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Continuity Strategies for Long-Stay PICU Patients: Consensus Statements From the Lucile Packard Foundation PICU Continuity Panel

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OBJECTIVES: To develop consensus statements on continuity strategies using primary intensivists, primary nurses, and recurring multidisciplinary team meetings for long-stay patients (LSPs) in PICUs.

PARTICIPANTS: The multidisciplinary Lucile Packard Foundation PICU Continuity Panel comprising parents of children who had prolonged PICU stays and experts in several specialties/professions that care for children with medical complexity in and out of PICUs.

DESIGN/METHODS: We used modified RAND Delphi methodology, with a comprehensive literature review, Delphi surveys, and a conference, to reach consensus. The literature review resulted in a synthesized bibliography, which was provided to panelists. We used an iterative process to generate draft statements following panelists' completion of four online surveys with open-ended questions on implementing and sustaining continuity strategies. Panelists were anonymous when they voted on revised draft statements. Agreement of 80% constituted consensus. At a 3-day virtual conference, we discussed, revised, and re-voted on statements not reaching or barely reaching consensus. We used Grading of Recommendations Assessment, Development, and Evaluation to assess the quality of the evidence and rate the statements' strength. The Panel also generated outcome, process, and balancing metrics to evaluate continuity strategies.

RESULTS: The Panel endorsed 17 consensus statements in five focus areas of continuity strategies (Eligibility Criteria, Initiation, Standard Responsibilities, Resources Needed to Implement, Resources Needed to Sustain). The quality of evidence of the statements was low to very low, highlighting the limited evidence and the importance of panelists' experiences/expertise. The strength of the statements was conditional. An extensive list of potential evaluation metrics was generated.

CONCLUSIONS: These expert/parent-developed consensus statements provide PICUs with novel summaries on how to operationalize, implement, and sustain continuity strategies for LSP, a rapidly growing, vulnerable, resource-intensive population in PICUs.

KEY WORDS: child; continuity of care; intensive care units; long-term care; models; nursing; physician's; practice patterns

Children with chronic conditions make up a significant proportion of patients in PICUs, especially larger units (1, 2). A subset of these patients requires prolonged PICU admission, sometimes for weeks or months, and this population and their prolonged stays disproportionately impact PICU organizations, practices, and families (3–5). For example, long-stay patients (LSP) described in various reports have high rates of adverse events,

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morbidity, and mortality (2–5), and their families face substantial social isolation (6, 7), anxiety and depression (8, 9), and financial burden (10). Additionally, the challenges of caring for some LSP contribute to provider distress (6, 7, 11–14).

Transitory PICU care—meaning intensivists working 1–2 weeks or in shifts and nurses changing every shift—is customary but can inadvertently lead to fragmented care and unmet needs of LSP, their families, and providers (6, 15–17). These problems can include ineffective within-team and team-family communication and transfer of information; variance in familiarity with patients, goals, management, and timelines among providers; failure to recognize relevant chronic and "big picture" issues; delayed or suboptimal shared decision-making; frustrated families because of fragmented care, leading to impaired rapport, trust, and confidence in providers (6, 17–19); and provider moral distress because of lack of continuity and poor communication (20, 21).

Some PICUs use primary or "continuity" intensivists, primary nurses, and/or recurring multidisciplinary team meetings (RMTM) to facilitate continuity of care for LSP (**Table 1**). These continuity strategies strive for, at minimum, continuity in information and management (22) in the PICU and augment usual care using existing PICU personnel. Continuity can be strengthened by other services that follow patients in (and out of) the PICU (e.g., subspecialists, palliative care, complex care, social work, etc.), but continuity from PICU providers differs and is advantageous because they are intrinsic to the team responsible for the LSP's care. Beyond continuity, these strategies seek to facilitate and expedite decision-making, decrease length of stay (LOS) and adverse events, provide primary palliative care, and mitigate providers' emotional and moral distress.

Even though there is abundant qualitative evidence on the inadequacies of transitory care for LSP and the association between continuity and perceived satisfaction with/quality of care, not all LSP receive continuity. In 2017, a Canadian panel endorsed ICU continuity (23), but others have found insufficient evidence to recommend ICU continuity strategies (24). Newer evidence has now emerged (25–29), and some PICUs use them, believing the benefits outweigh the required effort and costs (30). However, in general, PICUs seeking to address the continuity needs of their LSP do so with little guidance. Therefore, we convened the Lucile Packard Foundation PICU Continuity Panel, a multidisciplinary working group of professional and family stakeholders, to establish consensus statements for continuity strategies. These novel consensus statements offer practical guidance and have been endorsed by the Society of Critical Care Medicine (SCCM).

