

Birth Defects Surveillance Program Data Exchange

Obtaining access to efficient, timely, and accurate birth defects case information from partners and data resources is essential for the success of surveillance programs. This process is influenced by both the format of the data and the method of data exchange. Data is often exchanged between partners using multiple methods (e.g., internet, fax, or postal mail) and gathered in a variety of formats (e.g., paper or electronic record). Federal initiatives have encouraged the use of technology and electronic records to create more efficient data exchange systems.

Methods and Results

In 2009, ASTHO conducted an online survey of 43 state and territorial birth defects programs to assess their approaches to birth defects surveillance and tracking. State-based birth defects surveillance programs were asked to identify the format in which their data was collected from partners and data sources. The results in Table 1 show wide variability among the surveillance programs, even among the most common partners and data sources. Data collection through manual paper forms or non-real-time data upload were reported as the most common formats for partners/data sources to use.

Shifting to an integrated system or one that is technologically-based would allow for quicker exchange of data.

Table 1. Most Commonly Reported Data Collection Format by Partner or Data Source (n=33-35)*

The most frequently reported data collection format for each source is highlighted in dark orange.

Partner or Data Source	Paper (Manual)	Paper (Scan)	Web-based	Database/Data Entry	Data Upload:	Data Upload:	Integrated System	Other
					Non-Real-Time	Real Time		
Birth Certificate	5.7%	0.0%	5.7%	8.6%	54.3%	14.3%	17.1%	2.9%
Delivery Hospitals: Discharge Records	42.9%	5.7%	14.3%	37.1%	37.1%	11.4%	2.9%	5.7%
Delivery Hospitals: Chart Review	41.2%	8.8%	5.9%	58.8%	11.8%	11.8%	2.9%	5.9%
Vital Records: Death Certificates	14.3%	0.0%	2.9%	11.4%	40.0%	11.4%	8.6%	2.9%
Pediatric/Tertiary Care: Other	40.0%	8.6%	8.6%	34.3%	25.7%	8.6%	0.0%	5.7%
Vital Records: Fetal Death	20.0%	0.0%	5.7%	8.6%	40.0%	5.7%	5.7%	2.9%
Pediatric/Tertiary Care: Specialty Outpatient Clinic	38.2%	8.8%	8.8%	29.4%	26.5%	8.8%	0.0%	5.9%
Physicians Reports	45.7%	0.0%	8.6%	11.4%	5.7%	2.9%	0.0%	2.9%

*Note: Categories are not mutually exclusive; not all states responded to all partner or data source categories.

States were also asked to identify the method through which data are received from or exchanged with potential partners. Table 2 presents the most commonly reported partners or data sources and the specific method of data exchange used. The internet/network exchange method was the most common;

this may be the result of federal initiatives that promote the use of technology and electronic records for data exchange.

Table 2. Most Commonly Reported Data Exchange Method by Partner or Data Source (n=33-35)*

The most frequently reported data collection format for each source is highlighted in dark orange.

Partner or Data Source	Integrated System	Fax	E-mail	Portable Drive	Internet/ Network	Mail	Other
Birth Certificate	25.7%	0.0%	2.9%	17.1%	45.7%	2.9%	5.7%
Delivery Hospitals: Discharge Records	14.3%	17.1%	25.7%	8.6%	37.1%	17.1%	25.7%
Delivery Hospitals: Chart Review	2.9%	14.7%	5.9%	8.8%	44.1%	14.7%	41.2%
Vital Records: Death Certificates	14.3%	0.0%	5.7%	17.1%	34.3%	5.7%	11.4%
Pediatric/Tertiary Care: Specialty Outpatient Clinic	8.6%	20.0%	17.1%	2.9%	25.7%	17.1%	28.6%
Vital Records: Fetal Death	11.4%	0.0%	5.7%	11.4%	37.1%	5.7%	8.6%
Pediatric/Tertiary Care: Other	5.7%	14.3%	11.4%	2.9%	25.7%	17.1%	31.4%
Physicians Reports	5.9%	14.7%	8.8%	2.9%	20.6%	11.8%	20.6%

*Note: Categories are not mutually exclusive; not all states responded to all funding source categories.

Although most state programs are using the internet or some other network to exchange data, there is still a lot of variability. For example, while 44.1 percent of programs reported receiving hospital chart review data through the internet or a network, 41.2 percent of responding programs are using an “other” identified method to exchange this information.

Future

Variability exists between states and among partners and data sources both in data collection formats and methods of data exchange. Although programs anticipate only modest changes for the next two years (2010-2011), many are looking to shift to more technology-based approaches. Many programs intend to move toward an integrated data system for collecting and exchanging data with state health programs or services (i.e., vital records, metabolic/newborn screening). And several programs plan to shift to an electronic data record format and are hoping to use an internet-based or network data exchange system with all partners and data sources. These advances will create more effective and efficient exchange systems by allowing data to be more easily accessed and shared, increasing the potential impact of the surveillance programs.

While technology-based approaches involving electronic data uploads were relatively common, many programs still rely on paper forms. This provides an opportunity for federal initiatives to continue their efforts aimed at promoting the use of electronic health records. Many programs’ intended technological improvements involve individual partners, rather than larger, integrated efforts. By developing and using a standardized system for data collection, programs would facilitate a more integrated data exchange system and improve statewide surveillance by creating functional and fiscal long-term efficiencies.