Supporting communities as learning health systems:
a report to the HHS Data Council on NCVHS activities and plans

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Outline

- NCVHS: *shaping the health data vision for the 21st century*
  - Convergence: HHS data liberation and community learning systems for public health
  - Using data at the local level
  - Community driven change
  - Health data stewardship

- The Federal role in providing and supporting community driven change
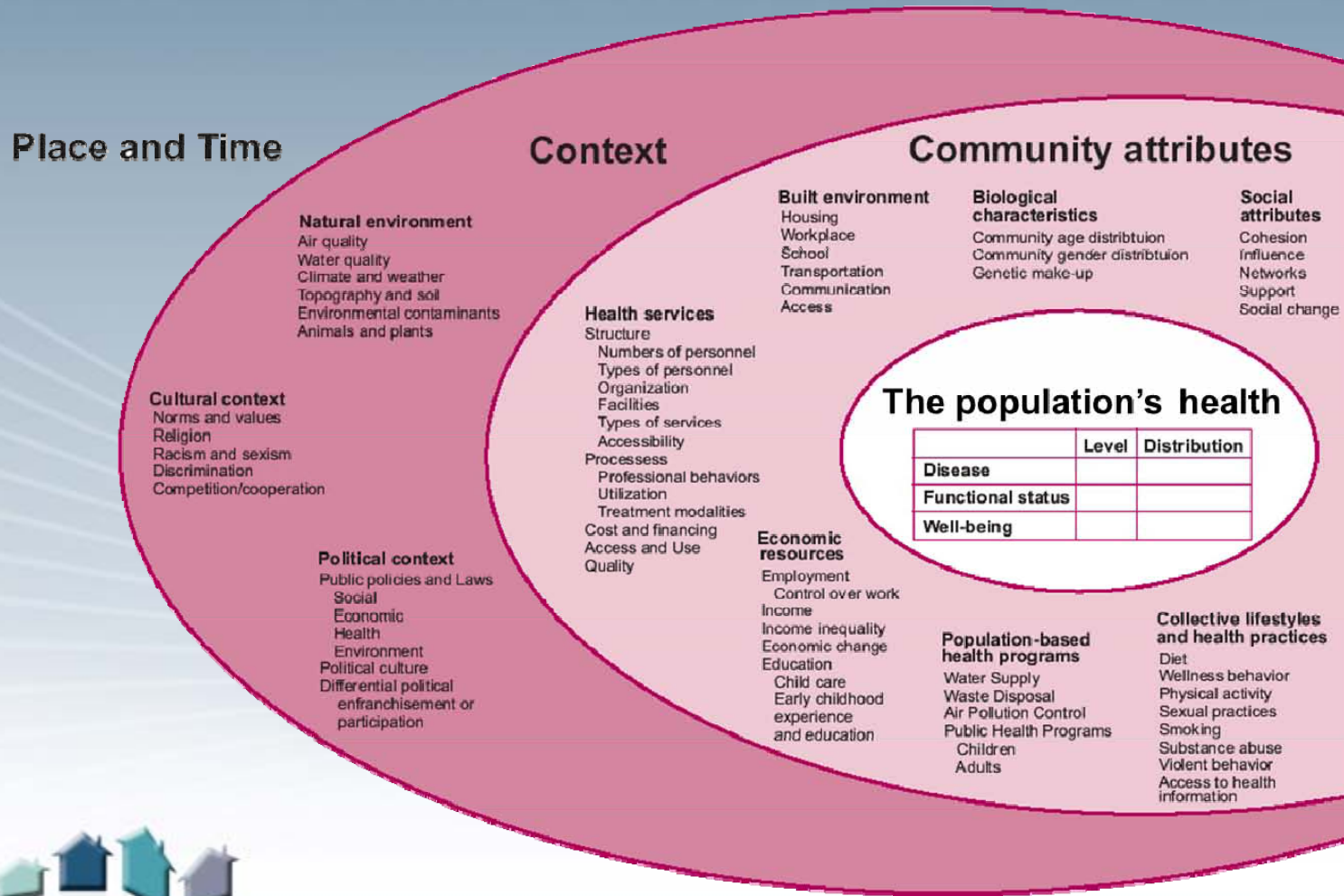- Aligning NCVHS and Data Council activities

The National Committee on Vital and Health Statistics

- The statutory public advisory body to the Secretary of Health and Human Services in the areas of health data, statistics and health information policy; established in 1949

- Serves as a forum for interaction with interested private and public sector groups on key health data issues

- 18 members appointed for four year terms; drawn from fields including medicine, law, public health, economics, privacy, security, informatics, health plans, consumers

- Through hearings and open deliberation, aims to develop practical, timely, thoughtful recommendations to the Secretary of HHS

Shaping a Health Statistics Vision for the 21st Century (2002)

Place and Time

Context

Community attributes

Natural environment
Air quality
Water quality
Climate and weather
Topography and soil
Environmental contaminants
Animals and plants

Cultural context
Norms and values
Religion
Racism and sexism
Discrimination
Competition/cooperation

Political context
Public policies and Laws
  Social
  Economic
  Health
  Environment
Political culture
Differential political
  enfranchisement or
  participation

Health services
Structure
  Numbers of personnel
  Types of personnel
  Organization
  Facilities
  Types of services
  Accessibility
Processess
  Professional behaviors
  Utilization
  Treatment modalities
Cost and financing
Access and Use
Quality

Economic resources
Employment
  Control over work
Income
Income inequality
Economic change
Education
  Child care
  Early childhood
  experience
  and education

Built environment
Housing
Workplace
School
Transportation
Communication
Access

Biological characteristics
Community age distribtuion
Community gender distribtuion
Genetic make-up

Social attributes
Cohesion
Influence
Networks
Support
Social change

Population-based health programs
Water Supply
Waste Disposal
Air Pollution Control
Public Health Programs
  Children
  Adults

Collective lifestyles and health practices
Diet
Wellness behavior
Physical activity
Sexual practices
Smoking
Substance abuse
Violent behavior
Access to health information

