



National Research Blueprint: Health Equity, Diversity, & Inclusion Working Group



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Keri Norris, PhD, JM, MPH, MCHES
Samantha Carlson, MSW, LMSW

Mission of the HEDI WG in NRB

The mission of the HEDI Workgroup is to establish the parameters around the influences of health equity, diversity, & inclusion and ensure that they are considered, monitored and evaluated as it pertains to PLWBD research and clinical trials. We shall consider all things that influence the health, engagement, and inclusion of people who are marginalized and minoritized in the US. By working collaboratively with and being imbedded within each working group, we ensure that HEDI & LEEs are at the forefront of everything research that NHF creates, implements, and presents to the larger scientific community.

** each working group SHOULD have ONE HEDI champion as a member going forward to ensure equity, diversity, and inclusion is embedded.

** Marginalized and minoritized populations include persons who have been traditionally underserved, excluded, and/or oppressed based on a given social standing or some characteristic including but not limited to race, ethnicity, sex, gender identity, sexuality, age, income, disability status, language, culture, faith, geographic location, and country of birth

THANK YOU!!



Vanessa Byams



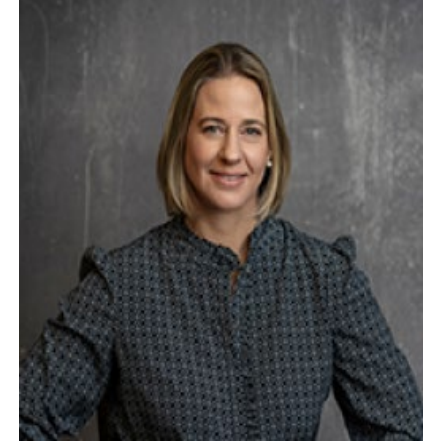
Samantha Carlson



Alexis Dinno



Keri Norris



Maria Santaella



Roshni Kulkarni



Marissa Melton



Esmeralda Vazquez

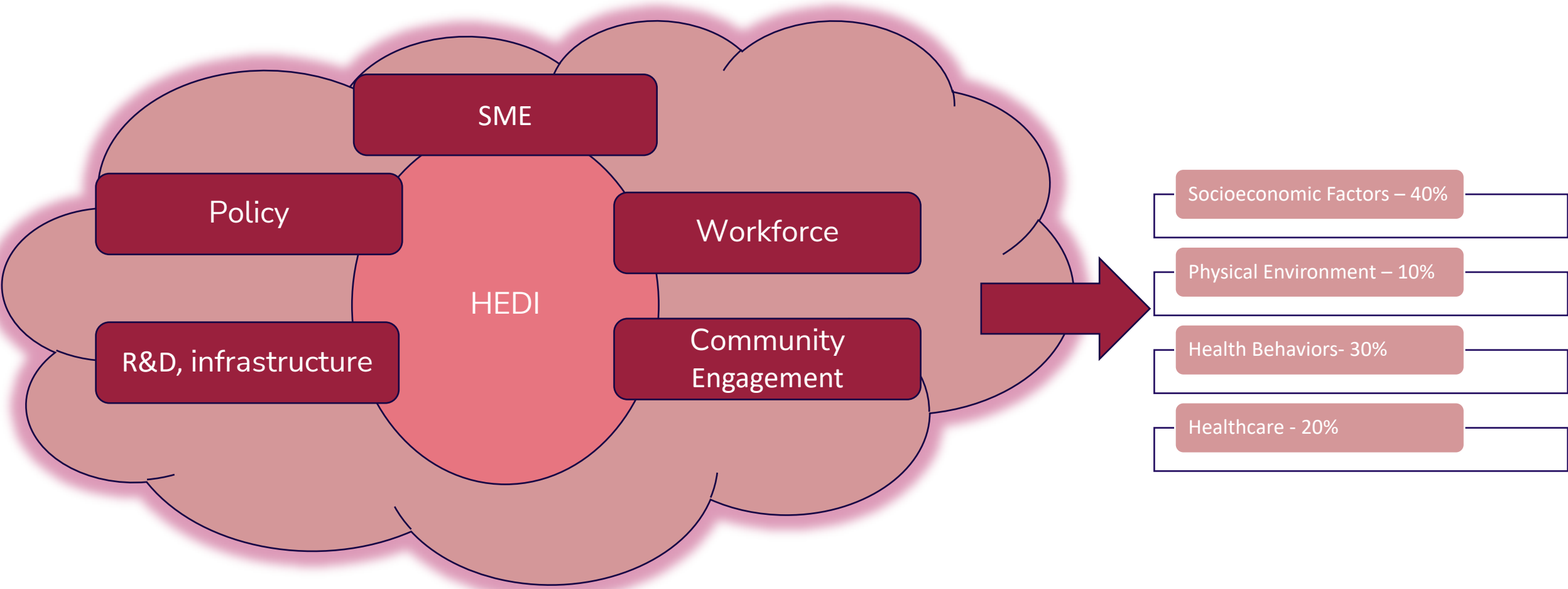


Mosi Williams



Len Valentino

HEDI NRB — Suggested Approach to Research



Continuum of Care from Birth to Senior Adult

Research Priority Questions: Diversity, Equity, & Inclusion (SOS)

- What conscious and unconscious biases are present within HTCs and amongst the multidisciplinary care team? What interventions can be implemented to mitigate identified biases?
- What policies/processes/practices can local and national patient organizations and other stakeholders implement to ensure active partnership with marginalized and minoritized populations* in the development and implementation of data collection (e.g., registries, surveillance, clinical trials, research, repositories) and educational initiatives?
- What data are viewed as important and meaningful to members of marginalized and minoritized populations* that are not currently being collected by clinical trials/surveillance studies?
- What are inequities in experiences of care between non-marginalized and marginalized populations in the HTC setting? (Conduct needs assessment to identify the problem.)
- What are barriers and facilitators for marginalized and minoritized populations* to substantively engage in the conceptualization, design, and conduct of and participate in research?
