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**SUMMARY MEASURES OF POPULATION HEALTH AND BEYOND:  
A LOOK AT U.S. FEDERAL ACTIVITIES IN MEASURING  
THE HEALTH OF POPULATIONS**

Paper submitted by the United States<sup>1</sup>

Using a 1998 Report by the Institute of Medicine of the National Academy of Sciences (IOM, 1998) as a spring board, my task is to describe interests and initiatives at the federal level in the U.S. in the areas of summary measures of population health (SMPH). By itself this is hardly a straight forward assignment, in large part because U.S. efforts in data collection are heavily decentralized and no single government entity acts as a repository that collects information on the many initiatives underway at any given time. In addition, for reasons that are explored further within this paper, federally sponsored initiatives in the U.S. that measure health based on self-reported health status, functional status, disability, or health-related quality of life typically do not make use of SMPH, as they are defined in the IOM and the WHO Annex.3 report.

Both reports describe SMPH as indicators that integrate information on mortality and morbidity into a single metric (IOM, 1998). Summary measures of population health include: health-adjusted life expectancy -- an umbrella term that covers disability adjusted life expectancy and quality-adjusted life expectancy -- and healthy and active life expectancy.

Given its wealth and disproportionately large investment in the health arena, the received wisdom is that the U.S. lags behind many other developed countries in crafting and disseminating a coherent set of work in this area. Although there is no systematic way to address that perception, it seems reasonable to explore the

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work and needs of federal agencies who have invested in the development of SMPH and others in this family of measures. Further, reviewing their application to differing policy questions may shed some light on the difficulties in developing common measures in the U.S.

First, some brief background. The IOM 1998 report emerged from a two day meeting of methodologists, ethicists and policymakers which was convened in Washington in late 1997. The purpose of the Department of Health and Human Services (DHHS) funded project was to provide guidance on future directions for the development and application of summary measures within the U.S. This relatively low budget project was fast-tracked, in large part to respond to interest within DHHS in gaining guidance for developing the next iteration of the “years of healthy life” measure - a summary measure that had been used over the decade of the 1990’s to provide tracking for an overarching goal of *Healthy People 2000* “Increase Years of Healthy Life for All Americans” (DHHS, 1990). Immediately following the workshop, a seven member committee drawn from experts in public health, ethics, policy analysis and measurement development met to draft recommendations for steps that could strengthen the credibility and utility of SMPH.

Major recommendations from that report included:

1. Initiate a process of analysis and discussion to (a) clarify the ethical assumptions and value judgments embedded in different measures of population health and (b) assess the critical ethical and policy implications of differing designs, implementation approaches, and uses of these measures.
2. Create a process to establish standards for population health metrics and to investigate the value and practicality of a compatible set of summary measures of population health that could be used for different descriptive and decision making purposes.
3. Invest in the education and training of public health and medical professionals to promote their understanding of the interpretation and appropriate use of summary measures of population health.

