# Analysis of Unlinked Infant Death Certificates from the NIMS Project

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**Synopsis**

*The National Infant Mortality Surveillance (NIMS) project used linked birth and infant death certificates to calculate birth weight-specific infant mortality risks for the 1980 U.S. birth cohort. Record linkage depends on complete registration of vital events, interstate exchange of vital records, accurate information on certificates, and a comprehensive linkage system.*

*States reported 2,604 unlinked infant death certificates for 1980, ranging from 0 to 397 per State. Age at death for these infants ranged from 1 minute to 11 months. More than 41 percent of the unlinked death certificates were for postneonates, compared with 32.5 percent found in the cohort's total infant death experience. Only 38.2 percent of the unlinked infant death certificates showed strictly intrastate events (birth and death occurrence, and residence at death all in one State), compared with 92.9 percent in the cohort's total infant death experience.*

*Estimates of the percentage successfully linked by State ranged from 86.0 to 100.0. After adjusting for the certainly unlinked infant death certificates, nine States' infant mortality risks increased by more than 0.2 per 1,000 live births. Improvements are needed both within and between States to ensure more complete birth and infant death certificate linkage.*

VARIOUS EPIDEMIOLOGIC INVESTIGATIONS of infant mortality (*1–5*) have emphasized the importance of analyzing infant and maternal characteristics such as birth weight, gestational age, parity, and maternal age. The death certificate alone yields little information. However, by linking infant death certificates to birth certificates for the infants who died, it is possible to relate data derived from the death certificate, such as age at death and cause of death, to data derived from the birth certificate, such as birth weight and maternal age.

In 1984, the Division of Reproductive Health of the Center for Health Promotion and Education, Centers for Disease Control, undertook the National Infant Mortality Surveillance (NIMS) project. The main purpose of the project was to determine birth weight-specific infant mortality risks for infants born in 1980 to mothers who were residents of the United States.

The methods for calculating the infant mortality risks for NIMS have been described elsewhere (*6*). A recognized limitation in the NIMS methodology was that restricting the numerator of the risks to successfully linked birth and death records would underestimate the 1980 birth cohort mortality experience because the unlinked death certificates would be omitted. The objectives of this study were to

- describe the unlinked infant death certificates for the 1980 birth cohort,
- compare characteristics of the infant deaths for which no corresponding birth certificates were

located, matched, or both to characteristics of all infant deaths for the cohort,
- estimate the proportion of the infant death certificates successfully linked by States,
- determine the effect the unlinked infant death certificates had on reported mortality risks, and
- provide possible explanations for why these infant death certificates were not successfully linked.

## Methods

**Unlinked infant death certificates.** NIMS project staff requested all 50 States, New York City, the District of Columbia, and Puerto Rico to submit some basic information on their unlinked infant death certificates, that is, those for infants for whom no corresponding birth certificates could be located or matched. Although a form was provided on which to summarize these data, States were encouraged to submit photocopies of the unlinked certificates, minus identifying information. Seventeen States submitted unlinked infant death certificate data on the summary forms. Of these, seven States reported no unlinked infant death certificates. The remaining 34 States submitted information on individual unlinked infant death certificates in the form of photocopies, computer tapes, or computer printouts.

For this study, we merged New York City and New York State information, and we excluded information from Puerto Rico. The occurrence of the vital events, birth and death, will be referred to as either intrastate (within a State) or interstate (between States). Areas that report vital statistics will be referred to as States.

**Synthetic Cohort.** One objective was to compare information from the infant death certificates for which no corresponding birth certificates could be located or matched with characteristics of all infant deaths in the 1980 U.S. birth cohort. We created a data file, referred to as the Synthetic Cohort, at CDC by using Public Use Mortality Data Tapes of the National Center for Health Statistics (NCHS) for 1980 and 1981. Only infants born in 1980 and identified by their age at death were selected for inclusion in the Synthetic Cohort. The Synthetic Cohort includes all 45,401 infant deaths among U.S. residents born in 1980.

The NCHS mortality tapes are limited to deaths that occurred in the United States. Three unlinked infant death certificates were for infants who had died outside the United States. We excluded these certificates when comparing the unlinked infant death certificates with the Synthetic Cohort.

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**Proportion successfully linked.** Two obstacles stood in the way of estimating the proportion of death certificates for the 1980 birth cohort successfully linked to birth certificates. Some death certificates submitted by one State as unlinked were undoubtedly linked by another State; it was not possible to do a follow-back survey of the 2,604 unlinked infant death certificates to determine this. In addition, States submitted linked data in tables based on the mothers' residence at the time of the infants' births, information not found on an infant death certificate.

We did not want to underestimate the proportion successfully linked by a State. Therefore, only unlinked death certificates for infants who were born, died, and resided at death in a particular State were eligible as "certainly" unlinked death certificates for that State. In all, it was possible to calculate the proportion successfully linked for 45 of the 51 States. The numerator was the total number of linked death certificates for a State. The denominator was the total linked plus certainly unlinked death certificates for that same State.

