

PEDIATRIC PSYCHOSOCIAL STANDARD OF CARE INSTITUTIONAL ASSESSMENT TOOL

Psychosocial care for youth with cancer and their families includes an interprofessional approach to assessment, treatment and follow-up services. This Institutional Assessment tool provides Standards for Psychosocial Care and a mechanism for your institution to determine strengths and areas for potential growth and partnership.

† “Youth” refers to children and adolescents with cancer. AYA refers to adolescent and young adults.

†† Monitoring may consist of clinical surveillance, screening, targeted, and/or comprehensive neuropsychological evaluation and may employ a range of tools, such parent, school, and child report (Baum et al 2017 †††). Monitoring for high risk groups consists of at least one objective neuropsychological assessment.

††† A Baum KT, Powell SK, Jacobson LA, Gragert MN, Janzen LA, Paltin I, Rey-Casserly CM, Wilkening GN. Implementing guidelines: Proposed definitions of neuropsychology services in pediatric oncology. *Pediatr Blood Cancer*. 2017 Aug;64(8). doi: 10.1002/pbc.26446. Epub 2017 Jan 25. PMID: 28121073.

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<i>1. Youth† with cancer and their families routinely receive systematic assessments of their psychosocial healthcare needs</i>	Consider that each of these have dimensions of the following: (a) periodicity (specified as at diagnosis, relapse/disease progression, and at end of treatment), (b) standardized process (systematic assessment), (c) content (see specified domains) A: Assessment domains: Youth <ul style="list-style-type: none"> • Youth pre-morbid and current adjustment • Cognitive and academic functioning/concerns • Developmental level and issues • Family relationships • Quality of social interactions • Disease and treatment related concerns 	No organized process in place for systematic assessments	*	There is a system in place to assure that all youth receive assessment of psychosocial functioning early in the treatment trajectory and again only if clinically indicated	*	All youth receives a comprehensive assessment at regularly scheduled points in their care
	B: Assessment domains: Parent/Primary Caregiver <ul style="list-style-type: none"> • Parental premorbid and current adjustment • Family resources and 	No organized process in place for systematic assessments	*	There is a system in place to assure that all parent/family caregiver(s) receive assessment of	*	The parent/family caregiver(s) receive a comprehensive assessment at regularly scheduled points in

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
	barriers <ul style="list-style-type: none"> • Work-life disruption • Family relationships • Social interaction and support • Family communication • Disease and treatment related concerns • Parent-child relationship Cultural and language issues			psychosocial functioning early in the treatment trajectory and again only if clinically indicated		their care

