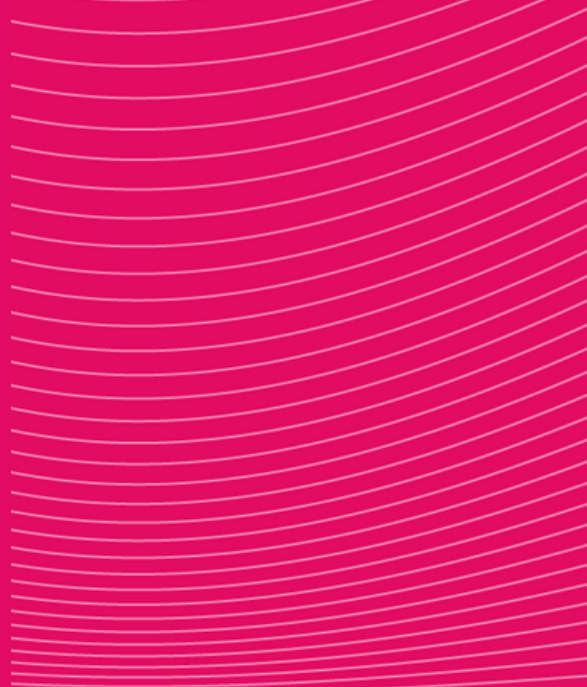


Family Experiences of Health & Health Care



Measurement Guide



The importance of family experience in health care settings

Families of young children often face challenges in health care settings—from barriers to access, to unsatisfactory experiences, to communication barriers (Wolters Kluwer, 2022). Yet family experiences with health care are not always captured. This information is crucial not only to inform health care practices and providers to better understand how to serve their communities, but also for policymakers making decisions impacting health care costs, and researchers looking to understand families' perspectives.

Numerous assessments exist to capture the priorities, challenges, and experiences of families navigating healthcare, advocacy, and daily life related to health. In this guide we provide a non-exhaustive sample of these assessments, including information on how they were developed with or without the input of families and clinicians. Visit the [IMPACT Measures Tool®](#) to find and compare these and other assessments that suit your specific measurement needs.



Family Experiences of Health & Health Care

Assessments of Family Experiences of Health & Health Care

	How were items initially developed?			Were interviews conducted?		What other input was sought?	
	Literature Review	Similar Measures	Community Input	Cognitive	Other	Focus Group	Advisory Panel
Barriers to Care Questionnaire (BCQ)	X		X	X		X	
Behavioral Information Preferences Scale (BIPS)	X	X	X	X			X
CAHPS® Child Hospital Survey (Child HCAHPS)	X	X	X	X		X	X
Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD®) Questionnaire		X	X				X
Family-Centered Care Assessment Tool (FCCA)	X		X		X	X	X
Family Management Measure (FaMM)	X		X	X	X		X
Parents' Perceptions of Primary Care (P3C)	X		X	X	X	X	
Pediatric Quality of Life Inventory (PedsQL)	X	X	X		X		X
Pediatric Transition Experience Measure (P-TEM)			X	X	X		X
PediHome	X	X	X	X	X		X

Information was drawn and interpreted from original validation articles and related materials.

Assessments of Family Experiences of Health & Health Care

Barriers to Care Questionnaire (BCQ):

Since the measure captures parents' barriers to care for children with special health care needs, developers sought input from parents of children with chronic health conditions. Six San Diego-based focus groups spanned two hours each and including English and Spanish options. Existing literature plus qualitative content analysis of focus group barriers yielded 320 items, which were categorized by the authors into 27 categories. A 39-item draft was tested through nine formal cognitive interviews, resulting in minor changes based on feedback from participants.

Behavioral Information Preferences Scale (BIPS):

Initial items drew from measures on child behavior and relevant literature and interventions. Eight pediatric psychologists reviewed initial items to propose suggestions for groupings and additional items. A panel of two pediatricians, one primary care psychologist, one parent of young children, and one parent advocate guided the measure's development. Cognitive interviews were completed with nine parents, which resulted in minor wording adjustments.

CAHPS® Child Hospital Survey (Child HCAHPS):

Background for initial items involved a systematic literature search reviewing over 1,500 abstracts and articles and exploration of similar surveys, including Adult HCAHPS. The authors interviewed experts on quality measurement, pediatric care, and patient experience; consulted CEPQM's National Stakeholder Panel; sought input from groups including Family Voices and the Child Life Council; and received public feedback on the measure in response to a notice in the Federal Register. Eight focus groups with parents of recently hospitalized children and adolescents were conducted in Boston, Los Angeles, and St. Louis. The authors also completed 94 full and 25 partial cognitive interviews in the same locations plus Miami. Focus groups and cognitive interviews were available in English and Spanish. Stakeholder input from expert review, focus groups, cognitive interviews, and more influenced aspects of measure development including suggestions for additional items or domains, wording, usefulness, and prioritization of aspects including age-appropriateness and cultural sensitivity.

Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD®) Questionnaire:

Initial items were drawn from the experiences of parents of children with severe cerebral palsy, healthcare professionals, and similar measures. Caregiver input during a pilot phase was also incorporated. Following validation, the questionnaire was revised based on caregiver feedback and ratings on items' importance, content, wording, and formatting. A survey of 34 health care professionals (developmental pediatricians, pediatric physiatrists, pediatric neurologists, orthopedic and neurosurgeons, physiotherapists, occupational therapists, orthotists, seating specialists, and nurses) resulted in clearer examples within the instructions, formatting changes, wording revisions, and the addition of descriptive rating labels.

