



June 25, 2021

National Cancer Institute
9000 Rockville Pike
Bethesda, MD, 20892

RE: RFI: Seeking Stakeholder Input on Enhancing Cancer Health Disparities (NOT-CA-21-066)

Submitted electronically to: NCI.RFI.CHDResearch@nih.gov

The American Society of Hematology (ASH) appreciates the opportunity to respond to the National Cancer Institute's (NCI) Request for Information (RFI) aimed at informing the institute's plans to address cancer health disparities (CHD). As a Society that represents over 18,000 scientists and clinicians, ASH is committed to diversity, equity, and inclusion (DEI) in hematology research and practice. The Society is also dedicated to advocating for policies and supporting programs that aim to eliminate health disparities in the care of people with malignant and non-malignant hematologic diseases.

On April 9, 2021, ASH [responded](#) to the National Institutes of Health's RFI on approaches it should take to advance DEI in biomedical research and the workforce. The Society believes its comments in that RFI related to research gaps that should be funded to advance scientific knowledge and ultimately mitigate health disparities are valuable and applicable to the NCI's request.

In response to NCI's specific requests on cancer health disparities (CHD) research, below are ASH's recommendations:

1. What understudied scientific areas (e.g. social determinants of health, genetic admixture, etc.) are crucial to addressing cancer health disparities (CHDs)?

- Inclusion of diversity and health disparities in preclinical discovery research and translational science is crucial to addressing CHDs. Specifically, research addressing the correlation between genetic and environmental factors involved in the onset and progression of hematologic cancers is an understudied scientific area. Knowledge gained from such studies could provide insights into patient outcomes and survival patterns.
- Conducting genomic research in more diverse populations and efficiently leveraging admixture mapping techniques are understudied areas that could inform genetic diagnosis and provide further insights into CHDs. In addition, training and education of scientists and physicians on admixture mapping is vital since this tool is primed to contribute directly to the understanding of health disparities.
- Development of technological tools (e.g., genotyping and admixture mapping) aimed at increasing diversity in genomic data in hematologic cancers could help mitigate inequities. With respect to genotyping, most existing commercial panels used were developed using DNA samples primarily from individuals from European descent. Such panels are likely to be less efficient at identifying genetic variants observed in individuals with from other ancestries (e.g., African, Asian, etc.) or predicting cancer risks.
- Multi-level models/approaches that measure the role of social determinants, germline genetics, and admixture, on clinical outcomes of individuals with hematologic malignancies should also be addressed.

Community engagement strategies and engaging primary care practitioners in discussions around CHD (as they serve as a key stakeholder in the early and accurate diagnosis of cancer) could help shed additional light on other important yet understudied scientific areas in CHD that NCI should focus on.

2. What emerging research strategies are needed to prevent, diagnose, and address a wide range of CHDs?

The following strategies should be included in the clinical research enterprise to enhance trial recruitment and retention from underrepresented groups, as well as address a wide range of hematologic CHDs:

- Effective community engagement with use of local and trusted groups.
- Education of primary care practitioners on the early and accurate diagnosis of hematologic cancers.
- Cultural competence training and education for hematologists and oncologists.

3. What high-priority scientific areas will help reduce the unequal burden of CHDs?

- Identifying the highest risk groups to justify and support appropriate screening tools and guidance would be vital to reducing unequal burden of CHDs.
- Ensuring that trials designed for hematologic malignancies enroll and reflect the patient population that might be disproportionately impacted by the disease in question. This will allow for more effective therapy development and application.
- Disseminating the policies and procedures of health systems found to have limited CHDs and engaging in research as to the adaptation of these approaches in other settings.

4. What innovative study designs, approaches, and data/resources might be important to address CHDs?

- Many solutions to address CHDs need to happen at the local level, as such including community-based outreach and even non-medical strategies (e.g., churches, barber shops, etc.) in the trial design process, is crucial.
- Leveraging real world data sets in drug development can enrich the understanding of efficacy and tolerability of therapies for hematologic malignancies. This is because such data sets typically represent a complete population and are not limited to individuals enrolled in clinical studies. Furthermore, the use of real-world data can inform clinical trial hypotheses and validate the existence of disparities in usual cancer care. Through data sharing, the possibility to recognize CHDs and the design of interventions to help ameliorate them can be significantly enhanced. For example, the ASH Research Collaborative Data Hub will provide an efficient source of real-world information concerning multiple myeloma in racial and ethnic groups that may be more broadly representative than the population of patients that participate in clinical trials.

5. Describe approaches to strengthen the science of community engagement.

- Prioritization of this type of science at NCI; soliciting grant applications that distinguish specific funding for these efforts; and establishing specialized study sections focused on this area will be vital.
- Inclusion of patient-voices in the design of cancer trials supported by the NCI.
- Trans-NIH cooperation to support investigators studying the science of community engagement as well as partnerships with groups invested in this space (e.g., Patient Centered Outcomes Research Institute) is also essential.

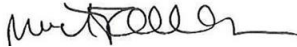
6. What new approaches can be taken to redesign clinical trials (e.g. inclusion and exclusion criteria, etc.) and increase enrollment of racial/ethnic underrepresented groups?

- Mandate that trials match the race distribution of the disease being studied (e.g. at least 15-20% of African Americans in myeloma).
- Engage more community-based centers in malignant hematology studies.
- Ensure that trials supported by NCI that are addressing a disease predominantly impacting an under-represented racial/ethnic group have sites in geographic areas where such patients reside (e.g., ~56% of African Americans live in 10 states according to the 2019 US census).
- Allocate significant funding for trials to cover potential patient participation costs (e.g., travel, caregiver support, etc.).

- Incorporate some clinical trial strategies necessitated by the COVID-19 pandemic that were vital to increasing the recruitment and retention of underrepresented groups during that time (e.g., telemedicine, establishment of satellite sites, etc.)
- Partner with other institutes within NIH and other federal agencies like the FDA to further determine evidence-based strategies that could be implemented to further streamline/redesign clinical trials for hematologic malignancies

Again, ASH thanks the NCI for the opportunity to comment on this important subject and looks forward to serving as a resource for the Institute on this issue. Please contact the ASH's Senior Manager of Scientific Affairs, Alice Kuaban, MS, at akuaban@hematology.org for any additional information.

Sincerely,

A handwritten signature in black ink, appearing to read "Martin Tallman", with a long horizontal flourish extending to the right.

Martin Tallman, MD
ASH President