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Tukisiviit: *Do You Understand?*



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PAUKTUUTIT
INUIT WOMEN OF CANADA
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Tukisiviit Summary Report

2012 – 2014

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The *Tukisiviit – Do You Understand?* Inuit Sexual Health Literacy Forum was held in Happy Valley-Goose Bay, Newfoundland and Labrador, on February 6-8, 2012. This event was organized by Pauktuutit and the Canadian Inuit HIV/AIDS Network (CIHAN), which functions as a consultative group to Pauktuutit on matters pertaining to HIV/AIDS prevention, care, treatment and support.

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2012 – 2014

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“Inuktitut has always and will always help the interpreters/translators and patients alike. Increasing your work power in medical terminology and different dialects is the most essential key for all of us professional linguists in Canada. It shows we are very smart and caring persons to provide the HIV/AIDS afflicted with assistance in caring.”

Participant: Tukisiviit National Inuit Sexual Health Literacy Forum (February 2012)

INTRODUCTION

Pauktuutit Inuit Women of Canada is the leading national organization addressing Inuit-specific sexual health and HIV/AIDS issues in Canada. Since 1995, Pauktuutit has broken new ground to bring these sensitive topics to the forefront of public health awareness and disease prevention among Inuit. This report documents the achievements and milestones of Pauktuutit's *Tukisiviit* Inuit Sexual Health Literacy project and the creation of the *Tukisiviit: Do You Understand?* glossary.

Through the years, Pauktuutit has stressed the need for sustained holistic initiatives that are sensitive to the unique cultural, linguistic, geographic, and economic circumstances of Inuit living in Inuit Nunangat and in Canada's southern urban centres.¹ In all matters related to Inuit health, effective communication is essential between patients and health care providers. Pauktuutit recognizes the need for relevant and culturally appropriate resources that are available in a plain-language format in English and major Inuktitut dialects. These resources support the work of health care providers and front line workers to provide effective, informed care, treatment, and support, and nurture greater health literacy among Inuit. Pauktuutit developed the *Tukisiviit: Do You Understand?* English-Inuktitut glossary to help health service providers explain commonly understood and used HIV and sexual health terms and procedures in an effective and accurate manner.

The *Tukisiviit* project serves as a model process for building local capacity. Critical to this evidence-based project was the engagement of project partners and local, regional, and national stakeholders during the project planning stage through to product rollout. Pauktuutit listened and learned, and made this a key part of the decision-making process. The result is a resource tool on sexual health that has deep meaning and value at the community level.

1. Inuit Nunangat is home to almost three-quarters of the 59,445 people identified as Inuit who live in Canada (Statistics Canada, Household Survey, 2011). Inuit Nunangat stretches from Labrador to the Northwest Territories and is comprised of four regions: Nunatsiavut, Nunavik, Nunavut and the Inuvialuit region.

BACKGROUND

The impact of sexually transmitted and blood borne infections (STBBIs), including HIV/AIDS and hepatitis C, continues to be a priority health concern among Inuit. As a result of greater travel between southern and northern communities, the challenges of health service delivery in smaller communities, and the higher than average rates of sexual assault, Inuit are at risk for sexually transmitted infections (STIs).² Though the actual rate of HIV infection among Inuit is not known, STI rates are high, as are the associated risk behaviours.³ Pauktuutit's research has found that fear, stigma, and discrimination have acted as barriers to prevention, awareness, and education initiatives. Many Inuit do not talk openly about sexual health and regard the topic as an intimate issue. The lack of appropriate Inuktitut terms and concepts compound the problem.

For Inuit, families, and caregivers who require information about the treatment and support needed to manage STBBIs and STIs, the lack of culturally and linguistically appropriate information limits their ability to navigate the health care system, to complete medical forms, to provide medical information and informed consent to health care providers, and limits their ability to effectively understand and comply with medical instruction and medication regimes. As well, health care providers, interpreters, and translators lack accurate and consistent terminology to communicate to Inuit patients about sexual health, prevention, and treatment. Without these resources, it is difficult for Inuit to be active partners in their personal health care.

Between 2006 and 2011, the number of Inuit in Canada increased by over 18 percent.⁴ With 34 percent of this population under the age of 14 years and 54 percent under the age of 25 years, a large proportion of the population is now becoming sexually active. As such, sexual health and HIV/AIDS prevention and education initiatives require sustained efforts to raise and maintain awareness of the risks of infection.

The Inuktitut language is a family of dialects that varies from region to region and sometimes from community to community. Its use remains strong, especially in the Nunavut and Nunavik. According to the 2011 Census, almost 80 percent of Inuit who report Inuktitut as their mother tongue indicated they use it at home. Another 15 percent stated they use Inuktitut in addition to a non-Inuktitut language use most often at home. In total, there are about 35,500 Inuit language speakers in Canada.

-
2. Within smaller Inuit communities, age and peer groups are small and individuals may share multiple sex partners, which can facilitate the spread of STIs and STBBIs. Because local health providers may know most individuals and their families, there are concerns about confidentiality and anonymity associated with testing for these diseases.
 3. For example, in Nunavut in 2009, the infection rate for Chlamydia was almost 15 times higher than for all of Canada and the rate for Gonorrhoea was 48 times higher. In 2011, STIs accounted for approximately 75% of all reportable diseases in the territory (Department of Health, Government of Nunavut (2013). *Sexually Transmitted Infections in Nunavut – 2006-2011*. (URL: <http://www.irespectmyself.ca>).
 4. Statistics Canada, National Household Survey, 2011.

ORIGINS OF THE *TUKISIVIIT* PROJECT

The *Tukisiviit* Inuit Sexual Health Literacy project began in 2011 with financial support from the Public Health Agency of Canada (PHAC) Non-Reserve First Nations, Inuit, and Métis Communities HIV/AIDS Project Fund. The project is a logical extension of Pauktuutit's earlier work on sexual health awareness — specifically the 2008 to 2010 project entitled *Increasing Sexual Health Capacity and Building Supportive Communities for Inuit Living with HIV/AIDS*. This latter project developed and disseminated Inuit-specific prevention, education, and information products and solicited expert advice for a five-year strategic plan on sexual health. To strengthen the development of the strategic plan, Pauktuutit conducted focus group sessions to assess Inuit knowledge, attitude, and behaviours regarding HIV and AIDS. The objective was to design and implement public health education strategies that better support behavioral changes among Inuit.

