Interagency Working Group on Summary Measures of Health
A “Starting Point Proposal

The Interagency Working Group on Summary Measures of Health (IAWG), chaired by NCHS Director Edward Sondik, and composed of staff from various DHHS agencies, proposes the development of a data resource of measures of health status, including summary health measures. The IAWG recognizes that the measurement of health is a rapidly advancing field that includes a variety of measurement approaches and involves researchers from a broad range of disciplines. However, it also recognizes that some areas of development of health status assessment and health preference assessment are limited by the lack of large-scale data collection, including different instruments and measurement approaches for a broad range of population measures. These limitations are particularly important for measurement of population health, for translations between different instruments, and for new, data-intensive instrument development and assessment strategies.

Recognizing these limitations, the primary aim of the proposed initiative is to develop a large-scale data resource of health status and health preference measures along with necessary additional data on participants (e.g., demographic data and information on health conditions). The primary goal of this resource would be to promote and support research into health status assessment, health preference assessment, and summary measures of health, which could not occur in the absence of such a resource. Secondarily, to the extent that such a resource measures the health of the population, a goal would be to track population health for use in guiding health policy. The IAWG proposes to build the research on recommendations from an Institute of Medicine sponsored meeting on summary measures of health,[1] as well as on recent recommendations from a peer review of the World Health Organization’s World Health Report 2000.[2,3] These recommendations address continued development of measures as well as the use and “field” testing of several different measures. This work would allow the various underlying assumptions on values, methods, and distributive aspects to be more fully developed. Work with decision-makers (and the public) would also be important to understand how characteristics of measures influence decision-making.

With respect to the public, research is needed on how to examine “public attitudes and reasoning processes related to resource allocations and valued health states[1].” Still additional research would address how best to capture the distributive aspects of health—more specifically the impact on decision-making of public and decision-maker preferences for various distributions of health status and health resources.

It is also important to address the philosophical and theoretical underpinnings of existing measures along with their capability to capture future uncertainties in health states and the critical area of relating current preferences for health states to the likelihood and preferences for future health states.

Along with these fundamental research lines, the IAWG believes it is very important to pursue the more focused goal of comparing the properties and performance of existing measures and instruments in assessing the health status of individuals, the U.S. population, and important sub-populations. Toward this end two specific “tools” may be especially useful.

Comparison of Existing Summary Measures

Important products of the research would be the detailed analyses of the performance of different summary measures in like populations, including head-to-head comparisons of different measures. These analyses, in turn, would facilitate comparisons across studies that use different assessment instruments. Such a data resource will provide, therefore, a critical resource to support future research efforts aimed at developing or refining summary measures of health and health assessment instruments.

One approach would be to collect health-related information from a stratified, nationally representative sample. There are clear advantages to comparing various summary measures of health using an existing survey. By combining responses on summary measures of health with additional information on respondents= health, behavior, and other characteristics, the properties and performance of the various summary measures may be examined in detail, including aspects of sensitivity, specificity, and inter-respondent reliability that may vary across sub-populations. Of particular interest, this approach can provide insight into the effects of co-morbid conditions on overall assessments of health. Also, through an intensive comparison of existing measures, this approach could allow us to better identify the gaps in current instruments and the needs for refining future versions and instruments.

Survey of Preferences for Health States

A separable, but important, second aspect of this project will be to develop better information on individuals' preferences for different health states. Estimates of the preference weights (also called "utility weights") associated with different health states are essential in constructing summary measures to be used for economic evaluations such as cost-effectiveness analysis. However, the preference weights used in existing summary measures are not necessarily representative of the U.S. resident population. Also, the implications of the methods used to elicit preferences often are not well understood by those who use the instruments to monitor changes in quality of life or by those who interpret the results to guide policy.

This second phase of the project will provide nationally representative estimates of preferences for health states for each of the major preference-weighted instruments recommended by workshop participants. These preference weights would strongly complement those that are being estimated for the EQ-5D states by Coons et al,[11] in work supported by AHRQ and the work on community-based preferences as represented by the Health Utilities Index[12, 13], the Quality of Well-Being Index [6,14] and the SF-6D index [15].

