

HELP!

I Need a Geek!

Kathy Phipps, DrPH
ASTDD Data Coordinator

Where to Find a Geek



innergeek



Finding a Geek Closer to Home

- State Health Department
 - Epidemiology/Evaluation section
- Local Health Department (in some cases)
- University
 - Biostatistics or epidemiology faculty
 - Graduate student
- ASTDD

ASTDD Geek Squad



- Mike Manz
 - mmanz@umich.edu
- Kathy Phipps
 - krp123@charter.net
- To request technical assistance
 - Complete request form
 - Email to Stuart Lockwood

**Basic Screening Survey & Oral Health Surveillance
Request for Technical Assistance from ASTDD**

Contact Information

Date: _____ State/Territory: _____
Contact Person: _____
Phone: _____ Fax: _____
Email: _____

Type of Technical Assistance Requested

Please check the type(s) of technical assistance you anticipate needing. Please note that ASTDD may be unable to cover the cost of all types of technical assistance.

Basic Screening Survey Related Technical Assistance

- Development of survey design including assistance with what age groups to include, what information to obtain, and planning steps
- Presentations to advisory groups/statewide meetings (cost must be covered by state)
- Sample design, including the determination of sampling frame and potential stratifications or sampling strata
- Sample selection, including the selection of specific schools to include in the survey along with replacement schools
- Training of examiners (cost must be covered by state)
- Data entry (cost must be covered by state)
- Data analysis
- Report preparation (cost must be covered by state)

General Oral Health Surveillance System Related Technical Assistance

- Development of overall oral health surveillance system
- PRAMS
- YRBS
- BRFSS
- Other (please describe): _____

What is the anticipated start date of your survey?

When would you like to start receiving technical assistance?

Financial Resources

ASTDD does not have the financial resources to provide unlimited technical assistance to all of the states currently requesting assistance. For this reason, we need to determine if a state has resources to cover the cost of some services.

Do you have any outside funding for portions of this project? Yes No
If yes, what is your source of funding?

Can you help defray the cost of this technical assistance? Yes No
If yes, approximately how much could you cover?

**Please Email the Completed Form to:
Stuart Lockwood, Chair, ASTDD Data Committee
slockwood@adph.state.al.us**

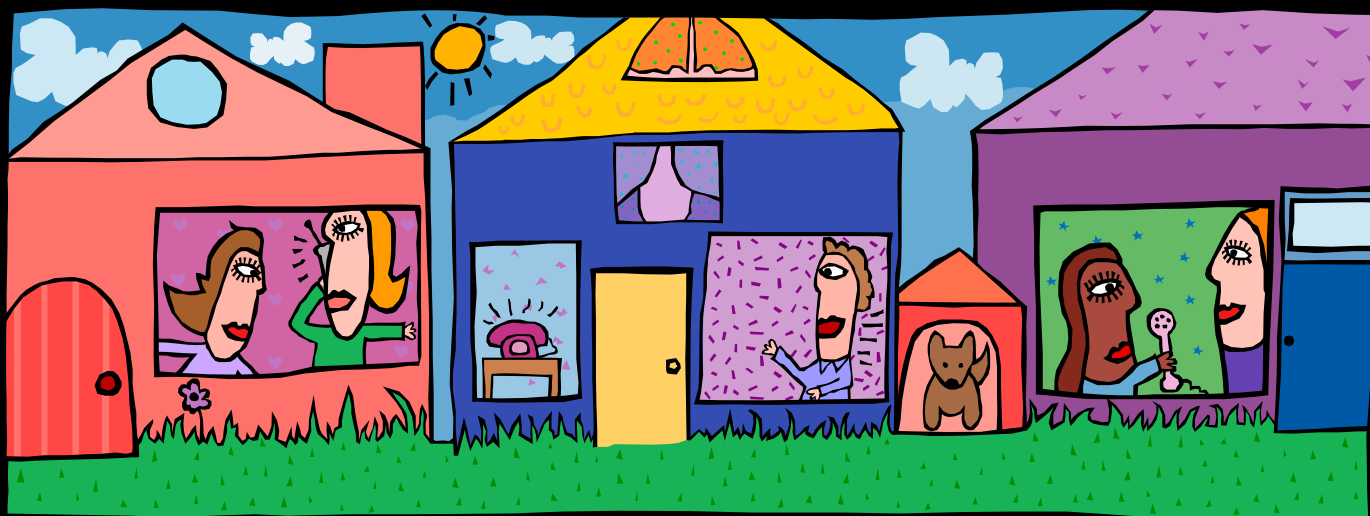
TA Available Through ASTDD

- Basic Screening Survey
 - Assistance with planning
 - Sample selection
 - Data entry programs
 - Data analysis
- Oral Health Surveillance Systems
 - Assistance with development of a system

Resources Available from ASTDD

- Epi Info data entry & analysis files
- BSS Planning Guide
- Sample BSS Examiner Training
- Best practices

