



Region IV Network for
Data Management and Utilization

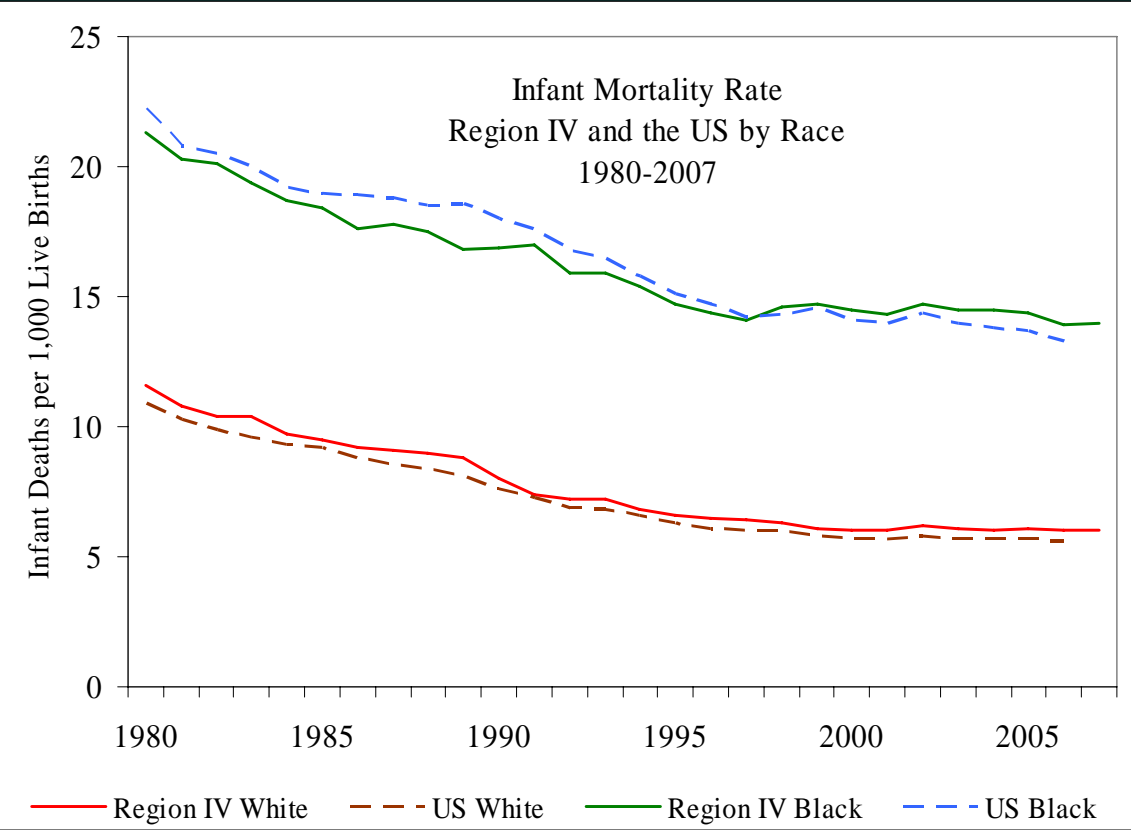
PROJECT OVERVIEW



UNC

THE CECIL G. SHEPS CENTER
FOR HEALTH SERVICES RESEARCH

Tracking Key Indicators Over the Decades



RNDMU Beginnings

Original concern over infant mortality led to the creation of RNDMU

Around thirty years ago, in 1980, the Southern Governors’ Association assigned infant mortality a high priority when their attention was focused on the disproportionate rates for their region. The problem was worsening and they felt compelled to do something to address it. In 1960, only 11 countries had lower infant mortality rates than those in the US. By 1980, among 37 countries with at least 1,000,000 population and complete counts of births and infant deaths as indicated in the United Nations Demographic Yearbook, 28 countries had lower infant mortality rates than the United States. The unacceptable IMR of the United States relative to the rest of the world masked even higher rates for specific subpopulations and/or certain parts of the country, especially states in Region IV.

