Supplemental Report

Quantitative Ethnic Health Survey Methods

UTAH HEALTH STATUS SURVEY ON ETHNIC POPULATIONS -- QUALITATIVE COMPONENT

Prepared for:

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Background

This report outlines selected methodological issues and suggests strategies that can increase the accuracy and usefulness of quantitative ethnic health survey data in Utah. The content of this report reflects the professional literature on ethnic health research, but does not represent a traditional academic review of the literature. This report has a very specific purpose: To outline strategies that will assist the Department of Health in conducting successful quantitative ethnic health surveys.

In this report the author presents the rationale for conducting ethnic health surveys; identifies selected methodological challenges to obtaining accurate and useful information; and outlines strategies to overcome these challenges. Each will be useful in identifying ethnic health needs and gaps in services, measuring the factors influencing ethnic health status, and understanding how to successfully address these issues within ethnic populations.

The Place of Ethnicity in Research

In discussing ethnic modeling in qualitative research, John Stanfield makes and defends three defining statements:

> *"We all have ethnicity, even though it may be entangled with status and social organizational attributes such as class, gender, age, ethnoregionalism, and religion."*
>
> *"Even the most 'rational' modes of scientific thought are fundamentally ethnic products."*
>
> *"Nowhere is there a structural framework for understanding the structures that organize and even marginalize and exclude knowledge production regarding Afro-Americans and other people of color."* (Stanfield, 1994)

Stanfield argues that there is a decided Eurocentric bias in the conceptualization, collection, interpretation and use of specialized information. He calls for the development of theories and methods "that more adequately reflects the plural character of American society and the global community." (Stanfield, 1994)

In sum, the literature echos Stanfield's call for ethno-sensitive research. It seems a reasonable approach toward successfully addressing needs in ethnic populations.

The Case for Ethnicity in Health Research

Norman Anderson, in his introduction to the special issue of *Health Psychology* devoted to ethnicity and health, makes sweeping statements in calling for "much needed future research on health behavior processes among ethnic minority populations." (Anderson, 1995). He states that:

> *"Wide disparities exist in the life expectancy and health status of ethnic minority populations and the majority population of the United States."*
>
> *"The health profiles of Latinos, Asian Americans and Pacific Islanders, and Native Americans do not show consistently poorer health relative to the majority population. Yet when the health status of subgroups within these populations is examined, several differences are observed between their health experience and that of the total population."*
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> *"Research clearly indicates that behavioral, sociocultural, and environmental factors contribute significantly to each of the causes of excess morbidity and mortality in ethnic minorities....Social and environmental factors such as poverty, culture, residential environment, access to health care, and exposure to racism form the context in which health behaviors arise."* (Anderson, 1995)

Numerous epidemiological analyses of national data cite measurable differences in disease rates across ethnic groups when compared to whites (see, for example Flack et al., 1995). Closer to home, we have estimated, for example, that the risk for HIV infection and AIDS for African Americans in Utah is twelve times higher than that for whites (Gray et al., 1996). Nickens and colleagues (1995) state that "race/ethnicity also matters" beyond socioeconomic status when explaining poorer health among ethnic populations. Anderson continues by stating that:

> *"Very little is known about the prevalence, antecedents, and consequences of health-promoting and health-damaging behavior in ethnic minority groups. Thus, there is a pressing need to document what is currently known and to begin to chart the direction for much needed future research on health behavior processes among ethnic minority populations." (Anderson, 1995)*

In sum, the literature makes a strong case for conducting local ethnic-specific health research that goes beyond traditional epidemiologic identification of relative risks for disease to an understanding of the factors influencing health status.

