2008 Qualitative Report

Public Health Messages from Utah's Racial and Ethnic Minority Populations

Prepared for:

Utah Department of Health
Center for Multicultural Health
PO Box 142001
Salt Lake City, Utah 84114-2001

Prepared by:

University of Utah
Department of Family and Preventive Medicine
Public Health Programs
375 Chipeta Way, Suite A
Salt Lake City, Utah 84108

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Executive Summary

The 2008 Qualitative Report summarizes the results of 17 community discussions with 180 members of four Utah racial and ethnic minority communities: African Americans, Asian Americans, Hispanic and Latino populations and representatives of Samoa, Tonga and other Pacific Island nations. These discussions were held to identify community needs, challenges and opportunities related to seven health topics: Access to Health Services, Asthma, Heart Disease and Stroke, HIV Prevention, Immunizations, Reproductive Health and Tobacco Prevention.

An experienced University of Utah investigator played a supporting role to the Utah Department of Health in designing the project and defining its objectives. Participants were recruited by trusted and respected members of each local community. Participants with experience relating to one or more of the seven health topics were specially recruited into the groups.

Seven of the sessions were conducted in Spanish. The discussion facilitators were respected members of their local communities. The University investigator observed and co-facilitated each two-hour discussion. The study met the requirements of the University of Utah Health Sciences Institutional Review Board to protect the privacy and rights of participants. All participants were compensated for their time and contributions. Meeting rooms and times were chosen for the convenience and comfort of the community in familiar surroundings.

The results summarized in the report reflect the interests of the participants and are not intended to represent every single point of view or every public health planning need. The report is not intended to be used in isolation, but in concert with existing information and what is known about health behavior theory and best practices. The investments in this project were intended to help in planning responsive health programs to benefit Utah's minority communities.

Eight common themes emerged from the groups:

1. Members of each community are *Credible Spokespersons* who understand the priority health issues in their local communities and are capable and caring representatives.

2. Access to affordable *Employee Health Insurance* is their greatest health need.

3. *Four Prevention Challenges* are common to each community:

   A. Prevention action will remain *"a luxury"* without access to health care through affordable employee health insurance.

   B. A community's traditional cultural choices can present significant challenges to adopting healthy behaviors.

   C. Community members understand the basics of health risk behaviors but lack the details, motivation and skills to successfully adopt and maintain healthy behaviors.

   D. Utah's racial and ethnic minorities face greater challenges to life basics, such as making a decent living and managing a family, and find it difficult to consistently invest in long-term healthy outcomes: *"We live in the now."*

4. *Messages about Messaging:* Each group engaged in detailed discussions of how public health messages could be adjusted to appeal to their local community. *"I want to see my face"* delivering the message; the message should be strong and direct to *"hit home;"* and the delivery of the message needs to be more grassroots and face-to-face. Participants explained that the ever-expanding, media-heavy *"one-size-fits-all"* effort does not get their attention in ways that encourage more Utah minorities to be healthy. Participants used the term "face-to-face" to describe their community's cultural tradition of learning by talking to each other. Life experience in their communities tells them that learning how to prevent health problems through community gatherings led by trained facilitators from their community will be more effective than, for example, statewide public service announcements. No one meant that they wanted prevention efforts to be one-on-one, that is, one person to one person. And, no one suggested eliminating media efforts altogether. Participants were responding to what they know works in their communities.

5. "Old" Suggestions for Action: Participants often repeated, without prompting, the concerns and suggestions identified in a similar 1997 study by the same investigator.[1]

[1] Final Report: Utah Health Status Survey on Ethnic Populations – Qualitative Component. November 24, 1997; Salt Lake City, Utah: University of Utah Research and Evaluation Program.

These messages emphasized the need for the community's direct involvement in planning and carrying out programs. The program that funded the 1997 study was discontinued by the legislature. While Utah's other public health workers have addressed these suggestions over time, community opinions persist about the lack of influence minorities have in planning publicly funded programs intended to impact them.

6. *Resource Investments:* Participants asserted that inadequate public resources are invested in their communities to successfully encourage and sustain healthy behaviors.

7. *Local Compensation:* Even more than in 1997, the community liaisons involved in the current study expressed the desire to be compensated for their ongoing public health efforts and more than in just a *"token"* way. They explained that they are *"asked to do more and more"* for free and are experiencing *"burn out."* These valuable leaders believe they and others in their communities deserve to be compensated for the considerable time and effort required to lead public health efforts in their communities and for their participation in higher level public health decision making.

8. *Ready to Participate:* Utah's racial and ethnic minority communities are ready and able to participate directly in public health decision making. They believe the current model for involvement—serving only as indirect advisors to state and local decision makers—is outdated. They suggest that Utah minorities can offer valuable insights and experience to all Utah residents as direct participants in state-level decision making. As taxpayers too, they argue that the smallest populations cannot be ignored as *"too small"* to fully participate in publicly funded decision making. Utah minorities are ready to contribute directly to setting policies and distributing resources.

The bulk of the report presents participant quotes, with a few investigator interpretations intended to guide planning and to support activities *"by and for"* each community. The results for any one health topic from any one community offer information any planner can use—with appropriate validation and testing—to develop responsive and successful health promotion strategies. Ultimately, public health workers' responses to the communities' messages should offer plans and resources for working together to build effective, self-sufficient strategies that communities can use to adopt and maintain healthy actions.

The report offers summary suggestions for actions that communities and public health workers can use together in planning future health programs. The suggestions range from considering each message from each participant as part of a road map to success in any public health endeavor, to directly including community members in planning and implementing *"by-and-for the community"* efforts. Suggestions also address refining social marketing efforts to attract and motivate specific communities and shifting resources from top-down statewide social marketing strategies to invest more directly in minority communities, particularly to develop skills in adopting and maintaining healthy actions.

Finally, the communities touched on, and the investigator supports, moving from complex surveys and multipurpose focus group projects toward less expensive and more flexible strategies. New research approaches enable more direct and continuous communications to reduce well-meaning but sometimes unproductive meeting time and support planners and community members in effectively working together toward common goals.

If utilized, the community messages summarized in the report—along with the adoption of a more interactive planning process in the future—will enhance efforts to eliminate health disparities among Utah's racial and ethnic communities.

Description

This qualitative report summarizes the results of 17 community discussions with members of Utah's racial and ethnic minority communities about seven health topics: Access to Health Services, Asthma, Heart Disease and Stroke, HIV Prevention, Immunizations, Reproductive Health and Tobacco Prevention. These discussions were held to identify needs, opinions, challenges and opportunities to plan responsive public health services for Utah's racial and ethnic populations.

Participants included 180 adult members of four Utah racial and ethnic groups: African Americans, Asian Americans, Hispanic and Latino populations and representatives of Samoa, Tonga and other Pacific Island nations. A health advisory board representing Utah's seven Indian Tribes and Bands chose not to support Native American participation in the study.

An experienced University of Utah (U of U) investigator played a supporting role to the Utah Department of Health (UDOH) in designing the project and defining its objectives. The discussion guides for each topic were written by seven UDOH programs that address the seven health topics. Decisions about the number of groups in each population and the topics addressed in each group were also finalized by the seven programs. Groups typically addressed two health topics and the facilitators followed the UDOH scripts whenever possible. The prevalence rates of health problems for each racial and ethnic group did not necessarily dictate the topic areas discussed by these groups.

The University investigator worked directly with community members to organize and conduct group sessions and to translate, summarize and validate findings. Participants were recruited by trusted and respected members of each community. The groups were facilitated by culturally appropriate and culturally competent community members. Seven of the sessions were conducted in Spanish. The University investigator observed and co-facilitated each two-hour discussion.

The analysis began with the university team and community representatives organizing recordings and notes from each the 17 discussions into a preliminary synthesis of findings. We outlined the issues and suggestions that emerged, and included representative quotes to illustrate participants' messages. At least two bilingual analysts, including the community facilitator and a member of the university team summarized the seven Spanish language discussions. The investigator reviewed these summaries with each analyst to clarify the importance of the issues and the meaning of participants' messages. As the facilitator of the English language discussions, the investigator also developed the syntheses for these groups. The investigator then organized the syntheses into this report, inserting clarifications and interpretations where appropriate. No attempt was made to quantify findings or further reduce the data across demographics or populations. The intent was to present as directly as possible the messages from the community.

The study was approved by the University of Utah Health Sciences Institutional Review Board to protect the rights and privacy of participants. Participation was voluntary and anonymous. The participants, community recruiters and facilitators were compensated for their efforts. Meeting rooms and times were chosen for the convenience and comfort of participants in familiar surroundings. Child care and food were provided as chosen by the groups.

The findings summarized in this report reflect the interests and offerings of participants in a community group process. When readers examine participants' quotes with health promotion theory and best practices in mind, the messages in this report will help to enhance future public health efforts that are intended to reach and respond to Utah's racial and ethnic populations.

Participants

The 17 group discussions were organized in the following Utah communities:

African American Men in Ogden
African American Men in Salt Lake City (two groups)
African American Women in Ogden
Asian American Men and Women in Salt Lake City
Hispanic and Latina Women in Midvale (two groups)
Hispanic and Latina Women in Ogden
Hispanic and Latina Women in Provo
Hispanic and Latina Women from Salt Lake Valley
Hispanic and Latino Men in Midvale
Hispanic and Latino Men in Salt Lake City
Pacific Islander Men and Women from Several Island Nations
Samoan Men and Women from Salt Lake and Utah Counties
Tongan Men and Women from Salt Lake and Utah Counties (two groups)
Mixed Culture Group in West Valley City

Prior to each discussion, 150 of the 180 participants voluntarily completed a descriptive survey, the results of which show:

- The average number of participants in the 17 groups was 11, ranging from seven to 15.
- The average age was 37, ranging from 18 to 82. Participants in most of the groups were purposefully distributed in age to reflect multiple generations.
- The average number of years participants had been living in Utah was 13, with 22% having lived in Utah five or less years and 20% living in Utah for 20 or more years.
- Sixty percent of participants were women, reflecting the skew of topics toward women's and children's issues.
- Twenty-one percent reported that family members had ever been enrolled in CHIP; 46% in Medicaid; and 11% in the Utah Premium Partnership for Health Insurance (UPP).
- Forty-three percent had ever had access to private health care.
- Twenty-seven persons with asthma or parents having a child with asthma were specially recruited into the groups addressing asthma. Similar efforts were made for other topics.
- One-half of the participants reported they had ever had the flu.

- Twenty-two percent have ever had a doctor tell them they had high blood pressure; 17% had high cholesterol; and 4% had experienced a heart attack.

- Twenty-six percent reported having ever regularly used tobacco and 16% regularly use tobacco now. The Utah cigarette smoking rate is 9.8%.

- By the investigator's count during all the focus groups, 46 of the 180 participants were African Americans, 11of participants were Asian Americans, 76 participants were Hispanic/Latino and 47 participants were Pacific Islanders.

Common Themes

Several themes emerged from the group discussions that are common to many participants, regardless of their racial or ethnic background:

Credible Spokespersons: Overall, participants revealed a basic understanding of the priority health issues in their local communities. They understand their cultures and are capable and caring representatives. Nearly all the participants were actively engaged in the discussions and helped to offer reasonable suggestions for addressing their community's public health needs.

Employee Health Insurance: Throughout the study, participants quickly and emphatically volunteered that their community lacked access to employee health insurance or lacked resources to purchase employee health insurance when available. Participants returned again and again to issues of employee health insurance as necessary to reducing the health disparities experienced by Utah's racial and ethnic populations. Participants clearly stated that access to affordable employee health insurance is their community's greatest health need.

Four Prevention Challenges:

1. A common theme was that learning how to choose and maintain healthy actions would remain *"a luxury"* until working members of the communities had access to medical treatment through affordable employee health insurance. Overcoming this perception—that access to health care is prerequisite to preventing health problems—may be crucial to engaging communities in successful health promotion efforts.

2. A second prevention theme revealed that a community's traditional cultural choices can present major challenges to adopting healthy behaviors. For example, socially supported dietary choices and conceptions about prenatal care still influence some cultures' ability or willingness to choose healthy actions.

3. Third, participants characterize their communities as understanding the basics of health risk behaviors and consequences, but lacking the details, motivation or skills to successfully adopt and maintain healthy behaviors. Several groups characterized their community's prevention process as, *"We put it off…until we feel guilty…then we try…then we're inconsistent…then we put it off."*

4. A fourth prevention challenge involves other priorities they say compete with healthy actions. According to many participants, basic life activities such as making a decent living and managing a family leave little time, energy or resources to act in the interest of what to them is an uncertain future. *"We live in the now"* is a common theme.

"Old" Messages about Messaging: Each group engaged in detailed discussions of how public health messages could be adjusted to appeal to their local community. Suggestions often echoed those identified in a similar 1997 study[2]: *"I want to see my face"* delivering the message; the message should be strong and direct to *"hit home;"* and that the medium for the message needs to be more grassroots, personal and *"from the bottom up."* The program that funded the 1997 study was discontinued by the legislature. Minority populations in Utah may have seen some progress over the past decade by other health programs, but they continue to characterize public health messages as appealing to the Utah Caucasian majority. Participants explained that the continuing top-down, media-heavy *"one-size-fits-all"* effort does not get their attention in ways that encourage more Utah minorities to be healthy.

