Use of Cancer Performance Measures in Population Health: A Macro-level Perspective

Steven B. Clauser

The use of performance measurement to inform macro-level studies of cancer control and quality of care is receiving increasing interest at the state, national, and international level. This article describes the use of these measures to inform health policy and monitor cancer disparities and disease burden. Applications are discussed in clinical and provider-reported outcomes such as cancer incidence, mortality and survival, and outcome-linked processes of care, and patient-reported outcomes such as health-related quality of life and patient satisfaction/experience with care. The use of economic measures to monitor and evaluate the burden of illness is also discussed. The growing demand for surveillance capability coupled with the need to expand both the quality and breadth of available measure sets, suggests that there is a need to supplement traditional clinical and provider-reported process and outcomes measures with patient-reported outcomes measures such as health-related quality of life and patient satisfaction and experience with care. In addition, there is also a need to broaden and standardize outcome-linked process-of-care measures to improve the ability to measure and monitor incremental progress in improving cancer care. Finally, better measures of indirect costs of cancer care, such as loss productivity and caregiver burden among the aged, would improve national estimates of the cost of illness associated with cancer. [J Natl Cancer Inst Monogr 2004;33:142–54]

The comparison and evaluation of cancer control efforts at the international, national, and state levels have received increased interest in recent years. Studies by the Institute of Medicine and the World Bank have highlighted the need for better summary measures of health and disease burden—measures that are sensitive to understanding how choices made by nations and states influence the quality of care and quality of life of cancer patients and survivors residing in their jurisdictions (1,2). There is also growing interest in using these measures to inform health policy by monitoring cancer disparities and disease burden against national goals. England and the United States are examples of countries evaluating national measurement systems (including those related to cancer) to develop national quality reports to assist in the establishment of priorities, track improvement against these priorities, and report these findings to the public (3,4).

Several measurement approaches have been developed to support population-based studies in the United States and abroad that address cancer control and quality of care. These measures include traditional endpoint measures of cancer burden, such as incidence, mortality, and survival, as well as outcomes measures that combine both mortality and morbidity into more global or generic multi-attribute indices of disease, such as healthy life expectancy and disability adjusted life years. Many countries have national or subregional initiatives to monitor and improve the quality of cancer care, especially in areas related to cancer prevention. These macro applications use process measures to track the effectiveness of these initiatives in improving cancer outcomes. This article categorizes these measures in terms of their strengths and limitations in population-based macro-level assessment of cancer control programs and will provide suggestions for the improvement of these measures to inform governmental health policies aimed at improving cancer outcomes.

WHAT IS MACRO-LEVEL ANALYSIS?

Macro-level measurement documents variations in health-related outcomes to assist decision makers in establishing and evaluating policies aimed at benefiting the health of entire populations. These studies define their geographic boundaries most often in terms of jurisdictions of government, whether they are at the international, national, state, or county level (5). Thus, macro-level studies differ from analyses at the micro-level or meso-level in that they typically define these populations at a level above the responsibilities of specific health systems, health plans, providers and practitioners, or patients. Macro-level studies also differ in that they are designed to define and track cancer outcomes and processes, compare and contrast variation across nations or subnational governmental units (e.g., states), and monitor trends in performance over time. These studies are not designed to explain the underlying causal determinants of these variations or trends.

Interest in macro-level studies of cancer control has increased in part because population health has become a major issue in the United States and in much of the rest of the developed world. Several national and international organizations have sponsored national surveillance initiatives that include the evaluation and assessment of cancer control programs: The World Health Organization (WHO) published World Health Report 2000, containing rankings of health systems performance in cancer control based on their variation in disability-adjusted life expectancy (1), and the Organization for Economic Cooperation and Development (OECD) has developed composite health status measures and specific health outcomes measures to compare performance in member nations on multiple dimensions including cancer (6–7). Several individual nations have sponsored studies of the burden of illness associated with cancer, and a few na-
Macro studies have a common objective to improve cancer outcomes for entire populations by influencing the policy process (2). These studies address this objective through a variety of analytic approaches (9). Cross-national studies often use these comparisons to illustrate shortcomings in cancer control and quality of care. For example, the EUROCare study of cancer survival in 12 European countries reported much lower improvement in cancer survival rates in the United Kingdom than in other advanced industrialized countries in northern and western Europe (10). This finding increased interest and concern in the United Kingdom over cancer survivorship (11), and cancer survival was included as a key cancer outcomes measure tracked and publicly reported in the first U.K. national quality report. Macro-level studies are also used to compare the burden of cancer with other diseases from one population (nation or state) to another to inform priority setting, health investments, and resource allocation in the health sector. The World Health Report 2000 involved estimating for each of 191 countries disease-specific disability-adjusted life years, and it contains a large number of performance scores for relative burden of disease including cancer (1). These scores and rankings have created considerable controversy from methodological, policy, and ethical perspectives (12–14).

Macro-level studies have also been used to track progress in reducing levels of burden relative to absolute or relative benchmarks. The U.S. Department of Health and Human Services (DHHS) tracks the U.S. performance in achieving national goals in the Healthy People 2010 (HP 2010) project across a number of health conditions, including cancer outcomes and processes related to early detection, diagnosis, and treatment of cancer (15). The U.S. National Cancer Institute (NCI) prepares the Cancer Progress Report, which supplements the HP 2010 goals by tracking additional cancer outcomes and processes not covered in HP 2010 (16). The U.S. DHHS is planning to incorporate several cancer outcomes and process measures from the HP 2010 project and the Cancer Progress Report as part of its National Health Quality Report, which will track the nation’s progress in improving the quality of care. (4)

Using macro-level studies to shape public policy in cancer control is more challenging. As stated above, the principal purpose of macro studies is to identify trends and relationships in performance and to motivate and point the direction for more detailed analyses of the causes of these trends and relationships. Thus, the ability of these studies to inform public policy depends to some extent on the salience of the measures to policymakers, the cancer community, and the general public; the sensitivity of the measures to influences in the medical care system; the relationship between the measures and the outcomes of interest; and supplemental analyses that shed light on the potential causal determinates of the observed variation. The next section provides an overview of measures typically used in macro-level studies of cancer control, examples of applications, and their strengths and weaknesses in facilitating an understanding of the burden of illness associated with cancer and interventions that can improve those outcomes over time. This background will serve as a basis to describe the progress and next steps in establishing a measurement strategy that resonates with key stakeholders in the policy process.

**Measuring Cancer Quality Outcomes: Macro-level Measures of Effectiveness**

This article focuses on cancer outcome and process-quality measures that matter to policy makers. Outcome measures refer to measures of change in health status—mortality, morbidity, quality of life—that are brought about by health care or health system activities. Also included in this definition are outcomes measures of the responsiveness of the health system to cancer patients and their families, including satisfaction and experience with care. In addition, outcomes measures that address the economic burden of illness for populations are discussed, given the centrality of importance of economic factors in evaluating cancer control programs. The term “process measures” is used here to refer to direct activities of the health delivery—therapies, procedures, and other services—that have been scientifically linked to health outcomes achieved by patients. These processes may include activities performed by health practitioners, for example, adjuvant therapy or surgery, or patient-related activities, such as compliance with therapy. Thus, some measures of behavioral risk reduction, for example, exercise and nutrition, which are related to cancer outcomes but are more a function of patient self-management, are not included in this definition. In addition, use-based measures typically used in population-based access to care studies are not included.

