

Using Linked Birth and Infant Death Files for Program Planning and Evaluation: NIMS Workshop Lessons

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Participating in the NIMS workshop held during the conference were the maternal and child health directors and vital registrars of the 53 vital statistics reporting areas. Their cooperation and responsiveness in providing data and supporting information contributed substantially to the workshop's success and to this report.

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Synopsis.....

Health planners should base program decisions on the best information available. Combining information from different sources can be valuable in identifying problems—the essential first step in program planning. To facilitate this process, a workshop was conducted during the National Infant Mortality Surveillance Conference in Atlanta, GA. Maternal and child health directors explored the use of linked birth and infant death data for program planning and evaluation.

Linked birth and infant death certificate files permit evaluation of infant mortality by birth weight and other infant and maternal characteristics, thus providing more detailed information than birth or death certificates alone. An assessment of the birth weight distribution of live births, birth weight specific-mortality risks, distribution of deaths by birth weight, and birth weight-specific causes of death can help identify problems in the childbearing population and with the delivery of health services. Once the infant health problems are defined clearly, the selection and delivery of services can be better targeted and evaluated for the reduction of these problems.

GIVEN LIMITED RESOURCES, maternal and child health (MCH) program directors must target scarce public health services toward high-risk populations in order to reduce infant mortality. Vital records and other statistics can be used effectively to target such limited resources. In this paper we will discuss how information from vital records can assist MCH program directors to effectively identify problems and select appropriate programs to address these problems.

We based this paper on a workshop conducted during the National Infant Mortality Surveillance (NIMS) Conference, which was held May 1-2, 1986, in Atlanta, GA. This is one of a series of papers from the NIMS Conference in this issue of *Public Health Reports*. During the workshop, MCH directors explored the use of linked birth

and infant death data for program planning and evaluation. MCH directors and other program personnel had the opportunity to review information from their States, including birth weight distribution of live births, birth weight-specific neonatal and postneonatal mortality rates, and birth weight distribution of infants who died. Discussions focused on the interpretation of this information, on the programs that affect these statistics, and on identifying additional information useful for planning and evaluation. A number of important issues were raised, including the variability of data reporting among States, the establishment of birth as opposed to death cohorts, and the significance of elevated infant mortality rates. We have attempted to capture the major points from these discussions.

Problem Identification

A variety of data can be used to describe infant health problems in a State. First, the distribution of live births by birth weight can be examined to determine the extent of low birth weight (LBW); data for this distribution are collected on birth certificates. Second, information from linked birth and death certificates can be used to calculate risks of infant mortality. Infant mortality "risks" differ from "rates," because risks estimate the probability of an infant dying, using deaths observed in a cohort of births (1). A review of neonatal and postneonatal mortality risks may provide additional specific information about maternal and infant characteristics associated with infant mortality. Third, linked birth and death certificates can be used to describe the infants who died. Fourth, birth weight-specific mortality risks can be examined to identify more precisely the infants at the highest risk of dying.

To determine whether a State has a problem with low birth weight, neonatal (less than 28 days) or postneonatal (28 days to under 1 year of age) mortality, or birth weight-specific mortality, one can compare the risks of the State's infants with risks of an appropriate group. Clearly, however, different comparison groups can yield different answers to questions regarding health problems. State risk may be compared with those in the United States as a whole, those in neighboring States, or those in States in the same region (defined by the U.S. census, the Public Health Service, or other groups of States, such as those organized by the Region IV Network for Data Management and Utilization (2)). States may be compared with a standard or goal, such as the 1990 objectives for the nation set by the Surgeon General, or States may compare themselves with States (or other nations) that have attained lower mortality. To the extent that higher mortality risks may reflect the composition of a State's population, group-specific standards may be helpful. For example, although the infant mortality rate for blacks is twice the rate for whites, in many infant weight group cells black mortality risks are lower than those for white infants. Racial composition and related birth weight distribution influence State infant mortality risks as well as individual group infant mortality risks. However, use of race- or other group-specific comparisons tends to decrease differences and should not be used to cause complacency regarding group disparities. We should always apply such standards with care.

Program Implications

Once a State has determined that a problem exists, the next step is to identify an appropriate intervention that may affect the problem. We will present a framework for evaluating the birth weight distribution of live births, birth weight-specific mortality risks, birth weight-specific causes of death, and the distribution of deaths by birth weight group (3). States can use this framework to target their interventions.

Birth weight distribution of live births. Numerous studies have identified low birth weight as the most important risk factor associated with infant mortality (4). Before we can specify programs that might have an effect on low birth weight, we need to recognize the risk factors that have been linked to this problem. These factors should be used to define groups at high risk of delivering low birth weight infants and to develop and target interventions for these groups (4).

