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Indexing
The *Journal of Registry Management* is indexed in the National Library of Medicine’s MEDLINE database. Citations from the articles indexed, the indexing terms (key words), and the English abstract printed in *JRM* are included and searchable using PubMed.

For your convenience, the *Journal of Registry Management* is indexed in the 4th issue of each year and on the Web (under “Resources” at [http://www.ncra-usa.org/jrm](http://www.ncra-usa.org/jrm)). The 4th issue indexes all articles for that particular year. The Web index is a cumulative index of all *JRM* articles ever published.
Guest Editor’s Introduction

Enhancing Methods for Population-Based Birth Defects Surveillance Programs

Russell S. Kirby, PhD, MS, FACE

This issue of the Journal of Registry Management (JRM) continues a collaboration with the National Birth Defects Prevention Network (NBDPN) to promote research aimed at improving and enhancing birth defects surveillance methods. The NBDPN is committed to the primary prevention of birth defects and to the improvement of outcomes for children and families living with birth defects through the use of birth defects surveillance data for research, program planning, and program evaluation. Members of NBDPN include staff from population-based birth defects surveillance programs across the United States, as well as clinicians, public health professionals, and researchers involved with birth defects epidemiology, primary and secondary prevention activities, program planning, and evaluation.

The articles included in this Spring 2012 issue of JRM were selected from those submitted in response to a call for manuscripts distributed to all state birth defects surveillance programs, NBDPN members, and the birth defects surveillance list serve, as well as posted on the NBDPN Website (http://www.nbdpn.org) and published in the Fall 2011 issue of JRM. The papers included here underwent both editorial and formal peer review.

It is our hope that the methods and findings from these papers will contribute to the continual improvement of the science and practice of birth defects surveillance in the United States and around the globe. We are honored to include a paper from Alberta, Canada, as well as papers from metropolitan Atlanta and surveillance programs in Minnesota and New Hampshire. Bedard et al describe their province-wide experience with the use of ICD-10 coding for birth defects, and their work may hold some interest for American programs as health information systems across the United States transition from ICD-9-CM to ICD-10 in the coming years. Azofeifa et al provide a formal evaluation of the stillbirth surveillance program for metropolitan Atlanta. Recent activities have demonstrated that vital records-based surveillance of fetal deaths is insufficient for providing both completeness of ascertainment and sufficient clinical details concerning each case, and we hope that the Atlanta experience may prompt the implementation of similar population-based programs elsewhere across the nation. The study by Banerjee et al reminds us once again that, while birth certificates are essential records for birth defects surveillance, their utility lies in the demographic and reproductive health data contained therein, not in what is shown to be rather limited and inaccurate information concerning birth defects. Gill et al examine the effects of recent legislation enabling parents to opt out of having identifiable information about their child included in the New Hampshire Birth Conditions Program.

Many dedicated individuals contributed their time and effort to assist with the publication of this issue. These include the authors of all the submitted manuscripts and the following peer reviewers: Jan Cragan, Russel Rickard, Carol Stanton, Eric Miller, Ying Wang, Charlotte Druschel, and Jean Paul Tanner. We also thank the members of the NBDPN Publications and Communications Committee. We would like to thank Vicki Nelson for her help and assistance with the submission and publication of these manuscripts. We would also like to thank Cara Mai for everything she does to support birth defects surveillance at the state and national levels. We also thank the Division of Birth Defects and Developmental Disabilities at the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, for its support of the NBDPN. With sadness, we thank Julianne Collins, co-editor of the birth defects themed issues for 2010 and 2011, who passed away on September 23, 2011. Julianne was a dedicated scientist and researcher in the fields of birth defects prevention and genetics, and we are deeply appreciative of all of her numerous contributions. She will be missed.

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ICD-10 Coding for Congenital Anomalies: A Canadian Experience

Tanya Bedard, MPH; R. Brian Lowry, MD, DSc, FRCPA; Barbara Sibbald, MSc

Abstract: The International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10 CM) will be implemented on October 1, 2013 in the United States by institutions such as hospitals and insurance companies, and by surveillance programs and registries. The Alberta Congenital Anomalies Surveillance System (ACASS) experienced a transition in 2000, changing from the British Paediatric Association version of ICD-9 (ICD-9 BPA) to the Royal College of Paediatrics and Child Health adaptation of ICD-10 (ICD-10 RCPCH). Although the United States will use ICD-10 CM, the experiences discussed are applicable to birth defects programs in the United States. ACASS is funded by the Alberta Ministry of Health known as Alberta Health and Wellness (AHW) and is primarily a passive system covering approximately 50,000 annual births in the province of Alberta. Hospitals in Alberta changed from ICD-9 to an enhanced version of ICD-10 developed by the Canadian Institute for Health Information (ICD-10 CA) in 2002. Both ICD-10 RCPCH and ICD-10 CA are comparable; however, ICD-10 RCPCH offers a more detailed breakdown of some congenital anomaly categories. Although the implementation date for ICD-10 CA was to be in 2002, Alberta hospitals were aware in 1999 that the change would occur. This 3-year period allowed for preparation by ACASS prior to the required implementation.

Key words: birth defects, congenital anomalies, ICD coding, classification, surveillance

Preparation

Hospitals are valuable ascertainment sources for birth defect diagnoses and, like many state birth defect programs in the United States, the Alberta Congenital Anomalies Surveillance System (ACASS) relies greatly on hospital notifications. Health records technologists (HRTs), who are employed by hospitals, are responsible for coding patient conditions and treatments based on the physicians’ discharge entries. These codes are used by hospitals for billing purposes, program planning, and resource allocation, and to assist in health research. They are submitted to the Canadian Institute of Health Information to contribute to information on the health of Canadians and the health system. HRTs also complete and send to ACASS a designated congenital anomalies reporting form (CARF) for each potential case and are thus integral to the ascertainment of cases for ACASS. Although HRTs are responsible for coding for hospitals, they forward information in text to ACASS where coding is done by ACASS staff. Consistency is preserved since the codes used by HRTs (ICD-9/ICD-10 CA) may differ from those used by ACASS (ICD-9 BPA/ICD-10 RCPCH). ACASS has also created additional codes used only by ACASS to further specify congenital anomalies (eg, creating a code for choanal stenosis to distinguish it from choanal atresia). Additionally, some codes encompass a large number of conditions, particularly with diagnosed syndromes. For example, Q87.0 includes a variety of syndromes: Acrocephalopolysyndactyly, Moebius syndrome, cyclopia, Goldenhar syndrome, etc. The ability to retrieve and examine specific case records for review is maintained when the CARF is submitted with a written description of an anomaly rather than a code. Information that might be lost in coding is thus preserved. An ACASS procedures manual for HRTs was available before the implementation of ICD-10 CA but was revised by ACASS staff and distributed again to all Alberta hospitals to reflect how the conversion from ICD-9 to ICD-10 would affect the reporting of cases to ACASS. The manual includes the ICD categories of eligible congenital anomalies with both the ICD-9 and corresponding ICD-10 chapter and codes to assist in the transition.

The manual also outlines the purpose and importance of congenital anomalies surveillance. It describes how birth defects are a leading cause of infant morbidity and mortality in Alberta and that surveillance system data are used to generate baseline rates. The manual reinforces that the Alberta Health Information Act allows ACASS to collect data on births or admissions of an infant up to 1 year of age with 1 or more congenital anomalies.

HRT procedures relating to congenital anomalies surveillance are also reviewed and emphasize the importance of being as specific as possible when describing a congenital anomaly. For example, instead of using “congenital heart disease,” which would encompass the Q20-Q26 codes, the type of congenital heart disease needs to be specified; eg, pulmonary valve stenosis (instead of just pulmonary stenosis which could refer to the valve or artery). Also the HRTs are encouraged to avoid using abbreviations such as CDH, which could stand for congenital diaphragmatic hernia, and to append additional...
information such as a copy of the autopsy report, radiology report, or consultation if the diagnosis is complex.

A major difference between ICD-9 and ICD-10 is that ICD-9 is numeric, while ICD-10 is alphanumerical. The field that housed the ICD-9 BPA code in the original ACASS database was strictly a numeric field. The ACASS database was changed to accept ICD-10 RCPCH codes as well as additional fields. The new database was completed in early 2000. This provided the opportunity to code anomalies with both ICD-9 BPA and ICD-10 RCPCH codes to appreciate the strengths and weaknesses of each coding system and to review and revise current coding practices and policies.

Although ICD-10 CA was implemented by Alberta hospitals in 2002, Alberta Health and Wellness (AHW) was not able to accept alphanumerical codes until 2003. Because ACASS sends data to AHW, we continued double coding until 2003. The earliest year of available ACASS data is 1980 and ACASS has added the ICD-10 RCPCH codes to cases back to 1993. Currently, ACASS continues to add ICD-10 RCPCH codes to cases born before 1993 to assist with the easier retrieval of cases. So, until ICD-10 RCPCH coding is complete, it is necessary to pull both ICD-9 BPA and ICD-10 RCPCH codes when data are requested. For instance, to retrieve cases with tetralogy of Fallot, including pentalogy of Fallot, the ICD-9 BPA code that would be abstracted from the database is easily collapsible to 7452. However, the ICD-10 RCPCH codes that capture 2 forms of tetralogy of Fallot would be Q21.3 (tetralogy of Fallot) and Q21.82 (pentalogy of Fallot) which is no longer a collapsible tetralogy of Fallot code but included in “other congenital malformations of the cardiac septa.”

ACASS has been involved with research projects that have provided the opportunity to abstract all cases with a specified congenital anomaly (eg, anorectal malformation,3 microphthalmia/anophthalmia,4 neural tube defects,5 and multiple congenital contractures) and add ICD-10 RCPCH codes to cases born before 1993. Thus ICD-10 RCPCH codes are added to cases chronologically and by congenital anomaly.

The preparation period was essential for a successful transition to familiarize ACASS staff with the new coding and classification system. The upgraded database contributed to a relatively seamless transition.

**Comparison of ICD-9 and ICD-10**

This section compares codes from the ICD-9 BPA with codes from the ICD-10 RCPCH.

**Codes Have Moved to Different Chapters, Sections, or Organ Systems**

Some anomaly codes have moved to different chapters such as congenital optic atrophy (377.10, disorders of optic nerve and visual pathways, to Q07.81, other congenital malformations of the nervous system) or to different systems such as epispadias (752.61, genital organs, to Q64.0, the urinary system). Additional examples include aortopulmonary window (74501, under common truncus rubric, to Q21.4, cardiac septa malformation); hip dysplasia (755.66, other anomalies of lower limb including pelvic girdle, to Q65, congenital deformities of the hip); congenital vesico-uretero-renal reflux (593.7, other disorders of kidney and ureter, to Q62.7, congenital obstructive defects of renal pelvis and congenital malformations of ureter); and von Recklinghausen’s disease (237.7, neoplasm of uncertain behavior of endocrine glands and nervous system, to Q85.0, phakomatoses not elsewhere classified).

**More Syndromes Have Unique Codes**

More syndromes in ICD-10, such as Meckel-Gruber syndrome, have their own codes. This syndrome is not specifically designated with a code in ICD-9 BPA; however, ACASS along with the Texas Birth Defects Registry and the Centers for Disease Control and Prevention have assigned 759.89 to Meckel-Gruber syndrome.7 Unlike the majority of syndromes that are included in 7598 (congenital malformation syndromes), Meckel-Gruber is coded Q61.90 in the urinary system section. Other syndromes which have their own ICD-10 RCPCH codes have moved to a specific organ system include Alagille syndrome (Q44.71, congenital malformations of the gallbladder, bile ducts, and liver), septo-optic dysplasia (Q04.4, other congenital malformations of the brain), and CHARGE (Q30.0, congenital malformation of nose).

Alternatively, Pierre Robin, Treacher-Collins, Hallerman-Streiff, and Goldenhar syndromes have all moved from 756.0 (anomalies of skull and face bones) to Q87.0 (congenital malformation syndromes predominantly affecting facial appearance), each with their own specific ICD-10 RCPCH code. Thrombocytopenia-radial aplasia has moved from 278.32 (primary thrombocytopenia) to Q87.25 (congenital malformation syndromes predominantly involving limbs); however, Fanconi’s anemia with absent radius has remained in the “ aplastic anemia” section with D61.0. Nail patella syndrome has also moved from 756.83 (other specified anomalies of muscle, tendon, fascia, and connective tissue) to Q87.22 (congenital malformation syndromes predominantly involving limbs).

The “other specified congenital malformation syndromes affecting multiple systems” section, which includes syndrome codes, has expanded to specify more syndromes. For example, while in ICD-9 BPA, congenital malformation syndromes involving limbs were all grouped with 1 code (759.84). In ICD-10 RCPCH, the corresponding section (Q87.2) is expandable to include specific codes for specific syndromes such as Holt–Oram syndrome (Q87.20), Rubinstein-Taybi syndrome (Q87.23), Klippel-Trenaunay-Weber syndrome (Q87.21), and sirenomelia (Q87.24).

**Some Codes in ICD-10 Are More Detailed**

In ICD-10 RCPCH, some codes are more detailed, which may be useful if such details are ascertained and reported. Classifying polydactyly further into preaxial, mesoaxial, and postaxial may be beneficial where the epidemiology and the mode of inheritance or etiology may differ for different types of polydactyly. Additional codes are also offered for hypospadias based on severity including Q54.0 for balanic, coronal and glandular, Q54.1 for penile, Q54.2 for penoscrotal, and Q54.3 for perineal.
Included in Table 1 are the additional ICD-10 RCPCH codes for cleft palate and cleft lip with cleft palate. There are nine ICD-9 BPA codes compared with fifteen ICD-10 RCPCH codes for cleft palate and four ICD-9 BPA codes compared with nine ICD-10 RCPCH codes for cleft lip with cleft palate. ICD-10 RCPCH probably provides too much detail for surveillance systems regarding clefts. Cleft palate is considered a midline defect. Whether the attachment of the palate is to the right or left side of the nasal septum may be of value and interest to the surgeon, but it does not contribute to the etiology or pathogenesis and is unlikely to be ascertained by most birth defects surveillance programs.

**Some Codes in ICD-10 Have Fewer Details**

ICD-9 BPA offered more specified codes for splenic anomalies such as absence (759.00), hypoplasia (759.01), hyperplasia (759.02), and accessory (759.04). ICD-10 RCPCH offers 1 specific code which is for asplenia (Q89.00) and Q89.08 for all other specified malformation of spleen. Different splenic anomalies are associated with different types of syndromes, such as heterotaxy associated with asplenia (Ivemark syndrome) or polysplenia syndrome. ACASS created an additional code for polysplenia (Q89.01).

Both coding systems may offer fewer details than required by specific surveillance systems. The anatomic and physiologic spectrum of tetralogy of Fallot is diverse and includes variants such as tetralogy of Fallot with absent pulmonary valve or pulmonary atresia. To capture the spectrum of pulmonary valve malformations with tetralogy Fallot and for consistency, ACASS has created additional codes in both ICD-9 BPA and ICD-10 RCPCH as listed in Table 2.