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<p>2. Youth† with brain tumors and others at high risk for neuropsychological deficits as a result of their cancer treatment are monitored†† for neuropsychological deficits during and after treatment</p>	<p>Suggested domains when monitoring results in need for neuropsychological assessment:</p> <ul style="list-style-type: none"> • General intelligence • Attention, memory, language, executive functions • Neurosensory functions • Perceptual processing • Processing speed • School/Academic performance • Behavior/Psychosocial adaptation <p>Domains identified above should be included as clinically indicated</p> <p>Periodicity: At diagnosis, post-treatment and/or at school reintegration, 2-3 years post-treatment</p>	<p>No neuropsychological monitoring provided (e.g., screening, brief assessment, research assessment, clinical assessment)</p>	<p>*</p>	<p>Youth receive monitoring of neuropsychological and academic functioning and, where needed, targeted or comprehensive testing as clinically indicated (either internal or external referral)</p>	<p>*</p>	<p>Comprehensive assessment of neuropsychological functioning of all high-risk youth, repeated as clinically indicated</p> <p>Monitoring for high-risk groups should include objective assessments</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<p>3a Adolescent and young adult survivors of childhood and adolescent cancers and their parents should receive anticipatory guidance on the need for life-long follow-up care by the time treatment ends and repeated at each follow-up visit.</p>	<ul style="list-style-type: none"> • Prevention and management of psychosocial long term / persistent / chronic and late occurring effects • Surveillance for recurrence and secondary cancers • Health promotion and risky behaviors • Education about transition to primary care and planning for transition to adult-focused care 	<p>No organized or structured program to provide anticipatory guidance related to medical and psychosocial care during the transition to adulthood and beyond</p>	*	<p>Survivors receive at least one anticipatory guidance discussion of all domains, including a survivorship care plan and planning for Long Term Follow-Up (LTFU) care as an adult</p>	*	<p>Anticipatory guidance discussion of all domains done annually and repeated at each follow-up visit. Health Links from COG, LTFU guidelines are given to survivor. A plan for transition to adult-based care is established with identification of adult-based medical team</p>
<p>3b. Long-term survivors of child and adolescent cancers should receive yearly psychosocial screening for a) adverse educational and/or vocational progress, social and relationship difficulties; b) distress, anxiety, and depression and c) risky health behaviors.</p>	<ul style="list-style-type: none"> • Academic achievement • Vocational/Employment • Social/family relationships • Mental health: Anxiety, depression, distress • Posttraumatic stress symptoms • Suicidality • Substance use • Other risky health behaviors • Coping and resilience strategies 	<p>No organized or systematic screening of long-term survivors for psychosocial needs</p>		<p>Long-term survivors receive at least one (1) psychosocial screening at a LTFU visit or when clinically indicated</p>		<p>Long-term survivors receive yearly psychosocial screening, using standardized tools utilizing LTFU guidelines</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<p>4. Youth† with cancer and their family members have access to psychosocial support and interventions throughout the cancer trajectory and access to psychiatry as needed (for the Youth)</p> <p>* Note: availability of psychiatry for the Parent/Primary Caregiver(s) is addressed in Standard 6</p>	<ul style="list-style-type: none"> • Parent/Primary Caregiver(s) 	Parent/Primary Caregiver has no access to psychosocial support and interventions	*	Parent/Primary Caregiver has access to psychosocial support at either the hospital or within the community	*	Parent/Primary Caregiver has access to psychosocial support and evidence-based interventions at either the hospital or within the community
	<ul style="list-style-type: none"> • Youth 	Youth has no access to psychosocial support or psychiatry		<p>Youth has access to psychosocial support at either the hospital or within the community</p> <p>Youth has access to psychiatry by referral to the community</p>		<p>Youth has access to psychosocial support, plus evidence-based interventions either at the hospital or within the community</p> <p>Psychiatry interventions are available to youth within the treatment center</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<p><i>5a. Assessment of risk for financial hardship is incorporated at time of diagnosis for all pediatric oncology families</i></p>	<ul style="list-style-type: none"> • Pre-existing low-income or financial hardship (ability to cover basic needs, e.g. food, rent, utilities, transportation) • Single-parent status • Transportation to and distance from treating center • Anticipated long/intense treatment protocol • Parental employment status • Family immigration and insurance status • Estimated out-of-pocket medical expenses (copays, deductibles) in relation to family income • Youth's age • Youth's prognosis 	<p>No formal process exists to assess financial hardships at initial screening</p> <p>Financial hardship screening or referral is available upon request only</p>	<p>*</p>	<p>Families receive a financial hardship screening at time of diagnosis</p> <p>Targeted referral for financial counseling and supportive resources (including both governmental, charitable supports and employer benefits) is offered based on results of family assessment</p> <p>Staff educated on impact of financial hardship</p>	<p>*</p>	<p>Families receive systematic screening for financial hardship with a uniform approach and / or use of a standardized assessment of resources at time of diagnosis</p> <p>Targeted referral for financial counseling and supportive resources (including governmental, charitable supports and employer benefits) is offered based on results of family assessment</p> <p>Staff educated on impact of financial hardship</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<p><i>5b. Longitudinal reassessment of and intervention for financial hardship occurs throughout the cancer treatment trajectory and into survivorship or bereavement</i></p>	<ul style="list-style-type: none"> • Re-assessment of financial hardship • Anticipated long-term financial needs • Parental employment status 	<p>No financial hardship screening beyond time of initial diagnosis</p>	<p>*</p>	<p>Families and young adults receive at least one financial hardship screening at time of diagnosis and again during the course of treatment</p> <p>Targeted referral for financial counseling and supportive resources (including governmental, charitable supports and employer benefits) is offered based on results of family assessment</p>	<p>*</p>	<p>Families and young adults receive systematic screening for financial hardship with a uniform approach and/or use of a standardized assessment of resources during treatment, at post-treatment follow-up visits (survivorship), and if appropriate for anticipatory bereavement needs</p> <p>Targeted referral for financial counseling and supportive resources (including governmental, charitable supports and employer benefits) is offered based on results of family assessment</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<p>6a. Parents and caregivers of children with cancer have early and ongoing assessment of their mental health needs</p>	<p>Parental coping</p> <ul style="list-style-type: none"> • Adjustment to illness • Traumatic stress symptoms • Cultural considerations • Anxiety, depression, and past mental health history <p>Parent risk/resiliency factors</p> <ul style="list-style-type: none"> • Socioeconomic status • Concrete resources • Educational/ health literacy level <p>Youth's illness trajectory</p> <ul style="list-style-type: none"> • Prior illness experience • Coping on the inpatient unit • Social and family stressors (e.g. separation/divorce), spiritual needs, community support 	<p>Parents and caregivers are not offered assessment of their own coping and mental health needs at any time</p>	<p>*</p>	<p>Parents and caregivers are routinely offered self-report assessment of their own coping at diagnosis or when significant needs are identified or interfere with the youth's medical care.</p>	<p>*</p>	<p>Parents and caregivers are routinely offered assessment of their own coping <i>and mental health needs</i> through self-report screening measures <i>and clinical assessment with follow through</i> at time of diagnosis and at regular intervals during the youth's treatment.</p>
<p>6b. Access to appropriate interventions for parents and caregivers should be facilitated to optimize parent, child, and family well-being</p>	<ul style="list-style-type: none"> • History of mental health treatment of anxiety, depression, and pre-existing mental health issues 	<p>Parents and caregivers have no access to psychosocial interventions for their own coping and mental health needs</p>	<p>*</p>	<p>Parents and caregivers have access to psychosocial interventions for their own coping and mental health needs as</p>	<p>*</p>	<p>Parents and caregivers have access to <i>psychoeducation, group and individual</i> psychosocial interventions for their</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
				<p>indicated or requested <i>through referral to an outside facility</i> or an <i>affiliated provider</i> for psychosocial services within pediatric oncology during the course of treatment by referral to an outside institution.</p> <p>Specific parent mental health issues are referred to an outside facility/provider or preferably, addressed (psychotherapy, psychopharmacology) by affiliated providers.</p> <p>Interventions and/or referrals are culturally and linguistically appropriate</p> <p>If additional mental health care is needed, a referral is made to an outside facility/provider. If parents cannot afford</p>		<p>own coping as indicated or requested through psychosocial services in pediatric oncology including specific standardized or evidence-based interventions.</p> <p>Specific parent mental health issues are addressed (psychotherapy, psychopharmacology) <i>by internal providers.</i></p> <p>Interventions are culturally and linguistically appropriate</p> <p>If additional mental health care is needed, a referral is made to an outside facility/provider. If parents cannot afford</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
				<p>interventions in the community, resources are explored for referrals to not-for-profit agencies.</p> <p>Follow-up is provided to ensure care is being provided.</p>		<p>interventions in the community, resources are explored for referrals to not-for-profit agencies.</p> <p>Follow-up is provided. Referrals are culturally and linguistically appropriate</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<p><i>7a. Youth† with cancer and their family members are provided with psychoeducation and information related to disease, treatment, acute and long-term effects, hospitalization, procedures, and psychosocial adaptation</i></p>	<ul style="list-style-type: none"> • Disease education: Diagnosis and treatment, anticipated side effects • Behavioral and emotional responses • Availability of developmentally appropriate interventions for coping, distress reduction, and/or behavior management; preparation for medical procedures; and legacy and meaning making, when appropriate • Informed consent and medical decision making, including advance care planning when appropriate • Getting to know the hospital system (e.g., unit, team, policies, resources) and preparing for hospitalization • Healthy lifestyle behaviors and self-care • Fertility and reproductive planning • Transitions of care (e.g., within hospital, off treatment, to hospice) 	<p>Youth and their families receive general medical information (e.g., diagnosis and treatment) but do not receive psychoeducation related to psychosocial adaptation, coping, or available support and interventions.</p>	*	<p>Youth and their families receive psychoeducation related to psychosocial adaptation, coping, and available support and interventions at the time of diagnosis only.</p>	*	<p>Youth and their families receive regularly scheduled psychoeducation related to psychosocial adaptation, coping, and available support and interventions at all key points along illness trajectory including (but not limited to): diagnosis, end of therapy, during the transition to long term survivorship, at relapse/recurrence, and/or end-of-life.</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
	<ul style="list-style-type: none"> • Cultural and language preferences for communication around disease, treatment, and end-of-life 					
