REPORT FROM THE *ad hoc* WORKING GROUP ON STRATEGIC APPROACHES AND OPPORTUNITIES FOR RESEARCH ON CANCER AMONG RACIAL AND ETHNIC MINORITIES AND UNDERSERVED POPULATIONS

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***Ad Hoc* Working Group on Strategic Approaches and Opportunities for Research on Cancer Among Racial and Ethnic Minorities and Underserved Populations**

CO-CHAIR

Chyke A. Doubeni, M.D., M.P.H
Professor, Department of Family and Community Medicine
Associate Director, DEI
The Ohio State University Comprehensive Cancer Center
Chief Health Equity Officer, Wexner Medical Center
Director, Center for Health Equity
The Ohio State University
Columbus, Ohio

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Moores Cancer Center
San Diego, California

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Co-Director, Center for Population Health Sciences
Associate Director for Population Sciences
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Stanford, California

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American Cancer Society Cancer Action Network
Philadelphia, Pennsylvania

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Interdisciplinary Breast Program
Weill Cornell Medicine
New York, New York

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Philip Castle, Ph.D., M.P.H.
Director
Division of Cancer Prevention
National Cancer Institute
National Institutes of Health

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Executive Summary of Findings and Recommendations

The creation of the National Cancer Institute through the National Cancer Act (1937/1971) has enabled great advances in cancer prevention, detection, and treatment in the United States (US) and globally across the scientific continuum. However, disparities in cancer health outcomes have persisted and sometimes widened as the benefits of scientific advancement continue to be unevenly distributed to groups that are historically underrepresented in cancer research and clinical studies due in part to structural barriers and social injustices. Disparate outcomes are well-documented across the cancer care continuum from cancer risk through survival and across the lifespan. While few studies have demonstrated elimination of disparities in cancer health outcomes, such strategies have not been implemented broadly or even fully in studies among populations that are underserved and underrepresented in research and cancer care. Ensuring inclusion and ensuring health equity in cancer research and clinical trials is needed to eliminate cancer health disparities.

This working group (WG) was charged by the National Cancer Advisory Board (NCAB) to identify and evaluate 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." To support this charge, the workgroup received analytic support from an NCI Center for Research Strategy Project Team to evaluate the NCI extramural funding portfolio. The workgroup recognizes that there are many efforts at the NCI that may relate to research on cancer health inequities that may be difficult to delineate accurately. Thus, while the absolute numbers may not be accurate, the general trends are.

To focus the evaluation through a health equity lens, the workgroup evaluated extramural research funding that focused on the populations win its charge. We considered the following population groups: Black or African American, American Indian, Hispanic/Latino, and Asian American, and Native Hawaiian and other Pacific Islander people, and Adolescent and Young Adult (AYA) cancer survivors, Older Adult, Rural, and LQBTQ+. The workgroup recognized that these are not all populations (e.g., those experiencing homelessness or housing insecurity or people who live with disabilities) that experience health disparities but limited its scope to the aforementioned population groups as examples to describe underlying issues.

The following were **key findings** of the portfolio analysis:

1) There is an imbalance in the funding of research relative to the distribution of cancer diagnosis, cancer morbidity, and cancer death in the United States;
2) Relative to the overall funding portfolio, the investment was small for research focused on racial and ethnic minorities, rural populations, and the other groups evaluated. The underrepresentation was observed across both the continuum of science and the lifespan;
3) Within the limited funding identified, there were proportionally more projects in population sciences and fewer studies in areas such as biological and clinical research, including clinical trials among racial and ethnic minorities;
4) Many funded projects draw on a limited number of the groups that are underserved, limiting the applicability of the current knowledge base and the findings; and
5) Details for some population groups were insufficient because of a) limited disaggregated data (e.g., Pacific Islander people from Asian people), b) the population groups were understudied (e.g., older and AYA and 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). **This significantly limited the WG's ability to complete the charge to the same degree across all population groups.**

In addition, presentations to the working group provided addition information and shared inaccuracies and inconsistency in the ability of current tracking systems at the NIH/NCI to

adequately capture or delineate the current investment in specific groups that hinder data-driven and intentional approach to direct future investments.

RECOMMENDATIONS OF THE WORKING GROUP:

Background/Supporting Documentation:

Published literature also shows important related areas:

1) The underrepresentation of racial and ethnic minorities in the current research ranging from discovery science to clinical trials despite disproportionately high rates of cancer diagnoses and death;
2) Communities (both in geography and population groups) disproportionately affected by cancer continue to be underrepresented in the research both in the population groups and in the geographic areas in which research is conducted;
3) There is a paucity of implementation of effective and evidence-based interventions that have shown to reduce cancer health disparities in all underserved populations; and
4) Surveillance data are limited in population groups that experience disparities, including rural areas, Pacific Islander people, and AI/AN, therefore hampering assessment of and thus progress towards health equity;

Specific Recommendations:

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 a standardized checklist for NIH grants to identify populations included and set standards in reporting of disaggregated data for all racial and ethnic groups.
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.

Broad Recommendations:

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 populations that are underserved/underrepresented consistent with the findings of 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 RFAs, FOAs and PARs in areas that specifically contribute to enhancing 1) understanding of why disparities in cancer outcomes occur or widen 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 inclusive diversity in the cancer workforce, at all levels.

A. CHARGE TO THE WORKING GROUP

The NCAB *ad hoc* Subcommittee on Population Science, Epidemiology, and Disparities was tasked with evaluating the representation of underserved and minority populations in NCI-funded research. To this end, the Subcommittee convened the *ad hoc* Working Group on Strategic Approaches and Opportunities for Research on Cancer Among Racial and Ethnic Minorities and Underserved Populations (Working Group) to advise on strategic approaches and opportunities for research on cancer among racial and ethnic minorities and underserved populations. The specific charge to the Working Group was:

"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 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*." (NIH Website, June 11, 2022)

The group agreed to focus on the following populations: Black/African American, American Indian and Alaska Natives, Hispanic/Latino, AYA, Older Adult, Rural, LQBTQ+ and Asian and Pacific Islander individuals.

B. BACKGROUND

DEFINITION OF HEALTH DISPARITIES

Health disparities reflect preventable differences in disease burden that can be attributed to disadvantage in disease risk and outcomes because of structural, social, economic, behavioral, or environmental factors[1]; cancer health disparities are differences that occur in cancer-related outcomes.[2] Studies show that disparities persist even after accounting for sociodemographic factors which supports the multi-level frameworks that describe the causes and potential solutions which extend beyond the individual to emphasize the critical role of social and structural factors.

Despite advances in prevention, early detection, and treatment, cancer health disparities persist and continue to be a significant public health challenge. Recent reports demonstrate that disparities exist along the entire continuum for cancer control and care because of persistent social and structural inequalities including adverse living conditions, reduced access to high quality health care, and other non-medical factors that contribute to prevention, early detection, and treatment (including standard of care and cancer clinical trials). Therefore, it is important to recognize that without addressing long-standing structural inequalities by removing obstacles to achieve health equity, it will not be possible to fully eliminate cancer health disparities.

As determinants of cancer health disparities have been identified through translational and transdisciplinary studies, conceptual frameworks have been developed to support and guide interventions and other strategies to enhance cancer outcomes, eliminate inequities and reduce disparities. Some of these frameworks include: the Socio-Ecological Framework,[3] the Centers for Population Health and Health Disparities Model for analysis of population health and health disparities,[4] the National Institute on Minority Health and Health Disparities (NIMHD) Research Framework,[5] and the Health Care Disparities framework.[6]

The Socio-Ecological framework[3] has been applied to the prevention of many chronic diseases including cancer. It provides a means for testing hypotheses about the implications of social and

ecological interactions across individual, interpersonal relationship, community, and societal levels. The individual level includes biological and personal factors and behaviors that influence

health outcomes. The interpersonal relationship level includes the influence of peers in an individuals' social circle including partners, family members, mentors, and close friends. The community level includes settings where social relationships occur including schools, workplaces, and neighborhoods, and seeks to understand the characteristics of these communities that are associated with cancer outcomes. The societal level seeks to understand how social and cultural norms including policy, education, and health systems contribute to cancer disparities.

The Centers for Population Health and Health Disparities Model[4] was developed through a research consortium that was funded by NCI, NHLBI, and OBSSR to identify and address disparities in cancer and cardiovascular disease through transdisciplinary research teams.[4] This model describes three type of determinants, proximal, intermediate, and distal factors that span biologic to environmental interactions respectively. Factors across these levels collectively contribute to health disparities. This framework promotes the development of interventions that address population factors as well as individual and biologic risk factors.

The Health Care Disparities Framework,[6] was developed to guide health services research. As with the frameworks described above, this model addresses multilevel determinants but has an emphasis on health care system factors (e.g., health care financing, patient variables, quality of clinical encounters, provider knowledge, bias, and competing demands), organizes the process of health disparities research into three phases: detection (measure disparities), understanding (identifying determinants), and reduction or elimination (intervention, evaluate or change policy).

The National Institute on Minority Health and Health Disparities Research Framework[5] expands four levels of the socio-ecological model (levels of influence) across five domains of influence over the life course (biological, behavioral, physical/built environment, sociocultural environment, and health care system). This framework encourages research that addresses the multi-level nature of health disparities that spans multiple domains and levels of influence. Efforts are now focused on increasing the precision of these multilevel frameworks by identifying specific mechanisms that link sociopolitical factors (e.g., structural racism) with disparities in cancer risk and outcomes. For instance, researchers developed a conceptual model of racial disparities in breast cancer subtypes by integrating empirical data from cancer epidemiology, stress biology, and health disparities.[7] This model, and ongoing studies in stress reactivity[8] is based on data from animal studies which show that social isolation among rats is associated with an increased risk of developing mammary tumors that are histologically similar to those that occur in African American women.[9] Other studies are using these multilevel frameworks to examine the association between environmental, interpersonal, and physiological stress responses and stressors on cancer risk behaviors and outcomes among diverse clinical and community-based samples.[10]

As empirical data are generated about the association between multilevel determinants and cancer health disparities, it is critically important for these findings to be translated into evidence-

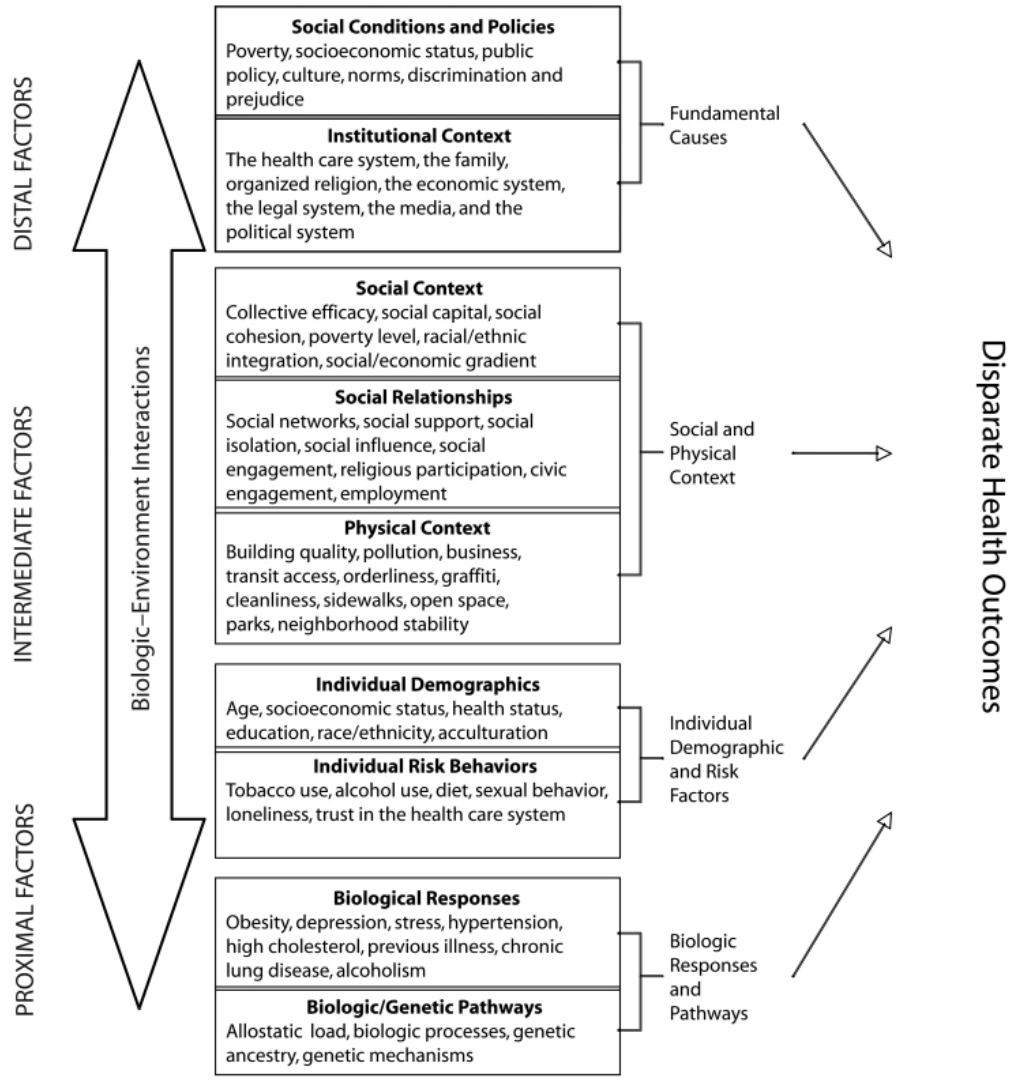
based interventions. Research is also needed to examine the effects of multilevel interventions on differences in risk behaviors, access to treatment, and cancer-related outcomes in populations that experience disparities. Patient navigation, for instance, has emerged as a key strategy for mitigating disparities in access to care and outcomes;[11,12] studies are now evaluating the effects of navigation to improve access across diverse stages in the continuum of cancer care (e.g., screening and treatment) for multiple disease sites (e.g., lung cancer and head and neck, etc.). Even though some process for patient navigation is required for accreditation by the Commission on Cancer, empirical data are still needed on best practices for implementing this approach and other strategies for reducing cancer health disparities into practice. Accordingly, conceptual

frameworks have been developed to guide the implementation of interventions for cancer control and cancer health disparities.

The Health Equity Implementation Framework[13] combines two conceptual models to guide implementation of clinical interventions to address multiple levels of influence to address health disparities. Similarly, the Integrated-Promoting Action on Research Implementation in Health Services (i-PARIHS) framework[14] describes three levels of implementation, context, recipients, and characteristics of the innovation. Together they work to conceptualize how implementation factors and health care disparities factors can be simultaneously studied and intervened upon. Both implementation frameworks can be applied to multi-level factors because health disparities are affected by multiple variables in complex healthcare systems.

