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Evaluation of an active population-based surveillance system for major birth defects in South Carolina

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Abstract

Introduction: Birth defects are common, costly, and contribute substantially to infant mortality. The South Carolina Birth Defects Program (SCBDP) employs active population-based surveillance to monitor major birth defects statewide. We evaluated SCBDP's system attributes using published CDC guidelines.

Methods: To determine timeliness, completeness, and accuracy of birth defects information, we examined SCBDP's reports, program and education materials, advisory group meeting minutes, and strategic plan. We also met with program staff and stakeholders ($n = 10$) to discuss program goals and data utilization. We calculated the percentage of birth defects cases found 6 months after a birth cohort year for 2016–2018.

Results: SCBDP identifies 900–1,200 birth defects cases for a birth population of approximately 55,000 live births annually through active case reviews. SCBDP uses trained medical staff to abstract detailed information from maternal and infant medical records; SCBDP also has established auto-linkage with state vital statistics to capture demographic and birth data. SCBDP is timely and captures 97.1% (range 96.7–97.6%) of birth defects cases within 6 months after the birth cohort year closes. Active case identification using medical records as the primary data source improves quality assurance and completeness, while prepopulating demographic information improves timeliness.

Conclusions: Given that birth defects significantly contribute to infant morbidity and mortality, monitoring these conditions is important to understand their impact on communities and to drive public health actions. SCBDP active surveillance and rigorous data quality practices provide the program with timely, complete, and accurate birth defects data.

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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

Keywords

birth defects; congenital anomalies; evaluation; population-based; South Carolina; surveillance

1 | INTRODUCTION

Periodic evaluation of birth defects surveillance systems ensures that data collected are useful for prevention and control of birth defects and to address public health needs (Centers for Disease Control and Prevention, 2018). The South Carolina Birth Defects Program (SCBDP) aims to promote healthy births, count every birth defect, and support families impacted by birth defects through the collection of comprehensive birth defects data (SC Birth Defects Program, 2020). To accomplish this, SCBDP has trained clinical abstractors who collect detailed maternal and infant medical information to improve case detection and ensure data quality and overall completeness. SCBDP employs active population-based surveillance to monitor 50+ major birth defects state-wide to help identify causes of birth defects and to provide timely referrals. Currently, only one-third of birth defects programs in the United States use active case-finding, and SCBDP is one of 14 U.S. population-based programs that contributes to national birth defects estimates (Mai et al., 2019).

The Centers for Disease Control and Prevention (CDC) published *Recommendations and Guidelines for Evaluating Public Health Surveillance Systems* to ensure efficient use of resources and best practices for promoting surveillance systems for conditions of public health importance (German et al., 2001). We used these guidelines to assess the attributes of SCBDP and to provide recommendations to strengthen SCBDP. We primarily focused on those attributes that are most important for the objectives of the system and highlight the importance of continuously evaluating birth defects programs to ensure that the information being collected can be used for its intended purpose.

2 | METHODS

To understand SCBDP's purpose, operation, and data utilization, we met with program staff and stakeholders ($n = 10$) at the Department of Health and Environmental Control (DHEC), Columbia, SC. We examined SCBDP's reports, data, program and education materials, advisory group meeting minutes, and strategic plan according to CDC guidelines to assess SCBDP's ability to use its public health resources for efficient and effective birth defects surveillance (German et al., 2001; Groseclose, German, & Nsubuga, 2010). Table 1 displays system attributes, definitions, and evaluation findings.

3 | RESULTS

SCBDP's methodology and data flow were assessed (Figure 1).

3.1 | Level of usefulness/system attributes

Usefulness: SCBDP is a useful system. It has well-trained clinical abstractors who collect detailed maternal and infant medical information to ensure completeness; performs auto-linkage with the state vital statistics data source to improve efficiency and timeliness; refers

families impacted by birth defects to helpful services; and contributes to understanding, preventing, and controlling birth defects in South Carolina.

