

NHANES Open Space

September 11-12, 2003

Session Title: Core Questionnaire Components 9/12/03 session 2 Room 1403A

Session Headlines:

- Q: Process used now to determine core questions?
- Q: What are the alternatives?
- Q: How are the age groups determined?

NCHS response:

- Some historical links are used in the planning process.
- Department-level requirements
- Collaborators have funded questions and have been part of past surveys or were added
- Some content is part of NHIS
- Exam link to questions is a factor
- Proxy issues for SPs under 16 years
- Cost, burden are issues
- Self-reported diabetes data with NHIS vs. NHANES exam findings are being looked at.

Action Item

Look at NHIS-NHANES linkage issues. Are we still supposed to have these questionnaire linkages?

Is there a better way to include questions in these surveys that meet data user needs more effectively? What type of process could/should be used?

Example: Removal of pain questions proposed. In the past, funding was not required. NIAMS learned of plans to drop due to lack of funding.

NHIS and NHANES each have different, complex analytic considerations—usually don't have folks with expertise in both. Here analytic centers would probably increase the use and inter-survey analytic project possibilities

Much of the questionnaire data is under-analyzed.

Funding has become a more important factor in questionnaire content development.

Communication with collaborators about proposed questionnaire changes is a need—tends to be by word of mouth.

NIH funding cycles constrain opportunities to fund the under/non-funded questionnaire components.

Status report on major questionnaire components would be useful. Clarify core elements and process to develop the core and obtain broader input. Clearly-structured process for funding components.

Cycling process for exam and lab components proposed to make room for new content. Is this something that should be used for questionnaire content? Collaborators would need to know about this process and/or intent, methodology

NHIS has periodic, rotating modules that rotate out in addition to the core. Problem: Funding issues prevented return of the component later. Analytic capabilities vary by amt of data

Age Group Priorities: Try to reduce respondent burden and select groups at greatest risk. To add something for older groups often means removing something else—argues for cycling content concept.

Do we need to have more concentrated, focused topics vs. more general overview? Folks argue for both. HHANES used to produce estimates for 3 Hispanic groups but had no national data for comparison purposes

Communication

When decisions are about to be made, are collaborators brought in for final decisions? In the past, not really done this way. Two-stage process used now with letters of intent and full proposals. NCHS does provide feedback on other material under consideration. Proposers have been told of other groups who are interested in similar topics.

Proposal solicitation is done via listserv, major agencies and survey partners, Consortium, website, etc.

Systematic questionnaire review has not been done in a while.

The questions we cannot change need to be communicated to data users and collaborators.

Consensus is difficult to achieve with questionnaires! Groups often have strong opinions on wording and focus of the questions.

Funding Sources

Collaborators funding survey tend to have precedence over the research community

May need to communicate utility of collaboration to cover costs

Communicating “core” questionnaire might make cost-sharing more palatable to the funders

Data Disclosure

Data release has become complicated due to disclosure concerns. Questionnaire content may need to be modified to reflect what we can reasonably expect to release either in public release or publicly accessible data format

Next Steps/Action Items:

NCHS should initiate a process quickly –transparent one to communicate core content. Needs to be more than internal/NCHS process

Meeting to bring key players together in review process, goals and decision-making—stakeholder meeting. NCHS could identify current questionnaire constraints/requirement. Clarify what can be modified. Need objective review of the core questionnaire components. De-mystify the process used to decide content/

Process mechanisms: Delphi process? Internal and external review components?

Missing questionnaire content? Quality of life and function status perhaps.

NHANES data used primarily for measured items in Healthy People 2010

Core Questionnaire components: clarify what they are—tend to be components that are related or essential to use exam and lab data.

Data not analyzed sufficiently to be able to evaluate current questionnaire content. Need outcome measures to be able to evaluate some of the questions.

Stakeholders—Who are they? Start with current and potential collaborators. Could then expand to include other groups. Collaborators vary—some ask a lot and pay nothing; some collaborators are not that involved with the survey day in and day out—pay for what they want and that's it.