

## Birth Defects Surveillance Program Data Use and Dissemination

Birth defects surveillance is more than just collecting data. The surveillance program’s disclosure of its completed data analysis findings informs the public and helps raise awareness of birth defects in the community. In addition, disseminating useful surveillance information to partner programs and agencies has the potential to build and expand surveillance programs by strengthening relationships and other connections with those who can benefit from the information.

### 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. States assessed how their programs used, shared, and disseminated information for public health-related activities, including informing the public and participating in research. Nearly 78 percent of programs reported using their data for statistical analysis to monitor rates or patterns of birth defects in their state, while 45.7 percent of programs reported engaging in cluster investigations with their data.

45.7 percent of states reported engaging in cluster investigations with their birth defects surveillance data.

To strengthen the partnerships between state programs and their partners or data sources, it is important for the state program to routinely (i.e., systematically rather than on request) provide information back to the partner agencies from which they originally obtained their data. Table 1 provides a summary of the partners or data sources with which state programs systematically exchange data. Despite the benefit that bi-directional data exchange systems would have for state surveillance programs, few indicate that such systems are in development.

**Table 1. Most Common Partners and Data Sources with Systematic Data Exchange (n=30-33)\***

The most frequently reported response for each partner or data source is highlighted in dark orange.

Partner or Data Source	Routine Bi-Directional Data Exchange			
	Yes	In Development	Not Working on One	N/A**
<b>Early Hearing Detection and Intervention (EHDl)</b>	34.4%	18.8%	34.4%	12.5%
<b>Children with Special Health Needs</b>	31.3%	21.9%	37.5%	9.4%
<b>Delivery Hospitals: Discharge Reports</b>	21.9%	18.8%	50.0%	9.4%
<b>Birth Certificate</b>	18.8%	6.3%	71.9%	3.1%
<b>Delivery Hospitals: Chart Review</b>	18.8%	21.9%	50.0%	9.4%
<b>Metabolic/Newborn Genetic Screening</b>	18.2%	21.2%	51.5%	9.1%
<b>Vital Records: Death Certificates</b>	15.6%	9.4%	71.9%	3.1%
<b>Pediatric/Tertiary Care: Other</b>	15.6%	15.6%	56.3%	12.5%
<b>Pediatric/Tertiary Care: Specialty Outpatient Clinic</b>	15.6%	15.6%	56.3%	12.5%
<b>Vital Records: Fetal Death</b>	12.5%	12.5%	65.6%	9.4%

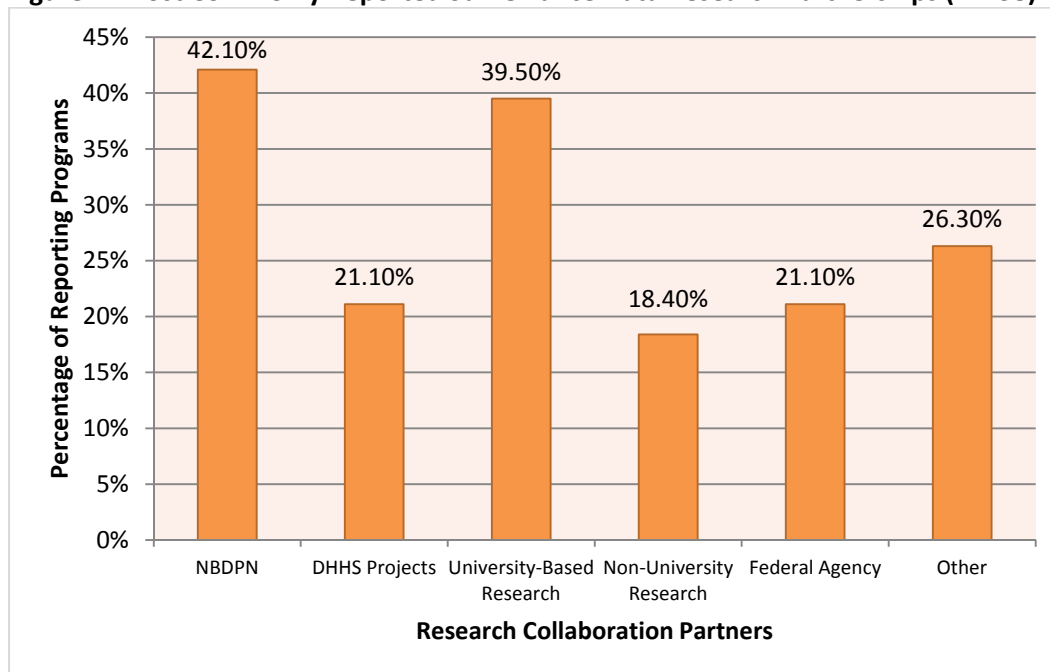
\*Note: Categories are not mutually exclusive; not all states responded to all partner or data source categories.

\*\*N/A indicates that the state does not have the corresponding program (e.g., does not have local health departments).

Seventy-seven percent of programs reported informing the public of birth defects trends both by responding to community inquiries and through general dissemination activities, including printed material, web-based communication, other education tools, and public outreach. Only 22.9 percent of responding programs indicated using a web-based query system that allows users to create personalized aggregated tables for specific areas or birth defects as part of these dissemination activities.

Birth defects programs also reported on their involvement in research activities using their surveillance data. Two-thirds (66.7%) of respondents indicated that they were engaged in different research or data projects. Figure 1 shows the research partnerships most commonly indicated by responding programs.

**Figure 1. Most Commonly Reported Surveillance Data Research Partnerships (n = 38)**



## Future

While birth defects programs have been active in the dissemination of their data to the public, only 50 percent of programs expect to increase their dissemination efforts over the next two years (2010-2011). Programs should continue to expand their outreach aimed at the general public, public health officials, and potential partners in order to verify the value of their surveillance activities. By creating a web-based query system, which 35.3 percent of respondents anticipate doing over the next 24 months, birth defects programs can give public users the opportunity to directly access data and generate simple, aggregate reports using surveillance data.

Surveillance programs should continue to expand their outreach and data exchange with partner programs and agencies from which they receive birth defects data, as well as other potential partners, to create more bi-directional data exchange systems. Strengthening these connections and creating a more efficient and effective two-way data exchange will improve the overall birth defects surveillance system. In addition, state programs should look to expand their research activities and research partnerships, as it is important to document these public health surveillance efforts.