METHODS

We used a modified RAND Delphi methodology to reach consensus and Grading of Recommendations Assessment, Development, and Evaluation (GRADE) methodology to assess the quality of evidence (QoE) and rate the strength of the Panel's recommendations (31). We also consulted a medical epidemiologist, experienced in consensus processes. Our methodology followed the Accurate Consensus Reporting Document guidelines (32).

The RAND/University of California, Los Angeles Appropriateness Method (33) is a structured process to develop recommendations by combining existing evidence and expert judgment. This process includes a comprehensive literature review, evidence synthesis, and iterative rounds of input from a group of knowledgeable stakeholders, using Delphi surveys and a conference (**Fig. 1**).

We first carried out a comprehensive literature search. With the assistance of a research librarian, we searched the PubMed/MEDLINE, CINAHL, Embase, and Cochrane databases for literature relevant to continuity strategies, LSP, transitory care limitations, moral distress in ICU, and ICU-related family-centered care. We created a bibliography, organized and cross-referenced by topics, with a synopsis of each article. Appended to the bibliography were: 1) details from the literature on how continuity practices were operationalized and 2) synopses of known unpublished relevant work (noted as non-peer reviewed), including a then-unpublished survey of continuity practices for LSP among PICUs with fellowship programs (30).

We organized a diverse panel of 37 (of 39 invited) professional and family stakeholders with varied expertise and experiences relevant to LSP and children with medical complexity. Professional panelists, many of whom had publications on relevant topics, represented many disciplines/professions, including

TABLE 1.
Continuity Strategies and Their Relative Advantages and Disadvantages

Strategy	Description	Advantages and Disadvantages
Primary intensivists	One intensivist serves as a consistent physician-resource and facilitator for the LSP and the medical team throughout the LSP's PICU stay and despite changes in the "on-service" intensivist. Primary intensivists seek to improve informational, management, and relational continuity, but they do not dictate daily management (unless "on-service") nor serve as the patient's/family's personal physician.	Advantages Promote relational continuity "Macro"-level management continuity (e.g., "big picture" matters) emphasized Continuity provided by a person with authority among the medical team Disadvantages Dependent on individual intensivists, including when they are off-service; so continuity may vary by the individual The number of patients receiving this strategy can be limited by the number of available and willing intensivists
Primary nurses	A team of PICU nurses (sometimes with one lead nurse and team of associate nurses or, less often, a single primary nurse) that seeks to ensure high-quality nursing care by providing most of the patient's bedside care and to improve informational, management, and relational continuity, despite changes in other medical team members. Because of their knowledge of the patient/family, primary nurses are resources for the PICU team. (Note: A nurse merely caring for the same patient for a string of consecutive days is not primary nursing.)	Advantages Promote relational continuity Enable "micro"-level management continuity (e.g., consistency in beside care) Disadvantages Dependent on individual nurses, so continuity may vary by the individual The number of patients receiving this strategy and the number of primary nurses assigned to them can be limited by the number of available and willing nurses Can constrain nurse staffing flexibility
Recurring multidisciplinary team meetings	At these meetings, LSP and their medical, ethical, and psychosocial complexities are discussed by all available intensivists (both on- and off-service) and any/all other providers/staff to improve informational and management continuity, despite changes in medical team members. A secondary goal is to create a supportive provider community. Families do not attend these meetings, so they are distinct from and do not replace family-team meetings/care conferences.	Advantages Less dependent on specific individuals Facilitate the sharing of information from multiple providers and different disciplines at a set time and place Provide a safe environment for discussing sensitive patient-related topics in an effort to support staff and mitigate moral distress "Macro"-level management continuity (e.g., "big picture" matters) emphasized Disadvantages Lack relational continuity Time limits for meetings can constrain the number of patients discussed or the depth of discussion if numerous concurrent LSPs

LSPs = long-stay patients.