The Socio-Ecological Model[3]

Centers for Population Health and Health Disparities Model[4]


DISTAL FACTORS
INTERMEDIATE FACTORS
PROXIMAL FACTORS
Biologic–Environment Interactions
Social Conditions and Policies
Poverty, socioeconomic status, public policy, culture, norms, discrimination and prejudice
Institutional Context
The health care system, the family, organized religion, the economic system, the legal system, the media, and the political system
Fundamental Causes
Social Context
Collective efficacy, social capital, social cohesion, poverty level, racial/ethnic integration, social/economic gradient
Social Relationships
Social networks, social support, social isolation, social influence, social engagement, religious participation, civic engagement, employment
Physical Context
Building quality, pollution, business, transit access, orderliness, graffiti, cleanliness, sidewalks, open space, parks, neighborhood stability
Social and Physical Context
Individual Demographics
Age, socioeconomic status, health status, education, race/ethnicity, acculturation
Individual Risk Behaviors
Tobacco use, alcohol use, diet, sexual behavior, loneliness, trust in the health care system
Individual Demographic and Risk Factors
Biological Responses
Obesity, depression, stress, hypertension, high cholesterol, previous illness, chronic lung disease, alcoholism
Biologic/Genetic Pathways
Allostatic load, biologic processes, genetic ancestry, genetic mechanisms
Biologic Responses and Pathways
Disparate Health Outcomes

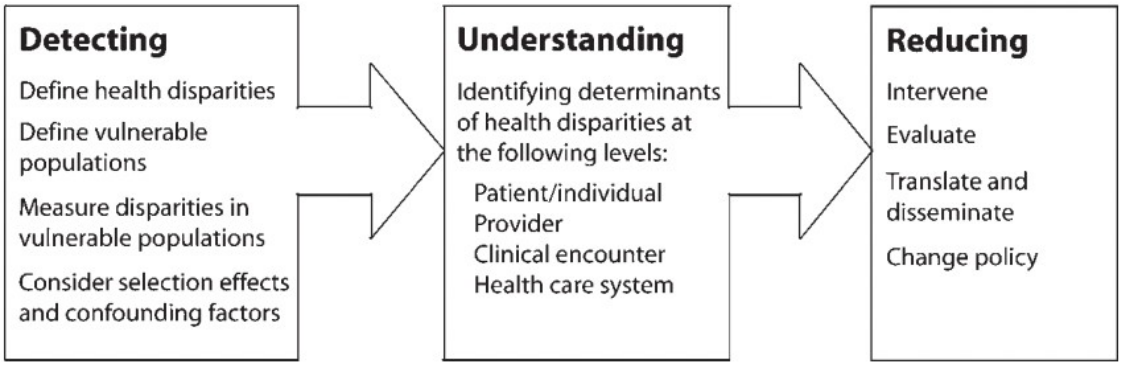
National Institute on Minority Health and Health Disparities Research Framework[5]

National Institute on Minority Health and Health Disparities Research Framework

		Levels of Influence*			
		Individual	**Interpersonal**	**Community**	**Societal**
Domains of Influence *(Over the Lifecourse)*	**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**

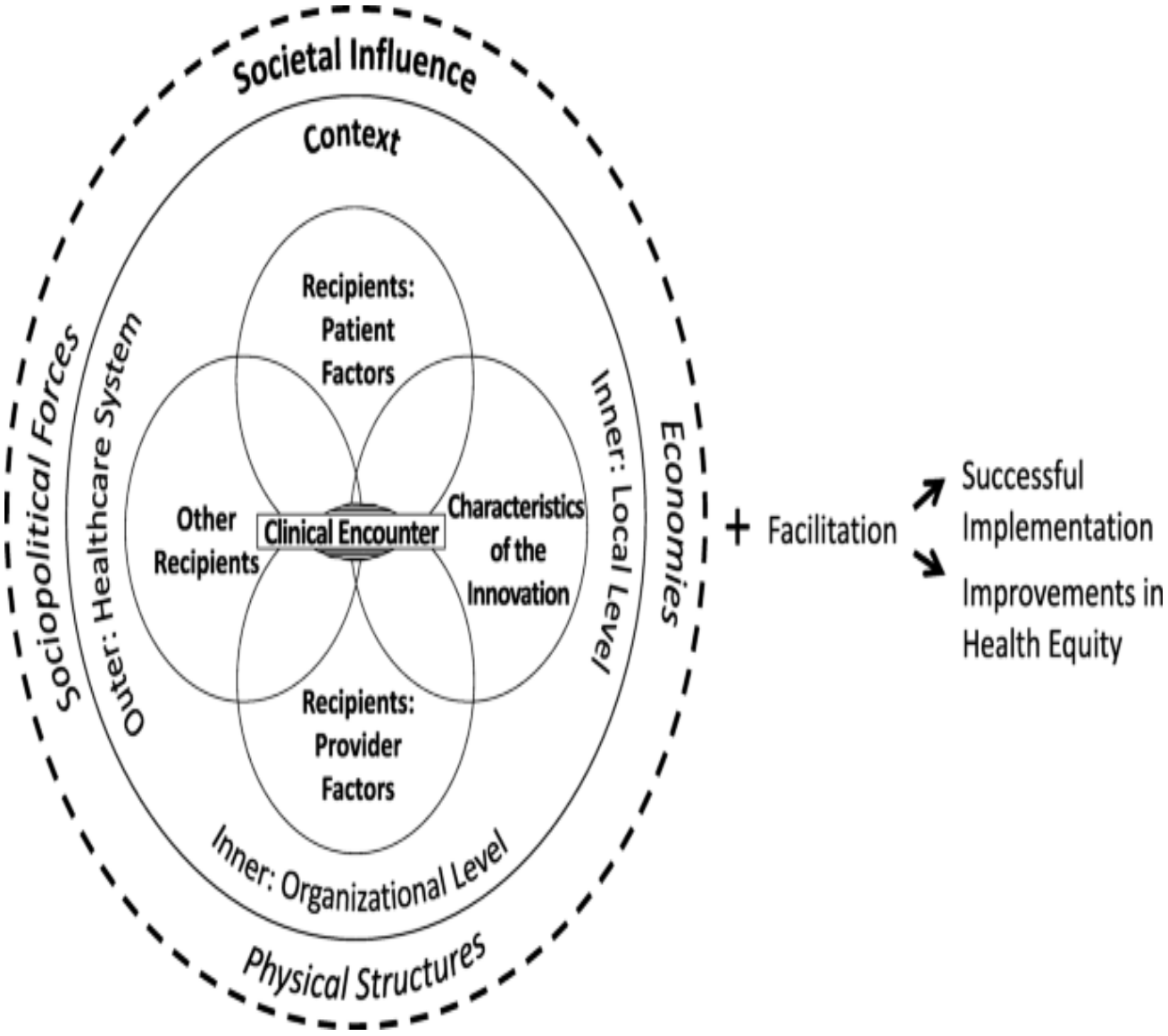
National Institute on Minority Health and Health Disparities, 2018
*Health Disparity Populations: Race/Ethnicity, Low SES, Rural, Sexual and Gender Minority
Other Fundamental Characteristics: Sex and Gender, Disability, Geographic Region

Health Care Disparities Framework[6]



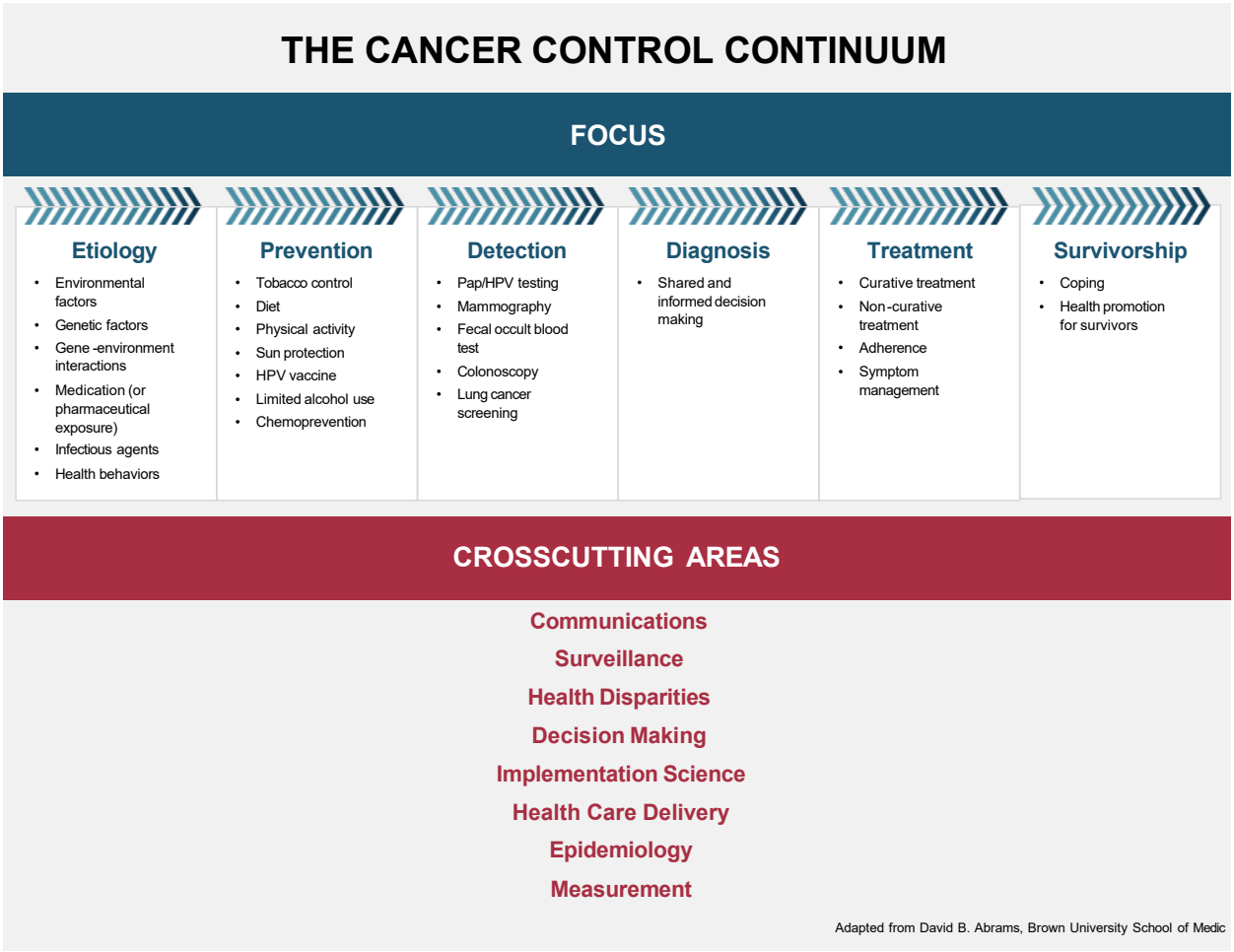
Note. In our framework, the health disparities research agenda progresses in 3 sequential phases of research. Phase 1 (detecting disparities) informs phase 2 studies (understanding disparities), which in turn informs phase 3 research (interventions to reduce or eliminate disparities).

Health Equity Implementation Framework[13]



CANCER CONTINUUM

The cancer control continuum was described in the mid-1970's and includes the stages from cancer development through to death (see Figure X). Areas included are etiology, prevention, early detection, diagnosis, treatment, survivorship, and end of life. Additionally, several cross-cutting research areas are included: communications, surveillance, health disparities, decision making, implementation science, health care delivery, epidemiology, and measurement. NCI uses this framework to review plans, progress, and priorities, allowing for gaps to be identified where research must be conducted or where resources should be allocated.[15] For this reason, the WG decided to examine research across the continuum within the populations of focus, in order to identify gaps where resources should be devoted and priorities assigned.



CANCER DISPARITIES IN POPULATIONS OF FOCUS

Introduction

Included in this report are brief descriptions of the various groups that are the foci of this report, including a general description of each population and information about cancer risk outcomes. These descriptions focus on racial and ethnic minority groups, and other groups that are underrepresented in terms of clinical and translational science or underserved in the United States (U.S.), which was part of the charge to the workgroup. Racial and ethnic groups included in the report are: Black or African American (hereafter referred to as Black), American Indian/Alaska Native, Asian American, Native Hawaiian and other Pacific Islander, and Hispanic/Latino communities. The report also focuses on adolescent and young adult (AYA) survivors, senior adult, rural, and lesbian, gay, bisexual, transgender, and lesbian, gay, bisexual, transgender, queer/questioning, and others (LGBTQ+). Distinct and shared sociodemographic characteristics of, and the experiences faced by, each group across the cancer care continuum are important to understand.

People may identify with several of the groups addressed in this report listed above or have other traits that may shape their cancer risk, care, and outcome experience. Those intersections across racial, ethnic, and other social and demographic characteristics, related to cancer risk and outcomes, are critical to understanding and creating meaningful initiatives, but are outside the scope of the workgroup, and therefore, are not included in the focus of this report. What is very apparent for each group is that there is significant heterogeneity with regard to ancestral heritage, generational immigrant status, and socioeconomic status within each group, and it is hard to tease these out in terms of risk factor and cancer outcome data. In this description, racial and ethnic groups are compared to non-Hispanic White (NHW) people as the reference, unless otherwise stated. Available statistics on incidence, mortality, and survival for selected cancers are provided in Table 1. Reliable estimates for the LGBTQ+ community were not found and are therefore not included in Table 1.

Black or African American

Brief Description and General Characteristics

Approximately 13% of the U.S. population identifies as Black.[16] A portion of the Black population comes from western sub-Saharan African ancestry through the trans-Atlantic slave trade.[17] Most Black people live in urban areas in the mid-Atlantic states and in the South.[16] The cancer health experiences of Black people in the US are acknowledged as being shaped by experiences of structural racism and social and health injustices. There is, therefore, a disproportionately high prevalence of socioeconomic disadvantage (e.g., percentage below the poverty line, unemployed, and with less than a high school diploma) among Black people compared to NHW people in the US that stem from systemic inequities.[18]

The impact of adverse social determinants of health in Black communities, including restricted access and lower quality of care, is also evident in disproportionately higher rates of comorbidities such as diabetes, heart disease, hypertension, stroke, and human immunodeficiency virus (HIV)/ acquired immunodeficiency syndrome (AIDS) that affect cancer risk and cancer care.[17] Factors contributing to these disparities include barriers to accessing health care, medical distrust, and differences in the quality of care received.[17]

Cancer Risk Factors

Prevalence estimates for some influences on cancer risk such as alcohol consumption and tobacco use are reportedly lower for Black populations, yet higher risks of related cancers are observed.[19] Compared to NHW individuals, the prevalence of obesity is higher among Black

people, especially among women.[17,19] The percentage of Black people without health insurance is higher than that of NHW people in the US.[18]

Cancer Burden

Compared with the NHW population, the Black population has lower prevalence of cancer screening and overall cancer incidence rates but higher overall cancer mortality rates (Table 1).[17,20] Incidence rates of prostate, colorectal, and cervical cancers are higher relative to the NHW population.[20] Multiple myeloma is approximately twice as common among Black populations compared to NHW Americans.[20] Mortality rates of breast, cervical, colon and rectum, uterus, liver and intrahepatic bile duct, and pancreas cancers are considerably higher among Black people, compared to NHW people, while mortality rates of myeloma, prostate and stomach cancers are more than double those of NHW people. Five-year relative survival probability for all cancers combined is lower among Black people compared to NHW people (Table 1), and survival is lower among Black people for most specific cancer sites.

