



Multidisciplinary Approaches to Cancer Symposium

Community Engagement and Activation in Cancer Research and Care



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Disclosures

I do not have any relevant financial relationships.

This presentation and/or comments will provide a balanced, non-promotional, and evidence-based approach to all diagnostic, therapeutic and/or research related content.



Cultural Linguistic Competency (CLC) & Implicit Bias (IB)

STATE LAW:

The California legislature has passed Assembly Bill (AB) 1195, which states that as of July 1, 2006, all Category 1 CME activities that relate to patient care must include a cultural diversity/linguistics component. It has also passed AB 241, which states that as of January 1, 2022, all continuing education courses for a physician and surgeon **must** contain curriculum that includes specified instruction in the understanding of implicit bias in medical treatment.

The cultural and linguistic competency (CLC) and implicit bias (IB) definitions reiterate how patients' diverse backgrounds may impact their access to care.

EXEMPTION:

Business and Professions Code 2190.1 exempts activities which are dedicated solely to research or other issues that do not contain a direct patient care component.

The following CLC & IB components will be addressed in this presentation:

- *Ethnically diverse patient and community informed approaches to engagement and activation in care and research.*
- *Discussion of disparities in care outcomes and research inclusion. Highlight systemic and provider level barriers.*



Faces of Cancer



Evidenced Based Practice

- EBP has emerged as a cornerstone of modern healthcare, promoting **the integration of the best available scientific evidence, clinical expertise, quality care, and patient values and preferences** to guide clinical decision-making and improve patient outcomes. Dustin et al, BMJ Open 2023 13(5):e071188
- **Patient, caregiver, and advocate engagement and experiences** are fundamental principles of EBP. At COH we have longstanding Patient Advisory Councils including a Latinx Patient Advisory Council
- The **benefits** of EBP are improved quality of treatment, quality of care, better patient outcomes, and improved efficiency in care delivery
- The **Science of Patient Engagement Engenders Whole Person Care**
 - Cancer patients are people first with lives and lived experiences before cancer and throughout survivorship
 - Personhood – Identities, meaning, roles, competing demands
 - Family – Living Situation, Family stability, Care-giving
 - Community – Neighborhood, Social Network, Support
 - Society – Social Status, Bias, Societal Drivers of Health