In October 2009, Pauktuutit organized the first Inuit National Policy Forum on Sexual Health in Iqaluit, Nunavut. The event was a key building block in the development of an Inuit-specific strategic plan. Completed in early 2010, the *Inuit Five-Year Strategic Plan on Sexual Health (2010-2015)* serves as a management tool that provides the vision, mandate, priorities, and strategic directions for Pauktuutit's ongoing work on HIV/AIDS, and STBBIs and its collaborations with PHAC and other stakeholders.⁵ A key objective is to address Inuit knowledge, attitudes, and behaviours regarding these diseases and the ways to reduce risk behaviours.

The Inuit National Policy Forum on Sexual Health and the resulting strategic plan identified language terminology as a priority issue. Specifically, the strategic plan identified the need for the following:

- Up-to-date standardized Inuktitut meaning for complex terminology;
- Regionally specific glossaries of Inuktitut terminology;
- Plain-language meaning of terms in each dialect;
- The avoidance of inappropriate terminology; and,
- The revision of Inuktitut language educational and awareness material to reflect new standards.

The need for accurate Inuktitut terminology has been recognized for over 25 years. For many medical terms related to sexual health there are few equivalent terms in the Inuktitut language. For example, the Inuktitut translation for an "HIV diagnosis" is an "incurable illness" which is the same translation for the term "cancer." Similarly, the word "vulva" is translated as "imitating a cheek." While some Inuktitut medical glossaries are available, some translations are more explanatory and use broad descriptions rather than actual words. Overall, there is no medical terminology glossary available in Inuktitut that consistently addresses HIV/AIDS and sexual health.

5. A copy of the *Inuit Five-Year Strategic Plan on Sexual Health* is available on the Pauktuutit website: <http://pauktuutit.ca/health/sexual-health>.

STRATEGIC PLAN

In 2010, Pauktuutit released the *Inuit Five-Year Strategic Plan on Sexual Health*. The plan prioritized awareness, health promotion, prevention, screening and care, and surveillance and research. These were integrated within a holistic and gender-relevant approach that recognized the unique social and environmental determinants of health within Inuit communities. The scope of the problem demands partnerships and Pauktuutit has worked to engage various levels of government, local health boards and health departments, school boards, various Inuit organizations and communities, Aboriginal and non-Aboriginal HIV/AIDS organizations, as well as private industry.

The priority for accurate Inuktitut terminology identified in the strategic plan gave rise to the *Tukisiviit* Inuit Sexual Health Literacy project.

OVERVIEW OF THE TUKISIVIIT PROJECT

Every person has a right to quality and reasonable services when accessing health care. However, some Inuit do not have the necessary knowledge and language about HIV/AIDS to know when they should access care, treatment, and support. The Inuktitut language mimics certain English words but these translations can lack vital information about the meaning of the word. There is a need for standardized up-to-date Inuktitut medical terminology on such topics as sexual health.

“With the ability to properly communicate with clients their understanding and compliance will be enhanced. They will have a level of care that is up to standard and provided in their own language. This benefit will have a ripple effect — a positive health care experience for all involved.”

Participant: *Tukisiviit* National Inuit Sexual Health Literacy Forum (February 2012)

The goal of the *Tukisiviit* Inuit Sexual Health Literacy project is to develop culturally and linguistically appropriate medical terminology that will help reduce the communication barriers associated with HIV/AIDS and sexual health. Accurate Inuktitut terminology will help increase Inuit health literacy, patient safety, and the capacity of health care providers to deliver culturally and linguistically appropriate services. Additionally, accurate terminology contributes to language preservation and cultural identity.

“This is so important to be able to have it in the health field, especially in the health field — it’s absolutely significant to have any resource material as it relates to people’s health available in their language and the dialect of the people. It’s so important.”

Informant: *Tukisiviit* Project Evaluation (January 2014)

The *Tukisiviit* project unfolded in two phases. The first phase of the project lasted 18 months (2011-2012) and involved two main activities:

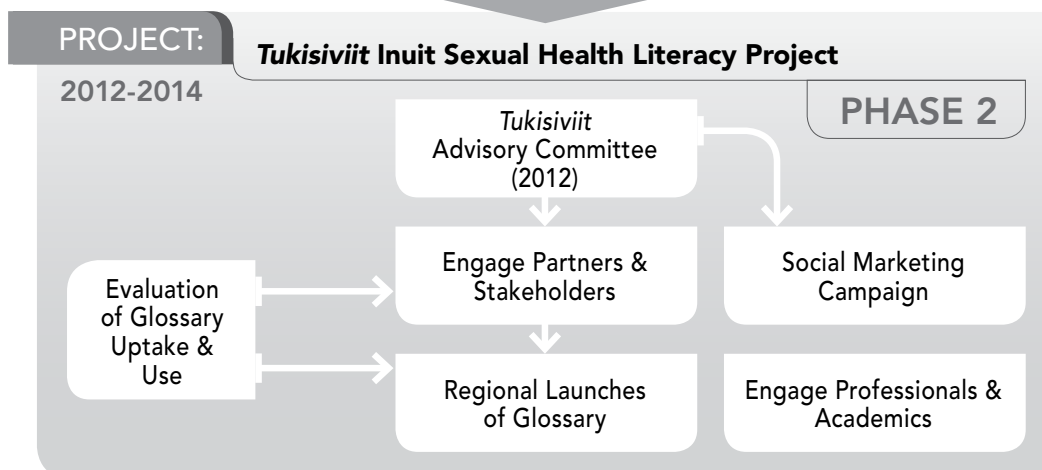
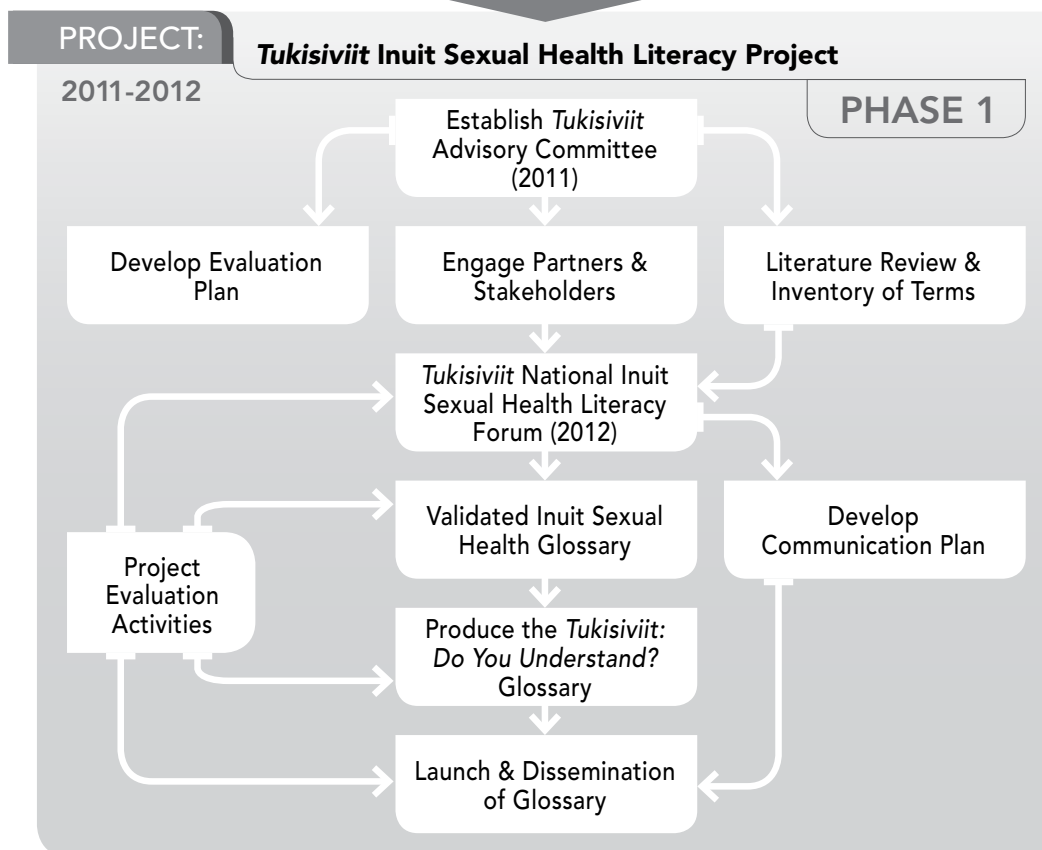
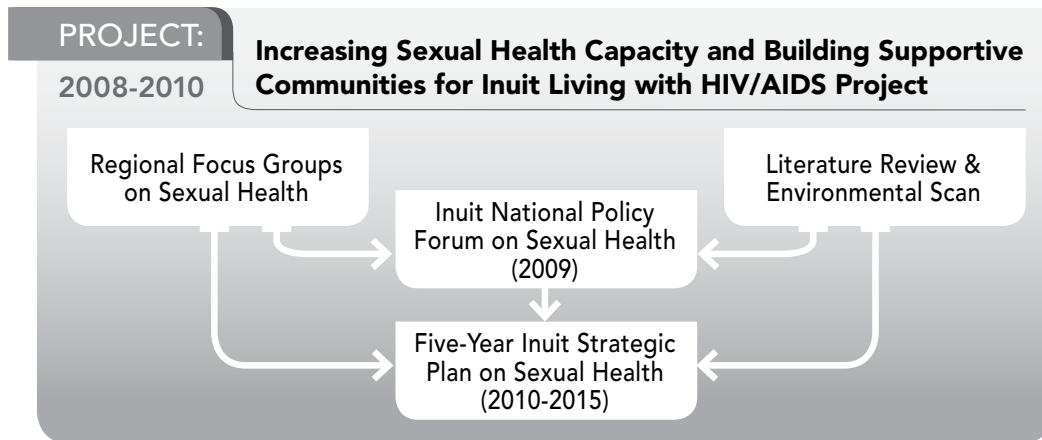
1. The planning, coordination, and hosting of a national Inuit HIV/AIDS language terminology forum; and,
2. The development and distribution of the bilingual *Tukisiviit: Do You Understand?* glossary of HIV/AIDS terminology in four of the most common Inuktitut dialects.

The success of the first phase and the support it received from sexual health experts, language experts, health organizations, and other key stakeholders encouraged PHAC to extend the project for another 18 months. The intent of the second phase was to facilitate the uptake and usage of the glossary. The second phase (2012-2014) involved three main activities:

1. Undertaking a social marketing and communication strategy to broaden the reach and promote the use of the glossary by Inuit and health care providers;
2. Ongoing collaboration and engagement of key stakeholders and partners; and,
3. Undertaking an evaluation of the project to assess the dissemination, use, uptake, and impact of the resource.

The *Tukisiviit* English-Inuktitut glossary is intended to be an accessible, living resource. The tool will be revised as language, medical, and health terminology related to HIV/AIDS continues to evolve and grow. The glossary provides health care providers, interpreters, and translators with accurate and understandable terminology that will improve the quality of care provided to Inuit and will empower Inuit to be active partners in their personal health care.

The Background and Elements of the *Tukisiviit* Sexual Health



PROJECT ADVISORY COMMITTEE AND PARTNERS

Critical to all health projects involving Inuit is the value of working closely with a range of stakeholders and experts. For the *Tukisiviit* project, Pauktuutit established a National Advisory Committee to help engage local, regional, and national stakeholders and to advise on the design and development of the terminology forum and the resulting glossary. Chaired by Pauktuutit, the committee included members of the Canadian Inuit HIV/AIDS Network (CIHAN) to represent all four Inuit regions as well as urban Inuit and youth. The Committee invited representatives from a number of organizations and government departments to attend the *Tukisiviit*: National Inuit Sexual Health Literacy Forum. These included the Government of Nunavut, Nunavut Tunngavik Inc. (NTI), Inuit Tapiriit Kanatami (ITK), the National Aboriginal Health Organization (NAHO), CATIE, and the Canadian Aboriginal AIDS Network (CAAN). As well, provisions were made to bring in language experts and medical interpreters from all four land claim areas and content experts from PHAC and First Nations and Inuit Health (FNIHB).

