

FasterCures Champions New Models of Patient Engagement to Improve Trial Quality

FasterCures Applies CTTI's Patient Group Engagement Recommendations

SUMMARY

For 20 years, [FasterCures](#) has been a hub for fostering venture philanthropy through its TRAIN (The Research Acceleration and Innovation Network) initiative. Through its programs, like Patients Count, FasterCures has also sought to advance the science of patient input, making patient engagement a more regular and rigorous practice across the research and development ecosystem. In 2019, the well-respected, innovative think tank published a manuscript titled "[Advancing Models of Patient Engagement](#)" that cites CTTI's [Patient Group Engagement](#) (PGE) recommendations and resources and expands those ideas across the clinical trials ecosystem. Here is what FasterCures finds valuable about CTTI's work.

GOAL(S)

Guided by a conviction that the best ideas, under-resourced, cannot succeed, FasterCures (of the Milken Institute), conducts research and analysis and convenes top experts, innovators, and influencers from different backgrounds and competing viewpoints. They leverage this expertise and insight to construct programs and policy initiatives to effect change and help people live better lives through improved health and economic prosperity. In response to the emerging focus on patient engagement across the clinical trials ecosystem, FasterCures sought to identify effective ways for research organizations of all types, including research data networks, to partner with patient organizations that can bring patients' perspective, participation, and data to the table.

CHALLENGES

FasterCures has a long history, through its TRAIN initiative and its Patients Count program, of supporting and learning from innovative patient organizations that want to follow a more entrepreneurial approach in their role as funders and intermediaries for patient engagement in research. How could FasterCures empower these groups to bring richer, real-world data about the patient experience to the planning and conduct of research?

SOLUTION(S)

With CTTI's PGE recommendations as one of several key resources, FasterCures set out to develop best practices for advancing models of patient engagement. The resulting effort was a three-part manuscript series, "[Advancing Models of Patient Engagement](#)," that explored patient organizations as research and data partners. Specifically, the series offered: 1) a high-level framing of patient engagement issues and trends, 2) a look at the critical role patient organizations play in the research ecosystem, and 3) in-depth recommendations for researchers to engage meaningfully with patients. The final recommendations section highly cited CTTI's work.

TAKING ACTION

To illustrate the capacity to add value across the research and development continuum, FasterCures' patient engagement manuscript referenced a Parent Project Muscular Dystrophy (PPMD) chevron diagram popularized by CTTI, "Patient Group Engagement Across the Clinical Trial Continuum." The diagram catalogs organizational assets relevant to each drug development stage, illuminating the ways that researchers and sponsors might draw on PPMD's expertise.

FasterCures' manuscript also calls out CTTI's set of tools, in the form of checklists or questionnaires, that sponsors can use to characterize patient organization skills and strengths and enable researchers to find partners with the expertise needed for their specific project. Those tools include [CTTI's Patient Group Organizational Expertise and Assets Evaluation Tool](#) which assists in exploring potential input from patient groups across the clinical trial lifecycle based on expertise, and the [Assessment of Patient Group Internal Aspects Tool](#) which encourages upfront assessment of patient groups in areas like vision, operations, and budget.

FasterCures' patient engagement manuscript refers to CTTI's PGE recommendations as "the most detailed, practical effort to create a framework for researchers seeking patient group partners."

IMPACT

FasterCures published its "[Advancing Models of Patient Engagement](#)" manuscript of recommendations in November 2019.

ADVICE

Some implementations of CTTI's work are "boots on the ground" organizational changes, but just as important are efforts by FasterCures and others, which influence the clinical trials landscape and can drive powerful change. The director of FasterCures' venture philanthropy and patient engagement explains that patient centricity has been a central driver of the organization's work, and it dovetailed nicely with CTTI's PGE efforts. By collaborating with and tapping into CTTI's work, FasterCures was able to expand these ideas across the clinical trials ecosystem and specifically within the organization's unique and expansive network.

ORGANIZATION

FasterCures, of the Milken Institute

CONTACT

Kristin Schneeman 

ORGANIZATION TYPE

Other

IMPLEMENTATION DATE

2019

TOPIC

Patient Engagement

RELATED CTTI PROJECT

[Patient Group Engagement](#)

CTTI RESOURCES

[CTTI Recommendations: Effective engagement with patient groups around clinical trials](#)

ADDITIONAL RESOURCES

[Advancing Models of Patient Engagement: Patient Organizations as Research and Data Partners](#)