<p><i>7b. Guidance should be tailored to the specific needs, cognitive abilities, and preferences of individual youth and families and be provided throughout the trajectory of cancer care.</i></p>	<ul style="list-style-type: none"> • Screening for youth and caregiver health literacy • Youth and family needs and preferences for receipt of information (e.g., who, how, when, where) • Cognitive abilities • Developmental level • Literacy • Language of origin • Need/desire for medical interpretation • Cultural considerations 	<p>Team members do not tailor psychoeducation, such that information provided to youth and families is generic (i.e., without consideration for language, culture, developmental level, literacy, preference for receipt of information).</p>	*	<p>Team members tailor psychoeducation (e.g., to youth and family language, culture, developmental level, literacy, preference for receipt of information) <i>inconsistently</i>—either for some youth and their families, but not all, or at some points along the cancer trajectory, but not all.</p>	*	<p>Team members carefully tailor psychoeducation (e.g., to youth and family language, culture, developmental level, literacy, preference for receipt of information) for all youth and their families according to their specific needs and preferences at all points along the cancer trajectory.</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<p><i>8a. Youth † with cancer should receive developmentally appropriate preparatory information about invasive medical procedures</i></p>	<ul style="list-style-type: none"> Youth’s developmental and cognitive abilities, affective style, as well as preference for provision of medical information (details vs. “big picture”) 	<p>No developmentally appropriate preparatory information about invasive and painful medical procedures provided (i.e., no information given, information only given to parents, information given that is not developmentally appropriate)</p>	<p>*</p>	<p>Youth meet with trained staff to assess strategies for coping with procedures and to receive developmentally appropriate preparatory information about invasive and painful medical procedures upon request or referral only</p> <p>Preparation is documented in the EHR.</p>	<p>*</p>	<p>Youth meet with trained staff to assess strategies for coping with procedures and to receive developmentally appropriate preparatory information for all new or invasive or painful medical procedures</p> <p>Assessments should be ongoing to assess for previous experiences with procedures, youth’s development and other factors that might affect preparation for and coping with procedures</p> <p>Information is documented in the EHR.</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<p><i>8b. All youth† with cancer should receive developmentally appropriate psychological intervention(s) to prepare and support them for invasive medical procedures</i></p>	<ul style="list-style-type: none"> • Distraction • Cognitive-behavioral techniques • Hypnosis, either direct or indirect • Psycho-pharmacological, psychological interventions or some combination for more painful procedures 	<p>No developmentally appropriate psychological / behavioral intervention(s) are provided to prepare and support youth for invasive medical procedures (i.e., no trained staff, no psychological or behavioral intervention to support/prepare youth, and/or preparation not developmentally appropriate)</p>		<p>Youth meet with trained staff to receive developmentally appropriate psychological / behavioral intervention(s) to prepare and support youth for invasive medical procedures upon request or referral</p>		<p>Youth meet with trained staff to receive developmentally appropriate psychological / behavioral intervention(s) to prepare and support them for all new and/or difficult invasive medical procedures throughout the treatment trajectory</p> <p>A plan is developed and followed each time the youth comes for an invasive procedure. The identified team member(s) are present to deliver and monitor the plan—along with the parent and youth</p> <p>Intervention(s) and plans are documented in the EHR</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<p>9. Youth† with cancer are provided opportunities for social interaction during cancer therapy and into survivorship following careful consideration of the youth’s unique characteristics, including developmental level, preferences for social interaction, and health status</p>	<ul style="list-style-type: none"> • Assessment time points, including diagnosis, during treatment, survivorship and school transitions • Social interaction/style prior to diagnosis • Current social interaction and needs • Preferences for social interaction with family and peers • Health status as it refers to ability to participate in social opportunities • Underlying diagnosis and how social interaction needs and experiences may vary • Assess for bullying and socialization needs for youth and caregivers throughout the cancer trajectory • Camps/activity programs available locally and nationally 	<p>No assessment of needs and preferences for social interaction offered</p> <p>No social interaction services or programs provided for youth during treatment and/or survivorship</p>	<p>*</p>	<p>Assessment of needs and preferences for social interaction offered at a single time point or upon request or referral</p> <p>Some services or programs exist to promote social interactions but may be limited to specific populations, during treatment only or upon request or referral</p> <p>Referrals are made to community programs throughout the disease trajectory available locally and nationally</p>	<p>*</p>	<p>Assessment of needs and preferences for social interaction offered and provided during treatment and post-treatment (i.e. survivorship)</p> <p>Coordinated care, resulting in a treatment plan that specifically includes a plan to address social interaction</p> <p>Community-based and hospital services or programs are available and offered to provide social interaction that meets the developmental or physical needs of youth with cancer, including those who require isolation during hospital / clinic stays</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<p><i>10a. Siblings of children with cancer are a psychosocially at-risk group and should be provided with appropriate supportive services</i></p>	<p>Areas of psychosocial need and risk include:</p> <ul style="list-style-type: none"> • Information • Acknowledgement • Attention • Involvement (to extent desired) • Expressing and coping with feelings • Family relationships • Peer support • Academics and activities • Respite/Recreation 	<p>Siblings of youth with cancer receive no assessment of their psychosocial risk, adjustment, or needs nor are they provided with any supportive services</p>	<p>*</p>	<p>Assessment of sibling psychosocial risk, adjustment, or needs is done sporadically or upon request</p> <p>Information is provided about community programs (e.g., camp) for siblings</p> <p>Hospital and clinic services are offered to siblings upon request or referral</p>	<p>*</p>	<p>The psychosocial risk, adjustment, <i>and</i> needs of siblings of youth with cancer are routinely assessed and documented at diagnosis and at key points during and after treatment (e.g. extended hospital stays, relapse, HSCT, palliative care)</p> <p>Siblings receive regularly scheduled, hospital-based supportive services through consultation with community providers as standard of care</p> <p>Hospital, clinic, community, and camp programs are available to all siblings</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<p><i>10b. Parents and professionals should be advised about ways to anticipate and meet siblings' needs, especially when siblings are unable to visit the hospital regularly.</i></p>	<ul style="list-style-type: none"> • “Parents” include caregivers of siblings and may involve extended family members and others • “Professionals” include teachers, other school personnel, and community-based providers (e.g., pediatrician) 	<p>Parents and professionals do not receive education and advisement about sibling psychosocial risk, adjustment, or needs</p>	<p>*</p>	<p>Parents and professionals receive education and advisement about sibling psychosocial risk, adjustment, or needs sporadically or upon request</p>	<p>*</p>	<p>All parents and professionals receive education and advisement about sibling psychosocial risk, adjustment, or needs routinely on an ongoing basis</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<p><i>11a. In collaboration with parents, school-age youth diagnosed with cancer receive school reentry support that focuses on providing information to school personnel about the youth's† diagnosis, treatment, and implications for the school environment and provides recommendations to support the child's school experience</i></p>	<p>Relevant school personnel (e.g., school nurse, counselor, teacher, administrator) should be informed of the following domains:</p> <ul style="list-style-type: none"> • Diagnosis and treatment: including length and frequency of treatment, anticipated absences, short and long-term treatment effects (e.g., physical, cognitive, and psychological impact of disease and treatment) • Alternative educational arrangements (if student cannot yet return to school): hospital/inpatient school programs, homebound instruction, virtual instruction, use of other technology • Recommendations for school reentry support and accommodations: including academic, physical, social, and emotional support; may include formal plans like school health plans, 504 	<p>Academic continuity, school reentry and post-secondary support is not available to school-aged youth and their families (e.g., no formal referral process for services exists, no point person for referrals has been identified, no alternative educational arrangements are available or offered if the youth is unable to attend school full time, and/or there is no communication with schools regarding school reentry support and accommodations)</p>	*	<p>Academic continuity, school reentry and post-secondary support is available to youth and families by referral only, on a limited/one-time basis, or in a generalized way (e.g., support is only for some youth, is not ongoing, and/or is not informed by individual assessment)</p>	*	<p>Individualized academic continuity, school reentry and post-secondary support is offered to all school-aged youth and their families, with regular follow-up throughout the cancer trajectory:</p> <p>Timely referrals are completed for appropriate educational arrangements for all school-age youth unable to attend school on a full-time basis</p> <p>School-age youth receive tailored school intervention support and advocacy based on diagnosis/ treatment and guided by a risk-based educational assessment</p> <p>Hospital/ inpatient school programs are available to all school-age youth</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
	<p>plans, IEP, or other, as indicated</p> <ul style="list-style-type: none"> • Classroom preparation: educational resources for teachers and peers • Transition to post-secondary education or employment, including vocational rehabilitation 					<p>Individualized recommendations for accommodations related to short- and long-term effects of treatment are provided to school personnel</p> <p>Regular follow-up is offered to all school-age youth to ensure implementation and efficacy of alternative arrangements (i.e., at diagnosis, continuing through school reentry and ongoing into survivorship)</p> <p>Referrals, evidence of school reentry plans, all school-based student plans (IEP, 504, IHP, SSP, etc.***) and ongoing school related supports are documented in the electronic health record</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<p><i>11b. Pediatric oncology programs should identify a team member with the requisite knowledge and skills who will coordinate communication between the youth†/ family, school, and the health care team</i></p>	<p>Knowledge:</p> <ul style="list-style-type: none"> • Impact of disease and treatment on social and academic functioning • Common barriers to the school re-entry process • Awareness of psychosocial resources to assist with re-entry as needed • Current state and federal laws that impact education (IDEA, ESSA, ADA, FAPE, LRE, 504, RTI, etc.**) • State standards and regulations • Common educational practices • Home and hospital instruction trends and policies • Policies and procedures for special education referral and eligibility • Local resources for advocacy, special education legal support, cancer scholarships, etc. 	<p>No member of the interdisciplinary team is identified as a school liaison</p> <p>No identified team member is responsible to maintain a working knowledge of education law and common educational practices</p>	<p>*</p>	<p>A member(s) of the interdisciplinary team is identified as the school liaison and provides services to youth when education related concerns are identified</p> <p>The identified liaison has moderate command of the requisite knowledge and skills to provide comprehensive school interventions</p>	<p>*</p>	<p>A member of the interdisciplinary team is identified as the school liaison and provides services to all school-age youth throughout the cancer trajectory</p> <p>The identified liaison has a mastery of the requisite knowledge and skills to provide comprehensive school interventions</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
	Skills and Approaches: <ul style="list-style-type: none"> • Strong communication, relationship management, and advocacy skills • Ability to leverage educational systems knowledge to uniquely support the needs of school-age youth with cancer 					