The Case for Ethnic Health Research in Utah

While all of these assertions from the literature ring true, authors offer no advice for timely action to address current ethnic health needs, calling only to institutionalize the process of understanding through "future research" on the subject. This is at odds with the demands of recent participants in Utah's qualitative ethnic health study for direct action steps to counteract what is seen as "the government's" penchant for further study and perpetual inaction. The Department of Health has begun to overcome this by identifying health needs and gaps in service through the qualitative ethnic health study. By seeking funds from the State Legislature to continue this work, the Department of Health is taking an important next step. Hopefully, internal actions based on the recent qualitative information are being taken as well. Regardless, if the State of Utah is to respond to the health needs of ethnic Utahns, the need remains for timely and ongoing efforts to understanding the factors influencing ethnic health status among and within diverse populations.

We have much to learn if we are to successfully respond to the health needs of ethnic populations in Utah. First of all, we still do not know if the resources for needed efforts would be made available by majority-group decision makers. We have not examined the importance of measured ethnic health status differences in practical, social or political terms. And, we really do not know that, even if armed with useful information, the health system in Utah (i.e., the providers and consumers of prevention and care), has the capacity to adopt and maintain successful strategies to enhance the health status of all or even one ethnic population. Further, we know very little about what distinguishes one population from another on a health issue, the extent of any differences between groups, or the consistency of these differences within any one group. We do not know the extent to which existing efforts can be modified to meet the needs of ethnic populations, or whether separate efforts to meet specific needs will be required. We do not know enough about the details of how to proceed with efforts to impact the health status of any one group, or whether we can actually succeed or maintain success. We do not collectively know what these efforts would cost, or if shifts in available resources would produce a health status deficit in another group. And, we do not know whether such efforts would be socially acceptable, or cost-effective.

What we *do* know is this: It seems that to *try* to meet the *Healthy People 2000* (USDHHS, 1990) goals of enhancing the health of *all* Americans is worthy of our careful attention. It seems appropriate then, that Utah invest in efforts to increase our understanding of the factors influencing the health status of ethnic populations.

Selected Issues in Ethnic Health Research

Many authors begin their discussions about ethnic health research from the viewpoint that the field is poorly developed due to simple neglect, stating that all that we do not know about appropriate health-related prevention and care in ethnic populations is somehow due to a lack of effort. This is contradicted somewhat by the substantial literature on the subject, but the authors' assertions fairly reflect our relative lack of understanding about the factors that influence ethnic health status.

Researchers have struggled, I believe, for three important reasons: 1) difficulties in identifying and accessing ethnic populations; 2) imprecise measurement of complex health constructs, and 3) heterogeneity within groups. The errors that these three factors introduce into quantitative analyses typically overwhelm any measurable between-group differences. Without considerable attention to minimizing these errors, ethnic health policy decisions will remain largely uninformed by traditional, Eurocentric efforts to quantify the health needs of ethnic populations.

There are other issues, such as emphasizing the quantitative measurement of ethnic health status and making "gold-standard" comparisons to European descendants, over identifying the factors influencing ethnic health status (see Flack et al., 1995). I will repeat this discussion for those who still need to ponder it: Merely knowing that there is a statistical difference in risk for some disease in an ethnic population relative to majority Americans, or Utahns, tells us nothing about how to address the issue. Collecting epidemiologic data by race and ethnicity can be valuable, but taking steps to identify the factors influencing a particular ethnic health state will be much more useful if we are to successfully address ethnic health issues. Further, experience dictates that taking steps to develop a practical understanding of *how* these factors influence a state of health -- from the perspective of those who will be affected by a system's actions -- will be needed in order to choose actions that actually have a chance to succeed. As in the ethnic health issues report, I recommend that Utah adopt a blend of qualitative and quantitative methods to measure ethnic health status, identify the factors that influence ethnic health status, and begin to understand the mechanisms through which these factors influence the health of ethnic populations.

In sum, the adoption of strategies to minimize sampling errors, imprecise measurement and heterogeneity within groups -- *all with an eye toward understanding the factors influencing health status and building strategies to address them* -- will be crucial to the success of efforts to enhance the health status of ethnic populations in Utah.

