

# Joint Roundtable on *Health Data Needs for Community Driven Change*

April 30-May 2, 2013

Subcommittee on Population Health, Subcommittee  
on Privacy, Confidentiality and Security and  
Subcommittee on Standards

Of the

National Committee on Vital and Health Statistics



# Purpose of the Roundtable

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



# Agenda

April 30

- Morning: Relevant recent NCVHS work  
Framing the Roundtable Issues  
Panel 1: *Collection and Compilation of Data*
- Afternoon: Small group work on Panel 1 topics  
Panel 2: *Using Data for Decision Making*  
Small group work on Panel 2 topics



# Agenda

May 1

Morning: Panel 3: *Using Data to Promote Community Driven Change*

Small group work on Panel 3 topics

Afternoon: Panel 4: *Recommendations for Supporting Health Data Needs for Community Driven Change*

Small group work on Panel 4

General discussion on recommendations



# Agenda

May 2

Morning:      Review and refine options for potential  
                     committee action  
  
                     Draft specific plan and timetable



# NCVHS Background I:

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

*NCVHS 2011 and*

## Environmental Scans and Feedback

*NCVHS 2013*

**Sallie Milam, JD**

**NCVHS and Co-chair, Population Health Subcommittee and  
member, Privacy, Confidentiality and Security Subcommittee**





**NCVHS**



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



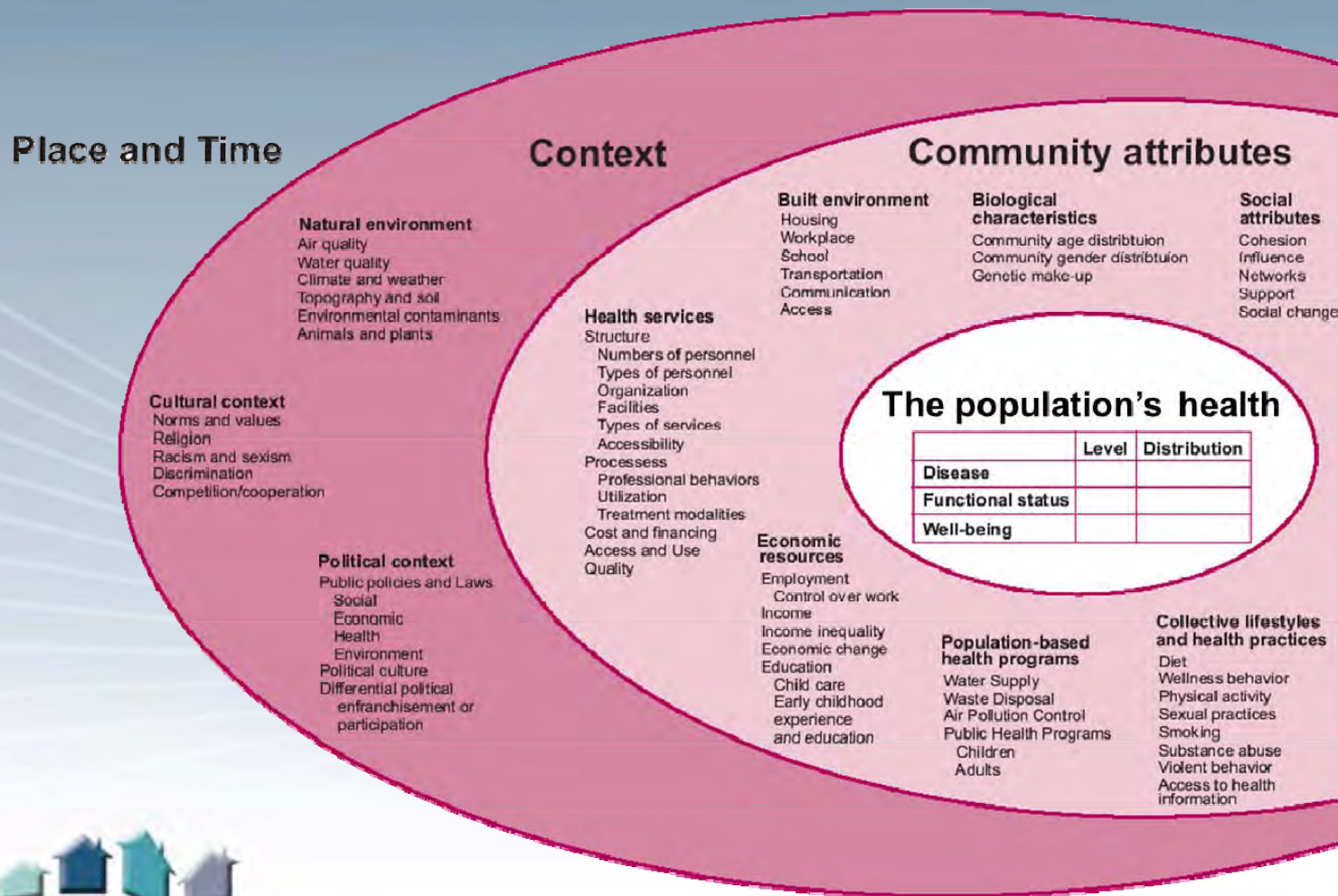
## The Community as a Learning System: Using Local Data To Improve Local Health