Therefore in 1984, the Governor’s Association commissioned the Southern Regional Task Force on Infant Mortality. In the following two years, the Task Force collected and reviewed data on infant mortality, its component parts, and interventions that had been implemented to ameliorate the problem. The Final Report of the Task Force (1985), led directly to the development of new infant mortality reduction initiatives: “Healthy Futures,” funded by the Robert Wood Johnson Foundation, and “Healthy Generations,” supported by the U.S. Department of Health and Human Services. Beginning in the early 1990s a series of federal initiatives known as “Healthy Start” was funded to address the high disparity in infant mortality rates. Many states and/or local communities initiated Fetal and Infant Morality Review (FIMR) as a strategy to identify community resources and service delivery systems that may improve birth outcomes. Other programs targeting specific causes of infant mortality included the “Back to Sleep Campaign” (to reduce sudden infant death syndrome) and periconceptional folic acid intake (to reduce congenital anomalies). Many models of care coordination and case management, such as Baby Love and the Nurse Family Partnership, evolved to focus on improving access to care and targeted family centered services during pregnancy and the postpartum period. Since the U.S. infant mortality rate increased for the first time in over 40 years in 2002 (7.0) and returned to the 2001 rate in 2004 (6.8), was at 6.7 in 2006, and it remains a critical rationale for focusing efforts on broader perinatal factors such as intended childbearing and women’s general health that might be contributing to high infant death rates.

Region IV MCH directors request assistance: RNDMU project is born

In Spring 1983, the Maternal and Child Health (MCH) Directors in Region IV collaborated with the MCH Regional Consultant and the Department of Maternal and Child Health at the University of North Carolina at Chapel Hill to develop a data network to improve the planning and assessment capabilities of the states — with a specific concern about infant mortality and related indicators. When the MCH Department agreed to do this, Earl Siegel and Mary Peoples-Sheps applied for a Special Project of Regional and National Significance (SPRANS) grant to develop the Regional Network for Data Management and Utilization (RNDMU) Project. This network was funded as a SPRANS by the Division of Maternal and Child Health, U.S. Department of Health and Human Services (USDHHS), and began to function in October, 1983.

One of the first activities of the RNDMU Project was to conduct a survey to assess maternal and infant health data capabilities in the Region. From the results of that survey, indicators of maternal and infant health status and services that most states had the capacity to produce were developed. At a workshop in 1984 these were presented to the directors of maternal and child health and statistical agencies from each state and consensus was reached on a “Minimal Set of Common Perinatal Health Indicators.” Once a consensus was reached, the RNDMU Project was requested—and agreed—to serve as a central agency for collection of the data and production of an annual maternal and infant health databook.

Subsequently the MCH, perinatal, and vital statistics agency directors or their representatives revised the indicators as needed. Since the major focus of RNDMU activities is the use of data for program planning and evaluation, interpretation of the data for use by the states was also considered a high priority and continues to be addressed in the annual workshops.

Key Points in RNDMU History

Early 1980's:	Southern Governor's Association Commissions Infant Mortality Taskforce
1983 – 1986:	SPRANS Grant Funding for RNDMU to UNC SPH through Title V SSA
1986:	Leadership shifts from UNC SPH to UNC Sheps Center
1990:	Funding shifts from MCH (Title V) to Family Planning (Title X)
1997:	Women's Health Indicators added to databook
2003:	Latino Supplement prepared with addition of 29 tables to RNDMU
2005:	Medicaid Waiver Evaluators' Workgroup begins at 2005 Workshop
2009:	Title X, Title V and Women's Health Leaders convene at 2009 Workshop to assess RNDMU data and new directions

Funding for RNDMU shifted from MCH to Family Planning

The project was funded initially in 1983 by the Division of Maternal and Child Health (Title V Social Services Act), Health Resources and Services Administration, USDHHS. The goals of the project were to: 1) maintain and strengthen the state MCH agency's capacity to identify factors that contribute to the high infant mortality rate in DHHS Region IV; 2) strengthen the MCH agency's leadership role in planning, promoting, coordinating, and providing health care to address the problems identified; and 3) foster coordination and cooperation between the state MCH agency and the state statistical agencies. It was a collaborative effort between the Department of Maternal and Child Health at the University of North Carolina at Chapel Hill's School of Public Health, the Department of Health and Human Services (DHHS) Region IV Office, and the Region's eight state MCH Directors.

