



## SPECIAL REPORT

# Tools to guide the identification and implementation of care consistent with the psychosocial Standards of care

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## Abstract

Fifteen evidence-based Standards of psychosocial care for children with cancer and their families have been established. Despite the importance of implementing the standards, significant barriers and challenges exist. In order to overcome barriers to implementation and assess the level of current psychosocial care, a model of evaluating psychosocial care (Matrix) and a set of pathways toward achieving optimal care (Guidelines) were developed. This special report describes the process involved in the creation of standard templates and development of content based on rigorous reviews from multidisciplinary psychosocial experts, focus groups, and multiple revisions based on further expert review. The resulting Matrix and Guidelines are included as Supplemental Information.

## KEYWORDS

implementation, pediatric, psychosocial, standards of care

## 1 | INTRODUCTION

A substantial body of research documents the psychosocial impact of cancer on children and families.<sup>1,2</sup> While most pediatric cancer centers offer services to children and families to mitigate that impact, providing comprehensive psychosocial care remains challenging. Care is often inconsistent across and even within centers.<sup>3,4</sup> Importantly, there is a growing demand for accountability and outcome-driven, cost-effective models of care. In response, psychosocial clinicians are being challenged to standardize their approach and evaluate the efficacy of their clinical efforts.<sup>5</sup> To that end, 15 evidence-based Standards for psychosocial care for children with cancer and their families were published in December 2015.<sup>6</sup>

The Standards address a broad range of psychosocial care from diagnosis through survivorship or end of life. Each Standard is supported by a rigorous systematic literature review and an evaluation of the evidence's rigor.<sup>7-10</sup> The Standards, which have been endorsed by key professional and advocacy organizations,<sup>11</sup> provide a blueprint for services for all children diagnosed with cancer and their families across treatment settings.

Several studies demonstrated that while the spirit of the Standards were being met in some centers, there were fiscal and institutional challenges to implementation, and overall uptake was slow.<sup>3,12-14</sup> Additionally, the authors received tremendous support to implement the Standards along with frequent requests for guidance on best practices for adopting the Standards across cancer centers of different sizes or current level of resources. These data and requests from frontline clinicians suggested that delivery models and implementation tools

for individual cancer site use were needed. Implementation of practice standards, however, requires attention to the day-to-day responsibilities of psychosocial providers, the constraints they face, and the practice of psychosocial care in medical settings. Implementation also requires an honest assessment of the quality of care currently provided at each pediatric cancer center. This paper provides the methodology used to develop tools that can now guide the identification and implementation of care consistent with the standards of psychosocial care.

## 2 | METHODS

A Matrix and Guidelines Working Group was formed, consisting of members of the Standards leadership group, first authors of each of the published Standards,<sup>6</sup> and other representatives from pediatric oncology, nursing, social work, psychology, psychiatry, education, and child life. The Standards leadership group explored potential implementation models<sup>15-19</sup> and shared their clinical experiences to ultimately create a checklist that delineated what would be needed to implement each Standard. The checklist was reviewed during a focus group held at the 2018 Association of Pediatric Oncology Social Workers (APOSW) conference. There was consensus that a checklist alone provided limited specificity in terms of rating how well their center was performing in implementing each Standard. Focus group members also suggested that specific strategies with an accompanying list of resources would be more useful.

In response, a 5-point scoring system was created in a *Matrix* format (*Institutional Assessment Tool*). A score of 1 indicated a lack or an insufficient level of implementation of the Standard and 5 reflected comprehensive care and complete implementation. Accompanying the Matrix, *Guidelines* were developed. The Guidelines provide specific guidance (ie, concrete action items) on "how to" improve implementation of each Standard and the center's level/quality of care. The Matrix and Guidelines development were informed by the Cancer Psychosocial Care Matrix (CPCM) assessment tool<sup>15</sup> that was created to assist community cancer centers in evaluating capacity to provide quality psychosocial care. The CPCM defines specific components of care that comprise a comprehensive psychosocial program and provides measurable milestones within each component of care.

### 2.1 | Matrix

For each Standard, the Matrix has three columns: (a) the published *Standard*; (b) the *domains and essential elements* to consider in the assessment or implementation of that Standard; and (c) *levels*, a 1-5 scoring rubric.

