

Celebrating Community Knowledge Encouraging Involvement, Achieving Ownership and Building Confidence Through Comprehensive Community Consultation.

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Introduction:

Pauktuutit Inuit Women's Association of Canada has demonstrated a historical commitment to addressing health care issues among Inuit communities, and HIV/AIDS is no exception. Since the story of Leetia Geetah, the first Inuk woman diagnosed with HIV, hit the news in 1988, Pauktuutit has been increasingly involved in HIV/AIDS issues. Leetia Geetah's experience as an Inuk living with HIV/AIDS has had a profound, lasting impact on Inuit communities and Inuit who have since been diagnosed with HIV. Her diagnosis coincided with the birth of her youngest child in the late 1980s. To say that a lack of confidentiality and HIV/AIDS awareness resulted in a community ill-prepared to understand, much less respond to Leetia and her young son's needs, is a gross understatement. The true result was a community terrified by the prospect that HIV/AIDS was among them, a community determined to get rid of the cause by whatever means necessary. Threats of violence fuelled by fear and misinformation followed the breach in confidentiality. Media coverage spread the alarm across the north.

For their own protection, Leetia and her son were confined to a hospital while health officials attempted to identify a safe alternative resource. In February, 1989, Leetia and her son boarded a plane and left their community and their family. Caring, yet culturally ignorant strangers from the south would now provide the support they needed most.

The Inuit experience with HIV/AIDS and Inuit culture differs significantly from those of First Nations and Métis. For example, despite the fact that Inuktitut is a living language, the first language of most Inuit, little HIV/AIDS information has been produced in Inuktitut until recently. The lack of accessible educational materials has resulted in a poorly informed population, unmotivated to deal with the threat of HIV/AIDS and years behind their southern counterparts with respect to HIV/AIDS awareness.

The distinct nature of Inuit culture, traditions and beliefs has rarely been reflected in HIV/AIDS educational materials developed for Aboriginal

peoples. The medicine wheel and sweet grass are examples of two corner stones of First Nations culture which are irrelevant to Inuit. The lack of cultural representation and context in educational materials has provided an opportunity for Inuit to ignore and sometimes to deny the likelihood that they are at risk of contracting HIV.

While intravenous drug use is a major risk factor in the spread of HIV/AIDS among southern Aboriginal populations, it is a far less significant risk among Inuit. Games like “torture and chicken” are a more substantial risk to Inuit children and youth. Likewise, while “two-spirited people” are a focus of substantial HIV/AIDS education for some Aboriginal populations, for Inuit, the focus is unprotected heterosexual intercourse. Focusing on risk groups and risk behaviors less prevalent among Inuit has resulted in a very limited recognition at the community level of the need for HIV/AIDS community action.

Inuit communities are geographically isolated, spanning the Arctic from the Northwest Territories to Newfoundland / Labrador (including Nunavik, Arctic Quebec), in size, an area more than one-third the total of Canada. Subsequently, there are broad variations from region to region and community to community. All fifty-three Inuit communities of the Arctic are coastal, and only one is accessible by land. There is a dramatic range of population among communities from approximately one hundred and fifty to four thousand. Inuit have often used geographical isolation to deny the threat of HIV/AIDS; however, many communities have large transient populations, which increase the potential for the introduction of HIV into even the smallest community.

The delivery of health services to Inuit communities is the responsibility of five governments: the federal government, the governments of the Northwest Territories, Nunavut, Quebec and Newfoundland/Labrador. The complexities of this health care delivery system create situations unique to Inuit and to Inuit communities with respect to continuity of service and care, as well as consistency with information and access to treatment. Additionally, the health care needs of urban Inuit are the responsibility of the province in which they live. Often, for Inuit living with HIV/AIDS and their families, this structure can create a difficult or impossible situation with respect to family reunification, consistency in treatment and the accessibility of optimal care and support.

Although community health workers and others have developed educational materials in some communities, the bulk of information available to Inuit is southern, white and male-oriented. By and large, it does not reflect the reality of life among Inuit communities in the north. It provides accurate information but lacks the necessary context to make it effective.

