

# Lessons Learned from Native C.I.R.C.L.E., a Culturally Specific Resource

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Published online: 25 February 2016  
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**Abstract** Cancer is now the second leading cause of death among American Indians and Alaska Natives (AIAN), and trends in cancer-related mortality over the past 2 decades show inferior control in AIAN compared to non-Hispanic Whites. The American Indian/Alaska Native Cancer Information Resource Center and Learning Exchange (Native C.I.R.C.L.E.) was developed in the year 2000 as part of a comprehensive network of partnerships to develop, maintain, and disseminate culturally appropriate cancer and other health information materials for AIAN educators and providers. Now, in its 15th year of existence, enough data has been accumulated by Native C.I.R.C.L.E. to analyze trends in the distribution of culturally relevant cancer information materials and compare access to both printed (hard copy) and online materials. The amount of culturally appropriate materials available since its creation has increased more than 10-fold. Print materials are now distributed throughout the world, and the number of materials requested from print and downloads combined are in the thousands on a monthly basis. Native C.I.R.C.L.E. is in the process of expanding its access and capabilities to target more of the lay AIAN public in order to address the digital divide.

**Keywords** American Indian/Alaska Native · Aommunity education · Digital divide

## Introduction

Cancer is now the second leading cause of death among American Indians and Alaska Natives (AIAN), superseding deaths caused by unintentional injuries, diabetes, chronic liver diseases, etc. [1]. Moreover, trends in cancer-related mortality over the past 2 decades show inferior control in AIAN compared to non-Hispanic Whites (NHW) [2]. Regional differences in cancer mortality and incidence have also been observed among AIAN, and in AIAN compared to NHW [2]. Additionally, there are significant variations in cancer by organ system. For instance, AIAN men and women in Alaska have higher death rates as a result of lung, colon, and rectal cancer compared to NHW. Moreover, AIAN women of the Northern and Southern Plains disproportionately die from lung, colorectal, and cervical cancer compared to AIAN women in all other regions [2].

In response to these disproportionate mortality trends, the Spirit of Eagles, a national Special Populations Network, was developed in the year 2000. Among its goals, it aims to reduce cancer morbidity and mortality in AIAN communities by building infrastructure to support strong partnerships enabling community-based participatory research [3]. The American Indian/Alaska Native Cancer Information Resource Center and Learning Exchange (Native C.I.R.C.L.E.) is the educational arm of this network of partnerships that develops, maintains, and disseminates a number of culturally appropriate cancer and other health information materials for AIAN educators, providers, and students [3]. Upon request, Native C.I.R.C.L.E. provides, via its website and at health conferences, brochures on a number of health topics, including

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Presented in part at the International Cancer Education Conference, Tucson, AZ 10/22/2015

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men’s and women’s cancers, tobacco cessation, nutrition, diabetes, and wellness.

Culturally tailored materials are imperative as certain barriers are known to affect patient participation in cancer screening, treatment, and even clinical trials [4–6]. In fact, one study found that cultural beliefs are more of a limiting factor in mammography screening among AIAN women than other barriers, including access to care [5]. In a study identifying barriers to participation in clinical trials, surveyed AIAN elders identified that they would prefer to have family support and a researcher or physician of AIAN descent, or one with experience working with AIAN populations, among other factors in order to participate [6]. Hence, programs such as Native C.I.R.C.L.E. are exceedingly relevant in acting as a central source for culturally appropriate cancer education materials.

In the age of increasingly available health information technology (HIT), programs such as Native C.I.R.C.L.E. provide further opportunities to promote culturally relevant care to improve health outcomes for AIAN people. However, despite technology making health information more readily accessible, studies show that only segments of the population with Internet access and knowledge benefit. Older adults, those who are less educated, those with lower income, and those from minority groups access HIT the least [7, 8]. This concept is known as the *digital divide*. Because many AIAN are at the poverty level and reside on tribal lands, the digital divide is of even more concern. It is well-documented that AIAN on tribal lands have less access to telecommunications services, including broadband services, than any other segment of the US population [9]. Living at the extreme end of the divide, broadband access in homes on tribal lands was about 5 % in 2009 [10]. Only one other known study has assessed the use of HIT