The population's health

|	Level	Distribution
Disease		
Functional status		
Well-being		

Convergence

- The Federal government wants to liberate its data

- Communities are becoming more sophisticated data users

- NCVHS is integrating its work on population health, security, privacy, standards, and quality

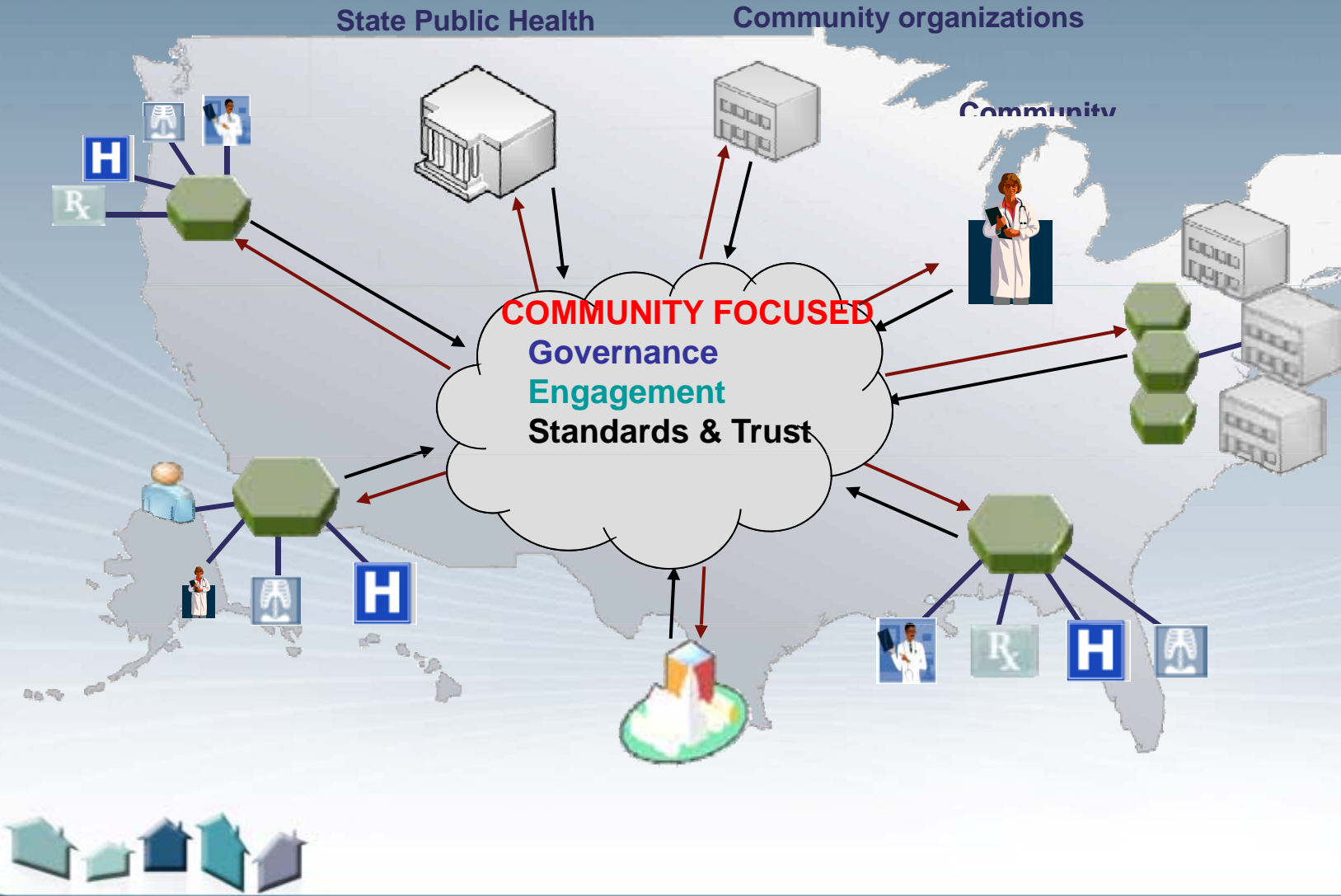# Impetus for Focus on Community Health Data

Community: an interdependent group of people who share a set of characteristics and are joined over time by a sense that what happens to one member affects many or all of the others

Upsurge in community health Initiatives

Learning Health System project
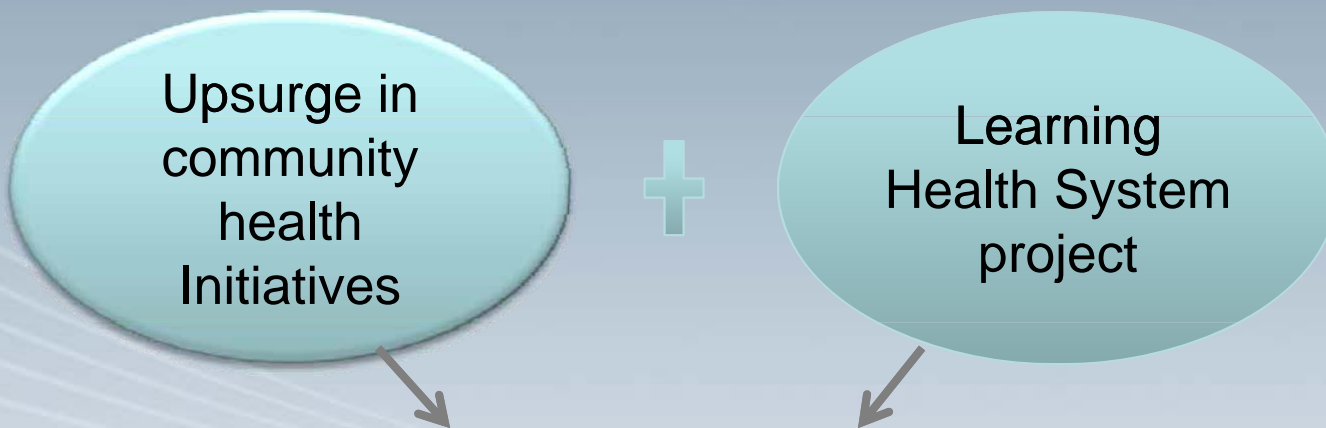
How communities can become learning systems for health and what resources exist and are needed to help them?

