Challenges in Building Disease-Based National Health Accounts

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**Background:** Measuring spending on diseases is critical to assessing the value of medical care.

**Objective:** To review the current state of cost of illness estimation methods, identifying their strengths, limitations, and uses. We briefly describe the current National Health Expenditure Accounts, and then go on to discuss the addition of cost of illness estimation to the National Health Expenditure Accounts.

**Conclusion:** Recommendations are made for future research aimed at identifying the best methods for developing and using disease-based national health accounts to optimize the information available to policy makers as they struggle with difficult resource allocation decisions.

**Key Words:** cost of illness, cost allocation, productivity, efficiency, econometrics, health economics, cost-effectiveness, health care costs, medical expenditures, research design, national health accounts

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The substantial increase in the cost of medical care over the past half century has fueled intense debate over the value of medical care. Is it worth it for the United States to spend so much on health care? What could we do to increase the benefits of medical spending relative to the costs? These issues are central in the academic literature,1–3 and in policy debates both in the United States4,5 and abroad.6–8 Yet, progress on these issues has been hampered by the lack of reliable information on the benefits of medical care relative to the costs, resulting in conflicting views of US health care productivity. While some studies suggest that productivity growth has been reasonable in aggregate,1,9 others indicate that there is substantial waste at the margin.10–12

To improve the value of care, interest has centered on revising the National Health Expenditure Accounts (NHEA)—the system that tracks US health care spending—to more systematically measure the productivity of health care spend-13,14 For policy purposes, the productivity (or value) of health care spending is measured by relating medical spending to health outcomes.

This article describes a framework for more systematically measuring productivity in health care via the creation of disease-based national health accounts, modeled on and existing alongside the NHEA. The disease accounts would provide a comprehensive picture of population health relative to health care spending (eg, productivity) on a disease-by-disease basis. We focus herein on expenditures by disease—one important input to productivity assessment. We review the ongoing debate over cost of illness (COI) studies and the absence of methodological standards guiding their performance.15–18 We close with recommendations for future research aimed at identifying the best methods for developing and using disease-based national health accounts.

**National Health Expenditure Accounts**

Aggregate data on medical spending have been compiled by the Office of the Actuary at the Centers for Medicare and Medicaid Statistics (CMS) since 1960.19,20 The accounts track the flow of funds into and out of the health care system, providing detailed information on payer type (eg, Medicare, private, out of pocket, etc.) and services purchased (eg, hospital care, pharmaceuticals, etc.). Table 1 shows a typical table and its “sources and uses” matrix, with payers on one axis and services purchased on the other. The accounts, which are described in more detail by Heffler and Nuccio,20 impose a specific set of accounting principles, ensuring that payers and services add up to the total.

The NHEAs contribute substantially to our understanding of medical spending. Yet they have limitations as well. Because they focus only on spending, the NHEAs provide no information on the value of health care spending, as they do not track the desired output of investment in health care—improved health. Indeed, these tabulations used to be termed...
National Health Accounts, but were recently renamed National Health Expenditure Accounts to reflect their focus on spending, not health per se. Further, the data are not necessarily at the right level of aggregation to measure value. To make these productivity calculations, one needs to understand spending at the same level as health outcomes, which are most naturally measured by disease. Thus, a central issue in expanding the NHEA is adding the more disaggregated (or micro) data needed to estimate disease costs.

