

# NATIONAL HEALTH INFORMATION INFRASTRUCTURE

- ◆ John R. Lumpkin, MD, MPH
- ◆ Jeffrey S. Blair, MBA
- ◆ Daniel Friedman, Ph.D.
- ◆ Richard K. Harding, MD
- ◆ Clement J. McDonald, MD
- ◆ Barbara Starfield, MD, MPH
- ◆ Kepa Zubeldia, MD
- ◆ Mary Jo Deering, Ph.D.
- ◆ Mike Carleton
- ◆ Betsy D'Jamoos
- ◆ Theresa Krol
- ◆ Dena Puskin, Sc.D.
- ◆ Steve Steindel, Ph.D.

# The Challenge that we face

- ◆ “THE MANAGED-CARE-BASED HEALTH SYSTEM IS FAILING. MEDICAL INFLATION IS BACK. CONSUMER DISTRUST, PROVIDER HOSTILITY, COSTLY NEW TECHNOLOGIES AND POLITICAL OPPORTUNISM WILL NO LONGER ALLOW COSTS AND QUALITY TO BE CONTROLLED BY MOST EXISTING MANAGED CARE ARRANGEMENTS”

# The Challenge that we face

- ◆ "OVERALL, QUALITY HAS NOT BEEN DELETERIOUSLY AFFECTED BY MANAGED CARE, BUT MANAGED CARE HAS NOT SUBSTANTIALLY REDUCED UNSAFE PRACTICES, OVERUSE, UNDERUSE AND MISUSE OF HEALTH CARE"  
- PAUL ELLWOOD

# HEALTH

## ◆ WHO

- ◆ HEALTH IS A STATE OF COMPLETE PHYSICAL, MENTAL AND SOCIAL WELL-BEING AND NOT MERELY THE ABSENCE OF DISEASE OR INFIRMITY
- ◆ HEALTH IS A STATE OF WELL-BEING AND THE CAPABILITY TO FUNCTION IN THE FACE OF CHANGING CIRCUMSTANCES

