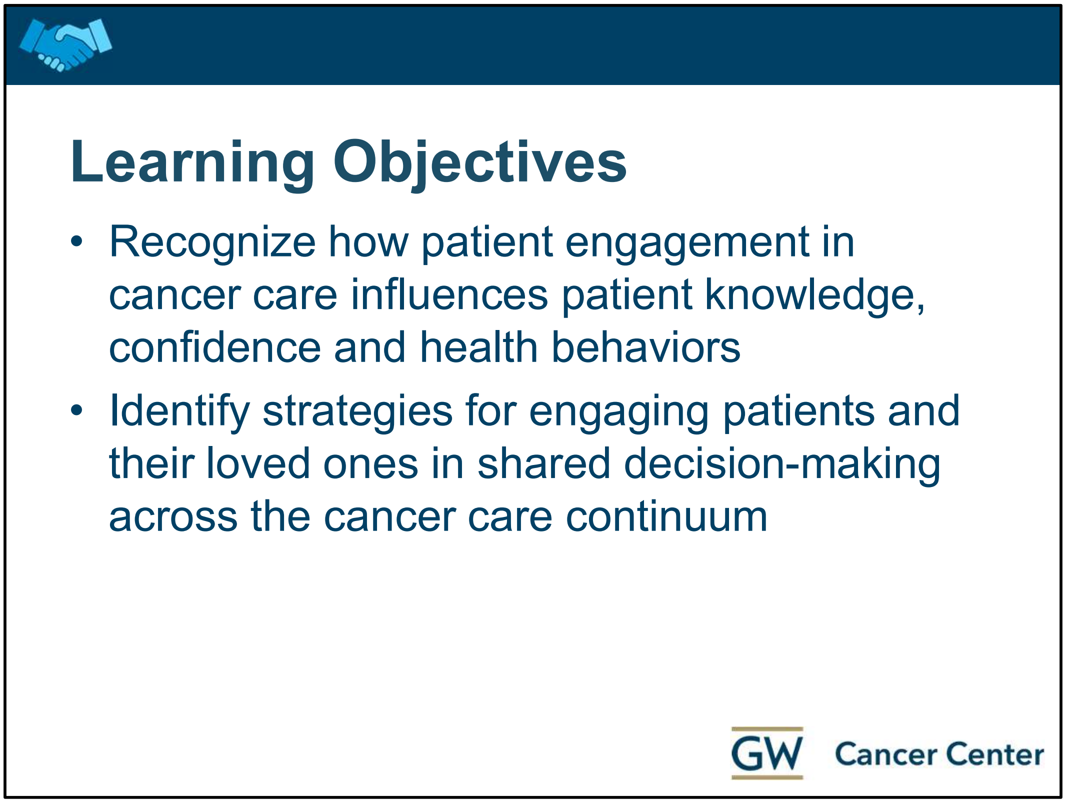

Learning Objectives

- Recognize how patient engagement in cancer care influences patient knowledge, confidence and health behaviors
- Identify strategies for engaging patients and their loved ones in shared decision-making across the cancer care continuum

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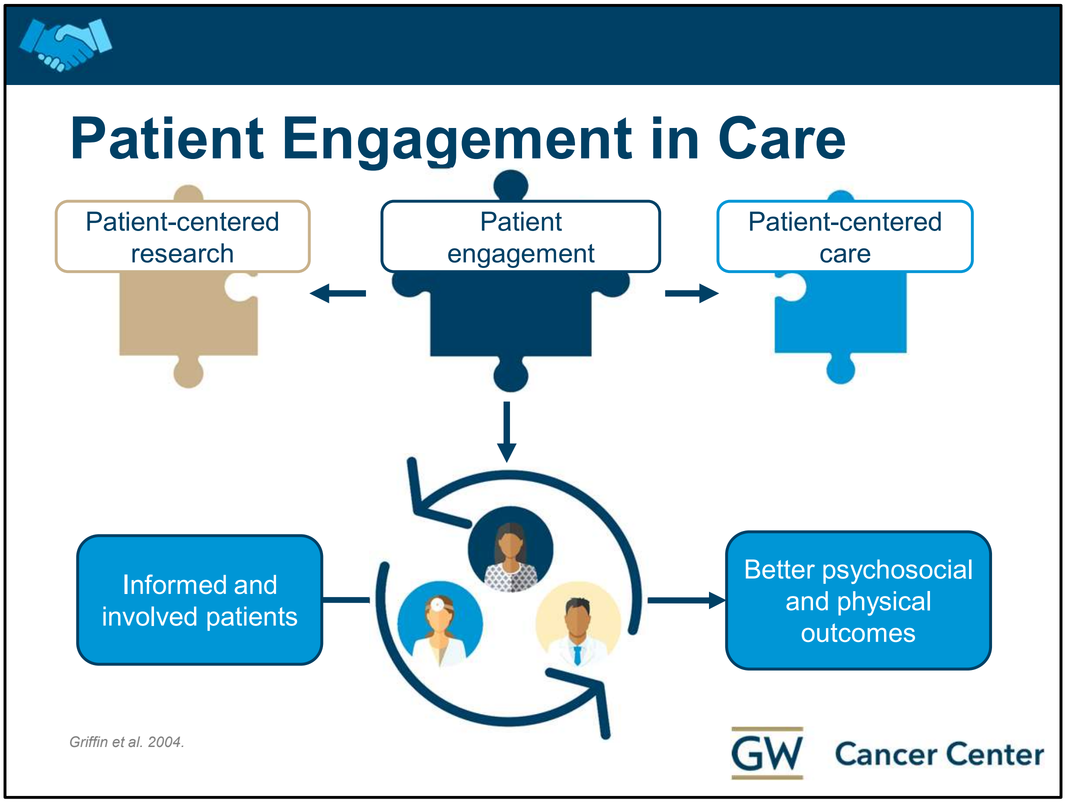
After completing this lesson, you will be able to:

- Recognize how patient engagement in cancer care influences patient knowledge, confidence and health behaviors

- Identify strategies for engaging patients and their loved ones in shared decision-making across the cancer care continuum



Patient Engagement in Care

Patient-centered research

Patient engagement

Patient-centered care

Informed and involved patients

Better psychosocial and physical outcomes

Griffin et al. 2004.

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As with research, there has been a growing emphasis on patient involvement in clinical care as a way to improve the quality of care and health of patients.

Studies have shown that more informed and involved patients may have better psychosocial and physical outcomes.

Furthermore, at the health system level, initiatives to promote patient-centered care have resulted in improved quality, safety and efficiency of care, reduced cost, and greater satisfaction of both patients and providers.

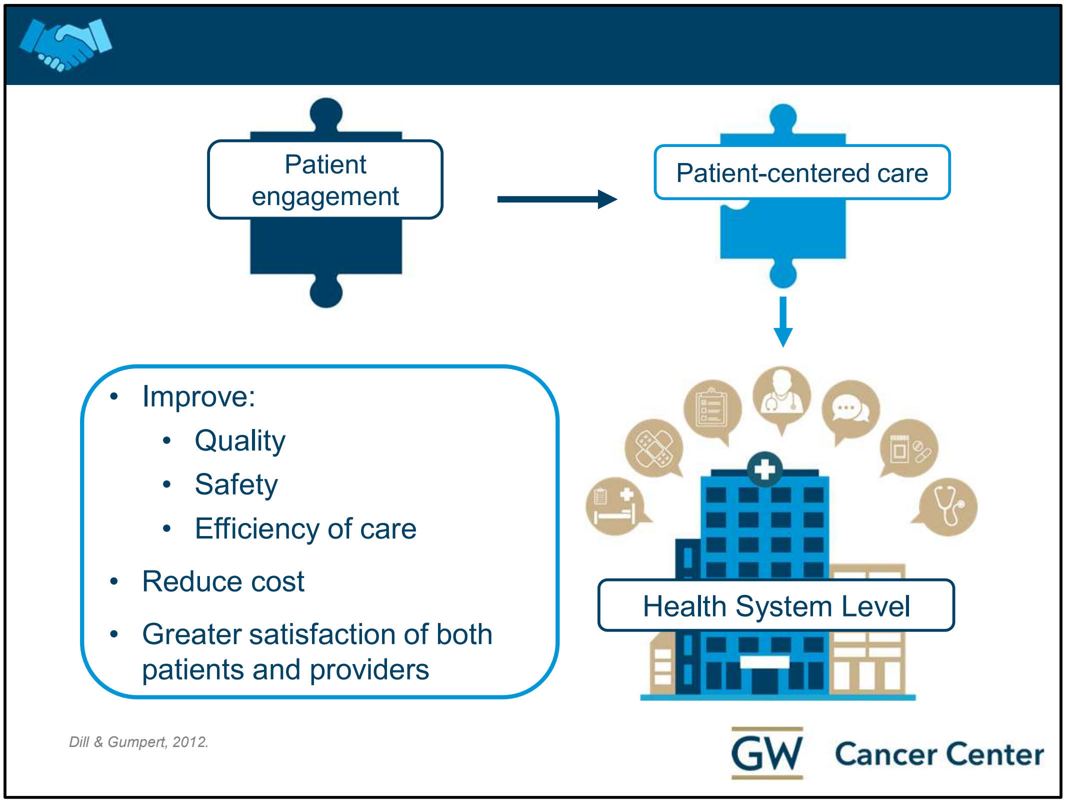
However, there are many levels and types of patient involvement in care.

For instance, increased patient activation refers to patients gaining the knowledge, skills and confidence necessary to manage their own health and health care. Yet, this does not necessarily mean that they are *contributing* to their health decisions.

In contrast, patient engagement refers to steps patients and providers take to have patients play a greater role in their health and care decision-making.

It is increasingly recognized that families or loved ones must be engaged in order to achieve patient-centered care.

Therefore, patient and family engaged care is “care planned, delivered, managed, and continuously improved in active partnership with patients and their families (or care partners as defined by the patient) to ensure integration of their health and health care goals, preferences, and values. It includes **explicit and partnered determination of goals and care options**, and it requires ongoing assessment of the care match with patient goals.”



Patient engagement

Patient-centered care

Health System Level

- Improve:
  - Quality
  - Safety
  - Efficiency of care
- Reduce cost
- Greater satisfaction of both patients and providers

Dill & Gumpert, 2012.

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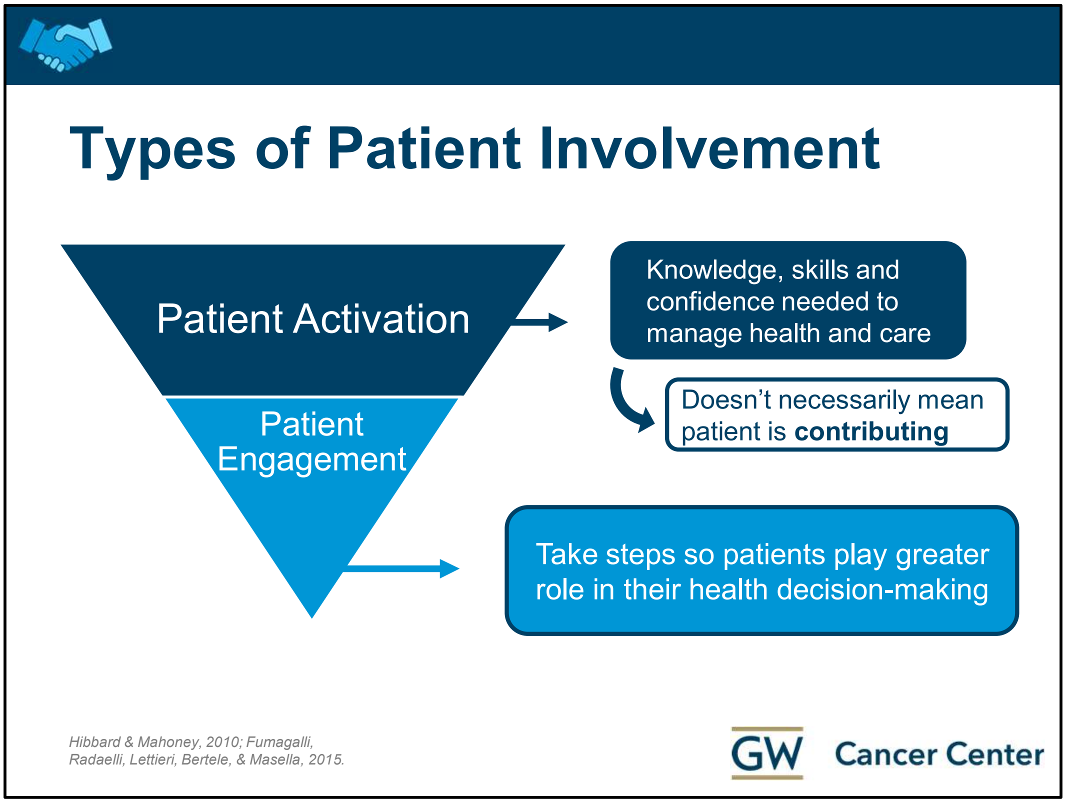

Types of Patient Involvement

Patient Activation

Knowledge, skills and confidence needed to manage health and care

Doesn’t necessarily mean patient is **contributing**

Patient Engagement

Take steps so patients play greater role in their health decision-making

Hibbard & Mahoney, 2010; Fumagalli, Radaelli, Lettieri, Bertele, & Masella, 2015.

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Patient and Family Engaged Care

Care that is:

Planned

Managed

Delivered

Continuously improved

Active partnership to integrate:
- Goals
- Preferences
- Values

Explicit determination of goals and care options

Ongoing assessment of care match with goals

Frampton et al., 2017.

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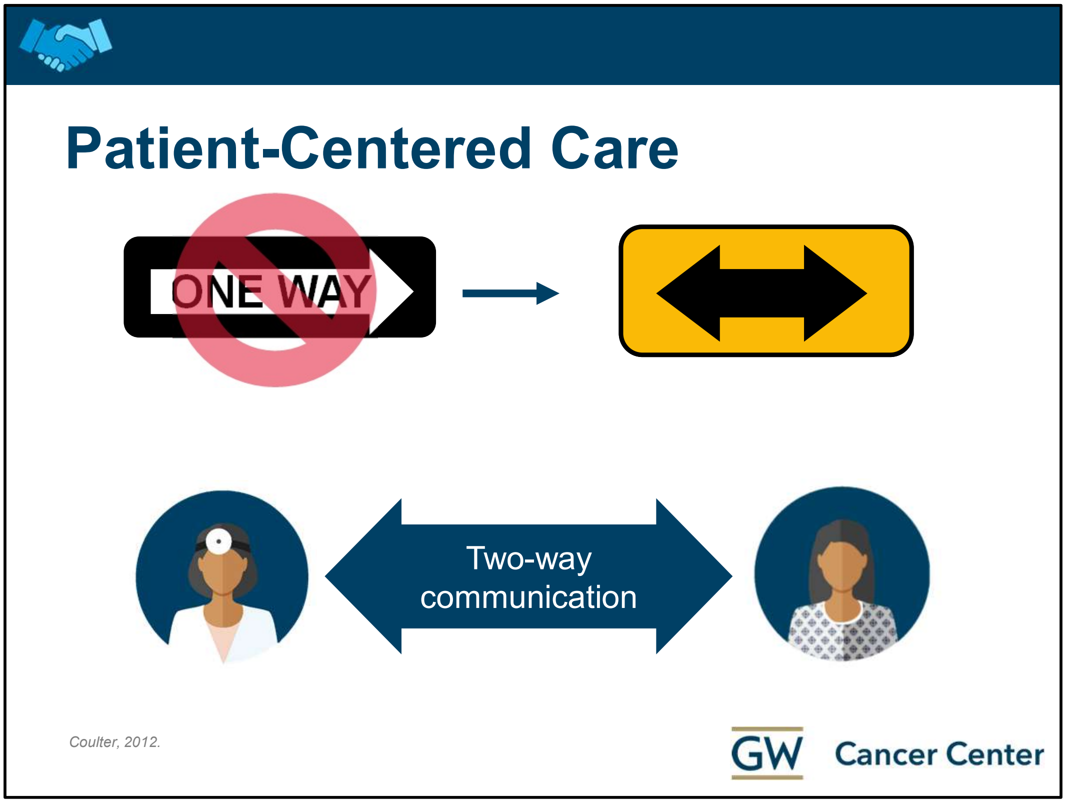

Patient-Centered Care

Two-way communication

Coulter, 2012.

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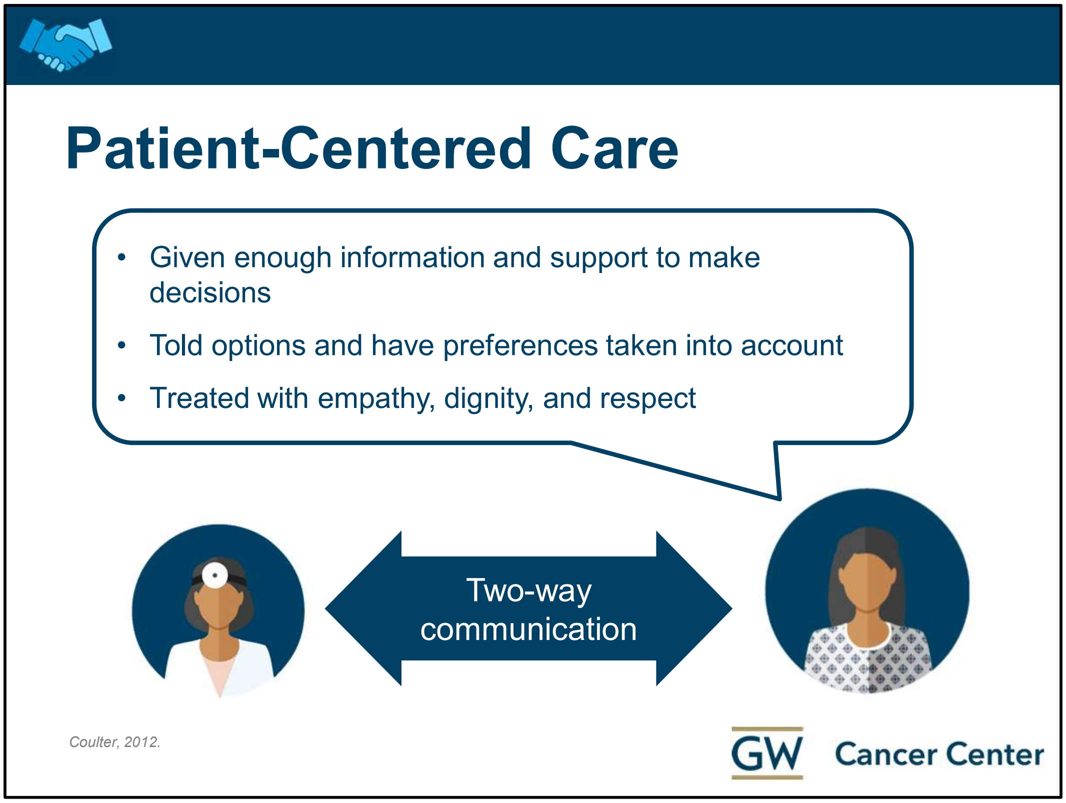
Patient-centered care moves away from a historical focus on treating disease to a model where the full patient is holistically cared for.

In contrast to the idea of the provider as the final decision-maker for treatment direction, patient-centered care involves two-way communication – from provider to patient and from patient to provider, as well.

So the question becomes: What makes communication between patients and health care professionals effective?

When patients were asked about their priorities for patient-centered care in the health care setting, they reported that they wanted to be:

- Given information and support to participate in decisions that affect them;
- Told options for treating and managing their health and have their preferences taken into account; and
- Treated with empathy, dignity and respect.

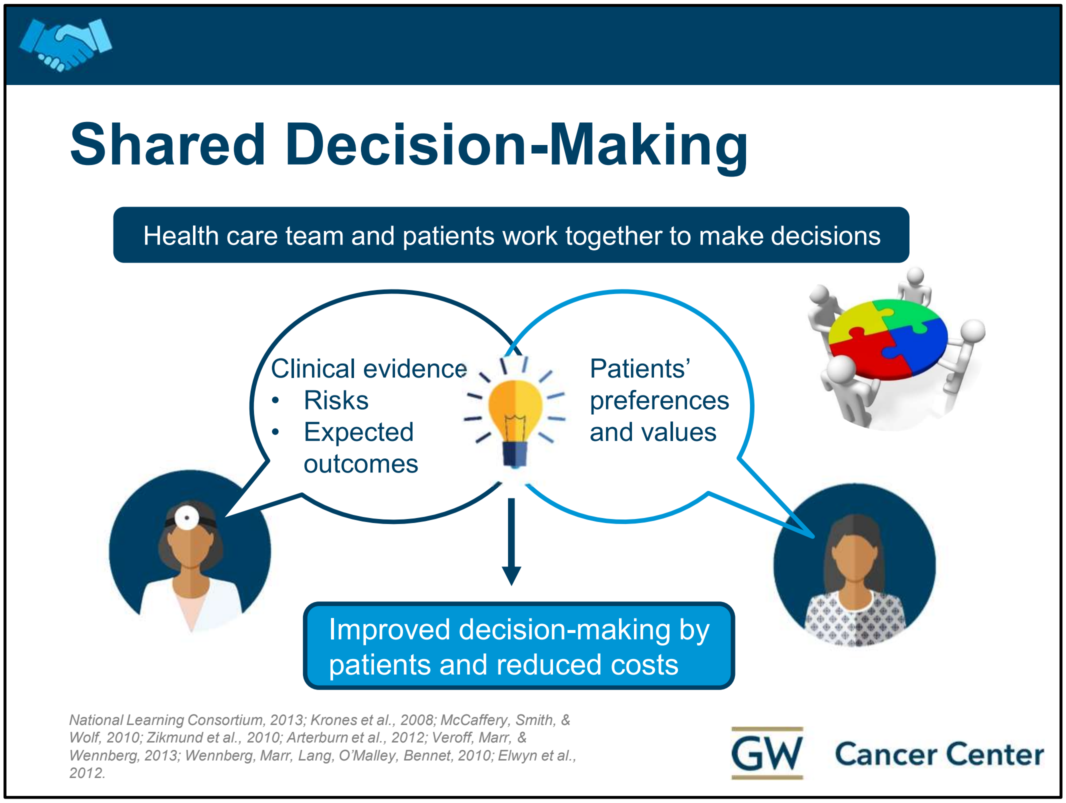


Patient-Centered Care

- Given enough information and support to make decisions
- Told options and have preferences taken into account
- Treated with empathy, dignity, and respect

Two-way communication

Coulter, 2012.



Shared Decision-Making

Health care team and patients work together to make decisions

Clinical evidence
- Risks
- Expected outcomes

Patients' preferences and values

Improved decision-making by patients and reduced costs

National Learning Consortium, 2013; Krones et al., 2008; McCaffery, Smith, & Wolf, 2010; Zikmund et al., 2010; Arterburn et al., 2012; Veroff, Marr, & Wennberg, 2013; Wennberg, Marr, Lang, O'Malley, Bennet, 2010; Elwyn et al., 2012.

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These priorities reflect the idea of shared decision-making among patients and providers.

Shared decision-making is a process in which the health care team and patients work together.

Together, they make decisions and select tests, treatments and care plans based on clinical evidence that balances risks and outcomes and includes patient preferences and values. Shared-decision making has been shown to lead to improved decision-making by patients and reduced costs.

Shared decision-making is aided by team-based care.

This requires ongoing, clear and coordinated communication among the patient, their loved ones and all health care professionals. It involves discussions about patients' goals, preferences, needs and values, as well as providers' assessments of health and care options.

It is ultimately based on a discussion of "what matters most to patients," such as being able to continue to work, being able to be present for an important milestone in a loved one's life or incorporating one's faith or spiritual beliefs into the treatment process.

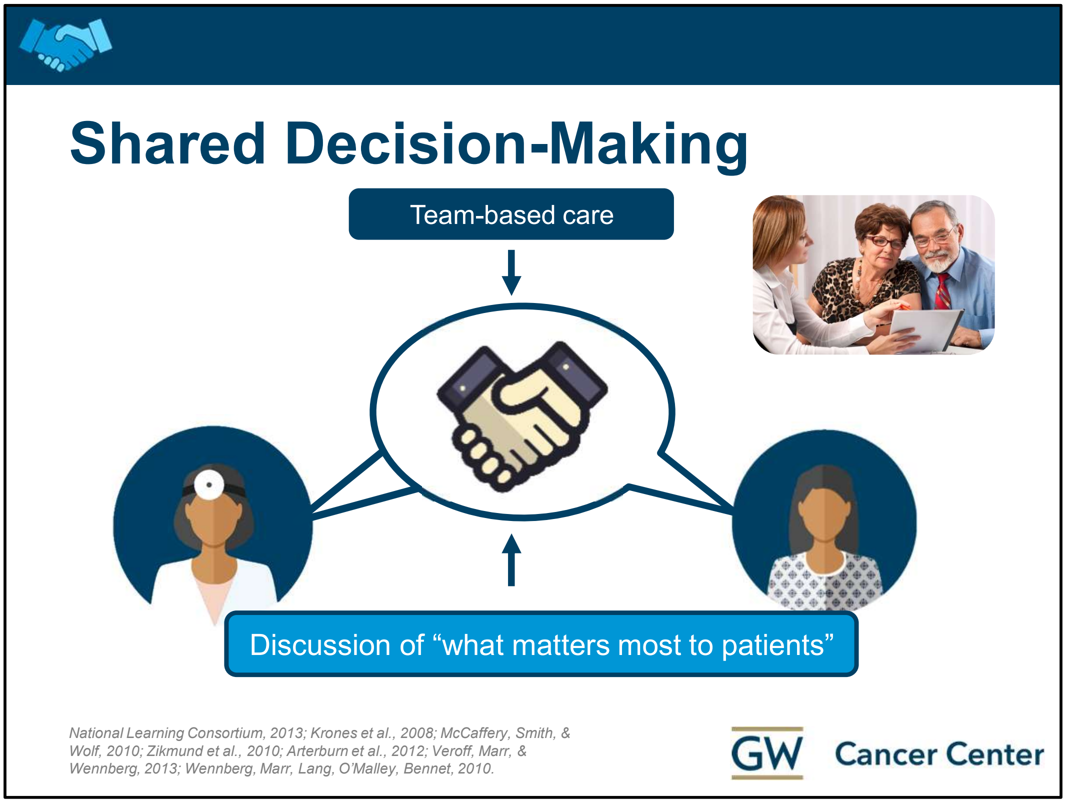
Strategies health care professionals can use to engage patients in these two-way conversations include:

- ask open-ended questions
- ask the patient’s perspective (for instance, what they believe is the cause of their disease and treatment preferences)
- confirm understanding of patients’ views and
- speak with empathy.

However, some things can make communication ineffective and pose barriers to shared decision-making.

For example, providers may use jargon that patients do not understand. Or they may have time constraints that limit them from having substantive discussions with patients.

Patients – particularly those recently diagnosed with cancer – may be overcome with emotions and unable to process information.



Shared Decision-Making

Team-based care

Discussion of “what matters most to patients”

National Learning Consortium, 2013; Krones et al., 2008; McCaffery, Smith, & Wolf, 2010; Zikmund et al., 2010; Arterburn et al., 2012; Veroff, Marr, & Wennberg, 2013; Wennberg, Marr, Lang, O'Malley, Bennet, 2010.

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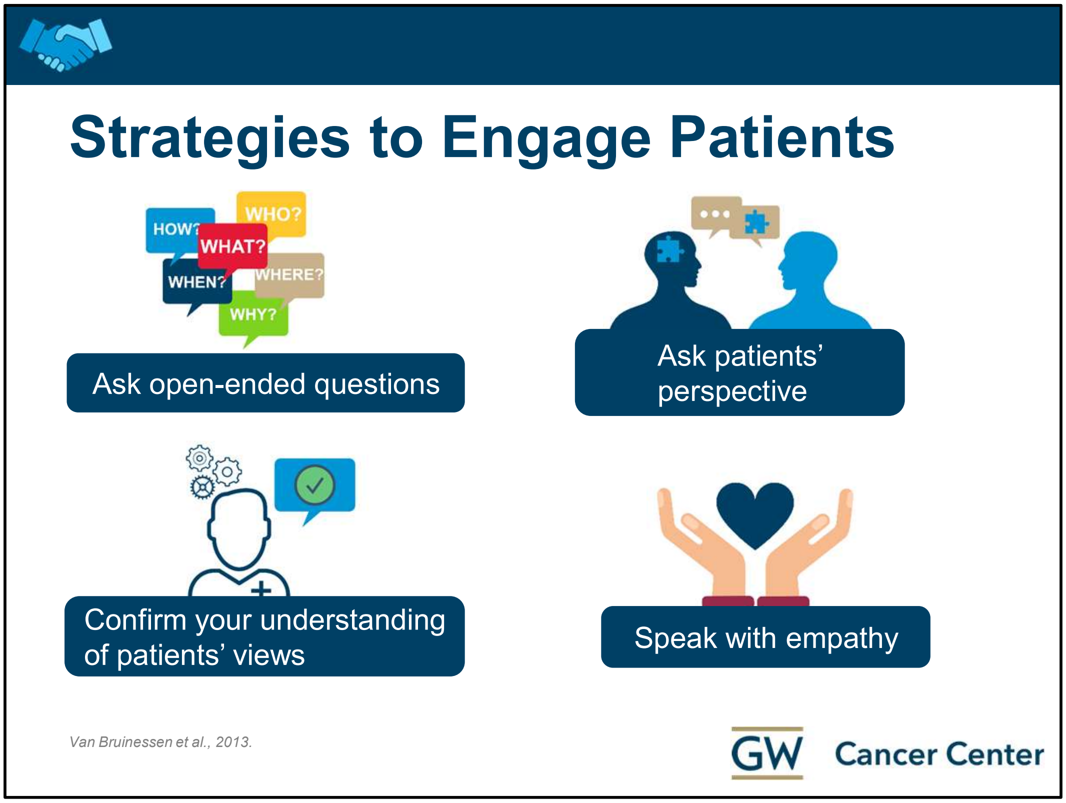

Strategies to Engage Patients

Ask open-ended questions

Ask patients' perspective

Confirm your understanding of patients' views

Speak with empathy

Van Bruinessen et al., 2013.

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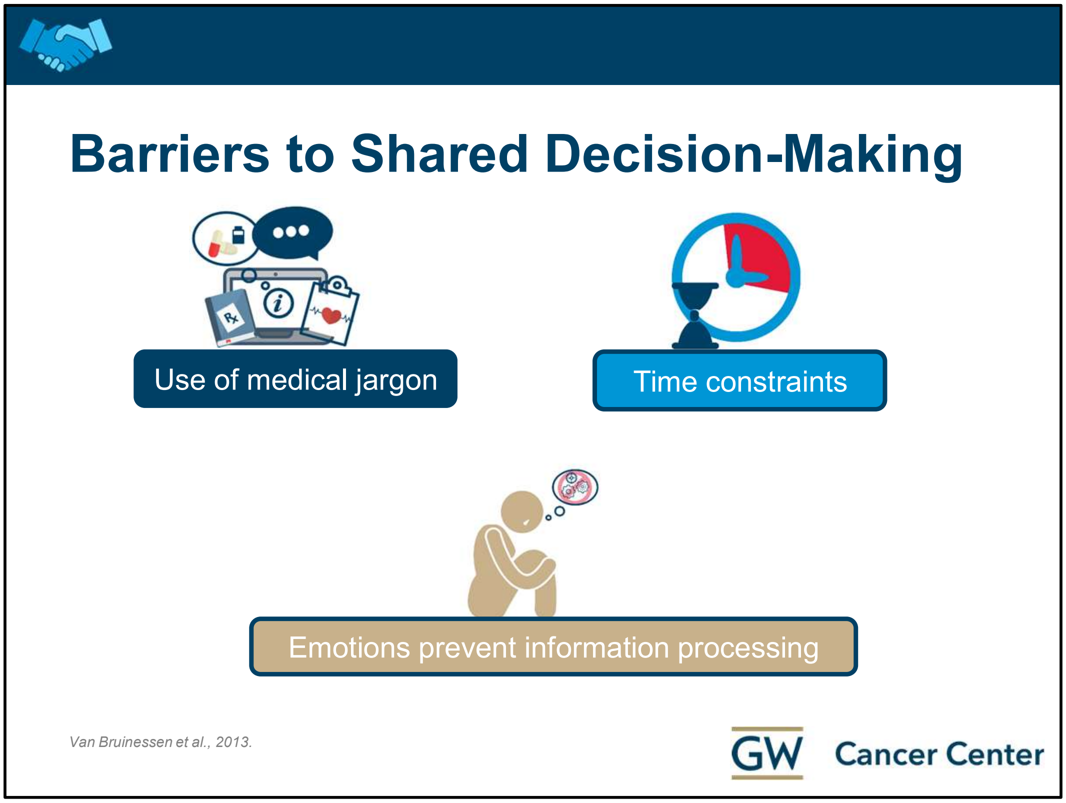

Barriers to Shared Decision-Making

- Use of medical jargon
- Time constraints
- Emotions prevent information processing

Van Bruinessen et al., 2013.

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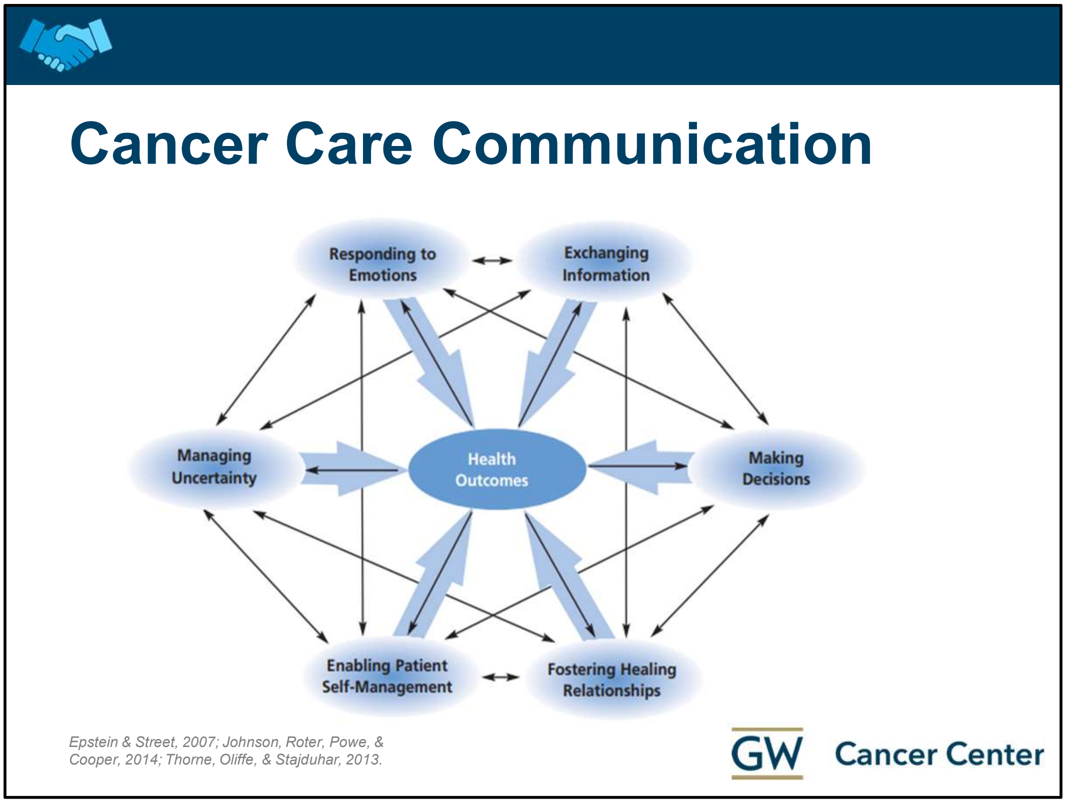

Cancer Care Communication

Responding to Emotions

Exchanging Information

Managing Uncertainty

Health Outcomes

Making Decisions

Enabling Patient Self-Management

Fostering Healing Relationships

Epstein & Street, 2007; Johnson, Roter, Powe, & Cooper, 2014; Thorne, Oliffe, & Stajduhar, 2013.

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Therefore, the NCI has a model for cancer care communication to support shared decision-making that considers these factors. It identifies six elements of communication that are interconnected:

- exchanging information
- responding to emotions
- managing uncertainty
- enabling patient self-management
- fostering healing relationships and
- making decisions.

Each of these factors influence and are influenced by an individual’s health outcomes.

While this model was originally developed for clinicians, one could apply elements of this model more broadly to non-clinical staff as well. For example, clinical and non-clinical staff can foster healing relationships by being aware of:

- How verbally dominant we are (or how many statements we make compared to how many patients make);

- The tone we are using (for instance, how interested or attentive we are to patient points of view, how friendly or warm we are or how sympathetic or empathetic we are to patient experiences); and

- The environment we are creating. A positive environment will be set if we recognize the patient and their needs as unique, value patient contributions to decisions, portray ourselves as advisors to patients rather than a sole decision-maker and include discussions of hope.

By using communication to signal this partnership with patients, health care professionals can take steps to address all of the other aspects noted in the model – exchanging information, responding to emotions, managing uncertainty, facilitating patient self-management and making decisions – and ultimately work towards improving the patient's health outcomes.

For example, in the National Cancer Care TEAM Survey, one patient navigator described their role and how they foster healing relationships with cancer patients as follows: "The role of the navigator is to advocate for and link patients to resources to remove barriers to care regardless of race, sexual orientation, religious views, etc. Lung cancer is a huge burden in my state and I meet with many patients who are smokers and sometimes inquire about smoking cessation resources and tools.

I find they sometimes apologize or offer explanations on why they smoke or make statements like 'I know I need to quit.' I always try to build rapport with them and gain their trust by reassuring them that I am not here to judge them but rather to help and support them."

Fostering Healing Relationships

Foster healing relationships by being aware of:

- Verbal dominance
- Tone of voice
- Environment created

Epstein & Street, 2007; Johnson, Roter, Powe, & Cooper, 2014; Thorne, Oliffe, & Stajduhar, 2013.

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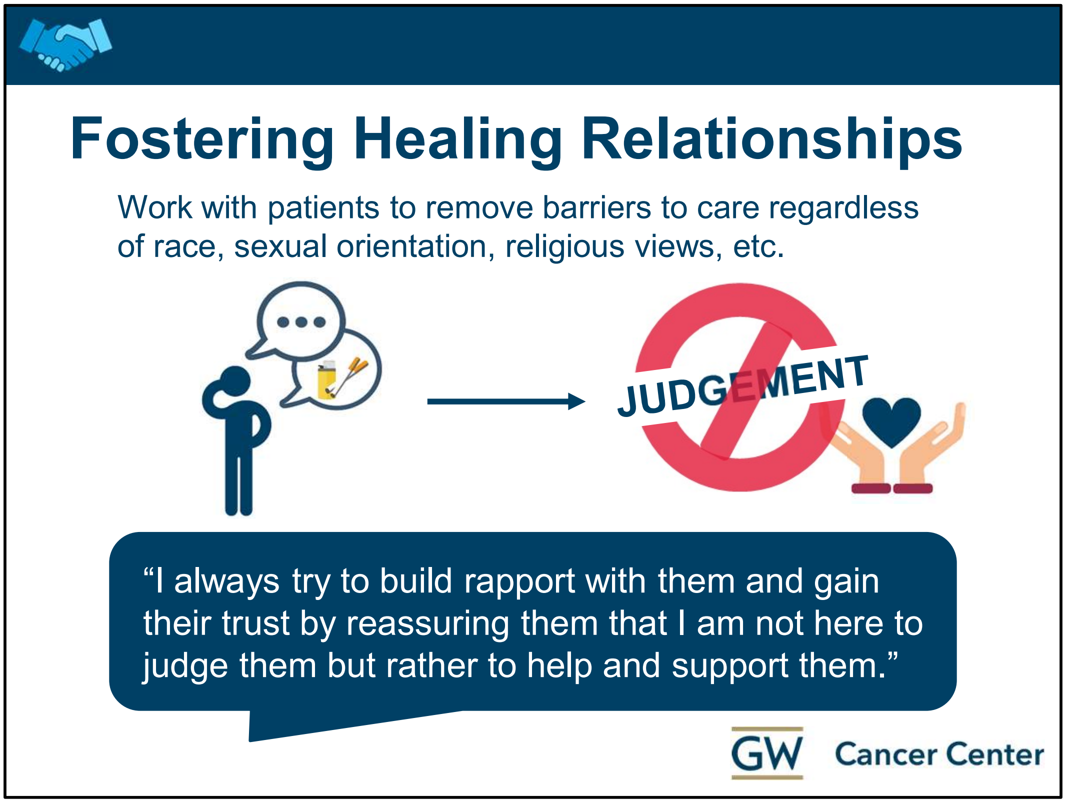

Fostering Healing Relationships

Work with patients to remove barriers to care regardless of race, sexual orientation, religious views, etc.

"I always try to build rapport with them and gain their trust by reassuring them that I am not here to judge them but rather to help and support them."

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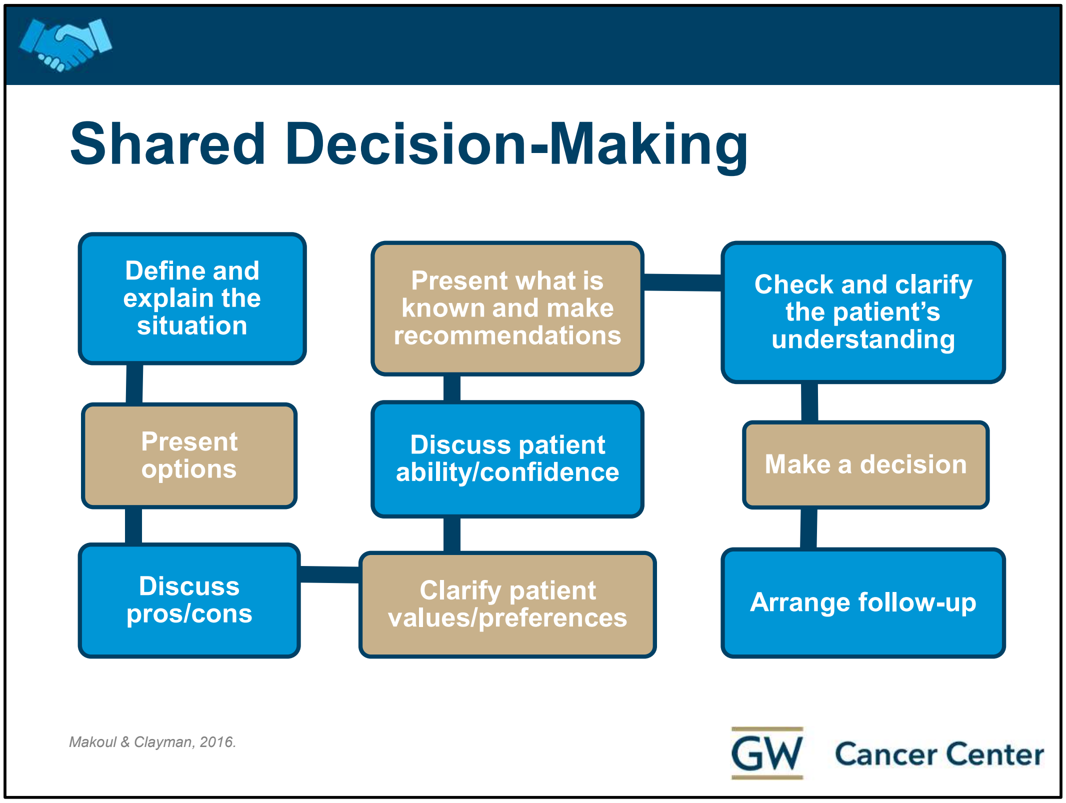

Shared Decision-Making

Define and explain the situation

Present options

Discuss pros/cons

Clarify patient values/preferences

Discuss patient ability/confidence

Present what is known and make recommendations

Check and clarify the patient's understanding

Make a decision

Arrange follow-up

Makoul & Clayman, 2016.

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The NCI model helps us think about communication through an inter-connected approach, but we can also think of shared decision-making through a stepwise approach.

A helpful guide to patient-centered consultations with patients includes the following nine actions:

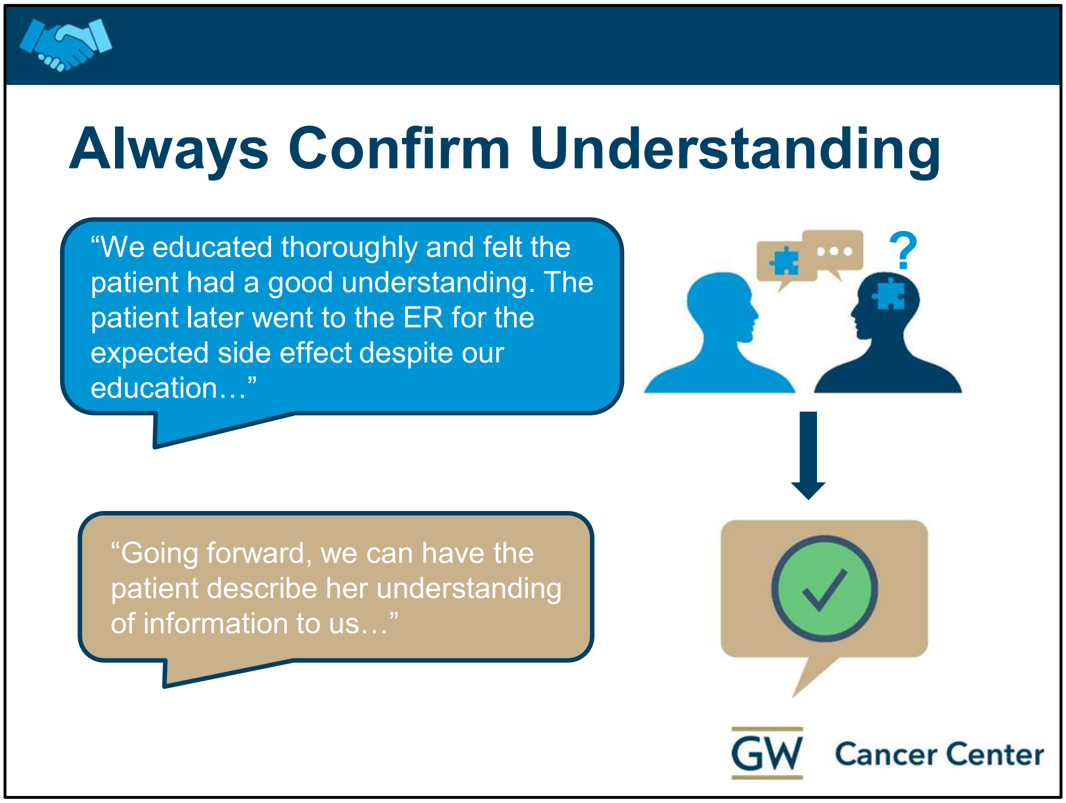
- Define and explain the situation
- present options
- discuss pros and cons (like benefit, risk and cost)
- clarify patient values and preferences
- discuss patient ability and confidence
- present what is known and make recommendations
- check and clarify the patient's understanding
- make or explicitly defer a decision

- and arrange follow-up.

An example of what can happen when the health care team is not checking and clarifying a patient’s understanding comes from the National Cancer Care TEAM Survey.

A provider said, “We were giving chemotherapy with a very specific side effect to a patient for whom English was a second language. We educated thoroughly and felt the patient had a good understanding.

The patient later went to the ER for the expected side effect despite our education. Going forward, we can have the patient describe her understanding of information to us and review what we've told her, so that we know there is full understanding.”



Always Confirm Understanding

"We educated thoroughly and felt the patient had a good understanding. The patient later went to the ER for the expected side effect despite our education…"

"Going forward, we can have the patient describe her understanding of information to us…"

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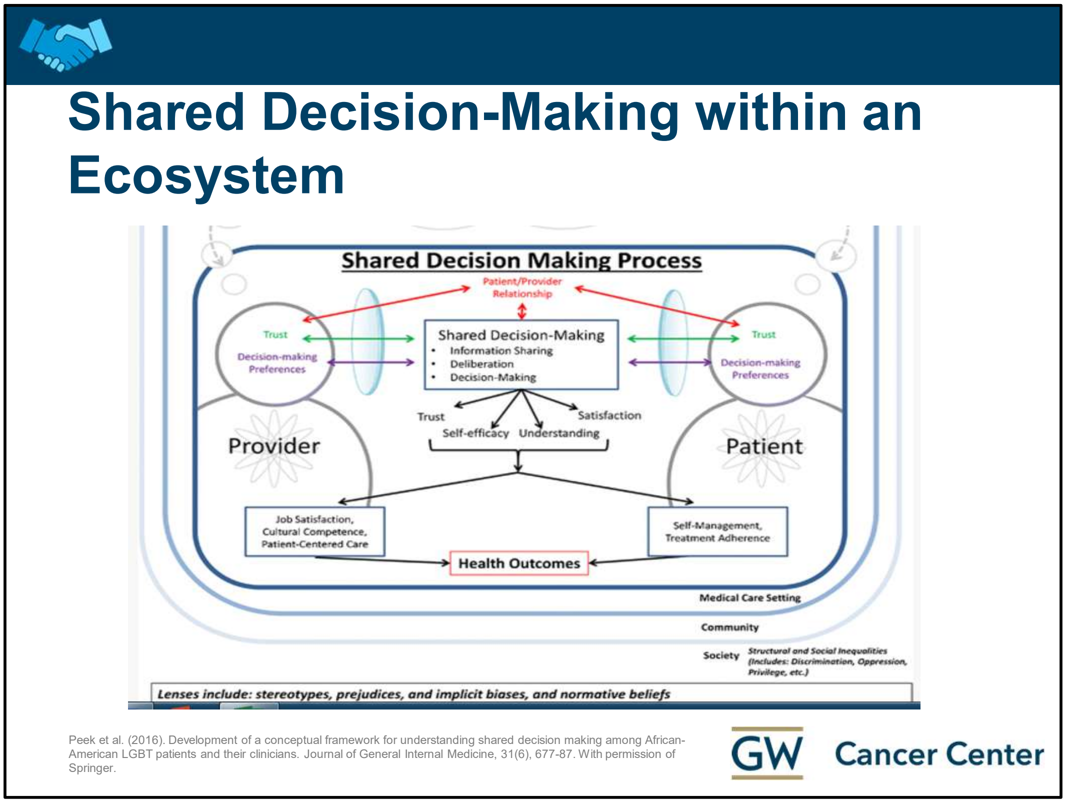

Shared Decision-Making within an Ecosystem

Peek et al. (2016). Development of a conceptual framework for understanding shared decision making among African-American LGBT patients and their clinicians. Journal of General Internal Medicine, 31(6), 677-87. With permission of Springer.

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We’ve thought about shared decision-making as an inter-connected approach and as a nine-step process with patients.

Shared decision-making is a process that happens in the health care setting, but it is influenced by factors outside of the health care setting, such as geographic location, physical and financial resources of the patient and their community, the cultural context and political climate.

For example, in the National Cancer Care TEAM Survey, one provider said, “I had a patient that came from a homeless shelter for his treatments and it was very difficult to try and talk with him about home support and comfort because he didn't really have any of that.

Sending a patient ‘home’ to the comfort of a house and bathroom facilities, etc. is something that we take for granted and there were no guarantees that he would have that every day.

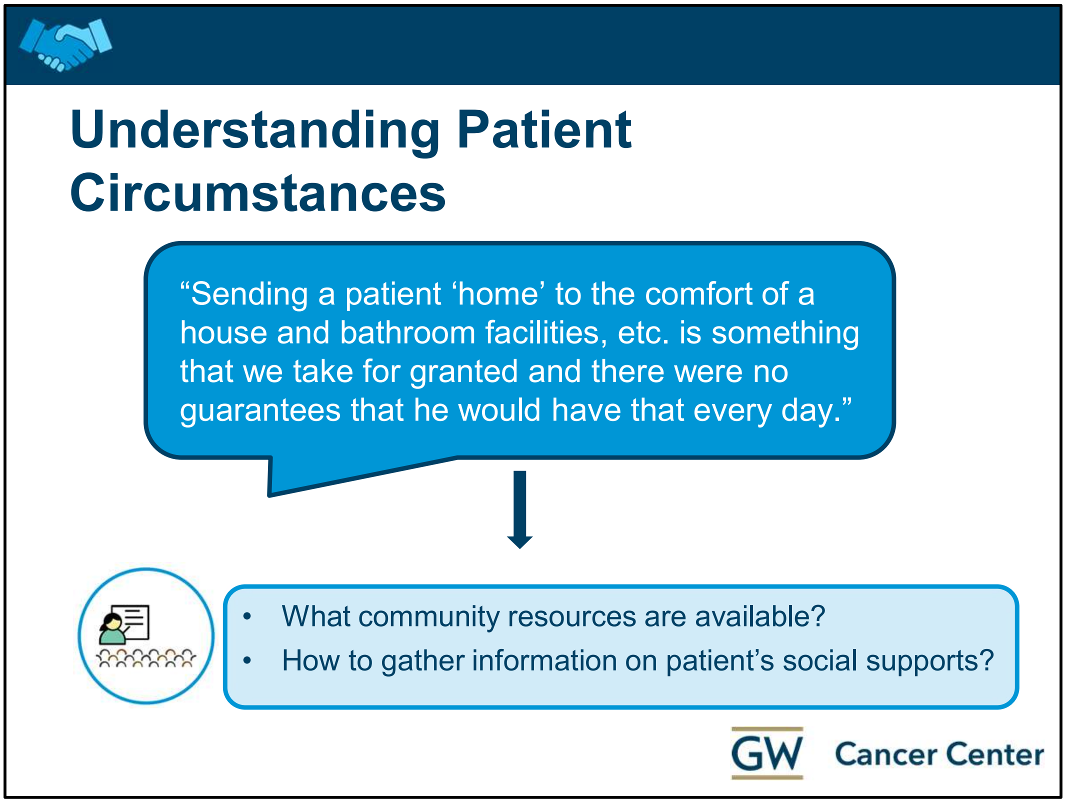
I think [having] better training [on] community resources that are available as well as how to elicit information from a patient about any family that may be able to help in some manner or what or who could help them would be useful information to gather.”

If we zoom into the figure depicting shared-decision making from this larger model of the ecosystem, we find that being able to engage in shared decision-making is dependent upon:

- the decision-making preferences of the patient and provider
- trust between patient and provider and
- their relationship

Ideally, patients and providers will experience increased trust and self-efficacy in their roles in the care team and understanding of and satisfaction in the care provided immediately following this process of shared decision-making.

Patients can gain a greater ability to manage their health and providers gain a greater ability to deliver culturally competent, patient-centered care – both of which lead to positive health outcomes for the patient.



Understanding Patient Circumstances

> “Sending a patient ‘home’ to the comfort of a house and bathroom facilities, etc. is something that we take for granted and there were no guarantees that he would have that every day.”

- What community resources are available?
- How to gather information on patient’s social supports?

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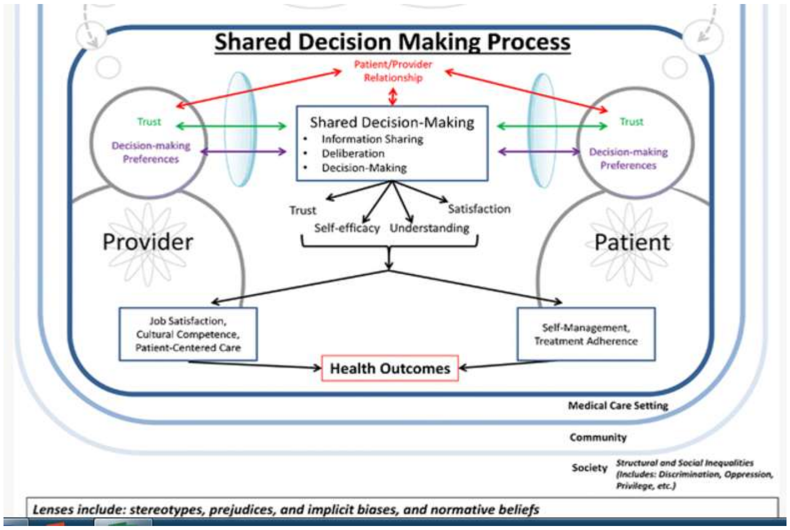
Shared Decision-Making



Peek et al. (2016). Development of a conceptual framework for understanding shared decision making among African-American LGBT patients and their clinicians. Journal of General Internal Medicine, 31(6), 677-87. With permission of Springer.

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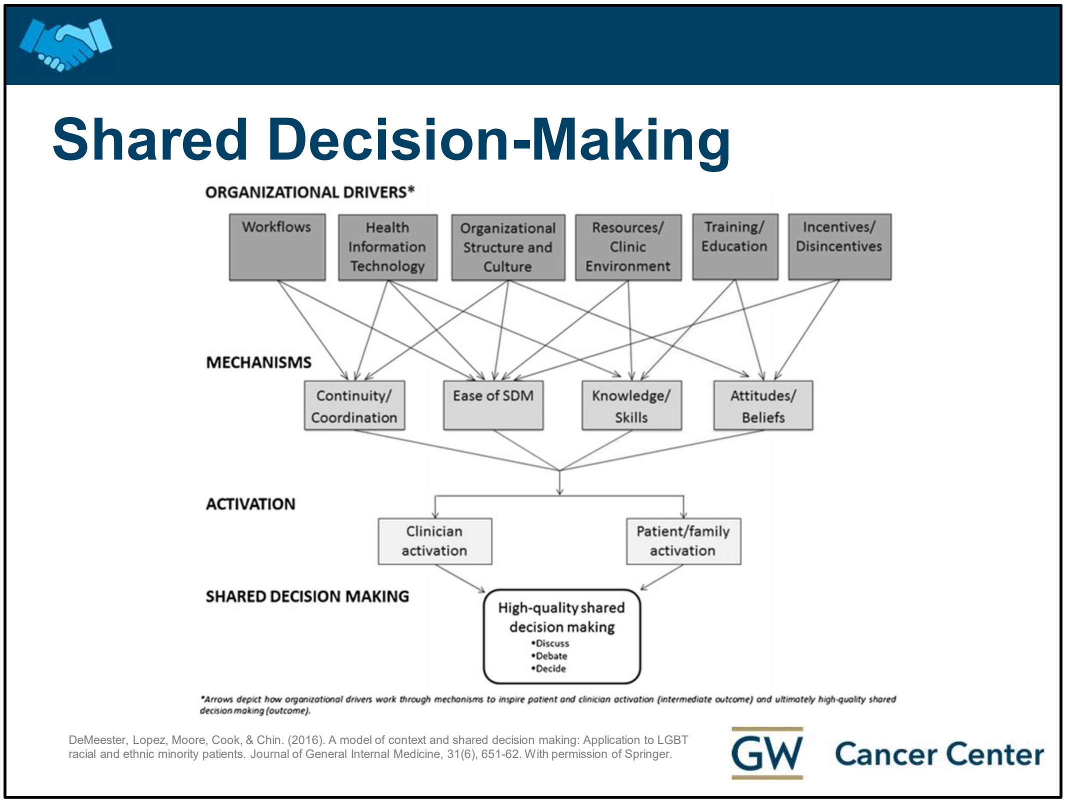

Shared Decision-Making

ORGANIZATIONAL DRIVERS*

Workflows
Health Information Technology
Organizational Structure and Culture
Resources/ Clinic Environment
Training/ Education
Incentives/ Disincentives

MECHANISMS

Continuity/ Coordination
Ease of SDM
Knowledge/ Skills
Attitudes/ Beliefs

ACTIVATION

Clinician activation
Patient/family activation

SHARED DECISION MAKING

High-quality shared decision making
- Discuss
- Debate
- Decide

*Arrows depict how organizational drivers work through mechanisms to inspire patient and clinician activation (intermediate outcome) and ultimately high-quality shared decision making (outcome).

DeMeester, Lopez, Moore, Cook, & Chin. (2016). A model of context and shared decision making: Application to LGBT racial and ethnic minority patients. Journal of General Internal Medicine, 31(6), 651-62. With permission of Springer.

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At an organizational level, health care organizations can promote shared decision-making by creating an environment that supports the ability and willingness of patients and providers to engage in shared decision-making. Six factors at the organizational level drive shared decision-making:

- workflows and procedures
- health information technology
- organizational structure and culture
- clinical resources and the physical environment
- training and education
- and incentives or disincentives for engaging in shared decision-making.

In addition to these organizational levers, providers can employ these four strategies to support shared decision-making:

- Promote coordination of care among various health care team members;

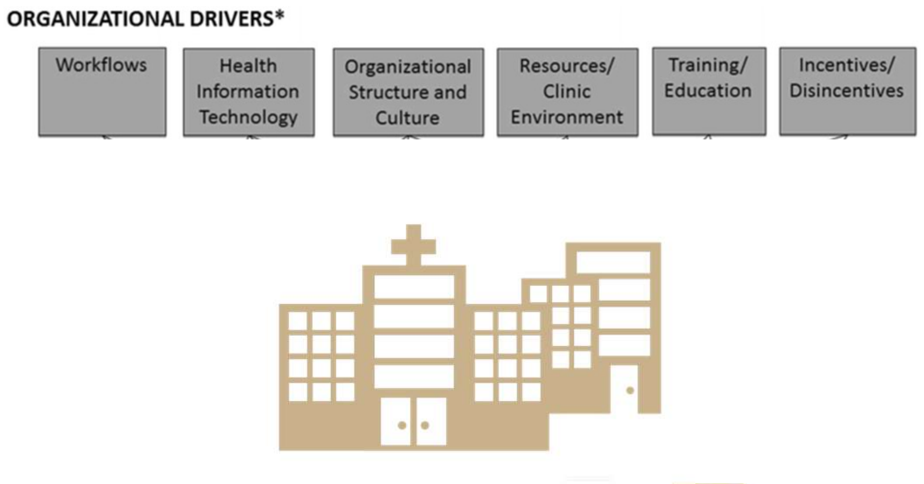
- Facilitate shared decision-making by integrating it into the culture and day-to-day operations of the facility;

- Improve their knowledge and skills as providers and educate patients to support their engagement in care decisions; and

- Promote attitudes and beliefs that support shared decision-making, such as the belief that shared decision-making will improve health outcomes.

Throughout the rest of this training, we will provide more in-depth discussion of how organizations and providers can support shared decision-making.

Organizational Drivers



ORGANIZATIONAL DRIVERS*

- Workflows
- Health Information Technology
- Organizational Structure and Culture
- Resources/ Clinic Environment
- Training/ Education
- Incentives/ Disincentives

DeMeester, Lopez, Moore, Cook, & Chin, 2016.

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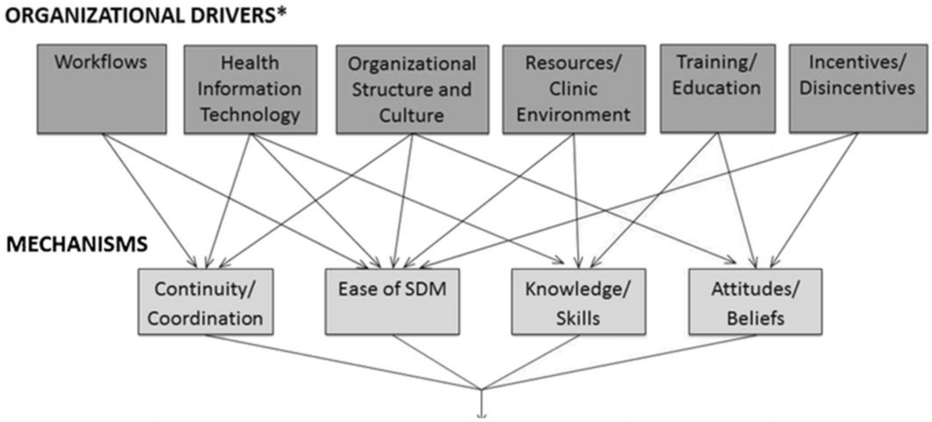
Mechanisms



ORGANIZATIONAL DRIVERS*

Workflows

Health Information Technology

Organizational Structure and Culture

Resources/ Clinic Environment

Training/ Education

Incentives/ Disincentives

MECHANISMS

Continuity/ Coordination

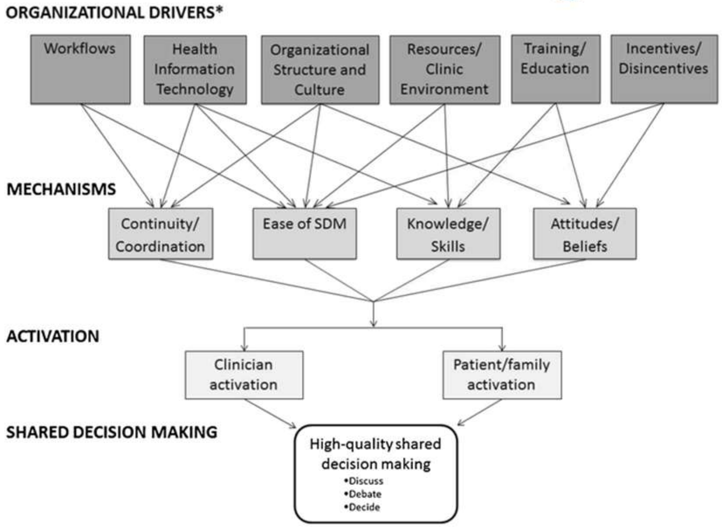
Ease of SDM

Knowledge/ Skills

Attitudes/ Beliefs

DeMeester, Lopez, Moore, Cook, & Chin, 2016.

Shared Decision-Making



ORGANIZATIONAL DRIVERS*

Workflows

Health Information Technology

Organizational Structure and Culture

Resources/ Clinic Environment

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High-quality shared decision making

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- Decide

DeMeester, Lopez, Moore, Cook, & Chin, 2016.

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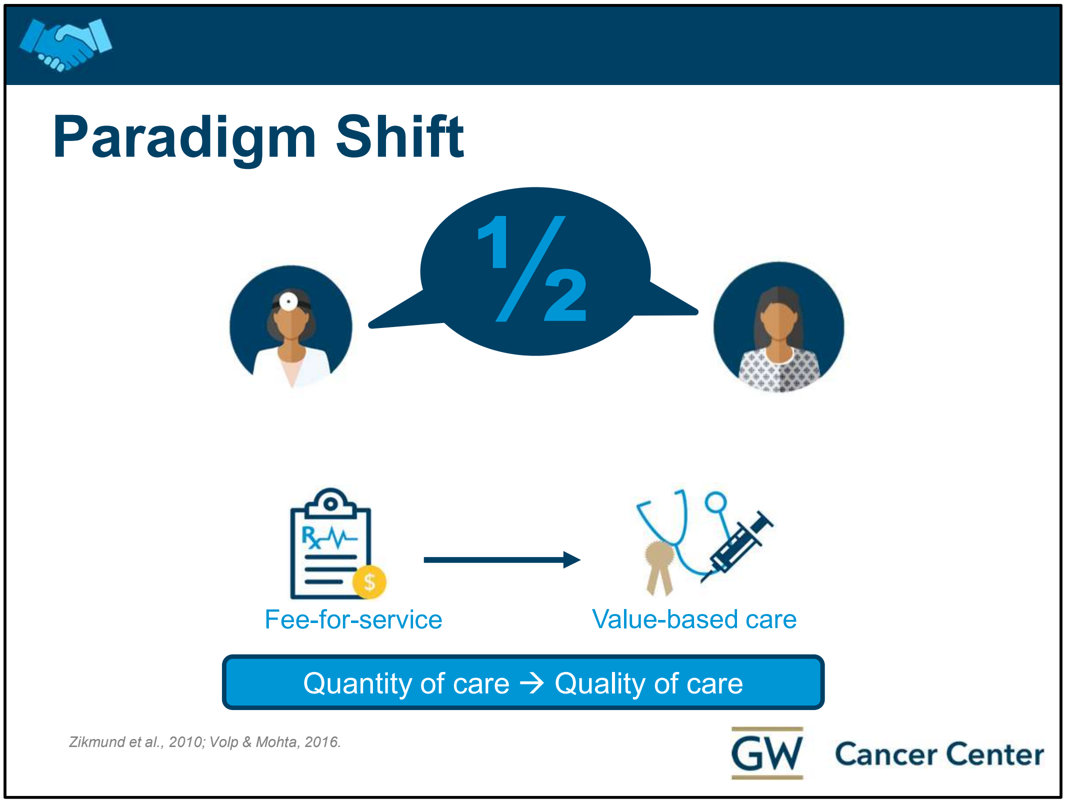

Paradigm Shift

½

Fee-for-service → Value-based care

Quantity of care → Quality of care

Zikmund et al., 2010; Volp & Mohta, 2016.

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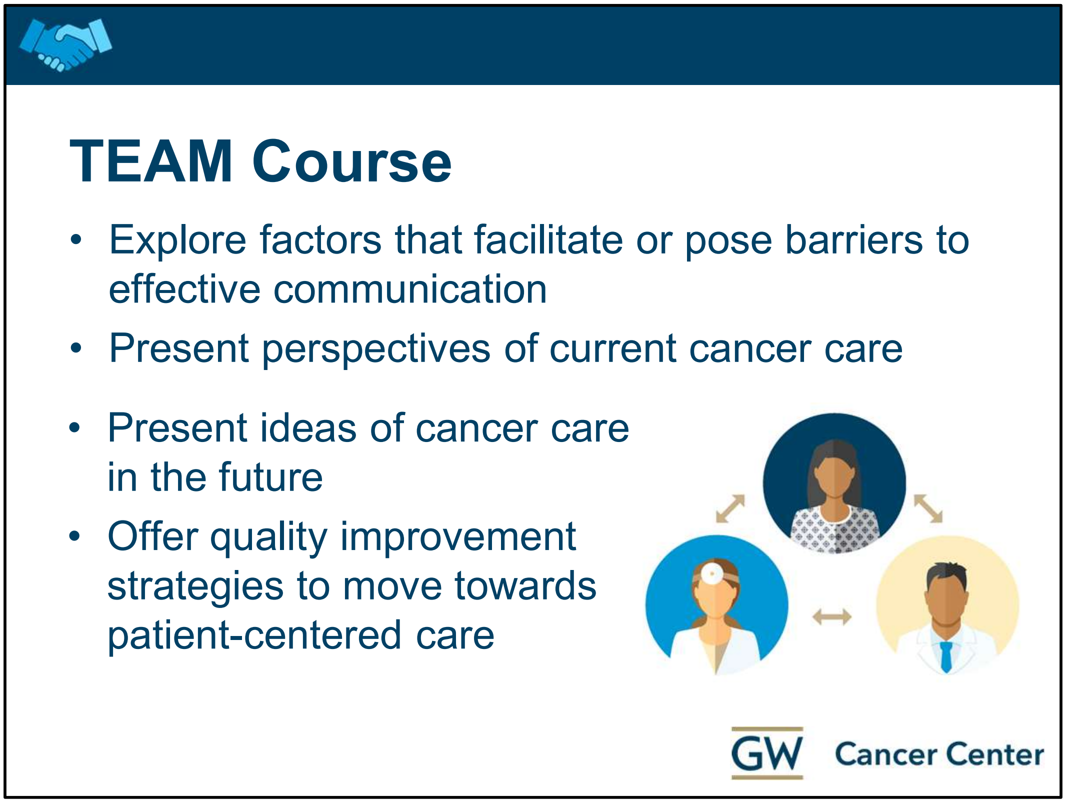
Shared decision-making is increasingly recognized as important for promoting better care, health and research. But it is not the norm in our current health care or public health systems.

For instance, a nationally representative survey found that only around half of medical decisions were shared between patients and providers. While many providers recognize the importance of patient engagement in decisions and seek to engage their patients, they report not having enough time with patients to adequately inform and engage them in care decisions.

But, it is important to note that many individuals with cancer may not be equipped or feel comfortable in engaging in their care. In the last half of the training, we will discuss specific strategies to help meet patients needs so they have the opportunity to engage in their care.

There are also policies and financial incentives being implemented that have started to shift from volume-based care to value-based care. These value-based strategies may support more provider time with patients, but it is too soon to tell definitively what the impact of these new financing approaches will be.

Many health systems are exploring other techniques like the use of technology to help communicate with patients outside of the traditional appointment.



TEAM Course

- Explore factors that facilitate or pose barriers to effective communication
- Present perspectives of current cancer care
- Present ideas of cancer care in the future
- Offer quality improvement strategies to move towards patient-centered care

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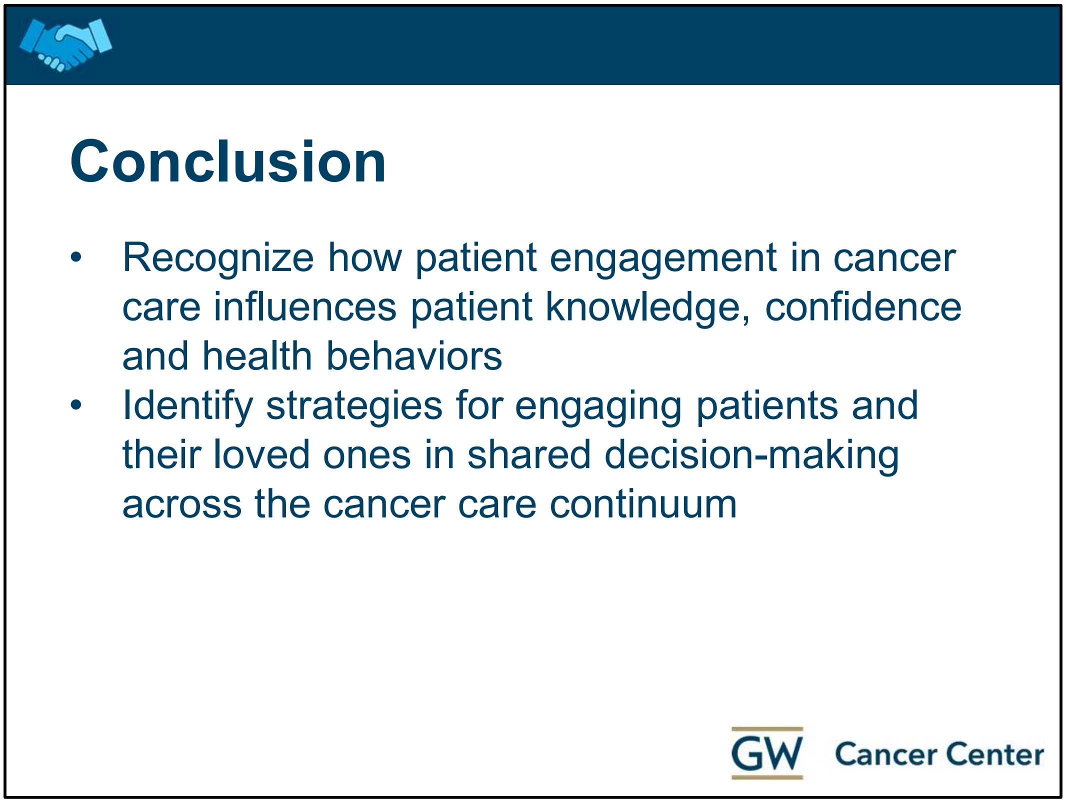
The TEAM course provides strategies to engage patients in care in ways that acknowledge where we are now and support where we want to go as a health system.

In the lessons that follow, we will explore what factors facilitate or pose barriers to effective communication and shared decision-making between patients and health care professionals.

We will present perspectives of what cancer care currently looks like for certain vulnerable populations and what shared decision-making in cancer care *can* look like in ways that account for patients' individual needs, experiences and values.

Lastly, we will offer quality improvement strategies that health care professionals and organizations can take to move toward patient-centered care that is culturally competent and equitable.



Conclusion

- Recognize how patient engagement in cancer care influences patient knowledge, confidence and health behaviors
- Identify strategies for engaging patients and their loved ones in shared decision-making across the cancer care continuum

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In this lesson, you learned to:

- Recognize how patient engagement in cancer care influences patient knowledge, confidence and health behaviors

- Identify strategies for engaging patients and their loved ones in shared decision-making across the cancer care continuum

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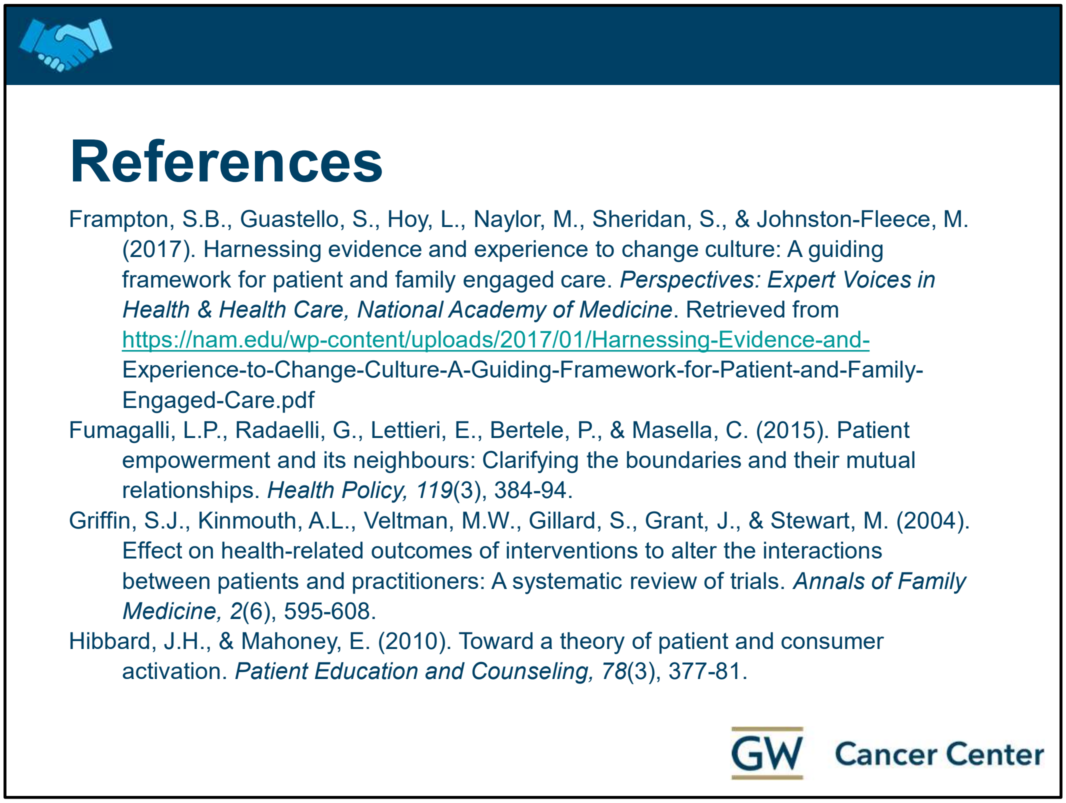

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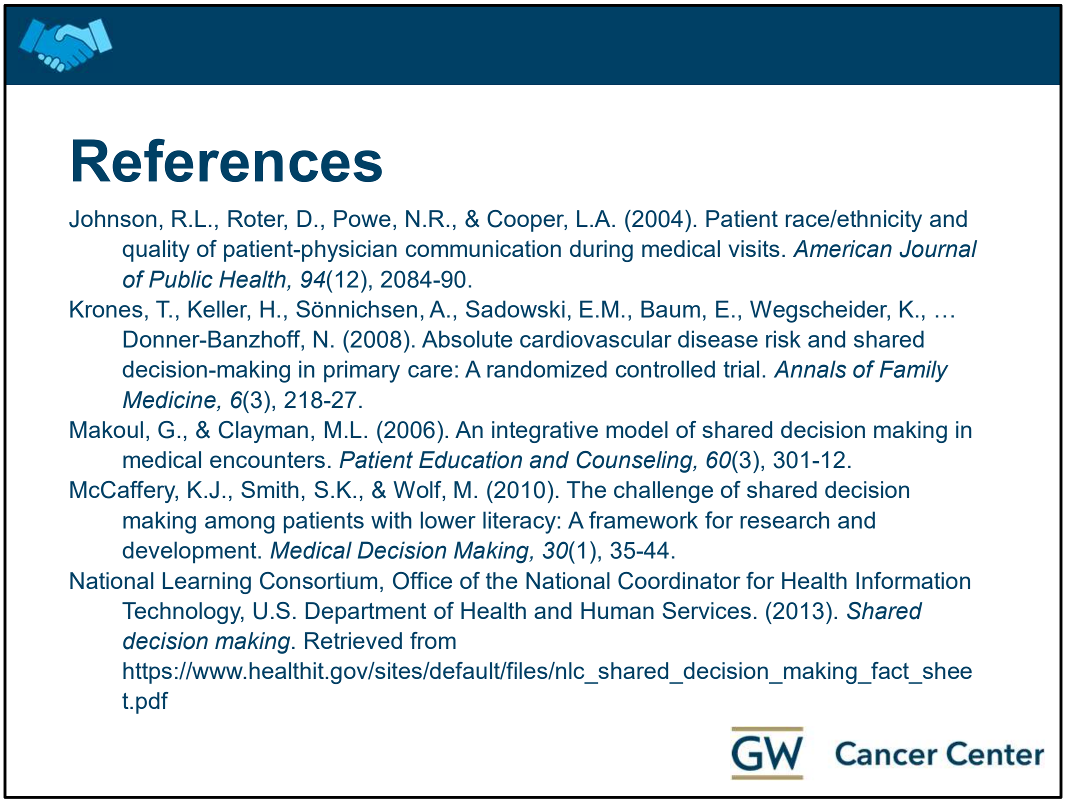

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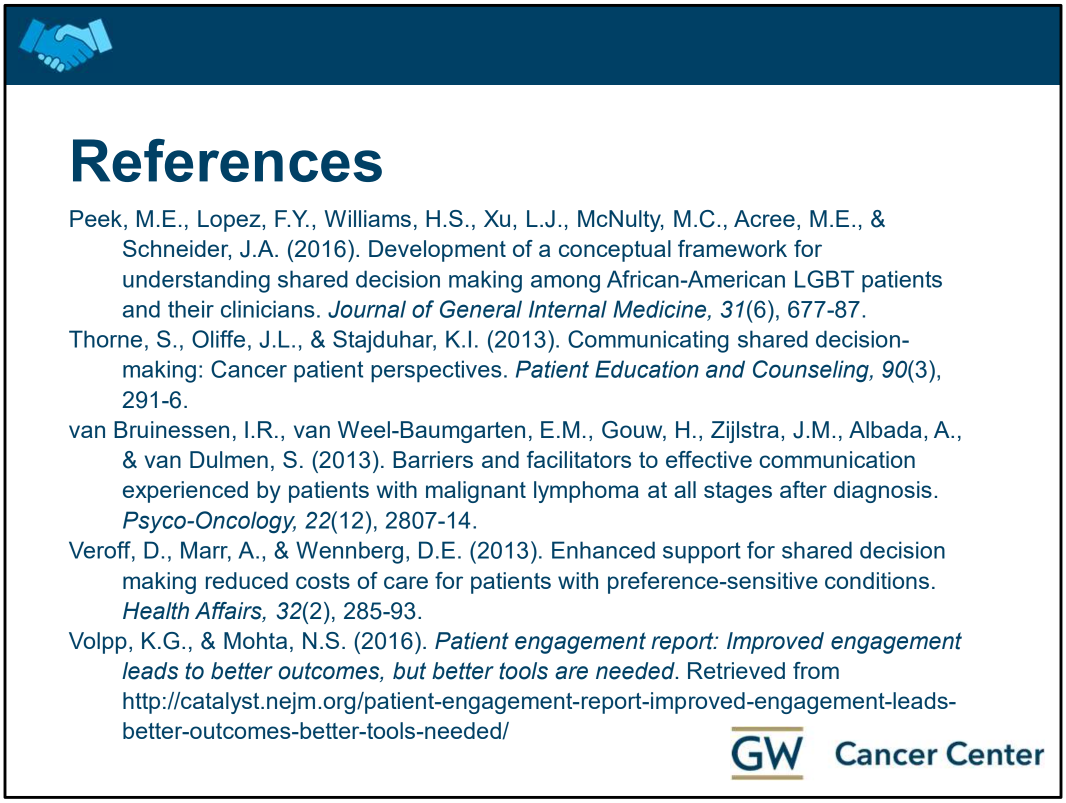

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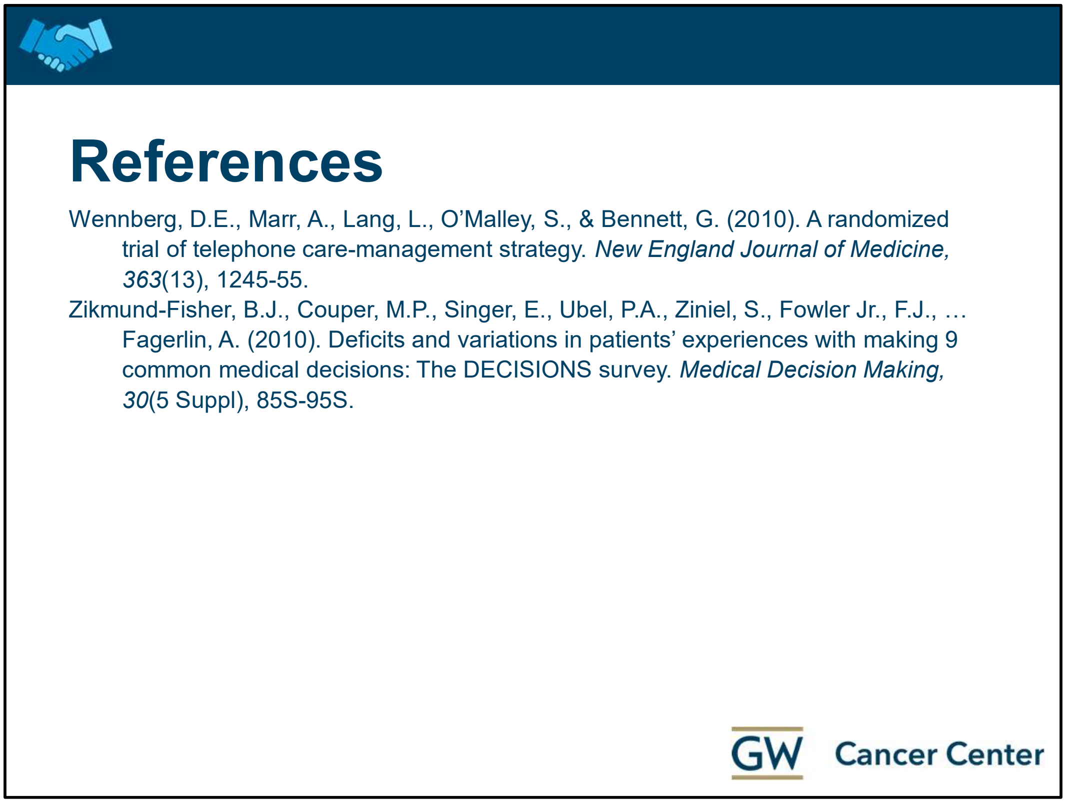

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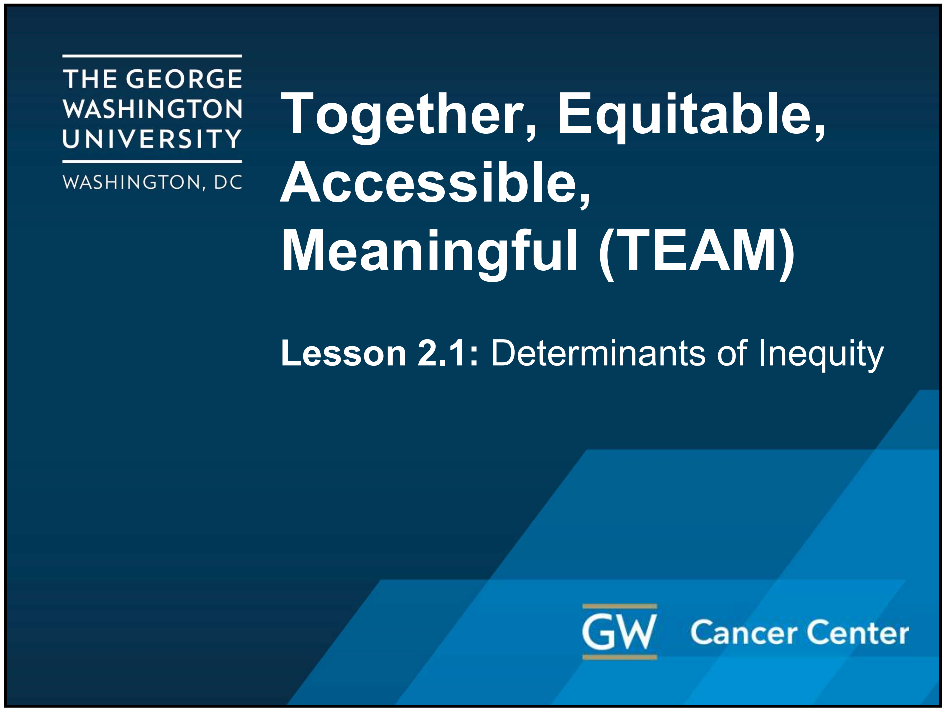

THE GEORGE WASHINGTON UNIVERSITY

WASHINGTON, DC

Together, Equitable, Accessible, Meaningful (TEAM)

Lesson 2.1: Determinants of Inequity

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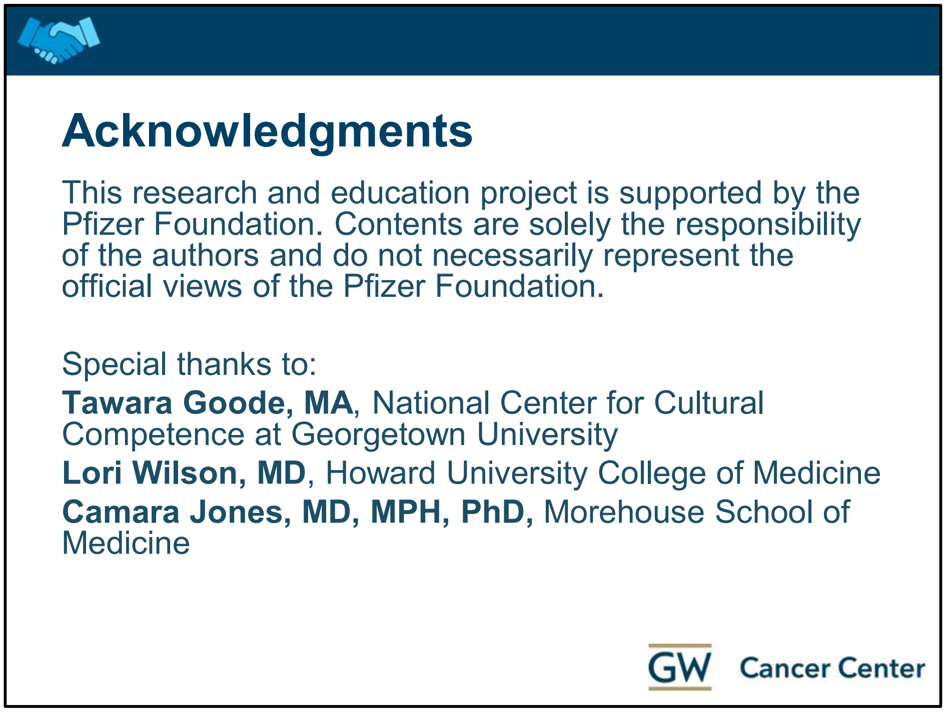
Welcome to Module 2, Lesson 1: Determinants of Inequity



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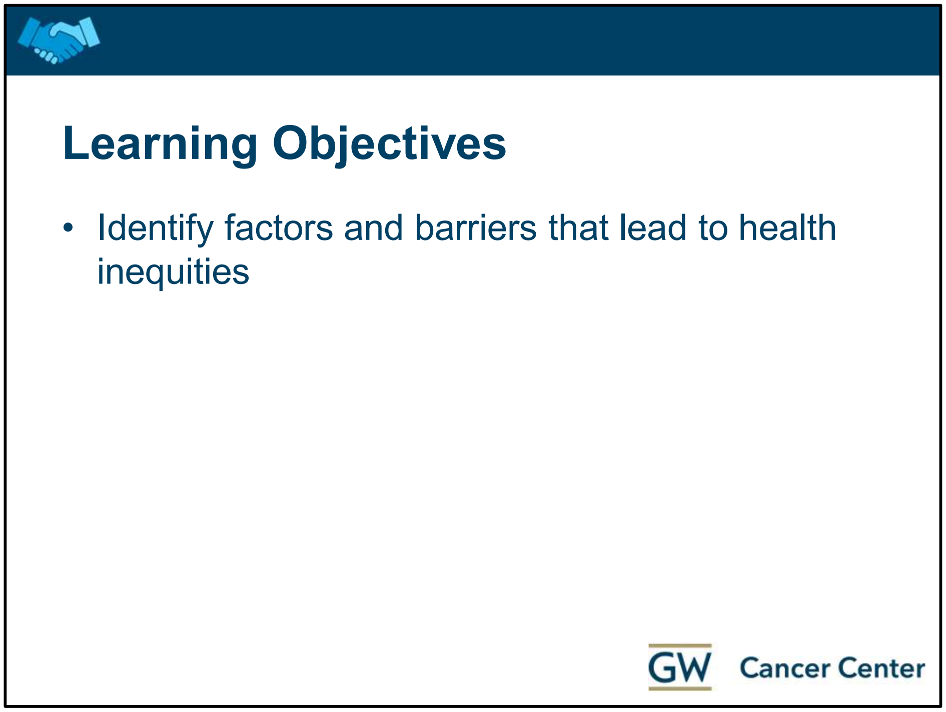

Learning Objectives

- Identify factors and barriers that lead to health inequities

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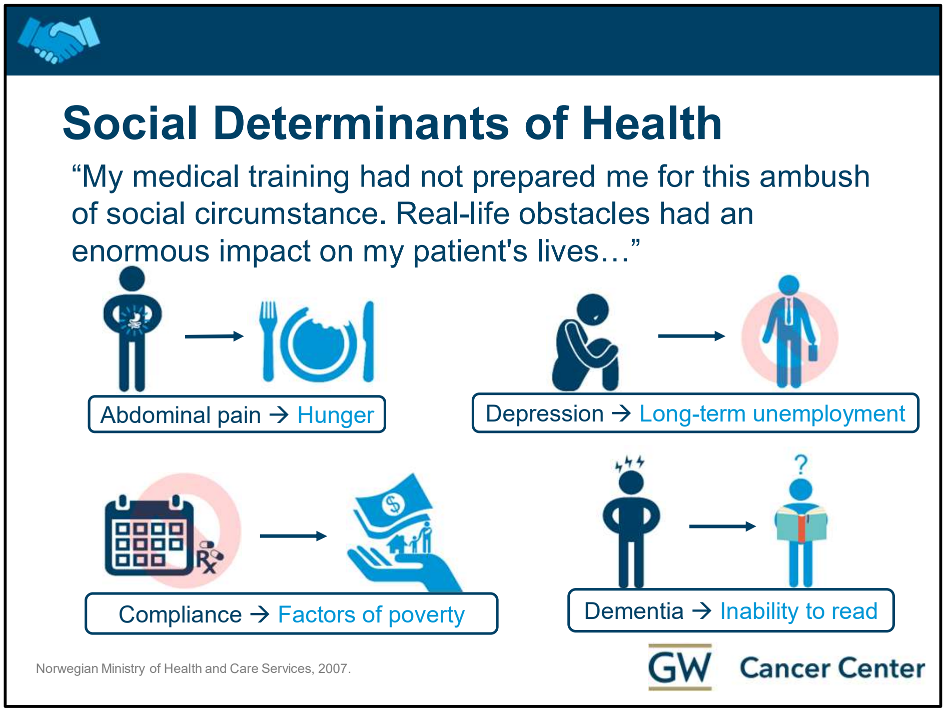
After completing this lesson, you will be able to:

- Identify factors and barriers that lead to health inequities



Social Determinants of Health

“My medical training had not prepared me for this ambush of social circumstance. Real-life obstacles had an enormous impact on my patient's lives…”

Abdominal pain → Hunger

Depression → Long-term unemployment

Compliance → Factors of poverty

Dementia → Inability to read

Norwegian Ministry of Health and Care Services, 2007.

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The first Module described the goal we are working to achieve– patient engagement in research and care. In this module we will discuss barriers to these types of patient-centered interactions.

In this lesson, we discuss a number of factors that influence health. Anyone who works in health care must have a basic understanding of determinants of health. This affects how patients receive care and interact with the health care system.

This is poignantly illustrated in a quote from Dr. Laura Gottlieb, who is Associate Professor of Family and Community Medicine and Director of the Social Interventions Research and Evaluation Network (SIREN) at the University of California, San Francisco.

She states, “...I had diagnosed "abdominal pain" when the real problem was hunger; I confused social issues with medical problems in other patients, too. I mislabeled the hopelessness of long-term unemployment as depression and the poverty that causes patients to miss pills or appointments as noncompliance. In one older patient, I mistook the inability to read for dementia. My medical training had not prepared me for this ambush of social circumstance. Real-life obstacles had an enormous impact on my patient's lives, but because I had neither the skills nor the resources for treating them, I ignored the social context of disease altogether.”

To decrease health disparities change must occur at many levels. This includes changes in how health care is delivered, which we will cover in Module 5. However, let’s first examine the impact of determinants that can lead to health inequities.

