



December 12, 2008

CDC Assistant Reports Clearing Officer  
1600 Clifton Road, MS D-74  
Atlanta, GA 30333

**Re: Proposed Data Collections Submitted for Public Comment and Recommendations:  
National Vital Statistics Report Forms [60Day-09-0213]**

Dear Sir/Madam:

The Friends of NCHS appreciates the opportunity to submit comments to the Centers for Disease Control and Prevention (CDC) on the National Vital Statistics System (NVSS) generally as you consider changes to the vital statistics report forms. The Friends of NCHS is a voluntary coalition of over 150 organizations and institutions that want to protect the National Center for Health Statistics (NCHS) and ensure the agency has a continued vital role in monitoring our nation's health. Our diverse membership—major corporations, professional societies, trade associations, health plans, research institutions, and patient groups—demonstrates the sweeping support for and impact of the health data collected by NCHS (list of members attached).

Background

The National Vital Statistics System (NVSS) is the oldest and most successful example of inter-governmental data sharing in public health. Through a contractual arrangement, approximately 6.5 million birth, death, and fetal death records per year are collected by 50 states, five territories, and two cities and provided to NCHS for the agency to disseminate as the nation's official vital statistics. This collective database is used to monitor the nation's health status, set priorities, and evaluate health programs. For example, mortality data are used to:

- Monitor the infant mortality rate as a leading international indicator of our nation's health status;
- Track progress and regress in reducing mortality from the leading causes of death, such as heart disease, cancer, stroke and diabetes;
- Provide the official life expectancy statistics for the United States;

- Monitor emerging and rare diseases; and
- Document racial disparities in mortality.

Just as fundamentally, birth data are used to:

- Establish the relationship between smoking and adverse pregnancy outcomes;
- Link the incidence of major birth defects to environmental factors;
- Establish trends in teenage births;
- Determine the risk factors associated with low birth weight; and
- Measure racial disparities in pregnancy outcomes.

#### Budget Shortfalls Undermine Data and Our Understanding of Health

Years of underinvestment have jeopardized and compromised NCHS's data collection activities, forcing the elimination of data collection and quality control efforts and stymieing the adoption of electronic data collection systems. Now the NVSS itself hangs in the balance.

Beginning April 2009, NCHS will purchase from states through the NVSS only "core" items of birth and death data (e.g., place of residence, age of mother, race of parents, and gender). By purchasing only core data items the NCHS will reduce by over three-fourths the number of "enhanced" data items that are routinely used to monitor maternal and infant health, such as use of prenatal care, smoking during pregnancy, medical risk factors, and educational attainment of parents, among others. Examples of this proposal's ramifications are highlighted below:

- Our ability to monitor and track select *Healthy People 2010* objectives—including those related to Maternal and Child Health, Tobacco Use, and Occupational Safety and Health—will be compromised.
- National research into the causes of, and reasons for, recent increases in preterm deliveries will be severely limited, compromising our ability to prevent infant mortality.
- We will be unable to study the impact of increasing birth rates among older mothers on the frequency of congenital anomalies and genetic disorders.
- Information on tobacco use during pregnancy—which is known to be one of the contributing factors to low birth weight and birth defects—will no longer be available for planning public health outreach and interventions.
- Our ability to understand the importance of socioeconomic status on health disparities in births and deaths will no longer be available.

- Information on work-related injuries will no longer be available to help improve workplace safety.

The NCHS proposes to redirect some of the money used to purchase these enhanced data to support data quality studies and other activities intended to improve the NVSS infrastructure (e.g., helping jurisdictions implement the 2003 birth and death certificates and electronic data collection systems). Yet because states and territories currently use NCHS funding for data quality purposes it is likely that a reduction in funding will result in poorer, rather than improved data quality. In addition, if funding for vital statistics collection is cut, jurisdictions will likely be forced to limit the collection of data to the items that NCHS purchases; if NCHS later finds funding to purchase these enhanced data, they may find that the data are no longer being collected.