Table 1 lists the types of outcome and outcome-linked process-quality measures used or under consideration for macro-level studies of cancer care. As the table illustrates, the most extensive application of measures is in clinical endpoint measures, reported by providers and captured through cancer registries and death certificate data. Outcome measures that are reported by patient-defined endpoints, such as health-related quality of life and satisfaction with care, and outcome-linked process measures have had much more limited application. Each of these classes of measures, with illustrative applications where available, is discussed in the following section.

**Cancer Incidence and Mortality**

Single-attribute outcomes measures such as incidence and mortality are among the most thoroughly researched indicators of the effectiveness of cancer control programs and are generally considered major indicators of cancer burden in population-based studies. These measures are important because they either affect a large number of people (e.g., high incidence) or have serious consequences for those who are affected (e.g., high case mortality rate or length of survival).

The NCI has tracked cancer incidence rates using the Surveillance, Epidemiology, and End Results (SEER) program since 1973 (17). SEER is the most authoritative source of information on long-term cancer incidence in the United States. The NCI collects and reports data on incidence from 11 registries, now covering 14% of the U.S. population, and has added four additional registries to expand its coverage to 26% of the U.S. population. NCI uses SEER to monitor trends in cancer rates including incidence, survival, and mortality and has developed statistical models to project cancer incidence from SEER for the nation as a whole (17). SEER studies have indicated that after several decades of steady increases, rates of new cancer began to decline overall about 1992. For the four most common cancers—breast, prostate, lung, and colorectal cancer—incidence...
Table 1. Profile of cancer performance measures and current or potential applications in macro-level studies

<table>
<thead>
<tr>
<th>Measure</th>
<th>Definition</th>
<th>Data source</th>
<th>Application</th>
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<tbody>
<tr>
<td>Health outcomes</td>
<td></td>
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<tr>
<td>1. Incidence</td>
<td>Total incidence, proportion of population diagnosed with cancer</td>
<td>Cancer registries</td>
<td>United States/Europe/Canada</td>
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<tr>
<td>2. Mortality</td>
<td>Cancer death rate</td>
<td>Death certificates</td>
<td>Globally</td>
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<tr>
<td>3. Survival</td>
<td>Years of life lost, date of death from disease minus estimated date of death based on average life expectancy</td>
<td>Death certificates</td>
<td>United States/Europe/Canada</td>
</tr>
<tr>
<td>Quality-of-life</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preference-based</td>
<td>Patient-defined endpoint measures</td>
<td>Patient sources</td>
<td>Limited</td>
</tr>
<tr>
<td>1. EQ-5D</td>
<td>Mobility, self-care, usual activities, pain</td>
<td>Population survey</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>2. HUI 1–3*</td>
<td>Physical, role, and social-emotional function, health problems</td>
<td>Population survey</td>
<td>Potential for United States</td>
</tr>
<tr>
<td>3. QWB*</td>
<td>Social function, physical activity, mobility, symptoms or impairments</td>
<td>Population survey</td>
<td>Potential for United States</td>
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<tr>
<td>Profile measures</td>
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<td>SF-36</td>
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<td>Potential for United States</td>
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<tr>
<td>Responsiveness to patients</td>
<td>Physical and emotional functioning</td>
<td>Population survey</td>
<td>Potential for United States</td>
</tr>
<tr>
<td>Health adjusted life years (HALYs)</td>
<td>Health-related quality of life adjusted for survival</td>
<td>Population survey</td>
<td>Global limited in United States</td>
</tr>
<tr>
<td>Quality adjusted life years (QALYs)†</td>
<td>Assignment of weights to mutually exclusive and exhaustive states of health, Disease states are mapped to health states and weights are applied to those states</td>
<td>Population survey</td>
<td>Global limited in United States</td>
</tr>
<tr>
<td>Disability adjusted life years (DALYs)</td>
<td>Sum of years of life lost caused by premature death, plus years lived adjusted for disability</td>
<td>Expert opinion or secondary survey data</td>
<td>Global limited in United States</td>
</tr>
<tr>
<td>Healthy life years (HLY)</td>
<td>Date of death adjusted life expectancy using weights derived for health states associated with disease. Health states are based on perceived health and activity limitations</td>
<td>Secondary survey data</td>
<td>United States</td>
</tr>
<tr>
<td>Years lived with disability (YLD)</td>
<td>Length of disability is adjusted for the severity of disability from the disease</td>
<td>Population survey</td>
<td>United States</td>
</tr>
<tr>
<td>Process measures</td>
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<td>Screening measures</td>
<td>Evidence-based treatment or screening interventions</td>
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<td>Cross-cutting measures</td>
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<td>Cost of illness</td>
<td>Economic burden of cancer care</td>
<td>Patient and provider</td>
<td>United States/Europe/Europe</td>
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<tr>
<td>Direct costs</td>
<td>Health services and out-of-pocket costs attributable to cancer treatment</td>
<td>Patient and provider</td>
<td>United States/Europe/Europe</td>
</tr>
<tr>
<td>Morbidity costs</td>
<td>Lost work income caused by disability and absenteeism</td>
<td>Patient and provider</td>
<td>United States</td>
</tr>
<tr>
<td>Indirect costs</td>
<td>Lost income due to premature death</td>
<td>Patient and provider</td>
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<td></td>
<td>Burden on family and individual life style</td>
<td>Population surveys</td>
<td>United States/Europe/Europe</td>
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*These outcomes measures—the EuroQol EQ-5D, the Health Utilities Index (HUI) versions 1 through 3, the Quality of Well-Being Scale (QWB), are classified as preference measures because they use procedure for weighting the relative health states addressed in the measure. The Medical Outcomes Study Short Form 36 (SF 36) is a profile-type measure because it yields psychometrically based scale scores independent of individual preferences.

†There are several health-related quality-of-life measures that can be used to compute QALYs, including the Health Utilities Index, the Quality of Well-Being Scale, the Health and Activity Limitation Index, and the EuroQol EQ-5D.

rates have either declined or remained stable throughout the 1990s, with the exception of slight increases in breast cancer among women aged 50–64 years and in lung cancer among women (16). Similarly, death rates from the four most common cancers have dropped consistently since the late 1980s, although deaths from some cancers, such as esophageal and non-Hodgkin’s lymphoma, are increasing (16).

WHO also monitors cancer mortality for 191 nations in six regional subdivisions. The data come from vital registration data, where available, and from national cancer registries. Cancer was estimated to account for more than 7 million deaths (12% of all deaths) in 1999, only exceeded by cardiovascular diseases (30%) and by infectious and parasitic diseases (19%). Globally, lung cancer (trachea, bronchus, and lung) is the leading cause of cancer deaths, claiming almost 1.2 million victims. Stomach cancer is the next most prevalent cause (30%) and by infectious and parasitic diseases (19%). Globally, lung cancer (trachea, bronchus, and lung) is the leading cause of cancer deaths, claiming almost 1.2 million victims. Stomach cancer is the next most prevalent cause (30%) and by infectious and parasitic diseases (19%).
countries, more than two-thirds of all cancer deaths occurred in low- to middle-income countries. International improvements in controlling communicable diseases, as well as the aging of the population in developed countries, are expected to increase the burden of cancer worldwide (18).

The utility of cancer incidence and mortality data within populations is often limited by the quality of cancer registries, the lag in reporting deaths, and the methods of extrapolation when samples are used or data are missing. This is especially important when comparing across nations or states. For example, Mathers and colleagues (19) found that the Global Burden of Disease estimate for cancer deaths worldwide was 11% higher than an estimate produced by the International Agency on Research in Cancer as part of GLOBOCAN 2000. This was in part because of methodological differences in the estimation of mortality. The largest differences occurred in two subregions (Africa and Southeast Asia), where the regional cancer registries may have incomplete data (19).

Comparative judgments across populations are also complicated by the need to adjust trends for population growth and differences in the underlying age and sex distribution of the population. Because age is correlated with cancer incidence and mortality, failure to adjust for this difference will result in misleading estimates. Also, the method of adjustment may make comparisons difficult. For example, recently the U.S. DHHS mandated all agencies to use 2000, rather than earlier, population standards in reporting health statistics. As part of this effort, the NCI adjusted all its incidence and mortality reporting from a 1970 population standard to a 2000 population standard, which resulted in cancer incidence and death rates 20%–50% higher than rates published to the 1970 standard (20).

Mortality alone does not give a complete picture of the burden of cancer deaths. As a result, many analysts combine mortality with life tables to estimate the reduction in life years associated with premature death caused by cancer. One commonly used measure is years of life lost (YLL). This measure is created by subtracting the date of death from cancer from the date of death that would have occurred had the person lived an average life expectancy. The average years of life lost (AYLL) is obtained by dividing the person-years of life lost divided by the number of deaths. NCI publishes the AYLL caused by early death from a particular cause as a measure of the extent to which life is reduced by cancer mortality (21). The NCI estimated that in 2000, the AYLL ranged from 9 years for prostate cancer to more than 35 years for testicular cancer (21). Deaths from cancer were responsible for more person-years of life lost than any other disease.

The availability of social and demographic characteristics of individuals on death certificates has allowed investigators to develop socioeconomic deprivation indices based on mortality (22). These indices have been widely used in studies to monitor health disparities in Europe, Australia, and New Zealand, and recently they have been applied to U.S. data. Singh et al. (23) examined trends in socioeconomic differences in all-cause cancer mortality for men from 1950 to 1998 and found a dramatic reversal in the socioeconomic gradient between 1950 and 1960 and later years, where by the late 1980s, cancer mortality rates were higher in lower-socioeconomic areas than in higher-socioeconomic areas. Singh et al. suggest that such “ecological surveillance of community-level data allows insights into the possible differences that cancer control interventions might make by socioeconomic characteristics” (23, p. 905). Such studies may point to interventions designed to reduce behavioral risk factors, lessen exposure to environmental pollutants, and eliminate barriers to medical care as means of reducing health disparities in cancer mortality.

Cancer Survival

Advances in the early diagnosis and treatment of cancer have resulted in many individuals living longer after diagnosis, which, in part, explains increasing survival rates for many cancers. As a result, patient survival—the proportion of cancer patients surviving a specified interval of time—is an increasingly accepted measure of effectiveness of treatment in cancer and has become a very important measurement issue in macro-level analyses. These studies typically examine trends in 5-year survival increments—the time period traditionally associated with cure. The NCI uses the SEER registries to project national survival rates by tumor site. In 1999, the United States had almost 9 million individuals with a history of cancer who were still alive. For cancers diagnosed between 1975 and 1993 and followed through 1999, the 5-year relative survival rate for all cancers combined was 62% and has been rising overall. Among the four most common disease sites, the highest 5-year relative survival rates are for prostate and breast cancers, and the lowest rates are for lung cancer (21).

The EUROCARE project analyzed 5-year cancer survival data from 45 population-based cancer registries in 12 European countries between 1978 and 1985, and for 17 European countries between 1985 and 1989, for 13 cancer sites (10). The study found consistent increases in survival rates across the cancer sites, with the largest increases for cancers of the testis, large bowel, and breast and the smallest increases for cancers of the lung, brain, and cervix (10). Trends in 5-year cancer survival varied widely, with increases generally highest in Northern Europe, followed by Western Europe, Denmark, the United Kingdom, and the Eastern European Countries of Estonia and Poland (10). EUROCARE investigators also reported that intercountry differences in survival are narrowest for cancers for which highly effective treatments have been identified and are in use; where highly effective treatments have been identified but are not widely used, differences across countries are large (11).

Canada recently released cancer survival rates for patients diagnosed with a primary lung, breast, prostate, or colorectal cancer in 1992. Survival rates varied widely among Canadians, with 5-year relative survival rates ranging from 15% for men diagnosed with lung cancer to more than 85% for men with prostate cancer. These differences are more likely to reflect screening than treatment (24).

Using patient survival as a quality performance measure adds additional complexities in macro-level analyses. First, there are two methods for computing survival rates: the cause-specific survival method and the relative survival method (25,26). Cause-specific survival identifies the time from diagnosis to death from cancer in a general population and censors deaths from causes other than cancer. The rates are usually expressed in terms of cancer deaths per 100,000 population. Cause-specific survival measures often work well for monitoring single-site cancers, especially cancers (e.g., childhood leukemia) for which death from causes other than cancer is rare. Also, cause-specific survival data have been shown to be very useful in tracking racial and ethnic survival rates (27). However, the cause-specific survival
method requires access to death certificates for all deaths, information that is sometimes missing, incomplete, or inaccurate (11).

The relative survival rate can be defined as the ratio of the observed survival rate in a group of cancer patients, during a specified time interval, to the expected survival rate. The expected survival rate is that of a group similar to the cancer-free group in such characteristics as age, sex, and race, but free of cancer. Relative survival rates are calculated by dividing observed survival by expected survival. Relative survival rates are sometimes considered superior to cause-specific survival rates because they express the probability of cancer survival after adjustment for competing causes of death. The approach works well when the expected-life tables are representative of the reference population of cancer patients. When competing causes of death are not independent, for example, lung cancer patients who smoke, comparisons become more difficult (28).

Care must be taken in comparing relative survival rates from different studies. How tables for expected rates are obtained and used and the quality of the mortality data all affect relative survival rates. Furthermore, cross-national studies use different methods for calculating expected survival. These methods have differing sensitivity to assumptions of the independence of the death censor process and proportionality of risks (29). Staging or adjustments for age may also reduce the differences between the two methods.

However they are calculated, interpreting the results of survival rate analyses is further compounded by differences in the effectiveness of screening and detecting cancer across populations. Macro-level studies may indicate an increase in cancer survival over time when the finding is an artifact of the ability to detect cancers earlier through effective screening and diagnosis. This “lead time” bias can also be a problem for cancer incidence measures. For example, Potosky et al. (30) found a dramatic increase from 1989 to 1992 and a marked decrease thereafter in prostate cancer incidence—a finding largely attributed to the rapid introduction of prostate cancer screening with prostate-specific antigen. Similar results were reported in Western Europe and in Italy, when recorded incidence of prostate cancer rose suddenly in the late 1980s and early 1990s; this increase in incidence coincided with the rapid introduction of prostate-specific antigen assay screening (31,32). High-resolution studies that collect standardized information on stage, staging procedures, and treatment help clarify how much survival differences are to the result of differential delay in diagnosis and how much the result of differences in treatment, because these studies permit stage-specific and stage-adjusted survival comparisons corrected for stage migration (i.e., corrected for the fact that staging examinations, practices, and facilities vary). Although a few investigators have used high-resolution studies as nested designs within macro studies of cancer survival (11), these studies are not often used in cross-national population-based research because they are expensive and require direct access to clinical records.

Cancer survival is a very broad indicator of health systems performance because it reflects several aspects of health care, including the quality and accessibility of prevention and diagnostic care, the speed of referral, and the quality of treatment services. It may also be a proxy for other factors not readily measured in the models, such as the degree of understanding of cancer symptoms and what to do about them in different populations, and variations in the staging of disease at diagnosis, the histology and grade of tumors, or other artifacts in the data. Accounting for these factors should be the basis for further inquiry into the interpretation of differences in macro studies of cancer survivorship.

Patient-Reported Outcomes Measures

Cancer incidence, mortality, and survival measures tell us much about the health state of populations, but they are limited in their representation of the burden of cancer disease within specific populations. These measures focus exclusively on the physician or health system’s perspective of cancer treatment because they rely on data sources, such as medical records, that are documented and only reported by clinicians and other health professionals. These measures provide almost no information on health-related quality of life or satisfaction with care as experienced and reported by cancer patients and survivors. Recognizing that cancer and its treatment may result in physical impairments and psychosocial losses, policymakers are increasingly becoming interested in the quality-of-life outcomes as measured through the cancer patient’s and survivor’s points of view (33).

Health-related quality of life. Several measures of health-related quality of life (HRQOL) have been used or developed to measure these outcomes for cancer patients. Most of these measures are based on generic quality-of-life instruments not designed particularly for cancer patients. In general, they can be classified into two types of outcomes measures—preference-based measures that are based on the individual’s numerically recorded or assigned values for health states, and psychometric measures, which provide numerical but non-preference-based assessments of health states (34). Preference-based measures incorporate values or utilities for health outcomes and can be used in cost-effectiveness analysis to aid resource allocation decisions. Preference-based approaches that have been used in cancer studies include the Euro-Qol EQ-5D, the Health Utilities Index, and the Quality-of-Well-Being Scale (35). Psychometric approaches are designed to discriminate among levels of health status and are often used to evaluate the change in health status over time, discriminating between health states among individuals with different diseases or predicting future health outcomes. The Medical Outcomes Survey 36-item short form (SF-36) is an example of a generic psychometric measure that has been applied to cancer (36,37). The Functional Assessment of Cancer Therapy—General is an example of a psychometric measure specifically adapted to cancer (38).

HRQOL measures have not been applied in macro-level studies focusing specifically on cancer in the United States. (To the extent single-attribute quality-of-life measures appear in the macro study literature, it is as part of multi-attribute measures that are discussed in the next section.) Most U.S. applications are at the meso-level, where for the last 20 years, HRQOL measures have become increasingly used in cancer clinical trials (39). The closest application is the Medicare Health Outcomes Survey (MHS), which uses the Medical Outcomes Study Short Form-36 (SF-36) to measure the performance of Medicare-Plus-Choice health plans across the nation in improving outcomes in eight domains: physical functioning, role—physical, bodily pain, general health, vitality, social functioning, role—emotional, and mental health (as measured by the SF-36) (40). The MHS contains several questions that enable the identification of Medicare enrollees who are either cancer survivors (because they have been told by a physician they were diagnosed with cancer in the past) or who are cancer patients under active treatment for the four main tumor sites—prostate, breast, colorectal, and lung.
The MHOS has been collecting data annually since 1998 and has received more than 167,000 completed surveys from the first cohort alone; 22,747 of this cohort (13.6%) identified themselves as cancer survivors. Baker et al. (41) have reported on the baseline results from the 1998 survey that show cancer survivors have lower scores than noncancer patients on all eight subscales that are not explainable simply by age.

**Patient satisfaction/experience with care.** Another outcome measure of increasing interest to policy makers is the responsiveness of the health system to consumers (42). Concepts vary, but the main distinctions are between satisfaction and acceptability on the one hand and patient experience with care on the other. Hurst and Jee-Hughes (7) note several recent or proposed applications of responsiveness indicators in macro-level analyses. For example, the United Kingdom is conducting an annual Survey of Patient and User Experience that first reported on general practice and that is introducing new modules to detail patient experiences in selected areas such as hospital care. The U.K. survey covers, among other items, access and waiting times; physician/patient communication; patient’s views on the knowledge, courtesy, and helpfulness of others and information provided at discharge.

The Picker Institute (now part of the National Research Corporation [NRC]) has conducted patient surveys for many years and asks patients to report on “what happened” to them rather than to rate how satisfied they were (43). NRC surveys measure seven dimensions of patient care, including respect for patients’ preferences, coordination of care, information and education, physical comfort, emotional support, involvement of family and friends, continuity, and transition. These surveys have been used in cross-national comparisons of hospital care in Germany, Sweden, Switzerland, the United Kingdom, and the United States. WHO intends supporting population surveys in a large number of its member states on patient-rated dignity of treatment, patient-rated communication, autonomy and confidentiality, patient-rated promptness of attention, patient-rated quality of basic amenities, patient-related access to support networks during care, and patient-rated choice of care provider (D. Valentinien, personal communication).

In addition, in the United States, the Agency for Healthcare Research and Quality has supported the development of the Consumer Assessment of Health Plans and is in the process of developing similar surveys for hospitals and physician group practices (C. Darby, personal communication) (44). Again, none of these macro-level studies focused on cancer care, but the concepts are potentially very relevant to the evaluation of cancer control and quality of care programs.

Such patient-reported outcomes measures are very important in macro-level studies of cancer because they reflect the entire process of care for conditions of interest. They tend to be of great interest to the public, and when clear links exist between measurable process of care and the outcomes of interest, inferences can be drawn on how to possibly improve cancer outcomes over time. These outcomes measures can serve as the baseline for monitoring and benchmarking the future effect of specific policies to improve cancer control. The types of process measures suitable to inform outcomes measurement in cancer control are discussed in the next section.

**Outcome-Linked Cancer Process Measures**

Process-of-care measures document the specific interventions (prevention, screening, diagnostics, or treatments) that cancer patients receive. Preventive-care indicators are the most commonly used process measures in macro-level studies of cancer control, in large part because of the importance of cancer prevention for the entire adult population and the general availability of survey and other data to easily create performance measures to effectively track some preventive measures, such as screening activities. Among the most commonly used process measures are breast cancer screening (mammography), cervical cancer screening (pap smear), and colorectal cancer screening (fecal occult blood test and sigmoidoscopy). The NCI uses the National Health Interview Survey (NHIS) to track self-report use of these process measures for the United States. According to data from the NHIS, all of these screening measures have increased steadily in the United States since 1987, but colorectal cancer screening rates still remain low among people ages 50 years and over (16). International comparisons have been made between Canadian, European, and U.S. screening practices. Although fully comparable data are difficult to assemble, most Western European countries, especially Nordic countries, achieve a fairly high rate of breast cancer screening (45).

Another complication with these comparisons is that the sources of screening data vary internationally. In contrast to the United States, where cancer screening occurs in many venues, many other countries primarily provide screening in organized programs (46). In a number of those countries, population-level data on use of screening is primarily obtained from medical records provided by these organized programs rather than from self-report survey data (47,48).

Process measures are attractive for population-based studies because when they are linked to evidence-based practice guidelines, they become more closely linked to the endpoint outcomes of interest to policy makers. Because process measures more closely reflect the actual practice of health care as it takes place, they tend to be more actionable than outcomes measures, and thus more suitable for measuring incremental progress in achieving national cancer control objectives. The Breast Cancer Surveillance Consortium, for example, supports a wide-ranging portfolio of research projects that use population-based databases to monitor and evaluate the performance of screening mammography in community practice (49).

However, because processes are usually measured independent of the total context of care, they may not always directly link to population-based health-related outcomes of interest to policymakers. This is especially true if their effect on routine practice is not as strong as in clinical trials. For example, evidence indicates that although breast cancer screening programs are narrowing the disparity in mammography screening between African-American and Caucasian women in the United States, disparities continue to persist in breast cancer mortality rates between the two populations. These results may not necessarily reflect that screening is not working, however (50). Similar results may also occur if the process-outcome linkage was based on evidence from treatment protocols in a delivery site (e.g., large academic medical center) that is atypical for most patients receiving treatment for the specific tumor site. Evidence-based process measures should be supplemented with epidemiological studies or health services research methods such as decision analytical modeling to provide insights into the process-outcome relationship in population-based studies.

A limitation in the use of process measures for cross-national comparisons is that the measures are often not standardized and,
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The U.S. Preventive Services Task Force revised their recommendation to lower the age threshold to include women aged 40 years and over; this is the age threshold being recommended for the forthcoming U.S. National Health Quality Report (52). In England, the breast cancer screening measure is for women aged 50–64 years who received screening mammography once during the past 3 years. Women aged 65–69 years are not routinely invited for screening, although there is a national commitment to extend the program to this group by 2004 (53). Canada uses another recommendation more consistent with the earlier U.S. Preventive Services Task Force guideline and that of most European countries, measuring women age 50–69 years who received mammography screening in the past 2 years (54). Thus, care must be taken to account for the inclusion and exclusion criteria for calculating the measure, and adjustments must be made when possible to account for these differences.

Clinical endpoint measures, HRQOL measures, patient-experience measures and process-of-care measures tell us a considerable amount about the health state of populations, but they are limited in their representation of the burden of cancer disease within specific populations. In particular, they do not define the relationship between quality of life and increased survival. Next, measures are reviewed that have the potential to address this concern because of their ability to adjust cancer survival for its quality.

Health-adjusted life years measures. Public health authorities, whether at the national or state level, are responsible for improving the mortality and morbidity of the populations they serve. Thus, developing global health measures that incorporate attributes of mortality and morbidity has been of interest for some time. As a class of population-based measures, they are often referred to as health-adjusted life years (HALYs) and are composed of two sets of partial measures. A complete description of this class of measures can be found in Gold, Stevens, and Fryback’s 2002 article, published in the Annual Review of Public Health (55). The first set, exemplified by the age-specific death rates, accounts for the mortality or life-expectancy component. The second set of measures, the age-specific rates of population morbidity, disability, or HQOL, accounts for the morbidity or quality-of-life component. These two sets of measures are then combined in a mathematical formula that transforms them into a single composite measure using life table methodology. Other summary measures that have been used in population-based research are the Health Adjusted Life Expectancy (HALE) and the Disability Adjusted Life Expectancy (DALE). WHO, in the Global Burden of Disease Study, used these measures. Although these measures are useful summary measures for years lived with disability, years of life lost, and their sum, quality-adjusted life years (QALYs), disability-adjusted life years (DALYs) are preferable summary measures when measuring disease-specific burden of disease such as cancer (56).

Table 1 also summarizes the variety of HALY measures that have been developed to evaluate the HRQOL experienced by populations with diagnoses of cancer. These measures include QALYs, DALYs, healthy life expectancy (HLE), years of healthy life (YHL), and years lived with disability (YLD). Each measure reflects a breadth of concepts and indicators related to HRQOL, and each measure addresses some of these elements and not others. For example, some measures use self-perceived health (e.g., YHL) and some do not (e.g., DALY). Some measures place greater weight on symptoms and abilities than others. Also, within QALYs, which is really a class of different measures, the Quality-of-Well-Being Scale places considerable weight on symptoms or problems, whereas the Health Utilities Index and the EQ-5D emphasize degree of functioning as a key indicator of health. DALYs and the YLD do not directly measure these attributes. These measures also differ in the source of data. QALYs, however measured, derive their data directly from primary self-report survey data. The YHL is based on secondary analysis of data from the U.S. National Health Interview Survey. The disability classification for computing DALYs relies on secondary data analysis, based on an expert panel classification of disease and disability to infer prevalence and degree of limitation in different populations.

HALY measures as a family can be reduced to two separate classes of measures. QALYs adjust expected years of remaining life for an individual to reflect the predicted health-related quality of that life. QALY measures accomplish this by asking individuals to assign weights to a set of mutually exclusive and exhaustive states of health. The weights are not linked to any particular disease, condition, or disability. The QALY is scaled from 0 to 1, where higher numbers mean better health states. Health status measures that have been used to create QALYs include the Quality of Well-Being Scale, the Health Utilities Index, The EuroQol EQ-5D, and the Health and Activity Limitation Index (55).

By implication, all HALY measures require some method to assign values to time spent in health states worse than ideal health. They can be assigned as dichotomous valuations (i.e., up to some threshold the valuation is 0, or equivalent to death, and beyond this threshold the value is 1, or equivalent to full health). Alternatively, values can be assigned categorically by a variety of methods (e.g., standard gamble, time trade-off, person trade-off, or visual analog). Because each instrument differs in terms of the health attributes and methods of assignment, they produce a different assessment of the healthiness of the population. The lack of a gold standard of health to benchmark these measures means that comparing the results from different QALY measures is difficult (55).

A variant of the QALY that has been used in macro-level analyses in the United States is the Centers for Disease Control YHL measure (57). YHL, developed at the National Center for Health Statistics to monitor HP 2000 goals, uses information on activity limitation and perceived health as derived from the National Health Interview Survey to identify specific health states. Weights are assigned to these health states and then combined with mortality statistics to produce the YHL measure. NCHS is currently developing a new measure to monitor overall Years of Health Expectancy (YHE) that will be used to monitor HP 2010 goals (58). Neither YHLs nor YHES have been reported by disease category.

The second class of HALYs, DALYs, attaches estimates of HRQOL specifically to diseases or disabilities. The DALY was developed expressly for the purpose of measuring the global...
burden of disease. In contrast to QALYs, DALYs reflect years lost because ill health rather than years lived with ill health. The measure is constructed using either secondary data or expert-derived weights for the value of additional years of life at each age and weights for more than 100 categories of health deficits from different diseases or injuries as defined in the International Classification of Impairments, Disabilities, and Handicaps (59). The DALY disability weights also range from 0 to 1, but the lower end of this scale indicates less disability, so lower numbers indicate better states of health.

DALYs have been used in various macro studies to compare the relative burden of specific diseases for entire nations or groups of nations. The WHO 2000 report noted that cancer presents a high burden on Western industrialized countries, including the United States. According to WHO, for the region that includes the United States (“The Americas”), and for the mortality-stratum assigned the United States, total DALYs for malignant neoplasms for 1999 were estimated at 5,680,000—ranking third behind only neuropsychiatric disorders (9,424,000) and cardiovascular disease (7,273,000) (1). WHO projects that DALYs from cancers are expected to rise from 5.1% to 9.9% of the worldwide total in 2020, with the largest increases in lung cancer, stomach cancer, liver cancer, and, for women in developing nations, breast cancer (60). The Centers for Disease Control is working with investigators at Harvard University to replicate the Global Burden of Disease methodology to produce cross-sectional U.S. estimates of DALYs by disease entity for the year 2000, including 22 cancer tumor sites (M. McKuen, personal communication). This work is still in progress, but the interim estimates from this project indicate that the results will be illuminating. DALY burden of cancer for the four major tumor sites—lung, breast, colorectal, and prostate—varies widely. For example, in 1996, lung cancer, with its short life expectancy, had more than twice the DALY burden of breast or colorectal cancer and more than four times the DALY burden of prostate cancer (61).

An advantage of HALY measures for macro-level analyses is that methods can be used to integrate mortality and morbidity into single summary scores. They also recognize that functional health status is an essential component of overall well-being and that it is important to supplement traditional incidence and mortality measures to illuminate the effect of disability on cancer. Furthermore, because they are often generic measures of disease burden, they facilitate comparisons of the burden of illness across diseases. In fact, this may be among their most powerful applications in macro studies. Gross and colleagues (62) used DALYs as a method of assessing whether the National Institutes of Health funding priorities correlated with the burden of various diseases, and found them reasonably correlated with spending differences. The analysis was somewhat limited in that U.S. DALY weights for incidence and prevalence of disease were unavailable to the authors. Nevertheless, this method presents interesting possibilities for cross-national research on the relationship between resources devoted to specific diseases and their burden on society.

Although applications of QALYs in cost-effectiveness analysis exist for specific cancer treatments and budget analyses of cancer programs relative to other diseases, very little application of this method has been used at the state or national level for resource allocation decisions (63). As described earlier, these measures are often expensive to collect on a population basis and create controversies over technical, ethical, and other issues related to measurement construction, reporting, and interpretation. Some researchers believe the science of these measures is not sufficiently developed to warrant selection of any one measure over all others; other researchers believe the resistance to selecting any measure is inhibiting policy and program development and rational resource allocation (55). However constructed, little guidance exists on how resource allocation decisions based on these data improve global cancer outcomes. In particular, it is unclear what population-based interventions (e.g., health education campaigns, basic or applied research programs, major legislative initiatives) may be deployed to influence QALYs or DALYs within disease categories over time. This is another example in which meso-level studies could complement population-based studies by examining the relationships among structure, process, and outcomes, including HALYs, that facilitate their use in setting national cancer control goals, monitoring progress over time, and informing the public on policy initiatives related to reducing the burden of cancer over time.

**ECONOMIC MEASURES OF CANCER BURDEN AND RESOURCE USE**

Patient- and provider-reported cancer quality measures are only partial measures of cancer burden and performance because they do not measure the resources expended by nations or individuals in producing these outcomes. Nations vary widely on health care spending, and effective monitoring of health systems performance requires information on the comparative costs as well as on the comparative benefits of cancer control and quality-of-care programs. Thus, economic measures play an essential role in macro studies of cancer.

The most common economic measure of cancer care used in macro studies is direct medical costs, reflecting information from national accounts or other data that attributes spending by governments, the private business or insurance sector, and out-of-pocket expenditure by individuals to specific disease categories. There are generally two approaches to derive these estimates. One is a “top-down” approach, working through national account data and using a variety of actuarial or statistical methods to estimate diagnosis-specific expenditures for each health service (e.g., hospital care, physician services). This is often done by weighting the diagnosis-distributed service use by the charge per service and summing the expenditure totals across all diagnosis categories to equal total health expenditures. An example of this approach is the work done by Thomas Hodgson and Allen Cohen of the National Center for Health Statistics, who built disease-specific expenditures based on data from the U.S. National Health Accounts (64). Using this methodology, Hodgson estimated that neoplasms, including all cancers, represented 5% of total personal health care expenditures in 1995, an estimate that has been surprisingly consistent over the last 20 years.

The second approach is a more of a microanalytic strategy (or “bottom-up”) that derives spending estimates from various sources and then projects spending based on economic expenditure models. An example of this approach is the economic modeling done by Brown et al. (65) on the basis of the Medicare-SEER data that enables an estimate of Medicare spending by tumor site. Brown et al. (65) produced incidence- and prevalence-based estimates of cancer-related medical care costs for...
samples of individuals enrolled in Medicare and projected those costs for the Medicare program nationally. Interestingly, they validated their national expenditure estimate with those produced by the health account approach described above and found the rank order of tumor specific expenditures for the entire population similar to Medicare, with the exception of cervical cancer, which had a much higher rank order among national expenditures than among Medicare expenditures (65).

Direct spending is only one facet of the cost of illness that can be measured in macro studies of cancer costs. A full accounting of the economic burden of cancer care also includes the indirect costs of cancer associated with the morbidity- and mortality-related aspects of cancer (66). These are costs of resources for which no payment is made, but that nevertheless have economic value to someone. The most common indirect cost measures are those related to foregone employment or reduced productivity because of illness (e.g., days lost from work, foregone wages), which is of considerable interest to policymakers and is often considered the morbidity cost of illness. Mortality costs are generally estimated by imputing age-specific and gender-specific earnings to the years of life lost attributable to the disease category, including the value of household work for individuals not employed in the formal labor force. These estimates are generally presented in terms of the present value of the accumulated earnings that are foregone because of premature mortality (61).

Table 2 illustrates the importance of indirect costs in measuring and monitoring the economic burden of illness associated with cancer. The National Heart Blood and Lung Institute estimated direct medical spending on neoplasms in 2003 at $64.2 billion in personal health care expenditures, or about 4.5% of total U.S. spending. It is the seventh-ranking disease-specific cause of direct spending on personal health in the United States. When the indirect costs associated with the mortality and morbidity of cancer are factored into the estimate, however, the total economic cost of cancer changes significantly—it was estimated to be $189.5 billion, or 8.9% of the total burden of illness in the United States, making cancer the second most expensive disease in the United States for the disease categories evaluated by National Heart Blood and Lung Institute (67).

The cost of illness is an important measure in macro studies of cancer care because it facilitates policymakers evaluating the comparative costs and comparative benefits of their cancer control and quality-of-care programs. Care must be taken in interpreting these measures, however, because they typically mix prevalence-based indicators such as direct medical costs and morbidity costs with incidence-based mortality costs. Although it is possible to express direct medical costs and morbidity costs in incidence terms, data limitations in cost of illness studies often make this translation very difficult (61).

Cancer expenditures, of course, are of limited value unless they are combined with comparative data on cancer outcomes. The challenge of population-based studies is to develop methods for linking direct and indirect cost data to provider-reported and patient-reported outcomes of care to better assess the efficiency and equity of national cancer control and quality-of-care programs. This may again be an area in which data-driven meso-level analyses can complement macro-level analyses by extrapolating estimates to the national level via statistical modeling.

### DISCUSSION

The growing interest in macro-applications of performance measurement, both nationally and internationally, is placing increasing demands on outcomes measurement science to address issues of interest to policymakers. As described in this article, significant strides have been made over the last decade in the

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**Table 2. Direct and indirect (morbidity and mortality) costs of cancer compared with other major disease categories, United States, 2003***

<table>
<thead>
<tr>
<th>Disease category</th>
<th>Direct costs</th>
<th>Morbidity</th>
<th>Mortality</th>
<th>Total</th>
<th>Direct costs</th>
<th>Morbidity</th>
<th>Mortality</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular disease</td>
<td>209.3</td>
<td>32.4</td>
<td>110.1</td>
<td>351.8</td>
<td>14.7</td>
<td>17</td>
<td>21.3</td>
<td>16.5</td>
</tr>
<tr>
<td>Cancer</td>
<td>64.2</td>
<td>16.3</td>
<td>109</td>
<td>189.5</td>
<td>4.5</td>
<td>8.5</td>
<td>21.1</td>
<td>8.9</td>
</tr>
<tr>
<td>Diseases of the digestive system</td>
<td>146.3</td>
<td>9.8</td>
<td>23</td>
<td>179.1</td>
<td>10.3</td>
<td>5.1</td>
<td>4.4</td>
<td>8.4</td>
</tr>
<tr>
<td>Diseases of the nervous system</td>
<td>117.7</td>
<td>7.4</td>
<td>11.1</td>
<td>136.2</td>
<td>8.2</td>
<td>3.9</td>
<td>2.1</td>
<td>6.4</td>
</tr>
<tr>
<td>Mental disorders</td>
<td>114.8</td>
<td>25.1</td>
<td>7.9</td>
<td>147.8</td>
<td>8</td>
<td>13.2</td>
<td>1.5</td>
<td>6.9</td>
</tr>
<tr>
<td>Diseases of the musculoskeletal system</td>
<td>81.7</td>
<td>19.5</td>
<td>2.6</td>
<td>103.8</td>
<td>5.7</td>
<td>10.2</td>
<td>0.5</td>
<td>4.9</td>
</tr>
<tr>
<td>Lung diseases†</td>
<td>70.2</td>
<td>25</td>
<td>31</td>
<td>126.2</td>
<td>4.9</td>
<td>13.1</td>
<td>6</td>
<td>5.9</td>
</tr>
<tr>
<td>Diseases of the genitourinary system</td>
<td>60.4</td>
<td>5</td>
<td>5.4</td>
<td>70.8</td>
<td>4.2</td>
<td>2.6</td>
<td>1</td>
<td>3.3</td>
</tr>
<tr>
<td>Endocrine, nutritional, and metabolic disease</td>
<td>56.9</td>
<td>6.3</td>
<td>16.9</td>
<td>80.1</td>
<td>4</td>
<td>3.3</td>
<td>3.3</td>
<td>3.8</td>
</tr>
<tr>
<td>Infectious and parasitic diseases</td>
<td>29.1</td>
<td>11.6</td>
<td>27.6</td>
<td>68.3</td>
<td>2</td>
<td>6.1</td>
<td>5.3</td>
<td>3.2</td>
</tr>
<tr>
<td>Diseases of the skin</td>
<td>32.1</td>
<td>1.6</td>
<td>0.5</td>
<td>34.2</td>
<td>2.2</td>
<td>0.8</td>
<td>0.1</td>
<td>1.6</td>
</tr>
<tr>
<td>Other respiratory diseases</td>
<td>40</td>
<td>7.7</td>
<td>2.8</td>
<td>50.5</td>
<td>2.8</td>
<td>4</td>
<td>0.5</td>
<td>2.4</td>
</tr>
<tr>
<td>Other and unallocated to diseases</td>
<td>394.9</td>
<td>22.3</td>
<td>165.9</td>
<td>583.1</td>
<td>27.7</td>
<td>11.7</td>
<td>32.1</td>
<td>27.3</td>
</tr>
</tbody>
</table>

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*Table adapted from the NHLBI FY 2002 Fact Book, Chapter 4, Disease Statistics, page, 64 (www.nhlbi.nih.gov/about/02factbkfa.pdf) with permission.
†Direct costs are personal health expenditures for hospital, nursing home, home health, physician services, and pharmaceuticals, and other professional services.
‡Does not include lung cancer or leukemia. NOTE: Estimates prepared by the National Heart, Blood and Lung Institute, National Institutes of Health.
development of cancer-specific clinical endpoint measures—incidence, mortality, and survival. These measures are increasingly being used to identify and inform national and international assessments of cancer burden and opportunities for quality improvement. Cancer-specific clinical endpoint measures can be expected to improve in the next decade as national and international efforts are made to expand, improve, and standardize registry practices that will increase the harmonization of registry data and measurement around the world (68).

Interest among policymakers in population-based interventions for improving cancer clinical outcomes and in patient-reported aspects of cancer care should increase demand for the development and application of these measures as well.

On the basis of the analyses reported here, gaps in measurement policy exist in five important areas, including the breadth and standardization of outcome-oriented process measures of cancer care, application of HRQOL measures in macro-level cancer studies, the need to develop and test cancer-specific patient satisfaction and experience with care measures in population-based studies, the creation of U.S.-specific weights for multiattribute measures and disease-specific synthetic studies using existing national data sets, and the development of better measures of the indirect costs of cancer. In this section, the challenges in closing these gaps are identified; potential solutions are discussed elsewhere in this monograph (69).

Improved Breadth and Standardization of Outcome-Linked Process Measures

As described earlier, cancer process measures are very valuable in macro studies of cancer care because, when linked to outcomes, they provide the basis for incremental assessment of the success or failure of national or state policy initiatives to improve the quality of care. Two limitations of this class of measures in improving cancer outcomes are the limited focus (clinical preventive services) and the lack of national and international standardization. Expanding outcome-oriented process measures to take advantage of the evidence base in cancer research beyond screening to address other phases of the cancer care process—diagnosis, treatment, rehabilitation, and palliation—would greatly enhance their utility for macro studies of cancer care. They also have the potential to examine aspects of cancer performance that cut across tumor sites, such as coordination and continuity of care. The U.K. national quality report provides an example of this type of application with their “patient/carer experience of NHS healthcare” measure that evaluates the percentage of patients seen within 2 weeks when urgently referred, by the general practitioner, with suspected cancer (70). This measure addresses the responsiveness of the cancer specialty care system to the primary care referral system to improve the likelihood that patients will be evaluated and treated at the earliest possible stage of their disease.

Outcome-linked process measures developed for population-based studies can address the “small sample” problem that has limited their application for plan and provider accountability and quality improvement. Population-based interventions are already being tracked and evaluated nationally in the Medicare program for breast cancer screening (71), and the approach could be extended to other aspects of cancer control and quality of care if the measures and interventions were available.

Once developed and standardized, data development activities will be necessary to make these measures suitable for macro studies of cancer outcomes. Enhancing cancer registries to include the recording of additional process-of-care measures may be one promising method for achieving this result. For example, NCI has linked SEER registry data with Medicare claims data for the purpose of identifying the use of specific treatments (i.e., processes of care) for selected cancers and the influence these treatments have on the outcome of their disease. Studies have been completed for lung cancer, breast cancer, head and neck cancer, ovarian cancer, and colon and rectal cancer (72). Again, as work continues by the North American Association of Central Cancer Registries to expand and increasingly standardize state registries, the ability to perform these analyses at a state level would improve the utility of these measures in macro studies.

Similar work is underway to create more sensitive endpoint measures to improve the interpretation of trends in population-based cancer screening programs. NCI has tracked the incidence of “late-stage” (newly diagnosed) cancers as a marker for the effectiveness of screening programs such as mammography (breast cancer), pap smear (cervical cancer), and sigmoidoscopy and fecal occult blood test (colorectal cancer) in reducing “avoidable” cancers (16). By staging the incidence data, macro-level studies can identify and monitor trends in the rate of newly diagnosed cancers that have high mortality and morbidity, but that should be detected and treated at earlier stages of disease where outcomes are better.

Although these measures are still evolving and the interpretation of these trends cannot be attributed to screening alone, continued efforts to improve the biological meaningfulness of measures that employ information on factors identified with the disease at the time of diagnosis will enhance our understanding of process-outcome relationships in macro-level population-based studies.

Increased Use of Patient-Reported Measures in Population-Based Studies

The Institute of Medicine’s call for a more patient-centered system of care for chronic disease, and international interest in the responsiveness of the health care system to patients’ social, emotional, and physical functioning, speak to the need for greater emphasis on patient-reported measures of cancer outcomes of care. Although these measures are increasingly applied in meso-level studies and in clinical trials, few applications exist in population-based studies of cancer. The Canadian Health Institute has used the Health Utilities Index as a generic outcomes measure of systems performance in Canada and is currently developing a new preference-based measure for national surveillance using the standard gamble model with focus groups throughout the nation (73). The EuroQol EQ-5D has been used in population studies in Europe for some time. However, to the author’s knowledge, none of these measures has been used to track systematically, on a population basis, quality-of-life issues related to cancer patients or survivors.

One approach to jump starting this effort is to rely on existing surveys that collect generic HRQOL data and that permit the identification of cancer patients or survivors. The large sample sizes in these surveys would facilitate tracking HRQOL by tumor site and would facilitate cancer comparisons of HRQOL with other diseases and the general population. As described earlier, the work by Baker et al. (74) to evaluate the utility of the Medicare Health Outcomes Survey to study the HRQOL experienced by cancer patients and survivors is an example of this approach.
These enhanced data sets will also facilitate the investigation of the psychometric properties of HRQOL measures in terms of their validity, reliability, and sensitivity to change for population cohorts. However, improved psychometric measurement is a necessary but not sufficient condition to enhance the utility of these measures for macro studies of cancer quality. As with clinical endpoint measures, there is a need to better establish the links between HRQOL measures and cancer interventions. One of the challenges in this area is that, compared with clinical endpoint measures, generic and disease-specific HRQOL outcomes are more likely to be affected by factors other than the disease, its treatment, or specific clinical interventions. Investigation of more systems-based or patient-centered interventions in population-based cancer studies may inform the intervention-outcome linkage in HRQOL.

Use of Patient-Reported Satisfaction/Experience with Care Measures

Significant work has begun to examine the responsiveness and sensitivity of disease-specific patient experience measures in cancer. For example, the NCI has begun a project to test the feasibility of a Consumer Assessment of Health Plans—like survey for cancer survivors, and the NRC is developing a patient experience-with-care model specifically adapted to cancer treatment. How these measures will be used in population-based research remains to be determined. Many believe that patient satisfaction is an important outcome in its own right, but research that focuses on delineating the causal pathways between intervention science and patient satisfaction and experience with care could potentially enhance the utility of these measures for macro studies.

Creation of U.S.-specific Weights for Synthetic Analyses with Multiattribute Measures

A limitation of single-attribute HRQOL measures is that they do not address the potential tradeoffs between survival and quality of life and the preferences different populations, cultures, and ethnic groups may place on these issues. Mounting these investigations on a disease-specific basis is expensive and often requires both national probability survey samples and information on life expectancy within and across disease categories. This has been a deterrent to the development of U.S. weights for multiattribute measures suitable for macroanalysis of cancer in the United States. Although the Centers for Disease Control is in the process of replicating the DALYs in WHO’s Global Burden of Disease study for the United States, the author is not aware of any other population-based estimates for different types of cancers.

Until the United States elects to create or adapt a multiattribute health outcomes measure for national surveillance, synthetic estimates may be derived from national surveys that can then be used to evaluate disease-specific differences in HALYs on a cross-sectional and longitudinal basis. Precedent for this approach exists where researchers have developed linking algorithms to produce disease-specific estimates for the Health and Activity Limitation Index, Euro-QoL EQ-5D, and the Health Utilities Index based on the National Health Interview Survey and the National Medical Expenditure Survey. Johnson et al. (77) have derived U.S. population weights for the health states described in the EQ-5D health questionnaire and found similar characteristics to visual analog scale valuations reported in European countries. Although the generalizability of their work to the entire U.S. adult population is limited, national preference weights that maximize comparability with European studies as well as preference weights for specific racial and ethnic groups would enhance the policy relevance of these measures for U.S. surveillance.

A limitation of the synthetic approach is the potential inability to explore QALY or DALY differences by tumor site. The NHIS and its cancer supplements, as large as they are, may not provide the sample size to explore these issues in depth. Although pooling across surveys may partially address the small sample size for some tumor sites, a better long-run approach may be to develop state-specific life-table estimates for survival on a tumor-specific basis and to apply the national weights to examine state variation based on state differences in cancer-specific survival.

However constructed, the availability of preference-based multiattribute measures will enable a richer understanding of the relationship between resource allocation, burden of illness, and the tradeoffs between mortality, morbidity, and quality of life than exists today with clinical endpoint measures alone.

Develop Better Indirect Estimates of the Cancer Burden of Illness

A final area is the development of better economic measures of the burden of illness of cancer. Measures of the direct costs of care have been used in macro studies for some time, and the consistency of accounting for direct costs has improved over time. The improvement of registries, both at the state and local level, will only enhance the quality of incidence-based costs underlying these estimates for specific cancer tumor sites. The challenge is to collect better data on private insurance expenditures to complete these estimates, as well as the growing out-of-pocket expenditures for nonprescription complementary and alternative medicines purchased over the counter with the purpose of preventing or treating cancer.

More methodological work and data collection work is needed to improve estimates of indirect costs of care. In particular, because nearly three-fourths of all cancer patients and survivors are age 65 years and over, the emphasis on employment (e.g., foregone wages, retraining, job search) in mortality and morbidity studies misses much of the economic burden of cancer in the elderly that involves caregiver burden on spouse and children. A comprehensive assessment of direct and indirect costs of cancer would be desirable, with periodic updates necessary to establish trends over time. Better estimation and tracking of the total costs of illness will enable U.S. policymakers to begin to explore more policy-relevant studies of economic concepts such as national equity or efficiency in the use of resources to improve cancer outcomes in a manner similar to European macro comparative studies that incorporate economic measures (78).

Conclusions

This article described the use of performance measures to inform macro-level studies of cancer control and quality of care. The growing demand for surveillance capability at the national level, coupled with the desire to set national goals and to publicly report on progress in meeting these goals, will increase the need for better quality and breadth in the measures available for macro studies of cancer. Specifically, there is a need to supple-
ment traditional clinical and provider-reported endpoint measures like incidence, mortality, and survival, with patient-reported outcome measures such as HRQOL and patient satisfaction and experience with care. In addition, there is a need to develop and standardize a broader set of outcome-linked process-of-care measures to monitor and track the incremental progress in improving cancer outcomes. Finally, better measures of the indirect costs of cancer care would improve national estimates of the cost of illness and economic burden associated with cancer. These measures will improve our ability to compare and contrast, both nationally and internationally, the return on the national investment in cancer control and quality-of-care activities designed to reduce the burden of cancer.

**NOTES**

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