A Learning Health System

State Public Health

Community organizations

Community

COMMUNITY FOCUSED
Governance
Engagement
Standards & Trust

Ongoing NCVHS work:
using local data
community driven change
data stewardship

Using local data

Health is a Community Affair

"Getting data into the hands of communities and ensuring they have tools and capacities to use them could move the nation toward realizing the public benefits of the informatics revolution."

The Community as a Learning System for Health, NCVHS, December 2011, p. 7

14 Leading edge Learning Communities

1. **Boone County,** MO – *Public Health*
2. **Bronx, NY** – *Care transitions*
3. **Denver, CO** – *cardiovascular health, childhood obesity*
4. **Grand Junction, CO** – *population health*
5. **Indiana and HIE** – *population health*
6. **King county, WA** – *data democratization*
7. **Mahoning Valley, OH** – *children's health insurance coverage*
8. **New York City**- BMI screening for children
9. **Olmsted County, MN** – childhood asthma
10. **Sonoma County, CA** – health information for citizens
11. **Columbia, SC** – data to improve childcare
12. **South Los Angeles, CA** – land use policies and health disparities
13. **State of Arkansas** – childhood obesity
14. **Utah** – consumer education about health data use

Feedback from Community Groups: online tool

- Collecting, Protecting, and Using Health Data in Communities: A Feedback Tool
- Strategic planning – leverage knowledge to expand thinking about potential options

We can't solve problems by using the same kind of thinking that we used when we created them. – Albert Einstein
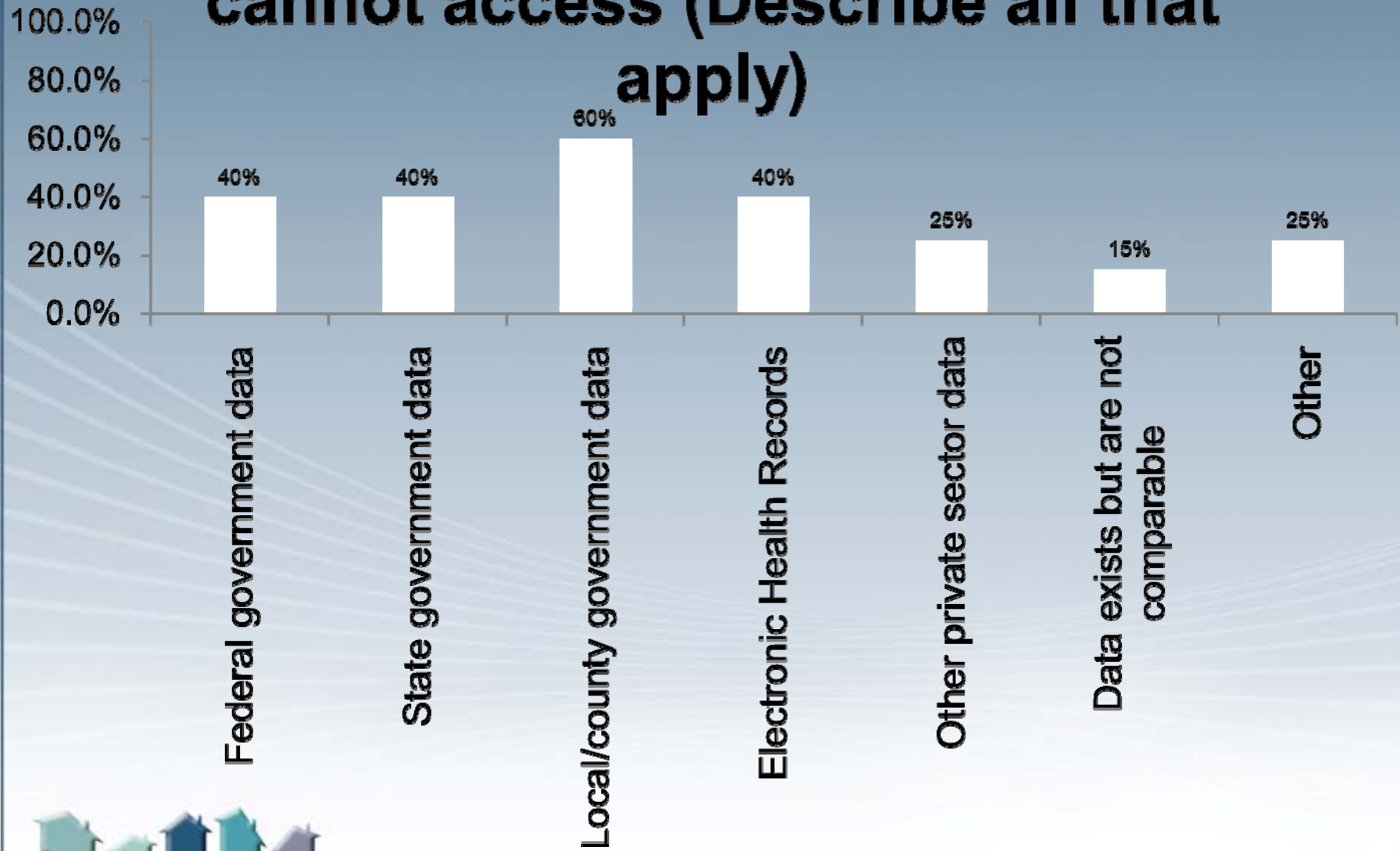
95 Organizations Responded

