

Expanding Patient and Community Engagement in HEAL Studies

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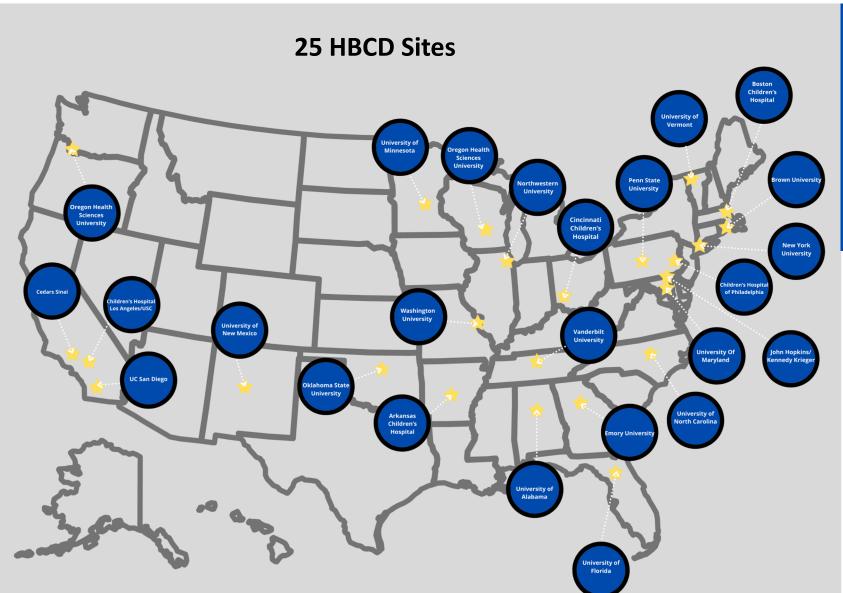
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UC San Diego
Cincinnati Children's Hospital
Children's Hospital Los
Angeles/USC
University of New Mexico
Cedars Sinai
Arkansas Children's Hospital
Boston Children's Hospital
Northwestern
University of North Carolina
Penn State
University Of Maryland
Children's Hospital of
Philadelphia
University of Minnesota



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Vanderbilt
University of Florida
Emory University
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Washington University
University of Alabama
University of Wisconsin,
Madison





DEI Coordinating Committee

 To establish effective approaches to promote
 Diversity, Equity, and Inclusion (DEI) across all facets of HBCD

• DEI goals are consistent with the overall goal of the study (i.e., to less health disparities and inequities) and will lead to better science.

- Coordinating committee will support DEI efforts:
 - Within HBCD investigator community
 - In our work with research participants
 - Analysis and dissemination of scientific findings





HEALthy Brain and Child Development Study Values Statement



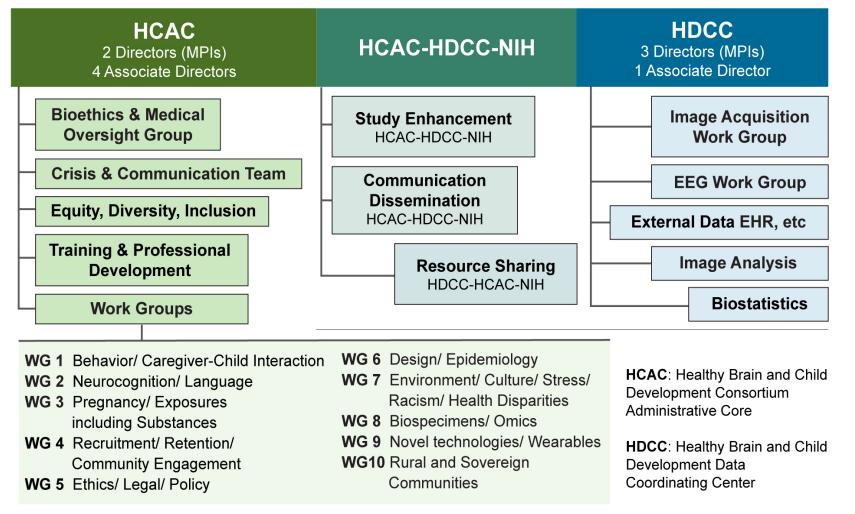
The Healthy Brain and Child Development (HBCD) study is committed to diversity, equity, and inclusion throughout every level of the initiative. Our staff, researchers, and administrators are guided by a core set of values designed to promote equity, antistigma, and anti-racism within the study consortium, in our work with study participants, and in the dissemination of our results. We are conducting this study to advance health equity and ensure that all children in the United States have the greatest possible chance for life-long health and wellbeing; accordingly, the equitable treatment of all people involved in the study is critical and should guide all of our efforts. Investigators and staff are committed to the following goals:

- 1. Participation is open to people of every race, ethnicity, religion, gender, and sexual orientation, regardless of national origin, education or income level, or health insurance status.
- 2. We will monitor diversity, equity, and inclusion across protocols, leadership roles, investigative teams, and community advisory boards.
- 3. We will work with and for our participants and their communities.
- 4. We will promote dignity and respect for all persons regardless of income level, physical and mental health, and identity, including racial and ethnic groups, gender, sexual orientation and family structure.
- 5. We will require responsible use of study data.
- 6. We will engage in activities to create a diverse community of scientists and staff and provide training and leadership opportunities for a diverse group of students, fellows, and junior faculty.





Infusion of DEI goals throughout all working groups







Short- and longer-term DEI activities

Generate a mission statement re: values of study

Consult with other national consortiums for best practices (e.g., ABCD, ECHO)

Representation from all sites

DEI-related policies, to be finalized by steering committee

Ensure DEI representation across working groups

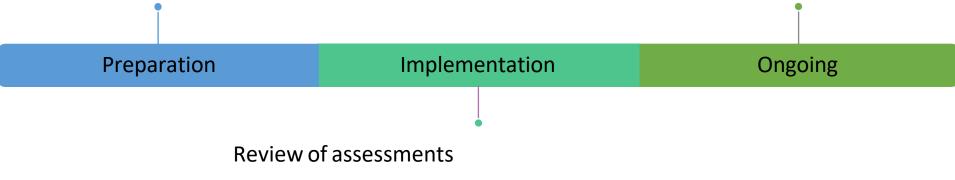
Monitoring progress/benchmarks (including

participant feedback)

Accountability for DEI goals

Ensure opportunities for dialogue

Etc.



Review of protocols

Ensure site-specific local advisory boards meet DEI objectives





Community Advisory Boards

- Comprised of community stakeholders that will meet regularly
 - Ensure research protocols are patient- and community-centered
 - Enable interfacing with the community
 - Allows link to community agencies that provide referral services.
 - Example CAB:
 - Stakeholders include nurse home visiting providers, peer recovery coaches, substance educators and treatment providers, family trauma treatment and community advocate organizations
- Under Consideration:
 - A member from each local CAB to sit on a consortium-wide CAB board
 - Pls report back about recommendations from their CABs
 - Structured survey to be distributed to the CABs





Washington University Community Advisory Board

Reducing substance abuse and co-occurring mental health problems through effective and efficient treatment programs.

Moves vulnerable children in the direction of hope by delivering comprehensive therapeutic and educational services to support families.

Provides a safety net for at risk families to prevent infant mortality, child abuse and neglect.

Address needs for families impacted by SU, co-occurring disorders and trauma.

Improve mental health outcomes through innovative research and program development/evaluation, community outreach, and professional training.

Alive and Well Communities uses an understanding of trauma, including the trauma of racism to transform and activate systems and communities that are just and equitable



Addiction Medicine. Saving Lives.















Study Navigators

• The HBCD study will benefit from engaging peer recovery navigators (PRNs), community health workers (CHWs), social workers,

Peer Recovery Navigator

Job Summary:

Provides peer support services to participants struggling with or in early recovery from substance misuse

Roles and Responsibilities:

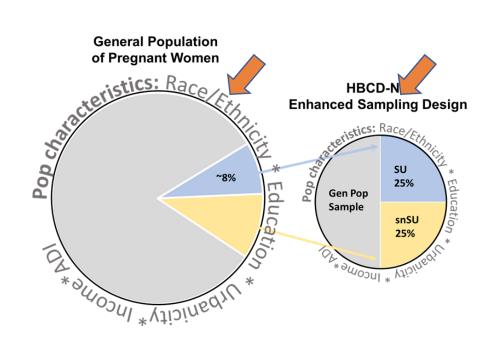
Participant/advocate liaison through lived experience

Identify needed community resources

Develop formal and informal community supports

Increase support for participants to aid study completion

Understand participant rights and policy procedures







Conclusions

- HBCD is aiming to have community involvement throughout the study
- DEI goals are central to the study
- Participant Navigators with lived experience will provide vital services to the participants and the study





ACKNOWLEDGEMENTS

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