Social determinants of health is a term used to explain factors outside of the health care setting that play a huge role in shaping health outcomes. The World Health Organization defines social determinants of health as “the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life.”

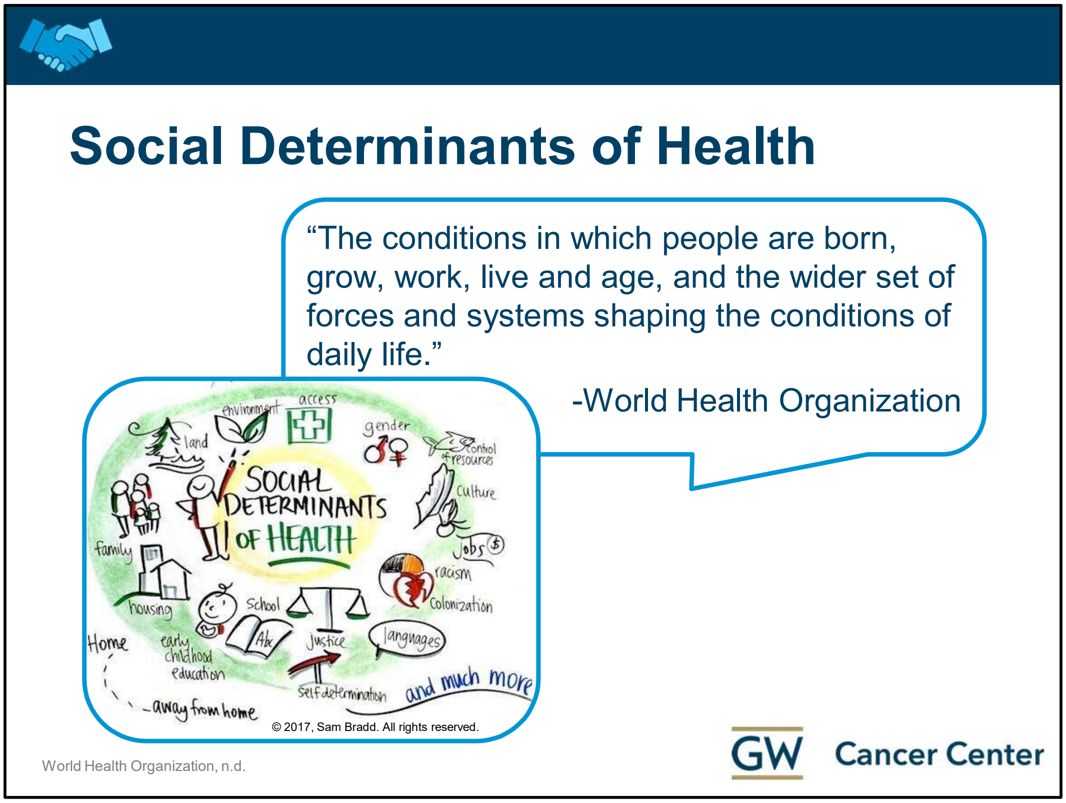
These determinants include economic, social and political policies and systems, as well as education, employment, health care services, social and community supports, public safety and availability of resources.

Social determinants of health are “beyond individual genes and individual behaviors” and can dictate whether and how those with cancer are able to access services across the continuum.

The National Academy of Medicine highlighted the importance of addressing health disparities in its 2002 report: *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*.

This seminal report emphasized that “racial and ethnic disparities in health care are not entirely explained by differences in access, clinical appropriateness, or patient preferences…disparities in health care exist in the broader historical and contemporary context of social and economic inequality, prejudice and systematic bias.”

(http://www.sfgate.com/opinion/openforum/article/Funding-healthy-society-helps-cure-health-care-3177542.php)



Social Determinants of Health

> "The conditions in which people are born, grow, work, live and age, and the wider set of forces and systems shaping the conditions of daily life."
>
> -World Health Organization

World Health Organization, n.d.

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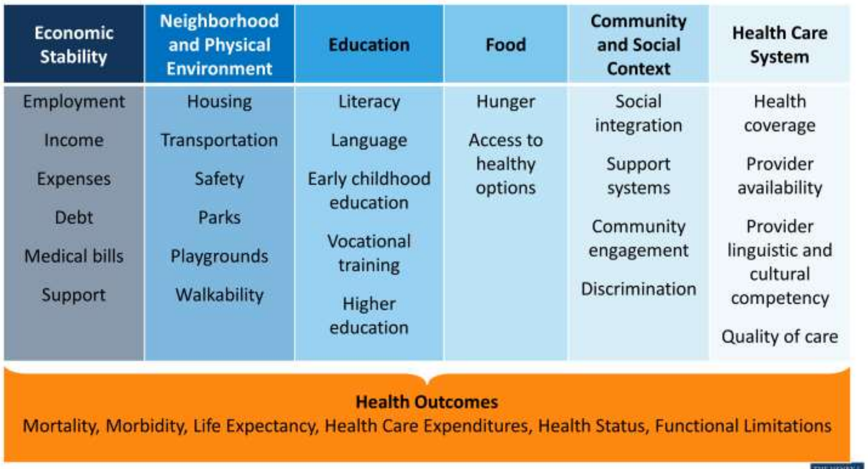
Picture: http://drawingchange.com/gathering-wisdom-visuals-for-a-healthy-future/

Factors “beyond individual genes and individual behaviors”



Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
Employment Income Expenses Debt Medical bills Support	Housing Transportation Safety Parks Playgrounds Walkability	Literacy Language Early childhood education Vocational training Higher education	Hunger Access to healthy options	Social integration Support systems Community engagement Discrimination	Health coverage Provider availability Provider linguistic and cultural competency Quality of care

Health Outcomes

Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations

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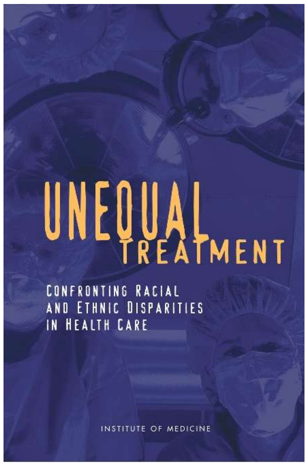
Healthy People 2020, 2017; Jones, Jones, Perry, Barclay, & Jones, 2009; Heiman & Artiga, 2015.

Health Disparities

Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare (2002):

“Disparities in health care exist in the broader historical and contemporary context of social and economic inequality, prejudice, and systematic bias.”



Smedley, Stith, & Nelson, 2002; Johnson, Saha, Arbelaez, Beach, & Cooper, 2004.

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Example: Access to Healthy Food

Problem: “Most of my patients are on food stamps, and cannot afford these recommended foods, and instead are left with what they can get in cans and boxes. All of these things can cause a great disconnect with patients and their care…”

GW Cancer Center, 2017.

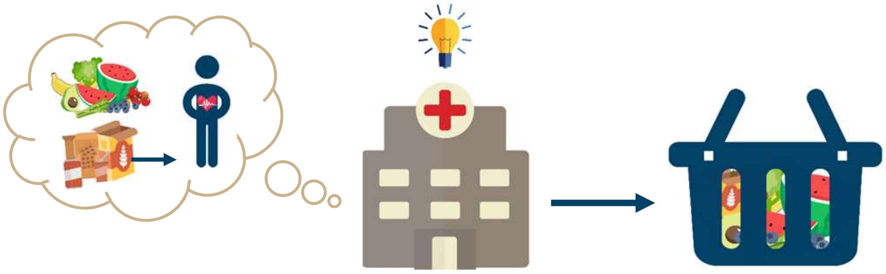
A prime example of social determinants’ impact on cancer patients’ is access to affordable, healthy food. In the National Cancer Care TEAM Survey, one navigator discusses this challenge: “...[t]here are recommended foods for cancer patients. I have seen many brochures, books, online sites recommending what foods to eat. Most push fresh fruits and vegetables, organic foods, high protein.

These foods are expensive. Most of my patients are on food stamps, and cannot afford these recommended foods, and instead are left with what they can get in cans and boxes. All of these things can cause a great disconnect with patients and their care. This is just [one example] of how low socioeconomic status can impact treatment.

I do however, feel that my hospital takes great consideration to these things and that our providers try to keep this in mind. For instance our [dietitian] recently held classes that took patients on a field trip [to] the grocery store to discuss what foods to buy. So even if patients cannot afford all fresh foods, they looked at the better canned foods for them, and what to look for in ingredients."

This example also highlights how cultural competence is important. The organization and staff have worked to understand the socio-cultural context of their patient population and find solutions to meet their needs. Again, we will discuss cultural competence more in Module 5.

Solution: "… Our [dietitian] recently held classes that took patients on a field trip [to] the grocery store to discuss what foods to buy. So even if patients cannot afford all fresh foods, they looked at the better canned foods for them, and what to look for in ingredients."



GW Cancer Center, 2017.

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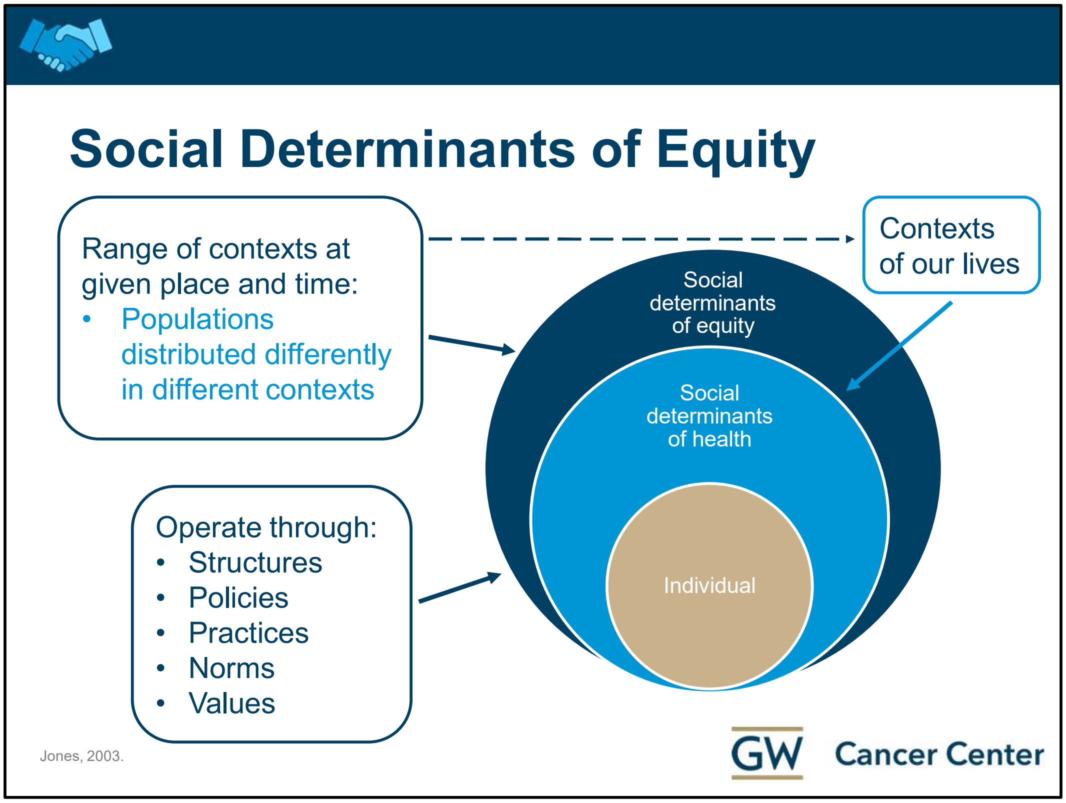

Social Determinants of Equity

Range of contexts at given place and time:
- Populations distributed differently in different contexts

Operate through:
- Structures
- Policies
- Practices
- Norms
- Values

Contexts of our lives

Social determinants of equity

Social determinants of health

Individual

Jones, 2003.

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People have also proposed the idea of *social determinants of equity* in addition to *social determinants of health*.

If the social determinants of health are the contexts of our lives, the social determinants of equity describe the structures, practices and norms, values and policies that influence the range of options we have as individuals.

Structures are the “who”, “what”, “when” and “where” of decision-making, especially who is at the table and who is not, or what is on the agenda and what is not;

Policies are the written “how” of decision-making, while practices and norms are the unwritten “how” of decision-making; and

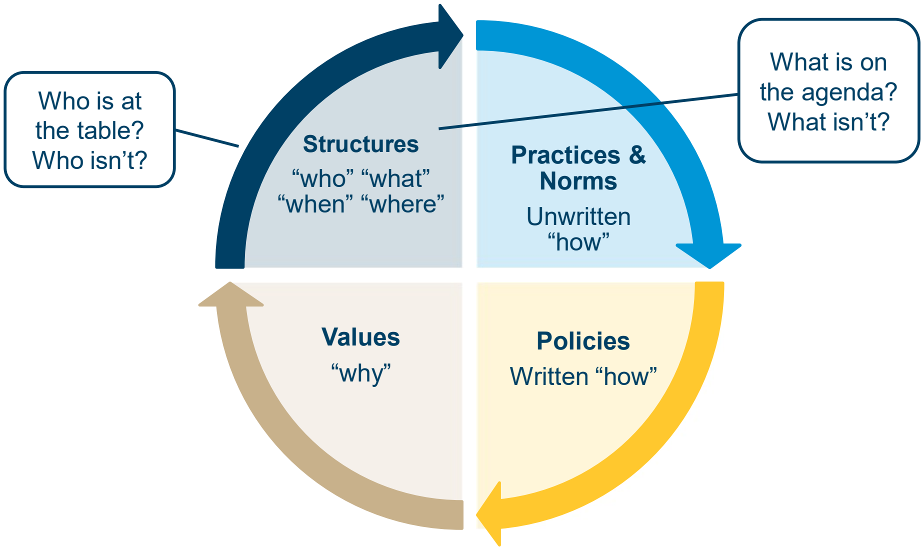
Values are the “why” of decision-making.

Social determinants of equity influence opportunities based on how one looks (“race”), the gender one expresses, one’s religion, one’s community, and more.

Systems that influence opportunities include racism, sexism, heterosexism, and other -isms.

All of these systems structure inequity, and unfairly disadvantage some individuals and communities while unfairly advantaging other individuals and communities. These systems also are an inefficient way for society to operate by not allowing all people to fully participate.

Social Determinants of Equity: Decision-Making



Who is at the table? Who isn't?

What is on the agenda? What isn't?

Structures
"who" "what"
"when" "where"

Practices & Norms
Unwritten
"how"

Values
"why"

Policies
Written "how"

Jones, 2003.

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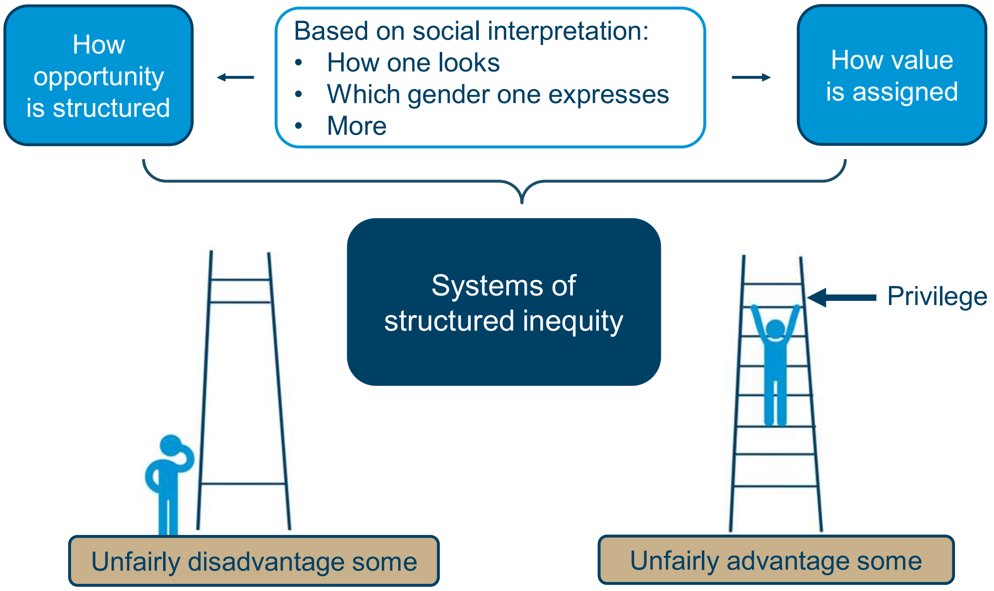


How opportunity is structured

Based on social interpretation:
- How one looks
- Which gender one expresses
- More

How value is assigned

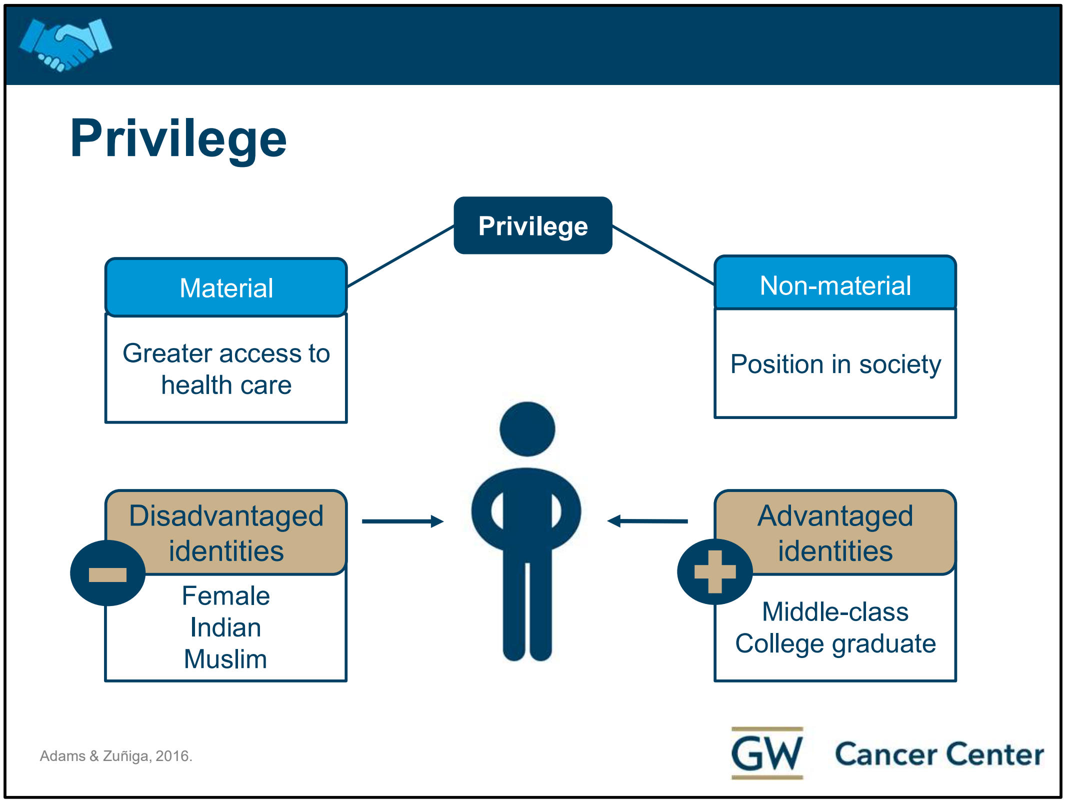
Systems of structured inequity

Privilege

Unfairly disadvantage some

Unfairly advantage some

Jones, 2003.



Privilege

Privilege

Material

Greater access to health care

Non-material

Position in society

Disadvantaged identities

Female
Indian
Muslim

Advantaged identities

Middle-class
College graduate

Adams & Zuñiga, 2016.

When systems provide unfair advantages or disadvantages to individuals or communities, this is called privilege.

Privilege can come in the form of material privilege, like greater access to health care. Or non-material privilege, like a position in society as normal or central. Any person can have both advantaged identities and disadvantaged identities.

For instance, a Muslim, second-generation, immigrant Indian woman may face disadvantage due to her gender, race and religion. But, she also may experience advantage by being middle class and a college graduate.

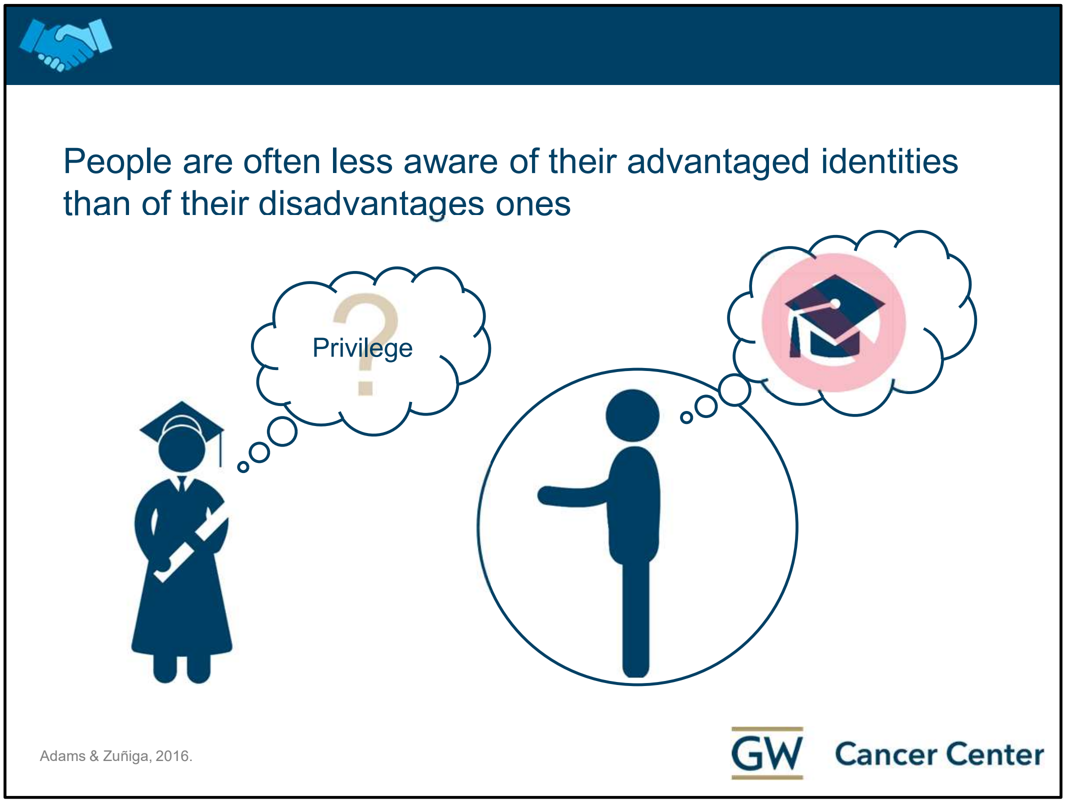
We are often less aware of our advantaged identities than we are of our disadvantaged ones. When we are in a dominant social group, these advantages are considered the norm in society and therefore go without notice.

However, being denied those same advantages by being part of a minority social group makes this lack of privilege apparent.

Privilege can be earned or unearned.

For instance, the concept of unearned “white privilege” is often mentioned to describe advantages individuals gain solely based on their appearance, like benefits in hiring.

However, individuals may also have earned privilege, like status and advantage conferred by virtue of being a medical professional.



People are often less aware of their advantaged identities than of their disadvantages ones

Privilege

Adams & Zuñiga, 2016.

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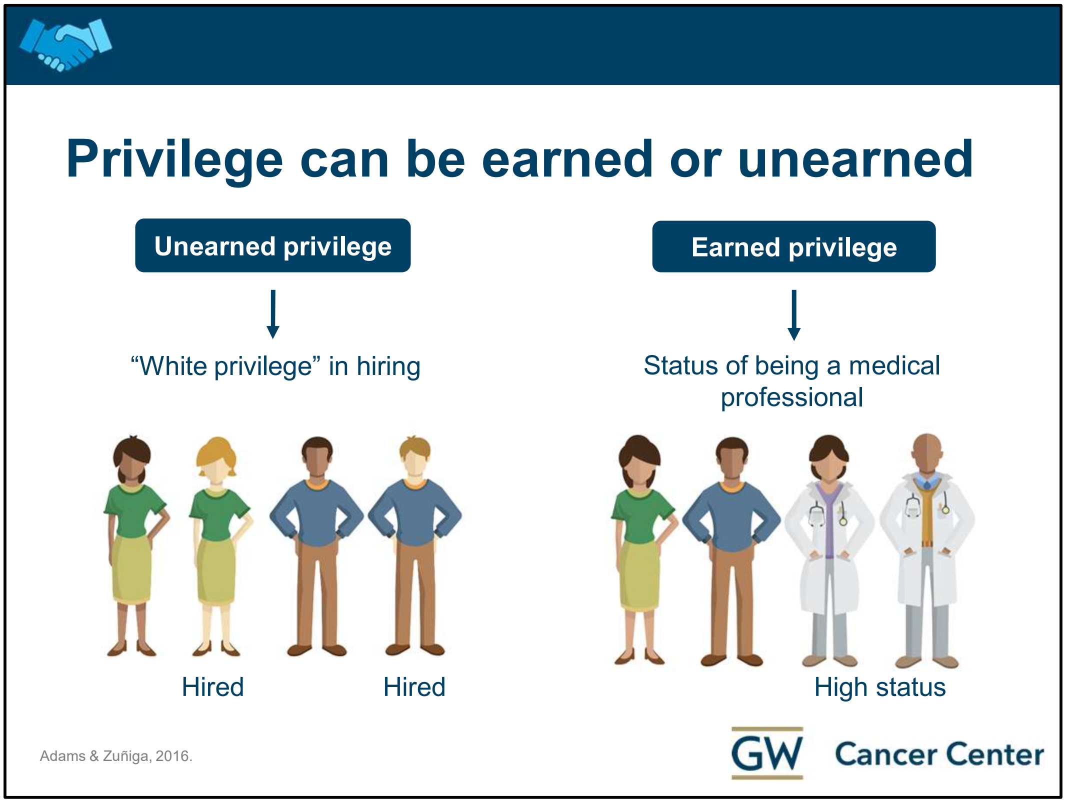

Privilege can be earned or unearned

Unearned privilege

“White privilege” in hiring

Hired

Hired

Earned privilege

Status of being a medical professional

High status

Adams & Zuñiga, 2016.

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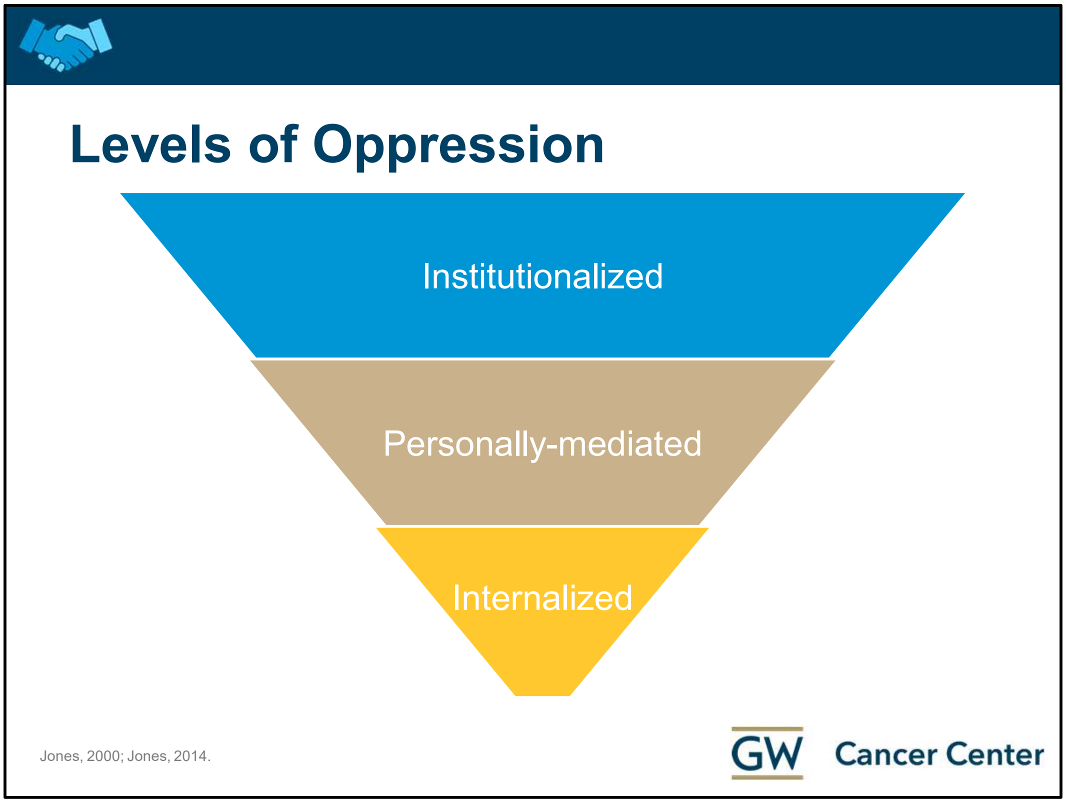

Levels of Oppression

Institutionalized

Personally-mediated

Internalized

Jones, 2000; Jones, 2014.

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In addition to privilege (earned or unearned), there is also discrimination and oppression. This manifests itself through –isms or -phobias (racism, islamophobia, sexism and so on) and affects health.

It can be helpful to think about discrimination and oppression on three levels: institutionalized, personally-mediated and internalized. These three levels were first offered to describe levels of racism. But, they can also be used to describe other things – like heterosexism.

Institutionalized oppression is the system of structures, policies, practices, norms, and values that result in a social group having different access to the goods, services and opportunities of society.

This type of oppression does not require an identifiable perpetrator because it is systemic and reinforced by our customs, policies, practices, laws, and norms.

Institutionalized oppression can occur through acts that should not be done or failure to act. For example, less than half of U.S. states have laws that protect LGBTQI individuals from discrimination on a day-to-day basis.

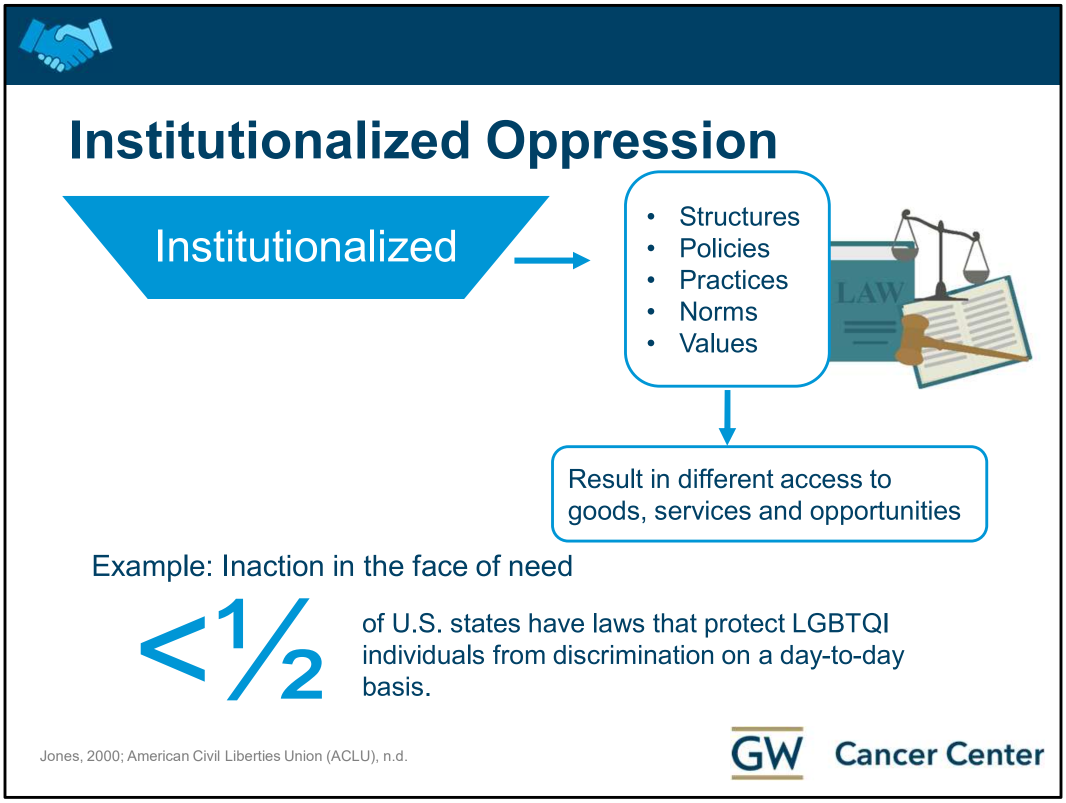
Personally-mediated oppression includes different assumptions or attitudes about the ability, motives and intents of others by social group (or prejudice). It also includes different actions or behaviors based on those assumptions (or discrimination).

Yet, personally-mediated oppression is not always conscious or intentionally done. Examples include microaggressions, which are everyday verbal or nonverbal cues that are intentionally or unintentionally targeted toward a group of people to reinforce a person’s status as a minority or outsider.

Imagine a microaggression as a mosquito bite. They happen to everyone but some people are bitten much more regularly than other people. For example, a Muslim American may consistently be asked in conversations, “where are you ‘really’ from?” Or, an Asian American mom might be regularly asked on the playground if she is the nanny to her mixed race child.

At first these bites are just annoying, but over time, these bites build up and can impact an individual’s life. Internalized oppression refers to acceptance by members of the stigmatized groups of the negative messages about their own abilities and intrinsic worth. For instance, eventually, microaggressions may establish a sense of helplessness or hopelessness within an individual and lead them to hold an internal belief that they are “less than” or the “other”.

An important note to remember is that all three levels of oppression reinforce one another. It is also important to acknowledge that institutionalized oppression has its roots in historical injustices.



Institutionalized Oppression

Institutionalized

- Structures
- Policies
- Practices
- Norms
- Values

Result in different access to goods, services and opportunities

Example: Inaction in the face of need

<½ of U.S. states have laws that protect LGBTQI individuals from discrimination on a day-to-day basis.

Jones, 2000; American Civil Liberties Union (ACLU), n.d.

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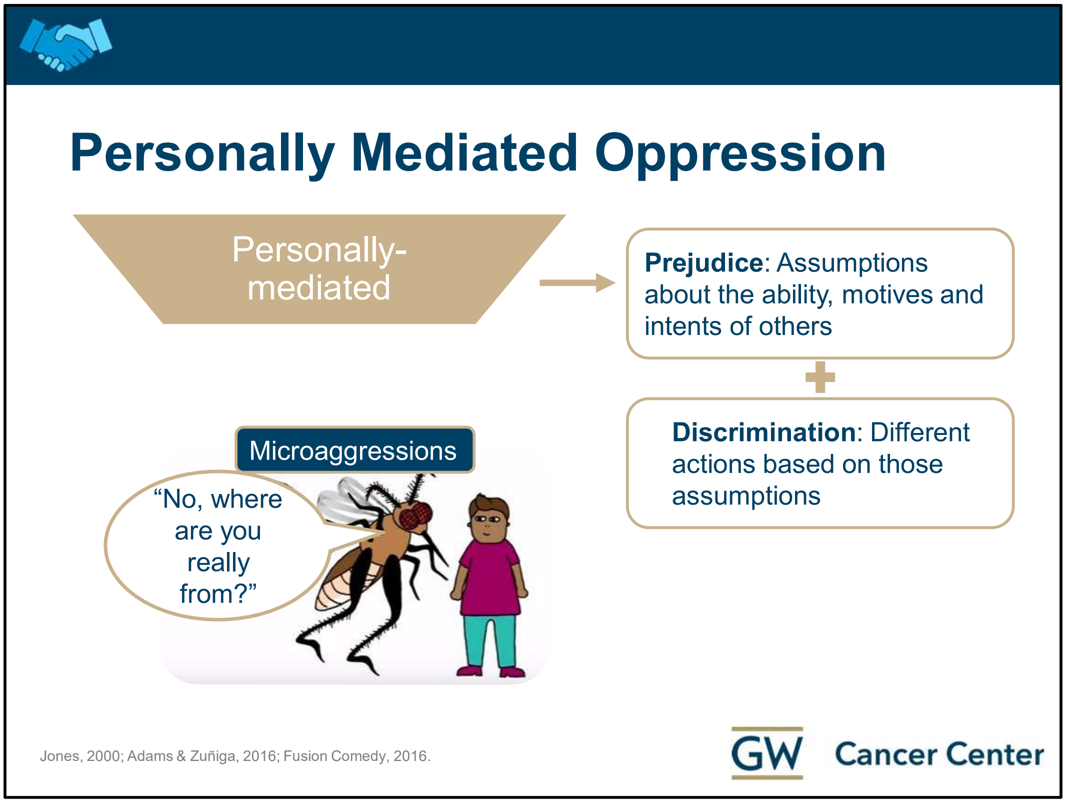

Personally Mediated Oppression

Personally-mediated

Prejudice: Assumptions about the ability, motives and intents of others

+

Discrimination: Different actions based on those assumptions

Microaggressions

Jones, 2000; Adams & Zuñiga, 2016; Fusion Comedy, 2016.

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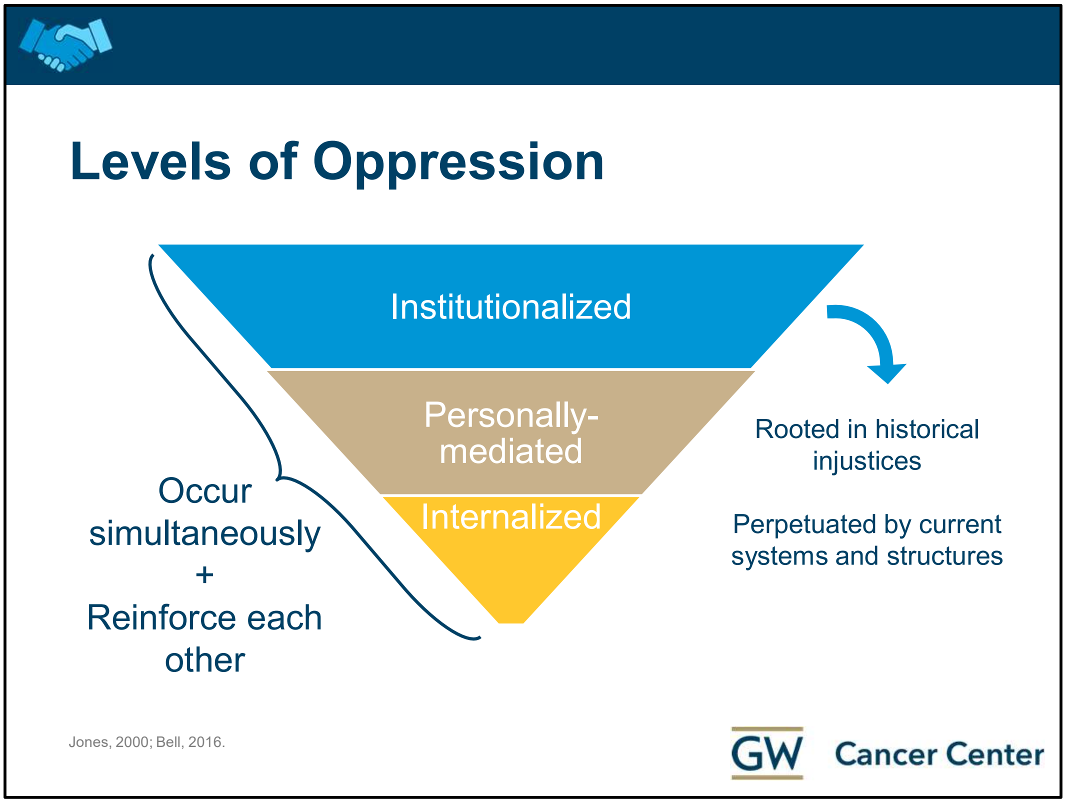
Internalized Oppression

Internalized → Acceptance of negative messages by members of the stigmatized group

↓

Affects abilities and self worth

Jones, 2000; Fusion Comedy, 2016.



Levels of Oppression

Institutionalized

Personally-mediated

Internalized

Occur simultaneously
+
Reinforce each other

Rooted in historical injustices

Perpetuated by current systems and structures

Jones, 2000; Bell, 2016.

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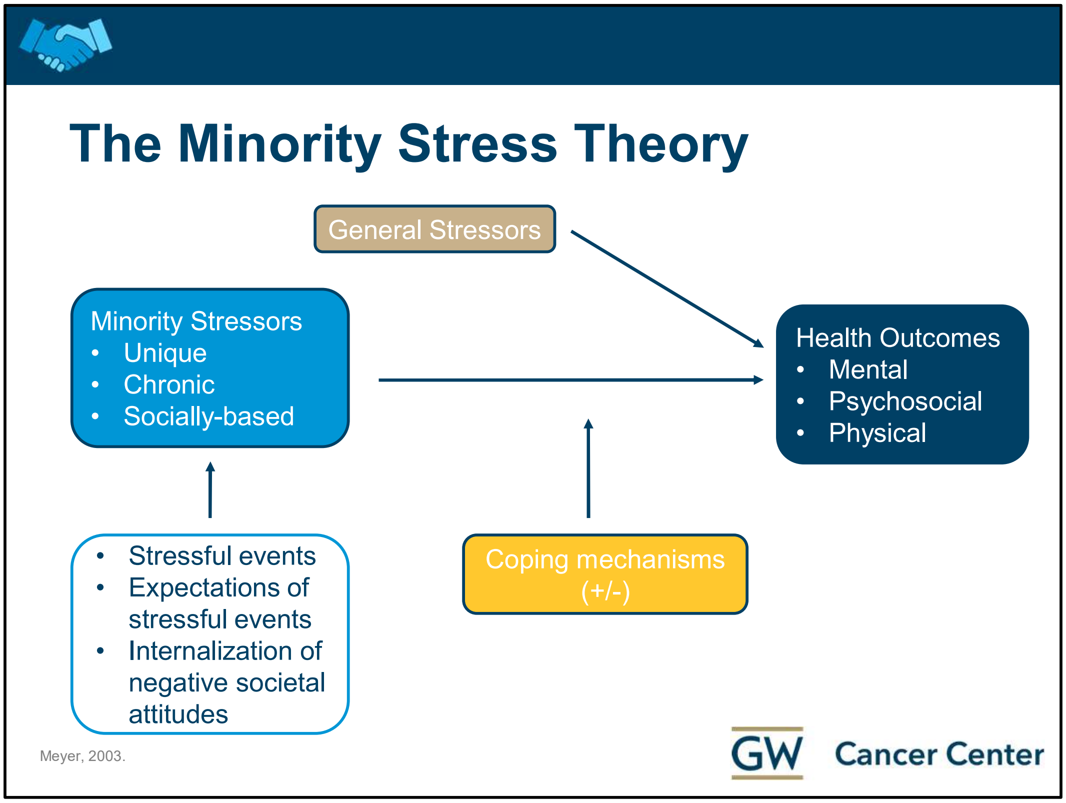


The Minority Stress Theory

General Stressors

Minority Stressors
- Unique
- Chronic
- Socially-based

Health Outcomes
- Mental
- Psychosocial
- Physical

- Stressful events
- Expectations of stressful events
- Internalization of negative societal attitudes

Coping mechanisms (+/-)

Meyer, 2003.

Oppression at any and all levels creates stress.

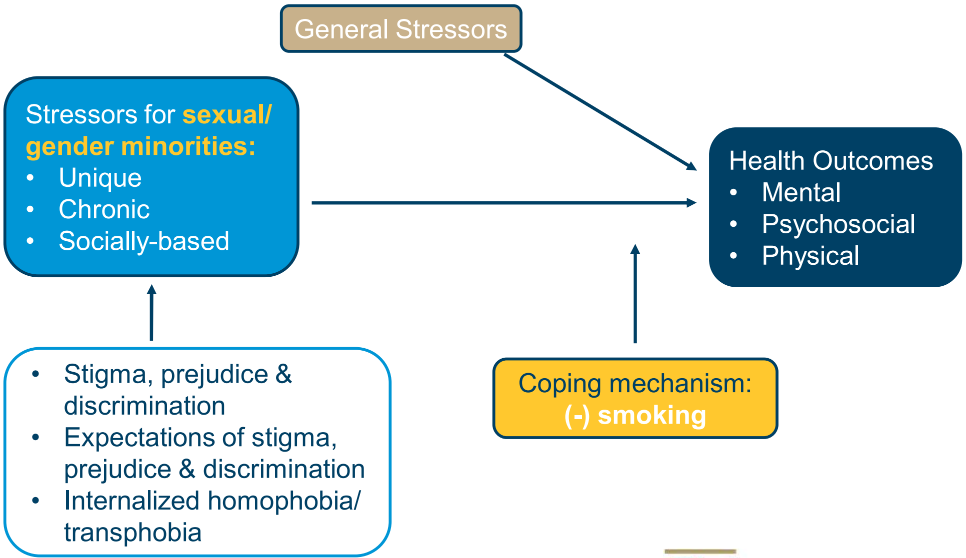
The Minority Stress Theory explains how stressors related to one’s social position as a minority can lead to poorer health. Stressors may lead minority individuals to behave in ways that negatively impact their health—like choosing to smoke. Minority stress describes stress that is in addition to stressors experienced by all people.

It is the result of social and cultural structures, and it is created from what a more privileged group decides is normal or preferred.

Stressors stem from social processes, institutions and structures. Minority stress may come from stressful events or conditions (whether acute or chronic), an expectation of these stressful events and an internalization of negative societal attitudes.

For example, a Muslim American experiencing heightened stress during air travel, a black family always worrying about what the outcome will be when pulled over while driving or a transgender individual fearing for their safety while walking down the street.

Minority stress leads to coping mechanisms – either positive or negative – and, at times, resilience, or being able to recover from or find positive outlets to adapt to stressors.



General Stressors

Stressors for **sexual/ gender minorities:**
- Unique
- Chronic
- Socially-based

Health Outcomes
- Mental
- Psychosocial
- Physical

- Stigma, prejudice & discrimination
- Expectations of stigma, prejudice & discrimination
- Internalized homophobia/ transphobia

Coping mechanism:
(-) smoking

Meyer, 2003; King, Dube, & Tynan, 2012.

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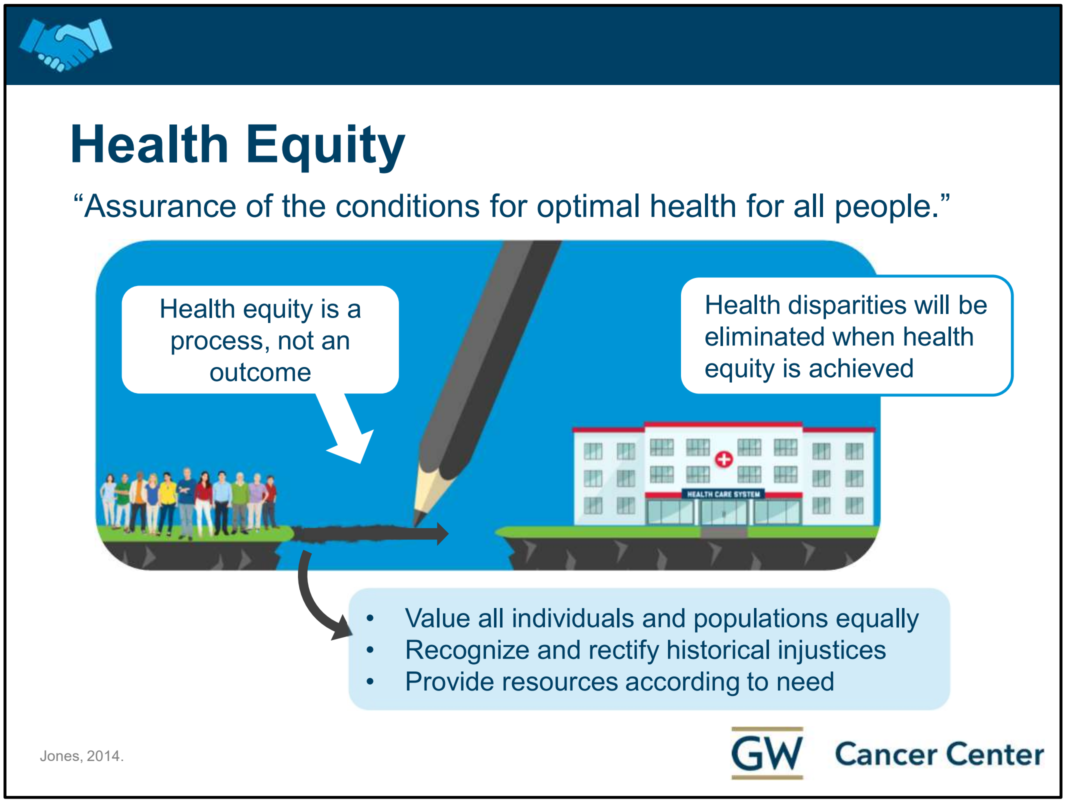


Health Equity

"Assurance of the conditions for optimal health for all people."

Health equity is a process, not an outcome

Health disparities will be eliminated when health equity is achieved

- Value all individuals and populations equally
- Recognize and rectify historical injustices
- Provide resources according to need

Jones, 2014.

Because minority individuals face oppression, inequities, stress and adverse health outcomes in a unique and disproportionate way, it is important that health care professionals strive to provide care that is equitable.

Instead of providing care in the exact same way regardless of the individual (or equal care), health care professionals should be providing care based on each person's need – equitable care.

Health equity has been defined as assurance of the conditions for optimal health for all people. That is, it is a process, not an outcome.

Achieving health equity requires valuing all individuals and populations equally, recognizing and rectifying historical injustices, and providing resources according to need. Health disparities will be eliminated when health equity is achieved.

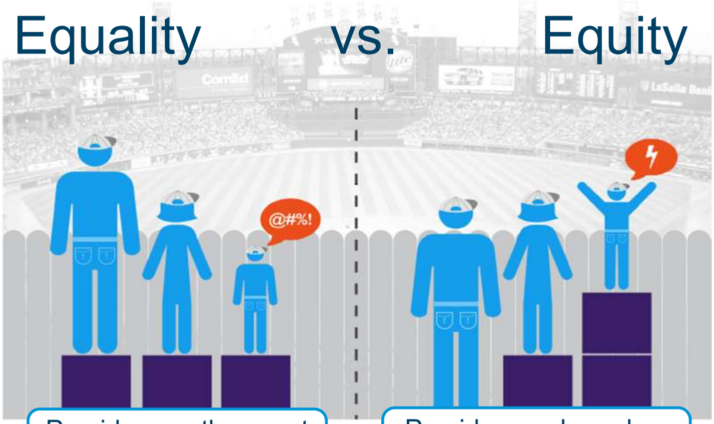
Take this graphic: If we provide a stool of the same height for each person, the shortest person may not be able to see over the fence.

But if we offer each person a stool that is as tall as needed for them to see and thereby addressing the disadvantage experienced by the shorter person(s), that is equity.

In health care, there is an entrenched view that providers should treat all patients the same, but we need to move towards a model of equity to meet patients’ needs.

Health Equity

Equality vs. Equity



Provide care the exact same way

Provide care based on each person’s need

Shetty et al., 2016; National LGBT Cancer Network, n.d.

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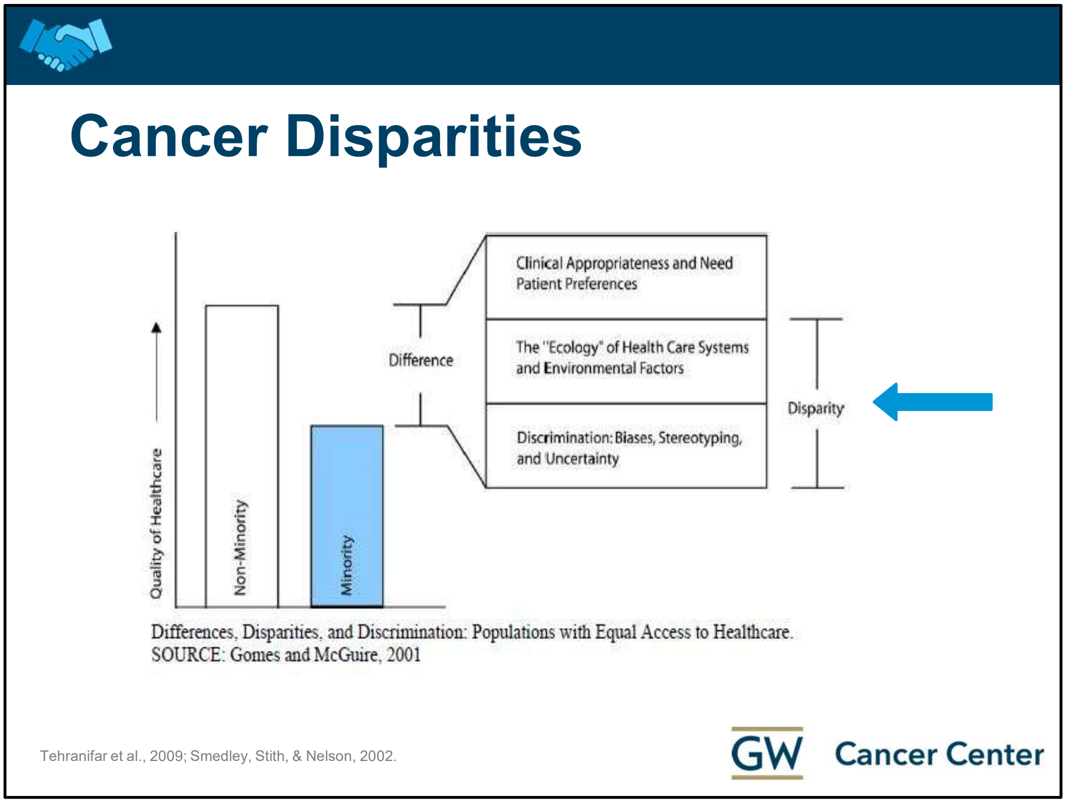

Cancer Disparities

Differences, Disparities, and Discrimination: Populations with Equal Access to Healthcare.
SOURCE: Gomes and McGuire, 2001

Tehranifar et al., 2009; Smedley, Stith, & Nelson, 2002.

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Let’s review some of the big-picture factors that perpetuate disparities in cancer and its care. By understanding these factors and others, we can begin to create strategies to achieve health equity.

Cancer disparities are often created or worsened when advances in the prevention or control of the disease do not reach all communities in the same way.

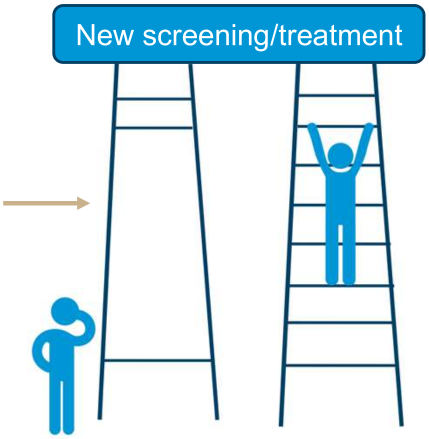
When a type of cancer is able to be screened for or treated more effectively with a new technique, people in positions of advantage are more likely to benefit from this advancement, whereas individuals who are disadvantaged may not benefit to the same extent due to barriers in access to or the delivery of care.

Barriers to accessing cancer treatment can include lack of specialized cancer care at local clinics or treatment facilities, distance to cancer care treatment or clinical trials, transportation issues, financial and insurance issues and more. These barriers in accessing cancer treatment can lead to a lower quality of life for cancer survivors.

Minority communities also continue to face disparities in the delivery of care, including quality of care, timeliness of care and health outcomes. These disparities can often be attributed to factors like poor provider-patient communication and provider bias that disproportionately affect minority communities.

Barriers to Accessing Care

- Lack of specialty cancer care at local clinics
- Distance to cancer care treatment
- Transportation
- Financial insecurity



Smedley, Stith, & Nelson, 2002.

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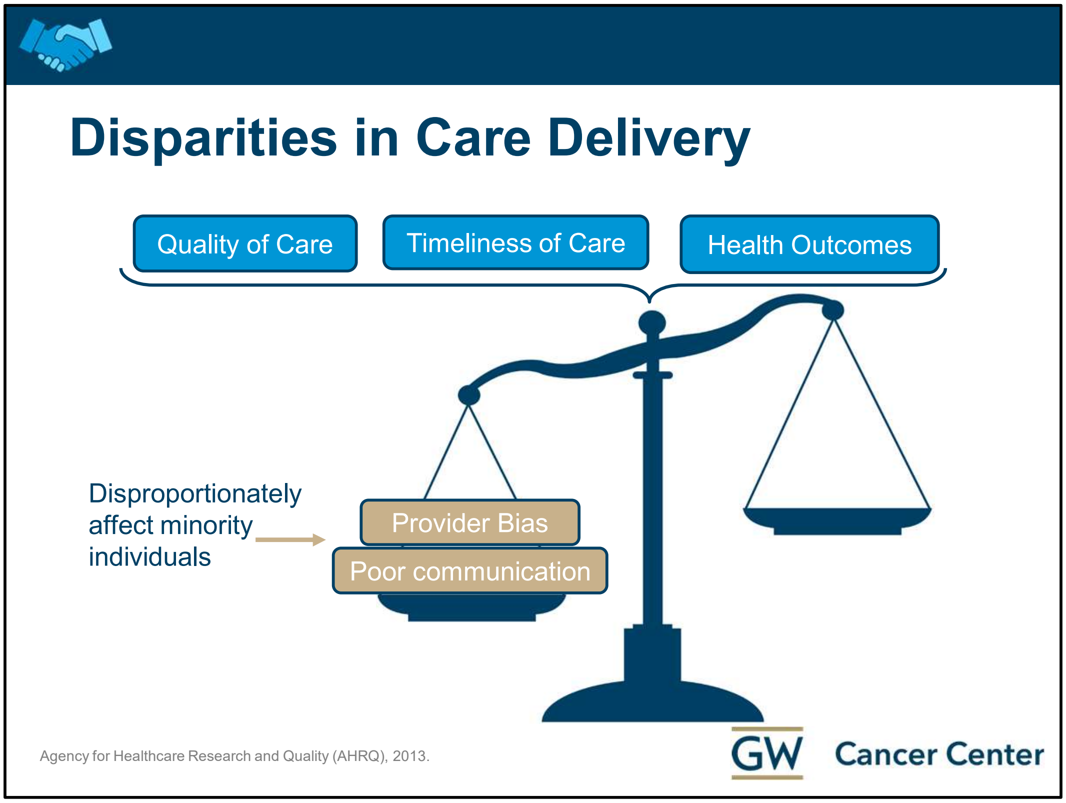

Disparities in Care Delivery

Quality of Care

Timeliness of Care

Health Outcomes

Disproportionately affect minority individuals

Provider Bias

Poor communication

Agency for Healthcare Research and Quality (AHRQ), 2013.

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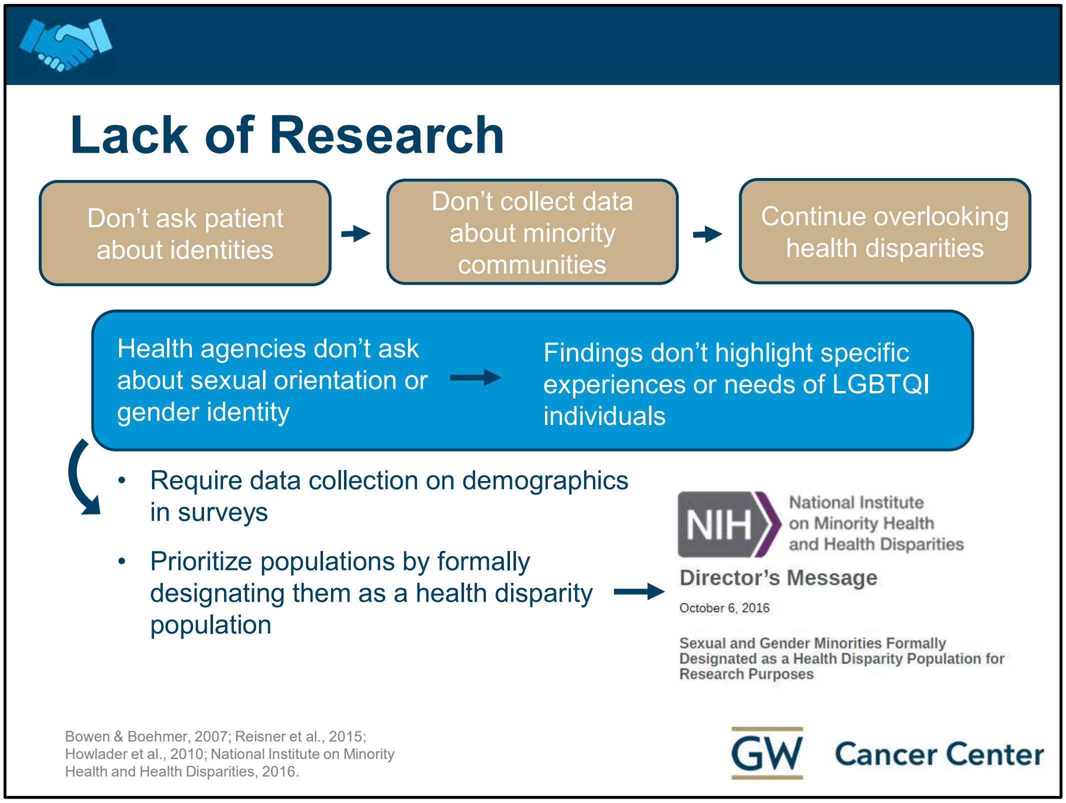

Lack of Research

Don't ask patient about identities → Don't collect data about minority communities → Continue overlooking health disparities

Health agencies don't ask about sexual orientation or gender identity → Findings don't highlight specific experiences or needs of LGBTQI individuals

- Require data collection on demographics in surveys
- Prioritize populations by formally designating them as a health disparity population →

NIH National Institute on Minority Health and Health Disparities

Director's Message

October 6, 2016

Sexual and Gender Minorities Formally Designated as a Health Disparity Population for Research Purposes

Bowen & Boehmer, 2007; Reisner et al., 2015; Howlader et al., 2010; National Institute on Minority Health and Health Disparities, 2016.

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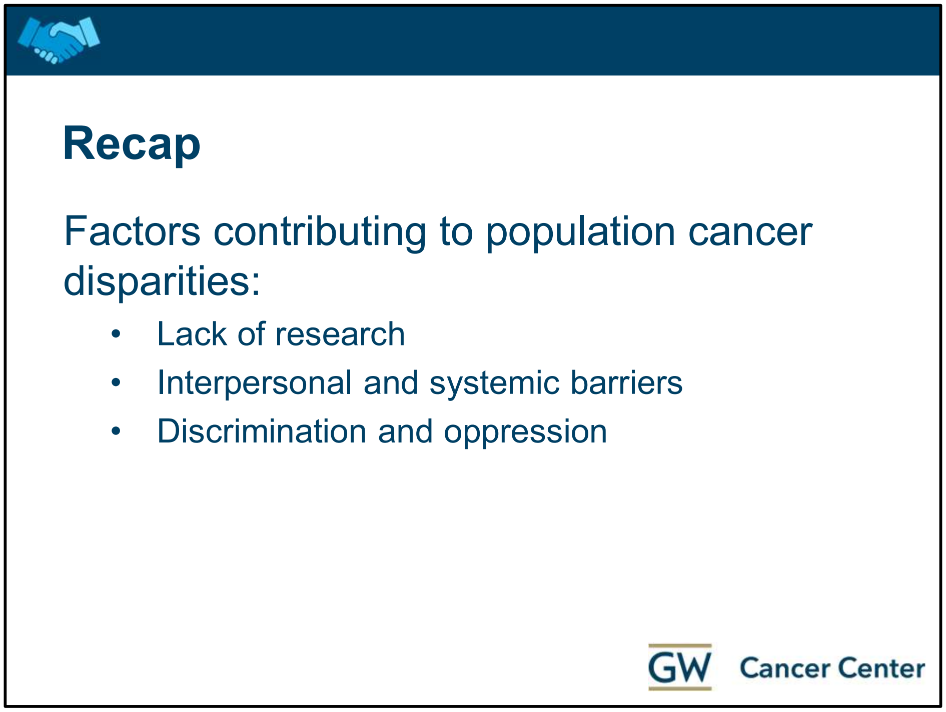
In addition to the social structures of inequity that lead to health disparities in the face of medical and public health advancements, the lack of research regarding certain underserved or vulnerable populations also perpetuates disparities. Without studies examining differences in groups' experiences with cancer, health disparities go overlooked.

A great example of this is in the LGBTQI communities. As we mentioned in the lesson on Patient Engagement in Research, people's sexual orientation and gender identity are not measured in cancer surveillance and large-scale data collection from national and international health agencies, and these data are not routinely collected in clinical electronic health records and public health cancer registries.

Federal and state governments can take a key step toward uncovering these masked health disparities by requiring the collection of demographics like race and ethnicity as well as sexual orientation and gender identity on large-scale surveys.

The NIH, in conjunction with the Agency for Healthcare Research and Quality (AHRQ), can also formally designate a population as a health disparity population.

By assigning this status – such as was assigned to the LGBTQI population in 2016 – NIH can leverage its role to advance and prioritize research on these health disparity populations. It does so by offering greater research opportunities, extending grant eligibility and providing greater research funding allocation to studies that examine the needs of health disparity populations.



Recap

Factors contributing to population cancer disparities:

- Lack of research
- Interpersonal and systemic barriers
- Discrimination and oppression

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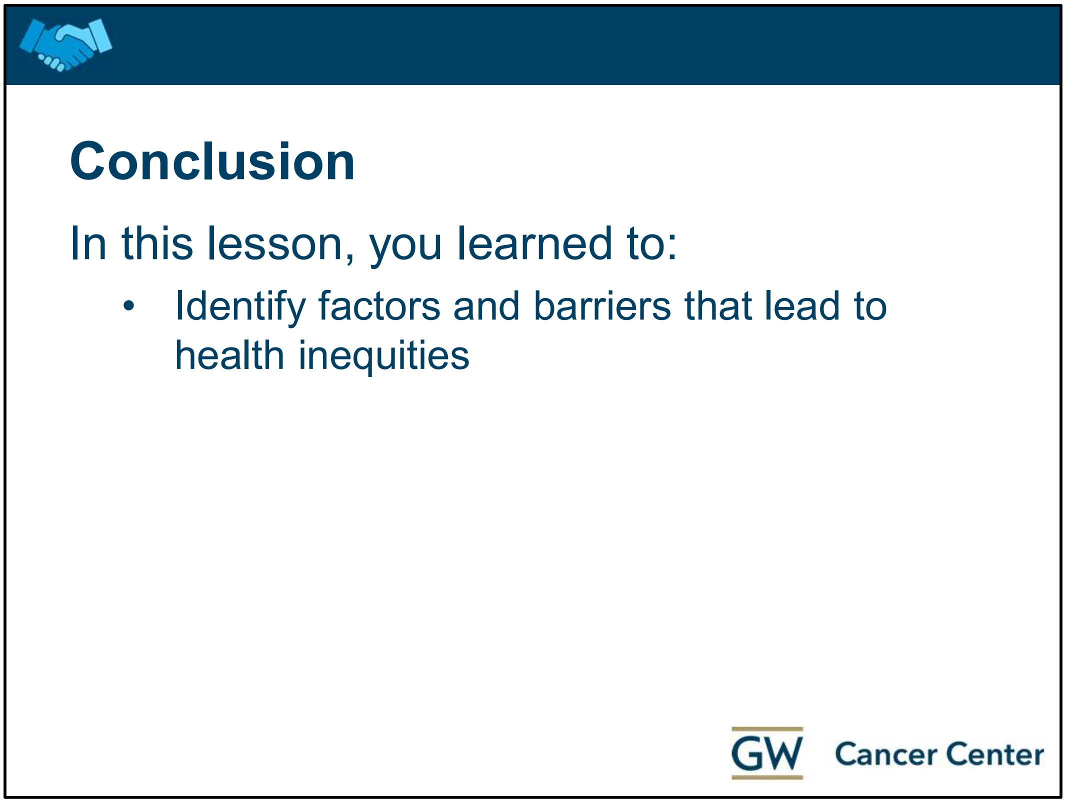
Now that we’ve discussed factors that broadly contribute to population cancer disparities— such as lack of research, system barriers to cancer care, discrimination and oppression—in the next lesson, we’ll touch more closely on implicit bias, which can create barriers for individuals in accessing and receiving cancer care.

We offer strategies that both individuals and systems can adopt to address implicit bias in order to improve cancer health equity.



Conclusion

In this lesson, you learned to:

- Identify factors and barriers that lead to health inequities

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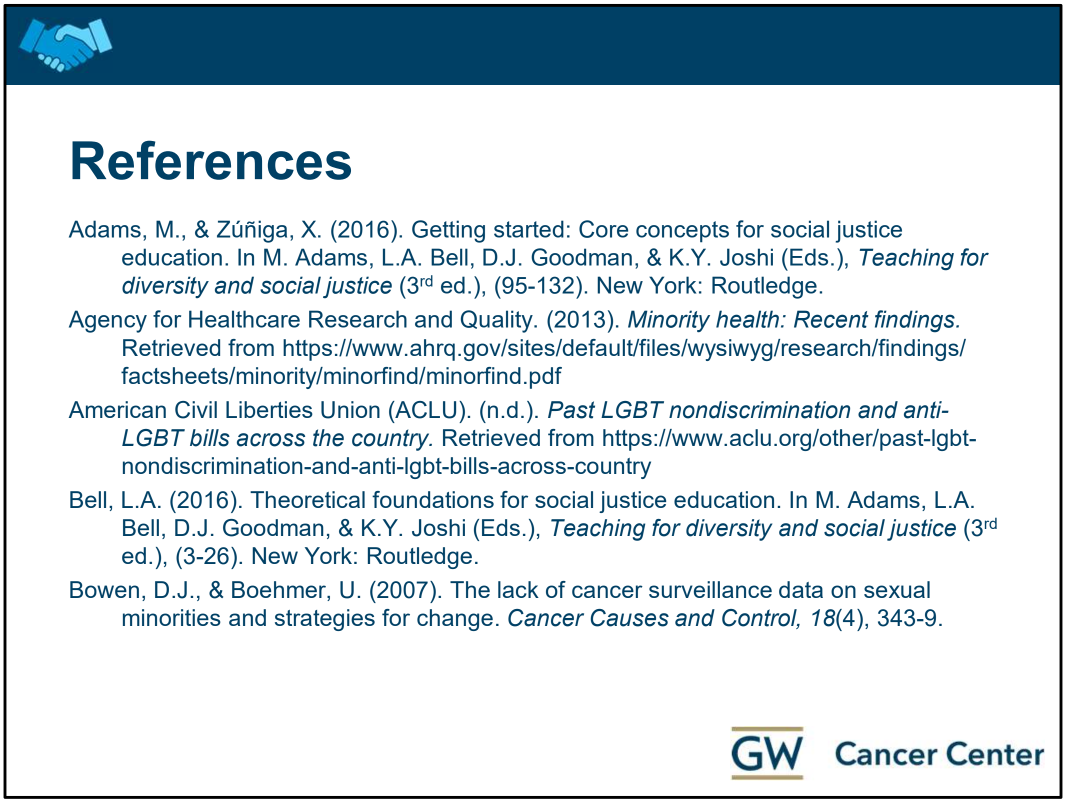
In this lesson, you learned to:

- Identify factors and barriers that lead to health inequities



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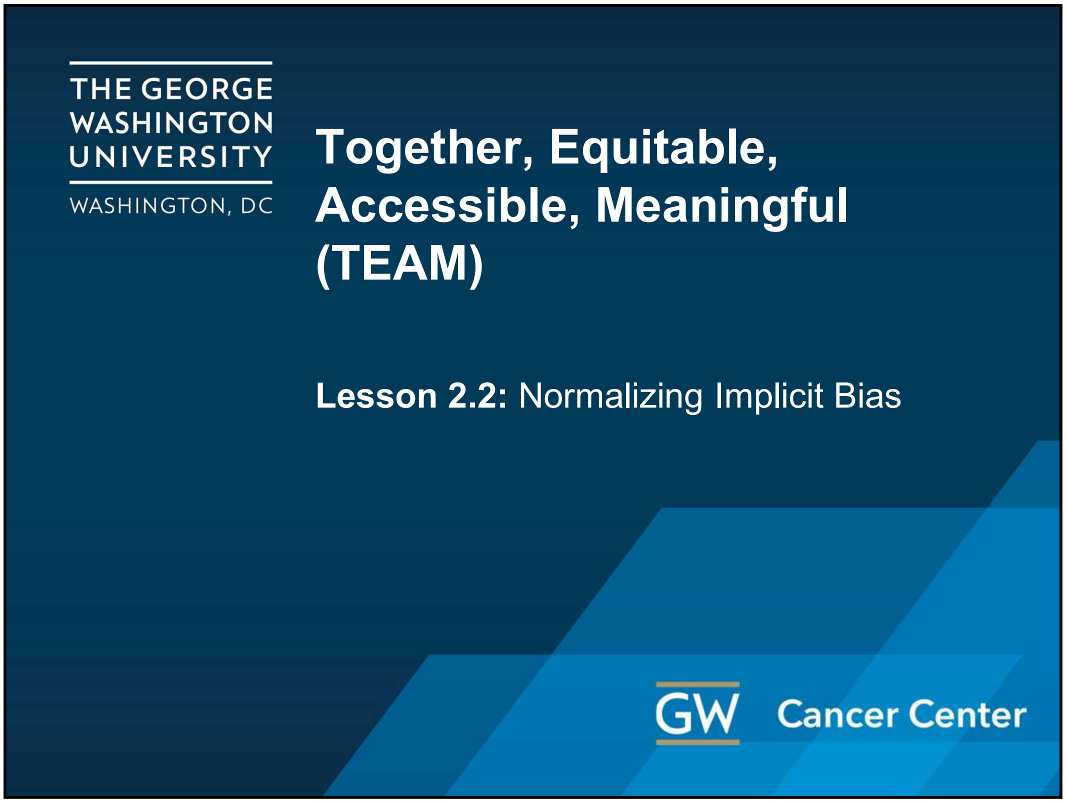

THE GEORGE WASHINGTON UNIVERSITY
WASHINGTON, DC

Together, Equitable, Accessible, Meaningful (TEAM)

Lesson 2.2: Normalizing Implicit Bias

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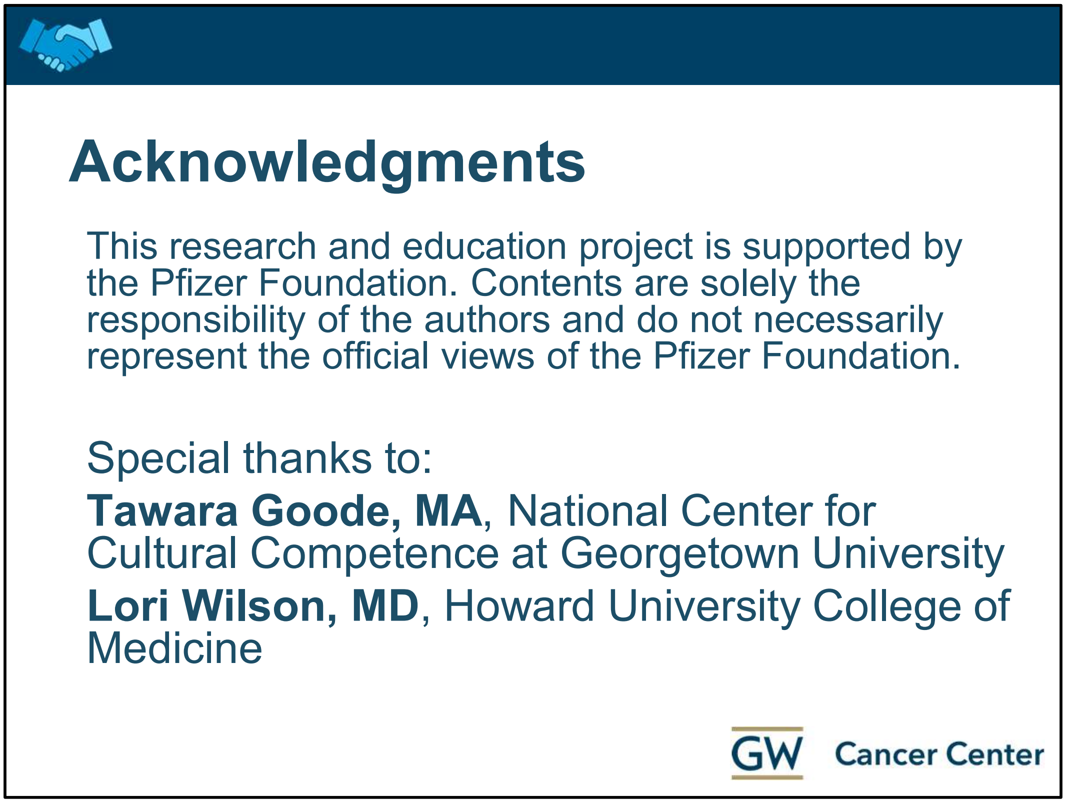
Welcome to Module 2, Lesson 2: Normalizing Implicit Bias



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Lori Wilson, MD, Howard University College of Medicine

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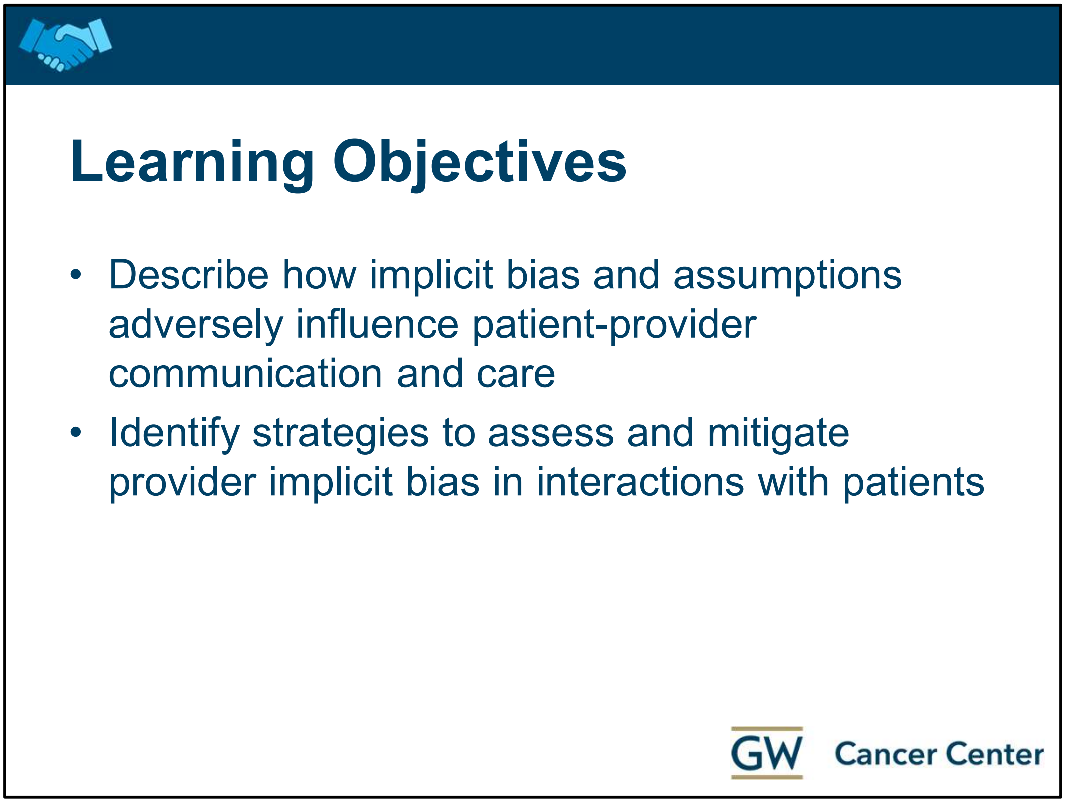

Learning Objectives

- Describe how implicit bias and assumptions adversely influence patient-provider communication and care
- Identify strategies to assess and mitigate provider implicit bias in interactions with patients

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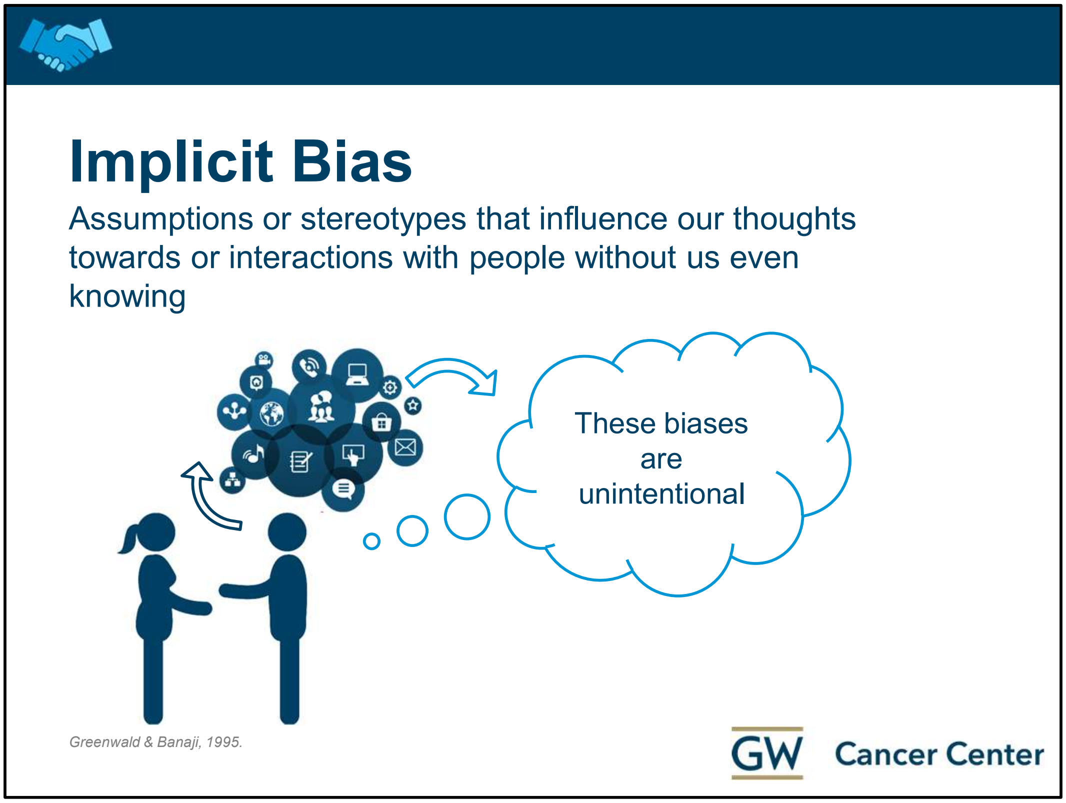
After completing this lesson, you will be able to:

Describe how implicit bias and assumptions adversely influence patient-provider communication and care

Identify strategies to assess and mitigate provider implicit bias in interactions with patients



Implicit Bias

Assumptions or stereotypes that influence our thoughts towards or interactions with people without us even knowing

These biases are unintentional

Greenwald & Banaji, 1995.

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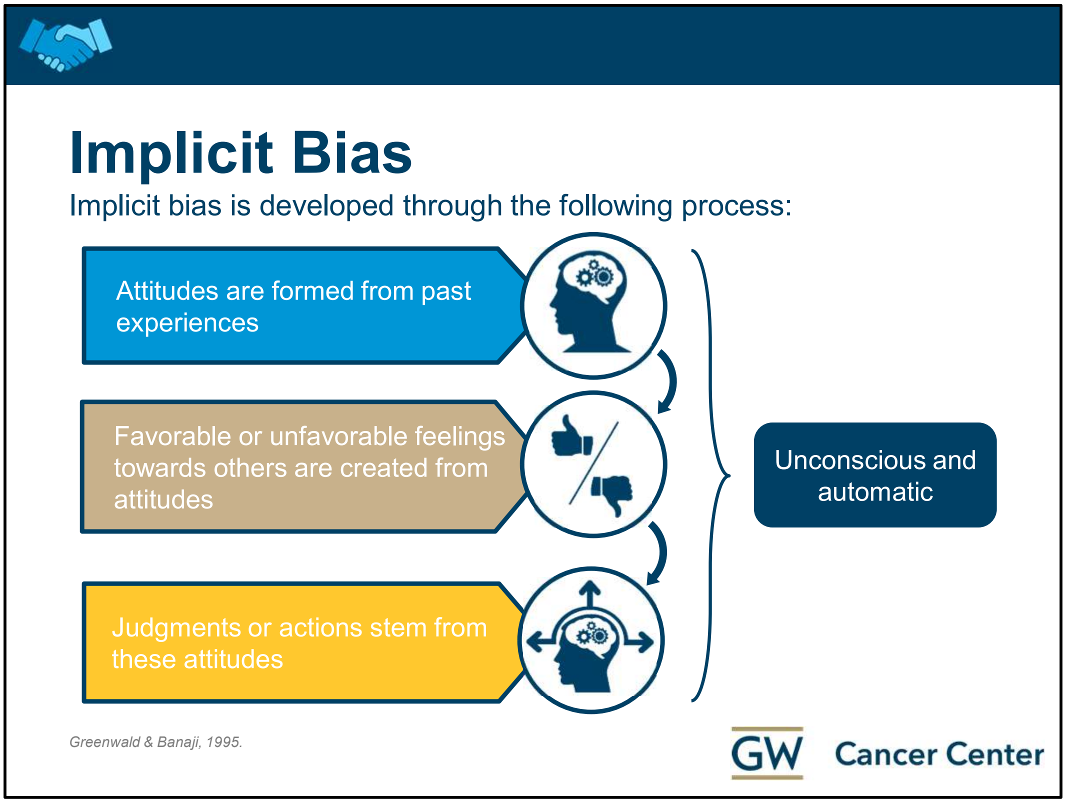
Implicit bias is a term used to describe the assumptions or stereotypes we hold that often influence our thoughts towards or interactions with people without us even knowing. These biases we hold are stimulated unintentionally. Implicit bias is developed through the following process:

- Attitudes are formed from past experiences, but a person cannot necessarily connect these attitudes to past experiences consciously;
- The attitudes then create favorable or unfavorable feelings or thoughts towards others; and
- The attitudes serve as the basis for judgments or actions. However, a person makes these judgments or actions automatically without realizing it or realizing that these existing, long-held attitudes are the cause.

Another way to think about implicit bias is through the analogy of a file cabinet. We use categories to organize our thoughts, and this process extends to people (categorizing them by age, gender, race and other factors). We develop thoughts about a person based on experience – whether it is our own experience or experiences shared with us through others, like our social networks or the media.

We then create files for that group of people based on those experiences. When we meet a new individual from that group, we pull out this file from our mental file cabinet to orient our thinking about that person even before interacting with them. It is human nature to use these files to guide our thinking, and this mental shortcut is something that everyone does through no fault of their own.

These “files” are called schemas. Our brain develops schemas to act as mental shortcuts. We create categories in our mind and recognize those categorized objects without thinking about them. For example, we have a schema for an equal four-sided figure: it is a square. We do not stop and think about the name of such object when we see it. Instead, it is unconscious. We also assign people into schemas using categories of race, age, gender and more. It is important to remember that schemas come from the world around us including families, friends, schools, media and much more.



Implicit Bias

Implicit bias is developed through the following process:

- Attitudes are formed from past experiences
- Favorable or unfavorable feelings towards others are created from attitudes
- Judgments or actions stem from these attitudes

Unconscious and automatic

Greenwald & Banaji, 1995.

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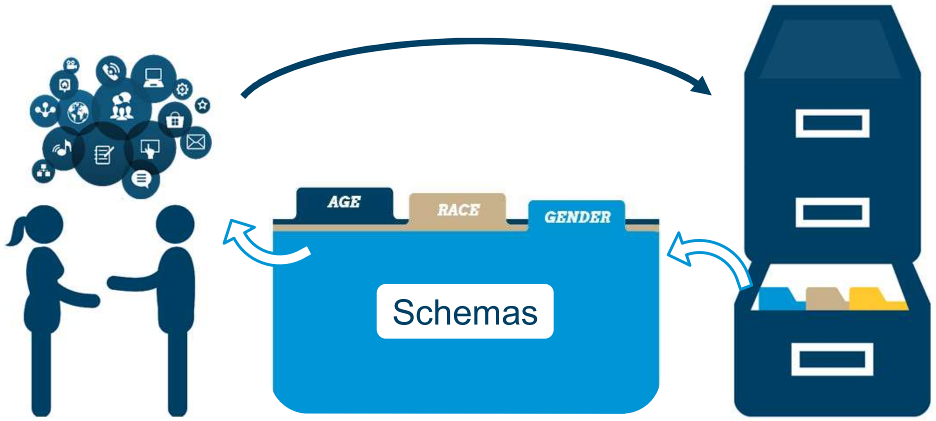
Implicit Bias

When we meet someone new, we pull out a file from our mental file cabinet to orient our thinking



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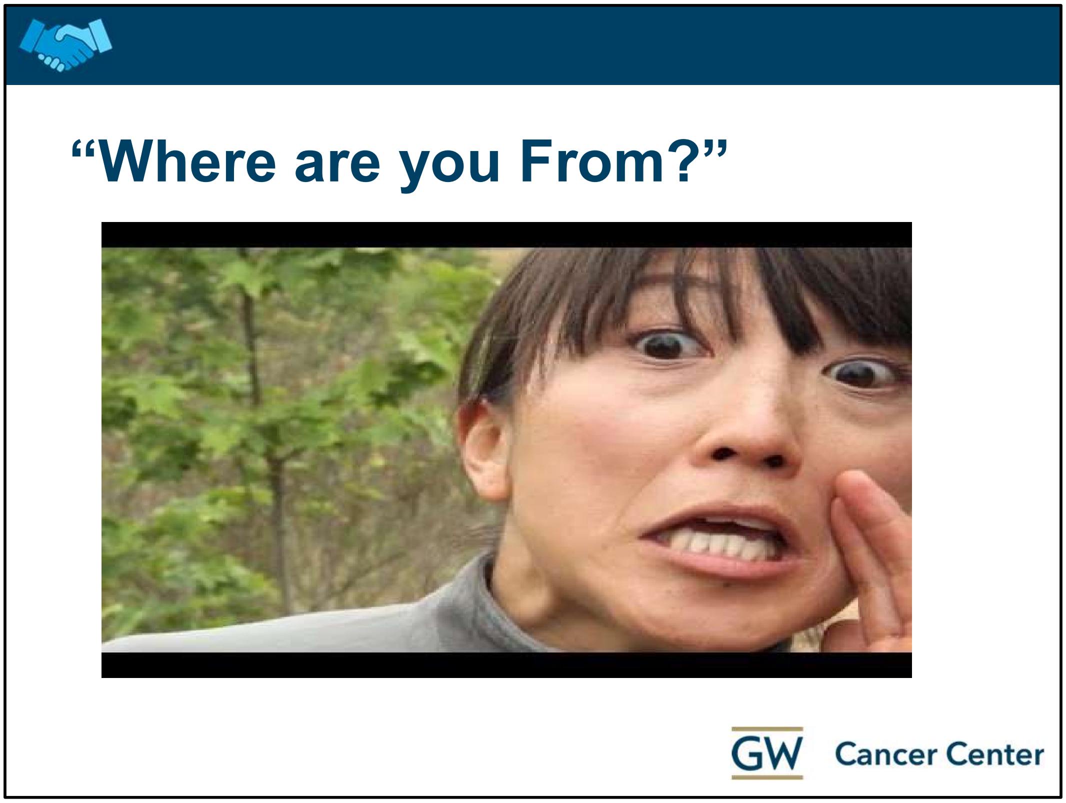
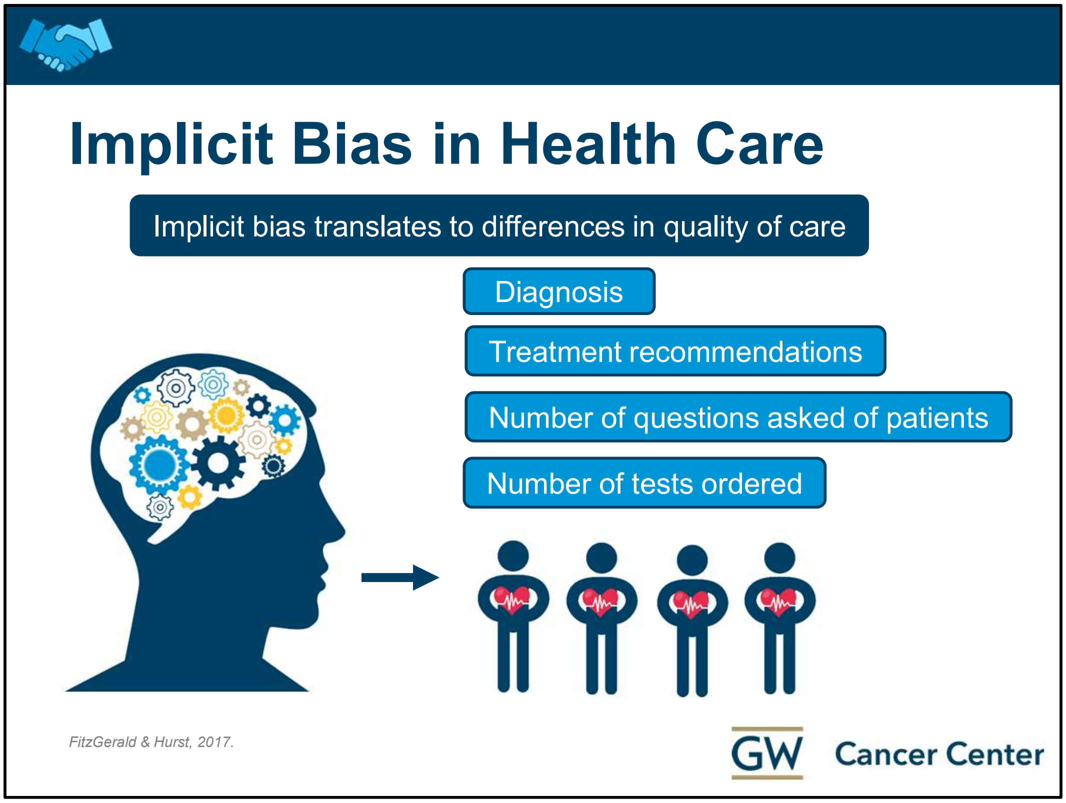


“Where are you From?”

Let’s watch a brief video that helps illustrate implicit bias:

While comical and perhaps over exaggerated, this video highlights how stereotypes and generalizations make a person feel like “other.”

https://www.youtube.com/watch?v=crAv5ttax2I



Implicit Bias in Health Care

Implicit bias translates to differences in quality of care

- Diagnosis
- Treatment recommendations
- Number of questions asked of patients
- Number of tests ordered

FitzGerald & Hurst, 2017.

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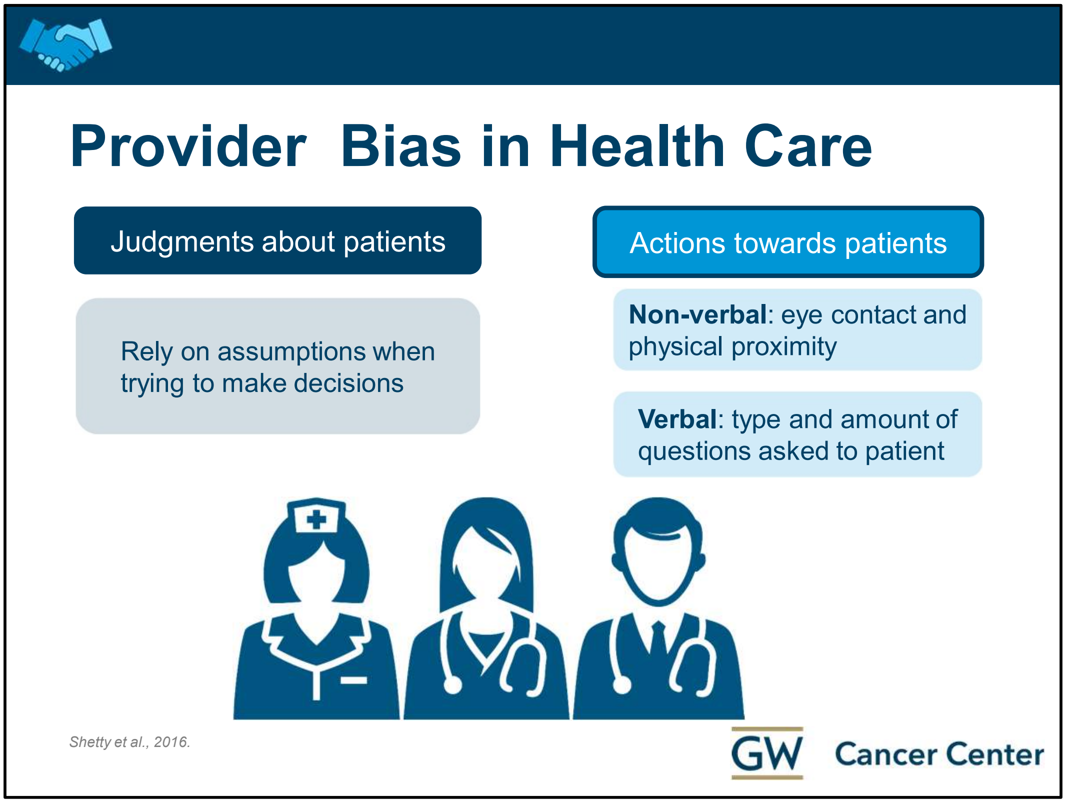
In addition to making someone feel like “other,” implicit bias can affect people’s health. For example, in a systematic review of implicit bias in health care, it has been demonstrated that implicit bias against vulnerable or minority communities translates to differences in the quality of care – whether in terms of diagnosis, treatment recommendations, number of questions asked of patients or number of tests ordered.

