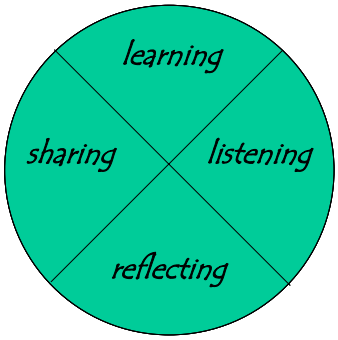
Reducing Tobacco Use Among Pregnant American Indian Women
Grant # RC 2002-0007

Final Report

"It's not an individual thing. It takes all of us"
Naida, American Indian Community Researcher



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Submitted to

Minnesota Partnership for Action Against Tobacco

by

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ABSTRACT

Introduction
To date, researchers have focused little attention on smoking rates among pregnant American Indian women. Our project is the first to analyze prevalence data and use action research to gain a deeper understanding of smoking among this population.

Method
The action research methodology consisted of a Community Research Team (CRT) of American Indian women, along with experienced Indian and non-Indian researchers known as Project Partners. We used a Medicine Wheel based research philosophy to emphasize the balance of four directions: learning, listening, reflecting and sharing. The CRT made decisions on the study and chose the methods of Photovoice and Talking Circles. Five community members trained in Photovoice took photographs and held reflective group discussions on their meaning for six weeks during the summer of 2003. They developed a calendar to disseminate their results to the community.

Results
Quantitative. Forty one percent of American Indian women reported smoking during their pregnancy from 1996-2000, with prevalence peaking at 45% in 2000. Smoking rates among all subgroups of American Indian women in Minnesota were higher than non-Indians.
Qualitative. The unconscious and continuous presence of commercial tobacco in the key spheres of influence affecting American Indian women – "Family" and "Indian Country" – is a major obstacle to cessation. We identified mixed messages coming from a "Changing Culture" – one that adapted to the prohibition of ceremonial use by incorporating tobacco into the everyday life and rituals of the community.

Conclusions
High smoking prevalence among pregnant American Indian women is a public health emergency that requires an emergency response. Resources must address the problem from multiple fronts, including the creative, indigenous development of programs, curricula, and interventions. We need to look beyond the medical model, reaching more deeply into the community and family to support positive changes.

INTRODUCTION

This successful project aimed to deepen our understanding of why and how American Indian women smoke during pregnancy, using an action research process to build community readiness to address this issue and critical inquiry to create intervention ideas to support pregnant women to reduce their commercial tobacco use and exposure to secondhand smoke.

These aims are important because no research had been conducted to investigate patterns of tobacco use among Minnesota's pregnant American Indian women or develop effective culturally-relevant programs to help them quit. Thus, this project conformed with two MPAAT priority funding areas: (1) "reduce tobacco (ab)use among communities of color" and (2) "reduce exposure to secondhand smoke."

The agreed upon plan was a 3-stage participatory action research project: The first phase "Learning" included compilation and review of secondary data, including underutilized data sets, and the development of a Community Research Team (CRT) which would develop the research design and make decisions on the methodology for the study. The second phase was called "Listening" which meant collaboration with community agencies to find participants and then use creative, culturally-appropriate data collection techniques, such as oral histories, Talking Circles and Photovoice sessions. The third phase of research was called "Reflection and Sharing" which meant that the CRT used techniques to analyze the data, and then disseminate the results through community networks, news media, and cultural events. The initial plan called for a feast/vision-retreat to bring Native and non-Native groups together to begin the next phase of action -- preparing an MPAAT intervention grant to nurture and support pregnant women to quit smoking and reduce exposure to secondhand smoke.

This project's reliance on a community-based participatory research model, along with development of culturally appropriate community interactions and research methods, all informed by cutting-edge social scientific and epidemiologic research, meant that this project enhanced both theory and practice of smoking cessation efforts. Few have endeavored to understand American Indian smoking rates, especially during pregnancy, from the smoker's perspective, cultural heritage, and socioeconomic location. Hardly anyone has endeavored to motivate and assist them to help themselves quit smoking through training and capacity building. Yet this is clearly the direction public health practice aimed at disadvantaged populations is moving. This project's contributions thus extend beyond any particular changes in American Indian smoking rates to provide advances in epidemiologic action research.

Research Questions

Because this project is a participatory action research project, the specific research questions were to be responsive to ideas and issues brought up by community researchers in an inductive approach. Nevertheless, the initial plans aimed to minimally answer the following broad research questions:

1) What statistical information is available on the smoking behavior of pregnant American Indian women and its effect on infant health in Minnesota?

Sub questions included:

a) How valid, reliable and available are the major data sources to answer this question, including Women, Infants, Children nutrition program (WIC), birth certificates and Pregnancy Risk Assessment Monitoring System (PRAMS)?

b) Does smoking behavior vary by independent variables such as age, geographic region or education level?

2) What do American Indian women themselves have to say about the issue of high rates of commercial tobacco product use during pregnancy?

Sub questions included:

a) Why do women smoke and what do cigarettes or commercial tobacco products mean to them?

b) What do women know and believe about the health effects of smoking during pregnancy and around infants in the home? What messages do they receive?

3) Do women try to quit smoking or cut down during pregnancy? If so, what methods do they use? What strategies and strengths do they draw on? Do family and friends participate? Are they motivated to quit during this time?

4) How can the community create a supportive environment and health care system for quitting and/or creating smoke-free homes for infants?

Finally, this project's team-oriented organizational model merits a note. The idea was to have a project driven mostly by leaders of the IPTF and American Indian community-members, with the consultation and guidance of "Project Partners", a team that included the co-PIs (Ms. Scott and Ms. Day), the Project Coordinator, (Jennifer Irving), a staff member from the Minnesota Department of Public Health (Ms. Cheryl Fogarty) and a research partner from the University of Minnesota (Dr. Michael Oakes). As it was untested, the success of this partnership was also at issue.

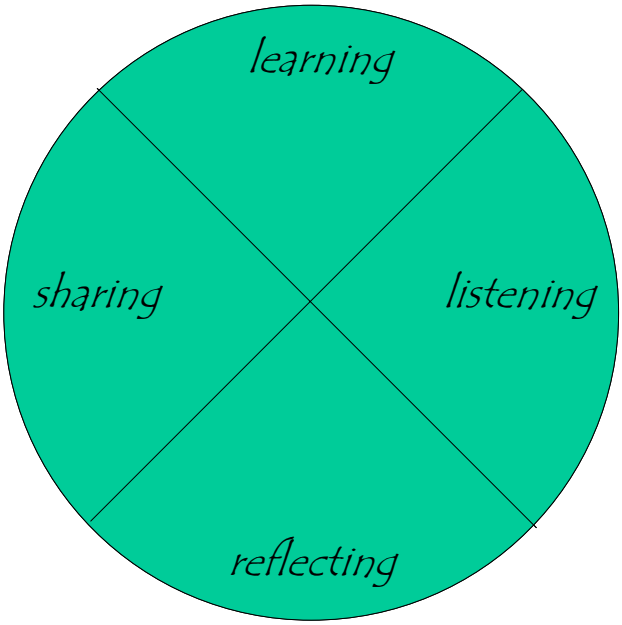
METHODS

Background

This study was an action research project seeking to generate a deeper understanding of cigarette smoking by American Indian pregnant women, and ways to address it. Rather than an experimental trial in the traditional medical-research sense, the study sought to use a research process that draws on indigenous ways of knowing[1] and allows American Indians to describe their view of the issue.[2] We developed a Medicine Wheel based model (Figure 1) to guide the action research process. The Medicine Wheel represents balance – the idea is that each aspect of the research is critical to the process and no one segment stands alone or is more privileged than another. One could use the term "respect" to share the underlying core principle that each person involved and each aspect of research would be approached with the same amount of effort. That

is, the same respectful attention is to be provided to each core component of listening, learning, reflecting and sharing.

Figure 1. Community Research Model based on Medicine Wheel Teachings



The study could also be described as community-based participatory action research (CBPR).[3] Such studies rely on mutually beneficial interactions between formally-trained researchers (often from universities or research institutes) and community members (who themselves have community knowledge or special skills). The idea is to work together to identify health-related problems and appropriate solutions for the benefit of the community itself, and not the scientific literature *per se*. Elimination of health disparities is central to the enterprise. Accordingly, this project sought to identify community members interested in smoking cessation, develop and build relationships with them, learn about both scientific and indigenous methods of research, enhance the skill capacities of both academic and community researchers, and work together toward not only more formal interventions, but deeper understanding of the place of tobacco in the lives of pregnant American Indian women.

Secondary Data Analysis

Early on, the Project Partners conducted a secondary (i.e., existing) data analysis of unexamined relationships between American Indian smoking, gender, socioeconomic status (SES), pregnancy, and infant mortality. Methodology for this component was conventional in the sense of identifying relevant data sets, evaluating their measures and completeness, and statistically analyzing such data. Dr. Michael Oakes shared his expertise in secondary data analyses, and worked with the MDH to format data for statistical processing. Once completed, the Partners worked to estimate proportions, rates, and other statistics germane to the questions at hand, and held discussions to clarify their meaning and interpret the data for community dissemination.

Community Review of Data and Choice of Methods

A core aspect of the project was to place as much decision-making as possible into the hands of trained community members. Thus, the initial step in our process was to develop a Community Research Team, or CRT. This process took longer than anticipated, and we developed an educational/outreach slide show using the secondary data analysis of birth certificate data to illustrate the problem of high smoking rates among Indian women in Minnesota (Attachment 1). The Project Coordinator spent several months conducting outreach sessions. These efforts resulted in a core CRT team of approximately 7 community women and 1 project partner from

the MN Department of Health (MDH) who participated at various stages throughout the life of the research project (and beyond). The CRT members include a majority of smokers and women with varied educational, social and income levels. Table 1 provides a detailed look at the membership of the CRT.

