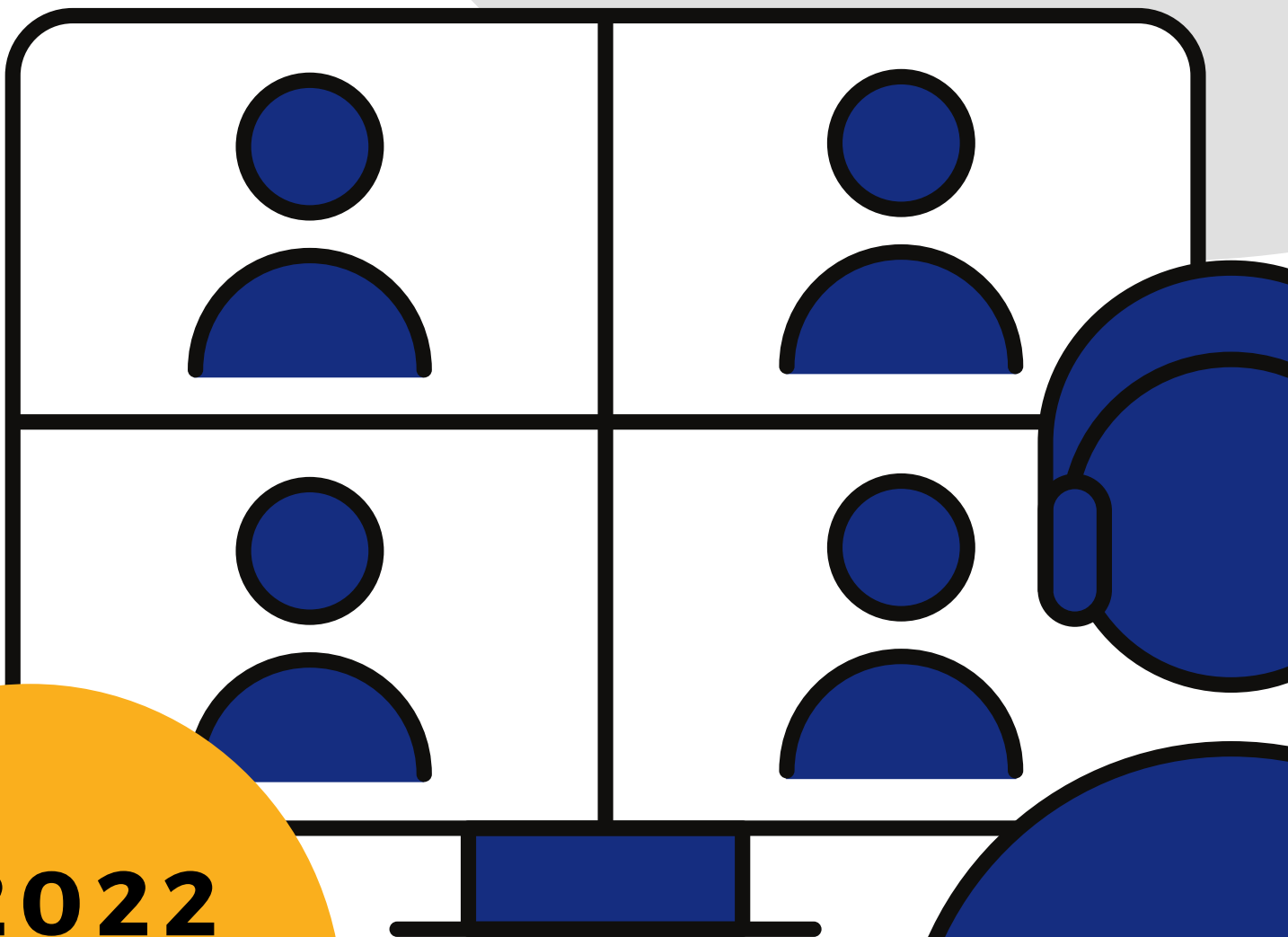# PATIENT INSiGHT

INSTITUTE

HEAR FOR ALL

A report capturing patient perspectives on biased and stigmatizing language used in research and care settings

2022

PAF Patient Advocate Foundation

Table of Contents

Acknowledgments

February 22, 2022 | Virtual Listening Session

Report Contributors:
Ono Abhulimen
Dymon Blango
Mary Mukira
Breanna Obando

Facilitators:
Dr. Rebekah Angove
Dr. Sarita Battish
Dymon Blango
Stephen Christoph
Sa'Brina Davis
Breanna Obando

**https://www.patientinsightinstitute.org/home/network**

Overview

Nearly 60 participants from around the country engaged in a listening session hosted by PAF's Patient Insight Institute. All attendees were recruited from a diverse pool of over 3k patients/caregivers, represent various medical diagnoses, and have experienced some level of access and/or affordability challenges in seeking health care.