Even when implicit bias is not directly measured, providers may make unconscious treatment decisions in ways that divide patients along lines of race or ethnicity. Differences have been found when comparing identical patients (except for a social category, such as race). For example, Black patients receiving less analgesia than White patients. (Chapman, Kaatz, & Carnes, 2013)

Let’s take a deeper dive into how implicit bias negatively affects health and care. Implicit bias influences providers’ judgments about and actions towards patients. In terms of judgments, health care providers may rely upon assumptions when trying to make care decisions efficiently in the face of time pressures. Implicit bias also influences providers’ actions towards patients – both non-verbal actions, like amount of eye contact with and physical proximity to the patient, or verbal actions, like type and amount of questions asked to the patient.

By nature of being unconscious, implicit bias often results in a disconnect between what we explicitly believe, state and want to do (like treating everyone in a respectful and appropriate manner) and what we actually do (like perceiving a Latino patient as less skilled and therefore not including them in the decision-making process). A common example of implicit bias in health care is when health care providers assume that their patient is heterosexual upon first meeting them. Another example of implicit bias is the assumption that African American individuals are less effective communicators in the health care setting than white individuals.

An example of implicit bias specific to cancer care is that health care providers may hold unconscious negative attitudes regarding lung cancer, to a greater extent than for breast cancer. These implicit biases against lung cancer align with the stigma surrounding the disease that people only get lung cancer because they are smokers. It has been suggested that this bias contributes to lung cancer patients' treatment decision-making process.



Provider Bias in Health Care

Judgments about patients

Rely on assumptions when trying to make decisions

Actions towards patients

Non-verbal: eye contact and physical proximity

Verbal: type and amount of questions asked to patient

Shetty et al., 2016.

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Implicit Bias in Health Care

Disconnect between what we believe and what we actually do

Treat everyone respectfully and appropriately

Perceive a Latino patient as less-skilled and not include them in decision-making

Shetty et al., 2016.

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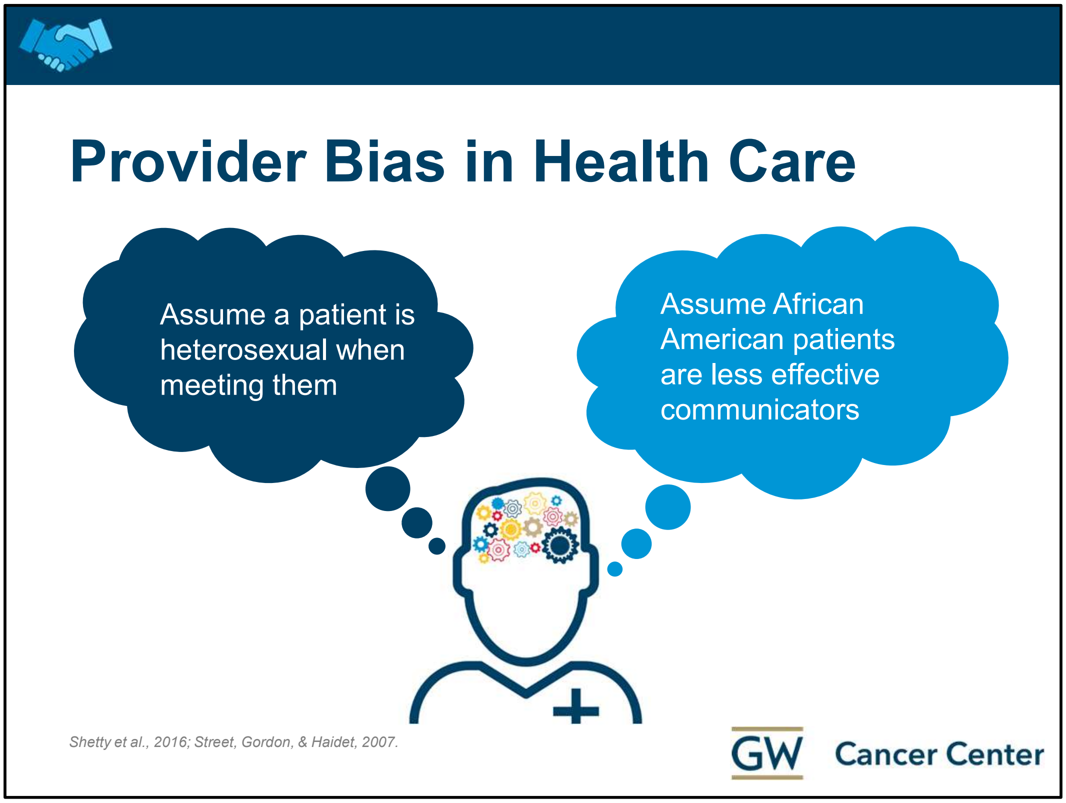

Provider Bias in Health Care

Assume a patient is heterosexual when meeting them

Assume African American patients are less effective communicators

Shetty et al., 2016; Street, Gordon, & Haidet, 2007.

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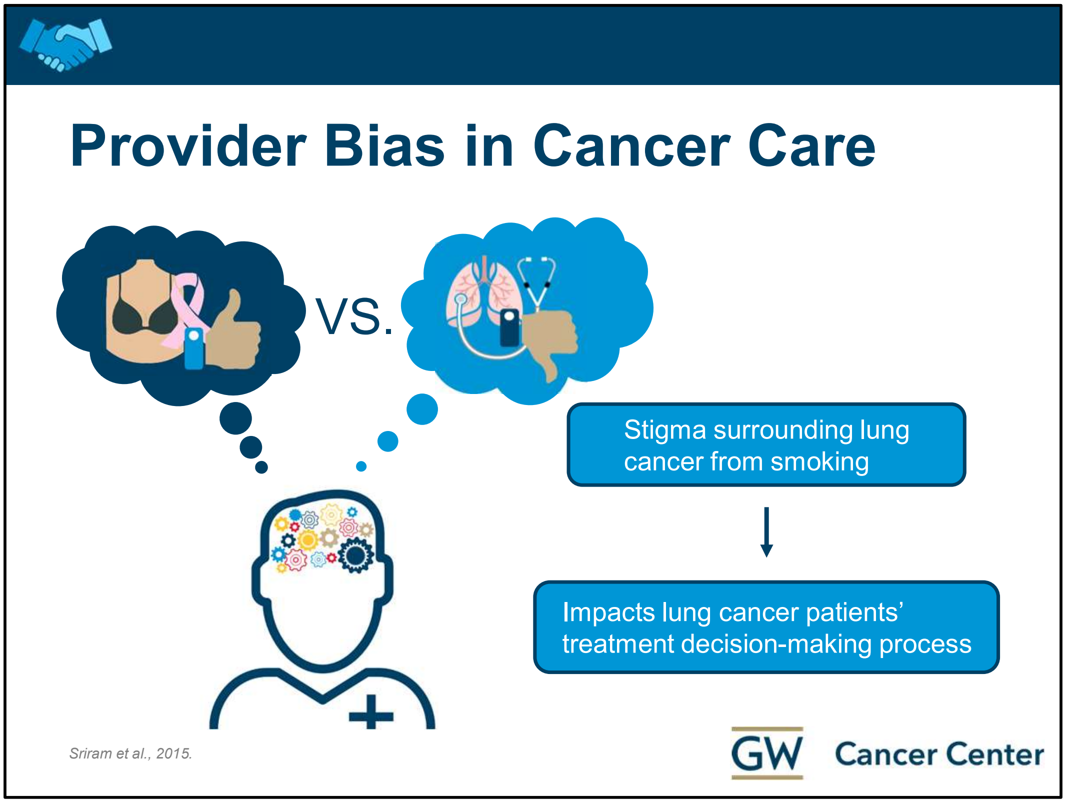

Provider Bias in Cancer Care

Stigma surrounding lung cancer from smoking

↓

Impacts lung cancer patients' treatment decision-making process

Sriram et al., 2015.

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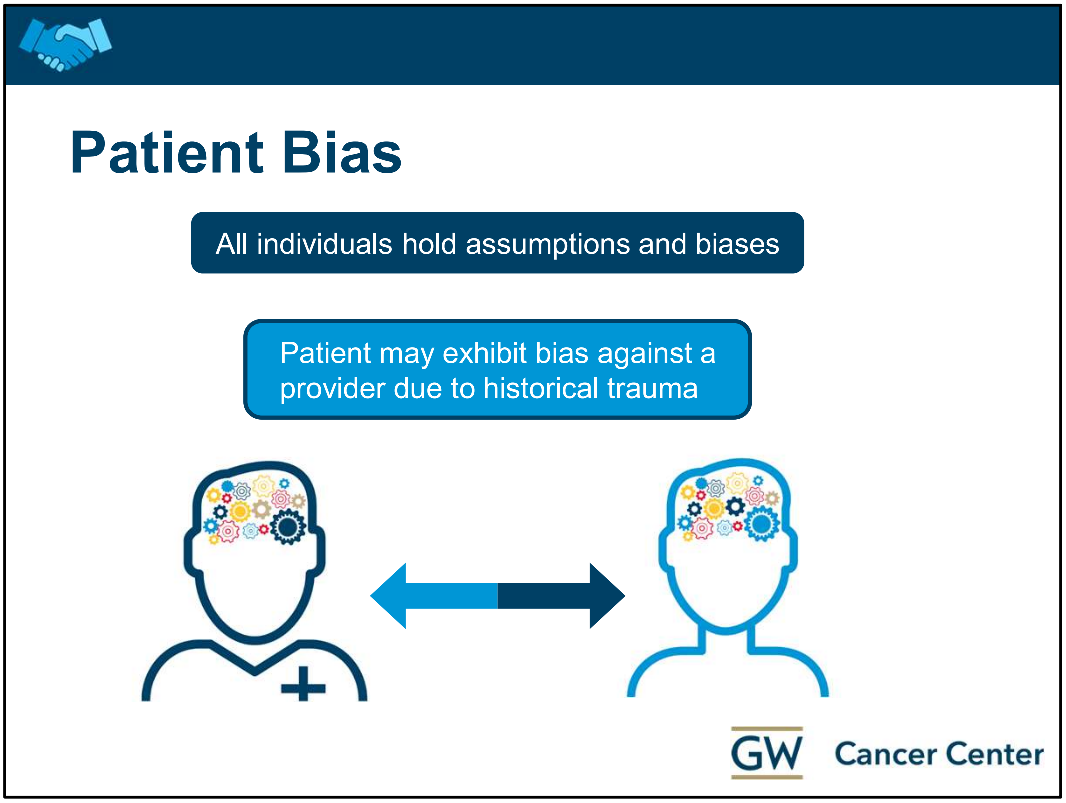

Patient Bias

All individuals hold assumptions and biases

Patient may exhibit bias against a provider due to historical trauma

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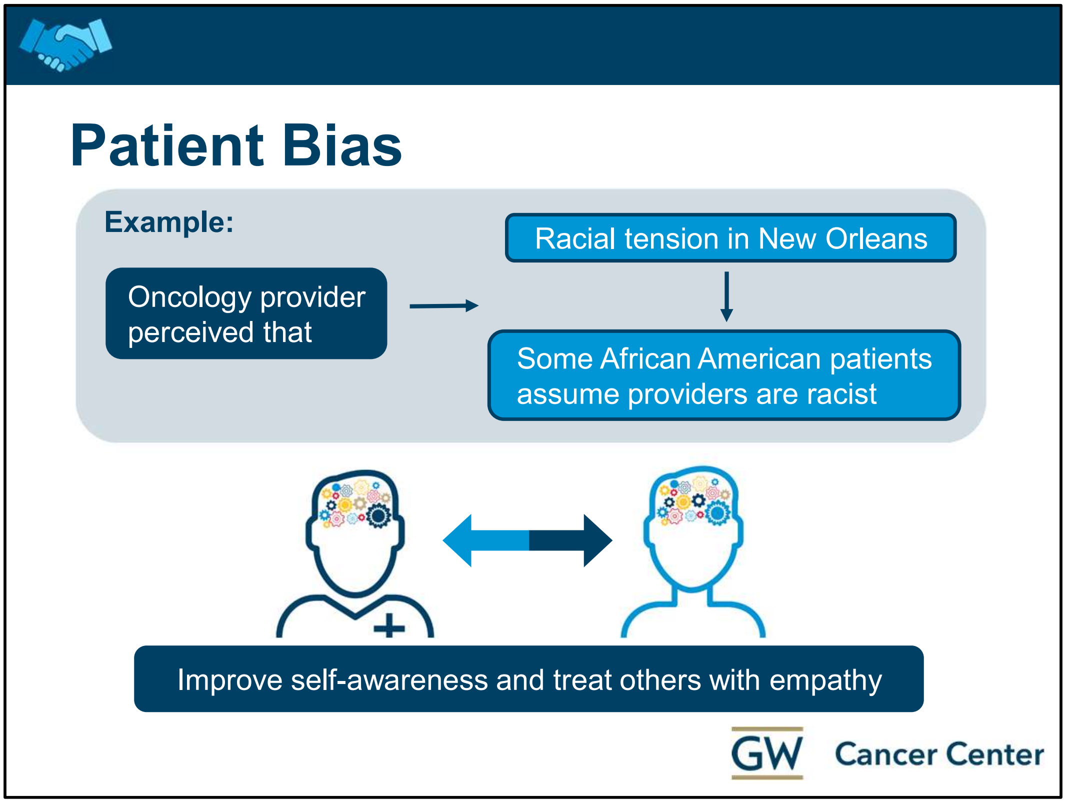
Because this training is geared towards health care professionals, we have talked in detail about the presence of health care professional bias towards patients. However, it is important to remember that all individuals hold assumptions and biases that are reflected in their actions – including patients.

Sometimes, if a patient exhibits bias against a health care professional, it may be due to personal history of poor health care experiences or knowledge of historical discrimination to others within their community that is projected onto that specific health care encounter.

For instance, an oncology provider in the National Cancer Care TEAM Survey reported that they perceived that certain African American patients assumed they were racist because of the racial tension in their city of New Orleans. Because everyone holds biases, what is most important is for all parties involved in the health care encounter to take steps to improve their self-awareness and channel this into empathetic treatment of others. It should be noted, however, that regardless of patients' experiences or biases, providers should always create a welcoming, safe and nonjudgmental environment for their patients.



Patient Bias

Example:

Oncology provider perceived that → Racial tension in New Orleans → Some African American patients assume providers are racist

Improve self-awareness and treat others with empathy

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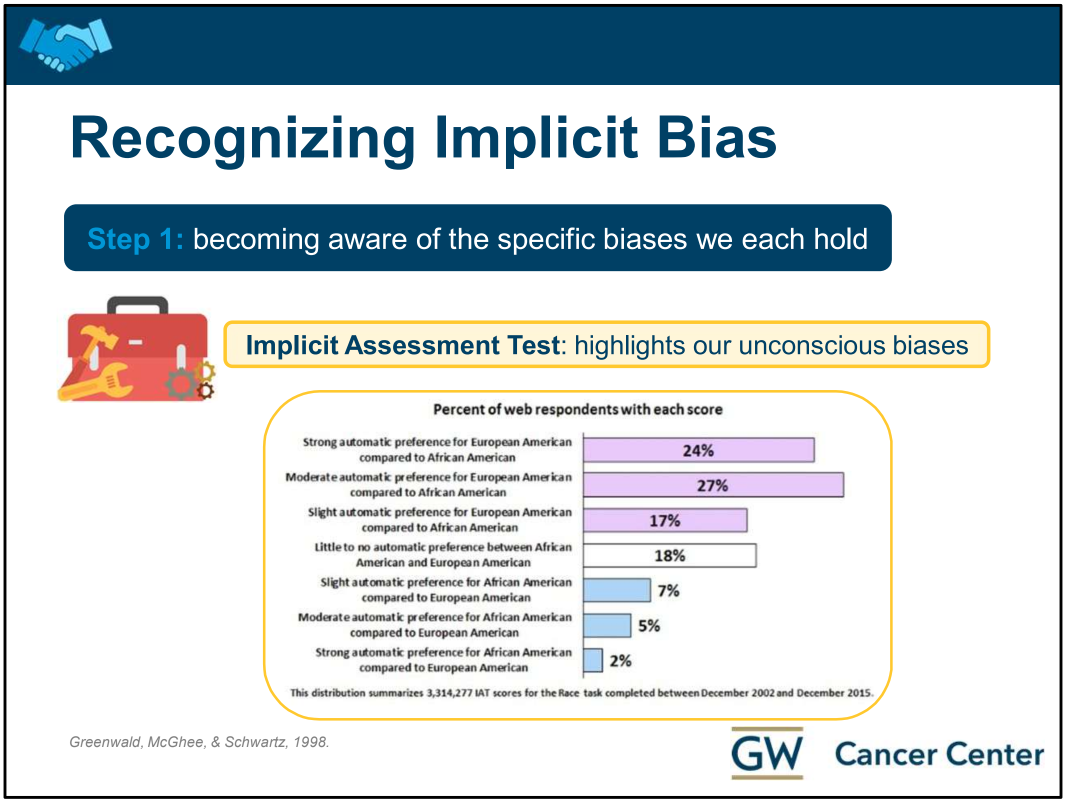

Recognizing Implicit Bias

Step 1: becoming aware of the specific biases we each hold

Implicit Assessment Test: highlights our unconscious biases

Percent of web respondents with each score

Strong automatic preference for European American compared to African American	24%
Moderate automatic preference for European American compared to African American	27%
Slight automatic preference for European American compared to African American	17%
Little to no automatic preference between African American and European American	18%
Slight automatic preference for African American compared to European American	7%
Moderate automatic preference for African American compared to European American	5%
Strong automatic preference for African American compared to European American	2%

This distribution summarizes 3,314,277 IAT scores for the Race task completed between December 2002 and December 2015.

Greenwald, McGhee, & Schwartz, 1998.

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The first step in addressing implicit bias is becoming aware of the idea of unconscious bias and the specific biases we each hold. A key tool used to recognize implicit bias is the Implicit Assessment Test, which has been used frequently in research and practice to assess and highlight unconscious biases. To take the Implicit Assessment Test, see the link in the resources section of the learning management system (https://implicit.harvard.edu/implicit/iatdetails.html).

Many people are often surprised or disappointed by the results of this test. The test is not meant to make you feel guilty, but rather raise awareness of the fact that everyone is susceptible to implicit bias and there are steps people can take to change their behavior.

For instance, a study linked provider implicit bias of African Americans as less adherent to treatment with lower rates of prescribing a certain treatment for heart attacks. However, participants in the study who were aware that the study was examining bias were more likely than their counterparts to prescribe this treatment for African Americans, even if they possessed bias against African Americans.

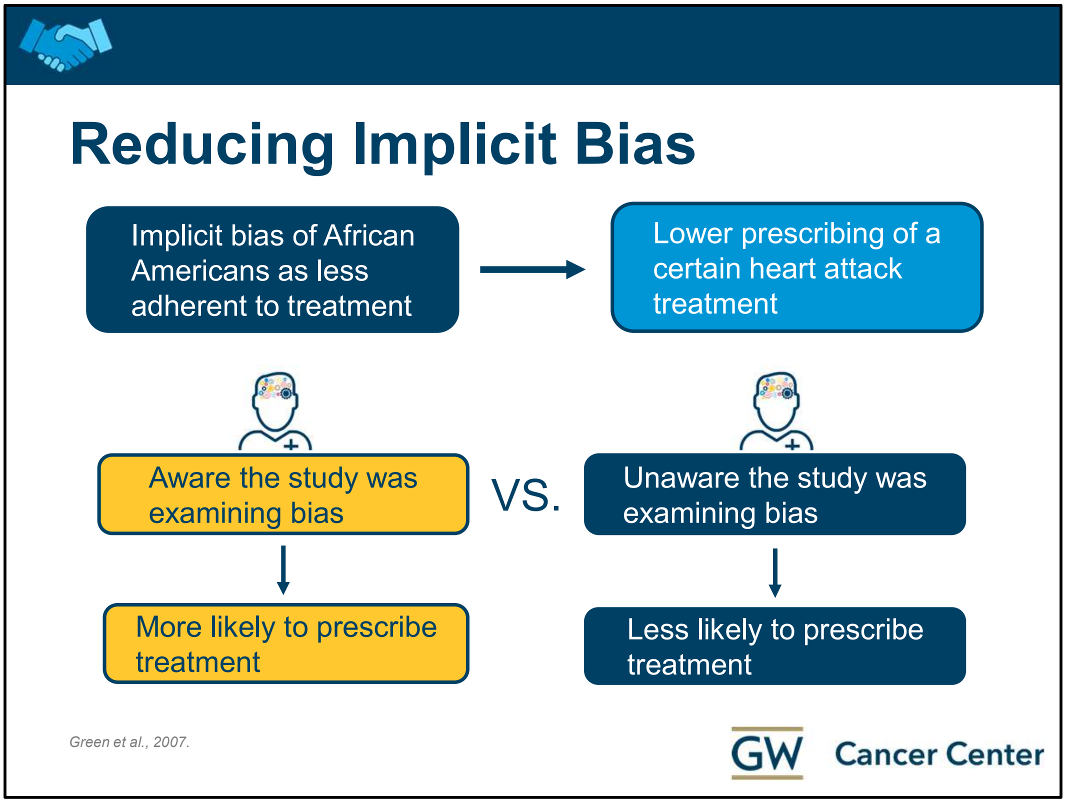
Some other strategies beyond raising awareness proven effective in reducing implicit bias in health care include:

- Individuation – or consciously focusing on the specific information of the individual patient to use that information in decision-making rather than a person’s social category like race or gender. For example, a health care clinician could learn more about what the patient values to further inform decision-making around care.

- Perspective taking – or consciously trying to understand a patient’s view or experience. For example, trying to understand a patient’s previous experience with health care providers, and how that experience could affect their willingness to be open about important sensitive information that could help inform care decisions.

Generally, increased contact with or exposure to a marginalized social group in a positive context may reduce prejudice towards that group over time. Reductions in implicit bias, specifically, have occurred as a result of long-term exposure to individuals who identify as minorities in roles that our society views as important, such as doctors, lawyers or professors.

Beyond just exposure, individuals can take a more active role to reduce their implicit bias. We can imagine counter-stereotypes or practice non-stereotypical judgments to reduce implicit bias or even stop these biases from forming in the first place.



Reducing Implicit Bias

Implicit bias of African Americans as less adherent to treatment → Lower prescribing of a certain heart attack treatment

Aware the study was examining bias → More likely to prescribe treatment

VS.

Unaware the study was examining bias → Less likely to prescribe treatment

Green et al., 2007.

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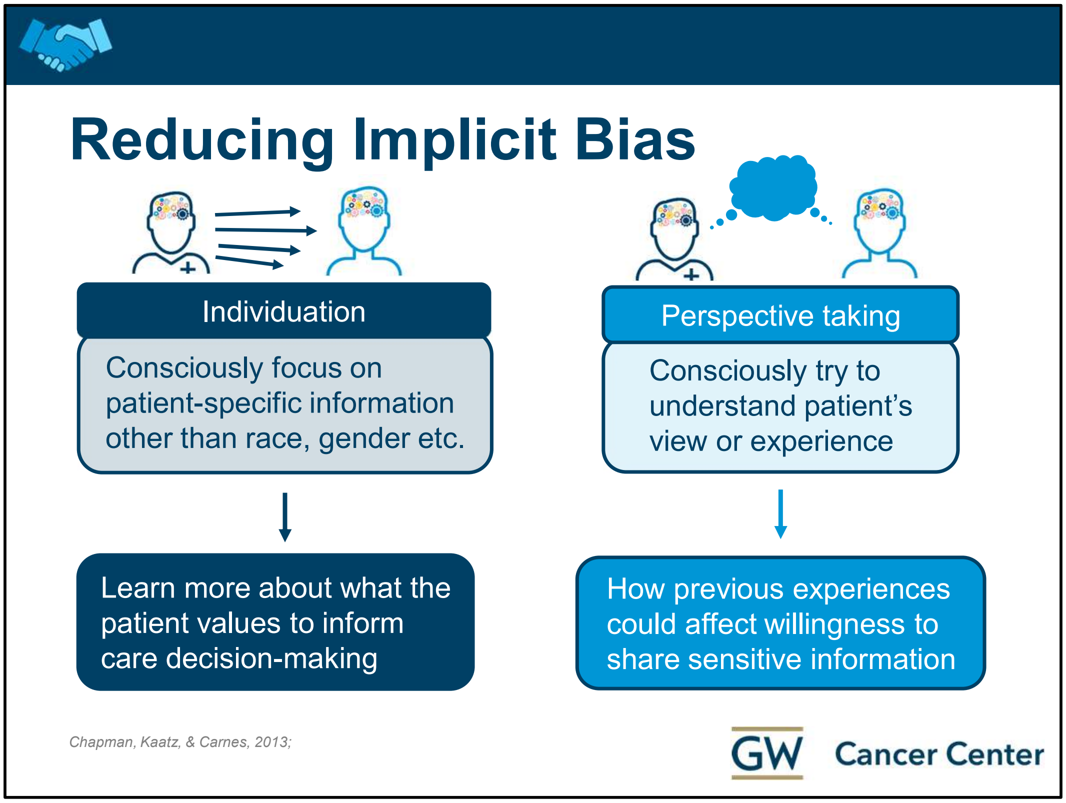

Reducing Implicit Bias

Individuation

Consciously focus on patient-specific information other than race, gender etc.

Learn more about what the patient values to inform care decision-making

Perspective taking

Consciously try to understand patient's view or experience

How previous experiences could affect willingness to share sensitive information

Chapman, Kaatz, & Carnes, 2013;

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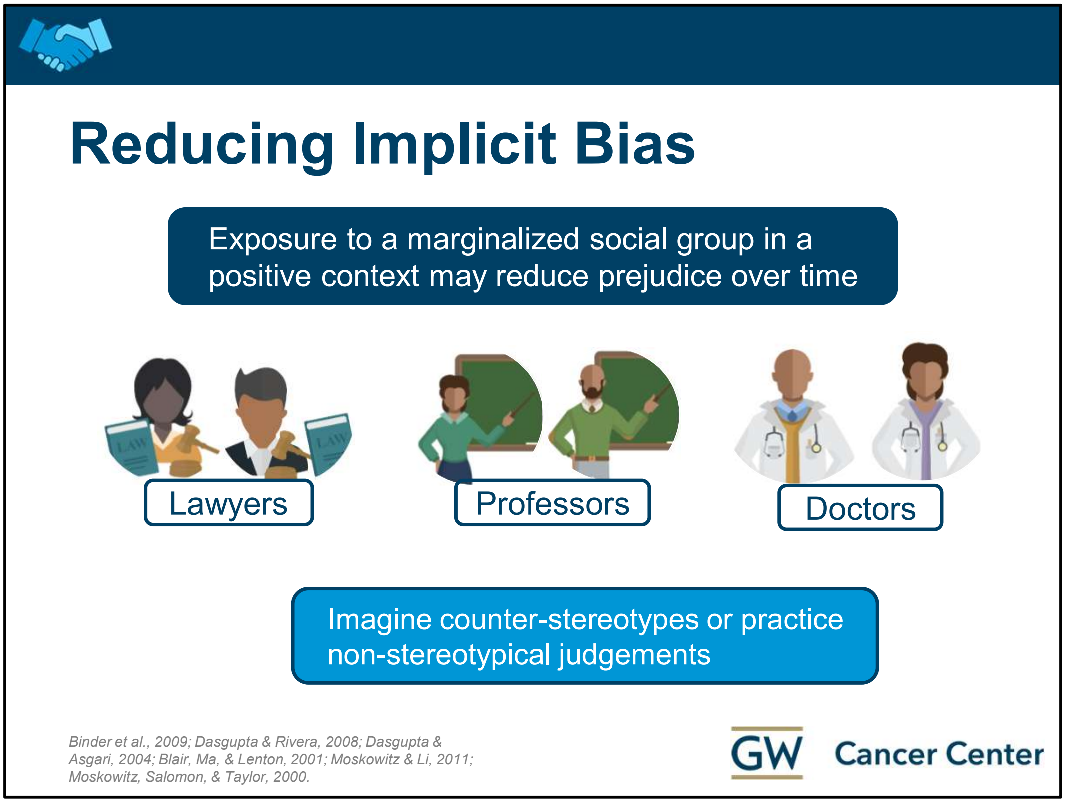

Reducing Implicit Bias

Exposure to a marginalized social group in a positive context may reduce prejudice over time

Lawyers

Professors

Doctors

Imagine counter-stereotypes or practice non-stereotypical judgements

Binder et al., 2009; Dasgupta & Rivera, 2008; Dasgupta & Asgari, 2004; Blair, Ma, & Lenton, 2001; Moskowitz & Li, 2011; Moskowitz, Salomon, & Taylor, 2000.

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Organizational Strategies

Negative comments about racial minority individuals

Increased implicit racial bias

Organizations can commit to tolerance and inclusion to counter this type of environment

Van Ryn et al., 2015.

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In addition to strategies individual health care professionals can take to combat bias in their interactions with patients, organizations can take the initiative to address bias at the systems level by establishing a culture in which all health care professionals are committed to countering bias.

For instance, a study of medical students found that hearing negative comments about racial minority individuals from physicians was associated with their increased implicit racial bias. Therefore, organizations can make explicit commitments to tolerance and inclusion to counter this damaging affect.

Organizations should consider strategies to address bias that meet the social and psychological needs of their staff.

Strategies are most effective at addressing bias when they:

- Enhance internal motivation to reduce bias, while avoiding external pressure or a threatening environment
- Suggest the idea that there is a psychological basis of bias, so that bias is acknowledged and addressed, and not denied or suppressed;
- Enhance providers’ confidence in their ability to interact with patients from different

backgrounds by providing opportunities for more encounters;

- Promote time for stress reduction to help staff avoid generalizations, focus on patients' needs and demonstrate empathy; and
- Encourage patient-provider partnerships founded on common goals.

While we all hold implicit biases, these biases can impact a patients' health outcomes – from not feeling welcomed upon entering the health care facility to the clinical care received. However, individuals and organizations can use the strategies discussed to address implicit bias to improve care and ultimately health outcomes.

Organizational Strategies

- ✓ Enhance motivation to reduce bias
- ✓ Present the idea there is a psychological basis of bias
- ✓ Increase providers’ confidence to interact with diverse patients
- ✓ Promote positive emotional states among staff
- ✓ Stress partnerships & finding common goal with patients

Burgess, van Ryn, Dovidio, & Saha, 2007.

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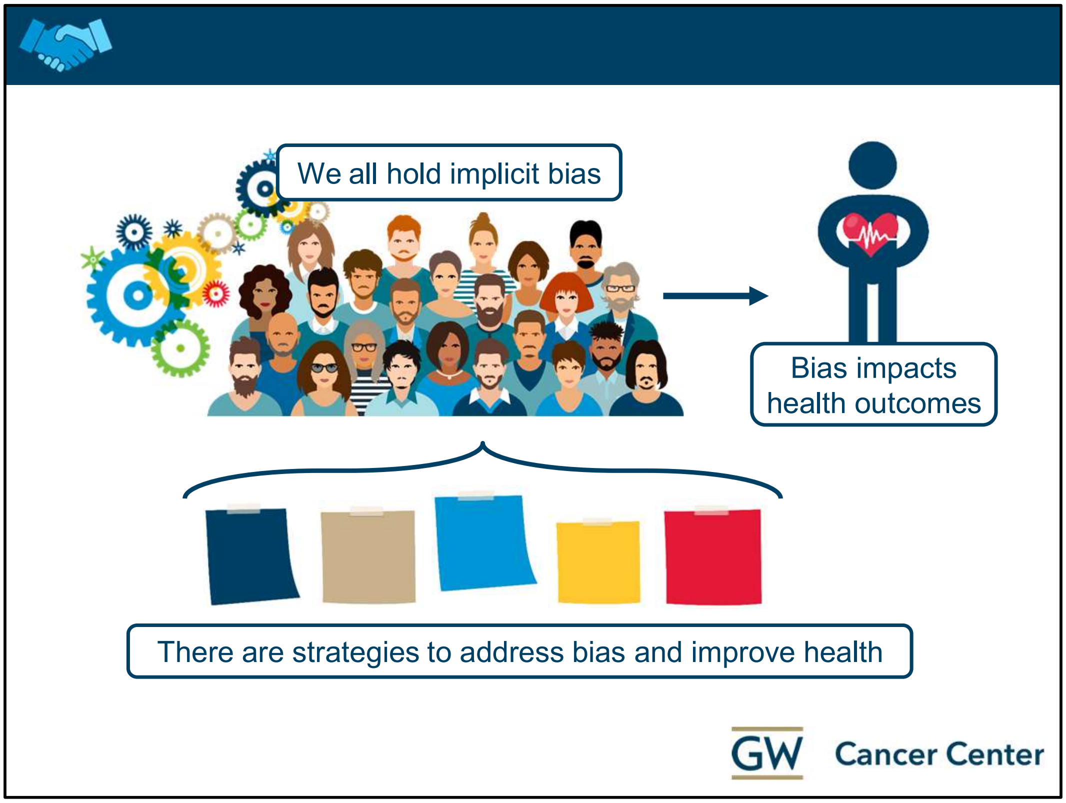

We all hold implicit bias

Bias impacts health outcomes

There are strategies to address bias and improve health

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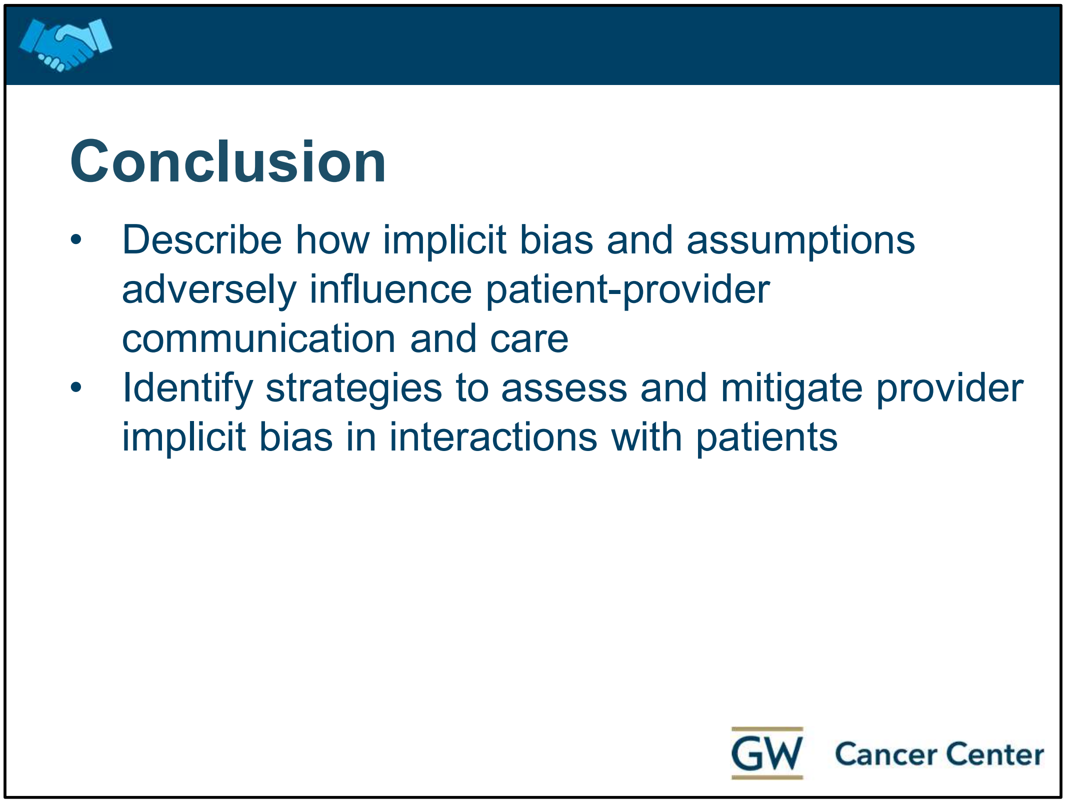
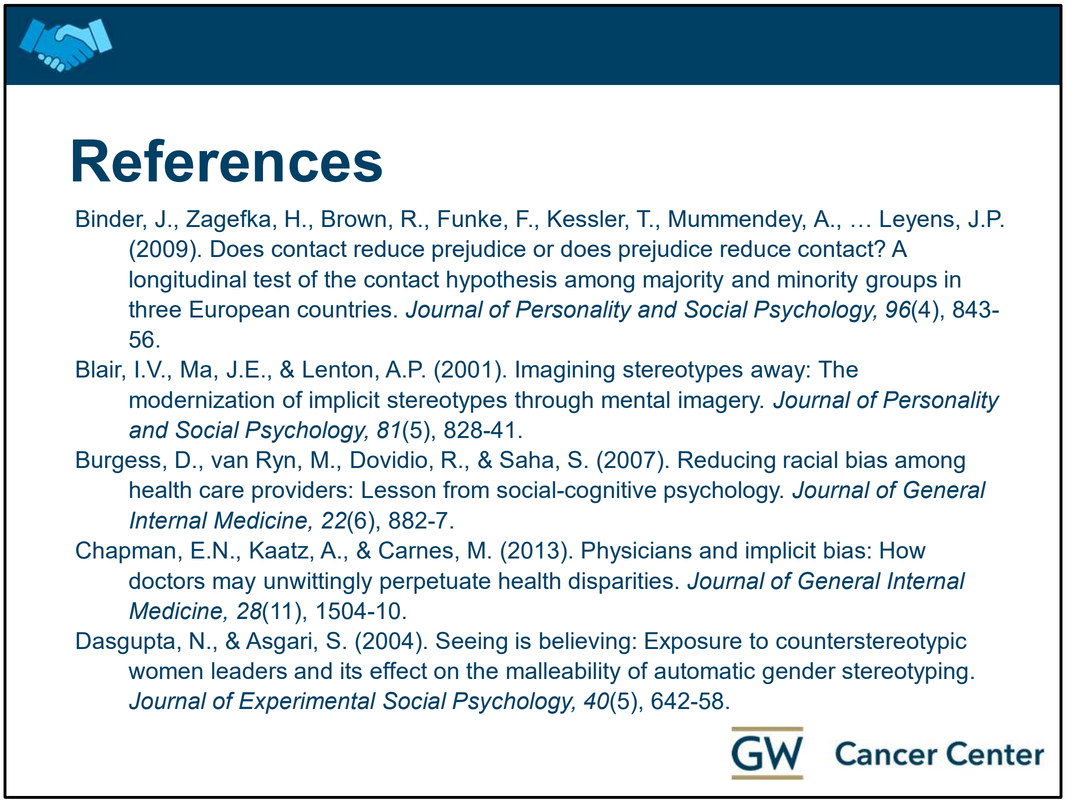


Conclusion

- Describe how implicit bias and assumptions adversely influence patient-provider communication and care
- Identify strategies to assess and mitigate provider implicit bias in interactions with patients

In this lesson, you learned to:
Describe how implicit bias and assumptions adversely influence patient-provider communication and care
Identify strategies to assess and mitigate provider implicit bias in interactions with patients



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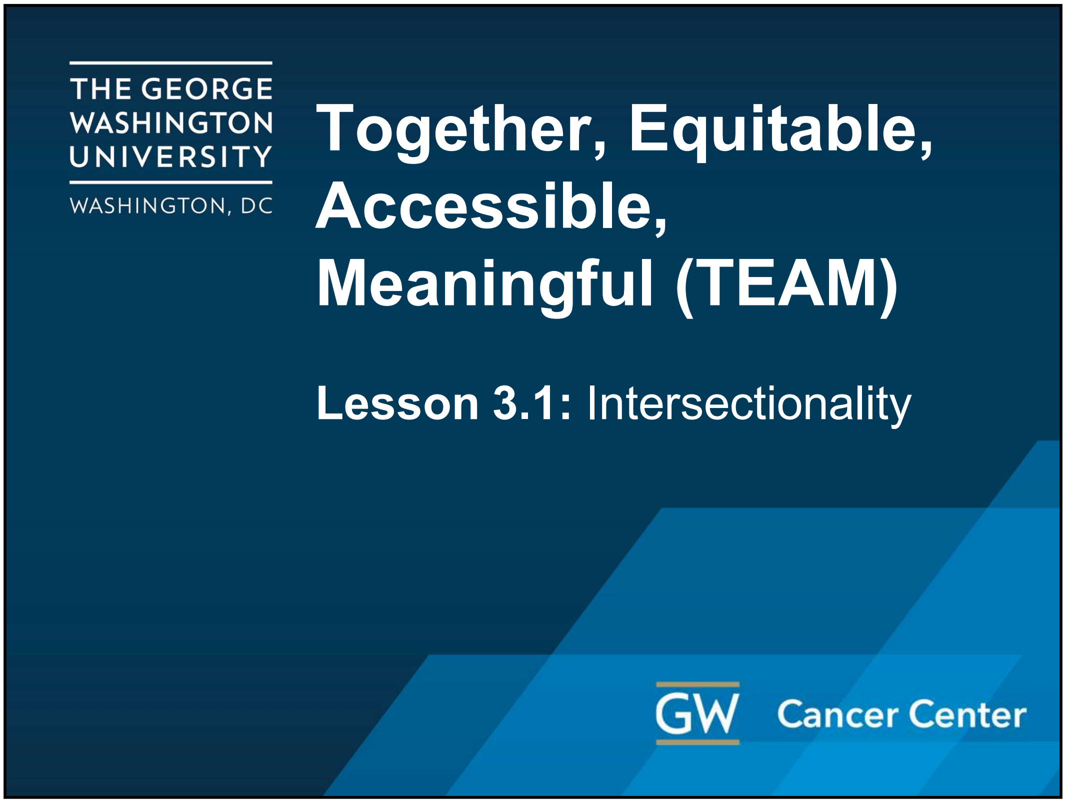

THE GEORGE
WASHINGTON
UNIVERSITY
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Together, Equitable, Accessible, Meaningful (TEAM)

Lesson 3.1: Intersectionality

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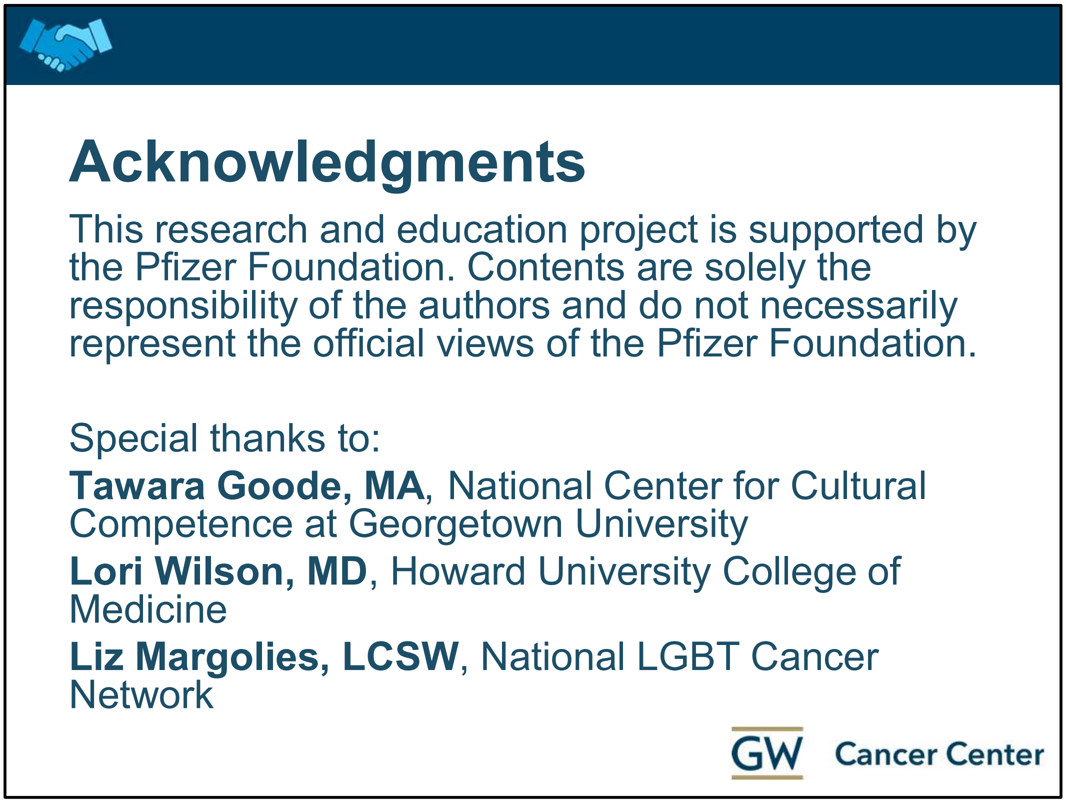
Welcome to Module 3, Lesson 1: Intersectionality



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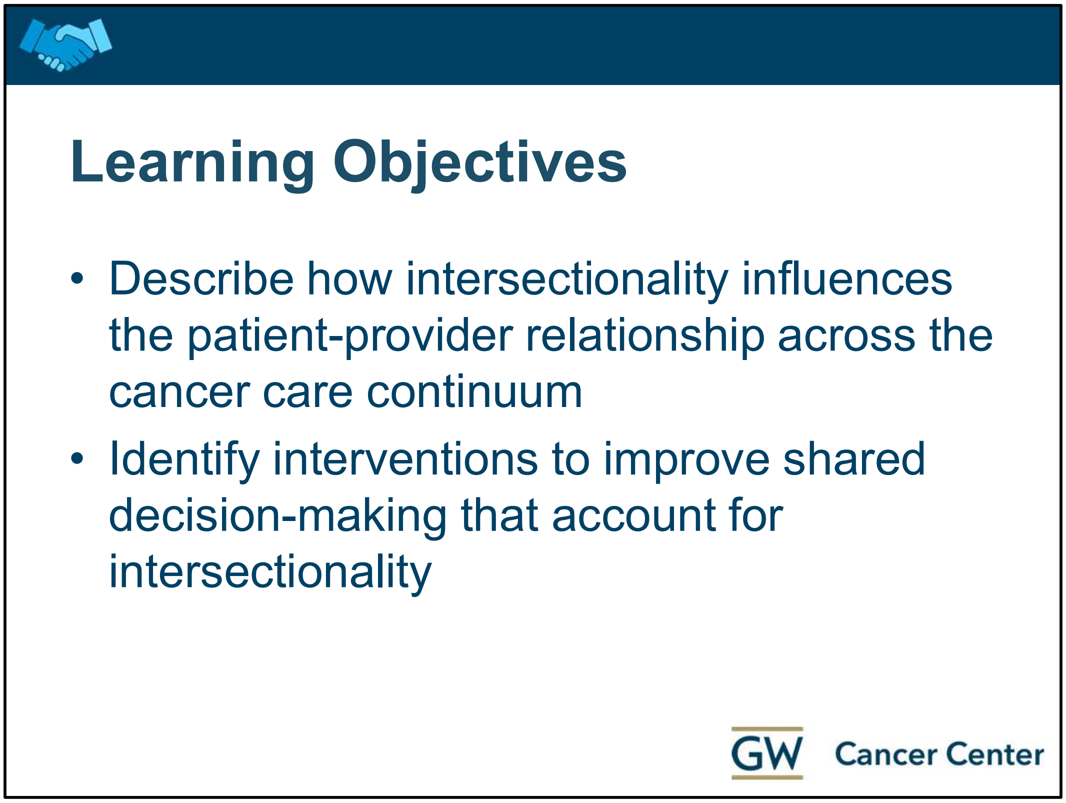

Learning Objectives

- Describe how intersectionality influences the patient-provider relationship across the cancer care continuum
- Identify interventions to improve shared decision-making that account for intersectionality

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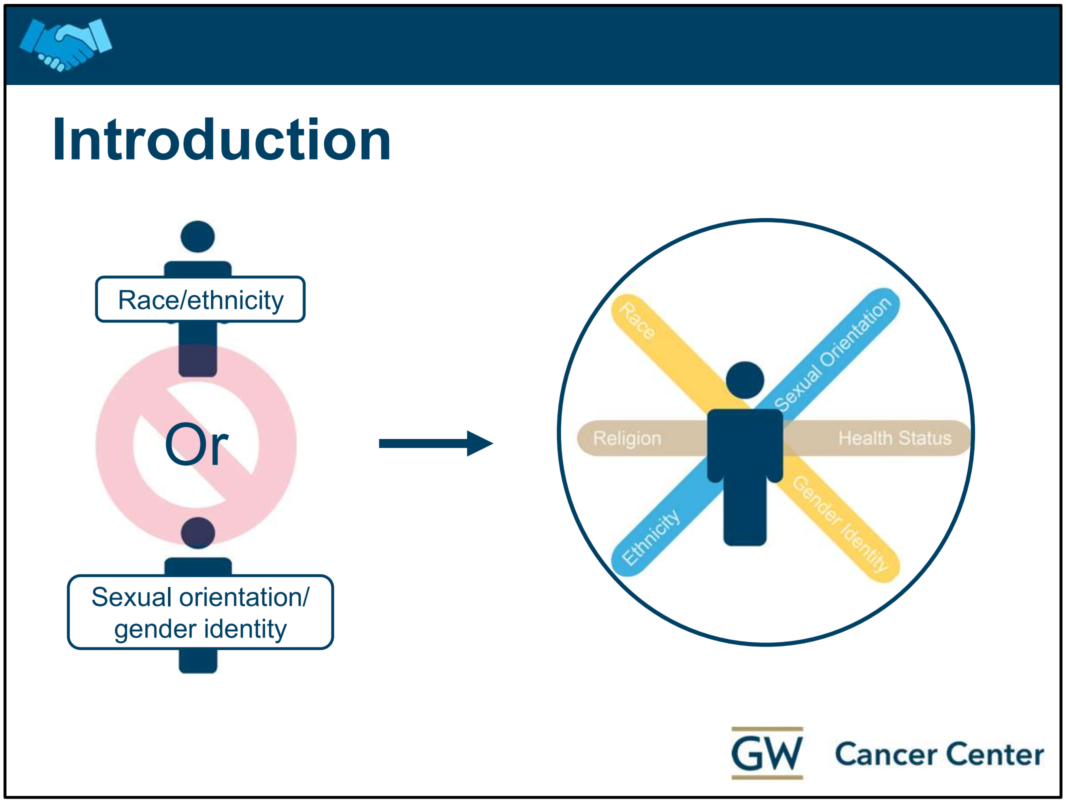
After completing this lesson, you will be able to:

- Describe how intersectionality influences the patient-provider relationship across the cancer care continuum
- Identify interventions to improve shared decision-making that account for intersectionality



Introduction

Any number of things make up our view of ourselves and the experiences we have with the world around us – not just race, ethnicity, sexual orientation and gender identity, but also health status, religion, political affiliation and more.

A person may hold one identity as their primary identity. That is an identity that they consider most important or most central to their life. For instance, this could be someone's religion. An individual's primary identity may change over the course of their life.

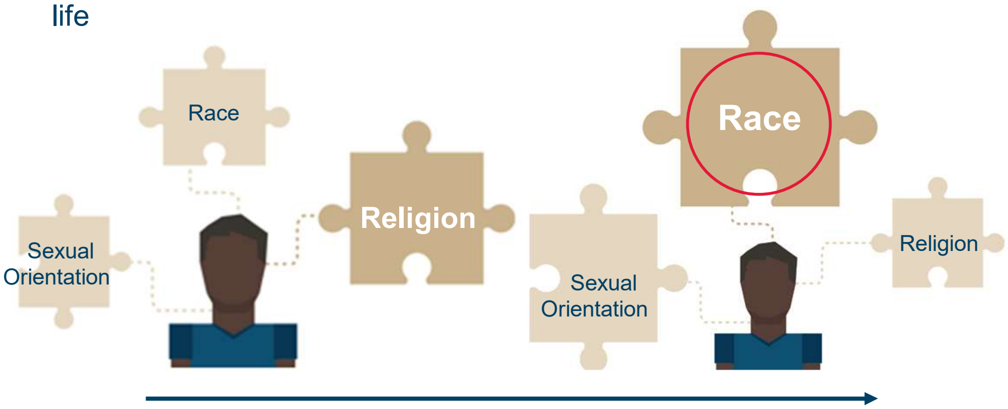
For example, a Somali refugee may feel like her cultural heritage or religion is the most important part of her identity during the first years of transitioning to living in the U.S. However, after overcoming challenges associated with living in the U.S and settling in her new community, her race may become her primary identity.

People have many identities that shape their lives. There are some identities visible to the world and some that are not. For example, a woman with multiple sclerosis may choose not to disclose her condition to others, but another woman who uses a wheelchair cannot hide this aspect of herself. Some lightskinned or biracial people of color may appear white to others. They may choose to disclose their racial identity or hide it.

Also, many trans people pass easily as their true gender with or without gender affirming surgeries. They may choose only to disclose their gender when necessary, like when dealing with relevant health issues. All of these identities, visible or not, public or private, can shape a person’s health needs, beliefs and experiences.

Individual Identity

An individual’s primary identity may change over the course of their life



Race

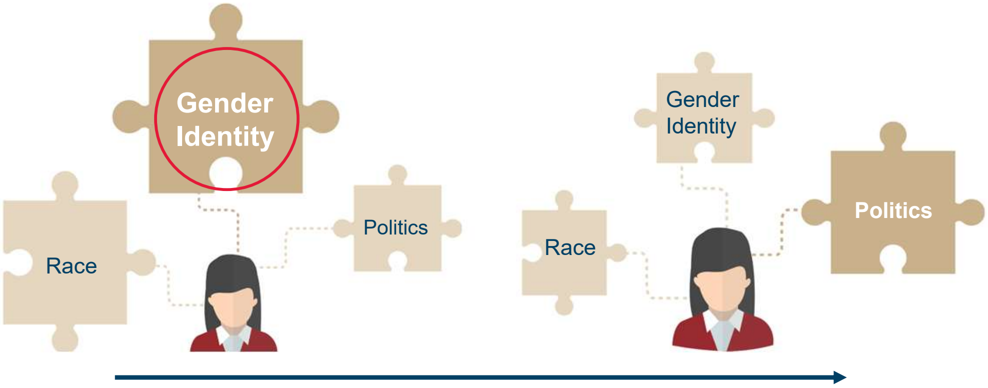
Sexual Orientation

Religion

Race

Sexual Orientation

Religion



Gender Identity

Race

Politics

Gender Identity

Race

Politics

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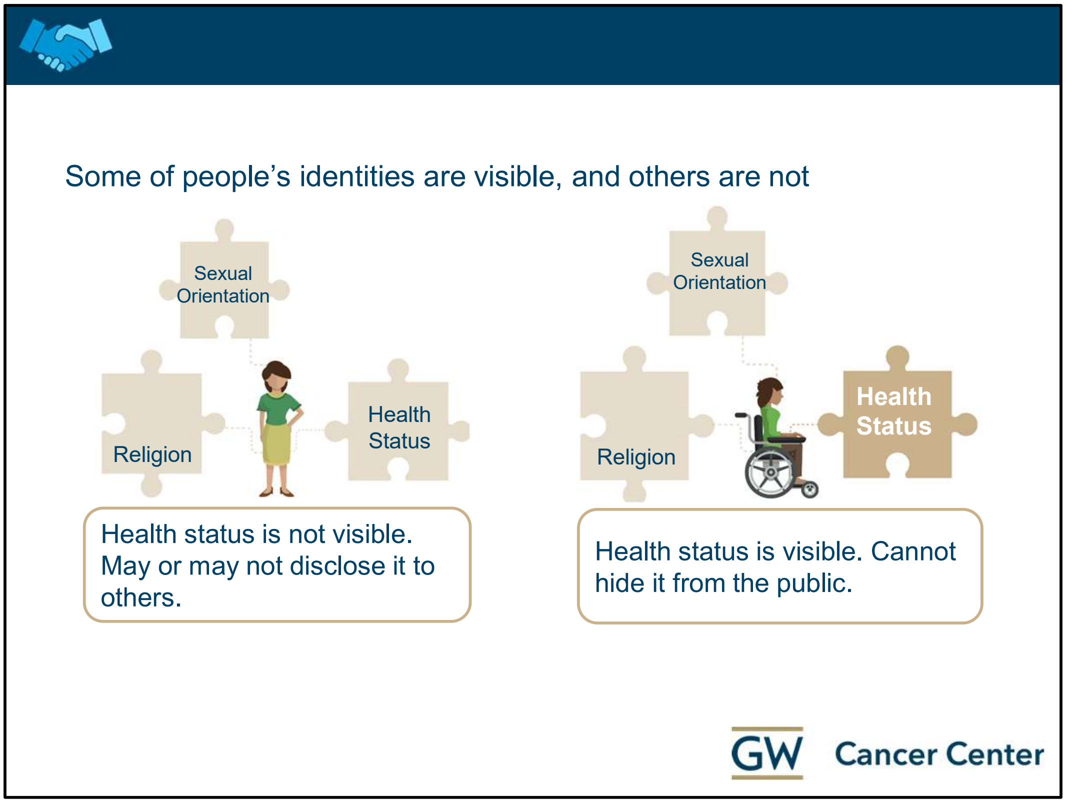

Some of people’s identities are visible, and others are not

Health status is not visible. May or may not disclose it to others.

Health status is visible. Cannot hide it from the public.

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Intersectionality

Multiple oppressions are **intertwined** and **inseparable**

Crenshaw, 1989; Crenshaw, 2003; Hankivsky, 2014.

The theory of intersectionality helps us better understand a person's lived experience and the many identities they have. Intersectional theory argues that multiple oppressions are intertwined and inseparable.

Simply put, a person's identities and the challenges they face due to these identities cannot be explained by only taking a single category into account and leaving the rest on the side.

Instead, every aspect of their experience must be acknowledged and honored. When health care professionals and organizations approach and interact with patients through an intersectional lens (rather than putting patients into a box that appears to be the best fit) it can result in more sensitive and productive interactions and care.

A person's identity and challenges cannot be explained by a single category

Every aspect of a person's experience must be acknowledged

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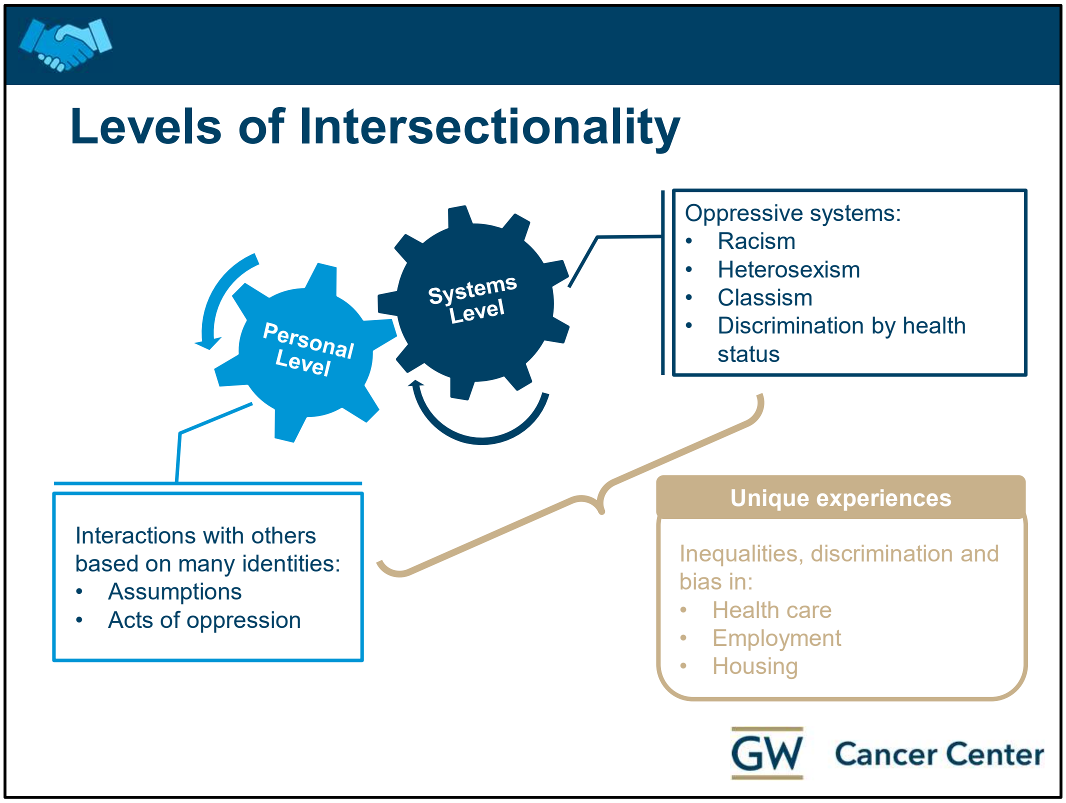

Levels of Intersectionality

Personal Level

Systems Level

Oppressive systems:
- Racism
- Heterosexism
- Classism
- Discrimination by health status

Interactions with others based on many identities:
- Assumptions
- Acts of oppression

Unique experiences

Inequalities, discrimination and bias in:
- Health care
- Employment
- Housing

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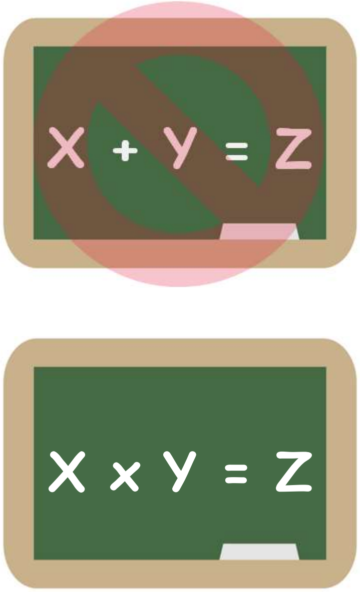
Intersectionality is experienced at the personal and systems levels. At the personal level, an individual has interactions with others, which can include assumptions and acts of oppression, based on their many identities. For example, when a white person expresses visual or verbal surprise when a woman of color states that she went to an Ivy league college.

These interactions work together to create unique experiences. At the systems level, systems that cause oppression, like racism, heterosexism, classism, and discrimination by health status reinforce each other to determine a person's experience. These experiences can include inequalities, discrimination and bias, and can happen in many places like health care, work, housing and more.

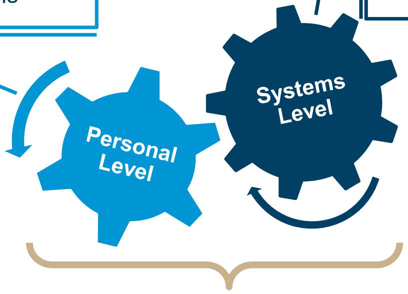
Let's take a moment to emphasize this point further. People experience –isms and –phobias (like racism, sexism, homophobia, transphobia and others) in person-to-person interactions in the form of discrimination. They also experience –isms and –phobias in the policies, structures and customs that shape the society they live in.

These –isms and –phobias (whether at the personal or societal levels) do not act freely of one another. Instead, they are a part of <u>interconnected</u> systems. They create experiences of oppression and discrimination that are different for each person. Because of this, we can't just add up every new struggle someone faces to understand their life. Instead, we have to look at their struggles as multiplying or compounding one another to create a system of challenges and barriers.



Discrimination in interpersonal interactions

Policies, structures and customs



-isms and -phobias

- Racism
- Sexism
- Homophobia
- Transphobia
- More

Dobson, 2013.

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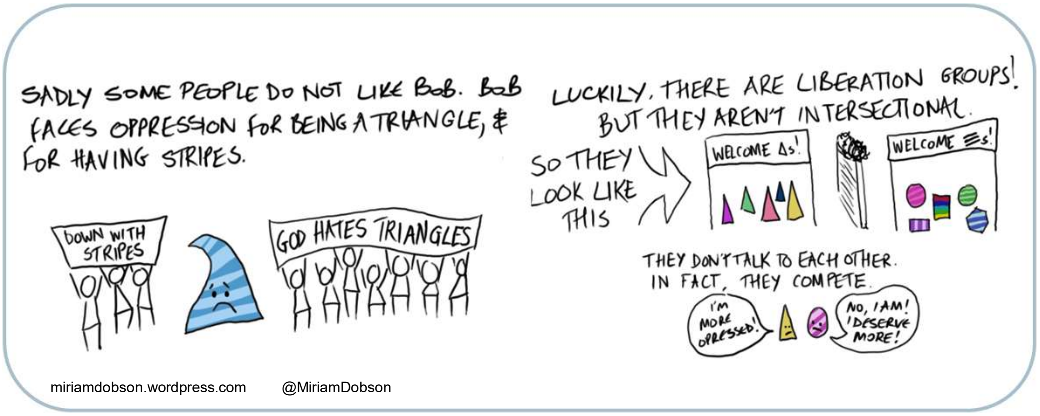
The cartoon of Bob the stripey blue triangle helps illustrate intersectionality. Bob faces unique experiences, including oppressions, for being a triangle and for having stripes.

However, efforts to address the oppressions Bob faces only deal with being a triangle or having stripes. Bob is not able to pick one aspect of himself and abandon the other. He is not just a triangle. He doesn’t just have stripes.

So any real approach to address Bob’s experiences, including the oppressions he faces, has to treat these oppressions as interrelated.

https://miriamdobson.com/2013/07/12/intersectionality-a-fun-guide-now-in-powerpoint-presentation-formation/
Miriam Dobson



miriamdobson.wordpress.com @MiriamDobson

Dobson, 2013.

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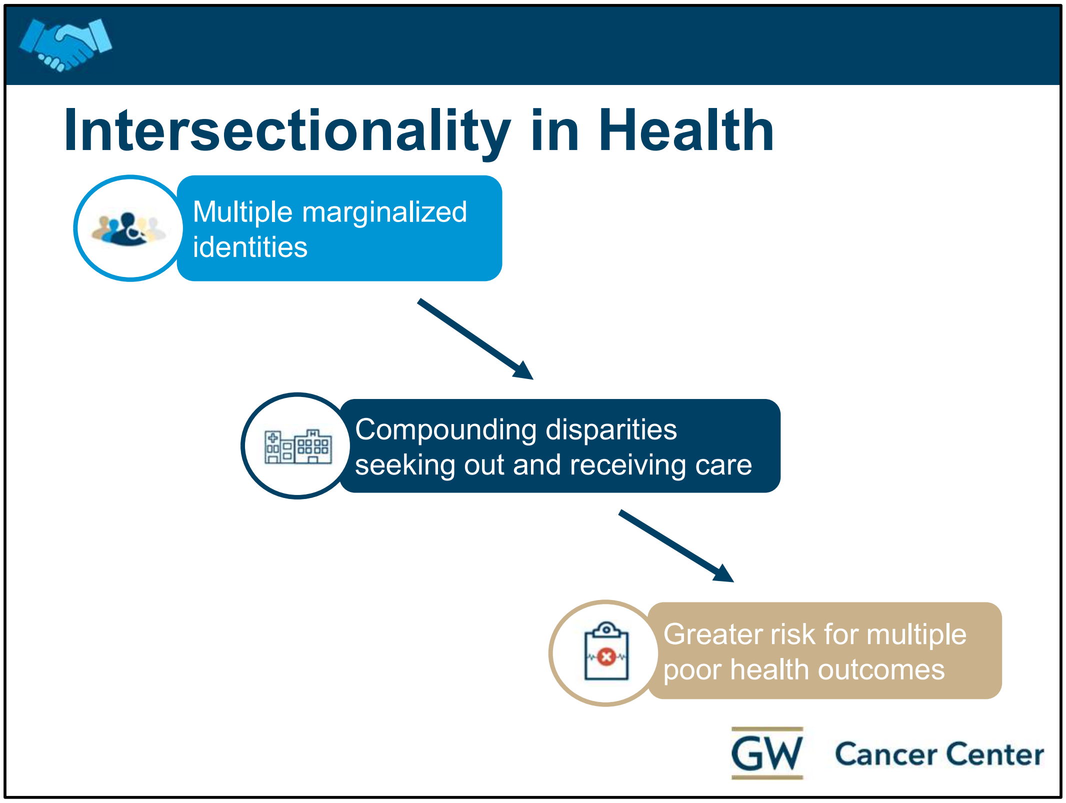
Dobson, 2013.



Intersectionality in Health

Multiple marginalized identities

Compounding disparities seeking out and receiving care

Greater risk for multiple poor health outcomes

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Intersectionality affects people’s health. Individuals who identify with more than one marginalized or vulnerable group (minority race, ethnicity, low socioeconomic status, etc.) are at greater risk for multiple poor health outcomes.

This is because they are members of many groups that face disparities in seeking and receiving care, so these disparities are compounded.

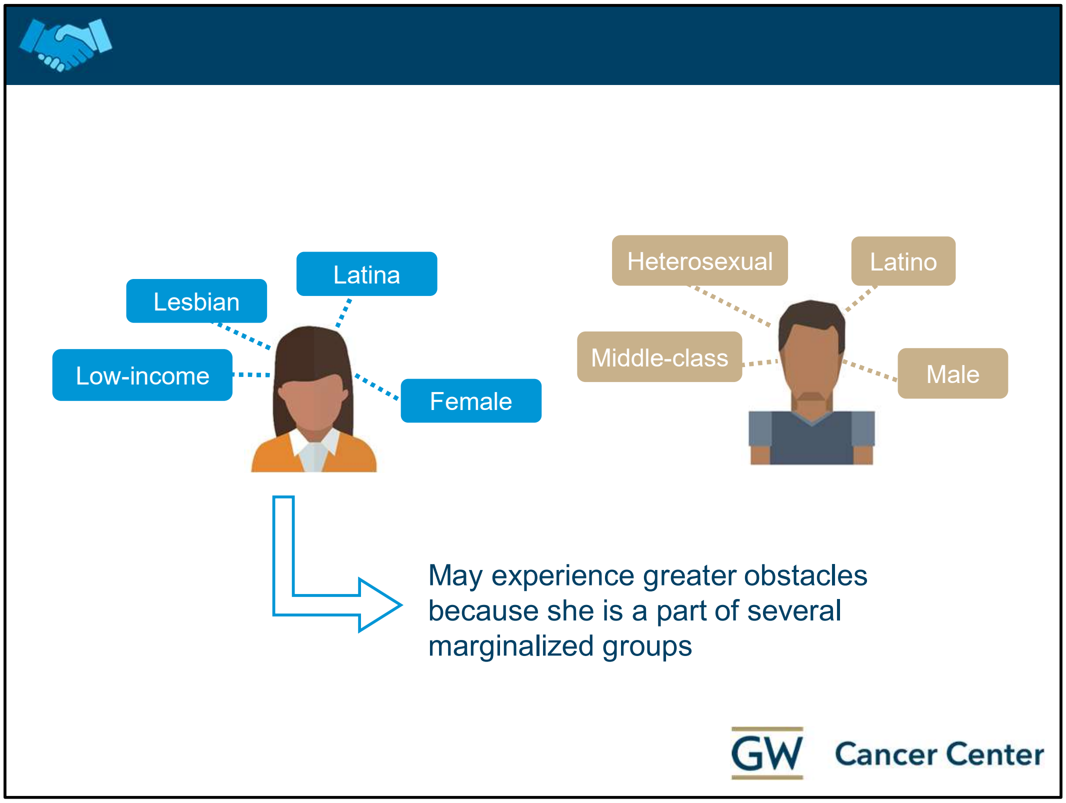
For example, two Latino individuals could be receiving cancer care from a health system at the same time.

One is a low-income, lesbian Latina woman and the other is a middle-class, heterosexual Latino man.

Despite being of the same ethnicity, these individuals can have vastly different experiences in the health care setting.

For instance, if both are examined by a Latina nurse, the Latino man may feel more comfortable with the nurse due to shared ethnicity, while the Latina woman may feel alienated and concerned that she cannot talk about sexual orientation or her partner.

Also, while they both may experience barriers in accessing care, the low-income, lesbian Latina woman could potentially experience greater obstacles due to the fact that she is a part of multiple marginalized groups compared to the middle-class, heterosexual Latino man.



Lesbian

Latina

Low-income

Female

Heterosexual

Latino

Middle-class

Male

May experience greater obstacles because she is a part of several marginalized groups

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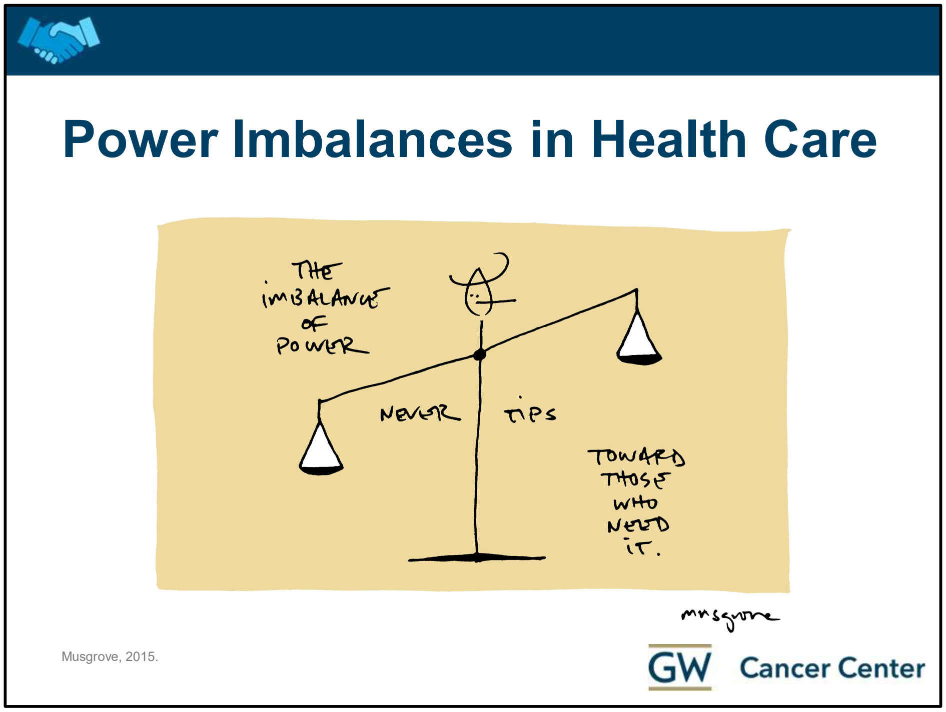


Power Imbalances in Health Care

Musgrove, 2015.

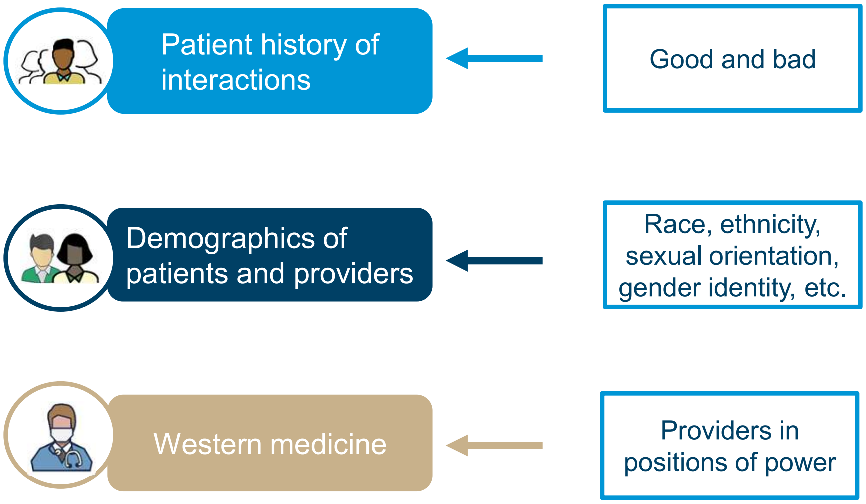
The intersection of a person’s identities, experiences and past oppressions cause significant power imbalances. In health care relationships, power dynamics are shaped by a patient’s history of interactions (both good and bad) in the health care setting.

They are also shaped by power differences between the patient and any given provider because of race, ethnicity, sexual orientation and gender identity.

Power dynamics are also shaped by the fact that Western medicine often puts providers in positions of power over patients.

For instance, in interviews and focus groups with African American men about prostate cancer screening, one participant explained why he thought African American men often don’t ask their providers questions: He said that, since slavery, it has not been culturally acceptable for African Americans to question white men, especially medical professionals.

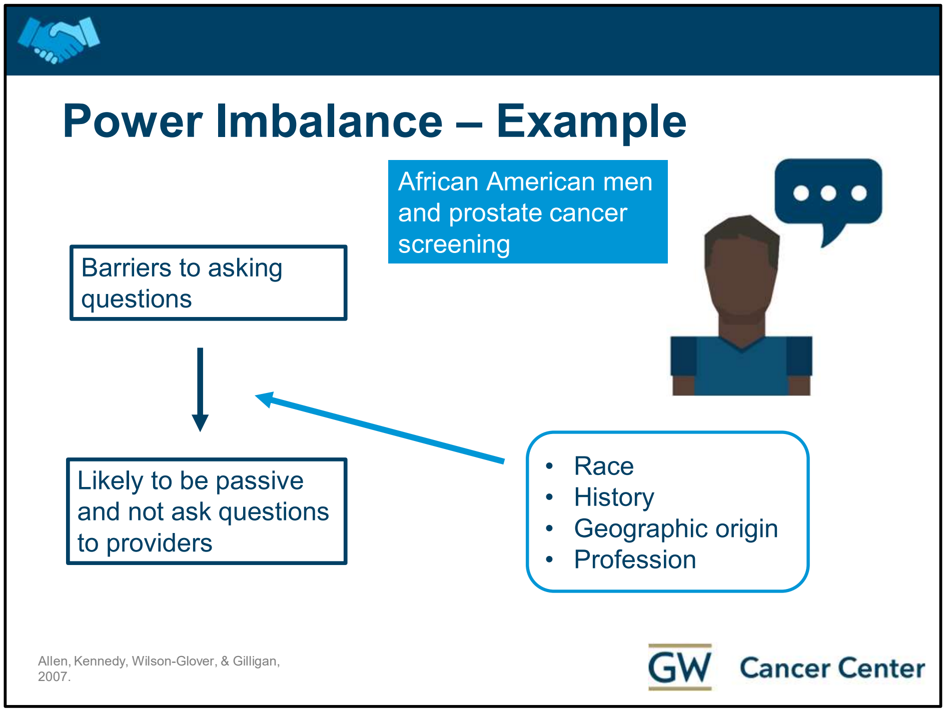
In this example, race, history, geographic origin, profession and other factors all come into play in causing a person to be more passive in interactions with a health care provider.



Patient history of interactions ← Good and bad

Demographics of patients and providers ← Race, ethnicity, sexual orientation, gender identity, etc.

Western medicine ← Providers in positions of power



Power Imbalance – Example

African American men and prostate cancer screening

Barriers to asking questions

Likely to be passive and not ask questions to providers

- Race
- History
- Geographic origin
- Profession

Allen, Kennedy, Wilson-Glover, & Gilligan, 2007.

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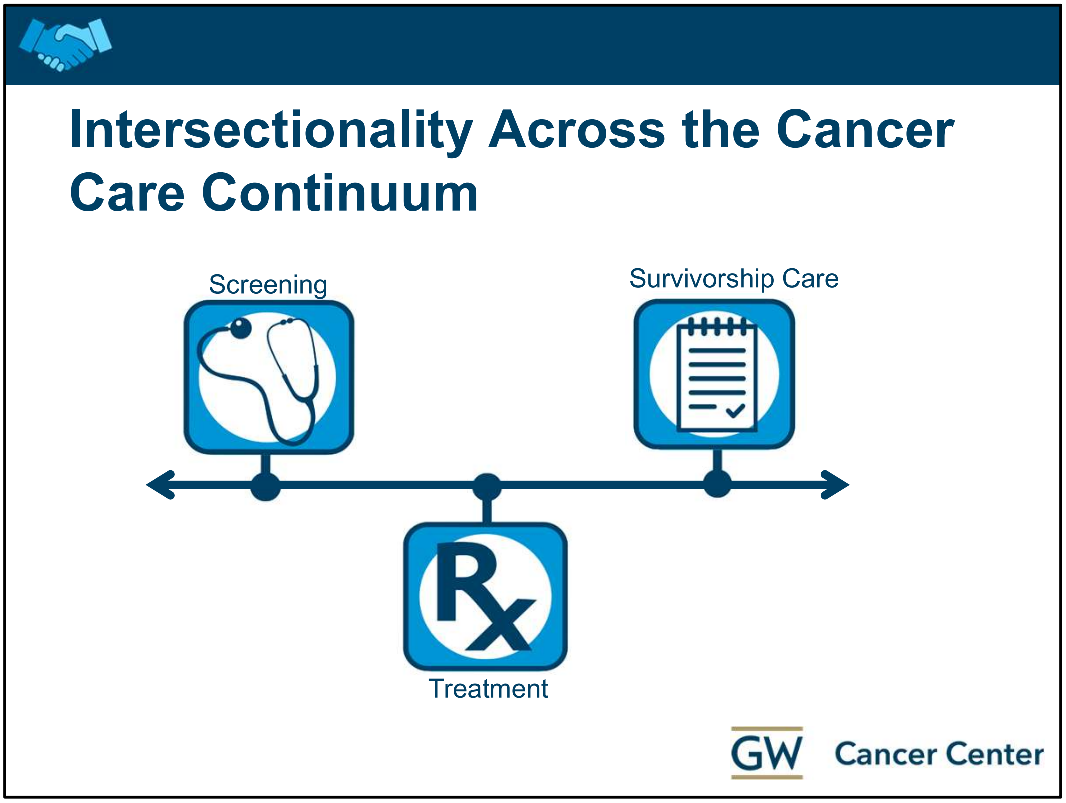

Intersectionality Across the Cancer Care Continuum

Screening

Survivorship Care

Treatment

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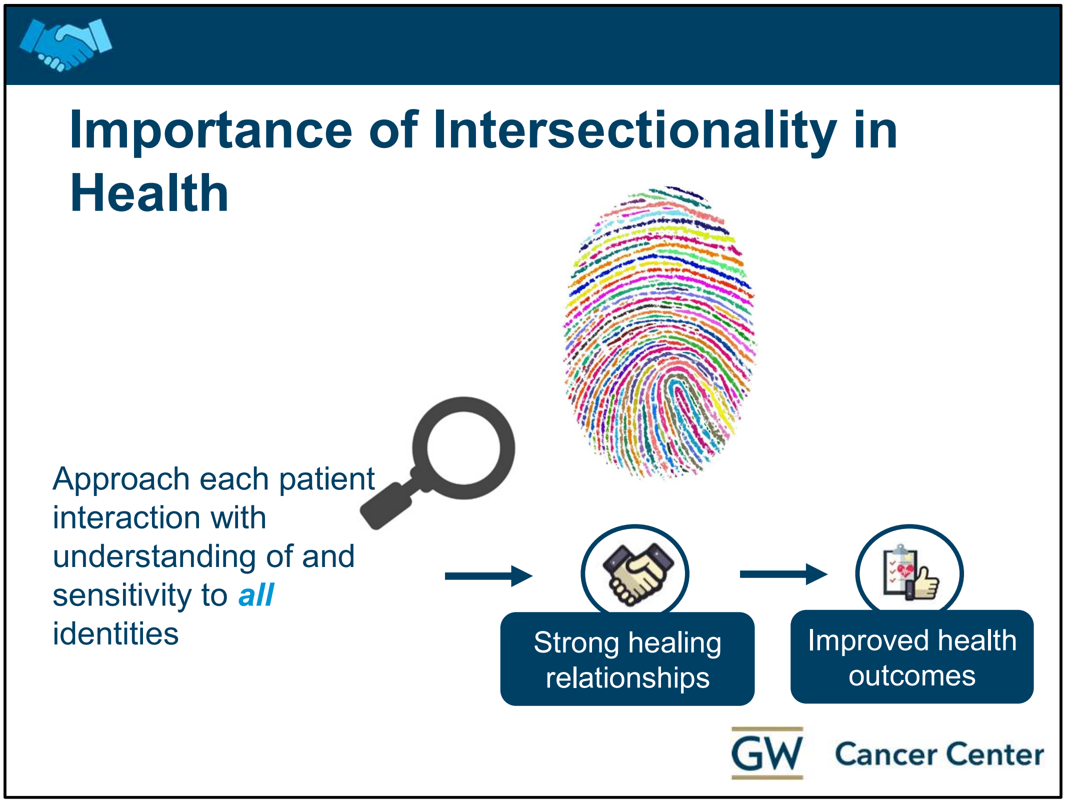
Let’s look at one example of how intersectionality affects health and care. In the National Cancer Care TEAM study, one patient described her care experiences and how her multiple identities affected her interactions with providers and the care she received, she said:

...they sent me to a… gynecologist oncologist...I went into her office, and she came in and openly admitted that she hadn’t looked at any of my images and hadn’t… looked at my transplant history and hadn’t looked at anything and told me that I was just bleeding in my ovary and it was fine. But every other doctor that I saw said it wasn’t anywhere near my ovary, that that was not the problem…. You know and that was very strange to me because she was a gynecologist...and I mean she is also an oncologist, so it just seemed like that would have been a little bit better of an interaction. But just the fact that she didn’t even look at anything and I think just assumed that because I’m a young woman, that you know that’s what was happening and it wasn’t a big deal and I was overreacting.

And then, there, and then there has also been a few times that, um, I [*laugh*], like my heart failure symptoms was written off as anxiety, because I was eighteen when my heart started failing, and I remember them telling me that I was just stressed out about going to college and that a lot of girls are just stressed out during that time. And at the time that my heart failed, I was also dating a girl, and...that was strange because I never really fully brought it up, but she would come with me to appointments sometimes, and they would be like, ‘Oh, it’s great that your friend it here,’ and I would be like, ‘Yah [*drawn out*].’ Um, cuz it wasn’t worth it to me, worth pushing at the time… I guess that specifically was never really discussed. And currently my partner is a boy, so I don’t necessarily have that same problem anymore. Um, but it was a problem at one point in time.



Importance of Intersectionality in Health

Approach each patient interaction with understanding of and sensitivity to ***all*** identities

Strong healing relationships

Improved health outcomes

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It is important for anyone working in health care to approach all interactions with patients with an understanding of intersectionality. When assessing a patient’s needs, using the lens of intersectionality can help make sure that we don’t overlook the nuances or individual circumstances of a patient’s life.

By approaching each patient as an individual, with understanding of and sensitivity to *all* the identities that shape a patient’s experiences, we make sure important information does not fall through the cracks.

We can work to create strong healing relationships at the individual and organizational level that allows for shared decision-making, and ultimately better health outcomes.

Keeping intersectionality in mind during interactions with patients is critical in establishing a safe and trusting relationship with patients and their loved ones.

To Treat Me, You Have to Know Who I am

National LGBT Cancer Network

Reexamining LGBT Healthcare:
https://www.youtube.com/watch?v=XqH6GU6TrzI

National LGBT Cancer Network, 2010.

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Let’s pause here and watch a brief excerpt from the film by the National LGBT Cancer Network— *To Treat Me, You Have to Know Who I Am: Welcoming lesbian, gay, bisexual, transgender (LGBT) patients into healthcare*.

To Treat Me, You Have to Know Who I am

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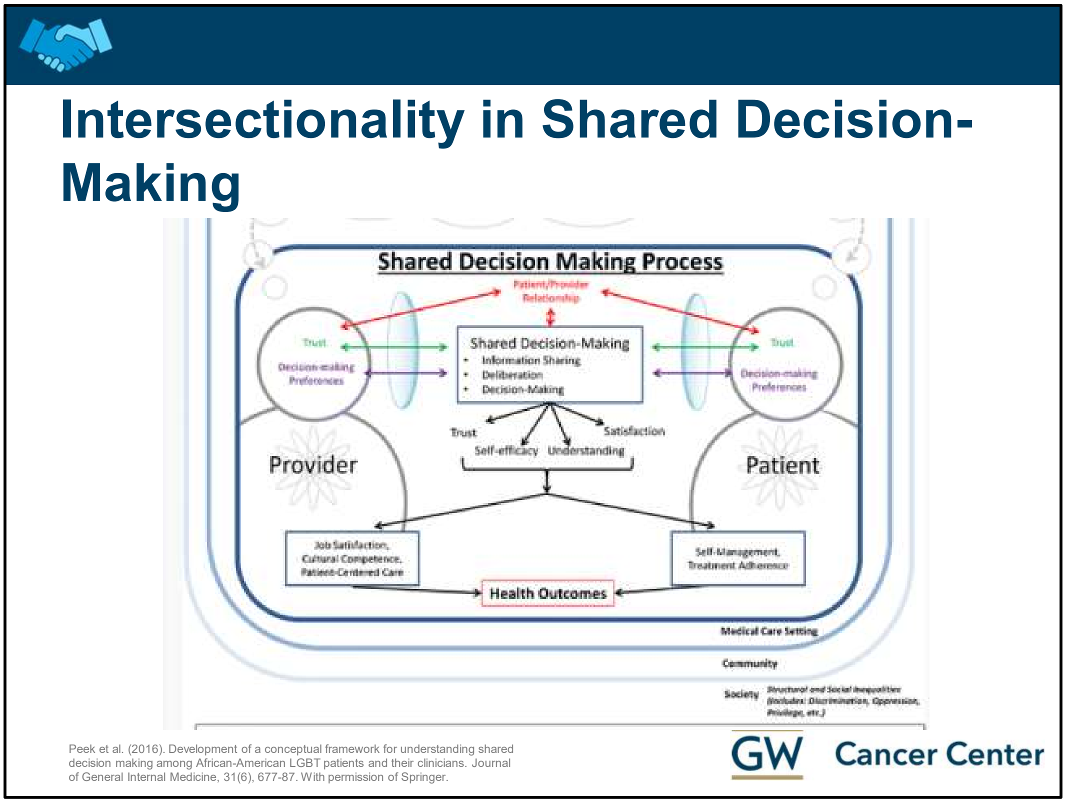
As you saw, this video pushes back on the idea and tendency to think of LGBTQI people as one big group.

Instead, the video highlights that LGBTQI individuals are diverse with many intersecting identities.

Taking the lessons from this video, providers and organizations can perform more effective health assessments by asking questions about all aspects of an individual's psychological, social and medical histories.

Answers to all these questions will give a more accurate description of the person's cancer risks, screening behaviors and survivorship needs. This video also highlights the importance of patient engagement in clinical care.



Intersectionality in Shared Decision-Making

Peek et al. (2016). Development of a conceptual framework for understanding shared decision making among African-American LGBT patients and their clinicians. Journal of General Internal Medicine, 31(6), 677-87. With permission of Springer.

In the lesson on patient engagement in clinical care, we showed a model for shared decision-making that describes how providers and patients share information to improve trust, self-efficacy, understanding and satisfaction, and how that ultimately improves health outcomes for patients.

But to understand what the process of shared decision-making looks like for each individual, we need to look at this model through the lens of intersectionality. People living with cancer have multiple identities so we need to look at the model from a wider view.

The figure now illustrates the shared decision-making process in an intersectional world. Before a patient and provider even walk into an appointment, their thoughts about themselves and of one another influence their encounter.

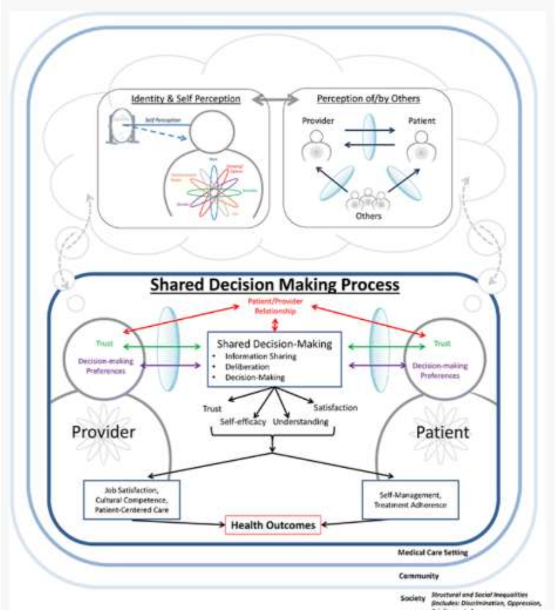
These thoughts are based on the individuals' multiple, intersecting identities like race, ethnicity, sexual orientation, gender identity, age and socioeconomic status – among others. The patient's and provider's thoughts also reflect the views of others and of society, including assumptions, stereotypes, prejudices and biases.

These thoughts enter into the health care encounter. They influence the decision-making preferences of the patient and provider, and the trust they have in each other.

This ultimately influences the shared decision-making process, by impacting how much information is shared and how decisions are made. Because of this, the result of shared decision-making, such as increased trust, self-efficacy, understanding and satisfaction, is not the same for everyone.

Specifically, individuals of multiple vulnerable groups face inequities that lead to negative outcomes like less access to care and feelings of helplessness. Health care organizations need to focus on building trust with these individuals and improving care that is easier to access and more welcoming. This will help these individuals engage in shared decision-making.

We will dig further into strategies for building or rebuilding trust and ensuring that care is culturally competent and equitable to all in Modules 4 and 5.



Peek et al. (2016). Development of a conceptual framework for understanding shared decision making among African-American LGBT patients and their clinicians. Journal of General Internal Medicine, 31(6), 677-87. With permission of Springer.

Peek et al., 2016.

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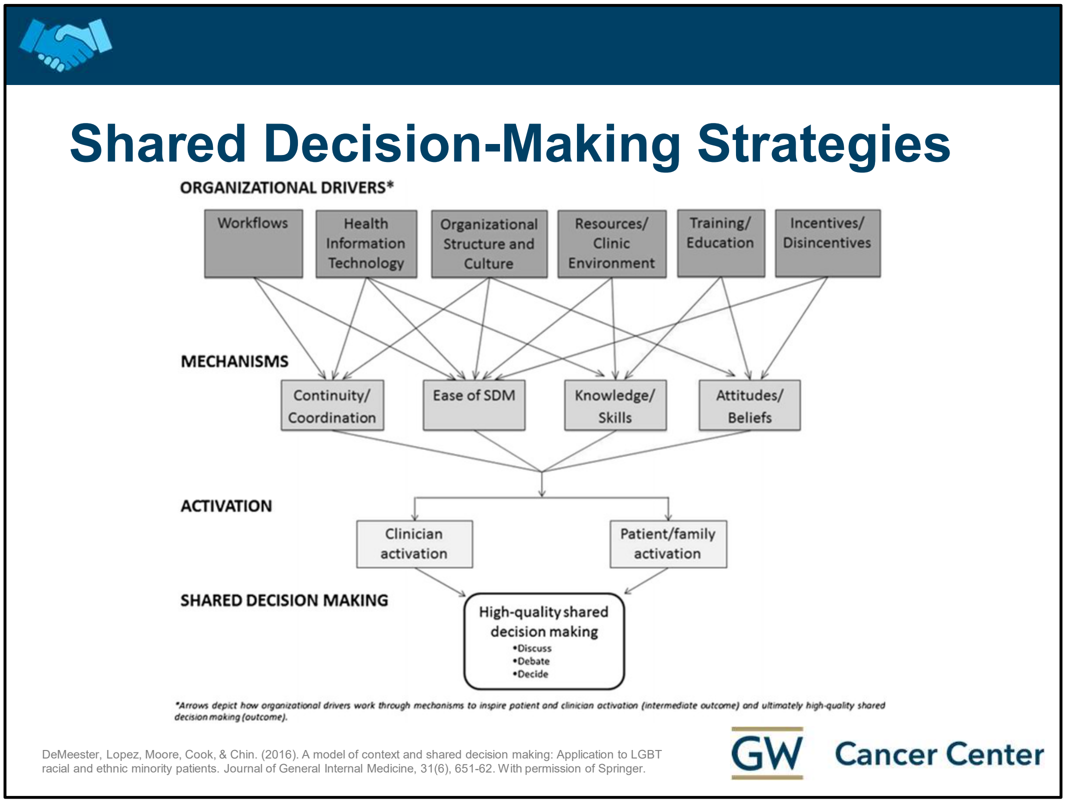

Shared Decision-Making Strategies

ORGANIZATIONAL DRIVERS*

Workflows
Health Information Technology
Organizational Structure and Culture
Resources/ Clinic Environment
Training/ Education
Incentives/ Disincentives

MECHANISMS

Continuity/ Coordination
Ease of SDM
Knowledge/ Skills
Attitudes/ Beliefs

ACTIVATION

Clinician activation
Patient/family activation

SHARED DECISION MAKING

High-quality shared decision making
- Discuss
- Debate
- Decide

*Arrows depict how organizational drivers work through mechanisms to inspire patient and clinician activation (intermediate outcome) and ultimately high-quality shared decision making (outcome).

DeMeester, Lopez, Moore, Cook, & Chin. (2016). A model of context and shared decision making: Application to LGBT racial and ethnic minority patients. Journal of General Internal Medicine, 31(6), 651-62. With permission of Springer.