Table 1. Selected Characteristics of Community Research Team

Number	11 (7 very active and 4 sporadic)
Gender	11 female
Ethnicity	8 Ojibwe, 1 Lakota, 1 Dakota, 1 Taos Pueblo
Educational Level	-9th grade -Working on GED -GED, NAR/HHA(nursing or home health aide certified) -High School Diploma -2 some college -BA (current Graduate Student)
Smoking Status	-5 people who identified as "used to smoke but quit" (2 have since resumed) -3 people who are smokers (2 of which are trying to quit) -1 never smoked -2 unknown
Age	19, 24, 25, 25, 27, 30, 33, 34, 40, 50, 55
# of children	2, 5, 4, 3, 1, 2, 3, 1, 1, 2, 1 unknown
Smoking Status during Pregnancy	-7 admitted to smoking during at least one of their pregnancies (2 quit once they had knowledge of pregnancy) -1 never smoked -1 did not smoke during pregnancies (had quit by then) -2 unknown

The "Learning" phase of our research circle included grounding in indigenous and scientific principles and discussion of the results of the secondary data analyses, followed by a review of potential methods for community research. We held two meetings and created educational materials devoted exclusively to developing a research plan. The Co-PIs and Project Coordinator designed an interactive exercise to educate members of the CRT and assist them in choosing methods most appropriate and responsive for exploring this issue with American Indian women. The methods included standard techniques such as focus groups, in-depth interviews, observations, oral histories and smoking diaries, as well as cutting-edge research techniques including photography, creative arts, storytelling, Talking Circles and Photovoice (see Attachment 2).

After discussing and reflecting on the various techniques available for community research, the CRT decided to use Talking Circles and Photovoice as their community research methods. A description of each method follows:

> ***Talking Circles*** gather community members into a circle, initiate the circle through a purifying ceremony, and then provide space for sharing personal issues inspired by spiritual and emotional truth. The setting seeks to give members a safe and open forum to share their thoughts and feelings and to listen and be listened to in a sincere, uninterrupted manner. Often, they are conducted by a respected individual or elder. The Talking Circle, a traditional practice for many but not all American Indian tribes, has spread to become relatively common

throughout Indian country. They have been used quite successfully in substance abuse treatment. Because of the group aspect, they have been considered and used by some Indian and non-Indian researchers as similar to standard focus groups. However, our conception of Talking Circles was not a modified focus group; rather, each member would speak in turn beginning with the facilitator and going clockwise until all had spoken. After the initial pass, the circle is completed one more time so all that needs to be said is said. The way in which a talking circle is different from focus groups or group therapy is the gentleness, there is no confrontation and everything that is said is considered to be the truth. Thus, sometimes a sacred object is passed along the circle and held by each person as they speak to ensure that all that is said, is the truth. No active recording (tape or note) would take place during the Circle.

Photovoice is a research "process by which people can identify, represent, and enhance their community through a specific photographic technique" (www.photovoice.com). The method aims to (1) enable people to record and reflect their community's strengths and concerns, (2) promote critical dialogue and knowledge about important issues through discussion of photographs, and (3) reach policymakers. The process works by training community members on the use and ethics of photography, providing resources and topics for community researchers to photograph their community and analyzing the photographic data to develop an understanding of community issues along with potential solutions. An important conclusion of the project is to share the results with key community leaders and decision-makers.[4-5]

Recruitment of Community Researchers

The Project Coordinator interviewed and selected 5 Photovoice researchers (3 CRT members and 2 community-at-large members) and 5 Talking Circle researchers (4 CRT members and 1 community-at-large member). All of the Photovoice researchers were in their 20s, three had infants and/or toddlers, and one was male. Four of the Photovoice researchers were smokers and one was never smoker (in addition, the Project Coordinator was a core member of the Photovoice team, and was a never smoker). Of the Talking Circle facilitators, 2 were smokers, 2 were former smokers and 1 never smoked.

Training of Community Researchers

Project Coordinator Jennifer Irving and Co-PI Sheryl Scott developed a 2-day training on photography and Talking Circles. Project Partner Dr. Michael Oakes presented information on IRBs and informed consent (Attachment 3). The photography session included an overview of Photovoice along with the insights of an American Indian photographer. Co-PI Sharon Day conducted a Talking Circle and then shared insights with the group on how to conduct their own. Role-plays were used throughout the training as a learning technique, and we also spent several hours in the afternoon on day one using cameras and taking photographs at the local community center. Those photos were then developed overnight and integrated into the training on the second day. Our photographer consultant provided feedback and tips/techniques for improving photographs.

Study Implementation
We implemented the Photovoice process over the course of 2 months in the summer of 2003, during which we held weekly sessions (6 total with 2 weeks skipped for vacation.) As implemented in our study, community researchers were asked to take photographs of tobacco use in their surroundings, including their family and community. At the beginning of the project, we used general themes, such as "What makes you want to smoke cigarettes?" or "What messages do you get about tobacco?" No illegal, sensitive, or otherwise "odd" activity was photographed.

Data Analysis
1) Community Reflection
The Project Coordinator used the smoking-related photographs to help community researchers 'tell a story' about Native smoking, especially during pregnancy. Each week, community researchers would gather to hold a "reflection" meeting during which they reviewed and discussed 2 photographs chosen by each participant. During the Photovoice reflection meetings, the Project Coordinator used the SHOWeD method to guide discussions; other questions complimented this method based on the nature of the photo. This method has been used in previous Photovoice projects. The questions that make up the method are as follows:

What do you <u>S</u>ee here?
What is really <u>H</u>appening?
How does this relate to <u>O</u>ur project?
<u>W</u>hy does this exist?
What can we <u>D</u>o about it?

The Project Coordinator taped and then transcribed each session, and catalogued the pictures that were chosen and reviewed during each session. All other photos were either photocopied or digitized (burned) onto a CD (most were digitized.)

2) Researcher Reflection/Secondary Qualitative analysis
The second analysis method used more standard qualitative analysis methods, although the data being reviewed were transcripts of analyses sessions as well as photographs. Three members of the Project Partners (Project Coordinator Ms. Irving, Research Consultant Dr. Oakes and co-PI Ms. Scott) independently reviewed and analyzed the Photovoice session transcripts. All three used an inductive approach with thematic analysis. Ms. Scott conducted a more extensive analysis, which included a variation of the constant comparison method that began with listening to the audio tapes of the actual Photovoice sessions, followed by detailed review of the transcripts and review of the chosen photographs. An important note is that the focus of the analysis was a conceptual model that related to *action research*, rather than *grounded theory* generation.

The three Partners came together to review analyses, and found independent confirmation of major themes. Ms. Irving and Ms. Scott continued to discuss and refine wording of major themes. Ms. Scott then reviewed and tested the conceptual model by "sampling" the additional data: volumes of unchosen photographs. An additional step was to share the conceptual model with the CRT and test its "fit" with their experience and knowledge (Attachment 4).

RESULTS

Research Questions

1) What statistical information is available on the smoking behavior of pregnant American Indian women and its effect on infant health in Minnesota?

1a) How valid, reliable and available are data sources to answer this question?

We were able to determine several issues related to data sources:

- *Birth certificate data* are readily available and can serve as a data source on the smoking behavior or pregnant women in Minnesota. We believe that these data can be used as a surveillance mechanism, though unfortunately limited to self-report prevalence of mother's smoking at some time during pregnancy.

- *Women, Infants, Children nutrition program (WIC) data* were obtained from the CDC with the assistance of MDH staff members Maggie Donohue and Cheryl Fogarty. Dr. Oakes dealt with some early challenges in terms of data formatting and delivery. After receiving the data set, Ms. Scott prepared graphs and tables of the prevalence of smoking reported at various points in the pregnancy (before, initial visit, last 3 months, post-birth). We confirmed the birth certificate data in that we found much higher rates of smoking among American Indian women compared to other races. The WIC data was limited for two reasons. The first is that while we did find data that would be worth exploring (a drop of 50% in reported smoking from before pregnancy to the last 3rd month of pregnancy), we also found what seemed to be duplicated individuals. MDH personnel noted that we would need to do significant work with the dataset due to potential problems with multiples. Unfortunately, the timeline for this project did not allow for such quality control work on the dataset. (However, hand, secondary data analyses using WIC data may be a fruitful endeavor to pursue for a future project that could explore quitting behavior during pregnancy.) Secondly, we were disappointed to find that the federal WIC program does not require states to collect data on the two secondhand smoke questions (whether anyone in the household smokes during pregnancy or postpartum). Minnesota does not currently collect them and according to the MDH WIC coordinator, the state has no plans to do so in the future. The questions would have been helpful in assessing the extent of secondhand smoke exposure in American Indian low-income households with infants.