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<i>12a. Medication adherence is assessed routinely and monitored throughout treatment</i>	<ul style="list-style-type: none"> • Adherence to medication type (i.e., taking the correct medication), dose (i.e., the right amount of medication), mode of administration (i.e., oral, injection), and timing (i.e., medication schedule) as detailed in the treatment regimen • Facilitators (e.g., strategies that promote successful adherence to a medication regimen, regimen knowledge) • Barriers (e.g., forgetting, difficulties swallowing pills, taste, side effects) to medication adherence 	No systematic process for assessing medication adherence or adherence facilitators/barriers	*	<p>Medication adherence and adherence barriers/facilitators only assessed when a concern is identified (e.g., caregiver reports difficulty with youth taking medication, labs inconsistent with what would be expected based on what is prescribed)</p> <p>Medication adherence and/or facilitators/barriers are assessed when a concern is identified but not consistently documented</p>	*	<p>Medication adherence assessed using standardized methods at least quarterly in all youth self-managing medication(s) throughout active treatment</p> <p>Facilitators and barriers to adherence assessed using standardized methods at least quarterly in all youth self-managing medication(s) throughout active treatment</p> <p>Medication adherence and facilitators/ barriers documented in a systematic manner</p>
<i>12b. Provide non-adherence interventional support to youth and family</i>	<ul style="list-style-type: none"> • Education regarding medication regimen (i.e., purpose, administration, and side effects of each medication) 	No interventions targeting adherence provided	*	<p>Education regarding the medication regimen and adherence <i>not</i> provided to all youth</p> <p>OR</p>	*	Education regarding the medication regimen and adherence provided to all youth

