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Using Community Resources to Build a Survivorship Program

In 2012 the Commission on Cancer (CoC) added new standards that enhance patient-centered functions and define performance criteria in quality measurement and outcomes. These standards included the provision of treatment and survivorship plans, palliative care services, genetics services, navigation programs, and psychosocial distress screening. Today, many community cancer centers are challenged to meet these standards in tight economic times and with little to no reimbursement for these services.

In 2010 UT Southwestern-Moncrief Cancer Institute began an innovative effort to unite and collaborate with local cancer care providers to address the psychosocial and behavioral needs of the cancer survivors—particularly underserved populations. Funded by the Cancer Prevention and Research Institute of Texas (CPRIT), the end result was the Fort Worth Program for Community Survivorship (ProComS), a community-wide, coordinated, evidence-based post-treatment survivorship program that is available to all cancer survivors—regardless of their ability to pay.

The Importance of Survivorship Programs

Advances in early detection, diagnosis, and treatment have increased the number of cancer survivors living in the United States to more than 13.7 million,[1,2] and this population is expected to reach 22 million by 2030.[3,4] The survivorship phase of care represents a distinct opportunity to improve the health and quality of life for cancer survivors by:

- Addressing lingering medical and psychosocial effects of illness
- Focusing on recurrent or new cancers
- Promoting health behavior changes.

However, evidence-based cancer survivorship programs are typically only found in large cancer centers and are often limited in scope because these programs are costly and poorly reimbursed.

Several studies highlight the need for a community survivorship program that provides education specific to health behavior change and other practical support needs of cancer survivors. For example, all cancer survivors struggling with health behavior changes should have the opportunity to participate in tobacco cessation, nutrition counseling, exercise programs, and other supportive care services. In addition, with longer survival, many forms of cancer are now regarded as chronic diseases that require long-term follow-up and further impact overall community health.

Program Goals

Fort Worth is the state's fifth largest city with a sophisticated healthcare system and mechanisms in place to provide cancer care for all socioeconomic levels and degrees of insurance coverage. However, prior to ProComS, survivorship services were fragmented, duplicative, and only offered at a few hospitals or clinics. This lack of an organized, integrated approach to cancer survivors, particularly those with few means or resources, supported the need for an evidence-based, coordinated, and systematic cancer survivorship program.

In developing and implementing a community-based survivorship initiative, the goals were to:

1. Create a dynamic city-wide partnership that facilitated referral of eligible cancer survivors and coordinated evidence-based survivorship services.
2. Establish a physical location for a survivorship clinic to serve as the focal point for ProComS, with special emphasis on recruiting and retaining the local medically underserved population.

In February 2011 UT Southwestern-Moncrief Cancer Institute was awarded two years of funding ($803,816) from the Cancer Prevention Institute of Texas to lead the development of ProComS. As the lead partner, the cancer institute provided the multidisciplinary professional team, support staff, and the physical space for the survivorship clinic. The oncology community and local organizations provided support with referrals, services for evidence-based specialty interventions, and clinical follow-up.

Survivorship Model

Various models of adult survivorship care have emerged and been implemented since the Institute of Medicine's (IOM) initial report; however, UT Southwestern-Moncrief Cancer Institute's "community-based" survivorship model is one not often seen nationally.[7-9] The program identifies partners representing all aspects of cancer care from detection through diagnosis, treatment, and follow-up care, ensuring the most complete range of survivorship resources and services or a "community of solution" (see Figure 1, above right). For more background information on this approach, see sidebar on page 43.

While the partners may serve different populations within the community, they maintain the common goal of providing evidence-based care. In keeping with the "community of solution" model, core services are provided on-site while some patient-specific services, such as speech and language therapy and lymphedema services, are delivered by a community partner. The model allows the cancer survivor to benefit from the services of the entire community rather than one provider.