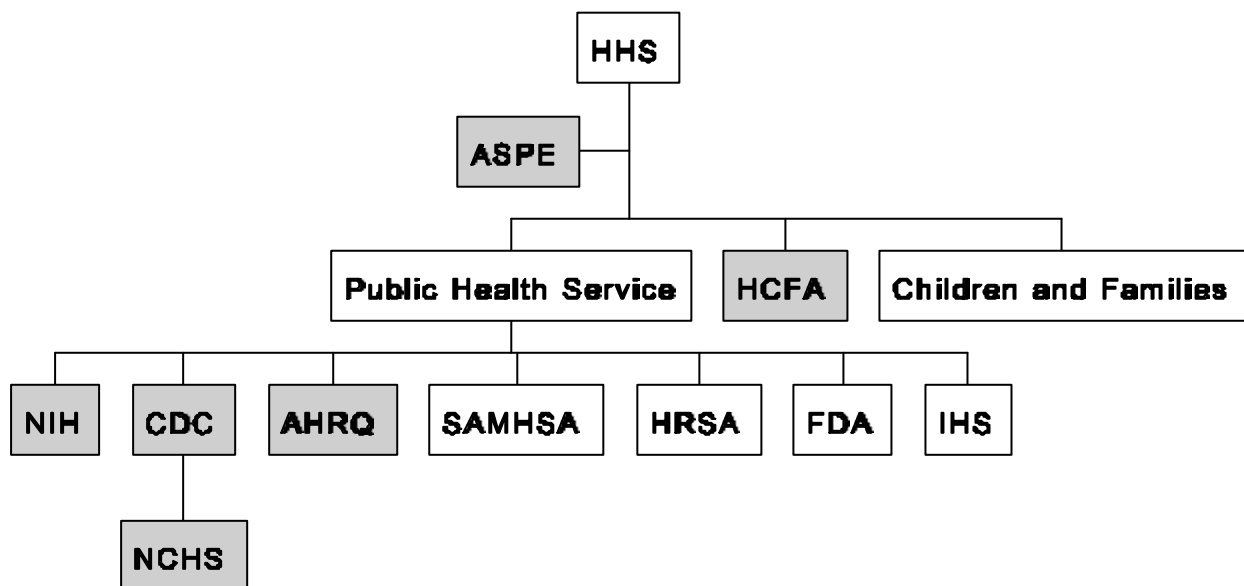
As is often true with reports which take on complex topics without furnishing sufficient resources or time to gain buy-in and ownership, no formally mandated Department-wide initiative has come from this document. The report itself lacked sufficient specificity to provide the NCHS with assistance in creating a new strategy to track years of healthy life for the next decade. Despite a follow up expert meeting held by NCHS in 1998, the Healthy People 2010 document dropped any explicit tracking method for summary measures. This is not to say, however, that the IOM report went unremarked, or that work is not moving forward in other venues.

In April of 2000, the Interagency Working Group on Summary Measures of Health was convened. A National Institutes of Health (NIH) response to a Congressionally mandated 1998 IOM study that advised NIH to strengthen its “analysis and use of health data such as burdens and costs of diseases, and of data on the impact of research on the health of the public” (IOM, 1998) provided the direct impetus for the formation of this ad hoc group. NIH, in turn, held a meeting in June of 1999 to review different measures of burden of illness and to consider how they might inform the setting of research priorities. Aware of other

federal health agencies with interests and/or portfolios in this area, the NIH turned to the Centers for Disease Control and Prevention (CDC), the National Center for Health Statistics (NCHS), the Agency for Healthcare Research and Quality (AHRQ), the Health Care Financing Administration (HCFA), and a number of other agencies, to request their participation in an inter-agency working group which would serve as a vehicle for idea exchange and exploration of common interests in this area of measurement. The group, which is chaired by the Director of the NCHS, was convened in the context of shared interests in exploring summary measure of population health that could inform health policy and research priority setting. In addition, aware of international efforts to develop and refine these measures, this working group was established to provide a forum in which to explore compatibility between different measures at the state, local and international levels. The differing objectives and range of activities of the agencies represented by this group are extensive however, and there is no explicit goal for the production of a formal report or strategy plan in this area.

An orientation to the structure of the Department of Health and Human Services is likely to be useful to an understanding of the work that is underway in different parts of the federal infrastructure. Figure 1 delineates the DHHS structure; agencies with explicit portfolios in population health status are highlighted.

**Figure 1:** Structure of Department of Health and Human Services



The Department has two major arms that are of relevance to this discussion. The Health Care Financing Administration (HCFA) administers the Medicare program, which provides insurance for the aged and disabled, and the federal component of the Medicaid program, which provides health insurance to low income persons. The Public Health Service (PHS) houses the remaining federal agencies with health and health care portfolios. Overarching Departmental policy making is coordinated through the Office of the Secretary of Health and Human Services. Within the PHS, the NIH receives the largest budget (\$17.8 billion.) The NIH research portfolio ranges from bench science to clinical trials to epidemiologic studies. The approximately 25 institutes of the NIH are primarily arranged around particular clusters of diseases, with some notable exceptions such as the National Institute on Aging. The Centers for Disease Control and Prevention (CDC), with 11 centers and an annual budget of \$3.2 billion, is the lead federal agency for promoting health and quality of life and preventing and controlling disease, injury and disability. The National Center for Health Statistics (NCHS) is the arm of the CDC responsible for monitoring and reporting health statistics for the nation. The Agency for Healthcare Research and Quality (AHRQ) is the health services research entity within the PHS, from which clinical guidelines, quality initiatives, outcomes research and economic analyses are created through a combination of intramural and extramural research. The budget of AHRQ is under 200 million dollars. Although a number of other PHS agencies, including the Health Resource and Service Administration (HRSA), the Substance Abuse and Mental Health Services Administration (SAMHSA) and the Food and Drug Administration (FDA) have end user interests in population health measures, these agencies do not have major developmental or implementation activities underway.