American Indian or Alaska Native

Brief Description and General Characteristics

American Indian or Alaska Native people are those who identify as belonging to any of the original inhabitants of North, Central or South America and maintain tribal affiliation. There are an estimated 9.7 million American Indian or Alaska Native people in the U.S. comprising about 2.9% of the overall total population.[16] There are 574 federally recognized tribes with 200 remaining "unrecognized".[21] The most recent estimates indicate that 22% of American Indian or Alaska Native people reside on reservations or other trust lands.[1] Misclassification of American Indian or Alaska Native identity in health data is common and can result in inaccurate estimates of cancer burden.[21]

The percentage of American Indian or Alaska Native people who have attained at least a high school diploma is 84.4%, which is less than the 93.3% of NHW people.[22] The median household income among American Indian or Alaska Native is considerably less than that of the NHW population.[22] Being underinsured/uninsured and/or unemployed is also more prevalent among American Indian or Alaska Native compared to NHW individuals.[22] American Indian or Alaska Native people may receive healthcare in different Purchased/Referred Care Delivery Areas (PRCDAs), which are counties that include all or part of a reservation which receives congressional appropriated funds for the Indian Health Service.[23] These counties comprise six broader PRCDA regions.[23] Common co-morbidities such as type-2 diabetes increase the risk of kidney cancer among American Indian or Alaska Native individuals.[21]

Cancer Risk Factors

While the data are highly variable among different tribal communities, as a group, smoking and alcohol use are more prevalent among American Indian or Alaska Native people compared to NHW people.[24] American Indian or Alaska Native people are more likely to develop problem drinking at an earlier age and other alcohol-related illnesses.[24] Major barriers to health include poor access to quality health care, geographic isolation, and low income.[23]

Cancer Burden

Prevalence estimates for breast, cervical, and colorectal cancer screening are lower among American Indian or Alaska Native people when compared to NHW people.[22] Relative to NHW people, incidence rates of kidney, colorectal, and lung and bronchus cancers are higher among certain American Indian or Alaska Native people.[22] Additionally, cancers caused by infectious agents – including cervical (human papillomavirus [HPV]) and stomach (*Heliobacter pylori)*

cancers – have disproportionately higher incidence rates among American Indian or Alaska Native people.[22] Notably, American Indian or Alaska Native people have the highest incidence rates of liver and intrahepatic bile duct cancer (which occur as a sequela of viral hepatitis) of any racial or ethnic group in the U.S. The overall cancer mortality rate is higher among American Indian or Alaska Native people than among NHW Americans (Table 1). Specifically, the mortality for liver and intrahepatic bile duct cancer among American Indian or Alaska Native is double that of NHW people.[20,22] Five-year relative survival probability for all cancers combined is lower for American Indian or Alaska Native people, compared with NHW people; American Indian or Alaska Native cancer survival is the lowest of any racial/ethnic group in the U.S.[22] Cancer risk and disparities vary by PRCDA region, both within the American Indian or Alaska Native population and relative to NHW people.[22]

Asian American

Brief Description and General Characteristics

Asian American people have origins in the East Asia, Southeast Asia, or the Indian subcontinent.[25] Asian American people have historically been categorized by the OMB as "Asian/Pacific Islander" (API), which compounds the heterogeneity from groups comprised of Asian American people and, Native Hawaiian, and other Pacific Islander (NHPI) people.[25] According to 2019 population estimates from the U.S. Census Bureau, there were 18.9 million Asian American people comprising 5.7% of the U.S. population.[25,26] According to 2019 U.S. Census data, there is a lower percentage of Asian Americans in the U.S. (aged 25 years and older) with at least a high school diploma compared to NHW people.[26] Despite having a higher median household income, Asian Americans have a higher percentage of people living at the poverty level compared to NHW people.[26]

Cancer Risk Factors

Asian American people have lower obesity prevalence estimates than NHW people. Asian American people have high rates of smoking and many experience limited access to cancer prevention and control programs.[26] Asian American people have lower prevalence of alcohol consumption compared to NHW people.[26] Some negative factors impacting health outcomes include infrequent medical visits, language and cultural barriers, and lack of health insurance.[26,27] As of 2019, Asian Americans were uninsured at similar rates as NHW people.[26]

Cancer Burden

Prevalence estimates for cancer screening behaviors among Asian American persons are limited because Asian American persons are commonly grouped with the NHPI population. Prevalence estimates of breast and cervical cancer screenings are lower among Asian American and NHPI women compared to NHW women.[26] Within the Asian population, incidence and mortality rates vary widely.[28] Most disaggregated groups within the Asian American population have more favorable rates than NHW groups, while others experience some of the highest incidence and mortality rates and later stage at diagnosis in the U.S.[20,29,30] For example, while the stomach cancer mortality rate among Filipino Californians is similar to that for NHW Californians, the rate among Korean Californians is more than four times higher. The use of the combined API and even "Asian American" as racial categories has contributed to a relative scarcity of disaggregated data, and SEER data dashboards do not currently show statistics separately for the Asian American and NHPI groups and for disaggregated Asian American groups.

The incidence rate for cancer among non-Hispanic Asian American is lower compared to the rate observed among NHW people (Table 1). Incidence rates for some cancers (e.g., stomach cancer) are higher among more recent Asian American immigrant populations, suggesting that the cancer burden associated with the country of origin is maintained until there is acculturation.[31] Cancer is

the leading cause of death in Asian American people.[26] Death rates were lower for Asian American and NHPI compared to NHW people (Table 1). The five-year relative survival probability is lower among the Asian American and NHPI population relative to NHW (Table 1).

Native Hawaiian and other Pacific Islander

Brief Description and General Characteristics

NHPI people have origins from the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.[25] The population of this group is estimated at 1.4 million (or 0.4% of the U.S. population) in 2019 with 355,000 in Hawaii and an estimated 169,000 in Guam in 2020.[25,26]

Cancer Risk Factors

In the US, NHPI people have historically been grouped with Asian American people as API limiting the availability of public health surveillance data for NHPI. For instance, current SEER or National Childhood Cancer Registry data dashboards do not currently show statistics separately for NHPI people from Asian American people. Based on available data, NHPI people have higher prevalence of smoking, alcohol consumption and obesity, and experience limited access to cancer prevention and control programs.[26] NHPI people report lower levels of adequate physical activity.[32] The health of NHPI people is also impacted by disproportionately high percentage without health insurance.[26,27]

Cancer Burden

Prevalence estimates for cancer screening behaviors among the NHPI population are limited because the NHPI population is commonly grouped with the Asian American population. (See above for cancer screening prevalence estimates for the combined group of Asian Americans and NHPI populations.) Cancer is the second leading cause of death among NHPI people.[26] The overall mortality rate among NHPI males has been reported to be similar to that among NHW males; however, the mortality rates are higher among NHPI males for cancers of the oral cavity, colon and rectum, stomach, and liver[33] compared to NHW populations. For NHPI females, the overall cancer mortality rate is higher than that for NHW females, and the mortality rates are considerably higher than those for NHW females for cancers of the oral cavity, colon and rectum, stomach, liver, breast, cervix and endometrium.[33] Compared to NHW people, NHPI people have a significantly higher comorbidity burden and have significantly lower overall survival probability for breast, endometrial, oral cavity, and prostate cancers, as well as lymphoma.[34]

Hispanic/Latino

Brief Description and General Characteristics

Hispanic or Latino (hereafter, referred to as Hispanic) refers to a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race.[35] Hispanic people make up the largest and the youngest racial/ethnic minority group in the U.S.[36] and make up 18.5% of the U.S. population.[35,37] In the last decade, the Hispanic population accounted for over half of U.S. population growth, and their population increased by 23% between 2010 and 2020.[36,38,39] It is projected that this growing ethnic group will reach nearly 111 million Americans by 2060.[35] Due to the heterogeneity within people categorized as Hispanic, there are significant variations in the group with regards to ancestry, culture, geography, and social/economic experiences.[35] Thus, it is important, whenever possible, to disaggregate Hispanic groups when assessing and addressing disease burdens.

The Hispanic population has lower educational attainment and lower household income, compared with the NHW population.[35,37] Further, Hispanic people have higher prevalence of unemployment than NHW people in the U.S.[35,37] Approximately 16% of U.S. Hispanic people lived

in poverty in 2019, compared to 7% of NHW people.[40] Other barriers specific to Hispanic people include those related to language, mistrust of the health care system, poor geographic access to healthcare, and clinician bias.[40]

Cancer Risk Factors

Although variable by the specific Hispanic group (e.g. Central/South American, Puerto Rican), prevalence estimates for both tobacco use and alcohol consumption are lower among Hispanic people, compared to NHW people.[19] The prevalence of overweight and obesity is also variable across specific Hispanic groups but, overall, is higher (men: 88%; women: 79%) than NHW people (men: 75%; women: 66%).[19] The percentage uninsured is highest among the Hispanic population than any other racial or ethnic group in the U.S.[35,37]

Cancer Burden

Prevalence estimates of screening for breast and colorectal cancers are lower among Hispanic people than NHW people, while the screening prevalence for cervical cancer is higher among Hispanic people.[19] Hispanic people who have lived in the U.S. for a long time may have cancer incidence rates that approach or even surpass those of NHW people, potentially as a result of acculturation, whereby immigrants to a host country adopt attitudes, customs, and behaviors of the host county, including high levels of obesity.[40,41] Overall, cancer incidence and mortality rates among Hispanic people are lower than those of NHW people and other racial or ethnic groups with the exception of the non-Hispanic Asian/Pacific Islander group (Table 1). Hispanic people have higher rates of infection-related cancers (stomach, liver and intrahepatic bile duct, and cervical cancer), and gallbladder cancer.[42] Hispanic children and adolescents have higher incidence rates of leukemia, especially acute lymphocytic leukemia.[42] Five-year relative survival probability is slightly lower among Hispanic people than for NHW people (Table 1).

Adolescent/Young Adult

Brief Description and General Characteristics

Adolescents and young adults (AYA), as defined in the cancer community, are people between the ages of 15 and 39 years[43] and make up approximately 34% of the U.S. population.[44] The AYA population is more racially and ethnically diverse than older US populations [44], following the trend of increasing diversity in the US over time. Adolescents (ages 10 -19 years) are often located in suburban areas.[45] AYA's typically experience a significant life stage change which includes entering adulthood, leaving home, and starting a career.[46] Because AYA's include reproductive years, there are related responsibilities of conceiving and raising children.[46] Young adults (ages 20-39 years) are less likely to be under the care of a primary care clinician compared to those aged 40 years and older.[47]

Measuring socioeconomic status is difficult among the AYA population because some do not typically hold full or part time employment positions nor are they reported as a distinct group in measurements of educational attainment (based on commonly used U.S. census assessments made for those aged 25 years and older). It is estimated that 13% of adolescents live in poverty.[45] For those AYAs between the ages of 18 to 34 years, 9.4% live below poverty. [48]

Cancer Risk Factors

People 18 to 44 years old may be more likely to participate in some activities such as binge drinking, cigarette smoking, and poor diet choices that increase cancer risk later in life.[49] Tobacco use is of particular importance since 99% of adults who smoke report using their first tobacco product before the age of 26 years.[50] Cervical cancer screening adherence is lower among women ages 21 to 29 years when compared to women 30 years and over.[51]

Cancer Burden

While overall cancer incidence and mortality rates are lower among AYA's compared to older populations (Table 1), rates have steadily increased over the last 20 years and are higher among females than males.[20] AYA males have a higher incidence rate than other age groups for testicular cancer.[20] The incidence rate for all cancers combined among White AYA's is lower those that of Black AYA's, while the mortality rate for all cancers combined in higher among Black AYA's (not shown in Table 1).[20] Relative five-year survival probability for all cancer combined is higher than for any other age group, at 85.5% (Table 1).

Senior Adults

Brief Description and General Characteristics

There are 54.1 million senior adults (aged 65 years and older), comprising 16% of the U.S. population.[52] The percentage of senior adults in the U.S. population is predicted to increase from 16% in 2019 to 21.6% by 2040.[52] One in four senior adults are members of a racial and ethnic minority. While senior adults most often live with a spouse, about one-third of senior adults live alone or in nursing homes.[52] More than 20% of senior adults live in a rural area.[25]

Roughly 10% of senior adults live below the Federal Poverty Line (FPL), with a median income of $27,398.[52] Senior adults have lower rates of high school diploma attainment and often encounter difficulties in health literacy, particularly with print and online materials.[19,52] Nearly all senior adults are covered by Medicare and report having a routine medical care provider, with less than 3% reporting failure to obtain necessary care due to cost.[52] However, private supplemental coverage is less common among Black and Hispanic Medicare beneficiaries than NHW people, and more Black and Hispanic people report difficulty getting needed care than NHW beneficiaries. Common chronic health conditions are age-related and therefore increase with advancing age. These include cancer, arthritis, coronary heart disease, myocardial infarction, and diabetes.[52]

Cancer Risk Factors

Senior adults have lower prevalence estimates of risky behaviors, such as tobacco use and alcohol consumption compared to younger populations,[53] but may still be susceptible to the sequelae of prior exposures such as smoking or occupational exposures. Additionally, the prevalence of obesity is lower, complemented by higher prevalence of healthcare utilization and coverage relative to younger adults.[52]

Cancer Burden

There are no recommendations for routine cancer screening after age of 75 years.[52] Senior adults have higher rates of cancer screening compared to other eligible adults (colorectal).[20] Cancer incidence increases with age[54-56] and the highest cancer mortality rates across the lifespan are found in seniors (Table 1). For older adult men, lung and prostate cancers are the most common causes of cancer death.[56] For older adult women, lung and breast cancers are the most common causes of cancer death.[55] Survival probability declines with advancing age, and cancer patients 85 years and older experience higher risk of late-stage diagnosis and the lowest relative survival probability of any age group.[20]

Rural (Residents of Non-metropolitan Counties)

Brief Description and General Characteristics

Rural populations live in the 72% of the U.S. land mass classified as "Rural" (or non-metropolitan) by the Rural Urban Commuting Codes (RUCC), one of the common classification schemes (i.e.,

RUCC codes 4+ are non-metropolitan), and comprise about 14% (or 46.1 million people) of the U.S. population.[57,58] Rural areas are not homogeneous and include farmland, mountains, frontier areas such as the Appalachian, Delta, Tribal lands, and Mountain West areas, which have unique needs.[58] Rural areas are inhabited by various racial and ethnic groups, including NHW, Black, AI/AN, and Hispanic people.[59]

Rural America, in general, has lower income and higher poverty.[60] It is less populated than urban areas, and the population is declining due to the emigration of younger residents and aging of those remaining.[18,60] Rural areas have access to fewer transportation options in addition to having to travel long distances for food and medical care, especially quality cancer care.[61] This isolation also causes poor internet access, fewer options for medical care, and more reliance on public health insurance.[61,62]

Cancer Risk Factors

Rural populations have higher prevalence estimates for health behaviors that increase cancer risk, including higher tobacco use, obesity, and physical inactivity, compared to urban areas.[57]

Cancer Burden

Prevalence estimates of screening for breast, cervical, colorectal and lung and bronchus cancers are lower in rural than in urban areas.[61] Cancer incidence rates in the rural population are slightly lower in general, compared to the urban population (Table 1); however, there are some exceptions, such as higher incidence rates of lung and bronchus, cervical, and colorectal cancers compared to urban areas.[57] Cancer mortality is higher in rural areas, compared to urban areas, and compared to the NHW population as a whole (Table 1), specifically for largely preventable cancers such as lung and bronchus, laryngeal, colorectal, and cervical cancers, which may be the result of geographical barriers to receiving high-quality cancer care.[60,63] Compared to the NHW population as a whole, the five-year relative survival probability among rural residents is lower (Table 1).

