



Health

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Reproductive Health Surveillance Volume I: Maternal and Infant

Role of Surveillance

**Pregnancy Risk
Assessment
Monitoring**

**Fetal Infant
Mortality Review**

**Infant Mortality:
A Social Mirror**

**Assessing Tragedy:
Maternal Mortality
Surveillance**

Birth Defects

**MCH Leaders
Reflect on
Surveillance Data**



UNIVERSITY OF MINNESOTA

School of Public Health

**Reproductive Health
Surveillance I:
Maternal and Infant**

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LETTER FROM THE EDITORS

As we welcomed 2009 we were struck by how different the world is today than it was even 18 months ago, never mind the way it looked 55 years ago when our program was born. We, as a program and as professionals, continue to evolve—and through that evolution there has been but one constant: change. We have seen this change in big and small ways. New people, projects, changes in funding and priorities, and changes in our understanding of the public health issues we face will shape how we move through 2009. We are pleased to bring another change to you with this volume of Healthy Generations. You will notice a dramatic transformation—from color palette to layout—but the high quality content you have come to expect from Healthy Generations and the Center for Leadership Education in Maternal and Child Public Health remains unchanged.

The focus of this volume, and its companion to follow, is Reproductive Health Surveillance. Reproductive health surveillance in the United States provides data necessary for evidence-based decision-making about health program and policies. We could not set health goals, nor measure our progress toward reaching them, if we could not measure the magnitude of disparities and the nature of wellness and poor health. Data alone may be dry and dusty, but its translation into innovative programs and ethical policies is poetry. We have created this volume, and a forthcoming volume, to celebrate surveillance and its precious product: data.

We would love to hear your feedback about the new design, the articles in this volume – or to learn more about topics or issues you would like to see featured in Healthy Generations.

—Wendy Hellerstedt, MPH, PhD, and Julia Johnsen, MPH

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The Role of Surveillance in

Assuring Reproductive Health

Wendy Hellerstedt, MPH, PhD



“Behind each number is a human face”

—William Foege, MD, MPH

Birth certificate registration is a form of reproductive health surveillance that has been conducted for centuries worldwide (its initial purpose may have been to facilitate tax collection). Birth registration has occurred in the U.S. since the beginning of the 20th century, but the National Survey of Family Growth (NSFG), initiated in 1973, may be the nation's first population-based surveillance system focused on reproductive health.³

Purpose of Reproductive Health Surveillance

Reproductive health problems cannot be addressed, and reproductive and sexual health cannot be enhanced, without high-quality data. According to the CDC,¹ surveillance is used to:

- Estimate the magnitude of a health problem (e.g., how many low birthweight births occur);
- Portray the natural history of a disease

The Centers for Disease Control and Prevention (CDC) directs some of the most important surveillance projects in the U.S. According to the CDC, “Public health surveillance is the systematic, ongoing assessment of the health of a community, based on the collection, interpretation, and use of health data and information. Surveillance provides information necessary for public health decision making.”¹ The first use of surveillance data may have been during the bubonic plague in the 14th century, when health authorities boarded ships near the Republic of Venice to prevent persons ill with plague-like symptoms from disembarking.² Until recently, surveillance was restricted to monitoring people exposed to serious communicable diseases, like smallpox, in order to institute isolation and control procedures if necessary. The use of surveillance to monitor health events in populations expanded in the 1960s to include collection, analysis, and dissemination of a variety of health indicators.²

- (e.g., how does toxic shock syndrome manifest in menstruating women?);
- Determine the distribution and spread of illness (e.g., how many cases of Chlamydia are there in southern Iowa?);
- Detect outbreaks (e.g., are rates of neonatal syphilis increasing?);
- Generate hypotheses and stimulate research (e.g., inadequate folate is associated with risk for neural tube defects);
- Evaluate control and prevention measures (e.g., what is the reach of a local mammography screening program?);
- Monitor changes in infectious agents (e.g., resistance of some cases of gonorrhea to treatment);
- Detect changes in health practices (e.g., cesarean deliveries are increasing in the U.S.); and
- Facilitate health planning (e.g., family planning clinics may be able to reduce rates of unintended pregnancy by expanding services to men).

Key Reproductive Health Indicators

International leaders, led by organizations like the World Health Organization and inspired by documents like the Millennium Development Goals, developed a “short list” of reproductive health indicators that should be monitored by every country (Table 1). These indicators are universally relevant and no country, including the U.S., successfully monitors all of them.

Considerations in Surveillance

Successful surveillance must have:

- Indicators with *carefully developed case definitions*: a set of standard criteria (clinical, laboratory, epidemiological) to evaluate whether someone has a particular disease or health related condition;
- *Valid sources of data* that may include birth and death certificates; insurance data; census data; health-facility registries or records; medical laboratory records; public health program and/or service delivery records; and community-, school-, worksite- or household-based surveys; and

Continued on page 2

TABLE I.

Shortlist of indicators for global monitoring of reproductive health

1. Total fertility rate	10. Prevalence of positive syphilis serology in pregnant women
2. Contraceptive prevalence	11. Prevalence of anemia in women
3. Maternal mortality ratio	12. Percentage of obstetric and gynecological admissions due to abortion
4. Prenatal care coverage	13. Reported prevalence of women with genital mutilation
5. Births attended by skilled health personnel	14. Prevalence of infertility in women
6. Availability of basic essential obstetric care	15. Reported incidence of urethritis in men
7. Availability of comprehensive essential obstetric care	16. Prevalence of HIV infection in pregnant women
8. Perinatal mortality rate	17. Knowledge of HIV-related preventive practices
9. Prevalence of low birth weight	

Note: This list is taken directly from the World Health Organization.⁴

- **Relevant time periods:** surveillance may be conducted monthly or in 3-5 year cycles; health-facility reports may be scanned daily or weekly; or census data may be collected every decade or every year. The time period depends on the indicators of interest, especially how rapidly incidence and prevalence may change.

Sentinel and Population-based Surveillance

The intent of *population-based surveillance* is to produce data that reflects a broad population (e.g., all residents of a state or a country). Birth certificate data in the U.S. are population-based in that almost 100% of births are documented. Both the NSFG and the Pregnancy Risk Assessment Monitoring System (PRAMS) are designed as population-based reproductive health surveillance tools. Such surveillance usually involves complex sample selection designs to ensure representativeness. *Sentinel surveillance* restricts surveillance to a specific geographic area (e.g., major metropolitan areas), a specific population (e.g., family planning clinic clients), or even a specific set of data sources (e.g., pediatric hospital laboratories). Such restriction may be related to a desire to capture data on high-risk individuals or to enhance population-based surveillance. For example, gonorrhea is a reportable infection for the entire population in the U.S. To enhance surveillance (and knowledge

about antibiotic resistant strains), the Gonococcal Isolate Surveillance Project (GISP) was established in 1986. It involves select sexually transmitted infection clinics in 28 cities and five regional laboratories. These sentinel sites involve more detailed biospecimen and demographic surveillance than conducted through the population-based surveillance for STIs.⁵

There are several advantages of sentinel surveillance compared with population-based surveillance, including lower cost and burden and the possibility of more timely or routine monitoring. The disadvantages include the fact that the monitored sample is biased and sometimes the data cannot be generalized beyond the sample.

Passive and Active Surveillance

A surveillance system may collect data passively or actively, or both ways. *Passive surveillance* refers to a system in which health authorities receive information passively from multiple sources through a standardized reporting system. Data sources may include hospitals, physicians or administrative databases (i.e. Medicaid data, vital records).⁶ For example, birth defects surveillance is often passive. Although passive surveillance is less costly than active surveillance, cases may be under-reported and submitted data may be incomplete. *Active surveillance* requires a greater commitment of time and resources



than passive.⁷ Instead of relying on data sources to report to a surveillance system, surveillance staff actively identify potential cases, abstract information from multiple data sources, and follow-up on each case to verify information.⁶ Sexually transmitted infection surveillance often use some form of active surveillance. Data from active systems are generally considered to be of higher quality than data from passive systems.

Analysis, Interpretation and Dissemination of Surveillance Data

Data from surveillance systems have to be analyzed in a timely and accessible manner, to assure use. The purpose of surveillance data is translation into health planning, program development and policy formation. The architects of surveillance systems must be as dedicated to the dissemination of interpretable data as they are to the design of their data collection protocols. The internet has expanded our ability to access data and apply it to our public health work. Data from reproductive health surveillance projects, like the NSFG and PRAMS, are in the public domain and available for analyses. The CDC also produces many surveillance reports, including: (1) the Morbidity and Mortality Weekly Report that provides summary data about many health conditions;^{8,9} (2) summary reports from the NSFG³ and PRAMS;¹⁰ (3) summary birth data;¹¹ and

(4) global reproductive health summaries from its MEASURE CDC project.¹² The CDC also maintains a website to allow users to create data reports from a variety of sources, covering many chronic disease, behavioral, and infectious disease health topics.¹³

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Definitions of Some Widely Used Maternal and Infant Health Indicators

General Fertility Rate. The rate of livebirths to 15-44 year-old women in a given population during a specific time period.

Total Fertility Rate. The average number of births to a hypothetical cohort of 1,000 women calculated with the age-specific birth rates observed in a given year for a specific population.

Pregnancy Rate. The ratio of the number of conceptions in a period of time (estimated from birth, abortion, and fetal loss data) divided by the mean number of women of reproductive age (i.e., 15-44 years-old) for a given population.

Crude Birth Rate. The number of livebirths in a population in a year (or other specified time period) divided by the midyear resident population.

Infertility. A couple, or an individual, is considered infertile if they have tried to conceive for 12 months or longer without the use of contraception and have not become pregnant.