"Old" Suggestions for Action: Participants often repeated, without prompting, the concerns and suggestions identified in the 1997 study. Messages emphasized the need for their direct involvement in planning and carrying out public health efforts and specific adjustments to how health promotion efforts are presented to them. While Utah's public health workers have addressed these suggestions over time, community opinions persist about the lack of influence

[2] Final Report: Utah Health Status Survey on Ethnic Populations – Qualitative Component. November 24, 1997; Salt Lake City, Utah: University of Utah Research and Evaluation Program

minorities have in planning publicly funded programs intended to impact them. The communities are clear that their previous messages have yet to be successfully addressed.

Resource Investments: Participants asserted that inadequate public resources are invested in their communities to successfully encourage and sustain healthy behaviors. They argue against the logic that resources must be distributed dollar-for-dollar relative to population size. Participants agree that smaller populations may need greater investments per person for public health efforts to succeed.

Local Compensation: Even more than in 1997, community contacts involved in the current study expressed the desire to be compensated for their ongoing public health efforts and more than in just a "token" way. They explained that they are "asked to do more and more" for free and are experiencing "burn out." These valuable leaders believe they and others in their communities deserve to be compensated for the considerable time and effort required to lead public health efforts in their communities and for participating in higher level decision making.

Ready to Participate: Utah's racial and ethnic minority communities are ready and able to participate directly in public health decision making. They see that the current model for involvement—serving only as indirect "advisors" to state and local decision makers—is outdated. They suggest Utah minorities can offer valuable insights and experience to all Utahns as direct participants in state level decision making. As taxpayers too, they argue that the smallest populations cannot be ignored as "too small" to fully participate in publicly funded decision making. Utah minorities are ready to contribute directly to setting policies and making decisions about how best to distribute and utilize public health resources in Utah.

Access to Health Services

At the request of the Utah Department of Health Bureau of Access, this topic was formally addressed in Hispanic and Latino groups only.

Participants in most of the other groups voluntarily commented on the issues they face in accessing and paying for health care.

Private Health Insurance

Access and Affordability: The strongest and most common theme across African American, Hispanic and Latino and Pacific Islander populations is that their communities need access to affordable employee health insurance. It appears that purchasing private health insurance is a major financial challenge to all but the most skilled and affluent minority workers. A majority of African American and Pacific Islander participants reported their employers do not offer health insurance. Among those whose employers did offer insurance, questions about purchasing it were often met with comments like, *"I can barely afford to feed my family. What makes me think I can afford health insurance?"* Exceptions are well-acculturated Asian Americans who reported that their overall health care access experiences are more like those of the White majority.

Knowledge and Choice: Overall, it does not appear that participants are prepared to ask the questions needed to choose from among several health plan options. As with delaying action to avoid preventable health problems, social and emotional forces come into play in studying health insurance choices. But the root issue seems to be competing financial priorities, closely followed by lack of availability. These are given as reasons many participants remain uninformed about health insurance. In what appears to be inconsistent messaging from participants, they may say *"why study it?"* but by all accounts health insurance is very important to all Utah minorities and their families.

Public Health Insurance

Awareness: Participants are generally aware of the existence of public health insurance assistance, including the Children's Health Insurance Program (CHIP) and supplemental insurance such as UPP, Utah's Premium Partnership for Health Insurance. This awareness comes from a combination of television and radio messages, friends and families and in some communities, door-to-door outreach. However, many participants do not see the value in paying attention to something they believe they do not qualify for or that is unavailable to them.

Barriers: Despite these insights, it is difficult to know what can reasonably be done to help Utah minorities get or keep health insurance. These populations see lack of access to health insurance as dangerous and frightening, and they believe it is almost impossible for them to overcome without help. But lack of access has proven relatively immune to efforts to increase access through larger social interventions aimed at job skills building and providing financial incentives to small businesses. While CHIP and UPP can and do bridge the gap for some, many more do not qualify.

Inequities: There is resentment that some populations enjoy easy access to publicly funded health insurance assistance, while others who might work just as hard do not qualify for this assistance. This is compounded by some communities' already firm experiences and opinions that life is harder for them in Utah and that they are being discriminated against. These participants admit that this leads to extended delays in seeking needed health care, which in turn results in more complications and higher health care costs.

Health Care Services

Cultural Gaps: Sometimes, group discussions about public health issues can be overwhelmed by a few participants' need to dominate with personal stories and opinions about their negative experiences with doctors and the U.S. medical system. Fortunately, this seldom occurred during this study. But some participants did want to underscore 1997 messages about their distrust in, or at least their discomfort with, accessing a system in which they did not see members of their

own community working or serving them. Being uninsured or underinsured also contributes to this outsider status when interacting with the health system.

This discomfort was most pronounced among African American males, who spoke about how stressful and "*uninviting*" doctor visits or hospital stays can be due to the cultural isolation they experience. They explained:

"If we're HIV, we can't get hired on a job with insurance, so we have to go to free clinic. It's not Magic Johnson medicine."

"They ignore us, give meds and send us to the house."

"We have to sound like them to get an appointment, to get them to listen to us to treat us."

"We need someone to relate to."

They suggested that training and hiring more African Americans in the medical field would help to address this. Hispanics and Pacific Islanders expressed similar concerns, but their examples were more about the lack of personal caring and listening among doctors and other health workers that the busy U.S. health care system discourages. For English speaking minorities, it isn't so much the phone call to make an appointment or the paperwork that is difficult, it is the cultural vacuum in which they find themselves when *"going to the doctor."* Participants explain that this out-of-culture experience contributes to delays in seeking needed health care, which in turn can compromise health status. To address this issue, perhaps more cultural sensitivity and cultural competence training are needed for health care workers.

Communication Barriers: While language remains an important barrier for Spanish-only speakers, the cultural gap in communication styles between patients and doctors appears to have a strong negative impact on accessing and receiving needed health care for all minorities. African American participants explained that they are treated poorly by health care workers, which encourages them to delay seeking needed health care. Exceptions seem to be Asians and Hispanics who are well-acculturated and speak English fluently. Elderly Asians and Hispanics

who have not acculturated or haven't sufficiently adopted English still appear to be at risk for greater health problems due to extended delays in seeking care.

CHIP Assistance

Most participants know what the Children's Health Insurance Program (CHIP) is and how and where to apply. Utah's African Americans, Hispanics, Pacific Islanders and Asian descendants are generally aware of these government health care programs, thanks in part to media messages, families and friends and to community-based outreach and awareness efforts. However, there was not much interest from group to group in discussing programs for which most participants do not qualify. Reasons given for not qualifying were either not being a U.S. citizen or having family incomes above the limit.

Similarly, in discussions about UPP, participants seemed to lose interest when they realized that UPP was not available to them until they could get qualifying employee health insurance. Some participants who could qualify did not seem to be aware of or clearly understand that UPP could help them pay for employee health insurance if available.

CHIP Marketing

African Americans regarded the English language CHIP pamphlet and TV spots as appealing to someone other than them. They are aware that these materials are aimed toward the majority White population, both in the pictures and the formatting style. When asked if they would read the pamphlet, most said they would be more likely to *"give it a look"* if they saw African Americans depicted and if the text included only basic information about how to learn more about CHIP. Reading written details generally occurs only when the topic has hit home.

The Spanish CHIP tri-fold brochure was seen as well-designed overall. Participants pointed out that the cover picture was appropriate and attractive to Hispanic audiences. Despite the brevity of this brochure, participants still suggested it had too many words and that community members would not thoroughly read it.

Spanish speakers as well as Pacific Islanders explained that culturally, they prefer to communicate personally (by phone and in person) with members of their own community to educate and motivate each other on any topic. This was less clear among non-elderly Asian descendants and African Americans, who appear to have adapted to Utah's *"Caucasian dominated"* patterns of public interaction as a necessary strategy to obtaining needed services.

Regarding the Spanish UPP two-fold brochure, participants did not understand why the people of color were on the back, while the Caucasian family was featured on the front. It is this type of cultural insensitivity, subtle and accidental as it may be, that minority participants perceive as off-putting. They explain that the message they are receiving from the government or the system is that *"we don't count."*

Although participants did not appear to be aware of the CHIP Van, this type of outreach may appeal to Utah's minorities for several reasons. These groups state that 1) they are less likely to be interested in reading written materials; 2) they are unlikely to read the details in written materials; and 3) perhaps most importantly, they prefer the verbal and visual learning styles and personal contact with a knowledgeable community representative they feel they can relate to.

Asthma

Asthma prevention and management was addressed in the following group sessions:

Hispanic and Latina Women in Midvale
Samoan Men and Women from Salt Lake and Utah Counties
Tongan Men and Women from Salt Lake and Utah Counties (two groups)

Hispanic and Latina Women in Midvale:

Importance of Asthma

This discussion began with participants agreeing that asthma is important in their community because it strongly impacts the families affected: *"In my family we have asthma and it's difficult to deal with because we don't have insurance."* When asked if asthma is worse than other health problems they face in the community, participants agreed that *"We have so many other illnesses, asthma is not the major one, but it is something we should be able to detect."* One participant who goes door-to-door in the community "*did find quite a few people with asthma."*

Knowledge

"Being new transplants in this country, we don't really know where to go, what to get, so messages need to be targeted to us because we need it the most."

"Be mindful that most of our families don't even have CHIP or Medicaid, so we don't have the resources to take care of it ourselves."

Participants know that asthma is "*clogged lungs that do not allow you to breathe normally,"* but members of the community do not know "*what is asthma and what is a plain cold.*" One participant said *"I don't believe that the community knows the difference between asthma and any other illness." "When kids have a problem, we don't know enough to recognize and act*

properly about the symptoms." They do know that asthma is a chronic illness that requires constant attention and they believe that the reasons people suffer and don't recognize asthma is due to a lack of knowledge and that it is not being diagnosed.

Several participants agreed that *"In our community we use a lot of Clorox and it has a lot of damaging aspects to health."* Others stated that asthma is caused *"by the environment, the use of harsh products."* Another offered that *"weather may have something to do with it."* One mother said, *"I believe this starts when babies are in the womb. If you don't take care of your health you are more likely to have a sick baby, so it is important to do prenatal care." "I wonder if my boy has asthma because I didn't take care of myself during pregnancy. I didn't go to the doctor."* These comments reveal the need for additional education about the basics of asthma.

Prevention

Participants seemed to know some of the basics about the conditions that can make asthma worse, including avoiding places where people smoke tobacco, where there is a lot of dust and outdoors when the air is polluted. However:

"We don't know about clean... When we take an apartment, it is very dusty and we don't always take care of our surroundings at first."

"I live in a small environment and even if I take care of the dust, we're still exposed to people smoking."

From this discussion about preventing asthma, it appears that members of the Hispanic community may need additional education and encouragement to minimize the conditions that lead to or worsen the signs and symptoms of asthma. Adding to the discussion:

"We have heard time and time again about this illness, as much as about cancer. The interest will only be awakened until it comes to your house. Prior to that, we don't care."

It will likely take very powerful targeted messages and repeated exposures to adequately address such a strong barrier to action in the community.

Treatment

"We don't have CHIP or Medicaid, so we run to the U of U Emergency Room, but they want half or all up front, so we just don't go unless it's obviously bad."

When asked if the community was prepared to know enough about asthma, participants had some questions and some suggestions:

"The medications, how to use them, is the hardest thing. We don't really understand how to treat this illness and the lack of knowledge makes it very difficult."

"When I treat my child, the problem is, is this going to be habit forming?"

"Most people think it's just a regular cold and do nothing."

Hispanic participants still have basic questions about asthma and how to act effectively in their families and their communities.

Asthma Education

"I strongly feel that education is the key and do not feel confident that we can recognize the symptoms and education is needed to recognize symptoms."

"I called CHIP, was told to take my child to the hospital and found the child has asthma.

It would be better if we knew the symptoms and what to do."

Participants said they have learned about asthma in hospitals, from pamphlets in clinics and that *"even schools are centers for information."* Most felt that asthma information was easy to get when they needed it: *"I lived in Washington and my child was sick with asthma. I didn't get the information there, but in Utah I received the information and the services I needed."* The

contradiction in participant comments about knowledge signals the need for more health education action in this community. One mother illustrates this need:

"When they're sick, you have to take them to the clinic. The doctor there is supposed to take better care of the child, but when a daughter had a cold and even though I brought the shot record showing that vaccines were up to date, the doctor ordered vaccines.

I felt strongly that the child had asthma and wanted information about what to do, but I didn't get it. What I really needed was a humidifier. I wish I had [written materials] *to inform me of different diseases."*

It is unclear whether this clinic was an exception by not having asthma information on that day, or the particular doctor did not provide it, or whether language or some other factor was involved. If not done already, it may be worthwhile to regularly contact potential asthma information outlets to ensure this information is available, especially to Spanish speakers.

A general discussion of education strategies followed:

"You see ads on TV, but it really doesn't mean anything to you until it comes to someone you know or your own house."

"We don't really pay attention to it on TV."

"The best way to get good information to our community is through door-to-door. This happened to me about diabetes. I went to get tested and found I had diabetes."

"People really believe that talking mouth-to-mouth after work is the way to spread the message. Word of mouth is the best thing. It's not TV."

"We need to go door-to-door in our community, because many of the people don't know how to read."

These comments emphasize what many of Utah's racial and ethnic minorities are saying; that as a matter of cultural choice and experience, they do not respond to the more abstract thinking approach to prevention that may resonate with people of European descent. Recognizing and acting on this is critical to bringing these communities to a level of knowledge and effective action about asthma as well as other health issues.