### 2.2 | Guidelines

The Guidelines include the Standard across the top and has three columns: (a) *Actions* describe what the Standard requires for imple-

mentation (eg, conduct systematic assessments of youth and family psychosocial health care needs); (b) *Strategies* are the specific tasks to assist providers and teams in their implementation of the Standard; and (c) *Resources/Tools* provide assessment tools, interventions, organizations, trainings, articles, and more (including live links) that may be helpful in implementing the recommended strategies.

The Matrix and Guidelines templates underwent five iterative revisions based on extensive reviews within our working group, multidisciplinary expert opinion, and a working group meeting with patient advocates and experts of the CPCM.

## 3 | RESULTS

Finalizing the 15-Standard Matrix and Guidelines to prepare it for dissemination and use was an eight-step process. Suggested edits for each Standard were reviewed by the leadership group (Lori Wiener, Mary Jo Kupst, Wendy Pelletier, and Amanda L. Thompson) as well as other content experts, and were accepted only after consensus agreement.

Step 1. Initial drafts of the Matrix and Guidelines for each Standard were created (Lori Wiener and Mary Jo Kupst).

Step 2. Each initial draft of the Matrix and Guidelines was sent to the primary authors for the paper on that Standard for review and edits. The primary authors were asked to bring the Matrix and Guidelines to their pediatric cancer site for review. They were specifically encouraged to ask, "Can the Matrix, as written, be used to confidently rate where we stand on implementing this Standard within our program?" and "Are the Guidelines clearly written, helpful, and potentially useful in increasing our score/full implementation?"

Step 3. Once all 15 standards were reviewed by the primary authors, the Matrix and Guidelines underwent additional reviews by multidisciplinary experts in psychosocial care and the specific standard topic (eg, neurocognitive monitoring [neuropsychologists], school reentry [education specialists], preparation for procedures [child life specialists], palliative care [physicians, nurses], and adherence [psychologists]).

Step 4. APOSW members who participated in the 2018 focus group were invited to participate in an in-depth review of the Matrix and Guidelines in advance of the 2019 APOSW conference. Eighteen participants from 15 cancer centers were provided the draft documents with a link to an online rating form (Table 1). They then attended a focus group during the conference to gather feedback on the quality and clarity of the wording, feasibility, and usefulness of the Matrix and Guidelines and to provide suggestions for changes on each of the 15 Standards.

Step 5. Following review of the online and in-person feedback from APOSW, revisions to the Matrix and Guidelines were made (Lori Wiener, Mary Jo Kupst, and Wendy Pelletier). Those with substantial changes were returned to the primary authors for approval or further revisions.

Step 6. The next layer of reviews was provided electronically by psychosocial experts within the American Psychosocial Oncology Society Pediatric Special Interest Group, psychologists from the Society of Pediatric Psychology (SPP) Hematology and Oncology Special Interest

**TABLE 1** Tool for review of Matrix and Guidelines for each Standard of care

	1	2	3	4	5	Comments
	Strongly disagree				Strongly agree	
Matrix						
Provides enough information for a center to score/grade how they are implementing the standard						
<b>Domains</b> are clear and helpful						
Provides enough flexibility for a center to score how they are implementing the Standard						
Guidelines						
<b>Standard</b> is clearly described						
Items in the <b>Actions</b> column are clear/easy to comprehend						
Items in the <b>Actions</b> column make implementation feasible for my center						
Items in the <b>Strategies</b> column are appropriate for most pediatric cancer programs						
Items in the <b>Strategies</b> column can help centers to improve their score/care						
What is missing from the <b>Strategies</b> column that can help centers to improve their score/care?						
Items listed in the <b>Resources/Tools</b> column are helpful						
What is missing from the <b>Resources/Tools</b> column that can help centers to improve their score/care?						
	Yes	Yes, with modifications	No, but advisable	No, why not		
Do you feel your center would be open to using the Matrix and Guidelines to improve care? If no, please tell us what would make these more acceptable to your center						

Note. Content has been converted from its original online form to table format for publication.

Group and Behavioral Science Committee of the Children's Oncology Group (COG), and child life specialists. Reviewers were also asked to comment on the helpfulness of the tools and resources provided within the Guidelines and the consistency across Standards in terms of specificity, length, and implementation strategies. Based on these reviews, further versions to the documents were created (Lori Wiener, Mary Jo Kupst, Wendy Pelletier, and Amanda L. Thompson).

