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■ Technical Brief

STAKEHOLDER FEEDBACK ON PEDIATRIC EXPERIENCE OF CARE FRAMEWORK

BACKGROUND

Globally, there is increasing recognition of the importance of improving quality of care (QoC) in order to achieve the Sustainable Development Goals for child health.¹ There is also growing recognition that in addition to coverage of care, “experience of care” and “provision of care” are now identified as important dimensions of QoC, according to the standards for quality of child and young adolescent care released by the World Health Organization (WHO).² Poor QoC may directly lead to poor health outcomes, but may also discourage future care-seeking, reduce trust in the health care system, and contribute to existing inequities between various subpopulations.

The lack of standardized and validated tools for measuring experience of care, especially for children and adolescents, represents a barrier to identifying programmatic needs, developing and implementing plans to address them, and measuring implementation progress. Efforts to measure experience of care in most low- and middle-income countries (LMIC) have been limited; existing work primarily revolves around women’s labor and delivery experience, focusing on the important aspects of respect and preservation of dignity.

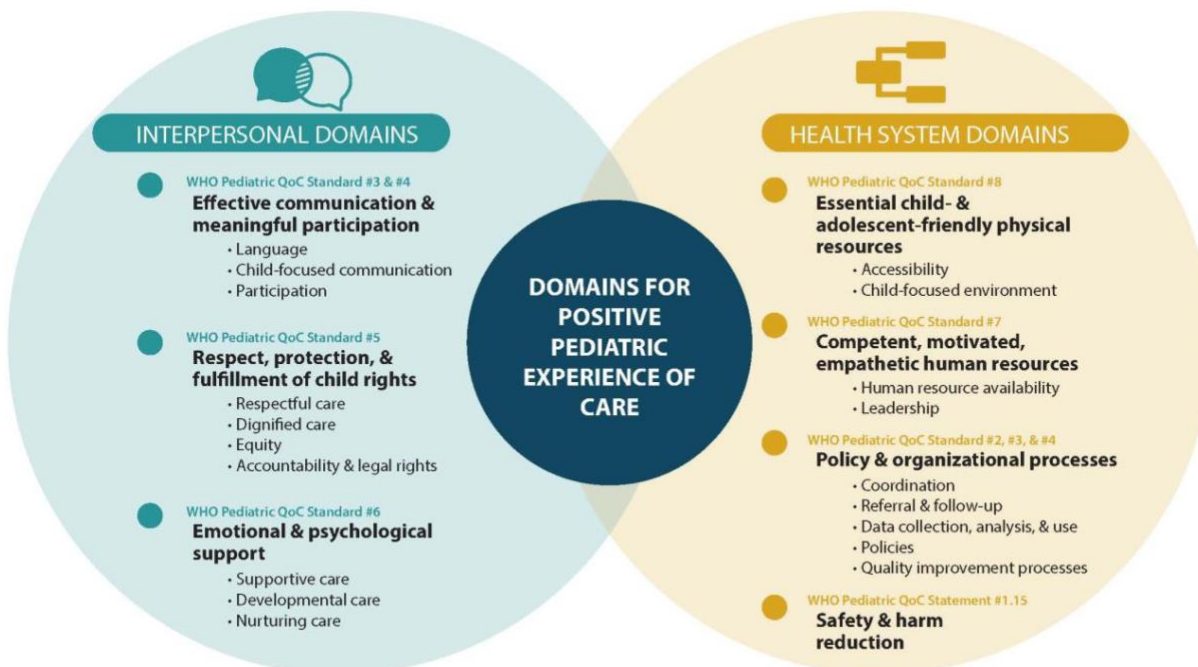
MOMENTUM Knowledge Accelerator undertook a [scoping review](#) in 2021–22 to examine the theoretical underpinnings and approaches for measuring pediatric experience of care in LMIC health facilities.⁵ Findings identified the lack of validated tools that are tailored to children’s ages or adapted to the care received or type of facility. In particular, there are few tools for measuring experience of care for well-child visits as compared to acute or chronic care services and few tools for primary outpatient care versus tertiary care. The review highlighted the need for dedicated tools that can be used for routine assessment of the experience of caregivers for pediatric care, especially for children aged 1-59 months. The use of improved metrics and methods over time will allow researchers and program implementers to design and evaluate interventions; these tools can also help understand the effects of experiences at facilities on care-seeking, future care utilization, and health outcomes, including child development. The scoping review proposed a comprehensive framework with domains and subdomains related to both interpersonal and health systems factors that can be used to guide the measurement of pediatric experience of care (Figure 1). It is a positive, holistic framework for providing optimal pediatric experience of care that also allows for identification of violations and abusive care, in order to eliminate those occurrences.