Cost-of-Illness Studies
While the NHEAs measure aggregate spending, a separate literature has focused on measuring the costs of particular illnesses. COI studies quantify the economic impact of a disease and, together with prevalence, incidence, morbidity, and mortality, help portray the overall burden of disease in society. Segal provides a recent review of the COI literature. \textsuperscript{21} The first analysis to distribute total personal medical spending by diagnosis was by Dorothy Rice in the early 1960s. \textsuperscript{22,23} This was followed by a series of subsequent studies estimating disease costs in 1976 by Cooper and Rice, \textsuperscript{24} 1978 by Berk et al, \textsuperscript{25} 1985 by Rice et al, \textsuperscript{26} and 1999 by Hodgson and Cohen. \textsuperscript{27} Since the ongoing Medical Expenditure Panel Survey (MEPS) was started, COI studies have been more common, with papers reporting direct disease costs by Druss et al for 2002, \textsuperscript{28} Cohen and Krauss for 2003, \textsuperscript{29} and Thorpe et al for 2004, \textsuperscript{30} and Roehrig et al for 1996–2005. \textsuperscript{30a}

Cost-of-illness studies have been enormously influential. They have been used to compare the importance of different diseases, assist in the allocation of research dollars to specific diseases, provide a basis for policy and planning activities, and provide an economic framework for program evaluation. \textsuperscript{31} The National Institutes of Health have produced several summaries of cost of disease estimates (1995, 1997, and 2000), \textsuperscript{32–34} and such estimates have been cited in Congressional testimony, official reports, and other publications. \textsuperscript{35–37} Congress has even expressed interest in using COI estimates as a measure for allocating research dollars among the National Institutes of Health \textsuperscript{38} and Institute of Medicine panels have recommended their routine production. \textsuperscript{39}

Cost-of-illness studies have their limitations too. Their methods and resultant cost estimates can vary substantially, provoking ongoing debate about their usefulness for policy purposes. \textsuperscript{15–18} The debate, however, often obscures an important distinction between 2 types of cost of illness studies: “disease-specific” studies, which measure the cost of a single disease, and “general” studies, which allocate total spending to several diseases. Most COI studies are disease-specific, and it is to these studies that most COI methodological concerns refer. \textsuperscript{15–18} Perhaps, the biggest issue in disease-specific studies is the adding-up constraint: it is not entirely clear what costs are associated with each disease, and how to ensure that all medical spending is allocated to one and only one disease.

### TABLE 1. National Health Expenditures, 2006 (Billions of Dollars)

<table>
<thead>
<tr>
<th>Type of Expenditure</th>
<th>Private Total</th>
<th>Consumer Total</th>
<th>Out-of-Pocket</th>
<th>Private Insurance</th>
<th>Other</th>
<th>Total Federal</th>
<th>Total State/Local</th>
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<tr>
<td>Total</td>
<td>$2106</td>
<td>$1135</td>
<td>$980</td>
<td>$257</td>
<td>$723</td>
<td>$155</td>
<td>$970</td>
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<td>Services and supplies</td>
<td>1966</td>
<td>1054</td>
<td>980</td>
<td>256</td>
<td>723</td>
<td>74</td>
<td>912</td>
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<td>Personal health care</td>
<td>1762</td>
<td>964</td>
<td>891</td>
<td>257</td>
<td>637</td>
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<td>798</td>
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<td>Hospital</td>
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<td>286</td>
<td>256</td>
<td>21</td>
<td>235</td>
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<td>Professional services</td>
<td>660</td>
<td>426</td>
<td>388</td>
<td>102</td>
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<td>Physician and clinical</td>
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<td>295</td>
<td>266</td>
<td>46</td>
<td>220</td>
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<td>153</td>
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<td>Other professional</td>
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<td>40</td>
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<td>15</td>
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<td>19</td>
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<td>Dental</td>
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<td>39</td>
<td>15</td>
<td>6</td>
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<td>12</td>
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<td>47</td>
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<td>Medical products</td>
<td>276</td>
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<td>94</td>
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<td>84</td>
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<td>Prescription drugs</td>
<td>217</td>
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<td>143</td>
<td>48</td>
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<td>Other medical products</td>
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<td>50</td>
<td>47</td>
<td>3</td>
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<td>10</td>
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<td>Durable equipment</td>
<td>24</td>
<td>16</td>
<td>16</td>
<td>13</td>
<td>3</td>
<td>-</td>
<td>8</td>
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<tr>
<td>Other non-durable</td>
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<td>89</td>
<td>1</td>
<td>55</td>
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<td>Public health</td>
<td>59</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<td>10</td>
</tr>
<tr>
<td>Investment</td>
<td>139</td>
<td>81</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>81</td>
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<tr>
<td>Research</td>
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<td>4</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>4</td>
<td>38</td>
</tr>
<tr>
<td>Structures and equipment</td>
<td>98</td>
<td>77</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>77</td>
<td>20</td>
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</tbody>
</table>

