Immunization Registry Data Collection & Information Exchange

Workgroup on National Health Information Infrastructure (NCVHS NHII)
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Background

• Vaccinations are a proven public health tool that reduces disease
• Threats to maintaining high national levels of vaccination coverage
• Immunization registries are one tool that can sustain and increase today’s high vaccination coverage rates

Immunization Registry Defined

• A computerized population-based tracking system that collects and securely discloses information on children and their vaccination history
• Registries contain a decision support module (internal algorithms) that determine the UTD status and “next dose due”
• Registries include a supporting communications infrastructure
• Registry benefits to parents, community and public & private healthcare delivery systems

Baltimore’s Immunization Registry Program

• Launched February 1995
• Authorized by City and Maryland state legislation
• Sources of funding
• Healthcare providers voluntarily participate in registry activities (1995 – Summer 1998)
• BIRP marketing campaign launched in the Summer 1998 that resulted in 85% sustained level of healthcare provider participation (reporting)
As of June 30, 97% of PMDs had submitted ≥1 BIRP report within the last 6 months.
**Barriers to Full BIRP Implementation**

- Improve data quality assurance (QA)
- Design – Develop – Deploy an updated registry platform & software application
- Grow the scale and scope of BIRP reporting
- Re-activate linkages to Maryland Department of Vital Records birth and child mortality reports

**Immunization Registries - State & National Perspective**

- A Healthy People 2010 objective is to enroll 95%+ of the nation’s < 6 year old cohort into a fully functional immunization registry
- As of December 31, 2001, 63% of states self reported operating a registry that potentially can capture 49% of the targeted <6 year old cohort
- State & local jurisdictions have developed disparate registry systems
- Deployment of a single national immunization registry platform is not currently feasible. Threading local and state registries together into regional “quilts” is doable

**Challenges to Fully Implementing Immunization Registries**

- Recruit & retain healthcare provider participation
- Functional standards
- Integration
- Cross jurisdictional connectivity
- Privacy – Confidentiality – Security
- Funding

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Recruit & Retain Healthcare Provider Participation
BIRP Marketing Campaign

- Healthcare provider participation is critical to registry activities.
- BIRP Marketing action steps include:
  - Define “target” clinical practices and other data sources
  - Saturate healthcare providers and parents with awareness and promotional materials
  - Couple a robust registry system with an array of technologically appropriate and staff friendly “wrap around” support services to both minimize provider burden and return value to clinical practices.
  - “One size does not fit all” ... give providers a menu of reporting options in order to ensure a best fit between the registry and their practice
  - Deliver on promised support in order to build trust
  - Establish a tracking system with person-to-person follow-up
  - Use defined punitive measures for non-compliance, as needed

Define Functional Standards

- Ensures that registries contain common core data elements and functionality in order to facilitate information exchange
- NVAC defined standards
- Immunization Registry Certification (IRC) process now being piloted

Integrate Immunization Registries with other Public Health Information Systems

- Connections between immunization registries and other public & private health reporting and patient management information systems
- Work being done by the Center for Innovation in Health Information Systems (AKC)
- CIRSET now working with a national vendor of patient management software to integrate registry data elements into their application
- Emerging opportunities to integrate immunization registries with disease surveillance and emergency/disaster/bio-terrorism preparedness & response systems

Build Cross-Jurisdictional Connectivity

- Allows immunization registries to exchange records across jurisdictional lines
- CIRSET published guide on HL-7 based code sets and transmission protocols, and developed a HL-7 parser
Privacy – Confidentiality - Security

- Registries must enact policies, procedures and practices to safeguard records access and disclosure in accordance with applicable local, state and federal (HIPAA) legislation.

- Current CDC / NIP interpretation of HIPAA allows some exemptions for authorized public health managed immunization registries.

Ensure Funding

- Start-up and maintenance costs to support state and local registries need to be measured, and necessary funding secured. Measurement includes cost-benefit analyses.

- Surveys suggest that registries capture funding from multiple public & private sources.

- Proposed: creation of a pool containing public domain registry software source code that can accessed as “shareware”

Conclusions & Recommendations - 1

- Immunization registries are a vital component in the public health information infrastructure.

- Local (city, county) registries should be allowed to operate semi-autonomously within the framework of state / federal standards.

- “One size does not fit all.” On the other hand, while customized methods of data collection and records exchange may lessen burdens placed on healthcare provider participation in immunization registry activities, more standardization will occur that realize economies of scale and cross-jurisdictional exchange.

Conclusions & Recommendations - 2

- NCVHS NHII should continue to encourage CDC NIP sponsored work towards meeting the six aforementioned challenges, especially in areas of standards, integration, connectivity, and privacy & confidentiality.

- Peer organizations must remain actively involved in the formulation of national policy on immunization registries and on health information infrastructure.

- NCVHS NHII should examine and consider supporting additional federal funding of local and state immunization registries.
For Additional Information

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