

## Frequently Asked Questions about Medical and Public Health Registries

### What is a registry?

A registry is an organized system for the collection, storage, retrieval, analysis, and dissemination of information on individual persons who have either a particular disease, a condition (e.g., a risk factor) that predisposes to the occurrence of a health-related event, or prior exposure to substances (or circumstances) known or suspected to cause adverse health effects.

### What are the uses of information in registries?

In public health and medicine, there are many uses for the information collected in registries. These include:

#### A. Estimating magnitude of a problem

Registries of blind persons are used to determine the extent of blindness within a population that is due to preventable or treatable conditions, such as diabetic retinopathy or cataracts.

#### B. Determining the incidence of disease

Registries that collect information on all cases of brain cancer within a defined region are used to calculate tumor specific cancer-rates, information that can be used for investigating suspected cancer clusters.

#### C. Examining trends of disease over time

Registry data have documented the rapid increase in the occurrence among women of lung cancer, now the most frequent cause of cancer in this group.

#### D. Assessing service delivery and identifying groups at high risk

Immunization registries are used to document the extent of vaccine coverage within a community and to identify groups with suboptimal coverage who are at increased risk for disease outbreak and transmission

#### E. Documenting the types of patients served by a health provider

Many hospitals maintain tumor registries of patients treated at their facilities

#### F. Conducting research

Registries have several characteristics and operating practices that make them conducive to conducting certain types of research, such as:

##### 1. Estimating survival analysis

Because registries frequently collect information about patients after their initial registration, these data can be used to examine the natural history or survivorship of a particular group. Information in cancer registries can be used to examine whether certain underlying factors (risk factors) or treatment modalities influence length of survival (and quality of life).

##### 2. Evaluating health effects of specific exposures

Exposure registries have been established to identify and register persons living near toxic waste sites who may have had low-level exposures to certain substances (e.g., benzene) that are known or suspected to cause long-term adverse health effects.

### 3. Investigating etiologic hypotheses

Because many registries are designed to capture all cases of a particular disease, the registries serve as a useful means for identifying or ascertaining cases for use in a case-control study. To investigate the association between service in Vietnam and risk of subsequent cancer, registries were used to identify persons with selected cancers, and the prior experiences (exposures) of these "cases" were compared with those of appropriately selected persons serving as "controls."

#### F. Serving as a source of potential donors

The National Bone Marrow Registry maintains information on individuals who are willing to be bone marrow donors if a suitable recipient is identified.

#### G. Serving as a source of potential participants in clinical trials

Commercial services will register persons with certain medical conditions who wish to be considered for enrollment in clinical trials.

### **What are some of the distinguishing characteristics of registries?**

Registries represent only one of many different sources of data available to provide public health officials with the information needed to assess and monitor the health of the population. Other sources include the legally mandated public health surveillance systems for notifiable diseases, electronic reports from laboratories, hospital discharge records, surveys, and vital statistics. Registries have several characteristics that, collectively, distinguish them from these other sources of data. Characteristically, registries:

- Focus their efforts on a particular disease (hemophilia), group of similar diseases (cancer), or specific exposure (a toxin like PCB found in hazardous waste sites)
- Collect data on individuals from multiple sources (physician records, hospital summaries, pathology reports, vital statistics)
- Ascertain cases actively by combing through likely sources for referrals (examining hospital discharge records for evidence of birth defects)
- Conduct follow-up investigation and data collection on persons enrolled in the registry (determining the status of cancer registrants by examining vital records)
- Incur high costs (actively seeking and linking data from multiple sources over time is expensive)

### **Who operates registries?**

Registries are operated by many different entities, including:

- The Federal government: (the National Exposure Registry)
- State governments: (registries of persons diagnosed with sexually transmitted diseases, such as gonorrhea)
- Universities: (the Surveillance, Epidemiology, and End Results (SEER) cancer registries, supported by funds from the federal government)
- Groups of hospitals: (a registry of persons diagnosed with primary pulmonary hypertension, assembled by researchers to understand the risk factors and causes of this rare medical condition. Registries such as these may be supported in part by federal research funds, as well as other organizations, such as pharmaceutical companies)
- Non-profit organizations: (the United States Eye Injury Registry)
- Private groups: (transplant registries, or registries that examine use of drugs during pregnancy)