- What programs and/or pilot projects should be implemented to mitigate individual provider behaviors, clinical and organizational structures, and other systems in place that hinder equitable delivery of care and services?

Research Priority Questions

Health Services (SOS)

- Among PWIBD and their caregivers, do those who use telehealth visits have the same quality of care, satisfaction, adherence to treatment, and clinical and health related quality of life outcomes as patients who are primarily treated in person?
- Do behavioral health support services* beyond psychosocial assessments completed as a part of annual comprehensive care visits improve the patient experience and clinical and health-related QoL outcomes? Do these services affect direct and/or indirect costs for inherited BD diagnosis and illness management?
- How do the type and characteristics of insurance coverage affect patient access to HTC care, treatment, bleeding, and other clinical and health-related QoL outcomes?
- In PWIBD, how do care, treatment, and clinical and health-related QoL outcomes of those receiving specialized/integrated care at HTCs compare to those outside the HTCs?
- How do provision of care components (e.g., access to care, patient satisfaction, and treatment) and clinical and health-related QoL outcomes of PWIBD from marginalized and minoritized populations** compare to PWIBD who do not identify as part of these populations?

Research Priority Questions: Implementation Science (SOS)

- For any given evidence-based treatment/intervention, what elements need to be adapted to enhance fit and cultural relevance to a specific sub-population (e.g., gender, language, marginalized and minoritized populations,* etc.) or setting?
- In HTC's caring for people with severe hemophilia, what practices, programs, or center characteristics lead to adherence to the prescribed treatment plan? What are factors that lead to concordance between PWIBD and HCP?
- What data-driven benchmarks and requirements for implementation of, and adherence to, VWD and hemophilia guidelines in health systems (starting with the US HTC Network/ATHN) could be developed and monitored, which also include markers of outcomes specific to marginalized and minoritized populations?*
- In HTC's caring for PWIBD, what characteristics increase the adoption of behavioral health support services** evidence-based interventions for PWIBD?
- What organizational factors, within HTC's or the institutions with which they are affiliated, promote or hinder health equity and anti-racism within an organization/institution (e.g. organizational climate and culture; internal policies supporting equity; employee and leader attitudes and motivations regarding equity)?