LGBTQ+

Brief Description and General Characteristics

The sexual and gender minority (SGM) population is heterogenous and includes, but is not limited to, the roughly 11 million Americans (about 3% of the population) self-identifying as part of the lesbian, gay, bisexual, and transgender (LGBT+ community. This number continues to grow, particularly among younger age groups, with increasing social acceptance. Moreover, the letter "Q" has been added to the community's acronym in recent years to account for individuals who identify as "queer" or "questioning".[64] "+" was added to be inclusive of those who do not identify with the other groups. Health data collection is inconsistent for the LGBTQ+ population due to an absence of questions regarding sex, sexual orientation, and gender identity on many national cancer registries and other data collection instruments.[64,65] Thus, comprehensive data about the LGBTQ+ community is typically limited.

Historically, the LGBTQ+ community has faced social, legal, and public health challenges to their identity and expression.[66] LGBTQ+ people tend to have lower rates of high school diploma attainment, lower incomes, higher rates of poverty, and higher rates of being uninsured or underinsured.[64,65] Disproportionately high rates of homelessness affect the LGBTQ+ community, particularly among transgender individuals.[67] LGBTQ+ health care needs – like gender-affirming care, HIV prevention and treatment, and mental health services – are unique.[64] Yet, such care may be prohibitively expensive and impacts interest in receiving of cancer prevention and treatment services. LGBTQ+ people seeking healthcare frequently encounter discrimination and alienating (gendered or heteronormative) language.[64,65,68] Moreover, 15 to 20% of LGBTQ+

individuals live in rural areas where public opinion tends to be less tolerant than in urban settings.[66,69] All of these unique factors impact cancer service delivery and receipt.

Cancer Risk Factors

Limitations in national health surveillance data on LGBTQ+ make it difficult to ascertain the true cancer burden among the LGBTQ+ community.[70,71] Prevalence estimates for behaviors that increase cancer risk, such as smoking and alcohol use, are higher among LGBTQ+ people than the sexual majority population.[72,73] Gender-affirming hormone therapy for gender minority individuals may be a risk factor for certain cancers.[74] Sexual minority women (e.g., cisgender lesbian or bisexual women) have higher odds of being obese compared to sexual majority women.[75] Sexual minority people are more likely to delay medical care due to cost compared to sexual majority poeple.[65] LGBTQ+ individuals also have higher prevalence of HPV infection compared to majority populations, and HPV vaccination uptake is notably low among sexual minority men compared to sexual majority men.[76] Human immunodeficiency virus (HIV)-positive sexual minority men have substantially higher prevalence of HPV and hepatitis C virus (HCV) infection compared to sexual majority men.[77-79]

Cancer Burden

Limitations in national health surveillance data on LGBTQ+ make it difficult to ascertain the true cancer burden among the LGBTQ+ community.[70,71] Notably, cancer screening prevalence estimates for LGBTQ+ people tend to be lower than majority populations, attributable to discrimination in healthcare, gender dysphoria, unclear screening guidelines, and lower insurance coverage rates.[65,77,80,81] Sexual minority women have a higher incidence of cancer overall (particularly breast) compared to sexual majority women, and sexual minority men have a higher incidence of anal cancer compared to sexual majority men,[81,82] with anal cancer being one of the fastest-rising causes of cancer incidence and mortality in sexual minority men.[83] For LGBTQ+ people, there are no reliable overall cancer screening, incidence, mortality, or survival data.[84]

Table 1: Average annual (2015-2019), age-adjusted incidence and mortality rates and five-year relative survival rates for race/ethnicity-, age-, and rurality-based populations of focus in the United States

Population of Focus	2015-2019 Average Annual, Age-Adjusted Incidence Rate (per 100,000) (95% CI)	2015-2019 Average Annual, Age-Adjusted Mortality Rate (per 100,000) (95% CI)	Five Year Relative Survival Rate (based on cases diagnosed 2012-2018) (95% CI)
Groups Based on Race/Ethnicity			
Non-Hispanic Black or African American	459.0 (457.6, 460.4)	178.6 (178.0, 179.2)	63.8% (63.5%, 64.0%)
Non-Hispanic American Indian/Alaska Native	420.4 (412.5, 428.3)	161.4 (158.4, 164.5)	60.7% (59.5%, 61.8%)
Non-Hispanic Asian/Pacific Islander	308.3 (307.0, 309.5)	96.4 (95.8, 97.0)	65.8% (65.6%, 66.1%)
Hispanic/Latino	354.3 (353.3, 355.3)	109.7 (109.2, 110.2)	66.8% (66.6%, 67.0%)
Non-Hispanic White (NHW)	476.3 (475.7, 476.9)	157.2 (157.0, 157.4)	68.7% (68.6%, 68.8%)

All Races	445.5 (445.1, 446.0)	149.4 (149.3, 149.6)	68.1% (68.0%, 68.2%)
Groups Based on Age			
Adolescents and Young Adults (ages 15-39 years)*	76.2 (75.8, 76.5)	8.8 (8.7, 8.9)	85.5% (85.2%, 85.7%)
Senior Adults (ages 65+ years)*	1,977.1 (1,974.4, 1,979.7)	871.8 (870.7, 873.0)	60.7% (60.5%, 60.8%)
Ages 15+ years	562.5 (562.0, 563.1)	193.6 (193.3, 193.8)	68.0% (67.9%, 68.0%)
Groups Based on Rurality			
Residents of Non-metropolitan Counties (based on Rural Urban Continuum Codes)	465.5 (464.1, 466.9)**	169.3 (168.9, 169.8)***	63.1% (62.8%, 63.3%)****

Source, unless otherwise noted: SEER*Explorer: An interactive website for SEER cancer statistics [Internet]. Surveillance Research Program, National Cancer Institute. [Cited 2021 September 27]. Available from https://seer.cancer.gov/statistics-network/explorer/.

*Not age-adjusted
** Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Incidence - SEER Research Limited-Field Data, 22 Registries, Nov 2021 Sub (2000-2019) - Linked To County Attributes - Time Dependent (1990-2019) Income/Rurality, 1969-2020 Counties, National Cancer Institute, DCCPS, Surveillance Research Program, released April 2022, based on the November 2021 submission.
*** Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Mortality - All COD, Aggregated With County, Total U.S. (1990-2019) <Katrina/Rita Population Adjustment> - Linked To County Attributes - Total U.S., 1969-2019 Counties, National Cancer Institute, DCCPS, Surveillance Research Program, released April 2021. Underlying mortality data provided by NCHS (www.cdc.gov/nchs).
****Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Incidence - SEER Research Plus Data, 17 Registries, Nov 2021 Sub (2000-2019) - Linked To County Attributes - Total U.S., 1969-2020 Counties, National Cancer Institute, DCCPS, Surveillance Research Program, released April 2022, based on the November 2021 submission.

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C. IDENTIFICATION OF FY21 AWARDED NIH CANCER RESEARCH GRANTS RELEVANT TO SPECIFIC POPULATIONS

NCI Center for Research Strategy Project Team: Joshua Collins, Christine Burgess, Roman Gorelik, Diane Palmieri
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Introduction

In support of, and in cooperation with, the NCAB ad hoc Working Group on Strategic Approaches and Opportunities for Research on Cancer Among Racial and Ethnic Minorities and Underserved Populations, CRS has identified awarded cancer research grants within the NIH research portfolio that were deemed relevant to the following populations of interest: Black or African Americans, American Indian or Alaska Natives, Asians, Hispanics, Pacific Islanders, Rural Americans, and Sexual & Gender Minorities. Additionally, CRS has provided a broad overview of the research portfolio for each population.

This document is intended to provide the Working Group with (1) a brief description of the methodology used to identify the FY21 NIH extramural awarded cancer research grants for each population of interest and (2) summarize the results for the Working Group report.

The underlying data are from the NIH Information for Management, Planning, Analysis, and Coordination (IMPAC II) database of extramural applications and awards. While CRS has leveraged some tools that are only available to NIH staff (see QVR, RCDC below), all NIH grant awards provided to the Working Group are publicly available through the NIH Research Portfolio Online Reporting Tools (RePORT) website at https://report.nih.gov/.

It is important to consider that due to periodic revisions of the underlying data by NIH administrative staff, reliance on machine learning algorithms that undergo episodic refinements, and analytical decisions by the working group that in some instances required manual curation of the data, *the portfolio counts in this analysis are considered FY21 estimates only*. Portfolio counts and analytical trends may differ significantly in other fiscal years.

Methods

Populations of Interest
The populations of interest identified by the Working Group are as follows: Black or African Americans, American Indian or Alaska Natives, Asians, Hispanics, Pacific Islanders, Rural Americans, and Sexual & Gender Minorities.

Query View Report (QVR)
QVR is a module within the NIH Electronic Research Administration (eRA) that integrates information from databases on extramural applications and awards, financial obligations, indexed journal citations and abstracts. QVR is designed to help NIH staff and agency partner staff to view detailed information about grant applications and awards.

Research Condition and Disease Categorization (RCDC)
The RCDC system is used by the NIH in its reporting process to categorize funding in biomedical research for each fiscal year. The NIH currently reports funding to the public for 308 categories. RCDC also manages categories for internal planning and analysis beyond what is publicly available.

The RCDC system uses an automated text mining process in combination with a mathematical formula to produce a project index that consists of a weighted list of *concepts* from the RCDC thesaurus. The RCDC thesaurus consists of more than 180,000 biomedical terms and synonyms curated by NIH scientific experts and compiled from the National Library of Medicine's MeSH thesaurus, CRISP thesaurus, NCI thesaurus, Metathesaurus, Jablonsky's dictionary, and other sources from NIH institutes and centers.

Similarly, RCDC *categories* are developed using a mathematical formula that produces weighted lists of *concepts*. Ultimately, this process is used to define a *research area, condition,* or *disease* made up of well-defined RCDC *concepts* and *categories*.

In sum, the RCDC system provides consistent text mining methods applied to all categories each year, clear and efficient processes for categorizing and reporting on NIH funding, tools for program and category analysis, and user and manual categories for specific reporting requirements.

More information on RCDC can be found at https://report.nih.gov/funding/categorical-spending/rcdc-faqs

RCDC Category and Concept Usage
Where possible, CRS has leveraged RCDC categories to identify awards relevant to each population of interest.

In some instances, an RCDC category was not available for a specific population. Thus, CRS used all available RCDC concepts relevant to the specific population. Awards were deemed relevant to the specific population if the RCDC concepts were found in the title, abstract, or specific aims.

RCDC categories and concepts were used for the selected populations in the following manner:

Black or African American
RCDC Category: None available
RCDC Concepts: African; African American; African Caribbean; African race; Afro American; Afro-Caribbean; Afroamerican; black American; black carib; black Caribbean; black ethnic subgroup; black female; black male; black men; black patient; Black Populations; Black race; black subgroup; black women; black/white disparity

American Indian or Alaska Natives
RCDC Category: American Indian or Alaska Native
RCDC Concepts: Not applicable

Asians
RCDC Category: None available
RCDC Concepts: Bhutanese; Bhutanese American; Bangladeshi; Asian Indian; Asian Americans; Chinese; Chinese American; Chinese People; Korean American; Koreans; Japanese; Japanese American; Japanese Population; Cambodian; Cambodian American; Indonesian New Guinea; Malaysian; Burmese; Filipino American

Hispanics
RCDC Category: None Available
RCDC Concepts: Caribbean Hispanic; Hispanic Americans; Hispanic community; Hispanic Community Health Study; Study of Latinos; Hispanic Populations; Hispanics; rural Hispanic; Latino; Latina; Latino Population; Study of Latinos; Amerindian; Argentinean; Bolivian; Central American; Chicanas; Chicanos; Chilean; Cuban; Cuban American; Dominican; Salvadoran;

Guatemalan; Haitian; Hispanic Americans; Honduran; Mexican; Mexican Americans; Peruvian; Puerto Rican; Quechua; Costa Rican; Chilean; South American; Uruguayan; Venezuelan; Latinx

Pacific Islanders
RCDC Category: None Available
RCDC Concepts: Asian Pacific American; Asian Pacific Islander; Native Hawaiian or Other Pacific Islander; Pacific Island Americans; Pacific Islander; Pacific Islander American; Hawaiian; Hawaiian population; Native Hawaiian; Guamanian; Samoan; Melanesian; Polynesian

Rural Americans
RCDC Category: Rural Health
RCDC Concepts: Not Applicable

Sexual and Gender Minorities
RCDC Category: Sexual and Gender Minorities (SGM/LGBT*)
RCDC Concepts: Not Applicable

Base Projects

NIH grants are either single- or multi-component awards that are issued with an alpha-numeric project identifier. Multi-component grants consist of a parent project and multiple subprojects that share the same base project number (a subset of the alpha-numeric identifier). Unique base projects function as the unit of measure for the analyses herein. In this regard, if more than one subproject within a multi-component grant is identified in the search strategy, the grant is only counted once via the unique base project number. Base projects were included if at least one subproject was identified in the search strategy.

Exclusion Criteria
Analytical decisions by the Working Group resulted in the exclusion of certain grant mechanisms from all portfolios. The following were excluded:

- Intramural projects
- Contracts
- Award supplements (Type 3)
- International/Domestic Training & Career awards with specific activity codes D43, D71, M01, R00, R13, R25, R90, U13 or those that begin with F, K, G, H, T
- P30 (Cancer Centers)
- NCI Community Oncology Research Program (NCORP) awards
- International Projects identified as
    1. Fogarty International Center grants
    2. Center for Global Health grants
    3. Grants with foreign countries in the project or FOA title
- Subproject Cores (Subprojects within Multicomponent awards that are primarily intended as project support i.e., bioinformatics, tissue-processing, data-management cores)

Identifying NIH Cancer Awards Relevant to Each Population of Interest
CRS queried the QVR module to identify all FY21 NIH extramural cancer awards by leveraging the RCDC category CANCER. This query returned all FY21 cancer awards administered across all NIH ICs. By default, all NCI administered awards fall within this category.

The exclusion criteria were then applied to this dataset to produce what CRS has generically termed the “NIH Cancer Comparator Portfolio.” It should be noted that due to the exclusion criteria applied, this dataset does not include the entirety of the NIH cancer research portfolio and should not be construed as such—this is a generic term used for ease of communication and for comparison purposes within the analytical parameters designed for this project analysis only.

To produce the portfolio for each specific population, CRS queried QVR for all FY21 NIH cancer awards using the RCDC category CANCER in combination with the appropriate RCDC category or concepts for the specific population. The exclusion criteria were then applied to each population dataset to produce the final portfolio.