One of the first activities of the RNDMU Project was to visit each of the states to document their maternal and infant health data capabilities. Based on these visits the project moved in two directions: 1) the development and collection of a set of common perinatal health indicators for each state (led by Earl Siegel and Priscilla Guild) and 2) the development of a set of synthetic estimates for children in-need of services addressed by the Children with Special Health Care Needs Program (led by Mary Peoples-Sheps and Anita Farel).

At the end of the initial SPRANS grant in the fall of 1986 the states asked that the RNDMU Project continue its work. None of the faculty from the MCH Department wanted to take the lead on obtaining a second SPRANS Grant, so Priscilla Guild took the lead and at this time the Project moved to the Cecil G. Sheps Center for Health Services Research, where it is still located. Ms. Guild led the RNDMU Project until her retirement in May 2008.

When the SPRANS funding ended, the RNDMU Project would have discontinued without the support of the Region IV Title X Program Consultants, the eight state Title X Directors, and the Office of Population Affairs (OPA), USDHHS, who initially used Title X year end funds to support the project. Currently the Project is funded by a line-item in the Region IV Title X budget. In addition, until 2009 the eight state MCH Programs made a minimal financial contribution annually to the Project. Region IV is the only DHHS region with such a project.

Shift in funding brought Family Planning focus to RNMDU in 1990

When SPRANS funding ended, a second group of collaborators, including the MCH, family planning, and statistical directors from the eight states in USDHHS Region IV and Title X consultants from New York and USDHHS Region X met in a workshop setting in November 1990 and came to a consensus on a number of additional indicators related to the provision of family planning services. Since family planning can be considered the first step in the prevention of high-risk pregnancies, indicators related to the provision of these services were given high priority as a basic strategy to address the high infant mortality problem in the Region.

Women's Health indicators added

In September 1997, a third group of collaborators including the state family planning, women's health, and statistical directors and the Title X and Women's Health Consultants from the Region met to achieve a consensus on the addition of eleven new, women's health indicators. Although these are non-reproductive health indicators, the case was made that the general health status of women indirectly affects the health of their infants.

Required Criteria for RNMDU Indicators

Throughout the RNMDU project the following criteria have been used for selection of databook indicators:

- 1) a clear rationale/use for the indicator in planning and assessment of perinatal programs,
- 2) current capability of the states to produce the indicator, and
- 3) feasibility for future production capabilities.

Increasing Latino population in Region IV results in added tables to Databook

In September 2002 at the RNMDU Workshop, participants including the family planning and statistical directors selected a number of indicators to collect data for the Latino population and, in 2003; a Latino supplement to the Databook was prepared. Since this is the largest growing ethnic group in the U.S. and in Region IV, data for Latino break-outs were added to 29 RNMDU Tables in 2004. The requirement was that a majority of the states must have had sufficient numbers to produce yearly rates for an indicator to be included in the databook.

Using Data for Program Planning and Evaluation

A major focus of RNMDU activities is the use of data for program planning and evaluation. Therefore, interpretation of the data for use by the states has always been and remains a high priority and is actively addressed in annual workshops. For each workshop, states bring program leaders along with the individual(s) who work with them on the collection and/or use of their data.