The Hispanic and Latino women discussed details about asthma prevention marketing and education. They cited local health clinics as the best or first place to provide educational materials. They believe the messages should be targeted to the Hispanic community *"because of language"* and *"go to everyone"* in the community. Previous discussions on other health topics in this population have identified the mothers-of-children and daughters-of-elders and the persons to target in raising awareness, knowledge and skills to act. The participants clearly want everyone in the community to learn about asthma and other health issues, regardless of who may take the lead in acting to prevent or control these issues in their families.

With regard to providing the very important skills-based education, participants say they need classes where educators *"literally show how to do things and that sticks with us. The visual works better with us."* And with written materials, participants wanted to be sure that *"the translation emphasis must be on the meaning, rather than just the words."*

Samoan Men and Women from Salt Lake and Utah Counties:

Importance of Asthma

"Asthma is important in our community, but not something we talk about."

"They [community members] *don't know much about it."*

"It doesn't faze us because we don't know about the risk."

"We don't pay attention to asthma, not until a loved one has it."

"This [hitting home] *opens our eyes."*

Coping with Asthma

"There is no health room in school, so they just send our child home at the drop of a hat."

This causes a chain reaction at the parents' place of employment when they have to leave to pick up their child. Parents are treated badly by managers and co-workers for urgently leaving work. Parents say the schools could help to avoid this major concern.

"The whole family suffers. We can't go out to places because a family member can't breathe."

"Asthma is expensive. We get Medicaid. Without it we'd spend $150 a month."

"Our insurance is depleted every time [there is an episode]*."*

"Grandparents, when caring for my asthmatic grandchild, didn't know the symptoms of attack and my child was blue and dying when I came home. Elders need information."

Prevention Strategies

"Show kids how to take care of themselves, know what asthma is, what triggers their episodes."

This "*empower the kids*" strategy was offered as a partial solution to the drop-of-the-hat urgency that parents have to answer to when their child has an asthma episode at school.

"Feature differences from Samoa to Utah [as a strategy for learning about risk]*."*

This community suggests focusing public health efforts to increase awareness of how the rich diet in the Islands goes hand-in-hand with higher physical activity levels there and that continuing the same diet in the U.S. while increasing fast-food intake and reducing physical activity is doubly risky. Participants believe this will increase Pacific Islanders' perceived risk of preventable health problems and help to motivate them to adopt healthier diet and exercise habits.

"Music is good, we love music, dancing. It has to be catchy."

"More meetings like this one. It's better than TV ads because of first-hand insights from families like ours."

"Keep education sessions short. Sharing a little bit at a time is more effective."

"Our elders have attention deficit problems. They only understand broken English, so it is important to teach in our language."

"A ten-minute presentation with pictures and easy information is needed."

Prevention Messenger

"Someone from our culture—The Rock, Troy Polamalu—to give importance to the message."

"The bottom- up action, building within the community."

"We tend to listen to elders, so educating them, we'll listen."

"With six generations of Samoans, we need to touch all, but parents and grandparents are dominant."

"The message to them [grandparents] *is to stop health problems for grandchildren."*

When discussing the asthma flier *"10 Steps to Making Your Home Asthma-Free,"* participants said some of the steps for clearing the air of asthma triggers were unexpected, including the advice to help clear the air by avoiding cockroaches. They also stated that, *"On the list, we don't know what dust mites are."* However, parents of children with asthma were very knowledgeable about asthma triggers and work diligently to manage triggers in their homes.

Tongans from Salt Lake and Utah Counties

Members of this group offered messages similar to those discussed in other Pacific Islander groups and added:

Prevention Importance

"In the Tongan community it is silent. We don't want it to be known if someone in our family has it."

"It's a sign of weakness. Your family is taboo, cursed."

"Same as TB [the tuberculosis epidemic] *was in Tonga. That belief is still carried on."*

Prevention Messages

"Credibility is important in the Tongan community."

"Have to have humor in presentations."

"Educate the younger folks. Need to see before and after video."

While Tongans offered messages that were similar to those of Pacific Islanders from other nations, it will be important to involve members of each population in planning for their respective communities.

Heart Disease and Stroke

Heart Disease and Stroke were addressed in the following discussion groups:

African American Men in Salt Lake City (two groups)
Pacific Islander Men and Women from Several Island Nations
Tongan Men and Women from Salt Lake and Utah Counties

African American Men in Salt Lake City:

Knowledge

African Americans reported that members of their community know that high blood pressure, diet, genetics and differences in access to quality medical care are factors in their risk for heart disease and stroke. They were asked if they know how to recognize the signs and symptoms of heart attack and stroke and how to act appropriately:

"Our community? No, not really."

"They know how to make the call when something's wrong, but in terms of the symptoms, knowing what the signs are; our people wouldn't know what they represent."

"Numbness, dizziness and the like, we might think that's a heart attack."

"I have heart symptoms and when I go to the hospital I'm glad I'm okay, but I worry about 'crying wolf' too much and that I might not go when I really need to."

These are clear messages that African American communities lack the knowledge to accurately recognize the signs and symptoms of heart attack versus a stroke. As a result, the overall community is unsure of its abilities to act appropriately *"when something's wrong."*

Lack of Prevention Support

"I haven't heard anything that's talking to us."

"[We get] *better health promotion in better ways elsewhere* [that is, in larger cities where there are more racially and ethnically diverse populations]*."*

"Talking to Blacks about risk factors and how to avoid [disease], *you don't see that here."*

"Meetings like this are more common in other states; this is the first African American meeting I've seen."

"African American doctors and health workers have more information and are more willing to teach that information to other African Americans."

This lack of prevention support has implications for all public health efforts. The absence of prevention efforts that appeal to and enhance the health knowledge of African Americans in Utah may be linked to messages elsewhere in this report that their community's lack of knowledge directly leads to inaction—regarding both prevention and health care seeking.

Lack of Social Support

"Here, the focus is on the white community. That plays a big role."

"We never find pictures like you see here [in the room were pictures of respected Black leaders] in Utah schools."

"You never see our faces, so, kids go out there in a hostile world, where you never see yourself."

"A lot of folks don't feel they have a voice."

"[African Americans in Utah are] *stressed because we're such a small number that it doesn't matter, no one listens."*

One implication these comments point to is that—given that public health workers cannot solve all social ills—it is even more important to build and support prevention efforts that are *"by and for"* local African American communities.

Powerful Social Stress

"This is a stressful state to be in over time because you find yourself living in at least two worlds, having to deal with at least two identities that you don't have to deal with in the larger world."

"It's a different environment here, taxing from kindergarten, being the only black child, through elementary school all the way through to our work life."

"It's almost like you're an island."

"There is more stress on us here in Utah six days a week, [but] *not when we go to our own church. There's no stress with all the black people there, but you don't see them for another week."*

As with the need to address the lack of social support available to African American communities in Utah, public health efforts will need to help neutralize social stress. Prevention programs that are appealing, convenient and supportive of community members are needed to be successful in encouraging healthy actions. This could be accomplished through expanded efforts to fund *"by and for"* grassroots health promotion strategies in socially isolated populations.

Cultural Diet

"Is our diet different here, or are African Americans in New York changing [their] diet as a result of health promotion efforts? Like substituting turkey wings for fatback."

The previous quote relates to the discussion that, in places with larger African American populations, participants notice positive changes in health behavior. They attribute this to having more prevention resources devoted to their population there and the greater social support there.

"The assumption in Utah is that everybody eats cheese, that everybody eats the same sort of things."

"They bring me red meat, beef, but we eat pork, the 'other white meat' [hearty laughter]*"*

Participants sent clear messages about the lack of culturally competent health promotion offered to African Americans in Utah.

How to Overcome Barriers

"African Americans need to be seen providing public health prevention services, too."

"Even if equal risk [statistically], *there's still going to be differences in what you see and do about our risk compared to whites. So, input should be diverse, not looking at percentages."*

"One, we have to change the political makeup, more of us participating at the policy level – in politics and the workplace and social settings."

"[We need to be] *full participants in the social setting. Daughter was school dance organizer, chose current music, but was overridden by white '60s music choices."*

"Not separate committees, but direct representation in the decision making."

"Hire at the highest level and get them on the decision making boards."

"There's value in input from people of different backgrounds for all groups."

"There's an African American on every volunteer board in the city. But they're not on the paying boards here [such as at the UDOH and the U of U]*."*

African Americans also want public health efforts to recognize the diverse makeup of individuals within their communities:

"Just because I'm Black [pointing to another Black man], *I'm not the same as you."*

"We struggle to keep what identity we have left, [we're] *pressured to blend."*

Other minority populations also mentioned that a one-size-fits-all prevention effort will miss the mark due to differences within populations based on acculturation, education, financial status, genetic differences and varied life experiences.

Prevention Strategy

"Put an African American doctor in our church or an African American local."

After additional discussion about the prevention messenger, participants agreed that if African American physicians were not available in sufficient numbers to share the effort, the messenger or health educator could be an African American nurse practitioner or student *"as long as they know their stuff"* and *"have good expertise."*

This *"by-and-for our community"* message is repeated across minority groups, not to be separatist, but from the desire to be taught by educators who understand their culture and how to present information and help their community build the skills needed to be successful.

Prevention Messages

"If we don't see a picture of an African American having a heart attack, we're likely to think 'that doesn't happen to us.'"

When asked to review the "Think of Stroke as a Time Bomb" tri-fold brochure, African American men instantly regarded the cover picture of a *"white man with a fuse on his head"* as a signal to disregard the brochure as *"not meant for us."* That is, if they hadn't been asked to look closely, the brochure would not have gotten their attention. They labeled the fuse-on-the-head as

being foolish, much as they disregarded the tobacco TV ads—the "*teen ones with the dudes* [who] *look like fools.*" The attempts at humor in these messages do not resonate with them.

Regarding the content of the "Time Bomb" brochure, participants would prefer even less text to read through *"to get to the information we need."* This was a common reaction to many of the written materials presented to all of the groups. Interestingly, none of the men mentioned the attached refrigerator magnet, which is direct and brief. Also, in some of the materials presented in every group, the attempt to depict multiple races and ethnicities in a single picture did not appeal to anyone. Finally, participants agreed that, because stroke is a serious issue in the African American community, messages should be available that are designed to attract and hold the attention of African Americans.

"In the brochures, don't just tell me if I do this I'll get a stroke, tell me how not to get a stroke."

"Show me some lifestyle changes so I won't have a stroke."

Cultural Competence

Additional comments illustrate another reason minority populations would like to see more minority health care and public health workers who better understand and perhaps are more alert or caring:

"White doctors were treating my son for asthma, he was missing school and they weren't doing anything. An African American doctor came through [town] *and after her one visit, he's better."*

"My daughter, born with no hair, same thing. One visit to an African American doctor, she's going to the hair place now."

"We used to have a full-time HIV prevention person through a CDC grant through the state, but the state grabbed them. We had a youth-in-science program, but that disappeared too."

Participants explained that the few resources African American communities have had in the past to provide culturally sensitive and competent services are no longer available.

Tongans from Salt Lake and Utah Counties:

Low Importance

When Tongans in Utah talk about the importance of heart disease to them they say it's *"Not until in the hospital."* That is, they pay little attention to it until they are in the hospital for treatment. They explain: *"They don't have doctors and don't take Medicaid."* So, they *"don't get check-ups"* to assess their risk or to learn how to prevent or manage it.

Lack of Knowledge

"Community doesn't know symptoms. [We] *don't know what 'light-headedness' is."*

"Not everyone realizes when it's happening."

Delayed Action

"When feeling ill, elders just try to sleep it off."

"Tongan men think they're macho, strong and would be a wimp to call for help, so they wait."

"One elder sat in church rubbing his chest, went into the bathroom and died of a heart attack. He didn't know the symptoms."

Risky Diet

"We live to eat, not eat to live."

"The more meat we eat the higher in status we feel."

"[We eat] *coconut milk and organ meats."*

"New Zealand sends the fattest meat to the Islands, we still go buy the same stuff here. It's cheaper, so we buy that."

"We can preach and talk all we want, but it's a cycle; parents feed children with diet that parents like."

"We eat at night until we fall asleep."

"Our mentality is we'll live forever. Everyone has the day that's pre-designed, so 'eat what you want.'"

"Younger have our diet and McDonald's too. It's double [trouble]*."*

Lack of Exercise

"No exercise: Too busy, or lazy, or 'I've worked hard enough.'"

Stress

"We hold in stress."

Prevention

"Prevention is not a priority."

"Too busy to tend to prevention."

"In the Islands, there are no resources, so our mentality is to be self-sufficient."

"We communicate with the dead, so our perspective of death is healthy."

"You're gonna die if you're gonna die."

Prevention Approaches

These Tongan comments may apply to all Utahns, but the public health approach needs to appeal to Tongan perspectives:

"We're social, so take the elders out to exercise, go with them."

"What about social exercising? It works, people go together, support each other."

"We love to dance, so build around that activity."

"[We need] *to get past 'we should go* [exercise].*'"*

Prevention Messages

"We react to fear."

"Need to see it in someone like us to sink in."

"It may work better to emphasize stopping eating after 7 pm, instead of saying what to eat and what not to eat."

"We like veggies, but it's how it's cooked in. For us, everything is about the taste, so show me how to cook healthy that puts a good taste in our mouths."