Pauktuutit began the process of developing HIV/AIDS prevention material for Inuit communities in 1998. Through funding (received in August 1998) provided by Medical Services Branch of Health Canada, that we have been able to provide Inuit communities with six booklets about HIV/AIDS available in English and in one dialect of Inuktitut. (Translation of the books in a second Inuktitut dialect is in process)

The value of comprehensive community consultation in the development of educational materials cannot be overstated. Community consultation sends a message of respect. It is recognition of the value of community expertise. One of the most important things to recognize is that your audience are invaluable experts.

In response to a resolution passed at the 1993-94 Annual General Meeting of Pauktuutit, we hosted a three-day HIV/AIDS/STD training workshop in Iqaluit. The goal of the workshop was multi-faceted, primarily focusing on increasing knowledge about HIV/AIDS issues for community health workers. It was also intended to gather information about attitudes and community needs as they relate to HIV/AIDS. The need for culturally appropriate, linguistically sensitive material about HIV and AIDS was identified as a priority.

This sentiment has been echoed by community representatives involved in other HIV related workshops including the Iqaluit Youth HIV/AIDS workshop (1998), the CHR Knowledge conference on HIV/AIDS and STDs (1995), and the Sharing the Message HIV/AIDS training seminars (2000). All participants seem to agree that the lack of relevant HIV/AIDS information hampers their efforts to provide their communities with accessible, appropriate education about HIV/AIDS.

The lack of contextual information is the predominant reason Inuit communities and community members have failed to “buy in” to southern HIV/AIDS prevention messages. Encouraging ownership of an issue is almost impossible when information used to promote it inadvertently provides a message of exclusion.

Providing less relevant information allowed Inuit to view themselves as outside any particular risk group and diminished the need to evaluate their own behavior with respect to the risk of HIV. While AIDS organizations in the south are wrestling with issues like homophobia and the “Gay Plague”, in northern communities, we wrestle with our own sort of misinformation: that HIV/AIDS is a southern white male disease unlikely to affect the north.

Underlying principles:

Interestingly enough, this on-going project is sponsored but not directed by Pauktuutit. It is community-driven. Past experience taught us

that ownership is a function of participation. It taught us that the success of this project would largely depend on our ability to perform our role as a facilitator and leave the decision making in the hands of the broader community.

Project Goal: To broaden the scope of understandable, relevant, accessible HIV/AIDS prevention, treatment and care information for Inuit communities.

Although this project goal may appear straight forward, it was, in fact, substantially more complex. It became apparent at the first meeting of the steering committee that producing the materials would not be sufficient unless we developed a process that encouraged ownership. Ownership, we came to realize, was the key to ensuring the documents were going to be used.

Rather than imposing a design for community consultation or picking a standard model, we remained flexible and allowed the process to shape itself. The process we used to encourage ownership and involve the community evolved. We were guided by a set of principles with respect being the primary one, respect for cultural expertise and regional difference, respect for the right of communities to determine their own standards, and respect for the fact that communities and community members knew what information they were ready to deal with and where they needed to begin the process of HIV/AIDS education.

For many reasons, Inuit have viewed HIV and AIDS as less of a threat than many other populations. On the face of it, the answer may seem quite simple: isolation. In reality, one of the main reasons Inuit have been slow to respond to the AIDS crisis is that they have been given permission to ignore it. As previously stated, until recently, the majority of HIV/AIDS educational material available to Inuit has been southern, Caucasian-based and provided only in English.

The Inuit language, Inuktitut, has been maintained from generation to generation. It is written in three ways and spoken in more than eight dialects. It is one of only three aboriginal languages, in Canada, expected to survive. Producing HIV/AIDS materials respectful of each dialect is a goal, although, a questionably realistic one. Although international law supports the rights of individuals to be educated in their own language, accessing the resources necessary to provide dialectically appropriate materials has proven impossible to date. When material is irrelevant and inaccessible, populations are not only robbed of the opportunity to recognize their own risk but are given tools which allow them to avoid connecting their own risk behavior with the threat of HIV/AIDS.

