

# Patient Reported Outcomes as Indicators of Pediatric Health Care Quality

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## ABSTRACT

Health care reform has increased demand for pediatric health care quality evaluations, particularly those that assess the impact of care on patient and population health outcomes. Many of today's most common childhood conditions are characterized by symptoms, behaviors, and functional limitations that are best assessed as patient reported outcomes (PROs). Although they remain greatly underutilized, PROs have the potential to improve pediatric health care quality assessment at the point of care and through system-level performance evaluations. The functions, benefits, and challenges of these PRO applications are described and illustrated in case examples. Although challenges remain, numerous methodological and technical innovations facilitate the use of PROs as health care quality metrics. These include advances in PRO measure devel-

opment methodologies, the integration of PRO measures into electronic health records, and developing consensus among providers that PROs provide valuable information that can be used to enhance patient care. Although additional work is needed to address remaining methodological challenges, pediatric PROs are increasingly recognized as valuable indicators of health care quality in the clinical environment and as measures of organization- and provider-level performance.

**KEYWORDS:** health care quality; patient reported outcomes; pediatric

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IN THE CURRENT context of health care reform, there is a critical need to evaluate the degree to which pediatric health services increase the likelihood of desired outcomes for individuals and the population. However, multiple barriers impede the measurement of children's health and health care quality.<sup>1</sup> These include the fragmentation of data sources that provide information about child health status and health care quality, a lack of standardized metrics, and inconsistencies in data collection methods.<sup>1,2</sup>

Recognizing the need to improve pediatric health care quality measurement, the Children's Health Insurance Program Reauthorization Act (CHIPRA) of 2009 mandated specification of an initial core set of quality measures for voluntary use by Medicaid and Children's Health Insurance Program (CHIP) programs, health insurance issuers, managed care entities, and providers.<sup>3</sup> Although CHIPRA required that the core set cover a full array of health care quality domains, the measures primarily focus on chil-

dren's receipt of services (eg, percentage of children who receive preventive dental services or well-child checkups at recommended ages). The core set instruments provide reliable and valid measures of services provided and family experiences of care.<sup>1,4</sup> However, despite long-standing recognition that health care quality evaluations should consider the effects of care on the health status of patients and populations, only 5 of the 24 core measures reflect patient health outcomes.<sup>4</sup>

CHIPRA mandated establishment of the Pediatric Quality Measures Program (PQMP) to expand the portfolio of evidence-based measures available to public and private purchasers of children's health care services, providers, and consumers.<sup>3</sup> In particular, the program is expanding the availability of pediatric outcome metrics that can be used to evaluate health care quality at the state, health plan, and provider levels. Patient outcomes include physiological functions, symptoms, health perceptions, quality of life, health behaviors, and health care experiences.<sup>5</sup>

Many of today's most common childhood conditions (eg, overweight/obesity, developmental delay, attention-deficit/hyperactivity disorder) are best characterized by symptoms, behaviors, and functional limitations. Therefore, relevant and valid pediatric health care quality evaluations should include measures of these outcome types. Because many symptoms, indicators of functioning, and behaviors are experienced by children or observed in their day-to-day lives, their measurement requires direct questioning of the child or an individual who has adequate knowledge of the child's experiences.<sup>6,7</sup> As such, they exemplify patient reported outcomes (PROs). PROs are any report of the status of a patient's health condition, health behavior, or health care experience that comes directly from the patient, without interpretation by a clinician or anyone else.<sup>7,8</sup>

Over the past decade, several initiatives were established to improve PRO measurement and generate easily administered, interpretable, and scientifically robust PRO measures (PROMs).<sup>9</sup> In 2004, the National Institutes of Health (NIH) launched the Patient Reported Outcome Measurement Information System (PROMIS). The cooperative group of research sites and centers that comprise PROMIS developed a unique mixed-methods PROM development process, a growing set of PROMs, and an informatics platform that enables Web-based PROM administration.<sup>9</sup> PROMIS has made substantial contributions to the advancement of PRO science by establishing measurement and psychometric standards for PROMs<sup>10</sup> that expand on previous recommendations for PROM development and utilization.<sup>7,8,11</sup>

