WORK IN PROGRESS AND LESSONS LEARNED

Turning community feedback into a culturally responsive program for American Indian/Alaska Native commercial tobacco users

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Submitted 31 March 2020, revised 10 September 2021, accepted 3 January 2022.

ABSTRACT

BACKGROUND: American Indian/Alaska Native (AI/AN) cigarette smoking prevalence is disproportionately high, especially in the northern U.S. Tailored quitlines are needed to support AI/AN commercial tobacco users with quitting.

OBJECTIVES: Obtain community feedback by working with trusted AI/AN partners; genuinely incorporate feedback into program design; collaboratively develop and implement culturally relevant quitline services for Minnesota's AI/AN community.

METHODS: Working in partnership, AI/AN community input was gathered, and community partners were engaged to inform the development, training, implementation and monitoring of a tailored program within the existing state quitline.

RESULTS: Findings suggest focusing on the commercial tobacco user/coach relationship, increased cultural understanding and program content adaptations could make quitlines more acceptable for AI/AN commercial tobacco users.

CONCLUSIONS: The development and launch of the AI Quitline demonstrated the feasibility of collaboration among AI/AN organizations and community members, funders and providers to create a culturally relevant cessation service for AI/AN commercial tobacco users.

KEYWORDS:

Community-engagement, American Indian/Alaska Native, traditional tobacco, commercial tobacco, quitlines, cessation, smoking

INTRODUCTION

Cigarette smoking prevalence has declined in the U.S. to an all-time low of 14%,[1] yet smoking prevalence among American Indians/Alaska Natives (AI/AN) is 26% higher than any other racial/ethnic group in the U.S.[2] In Minnesota, 59% of AI/AN adults smoke[3] compared to 13.8% of adults in the general population.[4] Recent national data show AI/AN adults report lower rates of both interest in quitting (55.6%) and past-year quit attempts (52.1%) compared to other racial and ethnic groups.[5] These trends contribute to disproportionately high rates of smoking-related death and disease among AI/AN, including cardiovascular disease, lung cancer, and diabetes, the leading causes of AI/AN deaths.[6-9]

Many American Indians have a spiritual relationship with traditional tobacco, making it important to distinguish between tobacco types and the two tobacco ways when talking about tobacco in Indian Country.[10] *Commercial tobacco* refers to products manufactured by the tobacco industry such as cigarettes and smokeless tobacco, and *traditional tobacco* consists of plants grown or gathered for the purpose of prayer and ceremony. The two tobacco ways are defined as the repetitive recreational or addictive use of *commercial tobacco* products versus the sacred and traditional use of tobacco for prayer and ceremony.[11] Most governments restrict commercial tobacco purchases and use to certain age groups. Likewise, there are inherent tribal and cultural rights and teachings that go along with obtaining and using traditional tobacco.

Multiple factors contribute to disproportionate rates of AI/AN commercial tobacco use including mainstream tobacco control's lack of sensitivity and understanding of the sacred, traditional use of tobacco. Consequently, mainstream programs fail to incorporate Native culture, history and needs especially regarding the importance of tobacco.[11] Lack of dedicated funding as well as exclusion of AI/AN partners in decision making around tobacco and other public health issues continues to be a challenge across government, mainstream philanthropic, and health system sectors. Decades of federal bans on traditional AI/AN practices (including use

of traditional tobacco for sacred, ceremonial purposes), historical trauma, and tobacco industry packaging and promotions that target AI/AN communities also contribute to high rates of commercial tobacco use.[11,12] Lack of insurance coverage for cessation treatment and the absence of culturally tailored cessation programs pose additional barriers to quitting.[3,13,14]

Collaborating or engaging with AI/AN community members and partners is essential to reduce disparities and design better cessation support for AI/AN commercial tobacco users.[11] As stated in the *Principles of Community Engagement (Second Edition)*, one benefit of community engagement is its positive impact on design and delivery of interventions and the use of findings to improve services.[15,16] Further emphasis is placed on the need for all involved partners to strive to understand perspectives of "insiders" – in this case, AI/AN commercial tobacco users and the AI/AN communities of Minnesota.[15]

Research points to both the need for tailored efforts to better serve AI/AN commercial tobacco users,[17] and the feasibility of adapting programs to meet the need.[18] Although tailored programs like The All Nations Breath of Life Program and Wiidookaawishin (Help Me) QUITPLAN® Center at the Fond du lac Reservation in Minnesota have proven feasible and effective in helping AI/AN commercial tobacco users,[19,20] they are unable to provide the reach and accessibility of telephonic coaching and other quitline services.

