The cultural framework for health:

An integrative approach for research and program design and evaluation

Marjorie Kagawa-Singer, PhD, MA MN, RN, FAAN
University of California, Los Angeles

William W. Dressler, PhD
The University of Alabama

Sheba M. George, PhD
Charles R. Drew University of Medicine and Science
University of California, Los Angeles

William N. Elwood, PhD
Office of Behavioral and Social Sciences Research
National Institutes of Health

With the assistance of a specially appointed expert panel

NIH National Institutes of Health
Office of Behavioral and Social Sciences Research

MEMBERS OF THE NIH EXPERT PANEL ON DEFINING AND OPERATIONALIZING CULTURE FOR HEALTH RESEARCH

Claudia Baquet, MD, MPH
University of Maryland School of Medicine

Ronny Bell, PhD, MPH
Wake Forest University Health Sciences

Linda Burhansstipanov, MSPH, DrPH
Native American Cancer Initiatives, Inc.

Nancy J. Burke, PhD
University of California, San Francisco

Suzanne Dibble, DNSc, RN
University of California, San Francisco

Linda Garro, PhD
University of California, Los Angeles

Clarence Gravlee, PhD
University of Florida

Peter Guarnaccia, PhD
Rutgers University

Michael L. Hecht, PhD
Pennsylvania State University

Jeffrey Henderson, MD, MPH
University of Colorado Health Sciences Center
Black Hills Center for American Indian Health

Daniel Hruschka, PhD, MPH
Arizona State University

Roberto Lewis-Fernandez, MD
Columbia University,
New York State Psychiatric Institute

Robert C. Like, MD, MS
Rutgers Robert Wood Johnson Medical School

Charles Mouton, MD
Meharry Medical College

Hector Myers, PhD
Vanderbilt University

J. Bryan Page, PhD
University of Miami

Rena Pasick, DrPH
University of California, San Francisco

Bernice A. Pescosolido, PhD
Indiana University

Nancy Schoenberg, PhD
University of Kentucky College of Medicine

Bradley Stoner, MD, PhD
Washington University Medical School

Gregory Strayhorn, MD, PhD
Morehouse School of Medicine

Laura A. Szalacha, PhD
Ohio State University

Joseph Trimble, PhD
Western Washington University

Thomas Weisner, PhD
University of California, Los Angeles

David Williams, PhD
Harvard University

ACKNOWLEDGEMENTS

We give special thanks to Dr. William Elwood, NIH OppNet Administrator, for his guidance and unwavering support throughout the process of creating this report.

Office Research Coordinator
Minelle David, MA

Project Director
Anne E. Fehrenbacher, MPH
University of California, Los Angeles

Project Assistants
Pari Sabado, PhD, MPH
Ashley Slight, MPH Student

Student Research Assistants

PhD Students
Héctor E. Alcalá, MPH
Heather Guentzel Frank, MPH
Darrah Goo Kuratani, PhD (c), MS
Isomi Miake-Lye, BA

Masters Student
Adrienne Isaac, MA

External Reviewers*

Arleen Brown, MD, PhD
University of California, Los Angeles

Carole Browner, PhD, MPH
University of California, Los Angeles

Chandak Ghosh, MD, MPH
U.S. Department of Health and Human Services/Health Resources and Services Administration

Joseph P. Gone, PhD
University of Michigan

JaWanna L. Henry, MPH
University of Maryland-Baltimore

Carla Herman, MD, MPH
University of New Mexico

Carol R. Horowitz, MD MPH
Mount Sinai School of Medicine

Graphic Artist
Sabrina YuChi Liao, MA

*Although the reviewers listed above have provided many constructive comments and suggestions, they did not see the final draft of the report before its release. The views and opinions expressed in this report do not necessarily reflect the positions of the National Institutes of Health, the U.S. Government, or the institutions with whom the experts are employed or affiliated.

NATIONAL INSTITUTES
OF HEALTH

Table of Contents

5 **EXECUTIVE SUMMARY**

6 **Section I: CULTURE AND HEALTH RESEARCH: AN OVERVIEW OF DEFINITIONS AND OPERATIONALIZATIONS**
7 What we know about culture and health
9 Evolving effort to include a more comprehensive use of culture
10 Project design
12 Section I: Introduction
12 Section II: Delineating culture
15 Section III: How to revise, extend and improve the operationalization of culture
16 Section IV: The Cultural Framework for Health Research (CFH)
17 Section V: Next steps and recommendations
24 EXEMPLAR STUDY 1: Culturally constructed concepts of race compared with 'ancestry informative markers' (AIMs; Gravlee, Non, & Mulligan, 2009)
24 Current practice
26 Whose culture are we studying?

28 **Section II. DELINEATING CULTURE**
29 What culture is*:
30 Time and place matter
33 What culture does:
34 Domains or constructs of culture
35 Science and evidence-based practice
38 Cross-cultural equivalence

42 FIGURE 2-3. Five-Step Process to Attain Cultural Relevance and Cultural Equivalence of the NLAAS Measures (Alegria et al., 2004).