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In the Patient Engagement in Care lesson, we discussed strategies organizations can take to facilitate the process of shared decision-making between providers and their patients.

Let’s consider an example of how organizations can support shared decision-making with adequate attention paid to intersectionality.

1. **Workflows:** We have previously discussed how establishing workflows can improve care coordination, facilitate the shared decision-making process and enhance the knowledge, skills, attitudes and beliefs of patients and providers – all to set them up to engage in shared decision-making.

Because minority patients may require more time to build trust with providers and gain the attitudes and beliefs that support shared decision-making, the health care setting can build in workflows that allow the patient to have multiple touch points with the health care system to build this trust over time.

Clinics can engage patients through communication before the appointment to prepare them for the shared decision-making process, and they can use different members of the health care team, like medical assistants, to help patients use decision aids that prepare them to make joint decisions with their providers.

2. **Environment:** As another example, making changes to resources or the clinical environment with attention paid to intersectionality can facilitate shared decision-making. If a person's first experience with the health care environment is the pamphlets they see in the waiting room, do they offer examples of individuals of various and multiple identities such that a person feels welcome?

To this end, a black lesbian woman in a focus group noted that seeing print materials in the waiting room that reflect her identity is important: "So maybe if they had more people of color, more queer…something. Just give me a little hint of something kind of like me. Someone like me. That would be nice."

Although the strategies (or organizational drivers) presented in this model are the same as when we presented them in Patient Engagement in Care lesson, we have just used intersectionality to show how to best put one of those drivers (workflows) into practice to meet individual patient needs.

DeMeester, Lopez, Moore, Cook, & Chin, 2016.

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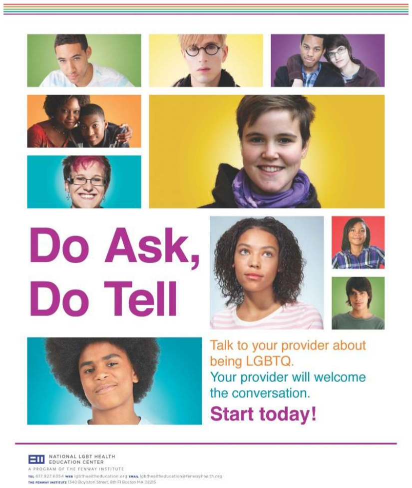
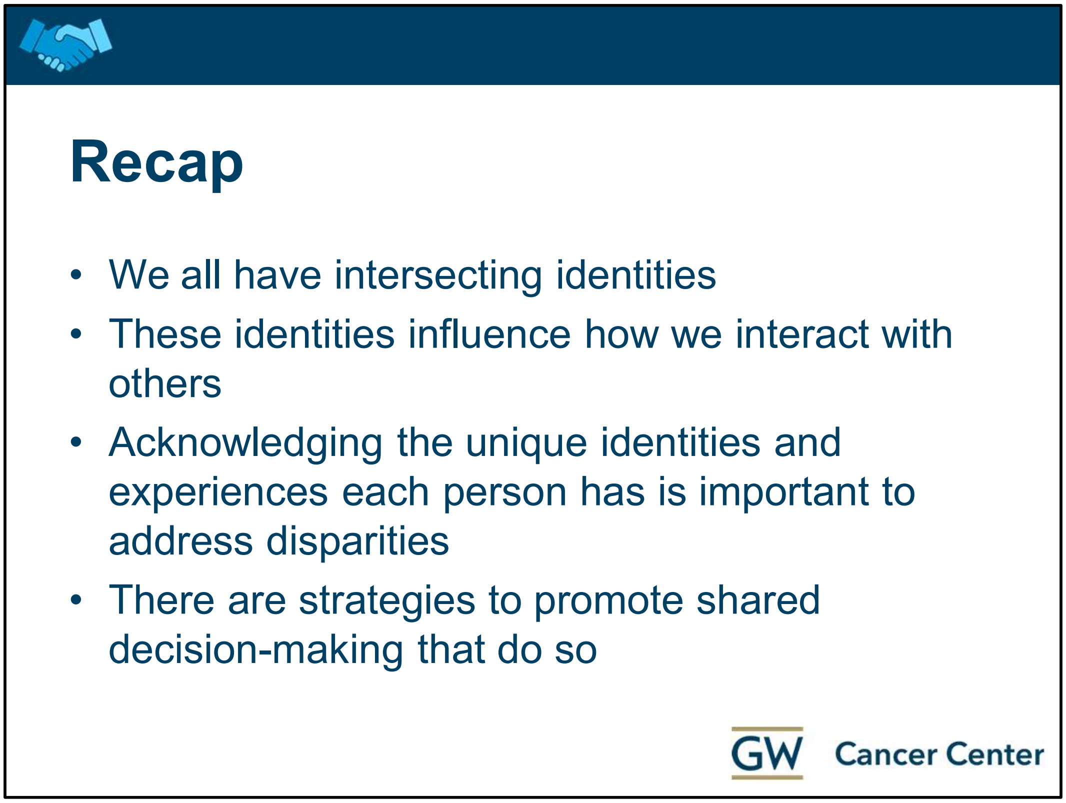
DeMeester, Lopez, Moore, Cook, & Chin, 2016;

“So maybe if they had more people of color, more queer…something. Just give me a little hint of something kind of like me. Someone like me. That would be nice.”



Agénor, Bailey, Krieger, Austin, & Gottlieb, 2015; National LGBT Health Education Center, n.d.



Recap

- We all have intersecting identities
- These identities influence how we interact with others
- Acknowledging the unique identities and experiences each person has is important to address disparities
- There are strategies to promote shared decision-making that do so

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In summary, we all have intersecting identities, which influence how we interact with others. Using strategies in health care encounters that account for intersectionality, and acknowledge the unique identities and experiences that each person holds, is important when working to address cancer care disparities and promote shared decision-making.

With intersectionality in mind, let’s next look at some of the challenges that LGBTQI, Black and African American, and Latino communities face in receiving equitable and culturally competent care.

Conclusion

In this lesson, you learned to:

- Describe how intersectionality influences the patient-provider relationship across the cancer care continuum
- Identify interventions to improve shared decision-making that account for intersectionality

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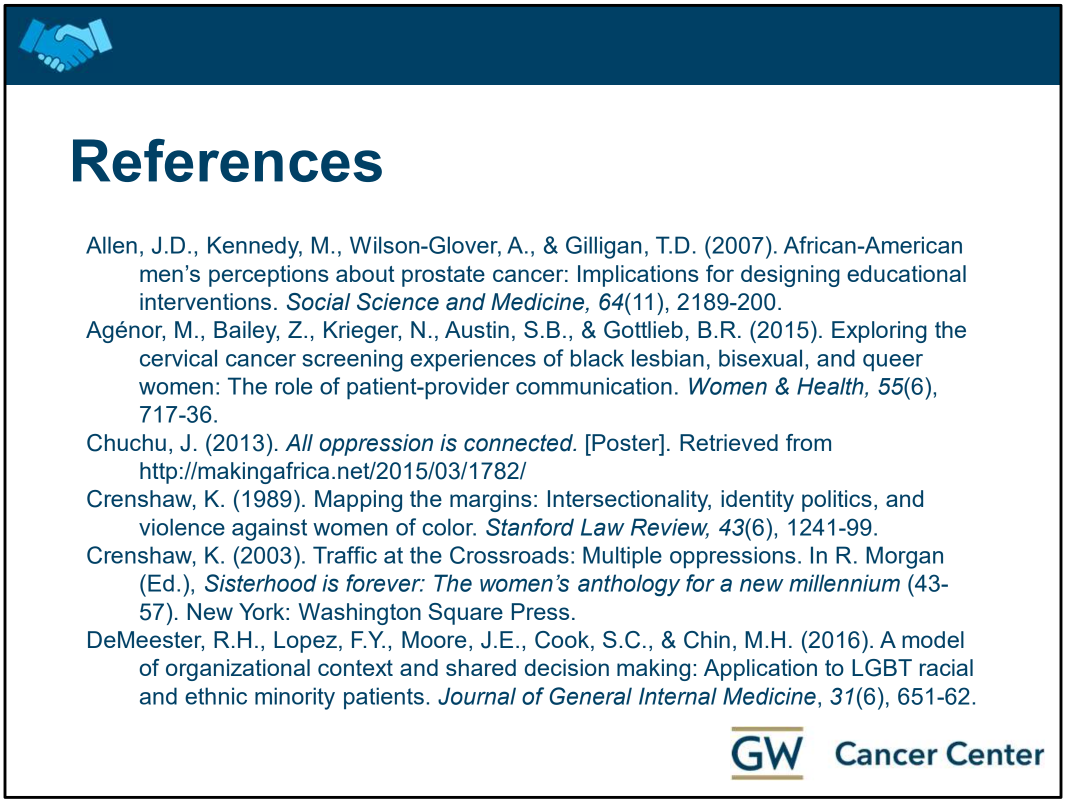

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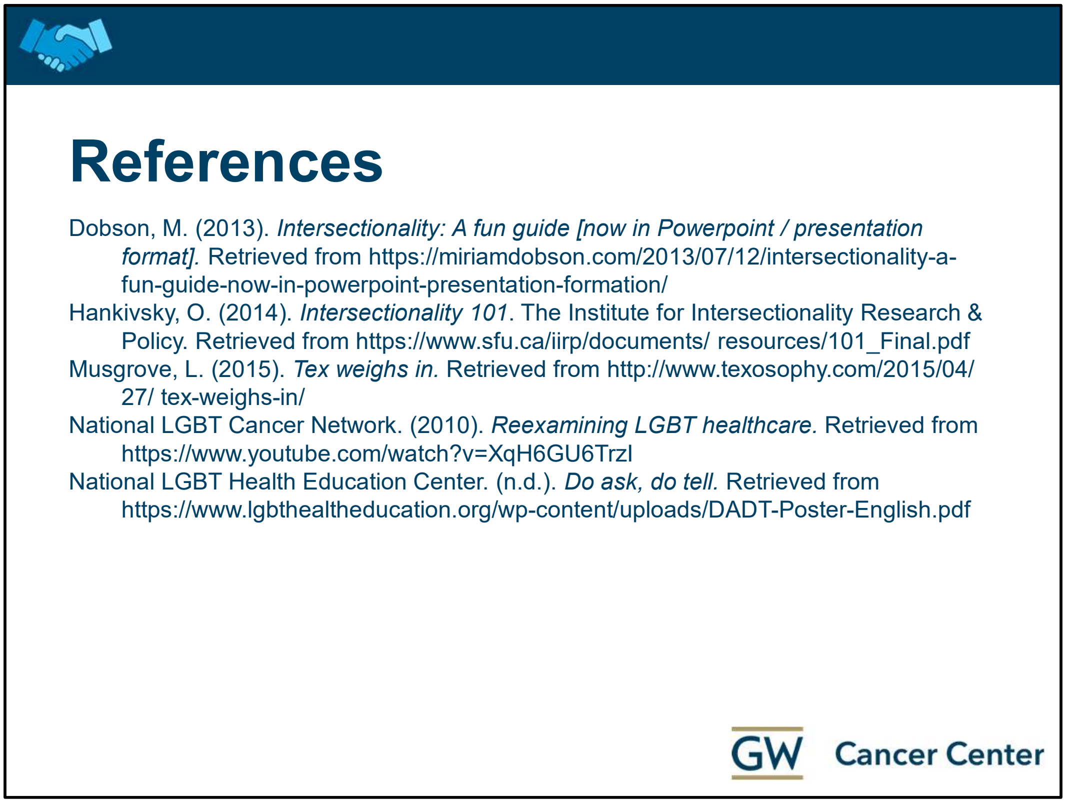

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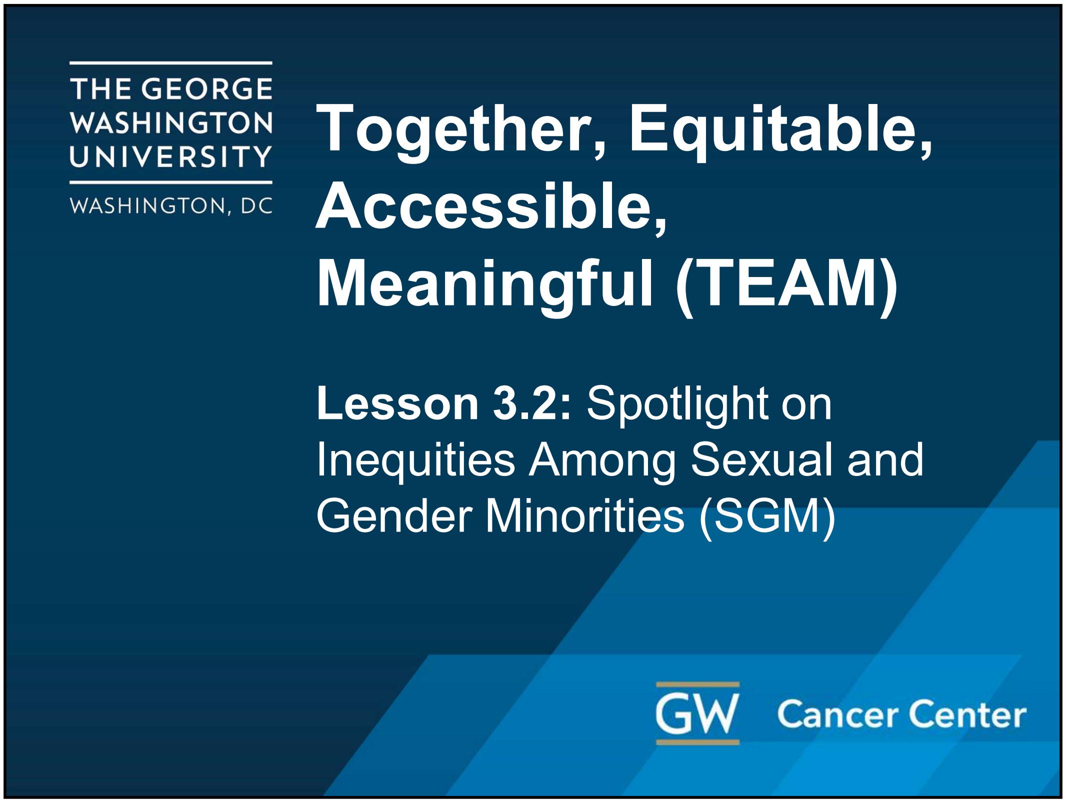

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Together, Equitable, Accessible, Meaningful (TEAM)

Lesson 3.2: Spotlight on Inequities Among Sexual and Gender Minorities (SGM)

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Welcome to Module 3, Lesson 2:

Acknowledgments

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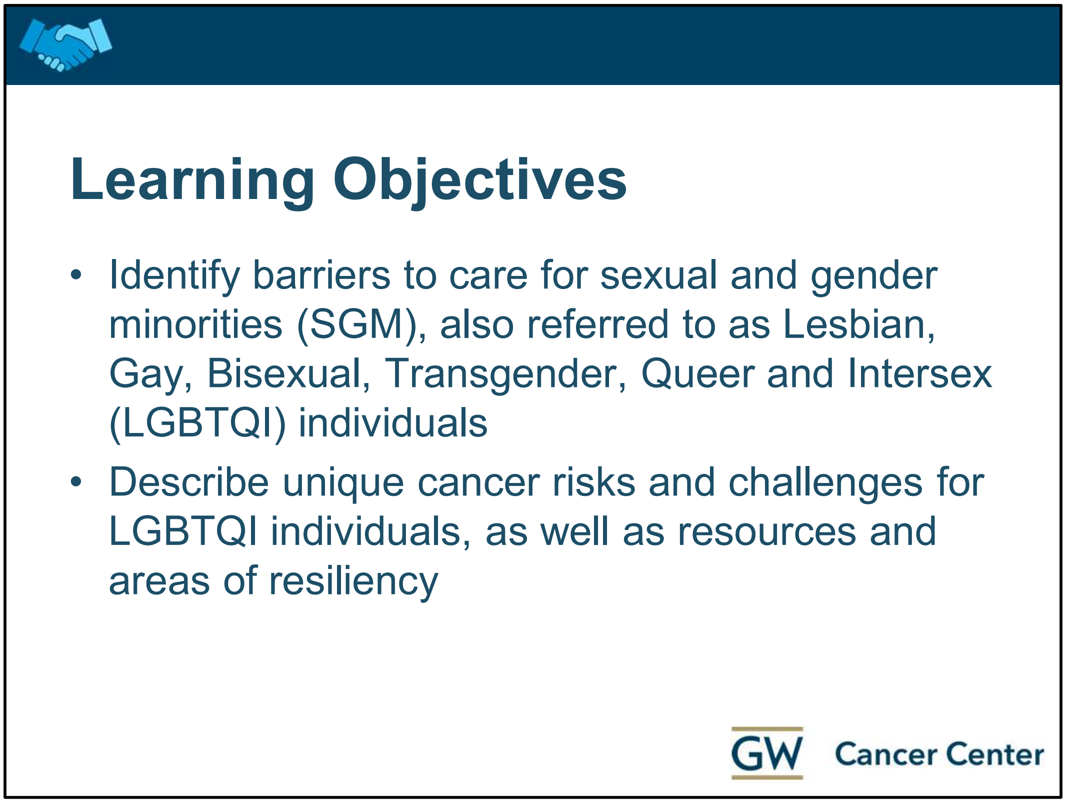

Learning Objectives

- Identify barriers to care for sexual and gender minorities (SGM), also referred to as Lesbian, Gay, Bisexual, Transgender, Queer and Intersex (LGBTQI) individuals
- Describe unique cancer risks and challenges for LGBTQI individuals, as well as resources and areas of resiliency

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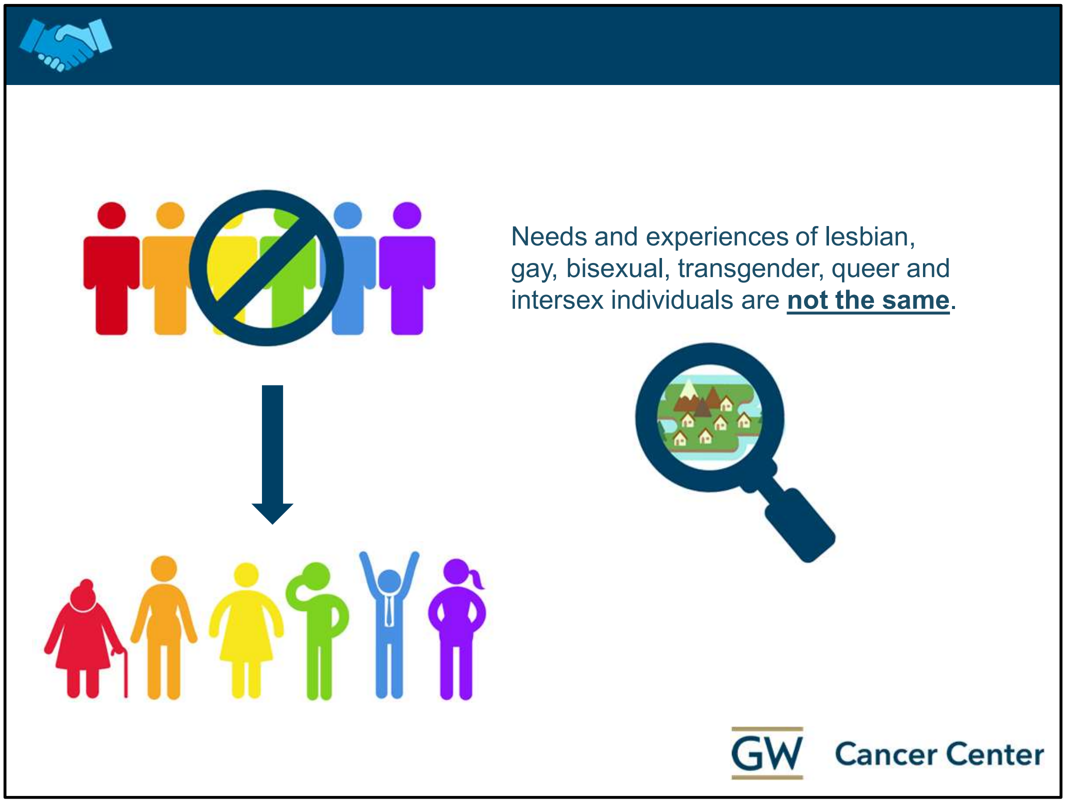
After completing this lesson, you will be able to:

- Identify barriers to care for sexual and gender minorities or (SGM), also referred to as lesbian, gay, bisexual, transgender, queer and intersex or (LGBTQI) individuals
- Describe unique cancer risks and challenges for LGBTQI individuals, as well as resources and areas of resiliency



Needs and experiences of lesbian, gay, bisexual, transgender, queer and intersex individuals are **not the same**.

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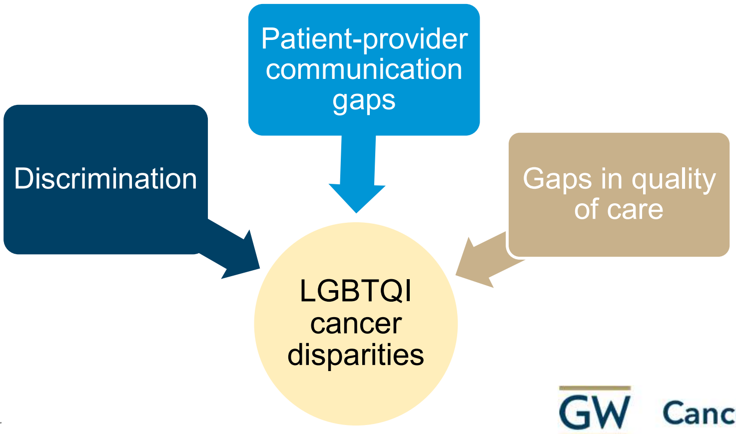
As we look at the inequities that sexual and gender minorities face, and create strategies to address these inequities, it is important to note that the needs and experiences of people who identify as lesbian, gay, bisexual, transgender, queer or intersex are not the same. As discussed in the previous lesson, these individuals also hold many other identities, which can lead to additional oppression and affect their lived experiences. However, sexual and gender minorities are often overlooked across the cancer care continuum.

As part of ASCO’s 2017 position statement outlining its strategies for reducing cancer health disparities among sexual and gender minority populations, ASCO states that “Sexual and gender minorities, including individuals who are lesbian, gay, bisexual, transgender, and intersex, bear a disproportionate cancer burden. Such disparities in cancer-specific outcomes among SGM populations stem from the unique cancer risks, needs, and challenges faced by SGM populations, including discrimination and other psychosocial issues, as well as gaps in patient-provider communication and quality of care.”

ASCO Position Statement

"Sexual and gender minorities (SGMs), including individuals who are lesbian, gay, bisexual, transgender, and intersex (LGBTI), bear a **disproportionate cancer burden.**"



Patient-provider communication gaps

Discrimination

Gaps in quality of care

LGBTQI cancer disparities

Griggs et al., 2017.

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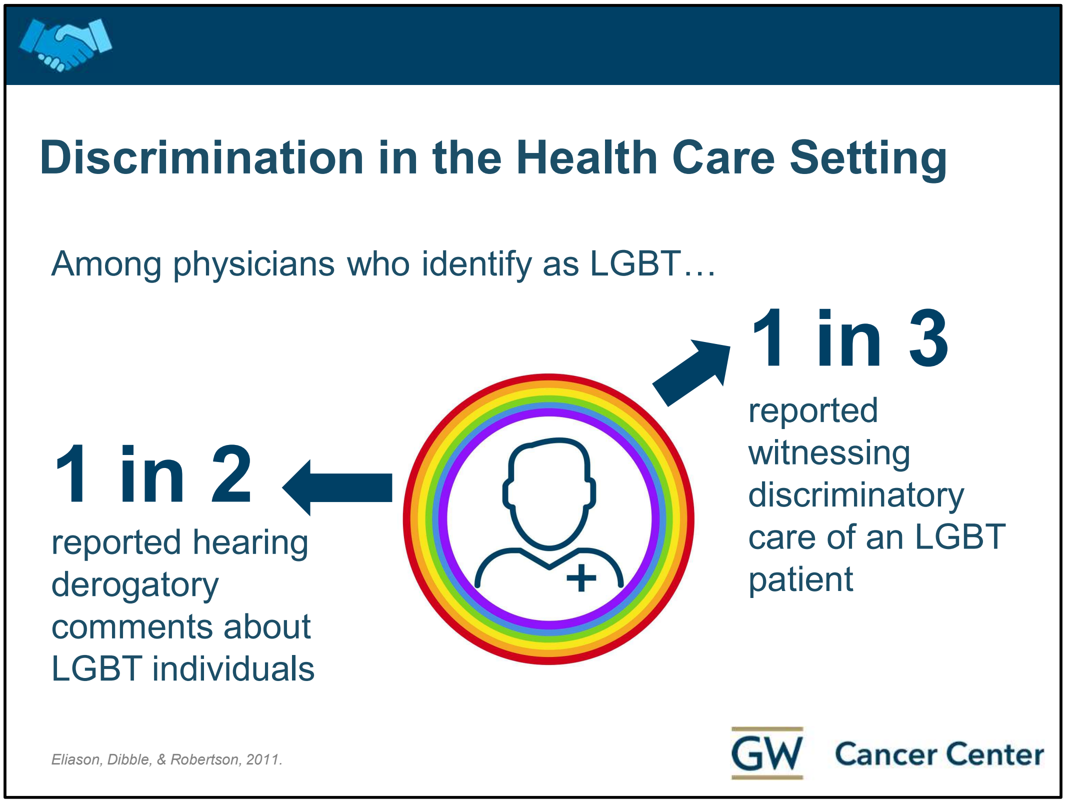


Discrimination in the Health Care Setting

Among physicians who identify as LGBT…

1 in 3

reported witnessing discriminatory care of an LGBT patient

1 in 2

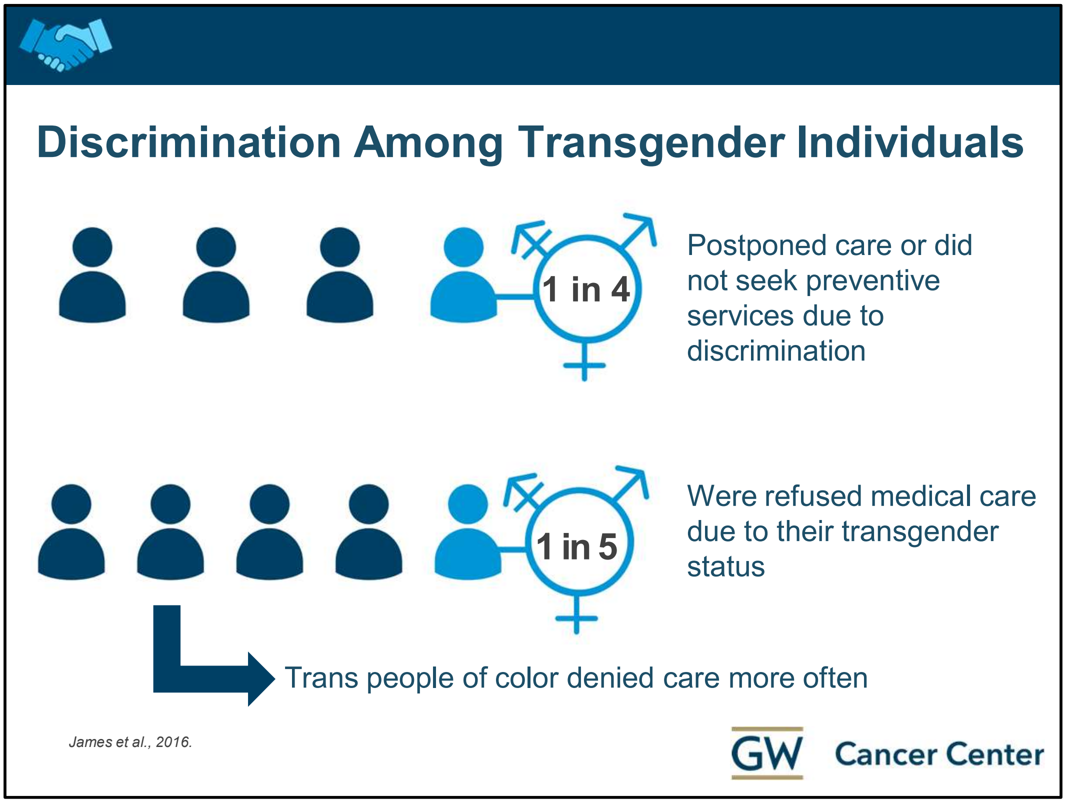
reported hearing derogatory comments about LGBT individuals

Eliason, Dibble, & Robertson, 2011.

Discrimination against LGBTQI individuals happens in many places– even in health care. For instance, in a study of physicians who identify as a sexual or gender minority, more than one-half reported hearing derogatory comments about LGBT individuals and one-third reported witnessing discriminatory care of an LGBT patient.

Many barriers to care, cancer risks and challenges discussed in this lesson apply to LGBTQI communities broadly, yet experiences of discrimination are even more prominent for the transgender community.

For example, in the 2016 National Transgender Discrimination Survey, conducted with almost 28,000 people who identify as transgender across the U.S. and territories, one-in-four individuals reported that they postponed care when they were sick or injured or did not seek preventive services due to discrimination. In addition, one-fifth of individuals indicated they had been refused medical care due to their transgender status, with trans people of color being denied care more often.



Discrimination Among Transgender Individuals

1 in 4

Postponed care or did not seek preventive services due to discrimination

1 in 5

Were refused medical care due to their transgender status

Trans people of color denied care more often

James et al., 2016.

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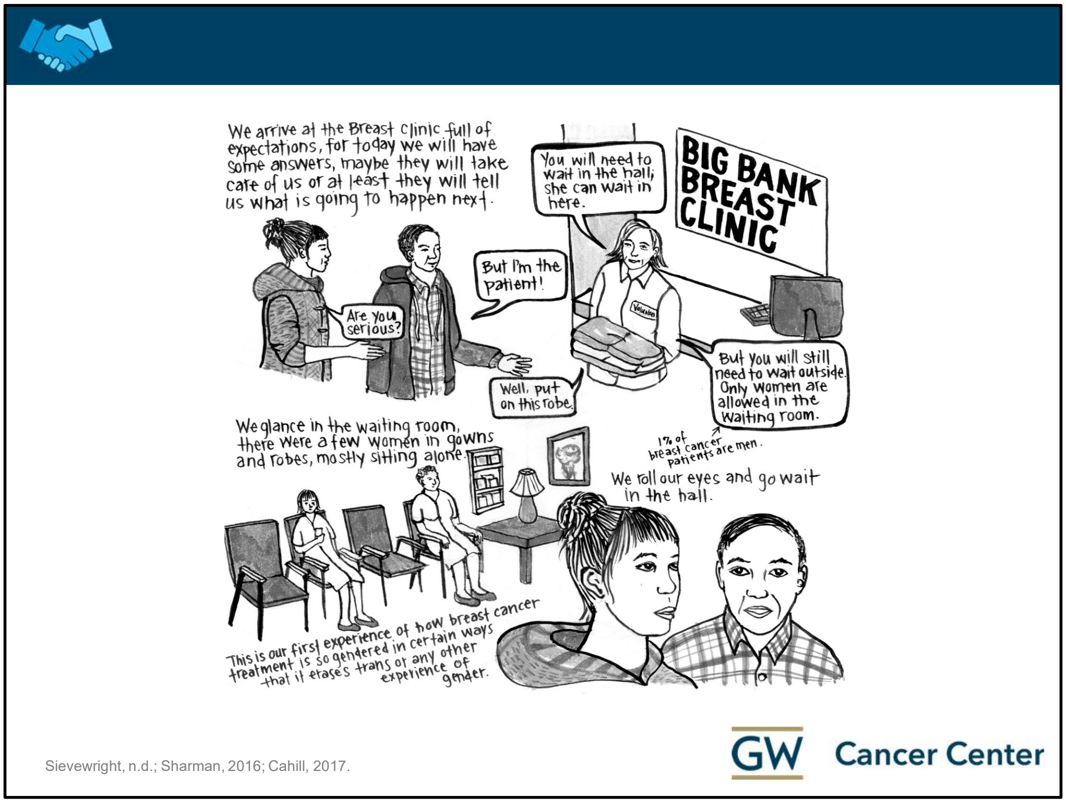
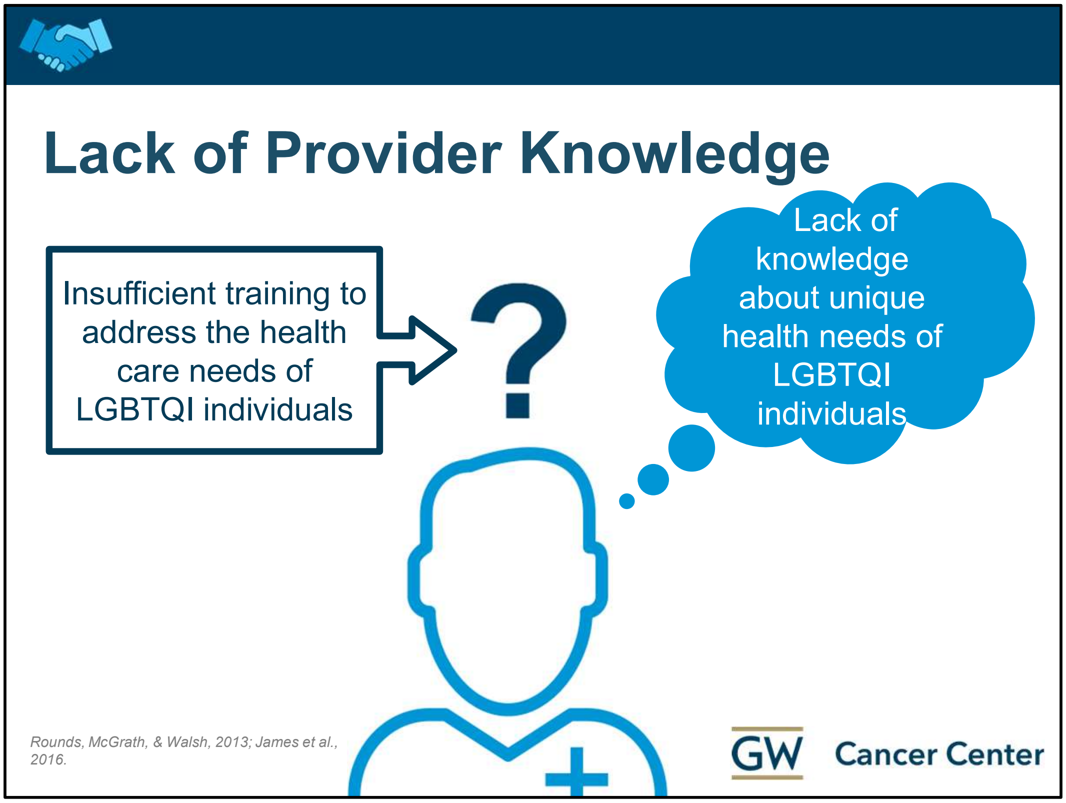


Sievewright, n.d.; Sharman, 2016; Cahill, 2017.

Let’s quickly look at an example of this kind of discrimination: In a graphic cartoon, Kara Sievewright provides an account of her partner Brady’s experience with breast cancer.

Brady identifies as a transgender male. In addition to the challenges all persons affected by cancer face, right before Brady’s operation, Brady and Kara are told to wait in the hallway, because “only women are allowed in the waiting room.”



Lack of Provider Knowledge

Insufficient training to address the health care needs of LGBTQI individuals

Lack of knowledge about unique health needs of LGBTQI individuals

Rounds, McGrath, & Walsh, 2013; James et al., 2016.

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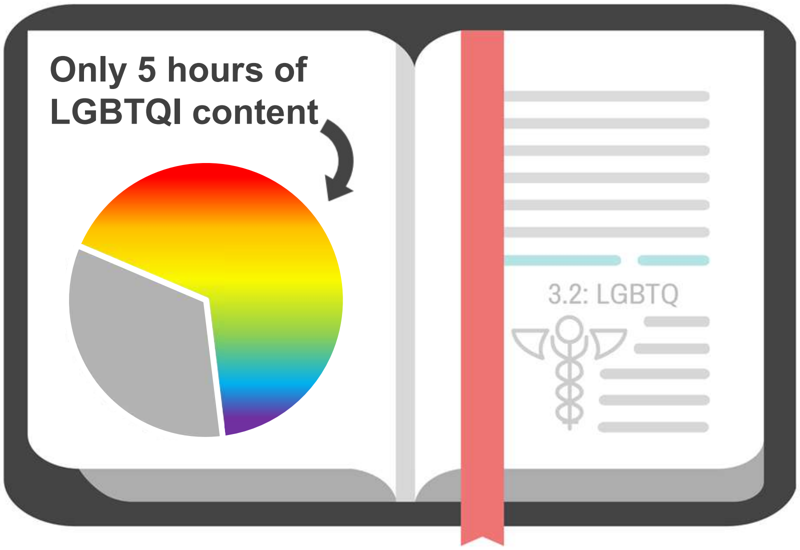
In addition to discrimination in health care, lack of knowledge among health care professionals about the unique health needs of sexual and gender minorities is seen as a main barrier to care.

This barrier to care is also more pronounced for transgender individuals, with many indicating having to teach their provider about their health needs. Many people who work in health care have also not received sufficient training in order to address the health care needs of sexual and gender minorities.

Sexual and gender minorities face other barriers to care including being underinsured and living below the poverty line.

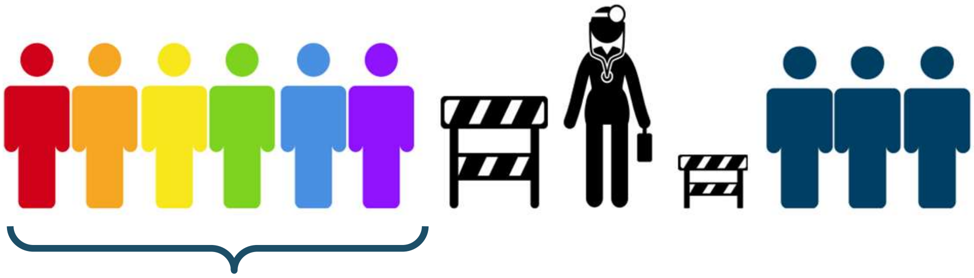
Lack of Provider Knowledge



Only 5 hours of LGBTQI content

Obedin-Maliver et al., 2011.

Other Barriers to Care



- Higher percentage **underinsured**

- Higher percentage **living below the poverty line**

Gates, 2014; Badgett, Durso, & Schneebaum, 2013.

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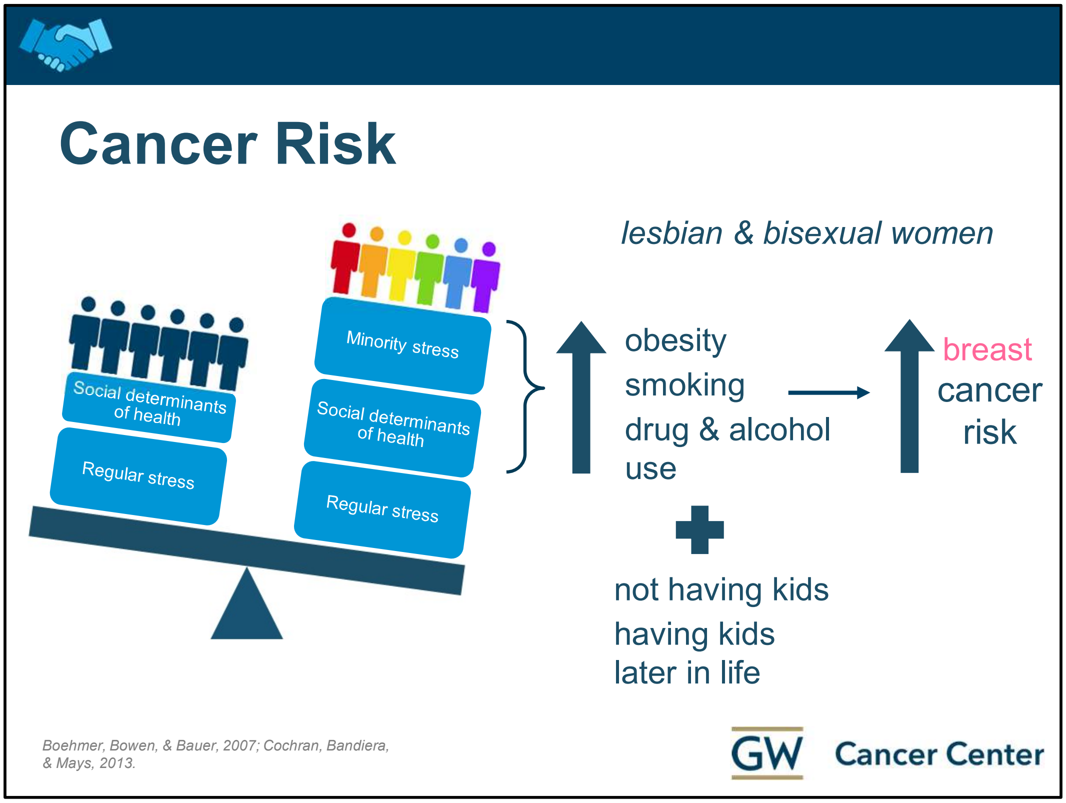

Cancer Risk

lesbian & bisexual women

obesity
smoking
drug & alcohol use

→ breast cancer risk

+

not having kids
having kids later in life

Boehmer, Bowen, & Bauer, 2007; Cochran, Bandiera, & Mays, 2013.

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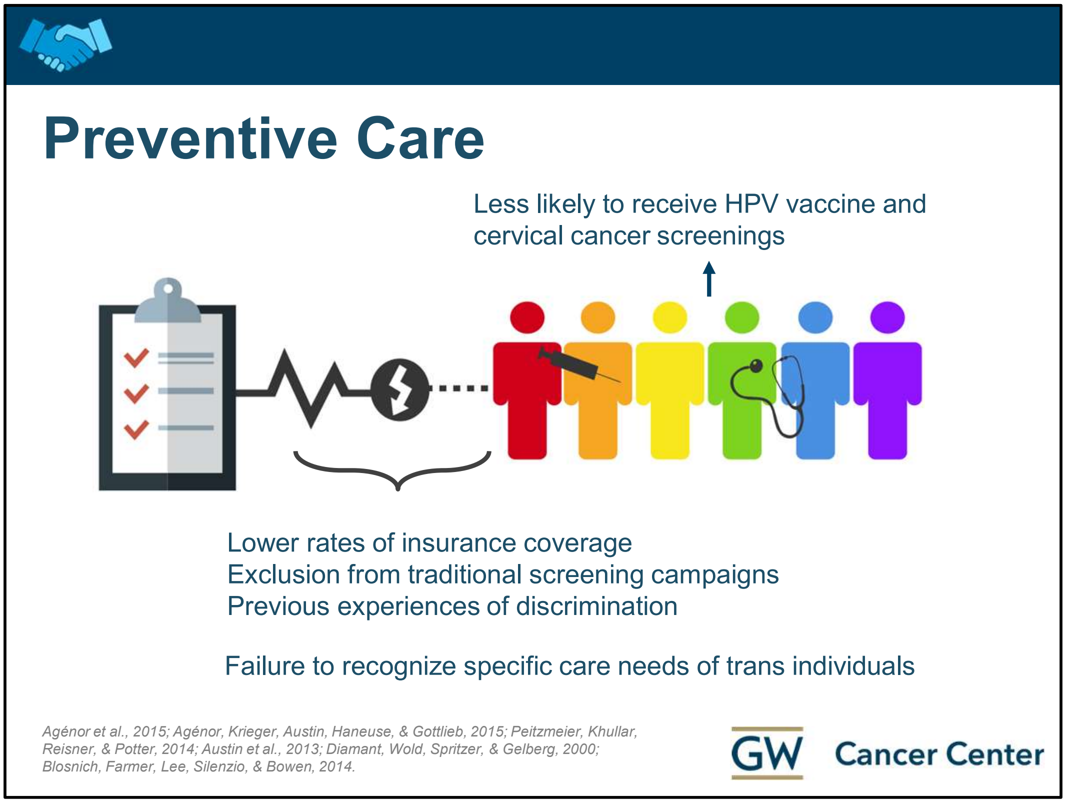
Potentially due to minority stress and other social determinants of health, an individual who identifies as LGBTQI may be at greater risk for obesity, smoking, and drug and alcohol use, which directly increases cancer risk.

When looking specifically at breast cancer, lesbian and bisexual women are at greater risk for breast cancer than heterosexual women. This is due to a number of reasons, including higher rates of smoking, alcohol use, obesity, not having children and having children later in life.

While the medical and research community is aware of this unique cluster of cancer risk factors for LGBTQI individuals, more research is needed to identify specific disparities in cancer incidence and mortality and to create and test interventions to better serve sexual and gender minorities diagnosed with cancer.

A crucial first step is better data collection.



Preventive Care

Less likely to receive HPV vaccine and cervical cancer screenings

Lower rates of insurance coverage
Exclusion from traditional screening campaigns
Previous experiences of discrimination

Failure to recognize specific care needs of trans individuals

Agénor et al., 2015; Agénor, Krieger, Austin, Haneuse, & Gottlieb, 2015; Peitzmeier, Khullar, Reisner, & Potter, 2014; Austin et al., 2013; Diamant, Wold, Spritzer, & Gelberg, 2000; Blosnich, Farmer, Lee, Silenzio, & Bowen, 2014.

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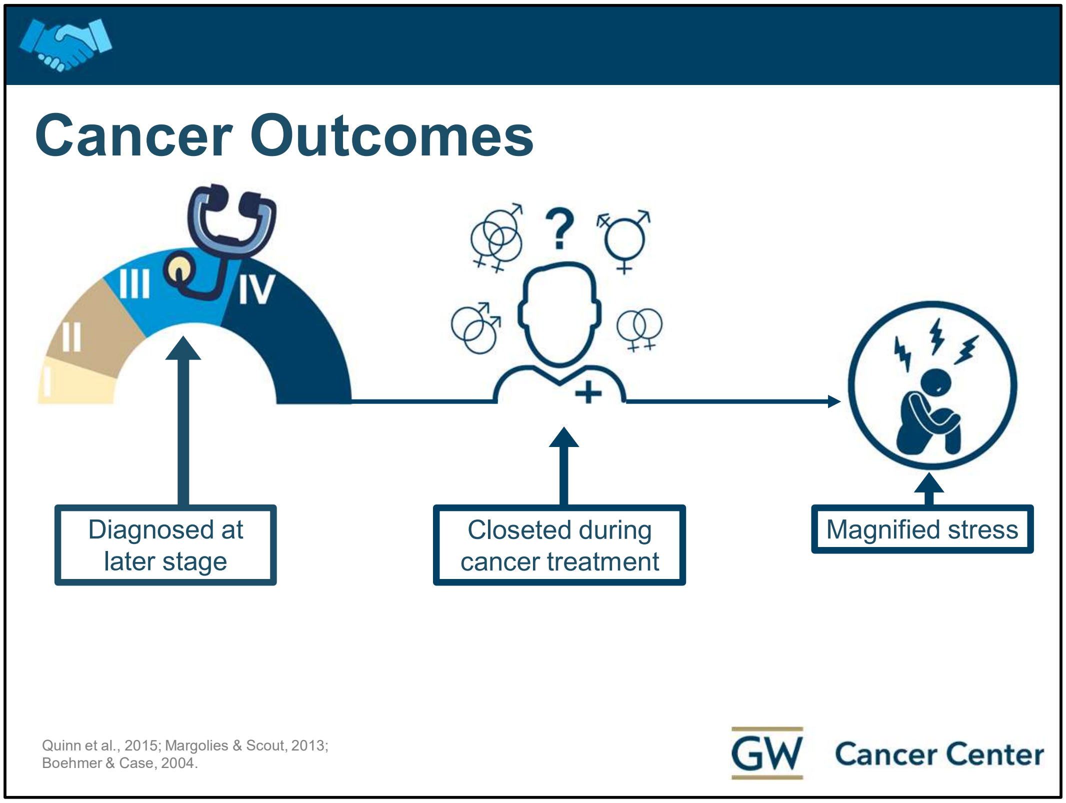
Lesbian women and transgender men are less likely to receive preventive services and screening for cervical cancer.

These lower screening rates may be due to a variety of factors, including lower rates of insurance coverage, exclusion from traditional cancer screening campaigns and previous experiences of discrimination when interacting with health care systems and providers.

Transgender individuals also face additional obstacles to receiving clinically-appropriate cancer screenings, including the fact that providers often do not realize that a patient is transgender and needs to be screened.



Cancer Outcomes

Diagnosed at later stage

Closeted during cancer treatment

Magnified stress

Quinn et al., 2015; Margolies & Scout, 2013; Boehmer & Case, 2004.

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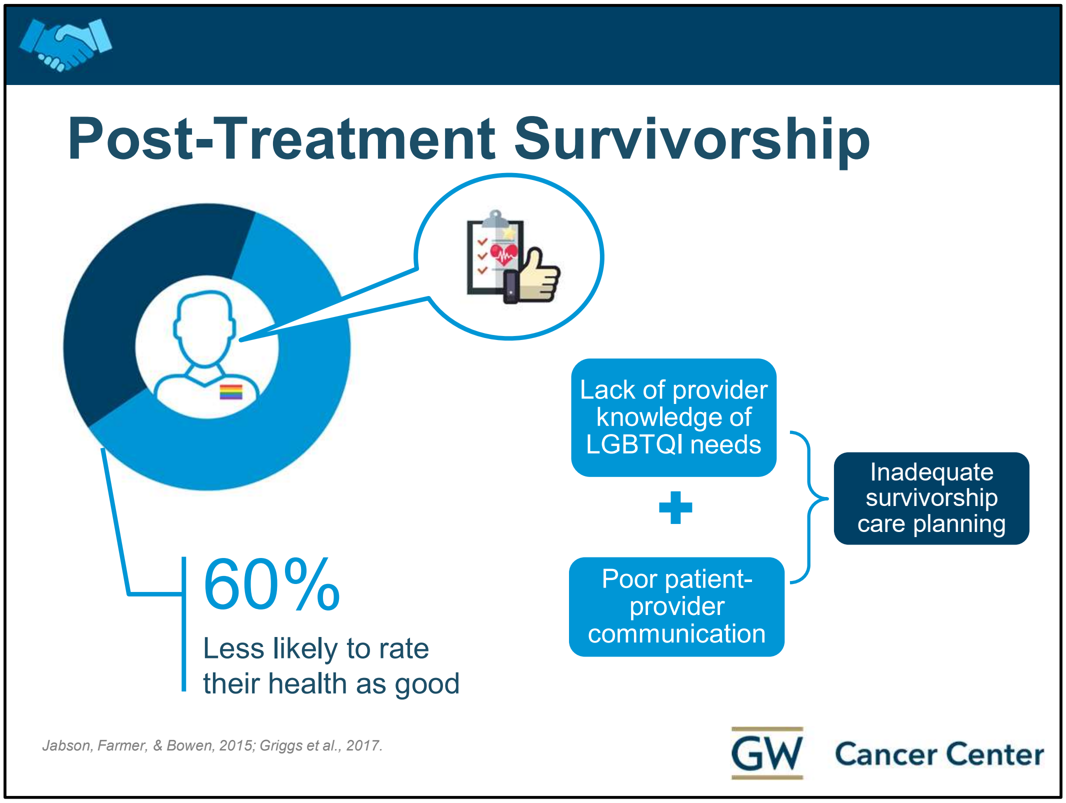
At diagnosis, sexual and gender minorities may be more likely to present with late-stage disease.

Furthermore, research shows that, while most individuals are “out” – or up front with their primary care physicians about their sexual orientation and/or gender identity - they are not always “out” during cancer treatment. This is often because oncology providers do not ask about sexual orientation or gender identity.

When sexual and gender minorities are not able to identify themselves within health care documentation and are not able to be genuinely themselves, the stress of cancer treatment can be magnified, potentially negatively impacting health outcomes.



Post-Treatment Survivorship

60%

Less likely to rate their health as good

Lack of provider knowledge of LGBTQI needs

+

Poor patient-provider communication

Inadequate survivorship care planning

Jabson, Farmer, & Bowen, 2015; Griggs et al., 2017.

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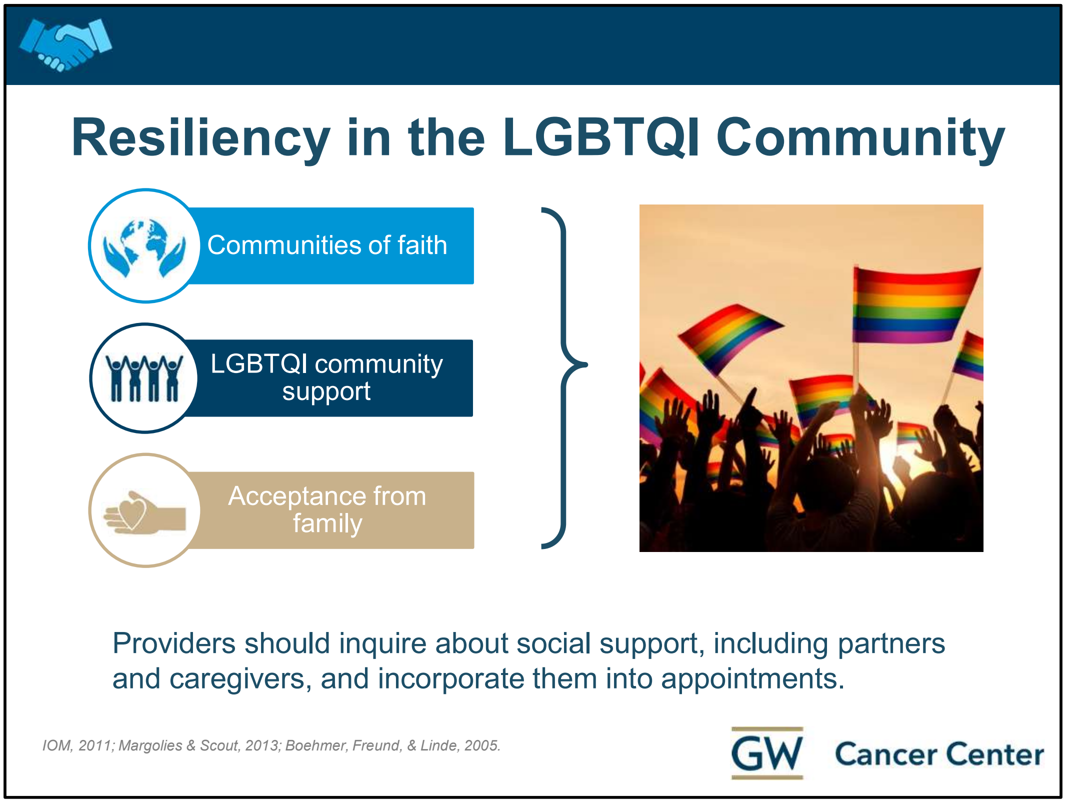
Sexual and gender minorities may also experience disparities in post-treatment survivorship.

Sexual minority cancer survivors are less likely to rate their health as good. It is likely that provider lack of knowledge of these patient’s health needs and poor communication with these patients, lead to inadequate care, and survivorship care planning.



Resiliency in the LGBTQI Community

- Communities of faith
- LGBTQI community support
- Acceptance from family

Providers should inquire about social support, including partners and caregivers, and incorporate them into appointments.

IOM, 2011; Margolies & Scout, 2013; Boehmer, Freund, & Linde, 2005.

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However, sexual and gender minorities also have specific areas of resiliency and protective health factors that should be acknowledged in interactions with health care professionals.

Protective factors include being part of communities of faith, having community support, and acceptance from one's family. Community may play a critical role in terms of social support for LGBTQI individuals. Because, in some circumstances, LGBTQI individuals may feel more accepted by their LGBTQI friends than by their family of origin.

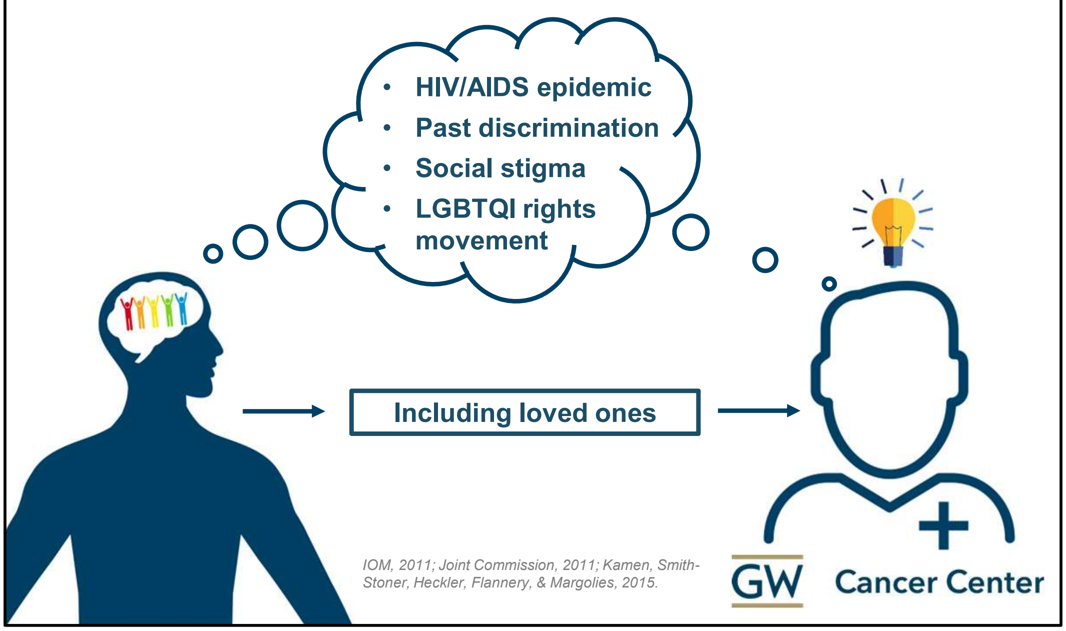
It is helpful for providers to inquire about social support, including partners and preferred caregivers. And then incorporate them into appointments and decision-making, based on the patient's preference.

Furthermore, some research demonstrates the impressive psychological resiliency displayed by members of the LGBTQI communities, often in the face of considerable stress. It has been suggested that the HIV/ AIDS epidemic, experiences of discrimination and social stigma and the LGBTQI rights movement have strengthened the sense of resilience and cohesiveness within the LGBTQI community.

By tailoring health messages and interventions to these areas of resiliency, health care professionals may encourage health-promoting behaviors or reduce high-risk behaviors.

For instance, studies have found that inclusion of patients’ partners or parents in health care encounters bolsters resilience.

Tailoring Strategies to Areas of Resiliency



- HIV/AIDS epidemic
- Past discrimination
- Social stigma
- LGBTQI rights movement

Including loved ones

IOM, 2011; Joint Commission, 2011; Kamen, Smith-Stoner, Heckler, Flannery, & Margolies, 2015.

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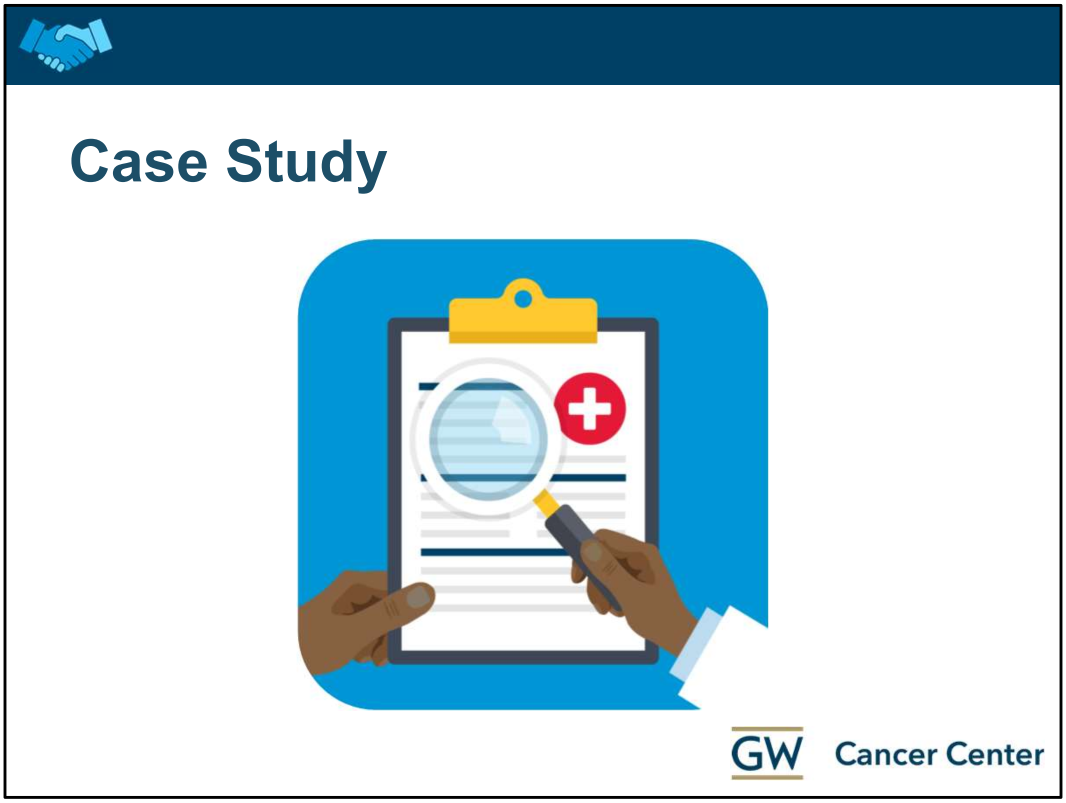

Case Study

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Let’s now look at a brief case study, which further illustrates the concepts we’ve talked about.

In 2009, authors published a case of a transgender woman of color who was diagnosed with metastatic breast cancer 14 months after presenting to her primary care doctor with a breast lump. In this case, the patient refused a mammogram until she had a large mass that had spread to her spine.

This clinical case highlighted some of the ways in which cultural myths and misinformation can put patients at risk.

Let’s take a look at this case to see what went wrong.

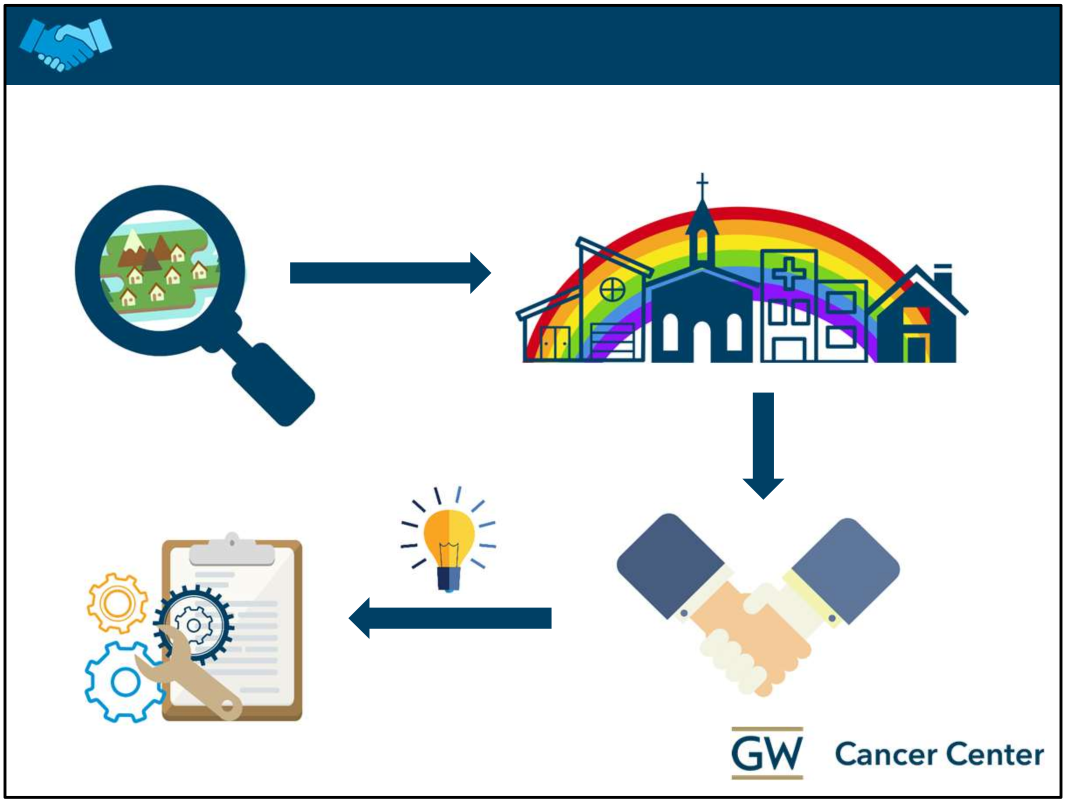
In this case, a few strategies could have helped the patient receive culturally competent care:

First, providers could have conducted a medical history to assess cancer risk prior to hormonal therapy for gender transition. Clinicians should discuss risks and benefits of hormone therapy with the patient and engage in shared decision making, with an understanding that patients may decline genetic testing for cancer risk so that they can undergo hormone therapy without a contraindication.

Second, the health care team could have done an assessment of patient beliefs and fears to explain the seriousness of the breast lump and the need for a mammogram, and frame this explanation to make sense from the patient's point of view. Had this been done the care team would have discovered:

- The patient believed she was not at risk for cancer because she was—using the patient's own words--born with a "male chest" and "Men and women cancers are different."
- She was not concerned with her breast lump because she believed her silicone implants caused many lumps.
- She believed that cutting cancer would make it spread.
- She believed she was at less of a risk for breast cancer because she received estrogen injections rather than pills—which in her words "can cause breast cancer."

Third, health care professionals could have engaged people respected by the patient to have them help the patient understand the seriousness of the breast lump and the importance of checking it early.



While we just discussed a specific case example, it is important to note that, when developing approaches to improve care it is helpful to partner with local community organizations that already serve LGBTQI individuals. These organizations can play a critical role in promoting and improving the health and wellbeing of sexual and gender minorities at risk for and diagnosed with cancer in your area.

However, here are a few examples of organizations that have a national presence across the care continuum: LGBT Health Link is a CDC-funded cancer and tobacco disparity network.

The program links people and information to educate on best practices in health departments and community organizations.

The National LGBT Cancer Network provides cultural competency trainings, a directory of LGBTQI-friendly cancer screening and treatment facilities across the country, free online support forums, and risk assessment and screening reminder programs.

National LGBT Health Education Center provides educational programs, LGBT cancer resources and consultation with health care organizations.

National LGBTQI Organizations

LGBT HEALTHLINK
The Network for Health Equity
A Program of CENTERLINK

- CDC-funded cancer and tobacco disparity network
- Education on best practices

national lgbt cancer network
ADVOCATING FOR HEALTH EQUALITY

- LGBTQI cultural competency trainings
- Directory of LGBTQI-friendly cancer facilities
- Online support forums
- Risk assessments
- Screening reminder programs

NATIONAL LGBT HEALTH EDUCATION CENTER
A PROGRAM OF THE FENWAY INSTITUTE

- Educational programs
- LGBTQI cancer resources
- Consultation with health care organizations

LGBT Health Link, n.d.; National LGBT Cancer Network, n.d.; National LGBT Health Education Center, n.d.

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https://pbs.twimg.com/profile_images/1319608375/square_LOGO.jpg
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Conclusion

- Identify barriers to care for sexual and gender minorities (SGM), also referred to as Lesbian, Gay, Bisexual, Transgender, Queer and Intersex (LGBTQI) individuals
- Describe unique cancer risks and challenges for LGBTQI individuals, as well as resources and areas of resiliency

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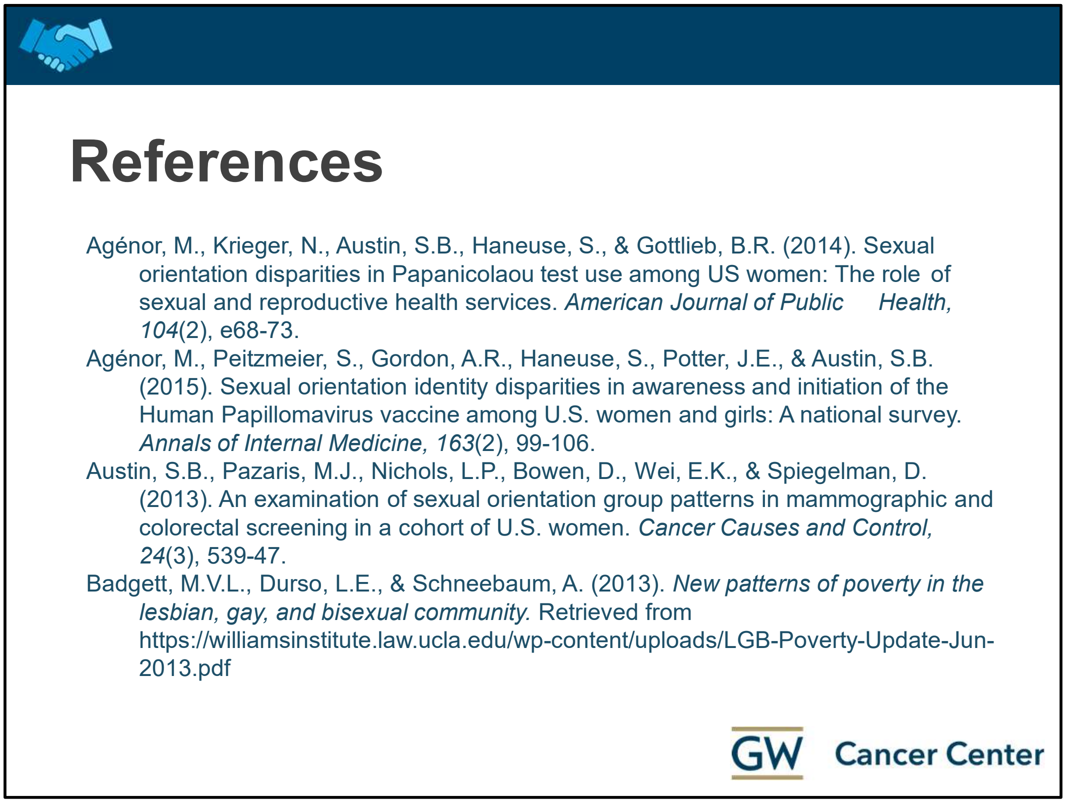
After completing this lesson, you are able to:
- Identify barriers to care for sexual and gender minorities or (SGM), also referred to as lesbian, gay, bisexual, transgender, queer and intersex or (LGBTQI) individuals
- Describe unique cancer risks and challenges for LGBTQI individuals, as well as resources and areas of resiliency



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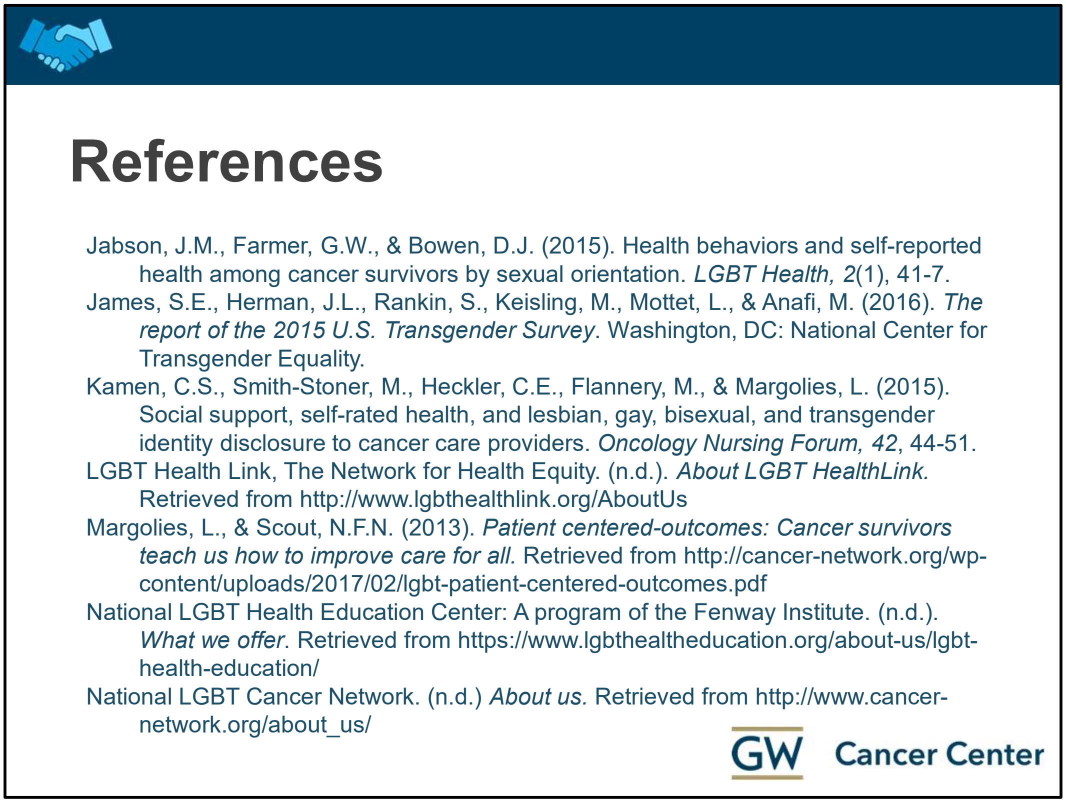

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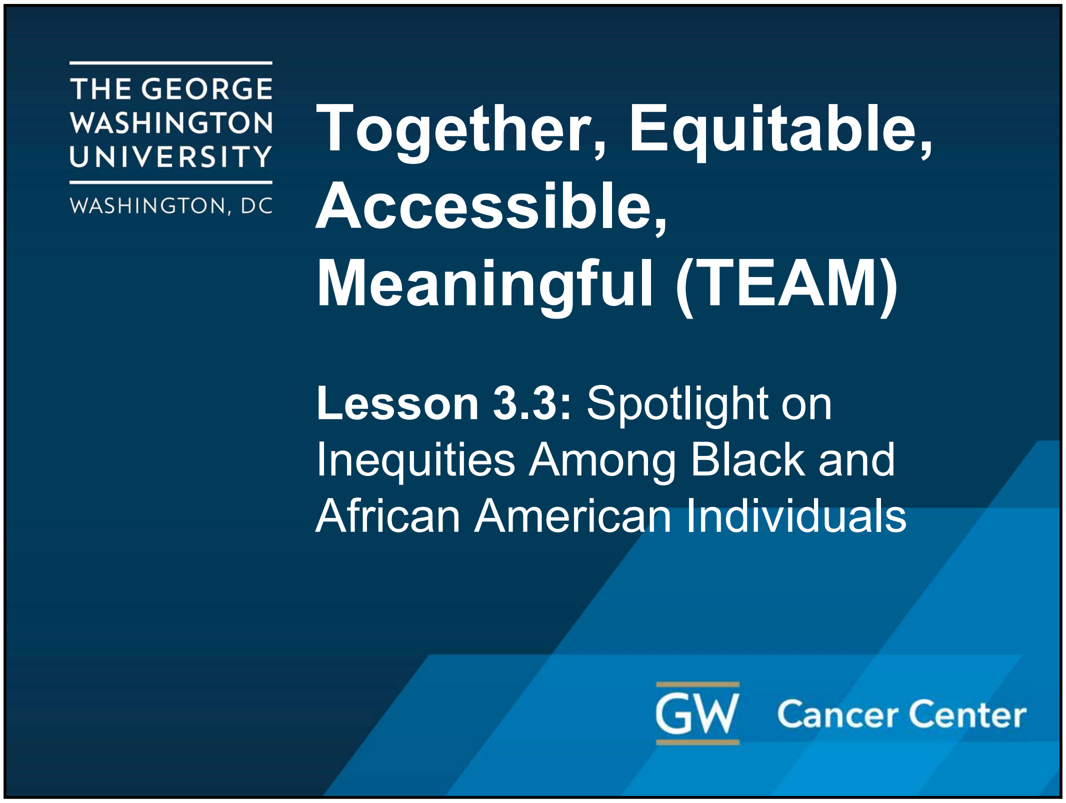

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Together, Equitable, Accessible, Meaningful (TEAM)

Lesson 3.3: Spotlight on Inequities Among Black and African American Individuals

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Welcome to Module 3, Lesson 3:

Acknowledgments

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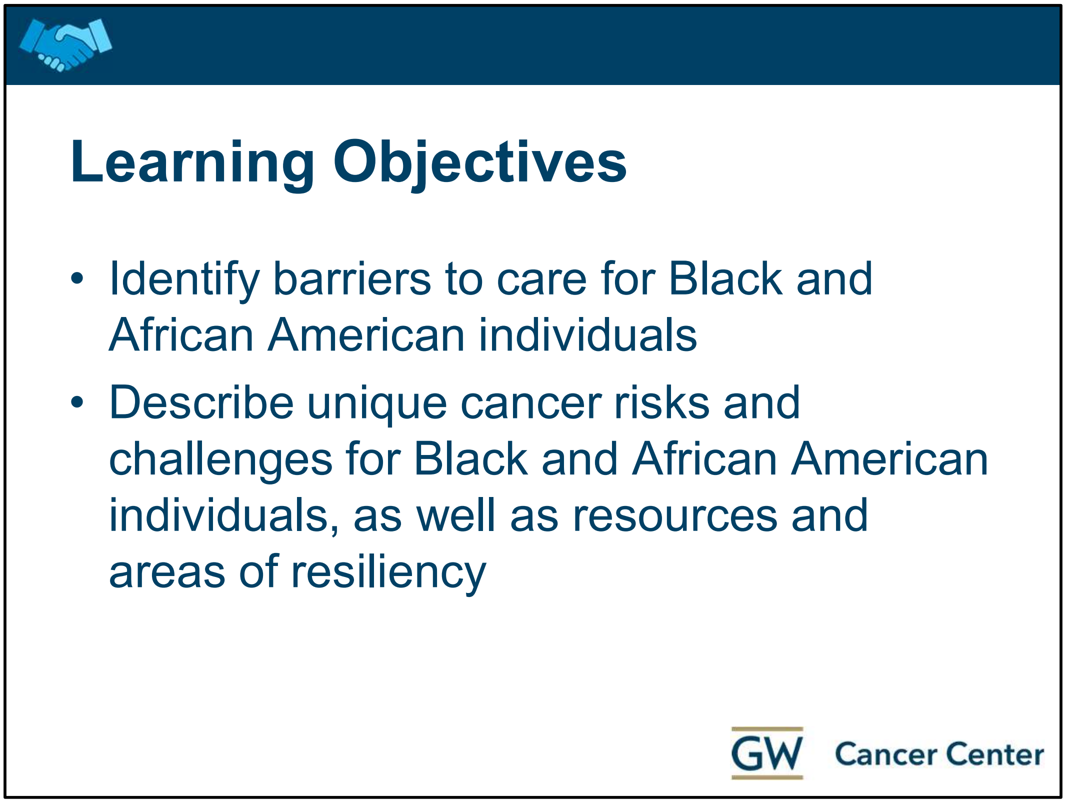

Learning Objectives

- Identify barriers to care for Black and African American individuals
- Describe unique cancer risks and challenges for Black and African American individuals, as well as resources and areas of resiliency

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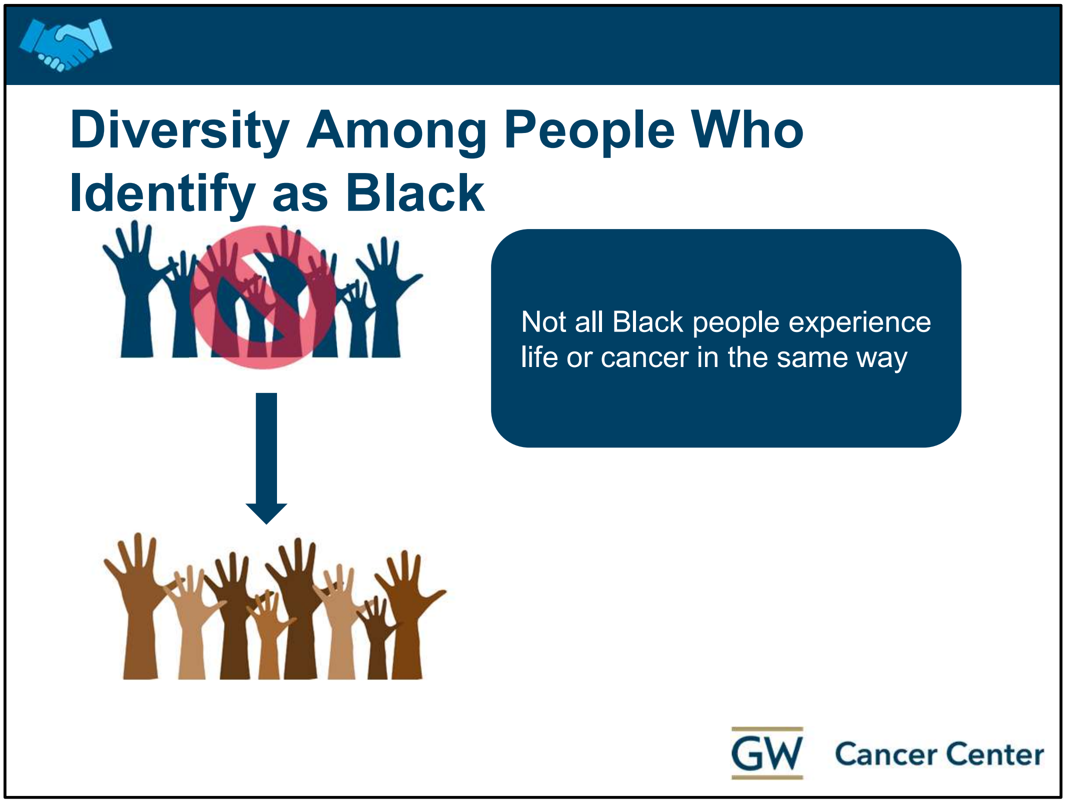
After completing this lesson, you will be able to:

- Identify barriers to care for Black and African American individuals

- Describe unique cancer risks and challenges for Black and African American individuals, as well as resources and areas of resiliency



Diversity Among People Who Identify as Black

Not all Black people experience life or cancer in the same way

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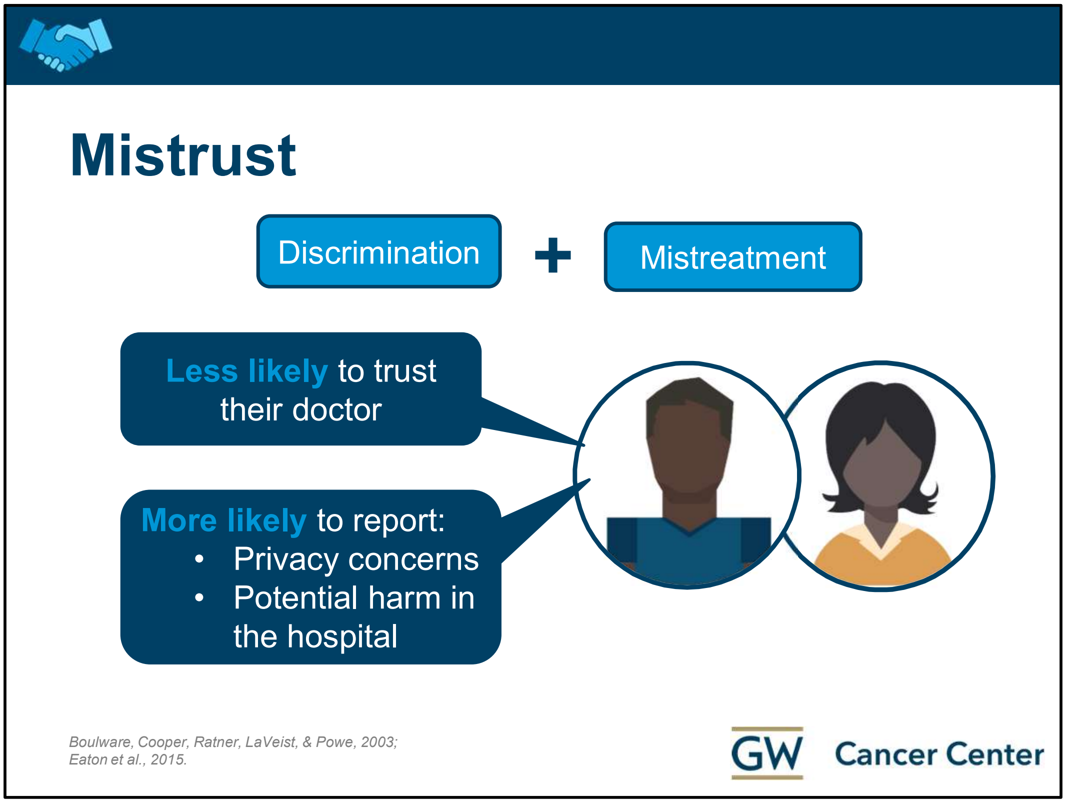
As we start this lesson, it is important to note that not all Black people experience life or cancer the same way. There are African, Haitian, Afro-Caribbean and Afro-Latino individuals who all may identify as Black or be identified in our health care system as Black.

Furthermore, U.S. Census has designated a number of racial and ethnic categories - all of which may not be consistent with how groups that reside in the United States and its territories self-identify.

In this and other lessons, we use the term Black and African American to refer to the myriad of people who reside in the United States and self-identify as members of either of these groups.

By using this term, we acknowledge the distinction between those individuals who have different histories and racial and ethnic identities, and we recognize these individuals hold other identities, and, different experiences, needs and values.



Mistrust

Discrimination + Mistreatment

Less likely to trust their doctor

More likely to report:
- Privacy concerns
- Potential harm in the hospital

Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Eaton et al., 2015.

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As mentioned in the lesson on Patient Engagement in Research, many black individuals in the U.S., like other marginalized groups have a mistrust of health care providers and the health care system. This is due to a variety of reasons including fear of being discriminated against and actual experiences of discrimination and mistreatment.

African Americans are less likely than whites to trust their doctor. They are also more likely to report concerns about privacy and potential for harm in the hospital setting.

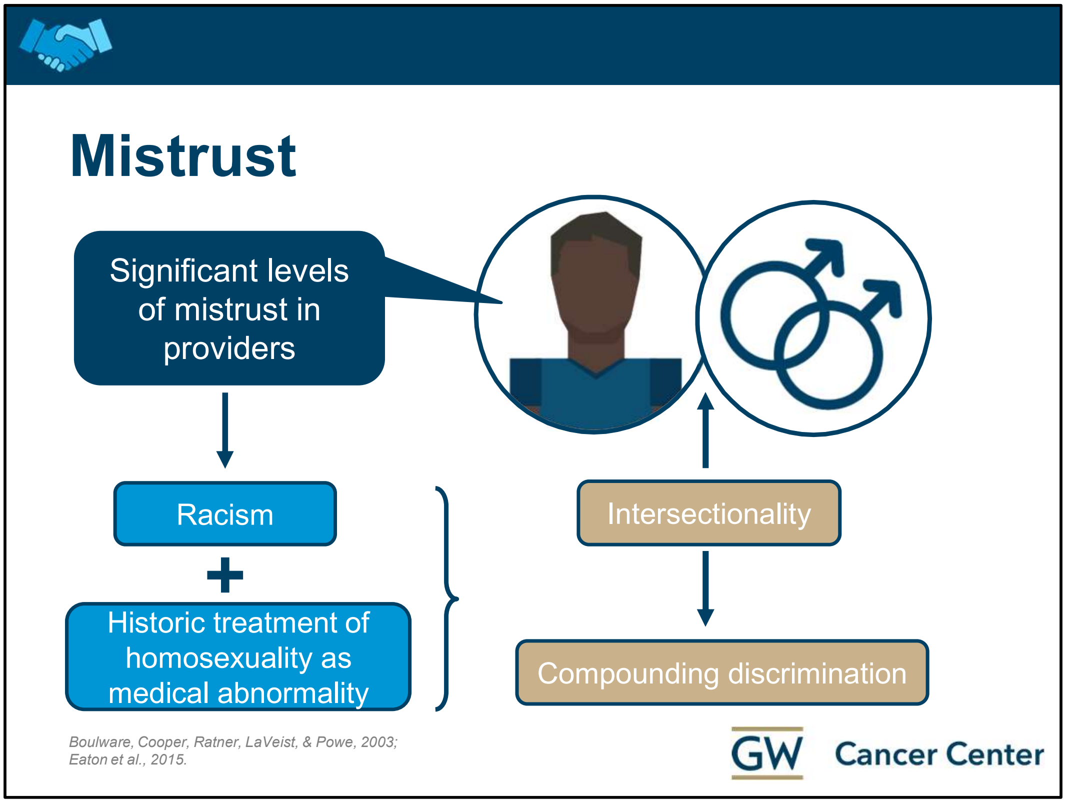
In particular, black men who have sex with men report significant levels of mistrust in health care providers. One can attribute this stigma and mistreatment in the health care setting, including racism and the historic treatment of homosexuality as a medical abnormality. This is also a key example of intersectionality – as black men who have sex with men face compounding discrimination due to their race and sexual orientation.

Mistrust creates barriers to care, which may lead to underutilization of health care services, being less likely to not take medical advice, being more likely not keep a follow-up appointment and being more likely to postpone seeking care.

Mistrust and underutilization of health care services also extends to cancer care. For example, black people may be less likely to obtain genetic counseling for mutations associated with hereditary breast cancer.

Black individuals may also be more likely to experience other barriers to care that affect health outcomes. These include fragmented care, lack of insurance, transportation issues, inability to take time off work, difficulty arranging childcare, inconvenient clinic hours and long wait times.

Discrimination also has an impact on health outcomes. For instance, a study of data from the Black Women's Health Study looked at the link between discrimination and breast cancer incidence. It found that everyday discrimination and major discrimination (related to housing, employment, and criminal justice) were associated with increased breast cancer incidence, and this association was significant for major discrimination related to employment.



Mistrust

Significant levels of mistrust in providers

Racism

+

Historic treatment of homosexuality as medical abnormality

Intersectionality

Compounding discrimination

Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Eaton et al., 2015.

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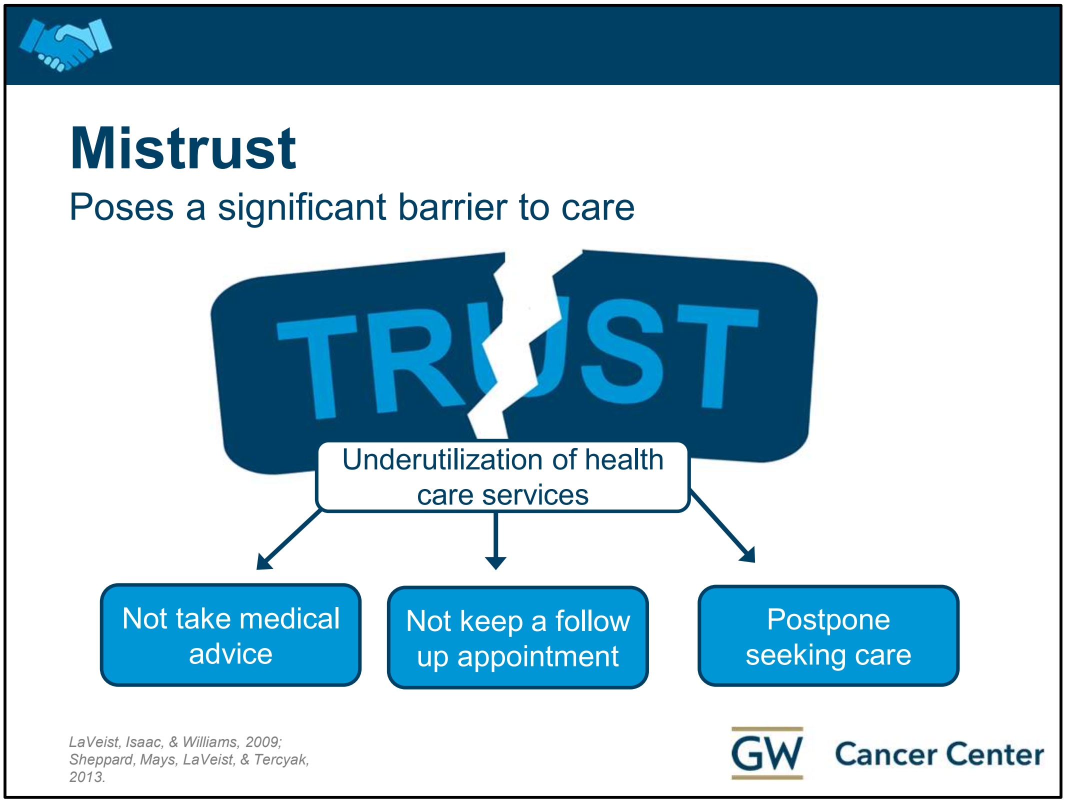

Mistrust

Poses a significant barrier to care

Underutilization of health care services

- Not take medical advice
- Not keep a follow up appointment
- Postpone seeking care

LaVeist, Isaac, & Williams, 2009; Sheppard, Mays, LaVeist, & Tercyak, 2013.

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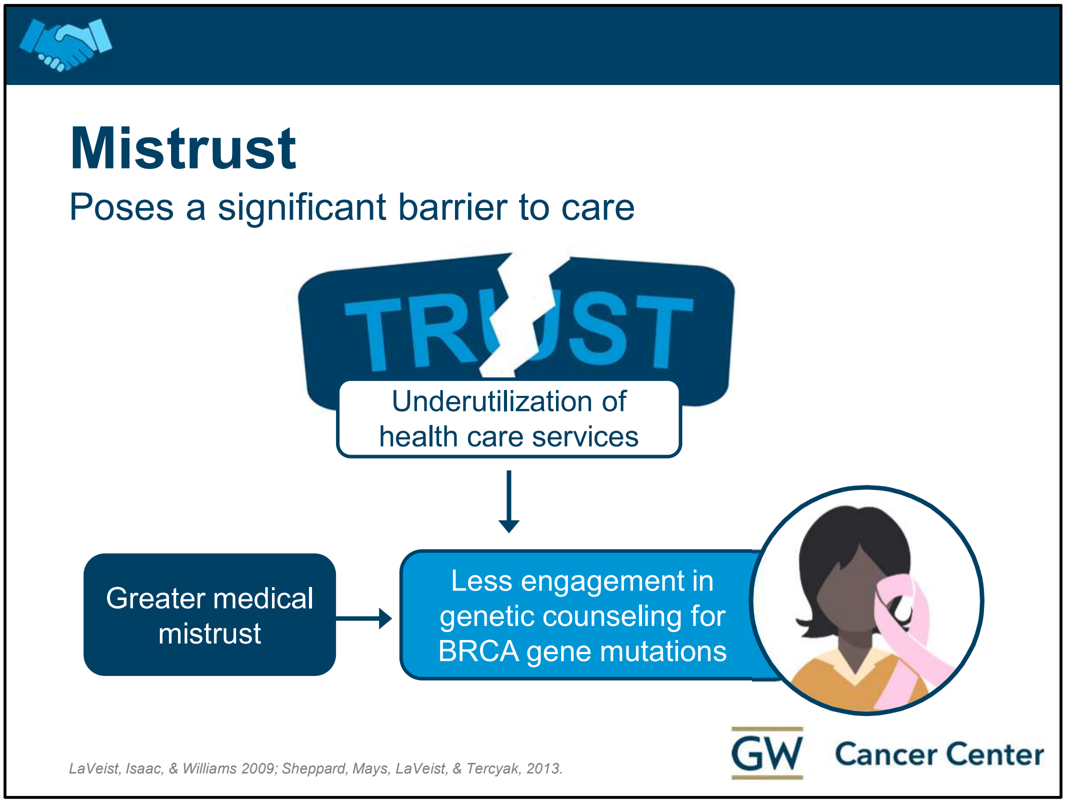

Mistrust

Poses a significant barrier to care

TRUST

Underutilization of health care services

Greater medical mistrust

Less engagement in genetic counseling for BRCA gene mutations

LaVeist, Isaac, & Williams 2009; Sheppard, Mays, LaVeist, & Tercyak, 2013.

