Research paper

Quality measurement and surveillance platforms in critically ill children: A scoping review

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**A B S T R A C T**

The objective of this study was to describe current surveillance platforms which support routine quality measurement in paediatric critical care.

**Method:** Scoping review. The search strategy consisted of a traditional database and grey literature search as well as expert consultation. Surveillance platforms were eligible for inclusion if they collected measures of quality in critically ill children.

**Results:** The search strategy identified 21 surveillance platforms, collecting 57 unique outcome (70%), process (23%), and structural (7%) quality measures. Hospital-associated infections were the most commonly collected outcome measure across all platforms (n = 11; 52%). In general, case definitions were not harmonised across platforms, with the exception of nationally mandated hospital-associated infections (e.g., central line–associated blood stream infection). Data collection relied on manual coding. Platforms typically did not provide an evidence-based rationale for measures collected, with no identifiable reports of co-designed, consensus-derived measures or consumer involvement in measure selection or prioritisation.

**Conclusions:** Quality measurement in critically ill children lacks uniformity in definition which limits local and international benchmarking. Current surveillance activities for critically ill children focus heavily on outcome measurement, with process, structural, and patient-reported measures largely overlooked. Long-term outcome measures were not routinely collected. Harmonisation of paediatric intensive care unit quality measures is needed and can be achieved using prioritisation and consensus/co-design methods.

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1. Introduction

The field of quality measurement in health care has advanced considerably in the past decades, with increased focus on the measurement and prevention of hospital-acquired harm. As a result, clinicians, researchers, and policymakers are increasingly

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seeking ways to develop systematic and standardised measures to monitor and benchmark care quality across care providers and locations. Quality measurement data can be used to drive healthcare quality initiatives and improve patient safety; however, due to the complex and heterogeneous nature of health care, specialised, targeted quality indicator sets are needed to provide a holistic picture of care quality across disciplines.

Critically ill children are susceptible to patient safety events including hospital-acquired complications (HACs) and hospital-acquired infections (HAIs)2,3 from both the underlying illness and related therapeutic interventions.4 Consequently, surveillance of healthcare quality in the paediatric intensive care unit (PICU) is important. However, deficiencies in PICU quality surveillance5,6 may mean health service providers do not know the true incidence of HACs7,8 and HAIs occurring in this high-risk cohort.2,4,12 Paediatric intensive care services need access to objective, comprehensive surveillance systems which support the delivery of high-quality care. Such activities facilitate cross-jurisdictional benchmarking and drive quality improvement programs. However, the range and scope of quality measurement and surveillance activities for critically ill children is currently ill-defined.2,13,14 Therefore, the objective of this review was to describe and categorise (i) currently collected quality measures, including any development/prioritisation efforts or patient involvement, and (ii) surveillance platforms scope and size, content acquisition and reporting, and public engagement characteristics.

2. Methods

A scoping review framework was used to identify quality measures and surveillance activities in paediatric intensive care.15,16 The scoping review framework16 consists of five stages and is a popular methodology to examine the breadth of evidence in healthcare research and quality.15,17,18 due to its focus on mapping content through iterative exploration and analysis.19 The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews was used to inform review conduct and reporting.20 The review framework was further underpinned by the Australian Health Performance Framework Dimension of ‘Safety’ (of care)21 and informed by the Australian Commission on Safety and Quality in Health Care Hospital-Acquired Complications List.21

For the purposes of the study, we defined quality measures as ‘tools that help measure or quantify healthcare processes, outcomes, patient perceptions, and organisational structure and/or systems that are associated with the ability to provide high-quality health care’.22 Measure definitions are further detailed in Table 1.

Surveillance platforms were anticipated to be broad; therefore, we defined these as mechanisms for repeated monitoring of the quality of health care delivered to critically ill children, including but not limited to local databases, clinical registries, surveillance systems, and international datasets.

2.1. Search strategy

The search strategy involved three components: a traditional database search, grey literature search, and consultation with experts.5 All searches were conducted between September 2020 and June 2021.