# HEALTH

- ◆ SHARED RESPONSIBILITY

- ◆ HEALTH CARE

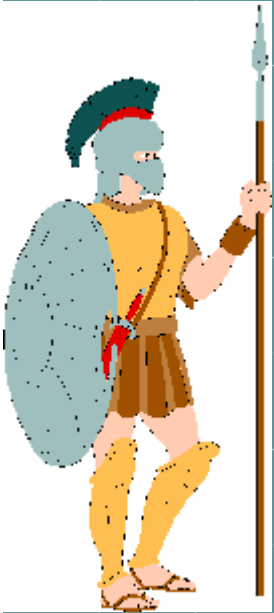
- ◆ PUBLIC HEALTH

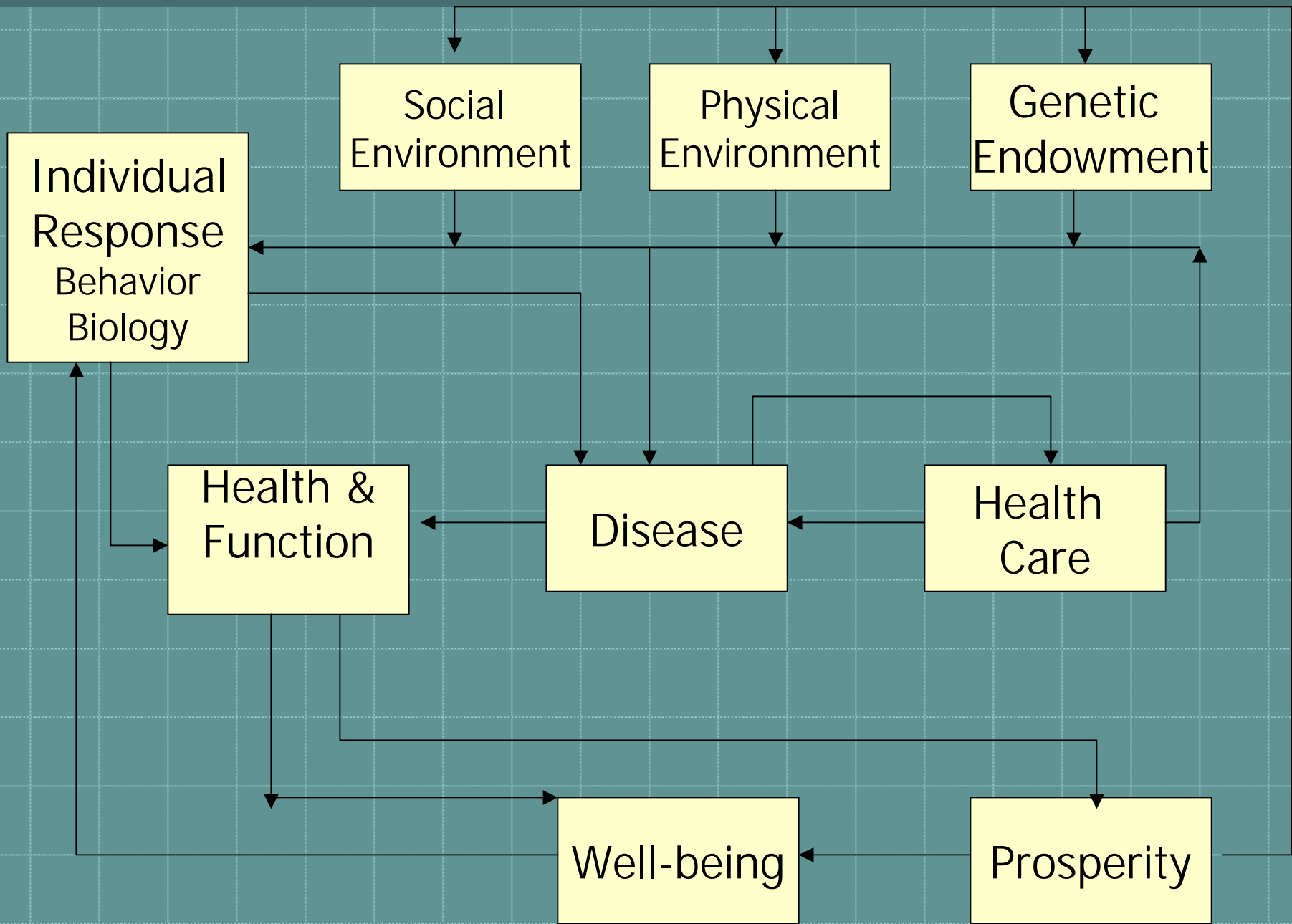
- ◆ OTHER

- ◆ -IOM 1997 IMPROVING HEALTH IN THE COMMUNITY-A  
ROLE FOR PERFORMANCE MONITORING

# HIPPOCRATES

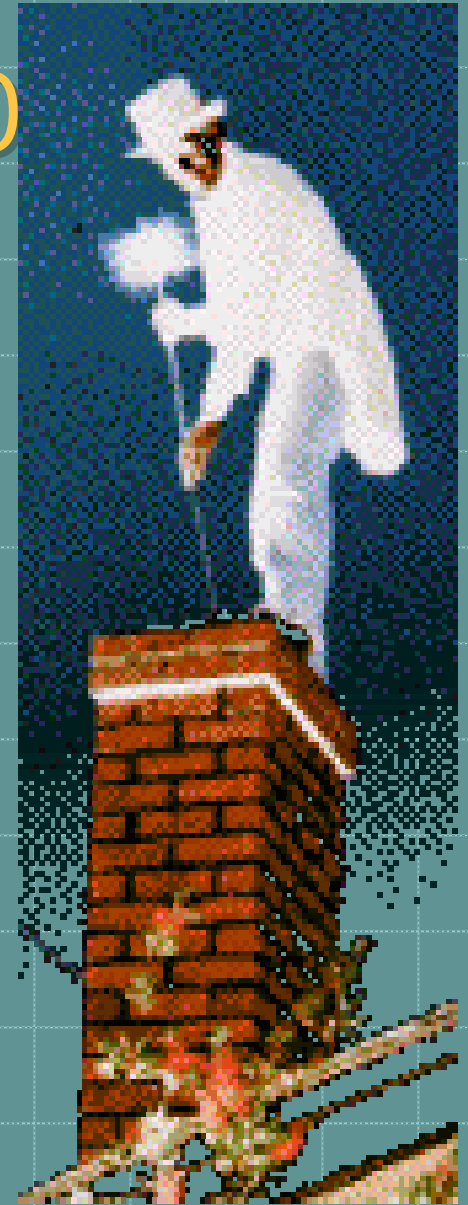