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
	<ul style="list-style-type: none"> • Education regarding adherence (i.e., prevalence of non-adherence, importance of adherence, facilitators/barriers of adherence) • Evidence-based interventions targeting relevant barriers to medication adherence • Standardized procedures for medical record documentation and communication with medical team of intervention goals, strategies, and outcomes 			<p>Interventions targeting non-adherence provided based on criteria other than standardized adherence assessment</p> <p>AND</p> <p>Documentation of intervention, goals, and planned follow-up are not standardized</p>		<p>Evidence-based interventions are provided targeting relevant barriers or risk factors for non-adherence (i.e., immediately prior to the transfer of self-management responsibilities to the youth and/or family, at least quarterly throughout treatment as indicated by assessment and whenever there is a change in the treatment regimen).</p> <p>Intervention, goals, and planned follow-up communicated with youth, caregiver, and relevant medical team members</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<p><i>13a. Youth† with cancer and their families are introduced to palliative care concepts to reduce suffering throughout the disease process regardless of disease status</i></p>	<p>General concepts</p> <ul style="list-style-type: none"> • Symptom assessment and intervention • Youth self-report • Decision-making capacity and interest in shared decision-making • Effective family-staff communication regarding preferences for care, including advance care planning (ACP) 	<p>Minimal discussion of palliative care concepts provided at diagnosis and over the course of treatment; limited primarily to end of life care</p>	*	<p>Consistent introduction of primary palliative care principles by primary oncology team</p> <p>Some youth with cancer and their families receive referral-based specialist palliative care in response to severe exacerbation of symptoms, disease recurrence or progression, high risk procedures (i.e. Phase 1 trial/ HSCT), or upon parent request</p>	*	<p>All youth with cancer and their families are introduced to ongoing longitudinal primary palliative care principles by primary oncology team</p> <p>A functional triage system exists for early referral to an embedded member of the specialist palliative care interdisciplinary team (e.g., physician, nurse, social work, chaplain, child life, therapists) for youth with high-risk diagnosis, treatment, or psycho-social needs regardless of the anticipated disease trajectory</p>
		<p>Primarily parent perspective sought for decision making</p> <p>ACP discussions limited</p>	<p>Youth/AYA intermittently involved in treatment discussions and decision making</p> <p>Discussions regarding</p>	<p>Youth/AYA routinely involved in treatment discussions and decision-making as they prefer to be involved</p>		

