

Evaluation of *Cancer 101*: An Educational Program for Native Settings

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Abstract This community-based intervention study examines the impact of *Cancer 101*, a cancer education resource developed in collaboration with American Indians/Alaska Natives to improve cancer knowledge, action regarding cancer control in tribal settings, and survival rates for members of their communities. Pre/post-surveys used to assess knowledge, attitudes, perceived benefits and future activities at baseline, immediately post-training, and at 4–6 months. Participants demonstrated significant change in knowledge, attitude, and cancer control activities. *Cancer 101* provides a critical pathway to increase knowledge and

promote action to reduce the burden and improve survival of cancer within tribal communities.

Keywords Cancer knowledge · Cancer control · Tribal setting

Introduction

American Indians and Alaska Natives (AI/AN) shoulder a disproportionate burden for many diseases including cancer. Over the last century, cancer has become the second leading cause of death for AIs over the age of 45 [1] and the leading cause of death for ANs [2]. In addition, data indicate that AI/ANs who experience a cancer diagnosis have the lowest 5-year relative survival rate of any racial group in the USA [3, 4].

In 1998, the Centers for Disease Control and Prevention (CDC) established the National Comprehensive Cancer Control Program (NCCCCP) in an effort to improve coordination of cancer control activities by engaging state and local healthcare agencies and tribal organizations [5]. The NCCCCP encouraged diverse organizations to work together and pool their resources, knowledge, and expertise to develop a comprehensive approach to cancer planning that would serve as a blueprint for reducing the burden of cancer for their constituencies.

With NCCCCP funding, the Northwest Portland Area Indian Health Board (NPAIHB) formed the first tribal cancer coalition to begin work on developing cancer control strategies. Recognizing that education is a critical component of outreach, coalition members began developing a tool that would help individuals better understand the dimensions of diseases like cancer and improve cancer

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survival [6]. They envisioned this tool would be culturally relevant, increase knowledge and understanding about cancer, and empower tribal communities to address cancer issues. The National Cancer Institute's Cancer Information Service Northwest Region (NCI's CIS) [7] and Spirit of EAGLES (SoE) [8] were partner organizations from the inception of the tribal cancer coalition and members of the original advisory committee. The tribal cancer coalition worked collaboratively with the SoE and the NCI's CIS to develop *Cancer 101—A Cancer Education and Training Program for American Indians and Alaska Natives (Cancer 101)*, a culturally relevant resource they envisioned would improve cancer knowledge and action regarding cancer control in tribal settings.

Prior to this effort, no studies had been undertaken to evaluate a community-based cancer education training resource developed by and for tribal use. It was hypothesized that individuals who participated in *Cancer 101* training sessions would increase their knowledge about cancer and cancer control, develop positive attitudes toward cancer risk reduction, identify personal and community benefits, and be able to identify at least one activity to participate in after the training that would improve cancer control outcomes within their communities. This paper describes how the use of a cancer education intervention contributed to these cancer control planning activities at the individual and the community level among Northwest urban and rural tribal community members that participated in training opportunities.

Methodology

Study Collaboration

The NPAIHB oversees the CDC funded Northwest Tribal Comprehensive Cancer Program (NTCCP) that is focused on reducing the burden of cancer within tribal communities served by the NPAIHB. The specific aims of the NTCCP are to: (1) facilitate a process for Northwest tribes to promote cancer risk reduction strategies; (2) provide information on the most current early detection, screening, and treatment practices through education and resource materials; (3) provide education regarding quality of life for cancer patients, their families, and caretakers; and (4) coordinate and collaborate with local and national cancer organizations [9]. The partnership created between NCI's CIS, SoE, and NPAIHB to implement this study was presented at a quarterly board meeting to tribal delegates and approved. A memorandum of agreement was signed and approved by the NPAIHB executive director. The administrative officer at the NPAIHB became a co-investigator to assure community involvement and NPAIHB protocol. This study received approval from the

Institutional Review Boards of the Portland Area Indian Health Service and the Fred Hutchinson Cancer Research Center.