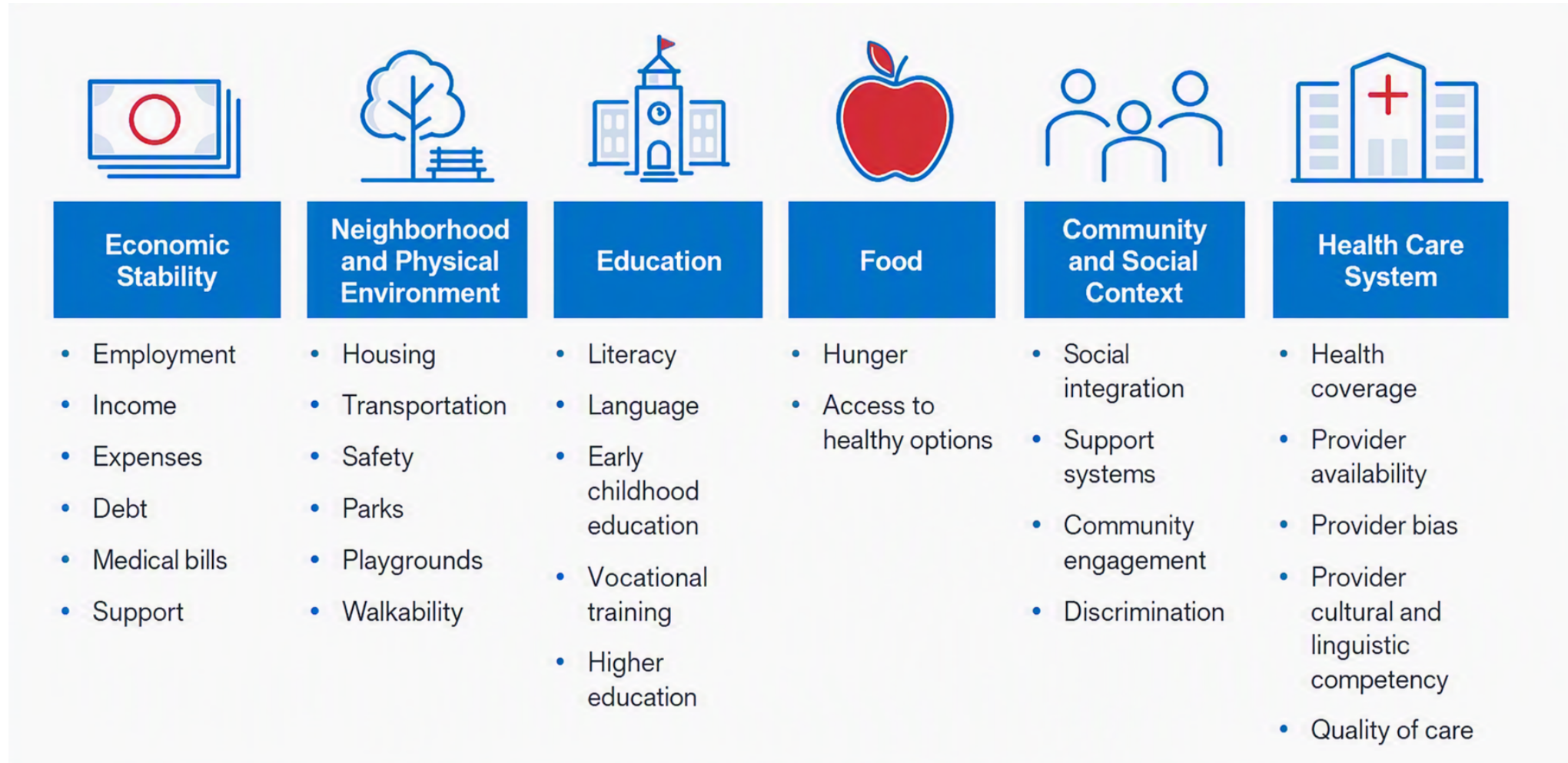


"Having confidence in your health care team and finding the inner strength to possess joy and beauty are keys to survivorship."

Sol Reyes, RN
Retired Nurse
Former President, OC, CA
Hispanic Nurses Association



Domains of the social/societal drivers of health



What Determines the Health of Populations?

Modifiable Societal Determinants of Health: Less/Non-Modifiable Determinants of Health:

- **ZNA (Zip Code)**

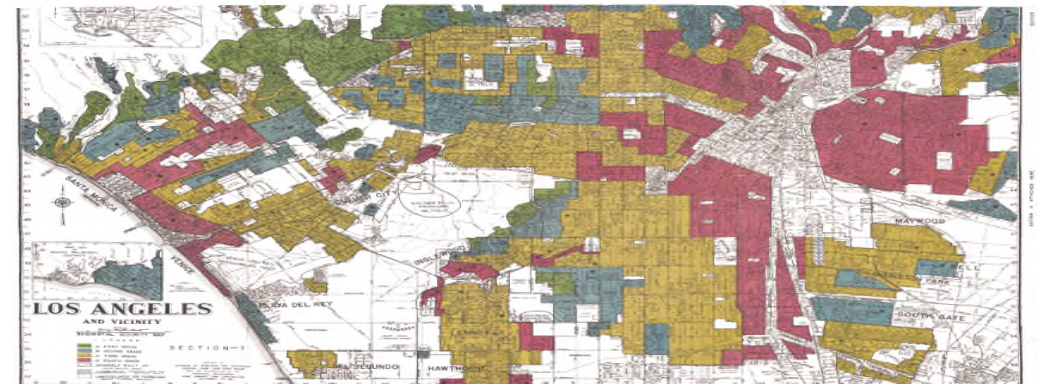
- Economic factors
- Physical environment factors
- Segregation, discrimination
- Health behaviors