From 2001 to 2020, ClearWay Minnesota[SM], a life-limited, independent nonprofit organization funded by tobacco-settlement dollars, administered QUITPLAN Services, Minnesota's free statewide quitline. One of the QUITPLAN Services programs was QUITPLAN Helpline (Helpline) - telephone coaching, nicotine replacement therapy (NRT), texts, emails and printed materials). Helpline enrollment was a two-step process requiring participants to speak to a registration agent who collected tobacco use data, demographics and contact information, and then connected them to a coach for counseling. Participants could also enroll online, and a coach would call them to deliver counseling.

ClearWay Minnesota calculated reach ratios (RR) to assess QUITPLAN Services' reach to priority populations. RR compares the proportion of a specific demographic group enrolling in services to the proportion of all commercial tobacco users in the state from that same group. A RR of one or higher indicates a group is being well served.[21] The RR for AI/AN smokers was 0.27 (95% CI: 0.24-0.30), demonstrating a clear need for improvement. (Unpublished data). Even after conducting a culturally specific promotional campaign, AI/AN program enrollments remained low. This paper describes a collaborative partnership formed among AI/AN community partners, researchers, the quitline service provider and funder to develop and implement the American Indian Quitline, an adaptation of the standard Helpline.

OBJECTIVES

In 2017 and 2018, the American Indian Quitline from QUITPLAN Services was developed collaboratively to better support quitting among AI/AN commercial tobacco users by improving relevance and reach of QUITPLAN Services. Three objectives drove program development:

1. Obtain community feedback working with trusted AI/AN community partners to design and lead the community input process and provide ongoing cultural advising;
2. Genuinely incorporate community feedback and community partners' recommendations into program design and coach training; and
3. Collaboratively implement and provide ongoing monitoring of culturally relevant quitline services for AI/AN communities to increase interest in and use of QUITPLAN Services and reduce the harms of commercial tobacco for AI/AN in Minnesota.

DESIGN AND METHODS

This project unfolded in multiple phases, with partners leading taking turns leading according to their unique strengths and expertise. The phases of the project included convening the partnership followed by gathering

community input, and using findings to inform the design and delivery of the AI Quitline. Here we describe the partnership, the community input process, and program design and delivery.

The Partnership. Building a strong partnership and engaging in collective decision-making was essential to assess feasibility and to develop and implement the AI Quitline. Each party contributed unique perspectives, knowledge, research, and programmatic and cultural expertise to help create a culturally relevant experience for commercial tobacco users who engaged with QUITPLAN Services. The partnership was structured so member(s) with the most expertise in each area led the effort. Table 1 provides information about each partner and their roles.

Relationships between individual partners existed well before the project's launch. ClearWay Minnesota worked for more than 15 years with staff of the American Indian Cancer Foundation (AICAF), tribal nations and urban AI/AN communities statewide to support research, cessation, policy and the restoration of traditional tobacco practices. ClearWay Minnesota's relationship with Optum began in 2001; Optum provided QUITPLAN Services through 2020. This was the first time all parties collaborated and the result was a productive, respectful partnership.

Community Input. AICAF coordinated and facilitated seven focus groups with 60 AI/AN commercial tobacco users across the state to gain an in-depth understanding about their experiences quitting, perceptions of quitlines and ideas on what culturally relevant cessation services could look like. To explore the same topics from the providers' perspective, two focus groups with 16 AI/AN community health program staff were conducted. Participants in the community health program group were a convenience sample of attendees at a tribal public health meeting. Guiding questions for the focus groups were driven by the project goals and are included in Table 2.