Description of *Cancer 101*

Cancer 101 is an educational resource tool designed to provide basic information about cancer. With guidance from members of the NTCCP Coalition, a SoE staff member who was also an oncology nurse formulated the core content of the *Cancer 101* curriculum. Key staff of the NTCCP and a tribal workgroup assisted with editing and review of the document along with input from NCI's CIS staff. A final draft was reviewed by NPAIHB tribal health directors, delegates, and NTCCP tribal contacts. A survey and pilot test were conducted to further determine acceptability and usability of the resource with suggested changes incorporated into the final version.

Cancer 101 was designed to be adaptable to meet the needs of the learner and is targeted towards community members, staff of Indian health programs, and community health representatives (CHRs). *Cancer 101* train-the-trainer sessions provided participants with an opportunity to increase their knowledge about cancer and to disseminate what they have learned to others within their families, organizations, and communities. Working with communities, sessions are tailored to meet learners' needs and develop effective strategies to transform what they learn into individual and/or community action.

Cancer 101 learning modules address the following topics: (1) overview of the cancer concern among the AI/AN population, (2) what is cancer?, (3) cancer screening and early detection, (4) cancer diagnosis and staging, (5) cancer risks and risk reduction, (6) basics of cancer treatment, and (7) support for patients and caregivers. Each learning module is designed for presentation as a 30-40 min education session; or the entire curriculum can be presented as a 1-day workshop on cancer education. Learning modules include: goals and objectives for each topic, pre- and post-self-assessment, PowerPoint presentation, glossary, references, and resource materials. Additional materials include an evaluation template, health change checklist, tips for trainers, and a list of suggested resources. The *Cancer 101* learning modules can be used as is or served as a template to be adapted for a specific purpose. The curriculum is currently available at <http://www.npaihb.org/programs/project/ntccp_cancer_101/>.

Overview of Study Design

This study was a longitudinal, pre/post-evaluation of the implementation of *Cancer 101* in five tribal communities in the Pacific Northwest. Study collaborators utilized a

community-based approach in the conduct of this non-randomized study. SoE and NCI's CIS staff worked in collaboration with NPAIHB staff to conduct a total of five *Cancer 101* 2-day trainings over a 17-month period between February 2006 and June 2007. Trainers were staff members of the SoE, NCI's CIS, and the NPAIHB, who had prior experience with use of the *Cancer 101* curriculum. Pre- and post-survey tools were used to assess knowledge, attitude change, perceived benefits, and future activities at three points in time: pre-training, immediately post-training, and at 4-6 months following the training. Field notes and observations from study staff were also included as part of the data collection.

Study Population and Eligibility

The curriculum was offered to all 43 tribes in the Pacific Northwest. The study itself was limited to individuals who were tribal community members, health professionals (health care providers, staff of Indian health programs) and CHRs working with Native American populations. Any person identifying as such, who was of any race or ethnicity, 18 years of age or older and lived in the NPAIHB service region in Idaho, Oregon, and Washington, was eligible to participate in the study. Due to the importance of maintaining working relationships with communities, additional persons were not excluded from participating in the trainings if they were interested. However, they were not enrolled into the study as participants.

Recruitment

Study participants were identified through multiple means at each tribal setting. Each site was represented by a tribal community liaison who assisted with coordinating logistics and recruitment at the host site including the tailoring and dissemination of promotional flyers to the community. NCI's CIS, SoE, and NPAIHB staff invited tribal community members, staff of Indian health programs, and CHRs from Idaho, Oregon, and Washington to participate in a *Cancer 101* train-the-trainer sessions by distributing flyers at meetings, through one-on-one interactions, and through mail and e-mail. For example, the NCI's CIS and SoE used their existing Native American partner mailing list to disseminate information about the trainings. The NTCCP coordinator made phone and e-mail contacts to cancer coalition members for recruitment to the trainings. Notifications about trainings were also distributed to tribal health directors, clinical directors, health educators, CHRs and cancer coalition members by the NPAIHB. The NTCCP and the SoE offered travel scholarships to tribal participants to offset travel expenses and as an incentive to encourage participation.

Description of Training

The first day of the training allowed time for participants to get to know one another and to cover the content of all seven *Cancer 101* learning modules. For example, at the beginning of each session, participants were asked to introduce themselves, share information about their role in the community, and what they hoped to learn and/or take away from the session. Participants were continually encouraged to dialog, ask questions, and share throughout the training. Trainings were informal, with food and stories shared, and small incentives were raffled throughout the 2-day period.