Adequacy of Prenatal Care Utilization (APNCU) Index. Using information from U.S. birth certificates, this is one of several indexes to characterize the utilization of prenatal care (e.g., timing of first visit and total number of visits during pregnancy).

Perinatal Period. Though the definition varies, the perinatal period refers to the time shortly before and after birth. According to several sources, including the Centers for Disease Control and Prevention and the World Health Organization, the period ranges from 20 to 28 weeks of gestation to one to four weeks after birth.

Postpartum Period. Often defined as the period between the day of birth and 42 days after a mother gives birth.

Gestational Age. There are several ways to estimate the gestational age of a fetus and of an infant at birth. One of the most common is to estimate gestational age as the period of time between the first day of the last menstrual period and the day of birth (or day of fetal examination) minus two weeks.

Preterm Birth. A birth that occurs before 37 weeks' gestation (i.e., term). Preterm is defined as a birth at 36 weeks' gestation or younger and extremely preterm is defined as a birth at 32 weeks' gestation or younger.

Low Birthweight. A weight at birth of less than 2,500 grams, or 5 pounds 8 ounces. Very Low Birthweight is defined as weight at birth of less than 1,500 grams or 3 pounds 4 ounces.

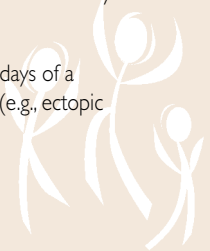
Small for Gestational Age (SGA). Usually defined as birthweight between 0-10%, for a given gestational age and sex, based on a population reference. Large for Gestational Age (LGA) is defined as a birthweight between 91-100%, for a given gestational age and sex, based on a population reference.

Spontaneous Abortion. A pregnancy loss before the 20th week of pregnancy. In contrast, an Induced Abortion is the intentional termination of a pregnancy.

Fetal Death. Definitions vary, but usually this refers to the death of a fetus that occurs after the 20th week of pregnancy, but prior to birth during a specific time period.

Infant Mortality. The death of a live-born infant anytime between 0 and 364 days (i.e., before the end of the first year of life). Neonatal Mortality is the death of a live-born infant during the first 27 days of life; Postneonatal Mortality is the death of a live-born infant during days 28-364 of life.

Maternal Mortality. The most common definition is the death of a woman within 42 days of a pregnancy termination (e.g., induced abortion, livebirth), irrespective of site of pregnancy (e.g., ectopic pregnancies are included), from a pregnancy-related cause.





The Pregnancy Risk Assessment Monitoring Systems (PRAMS)

Jessie Kemmick-Pintor and Sarah Klawitter

The Pregnancy Risk Assessment Monitoring System (PRAMS), launched in 1987, is a national, population-based public health surveillance system that gathers information from recent mothers about their own and their infant's behaviors and experiences before, during and immediately after delivery of a live infant. PRAMS is a collaboration between the Centers for Disease Control and Prevention (CDC) and the health departments of the participating states. Thirty-seven states (Figure 1) participate in PRAMS, as well as New York City and South Dakota (Yankton Sioux Tribe).

The Purpose of PRAMS

The purpose of PRAMS is to explore the relationships between prenatal behaviors and infant outcomes¹ in order to "... improve the health of mothers and infants by reducing adverse outcomes such as low birth weight, infant mortality and morbidity, and maternal morbidity."² The CDC launched PRAMS because the decline in infant mortality began to slow and the rate of low birthweight had not significantly changed in the previous 20 years. Before PRAMS was established there were insufficient maternal and infant data for state-by-state analyses of birth and prenatal health trends.¹ Each state has varying levels of data available, depending on when PRAMS was introduced locally. South Dakota, which started collecting data in 2008, has what is referred to as a "point in time" PRAMS, which involves data collection for a limited period.² By comparison, Minnesota and Michigan conduct annual data collection, but Minnesota only recently began doing so, while Michigan's data collection goes back to 1996.²

PRAMS Design

Sample. Health departments select participants from a stratified random sample of birth certificates. The strata are usually based on maternal race and infant

low birthweight (i.e., < 2500 grams), as reported on the birth certificate. Selected mothers are invited to participate in PRAMS two to four months after the birth of their infants. Women whose infants have died are also included in the sample. For women who have given birth to multiple infants, one infant is randomly selected as the study infant. States may oversample based on variables like maternal race/ethnicity to facilitate data analysis on smaller populations. The annual data collection period for PRAMS is from April to the following June. Participating states identify a random sample of 100-250 birth certificates every month. In Wisconsin, for example, 155 women are selected each month to participate.³

Data collection. PRAMS is primarily a mail survey. Selected mothers are sent a letter introducing PRAMS and later, a self-administered questionnaire. Telephone follow-up is conducted to reach those who don't respond. PRAMS is a confidential, but not anonymous, survey, because PRAMS data are linked to the infant's birth certificate.

The survey has two parts – a set of core questions that must be used in every state and a set of questions developed by the CDC or by states. The second set of questions allows each state's PRAMS to be unique to their site and particularly



FIGURE I.
Participating PRAMS states in dark gray

State map distinguishes PRAMS from non-PRAMS states. PRAMS states are dark gray.

Source: <http://www.cdc.gov/prams/states.htm>

meaningful for their constituency. The core questions asked by all states include information about:

- attitudes and feelings about the most recent pregnancy;
- content and source of prenatal care;
- maternal alcohol and tobacco consumption;

- physical abuse before and during pregnancy;
- pregnancy-related morbidity;
- infant health care;
- pre-conception contraceptive use; and
- mother's knowledge of pregnancy-related health issues, such as the adverse effects of tobacco and alcohol, benefits of folic acid, and risk factors for HIV.⁴

Questions about health insurance coverage, pre-conception and prenatal multivitamin use, household income, infant's sleeping position, breastfeeding, assisted reproductive technology use, postpartum depressive symptoms, and infant car seat use are also included.⁴

Analysis. State health departments generally analyze their own data and the CDC is responsible for comparative analysis between states. There is typically a 1 or 2 year lag time between the year of data collection and release of the data from the CDC to a state. National and state data are available to outside researchers. Interested individuals should submit a brief research proposal to either the CDC, for multi-state analyses, or to participating states' PRAMS Coordinators, for single state analysis.

Strengths

PRAMS is the only national surveillance tool that addresses maternal health, from pre-conception to the early postpartum period, and newborn health. PRAMS measures reflect key maternal and child health (MCH) indicators. The data are critical to monitoring regional, state, and national progress in meeting goals set forth by Healthy People.⁵ Sites are located in various regions of the country, and PRAMS is considered to be reasonably representative of the population of recent mothers. Because the design and measures in PRAMS are the same at every site, it is possible to compare data from states and regions.

Challenges

PRAMS isn't perfect. Not all sites have collected PRAMS for the same period of time, so there are limits to how many sites can be included in longterm trend analyses. The population, while randomly selected, may still be biased. For example,

adoptive mothers are not included in the sample. The CDC requires that a site achieve at least a 70% response rate for analyses and most sites do not exceed that minimum requirement by a great percentage. Therefore, the database does not include women who could not be located for the survey or who refused to participate in the survey. A study by Shulman, et al. examined PRAMS non-response in 23 states in 2001, by comparing data for their infants' birth certificates for women who did and did not respond to a request to participate in PRAMS. It was found that less than half of the 23 states were able to achieve the necessary 70% response rates in 2001 for several important high-risk groups including black women, teens, unmarried women, women with less than a high school education, and women who received late or no prenatal care.⁶ PRAMS weights data in an attempt to adjust for non-response bias. There may be some information biases as well. Women participate when their infants are 2 to 4 months of age and thus they may not be able to accurately respond to questions about events or behaviors that occurred up to 12 months before they got pregnant. Women may also be unwilling to disclose information that they feel is socially unacceptable, such as smoking or drinking alcohol during pregnancy.

From Data to Action

Data from PRAMS are used to identify high-risk populations, plan and evaluate MCH programs and policies, measure success in meeting MCH goals, and identify MCH research questions. The CDC aggregates PRAMS data to compare national trends over time, to assess regional differences, and to describe MCH indicators for the U.S. annually.⁵ One important achievement of PRAMS was to provide data to evaluate the effectiveness of the Back to Sleep campaign, a national initiative launched in 1994 by the American Academy of Pediatrics (AAP) to reduce the incidence of sleep related infant death. National PRAMS data demonstrated an observed decline in the prevalence of prone infant sleeping⁷ and also drew attention to the disparities between racial/ethnic groups and stressed the importance of focused interventions in populations where changes in sleeping position were not as pronounced.⁷

Individual sites use their data to identify trends, assess their progress in serving mothers and infants, and develop MCH goals. They prepare special reports of interest to their constituency. For example, in Minnesota, PRAMS data have been used to look at maternal depressive symptoms, pre-existing and gestational diabetes, risk factors for type II diabetes, pregnancy intention, and prenatal care initiation. In addition, learning more about health disparities, particularly low birthweight and infant mortality outcomes in African-American and American Indian population, has been a priority for PRAMS in Minnesota.⁸ Michigan uses its PRAMS data to develop periodic newsletters on topics such as violence, prenatal care, prenatal substance use, maternal folic acid use, infant sleep position and breastfeeding.⁹

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Fetal Infant Mortality Review:

Building Stories—Shaping Practice

Jessie Kemmick-Pintor and Julia Johnsen, MPH

When an infant dies, there are many questions that must be asked to better understand this tragic event and prevent future losses. Did the family receive the necessary services and/or resources? Do gaps exist in the service system or community resources? What can this infant's death tell us about how families can use existing local resources? Are services accessible and culturally appropriate?¹ Currently conducted by over 220 programs in 40 states, the Fetal and Infant Mortality Review (FIMR) process seeks to better understand the factors that contribute to fetal/infant deaths by answering some of these questions.



