

Supportive Oncology Collaborative for Adolescents and Young Adults Program

Requests # 115979, 115980, 115981, 115982

Total Request Amount:	\$893,639
Total Recommended Amount:	\$891,500
Duration:	18 months
Program Area:	Health and Rehabilitation\Clinical / Treatment Services
Population Served:	Cancer Patients / Families
Type of Support:	Program Support
Location:	Chicago, Oak Lawn, Park Ridge, IL
Staff:	Rosa Berardi

The proposal summary is comprised of program requests from four hospitals with a request for grant management. The summary includes the Coleman Supportive Oncology Goals, a program description with an overview of the Supportive Oncology Collaborative for Adolescents and Young Adults (AYA), a budget for each request, and program related support.

Coleman Supportive Oncology Goals

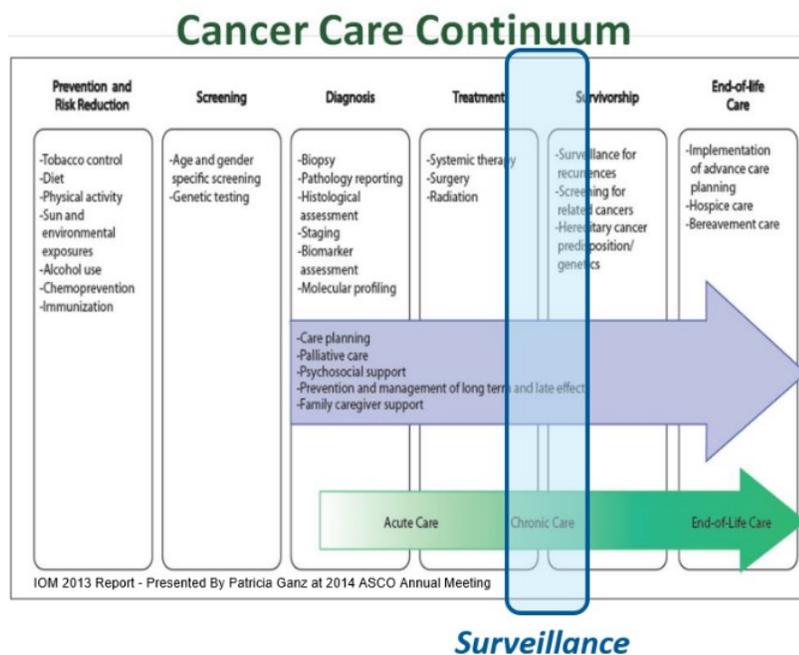
Since 2014, the Coleman Foundation has invested in the Supportive Oncology Collaborative programs for Adult and for Children at various Chicagoland institutions. The overarching goals of the Collaborative are that cancer patients:

- ▶ are regularly screened for distress, psychosocial support and palliative care needs,
- ▶ receive all appropriate services (from diagnosis through survivorship and end-of-life) from a collaboration of multiple, high-quality service providers that have core competencies in delivering care and support,
- ▶ are informed and empowered, along with their families, by personalized patient care sequence document(s), which are adjusted throughout treatment and supportive care.

Program Description

Overview of Adolescents and Young Adults with Cancer Care

Over 70,000 adolescents and young adults, ages 15 to 39, are diagnosed with cancer in the US each year. These young people are living with the long-term effects from cancer treatment including cognitive effects, cardiac issues, secondary cancers and psychosocial impacts. While AYA patients have some psychosocial support when they start treatment, as they move into the surveillance phase of the Cancer Care Continuum, there is little help to navigate the cancer journey. During the surveillance phase, the condition of AYA cancer survivors should be addressed for best possible quality of life. Surveillance (as shown in this diagram), lasts 3-10 years before the patient is moved into survivorship. The transition from pediatric to adult care and movement to surveillance and survivorship will be the focus of this program.



The Supportive Oncology Collaborative for Adolescents and Young Adults (AYA) program is designed to bridge the gap between the Coleman Supportive Oncology Collaborative (CSOC) for Adults and the Coleman Supportive Oncology Collaborative for Children (CSOC-CC). The AYA Collaborative will aim to utilize the elements (tools, resource, methodology and clinician training) developed for adults and children and adapt them to the unique needs of adolescents and young adults based on life stage, emotional state, physical needs, and other factors. Through the AYA program, we aim to:

- Operationalize processes at the cancer center and share patient materials
- Identify AYA’s need for supportive services and match them to care resources
- Test and expand use of CSOC content, tools and techniques for AYA patients
- Pilot and implement 4R Patient Care Sequences for AYA patients focusing on quality of life, supportive care, and holistic primary care

The objectives of the AYA Supportive Oncology Collaborative are to:

- Develop supportive care needs, including patient handouts, tools and other resources created by the Design Working Team
- Create 4R patient care sequences and update at key transitions into surveillance and survivorship
- Optimize use of existing reimbursement codes (~20% private payer)
- Measure improvements of providing care plans, specifically the impact on patient’s ability to follow the care plan, clinician effort, and care timeliness and appropriateness.

