

Objectives and Advantages:

Objectives of the Service

- Enhance collaborative research efforts within UPCI Centers of Excellence
- Monitor tissues and/or data use practices via a web-based tracking tool
- Assure IRB related documents contain required elements associated with use of the Service
- Centralize training and management of the Brokers

Advantages for Using the Service

- Direct access to a robust set of standardized data associated with cases of cancer, including: demographics, staging, treatment and outcomes
- De-identification of PHI facilitates retrospective research and eliminates the need for patient consenting processes when no clinical intervention with the patient is required
- Collaboration with Health Sciences Tissue Bank (HSTB) facilitates access to data annotation of precious tissues and other media
- Close communication with the IRB and Honest Broker Service management team facilitates guidance for completing required research application



Submitting a Request

For Data ONLY, contact:

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For Tissue and Data, contact:

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Service Fees

Unless direct funding is provided to the Registry for resource support, service charges may apply. Fees are discussed as a formal component of the request process.



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In partnership with the
Department of Biomedical Informatics (DBMI)
University of Pittsburgh
<http://www.dbmi.pitt.edu>

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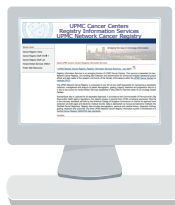
<http://CancerRegistryNetwork.UPMC.com>

Network Cancer Registry Information Services



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UPMC Network Cancer Registry



The UPMC Network Cancer Registry is comprised of full time staff responsible for maintaining a standardized data system designed for the collection, management and analysis of patient demographic, diagnosis, staging, grading, treatment and progression data on patients having a diagnosis of cancer. It is also a key resource for our collaborative **Honest Broker Services**, established in May 2003 to meet the needs of our oncology research environment at the UPMC Cancer Centers.

Facilities

The Registry currently includes data on patients from all UPMC managed facilities, including hospital-based facilities, stand-alone cancer centers and hematology / oncology offices. The Registry was expanded to community-based UPMC Cancer Center locations in January 2004; however, most datasets were established in the 1980s and early 1990s.

Standardized Data

More than 250 standardized data elements are captured cases having reportable diagnoses in accordance with **Commonwealth of Pennsylvania's Department of Health** regulations. Due to these public health agency regulations, this registry process is exempt from HIPAA patient consenting processes. Most facilities within the Registry also adhere to the voluntary standards set forth by the **American College of Surgeons Commission on Cancer** for cancer program approvals. Primary sources for data extraction are both paper and electronic medical records. Data is abstracted via manual and electronic methods into the cancer registry database by certified cancer registrars. Registry data include demographics, limited personal and medical history, diagnostic findings, primary cancer identification, staging, grading, treatment and outcomes. The entire UPMC Network Cancer Registry information system is based on the **North American Association of Central Cancer Registries (NAACCR) data standards**.

Casefinding Function

This Registry is required to report at least 97% of all eligible cases. This rigorous process of case identification is achieved via a variety of mechanisms including:

- **Hospital Information Systems:** Inpatient, outpatient and same day surgery episodes of care having primary or secondary diagnoses of specified billing codes are fed to the Registry for review on a monthly basis. (*ie. Medipac, EPIC*)
- **Pathology Systems:** Specimens having a specified diagnosis code within the neoplasm range of the SNOMED coding system are fed to the Registry for review on a weekly basis. (*ie. CoPath*)
- **Radiation Oncology:** Treatment and consultation reports are sent to the Registry for review on a daily basis. (*ie. VARiS and transcription services*)

Abstracting and Follow Up Functions

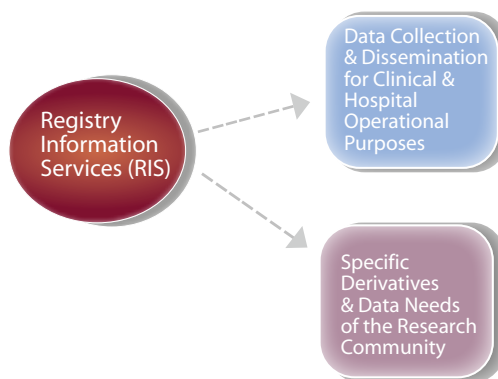
Registry staff access electronic data sources (MARS, EPIC, Medipac, CoPath, transcription services, Cerner PowerChart, Access Anywhere, etc.) as often as possible to capture the required and optional data elements related to demographics, diagnosis, extent of disease and outcomes. Depending on the facility, paper-based records may be used to capture data not available in electronic form. Data is coded according to NAACCR and other standardized coding systems based on nationally and internationally established rules and entered into standardized cancer registry software. The Registry has utilized **IMPAC MRS** registry software since 1998 for data capture. Outcomes data is essential to clinical and research needs. Every effort is made to capture recurrence, subsequent treatment, cancer status and vital status for the duration of the patient's lifetime using a variety of contact sources.

Use of Registry Data

There are more than 230,000 records in the Registry with over 23,000 new cases accessioned each year. With the addition of our Honest Broker Services in mid-2003, the requests for Registry data have continued to increase. The Registry filled close to 600 distinct requests in 2006 with 60% related to preparations for research or non-human subjects (de-identified) retrospective research and the other 40% related to clinical program needs.

Registry Information Services (RIS)

Registry Information Services (RIS) is an emerging division of UPMC Cancer Centers. This Service is separated into two distinct sub-divisions within the UPMC Network Cancer Registry, one handling data collection and dissemination for clinical and hospital operational purposes and the other dedicated to specific directives and data needs of the Centers of Excellence research community within UPMC Cancer Centers and University of Pittsburgh Cancer Institute.

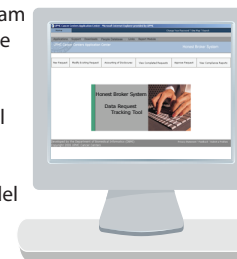


Disease Specific Research Registry Specialists

Registry Information Services (RIS) consists of disease specific research registry specialist positions developed based on research needs and funding made available by leadership of the UPCI Centers of Excellence. These positions assume responsibility for a portion of general registry functions, however, they serve primarily as the source for data needs related to preparations for research, retrospective non-human subject research and IRB approved research initiatives. Currently, RIS includes positions covering UPCI Programs in Head and Neck, Thoracic, Melanoma / Skin, GI / Hematology and Breast / Gynecologic malignancies.

Collaborative Honest Broker Services

The Oncology Informatics Program of UPMC Cancer Centers took the initiative of developing the first cross-divisional, collaborative honest broker service. The initial application was submitted in April 2003 and continues to be touted as a "gold standard" model by UPMC and the University IRB for optimal collaboration.



Mission of the Service

This Service ensures compliance with specific regulatory agency guidelines, including those of the Office of Human Research Protection (OHRP) of the Department of Human Services (HHS), the Health Insurance Portability and Accountability Act (HIPAA) and the UPMC / University of Pittsburgh Institutional Review Board (specifically policies and procedures established for the release of information, specifically protected health information (PHI), involving data stored in applications developed, managed and/or utilized by UPMC Cancer Centers / UPMC clinicians and researchers through de-identification of PHI).

Members of the Service

This Service was developed for the combined Department of Biomedical Informatics (DBMI) and Center for Pathology Quality and Healthcare Research. These facilities currently have faculty, staff and graduate students who perform research as interrelated groups. Included in the Service are the Health Sciences Tissue Bank (HSTB), Pathology Tissue Microarray Shared Services, Clinical Outcomes, and Registry Information Services (UPMC Network Cancer Registry).

<http://CancerRegistryNetwork.UPMC.com>