Source: Centers for Medicare and Medicaid Services, Office of the Actuary: Data from the National Health Expenditure Accounts, 2006.
**Disease-Specific COI Studies**

Disease-specific COI studies vary in a number of ways, in part because there is no standard COI methodology. Some studies produce prevalence-based (annual) COI estimates, while others produce incidence-based (lifetime) estimates. Some studies include direct costs only, while others also include indirect costs, such as those related to lost productivity. Studies vary in their perspective, time horizon, use and rate of discounting, data sources, and underlying purpose. Frequently studies do not include all components of direct spending and may, therefore, underestimate COI. For instance, a COI study using Medicare claims data would miss patient out-of-pocket costs. At the same time, disease-specific studies risk double counting the costs of comorbidities and complications common to multiple diseases. If, for example, the costs of heart attacks are attributed to diabetes in one study, hypertension in another, and pre-existing coronary heart disease (CHD) in yet another, the combined cost of all diseases will be overestimated. Indeed, a systematic review of COI studies by Bernie Bloom et al found up to a 7-fold difference in estimated direct costs within a given disease. Further, the total median cost of the 80 diagnoses reviewed was more than twice the actual 1992 US health care expenditures, and this ignored the majority of diseases for which there were no cost-of-illness estimates.

Over time, there have been calls for the development of standardized guidelines for performing and reporting COI studies, analogous to those for cost-effectiveness analyses. But standards can only go so far. In the case of the patient who has hypertension, diabetes, and a heart attack, to what condition should the heart attack be attributed? This is not a standardization question as much as it is a research motivation question.

**General COI Studies**

General COI studies allocate total expenditures for a population to a group of diseases. The methodology is usually top down: total costs for the health sector are used as the starting point and some fraction of the sector’s costs are attributed to each of the diseases of interest. The adding-up constraint makes general COI studies more methodologically sound and more readily aligned with the NHEA than are disease-specific studies. Thus, we focus on general COI studies for the remainder of this article.

General COI studies are not without limitations. As with the disease-specific studies, disease costs must be constrained to a national total to avoid double counting. General COI studies reduce (but do not preclude) this risk by creating disease groups that are usually mutually exclusive and exhaustive. Attribution issues in the setting of comorbidities remain a concern, though. If a person has diabetes and a prior MI, and is now taking an ACE inhibitor, to which condition should the costs of the ACE inhibitor be attributed?

The most common (though not exclusive) methodology for comorbidities is to assign each service to one condition, generally the principal diagnosis (in the example above, most likely the heart attack). However, this can result in substantial underestimation of costs for diseases that impact other conditions later on—for example, diabetes or hypertension. Another issue common to both types of COI studies is how to separate out prevention and screening costs from treatment costs. One would not want to consider a mammogram for screening of breast cancer in the same bucket as chemotherapy for a diagnosed case. Both apply to the same disease, but they have very different implications for how to view medical spending.

**Conceptual Framework for Disease-Based National Health Accounts**

The full value of disease-based national health accounts lies in their potential to better inform the policy process than either the NHEA or COI studies alone. The NHEA capture comprehensive health expenditures, but their highly aggregated data (and lack of information on health) preclude many policy analyses. The more disaggregated national survey data include detailed information on expenditures and health. While they can support COI estimation and microsimulation modeling, the cost estimates may exceed national totals. Institutionalizing micro survey data within the macro NHEA framework allows side-by-side comparisons of health and spending, and ensures that expenditures are constrained to NHEA totals. The combined analytic dataset builds on the strengths of each while addressing the weaknesses of the other.