- ◆ NOTED THAT IF YOU WANTED TO KNOW ABOUT THE HEALTH OF A PEOPLES NOTE
  - ◆ THE WINDS AND THE CHARACTER OF THE AIR
  - ◆ THE WATER AND THAT THEY DRINK
  - ◆ THE LAY OF THE LAND
  - ◆ THE HABITS OF THE PEOPLE





# PERCIVAL POTTS, MD

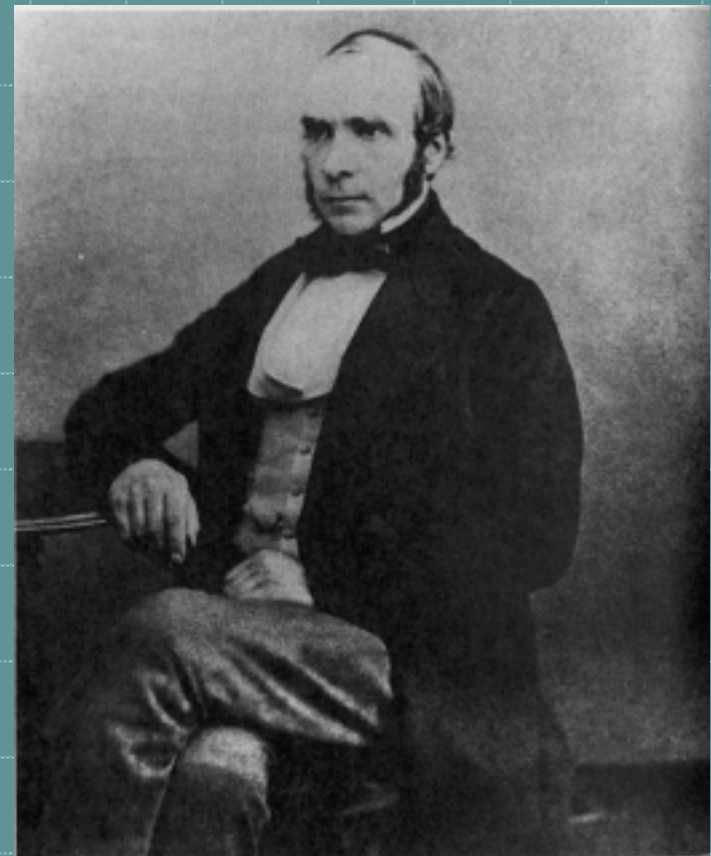
- ◆ IDENTIFIED LINK BETWEEN
- ◆ OCCUPATION AND CANCER
- ◆ RECOMMENDATIONS FOLLOWED?





