

**APPENDIX C: BURDEN OF ILLNESS ROUNDTABLE MEETING
SUMMARY**

Burden of Illness Roundtable Meeting Summary

November 10, 2010

RTI International, 701 13th Street, N.W., Suite 750, Washington, DC

Statement of Purpose

The meeting brought together leaders in burden of illness research for an in-depth discussion of the current state of the art in measuring the impact of disease and adverse conditions, to report on current research on burden estimation, and to identify remaining methodological challenges and data needs to advance the state of the art. The intended outcomes of the meeting were twofold: (1) to round out a report commissioned by the Office of the Assistant Secretary for Planning and Evaluation (ASPE) on the state of the art for measuring the burden of illness, and (2) to identify means to address the issues raised.

This meeting was the third part of the ASPE-commissioned study report, which is intended to provide policy makers with an understanding of the current landscape regarding metrics, methods, and data for quantifying the burden of illness. It built upon and complemented two preceding pieces of the project: a literature review and a summary of interviews with experts. Results of the meeting will be included in the Final Report for the project, which is expected to serve as a primer on the burden of illness for ASPE staff and other federal policy makers so that burden estimates can be better utilized in policy development.

Facilitators

Ansalan Stewart, Senior Policy Analyst, Office of the Assistant Secretary for Planning and Evaluation (ASPE).

The Assistant Secretary for Planning and Evaluation is the principal advisor to the Secretary of the U.S. Department of Health and Human Services on policy development and is responsible for major activities in policy coordination, legislation development, strategic planning, policy research, evaluation, and economic analysis.

Thomas Hoerger, Senior Fellow, RTI International.

RTI International is an independent nonprofit research institute that provides research and technical expertise to governments and businesses in the areas of health and pharmaceuticals, education, advanced technology, and other areas.

Schedule

1. Introductions and Purpose of the Meeting

Summary: Introduced participants, explained ASPE's objectives for the study and what ASPE will do with the information from this meeting and project, and encouraged comments and participation throughout the day.

Facilitator: Ansalan Stewart, ASPE

2. Brief Overview of Burden of Illness Measures

Summary: Introduced the three main categories of burden of illness measures, noted the most common similarities and differences between measures, and provided a brief overview of what was to come in the subsequent sessions.

Presenter: Thomas Hoerger, RTI

3. Epidemiologic Burden: Recent Developments and Remaining Challenges

Summary: Described the strengths and limitations of epidemiology-based studies and techniques in forming burden of illness estimates. Provided a quick review of developments from the literature review and environmental scan. Asked participants to assess whether the list of emerging developments in epidemiologic burden measurement is complete and to discuss future research needs. Highlighted the importance of epidemiologic measures of burden in forming the basis for economic and quality of life burden measures.

Presenter 1: Linda Brown, RTI: Described both descriptive and analytic measures of epidemiology. One example of a descriptive measure is years of life lost (YLL), which reflects burden of illness in terms of impact on years of life lost, sometimes before a given age (e.g., before age 65). An example of an analytic measure is an attributable fraction (AF), which provides an estimate of the proportional reduction in disease or mortality that would occur if exposure to a risk factor were eliminated or reduced. Discussed some recent developments and highlighted remaining questions: epidemiologic comparisons across countries; comorbidities among chronic disease patients and challenges of attributing illness or death to any one of these diseases in individuals; State of the USA Health Indicators; World Health Organization (WHO) Global Burden of Disease (GBD) project.

Presenter 2: Christa Fischer Walker, Johns Hopkins University: Discussed the objectives and methods of the GBD project. A key element of the GBD approach is that

each death must be attributed to a single cause. Dr. Walker discussed how GBD methodological advances are being used to overcome challenges of limited mortality and health-related data in many WHO countries.

Discussion Issues and Questions

- What are the most efficient methods of gathering relevant new data, especially at community levels? How can we gather consistent data across communities?

Some suggestions were to consider the use of disease registries and the implementation of new data collection efforts. The latter can be designed to produce reliable burden estimates, rather than using data that were not designed to measure burden, such as health insurance claims.

