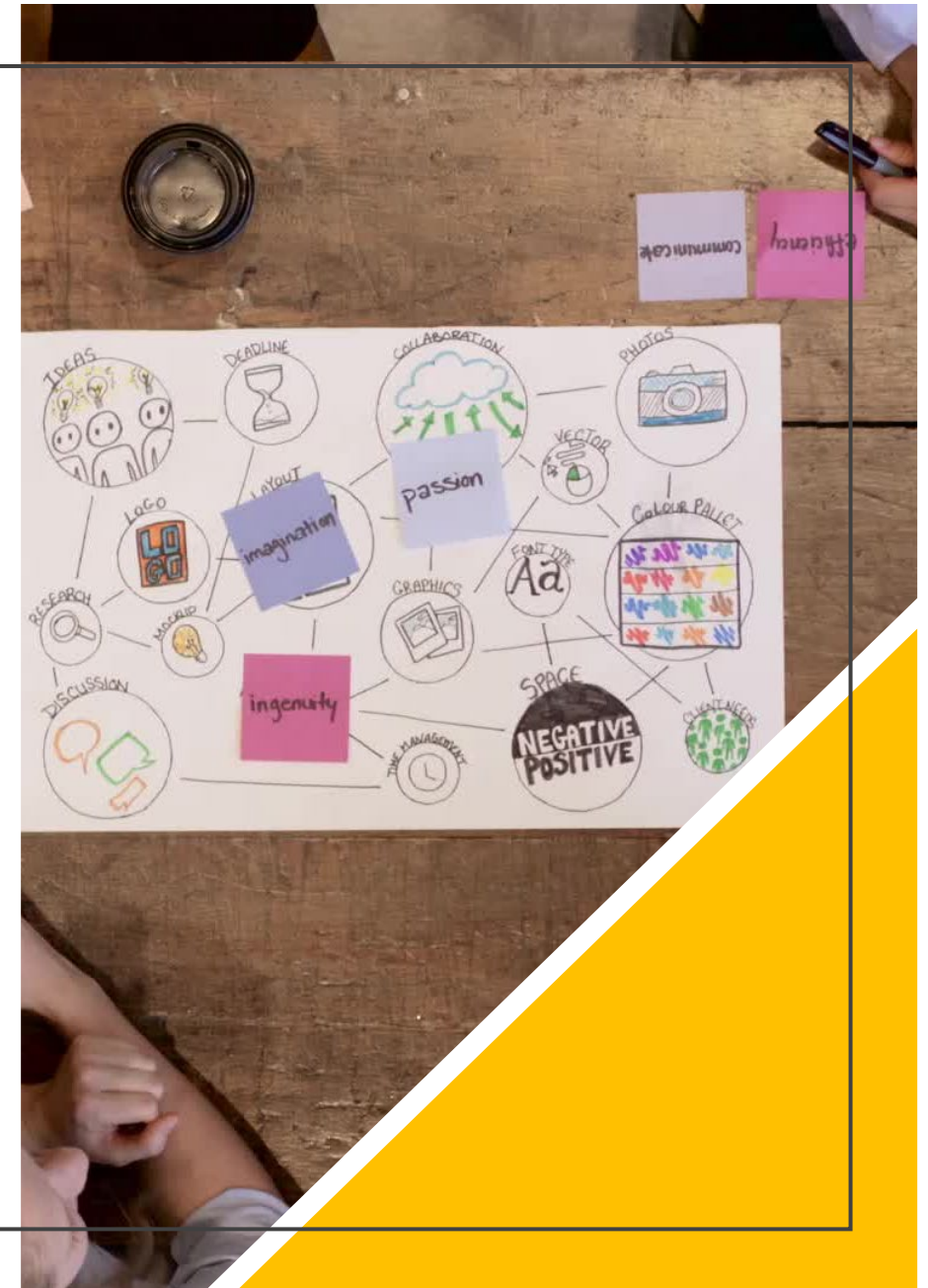


# *Ad Hoc* Population Science, Epidemiology, and Disparities Subcommittee

*December 5<sup>th</sup> Ad Hoc Subcommittee Presentation (2:20-3:20 PM)*

# Agenda

- Welcome and Introductions
- Review Charge of *ad hoc* Working Group and Membership
- Description of Sources of Data/Information
- Presentation of Report of *ad hoc* Working Group
- Open discussion
- Next Steps
  - Report
  - Charge for *ad hoc* Subcommittee



- “The National Cancer Advisory Board (NCAB) *ad hoc* Subcommittee on Population Science, Epidemiology and Disparities will convene an *ad hoc* Working Group that will advise on strategic approaches and opportunities for research on cancer among racial and ethnic minorities and underserved populations.
- The NCAB *ad hoc* Subcommittee has identified this area of focus as having high potential impact on reducing health disparities.
- The *ad hoc* Working Group is charged with identifying and evaluating the current status, barriers to progress, new potential strategic approaches to better address cancer research on racial and ethnic minorities and underserved populations, and potential actions to implement the new strategic research approaches effectively.”