As an example of RCDC category usage, the Rural American portfolio was produced via a QVR query for NIH FY21 awards using the RCDC category CANCER and RCDC category RURAL HEALTH. Awards matching the exclusion criteria were then removed from the dataset.

As an example of RCDC category and RCDC concept usage, the Black or African American portfolio was produced via a QVR query for NIH FY21 awards using the RCDC category CANCER and RCDC concepts African; African American; African Caribbean; African race; Afro American; Afro-Caribbean; Afroamerican; black American; black carib; black Caribbean; black ethnic subgroup; black female; black male; black men; black patient; Black Populations; Black race; black subgroup; black women; black/white disparity. Concepts were used in conjunction and separated by an "Or" statement. Awards matching the exclusion criteria were then removed from the dataset.

The remaining portfolios for the populations of interest were constructed in a similar manner.

All data remediation and analyses were performed using Python-based coding and data analytics.

All identified awards were confirmed to be publicly available through the NIH Research Portfolio Online Reporting Tools (RePORT) website at https://report.nih.gov/.

Portfolio Research Continua

The International Cancer Research Partnership (ICRP) has crafted a set of coding guidelines, referred to as the Common Scientific Outline (CSO), that are used for discussing, comparing, and presenting cancer research portfolios. Grants can be broadly categorized into CSO codes using a machine learning model. Grants can be assigned into more than one of the following categories: 1. Biology; 2. Etiology; 3. Prevention; 4. Early Detection, Diagnosis, and Prognosis; 5. Treatment; 6. Cancer Control, Survivorship, and Outcomes Research. In some instances, there is not enough information to assign a grant to a particular category.

CRS has leveraged CSO categories to model the research continuum for each population of interest. It is important to note that NCI/NIH does not assign CSO categories to grants and that categorization is independently applied in a retrospective manner.

Results

NIH Cancer Comparator Portfolio

As an initial screen, CRS identified 9,643 FY21 extramural base projects that were administered across all NIH ICs and were within the RCDC category CANCER. Of these, approximately 75% (n = 7,251) were administered by NCI.

Analytical decisions by the Working Group resulted in the exclusion of several award types and funding mechanisms. Specifically, intramural projects, contracts, award supplements (type 3), international/domestic training and career awards, P30 Cancer Center Support grants, NCI Community Oncology Research Program (NCORP) awards, international projects, and certain subproject cores that are primarily intended as project support have been removed from all portfolios.

After applying the exclusion criteria above, CRS refined the awards of interest to 7,327 FY21 extramural base projects that were administered across all NIH ICs and were within the RCDC category CANCER. This collection of awards is a comparator group for the analyses herein and has been generically termed the "NIH Cancer Comparator Portfolio". Note that this dataset does not include the entirety of the NIH cancer research portfolio and should not be construed as such. Further, due to periodic revisions of the underlying data by NIH administrative staff, reliance on machine learning algorithms that undergo episodic refinements, and analytical decisions by the working group that in some instances required manual curation of the data, *the portfolio counts in this analysis are considered FY21 estimates only*. Portfolio counts and analytical trends may differ significantly in other fiscal years.

Approximately 74% (n = 5,412) of the comparator portfolio was administered by NCI.

See Figure 1 for a summary of these results.

Portfolios for Populations of Interest

FY21 base projects for each population of interest were identified using the search criteria described in the Methods section. The portfolios of base projects for each population of interest are subsets of the NIH Cancer Comparator Portfolio and are not necessarily mutually exclusive of one another. For example, multiple projects leverage the Multiethnic Cohort Study that monitors primarily men and women from five ethnic groups (White, Japanese Americans, Native Hawaiians, African Americans and Latinos) for the development of cancer and other diseases (see https://www.uhcancercenter.org/for-researchers/mec-cohort-composition for more information). These projects will, therefore, be represented in multiple portfolios.

As noted, NCI administers ~74% of the awards in the NIH Cancer Comparator portfolio. NCI also administers the majority of awards in each portfolio though deviations from the expected ~74% range from a high of ~83% in the Asian portfolio to a low ~53% in the Sexual & Gender Minorities portfolio. These deviations may be due to the relatively low number of projects in each portfolio. The number of base projects for each population of interest are summarized in Table 1.

Portfolio Funding Mechanisms

The NIH uses three funding mechanisms for extramural research awards: grants, cooperative agreements, and contracts. The funding mechanisms are further delineated by activity codes to differentiate the wide variety of supported research-related programs. The following activity codes are broadly referred to by the NIH as Research Project Grants (RPG): R00, R01, R03, R15, R21, R33, R34, R35, R36, R37, R50, R56, R61, RC1, RC2, RC3, RC4, RF1, RL1, RL2, RL9, P01, P42, PM1, PN1, RM1, UA5, UC1, UC2, UC3, UC4, UC7, UF1, UG3, UH2, UH3, UH5, UM1, UM2, U01, U19, U34, U3R, DP1, DP2, DP3, DP4, DP5. RPGs include both grants and cooperative agreements.

For the purposes of this analysis, portfolio funding mechanisms were divided into three categories: RPGs, Research Centers (P20, P50 and U54), and Others (e.g. SBIR/STTR and non- RPG cooperative agreements). Contracts and some activity codes, such as P30s (Cancer Center Support grants), have been excluded from the analysis (see Methods). The funding mechanism breakdown revealed that RPGs account for the vast majority of funding for each portfolio. Additionally, compared to the NIH Cancer Comparator, the portfolio for each population of interest has a higher overall percentage of funding dedicated to Research Centers. See Figure 2 for summarized results.

Portfolio Research Continua

The International Cancer Research Partnership (ICRP) has crafted a set of coding guidelines, referred to as the Common Scientific Outline (CSO), that are used for discussing, comparing, and presenting cancer research portfolios (see Methods). ICRP categorization using CSO codes

allows for the exploration of the research continuum for each population of interest. It should be noted that base projects may be assigned to multiple categories (or may remain uncategorized due to insufficient assignment criteria). Further, NCI/NIH does not assign CSO categories to grants and categorization is independently applied in a retrospective manner.

Examination of the research continua revealed two evident trends. First, the NIH Cancer Comparator has a higher percentage of base projects categorized as Biology (~43%) or Treatment (~41%) than all populations of interest. Second, all populations of interest have a higher percentage of base projects categorized as Prevention or Cancer Control, Survivorship, and Outcomes Research than the NIH Cancer Comparator (~6% and ~10%, respectively).

On an individual portfolio comparison versus the NIH Cancer Comparator, the Black or African Population portfolio has significantly less projects categorized as Biology and Treatment (~27% vs ~43% and ~15% vs ~41%, respectively) with significantly more projects categorized as Etiology (~37% vs ~13%), Prevention (~19% vs ~6%), and Cancer Control, Survivorship, and Outcomes Research (~31% vs ~10%).

The American Indian or Alaska Native portfolio has significantly less projects categorized as Biology and Treatment (~17% vs ~43% and ~23% vs ~41%, respectively) with significantly more projects categorized as Etiology (~23% vs ~13%), Prevention (~47% vs ~6%), Early Detection, Diagnosis, and Prognosis (~30% vs ~20%) and Cancer Control, Survivorship, and Outcomes Research (~47% vs ~10%).

The Asian portfolio has significantly less projects categorized as Biology and Treatment (~14% vs ~43% and ~2% vs ~41%, respectively) with significantly more projects categorized as Etiology (~23% vs ~13%), Prevention (~15% vs ~6%), and Cancer Control, Survivorship, and Outcomes Research (~52% vs ~10%).

The Hispanic portfolio has significantly less projects categorized as Biology and Treatment (~13% vs ~43% and ~10% vs ~41%, respectively) with significantly more projects categorized as Etiology (~32% vs ~13%), Prevention (~22% vs ~6%), and Cancer Control, Survivorship, and Outcomes Research (~42% vs ~10%).

The Pacific Islander portfolio has significantly less projects categorized as Biology and Treatment (~5% vs ~43% and ~10% vs ~41%, respectively) with significantly more projects categorized as Etiology (~43% vs ~13%), Prevention (~19% vs ~6%), and Cancer Control, Survivorship, and Outcomes Research (~67% vs ~10%).

The Rural American portfolio has significantly less projects categorized as Biology and Treatment (~6% vs ~43% and ~10% vs ~41%, respectively) with significantly more projects categorized as Prevention (~38% vs ~6%), and Cancer Control, Survivorship, and Outcomes Research (~64% vs ~10%).

The Sexual & Gender Minorities portfolio has significantly less projects categorized as Biology and Treatment (~11% vs ~43% and ~5% vs ~41%, respectively) with significantly more projects categorized as Etiology (~53% vs ~13%), Prevention (~37% vs ~6%), and Cancer Control, Survivorship, and Outcomes Research (~21% vs ~10%).

The results are summarized in Table 2 and Figures 3 – 9.

Lastly, as noted earlier, NCI administers ~74% of awards within the NIH Cancer Comparator portfolio. As expected, NCI administers the vast majority of all awards within each CSO category for each population with some notable exceptions. NCI does not administer any awards within the Treatment category for the Asian portfolio, the Biology category for the Pacific Islander portfolio, nor the Biology or Treatment categories for the Sexual & Gender Minorities portfolio.

Table 1. 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%

Table 2. 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 American (N=104)	Sexual & Gender Minorites (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
7. 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.

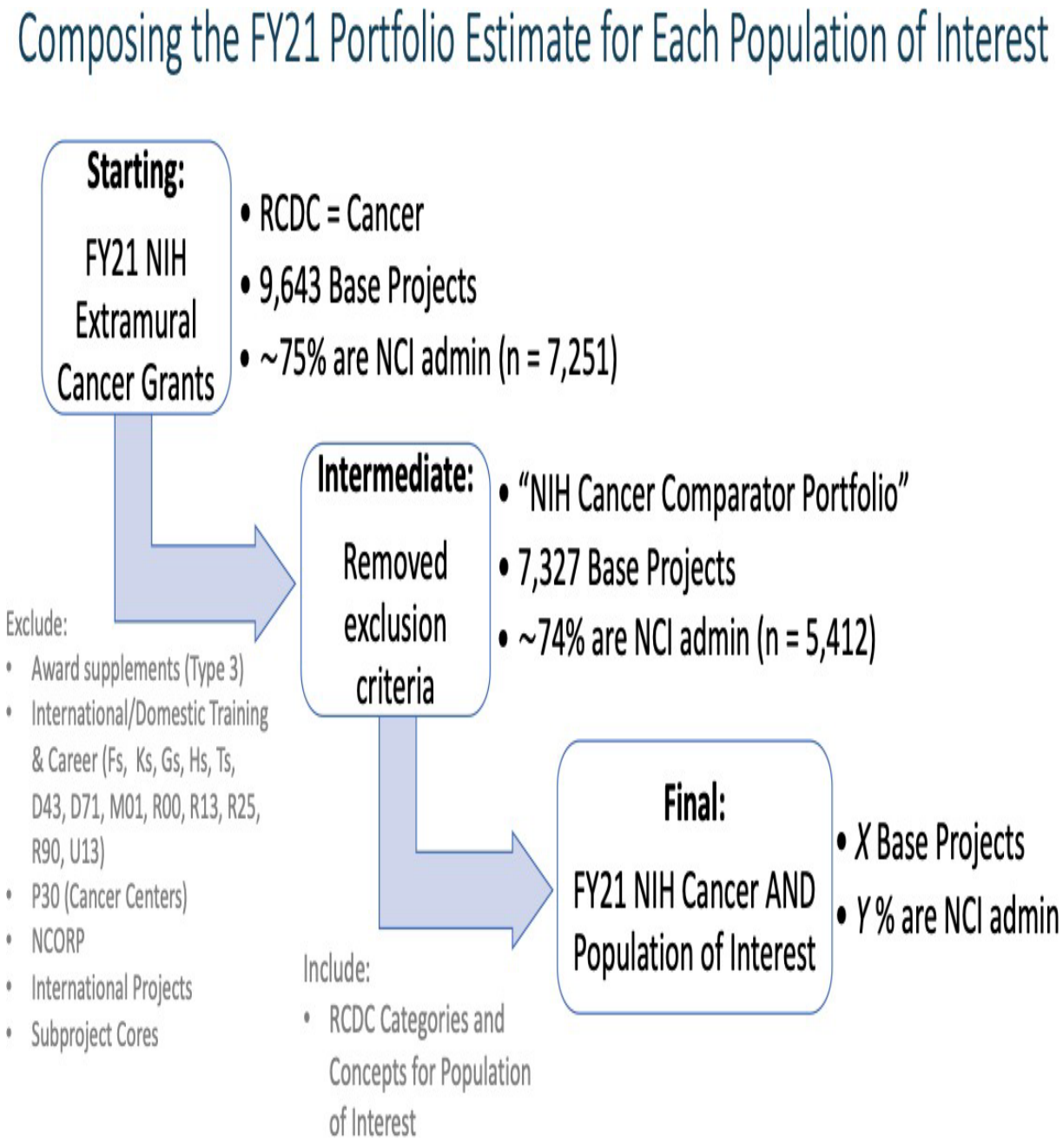

Figure 1. Summary of search criteria used to produce the comparator and population of interest portfolios. Briefly, all FY21 NIH cancer grants were identified by leveraging the RCDC category CANCER. This set of awards was then refined using exclusion criteria defined by the Working Group to produce the NIH Cancer Comparator Portfolio. The portfolio for each population of interest consists of a subset of the comparator portfolio identified via RCDC categories and concepts specific to each population.