Before we can conveniently examine the birth weight distribution, we must define the birth weight groups. Birth cohorts are often defined dichotomously in terms of infants weighing less than 2,500 grams (g) (low birth weight) and infants weighing 2,500 g or more. It may be more informative to examine birth weight distribution in 500-g intervals. This permits program managers to evaluate closely changes in birth weight distribution and mortality risks among narrowly defined groups. Many States will need to balance the desire for detailed information with the small numbers of births in some categories, which will preclude this specific breakdown. These States may prefer to aggregate data over several years or to combine several birth weight categories that have similar mortality risks. One approach has been to define birth weight groups for infants weighing less than 1,500 g (very low birth weight), 1,500–2,499 g, and 2,500 g or more. Because the risk of infant deaths again increases at higher birth weights, it may be useful to split the 2,500 g or more category into 2,500–3,999 g and 4,000 g or more.

One must decide whether babies weighing less than 500 g should be included in the less than 1,500-g category. The completeness of birth and birth weight reporting for this birth weight group may vary with location. Some persons may suggest that infants weighing less than 500 g should be excluded, because virtually all infants in this birth weight category die shortly after birth. Further, given the birth of such an infant, death is usually

not preventable. The evaluation of mortality in infants weighing less than 500 g, however, may identify a need for expanded prepregnancy and prenatal services specifically designed to prevent premature births in the community.

Three important questions arise when evaluating birth weight distributions:

- Which mothers are at high risk for delivering low birth weight babies?
- What are the characteristics of low birth weight babies?
- What efforts can improve the birth weight distribution?

As previously described, States may want to consider both the very low birth weight (VLBW) infants (less than 1,500 g) and low birth weight infants (less than 2,500 g) when considering these questions. Information on the birth certificates can be used to define the characteristics related to these LBW infants, such as mother's age, race, marital status, and educational level. From this analysis, specific high-risk groups for preconceptional or prenatal care may be identified, such as minority women, unmarried women, and teenage women. Depending on the risk factors identified, appropriate interventions and needed program targeting and changes may become evident.

For example, if a large proportion of LBW infants is born to mothers with term gestations (37 or more weeks), and in definable population groups, a nutritional intervention may be indicated, such as an enhanced Special Supplemental Food Program for Women, Infants, and Children (WIC), for those women during pregnancy. Further, if many LBW infants are born to unmarried teens, there may be a need for health education programs, expanded family planning services, and special prenatal care and support services targeted at teens. If States could examine the characteristics of VLBW babies, they could identify risk factors, including geographic areas, that may be different from those for intermediate LBW infants. Thus, a need for implementing different program strategies for preventing VLBW births would be indicated.

An examination of the birth weight distribution may also reveal that certain population groups have a greater proportion of births distributed in the high-risk-LBW cells. By implementing effective LBW prevention strategies, it may be possible to improve infant mortality by decreasing the number of infants born into these high-risk categories. That is, birth weight distribution could be changed

Table 1. Mortality risks by birth weight and age at death

Age at death	Less than	1,500–	2,500–	4,000 g
	1,500 g	2,499 g	3,999 g	or more
Neonatal mortality risk	A	B	C	D
Postneonatal mortality risk . . .	E	F	G	H

NOTE: Infant mortality risks estimate the probability of an infant dying, using deaths observed in a cohort of births. Infant mortality rates are calculated by dividing the number of infant deaths in a calendar year by the number of live births in that year.

so that VLBW and LBW babies are shifted to heavier birth weight groups.

Birth weight-specific mortality risks. Turning to birth weight as a risk factor, we can consider mortality risks for different birth weight groups and the intervention and program implications of this information. Questions that program directors can ask when examining this issue include

- What are the neonatal and postneonatal birth weight-specific mortality risks for different birth weight groups?
- Which approaches are likely to affect each birth weight group?

Table 1 presents a framework that can be used for evaluating the first question. Once the problem has been clearly defined (such as by comparing the State rates with an appropriate "standard," or reference group), interventions can be considered that are likely to lower the risk. For example, a problem of neonatal mortality risk among very low birth weight infants (table 1, cell A) may require an examination of many issues. These issues might range from effectiveness of preterm labor prevention, to access to services for mothers in preterm labor, to availability of facilities for neonatal management of preterm infants, to an evaluation of existing perinatal services (such as prenatal, intrapartum, and newborn care services) that may provide less than optimum care. In contrast, a problem among postneonatal infants with very low birth weights (cell E) may indicate poor quality of followup services provided to infants discharged from neonatal intensive care units, or possibly postponement of some deaths from the neonatal period to the postneonatal period as a result of advanced care. Insufficient or inadequate community-based health services, lack of followup of high-risk infants, inadequate parenting skills, and unsafe home environments in the community may result in elevated rates in cells F and G. Health