- How can we make epidemiological burden measures more readily understood by policy makers?

Use colloquial terms to convey information on complex terms like *attributable fraction* and *relative risk* to policy makers. Experts on risk communication may be needed to formulate messages.

- To generate new data, should researchers apply current methods to new areas or develop new methods? At what point does the importance of implementation surpass the debate over specific epidemiological methods (i.e., is it better to have some information that can inform debate than to have no information because it would not be possible to implement the “correct” approach given data limitations)?

Survey data are often available, but they typically have a purpose other than to estimate disease burden. For example, the Medical Expenditures Panel Survey (MEPS) is used to track health care spending in a sample of U.S. households, which is only one type of burden measure.

- What other issues should be addressed?

Lack of uniformity of local burden data collected in the United States and limited ability to estimate burden for many local areas.

Discussion: All participants

Moderator: Linda Brown, RTI

4. Economic Burden: Recent Developments and Remaining Challenges

Summary: Described the strengths and limitations of economics-based studies and techniques in forming burden of illness estimates. Provided a quick review of developments from the literature review and environmental scan. Asked

participants to assess whether the list of emerging developments is complete and discuss future research and data needs.

Presenter 1: Thomas Hoerger, RTI: Discussed recent developments and remaining questions, including attempts to reflect total opportunity costs of illness; approaches for placing a monetary value on mortality and/or morbidity impacts, such as human capital, value of a statistical life, and willingness to pay; and the wide variation in cost estimates for a given disease.

Presenter 2: Allison Rosen, University of Michigan: Discussed the issue of double-counting of costs when attempting to attribute health care spending to a particular disease or risk factor. One of the difficult characteristics of economic burden measures is that they do not always add up, or rather that the medical costs of different diseases often add up to more than the total of health care spending. Therefore, methods are needed to avoid double-counting. Presentation described three common approaches for allocating medical spending to specific diseases: encounter-based, episode-based, and person-based. Encounter-based approaches sum costs for specific diagnoses reported on claims (e.g., diabetes). Episode-based approaches group costs for clinically distinct episodes of care (e.g., a hospital visit for an MS flare-up). Person-based approaches allocate individual medical spending across all the conditions a person has (e.g., costs assigned to diabetes, heart disease, and kidney disease for someone with all three). Cost estimates for a disease, such as diabetes, differ across the alternative methods. However, none of these approaches is clearly best in all cases. The “best” approach depends on the nature of the disease, the question of interest, and the data available.

Discussion Issues and Questions

- How can we overcome the challenges of disaggregating and synthesizing data from multiple sources?

To avoid double-counting, it is necessary to constrain costs across all diseases to total health care spending.

- How can economic burden of illness information inform policies to reduce health care costs?

Policy makers tend to care a great deal about disease costs. For some groups, cost estimates are the best estimate of burden; for others, they are used for advocacy. The latter may encourage the use of approaches that double-count costs.

- How can researchers mitigate different estimates generated from different cost of illness approaches? Are there standard approaches that should be followed to ensure greater consistency in disease cost estimates?
- What other issues should be addressed?

Cost estimates provide an answer to the question of where we spend money for health care, but they do not answer questions of how to spend money to ensure the best allocation of resources across disease prevention and treatment strategies.

Discussant: Willard Manning, University of Chicago

Discussed challenges of valuing and including time costs in burden estimates. Time costs capture the social opportunity cost of an illness and may include time lost from work for adults who work for pay, but it is less easy to value time spent with an illness for people who do not work (e.g., children and older adults). Dr. Manning also highlighted that (1) MEPS does not allow researchers to estimate costs for diseases with relatively low prevalence, such as end-stage renal disease and schizophrenia and (2) regression-based approaches for estimating disease costs can result in widely varying cost estimates because of differences in the way researchers define the no-disease group in analyses.