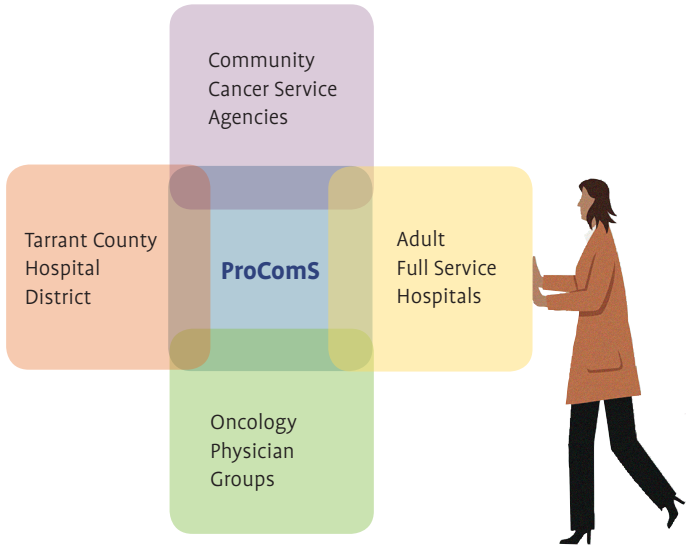
ProComS is open to all adult cancer survivors, enrolling participants regardless of healthcare provider, gender, diagnosis, stage, functional status, insurance level, or ability to pay. Cancer survivors have the option to participate in a longitudinal population science study; more than 50 percent of patients who were offered the study have consented.

Evidence-Based Program Development

Dedicated to addressing the ongoing needs of cancer survivors, ProComS incorporates the four essential components of care patterned after the IOM recommendations:

1. ***Prevention*** of new or recurrent cancers and side effects

Figure 1. ProComS Community Partners



2. ***Surveillance*** for metastases, recurrence, or second cancers, along with assessment of medical, psychosocial, and behavioral late effects
3. ***Intervention*** for consequences of cancer and its treatments
4. ***Coordination of care*** between specialists and the patient's primary care physician to ensure all healthcare providers are well informed and concerns are addressed.[10]

ProComS' quality standards of care are structured using guidelines from such cancer organizations as the:

- National Comprehensive Cancer Network (NCCN)[11]
- American Society of Clinical Oncology[12]
- National Heart Lung and Blood Institute [13]
- American Institute for Cancer Research[14]
- Oncology Nursing Society[15]
- Centers for Disease Control and Prevention[16]
- National Lymphedema Network[17]
- American Pain Society.

Establishing an evidence-based cancer survivorship program, such as ProComS, requires the coordination of multiple community entities and resources. Community partners that commit to the goals of the program and agree to actively promote post-treatment survivorship services in their practices are the foundation of the program. Representatives from local physician-owned oncology practices, hospitals, charitable organizations, and the

safety-net cancer center all serve as part of a community coalition advisory group to problem solve the issue of fragmented survivorship care in the community. Specifically, the community advisory board can:

- Develop methods to reach survivors
- Allow access to their referring staff
- Encourage survivor enrollment
- Provide survivorship care expertise.

Parallel to the "community of solution" concept, the advisory board maintains their commitment to serving the community and participating in the decision-making to provide evidence-based survivorship services.[5]

Clinical Services Program

ProComS' survivorship clinic, located at UT Southwestern-Moncrief Cancer Institute, is dedicated to the ongoing needs of all cancer survivors with special emphasis on uninsured, underinsured, and medically underserved survivors. The clinic includes outpatient clinic space with reception areas, consultation and examination rooms, and a phlebotomy station. A separate fitness area offers cancer survivors cardiovascular exercise, progressive weight training, balance work, resistance training, and group exercise activities.

With its community partners, UT Southwestern-Moncrief Cancer Institute developed a workflow to guide the progress of each cancer survivor (see Figure 2, page 44). This process requires assistance from community partners to identify survivors within their systems, while ProComS staff raise program awareness and recruit, enroll, and engage survivors from various community events.

The multidisciplinary survivorship team is led by an oncology-certified RN, with support from a clinical staff assistant and outreach personnel. Other team members include: oncology certified social workers and dietitians, clinical psychologists, certified genetic counselors, exercise specialists, and a financial advocate (see Figure 3, page 45).

The RN is the first point of contact with the cancer survivor; together they identify the survivor's needs and goals and design a care plan tailored to the individual. Each cancer survivor is offered a Survivorship Care Plan and a Treatment Summary using the Journey Forward™ format.