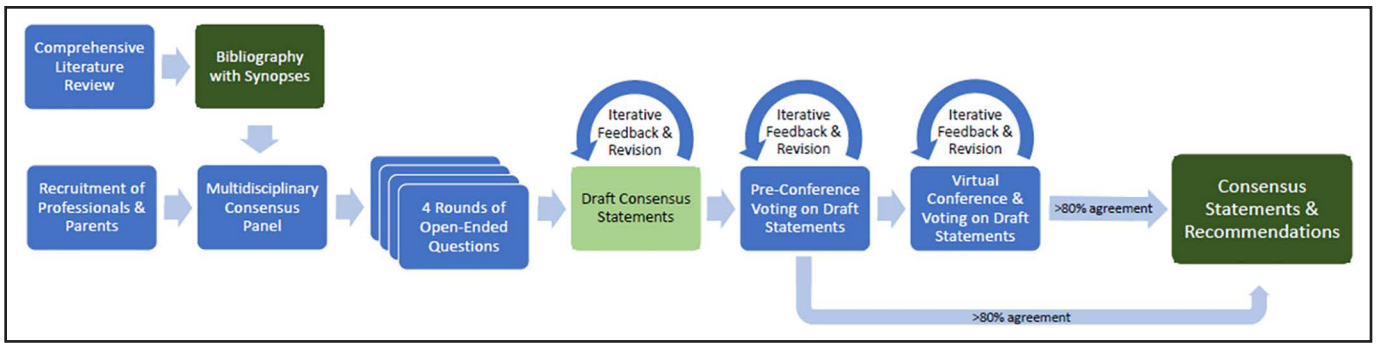

Figure 1. Flowchart of Lucile Packard Foundation PICU Continuity consensus effort methodology.

pediatric critical care, neonatology, nursing, complex care, palliative care, ethics, postacute/chronic care, social work, case management, chaplaincy, child life, music/art therapy, and language services. Professional panelists came from 21 academic and community institutions/organizations across the United States and Canada; many of which use continuity strategies in their PICUs. To ensure that LSP and their families were represented, seven parent advocates whose children had prolonged PICU admissions participated; parents were identified with the help of the Family Voices and Courageous Parents Networks.

Considering their experiences and the literature, panelists completed four sets of open-ended questions that addressed continuity strategies over 4 months. After each set, two co-authors (J.D.E., B.D.L.) synthesized responses into draft statements that reflected the majority perspective or exceptional points. All coauthors reviewed and revised these draft statements, which evolved into consensus statements. They were then shared with all panelists to solicit feedback for improvement.

Utilizing the online platform Qualtrics (Seattle, WA), panelists reviewed revised statements and anonymously agreed or disagreed with each. Panelists were able to comment on points of disagreement, anonymously or openly. Statements with greater than or equal to 80% agreement were considered to have achieved consensus.

On September 22, 2021, to September 24, 2021, the Panel met for a virtual conference, facilitated by a moderator who is an institutional leader in diversity, equity, and inclusion affairs and experienced with consensus conferences. Statements with less than 80% agreement were discussed, revised, and anonymously voted on. These procedures were repeated until greater than or equal to 80% agreement was achieved. When time allowed, statements with 80–90% agreement in preconference voting were discussed. If a statement was revised, a new vote occurred. The strength of the Panel's recommendations was rated using GRADE methodology.

Because research and quality improvement metrics for continuity strategies have not been established, the Panel generated potential metrics. These were synthesized and categorized as outcome, process, or balancing metrics. Twenty-two panelists with research experience were asked to determine by simple majority feasibility of assessing each metric. Choosing from those deemed feasible, all panelists designated their five most important outcome metrics, which were tallied and stratified by professional and family panelists.

RESULTS

The comprehensive review of the literature identified two randomized controlled trials and eight preintervention/postintervention or controlled observational studies that assessed the impact of continuity strategies. All but one study was conducted within a single center. Multiple other single-center uncontrolled observational studies were identified. Therefore, given these limited data, the Panel's consensus statements (summarized in **Supplemental digital content, Table 1**, http://links.lww.com/PCC/C396) were also based on panelists' experience/opinion. When supporting evidence existed to substantiate a statement, this evidence is cited in the text. Statements with more evidence and shared experience (6/17) were deemed to have low QoE. The majority of statements (11/17) were largely based on expert opinion and were deemed to have very low QoE. Overall, this means there is considerable uncertainty in the estimates of benefits; benefits

and burdens may be balanced; and/or further research is likely to change our understanding and confidence of this balance. Furthermore, the strength of all the recommendations is conditional, meaning any estimate of the benefits and burdens is uncertain and other alternatives may be equally reasonable. Ultimately, all consensus statements had greater than or equal to 90% agreement among panelists.

Focus Areas and Consensus Statements

1. Patient Eligibility Criteria

Consensus Statements.

1.1 We suggest patients who: 1) have been admitted to the PICU for 14 days (or other predetermined threshold period of time) with no expectation of transfer out of the PICU soon after (e.g., no estimated day of PICU discharge) and 2) have complex critical care need be eligible for a continuity strategy (QoE: low).

1.2 Continuity strategies may be initiated before an institution's established standard threshold when it is apparent that the patient will meet criteria and they will benefit from early initiation of a continuity strategy (QoE: very low).

