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Population Based Patient Navigation : 24-Hour Personalized Cancer Care for the Entire Cancer Continuum

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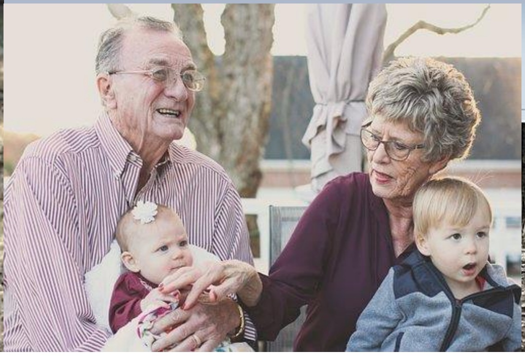

OVERVIEW

Cancer. One word that bears immense significance for so many individuals. For some, it is the word that took them by surprise, imposing new routines and adjustments to daily life as quickly and succinctly as it rolls off the tongue. For others, the word evokes complex and multifaceted emotions - fear, strength, apathy, gratitude, anger, hope, grief, determination – the list is endless and ever changing. The impact of this diagnosis extends far beyond the patient to their family, their care team, their community and more.

In 2017, there will be an estimated 1,688,780 new cancer cases diagnosed in the United States.[1] Of those diagnosed, every cancer journey will be unique. Standard differences in cancer site, stage, treatment modalities and outcomes, coupled with variances in patient age, receptivity to treatments, and patient preference of therapies compels oncologists and cancer care teams to design treatment plans patient-by-patient, providing a vastly individualized and intricate approach to the treatment of cancer.

With the complexities involved across the cancer care continuum, the need emerged for trained individuals uniquely qualified to assist patients, providers, and families navigate this expounded realm of cancer care. From this need arose the field of patient navigation.

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Patient Navigation:

Expanding Cancer Care Services from Prevention through Survivorship

As of January 1, 2016, there were more than 15.5 million Americans alive with a personal history of cancer.[1]

The concept of patient navigation was founded and pioneered by Harold P. Freeman in 1990 for the purpose of eliminating barriers to timely cancer screening, diagnosis, treatment, and supportive care. He initiated and developed the first program of its type in order to reduce disparities in access to diagnosis and treatment of cancer, particularly among disparate populations. The original program focused on the window of time between a suspicious finding and the resolution of the finding by further diagnosis and treatment.

Cancer patients may experience considerable barriers from diagnosis through active treatment. Commonly reported barriers include the financial barriers of medical costs or loss of wages; communication barriers including language and cultural blocks or lack of understanding; medical system barriers such as missed appointments, lost results, or a fragmented medical system; psychological barriers including fear, distress, or anxiety; and the list of barriers continues with many others including transportation, need for child care, and general questions.

Patient navigation programs aim to identify and resolve patient barriers to care, link patients and families to primary care services, specialist care, and community-based health and social services, all in an effort to provide more holistic, patient-centered care.

While patient-centric care has developed and expanded for the cancer patient, a report from the Institute of Medicine (IOM) in 2005 *“From Cancer Patient to Cancer Survivor: Lost in Transition”* exposed an urgency to recognize and address the burden that remains after treatment for cancer survivors.[2]

The term “survivor” or “survivorship” has been used in assorted ways, but in the sphere of oncology it encompasses “the process of living with, through and beyond cancer.”[3] As of January 1, 2016, there were more than 15.5 million Americans alive with a personal history of cancer, all of whom are considered cancer survivors.[1] Some of these individuals were diagnosed recently and are still undergoing treatment, while most were diagnosed many years ago and have no current evidence of cancer.

Cancer survivors may face numerous barriers following primary treatment. Potential long-term and late effects (some permanent and disabling) from cancer and its treatment include psychological distress, sexual dysfunction, infertility, impaired organ function, cosmetic changes, and limitation in mobility, communication, and cognition are among the issues faced in this cohort.[2] The 2005 IOM Report rendered awareness of the medical, functional, and psychosocial impact of cancer and its treatment and advanced the movement of survivorship care.

The scope of patient navigation has since evolved and expanded to include survivorship and is now employed across the entire healthcare continuum, including prevention, early detection, diagnosis, treatment, post treatment, quality of life and supportive care, and survivorship.■

Required Standards for Cancer Program Accreditation

Patient navigation has quickly become a central component to cancer care in health systems nationwide. Evidence-based research demonstrates the value of patient navigation in terms of reducing or removing many of the common barriers associated with cancer care. [4] These findings have led oncology-related accrediting organizations to integrate patient navigation as a required standard for cancer program accreditation. Survivorship standards have rapidly followed.