The Social Security Administration (SSA) is a freestanding federal agency that administers and provides payments to beneficiaries for Old Age Survivors and Disability Insurance (OASDI). Annual insurance distributions to recipients of this program total 375 billion dollars. Approximately 20 percent of the distributions are to disabled persons. Non-means tested disability payments total close to 50 billion dollars; an additional 30 billion is distributed in the means-tested Supplemental Security Insurance to disabled persons of low income.

### A Sampling of Agency Activities

The following information draws on a recent series of telephone interviews with program directors and methodologists from the DHHS and the SSA as well as from materials developed by the Office of Science Policy at the NIH and the Office of the Director, at the NCHS (NIH, 2000). A summary of this information is included in Table 1. The intent of the descriptions below is to illustrate the different types of uses that population health information is put to within the agencies described. An effort is made to provide insight as to how the measurement field is viewed from the vantage points of entities that have differing policy and research objectives. Any editorial content is particular to the individuals interviewed and is not intended to represent official agency policy. Finally, these interviews represent a convenience sample of agency interests and are not intended as an exhaustive overview of DHHS and SSA work.

### *The National Institutes of Health*

Although there is substantial commitment to the study and development of summary measures within the Office of Science Policy within the Office of the Director of the NIH, interest and investment at the Institute level is idiosyncratic and generally sparse. Most of the extramural work that is sponsored by the NIH is investigator-initiated and it is the research community that determines outcome and summary measures that are included in clinical trials. In general, institutes of the NIH are quite parochial in their interests. Because the institutes are invested in specific types of illnesses, health status measures that are sensitive to and most sharply reflect changes in these illnesses are regarded most highly. Very little work is done with SMPH, per se.

Institutes with interests in health status measures include the National Cancer Institute (NCI) which has substantial commitments to clinical trials, and is working to develop responsive outcome measures for use in assessment of treatment effectiveness, quality, and cost-effectiveness. The NCI is committed to fostering the development and dissemination of cancer-specific summary measures of health, as well as in exploring which generic measures of health status may be suited to more general policy uses. The National Eye Institute and the National Institute of Mental Health (NIMH) also support investigators use and development of disease-specific instruments. NIMH investigators utilize the SF 36, but the general sense of the mental health services research community appears to be that generic measures of health status lack sufficient sensitivity and specificity for their purposes. The National Institute on Aging (NIA) has a long history of supporting work with measures of functional status, disability, quality of life and well-being, perceptions of well-being, valuations of chronic disease states and health preference in the context of clinical work. For example, in collaboration with the NCHS, the NIA co-sponsored the Study on Aging (LSOA), a longitudinally followed sample of 16,148 person 55 years and older living in the community. A total of four interviews were conducted from 1984 to 1990 and gathered information about limitations of activities (long term) restriction of activities (short term), and chronic conditions and impairments.

Both NIMH and NIA fund and/or conduct surveys of population health that are used for epidemiological, as well as clinical research. Each has invested in the Global Burden of Disease project in pursuit of developing a policy tool that is useful to their interests. National Institute on Aging policy interests include economic impacts of disability, tracking disparities in disability in different sub populations, and charting overall changes in disability. The NIMH perception is that the disability-adjusted life year (DALY) portrayal of the burden of psychiatric illness has been useful in garnering attention to mental health issues, but that methodologists and program directors lack confidence in the accuracy of the estimates. The National Institute of Alcohol Abuse and Alcoholism (NIAAA) and the National Institute of Drug Abuse (NIDA) has contributed to the development of the WHO Disability Assessment Schedule II (WHODAS II) instrument, which is felt to provide potential for utility in domains of both physical and mental health.