What Is Fetal and Infant Mortality Review (FIMR)?

FIMR is a population-based intervention implemented with guidance from the National Fetal and Infant Mortality Review Program (NFIMR), a public-private partnership between the Maternal and Child Health Bureau (MCHB) and the American College of Obstetricians and Gynecologists (ACOG). The model dates back to 1988 when the MCHB funded the first eight demonstration projects. A FIMR is “an action-oriented community process that continually assesses, monitors, and works to improve service systems and community resources for women, infants, and families.”² A fetal or infant death is the sentinel event that begins the process. A FIMR generally involves:

- **Gathering information** about the infant death. Sources include public health and medical records.
- **Interviewing the mother** who has

suffered the loss, if she agrees. Professionals with training in grief counseling assess the needs of the family and refer to bereavement support and community resources.

- **Review by a Case Review Team** (health, social service and other community experts) of the summary case information and the interview to identify issues and make recommendations for community change, if appropriate.
- **Review by a Community Action Team** (community leaders) of the Case Review Team's recommendations in order to prioritize issues and to design and implement interventions to improve service systems and resources.

Throughout the review, the confidentiality of the affected mother, family, and infant is maintained. When rigorously conducted, a FIMR can provide information for program and policy development essential

“Infant mortality is the most sensitive index we possess in social welfare”

— Julia Lathrop, Children's Bureau, 1913

to improving services for women, infants and families. “Increasingly, FIMR is recognized as a strategy for contributing to implementation of the core public health functions of assessment, policy development, and quality assurance.”³

What Are the Aims of FIMR?

FIMR is a community coalition-building and action-oriented process model that seeks to identify creative solutions to improve local resources and systems of care. As a perinatal systems initiative, FIMR is a case-by-case review of fetal/infant deaths to determine medical, social, cultural, and environmental factors that may contribute to fetal and infant deaths. A FIMR can

be convened by any department of health, municipality, or program, but are frequently funded and convened through state or local departments of health. FIMR projects seek to:

Objectives⁴

1. Examine factors associated with fetal and infant mortality that emerge through case review.
2. Plan and prioritize community-based interventions and policies to address factors and improve service systems and community resources.
3. Participate in implementation of community-based interventions and policies.
4. Assess the progress of interventions.

The process of developing and implementing recommendations based on the case review process is a strength of FIMR projects. The aim of the FIMR model is to affect systems change with the ultimate goal of reducing preventable fetal and infant death. It is through this part of the process that FIMR projects have the greatest potential for influencing MCH programs, policies and practices.

Challenges to Implementation

According to the National Center for Health Statistics, the U.S. infant mortality rate for 2002 was 7.0 per 1,000 live births.⁵ This figure represents an increase from the 2001 rate of 6.8, the first time the rate had not either declined or stayed the same since 1958. In Minnesota, the infant mortality rate declined from 5.4 in 2001 to 5.3 in 2002, ranking the state among the lowest in the nation.⁶ Despite this decrease, disparities persist: African Americans and American Indians experience infant mortality at rates twice as high as whites.⁷ FIMR has been used in Minnesota to more fully understand the factors that contribute to these disparate rates. However, Minnesota statutory language and limited funding have made conducting reviews difficult. Legislation granting the authority to implement FIMRs was allowed to expire in 2000.⁸ Currently no funds have been allocated by the Minnesota state legislature to conduct fetal and infant mortality reviews, however, the Infant Mortality Reduction and Eliminating Health Disparities Initiatives do provide funding for the prevention of infant mortality. The Infant

Mortality Reduction Initiative supports the promotion of activities that improve pregnancy outcomes and reduce preventable mortality, while the EHDI funds community infant mortality prevention projects, as well as seven other priority areas, through a competitive grant process.

According to NFIMR, “most states have some type of general public health statutes that have been used to implement and safeguard FIMR proceedings.”⁹ For states like Minnesota, that do not have this type of statutory authority, FIMR can be a difficult process. Cheryl Fogarty, the Minnesota Department of Health (MDH) Infant Mortality Consultant, has experienced these hurdles firsthand. “While the interview with the mother is always the most valuable piece of information,” Fogarty said, “the lack of statutory language authorizing the review of death and vital records of those families that do not participate in these interviews puts FIMR projects at a disadvantage.” Fogarty goes on to describe one such challenge: that women who choose to participate in FIMR interviews may be different than those who do not. “You end up getting a very skewed picture of infant deaths in a community because often those mothers who agree to interviews and release of records are not the most at risk and the circumstances surrounding the death of the infant are likely very different from those who do not consent to the review process.” Despite these difficulties, communities in Minnesota and neighboring Wisconsin have been able to conduct some significant projects that have had important implications for their communities.

FIMR Projects in the Midwest

Minnesota American Indian Infant Mortality Review Project

From 2005 to 2007, a group of nearly 30 individuals conducted the Minnesota American Indian Infant Mortality Review Project as a collaborative effort of the Great Lakes EpiCenter, Bemidji Area Indian Health Service, and the MDH. The case review team was made up of social workers, physicians, nurses, a medical examiner, first responder, and other professionals representing the fields of public health, tribal health, behavioral health, education, and epidemiology. Case review team member and Executive

Director of the Division of Indian Work, Noya Woodrich, stressed the importance of these reviews: “Ongoing reviews of fetal and infant deaths in Minnesota’s American Indian tribal and urban communities are crucial to our understanding of the issue [disproportionately high rates of infant mortality among American Indians]. As we continue to grow our understanding of the issue we can truly find solutions for this long-lasting tragedy in our communities.”

City of Milwaukee Health Department

The Milwaukee Health Department recently released the findings of a FIMR project that reviewed infant deaths from 2002-2004 and fetal deaths in 2003 and 2004. The project was a component of the Milwaukee Healthy Beginnings Project, funded by the Black Health Coalition of Wisconsin through a U.S. Health Resources and Services Administration Healthy Start Grant. It examined fetal and infant deaths in Milwaukee and found that in 2003 the infant mortality rate for all races was 11.4/1000 live births. Here, too, disparities persist: among non-Hispanic whites the rate was 6.0/1000 and for non-Hispanic blacks it was 16.0/1000.¹⁰ This public health crisis came to the attention of policy makers and health and social service professionals, and the Commissioner of Health declared combating infant mortality a top public health priority.¹¹ The community came together to address these disparities through FIMR and are now putting recommendations from their report to work in the field. One accomplishment is a collaborative between local birthing hospitals that includes subcommittees on three major issues related to infant health: safe sleep practices, prenatal tobacco use, and prenatal care coordination. The health department’s FIMR Coordinator, Karen Michalski, notes that “as a result of this collaboration, institutions have come up with regulations, policies, and procedures that have never before been part of their organizations.” It is through the development and implementation of these systems based changes that the FIMR model seeks to influence the more distal outcome of fetal and infant mortality.

A National Evaluation of FIMR

A national evaluation of FIMR was conducted between 1996 and 1999 by the John Hopkins University’s Women’s and

Children's Health Policy Center.^{3,12} According to the Center's website, the evaluation had the following objectives:¹³

1. To understand the impacts of FIMR on community resources and MCH service delivery systems.
2. To identify the key factors contributing to the effectiveness of FIMRs in improving community resources and service systems available to women, infants, and their families.
3. To assess the implications of FIMR for maternal and child health practice in terms of public health core functions.

Findings revealed that FIMR programs make significant contributions to improving systems of care for women and infants by engaging in essential MCH services (EMCHS).¹³ They also found that when FIMRs were present in communities with other perinatal systems initiatives (PSI) both efforts are more likely to be engaged in EMCHS, suggesting a synergistic relationship between FIMRs and other PSIs.¹⁴ The full results are presented in a special issue of the *Maternal and Child Health Journal* (December, 2004).

For more information on the national evaluation, visit the Center's website at: www.jhsph.edu/WCHPC/Projects/fimr.html

The Future of FIMR

FIMR has emerged as an important public health strategy within the last two decades because it is a valuable tool for communities combating infant mortality. It is especially useful for communities with significant disparities in health primarily because the process is designed to assist public health professionals more fully understand and respond to factors that may influence fetal and infant mortality.

Statutory authority to convene a FIMR and funding for FIMR projects remain ongoing issues for many states and municipalities. Additionally, access to data (medical records, interviews with mothers and families) continue to be challenges for communities wishing to implement FIMR projects. FIMR projects across the country offer a roadmap to those agencies and professionals charged with designing and implementing fetal and infant mortality reviews in their own communities. The findings of the national



evaluation offer additional guidance for implementing FIMRs and for making policy recommendations.