- **In 2005**, the Patient Navigator, Outreach, and Chronic Disease Prevention Act of 2005 authorized federal grants to hire and train patient navigators to assist patients with cancer and other serious chronic disease to obtain access to timely diagnostic, treatment, and follow-up care.
- **In 2009**, the National Accreditation Program for Breast Centers (NAPBC) instituted standard 2.2 requiring that a patient navigation process be in place to guide the patient with a breast abnormality through provided or referred services.
- **In 2012**, the Commission on Cancer (CoC) of the American College of Surgeons initiated standard 3.1 that emphasized the need and importance of navigation services, requiring the phase-in and documentation of navigation services by 2015.
- **In 2015**, the CoC of the American College of Surgeons implemented standard 3.3 requiring cancer survivors be provided with a comprehensive treatment summary and survivorship care plan. By 2018 and beyond, 75% of eligible cancer survivors are required to receive a treatment summary and survivorship care plan.
- **In 2016,** the NAPBC instituted standard 2.20 for breast cancer survivorship care. This standard requires that a survivorship care plan and treatment summary be provided to 100% of eligible breast cancer survivors.

As the value of patient navigation and survivorship programs becomes more evident, medical institutions are looking for program models that fit the needs of their facility. Numerous models of patient navigation programs exist. Some are clinically-based with nurses or nurse practitioners, social workers, health educators, or clinic staff members practicing in a disease-specific or generalist role, others are community-based programs with intervention by lay navigators or other licensed staff. Still other models exist including case management and patient advocate models. While all program models focus on reducing or eliminating the common barriers associated with cancer care, the most successful model is one tailored to the needs of the population being served. However, implementing a sustainable navigation program model with the flexibility to adapt to the ever-changing standards while staying grounded in patient-centered care presents a challenge to health systems nationwide. This paper highlights one example of an innovative, community-driven yet health system based model of patient navigation that is successfully adapting to meet all of the aforementioned needs through 24-hour personalized cancer care providing resources, support, and access to expertise.

Personalizing Cancer Care:

Development of a 24-hour Patient Navigation Center within a Cancer Treatment Center in a Rural State

Nobody should face cancer alone. That's the philosophy behind the newly developed Avera Cancer Institute Navigation Center (ACINC). The ACINC is dedicated to being an around-the-clock source of comfort and support for anyone whose life has been touched by cancer.[5] Opening in March 2016, the center offers a unique model of patient navigation as a free community service. The model was thoughtfully developed based on the needs of the rural population the health system serves, with the ultimate goal of removing barriers to care and reducing the burdens related to cancer. The narrative below showcases how "out of the box" thinking can lead to valuable population-based care that extends beyond treatment.

Located in the Upper Midwest, Avera Cancer Institute serves patients from six regional cancer centers and 40 outreach sites across a 72,000 mile footprint in South Dakota and surrounding states. The demographic served by these centers is largely rural, with 32% of patients at the urban cancer center location traveling more than 100 miles to receive care. The system sees more than 2,000 new cancer patients come through its doors each year, every one with unique needs, questions and concerns related to their care.

> **"Cancer is so complex. You have so many providers involved with one patient. You have so many medications and so many treatment regimens. You have such a high volume of people traveling from very rural areas to any of the six Avera Cancer Institutes. All of the traditional burdens and barriers that fall into healthcare tend to be exacerbated for oncology,"** said Jamie Arens, Director of the ACINC.

A steering committee made up of Avera leaders, caregivers and patients was formed in order to address and lessen the exacerbated burdens of oncology. A collaborative and coordinated approach was pursued to design a system-wide patient navigation program that would be accessible for all of their patients, regardless of their primary treatment location. Conversations began in 2015 to assess the variety of patient navigation program models currently in use across the six cancer center's service line. Discussions centered on how the six cancer centers could collaborate to utilize best practices, streamline services, and evaluate options for creating navigation services with the greatest impact on their largely rural population.