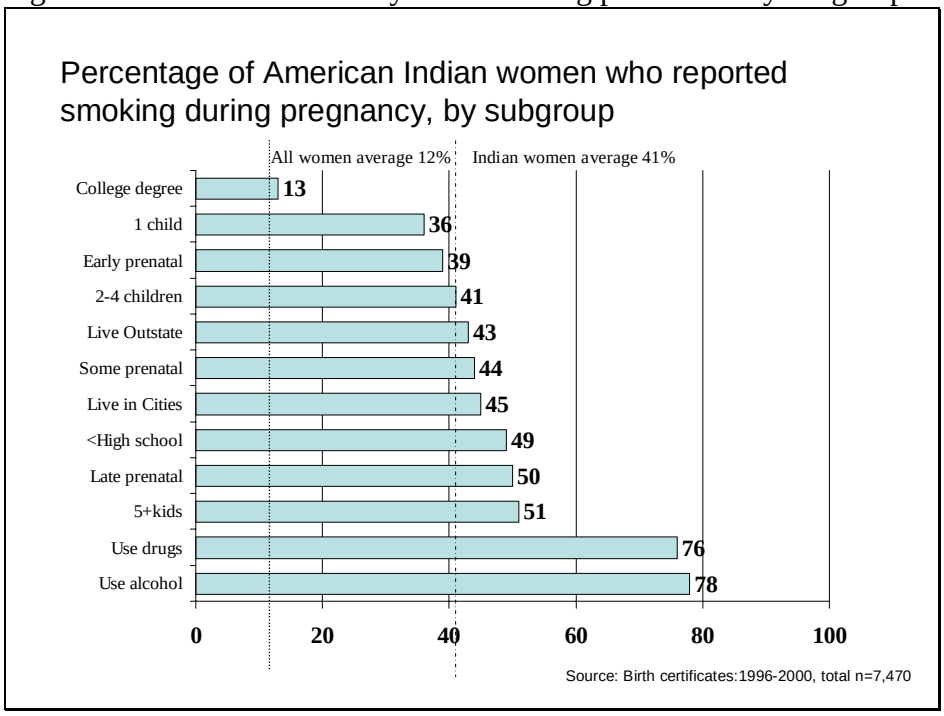
- *Pregnancy Risk Assessment Monitoring System (PRAMS) data* were not available for our study, as Minnesota did not participate in the PRAMS program until 2001. In the future, these data will be an excellent resource, as they include variables on secondhand smoke and socioeconomic status. Other states, notably North Carolina, have used the data to better understand disparities among women in social and racial groups.

1b) Does smoking behavior vary by independent variables such as age, geographic region or education level?

We combined 5 years of data (1996-2000) in order to have a sufficient population for sub setting the data. Our analysis of the birth certificate did show only minor variation by independent

variable (Figure 1). In all cases, American Indian women smoked at 2-3 times higher rates than their counterparts in Minnesota. The overall rate for MN women was 12%, for Caucasian women 12% and for American Indian women 41%. Our finding of such high rates of cigarette use among American Indian women across all walks of life will be critical information to share with tribal leaders, urban American Indian communities and public health professionals who have the ability to address these issues. Unfortunately, the lack of variation led to few clues as to "protective" effects or variables to further explore in future research. (The WIC data may be of use to help understand quitting or cutting down patterns in low-income American Indian women, as our preliminary analyses of those data did show some quitting during the course of the pregnancy and post-pregnancy.)

Figure 2. Birth certificate analysis of smoking prevalence by subgroup

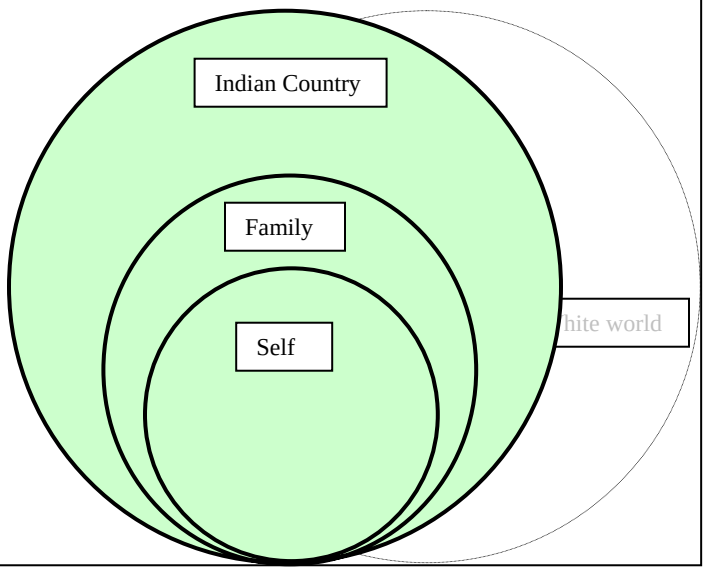


In summary, a college degree showed the most protective effective, however, this was less than 300 women or 4% of Indian birth certificates during this time. American Indian women living in rural and urban areas showed high prevalence, although women who lived in the suburban areas surrounding Minneapolis and St. Paul had lower prevalence (25%) but again, this was a very small number of women (664). We found no difference based on age. The reported use of alcohol or drugs was very highly correlated with reported cigarette use. The full table showing variables and smoking rates is available upon request.

2) What do American Indian women themselves have to say about the issue of high rates of commercial tobacco product use during pregnancy?

2a) Why do women smoke and what do cigarettes or commercial tobacco products mean to them?

Figure 3. Spheres of Influence



To answer 2a), we will summarize insights from the Photovoice research. A core concept emerged from our research: the focus of life, or sphere of influence, is about being in and around American Indians. *What is most important is what happens in "Indian country" and in the family.* No one explicitly stated "What happens in the non-Indian (white world) doesn't affect me"; in fact, some themes did emerge related to issues and actions in the non-Indian community - they were simply less frequent and intense than images in the Indian and family settings. Figure 2 graphically illustrates how these elements played out in the data.

Given our action research theoretical underpinning, we found the following four overarching organizational categories in the data: 1) *Obstacles to Overcome, 2) Strengths to Draw On, 3) Mixed Feelings/Mixed Messages* and 4) *Actions to Take*. Each of these categories played out somewhat differently depending on the sphere of influence and thus, we found it helpful to organize the findings in a matrix structure as shown in Table 2. The spheres of influence are listed vertically, while the four overarching categories run horizontally. For example, we found unique Obstacles to Overcome in Indian Country compared to Family or Self, although some overlap exists. For each of the themes within the cells, we have photographs and quotes to illustrate the meaning. While we cannot include all of the photographs in this report, examples of many of the matrix themes can be found in the results slide show (Attachment 4.)

Table 2. Photovoice Matrix

	Obstacles to Overcome	Strengths to Draw on	Mixed Feelings/Mixed Messages	Actions to Take
Non-Indian World	***Smoking in public places for low-income*** (bus stops, neighborhood diners) ***Advertising*** 1) Misleading items such as "additive free" (which looks like addictive free), "natural" or small size of warnings 2) Stereotypes such as "natural spirit" or being exotic (Egyptians)	***Non-smoking is a Priority for Community Agencies*** (Professional quality signs; cleaned up & better placed ashtrays) ***Educational campaigns*** (Images of brochures & posters)		***Lobbying/Protest for change*** 1) Lobby to place counter-ad with ads 2) Make larger labels with straight up messages 3) Letter writing group ***Create incentives to NOT smoke*** (create campaigns with incentives not to smoke)
The Changing Culture				
Indian Country	***Embedded Cultural Cues*** ***1) "Might as well smoke, everyone around me does…"*** 1. Social smoking -Many images of people smoking at powwows, picnics 2. Images of full ashtrays and butts on the ground ***2) Socialized activity part of cultural initiation and interaction*** 1. Lighting up together (drum group) 2. Smoking while doing crafts, beading, "sitting with the aunties", etc. 3. "Can't say no" don't want to say anything regarding other's behavior ***Addiction*** (Cigarettes smoked down to the nub; using the stove to light up) ***"Buy One, Get One Free" Advertising*** (lots of ads; ads for special deals) ***Lack of opportunities*** (Discussion of boredom with no jobs or places to go that are smoke-free) ***Lack of experiencing healing/tradition*** (trapped in museum) ***"They don't see anything wrong"*** (Lack of beliefs about effects, long-term don't see here and now effects, plus some kids get asthma, some don't)	***Value of Protecting Future Generations*** (Images of children; posters) ***Community Tradition*** 1) Images of powwow; fancy dancing 2) ceremonies (smudge bowl) ***Generosity & sharing*** ("don't be stingy with your tobacco", story of drum group and powwow hanging out, image of powwow parking lot) ***Surviving and Resisting Loss*** (not wanting early deaths, to lose elders, Image "In Loving Remembrance") ***Culturally specific Education*** (Images of posters)	***Images of smoking and non-smoking*** 1) No smoking signs besides piles of cigarette butts smoked to the nub 2) No smoking signs placed too high to see 3) No smoking posters compared to size & quantity of ads for "cheap smokes" ***Babies everywhere!*** Integral part of social life (not set apart) but then also being exposed to smoke ***Elders*** Elder as source of strength and knowledge but also as source of lots of secondhand smoke with fear of questioning their behavior ***"It's getting mixed up" Sacred & Addictive Use*** Tobacco is supposed to be sacred & shared as prayer but given out as packs of cigarettes to drum groups. ***"They really don't care"*** Most know effects but don't change their behavior	***Counter messages*** *1) Create new Posters* -cigarette butts as both environmental toxic and child danger ("Don't gamble" concept) -JerrBear "little eyes are watching" -"reasons not to smoke" pictures of children, create own signs -woman using stove to light "Is this you?" - Native men, not just women - tribal specific *2) Place posters in unexpected places* -- bars, Rainbow foods, home, not just prevention groups ***Personal Interaction*** "make her feel guilty as hell" or opposite "were you aware that…" and let you know you support them, suggest ways to quit ***Share widely/educate on tradition*** (give baskets for sacred things including tobacco, and share how to use them) **Take Pride in Community** *Use professional signs* *Clear ashtrays often* and away from the door *Pick up* litter and trash

