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Using health-related quality of life and quality-adjusted life expectancy for effective public health surveillance and prevention

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After major successes in the 20th century—increased life expectancy and decreased infant mortality and infectious disease burden—public health faces new challenges. Chief among

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these is reducing the incidence of chronic diseases like diabetes, heart disease, stroke, and cancer. Although these diseases increase mortality, much of their burden and cost is from reduced current physical and mental health. To fully assess and monitor their lifetime burden, we need to improve their tracking and surveillance to capture their fatal and nonfatal health burden. Doing this effectively and optimally requires using consistent surveillance measures, comparable across health conditions, time, population subgroups, and geographic regions, from local areas to countries.

A widely accepted measure of morbidity burden is health-related quality of life (HRQOL), a “multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life” that affects both physical and mental health [101]. HRQOL measures are used in various settings with different instruments. Many instruments are disease-specific, but others are generic (e.g., Healthy Days [102], PROMIS [103]). The latter are more suitable for public health surveillance because of their breadth and facilitation of comparisons across conditions. Some HRQOL instruments are “preference-weighted,” or scaled to reflect a ranking of different health outcomes from population surveys [1]. Such “health-preference measures” may also be shorter than other kinds of HRQOL instruments. Scaled responses from these measures can be collapsed into a summary index, the health-state utility [2].

To more fully capture chronic disease burden, we can combine the morbidity burden from a health-preference measures and mortality data to form a single, summary measure of population health [3]. Early U.S. efforts used the “health-adjusted life expectancy” (HALE) [4], which was not preference-weighted. Since then, combining mortality and health-state utilities into quality-adjusted life years (QALYs) allows for comparing alternative clinical health interventions over a pre-determined time interval. To compare burden of disease or alternative public health interventions, we also need to consider age and the entire expected lifespan. Quality-adjusted life expectancy (QALE) does this when health-state utilities are combined with estimates of life expectancy from vital statistics data.

All four of these measures—HRQOL, health-preference measures (and health-state utilities), QALYs, and QALE—can be used to compare burden across diseases, interventions, or populations. We will now focus on the value of QALE in public health. QALE estimates have shown the impact of chronic diseases and risk factors for several diseases, including arthritis [5], obesity [6], diabetes in adolescents and young adults [7], and tobacco [8, 9, 10]. Questions about major chronic conditions and health-preference measures (or “mappable” HRQOL measures as discussed next) on many national health surveys facilitate such studies. For instance, Jia et al. [10] recently compared QALE estimates across several different chronic diseases using the Behavioral Risk Factor Surveillance System (BRFSS). The number of chronic diseases and risk factors affecting QALE is almost limitless. However, before we implement, compare, and use QALE in public health surveillance and chronic disease monitoring, we need to address a few key questions.

First, given the many different health-preference measures and valuation methods to convert these into health-state utilities, does recommending a single measure for estimating QALE have significant advantages? Probably not. The various methods and measures generally

give the same average results but may differ in individuals. The few generic health-preference measures already available in U.S. populations include the Health Utilities Index, the EuroQol EQ-5D, and the Quality of Well-Being scale [9]. Others have compared these measures in broader populations (e.g., [2]). Current valuation studies with newer HRQOL disease burden measures such as those by the NIH PROMIS network will expand the number of these measures. Additionally, “mapping” indirectly measures health state utilities by linking health-preference measures and HRQOL measures to facilitate use of existing data (such as the BRFSS). Mapping thus greatly expands the set of instruments and data sources used to estimate QALE for monitoring health status. For example, the Centers for Disease Control and Prevention’s (CDC) Healthy Days measures, collected on the BRFSS since 1993 and the National Health and Nutrition Examination Survey (NHANES) since 2000, have been mapped to the EQ-5D [11]. Selected PROMIS® items have been mapped to the EQ-5D [12], and the SF-36 has also been mapped to the EQ-5D and included on several national surveys including the annual surveys by the Centers for Medicare and Medicaid Services, the Medicare Health Outcomes Survey.

There will never be a single answer to the question of “which instrument should we use” because different analysts and agencies will likely have their own reasons for selecting different instruments and find differences in results [2]. Rather, the important point is promoting the consistent application of good methods, the collection of data from large samples, and the tracking and reporting of QALE as much as possible. Consistent, broad-based measurement will allow us to construct benchmarks for different health conditions, to identify shifts in burden over time, and to monitor progress in public health. This leads us to two more key questions.

Second, why should we use QALE in public health surveillance? These measures have important applications for public health surveillance and for targeting diseases in need of public health attention. QALEs can be used as a routine health measure for tracking population health (e.g., [13]), estimating lifetime health losses for those with a chronic condition compared to those without the condition—the individual health loss [10]—and facilitate comparing the burden of disease for the target populations, such as across geographic locations, states, and local areas [14], monitoring trends, and measuring health disparities among populations. Highlighting areas of higher and lower burden may also help guide public health prevention activities. In contrast, measuring mortality alone would miss much of the chronic disease burden. For example, cataract disease, depression, and osteoarthritis are three major causes that limit roles in the elderly, and measures of mortality would completely overlook their importance. Measuring incidence alone also does not facilitate straightforward comparisons of the impact of different conditions.

Given the shift in public health toward preventing chronic disease, several U.S. groups have endorsed measuring burden by combining HRQOL and mortality. In 1990, when the U.S. Department of Health and Human Services (HHS) set the objectives for *Healthy People 2000*, the first overall goal was “to increase the span of healthy life” for the nation; ten years later goal one for *Healthy People 2010* was to “increase the quality and years of healthy life.” Both are essentially targets for QALE. Today, health-related quality of life and well-being continue to be listed among four overall goals for *Healthy People 2020* indicators

[104]. However, despite the interest in QALE as a national goal, we still do not have a national metric to track progress toward these objectives.

Lastly, how can we move ahead? The Institute of Medicine (IOM) specifically endorsed the collection and monitoring of HRQOL in *Healthy People 2020* and also suggested tracking HALE, which, as noted above, is closely related to QALE [105]. Numerous committees of the national academies have called for a meaningful summary measure like QALE (e.g., [15, 3]). In 1996, a U.S. Public Health Service-appointed expert group, the Panel on Cost Effectiveness in Health and Medicine, recommended the routine use of QALYs for making medical decisions [1]. Within a specific health priority area, specialized metrics or leading indicators [105] will always have a place. The advantage of using HRQOL and QALE is their concise ability to provide a straightforward measure of the chronic disease burden over time for surveillance, comparison, and public health improvements. Unlike alternative measures of chronic disease burden such as health care expenditures or financial costs, HRQOL includes health preferences (through the health-state utility) and captures aspects of the burden of morbidity people find most significant. This bridges the gap between abstract statistics and the impact of chronic disease burden on individual lives.

To best serve public health, we emphasize the need for expanded measurements of “preference weights,” the data required to scale health outcomes into health-state utilities. Currently, only a handful of weights exist for the U.S. population, and this affects all outputs based on these weights, whether they are QALE, QALY, or something else. We may also better address the interest in QALE as a national goal by considering the expanded use of open source measures, such as CDC’s Healthy Days, PROMIS, and a few others. These public domain measures may also be appealing to researchers for clinical studies.

Our continuing need for common national metrics for both population health surveillance and clinical intervention assessments suggests the need for a range of summary measures of population health. The application and use of these population summary measures has previously been encouraged by multiple committees of the national academies and by many other groups. The time has come to address the critical need for national health indicators so that we may better improve public health.

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