The concept of **experience of care** can be defined as “...the sum of interactions, shaped by multiple factors, that is experienced by the patients and their families across the continuum of care.”³ This experience includes **interpersonal factors**, such as respectful and dignified interactions with health providers, and **external factors**, such as cleanliness and availability of equipment at health facilities. Perceived QoC and patient experiences of care have been linked to health care service utilization, health outcomes, and intended or actual health behaviors.⁴ As a result, national ministries of health and country stakeholders are increasingly placing experience of care and people-centered care within their national strategies, including for inpatient and outpatient pediatric services.



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Figure 1: Pediatric Experience of Care Framework



The framework uses quality statements from the WHO [Standards for Improving the Quality of Care for Children and Young Adolescents](#),² as well as previously developed studies, frameworks from gray and published literature, and inputs from key informant interviews and consultations. After developing the framework, we solicited further expert feedback from country-level stakeholders, including policymakers, clinicians, and program implementers.

Once the framework was finalized, we designed a qualitative study to solicit expert feedback to explore the overall content and feasibility of a scale to measure pediatric experience of care using the domains and subdomains in the draft framework, to understand current country policies and programs focused on assessing and/or improving pediatric experience of care in LMIC health facilities, and to gain input about the type, length, and feasibility of using a scale in an operational setting of a health facility.

METHODS

We carried out semi-structured interviews with 12 national stakeholders from four countries where JSI or MOMENTUM projects have current field presence and have expressed interest to carry out follow-on work in measurement of pediatric experience of care. Specifically, we interviewed five expert respondents in Ethiopia, one in India, four in Laos, and two in Uganda, all of whom were identified through MOMENTUM projects or JSI contacts.

Interviews were conducted at an agreed-upon time over videoconference. Participants provided written informed consent for the interview to take place and to have the interview recorded. Each interview was facilitated by an interviewer with a notetaker present. Interviews followed a semi-structured format using an interview guide to ensure a basic set of topics were covered by each respondent. Participants were provided with a copy of the framework and asked to comment on its relevance to their countries' contexts, the utility

of measurement tools related that could be used to assess elements of the framework, and challenges related both to measurement and program implementation.

All interviews took place in English and lasted between one and two hours each. Interviews were transcribed verbatim and cleaned. Responses were analyzed by three team members familiar with pediatric experience of care. Responses were organized into pre-selected themes related to the interview guide questions and entered into an analysis matrix. Illustrative quotes were selected for each theme. Findings below are organized by the following themes: current national efforts to improve pediatric experience of care, challenges with implementation, challenges with measurement, and feedback on the experience of care framework.

FINDINGS

We interviewed 12 national stakeholders representing four countries in several global regions. Respondents were clinicians and instructors, program implementers, and national leaders in quality improvement. Table 1 summarizes the demographic characteristics of the respondents.

Table 1. Demographic characteristics of study respondents

	ETHIOPIA	UGANDA	LAOS	INDIA
Organizational Affiliation				
- Ministry of Health	2			
- International Non-governmental Organizations/Implementing Partners	3*	1		1
- Health Practitioners		1	4**	
Gender				
- Men	5	1	4	1
- Women		1		

*One respondent from Ethiopia was employed by an implementing partner but seconded to the Ministry of Health.

