

# Pediatric Ethics Consultation Services

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abstract

**BACKGROUND AND OBJECTIVE:** Although guidelines call for the presence of pediatric ethics consultation services (PECS), their existence in children's hospitals remains unquantified. This study determined the prevalence of PECS in children's hospitals and compared the practice environments of those with versus without PECS.

**METHOD:** The Children's Hospital Association Annual Benchmark Report survey from 2020 and PECS data were analyzed for the association of PECS with domains of care.

**RESULTS:** Two hundred thirty-one hospitals received survey requests, with 148 submitted and 144 reachable to determine PECS (62% response rate), inclusive of 50 states. Ninety-nine (69%) reported having ethics consultation services. Freestanding children's hospitals (28% of all hospitals) were more likely to report the presence of PECS ( $P < .001$ ), making up 41% of hospitals with a PECS. The median number of staffed beds was 203 (25<sup>th</sup> quartile 119, 75<sup>th</sup> quartile 326) for those with PECS compared with 80 for those without (25<sup>th</sup> quartile 40, 75<sup>th</sup> quartile 121). Facilities with palliative care, higher trauma ratio, intensive care, and comprehensive programs were more likely to have PECS. Academic affiliation was associated with PECS presence ( $P < .001$ ). Settings associated with skilled nursing facilities or long-term care programs were not more likely to have PECS. Hospitals designated as federally qualified health centers ( $P = .04$ ) and accountable care organizations ( $P = .001$ ) were more likely to have PECS.

**CONCLUSION:** Although PECS function as formal means to clarify values and mitigate conflict, one-third of children's hospitals lack PECS. Future research is needed to understand barriers to PECS and improve its presence.



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**WHAT'S KNOWN ON THIS SUBJECT:** PECS represent key means for clarifying values and mitigating conflicts. Although national guidelines and practice standards call for PECS presence in pediatric care settings, the integration of PECS into children's hospitals remains unmeasured.

**WHAT THIS STUDY ADDS:** This national registry study reveals that one-third of children's hospitals do not have ethics consult services with a notable presence in large, freestanding, academically affiliated, high-acuity settings.

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The increasing complexity of health care for children translates into multidimensional ethics issues arising in pediatric hospitals.<sup>1</sup> Pediatric ethics consultation services (PECS) offer a forum to help clarify values uncertainty and mitigate values conflicts. PECS' role includes the completion of case consultations, the review and development of hospital policies with attentiveness to values, the provision of ethics education, and the promotion of a moral climate.<sup>2-5</sup>

In 2007, a national survey of adult hospitals revealed the presence of interdisciplinary ethics consultation services in 81% of all general hospitals in the United States and 100% of hospitals with >400 beds.<sup>6</sup> More recent follow-up of this adult national study completed from 2017 to 2018 revealed that the number of ethics case consults performed annually in adult hospitals increased by 94% compared with the previous decade.<sup>7</sup>

The current literature on PECS is limited to individual institutions, primarily reporting on consult themes and trends. A retrospective review of 165 pediatric ethics consults at 1 academic health center from 2008 to 2017 revealed an increase in consult frequency over time, primarily arising from inpatient settings for patients <1 year of age.<sup>8</sup> Two pediatric cancer centers have analyzed ethical case themes over a decade, revealing complex themes among multiple stakeholders, including decision-making, risks-benefit ratio, resuscitation preferences, and requests to provide nonbeneficial treatment.<sup>9,10</sup> An analysis of 245 pediatric ethics consults at a large academic children's hospital revealed common contextual attributes relevant to relational, emotional, and pragmatic domains, including discord (43.3%), acknowledged dilemma (33.5%),

and articulate disagreement (29.8%).<sup>11</sup> These institution-specific studies are informative in recognizing that values uncertainties and complex ethical challenges exist in pediatric care settings.<sup>12</sup> Less is known about whether structured mechanisms, such as PECS, exist to help address these realities in other children's hospitals.

A 2010 survey including perspectives from ethicists at 33 freestanding children's hospitals revealed that ethics consultant methods, ethics policy, and financial support for ethics did not differ by respondent hospital size.<sup>13</sup> This landmark pediatric ethics survey offered valuable insight into ethics consultation staffing and ethics policy scope and yet only included a cohort reporting presence of PECS.<sup>13</sup> The extent to which PECS exist across children's hospitals remains largely unmeasured.