Next, a social worker assesses the psychosocial needs of survivors, caregivers, and families. If necessary, the social worker connects survivors and families to the team's psychologist.

Cancer survivors or family members may choose to consult with either a male or female psychologist for up to eight counseling sessions—free of charge. Psychologists also provide tobacco cessation counseling and education and, in conjunction with the social worker, facilitate bilingual support groups addressing issues related to diagnosis, treatment, side effects, and family coping.

If needed, the RN refers patients to the dietitian who provides

THE FOLSOM REPORT

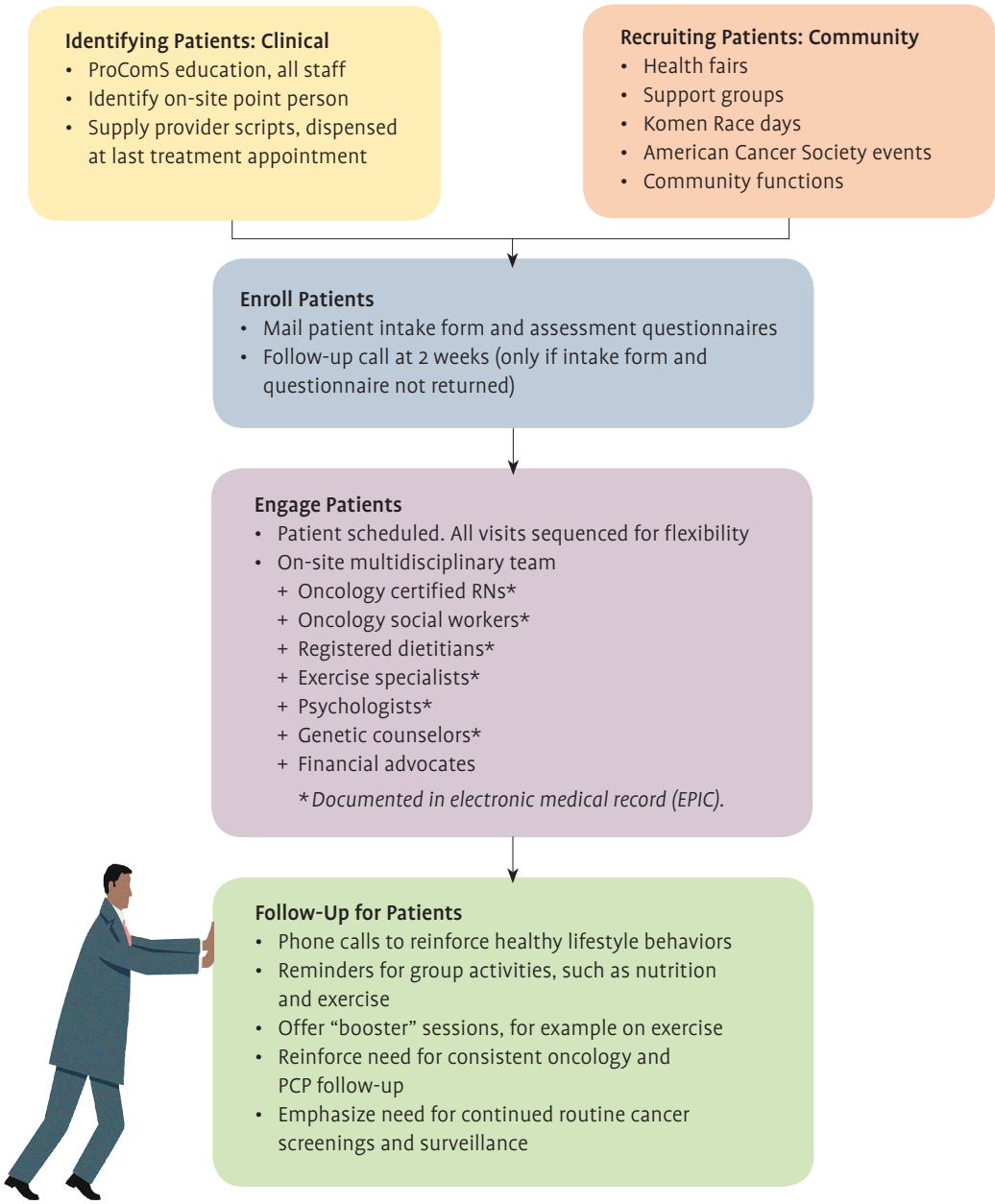
In the 1960s, the National Commission of Community Health Services, chaired by Eastman Kodak Director Marion B. Folsom and comprised of 32 prominent commissioners from the fields of medicine, business, health advocacy, and government, spent three years researching health service needs in 21 selected communities across the United States and formulating a rational action plan. The result was the 1967 Folsom Report, "Health is a Community Affair," which described comprehensive healthcare delivered by integrating services within the community, primary care, and public health, and placed emphasis on collaborations to implement "communities of solution."[5,6]