Moderator: Thomas Hoerger, RTI

5. Quality of Life: Recent Developments and Remaining Challenges

Summary: Described the strengths and limitations of quality of life-based studies and techniques in forming burden of illness estimates. Provided a brief review of developments from the literature review and environmental scan. Asked participants to assess whether the list of emerging developments is complete and discuss future research and data needs.

Presenter 1: Kevin Smith, RTI: Recent developments and remaining questions. Discussed three types of health-related quality of life (HRQoL) measures: functional status, utility measures, and quality-adjusted estimates. Functional status measures focus on health domains, such as cognition, mobility, and other physical and mental health functions. Utility measures rank preferences for various combinations of health states on a continuum scale from 0 (death) to 1 (perfect health). Quality-adjusted measures factor quality of life into the number of years lived with a disease or disability.

Presenter 2: Keiko Asakawa, Statistics Canada: Described Statistics Canada efforts over the past 10 years on data collection and standardization in developing HRQoL measures. Canada chose the Health Utilities Index-3 as a standard measure

of HRQoL to track among its population (both over time and across provinces). Other measures of HRQoL are likely to produce different values, even in the same population, because of differences in the methodologies underlying the measures.

Discussion Issues and Questions

- What are the challenges in selecting a utility-weighted HRQoL index to use as a repeated measure in national data sets, such as MEPS?

There is limited agreement in preference, or utility, scores across many common measures of HRQoL. One issue for additional research is why differences in the way sample respondents are asked about their preferences for living with different diseases lead to differences in people's preferences.

- What are the respective roles of HRQoL measures that are and are not based on preferences? In other words, what are the policy needs and usefulness of summary measures of physical and mental health functioning versus summary measures of utility-weighted health functioning?

It was noted that preference-based measures of HRQoL are not needed for clinical or public health research, but they are needed to inform policy decision making because they reflect population preferences.

- How can we aim for standardization of HRQoL measures, and how can standardization improve health policy?

Standardization is a challenge because the most common HRQoL measures result in wide differences in the estimated utility loss of a given illness, even for the same respondents. Moreover, each measure of HRQoL has advantages and disadvantages: although one measure may be preferred for certain assessments, another may be better for others.

- What other issues should be addressed?

Important to have health profile measures that underlie the functional status measures so researchers can understand what is driving the summary measures of HRQoL.

Discussant: Matthew Zack, Centers for Disease Control and Prevention (CDC)

Described CDC's Healthy Days Measures, which have been collected annually in the United States for about 17 years. Also discussed that a key challenge of measures of HRQoL is how to communicate with public health practitioners about what they can

do to improve quality of life in the population, but that HRQoL measures may not be the best metrics to inform public health decision making at the local level.

Moderator: Kevin Smith, RTI

6. New Initiatives on the Burden of Illness

Summary: Three new areas of research in the burden of illness field were described: the Bureau of Economic Analysis (BEA) health care satellite accounts, the Patient-Reported Outcomes Measurement Information System (PROMIS) Initiative, and county-based health rankings produced under the MATCH Initiative. Each presenter provided a description of expected outcomes, progress so far, and estimated completion times. They also discussed how they have addressed some of the issues raised earlier in the day (e.g., attributing costs to specific diseases).

Presenter 1: Ana Aizcorbe, BEA—Health care satellite accounts. Described that measurement problems in the health care sector create problems for macroeconomic uses. In particular, gross domestic product (GDP) growth could be overstated by as much as 0.2 percentage points per year as a result of these measurement problems. BEA is building a prototype account for medical care. This account provides new price indexes for medical care spending and estimates of spending by disease. Although different approaches for allocating disease costs to diseases can result in different disease cost estimates, as described by Allison Rosen, the three different costing approaches used by BEA all show increases in productivity and lower costs than the Bureau of Labor Statistics price index for medical care.

Presenter 2: Ron Hays, UCLA—The National Institutes of Health (NIH) PROMIS Network. Described the PROMIS Network, which is a 9-year, \$70 million commitment to standardize measures of patient-reported outcomes. Focus so far has been on profile measures, such as those that focus on cognitive functioning or mobility. The PROMIS researchers created a pool of questions that may be administered using computer testing, which allows researchers to ask only those questions that make sense based on past responses (e.g., do not ask those who reported no mobility limitations about trouble walking or climbing stairs). PROMIS gives decision makers data on how health care affects what patients are able to do and how they feel.

