Category: Community-Engaged Data Collection, Analysis, and Dissemination – Work in Progress – Student/Trainee

Harmonized Measures for NCI-Designated Cancer Center Catchment Area Assessments

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1. Background

Comprehensive Cancer Center designation through the Cancer Center Support Grant from the National Cancer Institute (NCI) comes with a requirement for the Community Outreach and Engagement (COE) to define and describe their center's catchment area, including geographic, demographic, and health characteristics. Each cancer center is tasked with defining their methods to assess cancer-relevant factors and needs in their catchment area. National and state-level data for cancer incidence, mortality, and clinical trial enrollments are readily available. However, data on social and behavioral factors are not collected in a standardized way at local levels. While not mandatory, many cancer centers choose to do a quantitative survey to gather information from a representative sample across their catchment areas. However, the survey design, including measured domains, sample sizes, survey delivery, and analytical approaches may be different across cancer centers.

2. Goals

Our initiative grew out of a regional data conference called Midwest Data Partners in February 2025. From the meeting, a smaller working group representing the states of Iowa, Kansas, Nebraska, Missouri, and Arkansas formed to produce a proposed set of standardized measures. Here we describe the process for selecting proposed domains for measurement, the domains proposed, and advantages of standardizing assessments.

3. Solutions and Methods

The working group developed a set of core survey items and domains that were designed to be incorporated into existing data collection efforts at individual cancer centers across the Midwest Data Partners. Where possible, existing, validated questions were used. The results are designed to be action-oriented in that they directly inform COE activities and research priorities for their cancer center.

4. Outcomes

The chosen domains were:

- Sociodemographic Measures
- Demographics
- Information Seeking, Knowledge, Attitude, and Behavioral
- Cancer Risk Factors, Screening Behavior
- Cancer Beliefs
- Diagnosis, Treatment
- Genetic Testing
- Clinical Trials
- Access to Care
- Physical and Mental Health

Current data gathering initiatives are either underway or in the planning phase at each cancer center in the working group. These cancer centers will collect their survey results and report their results to the group, noting which domains were helpful or not to their center's needs.

5. Lessons Learned and Future Directions

Members of our regional collaboration group appreciated efforts to standardize data collection and the action-oriented approach. Each group member has been tasked with gathering catchment area data, is new to the process, and is willing to collaborate in developing their data collection tool. A future goal of this initiative is to gather a nationally representative group to develop and publish a core set of questions and domains for our catchment area surveys.