The Folsom Report provides a roadmap for a sustainable, community-wide endeavor, including:[6]

- The integration of provider communication into survivorship areas
- The reframing of survivorship services into a community health orientation
- Accountability for measurable outcomes
- Connection to overall public health.

The report identifies the integration of community partnerships as the key in developing "communities of solution" when addressing population health issues.[5,6] The Folsom Report provided the framework on which ProComS was built, effectively bridging the community's fragmented survivorship services.

Figure 2. ProComS Workflow



one-on-one consultations for impaired nutrition and weight loss, as well as group nutrition education and cooking instruction in a state-of-the-art demonstration kitchen.

All cancer survivors that choose to participate in the exercise program are referred to both the dietitian and the exercise specialist by the RN. The exercise specialist guides the patient through 12 one-on-one supervised fitness sessions to address the cancer survivor's unique exercise and activity needs. Focus is on increasing physical activity, strengthening, and reconditioning. Group exercise opportunities are also available to survivors for additional cardio and resistance training.

For those cancer survivors who are identified as at-risk due to a family history of cancer, the RN refers them to a certified genetic counselor to receive genetic counseling and testing.

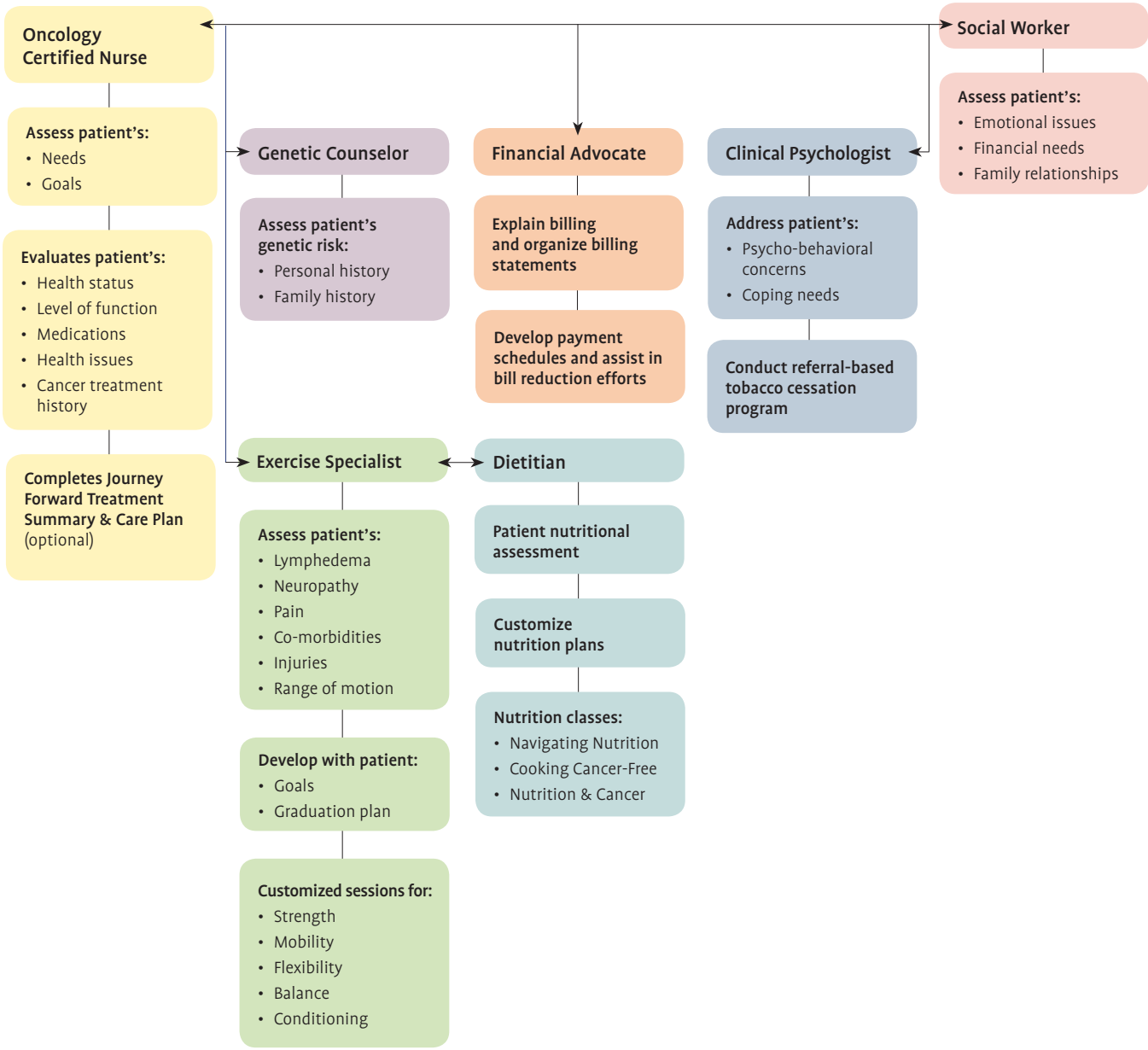
Finally, cancer survivors struggling with financial issues have access to a financial advocate. Any member of the multidisciplinary cancer care team can refer patients to this service.