LISTEN.GATHER. INFORM

The purpose of the listening session was to gather different views on stigmatizing language and terms used towards patients in research and clinical settings. To facilitate this discussion, members of the Patient Workgroup (PWG), Research Assistants (RSA's), and the project team facilitated six groups of five to seven participants each. By listening to the valuable perspectives offered, researchers and health care professionals can work towards connecting with patients in a more inclusive and understanding manner.

64% **36%**

Percentage of Participants by Gender Identity

Hispanic or Latino
7.1%

Asian
8.9%

White
53.6%

Black or African
28.6%
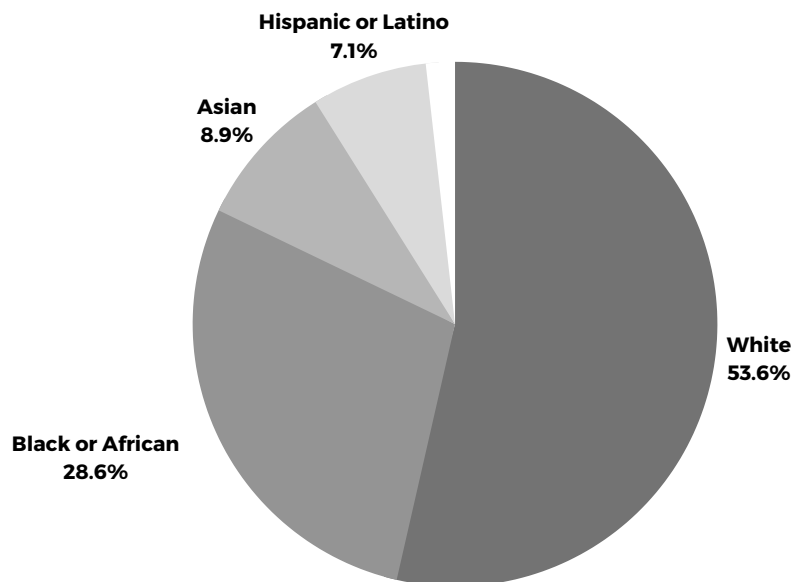
Percentage of Participants by Race/Ethnicity

Stigmatizing Language

Stereotypes are defined as widely held and often untrue generalized ideas or beliefs about a particular category of people. [1] Stereotypes are used as preconceived markers to categorize people who have similar attributes like culture, race, gender, religion etc. [2] Sometimes these preconceptions or assumptions are inaccurate because they fail to consider the unique characteristics of the individual. [1]

Negative Stereotypes

Implicit Bias

Negative stereotypes lead to stigmatizing language through implicit bias. Implicit bias is the automatic activation of stereotypes, which may override deliberate thought and influence one's judgment in unintentional and unrecognized ways. [3]