Methodology

We sought the help of the six regional health boards and requested that they select a regional representative to sit on an HIV/AIDS steering committee. We recruited an additional three members, one representing youth, one representing urban Inuit and one Inuk living with HIV. Our health coordinator represented Pauktuutit. The ten-member steering committee met for the first time in September 1998 to define the focus and basic format of the education materials, to determine an initial consultation process and to select an author for the documents.

The seven-month duration of the project meant that everyone involved in the project would have to work together and within explicit deadlines to meet the project goal. Fortunately, our project coordinator is a remarkably organized, highly motivated woman. Her skills, background in education, and cultural awareness provided the foundation necessary for the project to succeed. The steering committee was also able to identify an author with extensive HIV/AIDS community program experience, some Inuit cultural awareness and a connection with the north.

At their initial meeting the steering committee established the necessary criteria to guide the development of the educational materials. They identified topics to be included in the document, the language level and basic layout guidelines. Working together, under the direction of the steering committee, the coordinator and the author managed to produce one-hundred and fifty page draft document within the six week deadline necessary for project completion.

Community Consultation

The process of developing these educational materials taught us that technical expertise and cultural/community awareness are equally important in the fight against HIV/AIDS. "Recognizing knowledge" is a statement about expertise - expertise beyond an individual's technical knowledge or their ability to maneuver condoms in public. It is a combination of technical skill, experience, and cultural and regional awareness. It involves a deep knowledge of community standards and community needs. Developing information, which is both accessible and relevant, requires expertise only found that within the population the education program is designed to reach.

We learned that community consultation is a valuable tool because it is able to increase the effectiveness and the likelihood of ownership of the material and enhance distribution. The idea of community consultation is not a new one; however, it often only involves the "community" close to the end of the process, which provides a role more akin to evaluation - a sort of

report card of program design. Our approach differed somewhat in that we included the broader community early in the project, provided them with a role which respected and recognized the value of their expertise, and gave them both an individual and collective voice. We also provided alternate options for participation that included using community members to distribute the final document. The formation of the steering committee was the beginning of a comprehensive community consultation process which was somewhat cumbersome, time consuming and more costly, but based on the number of requests for additional documents, it appears to have been effective.

In addition to reviewing every draft, each member of the steering committee agreed to "recruit" as many as ten document reviewers. The only qualification the reviewers were expected to have was a willingness to read and comment on the documents. As a result, they came from various backgrounds, HIV/AIDS awareness and expertise levels.

Although predominantly Inuit, some of the recruited reviewers were non-Aboriginal. Each reviewer was provided a copy of the draft document and was asked to review and comment on the language, content, layout, and cultural appropriateness of each section. Reviewers were encouraged to share the information with other community members and to include any comments they felt were interesting or pertinent. Through this process, more than sixty community members reviewed the document in draft form. There were also several additional medical, legal, and governmental reviewers involved in the process.

The reviewers were given clear instructions about how to reference their comments and an extremely tight deadline for return of their responses. Communication with community reviewers was a function of each of the steering committee members. The coordinator worked closely with the steering committee members, the author and the "professional" reviewers, encouraging follow-up and confirming their progress with respect to the short deadlines.

Once the reviewed draft copies were returned to Pauktuutit, the coordinator began the onerous task of compiling the reviewers' comments page by page. The compilation of comments was reviewed, debated and decided upon by the steering committee, page by page, then passed to the author for review and an initial edit.

A second steering committee meeting was held in December when it became clear that a balance had to be struck between culture and essential content. Culturally, some of the issues addressed in the document were difficult for community members to deal with. Inuit are not particularly different than other ethnic groups in their reluctance to discuss sex and sexuality. Traditionally, these issues are viewed as very private issues, which are generally not discussed in mixed company, a particularly difficult

situation with respect to information about HIV/AIDS. That discomfort, however, had to be balanced with the rights of community members to know how to protect themselves. Decisions about finding a balance were made at this meeting

During the second steering committee meeting, discussions centered on the responsibility of health educators to provide information and on the need of the regional representatives to avoid offending the people they represent. One of the fears was if the information was too far beyond the community standard, the document would be rendered useless. Beyond sharing different points of view, the meeting provided an opportunity to listen to alternative ways of explaining or justifying to the community the need for the information. Collectively, the steering committee and the author were able to find a suitable balance and recognized how important on-going communication with the community would be to achieve the “buy in” necessary to make this document effective. In effect, we came to understand the broader scope of community consultation.