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
	<p>Symptom assessment, physical, psychological, spiritual/existential, and psychosocial aspects of care</p>	<p>to end of life and does not include the youth/AYA in planning</p> <p>Assessments limited to physical symptoms that are routinely documented. Minimal use of patient reported outcomes (PROs)</p>		<p>goals of care and ACP do not routinely occur at diagnosis but at a change in the child's condition</p> <p>Assessment includes physical, psychological, spiritual/existential, and psychosocial aspects of care in a standardized way</p>		<p>Developmentally-appropriate education resources are used to include early introduction to ACP communication tools</p> <p>Comprehensive assessments of physical, psychological, spiritual/existential, and psychosocial aspects of care by interdisciplinary team members consistently using parent and youth perspectives (PROs) with documentation of assessment, intervention, and outcome so all members of the care team have access</p>
<p><i>13b When necessary, youth † and families should receive</i></p>	<p>End of life care</p>	<p>End-of-life care occurs for dying youth when death is imminent</p>	<p>*</p>	<p>Limited end-of-life care preparation is provided within a few</p>	<p>*</p>	<p>Developmentally appropriate end-of-life care is consistently</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<p><i>developmentally appropriate end of life care (which includes bereavement care after the child's death).</i></p>		without access to community-based hospice resources		weeks of death for youth and families. Home location of death is limited by lack of integration of community-based hospice services		provided and concordant with disease progression/prognosis and youth/family wishes.
		Developmentally appropriate end-of-life care (including family bereavement care) is not available for families after death		Bereavement care is encouraged by individual staff members but not standardized		<p>Connectedness with community-based hospice services fosters care setting transitions (i.e. via telemedicine, shared clinics)</p> <p>Bereavement care is both standardized and personalized to family needs</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<p><i>14. A member of the health care team contacts the family after a child's death to assess family needs, to identify those for negative psychosocial sequelae, to continue care, and to provide resources for bereavement support</i></p>	<ul style="list-style-type: none"> Assessment of emotional/psychological, social, and spiritual needs and functioning 	<p>No contact is made with families after a youth's death</p>	<p>*</p>	<p>Some families receive at least a single contact from a member of the health care team while other families receive multiple contacts from a member of the healthcare team</p> <p>An assessment of bereavement needs is obtained inconsistently</p>	<p>*</p>	<p>A process is in place to ensure that <u>all</u> families receive contact from a health care team member. Components may include:</p> <ol style="list-style-type: none"> 1. A phone call by a health care team provider, ideally who knew the youth 2. Assessment of bereavement needs 3. Provision of resources/referrals tailored to the needs identified <p>Follow-up by a health care team member and/or bereavement specialist to ensure needs are assessed and addressed</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<p><i>15a. Psychosocial professionals are integrated into pediatric oncology care settings as integral team members and are participants in-patient care rounds/meetings</i></p>	<ul style="list-style-type: none"> • Communication • Collaboration • Consultation 	<p>The healthcare team has no dedicated (allocated) psychosocial support team members with expertise in pediatric oncology</p> <p>Psychosocial providers do not regularly attend medical rounds, or psychosocial rounds, or patient care conferences</p> <p>Psychosocial providers do not provide consultation or training to other team members</p>	*	<p>The healthcare team has access to at least one dedicated (allocated) psychosocial provider with expertise in pediatric oncology</p> <p>Psychosocial providers attend medical rounds and psychosocial rounds. Psychosocial providers attend most patient care conferences</p> <p>Psychosocial providers may provide consultation or training when requested by the medical team</p>	*	<p>The healthcare team has a dedicated (allocated) psychosocial provider with expertise in pediatric oncology</p> <p>Psychosocial providers fully participate in medical and psychosocial rounds, and patient conferences</p> <p>Psychosocial providers routinely provide consultation and training to other team members</p>
<p><i>15b. Pediatric psychosocial providers have access to medical records. Relevant reports are shared among care team professionals, with psychological report interpretation provided</i></p>	<ul style="list-style-type: none"> • Documentation policies of the health system • Practice in accordance with ethical requirements of profession and with state/federal laws 	<p>No access to medical records; relevant reports are not shared with care team; no interpretation provided by psychosocial providers</p>	*	<p>Access to medical records; relevant reports are shared with care team; no interpretation provided by psychosocial providers</p>	*	<p>Dedicated notes and assessments in the EHR. Access to medical record, relevant reports shared with care team; psychosocial providers interpret and</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains and Essential Elements	Levels				
		1	2	3	4	5
<i>by psychosocial providers to staff and patients/families for patient care planning</i>						communicate report information to staff, youth, and families
15c. Pediatric psychosocial providers have specialized training and education and be credentialed in their discipline to provide developmentally-appropriate assessment and treatment for children with cancer and their families	<ul style="list-style-type: none"> • Experience and specialized training in working with youth with serious, chronic illness • Supervision/peer support 	Psychosocial providers have no specialized training, education or credentialing in the field of pediatric psychosocial oncology to provide appropriate assessment and evidence-based treatment	*	Psychosocial providers have specialized training, education and credentialing in the field of pediatric psychosocial oncology to provide appropriate assessment and evidence-based treatment	*	<p>Psychosocial providers have specialized training, education and credentialing in the field of pediatric psychosocial oncology to provide appropriate assessment and evidence-based treatment</p> <p>There is formal, professional development program access for psychosocial care providers</p>

