

Public Health Registries Past- Present-Future

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Setting the Stage for a Registry Agenda for PHDSC

- ▶ What is a public health registry?
- ▶ Uses of public health registries
- ▶ Registry constituencies and organizations
- ▶ New registries- immunization, integrated child health and chronic disease management
- ▶ What's different about the new registries and what is their future?
- ▶ Our opportunities and challenges

What is a Public Health Registry ?

As defined by the NCVHS <http://www.ncvhs.hhs.gov/9701138b.htm>

- ▶ 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.
- ▶ Registries are operated by Federal, state and local governments, universities (SEER), non-profits (US Eye Injury Registry), private groups (transplant registries), hospitals (tumors)

Registries And Other Data Systems

- ▶ Registries represent only one of many sources of data to assess and monitor the health of the population.
- ▶ Other sources include
 - ▶ Vital Statistics
 - ▶ Legally mandated public health surveillance systems for notifiable diseases
 - ▶ Reports from laboratories
 - ▶ Hospital discharge records
 - ▶ Surveys
- ▶ Reporting data to public health has been moving
 - ▶ from paper to electronic media
 - ▶ from a separate reporting process to electronic transmission of data from one system to another
 - ▶ From periodic batch uploads to real time updates
 - ▶ From one-way transfer to bi-directional exchange

Registry Characteristics

- ▶ Registry characteristics that distinguish them from these other sources of data.
 - Focus 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)

How are Registries Used?

- ▶ Estimating the magnitude of a problem
 - ▶ Example: Cancer Registry, Black Lung Disease
- ▶ Determining the incidence of disease
 - ▶ Example: 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.
- ▶ Examining trends of disease over time
 - ▶ Example: 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.
- ▶ Assessing service delivery and identifying groups at high risk
 - ▶ Example: IIS, CHIS
- ▶ Documenting the types of patients served by a health provider
 - ▶ Example- Disease Registries, CHIS

How are Registries Used?

- ▶ Conducting research
 - ▶ Estimating survival analysis
 - ▶ Evaluating health impacts of specific exposures
 - ▶ Investigating etiologic hypotheses
- ▶ Serving as a source of potential donors
 - ▶ Example: National Bone Marrow Registry
- ▶ Serving as a source of participants in clinical trials
- ▶ Increasingly registry information and architectures are used in integrated systems and health information exchanges

Some Registries and Their Constituencies

- ▶ Vital Records
- ▶ Cancer Registry
- ▶ Disease Registries
- ▶ Immunization Registries-IIS
- ▶ Integrated Child Health Information Systems
- ▶ CDC-NCHS, NAPHSIIS
- ▶ CDC- NPCR, NCRA, NAACCR, Inc.
- ▶ CDC-CCDP, NACDD
- ▶ CDC-NCIRD, Vaccines Program-IIS, AIRA, ECBT
- ▶ HRSA-MCHB Genetics, CDC-NACPHI CoP, PHII, AMCHP

What are Immunization Registries, now known as Immunization Information Systems- IIS ?

- ▶ By two years of age, over 20% of the children in the U.S. typically have seen more than one healthcare provider, resulting in scattered paper medical records.
- ▶ Immunization information systems (IIS) help **providers and families** by consolidating immunization information into one reliable source.
- ▶ They also save money by ensuring that children get only the vaccines they need and improve office efficiency by reducing the time needed to gather and review immunization records.
- ▶ [CDC IIS home page](#)

What is a Chronic Disease Registry ? *

- ▶ Chronic disease registries are clinical information systems that capture and track a relatively narrow range of key data for a specified population, such as diabetes, asthma and congestive heart failure patients.
 - ▶ Range from free database programs to Web-based systems loaded with functionality
 - ▶ Serve as repositories of recommended clinical interventions, helping clinicians make proactive, consistent care decisions and anticipate problems
- ▶ They are not EHRs, nor as complex and costly to implement in a practice setting
 - ▶ Accept data from electronic EHR, laboratory, PM administrative data and data entry
 - ▶ May be difficult to integrate into practice workflow
 - ▶ May require additional data entry for clinicians
 - ▶ Used to engage patients individually and directly

How are disease registries used?

- ▶ As a guide at the **point of care**. It generates a worksheet of clinical guidelines, often called a "visit planner" attached to the patient's chart, reminding the physician to order disease-specific interventions.
- ▶ It enables providers to **identify** patients with gaps in care and contact them between visits to urge them to get a recommended test or treatment.
- ▶ It provides physicians with **feedback** on how well they're managing their patient panel and helps them adjust care.
- ▶ In the public health setting, it can be used as a data base or proactively to support care and services

Present to Future-Data Collection

- ▶ Public Health-defined formats
- ▶ Public health standards bodies
- ▶ Paper forms
- ▶ Data entry
- ▶ Flat batch files
- ▶ Data matching-standalone products
- ▶ More case-centric than person-centric
- ▶ Extensive manual review
- ▶ Collaboratively-defined formats
- ▶ PH participation in national standards bodies
- ▶ Electronic batch records
- ▶ Electronic individual records
- ▶ Sophisticated data matching products
- ▶ Use of record locator services
- ▶ Selective manual review

Present to Future-Data Use

- ▶ Retrospective
- ▶ Population
- ▶ Prevention-wellness
- ▶ Service Assessment
- ▶ Quality Assurance
- ▶ Siloed
- ▶ Static
- ▶ Reporting
- ▶ Public at large
- ▶ Situational
- ▶ Individual
- ▶ Prevention-Care
- ▶ Service Delivery
- ▶ Quality Improvement
- ▶ Integrated
- ▶ Interactive
- ▶ Tracking & intervening
- ▶ Individual consumers

Opportunities: Alignment of Registries with National Quality and Payment Initiatives

▶ Medical Home Models:

- ▶ AAFP- TransforMED program
- ▶ American College of Physicians-The Advanced Medical Home: A Patient-Centered, Physician-Guided Model of Health Care

▶ Quality Initiatives

- ▶ HHS Value-driven Health Care- Charter Value Exchanges
- ▶ NCQA, DPRP (Diabetes Physician Recognition Program)
HEDIS (Healthcare Effectiveness & Quality Measurement)

▶ Payment Initiatives

- ▶ Medicare- PQRI (Provider Quality Reporting Initiative)
- ▶ E Prescribing
- ▶ Medicaid Transformation grants



Challenges for Registries

- ▶ Governance and collaboration mechanisms
- ▶ Technical architectures that support integration
- ▶ Supporting privacy and security architecture and policies
 - ▶ Developing MOUs for interstate and intrastate data exchange
- ▶ Harmonized standards with balanced input
- ▶ Use of SOA for decision support and other services
- ▶ Resources
 - ▶ Workforce training in needed skills
 - ▶ Creative funding