

January 28, 2004

Outline of Presentation

Overview of vitals and then

Discussion of analytic data files

Births

Fetal deaths

Linked births and infant deaths

Deaths

National Vital Statistics System

An Overview

- 57 reporting areas
- Decentralized
- US historical development-self-governing States
- Nothing on registration in US Constitution
- Responsibility based in state law
- Responsibility with provider of services

Federal Role Defined by the Public Health Service Act – *Sec 306 (h) (1)*

- Annual collection of data from the records of births, deaths, marriages, and divorces
- Satisfactory data in necessary detail and form
- Encourage States to collect detailed data on ethnic and racial populations
- Each State or registration area shall be paid by the Secretary the Federal share of its reasonable (?!) costs

National Vital Statistics System

Individual Record Data:

- Births
- Deaths
- Fetal Deaths
- Linked Infant Birth and Death

Counts:

- Marriages
- Divorces



Vital Statistics

- Core of our health data system
- Base for public health, social science, economic planning and program development
- Monitor key indicators of health world-wide and at the local, state and national level
- Track progress to goals
- Identify disparities
- Alert to emerging problems

NCHS Roles: Promoting Consistency and Uniformity

- Model State Vital Statistics Act and Regulations
- Standard Certificates and Reports – standardized worksheets
 - Training materials – handbooks, videos, instruction manuals
 - Technical assistance – ICD 10
 - Software – ACME, MICAR, etc...

Data Release: Provisional Data

- Most timely data release of counts and rates
- Short “fact sheet” released monthly on the Internet in the NVSR series
- Includes counts only of births, deaths, infant deaths, marriages & divorces
- Estimates based on counts of certificates received during a one-month period, regardless of month of occurrence

Data Release: Preliminary Data

- Detail for basic variables and preview of data in final report; data track well with final report
- Based on substantial sample of records – 99% of all births for 2003; 97% of demographic-deaths and 92% of medical-deaths for 2002
- Sample of all records received and processed by cut-off date – 3-4 months after end of data year 2003 for births, 7 months for deaths
- Births published 6-11 months after end of year; 14-15 months for deaths

Data Release: Final Data

- Annual reports – based on all US births and deaths in a given year
- Final public use files available with release of final data reports
- Births released 12 months after end of data year , deaths about 21 months after end of data year
- Integration of data from 1989 and 2003 certificate revisions delayed 2003 release by 3-4 months

Development of the Revised Birth and Death Certificates 12th Revision

- 12 revisions during the 20th century: 11th revision is still in use in many jurisdictions
- In 1998, NCHS assembled an expert panel to evaluate the current certificate and recommend changes.
- Panel consisted of State vital registration and statistics executives representing 11 jurisdictions (**NAPHSIS**) as well as
- Researchers and representatives of data providers and user organizations - (e.g., AAP, ACNM, ACOG, AHA, AHIMA, AMA, and ASTHO).

Why revise?

-Research Implications-

Provide improved data for *each* of more than 4 million births, 2.4 million deaths, and about 25,000 fetal deaths annually. *For Example:*

Research on the etiology of premature birth will be substantially improved through the collection of data on important pregnancy risk factors.....

Why Re-engineer Vital Registration Systems?

- Automation of records at the source
- Flexibility to revise rapidly, address new data needs
- Speed the flow of data
- Implemented by states along with new standard certificates
- Potential for linking with other health data systems
- Protocols and standards for **Intelligence Reform Act**

Intelligence Reform Act

- Legislation just signed by the President contains **authorization** for grant programs to strengthen state registration and certification for identity purposes
- **If appropriations follow** ... we could have a rejuvenated vital statistics system for states and the nation through boot - strapping statistical needs with registration needs

Recent analytic additions

quality added to quality = the best



Quality Additions in the Last Year

Sharon Kirmeyer, Ph.D. – Brown University: Demographer: Strong skills in Reproductive Health and Demographic Data, and special interest in perinatal issues, modeling maternal health and demographic dynamics, immigrant health.

Jo Jones, Ph.D. – University of Washington: Sociologist: Strong skills in Survey Research Methods and Data Collection and special interest in effects of social and economic factors on women's and children's health and well-being.

Brittany Dawson, M.P.P. (Master of Public Policy)- Georgetown: An HHS Emerging Leader with concentration in Family and Social Policy Issues.