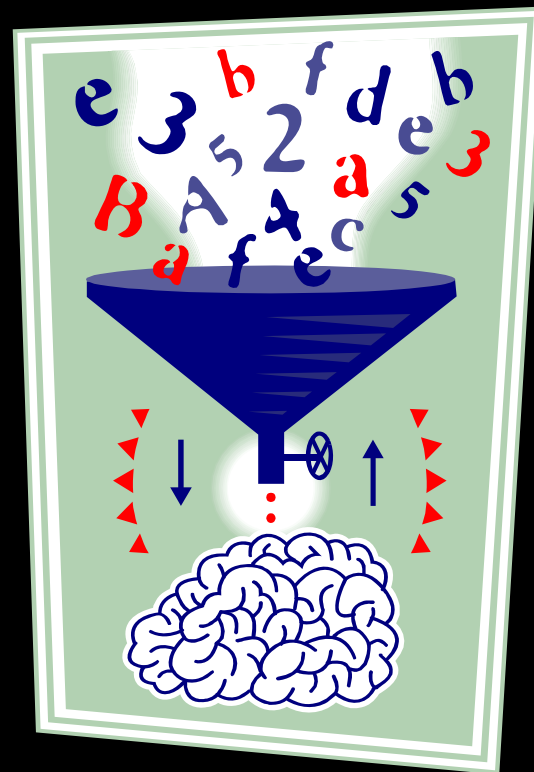
Engaging the Community



Engaging the Community

- Important to engage the community prior to collecting data
- Who is the “community”
 - Public
 - Providers
 - Agency staff
 - Research community

Engaging Your Agency and Research Community



Why is this Important?

- Can assist with
 - Protocol development
 - Data collection
 - Data analysis
 - Data interpretation
 - Report preparation

Acronyms Research Community will want to Talk About

MCH

ASTDD

CSTE

BSS

CDC



BMI

IRB & HIPAA

Human Subjects & Privacy Issues

- IRB review
- HIPAA compliance

Research & IRB Review

- Institutional Review Board
- Laws require IRB approval for research
 - Federal Policy for the Protection of Human Subjects (the “Common Rule”)
 - IRB must review federally-funded research
 - May apply to all research regardless of funding
 - Some state & local laws authorize IRB reviews

Research & IRB Review

- Legal requirements of IRB review do not address public health practice
- IRB review not required for non-research
- Responsibility to protect human participants in public health practice...
 - Federal, state, & local administrative oversight

What is Research?

- Common Rule & HIPAA definition
 - A systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge

Characteristics of Research

- Involves living individuals
- Involves, in part, identifiable health info
- Involves research subjects who are selected and voluntarily participate
- Supported by principles of bioethics

Public Health Practice

- Does not require IRB review
- Making the distinction between research and public health practice can be difficult
 - collection of identifiable health information
 - actual or potential risks
 - further the public good

Council of State and Territorial Epidemiologists

Leaders in Applied Public Health Epidemiology

Public Health Practice vs. Research

*A Report for Public Health Practitioners
Including Cases and Guidance for Making Distinctions*

May 24, 2004

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With the CSTE Advisory Committee

www.cste.org

What is Public Health Practice?

- Proven methods to monitor health status
- Investigate unusual occurrences of disease
- Implement preventive control measures

Characteristics of Public Health Practice

- Legal authorization
- Government duty to perform activity
- Directed by public health authority
- May involve persons who did not give informed consent
- Supported by public health ethics

CSTE Definition

- *The collection and analysis of identifiable health data by a public health authority for the purpose of protecting the health of a particular community, where the benefits and risks are primarily designed to accrue to the participating community.*

Public Health Practice

- Identifiable health data may be collected without informed consent
 - acquisition of data is a function to achieve public health goals
 - public has authorized the activity through laws
 - administrative protections of individual interests
 - public health officials are accountable to the public

OH Surveys - Research or PHP?

- Identifiable health data
 - No - Common Rule & HIPAA do not apply
- General legal authority
 - acquire any health data needed to monitor health conditions in the population
- Specific intent
 - test a hypothesis - research

OH Surveys - Research or PHP?

- Participant benefits
 - PHP should contribute to improving health
- Subject selection
 - control group - research
 - random selection of participants - research

Other State Surveys

■ PRAMS

- Not research - no need to receive IRB approval

■ YRBS

- Non-identifiable health data
- Not research
- No informed consent necessary

Oral Health Surveys

- Three IRBs waived oral health surveys
 - One university IRB
 - Two health department IRBs

Summary

- OH surveys are public health practice
- Who decides?
 - health agency or IRB
- My recommendation
 - submit letter to IRB
 - ask for waiver

HIPAA

- Health Insurance Portability and Accountability Act of 1996
- Protected health information
- Covered entities
 - health plans
 - health-care clearinghouses
 - health care providers

HIPAA

- Permits private health information to be shared for specified public health purposes such as surveillance.

HIPAA & Oral Health Surveys

- Collect non-identifiable data
 - do not collect name
 - collect date of birth only if you need it for BMI calculations
- Protect confidentiality
 - privacy envelopes

For More Information on HIPAA

- **HIPAA Privacy Rule and Public Health**
 - Guidance from CDC and the U.S. Department of Health and Human Services
 - www.cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.htm
- **Office for Civil Rights - HIPAA**
 - Medical Privacy - National Standards to Protect the Privacy of Personal Health Information
 - www.hhs.gov/ocr/hipaa

Questions?