For more information on the projects describe here:

- The Minnesota American Indian Infant Mortality Review
<http://www.health.state.mn.us/divs/fh/mch/mortality/amindianreport.pdf>
- The City of Milwaukee Fetal Infant Mortality Review
<http://www.milwaukee.gov/ImageLibrary/Groups/healthAuthors/MCH/PDFs/FIMR/20022004IMreport.pdf>

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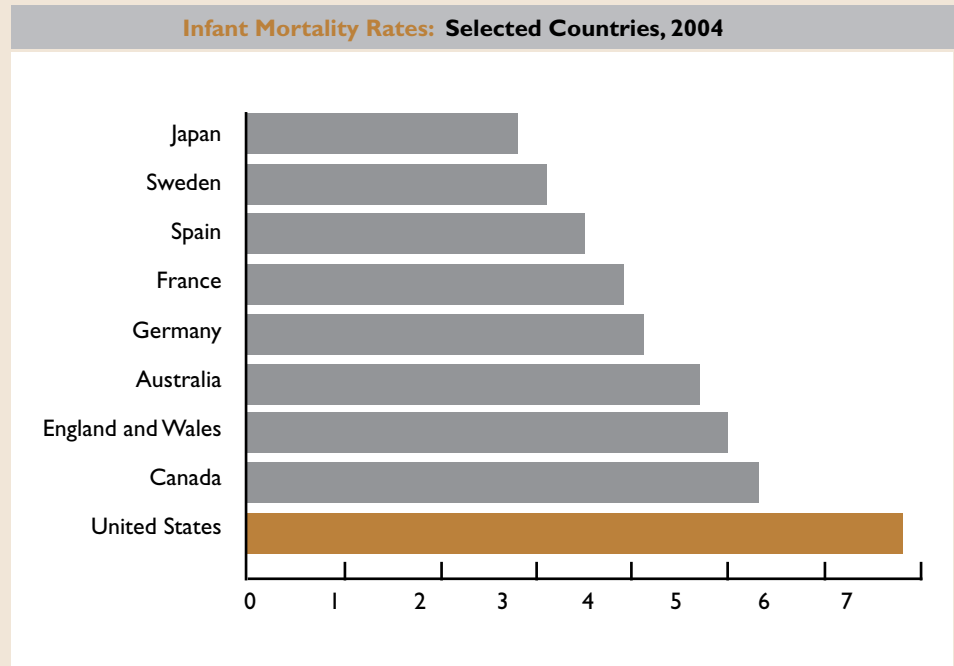
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Infant Mortality: A Social Mirror

Andrea Mayfield

The infant mortality rate is commonly used as an indicator of the general health of a society. Specifically, infant mortality is considered an indicator of the impact of socioeconomic disparities on population health because newborns are uniquely vulnerable to poverty and disadvantaged living conditions. Wise and Pursley called infant mortality a “social mirror” that reflects social injustice.¹ The following data, from the most recent report about U.S. infant mortality, indicate that infant mortality is high in the U.S., compared to other developed countries, and that reduction strategies are not clear.²



What Are the Historical Trends in Infant Mortality in the U.S.?

In the U.S., the infant mortality rate declined throughout the 20th century, from 100 infant deaths per 1,000 livebirths in the year 1900 to 6.89 infant deaths per 1,000 livebirths in the year 2000.

How Does the U.S. Rank in Infant Mortality Internationally?

The infant mortality rate reached a plateau between 2000 and 2005, bringing the U.S. to an international ranking of 29th in infant mortality among developed countries, on par with Poland and Slovakia. The infant mortality rate in the U.S. is one of the highest among developed countries—and this rank does not appear to be affected by differences in surveillance or enumeration.

Recent Infant Mortality Rates for Select Developed Countries

Source: Centers for Disease Control and Prevention² compiled from Health, United States, 2007 data, available at [http://www.cdc.gov/nchs/data/07.pdf#025](http://www.cdc.gov/nchs/data/hus/07.pdf#025)

What Do the Most Recent Data about Infant Mortality Reveal?

Preliminary data for 2006 estimate an infant mortality rate of 6.71 infant deaths per 1,000 livebirths, representing a 2% decline from 2005. However, the current infant mortality rate in the U.S. is still approximately 50% higher than the Healthy People 2010 target goal of 4.5 infant deaths per 1,000 livebirths.

Who Is at Highest Risk for Infant Death?

In 2005, there were differences in infant mortality by maternal race and Hispanic ethnicity, from a high of 13.6 deaths per 1,000 livebirths for infants born to non-Hispanic black women to a low of 4.4 deaths per 1,000 livebirths for infants born to Cuban women (the only group to achieve the Healthy People 2010 goal of 4.5 infant deaths per 1,000 livebirths). Differences in rates of low birthweight and/or preterm births explain some, but not all, of these differences in infant risk by maternal race and Hispanic ethnicity.

What Role Do Preterm Births Play in the Infant Mortality Rate?

The percentage of preterm births has increased since the mid-1980s. In recent years, from 2000 to 2005, preterm births have increased 9%, bringing the percent of preterm births to 12.7%. Some, but not all, of this increase is explained by the increase in multiple births. Because preterm is associated with about two-thirds of all infant deaths, preventing preterm births is critical to reducing infant mortality. However, the cause of most preterm births is unknown, so identification of at-risk women and successful intervention are often not possible.

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Assessing Tragedy:

Maternal Mortality Surveillance

Terra Carey and Wendy Hellerstedt, MPH, PhD

Complications of pregnancy and delivery are the leading causes of morbidity and mortality in women of reproductive age worldwide, accounting for 18% of the disease burden for 15-44 year-old women.¹ Maternal mortality is generally defined as the death of a woman while pregnant or within 42 days of the termination of pregnancy, irrespective of the site or duration of the pregnancy. It is a sentinel event: the tragic, and perhaps preventable, consequence of maternal illness. For every woman who dies of a pregnancy-related cause, there are likely thousands who suffer, and survive, a pregnancy-related illness.



Global Burden of Maternal Mortality

About 99% of the annual 536,000 maternal deaths occur to women in developing countries.^{2,3} Worldwide, the maternal mortality ratio for 2005 was about 402 deaths per 100,000 live births.^{2,3} Most maternal deaths occur in sub-Saharan Africa (50% of the deaths worldwide) and Asia (45% of the deaths worldwide).² Figure 1 shows the 2005 estimates of lifetime risk of maternal mortality for women in various regions of the world. The lifetime risk of maternal mortality is calculated using both the probability of a woman becoming pregnant and her probability of dying as a result of pregnancy, accumulated across a woman's reproductive years. These calculations establish that 1 in 92 women in the world will die as a result of pregnancy-related complications.

Causes of Maternal Mortality

Maternal mortality is strongly associated with high fertility, low literacy and educational attainment, poverty, lack of access to services, and poor quality medical care.¹ Maternal employment has been linked to increased use of maternal health services (even after controlling for education, age, household assets, and neighborhood characteristics).⁴

The major direct causes of maternal death are pre-eclampsia/eclampsia, postpartum hemorrhage, sepsis, obstructed labor, and unsafe abortion. However, maternal death is only the “tip of the iceberg” as an indicator of maternal health. For example, postpartum hemorrhage is estimated to be the cause of 132,000 maternal deaths and is estimated to have occurred in 13,795,000 women in 2000 (i.e., the case fatality rate is about 1%). An important consequence of postpartum hemorrhage is severe anemia.¹

“It is my aspiration that health finally will be seen not as a blessing to be wished for, but as a human right to be fought for.”

— Former United Nations Secretary-General
Kofi Annan

In the United States, maternal mortality declined during the 20th century, largely because of medical and technological advances. However, roughly 1000 women die every year in the U.S. because of pregnancy-related complications.⁵ Similar to developing countries, the women at highest risk in the U.S. are the economically and socially vulnerable. For example, in the U.S. it is estimated that African-American women have a four times higher risk of maternal mortality than white women.⁵

MILLENNIUM DEVELOPMENT GOALS

Goals to Reduce Maternal Mortality

Since the late 1980s, improving maternal health and reducing mortality have been important international health goals. In 1987, the Safe Motherhood Initiative was launched, with the aim to reduce maternal mortality globally by 50%.⁶ More recently, in 2000, the United Nations and heads of state adopted Millennium Development Goals (MDGs) to establish time-bound, measurable goals to address poverty, disease, maternal health and discrimination against women. One of the MDGs was to reduce maternal mortality from 1990 to 2015 by 75%.⁷ In the last two decades, maternal survival rates have improved in Latin America and northern Africa, but many areas, like sub-Saharan Africa and Asia, have not seen improvement.² Maternal mortality is a key health indicator for monitoring progress toward the achievement of the MDGs.

1. Eradicate extreme poverty and hunger: reduce by half those who live on less than a dollar a day
2. Universal primary education for all: achieve universal primary education
3. Promote gender equality and empower women
4. Reduce child mortality: reduce by two thirds the mortality rate for children under the age of five
5. Improve maternal health: reduce by three fourths the maternal mortality ratio and achieve universal access to reproductive health services
6. Combat HIV/AIDS, malaria and other diseases: halt and reduce the spread of HIV, malaria, and other major diseases, and provide universal access to treatment for HIV/AIDS
7. Ensure environmental sustainability: integrate programs of sustainable development, reduce biodiversity loss, reduce by half the number of people living without access to safe drinking water and adequate sanitation
8. Create a global partnership for development, with targets for aid, trade, and debt relief

These goals were agreed upon by all of the world's countries and major development institutions, and have a target achievement date of 2015.

