Public Health Registries
Past- Present-Future

PHDSC Annual Meeting, November 12-13-2008
Susan M. Salkowitz, Salkowitz Associates, LLC
Board Member, ex officio, AIRA
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
<table>
<thead>
<tr>
<th>Some Registries and Their Constituencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vital Records</td>
</tr>
<tr>
<td>Cancer Registry</td>
</tr>
<tr>
<td>Disease Registries</td>
</tr>
<tr>
<td>Immunization Registries-IIS</td>
</tr>
<tr>
<td>Integrated Child Health Information Systems</td>
</tr>
<tr>
<td>CDC-NCHS, NAPHSIIS</td>
</tr>
<tr>
<td>CDC- NPCR, NCRA, NAACCR, Inc.</td>
</tr>
<tr>
<td>CDC-CCDP, NACDD</td>
</tr>
<tr>
<td>CDC-NCIRD, Vaccines Program-IIS, AIRA, ECBT</td>
</tr>
<tr>
<td>HRSA-MCHB Genetics, CDC-NACPHI CoP, PHII, AMCHP</td>
</tr>
</tbody>
</table>
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

*From hospital connect.com
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 database 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