A Report of the  
National Committee on Vital Health Statistics



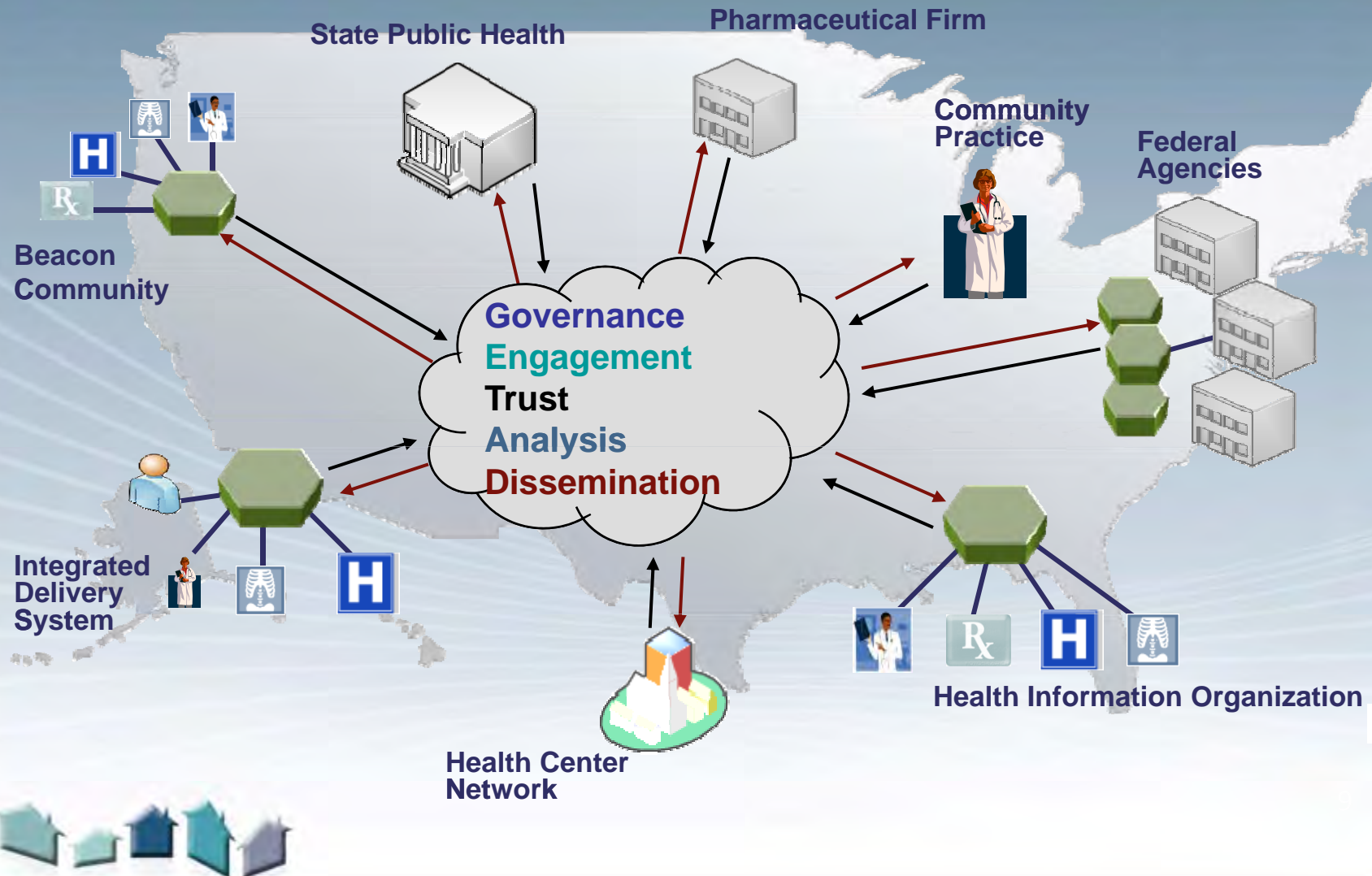
U.S. DEPARTMENT OF HEALTH  
AND HUMAN SERVICES

# Shaping a Health Statistics Vision for the 21<sup>st</sup> Century (2002)





# A Learning Health System



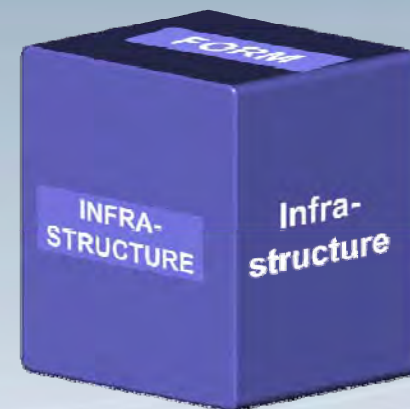
Needed: Support, Shared Learning and Economies of Scale



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



**Stewardship +  
privacy protection +  
engagement +  
governance = Trust**



**Support, facilitate  
shared learning, and  
create economies of  
scale**



# Examples of Enabling Federal Assists

- Better bridges between clinical and public health data systems
- Standardized community health, health status, environmental and resource use indicators
- Federal and state web-based data query systems for small area data, easy analytics and visualization
- Technical assistance perhaps through existing HIT initiatives such as regional extension centers
- Longer funding periods, and transitional support for institutionalization of promising new policies and program





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## Environmental Scan 1

1. Timing: December 2012 through January 2013
2. Focus: Initiatives and resources supporting community data use to improve local health
3. Purpose: To help NCVHS target where it can make the greatest contribution and identify potential partners and models.
4. Mode: 3 telephone interviews and 1 email exchange with 6 key informants, and 13 reviews of open source programs/projects