- **CNA (clinical)**

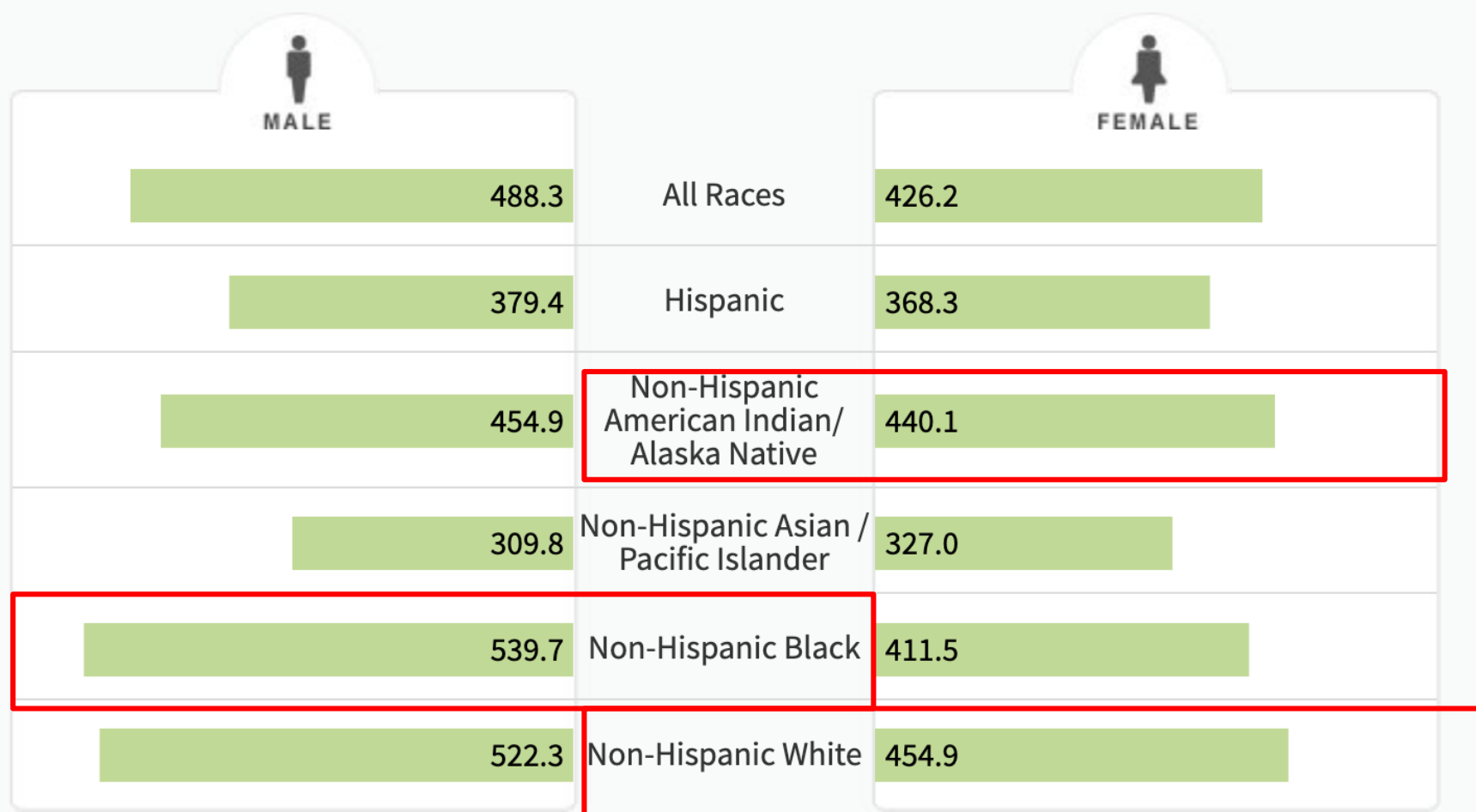
- Access
- Availability
- Affordability
- Quality of Treatment
- Quality of Care