CIHAN was established in 1999 as a consultative group to Pauktuutit on matters pertaining to sexual health, HIV/AIDS, and hepatitis C. It serves as a window to Inuit regions, facilitating outreach and the sharing of information at the regional and community level. Together, Pauktuutit and CIHAN work to raise awareness, support front-line health workers, support Inuit health fairs and AIDS walks, and advocate for Inuit.⁶

Pauktuutit also has a long-standing partnership with CAAN. It is the only recognized national Aboriginal AIDS organization and it provides an opportunity for Pauktuutit to ensure that the perspective and needs of Inuit are included at the national policy level. Pauktuutit is responsible for electing a Nunavut representative to the CAAN Board of Directors.

Since 2004, Pauktuutit and CATIE have been working together on HIV prevention, treatment, care, and support for Inuit. CATIE is a valuable clearinghouse for information and resources for HIV/AIDS and STBBIs and has helped Pauktuutit with the translation and distribution of Inuit-specific resources.⁷

Pauktuutit also has a close working relationship with ITK, the national voice of Inuit living in the four land claim regions of Inuit Nunangat. Pauktuutit is a member of the National Inuit Committee on Health (NICoH), which works to identify Inuit health priorities and seeks Inuit-specific solutions.⁸ Pauktuutit briefed NICoH on all stages of the project and sought input and guidance from the regional, territorial, and national stakeholders.

As part of the broad engagement process, linguistic experts from all four Inuit regions were invited to the national terminology forum. As well, sexual health content experts, community health and social service providers, AIDS service organizations, educators, elders and youth, and representatives from land claims organization were invited to collaborate on

6. Pauktuutit serves as CIHAN's secretariat, providing the Network financial and administrative support and assists its members to share information.

7. It should be noted that through the years CIHAN, CAAN, and CATIE have revised their mandates beyond HIV/AIDS to include hepatitis C and other STBBIs.

8. NICoH includes representatives from all four Inuit Land Claim Organizations as well as representatives from ITK, the Inuit Circumpolar Council, and Pauktuutit.

the explanation and translation of a wide-range of sexual health and HIV/AIDS-related terms, definitions, and concepts into four regional dialects of Inuktitut.

“It is written in dialects of the region, it’s a very user-friendly resource. I think it’s something my staff are going to be using as one of their primary teaching tools.”

Informant: *Tukisiviit* Project Evaluation (January 2014)

Ongoing relationship and partnership building to market the final *Tukisiviit* glossary was critical in the project’s second phase. Pauktuutit sought opportunities to promote the glossary through dialogue, conferences, and presentations to key health professional organizations. These included the Registered Nurses Association of Northwest Territories and Nunavut, the Registered Nurses Association of Newfoundland and Labrador, the Canadian Public Health Association, the Society of Obstetricians and Gynecologists of Canada, the Canadian Nurses Association, and the Canadian Association of Midwives. Pauktuutit also sought partnership opportunities with the Canadian Institute of Health Research’s Canadian HIV Trial Networks in an effort to explore options of adding the *Tukisiviit* glossary to an existing online continuing education course for physicians.

THE *TUKISIVIIT* LANGUAGE FORUM

The three-day *Tukisiviit* National Inuit Sexual Health Literacy Forum took place in Happy Valley-Goose Bay, Newfoundland and Labrador in February 2012.⁹ Forum participants were selected in partnership with regional officials to ensure the right mix of language and health experts. The event also assembled community health and social service providers, representatives from AIDS organizations, and representatives from three of the four Inuit land claims organizations. As well, Elders and youth participated. The Elders provided expertise in Inuktitut terminology and the youth introduced what they consider “everyday” use of sexual health language. Together they reviewed and collaborated on the translation of over 60 terms and concepts into Inuktitut.

“I have been impressed with the dedication and hard work people have devoted to the task at hand and the good humour that has attended discussions of a very serious topic.”

Participant: *Tukisiviit* National Inuit Sexual Health Literacy Forum (February 2012)

9. Pauktuutit took advantage of the assembled expertise for the *Tukisiviit* language form to conduct an additional one-day language form on the topic of hepatitis C on February 10, 2012.

The national forum originally envisioned translating the glossary into four major regional dialects of Inuktitut. However, representatives from Nunavik felt the linguistic differences between the Ungava Bay and Hudson Bay dialects were so distinct that there should be separate translations. In the end, the forum exceeded expectations and resulted in the drafting of a bilingual glossary using five Inuktitut regional dialects.

In advance of the forum, Pauktutit staff reviewed existing English-Inuktitut glossaries, consulted PHAC for additional medical terminology, and created a reference list for use during the forum. This list provided a baseline that was used to develop an improved glossary. An English-language template was then prepared listing the terminology that needed to be translated along with the plain-language definitions for each term. Participants then used this template to record their regional Inuktitut translations.

The forum employed a combination of presentations and small and large group discussions. The emphasis was on having regional breakout groups review sections of medical terms and concepts listed in the template, having the participants translate the terminology into regional Inuktitut dialects, and then having each regional group present their deliberations and terminology back to the larger forum. This dialogue promoted a synergy that refined the definitions further and informed the participants how different regions were approaching the task of translation.

Example of the Terminology Template

Male Anatomy • ᐱᐅᐅᐅᐅᐅ ᐅᐅᐅᐅᐅ • ᐱᐅᐅᐅᐅᐅ ᐅᐅᐅᐅᐅ • Angutiup Timinga • Agutim timeata ilagin