For more information about the Millennium Development Goals please visit:
<http://www.un.org/millenniumgoals/index.html>

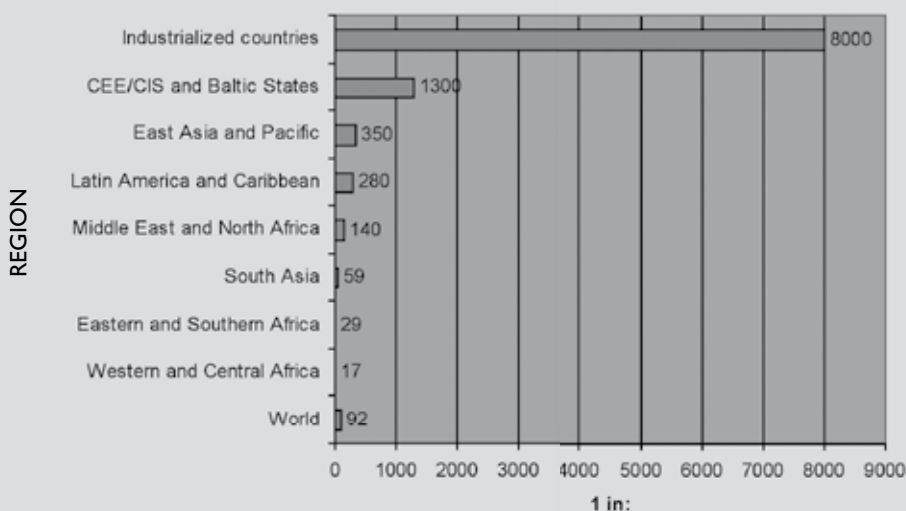
Maternal Mortality Surveillance

The Centers for Disease Control and Prevention (CDC) identifies four sequential steps in maternal mortality surveillance: identify pregnancy-related deaths, review the medical and non-medical causes of death, analyze and interpret the findings, and take action on the findings.⁸

The first step, identifying maternal deaths, may offer the greatest challenge. Many researchers believe that maternal mortality is underestimated, by anywhere from 25% to 70% for a variety of reasons:⁹

- Countries with the highest mortality are **resource-poor and have inadequate surveillance** mechanisms. In some countries the deaths of women of reproductive age may not be routinely recorded. Additionally, medical certification of cause of death does not exist in many developing countries.
- **Case definition is difficult**, despite some agreement that maternal mortality is a death within 42 days of a pregnancy termination. This definition demands knowledge that the woman was pregnant and understanding the timing of death in relation to the woman's pregnancy status. Some

LIFETIME RISK OF MATERNAL DEATH, 2005



Source: The State of the World's Children 2008, United Nations Children's Fund

researchers believe that the current case definition that restricts enumeration to deaths within 42 days of pregnancy termination is too conservative, as true pregnancy-related deaths can occur after this period.¹⁰

- Different countries use **different definitions of what constitutes a maternal death**, making cross-country comparisons difficult. Furthermore, definitions vary within countries, making even temporal comparisons difficult.

- **Women who die at home may be less accurately enumerated** as women who die in hospitals. Women who die at home and who die in the hospital may be very different in terms of overall risk and causes of death.

There are many approaches to monitoring maternal mortality and all have their strengths and weaknesses:³

- *Civil registration systems for births and deaths*, and census measures are subject to misclassification and



underestimation of maternal deaths.

- **Household surveys.** Because maternal mortality is a rare event, very large sample sizes are needed for good estimates of population risk.
- **Sisterhood methods** (obtaining information about adult sisters). One shortcoming of this method is it provides a retrospective—rather than a current—estimate of maternal mortality. Verbal autopsies (i.e., information from family members to assign cause of death) provide more timely information, but they are subject to misclassification (e.g., family members may not know about a pregnancy) and they are expensive to conduct.
- **Reproductive mortality research studies.** If well designed, these can provide good estimates, but they are complex, expensive, and time-consuming to conduct.

Recently the World Health Organization (WHO), the United Nations Children's Fund (UNICEF), the United Nations Population Fund (UNFPA), and The World Bank collaborated to develop national estimates of maternal mortality for 171 countries in 2005 based on any of the data available from any type of monitoring system.³ Depending on the quality of the data source, primary data for individual countries was adjusted for specific characteristics, including the potential extent of underreporting. While this effort did not result in precise estimates, the resulting product identified geographic

concentrations of risk.

Conclusion

Since the Safe Motherhood Initiative began, there is little evidence that maternal mortality risks have decreased in the poorest and most remote areas of the world. One of the greatest challenges to monitoring progress on international goals and the impact of interventions is the difficulty in conducting maternal mortality surveillance. It is also difficult, in countries like the U.S., to sustain public health interest in monitoring an event that is so rare.¹¹ Nonetheless, surveillance efforts persist in order to evaluate programs and strategies to reduce these premature and potentially preventable deaths.

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Material for this article provided by Terra Carey and Wendy Hellerstedt.

Healthy People 2010 Goal to Reduce Maternal Mortality

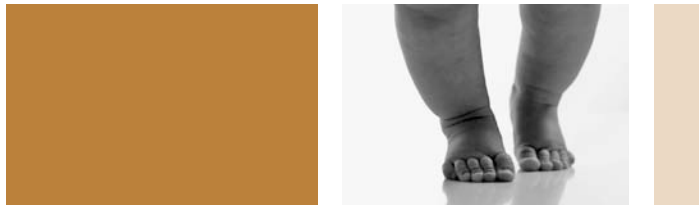
- Objective 16-4: Reduce maternal deaths to 3.3/100,000 livebirths (baseline, 7.1/100,000 livebirths)

Some Healthy People 2010 Goals that Address Fetal and Infant Mortality

- Objective 16-1a: Reduce fetal deaths at 20 or more weeks of gestation to 4.1/1,000 livebirths (baseline, 6.8/1,000 livebirths)
- Objective 16-1c: Reduce infant deaths (within 0-12 months of life) to 4.5/1,000 livebirths (baseline, 7.2/1,000 livebirths)
- Objective 16-1h: Reduce deaths from sudden infant death syndrome (SIDS) to 0.25/1,000 livebirths (baseline, 0.75/1,000 livebirths)

Some Healthy People 2010 Goals to Promote Maternal and Infant Health

- Objective 16-6b: Increase the proportion of pregnant women who receive early and adequate prenatal care to 90% of livebirths (baseline, 74% of livebirths)
- Objective 16-17c: Increase abstinence from cigarette smoking among pregnant women to 99% (baseline, 87% of pregnant women abstinent)
- Objective 16-9a: Reduce cesarean birthrate among women giving birth for the first time to 15% (baseline, 18% of women giving birth for the first time)
- Objective 16-9b: Reduce cesarean birthrate among women who had prior cesarean birth to 63% (baseline, 72% of women with prior cesarean deliveries)
- Objective 16-5a: Reduce maternal complications during hospitalized labor and delivery to 24/100 deliveries (baseline, 31.2/100 deliveries)
- Objective 16-19: Increase the proportion of mothers who breastfeed their babies:
 - Objective 16-19a: In early postpartum period to 75% of mothers (baseline, 64% of mothers)
 - Objective 16-19b: At 6 months to 50% (baseline, 29% of mothers)
 - Objective 16-19c: At 1 year to 25% (baseline, 16% of mothers)



Birth Defects Surveillance: Challenges to a Critical Public Health Activity

Jessie Kemmick-Pintor and Wendy Hellerstedt, MPH, PhD



The Centers for Disease Control and Prevention's (CDC) National Birth Defects Prevention Network (NBDPN) recommends that data be collected on 45 major defects/anomalies chosen on “the basis of their frequency, their impact on public health, and the state of knowledge about their etiologies and risk factors.”¹ The CDC defines major structural birth defects as “conditions that: (1) result from a malformation, deformation, or disruption in one or more parts of the body; (2) are present at birth; and (3) have serious, adverse effects on the affected person's health, development, or functioning.”² While it is estimated that 3% of all infants are born with one of the 45 major birth defects,² birth defects overall accounted for about 20% of all infant deaths in 2006 (consistent with data from past years)³ and often result in lifelong morbidity for survivors. A 2004 study that birth defects result in \$2.6 billion in hospital costs annually, accounting for more than 139,000 hospitalizations.⁴

Birth defects surveillance is important to not only monitor trends in these sometimes severe, heterogeneous conditions, but to understand causality. Seventy percent of birth defects are of unknown etiology; the other 30% are associated with a combination of genetic and environmental causes.⁵ The CDC funds state-based birth defects information systems (BDIS) to “address community concerns by identifying risk factors, tracking trends in prevalence, referring affected individuals and families to social and medical services, guiding service provision and policy development, and evaluating prevention efforts.”⁶ These systems monitor the 45 major birth defects, as recommended by the NBDPN, and additional anomalies as determined by each individual state. There is no systematic national surveillance about rare birth defects.

National Estimates of Birth Defects Is in Its Infancy

In 2006, the CDC pooled surveillance data from 11 states (representing 22% of the births in the U.S.) to provide estimates about 18 major defects—the first time that population-based national estimates were

ever provided.² This report, reflecting a small percentage of the known birth defects, estimated that, for 1999-2001 in the U.S.:

- Birth defects of the face and mouth (e.g., cleft palate and cleft lip) were the most common, affecting about 6,800 infants every year.
- Down syndrome, a genetic condition, was the second most prevalent, affecting more than 5,500 infants every year.