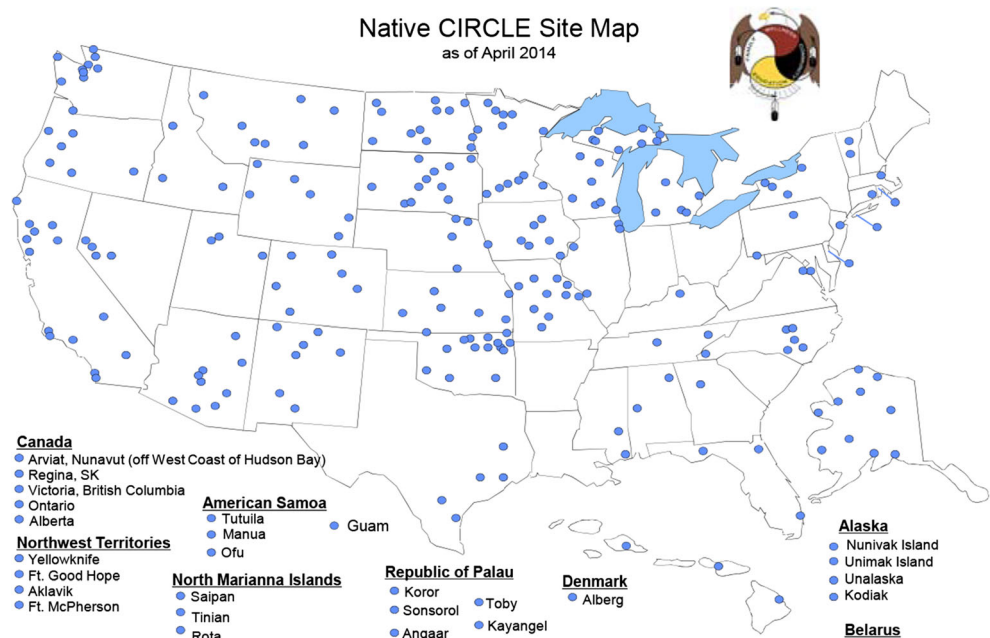
in AIAN, specifically in the Central Plains region [11]. This particular sample demonstrated high Internet use, but lower use of the Internet to access health information compared to the general population. This study also confirmed an age and gender divide, and importantly pointed out a minimal awareness to culturally appropriate health information resources [11].

Now, in its 15th year as the educational arm of Spirit of Eagles, enough data has been accumulated by Native C.I.R.C.L.E. to analyze trends in the distribution of culturally relevant cancer information materials. Other objectives for this review include determining which topic areas are most frequently requested and what mechanism of obtaining these materials was most utilized in light of developing technology and website changes (e.g., comparing access to print materials and other hard copy materials such as DVDs versus downloading online materials).

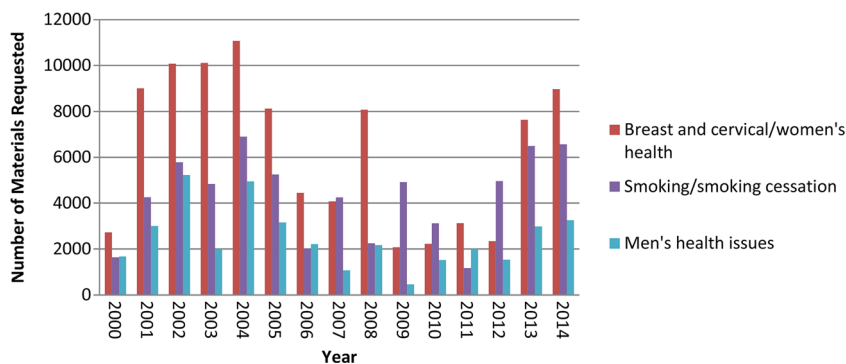
### Materials and Methods

Since its creation in 1999, Native C.I.R.C.L.E. has been tracking its annual distribution of cancer and other health information materials. A more detailed running tally of printed cancer information distribution materials has been kept since the year 2000. These data were recorded according to cancer topic (e.g., women’s cancers, men’s cancers, smoking and smoking cessation materials, general wellness, etc.). Only a static website was available to the general public from 2004 to 2009 and was subsequently updated in 2010. The initial target audience for this program was educators, providers, and students, but the program slowly evolved to directly target the