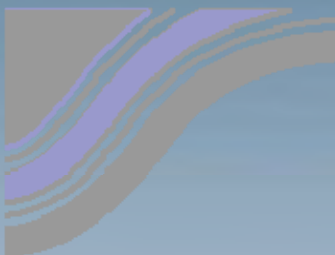






**The National Committee on Vital and Health Statistics**

*The Public Advisory Body to the Secretary of Health and Human Services*



## Environmental Scan1 : Observations

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



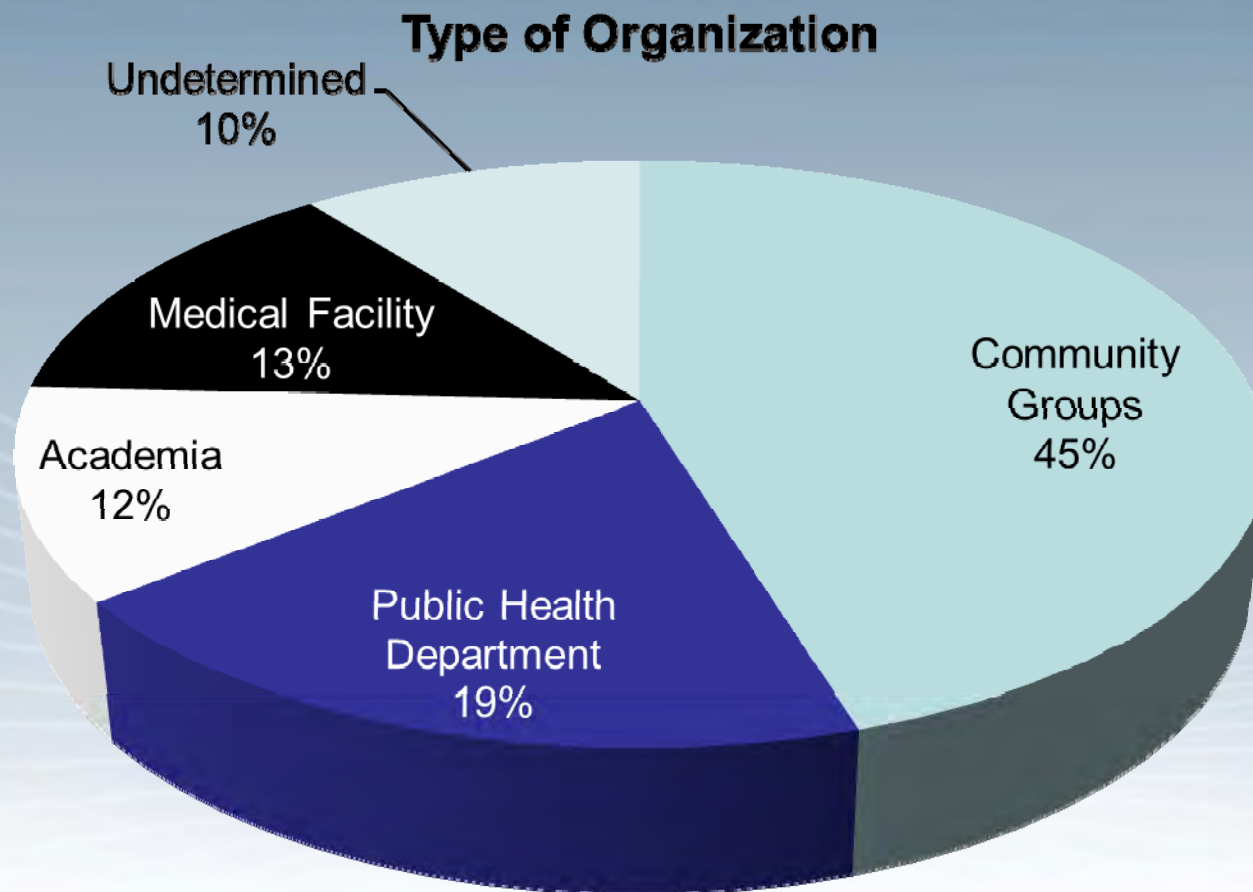
# Environmental Scan 2

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

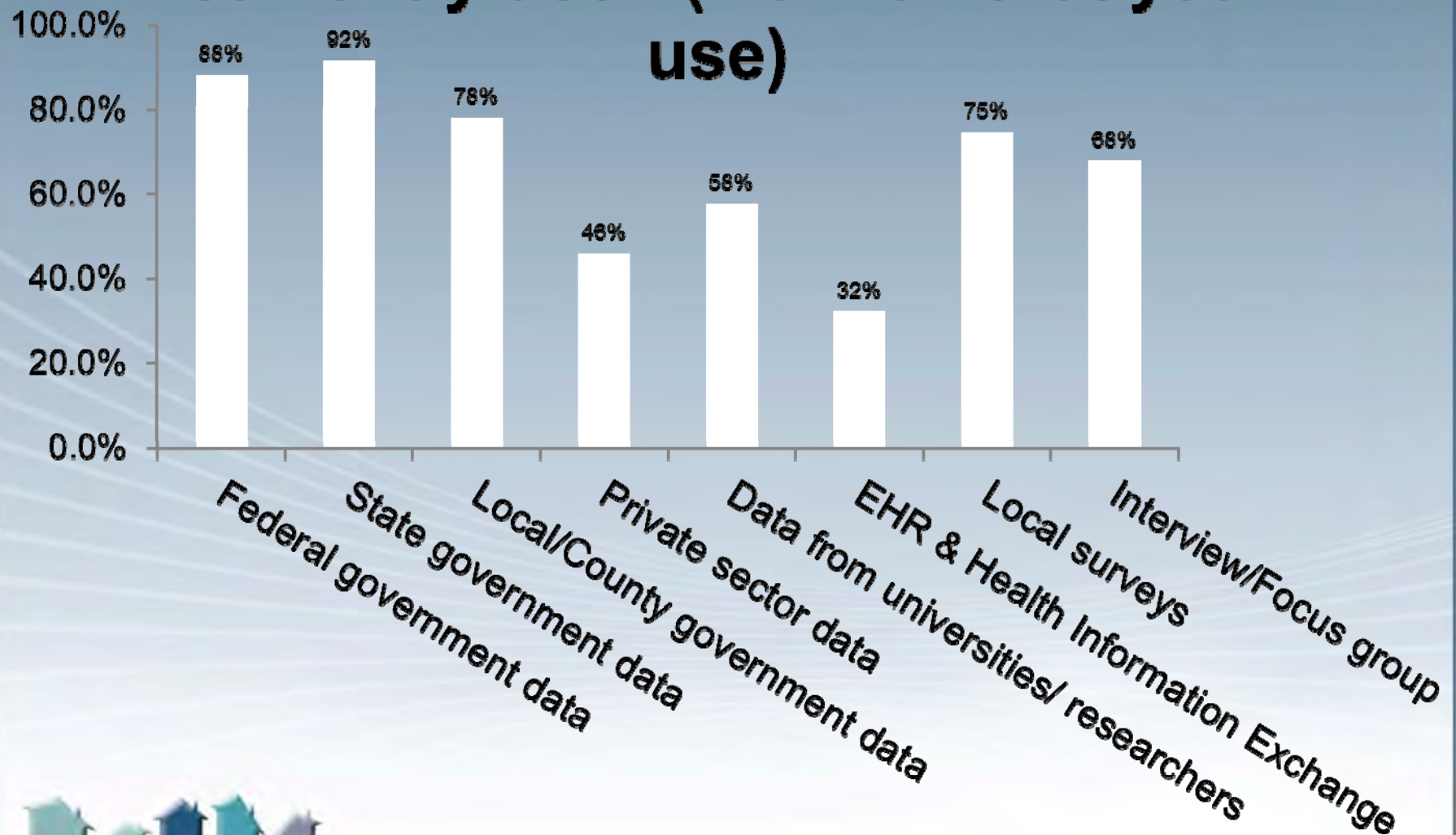


*We can't solve problems by using the same kind of thinking that we used when we created them. – Albert Einstein*