Prevention Messengers

"We respond to respected members of our community, church leaders, community leaders, not in their 20s, but 30s and 40s, with younger as learners and peer leaders."

"Best to team up and pay community members to be experts and lead toward health."

"Face-to-face expert who is affected to present at church."

"Also need affected people to share their experiences."

More Prevention Advice

"Need a budget to do it right, to attract good leaders who will sustain the effort."

"Also need to provide incentives for community members to participate. If you don't reward with something, they won't come."

"Posters, maybe, but have to have our faces big on it and minimal words."

"DVDs and podcasts for younger, but [need to know] *how to attract them to watch healthy casts over 'fun stuff.'"*

Each of these comments provides another insight into ways to craft prevention messages that can be successful in encouraging Pacific Islander communities to adopt healthy behaviors.

The Mixed Pacific Islander group included ten participants from Tahiti, Fiji and mixed Samoan/Tongans and Samoan/Fijians.

This group validated much of what the previous Samoan and Tongan groups said and moved right on to discussing how to change to a healthy diet, critiquing the *Dietary Approaches to Stop Hypertension* (DASH) cookbook[3] and the Stroke tri-fold brochure:

Healthy Diet Strategies

"The DASH cookbook uses U.S. measures. We grew up with metric, so we don't have the ability to convert measurements while reading this cookbook."

"In our culture we eat solid food. A roast pig is needed, not the pictures of salad."

"Book is too long. Get to the point."

"Have information in bullets, details at the bottom, later."

"It will go into the magazine piles; we won't get to it."

"Need it short so we can post it in the kitchen, where we'll see it and use it."

[3] Utah Department of Health, Heart Disease and Stroke Prevention Program and Intermountain Healthcare, 2006

Pacific Islanders were clear that their diet is the most influential lifestyle choice putting them at greater risk for heart disease and stroke. They clarified that they have blended the family dietary habits they follow from the Islands with the U.S. fast food diet to create an even greater risk of heart disease and stroke in their community.

To address this, Pacific Islanders believe the community would respond best to education and skills-building practice led by someone from the community who is trained and paid to do this work. Doing this in the community, in the context of their culture and in their language, will be crucial to the community's success in adopting and maintaining healthy diet and exercise alternatives.

HIV Prevention

HIV Prevention was addressed in the following group discussions:

African American Men in Ogden
African American Women in Ogden
Hispanic and Latino Men in Midvale
Hispanic and Latino Men in Salt Lake City
Hispanic and Latina Women in Midvale

African American Men in Ogden easily entered into discussions about HIV prevention:

Knowledge

"We know how it's transmitted and not."

Importance

"When Magic got it, made me pay attention, but he's got the money to pay for top treatment."

"We're at risk here in Utah."

"Stigma in our community. We don't talk about it."

Risky Behaviors

"A lotta us doin' it on the down low."

"Condoms: Just a matter of time, you're going to do it all [without protection]*."*

Susceptibility

"Once it hits home [in the extended family] *it gets attention."*

"Sex and drugs are being promoted heavier than they used to."

Rappers havin' their own liquor company, that's not helping our community."

Prevention Messages

"No one's readin' that stuff."

"Walkin' around campus I see HIV poster; just bypassin' that altogether."

"Still have to show fear. Instead of showing still-healthy people with HIV, show people sick with the disease for real."

"I believe AIDS patients speaking in school can be effective."

"Like that cigarette lung thing, it gets my attention."

"Need advocacy to counteract the sex messages in media.

"Need to attack sex messages and advocate to neutralize."

"Need more personal interactions in church about these issues."

Pamphlets

When asked about several HIV pamphlets which featured photos of African Americans, "If we hadn't asked you to look at this, would you have picked this up and looked at it?" participants said:

"No, this wouldn't get our attention. We wouldn't learn anything from it."

When asked "Did you hit on one fact that you didn't know?" participants said:

"No. You'd have to be interested on your own to pay attention to this."

"I see somebody wasted a lot of money that they could have used better."

"This one shows people that are happy. So, if they're happy, I'm happy too [and don't get the message about HIV]*."*

"[The Red Cross one] *is way too long, with too many words. I wouldn't read it."*

African American Women in Ogden:

HIV Knowledge & Importance

Participating women demonstrated a good knowledge of how HIV is spread. There was misinformation, however, about the incubation period and ways in which HIV is transmitted from a mother to the fetus/baby. The participants reported:

"There is lack of awareness in the general community."

They agree that everyone should know about the mode of transmission as well as be aware of preventive measures, but the African American community in Ogden has yet to accept the importance of HIV:

"The bitter truth is that most people are still in the dark."

"No one wants to talk about the issue openly."

"Some people have not progressed past the denial phase."

HIV Risk

"AIDS/HIV in the Black community is also spread by men who go in and out of jail."

"[Another contributing factor] *is reckless sexual behavior especially after drinking."*

There was a general consensus that *"every sexually active Black adult is at risk."* The greatest risk was thought to be among *"young Black females ages 18 to 40."* This age group was described as having *"little education about preventive measures."*

Another risk factor cited was the *"false sense of immunity that living in a small town in Utah* [Ogden] *is a protective factor—that HIV/AIDS is a disease of the big cities."*

HIV Prevention

Participants agreed that *"people should be encouraged to use condoms."*

"The issue should be brought up in church and addressed openly."

"Our churches ought to play a major role in promoting abstinence [too]*."*

"More education programs and media campaigns tailored to the African American communities could promote prevention efforts."

"Young people in particular need to be made aware of the fact that oral sex is sex and that HIV can still be spread through oral contact."

The idea of female condoms was not too appealing because the condoms are uncomfortable and don't fit well. The male condoms were described as not completely effective due to slippage and breakage, but since wearing condoms seems like the most effective protective measure, participants felt people should still be encouraged to use them. Despite this, some participants did not seem too enthusiastic about practicing condom use themselves.

One participant explained and others agreed that once a positive diagnosis of HIV is made, treatment should be sought right away. Those infected also need to be educated about how HIV progresses and to help them realize the diagnosis is not a death sentence.

Prevention Messages

There were mixed reactions from participants about the literature they were asked to review. According to some of the women, the picture on the cover of the Red Crosses' *"Women and HIV"* brochure projects a message that AIDS is a women's issue. Suggestions for the AIDS pamphlets and media messages are to project images that are more inclusive. A majority of the participants agreed that the images presented make a difference in how the message is received.

The colors used in the brochures do not matter to these participants. The message should, however, be clear and written with language that is simple enough for most people to understand.

The community's churches were seen as the best vehicle for community HIV prevention education. There were some misgivings about letting the school play an active role in sex education because not all school age children are sexually active and not all teachers are comfortable teaching about sexuality and sexual behaviors. For this reason, some participants were skeptical that any useful HIV education could be presented in schools.

When asked about discussing sex-related topics with their daughters or sons who had reached puberty, participants seemed to have a level of comfort. Parents stated that they would emphasize abstinence as well as other preventive measures. The participants seemed very positive and enthusiastic and look forward to another such meeting.

Hispanic and Latino Men in Midvale were relatively young, in their early to mid-20s, Spanish speaking, and were recruited to the group as men who have sex with men.

How important is HIV in your community?

"90% important."

"30% to 40% important."

"This is because there are many people who do not use condoms."

"It should be more important."

"It is not very important because there's a lack of information available."

What protection from HIV and AIDS is available to you?

"Basically just the condom."

So AIDS is transmitted through sex?

"Not exactly, but that is the surest way to get it."

"You can also get it from injections, but the risk of that happening is minimal."

What is it that transmits HIV? Which bodily fluids?

"Blood, saliva, vaginal fluids, semen."

"[One participant had heard that] *having a baby can transmit HIV to the baby."*

The moderator clarified that everyone in the group said "saliva," but saliva is not one of the transmitting fluids. He explained that in reality, four fluids spread HIV and they are blood, semen, vaginal fluids and breast milk. He explains that a kiss or hug won't spread HIV.

Who is most at risk for getting HIV?

"[Unanimously] *Everyone! Because you just never know who has it."*

What puts you at risk for getting HIV?

"Not having protection."

"Women having multiple sexual partners and they spread the disease to more people."

"Alcohol and drugs puts you at risk."

"Because you can't think and you don't know what you are doing when you take them."

Are drugs and alcohol big problems in your community?

"[Unanimous and emphatic] *YES! It is too much of a problem."*

"Everyone goes around drunk all of the time."

"When I drink alcohol and use drugs, my temper flares."

What types of drugs do you use?

"The majority of people use cocaine."

"There's also crystal meth, marijuana, ecstasy, pills and tobacco."

"There is some heroin use but that's too expensive."

"People use drugs every other day. It has to do with the person's economic situation."

What happens when people use drugs?

"When someone is on alcohol or drugs, they forget everything. It puts them at risk for HIV because they don't use protection."

"When someone uses drugs to escape from their problems, they find that when they're no longer on drugs, their problems are even worse. They just keep doing it because it's a vicious cycle."

"Drugs control a person. Many people say that just by drinking or seeing another person with alcohol makes them lose control."

When you share drugs or a syringe, what are you sharing?

"Your blood is shared."

"I don't think sharing a pipe or weed would spread HIV."

The moderator clarifies that if something burns the lips and exposes blood and then someone else uses it, they've come in contact with someone else's blood. He explains that hepatitis C is spread to many people who use drugs this way and there is no cure for that. Herpes can also be spread without sexual contact. Someone asks if the virus dies when it's exposed to open air.

The moderator explains that while the liquid is still wet, the virus can be spread and hepatitis C is still alive in the blood even after a few weeks.

What other things put you at risk?

"Forced sex, even with your own partner."

Does promiscuity exist in your community?

"[In emotional unison] *Too much!" "Everyone is doing it."*

Where does this attitude of acceptable promiscuity come from?

"Because everyone does it." "And it's not just our community that does it."

"For a man there's no risk of getting pregnant so maybe that's why men do it."

"Machismo plays a part."

Who is least at risk in your community?

"Nobody really is least at risk. Kids maybe? Everyone is at risk."

"Some people have sex every day which puts them more at risk."

"People who are more informed are least at risk because of the information that they have."

"People in the community have a notion that being gay means you have more sex. That's not true. It's just the same as being heterosexual."

What things help you or the members of your community to avoid the risks of HIV?

"This type of informational meeting."

"This meeting is good but I've been invited to other groups but I haven't gone because it's as if there are rivalries even among gays."

You feel there's discrimination in other groups like this?

"Yes. They invite me, but when I'm there I don't feel accepted because of the way I look."

"Some gays feel more comfortable dressed feminine and some more masculine."

Do you think that the stresses for transgenders in their community affect them psychologically?

"It's very hard. There are always those who say they are prettier than you or they are just 'more' than you. I don't know if they just want to make themselves feel better or what. I've always said that I'm not better than anyone and I'm not less than anyone."

"I think that to begin to overcome this, you need to ask yourself what you want out of this life."

"I tell myself that I am a woman but I don't want to dress like a woman all of the time."

"The fact that the outside community and their own transgender community sometimes is prejudiced against them is difficult."

What stops people from taking care of themselves in matters of health?

"They don't accept themselves. They don't know if they really want to be a woman or what."

"They have low self esteem and low self worth."

What can health workers do to reduce the spreading of HIV in your community?

"Have discussions and inform the members better. Invite more people."

"Encourage mental health because that leads to physical health."

"Private discussions with some people would help in case that person is afraid to share in front of people."

"Support from family and friends helps people to share openly. When someone knows that they have the support of their mother and father, they feel more comfortable sharing."

What helped you come out and move forward?

"Myself. Since I was young I knew I was gay. I loved playing with dolls. They bought me cars, but I played with the dolls."

"They told me if I was gay, I would lose my family. Everyone says that they have contemplated suicide or had feelings of desperation."

What kind of things would bring members of your community to these discussions?

"Activities."

"Food like a good carne asada."

"Having it at a gay bar."

What are the best ways to inform people of these discussions?

"Most of us don't read English, so we don't pay attention to stuff in the American magazines."

"More radio announcements would help. People listen to the Gran D and Magia Solo Exitos at work, so we would hear it there."

"At home, the TV would be effective."

What do you think of AIDS pamphlet?

"When I see a pamphlet like this, I remember that I have to use a condom."

"But even with that information, many people still don't want to use a condom."

"The information is good. If I had a free moment, I would read it."

"I don't like pamphlets. If I was given one, I would probably just throw it away because I don't like to read."

"[All say they] *would look at it more if it had more pictures."*

[Participants liked the way the short pamphlet on HIV was presented.]

"The Red Cross pamphlet needs more color and pictures. Nothing on it calls our attention."

Where do you go to get condoms?

"[Participants in unison] *The pharmacy."*

"Where can I go if I want to get tested or find out more or talk to somebody?"

The facilitator explains that he can go the Midvale Community Building Community (CBC) or the health clinic on 600 South or the Red Cross. He tells them they can't be rejected because they don't have money.

Hispanic and Latino Men in Salt Lake City were relatively older, in their late 20s to early 30s, appeared to be higher income than Midvale group, and were recruited as men who have sex with men.

How important is HIV in your community?

"It's super important. It's also important to look for a solution or a cure."

"People in Utah don't want to hear about HIV.

"I've had trouble talking about it since I came to Utah."

"In some homes, it's not even talked about. They think it will happen to somebody else."

How much do people in your community know about HIV infection and AIDS?