Stigmatizing Language

Stigmatizing language in healthcare can perpetuate negative discriminatory attitudes and influence clinicians' decision-making when treating a patient. This impacts the quality of care and contributes to health disparities. [4]
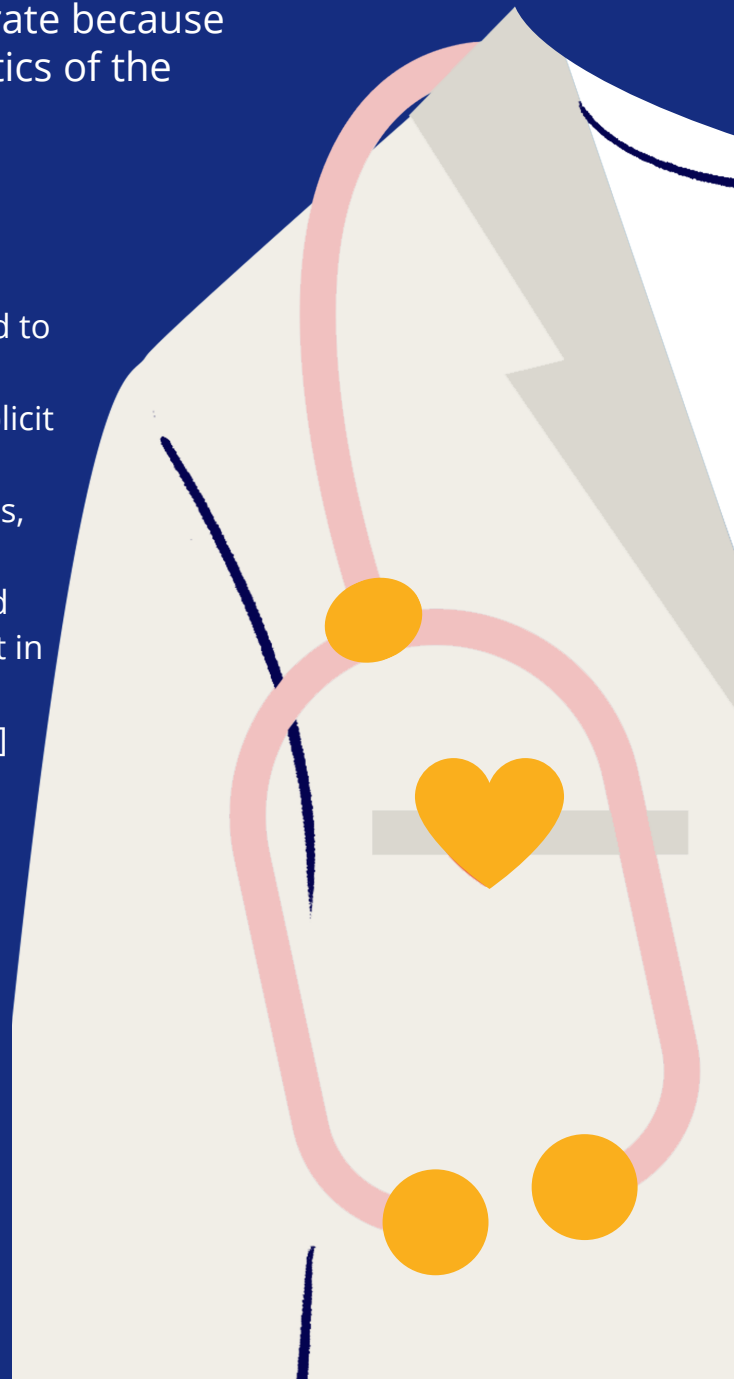
Patients' Experience in Bias

Topic 1 Findings:
What is potentially stigmatizing language, topics, or approaches?

Participants agree that assumptions based on **socioeconomic status, age, race, gender, and medical conditions** have the potential to undermine or invalidate a patient's lived experiences. As a consequence, a patient may develop distrust towards their medical provider and feel uncomfortable participating in research.

Ageism in Action: Patient Perspective

Ageism is systematic stereotyping or discrimination based on age. This can make patients less likely to seek health care, more likely to be under-treated, and less likely to engage in preventive behaviors such as regular exams, healthy eating, and exercise. [5]

Those who frequently experience ageism have a higher risk of developing a new disability or worsening existing ones. By characterizing all aches and pains of an older patient as "normal signs of aging" it makes it difficult for them to receive proper treatment. Many older patients are thus forced to convince themselves that what they are feeling is simply part of aging. [6]

"Assume nothing!"
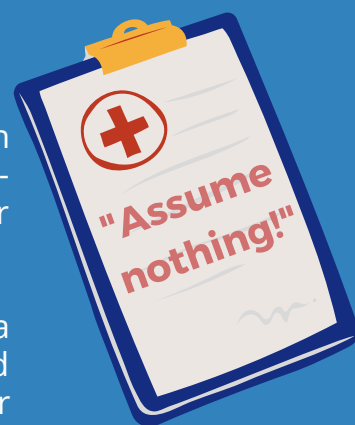
The assumption that only older patients are diagnosed with metastatic breast cancer fails to represent the prevalence of patients diagnosed at a younger age.