A difference in classification is evident for the musculoskeletal (MSK) system when the 2 coding systems are compared. ICD-9 does not further classify congenital MSK anomalies. ICD-10 classifies MSK anomalies as either deformations (Q65-Q68) or malformations (Q69-Q79). The challenge with this classification system became apparent when retrieving and categorizing cases for a multiple congenital contracture study. There is an increasing recognition of etiologic or pathogenetic syndromes with contractures. Classifying cases with multiple contractures as deformations or malformations may be unnecessary and irrelevant. Lowry et al have recommended a coding strategy based on the expansion of (and the ability to collapse) the Q74.3 arthrogryposis multiplex congenital code to permit easier retrieval of cases for future analyses and research. Cases with an isolated contracture could be coded with a specific code (Q74.31), while cases with multiple contractures could be further classified as arthrogryposis multiplex congenital (Q74.32); amylodalia congenita (Q74.33); distal arthrogryposis (Q74.34, with an optional sixth digit for differing types: type 1, Q74.341; type 2, Q74.342; etc); syndromic contractures (Q74.35 in addition to the syndrome code); contractures with multiple

<table>
<thead>
<tr>
<th>Type of Cleft</th>
<th>BPA-ICD-9 Code</th>
<th>RCPCH ICD-10 Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cleft Palate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cleft hard palate, unilateral</td>
<td>749.00</td>
<td>Q35.10</td>
</tr>
<tr>
<td>Cleft hard palate, bilateral</td>
<td>749.01</td>
<td>Q35.0</td>
</tr>
<tr>
<td>Cleft hard palate, central</td>
<td>749.02</td>
<td>Q35.6</td>
</tr>
<tr>
<td>Cleft hard palate, NOS</td>
<td>749.03</td>
<td>Q35.19</td>
</tr>
<tr>
<td>Cleft soft palate, unilateral</td>
<td>749.04</td>
<td>Q35.30</td>
</tr>
<tr>
<td>Cleft soft palate, bilateral</td>
<td>749.05</td>
<td>Q35.2</td>
</tr>
<tr>
<td>Cleft soft palate, central</td>
<td>749.06</td>
<td>Q35.6</td>
</tr>
<tr>
<td>Cleft soft palate, NOS</td>
<td>749.07</td>
<td>Q35.39</td>
</tr>
<tr>
<td>Cleft palate, NOS</td>
<td>749.09</td>
<td>Q35.99</td>
</tr>
<tr>
<td>Cleft palate with cleft soft palate, bilateral</td>
<td>Q35.4</td>
<td></td>
</tr>
<tr>
<td>Complete cleft palate</td>
<td>Q35.50</td>
<td></td>
</tr>
<tr>
<td>Cleft palate with cleft soft palate, unspecified</td>
<td>Q35.59</td>
<td></td>
</tr>
<tr>
<td>Complete cleft palate, unspecified</td>
<td>Q35.60</td>
<td></td>
</tr>
<tr>
<td>Central complete cleft palate</td>
<td>Q35.61</td>
<td></td>
</tr>
<tr>
<td>Central incomplete cleft palate</td>
<td>Q35.8</td>
<td></td>
</tr>
<tr>
<td>Cleft palate, unspecified, bilateral</td>
<td>Q35.9</td>
<td></td>
</tr>
<tr>
<td>Cleft palate, unspecified, unilateral</td>
<td>Q35.90</td>
<td></td>
</tr>
<tr>
<td>Cleft Lip with Cleft Palate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cleft lip, unilateral, with cleft palate (any)</td>
<td>749.20</td>
<td>Q37.10, Q37.50, or Q37.90</td>
</tr>
<tr>
<td>Cleft lip, bilateral, with cleft palate (any)</td>
<td>749.21</td>
<td>Q37.0, Q37.4, or Q37.8</td>
</tr>
<tr>
<td>Cleft lip, central, with cleft palate (any)</td>
<td>749.22</td>
<td></td>
</tr>
<tr>
<td>Cleft lip with cleft palate, NOS</td>
<td>749.29</td>
<td>Q37.99</td>
</tr>
<tr>
<td>Cleft hard palate with cleft lip, NOS</td>
<td>Q37.19</td>
<td></td>
</tr>
<tr>
<td>Cleft hard and soft palate with cleft lip, NOS</td>
<td>Q37.59</td>
<td></td>
</tr>
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<table>
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<tr>
<th>Type of Tetralogy of Fallot</th>
<th>BPA-ICD-9 code</th>
<th>ACASS ICD-9 code</th>
<th>RCPCH ICD-10 code</th>
<th>ACASS ICD-10 code</th>
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</thead>
<tbody>
<tr>
<td>Tetralogy of Fallot</td>
<td>745.20</td>
<td>745.20</td>
<td>Q21.3</td>
<td>Q21.30</td>
</tr>
<tr>
<td>With absent pulmonary valve</td>
<td>745.20</td>
<td>745.22</td>
<td>Q21.3</td>
<td>Q21.31</td>
</tr>
<tr>
<td>With pulmonary atresia</td>
<td>745.20</td>
<td>745.23</td>
<td>Q21.3</td>
<td>Q21.32</td>
</tr>
</tbody>
</table>
anomalies (Q74.36); other specified to include contractures of the knees, wrist, etc (Q74.38); and Q74.39 for other unspecified contractures. This type of coding strategy would assist with easier retrieval since all cases with contractures could be abstracted from the database with a collapsible code (Q74.3) rather than multiple codes (Q68.1, Q68.2, Q68.8, Q74.2, Q74.3, etc) with many of these codes for other specified anomalies of the musculoskeletal system.

Although these differences are not complex and this list is not exhaustive, these changes may influence retrieval and the reporting of prevalence.

Opportunities

The change from ICD-9 to ICD-10 CA by Alberta hospitals and ICD-10 RCPCH by ACASS have provided the opportunity to appreciate the strengths and weaknesses of 2 coding systems. This has allowed ACASS to review and enhance coding practices and policies. ACASS has started to develop a comprehensive coding manual to reflect corresponding ICD-9 and ICD-10 codes and the policies underpinning their use. This will contribute to consistency throughout ACASS and contribute to an easier retrieval of cases. Although no additional resources are required with the exception of a volunteer summer student, the development of a new coding manual and the addition of ICD-10 RCPCH codes to older cases are time consuming and labor intensive.

Additionally, examining the influence of new coding practices on reported prevalence of congenital anomalies is essential and would require additional resources for a comprehensive evaluation. However, ACASS has noted discrepancies in prevalence estimates due to ICD-10 coding in the most recent ACASS annual report. ACASS reports on the anomalies outlined by the National Birth Defects Prevention Network’s Guideline for Conducting Birth Defects Surveillance. Included in this list is congenital dislocation of the hip. Congenital hip dislocation did not include hip dysplasia in ICD-9 (754.3 for hip dislocation and 755.66 for hip dysplasia) while in ICD-10 both hip anomalies are included in Q65. The birth prevalence estimates per 1,000 total births significantly differed for the period 2000-2004. The reported birth prevalence was 0.66; 95% CI: 0.55-0.79 in the eighth annual report when both ICD-9 and the corresponding ICD-10 codes were used to retrieve cases born between 2000 and 2004. The reported birth prevalence in the ninth annual report is greater for the same period when only ICD-10 codes were used to retrieve cases (2.21; 95% CI: 2.01-2.43). The change from ICD-9 to ICD-10 CA by Alberta hospitals and ICD-10 RCPCH by ACASS have provided the opportunity to appreciate the strengths and weaknesses of 2 coding systems. This has allowed ACASS to review and enhance coding practices and policies. ACASS has started to develop a comprehensive coding manual to reflect corresponding ICD-9 and ICD-10 codes and the policies underpinning their use. This will contribute to consistency throughout ACASS and contribute to an easier retrieval of cases. Although no additional resources are required with the exception of a volunteer summer student, the development of a new coding manual and the addition of ICD-10 RCPCH codes to older cases are time consuming and labor intensive.

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Abstract: The purpose of this study was to examine the differences in birth defects identified through passive and active surveillance systems in Hennepin and Ramsey counties in Minnesota, 2006-2008. This was done by comparing birth defects identified on birth certificates through the Minnesota Department of Health’s Office of the State Registrar’s Birth and Death Registry (vital records) with those identified by the Minnesota Department of Health’s Birth Defects Information System (BDIS), an active birth defects surveillance system. The study population included 73,059 babies born to residents of Hennepin and Ramsey counties. There were 1,882 babies that either vital records and/or BDIS identified as having 1 or more birth defects. Cases identified by BDIS were then linked with matching birth certificates found in the vital records database. Using BDIS as the gold standard, it was observed that the vital records database had an overall underreporting rate of 89% when all broad groups of defects were compared, and 72% when 11 specific defects tracked by both registries were compared. The sensitivity and positive predictive values of vital records to identify cases were also compared using BDIS as the gold standard, and demonstrated low sensitivities for most of the 11 comparable defects (range: 0% for tracheoesophageal fistula to 80% for anencephalus). These observations indicate that BDIS has significantly improved the quality of birth defects surveillance in Minnesota.

Key words: birth defects, public health surveillance, birth certificates, sensitivity, comparison

Introduction

Congenital anomalies can be defined as functional or structural malformations which are present from birth. These include a large variety of neurodevelopmental, metabolic, and chromosomal disorders and syndromes. Congenital anomalies, or birth defects, are a relatively common phenomenon throughout the world, though their etiologies are not well known or understood. The causes of about 70% of all birth defects, for example, are not known. Birth defects and their complications are a major cause of infant mortality and long-term disability in the United States. Each year, approximately 150,000 babies are born in the United States with 1 or more birth defects. About 1 baby per every 33 live births will be diagnosed with a congenital anomaly. According to the Centers for Disease Control and Prevention (CDC), birth defects account for more than 20% of all infant deaths. Substantial societal costs are associated with birth defects, which impart a significant financial burden on families, caregivers, healthcare, and educational institutions. The lifetime cost for care is estimated to be between $6-$8 billion dollars for all babies born with 1 or more major birth defects such as spina bifida and Down syndrome.

Active birth defects surveillance in Minnesota began relatively recently with the inception of the Birth Defects Information System (BDIS) at the Minnesota Department of Health, whose first complete birth year of data available is 2006. In 2002, prior to the implementation of this program, Minnesota along with 10 other US states received the grade of “D” according to a study done by the Trust for America’s Health, indicating a lack of activity or progress in addressing birth defects in the state. Although vital records registries were not created for the purpose of surveillance in the public health sense, data from birth certificates have been and are still being used as a passive method for collecting information on birth defects in some states. Yet numerous studies have shown that birth certificates are inaccurate and unreliable sources for birth defect case finding when used alone.

The underreporting that occurs on birth certificates is partially due to the fact that many birth defects are not easily discernible in the first few hours or days of life. Rules and protocols involving birth certificate completion and registration may vary substantially across clinics, hospitals and states. Electronic reporting systems that permit missing data fields contribute to the problem. Furthermore, birth attendants may not understand how to code or record all items in the congenital anomalies check boxes provided on the birth certificate, and many babies may have more than 1 defect. For example, gastroschisis, a musculoskeletal defect similar to omphalocele, may be incorrectly recorded on the birth certificate as the terms are sometimes used interchangeably. On the birth certificate for Minnesota prior to 2011,
for example, omphalocele and gastroschisis were combined into 1 category. Similarly, the distinction between cleft lip with or without cleft palate on birth certificates isn’t always clear, leading to inaccurate defect counts.

The collective inability to fully comprehend birth defects and their etiologies, paired with the high morbidity and mortality associated with major defects, requires further research for the development of active surveillance, referral, and education programs. Monitoring the progress of BDIS is essential for the continued improvement and advancement of birth defects surveillance in the state of Minnesota. We report here the results of a comparative study that highlights the differences in the quality of birth defects identified in Hennepin and Ramsey counties by Minnesota’s vital records system with those of its active Birth Defects Information System from 2006-2008.

Methods

Data Sources

We obtained data from 2 sources: The Minnesota Department of Health’s Office of the State Registrar’s Birth and Death Registry and the Minnesota Department of Health’s Birth Defects Information System (BDIS) from 2006-2008. The Minnesota Department of Health’s Office of the State Registrar’s Birth and Death Registry (vital records) maintains records on all births and deaths in the state. The birth certificate used for years 2006-2008 (Minnesota Vital Records Vision Form 2000, or VRV) collected data on 13 specific congenital anomalies, as well as 9 non-specific or combined categories (eg, “heart malformations” and “other urogenital anomalies”). Every birth occurring in MN is assigned a state file number on the VRV form, which uniquely identifies each baby. The information needed to complete the VRV form originates from the mother, hospital, or clinic and is filled in by a birth attendant.

Department of Health’s Birth Defects Information System (BDIS)

BDIS was activated in June of 2005 to address the need for a comprehensive, active birth defects surveillance system in the state. Currently, the program tracks births occurring at all birthing facilities and neonatal intensive care units in Hennepin and Ramsey counties, as well as several birthing facilities in Washington and Olmsted counties. The births in these 4 heavily populated counties, however, represent about 50% of all births that occur in Minnesota each year. BDIS was cleared for statewide expansion in 2010 and continues to develop as more and more counties are included.

In an active birth defects surveillance system, a wide range of sources is necessary to ensure accurate and complete case finding. BDIS utilizes a variety of sources in its case ascertainment process, including, but not limited to, medical records, hospital discharge data, newborn hearing and screening data, Medicaid claims data, and birth certificates. As a primary case finding source, BDIS is notified by birthing facilities, neonatal intensive care units (NICUs), and specialty clinics whenever there is a potential birth defect identified in a baby upon discharge from a hospital or after receiving services at a clinic. Trained abstractors review medical records at these facilities to verify that each case meets National Birth Defects Prevention Network (NBDPN) and Minnesota-specific case criteria.

In addition, Medicaid claims data, newborn hearing and screening data, and vital records (birth certificate) data are transferred electronically into BDIS on an ongoing basis. Potential cases originating from vital records data are reviewed by abstractors for confirmation. Every case validated by BDIS abstractors, regardless of its original source, is paired with its matching birth certificate to confirm Minnesota residence and gather accurate demographic details about the mother and baby. Consequently, all babies in BDIS are also found in the vital records database and are assigned a state file number (vital records number).

BDIS monitors 45 major birth defects, 44 of which were used in the National Birth Defects Prevention Study, a joint effort of CDC and the NBDPN to improve birth defects surveillance and increase awareness on the topic in the United States. The single ventricle defect was also included at the suggestion of a local physician involved in the initial planning stages. Once a case has been identified, BDIS, like other birth defects registries, aims to ensure that families of those babies are connected to appropriate resources and services.

Study Population

The study population included babies with 1 or more birth defects that were identified through BDIS and vital records from 2006-2008. For the comparisons made in this paper, cases from both registries were restricted to babies born of mothers living in Hennepin or Ramsey counties at time of birth. Though every baby that was identified through BDIS by default was also found in the vital records database, the congenital anomalies identified by each group were not the same.

The birth denominator included 73,059 records representing residents of Hennepin or Ramsey counties who gave birth during 2006-2008. Cases were excluded if essential identifying information such as first or last name, date of birth, or state file number was missing. Birth plurality was not considered in case inclusion or exclusion. The vital records data (n=73,059) were merged with BDIS data (n=1276) using state file number, and 100% of the BDIS records were successfully linked with their matching birth certificate in the vital records database. All analyses and data cleaning were performed using SAS version 9.2.