Family-Centered Care Assessment Tool (FCCA):

A panel of 22 family leaders, pediatric practitioners, and academic pediatricians provided guidance through meetings led by Family Voices, the American Academy of Pediatrics, and the Maternal and Child Health Bureau. Initial survey drafts were drafted through in-person meetings, interviews, and conference calls, then reviewed by pediatric providers, policymakers, and researchers. Families and pediatricians in Pennsylvania and Massachusetts provided feedback on the tool's purpose and length. Focus groups with 36 parents of children with emotional/behavioral, developmental, or chronic illness diagnoses took place in New Jersey, New Mexico, and California. Participants had children under 3 years (3), 3-14 years (24), 14-21 years (7), or not specified (2); had public (18) or private (18) insurance; and race/ethnicity was reported as non-Hispanic white (14) or Hispanic and/or non-white (22). Focus group participants shared their thoughts on confusing or unanswerable items, resulting in a revised and shortened survey.

Family Management Measure (FaMM):

The authors created initial survey items based on the Family Management Style Framework, which was developed from literature reviews and parent interviews. Twelve nursing research and practice experts provided feedback on item clarity and relevance. Cognitive interviews were conducted with 27 parents (22 mothers, 5 fathers) of youth (13 boys, 12 girls) ages 3-20 with chronic conditions including type 1 diabetes, epilepsy, hemophilia, asthma, and Marfan's disease. Cognitive interview participants represented various family structures and marital statuses (22 partnered, 4 divorced or separated, 1 unknown), demographic characteristics including socioeconomic status, and type and severity of chronic conditions. Feedback on item clarity, wording, and tone resulted in the deletion or revision of some items.

Parents' Perceptions of Primary Care (P3C):

Initial items were generated from existing literature, parent interviews, and author input. Focus interviews were conducted with 36 parents in groups of three, eliciting feedback on relevance, redundancy, and additional items or domains. Cognitive interviews with 15 parents in elementary school and preschool settings led to the deletion or revision of some items.

Pediatric Quality of Life Inventory (PedsQL):

The measure was based on the Pediatric Cancer Quality of Life Inventory (PCQL). In a first phase, initial items stemmed from literature searches, interviews with patients and families, and conversations with pediatric healthcare workers including specialists, nurses, and psychosocial staff. In a second phase, other patients, families, and healthcare professionals provided feedback, resulting in additions, deletions, and modifications. Both phases were repeated over multiple years for a total of six versions. Pilot participants rated items on clarity and ease.

Pediatric Transition Experience Measure (P-TEM):

The P-TEM incorporated qualitative findings from a previous study and conducted in-person and telephone cognitive interviews with 18 caregivers of children who had been recently hospitalized. Parent demographics included gender (79% mothers), education level (61% college-educated), and age (67% under age 35). Four health care providers (two pediatric hospitalists, one general pediatrician, and one adolescent medicine physician) reviewed the 46 items and provided scores from zero to five and feedback based on face validity, significance, and understandability.

PediHome:

A review of literature, home healthcare (HHC) guidelines, and HHC surveys yielded initial items to capture the family perspective on HHC quality for children with medical complexity (CMC). Forty semistructured interviews were conducted — twenty with caregivers and twenty with providers. Caregiver, patient, or provider demographics included age, gender, race/ethnicity, education level, relationship to patient, marital status, employment outside of home, household size, family home location, insurance coverage, primary diagnosis, medical technology, current private duty nursing or personal care services, hospitalizations, emergency department visits, school enrollment, current job duration, job title, and practice setting. A panel of nineteen experts (four CMC family caregivers, one nursing researcher, five pediatricians, two state-based Title V or Medicaid official, two HHC agency physician medical directors, two HHC agency nursing supervisors, and three HHC agency administrators) reviewed content across four total sessions. Additional feedback from one pediatric rehabilitation and physical medicine physician with expertise in CMC, one clinical nurse with expertise in CMC, and one survey methodologist was sought. Family caregivers (twelve English-speaking and four Spanish-speaking) of CMC under age 21 participated in cognitive interviews, providing feedback on content, appropriateness, relevance, and flow.

Family Experiences of Health & Health Care

Definitions

Literature Review: Did the article specify conducting a literature review during the generation of initial items?

Exploration of Similar Measures: Did the article specify reviewing other measures during the generation of initial items?

Community Input: Did the article specify input from community stakeholders (e.g., parents, clinicians) during the generation of initial items?

Cognitive Interviews: Did the article specify conducting cognitive interviews at any point during the measure development process?

Other Interviews: Did the article specify conducting non-cognitive or unspecified types of interviews at any point during the measure development process?

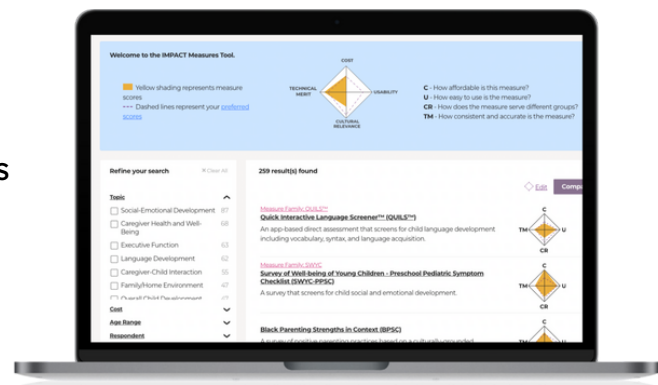
Focus Groups: Did the article specify conducting focus groups at any point during the measure development process?

Advisory Panel: Did the article specify involvement of a group of external experts to provide guidance on the development of the measure? (E.g., formal advisory panels or groups, discussions or ratings from stakeholders)

Interested in exploring other measurement options?

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