Shaping a Health Statistics Vision for the 21<sup>st</sup> Century: 3 Tactics for State Data Systems

National Committee on Vital and Health Statistics 4 March 2004

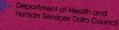
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# **Topics**

- Shaping a Health Statistics Vision for the 21<sup>st</sup> Century (NCVHS, 2002)
  - Definitions
  - Mission
  - Vision
    - Conceptual framework
    - Principles
- State health data
  - Archetypical state data systems
  - Archetypical problems
- 3 tactics for state health data systems

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# Shaping a Health Statistics Vision for the 21st Century



COCC Centers for Disease C and Prevention



National Committee on Vital and Health Statistic

#### **Defining Health Statistics**

Numerical data that characterize the health of a population and the influences and actions that affect the health of a population.

### **Defining Health Statistics Enterprise**

... infrastructure and the activities necessary to produce health statistics

- Public and private organizations and individuals at all geopolitical levels that perform the processes of health statistics
- Highly decentralized
- Includes organizations that collect, analyze, and disseminate data on the health of populations and the factors that influence health

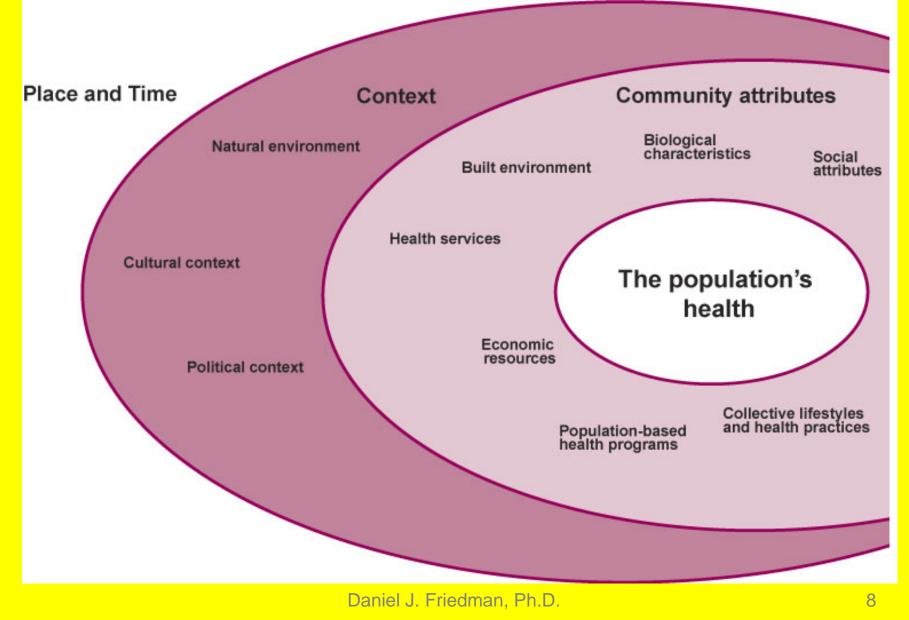
# Mission of the Health Statistics Enterprise

... to efficiently provide timely, accurate, and relevant information that can be used to improve the nation's health.

# Vision for Health Statistics Enterprise: Overarching Conceptual Framework

- ...helps to maintain a focus on needed data and guides the health statistics enterprise.
  - Focuses on health, the population, and the community
  - Emphasizes distribution and level of health
  - Delineates major influences on health
  - Defines research agenda for improving the population's health

### Influences on the Population's Health



# Vision for Health Statistics Enterprise: Ten Guiding Principles

- 1. Enterprise-wide planning and coordination
- 2. Broad collaboration among data users, producers, and suppliers at local, state, and national levels
- 3. Rigorous policies and procedures for protecting privacy, confidentiality, and security
- 4. Flexibility to identify and address emergent health issues and needs
- 5. Use of data standards

# Vision for Health Statistics Enterprise: Ten Guiding Principles

- 6. Sufficient detail at different levels of aggregation
- 7. Integrated, streamlined data collection for multiple purposes
- 8. Timely production of valid and reliable health statistics
- 9. Appropriate access to and ease of use of health statistics
- 10. Continuous evaluation of the completeness, accuracy, and timeliness of health statistics and the ability of the health statistics enterprise to support their production