The disease-based accounts would be a supplement, rather than a substitute, to the NHEA. The basic framework we envision would start with the NHEA sources and uses matrix, and add disease categories as a third dimension. This 3-way matrix would support multiple potential tables: “total expenditures by disease,” “payers by disease,” and “services purchased by disease” would likely be among the first. The accounts would allocate total personal health care expenditures to a mutually exclusive, exhaustive set of diseases. While tables would follow NHEA standards for classification and completeness, the dimensions of the tables would largely be dictated by data availability. Therefore, while it is not necessary to show every category of spending in a table, those categories that are shown must be distributed completely.

To proceed, what is needed is a methodologically rigorous, empirically feasible way of bringing the NHEA and COI studies together in a common framework. In this section, we describe 3 major steps required to attain this goal: (1) identification and reconciliation of individual level (or micro) data to NHEA, (2) choice of disease classification system, and (3) attribution of expenditures to diseases. Throughout, we comment on gaps in data, knowledge, or methodology that would benefit from additional research. Finally, we outline an agenda of future research aimed at improving the methodological rigor and policy impact of disease-based national health accounts.

**Identification and Linkage of Micro Data to the NHEA**

Disease-based health accounts require micro data on spending by particular individuals to tell what is spent for particular conditions. At the same time, the micro data need to add up to national spending totals. A central challenge for
disease-based national health accounts is identifying individual level data of sufficiently broad scope for linkage to the NHEA. In the United States, this has proven difficult. Several recent COI estimates have used AHRQ’s Medical Expenditure Panel Survey. However, MEPS underestimates national spending and requires adjustment if it is to match NHEA totals. In 2002, for example, national cost estimates from MEPS accounted for less than 70% of NHEA totals partly due to the MEPS restriction to the noninstitutionalized population. The Medicare Current Beneficiary Survey (MCBS) collects data on institutionalized Medicare beneficiaries that could be used to supplement MEPS. However, there is no straightforward way to link these surveys.

Ongoing work by AHRQ and CMS has made great strides in reconciling MEPS data to the NHEA, and additional ongoing work has focused on linking MEPS and MCBS data for reconciliation to the NHEA. These data set linkages and reconciliations are still progressing, and should allow better estimates in the near future.

While survey data are appropriate for high prevalence illnesses such as diabetes and cardiovascular disease, for lower prevalence conditions (or subgroup analyses), the national surveys suffer from small sample size problems. Low prevalence conditions, additional data are required, often in the form of population- or disease-specific registries. Another option is to combine the power of claims databases with the representativeness of household surveys. Claims data have additional drawbacks, however, including their limited accessibility and being relatively expensive to obtain.

Selection of Disease Classification System

While the issue of disease categorization is important, it has received little attention in the literature. When we talk about the cost of diabetes, should we separate type I and type II diabetes, or combine them? Should we differentiate people with complications from those without, or leave everyone in one bucket? There is no firm rule about what strategy is best, and as a result, different classification systems take different approaches. Most systems use the International Classification of Diseases, ninth or tenth revision codes as the basis of their classification. However, the number of disease “buckets” they employ and the combination of codes mapping into a given disease vary significantly across systems.

The validity of disease classifications can be optimized, in part, by grouping diagnoses into homogeneous, mutually exclusive, exhaustive buckets. Ironically, the first level categorization of the ICD-9-CM (the most frequently used system in the US) violates this rule. Of the 17 chapters in the ICD-9 manual, some represent organ systems (eg, circulatory diseases or respiratory diseases), while others represent conditions that span multiple organ systems (eg, infectious and parasitic diseases, neoplasms). One additional category is reserved for “symptoms, signs, and ill-defined conditions.” As a result, the chapters range from too broad to too narrow.