1.3 We suggest requests for a continuity strategy, from either family or medical team members, be considered, even when the patient does not meet eligibility criteria (QoE: very low).

1.4 We suggest readmitted patients who previously received a continuity strategy not be automatically re-enrolled in one until they again meet eligibility criteria (QoE: very low).

Standardized eligibility criteria are imperative to avoid biased selection of patients and ensure those most likely to benefit from the intervention receive it, permit comparisons across institutions, and balance initiating continuity early enough to allay problems of fragmented PICU care, but not so early that a prohibitive number of patients are enrolled simultaneously.

There is no universally agreed upon definition of "prolonged" PICU LOS or LSP. Studies have used various LOS thresholds, ranging from 8 (34) to more days (5) with a bimodal distribution toward 14 and 28 days. The Panel agreed that 14 days is the most appropriate threshold for eligibility (30). This threshold would capture most patients needing continuity across different institutions before many problems of fragmented care arise, but not so early as to result in exorbitant numbers of eligible patients. The Panel favored a numerical LOS threshold as a criterion, as opposed to percentile (35) (e.g., > 95th percentile of the median LOS) or age-/group-dependent (36) thresholds, to promote consistency across institutions and avoid recalibration over time.

Because initiating a strategy for patients who leave the PICU shortly thereafter would yield nominal benefit, the Panel suggested excluding patients anticipated to be transferred out of the PICU (i.e., to another unit/hospital or hospital discharge) soon after day 14. If this expectation changes, a continuity strategy could be applied. Anticipated timing of transfer is best determined by the on-service intensivist with input from the multidisciplinary team.

When unplanned readmissions occur within 48 hours of transfer, the Panel suggested using the initial PICU admission date to determine eligibility. Forty-eight hours is commonly used to define early unplanned readmission and has been advocated by the SCCM (37).

In line with Woodger et al (35), the Panel also suggested a patient-/family-need-based criterion for eligibility. These "complex critical care needs" encompass a broad range of LSP/family needs where usual PICU care might not suffice and exclude patients for whom continuity would be of nominal benefit (e.g., LSP medically cleared for transfer out of the PICU but waiting for appropriate disposition). Such needs can vary depending on the patient; examples include, but are not limited to, patients with multiple complex chronic conditions, poor prognoses, uncertain/unfavorable clinical trajectories, or facing difficult/important decisions. The presence or absence of complex critical care needs is best determined by the on-service intensivist with input from the multidisciplinary team.

Patients may be enrolled before day 14 based on anticipation of meeting criteria. Similarly, requests for a continuity strategy, whether from a family or team member and whether the patient meets criteria, may be considered, although a request does not obligate initiation of a strategy. Criteria should not be adjusted to grant a request because a patient/family is more vocal or "liked," and equitable provision of continuity to all appropriate patients must be a goal.

Eligibility criteria and the ability to expand or limit eligible patients will be dependent on individual PICU resources. Expanding or limiting patients can be accomplished by adopting an earlier or later LOS threshold or selecting specific patient populations to prioritize. See **Table 2** for suggested populations to prioritize. Irrespective of the number of days or patients prioritized, the criteria should be standardized to enable

TABLE 2.
Patient Populations to Prioritize for Continuity Strategies

Patients who do not have subspecialty services that follow them longitudinally and consistently in the PICU.
Patients at high risk of unfavorable outcomes (e.g., death, progressive or life-threatening condition, notably lower functional status upon discharge, chronic respiratory failure).
Patients who have support system barriers (e.g., familial, social, cultural, language, communicational, etc.) or whose care/outcomes may be negatively impacted by social determinants of health (e.g., persons belonging to traditionally under-served populations).
Patients/families who will have decisions that may have long-term impact on the patient/family, especially those with low health literacy or expectations (e.g., patient outcomes or clinical diagnosis/prognosis) that are disparate from the medical team's expectations.
Patients/families who have expressed frustration with fragmented PICU care and/or communication, resulting in impaired confidence, trust, or rapport.
Patients whose PICU course has created significant moral distress among the PICU staff.
Patients who have multiple complex care needs.

consistent practice and avoid biased selection of patients (e.g., patients/families perceived as "difficult" or "challenging" not receiving or receiving fewer primaries), potentially exacerbating healthcare disparities.