Data Analyses

To examine the differences in birth defects identified by vital records and BDIS, the sensitivity and positive predictive values (PPV) of vital records to identify cases were calculated. All children whom either BDIS and/or vital records had identified as having 1 or more defects from 2006-2008 (n=1882) were included in the calculations. Sensitivity was defined as the proportion of babies that vital records correctly identified as having a defect as per BDIS, while positive predictive value was defined as the
The proportion of babies that actually had a defect out of those that vital records initially indicated as having a defect. 

The BDIS defect counts were used as the standard to calculate the measures, run across 7 broad defect classes (central nervous system, musculoskeletal, orofacial, chromosomal, genitourinary, cardiovascular, and gastrointestinal defects) as well as for 11 specific defects that the 2 registries had in common (anencephalus, spina bifida, hydrocephalus, microcephalus, omphalocele/gastroschisis, cleft lip/palate, diaphragmatic hernia, renal agenesis, rectal atresia, trisomy 21, and tracheoesophageal fistula). Variables in “other” defects categories of both registries were not included in any underreporting, sensitivity, or positive predictive value (PPV) calculations.

In the 7 broad defect classes, these measures were more difficult to calculate as there are often multiple defects per child. When multiple defects were identified in a single child in either vital records or BDIS, separate records were created per defect before comparisons were made across records. Such was the case for calculating measures for cardiac defects, where 499 children had between 1-5 defects each in the BDIS dataset. Figure 1 reveals large differences in the defects identified by the 2 registries among the broad defect classes. Calculations performed on both registries’ cleft lip/palate and omphalocele/gastroschisis categories were complicated by the fact that the defects were independently recorded in BDIS and aggregated in vital records. For the purpose of rough comparison, the categories were aggregated in BDIS and measures were calculated despite the known limitations.

**Results**

The vital records database identified 606 babies as having 1 or more birth defects, but only 260 of those babies were also found in the BDIS database. The total number of children that both groups identified as having defects during that time period is 1,882 (1,016 children BDIS identified, 606 children vital records identified, and 260 shared).

Overall, BDIS identified more defects per defect class than vital records. The groups which had the largest differences between vital records and BDIS were cardiovascular, genitourinary, and gastrointestinal defects. Chromosomal and orofacial defect counts differed as well, but far less than the aforementioned classes. Vital records identified more defects than BDIS in the musculoskeletal and “other” defects categories. Birth defect counts from both registries displayed a high positive skewness and the majority of cases found had 1-2 defects recorded—89% for BDIS and 97% for vital records (n=1882 cases).

The 2 registries identified the same 116 babies with a 100% match by defect per baby (116 defects identified). If the assumption were made that BDIS was correct in all of the defects and babies it identified, then vital records would have completely missed 72% (302/418) of the 11 specific defects and 89% (1,680/1,895) of defects in the broad defects category. Counts and exact matches of the 2 registries’ 11 common defects can be viewed in Table 1.

In general, the sensitivity of vital records to identify babies with birth defects was low, with anencephalus being the highest at 80%, followed by omphalocele/gastroschisis (59%), hydrocephalus (50%), spina bifida (33%), and cleft lip/palate (32%), all defects that are more likely to be recognized within the first hours to days after birth. Microcephalus, rectal atresia, and tracheoesophageal fistula showed the lowest sensitivities, at 7%, 5%, and 0%, respectively. Similar to the individual defect calculations, the highest sensitivities for the broad defect categories were also found in the central nervous system, musculoskeletal,
and orofacial defect classes (Table 2).

PPV levels were highest for babies diagnosed with spina bifida (100%), trisomy 21 (92%), cleft lip/palate (90%), and omphalocele/gastroschisis (90%) and lowest for rectal atresia (25%) and tracheoesophageal fistula (0%). For all defects except hydrocephalus there were fewer false positives than false negatives, leading to higher PPV values.

**Discussion**

Using BDIS as the gold standard, it was observed that vital records correctly identified only 11% of defects found in BDIS when all broad groups of defects were compared, and 28% of defects when 11 specific defects were compared. These results are consistent with other studies’ findings of very low sensitivities for vital records/birth certificates in identifying congenital anomalies.11,15,20,21 Though BDIS itself was utilized as the gold standard to calculate sensitivity and PPV values of vital records, in reality it consists of an “alloyed” gold standard, as the true gold standard for validating birth defects would include the complete review of medical records by birth defects experts for every child born in a population.

The linkage of vital records data to BDIS data was done to highlight the improvement of BDIS as an active surveillance system in contrast to the passive approach previously utilized. The high underreporting rate of vital records to identify babies with birth defects in Minnesota indicates that active surveillance is necessary for complete and accurate case finding. While the usage of vital records data for birth defect case finding is not recommended and has been proven unreliable by multiple studies in other states,11-13 data illustrating these points as relevant to the state of Minnesota were lacking.

Given the 2 registries are fairly dissimilar in their primary purposes and designs, cross comparison of all variables was not possible. With the exception of hydrocephalus, BDIS identified more defects than vital records; however, only 14 of the 18 hydrocephalus cases were confirmed by BDIS abstractions and the other 4 vital records cases are assumed to be false positives. Up until 2012, BDIS had not systematically documented false positive cases resulting from vital records data. While BDIS intends to incorporate this change into its protocol, program staff feel confident that cases identified by vital records and not BDIS (in Hennepin and Ramsey counties) are “true” false positives. This is based on the fact that the program captures all births to mothers residing in Hennepin and Ramsey counties. The false positives in this study therefore cannot be confirmed but only assumed.

Attempting to link birth defects found on birth certificates to data obtained elsewhere is challenging in that birth certificates utilize check boxes to mark defects, while hospital discharge data and other systems use ICD-9 codes.22 The fact that there are often multiple defects per child complicates sensitivity calculations and makes the data difficult to

### Table 2. Sensitivity and Positive Predictive Values of Vital Records for Identifying Babies with Defects using BDIS* Gold Standard, Hennepin and Ramsey Counties, 2006-2008 (73,059 births)

<table>
<thead>
<tr>
<th>By Defect</th>
<th>Vital Records Sensitivity (%)</th>
<th>Vital Records PPV** (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anencephalus</td>
<td>4/5 (80)</td>
<td>4/5 (80)</td>
</tr>
<tr>
<td>Omphalocoele/Gastrochisis***</td>
<td>27/46 (59)</td>
<td>27/30 (90)</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>7/14 (50)</td>
<td>7/18 (39)</td>
</tr>
<tr>
<td>Spina Bifida</td>
<td>8/24 (33)</td>
<td>8/8 (100)</td>
</tr>
<tr>
<td>Cleft Lip/Palate***</td>
<td>38/118 (32)</td>
<td>38/42 (90)</td>
</tr>
<tr>
<td>Trisomy 21</td>
<td>23/103 (22)</td>
<td>23/25 (92)</td>
</tr>
<tr>
<td>Diaphragmatic Hernia</td>
<td>3/19 (16)</td>
<td>3/6 (50)</td>
</tr>
<tr>
<td>Renal Agenesis</td>
<td>3/23 (13)</td>
<td>3/8 (38)</td>
</tr>
<tr>
<td>Microcephalus</td>
<td>2/28 (7)</td>
<td>2/6 (33)</td>
</tr>
<tr>
<td>Rectal Atresia</td>
<td>1/22 (5)</td>
<td>1/4 (25)</td>
</tr>
<tr>
<td>Tracheo-Esophageal Fistula</td>
<td>0/16 (0)</td>
<td>0/3 (0)</td>
</tr>
</tbody>
</table>

*Birth Defects Information System, Minnesota Department of Health.

**Positive predictive value.

***Combined categories in VR and separate defects in BDIS.

### Table 2. Sensitivity and Positive Predictive Values of Vital Records for Identifying Babies with Defects using BDIS* Gold Standard, Hennepin and Ramsey Counties, 2006-2008 (73,059 births)

<table>
<thead>
<tr>
<th>By Class of Defect</th>
<th>Vital Records Sensitivity (%)</th>
<th>Vital Records PPV** (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Central Nervous System</td>
<td>27/74 (36)</td>
<td>27/58 (47)</td>
</tr>
<tr>
<td>Musculoskeletal</td>
<td>36/110 (33)</td>
<td>36/224 (16)</td>
</tr>
<tr>
<td>Orofacial</td>
<td>38/127 (30)</td>
<td>38/42 (90)</td>
</tr>
<tr>
<td>Chromosomal</td>
<td>34/121 (28)</td>
<td>34/54 (63)</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>26/346 (8)</td>
<td>26/115 (23)</td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>50/933 (5)</td>
<td>50/138 (36)</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>4/184 (2)</td>
<td>4/20 (20)</td>
</tr>
</tbody>
</table>

*Birth Defects Information System, Minnesota Department of Health.
veritably assess using a fixed number of births for a denominator. Though there were limitations, comparisons were made solely for the purpose of addressing the improvement of active birth defects surveillance in Minnesota and not for assessing the quality of birth certificates for the same purpose.

Conclusion

Active birth defects surveillance programs serve an important role in the continuing efforts to improve the detection and understanding of congenital anomalies in the state of Minnesota. BDIS has significantly improved birth defects surveillance in Minnesota since its creation in 2005 by fulfilling its primary objectives for monitoring birth defect prevalence trends and offering education and services to families, healthcare providers, and the general public.17

When contrasted with a more passive approach to monitoring birth defects using vital records/birth certificates alone, the large differences in the defects detected create a clear statement that active birth defects surveillance is necessary if a positive public health impact is expected. With the passing of legislation in 2010 to expand the BDIS program statewide, partnerships with local public health and tribal agencies are being formed and will continue to aid the program in providing timely notification and referral for affected families.

References

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Evaluation of an Active Surveillance System for Stillbirths in Metropolitan Atlanta

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Abstract: Background: In 2005, a pilot project was started at the Centers for Disease Control and Prevention (CDC) to expand an existing birth defects surveillance program, the Metropolitan Atlanta Congenital Defects Program (MACDP), to conduct active surveillance of stillbirth. This pilot project was evaluated using CDC’s current guidelines for evaluating surveillance systems. Methods: We conducted stakeholder interviews with the staff of MACDP’s stillbirth surveillance system. We reviewed the published literature on stillbirth ascertainment including 4 previous publications about the MACDP stillbirth surveillance system. Using fetal death certificates (FDC) as a second, independent data source, we estimated the total number and prevalence of stillbirths in metropolitan Atlanta using capture-recapture methods, and calculated the sensitivity of the MACDP stillbirth surveillance system. Results: The MACDP stillbirth surveillance system is useful, flexible, acceptable, and stable. The system’s data quality is improved because it uses multiple sources for case ascertainment. Based on 2006 data, estimated sensitivities of FDCs, MACDP, and both sources combined for identifying a stillbirth were 78.5%, 76.8%, and 95.0%, respectively. The prevalence of stillbirths per 1,000 live births and stillbirths was 8.2 (95% confidence interval [CI]: 7.5-9.0) based on FDC data alone and 9.9 (95% CI: 9.1-10.8) when combined with MACDP data. Conclusion: Use of MACDP as an additional data source for stillbirth surveillance resulted in higher levels of case ascertainment, better data quality, and a higher estimate of stillbirth prevalence than using FDC data alone. MACDP could be considered as a model to enhance stillbirth surveillance by other active birth defects surveillance programs.

Key words: surveillance, stillbirth, prevalence, sensitivity

Introduction

Stillbirth, often defined as an intrauterine fetal death after 20 weeks of gestation, affects about 1 in 100-200 deliveries; creating significant emotional and psychological distress for patients, families, and clinicians. With advances in antepartum care, the rates for late preterm stillbirths (ie, 34-36 weeks of gestation) and term stillbirths (more than 37 weeks of gestation) have declined, but the rate of early stillbirths (20-27 weeks) has remained stable. Stillbirths occur with greater frequency among pregnancies complicated by certain risk factors, such as diabetes, obesity, maternal hypertension, and smoking; among non-Hispanic black women compared to non-Hispanic white women in the United States; and in economically deprived communities compared to wealthier communities. However, in many cases, depending on the extent and expertise of the postmortem evaluation, the cause of the stillbirth is unknown.

Much of our understanding of the variations in the occurrence of stillbirth among different populations and over time is based on data from fetal death certificates (FDCs). However, the usefulness of FDCs as the sole data source for stillbirth surveillance and for epidemiologic studies might be limited. Certain information on the FDCs, particularly with respect to contributing causes to fetal death, is incomplete and unreliable. Furthermore, although fetal death is a reportable event in the United States, and the National Center for Health Statistics at the Centers for Disease Control and Prevention (CDC) recommends that all fetal deaths of more than 350 grams or, if weight is unknown, more than 20 weeks of gestation be reported, reporting requirements vary across states. The variations in gestational age and birth weight reporting criteria limit the ability to compare data across states.

In 2005, the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC initiated a pilot study to assess the feasibility of leveraging the resources of an existing population-based birth defects surveillance program, the Metropolitan Atlanta Congenital Defects Program (MACDP), to incorporate surveillance of stillbirths with and without birth defects. The goals of the MACDP stillbirth surveillance project are: (1) to assess the feasibility of expanding MACDP to incorporate existing medical record information on all stillbirths among the study population, (2) to monitor and report the occurrence of stillbirth among the study population, (3) to serve as a...
registry for etiologic studies on causes of stillbirth, and (4) to serve as a resource for education and evaluation of targeted prevention programs. Active ascertainment of stillbirths in this pilot project began with deliveries occurring in 2006. We evaluated the pilot project in 2010, using the CDC guidelines for the evaluation of the surveillance systems as our framework.

**Methods: Description of Surveillance System and Methods for Evaluation**

**Description of the MACDP Stillbirth Surveillance System**

MACDP is an ongoing, population-based birth defects surveillance system established in 1967 that actively monitors birth defects among the offspring of women living in the 5 central counties of metropolitan Atlanta at the time of delivery. The program routinely collects data on clinical and demographic characteristics of liveborn and stillborn infants, as well as pregnancy terminations for the presence of structural birth defects. Major structural defects, chromosomal abnormalities, and clinical syndromes diagnosed within 6 years of delivery are included in MACDP. MACDP conducts surveillance activities under the authority of the State of Georgia and uses multiple sources for case finding, including discharge summaries from area birth hospitals, prenatal diagnostic clinics, and cytogenetic laboratories, as well as live birth and fetal death records from the state.

**Inclusion Criteria and Stillbirth Ascertainment**

Pregnancy outcome classification is based on the definitions for live birth, fetal death, and induced termination of pregnancy provided by the 1992 Revision of the Model State Vital Statistics Act and Regulation (Model Law). There is no universally accepted definition of stillbirth that includes the criteria for gestational age or birth weight. For surveillance purposes, the MACDP pilot project defines a stillbirth as any intrauterine fetal death occurring at more than 20 weeks of gestation or more than 350 grams of weight if gestational age is unknown, and the mother must be a resident of the 5-county metropolitan Atlanta area. The assigned gestational age is the age of the fetus at death as determined by the physician and recorded in the medical record. The addresses for the mothers of stillbirths are confirmed through matching with US Postal Service ZIP Codes. If there is uncertainty about a mother’s address, the FDC is used to determine county of residence.