Source: NIH Website, June 11, 2022

# Working Group Charge

# Population Groups Included

- *Black or African American, Hispanic/Latino; American Indian/Alaska Native; Asian/Pacific Islander; rural; older adult; LGBTQ; AYA*

# Membership

## **Co-chairs:**

- Chyke Doubeni, M.D., M.P.H.
- Elena Martinez, Ph.D.
- Electra Paskett, Ph.D.

## **Designated Federal Official:**

- Philip E. Castle, Ph.D., M.P.H.

## **Members:**

- Melissa L. Bondy, Ph.D.
- Luis G. Carvajal-Carmona, Ph.D.
- Bettina F. Drake, Ph.D., M.P.H.
- Jeffrey A. Henderson, M.D., M.P.H.
- Chanita Ann Hughes-Halbert, Ph.D.
- Karen E. Knudsen, M.B.A., Ph.D.
- Lisa A. Newman, M.D., M.P.H., F.A.C.S.
- Augusto C. Ochoa, M.D.
- Colin Weekes, M.D., Ph.D.
- Cheryl L. Willman, M.D.

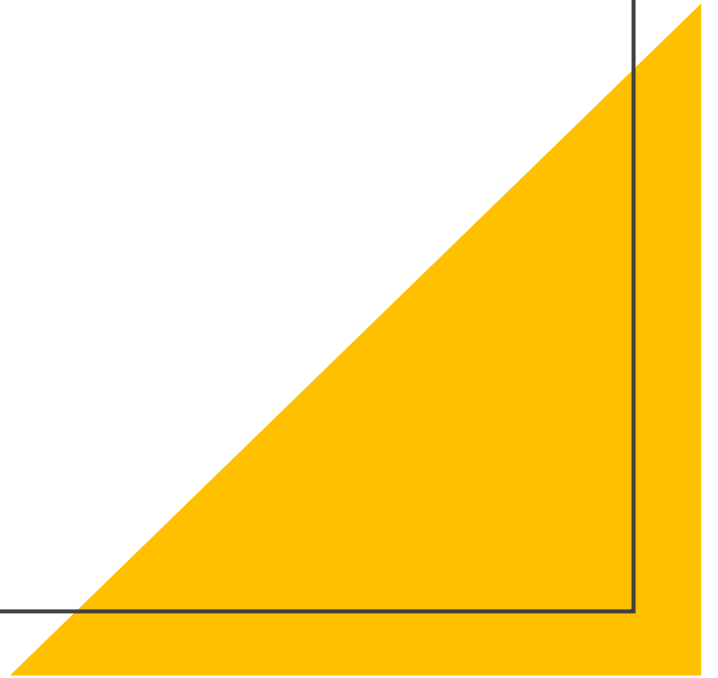
# Sources of Data/ Information

- First monthly meeting – July 2021
- Monthly co-chair meetings
- Speakers from NCI
  - Center for Research Strategy (CRS) – Michelle Bennett, PhD, Diane Palmieri, PhD, Christine Burgess, PhD
  - DCCPS - Shoba Srinivasan, PhD
  - CRCHD – Sanya Springfield, PhD

# Outline of Report

1. Executive Summary of Findings and Recommendations
2. Overview of Charge
3. Definition of Disparities and Frameworks
4. Cancer Continuum
5. Cancer Disparities in Populations of Focus
6. Analysis by NCI Center for Research Strategy ( FY21 NIH Cancer Research Grants)
7. Summary and Recommendations
8. References

# REPORT









# Background

- Definition of Disparities:
  - Health disparities reflect preventable differences in disease burden that can be attributed to disadvantage in disease risk and outcomes due primarily to structural and social factors.
  - Cancer health disparities are differences that occur in cancer-related outcomes, that should not occur.
- Multi-level Frameworks:
  - Developed to support and guide interventions and other strategies to enhance cancer outcomes and
  - Eliminate disparities and achieve equity among populations that experience disparities