A more appropriate schema is AHRQ’s Clinical Classification Software (CCS). The CCS groups diseases with similar etiologies together, regardless of whether they cross organ system (and ICD-9 chapter) boundaries. This consistency, along with AHRQ’s stewardship of the CCS (updated annually to capture the frequent changes to ICD-9 codes), make it an appealing instrument for standardization efforts. At the same time, though, use of the ICD-9 chapter structure as the foundation of many grouping systems has made mapping them to CCS challenging.

A variety of commercial risk-adjustment tools (such as Episode Treatment Groups (ETGs), Medical Episode Groups (MEGs), and Diagnosis Cost Groups (DCGs) have also been used as the basis for disease categorization schemes. To our knowledge, no comprehensive catalog of these various schemas exists. But there have been 2 excellent recent reviews of many of these disease classification systems, one developed for clinical outcomes and the other for risk adjusting costs. Lu et al compared 7 grouping schemes—5 for mortality and 2 for morbidity—and found limited comparability between them. The different schemes used different grouping logic, covered different ranges of codes, and named some groups the same but defined them with entirely different diagnostic codes. Curiously, these divergent grouping schemes are the ones used to make most international mortality comparisons.

The second review, by the Society of Actuaries, made side-by-side comparisons of 12 risk adjustment models, largely commercial products. The models varied markedly in the data fields used to define patient risk categories; some included age, sex, and or secondary diagnoses, while others did not. Some included pharmacy and laboratory data, while others did not. The number of risk categories varied substantially, as did the proportion of expenditures that could be allocated to disease groups.

Attribution of Expenditures to Diseases

Once the disease classification schema has been selected, the next step is to attribute spending to diseases. There are 3 distinct conceptual approaches to attributing medical costs to diseases, each with different implications for the unit of analysis: The first approach is an “encounter-based approach,” estimating disease-specific spending by diagnoses listed on individual medical claims; the unit of analysis is the encounter (or claim). The second is an “episode-based approach,” estimating spending on all services considered to be involved in the diagnosis, management, and treatment of a specific condition. The unit of analysis is an episode, which may have variable lengths of time. The third is a “person-based approach,” identifying all conditions a person has and then using regression analysis to allocate total spending to particular diseases.

Encounter-Based Approach

Most cost of illness studies take an encounter-based approach, assigning claims to disease buckets based upon their coded diagnoses. Comorbidities are a major problem here; attributing each spending item for a patient who is both hypertensive and diabetic is not easy. The usual approach is to assign claims based on the primary diagnosis, but in practice this dilutes the apparent cost impact of many important risk factors. For example, if a person with diabetes,
hypertension, and CHD visits a doctor, to which disease should the costs be attributed? What if only coronary heart disease is listed on the encounter despite the fact that the diabetes likely contributed to the CHD? In the same vein, this method has difficulty accounting for downstream complications. If a person with diabetes has a heart attack several years later, is the subsequent spending a result of the diabetes or the heart attack? Most analyses would assign the downstream costs to the heart attack, which underweights the future costs of diabetes. These issues are particularly important in individuals with conditions like CHD, where multiple comorbid diseases are the norm, rather than the exception.

The principal advantage of the encounter-based approach is the ease with which costs are attributed to diseases. At the same time, though, a nontrivial portion of spending has no associated claims or valid diagnosis codes, such that these costs cannot be allocated to diseases. For example, many over-the-counter medications are not formally linked to a diagnosis. Finally, and perhaps most importantly, encounter-based COI estimates are not readily compared with health outcomes (that are measured at the person level), thereby hampering meaningful estimation of health care productivity.

### Episode-Based Approach

Increasingly, analysts are estimating disease costs using episode groupers—software programs with algorithms that organize claims data into clinically distinct episodes of care. A treatment episode can be thought of as “a series of temporally contiguous health care services related to the treatment of a given spell of illness or provided in response to a specific request by the patient or other relevant entity.”