The purpose of this study was to quantify the number of children's hospitals with PECS in the United States and to describe their demographics and operational, missional, educational, and financial domains.

## METHODS

Because of the public and deidentified nature of the dataset, the University of Nebraska Institutional Review Board determined the study to not constitute human subject research. During an 8-month period (April to December 2021), the Children's Hospital Association (CHA) surveyed 231 children's hospitals in the United States regarding the programs and patient care services offered during fiscal year 2020 (July 2020 to June 2021). CHA membership hospitals received electronic invitations to complete 1 annual benchmark report (ABR) per facility. Reminders were sent

virtually until survey completion in 3-week intervals for 60 days. Financial incentives were not provided for study completion.

The CHA ABR was selected as the PECS data source because of the inclusion of children's hospitals throughout the United States. A data use agreement was completed between the study team and CHA. CHA provided demographic and programmatic data for research specific to this PECS analysis. Because the ABR did not ask respondents whether the care setting had a PECS, the responsible party from each children's hospital survey submission was recontacted by the study team via telephone or electronic correspondence between January and June 2022 to inquire whether the children's hospital did or did not have an ethics consultation service (binary inquiry) in fiscal year 2020.

Our study team determined a priori to analyze specific questions on the ABR on the basis of the first author and statistician's previous study of pediatric palliative care prevalence using the same methodology.<sup>14</sup> Demographic data included state, region, number of staffed beds, freestanding or embedded. Four health system domains were prioritized on the basis of the previous work of the first 2 authors:<sup>14</sup> (1) operational (presence of pediatric palliative care, trauma acuity, NICU level, association with a skilled nursing facility, home health access, medical day program, skilled nursing, and long-term care facility), (2) missional (magnet nursing designation, care coordination services [defined as staff hired to "deliberately organize patient care activities and to share information among all care participants concerned with a patient's care to achieve safer and more efficient care"<sup>15</sup>], social determinant of

health screening [defined as “systematic assessment of the nonmedical factors that influence health outcomes”<sup>16</sup>], (3) educational (Accreditation Council for Graduate Medical Education residency program-affiliated, American Medical Association medical school affiliation), and (4) financial (designation as an accountable care organization [ACO], designation as a federally qualified health center [FQHC]). ACOs “come together to deliver coordinated, high-quality care and share responsibility for the quality, cost, and overall care for a group of patients.”<sup>17,18</sup> FQHCs “qualify for funding under Section 330 of the Public Health Service Act, serve an underserved area or population, offer a sliding fee scale, and meet additional governing board requirements.”<sup>19</sup> These categories were predetermined to align with a previously described framework and conceptual model in pediatric care.<sup>20–22</sup>

The survey results were aggregated and anonymized. SAS version 9.4 was used to summarize and analyze the data. The staffed bed variable was summarized by using the median, quartiles, and minimum/maximum with analysis by using the nonparametric Mann-Whitney *U* test. Categorical variables were summarized by using frequencies and percentages. These variables were analyzed by using  $\chi^2$  tests or Fisher’s exact tests when expected cell counts fell to <5.

## RESULTS

A total of 231 CHA membership hospitals received ABR survey requests, with 148 submitted successfully for the 2020 fiscal year and 144 of the survey best informants reachable for the binary yes/no question about whether the children’s hospital had a PECS (response rate 62%). The District of

Columbia and all 50 states were included as respondents.

Of the 144 included children’s hospitals, 99 (69%) reported having PECS, and 45 (31%) reported not having PECS (Table 1). There was not a statistically significant difference in whether a children’s hospital had or did not have a PECS by geographic region.

Freestanding children’s hospitals (41%) were more likely to report the presence of a PECS ( $P < .001$ ) compared with settings embedded within adult hospitals (59%). For those care settings with PECS, the median number of staffed beds was 203 (minimum 15, maximum 782, 25th quartile 119, 75th quartile 326) compared with 80 median number of staffed beds for those without PECS (minimum 12, maximum 199, 25th quartile 40, 75th quartile 121).

