DCRI Improves Recruitment, Retention and Grant Proposals with Deep Patient Engagement Strategy

DCRI Uses CTTI's Patient Group Engagement Recommendations to Build its 'Research Together' Program

SUMMARY

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 Duke Clinical Research Institute (DCRI) felt that all people -- including patients, caregivers, community partners and other stakeholders -- should be partners in research. They used CTTI's Patient Group Engagement (PGE) recommendations as a foundational resource to build Research Together, DCRI's stakeholder engagement program that brings together sponsors, investigators, and patients to drive more meaningful research outcomes.

GOAL(S)

The DCRI wanted to more broadly operationalize patient engagement across its studies. The organization set out to develop a program that honors the patient voice at every stage of the study life cycle, including design, funding, recruitment, protocol development, monitoring, data analysis, and FDA approval.

CHALLENGES

The DCRI found that its project teams' experiences with engaging patient groups were largely anecdotal. Although there were commendable efforts to integrate these groups into DCRI studies, the teams lacked a solid road map or well-defined list of considerations to help them operationalize patient engagement across the study spectrum. The DCRI was also aware that effectively bringing patients into the research fold isn't always easy. Many patients are emotionally vulnerable and already dealing with the enormity of their medical condition. If engagement in research was not approached thoughtfully, there was a risk that patients would be overwhelmed or uninterested. From the researcher and funder side, the value of patient engagement is not easily captured in empirical data. DCRI needed a framework that would equally motivate patient groups, funders, and researchers to see value in clinical study participation.

SOLUTION(S)

When conversations among DCRI leadership began about formalizing patient engagement, CTTI's work was an obvious resource to kick off the process. CTTI's PGE recommendations aligned well with what the DCRI was trying to accomplish.

TAKING ACTION

Leaning on CTTI's guidance to engage early and often, from bench to bedside, DCRI leadership gathered a group of key opinion leaders in the patient advisory and advocacy space to begin developing guiding principles for its engagement program. They also secured funding for a one-day conference where they introduced DCRI's commitment to engagement with breakout sessions to learn more from the broader Duke and Durham, NC, community. Coming out of that conference, DCRI approved the following guiding principles for its engagement program, Research Together:

- **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.

From there, DCRI set out to launch the program across the larger DCRI leadership group and the community. The Research Together team continued to host learning opportunities with patient advisors, health care professionals, and multi-stakeholder groups to learn what was important to them in terms of successful engagement. These conversations informed the development of formal charters and engagement plans to guide every DCRI study.

IMPACT

Research Together launched in 2018 and continues to thrive as DCRI's stakeholder engagement program. Since that time, DCRI has worked collaboratively with research teams to emphasize cultural humility and inclusivity in outreach. Through ongoing connection, co-learning, and communication of value to patients and researchers, DCRI has successfully increased retention and improved adherence. The organization has also increased clarity across all stakeholders on expectations and opportunities for engagement. DCRI now brings in patient groups earlier in the development process -- even prior to funding. "Of course, patient input can bring value to areas like recruitment and retention, but we have also found tremendous insight and value from the patient voice even earlier, in grant proposals," said one Research Together leader. "Patients help us know if what we are proposing is feasible and meaningful to them. If we are conducting research that won't matter to the patient at the end of the day, we are missing the point." The same leader also stresses the need to delineate engagement from recruitment. Engagement, she says, is about understanding the value of participants across the study lifecycle. Good engagement positively impacts recruitment, but thinking of engagement in terms of recruitment

alone is too narrow a lens that limits the power of an engagement program.

ADVICE

Leadership buy in is critical, and good engagement requires a major culture change in the way most research organizations operate. A decade ago, engagement proponents stressed the importance of giving patients "a seat at the table" of clinical development. DCRI feels engagement must go even further. "We don't want patients to just have a chair at our table; we want them to partner in creating the entire environment of the table," said a Research Together leader. "This level of engagement takes time, but the benefits we are seeing are well worth it."

ORGANIZATION

Duke University

CONTACT

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ORGANIZATION TYPE

Academia

IMPLEMENTATION DATE

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TOPIC

Patient Engagement

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