Given that LSPs are likely to be readmitted (38), some PICUs automatically initiate continuity strategies for frequently readmitted patients (e.g., three times in 1 yr [30]). Despite appreciating their reasons, the Panel concluded that readmitted patients should be re-enrolled only after they again meet eligibility criteria. Automatic application of a continuity strategy may unnecessarily strain continuity resources when readmissions are short or for planned, straightforward reasons. However, the Panel agreed that when an enrolled LSP is transferred out but has early unplanned readmission within 48 hours, the patient should automatically resume their continuity strategy.

2. Initiating Strategies

Consensus Statements.

2.1 We suggest that prospective primary nurses/intensivists be actively and equitably solicited from a pool of volunteers (QoE: very low).

2.2 We suggest individuals who already have a rapport with the patient/family, experience caring for the patient, and/or have expertise relevant to the patient's needs serve as primary intensivists/nurses (QoE: very low).

PICUs using a continuity strategy need a process to identify which and when patients meet eligibility, inform patients/families of their inclusion and what to expect, and, in the case of primary intensivists and nurses, establish relationships with patients in a timely manner.

Pairings of primaries with LSP are generally accomplished using one of three approaches. First, announce that a patient needs a primary intensivist or nurses and wait for self-directed volunteers; this can result in no or suboptimal numbers of primaries volunteering, especially for patients/families who are negatively labeled (e.g., "difficult," "challenging") (39, 40). Second, solicit specific individuals. Third, assign individuals from an established pool of providers.

The Panel suggested senior PICU team members (e.g., physician/nursing directors, charge nurses, continuity program lead) actively solicit individuals from an established pool of volunteers, ensure there is fair distribution of primary responsibilities among its pool of volunteers, and ensure that LSPs have similar numbers of primary nurses. Individuals may decline a request to serve as a primary for nonbiased reasons (such as upcoming commitments/time away and already or recently serving as a primary). Individuals who have experience caring for the patient and have good rapport with the patient/family are ideal. Specific expertise relevant to the patient's needs may be another consideration (e.g., medical, cultural, language, etc). Although appreciating reasons for asking families their opinion on preferred individuals, including good rapport, the Panel favored not asking families who they prefer as primaries. Such requests may be infeasible and/or may result in unintended, avoidable consequences (e.g., discomfort if the request is declined or overburdening individuals

who are frequently requested). When PICUs do solicit names or families make an unsolicited request for a specific person(s), it should be communicated that it may not be possible to honor the request.

For readmitted LSP who meet criteria again, efforts should be made to reassign the prior primary intensivist/nurses. Conversely, re-enrollment creates an opportunity to identify new primaries if prior pairings did not work well. These processes require a means of tracking readmissions and recording prior primaries.

Patients/families may opt out of primary strategies. Because multidisciplinary collaboration is fundamental to high-quality care of complex patients, patients/families may not opt out of being discussed at RMTM, although they may choose not to be routinely informed of the meeting outcomes. For PICUs utilizing RMTM, newly eligible patients should be added to the list of patients for discussion at the next meeting.

Although the Panel believed that PICUs should recruit a minimum number of primary nurses for each patient (often 4–6 [30]), it did not suggest a number. Goal numbers of primary nurses depend on many factors, including the balance of the PICU's objectives (e.g., desired proportion of shifts covered by a primary nurse) with its resources (e.g., staff availability/flexibility). The Panel pointed out that daytime primary nurses are especially important to facilitate primary nurse participation in daily rounds and team/family meetings/conferences.

3. Standard Responsibilities

Consensus Statements.

3.1 We suggest primary intensivists and nurses: 1) strive to achieve a respectful, partnering relationship with the patient/family; 2) be a resource for the patient/family and other providers; 3) strive to enhance communication between the patient/family and other providers; 4) actively participate in team meetings and family conferences; 5) advocate for the patient/family; and 6) participate in planning of transfers out of the PICU (QoE: low).

3.2 We suggest primary intensivists aim to: 1) meet regularly (e.g., at least weekly) with the patient/family and with the medical team; 2) facilitate, support, and expedite patient/family decision-making and decision-making among providers (both PICU and other specialists); 3) help ensure consistency of messages and recommendations to the patient/family; and 4) document key elements of important conversations with the patient/family (QoE: low).

3.3 We suggest primary nurses (as a team) aim to: 1) provide a notable proportion of the bedside nursing care to the patient while they are in the PICU (e.g., ≥ 50% of nursing shifts); 2) have a shared, consistent approach to the patient's care, including iterative, comprehensive, holistic, individualized nursing care plans that reflect a collective understanding of the patient's/family's values; 3) actively participate in daily rounds when caring for their primary patient; 4) strive to support each other as they care for the patient/family; and 5) familiarize new nurses that join the primary nursing team with the patient and family (QoE: low).