WORD	ENGLISH	NUNAVIK (HUDSON)	NUNAVIK (UNGAVA)	NUNAVUT	NUNATSIAVUT	WESTERN ARCTIC
Scrotum	The sac that the testicles rest in. The scrotum protects the testicle and keeps it cooler than the rest of the body.	ᐅᐅᐅᐅᐅᐅ	ᐅᐅᐅᐅᐅ ᐅᐅᐅᐅ	ᐅᐅᐅᐅᐅᐅ	Fottanga pattangita Angutiup. Tamna pijuttallititkatatuk pattanginik nill-nanginitauammata timingatut.	Igyokalvik. Puk igyuk inigysni. Igyokalvik monagya igyuk niglamayagani ahenni timeoyum.
Testicle	The largest site of production of testosterone and the site of production of sperm.	ᐅᐅᐅᐅᐅ	ᐅᐅᐅᐅᐅ	ᐅᐅᐅᐅᐅ	Anginipok ininga Kapakluvalledunlu.	Igyuk. Timin tivogakhanik koyaktun iniktigaaganik nutagakkaleogu-tihamik haravea.
Vas Deferens	The tube that carries the sperm out of the testicles during ejaculation.	ᐅᐅᐅᐅᐅ ᐅᐅᐅᐅᐅᐅ ᐅᐅᐅᐅᐅᐅᐅ	ᐅᐅᐅᐅᐅ ᐅᐅᐅᐅᐅᐅ	ᐅᐅᐅᐅᐅ ᐅᐅᐅᐅᐅᐅ	ApKutinga Kapaup pemmat pattanginit.	Kapaom Igligaves. Ilgavik chum tivogakhanik iyhukigaktok koyaktun iniktigaaganik.
Perineum	The piece of skin between the testicles and the anus.	ᐅᐅᐅᐅᐅᐅ (ᐅᐅᐅᐅᐅ ᐅᐅᐅᐅᐅᐅ ᐅᐅᐅᐅᐅᐅ)	ᐅᐅᐅᐅᐅᐅ	ᐅᐅᐅᐅᐅ ᐅᐅᐅᐅᐅᐅ	Uvinik akungani pattangita itingatalu.	Akunaak. Uvinik chum itevio akungaretok.
Anus	The hole for removal of body waste.	ᐅᐅᐅᐅᐅ	ᐅᐅᐅᐅᐅ	ᐅᐅᐅᐅᐅ	Itinga anilimnat.	Itk. Inum anikvee.
Cowper's Gland	The gland that makes pre-ejaculatory fluid (pre-cum) and also contributes fluid to semen during an ejaculation.	ᐅᐅᐅᐅᐅ ᐅᐅᐅᐅᐅᐅᐅᐅᐅᐅ ᐅᐅᐅᐅᐅ	ᐅᐅᐅᐅᐅ ᐅᐅᐅᐅᐅᐅᐅᐅᐅᐅ ᐅᐅᐅᐅᐅ	ᐅᐅᐅᐅᐅᐅᐅ ᐅᐅᐅᐅᐅᐅᐅ	Kinidlik pejalings imigalannik (ivullinik) amma Kausillitsiok Pejagelimmat angutik.	Kapakakveom Kinkhinea. Kinyotsavaktok koyaktok tivogaeaktinago pijagutaovlonio.

Feedback from the forum confirms that the event was an especially engaging and interactive way to gather Inuktitut medical terminology. It would be challenging to have conducted this exercise without this face-to-face forum, given the current status of terminology, and the cultural and linguistic variations between regions. The event fostered a sense of ownership by the participants which stimulated enthusiasm, energy, and a spirit of collaboration for the project.

The working template listed over 60 anatomical and sexual health terms and concepts organized under the following seven broad subject categories:

- Male anatomy (16 terms)
- Female anatomy (14 terms)
- Sexually Transmitted Infections (14 terms)
- Risk Behaviours (5 terms)
- Fluids That Can Transmit STIs: (4 terms)
- Testing (What to expect) (4 terms)
- Treatment (4 terms)

The results of these translation sessions formed the basis for the *Tukisiviit: Do You Understand?* glossary.

“The forum is an example of how we must be proactive to address some of the challenges facing Inuit health care.”

Participant: *Tukisiviit* National Inuit Sexual Health Literacy Forum (February 2012)

In order for Pauktuutit to learn from the event, forum participants were asked to comment about the forum’s progress and format. Some stated that they first felt overwhelmed by the task, but soon found that the collaborative process was an effective way to meet the challenge of the work. Several others thought the work was very important and that it was good to see some progress in this area. Participants thanked Pauktuutit for organizing an event of this nature because it would be too challenging to do this on a region-by-region basis.

“This is not easy work but it always impresses me when I see Inuit women tackle such important issues so strongly.”

Participant: *Tukisiviit* National Inuit Sexual Health Literacy Forum (February 2012)

Importantly, the participants identified some of the challenges they faced when translating the terms. Participants not only identified the variation of Inuktitut terminology between regions, but also the variation of some terms within a region. Both the Nunavut and Nunavik participants noted that there were different dialects represented in their groups. For example, the Nunavut participants noted that some regions in the territory do not have words for gay and lesbian sex. The Nunavik participants opted to provide translations for the terminology in both the Ungava and Hudson Bay dialects.

At times, forum participants found it necessary to adjust or add words to the plain-language definitions to make them more meaningful at the regional level. This highlights the importance of having health practitioners and translators from different regions working together with sexual health experts so that the Inuktitut terminology can be adjusted to be regionally appropriate and remain medically accurate. For example, Nunavik participants found it difficult to translate the specific names of some STIs so they focused on translating the definitions. They felt it necessary to add words to the definitions for such diseases as Chlamydia, HIV, AIDS, and hepatitis A so they were more meaningful in the region.

“ It gets people talking about the disease, and not the stigma.”

Informant: *Tukisiviit* Project Evaluation (January 2014)

The Nunatsiavut participants expressed little difficulty with the STI terminology and definitions, however they added a short note stating, “Some STIs live in saliva and bodily fluids and can be passed this way – condoms can stop transmission.” For the term “anal sex” the group added “...the skin inside the anus is very sensitive and delicate.” In addition, terminology was developed for terms not included in the list including sexual assault, survival sex, gay sex, lesbian sex, and bisexual.

In the context of testing for STIs, Nunavut participants suggested that text should be added to assure male patients that they are provided a smock or drape and are not left without any pants. With respect to the terms bacteria and virus, the group felt that patients should not feel that there is nothing they can do if infected with a virus, so they changed the text to read “you can get treatment if it’s bacteria, but for viruses, you can only get help to relieve the symptoms.”

“ I feel that although I will be tired when I get home, ... it will be the fatigue that comes from doing hard and productive work.”

Participant: *Tukisiviit* National Inuit Sexual Health Literacy Forum (February 2012)

In the practical world of medical translators, the participants noted the general challenges of discussing sexual health topics. They identified the need to get away from the traditional practice of describing sexual behaviour as something that occurred “down there” and the difficulty of discussing such taboo practices as oral sex. Another concern is that Inuit youth tend to use slang for body parts, highlighting the need for youth to learn accurate medical terminology. Adding to the of complexity of using medical terminology among Inuit, some forum participants noted that translating a term from Inuktitut into English could involve just one word or sometimes a whole paragraph.

The success of the *Tukisiviit* National Inuit Sexual Health Literacy Forum validates the model for other projects that seek to access subject matter and cultural knowledge.