# Example of a Framework

## National Institute on Minority Health and Health Disparities Research Framework

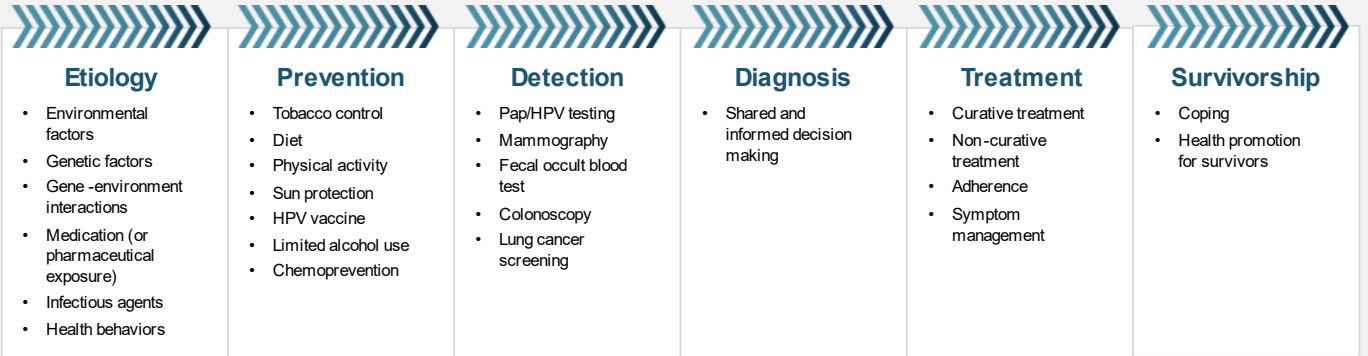
		Levels of Influence*			
		Individual	Interpersonal	Community	Societal
Domains of Influence <i>(Over the Lifecourse)</i>	Biological	Biological Vulnerability and Mechanisms	Caregiver–Child Interaction Family Microbiome	Community Illness Exposure Herd Immunity	Sanitation Immunization Pathogen Exposure
	Behavioral	Health Behaviors Coping Strategies	Family Functioning School/Work Functioning	Community Functioning	Policies and Laws
	Physical/Built Environment	Personal Environment	Household Environment School/Work Environment	Community Environment Community Resources	Societal Structure
	Sociocultural Environment	Sociodemographics Limited English Cultural Identity Response to Discrimination	Social Networks Family/Peer Norms Interpersonal Discrimination	Community Norms Local Structural Discrimination	Social Norms Societal Structural Discrimination
	Health Care System	Insurance Coverage Health Literacy Treatment Preferences	Patient–Clinician Relationship Medical Decision-Making	Availability of Services Safety Net Services	Quality of Care Health Care Policies
Health Outcomes		 Individual Health	 Family/ Organizational Health	 Community Health	 Population Health

# Cancer Continuum

The WG examined research across the continuum within the populations of focus, in order to identify gaps where attention is warranted and priority be assigned

## THE CANCER CONTROL CONTINUUM

### FOCUS



### CROSSCUTTING AREAS

- Communications
- Surveillance
- Health Disparities
- Decision Making
- Implementation Science
- Health Care Delivery
- Epidemiology
- Measurement

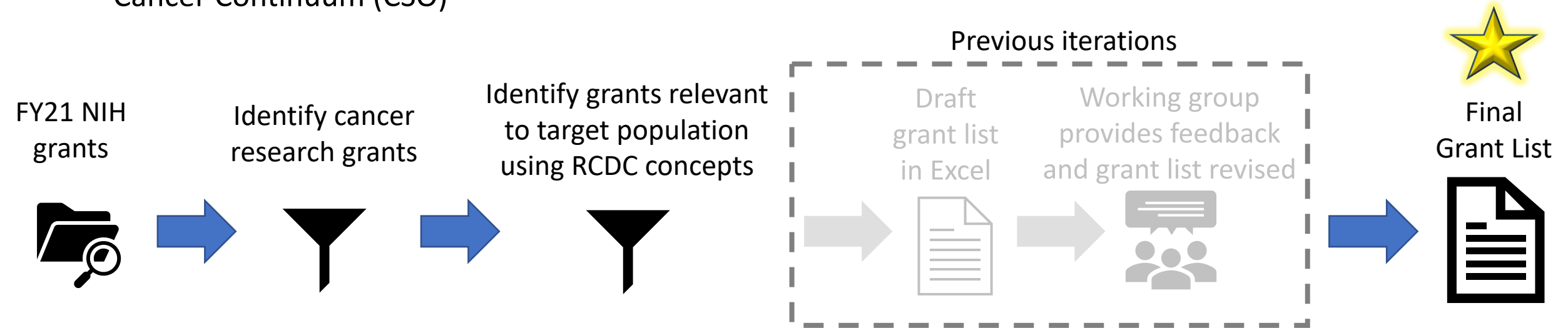
# NIH Funded Cancer Research Related to Selected Populations