# State Health Data

- Claims and billing
  - AIDS treatment
  - Breast and cervical cancer prevention programs
  - Dental
  - Early Intervention
  - Emergency Medical Services
  - Family Planning
  - Medicaid
    - Acute care
    - Clinics
    - Hospitals
    - Individual providers
    - Long term care
  - Substance abuse services
  - Tobacco prevention
  - WIC

- Client case management
  - AIDS Drug Assistance Program
  - Child and adolescent service encounters
  - Early Intervention
  - Family Planning
  - Healthy Start
  - Homecare and hospice
  - Medicaid eligibility
  - Pediatric nutrition services
  - Refugee and immigrant health
  - School health
  - Services for children with special health care needs
  - Substance abuse
  - WIC

- Cost reports
  - Ambulatory care centers
  - Bad debt and free care
  - Home health agencies
  - Hospitals
  - Mental health centers
  - Neighborhood health centers
  - Nursing homes
  - Substance abuse services

- Encounters
  - Ambulatory surgery
  - Cardiac surgery
  - Emergency departments
  - Hospital discharges

- Environmental health
  - Asthma
  - Emissions Inventory System
  - Environmental exposure reports
  - Food monitoring
  - Ground water and solid waste information system
  - Hazardous substance emergency reports
  - Hazardous waste information reporting system
  - Radon assessments
  - Restaurant monitoring
  - Swimming pool and bathing beach water quality
  - Water quality

- Facility surveys and reports
  - Abuse reports
    - Home health
    - Hospitals
    - Nursing homes
  - Annual surveys
    - Ambulatory care
    - Home health
    - Hospitals
    - Mental health
    - Neighborhood health centers
    - Nursing homes and long term care facilities
    - Substance abuse services
  - Health care facility complaints
  - Medical errors

- Licensure, health facilities and services
  - Adult care homes
  - Ambulances
  - Ambulatory surgery centers
  - Assisted living centers
  - Dialysis centers
  - Home health agencies
  - Hospitals
  - Mental health centers
  - Mental retardation homes
  - Neighborhood health centers
  - Nursing homes and long term care facilities

- Licensures, health professionals
  - Acupuncturists
  - Adult care home administrator
  - Asbestos abatement technicians
  - Audiologists
  - Dentist
  - Dental hygienist
  - Dietitian
  - Emergency medical technicians

- Lead abatement technicians
- Nurse
- Nurse midwife
- Nursing home administrator
- Optometrists
- Pharmacist
- Physical therapists
- Physician
- Physician assistant
- Podiatrists
- Veterinarians

- Occupational health
  - Census of Fatal
    Occupational Injuries
  - Fatal Accident
    Circumstances Evaluation
    system
  - Sentinel Event Notification
    System for Occupational
    Risks
  - Survey of Occupations and Industries

- Population based surveys
  - Behavioral Risk Factor Surveillance Systems
  - Community health
  - HIV Family of Seroprevalence Surveys
  - Insurance coverage
  - Pregnancy Risk
    Assessment Monitoring
    System
  - Smoking and tobacco use
  - Youth Risk Behavior Survey
  - Youth substance abuse

- Professional association memberships
  - Dental hygienist
  - Dentist
  - Nurse
  - Nurse practitioners
  - Pharmacist
  - Physician

- Registries
  - Adverse Pregnancy Reporting System
  - Births
  - Cancer incidence
  - Congenital anomalies
  - Deaths
  - Diabetes
  - Divorces
  - Genetic diseases
  - Immunization
  - Induced termination of pregnancies
  - Lead poisoning

- Linked births and deaths
- Marriages
- Maternal mortality review
- National Violent Death Reporting System
- Newborn hearing
- Newborn screening adverse outcomes
- Perinatal mortality monitoring
- Stillbirths
- Trauma
- Traumatic brain and spinal cord injuries