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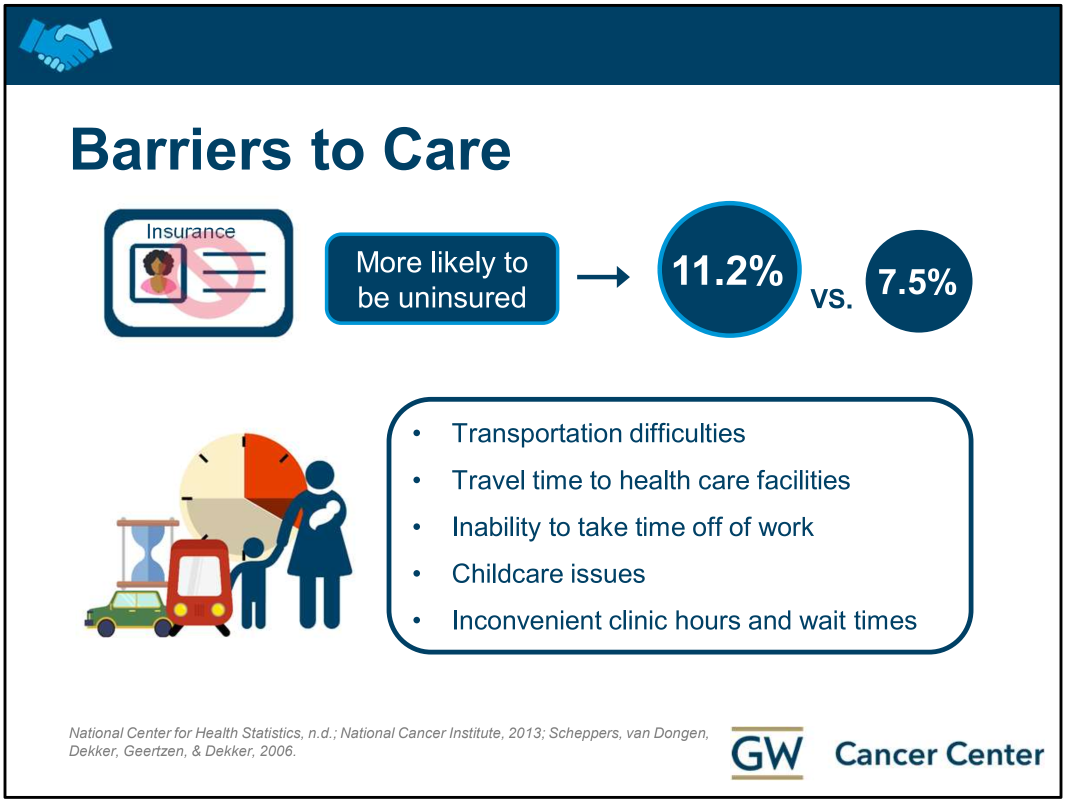

Barriers to Care

More likely to be uninsured → 11.2% vs. 7.5%

- Transportation difficulties
- Travel time to health care facilities
- Inability to take time off of work
- Childcare issues
- Inconvenient clinic hours and wait times

National Center for Health Statistics, n.d.; National Cancer Institute, 2013; Scheppers, van Dongen, Dekker, Geertzen, & Dekker, 2006.

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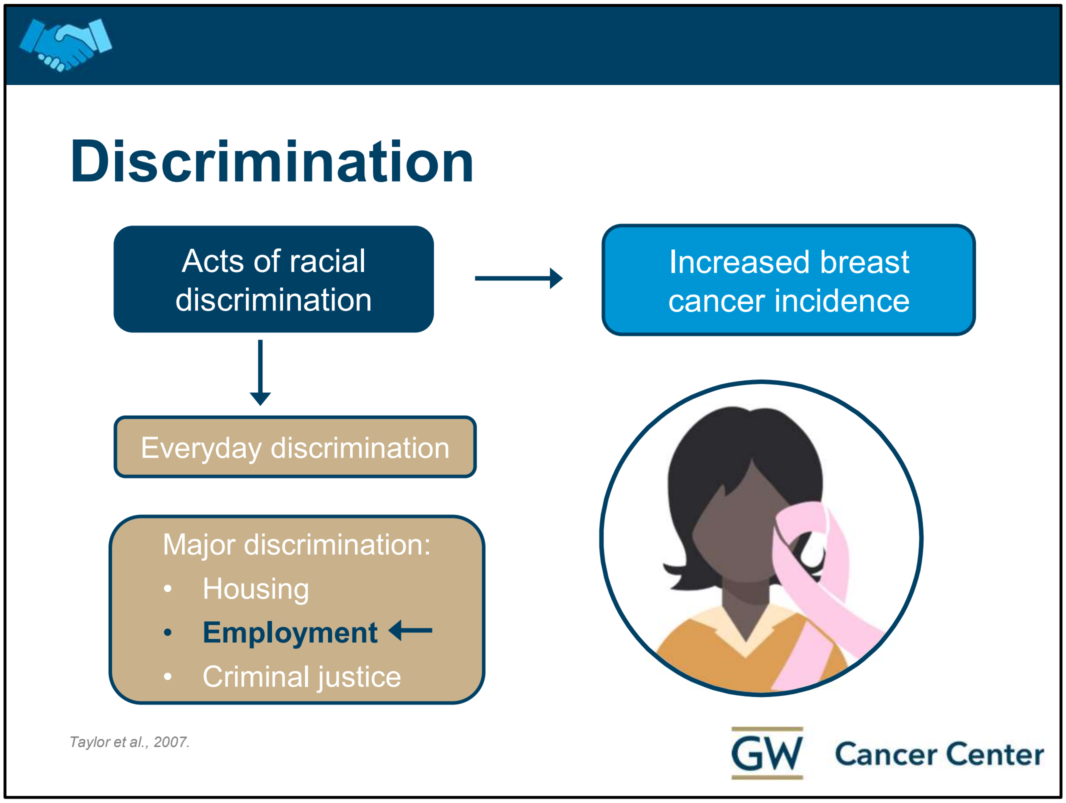

Discrimination

Acts of racial discrimination

Increased breast cancer incidence

Everyday discrimination

Major discrimination:
- Housing
- **Employment**
- Criminal justice

Taylor et al., 2007.

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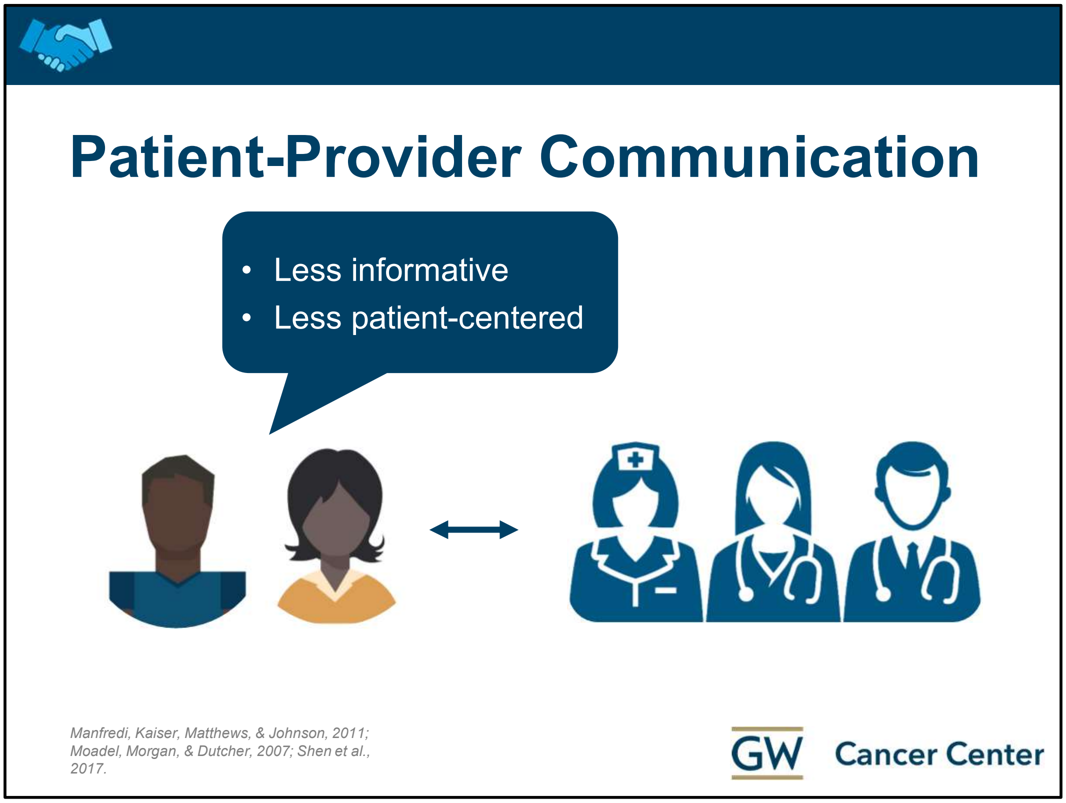

Patient-Provider Communication

- Less informative
- Less patient-centered

Manfredi, Kaiser, Matthews, & Johnson, 2011; Moadel, Morgan, & Dutcher, 2007; Shen et al., 2017.

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There are also well-documented instances of African Americans receiving poorer care in more subtle ways. Compared to whites, African American cancer patients have reported that communication with health care providers was less informative and less patient-centered.

Sometimes, when racial identities of patients and providers do not match there is a negative impact on communication. Studies have shown that black patients report poorer quality communication, less information-sharing by providers, and lower levels of patient participation in decision-making than white patients.

Yet, these disparities narrowed when the race of the provider matched that of the patient. Training of health care professionals (as well as patients) to engage in patient-centered communication is needed, and may be particularly important in cases of racial discordance. This includes more information sharing by both patients and providers, an emphasis on partnership building and patient engagement in the communication process.

It is also crucial for health care professionals to be aware of bias. We all have bias, but most of us do not receive any training to notice bias in our selves or in others. Bias takes a toll on the patient-provider relationship and it has a clear link to unequal care.

African American breast cancer patients are less likely to receive full doses of chemotherapy than white breast cancer patients. Researchers think this may be due to white doctors’ assumptions about their African American patients as well as communication issues between providers and patients.

It is important to note that while training existing medical providers to communicate better with diverse patients is critical, it is also critical to encourage diverse youth to pursue medical professions. A dual focus on communication skills and sociodemographic diversity of medical students will help relieve the negative impacts of racial discordance between providers and patients.

Patient-Provider Communication

- Lower quality
- Less effective
- Less information-sharing
- Less shared decision-making

Racial discordance

Racial concordance

Training in patient-centeredness is particularly important

Manfredi, Kaiser, Matthews, & Johnson, 2011; Moadel, Morgan, & Dutcher, 2007; Shen et al., 2017.

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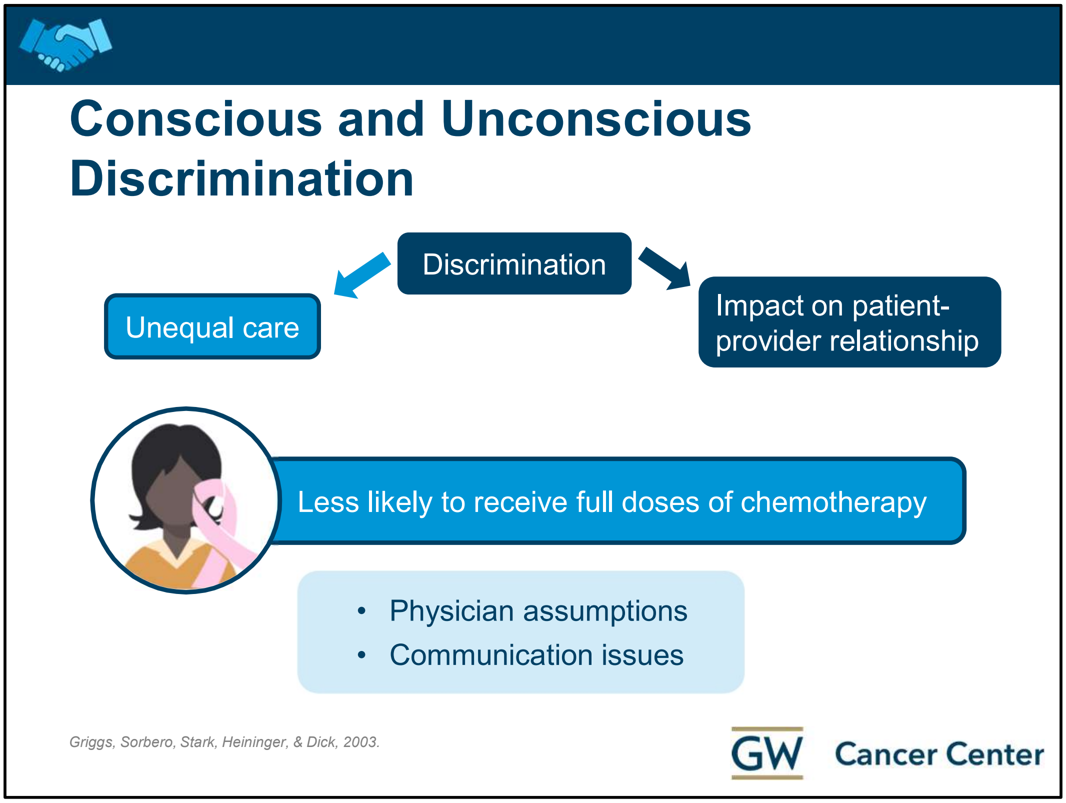

Conscious and Unconscious Discrimination

Discrimination

Unequal care

Impact on patient-provider relationship

Less likely to receive full doses of chemotherapy

- Physician assumptions
- Communication issues

Griggs, Sorbero, Stark, Heininger, & Dick, 2003.

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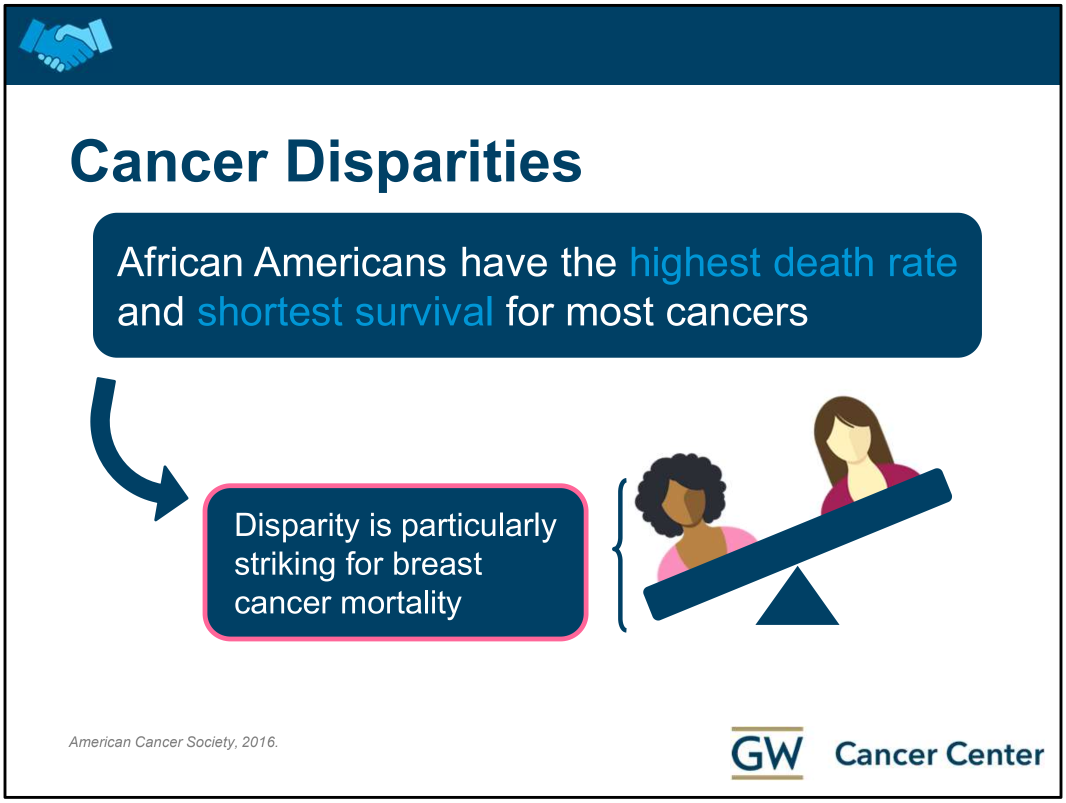

Cancer Disparities

African Americans have the highest death rate and shortest survival for most cancers

Disparity is particularly striking for breast cancer mortality

American Cancer Society, 2016.

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There are also alarming disparities in cancer mortality and overall survival, as African Americans, have the highest death rate and shortest survival for most cancers, of any racial and ethnic group in the U.S.

This disparity is particularly striking when looking at breast cancer. In general, there has been a steady decline in breast cancer deaths among U.S. women. Yet, this progress has not been seen in African American women. African American women are more likely to be diagnosed with later stage disease and have a much lower 5-year survival rate than white women: 78 percent, compared with 90 percent.

Furthermore, while white women and black women have similar incidence rates of breast cancer; black women are more like to die from it.

Even more disturbing is that the disparity in breast cancer mortality is growing. This may be due to that fact that access to and quality of screening and treatment are not equitably distributed among patient populations. African American women are also more likely than white women to be diagnosed with triple negative breast cancer, which is a very aggressive form of breast cancer.

Some researchers have suggested that the overall disparity in breast cancer mortality is due to differences in genetics. However, increasingly, the consensus is this is not a sufficient explanation. Only a small proportion of African American women are diagnosed with triple negative breast cancer. The vast majority of black women are diagnosed with other common types of breast cancer.

So this genetic difference does not explain such a dramatic disparity in mortality. Instead, social or environmental factors could be at play.

https://www.cancer.org/research/cancer-facts-statistics/cancer-facts-figures-for-african-americans.html
O'Keefe, E.B., Melzer, J.P. & Bethea, T.N. (2015). Heath disparities and cancer: racial disparities in cancer mortality in the United States; 2000-2010. *Frontiers in Public Health, 3*, 1-15.
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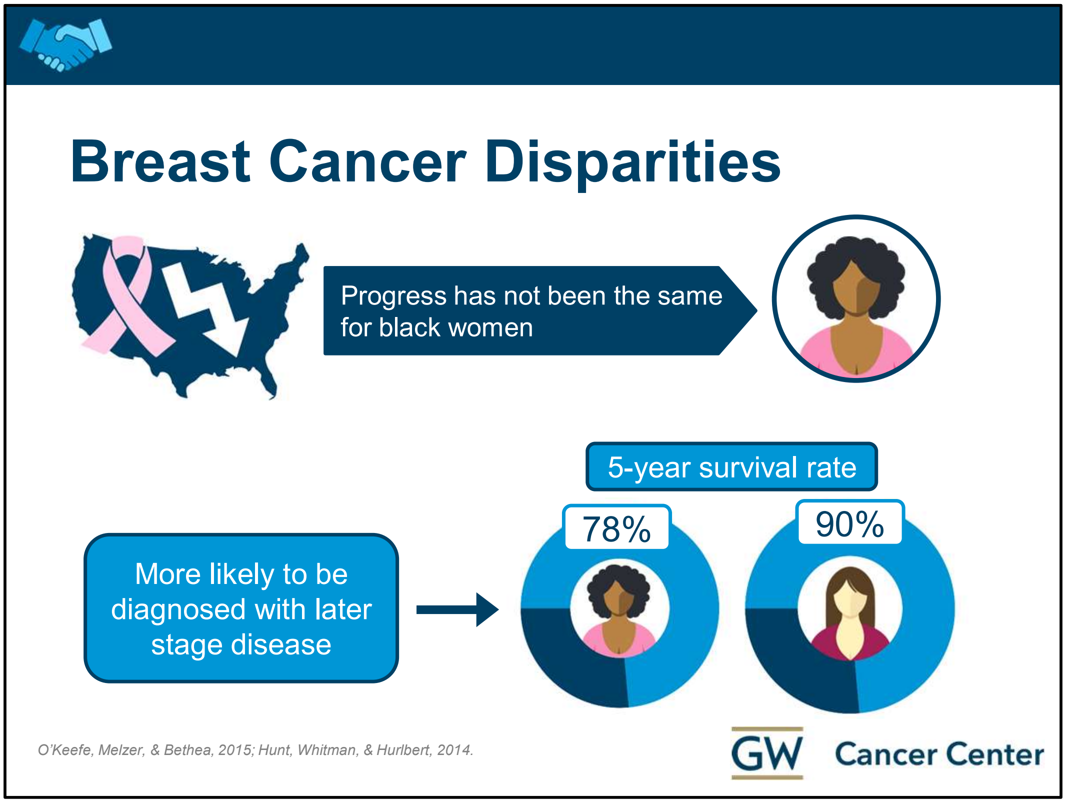

Breast Cancer Disparities

Progress has not been the same for black women

5-year survival rate

78%

90%

More likely to be diagnosed with later stage disease

O'Keefe, Melzer, & Bethea, 2015; Hunt, Whitman, & Hurlbert, 2014.

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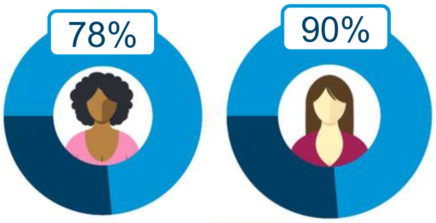
Breast Cancer Disparities

Black women are more likely to die from breast cancer

More likely to be diagnosed with later stage disease →

5-year survival rate



O'Keefe, Melzer, & Bethea, 2015; Hunt, Whitman, & Hurlbert, 2014; National Cancer Institute, n.d..

Breast Cancer Disparities

Disparity in mortality is increasing over time

↓

Inequitable access to and quality of screening and treatment

Genetic differences are not the only reason

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Social or environmental factors are also at play

Hunt, Whitman, & Hurlbert, 2014; Morris et al., 2007; Susan G. Komen, 2017; Huo et al., 2009.

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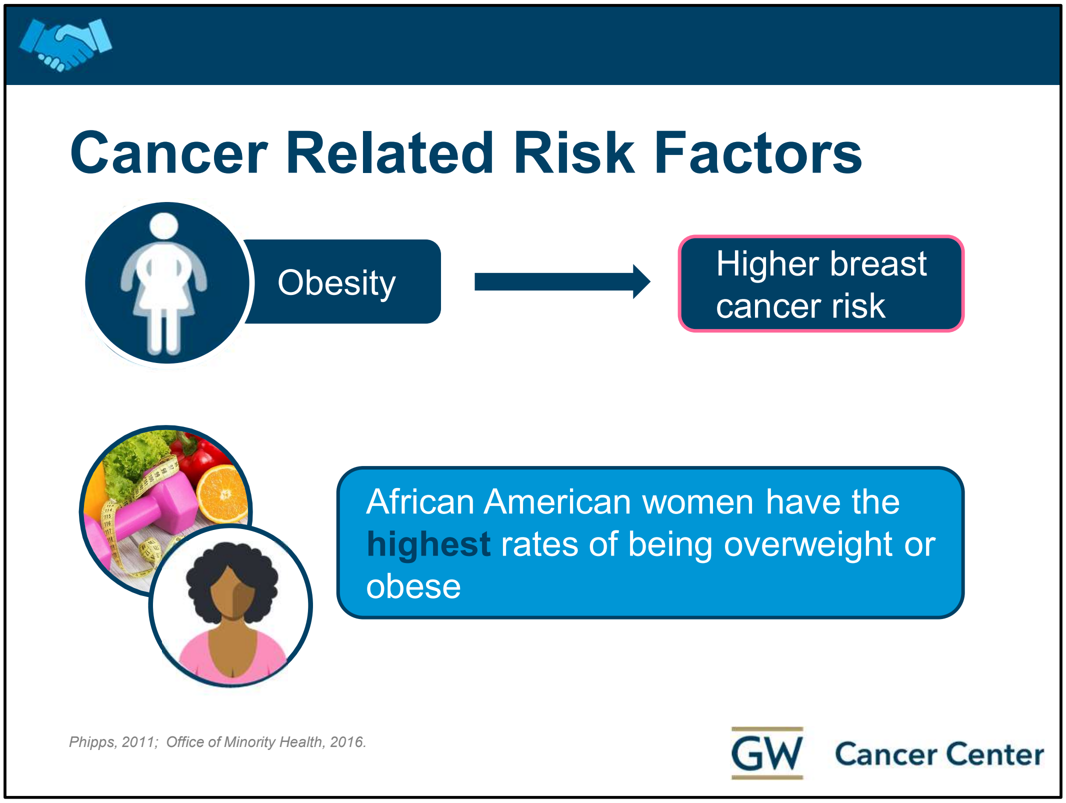

Cancer Related Risk Factors

Obesity → Higher breast cancer risk

African American women have the **highest** rates of being overweight or obese

Phipps, 2011; Office of Minority Health, 2016.

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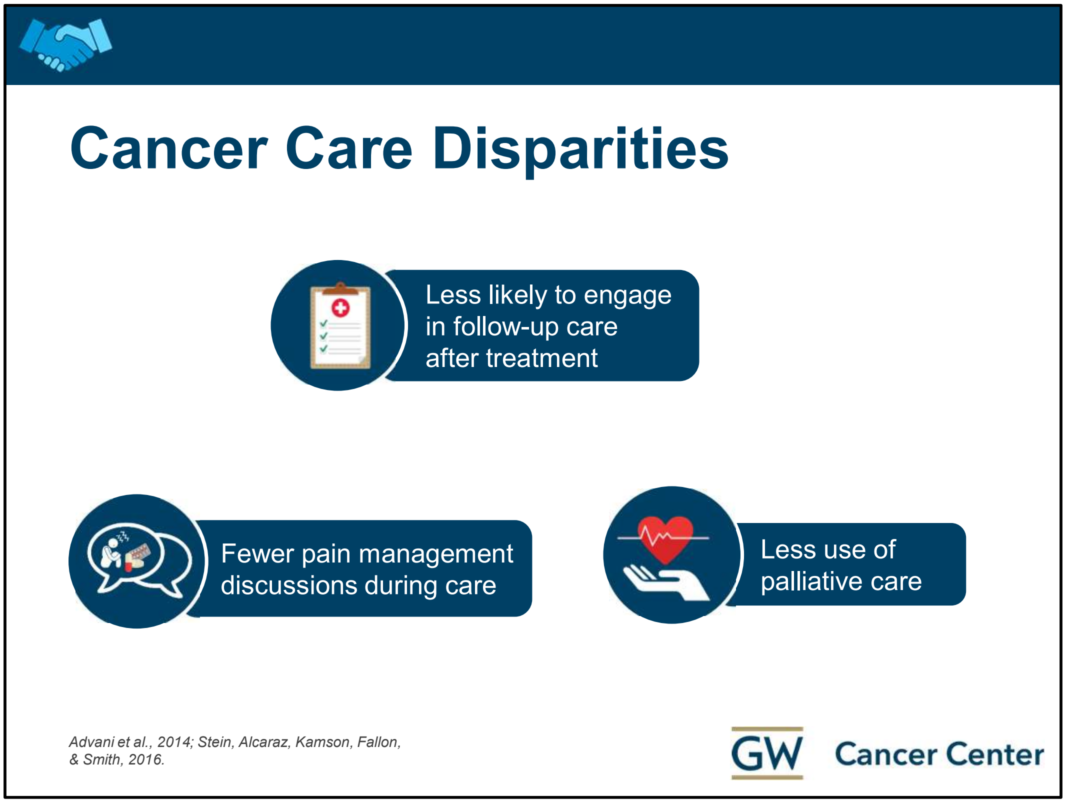
There are also other disparities in cancer-related risk factors and health behaviors for black women. For instance, obesity is linked with a higher breast cancer risk, and African American women have the highest rates of being overweight or obese among racial and ethnic groups.

Furthermore, black breast cancer survivors – as well as Latinas – were less likely to engage in follow-up care after treatment when compared with white counterparts. Studies of cancer survivors also show disparities among African Americans in pain management and palliative care when compared to whites.



Cancer Care Disparities

- Less likely to engage in follow-up care after treatment
- Fewer pain management discussions during care
- Less use of palliative care

Advani et al., 2014; Stein, Alcaraz, Kamson, Fallon, & Smith, 2016.

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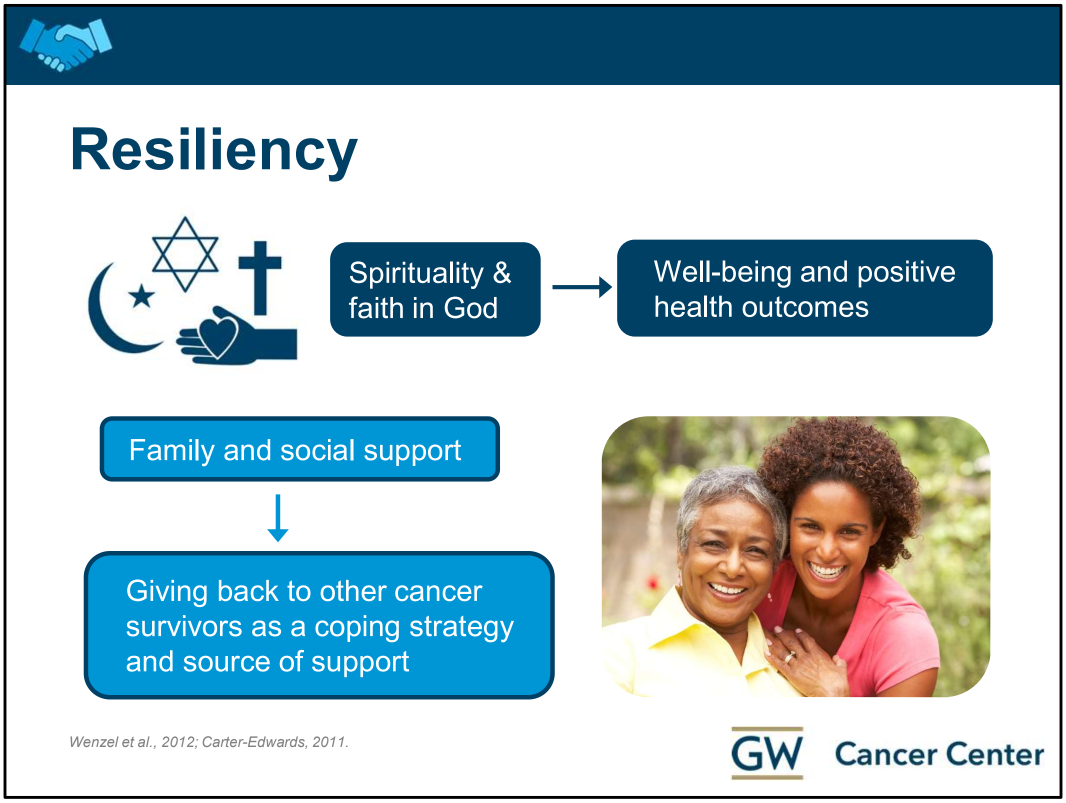

Resiliency

Spirituality & faith in God → Well-being and positive health outcomes

Family and social support

↓

Giving back to other cancer survivors as a coping strategy and source of support

Wenzel et al., 2012; Carter-Edwards, 2011.

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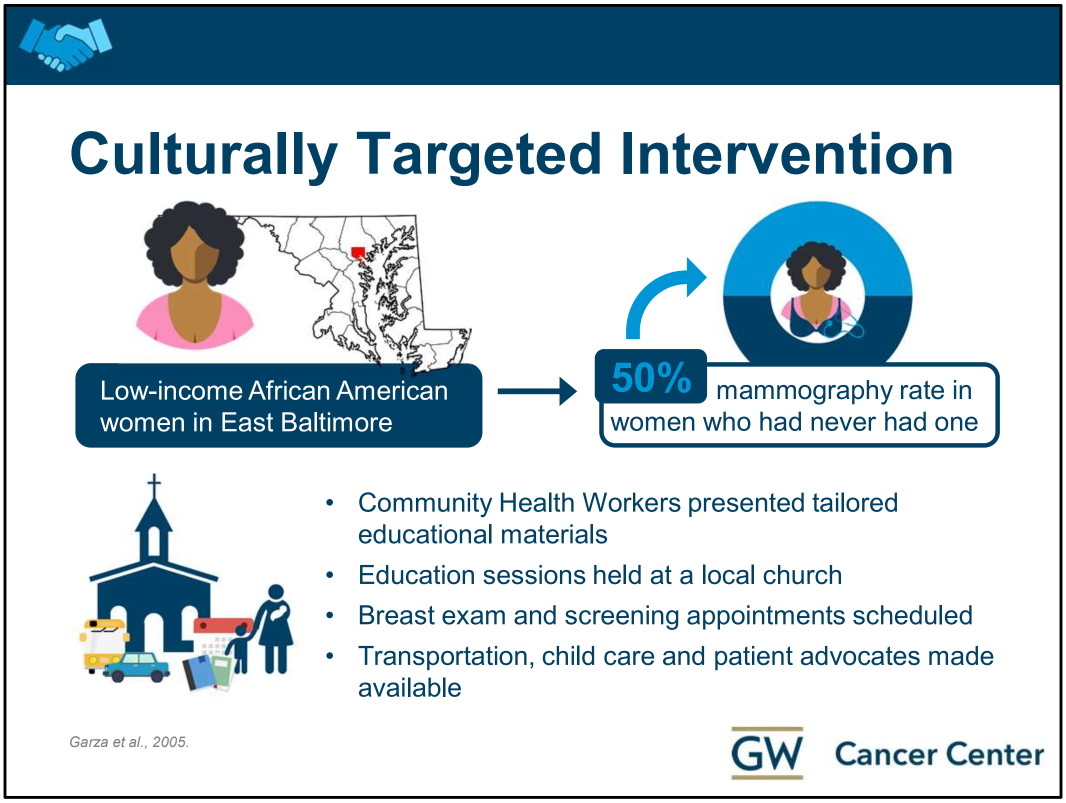
While Black and African American individuals face significant cancer disparities, they also possess resources and demonstrate resiliency in ways that positively influence their experience with cancer. Spirituality and family support are central factors to coping and resilience for Black and African American individuals.

Spirituality and faith in God among African Americans has been shown to be associated with well-being during cancer. This helps maintain positive thoughts and resilience, which result in positive health outcomes, including quality of life. African American cancer survivors have also reported giving back in the form of providing support to family, friends and other survivors as an important coping strategy and source of social support.

Recognizing that cultural traits, including spirituality, may serve as sources of support and resiliency in the context of cancer care is important when working with Black and African American people/individuals.



Culturally Targeted Intervention

Low-income African American women in East Baltimore

50% mammography rate in women who had never had one

- Community Health Workers presented tailored educational materials
- Education sessions held at a local church
- Breast exam and screening appointments scheduled
- Transportation, child care and patient advocates made available

Garza et al., 2005.

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In addition to clinicians recognizing the important role that spirituality and faith can have, let's look at an example of an intervention that has been successful in improving health outcomes for African Americans.

An educational intervention with low-income African American women in East Baltimore achieved a 50 percent rate in screening in women who had never had a mammogram. This intervention included:

- home visits by Community Health Workers sharing tailored educational materials
- an educational session at a local church conducted by a team consisting of a pastor, medical provider and health educators
- and breast examination and screening appointments.

Participants were also provided with transportation, childcare, patient advocates assisting in scheduling and community health workers that accompany patients on appointments to facilitate screenings.

While this example highlights a strategy that can improve the health of Black and African American individuals, it is important to work with local community organizations to learn more about local needs, the resources they provide, and ways you can partner.

Here are two examples of organizations that have a national presence in cancer care or research:

The National African American Tobacco Prevention Network provides tobacco cessation education resources and develops and implements "…comprehensive and community competent public health programs to benefit communities and people of African descent."

Sisters Network Inc. is a leading voice in African American breast cancer and is committed to increasing attention to the devastating impact that breast cancer has through educational resources, support and national and local events.

National Organizations

NAATPN
IT'S TIME ENERGIZE THE MOVEMENT

Sisters NETWORK® INC.
A National African American Breast Cancer Survivorship Organization

Develop and implement "…comprehensive and community competent public health programs to benefit communities and people of African descent"

Increase attention to the impact that breast cancer has among African Americans

Educational resources, support and national and local events

National African American Tobacco Prevention Network, Sisters Network Inc..

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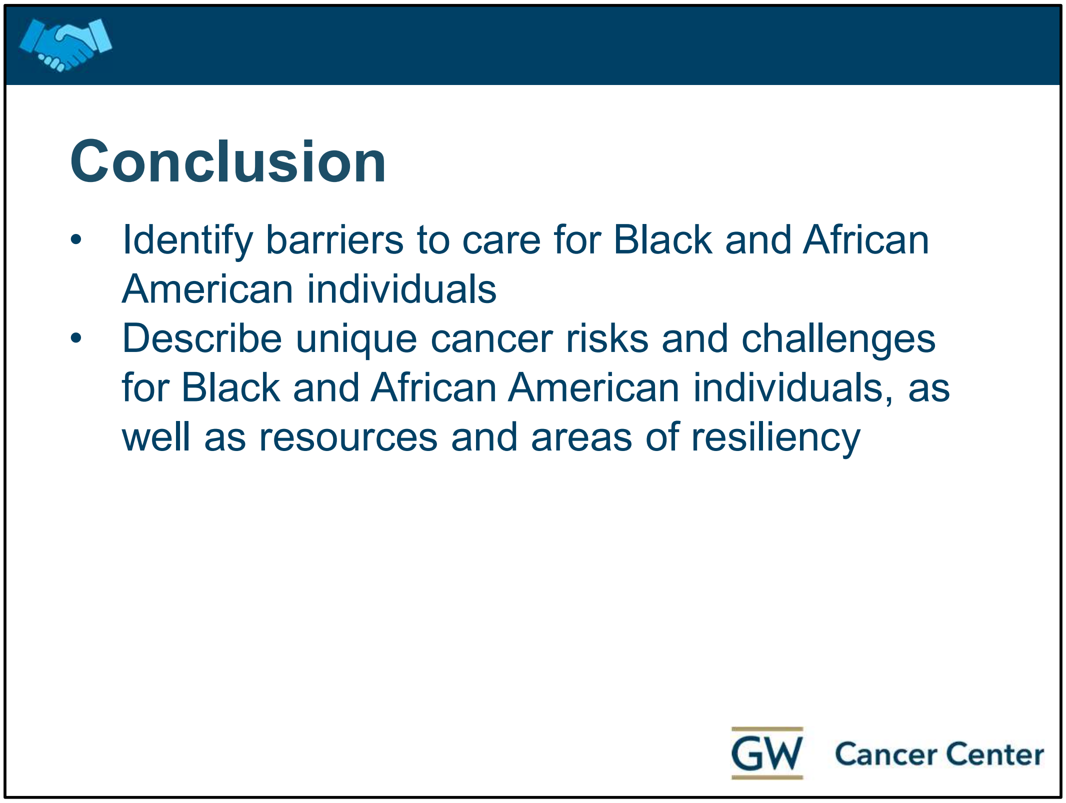

Conclusion

- Identify barriers to care for Black and African American individuals
- Describe unique cancer risks and challenges for Black and African American individuals, as well as resources and areas of resiliency

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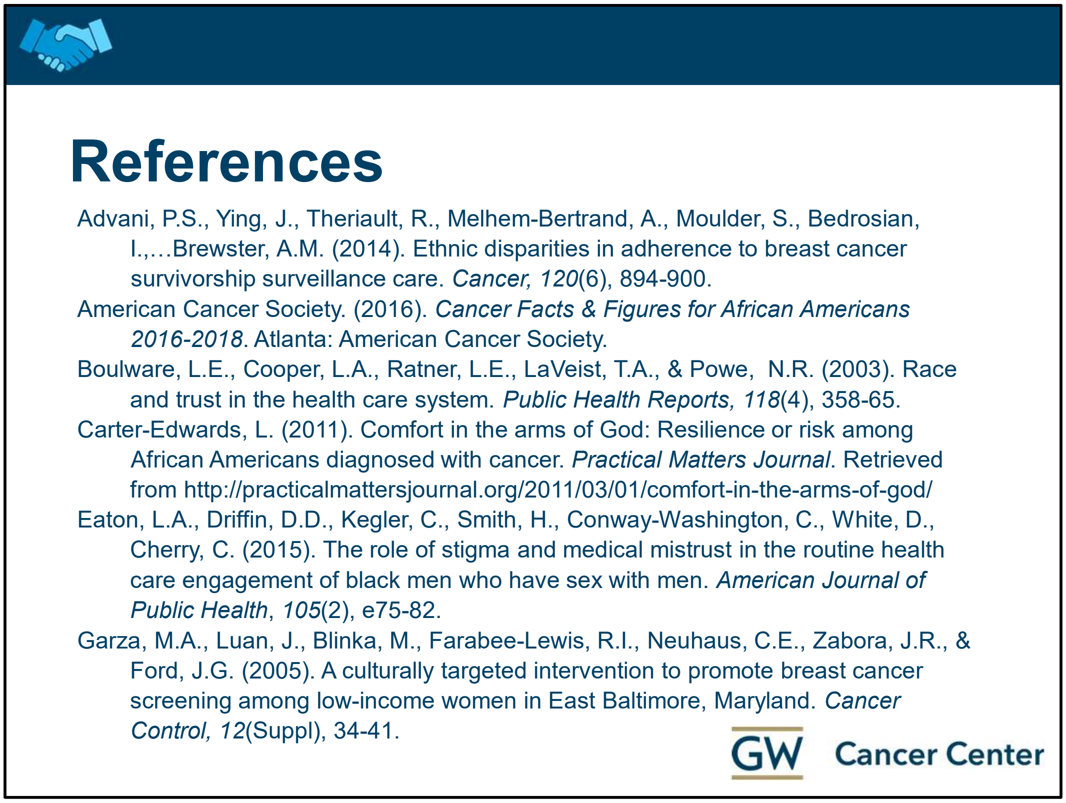
In this lesson, you learned to:

- Identify barriers to care for Black and African American individuals

- Describe unique cancer risks and challenges for Black and African American individuals, as well as resources and areas of resiliency



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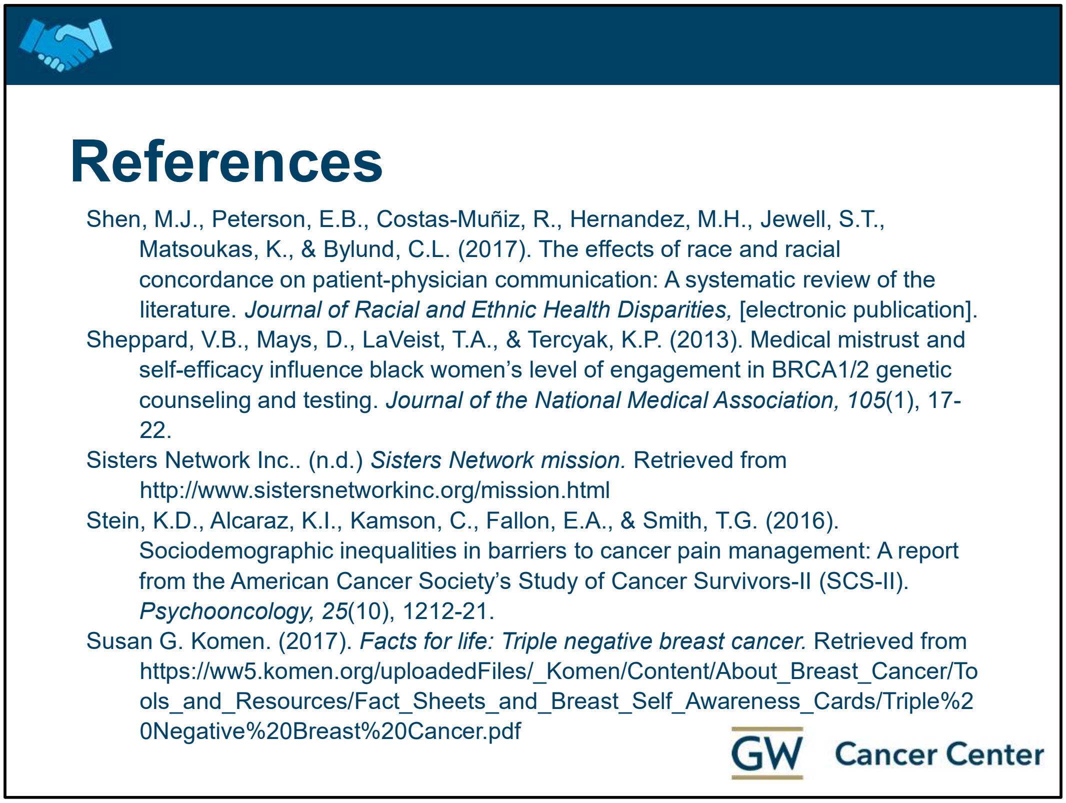

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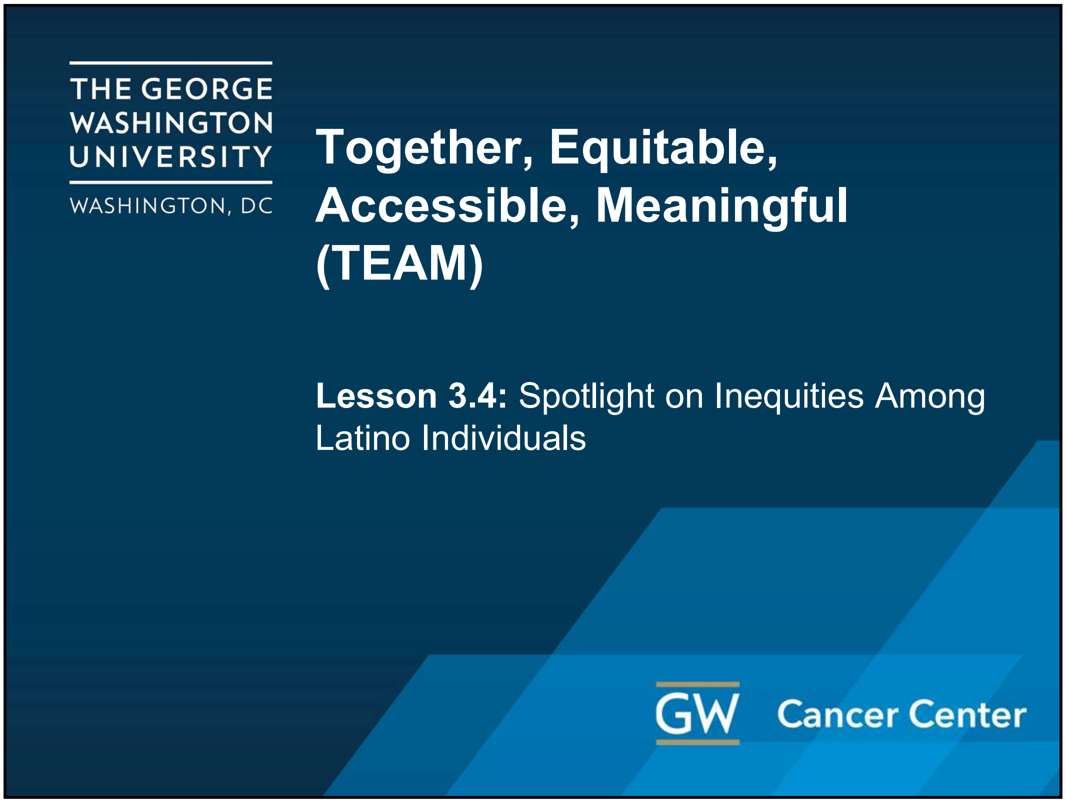

THE GEORGE WASHINGTON UNIVERSITY
WASHINGTON, DC

Together, Equitable, Accessible, Meaningful (TEAM)

Lesson 3.4: Spotlight on Inequities Among Latino Individuals

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Welcome to Module 3, Lesson 4:

Acknowledgments

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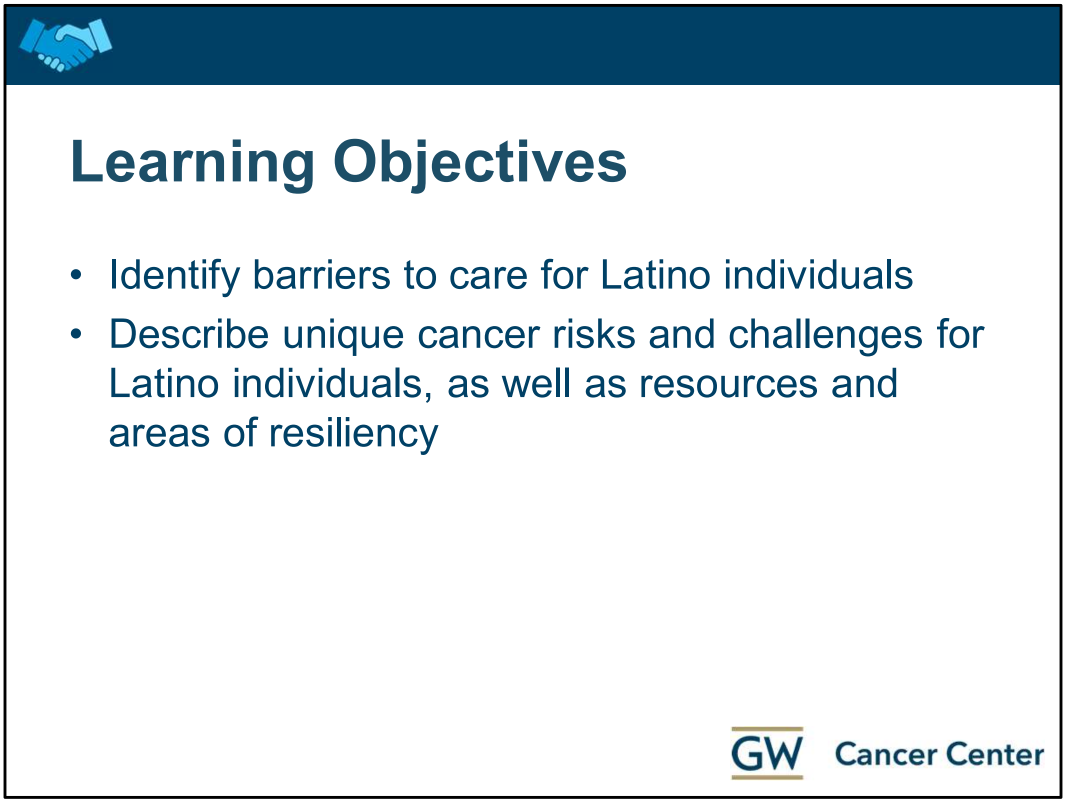

Learning Objectives

- Identify barriers to care for Latino individuals
- Describe unique cancer risks and challenges for Latino individuals, as well as resources and areas of resiliency

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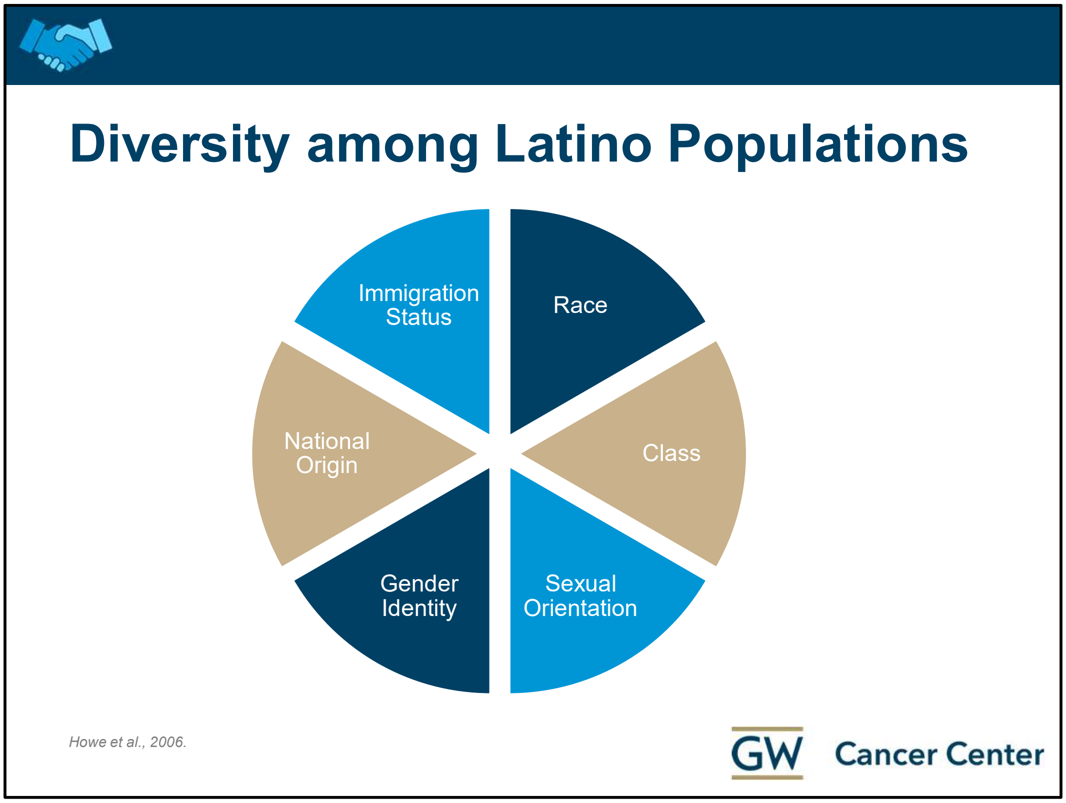
After completing this lesson, you will be able to:

- Identify barriers to care for Latino individuals
- Describe unique cancer risks and challenges for Latino individuals, as well as resources and areas of resiliency



Diversity among Latino Populations

Immigration Status

Race

Class

Sexual Orientation

Gender Identity

National Origin

Howe et al., 2006.

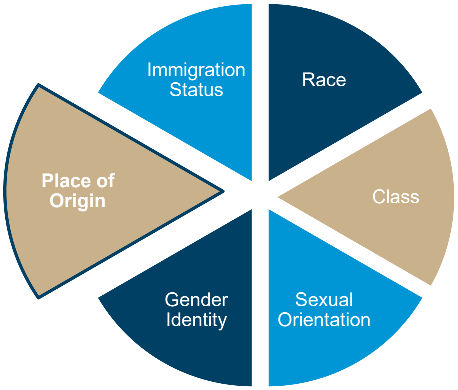
It must be noted that there is great diversity among Latino subpopulations – in terms of race, class, sexual orientation, gender identity, national origin, immigration status and more. Attention to regional diversity among Latino communities, for instance, is important because it may impact the effectiveness of interventions. For example, Puerto Rican women are more likely to be obese than all other racial/ethnic groups besides non-Hispanics. Cuban women are less likely to engage in leisure-time physical activity. These factors put both of these Latina subpopulations at a greater risk for breast and other cancers. Also, sexual and gender minorities in these communities have specific health, care and cancer needs. As we mentioned in the introductory lesson, sexual and gender minorities in Hispanic communities have embraced the term “Latinx” to refer to their ethnicity, as this term does not convey that a person or object is male or female. The use of this term is an example of a growing movement of recognizing multiple intersecting identities.

Diversity among Latina Populations

Some Latina subpopulations are at greater risk for certain cancers:

Puerto Rican women are more likely to be obese

Cuban women are less likely to engage in leisure-time physical activity



Immigration Status

Race

Place of Origin

Class

Gender Identity

Sexual Orientation

Howe et al., 2006.

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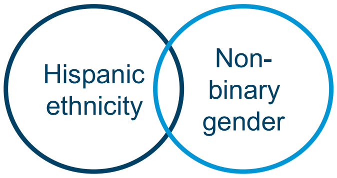
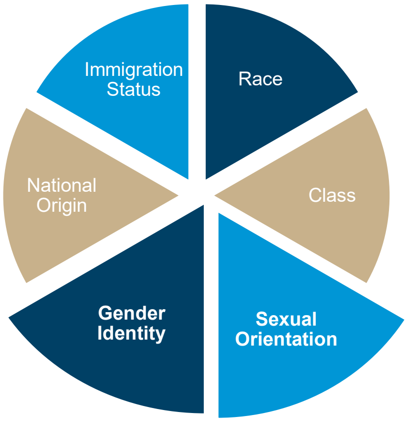
Diversity among Latino Populations

Individuals have embraced the term **“Latinx”** to refer to their ethnicity



Conveys that a person or object is not either male OR female



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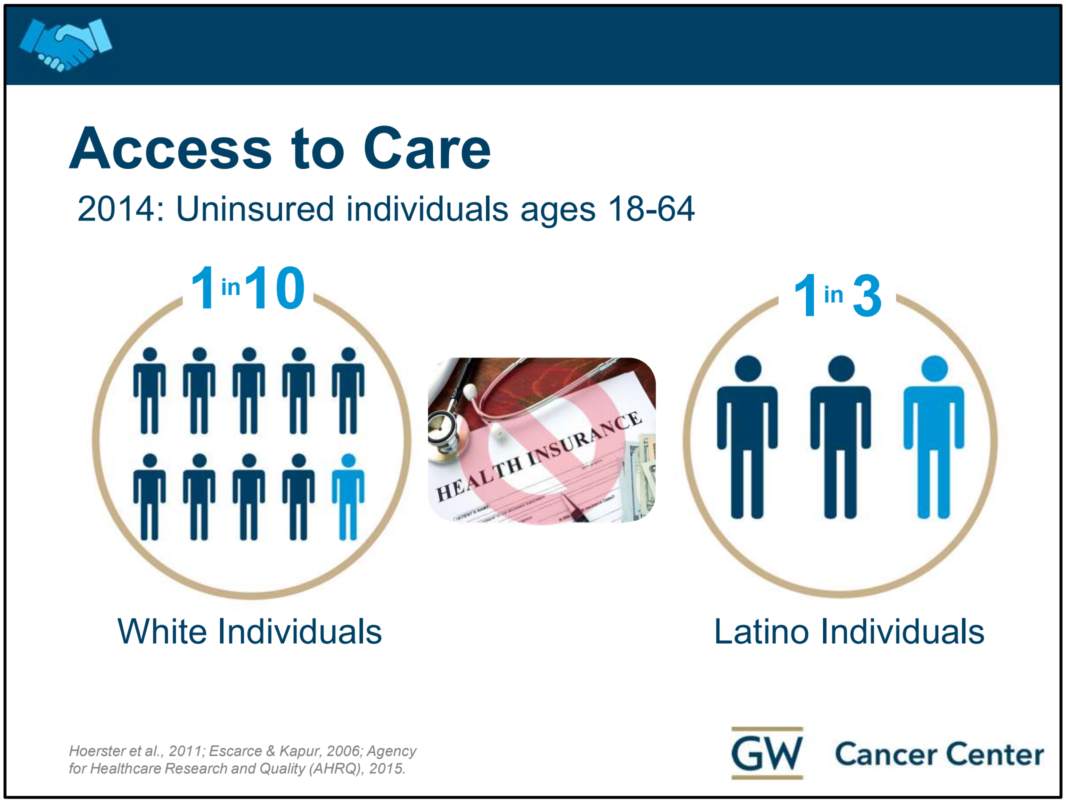

Access to Care

2014: Uninsured individuals ages 18-64

1 in 10

White Individuals

1 in 3

Latino Individuals

Hoerster et al., 2011; Escarce & Kapur, 2006; Agency for Healthcare Research and Quality (AHRQ), 2015.

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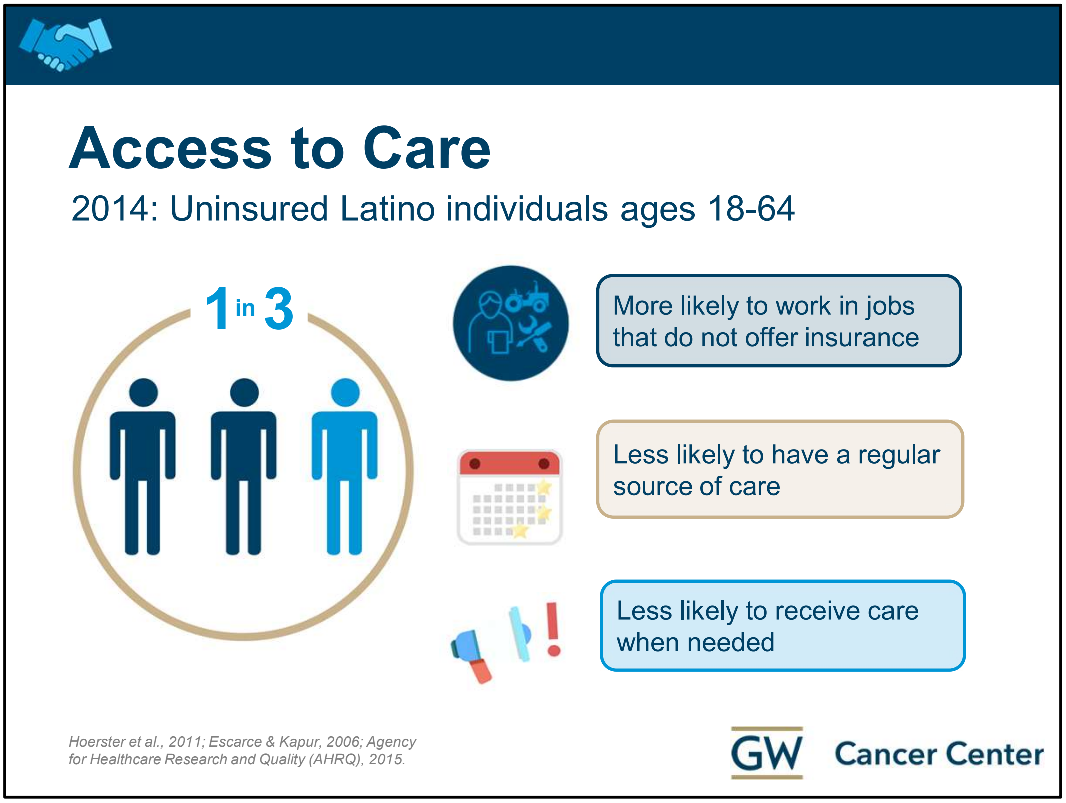
Latino individuals may experience significant disparities in access to health care. One in three Latinos ages 18-64 were uninsured in 2014, compared with just one in 10 for whites.

This lack of health coverage is tied to employment. Latinos are more likely to work as migrant workers or in occupations like agriculture, domestic or food service and construction. These occupations often do not offer employer-sponsored health insurance. Latinos are also less likely to have a regular source of care than whites and blacks. Latinos are less likely to receive care when needed compared to whites.

Other barriers Latinos may face include low socioeconomic status and lack of transportation to health care facilities. Limited English proficiency can also serve as a significant barrier to care. We will discuss strategies to address this barrier in the following lesson. Finally, immigration status – particularly for undocumented immigrants – can serve as a barrier to care due to ineligibility for public health insurance programs and fear of deportation.



Access to Care

2014: Uninsured Latino individuals ages 18-64

1 in 3

More likely to work in jobs that do not offer insurance

Less likely to have a regular source of care

Less likely to receive care when needed

Hoerster et al., 2011; Escarce & Kapur, 2006; Agency for Healthcare Research and Quality (AHRQ), 2015.

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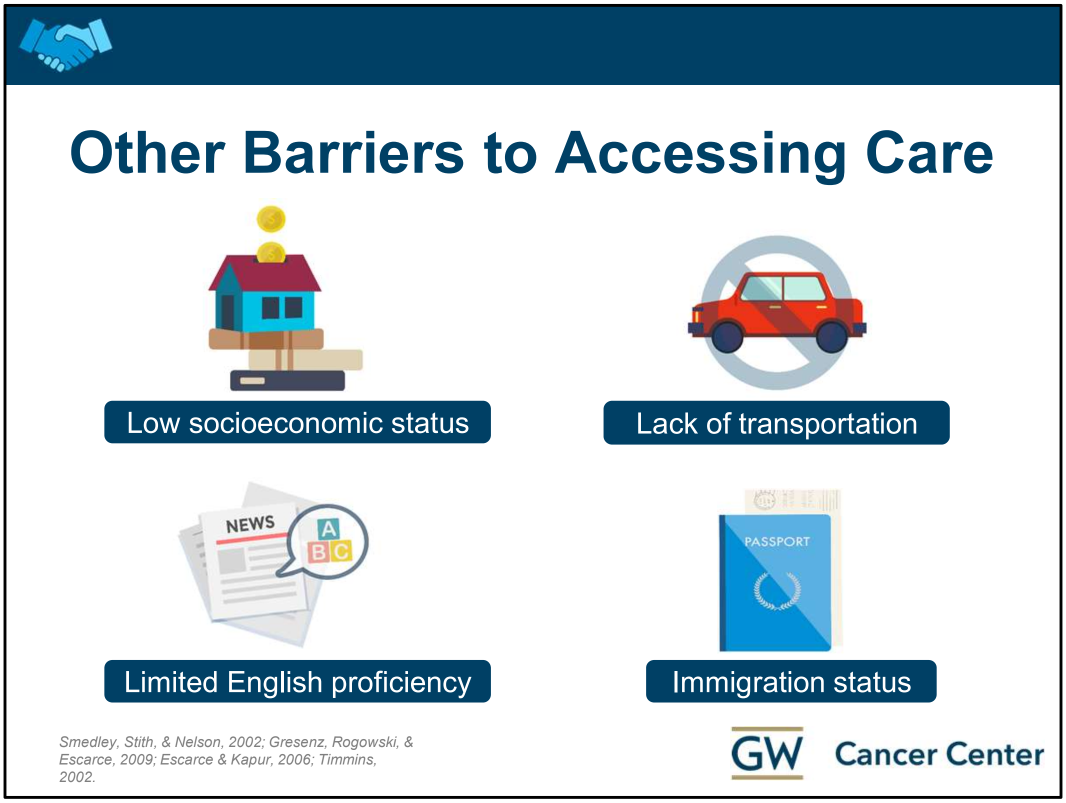

Other Barriers to Accessing Care

- Low socioeconomic status
- Lack of transportation
- Limited English proficiency
- Immigration status

Smedley, Stith, & Nelson, 2002; Gresenz, Rogowski, & Escarce, 2009; Escarce & Kapur, 2006; Timmins, 2002.

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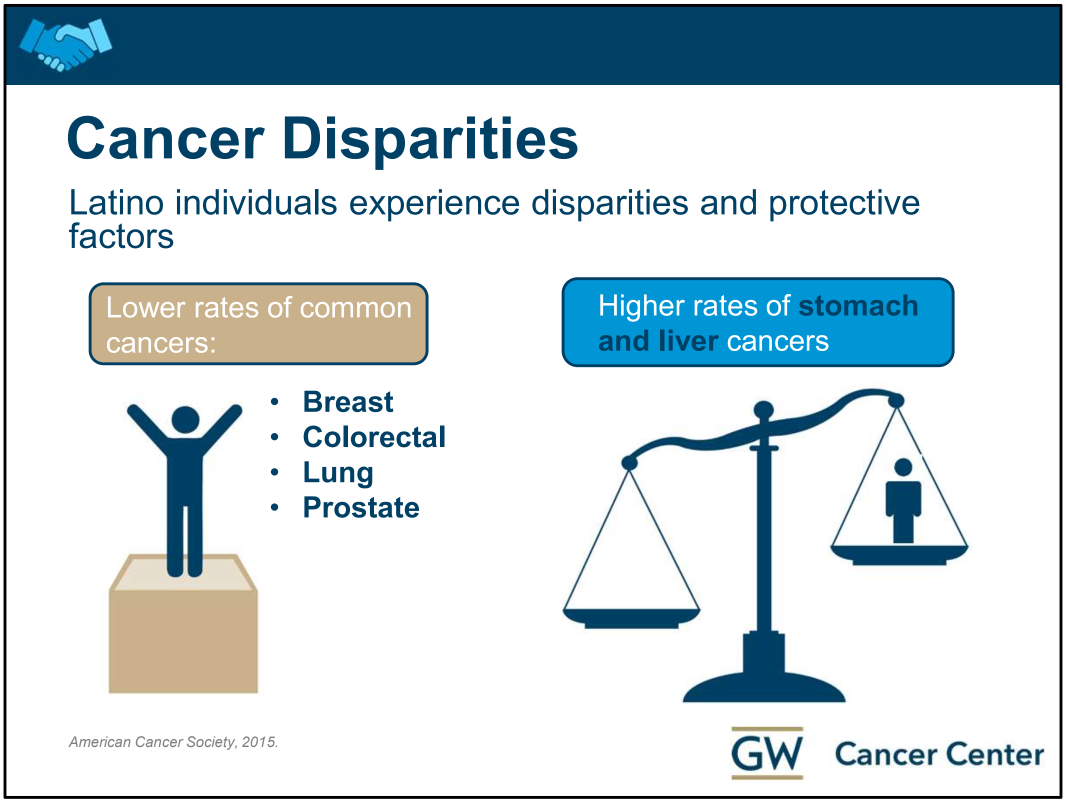

Cancer Disparities

Latino individuals experience disparities and protective factors

Lower rates of common cancers:

- **Breast**
- **Colorectal**
- **Lung**
- **Prostate**

Higher rates of **stomach and liver** cancers

American Cancer Society, 2015.

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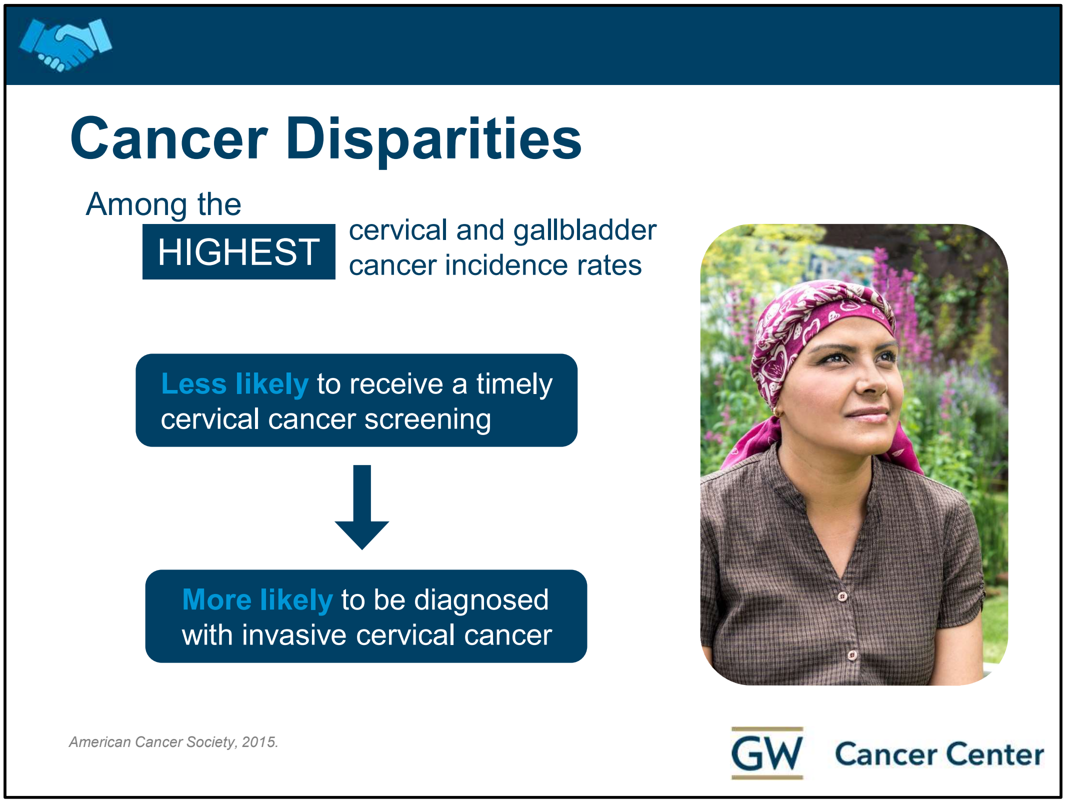
When looking at differences in cancer at a population level, Latinos experience disparities as well as protective factors. Latinos have lower rates of the most common cancers (breast, colorectal, lung, and prostate), but have higher rates of stomach and liver cancers. Latina women also have among the highest rates of new cases of cervical and gallbladder cancer. For cervical cancer, Latinas are less likely to receive a timely screening than whites, which could contribute to more Latinas diagnosed with invasive cervical cancer.

Latinas do experience lower incidence and death rates for breast cancer. Yet, they are less likely to be diagnosed with localized disease than whites. Furthermore, Latinas are less likely to receive radiation treatment after breast-conserving surgery (as clinically recommended) when compared to white women.

Latinos are also less likely to receive patient-centered care. For instance, Latinos were almost twice as likely as whites to report poor communication with their health care providers. They were also less likely to be involved in their treatment decisions. This is in part due language barriers. Latinos with limited English proficiency report worse explanation of side effects and less question-asking with providers.

One patient, interviewed as part of the National Cancer Care TEAM study, described her breast cancer care experience, she said, “One thing that really stood out to me is that they have this belief that, because we’re Latino–and I’m speaking about Latinos as in everyone who speaks Spanish in this country, whether they're Central American or South American–they have this idea that this means they don’t have to explain things to us... And they forget that we, that there are people who are educated, that there are people who have a college education who get cancer too, and we want them to explain things to us, and they don’t explain things to us....And that’s what happened to me.”



Cancer Disparities

Among the **HIGHEST** cervical and gallbladder cancer incidence rates

Less likely to receive a timely cervical cancer screening

↓

More likely to be diagnosed with invasive cervical cancer

American Cancer Society, 2015.

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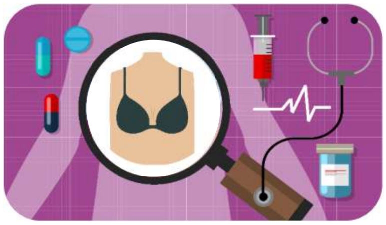
Cancer Disparities

Experience lower breast cancer incidence and death rates but:

- Less likely to be diagnosed with localized disease
- Less likely to receive radiation treatment after breast-conserving surgery



American Cancer Society, 2015; AHRQ, 2015.

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Disparities in Quality of Care

2x — Twice as likely to report poor communication with their provider

Less likely to be involved in treatment decisions

- Worse explanation of side effects
- Less question-asking with providers

Timmins, 2002.

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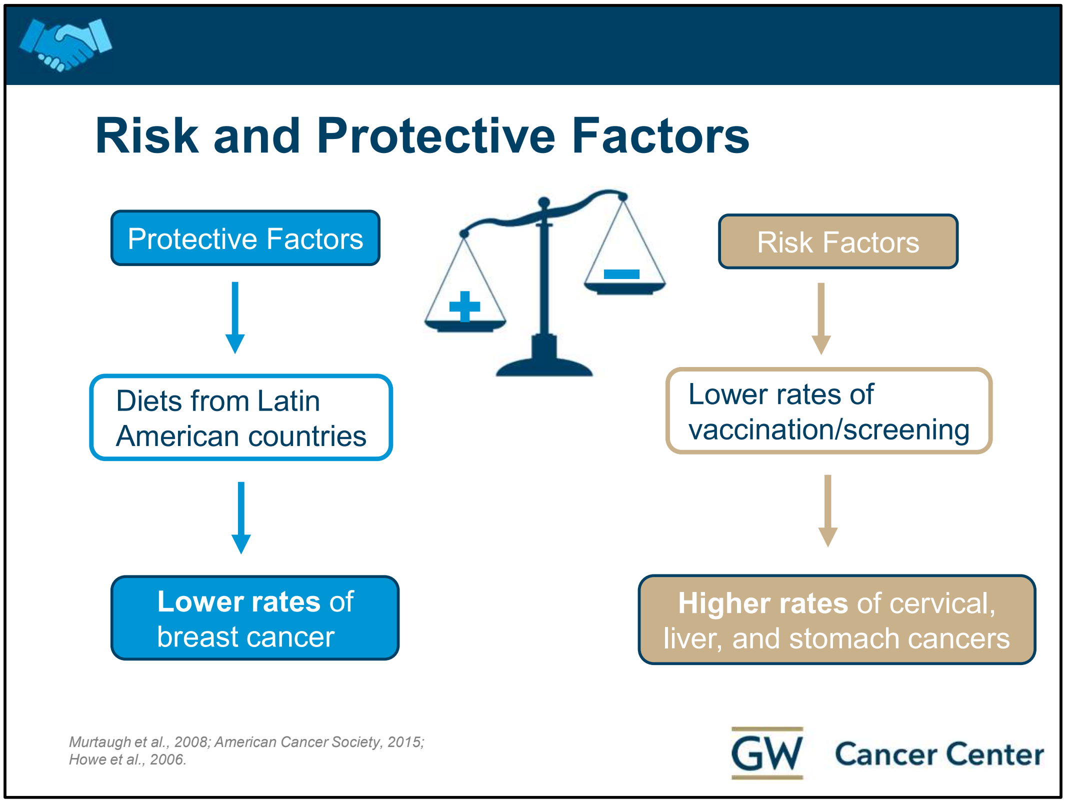

Risk and Protective Factors

Protective Factors

Diets from Latin American countries

Lower rates of breast cancer

Risk Factors

Lower rates of vaccination/screening

Higher rates of cervical, liver, and stomach cancers

Murtaugh et al., 2008; American Cancer Society, 2015; Howe et al., 2006.

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These disparities beg the question of what risk and protective factors are present that cause these differences? Some researchers have suggested that diets from Latin American countries, such as a Native Mexican diet, serve as protective factors against cancers like breast cancer. In contrast, higher rates of cervical, liver and stomach cancers (all infection-related cancers) may be related to a variety of factors.

The effects of acculturation, or adapting to another culture, are complex and can be associated with both positive and negative influences on health for Latinos. Acculturation is linked with improved access to care and use of preventive health services. But, it may also result in adoption of unhealthy behaviors such as smoking, alcohol, illicit drug use, poor diet quality and decrease in physical activity.

Latinos exhibit areas of resiliency in accessing cancer-related services in the face of barriers to care. For instance, although Latinas are less likely to receive cervical cancer screenings overall, cervical cancer screenings are more common among uninsured Hispanic women than among uninsured white women. This suggests that low-income Latinas may be more skilled at accessing safety net and other programs than whites. Sociocultural factors like a strong sense of family and collective attitudes can cause individuals to create networks of social support that allow individuals to better cope during times of stress and promote wellbeing.

Click on the link to watch a brief video from City of Hope that demonstrates how clinicians can draw upon the prominent role of family and strong social support to offer hope during cancer treatment and promote wellbeing.

https://vimeo.com/94700155

Acculturation

Both positive and negative influences on health:

Improved access to care and preventive services

Adoption of unhealthy behaviors:

- Smoking
- Alcohol
- Illicit drug use
- Poor diet
- Decrease in physical activity

Lara, Gamboa, Kahramanian, Morales, & Bautista, 2005.

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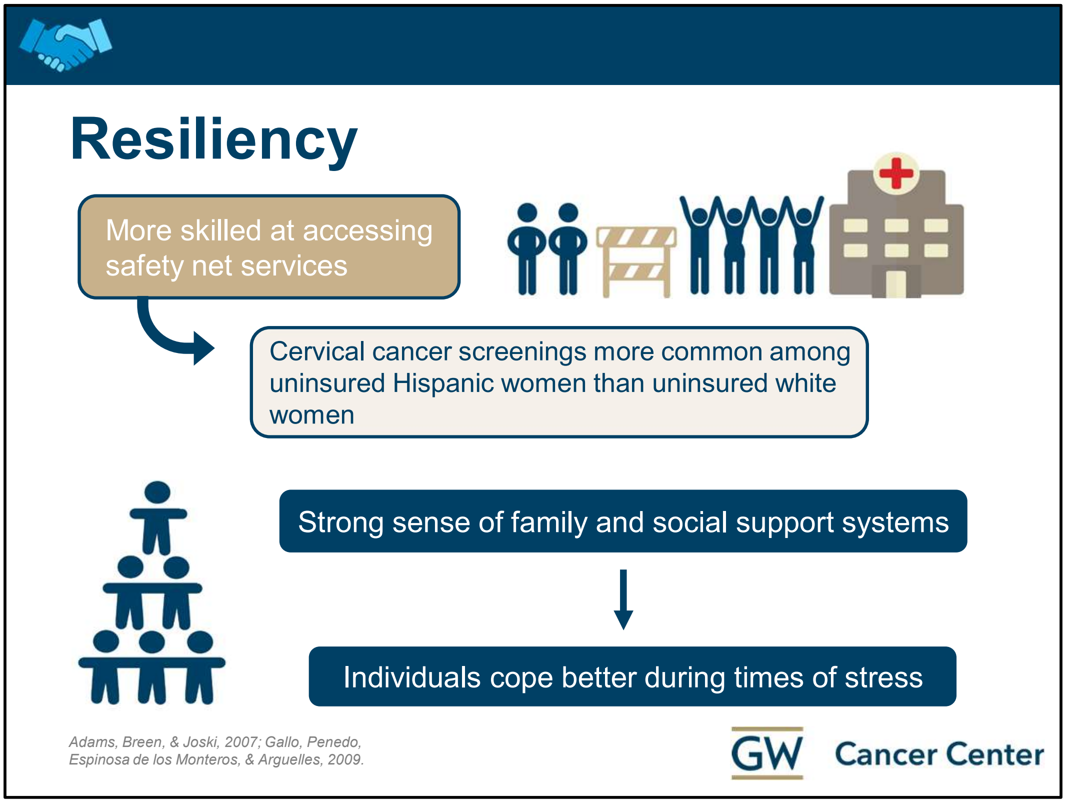

Resiliency

More skilled at accessing safety net services

Cervical cancer screenings more common among uninsured Hispanic women than uninsured white women

Strong sense of family and social support systems

Individuals cope better during times of stress

Adams, Breen, & Joski, 2007; Gallo, Penedo, Espinosa de los Monteros, & Arguelles, 2009.

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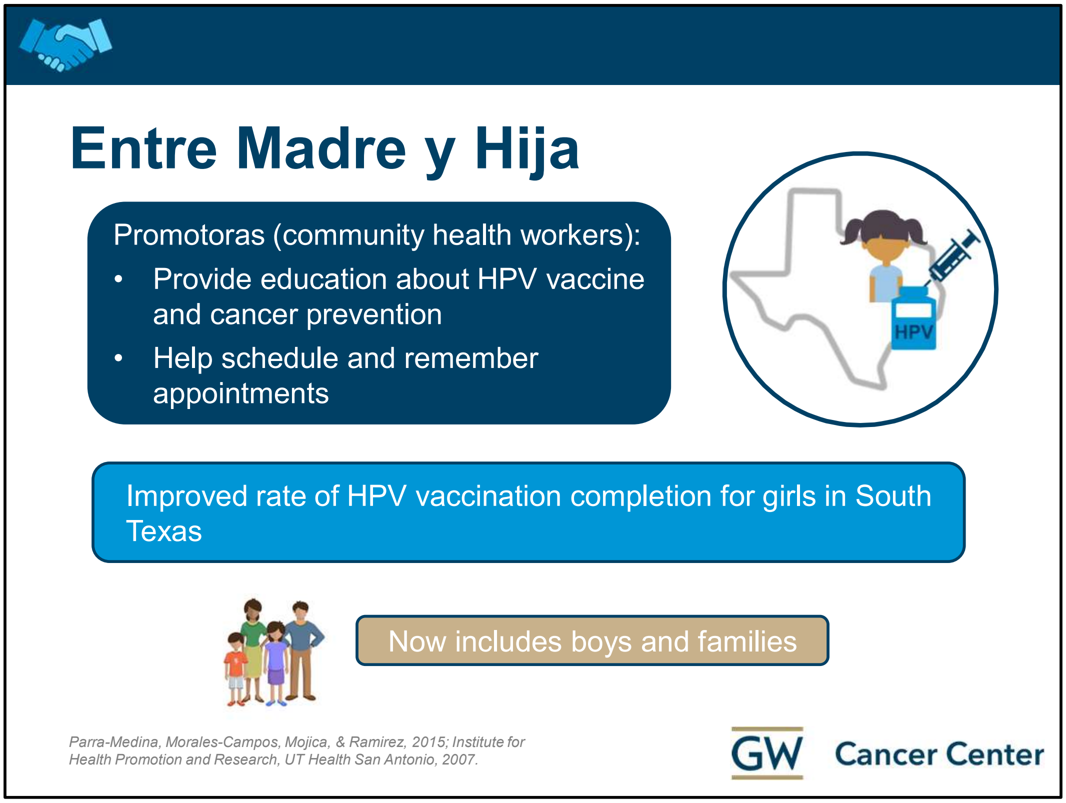

Entre Madre y Hija

Promotoras (community health workers):

- Provide education about HPV vaccine and cancer prevention
- Help schedule and remember appointments

Improved rate of HPV vaccination completion for girls in South Texas

Now includes boys and families

Parra-Medina, Morales-Campos, Mojica, & Ramirez, 2015; Institute for Health Promotion and Research, UT Health San Antonio, 2007.

In addition to clinicians working with families during cancer treatment, let's look at an example of an intervention that has been successful in improving health outcomes in a Latino community in South Texas. *Entre Madre y Hija*, a cancer prevention initiative, uses promotoras, or community health workers, to provide education about the HPV vaccine and cancer prevention.

The program also helps people schedule and remember vaccination appointments for girls ages 11-17. This program significantly improved the rate of completion of the HPV vaccination series for girls 11-17 and the program has now been adapted to include boys and families in this intervention following updated vaccine guidelines.

While this intervention is a promising example, it is important to get to know and work with your local community to understand specific barriers, needs and most effective strategies to meet these needs. As a starting point, here are a few examples of organizations that have a national presence in cancer care or research:

Redes En Acción: The National Latino Cancer Research Network is a national network of community leaders, researchers, governmental officials and advocates dedicated to fighting cancer among Latinos through research, training and education.

SHARE Cancer Support offers online educational resources and national telephone support programs in “English, Spanish, and 10 other languages” to individuals who have received a breast or ovarian cancer diagnosis.

Latinas Contra Cancer provides community cancer education, moves women into breast and cervical cancer screening, and offers patient support groups - all in Spanish.

National Organizations

Community leaders, researchers, governmental officials and advocates fighting cancer among Latinos through research, training, and education

Online resources and telephone support programs in “English, Spanish, and 10 other languages” for breast or ovarian cancer patients

Community cancer education, move women into breast and cervical screening, patient support groups - all in Spanish

Redes En Acción, 2013; SHARE Cancer Support, n.d.; Latinas Contra Cancer. n.d.

Resources

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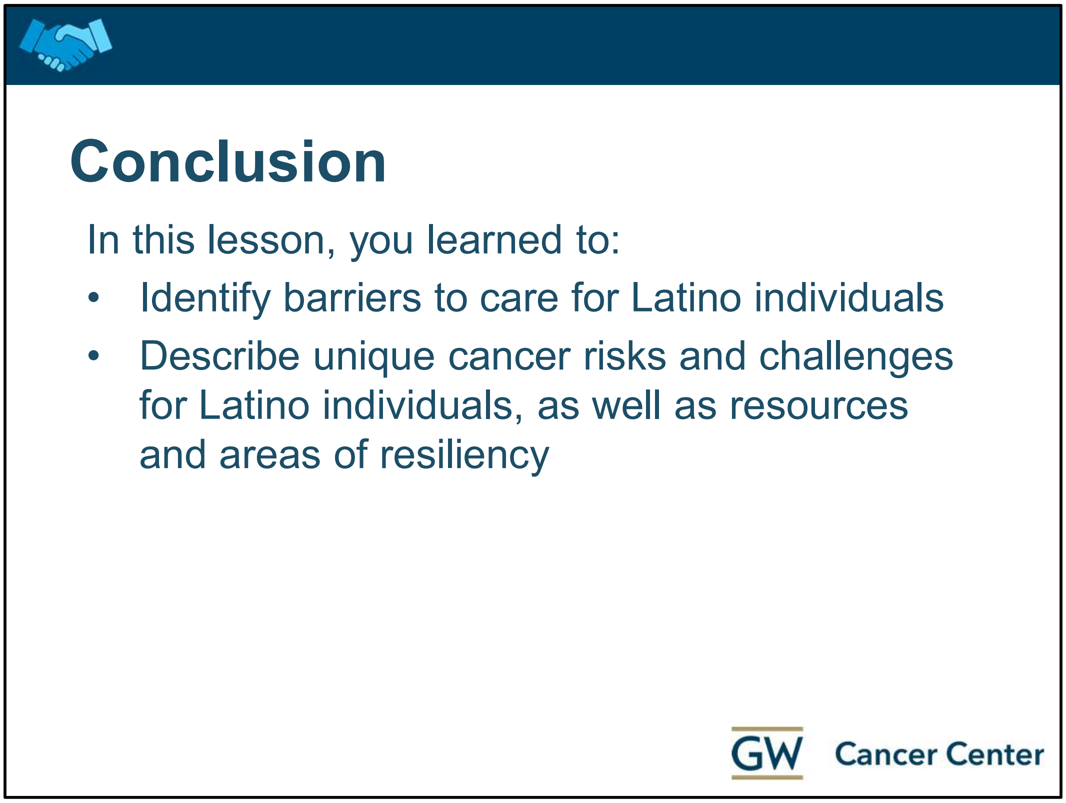
Here are some further readings and resources



Conclusion

In this lesson, you learned to:

- Identify barriers to care for Latino individuals
- Describe unique cancer risks and challenges for Latino individuals, as well as resources and areas of resiliency

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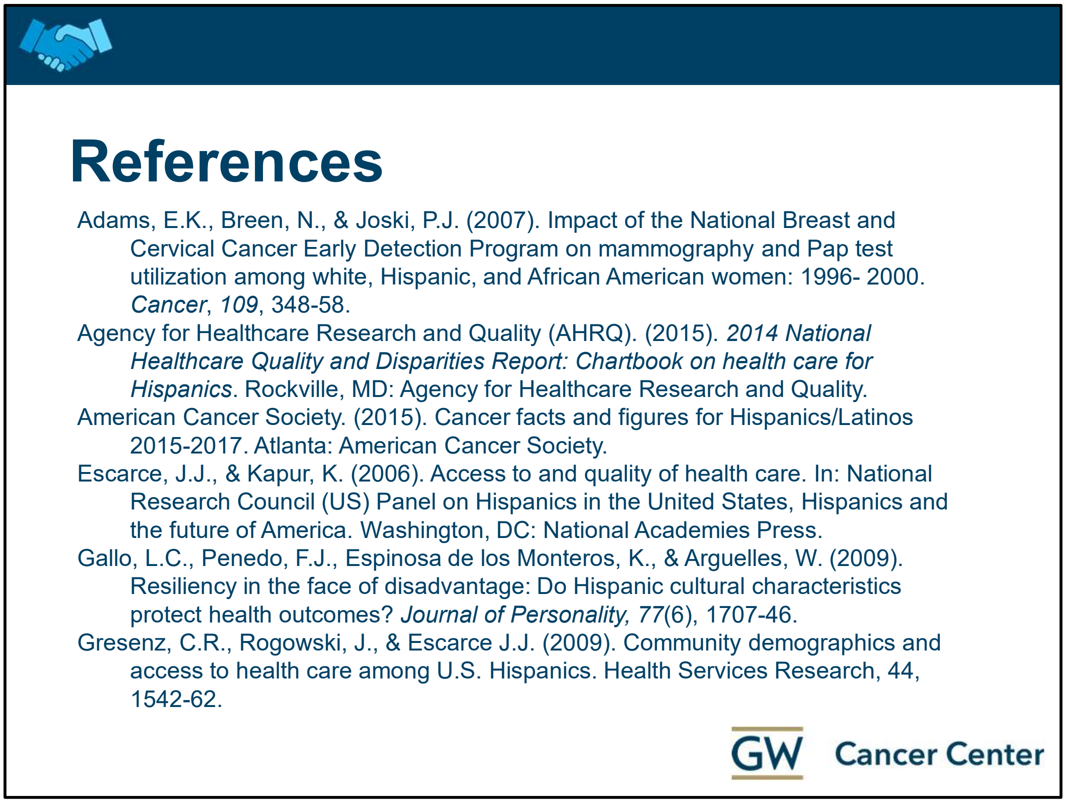
In this lesson, you learned to:

- Identify barriers to care for Latino individuals
- Describe unique cancer risks and challenges for Latino individuals, as well as resources and areas of resiliency



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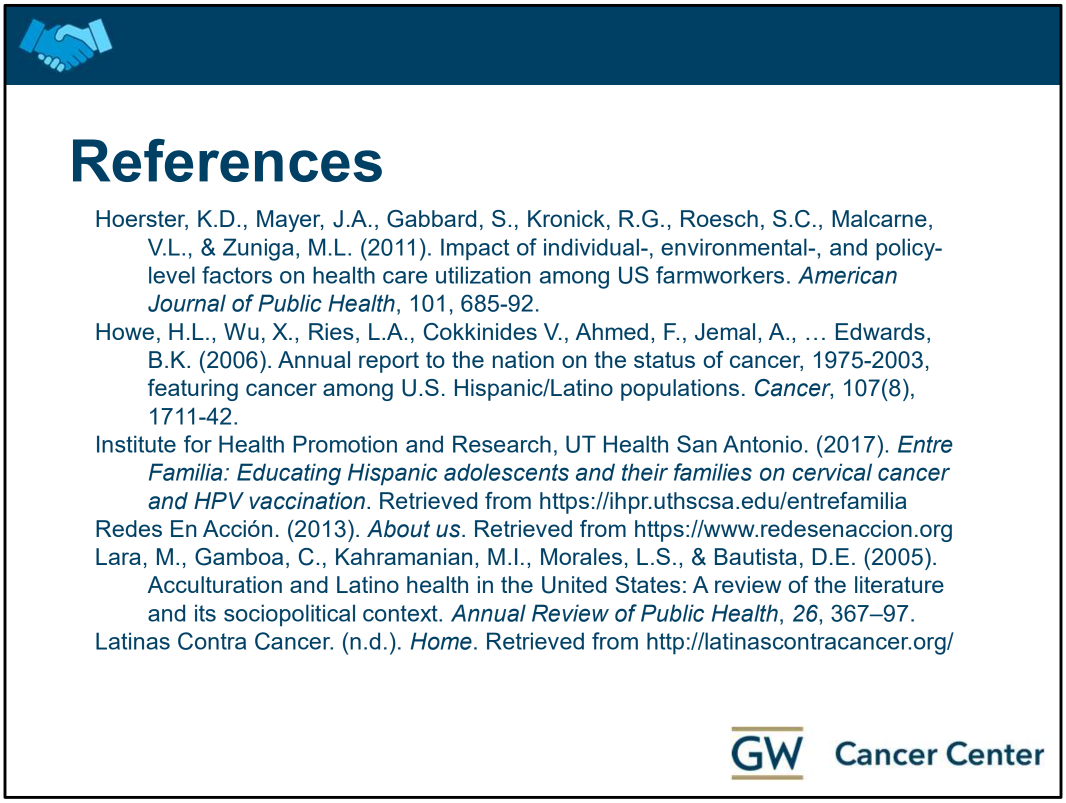

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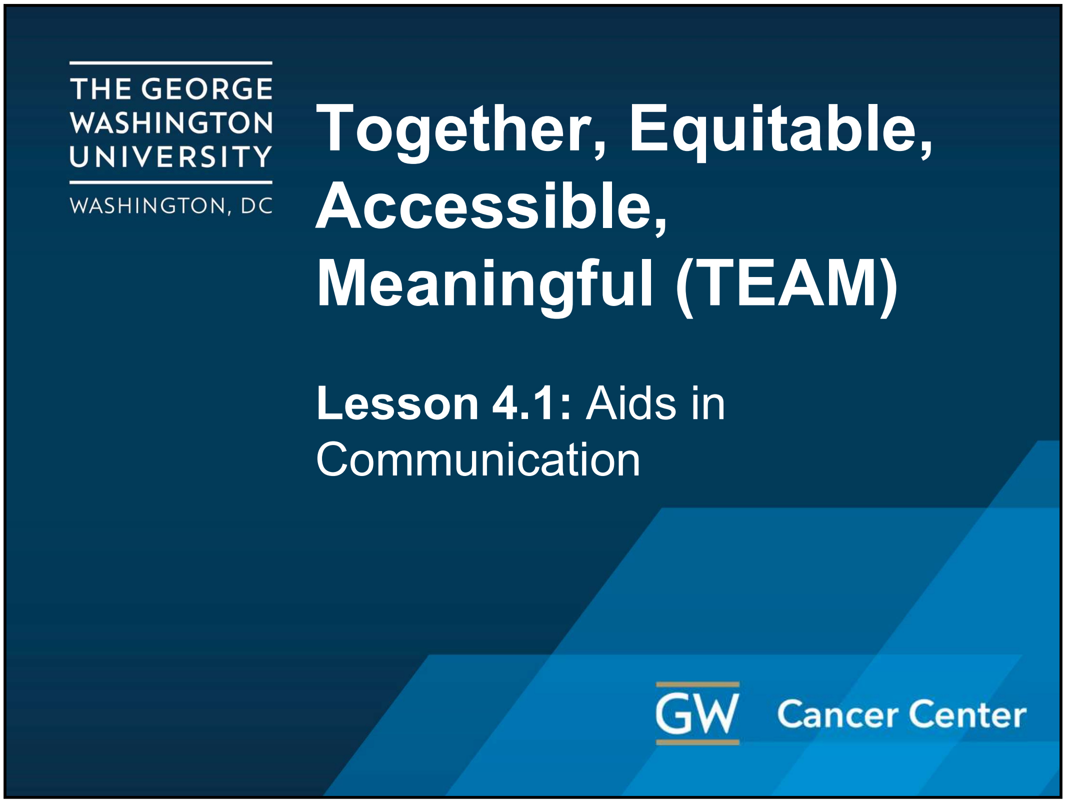

THE GEORGE
WASHINGTON
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WASHINGTON, DC

Together, Equitable, Accessible, Meaningful (TEAM)

Lesson 4.1: Aids in Communication

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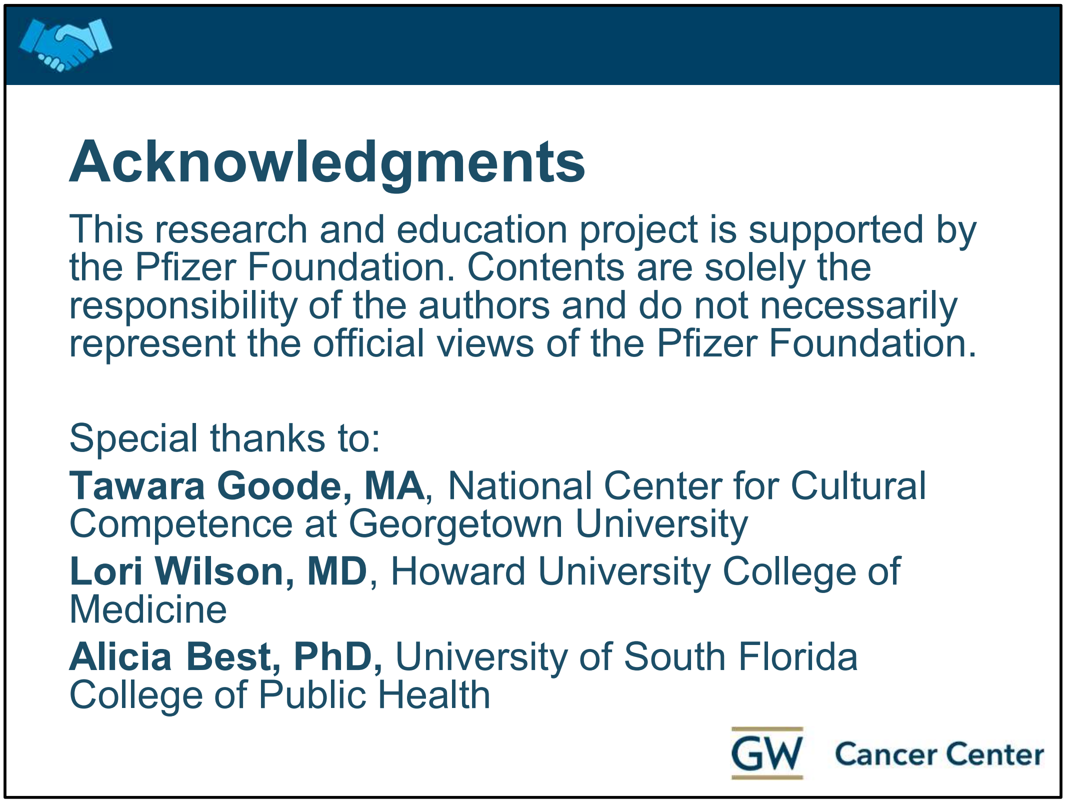
Welcome to Module 4, Lesson 1: Aids in Communication



Acknowledgments

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Special thanks to:

Tawara Goode, MA, National Center for Cultural Competence at Georgetown University

Lori Wilson, MD, Howard University College of Medicine

Alicia Best, PhD, University of South Florida College of Public Health

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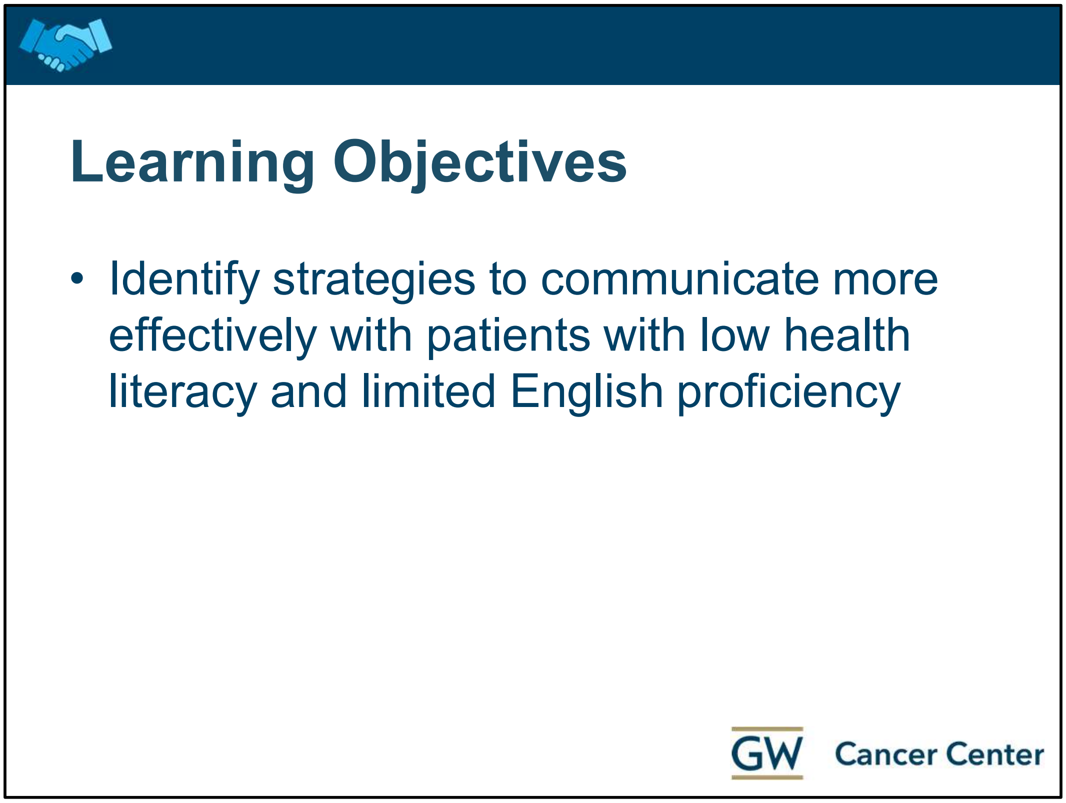
We would like to acknowledge the Pfizer Foundation for supporting this work. We would also like to thank our subject matter experts for their review of and contributions to this lesson.