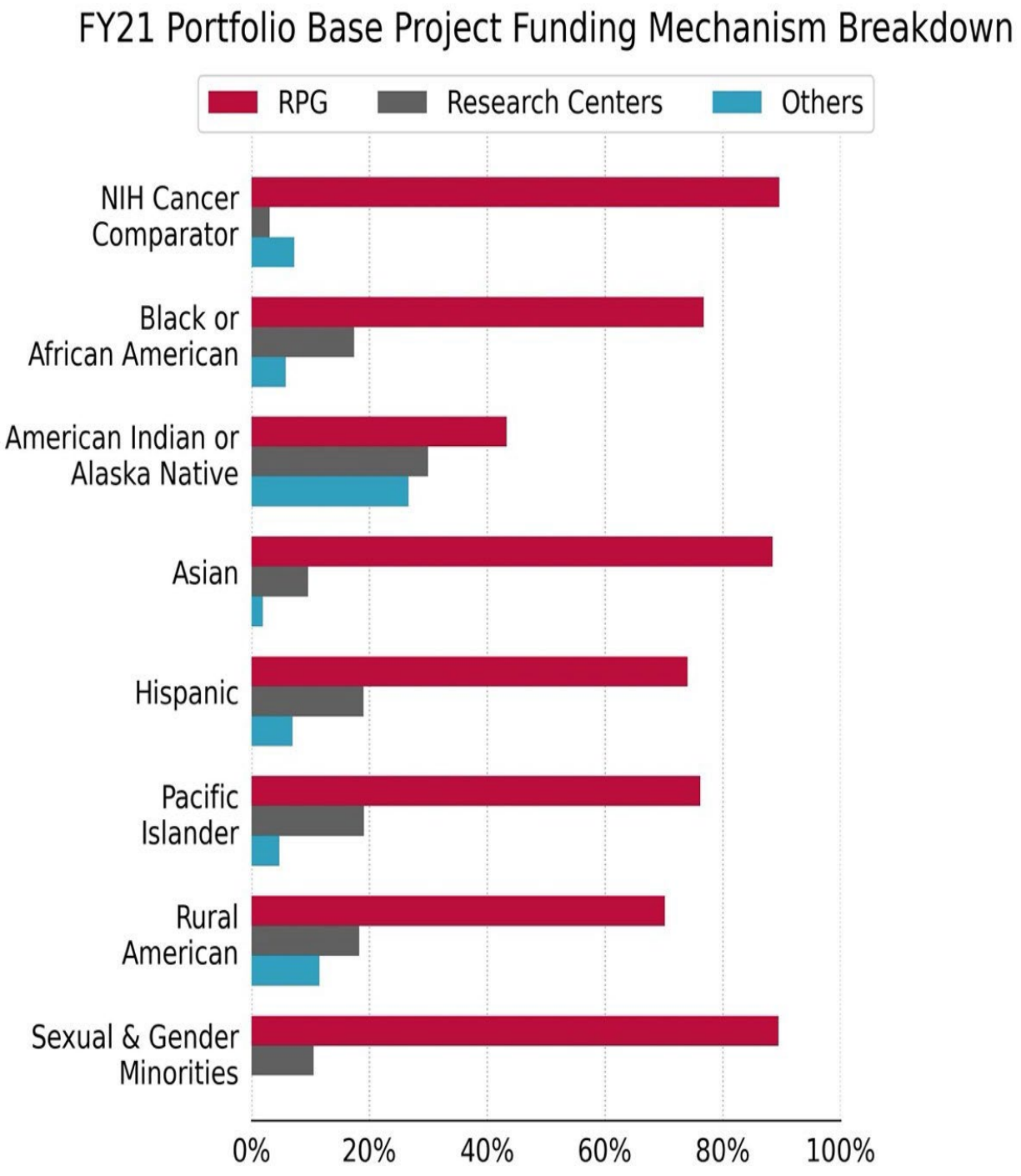

Figure 2. FY21 Portfolio Base Project Funding Mechanism Breakdown. Intramural projects, contracts, award supplements (Type 3), international/domestic training & career (Fs, Ks, Gs, Hs, Ts, D43, D71, M01, R00, R13, R25, R90, U13), P30 (Cancer Centers), NCORP, international projects, and subproject cores are excluded from all portfolios.

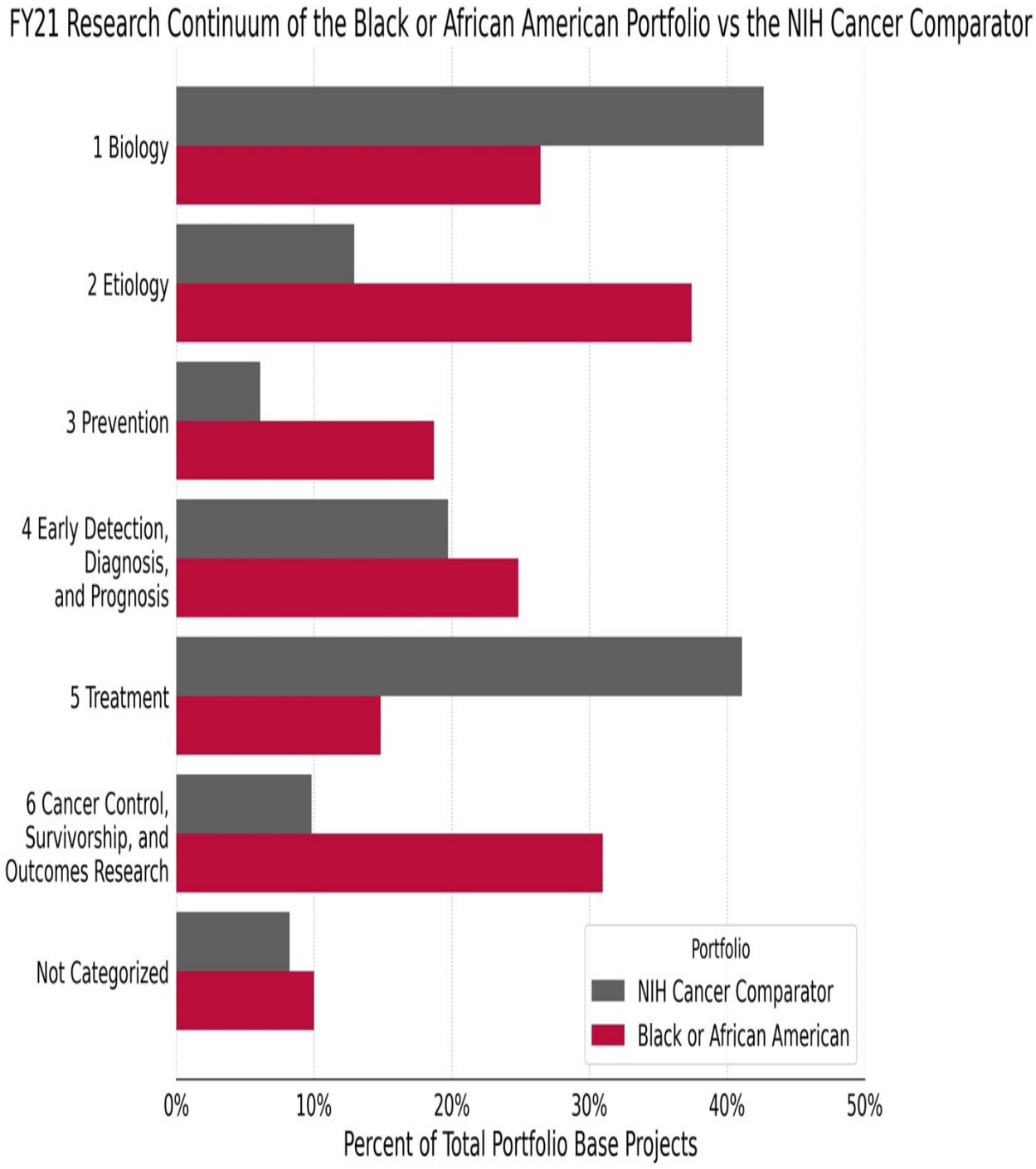

Figure 3. The research continuum for the Black or African American Portfolio in comparison to the NIH Cancer Comparator Portfolio. CSO category percentages are calculated as the number of base projects within each category divided by the total number of base projects in each portfolio. Note that base projects can fall into multiple categories. Portfolio counts are estimates. NIH Cancer Comparator (n = 7,327); Black or African American (n = 310). 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, and Subproject Cores are excluded from all portfolios.

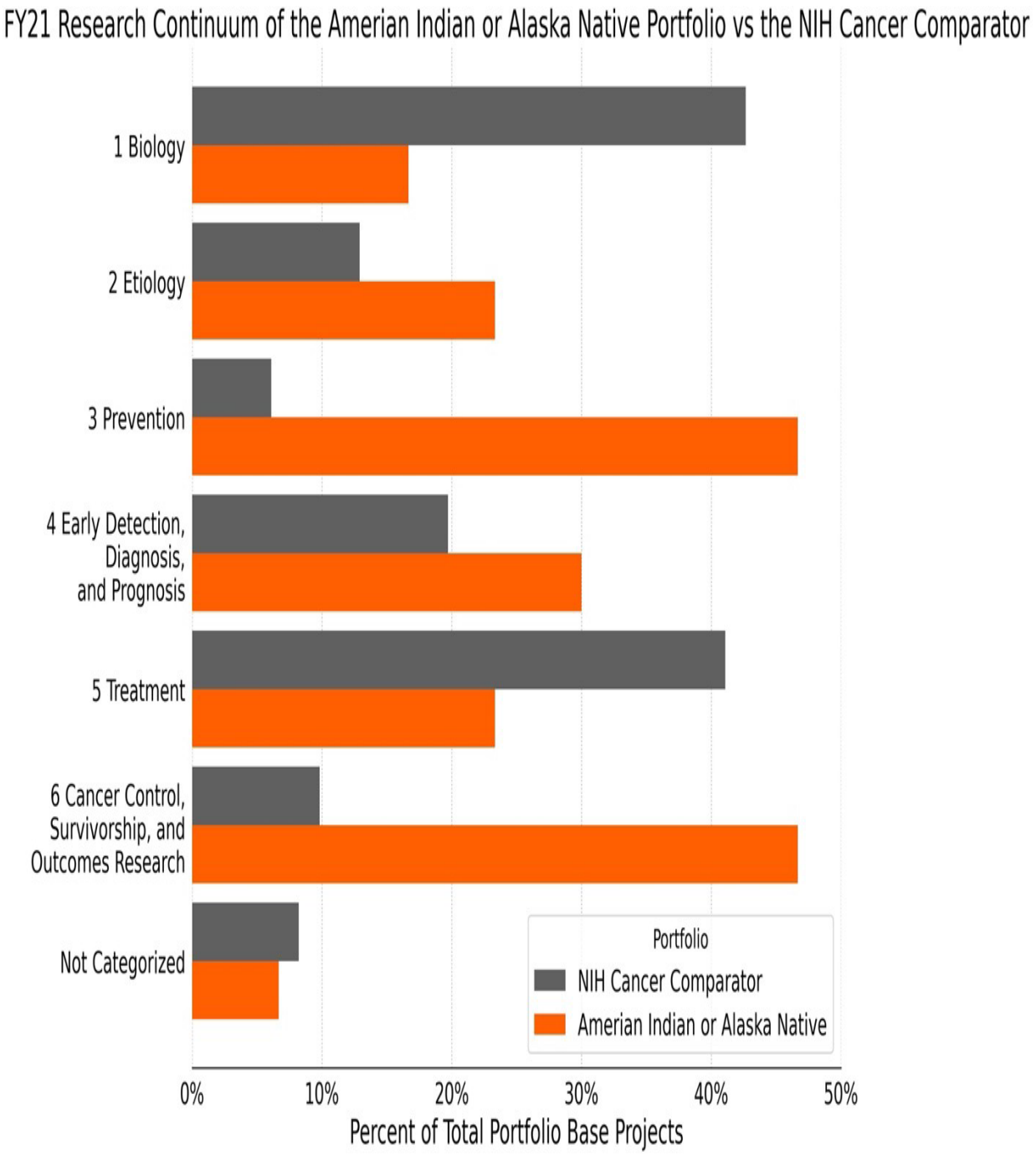

Figure 4. The research continuum for the American Indian or Alaska Native Portfolio in comparison to the NIH Cancer Comparator Portfolio. CSO category percentages are calculated as the number of base projects within each category divided by the total number of base projects in each portfolio. Note that base projects can fall into multiple categories. Portfolio counts are estimates. NIH Cancer Comparator (n = 7,327); American Indian or Alaska Native (n = 30). 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, and Subproject Cores are excluded from all portfolios.

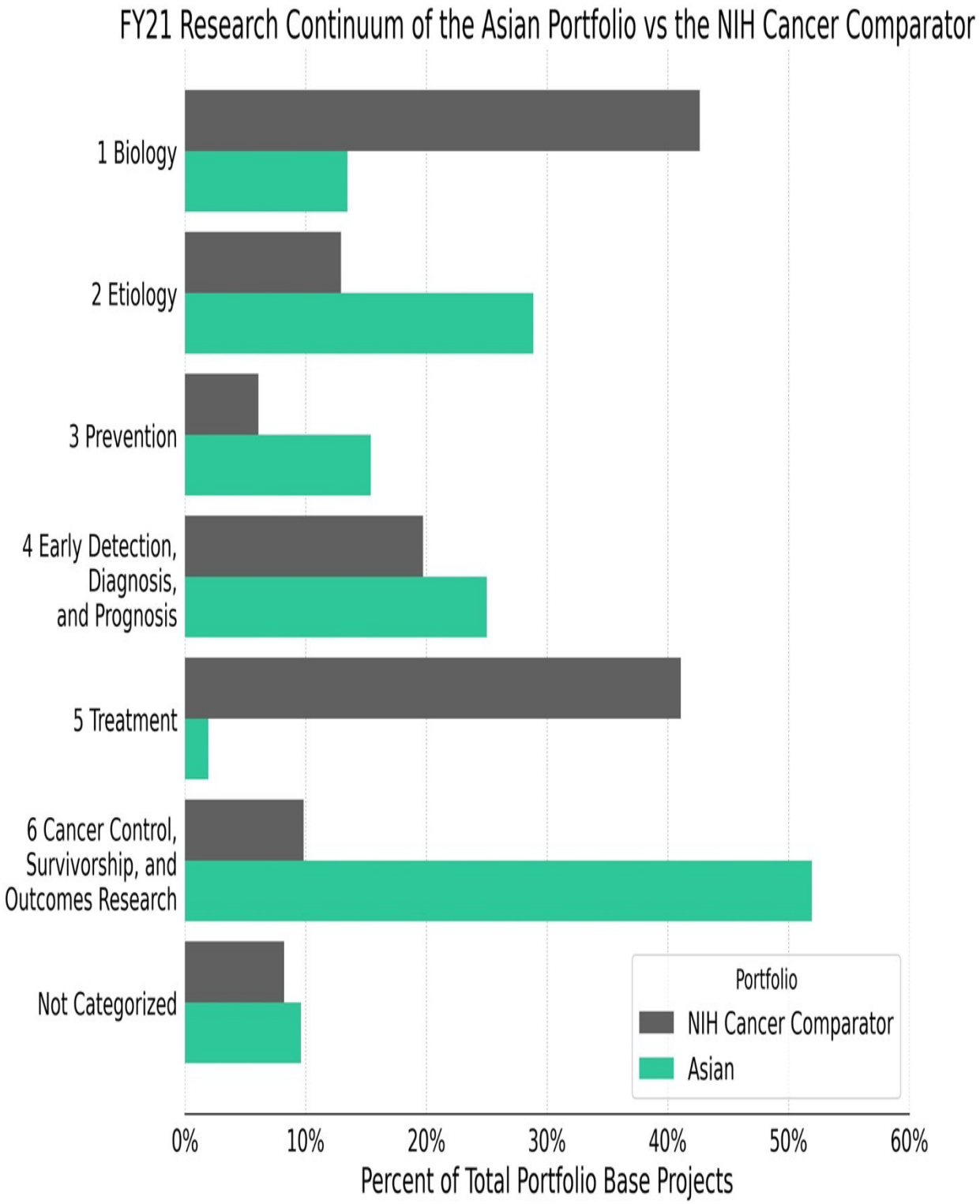

Figure 5. The research continuum for the Asian Portfolio in comparison to the NIH Cancer Comparator Portfolio. CSO category percentages are calculated as the number of base projects within each category divided by the total number of base projects in each portfolio. Note that base projects can fall into multiple categories. Portfolio counts are estimates. NIH Cancer Comparator (n = 7,327); Asian (n = 52). 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, and Subproject Cores are excluded from all portfolios.

