Health in Our Hands
HANDBOOK and GLOSSARY

HEALTH in Our HANDS

REACHnet
Research Action for Health Network

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Revised February 2025

HiOH Overview

Health in Our Hands (HiOH) is a network of patients committed to improving health by collaborating with researchers and healthcare providers to amplify patient voices in the research process. The unique perspectives and experiences of HiOH members greatly influence the design, conduct, and dissemination of research to improve health.

HiOH is a patient advisory group for the Research Action for Health Network (REACHnet), a partnership of health systems, academic centers, and public health organizations in Louisiana, Texas, and California. REACHnet implements research that addresses healthcare questions that are important to patients and clinicians and generates evidence to inform more effective healthcare decision-making to improve population health. For more information about REACHnet, visit reachnet.org.

To ensure that REACHnet is driven by patients' priorities, the HiOH administrative team collaborates frequently with HiOH members and REACHnet Patient Partners to inform network operations and key decisions.

The HiOH Administrative Team

HiOH is organized and facilitated by a team based at Louisiana Public Health Institute (LPHI) in New Orleans, Louisiana. LPHI is a public health institute that champions health for all people, within systems, and throughout communities. We welcome questions or feedback from HiOH members and are available to provide technological assistance to support participation in HiOH. To contact the HiOH Administrative Team, email info@hioh.org.

Thomas Carton, REACHnet Principal Investigator

Beth Nauman, REACHnet Dual Principal Investigator

Darcy Hannagan, Engagement Coordinator

Meagan Alley, Program Manager

The REACHnet Patient Partners

HiOH wouldn't be possible without our REACHnet Patient Partners, who provide crucial guidance on the content, structure, and leadership of HiOH. At REACHnet, we greatly value patient engagement in research, and Patient Partners help us develop relevant, patient-centered information and activities for HiOH members.

You can get to know the REACHnet Patient Partners by reading their biographies on the REACHnet website.

Ava Zebrick - Alexandria, VA

Lanissa Stewart - New Orleans, LA

Tiffany Jones - Dallas, TX

Jon Turner - San Francisco, CA

The HiOH Community

HiOH members offer essential perspectives to health research and are encouraged to actively engage as participants with an interest in advancing patient-centered health research.

Members have the opportunity to:

- Receive training on the principles of patient engagement in research.
- Connect with peers and share experiences within the HiOH Community.
- Participate in virtual meetings with researchers and other members of the HiOH Community to learn about current projects, provide patient perspectives, and guide research initiatives.
- Regularly receive information about new studies, opportunities to get involved, and research updates.

Members are required to complete the HiOH Community Partner Training. This training ensures that members are prepared to discuss clinical research, understand the structure and function of the research network, and know what is expected of them as a HiOH Community Partner. To become a HiOH Community Partner, a member must complete the following steps:

- Complete a self-guided research fundamentals training online provided by PCORI®.
- Attend a 1-hour orientation meeting led by the HiOH team.
- Sign the HiOH Community Partner Agreement

The HiOH Community Partner Agreement ensures that members are adequately prepared to participate in HiOH activities. It states that Community Partners should:

- Have an understanding of REACHnet and HiOH.
- Have an understanding of patient engagement in research.
- Be able to accurately define and describe the Community Partner role.
- Feel confident that they have the expertise, skills, and resources for success.
- Feel that they will benefit from their role in the HiOH community.

- Agree to respect the confidentiality of HiOH members when sharing personal information.
- Attend meetings, respond timely to emails, and actively engage with the HiOH community.

HiOH Engagement Opportunities

HiOH meets virtually on Zoom every other month. Meetings are typically held on a weekday at 5-6pm Central Time and feature representatives from study teams who seek input from patients on research ideas or projects. Between meetings, the HiOH administrative team sends a newsletter by email that includes research updates and health tips.

One of our primary strategic goals is to provide opportunities for patient engagement on REACHnet studies as they move through the research process. These opportunities may include joining a study's advisory group, participating in a focus group discussion, enrolling in a study, and more. These activities may offer compensation that will not be processed or delivered through HiOH. We will inform HiOH members via email when such opportunities arise. HiOH members may decide to take part in these additional engagement opportunities as available, eligible, and interested. Participation in such activities is not required to remain active in HiOH.

