

## Rhode Island

**Project title:** KIDSNET

**Organization responsible:** Rhode Island Department of Health

**Service coverage area:** State of Rhode Island

**Annual birth cohort:** Approximately 13,000

### Project scope and goals

KIDSNET facilitates the collection and appropriate sharing of health data with health-care providers, parents, MCH programs, and other child service providers for the provision of timely and appropriate preventive health services and follow-up. KIDSNET includes children born in Rhode Island, residing in the state, or being served by any health-care provider in the state. KIDSNET's affiliated programs include: Newborn Developmental Risk, Newborn Blood Spot Screening, Newborn Hearing Assessment, Immunization, Childhood Lead Poisoning, Vital Records, WIC, Early Intervention, Family Outreach Program, and Birth Defects.

### Funding

Because KIDSNET serves as Rhode Island's immunization registry, a significant proportion of the funding comes from federal support through the Immunizations Program. State vaccine accountability funds (assessed from insurers) provide another significant funding stream. Other federal grants also contribute, including CDC's EDHI (Early Hearing Detection and Intervention, 6 percent) and HRSA's SSDI (State Systems Development Initiative, 2.2 percent). A small fraction (3.4 percent) of funding comes from the state budget.

### History

KIDSNET is an online public health information management system that tracks children's preventive health services and promotes and shares information between providers and agencies for coordination of care.

These milestones show the evolution of the KIDSNET system:

<b>Early 1990s</b>	Policy development and planning
<b>Spring 1997</b>	Pilot dial-in application
<b>Fall 1997</b>	KIDSNET rollout
<b>Spring 2002</b>	Technology assessment for system's enhancements
<b>December 2002</b>	Web initiative begun
<b>February 2004</b>	Web rollout
<b>March 2004</b>	Integration of newborn blood spot screening results
<b>May 2004</b>	School rollout
<b>June 2004</b>	New matching, adding, and merging tools implemented

<b>2004-2005</b>	Integration of VR2000 (Vital Records) with Level I data
<b>April 2005</b>	ACIP compliant algorithm added

### **Executive leadership and organizational endorsements**

KIDSNET receives support from David Gifford, MD, Director of the Department of Health; William Hollinshead, MD, Medical Director of the Division of Family Health; and Peter R. Simon, MD, Assistant Medical Director.

Leaders and managers from the programs participating and feeding data into KIDSNET also provide strong support and advocacy for the system. These programs include Women, Infants, and Children (WIC); Family Outreach Program (FOP); the Newborn Screening programs; Childhood Lead Poisoning Prevention program; Immunizations, the Office of Children with Special Health Care Needs; and Vital Records.

Also, the Early Intervention program that feeds data into KIDSNET has been transferred to the Rhode Island Department of Human Services, and terms of the new relationship are being developed.

### **External endorsements**

The Rhode Island Chapter of the American Academy of Pediatrics has supported KIDSNET since its inception. U.S. Senator Jack Reed has been a vocal supporter of KIDSNET and immunization registries, and Governor Donald Carcieri and First Lady Sue Carcieri have agreed to include their signatures on KIDSNET congratulations cards sent – along with an introductory fact sheet about KIDSNET – to all newborns in the state.

### **Significant challenges**

1. Rapidly changing technology in inverse relationship with resources.
2. Resources (funding and staff) limitations to satisfy numerous demands.
3. Ongoing privacy and security.
4. Replacement of the KIDSNET's terminal based front end.
5. HL7 implementation.
6. Expansion of users and KIDSNET's ability to meet their increasing needs and demands.
7. External, national forces driving future of registries.
8. Competing priorities and scarce resources from providers' offices to supply immunizations data to KIDSNET.
9. Interfaces with EMRs.

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