The CDC also categorized 18 birth defects into six major types and estimated annual incidence:

1. Chromosomal defects (i.e., Down syndrome, Trisomy 13, Trisomy 18): 6,916 infants.
2. Oral/facial defects (i.e., cleft lip, cleft palate): 6,776 infants
3. Heart defects: 6,527 infants
4. Musculoskeletal defects (e.g., arm/leg defects): 5,799 infants
5. Gastrointestinal defects: 2,883 infants
6. Eye defects: 834 infants

Prior to 2006, there were no national population-based surveillance estimates about any birth defects other than neural

tube defects. Estimates had previously been made from data from the Birth Defects Monitoring Program (BDMP), a program initiated at the CDC in 1974 that used discharge data from select U.S. hospitals to routinely analyze temporal trends for 161 categories of birth defects.⁷

State-based Surveillance

Although the CDC has been tracking birth defects for over four decades, only in 1998, with the passage of the Birth Defects Prevention Act, was birth defects monitoring mandated at the federal level. The bill, which became Public Law 105-168, gave the CDC the authority to monitor birth defects, fund regional epidemiologic research, and inform and educate the public about prevention.⁵ As a result, the CDC began awarding grants to 15 states to track infants with major birth defects and to use the surveillance data to stimulate prevention research/education and to use for referrals for service. The CDC also made awards to eight additional states to partner with the CDC as National Centers for Birth Defects Research and Prevention (<http://www.cdc.gov/ncbddd/bd/state.html>). Irrespective of funding from CDC, all but five of the 50 states conduct some type of birth defects monitoring.⁸ *Continued on page 14*

ABCs for Babies: Birth Defects Surveillance in Minnesota

Minnesota is one of the 15 states funded by the CDC to have a birth defects tracking system, called Assessing Birth Conditions Statewide for Babies (ABCs for Babies). It is operated through the Division of Environmental Health at the Minnesota Department of Health (MDH). Through the CDC funding, and funds from the Minnesota legislature and MDH's Fetal Alcohol Syndrome (FAS) Program, Minnesota has established and maintained a BDIS since 2005. The surveillance system is a collaborative project involving several programs within MDH (i.e., the FAS Program, Newborn Blood Spot Screening, Newborn Hearing Screening, Minnesota Children with Special Health Needs, Genomics) as well as outside collaborations with the March of Dimes, the University of Minnesota, and the CDC. According to Myron Falken, PhD, the director of the MDH birth defects surveillance system, local public health agencies have been especially strong partners in using the surveillance data to serve families. "Minnesota is very fortunate to have local public health agencies that are responsive to public health issues statewide," Falken said.

Funding for Minnesota's program is very limited, allowing Minnesota to conduct active surveillance on only about 50% of all births.⁹ Surveillance is restricted to infants born in Ramsey and Hennepin counties, and select hospitals in Washington and Olmsted counties. Data from this limited surveillance suggest that between 2,100 to 3,500 infants are born each year in Minnesota with one of the 45 major birth defects.⁹ It is estimated that the total lifetime costs to the state of Minnesota for 12 selected birth defects is \$131 million.¹⁰

How Are Birth Defects Surveillance Data Used?

Minnesota's system provides a good example of how surveillance data can be translated into action. The birth defects data are shared with the Minnesota Children with Special Health Needs Program program at MDH and local public health agencies so families of infants with birth defects can be contacted for follow-up services and referrals. The data are also used to educate the public and professionals about birth defects and their

prevention (e.g., a recent folic acid education campaign conducted by MDH, described elsewhere in this volume).

Does Minnesota—or Any State—Need Birth Defects Surveillance?

Is it possible to get birth defects information from hospital discharge data or birth certificates? Not completely. A recent study, led by MCH graduates, Barbara Frohnert and Dr. Richard Lussky, examined the quality of data about cardiac defects from hospital discharge data. Dr. Falken, also an author on this study, found the study's results surprising because "even the most obvious birth defects were not always reported or were incorrectly listed on the birth certificate." Although hospital discharge data proved to be more comprehensive than birth certificate data, 15 to 20% of birth defects were not identified by hospital discharge data, leading the authors to conclude that "more labor intensive, active case-ascertainment techniques are needed to capture all cases of major birth defects diagnosed within the first year of life."¹⁰

Challenges

The major challenges to birth defects surveillance are assuring the quality of the data, maintaining confidentiality, and paying for the system.

Quality of data. Major defects may not result in a livebirth (i.e., the fetus may die), thus surveillance that focuses on livebirths will not capture the most lethal birth defects. Birth defects may also co-occur, so abstractors must be careful to document all recorded defects (and hospital personnel must record all diagnosed defects). Active surveillance systems depend on medical records, thus only infants for whom medical attention is sought and who are diagnosed are included. According to Marianne Keuhn, State Programs Director of the Minnesota Chapter of the March of Dimes, "Obtaining accurate records and medical information is vital to the longterm benefits of this program [surveillance]. If we are to truly understand and make an impact on the prevalence of birth defects, we must have accurate knowledge of when and where these birth defects occur."

Maintaining the privacy of individuals who are part of the database. Minnesota has an opt-out system to protect the privacy of families. According to Falken, "we follow statute to the letter. Data privacy questions are asked often, but the opt-out option has allowed us to diffuse any controversy." Protocol stipulates that an opt-out letter be sent to parents or guardians of every validated birth defect case notifying them of their right to request that their child and family's information not be included in the surveillance database, along with a factsheet about birth defects monitoring in Minnesota and a brochure outlining the services available to their family. They are also notified that if their child's identifying information is removed from the database, MDH will not be able to refer them on to services. The information of families who do not opt out is then forwarded to MDH's Minnesota Children with Special Health Needs and local public health agencies for follow-up and referrals; 53 of the 87 counties currently receive notification of children with select birth defects in their counties.⁹ Only 4.5% of parents or guardians have asked to opt out.⁴

Funding. Perhaps the greatest challenge to effective birth defects monitoring is the cost. According to the CDC, "it is critical to the success of surveillance systems that sources of funding are long-term and reliable. Ideally the primary source of funding for a state surveillance program would be base funding, which comes out of the general fund and is part of annual state budgeting," and any other monies should be considered as "additional sources of funding."¹² Furthermore, a recent report from the Trust for America's Health recommends that in order to effectively prevent birth defects nationwide, states "should provide 25% of the funding for its birth defects monitoring program...to ensure...sustainable programs in collaboration with CDC."¹³ Yet, at present, Minnesota is relying heavily on federal funds (95% of the total budget) and general state funds only cover 2.5% of the budget. In contrast, Iowa, which houses one of eight national Centers for Birth Defects Research and Prevention, receives almost half (46%) of its funding from general state funds.⁸ The March of Dimes Minnesota Chapter sees securing general funding for birth defects surveillance as one of its key issues for the January 2009 legislative session. Statutory

Advocating for Birth Defects Surveillance Funding in Minnesota

language (MS144.2215-2219) passed in March 2005 authorized the MDH to collect birth defects information,⁹ but did not include a commitment for funding. According to Keuhn, increased legislative funds would allow the expansion of data abstraction to all neonatal intensive care units and birthing hospitals in the state. And, she said, legislative funds are critical when the CDC grant runs out in 2010: “Starting in 2011, we absolutely need to have some funding in place,” Keuhn said. “The tough part is that the funding we currently receive is only at about \$150,000 per year, which is a very limited amount. Ideally we’d be looking at a budget of about \$1.5–2 million per year.”

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Marianne Keuhn suggests using the following points when encouraging your legislators to support, improve, and maintain birth defects surveillance in Minnesota:

- An estimated 150,000 babies nationwide are born with major birth defects each year; making birth defects the leading cause of infant death in this country.
- It is estimated that between 2,100 and 3,500 babies are born with major birth defects each year in Minnesota. Current funding allows the system to only reach approximately 1,000 of these babies. Delays in linking families with appropriate services can have a negative impact on health outcomes.
- By monitoring the trends of birth defects and participating in scientific investigations of potential causes, great strides will be made to help predict and prevent future birth defects.

For more information about Minnesota's birth defects surveillance efforts, go to <http://www.health.state.mn.us/divs/eh/birthdefects/statute.html>.

Minnesota's Folic Acid Guidelines for the Prevention of Neural Tube Defects

Neural tube defects (NTDs) are serious and often life-threatening defects of the spine and brain. Among the most common of birth defects, NTDs affect about 3,000 pregnancies per year.¹ Folic acid, when taken daily by pregnant women, can reduce the risk of NTDs by up to 70%. However, the Institute of Medicine (IOM) recommends 400 mcg of folic acid per day for all women between the ages of 19-50 years who have the potential to become pregnant.² This recommendation is based on the following:

1. most NTDs occur during the first 30 days of pregnancy, when many women are still unaware of their pregnancy; and
2. about 50% of pregnancies are unplanned.¹

Beginning in 2006, the Minnesota Department of Health's Birth Defects Program worked with a large group of physicians and public health experts to create folic acid guidelines and responses to frequently asked questions for health-care providers.³ These guidelines were officially endorsed by the Minnesota Medical Association and were released in January 2008. A reference manual with supporting documentation was also created.⁴

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MCH Leaders Reflect on Surveillance Data: What They Have and What They Want

We had the opportunity to chat with MCH leaders from six states in the Upper Midwest. Each one of them valued the surveillance they have and wished for more. With each interview, we heard about their passion for evidence-based program and policy formation, dedication to good MCH surveillance, commitment to serving our most vulnerable populations, and, often, frustration that data capacity does not always meet the challenging needs of MCH populations. The following are excerpts from our conversations with MCH leaders who, collectively, have decades of experience and a deep dedication to public health service, as reflected in their surveillance accomplishments and goals.

Iowa

Interview with M. Jane Borst, RN, MA, Director of the Bureau of Family Health, Iowa Department of Public Health, http://www.idph.state.ia.us/hpcdp/family_health.asp.

What surveillance tools do you find most useful? There are many surveillance sources we use, ranging from our state birth records to the National Survey of Family Growth (NSFG). There are two recently developed tools for Iowans that are particularly valuable because they will allow us to improve prenatal and postpartum education programs, especially for higher risk women. Our Barriers to Prenatal Care Survey is a cooperative project that involves all of Iowa's maternity hospitals, the Statewide Perinatal Care Program, the University of Northern Iowa Center for Social and Behavioral Research, and the



Iowa Department of Public Health. The survey is distributed to all birth mothers before they are discharged from Iowa's maternity hospitals (http://www.idph.state.ia.us/hpcdp/prenatal_care_barriers.asp). We are also excited about our Iowa Pregnancy Risk Assessment Monitoring System (I-PRAMS), which we are conducting with

"We are always interested in better measures of women who are both at high risk for poor perinatal outcomes and who historically do not respond to surveys."