Presenter 3: David Kindig, University of Wisconsin—The MATCH initiative. Mobilizing Action Towards Community Health (MATCH) is a new initiative to improve health by making county-level information available and visible to the public and

engaging policy makers to improve population health. They created a list of county health rankings that captures both mortality and morbidity. They placed weights on each different indicator included in the overall county health measure to generate an overall score that was used to create county-level rankings within the state. The transparency of the MATCH project is a key strength of the approach.

Discussion Issues and Questions:

- How do these projects fit into the existing field of burden of illness research?

These projects highlight advances in measurement of economic, quality of life, and summary measures of population health, and the focus on generating useful burden measures to inform local public health decision making.

- What is the timeline on these initiatives, and what returns can we expect in the near term?

All of the efforts have been underway for some time and are generating peer-reviewed research publications.

- What are some pressing issues that still require more research or data?

One issue with the BEA effort is that it is focused strictly on medical care as an input to health, and health outcomes may also be affected by non-medical inputs. An issue with PROMIS is that limited efforts have been made to generate utility measures of HRQoL from the health profile measures generated from the PROMIS test banks. An issue with MATCH is that limited efforts so far have focused on efforts that communities may adopt to improve health rankings (e.g., by investing in cost-effective programs or policies).

- Which grants and grant-providing organizations are most directed toward this topic? Although the question was raised, no comments directly addressed this question.

Discussion: All participants

Moderator: Thomas Hoerger, RTI

7. Using Burden Estimates to Inform Policy Decisions

Summary: Discussed ways to bridge the gap between research on burden of illness and health policy efforts designed to improve public health. Described and opened the floor to discussion on various ways that burden estimates may be used to inform policy. Potential uses of burden measures are to compare health outcomes across populations; compare health outcomes of the same

population over time; identify and quantify health inequalities within populations; provide balanced attention to morbidity impacts and not just focus on mortality impacts; inform debates on priorities for health service delivery, planning, and research priorities; and contribute to cost-effectiveness analysis of alternative intervention strategies.

Discussion Issues and Questions

- How has the GBD project influenced policy at WHO and for member countries?

It is unclear the extent to which GBD efforts have influenced policy at WHO and member countries. Advocacy groups can distort the overall picture of burden or influence resource allocations. Also, the GBD measures may not be transparent enough for policy makers to feel comfortable basing decisions on them.

- What does burden of illness tell us about how to direct policy? Can comparative metrics in the United States improve the way we set public health priorities?

Mention was made that the overall goal is to get utility improvement estimates per dollar spent on many particular illnesses, but we are not yet able to provide those estimates. Perhaps more attention should be focused on “What are the interventions into which we should invest?” and less on “What does a particular disease cost?” Yet, burden estimates are a prerequisite for accurately projecting the quality gain of investing in an intervention or the burden reduction.

- Is there a need for a single summary measure of population health in the United States to guide policy decisions? How might such a measure be used and what data are needed?

Consistency across time in summary measures would be very important. Although a summary burden measure could be useful for easily providing information about health disparities across groups or over time within the same groups, multiple measures are necessary to get a complete picture of disease impacts. It was noted that Healthy People 2020 is monitoring several indices: life expectancy, years of life lost, physical/mental unhealthy days, and disease prevalence. Different measures are suited to different purposes, so it would be difficult to choose just one. Also, existing measures, such as the disability-adjusted life years measure used in the GBD project, are under constant methodological revision.