- **DNA (Biology)**

- Biology and Genetics: some biological and genetic factors affect specific populations more than others (e.g., prostate cancer, sickle cell in African Americans/Blacks)
- Examples of biological and genetic determinants of health include age, sex, inherited mutation e.g., BRCA1 or BRCA2, family history



Rate of New Cases per 100,000 Persons by Race/Ethnicity & Sex: Cancer of Any Site



SEER 21 2019–2023, Age-Adjusted



Death Rate per 100,000 Persons by Race/Ethnicity & Sex: Cancer of Any Site

MALES	
All Races	168.3
Hispanic	121.9
Non-Hispanic American Indian/Alaska Native	175.8
Non-Hispanic Asian/Pacific Islander	104.2
Non-Hispanic Black	198.6
Non-Hispanic White	175.2

FEMALES	
All Races	124.7
Hispanic	92.3
Non-Hispanic American Indian/Alaska Native	139.5
Non-Hispanic Asian/Pacific Islander	81.6
Non-Hispanic Black	141.1
Non-Hispanic White	129.8

U.S. 2020–2024, Age-Adjusted

Addressing Cancer Burden and Engagement

[NCCN Patient Advocacy Summit: Advancing Family-Centered Cancer Care](#) 12/3/2026

ASCO Certified: Patient-Centered Cancer Care Standards

CancerCare.org

Cancer.org - American Cancer Society

Findhelp.org – SDH

Cancersupportcommunity.org - Cancer Support Community

Cancer Legal Resources Center **LawHelp.org**

cancer.gov/about-cancer/coping/survivorship

lcri.org - Latino Cancer Research Institute

iCCaREconsortium.org – Prostate Cancer in Black Men



Science of Engagement in Cancer Research and Policy



Science of Engagement in Cancer Research and Policy

Community engaged science emphasizes shared leadership and mutual benefit in scientific partnership with patients and advocates

Benefits from patient and advocate involvement in:



Research partnership: prioritization; inclusion of patient reported outcomes, HRQOL, survivorship; design; development; approach; implementation; recruitment and retention; interpretation of the results; and dissemination of findings → increase relevance, acceptability and benefit from research



Science Communication: sharing, science ambassadors, study champions, testimonies → improve the public perceptions, credibility, trust, support; and impact policy, prioritization, funding



Advocate Engagement in Research

- Research and clinical studies (trials) play an important role in discovering new treatments as well as new ways to detect, diagnose, and reduce the risk of disease. However, **participation is a challenge** in particular among minoritized communities including people of color, rural, low SES communities.
- To accelerate science and gain best population benefit from health research advancements, **we must increase participant diversity**. We know that community health leaders are central to community health knowledge and behaviors, including the decision to participate in research.
- We have heard from patients and advocates "***we must be included.***"



Advocates are the Pillars of Health and Science



Powerful Agents of Change

- Research - Improve research design, participation and results
- Practice, Health Care – Using research findings to improve practice/healthcare
- Public Trust – Public and community awareness, confidence and support for science
- Who are Prioritized - Findings inform priority populations
- Policy - What is prioritized
- Funding

Healthcare and Policy

- Care program CDC – [Breast and Cervical Cancer Early Detection Program](#)
- SB987 – [California Cancer Care Equity Act](#)
- NCCN – [National Comprehensive Cancer Network - Home](#)



Research

- DOD – [Congressionally Directed Research Program](#)
- PCORI – [Patient Centered Outcomes Research Program](#)
- CBCRP – [California Breast Cancer Research Program](#)
- TRDRP – [Tobacco Related Disease and Research Program](#)



Cultivating Community Partnerships: How

5 C's of community (patient, advocate) engagement:

1. Communication
2. Collaboration
3. Capacity-building
4. Commitment
5. Continuity

...is a value-based and strategic framework for nurturing lasting and impactful relationships with advocates.