# SNOW ON CHOLERA

- ◆ DATABASE ANALYSIS
- ◆ GIS SYSTEM







# The Business of Health

- ◆ Helping people stay healthy
- ◆ Helping people get better when they are ill
- ◆ Helping people live with illness when their illness is chronic
- ◆ Helping people manage a changing lifestyle when their illness impairs their functioning

★ based upon work by the Foundation for Accountability

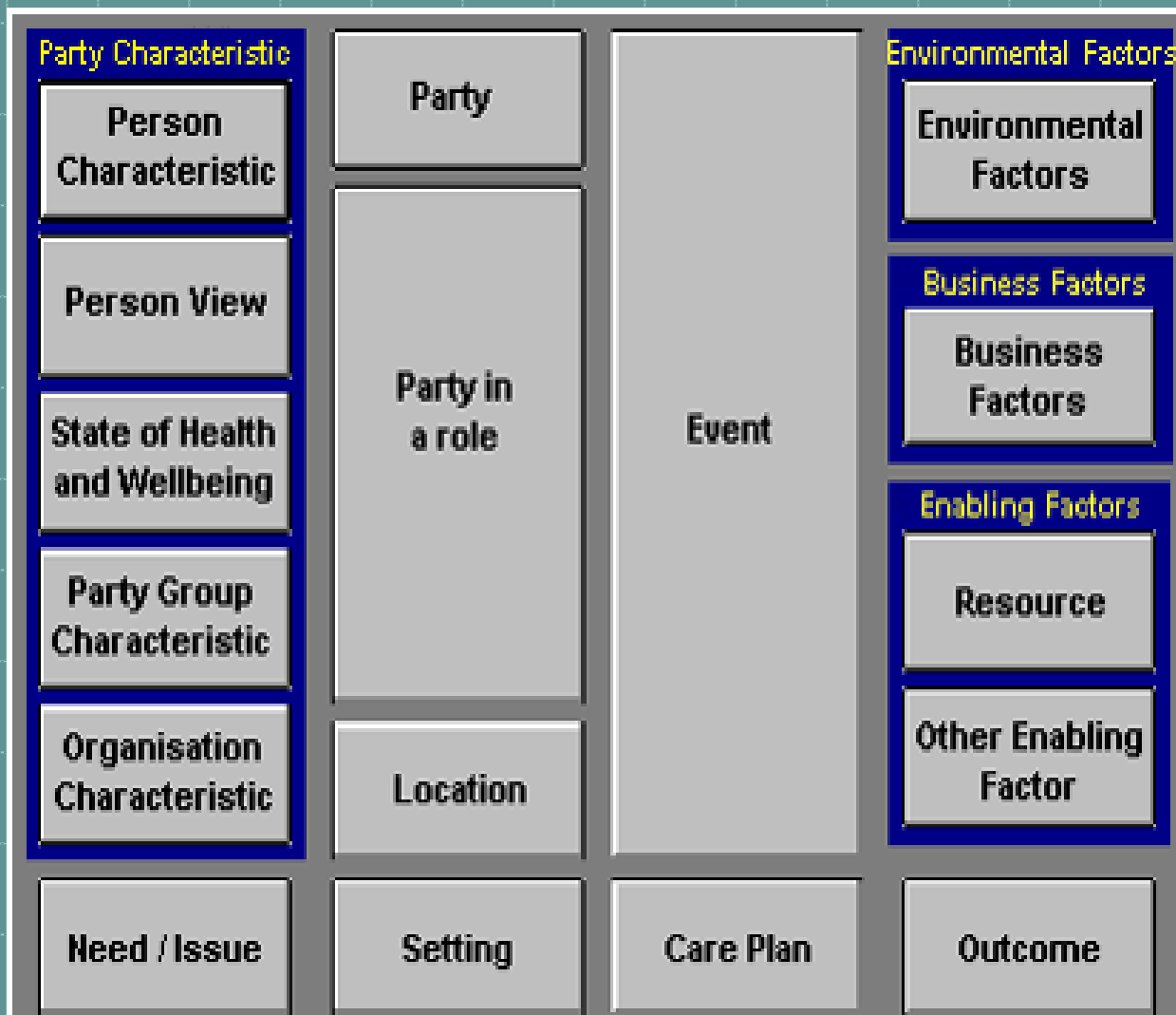
# Vision of the NHII

- ◆ The set of technologies, standards, applications, systems, values, and laws that support all facets of individual health, health care, and public health.
- ◆ NOT a centralized database.
- ◆ Connects distributed health information in the framework of a secure network with strict confidentiality protections.

