Colorectal Cancer Canada Leads the Charge to Promote Patient Engagement in Clinical Trials

CCC Adapts CTTI's Patient Group Engagement Recommendations and Resources to Create a Comprehensive Guide for Canada

SUMMARY

Colorectal Cancer Canada (CCC) is a patient led, non-profit organization on a powerful mission to change the lives of people living with colorectal cancer (CRC). Since 1998, they have worked to empower patients, increase awareness of CRC, advocate for better health policies, and improve research into the prevention, diagnosis, and treatment of the disease.

Colorectal cancer can refer to one of two types of cancer that occur in the gastrointestinal digestive tract. CRC is commonly caused by growths called polyps that form in the colon, the first five feet of the large intestine, or in the rectum which makes up the final six inches of the digestive tract. CRC is preventable and, if caught early, can be curable. However, it remains one of the leading causes of cancer deaths in Canada (1).

Clinical research participation can lead to improved treatment options but, in Canada, barriers to clinical trial access and a lack of patient engagement often limit research study enrollment. The team at CCC set out to improve options for colorectal cancer patients and change the clinical trial landscape by adapting CTTI's Patient Group Engagement recommendations and resources to fit the Canadian healthcare system.

GOAL(S)

As a colorectal cancer survivor, the president and CEO of Colorectal Cancer Canada knew from personal experience that receiving a CRC diagnosis was only the first challenge. Access to treatment options and research studies in Canada can sometimes be limited. What's more, he had experienced how a lack of patient input throughout the treatment development lifecycle can lead to issues with research study recruitment and adherence or result in medications that do not fit the needs of the patients.

In Canada, patients who want to try certain medications sometimes find that they are not yet available. Clinical trials can give patients greater access to potential new treatment options, but since there are fewer research studies conducted in Canada, they may not have access to a study. So, the CCC team knew that increasing the number of clinical trials conducted in Canada would bridge that gap. They also wanted to amplify patient awareness of the clinical trials actively enrolling and improve study site access so people could participate more easily.

Facilitating better patient engagement throughout the treatment development lifecycle by involving patient groups in the process would help to remove these barriers and improve clinical trial access, recruitment, and retention. Bringing such a wide range of collaborators together would integrate the patient perspective, streamline research processes, and enhance outcomes. But to make their goals a reality, the team needed a robust set of actionable recommendations and resources that key contributors could implement consistently.

CHALLENGES

For Canadians with colorectal cancer and other diseases, limited opportunities to participate in clinical research means that people who could benefit from a potentially life-saving treatment option may not receive it. The CCC team knew that incorporating patient groups and the patient perspective into the clinical trial continuum on a national scale was essential to reducing the barriers to clinical trial participation. Since there was no roadmap of policies and practices in place to facilitate this goal in Canada, they needed to create one. This would require a robust set of tools and recommendations partners could use to proactively guide the process. The guidelines would need to be expansive enough to bring together a range of teams including patient advocacy organizations, voluntary health agencies, health charities, nonprofit research foundations, public health organizations, research sponsors, CROs, and healthcare policymakers. Creating these guidelines from scratch would waste valuable time. Instead, the CCC team looked for a comprehensive set of recommendations and resources they could adapt and implement.

SOLUTION(S)

After an exhaustive, international search, CCC determined that CTTI's Patient Group Engagement work offered the best solution to help them improve the accessibility and frequency of research studies in Canada and enhance collaboration between research associates and patient groups throughout the clinical trial continuum. The team appreciated that CTTI's recommendations and resources are evidence-based solutions developed by experts and leaders across the clinical trials enterprise, including patients, industry sponsors, academic investigators, and other key contributors. During their analysis, the team determined that CTTI's collaborative approach to develop best practices that increase the quality and efficiency of clinical trials would allow CCC to adapt the Patient Group Engagement suite of recommendations to incorporate the voice of the patient into Canada's clinical development process.

TAKING ACTION

CCC pulled together a team of partners to create the Patient-centered Approach to Clinical Trials (PACT), an initiative to facilitate active patient engagement in cancer research. Since the Canadian and U.S. healthcare systems operate differently, the CCC and PACT team collaborated to adapt CTTI's patient engagement resources and recommendations to fit Canada's healthcare model. The most significant changes accounted for the effects of global decision-making on clinical trials and variances in the systems of regulatory and funding approvals in Canada.