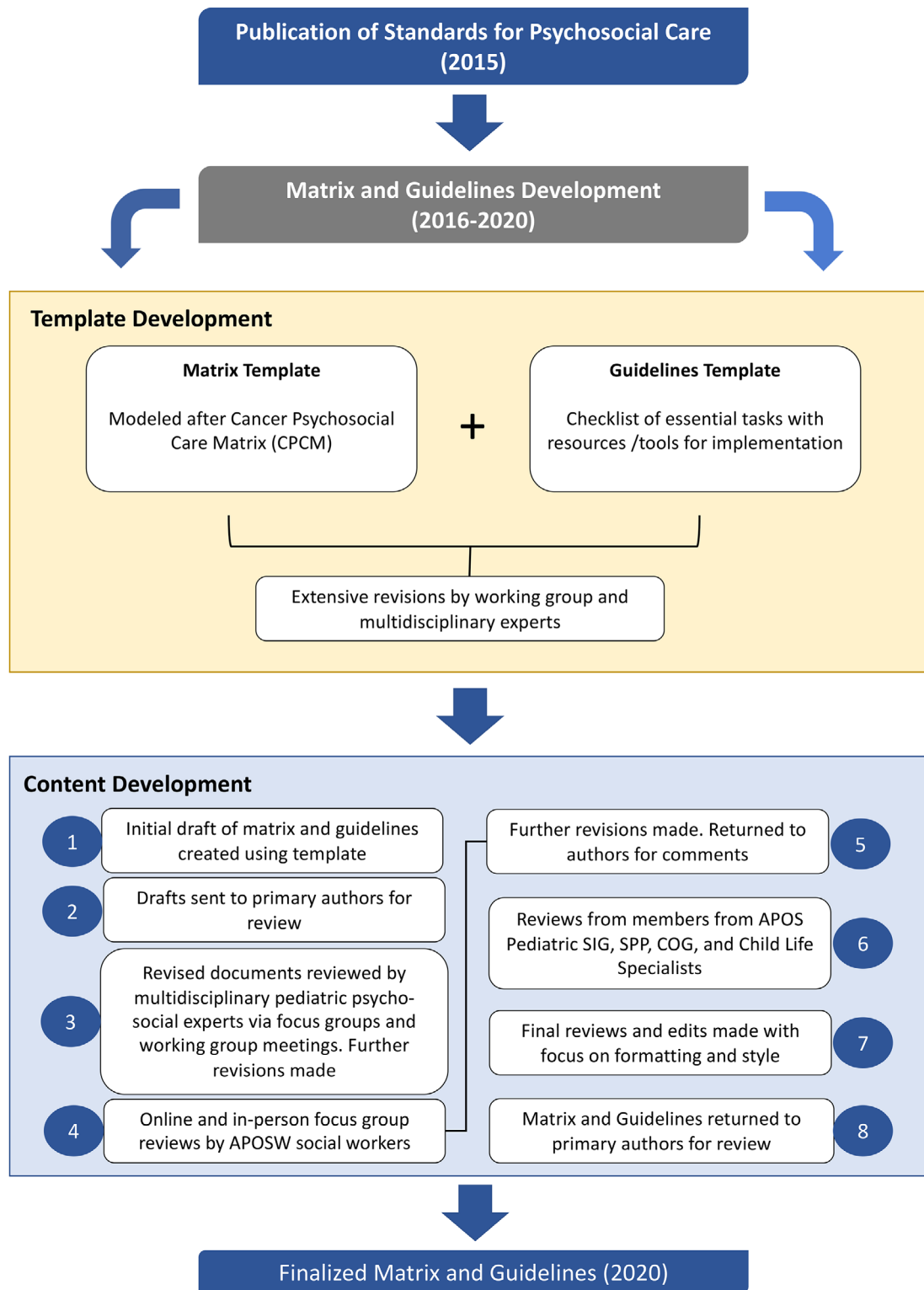
Step 7. Final reviews and edits were made, focusing on consistent formatting, content, and style.

Step 8. The Matrix and Guidelines were returned to the primary authors for their final review. As the primary author for each Standard was encouraged to share the Matrix and Guidelines with their pediatric cancer team for comments and recommended revisions, an accurate number of how many persons reviewed each Standard is unknown. However, in all, outside of the writing teams, external reviews of the Matrix and Guidelines were provided by at least 49 professionals at 37 pediatric cancer centers. Figure 1 provides a graphic illustration of the methods used to develop the Matrix and Guidelines. The Matrix and Guidelines can be found in Supplemental Information.