This model centralizes the services of the multidisciplinary team; however, cancer survivors may be referred to a community partner for specialty services based on need.

Evidence-Based Practice Service Referrals

While UT Southwestern-Moncrief Cancer Institute's survivorship clinic offers an array of services on-site, the program maintains a broad referral stream, using community partners to offer the most comprehensive care possible to cancer survivors. Survivors requiring the specialized medical or rehabilitative services listed below are referred to a community partner program:

Figure 3. ProComS Multidisciplinary Team



- Speech therapy for survivors who have had treatment to the head and neck area
- Professional instruction and support for survivors who have had ostomies
- Interventions for lymphedema
- Palliative care
- Pain management
- Hospice care.

In collaboration with the local YMCA/LIVE**STRONG**,™ ProComS encourages cancer survivors "graduating" from the exercise component to maintain their healthy lifestyle behaviors. Cancer survivors are transitioned from the survivorship clinic to YMCA/LIVE**STRONG** so that they can continue exercising in a safe, structured environment where the staff is educated and trained to meet their unique needs.

Program Results & Outcomes

Over the two years of grant funding, ProComS' location, services, and model of care were developed and implemented. Cancer survivors have benefitted from multidisciplinary services as collaborations between community physicians, hospitals, and local community agencies solidified.

The program has had a huge impact, logging over 4,000 cancer survivor encounters with survivorship clinic staff, and a 43 percent growth in program enrollment since initiation in 2011 (see Table 1, page 46). Demographic data and team encounters on all cancer survivors enrolled in the program are captured in a customized

database allowing for aggregate analysis of program components.

Consistent with other survivorship programs, participants have been primarily Stage II and III breast cancer survivors, who were treated with surgery, chemotherapy, and radiation.

The exercise team provides about 68 percent of all patient encounters, with 98 percent of survivors who received exercise training completing the 12-session survivorship exercise program. At the conclusion of these sessions, 80 percent transitioned to other exercise programs—either a personal gym membership, YMCA/LIVE**STRONG** programs, or a home-based gym. Fifty-five percent chose to attend YMCA/LIVE**STRONG** programs. After conclusion of the formal exercise program, 80 percent of survivors attended a follow-up visit to reinforce exercise techniques.