# 95 Organizations Responded

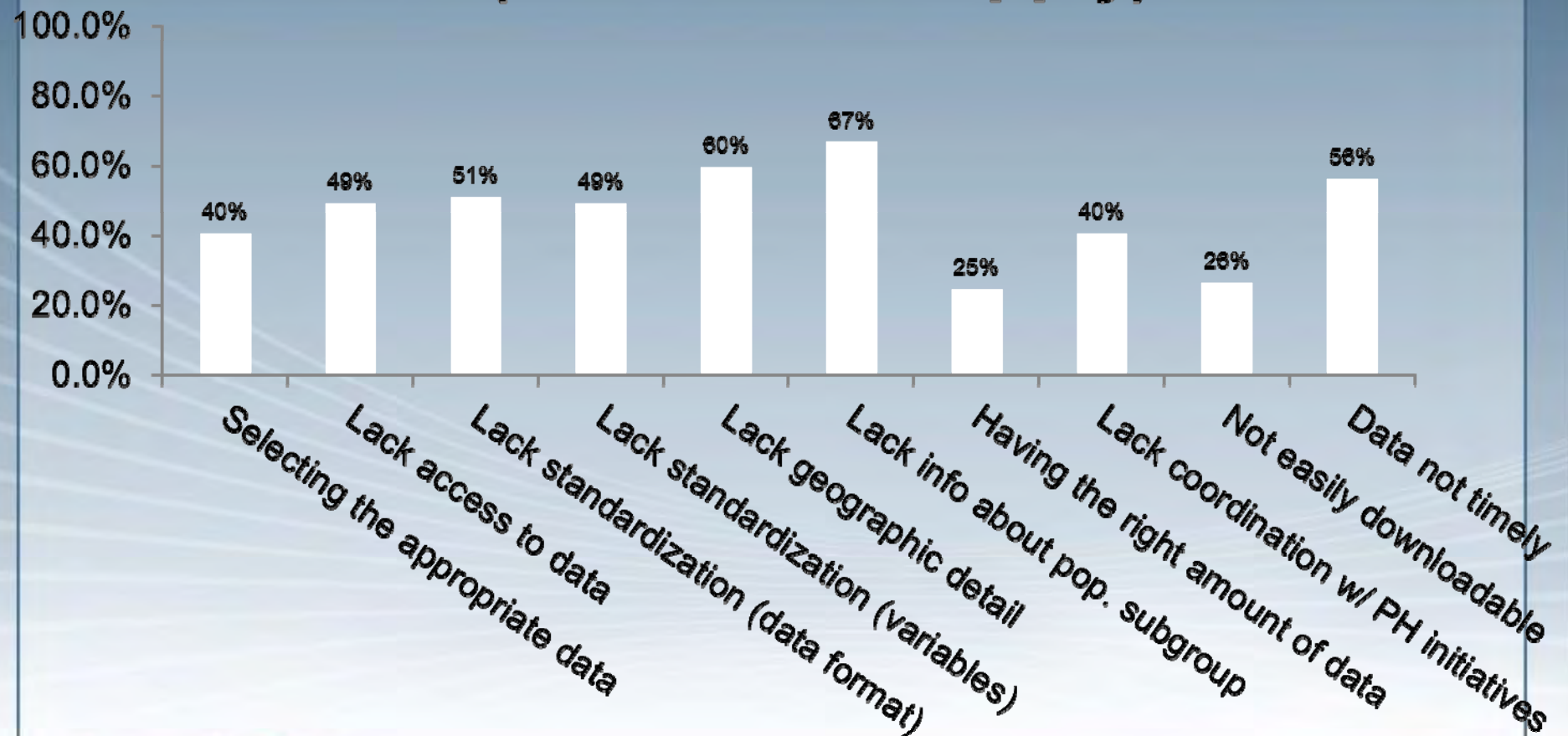


## What types of data do you currently use? (Mark all that you use)