Stillbirths are ascertained from multiple sources. Trained abstractors visit all birthing hospitals and review labor and delivery logs, stillbirth logs, neonatal intensive care logs, and postmortem or pathology logs. Additionally, MACDP routinely acquires a disease index from each hospital to identify deliveries potentially affected by a major birth defect. With the implementation of MACDP’s stillbirth surveillance activities, the disease index has been expanded to include additional codes that might assist in identifying stillbirths. Abstractors also routinely visit several high-risk obstetric providers and maternal-fetal medicine departments to identify pregnancies diagnosed with intrauterine fetal death in these settings. Detailed information is collected for each stillbirth and entered into an electronic data abstraction tool. This information includes demographic, diagnostic, and pregnancy information, as well as a maternal pregnancy history. Abstractors also collect additional information on stillbirth, including pregnancy complications and postmortem examinations from radiographs, autopsies, fetal examinations, and placentation histopathology. Information is entered into fingerprint-password access-secured laptops to protect the confidentiality of cases. Birth defects among stillbirths are coded using a modified British Pediatric Association 6-digit code developed specifically for MACDP. All clinical and postmortem evaluation information is reviewed and assessed for completeness and accuracy as potential contributors to fetal death.

**Fetal Death Certificates**

Fetal deaths are by law reportable events in all states and territories. Although reporting requirements vary by state, most states mandate that fetal deaths at 20 weeks of gestation or longer be reported. In Georgia, however, fetal deaths occurring at any gestational age are to be reported if brought to the attention of a health care provider. FDCs are routinely used by MACDP as a source for case finding.

**Methods for Evaluation**

We assessed the usefulness of the surveillance system and the following attributes using methods recommended in the CDC’s updated guidelines for evaluating public health surveillance systems:

1. **Usefulness** was assessed by determining the extent to which the system’s outputs (publications of its methods and data) are deemed of value, including measurement of the frequency of their citations in the published literature.
2. **Simplicity** was assessed by considering the system’s methods of data collection and the level of integration with other systems.
3. **Flexibility** was assessed by observing how the surveillance system (MACDP) has responded to a new demand.
4. **Data quality** was assessed based on the completeness and validity of data elements recorded by the system, as previously reported in 2 publications.
5. **Acceptability** was assessed based on the willingness of persons and organizations to participate in the surveillance activities.
6. **Sensitivity**, the proportion of “true” stillbirths reported by the surveillance system, was calculated using capture-recapture analysis to estimate the true number of stillbirths in metropolitan Atlanta.
7. **Representativeness** was assessed by comparing the distribution of demographic characteristics among the population in the surveillance system with those of the base population it is designed to represent (metropolitan Atlanta), as previously reported in 2 MACDP publications.
8. **Timeliness** was assessed by the speed in which data...
flow through the surveillance system and covered the time from case identification through abstraction, processing, and review to availability of data for use.

9. Stability was assessed by the system’s operational reliability and availability.10

To gather the information necessary to assess the aforementioned characteristics, we conducted structured stakeholder interviews with the staff of MACDP’s stillbirth surveillance system (including medical records abstractors, clinical reviewers, and managers), and with the director of a stillbirth advocacy organization. We also performed 2 hospital site visits to observe the abstraction of data from medical records, autopsy reports, placenta pathology reports, prenatal records, and other sources reviewed by MACDP abstractors. We reviewed the published literature on stillbirth ascertainment and gathered detailed information on MACDP methods for the capture of stillbirth data. Lastly, we conducted a capture-recapture analysis described below.

Capture-Recapture Analysis

Prevalence estimates from incomplete, independent data sources can be calculated using capture-recapture methods.20 We hypothesized that the ascertainment of stillbirths from both FDCs and MACDP was incomplete. In 2006, because of administrative issues, FDCs were not available as a data source to MACDP, allowing for independency of data sources for that year. We were thus able to apply capture-recapture methods to these independent data sources and estimate the total number of stillbirths in the surveillance population. We also calculated the 95% confidence intervals for stillbirth prevalence and the sensitivity of each data source independently as well as combined.

Results

Usefulness

MACDP stillbirth surveillance system is useful. Four peer-reviewed articles have been published by MACDP on methodologies and best practices of stillbirth surveillance activities.12,13,15,21 These publications have been cited 14 times as of March 1, 2012. One of these publications indicated that MACDP stillbirth surveillance pilot project data is useful for monitoring the occurrence of stillbirths in the metropolitan Atlanta area, and suggested that active surveillance of stillbirths, building on an existing birth defects surveillance system, might serve as a model for state programs that are considering initiating stillbirth surveillance.13 Two of these studies have assessed the utility of both MACDP’s active case identification and FDCs as sources for stillbirth surveillance data.12,15 In one study, the authors linked stillbirths with birth defects ascertained by MACDP over a 9-year period with FDCs and assessed the value of FDCs in monitoring birth defects among stillbirths. Using MACDP as the gold standard, the authors reported that the sensitivity and positive predictive value of FDCs for selected categories of birth defects ranged from 10% to 70% and 25% to 93% respectively. The values were higher for the more obvious defects such as anencephaly, spina bifida, and cleft lip/palate and less so for Down syndrome, heart defects, and renal agenesis.12 A second study reported on the potential enhancements to surveillance data collected on stillbirths through linkage of data sources.13 A random sample of 125 fetal deaths from 2004 were selected for abstraction using the revised MACDP abstraction protocol for stillbirth surveillance. Among the 102 cases abstracted (23 were excluded when no medical record could be found) and linked to FDCs, there was less missing information for selected variables, such as fetal sex, birth weight, and substance use, when both data sources were combined. Furthermore, 42% of stillbirth cases had no information recorded on the FDCs that indicated a cause of or contributor to death, whereas when data from MACDP were used to assess cause of and contributors to death, only 10 cases could not be classified as to the cause of death. Lastly, this study demonstrated that 3% of the 102 cases that were issued a FDC were in fact live births expiring shortly after delivery, and 13 of the 102 cases were stillborn after medical induction of labor for termination.13

Surveillance System Attributes

Simplicity

Because abstractors use multiple sources of information for case finding and data abstraction, active surveillance of stillbirth is not simple. Interpreting, classifying, and reporting information on birth defects and contributors of death for stillbirth entail the need for review of complex information by abstractors. In addition, different types of reporting systems (eg, paper or electronic formats) used by health care facilities contribute to the complexity of the data abstraction process. However, MACDP’s current electronic surveillance data entry module enables information to be entered faster than did the previous paper-based format. In addition, a recent in-house survey of MACDP abstractors on the efficacy of stillbirth surveillance activities indicated that incomplete and vague information in the medical records and incomplete prenatal records were major obstacles in abstracting stillbirth cases (survey data unpublished). Because medical records often are incomplete, abstractors might need to make several visits to a single hospital to capture information from distinct locations within the hospital, such as pathology departments for postmortem information. Although data collection can be complex and time consuming for abstractors, integration of stillbirth surveillance into an existing and established birth defects surveillance system like MACDP is potentially a more simple approach for enhancing data on stillbirths compared to developing and implementing a new surveillance system de novo.

Flexibility

MACDP adapted its methodology to incorporate the ascertainment of stillbirths without birth defects. Specifically, this meant the incorporation of regular visits to 4 birth hospitals in neighboring counties to ascertain potential stillbirths delivered outside of the catchment area. This protocol modification was made following a preliminary evaluation
The stillbirth surveillance pilot project has been accepted as an integral part of MACDP. MACDP has a long history of partnerships, having been founded in 1967 as a collaborative effort between CDC, Emory University and the Georgia Mental Health Institute. MACDP is administered by NCBDDD at CDC and has authority to conduct surveillance of birth defects from the Georgia Department of Human Resources on behalf of the Georgia Department of Public Health. Fetal deaths also are a reportable event in Georgia, and in 2005, MACDP requested and was given the authority to begin surveillance of stillbirths in a 5-county area of metropolitan Atlanta. This authority is renewed annually. All data are protected by the Privacy Act of 1974 and by an Assurance of Confidentiality granted by the director of CDC. All of these factors serve to provide a strong level of confidence and trust in the ongoing work of MACDP, including its expansion to active stillbirth surveillance. In fact, the National Birth Defects Prevention Network, a non-profit organization that addresses the issues of birth defects surveillance, research, and prevention under 1 umbrella by maintaining a national network of state and population-based birth defects programs, is planning to develop a chapter in its surveillance guidelines that addresses the integration of stillbirth surveillance into existing birth defects surveillance programs. In addition, hospitals and health care facility staff (eg, physicians, nurses, and administrative staff) have accepted and are cooperative with the MACDP stillbirth activities. Some facilities have even provided space to the MACDP abstractors to complete their work.

### Data Quality

As previously described, the MACDP method for stillbirth surveillance, which includes information both actively abstracted from medical records and passively ascertained through linkage with FDC data, results in increased case finding and improves the completeness of data collected compared with using either source of data alone. However, a major challenge affecting the overall quality of data is the incompleteness of information in medical records and the general lack of postmortem evaluations. The clinical review of stillbirth case records by MACDP staff allows for the accurate coding of birth defects if present, and ensures that all information, if available, is obtained to assess other contributors to fetal death. If a postmortem evaluation was conducted, that information will be included in the MACDP stillbirth case record; typically the FDC will not include this information since the vital record is typically completed prior to the availability of this information and is rarely amended. The electronic data abstraction application used by MACDP also has built-in logic checks to identify and control data entry errors. Likewise, data cleaning and management are centralized at MACDP, ensuring a standard and uniform process for data quality control. Furthermore, existing abstractors receive continuous training on topics such as placental pathology and the interpretation of autopsy reports. Such training allows the abstractors to have a better understanding of the importance of the information being collected.

### Acceptability

The stillbirth surveillance pilot project has been accepted as an integral part of MACDP. MACDP has a long history of partnerships, having been founded in 1967 as a collaborative effort between CDC, Emory University and the Georgia Mental Health Institute. MACDP is administered by NCBDDD at CDC and has authority to conduct surveillance of birth defects from the Georgia Department of Human Resources on behalf of the Georgia Department of Public Health. Fetal deaths also are a reportable event in Georgia, and in 2005, MACDP requested and was given the

### Table. Distribution of Stillbirths by Source of Identification: Metropolitan Atlanta Congenital Defects Program

<table>
<thead>
<tr>
<th>Identification by MACDP</th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification by FDC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>350</td>
<td>106</td>
<td>456</td>
</tr>
<tr>
<td>No</td>
<td>96</td>
<td>125</td>
<td>221</td>
</tr>
<tr>
<td>Total</td>
<td>446</td>
<td>135</td>
<td>581</td>
</tr>
</tbody>
</table>

Note: The cases missed by both sources (n=29) and the total number of stillbirths (n=581) were calculated with capture-recapture methodology. Missed cases=(106x96)/350=29. Sensitivity calculations: FDC (456/581=78.5%), MACDP (446/581=76.8%); FDC and MACDP (1323+96+106)/581=95.0%. MACDP=Metropolitan Atlanta Congenital Defects Program; FDC=fetal death certificate.

### Prevalence, Sensitivity, and Predictive Value Positive

#### Prevalence

Using 2006 data, we applied capture-recapture methods to estimate the total number of stillbirths among the surveillance population and the relative contribution of each data source (MACDP vs FDC) to case finding. Based on these methods, an estimated 581 cases of stillbirth occurred in the metropolitan Atlanta area. For each data source alone, MACDP identified 446 cases and FDCs identified 456 cases. MACDP identified 96 cases that did not link to an FDC, while 106 cases identified by FDCs were not captured by MACDP. Of these 106 cases, 79 were missed initially, but subsequently abstracted, by MACDP; 17 had medical records that could not be found; and 10 occurred in neighboring counties outside the catchment area. The estimated number of cases missed by both data sources and identified by capture-recapture methods was 29 (see table). Given that there were a total of 55,707 live births in Atlanta in 2006, the prevalence of stillbirths per 1,000 live births and stillbirths was 8.2 (95% CI: 7.5-9.0) based on FDC data alone, 8.0 (95%...
In the absence of a reference or “gold standard” for stillbirths, the sensitivity and predictive value positive of MACDP stillbirth surveillance system could not be calculated. However, using the results of the capture-recapture analysis, and assuming that the cases identified by both data sources (ie, combining FDCs and MACDP) represent the entire sample of cases of stillbirth in the population (missing cases by both sources [n=29] were not included), then the sensitivity of FDCs alone would be 78.5% and that of MACDP alone would be 76.8%. The estimated sensitivity of MACDP when FDCs are included as a source of case finding increased to 95.0% (see table).

Representativeness

Since the inception of MACDP in 1967, the population of the 5-central counties of metropolitan Atlanta has changed considerably and currently does not demographically represent the entire state of Georgia or the United States. In particular, metropolitan Atlanta has become progressively more urban over time, with an increasingly higher proportion of residents of races other than non-Hispanic white who have both higher median income and educational levels compared with residents of the rest of Georgia. Furthermore, the higher proportion of non-Hispanic black mothers in the 5 counties explains in large part the higher overall prevalence of stillbirths in the 5 counties compared with that of the national average.

On the other hand, a previous MACDP stillbirth publication determined that underreporting of stillbirth to vital records may not necessarily occur randomly with race/ethnicity and autopsy status both associated with a stillbirth being issued an FDC. Therefore, it is likely that improvements in case ascertainment utilizing data from MACDP will enhance the representativeness of surveillance data for population of interest.

Timeliness

There are approximately 400-500 stillbirths occurring annually within the MACDP stillbirth surveillance population. Stillbirths typically are identified by abstractors within 1 month of delivery. The timeliness of ascertainment, however, can be affected by the often delayed (up to 4 months) receipt of autopsy and placental pathology information. The average time of abstraction of a single stillbirth case ranges from 30-60 minutes. After abstraction, MACDP staff with clinical expertise review the case record. Cases needing additional information or clarification, such as those with documentation of an ultrasound but without ultrasound results in the record, are returned to the abstractor for completion. Typically, the ascertainment of this additional information takes 1-2 weeks. All abstraction takes place using MACDP’s electronic surveillance data entry module, enabling data entry to be faster than previous, paper-based format.

Stability

As mentioned previously, MACDP has been in operation since 1967 and is administered by CDC with dedicated staff and support. A full-time medical officer oversees and manages the project, and fellows and trainees regularly are utilized to assist in research and evaluation studies. The incorporation of stillbirth surveillance into MACDP is intended to be an ongoing surveillance activity. The MACDP stillbirth surveillance project is positioned to provide leadership, support, and technical assistance in the future to other state-based programs considering similar expansions.

Discussion

The MACDP stillbirth surveillance pilot project has proven to be useful, flexible, acceptable, and stable. In addition, initial studies have shown that the use of both sources (MACDP linked with FDCs) for surveillance of stillbirths with birth defects have resulted in greater ascertainment of stillbirths, more complete and reliable data, and more accurate estimates of stillbirth prevalence. This approach for enhancing stillbirth surveillance is extremely useful. It is built upon an active and ongoing surveillance system with an established methodology, resulting in reduced costs and time compared with the implementation of a new system.