2.2. Electronic database search

A systematic search of the Cochrane Library, United States National Library of Medicine National Institutes of Health (PubMed), Cumulative Index to Nursing and Allied Health (CINAHL), and Embase was undertaken on the 16th September 2021. Medical Subject Headings (e.g., pediatrics) and keyword searches were developed with a healthcare librarian and related to three key elements: surveillance activities and quality measures (including hospital-acquired terms) and paediatric intensive care. Notably, the database search sought to identify journal articles that would lead us to surveillance platforms and government health information regarding monitoring healthcare quality in critically ill children. This was a necessary preliminary step to inform subsequent search strategies and stakeholder consultation. We were also interested in any publications reporting patient or family involvement in quality measure reporting, co-design, or measure prioritisation across all categories.

2.3. Grey literature search

The review of grey literature included two components: (i) a targeted search of government and healthcare agencies involved in monitoring healthcare quality, originating with the Australian Institute of Health and Welfare,20,24 and (ii) a Google search on the topic using previously reported best practices for Google searching.25,26 The search terms utilised in database searches were applied in the Google search, in combination with advanced search operators (date limiters 2010–2020) and retrieval strategies (results limited to the first 50 results, five pages for relevancy). All Google search results were screened independently by two review authors (JS and KC), with any disagreements resolved by a third author (LH). Subsequent websites were reviewed and mediated in the same manner.

2.4. Expert consultation

After obtaining institutional ethical approval (Griffith University 2020/897), we consulted with experts and key stakeholders (identified through the databases and Google search results) in paediatric intensive care quality measurement across Australia, New Zealand, and the United States of America to augment and validate other search strategies. We sought input from tertiary paediatric facilities, government health representatives, clinical quality registry representatives, and international quality and safety experts. Experts were contacted via email and/or phone to provide feedback on a working list of quality measures, to confirm identified measures were a true representation of what was collected in the platforms they had experience, thereby minimising missing measures. Experts were asked to identify additional quality measures or surveillance activities they would like to see collected; participation implied consent. Quality measures and surveillance platforms identified through expert consultation were reviewed by two authors (JS and KC). Additional email correspondence was required with five international platforms representatives to clarify measures collected and/or processes.

2.5. Charting, summarising, and reporting the results

All data were extracted by two independent researchers (JS and KC) using a standardised data extraction form. We included international platforms but were particularly interested in surveillance activities and quality measures used within Australian and New Zealand PICUs. Data were analysed narratively. References were exported, screened, and managed in EndNoteTM.27 Due to the aim of the scoping review framework,16 we did not formally evaluate the methodological quality of identified journal articles.
3. Results

3.1. Search results

The traditional literature search yielded 39 articles which met review inclusion criteria (Fig. 1), with eight surveillance platforms identified.28 The grey literature search yielded a total of 15 surveillance platforms: 11 identified through a Google search and an additional four identified through a targeted search of organisations. Finally, consultation with experts (n = 8) identified a further three surveillance platforms.55,56 In total, 21 surveillance platforms were identified following duplicate removal. Table 2 outlines included platforms, host organisation, country of origin, and the number of contributing units.

3.2. Range of quality measures

A total of 57 unique quality measures were collected across identified platforms. Measures were organised into outcome, structural, and process measures (Fig. 2). Outcome measures (e.g., blood stream infection) were most frequently collected (40/57 platforms [70%], followed by process measures (e.g., hand hygiene compliance; 13/57 [23%]), with structural measures (e.g., nurse ratios) infrequently collected (4/57 [7%]). We identified no ‘meaningful measures’, that is measures which had been co-designed or prioritised by stakeholders and consumers and implemented in PICU surveillance activities.

Collectively, HAIs were the most commonly collected quality measure. Central line-associated bloodstream infections were collected in 11 of 21 (52%) platforms,44,47–49,51,53–55,59,60,67 followed by catheter-associated urinary tract infections (CAUTIs) (n = 6; 28%)44 and ventilator-associated pneumonia (VAP) also collected as ventilator-associated events (VAEs) (n = 3; 14%).45,51,67 Mortality (n = 9; 43%),48–52,56,59,63,66 standardised mortality rate (n = 7; 33%),51,52,55,56,59,63,66 and unplanned readmissions (n = 8; 38%)44,48,52,55,56,59,63,66 were the most common noninfectious measures collected, followed by accidental extubation (7/21 (33%))44,48,55,59,63,66 and cardiac arrest (n = 5, 24%).48,59,61,63,66 Acute renal failure requiring renal replacement therapy was collected by six (28%) platforms.44,54,56,59,63,66

