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

December 7h Presentation (1:35-2:05 PM)

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Working Group Charge

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

Source: NIH Website, June 11, 2022

Population Groups Included

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

Membership

Co-chairs:

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

Designated Federal Official:

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

Members:

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

Sources of Data/ Information

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

Outline of Report

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

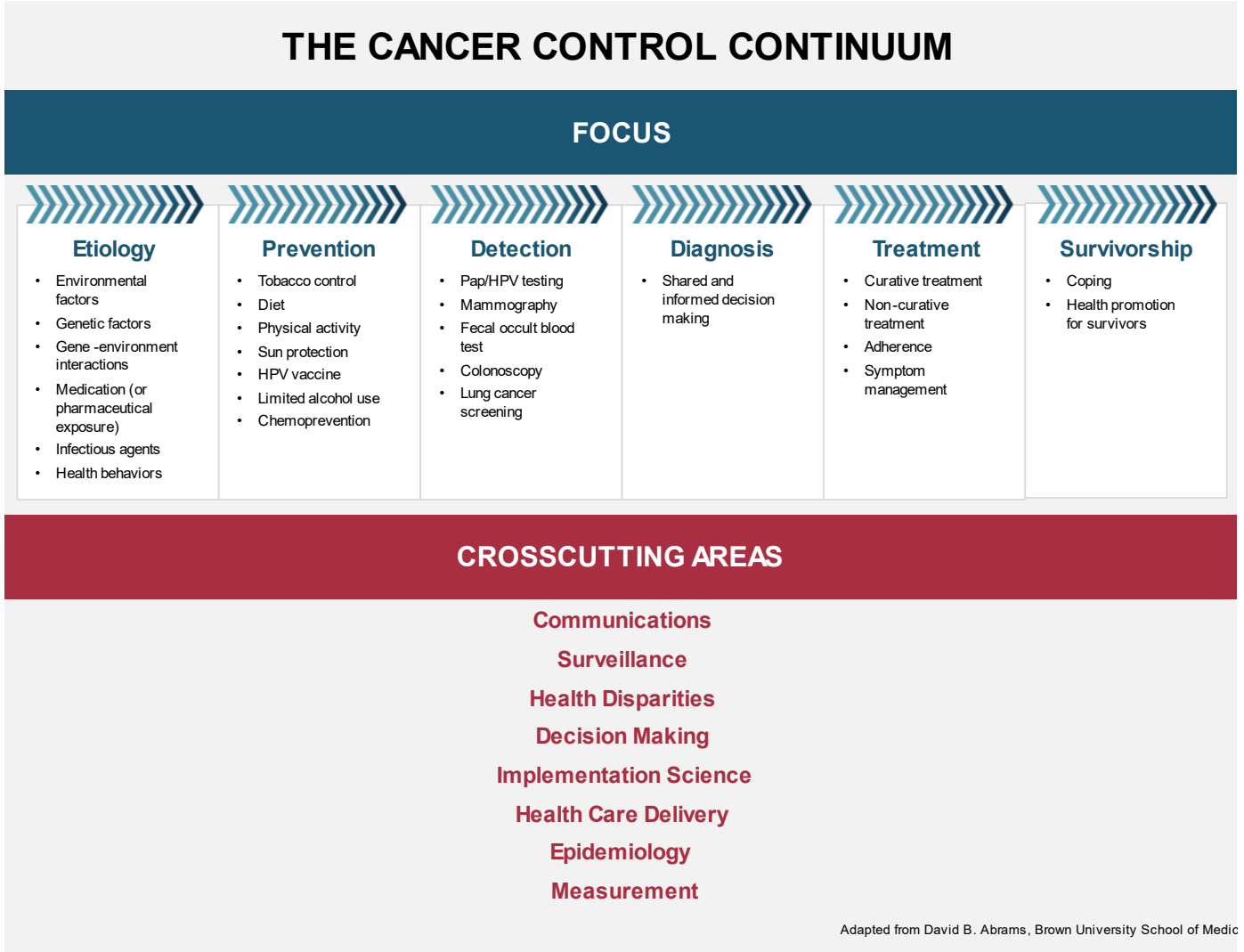
REPORT

Background

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

Cancer Continuum

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



NIH Funded Cancer Research Related to Selected Populations

Center for Research Strategy

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

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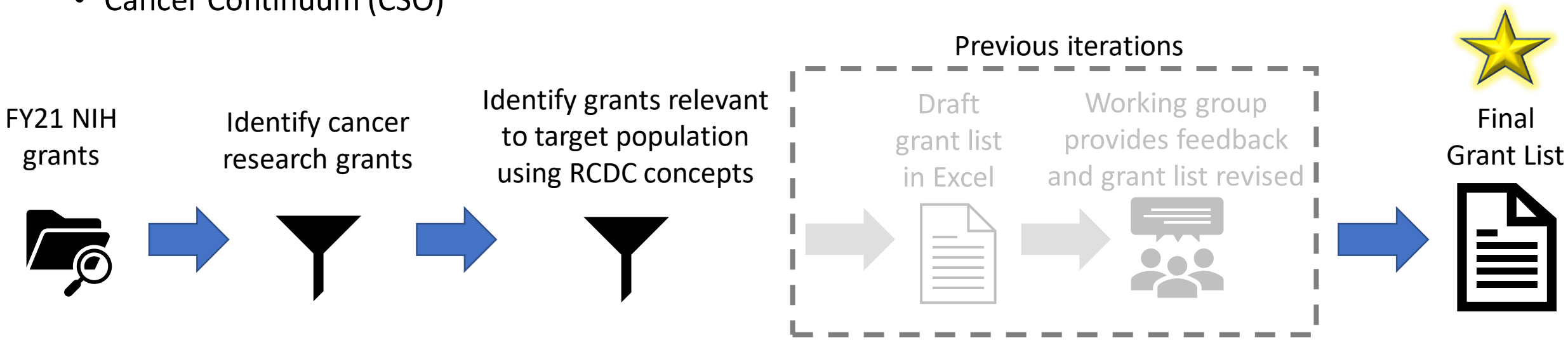
June 7, 2022

This information is provided to the NCAB working group for their deliberation and should not be made public without further discussion with the NCI

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

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



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

Exclusion Criteria

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

Research, Condition, and Disease Categorization (RCDC)*

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

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

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

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

- ICRP Cancer Types and CSO Codes refer to the International Cancer Research Partnership Coding Guidelines used to apply a common language (Common Scientific Outline) for discussing, comparing, and presenting cancer research portfolios

- Determined using a machine learning model

- Applications, and therefore base projects, can be assigned to more than one category

- In some cases, there is not enough information to assign an application to a particular category

ICRP International Cancer Research Partnership

CSO Codes

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

https://www.icrpartnership.org/sites/default/files/cso/ICRP_Coding_Guidelines.pdf

RESULTS

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

The FY21 Portfolio for Each Population of Interest

Starting:

FY21 NIH Cancer Grants

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

Exclude:

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

Intermediate:

Removed exclusion criteria

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

Include:

- RCDC Categories and Concepts for Population of Interest

Final:

FY21 NIH Cancer AND Population of Interest

- *X* Base Projects
- ~*Y* % are NCI

FY21 Extramural Base Projects for Populations of Interest

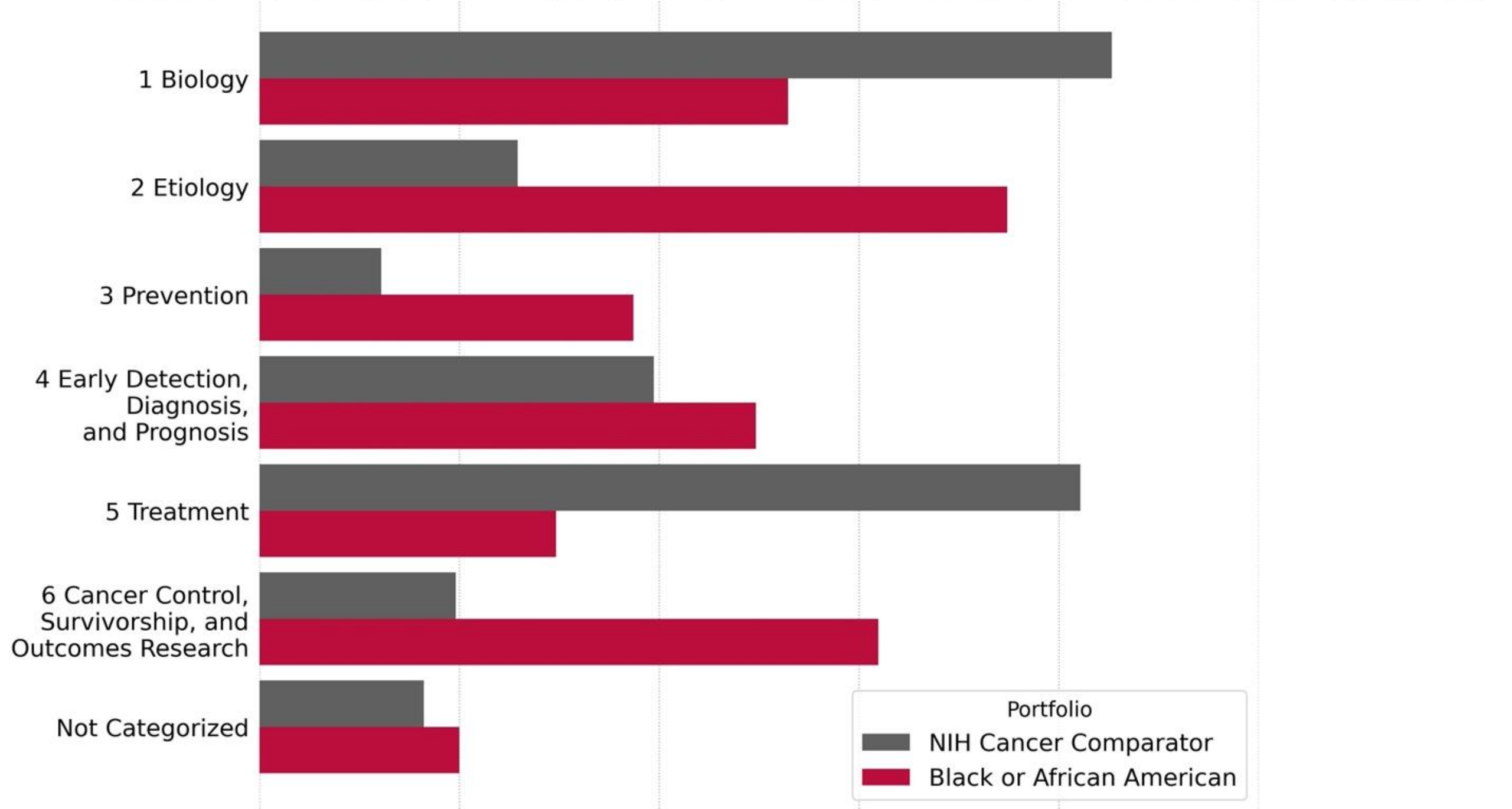
Population of Interest	Total Base Projects from all NIH ICs (% of total, 7327)	Total Base Projects Administered by NCI (% of total, 5412)	Percent Administered by NCI
Black or African American	310 (4.23%)	246 (4.55%)	79%
American Indian or Alaska Native	30 (0.41%)	18 (0.33%)	60%
Asian	52 (0.71%)	43 (0.79%)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

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

CSO Category	NIH Cancer Comparator (N=7327)	Black or African American (N=310)	American Indian or Alaska Native (N=30)	Asian (N=52)	Hispanic (N=158)	Pacific Islander (N=21)	Rural (N=104)	Sexual & Gender 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
Not Categorized	8.2	10.0	6.7	9.6	10.8	0	7.7	15.8

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

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



Summary and Recommendations

Summary of Findings

1) Imbalance in research relative to the distribution of cancer diagnosis, cancer morbidity, and cancer death in the United States;
2) Relative to overall portfolio, investment was:
   a) small for research that focused among racial and ethnic minorities, rural populations, and the other groups evaluated
   b) the underrepresentation was across both the continuum of science and the lifespan;
3) Within research identified, proportionally more projects in population sciences and fewer studies in biological research and clinical research;
4) Many projects draw on a limited number of underserved population groups, limiting the applicability of the current knowledge base; and
5) Information was lacking or not as in-depth for some population groups because:

   a) limited disaggregated data in those population groups (e.g., Pacific Islander people),

   b) populations were understudied (e.g., LGBTQ+ populations), or

   c) the population group was not adequately identifiable as a distinct group in the current research inventory at the NCI (e.g., AYA, older adults).

6) **This significantly limited the WG's ability to complete the charge to the same degree for all population groups.**

Recommendations

Specific:

1. ***Funding:*** Expand and/or initiate RFA's, FOA's, Investigator-initiated awards (RO1's, PO1's) and supplement opportunities in areas with intentional focus on eliminating disparities and inequities in the funded grant portfolio.

2. ***Data Collection:*** Adopt a standardized checklist for NIH grants to identify populations included and set standards in reporting of disaggregated data for all races and ethnicities.

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

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

Recommendations

Broad:

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


Open Discussion

Thank you!

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