Meeting Norms

Most HiOH meetings involve guest presenters from research teams. To ensure mutual respect between all attendees, and to make the most of our meeting time, all members, presenters, and administrators are encouraged to adhere to the following meeting norms:

- Raise your hand—Use the "raise hand" feature in Zoom to speak next. If possible, hold questions/comments until the presenter provides an opportunity for discussion.
- Turn on your mic to talk—Turn off your phone, computer, or device mic when you're not speaking.
- Say your name—Announce your name before you speak so others know who is talking, and make sure that your name is displayed on your Zoom account.
- Speak one at a time—Multiple conversations make it hard for others to hear.
- Build connections—Turning on your camera is encouraged to foster relationships with fellow members.
- Keep it confidential—Agree to respect the confidentiality of HiOH members when sharing personal information.
- Use the chat box—The chat box is available and monitored throughout the meeting for questions, input, or other feedback.

HiOH is a community where all members may:

- Ask questions and express curiosities freely.
- Learn and unlearn through research presentations, workshops, and discussing life experiences.
- Show respect for multiple perspectives and opinions.
- Reflect and provide feedback on HiOH meetings, including topics of discussion, logistics, efficiency, and opportunities for improvement

If you want to follow up on something:

- With your peers in HiOH—Understand that they may respond in different ways or not at all.
- With the HiOH administrative team or meeting presenters—You are welcome to do so in whatever way is best for you (email, phone, or Zoom).

As a HiOH member, it is very important to be respectful of all differences. Our community reflects a wide range of backgrounds, opinions, and health experiences. Any behavioral misconduct in the form of harassment or bullying will not be tolerated.

Diversity & Equity Statement

At REACHnet, we know that diversity is something to be celebrated. Diversity strengthens research by allowing us to examine the impact of diseases and effectiveness of treatments on all people, including populations that are often underrepresented in health research. We strive to include research participants and patient and community stakeholders from diverse backgrounds in our studies. We also welcome partnerships with researchers and organizations that demonstrate a commitment to health equity through their work.

By prioritizing diversity and inclusion, we contribute to advancing individualized care and achieving better health outcomes for all. As a HiOH member, it is your responsibility to help us maintain this priority by being respectful of the opinions, identities, and values of your fellow community members.

Compensation

HiOH offers compensation for members' time and contributions. Those who attend each meeting receive $50 delivered through TangoCard, an online gift card distribution service. A gift card is sent to each participant via email 1-2 business days after the meeting. Members can then choose the store(s) for which they would like to receive gift card(s) from the TangoCard website. The HiOH team is available to help with any issues related to compensation. HiOH is not responsible for compensation offered by external engagement opportunities.

Resources

Although HiOH members complete the Community Partner Training when joining HiOH, the PCORI® Research Fundamentals training modules are linked below for members to review key concepts about patient engagement in research, if needed.

- Engagement in Stakeholder-Driven Research
- Developing Research Questions
- Designing a Research Study
- Planning Patient-Centered Consent and Study Protocols
- Sampling, Recruiting, and Retaining Study Participants
- Understanding and Sharing Research Findings

Glossary

The following definitions may be useful to reference when participating in HiOH meetings and discussions. Addition terms not listed here may be found in the PCORI® Glossary or the National Institute on Aging Glossary of Clinical Research Terms.

Term	Definition
Advisory Panel	A group that provides recommendations to help plan, develop, implement, improve, and refine a research agenda. While the panels do not hold decision-making authority, they are critical to ensure that patients and stakeholders provide input into the refinement of the institute's research portfolio and other activities.
Attrition	A reduction in the number of participants in a clinical trial over the course of the trial.
Assent	A child's affirmative agreement to participate in a clinical investigation.
Baseline	The initial time point in a clinical trial that provides a basis for assessing changes in subsequent assessments or observations.
Belmont Report	A document that identifies three basic ethical principles for conducting research that involves human subjects. The three ethical principles described are: • Respect for persons • Beneficence • Justice
Bias	A point of view or preference which prevents impartial judgment in the way which a measurement, assessment, procedure, or analysis is carried out or reported.
Burden of Illness	The frequency of the condition, the expected mortality and morbidity, and/or the degree of suffering associated with symptoms or complications of a health condition.
Care Transition	The movement patients make between different clinicians or settings.
Caregiver	An individual who provides uncompensated care to a patient in a capacity outside of their professional responsibilities.
Clinical Practice Guidelines	Systematically developed statements or recommendations to aid practitioner and patient decisions about appropriate health care for one's clinical circumstances.
Clinical Significance	Important change in a subject's clinical condition that may or may not be due to the test intervention.
Clinical Trial	A research study in which one or more human subjects of prospectively assigned to one or more interventions to evaluate the effects of those interventions on health-related biomedical or behavioral outcomes. Clinical trials are used to