Over the years these workshops have trained state staff in the following areas:

- Collection of valid data and production of reliable indicators over time
- Using the indicators to monitor health status and services
- Assessing the needs for services and planning programs to address these needs
- Designing indices and using them to plan more effective programs
- Collection and the use of data to make program policy decisions
- Using secondary data to address the decline in the number of women served by Title X
- Addressing the needs of the growing Latino population in the Region
- Evaluation of Medicaid Family Planning Waivers
- Tracking preconception health

In addition to annual workshops, various themes have been addressed using the rich, historical data available through the project or organizing indicators into logic models for identifying environmental, system, program, and individual level factors for key outcomes. Examples have included modeling short birth interval, adult unintendedness, sexually transmitted diseases, and adolescent pregnancy. Policy issues such as factors associated with declining numbers of Title X users or increasing numbers of Latino populations have also been explored using RNMDU project data in combination with reports or survey data (Guttmacher, PRAMS, BRFSS) easily available.

The infrastructure established for the RNMDU project has also lent itself to development of spin-off groups with related interests. In 2005, the topic for the RNMDU workshop was Evaluation of Medicaid Family Planning Waivers. At that time five of the states had a waiver (AL, FL, MS, NC, and SC). Each of the states was asked to bring not only their Title X waiver contact but also their contact at Medicaid and their evaluator to the Workshop. This was the first time that such a group had convened across multiple states.

At the end of the workshop the evaluators asked the RNMDU Project to hold monthly conference calls for the waiver evaluators and other interested people from

the states. These started in October 2005 and are on-going. Early on, Adam Sonfield from the Guttmacher Institute joined the calls and a little later, staff from CMS also joined. Since this was the first forum for discussion among Family Planning Waiver evaluators and state staff from multiple states, quickly requests came from other states to join the calls. Currently the following states participate: Alabama, Arkansas, Florida, Illinois, Louisiana, North Carolina, South Carolina, Tennessee, Texas and Virginia. A set of common indicators to monitor family planning waiver activities has been developed and data collection from each state has begun for the following indicators:

- Percent of the Eligible Population Enrolled
- Percent of the Enrolled Population Seen for Any Waiver Service
- Percent of the Eligible Population Seen for Any Waiver Service
- Percent of the Waiver Clients Seen Primarily at the Health Department
- Percent of Title X/Health Department Clients Covered by the Waiver
- Number of Births Averted per Program Participant, and
- Percent of Expected Births Estimated to be Averted.

RNDMU has led to spin-off efforts such as the development of a Family Planning Medicaid Waiver Evaluator's Group that meets monthly:
<http://www.shepscenter.unc.edu/data/Rndmu/FPMedicaidWaiver>

Structure, Topics, and Sources of RNDMU Data

Up until 2009, the databook consisted of 149 indicators across 155 tables. Indicators were grouped into general topic areas. The major topic areas covered in the databook were:

- Fertility and pregnancy rates, including repeat pregnancy rates for teens
- Maternal risk factors including age, parity, smoking, short birth interval, low education and unintended pregnancy
- Women's health indicators
- Health services and financing including timing and adequacy of prenatal care, utilization of Title X, Medicaid, and prenatal WIC services
- Birth outcomes including birth weight, perinatal and infant mortality
- Effectiveness of regionalized perinatal care: very low birthweight and low birthweight births by hospital level; very low birthweight and low birthweight neonatal mortality by hospital level.

Each year's databook contains the most recent eleven years of data. All available years of data are archived in Excel and are available upon request so that state staff can easily select their state and a comparable state, or the Region and US, to create graphs to illustrate indicators of interest.

For the most part data tables are composed of the eight individual states in Region IV, the Regional total or Regional rate and US rates when available. Most tables are by race (White, Black and Total) and selected tables include Latino data where numbers are sufficiently large.

The RNDMU indicators can be extremely useful for tracking progress towards improving the infant mortality rate (IMR) and its component rates, neonatal mortality (NNMR) and postneonatal mortality (PNNMR). With the 2009 edition of *Consensus in Region IV: Women and Infant Health Indicators for Planning and Assessment*, 28 years of data on many of the indicators are now available. The data have become increasingly useful over time to distinguish real trends from random short-term shifts in values. Moreover, the data enable investigation of possible causes of changing trends in health status indicators by examining changes in maternal characteristics and health services over time. Health status indicators can be reviewed for trends that may coincide with program implementation such as Healthy Start or trends in utilization of services such as a state's Title X program, in the wake of a Medicaid waiver being introduced.

