

Draft Statement of Work
Technical Assistance for Cancer Surveillance

A. Objectives

The objective of this contract is to enhance national cancer surveillance efforts in three specific areas:

1. Strengthen the national capacity for collecting, analyzing, and using comparable cancer registry data for cancer surveillance and research.
2. Develop and improve methods for assessing the quality and comparability of cancer registry data. This includes, but is not limited to timeliness, completeness, and accuracy.
3. Improve the efficiency and quality of registry operations through promoting established standards, disseminating technical information, and facilitating collaboration among Federal, state, provincial and local registry professionals.

B. Statement of Work

The Statement of Work is divided into sections which provide for the day to day workings of this contract and cover the areas of 1) project management and administrative support; 2) support for technical committees and workshops; 3) conduct and coordination of special studies and reports; and 4) registry operations.

Independently and not as an agent of the Government, the Contractor shall furnish all the necessary services, qualified personnel, material, equipment and facilities, not otherwise provided by the Government, as needed to perform the following Scope of Work.

Task Area 1: PROJECT MANAGEMENT AND ADMINISTRATIVE SUPPORT

The Contractor shall provide administrative support for the steering committees, workgroups and task forces with activities supported by this task order.

The Contractor shall interact on a regular basis, either by phone or personal contact, with the Contracting Officer's Representative (COR) NCI staff, in order to report on status of tasks, discuss issues which need to be resolved, and any other contract matters.

Task Area 2: SUPPORT FOR TECHNICAL COMMITTEES AND WORKSHOPS

A. Steering Committees, Ad Hoc Committees, Other Special Committees

The Contractor shall establish and maintain a network of steering committees, work groups and task forces which support the development and promotion of uniform data standards for cancer registration; education and training; certification of population-based registries; aggregation and publishing of data from central cancer registries; and promotion of the use of cancer surveillance data and systems for cancer control and epidemiologic research, public health programs, and patient care to reduce the burden of cancer in North America. The Contractor shall have policies and procedures in place to guide the structure, mission, goals, and organization of all groups which ensure efficiency, collaboration, and effectiveness.

The Contractor shall:

1. Standardization and Registry Development

- Assess methodological issues as they apply to the policies, procedures and operation of central cancer registries and development of operational models and standards for the policies, procedures, and operations of central cancer registries.
- Facilitate peer-to-peer exchange of information on methods, procedures, and policies and practices among registries.
- Provide a formal mechanism for reviewing and recommending proposed changes in data codes and/or the addition of new items submitted by members to ensure that data remain comparable among central registries; provides a formal mechanism for reviewing and recommending edits of data items.
- Address the syntactic and semantic interoperability of cancer registration standards with national standards and electronic health records.
- Develop the format for exchange of data among members and for developing standards to ensure the security and accuracy of transmitted data.
- Work to develop plans for the future of cancer registries by monitoring trends in bioinformatics, data linkage, cancer surveillance etc. and incorporating important policies and procedures into cancer registry management and operations.

2. Data Use and Research

- Gather, review, and consider data from member organizations for publication.
- Identify issues related to the release of various types of data by central cancer registries and provides recommendations and guidelines on these issues, including confidentiality.
- Promote the dissemination, interpretation, and use of cancer registry and cancer surveillance data.