Building Partnerships: How

- Humility
- Relationship
- Communication
- Performance
- Best Practices
- Mutual Respect
- Ongoing, bi-directional learning
- Building Capacity
- Building Infrastructure
- Sharing and gift giving

What is "Cultural Humility"?

Emphasizes an ongoing process of self-reflection and personal growth rather than a finite set of skills or knowledge. It calls for individuals to acknowledge the limitations of their own cultural understanding, maintain an attitude of openness and respect, and continuously engage with other cultures in a way that is humble and nonjudgmental.



Best Practices in Communicating with Patient, Advocates and Communities

1. Be Genuine and Caring:

Understand Your Audience

- **Who are they?** demographics, sectors: policymakers, the general public, or a specific group?
- **What do they already know?** Tailor your message to their existing knowledge base.
- **What are their interests and concerns?** Address their unique needs, perspectives, concerns, & danger of stereotyping.

2. Clear and Simple Language:

- **Avoid jargon:** Use everyday language and explain technical terms when necessary.
- **Keep it concise:** Get to the point quickly and avoid unnecessary details.

3. Visuals:

- **Use images, graphs, videos:** Visuals can make complex information easier to understand and remember.
- **Create infographics:** Summarize key findings in a visually appealing way.



Best Practices in Communicating with Patients, Advocates and Communities

4. Storytelling:

- **Make it relatable:** Connect your research to people's lives and experiences.
- **Start with a hook:** Grab attention with a compelling question, anecdote, or problem statement.
- **Focus on the “why” “why me”, “why you”:** Share the overall and personal importance and impact.

5. Engage with Your Audience:

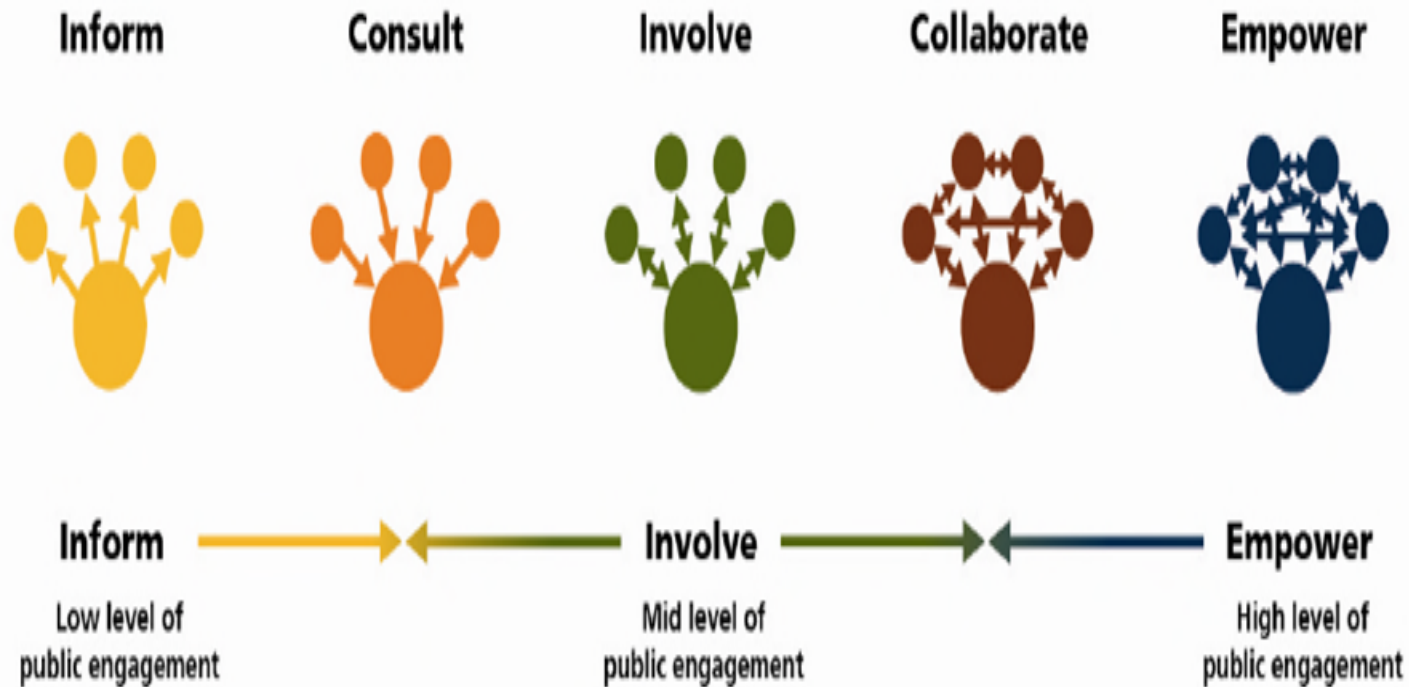
- **Ask questions:** Encourage dialogue and interaction.
- **Address misconceptions:** Create safe spaces, Correct common misunderstandings about science.
- **Be open to feedback:** Listen to your audience and be willing to adjust your approach.