The long history of partnerships and the infrastructure of MACDP has benefited stillbirth surveillance activities. Two planning workshops were held in 2005 to assess the challenges and priorities for conducting stillbirth surveillance as part of existing birth defects monitoring programs. These workshops informed and guided the development of a revised data collection tool for use in stillbirth surveillance and identified additional potential sources for case finding, such as emergency room and pathology departments. Thus, MACDP has shown the flexibility to adapt to challenges that might arise over time, including new developments in methods and medical technology.

A number of challenges remain for active stillbirth surveillance. A particularly important one is that results of postmortem examinations often are absent from medical records or are incomplete at the time of abstraction. In many cases, postmortem evaluations are not performed for a number of reasons, including parental refusal. Although the American Congress of Obstetricians and Gynecologists provides recommendations for the postmortem examination of stillbirths, there is a need for routine implementation of these recommendations in clinical settings. Likewise, there is a need to develop an appropriate classification protocol based on existing clinical and postmortem information for reporting descriptive surveillance data on stillbirths. Once the pilot phase of MACDP’s stillbirth surveillance program is completed, a further evaluation, including an assessment of the system’s cost-effectiveness, will be needed to ensure that the objectives of the system are being met adequately.

MACDP should consider publishing methods and guidelines for stillbirth surveillance which can be useful to other state-based birth defects surveillance programs that might be contemplating similar expansions of their systems to capture stillbirths. MACDP should also engage
stakeholders to address stillbirth as an important public health issue through better surveillance, identification of risk factors, and strategies for prevention. Addressing such challenges will be a key step towards the development and implementation of effective public health prevention strategies.

**Lessons Learned**

We learned through the capture-recapture methods that using MACDP stillbirth data can enhance the completeness of case ascertainment compared to FDC alone. Active surveillance activities require coordination and well-established working relationships with stakeholders. The fact that stillbirth surveillance is built on an existing birth defects surveillance system is a major strength and could be considered as a model for other surveillance systems.

**Acknowledgments**

We would like to acknowledge the continuing support of MACDP staff.

**References**

Original Article


Simerpal Gill\textsuperscript{a,b}; Stephanie Miller\textsuperscript{c}; Cheryl Broussard\textsuperscript{a}; Jennita Reefhuis\textsuperscript{a}

Abstract: Background: The New Hampshire Birth Conditions Program (NHBCP) is a population-based, active case ascertainment surveillance system that monitors the occurrence of 45 birth defects across the state. A 2008 law requires a new opt-out procedure whereby legal guardians can choose whether or not to have identifiable information retained in the NHBCP database. The purpose of this study was to determine the effects of implementing this opt-out legislation on data collection and surveillance of birth defects by the NHBCP. Methods: Using surveillance data collected following implementation of the opt out legislation for the period January 1, 2007, through December 31, 2009, 2 opt-out groups were created: the identifiable information retained (IIR) group, consisting of families who did not choose to opt out, and the de-identified information retained group (DIIR), consisting of those who either chose to opt out or were treated as opt-out birth defect cases because their opt-out package was undeliverable. Descriptive statistics were calculated for each group, and chi-square or Fisher’s exact tests were used to compare the proportion of select sociodemographic and medical characteristics between the 2 opt-out groups. Results: Of 776 infants, 120 (15.5\%) fell into the DIIR group. Differences were observed by race/ethnicity (among non-Hispanic whites, 15\% were in the DIIR group and among Hispanics, 33\% were in the DIIR group; \(p=0.01\)) and by maternal age (among women 30-34 years of age, 11\% were in the DIIR group, and among those 25 years of age or younger, 22\% were in the DIIR group; \(p=0.05\)). Birth outcomes, payer source, county of residence, and common birth defect diagnoses did not differ between the opt-out groups. Conclusion: This study demonstrated that there were significant differences in race/ethnicity and maternal age between parents who had de-identified information included in the NHBCP compared with those who did not choose to opt out. Although the surveillance of birth defects is not affected, the opportunities for certain types of research will be limited.

Key words: opt-out, birth defects, surveillance, congenital malformations

Introduction

Surveillance of birth defects is important for identifying patterns in prevalence and potential risk factors. Birth defects occur among 3\% of births, and are one of the leading causes of infant mortality in the United States.\textsuperscript{1} The causes of 65\%-80\% of birth defects are unknown; however, certain risk factors have been linked with abnormal fetal development.\textsuperscript{3} Using data from birth defects surveillance systems, research studies may identify these risk factors, resulting in preventative action to decrease the occurrence of specific birth defects (for example, using folic acid supplementation to reduce the incidence of neural tube defects).\textsuperscript{5,6} Birth defect surveillance systems have been essential in comparing the prevalence of neural tube defects before and after fortification of enriched cereal grains with folic acid in the United States, and in identifying ethnic and racial disparities, resulting in targeted preconception folic acid awareness campaigns.\textsuperscript{7}

In 2003, the New Hampshire Birth Conditions Program (NHBCP) was created. The NHBCP is a population-based, active case ascertainment surveillance system that monitors the occurrence of 45 birth defects among all newborns, stillborns, terminated fetuses (no gestational age limit), and infants up to 2 years of age. Although strict procedures are in place for protecting privacy and data confidentiality, a 2008 law (New Hampshire RSA 141:J) was passed requiring implementation of a new opt-out procedure that allows individuals the option to have identifiable information removed from the NHBCP database. This law applies to data collected from January 1, 2007 onwards. The purpose of this study was to assess the effects of the implementation of the opt-out legislation on data collection by the NHBCP and the surveillance of birth defects in New Hampshire.
Table 1. Sociodemographic and Medical Characteristics of Infants in the New Hampshire Birth Conditions Program for the Period 2007–2009\(^a\) in the Identifiable Information Retained (IIR) Group\(^b\) and the De-identified Information Retained (DIIR) Group\(^c\)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>IIR Group (n=656)(^d)</th>
<th>DIIR Group (n=120)(^d)</th>
<th>P-value(^e)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Infant Race/Ethnicity n=590 n=113</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic white</td>
<td>526</td>
<td>85</td>
<td>92</td>
</tr>
<tr>
<td>Non-Hispanic black or African American</td>
<td>6</td>
<td>75</td>
<td>2</td>
</tr>
<tr>
<td>Hispanic</td>
<td>22</td>
<td>67</td>
<td>11</td>
</tr>
<tr>
<td>Asian</td>
<td>19</td>
<td>95</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>17</td>
<td>71</td>
<td>7</td>
</tr>
<tr>
<td>Maternal Age at Delivery n=628 n=116</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;20 years</td>
<td>28</td>
<td>78</td>
<td>8</td>
</tr>
<tr>
<td>20–24 years</td>
<td>149</td>
<td>78</td>
<td>41</td>
</tr>
<tr>
<td>25–29 years</td>
<td>188</td>
<td>85</td>
<td>34</td>
</tr>
<tr>
<td>30–34 years</td>
<td>170</td>
<td>90</td>
<td>20</td>
</tr>
<tr>
<td>35–39 years</td>
<td>63</td>
<td>89</td>
<td>8</td>
</tr>
<tr>
<td>≥40 years</td>
<td>30</td>
<td>86</td>
<td>5</td>
</tr>
<tr>
<td>Infant Year of Birth n=656 n=120</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2007</td>
<td>235</td>
<td>83</td>
<td>48</td>
</tr>
<tr>
<td>2008</td>
<td>227</td>
<td>84</td>
<td>42</td>
</tr>
<tr>
<td>2009</td>
<td>194</td>
<td>87</td>
<td>30</td>
</tr>
<tr>
<td>Birth Outcome n=656 n=120</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Livebirth</td>
<td>632</td>
<td>84</td>
<td>119</td>
</tr>
<tr>
<td>Stillbirth</td>
<td>7</td>
<td>86</td>
<td>1</td>
</tr>
<tr>
<td>Termination</td>
<td>17</td>
<td>100</td>
<td>0</td>
</tr>
<tr>
<td>Payer Source n=644 n=117</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>405</td>
<td>88</td>
<td>58</td>
</tr>
<tr>
<td>Medicaid</td>
<td>225</td>
<td>80</td>
<td>56</td>
</tr>
<tr>
<td>Self-pay</td>
<td>13</td>
<td>81</td>
<td>3</td>
</tr>
<tr>
<td>None</td>
<td>1</td>
<td>100</td>
<td>0</td>
</tr>
<tr>
<td>County of Residence n=628 n=116</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Belknap</td>
<td>31</td>
<td>84</td>
<td>6</td>
</tr>
<tr>
<td>Carroll</td>
<td>6</td>
<td>75</td>
<td>2</td>
</tr>
<tr>
<td>Cheshire</td>
<td>31</td>
<td>84</td>
<td>6</td>
</tr>
<tr>
<td>Coos</td>
<td>20</td>
<td>87</td>
<td>3</td>
</tr>
<tr>
<td>Grafton</td>
<td>34</td>
<td>83</td>
<td>7</td>
</tr>
<tr>
<td>Hillsborough</td>
<td>218</td>
<td>84</td>
<td>43</td>
</tr>
<tr>
<td>Merrimack</td>
<td>79</td>
<td>85</td>
<td>14</td>
</tr>
<tr>
<td>Rockingham</td>
<td>123</td>
<td>87</td>
<td>19</td>
</tr>
<tr>
<td>Strafford</td>
<td>53</td>
<td>83</td>
<td>12</td>
</tr>
<tr>
<td>Sullivan</td>
<td>33</td>
<td>89</td>
<td>4</td>
</tr>
</tbody>
</table>

\(^a\)Opt out legislation applies to NHBCP data collected from 2007 and onwards.
\(^b\)Identifiable information retained (IIR) group consists of parents that did not choose to opt out.
\(^c\)De-identified information retained (DIIR) group consists of parents that either chose to opt out, or were treated as an opt-out case since the mailed opt-out package was not delivered.
\(^d\)Due to missing data, each group may not sum to the total sample size.
\(^e\)Differences between the IIR group and DIIR group were assessed using chi-square or Fisher’s exact tests.
Methods

Data Source

The NHBCP collects data from health care providers, health care facilities, clinics, laboratories, medical records departments, and state offices and agencies. Birth hospitals are visited at least annually for medical chart abstraction; cases confirmed through fetal pathology reports or clinical assessments also are included. The NHBCP birth defects list is based on guidance from the National Birth Defects Prevention Network and the Centers for Disease Control and Prevention (CDC). The NHBCP includes birth defect cases who meet the all of the following criteria: (1) offspring of a New Hampshire resident at time of birth; and (2) still-born fetus, terminated fetus, or liveborn infant for whom a diagnosis is made no later than 2 years of age; and (3) infants or fetuses found by clinical assessment or autopsy to have a structural condition that meets the diagnostic criteria for a reportable birth condition.

As indicated in the legislation, the NHBCP is required to notify in writing the legal guardian or guardians of each individual with a birth defect diagnosis before retaining any identifiable information. During case abstraction, all information is collected on a paper form. Before information is entered into the electronic NHBCP database, and within a week of case abstraction, opt-out packages are mailed. If no response is obtained within 60 days of providing the notice, the NHBCP may retain identifiable information and enter all information into the database; however, the legal guardians can elect at any time to not participate in the NHBCP (Figure 1). If the mailed package is undeliverable and returned to sender, the birth defect case is retained; however, no identifiable information is entered into the NHBCP database (Figure 1). If legal guardians choose to opt-out, they are required to return the signed opt out form requesting their identifiable information not be retained.

In addition to the birth defect diagnoses of offspring, information on other pregnancy outcomes, medical history, and demographics, as well as personal information, are collected. This information is collected from medical records and entered into the NHBCP database. The NHBCP obtains race/ethnicity data from birth certificates and uses the mother’s selection as a proxy for the baby. If the mother’s and father’s race differ, “more than one race listed” is selected. Personal identifiers and birth outcome data are also linked to birth certificate data for biannual data field checks to ensure accuracy and review missing fields such as maternal race and ethnicity, gestational age, maternal age, and paternal age. For those who choose to opt out or whose opt-out package is undeliverable, all information is retained within the NHBCP database with the exception of identifiable information such as names, street address, and day and month of birth.

Analytic Methods

Because the purpose of this study was to evaluate the effects of the opt-out procedure, NHBCP data following implementation of the opt-out legislation for the period January 1, 2007, through December 31, 2009, were used to create 2 opt-out groups for this time period: the identifiable information retained (IIR) group, consisting of birth defect cases for whom the legal guardian(s) did not choose to opt out, and the de-identifiable information retained (DIIR) group, consisting of those birth defect cases for whom their legal guardian(s) chose to opt out or who were treated as an opt-out case since the mailed opt-out package was not delivered.

Data regarding sociodemographic and medical characteristics, including infant race/ethnicity, maternal age at delivery, infant year of birth, birth outcome, payer source, county of residence, and birth defect diagnosis were assessed. Descriptive statistics were calculated for each

Table 2. Birth Defects in the NHBCP from 2007-2009 in the Identifiable Information Retained (IIR) Group and the De-identified Information Retained (DIIR) Group

<table>
<thead>
<tr>
<th>Birth Defect</th>
<th>IIR Group (n=656)</th>
<th>DIIR Group (n=120)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Spina bifida</td>
<td>7</td>
<td>100</td>
</tr>
<tr>
<td>Microcephaly</td>
<td>12</td>
<td>80</td>
</tr>
<tr>
<td>Macroelia</td>
<td>5</td>
<td>83</td>
</tr>
<tr>
<td>Tetralogy of Fallot</td>
<td>10</td>
<td>83</td>
</tr>
<tr>
<td>Ventricular septal defects</td>
<td>38</td>
<td>84</td>
</tr>
<tr>
<td>Patent foramen ovale</td>
<td>14</td>
<td>93</td>
</tr>
<tr>
<td>Pulmonary valve stenosis</td>
<td>10</td>
<td>83</td>
</tr>
<tr>
<td>Hypoplastic left heart syndrome</td>
<td>9</td>
<td>100</td>
</tr>
<tr>
<td>Pulmonary atresia</td>
<td>10</td>
<td>91</td>
</tr>
<tr>
<td>Coarctation of the aorta</td>
<td>4</td>
<td>80</td>
</tr>
<tr>
<td>Orofacial clefts</td>
<td>34</td>
<td>87</td>
</tr>
<tr>
<td>Pyloric stenosis</td>
<td>79</td>
<td>82</td>
</tr>
<tr>
<td>Intestinal atresia</td>
<td>8</td>
<td>80</td>
</tr>
<tr>
<td>Intestinal aganglionosis</td>
<td>6</td>
<td>100</td>
</tr>
<tr>
<td>Hypospadias</td>
<td>126</td>
<td>82</td>
</tr>
<tr>
<td>Unilateral renal agenesis</td>
<td>16</td>
<td>76</td>
</tr>
<tr>
<td>Hydronephrosis</td>
<td>75</td>
<td>83</td>
</tr>
<tr>
<td>Hip dislocation</td>
<td>20</td>
<td>87</td>
</tr>
<tr>
<td>Limb deficiency</td>
<td>7</td>
<td>78</td>
</tr>
<tr>
<td>Diaphragmatic hernia</td>
<td>7</td>
<td>100</td>
</tr>
<tr>
<td>Gastrochisis</td>
<td>6</td>
<td>75</td>
</tr>
<tr>
<td>Trisomy 21</td>
<td>20</td>
<td>83</td>
</tr>
<tr>
<td>Multiple defects</td>
<td>95</td>
<td>86</td>
</tr>
</tbody>
</table>

*Only displaying birth defects that had 5 or more cases, by infant.
*Identifiable information retained (IIR) group consists of parents that did not choose to opt out.
*De-identified information retained (DIIR) group consists of parents that either chose to opt out, or were treated as an opt-out case since the mailed opt-out package was not delivered.
opt-out group, and chi-square tests, or Fisher’s exact tests, when the expected cell counts were less than 5, were used to compare characteristics between the 2 groups. Statistical significance was assessed at \( p < 0.05 \) using SAS version 9.2 (SAS Institute Inc., Cary, North Carolina).