Based on past precedent, the Friends of NCHS are very concerned that the enhanced data collection efforts, once cut, will not be restored. By way of background, when NCHS has faced budget shortfalls and cut data collection in the past the data are only restored years later. Under severe budget constraints, as we see now, the data are never restored (e.g., the elimination of data collection on marriage, divorce, and abortions). In the case of vital statistics, eliminating the collection of enhanced data, even in the short term, could have devastating effects on public health planning.

#### Action Needed Now to Protect Vital Statistics

The Friends of NCHS has deep reservations concerning the implementation of the core v. enhanced data approach proposed by NCHS. Vital statistics allow us to monitor the health of the nation, and it is essential that data from all vital records jurisdictions be included in the national data set. The Friends of NCHS urge the CDC and the Department of Health and Human Services to prevent NCHS from implementing the core v. enhanced proposal and provide NCHS adequate funding in FY 2010 and beyond to: preserve the core and enhanced data currently collected by vital statistics jurisdictions; collect 12 months of these data within a calendar year; and modernize the infrastructure so that all states collect enhanced data using the 2003 birth and death certificates, and all states collect these data electronically. Today only about half of the states and territories use the 2003 birth or death certificates to collect enhanced vital statistics; fewer jurisdictions collect both and only about half do so electronically. Modernizing the NVSS will improve data quality, efficiency, interoperability, and security.

At a time when both the new administration and Members of Congress are considering major health reform, the data NCHS collects are needed now more than ever to track Americans' health and evaluate our progress improving it. The priority should be to strengthen the vital statistics system, rather than to chip away at its very foundation. We hope these comments are useful as the agency continues to refine the NVSS and evaluate its future needs. Please do not hesitate to contact Emily Holubowich at [eholubowich@dc-crd.com](mailto:eholubowich@dc-crd.com) should you have any questions.



AARP

Abt Associates, Inc.

Alaska Native Tribal Health Consortium

Alliance for Aging Research

Alpha-1 Association

Alpha-1 Foundation

Altarum Institute

American Academy of Pediatrics

American Academy of Physician Assistants

American Association for Clinical Chemistry

American Association for Dental Research

American Association for Health Education

American Association for Respiratory Care

American Association of Colleges of Nursing

American Association of Colleges of Pharmacy

American Autoimmune Related Diseases Association

American Brain Coalition

American Cancer Society Cancer Action Network

American College of Clinical Pharmacy

American College of Emergency Physicians

American College of Healthcare Executives

American College of Nurse-Midwives

American College of Obstetrics & Gynecology

American College of Preventive Medicine

American Dental Education Association

American Diabetes Association  
American Dietetic Association  
American Geriatrics Society  
American Health Information Management Association  
American Heart Association  
American Medical Informatics Association  
American Nurses Association  
American Optometric Association  
American Osteopathic Association  
American Public Health Association  
American Psychiatric Association  
American Psychological Association  
American Speech-Language-Hearing Association  
American Society of Nephrology  
American Society of Pediatric Nephrology  
American Society for Reproductive Medicine  
American Society for Nutrition  
American Urological Association Foundation  
American Thoracic Society  
Aplastic Anemia & MDS International Foundation  
The Arc of the United States  
Arthritis Foundation  
Asian & Pacific Islander American Health Forum  
Association for Clinical Research Training  
Association of American Medical Colleges  
Association of Black Cardiologists, Inc.  
Association of Maternal and Child Health Programs  
Association of Minority Health Professions Schools  
Association of Population Centers  
Association of Public Health Laboratories

