

Table 4. Patient Health Outcomes from the Framework for Outcomes in Clinical communication Services (FOCUS)

Patient Health Outcome Categories^a	Description (examples of relationship to patient changes)	Example Measures^b
Survival [1–3] (i.e., reduced mortality)	Longer life as the result of diagnosing and managing a condition or risk factor. (Improving timely access to appropriate care can lead to increased survival. Quality health decisions and adherence or self-care can also improve survival.)	Overall survival; disease-free survival; net cancer-specific survival [4] Survival has been proven to increase if patients with Lynch syndrome adhere to cancer screening/surveillance recommendations. [5]
Symptoms and suffering [1–3] (i.e., reduced morbidity)	Reduction or prevention of disease-related symptoms or side effects of treatment (i.e., reduction in fatigue, pain, sleep disturbance, etc). (Eliciting information from the patient about side-effects may lead to a change in treatment and decrease in suffering. Discussing pain is critical to ensure appropriate medication is provided to reduce the pain. Sleep can be impacted by negative emotions related to a health risk, side effects of medication, or pain.)	Proportion of patients who report a reduction in physical suffering (scale measures how often symptoms were experienced and how much they bothered the patient) [6] Proportion of patients who report a decrease in side effects of treatment. ^c PROMIS measures: Proportion of patients who report improvements in pain intensity or interference ; or sleep disturbance, sleep-related impairment. [7, 8]
Physical functioning [9] (includes physical aspects of Health Related Quality of Life (HRQoL) measures)	Ability to carry out activities that require physical actions (i.e., mobility levels, energy/vitality levels, self-care skills, sexual activity, exercise, work or school) (Access to appropriate care, reductions in negative emotions, and increases in positive coping can improve physical functioning.)	Loss of function sub-scale of the SOS-V [10] ^c PROMIS measures: Physical function [11] SF-36: Physical function, limitations to physical health, vitality subscales Validating the SF-36 health survey questionnaire [12] Global Assessment of Functioning (clinician rated) [13] ^c PROMIS measure: Sexual function [14] Days missed from work or school within a certain time period

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<p>Social functioning [9] (includes social health aspects of HRQoL measures)</p>	<p>Overall participation in social activities that a patient desires. Provision and receipt of support from family friends, and others. (Reductions in negative emotions, positive coping and feeling empowered to access support resources can improve social functioning.)</p>	<p>Social functioning from the SF-36 Validating the SF-36 health survey questionnaire [12] ° PROMIS measures: Ability to participate in social roles/activities, social support, social isolation [16–18]</p>
<p>Cognitive functioning [1]–[3], [18]</p>	<p>Ability to concentrate and perform cognitive tasks that are desired by a patient. These include executing activities such as: logical speech, mental calculations, reading, learning, and work requiring cognitive functions. (An accurate diagnosis can reduce time spent worrying, thereby improving ability to concentrate on other tasks.)</p>	<p>Functional capacity in mental health [19]</p>
<p>Existential well-being [1–3, 5, 6]</p>	<p>Overall sense of purpose, hope, completeness, contentment, and satisfaction with life. (People who demonstrate positive coping behaviors and find a sense of purpose to their health situation may have improved overall well-being.)</p>	<p>Measure of “existential distress” which is the reverse of existential well-being [22] ° PROMIS measures for children: life satisfaction, meaning and purpose in life [23]</p>
<p>Mental Health [9] (includes mental health aspects of HRQoL measures)</p>	<p>Absence of psychological problems including anxiety and depression. (Having a diagnosis can reduce depression and anxiety even if there is no treatment because a diagnosis can help people cope, adapt, and access support resources.)</p>	<p>PROMIS measures: Anxiety and depression scales ° [24, 25] Overview of Measures of Anxiety [26] State Trait Anxiety Inventory (STAI) [27] Hospital anxiety and depression scale (HADS) [28] Center for Epidemiological studies depression scale (CES-D) [29]</p>

- a. Patient Health Outcomes include changes in health and well-being that occur as a direct or indirect result of receiving health services.
- b. Measures are often patient reported, but can be performance-based measures, caregiver/proxy reported or direct observation.
- c. Patient reported outcomes measurement information system (PROMIS) has many assessment measures that reflect patient-reported health. These are calibrated item banks or scales, item pools or short forms http://www.nihpromis.org/Documents/InstrumentsAvailable_11516_508.pdf

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