	Obstacles to Overcome	Strengths to Draw on	Mixed Feelings/Mixed Messages	Actions to Take
Family	***Home as Danger Zone*** *1) Extended family & Partners* (Elders are smoking, "set in their ways", photos of 2 ashtrays and remote, ashtray in bedroom) *2) Socialized activity* (Image of sitting on the deck ashtray with toy in background, story of doing crafts with aunties) 3) Passes down in family ***Smoky Parties and Picnics*** (Images of picnic with smoking and outdoor party with smoking)	***Home as Place of Safety*** (make rules against smoking for my children; image of home-made sign) ***Home as Place of Tradition*** 1) Sage drying 2) personal altar	***Home as both sanctuary from and source of dangerous second hand smoke*** (What do you do if your parents or extended family smoke?)	***Creating your safe place*** (individuals create their own signs with children's images) ***Promote Teamwork*** (develop quitting teams with family, partners, friends)
Self	***Pleasurable addiction:*** (Image enjoying a cigarette – 2 images) ***Strong Addiction:*** Seeing cigarettes everywhere ("makes me want to grab a butt and smoke") ***Feeling trapped*** (Dreary days, no way to escape children) ***Habit*** (lighting up while on the phone Image of "triangle of addiction") ***Coping with Stress & Anger***	***Being around children*** (Images of children in the home) ***Being together in smoke-free places, home, apartments and jobs*** (Images of no smoking signs at buildings)	***Our Children*** both as causes of stress and causes of not smoking ***Perception*** A shady spot with a park bench seen as a cool place to relax in fresh air and a great place to have a smoke ***Do What I Say, Not What I Show You*** Strong desire for children to not smoke but can't stop themselves so continue to model the behavior to their kids (Doula smoking in the parking lot – ashamed)	***Positive, not negative, messages*** (sick of hearing what we can't do) ***Be supportive*** Talk to women, be supportive role models and let them know that it can be done "recovery is possible" ***Use tradition*** Learn about healing (smudge to start the process of quitting)

Several categories and themes in the data shed light on why women smoke and the meaning attached to it.

The Changing Culture

An important finding that cuts across categories is that in Indian communities in Minnesota, cigarette smoking has become embedded into the *culture* of the community, in unconscious but understandable ways that represent strengths, not just a simplistic notion of "addiction" (Table 2, row 2). We termed this The Changing Culture where "lighting up together" is an important social bonding ritual, that affirms strengths of the culture (sharing, generosity, group cooperation). We found elements of the Changing Culture within spheres of influence spanning the Self, Family and Indian Country, including many images of people smoking at powwows and social gatherings, as well as discussing issues in the reflection session transcripts. Stories included growing up doing crafts "sitting with the aunties" smoking cigarettes; being a part of a drum group where one lights up, then the others follow; "smoke breaks" being an important avenue for socializing; and cigarette cartons being given out as offering of tobacco. One individual shared a strong teaching, "That's what my elders taught me. Never be stingy with

tobacco." - sharing tobacco being a component of the Indian spirit of generosity. Two aspects of the Changing Culture, described in detail below, are especially potent.

1) *"Might as well smoke, everyone around me does…"*
The fact that is cigarette smoking is so pervasive is one of the most critical "Obstacles to Overcome", especially within the realm of Indian Country, but also within the Family. We saw numerous pictures of smoking (individuals smoking at picnics, house parties, bus stops) and the results of smoking (filled ashtrays, butts on the ground). We also saw photos that depicted the "readiness" for and ubiquitous aspect of smoking, e.g., 2 ashtrays (they each have their own) next to the remote and TV guide, full ashtrays next to the baby bag in the bedroom. One community researcher simply stated "people do stuff while they're smoking". Another shared a photo of a pack of cigarettes besides a phone and a can of soda and stated "Three major things you need in life. Nicotine, caffeine and a phone!" An interesting exchange occurred during the reflection section talking about a photograph of a birthday party on someone's back porch:

L: A lot of people sitting around smoking. Smoking cigarettes.
N: Chilling. Socializing.
Je: Do you think that's common for Indian people? Or do you think everybody does that? Like just sits around talking, smoking. Is that common for Indian people? Or is that common for just about everybody you think?
L: They're not just only smoking. I think a lot of people do that. Sit around, drink and socialize. And they end up all smoking. When you're drinking you're more likely to smoke. Because you, I don't know.
N: Or just smoking, having some coffee, talking too. You know, just talking. Catching up on the news.
….
Je: Yeah. I remember being little. Everybody would come over to the house; they'd sit around the kitchen table. They'd start talking and then they would, it's like they would have to smoke.
N: Yeah.
Je: It was just like normal. Then my mom when she was by herself, didn't smoke that much. Not like…I don't know. Ok, how does this relate to our project?
J: Social drinking. Or, I mean, social, um, um.
L: Social smoking. Is that what you were trying to say J?
J: Yeah.
Je: What do we want to say about social smoking? Because this is the perfect time to address it, I think.
T: It's like a chain reaction. A couple people who smoke, sitting around, start laughing and b.s'ing. Pretty soon, everybody else, too. Sitting around too, pulling our their…
N: "Gotta smoke, gotta smoke?"
T: "Gotta smoke? Let me borrow a cigarette from you."
N: "Gotta make a smoke run."
Je: So how do we help people then? That's pretty tough I think.

N: Well, everybody looks at me weird. 'You don't smoke?' I'm the outsider, because I don't smoke.
Je: Um, huh.
N: 'You don't smoke? What's a matter with you?' You know.
J: Do they all smoke in that picture or no?
N: Most. Most of 'em.
T: Most of 'em. There's only like three people in that picture that don't smoke.

2) *"It's getting mixed up"*
Despite efforts to educate and promote the "sacred use" of tobacco (common to many of the Northern tribes), we saw photos and heard stories of ways in which traditional and commercial tobacco became commingled, leading to confusion around the meaning and use of cigarettes. A direct example included the story of the sharing of cigarettes as tobacco offerings to drum groups during powwows and as offerings during funerals.

N: Because I don't think some people even know that…
Je: Know the traditional use.
N: Yeah. Know that traditional uses.
Je: Ok.
N: Oh, I was going to make the point, too. That they hand out cigarettes.
T: Yeah, at the pow-wow.
N: At the pow-wow.
Je: At the pow-wow. To like singers or to everybody?
N: To the singers.
T: They come by with like, they offer each drum group tobacco, but they give them out in packs.
N: In the form of packs.
T: So they come by and drop, like, four packs a piece. Give you some Halls and some water.
Je: So on one hand they give you stuff to protect your voice. But yet they give you…
M: But can't they use the cigarettes to put it by a tree? Couldn't that be the purpose, too?
T: Some pow-wows are different, some pow-wows hand out pouches of tobacco, some hand out packs, some of them have a big ol' birch bark basket full of all kinds of cigarettes.
Je: Oh, really.
T: Put it out in the middle, so if you need a cigarette go out there and look around. Or if you got to put tobacco out.
N: See that's where we're getting the commercial use and the traditional use. It's getting mixed up.
M: Oh yeah, especially at funerals. My um, my cousin, um, had a traditional funeral. They had a big thing of cigarettes in a birch bark thing, a basket. And then, people didn't smoke, and they didn't really want to take that cigarette. But they just give it to them anyways and said it was disrespectful if you don't smoke.

So, I mean, that had to at least, not smoke it all, but just puff it. Or let it burn. Or just take it out and put it by a tree.

Je: So, it's like, somewhere we got mixed up. Like about, our traditional use and then incorporating cigarettes.

N: Everyday, modern life now they're using commercial tobacco in the form of cigarettes instead of using the tobacco pouches.

Interestingly, the discussion did not include an important historical reason that tobacco has become so much a part of the Changing Culture – the outlawing of Indian ceremonies. Traditional indigenous spiritual ceremonies were forbidden expressly by Federal Law from 1890- 1978. Since tobacco was one of the first medicines given to native people to send their prayers to the creator, smoking commercial tobacco was one way to prevent arrest by federal or tribal police. As Co-PI Sharon Day notes, these practices are a unique form of cultural survival from a time when Indians had to find creative ways to continue their beliefs under the hostile and watchful eye of the United States government.

Another related issue alluded to above, that came through at both the Indian Country and Self levels, was that many community members lack direct experience with healing traditions. The photographs of traditional use of tobacco taken by Community Researchers came from two places: a museum exhibit and educational posters put up in community centers. On the other hand, no one shared photos or discussed participating in community ceremonies with tobacco used in a traditional manner. However, this may be at least in part due to the fact that photography and recording are often forbidden at ceremonies -this may be why none were shown or even taken. The museum and educational posters may have been "safe" cultural images to photograph. Another reason could be limited access to ceremonies, many community members have to travel outside the city limits to attend various ceremonies and travel for this group of participants was limited and often difficult.

During meeting #3, when the photo of the museum was being discussed, the Project Coordinator asked about its importance:

N: …trying to teach women the difference between ceremonial usage and everyday usage….

….

N: That's how we used to do that back in the day. Well, we still do.

Ja: That's how we still do, but most people they…

L: But they still are misusing it. Even though, they are still going to ceremonial things and then after they leave there, they still are misusing the tobacco.

Later, in meeting #4, the Project Coordinator asked about the meaning of traditional tobacco:

Je: When I say the word 'tobacco' what do you think of? What's your first image?

Multiple: Cigarettes.

Je: Ok. Now if I say 'traditional tobacco' what's your first image?
J: Passing it to an elder to do like, a ceremony for….
Je: What kinda of tobacco, though?
M: Tobacco in a bag.
L: In a bag.
Je: Like a, like a, what kind of bag?
L: That Prince Albert. That's the kind of, when I get an image of 'traditional tobacco' or anything. I think of Prince Albert in the red bag.
M: I think of American Spirit. (Laugh).

Another issue that came up was a very prevalent "mixed message" of elders smoking cigarettes in front of children. "I see an elder misusing our tobacco"…but "elders should be teaching the young ones…elders are the ones that should be wise". While there was a discussion of wanting to help elders quit, more often stories had an underlying sense of indignation that those elders who adamantly stuck to their cigarette smoking indoors and around children were not playing their part but in fact, contributing to the ongoing problem.