Adherence to scheduled appointments across all survivorship disciplines is 80 percent and 180 survivors have requested and received a Survivorship Care Plan and Treatment Summary. Overall patient satisfaction with the multidisciplinary survivorship services continues at 93 percent.

Table 1. Multidisciplinary Team Encounters

SERVICE	ENCOUNTERS
RN OCN Navigator	453
Social Worker	270
Exercise	3,980
Dietitian	420
Psychotherapy	477
Genetic Counselor	22
Financial Advocacy	10
Total Encounters	5,632

Discussion & Lessons Learned

With the community engaged and the survivorship clinic operational, persistent outreach to providers and cancer clinics is essential to program success. Clinical collaborations are strengthened by regularly scheduled Community Advisory Board meetings throughout the year. These formal meetings with the board allow communication to remain open.

UT Southwestern-Moncrief Cancer Institute is not a cancer treatment facility, but rather a community cancer foundation that relies on referrals from oncology providers, community and local agencies, self-referrals, and word-of-mouth from program participants. Therefore, maintaining these strategic partnerships is a critical component to programmatic success. Extending outreach directly to primary care practices, treatment centers, service agencies, and survivor-related events, and through local media and public service announcements is essential. For example, 40 Parish nurses, representing 20 African American community churches, attended a structured educational program and were given survivorship brochures to distribute to their congregants.

The primary challenge is consistent referrals and enrollments from underserved patients receiving treatment at Forth Worth's safety-net cancer center. To address this issue, a full time bilingual program manager with a social service background focuses on engaging the community oncologists and safety-net providers.

In the ProComS patient population, barriers to care mirror those described in the literature.[18,19] Transportation needs are met by providing gasoline cards and public transportation vouchers to cancer survivors.

Bilingual staff is available to resolve language barriers. When ProComS focused on meeting the specific social and cultural needs of Hispanic women, it was able to increase their attendance at support groups and exercise sessions—both in terms of total number and consistency. In fact, one group of Hispanic women formed a "spontaneous" support group that chose to exercise at the fitness center at the same time, completing their exercise routines while talking, encouraging one another, and socializing in their primary language.

Cancer survivors returning to work are often unable to attend daytime appointments; these barriers are addressed through "as needed" scheduling of evening appointments.

Complementary and alternative medicine techniques are increasingly popular in the management of post-cancer treatment symptoms. ProComS participants are offered Yoga and Tai Chi on-site at the UT Southwestern-Moncrief Cancer Institute survivorship clinic.

ProComS demonstrates how a local community is able to partner with leadership across different organizational systems to provide multidisciplinary cancer survivorship services. Successful survivorship programs require sensitivity to the local values and culture, particularly with regard to established patterns of healthcare communication. Survivorship staff at UT Southwestern-Moncrief Cancer Institute continue to immerse themselves in this diverse community, and recognize the key to success is the willingness of each provider to operate as a collaborating partner on multiple levels.

Using a community engagement framework, program leaders at all partner organizations are able to provide a "top down, bottom up" approach to community engagement and stakeholder involvement.[20] A critical success factor in the establishment and management of ProComS has been the unceasing effort of the "central organization," in this case UT Southwestern-Moncrief Cancer Institute, to maintain consistent outreach. Cancer patients emerge from treatment with a case of tunnel vision. Many have

been so focused on the next treatment step that they are overwhelmed when there is no clear "next step" in survivorship. While a comprehensive survivorship program can offer those much needed next steps, these patients require guidance and ongoing communication with providers.

Although this approach works for a majority of the survivor population in the ProComS community, the medically underserved cancer survivors remain under-represented in terms of enrollment. Additional recruitment efforts are aimed at engaging the medically disadvantaged who are treated in the safety-net system. Embedding staff directly at the safety-net oncology clinic, direct dialogue with the Cancer Committee, providing additional follow-up telephone calls and transportation vouchers, contacting Parish nurses, and mailing re-invitations, have all been well received.

Further research is still needed to understand how to best educate and engage uninsured, underinsured, and medically underserved patients in essential survivorship services. The services provided to ProComS survivors were funded through a CPRIT grant at no cost to the survivor. The completion of a cost and benefit analysis will be a next step towards a better understanding of survivorship funding and program sustainability. OI

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