# What are some examples of registries?

## A. The National Exposure Registry

The National Exposure Registry, operated by the Agency for Toxic Substances and Disease Registries (ATSDR), is designed to identify and enroll persons who may have been exposed to a hazardous environmental substance, and to conduct follow-up monitoring of these persons. The purpose of the National Exposure Registry is to aid in assessing the long-term consequences of low-level exposures, such as those from waste sites, on the health of the general population. After a particular chemical (e.g., dioxin) and study sites are selected, all persons at a site with a documented exposure to the chemical are invited to participate in the registry. Currently ATSDR has enrolled about 10,000 persons in three subregistries that are focusing on exposure to trichlorethylene, dioxin, and benzene.

## B. The Metropolitan Atlanta Congenital Defects Program

The purpose of this registry, operated by CDC, is to monitor the occurrence of serious malformations in a defined population for changes in trends and unusual patterns that may suggest avoidable risk factors; and to maintain a case registry for epidemiologic and genetic studies. All births within the Atlanta metropolitan area (about 40,000 per year) are monitored, and information is collected on about 800 cases each year. This registry has provided cases for a large number of important epidemiologic studies (e.g., demonstrating the protective effect of peri-conceptional use of folic acid on risk of neural tube defects). The registry has served as a prototype for methods of active case ascertainment.

## C. Immunization registries

Immunization registries, supported by both federal and state funds, are currently being established in many states. These registries are computerized systems that will consolidate and record vaccination histories of numerous individuals--and that will have information for an entire community--on the basis of information provided from a large number of health care providers. The purpose of these registries is to: a) assist providers in evaluating the immunization status of their patients; b) facilitate the issuance of vaccination reminders to patients by providers and public health officials; c) permit public health officials to assess vaccination coverage within a community and identify any subgroups who may need targeted interventions.

## D. Surveillance, Epidemiology, and End Results (SEER) Program

The SEER Program, supported by the National Cancer Institute, collects cancer data on a routine basis from designated population-based cancer registries in nine areas of the United States. The goals of the SEER program are to: a) report estimates of cancer incidence and mortality in the U.S.; b) monitor annual cancer incidence trends to identify unusual changes in specific forms of cancer in population subgroups; c) provide ongoing information on clinical presentation, modifications in therapy, and subsequent influence upon survival; d) promote studies to identify factors that may be modified by cancer control interventions (e.g., screening practices).

## E. Insulin-dependent Diabetes Mellitus Registries

Currently there are over 20 Insulin-dependent diabetes mellitus (IDDM) registries in the United States and throughout the world. In the U.S., these registries are frequently supported by federal research funds through the National Institutes of Health. The purpose of these registries is to determine the incidence of IDDM in defined populations, and to identify persons for subsequent enrollment in case-control studies and other research projects. Active case finding procedures use hospital and other medical records to identify potential registrants.

## F. The United States Eye Injury Registry

The United States Eye Injury Registry (USEIR), a nonprofit organization sponsored by the Helen Keller Eye Research Foundation, is a federation of state eye registries that uses a standardized form to obtain voluntarily

reported data on eye injuries and to obtain 6-month follow-up information. The primary purpose of USEIR is to provide prospective, population-based, epidemiologic data to improve the prevention and control of eye injuries.

#### G. Rare disease registries

There are over a dozen registries listed on the Internet in the Organizational Database maintained by the National Organization for Rare Disorders. The Li-Fraumeni Syndrome International Registry, for example, was established in 1969 and is operated by a not-for-profit health organization that compiles data on persons and their families with Li-Fraumeni Syndrome. The registry provides referrals to genetic counseling and other services. The Bloom's Syndrome Registry, operated out of the New York Blood Center, is a research organization that was established in 1960 to collect clinical and genetic data on Bloom's Syndrome. Staff of the registry collects information, including DNA and other biologic specimens, from affected persons and their families. The registry conducts ongoing research published in the medical literature.