6. Practice and Seek Feedback:

- **Practice your communication skills:** Seek opportunities to present your research to different audiences.
- **Get feedback from others:** Ask for constructive criticism and use it to improve.
- **Stay up-to-date and data:** Keep learning, access current data and cultivate learning and doing collaboratives.



Advocacy in Science: Engagement Spectrum



Identifying and Selecting Advocate Partners

- **Brainstorming**

- What organizations should we be working with?
- Who are the leaders and gatekeepers (formal and informal)?
- How is information shared in our community?
- What research positions might our research project need and who, from the community, could fill those positions?
- Who (or what kinds of people) could be on a Community Advisory Board?

- **Defining a priority population**

- Defining the community
- Documenting community resources and services
- Documenting community members' perspectives on care quality, delivery; systemic, clinic, provider, cultural/personal barriers to care; community resources and need



Community Health Workers as Advocates

Community Health Workers (CHWs)

- Represent a Unique Workforce to Facilitate Cancer Screening, Patient Care, and acceptability and participation in research including clinical trials.
- Frontline, Community health representatives, promotoras, lay health workers
- Trusted members of the team and have a deep understanding of the community they serve.

In patients with metastatic cancer, CHW-led ACP interventions after the initial oncology visit, reduced acute care costs and improved engagement.





The Community Scientist Advocate (CSA) Training Program aims to:

Propel health advocacy to increase community voice, representation, and benefit from biomedical science, especially focused on cancer prevention, care, and research

Enhance science communication and public speaking skills

Expand advocacy network and resources

Accelerate community awareness and benefit from science

Advance public trust in science

Amplify advocacy role in science



Community Impacts (N= 125 trained)

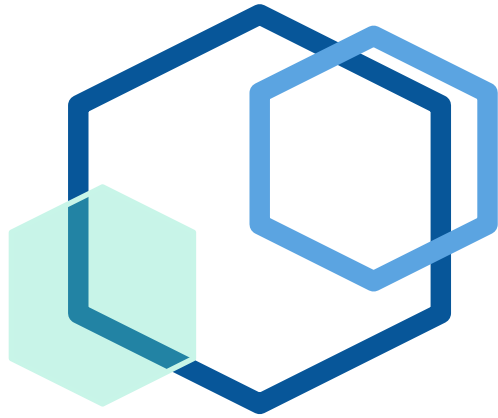
197 community activities have been conducted by CSA trainees to increase awareness and uptake of cancer prevention, screening and clinical study in their communities

- o Implementation: Formal and Informal Health education, research referral, research navigation, referral to SDH resources
- o Reach: 3,500+ Community Members

12 people participated in clinical studies (CSA action).