The second day of the training was focused on how to transform the knowledge gained during the first day into action to address cancer issues and concerns in the community. Activities included providing participants time to work in small groups, develop action plans, share and receive feedback from the group, learn about cancer resources for use in the community, and hear presentations from local cancer service organizations. The Northwest Tribal Twenty-Year Comprehensive Cancer Control Plan and tribal action template served as the guides for helping tribal programs in developing their tribal action plans, relating planned activities to at least one of the objectives in the cancer plan.

Data Collection Methods

All participants were provided with a detailed explanation of the study at the beginning of the session including the study purpose, rationale, procedures, potential risks/anticipated benefits, and maintenance of confidentiality. Survey data was collected at three time points for each participant: pre-training (demographic and baseline data completed after informed consent process at the beginning of the first day of training), immediately post-training (completed at the end of the second day of the training), and at 4-6 months following the training (interview). All instruments were paper questionnaires, with the exception of the 4-6 month follow-up interview; participants were given the option to complete it either on paper (mail back in self-addressed stamped envelope), over the phone (oral interview), or online via a secure web portal. Additional data collected during the conduct of the trainings included field notes and observations made by study staff.

The demographic data consisted of nine questions on study participants' gender, race/ethnicity, education, age, role in the community, primary tribal affiliation, residence setting, and ability to speak Native language. Baseline data consisted of 54 items and established a baseline of study participants' knowledge, attitudes, and behavioral intentions related to cancer. The post-training assessments

included the baseline measures plus the training evaluation items.

Description of Measures

Cancer knowledge was assessed by using a total of 35 items, drafted from the *Cancer 101* curriculum's pre/post-self-assessment tool. This tool used five pre/post-self-assessment knowledge items per learning module to measure knowledge change. Participants were asked to respond to statements that covered topics such as cancer causes, risk, risk reduction, diagnosis, staging, treatment, and survivorship by indicating "Agree", "Disagree", or "Not Sure" for each statement. All items were re-coded to correct = 1, incorrect or not sure = 0 for scaling. Within each module, items were summed to produce a score.

Attitudes about cancer were assessed by asking participants to respond to 11 items using a five-point Likert scale to rate how much they agreed or disagreed with statements about the importance of cancer as a health issue in their community, perceptions about preventing cancer and reducing cancer burden, concern about developing cancer, understanding of risk factors, and ability to influence cancer risk by changing lifestyle behaviors. We performed principal components analysis with varimax rotation to identify two scales within the attitude items: community attitudes and cancer fatalism. Higher scores on the community scale indicated that community members endorsed more highly that cancer is an important issue, one that warrants attention and action in order to reduce the burden of this disease among its membership. Higher scores on cancer fatalism indicated a more positive, less fatalistic view of cancer, due to reverse coding of the items.

Behavioral intentions of participants were assessed by their response to eight survey items adapted from the *Cancer 101* curriculum health change checklist. Participants utilized a five-point Likert scale to rate how likely they were to participate in activities that have the potential to reduce cancer risk, such as taking part in regular physical exams and screenings for cancer, engaging in some form of physical activity for at least 30 min at least five times a week, eating a healthy diet, or abstaining from use of commercial tobacco. We performed a principal components analysis on the eight items, and found that one factor accounted for all items. The items were averaged to produce a single-scale score.

The *training process evaluation* consisted of 34 items to assess the usefulness and general quality of the training. Participants used a five-point Likert scale to rate aspects such as length of training, how well the training met the learning objectives, the value of the training for work and/or community service, how well the training prepared participants to implement *Cancer 101* events or programs

in the community, and how well the training met participants' expectations. Participants were also asked to rate the likelihood of engaging in activities that included sharing information about cancer issues in family and friends, talking about cancer prevention with family and friends, planning a cancer education event in the community, and/or using the information for their own knowledge and awareness. Additionally, participants were asked to state any additional training needs, whether they would recommend the training to others, and provide suggestions on how the training could have been improved.

Within 15 days following the training, study participants were contacted by study staff to schedule the 47-item 4-6 month follow-up interview. Behavioral intentions of participants were assessed using the eight survey items also used in the pre- and post-self assessments. Similarly, benefit to family, friends, and/or community members was assessed by asking how likely participants were to encourage participation in these same activities for each group. The longer term effect of the training was assessed by asking study participants to use a five-point Likert scale to rate how strongly they agreed with statements that asked if the training made them think more about cancer, raised their awareness about cancer as a health concern, or contributed to their awareness and ability to take action against cancer at the individual and/or community level. Participants were also asked whether or not they had planned or conducted any activities since attending the training, any benefits to the community from these activities, and, if so, a description of those benefits.