Learning Objectives

- Identify strategies to communicate more effectively with patients with low health literacy and limited English proficiency

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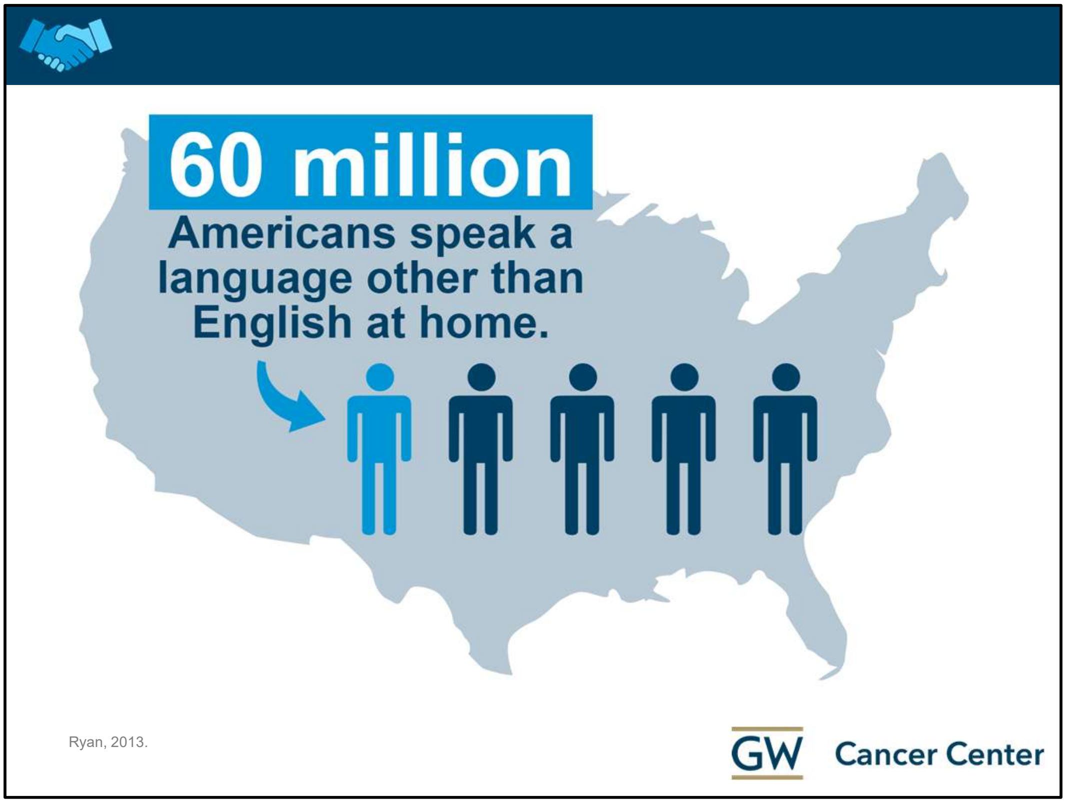
After completing this lesson, you will be able to:

Identify strategies to communicate more effectively with patients with low health literacy and limited English proficiency



60 million

Americans speak a language other than English at home.

Ryan, 2013.

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Approximately 60 million Americans (or one in five) speak a language other than English at home. Also, 90 million Americans (or almost one in three) have trouble understanding and acting on health information. This is important to note.

Regardless of your role in your organization, you are most likely serving a large number of patients who need some form of help in understanding information given to them—whether that is by providing written materials or having conversations in places like the front desk or the exam room. Addressing communication challenges with cancer patients is critical.

In this lesson, we will look at health literacy and limited English proficiency and identify strategies to improve communication with patients in the face of these challenges.

90 million

Americans have trouble understanding and acting on health information

Nielsen-Bohlman, Panzer, & Kindig, 2004.

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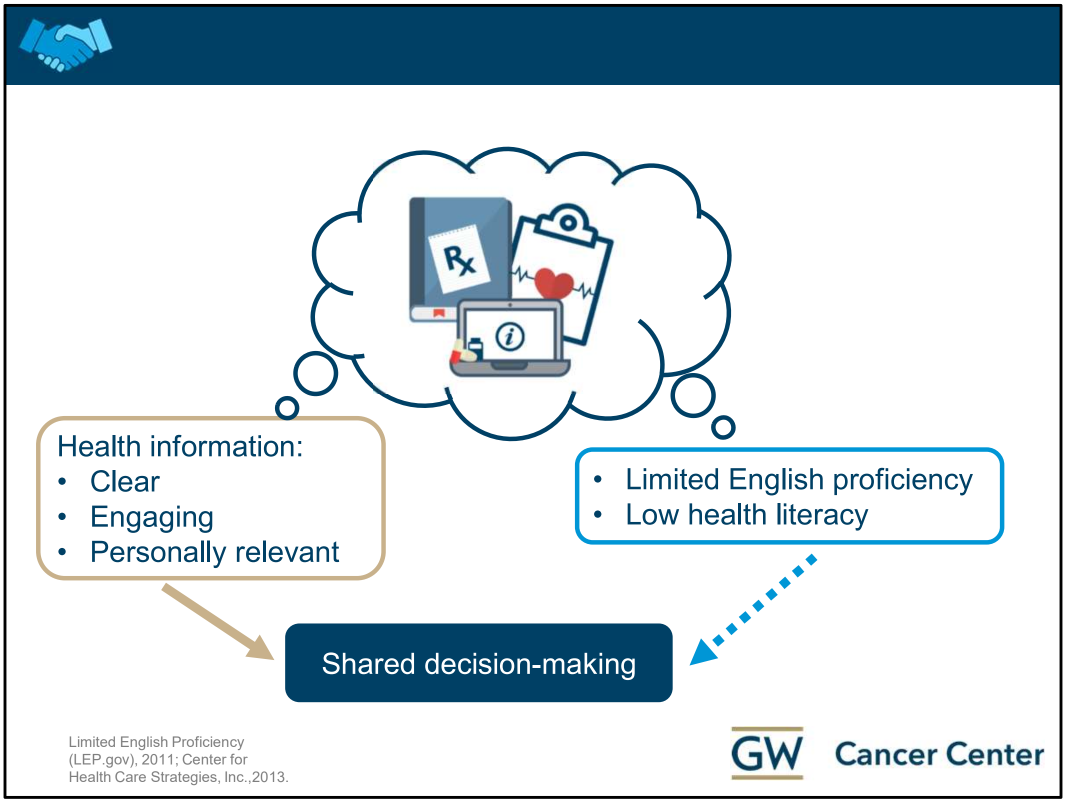

Health information:
- Clear
- Engaging
- Personally relevant

- Limited English proficiency
- Low health literacy

Shared decision-making

Limited English Proficiency (LEP.gov), 2011; Center for Health Care Strategies, Inc.,2013.

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Health information that is delivered in a clear, engaging, and personally relevant way can help shared decision-making between patients and their providers. However, many people often do not fully understand basic medical vocabulary and health care concepts if they have low health literacy or limited English proficiency.

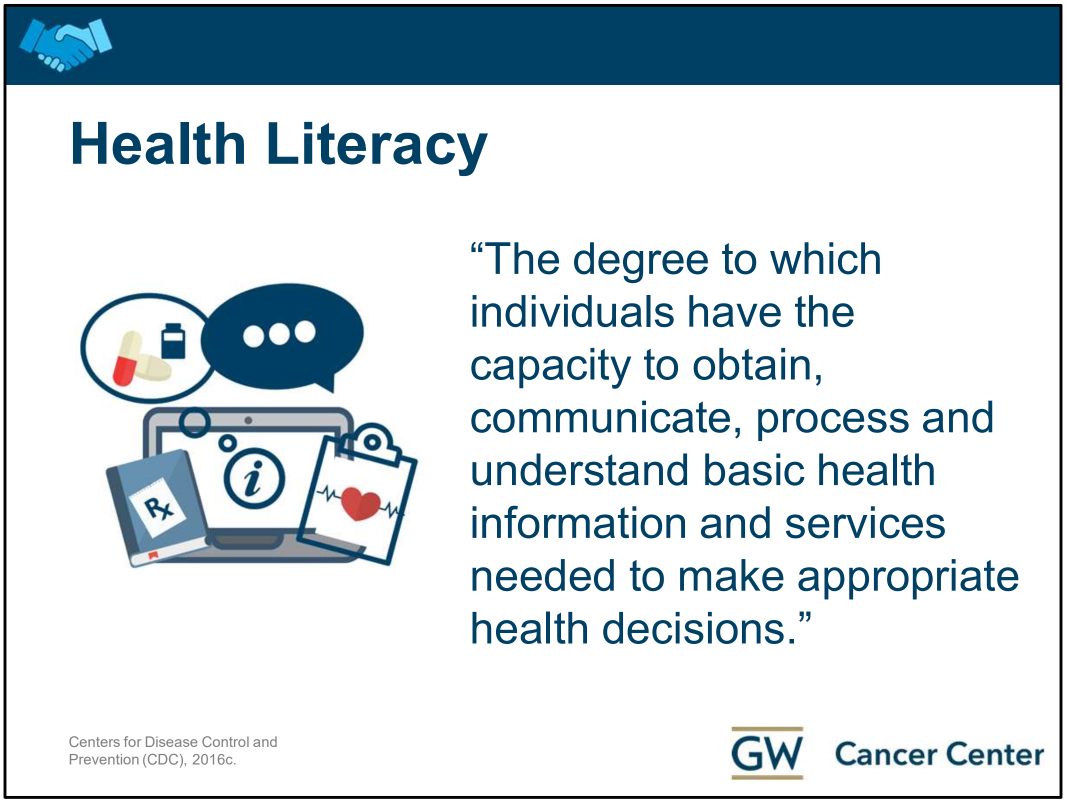
An individual with Limited English proficiency means an individual does not speak English as their primary language and has a limited ability to read, speak, write, or understand English.

This language barrier can affect how both patients and healthcare providers process critical information impacting care. Clinicians may struggle with understanding patient symptoms and health history information, which can have serious consequences.

Patients may have a poorer understanding of what is happening to them, limiting their ability to be actively involved in decision-making and accurately follow self-care instructions.

For example, a Mandarin-speaking breast cancer patient stopped chemotherapy because she did not know that peripheral neuropathy was a possible side effect and she got scared when she felt progressive numbness in her arm. She assumed she would permanently lose use of her whole arm if she continued. Her oncologist did not know she was experiencing these symptoms, did not probe reasons for refusal, and responded by telling the patient she would die if she refused chemotherapy.

The patient confided in a Mandarin-speaking navigator who recognized the miscommunication and helped the patient inform her oncologist of her symptoms and formulate questions to ask. With her symptoms managed and better understood, the patient made an informed decision to continue chemotherapy.



Health Literacy

"The degree to which individuals have the capacity to obtain, communicate, process and understand basic health information and services needed to make appropriate health decisions."

Centers for Disease Control and Prevention (CDC), 2016c.

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The CDC defines health literacy as "the degree to which individuals have the capacity to obtain, communicate, process, and understand basic health information and services needed to make appropriate health decisions."

For example, people who have low health literacy are less likely to get preventive care (like get vaccinations or screenings) or follow treatment recommendations. They have more hospitalizations, worse health and higher death rates compared to those with high health literacy.

There are also other related factors that affect a person's ability to understand information and participate in their care.

These include:
- **Literacy,** which means "understanding, evaluating, using and engaging with written text;"
- **Numeracy,** which means "the ability to access, use, interpret, and communicate mathematical information and ideas;" and
- **Reading level**, which can affect a person's access to information. It is important to know there is a difference between literacy and reading level.

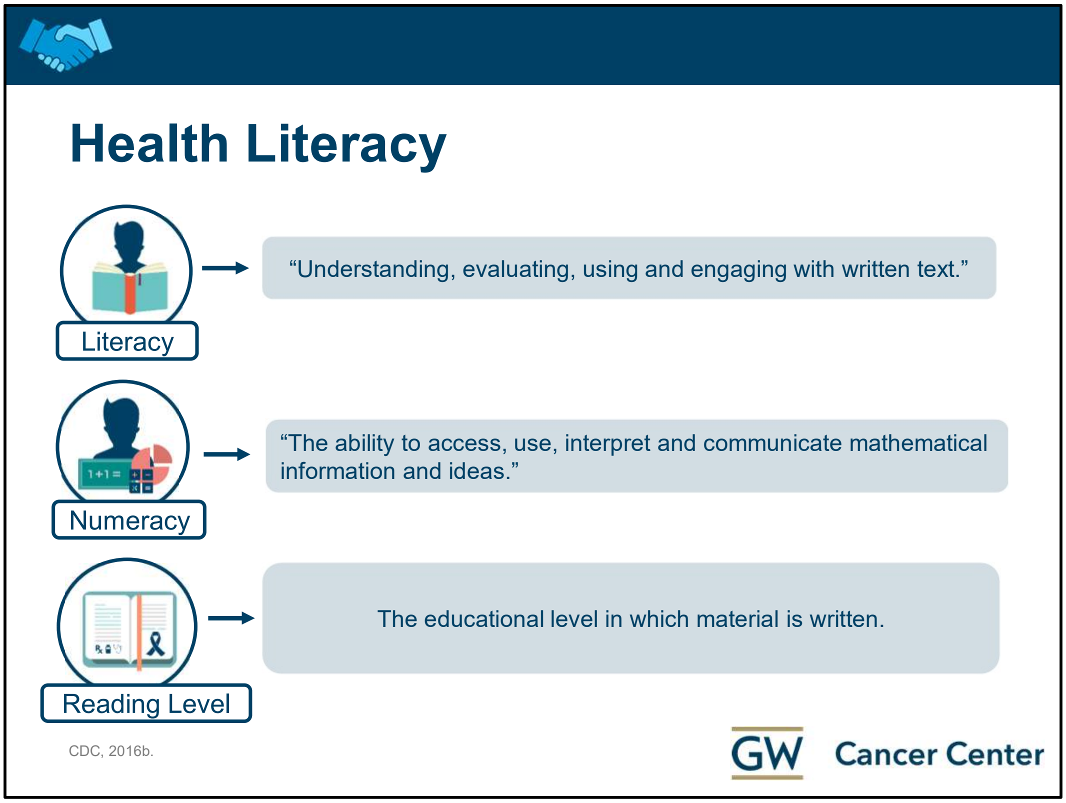
Literacy is a person's ability to understand information, but reading level is how understandable the written material is. For instance, if a pamphlet describing types of treatment options for breast cancer is written at a 12th-grade reading level, a patient may not understand it based on their level of health literacy.

Health literacy can be influenced by a person’s education level. Yet, health literacy and level of education do not always go hand-in-hand.

It is common for people to have low levels of health literacy even if they have a high level of education. It has also been shown that even people with high levels of education or health literacy appreciate health information presented in easy-to-understand formats.

Always look for warning signs that your patient may have issues with literacy, and do not assume. Some people with low literacy may appear very articulate and may have developed strategies to hide their literacy level, like saying that they forgot their glasses to avoid reading in front of others.

Low literacy may also be at play for people with language barriers. For instance, it is not safe to assume that a Russian-speaking lung cancer patient has been informed of her rights as a patient if a Russian translated document was given to her, but she has no formal education and cannot read in her native language.



Health Literacy

Literacy → "Understanding, evaluating, using and engaging with written text."

Numeracy → "The ability to access, use, interpret and communicate mathematical information and ideas."

Reading Level → The educational level in which material is written.

CDC, 2016b.

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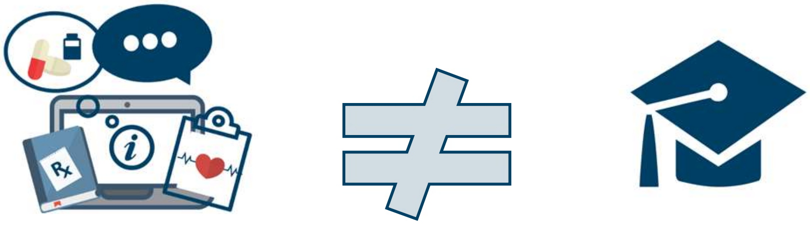
Health Literacy and Education



Health Literacy ≠ **Education**

Nielsen-Bohlman, Panzer, & Kindig, 2004.

LOW HEALTH LITERACY

is linked to…

Lower use of PREVENTIVE CARE

Less adherence to TREATMENT

More HOSPITAL STAYS

Poor health status and higher MORTALITY RATES

Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011.

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National Policies and Standards

- National Standards on Culturally and Linguistically Appropriate Services (CLAS)
- Title VI of the Civil Rights Act
- Joint Commission Accreditation Standards

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National policies and standards have been put in place to encourage health systems to provide clear and useful information to patients to address these problems.

One example is the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care. Many of these standards focus on providing high-quality services to patients with different preferred languages, health literacy levels, and other communication needs. Some of the CLAS standards include:

- “Offer language assistance to individuals who have limited English proficiency and/or other communication needs, at no cost to them, to facilitate timely access to all health care and services.
- Inform all individuals of the availability of language assistance services clearly and in their preferred language, verbally and in writing.
- Ensure the competence of individuals providing language assistance, recognizing that the use of untrained individuals and/or minors as interpreters should be avoided.
- Provide easy-to-understand print and multimedia materials and signage in the languages commonly used by the populations in the service area.”

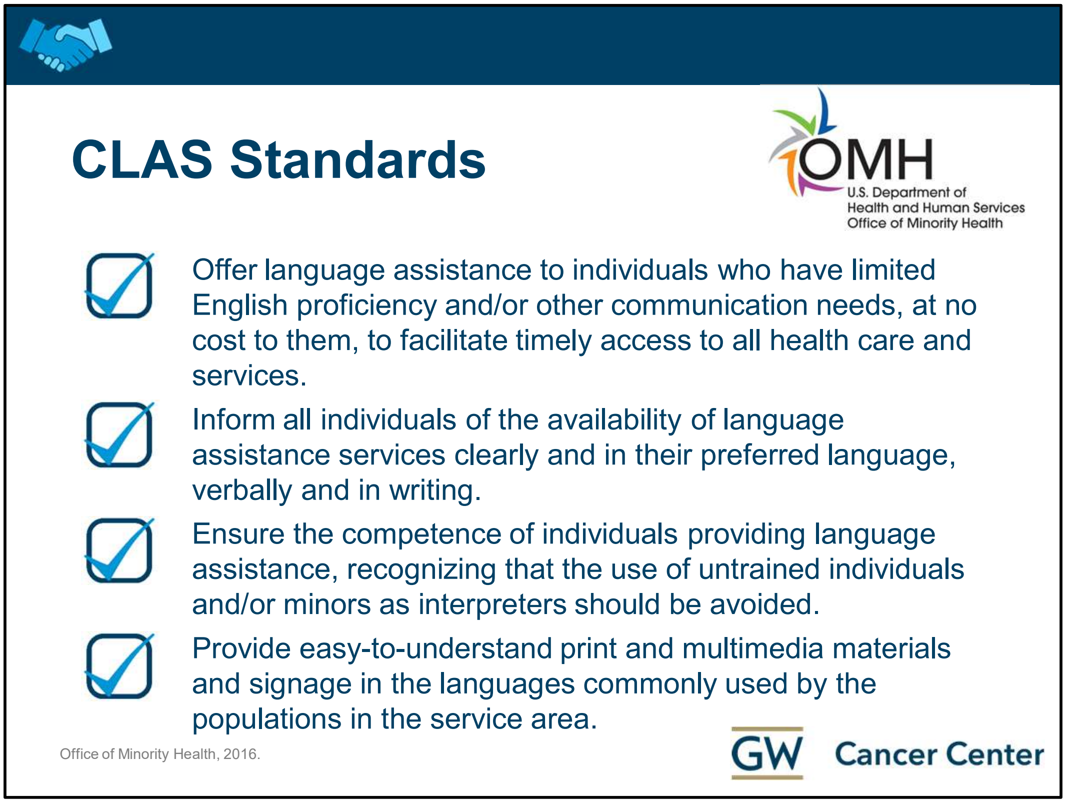
Title VI of the Civil Rights Act also requires that organizations that receive money from the federal government provide individuals with limited English proficiency “meaningful access” to their programs and services.

Providing “meaningful access” might require the use of interpretation services (for spoken information) and/or translation services (for written information). Organizations have been sued for not providing interpretation or translation services in a way that meets Title VI.

Also, in order for hospitals to become accredited by the Joint Commission, they must show they meet the communication needs of their patients, including those with low health literacy.

By following these national policies and standards, health care organizations can meet the communication needs of their patients and – most importantly – improve the health of their patients.

DOJ logo: https://www.justice.gov/archive/jmd/irm/lifecycle/images/doj.gif
OMH: https://minorityhealth.hhs.gov/



CLAS Standards

OMH
U.S. Department of
Health and Human Services
Office of Minority Health

- ☑ Offer language assistance to individuals who have limited English proficiency and/or other communication needs, at no cost to them, to facilitate timely access to all health care and services.
- ☑ Inform all individuals of the availability of language assistance services clearly and in their preferred language, verbally and in writing.
- ☑ Ensure the competence of individuals providing language assistance, recognizing that the use of untrained individuals and/or minors as interpreters should be avoided.
- ☑ Provide easy-to-understand print and multimedia materials and signage in the languages commonly used by the populations in the service area.

Office of Minority Health, 2016.

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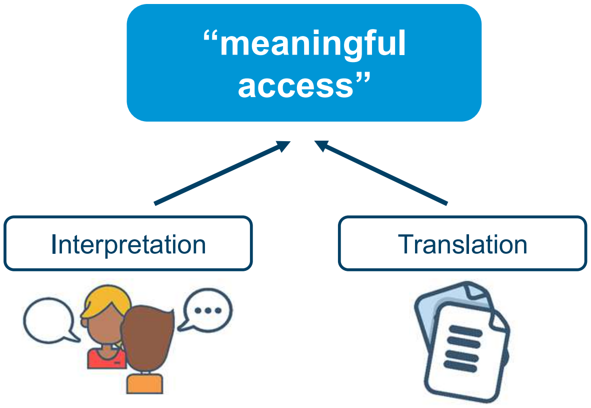
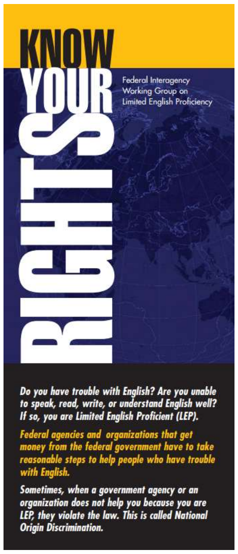
Title VI

Activities and programs that receive funding from U.S. Department of Health and Human Services must provide:


“meaningful access”

Interpretation

Translation


KNOW YOUR RIGHTS

Federal Interagency Working Group on Limited English Proficiency

Do you have trouble with English? Are you unable to speak, read, write, or understand English well? If so, you are Limited English Proficient (LEP).

Federal agencies and organizations that get money from the federal government have to take reasonable steps to help people who have trouble with English.

Sometimes, when a government agency or an organization does not help you because you are LEP, they violate the law. This is called National Origin Discrimination.

Limited English Proficiency (LEP.gov), 2011.

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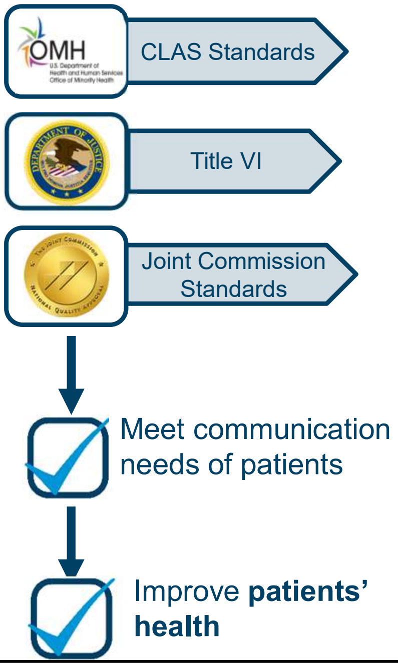
https://www.justice.gov/sites/default/files/crt/legacy/2010/12/14/LEPKYR_English.pdf

Joint Commission Standards

Accreditation standards for hospitals:

- ☑ Provide written information appropriate to age, understanding and language of population served
- ☑ Present educational content to patients in an understandable manner

The Joint Commission, 2009.



CLAS Standards

Title VI

Joint Commission Standards

Meet communication needs of patients

Improve **patients’ health**

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Shared Approach to Health Literacy

Health care professionals’ role in health literacy:

- Provide patients access to information
- Support patients in actively engaging in care discussions

Rudd, McCray, & Nutbeam, 2012.

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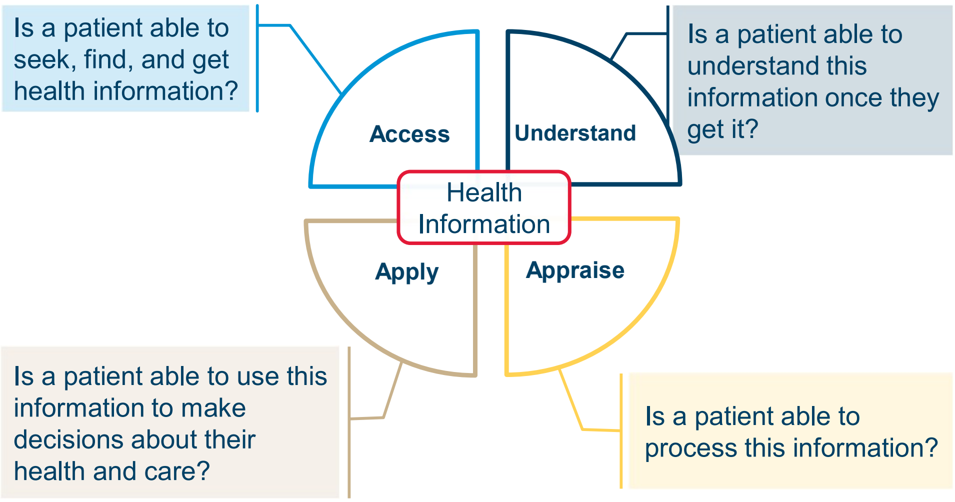
It is not sole responsibility of patients to gain the skills and resources to participate actively in their care. Health care professionals and organizations can and should play an important role in addressing health literacy challenges by providing patients access to information and supporting patients in engaging in discussions about their care.

A good way to approach communication with patients of all levels of health literacy is to think about it in four steps:

- **Access –** Is a patient able to seek, find, and get health information?
- **Understand** – Is a patient able to understand this information once they get it?
- **Appraise** – Is a patient able to process this information?
- **Apply** – Is a patient able to use this information to make decisions about their health and care?

Patient Engagement with Health Information



Is a patient able to seek, find, and get health information?

Access

Is a patient able to understand this information once they get it?

Understand

Health Information

Apply

Appraise

Is a patient able to use this information to make decisions about their health and care?

Is a patient able to process this information?

Best et al., 2017

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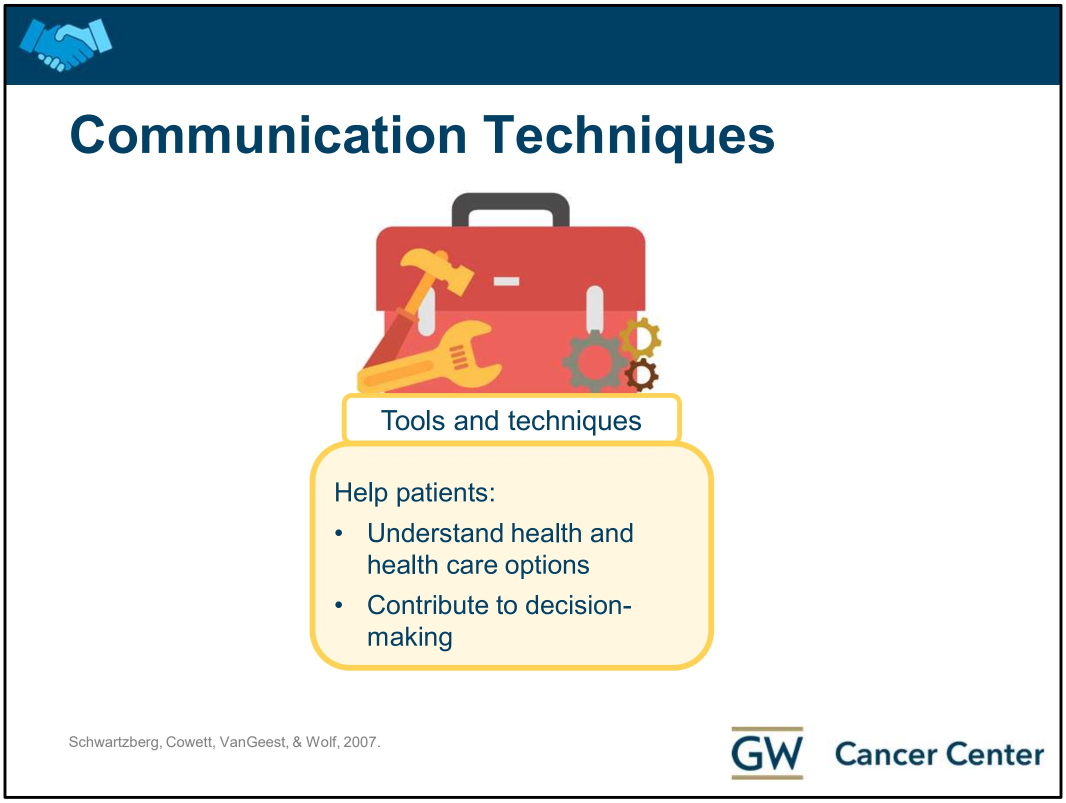

Communication Techniques

Tools and techniques

Help patients:
- Understand health and health care options
- Contribute to decision-making

Schwartzberg, Cowett, VanGeest, & Wolf, 2007.

Health care professionals can use tools and techniques to help their patients understand their health and care options and contribute to the decision-making process.

In the rest of this lesson, we will provide some techniques health care professionals can use to communicate effectively with people who have low health literacy and/or limited English proficiency.

Plain language can be used instead of medical terms and jargon. As mentioned earlier, people with limited health literacy often do not know medical terms and jargon.

Instead of saying something using medical terms/jargon, like “Screening for breast cancer helps find the disease at an early stage when treatment works best,” a health care professional can instead use plain language to say: “Go to the doctor so they can check your body for cancer. Even if you don’t have signs of breast cancer, being tested helps find illness early when treatment works best.”

In this example, important words were changed to make the recommendation more accessible to patients: screening becomes checking/testing, and disease becomes illness.

Using plain language is also important when communicating opinions or recommendations. Using examples can make these recommendations even clearer. For example, instead of saying “Increase exercise gradually over time,” you could say, “Add five more minutes of exercise to your routine each week.”

The University of Michigan has created a Plain Language Medical Dictionary. Use this dictionary to look up common medical terms and find out how to say them in plain language. You can find the link to these and other resources in the LMS.

Plain Language

Medical terminology

"**Screening** for breast cancer helps find the disease at an early stage when treatment works best."

Plain language

"Go to the doctor so they can **check** your body for cancer. Even if you don't have signs of breast cancer, being **tested** helps find illness early when treatment works best."

Screening → **Checking/testing**

CDC, 2016a.

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Plain Language

For recommendations, use examples to be clear:

Increase exercise gradually over time → Add five more minutes of exercise to your routine each week

Plain Language Medical Dictionary

As you type, matching results will be listed below automatically.

Search for a term: biopsy

You can also browse all terms, or view all terms starting with a letter.

Browse by letter: -

Possible matches for ***biopsy****:*

biopsy
take tissue (usually for testing)

National Patient Safety Foundation, 2016; University of Michigan Taubman Health Sciences Library, 2015.

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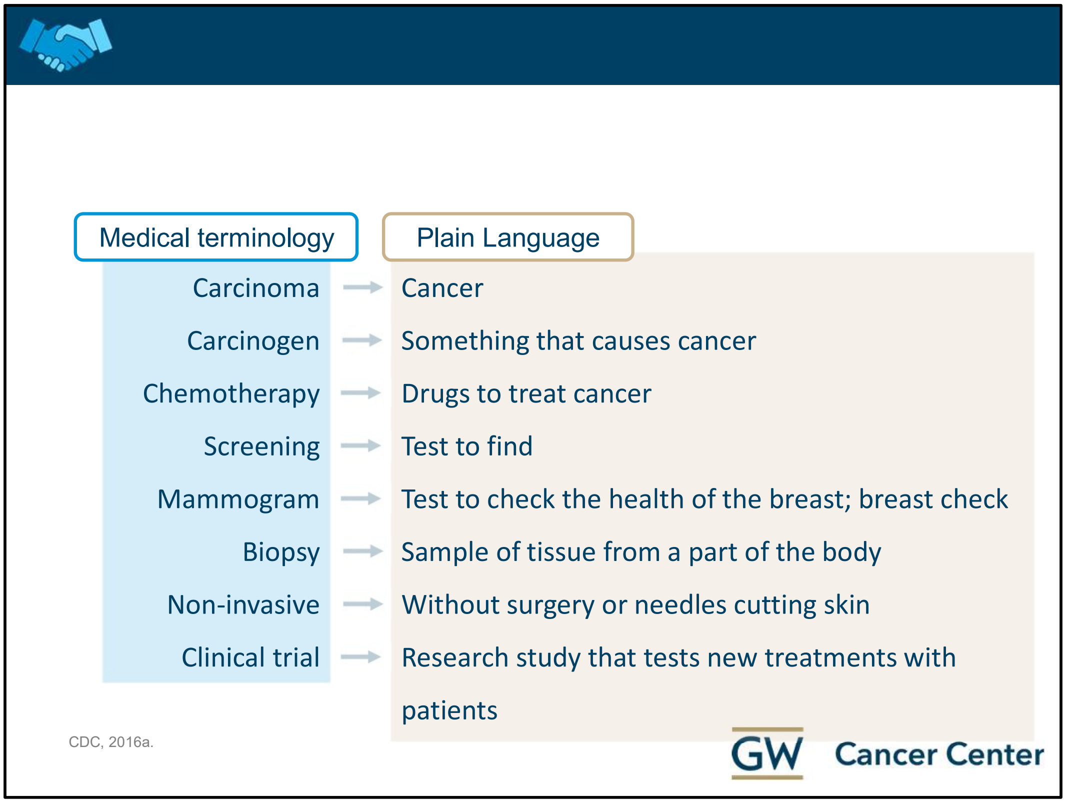

Medical terminology	Plain Language
Carcinoma	Cancer
Carcinogen	Something that causes cancer
Chemotherapy	Drugs to treat cancer
Screening	Test to find
Mammogram	Test to check the health of the breast; breast check
Biopsy	Sample of tissue from a part of the body
Non-invasive	Without surgery or needles cutting skin
Clinical trial	Research study that tests new treatments with patients

CDC, 2016a.

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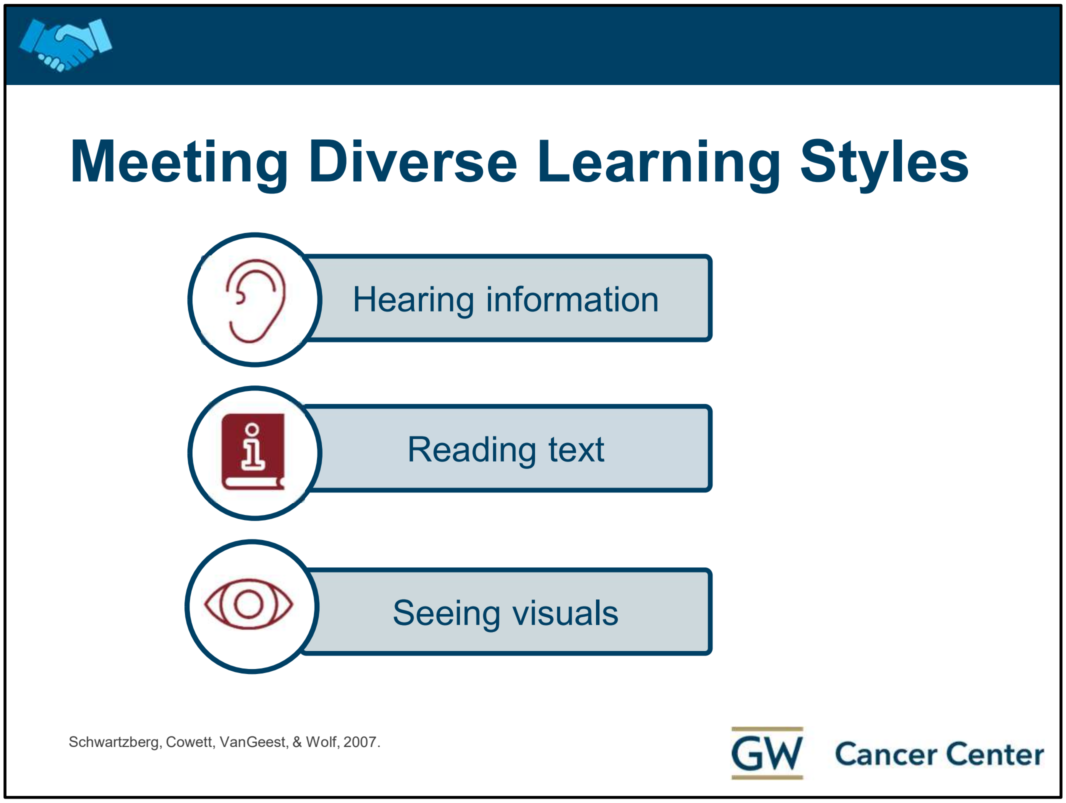
Let’s pause here for a brief checkpoint. See if you can match the medical term to the plain language term or description.



Meeting Diverse Learning Styles

- Hearing information
- Reading text
- Seeing visuals

Schwartzberg, Cowett, VanGeest, & Wolf, 2007.

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The American Medical Association (AMA) suggests that health care professionals provide a combination of information to patients verbally, in writing, and through visuals whenever possible.

This is because patients have different learning styles – just like they have different communication needs. For example, some patients learn better by seeing visuals rather than by just reading.

Another technique is the teach back method, which is widely used to ensure that the provider communicated clearly to the patient.

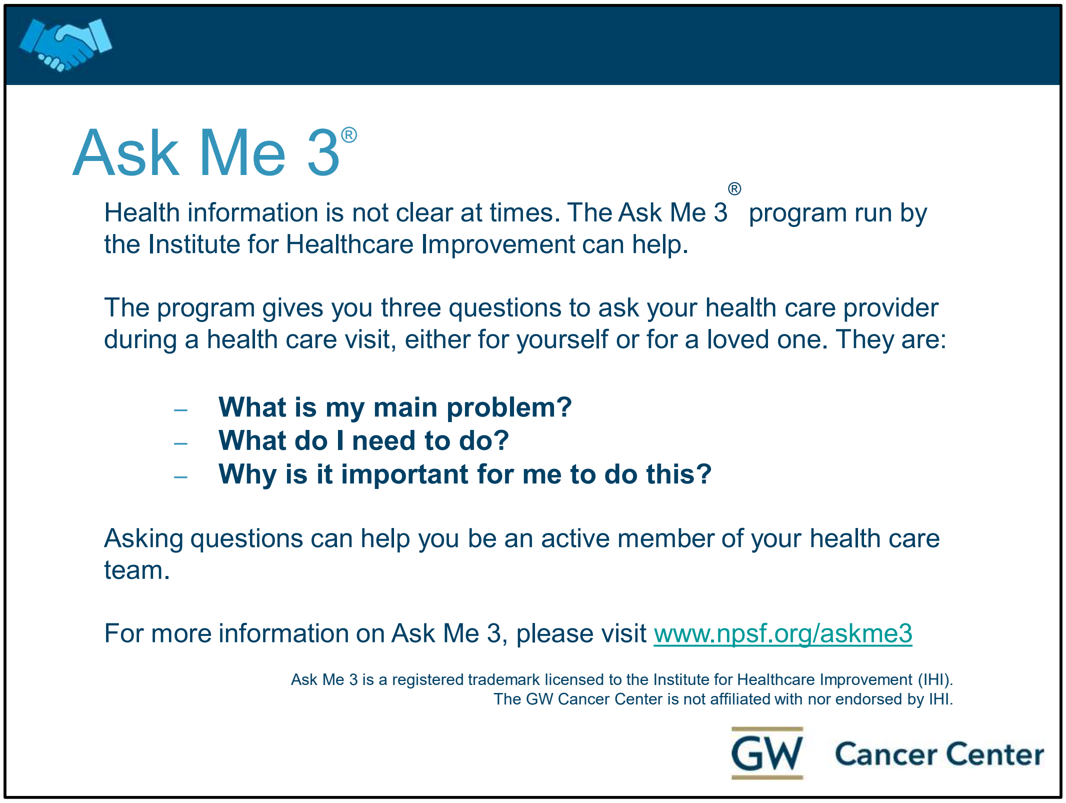
Click on the link to watch a brief video of a provider describing the teach back method and providing some examples of questions you can ask.

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

Teach Back Method

[What is Teach-Back?]

Institute for Healthcare Improvement, 2016.



Ask Me 3®

Health information is not clear at times. The Ask Me 3® program run by the Institute for Healthcare Improvement can help.

The program gives you three questions to ask your health care provider during a health care visit, either for yourself or for a loved one. They are:

- **What is my main problem?**
- **What do I need to do?**
- **Why is it important for me to do this?**

Asking questions can help you be an active member of your health care team.

For more information on Ask Me 3, please visit www.npsf.org/askme3

Ask Me 3 is a registered trademark licensed to the Institute for Healthcare Improvement (IHI).
The GW Cancer Center is not affiliated with nor endorsed by IHI.

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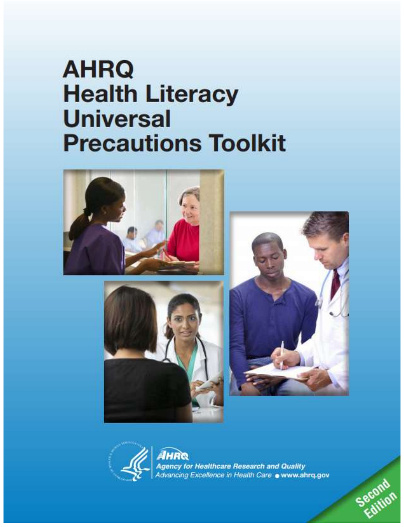
Similarly, the Ask Me 3 program has providers encourage their patients to ask them three questions to facilitate conversation and clarify misunderstandings. The three questions are:

- “What is my main problem?”
- “What do I need to do?”
- “Why is it important for me to do this?”

Slide
The AHRQ’s Health Literacy Universal Precautions Toolkit includes the Ask Me 3 program and 20 other tools that health systems can use to improve spoken and written communication with persons living with cancer.

You can find the Universal Precautions Toolkit in the LMS.



AHRQ
Health Literacy
Universal
Precautions Toolkit

AHRQ
Agency for Healthcare Research and Quality
Advancing Excellence in Health Care www.ahrq.gov

Second Edition

Agency for Healthcare Research and Quality's (AHRQ) **Health Literacy Universal Precautions Toolkit** includes additional tools to improve communication.

https://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/index.html

Brega et al., 2015

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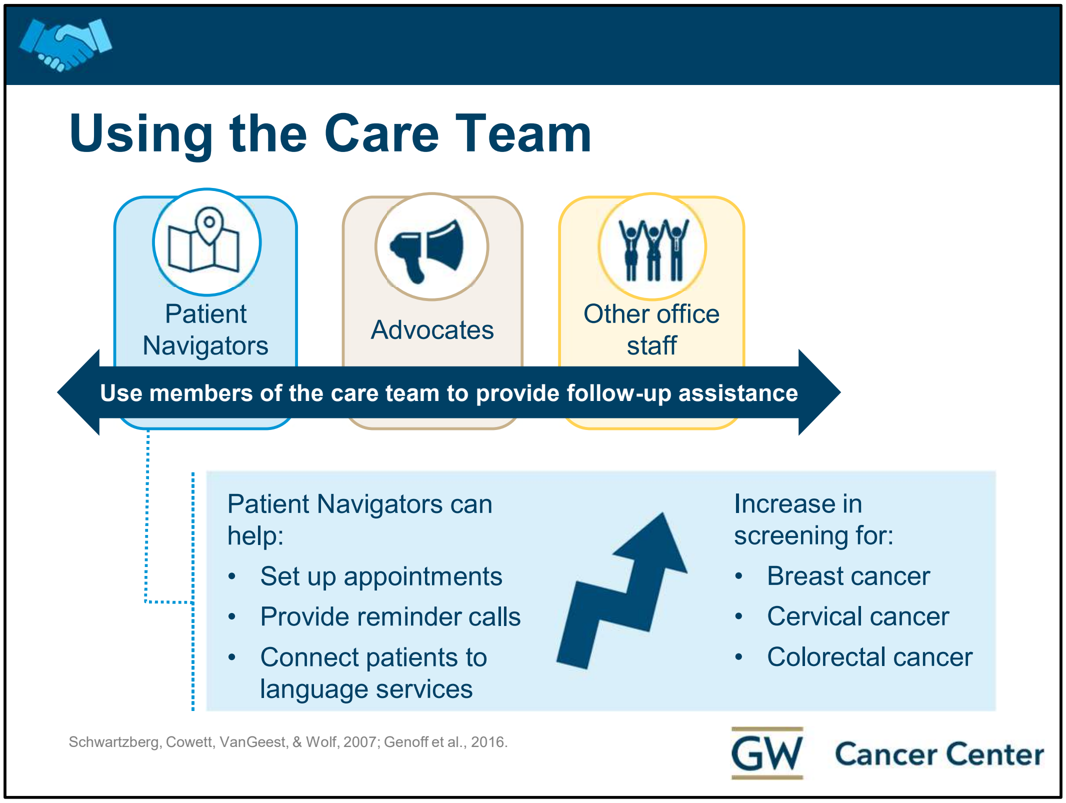

Using the Care Team

Patient Navigators

Advocates

Other office staff

Use members of the care team to provide follow-up assistance

Patient Navigators can help:

- Set up appointments
- Provide reminder calls
- Connect patients to language services

Increase in screening for:

- Breast cancer
- Cervical cancer
- Colorectal cancer

Schwartzberg, Cowett, VanGeest, & Wolf, 2007; Genoff et al., 2016.

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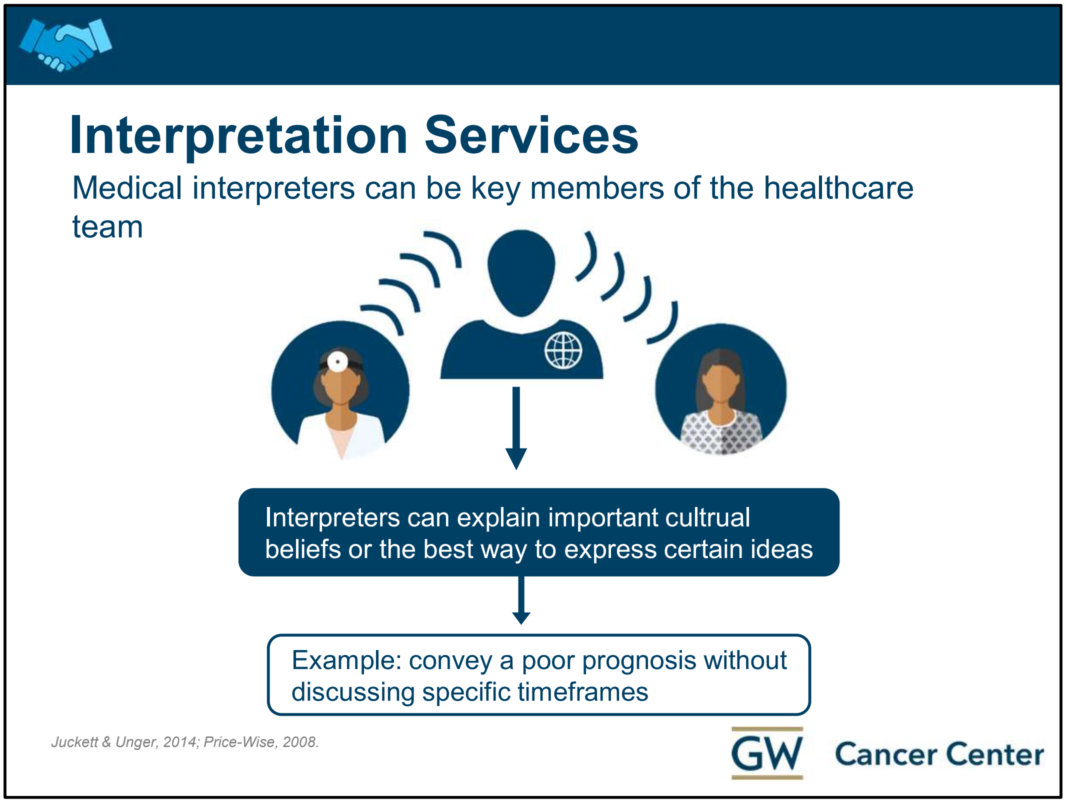
Another important strategy is using members of the care team to provide communication assistance. This can include staff members like patient navigators, advocates or other office staff who follow up with patients to confirm their understanding of the health information that was presented in their appointments. For example, using navigators to work with patients to set up appointments, provide reminder calls and connect patients to language assistance services has been shown to increase breast, cervical and colorectal cancer screening.



Interpretation Services

Medical interpreters can be key members of the healthcare team

Interpreters can explain important cultrual beliefs or the best way to express certain ideas

Example: convey a poor prognosis without discussing specific timeframes

Juckett & Unger, 2014; Price-Wise, 2008.

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Medical interpreters can also be critical members of the health care team who assist with effective communication for patients with limited English proficiency.

In addition to having linguistic and medical knowledge, professional medical interpreters may also be able to serve as cultural brokers, to explain important cultural beliefs about an illness or to manage nuances of how best to express certain ideas in a culturally competent way.

In the National Cancer Care TEAM Survey, one provider described this experience: "Patient was from Mexico where culturally it is inappropriate to discuss cancer prognosis in terms of months, [and] years. Using a medically trained [interpreter] they were able to convey a poor prognosis without discussing specific timeframes."

When they are available, every effort should be made to use professional medical interpreters for conversations where medical information is communicated, rather than untrained interpreters, family members, or bilingual staff with limited medical knowledge.

Untrained interpreters and family members may: be unfamiliar with medical concepts and terms, have their own agendas and insert unsolicited opinions, feel uncomfortable and use euphemisms interpreting bad news or sensitive sex-related information, and violate patient confidentiality. Unless it is an emergency, children should never be used as interpreters.

Also, although it can be useful for healthcare team members to know other languages, overestimating the fluency of partially bilingual people can be dangerous to patients.

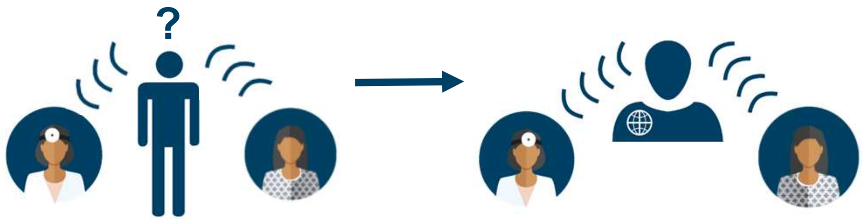
For example, in a case involving a 2-year old girl who sustained a fracture after falling off her tricycle, a medical resident misunderstood the Spanish phrase “se pegó” to mean “she was hit” rather than “she hit herself,” and the child was mistakenly put under protective custody for suspected abuse.

In the case of Willie Ramirez, the false cognate “intoxicado” was misunderstood as “intoxicated,” and he was mistakenly treated for a drug overdose. He actually had hemorrhaging in his brain which went untreated for 2 days, leaving him a quadriplegic.

In these cases, professional medical interpreters were not called and might have been able to avoid these tragedies.

Interpretation Services

When available, every effort should be made to use interpreters



Untrained interpreters or family may:

- Be unfamiliar with medical terms
- Give unsolicited opinions
- Feel uncomfortable interpreting bad news or sensitive information
- Violate patient confidentiality

Juckett & Unger, 2014; Price-Wise, 2008.

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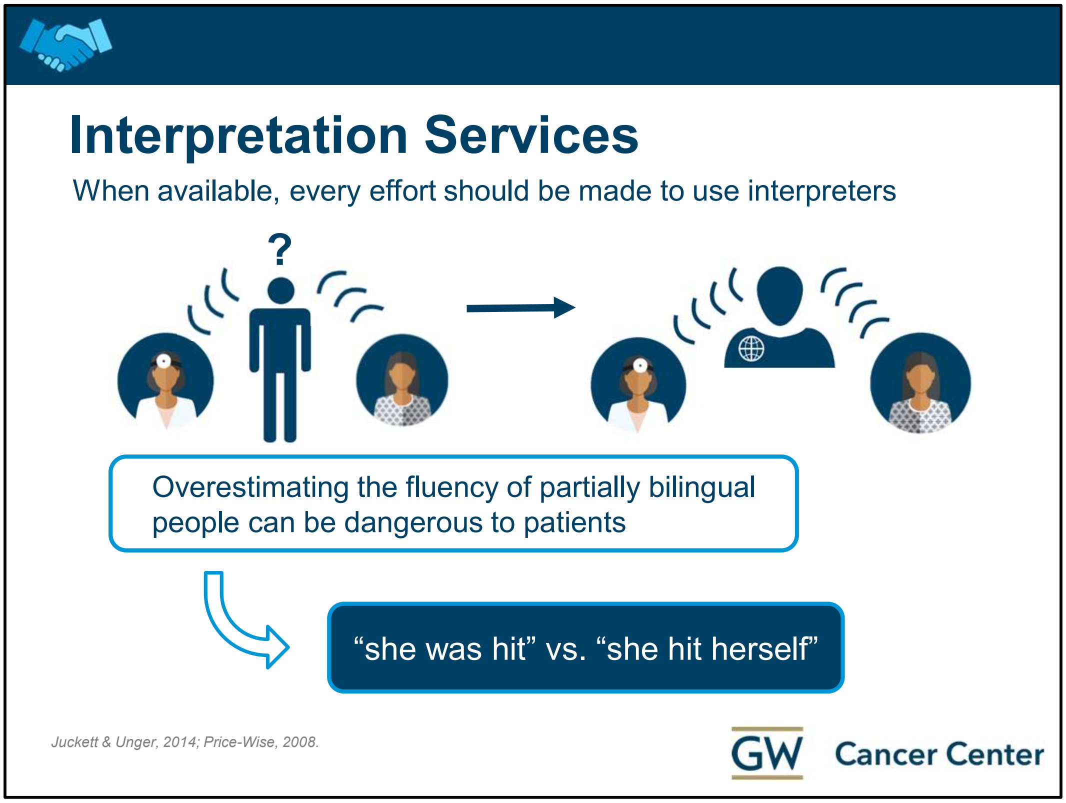

Interpretation Services

When available, every effort should be made to use interpreters

Overestimating the fluency of partially bilingual people can be dangerous to patients

“she was hit” vs. “she hit herself”

Juckett & Unger, 2014; Price-Wise, 2008.

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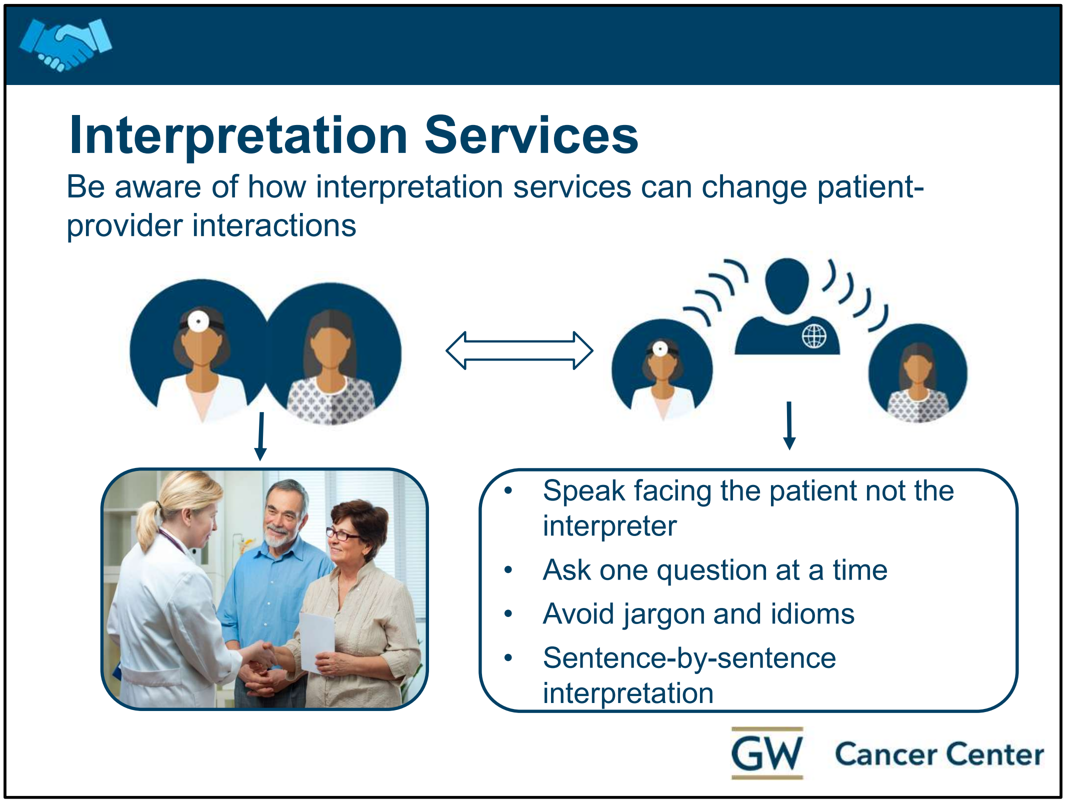

Interpretation Services

Be aware of how interpretation services can change patient-provider interactions

- Speak facing the patient not the interpreter
- Ask one question at a time
- Avoid jargon and idioms
- Sentence-by-sentence interpretation

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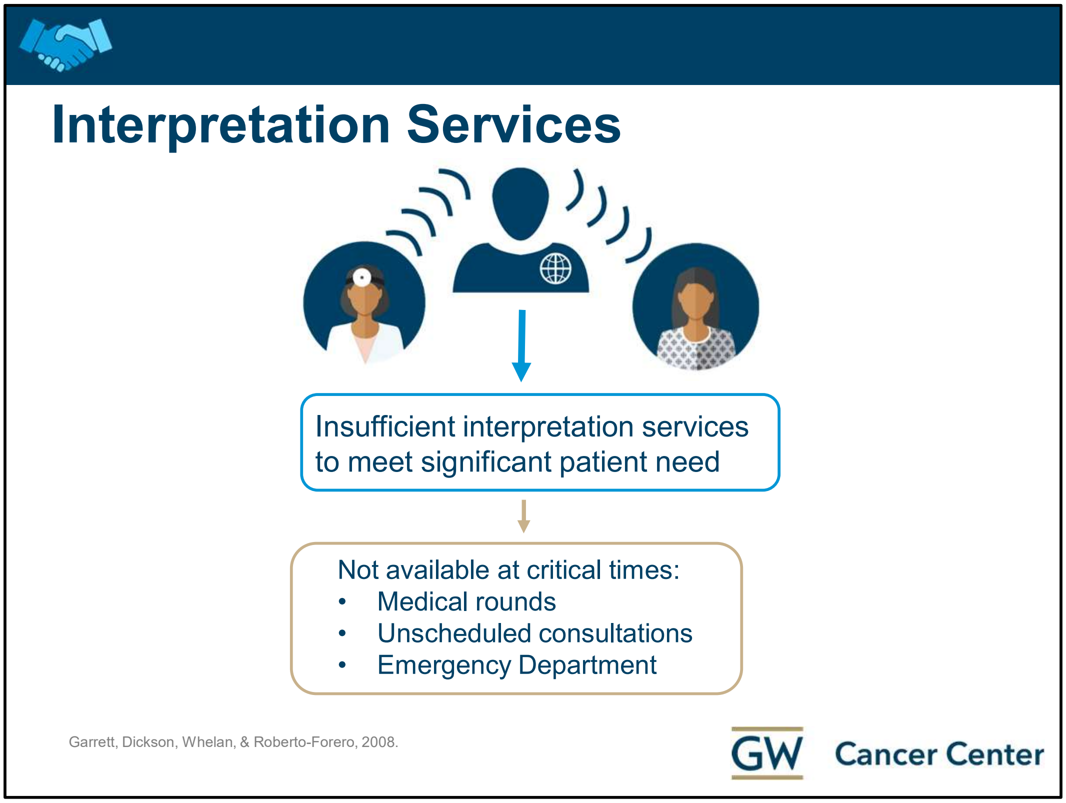
Sometimes, even when interpretation services are available, they are underutilized. Are there interpretation services in your setting? Find out exactly how to request services and have this information at the ready. Think ahead and anticipate encounters with limited English-proficient patients so that you can request services and allot additional time for these interactions when possible. You can also encourage a culture of providing high quality care to limited English-proficient patients by setting the norm of consistently and appropriately utilizing interpretation services.

When using interpretation services, keep the following tips in mind for a successful interaction:

- Speak directly to the patient rather than the interpreter. Face the patient and position the interpreter to the side or slightly behind the patient. Use language like “I” and “you”, rather than “tell him” or “tell her…”
- Be aware of body language.
- To avoid information getting lost, be concise. Ask one question at a time. Use short sentences and limit key points to three or fewer before pausing for interpretation.
- Avoid medical jargon and idioms.
- Insist on sentence-by-sentence interpretation to avoid side-conversations.
- Probe any inconsistencies that you notice and ask for clarification.
- Ask patients to repeat back or demonstrate what you said to ensure understanding.
- Debrief with the interpreter after the conversation in case there are clarifications that need to be discussed.

- Note details about the patient’s language and interpreter’s name in your documentation.



Interpretation Services

Insufficient interpretation services to meet significant patient need

Not available at critical times:
- Medical rounds
- Unscheduled consultations
- Emergency Department

Garrett, Dickson, Whelan, & Roberto-Forero, 2008.

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While it is ideal to have interpreters on staff who are proficient in the most common languages spoken by patients served by the health care organization, it is often impossible to provide interpretation services in person for all first languages of any particular patient population.

Also, interpreters are often not immediately available at certain critical times, like in medical rounds, unscheduled conversations and during emergencies. Telephone or online interpretation services are important complements to in-person interpretation.

For instance, MARTTI (My Accessible Real-Time Trusted Interpreter) connects patients to interpreters through live video over a HIPPA-compliant secure connection. However, there are limitations to remote interpretation technologies.

Many providers note that using the interpretation phone is difficult because there is a long delay between when they speak and when patients hear the interpretation.

There is also a strong benefit of having an interpreter present in the room to pick up on body language, tone and other factors and reflect that when speaking with patients. While interpretation via phone may cause some frustration, you can help by role modeling patience and explaining that there may be a delay between when the patient speaks and when the interpretation is heard.

You can explain that while this may feel awkward, making sure you have clear information is important to the quality of care you can provide.

Interpretation Services

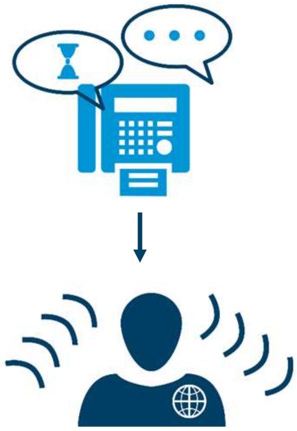
Welcome to martti

Connect to an interpreter directly through the 4 language quick links. For our other languages, choose All Other Languages.

My Accessible Real-Time Trusted Interpreter (MARRTI)

martti, n.d.

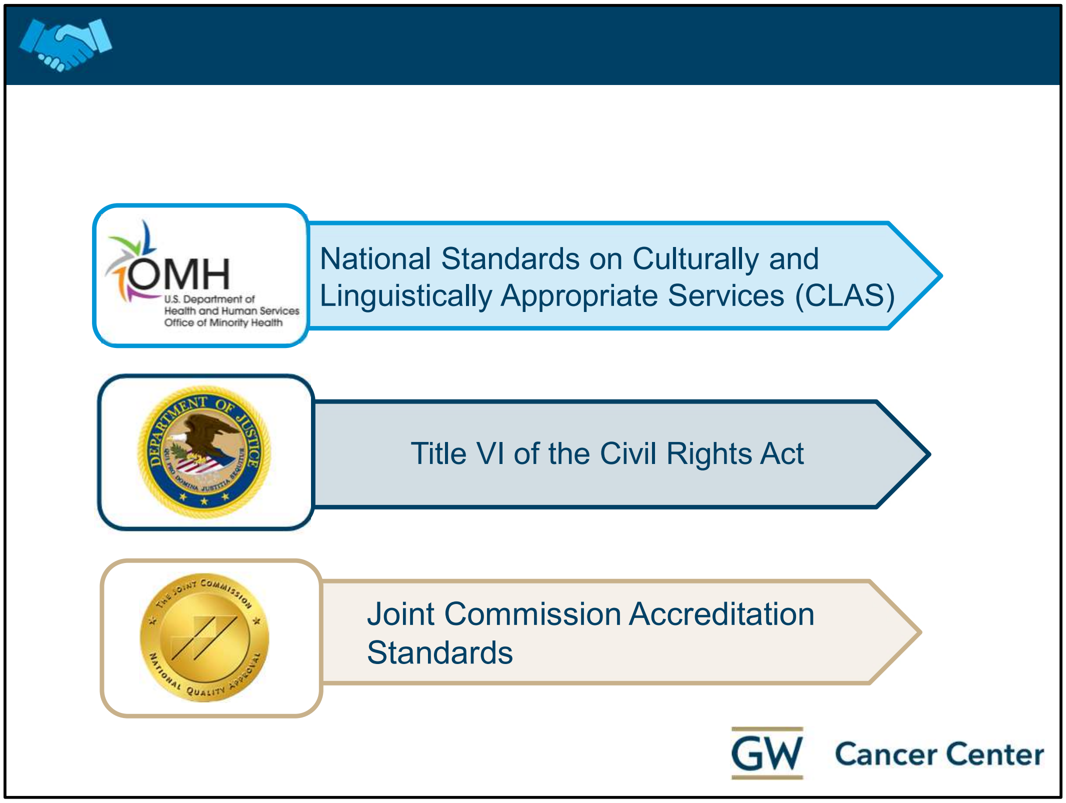
Interpretation Services



“Blue phone” interpretation services are difficult because there is a long delay between spoken conversation and the translation.

However, these services are critical and you can role model patience and explain the importance of accurate translation.

Butow et al., 2012.



OMH
U.S. Department of Health and Human Services Office of Minority Health

National Standards on Culturally and Linguistically Appropriate Services (CLAS)

DEPARTMENT OF JUSTICE

Title VI of the Civil Rights Act

Joint Commission Accreditation Standards

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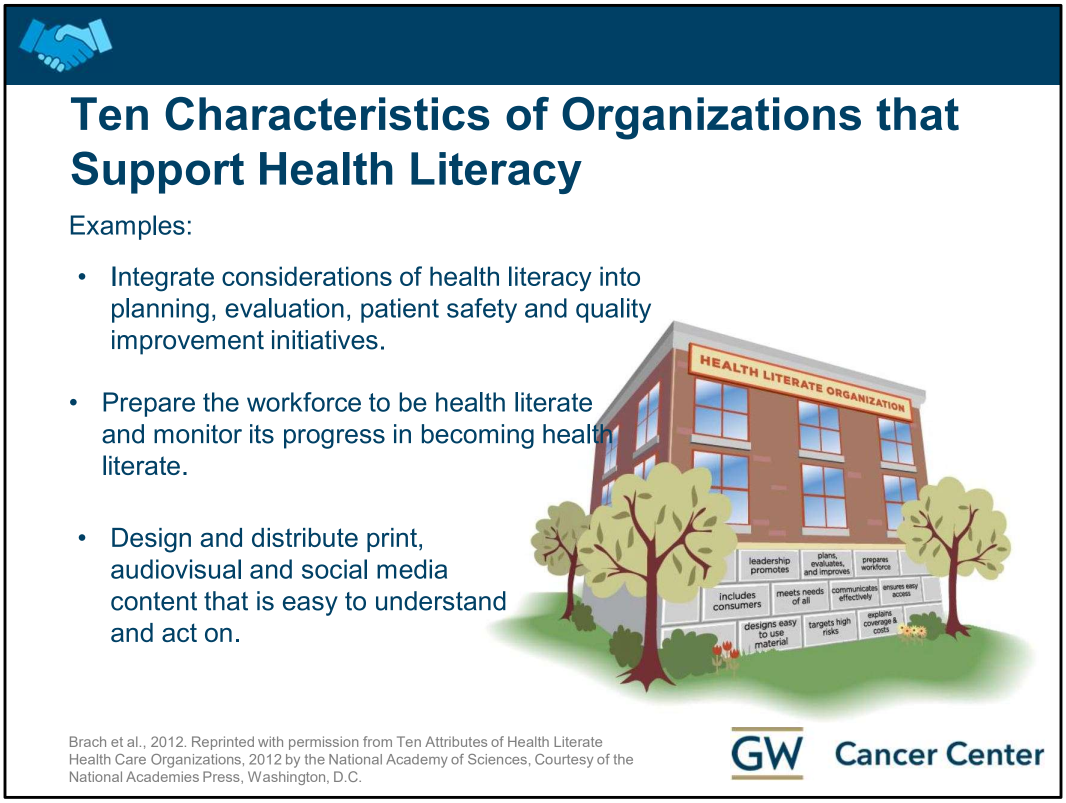
Some of you may work in settings where the language support that you need is simply not available. You can be a leader and advocate for services.

When trying to make the case to administrators or executives for organizations to invest in any of these types of interpretation services, health care professionals can point to the federal policies and standards that require the organization to provide interpretation.

These include policies we discussed at the beginning of this lesson – CLAS standards, Title VI, or Joint Commission accreditation standards.

We will go over broader strategies for how to get health care leadership to buy-into these types of initiatives in a later lesson.



Ten Characteristics of Organizations that Support Health Literacy

Examples:

- Integrate considerations of health literacy into planning, evaluation, patient safety and quality improvement initiatives.
- Prepare the workforce to be health literate and monitor its progress in becoming health literate.
- Design and distribute print, audiovisual and social media content that is easy to understand and act on.

Brach et al., 2012. Reprinted with permission from Ten Attributes of Health Literate Health Care Organizations, 2012 by the National Academy of Sciences, Courtesy of the National Academies Press, Washington, D.C.

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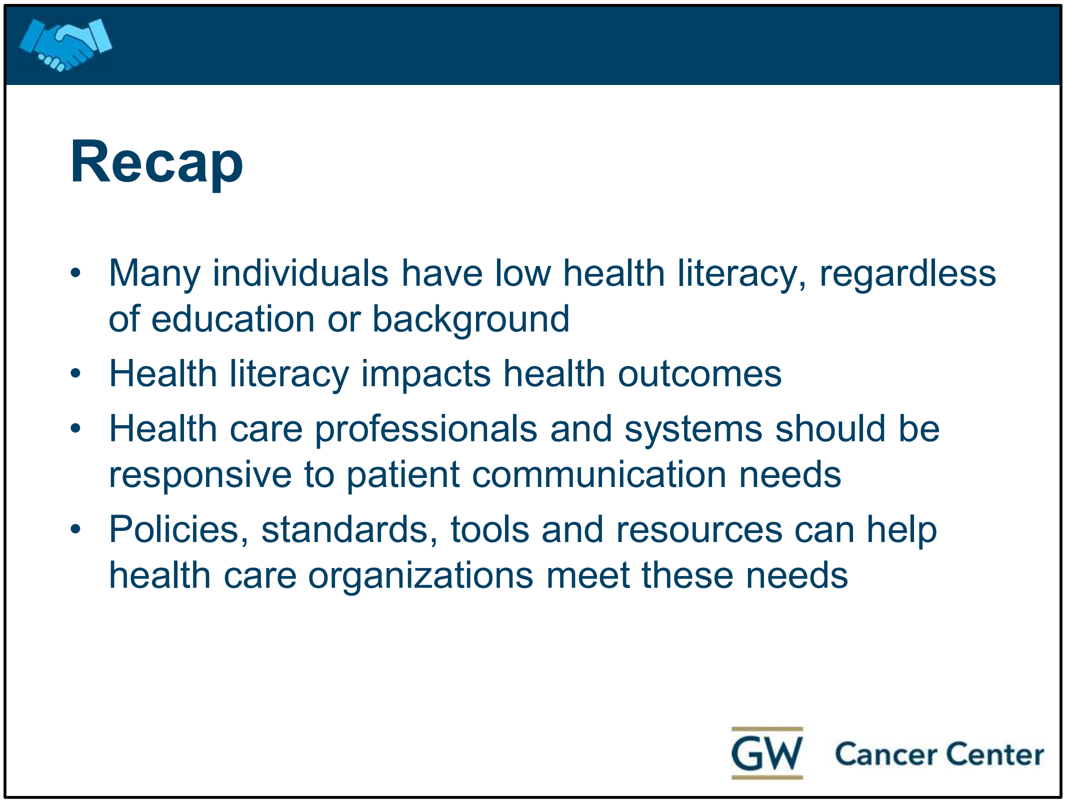
Finally, there are strategies that a health organization can take at the institutional level to meet the communication needs of its patients.

The National Academy of Medicine (formerly the Institute of Medicine) has published a list of 10 characteristics of health care organizations that meet the communication needs of patients with all levels of health literacy. For example, these types of organizations:

- Integrate considerations of health literacy into planning, evaluation, patient safety and quality improvement initiatives;
- Prepare the workforce to be health literate and monitor its progress; and
- Design and distribute print, audiovisual and social media content that is easy to understand and act on.

This list, called the Ten Attributes of Health Literate Health Care Organizations, can be found in the LMS.



Recap

- Many individuals have low health literacy, regardless of education or background
- Health literacy impacts health outcomes
- Health care professionals and systems should be responsive to patient communication needs
- Policies, standards, tools and resources can help health care organizations meet these needs

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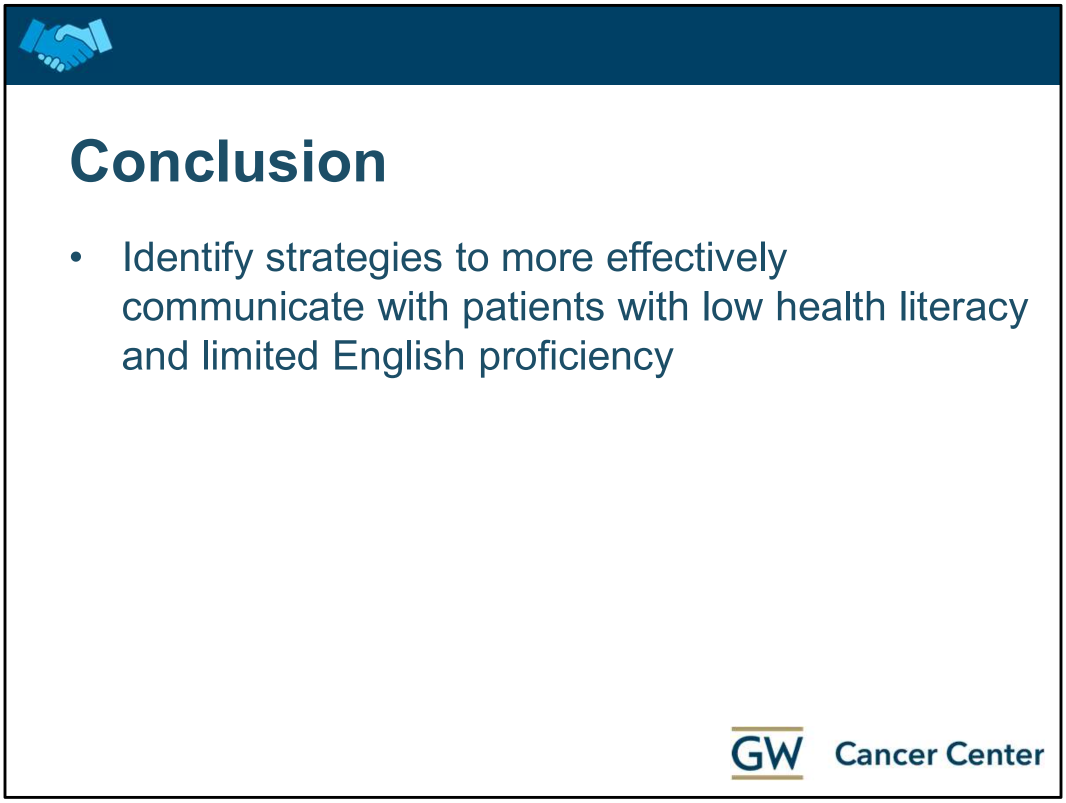
As we've discussed, many individuals, regardless of background, have low levels of health literacy, which impact their health and health outcomes.

It is important for health care professionals and health systems to be responsive to this need, and to the needs of individuals with limited English proficiency.

National policies and standards are in place to help guide health care professionals and systems to meet patient communication needs, along with tools and resources to help with implementation.



Conclusion

- Identify strategies to more effectively communicate with patients with low health literacy and limited English proficiency

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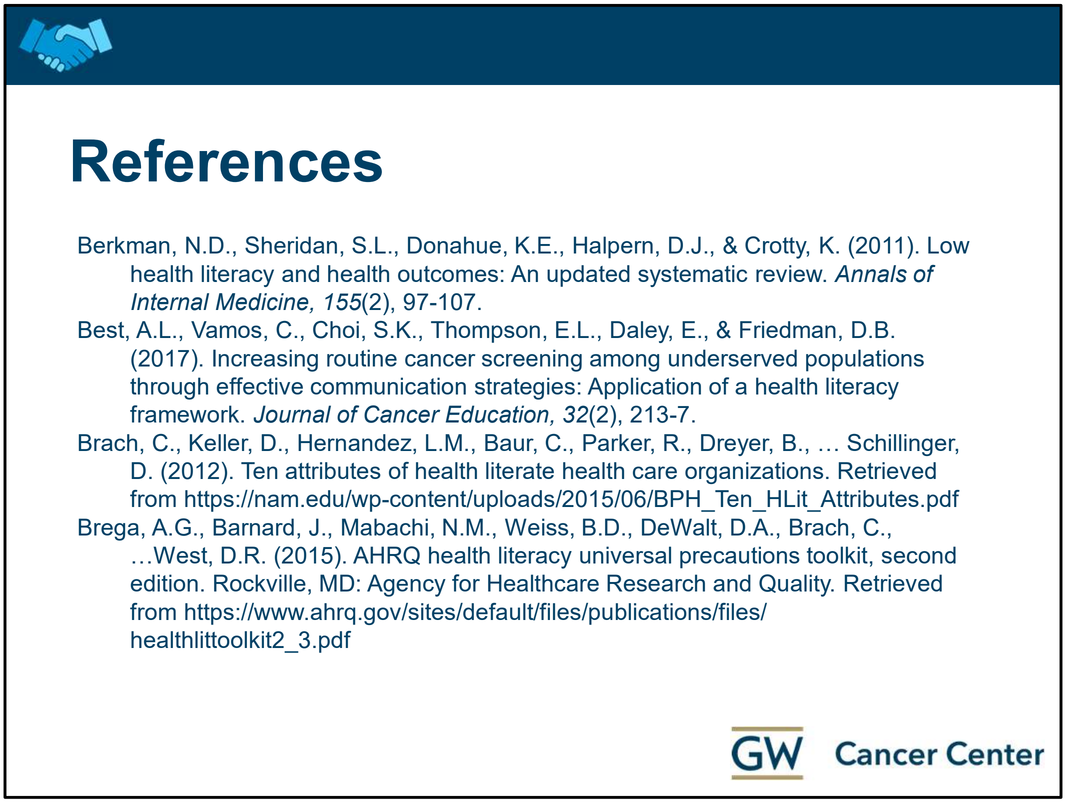
In this lesson, you learned to:

- Identify strategies to more effectively communicate with patients with low health literacy and limited English proficiency



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Here is the full reference list of sources cited in this lesson.

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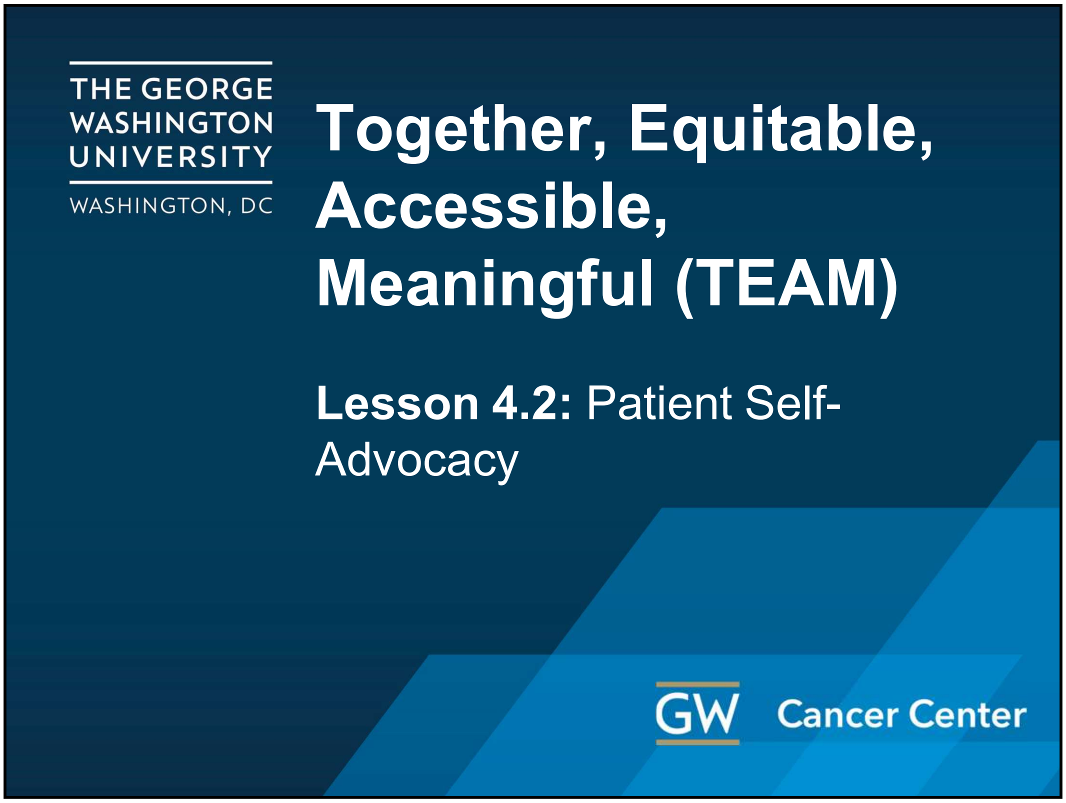

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Together, Equitable, Accessible, Meaningful (TEAM)

Lesson 4.2: Patient Self-Advocacy

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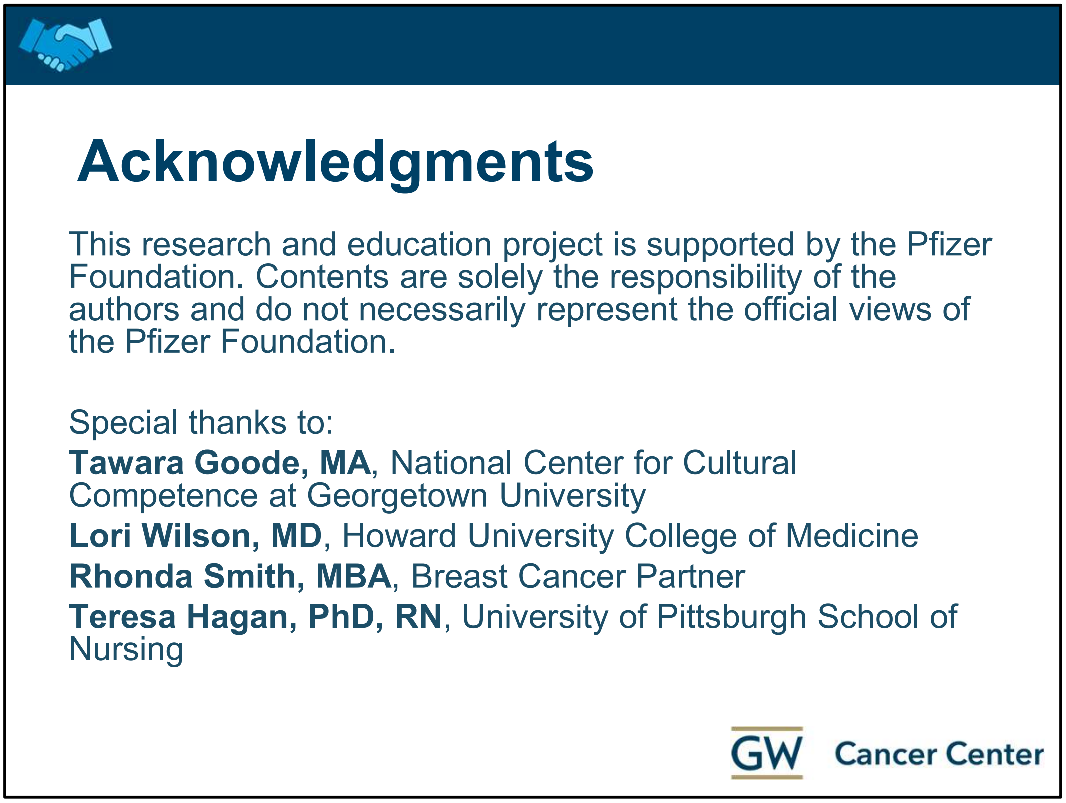
Welcome to Module 4, Lesson 2: Patient Self-Advocacy.



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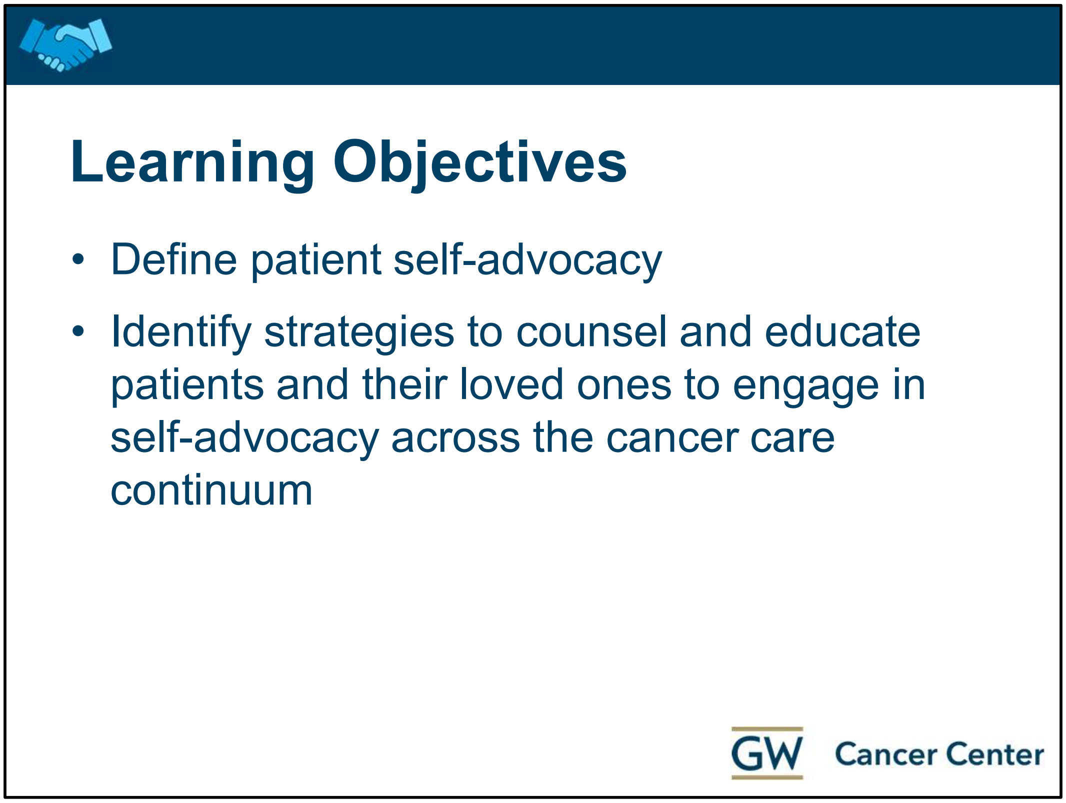

Learning Objectives

- Define patient self-advocacy
- Identify strategies to counsel and educate patients and their loved ones to engage in self-advocacy across the cancer care continuum

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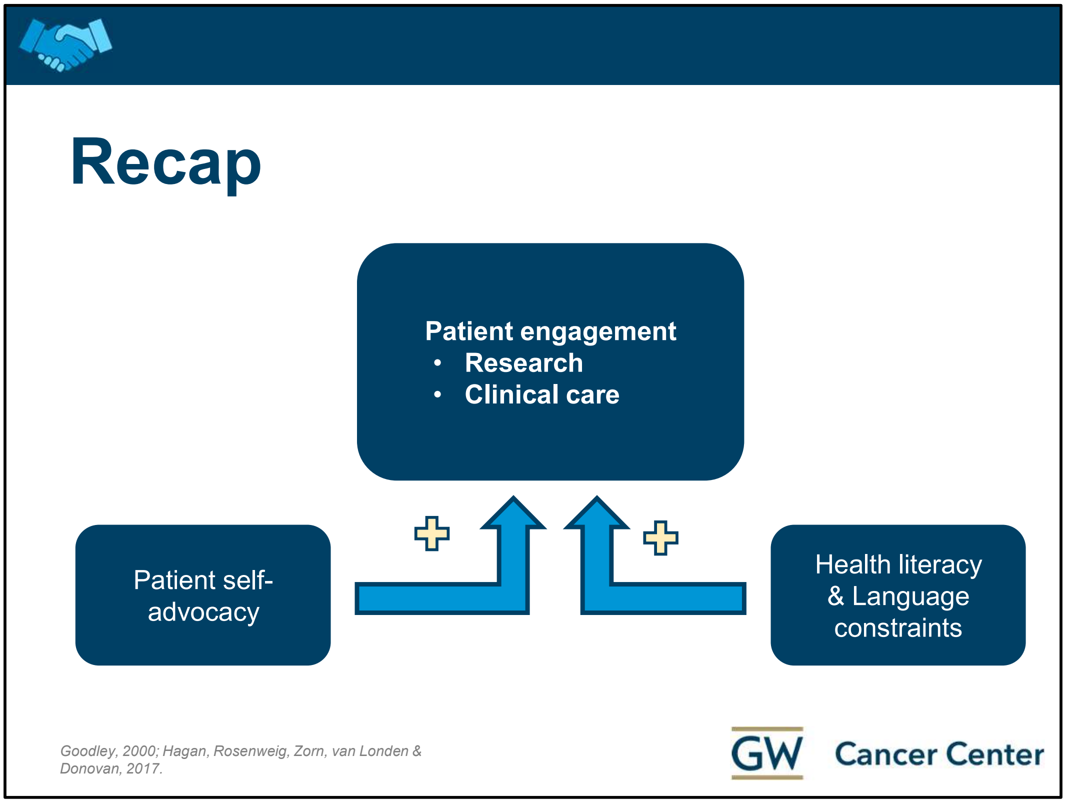
After completing this lesson, you will be able to:

- Define patient self-advocacy
- Identify strategies to counsel and educate patients and their loved ones to engage in self-advocacy across the cancer care continuum



Recap

Patient engagement
- **Research**
- **Clinical care**

Patient self-advocacy

Health literacy & Language constraints

Goodley, 2000; Hagan, Rosenweig, Zorn, van Londen & Donovan, 2017.

Another key component to patient engagement and shared decision-making is patient self-advocacy. The concept of self-advocacy originated in the disability community. It referred to a person's ability to have a say in the decisions affecting their life and gain the skills to do so.

In the health care setting and in cancer care specifically, self-advocacy refers to an individual's ability to make informed decisions, find strength through connections with others and communicate effectively with the cancer care team. Self-advocacy also describes an individual's motivation and urgency to apply these skills to problems they face with their health and care.