The CCC and PACT team harnessed CTTI's Patient Group Engagement Across the Clinical Trial Continuum infographic to carve out a unique process and path to fit the Canadian cancer clinical research and development landscape. Then, they referenced CTTI's patient engagement recommendations to create a tailored set of guidelines for Canadian sponsors, industry, academia, and patient groups.

To help sponsors implement these recommendations and determine which patient groups to engage, CCC led PACT to create a set of tools based on some of CTTI's patient group engagement resources. They adapted CTTI's Patient Group Engagement Across the Clinical Trial Continuum resource which is designed to help research colleagues engage the patient voice and improve trial design and execution by establishing partnerships from the beginning of the research and development program. The CCC and PACT team also developed Canadian versions of CTTI's Assessment of Patient Group Internal Aspects and Assessment of Patient Group External Relationships tools which give sponsors insight into a patient group's priorities, programs, policies, financial strengths, and research before engagement begins.

Finally, the team developed the Canadian Cancer Clinical Trials Stakeholder Charter, which provides guidance and a framework to help research collaborators fully integrate patient groups in the clinical trial process as equal, participating partners. Its five guiding principles promote a patient centered approach, commitment to education and training, equal and independent partner collaboration, transparency and accountability, and high standards in data collection.

In an effort to facilitate wider adoption of patient engagement in clinical trials, the CCC and PACT team published an article, Developing a Patient Group Pathway Model to Accessing Cancer Clinical Trials in Canada, in *Current Oncology* detailing their work to adapt CTTI's recommendations and resources for Canada. They followed that publication with Patient and Patient Group Engagement in Cancer Clinical Trials: A Stakeholder Charter, outlining the team’s work on the charter.

IMPACT

By facilitating cross-team collaboration that incorporates patient groups, CCC's work benefits sponsors and researchers through improved development strategies, shorter timelines, lower costs, and higher approval rates for new treatment options. As a result, Canadian patients may receive faster access to innovative treatments and gain awareness of new cancer therapies.

After the development of the Canadian patient engagement recommendations and resources, the CCC and PACT team created the Patient-Centered Approach to Clinical Trials Conference. This annual event brings together international experts, advocates, and policymakers including members of CTTI who discuss and collaborate on new ways to facilitate patient engagement in clinical trials.

CCC's patient engagement work has also inspired other organizations to develop similar approaches to incorporate the patient voice into clinical research and share those efforts with others. One example involves a group of clinical trial networks who developed navigator tools that help connect patients to clinical studies – something they weren't doing before. The team has improved clinical trial access by encouraging the use of digital pathology and decentralized trials, helped researchers to reach new patient populations, and worked with sponsors to incorporate the voice of the patient in the early stages of clinical trial planning.

ADVICE

For the CCC team, developing their patient engagement recommendations and resources for Canada led to many synergies and opportunities they couldn't have imagined at the time. Although the initiative has been highly successful, fully integrating the patient voice into clinical trials requires ongoing work to overcome challenges and show research collaborators why the effort provides value.

"For key players with a vested interest in improving patient engagement in clinical trials, one of the biggest barriers is that research design and implementation involves many different teams," says CCC's president and CEO. "We have to work on bringing these groups closer together so that patients are involved from the earliest stages of planning all the way through the final phases of the research. Another issue is that clinical trials take a lot of time and no one patient group is big enough to be involved with all of them. One solution we've explored is allowing different patient groups to collaborate under the guidance of an advisor patient group."

"But no matter how you approach the challenges," CCC's president says, "you cannot just create a model for patient engagement and leave it at that. Starting with a solid approach like CTTI's patient engagement suite of recommendations is an incredibly important first step. From there, it takes ongoing work to bring the vision to reality. Bringing the patient voice into clinical research will not happen unless people want it to happen. When we work with research associates, we walk them through the literature that shows the benefits of engaging with patient groups. This includes the fact that it's more cost-effective in the long run. Incorporating patient preferences into research provides many clinical advantages as well, which is why the idea of patient engagement is gaining traction on a global scale. Hopefully, this momentum will help to streamline patient engagement implementation as people begin to see its potential to benefit researchers, policymakers, sponsors, and patients alike."

CITATIONS

(1) Canadian Cancer Society. Canadian Cancer Statistics Dashboard 2024. Available online: https://cancerstats.ca/ (accessed on 28 February 2025).

ORGANIZATION

Colorectal Cancer Canada

CONTACT

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ORGANIZATION TYPE

Patient

IMPLEMENTATION DATE

2016

TOPIC

Patient Engagement

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