Melonie Heron, Ph.D. – Penn State: Demographer: Strong skills in data analysis and research methodology and special interest in health disparities, immigrant health and chronic disease outcomes.

Michael Spittel, Ph.D. – University of Wisconsin: Demographer: Strong skills in data analysis and modeling and special interest in the relationship between inequality and mortality.

Some Recent Journal Articles authored by DVS analysts:

Rise in “no indicated risk” primary cesarean in the United States, 1991-2001: cross sectional analysis. *British Medical Journal*. 2005.

Racial differences in leading causes of infant death in the United States. *Pediatric and Perinatal Epidemiology*. 2004.

Delayed Interval Delivery and Infant Survival : A Population-Based Study. *American Journal of Obstetrics and Gynecology*. 2004.

The Rise in Multiple Births in the U.S., Who, What, When, Where and Why. *Clinical Obstetrics and Gynecology*. 2004.

Trends in Multiple Births Conceived Using Assisted Reproductive Technology. *Pediatrics*. 2003.

Annual Report to the Nation on the Status of Cancer, 1975–2001, with a Special Feature Regarding Survival. *Cancer*. 2004.

Some Recent Journal Articles authored by DVS analysts:

Paradox Lost: Explaining the Hispanic Adult Mortality Advantage. *Demography*. 2004.

Mortality associated with birth defects: Influence of successive disease classification revisions. *Birth Defects Research*. 2003.

Disease Classification: Measuring the Effect of the Tenth Revision of the International Classification of Diseases on Cause of Death Data in the United States. *Statistics in Medicine*. 2003.

Long Term Trends in Cancer Mortality in the United States, 1930-1998. *Cancer*. 2003.

Increase in HIV Deaths Due to Changes in Rules for Selecting Underlying Cause of Death. *Journal of Acquired Immune Deficiency Syndromes*. 2003.

Classification of deaths resulting from terrorism. *Homicide Studies*. 2003.

Influence of Rules from the Tenth Revision of the International Classification of Diseases on U.S. Cancer Mortality Trends. *Journal of the National Cancer Institute*. 2003.

-Birth file-

**with the 2003 revision there
will be an almost completely
new analytic file**

Leading indicators from birth certificate data:

Birth Rates by Age

Teenage Pregnancy and Childbearing

Timing and Adequacy of Prenatal Care

Cesarean Delivery and VBAC

Preterm Birth and Low Birthweight

Multiple Births

Leading indicators from birth certificate data

Fertility and Maternal/Infant Health Differences by
Race/Hispanic Origin and Educational Attainment

Geographic Differences (State, county-level data)

Neural Tube Defects

Maternal Medical Risk Factors (Diabetes, Hypertension)

Smoking During Pregnancy

The New Birth Certificate: Additional New and Improved Items

Maternal Demographic and Social Factors

- Age and parity
- Marital status
- Educational attainment (captures highest degree)
- Race and Hispanic ethnicity (captures multiple race)
- Use of WIC food during this pregnancy
- Principal source of payment for the delivery
- Breastfeeding

The New Birth Certificate: Modified Items

- Cigarette smoking before and during pregnancy, captures levels of smoking
- Pre-pregnancy weight, weight at delivery and height, used to calculate Body Mass Index and weight gain

Detailed Specifications for Electronic Systems

Because states have automated systems in hospitals -detailed specifications for birth certificate were been developed. The specifications include:

- Suggested electronic screens
- Response categories
- Drop-down menus
- Edits
- Help screens
- Ability to edit and query at data entry; resolution of data issues at the source



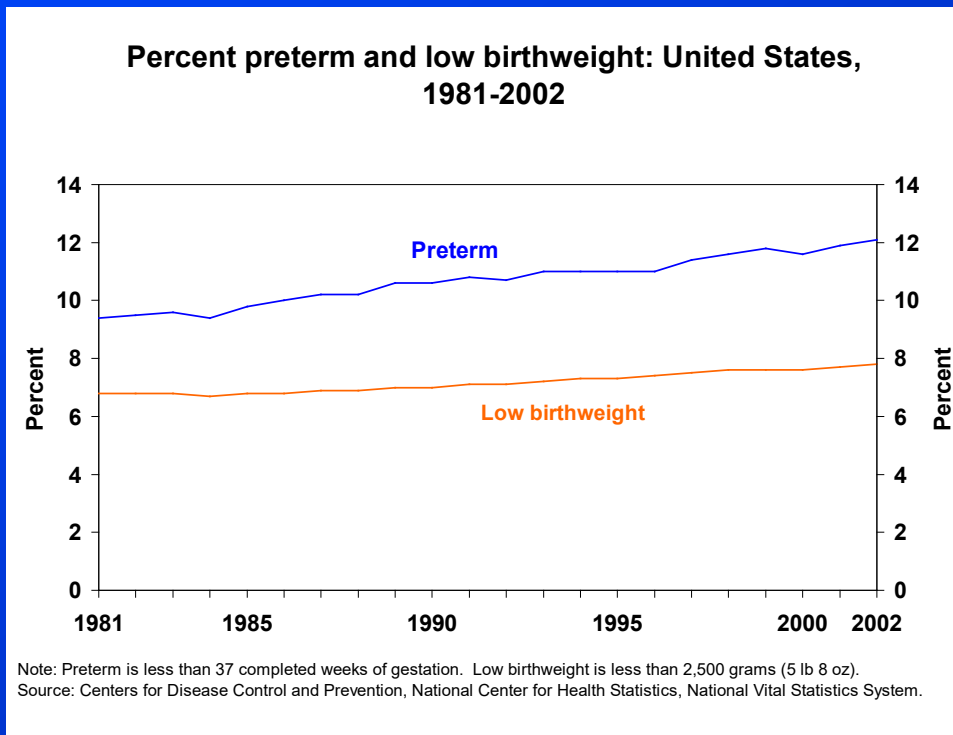


**Birth reporting is automated in
hospitals -**

**however systems are inflexible
and antiquated and can't make
these needed changes**

Research Implications for New Items

More accurate and comprehensive reporting on the birth certificate will enhance our ability to analyze and track crucial indicators of maternal and child health.



- Hypertension
- PROM
- Maternal infections
- Low birthweight
- Preterm birth
- Fertility therapy
- Maternal demographic factors
- Participation in the WIC program
- Prenatal care utilization
- Induction of labor
- Neural tube defects

But it is not just Vitals:

**Two recent reports focusing on teens
for birth and infant health and
pregnancy rates using vital stats for
births, CDC and AGI for abortions,
and NSFG for fetal losses**

Major Users of Birth and Infant Health Data

Federal Agencies and Other Governmental:

CDC's Division of Reproductive Health, NCCDPHP

CDC's National Center for Birth Defects and
Developmental Disabilities

Surgeon General

National Institute for Child Health and Human Development

HHS Assistant Secretary for Planning and Evaluation

HHS Administration for Children and Families

HHS Office of Population Affairs

U.S. Census Bureau

Social Security Administration

Indian Health Service

Department of Homeland Security

Canadian Institute for Health Information

Maternal and Child Health Bureau, HRSA

Georgia Campaign for Adolescent Pregnancy Prevention

The Kentucky Cancer Registry

United Nations

Advocacy Groups, Think Tanks, Professional Groups

Using Birth and Infant Health Data

March of Dimes

The Urban Institute

National Campaign to Prevent Teen Pregnancy

Child Trends

Annie E. Casey Foundation (*Kids Count* reports)

Population Reference Bureau

SIDS Alliance

Child Health USA

American College of Obstetricians and Gynecologists

American College of Nurse-Midwives

National Partnership to Help Pregnant Smokers Quit

International Cesarean Section Awareness Network

Planned Parenthood

National Organization on Fetal Alcohol Syndrome

Negative Population Growth

Maternal and Child Health Policy Research Center

Association of Maternal and Child Health Programs

Marvelous Multiples

Commercial Organizations Using Birth and Infant Health Data

Nestles

Westat

Hasbro

Fisher-Price

Pfizer

Toys R Us

Novartis

Porter-Novelli

Land's End

Honeywell

Methodological Challenges: Births

- Testing the quality of new data
- “Integration” of different data items from states operating under different revisions
- Use of expanded race/ethnicity data and bridging back to old categories
- How best to utilize new data from selected states?
- Future: How to provide and publish data on a current flow basis?

Fetal Death File

The U.S. Standard Report of Fetal Death: Modified Items

The U.S. Standard Report of Fetal Death was also revised with changes similar to the birth certificate.

Modified items include:

- **Maternal morbidity**
- **Smoking**
- **Method of delivery**
- **Congenital anomalies**
- **Cause of death**

Leading indicators – using fetal death data:

Pregnancy Health

Pregnancy Rates

Perinatal Mortality Rates

Tracking Causes of Pregnancy Loss

Differences in Pregnancy Outcomes by Race/Ethnicity

Tracking outcomes for multiple deliveries

Major Agency/Foundation Users of Fetal Mortality Data

CDC's Division of Reproductive Health, NCCDPHP
National Institute for Child Health and Human Development
HHS Assistant Secretary for Planning and Evaluation
Maternal and Child Health Bureau, HRSA

March of Dimes
International Cesarean Section Awareness Network
American College of Nurse-Midwives
American College of Obstetricians and Gynecologists
Association of Maternal and Child Health Programs
National Organization on Fetal Alcohol Syndrome

Methodological and Analytic Challenges for Fetal Death Reporting

- **reporting issues impact infant mortality reporting**
- **not receiving early fetal loss**
- **quality of cause of death**

Linked Birth and Infant Death File

Leading Indicators Linked Birth/Infant Death Data:

Differences in Pregnancy Outcomes by:

Race/Ethnicity

Marital Status

Educational Attainment

Maternal Medical Risk Status

Smoking Status During Pregnancy

Gestation and Birthweight-Specific
Infant Mortality Rates

Infant Mortality Rates by Plurality

Geographic Variation in Infant Mortality

Leading Causes of Infant Death

Why is the linked file important for examining changes in IMR?

Is the change in IMR the result of changes in risk BEFORE birth?

- Maternal characteristics
- Infant characteristics
- Characteristics of labor and delivery
- **OR**

Why use the linked file for IMR?

If not before - Is the change in IMR primarily the result of an increase in the risk of death AFTER birth:

- changes in birthweight/gestation-specific mortality?
- changes in obstetric and neonatal care?

**Example of improved analysis of
infant mortality reporting through the
use of the linked Birth and Infant
Death File**

Results of DVS Analysts' Research:

- An increase in the birth of very small infants is the major reason behind the increase in U.S. infant mortality in 2002.
- Infant mortality rates also increased for low birthweight, very low birthweight, and preterm infants.
- Increases in births at <750 grams found for all race/ethnicity groups.
- Most of increase occurred among mothers 20-34 years, the prime childbearing ages.
- Singleton births accounted for most of increase though multiple births accounted for 25% .

Major Agency/Foundation Users of Linked Birth/Infant Death Data

CDC's Division of Reproductive Health, NCCDPHP
National Institute for Child Health and Human Development
HHS Assistant Secretary for Planning and Evaluation
Maternal and Child Health Bureau, HRSA

March of Dimes
SIDS Alliance

National SIDS and Infant Death Resource Center
Association of Maternal and Child Health Programs
International Cesarean Section Awareness Network
American College of Nurse-Midwives
American College of Obstetricians and Gynecologists
Association of Maternal and Child Health Programs
National Organization on Fetal Alcohol Syndrome

Mortality File

Data Items on the Mortality File

- **Demographic and other characteristics**
 - **Age, race, Hispanic origin, sex, marital status, education**
- **Geographic**
 - **State, MSA, county – of occurrence and residence, State of birth**

Data Items on the Mortality File

- **Medical**
 - **Underlying cause of death**
 - **Other diseases/injuries reported (max 20)**
 - **Manner of death, place of death, place of injury, injury at work**

Death Registration Process: Two Responsible Parties and an Old Story

- Hospital (or ME/coroner) initiates **paper** certificate and gives to funeral director
- Funeral director obtains personal facts about decedent, completes certificate, and obtains cause of death from attending physician as needed
- FD files certificate with local office or State office, per State law; obtains burial permit
- Local office may hold records for fixed period (e.g. 2 months) to provide copies to family members
- State office receives certificate and codes/keys demographic and medical information
- State office transmits demographic and medical data electronically to NCHS for editing and possible additional coding of medical data.

Collecting cause of death data

- Physician, medical examiner or coroner fills out the medical portion of the death certificate

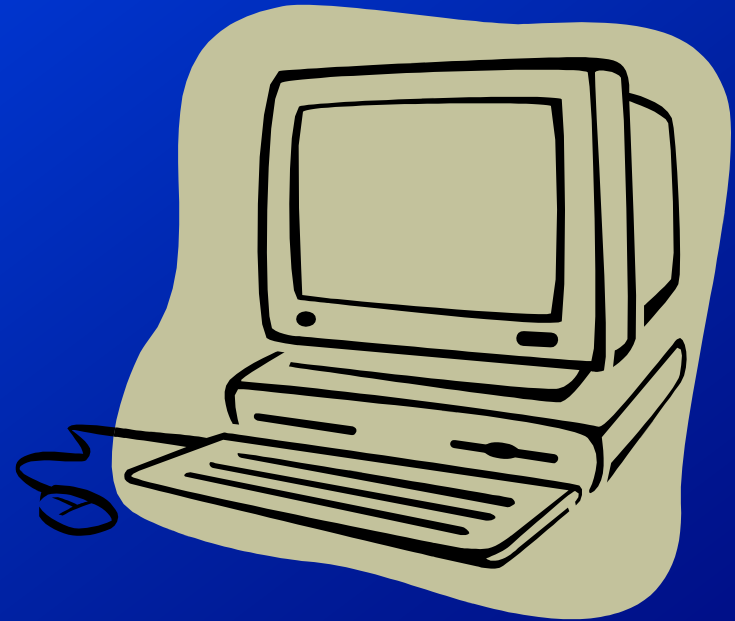
<p>27. PART I. Enter the diseases, injuries, or complications that caused the death. Do not enter the mode of dying, such as cardiac or respiratory arrest, shock, or heart failure. List only one cause on each line.</p>					<p>Approximate Interval Between Onset and Death</p>
<p>IMMEDIATE CAUSE (Final disease or condition resulting in death) →</p>		a.	_____		
<p>Sequentially list conditions, if any, leading to immediate cause. Enter UNDERLYING CAUSE (Disease or injury that initiated events resulting in death) LAST</p>		b.	_____		
		c.	_____		
<p>PART II. <u>Other significant conditions</u> contributing to death but not resulting in the underlying cause given in Part I.</p>					
					<p>28a. WAS AN AUTOPSY PERFORMED? (Yes or no)</p>
					<p>28b. WERE AUTOPSY FINDINGS AVAILABLE PRIOR TO COMPLETION OF CAUSE OF DEATH? (Yes or no)</p>
<p>29. MANNER OF DEATH</p> <p><input type="checkbox"/> Natural <input type="checkbox"/> Pending Investigation</p> <p><input type="checkbox"/> Accident</p> <p><input type="checkbox"/> Suicide <input type="checkbox"/> Could not be Determined</p> <p><input type="checkbox"/> Homicide</p>		<p>30a. DATE OF INJURY (Month, Day, Year)</p>	<p>30b. TIME OF INJURY</p> <p>M</p>	<p>30c. INJURY AT WORK? (Yes or no)</p>	<p>30d. DESCRIBE HOW INJURY OCCURRED</p>
<p>30e. PLACE OF INJURY – At home, farm, street, factory, office building, etc. (Specify)</p>			<p>30f. LOCATION (Street and Number or Rural Route Number, City or Town, State)</p>		

- Literal text from Parts I and II are processed using a suite of software designed to convert the text to ICD-10 codes and select the underlying cause of death

There is hope for Electronic Systems at the Source

Eventually, deaths are expected to be registered electronically. Therefore, detailed specifications for each data item on the electronic death certificate have been developed. The specifications include:

- Suggested electronic screens
- Response categories
- Drop-down menus
- Edits
- Help screens
- Ability to edit and query at data entry; resolution of data issues at the source



New Death Certificate: Modified Items

- Decedent's race, captures multiple race identification
- Decedent's education, captures highest degree attained
- Decedent's marital status distinguishes "Married" from "Married, but separated"
- Place of death includes hospice facility

New Death Certificate: Important New Items

- If female, pregnancy status at time of death that will help identify maternal and pregnancy-related deaths
- If transportation injury, decedent's role with respect to vehicles
- Did tobacco use contribute to death?
- Separate instructions for funeral director and person completing medical portion

Major Users of Death Data

Federal Agencies:

Office of the Surgeon General

HHS Assistant Secretary for Planning and Evaluation

Government Accountability Office

CDC's Nat'l Center for Chronic Disease Prevention and Health Promotion

CDC's National Center for Injury Prevention and Control

CDC's National Center for Infectious Diseases

CDC's National Institute of Occupational Safety and Health

CDC's National Center for HIV, STD and TB Prevention

U.S. Census Bureau

Social Security Administration

Food and Drug Administration

Indian Health Service

National Cancer Institute

National Heart, Lung and Blood Institute

National Institute on Aging

National Institute on Drug Abuse

National Highway Traffic Safety Administration

Agency for Healthcare Research and Quality

Substance Abuse and Mental Health Services Administration

Other Users of Death Data

United Nations

World Health Organization

Pan American Health Organization

American Cancer Society

American Heart Association

American Lung Association

American Diabetes Association

American College of Surgeons

National Association of Medical Examiners

National Bureau of Economic Research

Max Planck Institute for Demographic Research

North American Association of Central Cancer Registries

Population Reference Bureau

Various State and Local Departments of Health

Various Marketing, Investment, Insurance, Pharmaceutical, Healthcare
and Law Firms

Various Colleges and Universities

Methodological and Systems Challenges

- Integrating 2 separate providers of data
 - Funeral Director and Physician
- Collecting cause of death information and automated medical coding
- Quality of cause of death information
- Proxy reporting of demographic information – e.g., age, race, Hispanic origin

Problems in the Reporting of Cause of Death

- Overall the consistency and quality of the coding is very good – but, of course, output is only as good as the input provided
- Problems with the input
 - Ill-defined conditions and modes of dying
 - Lack of specificity
 - Improper completion of the form
 - Misdiagnosis

Ill-defined conditions and modes of dying

Cause of death	Underlying cause		Any mention	
	Deaths	Percent of total deaths	Deaths	Percent of total deaths
All ill-defined conditions and modes of dying	108,108	4.5	954,892	39.5
Cardiac arrest (I46)	17,331	0.7	354,958	14.7
Heart failure (I50)	56,934	2.4	293,651	12.2
Respiratory arrest (R09.2)	2,106	0.1	69,201	2.9
Respiratory failure (J96)	3,246	0.1	162,264	6.7
Senility (R54)	4,189	0.2	21,685	0.9
Unknown or unspecified causes (R99)	17,707	0.7	35,293	1.5

Source: National Vital Statistics System, 2001

Improper completion of the form

- Improper sequences
 - Underlying cause designated by certifier was consistent with that selected by ACME 71% of the time (62%, excluding cases where only 1 condition was mentioned)
- Multiple conditions on the same line in Part I
 - 10% of records contain at least 1 line in Part I with more than 1 condition listed

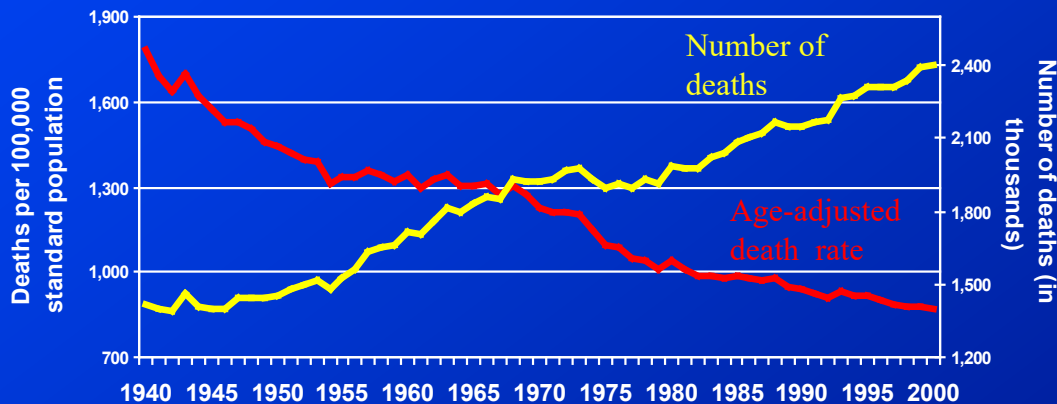
How can a re-engineered help us get better cause of death information?

- More accessible instructions – help screens
- Flexibility to add or modify data items to get additional information about causes of special interest
- Real-time querying
 - Spelling and decipherability of terms
 - Abbreviations
 - Prompts to include more specific information
 - Prompts to avoid certain terms or certification practices

Public Health Implications

More accurate and comprehensive reporting on the death certificate will enhance our ability to analyze and track crucial indicators of health, particularly with regard to causes of death.

Number of deaths and age-adjusted death rates: United States, 1940-2000



- Cause-of-death trends
- Leading causes of death
- Life expectancy
- Socio-economic differentials
- Demographic differentials

**This is the beginning
of a new era for vital registration
and statistics**

**Measuring “what is”
not just
“what was”**