Type of Organization

- Undetermined 16%
- Medical Facility 13%
- Academia 11%
- Public Health Department 18%
- Community Groups 42%
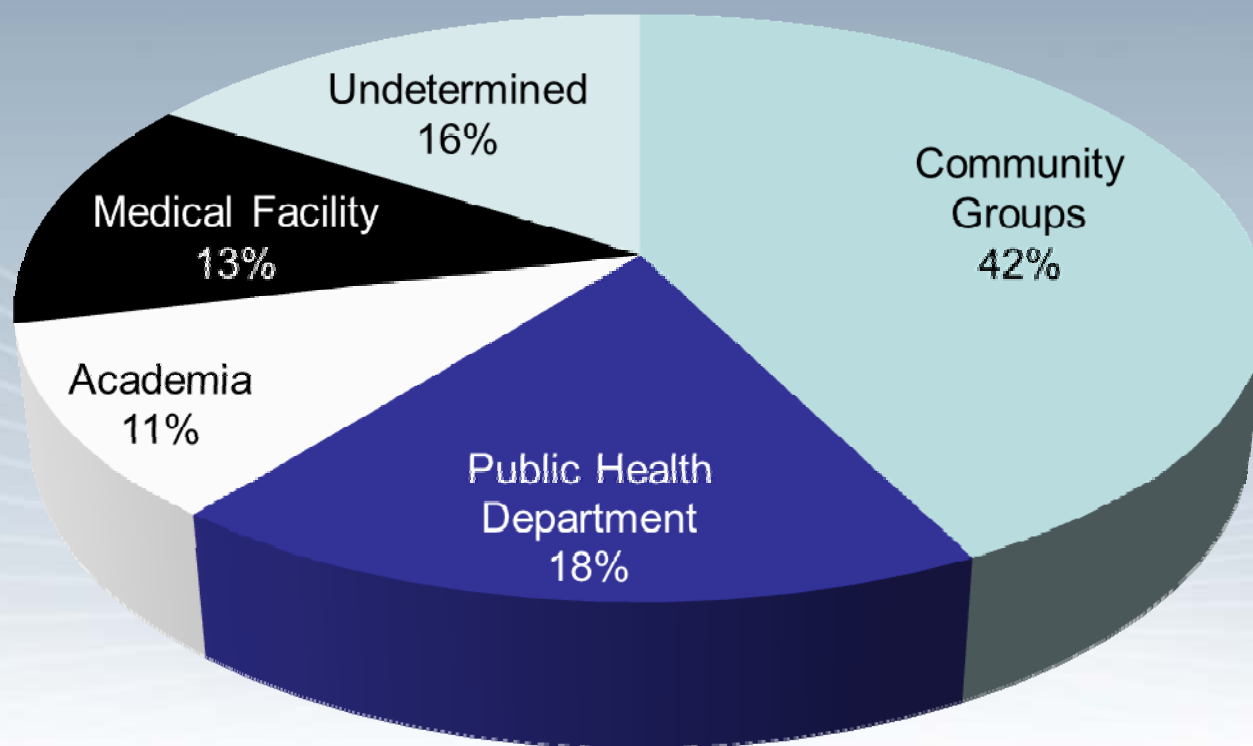
What types of data do you currently use? (Mark all that you use)
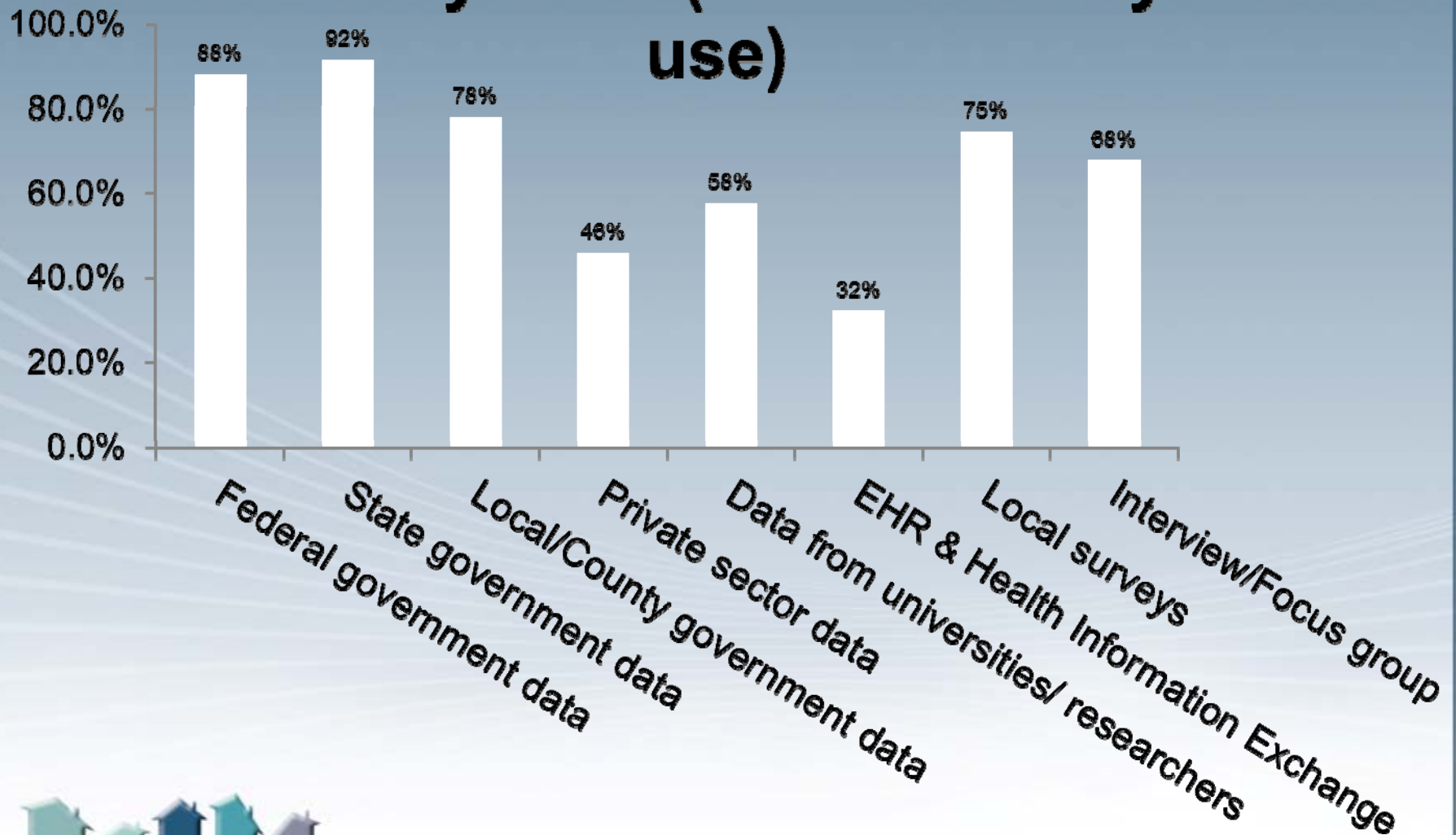
Are there data you would use but cannot access (Describe all that apply)

