

# CRN Data Request Instructions

## Background

The Preparatory-to-Research (PTR) form should be reviewed, completed, and submitted by any investigator who wishes to obtain data from the Cancer Research Network (CRN). The CRN Coordinating Center (CC) and Informatics Core (IC) are tasked with facilitating PTR and other requests for CRN data. Both the CC and IC will review each request with respect to feasibility, priority, effort, and consistency with CRN objectives. The basic data request process is as follows:

### 1. Requester submits completed data request form to CC for approval

The CC will review all submissions within five working days and, if necessary, notify the requester of any general concerns about the request.

### 2. Upon approval, CC forwards request to IC for review

The IC will review all requests and initiate contact with the requester within 10 working days of receipt. This stage of the process may involve email and/or telephone discussions as the IC attempts to clarify exactly what the requester needs.

### 3. IC prepares requested data

After verifying the desired outcome of the data request, the IC programmer will determine which of three methods should be used to fulfill the request. Each method has various pros and cons, which are summarized below.

#### Cancer Counter

The Cancer Counter application allows a single IC programmer to quickly generate simple frequency and crosstab tables on incident primary tumors across all CRN sites. Counts can be limited and stratified by: tumor location, behavior, and morphology; CRN site; race and ethnicity; stage (AJCC or SEER Summary); vital status; gender; diagnosis year; and age at diagnosis. The Cancer Counter does not facilitate linkage to medical utilization data (e.g., related diagnoses, procedures, drug exposure), and the underlying data are only updated by the participating CRN sites every one to two years.

Once the details of a Cancer Counter query have been finalized, results can usually be obtained in less than one week.

#### PopMedNet Distributed Query Tool

The CRN supports a rapid-response querying tool that facilitates quick answers to simple questions about medical utilization across CRN sites. The tool provides nine prevalence, three incidence, and eight most-frequent utilization queries, each of which can be stratified by setting (e.g., inpatient vs. outpatient), predefined age group, sex, and year.

Prevalence queries can be used to summarize *overall* enrollment, HCPCS procedures, ICD-9 diagnoses (3-, 4-, and 5-digit codes), ICD-9 procedures (3- and 4-digit codes), and pharmacy dispensings (by drug class and generic name).

Incidence queries can be used to count *new* ICD-9 diagnoses (3-digit codes) and pharmacy dispensings (by drug class and generic name).

Most-frequent utilization queries can be used to summarize the most frequently observed HCPCS procedures, ICD-9 diagnoses (3-, 4-, and 5-digit codes), ICD-9 procedures (3- and 4-digit codes), and pharmacy dispensings (by drug class and generic name).

Unlike the Cancer Counter, the Distributed Query Tool cannot be used to access all CRN sites' data at once; instead, queries are designed by a single IC programmer and then distributed to selected sites to be run locally against proprietary data. Individual CRN site programmers upload query results via the PopMedNet website.

Once the details of a Distributed Query request have been finalized, results can usually be obtained in one to two weeks.

#### **Custom SAS Program**

When an approved data request cannot be fulfilled via the Cancer Counter or PopMedNet Distributed Query Tool, an IC programmer can develop a custom SAS program to prepare the requested data. The program can then be distributed to participating CRN sites to be run by local programmers, who later return results to the initiating IC programmer. Any requests that necessitate a custom SAS program are subject to additional review and prioritization to ensure the best use of limited programming resources.

The custom SAS program is the most flexible but also the most time-consuming method of obtaining CRN data. Once the details of a custom SAS program have been finalized, results can usually be obtained in three to four weeks: i.e., one to two weeks for program development plus two weeks for CRN site programmers to return results to the IC.

#### **4. IC compiles results and returns to requester**

Upon receiving requested data from the Cancer Counter, PopMedNet Distributed Query Tool, or a custom SAS program, an IC programmer will compile the results and return them to the requester within five working days.