What is Patient Self-Advocacy?

- Make informed decisions
- Find strength through connections
- Communicate with the cancer care team

Goodley, 2000; Hagan, Rosenweig, Zorn, van Londen & Donovan, 2017.

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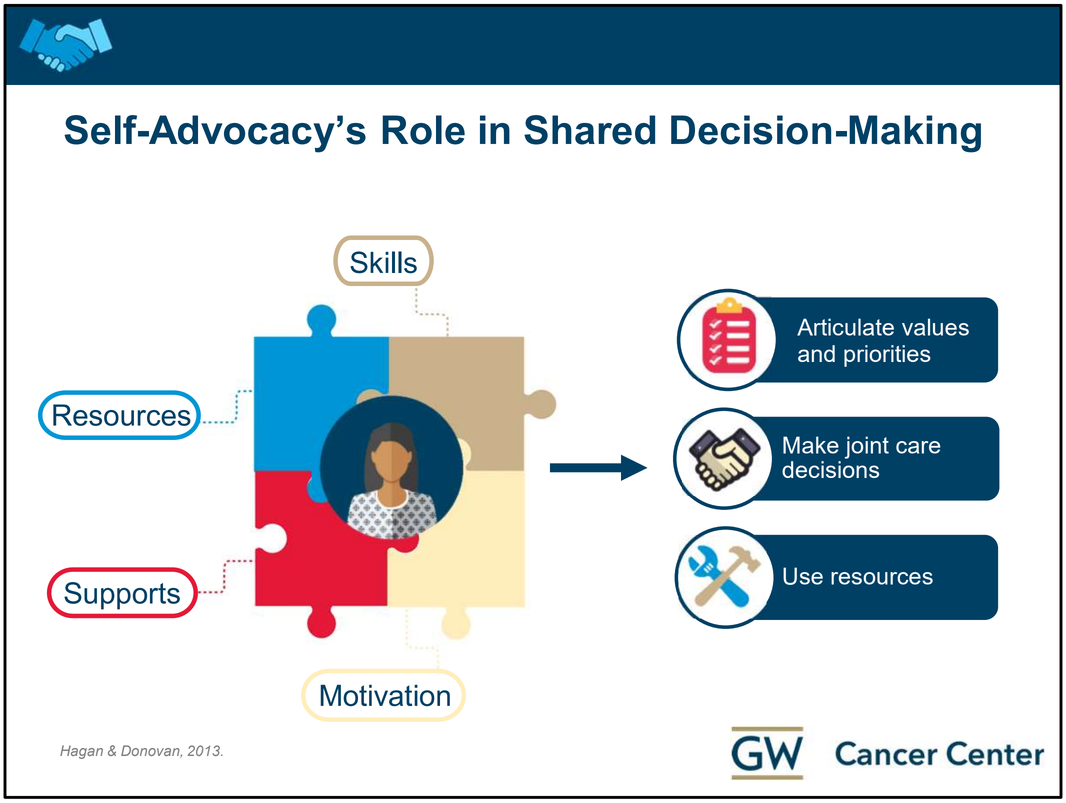

Self-Advocacy’s Role in Shared Decision-Making

Skills

Resources

Supports

Motivation

Articulate values and priorities

Make joint care decisions

Use resources

Hagan & Donovan, 2013.

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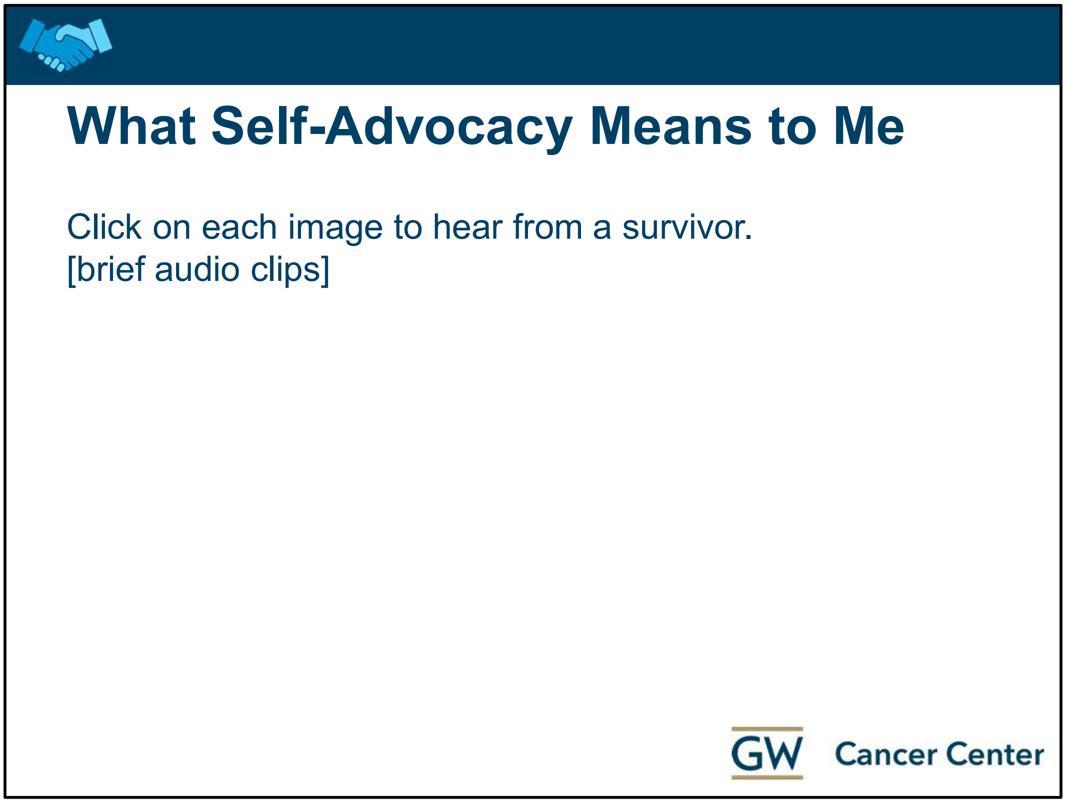
Health care professionals can maximize shared decision-making by helping ensure that patients:

- have the skills, resources, supports and motivation to advocate for themselves
- can talk about their values and priorities
- are a part of the health care team
- and have resources to support themselves and others.

Using tools discussed in the previous lesson will help you support patients with or through this process.



What Self-Advocacy Means to Me

Click on each image to hear from a survivor.
[brief audio clips]

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Let’s pause here, and take a moment to hear from cancer survivors about what self-advocacy means to them. Click on each image to hear from a survivor.

Why Do Patients Need to Self-Advocate?

Illustration by: Lola & Bek

Tarkan, 2008.

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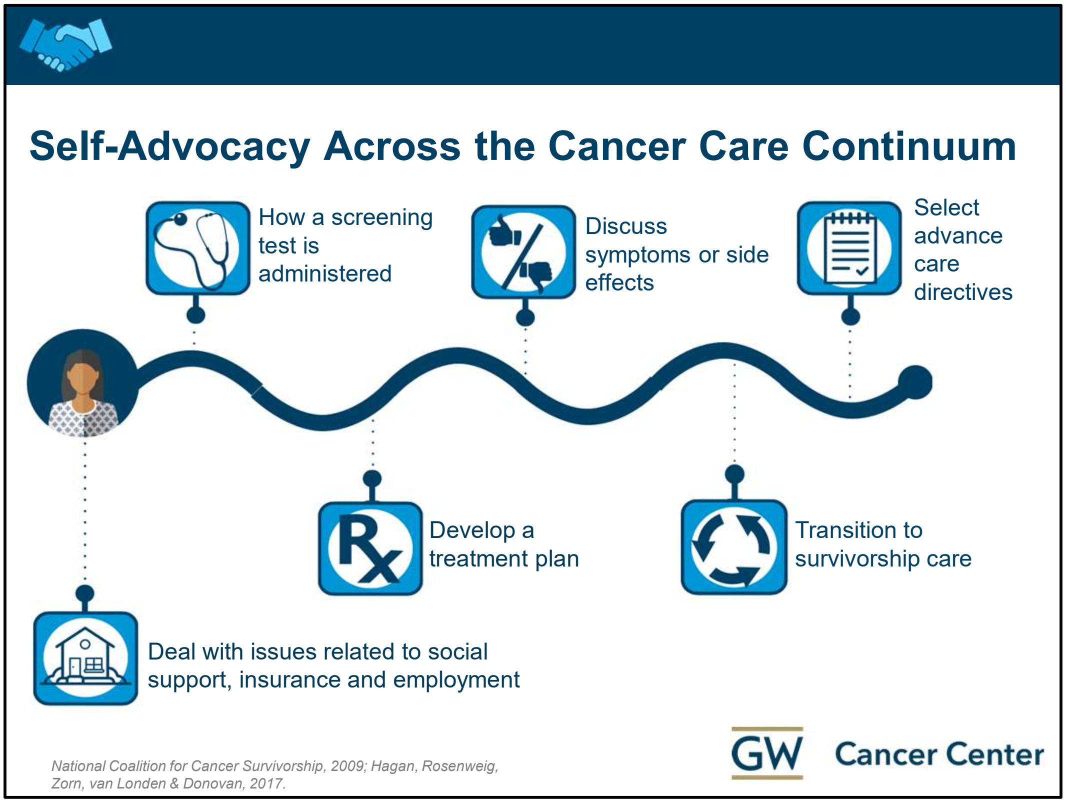
Because cancer care is often fragmented, patients are regularly put into positions where they have to advocate for themselves.

Often they must inform each new provider of their history, the state of their disease, treatment, care needs and preferences.

Also, how we understand cancer and available treatments for it are constantly changing, which adds another layer of difficultly for both patients and providers.

Therefore, patients need the knowledge and skills to express their health needs, determine the course of their care in partnership with their providers and manage their disease.



Self-Advocacy Across the Cancer Care Continuum

How a screening test is administered

Discuss symptoms or side effects

Select advance care directives

Develop a treatment plan

Transition to survivorship care

Deal with issues related to social support, insurance and employment

National Coalition for Cancer Survivorship, 2009; Hagan, Rosenweig, Zorn, van Londen & Donovan, 2017.

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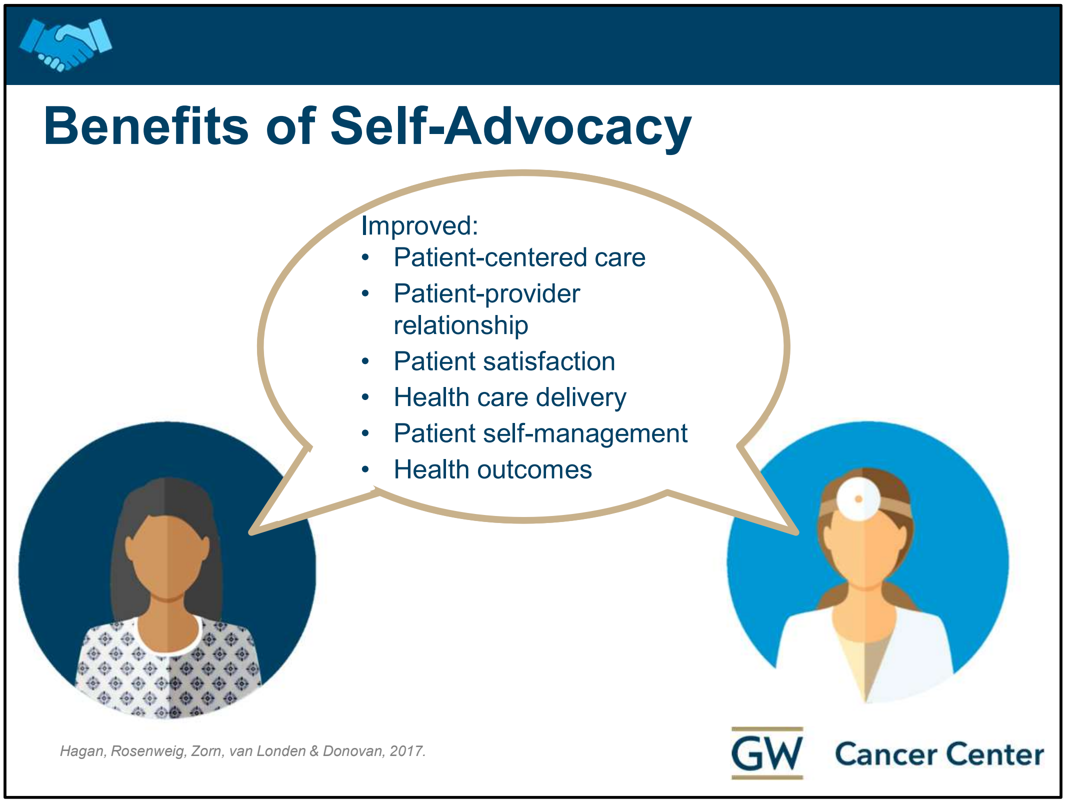
Self-advocacy can facilitate shared decision-making throughout the cancer care continuum—from screening to end of life.

For example, self-advocacy can occur when deciding how a screening test is given, developing a treatment plan, communicating side effects, transitioning from treatment to follow-up survivorship care and selecting advance care directives and priorities at end of life.

Self-advocacy is also key outside of the immediate care setting. For instance, in dealing with issues related to social support, insurance or employment.



Benefits of Self-Advocacy

Improved:
- Patient-centered care
- Patient-provider relationship
- Patient satisfaction
- Health care delivery
- Patient self-management
- Health outcomes

Hagan, Rosenweig, Zorn, van Londen & Donovan, 2017.

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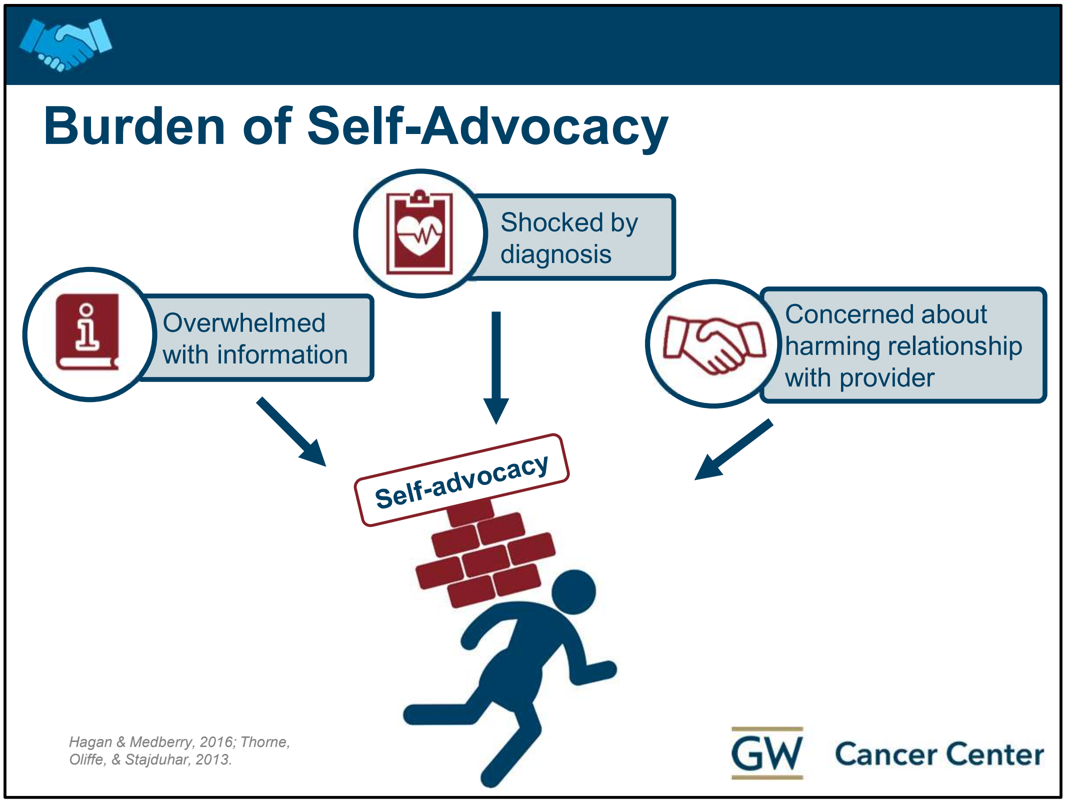
When providers and patients were asked about patient self-advocacy (defined as a patient getting their needs, priorities and desires met), both recognized several benefits.

Benefits include improved: patient-centered care, patient-provider relationship, patient satisfaction, health care delivery, and patient self-management of their health condition and health outcomes.



Burden of Self-Advocacy

Shocked by diagnosis

Overwhelmed with information

Concerned about harming relationship with provider

Hagan & Medberry, 2016; Thorne, Oliffe, & Stajduhar, 2013.

However, it is important to note that while policymakers, clinicians, researchers and patient support organizations are calling for patient self-advocacy more and more, they often do so in a way that unfairly places a disproportionate burden on patients to communicate their health and care needs.

In cancer care, self-advocacy is often equated with a person “fighting” or “speaking up.”

But it is important to realize that many individuals with cancer may not be equipped or feel comfortable doing so.

Patients and their family members may be overwhelmed with information and shocked by the diagnosis. Patients may also worry about offending the provider by “challenging” them and be less comfortable in speaking up.

It is also important to recognize the role of culture and upbringing in how patients expect to communicate with providers. It may not occur to some patients that they can advocate for themselves.

The case of Willie Ramirez (mentioned in a previous lesson) is a good example of this. Willie’s doctor mistakenly treated him for a drug overdose rather than a brain hemorrhage, which caused him to become a quadriplegic.

Willie’s sister recalls: “The ER doc said to my mom that he thought it was drugs – that Willie’s condition looked like a drug overdose. My Mom was really upset that they said it was drugs.

My mom and I spoke to each other in Spanish. My brother was an all-star baseball player, an athlete. He was really concerned about taking care of his body. We couldn’t imagine that he would use drugs. But a doctor said it – and you tend to believe what a doctor says. So we didn’t protest.

We didn’t tell him this was impossible – that Willie never took drugs. In front of the doctor, we just said to each other in Spanish, ‘This just cannot be true.’”

As members of the healthcare team, it is important to remember and not underestimate the power dynamic between patients and providers. Some patients may not feel comfortable challenging or contradicting an authority figure.

Instead of putting the responsibility for bringing up concerns on the patient and family, you can explicitly set expectations for a more equal relationship, and regularly ask for their input.

Providers can also communicate in ways that signal their commitment to a partnership with patients to show they welcome and support patients advocating for themselves.

As we discussed in a previous lesson, this could be through verbal cues like using a welcoming tone, not dominating the conversation and welcoming and inviting patient contributions.

It is also important to realize that persons living with cancer may value or engage in self-advocacy differently at various times and depending on what concerns arise. Although we talk about self-advocacy positively, it is not helpful to impose expectations of a “model self-advocate” onto patients.

The role self-advocacy plays and how it looks in a patient’s cancer care will differ for each patient. This makes sense, because self-advocacy entails promoting a patient’s own needs, priorities, and values, not those of their health care providers.

Supporting patient self-advocacy:

- Use a welcoming tone
- Do not dominate the conversation
- Invite patient contributions

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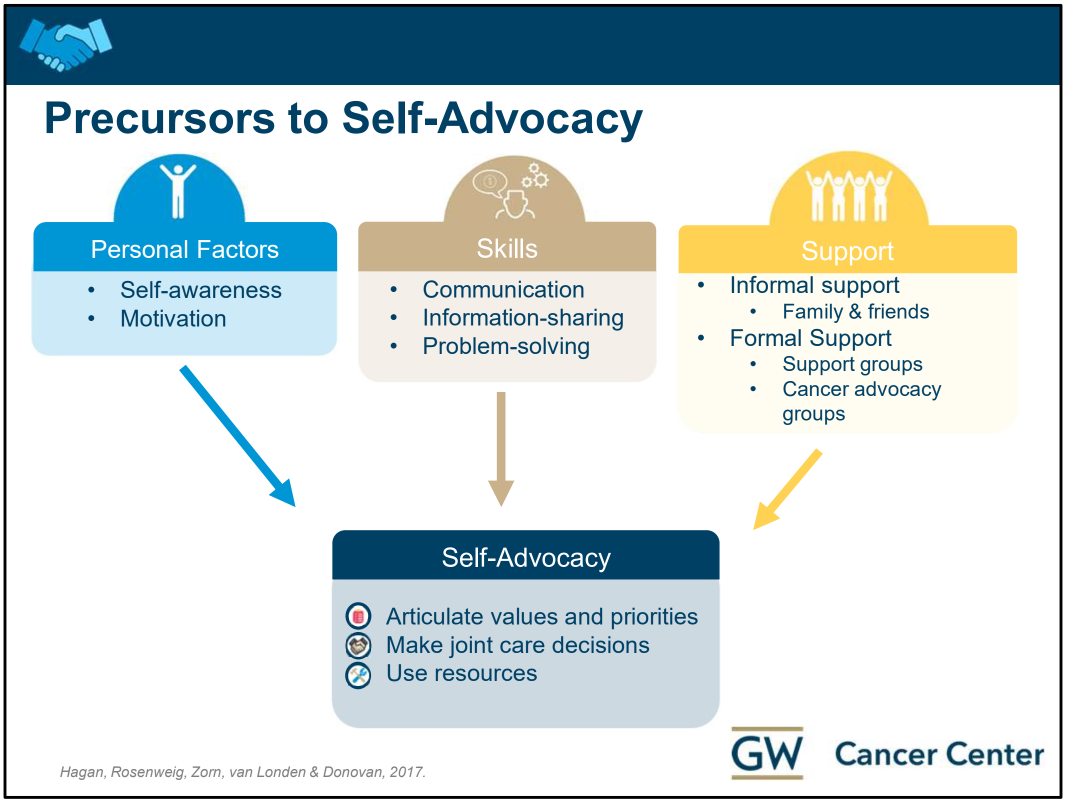

Precursors to Self-Advocacy

Personal Factors
- Self-awareness
- Motivation

Skills
- Communication
- Information-sharing
- Problem-solving

Support
- Informal support
  - Family & friends
- Formal Support
  - Support groups
  - Cancer advocacy groups

Self-Advocacy
- Articulate values and priorities
- Make joint care decisions
- Use resources

Hagan, Rosenweig, Zorn, van Londen & Donovan, 2017.

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Certain factors lay the foundation for patient self-advocacy. Patients have personal factors that drive their participation in self-advocacy. These factors include self-awareness and motivation to engage in conversations about their priorities and needs in the health care setting.

Patients also need skills to have these conversations, which include being able to communicate, seek information and solve problems together with health care professionals.

Finally, patients need to be able to seek out and get support to prepare them to have these conversations. This can be through informal support such as loved ones or formal support such as support or cancer advocacy groups.

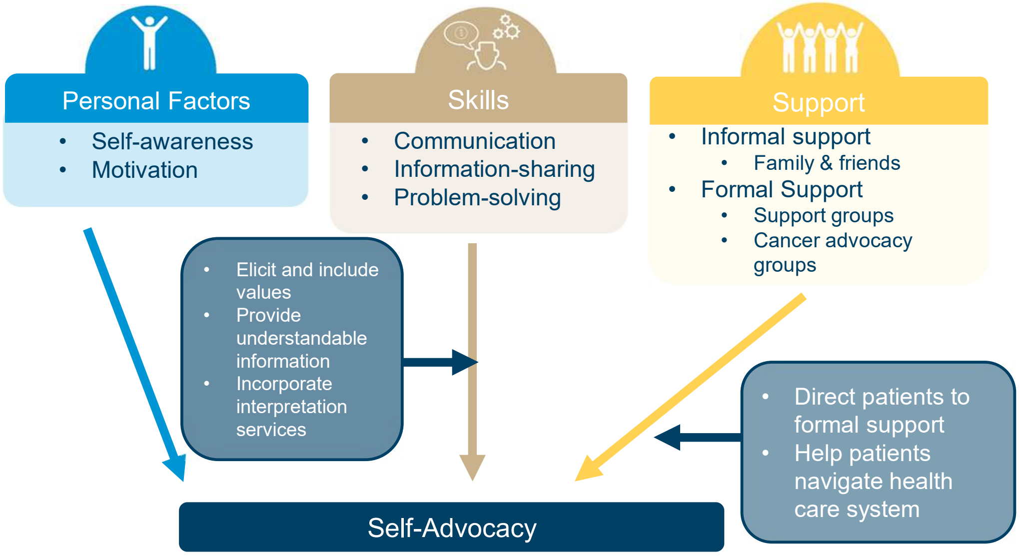
The cancer care team plays an important part in helping cancer patients gain the skills, resources and supports they need to engage in self-advocacy.

Team members can elicit patients' values through honest discussions of priorities, concerns and questions. Once these values and priorities are known, providers can work with patients and their loved ones to include these factors when making care decisions.

As discussed in the previous lesson, the care team can aid communication by providing patients and their loved ones with information that is accessible and understandable or incorporate interpretation services.

Navigators, patient advocates or other team members can also direct patients to formal support communities or assist patients in navigating the health system.

Precursors to Self-Advocacy



Personal Factors
- Self-awareness
- Motivation

Skills
- Communication
- Information-sharing
- Problem-solving

Support
- Informal support
  - Family & friends
- Formal Support
  - Support groups
  - Cancer advocacy groups

- Elicit and include values
- Provide understandable information
- Incorporate interpretation services

- Direct patients to formal support
- Help patients navigate health care system

Self-Advocacy

Hagan, Rosenweig, Zorn, van Londen & Donovan, 2017.

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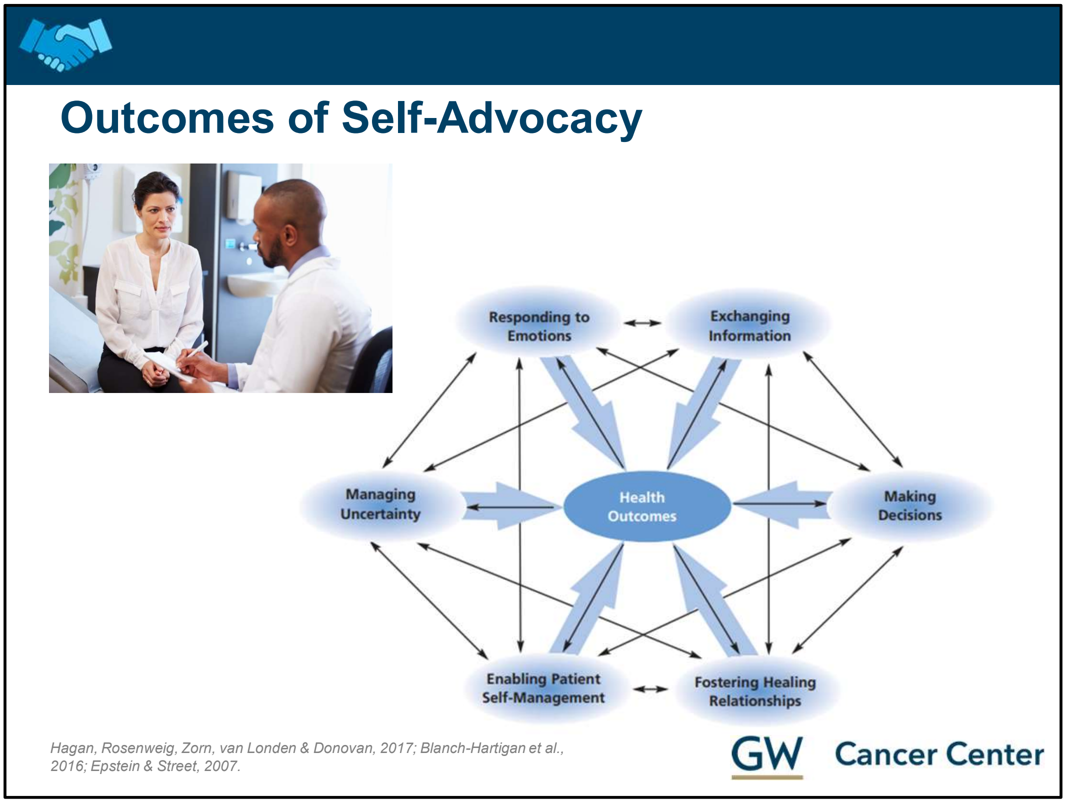

Outcomes of Self-Advocacy

Hagan, Rosenweig, Zorn, van Londen & Donovan, 2017; Blanch-Hartigan et al., 2016; Epstein & Street, 2007.

Sometimes, however, people living with cancer feel their providers do not help them, manage uncertainty, respond to their emotional needs, make sure they understand their health and care or involve them in decisions-- all of which are components of effective cancer communication, based on the NCI model presented in a previous lesson.

Supporting self-advocacy and meeting communication needs is particularly important when serving vulnerable populations.

As we've talked about, self-advocacy allows patients to:
- express their values and preferences
- make joint care decisions with their health care providers, and
- use resources to support their care and health management.

Health care professionals support patients in advocating for themselves by using effective and open communication through tactics like motivational interviewing. This involves eliciting patients' and family members' priorities, concerns and questions so that they can be integrated into decision-making.

Therefore, by health care professionals supporting patient self-advocacy and patients engaging in self-advocacy, a key short-term outcome is improved: patient-provider communication in cancer care.

As noted before, long-term outcomes associated with self-advocacy include improved patient-provider relationship, greater patient satisfaction, more efficient health care delivery, better patient self-management of health and improved health outcomes.

Outcomes of Self-Advocacy

Self-Advocacy

- Articulate values and priorities
- Make joint care decisions
- Use resources

↓

Short-Term Outcome

Improved patient-provider communication

↓

Long-Term Outcomes

Improved:
- Patient-provider relationship
- Patient satisfaction
- Health care delivery
- Patient self-management
- Health outcomes

Hagan, Rosenweig, Zorn, van Londen & Donovan, 2017; Blanch-Hartigan et al., 2016; Epstein & Street, 2007. Manfredi, Kaiser, Matthews, & *Johnson*, 2010.

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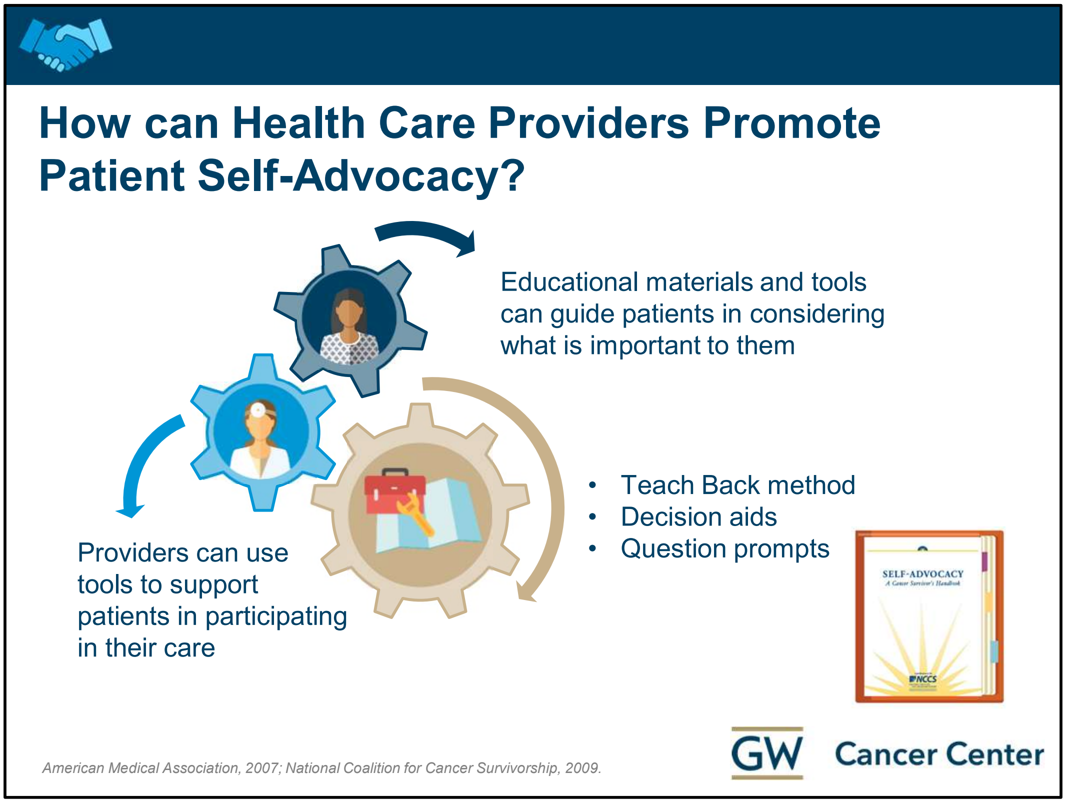

How can Health Care Providers Promote Patient Self-Advocacy?

Educational materials and tools can guide patients in considering what is important to them

Providers can use tools to support patients in participating in their care

- Teach Back method
- Decision aids
- Question prompts

American Medical Association, 2007; National Coalition for Cancer Survivorship, 2009.

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For those patients who are able and want to engage in self-advocacy, there are tools that providers can use to support patients in participating in their care, such as the Teach Back method.

Educational materials and tools like decision aids and question prompts can guide patients in considering what is important to them. A good example is a set of questions created by the National Coalition for Cancer Survivorship for patients to consider before engaging in shared decision-making with their providers.

Questions include:

- Is there any evidence the cancer has spread? What is the stage of the disease?
- What new treatments are being studied? Would a clinical trial be appropriate for me?
- What are the expected benefits of each kind of treatment? What are the risks and possible side effects?
- Is infertility a side effect of cancer treatment? Can anything be done about it?
- How often will I have treatments? How long will treatment last?
- What is treatment likely to cost?

Patient advocates also recommend that providers consider framing their discussions with patients in ways that answer questions like:

- “What does my diagnosis mean?”

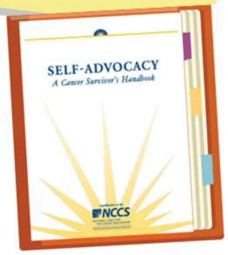
- What is my prognosis?”
- “What should I expect during treatment?” and
- “How will I know if the treatment is working?”

In addition to using tools and resources highlighted in the LMS, providers should consider more generally how to handle the power imbalance that exists between patients and providers and how to facilitate an environment that conveys trust, mutual respect and partnership, which we will cover in the next module.

NCCS
NATIONAL COALITION
FOR CANCER SURVIVORSHIP

- ☐ Is there any evidence the cancer has spread? What is the stage of the disease?
- ☐ What are my treatment choices? Which do you recommend for me, and why?
- ☐ What new treatments are being studied? Would a clinical trial be appropriate for me?
- ☐ What are the expected benefits of each kind of treatment? What are the risks and possible side effects?
- ☐ Is infertility a side effect of cancer treatment? Can anything be done about it?
- ☐ What can I do to prepare for treatment?
- ☐ How often will I have treatments? How long will treatment last?
- ☐ What is treatment likely to cost?
- ☐ Will I have to change my normal activities? For how long?

My own questions:
- What does my diagnosis mean?
- What is my prognosis?
- What should I expect during treatment?
- How will I know if the treatment is working?



SELF-ADVOCACY
A Cancer Survivor's Handbook

National Coalition for Cancer Survivorship (NCCS), 2009; Joseph-Williams, Elwyn, & Edwards, 2014.; NCCS, n.d.

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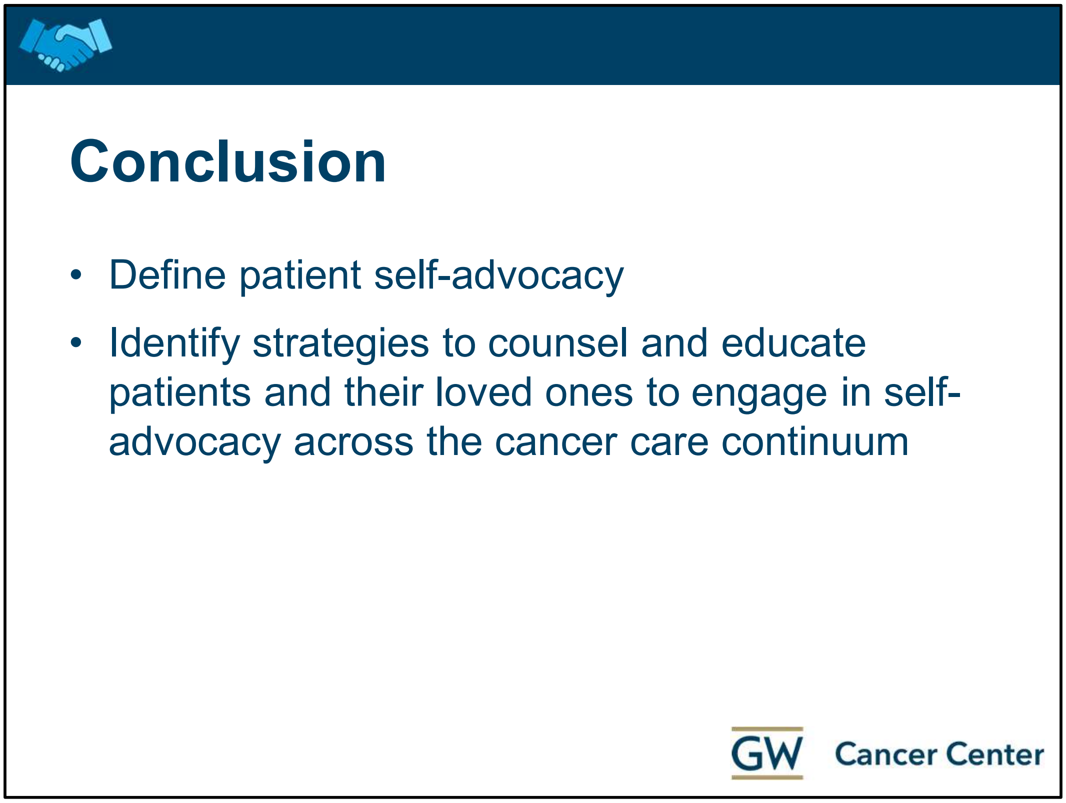

Conclusion

- Define patient self-advocacy
- Identify strategies to counsel and educate patients and their loved ones to engage in self-advocacy across the cancer care continuum

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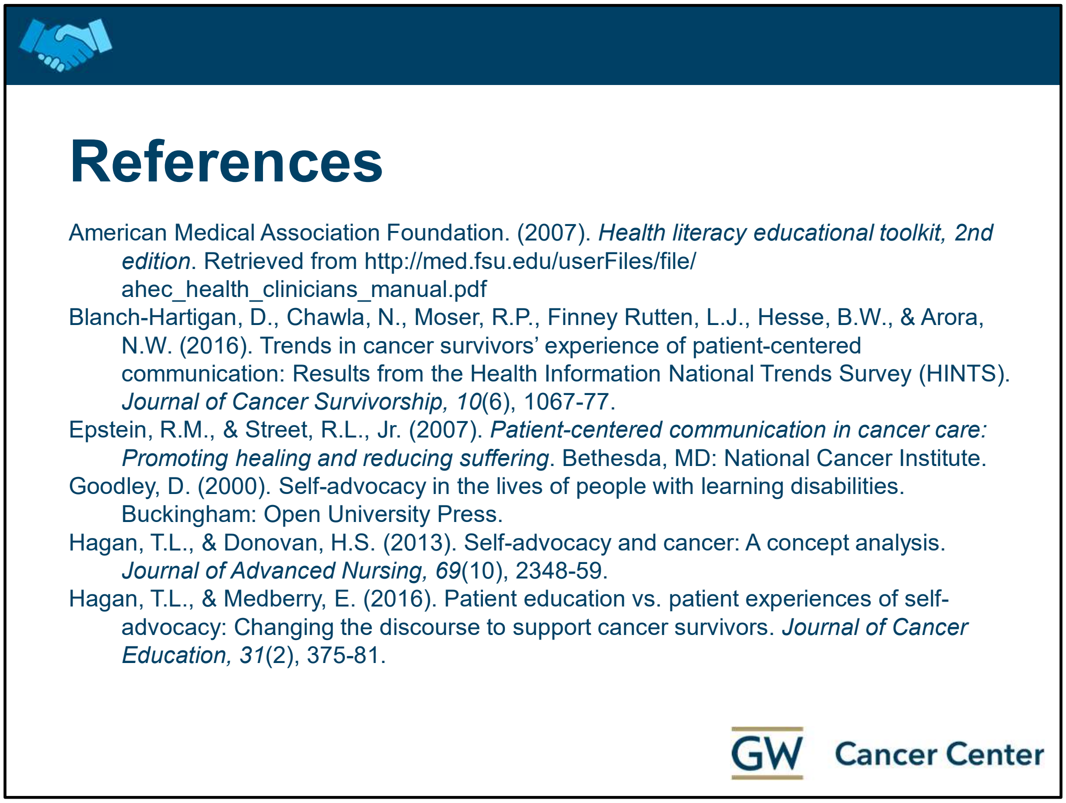
In this lesson, you learned to:

- Define patient self-advocacy
- Identify strategies to counsel and educate patients and their loved ones to engage in self-advocacy across the cancer care continuum



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Here is the full reference list of sources cited in this lesson.

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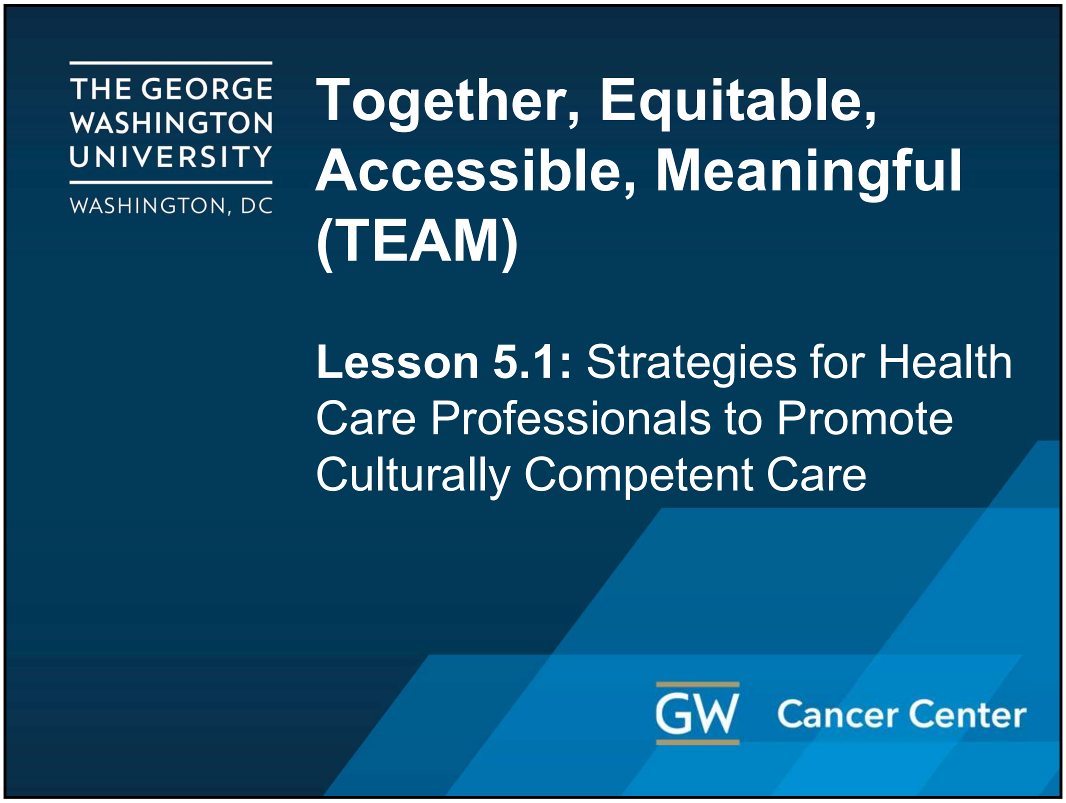

THE GEORGE
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WASHINGTON, DC

Together, Equitable, Accessible, Meaningful (TEAM)

Lesson 5.1: Strategies for Health Care Professionals to Promote Culturally Competent Care

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Welcome to Module 5, Lesson 1: Strategies for Health Care Professionals to Promote Culturally Competent Cancer Care.

Acknowledgments

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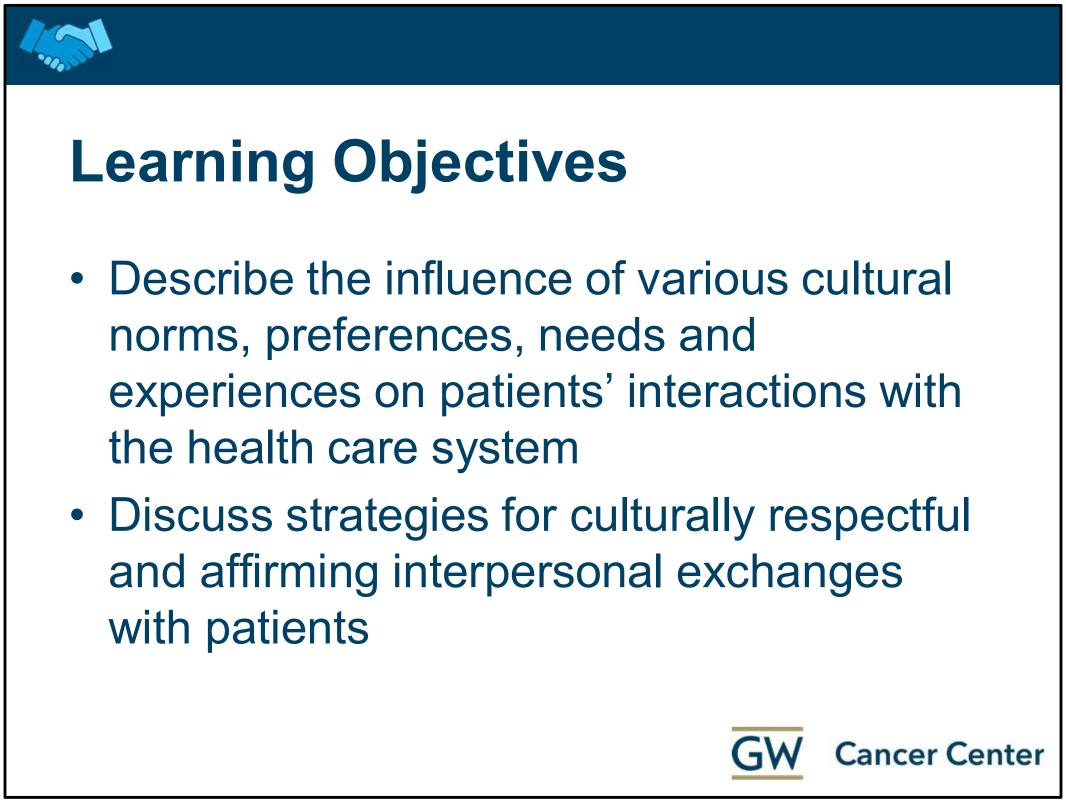

Learning Objectives

- Describe the influence of various cultural norms, preferences, needs and experiences on patients’ interactions with the health care system
- Discuss strategies for culturally respectful and affirming interpersonal exchanges with patients

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After completing this lesson, you will be able to:

- Describe the influence of various cultural norms, preferences, needs and experiences on patients’ interactions with the health care system
- Discuss strategies for culturally respectful and affirming interpersonal exchanges with patients

Recap

Cultural competency in health care:

> “the ability of systems to provide care to patients with diverse values, beliefs and behaviors, including ***tailoring delivery to meet patients’ social, cultural, and linguistic needs***.”

Betancourt, Green, & Carrillo, 2002.

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Cultural competency in health care has been described as “the ability of systems to provide care to patients with diverse values, beliefs and behaviors, including tailoring delivery to meet patients’ social, cultural, and linguistic needs.”

Up until this point in the training, we have highlighted the second part of this definition – the social, cultural and linguistic needs of patients – and presented strategies to address them. The figure on the screen highlights strategies we have presented in the course thus far [pause here].

In this lesson, we will look at the first half of the definition of cultural competency – providing care to patients with diverse values, beliefs and behaviors.

Lessons	Strategies
Patient Engagement in Research	• Community Based Participatory Research (CBPR) ○ Create reciprocal relationships ○ Involve communities in all stages ○ Methods: part of research team, advisory groups, FG/interviews, pilot testing • Increase minority participant representation ○ Physician referrals for clinical trials ○ Ask questions about minority status in cancer surveillance ○ Federal funding/workforce development ○ Partner with community-based organizations
Patient Engagement in Cancer Care	• Engage in two-way communication ○ Ask open-ended questions ○ Ask patients' perspective ○ Confirm your understanding of patients' views ○ Speak with empathy • Utilize the National Cancer Institute (NCI) model for cancer care communication, the nine actions to patient-centered consultations and the organizational level drivers that promote shared decision-making
Determinants of Inequity	• Understand the social determinants of health and social determinants of equity • Understand factors that contribute to population cancer disparities ○ Lack of research ○ Interpersonal and systemic barriers ○ Discrimination and oppression
Implicit Bias	• Become aware of bias • Individuation • Perspective-taking • Proactively work with patients and families from different backgrounds than yours • Counter-stereotypes/non-stereotypical thinking • Organizational commitment to counter bias (that normalizes bias)

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Lessons	Strategies
Intersectionality	• Approach each patient as an individual • Acknowledge all identities that shape a patients' experiences • Ask questions about all aspects of an individual's psychological, social and medical histories • Organizational drivers ○ Build in workflows that allow the patient to have multiple touch points with the health care system ○ Make changes to resources or the clinical environment with attention paid to intersectionality
Spotlight on Inequities Among Sexual and Gender Minorities (SGM), Black and African American and Latino Individuals	• Draw upon community/social support • Draw upon areas of resiliency • Recognize the role of spirituality • Tap into connectedness of community (patient gaining and giving support)
Aids in Communication	• Adhere to national policies/standards (CLAS, Sect. 1557, JCo) • Employ effective communication techniques: ○ Plain language ○ Teach-back method ○ Ask Me 3 ○ Use medical interpreters or devices • Use patient navigators • Organizational commitment to health literacy
Patient Self-Advocacy	• Support and ensure patients: ○ Have skills, resources, supports and motivation to advocate for themselves ○ Can talk about their values and priorities ○ Are part of the health care team ○ Have resources to support themselves and others • Remember there is no "ideal" self-advocate

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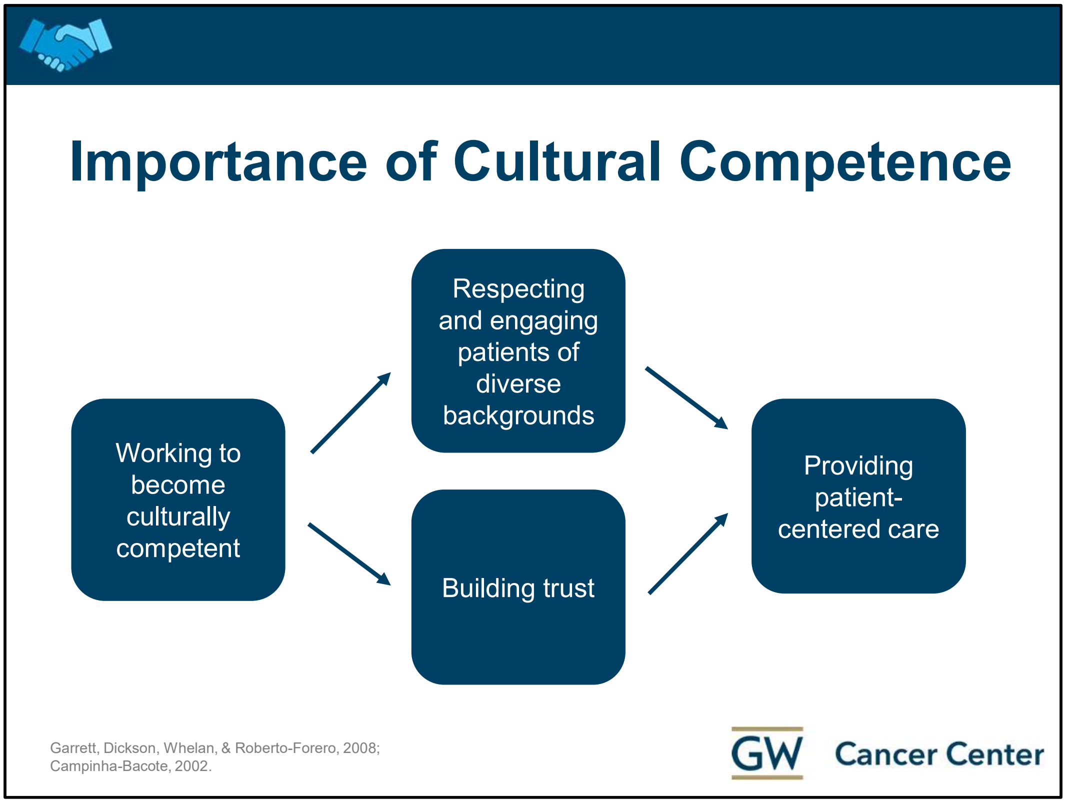

Importance of Cultural Competence

Working to become culturally competent

Respecting and engaging patients of diverse backgrounds

Building trust

Providing patient-centered care

Garrett, Dickson, Whelan, & Roberto-Forero, 2008;
Campinha-Bacote, 2002.

The ability to provide health care services in ways that respect different cultural needs and preferences is critical. Often patients can have negative experiences when providers, administrators and health care organization do not consider culture.

Taking steps to become culturally competent is important for anyone who works in a health care setting. It directly relates to the ability to respect and engage culturally and ethnically diverse patients during interactions and help patients build trust with providers to result in effective care.

What does cultural competence mean?

~~Competence reached~~

Continuous learning!

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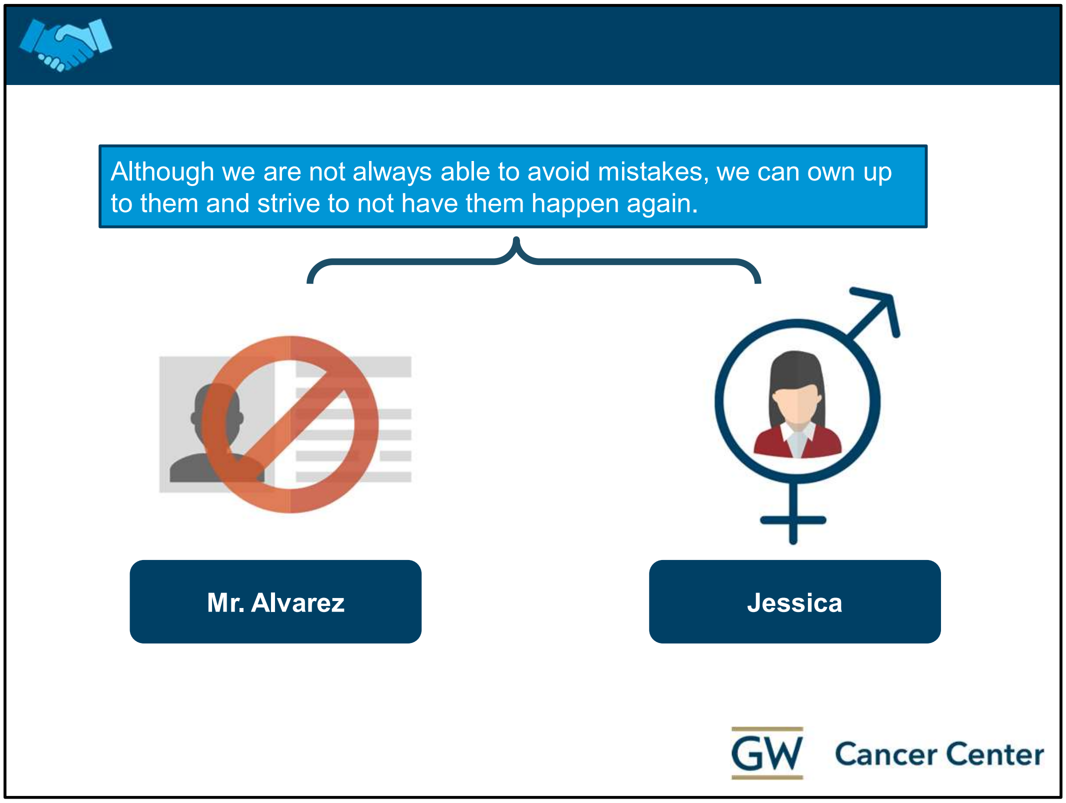
Being culturally competent does not mean we reach a milestone where we are fully knowledgeable of diverse patient needs and experiences or perfectly capable of delivering appropriate care.

Cultural competence is an ongoing process. But, there are frameworks and models that individuals and organizations can follow to improve upon cultural competence, which we will discuss in this and the next lesson.

We all make mistakes in these cross-cultural interactions. The key is to acknowledge these mistakes, learn from them and change practice in the future. For example, referring to Jessica, a transgender woman, as “Mr. Alvarez” because her name on her insurance card is Michael. Calling Jessica “Michael” may cause her to feel embarrassed or uncomfortable when being called into her appointment. This can then set a negative tone for her entire appointment. We are not always able to avoid mistakes like using the wrong name for a person. Yet, we can own up to these mistakes and work so that they do not happen again.

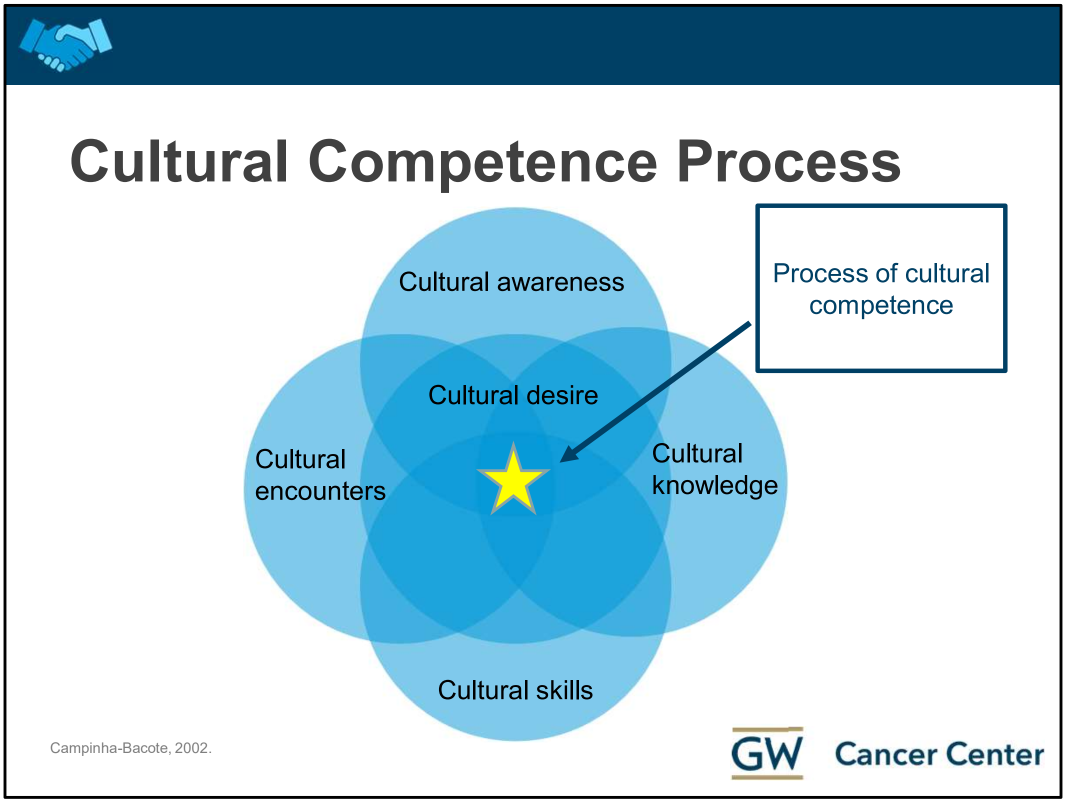
While there are many terms used to describe how to approach care with patients from different cultures, we will use the term cultural competency because this term is commonly used when it comes to policies, legislation and funding to address cross-cultural care.



Although we are not always able to avoid mistakes, we can own up to them and strive to not have them happen again.

Mr. Alvarez

Jessica



Cultural Competence Process

Cultural awareness

Cultural desire

Cultural encounters

Cultural knowledge

Cultural skills

Process of cultural competence

Campinha-Bacote, 2002.

Gaining cultural competence can be thought of as a model of overlapping circles. At the very center, the process of cultural competence occurs when increased cultural awareness, knowledge, skill and encounters come together and are reinforced by cultural desire.

Let’s briefly walk through the steps that comprise the process of enhancing cultural competence:

- **Gaining cultural awareness**. Cultural awareness requires us to examine our own cultural and professional backgrounds. By doing this we recognize assumptions, biases and prejudices that we hold about people who are different from us – as we have just talked about in the last lesson.

- **Gaining cultural knowledge**. Gaining knowledge is the process of seeking out information on diverse cultural groups to establish an educational foundation for their care. This can include learning about health-related beliefs and cultural values, as well as differences in risks, rates of disease and effective health interventions, to inform care recommendations.

- **Gaining cultural skill**. Cultural skill entails the ability to do a cultural assessment on an individual patient. This includes the collection of important cultural information, such as perceived cause of illness and healing traditions, then working to tailor care that recognizes cultural differences.

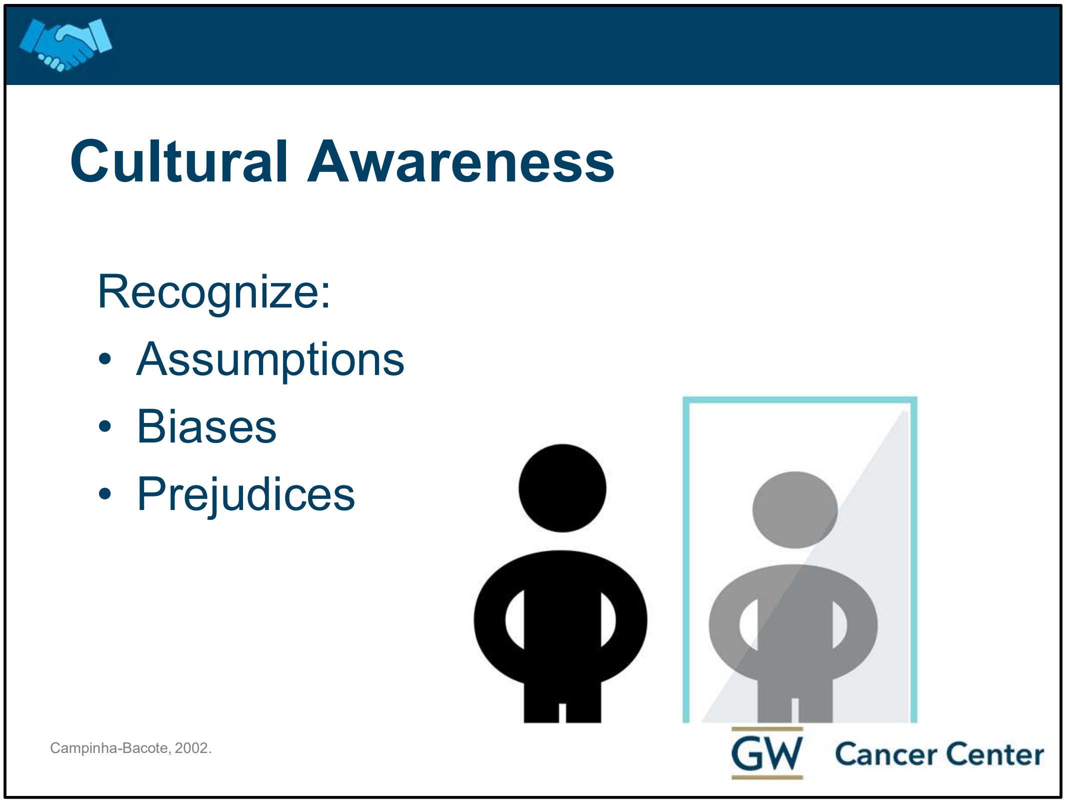
- **Having cultural encounters**. Having cultural encounters means directly engaging in interactions with people from diverse backgrounds who are living with cancer. Through these encounters, we can gain cultural knowledge and cultural skill.

- **Possessing a cultural desire**. This step relates to all other steps. It moves us to provide culturally competent care. Cultural desire is a person's motivation to *want* to, rather than have to, engage in the processes to become culturally competent. This step can be boiled down to the idea that "people don't care how much you know until they first know how much you care."

This lesson can help learners take the first steps in the process of becoming culturally competent. We will provide examples to increase cultural awareness and knowledge and present some common examples of cultural beliefs, values and norms that affect the health care interaction.

We will also offer strategies for health care professionals to interact with patients in ways that align with these cultural needs and preferences. However, this lesson does not provide a complete picture of the experiences and views of all patients of diverse cultural backgrounds.

Examples are meant to provide diverse cases in cancer care and spark your own self-reflection, but are not meant as generalizations about cultures or groups of people.



Cultural Awareness

Recognize:

- Assumptions
- Biases
- Prejudices

Campinha-Bacote, 2002.

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Cultural Knowledge

Health-related beliefs and cultural values

Disease risks and rates

Effective health interventions

Educational foundation for culturally competent care

Campinha-Bacote, 2002.

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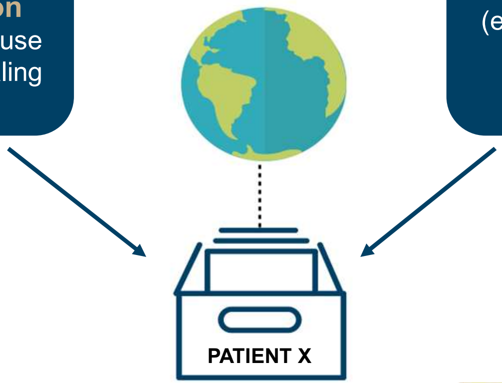
Cultural Skill

Collect relevant cultural information
(perceived cause of illness, healing traditions)

Tailor Care
(exams, physical contact)



Campinha-Bacote, 2002.

Cultural Encounters

Engage in interactions with people from diverse backgrounds

↑ Cultural knowledge
↑ Cultural skill

Campinha-Bacote, 2002.

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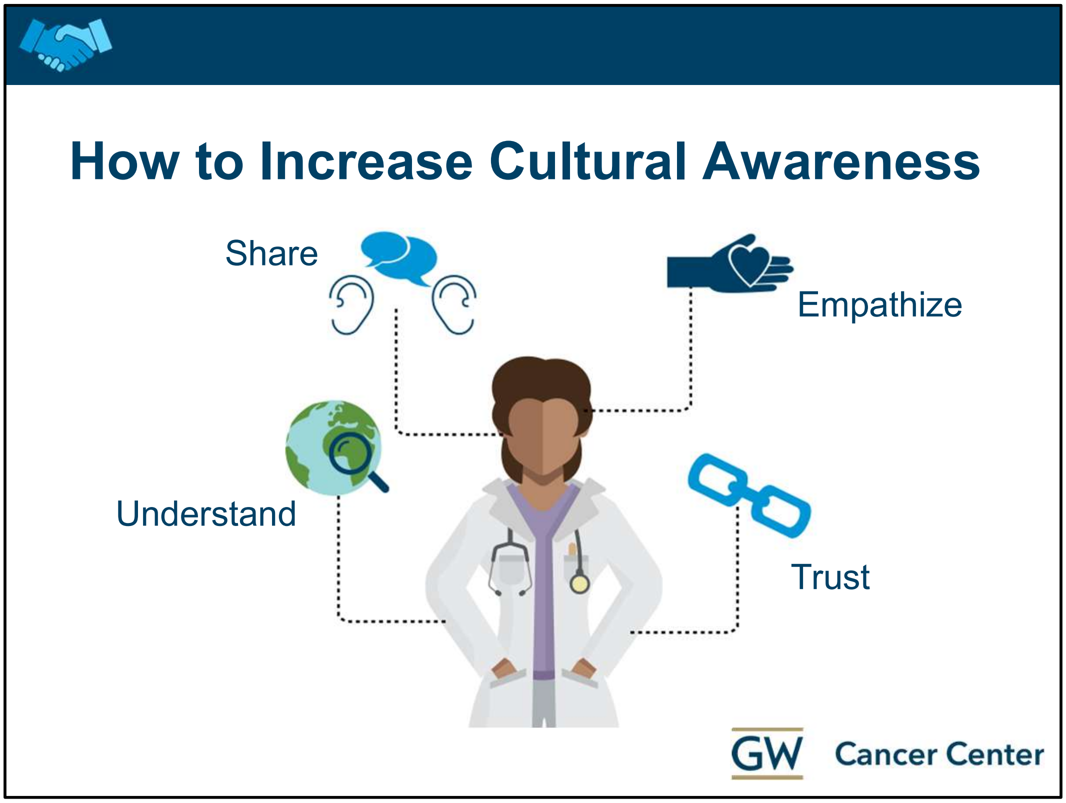
Cultural Desire


Desire **to become culturally competent**

"People don't care how much you know until they first know how much you care."

Campinha-Bacote, 2002; Campinha-Bacote, 1999.



How to Increase Cultural Awareness

Share

Empathize

Understand

Trust

A starting point in any interaction in the health care setting is to try to understand the patient’s world.

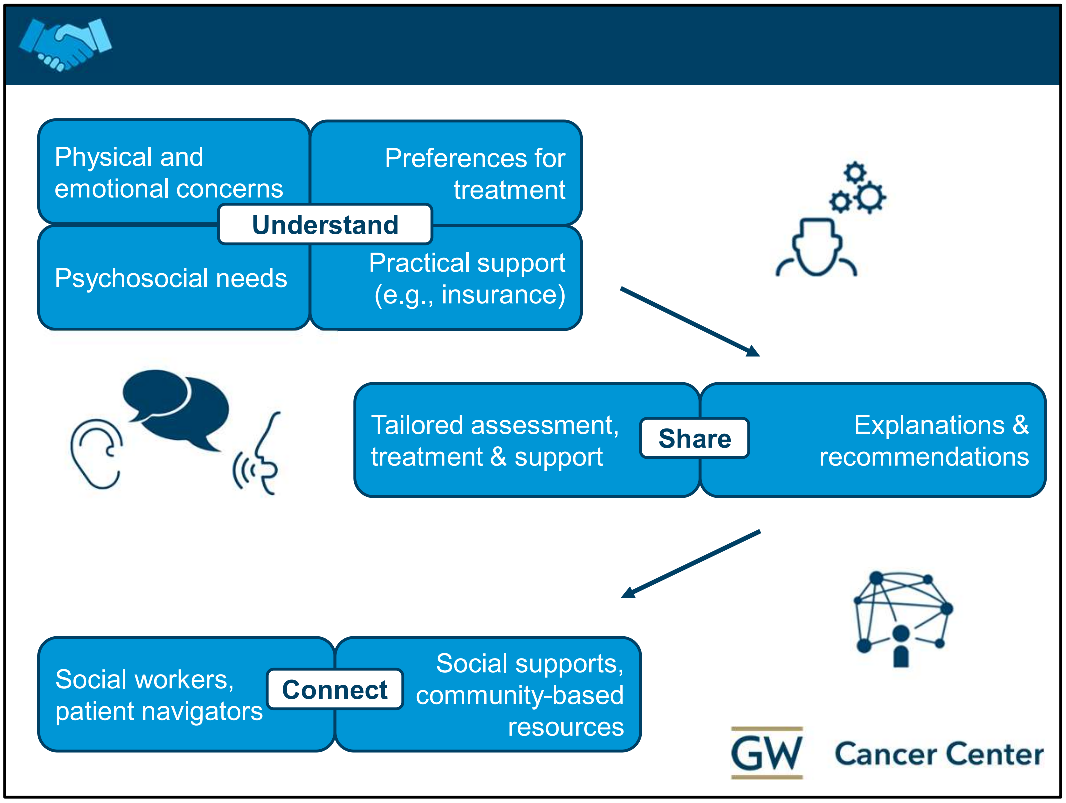
This means their social, cultural and environmental contexts that shape their perceptions, concerns and needs. By providers reflecting their understanding of the patient’s world back to the patient, health care professionals can set a tone of empathy and establish trust.

Providers can then ask patients about their views of the health care issue or procedure in question and patients may be more willing to reveal their worries and health practices to providers. This reciprocal process enhances ideal interactions and effective care.

In the case of diagnosis and treatment decision-making, providers can ask patients about their physical and emotional concerns surrounding the diagnosis, preferences for treatment options, psychosocial needs and support, insurance coverage and financial concerns to best support and optimize their care.

After gaining this understanding, providers can tailor assessment, treatment and support to patients’ needs. Providers can frame explanations and recommendations in ways that patients understand and appreciate, such as using strategies discussed in the aids in communication lesson.

Providers can call upon other members of the health team and additional resources to help patients in making decisions that are clinically appropriate but also meet patients' needs. For example, health care professionals like social workers and patient navigators can schedule appointments with patients to have in-depth discussions. During these discussions, navigators or social workers can identify social supports and community-based resources and refer patients to them.



Physical and emotional concerns

Preferences for treatment

Understand

Psychosocial needs

Practical support (e.g., insurance)

Tailored assessment, treatment & support

Share

Explanations & recommendations

Social workers, patient navigators

Connect

Social supports, community-based resources

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Stigma

Ashing-Giwa et al., 2004.

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Let’s first explore stigma in many aspects of cancer care. Stigma may deter cancer screening or treatment for people of various cultures. For instance, cultural taboos about talking about or touching areas of one’s body can often result in the avoidance of self-exams or screenings for cancer in certain Latino and Asian cultures. There is also stigma surrounding the diagnosis of cancer. People from some cultures may view it as a curse from God.

<u>Strategy</u>: To understand patients’ beliefs and experiences and set the stage for a care partnership, health care professionals should:

- Ask questions in an open-ended, respectful and empathetic manner about the patient and family's view of the cause of the illness, what they call the problem, and when and how the problem started; and
- They should also: Seek advice with respect to care preferences, from the patient and their loved ones and from people that serve as cultural mediators (such as patient navigators or Community Health Workers).

Stigma is also linked with the effects of cancer treatment.

For example, in the National Cancer Care TEAM Survey, one provider explained, “Certain patients from the Muslim culture have a very hard time accepting hair loss related to chemotherapy. I personally have an elderly Muslim woman patient who tells me if she loses her hair it is a shame to her family. She explained to me that in her culture they would shave a woman's head if she did something disrespectful to her family. She is very upset when her hair comes out from chemotherapy treatments.”

Due to stigma about hair loss, patients may decide to decline chemotherapy, despite this being the clinical recommendation.

Strategy: Providers have the responsibility to share evidence-based information with patients regarding treatment recommendations, the benefits and risks of this treatment and ways to manage side effects (like hair loss after chemotherapy). However, ultimately, health care professionals must accept patients’ rights to determine the course of their care, including refusing care.

In the National Cancer Care TEAM Survey, many oncology providers expressed frustration in wanting to deliver care they felt was medically necessary or that promoted the best chance for survival. However, per medical professional codes of ethics, providers have a responsibility to share all treatment options in a clear and balanced manner (including no treatment), and have to respect the wishes of patients and their loved ones in determining their care.

As we've discussed throughout this training, it is important to remember that people who identify with a cultural, racial/ethnic or religious group are not all alike, so another patient with similar demographics (from a similar background) may not have the same experience regarding hair loss and shame as the what was experienced by the patient presented in the example.

Also, since hair loss can be upsetting to so many women of many different cultural backgrounds, providers can share resources with patients to help them cope with emotions surrounding this side effect if they do decide to have chemotherapy. This can include support groups.

Strategies:

Ask open-ended questions

- What do you think caused the illness?
- What do you call the problem?
- When and how did the problem start?

Seek advice on care decisions

- Patient & loved ones
- Patient navigators, community health workers

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Strategy: Fulfill responsibility to share evidence-based information on:

- Treatment recommendations
- Benefits and risks of treatment recommendations
- Side effects and ways to manage them

Respect patient right to determine course of care, including refusing care

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Family Roles

Note: Placeholder image – Kelli to download similar one

GW Cancer Center, 2017.

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Different family structures and roles can also affect how the patient interacts with health care professionals.

For instance, an oncology provider in the National Cancer Care TEAM Survey said, “I was working with a Hmong family and assisting them in making some healthcare decisions. The patient was not responding at all to my questions but looking at one of the males in the family. I understood from an in-service [staff training] on cultural differences that Hmong families always [look] to the eldest male for decision making.”

Even when patients have the power to make care decisions, they may turn to older family members to make these decisions.

<u>Strategy</u>: Providers can start conversations with patients and family members by explaining how the health care system works when it comes to family member involvement.

For instance, it is often standard procedure that patients sign waiver forms if they wish to fully disclose their medical information to family members or include them in the decision-making process. Health care professionals can also set up a process of routinely and privately asking patients if and how they want their family to be involved. Medical interpreters or religious leaders can also assist in these conversations.

Providers have also reported that families in some cultures did not wish to tell their family member's diagnosis to them to prevent emotional distress.

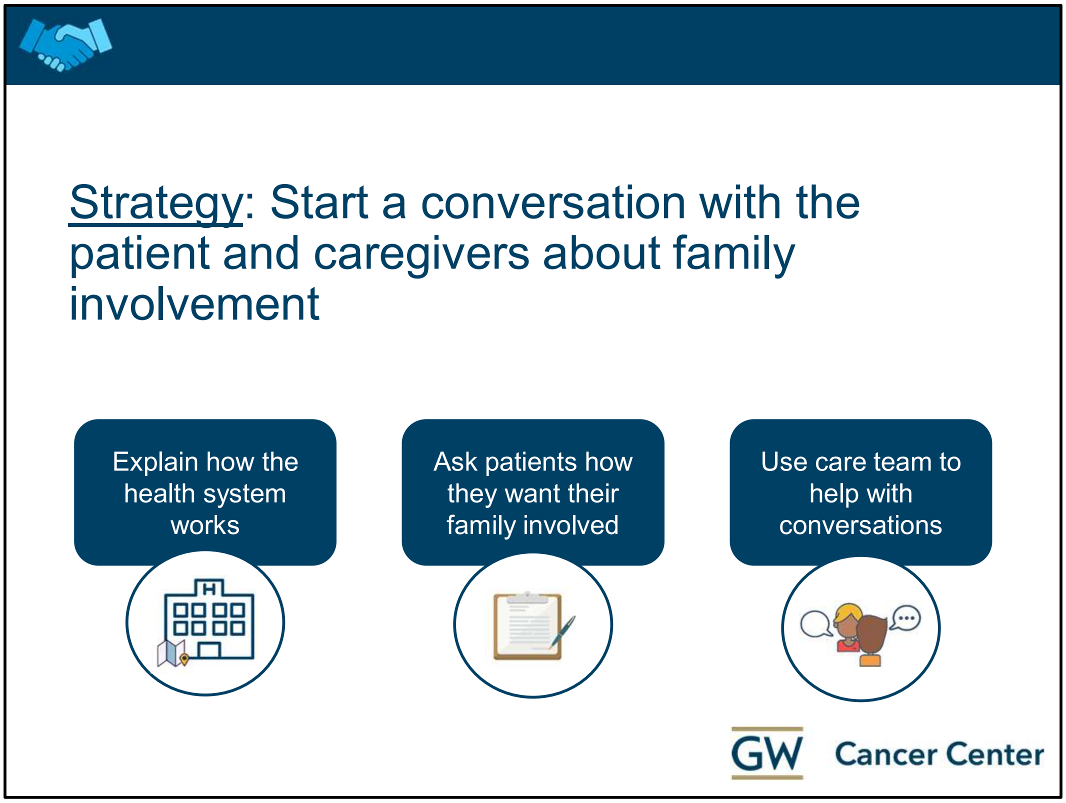
Strategy: In cases where family members do not want to tell the diagnosis to the patient, providers should talk with the family to understand the family's point of view in order to address anxiety and prevent the relationship from becoming combative. Again, interpreters can be helpful in guiding these conversations.

Discussions with family members must also explain the ethical issues of withholding information from a patient, patients' rights and steps providers must follow to ensure their own ethical behavior.

Providers should work with families to ensure they understand how the health care system works with respect to patient diagnosis (including an explanation of patient rights policies and the role of ethics committees). Then call upon organizational supports like ethics committees only if necessary. Providers should also communicate with patients directly to understand how they want to receive information.

Do they want it from providers directly?
With family members present?
Or only from family members?

These answers should guide how the provider decides to engage the patient in discussions about diagnosis.



Strategy: Start a conversation with the patient and caregivers about family involvement

- Explain how the health system works
- Ask patients how they want their family involved
- Use care team to help with conversations

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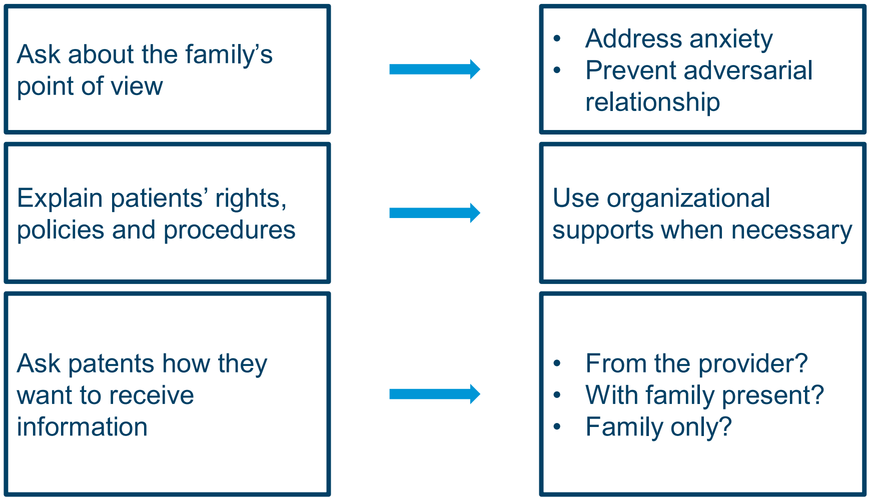
Strategies:



Ask about the family’s point of view →
- Address anxiety
- Prevent adversarial relationship

Explain patients’ rights, policies and procedures → Use organizational supports when necessary

Ask patents how they want to receive information →
- From the provider?
- With family present?
- Family only?

McCabe, Wood, & Goldberg, 2010.

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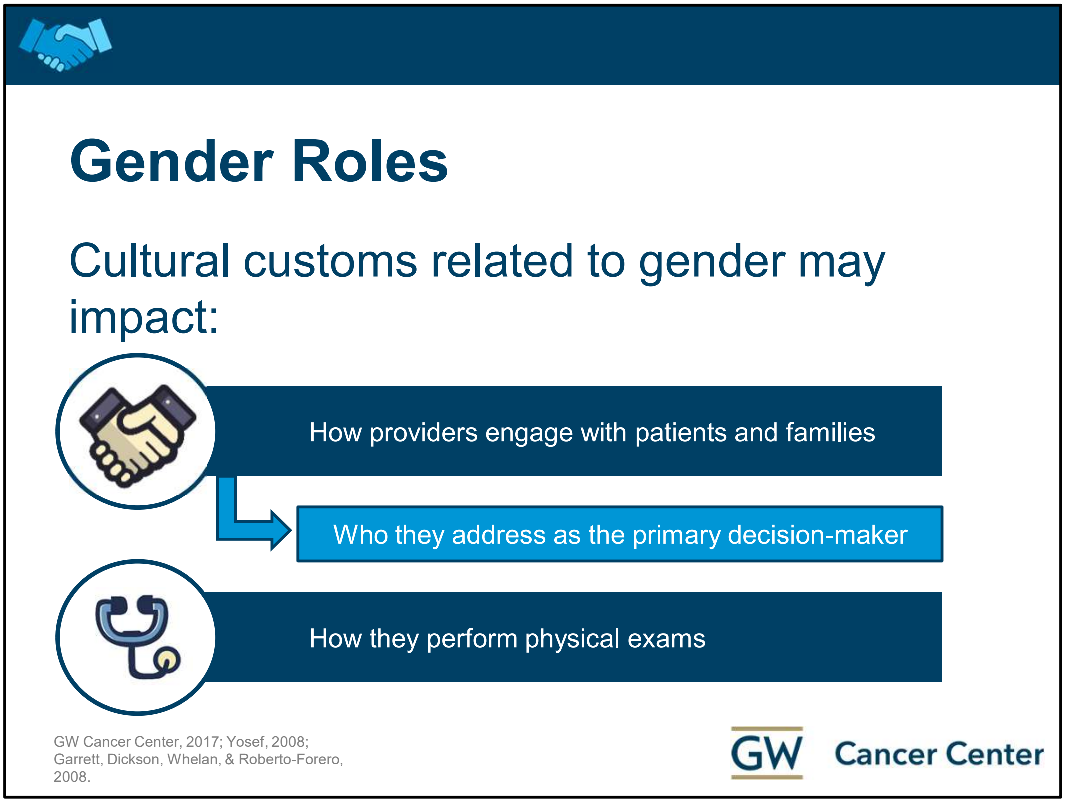

Gender Roles

Cultural customs related to gender may impact:

- How providers engage with patients and families
  - Who they address as the primary decision-maker
- How they perform physical exams

GW Cancer Center, 2017; Yosef, 2008; Garrett, Dickson, Whelan, & Roberto-Forero, 2008.

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Another cultural factor that often overlaps with family roles is gender customs. Providers may struggle when a patient's cultural customs related to gender are discordant with the way they are used to addressing or engaging patients and their families. For instance, a Muslim individuals beliefs may preclude them from shaking the hand of a provider of the opposite sex. Or, the husband of an Orthodox Jewish patient might prefer to speak with a member of his wife's health care team who is also male.

Cultural norms surrounding gender may also pose an issue when conducting physical exams.

For example, Iraqi refugee women in Philadelphia discussed the barriers and facilitators to cervical cancer screening during key focus groups. One participant explained her discomfort in interacting with a male provider for cervical cancer screening indicating that "If the doctor is male, I won't do it [cervical cancer screening]." [1]

In a study exploring barriers around breast cancer screening among Iraqi refugees at The Massachusetts General Hospital Chelsea HealthCare Center, one finding revealed that "while a few women mentioned modesty, they provided the important insight that their Islamic faith was ultimately facilitative of their health activities, rather than a hindrance." [2]

<u>Strategy</u>: Health care professionals – whether clinicians, administrators or other

professionals – can help providers perform physical exams that are tailored to cultural needs and preferences by:

- Consulting or taking cues from patients regarding frequency and appropriateness of eye contact and touch;
- Verbally saying when the clinician is starting a physical exam and explicitly getting the patient's agreement to perform the exam;
- Respecting modesty issues related to undressing and offering gowns that provide greater body coverage; and
- Providing options, where possible, for patients to be seen by providers of the same gender.

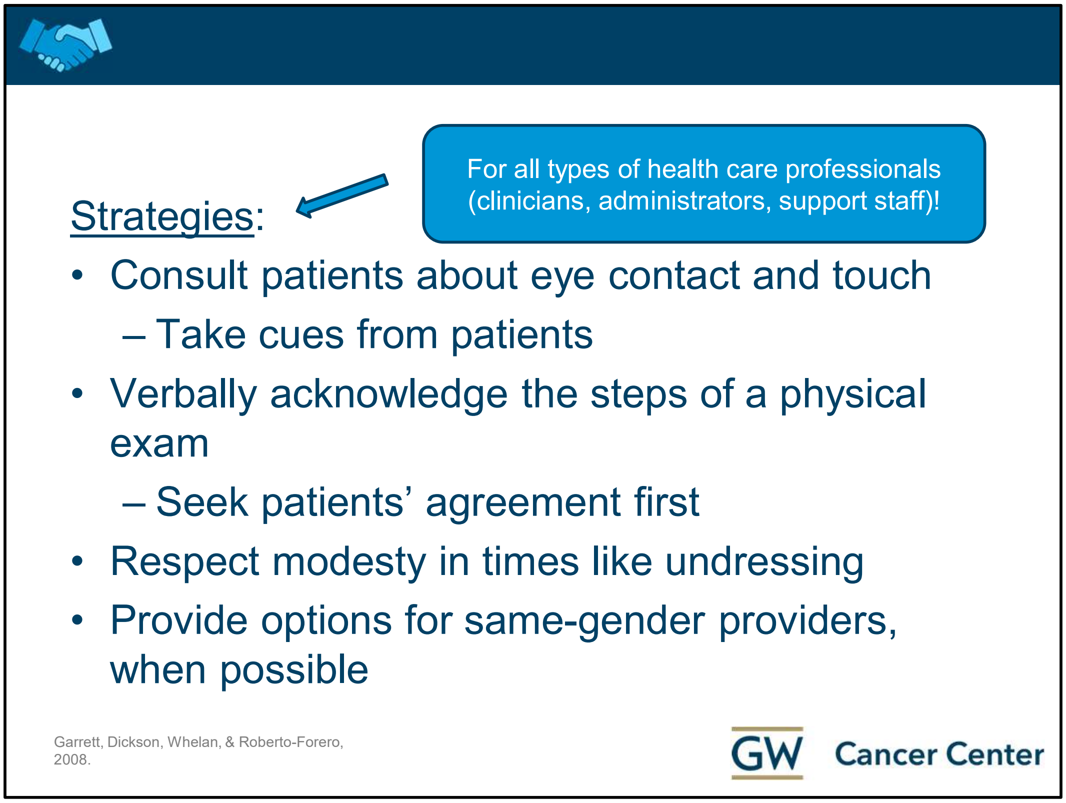
Gender shapes a person's care preferences not just through cultural norms regarding gender, but also in the views about gender that that person holds.

For example, some lesbian, bisexual or transgender individuals may choose to not have breast reconstruction surgery after their mastectomy (choosing to "go flat") because they find that it is more affirming of their view of their gender or their body image.

This choice to "go flat" is not limited to sexual and gender minority women either. This example is important to note because breast reconstruction surgery is so frequently recommended to breast cancer patients (often without recognition of any other option).

Strategy: Like we discussed in the lesson on Normalizing Implicit Bias, providers should be aware of and check their assumptions when interacting with any patient. Such as being cautious to not stereotype about patients' relationships, views of body image, preferences, values and so on. We can take steps to present options in a clear, balanced manner without pressure or judgment.

[1] http://centerforrefugeehealth.com/wp-content/uploads/2016/06/6-12-215-PM-Barriers-and-Facilitators-to-Cervical-Cancer-Screening-in-Middle-Eastern-Refugee-Women-Resettled-in-Philadelphia-A-Qualative-Analysis-of-Patient-and-Provider-Perceptions-Payton.pdf)
[2] http://www.massgeneral.org/cchi/assets/Sanja%20Breast%20Scrng%20Iraqi%20RJIMH%202011.pdf



For all types of health care professionals (clinicians, administrators, support staff)!

Strategies:

- Consult patients about eye contact and touch
  - Take cues from patients
- Verbally acknowledge the steps of a physical exam
  - Seek patients' agreement first
- Respect modesty in times like undressing
- Provide options for same-gender providers, when possible

Garrett, Dickson, Whelan, & Roberto-Forero, 2008.

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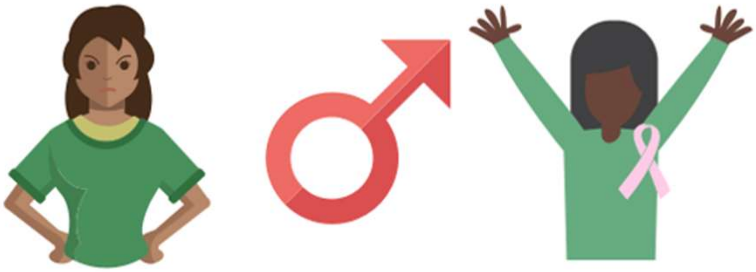
Gender Roles

View of gender also impacts care decisions



Rubin & Tanenbaum, 2011; Boehmer, Linde, & Freund, 2007; Taylor & Bryson, 2016.

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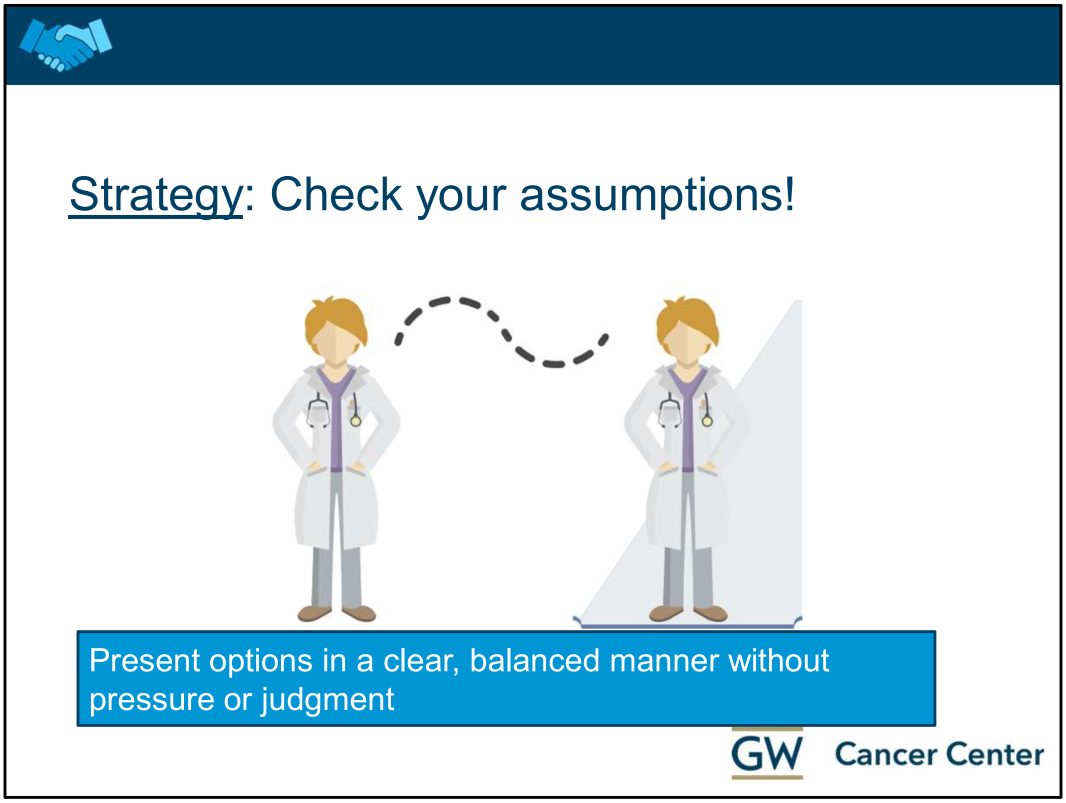
Flattopper® Pride, n.d.

Cancer Center



Strategy: Check your assumptions!

Present options in a clear, balanced manner without pressure or judgment

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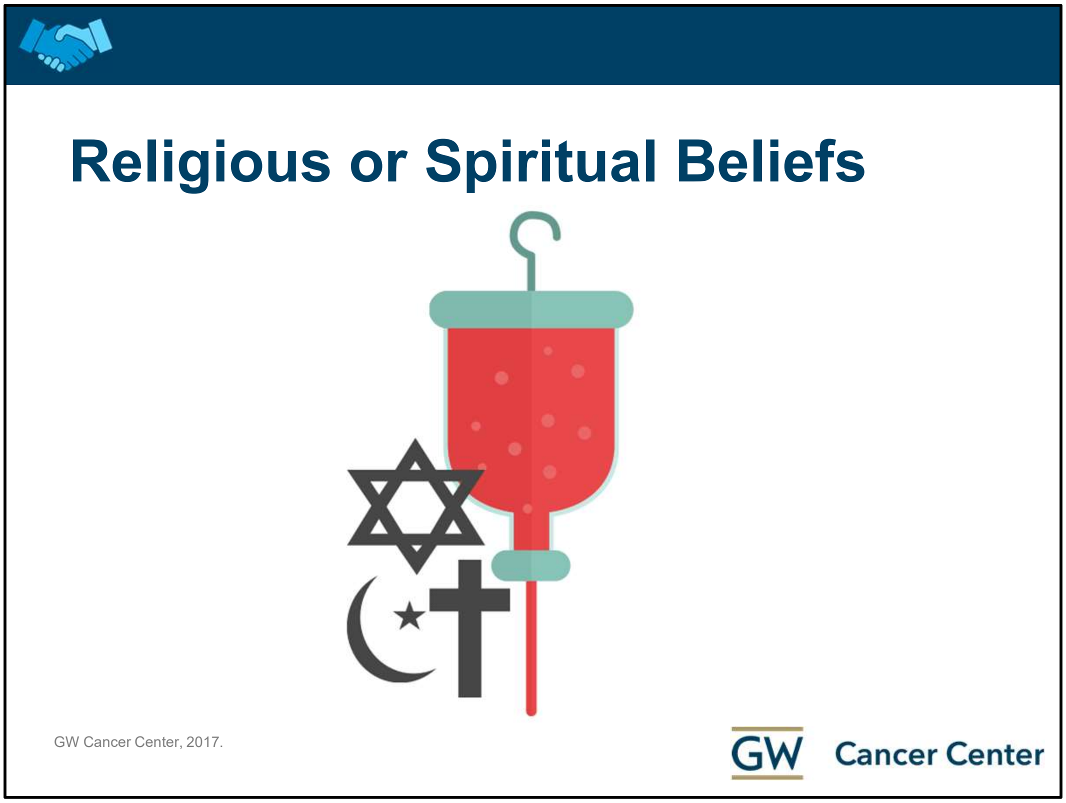


Religious or Spiritual Beliefs

GW Cancer Center, 2017.