Themes and learnings

1. Much secondary data exist online: how to determine what to use and how to use them are the challenges.

2. Technical assistance is not universally available

3. Data start conversations; people make decisions: empowerment, dialogue, and engagement are key

4. NCVHS through leveraging Federal involvement can promote important partnerships and provide resources and support to promote the use of data for community driven change

Themes and learnings: factors for success

1. A galvanizing health concern.

2. A comprehensive understanding of health and community health.

3. Collaborative culture; social capital.

4. Trust and community engagement.

5. Access to data on local health and its determinants, plus analytic capacities.

6. Data display and dissemination capacities.

7. Functioning coalitions, community engagement, agreement on priorities.

8. Organizational and technical support.

9. Political and financial support.

10. Processes and systems to translate information and priorities into action, evaluate results, and modify as needed.

NCVHS
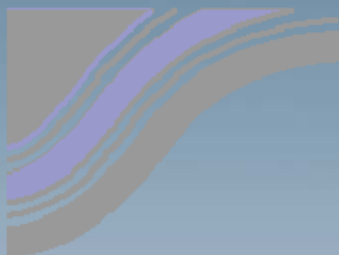
Published, November 2011
Joint Project of the
Population Health and
Privacy, Confidentiality and
Security Subcommittees

The Community as a
Learning System:
Using Local Data To Improve
Local Health

A Report of the
National Committee on Vital Health Statistics

U.S. DEPARTMENT OF HEALTH
AND HUMAN SERVICES

Current activities

- Making recommendations to the Secretary to enhance usability of data by linking three key data constituencies: technically savvy but clinically naïve, clinically savvy but technically naïve; and community

- Proposing content and transactional standards for community health data: harmonizing health indicators

- Evaluating the 'repurposing' and expanded use of data (surveys, surveillance, clinical/EHR, local)

Community driven change

Community Roundtable
April 2013

1. Advance the understanding of access to and use of data by communities to improve population health;

2. Refine our Stewardship Framework for the Use of Community Health data to support the needs of various types of community initiatives;

3. Better understand the role of government in providing data, tools, and resources to promote community driven change; and

4. Understand current state and possible gaps in data content and variable standardization for community data collection and use.

Roundtable Presenters

- ## Local Initiatives
  - Barbara Zappia, Greater Rochester Health Foundation, Neighborhood Health Status Improvement Initiative
  - Lacey Hart, Southeast Minnesota Beacon Community
  - Ninez Ponce, UCLA Center for Health Policy Research, California Health Interview Survey

- ## Privacy and Public Health Law Experts
  - Eve Powell-Griner, NCHS Confidentiality Officer
  - Sharona Hoffman, Professor of Law and Bioethics, Case Western Reserve University
  - Denise Chrysler, Network for Public Health Law

- ## National-scale Organizations and Activities
  - Andrew Bazemore, Robert Graham Center for Policy Studies in Primary Care
  - Bridget Catlin, County Health Rankings and Roadmaps
  - Carladenise Edwards, Senior eHealth Advisor, ZeroDivide
  - Donald Malec, NCHS Office of Research and Methodology – small area estimation research
  - Chris Fulcher, Community Commons
  - Denise Love, National Association of Health Data Organizations

Themes and Learnings

1. Co-production and co-ownership of data
2. Assessing the continuum of community readiness
3. Leveraging a key event to drive longer term change
4. Assistance using the data
5. Collaboration as key to success
6. 'Authentic' communities
7. Importance of qualitative data
8. Using the law to solve public health problems
9. Untapped potential of aligning clinical and public health data
10. Bi-directionality and reciprocity

Joint Roundtable on Health Data Needs for Community-Driven Change

A Summary Report of the National Committee on Vital Health Statistics

U.S. Department of Health and Human Services

Current Activities

- Assess community readiness to make Federal data dissemination more valuable and technical support more useful for decision making

- Explore the continuum of clinical through population health data to provide consistent messaging and compatible data streams

- Investigate new data sources and dissemination modalities (social media, m-health, sub-county data, etc.) to supplement Federal traditional data sources and technical assistance