Association of State & Territorial Health Officials  
Association of Women's Health, Obstetric, and Neonatal Nurses  
Asthma and Allergy Foundation of America  
Aveta, Inc.  
Brown University, Warren Alpert Medical School, Center for Gerontology and Health Care Research  
Building Bridges, Inc.  
C3: Colorectal Cancer Coalition  
Case Western Reserve University School of Medicine  
Center for Science in the Public Interest  
Children and Adults with Attention-Deficit/Hyperactivity Disorder  
Coalition for the Advancement of Health through Behavioral and Social Sciences Research  
Coalition for Health Services Research  
Commonwealth of the Northern Mariana Islands Health and Vital Statistics Office  
Congressional Black Caucus Foundation, Inc.  
Consortium of Social Science Associations  
COPD Foundation  
Council of Professional Associations on Federal Statistics  
Diabetes Action Research and Education Foundation  
District of Columbia State Center for Health Statistics, Vital Records Division  
Early Intervention Research Institute, Utah State University  
Easter Seals  
Emergency Medicine Network  
Epilepsy Foundation of America  
Fenway Community Health Center  
Gay Men's Health Crisis, Inc.  
General Mills  
Grocery Manufacturers Association  
Gundersen Lutheran Medical Center  
Hadassah

Health Capital Consultants, LLC  
Hearing Industries Association  
Hearing Loss Association of America  
Hirshberg Foundation for Pancreatic Cancer Research  
Huntington's Disease Society of America  
Infectious Diseases Society of America  
Institute for the Advancement of Social Work Research  
The Institute for Healthcare Quality Research and Education  
International Waldenstrom's Macroglobulinemia Foundation  
International & American Associations for Dental Research  
Jacksonville Emergency Consultants, Inc.  
The Jewish Guild for the Blind  
Johns Hopkins University  
The Joint Commission  
Kidney Cancer Association  
Kraft  
Last Acts Partnership  
Leonard Davis Institute of Health Economics  
Lymphoma Foundation of America  
March of Dimes Foundation  
Maryland Department of Health and Mental Hygiene  
Maryland Patient Advocacy Group  
MATRIX Public Health Consultants, Inc.  
Mental Health America  
MJSahl Consulting  
MMM Healthcare, Inc.  
Musella Foundation for Brain Tumor Research & Information, Inc.  
Medstat  
The Melody Arons Center for Pre-School Research and Education  
National Association for Public Health Statistics and Information Systems

National Committee for Quality Assurance  
National Health Council  
National Association of the Deaf  
National Association of County and City Health Officials  
National Business Group on Health  
National Campaign to Prevent Teen Pregnancy  
National Coalition for LGBT Health  
National WIC Association  
National Cued Speech Association  
National Disability Sports Alliance  
National Fragile X Foundation  
National Health Law Program  
National Hispanic Medical Association  
National Hospice and Palliative Care Organization  
National Multiple Sclerosis Society  
National Organization for Hearing Research Foundation  
National Osteoporosis Foundation  
National Psoriasis Foundation  
National Quality Forum  
National Sleep Foundation  
Nestle USA  
North American Society for Pediatric Gastroenterology, Hepatology and Nutrition  
NTM Info & Research, Inc.  
Oklahoma State Department of Health  
Parent Project Muscular Dystrophy  
Parkland Health and Hospital System  
Pfeiffer University  
Pituitary Network Association  
Platelet Disorder Support Association  
Post-Polio Health International



The Ohio State University College of Public Health  
Partnership for Caring  
Physicians for Human Rights  
Population Association of America  
Prevent Blindness America  
Public Health Foundation  
Quality Community Health Care, Inc.  
Research! America  
RTI International  
Service Employees International Union  
Simmons School for Health Studies, Center for Health Policy Research  
Snack Food Association  
Society for Investigative Dermatology  
Society for Neuroscience  
Society for Women's Health Research  
Southeast Emergency Consultants, Inc.  
State and Territorial Injury Prevention Directors Association  
Strategic Affairs Forecasting  
Trust for America's Health  
Tulane Center for Applied Environmental Public Health  
UCB, Inc.  
United Cerebral Palsy  
University of California, San Francisco  
The University of Georgia College of Pharmacy  
University of Illinois at Chicago-School of Public Health  
University of Michigan School of Public Health  
University of Southern Maine, Institute for Health Policy, Muskie School of Public Service  
University of Washington Department of Health Services  
VHL Family Alliance

Virginia Commonwealth University, Department of Health Administration

Virginia Department of Health, Division of Health Statistics\_

Vision Council of America

WellPoint, Inc.

Well Spouse Association