Analyses

Data from pre- and post-surveys were linked via a study ID number; and all personal identifiers were removed from the dataset. The final dataset was a combined version of data from all surveys without personal or tribal identifiers. This is particularly important for research conducted with American Indians and Alaska Natives, where tribal communities are small and both communities and members can easily be identified and discussed.

Data analysis, using the Statistical Package of the Social Sciences, included Pearson correlations and chi-square tests of association. Knowledge scores and attitudinal measures were created based on factor analyses of the continuous data and indexes of participation based on the categorical indicators of behaviors. These scales and indexes served as pre/post-measures of outcomes. Then, simple descriptive data were reviewed from pre- and from post-surveys to determine any changes in levels of knowledge, attitudes, and behavioral intentions. Multivariate analyses were performed with post-measures as outcomes and baseline and demographic measures as covariates.

Results

Five *Cancer 101* study trainings were conducted over a 17-month period between February 2006 and June 2007 at five different tribal sites located in Idaho, Oregon, and Washington. A total of 99 individuals attended the trainings, and 70 consented to participate in the study. Amongst all study participants, 70 (100%) completed the demographic questionnaire and the pre-self assessment and 67 (96%) completed the post-self-assessment and the training evaluation. At 4-6 months post-training, 57 (81%) participants completed the follow-up interview.

Characteristics of Study Population

In general, study participants were American Indian or Alaska Native (79.4%), tribal affiliation Pacific Coast (77.3%), female (88.6%), between 40 and 59 years of age (65.6%), possessed a high school education or higher (96.6%), and resided on a reservation (50%). The roles participants held in the community were varied and included community health educators, healthcare providers or professionals, tribal program administrative staff, tribal community members, academia (e.g., student, faculty, researcher), tribal leader/elder, or other (social services for elders, support group member, Community Health Education Team volunteer). Participants indicated their association with cancer was through a relative or friend of a cancer patient/survivor, someone interested in cancer, or as a cancer patient/survivor (see Table 1).

Primary reasons chosen for attending the training ranked by percentage included: develop knowledge and skills to educate others, understand cancer issues and concerns, learn basic information about cancer, learn about cancer resources for patients and caregivers, and develop knowledge and skills to participate in cancer control activities (data not shown).

Effect of Training on Knowledge, Attitudes and Behavioral Intentions

Knowledge scores from pre- to post-exposure changed significantly ($p < 0.01$) for all modules with the exception of module 3 (screening and early detection). Scores are detailed in Table 2. Module 3 content provides learners with an overview of the components of early detection, and reviews common methods used to screen for cancer (e.g., mammogram, Pap test, colonoscopy, etc.). Prior knowledge gained from tribal involvement in the CDC-funded National Breast and Cervical Cancer Early Detection Program may have provided participants with knowledge of early detection, as evidenced by the high score at pretest for module 3. Therefore, it was harder to improve the already high score.

Table 1 Baseline characteristics of participants in the evaluation of *Cancer 101*

Characteristic	Percentage	Total <i>n</i>
Sex		
Female	88.6	62
Male	11.4	8
Race/ethnicity		
American Indian/Alaska Native	79.4	54
Caucasian/other	20.6	14
Missing		2
Education		
High school graduate or less	38.5	25
Technical school/apprentice training	10.8	7
College Associate's Degree	21.5	14
College Bachelor's Degree	20.0	13
Master's Degree	9.2	6
Missing		5
Age		
18-29	9.0	6
30-39	11.9	8
40-49	32.8	22
50-59	32.8	22
60 or older	13.4	9
Missing		3
Region of primary tribal affiliation		
Alaska	1.5	1
Pacific Coast	77.3	51
South Central	3.0	2
Northern plains	3.0	2
Canada	1.5	1
NA/non-native respondent	13.6	9
Missing		4
Residence		
Reservation	50.0	33
Off reservation	50.0	33
Missing		4
Role that best describes participant^a		
Tribal leader/elder	5.8	4
Community health educator	32.4	22
Tribal program admin staff	17.6	12
Academia (faculty, student, researcher)	7.4	5
Healthcare provider/professional	25.0	17
Tribal community leader	7.4	5
Other	4.4	3
Missing		2
Association with cancer^b		
Is relative/friend of cancer patient/survivor	81.4	57
Is someone interested in cancer	58.6	41
Is cancer patient or survivor	15.7	11

