

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

5 December 2022
2:20–3:20 p.m. EST

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)

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

Other Participants

Dr. Chandrakanth Are, Board of Scientific
Advisors (BSA)
Dr. Nilofer S. Azad, NCAB
Mr. Timothy Babich, BSA*
Dr. Karen M. Basen-Engquist, BSA
Dr. Monica Bertagnolli, Director, National
Cancer Institute (NCI)
Dr. Melissa L. Bondy, BSA
Dr. John D. Carpten, Chair, NCAB
Dr. Nelson J. Chao, BSA
Dr. Luis Alberto Diaz, Jr., NCAB
Dr. Mark P. Doescher, BSA*
Dr. Chyke A. Doubeni, BSA
Dr. Shelton Earp, BSA
Dr. Howard J. Fingert, NCAB
Dr. Paulette S. Gray, NCI
Dr. Dorothy K. Hatsukami, BSA
Dr. Amy B. Heimberger, NCAB
Dr. Scott W. Hiebert, NCAB
Dr. Karen E. Knudsen, BSA

Dr. Michelle M. Le Beau, BSA
Dr. Ana Maria Lopez, BSA*
Dr. Douglas R. Lowy, NCI
Ms. Anne Lubenow, NCI
Dr. Elena Martinez, University of California,
San Diego
Dr. Karen M. Mustian, BSA
Dr. Lisa A. Newman, BSA*
Ms. Thu Nguyen, NCI
Dr. Raymond U. Osarogiagbon, BSA*
Mr. Ricardo W. Rawle, NCI
Dr. Leslie L. Robison, BSA
Dr. Cornelia M. Ulrich, BSA*
Dr. Samuel L. Volchenboum, BSA*
Dr. Ashani T. Weeraratna, NCAB
Ms. Joy Wiszneauckas, NCI
Dr. Tamara Korolnek, The Scientific Consulting
Group, Inc., Rapporteur

***pending appointment**

Welcome and Opening Remarks

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

Dr. Electra D. Paskett, Subcommittee Chair, welcomed the participants to the NCAB *Ad Hoc* Subcommittee on Population Science, Epidemiology, and Disparities (Subcommittee) meeting. She thanked Dr. Monica Bertagnolli, NCI Director, for attending and invited her to address the Subcommittee. Dr. Bertagnolli thanked Dr. Paskett for her efforts and expressed enthusiasm and support for the efforts of the Subcommittee.

Review of the *Ad Hoc* Working Group Charge, Membership, and Data Sources

Dr. Electra D. Paskett

Dr. Paskett reminded the Subcommittee that they had been 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 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. These population groups included Black or African American, Hispanic/Latino, American Indian/Alaska Native, Asian/Pacific Islander, rural, older adult, LGBTQ+, and adolescent and young adult (AYA) populations. Dr. Paskett explained that Working Group membership has included the Working Group co-chairs, Drs. Chyke A. Doubeni, Elena Martinez, and herself; the executive secretary, Dr. Philip E. Castle; and Drs. Melissa L. Bondy, Luis G. Carvajal-Carmona, Bettina F. Drake, Jeffrey A. Henderson, Chanita Ann Hughes-Halbert, Karen E. Knudsen, Lisa A. Newman, Augusto C. Ochoa, Colin Weekes, and Cheryl L. Willman. Dr. Paskett thanked the co-chairs and members for their efforts.

Dr. Paskett noted that the first Working Group meeting took place in July 2021. The co-chairs have since met monthly to discuss the Working Group’s agenda and next steps. Monthly full committee meetings involve discussion of progress and have featured speakers from various NCI centers and divisions: Drs. Michelle Bennett, Christine Burgess, and Diane Palmieri (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. Paskett presented an outline of the Working Group’s report:

1. Executive Summary of Findings and Recommendations
2. Overview of the Charge
3. Definition of Disparities and Frameworks
4. Cancer Continuum
5. Cancer Disparities in Populations of Focus
6. Analysis of Fiscal Year 2021 National Institutes of Health Cancer Research Grants
7. Summary and Recommendations
8. References

Presentation of the *Ad Hoc* Working Group Report

Dr. Chyke A. Doubeni, Chief Health Equity Officer and Director, Office of Health Equity, Diversity, and Inclusion, The Ohio State University Wexner Medical Center, Columbus, Ohio, and Dr. Electra D. Paskett

Dr. Doubeni presented background information and methodology used to produce the Working Group’s report. He provided the definition of health disparities used in the report—preventable differences in disease burden that can be attributed to disadvantages in disease risk and outcomes due primarily to structural and social factors—and noted that cancer health disparities are differences that should not occur in cancer-related outcomes among populations. Dr. Doubeni reviewed the concept of multilevel frameworks, which are developed to guide interventions and other strategies to enhance cancer outcomes and achieve equity among populations that experience disparities. He presented the National Institute on

Minority Health and Health Disparities Research Framework—one of several model frameworks used in the report—which describes multiple levels of influence (e.g., individual, interpersonal, community, societal) interacting with different domains of influence (e.g., biological, behavioral, physical/built environment, sociocultural environment, health care system) to shape various health outcomes (e.g., individual health, family/organizational health, community health, population health). Dr. Doubeni explained that the Working Group examined research across the cancer control continuum (e.g., etiology, prevention, detection, diagnosis, treatment, survivorship) to identify gaps where attention is warranted. Crosscutting areas of research in the cancer control continuum included communications, surveillance, health disparities, decision-making, implementation science, health care delivery, epidemiology, and measurement.