**Fig. 1** Locations from which educational materials have been requested



**Fig. 2** Trends of printed educational material distribution over time



general AIAN population given the advancing technologic capabilities and increased outreach at annual conferences. Materials were ordered by phone, fax, or email and later, in 2010, a method for ordering over the Internet via an online catalog was developed. Currently, all orders are required to be submitted via Internet. When PDFs were developed for the Internet website, downloads became available to the general public as well as allied health professionals. Materials available include pamphlets, pocket cards, an updated bibliography on literature focusing on AIAN health, and DVDs.

Since the development of its new website, <http://www.nativeamericanprograms.net/native-circle/>, in the year 2010, Native C.I.R.C.L.E. has also been able to track the number of electronically downloaded educational materials. Other information, such as website hits, Native C.I.R.C.L.E. bibliography requests, specific locations of distribution (including clinics, hospitals, academic centers, and American Indian health-related conferences), and partner organizations, were also recorded manually, at first, and later electronically. Microsoft Office Excel 2010 was used for development of bar graphs to plot the printed and DVD material distribution over time (years), as well as the number of downloaded materials during a 1 month time period. For Fig. 1, a US map was used to plot the approximate locations to which the materials were mailed.

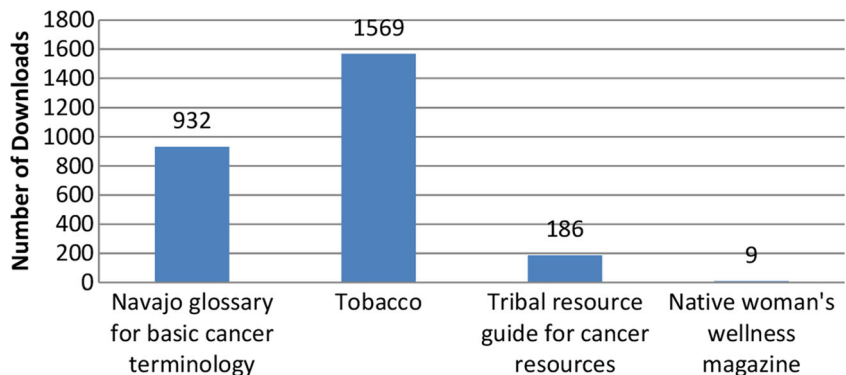
No human or animal subjects were used in this research. No individual identifying information for any patient was recorded.

**Results**

Analysis of the use of Native C.I.R.C.L.E. showed that culturally specific health information materials have been distributed across the USA since its inception in 1999. The most commonly requested print materials were in the categories of breast and cervical cancer, tobacco and smoking cessation, and men’s health.

Figure 2 shows the distribution of printed and DVD cancer and other health educational materials between the years 2000 and 2014. Usage varied in different years. In particular, in the years 2000–2006, breast and cervical/women’s health educational materials were requested approximately one third to one half more often than the other types of available materials. This coincided with a strong effort by the Centers for Disease Control to fund programs for breast and cervical cancer screening in AIAN communities. As communities sought to develop their educational resources for this effort, requests were made for materials from the Native C.I.R.C.L.E. repository and new materials were added and released for distribution to other interested tribes. In the years 2007, 2009, 2010, and 2012, smoking cessation materials were requested the most. Of note, the overall number of items requested among these categories decreased in 2009–2012, corresponding with the economic downturn and the lack of money for clinic sponsored health fairs and other gatherings where Native C.I.R.C.L.E. materials were usually distributed (visibility of Native C.I.R.C.L.E. displays at these conferences has always been followed by

**Fig. 3** Electronically downloaded cancer educational material



increased requests for materials). Increases in requests of each category of material were then noted in 2013 and 2014.