Strategies to Minimize Sampling Errors, Imprecise Measurement, and Heterogeneity Within Groups

The literature and our qualitative study results offer several strategies to increase the representativeness, accuracy, and usefulness of quantitative ethnic survey data:

1. Define More Homogeneous Ethnic Groups

That there is great diversity both within and across ethnic populations is a common observation among ethnic health investigators, along with the warning that generalizations about any one ethnic population are difficult to make. This observation and warning also was offered without prompt by many non-researcher participants in our recent qualitative ethnic health study. *The common wisdom then, is that health promoting actions must respond to within-group variations in order to have a chance to succeed.*

As we discussed during the first public meeting on the qualitative ethnic health study results, not all across- or within-group variations in health status or the factors influencing health status will require separate programs or variation-specific strategies. It is quite possible that existing strategies, enhanced by group-specific information and evaluative feedback, can be successful. (This, of course, should be examined in planning and piloting actions to address any health need.) Further, it would prove unwieldy and impossibly expensive for the public health system to increasingly tailor every activity toward a one-to-one style of service orientation. *Despite obvious resource limitations, the quality and usefulness of ethnic health information, and the ultimate success of actions in response to this information, will depend on our ability to identify relatively homogeneous populations for separate analysis and program planning attention.*

The possibilities are endless; we could attend to numerous categories of within-group differences that may differentially influence the health status of individuals: age, income, education, employment status, generational status, immigration status, length of exposure to U.S., year of immigration if foreign born, country or culture of origin, county or zip code of residence in Utah, social exposure, language proficiency, and many others. To measure all of the possible descriptors, and to obtain representative samples of all possible combinations of people representing these descriptors would be neither practical nor feasible. *Some **a priori** grouping decisions will need to be made to ensure that representative data for selected groups are obtained.*

The literature offers few clues as to selection criteria upon which to base grouping decisions. Such decisions are complicated by the overlap between descriptors. It would seem obvious that we begin with the five major ethnic categories adopted for the qualitative study. There is nothing obvious about where to go next. Decisions about which sub-groups to study in depth and which to ignore are, in the end, more political than methodological. Again, we do not know enough about differing needs, or which group will benefit most from informed actions to decide who to study in depth and who to leave out. *In the absence of clear selection criteria, sampling decisions in a quantitative ethnic health survey will require greater investments to understand the options and consequences than is usual for other surveys.*

Sampling decisions will also be constrained by available resources. Do we want representative data from 200 elderly Asian Americans and 200 young Latinos? If both, this decision alone will increase data collection costs by up to 40% over the original five group by 200 per group design. Do we want to distinguish between the health needs of established 3rd generation Pacific Islanders and 1st generation newly immigrated Pacific Islanders? Our qualitative results say we should for this and three other populations. *Even if fewer than 200 responses to a survey will be accepted as representative for any sub-group, each decision to separately study and respond to the needs of another group arithmetically increases the instrument development, data collection, analysis, and reporting costs of the quantitative survey.*

One view of group selection is based on practical considerations: Choose groups to study in depth according to your capacity to apply actions that will foster the greatest positive shift in health status among the greatest number of people. This ignores political considerations which more likely than not will dilute the impact of any action you apply. *In the face of what will be very difficult decisions to make, it will be useful to involve ethnic populations to help define a limited number of key sub-groups for in-depth analysis.*

2. *Adopt More Direct Sampling Strategies*

The Department of Health is intimately knowledgeable of the weaknesses of random digit dialing strategies used to sample ethnic minorities. In Utah, small population sizes, frequent moving, and less access to a telephone all have made this relatively inexpensive survey method an undesirable option in other than a majority population. Studies reported in the literature that have successfully used this method have been fortunate to have large clusters of

ethnic populations that can be identified by well-defined inner-city neighborhoods, zip codes or telephone exchanges. *Clearly, it will be difficult to locate and enumerate all members of ethnic populations in Utah.*