Surveillance definitions were not standardised or harmonised across platforms, with the exception of some HAIs (e.g., CLABSI). For CLABSI, platforms utilised case definitions (including reporting denominator data) from the Centers for Disease Control and Prevention and the National Healthcare Safety Network with manual validation often via discharge code review (in Australia — using the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification; ICD-10-AM). VAP, VAE, and pneumonia were infrequently measured with variability in use of clinical versus surveillance definitions. Overall, methods of case ascertainment relied largely on manual chart review of diagnostic and pathology reports sourced from hospital admissions records or routine unit-level screening. Several measures were collected by single platforms only, limiting comparison.

A rationale for measures collected was not identified for most platforms. Consequently, it is unclear what evidence-based approach was used to determine quality measure inclusion (e.g.,...
Public consultation and involvement

3.3. Scope of surveillance platforms

Surveillance platforms were hosted in the USA (n = 7, 33%), Australia (n = 3, 14%), or South America (n = 3, 14%). Europe and Asia hosted three platforms each.54

Platforms were sponsored by government, non-profit healthcare organisations, private foundations, and/or publicly funded granting agencies or were pay-per-use (e.g., Virtual Pediatric Systems LLC, PC4). Overall, 11 of 21 (52%) surveillance platforms were designed exclusively for the PICU cohort.44,48,50,52,56,61 Four (19%) surveillance platforms were for both adult and paediatric ICU cohorts.52,55,56

Five platforms focused on HAIs; this included one international registry based in developing nations (INIC-consortium),67 and the remaining three based in Australia (VICNISS),60 the United Kingdom (LabBase2)69 and the US (NHSN).61 One US-based multisite platform focused solely on thrombosis (Children’s Hospital-Acquired Thrombosis).73

The remaining registry collected various quality measures from paediatric hospitals within the US (Solutions for Patient Safety National Children’s Network).54

Surveillance platform data sources were largely based on user contributions—the submission of an online form with unidentified patient-level data. Automated surveillance platforms or electronic health record linkage with surveillance platforms was not reported. For the single-site platforms (local databases), information about how and when they were established, content acquisition, and ability to initiate novel enquiries against the data were, in general, not explicitly available, e.g., closed registries for participating institutions.

PICU Cloud, Australian and New Zealand Paediatric Intensive Care Registry (ANZPICR), Paediatric Intensive Care Audit Network, Virtual Pediatric Systems LLC, International Nosocomial Infection Control Consortium Australian and New Zealand Intensive Care Society Centre for Outcome and Resource Evaluation Central Line Associated Bloodstream Infection Registry, and paediatric cardiac critical-care consortium (PC4) reported national/international benchmarking activity. Participation in national and international surveillance efforts was difficult to determine for the remaining platforms.

There was variation in the external, public (consumer)-facing websites of surveillance platforms. Whilst larger surveillance platforms provided public access to aggregated data via an annual report (e.g., ANZPICR),51,53,56,63 the majority of platforms restricted access to contributing sites, with data not publicly available.44,48,49,53,55,61,66,69

Public consultation and involvement in platform/measure piloting was infrequently reported.

3.4. Additional measures and future developments

Expert consultation (8/12; 66% response rate) revealed quality measurement in critically ill children is largely determined by the individual PICU (except for nationally mandated measures). Stakeholders reported collecting additional (single site) measures within their unit surveillance programs (additional measures outlined in Table 3); however, reported benchmarking capacity was ‘limited’ due to varied case definitions and local restriction on the disclosure, collection, and use of patient-level data sharing. Overall expert consultation revealed a desire for a clinically meaningful set of PICU quality measures that ‘take the inconsistencies out of it’ (C04), with one stakeholder reporting ‘I don’t know what other units collect, this is just what we decided to collect as the quality and safety committee’ (C01).

