

EMPACT

Methods for Improving Clinical Trial Awareness among Patients and Patient Advocates

A presentation by the EMPACT consortium

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An important question to ask when trying to improve minority accrual to clinical trial is:

How are we communicating as a team or institution to ensure all patients are considered as potential candidates for clinical trial enrollment?

In this session, we will present strategies for reaching patients directly, as well as through patient navigators and other patient advocates

What are some Strategies for Targeting Patients?

One way to improve patient knowledge surrounding Cancer Clinical Trials is to provide all new patients with generic CCT educational materials to introduce them to clinical trials or to simply enhance their understanding.

It can also be helpful to provide patients with a welcome letter signed by program leader and patient's oncologist letting them know clinical trials may be discussed during their visit. To minimize cost, letters can be included in existing new patient packets.

Overall, it is important to ensure all patients are systematically screened for eligibility, and eligible patients approached.

Strategies for Targeting Patients for Enrollment include the following:

Study and address cultural values, biases, and beliefs of patients that could potentially act as barriers to awareness & enrollment.

Discuss potentially eligible patients at team or group meetings. Strategies for reaching out to patients in-between the point of diagnosis and initial treatment are particularly useful.

Track screening, eligibility and approach rates and reasons for decline, by ethnic/racial groups.

Document the approach used; respond and adapt accordingly.

Additional Strategies for targeting patients include

...using culturally relevant educational materials. These may include print materials and educational video delivered passively in office waiting rooms, exam rooms, and other patient areas or more active delivery via clinical trial brochures handed out by staff. All cancer patients should be provided relevant information regarding clinical trials.

Strategies for Targeting Patients

For general Clinical Trial patient Education, educational videos may be useful. Some helpful resource links are provided:

- Participating In Cancer Clinical Trials: What You Need To Know
- Stories of Strength: Making the Decision to Enter a Lung Cancer Clinical Trial (Part 1 of 3)
- Stories of Strength: Making the Decision to Enter a Lung Cancer Clinical Trial (Part 2 of 3)

How can Patient Navigators be helpful?

Patient navigators have been successfully used to engage minority cancer patients in clinical trial participation. For example, oncology nurse navigators have been used to educate and recruit patients in community clinic settings.

Establishing a clinical trial navigation service that includes a free web- and phone-based system accessible to both patients and clinicians with access to a bilingual navigator has been shown to improve clinical trial awareness among patients. The ability to review available trials in a low-literacy, bilingual format with support may be an asset.

Case Study 1: Community-based Oncology Nurse Navigation Program at University of Southern California (USC), Norris

The oncology nurse navigator program implemented by USC Norris is an innovative approach for improving minority accrual to clinical trials—they facilitate access to cancer clinical trials in communities where minority patients live. The goal of the program was to increase clinical trial awareness and facilitate community-based recruitment of patients to cancer clinical trials.

The role of the research nurse was merged with that of a professional patient navigator to create an oncology nurse navigator.

The nurse navigator engaged Black cancer patients in the office of their community physicians. She informed patients about clinical trials and enrolled those that were eligible into cancer clinical trials sponsored by USC Norris.

Case Study 1: Community-based Oncology Nurse Navigation Program at USC Norris

The nurse navigator also facilitated physician participation in cancer clinical trials by keeping providers informed about available trials at USC Norris Cancer Center and reducing trial-related workload.

As a result, cancer clinical trials enrollment of black patients rose from 3% to 7% at USC Norris during the program period.

Case Study 2: The IMPaCT Program at the University of Alabama at Birmingham (UAB)

IMPaCT: Increasing Minority Participation in Clinical Trials.

IMPaCT patient navigators are integrated into the multidisciplinary coordinated care system for newly diagnosed cancer patients at the UAB Comprehensive Cancer Center.

These patient navigators work to educate new and returning minority patients about clinical trials prior to their clinic visit.

Case Study 2: IMPaCT Program at the University of Alabama at Birmingham

Patients are also assessed for any barriers that could hinder clinical trial enrollment and participation and navigators help patients problem-solve and overcome those barriers.

Encounters with patient navigators help enhance patient experiences, facilitate their introduction to clinical trials, and provide overall support.

Using Patient Advocates

Patient advocates can play vital roles in raising awareness about CCTs through peer education and support (much like a buddy system) and community outreach by sharing their own experiences/testimonials as prior patients.

Cancer patients, clinical trial participants, survivors and family members or other support persons can act as patient advocates to improve awareness about clinical trials. Patient advocate recruitment can be accomplished by simply inviting patients, including clinical trial participants, survivors, and family members to a meeting where the importance of clinical trial to the patient and community at large, is discussed. Volunteers from this meeting may later choose to act as community advocates.

Patient advocates may also be handpicked—certain patients may be selected to act as clinical trial advocates. Nurses or other providers at the practice or institution are often well-equipped to identify individuals who may be appropriate to serve in this capacity.

Case Study: Patient Advocates at the Carle Cancer Center (Urbana Illinois)

Patient advocates at Carle raise awareness about CCTs by working with the research team to coordinate seminars and other outreach projects. In this way, they educate patients and the community about clinical trials.

Patient Advocates at MD Anderson Cancer Center

In this video, longtime friends and MD Anderson patients Claudine James and Pamela Lewis discuss their involvement with the Breast Cancer Research Program, a national patient advocacy group funded by the Department of Defense.

The Ohio State University Cancer Center Clinical Trials: Pathways in the Quest

Clinical Trials: Pathways in the Quest is a multimedia presentation that introduces early-phase cancer clinical trials to the urban community. The presentation includes a 9-minute video and slide presentation that can be used in multiple settings.

Watch it online at this website address.

In summary: increasing clinical trial awareness for patients and patient advocate may be accomplished through increasing efforts to:

Provide educational materials on clinical trials to all new patients, systematically screen all patients and match with clinical trials, and using patient navigators and patient advocates.

Would you like to partner with EMPaCT in the work of improving clinical trial awareness?

For more information and opportunities to implement and evaluate the strategies presented, please refer to the following pages in this Training Course:

Resources for Improving Clinical Trial Awareness

Review & Rate Existing Resources

Important Literature on Methods for Improving Clinical Trial Awareness and Enrollment

This presentation has been brought to you by EMPACT, enhancing minority participation in clinical trials.