**Results**

For the period 2007-2009, 776 infants were identified for inclusion by the NHBCP, of whom 120 (15.5%) fell into the DIIR group. Among the mothers of Hispanic and “other” ethnicities, larger proportions (33% and 29%, respectively) were in the DIIR group when compared to non-Hispanic white mothers at 15% (Table 1). For the different age categories, the largest proportion of mothers who were in the DIIR group were those younger than 25 years of age (Table 1). No significant differences by infant year of birth were observed; however, the higher number of birth defect cases among the DIIR group during the initial implementation of the law most likely was due to delayed mailings and, hence, a higher proportion of undeliverable opt-out packages (Table 1). Although there were no statistically significant differences by payer source, of those with private insurance, only 12% were in the DIIR group; whereas, of those with Medicaid or who self-paid, 20% and 19% (respectively) were in the DIIR group (Table 1). No substantial differences by birth outcome, county of residence (Table 1), or birth defect diagnoses (Table 2) were observed.

**Discussion**

Results from this study demonstrated that certain factors could be associated with a family’s willingness to have their identifiable information included in a birth defect surveillance system. Key differences in some sociodemographic characteristics existed between the IIR group, consisting of families who did not choose to opt out of the NHBCP surveillance system, and the DIIR group, consisting of those who either did choose to opt out or were treated as opt-out birth defect cases because the mailed opt-out package was not deliverable. There were significant differences in infant race/ethnicity and maternal age at delivery, suggesting that there might have been socioeconomic differences influencing the decision to opt out, or that younger mothers and those of Hispanic ethnicity might have been more transient and harder to reach via mail. In a study that examined characteristics between mothers who had a baby born with a birth defect who either consented or did not consent to follow-up, significant differences were also observed by race and maternal age; however, these differences disappeared after adjustment for perinatal mortality. Although not statistically significant, in the current study, the differences observed by payer source, a proxy for socioeconomic status, also suggests that there might have been notable socioeconomic differences between the IIR and DIIR groups, as a greater proportion of those with Medicaid or who self-paid were more likely to opt out or have the opt-out package be undeliverable.

Within the DIIR group, we were not able to distinguish between the parents who chose to have their identifiable information removed from those parents who were considered to have opted out due to an undeliverable mail package as the reason why a case is in the DIIR group is not included in the NHBCP database. As a result, we were not able to assess differences between these 2 subgroups. Fortunately, the NHBCP is required to remove only identifiable information for the DIIR group regardless of whether the parent chose to opt out or the mail was undeliverable; if all data were to be removed for true opt-outs, for those classified as having opted out because of undeliverable mail, or for both of these subgroups, there would be a considerable impact on accurate surveillance as prevalence rates for specific birth defects would be affected. Incomplete case inclusion in a given region would result in distorted prevalence estimates, resulting, in turn, in underestimation of the health care service needs of infants born with specific birth conditions. Additionally, differences in birth defect occurrence between the 2 opt-out groups could affect the accuracy and usefulness of the birth defect surveillance system; however, there did not appear to be substantial differences in the

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**Figure 1. Flowchart Describing the Inclusion and Exclusion of Identifiable Information in the New Hampshire Birth Conditions Program (NHBCP) Depending on Opt-out Status**

- Opt-out packages mailed to all confirmed birth defect cases
  - Undeliverable Mail: opt-out package is returned to the NHBCP
  - Signed opt-out form is mailed by parent/guardian back to the NHBCP
  - No response in 60 days
    - All de-identified information can be retained; name, street address and days and months of birth dates cannot be retained
      - All information can be retained

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proportion of specific birth defects between the 2 groups. As it stands, the lack of identifiable information in the NHBCP will affect research studies if long-term follow-up is required, or if geospatial analysis is to be conducted for birth defect cluster analysis. Fortunately, researchers are still able to link infant records with maternal and paternal records; therefore, most risk factors for birth defects can be assessed in future studies.

Public health surveillance is critical for monitoring diseases or conditions for their prevalence, potential risk factors, and health service requirements. To ensure appropriate evidence-based activities are created, complete and accurate surveillance data are necessary. Birth defects surveillance systems have access to data sources containing individual, health-related information under public health authority; however, as data protection and security concerns are increasing, state legislatures can mandate additional reporting guidelines and procedures. Privacy concerns and their effects on accurate surveillance are national issues, and not unique to New Hampshire. As is the case in New Hampshire, if opt-out procedures are mandated by law, it will be critical to improve these procedures to ensure surveillance is maximized for optimal public health benefit.

References
A number of years ago I had the privilege to live close to my niece and her twin boys, my great nephews. What a privilege to watch Brock and Clayton grow and explore every inch of their world! As you know, kids love music. And, when they really like a song, they play it over and over and over. I still remember the twins belting out “The Bus Song” with its unlimited number of verses. The first verse goes like this:

The wheels on the bus go round and round
Round and round, round and round
The wheels on the bus go round and round
All through the town.

You may be wondering what a kids’ song has to do with cancer registrars. The bus describes who we are as healthcare professionals and what our industry is about. Each of us has a place on the bus. We climb aboard, find a seat, and start our journey. We network together, problem solve, socialize, and have fun together. It’s like a big road trip we will remember for the rest of our lives!

But just imagine we’re on this road trip together and the wheels on the bus are square, not round. It is a rough and bumpy ride and someone might get hurt as we pick up speed and start getting bounced around. Some registrars will hang on to their seats and others will not. A few may even get off the bus, and the bus itself may not withstand the stress of the ride.

So, what do you do to get a smooth ride everyone can enjoy? Of course, the answer is obvious. Replace the square wheels with new, well-treaded, round wheels! As you head off down the road with your new round wheels, you will see other vehicles on the road with you. You notice these vehicles have square wheels too and that the registrars are struggling to endure the rough ride. You bring the bus to a stop, open the door and invite them to join you. If they’re savvy registrars, they’ll abandon their vehicle and climb aboard the bus. As you go along, more cancer registrars leave their bumpy rides in favor of the smooth riding bus. Everyone has such a good time together! They take in the sights, admire the scenery, share snacks, laugh, tell stories, and make friends for a lifetime as they go on this journey.

Isn’t it amazing how much more comfortable the ride is with round wheels instead of square wheels? Just imagine that your professional development is like the wheels on the bus. If you invest in the wrong opportunities and select the bargain-brand programs, the choices will be reflected in your behavior, value, and success as a cancer registrar.

The cancer registrar’s professional development must be balanced and perform well like a round wheel on a bus. The wheel is created from the underlying structure that comes from developing our knowledge in research, quality management/improvement, cancer program development, cancer prevention and surveillance, survival and outcomes, compliance with reporting standards and the accreditation or best practice standards for registry operations. Without this knowledge, the wheels on the bus would not exist. But, what is the tread that holds it together and forms a round wheel that gives a smooth ride that can withstand potholes, road hazards and other bumps along the way?

The tread, so to speak, is what we need to bring the structure (required elements) together with our professional development (soft skills). Professional development must include training in behavior, attitude, relationships, time management, verbal and written communications, stress and change management, scheduling and project management, setting priorities, goals and identifying our mission, vision, and value statements for our career. Some registrars refer to this as the “touchy-feely stuff.” And, sadly, some will choose to skimp on their growth in these areas, much like investing in the bargain brand of wheels, or avoid it entirely, jeopardize their future and risk their success.

If you invest in the bargain brand of professionalism, the wheels on your bus will become square, bumpy, and eventually toss you out of your seat or entirely off the bus. It will prevent you from being successful and performing your best work as a cancer registrar. And, just like the wheels on the bus, if you only invest in the good ones in the beginning and do not maintain them, or replace them due to normal wear and tear, you will not be successful either. It’s as simple as that.

The quality of your wheels will be evidenced by your behavior, attitude, and the contribution you make to your work and the organizations you serve. Each year consciously choose to invest in activities that will enhance your touchy-feely skills and professionalism. If you only concern yourself with the reporting standards or collaborative staging, you will miss the high-quality tread you need to hold your career together. Investing in yourself must include all continual learning activities designed to help you grow and achieve balance.

Maintaining your wheels is important. Continual learning means that you participate in activities routinely, frequently, and on a weekly, monthly, and annual basis. Simply attending an annual meeting or 2 is not enough.
Fluidity in science and healthcare demands the cancer registrar balance foundational (ie, standards and guidelines), clinical and scientific, and soft skills (ie, leadership and marketing) activities.

Create a professional development plan for yourself that includes activities in all areas for balance and growth. Write your plan down on paper and schedule it into your calendar in at least monthly intervals. Hold yourself accountable to the plan. Include self-directed activities and programs with small and large groups. Actively engage in mentoring opportunities and be open to learning from others. Your work as a cancer registrar is a journey that should be collaborative, comfortable, and enjoyable. Your professional development should enhance your value and contribution to cancer registry and our healthcare partners and organizations.

Last July, the Centers for Medicare and Medicaid Services (CMS) published its annual updates to ICD-9-CM that became effective on October 1, 2011 for fiscal year 2012. Included was a short series of new codes that can make your disease index case finding easier. By adding a second decimal digit (also known as the fifth digit) to the 173 (malignant neoplasms of skin) codes, health information management coders can distinguish between reportable and non-reportable skin cancers. Table 1 shows the complete list of codes, but the short version is that the following fifth digits have been added to each 173 four-digit rubric.

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>173.00</td>
<td>Unspecified malignant neoplasm of skin of lip</td>
</tr>
<tr>
<td>173.01</td>
<td>Basal cell carcinoma of skin of lip</td>
</tr>
<tr>
<td>173.02</td>
<td>Squamous cell carcinoma of skin of lip</td>
</tr>
<tr>
<td>173.09</td>
<td>Other specified malignant neoplasm of skin of lip</td>
</tr>
<tr>
<td>173.10</td>
<td>Unspecified malignant neoplasm of eyelid, including canthus</td>
</tr>
<tr>
<td>173.11</td>
<td>Basal cell carcinoma of eyelid, including canthus</td>
</tr>
<tr>
<td>173.12</td>
<td>Squamous cell carcinoma of eyelid, including canthus</td>
</tr>
<tr>
<td>173.19</td>
<td>Other specified malignant neoplasm of eyelid, including canthus</td>
</tr>
<tr>
<td>173.20</td>
<td>Unspecified malignant neoplasm of skin of ear and external auditory canal</td>
</tr>
<tr>
<td>173.21</td>
<td>Basal cell carcinoma of skin of ear and external auditory canal</td>
</tr>
<tr>
<td>173.22</td>
<td>Squamous cell carcinoma of skin of ear and external auditory canal</td>
</tr>
<tr>
<td>173.29</td>
<td>Other specified malignant neoplasm of skin of ear and external auditory canal</td>
</tr>
<tr>
<td>173.30</td>
<td>Unspecified malignant neoplasm of skin of other and unspecified parts of face</td>
</tr>
<tr>
<td>173.31</td>
<td>Basal cell carcinoma of skin of other and unspecified parts of face</td>
</tr>
<tr>
<td>173.32</td>
<td>Squamous cell carcinoma of skin of other and unspecified parts of face</td>
</tr>
<tr>
<td>173.39</td>
<td>Other specified malignant neoplasm of skin of other and unspecified parts of face</td>
</tr>
<tr>
<td>173.40</td>
<td>Unspecified malignant neoplasm of scalp and skin of neck</td>
</tr>
<tr>
<td>173.41</td>
<td>Basal cell carcinoma of scalp and skin of neck</td>
</tr>
<tr>
<td>173.42</td>
<td>Squamous cell carcinoma of scalp and skin of neck</td>
</tr>
<tr>
<td>173.49</td>
<td>Other specified malignant neoplasm of scalp and skin of neck</td>
</tr>
<tr>
<td>173.50</td>
<td>Unspecified malignant neoplasm of skin of trunk, except scrotum</td>
</tr>
<tr>
<td>173.51</td>
<td>Basal cell carcinoma of skin of trunk, except scrotum</td>
</tr>
<tr>
<td>173.52</td>
<td>Squamous cell carcinoma of skin of trunk, except scrotum</td>
</tr>
<tr>
<td>173.59</td>
<td>Other specified malignant neoplasm of skin of trunk, except scrotum</td>
</tr>
<tr>
<td>173.60</td>
<td>Unspecified malignant neoplasm of skin of upper limb, including shoulder</td>
</tr>
<tr>
<td>173.61</td>
<td>Basal cell carcinoma of skin of upper limb, including shoulder</td>
</tr>
<tr>
<td>173.62</td>
<td>Squamous cell carcinoma of skin of upper limb, including shoulder</td>
</tr>
<tr>
<td>173.69</td>
<td>Other specified malignant neoplasm of skin of upper limb, including shoulder</td>
</tr>
<tr>
<td>173.70</td>
<td>Unspecified malignant neoplasm of skin of lower limb, including hip</td>
</tr>
<tr>
<td>173.71</td>
<td>Basal cell carcinoma of skin of lower limb, including hip</td>
</tr>
<tr>
<td>173.72</td>
<td>Squamous cell carcinoma of skin of lower limb, including hip</td>
</tr>
<tr>
<td>173.79</td>
<td>Other specified malignant neoplasm of skin of lower limb, including hip</td>
</tr>
<tr>
<td>173.80</td>
<td>Unspecified malignant neoplasm of other specified sites of skin</td>
</tr>
<tr>
<td>173.81</td>
<td>Basal cell carcinoma of other specified sites of skin</td>
</tr>
<tr>
<td>173.82</td>
<td>Squamous cell carcinoma of other specified sites of skin</td>
</tr>
<tr>
<td>173.89</td>
<td>Other specified malignant neoplasm of other specified sites of skin</td>
</tr>
<tr>
<td>173.90</td>
<td>Unspecified malignant neoplasm of skin, site unspecified</td>
</tr>
<tr>
<td>173.91</td>
<td>Basal cell carcinoma of skin, site unspecified</td>
</tr>
<tr>
<td>173.92</td>
<td>Squamous cell carcinoma of skin, site unspecified</td>
</tr>
<tr>
<td>173.99</td>
<td>Other specified malignant neoplasm of skin, site unspecified</td>
</tr>
</tbody>
</table>

We all know that in most population-based cancer registries in the US, basal cell and squamous cell carcinomas of the skin are not reportable conditions, so the fifth digits

In My Opinion

Case Finding—Now and (Sometime) in the Future

April Fritz, BA, RHIT, CTR
1 and 2 can be excluded from computer-generated disease index listings. On the other hand, health records coded with fifth digits 0 and 9 should be reviewed for reportable skin cancers such as adenoid cystic carcinoma, Bowen disease, pilomatrix carcinoma, sweat gland adenocarcinoma, and various sarcomas coded to skin as the primary site. Malignant melanoma cases have long been identified by their own ICD-9-CM code of 172._. Two years ago (for fiscal year 2010), a new code series was added to identify the rare but highly malignant cutaneous Merkel cell carcinomas, 209.3_. The fact that the Merkel cell codes are far outside the numeric sequence of other cutaneous malignancies highlights a developing problem with ICD-9-CM—the neoplasms chapter is running out of empty codes available for use with newly identified or clinically important entities.