Data stewardship

HEALTH DATA STEWARDSHIP

Health Data Stewardship: What, Why, Who, How-- An NCVHS Primer (2009)
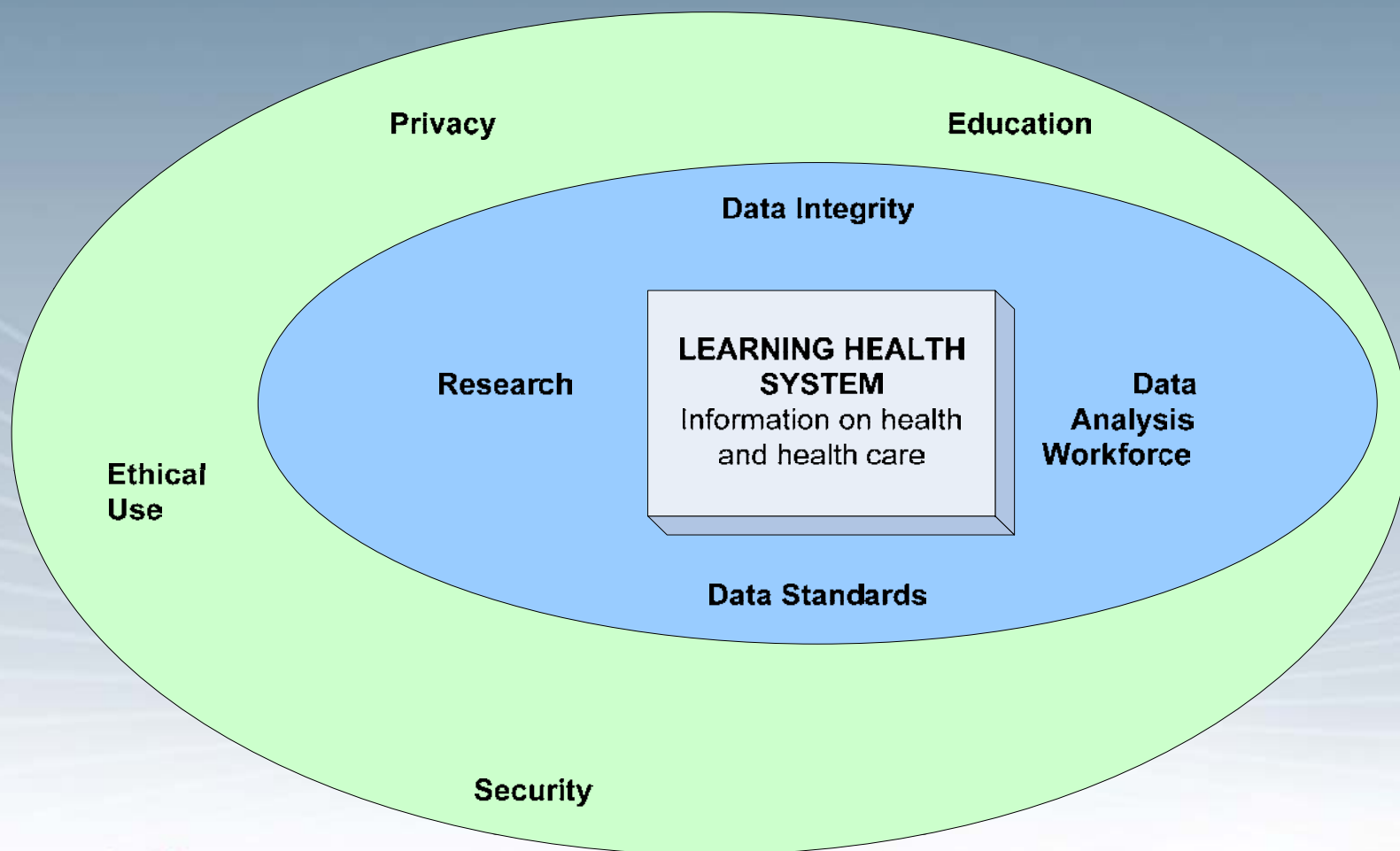
NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

Privacy Report

Recommendations on Privacy and Confidentiality,

2006—2008

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

NCVHS

Stewardship Letter: Framework
December 2012

1. Openness, transparency and choice
2. Purpose specification
3. Community engagement and participation
4. Data integrity and security
5. Accountability
6. Protecting deidentified data
7. Attending to the risks of enhanced data sets
8. Stigma and discrimination

Privacy, Confidentiality, and Security Sub-committee Recommendations to the Secretary:

1. Facilitate development and promulgation of models for stewardship of community health data.

2. Support the development of dynamic guidance resources that compile best practices that experts, communities and other data users are learning about stewardship.

3. Compile case studies of results that communities achieve through their uses of data so that other communities might learn and be inspired.

4. Promote the creation of training materials for researchers who collect and use community health data.

Current Activities

- Developing and promulgating models of stewardship and best practices for protecting data for community users

- Preparing case studies

- Integrating data stewardship and privacy concerns into community learning systems
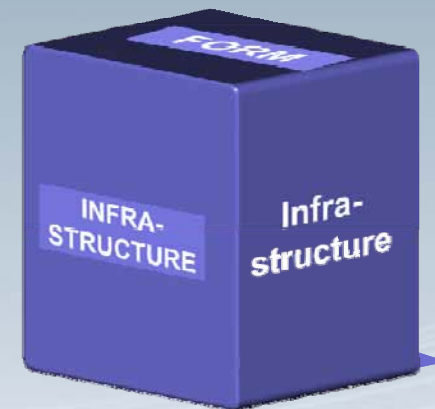
Convergence framework

Framework for community-focused learning health system

Access + analytics + skills to make data usable and useful.

Stewardship + privacy protection + engagement + governance = Trust

Support, facilitate shared learning, and create economies of scale

Reinvigorating the Federal role

Modernizing the Federal public health data infrastructure

1. Serve as intermediary to connect communities and data

2. Redefine public health to meet broader community definitions

3. Reorient Federal workforce to reach communities and provide direct assistance

4. Leverage data collection mandates: IRS requirements for community health needs assessments, HIE's, ACA

5. Promote models of stewardship and best privacy practices

6. Support public health departments to take advantage of Meaningful Use criteria

Modernizing the Federal public health data infrastructure

7. Standardize community health, health status, environmental and resource use indicators

8. Train and provide technical assistance and easy to use tools for data management, display and analysis, local data collection (including surveys and mapping) perhaps through existing HIT initiatives such as regional extension centers

9. Promote Federal and state web-based data query systems

10. Longer funding periods, and transitional support for institutionalization of promising new policies and program

Aligning NCVHS and Data Council activities

1. Data liberation
   Access and release
   Protection/stewardship
   Definitions/standards
2. Analytic Support/tools
   Mapping
   SAE's,
   Statistical software
   WDQS, etc.)
3. Workforce/human support
4. Funding
5. Facilitation: connecting communities to both
Federal and non-Federal resources

"Someday, all this will be infrastructure."

The Community as a Learning System Report:
http://www.ncvhs.hhs.gov/111213chip.pdf

Next Step for Community Data Use
http://www.ncvhs.hhs.gov/120417ag.htm

Health Data Needs for Community Driven Change
http://www.ncvhs.hhs.gov/130430ag.htm

NCVHS

http://www.ncvhs.hhs.gov/

Additional Slides

Identifying priorities and building partnerships and collaboration

- Involving citizens and community groups; generating new partnerships
- The role of local data

"Consensus about local priorities emerges when quantitative data are combined with community members' insights and preferences."