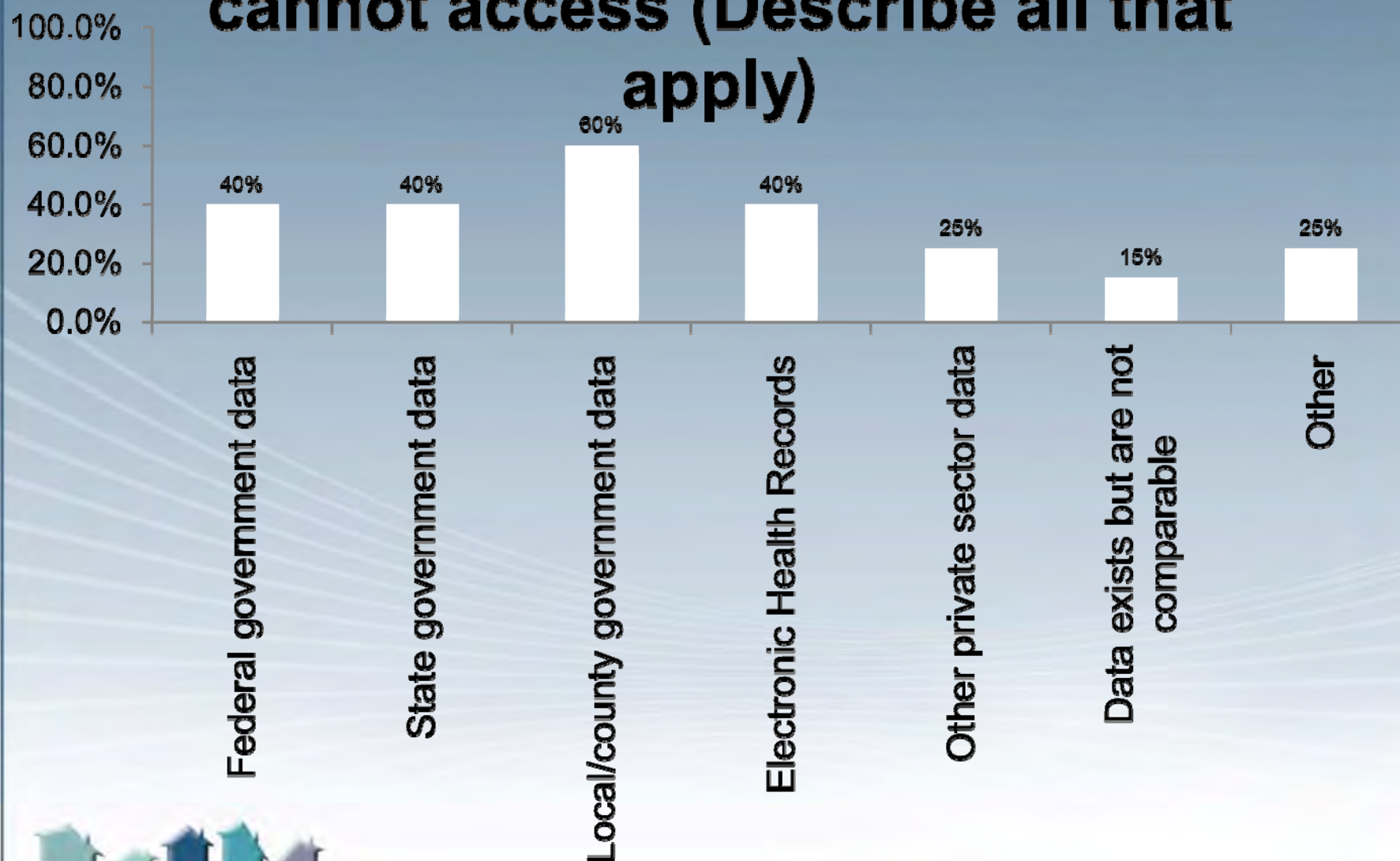




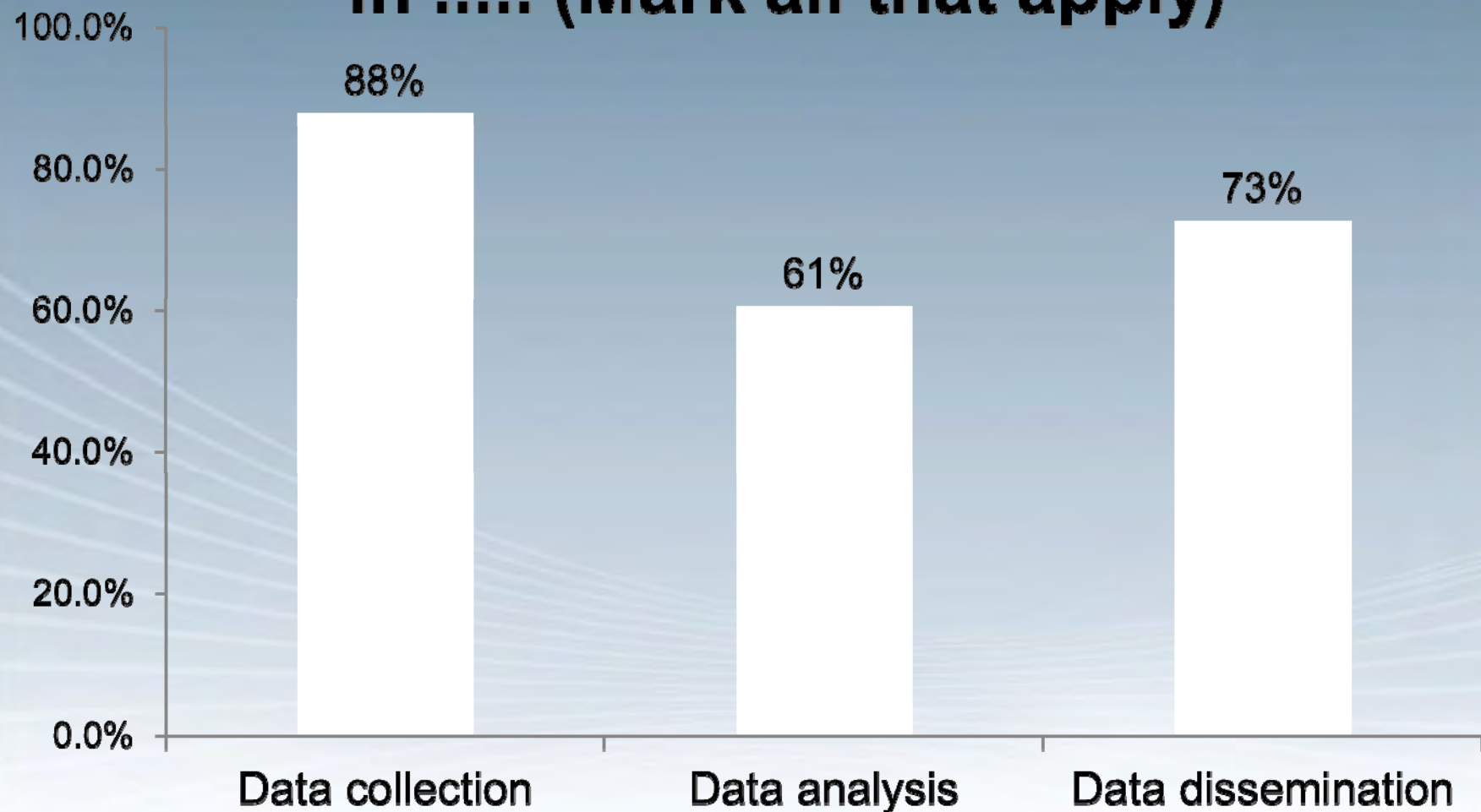
# What are the limitations or challenges of the data that you use? (Mark all that apply)