One alternative in Utah's ethnic populations is to enlist the communities' help in compiling rosters of each population based on listings from organizations in the community serving these groups: Church roles, provider listings, service groups, and other sources. From this roster, it may be possible to take a second step through census tract data to identify neighborhoods where population members are clustered. However, limited resources will likely preclude "snowballing" by actually canvasing neighborhoods. These methods are labor intensive, time consuming and costly, but can produce a much more complete listing of ethnic populations than more indirect methods (e.g. telephone listings). *It may be worthwhile to consider less-expensive quota-based sampling procedures that do not require a complete enumeration of population membership.*

3. Adopt More Inclusive Recruiting Strategies

Blumenthal and colleagues (1995) found through experience what participants in our qualitative study clearly understood from the beginning: Personal contact and trust building within an ethnic population will greatly improve the representativeness and participation in a survey. Blumenthal and colleagues were more successful in enrolling subjects when they "began recruiting directly from the community -- that is, when we substituted a *community-based* recruitment strategy for the previous *institution-based* (or clinic-based) strategy." They also found that face-to-face communication was superior to communications by telephone, and concluded that "special attention must be given to [community-based recruitment strategies] if the validity of the study is to be preserved." Marin and Marin (1991) cite research in stating that Hispanic populations are willing participants in studies. However, they also suggest community acceptance and involvement is important to survey success. Participants in our qualitative study reported that their communities would, with the appropriate preparation, be willing to help with the actual recruitment of participants -- from "getting the word out" to transporting community members to a common survey site. *Recruiting and retaining participation of ethnic populations will require their knowledgable support, ongoing involvement, and willing participation in all phases of a survey.*

4. Ensure More Precise Measurement

The more enlightened literature calls for investigators to ensure more valid quantitative measurement of socioeconomic status and health status, and broader coverage of factors influencing health status. The issues involved are complex, and will require significant efforts to successfully address them. *Issues of the appropriateness of common assumptions about meaning and the importance of constructs (which may not be consistent across or within cultures), complexity, measurement strategies, cultural adaptations, question wording, translations, and interpretation all need to be addressed if Utah's quantitative ethnic health survey is to provide accurate and interpretable data.*

Some investigators offer cogent arguments against traditional measurement of socioeconomic status for a variety of reasons. Investigators in Britain conclude that a "new approach that directly measures individuals' material and social needs" would resolve current problems in using class and ethnicity to stratify the population (Benzeval, Judge, & Smaje, 1995). Other investigators in the United States have drawn similar conclusions and question whether valid comparisons between groups can even be made through measurements of social, economic, and political status, and ask in their conclusion "Can human variability be explained by the concepts of race and ethnicity? (Schulman et al., 1995)." *It may be necessary to adopt new measures of socioeconomic status or "material and social needs" to ensure precision and meaning in ethnic populations.*

Other investigators call for measurement of the impact of culture and acculturation, and the health impact of racism on ethnic populations (Anderson, 1995). The importance of culture, acculturation, racism and ethnically-unique life stressors as factors influencing ethnic health status in Utah was independently supported by participants in our qualitative study. The Flack article (Flack et al., 1995) provides a detailed discussion of these and other "influencing factors" with numerous literature references for each of the major ethnic groupings. *It will be important to measure cultural constructs in the quantitative survey in order to identify and better understand the factors influencing ethnic health status in Utah.*

5. Incorporate more culturally responsive data collection strategies

Again, the literature, Utah's quantitative survey experiences and our qualitative study participants tell a very consistent story: Impersonal mail and phone methods of collecting data must be replaced with more personal, community-based data collection strategies in ethnic populations. When we asked qualitative study participants how to do this, several participants offered comments similar to this one: "The way you are doing this study is the way it ought to be done." The basic strategy we adopted was to involve community members in all phases of the project; to collaborate with ethnic populations in "telling their story." We worked to build trust in the community and develop their understanding of the purposes and desired outcomes of the study. We asked for their advice on what questions to ask in the community, and where, when and how to ask these questions. We employed community members in key positions to ensure cultural input and demonstrate community ownership of the study products. We also attempted to share the results with community members, and encouraged decision makers to take timely action in response to results. We were following protocols built from our own experiences, which we subsequently found coincided with suggestions in the literature (Anderson et al., 1995). *It will be crucial to the success of the quantitative ethnic health survey to actively enroll ethnic populations in all phases of the survey process; from conceptualization, sampling, instrument development, data collection and analysis to reporting and acting upon results.*