Other materials not shown graphically disseminated from Native C.I.R.C.L.E. included nutrition and diabetes materials. Native C.I.R.C.L.E. was honored by the Association of American Indian Physicians as a partner in their diabetes education programs. From 2009 to 2010, over 2000 nutrition and diabetes brochures and videos were distributed, making them the third most requested educational materials. Almost 1000 copies of literature and videos in the category called *wellness* were distributed that year as well. Over 300 medical articles from the bibliography were also requested. Notably, in the year 2014, there were over 100 educational materials available for order in the catalog, with titles ranging from types of cancer, cancer treatments, clinical trial participation, wellness, diabetes, cardiovascular disease, language specific materials, and more.

Figure 1 is a map of the sites where Native C.I.R.C.L.E. printed items were requested. Overall, materials were distributed to 43 of the 50 US states, Canada, Northwest Territories, American Samoa, North Mariana Islands, the Republic of Palau, Denmark, and Belarus. The popularity outside the USA likely reflects the importance of attractive, easy-to-read educational pieces for use in low literacy communities. Materials were allowed to be adapted to language and culture as needed. All Native C.I.R.C.L.E. materials had copyright releases for use for educational purposes only, which also aided in broad distribution.

Figure 3 shows the number of downloaded educational material in each of the most requested categories in a single month in 2014. Materials pertaining to tobacco (e.g., tobacco cessation, education surrounding traditional uses of tobacco, and physician flow charts for aiding smoking cessation) were downloaded the most, with 1569 downloads. The Navajo glossary for basic cancer terminology was downloaded second most often, approximately 932 times. A general Northwest tribal cancer resource guide was third. Unfortunately, since the website was changed to a different server, data was not available to tally the number of downloads over a year's time in order to compare the number of printed versus online materials accessed. Also, with downloads, it is not possible to tell whether individuals or groups were utilizing the materials. Information not shown includes analytics from one sample year, 2013–2014. During this time, there were 14,558 website hits, but it is unclear how many downloads in total.

## Discussion

When Native C.I.R.C.L.E. was developed, there were only eight titles of culturally specific cancer or cancer prevention materials available. Now, 15 years after its creation, there are well over 100 titles of culturally specific educational materials. A major goal of the program is to stimulate culturally

specific and sensitive educational materials that can be widely shared. Therefore, communities would not have to start from the beginning with outreach campaigns, but rather, build on the success of readily available quality materials. This review of the growing Native C.I.R.C.L.E. inventory proves the popularity of using these materials.

However, in a limited email questionnaire, we asked some of our frequent fliers, most of whom are providers for community health centers, for their experience with downloads from the website. Many are only able to use the Internet at the health facility, and unfortunately, many facilities' policies forbid downloads, and facilities that allow downloads do not have color printers, making any printed materials less appealing. Some respondents indicated their preference for Native C.I.R.C.L.E. staff to send hard copies. Thus, expansion of our download capabilities may not provide better access to the materials for many of our heaviest users.

In addressing the concept of the *digital divide*, Native C.I.R.C.L.E. has also had some limited social networking efforts with outreach to the lay AIAN community, particularly around the national triennial conferences it sponsored in 2007, 2010, and 2013. The conference applications and agendas were avidly downloaded in those years. Most recently, a men's health group proposed having a section of the Native C.I.R.C.L.E. website devoted to information about men's health programs and materials available across the country. This evolution of Native C.I.R.C.L.E. would also provide a password protected blog. As Native C.I.R.C.L.E. continues to participate in more AIAN conferences, expands its nationwide partnerships, and disseminates the wealth of information on its website, perhaps more of the lay AIAN public will turn to Native C.I.R.C.L.E. as a trusted source of cancer-related information.

As Native C.I.R.C.L.E. improves its repository of culturally appropriate materials and an Internet presence, it will also be able to gain the capacity to more accurately track specific demographics of its users. Social networking may be the next phase of expansion as cell phone and Internet access becomes ever more available across all of Indian country.

**Acknowledgments** We thank Ms. Vicki Shea and Ms. Alison Dowdell for manuscript preparation.

**Compliance with Ethical Standards**

**Conflict of Interest** The authors declare that they have no competing interest.

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