Studies include: Severe Aplastic Anemia (IRB#23139), Lung Cancer Biopsy, Smoldering Multiple Myeloma_LEF (IRB#1301817), AMBER-LA, HEAL Study, COUCH Study, Pancreatic Cancer –Phase 1 study, HARMONi-GI3-Colorectal Cancer, Autism Study 22_001547, Adjuvant WIDER for BCA, and the Dementia Caregiving Study





LEGISLATIVE PROPOSAL: THE CALIFORNIA CANCER CARE EQUITY ACT (SB 987)

2021 saw exciting advances: The Cancer Patients Bill of Rights resolution passed unanimously by the California Legislature, making it the first state to adopt a bill of rights for cancer patients.

The Bill of Rights lays out six rights that every cancer patient should be entitled to, from access to promising new innovations, experts specializing in various cancer types, and advances in personalized, precision cancer treatments.

In order to make this a reality for California's most vulnerable, we need a legislative solution.





California Cancer Care Equity Act (SB-987)
expands access to specialized cancer care at
NCI-designated comprehensive cancer centers
and other qualifying cancer centers
for Medicaid beneficiaries with complex cancers

A PROJECT OF





United We Stand

We are all part of strides for success in cancer advocacy that is the confluence of good therapeutic care and quality patient care that attends to the compelling needs of patients and care-givers in the cancer contexts as well as their lived experiences and identities – ethnicity, language, rurality, low socio-economic status, etc-- to care for the whole person.

Thank You



CCARE Community Partners

FQHCs	Advocacy & Policy Organizations	Community Based Organizations
		
		
		
		
		
		
		

Center of Community Alliance for Research & Education (CCARE)



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*Organizations may span multiple roles; primary classification reflects core function



Table I. Patient Engagement Processes in EBP Models and Frameworks.

Evidence-based practice frameworks	Components of engagement extracted from the literature
ACE Star Model ⁸	- Measures patient outcomes - Does not mention processes for engaging patients.
Advancing Research and Clinical Practice ⁵	- Focuses on supporting a culture for EBP. - Recommends the EBP paradigm (best evidence, clinical expertise, and patient values and preferences) for the implementation phase.
Clinical Excellence Through Evidence-Based Practice ⁹	- Does not include any structure or processes for engagement of patients. - Recommends the integration of qualitative research on patient preference (if available) before the evidence can be determined to be applicable. - Identifies patient factors as critical appraisal components prior to piloting and implementing a change in clinical practice. - There is no description of how these data are obtained and the degree of engagement beyond consultation for direct care.
The Clinical Scholar Model ¹⁰	Focuses on patient values and preferences in the evidence and the patient experience during implementation.
The Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Health Care ¹¹	- Advocates for inclusion of diverse populations and diverse perspectives that reflect variation in priorities. - Promotes engagement by providing synthesis of literature if qualitative research is not available to gain additional insights from population of interest. - Uses co-design principles in implementation of pilot project with patient advisory boards and considers patient-led/patient-focused evaluation. - Reviews patient-specific data and learns patients' experiences and preferences; identifies patient outcomes; adjusts implementation plan. - Engages patients at policy level through advocacy for change in policy or practice; patient stakeholders may be part of the shared governance team. - Does not specifically include patient involvement in EBP processes in the EBP manual. - Includes stakeholder engagement in the implementation manual. - Does not fully integrate patients as stakeholders in planning and implementation.
Johns Hopkins Evidence-Based Practice Model ¹³	- Uses organizational data (eg, quality improvement or financial data, local clinical expertise, patient/family preferences) - Engages stakeholders which includes patients and/or families, patient and family advisory committee. - Includes evaluation of patient's perspectives in the levels of evidence. - Recommends the EBP team discuss potential harm associated with the best evidence recommendations with patients, staff, and the community.