Armed with the direction provided at the second steering committee meeting, the author and the coordinator began the arduous task of editing the draft document for final review. Once the changes were made, the steering committee was provided with copies of the final draft document for approval.

The questions that remained seemed, at first, to be rudimentary. What font to use? What paper weight? What color/type of cover? In truth, we learned from previous experience that even these decisions would impact the effectiveness of the document and would require community input. The steering committee was provided with options and rationales and asked to decide on each component of the design. One of the best examples displaying the importance of design relates to the final layout of the publication. As it happens, an evaluation of another health related project was nearing completion as we faced decisions about the layout. One part of the evaluation focused on how well the document in question was being used by community health educators. It is a large, glossy, well-designed product complete with video and support information in one big binder. The evaluators’ initial finding was that the size alone was intimidating to the people intended to use it. Even some of the people involved in the design process confessed they had never even opened it because it was overwhelming.

When that information was provided to the steering committee of the HIV/AIDS project, they recognized the need to rethink the original layout idea of one large book and find ways to make this document more user friendly. The steering committee guided the process down to how

much information was on each page and what font they felt would be easiest to read.

The end result is a series of six smaller booklets, each addressing one HIV/AIDS issue written for Inuit communities. Each has a different colored, plain, heavy stock cover. Inuit artwork was used, and the series is dedicated to the memory of Leetia Geetah. Each of the six booklets cover a different HIV/AIDS issue in less than fifteen pages. Booklet one, *The Basics*, covers the facts and fiction about HIV and AIDS. Booklet two, *Your Immune System and Testing for HIV*, describes the immune system and the effect HIV has on it in simple language. Testing methods and the implication of being tested are also covered in booklet two. Booklet three, *HIV: The Risks*, is about risk behaviour at home and at work. Booklet four, *Protecting Yourself from HIV*, is a guide to safe sex, safer sex and universal precautions. Booklet five, *Women and HIV/AIDS*, is a booklet dealing with issues specifically for women from pregnancy and sexual assault to post exposure prophylaxis. Booklet six, *Sexually Transmitted Diseases and HIV*, describes other sexually transmitted diseases emphasizing the increased risk of HIV infection when a person has STD.

Community consultation did not stop there. Recognizing that the review process was overwhelming for some of the people who wanted to participate, we enlisted their talents as distributors of the booklets. Rather than shipping the completed booklets to a health centre, school or other community building, we shipped them to these “community distribution consultants”. Each of them used their community knowledge to identify the people and agencies most likely to share the information with other community members. Several of the community distribution consultants have since expressed an interest in becoming more involved in other HIV/AIDS projects.

Recommendations for Best Practices

From our perspective, the notion of identifying the content of this article or the following conclusions as “best practices for Aboriginal communities” is presumptuous at best. Inuit know all too well what it is like to be lumped in with others, more often due to difference from the majority rather than similarity to the minority group in question. The cultural difference between Inuit and other cultures, including other Aboriginal nations, are distinct. Out of respect for other aboriginal groups the following can only be termed food for thought. Something you might think about as tools which may be useful as you explore what your experts share with you.

Broad community representation and meaningful community consultation is at the forefront of our recommendation. Often the assumption is made that one member of a group is sufficient representation.

One Inuk cannot adequately represent the needs of all Inuit any more than one person living with HIV or AIDS can represent the varying needs of all people living with HIV or AIDS. Beyond culture, representation is about gender, age, regional difference and life experience. It involves the balance between modern life and traditional life.

Inclusion

The basis of community consultation is inclusion. Too often, the standards set for membership in a consultative group exclude many community members who have much to share. Although individuals may need to be recruited in order to ensure broad and inclusive representation, when the primary qualification for membership in a consultative group is interest in the topic in question, everyone benefits. More people feel they have a voice, and a broader range of perspectives is represented.

An additional benefit from this type of inclusion is increased community interest in the end product. To some degree, the members of the consultative group become project advertisers by emphasizing their involvement, by sharing what they have learned, and subsequently, by stimulating a broader base of community interest. Ultimately, a larger part of the population has a vested interest in the project.

