

2021 L Street, NW, Suite 900, Washington, DC 20036 ph 202.776.0544 fax 202.776.0545 e-mail ASH@hematology.org

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President
Armand Keating, MD
Princess Margaret Hospital
610 University Avenue, Suite 5-303
Toronto, ON M5G 2M9
CANADA

phone 416-946-4595 fax 416-946-4530 armand.keating@uhn.on.ca

President-Elect

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University of Washington Box 357710 Seattle, WA 98195-0001 phone 206-685-7877 fax 206-543-3560 janabk@u.washington.edu

Vice President

Linda J. Burns, MD
Division of Hematblogy, Oncology,
and Transplantation
420 Delaware Street, SE
MMC 480/Room 14–154A Moos Tower
Minneapolis, MN 55455-0341
phone 612-624-8144

fax 612-625-9988 burns019@umn.edu

Secretary

Charles S. Abrams, MD University of Pennsylvania School of Medicine 421 Curie Boulevard, #912 Philadelphia, PA 19104-6140

phone 215-573-3288 fax 215-573-7400 abrams@mail.med.upenn.edu

Treasurer

Richard A. Larson, MD University of Chicago 5841 S. Maryland Avenue, MC-2115 Chicago, IL 60637-1470

phone 773-702-6783 fax 773-702-3002 rlarson@medicine.bsd.uchicago.edu

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Martha L. Liggett, Esq. mliggett@hematology.org

Joseph Selby, MD Executive Director Patient-Centered Outcomes Research Institute Public Comments 1701 Pennsylvania Avenue, NW Suite 300 Washington, DC 20006

Dear Dr. Selby:

The American Society of Hematology (ASH) appreciates the opportunity to provide comments on the Patient-Centered Outcomes Research Institute's (PCORI) draft National Priorities for Research and Research Agenda. ASH represents over 16,000 clinicians and scientists committed to the study and treatment of malignant and non-malignant blood and blood-related diseases such as leukemia, lymphoma, sickle cell disease, anemia and hemophilia. ASH's mission is to promote the understanding, prevention and treatment of blood disorders, and improve healthcare and patient outcomes with hematologic disease. As such, ASH supports PCORI's focus and investment in comparative effectiveness research (CER) which will expand the evidence base of medicine and improve the quality of health care.

Although broad, ASH finds the PCORI research agenda comprehensive and valuable and is supportive of all five of the proposed research priorities; all are applicable to the specialty of hematology:

- 1) Assessment of Prevention, Diagnosis, and Treatment Options
- 2) Improving Healthcare Systems
- 3) Communication and Dissemination Research
- 4) Addressing Disparities
- 5) Accelerating PCOR and Methodological Research

For the purpose of this comment letter, ASH will focus on three of the priority areas: assessment of prevention, diagnosis and treatment options; improving healthcare systems, and addressing disparities.

The Society supports research in assessing the prevention, diagnosis, and treatment options for benign and malignant hematology. For example, little is known about how best to predict—and how best to prevent—the development of thrombosis in cancer patients. The risk of thrombosis complications of cancer is greatly increased, including for patients with hematologic malignancies such as lymphoma. The mortality among cancer patients who develop thrombosis is high, with a rate of about 25 percent at 30 days after the thrombosis. Complications and side effects of treatment are problematic for those patients who survive. Optimal treatment is cumbersome and requires injected anticoagulant medications. CER research assessing the prevention, diagnosis and treatment options for thrombosis in hematological malignancies will improve the understanding of fundamental mechanisms and novel prevention and treatment strategies, which is urgently needed for quality patient care.

Improving health care systems is an area where CER could investigate strategies and innovations for optimal patient care. In particular, ASH notes PCORI's interest in supporting comparative studies of healthcare system-level interventions, including the areas of disease management, care management, performance measurement and quality improvement. Research is lacking in these areas, particularly across healthcare services or settings for patients with complex chronic conditions. In studying this priority area, ASH recommends particular attention to the complexity of care for patients with benign and malignant hematologic disease. "Chronic" cancer patients are now living through third, fourth, and fifth line therapy with more co-morbidities, costlier drugs, and more frequent visits to their caregivers. Often, the complexity of care gets defined at a point in time instead of being evaluated as a continuum of care. ASH recommends research in this area to truly understand the most appropriate treatment options to ensure quality of care for this population.

ASH supports the PCORI research priority that addresses hematologic disparities. Solid tumors are well studied; however, disparities in hematologic malignancies are relatively underexplored especially for adults with certain hematological malignancies such as acute leukemia. ASH notes that disparities research is an absolute MUST for research in any of the priority areas. ASH is concerned that separating the disparities priority into its own priority area implies that the other research priorities will not adequately focus on or evaluate disparities in health status and healthcare. The Society recommends that disparities research is included as a separate priority area of focus in addition to being included as a subcategory within each priority. For instance, the first research priority of assessment of prevention, diagnosis, and treatment option could focus on diseases and disorders in all patient populations; however, a subcategory of the particular research should focus on disparities in distinct patient populations.

ASH commends PCORI for creating a public forum that underscores the importance of input from a broad range of stakeholders interested in CER. The Society also appreciates PCORI's strong commitment towards processes that promote transparency. We encourage PCORI to facilitate ongoing input from national medical specialty societies, including ASH, regarding its national priorities as well as physician participation in other components of the CER enterprise, including research and the dissemination of research results. PCORI's success hinges on partnering and leveraging relationships with organizations that are trusted sources to physicians in their practice management and medical decision-making. Additionally, ASH urges PCORI to identify strategies and initiatives to expand CER in community physician practices as well as academic medical centers. The Society believes that a continued dialogue with these entities will ensure that the future research needs for the care of patients will be met.

Again, thank you for the opportunity to submit comments on PRORI's draft research priorities. If you have additional questions, please contact Suzanne Leous, Senior Manager for Quality and Practice at 202-776-0544 or <u>sleous@hematology.org</u>.

Best regards,

Armand Keating, MD

Lew Kesting

President