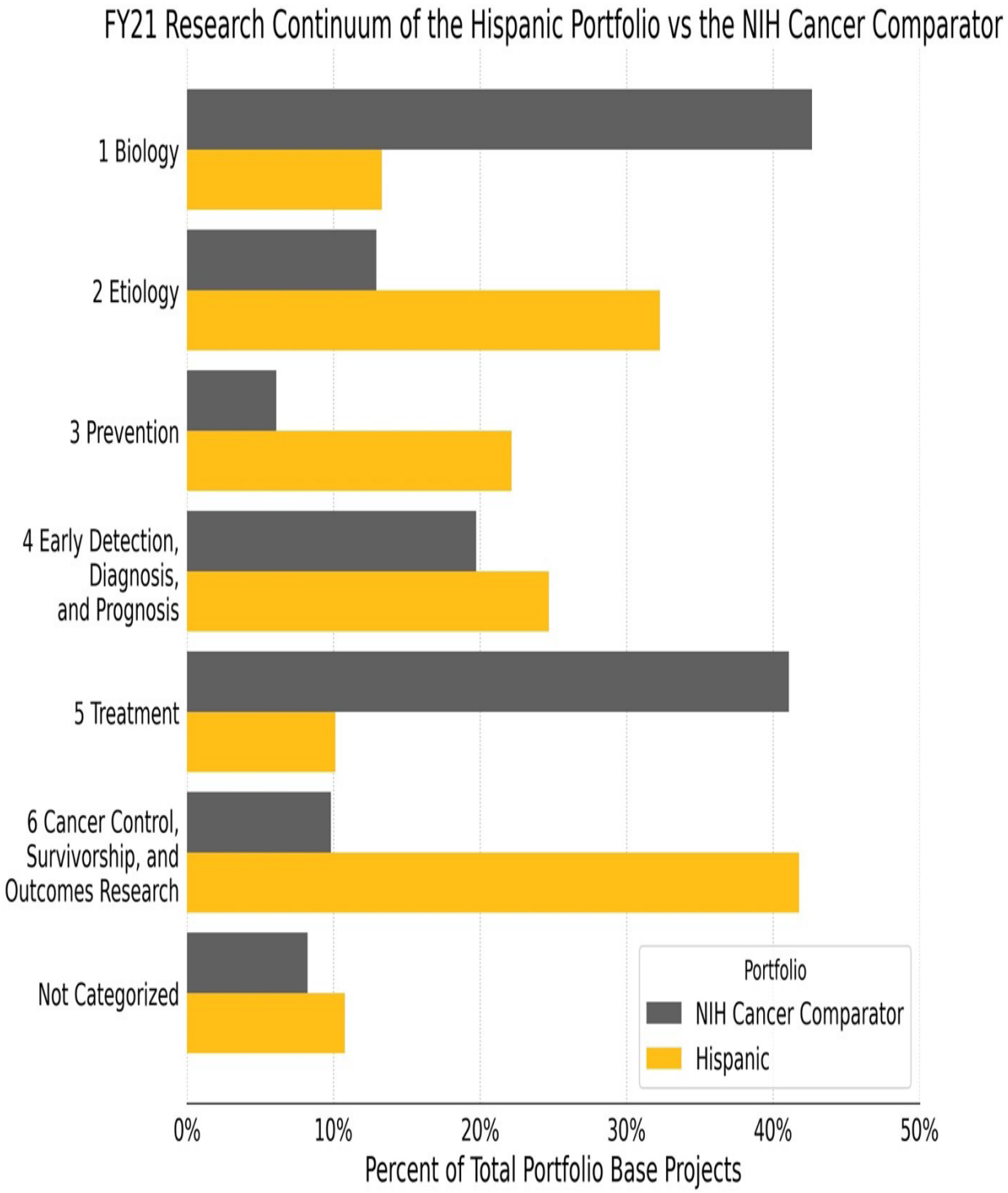

Figure 6. The research continuum for the Hispanic Portfolio in comparison to the NIH Cancer Comparator Portfolio. CSO category percentages are calculated as the number of base projects within each category divided by the total number of base projects in each portfolio. Note that base projects can fall into multiple categories. Portfolio counts are estimates. NIH Cancer Comparator (n = 7,327); Hispanic (n = 158). 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, and Subproject Cores are excluded from all portfolios.

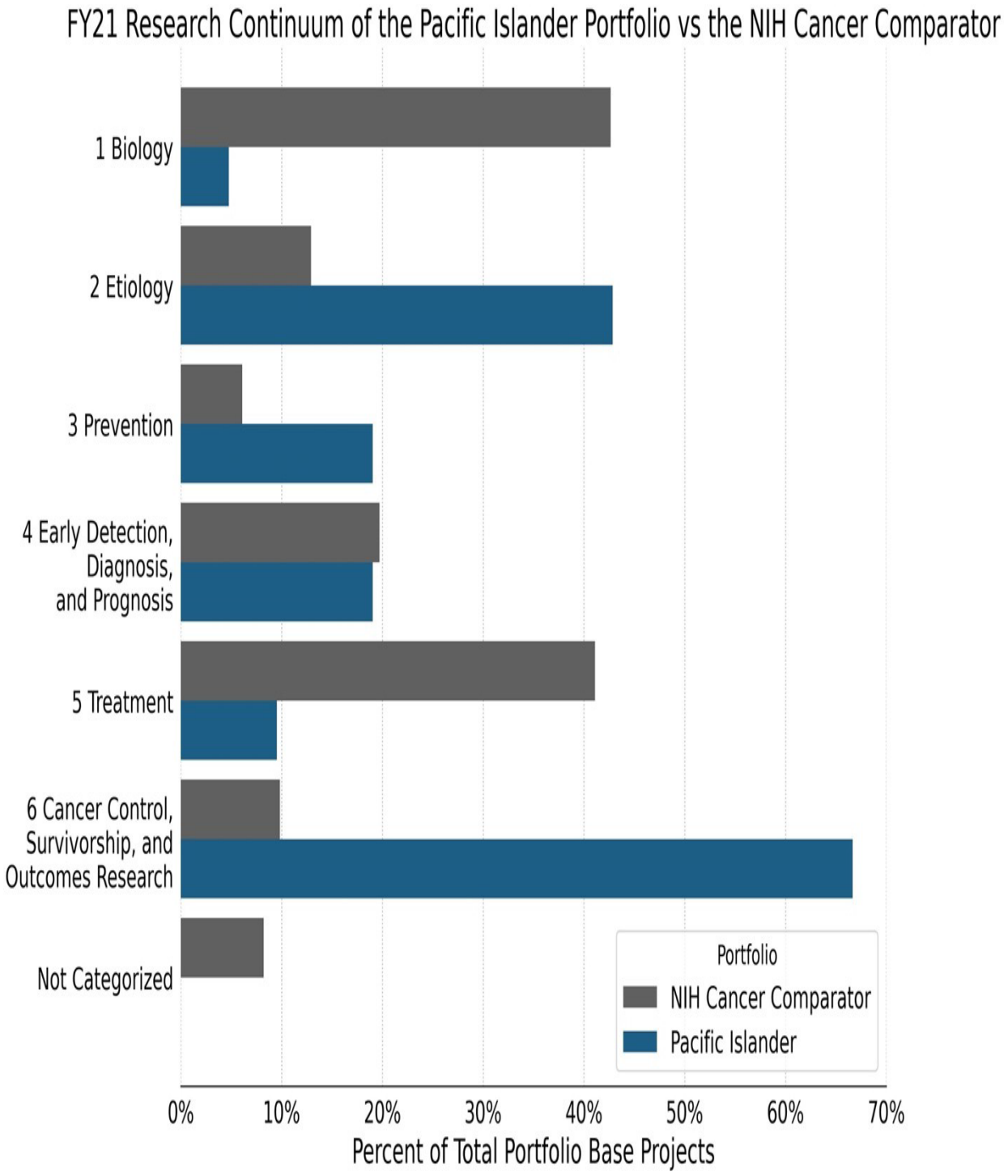

Figure 7. The research continuum for the Pacific Islander Portfolio in comparison to the NIH Cancer Comparator Portfolio. CSO category percentages are calculated as the number of base projects within each category divided by the total number of base projects in each portfolio. Note that base projects can fall into multiple categories. Portfolio counts are estimates. NIH Cancer Comparator (n = 7,327); Pacific Islander (n = 21). 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, and Subproject Cores are excluded from all portfolios.

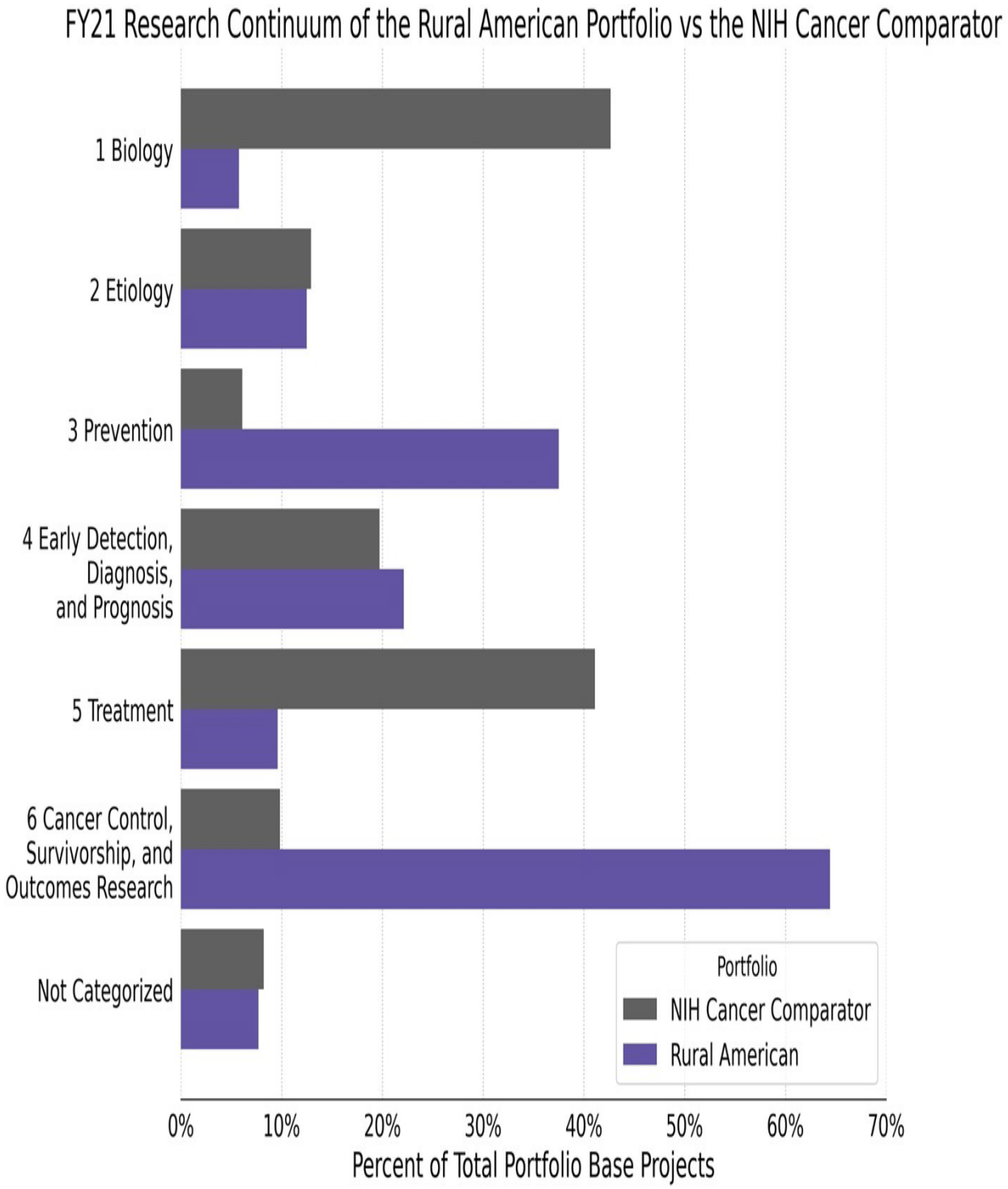

Figure 8. The research continuum for the Rural American Portfolio in comparison to the NIH Cancer Comparator Portfolio. CSO category percentages are calculated as the number of base projects within each category divided by the total number of base projects in each portfolio. Note that base projects can fall into multiple categories. Portfolio counts are estimates. NIH Cancer Comparator (n = 7,327); Rural American (n = 104). 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, and Subproject Cores are excluded from all portfolios.

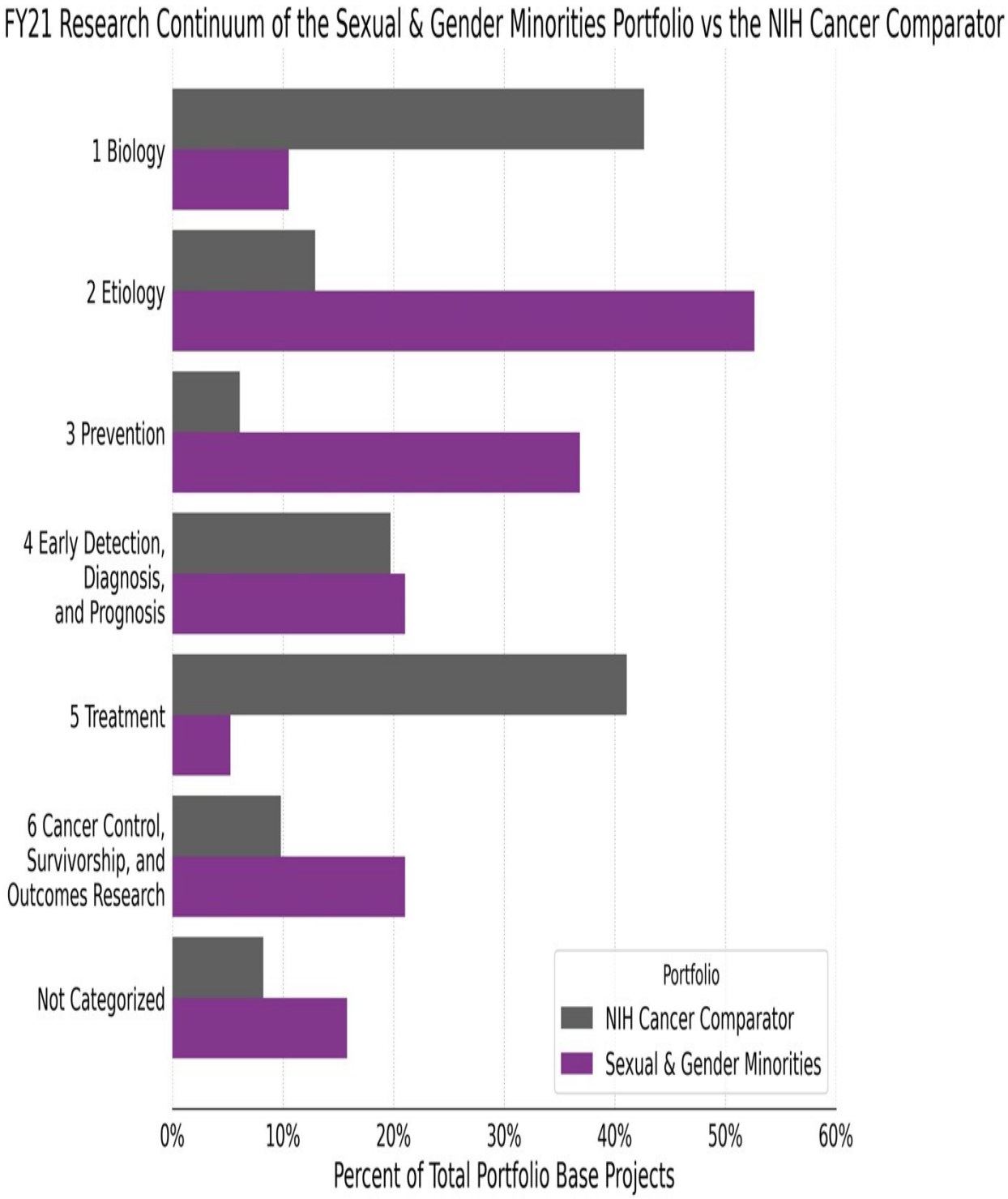

Figure 9. The research continuum for the Sexual & Gender Minorities Portfolio in comparison to the NIH Cancer Comparator Portfolio. CSO category percentages are calculated as the number of base projects within each category divided by the total number of base projects in each portfolio. Note that base projects can fall into multiple categories. Portfolio counts are estimates. NIH Cancer Comparator (n = 7,327); Sexual & Gender Minorities (n = 19). 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, and Subproject Cores are excluded from all portfolios