LAUNCH OF THE *TUKISIVIIT: DO YOU UNDERSTAND?* GLOSSARY

The *Tukisiviit* language forum surpassed expectations and resulted in the production of a glossary in five Inuktitut dialects instead of the planned four. The resulting *Tukisiviit: Do You Understand?* glossary provides information about HIV/AIDS and sexual health terms in English, and in the Inuktitut dialects found in Nunavik (Hudson and Ungava), Nunavut, Nunatsiavut, and the Western Arctic.

The *Tukisiviit: Do You Understand?* glossary is a brightly coloured 34-page booklet that highlights male and female anatomy, STIs, testing, treatment, and prevention. The document is now available in a limited number of print copies, as CDs, and online on Pauktuutit's website. A link to the document also is provided on the CATIE website.¹⁰

As part of Phase One, Pauktuutit assembled the results from the national language forum and produced the glossary. During Phase Two of the project, Pauktuutit developed and implemented a communication and social marketing strategy to raise awareness and use of the glossary. The effort was to encourage greater uptake and use of the resource by health service providers and Inuit in general. The plan included the production of promotional tools, and the engagement of stakeholders through media launches, dialogues, and various presentations.

The immediate goals are to increase awareness and knowledge of Inuit terminology related to HIV/AIDS and to improve the capacity to communicate accurate information to those Inuit affected by the disease. The long-term goal is to help to reduce the differences between the health of Inuit and the health of other Canadians, and to improve the health of those Inuit affected by HIV/AIDS.

Though the *Tukisiviit: Do You Understand?* glossary is available to everyone on Pauktuutit's web page, it is expected that the primary users will be health service providers and their professional associations and organizations (e.g., medical associations, nursing associations, and academic institutions). Other potential users include linguistic and cultural experts and such stakeholders as Inuit representative organizations, non-government organizations, and government officials. The uptake of the glossary by these users is critical for reaching out to the wider Inuit population and empowering Inuit through increased health literacy to be active partners in their personal health care.

“Overall I really like this resource; I like the layout and having all dialects on the one page.”

Informant: *Tukisiviit* Project Evaluation (February 2014)

10. URL: <http://www.catie.ca/en/resources/tukisiviit-do-you-understand>.

Key to the Phase Two communication and marketing strategy was the planning for national and regional “launch” events to raise awareness, promote distribution, and initiate dialogue. Pauktuutit also expanded the use of social media to promote the glossary within Inuit regions and communities and within the broader health sector. In 2012 and 2013 Pauktuutit set up information booths at the Society of Obstetricians and Gynecologists of Canada meeting, the Inuit Circumpolar Health Gathering, at provincial and territorial nursing association meetings, and at university and college health career forums. As well, efforts were made to take advantage of telemedicine and webinars to broadcast presentations about the *Tukisiviit* resource.

The national launch of *Tukisiviit* was reserved for Pauktuutit’s Annual General Meeting on March 4-7, 2013. However, the *Tukisiviit* website was launched on November 6, 2012 and a number of regional launches took place before and after the national event.¹¹

- Winnipeg (November 30, 2012): In partnership with the Manitoba Urban Inuit Association, Pauktuutit conducted a regional launch in Winnipeg, Manitoba, to coincide with Aboriginal AIDS Awareness Week (AAAW). The city is a major gateway for travel into the Kivalliq region of Nunavut.
- Winnipeg (December 1, 2012): During a launch of an AAAW event organized by CAAN, Pauktuutit distributed copies of the *Tukisiviit* glossary.
- Iqaluit (December 1, 2012): The Nunavut regional launch took place during a youth-oriented AAAW event in Iqaluit co-hosted by Pauktuutit and the Native Youth Sexual Health Network, Nunavut Tunngavik Inc., and the National Inuit Youth Council. Coordinated press releases were made by Pauktuutit, the Government of Nunavut, CAAN, and the National Inuit Youth Council. Press coverage was provided by Nunatsiaq News and CBC in Iqaluit.
- Kuujuaq (January 19-24, 2013): A Nunavik regional launch of *Tukisiviit* took place during Pauktuutit’s Hepatitis C Strategy Planning Session in Kuujuaq and during a concurrent meeting of Nunavik community workers.
- Ottawa (February 2013): A regional launch took place in Ottawa at a meeting of the Inuit Public Health Task Force Group.
- Ottawa (March 2013): Another regional launch took place in Ottawa during the NICOH meeting.
- Inuvik (July 9, 2013): An Inuvialuit regional launch took place in Inuvik during Pauktuutit’s Inuit Cancer Terminology Forum. The event provided an opportunity for forum participants to get a sense of what to expect from their work on cancer terminology.

As noted the *Tukisiviit* resource also has been promoted at other health events, including a meeting of the Society of Obstetricians and Gynecologists of Canada in Calgary, Alberta. Over 200 *Tukisiviit* CDs were distributed and several professors who attended the event indicated they will use the resource in their teachings.

Pauktuutit partnered with the Canadian Institute of Health Research’s Canadian HIV Trial Networks and is now engaged in an advisory capacity. As well, the *Tukisiviit: Do You Understand?* glossary has been added to Memorial University of Newfoundland’s online Continuing Medical Education program for physicians.

11. The *Tukisiviit: Do You Understand?* online resource is available at URL: <http://pauktuutit.ca/tukisiviit>.

During Phase Two of the project, the President of Pauktuutit was interviewed about *Tukisiviit* by CBC North Yellowknife, CBC Salluit, and CBC Iqaluit. As well, the resource has received print and electronic media attention. Significantly, Nunatsiaq News carried a story in November 2012 that reached across Inuit Nunangat in print and on the Internet.¹² Articles also were published by the Toronto Star and metronews.ca.¹³

In April 2013, the newsletter for the Society of Obstetricians and Gynecologists of Canada (SOGC News) published *Pauktuutit Inuit Women of Canada: Spotlight on one of our partners*, which described Pauktuutit's ongoing work in the area of HIV/AIDS programming and described the *Tukisiviit* language forum and glossary. The article describes how the *Tukisiviit* project serves as a model supporting the use of Inuktitut and improving Inuit health literacy.

Unfortunately health fairs coordinated with Correctional Service Canada for correctional staff and Inuit offenders at the Beaver Creek and Fenbrook correctional facilities in Gravenhurst, Ontario were cancelled due to delays in security clearance procedures.