# NHII

- ◆ DATA MODEL
- ◆ DATA STANDARDS
- ◆ CONNECTIVITY STANDARDS

# Australian Data Model





# AMERICAN APPROACH

- ◆ RESPECT INDIVIDUAL PRIVACY
- ◆ ASSURE CONFIDENTIALITY
- ◆ ENGINEERED FOR SECURITY



# NHII

## ◆ DATA STANDARDS

- ◆ HIPAA

- ◆ X12

- ◆ HL7

- ◆ NCPDP

- ◆ NPI

- ◆ OTHER STANDARDS

# NHII

- ◆ EDI
- ◆ INTERNET
- ◆ INTRANET
- ◆ OTHER CONNECTIVITY STANDARDS

NHII

◆ **STANDARDS ARE NOT ENOUGH**

# NHII

- ◆ THE GOAL IS TO PUSH KNOWLEDGE TO THE POINT OF SERVICE (CONTACT)
  - ◆ EXPERT SYSTEMS
  - ◆ DECISION SUPPORT
  - ◆ PRACTICE GUIDELINES

NHII

# Universe of Health Data

NHII

**PROVIDER DATA**

Universe of Health Data

NHII

Universe of Health Data

**ADMINISTRATIVE DATA**

NHII

Universe of Health Data

**PERSONAL DATA**



NHII

**COMMUNITY  
BASED DATA**

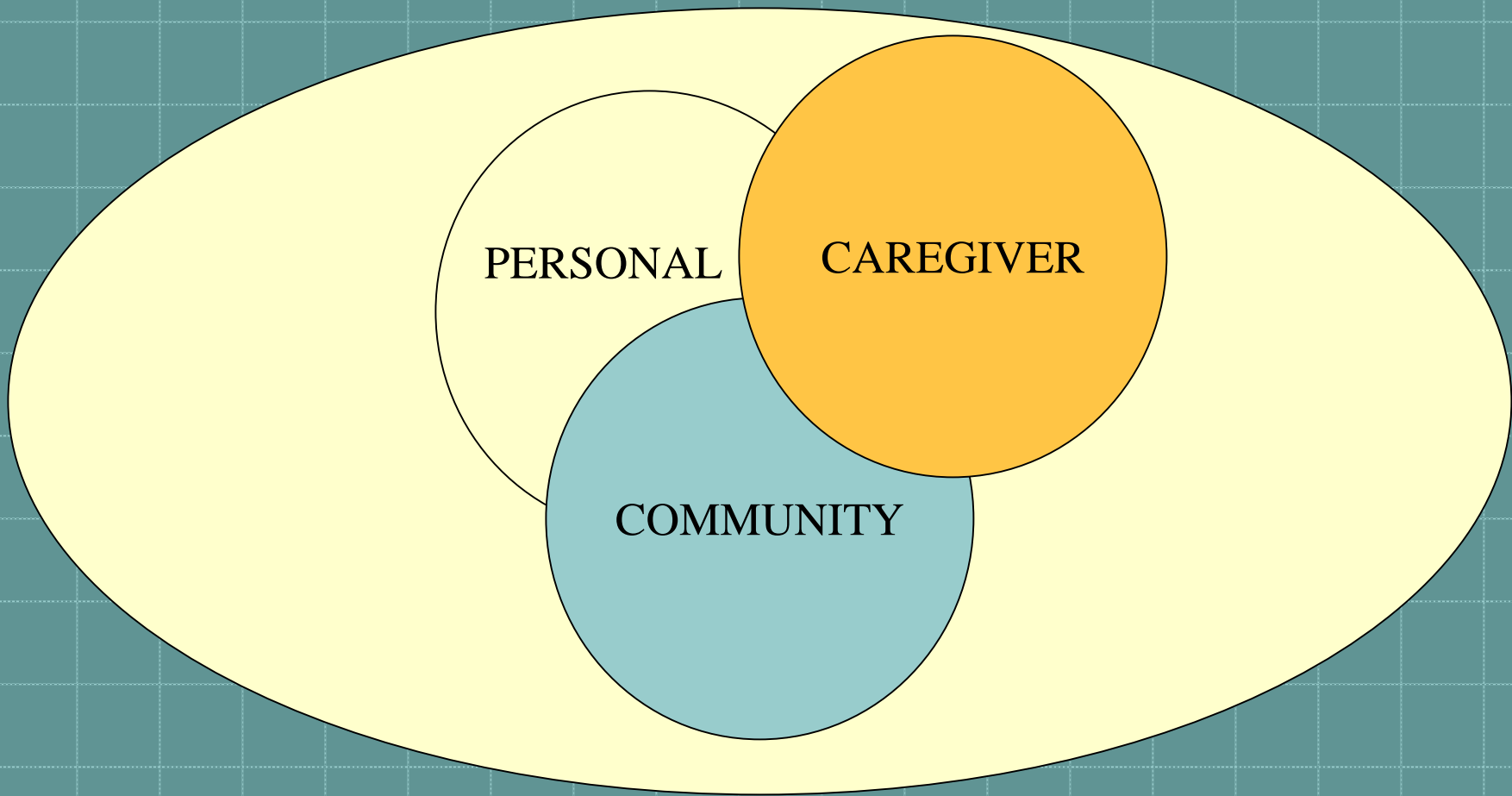
Universe of Health Data

NHII

Universe of Health Data

**QUALITY DATA**

# NHII



# Personal Health Dimension

- ◆ Supports the management of individual wellness and health care decision-making
- ◆ Includes a personal health record, created and controlled by the individual or family
- ◆ Includes non-clinical information such as self-care trackers, health materials, local public health and health care services

# Personal Health Dimension

- ◆ Personal health record component could be stored in a variety of repositories--smart card, home computer, third party information guardian service, health plan/provider server, etceteras
- ◆ Individual authorizes access to specific categories of information in their PHD by specific people, organizations, or categories of users

# PHD Core Data

- ◆ Patient identification information
