Linking Data for Public Health and Research: Model Approaches
NAHDO Webinar
March 19, 2009
Common Barriers to Acquiring Hospital Discharge Data for Linking

■ **Data Needs Assessment**
  - Purpose/uses of the data
  - What do you need?
  - What data exist?
  - Specifics: time frames, scope, data elements needed?

■ **Administrative hurdles:**
  - What is the process for acquisition?
  - Data use agreements or IRBs

■ **Legal provisions**
Common Barriers to Data Acquisition (continued)

- Cost of the data (price not published or too high)
- Uncertainty about the ownership, use of and access to the linked data set
  - Issues of secondary release of the data
- Process for requesting/acquiring data is lengthy and time-consuming
Common Data Issues

- Data linkage elements not collected or not releasable
- Missing, invalid data elements or duplicate records
- Data only available in deidentifiable or aggregated format
Model Practices

- **Readmissions/CODES-Virginia**
  - Michael Lundberg, Executive Director, Virginia Health Information (michael@vhi.org)

- **CDC Assessment Initiative-Florida**
  - Karen Freeman, Health Statistics Manager, Bureau of Community Health Assessment (Karen_Freeman@doh.state.fl.us)

- **CDC Tracking- Utah**
  - Sam LeFevre, Program Manager, Utah Environmental Public Health Tracking Network (slefevre@utah.gov)
Resources

- “Lessons Learned in Using Hospital Discharge Data” JPHMP, Nov-Dec 2008 14:6
  available at http://www.jphmp.com/pt/re/jphmp/abstract.00124784-20081100000005.htm;jsessionid=JBMN7nBh2lYkh1wT8KNQs2jGkhN1cGm8vug2Rh97JsQ7cQTV2PdL!269263472!181195628!8091!1?index=1&database=ppvovft&results=1&count=10&searchid=1&nav=search

- “Nation At Risk: Policy Makers Need Better Information to Protect the Country” The Markle Foundation Task Force on National Security in the Information Age, March 2009

- NAHDO website- www.nahdo.org
  - Coming soon- Data acquisition toolkit
  - Discussion forums and links to reports and technical papers