3.4 We suggest recurring multidisciplinary team meetings: 1) convene weekly on a pre-set day/time and in a set location (physical and/or virtual); 2) include the on-service intensivist, available off-service intensivists, social work, case management, primary nurses, nursing leadership, and active consultants, with all other team members encouraged to attend; 3) have a designated facilitator to guide meeting discussions; 4) address 3 overarching areas for each patient discussed: a) patient course/trajectory and current treatment plans; b) patient/family needs and goals; c) medical team member perspectives and concerns to achieve consensus on recommendations, unify messaging, and support team members; and 5) disseminate the pertinent discussion points to relevant providers and the patient/family (QoE: low).

The Panel also reached consensus on supplemental responsibilities that PICUs may consider (**Table 3**). Their strength of recommendations is conditional, and their QoE was very low. Taken together with the above, the role responsibilities for continuity strategies reflect the overarching objectives of augmenting continuity of information and management, and relational continuity for primary intensivists and nurses. The label "standard" indicates the panel consensus that these duties are vital and under most circumstances not onerous. Although responsibilities are "standard," to the extent possible, they can be adapted to serve the distinct needs of individual LSP.

Because continuity of information is necessary for management continuity, strategies are intended to facilitate the effective transmission of important information between providers by leveraging individual and collective memories. Critical information includes, but is not limited to, the patient's PICU course, "big picture" issues, goals of care, previous successful and unsuccessful management approaches, communication preferences, and relevant psychosocial dynamics. Much of this exceeds what is expected and feasible in routine handoffs between PICU providers, especially for children with medical complexity (15, 17). Thus, primary intensivists and nurses serve as a resource to

TABLE 3.
Additional Role Responsibilities of Continuity Strategies for PICUs to Consider

Primary intensivists and nurses
Be a resource to other providers after the patient is transferred out of the PICU, especially if the patient is still in the hospital.
Primary intensivists
Join the patient's bedside rounds occasionally when not on service.
Communicate important information to the patient's and collaborate with key out-of-hospital providers (e.g., primary care provider, subspecialists) about important matters during the patient's PICU admission and upon transfer of the patient out of the PICU.
Be available as a resource to patient's out-of-hospital providers and/or patient/family after transfer of the patient out of the PICU.
Primary nurses
Keep each other updated on patient-/family-related matters using their own Health Insurance Portability and Accountability Act-compliant method of communication.
Recurring multidisciplinary team meetings
Requiring attendance by the previous and upcoming on-service intensivists.
Inviting the patient's key outpatient providers to attend meetings.
Offer additional separate meetings if multiple team members are experiencing distress in association with a patient's care.

both patients/families and the PICU team, by offering input and facilitating important management/decisions, advocating for patients/families, and encouraging care consistent with primary palliative care.

Given their longitudinal relationships with patients/families, primary intensivists and nurses can augment relational continuity. A respectful, partnering relationship can facilitate open communication between parties, engender trust, promote patients'/families' understanding and processing of information, help alleviate stress, and expedite decision-making (18, 29, 41). To sustain this relationship, primaries need consistent interactions with the LSP/family (i.e., at least weekly visits for off-service primary intensivists; repeated bedside care for primary nurses) and be involved in consequential junctures (e.g., family conferences). To achieve the latter, off-service primary intensivists need regular contact with the PICU team, and the team needs to keep primaries informed when important circumstances unexpectedly arise.

Importantly, the Panel suggested that off-service primary intensivists not dictate daily/routine or emergent management (28). Likewise, they are not the patient's/family's personal physician (e.g., the sharing of direct contact information is unadvisable). Clear boundaries help reinforce that the on-service intensivist is the PICU team leader and is ultimately responsible for the patient's care. Blurring these boundaries may lead to confusion and could negatively impact decisions, which could be detrimental in time-sensitive situations. Requests from the patient/family to involve or speak to their primary intensivist/nurse, when they are off-service, should be made through the PICU team.

Primary nurses are also tasked with working collaboratively, sharing a consistent approach to the patient's care and iterative, comprehensive, holistic, individualized nursing care plans. Such care plans should include the patient's unique needs and short- and long-term care goals that reflect the patient's/family's values and preferences. Additionally, when new nurses join the primary team, the team familiarizes them with the patient and family.

The Panel suggested that a nurse should have no more than one primary patient at a time and an intensivist no more than 1–2 primary patients (27, 28). Rarely, a PICU may choose to allow intensivists, who are especially drawn to the primary role, to follow greater than two primary patients at a time. In these cases, PICU physician leadership may consider allowing the role to count toward a portion of their full-time equivalent effort.