**All four respondents from Laos occupied Director positions at a Children's Hospital.

Current Efforts to Improve Experience

Many countries have undertaken efforts to improve the quality and experience of health care for patients, although few respondents reported on specific efforts around pediatrics. Respondents from Ethiopia and Laos specifically spoke about national policies and initiatives around compassion/respect and satisfaction, respectively. When asked, respondents spoke primarily about efforts to improve quality and safety, which are important components of patient experience. However, respondents acknowledged challenges with implementing broader improvements in experience. Most felt that the existing policies around QoC encompassed improved patient experience, but many felt that funding, training, implementation, and monitoring were lacking.

Challenges with Implementation

Study respondents were asked about elements of pediatric respectful care that are lacking or could use improvement within their country contexts. Responses varied, with some common themes across key informants and countries.

Respondents from Ethiopia and Uganda highlighted the fact that despite the presence of enabling policies, the systematic operationalization and implementation of these policies is hindered by a lack of government funding. Due to insufficient resources, facilities have limited capacity to independently improve pediatric experience of care, resulting in significant disparities between regions. One respondent from Ethiopia described the implementation of initiatives aimed at enhancing pediatric experience of care as consequently inconsistent and "disjointed," with certain facilities, mostly private ones, making more efforts to meet quality standards, while others struggle significantly. Another respondent from Ethiopia stated that respectful care in general is regarded as "luxury care, something for people to seek out in private facilities if they can afford to." Several respondents in Ethiopia and Uganda also mentioned that the majority of prior work related to experience of care in their respective countries has focused on maternity care. The respondent from India shared a similar perspective, describing the country as being "policy-rich, implementation-poor" with vast disparities between states in terms of implementation, and highlighted the lack of government oversight in private sector facilities that deliver services without sufficient monitoring of quality or adherence to care standards. In each of the study countries, respondents mentioned few implementation initiatives specific to the experience of children and their families.

Respondents from Uganda, Laos, and India highlighted another challenge related to the fragmented implementation of initiatives aimed at improving experience of care: the inadequate dissemination and sharing of best practices and lessons learned from these efforts. One respondent from Uganda expressed concern about valuable information that is lost when implementing partners fail to share their knowledge with the government or other partners on the ground or ensure the sustainability of successful practices beyond the completion of a project. This loss of knowledge often leads to regression, as the respondent explained, stating, "Today you are doing well, and tomorrow you go back to zero." The respondent from India noted that, while a considerable amount of data on satisfaction or experience is being collected, it is not being effectively analyzed or utilized for decision-making purposes.

Challenges with Measurement

Participants from Ethiopia and Laos identified several common themes in the challenges associated with assessing pediatric experience of care. In Ethiopia, two participants highlighted the limited health literacy in the general population and communities' low or varying expectations for high quality and respectful care, underlining the fact that caregivers of pediatric patients may lack awareness of the established standards or their entitlements. Two participants shared instances where caregivers rated their satisfaction with health care services positively merely because their child's health condition improved, despite receiving subpar care. Furthermore, respondents in Ethiopia emphasized the need to explore the true meaning of quality within the local context given that, in many low-income settings, the primary concerns of most individuals revolve around accessing care, essential medication, and diagnostics. The quality of the provider-patient interaction or the overall care experience is not given as much importance in settings where the basic services are not delivered.

In Ethiopia, two participants raised the issue of the reluctance of community members to voice complaints, which poses a potential challenge in effectively measuring experience of care. There is a pervasive fear of

retaliation not only by the public health care system but also in general when receiving any government services. As one participant aptly expressed, "people don't opt for the negatives." Another participant cautioned against inquiring about overall experience of care, based on his prior experience collecting data on patient satisfaction, stating that caregivers have a tendency to respond positively to broader questions. Therefore, any useful tool aimed at assessing experience and guiding efforts for improvement would need to incorporate specific questions pertaining to multiple domains or specific components of care. However, it is also important to strike a balance between the required level of detail during data collection and the need for a simple, aggregated indicator for inclusion in already overloaded health information systems—a point that was underlined by one respondent in Ethiopia and another in Uganda.