While discussions on streamlining services occurred, Avera Cancer Institute also launched a Rural Cancer Advisory Board, a group of stakeholders providing input on how to better understand the barriers to cancer treatment for rural populations. Navigation, or how to connect patients and families to resources, particularly after hours, was a key issue for the Advisory Board. "How can you incorporate people to fill gaps, to reduce burdens, to remove barriers, to streamline things, and to really be there when somebody needs it?" This question, asked within the Rural Cancer Advisory Board, led the group to insightful discussions about the burdens that patients encounter throughout their cancer journey and the services that could address them.

Current and former patients, rural community members, and the steering committee identified a critical need for a resource that, 1) would extend beyond the normal office hours, 2) could provide access to a navigator for anyone affected by cancer, and 3) would create a centralized process for all patients and caregivers at their time of need. From these discussions, the design of the program grew and developed into a 24-hour, primarily phone-based patient navigation center that serves not only patients receiving care at one of the Avera Cancer Institutes, but also providing a community service that connects patients, families, and healthcare providers with information and resources to navigate the cancer journey from screening and early detection, to initial diagnosis throughout survivorship.

The process of developing the ACINC started with a review of existing models, reading journal articles, and understanding what models other health systems were implementing. What they found is that when it comes to oncology navigation, there isn't a clear definition or process.

"I always say that navigation is provided based on the needs of the people you are trying to serve. That's how I define what navigation should be in place. That's how we figured out our navigation model – we are here to remove barriers to care and reduce burdens related to care. The research helped us understand that it's okay to design it out-of-the-box and create our model based on what our patients need. That's probably going to end up being a better product than trying to budget for and fit an existing model into our system," Arens said.

The team also used the history of patient navigation for their design. The founder of patient navigation, Harold Freeman, simply looked at what was needed in his community. By applying a grass roots method and building relationships within the community, the original program was able to make a significant impact applying a longitudinal model of navigation that shepherds patients through each phase of care. Avera Cancer Institute hopes to replicate that impact by having a presence in the communities they serve and a relational approach to patient interaction and support.

To better understand the cancer related needs within the service area, it was vital for the steering committee to assess the needs of the region. This research included an analysis of existing community health needs assessments, review of the *South Dakota Cancer Control Plan 2011-2015*[6] and other state data provided by the South Dakota Department of Health, a focus group of existing navigation staff within Avera Cancer Institute, and a thorough review of best practices around patient navigation services. Trends discovered throughout the assessment revealed common needs including (in no particular order): transportation, access to care, mental health services, chronic condition management, availability of cancer support services, navigators, and social workers, timely treatment, financial/insurance concerns, cancer education and support. This extensive list also validated the belief that patients rarely present with a singular need; rather, almost every interaction involves a combination of clinical and psychosocial needs.

Building upon a community-based generalist model of navigation and armed with the data from the community needs assessments, the ACINC was shaped. The navigation center provides services by telephone at any hour of the day to anyone who needs support or referrals. Walk-in services are available at the urban cancer center location from 8:00 a.m. to 5:00 p.m. A registered nurse navigator as well as a master's prepared social work navigator, both with backgrounds in oncology, are available during walk-in hours or by phone until 8:00 p.m. Outside of those hours, calls are answered by the Avera Call Center, and triaged as needed to the appropriate resource to address immediate concerns. A log of all triaged calls is provided to ACINC staff the next day, who then follow up with each caller to provide further oncology support. Call volume and staffing needs are continuously monitored in order to adjust services to match the needs of the community.

Provision of services by phone ensures that care is available immediately, alleviating access concerns for the rural population. Arens stated, ***"I would say that our model is unique to any model that I've seen….you have national support lines, online resources, and then you have hospital systems that have a clinical piece, all which provide needed care to cancer patients and their families. But, offering a free community service that provides support, connection to resources, triage education, and clinical experts…all of that is something that I haven't found yet."***

The ACINC is available to anyone whose life has been touched by cancer, including patients and families of all six Avera Cancer Institute centers and outreach sites, as well as community members and callers from anywhere in the nation. The staff at the ACINC work with existing clinical navigators and care teams for patients undergoing treatment at one of their six cancer center sites, providing the after hours support and connection to resources that may be needed outside of direct clinical care.

"We do a lot of communicating within the care teams, so if it's somebody that uses the Avera Cancer Institutes, we are an extension of all of our physicians and staff, so we can pull that patient's chart up from any of the six cancer center locations. We are able to read the progress note of that oncologist or look at their schedule or review their treatment regimen, so we're really an extension of them. We are also able to keep providers updated, so whether it's getting back to their primary care or the specialist who referred them – we really look at who on their oncology care team needs to know this," Arens said.

