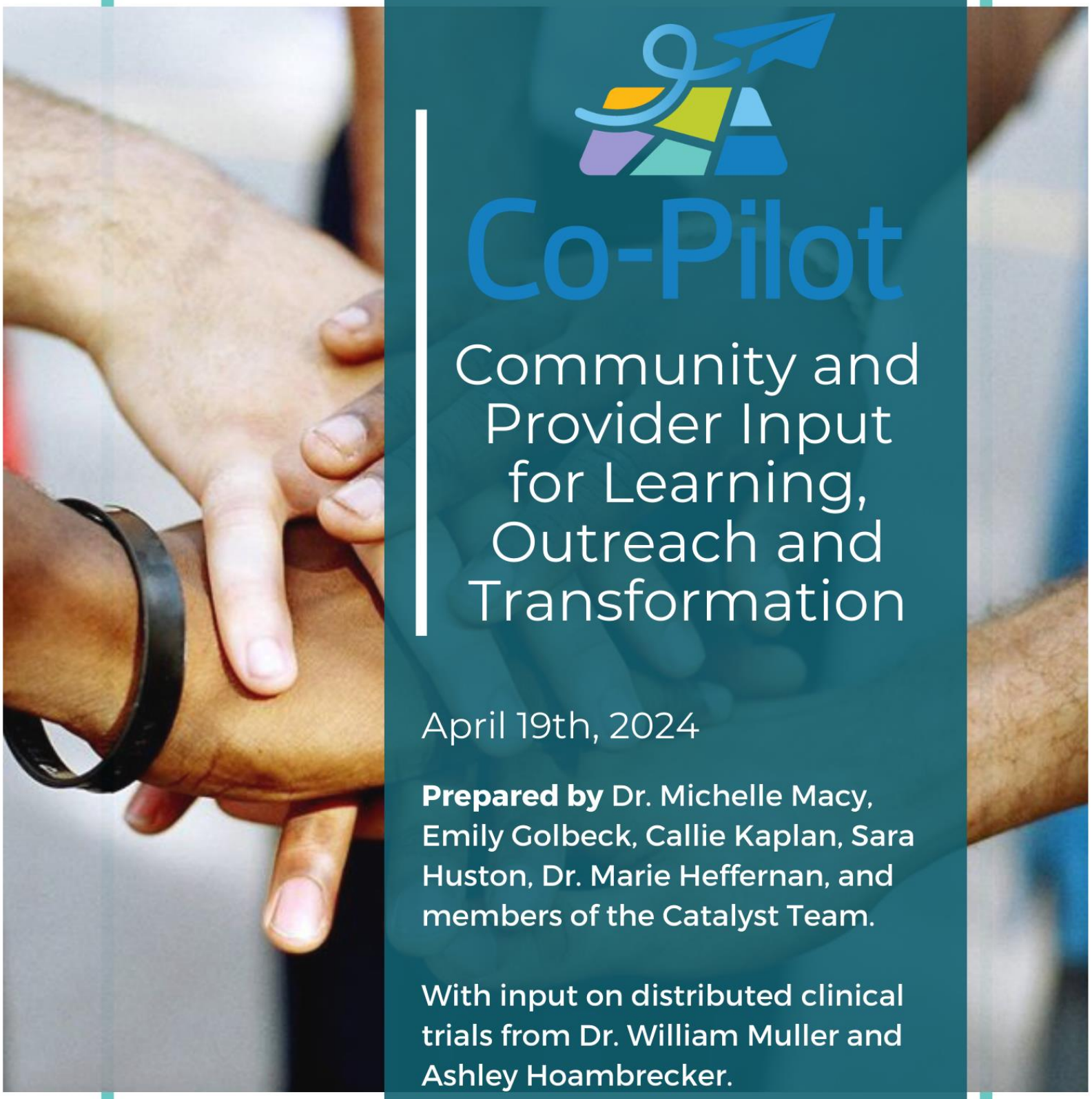

Co-Pilot

Community and Provider Input for Learning, Outreach and Transformation

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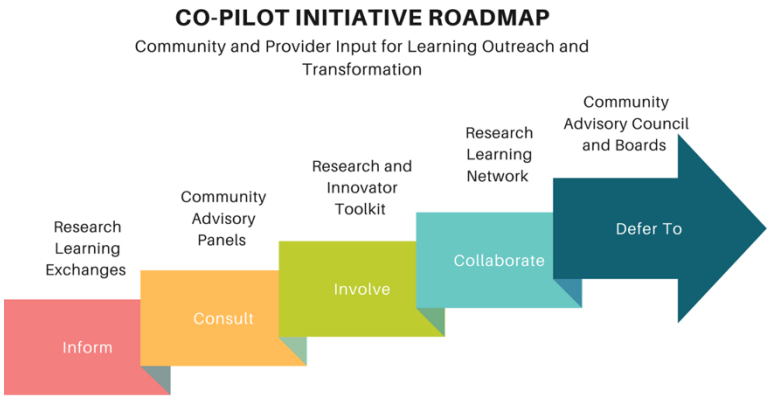
With input on distributed clinical trials from Dr. William Muller and Ashley Hoambrecker.

Community, Population Health, and Outcomes

Goals

Our goal in launching the **C**ommunity and **P**rovider **I**nput for **L**earning, **O**utreach and **T**ransformation (Co-Pilot) Initiative is to raise awareness, cultivate trust, and increase participation in all stages of research, including how research is designed, conducted and put into action. The proposed Co-Pilot activities will foster collaborations among community members, healthcare providers, and researchers, harnessing their collective insights to strengthen research and innovation endeavors at Stanley Manne Children's Research Institute within Ann & Robert H. Lurie Children's Hospital of Chicago. Through Co-Pilot, we will strengthen our existing partnerships with the Patrick M. Magoon Institute for Healthy Communities.

The Co-Pilot Initiative aligns with the research institute's foundational principles of access and equity, goals and strategic objectives, with the strongest connections to the Health@Home hallmark initiative. Co-Pilot also aligns with Lurie Children's goal to enhance communication between patients, families, and providers. Our Co-Pilot roadmap outlines our journey toward increased intensity of community engagement.[1] As we progress along the roadmap, we will carry forward each of the earlier steps of engagement. Co-Pilot activities will be assessed within clinic and community contexts using the Health Equity Implementation Framework[2] and Conceptual Model to Advance Health Equity through Transformed Systems for Health.[3]



Strategic Priorities

The resources proposed in the Co-Pilot Initiative will provide the necessary infrastructure and build capacity to support clinical and translational research. By equipping our researchers with a community and participant engagement skillset, we will initiate activities that will transform the way we conduct research allowing us to join national leaders in this space.

Inform: Research Learning Exchanges – "Runway Events"

Research Learning Exchanges include three components: 1) Experiences, 2) Events, and 3) Electronic Sharing of Information. Experiences will take place in community spaces and are designed as enrichment activities for both the community participants and the researchers to engage in open dialogue, learn from one another, share thoughts on research topics, and discuss how and why research is conducted. Experiences will inspire new ways of thinking and may generate hypotheses for further exploration and testing. Including researchers and innovators in Lurie Children's and Magoon Institute Events will provide a casual environment for community members to learn about research and innovation teams and their role in science and discovery. Electronic sharing of information, including development and posting of web content, will be coordinated with the Office of Research Development (ORD). The overall goal of Research Learning Exchanges is to increase the community's comfort with research concepts, expand understanding of the scope and importance of research, open channels for dialogue between parents, caregivers, and providers in the community and Lurie Children's researchers, and provide pathways for community members to engage with the research institute.