2b) What do women know and believe about the health effects of smoking during pregnancy and around infants in the home? What messages do they receive?

Beliefs. We have little "direct" data on what women believe about the health effects smoking during pregnancy -- this did not come up often in reflection sessions. Most of the photos that were taken showed educational posters, including several that elicited discussion specifically related to pregnancy and health effects. It was hard to ascertain if those posters would have been much noticed if they weren't part of the scope of this project.

However, during discussions, certain facts would be thrown out regarding health problems caused by smoking. It seems that children's health, the possibility of SIDS in particular, is a very real fear for moms. At the same time, however, there is a sense that women (and family members) can get around the danger because they see the children of their friends and family who smoke and "they don't have problems". Community researchers provided an interesting exchange on how community members hold this fatalistic frame of thinking about smoking because the effects are not immediate:

T: And then Mr. [Nickname of child] there, that one I'm holding. His Ma smoked too, while she was pregnant with him. That's why I picked that one out, both of them had smoking mothers while they were pregnant with them.
Je: Ok. So how would you relate that back to our project?
T: That, little [Nickname], he turned out pretty good, because he's a pretty good grassdancer, now. He don't have no problems. But this little guy here does.
Je: Uh, huh.
T: He has to be put on a nebulizer, once and awhile.
N: Oh, you're other nephew too, huh?
T: Yeah. [Nickname] he's got asthma.

N: His Mom smoked with him, too. And they have, um, breathing problems, asthma attacks, and not so good. Just to show everybody that it does affect your kids when they get older. Or when they're young. They're going to have health problems.
T: They're going to have health problems. Kids are having asthma attacks and got to be put on nebulizers. And can't run around too much because they'll start…
N: They can't play as much. Can't be as active.
T: …yup, as active. Or else, they'll start having an asthma attack.
N: And second hand smoke is just as bad as if, you know, so.
….
Je: Do you think that contributed to like, to the other family smoking as well? Like, seeing one child turn out ok. You know, like the older one, you said the older is fine. He didn't really have too many other problems.
T: Yup. He don't have no problems at all right there. Not like the other little guys do. I don't know, because they were from different sides of the family.
N: I guess it just depends.
T: They're all from Cass Lake. They must know each other.
N: But why would he be alright and the other one is….
T: I don't know why one would be alright and one wouldn't. Maybe I was thinking too. He's got an older brother, named [Nickname]. And he's alright and she smoked with him.
Je: Uh, huh.
T: And she smoked with him (the baby) and he's got problems, got health problems.
Je: Do you think, um, do you think people realize how, how smoking effects their health? Their own health, not their baby's or. 'Cause I know we're talking about pregnant women and stuff like that. But do you think people really think about, I mean do you think they really know or understand how it effects themselves?
J: They probably know. My grandma and grandpa they know. But they…
L: I think they do.
J: ...they don't really care.
L: Yeah.
N: Because it's not immediately putting you in the hospital or something. Or it's…
L: It's long-term.
N: …not an immediate crisis or something.
Je: Um, huh.
L: It's long-term, so I think they don't really care. Because it's not right now, the effects of it, it's not right then and there.
N: Yeah.
J: And when you're smoking a cigarette, you don't sit there and think, 'my lungs are getting black right now'. Or, whatever.
Je: Right. Do you think people think they're going to quit? So that's why they just smoke now. You know what I mean?

T: They think they'll quit when they get older.
Je: Yeah. Do you think that's what they figure? They think, 'well I'm young, I'm this and that, I have time to quit, so I'll just quit when I'm older."
L: Some, yeah.
N: Sure, some people. Yeah.
T: That's what I said.
Je: I mean because, I guess I'm just trying to figure out. Like, if people know something is harmful to their health, even though they know it's going to be in the future, it's not right now. Or do they figure, 'well I'm just going to get old and sickly anyway, so it don't matter.'
N: 'I'm going to die anyway.'
T: Yeah. 'I'm going to die anyway.'

Messages. The most notable finding in this area was actually a non-finding –the complete absence of health care or social service providers as a source of messages on risks of smoking or benefits of quitting. No one mentioned receiving information, special messages or encouragement from a health professional, even though several of these women were pregnant, had infants and/or gave birth during the study and had frequent appointments with providers.

We saw numerous photos of educational posters, mainly found on the walls of the social service agencies visited by these community researchers, some Indian specific, some not, some pregnancy related and some general. There was also discussion and photos of the preponderance of advertising for "low cost smokes" in the neighborhoods where these community researchers lived or worked. One of the women mentioned that her partner gave her strong messages about her smoking behavior during pregnancy. During a discussion of "social smoking" at a birthday party picnic, the Project Coordinator brought up what would happen if there was smoking around a pregnant woman:

T: [This] woman is pregnant. Standing right behind him. And she was.
N: I wanted to say something to her.
Je: Really? Do people, that's what I was going to say, do people change? Like if, you're a smoke and you get pregnant, do people say stuff to you? Like your friends and stuff. Or not really. Or do people say well, it's not my business and it's not my kid. How do you think people react? Like if one of them girls was nine months pregnant and she lit up…
T: Everybody would put their two cents in there.
Je: You think they would?
N: But then they're all smoking around her? So, they can try to say something, but then they'll smoke around her. That's pretty much going…
M: Did you see that there's a baby bottle right there?
….
N: I was going to say something to her, too. But I didn't.
T: But she hid by [name]… She was standing right behind him, like right here. She's like hiding in the background. We seen her sitting on the couch, too. She just hid by him.

J: Because I'm just thinking, too. Like think of your friends, or the people you hang around with, or stuff like that—if one of them came in nine months pregnant and lit up and smoked. Would your friends say something to them?
J: No.
L: I mean like it's not their business. For most people.
Je: So nobody. You don't think they would?
N: Just try to mind their business. That's kinda how it is.
M: Oh. I've never thought about it.
Je: How come you don't think people say stuff? Do you think they say stuff behind their back?
L: Yeah.
J: Yeah.
L: Look at her smoking. She's all pregnant.
M: Don't hang around with her, ick.
Je: So do you think we're just too polite, like as people?
M: Like I really don't think about it. 'Cause they don't really stress on smoking cigarettes too much.
Je: Um huh.
J: I mean if I knew somebody than I would. But if I…
N: Yeah. See if I didn't know her that well, but if I was all tight with her than…
J: …didn't know her, than I wouldn't say nothing because it's none of my business.
Je: So then, well then, what would you say?
N: If it was like a best friend, than I would tell her. But if it's somebody I don't know very well or anything, than I don't think I would start with that.
J: Like if Marilyn was like pregnant and smoking. I would say something like, Please don't smoke around me while you're pregnant." She would do that for me.
Je: What would you say?
J: I would tell her not too smoke because of the baby and if she's going to smoke don't so it around me.
Je: What if she won't?
T: My brother's first four kids, he had, she was trying to smoke right when she got pregnant.
Je: Um huh.
T: And we made her feel guilty, guilty as hell. Just saying all kinds of stuff, "hey that's my niece in there, she's going to have lung problems when she gets older."
Je: Did she quit or no?
T: Yup. We kept saying stuff, making her feel so guilty, she quit.
N: Kept nagging on her.
T: She didn't smoke for like five years after that.
Je: Scared her. Scared her for five years.

3) Do women try to quit smoking or cut down during pregnancy? If so, what methods do they use? What strategies and strengths do they draw on? Do family and friends participate? Are they motivated to quit during this time?

The WIC data showed preliminary (but qualified –see footnote[1]) evidence of quitting behavior during pregnancy: in 2001, 65% reported smoking before pregnancy, 46% reported smoking at initial WIC visit, 32% reported smoking during last trimester and 48% reported smoking after birth.

We had very little discussion of strategies or successes with quitting or cutting down during pregnancy. There did seem to be an implicit understanding that a woman should quit during her pregnancy, but most discussions revolved around the difficulties that this presented. The Photovoice reflection sessions revealed a theme of women being "left out" or "isolated" from socializing during pregnancy because they couldn't socialize through smoking. However, this did not turn into a discussion of strategy to get partners and families to quit or to change the environment. In fact, one person said "You can't, can't really change it, because…I mean it's just society". Another woman whose partner smoked stated "I mean if I was still pregnant, ya know, I would still want to smoke a cigarette cause he's smoking a cigarette too." While never directly addressed, some remarks implied that women actually wanted to smoke more or did smoke more during pregnancy, for a variety of factors such as stress or boredom. One CRT member (not a Photovoice participant), shared that her current pregnancy made her feel nauseous when she smoked, but instead of being motivated to quit, she switched to smokeless (and pulled out the pouch to show us.)

On the other hand, the issue of protecting children was paramount as a motivation for not smoking around children. One of the community researchers photographed a hand-made "no smoking around my children" sign. Another shared pictures of her two children and said "This is a house where there is no smoking…cause they're babies and I don't want no smoking around 'em and I love 'me. And I don't want them growing up with, like, cancer, anything or lung –I don't know what that's called."

During the Photovoice process, we realized that the community research was not answering this particular question, so we decided to have our Talking Circles focus on this issue. However, we also had logistics and conceptual problems with Talking Circles. These will be discussed in more detail under our discussion of the section of Results - Community Based Participatory Process.

In summary, we answered these questions only partially. Women may be motivated to quit but may feel pulled to continue smoking for biological or psychological reasons. Family and friends may be more of a hindrance than help because of high smoking prevalence and lack of role modeling for quitting– plus, those that are trying to "help" may use coercive and guilt inducing strategies.

Another reason that these questions were difficult to answer may be that among our community researchers within their core spheres of influence (Self, Family, Indian Country); they have few

[1] These data are simple frequencies and have not been matched over time, nor processed for duplicates.

examples of "successful quitting strategies". We know that they have Strengths to Draw On but are seemingly overwhelmed by the Obstacles to Overcome and the Mixed Feelings/Mixed Messages.

