Introduction
The number of American Indian and Alaska Native (AI/AN) cancer survivors is increasing every day. They live all over the country, on reservations, in rural communities, and in urban areas. There is also a growing need for services to support a healthy lifestyle and long life. Once a person has been diagnosed with cancer, has gone through surgery and/or other treatments and has survived, they rarely see their cancer doctor again. They go back to their previous lifestyle and often do not have access to guidance from anyone on how to manage side and long term effects from treatments, adhere to a new screening schedule, and develop healthy eating and exercise habits. All cancer survivors have an increased risk of having a reoccurrence or a new cancer. The best way to prevent this is to maintain a healthy lifestyle. Without support to develop cancer survivor care plans and implement them, many AI/AN survivors look to their communities for services and supports.

There are currently 25 tribes or tribal organizations funded directly by the Centers for Disease Control and Prevention (CDC) to implement cancer control programs, including breast, cervical, and colorectal cancer screening and comprehensive cancer control programs. Four of the organizations receive funding for screening and comprehensive cancer control programs. Outside of these CDC-funded cancer control programs, few tribes or tribal clinics have cancer specific programs, services, or staffing. Many of the tribal clinics, both on reservations and in urban sites, have limited staff and unending responsibilities to the community and current patients. There is little time remaining for cancer survivor support services.

2013 Survivorship Survey
During spring 2013, NACR, with support from CDC Tribal Program staff, solicited surveys about cancer survivorship care and services from the funded tribal programs across the country and encouraged other AI/AN programs to take part. Only six programs (5 CDC-funded programs and 1 non-CDC-funded tribal program) responded. The information collected, however, is reflective of the broader AI/AN community.

In response to the survey, there were no formal AI/AN cancer survivor programs. All programs reported providing some components of survivorship supportive care, but none had comprehensive quality of life supportive care programs. Only 2 provided the following additional components:

- Cancer survivorship support groups / Circles
- Patient navigation for one-on-one support for cancer care
- Healthy eating/nutrition programs specifically for cancer survivors
- Support programs specifically for those who are the caregivers (i.e., family members or loved ones)
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Disclaimer
This publication should not substitute for professional advice from a healthcare professional. Readers should always consult a physician or other healthcare professional for medical screening, treatment and advice. Please note the phrase “health care provider” also refers to tribal clinic professionals such as a Doctor, a Nurse, a Nurse Practitioner, a Physician’s Assistant and/or a Nurse Midwife.

The Native American Cancer Research Corporation (NACR) is a national non-profit organization dedicated to improving the lives of American Indian and Alaska Natives by helping prevent cancer, detect cancer early and provide the highest quality care and lifestyle for cancer survivors and their loved ones.

3110 S. Wadsworth Blvd, #103
Denver, CO  80227
P: 303-975-2449 | 1-800-537-8295
F: 303-975-2463
www.natamcancer.org

2014 Native American Cancer Research Corporation Case Study Series:
Tribes and Native Communities Work to Meet the Needs of American Indian Cancer Survivors

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Native American Cancer Education for Survivors

Native American Cancer Education for Survivors (NACES) is the largest AI/AN cancer survivor support education program in the US. An average of 1,000 people visit this webpage daily. It is a free resource available online at http://www.NatAmCancer.org. Its purpose is to improve quality of life for AI/AN cancer survivors by increasing knowledge and informed choice. Cancer survivors, family members, patient advocates and navigators, or anyone interested in helping people survive cancer can use NACES. While originally for Native breast cancer survivors, most information fits both men and women with any type of cancer.

For more information about support programs and services, for AI/AN cancer survivors, contact NACR.
Digital Storytelling and Print Materials for Education and Outreach

Several programs provide different types of survivorship resources. Three programs record and disseminate digital stories. Digital storytelling is the practice of combining narrative with digital content, including images, sound and video, to create a short movie, typically with a strong emotional component. Most are 2 to 4 minutes long. Multiple websites are available to help people learn how to create their own digital stories. Digital stories have a significant impact in tribal communities in promoting early detection and screening.

Two programs disseminated booklets, pamphlets, and/or hung posters highlighting AI/AN survivors. One also provided a pocket guide and another used videos. The sources for the posters were NACR, American Cancer Society, Mayo Clinic’s Native American Programs and CDC.

Several also distributed survivorship care plans or products that include an excerpt for a care plan or resources for cancer survivorship. These included Livestrong, Journey Forward, the National Coalition for Cancer Survivorship “Cancer Survivor Toolbox”, the Minnesota Cancer Alliance’s “Cancer Survivor Care Plan” and Susan G. Komen for the Cure® Survivors’ resources.