If you have not updated your list of case-finding codes for the medical records disease index, it is important that you do so, because when these fifth digit codes were added, the basic 4-digit skin cancer codes (173._) were made obsolete. Also, the 209.3_ codes did not exist prior to October 1, 2009. That means that if your list specifically looks for 173 codes at the decimal level, none will be found. In contrast, if you request every diagnosis in the 140-209 range plus the straggler malignant codes outside that range, the new 5-digit 173 and 209 codes should appear on the list.

Both CMS and the American Health Information Management Association (AHIMA) indicated that the fiscal year 2012 update would be the last for ICD-9 because of the planned conversion to ICD-10-CM on October 1, 2013. But that is so last year.

In February 2012, the US Department of Health and Human Services (HHS) announced a delay in implementing ICD-10-CM as the result of pressure from the American Medical Association (AMA), which claims that converting from ICD-9-CM to ICD-10-CM places an undue burden on medical office staffs, not to mention hospital coders. This is the second delay in implementing ICD-10-CM. The original implementation date of October 1, 2011 was extended to 2013 several years ago. HHS officials have not announced a new implementation date. Industry experts believe that the implementation delay will be a minimum of 1 year, and probably longer. This delay puts AHIMA, which supports the 2013 implementation date, at odds with the AMA, a vastly larger and more powerful lobbying organization.

<table>
<thead>
<tr>
<th>Table 2. Comparison of ICD-9-CM and ICD-10-CM Lymphoma and Hematopoietic Code Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>C81._ Hodgkin lymphoma (was 201._)</td>
</tr>
<tr>
<td>C82._ Follicular lymphoma (was 202.0_, 202.8_)</td>
</tr>
<tr>
<td>C83._ Non-follicular lymphoma</td>
</tr>
<tr>
<td>Includes small B-cell (202.8_), mantle cell (202.4_), diffuse large B-cell (202.0_), lymphoblastic (200.1_), Burkitt (200.2_), other non-follicular (200.3_, 200.5_, and 200.8_), and unspecified non-follicular lymphomas (200.8_)</td>
</tr>
<tr>
<td>C84._ Mature T/NK-cell lymphomas</td>
</tr>
<tr>
<td>Includes mycosis fungoides (202.1_); Sezary disease (202.2_); peripheral T-cell lymphoma, not classified (202.7_); anaplastic large cell lymphoma, ALK-positive (200.6_); anaplastic large cell lymphoma, ALK-negative (200.6_); cutaneous T-cell lymphoma, unspecified (202.8_); other mature T/NK-cell lymphomas (202.8_); and mature T/NK-cell lymphomas, unspecified (202.8_)</td>
</tr>
<tr>
<td>C85._ Other specified and unspecified types of non-Hodgkin lymphoma</td>
</tr>
<tr>
<td>Includes unspecified B-cell lymphoma (202.8_), mediastinal (thymic) large B-cell lymphoma (202.7_, 202.8_), other specified types of non-Hodgkin lymphoma (202.8_), and non-Hodgkin lymphoma unspecified (202.8_)</td>
</tr>
<tr>
<td>C86._ Other specified types of T/NK-cell lymphoma</td>
</tr>
<tr>
<td>Includes extranodal NK/T-cell lymphoma, nasal type (202.81); hepatosplenic T-cell lymphoma (202.87); enteropathy-type T-cell lymphoma (202.83); subcutaneous panniculitis-like T-cell lymphoma (202.83); blastic NK-cell lymphoma (202.80); angioimmunoblastic T-cell lymphoma (200.80); and primary cutaneous CD30-positive T-cell proliferations (200.80)</td>
</tr>
<tr>
<td>C88._ Malignant immunoproliferative diseases and certain other B-cell lymphomas</td>
</tr>
<tr>
<td>Includes Waldenstrom macroglobulinemia (273.3), heavy chain disease (203.80, 203.81), immunoproliferative small intestinal disease (203.80), extranodal marginal zone B-cell lymphoma of mucosa-associated lymphoid tissue [MALT lymphoma] (200.30), other malignant immunoproliferative diseases (203.80, 238.79), and malignant immunoproliferative disease unspecified (203.80)</td>
</tr>
<tr>
<td>C90._ Multiple myeloma and malignant plasma cell neoplasms (was 203._)</td>
</tr>
<tr>
<td>C91._ Lymphoid leukemia (was 204._, 202.40)</td>
</tr>
<tr>
<td>C92._ Myeloid leukemia (was 205._)</td>
</tr>
<tr>
<td>C93._ Monocytic leukemia (was 206._)</td>
</tr>
<tr>
<td>C94._ Other leukemias of specified cell type (was 207._, 238.79)</td>
</tr>
<tr>
<td>C95._ Leukemia of unspecified cell type (was 208._)</td>
</tr>
<tr>
<td>C96._ Other and unspecified malignant neoplasms of lymphoid, hematopoietic and related tissue (was 202.30, 202.50, 202.60, 202.90, 277.89)</td>
</tr>
</tbody>
</table>
From a cancer registry perspective this is also bad news. ICD-9-CM has been used for health records coding, Medicare claims coding, and DRG grouping since 1983—almost 30 years. Cancer registries successfully made the transition from numeric ICD-9 to alphanumeric ICD-10 with the implementation of the International Classification of Diseases for Oncology, second edition in 1992. Most currently active registrars probably don’t even remember coding breast primaries as 174 and prostate primaries as 185 in the registry.

The biggest problem with ICD-9-CM is that the lymphoma and leukemia section (200-209) is hopelessly out of date. The terminology in the 200 and 202 codes, such as lymphosarcoma, reticulosarcoma, and Letterer-Siwe disease, dates back to the 1960s, making health record coding a nightmare because lymphoma and leukemia terminology has undergone significant revision and reorganization at least twice in the past 2 decades. In ICD-9-CM, T-cell and B-cell lymphomas are scattered throughout the lymphoma codes and mixed within individual rubrics. Without a good, annotated ICD-9-CM code book, how can a health record coder know that the largest category of malignant lymphomas, diffuse large B-cell (ICD-O-3 morphology code 9680/3), should be assigned to 200.7, (generic) large cell lymphoma, and that primary cutaneous gamma-delta T-cell lymphoma (9826/3) should be coded to 200.1, lymphosarcoma?

In my opinion, the health care field cannot afford another delay in the implementation of ICD-10-CM. Accurate coding of hematopoietic and lymphoid diagnoses would make our registry lives so much easier when it comes to case finding. ICD-10-CM lists many more lymphoma terms and assigns them to an expanded code set. It does a better job of distinguishing separate rubrics for B-cell and T-cell neoplasms as well as other hematopoietic disease entities. Table 2 shows some of the reorganized and more granular codes in the hematopoietic and lymphoid neoplasm ICD-10-CM code range with their corresponding ICD-9-CM codes. It is interesting that as the cancer registry hematopoietic multiple primary and histology coding rules have collapsed all types of Langerhans cell diseases into 9751/3, ICD-10-CM has split them into multifocal/multisystemic, multifocal/unisystemic, and unifocal Langerhans cell histiocytosis codes.


So will we have more ICD-9-CM annual updates? Will ICD-10-CM be implemented in 2013 or later? HHS has made no announcements as of March 1, 2012. Meanwhile, the National Cancer Registrars Association is continuing to work on ICD-10-CM implementation materials and there are US representatives on the international committee already at work on the neoplasms chapter of ICD-11. Stay tuned...

April Fritz, BA, RHIT, CTR, is CEO of A.Fritz and Associates in Reno, Nevada. The opinions in this column are hers. She can be reached for comments and feedback at april@afritz.org.
Scoping It Out: A Change in Sentinel Lymph Node Surgery Coding Practice

Jerri Linn Phillips, MA, CTR; Andrew Stewart, MA

Abstract: Recently, a committee of clinicians noted that registry data regarding the Scope of Regional Lymph Node Surgery did not match the expected standards of clinical practice. Review of data from their own registries led them to the conclusion that much of the problem lay not in clinical practice or in registry coding, but in the coding instructions themselves. In particular, the existing instructions for this surgery did not make clear that coding should be based on the operative report rather than the pathology report. As a result, the instructions failed to give adequate guidance for distinguishing sentinel lymph node biopsies from regional lymph node dissections where multiple nodes were removed. In addition, somewhat separately from these issues, the problem of coding multiple surgeries to show the cumulative effect of the surgery contributed to the miscoding of Scope of Regional Lymph Node Surgery. This article describes the Commission on Cancer’s (CoC) exploration of the problem through a field test, and provides background for the changes in coding instructions introduced for use beginning with cases diagnosed in 2012.

Key words: lymph nodes, registry, Scope of Regional Lymph Node Surgery, sentinel lymph node

Scope of Regional Lymph Node Surgery is 1 of 3 registry data items that, taken together, describe first-course surgical care of cancer patients. The other 2 items are Surgical Procedure of Primary Site, and Surgical Procedure/Other Site. Scope of Regional Lymph Node Surgery describes whether regional lymph node surgery is limited to a biopsy or aspiration of the nodes, is a sentinel lymph node biopsy, or involves removal of a larger number of lymph nodes. As such, it combines 2 important pieces of information: lymph node surgery for the purpose of diagnosis, and lymph node surgery as part of treatment of the cancer. As with the other 2 items, the emphasis should be on the nature of the surgery. However, when a team of breast clinicians attempted to use the item for clinical evaluation, they concluded that the instructions used by registries for many years did not match surgical reality.

What are sentinel lymph node biopsies?

The word “sentinel” implies that the lymph node “stands guard” or provides an early warning for some condition; in this case, the possibility that the cancer is spreading through the lymph nodes. When a dye or radioactive marker is injected into a tumor with clinically-negative lymph nodes, it will follow the lymphatic draining pattern for the tumor (See Figure 1). The use of markers in this fashion is called “ sentinel lymph node mapping.” The surgeon excises the marked node closest to the primary tumor and sends it for pathologic analysis. The closest lymph node is the one that must be passed if the cancer is going to spread further in the body. If the node is pathologically negative, then it is highly unlikely that there is any lymph node involvement. If it is positive, then treatment for lymphatic spread is warranted. Surgical removal of the remaining regional nodes is referred to as “completion” axillary lymph node dissection when it is performed following a positive sentinel lymph node biopsy for breast cancer patients.

Sentinel lymph node biopsies are not generally appropriate for clinically node-positive cancer or for metastatic...
cancer. They also are not applicable for patients who received neo-adjuvant (pursurgical) treatment or under some other medical conditions.

What were the problems with the old coding instructions?

A committee of breast cancer clinicians responsible for developing new breast cancer quality of care measures wanted to measure the rate of axillary lymph node dissection for clinically node-negative patients. However, the rates based on the National Cancer Data Base (NCDB) were far from the current standard of clinical care they expected. Too many clinically node-negative patients were undergoing axillary lymph node dissections, and too many pathologically node-negative patients were undergoing completion surgery. The use of axillary lymph node dissection in the NCDB is generally high across all regions of the United States, and those data are mirrored by data from other major standard setters like the Surveillance, Epidemiology and End Results Program (SEER) and the National Program of Cancer Registries (NPCR). The crux of the problem was not necessarily in registrar coding or surgeon choices, but in the instructions used by all cancer registries.

The problems can be summarized as the following:

- **Use of the pathology report to code Scope of Regional Lymph Node Surgery.**
  The pathology report identifies the number and source of the lymph nodes examined, but is a much less reliable source of information about the surgical procedure. The revised guidelines explicitly state that the operative report should be used to code this item.

- **Distinguishing between nodes removed as part of a sentinel lymph node biopsy and as part of a completion axillary lymph node dissection.**
  When the physician cuts into the patient to excise the marked node, it may be among a cluster of nodes or positioned behind other nodes, such that the marker from the sentinel node “shines through” the nodes on top or around it. When that happens, the surgeon will excise the group of nodes, though the surgical intent is simply to remove the sentinel node. Consequently, it is not unusual for more than 1 lymph node to be excised as part of sentinel lymph node surgery. The revised instructions provide guidance for checking for further information when there might be questions.

- **Failing to code multiple surgical procedures cumulatively.**
  The surgical resection of the primary tumor, the sentinel lymph node biopsy, and the completion axillary lymph node dissection (if needed) may take place in 1, 2, 3, or more separate trips to the operating room. For coding Scope of Regional Lymph Node Surgery when more than 1 regional lymph node surgery is performed, it is extremely important that registrars code the cumulative effect of the surgeries, just as with the other surgery items. When a sentinel lymph node biopsy is followed by completion surgery at a different time, the entry for the second surgery must be code 7, “Sentinel node biopsy and code 3, 4, or 5 at different times.” It is not sufficient to enter the sentinel node biopsy for the first surgery into the database, and then follow it later with an entry...
for code 3, 4, or 5 (regional lymph node dissection). If that is done, only the regional lymph node dissection will be transmitted to the NCDB and to state or regional registries (and, therefore to SEER or NPCR). This is not a new requirement for registry coding; however, it has been ignored by many abstractors.

How were the new instructions developed?

The registry data submitted to the NCDB by the hospitals where the clinicians who initially identified the problem are located were much like those for all of the NCDB. Registrars at 4 of those hospitals worked with their surgeons to recode a set of eligible cases using information available in the surgery report. The eligible cases selected were for women with non-metastatic, clinically node-negative breast cancer coded as T1, T2 or T3 who were surgically treated at the respective facility and had at least 1 lymph node examined. The revised instructions were a product of extensive discussions with the registrars and physicians from those programs. Following that, registrars and surgeons from 12 programs of varying sizes and types from around the United States were asked to participate in a field test of the new instructions. Case and hospital selection criteria are listed in Figure 2. Again, there were follow-up interviews with the participants about their use of the newly developed instructions.