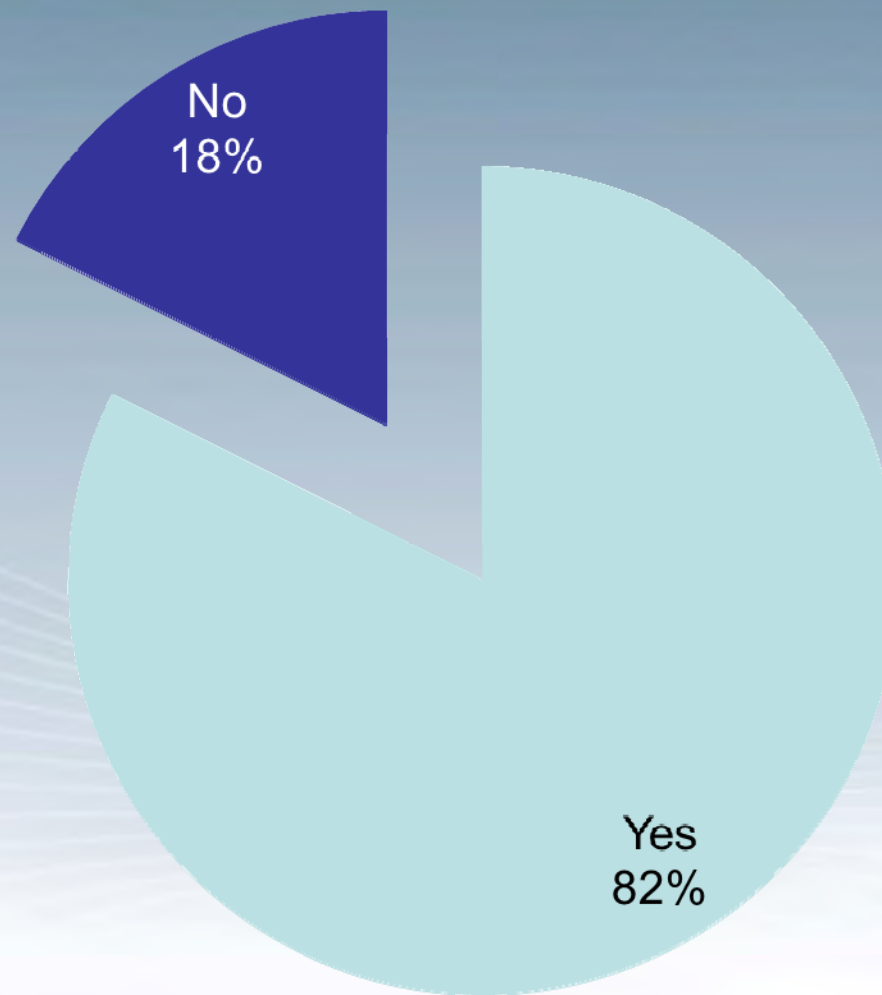
## Are there data you would use but cannot access (Describe all that apply)



