

# DCRI RESEARCH TOGETHER™

## A Commitment to Stakeholder Engagement

For too long people outside of the research world have not been embraced as full partners in the design and conduct of clinical research. The DCRI believes that all people – including patients, caregivers, community partners and other stakeholders – should be partners in research. These stakeholders have the potential to impact every stage of the clinical trial life cycle, including study design, funding, recruitment, protocol development, monitoring, data analysis, and FDA approval. Through DCRI's Research Together™ program, sponsors and investigators have access to DCRI thought leaders who understand the science of engagement.

DCRI Research Together(™) provides participant engagement and communications expertise in:

- Engagement and communications strategy, support, and evaluation;
- Patient advisory groups, patient representatives, and collaboration with community and advocacy organizations;
- Digital engagement and community building;
- Journey mapping;
- User-centered design;
- Frictionless research participation;
- Empiric development of consent process and forms;
- Patient preferences;
- Behavioral economics;
- Return of value; and
- Dissemination of research results.

### PATIENT PARTNERS

#### ADAPTABLE's Adaptors



*What is the best aspirin dose to protect patients with heart disease?*

Study Contributions: Assist in the design of protocol, consent form, study portal, and study materials; dissemination of study updates/results; and participation in investigator meetings, the Steering Committee, and Executive Committee.

#### AEGIS-II Kardias



*Can an experimental lipid treatment effectively prevent additional cardiovascular events?*

Study Contributions: Inform the consent process, educational needs, recruitment and retention strategies, and overall ways of enhancing the study participant experience; and participation in investigator meetings.

#### CONNECT-HF's Cardi-Yacks



*How can we improve heart failure care and outcomes through behavioral economics?*

Study Contributions: Provide feedback on the informed consent process, instructions and handouts for patients, patient resources, and more; study-app testing in a real-world setting.

DCRI Research Together™ leads the way in promoting participant engagement by collaborating with investigators, industry groups, the NIH, PCORI, and the FDA to find opportunities to co-design research with patients and other stakeholders.

Visit [dcri.org/stakeholder-engagement/](https://dcri.org/stakeholder-engagement/) to learn more about our patient partners.

# DCRI RESEARCH TOGETHER™

## Find Out More About Stakeholder Engagement

DCRI Research Together™  
DCRI-ResearchTogether@duke.edu  
919-668-9210

### GUIDING PRINCIPLES OF STAKEHOLDER ENGAGEMENT

DCRI Research Together™ means that relationships are bidirectional – everyone learns from each other and everyone gains value. The following principles guide these partnerships to ensure mutually beneficial outcomes:

- **People** come first. Always.
- We recognize that people are embedded in **dynamic family and community frameworks** that we honor and respect across the continuum of life care.
- **People are our partners in research**; not our subjects. We believe in taking every opportunity to co-learn. We engage participants, families, and community members in our research design, conduct, oversight, and dissemination activities.
- We are transparent and trustworthy. We communicate to research participants how valuable their contributions are to science and medicine. **We take the time to thank research participants, update them on progress, and share our findings in language understandable to everyone.**
- We create value. **We work to return results in a responsible and meaningful manner and maximize what can be learned by sharing data with other researchers.** We give back.
- We are not transactional in our approach. We encourage and incentivize collaborations with people and communities that look past the end of a project or last study visit. We create opportunities to continue **co-learning and working in partnership** with participants, families, and community members to improve health outcomes.

### DCRI RESEARCH TOGETHER™ PEOPLE

*“A person’s lived experience allows us a window into a disease in a way that we, from the outside, cannot truly understand. At DCRI, we create value driven models to optimize participant input, and then provide support and infrastructure for success. The result is working together to improve health through research.” - Renee Leverty*



**Renee Leverty, BSN, MA**, combines her unique experience as a patient advocate and social justice activist with 14 years of DCRI clinical trial project management to the Research Together program. Leverty brings a deep understanding of the importance of creating systems and processes to support value-driven, inclusive, patient-centered engagement models for clinical research. She has served as a project manager for a Patient-Powered Research Network (PPRN) funded by the Patient Centered Outcome Research Institute (PCORI).

Leverty has broad experience engaging diverse pediatric, adult, and aging populations, ranging from acutely to chronically ill in clinical trial design and conduct. She has led numerous patient advisory strategies for industry-sponsored trials and NIH-funded studies, as well as community co-design sessions for comparative effectiveness research. Leverty works with sponsors and investigators to skillfully deploy patient perspectives across the clinical trial and translational continuum.



Duke Clinical Research Institute

FROM THOUGHT LEADERSHIP  
TO CLINICAL PRACTICE