### *The Centers for Disease Control and Prevention*

The Office of the Director of CDC has indicated significant interest in SMPH. As the “prevention” agency for the U.S., with a long track record in surveillance and epidemiologic inquiry, CDC is committed to incorporation of SMPH into regular information tracking and reporting efforts. Historical methods for tracking population health such as Years of Productive Life Lost (YPLL) are seen as inadequate to disability-related surveillance and evaluation activities associated with chronic diseases. In addition, CDC conducts and supports economic analyses, including cost-effectiveness analyses, which require use of SMPH. A number of initiatives are currently under way within CDC, some of which are noted below. Activities of the National Center for Statistics are not reviewed here.

The National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) has implemented a Burden of Disease and Injury project in order to quantify the burden of premature mortality and disability by individual health conditions, race, sex, and by state. The project is intended to look at the contribution of selected risk factors to disease and injury burden, and to develop a policy model that allows prognostication of the contribution of various illnesses and risk factors in the future. DALYs are being used in this effort, which is partnered with the Burden of Disease Unit at Harvard and with WHO. Other CDC efforts that use DALYs include a study of the Burden of Disease at General Motors, run through the Epidemiology Program Office (EPO). CDC has also assisted Los Angeles County in using DALYs to explore burden of disease in Los Angeles.

Divisions within NCCDPHP make use of QALYs for conducting cost-effectiveness analyses. Health-related quality of life is measured non-uniformly within these studies. The Agency for Toxic Substances and Disease Registry also uses QALYS as part of a broader effort conducted with the National Center for Environment to develop a comparative risk framework for evaluating risks associated with drinking water treatment decisions.

Also located within the NCCDPHP in the Division of Adult and Community Health are activities related to the CDC-developed Health-Related Quality of Life Measure. Developed in the early 1990's, a four item measure has been included as part of the Behavioral Risk Factor Surveillance System (BRFSS) core since 1993. The BRFSS is a state-based telephone survey of the adult civilian, non-institutionalized U.S. population. Ten additional questions were developed for optional inclusion as of 1995 and validation studies of the 14-item set have been conducted using the SF 36, the QWB, and morbidity and mortality outcomes in various general and special populations. The items are not designed to be aggregated into a summary score, although a “healthy days” summary index combines responses from the 2 global physical and mental health questions. Over a million adults have completed the core questions and as of 2000 they have been included in the NCHS administered National Health and Nutrition Examination Survey (NHANES). The HRQOL measure has also been used in other national samples including populations in Norway, Sweden and Romania. The measure is intended to help support State and local data needs in tracking years of healthy life and health disparities within the Healthy People 2010 initiative (DHHS, 2000).

An internal “Burden of Disease Workgroup” has recently issued recommendations to CDC leadership calling for the creation of an office within CDC that could coordinate efforts to promote agency-wide capacity regarding SMPH, encourage collaborations with other partners and provide training internally. (CDC, 2000)

### *Agency for Healthcare Research and Quality*

Summary measures are used in AHRQ sponsored research in quality, in outcomes and in economic analyses. Supporting work on methodology development in health services research is central to the mission of the agency. AHRQ has funded work correlating the Quality of Well Being (QWB) instrument with the SF 36, preference assessments for specific diseases, and the Child Health and Illness Profile. Most of its funded studies are clinical, however, and issues of responsiveness to change and sensitivity are central to measure choice. The dominant generic health status measure being used by investigators is the SF12/SF36, although some studies have used HUI, EQ5D and the QWB. An estimated five to ten percent of Agency-sponsored research supports health status measures, either as outcomes or in methodology development.

