

Healthy People 2020
Foundation Health Measure Report
Health-Related Quality of Life and Well-Being

Introduction

Life expectancy and causes of death have traditionally been used as key indicators of population health. While these indicators provide critical information about the health status of populations, they do not offer any information about the quality of the physical, mental, and social domains of life. Increasing life expectancy has also highlighted the need for other measures of health, especially those that capture the quality of the years lived. In 1995, the WHO recognized the importance of evaluating and improving people's quality of life.¹

When quality of life is considered in the context of health and disease, it is commonly referred to as health-related quality of life (HRQoL) to differentiate it from other aspects of quality of life. Since health is a multidimensional concept, HRQoL is also multidimensional and incorporates domains related to physical, mental and emotional, and social functioning.² HRQoL goes beyond the direct measures of health and focuses on the quality-of-life consequences of health status. Another related concept to HRQoL is well-being. Measures of well-being typically assess the positive aspects of a person's life such as positive emotions and life satisfaction.

Clinicians and public health officials have used HRQoL and well-being to measure the effects of chronic illness, treatments, and short- and long-term disabilities. In addition, institutes in the National Institutes of Health (NIH) – such as the National Cancer Institute (NCI) – and centers within the Centers for Disease Control and Prevention (CDC) – such as the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) – have included the evaluation and improvement of HRQoL and well-being as a public health priority.

While there are several existing measures of HRQoL and well-being, methodological development in this area is still ongoing. *Healthy People 2020* will evaluate the following measures for monitoring HRQoL and well-being in the United States:

- Patient-Reported Outcomes Measurement Information System (PROMIS) Measure of Global Health
- Well-Being Measures
- Participation Measures

NIH PROMIS Measures

The Patient Reported Outcomes Measurement Information System (PROMIS) global health measure assesses global physical, mental, and social HRQoL. This 10-question measure was developed through PROMIS, a NIH Roadmap initiative designed to develop an electronic system to collect self-reported HRQoL data from diverse populations with a variety of chronic diseases and demographic characteristics.³ The PROMIS global measure includes questions that assess

self-rated health, physical HRQoL, mental HRQoL, and individual questions on fatigue, pain, emotional distress, social activities, and roles.

The PROMIS measure includes HRQoL questions that have undergone qualitative and quantitative testing in several chronic disease populations and in the general U.S. population. Content experts, as well as patients who participated in cognitive interviewing, reviewed the questions.⁴ Each question was examined for its psychometric properties. These properties included conceptual equivalence across key demographic groups such as age and sex.⁵

A recent psychometric evaluation of the PROMIS global health questions identified two global physical and mental health summary scales and separate scoring for global health, social activities, and roles.⁶ Individual questions or the summary scales can be used to assess physical and mental HRQoL. Social questions are included to evaluate social HRQoL.

The questions also have been calibrated onto a common metric and normed to the general U.S. population. As a result, scores provided by PROMIS are relative to a mean of 50 and standard deviation of 10. This common metric allows researchers to derive precise and valid short forms, yet it maintains the ability to compare or combine data collected on any other set of questions created from the PROMIS banks.

The PROMIS global health measure is scheduled to be administered on the National Health Interview Survey (NHIS) every 5 years (2010, 2015, and 2020). Analysis of both summary scores and individual questions are expected to provide useful outcome information. The results are expected to be reported in 2011, 2016, and 2021.

Well-Being Measures

While many HRQoL indicators measure when people feel ill or sad or when they are limited in their daily tasks, well-being indicators measure when people feel very healthy and satisfied or content with life. Many traditional HRQoL and social indicators fail to capture these types of positive experiences of people's daily lives – the quality of their relationships, their positive emotions, resilience, and realization of their potential.⁷