## Operational Characteristics

The presence of a pediatric palliative care program was associated with the presence of PECS ( $P < .001$ ). Higher-level trauma center accreditation was associated with the presence of PECS ( $P < .001$ ), and Level I trauma centers, recognized as tertiary care regional resources, were most likely to report the presence of PECS (61%). Similarly, higher NICU designation was associated with the presence of PECS ( $P < .001$ ). Less than 10% of settings without a NICU reported having PECS ( $n = 8\%$ ).

Those children’s hospitals affiliated with a skilled nursing facility for children ( $P = .15$ ) or a long-term care facility for pediatric patients ( $P = .52$ ) were not more likely to have PECS. However, there was a higher likelihood of home health services existing in settings with PECS ( $P = .001$ ). Twenty-six children’s hospitals reported the presence of a medical day program

for children with complex needs, also with a higher likelihood in settings with PECS ( $P = .02$ ).

## Missional and Educational Characteristics

Magnet nursing designation was associated with the presence of PECS ( $P < .001$ ). The presence of care coordination services for pediatric primary medical homes was reported by 133 children’s hospitals, although this was not associated with the presence of PECS ( $P = .13$ ). Screening processes for social determinant of health needs among the hospitalized pediatric population (78%) was more likely in settings with PECS ( $P = .003$ ).

Children’s hospitals with American College of General Medical Education residency programs were more likely to report PECS (86%,  $P < .001$ ) as were those with American Medical Association medical school affiliations (88%,  $P < .001$ ).

## Financial Characteristics

Twenty of 23 care settings that self-designated as an FQHC reported the presence of a PECS (20%,  $P = .04$ ). Among the 41% of children’s hospitals designated as ACOs in the ABR, 50 (51%  $P = .001$ ) reported having PECS.

## DISCUSSION

As of 2020, almost one-third of children’s hospitals do not host PECS with a clear presence of this resource within larger, freestanding, academic-affiliated pediatric care settings.

The lack of PECS presence in children’s hospitals stands counter to national standards and practice guidelines. The American Medical Association Code of Medical Ethics Opinion 9.115 declares “all hospitals and other health care institutions should provide access to ethics

**TABLE 1** Children’s Hospital Characteristics and the Presence of PECS

Variable	Total Distribution, <i>n</i> (%), <i>N</i> = 144	Presence of PECS, <i>n</i> (%), <i>n</i> = 99 (69%)	<i>P</i>
Region			.37
Midwest	35 (24)	28 (28)	
Northeast	24 (17)	15 (15)	
South	56 (39)	38 (38)	
West	29 (20)	18 (18)	
Setting			<.001
Embedded	103 (72)	58 (59)	
Freestanding	41 (28)	41 (41)	
Palliative care			<.001
No	45 (31)	24 (21)	
Yes	99 (69)	91 (79)	
Trauma center			<.001
Level I	67 (47)	60 (61)	
Level II	22 (15)	14 (14)	
Level III	2 (1)	1 (1)	
None	53 (37)	24 (24)	
NICU			<.001
Level II	1 (1)	1 (1)	
Level III	31 (22)	20 (20)	
Level IV	85 (59)	70 (71)	
None	27 (19)	8 (8)	
Home health access			.001
No	91 (63)	54 (55)	
Yes	53 (37)	45 (45)	
Medical day program			.02
No	118 (82)	76 (77)	
Yes	26 (18)	23 (23)	
Skilled nursing facility			.15
No	126 (87)	84 (85)	
Yes	18 (13)	15 (15)	
Long-term care			.52
No	132 (92)	92 (93)	
Yes	12 (8)	7 (7)	
Magnet designation			.001
No	66 (46)	36 (36)	
Yes	78 (54)	63 (64)	
Care coordination			.001
No	17 (12)	9 (9)	
Yes	127 (88)	90 (91)	
Social determinant screen			.003
No	43 (30)	22 (22)	
Yes	101 (70)	77 (78)	
Residency affiliation			<.001
No	37 (26)	14 (14)	
Yes	107 (74)	85 (86)	
Medical school affiliation			<.001
No	34 (24)	12 (12)	
Yes	110 (76)	87 (88)	
FQHC			.04
No	121 (84)	79 (80)	
Yes	23 (16)	20 (20)	
ACO			.001
No	85 (59)	49 (49)	
Yes	59 (41)	50 (51)	

recognizes IEC’s role in organizational ethics and policy development.<sup>24</sup>