**Underreporting of infant mortality risks.** To examine the effect that the unlinked infant death certificates had on infant mortality risks (IMR), we used the following formula to calculate mortality risk adjusted for the unlinked infant death certificates:

$$\text{Adjusted infant mortality risk} = \frac{\text{(Successfully linked certificates + certainly unlinked infant death certificates)}}{\text{(Total births + certainly unlinked death certificates)}}$$

We added these certainly unlinked infant death certificates to the denominator, assuming that

Table 1. Demographic variables, Synthetic Cohort, and NIMS unlinked infant death certificates

| Variable | Synthetic Cohort total deaths | | NIMS unlinked death certificates | |
|---|---|---|---|---|
| | Percent | Number [1] | Percent [2] | Number [3] |
| Age at death: | | | | |
| Neonate | 67.5 | 30,637 | 58.7 | 781 |
| Postneonate | 32.5 | 14,764 | 41.3 | 550 |
| Age at death: | | | | |
| Minutes | 9.9 | 4,502 | 6.8 | 90 |
| Hours | 27.0 | 12,247 | 19.8 | 263 |
| Days or weeks | 30.6 | 13,888 | 32.1 | 427 |
| Months | 32.5 | 14,764 | 41.4 | 550 |
| Race: | | | | |
| White | 70.1 | 31,816 | 68.8 | 913 |
| Black | 27.5 | 12,489 | 26.8 | 355 |
| Other | 2.4 | 1,096 | 4.4 | 59 |
| Sex: | | | | |
| Male | 56.6 | 25,695 | 55.7 | 742 |
| Female | 43.4 | 19,706 | 44.3 | 590 |

[1] $N$ = 45,401.
[2] Percentages are based on total known. These may not add to 100.0 due to rounding.
[3] $N$ = 1,333. This information excludes three infant death certificates of infants who died outside the United States. Certificates with unknown characteristics are not included in counts.

those infants' birth certificates were not already represented there. This method will slightly underestimate the effect of the unlinked infant death certificates, because of the conservative definition used for certainly unlinked infant death certificates and because of possible duplication of these infants in the denominator.

## Results

The total number of reported unlinked infant death certificates for the 1980 birth cohort was 2,604, ranging from 0 to 397 per State. This represents 5.7 percent of all deaths in the Synthetic Cohort. States sent 1,336 photocopies of unlinked infant death certificates to CDC; table 1 presents demographic variables. Age at death for these infants without corresponding birth certificates ranged from 1 minute to 11 months. Ninety of the 781 neonates (less than 28 days) were less than 1 hour old at the time of death. There were 353 infants who died at less than 1 day of age. Postneonates (28 days to less than 1 year) were overrepresented in the unlinked infant death certificate subset (41.3 percent) when compared with 32.5 percent in the Synthetic Cohort. The proportions of whites and blacks and boys and girls did not differ substantially between the two groups.

Table 2 summarizes and compares the locale of vital events and residence at death between the Synthetic Cohort and the unlinked infant death certificates. Only 38.2 percent (507) of the unlinked death certificates were for intrastate birth, death, and residence at death, compared with 92.9 percent for the Synthetic Cohort. Stratification of this variable by age at death showed an even greater difference for older infants.

**Proportion successfully linked.** There was a total of 648 certainly unlinked infant death certificates from 45 States. The percentage of certificates successfully linked ranged from 86.0 to 100.0 (table 3). These 45 States had a 98.1 percent overall success in linkage, and only five States had linkage successes less than 97 percent.

**Effect of unlinked certificates on infant mortality risks.** The increase in a State's IMR ranged from 0.0 to 2.0 per 1,000 live births after adjusting for the 648 certainly unlinked infant death certificates:

| Increase in infant mortality risk per 1,000 births | Number of States |
|---|---|
| 0.0–0.2 | 36 |
| 0.3–0.5 | 5 |
| 0.6–0.8 | 1 |
| 0.9–1.1 | 1 |
| 1.2–1.4 | 1 |
| 1.5–1.7 | 0 |
| 1.8–2.0 | 1 |
| Total | 45 |

Infant mortality risks for nine States increased by more than 0.2 per 1,000 live births. In 15 States, risks were not affected by this adjustment procedure.

## Discussion

The 51 States reported 2,604 unlinked infant death certificates. This undoubtedly overestimated the unlinked infant death certificates, since some with interstate events could have been reported as correctly linked by the States in which mothers resided when giving birth. Unlinked infant death certificates represented problems in the registration system, either in birth registration completeness, the State linkage system, or the interstate exchange system.