Positive evaluations of a person's life can include the presence of positive emotions in daily activities, participation in society, satisfying relationships, and overall life satisfaction. These attributes are commonly referred to as *well-being* and are associated with numerous benefits related to health, work, family, and economics.^{8,9} For example, positive emotions and evaluations of life are associated with decreased risk of disease, illness, and injury; better immune functioning; speedier recovery; and increased longevity.¹⁰⁻¹⁵ People with high levels of well-being are more productive at work and are more likely to contribute to their communities.¹⁶ In addition, more research is supporting the view that positive emotions – which are central components of well-being – are not merely the opposite of negative emotions but rather may be independent dimensions of mental health.¹⁷

Measures of well-being can resonate with the public because they track outcomes such as meaningful work and relationships and happiness. These outcomes are personally meaningful,

are easily understood, and can motivate change.¹⁸ While one or two questions related to well-being have been included on public health surveillance systems in the past, the use of additional and extensively tested measures that are now available can help highlight differences between groups in areas insufficiently examined in the past. Examples of these areas include the presence of positive affect and satisfaction with different life domains, such as a person's neighborhood or educational opportunities. Examining these areas can help identify particularly vulnerable groups to guide intervention or to evaluate policy outcomes.

Ultimately, well-being is a resource for everyday living and a result of individual and community assets which contribute to one's overall HRQoL. Societies and policy makers need different types of indicators related to both low and high functioning because each type of indicator offers complementary information for understanding population HRQoL and well-being and for suggesting areas of improvement.¹⁹⁻²¹

CDC has carried out a well-being pilot study using previously validated well-being questions and collaborated with the NIH Toolbox initiative to examine these data. Based on this pilot study, CDC and interested states have selected a smaller set of well-being questions to be tested on the 2010 Behavioral Risk Factor Surveillance System (BRFSS). Once the 2010 BRFSS pilot study is completed and analyses have been conducted, CDC, in consultation with states and other partners, will recommend questions to be added to the annual BRFSS survey so that well-being can be monitored in all states.

Participation Measures

HRQOL is also reflected in individuals' assessments of the impact of their health on their social participation within their current environment. Social participation is meant to include education, employment, and civic, social and leisure activities. Based on this approach, the measurement of *participation* is an important addition to the assessment of quality of life. Participation is measured in the context of a person's current health state and within his or her current social and physical environments.

By operationalizing HRQoL through participation, quality of life is no longer directly equated with health or functional status. Instead, it is based on people's ability to participate in society, which is a consequence of their health or functional status and their environment. Therefore, the proposed participation measure does not directly assess either functional status or the environment; but measures the outcome of people's functioning within an environment in terms of their participation in society.

Underlying this participation measure is the principle that a person with a functional limitation – for example, vision loss, mobility difficulty, or intellectual disability – can live a long and productive life and enjoy a good quality of life.^{22,23} Poorer functional status, or more generally poorer health, should not be equated with poorer quality of life. Quality of life encompasses more than activities of daily living, health status, disease categories, or functional ability “because it directs attention to the more complete social, psychological and spiritual being.”²² In other words, quality of life does not reflect people's physical, mental, or emotional functioning or disease status, but instead expresses their ability to participate in the world around them,

which is defined here as an ability to participate in activities that are common to most people in a society.

This approach is supported in a model proposed by Schwartz and colleagues.²⁴ This model defines health state and the social and physical environment as causal or background factors that impact HRQoL. Social participation and a sense of well-being are effects or outcome indicators that, in turn, reflect or define HRQoL. Social participation can be accessed through determination of the degree to which people experience barriers to full participation because of their current health state and the environment. An accommodating environment can include available aids, assistive devices or technologies, the assistance of others, an accessible physical environment, and laws and regulations that support inclusion and the equalization of opportunities. Thus, this formulation of HRQoL provides a way to assess the success of clinical, rehabilitative, and public health programs and policies for improving quality of life.

Questions to measure HRQoL through participation in society are being developed, tested and added to the NHIS in 2010.

Related Links

[The National Cancer Institute's Health-Related Quality of Life Assessment & Application Patient-Reported Outcomes Measurement Information System \(PROMIS\)](#)
[The NIH Toolbox Initiative](#)

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