National Cancer Advisory Board (NCAB) ad hoc Subcommittee on Population Science, Epidemiology, and Disparities

June 13, 2022 2:05 – 3:05 p.m. EDT

Virtual Meeting

SUMMARY

Subcommittee Members Dr. Electra D. Paskett, Chair Dr. Francis Ali-Osman Dr. Philip E. Castle, Executive Secretary Dr. Christopher R. Friese Mr. Lawrence O. Gostin (absent)

Other Participants Dr. Chandrakanth Are, Board of Scientific Advisors (BSA) Dr. Nilofer S. Azad, NCAB Dr. Anna D. Barker, NCAB Dr. Karen M. Basen-Engquist, BSA Dr. Michael John Becich, BSA Dr. Melissa L. Bondy, BSA Dr. John D. Carpten, Chair, NCAB Dr. Andrew T. Chan, BSA Dr. Joshua Collins, National Cancer Institute (NCI) Dr. Chyke A. Doubeni, BSA Dr. Howard J. Fingert, NCAB Dr. Keith T. Flaherty, Chair, BSA Dr. Jennifer R. Grandis, BSA Dr. Paulette S. Gray, NCI Dr. Dorothy K. Hatsukami, BSA

Dr. Scott Hiebert, NCAB

Dr. Nikan Khatibi Dr. Margaret R. Spitz Dr. Susan Thomas Vadaparampil Dr. Karen M. Winkfield

Dr. Michelle M. Le Beau, BSA Dr. Douglas R. Lowy, NCI Ms. Anne Lubenow, NCI Dr. Elena Martinez, University of California, San Diego Dr. Karen M. Mustian, BSA Ms. Thu Nguyen, NCI Dr. Diane Palmieri, NCI Dr. W. Kimryn Rathmell, BSA Mr. Ricardo Rawle, NCI Dr. Erle S. Robertson, BSA Dr. Leslie L. Robison, BSA Dr. Ashani T. Weeraratna, NCAB Dr. Peter Wirth, NCI Ms. Joy Wiszneauckas, NCI Dr. Richard C. Zellars, BSA Dr. Tamara Korolnek, The Scientific Consulting Group, Inc., Rapporteur

Welcome and Opening Remarks

Dr. Electra D. Paskett, Marion N. Rowley Professor of Cancer Research, Director, Division of Cancer Prevention and Control, Department of Internal Medicine, College of Medicine, The Ohio State University

Dr. Electra D. Paskett, Subcommittee Chair, welcomed the participants to the NCAB *ad hoc* Subcommittee on Population Science, Epidemiology, and Disparities (Subcommittee) meeting. After assessing NCI cohorts, the Subcommittee 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.

Progress to Date of the Ad Hoc Working Group

Dr. Elena Martinez, Sam M. Walton Endowed Chair for Cancer Research, Associate Director, Population Science, Disparities, and Community Engagement, Professor, Department of Family Medicine and Public Health, University of California, San Diego

Dr. Elena Martinez, Working Group Co-Chair, highlighted the Working Group's aim to advise on strategic approaches and opportunities for research on cancer among racial and ethnic minorities and underserved populations. The Working Group is charged with identifying and evaluating the current status of—and barriers to progress on—cancer research on racial and ethnic minorities and underserved populations, as well as potential strategic approaches to better support such research. Dr. Martinez emphasized that the Working Group's charge was related to cancer research, rather than other areas of focus.

Dr. Martinez provided the Subcommittee with an overview of progress made by the Working Group. Group membership was confirmed in April 2021, and the first Working Group meeting took place in July 2021. The co-chairs have met monthly to discuss progress and next steps and to set the agenda for the Working Group. Monthly full committee meetings involve discussion of progress and have featured speakers from different NCI Centers and Divisions: Drs. Michelle Bennett and Christine Burgess (Center for Research Strategy [CRS]), Dr. Shobha Srinivasan (Division of Cancer Control and Population Sciences), and Dr. Sanya Springfield (Center to Reduce Cancer Health Disparities). Dr. Martinez explained that a smaller portfolio analysis task group (Subgroup), led by Dr. Chanita Hughes-Halbert (University of Southern California), worked with the CRS team to operationalize a definition of health disparities and refine the NIH funding portfolio search criteria.