Table 2. Data grid for evaluating infant deaths by birth weight and underlying cause of death

Cause of death	500- 1,499 g	1,500- 2,499 g	2,500- 3,999 g	4,000 g or more
Perinatal conditions				
Infections				
Congenital anomalies				
Injuries				
Sudden infant death syndrome				
Other				

officials can also use these data to evaluate the effectiveness of certain programs. For example, if a State has well-established regionalized services for perinatal care, one would not expect a problem in cells A through C. The more clearly one can define the issue in terms of birth weight-specific mortality, the easier it may be to relate the problem to needed programmatic changes.

It may also be important to examine a frequency distribution of the specific timing of neonatal deaths within birth weight cells. This analysis can indicate critical times, associated with an increased risk of neonatal mortality. In addition, problems in the perinatal care system may be identified, suggesting needed areas for change.

Birth weight-specific causes of death. Another article in this issue (5) examines causes of death by birth weight. Information on causes of mortality is available from linked data and may further identify appropriate interventions that should be implemented.

To use cause-of-death information for program planning and evaluation, program directors should consider two questions:

- What are the major causes of death for each birth weight group?
- What interventions are likely to affect those causes?

Table 2 may be helpful in organizing an examination of cases of death by birth weight groups. We grouped diagnoses into categories that are logical from an analytic and a programmatic perspective (5). Analyzing this information by neonatal and postneonatal age groups provides additional useful information. For example, injuries are the fourth leading cause of postneonatal death, and the majority occur among infants weighing 2,500 g or more (5). Thus, a parenting

education program covering injury prevention may have its greatest impact on postneonatal mortality in this birth weight group. Many such programs may appropriately begin in the neonatal period, such as promoting the use of car seats for infants discharged from newborn nurseries. On the other hand, improved access to advanced neonatal technology, such as a new neonatal intensive care unit, would have a greater impact on neonates weighing less than 1,500 g. The leading causes of death for these infants are prematurity-LBW and respiratory distress syndrome-bronchopulmonary dysplasia (5).

Birth weight distribution of deaths. The birth weight distribution by age at death combines the effects of the birth weight distribution of births and age- and birth weight-specific mortality rates. Combining the effects of birth weight on neonatal mortality and on postneonatal mortality, the NIMS data showed that in 1980 babies of known low birth weight (less than 2,500 g) accounted for 57 percent of all infant deaths among single-delivery infants, while babies of known birth weights of 2,500 g or more accounted for 43 percent of infant deaths (1,6). Neonatal mortality is largely a problem of deaths among VLBW and intermediate low birth weight (1,500-2,499 g) babies, reflecting the extremely high infant mortality risks among these smaller babies.

Some groups may be at lowest risk, yet still represent a substantial proportion of deaths because of the high number of births in that group (table 3). Of all live births, approximately 93 percent of infants weigh 2,500 g or more; only 1 percent weigh less than 1,500 g (6). Even though small infants have a higher risk of death, many deaths occur to normal weight infants. Some of the deaths among infants weighing 2,500 g or more may not be preventable, such as deaths due to severe congenital anomalies, but further investigation is needed to identify high-risk subgroups within this larger low-risk population. Thus, a critical issue arises: should efforts be directed toward highly effective and improved interventions and services more likely to benefit the low-risk group or toward increased services for high-risk infants? This issue emphasizes the importance of analyzing birth weight-specific data as well as examining the cost-effectiveness of intervention programs.

The foregoing examples illustrate that the identification of appropriate interventions can be improved by carefully defining the problem. These examples also illustrate that interventions which

might alleviate one problem in a specified birth weight group may have only a minimal effect on other birth weight groups. It is thus important to consider these data both when selecting an intervention and when evaluating its effects.

Data Limitations

When using State-specific infant mortality data, several limitations of the birth weight-specific mortality data should be kept in mind. Because some categories contain small numbers of births and deaths, some numbers will be "unstable." Reliance on these data may lead to incorrect conclusions. For example, in several States that reported birth weight-specific neonatal or postneonatal risks higher than U.S. risks, closer examination revealed that a few deaths in a small population of births can result in elevated risks within subgroups of that population. Marks and coauthors (7) discuss this problem in detail in this issue of *Public Health Reports*, looking at State ranges of birth weight-specific mortality. Thus, we advise caution in interpreting risks that involve small numbers. Correcting this problem may require aggregating data over several years.