GW Cancer Center

Patients’ religious beliefs can play a large role in cancer treatment.

For instance, a provider from the National Cancer Care TEAM Survey recounted a striking example: “Patients [of some religions] often refuse blood transfusions. We perform major abdominal surgeries and there are situations when blood products are needed intra-operatively. This particular woman was very explicit in saying that she would rather die from bleeding than to have a blood transfusion during surgery. I wasn't prepared for such a response, as I assumed in a life or death situation, she would agree to a blood transfusion.”

<u>Strategy:</u> With the support of other members of the health care team, community members, the patient and their loved ones, providers can offer treatment options that allow patients to decide what best meets their needs. By consulting others, providers can try to identify creative treatments that align with a patient’s religious beliefs but are still in line with medical recommendations.

For instance, providers can suggest that the patient consult with religious leaders or, in the case of the earlier example, use a protein substitute for blood transfusion.

In addition, sometimes patients will choose to use their cultural healing traditions as a complement to or in lieu of traditional Western medical treatment.

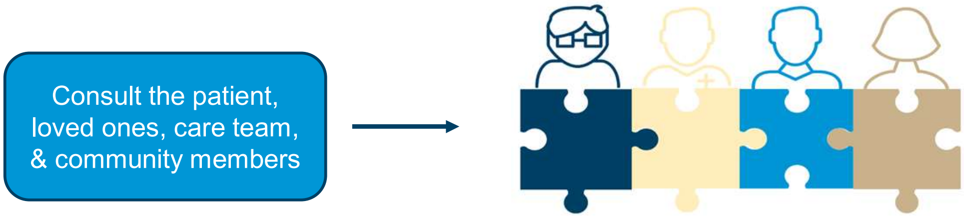
Strategy: To better understand patients' beliefs and values, providers can ask open-ended questions during the clinical visit. This can help gain a better sense of how patients may want to add in their own healing traditions. Working closely with and speaking regularly with other members on the team, such as navigators, nurses and social workers, is also important. These professionals are often aware of potential problems, can seek help and communicate issues back to clinicians.

For example, in the National Cancer Care TEAM Survey, one navigator said, "Often I am in the position to discuss the home remedies and have more time to listen to descriptions of symptoms in the 'patient's own words' so I try an[d] support them in continuing the behaviors that they find supportive, understanding possible interactions to help avoid problems and clearer communication of needs to the provider. I also try and help understand the nature of their support system and how it can be used to meet their individual needs during treatment and how other things with the cancer center and the community can supplement."

Health care professionals can also take the opportunity to discuss living will and medical power of attorney with patients and their families before treatment begins. This ensures that wishes are respected, known and legally documented, which can also help with communication between health care professionals, patients and families if an emergency situation were to arise during treatment.

Strategy:

Provide options for treatment to patients so they can make decisions of what best meets their needs



Consult the patient, loved ones, care team, & community members

GW Cancer Center, 2017; Amgen, Inc., 2012.

Cultural Healing Traditions

Note: Placeholder image – Kelli to download similar one

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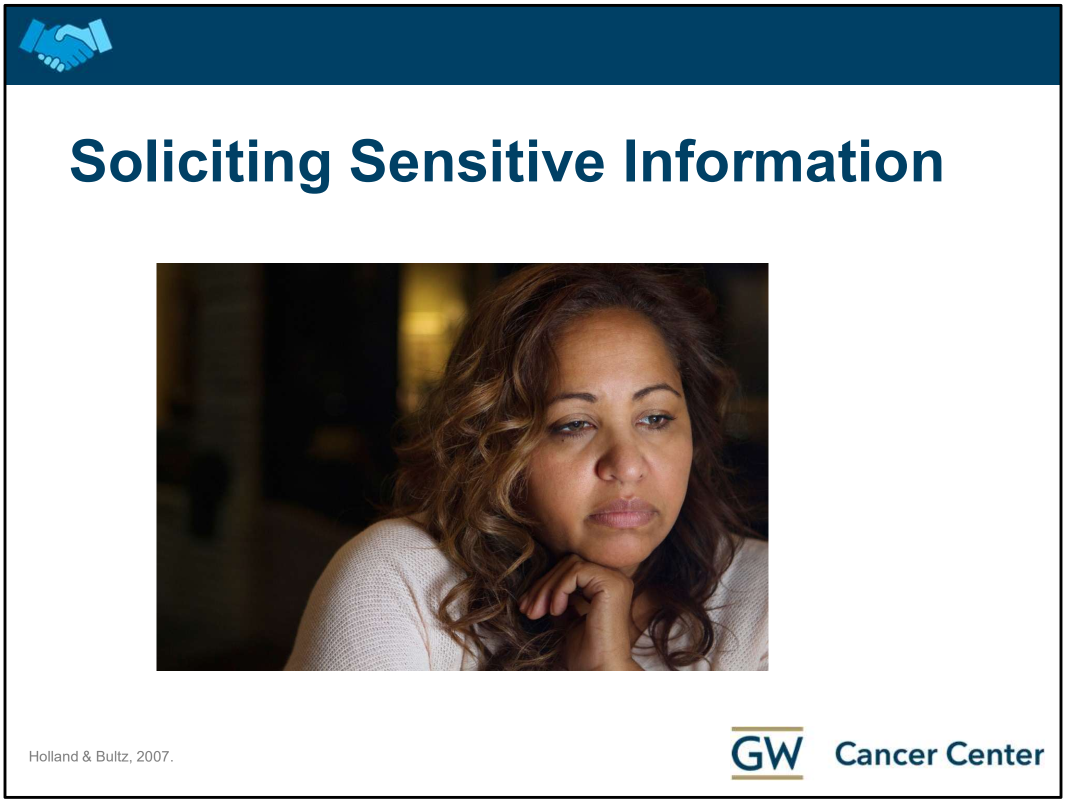
Strategy:

- Ask open-ended questions about patients' preferences regarding healing traditions
- Work closely with care team members like nurses, navigators and social workers

GW Cancer Center, 2017.

GW Cancer Center



Soliciting Sensitive Information

Holland & Bultz, 2007.

GW Cancer Center

We have looked at categories of stigma, family roles, gender norms and views and religious and/or spiritual beliefs to offer examples for strategies for culturally affirming care. At the most basic level, providing culturally affirming care involves asking about information that may be difficult for patients to talk about. For example, it can be difficult for patients to talk about mental health issues because there is often stigma around mental health. However, addressing mental health as a part of cancer care, including post-treatment survivorship, is critical.

<u>Strategy</u>: In understanding the need for a sensitive way to ask about mental health status, the National Comprehensive Cancer Network recommends a simple question of "How is your distress on a scale from 0 to 10?" Patients responded well to the umbrella term "distress" because it did not carry the same stigma as discussion of mental health. It is recommended that clinicians follow up with additional questions if patients report a score of four or higher.

Another example of soliciting important but sensitive clinical information is asking about sexual orientation and gender identity. It is important to understand a patient's identities to improve service delivery, increase knowledge of support systems, identify potential stressors or health risks, and encourage trust. In many situations, providers who do not know whether their patient is LGBTQI cannot deliver appropriate or complete services. For example, if a doctor does not know that a man engages in receptive anal sex, the patient will not be referred for an anal pap smear. On the other hand, when people do not feel safe being their whole selves, many lie about who they are or simply leave and forego treatment completely.

Strategy: An important first step to asking about sexual orientation and gender identity is to normalize these questions. By stressing that all health care professionals at the organization ask this of all patients, health care professionals may lessen patient worries of why they are being asked about their sexual orientation and gender identity. When asking the actual questions, leading national organizations suggest that health care professionals use a two-step method to ask about gender identity: First, by asking: "what is your current gender identity?" And then by asking, "what sex were you assigned on your original birth certificate?" This two-step method is affirming because the order of questions conveys to patients that a patient's internal sense of self is prioritized beyond the anatomy the patient was born with. Health care professionals must also remember to ask patients who share their gender identity whether it is acceptable to place that information into the medical chart. Some patients are not "out" to the rest of the world. Placing such information into a medical chart could be dangerous to their well-being if it is disclosed to the wrong person. In addition to keeping the patient safe, health care professionals should take care where gender identity information is stored within the chart to ensure that only staff members who must know this information have access to it.

Soliciting Sensitive Information

Identifying patients' sexual orientation and gender identity can help:

- Improve service delivery
- Increase knowledge of support systems
- Encourage trust

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Strategy: Two-step data collection

Ask every patient these questions – it's routine!

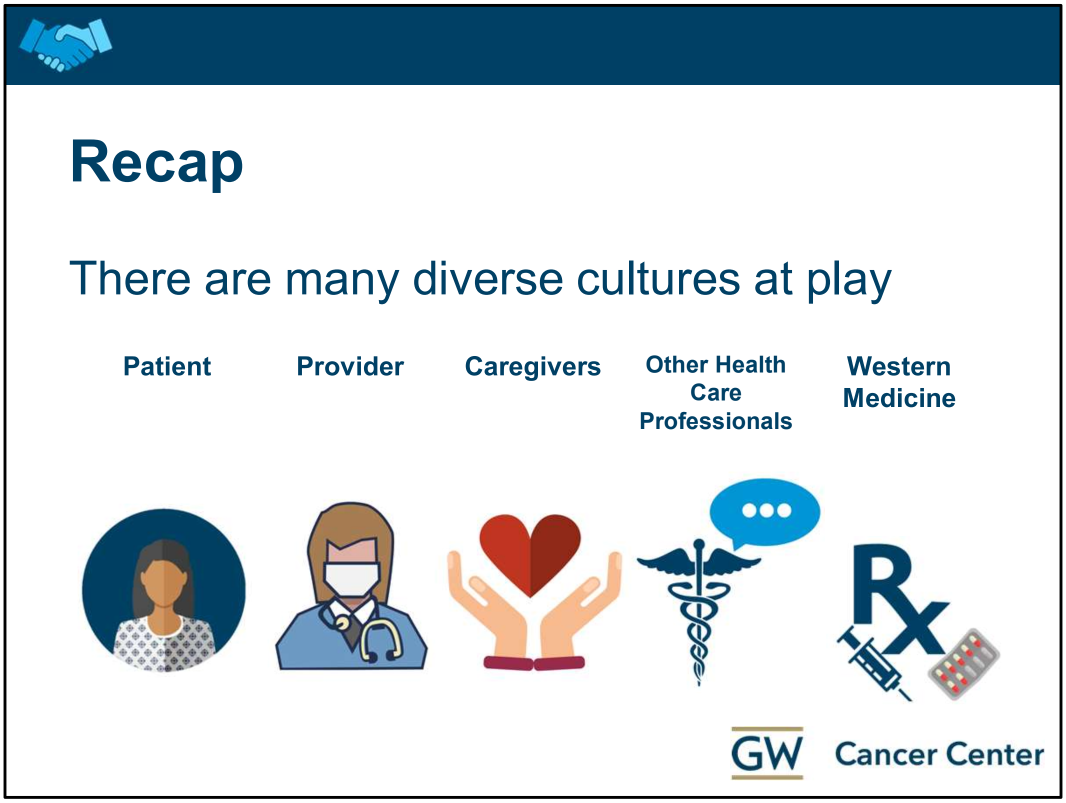
⚥ What is your current gender identity?

⚥ What sex were you assigned on your original birth certificate?

Respect patients' privacy & confidentiality!

Cahill et al., 2014; Deutsch, n.d.

Cancer Center



Recap

There are many diverse cultures at play

Patient

Provider

Caregivers

Other Health Care Professionals

Western Medicine

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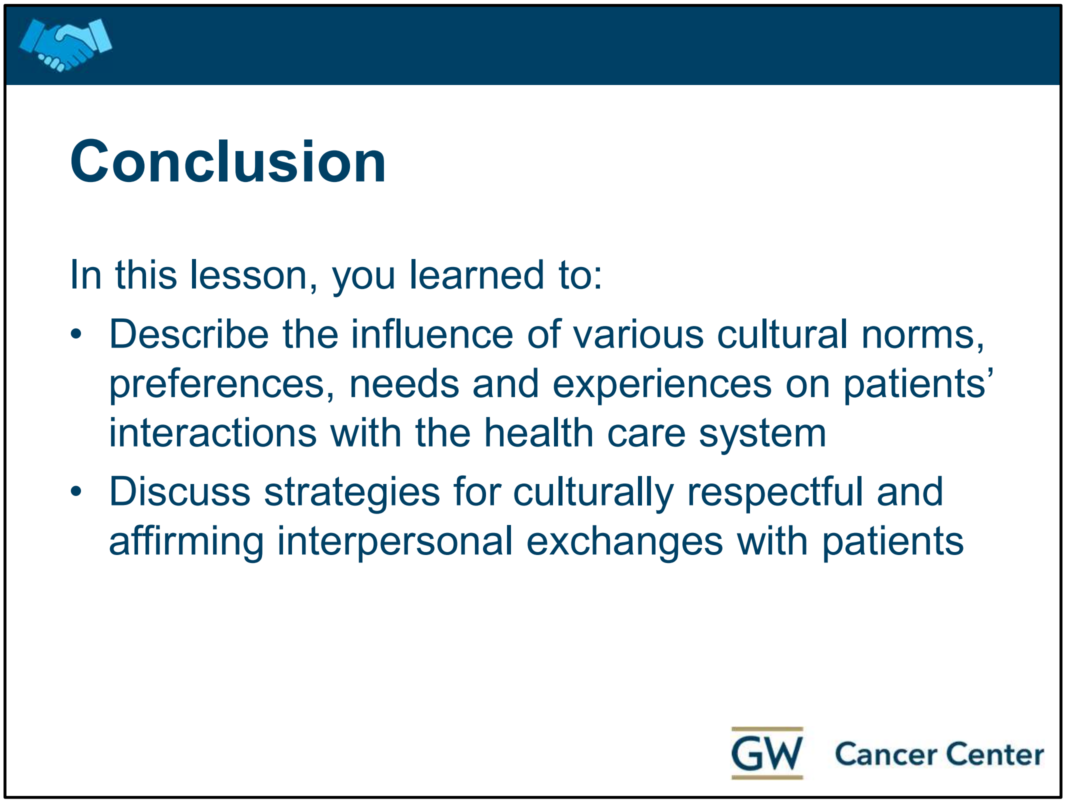
As we have seen through the examples, there are many cultural influences guiding a person’s interaction with the health system.

These influences will vary greatly by each person. It is also important to remember there are multiple cultures interacting during the medical visit. Those of the provider, the patient, caregivers present, other health care professionals present and the culture of Western medicine itself.

In the final lesson of the training, we will bring together the knowledge and skills gained throughout the previous lessons and discuss initiatives that organizations can undertake to enact institutional change that supports the provision of culturally competent, inclusive, equitable and patient-centered care for all of its patients.



Conclusion

In this lesson, you learned to:

- Describe the influence of various cultural norms, preferences, needs and experiences on patients’ interactions with the health care system
- Discuss strategies for culturally respectful and affirming interpersonal exchanges with patients

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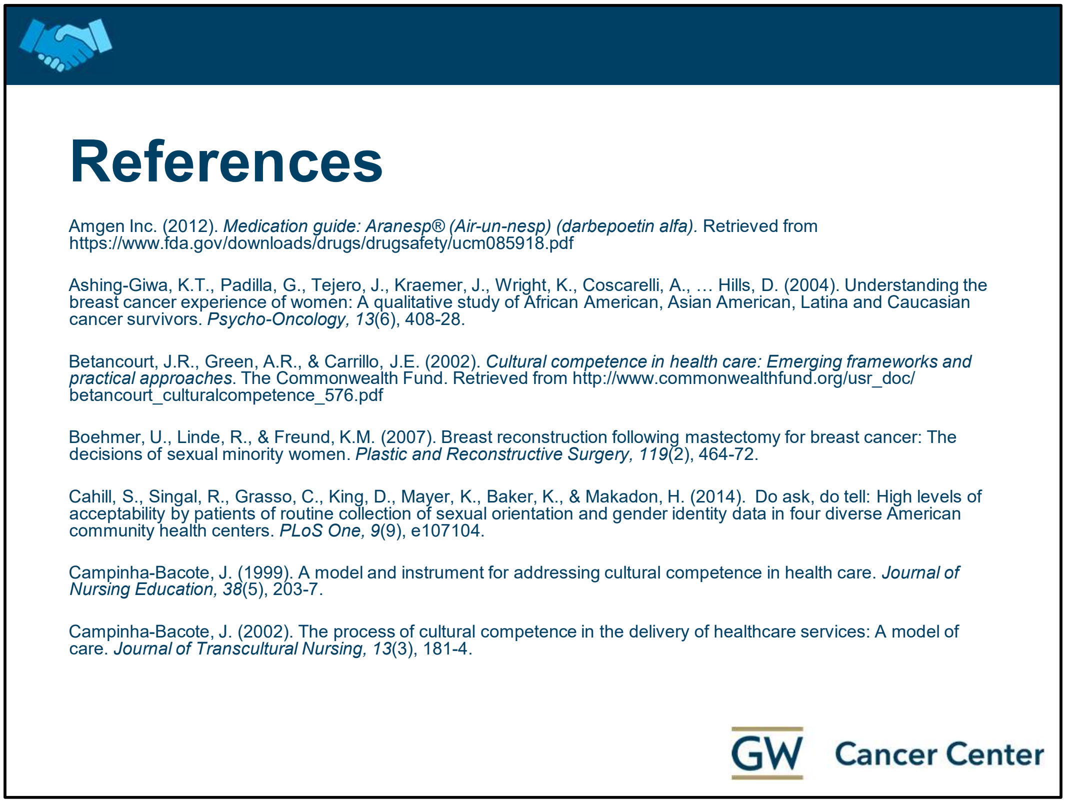
In this lesson, you learned to:

Describe the influence of various cultural norms, preferences, needs and experiences on patients’ interactions with the health care system

Discuss strategies for culturally respectful and affirming interpersonal exchanges with patients



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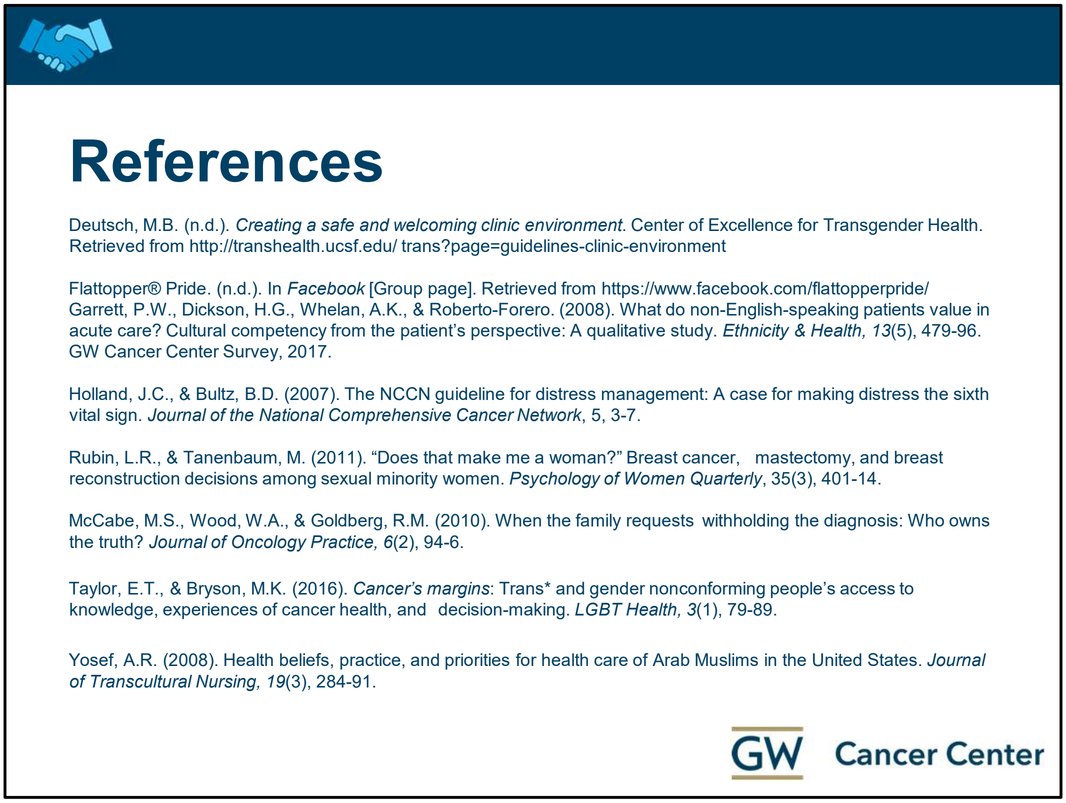

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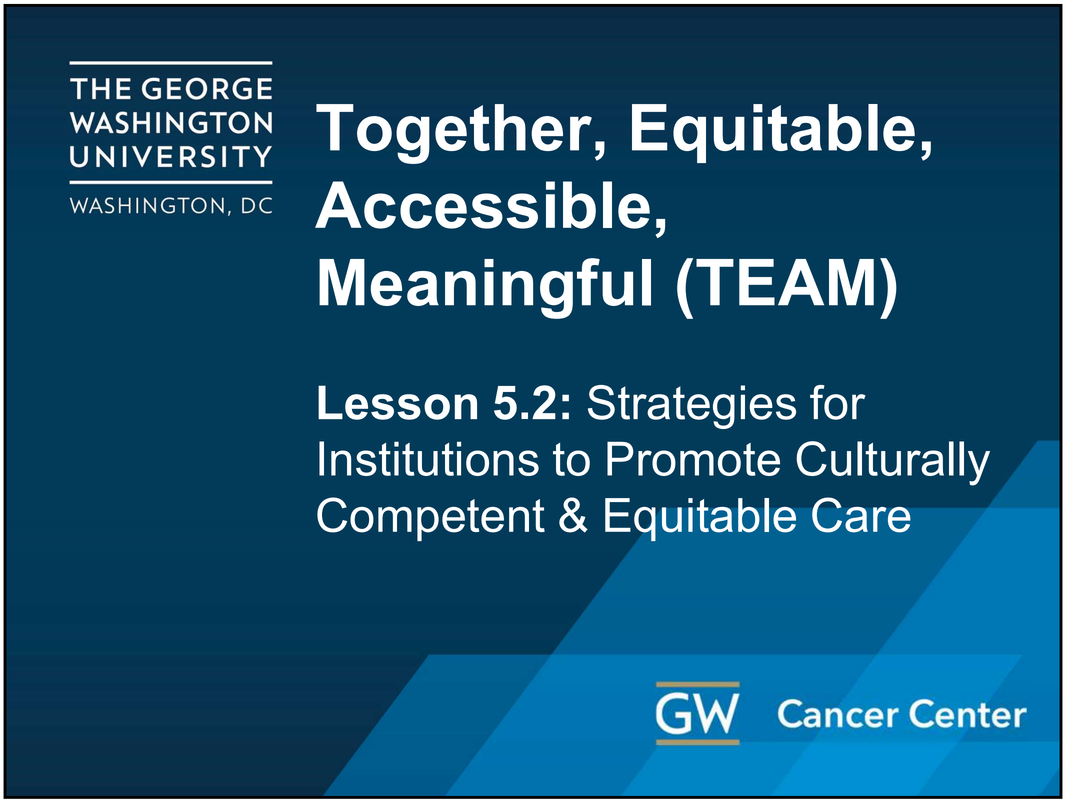

THE GEORGE
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WASHINGTON, DC

Together, Equitable, Accessible, Meaningful (TEAM)

Lesson 5.2: Strategies for Institutions to Promote Culturally Competent & Equitable Care

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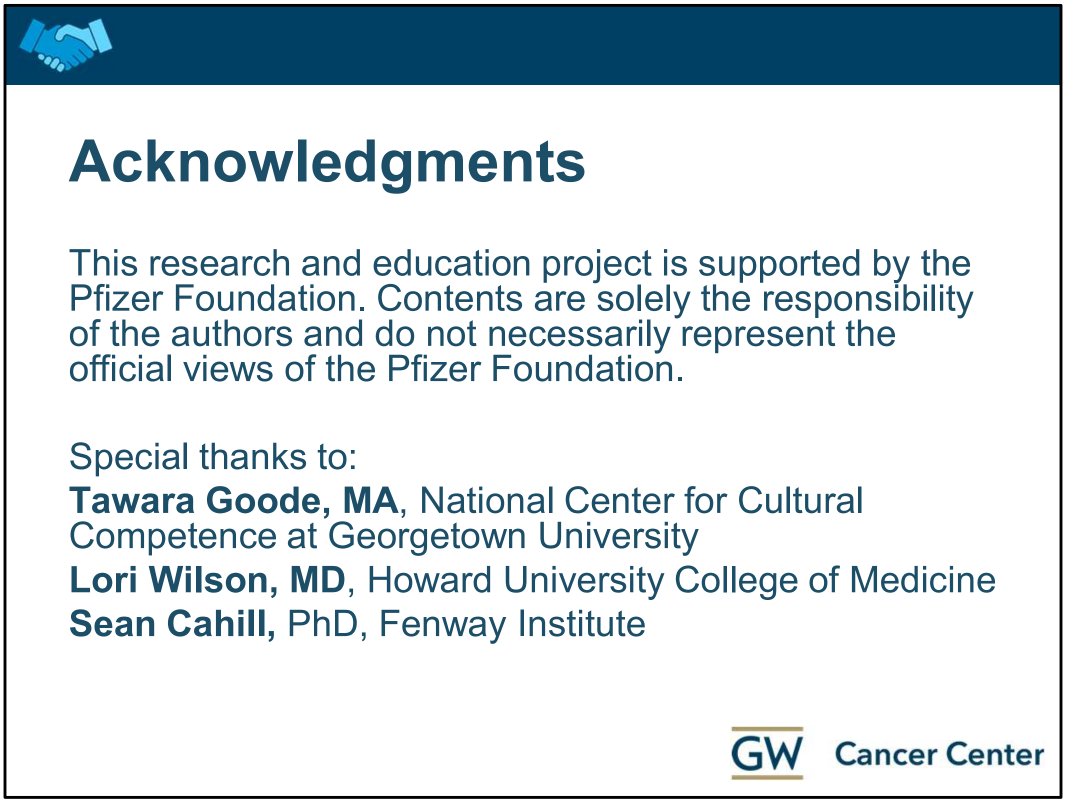
Welcome to Module 5, Lesson 2: Strategies for Institutions to Promote Culturally Competent & Equitable Care.



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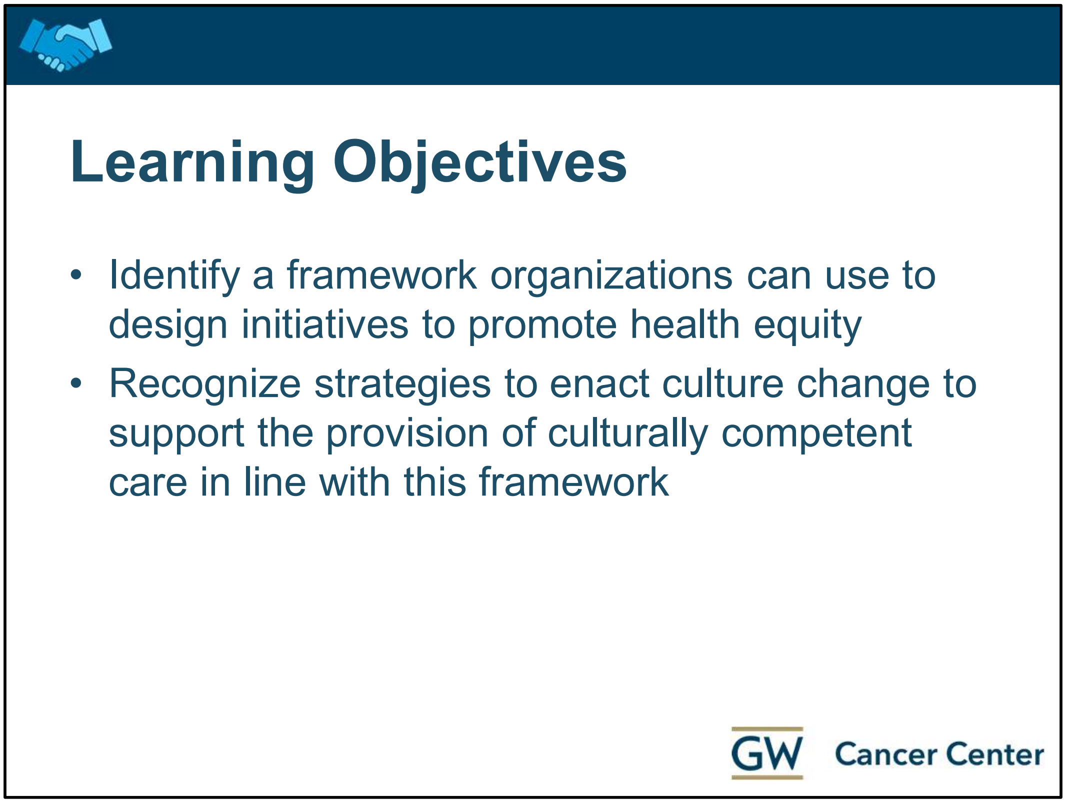

Learning Objectives

- Identify a framework organizations can use to design initiatives to promote health equity
- Recognize strategies to enact culture change to support the provision of culturally competent care in line with this framework

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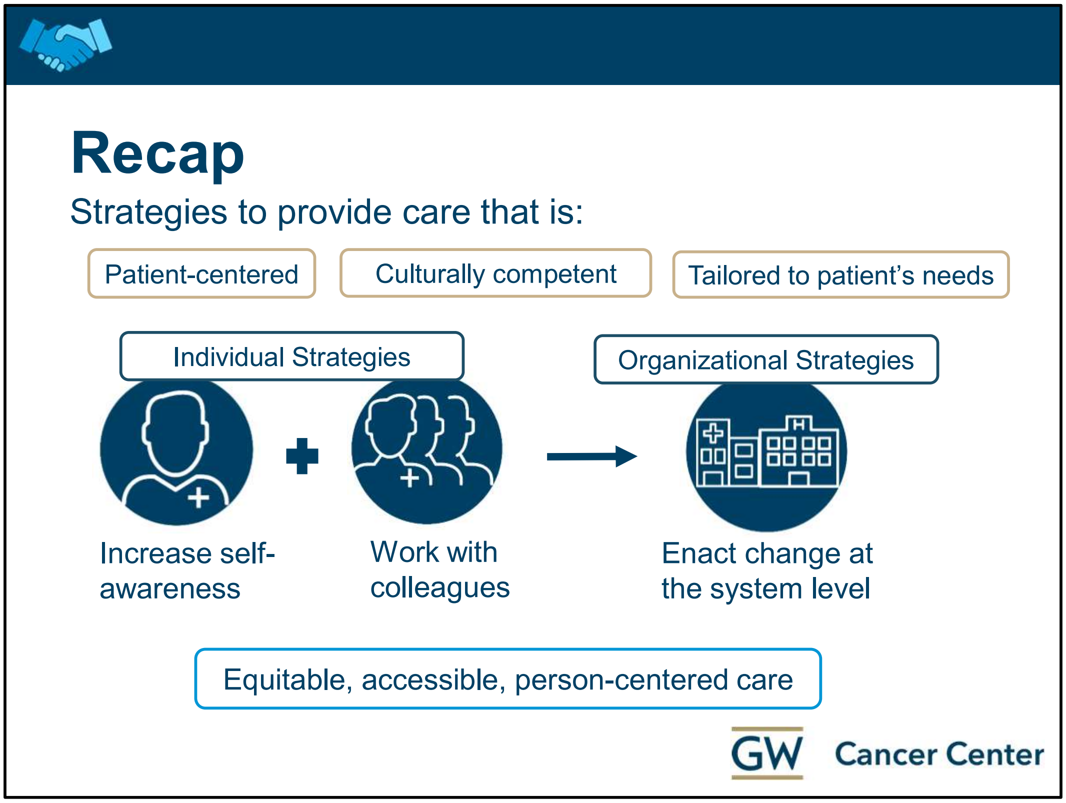
After completing this lesson, you will be able to:

- Identify a framework organizations can use to design initiatives to promote health equity
- Recognize strategies to enact culture change to support the provision of culturally competent care in line with this framework



Recap

Strategies to provide care that is:

Patient-centered

Culturally competent

Tailored to patient's needs

Individual Strategies

Increase self-awareness

Work with colleagues

Organizational Strategies

Enact change at the system level

Equitable, accessible, person-centered care

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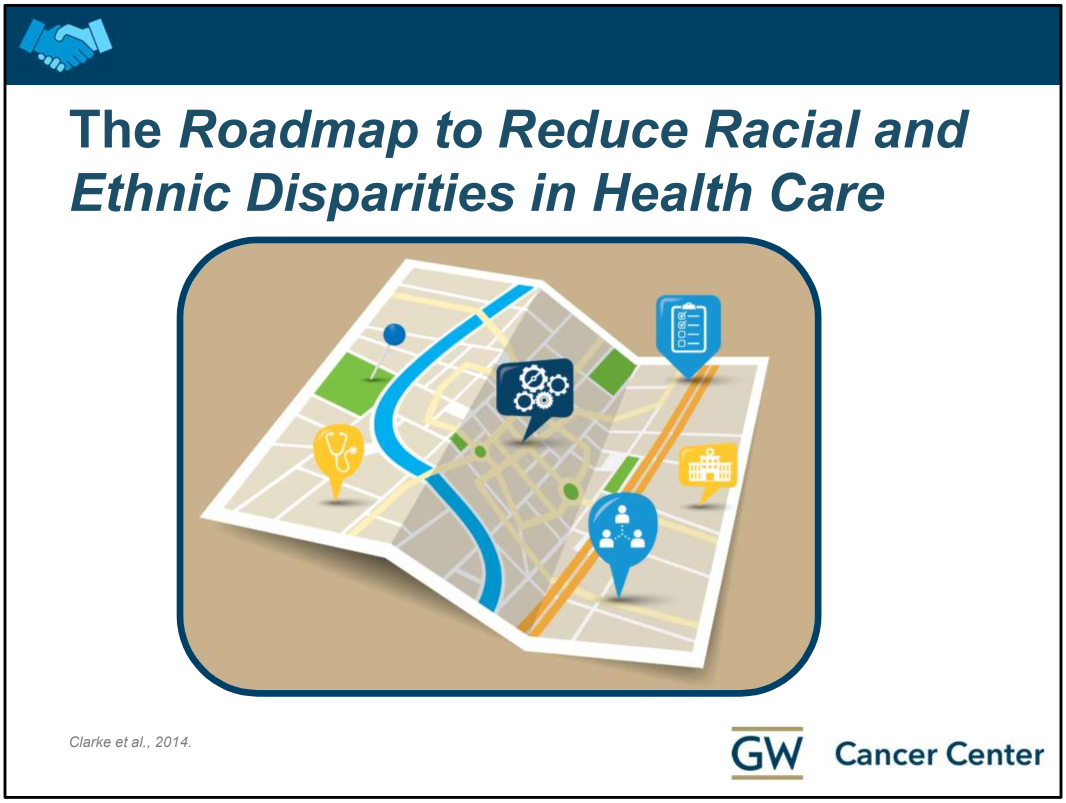
Throughout this training, we have presented strategies to provide care that is patient-centered, culturally competent and tailored to the patient's unique needs.

Often, the strategies we presented were targeted to health care professionals as individuals. These individual-level strategies are helpful in creating a more culturally competent and equitable health care system because, ultimately, health care organizations are made up of people.

Individual health care professionals can and should take steps to become more self-aware and work with their colleagues to improve the cultural sensitivity, equity and patient-centeredness of the care they provide.

However, organizations must enact change at the systems level to truly establish an environment where all patients are being provided equitable, accessible, person-centered care.



The *Roadmap to Reduce Racial and Ethnic Disparities in Health Care*

Clarke et al., 2014.

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The *Roadmap to Reduce Racial and Ethnic Disparities in Health Care* was created as a part of the Robert Wood Johnson Foundation national program, Finding Answers: Disparities Research for Change. This resource helps guide organizations in implementing equity-focused quality improvements in ways that are feasible to implement and sustainable in the long term.

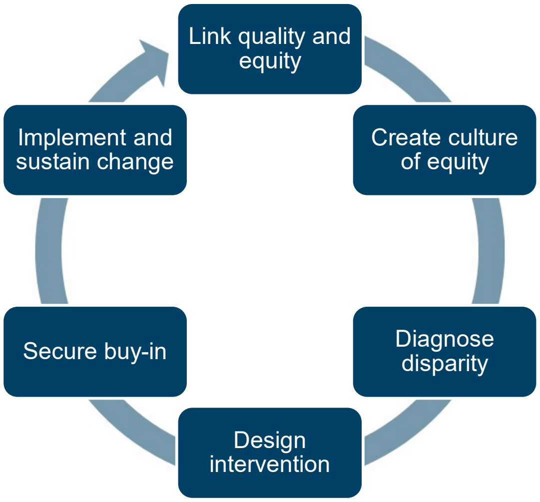
While this project has a focus on reducing racial and ethnic disparities, the structure provided through the Roadmap can guide interventions to improve equity for diverse patient populations.

The Roadmap offers a comprehensive six-stage approach for organizations to implement equity-focused quality improvements as a part of or as a parallel to existing quality improvement work. These six steps are:

- Link quality and equity
- Create a culture of equity
- Diagnose the disparity
- Design the intervention
- Secure buy-in
- Implement and sustain change

The philosophy guiding the Roadmap is that achieving each of the six steps will create sufficient culture change and infrastructure to make equity initiatives feasible to implement and sustainable in the long term. Here we will briefly explain each of the steps of the Roadmap.

Six Stages of Implementation



Link quality and equity

Create culture of equity

Diagnose disparity

Design intervention

Secure buy-in

Implement and sustain change

Clarke et al., 2014.

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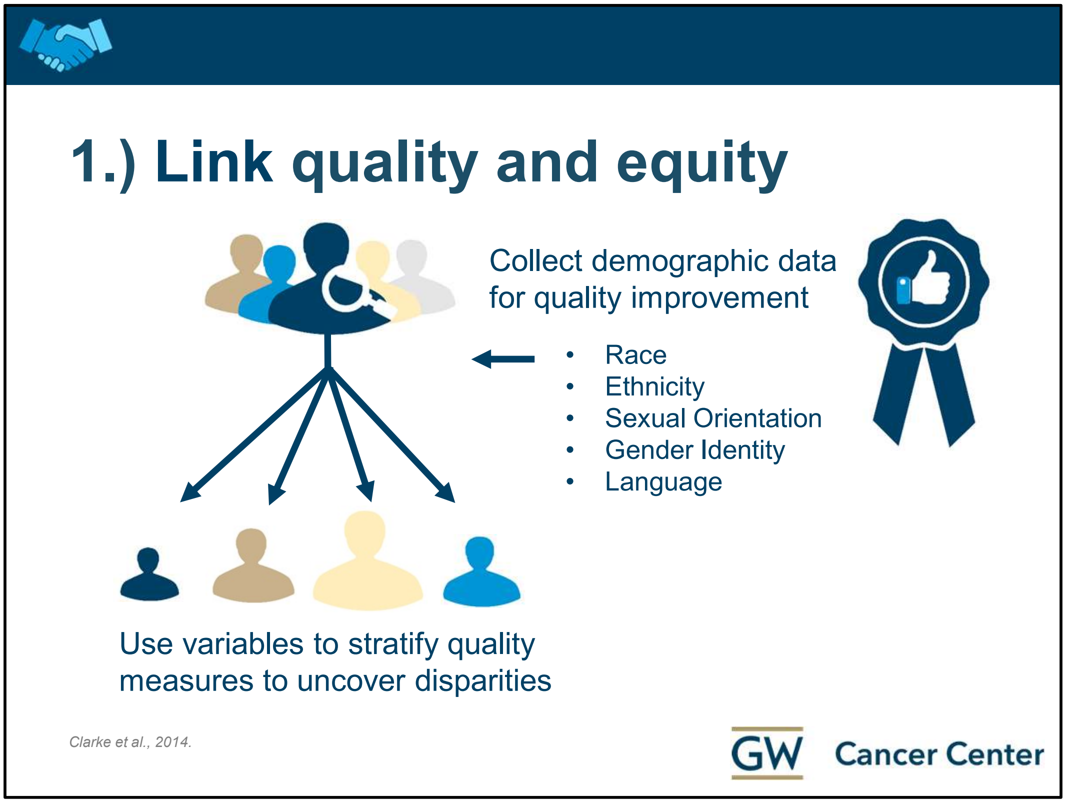

1.) Link quality and equity

Collect demographic data for quality improvement

- Race
- Ethnicity
- Sexual Orientation
- Gender Identity
- Language

Use variables to stratify quality measures to uncover disparities

Clarke et al., 2014.

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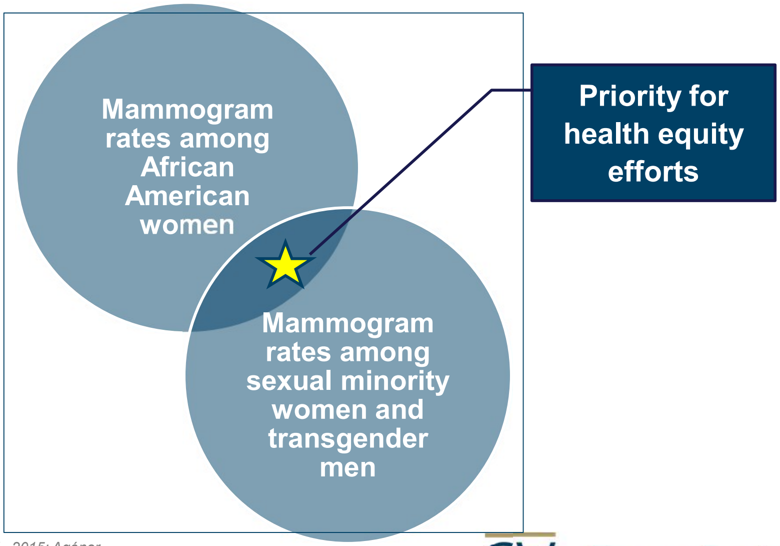
1.) Link quality and equity. This step emphasizes the need to collect demographic data for quality improvement. Data such as race, ethnicity, sexual orientation, gender identity and language can be used to discover and address disparities.

For instance, by examining rates of breast cancer screening by race and not just as a whole, a hospital system may detect disparities in the frequency and timeliness of screenings between black and white women served in their clinics.

Examining screening rates by sexual orientation or gender identity can also be done.

Since lesbian and bisexual women as well as transgender men may be less likely to access preventive services like cervical cancer screening than heterosexual or cisgender women. The intersection of these populations – racial and ethnic and sexual and gender minorities – may be a priority for health equity efforts.

1.) Link quality and equity



Mammogram rates among African American women

Mammogram rates among sexual minority women and transgender men

Priority for health equity efforts

Clarke et al., 2014; Agénor et al., 2015; Agénor, Krieger, Austin, Haneuse, & Gottlieb, 2015; Peitzmeier, Khullar, Reisner, & Potter, 2014;

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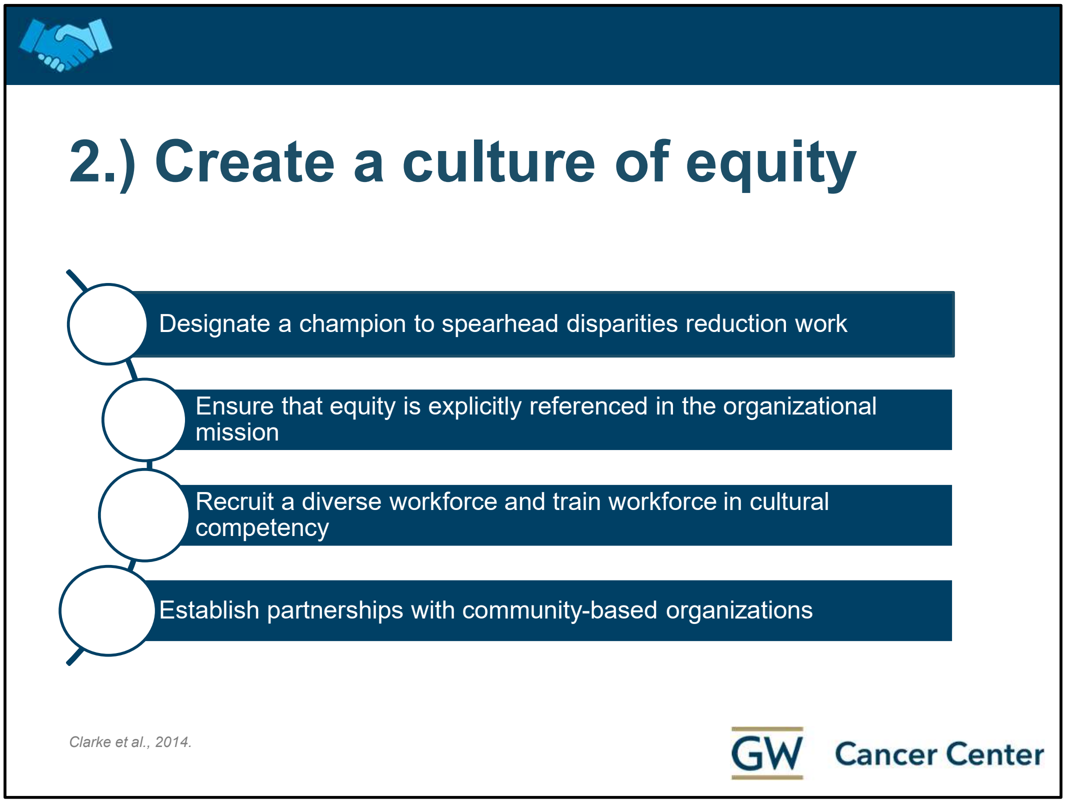


2.) Create a culture of equity

- Designate a champion to spearhead disparities reduction work
- Ensure that equity is explicitly referenced in the organizational mission
- Recruit a diverse workforce and train workforce in cultural competency
- Establish partnerships with community-based organizations

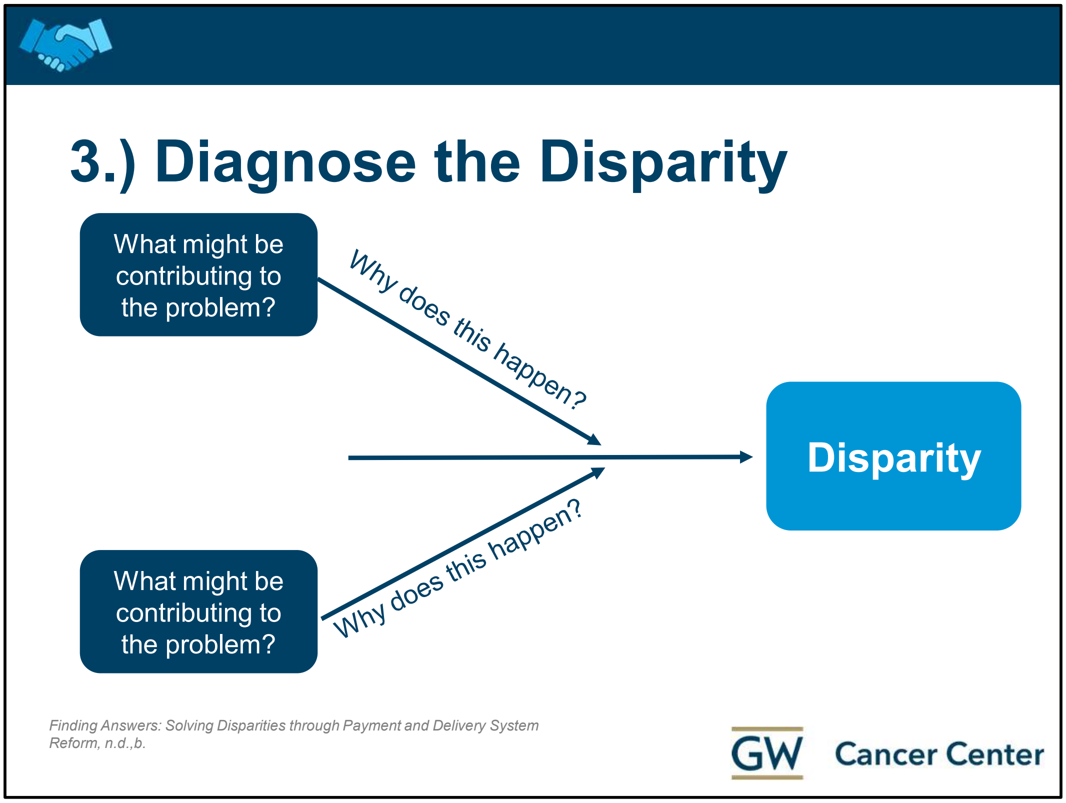
Clarke et al., 2014.

GW Cancer Center

2.) Create a culture of equity. Creating a culture of equity involves getting all individuals at all levels of the health care organization to understand a shared definition of equity and commit to working to enhance equity.

Creating culture change requires organizations to employ such tactics as:

- Designating a champion to spearhead disparities reduction efforts who is in a position of leadership and accountable for this work;
- Ensuring that equity is explicitly referenced in the organizational mission;
- Recruiting a diverse workforce and training it in cultural competency; and
- Establishing partnerships with community-based organizations.



3.) Diagnose the Disparity

What might be contributing to the problem?

Why does this happen?

What might be contributing to the problem?

Why does this happen?

Disparity

Finding Answers: Solving Disparities through Payment and Delivery System Reform, n.d.,b.

GW Cancer Center

3.) Diagnose the disparity. This step describes work to understand the cause of the disparity after it is revealed through data, in order to design an effective intervention.

This involves conducting a root cause analysis, with a mix of staff, including leadership, engaged in this process. It also suggests the use of a priority matrix to determine which causes identified in the root cause analysis should be addressed in an intervention, based on importance and feasibility.

3.) Diagnose the Disparity

Which of our root causes are…	**Very important to address**	**Less important to address**
Very feasible to address	▨	
Less feasible to address		

Clarke et al., 2014.

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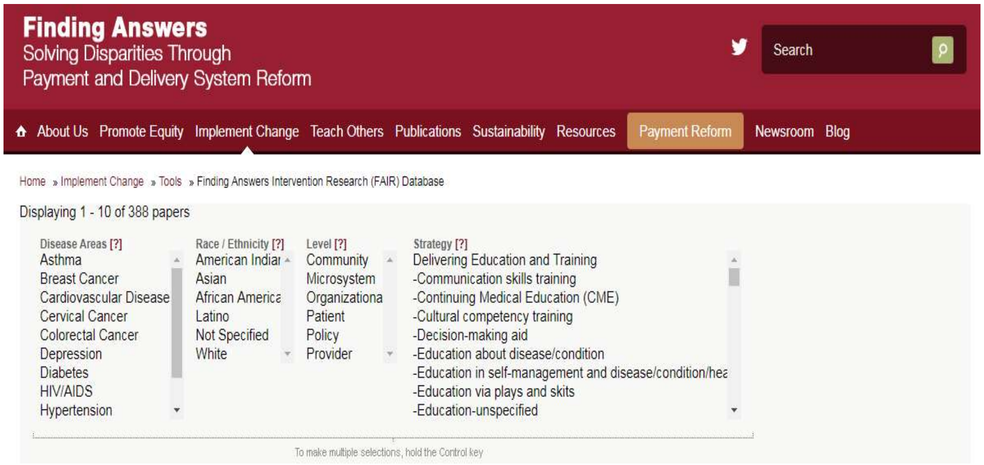
4.) Design the Intervention



Finding Answers
Solving Disparities Through
Payment and Delivery System Reform

Home » Implement Change » Tools » Finding Answers Intervention Research (FAIR) Database

Displaying 1 - 10 of 388 papers

Disease Areas [?]
Asthma
Breast Cancer
Cardiovascular Disease
Cervical Cancer
Colorectal Cancer
Depression
Diabetes
HIV/AIDS
Hypertension

Race / Ethnicity [?]
American Indiar
Asian
African America
Latino
Not Specified
White

Level [?]
Community
Microsystem
Organizationa
Patient
Policy
Provider

Strategy [?]
Delivering Education and Training
-Communication skills training
-Continuing Medical Education (CME)
-Cultural competency training
-Decision-making aid
-Education about disease/condition
-Education in self-management and disease/condition/hea
-Education via plays and skits
-Education-unspecified

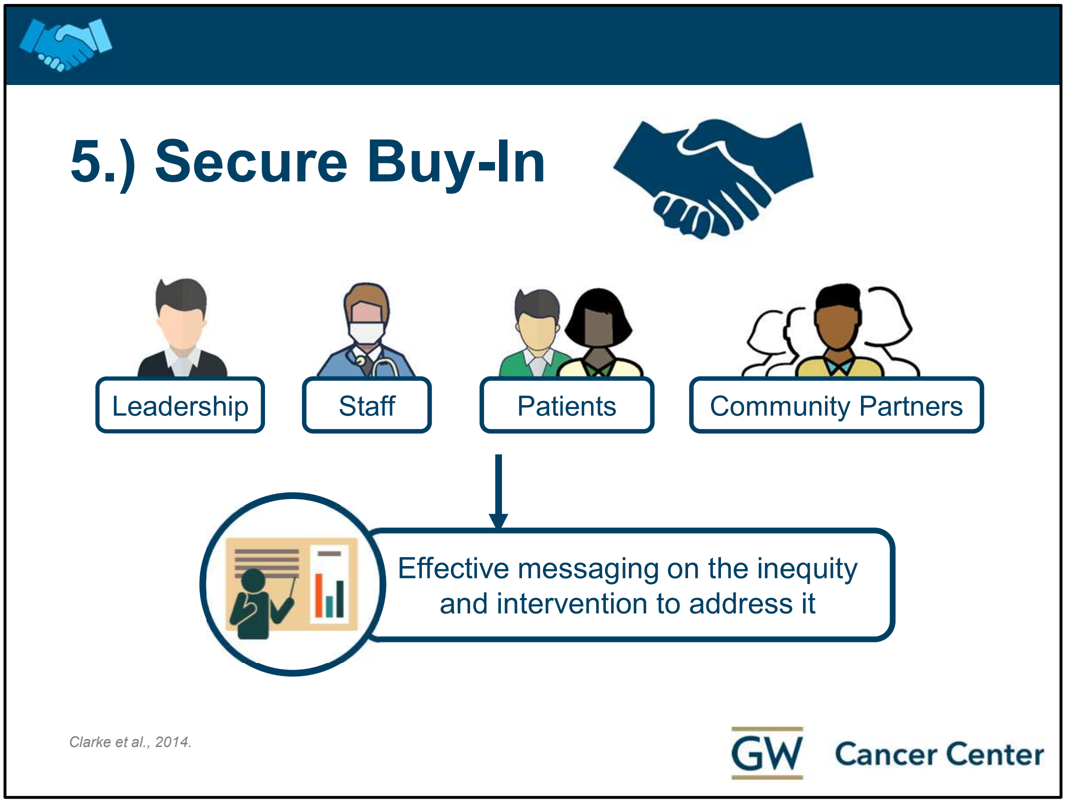
To make multiple selections, hold the Control key

Finding Answers: Solving Disparities through Payment and Delivery System Reform, n.d.,a

GW Cancer Center

4.) Design the intervention. In this step, health systems are encouraged to design interventions with attention given to evidence-based practices, as well as different levels, strategies and modes for the intervention.

The Roadmap highlights the Finding Answers Intervention Research (FAIR) database of published disparities interventions, which can be sorted by level, strategy and mode. You can find a link to the FAIR database in the resources section of the LMS.



5.) Secure Buy-In

Leadership

Staff

Patients

Community Partners

Effective messaging on the inequity and intervention to address it

Clarke et al., 2014.

5.) Secure buy-in. This step emphasizes the need to secure buy-in from all involved in the equity initiatives, including leadership, staff, patients and community partners.

It provides best practices for doing so and highlights the need for effective messaging on the inequity and the intervention to address it.

6.) Implement and Sustain Change

Implementation:

- Set SMART goals and objectives
- Pilot test
- Evaluate the program

Clarke et al., 2014.

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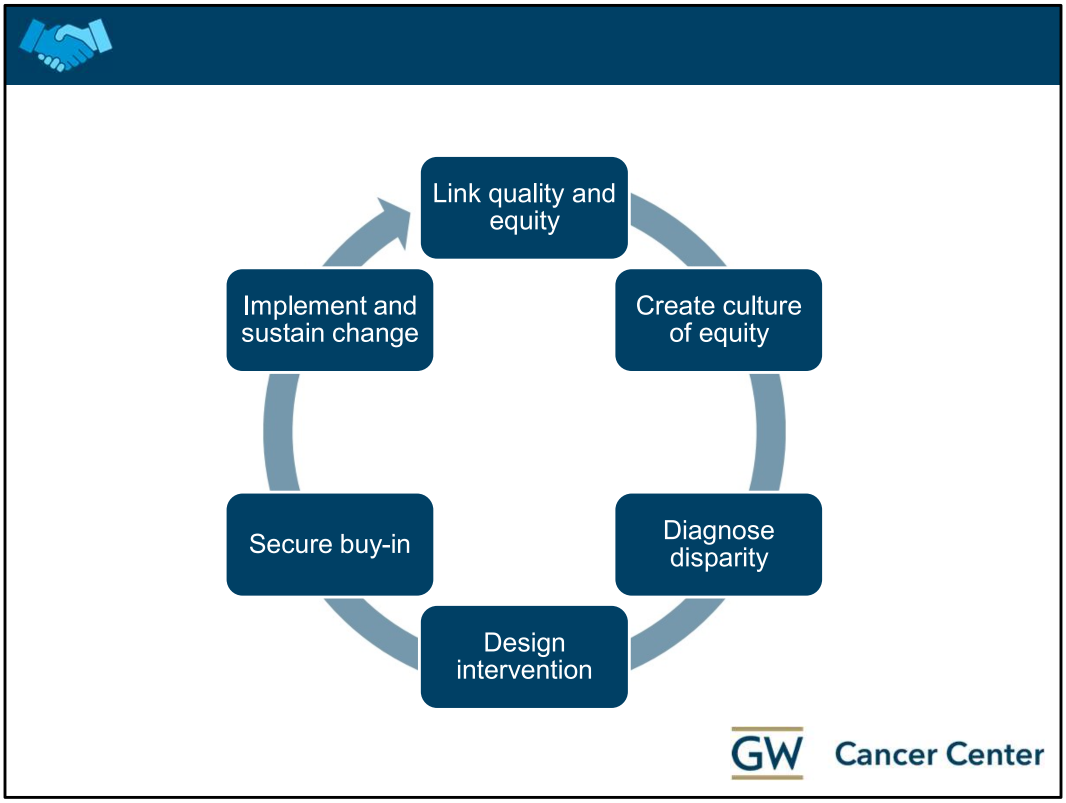
6.) Implement and sustain change. This step offers guidance on how to implement the intervention effectively. It suggests employing strategies like SMART goals and objectives, pilot testing and evaluation. If you are not familiar with developing SMART goals and objectives, please see the resources section in the LMS for more information.



Link quality and equity

Create culture of equity

Diagnose disparity

Design intervention

Secure buy-in

Implement and sustain change

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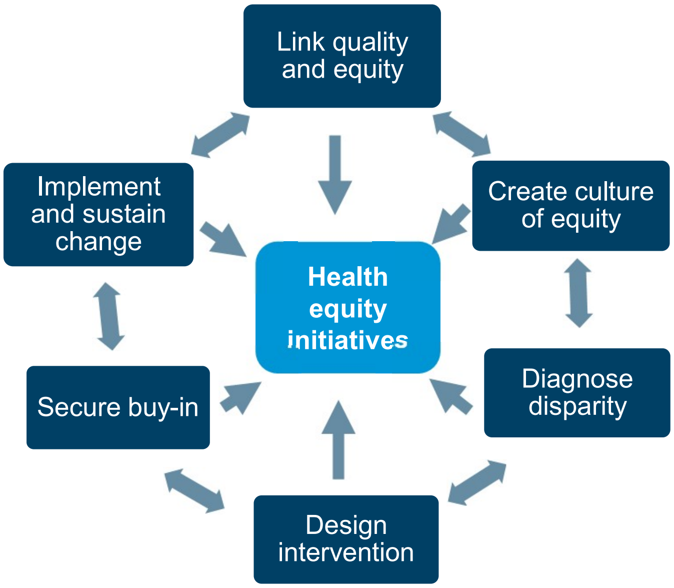
Following the steps of this Roadmap in a prescribed order may not be the right strategy for every health care organization. Some organizations may already have a strong culture of equity, whereas others may not be empowered to change data collection methods.

Based on their unique characteristics, organizations can and should start at various points along this Roadmap and, importantly, use the Roadmap as an iterative process. Perhaps an organization assumed they had strong buy-in at all levels of the organization, but evaluation revealed that front desk staff were unaware of a change in practice. This may require the organization to reaffirm and strengthen its organization-wide commitment to equity.

In the rest of this lesson, we present examples of strategies that align with each step of the Roadmap. Taking into consideration their needs and capacity, health care organizations can use these examples to promote culturally competent and equitable care.



Link quality and equity

Create culture of equity

Diagnose disparity

Design intervention

Secure buy-in

Implement and sustain change

Health equity initiatives

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Organizational Strategies to Promote Equity

1. Collect data to support health equity
2. Participate in public organizational assessments
3. Create a welcoming environment
4. Support team-based care
5. Adhere to national policies and standards
6. Draft, disseminate and enforce non-discrimination policies

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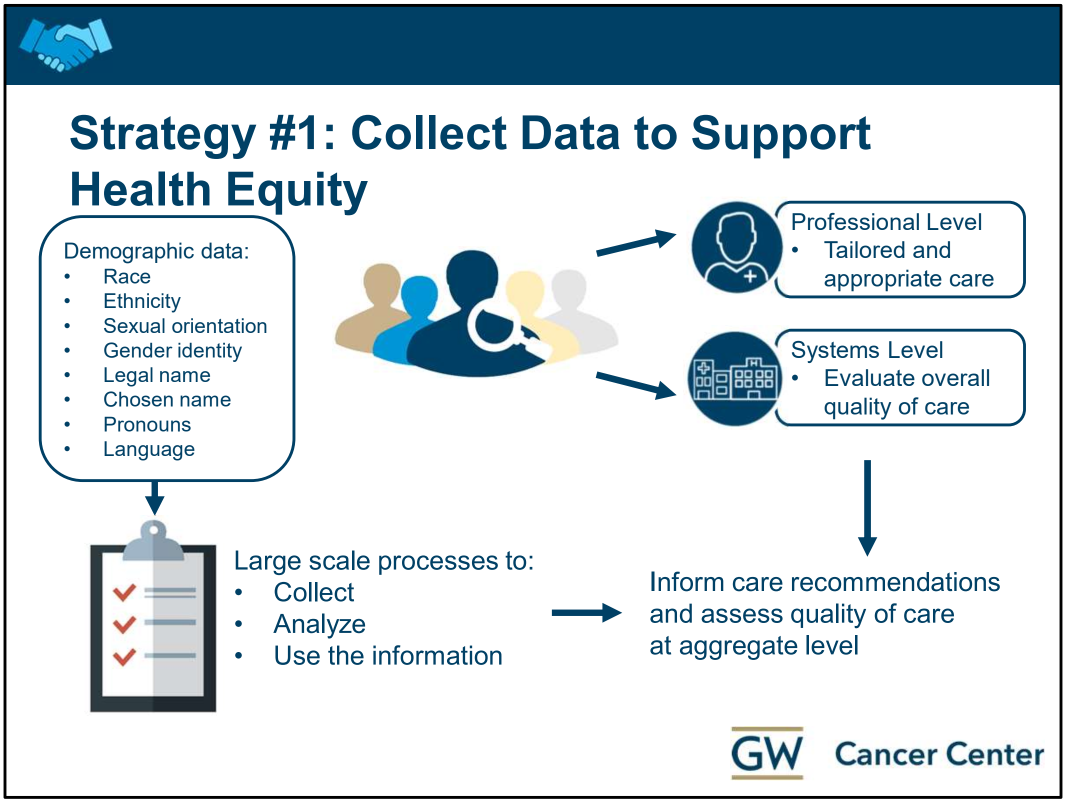

Strategy #1: Collect Data to Support Health Equity

Demographic data:
- Race
- Ethnicity
- Sexual orientation
- Gender identity
- Legal name
- Chosen name
- Pronouns
- Language

Professional Level
- Tailored and appropriate care

Systems Level
- Evaluate overall quality of care

Large scale processes to:
- Collect
- Analyze
- Use the information

Inform care recommendations and assess quality of care at aggregate level

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Collecting demographic data like race, ethnicity, sexual orientation, gender identity, legal and preferred name, pronouns and preferred language provides health care facilities with the information they need to serve patients effectively – both at the professional level to provide tailored and appropriate care and at the systems level to evaluate the overall quality of care.

Setting up processes to collect, analyze and use this information on a large scale is necessary for the health system to be able to share data to inform care recommendations and assess the quality of care at the aggregate level. In this way, this type of data collection aligns with Step 1 of the Roadmap, *Link quality and equity.*

Electronic Health Records (or EHR) can play a key role in documenting and sharing this information because they are equipped with fields to collect information on race, ethnicity, sex assigned at birth, preferred language and, increasingly, sexual orientation and gender identity.

Fields can also be customized to capture a patient’s legal name that is on their health insurance, as well as their chosen name and pronouns. These data can be shared electronically with other providers when patients have a transition in care, and they can be analyzed at the systems level to unmask disparities in care.

Through their *Do Ask, Do Tell* campaign, the Fenway Institute and Center for American

Progress provide helpful information at each step of the process to facilitate the collection of sexual orientation and gender identity data.

Including questions to ask that have been recommended by leading sexual and gender minority-serving organizations that have evidence of acceptability for patients in diverse settings, training information for clinical staff who collect this information from sexual and gender minority patients and instructions for how to collect this information systematically through the EHR.

You can find a link to *Do Ask, Do Tell* in the resources section in the LMS.

Collecting information on patient experience is also important to ensure the provision of high-quality, patient-centered care. Patient experience can be captured through surveys like the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Survey. There is also now a CAHPS Cancer Care Survey.

Health care organizations can also solicit feedback without using standardized instruments by conducting focus groups or administering simple paper surveys.

Strategy #1: Collect Data to Support Health Equity

Legal last name: ____________

Legal first name: ____________

Chosen first name (if different): ______________________

Chosen pronouns:
- ☐ He/Him/His
- ☐ She/Her/Hers
- ☐ They/Them/Theirs
- ☐ Other: ______________

Sex listed in insured's health insurance plan:
- ☐ Male
- ☐ Female

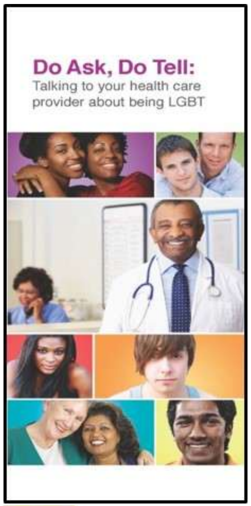
Sex assigned at birth:
- ☐ Male
- ☐ Female
- ☐ Intersex

Gender identity:
- ☐ Male/Man
- ☐ Female/Woman
- ☐ TransMale/ Transman
- ☐ TransFemale/ Transwoman
- ☐ Gender-queer/ -nonconforming
- ☐ Something else
- ☐ Decline to answer

Sexual orientation:
- ☐ Lesbian
- ☐ Gay
- ☐ Bisexual
- ☐ Queer
- ☐ Straight
- ☐ Something else
- ☐ Decline to answer

Veteran?
- ☐ Yes
- ☐ No

Hispanic?
- ☐ Yes
- ☐ No



Do Ask, Do Tell:
Talking to your health care provider about being LGBT

National LGBT Cancer Network, n.d.; Fenway Institute & Center for American Progress, 2015.

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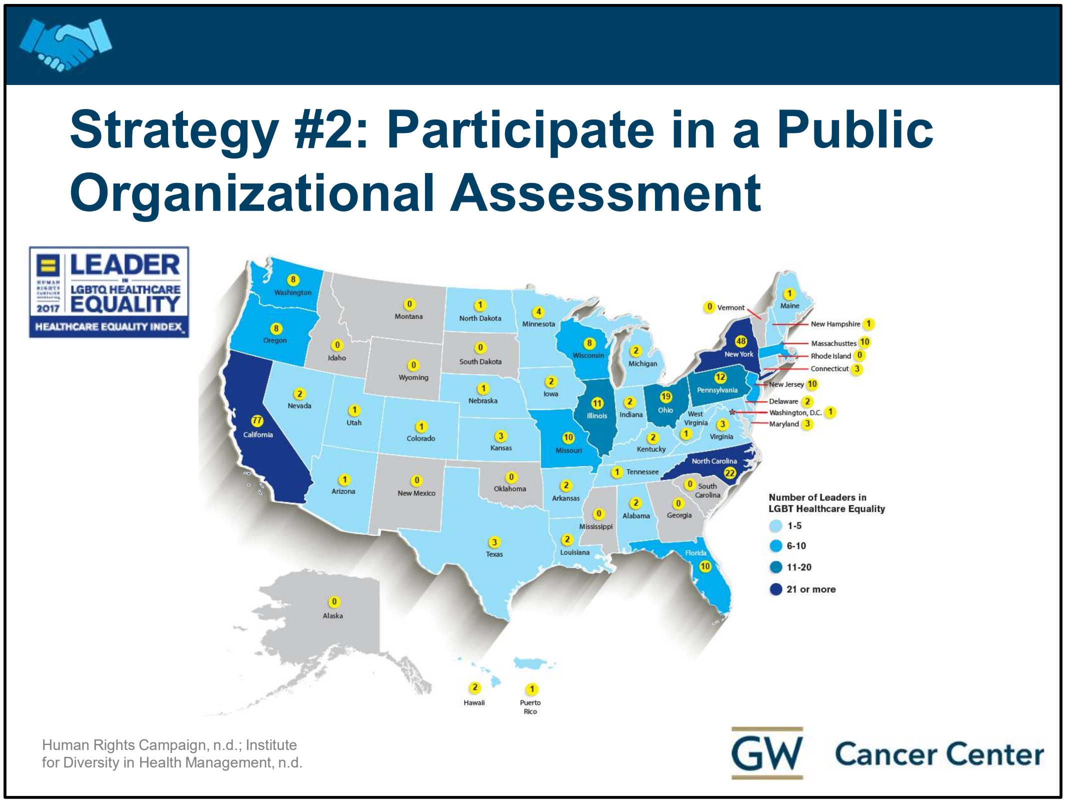
Strategy #1: Collect Data to Support Health Equity



Strategy #2: Participate in a Public Organizational Assessment

Human Rights Campaign, n.d.; Institute for Diversity in Health Management, n.d.

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Organizations can engage in the second step of the Roadmap, *Create a culture of equity,* by participating in a public assessment of the organization's state of equity and inclusion.

For example, the Human Rights Campaign's Healthcare Equality Index or (HEI) is a benchmarking tool that evaluates health care facilities' policies and practices related to the equity and inclusion of their sexual and gender minority patients, family members, visitors and employees.

Another example of a survey tool that assesses and reports on diversity is the Institute for Diversity in Health Management's benchmarking study of U.S. hospitals.

Strategy #3: Create a Welcome Environment

Display diverse signage to send a message of inclusion

Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson, 2003. HRC Pin.

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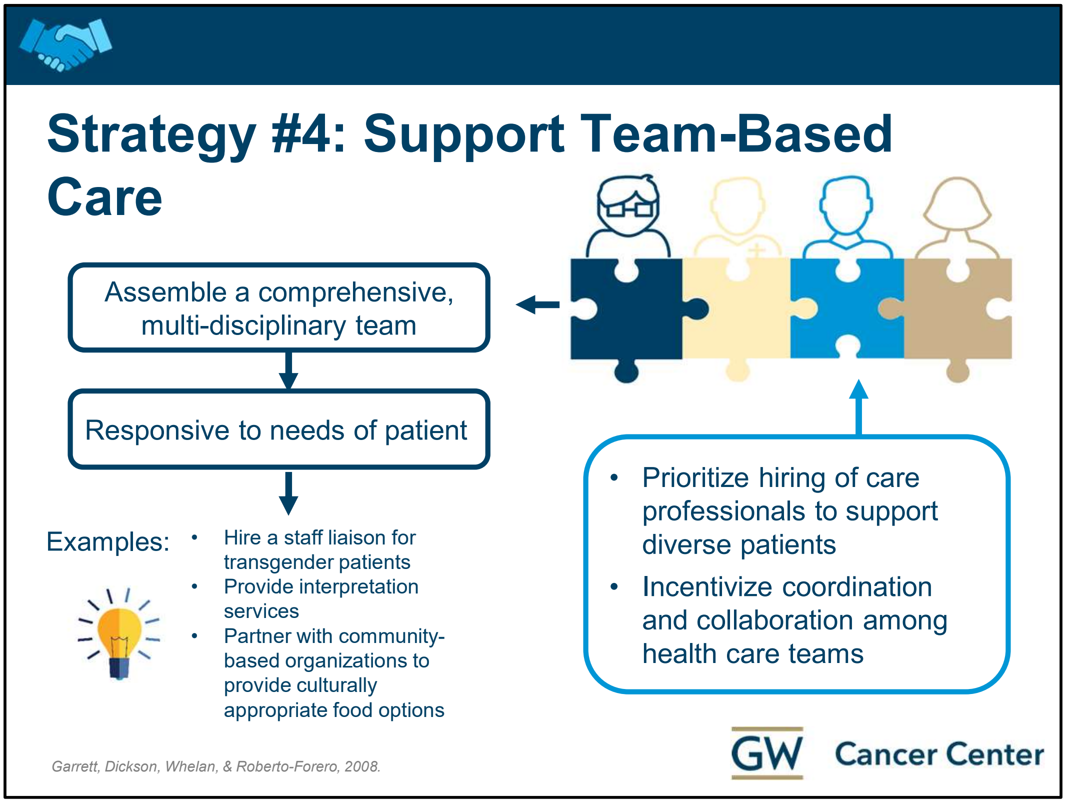
We use the example of creating a welcoming environment to illustrate how an organization may work through Step 3 of the Roadmap, *Diagnose the disparity,* and take steps to build the intervention from there.

Say that data collection on patient experience conducted in Step 1 revealed that sexual and gender minority patients were reporting much lower levels of satisfaction than heterosexual and cisgender patients.

In discussing the issue with staff and trying to pinpoint the cause, the organization learns that it could improve its methods of welcoming sexual and gender minority patients. Both in terms of the physical features of the health care setting and the first interactions patients have with office staff.

From this diagnosis of the problem, the organization can decide to use visual cues to signal to patients that the practice is culturally sensitive, such as using signs with rainbow flags to signal that LGBTQI patients are welcome. It can also train front desk staff to practice a protocol where they call a patient in the waiting room solely by their last name (for example, “Patient Alvarez” instead of “Mr. or Mrs. Alvarez”) so as to not make transgender individuals uncomfortable.



Strategy #4: Support Team-Based Care

Assemble a comprehensive, multi-disciplinary team

Responsive to needs of patient

Examples:

- Hire a staff liaison for transgender patients
- Provide interpretation services
- Partner with community-based organizations to provide culturally appropriate food options

- Prioritize hiring of care professionals to support diverse patients
- Incentivize coordination and collaboration among health care teams

Garrett, Dickson, Whelan, & Roberto-Forero, 2008.

For Step 4 of the Roadmap, *Design the intervention*, let's look at supporting team-based care as an example because it draws upon an evidence-based strategy.

A health care organization can promote culturally competent care by assembling a comprehensive, multi-disciplinary team that is responsive to the health needs of the patient, both within and outside the clinical care setting.

Assembling this care team goes beyond traditional providers and can include staff that provide culturally appropriate food options for patients, for instance. Organizations play a role in promoting team-based care by prioritizing the hiring of diverse care professionals that can help compose this multidisciplinary team and incentivizing coordination and collaboration among these health care teams.

Strategy #5: Adhere to National Policies and Standards

Benefits of becoming a culturally competent health care organization:

Social Benefits	Health Benefits	Business Benefits
• Increases trust between patients and organization • Promotes community inclusion • Assists patients and families in managing health and care	• Increases use of preventive care • Reduces number of missed medical visits • Reduces disparities • Reduces medical errors	• Improves data collection • Improves efficiency of care • Meets legal and regulatory guidelines • Increases market share

Health Research & Educational Trust, 2013.

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When thinking about achieving Step 5 of the Roadmap, *Secure buy-in,* an organization can make the case to its leadership that interventions to enhance cultural competency provide social, health and business benefits to the organization.

We previously presented this figure, which was adapted from the Health Research & Educational Trust, in the Introduction to the TEAM training to explain the various benefits an organization stands to gain from improving its cultural competency.

Consider your audience when you are trying to introduce and implement culture change in your health care system.

- Social benefits of culturally competent organizations may be particularly convincing for social work and nursing colleagues

- Health benefits may be particularly convincing for physician, nurse practitioner and physician assistant colleagues

- Business benefits could be particularly compelling to the executive leadership, health care administrators and operations managers within a health care organization because market share of the organization could increase if the organization is known as a welcoming and supportive environment for diverse patient populations.

Staff members dedicated to health equity could make the case that their proposed intervention is important because it allows them to adhere to national policies and standards - for instance, to be accredited by the Joint Commission or to be eligible to receive payments from Medicare and Medicaid.

In 2011, the Joint Commission began to require health care organizations to have non-discrimination policies that include sexual orientation and gender identity as protected classes in order to maintain accreditation.

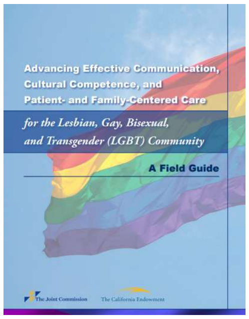
The Joint Commission, as well as government bodies, including the Department of Health and Human Services, Centers for Medicare & Medicaid Services and National Academy of Medicine, have encouraged the collection of sexual orientation and gender identity data.

Champions of LGBTQI cultural competency and data collection of sexual orientation and gender identity in hospitals have reported that calling upon these developments from government and non-government agencies has helped gain administrators’ support of these initiatives.

In addition, CLAS standards, which we have previously discussed, include a standard directing health care organizations to “Conduct regular assessments of community health assets and needs and use the results to plan and implement services that respond to the cultural and linguistic diversity of populations in the service area.”

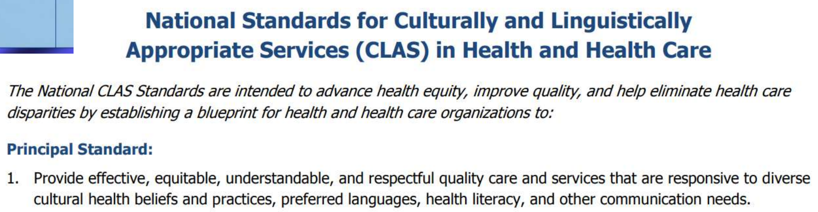
Therefore, in making the case to leadership that the organization should engage the community to assess their needs and plan an intervention that is responsive to these needs, a staff member could point to this CLAS standard as justification.

Strategy #5: Adhere to National Policies and Standards


Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care
for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community
A Field Guide
The Joint Commission
The California Endowment

OMH U.S. Department of Health and Human Services Office of Minority Health

NAM


National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care

The National CLAS Standards are intended to advance health equity, improve quality, and help eliminate health care disparities by establishing a blueprint for health and health care organizations to:

Principal Standard:

1. Provide effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs.

The Joint Commission, 2011; Office of Disease Prevention and Health Promotion, n.d.; Centers for Medicare & Medicaid Services, 2015; Institute of Medicine, 2011; Office of Minority Health, n.d.

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Strategy #6: Draft, Disseminate & Enforce Non-Discrimination Policies

- Create and display non-discrimination policies
- Distribute LGBT Healthlink's Patient Bill of Rights to all patients
- Enforce nondiscrimination through staff & provider training, providing information for patients to submit grievances and by taking patient grievances seriously

Healthcare Bill of Rights, n.d.

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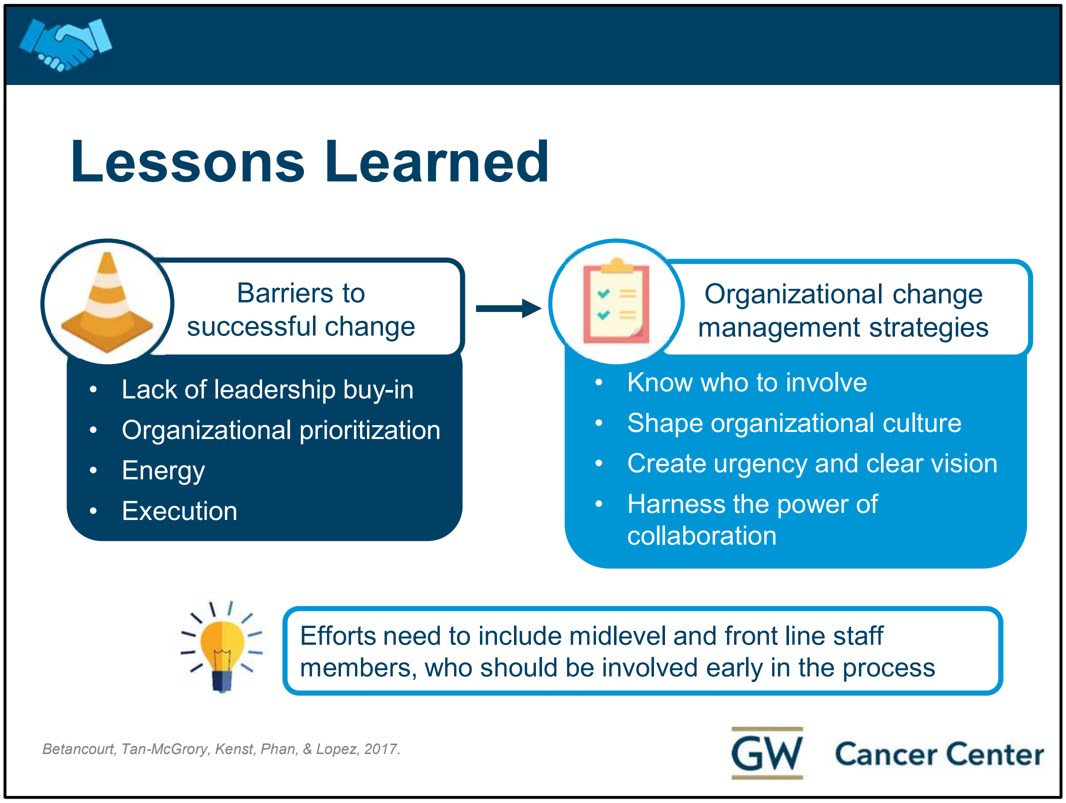
Finally, we'll use an example of revising non-discrimination policies to exemplify how an organization would undertake Step 6, *Implement and sustain change.* In our earlier example, data collection on patient experience conducted in Step 1 revealed that sexual and gender minority patients were reporting much lower levels of satisfaction than heterosexual and cisgender patients.

Step 3 helped the organization recognize that patients did not feel welcome upon entering the health care organization. The organization could examine its resources and decide that the most important and feasible step it could take to promote a more welcoming environment would be to revise and more widely disseminate its non-discrimination policies. Doing so would provide patients and employees, including those who identify as a sexual and gender minority, with an unequivocal statement of their rights.

The organization could design its intervention (in Step 4 of the Roadmap) by consulting the evidence base for effective and widely accepted material. In this case, it would identify that the organization LGBT Health Link has created its Healthcare Bill of Rights to outline the rights and protections for sexual and gender minority patients. For information on the Healthcare Bill of Rights, visit the resource section in the LMS.

After designing this intervention (Step 4) and securing buy-in across the organization and community to revise the non-discrimination policy (Step 5), what could ultimately

make this intervention effective is:
- Ensuring staff and provider training
- Letting patients know who to contact if they have a problem
- Taking patient complaints seriously
- Training staff and clinicians routinely for ongoing improvement



Lessons Learned

Barriers to successful change

- Lack of leadership buy-in
- Organizational prioritization
- Energy
- Execution

Organizational change management strategies

- Know who to involve
- Shape organizational culture
- Create urgency and clear vision
- Harness the power of collaboration

Efforts need to include midlevel and front line staff members, who should be involved early in the process

Betancourt, Tan-McGrory, Kenst, Phan, & Lopez, 2017.

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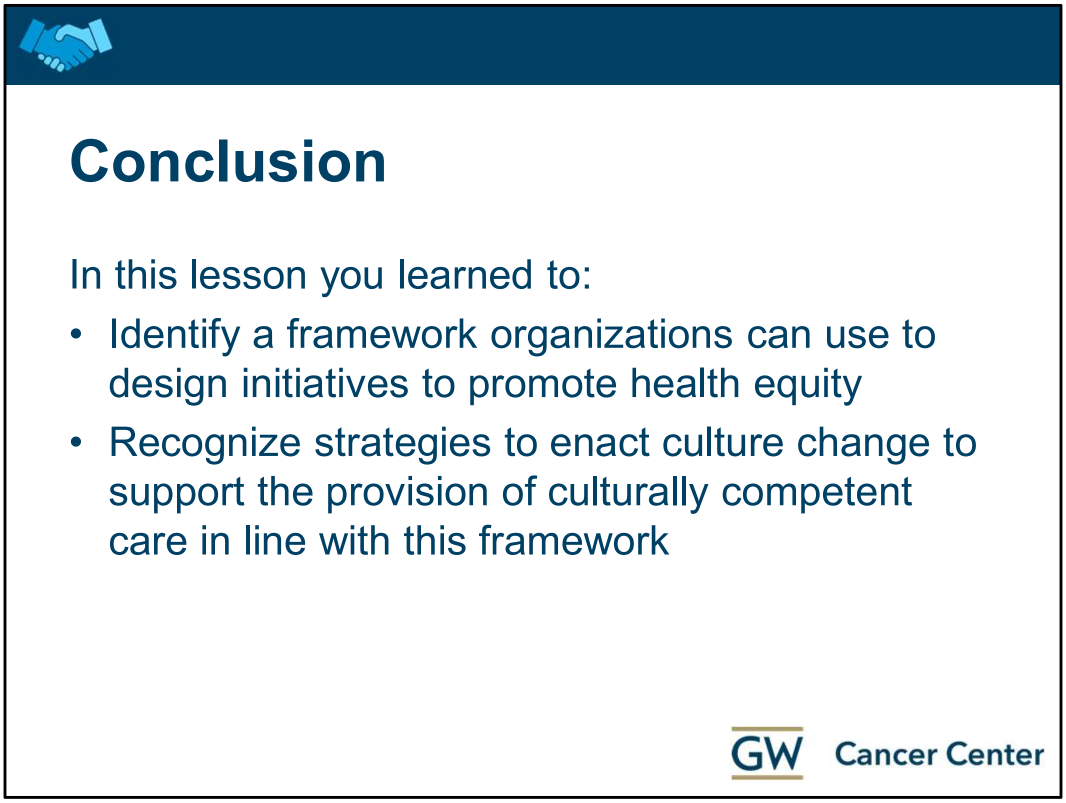
Even though the Roadmap provides a strong structure to create feasible and sustainable change, it is important to note that often barriers occur that hinder organizations in making needed changes.

According to data collected from nine years of the Disparities Leadership Program, barriers to success relate to lack of leadership buy-in, organizational prioritization, energy, and execution.

These obstacles can be addressed through organizational change management strategies, such as knowing who to involve, shaping organizational culture, creating urgency and a clear vision, and harnessing the power of collaboration. For example, efforts need to include midlevel and front line staff members, who should be involved early in the process.

Organizations can learn from these pitfalls when designing their own interventions.



Conclusion

In this lesson you learned to:

- Identify a framework organizations can use to design initiatives to promote health equity
- Recognize strategies to enact culture change to support the provision of culturally competent care in line with this framework

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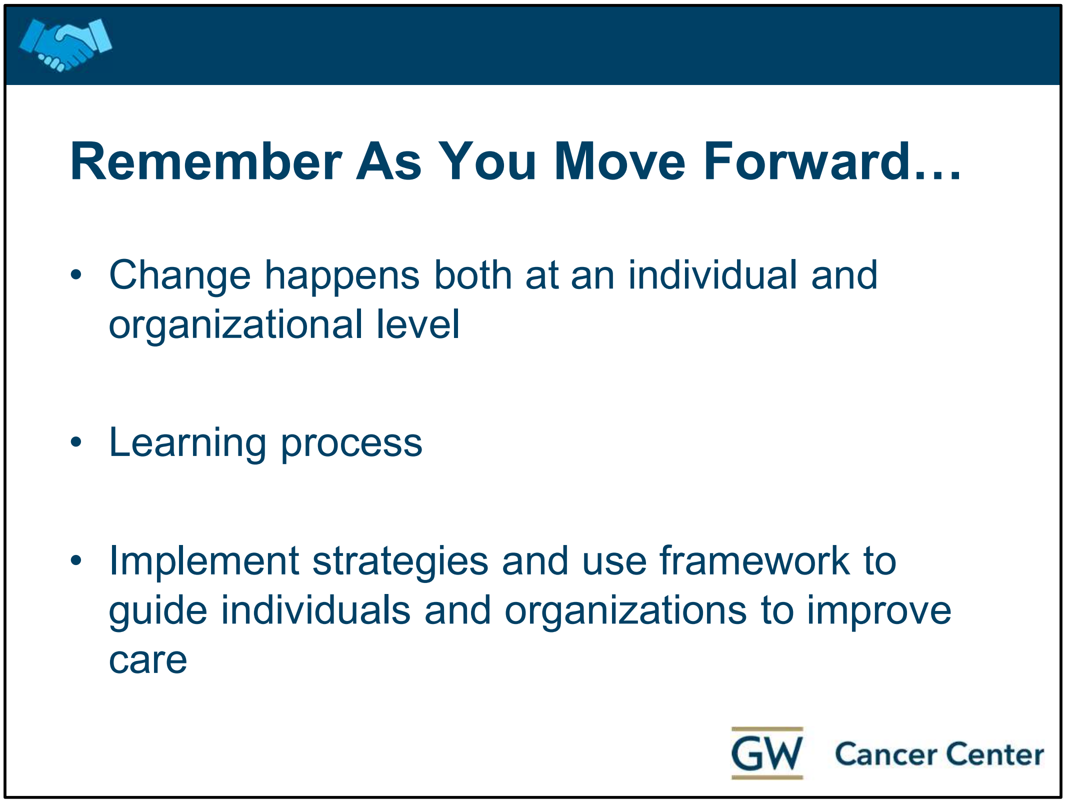
In this lesson, you learned to:
Identify a framework organizations can use to design initiatives to promote health equity
Recognize strategies to enact culture change to support the provision of culturally competent care in line with this framework



Remember As You Move Forward…

- Change happens both at an individual and organizational level
- Learning process
- Implement strategies and use framework to guide individuals and organizations to improve care

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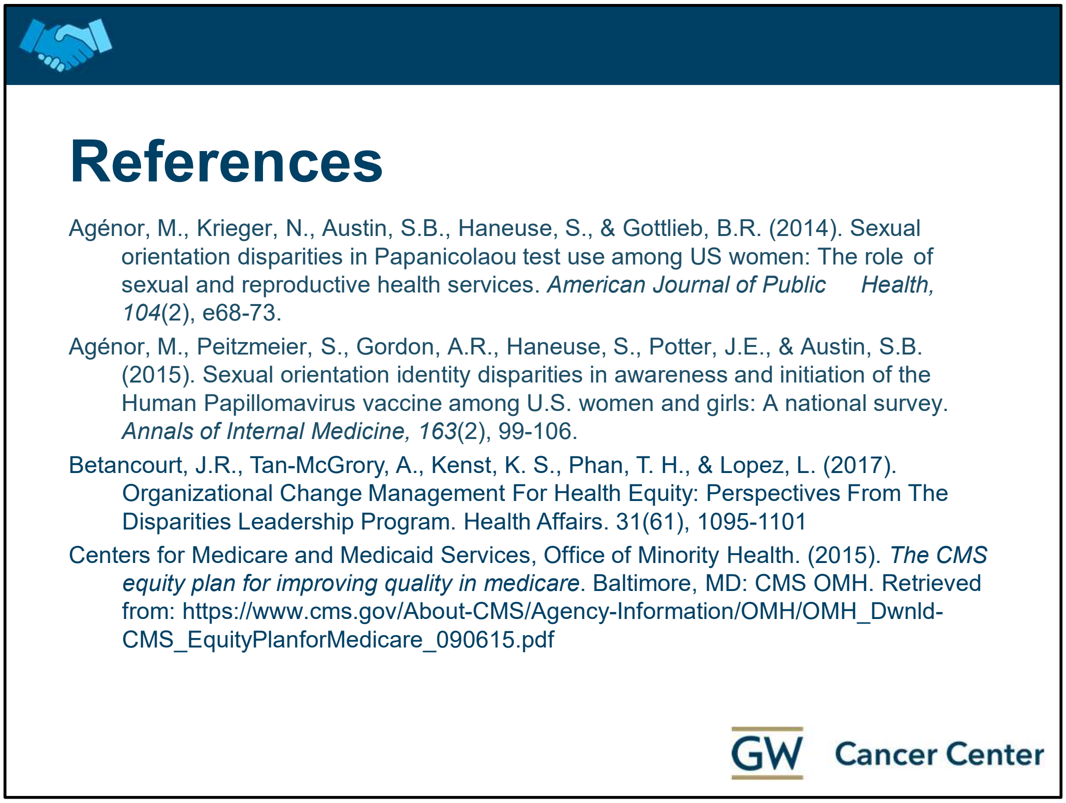
We have covered a great deal of material and concepts as part of the TEAM training, which is meant to serve as a starting point as you move forward in fostering an environment for patient-centered, equitable care across the cancer continuum.

It is important to remember that creating this change happens both at an individual and organizational level and that it will be a learning process for all involved. Throughout this training, we have highlighted strategies to help guide individuals and organizations to improve care, such as supporting patient-centered care through shared decision-making, self-advocacy, health literacy and culturally competent interactions.

We've concluded with a broader framework, the *Roadmap to Reduce Racial and Ethnic Disparities in Health Care,* which organizations can use to address cancer inequities and improve patient-centered care.

Thank you for taking time to participate in the TEAM training in order to help improve patient-centered and equitable care.



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Here is the full reference list of sources cited in this lesson.

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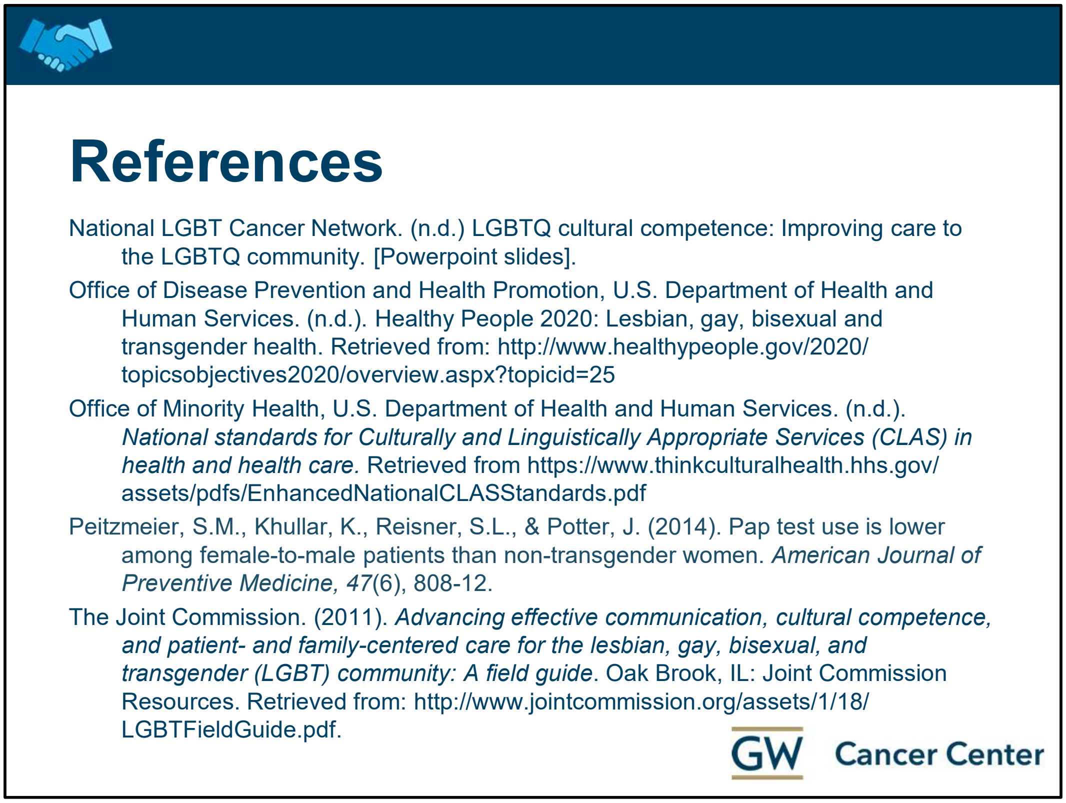

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