How to incorporate DEI into research

Carefully vet for and integrate researchers TRAINED IN equity research; in my judgment, these will typically NOT be individuals trained in clinical research and operations assessment

Commit to training in equity research: equity research questions do not simply “add the effect of ‘race’”

Center diversity policies on elevating perspectives of individuals from groups on the wrong end of power against that power

Meeting underrepresented communities where they are and inviting people to be meaningfully involved – representation, accountability

Delineate more time for community building

Train the workforce to value equity

Be prepared to pay research participants

Assess the social determinants that represent systemic and individual barriers

Critical Topics

- Examining existing research and institutional biases, impact of SDOH
- Women and girls
- People living at a distance
- Federally qualifying health centers
- Homeless and incarcerated individuals
- SOS priority questions
- Equity in healthcare
- Needs assessment
- Future therapies
- Clinical trials

Road from DEI to Health Equity

- If DEI is simply statements about values without commitment to specific skills, then they perpetuate all the -isms as normal parts of research.
- Inclusion of minoritized, marginalized, and/or underrepresented populations in research projects will help us to understand impact of IBDs, treatments, etc and whether certain groups experience complications, gaps in care, etc.
- It ensures that new discoveries/treatment are available/appropriate for everyone
 - <https://www.socra.org/blog/health-disparities-why-inclusion-and-health-equity-matter-in-clinical-research/>
 - Boulware, L. Ebony, Giselle Corbie, Sergio Aguilar-Gaxiola, Consuelo H. Wilkins, Raquel Ruiz, Alfred Vitale, and Leonard E. Egede. "Combating structural inequities—Diversity, equity, and inclusion in clinical and translational research." *N Engl J Med* 386 (2022): 201-203.
- Ensure that everyone is represented and that changes/recommendations reflect the whole population

NRB HEDI Value Statement

- **Diversity**
 - The goal of the National Research Blueprint (NRB) is to establish a clear understanding of the most pressing issues challenging people and families with bleeding disorders. This effort aims to bring the experiences of people who live with bleeding disorders to the forefront of transformational research and examine where research can have the most community impact. To do so, the NRB seeks and values the diverse voices of the bleeding disorders community. We strive to promote inclusion of all persons in research regardless of age, race, ethnicity, national origin, gender identity, gender expression, sexual orientation, disability, or financial status. A diverse group of participants with unique perspectives and experience can lead to breakthroughs and improve the lives of all persons living with bleeding disorders. Participation is open to all.
- **Accountability**
 - The NRB strives to honor commitments to members of the bleeding disorders community. We take responsibility to accomplish our mission with the highest quality possible and strive to work and think with integrity. A culture of accountability is important to build trust with community members so they can provide feedback and together we can work towards transformational research with community impact.
- **Transparency**
 - The NRB values transparency in order to build trust with participants. We value open and honest communication and strive to keep participants informed of our successes and victories, as well as where we have fallen short.
- **Respect**
 - The NRB values the diversity of researchers, participants, and partners in background, lived experience, and culture. We strive to create a culture of belonging where all persons are treated with dignity and respect. We value the collective power of teamwork and understand that by working together, we will be able to create meaningful change in research for the bleeding disorders community.

❖ We listen..., we respond..., we reflect..., we act...

HEDI Research Guidepost Questions

Questions that researchers must answer BEFORE creating study/initiative /service

1. What are the needs of the community being highlighted for the study/initiative/service? Do they align with or conflict with those of the researchers? What is the purpose of researching the specific community (i.e. African-Americans) – how does this identity see the benefits and risks of the research?
2. What kinds of relationships are existing between the institutions/researchers and the research communities?
3. Have you done a needs/impact assessment? This could include asking about historical narratives (implications of past experiences of community & research participants with research/medicine), past community relationships research projects, competing priorities of communities; Is it exploitive? How much need does the community have for the data? What are the barriers to the research for the subjects you are interested in?
4. Has the research team completed appropriate training to understand the implications of diversity, equity, and inclusion for study/initiative /service?
5. Is your research team diverse? Is your subject pool diverse (gender, race, ability)? How does it engage women, communities of color, and other intersecting identities (i.e. Hispanic pregnant women)?
6. Can the research team ensure that:
 - a. There is diverse representation and involvement from minoritized and marginalized population in the clinical trial design
 - b. Implicit bias is addressed,
 - c. Cultural awareness /competence is addressed
 - d. Social determinants of health such as distance, education, economic status, homelessness is taken into consideration
 - e. Barriers to study access have been considered/addressed (i.e. flexible timelines, home care, compensation for loss of work, appropriate access for those whom are disabled)
7. What engagement plans are set in place to encourage and raise awareness in diverse communities (advertisements, info sessions, town halls, etc.)?
8. Do outcome measures reflect and/or capture the diversity of experience and culture?