The Panel suggested RMTM be held weekly at a consistent time and place (physically and/or virtually). Inclusiveness of all providers is a hallmark of these meetings, and the presence of the on-service intensivist, available off-service intensivists, social worker(s), case manager(s), nurse leader(s), active consultants, and, if

applicable, primary nurses is fundamental to success (25). Additional invitees should include other patient-facing providers and members of ethics and palliative care services. As meeting duration is limited, a designated facilitator and the on-service team should decide the order in which patients will be discussed (based on critical clinical or psychosocial issues) and/or if there are patients that do not need to be discussed that week. The facilitator is responsible for guiding the discussion of three overarching areas for each patient. First, the on-service intensivist or designee, with input from others, briefly presents the LSP's current clinical course/trajectory and treatment plans. Second, the patient's/family's needs are discussed, including, but not limited to, stressors and concerns, goals of care, strategies for effective communication, available resources to support them, and transitions out of the PICU. Third, to address barriers to consensus on recommended treatment plans and align plans with the patient's/family's goals and values, the facilitator solicits perspectives and concerns of team members. Specific actions may be recommended to the PICU team (e.g., schedule a family conference, request subspecialty palliative care, or ethics consultation). Documentation and dissemination of key discussion points to relevant providers through HIPAA compliant means is also crucial. Patients/families should be updated on what was discussed, as appropriate, by the on-service intensivist or other designee (25).

Because RMTM can provide a safe environment to discuss providers' concerns, they can alleviate the moral distress experienced by providers caring for LSP (25). Such support is especially important for ICU nurses and trainees, as they consistently report more moral distress than intensivists (12, 14, 42).

4. Resources Needed to Implement Strategies

Consensus Statements.

4.1 Staffing/commitment

- 4.1.1 We suggest there be enough willing and committed providers to be primary intensivists and nurses and senior team members to serve as meeting facilitators for recurring multidisciplinary team meetings.
- 4.1.2 We suggest each continuity strategy have a program lead(s) who oversees operations and serves as the strategy's point person(s) (QoE: very low).

4.2 Education

- 4.2 We suggest education on the strategy for all PICU providers, PICU leadership, and providers from other services/disciplines that follow patients in the PICU (QoE: very low).

4.3 Administrative

- 4.3.1 We suggest establishing a person(s) or method to identify newly eligible patients for continuity strategies and to track enrolled patients.
- 4.3.2 For primary intensivists and nurses, we suggest a person(s) or method to: 1) solicit and pair primary providers with patients in a timely manner and 2) document, disseminate, and track patient-primary assignments (QoE: very low).

The Panel identified elements and resources necessary to implement continuity strategies for LSP, categorized as Staffing/Commitment, Education, and Administrative resources.

All strategies require an adequate number of individuals committed to fulfilling their respective responsibilities to ensure that participation does not become onerous for anyone. We estimate that greater than or equal to 50% provider participation is needed for primary practices to be successful. The actual number will depend on the number of patients expected to be simultaneously receiving a continuity strategy. We support third-year PICU fellows serving as primary intensivists (30), with the approval of their fellowship and medical directors. For RMTM, representatives from involved services/disciplines should be willing to attend and contribute, and a cohort of senior PICU team members should serve as meeting facilitators.

The Panel acknowledged that primary nursing requires particular attention to staffing because of the number of individuals needed and its impact on staffing flexibility (e.g., assigning primary nurses to primary patients influences other assignments) (30, 43, 44). Nurse staffing models and available resources ultimately influence a PICU's ability to actualize primary nursing. For example, PICUs that heavily rely on float pools or other temporary nurses may be challenged to appropriately staff primary nursing strategies.

Besides individuals providing continuity, strategies require one or more program leads to oversee operations and serve as point person(s). Program lead responsibilities include initial and continuing education on the strategy, collecting or soliciting provider and patient/family feedback, and evaluation/improvement efforts. Other duties would include, but are not limited to, identification of patients who meet eligibility criteria and solicitation of primary providers.

Providing education and training before implementing a strategy is essential for program success. Those who will actively participate in the strategy will need instruction on their responsibilities. Prospective primary nurses and intensivists would benefit from additional training (initially and then periodically) in family-centered communication, care of children with medical complexity, primary palliative care, avoiding disability discrimination, trauma-informed care, health equity and social determinants of health, and mediation strategies (45). All PICU providers and members from other services/disciplines should be informed of the program and asked to respect the strategy's structure, goals, and limitations.