Simplicity: SCBDP's use of trained clinical staff or abstractors to review medical records to identify birth defects cases is a complex method of tracking cases that increases the certainty that all infants with a birth defect are correctly identified and included in the system. This allows for more complete and quality data that can then be used for broader public health action for prevention, research, and referrals. To better manage the complexity of the system, SCBDP streamlines certain processes by linking its information to vital statistics to prepopulate demographic and birth information. In 2016–2018, SCBDP had complete information (demographic, diagnostic testing, maternal exposures and medical conditions) for the majority (>95%) of the birth defects cases (Table S1) on selected variables that the program frequently uses. As the data being collected from hospitals becomes more automated, the system will become more streamlined.

Flexibility: SCBDP is extremely responsive to emerging health needs, builds needed partnerships, and updates data collection methods to include new sources and strategies as needed. South Carolina has robust legislation that supports SCBDP's mission and allows flexibility in program operations as it adapts to changing public health needs. During the Zika epidemic, SCBDP was able to demonstrate its flexibility by quickly updating its system for rapidly changing demands on case ascertainment and reporting.

Data quality: South Carolina uses active case-finding with multiple data sources and has different layers built in for case verification (e.g., clinical review) to ensure good data quality. Complete demographic and birth data were available for more than 95% of birth defects cases from 2016–2018. This is accomplished by using a combination of data from vital statistics and medical records.

Acceptability: There is high acceptability for SCBDP, and all delivering hospitals participate in and continue reporting relevant birth defects. SCBDP has a very engaged advisory committee to ensure continuous feedback and community engagement and participation.

Representativeness: SCBDP includes all delivering hospitals ($n = 41$) in South Carolina, and the surveillance system is representative of all inpatient admissions. Potential birth defects cases are captured from complicated pregnancies, any pregnancy outcome, and inpatient hospitalizations for children up to the age of two. A case could potentially be missed if the infant is born out-of-state and does not have any hospitalizations in South Carolina by age two. However, this is expected to be a small percentage of all resident births in the state.

Timeliness: SCBDP abstractors routinely review medical records of all newborns with a possible defect. In 2016–2018, SCBDP captured 97.1% (range 96.7–97.6%) of birth defects cases within 6 months following the birth year. Active case identification using medical records as the primary data source improves quality assurance and completeness, while prepopulating demographic information from vital statistics enhances timeliness.

Stability: Amid leadership transitions and reorganizational changes, SCBDP has continued to operate since 2006 and built a strong infrastructure, including establishing stable state funding and a reliable team that is committed to improving the program.

4 | DISCUSSION

This report assessed SCBDP using a well-defined program evaluation tool that provides insight to birth defects surveillance in South Carolina and can be used to guide other birth defects programs' evaluation efforts. Program effectiveness depends on timeliness, completeness, and accuracy; evaluating surveillance program attributes ensures that these programs are serving their intended purpose (Salemi et al., 2017).

Given that birth defects are an important contributor to infant mortality and morbidity, monitoring these conditions and evaluating the monitoring systems are important to understand the impact of birth defects on communities and to drive public health actions (Correa, Cragan, & Kucik, 2008; Honein & Paulozzi, 1999). Periodic evaluation of state birth defects surveillance systems ensures that data collected are useful to prevent birth defects, address public health needs, provide recommendations for improving efficiency and data quality, and aid staff members in identifying their strengths and weaknesses (Miller, 2006). SCBDP's strength is its ability to respond to emerging health needs due to its dedicated staff members and stakeholders, available resources, and the SC Birth Defect Code of Laws (Gill, Miller, Broussard, & Reefhuis, 2012; Code of Laws—Title 44—Chapter 44—Birth Defects, 2004). Strong state and federal public health and legal mandates enable more complete collection and use of data (Mai et al., 2007). These laws, combined with skilled and dedicated staff, provide the backbone for the robust surveillance program in SC and equip SCBDP with the tools to maintain a system that is useful, flexible, accepted, representative, timely, stable, and that has complete data on birth defects.

We provided several suggestions for action to the program. First, while all delivering hospitals in South Carolina are captured in the SCBDP database and the surveillance system is representative of all inpatient births, the program can capitalize on its legislation and partnerships to expand data sources for case-finding. This includes hospital outpatient facilities/clinics to capture any missed cases not seen at a delivering facility, and cytogenetic lab information as a new automated data source to improve the system's data capture. It is also important to gain a better understanding of potential missed cases (births that are delivered outside the state, specifically in the regions around Augusta, GA and Charlotte, NC). Second, SCBDP has been granted remote access to records for large and medium-sized hospitals. Remote access to rural hospitals would reduce abstractors' workload and resources spent on acquiring data (e.g., driving, time); however, this would only affect <5% of the state's births. An automated system may reduce the system's complexity and would provide additional opportunities for quality checks. Finally, although SCBDP's use of well-trained clinical abstractors and rigorous data quality practices suggests that the number of cases captured by the registry approaches the true number of birth defects cases in SC, it is difficult to calculate the sensitivity of the system. SCBDP may consider verifying that their system is sensitive and has a high predictive value positivity (PVP) by adding a process to assess these attributes for selected birth defects. To quantify SCBDP's impact, it would

be helpful for SCBDP to implement measures that estimate the sensitivity and PVP of the system for a percentage of cases or birth defects.

5 | CONCLUSION

Due to impactful legislation in South Carolina, funding for the birth defects program, community and partner engagement, and staff capacity, South Carolina has been able to use an active case-finding methodology, which is considered the gold standard for birth defects data collection to provide timely, accurate, and complete birth defects information.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the South Carolina Department of Health and Environmental Control/ on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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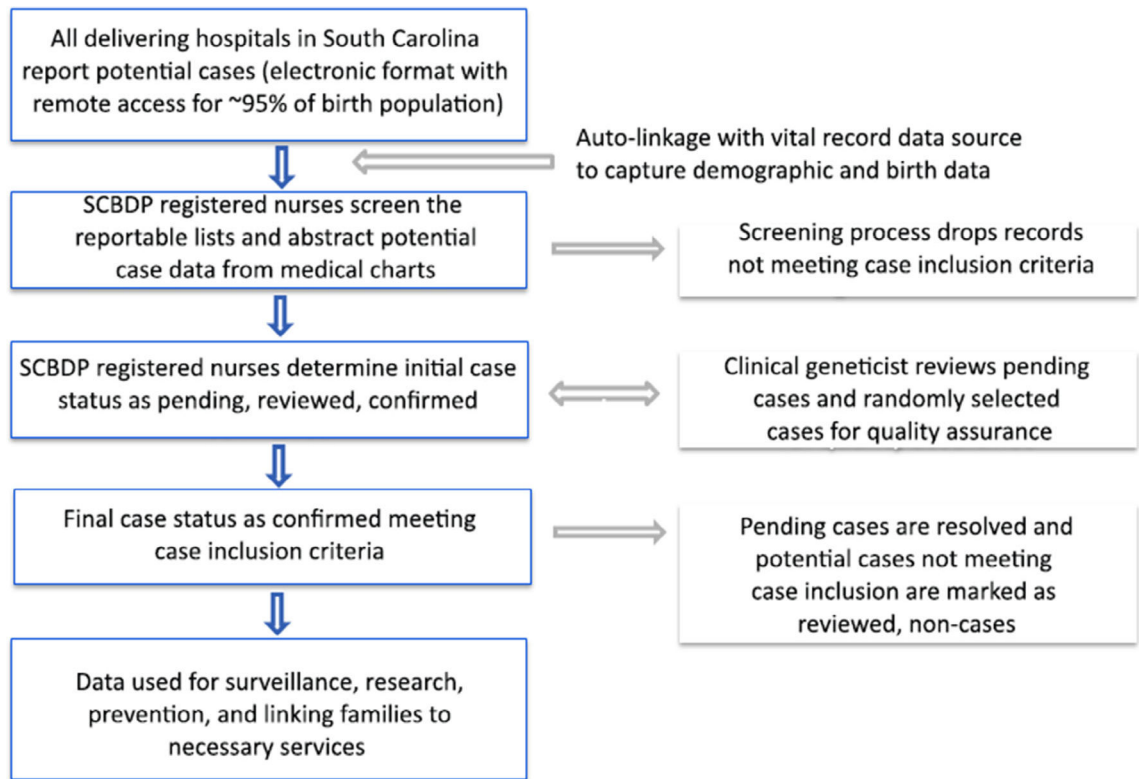


FIGURE 1. South Carolina Birth Defects Program (SCBDP) data flow

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TABLE 1

South Carolina Birth Defects Program (SCBDP) system attributes, definitions, and findings

Level of usefulness/ system attributes	Definition	Findings	Source of information
Usefulness	Ability of the system to contribute to the prevention and control of birth defects	SCBDP is useful; it contributes to understanding, preventing, and controlling birth defects in South Carolina. Registry data have primarily aided in connecting >2,000 children to early intervention, including NTD program and genetic counseling. Data are also used for research and shared with policymakers to obtain additional resources. The advisory committee ^a guides SCBDP's program activities and strategic plan, reviews program products, and helps with overall program improvement and evaluation. SCBDP continually works to improve its birth defects program and can serve as a model for other registries.	Program materials Interviews with staff and stakeholders ^b
Simplicity	The structure and ease of operation; often assessed through a flow chart	SCBDP uses a complex method of tracking cases that increases the certainty that all infants with a birth defect are correctly identified and included in the system. As improvements in data reporting become more automated from hospitals and other sources, the system will become more streamlined.	Program materials Interviews with staff and stakeholders
Flexibility	A system that can adapt to changing information needs or operating conditions with short notice and limited additional personnel or allocated funds	SCBDP is flexible and has robust legislation that supports its mission, which helps the program adapt to changing public health needs and operations. For example, permissive legislation allows program access to all data sources with birth defects information (section 44-44-80, SC Code of Laws).	Program materials Interviews with staff and stakeholders
Data quality	The completeness and validity of the data recorded in the system	SCBDP uses active, case-finding with multiple data sources and has different layers built in for case verification (e.g., clinical review by registered nurses, and for selected cases, by a clinical geneticist) to ensure good data quality.	Program materials Interviews with staff and stakeholders Data from the program used to calculate completeness of key variables (Table S1)
Acceptability	The willingness of entities to provide accurate, consistent, complete, and timely data	SCBDP is accepted by reporting sources, that is, all delivering hospitals participate in and continue reporting relevant birth defects. The program also has an active advisory group and engaged stakeholders.	Program materials Interviews with staff and stakeholders
Representativeness	The distribution in the population by place and person over time	SCBDP is representative of all inpatient admissions in the state.	Program materials Interviews with staff and stakeholders Program and vital statistics data
Timeliness	The speed at which the system operates	SCBDP is timely; abstractors review medical records of all newborns with a potential defect on an ongoing basis, and the system captures >97% of birth defects cases within 6 months following the birth year.	Interviews with staff and stakeholders Data from the program used to calculate timeliness of key variables
Stability	The reliability and availability of the birth defects program over time (e.g., ability to collect, manage, and provide data, especially when it is needed)	SCBDP is stable; amid leadership transitions and reorganizational changes, SCBDP has continued to operate with stable state funding and a reliable core team.	Program materials Interviews with staff and stakeholders
Sensitivity	The proportion of birth defects cases detected by the surveillance system and ability to detect outbreaks	Could not be assessed in this evaluation, but approaches to quantify sensitivity have been proposed.	Not applicable
Predictive value positive (PVP)	The ability to monitor changes in the number of cases over time as well as the proportion of reported birth defects cases	Could not be assessed in this evaluation, but methods to quantify PVP have been proposed.	Not applicable

Level of usefulness/ system attributes	Definition	Findings	Source of information
	that have a birth defects (e.g., confirmation of cases reported)		

^aBirth Defects Advisory Council was established according to legislations (section 44–44–40, SC Code of Laws). The group comprises individuals representing medical and public health groups interested in birth defects as well as families and individuals personally affected by birth defects.

^bStakeholders who were interviewed for this evaluation include public health practitioners/abstractors; health-care providers; data providers and users; managers of birth defects program and data analytics/informatics; and Title V Bureau Director.

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