Although the Joint Commission includes standards requiring hospitals to establish a “mechanism to consider ethical issues in patient care,” how to operationalize this recommended multidisciplinary ethics committee is not clearly delineated or defined.<sup>25</sup> This study reveals variation in whether institutions have PECS and encourages further research into the most efficient and effective mechanism of addressing ethics needs within children’s hospitals.<sup>26</sup> Reliance on concurrent existing mechanisms, such as patient advocacy or navigation, chaplaincy or palliative care, and regulatory administrative offices or compliance may not be fully adequate to meet the ethically complex case needs and range of ethical challenges occurring in pediatric care settings.<sup>2, 12,27,28</sup> Additional consideration should be given to systematizing PECS through train-the-trainer models, local capacity-building, and spoke-hub service models.<sup>29,30</sup>

The high rate of PECS presence in settings with intensive care or trauma beds may reflect a priority of high-acuity settings to establish and maintain PECS services as compared with long-term care settings. Pediatric ethics focus seems to be on moments of trauma or imminent life-sustaining treatment decisions in the acute or clinically critical period.<sup>31–35</sup> Because values considerations and values conflicts occur in settings caring for children with chronic, complex conditions and longitudinal technology dependence, the role of ethics consultation services across settings warrants ongoing consideration.<sup>36,37</sup>

The higher likelihood of PECS presence in settings with academic affiliations bodes well for expanding

consultation services.”<sup>23</sup> Specific to pediatric populations, the American Academy of Pediatrics Institutional Ethics Committees (IEC) Policy Statement calls for “the availability

and use of an IEC as an important mechanism for the discussion and resolution of ethical issues raised in the individual and institutional provision of patient care” and also

the pipeline of trainees with an interest in ethics and recognition of its value based on exposure during training. PECS's presence in learning environments should commit to expanding the diversity of students exposed to ethics to broaden the diversity of ethics consultants entering practice. Because the integration of ethics in medical school and residency curricula varies widely,<sup>38</sup> conscientious effort should be invested in exposing learners from diverse backgrounds to the work and impact of PECS for reflection, professional development, and future career commitments.<sup>39-41</sup> A future consideration would be the integration of ethics curricula as "tracks" of training for learners more likely to end up in smaller care settings, such as within rural health or community care training programs.

The finding that PECS presence was more likely in settings designated on the ABR survey as being an FQHC or ACO may reflect the prioritization of values clarity as a service. Although we would be hesitant to imply that PECS should be operationally motivated toward reducing organizational costs of care,<sup>42</sup> issues of equity, stewardship, resource allocation, and justice remain within the scope of macro ethics considerations.

Limitations of this study include potential inaccuracies in ABR data reporting, although this was minimized by reliance on a point

person assigned by hospital administration in each setting. As with any survey data, there may have been demographic differences among those who did or did not complete the survey, although CHA did not appreciate a notable difference in terms of hospital size, location, or annual budget between responders and nonresponders. Another potential limitation is that the binary question of whether a children's hospital has a PECS does not reliably answer the greater question of whether children and families receiving care in that setting actually have access to these services because PECS may not have a mechanism for either informing families about PECS or the family-initiation of consults.<sup>43</sup> The ABR did not inquire about the rurality of the children's hospital and so, potential association with geography was not recognized in this study, although rurality has been associated with less access to formal ethics consultation services in adult settings.<sup>44,45</sup> The lack of a multivariable model represents a study limitation. Additional research is warranted to explore the actual staffing, function, scope of services, and quality outcomes of PECS as well as barriers to their implementation.

This study provided an overview of the prevalence of PECS in children's hospitals, identifying that PECS tended to center around freestanding, academically affiliated,

larger, higher-acuity children's hospital settings. Despite practice guidelines and standards calling for PECS in all children's hospitals, approximately one-third of pediatric inpatient settings in the United States lack PECS. The lack of PECS existence risks gaps in robust mechanisms to not only help clarify values uncertainty but to also mitigate values conflict and prevent ethical crises. The findings from this national study warrant the proactive engagement of national leadership with hospital administration to improve the presence of PECS in children's hospitals.

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## ABBREVIATIONS

ABR: annual benchmark report  
ACO: accountable care organization  
CHA: Children's Hospital Association  
FQHC: federally qualified health center  
IEC: Institutional Ethics Committees  
PECS: pediatric ethics consultation services

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