In addition, isolated statistically significant risks do not always imply program or clinical importance. Careful evaluation of all data should help clarify the meaning of a given significant measure. Consideration of birth and death data, birth weight-specific mortality, and causes of death may reveal an underlying pattern of excess mortality and may suggest the need for intervention strategies.

Additional Planning and Evaluation Issues

Effective communication between program managers and statisticians is essential to program planning because the latter produce the data used by the former. However, communication may be difficult, given the different backgrounds and perspectives of persons working in the two areas. Vital statisticians are often concerned with the maintenance of records and reporting issues, including data collection methods and the accuracy, completeness, and timeliness of vital records. Vital registrars are also concerned with efficient service to the many citizens needing copies of birth, death, marriage, and other certificates. Program managers are interested in the delivery of quality health services and reducing morbidity and mortality associated with a variety of health problems.

Table 3. Percentage distribution of single-delivery infant deaths by birth weight and age at death, 1980 U.S. birth cohort

Age at death	Less than 1,500 g	1,500– 2,499 g	2,500 g or more	Unknown	Total ¹
Neonatal	36.1	10.5	17.3	2.8	66.7
Postneonatal	3.3	5.5	24.2	0.4	33.3
Infant ¹	39.3	16.0	41.5	3.2	100.0

¹ Percentages may not add to total because of rounding.
SOURCE: National Infant Mortality Surveillance.

The NIMS Conference included a joint workshop, comprising both MCH directors and vital statisticians, that focused on communication between these two groups.

As an example of the benefits of effective communication, the joint workshop participants discussed the importance to program planners and evaluators of establishing a birth cohort rather than a death cohort. If linkages are made, they are done when death certificates are registered and are often initially arranged in death cohort files—all deaths that occurred in a given year linked to birth certificates. It is a relatively simple step to convert such files back to birth cohort files, using the entire birth records for a given year. The result is a birth cohort file—all births in a given year including linked certificates for cohort members who died in the first year of life. The birth cohort permits calculation of infant mortality risks. This linkage also allows for the analysis of infant mortality risks according to characteristics reported on the birth certificate, which may be extremely useful for making comparisons between favorable and unfavorable outcomes. The NIMS data, for example, are based on a birth cohort file.

To improve interpretation and usefulness of data for program evaluation, linked birth and infant death files can be linked with program files. This may not necessarily be easy to do, especially if program files do not have good identifiers that can be linked with vital records. However, a number of States have successfully linked Medicaid files, WIC files, program service files, and hospital discharge files to the NIMS data base. This allows further analyses of pregnancy outcomes by many additional variables, such as measures of socioeconomic status, presence of maternal and neonatal complications, and provider of care. Linking these program records to birth-death files adds another dimension to the evaluation capabilities of the file. It permits assessment of birth weight and birth weight-specific infant mortality risks for persons

served by various programs, comparison of those persons enrolled in programs with nonparticipants, and assessment of the penetration of programs among high-risk groups. As data and program personnel begin to understand the value of linked files, they can develop records that will facilitate future linkage efforts.

Conclusion

The linked birth and infant death file, organized as a birth cohort, provides State and national researchers with a unique and powerful tool to analyze infant mortality. The linked file can be readily created to identify maternal and infant factors associated with increased risks of infant mortality. These risk factors can be identified by comparing a State's or an area's infant mortality risks with an appropriate standard. The periodic preparation of a national linked birth and infant death cohort file is an important element in this process (8), because it allows individual areas to make comparisons with national infant mortality risks.

Once the birth outcome file has been created, linkage with other program and service files provides State MCH personnel with an ongoing

system for program evaluation based on firm outcome measures. The creation and routine use of this powerful tool can become a part of the State's process for problem identification, program design, and evaluation.

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The NCHS Pilot Project To Link Birth and Infant Death Records: Stage 1

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Synopsis.....

The National Center for Health Statistics (NCHS) has completed a pilot test of its method to develop national linked files of birth and infant death records. A linked file of the 1982 birth

cohort was produced that successfully linked 97 percent of the death records for infants who died in a nine-State area.

The method NCHS uses to create national linked files takes full advantage of two existing data sources: the NCHS fully coded natality and mortality files and State files of matched births and infant deaths. For the nine-State pilot area, NCHS obtained computerized linked files from the States and extracted from them the certificate numbers on matching birth and death records. With the use of these numbers, NCHS selected and linked birth and death statistical records from its final natality and mortality files, thus creating new statistical linked records. The initial match rate of 93.2 percent for the project's linked record file was increased to 96.7 percent as a result of efforts by the pilot States to complete the matching of birth and infant death records. Matching in the nine-State linked file appears to be highly accurate, based on the results of two evaluation studies.