This second phase effort will also generate critical information about how individuals respond to different methods used to elicit preferences (e.g., standard gamble, time tradeoff, visual rating scale) and how health preferences vary with demographic, socioeconomic, or other factors. The proposed initiative will allow researchers to explore factors that lead to differences in individuals= assessments of their own health, including how these self-assessments vary with socioeconomic and demographic characteristics and among individuals at different stages of illness. The project also presents opportunities to gain insight into the effects of comorbidity and risk factors on health preferences and self-assessed health status. Employing a representative sample of sufficient size will allow stratification of the findings by various factors, including age, sex, and race/ethnicity.

THE ROLE OF THE WORKSHOP

The role of the workshop is to provide a structured forum for the IAWG to ask for your help. The proposed data resource would be costly to implement, and if longitudinal, to maintain. An extensive inventory of instruments asked of all participants in such a data collection exercise would represent an infeasible respondent burden. Thus, the IAWG has developed this proposal as a starting point to receive feedback to insure such a resource would be developed to most optimally promote future research. The IAWG asks that workshop participants help answer the following questions to further develop this proposal.

1) What are the research priorities in the different areas of measurement of health which could be addressed by a large-scale data collection effort of health status and health preference instruments? The focus on answering this question should pertain to such a data resource. The IAWG is interested in receiving input from a broad range of experts on the priorities identified as well as additional priorities, including potentially:

    a. Are measures responsive to change over time?

    b. What is the relationship between health status measures, health preference measures, and clinical and biologic measures; are measures responsive to clinically significant conditions and events?

2) What instruments and assessments should be included in such a data resource? Candidate measures include, although are not necessarily limited to: the Health Utilities Index (Mark 2[4] and/or Mark 3[5]); the Quality of Well-Being Scale[6] (QWB); the SF-36[7] (or RAND-36) and its derivatives; the EQ-5D[8] instrument developed by the EuroQol group; the Health and Activity Limitation Index[9] (HALex); and the World Health Organization=s WHOQOL-BREF[10] instrument, among other possibilities. The scope and design of the final augmented data set must necessarily balance the goal of facilitating detailed comparisons among many summary measures against the need to limit the burden on survey respondents.

3) What are the additional data needs of such a resource? Essentially, a goal is to find the “minimum data set” with which to foster research into the measurement of health. Thus, research into using novel psychometric techniques to refine current instruments might require further domain-specific questions to refine the responsiveness of current instruments to a broad range of function on a specific domain. Understanding whether an instrument is responsive to the presence or absence of a health condition would require collecting data on respondents’ health histories. What other data are needed to produce an optimal resource, within the constraints of respondent burden?

4) Whom does the IAWG need to survey for this resource? The answer to this question will depend on the perceived research priorities. Measurement of population health would require a nationally representative sample, yet this approach might not yield sufficient numbers to examine in detail the relationship between measures and specific conditions. A detailed comparison of measures against clinical and biologic measures for a specific condition would require sufficient rationale for the need for a large-scale data collection effort as opposed to research through current funding systems. A hybrid approach with a nationally representative sample with over-sampling for priority populations or conditions may be ideal but would need to be considered

within the constraints of available survey mechanisms. Ensuring adequate power to answer important research questions will also be a priority.

5) What is the ideal vehicle for data collection for such a resource? Within the framework of issues developed from the prior questions, the IAWG needs to determine the optimal mechanism for collecting the data that will form the resource. While several national surveys, such as the NHIS, NHANES, and MEPS, have been identified, the capacity for additional data collection for these surveys is limited, and the resource would be constrained to their sampling frames. However, development of a new survey mechanism would dramatically increase the resources necessary to implement the resource. Identifying the priorities for research and the necessary populations to survey will assist with identifying the optimal mechanism for collecting the health status data.

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