

KPCRTF State Funded Projects Reporting Template

University of Louisville and Norton Children's Cancer Institute
The Psychosocial Roadmap for Operationalized Treatment in Pediatric Cancer:
A Standardized Approach for Provider and Patient
Principal Investigators: Sunnye Mayes, PhD & Spencer Moorman, LCSW
Project Coordinator: Spencer Moorman
Reporting Period: April through June 2021

Brief Summary of Project Status for each Objective:

The Psychosocial Roadmap for Operationalized Treatment in Pediatric Cancer Project is in implementation phase at Norton Children's Cancer Institute. A comprehensive psychosocial roadmap template with listed evidence based standards of care, services, resources and interventions is now in Redcap and also in EPIC via Smart Phrase folders. These oversight mechanisms and tools are implemented to systematically measure, track, and deliver the pediatric oncology psychosocial standards of care for patients during their care. Psychosocial roadmap consultations and systematic screenings are occurring regularly. Screening tools include the Psychosocial Assessment Tool, Arlington Screen for Financial Hardship, The Children's Hope Scale, Grit Scale, The Pediatric Quality of Life, Sibling Needs Instrument, Severity of Illness Scale, Colorado Learning Difficulties Tool, Patient Symptom Checklist-17 and a fun fact "I Am a Person Who..." questionnaire. A psychosocial action plan is tailored for patient and family needs following each roadmap consult. In addition, qualitative interviews, Post Time Point 1, are underway to obtain patient and parent feedback about the process and their experience thus far. With this comprehensive roadmap monitoring process now implemented, and subsequent time-point assessments approaching for previously diagnosed patients, the patient and family's psychosocial wellness can soon be measured against their baseline results. This intensive monitoring method has already benefitted psychosocial care and allowed for appropriate follow up for referrals and services.

Plans for Quarter July through August 2021:

This extensive project will continue in implementation phase. Plans for the upcoming quarter include the actual hiring of a data coordinator to allow for more clinical frontline project engagement with patients and community based organizations, the final design and approval of a resource guide for publication, and the identification of an online platform for development and further resource access. We are obtaining quotes for the resource guide. Norton EPIC specialists are working on a psychosocial service flowchart and web page. Although the timeline has been delayed secondary to COVID-19, we are making excellent progress, realizing a shift to a proactive vs reactive care model, and anticipate continuing to move this project forward.

Primary Objective #1 – Develop an operationalized treatment pathway for the systematic assessment, coordination, and measurement of standards.

Secondary Objective # 1: Create a provider template and psychosocial roadmap for standard of care delivery, planning, tracking, and implementation -Provider and Patient Versions

Summarized Update:

(a) Roadmap Assessment Questionnaire- Completed (Psychosocial Assessment Tool)

(b) Patient's Psychosocial Action Plan-Completed

A basic Map Action Plan Template is in active use with a more enhanced graphic design being discussed for completion within the year

(c) Provider Template-Completed

(d) Red Cap Data Registry Design-Completed

The finalized protocol was completed in REDCap with all assessment tools, map checklists, and their timelines per diagnosis. New diagnoses and all map-oriented information are now being tracked in RedCap and are also available in EPIC via Smart Phrase folders

(e) Visual Aids for Clinic: Laminated Poster, Family/User Friendly Map of Controllables- Currently Under Creation via Artistic Designer, Estimated Launch Month 15

Approximate # of New Diagnoses	# January thru March 2021	# April thru June 2021
ALL	8	2
Brain Tumor	3	3
Hodgkin Lymphoma	1	1
Germ Cell Tumor	1	3
Neuroblastoma	2	0
Rhabdosarcoma	1	0
Nephroblastoma	1	0
Burkitts Lymphoma	1	0
Salivary Gland Carcinoma	0	1
Approximate Total	18	10

Example: One of Several Project Measures Collected QOL at Baseline (Diagnosis Window) Parent Report for Patients Ages 2-4		
Types of Functioning	Scores for Ages 2-4 Parent Report	Mean for Ages 2-4 Parent Report <small>*Higher Scores indicate > QOL</small>
Physical Functioning	9, 28, 91, 97, 13	50
Emotional Functioning	25, 50, 65, 100, 30	54
Social Functioning	NA, 40, 85, 100, 50	69
School Functioning	NA, NA, 50, NA, 50	50
Overall Score	15, 38, 77, 97, 28	51

Primary Objective #2 – Educate patients, family members, and healthcare providers via various means on the Pediatric Oncology Psychosocial Standards of Care to optimize knowledge, adherence, access, experience of care, and navigation of a complex and often disjointed system of cancer care.
Secondary Objective #2- Inform and empower patients and families with knowledge regarding the psychosocial standards of care and what they can expect during their cancer journey via patient centered provisions

Summarized Update:

(f) Kentucky Based Standard Specific National and Regional Resource Guide– Currently under Design- Estimated Completion/Distribution Month 17-18

- Resource summarization of 250+ standard oriented organizations and supports are completed categorized by a cityscape with locations (house, hospital, school, park, bank, garden, roadway, etc) which represent various resources and organizational supports affiliated with medical treatment, caregiver/family supports, school and financial assistance, psychosocial supports, socialization opportunities, disease education.
- A graphic designer was identified and initial meetings for the manual's design are underway. A professional printer was also identified and ballpark quotes have been received for bulk printing of the guide.
- Project completion estimated Month 13-15.

(g) Electronic Psychosocial Pediatric Cancer Roadmap App with KY Specific Information-Develop Months 1-12. Still in investigative phase and will be prioritized project focus in year 2 upon the hiring of data coordinator and completion of published resource guide

- Similar technological platform such as a one stop standard oriented psychosocial website link for patient access is being investigated via IT/Epic Specialist

Primary Objective #3: Establish Standardized Coordination of Care Pathway via Operationalized Process

Summarized Update:

- Roadmap Consultations are now occurring regularly with the treatment roadmap and summary as guide for care.
- The systematic identification of needs combined with follow up care planning, interventions, referrals, and tracking of outcomes is underway through bi-weekly psychosocial care meetings. These formalized consultations allow for analyses of assessment findings and foster a collaborative approach to ensuring the patient's roadmap and applicable standards are being delivered in a prompt fashion. Data Collection forms in REDCap are utilized to document all assessments, referrals, grand rounds discussions, questions, concerns, identified needs and roadmap interventions, services, and resources.

Deliverables (check appropriate time period when each deliverable is completed)	Month 1-3	Month 4-6	Month 7-9	Month 10-12	Month 13-15	Month 16-18	Month 19-21	Month 22-24	v
Notify DPH when IRB approval is received or if not required	X	X	X	X					
Roadmap Assessment Questionnaire Develop Implement		X	X	X					
Patient's Psychosocial Action Plan Develop Template Implement		X	X	X					
Provider Template Develop/Finalize Implement			X	X					
Red Cap Data Registry Design		X	X	X					
Visual Aids for Clinic – laminated poster, family/user friendly game board Develop Implement		X	X	X					
Kentucky Based SOC specific Regional and National Resource Guide Develop Distribute		X	X	X					
Electronic Psychosocial Pediatric Cancer Roadmap App with Kentucky Specific Information Develop Implement		X	X	X					

Quarterly Reports are due:

October 15, 2020

January 15, 2021

April 15, 2021

July 15, 2021

October 15, 2021

January 15, 2022

April 15, 2022

July 15, 2022

Reports should be returned to:

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