Survivorship Events Honor Survivors

Many American Indian communities and Tribal Nations sponsor annual cancer survivor events to share resources and services, provide time for survivors to share their stories, to highlight available cancer screening and treatment opportunities. Each community initiates their own activities based on local interest and needs, and they take different forms.

The Tohono O’odham Nation reaches out to cancer survivors in their community through an annual event that is hosted by the Tohono O’odham Cancer Program (TOCP) and held at various sites throughout the Nation. This annual event is a culmination of efforts between many resources in the Nation, surrounding areas, and a plethora of resources outside the Nation. This year’s event focused on how the cancer survivors negotiated their journey following a cancer diagnosis. Presentations by academic professionals addressed traditional healing and prevention with screening breakout sessions during the afternoon. The highlights as always, however, are the individuals who comprise the survivor panel.

The Oglala Sioux Tribe promotes cancer awareness and survivor support through an annual event that brings in community resources including American Cancer Society, the Walking Forward Program from Rapid City Regional Hospital, and the Great Plains Tribal Chairman’s Health Board. They honor the memory of cancer Survivors with the reading of their names, the release of balloons and an Honor Song with local drum group the Hehaka Singers. They also invite a panel of American Indian cancer survivors to share their stories.

Native American Cancer Research Intertribal Cancer Survivor Circle

American Indians of all ages and tribes who have been diagnosed with cancer come together with their families to eat and share their stories once a month in Denver, CO. Sometimes there are speakers, while on other nights the group goes around the room and everyone shares their stories. They give each other support, education, and hope. They also transport each other to treatments, hold hands during hard times, and help with families’ needs. The group has operated for more than 14 years.

Fond du Lac Utilizes Patient Navigators to Support Survivors

Fond du Lac partners have multiple programs to provide more comprehensive survivorship support. They have a trained Patient Navigator
who works as their Cancer Program Outreach Worker. She is able to link individuals with cancer and their caregivers to supportive services. The Patient Navigator also works within their grant funded Caregivers program (a program for all caregivers including those who provide care and support for someone with cancer) to provide education, links to support services and limited respite care. Of significance, their Tobacco Cessation program is available to everyone eligible for Fond du Lac Human Services Division services. The Fond du Lac programs address the broader community base, but are inclusive of cancer patients, and are regarded as very important components of their Chronic Diseases Human Services Division. Such coordination of services is possible because Fond du Lac has one of the tribal CDC National Comprehensive Cancer Control grants.

Cherokee Nation Breast Cancer Survivor’s Celebration
I am Barbara Neal, public health educator for the Cherokee Nation Breast and Cervical Cancer Early Detection Program.

As a 15-year colon cancer survivor, I am honored to work in a program that affords me the opportunity to tell people about the need for early detection of breast and cervical cancer. I am a member of the ‘Native American Circle of Hope’ survivor group that meets monthly in Tahlequah, OK., which is in the Cherokee Nation tribal jurisdiction. Throughout the years the survivor group, which is open to all cancer survivors, has had many speakers and fun activities, including Cherokee basket making, origami and traditional finger pots.

Recently the group met for Thanksgiving dinner and had more than 30 survivors and supporters in attendance, which shows how needed and valued our group is in our community. A second survivor group has also now started in neighboring Stilwell, OK, to help meet the needs of cancer survivors in that area. Our hope is that many more groups will form throughout the Cherokee Nation’s 14-county region to continue this tradition of helping as many cancer survivors enjoy learning new activities and giving each other the support as a group to continue on in good health.

Summary
While there are no formal AIAN cancer survivor programs in tribal communities or urban centers, many tribes, tribal clinics, IHS clinics, and American Indian organizations offer a wide array of services that can be accessed by AIAN cancer survivors. The few tribes who receive CDC funds for screening programs and comprehensive cancer programs, along with a handful of other tribes and tribal organizations such as the Inter-tribal Council of Michigan Incorporated (ITCMI) are taking the lead by offering services and programs specifically directed at cancer prevention and early detection. Cancer survivor support groups are being initiated in local native communities and special events and days of recognition are being held across the country. Along with the diabetes programs, the exercise programs, the nutrition programs, heart healthy programs and other services within communities, AIAN cancer survivors can find some support to learn how to eat healthy, exercise, get screenings, and annual physicals, and live a healthy lifestyle.

End Notes
1 http://courseweb.lis.illinois.edu/~jevogel2/lis506/howto.html
2 http://electronicportfolios.org/digistory/howto.html
3 http://digistories.yolasite.com/