Although qualitative study participants universally endorsed more personal, face-to-face contact for collecting health information in ethnic populations, the costs of doing so are prohibitive. This is the primary reason that Utah has yet to collect quantitative generalizable ethnic health data. During qualitative study group session, I began to offer a compromise solution designed to control data collection costs and overcome some of the conceptual and language difficulties in measurement, while achieving sample sizes large enough to complete meaningful analyses. The compromise involves a form of cluster sampling, and blends quantitative checklists and multiple choice questions with group- and individual-level assistance designed to support accurate completion of the survey. This assistance could include verbal recitation and visual representations of each question and potential response, combined with personal assistance from trained, culturally- and linguistically-appropriate members of each population or sub-group. *A cluster-sampling blend of qualitative and quantitative methods may work.*

Essentially, we would approximate expensive face-to-face interviewing techniques in less costly large-group settings. The basic strategy involves gathering community members together in a well-respected community location to complete -- with ample language and content support -- an oral/visual/written survey. There are several strengths to this approach. With enough groups within each study population, we could achieve a much greater representation of population sub-groups than through traditional random sampling techniques. With personal assistance to respondents, and their added comfort in participating along with other members of their community, we could achieve a much greater quality of data than is possible through individual face-to-face or telephone interviews. And, to reduce respondent burden and thus maintain the quality of data collected, we could consider item sampling (giving some respondents question "six" but not question "seven," and giving others question "seven" but not "six"). *This blended approach offers a feasible alternative to costly interviews and ineffective phone survey methods, and shows promise for enhancing the quality and usefulness of data collected.*

It would seem reasonable to expect that even newly immigrated members of ethnic populations would have had similar experiences of completing forms or "paperwork" in group settings such as schools, at work or in accessing health system or government services. Still, it may require a good deal of explaining and demonstrating the protocol before respondents would feel comfortable in making accurate responses. Of course, the details of this data collection method remain to be specified and put to a meaningful test. *When asked about the feasibility of this unique blend of quantitative and qualitative data collection strategies, qualitative study participants responded positively; reasoning that with their help, we could accomplish our data collection objectives.*

As an added step in the data validation process, survey results could be shared with a sub-set of survey participants for group discussion and clarification. This step could easily become the first post-survey planning activity, and could serve a second purpose to inform the design of actions in response to survey findings. *It would be very useful to share findings with survey participants to clarify interpretations and begin to define next-steps.*

6. Invest in Survey Design and Preparation

The previous discussion emphasizes five methodological strategies to limit errors introduced by traditional sampling, measurement and analysis strategies, and to increase the usefulness of results in planning responsive actions. Embedded within each of the five overall strategies are multiple issues to address, decisions to make, and tasks to complete. *To properly design and implement these strategies will require greater investments in survey preparation than usual.*

Findings from the literature and our qualitative study suggest that there are two major elements of survey preparation that we usually do not face in conducting quantitative surveys: Community preparation and a significant amount of strategy development and testing. Both can and should be addressed simultaneously, but will require several months to complete. The time line for legislative approval of the quantitative ethnic health survey (January-February, 1998), and the projected date for release of funds (July, 1998) provides an ideal window of opportunity to begin the community preparation process and complete some of the strategy development work in advance of the July start date. This would virtually ensure that fieldwork could be completed during Fall, 1998. Should fieldwork be pushed back to Winter, 1999, the State would surely solidify the perception of nonresponsiveness and inaction that ethnic populations in Utah already share. *Thus, investments in survey design and preparation during the March-June, 1998 are strongly recommended.*

