

# Barriers to Accessing/Sharing Data

SND Workgroup -  
Data Sharing and Access Subgroup  
Presentation by  
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# Objectives

- Identify barriers to accessing and sharing data (encountered and perceived)
- Identify ways to resolve the barriers

# Data Collection Instrument

- Have you encountered or do you perceive these issues as barriers to accessing/sharing data?
  - Lack of knowledge about where data exist.
  - Lack of knowledge about how to access data
  - Data not in electronic form
  - Data in incompatible format
  - Only aggregated data is available
  - Frequency of data release
  - Approval process for accessing data
  - Previous interactions and history of partnerships (e.g. lack of trust)
  - Fear of misinterpretation/misuse of data
  - Confidentiality and privacy concerns
  - Policies, including federal and state laws that limit access
  - Limited resources (e.g. staff time)

# Data Collection Instrument

- If you've encountered the barrier:
  - What database and type of data were you trying to access or share?
  - Who were you trying to access from or share with?
  - Were you able to resolve the barrier?
  - If you were able to resolve, please describe how the barrier was overcome?
  - If you did not resolve the barrier, what was the impact to your EPHT efforts?

# Perceived Barriers

- Fear of misinterpretation/misuse (39%)
- Confidentiality and privacy concerns (34%)
- Approval process long and not well-defined (33%)
- Policies that limit access (31%)
- Lack of knowledge about where data exist (27%)

# Encountered Barriers

- Data not in electronic form (54%)
- Limited resources (42%)
- Lack of knowledge about where data exist (40%)
- Confidentiality and privacy concerns (37%)
- Lack of knowledge about how to access data (28%)

# Respondent Defined Barriers

- Lack of data collection
- Lack of or poor metadata
- Technical incapability
- Incomplete or inaccurate dataset
- Challenges to current public health laws

# Encountered Barriers

- Categorizations of data types
  - Type of data – Health, Environmental, Geographic, ‘All’,
  - Health and environmental data types were further categorized

# Health Data Types

Count	Description
15	Cancer
15	School Health
7	Developmental Disability/Autism
7	Hospital Discharge
4	Lead
4	Other/Not Specified
3	Medicare/Medicaid/Other Insurance
3	Vital Statistics
3	Labs
2	National Surveys (NHANES, etc)
2	Occupational/Industrial

# Environmental Data Types

Count	Description
12	Water
7	Air
5	Solid/Hazardous Waste
3	Soil
3	Pesticides
3	Release (TRI)
3	School Environmental
13	Other/Not Specified

# Resolutions to Barriers

- Means of resolving barriers were categorized:
  - **Formal Agreements** – defining scope of use through trading partner agreements, data sharing agreements, MOUs, confidentiality agreements, obtaining permission, IRB
  - **Collaboration** – communication between individuals and/or agencies, diplomacy, working with a liaison
  - **IT** – technical solution
  - **Staff Resources** – utilization of staff time and effort to prepare the data for use

# Resolution to Barriers

Data Type	Formal Agreement	Collaboration	IT	Staff Resources	Pending
Health	13	9	1	1	3
Environmental	2	7	2	8	0
GIS	0	0	2	0	0
Not Specified	0	0	2	3	0
Total	15	16	7	12	3

# SND Addressing Barriers

- Metadata
  - Lack of knowledge about where data exist
  - Lack of knowledge about how to access data
  - Approval process for accessing data long/not well defined
- Trading Partner Agreement
  - Only aggregated data is available
  - Fear of misinterpretation/misuse of data
  - Confidentiality and privacy concerns

# Future Activities

- The workgroup will continue to compile information and create a report on the findings.