Expert consultation revealed the ANZPICR has recently expanded its dataset with additional codes for methicillin-resistant \textit{S. aureus}, pneumothorax, dysrhythmia requiring intervention, and nontraumatic intracranial haemorrhage.70 Platforms identified as in development included the Victorian Congenital Anomalies Register, the Congenital Heart Alliance of Australia and New Zealand, and the French Paediatric Intensive Care Registry (planned measures: nosocomial infections including pneumonia, sepsis, accidental extubation, CAUTI, mortality).71

4. Discussion

Our review provides insights into current surveillance activities employed in paediatric intensive care. Unsurprisingly, we found variability in the types of quality measures (n = 57 unique measures) collected, with a lack of uniformity across measures, which limited benchmarking ability.62 Consultation with key stakeholders revealed a perceived uncertainty around ‘what to measure’ (which surveillance measures to prioritise) with key challenges noted to include lack of automation and data linkage, a focus on outcome measures when compared to structure and process measures, and scant measurement of patient and family measures. No platform reported collecting long-term outcomes in survivors of critical illness, with a notable lack of functional, neurocognitive, or quality of life outcome measurement. It is clear that work remains to identify optimal, yet feasible quality metrics that add value to clinical care processes and support patient safety measurement in the PICU.

Surveillance platforms primarily collected outcome measures (e.g., mortality was collected by 43% of platforms, unplanned readmission by 33%).73,74 In general, outcome measures were not balanced by the routine collection of associated process measures, that is a measure that collects information relating to the steps preceding the specified outcome. For example, units may track incidence of new delirium per admission; however, the process measure—percentage of children with delirium screening completed—was not routinely collected, making it difficult for policymakers to drive change or fully understand contributing factors. Outcome measures may be perceived as ‘gold standard’ for measuring healthcare quality; yet clinical outcome measurement often requires risk adjustment75 and measuring compliance with prevention strategies such as care bundle compliance (e.g., early sepsis identification triggers) can provide important driving data. Measurement of clinical processes (how often we do what we say we will) has a distinct advantage over measuring clinical outcomes.76,77 Process measures highlight what we (as a collective) can change rather than what we have done badly and is a catalyst for wider action and ownership. Further, process measures are the most suitable tool for performance management, for example, how many patients who developed sepsis were placed on the sepsis pathway. This is an area of potential development for the PICU community as process measures may be more sensitive to differences in the quality of care.79

Our findings demonstrate that surveillance programs currently rely heavily on manual processes such as chart review and discharge coding for data collection. Such processes are costly, time-consuming, and labour-intensive, creating delays in feedback of data to stakeholders. With advances in technology and clinical analytics/business intelligence frameworks, greater automation of surveillance platforms could be achieved with improved data,
<table>
<thead>
<tr>
<th>Database/registry name and country</th>
<th>Coverage</th>
<th>Established (yr)</th>
<th>Registry population</th>
<th>Number of contributing units</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>International</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>3. Victorian Healthcare Associated Infection Surveillance System (VICNISS), AUSTRALIA</td>
<td>Regional</td>
<td>2002</td>
<td>All cohorts, public and private hospitals, 26 hospitals with adult and/or paediatric ICUs</td>
<td>2 PICUs (2018 report)</td>
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<tr>
<td><strong>Asia</strong></td>
<td></td>
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<tr>
<td>5. Indian Registry of Intensive Care (IRIS), INDIA</td>
<td>National</td>
<td>ND</td>
<td>Paediatric and mixed ICUs</td>
<td>1 PICU</td>
<td></td>
</tr>
<tr>
<td>7. Paediatric Intensive Care Database (PIC), CHINA</td>
<td>Regional</td>
<td>2009</td>
<td>Paediatric ICU</td>
<td>1 PICU</td>
<td></td>
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<tr>
<td><strong>North America</strong></td>
<td></td>
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<td>9. PICU Collaborative Learning through Outcomes Data (PICU Cloud), USA</td>
<td>International</td>
<td>2014</td>
<td>Paediatric ICU</td>
<td>23 PICUs</td>
<td></td>
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<tr>
<td><strong>South America</strong></td>
<td></td>
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<td>11. Sociedad Argentina de Terapia Argentina Quality (SATIQ), ARGENTINA</td>
<td>National</td>
<td>1997</td>
<td>Paediatric ICU</td>
<td>50 PICUs</td>
<td></td>
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<tr>
<td><strong>United Kingdom</strong></td>
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<td></td>
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<tr>
<td>12. LabBase2B, UK</td>
<td>National</td>
<td>ND</td>
<td>All cohorts, public and private hospitals, and primary healthcare</td>
<td>3 PICUs</td>
<td></td>
</tr>
<tr>
<td>14. Children's Hospital-Acquired Thrombosis (CHAT) registry, USA</td>
<td>National</td>
<td>2014</td>
<td>Children's hospitals</td>
<td>7 children's hospitals</td>
<td></td>
</tr>
<tr>
<td>16. Pediatric Cardiac Critical Care Consortium (PC4) USA</td>
<td>National</td>
<td>2009</td>
<td>Paediatric, cardiac ICU</td>
<td>66 PICUs</td>
<td></td>
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<tr>
<td><strong>Europe</strong></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>19. Italian Paediatric Intensive Care Units Network TIPNet, ITALY</td>
<td>National</td>
<td>ND</td>
<td>Paediatric ICU</td>
<td>18 PICUs</td>
<td></td>
</tr>
<tr>
<td>20. Paediatric Intensive care Evaluation (PICE), NETHERLANDS</td>
<td>National</td>
<td>2000</td>
<td>Paediatric ICU</td>
<td>7 PICUs</td>
<td></td>
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</table>