Dr. Martinez presented an outline of the Working Group's upcoming report:

- 1. Executive Summary of Findings and Recommendations
- 2. Overview of the Charge
- 3. Definition of Disparities
- 4. Cancer Continuum and Frameworks
- 5. Cancer Disparities in Populations of Focus
- 6. Methodology
- 7. Results by Population Group
- 8. Overall Summary and Recommendations
- 9. Supplementary Material
- 10. References

To generate the report, the Working Group began with a pilot process for information gathering developed by the CRS to review grants related to Black or African American people. An initial list of search terms was drafted and refined by the Working Group. Subsequently, searches were expanded to include Hispanic or Latino, American Indian or Alaska Native, Asian or Pacific Islander, rural, older adult, LGBTQ+, and adolescent and young adult (AYA) populations. After the pilot strategy was assessed and repeated, and the results presented to the Working Group, permission was granted to use the approved methodology for all populations. Final results will be reported to the Working Group at the June meeting.

Interim Report from the Scoping Project on Cancer Research Related to Selected Populations Dr. Electra Paskett

Dr. Paskett thanked Working Group and CRS members for their contributions to the scoping project. She particularly highlighted efforts of the CRS Project Team: Drs. Burgess, Joshua Collins, and Diane Palmieri. Dr. Paskett presented an interim report on the scoping project to evaluate the National Institutes of Health (NIH) cancer research grant portfolio. The primary goal of the portfolio analysis is to identify awarded NIH cancer research grants relevant to populations of interest; the secondary goal is to provide a broad overview of the research portfolio for each population of interest.

Dr. Paskett reported on the CRS team's search strategy. The team leveraged Research, Condition, and Disease Categorization (RCDC) system categories to evaluate all NIH grants from fiscal year (FY) 2021. From that group of grants, the team identified specific cancer research project proposals and projects of interest to relevant populations using appropriate RCDC concepts and categories. The resulting list of projects was shared with the Working Group to obtain feedback on which projects were truly relevant, and a final list of relevant projects was compiled. The populations of interest comprised Black or African American, American Indian or Alaska Native, Asian, Hispanic, Pacific Islander, rural, and sexual and gender minority populations.

Dr. Paskett highlighted several important considerations regarding the search strategy. The analysis approach relied on language used by applicants in the Title, Abstract, and Specific Aims sections of project proposals. This strategy did not distinguish between proposals that simply mentioned certain populations and proposals that focused more strongly on those populations of interest. Dr. Paskett added that although this search strategy is sufficient to provide insight into the portfolio, it cannot provide a precise measure of all health investments made in any one population. Additionally, analytical decisions by the Working Group involved exclusion criteria (e.g., training, career, international grants), resulting in limited portfolios that primarily focus on research grants.

Dr. Paskett provided the Subcommittee with further insight into the search methods. NIH grants consist of either single-component (e.g., R01) or multicomponent (e.g., P01 or U54) awards. Multicomponent grants comprise a single parent project and subprojects, which all share the same base project number. The Working Group's analysis counted unique base projects, and a base project was included if at least one component (i.e., subproject) was identified by the search strategy. Dr. Paskett elaborated on the RCDC system, which 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 RCDC concepts (referred to as a project index) from the RCDC Thesaurus. RCDC categories are weighted with lists of concepts that define a research area, condition, or disease. Category concepts are matched to project indices to produce the category project listing.

Dr. Paskett emphasized that all NCI grants fall within the RCDC "cancer" category. She provided a sample list of RCDC concepts (with synonyms) used to produce the Black or African American cancer portfolio, which included such terms as "African American" ("Afro American," "Afroamerican," "Black American," "Black populations"), "African Caribbean" ("Afro-Caribbean," "Black Caribbean," "Black Carib"), "African race," "African," "Black race," "Black subgroup" ("Black racial subgroup"), "Black men" ("Black male"), "Black women" ("Black female"), "Black patient," and "Black/white disparity" in combination with the RCDC concept "cancer." Grant exclusion criteria included award supplements; international and domestic training and career grants; P30 awards to Cancer Centers; NCI Community Oncology Research Program awards; international projects (e.g., Fogarty International Center grants,

Center for Global Health grants, grants with foreign countries in the title); and subproject cores. After initiating the search process with roughly 9,650 cancer-related base projects (75% NCI-funded), approximately 7,300 base projects (74% NCI-funded) remained when exclusions had been removed. This collection of projects, the NIH Cancer Research Portfolio, is in the process of being further refined using RCDC categories and concepts to generate multiple FY 2021 NIH Cancer *and* Population of Interest research portfolios.

Dr. Paskett discussed categorizing types of research along the cancer continuum using the International Cancer Research Partnership (ICRP) Common Scientific Outline (CSO). ICRP Coding Guidelines (i.e., ICRP cancer types and CSO codes) are determined using a machine learning model and are used to apply a common language for discussing, comparing, and presenting cancer research portfolios. Applications and base projects can be assigned to more than one category; in some cases, the information is insufficient to assign an application to a particular category. CSO codes include "biology," "etiology," "prevention," "early detection, diagnosis, and prognosis," "treatment," and "cancer control, survivorship, and outcomes research."