**Possible explanations for linkage failures.** Record linkage is never easy because of difficulties with identifiers such as name, address, and race. Because the State of birth and death may be different, States must exchange certificates to ensure linkage; this compounds the linkage problem in infant mortality studies. Many possible

explanations for linkage failure have been suggested in earlier works (*7–9*). Our study found several more reasons for unsuccessful linkage of birth and infant death certificates:

- Information used for identification and linkage was incorrectly recorded on one of the certificates. Sometimes names were misspelled or dates of birth was incorrect.
- Coding errors occurred when data from certificates were transferred to computer data files.
- Some birth certificates were received through the interstate exchange too late for inclusion on computer data files.
- Some infants were found dead. No information on name, parentage, residence, or birth occurrence was available for these foundlings.
- Some infants were foreign-born and adopted by U.S. residents.
- Some infants' last names changed between birth and death.
- The interstate exchange of vital records was incomplete, resulting, for example, in unlinked death certificates for infants born out-of-State.
- Several States noted that they attempted to link only certificates of infants who were residents of that State at birth and death.
- Some births, especially for the very young neonates, either were not registered or never had certificates filed.

**Limitations.** Because of the NIMS project design, we could not verify unlinked infant death certificate data. No follow-back survey of the unlinked infant death certificates was possible because the certificates lacked personal identifying information.

Unlinked infant death certificates depended on a State's definition of what should be linked (*10*). We made no attempt to define "unlinked infant death certificate" for the States. There was, no doubt, great variance both in definitions and in content of the States' linked files. For example, birth record files may have contained only residents at birth, and death files only residents at death. One State attempted to link birth and death certificates only if the infant was a resident of that State at birth and death. Therefore, it is possible that some death certificates were not submitted as either linked or unlinked. Most States used both computer matching and hand linkage to ensure more complete birth and infant death certificate linkage.

Linked birth and infant death certificate data were presented based on residence of the mother at the time of the infant's birth. This information was not available on the unlinked infant death certificates. We used the subset of certainly unlinked infant death certificates to estimate the proportion of death certificates successfully linked and the effect of unlinked death certificates on infant mortality risks. These calculations should be used cautiously because of these underlying assumptions.

McCarthy and others (*11*) have also shown that underregistration of infant deaths can result in artificially low infant mortality risks, an important issue in any study of infant mortality. However,

Table 2. Intrastate and interstate vital events, Synthetic Cohort and NIMS unlinked infant death certificates

| State of vital events, age at death | Synthetic Cohort total deaths | | NIMS unlinked death certificates | |
|---|---|---|---|---|
| | Percent [1] | Number [2] | Percent [1] | Number [3] |
| Birth and death occurrence and residence at death: | | | | |
| Same State | 92.9 | 42,031 | 38.2 | 507 |
| Not all Same State | 7.1 | 3,194 | 61.8 | 821 |
| Birth and death occurrence and residence at death: | | | | |
| Neonates, same State | 94.0 | 28,685 | 47.9 | 373 |
| Postneonates, same State | 90.6 | 13,346 | 24.4 | 134 |

[1] Percentages are based on total known.
[2] *N* = 45,401. Certificates with unknown characteristics are not included in counts.
[3] *N* = 1,333. This information excludes three unlinked infant death certificates of infants who died outside the United States. Certificates with unknown place of occurrence of vital events or residence at death or both are not included in counts.

Table 3. Percentage of infant death certificates successfully linked with birth certificates by number of States, 1980 birth cohort

| Certificates successfully linked | States [1] | |
|---|---|---|
| | Number | Cumulative percent |
| 85–86 percent | 1 | 2.2 |
| 87–88 percent | 0 | 2.2 |
| 89–90 percent | 0 | 2.2 |
| 91–92 percent | 2 | 6.7 |
| 93–94 percent | 0 | 6.7 |
| 95–96 percent | 2 | 11.1 |
| 97–98 percent | 6 | 24.4 |
| 99–100 percent | 34 | 100.0 |
| Total | 45 | 100.0 |

[1] Data were available for 45 States.

the NIMS project was unable to quantify this potential source of bias.

## Conclusions

The record linkage process both within and between States could be improved to attain more complete linkage of birth and infant death certificates. Although unlinked infant death certificates had little effect on the infant mortality risks overall at the State and national levels, the underreporting of births may be different for various subgroups, such as low birth weight infants. When linked record data are used, those persons doing epidemiologic studies and developing programs and policies should consider carefully the quality of record linkage.

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# Experiences with Linked Birth and Infant Death Certificates from the NIMS Project


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## Synopsis


*The National Infant Mortality Surveillance (NIMS) project aggregated data provided by 53 vital statistics reporting areas—50 States, New York City, the District of Columbia, and Puerto Rico (subsequently called States)—from their files of linked birth and death certificates and compared individual States' total infant mortality experiences for the 1980 birth cohort by age at death, race, birth weight, and plurality. Therefore, it was essential to achieve maximum uniformity among the separate data sets and to specify when this uniformity could not be obtained.*