One of the key principles of the service however, is that the ACINC is available to any cancer patient or family member, even those who receive care outside of the Avera system. Additionally, a surprisingly large portion of the calls received in the ACINC are from medical professionals, including oncology and non-oncology staff.

"We see a lot of medical professionals utilizing the center as a hub to ask questions, figure out who to go to, send a patient referral, or whatever it might be. I think the amount of communicating with other medical professionals is just a natural fit with the work that we do, but it wasn't anticipated. It just naturally happens when we're working with somebody and things arise that their provider needs to be aware of," Arens said.

As services were established in the first year of operation (March 1, 2016 – March 1, 2017), the ACINC addressed 511 patient concerns across 165 unique zip codes. Callers were most commonly seeking information about cancer treatment or diagnosis, location or contact information for a medical facility, anxiety or emotional concerns, communication concerns with medical staff, or issues scheduling care. Cancer patients were the most likely to reach out, followed by oncology staff and providers, non-oncology medical staff and providers, survivors, and the family, friends, and caregivers of patients.

Approximately 90% of services are provided by phone/remotely, with the remaining 10% of clients utilizing the walk-in option at the physical navigation center location. Staff of the ACINC emphasized the diversity of the needs they've helped address.

"We literally never know what's on the other line," said Jordan Fiegen, Social Work Navigator at the ACINC. ***"It could be as simple as a transfer, or it could be someone who is going through an emotional breakdown. It could be someone who is vomiting uncontrollably and needs to go to the emergency room immediately. It is just so broad. You never know what you're going to be doing on a daily basis, or what 10:00 AM is going to look like in comparison to 7:00 PM. One of the biggest struggles we face is in working over the phone. It is not like working in a clinical setting or in an outpatient setting where you are face-to-face with a patient and you can pick up on their body language and physical queues that accompany their words. You have to be comfortable allowing them to cry, or just keep talking, or maybe they just need to grieve. If a person is picking up the phone and reaching this number, they really want someone who is going to be able to be comfortable in that setting and take their time with them,"*** said Fiegen.

Due to the variability of calls, the combination of nursing staff and social work staff has been an enormous benefit to the center and to the individual callers.

Arens stated, ***"It was clear from everybody's perspective on the steering committee and the rural cancer advisory board that almost every interaction is never just a clinical need or a psychosocial need. It is just intertwined. It is great to have a master's level social work navigator as well as a registered nurse navigator who know and live and breathe oncology to be able to team approach any need that comes in."***

Funding for the ACINC was fairly organically derived as well. The very first navigator position for the Avera Cancer Institute was philanthropically funded through a donation to the Avera Foundation. With a philanthropic tie to patient navigation from the beginning, it was clear that the Avera Foundation would be a valued voice to have on the steering committee for the development of the ACINC. Support of the Avera Foundation, through contributions from donors and community organizations, opened the door of possibility prompting conversations of providing the ACINC as a free community benefit. With three years of donor funding in place, plans could be verbalized for the center and fundraising events were hosted in many of the six cancer center communities. The combination of donor support and fiscal responsibility allowed the ACINC to provide services free of charge to the community. Additionally, grant opportunities were sought out to complement existing avenues of support.

“We’ve never had a conversation with anybody who has utilized our service about giving back to us. It has never entered the conversation. I think the benefit of operating from donor funding is it makes it very meaningful. You have more opportunity to think outside of the box and develop something that you, at the end of the day, can say is for the people who are funding it. You don’t have quite as much constraint to normal healthcare system practices. But, the biggest benefit is just that the center was able to open. If we wouldn’t have had the donor support, I don’t know what it would look like. We wouldn’t exist in the manner that we do,” said Arens.

Arens stated, ***“The drawback or fear when something is philanthropically funded is what happens if funding runs out. Realistically, that is the downfall of having something funded this way. I am not concerned about that. I think there is downstream revenue that is generated from something like this, but there are also success metrics that reflect the impact we’re making on our communities. Hopefully that data can reflect the center’s impact when we apply for grants. We’ve been afforded the opportunity to prove ourselves, and I think that has allowed us to be sustainable.”***

Marketing of services follows inline with the grass roots approach of the center. Promotion occurs via speaking engagements and vendor tables at community events. The ACINC also partners with healthcare systems to make sure information is available to nurses and providers, as well as in the waiting rooms within community healthcare facilities so that community members are informed of the service at diagnosis. The ACINC service is also promoted to current oncology patients as an extended resource, available in addition to the support from their care team.