Episodes are natural to examine because they group related claims regardless of which specific diagnosis is coded on the claim.

Still, episode-based disease costing faces a number of challenges. A central issue is how to identify the start and end point of an episode of treatment, and how to identify the groups of specific services and costs relating to a particular episode of care. Episode groupers differ in how they do this, with no clear consensus on best practice. Comorbidity and joint cost issues are problematic as well, just as they are in the encounter approach. Other challenges include how to handle chronic disease episodes (length is often set arbitrarily at 1 year), what to do with complications of treatment (assign to a new episode or an old one), and how to handle medical treatments that do not fall neatly into a disease category (such as a screening study). Finally, while a number of different commercial episode groupers are already widely in use, they have received little scientific evaluation to date, and the small but growing body of research by CMS and others points to very real differences in the output of different vendors’ groupers. Pending further evaluation and standardization, it will be difficult to use these proprietary algorithms for public work.

### Person-Based Approach

The final approach to cost estimation is the person-based approach. In this approach, a person’s total annual health care spending is regressed on indicators for the set of conditions a person has. The coefficient on the disease dummy variable is the average cost of that condition, controlling for the other conditions the person has (ie, the incremental additional cost of the disease).

The person-based approach is designed to produce more valid estimates for patients with multiple chronic conditions, as it better captures expenditures for comorbidities and complications. That said, the regression specification is sensitive to how comorbidities are entered. A standard linear regression may not be right, since it imposes additivity of joint conditions. However, if 1 condition increases (or decreases) the costs of another, adjustment is needed to ensure that condition-specific spending does not sum to more (or less) than the total. Another empirical issue is what interaction terms to include. For the most part, clinical expertise is needed to identify the appropriate group(s) of co-occurring diseases, which may represent a limitation for policy purposes.

An advantage of person-based cost estimation is that the costs of utilization events for which there are no valid claims or ICD-9 codes can still be attributed. Another attractive conceptual feature of person-based cost estimates is that they can be readily matched to health outcomes, such as mortality and quality of life, thereby providing the critical link between spending and health needed to more systematically measure value.

### Which Approach is Best?

Conceptually, there is no “best” method for allocating expenditures to disease groups. Rather, the most appropriate method will be contextual, depending largely on the question at hand and the target audience. For example, if the goal is to compare costs and health effects within a given disease, as is done in cost-effectiveness analyses, a person-based approach is likely best. In contrast, if price index construction is the goal, federal agencies may find an episode of treatment approach more meaningful. For evaluating changes in acute care spending patterns, though, real-time answers may only be possible with an encounter-based approach. In the long-term, what is needed is more empirical work to compare different approaches and to determine more definitively which is best under particular conditions.

### DISCUSSION

Timely, reliable, and complete information on medical spending relative to health is critical for sound policy-making and planning. As calls for health care cost containment escalate, the need for such data has never been more apparent. We describe 1 option—the development of disease-based national health accounts—for systematically developing this knowledge base.

A number of methodological challenges will arise in implementing disease-based health accounts. We focus herein on 3 major steps: linking micro spending data with macro totals; determining a set of diseases for which costs can be measured; and allocating spending to particular conditions. Each of these steps involves conceptual as well as applied questions. Further, while some immediate ways to make progress exist, the difficult and longer term issues of...
data availability and reliability (while not discussed in detail here) will be central to the success of these efforts.

While additional research on disease-based medical spending is an important step in forming disease-based accounts, it is not the only step. Future research will need to address nonmedical inputs to health (such as education and the environment), indirect costs of care (such as lost productivity, and caregiver costs), and measurement of population health.

Along these lines, it is important to note that existing national accounts, such as the National Income and Product Accounts, are not static. New measures of inflation are introduced, adjustments for changes in quality are developed, and so on. The key to the accounts is not that they are perfect, but rather that they have a coherent organizing structure that guides ongoing refinements. We envision the type of cost assessment we propose as a first step toward this broader agenda.

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