^a Only one role allowed

^b Percent total is >100 due to more than one category selection allowed

Table 2 Effects of *Cancer 101* on knowledge change from pre- to post-exposure

Module ^a	Pre-test (n=70) Mean (SD)	Post-test (n=67) Mean (SD)	Post-test-pre-test Change (SD)
1. Cancer and AI/ANs ^b	3.76 (1.01)	4.40 (0.74)	0.64 (1.06)
2. What is cancer? ^b	4.00 (1.16)	4.67 (0.61)	0.67 (1.15)
3. Screening and early detection	4.43 (0.71)	4.60 (0.65)	0.15 (0.84)
4. Diagnosis and staging ^b	3.70 (1.13)	4.43 (0.56)	0.73 (1.19)
5. Risk and risk reduction ^b	3.90 (0.84)	4.43 (0.63)	0.51 (0.77)
6. Treatment ^b	3.33 (1.00)	4.31 (0.74)	0.99 (1.05)
7. Patient and caregiver support ^b	4.57 (0.67)	4.82 (0.42)	0.22 (0.65)
Overall	27.7 (4.17)	31.67 (2.52)	3.91 (3.35)

n number of study participants
SD standard deviation

^a Coding values were correct = 1 and incorrect = 0

^b Mean change is significant for all modules ($p < 0.01$, two-sided *t* test), except module 3 ($p = 0.15$)

The attitudes of participants also showed a significant positive change ($p < 0.05$) from pre- to post-training (see Table 3). Attitudes about community increased slightly and significantly from pre- to post-test and attitudes about fatalism increased significantly from pre- to post-test. Trainees indicated more positive views of improving the community’s outlook about cancer activities and less fatalistic perspectives on cancer.

The effects of the training on behavioral intentions from pre- to post-training were positive and are noted in Table 4. Participants were more likely to say that they were either “very likely” or “extremely likely” to engage in behavioral activities to reduce their risk for cancer after the training. These activities included physical exams that include cancer screening, physical activity, diet, smoking cessation, among others.

Effects of Training on Participants’ Cancer Control Activities

At post-training, 83.3% of the participants ($n = 66$) indicated they were either “very likely” or “extremely likely” to plan cancer activities in their community. At 4-6 months following the training, 42.1% ($n = 24$) reported they had conducted an activity, and 24.6% ($n = 14$) indicated they were in the process of planning an activity. Of those participants who had already conducted an activity, 95.9% felt that the activity benefited the community.

Participants’ cancer control activities addressed three broad categories of need: raising awareness about cancer, prevention and screening, and survivor support. While the types of activities within each category varied, the major

focus was directed towards reaching the community. For example, awareness and education activities included health fairs, cancer walks, posting of educational flyers, cancer educational sessions for community members and health professionals, women’s health day, mother and daughter teas, development of tribal cancer coalitions, and grant writing to support education efforts. Prevention and screening activities included developing educational materials for cancer prevention and screening, hosting screening events, and providing in-kind financial incentives for completion of physical exams. Support for cancer survivors within the community also emerged as a priority, with activities focused on starting survivor support groups or partnering with existing support groups to share information about cancer, raise funds, and provide transportation among other activities (Table 5).

Discussion

The results of this study indicate that use of *Cancer 101* has a positive impact at the individual and the community level among Northwest urban and rural tribal community members who participate in training opportunities. Working with organizations that are credible and had established relationships with tribal communities facilitated the research process. The NPAIHB has a strong history of health promotion and disease prevention; the partnerships that were formed to conduct this work carried it forward. Cancer is a NPAIHB priority identified in the organization’s strategic plan, so this fit well with ongoing plans. NTCCP provided a strong recruitment base for the *Cancer 101* curriculum.