Summary and Recommendations

Summary of Findings

The following were **key findings** of the portfolio analysis:

1) There is an imbalance in the funding of research relative to the distribution of cancer diagnosis, cancer morbidity, and cancer death in the United States;
2) Relative to the overall funding portfolio, the investment was small for research that focused among racial and ethnic minorities, rural populations, and the other groups evaluated. The underrepresentation was across both the continuum of science and the lifespan;
3) Within the limited funding identified, there were proportionally more projects in population sciences and fewer studies in areas such as biological research and clinical research;
4) Many funded projects draw on a limited number of underserved population groups, limiting the applicability of the current knowledge base; and
5) Details for some population groups were insufficient because of a) limited disaggregated data in those population groups (e.g., Pacific Islander people), b) populations were understudied (e.g., older and AYA, 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). **This significantly limited the WG's ability to complete the charge to the same degree for all population groups.**

In addition, presentations to the working group provided addition information and shared inaccuracies and inconsistency in the ability of current tracking systems at the NIH/NCI to adequately capture or delineate the current investment in specific groups that hinder data-driven and intentional approach to direct future investments.

Specific Recommendations

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.

RATIONALE: Research conducted in all populations of interest was low. Across the continuum, projects focused on the population groups varied and many had little research being conducted. Biology was an area of most concern, as was the lack of focused research in Treatment.

a. To address this paucity of research: it is recommended that all grants, including RFAs, FOAs, PARs and investigator-initiated research (e.g., RO1's, PO1's) include requirements to recruit populations underrepresented in research at least to the degree that they are represented by the cancer(s) studied. In addition, where the data indicate disparities in a cancer studied, adequate numbers of the populations most at risk should be recruited so that the impact of the treatment, intervention, etc., can be assessed in these specific populations.
b. Projects should also be encouraged to focus solely on the cancer/risk factor/intervention effectiveness in a single underserved population – without the need for a comparator population group: For example, studies of Asian American or Hispanic people could uncover unique and important within group heterogeneity in risk and outcomes as well as biological determinants related to these. This requires disaggregation of race and ethnicity.
c. In addition to the above, supplements should be made available to funded research grants (RO1's, PO1's, P30's, etc.) to allow for increased recruitment and enrichment of underserved populations that were not included in the initial funded

study: this will enhance sample representation to allow for above-mentioned assessments.

d. Research should be encouraged in the following areas: Understanding the social vs. biological components; intersectionality (biology, genetics, and social); rurality; cancer models; create tissue/genetic databases of representative populations to support the biologic evaluation of disease by ancestry; translation into practice; and access to care.
e. Expand and develop strategies to increase funding for URM/diverse investigators to develop and implement funded research in underserved populations: Work with PED and CRTEC initiatives in CCC's and CRCHD.

2. ***Data Collection:*** Adopt standards in reporting of disaggregated data

RATIONALE: Certain population groups were not assessed due to the lack of data-abstraction key words: older adults, AYA

a. Checklist: In accordance with the broadened NIH definition of Populations Underrepresented in the Extramural Scientific Workforce (NOT-OD-20-031) and of minority, diverse, and underserved populations who engage in collaborative research, we recommend the creation of a checklist to denote specific populations under study on all NIH grant applications, progress reports, and summary reports – at the initiation of a study and at its completion. Such categorization might also be considered to monitor inclusion on clinical and community trials or interventions and population-based studies. Such categories might include: Non-Hispanic White, Black or African American, American Indian or Alaskan Native, Pacific Islander, Asian, Hispanic/Latino, Rural (could be modified by RUCA code depth), Age across the continuum (by decade, or by specific categories such as AYA, Senior, etc.), and means to capture Sexual and Gender Minorities or LGBTQ+. Prospective or funded researchers might check one or more relevant categories and be asked to provide the relative distribution or percent of these various categories under study.
b. Disaggregation of data: All data should be reported as disaggregated race – e.g., Asian American and NHPI separately. Moreover, all ethnicity and race categories (including White) should each be expanded to collect country of origin, e.g., for Hispanics: Mexico, Caribbean, etc. and Black or African American: Africa, Caribbean, etc.

3. ***Monitoring and evaluation*****:** Develop effective and efficient strategies for tracking, monitoring, and evaluating the federal investment in addressing health disparities and advancing cancer health equity to address the gaps identified in this report.

RATIONALE: This is the first time these data were examined. Automatic and real-time reports to allow for assessments over time are not available. Thus, measurement of change or impact is not currently possible.

a. Track numbers and types of projects over a 10-15-year horizon.
b. Create procedures to prospectively track the populations studied and the amount of health disparity research including checklists in applications and progress reports, similar to processes used to monitor inclusion of women and minorities in clinical trials.
c. Improve reporting of race and ethnicity, and sex, sexual orientation and gender identity while being sensitive to concerns in particular communities.
d. Develop a system for tracking number of projects vs overall portfolio in health disparities in the NCI and in each division/center at regular intervals focused on all population groups of interest.

4. ***Reporting*****:** Create annual report of activities in this area and provide congressional briefing on the state of cancer health disparities research leading to equity.

   RATIONALE: No standard reporting or accountability exists. A report would allow for accountability and transparency as well as reporting to community groups and relevant stakeholders.

   An annual cancer health disparities report with focus areas of:
   a. Research investment;
   b. Specific projects;
   c. Areas of research support; and
   d. Progress towards eliminating disparities in key areas prioritized by the NCI in consultation with stakeholders, and the areas of opportunity, gaps, or unmet needs.

Broad Recommendations:

1. ***Implementation Strategy:*** Establish a set of guiding principles and priorities using these recommendations to move the recommendations into action.

   a. The diversity and inclusion should extend beyond traditional definitions of community to both a place-based principle as well as ones that acknowledge the role of cultures or shared priorities.
   b. This recognizes and addresses a concern in communities disproportionately affected by cancer for research. This is also consistent with growing consensus that research led by communities or derives from communities has greater chance of sustainability and is more aligned with cultures and preferences within communities.
   c. Promote a culture of inclusive language within the cancer community.
   d. Promote adherence to principles of community-engaged research to align programs with community priorities.

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.

   a. All research within the portfolio of NCI centers and programs should be inclusive both in groups represented and in geographies included, even in basic research. For example, biomarker research should include tissues from representative populations to avoid systemic biases that will subsequently be embedded into interventions stemming from that research. Context matters and the importance of geographic diversity within studies is critical to understanding and integrating the context in which cancer occurs and cancer care outcomes result, including attention to increasing cohorts beyond existing ones (i.e., Multi-ethnic Cohort, Southern Community MEC, Southern Community Cohort Study, etc.)
   b. Clarifying what representation means in terms of the distribution of the disease in the population such that there is adequate inclusion in terms of numbers of people or participants and data elements collected for adequately powered assessment of heterogeneity in risk and treatments across population groups.

3. ***Resources***: Ensure that a portion of grants is focused on the underserved/ underrepresented populations included in this report. Progress in this area should be measured by unique awards funded, the inclusion of health disparities in major awards, and the proportion of NCI funded awards in this area. The evaluation should be disaggregated so that it would be apparent how many people from each population group (i.e., Black, American Indian, etc.) are included in the research as well as the unique research programs or cohorts. We recommend:

a. This may take the form of Cancer Health Disparities "Moonshot" with multi-year investment to address key priority areas such as the limited representation of racial and ethnicity minorities in treatment trials and other research.
b. Using RFAs as a way of spur research on methodology, and in specific high-priority or high-risk areas.

Supporting the creation of specific cohorts for which descriptive information is publicly available as a resource for populations that are understudied. Current cohorts such as The Cancer Epidemiology Descriptive Cohort Database (CEDCD) lack adequate representation of priority populations.

c. Supporting research that can demonstrate elimination of disparities. The frameworks to understand and address health disparities all include multi-level factors including social determinants of health that contribute to the disparities that are observed within populations. Research that seeks to eliminate disparities should consider how and address the SDOH can be targeted. A report by the US Preventive Services Task Force found that while many interventions have been studied, few have not been shown to eliminate inequities because they have not been implemented in the underserved populations. Synergy with other federal investments may accelerate progress towards eliminating cancer health inequities in key priorities areas to serve as a model for others.
d. Address the science and treatments that underly cancer disparities with same level of vigor as the general cancer diaspora with the addition of population science.
e. Include more research on the intersectionality of populations (e.g., Black, older adults, of Hispanic rural populations) that suffer disparities and understand how these factors interact as well as unique solutions/treatments to disparities.

4. ***Uniform Measures***: Implement a set of core elements to facilitate the analysis and reporting of progress in research across the continuum. This data-driven approach is critical to addressing health disparities and advancing health equity but is hampered by lack of consistency in the collection, and reporting of data as well as the language used to describe groups of people.

   a. NCI should use authority within its mandate to define such core element in research studies. Such core elements may include race, ethnicity, sex, gender, and other social variables including insurance status, language and language preference, and digital access and should include contextual data and assess how SOGI data may also be safely collected.
   b. Data should be consistently disaggregated to enable tracking of specific groups with suspected or confirmed inequities and to monitor progress.

5. ***Intentionality:*** Accelerate research by offering RFA's or PARs on areas that specifically contribute to 1) our 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.

   a. For instance, little is known of the underlying mechanisms by which race, or other social constructs may produce biological or molecular changes that increase differential cancer risk or treatment response (i.e., does social injustice create unique epigenetic signatures and does intersectional effects such as the combination of racism and other social factors create unique biological effects?). There are opportunities for transdisciplinary science on intersectional patterns of disease or gene-environment influences on disease risk or treatment response. Potential areas of focus may include:

i. Address gaps in knowledge about the drivers of cancer health disparities to elucidate understanding of the social and biological components. This may include intersectional effects on biological mechanisms including effects of social inequities (i.e., systemic racism and rurality). Approaches may include cancer models and translational research.
ii. Some specific areas across the disease and care continuum and the lifespan include the underrepresentation of mechanistic and treatment studies in the current limited disparity portfolio.

b. A pernicious cause of disparities stem from structural and social barriers to access and quality of healthcare. Research areas that identify and scale effective strategies to barriers to care are needed. This may build on current programs. Emphasis may be placed on interventions that can dismantle structural barriers and create sustainable change to address systemic barriers.
c. Have an intentional focus on inclusiveness groups in discovery science – HPV discovery, for instance did not adequately include cervical cancers from representative populations. As a result, HPV35, which causes 2% of cervical cancer in populations of European descent but 10% in those of African descent, is not included in the current HPV vaccines. These point to the need for a careful an ongoing review of interventions and algorithms for the presence of bias such as Oncotype Dx and as science moves to testing multi-cancer detection techniques, for example.

6. **Intersection with Other Ongoing NCI Efforts in Training:** NCI has already identified the lack of diverse researchers and leadership both within the NCI and in the extramural scientific community as a major impediment to increasing research broadly across the underserved population groups. Without a doubt, the recommendations above can only be fully realized with the realization of the goals of increasing diversity in the cancer workforce, at all levels. We recommend:

a. Encouraging the training branch to adopt our recommendations, as appropriate, when guiding new investigators to areas of research.
b. Interacting with CRCHD to promote diversity in the research portfolio amongst their cohorts of young and new investigators and increase funds available to fund all highly scored applications, including fellowship and other intramural investigators.
c. Supporting NCI initiatives to train undergraduate college/ high school students in STEM/Research?
d. Monitoring progress in both areas and asses any progress and training areas for improvement.

Abbreviations

AI – American Indian

AIDS – Acquired Immunodeficiency Syndrome

AN – Alaska Native

API – Asian/Pacific Islander

AYA – Adolescent and Young Adult

CEDCD – Cancer Epidemiology Descriptive Cohort Database

COD – Cause of Death

CRCHD – Center to Reduce Cancer Health Disparities

CRISP – Computer Retrieval of Information on Scientific Projects

CRS – Center for Research Strategy

CRTEC – Cancer Research Training and Education Coordination

CSO – Common Scientific Outline

DCCPS – Division of Cancer Control & Population Sciences

eRA – Electronic Research Administration

FPL – Federal Poverty Line

FOA – Funding Opportunities Announcement

HCV – Hepatitis C Virus

HIV – Human Immunodeficiency Virus

HPV – Human Papillomavirus Virus

IC – Institutes and Centers

ICRP – International Cancer Research Partnership

IMPAC II – Information for Management, Planning, Analysis, and Coordination

i-PARIHS – Integrated-Promoting Action on Research Implementation in Health Services

LGBTQ+ – Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, and others

MEC – Multi-ethnic Cohort

MeSH – Medical Subject Headings

NCAB – National Cancer Advisory Board

NCI – National Cancer Institute

NCORP – NCI Community Oncology Research Program

NHLBI – National Heart Lung and Blood Institute

NHPI – Native Hawaiian, and other Pacific Islander

NIH – National Institutes of Health

NIMHD – National Institute on Minority Health and Health Disparities

NWH – Non-Hispanic White

OMB – Office of Management and Budget

OBSSR – Office of Behavioral and Social Sciences Research

P30 – Cancer Center

PAR – Program Announcement with Special Receipt, Referral and/or Review

PO1 – Program Project Grant

PED – Pathophysiology of Eye Disease Study Section

PRCDAs – Purchased/Referred Care Delivery Areas

QVR – Query View Report

RCDC – Research Condition and Disease Categorization

RePORT – Research Portfolio Online Reporting Tools

RFA – Research Funding Announcement

RO1 – Research Project Grant

RPG – Research Project Grants

RUCA – Rural Urban Commuting Area Codes

RUCC – Rural Urban Commuting Codes

SDOH – Social Detriments of Health

SEER – Surveillance, Epidemiology, and End Results

SGM – Sexual and Gender Minority

SOGI – Sexual Orientation and Gender Identity

US – United States

URM – Underrepresented Minority

WG – Working Group