

Fight CRC Boosts Study Enrollment by Improving Patient Engagement

Fight CRC Applies CTTI's Patient Group Engagement Recommendations

SUMMARY

Fight Colorectal Cancer (CRC), a patient advocacy organization, successfully partnered with patients to help them find relevant trials ongoing in the research community-- a win-win development that would boost trial enrollment while also empowering patients to take charge of their care via participation in clinical trials of interest.

GOAL(S)

As the power of the patient voice to drive better research is increasingly embraced, there is a growing wave of individual patients who are willing to speak up, be engaged, and provide insights to help the industry identify opportunities to improve both the patient experience and care. From the bench to the bedside, individual patients have the power to make a difference. One organization, Fight CRC, wanted to harness this power by training people who've lived through CRC to engage in research and take their knowledge and experiences into the research world.

CHALLENGES

In 2015, Fight CRC had an active community of patients and caregivers supporting its organization, but no formal support and training program for building a cadre of patient advocates and research participants. Many individuals who voiced an interest in getting involved in research to move the needle on CRC were left to blaze their own path forward and find ways to contribute. Unsatisfied with this approach, the organization's founder developed a division known as RATS (Research Advocacy Training and Support) to formalize a patient advocacy program that would train and support interested individuals on how to engage in the research process effectively, largely by sitting on study and review committees for various organizations. As part of RATS, Fight CRC set out to design a program for "clinical trial curators" that would help align interested patients with relevant trials ongoing in the research community and support the Fight CRC Clinical Trial Finder.

SOLUTION(S)

To build its team of clinical trial curators for CRC, Fight CRC referenced CTTI's Patient Group Engagement (PGE) recommendations. The recommendations highlight important roles for patient groups throughout all stages of the process. These solutions also provide best practices that sponsors, patient groups, and other stakeholders can use to ensure the relationship is mutually beneficial.

TAKING ACTION

As CTTI notes in its first PGE recommendation, effective patient engagement in research starts with building communication pathways between patients and sponsors. That's why Fight CRC partnered with a well-respected scientist who worked in the industry to provide the sponsor perspective across the effort. The individual brought a unique voice as both a stage IV CRC patient and a scientist and helped Fight CRC build a clinical trial finder (pulled from ClinicalTrials.gov) that aligned with the needs voiced by both the patient community and vision of the research community. Along with a health technology services company, the scientist and Fight CRC began to build a patient-facing tool that served as a central location for late-stage CRC patients to find relevant trials in which they might participate. One of the first challenges the team encountered was how to educate patients who would be curating clinical trials into the tool. Even with an eight-month training program in place to build awareness of the nuts and bolts of clinical trials, curators still often struggled with the jargon, nuance, and ever-changing parameters of the clinical research world. To mitigate this, Fight CRC set up regular online and in-person meetings to air confusion and questions with the Fight CRC research advocacy team. Through this forum, the team designed tools, educational materials, and other documentation to increase understanding and quickly bring curators up to speed.

IMPACT

RATS and the clinical trials curator program continues to thrive, with more than 40 individuals having completed the RATS training and six advocates having completed the curator educational process. Via Google Analytics, Fight CRC can confirm the trial finder is being utilized and the curation process is a success based on organic interactions with the tool.

ADVICE

Fight CRC firmly believes that every part of the cancer research system needs to engage patients, because they have a unique perspective as the ultimate consumers of the system's products. While Fight CRC did not build the RATS and Trial Finder programs directly off of the CTTI PGE recommendations, they used the recommendations as a touch-point to confirm they were on base at pivotal milestones. In addition, the evidence-based nature of CTTI's PGE recommendations served as a valuable proof of concept that the approach works and is necessary, which helped to increase the legitimacy of the work to those outside of the programs and across the research field. For others looking to implement a similar approach, Fight CRC recommends bringing the patient voice in as early on as possible. The Fight CRC team developed curator training and then amended as needed based on patient feedback. A more applicable approach, they suggest, would be to partner with patients as the training is designed. Others should also keep in mind that research is continually evolving, so any training program must evolve in kind. As new therapies and new criteria emerge, stay flexible and ready to adapt.

ORGANIZATION

Fight Colorectal Cancer Coalition

CONTACT

Reese Garcia ▢

ORGANIZATION TYPE

Patient

IMPLEMENTATION DATE

2015

TOPIC

Patient Engagement

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