DISTRIBUTION OF THE *TUKISIVIIT* GLOSSARY

Pauktuutit planned to use its website as an important mechanism for distributing the *Tukisiviit: Do You Understand?* glossary. It is promoted on Pauktuutit's website and links have been made to the resource on other sites, such as the CATIE website. Pauktuutit produced 1000 print copies as well as CD versions of the glossary and the demand has been high. All 53 Inuit communities have received print and CD versions (approximately five copies of each) and copies have been distributed to northern hospitals. As well, members of the Project Advisory Committee and project partners and stakeholders have received copies, along with NiCoH members, the Inuit Public Health Task Group. Copies also have been distributed to members of the Pauktuutit Board of Directors, delegates attending Pauktuutit's 2013 Annual General Meeting, the federal Minister of Health, and PHAC, the project's funder.

During the various launch and information events organized for *Tukisiviit*, print and CD copies were distributed to those in attendance. For example, the Northern Health Unit of the University of Manitoba received 25 copies and during the Society of Obstetricians and Gynecologists of Canada meeting in Calgary, 300 CDs and 200 hard copies were distributed. University professors at various medical schools have requested and received copies of the *Tukisiviit* glossary to include in their program curriculums, and university students also have requested copies. Pauktuutit continues to receive requests for the resource.

As an online resource, interest in the *Tukisiviit* glossary has been high. In the 11-month period between November 2012 and September 2013, there were 945 online visits to Pauktuutit's website to view the resource. Increased online activity corresponds with the project's launch and promotional activities, confirming the importance these events for stimulating interest and wider distribution.

12. See Nunatsiaq Online. URL: http://www.nunatsiaqonline.ca/stories/article/65674pauktuutit_publishes_inuit_language_sex-health_word_book/

13. See, for example, the Toronto Star. URL: http://www.thestar.com/news/canada/2012/11/17/inuit_health_group_is_giving_voice_and_vocabulary_to_sex_terms_in_inuktitut.html

Northern health providers and health authorities are now sharing and using the *Tukisiviit* glossary. Some are using it as a sexual health resource and as an educational tool, and it has been listed in some policy and resource manuals. Evaluation results show that many believe the glossary makes things easier for clients and health care providers to talk about the topic of sexual health.

PROJECT EVALUATION

In order to demonstrate the utility of the model practices used to develop the *Tukisiviit: Do You Understand?* glossary, Pauktuutit integrated a strong evaluation component into the project. An evaluator was contracted at the beginning of the project to develop a logic model and to establish the methodology needed to assess the project's implementation and outcomes, and to document the lessons learned. Particular attention was given to the processes of engagement, consultation, and collaboration undertaken by Pauktuutit. In total, the evaluator submitted five reports for the *Tukisiviit* Inuit Sexual Health Literacy project.

The evaluation involved a participatory, collaborative process. This included:

- Consulting with Pauktuutit staff, project participants, forum attendees, and other stakeholders;
- Reviewing project documentation and implementation plans;
- Reviewing the social marketing and communications strategy;
- Reviewing the distribution of the *Tukisiviit* glossary, press releases, media articles, and relevant social marketing activities on Pauktuutit's website; and,
- Tracking activities and events such as meetings, presentations, and product launches.

Assembling experts and professionals from various fields is a key to the project's success. For example, during the national language forum in Happy Valley-Goose Bay, the evaluation found that the health, cultural, and linguistic experts and other participants recognized the value of the collaborative effort. The participants commented on how the forum had heightened their appreciation for developing a medical glossary in multiple Inuktitut dialects and that the gathering generated a synergy that was needed to overcome the complexities of translating medical terminology into multiple dialects. In the end, the participants acknowledged that the event had increased their own awareness and knowledge of HIV/AIDS and sexual health terminology.

The final product also has generated positive feedback. Those directly involved in the project are impressed how quickly the glossary came together. People have commented about the quality of the resource, that it addresses a need, and that the layout is user-friendly, colourful, engaging, and easy to use.

The outcomes of the *Tukisiviit* project can only be measured over time. A primary and immediate outcome has been the distribution of the *Tukisiviit* glossary to health centres and linguistic experts in all Inuit communities and northern hospitals, as well as to hospitals and service providers in the south that receive Inuit patients. With the glossary, they have the capacity to communicate effectively about HIV/AIDS related issues to Inuit from any region. Through a social media and communication campaign, the project's second phase

has expanded the distribution to professional institutions and academic institutions and has campaigned to inform Inuit everywhere about the glossary. To this end, the project has been a success. The national and regional launches, and the engagement of professional organizations have resulted in the wide distribution of print and CD versions of the *Tukisiviit* glossary. More importantly, the social media and communication campaign solicited interest in the electronic version of the glossary. In the ten months following the start of the regional launches in late November 2012, the *Tukisiviit* website received 945 views.

An intermediate outcome of the project is to ensure that the glossary is being used in a consistent manner in health and support settings. It is not just a matter of distribution, but also a matter of use — health service providers need to utilize the glossary in order to increase Inuit awareness and knowledge of HIV/AIDS and sexual health. Over time, this will contribute to better health services for Inuit affected or impacted by HIV/AIDS, will increase access to services, and will contribute to better health outcomes, and lower health care costs.

The evaluation documented a number of lessons about conducting a project of this nature that contribute to a model of success through partnership and participant engagement.

1. Dynamic team leadership kept the production team motivated and on track as they coordinated multiple tasks and activities, and which contributed to the team's overall satisfaction with final the products.
2. A strong, committed, and effective project team successfully coordinated the planning of the national language forum and then guided the development of the multi-dialect glossary through the selection of expert translators and skilled graphic and web page designers.
3. Participants to the language forum were identified in partnership with regional officials to ensure the right mix of language, cultural, and sexual health expertise.
4. The format for the language forum and the design of the working template used to develop the multiple translations encouraged an open dialogue that engaged participants in a cooperative spirit that overcame the challenges of working with multiple dialects.
5. Participants took ownership of the project in the sense that it fostered enthusiasm, energy, and cooperation among participants.
6. Social marketing and product promotion are critical to ensuring end-user recognition and use of the product.
7. The project demonstrated the need to distribute the glossary to health institutions, health authorities at the national, provincial/territorial, and local, and to various academic institutions.
8. The project demonstrated the interest of health professionals and their organizations in the availability of products of this nature.
9. The project generated interest nationally and abroad as a promising practice for improving the health outcomes of Aboriginal peoples.