In addition to adapting elements created for adult and pediatric cancer patients, management consultants and will adapt the 4R Oncology Model for adolescents and young adults. The 4R Patient Care Sequences utilizes a methodology to create plans for the whole episode of cancer care, which is intended to assist the clinical team and empower the patient to understand and improve self-management; manage timing and sequencing of supportive care across specialties; and engage caregivers/family with the care team. The focus of the Patient Care Sequences is to incorporate multiple factors and target the supportive needs of AYAs based on where they are in their cancer journey.

One of the challenges in the care continuum for AYAs is bridging treatment and services among oncology, psychology, and social work. In order to bridge services at the institutional level, clinicians from both pediatric and adult cancer programs are expected to participate in the work at their site and on the Design Working Team. The Design Working Team will include contributors from CSOC, AYA patient advisors, and AYA patient advocates. The team will be responsible to adapt tools for AYA patients, based on life stage, starting work or family; revise training to support process improvements; and address issues encountered by participating site. In addition, each institution is expected to participate in collection of patient level clinical data based on the metrics identified by the working team(s) and/or the core program support team.

This full request is to support participation by four institutions, Northwestern University, Rush University Medical Center, University of Chicago Medicine, and Advocate Health. The Northwestern request includes grant administration as described below.

Northwestern University Request # 115979

While it is challenging to address services across oncology, psychology, and social work within one institution, it is noticeably more so across two institutions. At the Anne & Robert H. Lurie Children's Hospital, approximately 220 patients were diagnosed last year. At Northwestern Hospital, 500 patients were diagnosed patients last year. Through this project, we aim to improve the linkages between Lurie and Northwestern for transition, surveillance and survivorship of AYA patients.

Grant Management

Northwestern will provide fiduciary support, grant management and administration for this project. Grant management includes provisions of program elements to enable collaborative efforts, subject matter expertise, content development and overall project coordination. Grant administration will include:

- Drafting and processing Memorandums of Understanding (MOUs) for 10-15 of the Design Working Group and Advisory members.
- Making quarterly payments for up to 15 working team members
- Paying honorariums to advisory team members
- Processing payments over an 18-month period for management consultants and program coordination

Program Elements to Enable Collaborative Efforts

Management Consultants

Executive Frameworks, Ltd. (a/k/a Center for Business Models in Healthcare) holds expertise in creation and integration of new delivery models to help accelerate advancement and adoption of personalized medicine and care. As management consultants, Executive Frameworks will support this project with an emphasis on adapting the 4R Model Patient Care Sequences to improve the pathway process for AYA patients at four sites. Responsibilities include assessing current state of care planning, services and events; designing staff orientation, creating patient self-management materials, designing and revising care plans, and coaching clinicians.

Project Management and Coordination

The Project Manager will supervise all team members and be responsible for managing design teams, tracking participation, overseeing deliverables and quality of work, and overseeing grant management. Project Management responsibilities include assisting in content design, disbursing information between working teams, and monitoring project progress. Other responsibilities are to manage cross-site workgroups, coordinate data collection, develop and/or revise quality improvement protocols with sites, work with site coordinators for consistency and efficiency, design staff orientation materials, create patient support materials, and revise care sequence plans based on clinician/staff feedback.

Design Working Group

Consists of clinicians from each site including physicians, psychologists, social workers, and contributors from the pediatric and adult Supportive Oncology Collaboratives, AYA patient advisors, and AYA advocacy groups.

Advisory Team

Representatives of national leadership in supportive oncology will serve to review documents and concepts developed by the Working Team. They are offered a stipend based on actual time spent reviewing and providing input on various products created and developed by this collaborative effort.

Northwestern University Budget

Expenditure Category	Requested
Salaries & Fringes (12 clinicians, various % of effort)	\$166,411
Data/EDW/Cancer Registry/Medical Records	\$6,000
Subtotal	\$172,411
AYA Symposium at Northwestern	\$51,725
Subtotal	\$51,725

Grant Management and Administration	
Expenditure Category	Requested
Management Consultant/ Content Development	\$69,440
Project Coordination/Content Development Assistance	\$97,440
Patient Advocates	\$25,600
Advisory/National Expert Honorariums	\$27,600
Clinician Training	\$20,000
Fiduciary Administration	\$12,000
Subtotal	\$252,080
Total	\$476,216

Prior Grants to Northwestern University

Last Grant Date: 3/11/2019

Number of Prior Grants: 5

Last Grant Amount: \$134,000

Total Amount Granted: \$1,849,800

Rush University Medical Center Request #115980

During the time period between 2016-2018, 1,035 AYA were newly diagnosed. In early 2018, Rush adult and pediatric providers formed an AYA Multidisciplinary Working Group to craft recommendations to better serve patients 15-39 years of age. Rush mainly provides care for sarcoma (bone, blood, and soft tissue) and neuro-oncology for AYA patients.

