

A Community Effort to Develop a National Research Blueprint for Inheritable Bleeding Disorders

Authors: †Maria E. Santaella, RN-BC, MSN, CPHON, †Michelle L. Witkop, DNP, FNP-BC, §Michael Recht, MD, PhD,
†Keri Norris, PhD, JM, MPH, MCHES, †Brett Spitale, Esmeralda Vazquez, ‡Donna M. DiMichele, MD, †Kevin Mills, PhD



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

†National Hemophilia Foundation (NHF), 7 Penn Plaza Suite 1204, New York, NY 10001; §ATHN American Thrombosis and Hemostasis Network, Rochester, NY, USA ;

‡ Donna DiMichele Consulting, LLC, Washington DC

BACKGROUND

The inherited bleeding disorders (IBD) community has witnessed significant advances in recent years, yet important gaps persist, particularly for those with rare disorders and underserved populations. A new initiative led by the National Hemophilia Foundation (NHF) and shaped by the voices of the patient community is underway to design and implement a national research roadmap to accelerate progress through coordinated collaboration.

OBJECTIVE

Develop and implement a National Research Blueprint (NRB) that embraces patient-centric and social justice principles to accelerate the priorities of the IBD community identified in the State of the Summit Research Summit (SOS).

METHODS

Starting with the SOS initiative and continuing with the NRB, over the last 2 years, NHF has convened multiple diverse forums of representatives from across the IBD community, including most importantly patients and caregivers (also known to NHF as subject matter experts [SMEs]), to inform a research blueprint defining actionable research priorities that can affect lasting change in patient care. This started with a series of focus groups and virtual community listening sessions among adults with IBDs, caregivers, patient organizations, chapter and member organization directors, healthcare providers, and industry. These discussions were supplemented by surveys to patients, caregivers, and health professionals, as well as insights generated through NHF's community powered registry, Community Voices in Research.

The themes collated from that initial work informed the agenda for the SOS, a virtual meeting that took place in September 2021. During the three-day forum, working groups discussed each of six major areas of focus (see Table 1) and fueled debate from community members on how research should be prioritized to generate the greatest impact. The recommendations from that Summit are included in manuscripts currently under preparation and have been consolidated into a methodology to build the NRB for IBDs.

The NRB Steering Committee has defined a methodology through which five working groups (see Figure 1) will work individually and collectively to identify the essential elements of a platform from which to initially launch a successful national research network. To begin building this roadmap, NHF convened two workshops in March and April of this year: one to solicit the perspectives of health care providers, government, and industry; and one specifically to infuse patient SME insights into the plans.

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5. Diversity, equity & inclusion health services research & implementation science	<ul style="list-style-type: none"> SOC Implementation DE&I health services research Telehealth and delivery network development Communications
6. Facilitating priority research in the IBDs community	<ul style="list-style-type: none"> Infrastructure Resource Procurement/Development Workforce Development

RESULTS

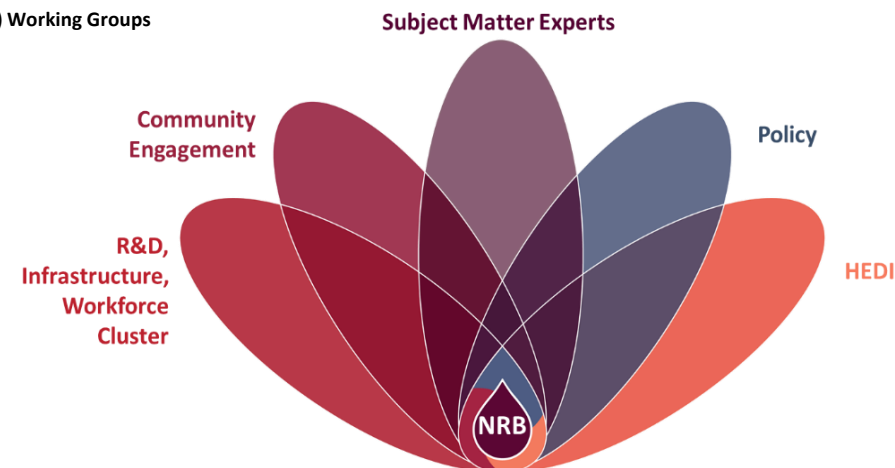
Community engagement and partnering, particularly among SMEs, has been a foundational element of the progress on this journey. In total, ~98 individuals participated in 14 listening sessions; ~125 contributed to the community survey; ~900 actively participated in the SOS, with ~2,300 views of the virtual sessions. So far in 2022, ~67 health professionals, government and industry representatives attended the March NRB workshop, and >85 SMEs and experts attended the April workshop.

