Michigan Cancer Healthlink for Equity in Cancer Care – Cancer Action Councils


Project description and outcomes

The Karmanos Cancer Institute (KCI) Michigan Cancer Healthlink for Equity in Cancer Care initiative is a region-wide coalition that addresses cancer related needs in the Metropolitan Detroit area. Several cancer action councils (including Western Wayne, Conner Creek, KCI, ACCESS of Dearborn, and LGBT Detroit) have been developed to empower cancer patients, caregivers, survivors and community members to address cancer issues in their communities through increased engagement in cancer research.

Cancer Action Councils are groups made up of community members and representatives from community-based organizations who apply their knowledge about local cancer issues to improve the lives of cancer patients, survivors, and caregivers within their communities. The council members represent the various ethnic and social groups living in their neighborhoods.

The project aims for KCI Michigan Cancer Healthlink for Equity in Cancer Care are:

- Increase capacity among community stakeholders
- Build trusting and collaborative relationships between community stakeholders and cancer researchers
- Identify cancer specific Patient Centered Outcome Research priorities based on the Cancer Action Councils input

In order to recruit members, nominations were solicited through Karmanos Cancer Institutes’ partnering community-based organizations along with self-nominations. A Detroit HealthLink website was also created (www.DetroitHealthLink.org) through which interested individuals could apply online. Individuals were formally invited to become a CAC member based on their expressed interest in advancing cancer research, demonstration of prior community participation or activism, understanding of the role of CAC member, and willingness/ability to attend CAC meetings over the course of 18 months.

There were two types of CAC members. Core members were expected to be fully involved in all meetings and activities over an 18-month period. This type of member was eligible for a $1000
stipend. Associate members were individuals willing and interested in playing a role in setting cancer care and research priorities in their community but may not be able to attend all activities and meetings. They could also be employees of non-profit agencies with goals aligned with HealthLink goals, such as the American Cancer Society.

The CACs participated in a process of evidence prioritization in which they identified and prioritized research topics. This process began with the identification of critical needs along the cancer care continuum that they observed in their communities and was consistent with the steps in the Tufts Clinical and Translational Service Institutes Engaging Stakeholders in Comparative Effectiveness Research program, specifically, the identification of the mission, vision, and objectives for research. This step was followed by the identification and prioritization of research topics and research questions.

A key strategy in this process was concept mapping. Steps in concept mapping included the following: 1) starting with a main topic or idea in the center of the map; 2) adding an idea that connects to the main topic; 3) taking these ideas to branch off even more; 4) using one branch of inquiry on the map to help form a question. CAC members worked in small groups to collaboratively generate concept maps.

The program started with three Cancer Action Council locations: Karmanos Cancer Institute, Conner Creek (hosted by Voices of Detroit Initiative) and Inkster (hosted by Western Wayne Family Health Centers). The KCI CAC identified 7 research domains; Conner Creek CAC identified 10 research domains and Inkster CAC identified 11 research domains. Each then selected 4 research domains that were identified as the leading priorities for their group and in turn, developed specific patient-centered outcome research questions relative to these domains.

The efforts of Detroit HealthLink are housed within KCI’s newly established Office of Cancer Health Equity & Community Engagement. Detroit HealthLink for Equity in Cancer Care is now a part of Michigan Cancer HealthLink which covers KCI’s 46-county catchment area in the state of Michigan. New CAC members are currently being recruited for the next phase.

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