The distributions of codes for Scope of Regional Lymph Node Surgery using the old instructions and the new ones are shown in Figure 3. The results were quite similar in the 2 groups. The outstanding findings for the 479 field study cases recoded were:

- 43.2% of the 141 patients originally coded as having an axillary lymph node dissection ONLY were recoded to sentinel lymph node biopsy ONLY, and 29.1% were recoded to sentinel lymph node biopsy AND axillary lymph node dissection.
- 29.9% of the 87 patients originally coded as having sentinel lymph node biopsy AND axillary lymph node dissection were recoded to sentinel lymph node biopsy ONLY.
- The overall proportion of patients who underwent axillary lymph node dissections dropped substantially for

<p>| Table 1. Code-Specific Instructions from FORDS: Revised for 2012 (Codes and Labels) |
|---|---|---|
| <strong>General Instructions</strong> | Use the operative report as the primary source document to determine whether the operative procedure was a sentinel lymph node biopsy (SLNBx), or a more extensive dissection of regional lymph nodes, or a combination of both SLNBx and regional lymph node dissection. The operative report will designate the surgeon’s planned procedure as well as a description of the procedure that was actually performed. The pathology report may be used to complement the information appearing in the operative report, but the operative report takes precedence when attempting to distinguish between SLNBx and regional lymph node dissection or a combination of these 2 procedures. Do not use the number of lymph nodes removed and pathologically examined as the sole means of distinguishing between a SLNBx and a regional lymph node dissection. | Use the operative report as the primary source document to determine whether the operative procedure was a sentinel lymph node biopsy (SLNBx), an axillary node dissection (ALND), or a combination of both SLNBx and ALND. The operative report will designate the surgeon’s planned procedure as well as a description of the procedure that was actually performed. The pathology report may be used to complement the information appearing in the operative report, but the operative report takes precedence when attempting to distinguish between SLNBx and ALND, or a combination of these 2 procedures. Do not use the number of lymph nodes removed and pathologically examined as the sole means of distinguishing between a SLNBx and an ALND. |</p>
<table>
<thead>
<tr>
<th><strong>Code</strong></th>
<th><strong>Label</strong></th>
<th><strong>General Instructions Applying to All Sites</strong></th>
<th><strong>Additional Notes Specific to Breast (C50.x)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No regional lymph node surgery</td>
<td>No regional lymph node surgery.</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Biopsy or aspiration of regional lymph nodes</td>
<td>Review the operative report to confirm whether an excisional biopsy or aspiration of regional lymph nodes was actually performed. If additional procedures were performed on the lymph nodes, use the appropriate code 2-7.</td>
<td>Excisional biopsy or aspiration of regional lymph nodes for breast cancer is uncommon. Review the operative report of to confirm whether an excisional biopsy or aspiration of regional lymph nodes was actually performed; it is highly possible that the procedure is a SLNBx (code 2) instead. If additional procedures were performed on the lymph nodes, such as axillary lymph node dissection, use the appropriate code 2-7.</td>
</tr>
<tr>
<td>Code</td>
<td>Label</td>
<td>General Instructions Applying to All Sites</td>
<td>Additional Notes Specific to Breast (C50.x)</td>
</tr>
<tr>
<td>------</td>
<td>-------------------------------------</td>
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<td>-----------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>2</td>
<td>Sentinel Lymph Node Biopsy</td>
<td>The operative report states that a SLNBx was performed.</td>
<td>If a relatively large number of lymph nodes, more than 5, are pathologically examined, review the operative report to confirm the procedure was limited to a SLNBx and did not include an axillary lymph node dissection (ALND).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Code 2 SLNBx when the operative report describes a procedure using injection of a dye, radio label, or combination to identify a lymph node (possibly more than one) for removal/examination.</td>
<td>Infrequently, a SLNBx is attempted and the patient fails to map (ie, no sentinel lymph nodes are identified by the dye and/or radio label injection) and no sentinel nodes are removed. Review the operative report to confirm that an axillary incision was made and a node exploration was conducted. Patients undergoing SLNBx who fail to map will often undergo ALND. Code these cases as 2 if no ALND was performed, or 6 when ALND was performed during the same operative event. Enter the appropriate number of nodes examined and positive in the data items Regional Lymph Nodes Examined (NAACCR Item #830) and Regional Lymph Nodes Positive (NAACCR Item #820).</td>
</tr>
<tr>
<td>3</td>
<td>Number of regional lymph nodes removed unknown or not stated; regional lymph nodes removed, NOS</td>
<td>The operative report states that a regional lymph node dissection was performed (a SLNBx was not done during this procedure or in a prior procedure).</td>
<td>Generally, ALND removes at least 7-9 nodes. However, it is possible for these procedures to remove or harvest fewer nodes. Review the operative report to confirm that there was not a SLNBx in addition to a more extensive regional lymph node dissection during the same procedure (code 6 or 7).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Code 3 (Number of regional lymph nodes removed unknown, not stated; regional lymph nodes removed, NOS). Check the operative report to ensure this procedure is not a SLNBx only (code 2), or a SLNBx with a regional lymph node dissection (code 6 or 7).</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Code 4 (1-3 regional lymph nodes removed) should be used infrequently. Review the operative report to ensure the procedure was not a SLNBx only.</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>1-3 regional lymph nodes removed</td>
<td>Code 5 (4 or more regional lymph nodes removed). If a relatively small number of nodes was examined pathologically, review the operative report to confirm the procedure was not a SLNBx only (code 2). If a relatively large number of nodes was examined pathologically, review the operative report to confirm that there was not a SLNBx in addition to a more extensive regional lymph node dissection during the same, or separate, procedure (code 6 or 7).</td>
<td></td>
</tr>
<tr>
<td>Code</td>
<td>Label</td>
<td>General Instructions Applying to All Sites</td>
<td>Additional Notes Specific to Breast (C50.x)</td>
</tr>
<tr>
<td>------</td>
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</tr>
<tr>
<td>5</td>
<td>4 or more regional lymph nodes removed</td>
<td>Infrequently, a SNLBx is attempted and the patient fails to map (ie, no sentinel lymph nodes are identified by the dye and/or radio label injection). When mapping fails, surgeons usually perform a more extensive dissection of regional lymph nodes. Code these cases as 2 if no further dissection of regional lymph nodes was undertaken, or 6 when regional lymph nodes were dissected during the same operative event.</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Sentinel node biopsy and code 3, 4, or 5 at same time, or timing not stated</td>
<td>SNLBx and regional lymph node dissection (code 3, 4, or 5) during the same surgical event, or timing not known</td>
<td>Generally, SLNBx followed by ALND will yield a minimum of 7-9 nodes. However it is possible for these procedures to harvest fewer (or more) nodes.</td>
</tr>
<tr>
<td>7</td>
<td>Sentinel node biopsy and code 3, 4, or 5 at different times</td>
<td>SNLBx and regional lymph node dissection (code 3, 4, or 5) in separate surgical events.</td>
<td>Generally, SLNBx followed by ALND will yield a minimum of 7-9 nodes. However, it is possible for these procedures to harvest fewer (or more) nodes.</td>
</tr>
<tr>
<td>9</td>
<td>Unknown or not applicable</td>
<td>The status of regional lymph node evaluation should be known for surgically-treated cases (ie, cases coded 19-90 in the data item Surgery of Primary Site [NAACCR Item #1290]). Review surgically treated cases coded 9 in Scope of Regional Lymph Node Surgery to confirm the code.</td>
<td></td>
</tr>
</tbody>
</table>

Source: Facility Oncology Registry Data Standards (FORDS): Revised for 2012.

*Central registries only: If you do not have access to the operative report and the path report does not contain enough information, use code 2 when a small number of lymph nodes were examined and none were positive. (This note does not appear in FORDS and should not be applied by CoC accredited programs.)
every hospital except the one that had the lowest rate at the outset.

The numbers of nodes examined in each situation were evaluated to refine the new coding guidelines.

Table 1 shows the new code-specific guidelines as they appear in FORDS: Revised for 2012. There are 2 columns of code-specific guidelines. The first applies to Scope of Regional Lymph Node Surgery for all primary sites. The second provides additional help for breast cancers, which account for the vast majority of sentinel lymph node biopsies. In all cases, the principle source of information is the operative report, and pointers are provided to help resolve questionable codes based on the number of nodes examined. These guidelines apply to all cancers beginning with 2012 diagnoses. No standard setter is requesting recoding of older cases. Though the instructions for coding changed, the meanings of the individual codes did not change with the exception of codes assigned when an attempt to perform a sentinel lymph node biopsy fails to map.

Announcements and Registrar Education

Each standard setter took responsibility for notifying and educating abstractors, data users, and researchers in their own area of responsibility.

The NCDB developed a training survey for registrars and surgeons at its accredited programs based on 2010 non-metastatic, node-negative breast cancer cases that was modeled after the field test, so that both the registrars and the surgeons could see the effects of moving from the old to the new rules. In addition, the NCDB provided researchers who were known to be using regional lymph node surgery data with an evaluation of the potential effects of the findings on their studies. Detailed codes for Scope of Regional Lymph Node Surgery for cases diagnosed prior to 2012 will no longer be provided to any data user, so that information is limited to whether or not regional lymph node surgery took place.

SEER provided training for its state and regional staff, contacted researchers using the data item, and are suppressing the detailed codes for the item in pre-2012 breast cancer data. NPCR provided training to its program staff, and does not collect the item nationally. The North American Association of Central Cancer Registries (NAACCR) notified its members of the change through routine communications. The revised coding instructions were presented in a monthly NAACCR webinar. NAACCR plans to create a training module on the revised coding instructions and post it on the NAACCR website.

Conclusions

Cancer registry data are widely used, and coding problems of any origin can have ramifications well beyond the local registry. In this instance, a problem with the way Scope of Regional Lymph Node Surgery was collected became evident when a new use was explored. It was apparent that the problem arose from limitations in the original instructions; registrars had been following those instructions as written. The Commission on Cancer (CoC) worked with clinicians to develop a clinically-applicable set of code-specific instructions, then notified other major standard setters about the problem whose effects were confirmed by all. A careful and deliberate information and educational campaign was devised and coordinated jointly by the standard setters.

Reference

CORRECT ANSWERS FOR WINTER 2011

JOURNAL OF REGISTRY MANAGEMENT CONTINUING EDUCATION QUIZ

SURVEILLANCE OF US DEATHS RELATED TO MYELODYSPLASTIC SYNDROMES, AND THE NEED FOR LINKAGES WITH CENTRAL CANCER REGISTRIES

1. Myelodysplastic syndromes (MDS) may be described by all of the following statements, except:
   a) rarely diagnosed in children and young adults
   b) a homogeneous group of clonal myeloid neoplasms
   c) diagnosed most commonly in elderly persons
   d) risk increases with rising age

2. MDS has been a reportable diagnosis since 2001.
   a) True
   b) False

3. MDS patients have high morbidity and mortality from infections and bleeding because symptoms or complications may include:
   a) neutropenia, associated with increased risk of infection
   b) thrombocytopenia, associated with increased risk of bleeding (hemorrhage)
   c) both a and b above
   d) neither a nor b above

4. Improving the estimation of the true burden of MDS-related deaths in the U.S. population could enhance:
   a) the utility of mortality surveillance data in cancer epidemiology
   b) cancer control
   c) planning for research and treatment resources in an “aging” population
   d) all of the above

5. In ICD-10 (International Classification of Diseases Version 10), MDS:
   a) is coded under “D” for “neoplasms of uncertain or unknown behavior”
   b) is coded as malignant behavior
   c) includes the subgroup with isolated deletion of the long arm of chromosome 5
   d) distinguishes “therapy-related” MDS (t-MDS)

6. Potential errors in the death certification process may result from:
   a) the high degree of familiarity of the certifying physician or coroner with the clinical history of the decedent
   b) the difficulty in discerning the role of each specific condition in causing death
   c) taking the necessary time to properly complete the certificate
   d) all of the above

7. According to Table 1, in 2005-2006, age-standardized rates (ASR) were higher in:
   a) females than in males
   b) African Americans/blacks or other groups than in whites
   c) non-Hispanics than Hispanics
   d) the 55-64 age group than the 65-74 age group

8. According to Table 2, the most common underlying cause of death coded among deaths with myelodysplastic syndromes is:
   a) cardiovascular system
   b) diabetes mellitus
   c) respiratory
   d) malignant neoplasms

9. Death records may be used to identify high-risk subgroups of MDS, since most MDS deaths are coded to a specific MDS subgroup (Table 1).
   a) True
   b) False

10. Recent developments that may encourage more diagnostic testing are related to:
    a) the approval of new drugs for MDS that offer promise for improved survival
    b) the increase in use of potentially curative allogenic hematopoietic stem-cell transplants in elderly MDS patients
    c) a desire by clinicians to provide patients with unexplained cytopenias access to effective treatments for MDS
    d) all of the above
1. Stillbirths occur with greater frequency among:
   a) pregnancies complicated by risk factors such as diabetes, obesity, maternal hypertension, and smoking
   b) economically deprived communities compared to wealthier communities
   c) non-Hispanic black women compared to non-Hispanic white women in the United States
   d) all of the above

2. The usefulness of fetal death certificates (FDCs) as the sole data source for stillbirth surveillance might be limited because:
   a) FDCs contain complete and reliable information regarding contributing causes to fetal death
   b) variations in gestational age and birth weight reporting criteria limit the ability to compare data across states
   c) fetal death is not a reportable event in the United States
   d) all of the above

3. The primary purpose of the Metropolitan Atlanta Congenital Defects Program (MACDP) is to:
   a) perform passive surveillance of stillbirths with and without birth defects
   b) serve as a resource for education and evaluation of cancer prevention programs
   c) actively monitor birth defects among the offspring of women living in the 5 central counties of metropolitan Atlanta at the time of delivery
   d) serve as a registry for etiologic studies on causes of cancer in infants

4. Which of the following describes the inclusion criteria of the MACDP stillbirth surveillance system?
   a) Any intrauterine fetal death occurring at ≥20 weeks of gestation or ≥350 grams of weight if gestational age is unknown AND the mother is a resident of the 5-county metropolitan Atlanta area
   b) Any intrauterine fetal death occurring at ≥20 weeks of gestation or ≥350 grams of weight if gestational age is unknown AND the stillbirth occurs within the 5-county metropolitan Atlanta area
   c) Any intrauterine fetal death AND the mother is a resident of the 5-county metropolitan Atlanta area
   d) Any intrauterine fetal death AND the stillbirth occurs within the 5-county metropolitan Atlanta area

5. According to the article, active surveillance of stillbirths, building on an existing birth defects surveillance system, might serve as a model for state programs that are considering initiating stillbirth surveillance.
   a) True
   b) False

6. An in-house survey of MACDP abstractors on the efficacy of stillbirth surveillance activities indicated:
   a) active surveillance of stillbirth is simple
   b) abstractors were able to capture all needed information from a single location within the hospital
   c) obstacles in abstracting stillbirth cases included incomplete and vague information in the medical records
   d) the paper-based format of data entry was faster than the electronic surveillance data entry module

7. The MACDP method for stillbirth surveillance, which includes information both actively abstracted from medical records and passively ascertained through linkage with FDC data:
   a) results in increased case finding
   b) improves the completeness of data collected compared with using either source of data alone
   c) allows for the accurate coding of birth defects if present
   d) all of the above

8. Challenges affecting the overall quality of data include the:
   a) incompleteness of information in medical records
   b) general lack of postmortem evaluations
   c) both of the above
   d) neither of the above

9. The population of the 5-central counties of metropolitan Atlanta is demographically representative of the entire state of Georgia and the United States.
   a) True
   b) False

10. According to the table Distribution of Stillbirths by Source of Identification: Metropolitan Atlanta Congenital Defects Program:
    a) the estimated number of cases missed by both data sources (FDC and MACDP), but identified by capture-recapture methods was 29
    b) MACDP identified 106 cases that did not link to an FDC
    c) 96 cases identified by FDCs were not captured by MACDP
    d) an estimated 556 cases of stillbirth occurred in the metropolitan Atlanta area
Instructions: Mark your answers clearly by filling in the correct answer, like this □ not like this ✗. Passing score of 70% entitles one (1) CE clock hour per quiz. Please use black ballpoint pen.

1 □ □ □ □ □ □ □
2 □ □ □ □ □ □ □
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Submit the original quiz answer sheet only! No photocopies will be accepted.
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