Sources of data for RNDMU tables include the following:

- ✚ Vital records (birth, fetal death, death and abortion files)
- ✚ Surveillance (PRAMS and BRFSS)
- ✚ Program administrative files (Prenatal WIC, Medicaid Births, Women <150% FPL served by Title X, Selected Infectious Disease reports)
- ✚ Family Planning Annual Reports (Title X FPAR)
- ✚ Population estimates (US Census)
- ✚ Estimates of women in need of publicly-funded family planning services (Guttmacher)

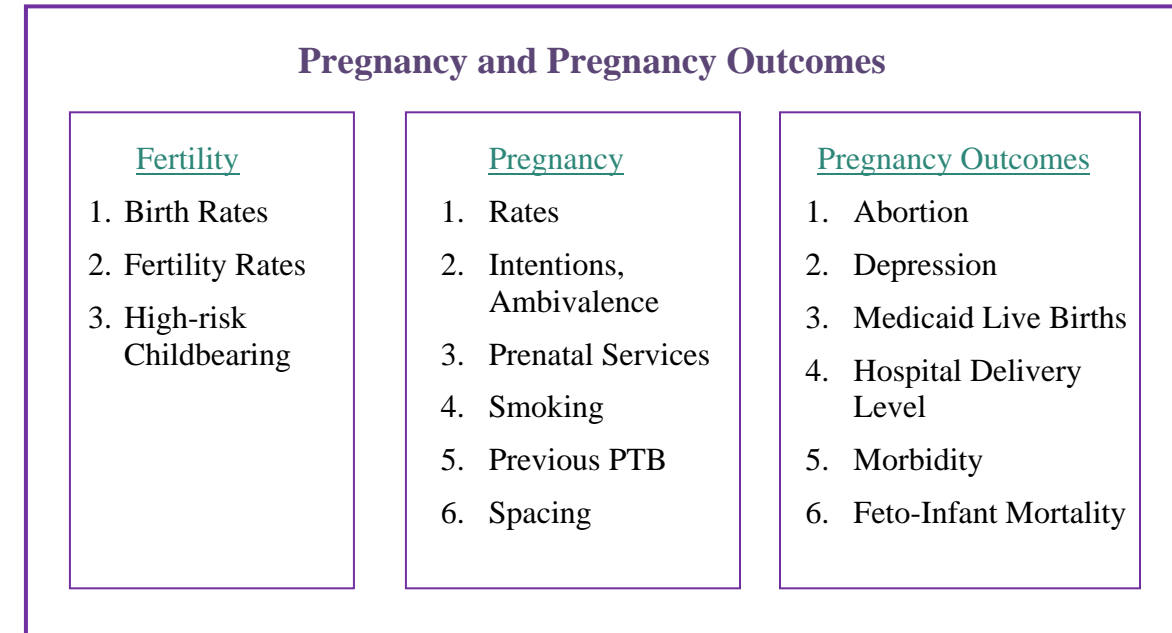
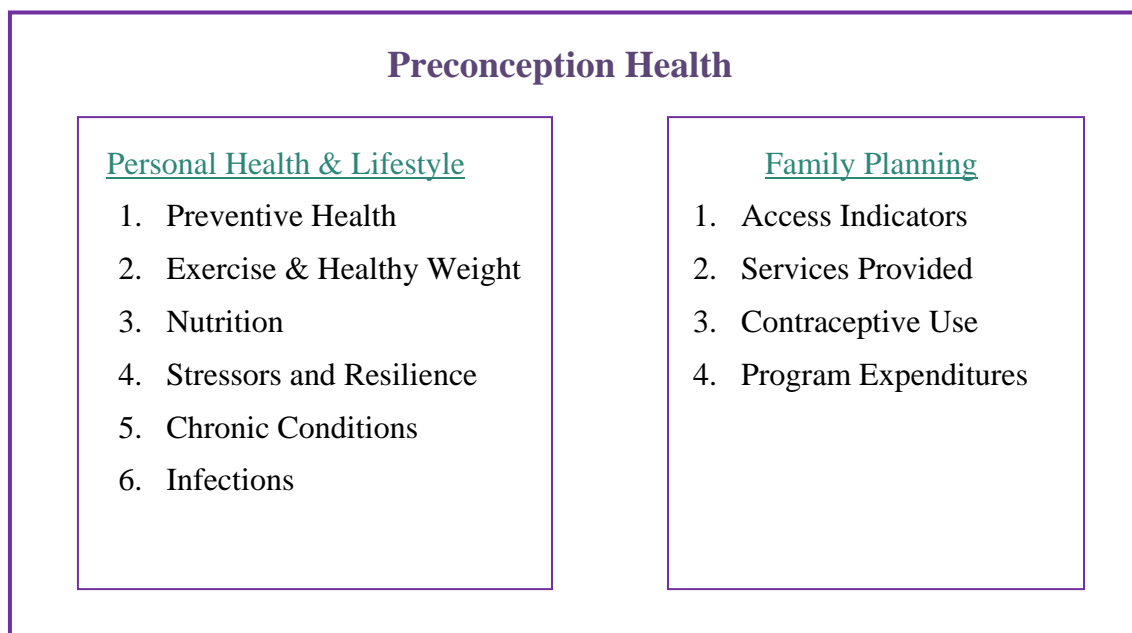
Revisions to Databook 2010