To date, PROMIS measures have been developed to assess pediatric global health<sup>12</sup> and 18 physical, mental, and social health outcomes by child and parent report.<sup>13–15</sup> Researchers at a CHIPRA PQMP Center of Excellence (the Children's Hospital of Philadelphia) applied the PROMIS methodology to develop and validate the Pediatric Global Health-7 measure (PGH-7), a 7-item PROM that assesses children's perceptions of their overall health.<sup>12</sup> The same research team is currently working with patients, caregivers, clinicians, the Dental Quality Alliance, and Medicaid leaders to generate child- and parent-report measures of pediatric oral health.

PROMs can be used to evaluate pediatric health care quality in 2 contexts: at the point of care and in health care system performance evaluations. In both cases, PROMs provide information about health and the impact of health care that is unique and complementary to information derived from measures of clinical outcomes and health care processes. As described below, individual- and population-based PRO applications have unique functions, benefits, and practical and analytic challenges.

### ENHANCING HEALTH CARE QUALITY AT THE POINT OF CARE

PRO measurement in clinical practice is increasing, but remains relatively uncommon, especially in pediatric care.<sup>2,5</sup> PRO assessment informs patient-centered care by exposing child and family health concerns and treatment preferences, which often differ from those of clinicians.<sup>16,17</sup>

This information can be used to engage patients and their families in medical decision making and treatment planning.<sup>17</sup> PROs tracked over time reveal changes in child health. When monitored in the context of intervention, PROs can be used to evaluate treatment effectiveness and inform treatment modifications.<sup>16</sup> PRO evaluations in clinical care may enhance patient-provider communication, patient activation, and treatment adherence,<sup>16,18,19</sup> which is particularly important during adolescence when compliance with treatment recommendations often declines. Given these promising trends, additional research is needed to evaluate other ways that PRO measurement impacts pediatric treatment planning and outcomes.<sup>2,16</sup>

Two case examples are presented to illustrate the advantages and challenges of PRO use in clinical care.

#### KLIK ePROFILE: EMMA CHILDREN'S HOSPITAL AND SAINT LUCAS ANDREAS HOSPITAL, AMSTERDAM

KLIK is a Web-based application that supports the use of PROMs in clinical practice (<http://www.hetklike.nl>).<sup>20,21</sup> KLIK utilization procedures were developed on the basis of many years of experience using PROs in diverse clinical contexts.<sup>21,22</sup> Several days before a scheduled appointment, the KLIK Web site generates an automatic e-mail that invites children aged 8 to 18 years or parents of children aged 0 to 7 years to complete electronic PRO (ePRO) measures through a secure Web site. The measures include generic and condition-specific PROMs that assess multiple dimensions of health-related quality of life (HRQoL).

Child or parent responses are used to generate ePROFILE reports, which can be retrieved by the child's health care providers and used during the clinical encounter to identify, monitor, and discuss HRQoL problems.<sup>4,5</sup> On the basis of prior recommendations,<sup>22,23</sup> the ePROFILE report consists of 2 parts: 1) PROM item-level responses that are color-coded such that "always" or "often" a problem are red; PROs that are "sometimes" a problem are orange; and PROs that are "never" or "almost never" a problem are green; and 2) graphs of longitudinally assessed PROM scores relative to healthy population norms. These graphs enable clinicians to inquire about specific HRQoL problems and to monitor the improvement or worsening of these outcomes over time.<sup>21</sup>

A multicenter control group study involving 176 children with juvenile idiopathic arthritis provides preliminary evidence of KLIK's impact on pediatric care. Although all participating child-parent dyads completed HRQoL measures using KLIK, only those in the intervention group (n = 109 dyads) reviewed their ePROFILE report (PROM scores) with a physician during a routine appointment. This study demonstrated that physician access to the ePROFILE led to more frequent discussions about children's emotional health and social functioning and greater physician satisfaction with the care they provided, particularly their capacity to provide emotional support.<sup>20</sup> Given its positive impact, the KLIK/ePROFILE is now implemented in routine clinical care throughout Emma Children's Hospital and Sint Lucas Andreas Hospital.<sup>20</sup>

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