- ◆ Lifetime health history
- ◆ Treatment plans and instructions
- ◆ Health risk factor profile
- ◆ Self-care trackers
- ◆ Personal library of quality health information resources
- ◆ Healthcare proxies and living wills

# Health Care Provider Dimension

- ◆ The vision of the Caregiver Dimension was generally described in the Institute of Medicine's study entitled "Computer-Based Patient Record: An Essential Technology for Health Care".
- ◆ Information systems will assist the caregiver by reviewing the data within the encounter record and providing appropriate warnings, alerts and reminders.

# Health Care Provider Dimension

- ◆ Encompasses information to enhance the quality and efficiency of health services for individual
- ◆ Includes information captured during patient care process
- ◆ Integrates clinical guidelines and protocols, specific information from PHD, as authorized, and from Community Health Dimension



# Health Care Provider Dimension

- ◆ Primary record of care is under the control of the provider who captures original information
- ◆ May be stored on site or on server of a third-party health information guardian
- ◆ Confidentiality protections include technologies for authorization, authentication, encryption and electronic signatures; restricted access by class, role, or location of user

# Community Health Dimension

- ◆ Supports the identification of health threats, assessment of population health status, focussing programs and services, research and evaluation
- ◆ Encompasses population-based health data and resources, statutorily authorized data in public health systems and the Health Care Provider Dimension, and other anonymous data