Tribal and urban community health program staff recruited focus group participants by posting flyers in community locations and through word of mouth. AICAF screened interested participants over the phone to determine if they met the following eligibility criteria: self-identified as AI/AN, at least 18 years of age, live in Minnesota, smoked commercial tobacco in the past 30 days or quit within the past year, and made at least one quit attempt in the past year. This criteria was designed to recruit the intended population served by the American Indian Quitline.

A short pre-survey was administered to participants prior to each focus group to collect demographic and other information about current commercial tobacco use. Survey questions on tobacco use originated from the Tribal Tobacco Use Project (TTUP) questionnaire to explore frequency and type of commercial tobacco use, use of tobacco for ceremonial purposes, readiness to quit, and quitting behaviors. AICAF staff led development of the pre-survey and focus group guide with input from other partners provided through initial brainstorming and several stages of review. Each focus group lasted 90 minutes and was held in a community location.

Building trust, rapport and open communication with tribal communities was key to conducting and completing the focus groups. AICAF secured tribal approval prior to conducting the focus groups within tribal boundaries. The project grew out of a need to improve a public health program. According to CDC policy, CDC-SA-2010-02, distinguishing public health research and public health nonresearch, this was a public health improvement project and not a research study, therefore IRB approval was not sought.[22] Furthermore, in accordance with the US Department of Human Services' Office on Human Research Protections FAQ on this subject, there is no requirement for such activities to undergo IRB review.[23] Consent forms were not collected nor were participants explicitly told their participation was voluntary, but at the start of each focus group, moderators stated "names would not be used in any reports created from the discussion, so confidentiality is ensured." Participants

received a meal and a $40 gift card for their participation. AICAF staff created a respectful and safe environment for participants to speak openly.

The community input process was guided by the Principles of Community Engagement, which values the perspectives of community partners and their understanding of community life and health issues.[15,24] Although not a research study, this project adhered to the community engagement values laid out by Ahmed and Palermo, most notably the formation of a strong partnership, shared power and responsibility, incorporation of diverse perspectives, clear goals and mutual benefit.[24] Indeed, AI/AN community members and stakeholders linked by geographic proximity and a common interest in reducing commercial tobacco use to improve the lives of Minnesota's tribal communities were critical to the project's success.[25-27] These principles helped define an iterative process in which tribal members and cultural experts from the community joined a partnership that: shaped focus group questions, led discussions, determined program elements and promotional approaches, identified training elements, supported implementation, and provided post-launch monitoring. Community connections were sustained through well-established relationships that members of the partnership had with each other and AI/AN community members.

Program Design and Delivery. The collaborative process of incorporating findings, feedback and recommendations to inform the AI Quitline design and delivery process was led by Optum. All partners participated in a series of discovery sessions to inform the program design and delivery elements. Central to the discovery was AI/AN partners sharing relevant American Indian history and culture. These sessions revealed the need for AI/AN partners to orient coaches to this history during the training to help coaches discuss commercial tobacco use with sensitivity. Following the discovery sessions, the partnership collaborated on objectives and lesson planning.

Analysis. The Pre-*S*urvey data was analyzed using descriptive statistics in Stata 13[28] to understand who we heard from in the focus groups and to better guide the discussion. The survey data were not used in subsequent analyses. Focus group transcripts and field notes were analyzed using thematic analysis to identify themes that answered the guiding questions in Table 2.[29] Analysis was an iterative process consisting of reading each transcript, assigning initial codes, organizing and combining codes into themes, reviewing codes within themes to ensure homogeneity, and reviewing the final themes to ensure they were distinct. Throughout the analysis process, two Native and one non-Native AICAF staff who moderated and took notes at the focus groups met frequently to compare notes and discuss differences in interpretation of codes and themes to reach agreement on the findings. Findings from quantitative and qualitative analyses were summarized in a written report and presented to the full partnership at a large group meeting. AICAF also facilitated a discussion on the findings at this meeting. The partnership used this report as its key resource for programmatic and training decisions engaging in follow up discussions as needed with AI/AN partners to obtain additional insight. These working sessions embraced relationship and trust-building, learning about each party's strengths and limitations, and ultimately building consensus on the programmatic elements that best address the community's needs within the operational framework of an AI/AN statewide quitline.