You have suggested that because of the work loads in the Department, a consultant could drive this background work, which could take the following general form: On a monthly basis over the four months, the consultant would study one or more of the issues outlined in this report; organize findings into an outline proposing methods to adopt in addressing the issues; list decisions that need to be made; meet with the quantitative ethnic health survey work group to discuss issues and make preliminary decisions; and then develop a written protocol for that portion of the survey. *Survey design and preparation work could proceed through a monthly process whereby the issues and decisions broached in this report are addressed, culminating in a written protocol for completing each phase of the survey.*

For example, during the first month the most timely topic would be Community Preparation for involvement and support. The consultant could informally contact members of the community for advice on how to organize

community preparation efforts; identify who would be involved in these efforts; and specify methods for obtaining community support and involvement in the various stages of the survey process. This plan could then be implemented through the Ethnic Health Committee. Another topic, community-based sampling strategies, could be addressed simultaneously with Community Preparation. The consultant would outline suggested strategies with community input, identify community resources for identifying population members, discuss strategies and decisions with the survey work group, and develop a protocol for completing community-based population identification and sampling. This process would be repeated for other topics on a monthly basis, culminating in specific protocols for completing the various phases of the survey. For example, important decisions about what to measure, how to measure and how the measures fit into an overall analysis plan should be made with substantial direction from the survey work group. *With this preparation completed, the survey contractor could proceed more smoothly into the data collection phase of the quantitative survey, with a larger share of contract resources available for data collection activities.*

Recapitulation

"Research and experience have demonstrated that traditional sampling and data collection methods are problematic in ethnic communities. Special strategies designed for gathering survey data from representative samples of small populations are expensive, and have to date precluded any health survey activities in Utah's ethnic communities. While acknowledging that there are limits to the amount of dollars that are available, we propose a methodology that can be designed to gather survey data from reasonably representative samples from each ethnic population (at least as representative as traditional survey methods can produce). In addition, the proposed methodology will serve to enhance the quality of the data collected far beyond that which traditional methods can produce, short of prohibitively expensive face-to-face interviews conducted by trained, native-speaking, culturally competent interviewers." (Haggard, 1997; Excerpted from a personal communication)

To this end, I have offered suggestions for collecting ethnic health information in Utah to enhance the quality of data collected, the acceptability of results to providers and consumers alike, and the usefulness of results in addressing ethnic health needs. I will be happy to discuss this with you at your convenience.

References

Anderson, N. B. (1995). Summary of Task Group Research Recommendations. *Health Psychology 14*(7), 649-653.

Benzeval, M., Judge, K. & Smaje, C. (1995). Beyond Class, Race, and Ethnicity: Deprivation and Health in Britain. *Health Services Research 30(1)*, 163-177.

Blumenthal, D., Mort, E., & Edwards, J. (11995). The Efficacy of Primary Care for Vulnerable Population Groups. *Health Services Research 30(1)*, 253-273.

Flack, J. M. et al. (1995). Panel I: Epidemiology of Minority Health. *Health Psychology 14(7)*, 592-600.

Gray, D. Z. et al. (1996). *Utah 1995 HIV/AIDS Data Profile and Year 2000 Projections*. Salt Lake City, UT: University of Utah, Research and Evaluation Program.

Haggard, L. M. (1997). Personal Communication.

Marin, G. & Marin, B. V. (1991). *Research with Hispanic Populations*. Newbury Park, CA: Sage Publications.

Nickens, H. W. (1995). The Role of Race/Ethnicity and Social Class in Minority Health Status. *Health Services Research 30(1)*, 151-162.

Schulman, K. A., Rubenstein, E., Chesley, F. D., & Eisenberg, J. M. (1995). The Roles of Race and Socioeconomic Factors in Health Services Research. *Health Services Research 30(1)*, 179-195.

Stanfield, J. H. (1994). Ethnic Modeling in Qualitative Research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 175-188). Thousand Oaks, CA: Sage Publications.

United States Department of Health and Human Services. (1990). *Healthy People 2000*. Washington, DC: U.S. Government Printing Office.