The AHRQ fields the Medical Expenditures Panel Survey (MEPS), a survey that assesses issues of cost and quality in a nationally representative sample of 20,000 adults. Earlier iterations of the MEPS have included the SF 12. This year the EQ 5D has been added, in an effort to provide a SMPH that could be used in cost-effectiveness analyses and could be aligned with other international efforts. The agency has received at least one investigator-initiated proposal that seeks to collect EQ 5D preference weights for the U.S. population. An additional policy- relevant application for the EQ 5D is to furnish a mechanism by which clinical information regarding health status can be mapped to with population based information, allowing comparisons to be made between outcomes of different types of interventions.

### *Health Care Financing Administration*

The Medical Health Outcomes Survey (HOS), a self-administered mailed survey that samples 1000 Medicare beneficiaries in each of 308 health plans is directed by the Office of Clinical Standards and Quality of the Health Care Financing Administration. The survey is intended to provide plan comparisons to beneficiaries seeking plan performance information, for internal use by plans for quality improvement, for monitoring plans and setting plan performance goals, and to provide data for applied research and analysis based on specific topics of interest. The HOS, which uses the SF 36 as its core, is in its third year of fielding. The first two years (1998 and 1999) were used to establish baselines within cohorts who will be assessed every two years for follow up.

### *Social Security Administration*

From 1989-1994 there was a 65 percent growth in payments of Social Security Disability Insurance (SSDI) (from \$23 to \$38 billion) to beneficiaries who had increased by 40 percent. During that same period, dramatic trends in eligibility for the Supplemental Security Income (SSI) were also seen. Disabled

SSI recipients rose from 2.1 million in 1989 to 3.2 million in 1994. In response to a shortfall for the DI Trust Funds, Congress requested information that would better inform SSA of trends and factors that were likely to bear on the future of SSA programs. Funded initially at \$40 million, the National Study of Health and Activity (NSHA) is seen as critical to making informed decisions about future needs of the SSDI and SSI programs.

The NSHA is collecting health, employment, income and social/family data on a nationally representative sample of 5500 persons through self-reports, medical examinations and medical records. The final sample will be drawn from two initial screens, the first of which involves approximately 100,000 households drawn from the civilian non-institutionalized U.S. population. Information collected from this screen will divide respondents into four study groups: persons who receive disability benefits, non-beneficiaries likely to be severely disabled, non-beneficiaries who are less severely disabled, and non-impaired/slightly impaired non-beneficiaries. A 10% sample of this group participates in a comprehensive survey of questions on employment, education, health insurance, income and program participation. Self-reported questions piloted within the first stages of this study included ADLs, functional status, mental health function, SF12 and some items adapted from the WHO DASII. In order to determine the pool of potential eligibles, NSHA will combine self-reported information from the comprehensive survey, information from the NSHA medical examination, and medical records from the preceding three years, to create simulated SSA disability folders for each of the 5500 participants. Examiners will be asked to make disability determinations based on the medical information in the simulated folders. Those subjects deemed disabled by examiners will make up the pool of persons who are potentially eligible and /or currently qualified to receive benefits in the event of job loss or other provocation for an application for SSA disability benefits.

The NSHA is designed to allow SSA to forecast the number of beneficiaries within the pipeline. As a side product of its own needs, the NSHA is also expected to provide an extensive database for disability researchers.

#### Aligning Surveys: Opportunities for Increasing Comparability - A Tale of Two Policy Needs

Two federal policy making entities have had occasion to forecast the economic implications of caring for and paying for disabled Americans. The Office of the Assistant Secretary for Planning and Evaluation (ASPE) was asked by the Office of Management and Budget (OMB) to investigate costs to the government of providing long term tax credit benefits to family members who care for people with long term disability needs. ASPE has relied heavily on surveys that use functional measures of disability as measured by IADLs and ADLs in predicting the numbers of households that will be eligible to receive such income tax credits.

At SSA, as we have seen, the policy questions go the heart of the economic viability of that program. Through the NSHA, the SSA seeks to understand the number of people who although currently working, could become eligible at any time to receive disability benefits. The SSA also wishes to explore factors that enable disabled persons to remain in the workforce. Finally, SSA is interested in knowing the effects of possible increases in the retirement age on the disability program. Pilot experience with the NSHA, which

has used a number of summary measures of health status (noted above), has suggested to investigators that neither ADLs nor the SF 12 provide information that is useful for their particular needs.