## Are community members involved in ..... (Mark all that apply)

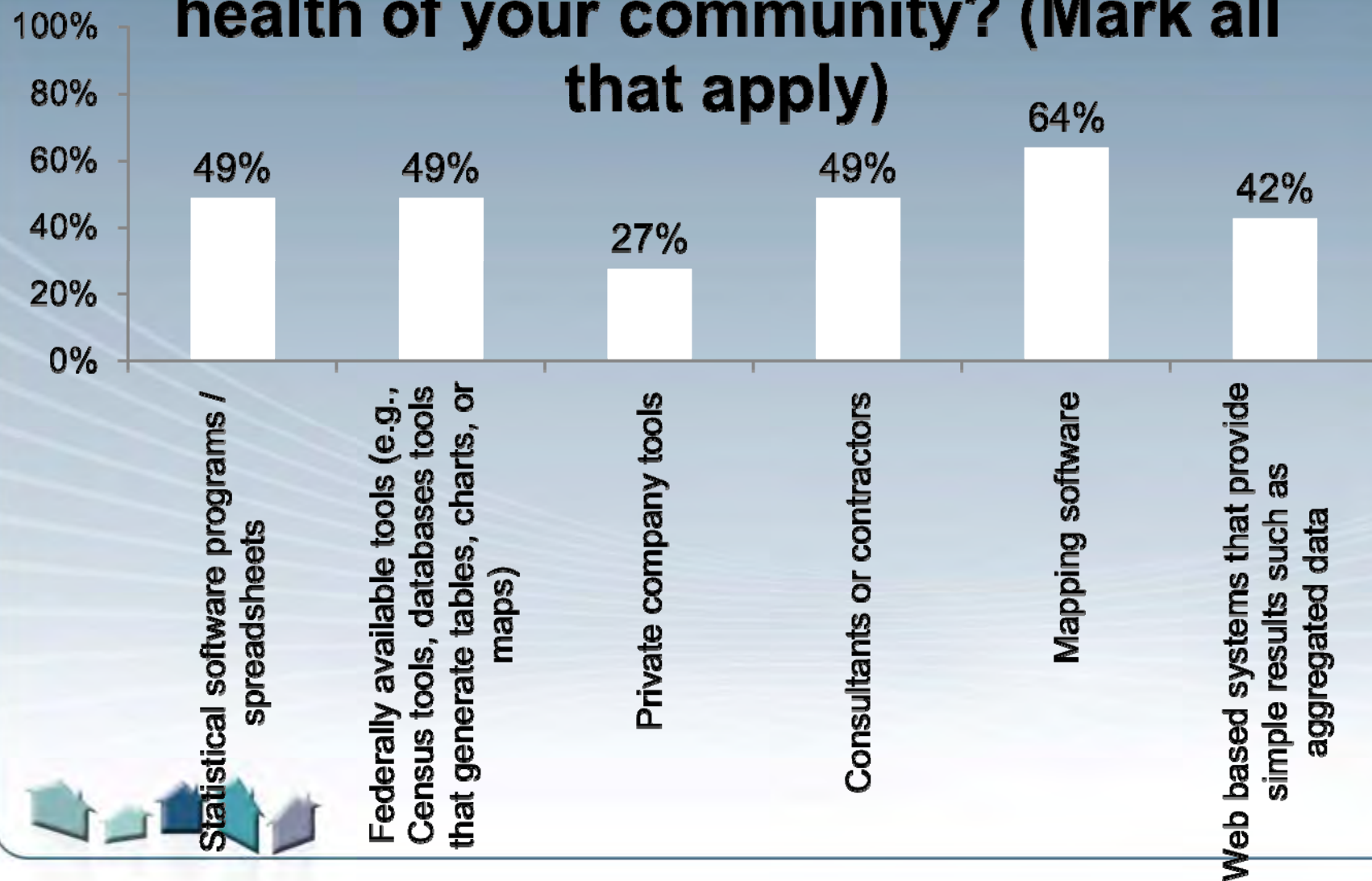


# Do you collect your own data?





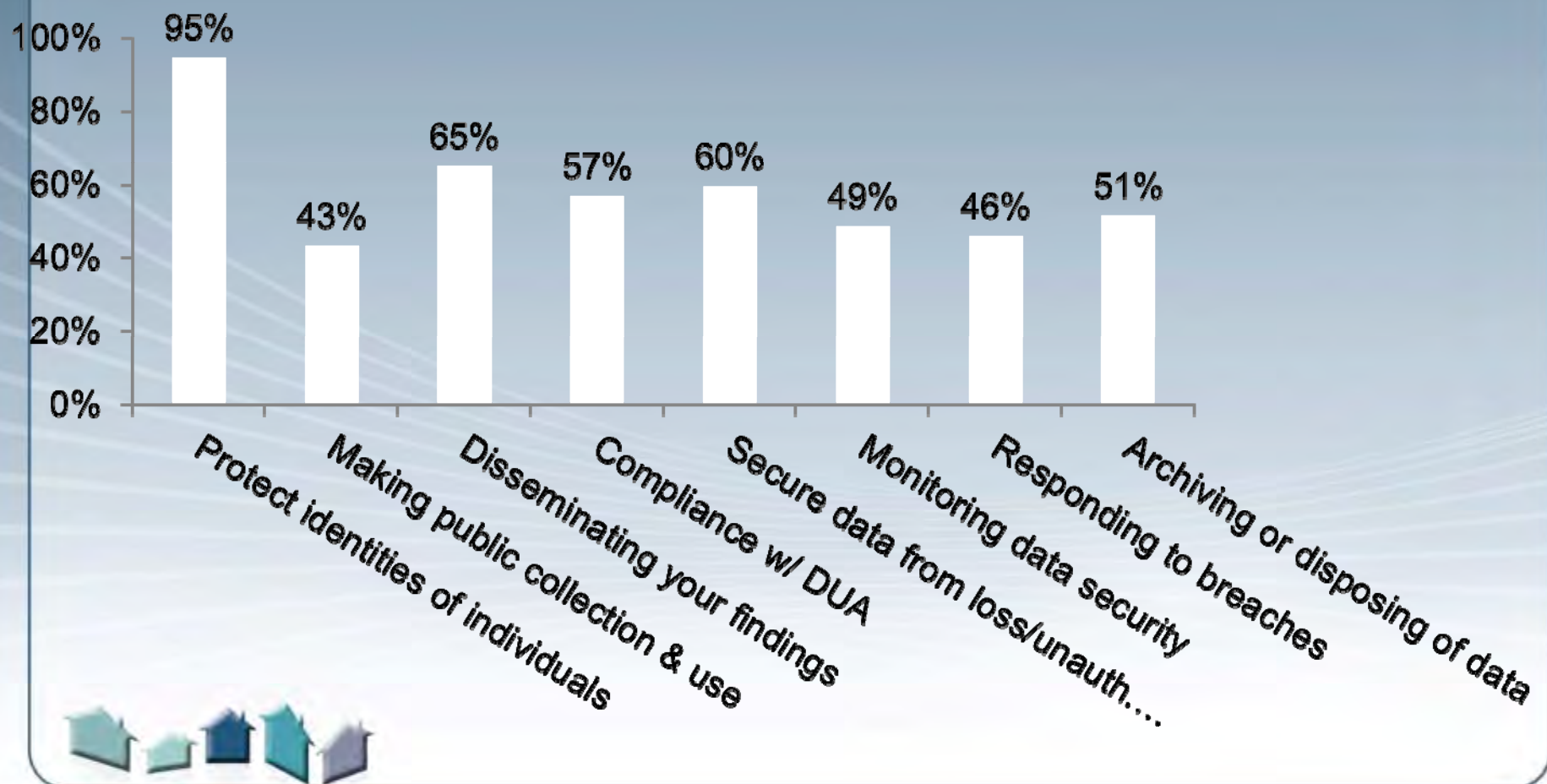
# What tools and support do you need to better analyze data to improve the health of your community? (Mark all that apply)



**For the data that you collect, obtain from others, or provide to others, please rate your sense of how well that data are protected from anyone's identify being revealed?**



## Do you have processes in place for (Mark all that apply)



## **NCVHS Background II:**

# **A Stewardship Framework for the Use of Community Health Data**

**Letter to the Secretary, 12/5/2012**

**Leslie Pickering Francis, JD, PhD**

**NCVHS and Co-chair Privacy, Confidentiality and Security  
Subcommittee**





# The “CHIP” Report: our charge

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



- “...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,” p. 19

# Hearing (April 2012): what we heard

- The importance of educating community members and leaders about data use and benefits
- The need to involve community members in decisions about data collection, use, and communication
- The critical nature of trust-building among organizations and agencies that are data sources
- The judgment that governance fosters a sense of ownership and control



## Hearing (April 2012): what we heard

- Privacy is not an individual issue only, it's societal and family
- Chain of trust must involve the complete life cycle of data, from the outset to the point at which data are no longer needed
- Data stewards have special obligations to the community of concern



# Stewardship Frameworks: a scan

- Many frameworks, from the Privacy Act (1974) to the present
- Address protection of individually identifiable data, typically by consent
- Not a good fit for many of the types of community uses of data
- Need for a new stewardship framework for community data use



# Stewardship Letter: Framework

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





# Stewardship Letter: Recommendations

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



NCVHS Background III:

## **Framing the Major Issues for this Roundtable**

**Bruce Cohen, PhD**

**NCVHS and Co-chair, Population Health Subcommittee**



# Framing the Roundtable: the 7 “C’s”



- **C**ontext
- **C**onvergence
- **C**onsistency
- **C**ollaboration and Partnerships
- **C**onceptual framework
- **C**ourse of action
- **C**ommunity driven **C**hange



# Context

- Communities are becoming more proactive in planning and priority setting
- More data are being collected by everyone
- Local, state, and Federal policies, laws, and regulations are changing
- Questions are being asked about how to harness the power of this information
- Notions of public health are broadening to focus on quality of life



# Convergence of themes

- 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





# Consistency

- Messages among communities, data providers and governments need to be consistent
- Values related to data collection, use, and privacy need to be shared
- Broad concepts, variables used to measure those concepts, and definitions for those measures need to be consistent and comparable



# Collaborations and partnerships

- The whole is greater than the sum of its individual parts...
- The key is to put different perspectives together to develop the best strategies and policies
- This interactive round table includes community members, community-based organizations, different levels of government, care providers, data providers, researchers, data developers, policy makers, data guardians, national organizations to think and plan together



# Conceptual framework: goals

- Advance its understanding of access to and use of data by communities to improve population health;
- Refine its Stewardship Framework for the Use of Community Health data to support the needs of various types of community initiatives;
- Better understand the role of government in providing data, tools, and resources to promote community driven change; and
- Understand current state and possible gaps in data content and variable standardization for community data collection and use.