In Laos, two respondents emphasized the significance of regularly collecting information on experience of care and monitoring it consistently over time. They pointed out the need for subsequent action plans or recommendations to be implemented, which has been lacking thus far. Both respondents drew attention to the limited sharing and utilization of data for improvement, drawing from their experiences with previous "one time" client satisfaction surveys conducted in hospitals.

Use of Pediatric Experience of Care Data

The respondents were asked about existing data collection practices related to the experience of care. Across countries, the majority of respondents mentioned small-scale, ad hoc data collection activities that incorporated elements of pediatric experience of care (from the caregivers' perspectives) but were not solely focused on it. These activities included exit interviews focused on patient satisfaction that did not cover all domains outlined in the experience of care framework and were not implemented in any systematic manner. The clear need for a standardized scale to measure experience of care, especially one that could measure experience at multiple time points, was apparent. When asked about how they might use data on experience, if a standardized and validated scale were available to measure it, participants across countries responded that it would provide critical insight. One respondent from Laos explained that such data could play a crucial role in helping raise the standard of pediatric care by identifying gaps and informing necessary interventions. Ethiopian respondents expressed similar sentiments, stating that having this information would bring the topic to the forefront for decision-makers, making it easier to advocate and mobilize resources within the government. One of the Ugandan respondents was less optimistic, suggesting that while this type of data may create awareness, limited resources might hinder its translation into action from the government or higher levels.

Feedback on Pediatric Experience of Care Domains

We provided respondents a copy of the draft pediatric experience of care framework and provided the opportunity to comment on the domains, including the relevance of each to their particular country context and which components needed to be included or emphasized. Their responses are summarized by country and presented in Table 2.

Table 2. Summary of feedback on experience of care framework domains

EXPERIENCE OF CARE DOMAINS	ETHIOPIA	UGANDA	LAOS	INDIA
Effective Communication and Participation	<ul style="list-style-type: none"> • Important to consider low literacy and health literacy rates • Need to address potential language barriers between providers and caretakers • Important to incorporate child-focused communication 	<ul style="list-style-type: none"> • Poor guidance to caretakers about how to care for child at home 	<ul style="list-style-type: none"> • Important to consider low health literacy • Need for clear and precise communication and “soft comfort” to appease caretaker concerns • Need to address potential language barriers between providers and caretakers • Important to incorporate child-focused communication • Effective communication is very important but difficult to change “health workers’ long-standing behavior” 	<ul style="list-style-type: none"> • No comment
Respect, Child Protection, and Fulfillment of Rights	<ul style="list-style-type: none"> • Interconnectedness of privacy and built environment—impossible to adhere to standards if the infrastructure does not allow for it 	<ul style="list-style-type: none"> • Limited space in facilities does not allow for privacy • Caretakers separated from their children during inpatient stays due to lack of space 	<ul style="list-style-type: none"> • No guideline for health workers to introduce themselves or keep client information confidential • Child Rights Protection Unit exists to advocate for child victims seeking care • Some hospitals have separate room for child victims of violence, abuse, 	<ul style="list-style-type: none"> • Need to expand respectful care beyond maternity care; some focus on newborn care, but not much for children