As the navigation center grows, expansion of services is planned using outbound phone calls to reach patients at intentional points in their cancer journey, such as after their initial diagnosis, after their first round of chemo, or following their survivorship visit at the end of active treatment. Through experience, the center has learned that these pivotal points in the cancer journey are commonly filled with questions, fear, resistance in moving forward or other matters which the navigation center could help patients address.

Survivor Navigation:

An Innovative Model for Survivorship Care

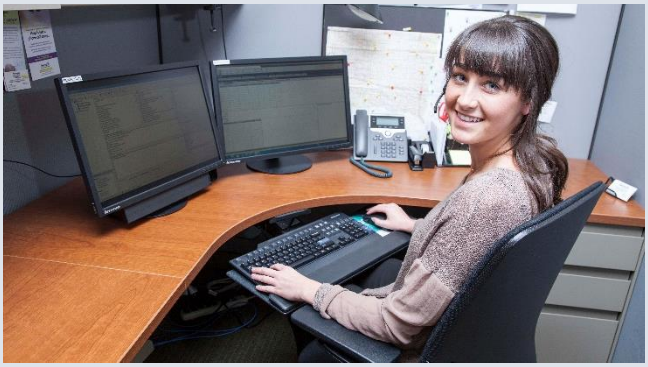
With the goal of providing support in a pivotal time point, a Survivorship Program was piloted at the ACINC in August of 2016. An outbound call is placed to a survivor roughly two weeks following the survivorship visit as an additional means to provide resources, assess remaining patient needs, and offer continued support and encouragement to survivors.

Rita Sanem, registered nurse navigator at the ACINC stated, ***"The survivorship outbound call lets the patient know that they are not just cut off from care once their treatment ends. We want them to know that we are always here for them. We want to remind them that they can call us for any reason at any time….it's a free call. Following the survivorship outbound calls, we send out resources and information that they might need down the road. For survivors, one of their biggest fears is that they've lost control. Their whole life has been given over to their care team during treatment. Sending them resources and information gives them back control, or at least they have it when they are ready."***

The process for survivorship outbound calls was arranged in a linear fashion. Using existing clinical processes, a survivorship care plan (SCP) is created for eligible patients and delivered during a survivorship visit with an advanced practice provider. During that visit, the provider completes an assessment in the patient's electronic medical record (EMR) which covers physical activity, nutrition, body mass index, tobacco cessation, colorectal cancer screening status, anxiety and depression screening, physical rehabilitation needs, and also gathers information about the patient's primary care provider. When the assessment is reviewed and approved in the EMR, a notification is automatically sent to the navigation center to follow-up with the survivor by phone, within 2-4 weeks following the survivorship visit.

Sam Gaster, Survivorship Program Manager at Avera Cancer Institutes stated, ***"The whole process is set up like a series of dominos. One of the side benefits of a domino process is that while every individual may perceive one domino or one component as being especially valuable, every component in the process needs to be completed for the final component to occur. Let's say a provider really loves the survivorship outbound calls; well, the only way that can happen is if a person gets a survivorship care plan. So, the provider must deliver a SCP. Or, if a provider says they really love the assessment that was created because it helps guide the patient conversation; well, the provider has to deliver a SCP, which triggers the assessment, which then triggers the outbound call. So everything has to happen in a certain sequence."***

When staff at the ACINC receive a survivorship notification for a patient, they know that the patient has received a SCP, had an assessment completed during a survivorship visit, and in 2-4 weeks an outbound survivorship follow-up call can be made from the navigation center. Staff of the ACINC can access the patient's information then to review and learn a little about the survivor before they place that outbound call, which allows them to personalize and tailor the call to achieve the highest patient benefit and prepare for a very meaningful call. They can review the completed assessment from the last visit and, based on patient needs, can prepare further resources to offer to the survivor and discuss potential concerns during the outbound call.