Dr. Doubeni thanked the CRS project team—Drs. Burgess, Palmieri, and Joshua Collins—for their contributions to evaluating the National Institutes of Health (NIH) cancer research grant portfolio and identifying cancer research relevant to the populations of interest. The CRS team leveraged Research, Condition, and Disease Categorization (RCDC) system categories to evaluate all NIH grants from fiscal year 2021 (FY21) and identify all FY21 cancer research grants (i.e., NIH cancer comparator). From this 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 grants was shared with the Working Group to obtain feedback on which grants were truly relevant, and a final list of projects was compiled. Grants were categorized along the cancer research continuum using International Cancer Research Partnership (ICRP) Common Scientific Outline (CSO) codes. Dr. Doubeni reminded the Subcommittee that the populations of interest comprised Black or African American, American Indian or Alaska Native, Asian, Hispanic, Pacific Islander, rural, AYA, and sexual and gender minority populations.

Dr. Doubeni 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. 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.

Dr. Doubeni elaborated on the RCDC system, which NIH utilizes 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. Doubeni discussed categorizing types of research along the cancer continuum using ICRP CSO codes, which 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. CSO codes include “biology”; “etiology”; “prevention”; “early detection, diagnosis, and prognosis”; “treatment”; and “cancer control, survivorship, and outcomes research.” In some cases, the information in an application is insufficient to assign that grant to a particular category.

Dr. Paskett presented the results of the FY21 portfolio analysis. After initiating the search process with roughly 9,650 cancer-related FY21 NIH 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 or NIH cancer comparator, was further refined using RCDC categories and concepts to generate FY21 NIH cancer research portfolios for each population of interest. Dr. Paskett presented a list of FY21 extramural base projects for populations of interest from all NIH Institutes and Centers (ICs), as well as the total number of base projects administered by the NCI for each population. For example, of 310 total NIH grants related to Black or African American populations (4.23% of 7,327 total NIH cancer grants), 246 were administered by the NCI (4.55% of 5,412 total NCI cancer grants). Thus, 246 out of 310 (or 79%) of all FY21 NIH cancer grants related to Black or African American populations were administered by the NCI. Dr. Paskett presented a table listing percentages of FY21 NIH portfolio base projects classified within ICRP CSO categories (i.e., across the cancer continuum) by populations of interest. For example, of 7,327 total NIH cancer grants, 42.7 percent were classified as “biology”; 12.9 percent were classified as “etiology”; 6.1 percent were classified as “prevention”; 19.7 percent were classified as “early detection, diagnosis, and prognosis”; 41.1 percent were classified as “treatment”; 9.8 percent were classified as “cancer control, survivorship, and outcomes research”; and 8.2 percent were not categorized. By contrast, of 310 NIH cancer grants focused on Black or African American populations, 26.5 percent were classified as “biology”; 37.4 percent were classified as “etiology”; 18.7 percent were classified as “prevention”; 24.8 percent were classified as “early detection, diagnosis, and prognosis”; 14.8 percent were classified as “treatment”; 31.0 percent were classified as “cancer control, survivorship, and outcomes research”; and 10.0 percent were not categorized. In the slides presented, these data were displayed in bar graph form for each population of interest. Dr. Paskett highlighted that, when compared to the total NIH cancer portfolio, grants focused on the populations of interest were less likely to be classified under the “biology” or “treatment” CSO codes.

Dr. Doubeni reviewed a summary of the Working Group’s findings. The Working Group report uncovered an imbalance in research funding relative to the distribution of cancer diagnosis, cancer morbidity, and cancer death in the United States. Relative to the overall NIH portfolio, investment was small for research focused on racial and ethnic minorities, rural populations, and the other groups evaluated, and this underrepresentation existed across both the continuum of science and the human life span. Within identified research associated with populations of interest, proportionally more projects in population sciences and fewer biological and clinical research studies were observed. Many projects draw on a limited number of underserved population groups, constraining the applicability of the current knowledge base. Information was lacking for some population groups because of limited disaggregated data in those groups (e.g., Pacific Islander population); populations’ being understudied (e.g., LGBTQ+ populations); or the population group’s not being identified as a distinct group within the current research inventory at the NIH (e.g., AYA, older adults). Dr. Doubeni emphasized that these factors considerably limited the Working Group’s ability to complete the charge to the same degree for all population groups.

Dr. Doubeni presented recommendations for the NCI from the Working Group. Specific recommendations in the areas of funding, data collection, monitoring and evaluation, and reporting were provided:

1. Expand or initiate requests for applications, funding opportunity announcements, investigator-initiated awards (e.g., R01s, P01s), and supplement opportunities with an intentional focus on eliminating disparities and inequities in the funded grant portfolio.