Assuming an elderly patient is not equipped to discuss their diagnosis because of age is a common occurrence in healthcare. [7] Patients find it specifically frustrating when their symptoms are underestimated because of preconceived judgments held by their providers.

Lack of effective communication from physicians is demonstrated when they address a patient as a third party and use a "condescending tone of voice" to speak.

Patients' Experience in Bias

Topic 2 Findings: What are some acceptable terms that can be used to describe patients who have challenges accessing or affording care?

Commonly used terms to describe patients who have challenges accessing or affording health care include: underserved, vulnerable, marginalized, socially disadvantaged, under-resourced, and limited resourced. However, patients regard these terms to have a **negative** connotation.

Underserved?

Vulnerable?

Marginalized?

Socially Disadvantaged?

Under-resourced?

Limited resourced?

Participants feel such terms inaccurately group patient's into categories that **do not** serve their individual needs. For instance, a patient's ability to fulfill their health needs heavily depends on factors that vary from person to person; geographic location is the main one. While all require health care, the quest to obtain it is specific to the cost of living and resources available in an area; this raises the importance of achieving **equitable** health care access.

Attendees would be **more** willing to participate in research if the language used to describe them resonated with their circumstances.

Patients want to feel
"welcomed, needed, and valued"

The patients and caregivers we spoke to suggest that researchers utilize person-centered communication as it "places a person's identity before any disability or medical condition they may have. Using person-centered language reduces stigma and improves the patient-physician relationship, potentially optimizing health outcomes." [8]

To combat "red flags" when communicating with patients, it is most effective to simply ask how they would like to be addressed.

This tactic promotes comfortability amongst patients. By training others to replace biased language (verbal or written), we can enact equitable care, create a trustworthy environment, and encourage authentic interactions.

"It's important to find words that are less stigmatizing because it affects how we see ourselves and others"

What You Can Do

Create generic surveys that ask patients to provide a self-description. Upon acquiring this information, researchers may reach out to those who fit the criteria needed for their study.

Refrain from labeling patients based on their job, income, or health condition.

Avoid generalizing patients. Each person has a unique situation and should not be categorized when spoken to individually.

References

[1]
Mcleod, S. A. (2015, October 24). *Stereotypes*. Simply Psychology. Retrieved from http://www.simplypsychology.org/katz-braly.html

[2]
Schiebinger, L., Klinge, I., Paik, H. Y., Sánchez de Madariaga, I., Schraudner, M., & Stefanick, M. (2011-2020). *Stereotypes*. Gendered Innovations in Science, Health & Medicine, Engineering, and Environment. Retrieved from https://genderedinnovations.stanford.edu/

[3]
P. Goddu, A., O'Conor, K. J., Lanzkron, S., Saheed, M. O., Saha, S., Peek, M. E., Haywood, C., & Beach, M. C. (2018). Do Words Matter? Stigmatizing Language and the Transmission of Bias in the Medical Record. *Journal of General Internal Medicine*, 33(5), 685–691. https://doi.org/10.1007/s11606-017-4289-2

[4]
Park, J., Saha, S., Chee, B., Taylor, J., & Beach, M. C. (2021). Physician Use of Stigmatizing Language in Patient Medical Records. *JAMA Network Open*, 4(7). https://doi.org/10.1001/jamanetworkopen.2021.17052

[5]
Understanding Why Ageism in Health Care is a Serious Concern. Regis College Online. (2019). Retrieved from https://online.regiscollege.edu/blog/why-ageism-in-health-care-is-a-growing-concern/

[6]
Hoyt, J. (2022, May 20). *How Ageism in Health Care Is Affecting Society*. SeniorLiving.org. Retrieved from https://www.seniorliving.org/health/ageism/

[7]
Elwell, V. (2022, March 8). *Fighting Ageism in Healthcare*. UCI Health. Retrieved from https://www.ucihealth.org/blog/2022/03/combatting-ageism-in-healthcare

[8]
Ottwell, R., Heigle, B., Reddy, A. K., Sajjadi, N., Wirtz, A., Cook, C., Howard, H., Hartwell, M., & Vassar, M. (2021). The Use of Person-Centered Language in Medical Research Journals Focusing on Psoriasis: Cross-sectional Analysis. *JMIR Dermatology*, 4(1). https://doi.org/10.2196/28415