"Infection is a problem in our community because there are a high percentage of illegals."

"Many of the programs are directed to the legals."

"There's also the lack of knowledge. Illegals can be helped as much as legals."

"When I'm at work and I hear guys talking about what they did over the weekend, I ask if they used protection and they make excuses and say that I don't understand because I'm old. I tell them that they need to use protection. I tell them that youth are infected more often.

"HIV doesn't care who you are."

What does your community need to stop the spread of HIV?

"What we need to do is think to ask if someone is infected before we sleep with them."

"It's too easy in the bars or clubs to not ask. Respect yourself and your partner and tell your partner if you are infected."

"When I lived in L.A., I never had problems telling people what I was, or what I had, but when I came to Utah…."

"Many people come from Catholic countries where these things just aren't spoken of."

"Latinos don't communicate enough about HIV and AIDS."

"We just need education."

"Culturally, prevention doesn't interest us much. We know about it, but we take a casual approach to it. It's the culture."

What about HIV testing?

"Most people are ignorant. They just have misconceptions about HIV. They think because they feel ok, that they are ok."

"I read a recent study and I was shocked that most had never had an HIV test. It had advanced to AIDS and they still hadn't been tested."

"It could be that people are afraid that they'll get deported if they get tested."

"Or they know that they won't understand what they're being told because the information is in English and they don't even read and write in their own language."

"The majority of us know how to protect ourselves. Many people don't want to know that they have a sickness, so they avoid the testing."

Do you think the messages that you hear about how to protect yourself are effective?

"Young people aren't really afraid of the sickness because they think medicine will solve everything. They don't use condoms because they aren't afraid of the consequences."

"*There's lots of information in Spanish and English. So it's not that people don't have access because of their legal situation…."*

How frequent is drug use in your community?

"Alcohol is very predominant in our community. [Everyone agrees.]"

"It's part of our culture to drink, so we're introduced to it a young age. Here in the U.S. you can't have it if you're not 21."

"Drugs are more predominant among Americans and Chicanos. Among Latinos and immigrants, alcohol is preferred and drugs aren't as much of a problem."

Is alcohol putting your community at risk for HIV?

"If you're drunk and you have unprotected sex, it's the same as if you are sober and you choose not to have protected sex."

"Without a doubt, you are more at risk for HIV when you are drinking."

"Unfortunately, alcohol and drugs mess with your senses."

Do you in your community feel that you have the control to have safe sexual relationships?

Everyone in the group says they feel sure that they would be responsible and use a condom.

"I'm sure of what I do."

"I've learned to respect myself and protect myself."

"There shouldn't be negotiations about whether or not we use condoms. We should demand it of our partner and of ourselves."

"Some people think using condoms means you don't have trust in your partner."

How accessible are prevention services in your community?

"Many people don't know who can help them when they have certain conditions."

"Sexual education is impossible in Utah schools. I don't know if the counselors are doing a good job."

What about HIV prevention messages?

"Preventative advertisements in Spanish have too many words and nobody will read them. In English, they're easier to understand."

"I'll pick up fliers and brochures but I don't read them because I don't have time."

"We don't read very much in our Latino families. It's not something we are raised with. The TV is much more effective for us for that reason. The Hispanic person will choose the visual and sound before he'll choose to read something."

[Everyone says they know where to go to get condoms and get tested: The UDOH, Red Cross, Gay and Lesbian Center.]

"In Provo and Utah County, people are much less informed and there are fewer places to go for information."

"If we're not bilingual, where would we go to get mental help? There needs to be places in Spanish."

How culturally acceptable is the information that you have received?

"It was acceptable to me. It helped me have a better perspective on things."

"I liked the social aspect of it. How to interact as people."

"If there was an advertisement in the paper directed toward Hispanics, it would attract us more. Advertising that a group of Hispanic friends are going to get together."

"Something on Sunday night would attract us."

Who has seen Jeremiah's advertisements?

"They're in your face. Ads need to use words that relate to the group they're directed at. They should be fun."

What recommendations do you have to make our services better?

"To have person who is accessible to Latinos to be there for us. If I have an idea, I need to be able to call and talk to someone accessible."

Hispanic and Latina Women in Midvale:

This conversation focused on several messages that participants wanted to share:

HIV, AIDS *(SIDA is Spanish for AIDS)*:

"Should never say you have AIDS infection, should say HIV."

"The impact, it's so powerful when they say AIDS."

"It's not as scandalous to say HIV, but if you say SIDA, the impact of SIDA is so powerful that we will stay away from them."

Spanish Soap Operas *(Novelas)*:

"Through videos you can give the message to young people about SIDA. It's touching their minds and their bodies and even when you are just watching a novela, the impact SIDA has is tremendous."

Pictures:

"Pictures are very powerful means to teach children. Have real pictures of the last stage, people they knew [or knew about], *it's real and they will pay attention."*

For example, *"this SIDA, this is what it does to your body."*

"Don't try to show a picture that doesn't say much, it won't have an effect, like a collage of different faces. That has no meaning."

Door-to-Door:

"We need to bring to the community the message with real pictures. The message should be given door-to-door to reach the people, not by the health department, if they come we immediately think we'll be jailed or given a fine. We can open up to people if we know them, rather than if it's the health department. Being comfortable with someone you can talk to is very important to us."

Counseling, Follow-up:

"And if they could have counseling [more detailed education] *and follow-up this would be good, for families with teens especially."*

HIV Testing:

"I have gone to testing at a clinic which was good. But if there's a charge, you just don't do it."

"We would not go to the health department. We are fearful."

Prevention:

"To take the HIV prevention message to the community, they should be bombarded much more than now, because the community is lax about this terrible problem."

"Teens, they steal each other's condoms because they have no money to buy them. I take my son to the clinic in Midvale, or Greenwood to provide condoms to my son."

"Everything that I need [to learn about health issues] *I can usually find at CBC, for breast cancer, diabetes, HIV, etc."*

Hispanic Women in Provo:
Knowledge

"We don't make a difference between HIV and AIDS."

"[Members of our community] *don't really understand the symptoms of the disease and how it is spread."*

Prevention Actions

"Safer sex practices: One form of protection is use of condom."

"We know abstinence is a more secure one, but not practiced in the community."

Risky Behaviors

"The community, they do a lot [of] *high risk practices such as multiple partners."*

"We have heard that men and women do during work break 'una sacudida'—a 'quickie.'"

"Also do this practice in the bars when they consume a lot of alcohol and have quickies for pleasure and/or for money."

"Alcohol and drugs are really linked to casual sex. Also happens within stable families."

"Important: More often the men in the community do drugs and they usually do cocaine to overcome tiredness from work and work is often physical, so more often the guys do cocaine, in construction, landscaping and working two shifts especially in summer."

"[Participants] *also consider a high risk behavior doing tattoos."*

Risky Situations

"When teens start driving and lose shyness and they start having sex."

Participants expressed that although everyone in the community has the same opportunity to become infected, the married women are at higher risk and defenseless to protect themselves from HIV and AIDS because they have to make the assumption that the partner is faithful, so they don't take action for protection.

"When women try to negotiate condom use with husbands, it's an issue of mistrust causing arguments and domestic violence."

"Women are in a very hard situation."

"Women are afraid."

"They cannot say or do anything because the husband gets offended, defensive and violent."

"Women in the community cannot tell anything to husband [about protection]. *They are exposed to get the disease because they have 'low self esteem' and feel powerless and they have to have sex because they are financially dependent on husband."*

Suggested Prevention Model

After a good deal of discussion about prevention options, participants suggested that:

- Written materials and other resources should be available in the bars and at work.
- The prevention work should start in home and then in school.
- Mothers should be educated first, so they can teach their children at home and talk with their neighbors.

Prevention Pamphlets

"Really little HIV/AIDS information in Spanish in the community, but it's more effective to have personal education anyway."

"The people don't read pamphlets, because they try not to be noticed, it has a lot of words."

"We [prefer] *less words and the information more summarized."*

"The images are important in pamphlets. Use more pictures rather than simple drawings, less words, more colors."

Pamphlet Critiques

Lo que debes saber sobre a HIV: *"It has a lot of words, but it doesn't have all the information they are looking for and they wouldn't read it. It doesn't really have an impact and it's not related to the topic."*

Planned Parenthood Pamphlet: *"It has a lot of words. Could use more bright colors and more images to be attractive."*

Community Promise Poster: *"It doesn't have a clear idea about the topic they are trying to present. The images don't mean anything and the message doesn't say anything about the topic and they should use color."*

Prevention Media

"Suggestion: Use soap opera message design and do during soap opera time."

"In soap opera have part HIV, not all of it."

"Publicity hasn't been effective. In the media there is more information about tobacco than HIV."

"More often TV commercials in Spanish would have more impact, especially when on Spanish channels."

"TV commercials, use big pictures, strong messages so people can see the consequences so it has impact."

"For teens, it is important to involve this topic in music videos and also in cartoons."

The UDOH HIV Prevention program requested validation of the results of a 2004 HIV Prevention Needs Assessment[4]. The five Needs Assessment findings that could be compared to the qualitative information collected in the discussion groups are:

- Hispanic men who have sex with men continue to report a high incidence of alcohol use resulting in higher rates of unprotected sex.
- Hispanic women continue to report that alcohol use is prevalent, but that drug use was less so among married Hispanic men.
- Barriers to receiving HIV prevention services continue to be related to cultural factors, fear of being identified, social stigma and the lack of readily available, accessible or culturally sensitive and culturally competent HIV prevention services.
- Current results did not validate previous findings that survey respondents *"don't need HIV prevention services."* Hispanic MSM reported that they do want and need HIV prevention services.
- Minority populations continue to perceive costs to be a significant barrier to accessing HIV and other health services.

[4] Utah HIV Prevention and HIV/AIDS Treatment and Care Needs Assessment Report. December, 2004. Salt Lake City, Utah; Utah Department of Health, Bureau of Communicable Disease Control.

Immunization

Immunization was addressed in the following focus group sessions:
African American Women in Ogden
Asian Men and Women in Salt Lake City
Hispanic Women in Provo
Tongans from Salt Lake and Utah Counties
Mixed Pacific Islanders from Salt Lake and Utah Counties

The primary purpose of immunization discussions was to address adult flu shots and the Immunization Care-A-Van.

African American Women in Ogden:

Do African American women in Ogden get flu shots? If so, where and how often?

A mix of younger and older women reported they have had the flu shot in the recent past and did so generally as a preventive measure. Others were immunized because they were already suffering from chronic diseases or because their jobs exposed them to the flu virus. When asked if they would get it again, their answers were generally yes. Only one participant reported serious side effects. They would generally recommend it, especially to those who suffer from chronic diseases.

All of the participants knew where to go for adult flu shots. It did not appear that they needed or wanted public health reminders or external motivation to get flu shots. This, however does not mean that social marketing of flu shots wouldn't be useful to other members of the community. For a few of the youngest and oldest participants, cost may be a barrier to regularly getting flu shots. Convenience in Ogden does not appear to be an issue.

Among those participants who did not get the flu shot or would not recommend it to anyone, they were of the idea that flu shots were some sort of *"guinea pig"* experiment. There was also concern about the shot being administered to children—that it would make them sick with the disease.

Do African American women in Ogden take their children for immunizations?

Nearly all participants reported taking their child or children for immunizations. Most favored the Local Health Department for cost reasons. A few went to other local clinics as part of doctor visits for other reasons. Registering their children for school seemed to be the motivation needed by some participants to catch their child up on vaccines. If anyone was against childhood immunizations, they did not speak out in this meeting. Participants want to see the Care-A-Van more often in their community.

What else do you want to share about your immunization experiences in Ogden?

As with the African American men's group in Ogden, an important issue was that Spanish-speaking people are given priority and are receiving better health care. According to participants this compounds the already existing problems of Caucasians dominating the U.S. culture and health care system. Blacks in Utah believe they are treated much worse than any other racial or ethnic minority and report that this translates into inequality in health care. Racial prejudice was discussed at length in the group.

Participants reported feeling more comfortable going to a Black doctor because that doctor is more likely to understand and be sensitive to the health issues that are unique to Blacks. They also reported that there are very few Black doctors in Utah, which may lead to delays in seeking timely prevention and care services. This may contribute to observed health disparities.

Asian Americans in Salt Lake City:

Five of the 11 participants regularly get flu shots. Older participants who get flu shots every year do so to prevent the flu and to avoid complications with other age-related illnesses they may have. Younger participants feel the flu is *"not a really serious thing; four days and it's gone."*

Cost is not an issue: *"I can get flu shots at Smith's for $19."* Some go to the Health Department, because they feel *"it is cheaper."*

If messages come through TV ads, the messenger doesn't matter to younger participants. Middle-aged participants would rather see a health professional: *"I prefer those people; they're more knowledgeable and convincing."* Others would like to have a real patient to encourage getting the flu shot. Still another said *"If my friends all talked about the flu, I think I'd get a flu shot."* These comments reflect the diversity of Asian participants by age and by culture.