## 4 | DISCUSSION

The Institute of Medicine (IOM), American Academy of Pediatrics (AAP), International Society of Paediatric Oncology (SIOP), and other professional and parent advocacy organizations have issued urgent calls to reduce the suffering of children with cancer by addressing their psychosocial needs during and after treatment. Despite these pleas, comprehensive standards that are up-to-date, evidence- and consensus-based, and able to guide provision of essential psychosocial services to all children with cancer are not being consistently implemented in pediatric cancer centers.

The evidence-based Standards of care provide a structure or blueprint to guide state-of-the-art pediatric psychosocial services. These standards were published 5 years ago. Unfortunately, there was previously limited guidance for cancer centers on implementation. The Matrix presented in this paper allows centers to gauge how well they are implementing these Standards through specific quantitative ratings. The Guidelines provide "how to" assistance to provide optimal care by providing centers with ideal care goals, which may not be fully



**FIGURE 1** Pathway to Matrix and Guidelines development

achievable in less well-resourced programs but includes resources and clinical tools to improve care.

To our knowledge, this is the first set of tools developed to assess the capacity of pediatric cancer centers to implement pediatric Standards of psychosocial care. These tools were developed by psychosocial

clinicians in collaboration with psychosocial experts, informed by both practical experience and empirical evidence. With growing demand on centers to meet new metrics of quality psychosocial care delivery (eg, The American College of Surgeons Commission on Cancer requires distress screening for accreditation),<sup>20</sup> use of the psychosocial Matrix

and Guidelines has the potential to help cancer centers systematically identify and develop steps to address gap areas in their capacity to meet these Standards.

There are several other potential benefits to utilizing the Matrix and Guidelines. These tools can help academic and community-based centers identify areas where care can be improved. They can be used at multiple time points to chart changes, review growth, and identify resources that enable changes (eg, moving from no systematic process for psychosocial screening to consistent screening using a standardized method), which can link changes to care.<sup>15</sup> They provide QI/QA opportunities, as well as support for psychosocial programs to upgrade their services with their institutions.

While the reviewers reported that the Matrix and Guidelines appear to be user friendly and feasible to utilize in pediatric oncology settings, additional steps are needed, particularly to ensure sustainability. These would include assessing the use of Matrix and Guidelines by pediatric cancer centers, as well as barriers that interfere with their use. If the Matrix and Guidelines are being used, how are they being used, what changes have been implemented (ie, did they lead to more interventions utilized and evaluated), and has the perception of psychosocial care changed (based on patient, caregiver, and provider perspectives)? Additionally, at the systems level, has there been an increase or reallocation of resources toward psychosocial services? Coordination of the results of implementation research, potentially spearheaded by childhood cancer stakeholder organizations (eg, Mattie Miracle Cancer Foundation), may lead to the creation of even more firmly evidence-based Standards. It will be particularly important to explore feasibility of implementation in smaller treatment centers and community-based centers and to continue including/increasing representation from less well-resourced sites in future iterations of both the Standards and the Matrix and Guidelines. Additional inclusion of patients and parent advocates will be valuable as well, to ensure representation of all critical stakeholders. Finally, a future goal would also include the legislation of the Standards as essential care, influencing accreditation and licensure programs.

While the Matrix and Guidelines were created by an extensive network of multidisciplinary stakeholders and represent critical progress in the implementation of the Standards of Psychosocial Care, there are some limitations to the current tools and important caveats that must be considered by users. In the Guidelines, links are provided for resources and tools, where available; however, authors cannot guarantee the currency, accuracy, relevance, or completeness of information found on linked, external websites as these change over time. We aimed to include resources and clinical tools that have a strong evidence base, but where these were limited, those commonly used in pediatric oncology settings were included. In addition, we recognize that new assessment tools and interventions are continuously being developed and tested for youth and families, so the list cannot be exhaustive and will require updating. Further, we recognize that most resources are US-based and may not be applicable to psychosocial providers practicing in international centers. There may be other appropriate resources not included in these Guidelines that are available in other countries.

In summary, there is a critical need to establish clear indicators and to effectively assess quality of care across multiple pediatric cancer centers. This is now possible with the publication of the evidence-based Standards of care and the Matrix and Guidelines as implementation tools. These tools can be disseminated widely at no cost, and they have the potential to provide greater uniformity of the highest quality of psychosocial care across.

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### CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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### SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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