4) How can the community create a supportive environment and health care system for quitting or creating smoke-free homes for infants?

The community researchers, with their Photovoice process, gave us with much food for thought as well as specific ideas for Action to Take (see Column 4 on Table 2). A message that came through very clear, (though interestingly in itself more indirect than direct), was that an individual approach would fail in the face of the overwhelming amount of smoking and enticements to smoke (e.g., advertisements, ashtrays, social smoking, butt litter, etc.) documented by community researchers in their major spheres of influence (Indian Country and Family).

To summarize the Photovoice reflection session results on Actions to Take:

- It will take teamwork.
- It will take the community as a whole.
- It will take a sustained campaign to counter the preponderance of cigarette images and provide alternatives to cigarettes (incentive campaigns NOT to smoke).
- We must provide opportunities for direct experience with healthy ceremonies and traditions, not just posters and educational messages.
- Create messages and creatively disseminate them (at "unexpected" places), some suggestions:
  - "Don't gamble – it could happen to you."
  - "Little eyes are watching you…"
  - "My reasons not to smoke" (families "create their own" signs of their children)
  - "Is this you?" (pictures of addiction - desperation lighting off of stove)
  - "Toxic cigarettes" both environmental pollution and child danger
- Because of the absence of a discussion of health providers, we must question the usual role given the health provider as the core of the cessation/community change process.

We will also need to develop strategies for approaching and educating pregnant women in the community. An exchange during a Photovoice session addressed this:

> Je: Ok, so, how do we help? Back to the main questions, what do we say then? How do we approach women that are pregnant? Or people in this situation? Like if you guys could do it over again? It's kinda hard, huh?
> N: Yeah. Because you don't want to come off, like, you're all…
> Je: You're all that.
> J: Unless you say it like, "Can I ask you a question?" or "I just want to something…" like that.
> Je: Um huh.
> J: Be real polite to 'em.
> Je: Do you think it would help if like…what if we were to ask, like, I mean, not we. But you know, like if somebody were to come up with stuff, but. I don't

know, I just wanted to you know. Do you think it would be rude or ruder, if we were to ask, "Why do you keep smoking, if you know you're pregnant?"
M: Yeah.
Je: Or would that sound too snotty?
M: No, because it makes them, you'll shame them. I mean that's not the whole point is to shame the person.
Je: Right, that's what I'm saying.
M: you just want to let them know…
N: …this is what they're doing.
M: …this is what could happen or you know. "are you aware that this is what happens when you smoke?" I mean the whole…I wouldn't want to be shamed about smoking. I would just want to be told. You know? I don't want to be…
Je: Right.
N: Maybe that's all they need to. Is somebody to point them in the right direction or educate them too. A little push in that direction, that nobody else might give it to them.
Je: So maybe instead of asking like, 'why do you keep smoking' or something, it's like, "Are you thinking about smoking now that you're pregnant?" or something, like encouraging, instead of.
M: That sounds concerning and that's educating at the same time.
N: More supportive.
M: Yeah. You're not just nagging at them.
N: Like, "Why are you doing that?"
Je: Right. It just like, how do we help? What do we say to them then? How do we prepare?
N: In a good way.
Je: Yeah. Nobody like to be talked down too. How de we point them in the right way?
M: "What? That is my business to be smoking! What?"
Je: Because, like you said, it is addictive. You know and that's a big thing, it's like really addictive. It's as hard as somebody on crack, and there's probably more help for people on crack to get help. You now what I'm saying to quit smoking. I mean to quit smoking crack that it is to quit smoking cigarettes.
M: Yeah, but medical assistance, some medical programs help people who want to quit.
L: Like Blue Cross.
M: Like U Care. Will give incens…incenses.
N: Incentives.
M: …incentives. That if you quit smoking or if you at least try. Or they give you the patch, or the gum, you know.

Results of the Community Based Participatory Research Process
Implementing the Research Model
Our action research process included 2 core culturally-relevant components: 1) a culturally-based Medicine Wheel-based model of "Learning, Listening, Reflection & Sharing" and 2) a community research team (CRT) in a decision-making capacity, with guidance from a seasoned group of applied researchers and health professionals called the Project Partners. The Medicine Wheel model helped to keep make the process of research more accessible to community members, and to allow indigenous "ways of knowing" to be acknowledged as akin to and integral to the scientific research process. The model also helped us all to keep a focus on moving through each stage with the active participation of community members.

The CRT process was difficult to initiate, and took longer than we had anticipated to build a core team. We made a difficult decision during the first year to add more time to the CRT recruitment phase rather than move ahead with only a couple of members. We moved ahead with the secondary data analysis and used the results to create a "take it on the road" slide show for the Project Coordinator to use for community meetings. This ultimately helped to generate more interest in the project while at the same time educating the community on the high rates of smoking found among pregnant Indian women.

Three very important results of the 2 component action research process include:

1) The study, from design to data collection to analyses, was community driven and community focused. We made time for each phase and reminded ourselves of the importance of reflection and dissemination, which often gets short shrift in research.

2) Especially exciting for us was that our study was *completed* during the timeline specified, despite changes in the predicted timeline. While much more time could be spent on data analyses and dissemination (and could still be accomplished as an extension of the study); initial analysis and dissemination have been completed.

3) The analyses, the results framework and the dissemination focused on the community and were action-oriented.

Conducting Photovoice
Learning and Reflecting Phases. We conducted six Photovoice sessions and held six Photovoice Reflection meetings. The Project Coordinator collected film from researchers every Monday for processing. Each researcher turned in 1-2 rolls of film every week. Reflection meetings were held every Tuesday and lasted from 1 to 1.5 hours. During the meeting, researchers would view their photos and chose two or a series of photos they felt best encompassed the topic or question of the week. Sometimes the pictures they chose related to a past topic or to the project goal overall (helping pregnant women quit smoking). Some topics included: friends/family smoking behaviors and usage, traditional tobacco usage, tobacco-related advertisements or media they see in their community. The topics/questions were chosen by the Project Coordinator and co-PI Sheri Scott in weekly phone calls held during the Photovoice data collection period. The reflecting component of the process included a discussion of varying intensity on the meaning of the photos, using the SHOWeD method, described previously.

The need for daycare was a continuous issue throughout the Photovoice sessions. Participants brought children to each session and the children were a constant distraction from the process. Dealing with the children may have interfered with participants sharing and further exploration of topics and questions. The alternative would have been to postpone the Reflection meetings until each participant could get daycare or to struggle and persevere through each session. The Project Coordinator decided to proceed with the latter option. Despite the difficulties, she felt it was important to continue because these were "real" community members talking about issues that they themselves had to face during their recent or current pregnancies, and their insight was invaluable.

Sharing (Dissemination) Phase. We began to see themes repeating during the fifth and sixth weeks, and as we needed to move along with our process, we decided to wrap up Photovoice. At the next CRT meeting, we discussed how to disseminate our Photovoice data results. The ideas included: an exhibit at the Two Rivers Gallery (MAIC), a moving exhibit, a calendar, a pocket planner, coffee mugs with pictures/slogans, open house, hosting a pow-wow, a run/walk, a feast/dinner, workshop, a panel discussion, or building a display/banner. The CRT ultimately came up with a completely new and creative option – put together the photographs into a 2005 calendar to disseminate to the community through a Mother's Day event.

1) Calendar. After this decision, a planning group of the CRT began meeting in January of 2004 to begin planning the calendar and walk. They met every Thursday, 4:30– 6:30 p.m. and worked hard on creating a means to share the research. One member volunteered to research printers and the cost to print up a colored calendar. Another member researched the holidays and moon cycles. Another researched "fun" facts on all 11 Indian reservations in Minnesota.

The next component, choosing themes for each month, also served as an additional "reflecting" phase of research and brought in some new faces from the CRT (not just Community Researchers). The team chose themes after reading through the Photovoice transcripts. They then decided what month would be the most appropriate for each theme. The group began sifting through the transcripts for quotes and language that would express the theme well. At this point, they also began sifting through the pictures to accompany the quote. Once the theme, month, picture and quote were determined they began looking at brochures and other resources for tips and information that could be included with each month. The "fun" facts on the reservations were also determined at this time.

Once everything was compiled, the Project Coordinator transferred the information, pictures and text to the computer and began the layout and design of the calendar. The planning group was the first round of approval for the calendar, made any changes and did minor proofing. Then a CRT meeting was held where the rest of the CRT got to make any changes or suggestions to the calendar (Attachment 5)

The calendars were disseminated throughout the community:

- Three calendars were mailed out to all 11 Tribal Presidents and Health Directors
- A calendar was mailed to all invitees who were unable to attend the walk.
- 50 calendars were given out during the Walk

- 50 Calendars were given out during the Native Women's' Path to Prevention (a collaboration between IPTF and 3 other community organizations –MIWRC, NACC, YWCA)
- 50 given to the expecting moms group at the Native American Community Clinic
- 50 calendars were given to Fond du Lac tribal cessation program.

2) Fun Walk and Stroll
The planning group decided to host a community based activity that would be healthy (a walk) and also honor mothers in their predominantly Indian neighborhood. The CRT developed a list of Indian organizations and programs to invite to the walk. In this list, we included Tribal Presidents and Health Directors. We also included some of the State Representatives that serve Indian populated neighborhoods, and we invited the Mayors of both Minneapolis and St. Paul. In total, we invited 96 different organizations and individuals to the Fun Walk and Stroll.