2. Adopt and standardize a checklist for NIH grants to identify populations that are included, and develop standards for reporting disaggregated data for all races and ethnicities.
3. 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 the report.
4. Create an annual report of activities in this area and provide congressional briefings on the state of cancer health equity.

Broader recommendations in the areas of implementation strategy, frameworks for inclusive research, resources, uniform measures, intentionality, and ongoing NCI training efforts also were provided by the Working Group:

1. Establish a set of guiding principles and priorities to move the Working Group recommendations into action.
2. Utilize a framework for research that relates to the practice of inclusive cancer research and includes implementing strategies to increase funding to diverse and underrepresented investigators.
3. Ensure that a portion of grants is focused on the underserved and underrepresented populations included in this report.
4. 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. Accelerate research by offering funding opportunities in areas across the cancer continuum that specifically enhance the understanding of why disparities in cancer outcomes exist for certain groups and how to eliminate these disparities and achieve health equity in these groups.
6. Realize the goal of increasing diversity at all levels of the cancer workforce.

Dr. Paskett emphasized that the highest-priority recommendations endorsed by the Working Group are increased funding for research focused on these populations of interest, disaggregation of population data, and a checklist for identifying populations of focus in NIH grant applications.

Discussion

Dr. John D. Carpten, Chair, NCAB, asked for more information about the pool of clinical research grants used in the Working Group's analysis. He wondered whether this pool included, for example, Specialized Programs of Research Excellence (SPOR) grants. Dr. Paskett answered that SPOR grants were included in the analysis, which was focused on research-related projects and did not include clinical trial accrual information. She noted that the present procedures for coding grant-related data were a significant barrier to understanding disparities in cancer research and an issue that must be addressed by NIH.

Dr. Newman pointed out that the lack of tumor biology research focused on certain population groups would result in an inadequate understanding of the genetics of cancer that could be relevant to novel treatments and outcomes. Dr. Paskett agreed.

Dr. Shelton Earp requested that all NIH ICs work together to improve implementation science related to health care access and health disparities associated with all diseases. Dr. Paskett agreed and noted that the entire NIH research portfolio was available for evaluation using the Working Group's analysis as a template.

Dr. Raymond U. Osarogiagbon asked whether the NCI has developed a framework for connecting with such potential partners as professional groups—which work more closely with the populations of interest—in efforts to reduce health disparities. Dr. Paskett pointed out the presence of Dr. Knudsen, Chief Executive Officer of the American Cancer Society, and Dr. Martinez, President of the American Society of Preventive Oncology, at the virtual meeting. She and Dr. Doubeni agreed that efforts to collaborate with partners would align well with the Working Group’s recommendations for more inclusive cancer research.

Dr. Bertagnolli commented that two main areas of focus are necessary to address health disparities in cancer research: (1) including every population and (2) understanding and eliminating barriers to health equity. She emphasized that inclusion does not mean proportional representation and affirmed that the NCI would aim to address both areas of focus and advocate change at the societal level. Dr. Paskett agreed and commented that inclusion should go beyond inclusion in clinical trials. Dr. Doubeni agreed with Dr. Bertagnolli’s framework and noted that the concept of inclusion should be applied to both cancer research and cancer care.

Dr. Cornelia M. Ulrich asked whether the keywords used in the analysis of the NIH cancer research portfolio might have missed certain grants of interest. She provided the example of the word “telehealth,” which might be found in grants related to rural populations. Dr. Paskett responded that telehealth grants focused on rural populations would have been found by the search only if they mentioned a population of interest.

Dr. Knudsen commented that the barriers to health equity are fairly well understood and that implementation efforts to overcome these barriers should be prioritized. She asked about work to prioritize implementation science efforts and about advocacy by the NIH, the NCI, and nonprofit and professional organizations. She noted that advocacy strategies depended on data generated by NCI-funded grants and commented that the influence of research on advocacy efforts should be monitored and measured.

Dr. Paskett emphasized the main findings of the report—that research related to the populations of interest is not being performed.

Dr. Karen M. Winkfield recommended caution when using certain language to refer to the populations of interest. She noted that such populations should not be referred to as “difficult to reach”; these populations merely have not been engaged by the scientific community. Dr. Paskett agreed.

Next Steps: Report and Charge for the *Ad Hoc* Subcommittee

Dr. Electra D. Paskett

Dr. Paskett announced that the Working Group’s report would be presented at the joint BSA and NCAB Meeting on 7 December 2022 and provided to NCI leadership after it is accepted by the NCAB. Dr. Paskett called for a motion to accept the report. The Subcommittee voted unanimously to accept the Working Group’s report. Dr. Paskett noted that further charges for the Subcommittee would be discussed at the next Subcommittee meeting.

Questions and Closing Remarks

Dr. Electra D. Paskett

Dr. Paskett thanked the participants for their comments and welcomed feedback after the meeting.

Adjournment

Dr. Paskett adjourned the meeting at 3:21 p.m. EST.

Dr. Electra D. Paskett
Chair

Date

Dr. Philip E. Castle
Executive Secretary

Date