	determine whether new biomedical or behavioral interventions are safe, efficacious, and effective.
Common Rule	Refers to the current federal regulations to protect individuals who participate in research as human subjects. The Common Rule: • Describes the types of research subject to regulation. • Defines key terms such as research, human subject, and minimal risk. • Lists the general requirements for informed consent.
Community	A group of people linked by an affinity (e.g., social ties, common perspectives, joint action or concern, or geography).
Comparators	Two or more options for diagnosis, treatment, prevention, or healthcare delivery.
Conflict of Interest	A conflict of interest occurs when individuals involved with the conduct, reporting, oversight, or review of research also have financial or other beneficial interests depending on the results of the research.
Control Group	The group of individuals in a clinical trial assigned to a comparison intervention.
Dissemination	The process of identifying target audiences and tailoring communication strategies to increase awareness and understanding of clinical research findings.
Eligibility Criteria	List of criteria guiding enrollment of participants into a study. The criteria can describe both inclusionary and exclusionary factors.
Endpoint	Principal indicator(s) used for assessing the primary question (I.e., hypothesis) of a clinical trial at the end of the trial period. An endpoint is more specific as compared to an outcome since it relates to the planned objective of the study.
Engagement	A bidirectional process by which participants, clinicians, and investigators collaborate on the development of meaningful patient-centered research.
Engagement Plan	A defined strategy to effectively involve patients, caregivers, clinicians, and relevant healthcare stakeholders throughout the research process.
Enrollment	The process of registering or entering a patient into a clinical trial. Once a patient has been enrolled, the participant would then follow the clinical trial protocol. Clinical investigations are designed to enroll a set number of participants to increase the likelihood of answering the trial questions.
Human Subject	A patient or healthy individual who is or becomes a participant in research, either as a recipient of the intervention or as a control.
Implementation	The deliberate process of integrating evidence into health policy and practice through facilitating behavior change and decision making across individuals, communities, and healthcare systems.
Informed Consent	A process by which a participant or legal guardian voluntarily confirms their willingness to participate in a particular trial after having been informed of all aspects of the trial that are relevant to the participant's decision to take part in the clinical trial.
Informed Consent Form	A document that describes the rights of a participant and provides details about the study, such as its purpose, duration, required procedures, and key contacts. Risks and potential benefits are explained in the informed consent document.

Intervention	A procedure or treatment such as a drug, nutritional supplement, gene transfer, vaccine, behavior or device modification that is performed for clinical research purposes.
Lost to Follow-Up	The act of concluding participation, prior to completion of all protocol-required elements, in a trial by an enrolled subject.
Masking/Blinding	A procedure in which the investigator administering the assessments/interventions as well as the participants in a clinical trial are kept unaware of the treatment assignment(s). **Single blinding** usually refers to the study participant(s) being unaware, and **double blinding** usually refers to the study participant(s) and any of the following being unaware of the treatment assignment(s): investigator(s), monitor, and data analyst(s).
Outcome	Events or experiences measured by clinicians or investigators. Outcomes are more general than endpoints in that they do not necessarily relate to a planned objective of the study.
Participant	An individual who is engaged in a research activity as a: • Patient • Caregiver • Family member • Community member • Interest and/or affinity group member
Patient	An individual affected by a condition, illness, or disease, and/or an individual who personally identifies as a patient and has sought or received care.
Patient Investigator	Patients or other community members involved in the investigation of research who have a role in guiding the aims of the study.
Patient Partner	An individual with experience living with a condition, illness, or disease who works closely with researchers to inform clinical projects.
Payers	Those who function as financial intermediaries in the health system, including private insurers, public insurers, and organizations representing insurers.
Peer Review	Review of study findings by content experts, methodologists, patients, and other healthcare stakeholders to ensure that the primary research studies are held to the highest standards of scientific integrity, methodological rigor, and relevance and usefulness to patients, caregivers, clinicians, and all involved in healthcare.
Placebo	An inactive pill, liquid, powder, or other intervention that has no treatment value. In clinical trials, experimental treatments are often compared with placebos to assess the treatment effectiveness.
Protocol	A document that describes the objective(s), design, methodology, and organization of a trial.
Randomization	The process of assigning clinical trial participants to treatment or control groups using an element of chance to determine the assignments and reduce bias.
Recruitment Plan	A document that outlines how individuals will be recruited for the study and how the study will reach the recruitment goal.
Research Funder	Organizations or entities responsible for funding the engagement or health research described.
Retention Plan	A document that details the methods the study will use in order to retain study participation in the clinical trial.