*Center for Research Strategy*

*CRS Project Team: Josh Collins, Christine Burgess, Diane Palmieri*

# Overview of CRS Approach to Identify Cancer Research Relevant to Populations of Interest

- Base Project (Research)
- Target population (RCDC concepts)
- Cancer Continuum (CSO)



- Populations of Interest: Black or African American, American Indian or Alaska Native, Asian, Hispanic, Pacific Islander, Rural American, Sexual & Gender Minorities

# What is a Base Project?

- NIH grants are either single component (such as an R01) or multi- component (such as a P01 or a U54)
- Multi-component grants are comprised of a parent project and sub-projects which all share the same base project number (such as U54CA654321)
- In this analysis counted unique base projects and a base project is included if at least one component (i.e., subproject) was identified as relevant in a search strategy

# Exclusion Criteria

- Award supplements (Type 3)
- International/Domestic Training & Career (Fs, Ks, Gs, Hs, Ts, D43, D71, M01, R00, R13, R25, R90, U13)
- P30 (Cancer Centers)
- NCORP
- International Projects
  - Fogarty International Center grants
  - Center for Global Health grants
  - Grants with foreign countries in title
- Subproject Cores

## Research, Condition, and Disease Categorization (RCDC)\*

- The Research, Condition, and Disease Categorization (RCDC) system is utilized by the NIH in its reporting process to categorize funding in biomedical research for each fiscal year
- Automated text mining of projects produces a weighted list of *concepts* from the RCDC Thesaurus called a project index
- The *categories* are also weighted with lists of concepts that define a research area, condition, or disease

\* Research Condition and Disease Categorization (RCDC) is an NIH project categorization system

<https://report.nih.gov/funding/categorical-spending/rcdc>



# Perspective on Type of Research Using the ICRP Common Scientific Outline (CSO)

- ICRP Cancer Types and CSO Codes refer to the International Cancer Research Partnership Coding Guidelines used to apply a common language (Common Scientific Outline) for discussing, comparing, and presenting cancer research portfolios
- Determined using a machine learning model
- Applications, and therefore base projects, can be assigned to more than one category
- In some cases, there is not enough information to assign an application to a particular category



## **CSO Codes**

1. Biology
2. Etiology
3. Prevention
4. Early Detection, Diagnosis, and Prognosis
5. Treatment
6. Cancer Control, Survivorship, and Outcomes Research

# RESULTS

- FY21 Portfolio
- Base Projects within Populations by Continuum
- Example of Research Across the Continuum for Blacks/African Americans vs NIH Comparator

# The FY21 Portfolio for Each Population of Interest

**Starting:**  
FY21 NIH  
Cancer Grants

- RCDC = Cancer
- ~9,650 Base Projects
- ~75% are NCI (n = ~7,250)

Exclude:

- Award supplements (Type 3)
- International/Domestic Training & Career (Fs, Ks, Gs, Hs, Ts, D43, D71, M01, R00, R13, R25, R90, U13)
- P30 (Cancer Centers)
- NCORP
- International Projects
- Subproject Cores

**Intermediate:**  
Removed  
exclusion  
criteria

- “NIH Cancer Research Portfolio”
- ~7,300 Base Projects
- ~74% are NCI (n = ~5,400)

Include:

- RCDC Categories and Concepts for Population of Interest

**Final:**  
FY21 NIH Cancer AND  
Population of Interest

- X Base Projects
- ~Y % are NCI

# FY21 Extramural Base Projects for Populations of Interest

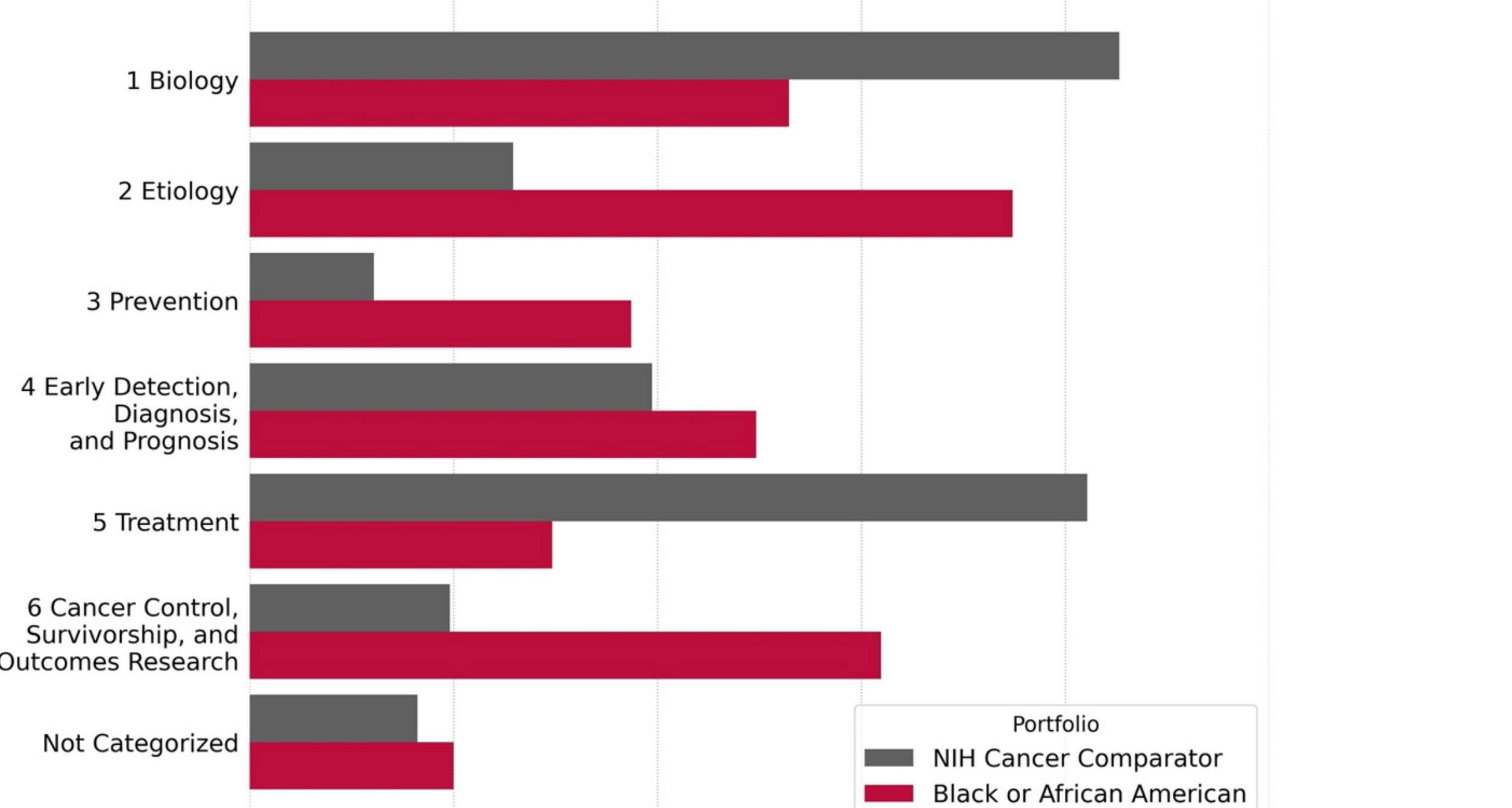
Population of Interest	Total Base Projects from all NIH ICs (% of total, 7327)	Total Base Projects Administered by NCI (% of total, 5412)	Percent Administered by NCI
Black or African American	310 (4.23%)	246 (4.55%)	79%
American Indian or Alaska Native	30 (0.41%)	18 (0.33%)	60%
Asian	52 (0.71%)	43 (0.79%)	83%
Hispanic	158 (2.16%)	126 (2.33%)	80%
Pacific Islander	21 (0.29%)	17 (0.31%)	81%
Rural American	104 (1.42%)	84 (1.56%)	81%
Sexual & Gender Minorities	19 (0.26%)	10 (0.18%)	53%