A: Measures reported as per available registry data; B: Now known as second-generation surveillance systems (SSGSs); ND, no date; ANZ, Australia and New Zealand; ANZICS, Australian and New Zealand Intensive Care Society; CORE, Centre for Outcome and Resource Evaluation; ICU, intensive care unit; CLABSI, central line–associated blood stream infection; USA, United States of America; LOS, length of stay; UK, United Kingdom

*States complications, outcomes, and patient-reported outcomes.
linkage and interoperability.65,97 This issue has been recognised by the intensive care community. Yet solutions remain some time off, with stakeholders reporting challenges associated with data collection, including issues with data linkage, software integration, and data transfer from one system to another, which limits comparison across sites.

4.1. Stakeholder and consumer involvement

To enhance the useability and validity of surveillance data, the co-design and application of standardised quality measures for critically ill children is necessary.82 Despite the relatively large number of platforms identified, few provided a rationale for quality measure choice, with limited reports of consensus or prioritisation work. No reports of consumer involvement in measure selection or development were identified. Internationally, few studies have been undertaken to address this gap. A recent Delphi study78 conducted in Spain led to the development of a 20-item PICU quality indicator (measure) set. As one of the only consensus derived quality measure sets for PICU, the results can be used to inform surveillance practices and policy in the PICU. However, the generalisability of measures to the international PICU community is uncertain, with study sampling limited to individuals from the Spanish Society of Pediatric Intensive Care and consumers not involved in the development process. Additional work to develop quality measures in specialty PICU populations has also been undertaken. An indicator set for paediatric oncology patients with critical illness has been published; however, this work is limited in its generalisability with a focus on resource-limited settings.83 The current limitations of PICU quality surveillance activities have led to
an unequal focus on outcomes associated with care, with limited work to develop harmonised, simplified measures that are applicable across jurisdictions and PICU populations.

Criteria for meaningful quality surveillance in hospitals include the selection of quality measures that matter most to key stakeholders including patients and families.\textsuperscript{22,96} Furthermore, effectual surveillance requires selection of quality measures that reflect public health importance associated with high resource expenditure, mortality, and morbidity.\textsuperscript{84–86} It is conceivable that several measures that meet this requirement in the PICU cohort are not captured within current quality measurement sets. This limitation is not isolated to the PICU quality surveillance and has been noted in high-risk groups including immunocompromised adults,\textsuperscript{57} adult sepsis events,\textsuperscript{97} and paediatric patients with invasive fungal infections.\textsuperscript{88} Identifying the unique safety needs of critically ill children has been identified by health system executives as an important safety issue in international surveys.\textsuperscript{81} A national, even global, description and balanced assessment of PICU performance is needed to understand the burden of disease,\textsuperscript{87} what we do well, what we can do better, and ‘how everyday actions achieve safety’.\textsuperscript{99} Particularly as health services transition from the Safety 1 (focused on preventing adverse events) to the Safety 2 framework (focused on overall safety management approach including looking at what works well).\textsuperscript{90,91}

4.2. Future directions and implications

Key recommendations of this review are as follows: (i) prioritisation work to determine which measures matter most to clinicians, families, and the health service; (ii) greater inclusion of process measures and meaningful patient measures; (iii) standardised minimum dataset with clearly defined case definitions for international benchmarking; and (iv) plan for and where possible increase data linkage across systems to work towards automated surveillance platforms in the coming decades.