Regarding pamphlets promoting immunizations: A brochure with detailed information attracted this reaction: *"It shows my age group, so because of that, I will pay attention."*

Message location comments included: *"I would see it* [notice it] *in the newspaper." "The pharmacy." "Hospital." "In the mail."* Participants said they tend to read when in a waiting room or in a line. Another said *"I pay attention because it is important to me."* The glib media messages participants have seen do not appeal to members of the Asian community. The pictures with faces from different races and ethnicities also have no effect with Asian participants. They would be more likely to notice if an Asian was giving the message. They prefer information that has meaning to them personally so they can *"study and make a decision."*

These give-us-the-details responses from Asian participants are different from the marketing suggestions offered by other racial and ethnic groups, many of whom prefer brief, visual educational messages. This is a clear example of what all groups are saying; that they will be attracted to and respond to messages that reflect their culture and are presented in the ways they learn and share information in their community.

Hispanic Women in Provo:

Are adult flu shots important? Participants agreed that flu shots are important. Most have received the shot and nearly all go the Community Health Center for the shots. Cost would be an issue at a private doctor's office. They understand that the benefits of flu shots are that they *"Don't get sick so often."*

Do they know about other vaccines? Participants are aware of other adult vaccines, naming hepatitis, HPV, malaria, cholera and tetanus. And they have heard that teens need HPV shots

and that they can go to the Community Health Center. The information from Mexico and the information here is not the same. They are told to get vaccinations there, for free, but not here. In the U.S. they are more on their own to decide whether or not to take their children for vaccines.

Where do they go for childhood immunizations? In Provo, mothers take their children to the Community Health Center for immunizations when they go for doctor appointments. They report that every time they need vaccine service, they have bought it and consider it an appropriate expenditure.

Is cost a factor in getting immunizations? In other countries they come from, vaccines are provided for free, so participants hope they can receive these services in Utah for free. When families have a lot of children they have to choose which child gets the shots. For many participants, transportation is a barrier. It is really hard to go out, especially with more than one child and no car. The man has the car for work, if they have a car at all.

What do they know about immunizations? Participants agree they need to learn which childhood immunizations to get and how often. What they have learned about this is through their medical appointments and from information through the mail. The doctor's records and mail reminders tell them what and when to get vaccines and for them this is really important information. Participants gave no clear messages about whether or not they keep and use their own childhood immunization record card, or if this method of keeping track would be useful to them.

Do they value immunizations? They report that, in general, Hispanics in the community are not against vaccines. Participants also reported that when some people in their community have learned that sometimes children get sick from the shots, they have come to believe that vaccines are not effective to prevent disease. They also have heard that some people from different religions don't get the vaccines. Perhaps more education about immunizations could clarify issues for Spanish-speaking mothers in Utah Valley.

What do they know about Care-A-Van? They don't personally know the program, but have heard it exists in Salt Lake and would like to have it in Provo two times a year, in the library or close to the library for best response. And they would also like the schools to do the immunization campaigns. When asked if they had seen any Spanish language ads for Care-A-Van, no one commented.

How do they prefer to receive immunization information? They would like to receive information through mail and at medical appointments, especially Medicaid. They have noticed there is little information in Spanish, so they have to clarify with or learn from friends or neighbors.

Are written materials valued? They have seen pamphlets in English and Spanish at Mountainland Clinic and suggest posters be placed where they can't be missed, where they go frequently, such as the library and Mountainland. They prefer information be presented in English and Spanish, because a lot of times this information is given in English and they don't see it in Spanish so they don't understand. Even Hispanics who have been in the U.S. a long time can speak English but cannot read or write it, so written information in Spanish is very important.

Tongans from Salt Lake and Utah Counties:

Of the 12 Tongan men and women, 10 had ever had a flu shot. Five had the flu shot this year and four planned to. They believe in flu shots and it's *"better to get the shot than not."* Those who don't get the flu shot say *"I'm healthy, it's a Tonga thing."*

Some said they don't get the shot because insurance that covers it is too expensive. Others say it is inconvenient to go *"just to get a shot."* They are more likely to get immunized if they are at the doctor's for another reason. And, *"Our seniors won't take the shot, they are very scared of needles."*

Ordinarily, community members hear about the shot, have the flu experience or see it happen but they still wait to get immunized. To encourage flu shots, the messages need to stress how important getting the flu shot is. *"You need to instill fear."*

All agreed that messages on the radio, in their own language, during their public radio show, is the best way to reach Pacific Islander adults and elders. And the messenger needs to be a *"person we know."*

They would like to see the Care-A-Van more often in their community. They are willing to pay $6 for their children. But the van doesn't say it's not for free, which causes negative feelings about the Care-A-Van when members of the community go there and then learn they have to pay.

Mixed Pacific Islanders from Salt Lake and Utah Counties:
Participants examined and critiqued the Immunization Chart:

"It looks like a chemistry chart."

"What is this?"

"[It uses acronyms] *which we don't know."*

"PVC to me is a pipe."

"Instead, tell us why my child needs DTP."

"Knowing why helps me know they need it, so that's more motivating to get the shots."

"We need a reason to do it."

"This chart doesn't do it."

"Explain it [why, when and how]*."*

"Use brighter colors, will stick in mind."

"In Samoa, the message not to have the next child too soon is 'Space your coconuts.' This makes sense to us as subsistence farmers. So, we need to be in planning process for messages to work in our community."

Again, Pacific Islanders say they prefer simple, visual messages with limited English text. The Immunization Chart is so visually complex it overwhelms their senses and they don't pay attention to it. It is not that they cannot study such detailed presentations, it is that they choose to learn directly from knowledgeable people in their community whom they respect and trust.

Reproductive Health

Reproductive Health was addressed in four group sessions with
Hispanic and Latina Women in
Midvale, Provo, Salt Lake City and Ogden

Hispanic Women in Midvale, Provo, Salt Lake City and Ogden:

How important is action to prevent poor pregnancy outcomes?

In general, participants say that pregnancies are not planned, especially the first pregnancy, and particularly in the Mexican community. They report that good pregnancy outcomes are important, but they did not have the knowledge before or during their first pregnancy. And they don't necessarily see that it's about their health (diet, etc.). To them, being pregnant is more about *"What are you giving me now that I'm pregnant?"*

Participants say they have learned from their first pregnancy that the second child can have malformations and other diseases if they don't take care of themselves before the second pregnancy. They know to consider *"the baby's needs, to stay away from drugs, etc."* But quite often it's *"Oh well, it happened again"* with the second pregnancy, too. Participants say we have to teach *"Do you know how to take actions* [to prevent another pregnancy]*?"*

What has supported your prevention and health care actions in the past?

The knowledge they have acquired has been through "*family and friends in the same community."* They say they know what to do, to *"dress properly with winter coats," "see about your surroundings," "don't be around people who are sick"* and *"make sure they're eating their food."* These seem like reasonable actions to prevent illness in general. When asked to talk directly about preventing reproductive health issues, they said they *"go to the clinic to find out about pregnancy,"* but mostly after they suspect or know they are pregnant. One woman said she was fortunate that she was informed about folic acid when she came to the U.S. and *"so I took care of what the baby needed."*

Especially during the first pregnancy, young Spanish-speaking women are intimidated by the receptionists, nurses and doctors in the U.S. health system, so they tend to learn from friends and family.

"The cultural issue is a big thing…they're not going to open up to anybody. You have to develop a relationship with them, so, talking in their own language, not just Spanish words, is very important."

"They have very little education, so you have to be very savvy to get all the information you need from them."

"Then, they have to feel safe, they have so many issues. Immigration status is huge, they're afraid to go anywhere, fearing that if they say something, someone will call Immigration."

"Referrals to clinics have to assure them that they're going to get help and not to fear about being turned in."

Women discussed how they resent male doctors who pry about personal things and judge them. One said, "*I had ten kids, on the 11th the doctor said, 'How many more are you going to have?' He was questioning me about it and it's not for a man to question about this, it's not his place."* Another woman wanted to *"have the surgery,"* that is, terminate her pregnancy. But the doctor said *"Unless your husband is with you, you can't do it."* She asks *"Why is my husband involved? It's my body, my choice. Is there a place I can go where they'll hear that this is my need, my choice?* Still another said *"As patients we have rights, but many of our rights are not heard. Doctors should not make decisions for you and should respect your desires. Everything is 'your husband, your husband, your husband.'"*

Hispanic women clearly described the challenges they face in accessing quality preventive, prenatal and postnatal care. Prevention is not something they address until they are older, wiser about U.S. culture and the U.S. health care system and have several children. They are intimidated, tend not to plan ahead and delay preventive and prenatal care, resulting in additional

runs to the Emergency Room and perhaps poorer pregnancy outcomes. The language barrier can be a problem. Most do not speak enough English to talk even a little.

Participants asked why there is no health insurance like CHIP for adults. When they want to terminate a pregnancy, they feel they are denied their rights as patients. One woman said she went to the clinic and wanted to terminate her pregnancy and *"they sent me away."* The surgery costs $2,000 and they are willing to pay a little at a time, but doctors want payment up front, so they are denied in this way, too. Participants summarized the discussions about terminating pregnancies with:

"One greatest help that can come our way is if we had a clinic for women to go to have the surgical process to not have a baby. It is not that we don't want to have more kids, it's just that it happens. If we can pay a little bit of the [cost at a] *time we are willing to do it. That's a big thing."*

"Why isn't this service available, the state pays so much for childbirth and care?"

<u>How do you know what to do when you are pregnant?</u>

They listen to their friends who say:

"You have these symptoms, probably you're pregnant."

"A lot of women don't even know how their reproductive system works."

When asked what they would do if they started contractions, most said *"I would go to the Emergency Room."* According to community outreach workers in mid-Salt Lake Valley, *"They always run to the ER."* Participants explain that *"The clinics are not open all the time, so we have to go to the Emergency Room."*

<u>What can you do to have a healthy pregnancy?</u>

"We eat fruits and vegetables, exercise, ultrasound, vitamins, iron, etc."

"It helps to be healthy when pregnant."

What are the danger signs of pregnancy and what would you do when you experience them?

Some participants offer that they *"know it is water from vagina, backache or vaginal pains."* They know they could go to the doctor or the Emergency Room, but they think *"most women don't do it and ask experienced family and friends instead."* This is because they feel health care in the U.S. doesn't give personal attention to them. This is true especially if it's the first pregnancy, which, being a new experience, prevention or knowing danger signs *"is not of great importance to them."* What they are saying is that a lack of knowledge and the cultural and social barriers they face tend to keep them from acting to prevent problems with pregnancy. And doctors think these young women are exaggerating the symptoms, so they are discouraged from saying what their problems are when they go to the doctor.

How do depression and domestic violence influence pregnancy outcomes?

Hispanic women, especially newer immigrants, consider the emotional aspects of pregnancy to be very, very important, because they think strong emotions have strong consequences for the future behavior of the children. If they get mad a lot when they're pregnant, they believe *"the child will be aggressive."* If they have a bad moment, the child could be *"too quiet."* The women agreed that their culture does tend to present challenges to their autonomy and self esteem, leading to depression, which compromises their ability to get good prenatal care. This is a very sensitive topic and the women may have been hesitant to talk more about it in a group setting. Perhaps a short clinic survey conducted by health care provider could shed more light on these issues.

What helps you receive preventive services and Emergency Room care for pregnancy and what keeps you from it?

The cost and the legal status of pregnant women are barriers to accessing services, *"specifically in the reproductive health."* They run to the hospital when their children are sick, but for

themselves they are not so willing to go. Being recent immigrants, some participants say that even if they are a legal resident, they cannot apply for assistance for the next five years, there's a waiting period. They argue *"That's when you need the most help, even if you're a professional and have to take menial jobs in the U.S."* The lack of acceptable and affordable health care keeps Hispanic women from accessing preventive services, though they are less hesitant to take their children to the Emergency Room, even if it is relatively expensive.

Participants stated that in Mexico, birth control is not available, but in the U.S. it is *"so easy to get condoms and birth control pills." "So if we want to have kids, we have kids, but why have so many kids, definitely* [birth control] *is everywhere."*

How acceptable are prenatal care services to you?

Most participants say they are not satisfied with U.S health services in general, including reproductive health. This is because doctors don't take time with them and the information they give to Hispanic women about their health is very little. It's a problem for them. When they go to the doctor, they don't know what to tell him, what to say. They don't feel comfortable enough to *"tell him what I need."* They talked about how embarrassing it is to go to the doctor, to expose themselves to a male, so they don't go for pelvic exams. It's uncomfortable for them to go to a doctor for reproductive care.

One mom shared her experience going to the doctor: Her daughter was not feeling well so she went to a local doctor, who said there was nothing wrong. But the daughter was sick that night, *"so how can I trust the doctor?"* He was dismissive, to him it was nothing. Another mom took her son to a local clinic and the doctor told her it was an ear infection. She got ear drops, but her son became very sick. She then went to a Chinese doctor, who *"put him on the machine"* and found out what was wrong with him. Participants feel U.S. doctors aren't trying to treat them.

Hispanic women also don't like the local clinics because *"it takes two months to get an appointment."* They're used to walking right in at home in Mexico. Outreach workers in Midvale are trying to educate people about the local clinics and how to work the system so they

don't have to wait. They enjoy learning about health issues and services face-to-face in their home with someone like them who speaks their language and knows what their lives are like.

While finances are an issue, mothers *"don't care about the costs"* of taking their child to the doctor: *"We do it and worry about paying later." "As long as your health is taken care of, you don't worry about the finances, you just go and do it."* They *"don't measure the cost and check into Medicaid afterward." "There is no planning whatsoever."*

Many go the U of U Emergency Room, because *"they treat us with respect, give us better care and they make me feel better and safe to go there."* They cannot afford to pay all at once, as local doctors demand, or sometimes at the University which charges half up front, but they are willing to pay over time. Something they like about the University is that parents *"get a piece of paper"* that tells them what's being done for their child, so *"I feel included."*

How do you rate the prevention education you receive?