# Community Health Dimension

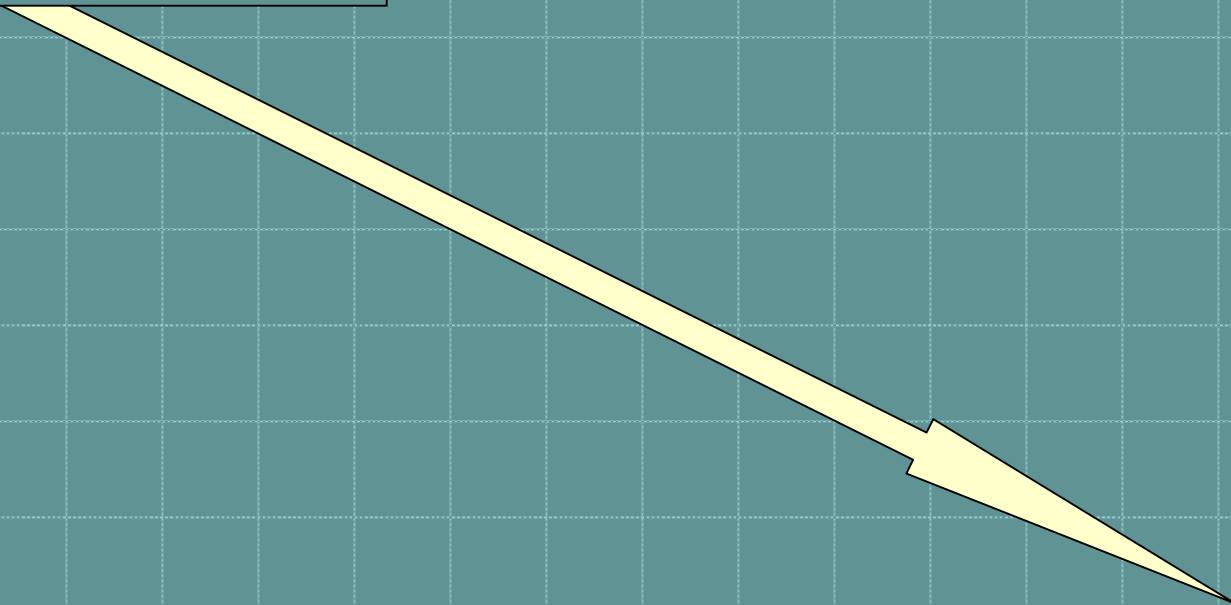
- ◆ No single database of public health information
- ◆ Improved vertical and horizontal integration of federal, state, and local systems through electronic data exchange standards
- ◆ Data aggregated by geographic area, demographic element, health event, etceteras
- ◆ Access defined along a continuum with strict protocols and monitoring

# CHD Core Data

- 1 Health of community members
  - ◆ health status, behaviors and outcomes
  - ◆ social, economic, and demographic characteristics
- 2 Health care of community members
- 3 Community attributes affecting health
- 4 Community health resources
- 5 Community health
  - ◆ receipt of preventive care
  - ◆ disease rates
  - ◆ morbidity burden rates