RESULTS

Focus Group Findings

Focus group participant characteristics are presented in Table 3. Participants were 76% female with an average age of 43.2 years. Most (58%) resided in urban areas.

Pre-survey findings report 86% of participants (n=59) felt it was "important" or "very important" for quitline coaches to understand traditional tobacco; 52% had used tobacco for ceremonial or sacred use in the past month

and an additional 18% had done so in the past year. Overall, 93% were "very likely" or "likely" to use a quitline with AI/AN coaches, but only 7% reported having used a quitline to help previously.

Focus group findings suggested an AI/AN specific quitline with customized elements would be more acceptable than the standard quitline service.[30] These elements focus on the relationship between participants and coaches, the need for increased cultural understanding, and adaptations of the program content and structure. Furthermore, key contextual considerations were identified that heavily "influence the way participants approach quitting and engage with services."[30] These factors include: life stressors such as family loss or "bigger issues" that can lead to relapse; feeling that programs do not account for unique needs of AI/AN communities; high smoking prevalence in the community; limited access to others who have quit; ceremonial use of commercial tobacco; limited information about cessation services and how they work; and readiness to quit. AICAF advised the quitline provider to keep this context in mind when designing and delivering services.[30] A summary of the themes identified from the focus group analysis follows.

Coach/participant relationship. AI/AN commercial tobacco users indicated the quitline must find ways to make the service more personal and individualized. Examples include: taking time to build a relationship with participants; sharing personal stories; conducting empathetic and nonjudgmental conversations with humor to make phone calls fun; and engaging energetic, positive coaches who create a conversational experience rather than the feeling of "taking a survey."

The first call to the quitline is critical to making participants feel comfortable. In the standard Helpline, callers speak to a registration specialist who collects demographic and other data before speaking to a coach. The battery of registration questions at the outset feels impersonal and makes it difficult to build a connection with quitline staff.

Understanding Native culture. The need to create a more comfortable and relevant experience by demonstrating an understanding of Native realities of culture, history and stresses was frequently mentioned. Findings were mixed as to whether coaches should identify as AI/AN, however participants ultimately want coaches who understand their struggles and culture.

Content of services. Participants recommended providing information about: 1) feedback on the benefits of quitting (e.g. the amount of money saved, health improvements); 2) tips for quitting such as how to deal with cravings in a positive way (e.g. lessons learned from Natives who successfully quit); 3) mental health support to help participants with trauma and stress; and 4) availability of nicotine replacement therapy and its proper use.

Program structure. Participants indicated they would like to access services on their own in real time, thus controlling when they engage with services. Texting was suggested as a popular way to deliver services especially among younger smokers because of the convenience, ease and immediacy of messaging. Changing how registration is conducted to reduce participant burden, expediting the process and allowing participants to self-identify as AI/AN and thus self-select into the program was recommended. Additional advice included hiring AI/AN coaches who are former smokers, and adequately training coaches to equip them to handle difficult challenges with helping AI/AN commercial tobacco users quit. Furthermore, offering incentives to maintain engagement and ensuring services are timely, responsive and inclusive of commercial tobacco users in all stages of quitting was proposed.

Program Adaptations

To best address AI/AN smokers' needs, the standard Helpline program was adapted to increase participant trust, program engagement, and sustainable implementation within a population-based public health program. This included a dedicated coaching model and enhanced support (increase number of calls and 12 weeks of Nicotine

Replacement Therapy (NRT). Table 4 summarizes key program elements that were implemented to address the focus group findings.

Findings revealed AI/AN commercial tobacco users may not be aware of how existing quitline services operate, thus providing additional guidance for quitline staff when working with AI/AN participants on creating a quit plan.