Discussion: All participants

Moderator: Amanda Honeycutt, RTI

8. Final Discussion, Summary, and Debriefing

Summarized areas of consensus and remaining debate. Asked participants to discuss needed studies and next steps and explained our plans to incorporate the day's findings in our Final Report. Key points from the discussion were as follows:

- Agreement that no measure of burden is perfect.
- More work is needed on the allocation of costs to specific diseases and in the area of preference-based measurement of HRQoL.
- New initiatives that were discussed are exciting and promising.
- Burden measures are important to inform policy decisions.
- Burden measures are necessary, but are not sufficient by themselves; information is also needed on the projected incremental improvement in disease treatment from additional research.
- Policy makers will likely want to look at several burden measures and integrate them pragmatically.
- Burden measurement issues are highly related to policies dealing with GDP and inflation, including Social Security and Medicare payments.
- The success of MATCH suggests that public health practitioners and policy makers want local-level information.
- Some tensions that are important to consider are rare diseases and how to estimate burden for these and whether estimates adequately capture burden for subpopulations of the population most affected by health care policy, such as people with disabilities and older adults.

Moderator: Thomas Hoerger, RTI

Attendees, in order of appearance

1. Ansalan Stewart, ASPE. Senior Policy Analyst in ASPE, which is responsible for major activities in policy coordination, legislation development, strategic planning, policy research, evaluation, and economic analysis.
2. Thomas Hoerger, RTI. Director of the RTI-UNC Center of Excellence in Health Promotion Economics. He specializes in health economics, health care reform, and cost-effectiveness analysis. Dr. Hoerger has led numerous research projects for CDC and the Centers for Medicare & Medicaid Services.
3. Christa Fischer Walker, Johns Hopkins University Bloomberg School of Public Health. Assistant Scientist in the Department of International Health. Her research is focused on the epidemiology and global burden of disease for the most common childhood illnesses and the interaction between infectious disease and malnutrition.

4. Linda Brown, RTI. Senior research epidemiologist with experience in study design and analytical plans; providing oversight and direction of epidemiologic studies; and in the analysis of epidemiologic data for large-scale, multidisciplinary epidemiological studies.
5. Allison Rosen, University of Michigan. Assistant Professor in the Department of Internal Medicine and Clinical Director of University of Michigan's Center for Value-Based Insurance Design. Co-Principal Investigator with David Cutler on NIH grant to revise National Health Expenditure Accounts.
6. Willard Manning, University of Chicago. Professor in the Harris School of Public Policy and the Department of Health Studies. He is an expert on modeling the use of health services and health care expenditures.
7. Kevin Smith, RTI. Behavioral scientist with a focus in survey methods, psychometric assessment, evaluation research, sampling methodology, and multivariate statistical analysis.
8. Keiko Asakawa, Canadian Agency for Drugs and Technologies in Health. Health economist who has worked to improve consistency in QALY utility weights for pediatric health states. Has also assessed the cross-sectional validity of the HUI3 in Alzheimer's disease, arthritis, and cataracts.
9. Matthew Zack, Centers for Disease Control and Prevention (CDC). Science Director for the CDC Health Related Quality of Life Program. Played a key role in the development of CDC's Healthy Days Measures and is experienced in analyzing trends in large-scale surveys, such as the Behavioral Risk Factor Surveillance System.
10. Ana Aizcorbe, Bureau of Economic Analysis (BEA). Chief Economist of BEA, currently focused on construction of a satellite account for health care spending that would allow analysts to better assess the returns to specific disease treatments.
11. Ron Hays, UCLA. Professor of medicine and an expert on patient-reported outcomes in clinical practice. Leader of the PROMIS Network's psychometric workgroup and former Principal Investigator of the UCLA subcontract to the Statistical Coordinating Center of the NIH-supported PROMIS Initiative.
12. David Kindig, University of Wisconsin. With Patrick Remington, he is MATCH project co-director. Professor Emeritus and Vice-Chancellor for Health Sciences. Would be able to elaborate on the integration of health outcomes (mortality and morbidity) and health factors (health behaviors, social and economic factors, clinical care, and physical environment) used to produce the County Health Rankings.
13. Amanda Honeycutt, RTI. Senior economist whose research focuses on cost of illness methodologies and cost effectiveness analyses. Has estimated cost of illness for diabetes, obesity, and chronic kidney disease and has compared alternative approaches for estimating cost of illness.