In the best of all possible data collection worlds, policy questions that applied to persons with particular diseases or disabilities should be able to do dual service. As illustrated, even within a relatively discreet series of economic forecasting issues for disabled persons and their caretakers, each enterprise relies on a vastly different set of measures.

### Toward Standardization of Health Status Measurement: Issues and Concerns

Most of the federal program directors and methodologists who were interviewed for purposes of this paper shared an underlying commitment and interest toward participating in activities that would help standardize health data. Many believed, however, that there is still much developmental work to do, even for the specific tasks required by their individual agencies or undertakings. An important early step in moving forward in standardization both at international and federal levels, would be to identify major policy uses for which measurement is required. To the extent that policy questions are congruent across nations, States and programs, harmonizing data seems a realistic goal. Where there is substantial variation in the policy issues for the different entities, motivation and resources to align surveys and other health statistics is likely to be scarce.

Recurring points that emerged during recent interviews include:

1. No single measure could/should be used to summarize population health or burden of disease and injury. (NIH, CDC, AHRQ, ASPE)
2. Refining preference-based generic measures that permit creation of SMPH would be useful (NIH, AHRQ, CDC)
3. An integrated family of measures for use at clinical and public health levels would be useful (CDC, AHRQ)
4. Generic measures of clinical health status may lack sensitivity and specificity for monitoring clinical interventions. (NIH, AHRQ)
5. Policy uses very widely; people become attached to their measurement strategies (AHRQ, ASPE, NIMH)
6. Moving toward compatibility/comparability would be costly. All new items will require new funding sources. Investigators who have longitudinal data collection efforts will not readily replace historical questions with new ones. (ASPE, SSA, CDC)

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TABLE 1: MEASURES AND THEIR USES IN DIFFERENT U.S. FEDERAL SETTINGS

| AGENCY      | USES   | SMPH     |     | MEASURES USED   | ADEQUACY OF MEASURES | SAMPLE SIZE         |
|-------------|--|----------|-----|---|----------------------|---------------------|
|             |  | Clinical | PH  |   |                      |                     |
| <b>NIH</b>  | Burden of Disease for Prioritization   |          |     |   |                      |                     |
| NCI         | Outcomes in Clinical Trials<br>Economic Analyses ,<br>Clinical Interventions | +/-      |     | DALYs, QALYs<br>Cancer Specific/SF 36                 | Unclear              |                     |
| NIMH        |  | -        |     | SF 12/36, Mental Health Specific<br>DALYs, WHO DAS II | Not ready            |                     |
| NIA         |  | -        | +   | DALYs, HUI  | Not ready            |                     |
| <b>CDC</b>  | Burden of Disease for Prioritization   |          |     |   |                      |                     |
| NCCDPHP     | Disparities<br>Economic Analysis   |          | +/- | DALYs, HRQOL 4/14                                     | Not ready/OK         | > 1x10 <sup>6</sup> |
| ATSDR       |  |          | +   | QALYs   | Unclear              |                     |
| EPO         |  |          |     | +   | QALYs, DALYs         | Unclear             |
| <b>AHRQ</b> |  |          |     |   |                      |                     |
| Outcomes    | Clinical Outcomes  | +/-      |     | SF 12/36, HUI, QWB, EQ 5D                             | Unclear              |                     |
| MEPS        | Cost Effective Analysis  |          | +/- | SF 12, EQ 5D  | Unclear              | 30,000              |
| <b>HCEA</b> |  |          |     |   |                      |                     |
| HOS         | Quality Comparisons<br>Quality Improvement<br>Plan Monitoring                |          |     |   |                      |                     |
| <b>SSA</b>  |  |          | -   | SF 36   | OK                   | 308,000             |
| NSHA        | #=s of Beneficiaries<br>What enables people to remain in workforce?          | -        | -   | SF 12 , ADLs<br>WHO DAS II                            | OK                   | 100,000             |