Although electronic health records can potentially aid these efforts, one or more persons are needed to manage the day-to-day activities of the program (e.g., identifying eligible patients, tracking transfers out of the PICU and early unplanned readmissions, timely solicitation of and pairing providers with patients, documenting and disseminating assignments).

5. Resources Needed to Sustain Strategies

Consensus Statements.

5.1 We suggest at least annual evaluations of the continuity strategy program (QoE: very low).

5.2 We suggest an individual's commitment and excellence as a primary nurse, primary intensivist, or program lead be formally recognized (QoE: very low).

5.3 We suggest the demands and stress of being a primary nurse and intensivist be acknowledged and appropriate supports be accessible (QoE: low).

5.4 We suggest a standardized approach for replacing a primary nurse or intensivist when necessary (QoE: very low).

Sustaining a continuity program requires ongoing effort. Dedicated personnel time is needed for educating new participants, continuing education, program evaluations, and activating contingency plans when primary providers need respite or replacement.

To affect process improvement, the Panel suggested at least annual evaluations to identify program strengths and areas for improvement. Evaluations should include feedback from providers, especially those serving as strategy participants, and patients/families (46). When significant changes are proposed, they should be vetted and agreed upon by participants and PICU leadership.

Notably, a nurse caring for the same patient for weeks risks impeding their professional development (12, 16, 29). To help ensure primary nurses have opportunities to maintain/develop their skills, primary nurses need to intermittently care for other patients and serve in other roles (e.g., charge nurse). Nurses may also rotate on/off the primary team (e.g., after several weeks), ideally in a staggered fashion to ensure some team members are always familiar with the patient.

Being a primary intensivist/nurse can be time-consuming and emotionally demanding (7, 18, 27, 29). Primary nurses are especially susceptible to distress (16, 29, 30). Besides allowing nurses to rotate off primary teams, PICUs should have mechanisms to respond to patient-specific or program-focused concerns of primary providers. Such mechanisms may use resources that are already in place (e.g., ethics consultation, palliative care service, chaplains, PICU leadership) and/or be a responsibility of the program itself. When the demands of being a primary nurse become prohibitive, the Panel suggested that primary nurses be permitted respite from providing bedside care to their primary patients (46). When an untenable primary patient/family relationship exists, primaries should be replaced. Respite or replacement can be requested by the provider or recommended by PICU leadership. Although replacement requests from patients/families should be explored and, in most cases, honored, patients/families, should not be asked who they would prefer as a new primary. Successive requests from patients/families to replace primaries should not be honored, as they likely indicate a need to explore a larger problem.

Finally, the Panel suggested that individuals demonstrating notable commitment and excellence as a primary nurse/intensivist or program lead should be formally recognized. Examples include commendation in their professional record or as a factor in career advancement or financial compensation.

Continuity Strategy Metrics

Beyond local evaluations, evidence of strategies' benefits and shortcomings is needed to help discern if wider implementation is warranted and to further elucidate best practices. For evidence to be generalizable and robust, multicenter studies using comparison groups and standardized practices are needed. To introduce a research agenda and stimulate such efforts, the Panel generated an extensive list of potential outcomes,

TABLE 4.
Five Most Important Outcome Measures for Continuity Strategies Stratified by Professional and Family Participants

Professional Participants	Family Participants
Patient/family satisfaction with continuity	Patient/family satisfaction with continuity
Alignment of family and PICU on goals/perspectives	Alignment of family and PICU on goals/perspectives
Team communication effectiveness	Team communication effectiveness
PICU length of stay	PICU length of stay
Timing of/delays in decision-making	Family discharge readiness/caregiver preparedness

processes, and balancing metrics. This list of metrics is provided in **Supplemental digital content, Table 2** (http://links.lww.com/PCC/C396). **Table 4** shows the five most important outcome metrics as selected by professional and family panelists.

Children with medical complexity are living longer and with greater complexity, resulting in great utilization of critical care resources. One consequence is that there is an increasing number of LSP (3, 4). This trend makes augmentation of transitory PICU care models imperative. Although research on continuity strategies is in its infancy and many of their potential benefits are unproven or intuitive, we believe primary intensivists, primary nurses, and RMTM provide beneficial continuity beyond that provided by longitudinal consultants. These expert-/parent-developed, evidence-informed consensus statements provide PICUs with novel guidance on how to operationalize, implement, and sustain these strategies. We hope these statements will prompt greater adoption of continuity practices; they may also be applicable in other inpatient settings that also have LSP, such as neonatal ICUs, intermediate units, and general wards. Finally, we hope these statements will stimulate more research on these practices and be the basis for future practice guidelines.

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APPENDIX

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