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# Prevalence of hospital websites with Post-Intensive Care Syndrome-pediatrics (PICS-p) information





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Survival after critical illness and Pediatric Intensive Care Unit (PICU) stays has increased substantially and lasting impacts on survivors and parents is increasingly identified.[1–3] The Post-Intensive Care Syndrome—Pediatrics (PICS-p) framework describes the physical, cognitive, emotional, and social health sequelae following critical illness in children.[3] This framework places parents and their experiences along side their child's experience.[4] Despite increasing provider information about PICS-p, little is known about the availability of information for parents and caregivers about PICS-p.

Up to 98% of parents will turn to the Internet for information about their child's health and most parents will use this information to ask more questions of their health care providers.[5,6] Furthermore, nearly 20% will change a health care decision based on what they find on the Internet.[7] While social media has a growing influence on parental health care decisions, nearly 75% of parents cite hospital-based websites as the most trusted source of disease information on the Internet.[6]

As such, we performed an environmental scan and structured search of children's hospital websites for the presence of patient-facing information regarding PICS-p.[8] We hypothesized that many hospitals will have patient education materials but few will have information about PICS-p. Further, we hypothesize that hospitals with PICS-p information will have larger PICUs and be associated with PICU training programs.

This study was exempted and not regulated by the Institutional Review Board at the University of Michigan (HUM00214815).

We identified hospitals in the United States with Pediatric Intensive Care services using the 2020 American Hospital Association (AHA) annual survey and Children's Hospital Association (CHA) membership rosters. We followed a standardized protocol with systematic searching of participating hospitals' websites to identify and analyze patient-facing educational material about PICS-p as well as balancing measures of any pediatric-specific patient education materials. Specifically, we searched for the most common reasons for children to present for hospital-based care, including "bronchiolitis", "asthma", and "hyperbilirubinemia" (Supplemental Material).[9] We included only patient education materials and excluded other sources of information such as news articles and blog posts that may not be assessed for accuracy or completeness.

We collected general information about hospitals and content of hospital websites, including hospital name and the state location, availability of a hospital website, a PICU specific webpage, PICS-p educational materials, post-ICU follow up information, and presence of any pediatric health education materials.

After identifying hospitals which provide Pediatric Intensive Care services, three members of the research team independently extracted website information using the data collection tool. Questions or discrepancies were adjudicated by a second member of the research team. Data were collected from April to October, 2022. All results were aggregated using descriptive statistics. Statistical analysis was performed using Stata 16 (StataCorp, LLC, College Station, TX).

We identified 340 hospitals that provided critical care services to children and had publicly available websites (Table 1). Among these, 8 (2.4%) had any information about PICS-p. One hundred and forty-one (41.5%) provided information about pediatric-specific health conditions. While every state but Wyoming provided pediatric intensive care services, 41/50 (82%) provided information about pediatric-specific disease information (Fig. 1). The eight centers which had PICS-p information were in 6/50 (12%) states and 5/8 centers with PICS-p information (62.5%) had post-PICU follow up clinics or contact information.

After the eight centers were identified, specific hospital characteristics were compiled. There was variation in the hospital characteristics in those PICS-p information available, with ranges in PICU bed size (10 to >30) and PICU training program associations (5/8, 62.5%) (Supplementary Table 1).

In this environmental scan of patient-facing hospital websites, we found that public-facing hospital websites are common but PICS-p information was publicly available in only 2.4% of hospital websites which provide pediatric intensive care services. Furthermore, we found that many hospitals have existing infrastructure to support public availability of pediatric-specific health condition information.

We found that hospitals that have publicly available PICS-p information are few and far between. Over 5 million children are admitted to a hospital each year in the United States, and up to 15% will require PICU care.[9,10] While admissions to PICUs continue to increase, mortality continues to decrease, creating an ever-growing cohort of PICU survivors with increasing focus on the optimization of survivor outcomes.[1,10] The PICS-p framework

**Table 1.** Hospital website content characteristics.

| Hospital Website Characteristic | Websites Possible ($N = 340$) |
|---|---|
| PICU Specific Webpage | 229 (67.3%) |
| Pediatric Education Materials | 141 (41.5%) |
| Post-ICU Follow Up Information | 8 (2.4%) |
| PICS-p Information | 8 (2.4%) |

The characteristics and content of publicly available websites. Presented as counts (*N*) and percentages (%).
*PICU* Pediatric Intensive Care Unit, *PICS-p* Post Intensive Care Syndrome – Pediatrics.