Screening Process	A process designed to determine an individual's eligibility for participation in a clinical research study.
Sponsor	An individual, company, institution, or organization that takes responsibility for the initiation, management, and/or financing of a clinical trial.
Stratification	Separation of a study cohort into subgroups according to specific characteristics (age, gender, racial identity, etc.) to consider factors which might affect the outcome of the study.
Systematic Review	A synthesis and critique of existing literature
Underserved Population	A population whose needs are often unintentionally overlooked.

Commonly Used Acronyms

- **(AE**) Adverse Event: Any untoward or unfavorable medical occurrence in a clinical research study participant, including any abnormal sign, symptom, or disease, temporally associated with the participants' involvement in the research, whether considered related to their participation in the research.
- **(CDM)** Common Data Model: A model that establishes a standard way of defining and formatting data.
- **(CRC**) Clinical Research Study Coordinator: An individual that handles the administrative and day-to-day responsibilities of a clinical trial and acts as a liaison for the clinical site.
- **(EHR/EMR)** Electronic Health Record/Electronic Medical Record: A repository of electronic information about an individual's health status and health care.
- **(GCP**) Good Clinical Practice: An international set of guidelines that helps make sure that helps ensure the results of a clinical trial are reliable and that the patients are protected.
- **(HiOH)** Health in Our Hands: A network of patients with a vested interest in their own health and the health of their communities that collaborate with researchers and care providers to make sure patient voices are heard.
- **(HIPAA**) Health Insurance Portability and Accountability Act: A federal law that protects patients' health information and establishes standards for electronic health information.
- **(IRB**) Institutional Review Board: A committee that reviews research involving human subjects to ensure it is ethical and meets regulatory requirements.
- **(IEC**) Independent Ethics Committee: A group of people who review research involving human subjects to ensure that the research is ethical and protects the rights and well-being of the subjects.
- **(LOI)** Letter of Intent/Inquiry: A notification to PCORI® that an organization intends to apply for funding that includes information describing the proposed project.
- **(LPHI**) Louisiana Public Institute: A public health institute that champions health for people, within systems, and throughout communities.
- **(PCOR)** Patient-Centered Outcomes Research: Research that helps people and their caregivers communicate and make informed health decisions, while allowing their voices to be heard in assessing the value of healthcare options.

- **(PCORI®)** Patient-Centered Outcomes Research Institute: An independent, nonprofit research funding organization that seeks to empower patients and others with actionable information about their health and healthcare choices.
- **(PCORnet®)** A national resource funded by PCORI® that enables insights from high quality health data, patient partnership, and research expertise to deliver fast, trustworthy answers that advance health outcomes.
- **(PHI)** Protected Health Information: Any information that can identify a patient and relates to their health, including their past, present or future health.
- **(PI, co-PI)** Co-/Principal Investigator: The lead scientist(s) for a research project who has scientific, administrative, and leadership responsibilities for the entire project.
- **(RCT)** Randomized Controlled Trial: A study in which randomization is used to assign patients to treatments.
- **(REACHnet)** Research Action for Health Network: A partnership of health systems, academic centers, and public health organizations that constitute a data network for conducting efficient, multi-site research.

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