# Percent of FY21 NIH Portfolio Base Projects Classified Within ICRP CSO Categories

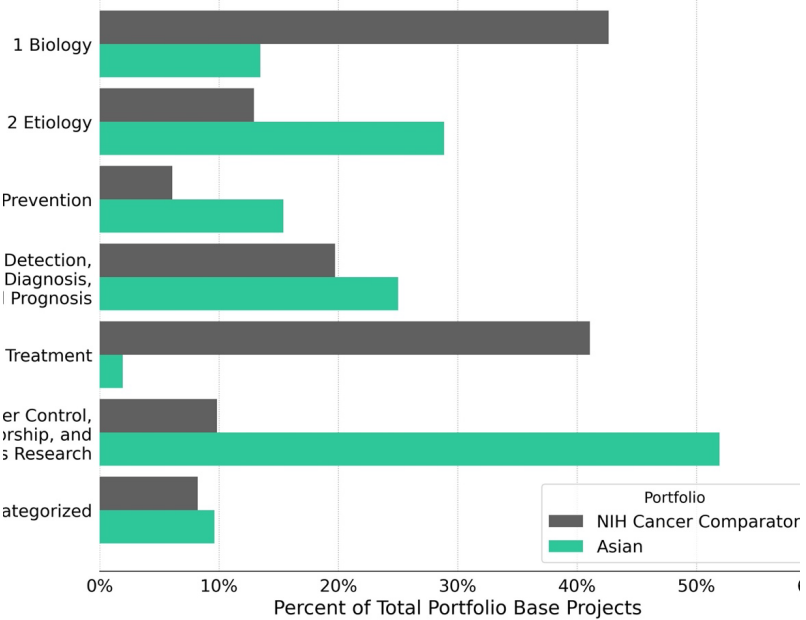
CSO Category	NIH Cancer Comparator (N=7327)	Black or African American (N=310)	American Indian or Alaska Native (N=30)	Asian (N=52)	Hispanic (N=158)	Pacific Islander (N=21)	Rural (N=104)	Sexual & Gender Minorities (N=19)
1 Biology	42.7	26.5	16.7	13.5	13.3	4.8	5.8	10.5
2 Etiology	12.9	37.4	23.3	28.8	32.3	42.9	12.5	52.6
3 Prevention	6.1	18.7	46.7	15.4	22.2	19.0	37.5	36.8
4 Early Detection, Diagnosis, and Prognosis	19.7	24.8	30.0	25.0	24.7	19.0	22.1	21.1
5 Treatment	41.1	14.8	23.3	1.9	10.1	9.5	9.6	5.3
6 Cancer Control, Survivorship, and Outcomes Research	9.8	31.0	46.7	51.9	41.8	66.7	64.4	21.1
Not Categorized	8.2	10.0	6.7	9.6	10.8	0	7.7	15.8

Note: Base projects may be assigned to more than one category. Percentages for a given portfolio may therefore add to greater than 100. In some cases, there is not enough information to assign a project to a category.

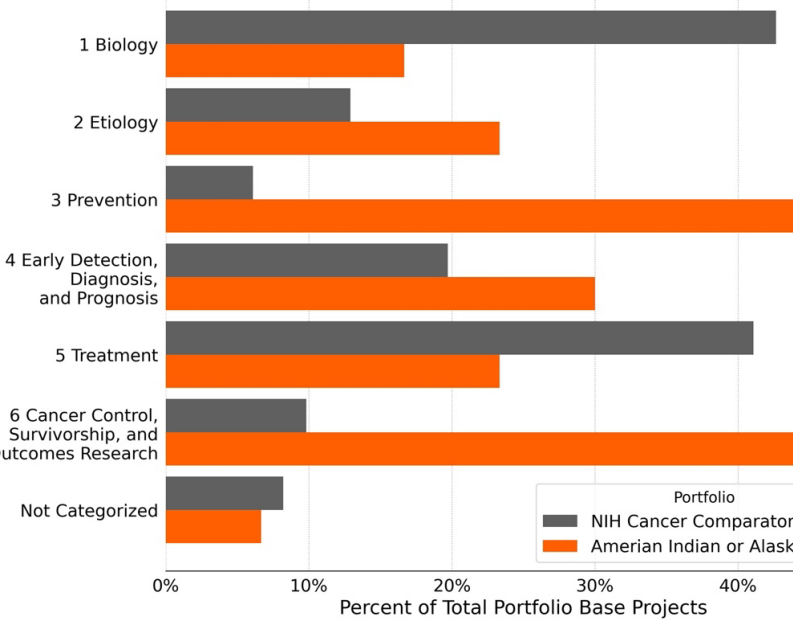
# FY21 Research Continuum of the Black or African American Portfolio vs the NIH Cancer Comparator



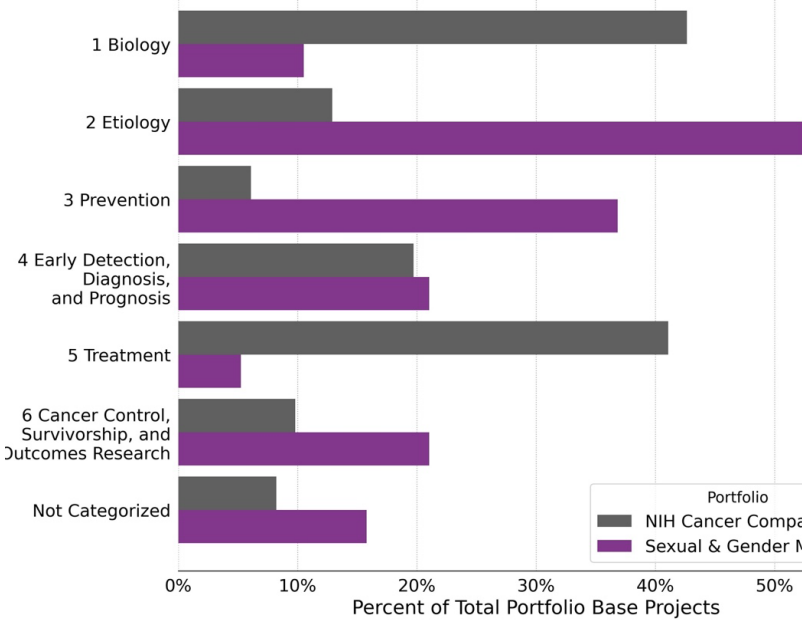
FY21 Research Continuum of the Asian Portfolio vs the NIH Cancer Com