Rush University Medical Center Budget

Expenditure Category	Requested
Salaries & Fringes (9 clinicians, various % of effort)	\$90,227
Printing/postage for surveys	\$2,500
Patient Family Advisory Council meetings	\$2,500
Laptop	\$2,500
Supplies	\$5,000
Total	\$102,727

Prior Grants to Rush

Last Grant Date: 10/9/2018

Number of Prior Grants: 33

Last Grant Amount: \$220,000

Total Amount Granted: \$13,723,798

University of Chicago Medical Center Request #115981

Last year, 200 AYA patients were newly diagnosed with 2,400 in surveillance/maintenance mode as of 2018. As an aside, this past year, Comer Children’s Hospital announced a partnership with Advocate Children’s Hospital and pediatrics at NorthShore University HealthSystem, for childhood cancer and blood diseases.

University of Chicago Budget

Expenditure Category	Requested
Salaries & Fringes (9 clinicians, various % effort)	\$160,196
Printing care sequences/postage for surveys	\$3,000
Data/Cancer Registry/Medical Records	\$500
iPad x 2	\$1,000
Total	\$164,696

Prior Grants to University of Chicago Medical Center

Last Grant Date: 10/9/2018

Number of Prior Grants: 11

Last Grant Amount: \$220,000

Total Amount Granted: \$2,564,170

Advocate Health #115982

In 2018, 475 AYAs were newly diagnosed and 685 are in surveillance/maintenance mode. Through a joint venture agreement, the Advocate’s Hematology/Oncology Division has been reorganized with administrative and clinical oversight from University of Chicago Medicine. The Advocate oncology team partners with UC Medicine and refers patients to clinical trials that involve a bone marrow transplant.

Expenditure Category	Requested
Salaries & Fringes (10 clinicians, various % of effort)	\$140,000
Quality/Data Management	\$10,000
Total	\$150,000

Prior Grants to Advocate

Last Grant Date: 6/6/2017

Number of Prior Grants: 1

Last Grant Amount: \$75,000

Total Amount Granted: \$75,000

Strengths / Weaknesses

Strengths

- Through the Supportive Oncology Collaborative, various elements were produced that can be adapted for AYA population. This program builds on that work and aims to connect pediatric and adult care to improve services.
- Each institution brings a level of expertise. Clinicians from four institutions will have the opportunity to learn together and design services to improve care.
- Proven support by management consultant and program coordinator assures collaboration rather than competition among clinicians and delivery of quality outcomes.

Weakness

- Frequently transition from pediatric to adult care are not well defined.
- It seems AYAs receive better attention in pediatric care where guidelines exist, although the patient may be over 21 years of age.
- Lack of compliance by AYAs on treatment adherence and follow up, often from not having clear understanding of what is needed and why
- Lack of social/emotional support for AYAs throughout the continuum of care
- Fertility not addressed early enough (or at all) by all clinicians

Why Fund

This project allows us to build on the work and lessons learned from the Supportive Oncology Collaboratives and adapt them to adolescents and young adults. AYAs have an array of issues and needs not addressed by pediatric or adult care. Through this project, we aim to engage pediatric and adult oncology clinicians to work together to improve patient care. This will include efforts to operationalize processes to share patient care tools and resources and connect AYA patients with supportive oncology services. In addition, we will adapt and expand the use of CSOC content, tools and approaches to care for the AYA population. We will work with the clinical teams to create and implement the 4R Oncology Model for Patient Care Sequences for AYA patients, which focuses on quality of life, supportive care, and holistic primary care.

Supportive Oncology Collaborative for Adolescents and Young Adults Request Summary

Grantee	Requested	Recommended
Northwestern University – Grant Management	\$252,080	\$252,000
Northwestern University – Pediatric & Adult	\$172,411	\$172,500
Northwestern – AYA Symposium*	\$51,725	\$51,000
Total	\$476,215	\$475,500
Rush University Medical Center	\$102,727	\$103,000
University of Chicago Medical Center	\$164,696	\$163,000
Advocate Health – Oak Lawn & Park Ridge	\$150,000	\$150,000
Total Grants	\$893,639	\$891,500

* Please note: Northwestern also requests support for an AYA Symposium. We are including approval in the recommendation contingent upon the symposium being a collaborative lead effort with participation by all four sites. If the collaborative is unable to deliver this symposium, we would rescind \$51,000 from the grant. In terms of grant management, it is easier to rescind if not successful, than to amend the grant.

Program Related Support

While the work and process of grant making is conducted by Coleman program staff, core program support and facilitation of working teams will be provided by Executive Frameworks, d/b/a as the Center for Business Models in Healthcare. The Center provides subject matter expertise in cancer care, which is valuable to leading and guiding clinicians on the most current, best practices in delivering oncology care. Core program support and facilitation are essential to creating, implementing and producing outcomes. Program related support of \$12,000 would cover an 18-month period - January 1, 2020 until December 31, 2021.