For many participants, the best source of education is the doctor telling them *"how to do it,"* that is, how to prevent reproductive health issues *"at the same moment they are in their appointment."* Participants strongly suggest that when health workers talk about reproductive health that they talk about prevention, especially with younger people. They suggest that going through the Internet is *"definitely not for us, but for young people it should go through the Internet."*

Parents want prevention people to talk with youth about contraception because parents *"don't feel good"* talking about it. Parents also want experts to teach them how to talk to kids, because they don't have accurate or enough information. Some Hispanic women in Provo want all information about reproductive health to be focused on "*the responsibility for* [choosing not to have] *sex before marriage."*

How do you rate the media information?

Participants agreed that the written information about pregnancy is available and easily understood and *"if you don't know English it's always available in Spanish."* The information in the pamphlets is considered clear and appropriate, especially the one called "*Valgo la pena"* because it talks about the danger signs during pregnancy. They suggest modifications to the design of this pamphlet to separate *"the message for the mother from the message about the baby."* They also suggest that pamphlets include some information about mental health, because it is such an important aspect of pregnancy to them and because of the serious effects they believe a mother's mental health has on the mother and the baby.

Tobacco Prevention

Tobacco Prevention was addressed in the following group discussions:
African American Men in Ogden
African American Men in Salt Lake City
Asian American Men and Women in Salt Lake City
Samoan Men and Women from Salt Lake and Utah Counties
Tongan Men and Women from Salt Lake and Utah Counties (two groups)

African American Men in Ogden:

When the facilitator mentioned that tobacco was the first topic, participants immediately offered that tobacco use was an important issue in their community and that prevention was important, especially with youth:

"African American youth are more than twice as likely to smoke."

"*They need* [resources and messages] *'to stop you in your tracks.'"*

When asked whether or not their community was knowledgeable about the health effects of tobacco use, participants agreed that the:

"*Messages are out there so everybody knows* [the] *health effects, but it's not enough to keep from smoking."*

Two participants then shared the reasons they had avoided tobacco use in their youth:

"*If you're raised that it's just a dirty habit…."*

"*Neighbors tellin' grandma* [that you're smoking] *works.* [You will] *get a whippin'!"*

Several participants went on to explain that these reasons are not enough to keep today's African American youth from trying smoking and offered these suggestions:

"If you show the kid in the back seat of the car with parents smoking and then show the kid with an oxygen mask 20 years later, [we] *can relate to it."*

"I think the first thing that stops you in your tracks is fear."

"You gotta instill fear. If you don't fear your parents you don't listen to 'em. If you don't fear the police, you do what you want to in the street. If you don't fear the military you know, you do whatever. It's fear. If you don't fear God, you know."

"[The messages showing aging effects like facial wrinkling] *make you think. To 15 year olds, the 'this is what you look like at 30 if you smoke' gets their attention."*

"Showing a real lung is still effective. That's 'deep to me.'

"When I saw that lung, you know, I'm cool [that is, I get the message]*."*

"A strong 'slap in the face' [is needed]*."*

Ogden African American participants asserted that tobacco prevention messages to youth must be very strong, visual and fear based. These men were of all adult ages, but it is unclear whether or not this approach would be successful with Ogden youth. Tobacco prevention messages that participants said do not work include:

"Teen ones with the dudes 'look like fools' and adults don't pay attention to them."

"Incentives like having [that is, winning] *a concert at their school, the message gets lost in the competition."*

"The Surgeon's message has no effect."

The discussions around these quotes revealed that African American participants in Ogden believe their community is less likely to respond to indirect or less strong or less visual prevention messages. For example, a written warning on the side of a cigarette pack has little

impact when compared to strong visual messages about the effects of smoking such as diseased lungs. Additional advice about tobacco prevention messages for African Americans include:

"Need to show Black people against smoking, but most [media] *show them smoking."*

"Back in the day when I was young enough, athletes' messages showing what will happen 'in real life' had more impact on me than somebody talking in the parking lot. You say 'yeah, whatever' you go along with that person [until they] *shut up."*

"I believe parents' smoking leads to children smoking, so show messages with implications to both."

"Youth ride you [about smoking]. *Need to focus on them to not start but to put the pressure on to back myself away from people that smoke."*

"Peer pressure needed."

"You're gonna hang that poster up in the building where you can't smoke anyway."

"You gotta show [our] *faces.* [Otherwise] *not the same giddy up."*

The quotes above illustrate several issues or strategies that—with further validation and understanding—can be addressed to enhance the effectiveness of tobacco prevention efforts. For example, message placement could have a greater impact in locations where people smoke, such at home and in cars. It doesn't make sense to participants to place anti-smoking messages in public buildings and hospitals where smoking is prohibited. And, it may be possible to emphasize messages showing a teen smoker being left behind because he's out of breath. Participants believe that such messages may have the needed strength to impact youth smoking.

What these participants and other groups are saying is that health promotion efforts need to match the message, messenger and medium to their community. For example, show African Americans as messengers to get the community's attention so that they will be attracted to and

actually receive the message. Similarly, additional validation of the type and strength of messages is needed. Equally important is to identify and test the specific time, place and medium for sending messages effectively and efficiently to specific members of the community.

African American men in Salt Lake City:

Who in the community uses tobacco the most?

"Young African American males."

"Women, to lose weight."

"The young, to look cool."

What types of tobacco do they use?

"Young African Americans in Utah, they smoke the Black & Mild, the ones with taste, flavors."

"You go to the clubs, you see them pulling out -- not the usual cigarettes -- but the cool looking cigarettes like Black & Mild, the trendy smokes like seen on MTV."

"You go to the corner store, you go to the gas stations, you look behind the counter, what's most visible is those kinds of cigarettes."

"They're set right in front, for the kids, just like candy."

"Anywhere in SLC."

Where in public do they usually smoke?

"In clubs, at concerts and in cars."

"You go to Atlanta, Chicago, D.C., young people don't have public places to smoke, so they don't smoke. But in Utah, they can smoke, in clubs, at concerts, designated smoking areas."

In Utah, tobacco use among African Americans is almost exclusively smoking cigarettes. Use of pipes is rare these days and kids use dip only when influenced by "cowboy" peers. *"I haven't seen young people using chew or snuff…except for athletes."* Some kids make a "half-and-half" or a "blunt," they call it, by hollowing out a cigar, putting marijuana in and then finishing with tobacco to camouflage the contraband. If they get pulled over while driving, *"they're good to go."* That is, they do that so they won't get caught.

One participant asked the group *"Of those of you who smoke or used to smoke, what made you start?* Another participant answered, referring to the singular result of an identical question in a UCLA survey that he knew about: *"I started simply because I was asked* [that is, invited to]." The first participant then asked another, *"Why didn't you start?"* He answered *"Because of the smell, the kind of woman I was trying to attract."*

As the conversation shifted to prevention messages, two participants quickly concluded:

"The problem with the non-smoking campaign is:

"That information has been out there for 30 years and kids today are starting smoking at the same rate that they were when I was a kid."

"You can't watch TV without seeing anti-smoking messages, but I don't see people getting the message."

These initial comments set the stage for extended discussion about how:

"Even back in my day, you tell a teenager NOT to do something, they're going to do it."

"You've got the negative marketing, but you also have the counter-marketing going on from the tobacco companies."

"And you see it [smoking] *in the movies all the time, so that image is out there too."*

When asked if the fear-based messages suggested by other groups would be successful with this group, participants concluded that a more positive skills-building approach would have a better chance to succeed. They explained that:

"We do not operate by fear."

"The scare tactics, they really don't work."

"Some of the scare tactic advertising, people my age [younger, still in their 20s] *laugh at those things, because they make them funny. You know, The Truth commercials, the truth about smoking. They're funny, but it's not funny and they don't really get the message."*

"We prefer to emphasize the positive, to be healthy so we can enjoy life to the fullest."

This positive affirmation led participants as a group to offer an alternative to the negative, fear-based tobacco prevention strategy suggested by others:

"People come to the doctor to find out 'how can I do this, how can I get this result,' not to hear how bad they [or their behaviors, or the diseases] *are."*

"People need steps [to follow], *don't just tell me the negative, what will happen to me if I* [engage in a risky behavior]. *Show me **how** to* [adopt the healthy behavior]*."*

*"The message should be: 'We want less people to have lung cancer, this is **how** you do it.'"*

*"Tell us: 'If you want to stop smoking, this is **how** you do it.'"*

This group of men clearly stated that clever ads or emotional appeals are no substitute for teaching them how to adopt and maintain healthy behaviors. This positive, skills-based education theme was broached in several other groups of men and women alike on several health topics. These discussions would likely have been expanded upon had time allowed. In summing up, one African American young man said "*Give us choice, but give us information to make a more intelligent decision."*

Commentary

This participant-initiated emphasis on practical skills-building over *"catchy"* cognitive marketing has enormous implications for current public health efforts, including tobacco prevention and control. Over the past two decades, health promotion efforts have increasingly relied on mass-appeal awareness marketing. Behavioral science theory suggests that awareness, general knowledge and even the element of fear (that is, perceived susceptibility and severity) as a motivational tool are key steps along the path to healthy actions. However, in practice we have learned that such emotional and mental preparation is insufficient to bring us to actually adopt and maintain healthy behaviors. And, as many of this study's participants have suggested, perhaps the fear element is unnecessary and can be replaced with more positive motivations related to the innate desire to be healthy and make the most of life.

This is precisely the 'elephant-in-the-room' message that hundreds of Utah participants in this and previous qualitative studies have been saying. They are aware of the consequences of health risk behaviors and they want to do something about it, but they lack the detailed understanding and practical skills to adopt and maintain healthy actions.

Surely there are challenges to effective action, for citizens and public health workers alike. But if we actually listen and respond to what the communities are saying, a shift toward a more balanced approach to getting people's attention (through clever marketing) and teaching us how to be healthy (skills-building health education) is needed. This shift would require the redistribution (not elimination) of resources from mass-marketing to *"for and by our community"* action, which is just what participants have been telling us all along.

Asian Americans in Salt Lake City:

Participants from the Utah Asian community confirmed that cigarette smoking is a health issue and quickly moved to modifying prevention messages:

The poster of a woman holding a cigarette by the wrong end *"at first glance looks like a tobacco ad." I had to study it to know it was a 'smoking is not cool' message, so,* [if you hadn't called my attention to study it] *I would never get the message."*

"[The poster with the message about cost] *worked for me. The money angle is good, something that gets my attention."*

"Again [as with immunization posters], *cuteness doesn't really resonate with me."*

The poster depicting the 1950s doesn't grab them:

"It's something we don't know about, so it doesn't get our attention."

"The messenger doesn't have to look like me, if I care about the issue. But if I don't care, then you'd have a hard time getting me to pay attention."

"If the messenger in a U.S. ad were Asian, it would be rare and it would catch my attention."

As with the other groupings of participant quotes throughout this report, the six quotes above provide specific advice for targeting tobacco prevention messages to Utah's Asian community. With appropriate validation, messages that show Asians as messengers in more contemporary situations and emphasizing the costs of smoking could have more impact than "*cuteness*" messages set in a bygone era.

It is also possible that the advice from the Asian community, with population-specific validation, could be applied or modified to strengthening health promotion messages in other Utah populations. Said another way, *"one-size-fits-all"* health promotion messages are diluted and need to be strengthened by matching the appropriate messenger to an attractive message through selected points of delivery, all tailored to specific audiences.

Samoans from Salt Lake and Utah Counties:
Importance

"Tobacco use is important to Samoans."

"My dad died of lung cancer but family members still smoke."

Messages about the importance of tobacco use among Samoans were mixed, saying that it still is important to some, but for others it isn't or it shouldn't have to be important by now.

Prevention

"Bring out real lungs."

"Use the visuals of the sick baby of smoker to get message across."

"Beyond the shock message, schools need to come down hard on the kids."

"Need consistent messaging, daily, not just 'drug day.'"

"Red Ribbon week doesn't work in the long run. Should be getting everyone involved."

"Administrators don't enforce rules. Kids smoke in the baseball dugout all the time. There are no security or campus walkers. No teacher or administrator accountability. Need to enforce the rules at school. Bring the dogs through weekly."

"Smoking was a social norm for me, growing up in Los Angeles. The negative messages I see now don't hit me. There's no incentive for me. We're bombarded with all this negative stuff. I'm not really going to listen to it. On Oprah, with Dr. Haas, says smoking is bad, but that's not really personal to me. The shock message and TV ads don't have lasting impact."

As in other groups, the discussions quickly turned to problem solving. Samoans agree that tobacco use is an important issue in their community, but even when the effects of smoking hit a member of the family it isn't enough to get other family members to quit.

Discussions revealed that not trying to quit may be related to a perceived lack of affordable access to quit smoking programs or to the hold that nicotine has on smokers, as well as the peer support of and media encouragement for smoking that surrounds us. Samoans in Utah may benefit from learning more about stop smoking programs, assistance paying for these programs,

along with increased community support for quitting and renewed efforts to energize school-based policy enforcement and prevention efforts.

Samoans and Tongans from Salt Lake and Utah Counties:

Is tobacco use an issue in our community?