Additional conclusions arising from the evaluation include:

1. Recommendation to provide local training and workshops to promote the use of the *Tukisiviit* glossary;
2. Recommendation to enlist local media in product promotion in the form of public service announcements;
3. Recommendation to develop additional multi-language resources like the glossary that are relevant, accessible, and culturally appropriate; and,
4. Evaluate the utility of additional tools to promote the distribution and use of the glossary, including posters and pictures that illustrate the terminology being described.

CONCLUSIONS AND NEXT STEPS

The success of the *Tukisiviit* Inuit Sexual Health Literacy project rests on a model of engagement, consultation, and collaboration. From the beginning, with the 2009 Inuit National Policy Forum on Sexual Health, Pauktuutit assembled health practitioners, administrators, and subject-matter experts to listen and learn. A five-year strategic plan on sexual health resulted from the successful national policy forum. A key message from the delegates was that more and better medical terminology is needed in Inuktitut to effectively communicate with Inuit patients and improve the quality of care and services.

In the process of implementing the *Inuit Five-Year Strategic Plan on Sexual Health*, Pauktuutit received financial support from PHAC to undertake the *Tukisiviit* Inuit Sexual Health Literacy project. Again, a key ingredient to the project's success was to bring stakeholders together to learn and collaborate on a practical and user-friendly glossary of medical terminology on the topic of HIV/AIDS and sexual health. With the guidance of an advisory committee that has close links to Inuit communities and represents Inuit organizations and HIV/AIDS groups, a national language forum was organized. Participants included linguistic experts, sexual health content experts, community health and social service providers, AIDS service organizations, educators, elders, youth, and representatives from Inuit land claims organizations. The collaborative work of these dedicated people resulted in the creation of the *Tukisiviit: Do You Understand?* glossary.

In order to capitalize on the investment of the *Tukisiviit* project, Pauktuutit undertook a communication and distribution strategy that took advantage of existing events and meetings. For example, Aboriginal AIDS Awareness Week celebrations in 2012 proved to be the perfect opportunity to introduce the *Tukisiviit: Do You Understand?* glossary and serve as a springboard for regional launches. Pauktuutit also took advantage of professional gatherings to showcase the glossary.

Ultimately, the *Tukisiviit* glossary remains a living document. It is hoped that *Tukisiviit* will become an online resource in the style of Wikipedia that can be continually updated by language experts, as Inuktitut and medical terminology dynamically evolve over time.¹⁴ The long-term goal of increasing awareness about HIV/AIDS by overcoming linguistic and

14. Inuktitut is a living language and it is anticipated that sexual health and medical terminology will continue to evolve over time.

cultural barriers and creating better terminology remains. Increasing Inuit awareness and knowledge about sexual transmitted diseases does not happen overnight. Changing Inuit demographics, changing health priorities, and the changing northern economy drive the need for ongoing work.

As for next steps, Pauktuutit has secured additional financial support to extend the *Tukisiviit* Inuit Sexual Health Literacy project for another three years in order to capitalize on its early successes. Time is needed to continue promoting awareness about the resource and promoting its use. For example, Pauktuutit hopes to collaborate with Correctional Service Canada to undertake training for their health care staff and to work with Inuit inmates. As well, the extension will give Pauktuutit the opportunity to better assess the uptake of the glossary's HIV/AIDS knowledge and to better measure the intermediate and long-term outcomes of the project.

Planned evaluation activities include focus group research about changing knowledge, awareness, and behaviour regarding HIV/AIDS. In 2008-2009, Pauktuutit conducted this type of research as part of the Increasing Sexual Health Capacity and Building Supportive Communities for Inuit Living with HIV/AIDS project. This research supported the strategic planning session on sexual health that took place in Iqaluit in 2009 and contributed to the development of the five-year strategic plan on sexual health. It is now time to revisit this research and compare it with what is known and practiced by Inuit today. Pauktuutit wants to measure how effectively it has informed Inuit about their sexual health and to what extent Inuit have reduced their risk of exposure to HIV/AIDS, hepatitis C, STIs, and STBBIs.

The proposed extension will allow Pauktuutit to combine the priorities and actions of two complementary strategic plans: the near complete *Inuit Five-Year Strategic Plan on Sexual Health* (2010-2015) and the more recent *Inuit Five-Year Strategic Plan on Hepatitis C* (2013-2018). Both strategies prioritize disease awareness and prevention, health promotion and screening, and ongoing research. An integrated strategic plan will carry forward the significant gains made regarding HIV/AIDS and sexual health within the broader perspective of co-infection — the idea that diseases like HIV/AIDS, hepatitis C, tuberculosis, and other STBBIs, should be addressed together in a complementary manner.

Pauktuutit continues its vital work on HIV/AIDS, sexual health, and hepatitis C. The Inuit population is young, dynamic, and growing. Fifty-four percent of the population is under the age of 25 years and they are becoming sexually active at a younger age. STI rates are disproportionately high among Inuit and Pauktuutit's research reveals that many young people still engage in high risk behaviours. As a result, there is an ongoing need for education and awareness about disease prevention and testing.

The northern economy is further changing and a key concern is that the resource industry, especially mining, will result in the spread of STIs and STBBIs. Migrant, short-term labourers from the south need to arrive and leave disease-free. Inuit need to be informed about reducing their exposure to sexual transmitted diseases and sexual exploitation, and to learn about the risks associated with survivor sex. Partnerships need to be established within the resource industry to promote awareness and prevention within their workforce. Pauktuutit believes it has a vital role to play in this initiative.

Driven by a strategic plan on sexual health that meets the specific needs and circumstances of Inuit, Pauktuutit has completed a model process that has resulted in an English-Inuktitut

glossary on HIV/AIDS and sexual health that has deep meaning at the community level. The multi-dialect *Tukisiviit: Do You Understand?* glossary was developed through partnerships and cooperation with language and health experts and has involved stakeholders at the local, regional, provincial/territorial, and national level. This resource contributes to the capacity of northern health service providers to communicate effectively in Inuktitut with all Inuit patients and contributes to the quality of care and services offered. The glossary encourages Inuit to make informed decisions about their health and to be active partners in their health care.

