

NHANES Open Space

September 11-12, 2003

Session Title: Linking NHANES and other data sources

Session Headlines:

Current Links to NHANES:

- 1) NHANES data currently linkable via Research Data Center**
- 2) Bureau of Census tract data currently linked**
- 3) NHANES II & III currently linked to HCFA (65+ yr) and National Death Index by other NCHS groups—non-DHANES groups at NCHS.**

Status of '99+ data linkages uncertain

- NHIS link mentioned as possibility—sample design issues make it a bit complex**
- SEER linkage and CDC cancer surveillance registries in states would be of interest to be able to link to**
- Doctor visits might be linkable—feasible? Confidentiality issues?**

NCHS can't disclose who participated in NHANES

Looking at NHANES data today gives sense of what we can be doing to prevent premature death

NHANES I Epi Follow-up data widely used. Nice to see something for other NHANES—periodic cohort follow-up to monitor behaviors & outcomes

NHANES 3 mortality follow-up—in the works by another group. CMS provided preliminary files—not user friendly and need clean-up of SSANs and suffixes for persons in the file. Also other surveys such NHIS are

incorporated into this project effort. Can look at pre-endpoints that impact on hospitalization

Census data and use of Fed nutr pgms—food expenditure data for examples—role of these pgms in health promotion. Is there a way to link NHANES to Census demo data.

Pediatric Surveillance System has info (sometimes different info) but can it feed into NHANES groups? Comparisons? Links? Sample issues sometimes, but CMS and NDI link to NHANES.

How can we design a system to link to multiple data collection systems?

3 types of linkages-1) person level (NHANES person in another data set such as NHIS); 2) geographic links from Census, ACS, you have info such as state, county, neighborhood characteristics—ecological work possible; 3) studies w/similar neighborhoods and have sets of common questions in more than one survey. Can model back & forth. NHANES & NHIS have some common questionnaire links and may be able to model w/biomarker data. Need to differentiate between linkages

Census data- Anything collected for Census under Title 9 restrictions. May need walk-through to link

Linkage inhibited by 1) disclosure/confidentiality issues. Census data highly restrictive. 2) Also, informed consent issues that are not part of baseline data collection

What would make optimum linkage possible for NHANES in terms of future planning?

Coordination: As an outsider who tries to promote survey collection, how can coordination and collaboration effort be improved? Would improve ability to compare systems. Discussion: OMB review is supposed to examine these comparability issues. Also Data Council discusses some of these issues, data collection instruments, etc. Other groups that don't notify NCHS though collect data and often there is no mechanism to coordinate with them. Mostly these efforts are formal efforts. Knowledge of NHANES is not that widespread outside major health agencies. Board of Scientific Counselors is a

new NCHS group that is supposed to identify some of the potential linkages and reduce redundancies.

Children's Longitudinal Study is enormous undertaking that has a lot of NCHS input.

Survey/Study Linkages:

Linking to cancer incidence outcomes (e.g. SEER): If we/state has a cancer registry, can NHANES link to it? Are there informed consent issues? Informed consent kept fairly loose/open on purpose. In order to do that, need to know NHANES PSUs—confidentiality issues involved... may be Research Data Center issue. Also data sharing agreements are in the works. NHIS may use ACS locales for its design. CDC would like registries in every state.

Practical issues--Sample selection/coordination might provide mechanism to nest surveys; burden issues if same folks participate; data interface issues with different contractors; Title 9; legal and confidentiality issues. Need a disciple in each agency to make it work.

Genetic data linkages to health & behavior data: NHANES blood cells immortalized to be able to get polymorphisms. Also have stored sera for future projects to look at genetic conditions. Tremendous interest in NHANES DNA bank; used in human genome project.

Need a group to perhaps help NCHS plan projects & priorities. Identify how genetic data will be made available to interested parties. Proprietary issues involved too.

Report of Findings Possibilities: NHANES does not follow up actions taken. A mechanism to follow folks with severe conditions to see what they did in response and ultimately the actions taken, care sought, and health behavior issues. Could do some modeling and link to other data sources. Evaluation of ROF system not enough...behavior modification, care seeking behaviors, lifestyle modification, funding parties. Health disparities links here would be relevant, geographic distribution, etc. Might be something that a foundation would want to address.

Agency notification mechanism of intent to do a study?

Next Steps/Action Items:

- **Suggest mechanism to notify within the Department of HHS to let folks know of impending research studies. Sort of a 30 day comment period-- Might help reduce redundancies, add linkages**
- **Better website information**
- **Web-base data collection: NHANES should try to have blood analysis results reported to participants and then perhaps have a feedback mechanism for survey participants. Could modify for diet collection. Can have links and information to help respondent answer question.**
- **Statistical website/clearinghouse of proposed research on survey design? Check out FedStats.gov; can search by agency, topic. Quality and completeness varies. CDC website has this type of information**