Future work should situate on refining current quality measures, to gather more meaningful, uniform, and comparable data in the PICU. This could include measures derived from existing data (patient experience surveys) that reflect activities to improve care outcomes and the patient experience. To ensure a more holistic and ‘connected’ view of PICU care quality,\textsuperscript{92} consensus and prioritisation methods underpinned by a co-design framework should be used to generate measures that are not only meaningful to clinicians and policymakers but to patients and their families. This will help to ensure that critical care leaders avoid pitfalls such as creating surrogate measures or the overinterpretation of results (resulting from small numbers) to successfully utilise quality metrics and accurately assess quality of care to add value for our patients and health system.\textsuperscript{53}

Finally, there are significant opportunities to develop automated surveillance methods and utilise novel machine learning algorithms and natural language processing tools in the PICU using electronic health data. Resulting clinical algorithms could be integrated as ‘early warning systems’ to support clinical decision-making and to reduce the incidence of costly complications such as CLABSIs and surgical site infections.\textsuperscript{94}

4.3. Strengths and limitations

There are some strengths and limitations to our review. While we identified inconsistent approaches to quality measurement, it is conceivable that hospitalised, critically ill children are included within hospital-wide surveillance programs with aggregated data not publicly available. However, given the high risk this population poses, risk adjustment strategies may not appropriately or accurately gauge the true burden of disease or address epidemiological risk factors (specific to this group) in whole of hospital efforts. Secondly, stakeholder consultation was limited to Australia, New Zealand, and USA PICUs due to sampling feasibility (investigator network). Therefore, it is feasible that single-site, international platforms may have been missed. This risk was lessened through international collaboration on the search strategy and email correspondence with included platform representatives/chairs. Finally, the heterogeneity of surveillance activities and measures limited our discussion of the feasibility of benchmarking and the effectiveness of surveillance activities to deliver quality improvement in the real-world setting.

5. Conclusion

In conclusion, we demonstrated considerable heterogeneity in surveillance platforms for critically ill children, particularly with respect to siloed efforts. While standardised case definitions appear to be employed for specific measures of healthcare-associated infection, the majority of quality measures were based on unit preferences limiting benchmarking capability. Greater harmonisation of quality measures is needed to address this issue, using consensus and prioritisation methods. Data linkage and electronic methods (automation) for quality surveillance are yet to be applied broadly within paediatric intensive care settings. Future research agendas should address increased collaboration with consumers and key stakeholders to develop more meaningful measures of quality and safety in the PICU. Expansion of currently collected measures to include more process and structural measures would be valuable. There are significant opportunities for health services and patient safety researchers to generate new partnerships and establish mechanisms to ensure the development and benchmarking of meaningful validated measures of quality in the PICU.

Conflict of interest

The authors have no conflicts of interest to declare.

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CReDiT authorship contribution statement

Jessica Schults: Conceptualisation, funding acquisition, methodology, investigation, writing — original draft, visualization. Claire Rickard: Investigation, validation, writing — review and editing. Karina Charles: Methodology, investigation, resources, data curation, writing — original draft, visualisation, project administration. Sarfaraz Rahman: Investigation, validation, writing — review and editing. Johnny Millar: Investigation, validation, writing — review and editing. Thimitra Baveas: Investigation, validation, writing — review and editing. Debbie Long: Conceptualisation, funding acquisition, methodology, writing — review and editing. Fiona Macfarlane: Investigation, validation, writing — review and editing. Nilesh M Mehta: Investigation, validation, writing — review and editing. Naomi Runnegar: Investigation, validation, writing — review and editing. Lisa Hall: Investigation, validation, writing — review and editing.
Appendix A. Supplementary data

Supplementary data related to this article can be found at https://doi.org/10.1016/j.aucc.2022.07.006.

References