EXPERIENCE OF CARE DOMAINS	ETHIOPIA	UGANDA	LAOS	INDIA
			<p>and sexual harassment to ensure privacy</p> <ul style="list-style-type: none"> • Lack of beds or accommodations for caretakers whose children are receiving inpatient care 	
Emotional and Psychological Support	<ul style="list-style-type: none"> • No existing emotional support mechanism • Especially important for children (and families) with chronic conditions, long-term mental and physical disabilities • Need to allow clergy, counselors, and other non-family members in the community to provide some of this support 	<ul style="list-style-type: none"> • No comment 	<ul style="list-style-type: none"> • Child Rights Committee for “sensitive and emotional cases,” but no proper training is provided 	<ul style="list-style-type: none"> • Inadequate resources to respond to increasing needs for support, especially for children—both in terms of building competency amongst providers and raising awareness in the community
Child-friendly Physical Space and Resources	<ul style="list-style-type: none"> • Built environment and physical space design are “afterthoughts” • Need for child-sized facilities and equipment and stimulating environment for early childhood development • Accessibility of pediatric units, especially in larger hospitals, is an issue 	<ul style="list-style-type: none"> • Need for early childhood development guidelines for day-to-day implementation in facilities 	<ul style="list-style-type: none"> • Lack of tools to assess availability and condition of physical resources 	<ul style="list-style-type: none"> • Hard to find and poorly labeled pediatric wards

EXPERIENCE OF CARE DOMAINS	ETHIOPIA	UGANDA	LAOS	INDIA
Competent, Motivated, and Empathetic Human Resources for Health	<ul style="list-style-type: none"> • Facility readiness is an important factor to consider—regardless of how competent, motivated, and empathetic health workers are, they cannot perform their work without proper equipment, drugs, etc. • Competency and empathy need to extend to leadership, not just health workers, and the latter should be champions of respectful care 	<ul style="list-style-type: none"> • Considerable efforts in Uganda to build competency of health workers, but “still a long way to go” • Need to identify and implement different ways to motivate staff, including recognition, promotion, and monetary incentives 	<ul style="list-style-type: none"> • Insufficient human resources is a major challenge that leads to long wait times • Low commitment and motivation of overworked staff 	<ul style="list-style-type: none"> • Human resources is a “generic problem” across all levels of care • Lack of accountability of decision-makers is an issue
Policy and Organizational Processes	<ul style="list-style-type: none"> • Some child health treatments are cost-exempt, but due to shortage of resources and supplies, families are forced to pay out-of-pocket • Addressing cost is important, as it is the reason many caretakers seek care from traditional healers instead • Integration of referral, care coordination, and follow-up mechanisms is paramount 	<ul style="list-style-type: none"> • No comment 	<ul style="list-style-type: none"> • Existing policy of free care for families who cannot afford to pay at some hospitals—determined on a case-by-case basis 	<ul style="list-style-type: none"> • No comment
Safety and Harm Reduction	<ul style="list-style-type: none"> • No comment 	<ul style="list-style-type: none"> • No comment 	<ul style="list-style-type: none"> • No comment 	<ul style="list-style-type: none"> • Little focus on safety and harm reduction


RECOMMENDATIONS AND CONCLUSION

The need for validated tools to measure experience of care in LMICs is clear and urgent. It is equally important that these tools be adapted to the local context, if possible, through formative and qualitative research to understand children’s and caretakers’ expectations and experience of care. Another element to consider is the integration of collected data into national routine health information systems to enable monitoring across facilities and time, increase visibility, and facilitate advocacy efforts. As a next step, MOMENTUM Knowledge Accelerator is carrying out the cognitive testing of a draft survey to measure pediatric experience across the domains prioritized in the framework through interviews with caregivers of pediatric patients in Laos. The survey will be revised based on findings from the cognitive testing and subsequently incorporated into a health facility assessment planned by USAID’s Laos Maternal Child Health and Nutrition project before it is ultimately refined into a scale for pediatric experience of care.


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MOMENTUM Knowledge Accelerator is funded by the U.S. Agency for International Development (USAID) as part of the MOMENTUM suite of awards and implemented by Population Reference Bureau (PRB) with partners JSI Research and Training Institute, Inc. and Ariadne Labs under USAID cooperative agreement #7200AA20CA00003. For more information about MOMENTUM, visit www.usaidmomentum.org. The contents of this technical brief are the sole responsibility of PRB and do not necessarily reflect the views of USAID or the United States Government.

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