The goal of RNMDU has always been to provide an essential tool to State program leadership in a Region with a history of poor birth outcomes and enable them to monitor trends in their constituents' health and the delivery of health-related services. With the advent of the internet as a powerful information resource, and ready access to data such as those available through RNMDU, it was time to assess the relevance of the databook in its present form. In early 2009, RNMDU surveyed leadership from the Region about recommendations and future directions. The 2009 Workshop also focused on future directions for RNMDU and provided a forum to review data needs. In addition to the Title X Family Planning Program Directors and statistical data staff, each state invited participants from MCH leadership. Based on survey feedback and decisions reached among the Workshop participants, the group revised the overall RNMDU data framework. They emphasized more of a Life Course Approach to addressing women's health and promoting healthy pregnancies through strengthening care before and between conception. The new Concept Map organizes the RNMDU data into five domains and will guide the reordering of the databook tables for future years.

Future Directions

In addition to shifting the emphasis from infant mortality to women's health and preconception care in the future, RNMDU will continue to produce data and hold workshops for reviewing trends in key areas of perinatal health disparity and women's health. RNMDU will focus more actively on creation of composite measures that provide at-a-glance information for busy program directors and policy makers. Measures that capture trends in *quality* of services provided, trends in levels of *effective* contraceptive use, and trends in *disparity reduction* for core measures will be produced and included in the annual databooks. Future activities include expanding the availability of resources on the RNMDU website — posting useful reports, data trends, and products from current and past Workshops. RNMDU will continue to sponsor the Family Planning Medicaid Waiver Evaluators' Workgroup and foster communications for Data-to-Policy decision-making between State and Federal partners. RNMDU has begun to reach out more actively to other partners, such as the Region IV Training Center and the National Preconception Core States' Workgroup, to promote the use of rich, trend data that spans more than a quarter century.

Reproductive Health and Well-Being Concept Map





**Region IV Network for Data
Management and Utilization**

Current funding for the RNDMU Project comes from the Region IV Title X Program, U.S. Department of Health and Human Services and the eight MCH offices. Original funding came from two Special Project of Regional and National Significance grants supported by the Maternal and Child Health Bureaus, Human Resources and Services Administration, Public Health Service, U.S. Department of Health and Human Services. The project is administered by the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill.