



Up North They're Talking Sex: A collaborative and community driven model for sexual health knowledge mobilization

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### Up North They're Talking Sex: A collaborative and community driven model for sexual health knowledge mobilization

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### Abstract

To address high STI rates in their aboriginal communities, the Tłıchǫ of the Northwest Territories adopted a collaborative participatory research approach to sexual health based on four key stages of development. First was community initiation and engagement, where local leaders identified a priority need and began community discussions around sexual health. Secondly, identifying that existing government statistics did not provide them with adequate information, the Tlıcho Community Services Agency partnered with the University of Alberta and CIETcanda to conduct a baseline study in all four Tlıcho communities, designed and administered by community-based researchers. Third, a community action research team (CART) developed evidence-based interventions and partnered with local community health researchers and public health personnel. The fourth phase included a follow-up evaluation of the CART activities and ongoing community-led action planning based on the results from the surveys. Key elements contributing to the success of the community based participatory research approach include community readiness, community and researcher collaboration, local evidence-based planning, and ongoing capacity building and monitoring. The process has led to an increase in interdepartmental collaboration, and the development of culturally relevant knowledge translation resources. Key to continued success is the sustainability and transferability of the CART approach to other priority concerns, and the strengthening of integration within the various programs to ensure continuing collaborative interventions.

### Keywords

Aboriginal health; CBPR; community-led research; interventions; sexual health

### Cover Page Footnote

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## **Up North They're Talking Sex: A Collaborative and Community Driven Model for Sexual Health Knowledge Mobilization**

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### **ABSTRACT**

To address high STI rates in their aboriginal communities, the Tlicho of the Northwest Territories adopted a collaborative participatory research approach to sexual health based on four key stages of development. First was community initiation and engagement, where local leaders identified a priority need and began community discussions around sexual health. Secondly, identifying that existing government statistics could not provide them with specific enough information, the Tlicho Community Services Agency partnered with the University of Alberta and CIETcanada to conduct a baseline study in all four Tlicho communities, designed and administered by community-based researchers. Third, a Community Action Research Team (CART) developed evidence-based interventions and partnered with local community health researchers and public health personnel. The fourth phase included a follow-up evaluation of the CART activities and ongoing community-led action planning based on the results from the surveys. Key elements contributing to the success of the community-based participatory research approach include community readiness, community and researcher collaboration, local evidence-based planning, and ongoing capacity building and monitoring. The process has led to an increase in interdepartmental collaboration and the development of culturally relevant knowledge translation resources. Key to continued success is the sustainability and transferability of the CART approach to other priority concerns, and the strengthening of integration within the various programs to ensure continuing collaborative interventions.

**Keywords:** Aboriginal health, community-based participatory research, community-led research, sexual health

## **INTRODUCTION**

Despite many well-intentioned programs and policies, the burden of illness among rural Aboriginal communities continues to grow in northern Canada (Adelson, 2005; Gesink Law, Rink, Mulvad, & Koch, 2008). In 2006, Sexually Transmitted Infection (STI) rates in the Northwest Territories (NT) were eight times higher than the national rate, and Tlicho regional rates were three times that of the NT – 66.3 cases per 1,000 (Government of Northwest Territories unpublished data, 2006). These unpublished government statistics are regularly collected from the local health centres. To the Tlicho community leaders the numbers indicated that prevention initiatives such as posters and brochures, and workshops, most of which originated from outside the communities, were having limited success in reducing outbreaks of sexually transmitted infections. The community leadership decided to add an internal approach.

Community-based participatory research (CBPR) promotes partnerships between communities and external researchers, with collaboration at each stage of the research process (Bogart & Uyeda, 2009; Wallerstein & Duran, 2006; Israel, Schulz, Parker & Becker, 2001). The approach recognizes different types of expertise and values each in turn. With its emphasis on shared responsibility and community-driven research priorities, CBPR reduces mistrust of external research and inherently builds community values and perspectives into the planning process (Wallerstein & Duran, 2010; Leung, Yen, & Minkler, 2004). CBPR has proven to be a successful approach for Aboriginal research in Canada; for example, the Kahnawake Schools Diabetes Prevention Project (KSDPP) (Potvin, Cargo, McComber, Delormier & Macaulay, 2003; Macaulay, Ing, Salsberg & McGregor, 2007), is characterized by strong community engagement, capacity building, and community control of interventions. That project, sustained now for twenty years, continues to provide community-wide education for students, parents and families to prevent type 2 diabetes through improved curriculum, physical activity in the schools and community, and healthy eating habits. The KSDPP community researchers regularly measure their interventions in concert with academic partners. The Tlicho have invited a Kahnawake trainer to visit the Tlicho to provide new skills to address the range of health challenges in their region. This paper describes how the four rural Aboriginal communities in the Tlicho region of the Northwest Territories of Canada implemented a CBPR approach to research, helping reduce their rates of sexually transmitted infections (STIs) and improve overall sexual health.

The key to successful CBPR is the acknowledgement that it is not an immediate or short-term solution, but rather a process that requires longer term engagement to facilitate sustainability. For the Tlicho sexual health program, four incremental and complementary phases of the project provide important context to the development of the participatory process.

## **BACKGROUND**

The Tlicho people, formerly called Dogrib, are part of the Dene cultural group in the Northwest Territories of Canada. The Tlicho, with a population of about 3,000 people in four remote communities, have their own distinctive language and culture. As they take control of their own government, they are focusing on sustaining their lands, culture and language in a manner that includes policies and programs promoting community well-being (Edwards & Martin, 2012).

### ***Phase 1 – Community initiation and engagement***

The Tlicho Community Services Agency (TCSA), located in Behchoko – the largest and

most accessible of the four Tlicho communities - is part of an intergovernmental services agreement between the Government of Canada, the Government of the Northwest Territories (GNT) and the Tlicho Government. The TCSA manages, administers and delivers services for the public territorial government and the Tlicho Government. In 2006, in response to the high rates of STIs in the Tlicho region, TCSA recruited a team of Tlicho Elders and community health representatives (CHRs). The CHRs are locally trained Tlicho people who work in the community health centres to implement prevention programs in a culturally appropriate manner. The research was considered part of the responsibilities of those already on salary, while Elders were paid for their work on the project. This group was deeply concerned about preventing further spread of STIs in the region and although there were no diagnosed cases of Human Immunodeficiency Virus (HIV) they were also concerned about the potential for rapid transmission of HIV in the communities if it were to emerge.

Representatives of this team visited each household in the four communities to provide information about sexual health and STI prevention. The team developed 'kitchen table talks' which were lay interventions that used STI information (signs, symptoms, and treatments) provided by nursing staff from the local health centre. During these 'talks', team members discussed healthy sexual practices, behaviors and prevention with all family members from Elders to teenagers. This community driven approach to sexual health intervention caught the attention of the media and resulted in the headline "Up North They're Talking Sex" (Vanderklippe, 2006). The Elders and CHRs also actively used public forums across the region such as local radio to provide information about STI prevention in the Tlicho language. This approach contrasted with the conventional broad spectrum models of intervention characteristic of government programs, based on posters, brochures, and websites designed outside of the community. The local leaders and team members who led the development and implementation of the 'kitchen table talks' later became the Healing Wind Advisory Committee (HWAC). The members continue to guide and participate in subsequent regional health research programming.

### ***Phase 2: Partnerships and collaboration***

Community-based research is an approach whereby communities play a strong role in the identification of the research question, take part in the data collection and analysis, the dissemination of results in the communities and in developing evidence-based interventions. The degree of community engagement can vary, yet in this project the Tlicho initiated the research, and took part in every aspect.

The TCSA realized that existing government statistics did not provide them with the detailed information they needed to inform local interventions or programs in these small communities – such as breakdowns of data specific to particular high risk groups (i.e., out of school youth) or the need for tailored information around sexual behaviours (i.e., knowledge, attitudes, social norms and agency around sexual health). TCSA was encouraged by the community acceptance of the 'kitchen table talks' and decided more needed to be done to further their understanding of the problem. In 2006, the TCSA and HWAC invited researchers from the University of Alberta and CIETcanada ([www.ciet.org](http://www.ciet.org)), a non-government organisation operating from Ottawa, to work with the community. Since 1995 CIET has built research and planning capacities in First Nations, Métis and Inuit communities across Canada, enabling them to design and carry out their own research with little external assistance. CIET includes academics and community members with relevant expertise to facilitate training and research. The goal was to work together to enhance the kitchen table approach established by the original community team with a research project that would provide a more systematic profile of sexual health knowledge,

attitudes and behaviours across the region. The TCSA research project was linked to CIET's sexual health research program which had been funded in Canada by the Canadian Institutes of Health Research. The Tlicho also contributed through in-kind time for employees and travel costs, and the project received annual licensing by the Aurora Research Institute on behalf of the Government of the Northwest Territories. HWAC provided local community approval. The project objectives were to define the underlying issues driving the high STI rates and to develop evidence-based community driven prevention programs to effect positive change.

The Tlicho Community Services Agency, with CIETcanada's technical support, led the regional baseline survey in 2006/07. HWAC grounded the research process in community context, protocols, and values while advising on survey development by identifying target groups, designing participant recruitment strategies, developing and reviewing questionnaires and consent protocols. The survey targeted those aged nine and older to provide a comprehensive profile of sexual health knowledge and issues across all relevant age groups. The actual research itself was seen by the communities as an education process. The survey was to be carried out in all four communities as well as the schools. The questionnaire explored individual beliefs, knowledge, attitudes and behaviours around HIV, STIs and sexual health, use of alcohol and drugs, access to sexual health information, partner violence, condom use, multiple partners, and participation in Tlicho cultural traditions. The questionnaire for 9-13 year olds was shorter and more age appropriate, while still collecting comparable information. Local community-based researchers (CBRs) administered the survey, applying their knowledge of the cultural values around sexual health in their communities. They received rigorous training in questionnaire administration to reduce bias and maximize consistency of data collection. CBRs who spoke the Tlicho language delivered the survey orally to participants who were non-literate or non-English-speaking, such as Elders. Words for sexuality in the Tlicho language had very negative connotations derived from colonial translations and biases and the community members developed more positive words and phrases. Translation of the survey into Tlicho took several days. The CBRs collected data from more than two-thirds, or 1656, of the target adult population in the Tlicho region (total target age group, approximately 2400). Those community members not reached were either out on the land, travelling outside the region, participating in education programs in other regions, or otherwise unavailable. CBRs and HWAC members participated in the data entry and analysis process and CIETcanada completed the analysis and report for review by the community. We reported the results from the baseline survey in *Pimatisiwin* (*Pimatisiwin*, 2013) an open access journal dedicated to Aboriginal and Indigenous community health, with both researchers and community members as co-authors (Edwards, Mitchell, Gibson, Martin, & Zoe-Martin, 2008). Locally, HWAC and regional health care professionals reviewed the results and developed a detailed evidence-based action plan. The action plan targeted four key priority issues arising from the survey outcomes: 1) lack of knowledge of healthy sexual practices, 2) a link between substance abuse and risky sexual behaviour, 3) lack of awareness around testing, and 4) a cycle of violence (where victims become perpetrators). Interventions designed to increase community discussion around these issues was seen as a key component of the action plan.

### ***Phase 3: Emergence of the Community Action Research Team***

A year after the baseline survey, the action plan had still not been consistently implemented due to the lack of dedicated personnel, sustained training, and financial and administrative support. The excitement generated by the STI crisis had abated, and those seconded to the research project returned to their everyday work responsibilities.

In August 2008 there was an outbreak of syphilis in the Tlicho region, a disease that was nearly non-existent in the Northwest Territories over the previous eight years. In 2009, STI rates in the NWT were nearly 30 cases per 1,000 and Tlicho regional rates were nearly three times higher at 91 cases per 1,000 (Government of Northwest Territories unpublished data, 2009). In May 2009, TCSA established a Community Action Research Team (CART) to revitalize and sustain STI prevention activities in the region. CART members had full time permanent positions within TCSA, and helped maintain momentum throughout personnel turnover (a common limitation of the CBR approach) (Edwards, Lund, Mitchell, & Andersson, 2008). The CART members were five young Tlicho people, 24-37 years of age. Each had a high school diploma and a working knowledge of the Tlicho language; several were fluent speakers. They had complementary experiences from previous positions within the community and were committed to staying in the Tlicho region. The CART model was ground-breaking for the TCSA as it included both female and male team members to address sexual health issues in a region where health and family well-being were traditionally women's responsibilities. CART's mandate was to implement culturally appropriate interventions and knowledge translation initiatives based on the 2006/07 survey action plan across the region. Team members required additional training to implement the intervention development and knowledge translation strategy. Training was grounded in Tlicho history, culture, cosmology, language (when possible) and community structure, and included all aspects of the research process such as proposal writing, financial and project management, partner development, ethics, qualitative and quantitative data collection and analysis, knowledge translation, program design and evaluation.

One of the related interventions implemented by TCSA in 2010 included the addition of a CHR liaison to work with the public health nurse in charge of the clinical STI program. The CHR liaised between the health centre and those individuals hardest to reach and at highest risk for STIs in the region. The CHR and the public health nurse reviewed client files and developed an action plan to encourage testing, increase knowledge and change behaviours. Within a six-month period they treated all positive cases of syphilis and reduced new known cases to zero (Government of the Northwest Territories unpublished data, 2010; Tlicho Community Services Agency unpublished data, 2010). Due to the success of this program, training sessions were conducted for CHRs in each of the three outlying communities as well. This became a sustained program, as the Public Health Nurse and CHRs continue to work collaboratively with CART on other community health issues.

#### ***Phase 4: Follow-up community-led measurement and ongoing action planning***

A follow-up survey conducted in April/May 2011 identified changes in behaviour and attitudes, provided a current overview of sexual health in the region, and helped tailor existing and new sexual health interventions. This follow-up survey, again conducted by CBRs with CIETcanada support, targeted those aged 13 to 99 years (excluding those aged 9-12 this time, as this second survey was considered too complex for the younger age group). The survey incorporated new questions in response to HWAC's concerns about changing attitudes and practices around forced sex, substance abuse and sexual practices, gossiping, bullying, and domestic violence. This survey also explored the impact of participation in CART interventions implemented after the baseline survey. The 2011 survey training added new CBR researchers to the research cohort and strengthened evidence-based planning skills for experienced CBRs, CART, and HWAC members. The participant recruitment strategy targeted residential areas, workplaces, youth centers, and community service buildings. In an effort to reach higher risk sub-groups that were difficult to engage during the baseline survey, CBRs identified and visited

houses known as suppliers for substance abuse (locally called 'party houses') frequented by the high risk participants. The 2011 survey identified an overall improvement in levels of sexual health knowledge and attitudes between the baseline and follow-up surveys, and evidence of CART's impact, as those who participated in at least one CART intervention were nearly twice as likely to use a condom the last time they had sex. The full results from the baseline and follow-up are published elsewhere (Edwards et al, 2008; Edwards, Gibson, Martin, Mitchell & Andersson, 2011). Once the results had been collated and reviewed by HWAC, CART and senior TCSA management, a revised action plan was developed and approved. TCSA, along with CART, identified all existing activities and resources in the communities relevant to STI and HIV/AIDS prevention – including those not specifically health related such as education, social services and housing. Updated action plans were based on partnerships among these services, thus increasing program effectiveness without additional investment.

## **KEY ELEMENTS OF THE CBPR APPROACH IN THE TLICHO REGION**

### ***Community readiness***

A key reason for the success of the community-based research approach was community readiness (Edwards, Jumper-Thurman, Plested, Oetting, & Swanson, 2000). The community has a previous history of taking ownership of key issues and providing leadership in addressing them. Their leadership capacity is best reflected in the ratified Tlicho Agreement, a modern Treaty with the Government of Canada, the first combined comprehensive land claim and self-government agreement in the Northwest Territories (Tlicho Government, 2003). Also, research was not new to the Tlicho as previous research experience had already shaped TCSA policies and programs (Zoe-Martin, 1999; Tlicho Community Services Agency, 2006). The community leadership demonstrated their readiness to address sexual health issues by supporting the development of the initial kitchen table talks. Community members corroborated their leaders' belief that sexual health was no longer a taboo subject with their high response rate to the baseline survey when over two thirds of the target population aged nine and over had participated.

