## NHANES Open Space September 11-12, 2003

**Session Title:** Health related quality of life

**Session Headlines:** This is of great interest to a cross section of survey users.

Should be looked at globally.

Are the current ones the best ones?

Are they related to HP 2010?

Is it perceived quality or function?

Consensus is that quality of life and ADLs should be approached as a linked theme.

Can there be a master plan for 2 year NHANES cycles for disease specific quality of life?

Distinguish physical, mental and emotional functioning for QOL. NIDCR, NIAMS and NIMH are interested in QOL measures. This was a major focus at the Office of Dietary Supplements strategic planning—is an improved self perceived QOL the outcome of importance from dietary supplement (particularly herbals) use? Also at an EPA strategic planning meeting environmental quality of life and WHO developed scales to measure quality of life were a major theme.

QOL measurement must acknowledge the relationship of QOL to the domains of disease, impairment, physical, mental and emotional functioning, activities, and participation. QOL has different impact along each domain.

RWJF should be interested in funding conference and the attendees at this session think that we could easily found.

QOL as measured in NHANES is not conceptually coherent and is fragmented. Organize QOL measures according to the NAGI and ICF frameworks.

QOL is how people go about their daily life and NHANES is the medical model of health—how to wed? To address QOL in NHANES can we look more at the linkage between the surveys. Interviewed in NHIS and examined in NHANES. Can a pilot test be done? Where do we need to go—TO LOOK AT THE WHOLE PERSON. Is there a longitudinal solution that could handle the respondent burden?

Group thinks in this area and the questionnaire as a whole should be approached this way because they understand that NHANES can only have necessary questions not "it would be nice" questions.

A great deal of effort needs to go into encouraging use of the NHANES data that is already collected.

## **Next Steps/Action Items:**

There should be a conference to determine what the minimum set of questions should be on NHANES.

NCHS should review QOL measures according to the domains above and to convene a panel to select the measures to be in NHANES. Include the WHO and European collaborators.

Explicitly link NHIS with NHANES so there is an interview in NHIS and then an NHANES examination.

NIH NHANES interest group will be approached to see if they can contribute intellectually, conceptually or financially to this effort related to QOLmeasures and potentially more broadly to other global questionnaire issues.