-M. Jane Borst, Iowa

a grant from the March of Dimes. We are surveying new mothers four months after delivery to see if they are caring for their newborns as planned. We know that new

mothers receive instructions in the hospital about newborn care after they give birth. This survey will give us an idea about how much of that information they retain and actually put to use. It will also give us a snapshot of the behaviors and health status of recent mothers in Iowa. The results should be available by early 2009.

What measures do you wish you had?

We would like more information about unintended pregnancy and about male reproductive health. We are also very interested in the status of women at six weeks' postpartum. We collect some data about things like breastfeeding and infant sleep position, but we would like to know more about this important population. We are always interested in better measures of women who are both at high risk for poor perinatal outcomes and who historically do not respond to surveys. The status of such

women is particularly significant in states with large rural populations, like ours.

Michigan

Interview with Alethia Carr, RD, MBA, Director, Bureau of Family, Maternal and Child Health, Michigan Department of Community Health, State of Michigan.

What surveillance tools do you find most useful? We use PRAMS quite a bit and your readers can find PRAMS data, as well as data, publications, and presentations on many other topics (e.g., birth outcomes, family planning, children with special health care needs, oral health), on Michigan's Maternal and Child Health Epidemiology site (http://www.michigan.gov/mdch/0,1607,7-132-2942_41657---,00.html). We also use our family planning program data quite a bit, but we do not have a public website for it. We use our vital

"I think it may be especially important to understand the number and characteristics of young girls who are victims of older men."

-Alethia Carr, Michigan

records and our HIV data frequently. Your readers might be interested in Michigan's community health information on <http://www.mdch.state.mi.us/pha/osr/chi/index.asp>, which has resources for natality, sexually transmitted infections, birth defects, fetal injuries and other reproductive and general health topics. HIV/AIDS information can be found on http://www.michigan.gov/mdch/0,1607,7-132-2944_5320_5331---,00.html. Michigan has a large WIC program and we always monitor the number of women and families served. WIC information is on http://www.michigan.gov/mdch/0,1607,7-132-2942_4910---,00.html.

In addition, we have fetal infant mortality review (FIMR) teams in several areas of the state and we use the information that comes from that work to inform our programming. Michigan has had a longstanding Maternal Mortality Surveillance System supported by very dedicated professionals in the state that helps us understand the cause of maternal deaths and recommends prevention. Other tools include our Youth Risk Behavior Survey (YRBS) reports and various MCH

epidemiology studies that are conducted through joint efforts of epidemiology and program staff.

What measures do you wish you had?

Good data on pregnancy intention would be very useful. We use the national data from NSFG but they don't specifically apply to Michigan residents. We also do focus groups, occasionally, to try to understand how women feel about their pregnancies and we have some data from Michigan's PRAMS, but we really wish we understood pregnancy intention better. We also need better sexual abuse data. I think it may be especially important to understand the number and characteristics of young girls who are victims of older men. I know such data are not available, and may be impossible to collect, but this issue is important. I also wish we had much better data on adolescent pregnancy and adolescent childbearing, so we could figure out what we can do to prevent early unwanted pregnancies and births. We could also benefit from more information about depression and the mental health needs of women.

Minnesota

Interview with Mary Jo Chippendale, M.S., P.H.N., Family and Women's Health Supervisor, Community and Family Health Division, Minnesota Department of Health, <http://www.health.state.mn.us/divs/cfh>

What surveillance tools do you find most useful? Minnesota PRAMS provides us with information on the health of women during pregnancy and the early postpartum period (<http://www.health.state.mn.us/divs/chs/prams/>). We have had PRAMS data in Minnesota since 2002 and the system has continued to evolve and improve, especially in terms of turnaround time and the flexibility of the survey. PRAMS has a great deal to offer because it represents the population of Minnesota mothers, including women who are historically underserved. We are always looking for ways to disseminate PRAMS findings for educational purposes and for its application to program and policy development. PRAMS data have utility beyond reproductive health issues. Even though PRAMS focuses on a specific population—women who gave birth in the previous 2-4 months—some of the prenatal and postpartum health indicators



are applicable to chronic disease risks, including hypertension, obesity, diabetes, and mental health. In terms of other measures, we use our vital records database heavily. We always hope to improve data control and quality assurance because vital records are used to help us assess newborn screening, select the sample for PRAMS, conduct infant mortality reviews, etc. We also value our Minnesota Student Survey (MSS) (<http://www.health.state.mn.us/divs/chs/mss/>). This survey is conducted with 6th, 9th, and 12th graders every 3 years in Minnesota's public, alternative, and juvenile justice schools. It is a wonderful resource that allows us to understand what is going on with adolescents in the state:

"Pregnancy intention is a difficult concept to define and, therefore, to measure."

-Mary Jo Chippendale, Minnesota

their activities, experiences, and health behaviors, including sexual activities. The MSS not only gives us some idea about the reproductive health needs of Minnesota's youth, but the data allow us to examine the correlates of sexual behavior as well. We also use national surveillance data--like those from NSFG and YRBS--to estimate reproductive health needs in Minnesota, but they are less useful to us than local data.

What measures do you wish you had?

Pregnancy intention is a difficult concept to define and, therefore, to measure. We gather some information about satisfaction with pregnancy timing and happiness about pregnancy through PRAMS and NSFG, but

we would like something more substantive to help us better understand women's satisfaction with things like pregnancy spacing as well as couples' unmet needs for contraception. We also feel it is important to conduct fetal-infant mortality reviews at the community or population level because they provide critical information about our most vulnerable citizens. Often, communities do not have the resources or capacity to conduct them. A community-based American Indian infant mortality review was recently completed and is available at <http://www.health.state.mn.us/divs/fh/mch/mortality/amindianreport.pdf>.

For an example of how Minnesota uses a variety of data sources, go to <http://www.health.state.mn.us/divs/cfh/na/factsheets/index.html>). This site contains information on data used in the 2005 MCH needs assessment, which focused on a variety of reproductive and other MCH topics, including teen pregnancy, oral health, child abuse, and mental health.

North Dakota

Interview with Kim Senn, RN, BNSc, Director, Division of Family Health, Community Health Section, North Dakota Department of Health, <http://www.health.state.nd.us/FamilyHealth/>

What surveillance tools do you find most useful? Like other departments of health, we find our birth records are very important. We also use family planning client visit record data to assess how well we are meeting our clients' needs. We are fortunate to have good sources of state- and county-level behavioral data from BRFSS <http://www.ndhealth.gov/brfss/CountyLevelSummaries> and economic and demographic data from the North Dakota State Data Center (<http://www.ndsu.nodak.edu/sdc/>). We conducted a Point-in-Time PRAMS surveillance project in 2002; we created a full report of our findings (<http://www.ndhealth.gov/familyhealth/publications/NDPRAMS2002SurveyResults.pdf>) and factsheets (PRAM-A-GRAMS) for public and professional education (<http://www.ndhealth.gov/prams/Publications.asp?ProgramID=107>).

What measures do you wish you had? We would like to have PRAMS. Our experience with the 2002 project was positive and provided so much good data



to use, but those data are getting old and the reproductive needs of our residents continue!

Ohio

Interview with Karen Hughes, MPH, Division Chief, Family & Community Health, Ohio Department of Health, <http://www.odh.ohio.gov/>

What surveillance tools do you find most useful? We are big consumers of national and state resources, including Ohio vital statistics, the National Survey

components of surveillance are analysis and interpretation. Specifically, we need to maximize the use of our data by turning them into accessible products that can be used by legislators and program developers. All of us in public health need to stimulate people to write well so our data can tell stories that prompt action. For some data on Ohio's maternal and child health populations, go to <http://www.odh.ohio.gov/healthStats/data/maternalmainpage.aspx> or search by topic on <http://www.odh.ohio.gov/odhPrograms/odhPrograms.aspx>.

What measures do you wish you had?

The measures I am most interested in concern women of reproductive age because of our interest in promoting healthy, intended pregnancies. We have some data on pregnancy intention for women who have had livebirths (from the NSFG), but we would like to better understand attitudes about pregnancy among all women who become pregnant, irrespective of pregnancy resolution. If we had that knowledge, we could better address their family planning needs. We want to see healthy pregnancies in Ohio and we need more data to create good programs and policies. For example, we would like information from chart audits, on topics like the quality and content of prenatal care. All we currently have are data from birth records, which only tell us about the timing of the first prenatal care visit and the number of visits the infant's mother had. We would like to understand what kind of counseling and services are

“While we recognize the critical need for data, it is also clear that important components of surveillance are analysis and interpretation.”

-Karen Hughes, Ohio

of Family Growth, and data from the Alan Guttmacher Institute. We also have Ohio Connections for Children with Special Needs (OCCSN), a birth defects surveillance program committed to ensuring that children with birth defects are linked to medical and other health services. OCCSN receives data about children with special needs through a passive, electronic reporting system. This program is in its early stages (<http://www.cdc.gov/ncbddd/bd/states/ohio.htm>).

While we recognize the critical need for data, it is also clear that important

Birth Defects Surveillance in Iowa

The Iowa Registry for Congenital and Inherited Disorders, established in 1983 is a collaborative effort between the University of Iowa, the Iowa Department of Public Health, and the Iowa Department of Human Services.¹ One of eight registries participating in the Centers for Disease Control and Prevention (CDC) National Birth Defects Prevention Study, its mission is to:

1. maintain statewide surveillance on selected congenital and inherited disorders in Iowa;
2. monitor annual trends in the incidence and mortality of these disorders; and
3. provide data for research studies and educational activities to prevent and treat these disorders. To date, the registry has collected information for more than 40,000 children with various birth defects through its active surveillance system.