# CHD Access Continuum

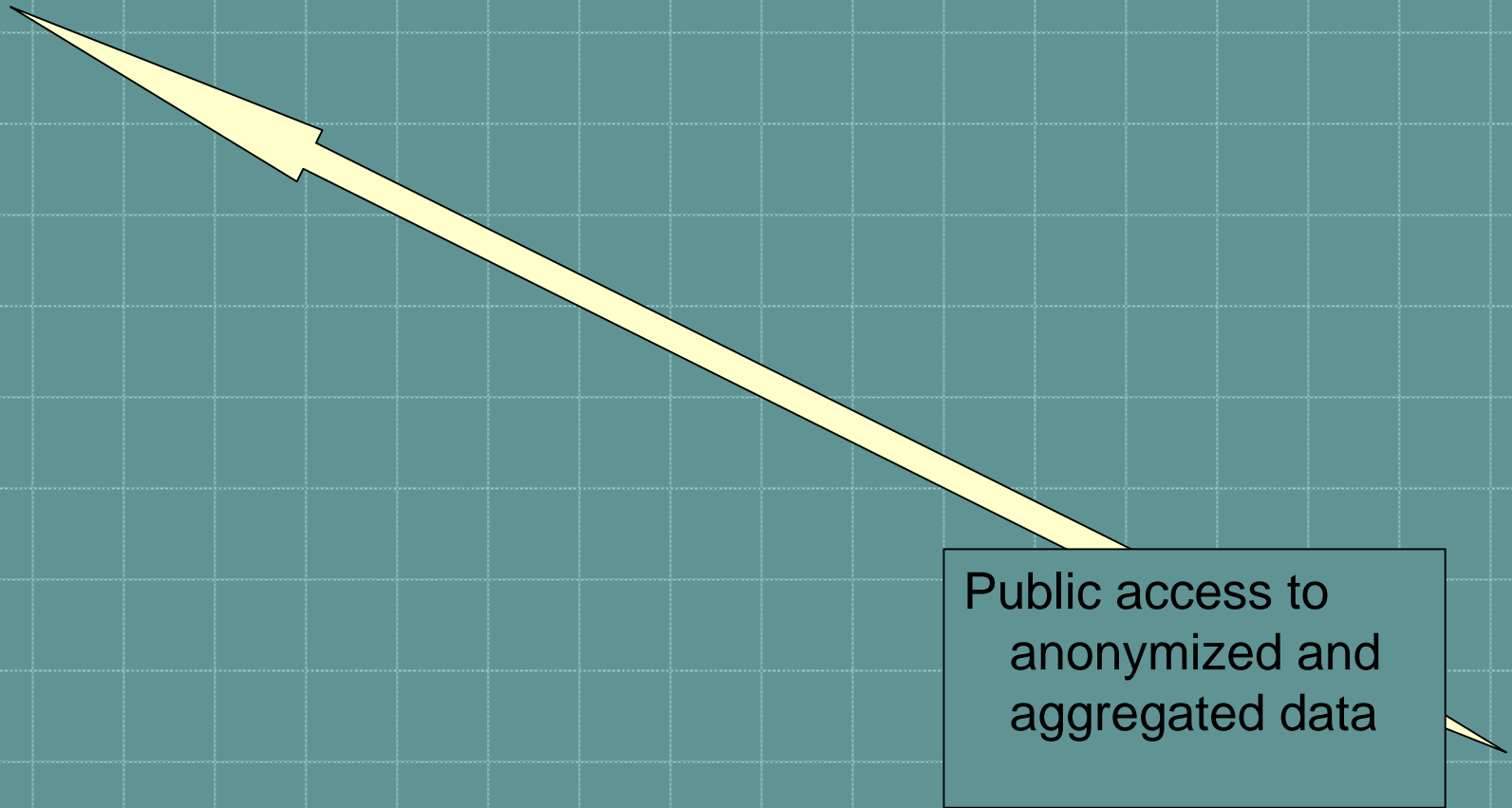
Individually identifiable  
data by authorized  
public health workers



# CHD Access Continuum



# CHD Access Continuum



# Privacy, Confidentiality, and Security

Legal and policy framework to maximize confidentiality, security and appropriate use

Issues requiring resolution

- ◆ Anonymized linkage variable
- ◆ Access continuum
- ◆ Decision rules
  - ◆ cell size suppression
  - ◆ IRB approval of research uses and linkages



# Requirements

- ◆ “It’s not just the technology”
- ◆ Privacy protections
- ◆ Standards
- ◆ Business models
- ◆ Attitudes and practices
- ◆ Equity

# NHII next steps

- ◆ Validation of the vision
- ◆ Identification of the barriers
  - ◆ Privacy Protection
  - ◆ Standards
  - ◆ Technology
- ◆ Development of recommendations
- ◆ Commitment to implementation