### ***Community and researcher collaboration***

A collaborative approach built on mutual respect and trust allowed for open discussion at each stage of the research process. Several CIETcanada members had well-established relationships with TCSA from previous projects and collaborations, and the importance of these long term trusting relationships cannot be overstated (Gibson, Edwards, Zoe, Martin, & Gibson, 2008). The TCSA's vision statement, "strong like two people", is drawn from the wisdom of a respected Tlicho Elder in 1991 who emphasized the need to draw from the strengths of both the traditional culture and western culture. The partnership between the TCSA and CIET was recognized by the Northwest Territories Premier's Award for Collaboration in June 2008. A key component of the collaboration was, and continues to be, two-way capacity building, with community and academic partners learning from each other as the research process evolves. While community members gain confidence and capacity in research skills, academic partners learn about the value of local knowledge and experience, the increased validity and relevance of the data when local researchers conduct the research and interpret the findings, and the importance of contextual knowledge for effective implementation of research results.

### ***Community-led evidence-based planning***

Key baseline survey results influence CART's training and intervention development. For example, CART explored reasons for a lack of condom use through focus groups as part of

their ongoing interaction with youth in the communities. The youth indicated these unsafe behaviours primarily occurred in the largest community, Behchoko, during major community events, such as drum dances and other gatherings, which could be higher risk times. In response CART regularly replaced supplies of free condoms in all sites specified by the respondents. They also operated a weekend outreach van to distribute condoms and safe sex information during several high risk weekends in winter, from 11PM to 3AM. In this manner, survey evidence strengthened CART training and tailored community interventions. Other evidence-based CART activities include an annual youth conference, puberty camps on the land for boys and girls, classroom information sessions, and media activities. These programs are in their fourth year.

### ***Ongoing capacity building and monitoring***

Throughout our research partnership, capacity building has been responsive and community relevant (Minkler & Wallerstein, 2003; Israel, End, Schulz, & Parker, 2005; Marais, 2007). With the assistance of long term ongoing mentoring and training with CIETcanada and community leaders, CART is becoming skilled in all aspects of research and capacity building. By engaging TCSA staff and community members in the research process, CART strengthens community capacity and contributes to meaningful program and policy development. Through research-to-action projects, CART integrates Tlicho values in all their intervention research, community programs and communication activities, including resource materials (e.g. pamphlets, booklets, manuals, posters), media (e.g. radio, DVDs, web, blog), and community events (e.g. workshops in the community, youth conferences, focus group discussions). In order to ensure consistency and sustainability of planning and coordination, CART holds biweekly meetings for planning and project management. Advisory workshops with HWAC occur three times a year and as needed, as well as annual joint strategic planning meetings. CART regularly evaluates training outcomes and impacts to ensure learning objectives are met systematically within the Tlicho cultural framework. The personal and professional growth of CART members is also reviewed regularly to ensure progress towards goals and to ensure cultural safety as they address sensitive topics such as sexual health within their own communities (Cameron, Andersson, McDowell, & Ledogar, 2010).

## **BROADER IMPACTS**

There are three areas where our CBPR approach influenced systemic change in STI management across the region:

**1) *Interdepartmental collaboration:*** The initial community response to the increased rates of STIs in the Tlicho region was community oriented, including 'kitchen table talks' with Elders, local health care professionals, and community members, to increase regional awareness and engagement. TCSA adopted a multi-service coordination approach with the managers of the various services which included regular meetings where shared strategies were developed, discussed and implemented. Involvement and collaboration between frontline service workers and managers supported the development of four linked goals: a) raising awareness about gaps in collaboration and potential synergies; b) generating action-oriented dialogue and helping to build trust between services; c) anchoring this dialogue in evidence from the communities; and d) ensuring programs are grounded in Tlicho values.

**2) *Culturally relevant resources and knowledge translation:*** Before the baseline survey, when HWAC noticed that the Tlicho terminology used to describe sexuality and sexual health had strongly negative connotations linked to an imposed religious value system, they organized a sexual terminology workshop. Tlicho language experts identified more neutral Tlicho terms to

decrease potential bias and to develop positive ways to discuss sexual health. CART regularly uses this new terminology in intervention programming. As well, the interviews and focus groups that came after the baseline and follow-up surveys revealed the desire for more visual sexual health information. In response, CART developed a range of materials for the internet (Facebook site, videos posted on YouTube, VIMEO, and other web sites) for region wide communication (Tlichó CART, 2013). Two members of CART are now engaged full time in training and production of media resources for culturally effective knowledge translation. Uptake and outreach has been international. For example, CART is now advising a research team in Sheffield, United Kingdom addressing the health of Travelers in a community-based project. CART has also shared their work and the results of their studies at venues such as the Qualitative Health Research annual conferences held by the International Institute for Qualitative Methodology, and the Community-Campus Partnerships for Health, CU Expo, drawing from their experiences to shift the perspective from what is 'wrong' in the community towards highlighting positive community-based approaches.