Coaches' Training

A key finding was the critical need for an additional coach training component to ensure coaches understand relevant AI/AN history, especially why tobacco is sacred and the distinction between sacred and commercial tobacco. The three curriculum components were knowledge, skill and empathy. The knowledge component covered the two tobacco ways framework, incorporating the value of sacred tobacco alongside the goal of quitting commercial tobacco. The skill segment included strategies for flexing communication and integrating culturally specific content and terminology. A component on empathy provided insight into the AI/AN population's unique challenges. American Indian community partners with extensive experience addressing commercial tobacco use delivered the training to 21 Helpline coaches. The training included a pre-reading packet with relevant tribal history, sacred tobacco use, and commercial tobacco use prevalence, case studies and open discussions. Coaches receive periodic refresher training and ongoing coaching from their supervisors (Table 5).

LESSONS LEARNED

The development and launch of the American Indian Quitline demonstrated collaboration among AI/AN community partners, funders and service providers to create a culturally relevant cessation service for AI/AN

commercial tobacco users. Lessons learned from the partnership continued to drive monitoring and assessment of the program.

Relationships. Building and maintaining authentic relationships takes time. In this case, existing relationships were leveraged to bring multiple partners together to create this new partnership. Allowing enough time to develop meaningful, trusting relationships and understanding of community and vendor needs is as critical as providing a safe environment for open discussion, sharing stories and providing honest feedback. With strong relationships, difficult topics and concerns can be more easily discussed and addressed.

Collaboration. Genuine collaboration and participation were essential for program design and buy-in from all parties. This required flexibility and respecting each partners' expertise and limitations as equally important. The interdisciplinary approach led each party to contribute to a shared goal that helped focus and support the collaboration, program design and successful launch.

Organizational Commitment. Leadership and program staff from all partner organizations demonstrated a commitment to improving services to better serve the AI/AN community. The project aligned well with each organizations' mission which led each to dedicated staff expertise, time and funding for the collaborative process.

Adequate resources. Funding is essential when embarking on a collaborative development project to address unique community needs. Supporting community organizations to conduct formative research and allocating resources for ongoing advising and community outreach is important.

Context. Keeping individual, community and environmental factors at the forefront during program development and implementation can help build trust and, ultimately, better services. Addressing commercial

tobacco use independent of competing priorities is likely to be ineffective. Smoking is often a symptom of larger issues such as stress and mental health that may also need to be addressed.

Community engagement. All partners should agree to engage the community in all aspects of development and implementation. Given the status quo often relies on "do what we know," this commitment requires a generous timeline and check and balances to ensure community input drives the process.

Considerations for conducting focus groups in AI/AN communities. Organizing communities to share their ideas and feedback must be done by a trusted partner who knows the community's norms and environment to successfully recruit and engage participants and elicit honest advice. Finally, the community and participants must receive a timely summary of how their input was used.

LIMITATIONS

While the focus groups with community advocates and commercial tobacco users did not include enough participants for saturation nor did participants adequately represent all American Indian demographics, ongoing engagement with community stakeholders and community members provided continuous community input and feedback on the program. Although the program was being developed for one state's quitline, variations in tribal traditions were considered to increase broader appeal. Finally, time and funding constraints did not allow for evaluation; such data are important to inform future work.

CONCLUSIONS

The pilot project presented an the opportunity to co-create culturally informed, population-based quitline programs for communities disproportionately impacted by commercial tobacco use. Receptivity and active participation in the design and development process demonstrated all parties willingness to collaborate. Once launched, it is critical to continue working in partnership with all partners to provide cultural input to ensure the

service is being delivered as intended. Using a collaborative approach to develop the American Indian Quitline resulted in a new program addressing a significant health disparity among Minnesota's AI/AN community, and contributed to greater understanding, improved relationships and ongoing connections to impact other public health programs.

ACKNOWLEDGEMENTS

The authors would like to acknowledge the contributions of the tribal and urban community health program staff, the urban community program staff and focus group participants along with the following AICAF staff: Daanis Chosa, Delilah Robb, Meggan McCann and Tina Murphy. We would also like to thank Lori New Breast and Carole Specktor. We are grateful for everyone's contributions and dedication to this work.