Pediatric Psychosocial Standard Institutional Assessment

Matrix and Guideline Authors:

Standard 1. Psychosocial Assessment as a Standard of Care in Pediatric Cancer

Anne E. Kazak, Ph.D., ABPP, Center for Healthcare Delivery Science, Nemours Children's Health System; Department of Pediatrics, Sidney Kimmel Medical College at Thomas Jefferson University
Mary Jo Kupst, Ph.D., Department of Pediatrics, Medical College of Wisconsin

Standard 2. Monitoring and Assessment of Neuropsychological Outcomes as a Standard of Care in Pediatric Oncology

Robert D. Annett, Ph.D., Department of Pediatrics, University of Mississippi Medical Center
Sunita Patel, Ph.D., Department of Supportive Care Medicine and Department of Population Sciences, City of Hope Medical Center and Beckman Research Institute
Sean Phipps, Ph.D., Psychology Department, St. Jude Children's Research Hospital

Standard 3. Psychosocial Follow-Up in Survivorship as a Standard of Care in Pediatric Oncology

E. Anne Lown, Dr.PH, Department of Social and Behavioral Sciences, School of Nursing, University of California
Lisa A. Schwartz, Ph.D., The Children's Hospital of Philadelphia and Perelman School of Medicine
Abby R. Rosenberg, MD, MS, Palliative Care and Resilience Lab, Seattle Children's Research Institute; Department of Pediatrics, Division of Hematology/Oncology, University of Washington School of Medicine
Barbara Jones, Ph.D., MSW, School of Social Work, University of Texas at Austin
Farya Phillips, Ph.D., CCLS, School of Social Work, University of Texas at Austin

Standard 4. Psychosocial Interventions and Therapeutic Support as a Standard of Care in Pediatric Oncology

Amii C. Steele, Ph.D., Division of Pediatric Psychology and Neuropsychology, Levine Children's Hospital
Larry Mullins, Ph.D., Department of Psychology, Oklahoma State University
Alexandria M. Delozier, Ph.D., Department of Psychiatry & Human Behavior, University of Mississippi Medical Center
Anna C. Muriel, MD, Division of Pediatric Psychosocial Oncology, Dana-Farber Cancer Institute

Standard 5. Assessment of Financial Burden as a Standard of Care in Pediatric Oncology

Wendy Pelletier, MSW, RSW, Hematology, Oncology, Blood & Marrow Transplant Program, Alberta Children's Hospital
Kira Bona, MD, MPH, Dana-Farber/Boston Children's Cancer and Blood Disorders Center, Harvard Medical School

Standard 6. Standards of Psychosocial Care for Parents of Children with Cancer

Julia Kearney, MD, Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center

Pediatric Psychosocial Standard Institutional Assessment

Anna Muriel, MD, Division of Pediatric Psychosocial Oncology, Dana-Farber Cancer Institute

Christina Salley, Ph.D., Department of Child and Adolescent Psychiatry, Hassenfeld Children's Hospital at NYU Langone

Standard 7. Anticipatory Guidance and Psychoeducation as a Standard of Care in Pediatric Oncology

Amanda Thompson, Ph.D., Life with Cancer, Inova Schar Cancer Institute

Tammi Young-Saleme, Ph.D., Division of Pediatric Psychology and Neuropsychology, Nationwide Children's Hospital

Standard 8. Procedural Preparation and Support as a Standard of Care in Pediatric Oncology

Stacy Flowers, Ph.D., Department of Family Medicine, Wright State University

Kelly Foy, MS, CCLS, Hematology/Oncology and Child and Family Support Services, Connecticut Children's Medical Center