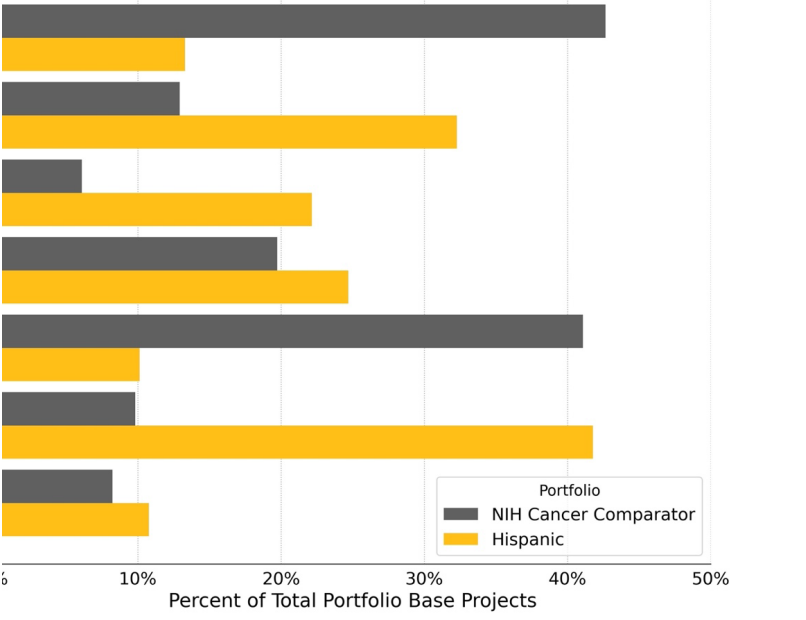
FY21 Research Continuum of the American Indian or Alaska Native Portfolio vs the NIH Cancer Com



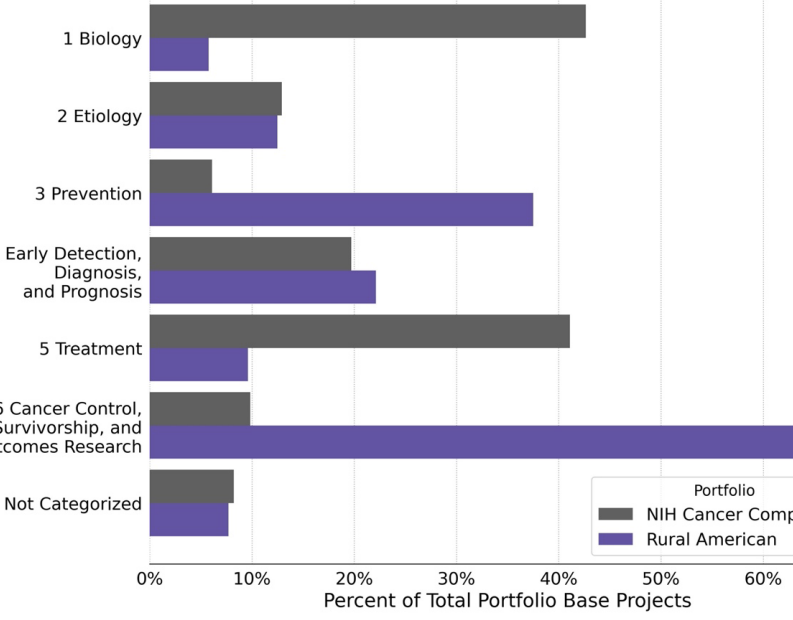
FY21 Research Continuum of the Sexual & Gender Minorities Portfolio vs the NIH Cancer Com