- Evaluate member data submissions; determine measures for identifying and assessing data quality, including objective certification criteria and standards for research data; re-examine existing criteria as necessary and implement an annual process to evaluate data collected by central cancer registries.
 - Address the appropriate uses of geographic information systems (GIS) in cancer registry practice.
 - Organize and implements a peer-review process for scientific work by members or researchers that results in manuscripts for public dissemination.
 - Maintain a review board to review all projects that are sponsored by the Contractor or that use data files prepared from the aggregation of registries' data through the annual Call for Data or through special studies using criteria to protect human subjects.
3. Professional Development
- Determine the educational needs of the cancer surveillance community for cancer registry operations including, but not limited to, the offering of short-term training courses, webinar series and modern learning techniques.
 - Support an annual conference that provides educational and networking opportunities to the cancer surveillance community.
 - Address issues of cancer registry staff on the development of appropriate skill sets.
4. Strategic Alliances
- Ensure coordination among all organizations regarding the development and implementation of major data items, standards, and procedures; provide a forum for policy-level discussion of transitions to electronic medical records systems, and other developments outside the direct control of the cancer registry community.
 - Strengthen relationships with Sponsoring Member Organizations and existing partners, while establishing new alliances with key organizations.
5. Communications
- Disseminate information regarding breakthroughs in cancer surveillance, research and related topics via web-based communications, newsletters, press releases, press conferences, social media where appropriate, and oversight and direction of the Contractor's website.
 - Serve as a facilitator for the cancer surveillance community, offering opportunities to freely exchange ideas, develop best practices and provide feedback to standard setters, other registries and stake holders.

B. Workshop Support

1. Technical Workshops

The Contractor shall organize, manage, and assure effective conduct of workshops on technical topics and issues identified through the organization's steering committee and workgroup structure, for example, workshops on statistical methods and approaches for cancer surveillance, registry operations, training/education needs, leadership, interoperability issues, etc. The approach should consist of a planning group; review and commentary obtained from Sponsoring Member Organizations and, as appropriate, other organizations or entities with a vested interest in the technical matters; involve appropriate experts for the faculty and be accessible to all cancer registry members; virtual, web-based and/or video satellite training sessions timed to optimize effective dissemination, as well as reinforce and retain technical information by the participants; employ technology relevant for professional education; provide feedback through a variety of mechanisms to the constituents; and increase the national capacity to use more advanced and/or current standard procedures in registry operations and in reporting.

2. Communications and Collaboration

The Contractor shall support a variety of methods to communicate with the cancer surveillance community via print media, web-based strategies and other emerging technologies for the dissemination of critical and relevant information to the cancer surveillance community, population-based cancer registries, and material deemed important by the NCI. The Contractor shall support the enhancement of data quality through programs that promote collaboration and communication between central cancer registries and state/province and local tumor registrar associations, reporting sources, key stakeholders or other groups of cancer registry professionals.

The Contractor shall organize and run workshops or retreats to foster leadership, team building, and work products to address the goals and objectives of the cancer surveillance community. These would include meetings of the Contractor's leadership, sponsoring member organizations, external experts, Board, and Chairs, including liaisons and sub-committee and task force leaders.

The Contractor shall build and enhance ties with cancer surveillance organizations in the international arena. This may include presentations at international cancer registry meetings, collaborative articles, dissemination of information about cancer registry documents and helpful training tools to the international community, harmonization of data standards and registry processes, and promotion of the Contractor's website as a vehicle for international access to these materials.

Task Area 3: SPECIAL STUDIES AND REPORTS

The evolving field of cancer surveillance may lead to the need for special requests for additional investigations which require resources. The Contractor may also be required to actively participate in collaborative efforts that use high quality population-based cancer registry data and prepare technical and scientific reports (e.g. the Annual Report to the Nation). Areas of focus include, but are not limited to, Data Use and Quality, Research Metrics and Methods, and Social and Economic determinants of disease.

A. Data Use and Quality

The Contractor shall identify and coordinate a series of special studies required to develop procedures and techniques applicable to the release of the Contractor's pooled data files and their use in research and in public health surveillance. The approach shall include the following elements: (a) assemble a broad-based representative group(s) to plan the series of studies, refine the study objectives, define critical elements of the study protocols, select and subcontract for NCI authorized projects based on objective criteria, and evaluate study findings through an interactive process that is designed to improve future studies and establish standards for data use; (b) disseminate study results using a variety of mechanisms ranging from web-based technology to peer-reviewed publications; and (c) through a participatory process involving major organizations involved in cancer surveillance research, develop recommended policies, procedures, and products relevant to best practices for release of pooled cancer registry data files that balance issues of confidentiality, comparability of data items for pooled analyses, and access to cancer surveillance data by researchers and the public. Projects will focus on issues such as, but not limited to: data quality and data use issues of the Cancer In North America (CINA) Deluxe file, simplifying and improving access to data in multiple registries by researchers, and addressing issues of data quality across registries including duplicate reporting based on jurisdiction. This activity may offer an opportunity for junior investigators to work with more senior surveillance researchers and epidemiologists in a mentoring capacity and promote use of the CINA Deluxe file.