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Table 1. Partnership Roles, Responsibilities and Descriptions

Partner	Role(s)	Organizational Description
ClearWay[SM] Minnesota	• Funder • Project management • Relationship management	An independent, non-profit organization that improves the health of Minnesotans by reducing the harm caused by tobacco. ClearWay Minnesota serves Minnesota through its research, policy and community development grant-making programs, through QUITPLAN® Services and through statewide outreach activities. It is funded with 3 percent of the state's 1998 tobacco settlement and has a limited lifespan.
American Indian Cancer Foundation (AICAF)	• Planned and led the focus groups and community input processes • Provided ongoing community guidance for every phase	National nonprofit organization focused on eliminating the cancer burdens of AI/AN people through improved access to prevention, early detection, treatment, research and survivor support with partnerships in several AI/AN communities
Optum	• Program development • Clinical expertise • Coaches' training • Program implementation	QUITPLAN Services vendor and a services and innovation company on a mission to help people live healthier lives and to help make the health system work better for everyone. Optum's services include Quit For Life (QFL), the largest operator of quitline services. QFL uses an evidence-based combination of physical, psychological and behavioral strategies to help participants overcome their addiction to tobacco.

Other AI/AN community partners and advisors	• Cultural input, perspectives and feedback	• Lori NewBreast, Blackfeet Nation • Minnesota Department of Health Tribal Grantees • ClearWay Minnesota, Tribal Tobacco Education and Policy Grantees

TABLE 2. Guiding questions for focus groups with American Indian commercial tobacco users and health advocates

1. What would make American Indian commercial tobacco users want to call a quitline?
2. What would keep callers engaged?
3. How can coaches best support American Indian callers wanting to quit commercial tobacco?
4. What is the best way to promote the proposed American Indian quitline? (not included in this paper)

Table 3. Participant demographics for the seven focus groups with commercial tobacco users.

	TOTAL	**Urban Older** (5/12/17)	**Urban Young Adult** (5/24/17)	**Tribal #1** (5/30/17)	**Urban #1** (6/20/17)	**Urban #2** (6/21/17)	**Tribal #3** (6/22/17)	**Tribal #3** (6/22/17)
N participants	**60**	12	7	10	10	6	8	7
Gender								
Male	**14 (24%)**	0	3	2	2	1	3	3
Female	**44 (76%)**	12	3	8	8	5	4	4
Age								
Mean	**43.2**	53.4	25.5	35.5	47.7	31.7	43.3	55.1
Median	**42**	52.5	26	31.5	47	27	47	59
Range	**20-73**	31-72	20-28	20-57	28-73	20-58	25-71	38-71
Health Insurance								
No insurance	**3 (5%)**	0	1	0	1	0	1	0
Employer	**10 (17%)**	1	0	4	0	1	3	1
MA or Medicaid	**34 (58%)**	10	6	1	6	5	1	5
Other	**12 (20%)**	1	0	5	3	0	2	1

Table 4. American Indian Quitline Key Program Elements Designed to Address Focus Group Findings

Focus Group Findings	AI Quitline Program Revisions
Personalization, relationship building and need for conversational approach	Dedicated coaching model and streamlined enrollment (no hand-off from registration staff to coach)
Knowledge about and understanding of AI/AN culture, history, traditional tobacco and cultural realities, approaches and concepts	Culturally-tailored service including culturally-specific initial coaches' training and on-going performance coaching that assesses when it is appropriate to include traditional tobacco
Relationship development and more time to share information	Coaching calls ● Up to seven calls ● Increased focus on listening and storytelling ● Time allowed for slower pace and long pauses as needed
Improves probability of a successful quit by reducing the barriers to access and providing constant levels of nicotine replacement with a long and short acting formulation to address cravings	Up to 12-week supply of quit medication (NRT including combination therapy[1])

[1] Combination therapy is offered to participants who select patches and would benefit from also using gum or lozenge with the patches.

Table 5. Refresher Training for Coaches

Training Topics	Training Strategies
● Historical context ● Historical trauma ● Social stressors ● Traditional tobacco use – Two-Tobacco Ways framework[10] ● Facilitation skills ● Program elements	● Presentation/Storytelling ● Case studies ● Demonstrations ● Discussions ● Role plays