The Community as a Learning System for Health, NCVHS, December 2011, p. 12

Building Trust

- Educating community members and leaders about data use and benefits

- Involving community members in decisions about data use and more

- Trust-building among organizations and agencies that are data sources

- Governance fosters a sense of ownership and control

"…further efforts and leadership are needed to define a privacy and security framework to guide the innovative uses of local data emerging in communities across the country."
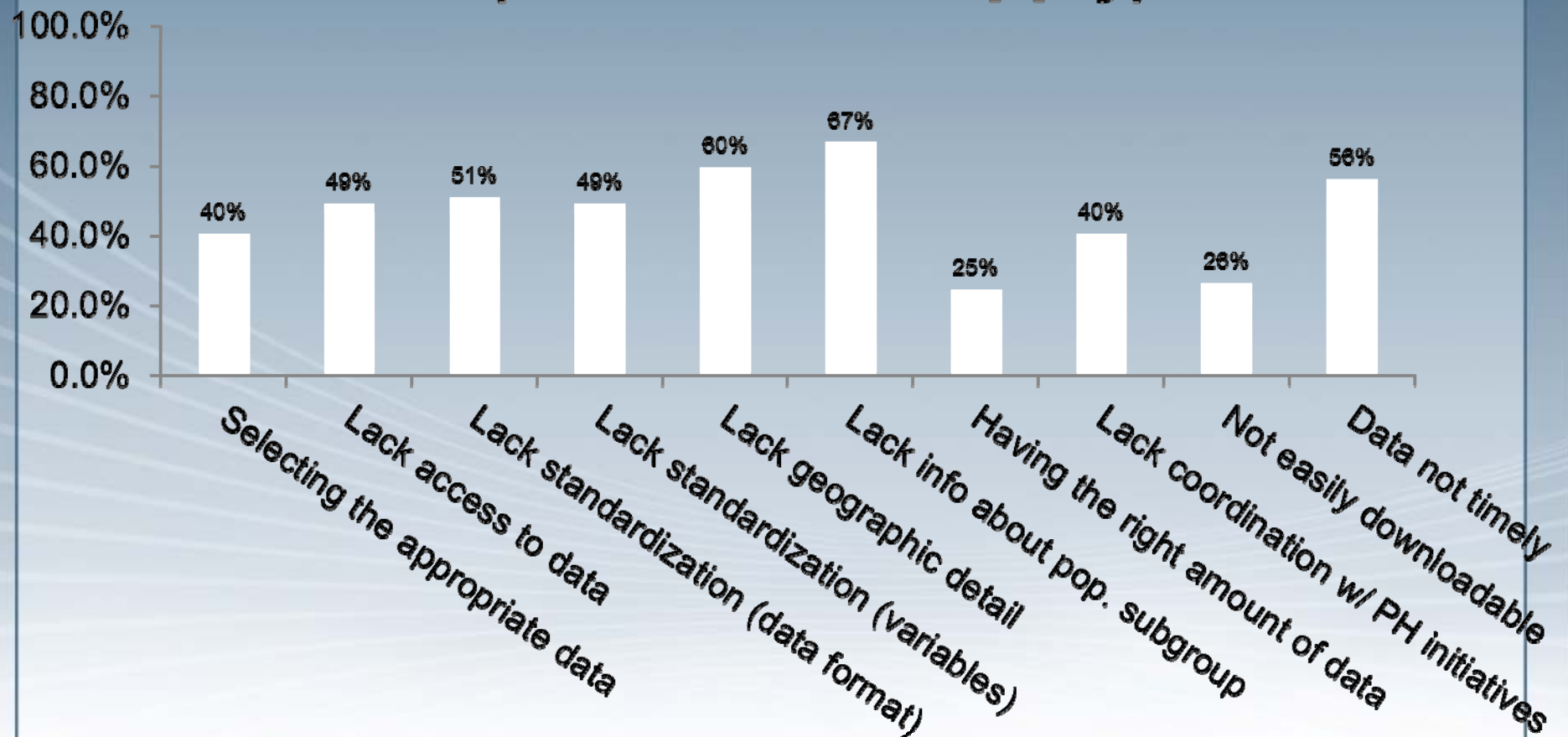
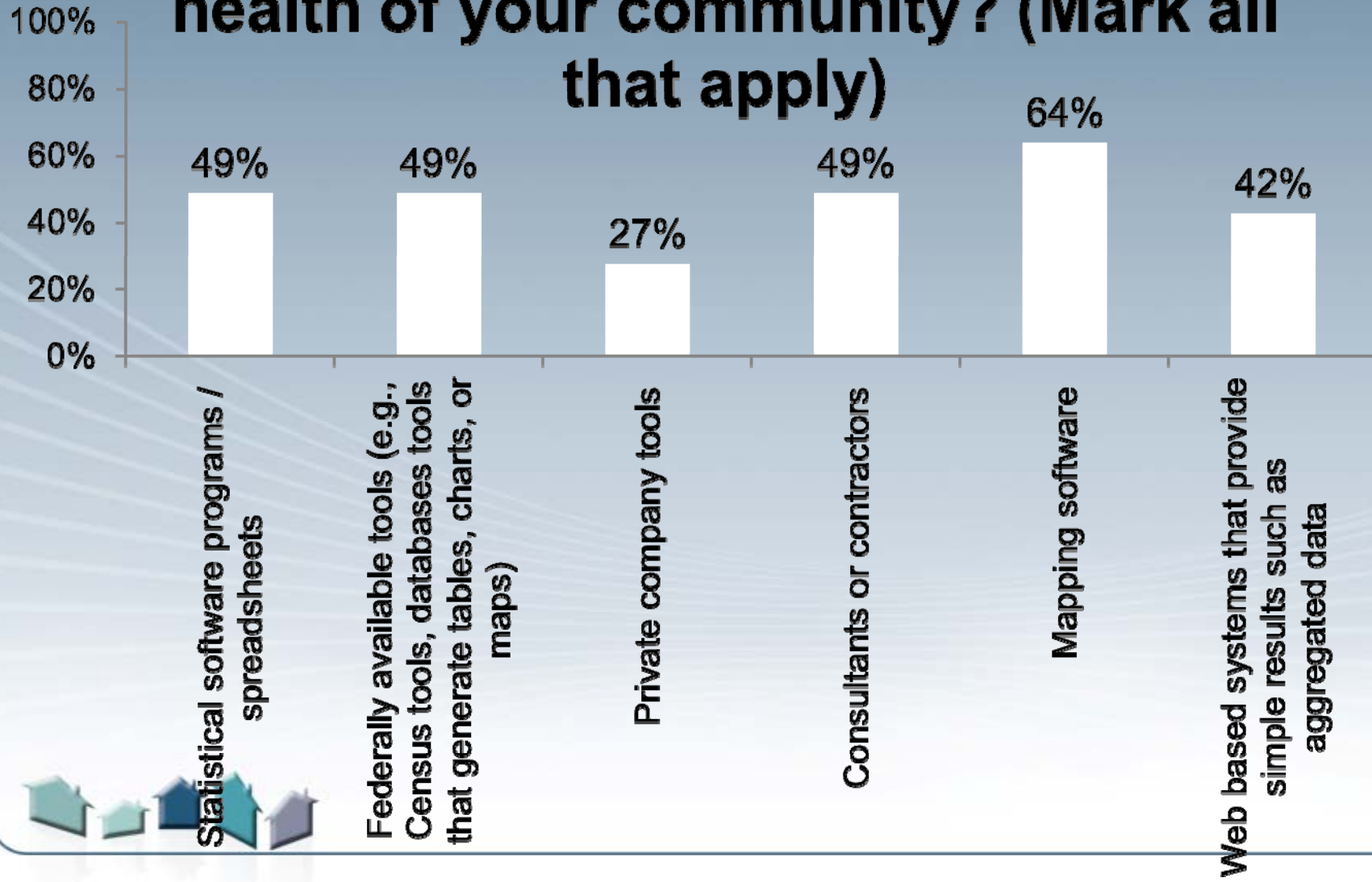*The Community as a Learning System for Health, NCVHS, December 2011, p. 19*   42