B. Research Metrics and Methods

The process and approach to conducting these studies should conform to those established for the special studies described in Item A, recognizing that implementation external to the special studies occurs primarily because of constraints imposed by time, access to the data base, and/or concerns related to data validity. This work includes, but is not limited to studies to develop, refine, improve and validate metrics and methods that are useful in measuring completeness, timeliness and quality of data collected by

population-based cancer registries. Methodological approaches include empirical, statistical, ecological, and other quantitative research techniques related to characterizing attributes and performance of these metrics for populations and subgroups defined by geography time, and/or socio-demographic/socio-economics, or other factors.

The Contractor shall develop methods and procedures for linkage of confidential registry databases with ecological, epidemiological and clinical databases and research cohorts that enhance the utility of these research and public investments for advancing cancer epidemiology, cancer surveillance and cancer control and reduction of disease.

C. Socio-Demographic/Socio-Economic

Of specific interest are studies that investigate data standards and quality related to collecting, computing, and reporting cancer rates for diverse socio-demographic and socio-economic populations (e.g., racial and ethnic minorities, socio-economic status defined groups, urbanicity, etc.). The process and approach to conducting these studies should conform to those established for the special studies described in Item A. Specific interest should be given to proposals related to information on assessing procedures and practices used by registries to collect and process data on population subgroups [e.g., status of practices, names list, standards that are region-specific], measure the reliability and/or validity of registry data compared to self-reported measures and/or ecological data, promote the use of standards that improve the quality of data on population groups and self-reported data, and assess changes and/or quality in socio-demographic and socio-economic data quality collected and reported by cancer registries.

Task Area 4: REGISTRY OPERATIONS

A. Best Practices, Guidelines/Standards & Dissemination

The Contractor shall develop, implement, and disseminate technical procedures, guidelines and standards in cancer registry operations that advance the field toward more consistent, efficient, and effective performance. The Contractor shall coordinate a series of strategic activities designed to develop, codify, and promote guidelines pertinent to effective and efficient operations of population-based cancer registries. Development of these guidelines (i.e., registry operations standards) should be built upon systematic identification and assessment of various “models” in use by diverse central population registries. The scope of these models includes, but is not limited to, staffing patterns, use of bio-informatics technology and other information systems, timing and flow of data from multiple sources, data management and quality control, reporting data and communications, integration with other public health and research programs, and liaison with the community and other entities that derive a benefit from cancer surveillance. Approaches to development of guidance to the cancer surveillance community derived from best practices include, but are not limited to, convening expert panels, workshops

and use of the Delphi method to prepare experienced-based manuals and position papers, conduct focus groups, develop distance learning and dissemination of educational materials, and subcontract for small-scale special studies that assess effectiveness in one or more components of registry operations. Implementation of these activities should include a steering committee with broad representation from relevant major professional and technical organizations, and recognized experts and leaders in the field of cancer registry operations. The Contractor shall ensure adequate planning and participant preparation time, as well as review and commentary from sponsoring member organizations, and as appropriate, other organizations with a vested interest in the technical matters.

B. Methods

The Contractor shall support studies critical to refining and promoting standards for registry operations methodology, including evaluation of comparability of methods for consolidation of records from different sources on the same cancer to promote and advance best practices related to quality improvement, recommendations processing different types of incomplete cancer records, and the use of emerging bioinformatics technologies and data systems.

C. Consensus of Standards in the U.S., Canada, and other countries

The Contractor shall work with the Canadian provinces and national organizations to promote and implement registry standards in Canada and other countries through the promotion of uniform data definitions and classification, promotion of comparable data sets, and expansion of training opportunities, information, and materials. The process should take into consideration the extent to which international consensus on standards is desirable and achievable.