"It was important for us when we first started the outbound survivorship calls to know which specific documents to review prior to calling. We review the patient's SCP and are now comfortable with the patient's charts that are in the EMR, so we know where to look for notes from their care team, their social worker, or their nurse practitioner. Collectively, that information is a great connection piece. When we call the survivor then, we can make it a conversation and let them know that we are calling to care about them, not to take a survey or get these tasks done. We are calling as a courtesy to care about them and to ask How are you doing?, How is your family doing?, Have you done these things?, and if not, we are going to take the opportunity to remind them," said Fiegen.

The content of the calls is primarily patient-driven. Staff ask standard questions for assessment of tobacco use, physical activity and nutrition, and assessment for colonoscopy screening, but the remainder of the call is open-ended to allow the patient to determine the course of the conversation.

"The call is really quite open-ended based on what the navigator sees in the patient's chart and what that assessment during the visit tells about the needs, so it was designed to be very patient-centered. The content of the call is up to the patient. That's the goal. We know there are going to be some very important things to always cover with everybody, but we want it to be as much driven by the patient as humanly possible," Gaster stated.

In the first year of survivorship outbound call implementation (August 1, 2016 – July 31, 2017), 299 survivors were successfully contacted for this additional service, representing an estimated one-fifth of the health system's total eligible survivor population in a one year period.

Initial planning is underway for the next step in assisting survivors in their journey, which is transition of care back to the patient's primary care provider. ***"We are planning to structure communication between the ACINC and primary care providers. For survivors that have gone through our center, we have their SCP, a survivorship assessment, and a follow-up assessment completed during the survivorship outbound call. We have a record that says here's everything about the patient and their care, here's what's concerning them right now, here's what we've done to address those concerns, and here are the concerns that remain unaddressed. I would love to have the ACINC staff standardly provide a document that encapsulates all of that information to the patient's primary care provider,"*** said Gaster.

According to Gaster, plans are underway to trial delivery of a document such as this to primary care providers on a small scale, with hopes to expand the practice to the larger scale.

In summarizing the ACINC, he stated ***"Each component of the Survivorship Program is just a drop in the bucket. It is one document, or one phone call, or one person transitioning care, and so I don't know if [the survivorship outbound call] makes the critical difference in a person's care at all times. But, it's the additional service and I think that's how the ACINC is always described – it's an additional service to provide further support to patients and staff. So you just need drops in the bucket. And when we can start making connections back with primary care, then it becomes a splash because then you're truly bridging silos."***

As the ACINC continues to grow and expand, the center hopes to add further standardized outreach services at pivotal time points in the cancer journey. Currently, staff only conduct outbound calls for the Survivorship Program, or at the request of care team members. The center also hopes to sustain and expand community connections and outreach to stay consistent with their grassroots mission and to continue to tailor services to meet the needs of the community. Growth is also anticipated in terms of telemedicine, especially with the high demand from the center's rural population.

> ***"As far as the services we want to provide, we're going to keep molding and adding to meet the needs of our community,"*** said Arens.

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Avera

SOUTH DAKOTA
DEPARTMENT OF HEALTH

Executive Summary

Launched in 2016, the Avera Cancer Institute Navigation Center (ACINC) was developed as a community-based model of patient navigation adapted to meet the needs of the highly rural population in the region. The 24-hour, 7 day a week phone based delivery model provides the same level of service to patients and families at all six cancer centers within the system in a centralized manner by staff specialized in oncology navigation. With the model in place, the ACINC quickly became a resource not only for cancer patients undergoing treatment in the health system, but also to health care providers, survivors, caregivers and the community inside and outside of the health system.

Building on the initial success of the ACINC and literature demonstrating the medical, functional and psychosocial barriers patients face following primary treatment of cancer, a Survivorship Program was added in 2016. The Survivorship Program provides outbound phone calls to cancer survivors a few weeks after they've received a survivorship care plan. This outbound survivorship call occurs at a pivotal time point in the transition out of treatment, adding another opportunity to ensure that patients' needs are addressed, and preventative and rehabilitative health needs are assessed with referrals provided as needed. All services of the ACINC are provided at no cost to the patient or provider, which is a key aspect of the service. To accomplish this, the center is funded through both philanthropic gifts and grant funding.

The ACINC model provides the opportunity to scale services to better meet the needs of both patients and health care providers. Future components of the center include expansion of the services provided to survivors, as well as additional work with primary care providers as survivors transition back to care in their community settings. The rapid rate of growth at the ACINC demonstrates that the service is filling a critical gap for the rural population in the region.