Table 3 Effects of *Cancer 101* on cancer attitude change from pre- to post-exposure

	Pre-test n=70 Mean (SD)	Post-test n=66 Mean (SD)	Post-test-pre-test Change (SD)
Cancer and community*	28.53 (5.03)	29.98 (4.81)	1.33 (5.33)
Cancer fatalism**	12.00 (1.87)	13.23 (1.86)	1.12 (1.93)

* $p = 0.046$ (two-sided *t* test)

** $p = 0.000$ (two-sided *t* test)

Table 4 Effects of *Cancer 101* on behavioral intentions from pre- to post-exposure and post-exposure to follow-up

	Pre-test <i>n</i> =70 Mean (SD)	Post-test <i>n</i> =66 Mean (SD)	Follow-up Mean (SD)	Change Pre- to post (SD)*	Change Post to follow-up (SD)**
Behavioral intentions	32.30 (5.08)	35.27 (4.09)	34.0 (4.01)	3.00 (4.52)	-1.27 (4.72)

* *p*=0.000 (two-sided *t* test)

** *p*=0.049 (two-sided *t* test)

By providing *Cancer 101* training opportunities, raising awareness about available resources, and offering technical assistance as follow-up, some participants were motivated to do cancer awareness and education activities in their communities. This is the most innovative of the findings. The idea that training with a small group of leaders in cancer control could have larger community effects is very exciting, as it means that with small amounts of effort in the beginning one can effect larger change.

There were several limitations to this study that effect generalizability. First, this was an uncontrolled study, so any information on secular trends in cancer control was not taken into account in the design and analysis. Participants volunteered for the project and were not proactively approached. Therefore, there is potential for self-selection bias. There were more females than males in the study, reflecting the gender make-up of tribal administrative staff. Many of the participants were already engaged in work and/or community health-related activities and this drove their interest in participating in training.

The relatively short follow-up time meant that we might not have captured all the changes that occurred after the

training program. At the 4-6 month follow-up, it was clear that several participants were still engaged in the planning phase of their activities. Factors that facilitated or inhibited participants to take action post-training are yet to be explored. Future evaluation efforts should consider lengthening the time frame and intervals for follow-up as well as items that address barriers or enhancement to action planning post-training.

There is a strong likelihood that prior cancer education program efforts targeting community members, among others, about breast and cervical cancer screening and early detection may have influenced pre- self-assessment knowledge scores. Many study participants indicated they served their community in a health-related capacity such as a community health educator or healthcare provider/professional which includes CHRs. These individuals are likely to have received information about cancer screening as part of their involvement in the CDC-funded National Breast and Cervical Cancer Early Detection Program.

Strengths of the study were also present, centering on collaborations and cooperation among the partners. The collaborative process occurred across the study, due to

Table 5 Summary of participants’ cancer control activities at 4-6 month follow-up sample *n*=24

Awareness/education	Prevention/screening	Survivor support
Cancer fair for community	Host cancer screening events	Start a cancer support group
Cancer education events targeting health professionals	Provide in-kind financial incentives to community members who complete physical exam	Fund raiser for cancer patients
Participate in cancer walk	Develop educational materials about cancer screening and prevention for community	Share cancer information informally, via word-of-mouth to community members/cancer survivors
Present cancer information at work; schedule to present during meeting or lunch		
Post cancer information flyers		
Distribute cancer educational materials to community members		Partner with existing support groups; present cancer information, host luncheons, provide transportation
Share cancer information informally, via word-of-mouth to community members/cancer survivors		
Write grants to support cancer education efforts		

consciously selecting a community-oriented approach. As such, we hope that the product is reflective of communities' needs and priorities. As evidence of this, the NPaiHB passed a resolution to seek dissemination and publication at the end of the project, indicating their approval of the project. Indeed, all parties increased their capacity to do this work. Tribal staff learned new training techniques and tools. NTCCP staff learned research and study design skills. SoE and NCI's CIS increased knowledge of Indian-specific issues and concerns through this project.

Study staff benefited greatly from the wisdom, expertise, and vision of all those involved in the development, implementation, and evaluation of the *Cancer 101* curriculum. The study findings, as well as continued reports from tribes and other diverse groups that have successfully utilized *Cancer 101* as an intervention tool to address cancer control issues and concerns are encouraging. Future plans include efforts to disseminate *Cancer 101* as an evidence-based education resource for those seeking funding for community education about cancer. These activities move us closer to realizing our shared vision of cancer-free tribal communities for generations to come.

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