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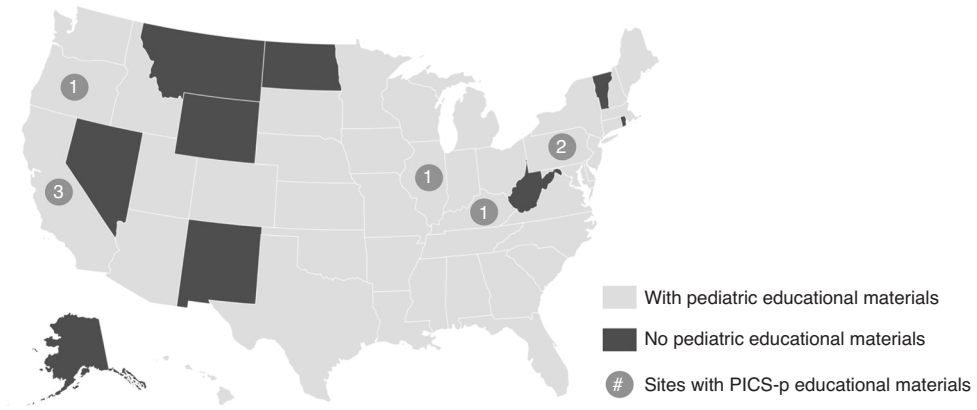


**Fig. 1 Distribution of educational materials on Children's Hospital Websites.** Distribution of Hospitals in the United States which provide patient-facing educational materials on websites. States with educational materials are shaded. The number of hospitals within a state where PICS-p materials are available is represented by *dots* and *numbers*.

conceptualizes that the family is an interdependent unit.[3] Given the integral role that caregivers play on the pathway to recovery and parents' propensity to use the Internet for health information regarding their children's illness, it is imperative that reliable information is readily available and easily digestible.[6] General Internet-sourced health information for parents and caregivers has repeatedly shown poor quality and reliability and may not be written at a comprehension level appropriate for parents.[5,11] The lack of easily accessible and reliable information from sources that parents trust may create a gap in a child's recovery after critical illness. The impact of this gap in communication requires further investigation.

We found no common characteristics among the eight hospitals with PICS-p publicly available information. We hypothesized that larger PICUs with associated PICU training programs would be more likely to have PICS-p publicly available information. However, nearly half of the hospitals had no training program and PICU sizes ranged from small to large. This may be related to the novel concept of PICS-p with local champions more likely to drive change.[12] Additionally, we may not have been able to draw conclusions regarding hospital characteristics based on the small number of hospitals available.

We found that fewer than half of hospital websites had publicly available information on selected pediatric-specific health conditions. The infrastructure required to create a repository of information may be a barrier to provide information to families. However, because infrastructure already exists in the remaining 133 websites, inclusion of this information may be easier. Independent websites and society guidelines do provide patient and family education material about PICS-p.[13–15] These websites may be inadequate sources, as parents trust hospital-based websites for health information for their children.[6] International societies and experts should create comprehensive patient education materials about PICS-p that can be adapted or shared through children's hospital websites. In doing so, this information would then be available in at least 41 states, thus improving the education gap that currently exists.

The strengths of this study include the systematic approach to searches. It is possible that we missed other relevant sources due to the search strategy and protocol and it is unlikely that this would capture every source. However, given the multiple synonyms and structured search of a large number of hospitals that provide pediatric intensive care services, we intended to simulate what a family member may use to search health-related conditions. While we selected specific balancing measures for our search protocol to include common diagnoses for hospitalized conditions, asthma, bronchiolitis, and hyperbilirubinemia are also common pediatric conditions that may be treated as outpatient or emergency department visits. As such, these conditions may not completely reflect inpatient-specific conditions and may be too sensitive of a measure of educational material presence. However, as these conditions are among the top 5 inpatient diagnoses in 2022 across age groups, it likely represents a reasonable sample of conditions which caregivers may search.[9] We acknowledge that physical materials regarding PICS-p may be given to families and would not be included in this search. Furthermore, we did not evaluate the language in which the materials are presented, only their presence. Additional research is needed to evaluate the impact Internet-based educational materials for non-English speaking children and families, as well as healthcare systems outside of the United States. Lastly, the accuracy and content of the educational materials was not evaluated. Further research should seek to understand the health condition educational needs and content gaps that currently exist for patients and families after critical illness.

Hospital-based, publicly available, trusted information about PICS-p is lacking. As parents trust hospital-based websites, it is imperative that more hospitals provide this information for families. An opportunity exists for international societies and experts to partner with hospitals to create reliable patient education regarding PICS-p.

## DISCLAIMER

This manuscript represents the views of the authors and does not represent the views of the Department of Veterans Affairs or the US government.

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## DATA AVAILABILITY

The datasets generated during and/or analysed during the current study are available from the corresponding author upon reasonable request.

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## AUTHOR CONTRIBUTIONS

S.M.G. and E.F.C. participated in the study design. All authors participated in data analysis and interpretation and contributed important intellectual content during manuscript drafting and revision. All authors have read and approved the final manuscript.

## COMPETING INTERESTS

The authors declare no competing interests.

## ETHICS APPROVAL AND CONSENT TO PARTICIPATE

This research was approved by the Institutional Review Board at the University of Michigan (HUM00214815). Written informed consent was applicable for patients.

## ADDITIONAL INFORMATION

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