**3) Policy Development:** The inclusion of representatives of the Tlichó Government in the research process ensures that research and intervention activities have full community support and that they inform regional policies and programs. The partnership with the relevant departments of the Government of the Northwest Territories provides a continuing foundation for collaborative evidence-based program design. In early 2013, the Tlichó Government established the Tlichó Research and Training Institute, bringing together academic, government, NGO, corporate and local Tlichó resources to address community research priorities and coordinate ongoing research.

## **CHALLENGES ENCOUNTERED**

While the CBPR approach has been well-received by the community, the process has not been without its challenges. For example, confidentiality in small communities is complex and sexual health remains a sensitive topic, even though it is discussed more openly than in the past. HWAC and CART stress the importance of high standards and appropriate strategies for ensuring confidentiality. For example, CBRs and CART members sign confidentiality agreements which state that information collected as part of the research process is not shared with anyone outside of the research team. During data collection, no names or identifying information is recorded, and respondents seal their questionnaires in envelopes, removing the link between a given response and a particular individual. As trust is an important part of the CBPR process – both between the community and researchers, and within the community itself – standards to ensure confidentiality need to be consistently maintained.

Secondly, community readiness is a transitional process that fluctuates over the course of a research program. Unexpected events such as illness, suicide and death can stall community activities, let alone research initiatives. Changes in leadership and personnel can also influence research timelines and goals, illustrated by the delay in implementing the action plan following the baseline survey. An important task of HWAC, with support from CART, is to promote the balance between community priorities and research protocols and objectives.

Thirdly, although the recent survey and interview data indicate a link between the lowered STI rates and the community actions recounted here, we have little evidence to support any particular activity. Although TCSA and HWAC strongly acknowledge the impact of the collective activities, we have yet to fully measure the impact of specific interventions.

## **NEXT STEPS**

The CBPR process is cyclical: evidence is gathered, interventions developed, piloted, implemented, and evaluated, and new strategies emerge. The regional health centers will continue to monitor biomedical indicators and future research will explore the link between the drop in STI rates and behaviour change. More research will go deeper into the data and other studies will explore behaviour change and seek models to support it in various gender/age groups.

The evolving focus for CART is to improve the sexual health program while developing related strengths-based programs related to parenting and men's health. These actions are based on the focus group and follow-up survey findings that related sexual health to lack of resources for parents, and the need to address aggressive behaviours and addictions. Each intervention is a learning process for those involved, with community-based training provided at every opportunity by HWAC members, TCSA staff, CIETcanada and others as needed.

The community engagement strategy continues to involve Tlicho Government representatives and TCSA managers as co-investigators and collaborators in research and intervention activities. CART's role continues to expand as they become trainers within the community and we continue to recruit community members (youth, males, parents and Elders) into research and intervention projects. As well as on-going training and programming for the sexual health program, the CART model is now being applied to other community-identified issues such as healthy nutrition and diabetes prevention.

Funding and personnel recruitment will influence the existing programs. Despite several years of intensive work, much remains to be done. Key factors will be the sustainability of the sexual health program and its application to other issues, the transferability and sustainability of the CART approach, and the strengthening of integration within the various programs to ensure continuing collaborative interventions.

## **CONCLUSION**

The leaders and professionals in the community acknowledge the impact of this five-year research program in reducing the rates of sexually transmitted infections in the Tlicho region. Rates have been consistency low since the last round of surveys, with no new cases of syphilis. However in 2013, the rise in gonorrhea and chlamydia rates in one community inspired immediate house-to-house visits, implemented by CART. The process requires constant vigilance. There is community ownership and pride in this program, however, more research is needed to measure the range of other factors that may have contributed to the behaviour changes in the most affected groups, particularly younger women. The success to date is grounded in the ongoing support of community leadership and Elders. The increasing acceptance of openly discussing healthy sexuality is another indication of success. The development of the CART approach has contributed to an integrated strategy at TCSA. Guidance from HWAC ensures that research activities are culturally appropriate, a key factor in the CBPR model for the Tlicho.

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