The IBD community will reconvene for an NRB-focused Summit in 2023 where the initial recommendations to develop a research network will be presented. Formal NRB manuscripts will be published to guide and accelerate community efforts.

CONCLUSIONS

Actively seeking partnerships with the community has been central in our process to advance research in IBDs. The NRB will help to shape community research that could fundamentally redefine the experience of living with IBDs.

Figure 1. National Research Blueprint (NRB) Working Groups



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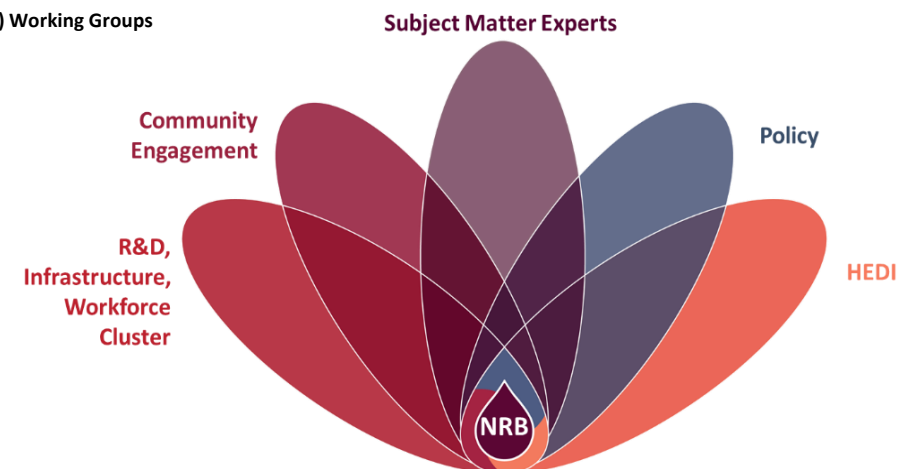
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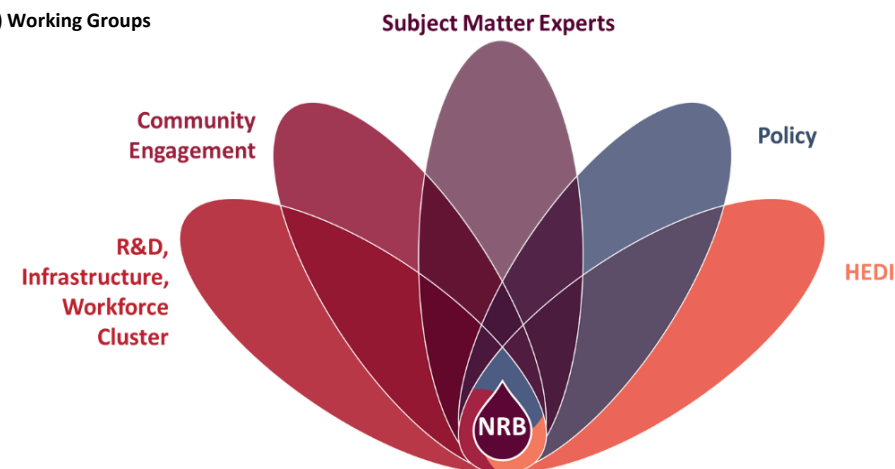
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