## Course of action: *before the round table*

- Previous community focused work
- Direct online feedback from community organizations and data-focused concerns
- Planning an interactive gathering



# Course of action: *during the round table*

- Creating the structure to promote sharing of ideas: panels, break-outs, and feedback loops culminating in brainstorming for future actions
- Key questions for consideration:
  - How do communities *collect and compile* data?
  - How do communities *use data and incorporate them into priority setting* and decision-making to create change?
  - How can stakeholders promote and support *information-enabled community-driven change*?
  - What *standards* exist for data collection, data content harmonization, data security, and data compilation, and where are the gaps?





## Course of action: *after the round table*

- Essential to continue the conversation
- NCVHS will review output and develop plans that may include recommendations to Secretary, reports, and other avenues of information dissemination
- NCVHS will prepare meeting summary and will consider future activities in this area
- Participants will be encouraged to build on the ideas and implement the suggestions shared



# Community driven change

- Getting data
- Protecting data
- Integrating data into a broader decision-making framework
- Expanding the traditional notion of public health to include housing, education, community institutions and systems
- Understanding resources and assets as well as deficits
- New paradigms of information sharing and dissemination
- Understanding government's role in community transformation



# Panel 1: Collection and Compilation of Data

Andrew Bazemore, MD, MPH

*Director, Robert Graham Center for Policy Studies in Primary Care  
American Academy of Family Physicians*

Bridget Catlin, PhD, MHSA

*Senior Scientist & Program Director, Mobilizing Action Toward Community  
Health (MATCH), Population Health Institute, University of Wisconsin*

Barbara Zappia, EdD, MPA

*Senior Program Officer, Greater Rochester Health Foundation*

Moderator:

Paul Tang, MD

NCVHS and Co-chair Quality Subcommittee and member of Privacy  
Confidentiality and Security Subcommittee



# Small Group Discussion 1:

## ***How do communities collect and compile data?***

**75 minutes**

15 minutes – Self introductions  
Group process overview

50 minutes - Discussion

10 minutes - Consensus on report out

*Detailed discussion will be  
captured. Focus report on*

- *Successful models that may be replicable*
- *Breakthrough ideas and examples*
- *Important gaps identified*





# Small Group Discussion 1:

## ***How do communities collect & compile data?***

### Discussion questions

- a. How do communities find and use data? Where are there gaps?
- b. With the proliferation of data/data sources that already exist, how does a community know how to choose data? What are the methodologies for asset/resources assessment?
- c. How best to promote openness, transparency, and choice when collecting data?
- d. What analytic and technical support can local, state and Federal governments provide?
- e. How do communities partner with health care providers and academia?
- a. How do communities deal with the lack of data content standards and variability across data sources? What can be done to address these challenges?

**75 minutes**





## Panel 2: Using Data for Decision Making

Lacey Hart, MBA

*Director, BSI PMO & Program/Project Manager, Mayo Clinic Rochester, MN*

Ninez Ponce, PhD (via videoconference)

*Associate Professor, School of Public Health*

*University of California – Los Angeles*

Eve Powell-Griner, PhD

*Confidentiality Officer, National Center for Health Statistics, CDC*

*[or Al Zarate, PhD Former Confidentiality Officer*

*National Center for Health Statistics, CDC]*

Moderator:

John J. Burke, M.B.A, MSPharm.

NCVHS and Privacy, Confidentiality & Security and Population Health  
Subcommittees



## Small Group Discussion 2:

***How do communities use data and incorporate them into priority setting and decision-making?***

5 minutes – Review discussion questions

45 minutes - Discussion

10 minutes - Consensus on report out

**60 minutes**



## Small Group Discussion 2:

### ***How do communities use data and incorporate them into priority setting and decision-making?***

Discussion questions

**60 minutes**

- a. Is there a basic set of standard measures, variables that all communities should use?
- b. What is the need for standardized approaches for generating qualitative information?
- c. How to promote secure practices, data Integrity, creative use of de-identified data, and reduced risk of “enhanced” data sets when using data?
- d. How are communities transforming data into policy actionable information and priorities?
- e. How do communities choose among planning tools or decide to use own approach?



## Panel 3: Using Data to Promote Community Driven Change

Carladenise Edwards, PhD  
*Senior eHealth Advisor, Zerodivide, Inc.*

Sharona Hoffman, JD  
*Professor of Law and Bioethics, Case Western Reserve University*

Donald Malec, PhD  
*Mathematical Statistician, National Center for Health Statistics, CDC*

Moderator:  
Len Nichols, PhD  
NCVHS and Population Health and Quality Subcommittee





## Small Group Discussion 3:

### ***How do we promote information-enabled community-driven change?***

- 5 minutes – Review discussion questions
- 45 minutes - Discussion
- 10 minutes - Consensus on report out

**60 minutes**





## Small Group Discussion 3:

### ***How do we promote information-enabled community-driven change?***

Discussion questions

- a. How best to promote community engagement and participation?
- b. What role does government have in promoting and supporting community change?
- c. What specific analytic and technical resources can state and federal governments provide?
- d. How can local health care organizations, academia, and other organizations partner to support community change?

**60 minutes**



## Panel 4: Recommendations for supporting Health Data Needs for Community Driven Change

Denise Chrysler, JD

*Director, Mid-States Regional Center, Network for Public Health Law*

Christopher Fulcher, PhD

*Co-Chair, Center for Applied Research and Environmental Systems  
University of Missouri (Community Commons)*

Denise Love, BSN, MBA

*Executive Director, National Association of Health Data Organizations*

Moderator:

Walter Suarez, MD, MPH

NCVHS and Co-chair, Standards Subcommittee and member Population Health, Privacy, Confidentiality and Security Subcommittees



## Small Group Discussion 4:

***What recommendations might NCVHS advance to support data-enabled community health?***

**60 minutes**

5 minutes – Review discussion questions

45 minutes - Discussion

10 minutes - Consensus on report out



## Small Group Discussion 4:

### ***What recommendations might NCVHS advance to support data-enabled community health?***

**60 minutes**

Discussion questions

- a. Which priorities are most important?
- b. What steps can the federal government take to advance community health?
- c. What is the role of state government?
- d. What can communities do?





# Joint Roundtable on *Health Data Needs for Community Driven Change*

April 30-May 2, 2013

*Thank you for helping advance this important priority!*