With CDC funding, the Iowa Registry and the Colleges of Public Health and Medicine at the University of Iowa have formed the Iowa Center for Birth Defects Research and Prevention to examine:

- The link between compounds in drinking water and adverse birth outcomes;
- The link between exposure to farming chemicals and birth defects;
- The association of genes, maternal exposures, and their interactions as risk factors for cleft lip and/or cleft palate; and
- The effects of fertility treatments on the risk for birth defects.²

The surveillance and research data produced in Iowa is responsive to local, regional, and national concerns about birth defects, especially those that may be associated with exposures unique to rural environments.

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actually provided. We know that even early and adequate prenatal care does not always produce the desired results. Our ability to promote healthy pregnancies would be enhanced if we understood [the content of services provided] better and what components could be improved. We also want data about why women do not seek pre-conception care. Further, we do not know what women are interested and willing to do to change health behavior in order to promote a healthy pregnancy. One of the things we are concerned about is obesity and overweight among women of reproductive age. We are not only interested in what women think about behavioral change, body mass index (BMI), and pregnancy outcome, but in simply having better measures of BMI among young women. We also need better data about health insurance coverage and health care access for women of reproductive age. Finally, we need to have a better understanding of the social, emotional, and psychological environments of women of reproductive age. If we better understood, for example, risks for exposure to intimate partner violence, we could intervene before women become pregnant and break the intergenerational effects of maternal violence exposure.

Wisconsin

Interview with Linda Hale, BSN, RN, EMT, Section Chief, Family Health, Bureau of Community Health, Division of Public Health, Department of Health & Family Services. http://dhfs.wisconsin.gov/DPH_BFCH/index.htm

What surveillance tools do you find most useful? We find the birth records and Medicaid encounter and billing forms useful to help us understand if we are meeting the needs of our most socially vulnerable families. In Wisconsin, we are experiencing a paradigm shift in the way we think about family planning and reproductive health. We are not only looking at traditional indicators of health, but at quality assurance and accountability indicators. We want to understand how the funds that go to partners are being used and how to link data from several databases. We have developed an electronic assessment system that helps us go beyond process evaluation in order to do so, the Secure Public Health Electronic Record Environment (SPHERE)

(http://www.dhfs.state.wi.us/aboutdhfs/ITcollaboration/SPHERE_LSE_9_03.pdf). SPHERE allows us examine how multiple services and programs are meeting the needs of our residents. We can examine how contraceptive services are associated with birth outcomes. Or we can review, by county, how many women were eligible for Prenatal Care Coordination through Medicaid (<http://www.dhfs.state.wi.us/Medicaid1/recpubs/pncc/phc1046.htm>), how many eligible women received services, how many needs were met, and how outcomes, like breastfeeding and

white paper on reducing racial disparities in birth outcomes on our Healthy Births website (<http://www.dhfs.wisconsin.gov/healthybirths/>). A data source that we are looking forward to is our own PRAMS data: we will be getting the first round of data soon (<http://www.cdc.gov/PRAMS/States/Wisconsin.htm>). We are fortunate to have so many good sources of data in Wisconsin; we also make great use of other data sources, such as those from www.guttmacher.org, to understand trends in reproductive health.

What measures do you wish you had? We are interested in understanding pregnancy planning and child spacing needs of the women we serve. Our PRAMS data will be of some help to us, but we also understand its limits. We are also interested in measures to assess pre-conception health, ranging from pre-conception health conditions, behaviors, and health-care needs.

“We are not only looking at traditional indicators of health, but at quality assurance and accountability indicators.”

-Linda Hale, Wisconsin

depression, might be tied to services. In addition to state databases, we truly value the fetal-infant mortality review projects that have been conducted in many counties in Wisconsin. There is an active infant mortality action group (<http://www.cuph.org/projects/343/>) and there is also a recent

Interested in Making a Difference?

Consider a Master's in Public Health (MPH) degree in Maternal and Child Health (MCH)



Barbara Frohnert earned a Master's in Public Health (MPH) in Maternal and Child Health (MCH) from the University of Minnesota's School of Public Health in 2005. Prior to enrolling in the MPH Program, Barbara was a talented young professional who excelled in her career, but never felt fully engaged in it. She wanted a profession that would be intellectually challenging, personally motivating, and make a difference to the health of families and children. Barbara struggled to find a graduate program that would meet her desire to conduct both scholarly and applied work. A friend encouraged her to explore the MCH MPH program, so Barbara enrolled in an MCH course in reproductive health as a continuing education student to better understand the philosophy of the program. Impressed with the diverse backgrounds of fellow MCH students, the course sparked her interests and she successfully applied to the MPH program in MCH.

Barbara focused her training in maternal and child health to include an epidemiology emphasis because she valued the number of skill-based classes that the curriculum offered. She pursued a field experience with the Refugee Health Program at the Minnesota Department of Health that gave her the opportunity to write a federal grant and assist in a pilot project to provide hepatitis screening and immunization to Somali refugees. After completing her coursework in 2003 Barbara was awarded a two-year Applied Epidemiology Fellowship through the Center for Disease Control and Prevention (CDC) and the Council of State and Territorial Epidemiologists (CSTE). This fellowship is designed to give recent graduates an opportunity to receive in-depth training in applied epidemiology and to place fellows in long-term public health positions at the state or local level upon completion of the fellowship.

Barbara's fellowship placed her at the Minnesota Department of Health (MDH), where she worked on the development of a birth defects surveillance system for Minnesota and produced a scholarly article for publication with another U of M MCH graduate, Dr. Richard Lussky.¹ She also analyzed data from the Pregnancy Risk Assessment Monitoring System (PRAMS).

Barbara took a risk and followed her passion. Her contributions to maternal and child health are proof that it was a risk worth taking. Barbara is currently employed by the MDH as a Senior Epidemiologist and Project Coordinator for PRAMS (see related article in this publication). She ensures that PRAMS operations and data collection are running according to protocol and she analyzes data for many users. Her current passion? To find new users of PRAMS data to assure that results of this surveillance tool are translated into programs and policies that support women, families, and children.

For more information about the CDC/CSTE Applied Epidemiology Fellowship, go to: www.cste.org/Workforcedev/main1.htm.

For more information on PRAMS, go to: www.health.state.mn.us/divs/chs/prams/index.html or <http://www.cdc.gov/prams/>

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The Maternal and Child Health program is a Master in Public Health graduate training program. The curriculum is designed to prepare graduates to address the public health needs of vulnerable populations in domestic and international settings.

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The program faculty have expertise in medicine, nursing, psychology, sociology, nutrition, and epidemiology. Research and training opportunities focus on children with chronic health conditions; reproductive health and family planning; pregnancy outcomes; social inequities in health; women's health; infectious disease; substance use; community health promotion; and community-centered interventions.

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Web-Based Resources on Maternal and Infant Reproductive Health Surveillance

The following organizations represent a sample of web resources for domestic and international maternal and infant reproductive health surveillance. Our interview with MCH leaders in this volume has many additional state-based resources listed.

ABORTION SURVEILLANCE

The Guttmacher Institute (U.S./International):

<http://www.guttmacher.org/index.html>

CDC Abortion Surveillance System (U.S.):

http://www.cdc.gov/reproductivehealth/Data_Stats/Abortion.htm

World Health Organization (International):

http://www.who.int/reproductive-health/unsafe_abortion/index.html

ASSISTED REPRODUCTIVE HEALTH SURVEILLANCE

Assisted Reproductive Technology system (U.S.):

<http://www.cdc.gov/ART/index.htm>

World Health Organization (International):

<http://www.who.int/reproductive-health/publications/infertility.html>

REPRODUCTIVE SURVEILLANCE RESOURCES

The Guttmacher Institute (U.S./International):

<http://www.guttmacher.org/index.html>

CDC Reproductive Surveillance (U.S.):

<http://www.cdc.gov/reproductivehealth/DRH/activities/Surveillance.htm>

CDC Reproductive Surveillance (International):

<http://www.cdc.gov/reproductivehealth/Global/index.htm>

The INFO project / Reproductive Health Gateway (U.S.):

<http://www.infoforhealth.org/RHGateway/index.shtml>

National Survey of Family Growth (U.S.):

<http://www.cdc.gov/nchs/NSFG.htm>

Adolescent Reproductive and Sexual Health (International):

<http://www.unescobkk.org/index.php?id=68>

World Health Organization (International):

<http://www.who.int/reproductive-health/>

SAFE MOTHERHOOD

Pregnancy Mortality Surveillance System (U.S.):

<http://www.cdc.gov/nccdpdp/publications/aag/drh.htm>

Pregnancy Risk Assessment Monitoring System (U.S.):

<http://www.cdc.gov/PRAMS/index.htm>

Safe Motherhood Initiative (International):

http://www.rho.org/html/sm_overview.htm

World Health Organization (International):

http://www.who.int/reproductive-health/global_monitoring/RHRxmls/RHRmainpage.htm

Save these dates

for upcoming conferences and events

Conferences and Events

The following events are sponsored by the Center for Leadership Education in Maternal and Child Public Health:

MARCH 26, 2009

Childhood Asthma: Potential Causes and Consequences. Wilder Center, 451 Lexington Parkway North, Saint Paul, MN (<http://www.epi.umn.edu/mch>)

APRIL 7-8, 2009

2009 Iowa Public Health Conference. Iowa State University. Ames, IA (<http://www.iowapha.org/Default.aspx?pageId=62918>)

APRIL 20-21, 2009

Girls Coalition of Minnesota 19th Annual Conference: Celebrating Change. Various locations, Twin Cities, MN. (<http://www.mngirls.org>)

MAY 7-8, 2009

MOAPPP's 18th Annual Conference, Brooklyn Center, MN (http://moappp.org/outreach/events.html#conference_may7-8)



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