

ACTA Uses CTTI's Patient Group Engagement Recommendations to Build an Influential Toolkit for Improving Research

ACTA Applies CTTI's Patient Group Engagement Recommendations

SUMMARY

Australian Clinical Trials Alliance (ACTA) represents networks of clinician researchers conducting investigator-initiated clinical trials, clinical quality registries and clinical trial coordinating centers within the Australian healthcare system. ACTA contracted with T Symons Associates to lead the development of the [Consumer Involvement and Engagement Toolkit](#), which provides guidance to researchers and research organizations wishing to conduct patient-centered clinical trials.

GOAL(S)

ACTA's vision is "better health through best evidence," and in its effort to realize that vision, ACTA, in collaboration with CT:IQ (an Australia-based organization modeled on CTTI), contracted T Symons Associates to lead the development of the Consumer Involvement and Engagement Toolkit. The Toolkit is a national resource that provides guidance and tools to encourage the design and conduct of patient-centered trials where consumers and their communities shape all stages of the trial process.

CHALLENGES

Researchers and research organizations often want (and are increasingly required to) engage with consumers and the community, but often do not know how to go about it. The challenge for ACTA and T Symons was to create a resource that provides a clear roadmap to enable meaningful consumer involvement across the trial lifecycle within tight project timelines. As the positive impact of consumer involvement is rarely reported in the literature, the second challenge was to locate and report existing evidence of its value and impact to secure greater buy-in.

SOLUTION(S)

ACTA convened an Expert Working Group comprising of clinicians and consumers to steer the development of the Toolkit. To inform the Toolkit's content, ACTA also surveyed its stakeholders to define their needs. It was important to the Expert Working Group that the Toolkit was underpinned by high-quality evidence, and many of CTTI's recommendations were utilized to achieve this goal. Like CTTI, ACTA was committed to bringing solutions to problems by developing best-practice guidance. ACTA appreciated that CTTI took a collaborative evidence-based approach in all its work, showing real-world outcomes and experiences to inform best practice.

TAKING ACTION

CTTI's [Patient Group Engagement \(PGE\) recommendations](#) heavily informed ACTA's Consumer Involvement and Engagement Toolkit. To ensure the Toolkit was populated with the most current and evidence-based information, ACTA conducted a scan of both national and international practices for consumer involvement. CTTI's PGE recommendations were particularly valuable because ACTA identified few resources to help organizations involve and engage with patient groups at a strategic level (most resources focus on consumer involvement at a trial level). ACTA incorporated and signposted to CTTI's work, which will guide healthcare organizations and clinical trial networks to improve the way they manage their clinical trials services. By demonstrating that consumer involvement in research is strategically and economically beneficial, CTTI's work helped the Consumer Involvement and Engagement Toolkit demonstrate the "value proposition" for consumer involvement.

IMPACT

ACTA launched the Consumer Involvement and Engagement Toolkit in 2019, on time and on budget. The ability to access and learn from resources like CTTI's recommendations contributed to its successful completion despite limited funding.

ADVICE

Consumer involvement is rapidly becoming an important global movement, and ACTA finds the collaborative perspective CTTI endorses incredibly impactful. The clinical trials enterprise has challenges to work through, including the trial prioritization, design, conduct and implementation of research. These are not Australia-only issues, and we can address them much more effectively and efficiently if we work together. ACTA's advice to others considering a similar project is to model that perspective. Bring people along with you, develop policies and processes as a community, and bring experts and people into the fold early on so they can understand problems and be part of the designing the solutions. In the end, it's about doing better and faster and more efficient research for the benefit of the community at large.

ORGANIZATION

Australian Clinical Trials Alliance
T Symons Associates Pty Ltd

CONTACT

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ORGANIZATION TYPE

Professional Service
Other

IMPLEMENTATION DATE

2019

TOPIC

Patient Engagement

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CTTI RESOURCES

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