The fun Walk and Stroll was held on Mother's Day, 2004. The CRT chose to hold it in a location accessible to community members. They choose to begin their walk at the Little Earth of United Tribes housing in South Minneapolis and end at the local East Philips park. The walk route took about twenty minutes. Each walk participant received a free calendar and chidren received coloring books with a Trickster tobacco story (cultural prevention theme), along with crayons. We also were able to get donations of water and snacks for 200 people. We had a total of 53 people that registered at the walk.

Conducting the Talking Circles
After conducting only one Talking Circle, we decided to forego this component of the data collection. The first Talking Circle drew only 6 participants after recruiting with over 50 flyers put up throughout the community, through word-of-mouth by CRT members and making contacts with staff at two community agencies (MN Indian Women's Resource Center and Division of Indian Work). While the actual data collection component of the Talking Circle process went well (the Project Coordinator noted that it was surprisingly easy to recall details and specific points for filling out the post-event forms), other factors discussed below led to our discontinuing this data collection component:

Logistics considerations- With a part-time coordinator, the logistics of working with Community Researchers to "mentor" their participation and help them recruit and implement Talking Circles was unmanageable. Even doing the Talking Circles herself (rather than relying on community researchers) proved to be too time-consuming for the Project Coordinator, due to the difficulty of managing recruitment along with the intense calendar creation schedule for the final Sharing phase. The decision to create a calendar was creative, exciting and unexpected but took many hours and meetings to develop. The other logistics issue was the amount of data already available from the Photovoice sessions. As it was, analyzing the volume of text along with the volume of photos was a formidable task.

Timeline considerations – In order to have the time to analyze the data, the co-PIs needed the Project Coordinator to focus on completing the transcripts and getting the photographs organized and burned onto CDs. Given the volume of data already collected by the Photovoice method, we deemed this a priority in the timeline over a focus on new data collection. The transcription took

a great deal of time (six sessions amounted to 174 pages of data in 11 point font) as the Project Coordinator an *excellent* job – the transcripts are easy to read and are very professionally done, with additional information included on tone and background.

Cultural considerations- While logistics considerations were the most important in the decision to suspend this data collection activity, Co-PI Sheryl Scott voiced a concern that the difficulty recruiting participants might be a sign that some individuals are unfamiliar with Talking Circles or consider them more of a spiritual experience that does not lend itself to "data collection". Or it may simply be that Talking Circles are new and less appealing than focus groups, which are by now a "known quantity" in the Indian community. The Project Coordinator also noted that participants did not express their emotional concerns or dilemmas around smoking, or dig deeply to describe their lack of success or interest in quitting despite knowing the harms caused during pregnancy.

Building Capacity for Community Research

This project was successful, but not completely so, in building community capacity for conducting research. Successes included a 2-day training of 7 community researchers in photography, the Photovoice methodology, conducting Talking Circles and obtaining informed consent. We also successfully activated community members in smoking prevention and cessation, especially among American Indian pregnant women. We helped to mentor and build the skills of an emerging American Indian researcher (the Project Coordinator) to carry out a challenging community based project. We provided an opportunity for health department and university staff to participate and engage community researchers in a health priority area. As Co-PIs, we had the opportunity to learn from professional colleagues and community members alike. The Co-PIs and Project Coordinator learned more about their abilities and limitations (what may be termed initial "best practices") in engaging a CRT of low-income American Indian women, that should be applied in future projects. Finally, and most importantly, we provided individuals within the community an opportunity to share their important voices that often go unheard by implementing a new method that may be useful for future research projects. Community researchers now have the experience of conducting research within, as well as an enhanced understanding of, their own spheres of influence related to tobacco. We can build on this experience in the future for conducting meaningful research on tobacco and on critical public health disparities.

Ways in which our study was less successful at building community capacity was in activating community agencies to participate in the research process. It took much longer than anticipated to build administrative support from the Minnesota Indian Women's Resource Center and they did not participate fully enough in the CRT to develop their own community research skills. Other agencies that seemed like a perfect "fit" with the project, such as the Division of Indian Works, also did not follow up on numerous invitations to be a part of this process.

In addition, we were unable to provide opportunities for trained community researchers to conduct Talking Circles or for the CRT to implement media advocacy or dissemination to community leaders. One meeting was held to develop press releases, but the time was just not available for follow-up. We also did not conduct an activity that allowed us obtain community input on the results and actions to take. The CRT chose a Calendar and Mother's Day Walk for

dissemination, and we choose to honor these choices even though it limited our ability to obtain community feedback.

Study Implementation
Overall, the CART study was successfully implemented: We have accomplished the following:

- quantitative and qualitative results to sift through and continue to learn from as we move into intervention design;
- a tested model for conducting action research using community researchers in the American Indian community;
- a tested implementation of the Photovoice method by American Indian community researchers;
- a cadre of dedicated community members and health department staff who are willing to continue with this work;
- the "full circle" of our community research model (learning, listening, reflecting and sharing) completed during the timeline of the CART study; and
- a successful first phase funded MPAAT CARA research study where we can apply some of our "listening" and "reflection".

DISCUSSION

Limitations and strengths of the study

Limitations. The limitations of the present study include the lack of resources and time for a more extensive "reflection and sharing" phase of the study. We could have written materials to share a more "standard", scientific analysis of the data by researchers for dissemination to the research community as well as for the dissemination of policy implications/media advocacy activities by the CRT. As noted previously, the action analysis and dissemination of the calendar were the most critical factors for this study. We were able to have one final meeting where we presented the initial matrix of results, but could have benefited greatly from more time for community "feedback circles" as have been implemented in successful studies in Canada.

The community researchers for this study were young and lived in Minneapolis and represented a typical "urban" mix of tribal affiliation. Members varied in the strength of their ties to tribal reservation communities. The similarity or differences of results if the Photovoice study had been conducted on a reservation, or in a different region of the country, can not be determined. However, it should also be noted that the membership on the CRT, which provided insights for this study, reviewed the results and developed the calendar for dissemination, included a wider variety of ages and individuals of various tribes within Minnesota.

This study lacked the resources to conduct additional focus groups or interviews to delve into the more "personal" or individual emotional/stress issues related to success or failure at smoking cessation during pregnancy that were not directly addressed during the Photovoice process.

Strengths. The results of this study provide critical information on both the scope of smoking among pregnant women in Minnesota and the myriad of reasons that these rates continue to be two to three times higher than other groups in our state. The fact that study results include both

quantitative and qualitative components, make it a very important achievement (especially given the relatively short timeframe and limited funding.)

The study used and tested a research model that "inverts the paradigm" of traditional community research (which privileges science and academic members) because the community agency (rather than the university) controlled the funding decisions. In addition, community members, through the mechanism of the CRT, were in the decision-making role from design through analyses. At the same time, Project Partners with special expertise in research and practice shared their skills and knowledge that are so necessary for successful research. Our overall research model builds on community and indigenous strengths, and is action-oriented. The four components: "learning, listening, reflection & sharing" provide an important foundation for ensuring that the community receives the results of the research and that researchers recognize that the process is continual, and action for creating change or addressing needs found during the research must be built into the research process.

Finally, this project's team-oriented members merit special appreciation. As previously described, the project was driven by leaders of the IPTF and American Indian community, yet the project benefited by close partnerships with the Minnesota Department of Public Health (Ms. Cheryl Fogarty) and the University of Minnesota (Dr. Michael Oakes) in the form of Project Partners. Together the principal researchers, community members, and consultants each provided an essential contribution based on their experience. They worked to achieve each outlined project aim, with a respectful appreciation of both their individual limitations and their team members' strengths.

Interpret findings in light of research questions

Four out of every 10 American Indian women report smoking during their pregnancy, with the prevalence peaking at 45% during the year 2000. We found smoking rates 2 to 3 times higher among all subgroups of American Indian women in Minnesota when compared to similar women in Minnesota.

Cigarette smoking among Indian women is a public health epidemic that should be treated as an emergency – with the concomitant "emergency response" resources allocated to address the problem from multiple perspectives, including research and the creative, indigenous development of programs, curricula, and interventions.

The reason for such high prevalence is due in large measure, to the unconscious and continuous presence of commercial tobacco in the key spheres of influence affecting American Indian women, the family and Indian community-at-large, or Indian Country. We need our most creative hearts and minds thinking up solutions, we need perseverance in the face of entrenched obstacles and we need resources that will be allocated for the "long-haul", not short-term fixes. We also need to look beyond the medical model for providing cessation services, reaching more deeply into the community and family to support positive changes.

Unintended outcomes

We did not experience unintended outcomes as part of this study.

Challenges and lessons learned
Many lessons have been alluded to during previous discussions, but a summary follows:

1) Developing the CRT and Partnerships
The recruitment and retention of community members proved to be challenging. Issues such as transportation and childcare were far more important than first imagined. A staff person is critical for keeping momentum and contacts going even when it seems "futile"; seeds planted take encouragement and time to grow.

We had some trouble recruiting and retaining members and finding a place to hold meetings. Despite pledges to attend, actual participation for the first few months was low, often three or less. We found it necessary to offer a monetary stipend of $15.00/hour to compensate participants for their knowledge and time.

Overall, community action takes time and patience. This doesn't seem like an innovative finding, but we may have overestimated how quickly we could move along because of our own passion and determination to address this issue. Even though we already have community connections around general health and human service issues for American Indians, we still have to take the time to build relationships and interest around this particular issue since it has never before been addressed. In particular, we had a major challenge of getting our community partner – the MN Indian Women's Resource Center -- to collaborate, despite the offer of funding. We were also unable to interest other community agencies that seemed to be a natural fit. We feel that this has to do with a combination of things, including lack of embracing tobacco as a critical health issue, the fact that a majority of our community smokes (60% of adults) and the reality that funding for tobacco issues is fading.

2) Timeframe and Resources
Timeframe. The CRT met over the course of a year and a half, and we found that lack of planning for "holiday breaks" complicated timing of meetings and led to some difficulties in keeping up the momentum among all team members.

