

Learning from Patients and Communities: Shared Decision Making for People Living with Cancer

Value in Cancer Care Summit

November 6, 2025

Gwen Darien, EVP, Patient Advocacy,

Engagement and Education

Patient Advocate Foundation

Three Communities, One Mission

Fannie Lou Hamer Cancer Foundation,
Ruleville, MS

Los Angeles Alliance for Community Health and
Again, Los Angeles

VCU Massey Comprehensive Cancer Center,
Richmond, VA

Connected By Common Threads

- Most knew about SDM
- Important to understand how to ask questions and get answers about their illness/condition
- Finding providers that they trusted
- Discussing cost of care with providers was difficult
Insurance benefits and coverage were limited
- Access to transportation/travel time created obstacles
- Most wanted to learn about self-advocacy
- Many wanted to “pay it forward” by advocating for others

Primacy of Relationships

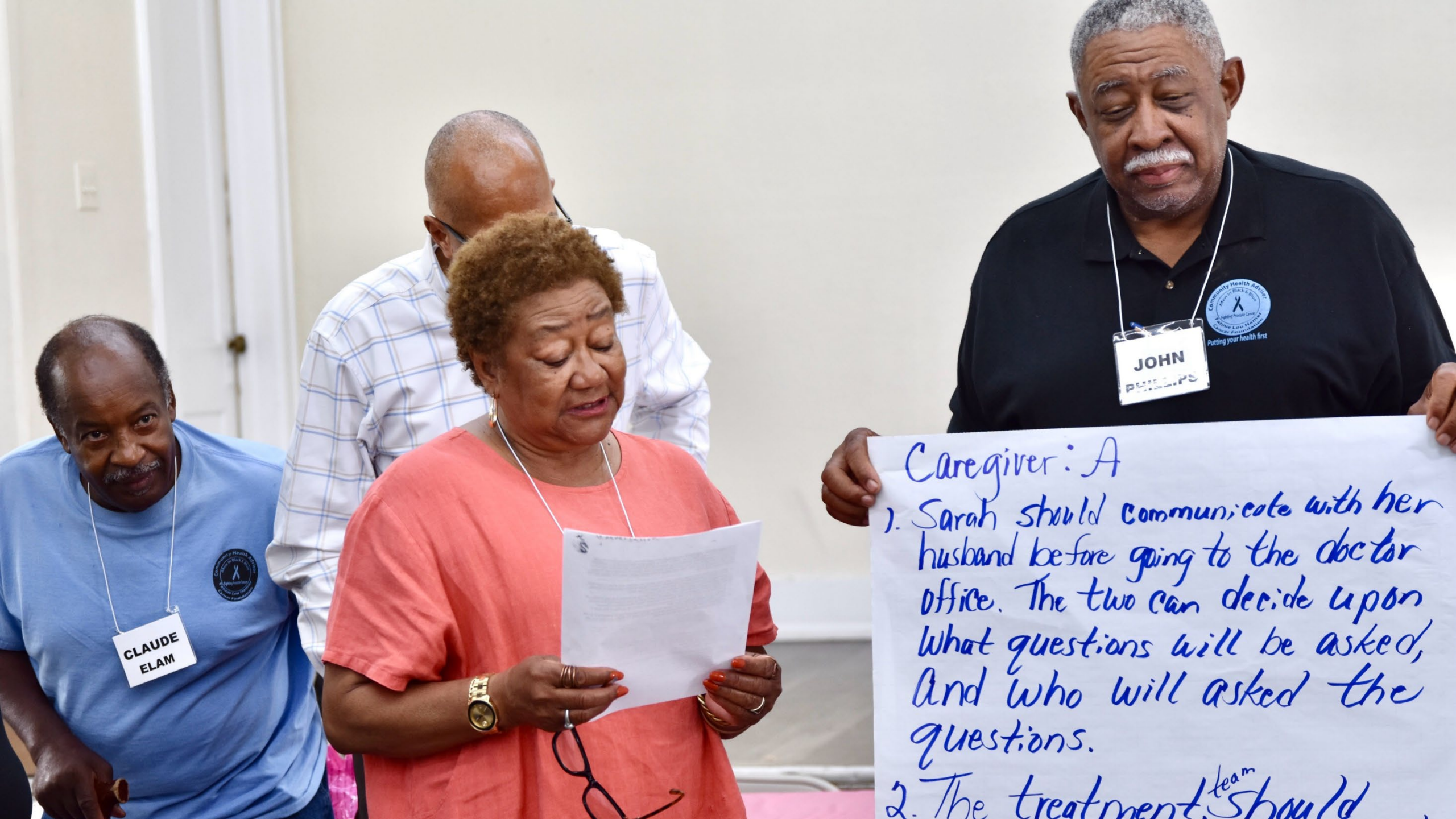
- Mutual Trust and Trustworthiness
- Being Seen, Known and Heard
- Respect











CLAUDE
ELAM

JOHN
PHILLIPS

Caregiver: A

1. Sarah should communicate with her husband before going to the doctor office. The two can decide upon what questions will be asked, And who will asked the questions.

2. The treatment ^{team} should





SAMMY

FIGHT IN BLACK & BLUE
FIGHTING HOSPITAL CANCER

SAMMY
McCASKILL

CO-PAY RELIEF



Hard Issues. Difficult Conversations

- Changing treatments or ending treatment
- Costs of care and daily living
- Impact on sexual functioning



Vanessa
Spurlock







Robin Klöncke

Robin
Klöncke

KN95
EQUIVALENT
UL-USA-2562







Without Judgment

- Impact of real or perceived judgments of biases about race, sexuality, and personal qualities, individual choices











Freddie
Muse, Jr.

The
LYN'S CANCER
Network





Building Self- Trust

- Self-esteem—global sense of self-worthiness
- Self-efficacy—confidence in ability to perform specific behavior/s in a context
- Self-trust—both the one trusted and the one extending trust

Grob, van Gorp, Evered

Thank you!

gwen.darien@patientadvocate.org