HEDI NRB Research Guideline Questions

- It is the responsibility of every funder, sponsor, organization, and investigator to ensure diversity and inclusion in research. These efforts seek to promote greater fairness in the distribution of the benefits and risks of research. The health needs, and responses to interventions, of populations and individuals can only be identified, considered, and managed if those populations and individuals are represented and studied.
- Collaborate with diverse, multidisciplinary stakeholders during planning and design phase of research and throughout research lifecycle to help inform and guide research. Includes engagement with lived experience experts (LEEs) and persons from marginalized and minoritized populations. Consider involvement of these stakeholders in the development of funding applications, study steering committees, and in hiring of study staff.
- Engage with communities to learn from their experiences and establish trust. Seek community input on the purposes, goals, and impacts that are relevant to them, and compare those to the research project goals. Consider cultural humility and competence in research participant recruitment and retention efforts. Make intentional efforts to recruit from marginalized and minoritized populations. Offer meaningful incentives for their time and efforts (e.g. gas and grocery gift cards.)
- Regarding informed consent, confidentiality, and privacy safeguards, consider the perceived risks and benefits for marginalized and minoritized populations given historic and social contextual factors.
- Examine and mitigate the presence of conscious and unconscious bias in how research is conducted, data are interpreted, and findings are presented and disseminated. Bias influences decisions made throughout the research process, including who is eligible, what research questions are asked (and by whom), how data are collected, how findings are interpreted and communicated, and which audiences and methods are selected for dissemination².
- Ensure research study findings are interpreted and translated for diverse audiences and widely disseminated. LEEs, including marginalized and minoritized populations, should be considered a primary audience. Consider how to present the findings in a format that is useful for and relevant to them².
- Strive for open and transparent communication about the study throughout research lifecycle. Ethical research must be reciprocal² - share information with community stakeholders and listen to their perspectives and concerns about the research.

Adapted from "Achieving Diversity, Inclusion and Equity in Clinical Trial Research Guidance Document". Multi-Regional Clinical Trials Center of Brigham and Women's Hospital and Harvard (MRCT Center). 2021.

Kristine Andrews, Jenita Parekh, and Shantai Peckoo. How to Embed a Racial and Ethnic Equity Perspective in Research Practical Guidance for the Research Process. A Child Trends Working Paper, August 2019.



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INPUTS

- LEEs (Diverse)
- Providers
- Researchers
- Funding
- HEDI Champions
- Industry
- Chapters
- HTC
- Community Orgs
- Advocates

ACTIVITIES

- NRB Workgroups
- NRB Collaborations
- Assessments
- Training for LEEs
- Training for researcher
- Committee to review research protocols
- HEDI value statements
- HEDI guidepost questions

OUTPUTS

- HEDI research Guidelines
- Collaborating with LEEs guidelines
- Shared decision making
- Research Protocols
- Trained researchers (SDoH & working with minoritized/marginalized populations)
- Advisory boards

SHORT TERM OUTCOMES 1-3 YEARS

- Engagement of diverse stakeholders
- Internal increase in equity and inclusion
- Increased community-based research
- Increase DEI skills/problem solving

INTERMEDIATE OUTCOMES 3-5 YEARS

- Linguistically and culturally accurate education and care
- Research protocols reflective of LEE/DEI
- External practice of DEI inherent in HTC work
- LEE/DEI in Research, Education and Advocacy

IMPACT 5-10 YEARS

- Diverse providers/researchers
- Equitable access and treatments
- Affordable care/treatment
- Thriving persons living with inherited blood disorders
- Research co-authored by LEEs
- Increased diversity in clinical/research trials
- LEEs as valued partners in research

Long Term (IMPACT) Outcomes (5-10 years)

Logic Model

- Diverse providers/researchers – diversity in background, lived experience, geographic location, age, etc.
- Equitable access to care and treatments - for all
- Affordable care/treatment – for all
- Thriving persons living with inherited blood disorders
- Research co-authored by LEEs
- Increased diversity in clinical/research trials
- LEEs as valued partners in research

Q/A



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