We also found that the initial Photovoice qualitative data analysis based on the reflection sessions was completed on time, however, not enough time was available for the "secondary" analysis phase by Project Partners. Providing data sets for analyses entailed the logistics issues of transcribing the sessions, collecting and labeling the photographs, and burning them onto CDs for dissemination – all of which was done by the Project Coordinator. It also took more time for the Co-PI involved in analysis to conduct qualitative analysis with "two" datasets – the notes and the photos. This led to limited time for the final sharing phase of the study, which ideally would have included several sessions with the full membership of the CRT along with the community researchers to review the "summary" of the data and share their insights into other strategies for organization, categorization and themes.

Resources. An important lesson learned is that a study with this population of low-income women that uses innovative qualitative methodology requires funding for a full-time Project Coordinator in order to be successful. We were lucky enough to have a Project Coordinator with experience in and dedication for working with community members, otherwise, it would not

have been possible to complete the four phases of our research study. The Coordinator worked overtime and on weekends, dropped other things to provide transportation and child care, and generally had to roll with a lot of punches, so to speak, in order to get activities completed as planned.

Another lesson is that to truly create community capacity, we must consider the amount of infrastructure and resources available to community organizations to conduct research. Universities and research institutes have indirect costs and overhead, but even more importantly, support staff or graduate students to draw on throughout a study when needed for special components (e.g., transcribing) or project activities (event planning) requiring more than one person, extra resources or special expertise. How can community groups ever have an "even playing field" to conduct research when the resources that they are provided are at such a reduced level compared to academic and other settings?

3) Data Challenges

In musing on the core research question (why do so many Indian women smoke) and in thinking about the use of the Photovoice method, we would like to share a potential reservation about this method when it comes to a personal behavior. Most of the previous uses of Photovoice have been on issues such as community assessment, neighborhood violence and homelessness. During Photovoice sessions, we sometimes felt that the individuals were "dancing around" the central question because they themselves smoked. Smoking behavior is environmental, but it is also very personal. Environmental influences were well documented; however, it was harder to get to some of the emotional core issues, when those issues were personal. They did come out, again, in more peripheral ways, and that was the real challenge of data analysis, but also the real value of the photographs and reflective discussions.

Another factor at play may be that the tendency of the group members to be descriptive rather than analytic. Critical thinking and analysis is not encouraged in our society, if fact, it is often actively discouraged (as well noted by Friere and other empowerment authors). For most people, and especially for those struggling and on the margins, it needs to be nurtured through learning, practice and an encouraging environment. In the initial sessions, the discussions were shorter and less reflective; at times, the Project Coordinator had to "pull teeth" to get a discussion going. Thus, more time and practice as a group may have increased this ability of the participants. This was borne out in the fact that the final session (#6) generated several excellent and poignant discussion threads, with more depth and honesty on personal and family issues.

A related issue may have come up with the Talking Circles. The Project Coordinator provided thoughtful comments on the process:

> *Participants shared their experience but they were almost TOO blunt and honest. They seemed to be disconnected from the emotional aspects of smoking during pregnancy. Responses seemed honest but yet very superficial, "Yeah I smoked and I feel bad about it". They readily volunteered that they smoked during pregnancies and that they worried about the health of their baby, but never took it beyond that. They didn't address guilt, shame, or responsibility issues or matters like that. That's what I was after -- how they felt about their smoking during their*

pregnancy, maybe a little bit of why they continued to smoke—but they never really addressed those things.

One explanation may be that when individuals are living with personal pain and practical obstacles, it may be asking a lot to dig deep into this particular issue – smoking commercial tobacco -- which touches on mothering, responsibilities for infant health, misusing cultural medicines, personal stress and/or self-esteem.

In retrospect, perhaps, taking CRT and researchers to a sweat lodge, and showing them the use of tobacco in a ceremonial way, might have led to increased trust in a shorter period of time as well as serving as the conduit to the inner sanctuaries of the CRT team. It would also have addressed one of the "Obstacles to Overcome" found in our Photovoice results: providing opportunities for community members to experience the power and beauty of ceremonies.

Translating these issues into lessons learned: 1) Research asking for personal sharing may require more time and effort to develop trust; 2) research on personal behavior in American Indian communities may require both group data collection methods and individual in-depth interviews to capture the full complexity of the experience and the range of individual factors involved, 3) research drawing on culture needs to be very thoughtful about how to explore cultural practices, if those practices have become "unhealthy", and 4) community members should be respected and paid for their time in sharing cultural/practical/indigenous knowledge.

Implications for future research, intervention, and policy

An overarching, critical issue for future research relates to empowerment and community norms. As Jennifer Irving, Project Coordinator notes:

One issue … I hoped would be included, was regarding the standard or expectations we set for ourselves in our own community. The main example was the picture about the Science Museum and then compared to pictures of the Indian Center; and basically, how different the main entrance is to both of these places. I have difficulty writing about this issue because it delves into issues regarding empowerment and self worth (and I could go on and on) and others I don't really understand or have answers to. It's as though somehow, how we feel about ourselves somehow gets manifested into all that we do. So that our main entrance into our main community organization somehow reflects how we feel about ourselves and our community. Why shouldn't we have the same expectations of beauty, cleanliness, and health in our own community? And why do we have to walk ourselves and our children past cigarette butts, ashtrays, smokers, and burning cigarettes to get to a community event. Is it because of the expectations we place on ourselves, our children, our friends, our families, our organizations? Why aren't we as a community demanding better? And most importantly, why aren't we working for better? What's holding us back? Just some thoughts and it's really complex, because it goes back to oppression. But I think it's something that needs to be addressed. Even if it's difficult to look at. Maybe we place the same expectations on ourselves regarding smoking.

Perhaps our findings point to the fact that abuse of tobacco can not be readily separated from the either the cultural strengths or the intense oppression from which a Changing Culture was born. How can we draw on strengths while squarely facing such intense challenges, and turn a Changing Culture into a Thriving, Healthy Culture? How does a tobacco related prevention and treatment program draw on this knowledge and build connections to the larger issues that need to be addressed?

Research. This study is a marvelous beginning step in the process of understanding smoking behavior among pregnant American Indian women. Future research is desperately needed and should include continued surveillance of birth certificate data along with more in-depth analyses of other data sources, including PRAMS and WIC. It is especially important that more qualitative studies be conducted in a variety of settings and more varied ages of pregnant women. We would suggest that Photovoice methods be used if enough resources are available and for long enough to establish trust and build the skills of the group. Other methods should include in-depth interviews, or oral histories that allow for sharing of personal emotional, physical, mental and spiritual challenges presented by smoking cessation.

Intervention. Results of our study strongly suggest that an environmental approach will be necessary to successfully address the issue of commercial tobacco use, and should focus on the spheres of influence of Family and Indian Country. Innovative aspects of interventions should include strong, culturally-based social marketing campaigns, along with opportunities for real experiences with traditional ceremonies and the appropriate cultural use of tobacco as well as discussions of how a Healthy Culture could emerge to replace the Changing Culture, into which tobacco has become so embedded in both positive and negative ways. Creative strategies to address boredom and stress at the Self level will also be critical to success.

A key finding is that we found little to suggest that the standard clinical-based approach would work well for this population, as health providers were not even mentioned during the course of the research.

Policy. Increasing the number of homes and community places that establish strong no-smoking policies will be very important for successful reduction of smoking in the American Indian community. Policies should also be enacted to increase the signs posted in the community that affirm smoke-free policies and endorse a healthy clean indoor air environment. Policies must be developed to reduce the constant barrage of smoking advertisements such as those found in low-income neighborhoods or at tribal businesses. One action proposed included requiring a one-to-one match of large counter-ads for each cigarette ad.

Policy initiatives should address improving overall community environments, bring in ways to beautify neighborhoods and fund professional signs or non-smoking accessories for high traffic community agencies. Providing resources to generate community policies that help build ownership and pride could address several issues simultaneously. For example, create neighborhood beautification projects that reduce cigarette litter while providing meaningful activities for community members who are underemployed or simply bored (i.e. high risk).

In terms of improving the validity of community based results and the practice of community based participatory research, we suggest that funding mechanisms be developed to continue funding action research at levels that help community agencies build long-term capacity to conduct meaningful studies rather than "one-shot" projects. For example, fund studies with five to 10 year, rather than one to two year, timelines.

Describe dissemination plans

The Indigenous Peoples Task Force will work with the Native American Tobacco Council (the newly forming network funded by MPAAT) to develop a plan for dissemination of the additional calendars, and any additional calendars we obtain funding to publish. The calendars have already been distributed to all tribal governments and tribal health clinics in the state of Minnesota. We distributed them to several programs around the country at the National Native Tobacco Conference held in San Diego in May. Several community organizations and tribes have already requested more copies of the calendar (Shakopee, Fond du Lac, St. Paul American Indian Family Center, Native American Community Clinic), and we may exploring printing more copies to sell at a cost-recovery fee.

We will work to provide our findings – both quantitative and qualitative data-- for the MN Council to use in proposals and for policy development activities within their communities.

Finally, we are seeking additional funds to expand dissemination activities from the community level to the professional and academic level. Project Partners have expressed interest in supporting this activity, but the Task Force and the Co-PIs do not have the infrastructure in place (time, funds) to conduct such dissemination activities at this time. At a minimum, we will explore presenting our findings to at least one conference during 2005.

Attachments:

Learning

1. Community presentation of birth certificate data
2. Method selection slideshow handout

Listening

3. Community Researcher training agenda

(Photographs are available for review by contacting Sheryl Scott at sherscott@earthlink.net)

Reflecting

4. Presentation of Photovoice secondary analysis to the CRT

Sharing

5. Calendar

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