"Everyone knows smoking is unhealthy, but some are still smoking in Tongan churches. [More and more] *others stop them from smoking though."*

"There is denial about youth smoking. I caught LDS kids, knew them, who were smoking at a dance club."

"Smoking used to be everywhere, even on airplanes, but now [gradually] *all people are smoking less."*

"People are moving on with the times, fewer people are smoking now. It's a natural progression."

These statements seem clear enough: Tobacco use is an important issue in the community, but the good news is that over time, fewer Pacific Islander adults are using tobacco. The older participants have observed this gradual reduction in all populations, not just Pacific Islanders. Although the elders recognize the impact of anti-tobacco messages – from the Surgeon General's warnings to the more recent media barrage, to the laws prohibiting public tobacco use – they see the gradual drop in tobacco use as being influenced just as much by the natural result of people wanting to be healthy and live *"to be there for our grandchildren."*

Though not stated as directly in this group as it was in others, participants recognize that positive messages and motivations may be just as influential and potentially longer lasting than the *"anti-smoking"* messages they see.

Who uses tobacco in our community?

"Men and women between ages 20 and 50 use tobacco the most, they seem to quit later in life."

"Younger women because they think it makes them look cool; they're social smokers; ages 20 and up."

"Younger people smoke, even LDS kids, though they're not supposed to."

This question may be better suited to a population survey if asked more directly (that is: Do you use tobacco?). No one was sure of their answer speaking for the community but they gave their best impression of the incomplete snapshot they recall seeing. Each comment in this group could have come from any of the populations participating in the study.

Participants see a natural drop-off in smoking as people age, believe that younger adults, especially women, tend to be *"social smokers"* [their term], and are concerned that too many youth try smoking and too many become regular smokers. They see the need for tobacco prevention efforts to start with the very young, in grade school as well as at home, and to reinforce prevention messages into young adulthood.

<u>What kind of tobacco do we use?</u>

"Marlboro Lights, that's the choice in our community."

"Other types of tobacco we don't use much."

While it may be worthwhile to conduct a population survey to validate participant impressions before acting, it would appear that in Pacific Islander populations, tobacco prevention could be the most effective and efficient by focusing on cigarette smoking.

<u>Where do people in our community use tobacco?</u>

"If there are young children in the house, most people go outside to smoke now."

"At church, everybody goes outside to smoke now."

"We don't smoke in the Kava room anymore." (Kava is a traditional Pacific Island herbal drink used for ceremonies and celebrations.)

Participants were politely unwilling to talk about the "Kava Clubs" or what occurs there. They did share that the reason they smoked in the rooms before is that cigarettes are a natural "complement" to drinking Kava, just as cigarettes are to drinking beer. *"They just go together."* As for why they have stopped this practice and that Pacific Islander congregations generally smoke outside now, they say that there is more awareness of the negative effects of smoking and second-hand smoke and that recent community-based prevention efforts have been helpful.

What about quitting smoking?

"Help us stop only when we are ready and in the way we can accept, or it will not work."

"Quitting really doesn't separate us from each other."

"Stopping doesn't really change things with us."

"They shouldn't go into places and force us to ban smoking; it should come from within, voluntarily."

Prevention Messages

"Prevention is not part of the Tongan mentality. Tongans don't quit because of a program, just because I decide to quit."

"[You] *can't give us programs made for others. Need to show us the program and let us decide for ourselves."*

"I still agree if they put it in print and on TV, we'll know [be reminded that] *smoking is bad for us. If that's the way some people will get the message, then keep it in there."*

"I remember the TV ad with 12,000 people going to the tobacco company building and all laying down to show how many people die from smoking."

"They did an ad on the bus about being diabetic, with a 'sister,' and it really got the attention of a lot of people…and it still does."

"The peer 'yech' message is really good."

Participants in the fourth Pacific Islander group reinforced the messages of the first three, that media messages are part of effective tobacco prevention efforts in their communities, suggesting:

"Messages would have more impact if we see our own face in messages, in our language. This way it will get our attention more and the message will get through to us and last longer for us."

"If they show that they care enough to present messages in our language, then we are naturally more receptive and likely to act."

"They will get more 'bang for their buck' if they do it in our own language, because we'll remember it and think about it for a longer time."

"There's some power in your own language, it gets people to move."

One participant summed up the discussion about written materials with: *"Even with the fliers, if they're in our own language showing people from our community, the people will pick it up, take it home and read it. If it's an English reading flier, then just forget it."* A participant who works on the radio during a Pacific Islander show stated that when they do an ad for Western Union in Tongan, the people are responsive. If they do it in English, there's little response.

Throughout this study, participants across racial and ethnic minority populations have sent this common message: Prevention efforts reflecting a person's culture and language are worthwhile because these messages get "our" immediate and longer-lasting attention, teach us in our own way and encourage us to act. The generic message style loses its influence in communities whose cultural identities are already being eroded by the "fit into the majority" approach.

Prevention Resources

The proportion of prevention resources distributed to Utah's racial and ethnic populations came up in many of the 17 groups. Pacific Islanders stated that:

"The percent [invested] *in the ethnic communities is not reflective of ethnic taxpayers."*

"We get the crumbs. The larger community is satisfied giving some crumbs."

"The piece of the pie we used to share with [another population]*, we used to get nothing, they gave us a crumb, or nothing."*

"So why are they not reaching these different communities? It doesn't take that much in the little communities."

Once again, participants across populations are sending the same message about prevention:

> *"We need a budget to* [pay for] *face-to-face* [interventions] *in our community."*

Participants used the term "face-to-face" to describe their community's cultural tradition of learning by talking to each other. Life experience in their communities tells them that learning how to prevent health problems through community gatherings led by trained facilitators from their community will be more effective than, for example, statewide public service announcements. No one meant that they wanted prevention efforts to be one-on-one, that is, one person to one person. And, no one suggested eliminating media efforts altogether. Participants were responding to what they know works in their communities.

Suggestions for Action

Participant suggestions reflect an understanding that Utah's racial and ethnic minorities must take responsibility for encouraging families and individuals to be healthy. As in 1997, the current participants clearly state that successful health promotion will come only through a *"bottom up, grassroots"* approach that is culturally sensitive and competent. Some readers of this report may conclude *"that's nothing new,"* but the communities' continued call for action indicates the call has yet to be answered to empower minority communities to act.

Participants do appreciate state and local health promotion efforts, but believe that adequate resources must be directly invested in the communities to be successful. Overall, the discussions about pamphlets, brochures and media spots suggest that these strategies do not substitute for community-based, culturally-relevant, peer-led health promotion. At best, it appears that written materials and media messages can reinforce more grassroots, personal efforts in the community.

Participants explain that they respond best to respected members of their own community who are trained and paid to encourage and teach them why and how to adopt and maintain healthy actions. Experienced volunteers from minority communities have, for some time now, warned that continually tapping those who are willing to do this work, without compensation, is wearing thin.

Consider the Implications for Action that Each Participant Comment Offers

When examined in the context of health behavior theory and best practices, nearly every comment in this report can provide context and insight to help guide program planning and implementation regardless of the health issue being addressed. This is not to give outsized weight to every comment, or to say that everything we need to know or act upon is here. But taken as a whole, participant comments can serve as a road map to successfully encouraging members of diverse communities to adopt and maintain healthy behaviors.

This report represents a unique body of knowledge that, when compared and contrasted with existing quantitative data, can inform decisions about any public health effort. It may be useful to utilize the entire report in designing strategies to address any one health topic.

Increase Access to Affordable Employee Health Insurance

While this complex issue continues to defy simple solutions, it remains the greatest health concern of the majority of participants. They explain that many members of their communities have incomes that disqualify them from publicly funded health care services, yet they do not have the expendable income to pay health insurance premiums and co-payments. According to the participants, this leads to significant delays in seeking care, which in turn aggravates health problems, leading to higher costs of care for all. They also understand that given the lack of progress over the past 15 years, "universal" health insurance may not be coming anytime soon.

Include Us at All Levels of Decision Making

This is a message about true inclusiveness. As in 1997, current participants believe they have much to offer all Utahns in planning and implementing public health efforts. They assert that having separate "minority health" committees in effect disenfranchises them from state decisions about how to successfully design programs and allocate resources. This is a reflection of how Utah minorities communicate and learn within their local communities, which they believe is fundamentally different from how the majority population learns and communicates. This is a call to adopt a truly inclusive program planning and evaluation process. Community leaders and ordinary citizens want us to embrace their diversity and help them to build the capacity and skills to take a leadership role in enhancing their communities' health.

Support Grassroots Strategies

Communities want us to understand that generic, top-down efforts do not stimulate interest or action. They are sending clear messages that their styles of communication and learning are more social and person-to-person than the traditional public health efforts they see. Community members recognize they need a budget to build community capacity. They also recognize this is a call to state and local entities to shift resources in order to successfully support Utah's minority communities. A greater emphasis on building capacity and strengthening local community-based organizations could be useful.

Address the Common Themes (page 11) Including the Four Prevention Challenges

Regardless of whether affordable health care for all is coming, it will be important to address the perception that access to doctors is prerequisite to adopting and maintaining healthy behaviors. Participants do recognize they must fully participate in public health efforts in their community and with their families. But to see doctors as the answer or gateway to adopting health actions is to avoid the true first step for healthy actions: taking personal responsibility for one's health. To realize community prevention goals, it will take true community partnerships with state and local programs to enable members to take action.

Emphasize Understanding of the Details of Health Issues Beyond Simple Awareness

Most participants know the basics of health issues that affect their communities. They are aware of the consequences of health risk behaviors, but not as comfortable with the details, such as the signs and symptoms of stroke, or when to call 911. This is not to suggest that continued mass awareness marketing efforts are to be overlooked, but increasing reliance on clever attention-getting media messages in place of detailed community health education ignores important messages from the community that can be found throughout this report.

Invest More Resources in Skills-building Strategies

Participants uniformly state that they do not feel equipped to plan and act effectively in the long-term to lower their risks of preventable health problems. They understand the importance, but are inconsistent in their efforts. Adopting and maintaining healthy behaviors is a challenge for everyone. Minority communities explain that they are faced with stronger cultural and social challenges and are more easily discouraged. They know that clever ads and emotional appeals are no substitute for teaching them how to adopt and maintain healthy behaviors.

(This commentary is repeated from the Tobacco Prevention Section, page 73) This participant-initiated emphasis on practical skills-building over *"catchy"* cognitive marketing has enormous implications for current public health efforts, including tobacco prevention and control. Over the past two decades, health promotion efforts have increasingly relied on mass-appeal awareness marketing. Behavioral science theory suggests that awareness, general knowledge and even the

element of fear (that is, perceived susceptibility and severity) as a motivational tool are key steps along the path to healthy actions. However, in practice we have learned that such emotional and mental preparation is insufficient to bring us to actually adopt and maintain healthy behaviors. And, as many of this study's participants have suggested, perhaps the fear element is unnecessary and can be replaced with more positive motivations related to the innate desire to be healthy and make the most of life.

This is precisely the 'elephant-in-the-room' message that hundreds of Utah participants in this and previous qualitative studies have been saying. They are aware of the consequences of health risk behaviors and they want to do something about it, but they lack the detailed understanding and practical skills to adopt and maintain healthy actions.

Surely there are challenges to effective action, for citizens and public health workers alike. But if we actually listen and respond to what the communities are saying, a shift toward a more balanced approach to getting people's attention (through clever marketing) and teaching us how to be healthy (skills-building health education) is needed. This shift would require the redistribution (not elimination) of resources from mass-marketing to *"for and by our community"* action, which is just what participants have been telling us all along.

Refine Social Marketing Messages to Attract Us

Throughout this report, participants have provided specific suggestions for making minor adjustments to current marketing efforts that can increase the appeal of messages to specific communities. Much has already been done for Spanish speakers, but African Americans and Pacific Islanders believe that messages need to be modified to attract attention in their communities. These communities assert, however, that written materials and media ads are needed only to reinforce the person-to-person influence model they advocate as necessary to encouraging healthy behaviors in their communities.

Adopt a Less Formal Qualitative Process

Personal, face-to-face input from those who will plan, implement and be targeted for public health programs is crucial to the success of any such effort. From the communities' point of

view, it is no longer necessary to employ a formal research process to promote communications about needs and strategies. And from the investigator's point of view, asking the communities to help plan in the abstract, practically "off the top of their heads" in formal group discussions has served its purpose.

What is needed now is timely, continuous feedback as programs are formed and grow. Ongoing "spot checks" between planners and community members can help to ensure that all parties are understood in creating flexible, responsive and successful strategies. *"Working together"* to serve the community is the message. Public Health planners can ask community members to informally review plans before they are fully formed and disseminated and community members can continue to provide feedback as planning progresses.

To facilitate this mutual learning process, a new, relatively inexpensive Tablet PC survey system is available that, in addition to easily facilitating multiple surveys in the community, allows quick and unobtrusive reviews of curricula, pamphlets, or potential TV messages, while providing feedback to developers without delay. This system is proving to be more user-friendly to many of our community members than e-mail or online surveys or focus groups. It also supports ongoing dynamic survey assessments of progress, which can include open-ended audio and video messages from community members to illustrate survey findings. And, planners can simultaneously identify timely program enhancements, while evaluating the short-term and intermediate impacts of their efforts.

It is the authors' belief that the current messages from the community summarized in this report—along with the adoption of a more interactive planning process in the future—will enhance our efforts to eliminate health disparities in Utah's racial and ethnic communities.