Consult: Community Advisory Panels

Community advisory panels will be established for the administration of surveys to bridge the gap between academia and society on timely issues. Panel surveys allow us to efficiently gather the pulse of the larger community on their opinions, experiences, and perspectives on a wide range of health and societal topics. Data

collected through surveys can be used to make research more relevant and responsive to community needs. It can directly influence public discourse and impact policy decisions. We will recruit standing panels of Chicago and Illinois parents, drawn from VOCHIC and Lurie Children's patient families. We will retain participants through biennial surveys and return of results. We will survey families to gather caregiver perspectives on general research topics, ethical concerns, and study design considerations. We will partner with Lurie Children's Investigators to field questions that are of relevance to their fields of interest, spanning all four research pillars. In future partnerships with the Quantitative Sciences pillar, condition-specific panels will be established.

Involve: Researcher and Innovator Toolkit

The Co-PILOT Toolkit will support investigators at the research institute with integrating participant and community-engaged principles throughout all phases of research and innovation, including question generation, study design and conduct, and dissemination and implementation of findings. ORD navigators and educators will be channels for dissemination of the toolkit resources internally. Catalyst team members will be available to coach investigators, innovators, and research professionals to ensure participants are respected and the perspectives of populations being studied are being represented. The toolkit will focus on unique aspects of pediatric research, drawing on existing published resources and ongoing initiatives within Northwestern University, and NUCATS.

Research participant demographic reports will be a key component of the toolkit. In partnership with the Office of Clinical and Community Trials (OCCT) and Quantitative Sciences, we will draw on data from Epic Research and Study Tracker to characterize research participants who enroll, withdraw, complete studies, or are lost to follow-up. Comparisons will be made to the study-eligible population and institutional benchmarks. Study- and investigator-specific reports will be paired with toolkit resources for design of QI strategies to ensure equitable recruitment and retention of diverse study populations. Catalyst coaching will be available to interested teams.

Collaborate: Research Learning Network

The Research Learning Network will invite diverse primary care practices and community organizations to partner with us on research through various levels of engagement, ranging from not engaged (e.g., disseminating recruitment flyers) to lightly engaged [e.g., sharing secondary data for analysis or direct recruitment of participants into Distributed Clinical Trials (DCT)] to highly engaged (e.g., co-design of implementation and comparative effectiveness studies). As trust builds, the complexity and richness of engagement across levels will increase. Lurie Children's researchers and innovators will benefit by learning the who, what, when, why, and how of ethically partnering with community practices on research projects and centering their work on community priorities. OCCT will play a crucial role in developing standard operating procedures related to the compliant and rigorous conduct of clinical trials with the initial roll out of DCT activities in Lurie Children's satellite locations and owned practices. Office of Research Integrity and Compliance (ORIC) will provide relevant resources to researchers, community practices, and community organizations.

Defer to: Research Advisory Boards and Council

Finally, the Co-Pilot initiative will facilitate Research Community Advisory Boards and a research institute Community Advisory Council where community members will have seats at the table for decision-making and renumeration for service. This highest level of engagement is essential for research as it fosters collaboration and ensures that research questions are relevant to real-world concerns. It also promotes transparency and trust between researchers and the communities they seek to involve in studies, enhancing the quality of data collection and dissemination of findings. Community research advisory boards would be created around disease states and at departmental, divisional and study levels. Research advisory board charters would include co-design of research projects, selection of methods that are ethical and relevant in the context of community, contributions to interpretation of results, involvement as co-authors on research products, identification of channels for dissemination and raising study awareness in the broader community.

References:

1. The Spectrum of Community Engagement to Ownership. Facilitating Power. Accessed Mar 15, 2024, https://www.facilitatingpower.com/spectrum_of_community_engagement_to_ownership
2. Woodward EN, Matthieu MM, Uchendu US, Rogal S, Kirchner JE. The health equity implementation framework: proposal and preliminary study of hepatitis C virus treatment. *Implement Sci*. Mar 12 2019;14(1):26. doi:10.1186/s13012-019-0861-y
3. Organizing Committee for Assessing Meaningful Community Engagement in Health & Health Care Programs & Policies. Assessing Meaningful Community Engagement: A Conceptual Model to Advance Health Equity through Transformed Systems for Health. *NAM Perspectives*. 2022;doi:https://doi.org/10.31478/202202c.