Do you collect your own data?

No
18%

Yes
82%
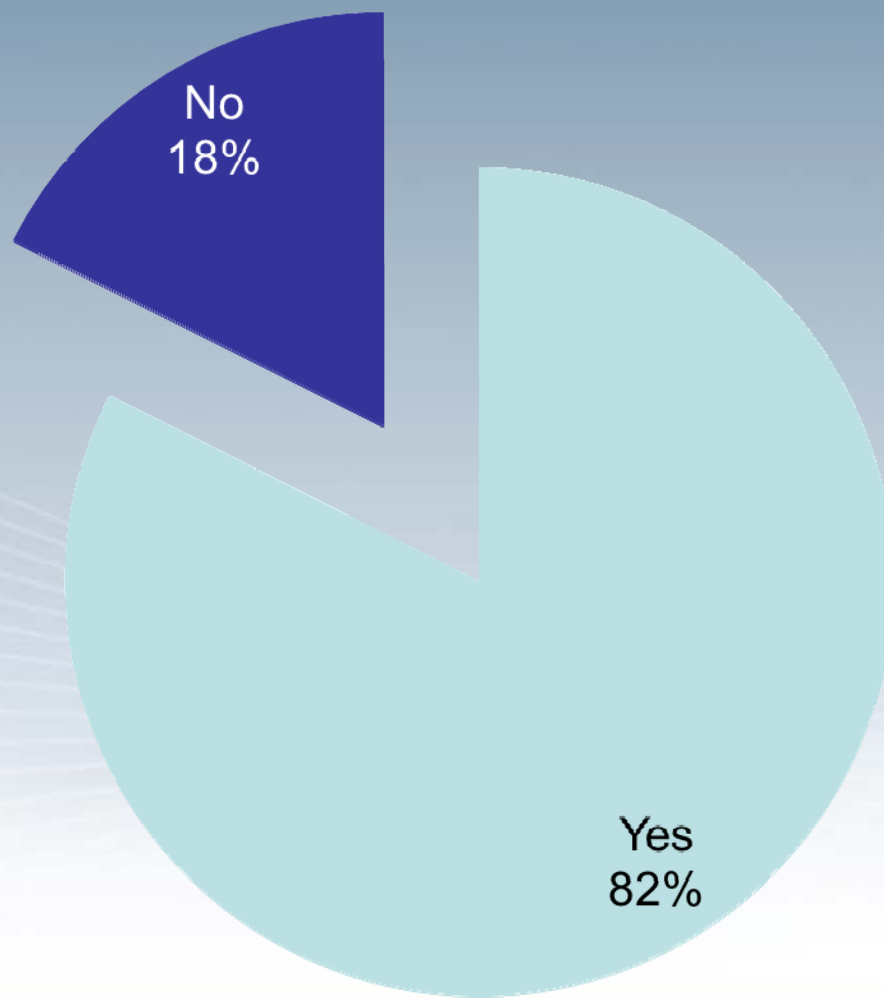
What are the limitations or challenges of the data that you use? (Mark all that apply)

What tools and support do you need to better analyze data to improve the health of your community? (Mark all that apply)

The following picture of communities emerges:

- Local Leaders create opportunities for collaboration and coalition-building

- Community members and organizations are engaged

- Partnerships are established with public health, health care and related sectors, such as schools, churches, housing

- The partners draw on multiple data sources, perhaps conducting their own local research

The following picture of communities emerges:

- They assure privacy and build trust through a web of interrelated practices and protections
- They use the data to analyze major health issues, agree on priorities, enlist additional partners and develop policies and programs
- They create communication and data visualization tools to inform and educate stakeholders and influence decision-makers
- They monitor progress and evaluate results