Kathryn Birnie, Ph.D., Department of Anesthesiology, Perioperative and Pain Medicine, University of Calgary, Alberta Children's Hospital

Standard 9. Providing Children and Adolescents Opportunities for Social Interaction as a Standard of Care in Pediatric Oncology

Heather L Soyer, PsyD, Blank Children's Psychological Services, Unity Point Health

Kristin Bingen, Ph.D., Department of Pediatrics, Medical College of Wisconsin

Jennifer A Hoag, Ph.D., Department of Pediatrics, Medical College of Wisconsin

Jeffrey S Karst, Ph.D., Department of Pediatrics, Medical College of Wisconsin

Lamia P Barakat, Ph.D., Children's Hospital of Philadelphia Cancer Center; Department of Pediatrics, University of Pennsylvania Perelman School of Medicine

Standard 10. Supporting Siblings as a Standard of Care in Pediatric Oncology

Cynthia A. Gerhardt, Ph.D., Center for Biobehavioral Health, The Abigail Wexner Research Institute at Nationwide Children's Hospital;

Departments of Pediatrics and Psychology, The Ohio State University

Vicki Lehmann, Ph.D., Department of Medical Psychology, Amsterdam University Medical Centers, University of Amsterdam

Kristin A. Long, Ph.D., Department of Psychological and Brain Sciences, Boston University

Pandora Patterson, Ph.D., Research, Evaluation, and Social Policy Team, CanTeen Australia; Cancer Nursing Research Unit, The University of Sydney

Tammi Young-Saleme, Ph.D., Division of Pediatric Psychology and Neuropsychology, Nationwide Children's Hospital

Melissa A. Alderfer, Ph.D., Center for Healthcare Delivery Science, Nemours Children's Health System & Department of Pediatrics, Sidney Kimmel Medical College at Thomas Jefferson University

Standard 11. Academic Continuity and School Reentry Support as a Standard of Care in Pediatric Oncology.

Amanda Thompson, Ph.D., Life with Cancer, Inova Schar Cancer Institute

Mary Kay Irwin, EdD, School Health Services, Nationwide Children's Hospital

Pediatric Psychosocial Standard Institutional Assessment

Kathryn Kirkpatrick, Ph.D., LISW-S, Department of Hematology/Oncology, Nationwide Children's Hospital

Heather L Soyer, PsyD, Blank Children's Psychological Services, Unity Point Health

Jennifer A Hoag, Ph.D., Department of Pediatrics, Medical College of Wisconsin

Megan Voll, LPC, MS, Department of Pediatrics, University of Pittsburgh

Robert B Noll, Ph.D., Department of Pediatrics, University of Pittsburgh

Katherine Patterson Kelly, Ph.D., RN, Children's National Hospital, George Washington University School of Medicine and Health Sciences

Standard 12. Assessing Medication Adherence as a Standard of Care in Pediatric Oncology

Ahna LH Pai, Ph.D., Meghan E. McGrady, Ph.D.

Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital & Department of Pediatrics, University of Cincinnati College of Medicine

Standard 13. Palliative Care as a Standard of Care in Pediatric Oncology

Katherine Patterson Kelly, Ph.D., RN, Children's National Hospital, George Washington University School of Medicine and Health Sciences

Justin N. Baker, MD, FAAHPM, Division of Quality of Life and Palliative Care, QoLA Team (Quality of Life for All), Hematology/ Oncology

Fellowship Program, St Jude Children's Research Hospital

Cynthia J. Bell Ph.D., RN, College of Nursing, Wayne State University

Christine A. Fortney, Ph.D., RN, College of Nursing, Martha S. Pitzer Center for Women, Children & Youth, Ohio State University

Kim Mooney-Doyle, Ph.D., RN, CPNP-AC, Department of Family and Community Health, University of Maryland, School of Nursing

Elizabeth Smythe BSN, RN, Bone Marrow Transplant Coordinator, Children's Hospital of Michigan

Jessica L. Spruit, DNP, CPNP-AC, College of Nursing, Wayne State University

Christina Torkildson, Ph.D., RN, PHN, FPCN, Post-Acute Services; Banner Hospice and Palliative Care, San Francisco Benioff Children's Hospital Oakland

Meaghann Shaw Weaver, MD, MPH, FAAP, Hand In Hand/Pediatric Palliative Care, Pediatric Oncology, Children's Hospital & Medical Center

Standard 14. Bereavement Follow-Up After the Death of a Child as a Standard of Care in Pediatric Oncology

Wendy Lichenthal, Ph.D., Department of Psychiatry & Behavioral Sciences, Memorial Sloan Kettering Cancer Center

Kailey Roberts, Ph.D., Department of Psychiatry & Behavioral Sciences, Memorial Sloan Kettering Cancer Center

Lori Wiener, Ph.D., Pediatric Oncology Branch, National Cancer Institute, Center for Cancer Research, National Institutes of Health

Standard 15. Communication, Documentation, and Training Standards in Pediatric Psychosocial Oncology

Wendy Pelletier, MSW, RSW, Hematology, Oncology, Blood & Marrow Transplant Program, Alberta Children's Hospital

Kristin Bingen, Ph.D., Department of Pediatrics, Medical College of Wisconsin