Emerging Gaps for Consideration in Recommendations and Open Discussion

Dr. Chyke A. Doubeni, Professor of Family Medicine, Center for Health Equity and Community Engagement Research, Mayo Clinic Cancer Center, Center for Clinical and Translational Science, Mayo Clinic

Dr. Chyke A. Doubeni, Working Group Co-Chair, described emerging gaps and opportunities identified by the Working Group for consideration in future recommendations: Research focused on age-specific populations (e.g., AYA, older adult) must be identified and tracked; data collection for LGBTQ+ populations must be improved; gaps across the continuum of cancer science and across lifespans must be assessed; participation of underserved populations in clinical trials should be increased; cancer disparities must be investigated and understood; and tracking of future NCI grants should be improved.

Dr. Doubeni thanked Dr. Philip E. Castle, Working Group Executive Secretary, Dr. Hughes-Halbert, Subgroup members, the CRS team, and Working Group members for their considerable efforts, which included manual reviews of each grant.

Open Discussion

Dr. Francis Ali-Osman inquired about Working Group outcomes that will be delivered to the Subcommittee. Dr. Paskett responded that the report will include a summary of the Working Group findings and recommendations for the future. Drs. Doubeni, Martinez, and Paskett discussed preliminary Working Group findings, which include the inability to assess current research portfolios related to certain populations (e.g., AYA and older populations). Other groups, such as LGBTQ+ populations, could be assessed, but only in a limited capacity. The report will include recommendations for future assessments of research related to each of these groups. In response to a comment from Dr. Ali-Osman about the broad focus of the group, Dr. Doubeni acknowledged that the Working Group has had to exert significant efforts to keep the scope manageable. The report will be carefully structured and focused, with actionable recommendations (e.g., improved portfolio assessments for certain groups, targeted investments in populations that have been properly evaluated). Dr. Ali-Osman wondered whether it would be helpful to add more checkboxes to NIH grant applications to better categorize cancer research funding. Dr. Paskett expressed her uncertainty about whether requiring more checkboxes would conflict with Office of Management and Budget regulations. She noted the importance of detailed abstracts when categorizing research proposals.

Dr. Leslie L. Robison asked whether the Working Group has considered cancer diagnosis gaps within each of the populations. Dr. Paskett answered that capturing this level of detail in awards likely will require manual curation. She agreed to discuss the subdivision of population-related grants with the CRS team during the June Working Group meeting.

In response to a question from Dr. Margaret R. Spitz about whether the Working Group report would address a specific request that Dr. Norman E. Sharpless, then–NCI Director, had made of the newly formed *ad hoc* Working Group, Dr. Paskett responded that this question would not be addressed in the current analysis but agreed that this issue should be covered in the future and would be discussed during the June meeting.

In response to a question from Dr. Andrew T. Chan about classifying grants that study multiple populations, Dr. Paskett answered that grants that were focused on two or more populations of interest were counted independently in each analysis; funds associated with a single award were not split between populations. She emphasized that dollar amounts have not yet been considered in the analysis. Drs. Castle, Doubeni, and Palmieri discussed challenges associated with analyzing the funding aspects of cancer research related to populations of interest.

Dr. Anna D. Barker wondered whether research priorities could be defined for each group. Dr. Paskett responded that the priority for the Working Group was to assess baseline levels of funding across the cancer continuum for each group. She added that priorities should be determined with input from the populations themselves.

Dr. Douglas R. Lowy, Acting NCI Director, pointed out that the NCI is in the process of updating its internal assessment of finances and projects, an initiative led by Mr. Jeff Shilling, the NCI Chief Information Officer and Branch Chief, and Ms. Crystal Wolfrey, the Director of the Office of Grants Administration and Chief Grants Management Officer. Dr. Lowy recommended consulting with Mr. Shilling and Ms. Wolfrey regarding the new electronic process and the possibility of using the new system to make award searches more straightforward. Dr. Paskett noted this as an agenda item for the June Working Group meeting.

Questions and Closing Remarks

Dr. Electra Paskett

Dr. Paskett thanked participants for their comments and welcomed feedback after the meeting. She announced that the Working Group's final report will be presented to the Subcommittee at the December 2022 Joint BSA and NCAB Meeting.

Adjournment

Dr. Paskett adjourned the meeting at 2:56 p.m. EDT.

Dr. Electra D. Paskett Chair Date

Dr. Philip E. Castle Executive Secretary Date