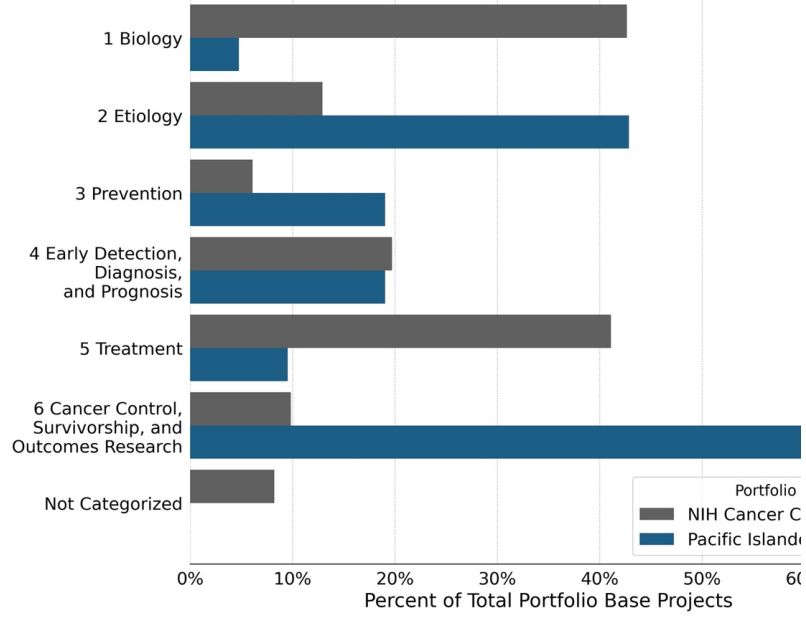
FY21 Research Continuum of the Hispanic Portfolio vs the NIH Cancer Comparator



FY21 Research Continuum of the Rural American Portfolio vs the NIH Cancer Comparator



FY21 Research Continuum of the Pacific Islander Portfolio vs the NIH Cancer Comparator



# Summary and Recommendations



# Summary of Findings

- 1) Imbalance in research relative to the distribution of cancer diagnosis, cancer morbidity, and cancer death in the United States;
- 2) Relative to overall portfolio, investment was:
  - a) small for research that focused among racial and ethnic minorities, rural populations, and the other groups evaluated
  - b) the underrepresentation was across both the continuum of science and the lifespan;
- 3) Within research identified, proportionally more projects in population sciences and fewer studies in biological research and clinical research;
- 4) Many projects draw on a limited number of underserved population groups, limiting the applicability of the current knowledge base; and
- 5) Information was lacking or not as in-depth for some population groups because:
  - a) limited disaggregated data in those population groups (e.g., Pacific Islander people),
  - b) populations were understudied (e.g., LGBTQ+ populations), or
  - c) the population group was not adequately identifiable as a distinct group in the current research inventory at the NCI (e.g., AYA, older adults).
- 6) **This significantly limited the WG's ability to complete the charge to the same degree for all population groups.**

# Recommendations

## Specific:

1. **Funding:** Expand and/or initiate RFA's, FOA's, Investigator-initiated awards (RO1's, PO1's) and supplement opportunities in areas with intentional focus on eliminating disparities and inequities in the funded grant portfolio.
2. **Data Collection:** Adopt and standardized checklist for NIH grants to identify populations included and set standards in reporting of disaggregated data for all races and ethnicities.
3. **Monitoring and evaluation:** Develop effective and efficient strategies for tracking, monitoring, and evaluating the federal investment in advancing cancer health equity to address the gaps in health disparities identified in this report.
4. **Reporting:** Create an annual report of activities in this area and provide congressional briefing on the state of cancer health equity.

# Recommendations

## Broad:

1. **Implementation Strategy:** Establish a set of guiding principles and priorities using these recommendations to move the recommendations into action.
2. **Framework for Inclusive Research:** Utilize a framework for research that relates to the science, art, and practice of inclusive cancer research and includes implementing strategies to increase funding to diverse/underrepresented investigators.
3. **Resources:** Ensure that a portion of grants is focused on the underserved/underrepresented populations included in this report.
4. **Uniform Measures:** Implement a set of core elements to facilitate the analysis and reporting of progress in research across the continuum by each of the populations included in this report.
5. **Intentionality:** Accelerate research by offering RFA's, FOA's and PAR's in areas that specifically contribute to enhancing: 1) understanding of why there are disparities in cancer outcomes for certain groups; and 2) how to eliminate disparities and achieve health equity in these groups, across the continuum.
6. **Intersection with Other Ongoing NCI Efforts in Training:** Recommendations above can only be fully realized with the realization of the goals of increasing diversity in the cancer workforce, at all levels.



# Open Discussion

# Next Steps

- Report
  - Presented at NCAB/BSA Combined Mtg on December 7<sup>th</sup>, 2022
  - Vote for Acceptance
  - Distributed to NCI
- Further Charges for the *ad hoc* Subcommittee
  - Open Discussion

Thank you!