- Reportable diseases and conditions
  - AIDS/HIV
  - Burn Injury Reporting System
  - Chicken pox
  - Chlamydia
  - Eastern equine encephelitis
  - Gonorrhea
  - Hepatitis B, C
  - Lyme disease
  - Measles
  - Mumps

- Polio
- Rabies
- Rubella
- Salmonella
- Syphilis
- Tuberculosis
- Vaccine reactions
- West Nile virus
- Work-related carpal tunnel syndrome
- Work-related injuries to teens

# Archetypical Problems

152 data sets:

- 1. Unifying conceptual framework?
  - Population health focus
  - Models of population
- 2. Inter-operability?
  - Common identifiers
  - Common definitions
  - Common content
  - Common codes
  - Common transaction standards
- 3. Communication among. . . ?
  - Data providers
  - Data collectors
  - Data analysts

First Tactic—Conceptual: Learning What Data We Have and What We Don't Have

- Population health focus
- Models of population health

### **Population Health Focus**

#### Population health focus implies:

#### 1. Populations, not individuals

- Populations not merely aggregations of individuals
- Unique characteristics of populations, including dispersion of health outcomes and disparities
- Differences between causes of incidence and causes of individual cases
- Variation between populations as well as variation within populations
- 2. Health, not disease or absence of disease
- 3. Proximate as well as distal influences on health of populations
- 4. Prevention, with priority given to:
  - Influences with greatest potential for most efficient population prevention strategies

#### **Population Health Focus**

- Assumptions
  - Population health is *not* individual health aggregated or writ large
  - Multiple factors affect population health
  - Information needs for health policy extend far beyond health care, health status, and health outcomes

#### **Population Health Focus**

- Implications of assumptions
  - No single data set will suffice and no static repository of data sets will suffice for meeting information needs for health policy
  - Keys to understanding population health and meeting health policy needs:
    - Inter-sectoral approach to data
    - Data set and data record linkage

#### **Population Health Models**

- Provide framework for:
  - Formal, concept-based audits and assessments of data investments
  - Re-orienting data investments through identifying gaps and imbalances
  - Increasing returns on data investments

Second Tactic—Methodological: Increasing Data Set Inter-operability

- Increasing data set interoperability through
  - Common identifiers, with
  - Common variable definitions,
  - Common content,
  - Common codes, and
  - Common transaction standards
- Not

- Common health identification numbers

Third Tactic—Procedural: Fostering Collaboration

- 152 data sets
  - Different data set holders
  - Different data set release protocols
  - Different data set mandates
  - Different data set governing legislation
  - Different data set
    - Programmers
    - Analysts
    - Researchers

Current Organizational Models for Meeting Information Needs for Health Policy

- Organizational governance continuum
  - Governmental: Australian Institute for Health and Welfare, U. S. state health data centers, CDC, AHRQ
  - Quasi-governmental: Canadian Institute for Health Information, UK public health observatories
  - Non-governmental: Manitoba Centre for Health Policy

### **Organizational Models**

- Current organizational models
  - No single correct organizational model exists
  - Choice of organizational model needs to be determined by
    - National, state, or provincial climate and culture
    - Professional resources
    - Recognition of strengths and requirements of each stakeholder
    - Information needs

# **Organizational Models**

- Virtual network--new point on the organizational governance continuum
  - Ongoing, highly structured collaboration among participant organizations and individuals within clear legal or contractual framework
  - Builds on strengths and capabilities of each participant, both organizational and individual
  - Distributes functions and responsibilities to where most appropriate
  - Maximizes collaboration, inter-sectoral approaches, linkage options
  - Recognizes need for flexible funding

### **Organizational Models**

- Requirements for virtual network
  - Nerve Center
    - Assesses population health information needs
    - Establishes priorities
    - Convenes participants, stakeholders, and public
    - Coordinates planning among participants
    - Facilitates data sharing and linkage through
      - Adopting and adapting standards
      - Establishing legislative framework
      - Developing data sharing protocols and review process
      - Providing home for Human Subjects Review Board and other formal confidential data release mechanisms