Increasing Culturally-Based Resources

There are opportunities for community consultation, which are often overlooked because the tasks seem to be strictly administrative. People are often reluctant to participate in a project because they feel their talents do not apply. Recognizing that community consultation is about sharing information and not only gleaning it can help open up possibilities for participation to a larger part of the population. Providing opportunities for involvement in a project at a comfortable level for an individual increases options for capacity building. Too often people who are seen to have capacity are called upon to participate in too many projects. Individual capacity can be developed through project participation at varying levels. Over time, it provides us with an increase in culturally based resources.

Appreciation of Participants

It is important to recognize that the members of the consultative group are volunteers. Likely this project is not their first priority. The task may sound manageable when they agree to participate but may, in reality, be more than they bargained for. Clearly define your expectations and include a realistic indication of the time participation would require.

Whenever possible, allow people to share participation either by sharing a position or splitting a task.

Support of Participants

Keep in mind that participation may involve activities or processes, which are new to members of the consultant group. Consistent communication and support are necessary to ensure tasks are completed. It is important to clearly explain deadlines, including who sets the deadlines and the effect of non-completion on the overall project. Emphasizing the value of someone's contribution is generally motivating. Too often people think that their contribution is less important than others.

Our project involved sending large amounts of information to the consultant group for review. Experience taught us that clear directions were paramount. Be specific about what you need them to do. Remember that your involvement in the project may make things obvious to you, but it may not be clear to someone only working on a portion of the project. State the obvious. An example, from our experience with this project, involves referencing comments to page numbers. Reviewers were provided with instructions, which included "make sure to tell us the number of the page you are commenting on". Although this may seem somewhat condescending, it was, in fact, a necessary direction for reviewers who had never participated in a process like this one before.

Language

Never underestimate the power of words. Remember that for many people, and almost all Inuit, English is a second language. Often people with limited written language comprehension skills dislike reading and avoid it whenever possible. Focus on information, which is essential. Avoid information that could be termed "nice to know". Make messages clear and simple. Use language that is commonly used and easily understood. Keep sentences short.

In publications like this one, community standards are often reflected in the language that the consultant group chooses to use. In the case of our booklets, some language is paired -medical with vernacular - as a balance between what might be common to many and what is believed to be most appropriate. Community consultants were provided with options such as sperm, semen and cum and asked to choose. In the end, their choice reflected what would be tolerated and understood by the majority.

Context

Context is an important component of all education. It is the component that makes information valid, useful, and real. Context is about language, making references to circumstances or to events to which people can relate. It is also about allowing people to see a reflection of themselves in the material intended for their own education. Lack of context is at the root of why people often discount the HIV/AIDS messages. Our community consultants were asked to provide contextual references and to identify parts of the documents they felt distanced them or could distance others from the message. An Inuit artist was commissioned to provide the artwork for each of the booklets. It reflects the circumstances of community life with symbols and faces that are clearly Inuit.

Conclusion

Comprehensive community consultation prevented us from producing a document which was too large and possibly too technical to be effective. Without it we may have produced a document which was remarkably thorough and completely accurate but which no one would use. In the final analysis, comprehensive community consultation made the difference between providing HIV/AIDS education materials and providing, in essence, nothing.

The proof, for us, is in the enthusiasm we are encountering now as we embark on our next projects. Recently, we were asked to adapt a pamphlet on *Women, Sexual Assault and HIV*. Unlike our previous project, where we had to encourage participation, community members have approached us, asking to be involved in the review process.

We are continuing to develop educational materials for Inuit communities, in fact, booklet seven, *Living with HIV/AIDS*, a guide for Inuit living with HIV/AIDS and their caregivers, was released in February of this year. Several other booklets are planned and will be developed, as funding becomes available: one for teens, one for elders and parents, and one specifically for Inuit men.

On a much larger scale, we are beginning the process of developing the Canadian Inuit HIV/AIDS Network. The fact that the community was so intimately involved in the development of the booklets has provided the "buy in" necessary to make this Inuit specific networks a reality.

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