44 EXEMPLAR STUDY 2: Community Psychosocial Intervention for Child Soldiers with Posttraumatic Stress Disorder (PTSD) and other Mental Health Problems: The Role of Culture in Health Intervention Development (Kohrt et al., 2013)

46 **Section III. THE CULTURAL FRAMEWORK FOR HEALTH**
48 FIGURE 3-1 Cultural Framework for Health process
49 FIGURE 3-2
50 FIGURE 3-3
51 FIGURE 3-4
52 FIGURE 3-5

56 **Section IV. HOW TO REFINE, EXTEND, AND IMPROVE THE OPERATIONALIZATION OF CULTURE IN HEALTH RESEARCH**
58 Further considerations
60 Recommendations for operationalizing culture
64 TABLE 4-1 Logical Issues in Linking Theoretical and Cultural Constructs
67 Checklist on defining, operationalizing, and applying culture in exemplar studies

68 **Section V: NEXT STEPS AND RECOMMENDATIONS**
69 1. GENERAL RECOMMENDATIONS FOR RESEARCHERS. REVIEWERS, FUNDERS AND AGENCY LEADERS
73 2. RESEARCHERS
75 3. REVIEWERS
76 4. FUNDERS and AGENCY LEADERS:

78 REPORT REFERENCES

89 **Appendices**
Table of Contents for Appendices

91 **Appendix A:** Contact Information for Members of the NIH Expert Panel on Defining and Operationalizing Culture for Health Research

97 **Appendix B:** Literature Review of Articles Submitted by Members of the NIH Expert Panel on Defining and Operationalizing Culture in Health Research
98 Extended Abstract
104 Table of Literature Review Model Articles
108 Poster Design

109 **Appendix C:** Reflection Papers Submitted by Members of the NIH Expert Panel on Defining and Operationalizing Culture for Health Research

180 **Appendix D:** Scientific Challenges Posed by the Current Use of Culture in Research

187 **Appendix E:** Definitions of Culture from National Health Organizations
Association of American Medical Colleges
Centers for Disease Control and Prevention
188 Institute of Medicine

National Institute of Mental Health, Child and Adolescent Health Service System Program
National Institute of Mental Health, Culture and Diagnosis Group
189 Office of the Surgeon General, Center for Mental Health Services, National Institute of Mental Health Culture is “a common heritage or set of beliefs, norms, and values”
U.S. Department of Health and Human Services, Office of Minority Health

190 **Appendix F:** A Working Definition of Culture

203 **Appendix G:** Exemplar Intervention Studies that Operationalize Culture across the Research Continuum
203 Table 1. Formative Research Exemplars
205 Table 2. Applied Intervention Research Exemplars
206 Table 3. Evaluation Exemplars
208 Table 4. Dissemination Exemplars

209 **Appendix H:** Examples of Section III and IV: Methods Along the Research Continuum with Native American Groups
Joseph E. Trimble -- Intervention Exemplars
209 Dissemination Exemplar - 1
210 Formative Research Exemplar -1
214 Formative Research Exemplar -2
215 Formative Research Exemplar -3

219 **Appendix I:** Application of the Cultural Framework for Health to a Native-American health project; Linda Burhansstipanov, Dr.P.H.

225 **Appendix J:** NIH model FOAs that account for culture

265 **Appendix K:** BSSR panel lecture to launch, *The cultural framework for health: An integrative approach for research and program design and evaluation;* Poster, videocast link, PowerPoint presentations, COSSA feature story on presentation

319 **Appendix L**: Poster presented at the 35th annual Society of Behavioral Medicine meeting, Philadelphia, 2014, April 25

EXECUTIVE SUMMARY

Culture informs all human behavior; it allows us to exist as social animals. Yet no other variable used in health research is as poorly defined or tested as is culture (Dressler, Oths, & Gravlee, 2005; Hruschka, 2009). There has been surprisingly little attention to identify how culture works or to develop standards to guide the integration or application of *culture* in health research. This report provides the first multidisciplinary, consensus effort to define culture and identify the necessary scientific elements and methods required to identify what culture is and how it functions to influence health differentially among diverse population groups along the entire disease continuum from prevention and incidence to morbidity and mortality from most diseases.

The *Cultural Framework for Health* (CFH) presented in this report:

1. Provides a tool for researchers and program evaluators to use in project design.
2. Identifies why culture is fundamental for understanding human behavior and the impact of cultural ways of life on mental and physical health and well-being.
3. Identifies the major scientific challenges with the current use of the concept of culture for health behavior research (see Table 1.1),
4. Presents the methods and tools to discover the salient cultural processes involved with health behaviors, and how the processes and behaviors influence health and well-being. The framework also suggests techniques to develop measures for these processes. We augment these guidelines with case studies that demonstrate the integration of this framework into health programs and services for specific subpopulations,
    - across the disease spectrum, including genetic, infectious, and chronic diseases, and
    - from prevention to end-of-life care; and,
5. Provides a processual framework that guides researchers through six steps that more effectively distinguish cultural processes relevant in any given study context, and how they likely influence health outcomes. The cultural influences identified can be tested to differentiate universally-human from culturally-specific practices that ultimately can be used to improve health outcomes for all populations. These techniques are applicable across the health, wellness, and disease spectra.

Application of this framework across the research continuum and across multiple disciplines likely will increase the explanatory power of research and the positive impact of interventions by ensuring that research plans are reliable and valid scientifically and to target populations. The ultimate goal is to develop interventions that improve the well-being of all populations we work with locally and globally. Application of the CFH will increase the likelihood for future research findings that provide more comprehensive reasons why health outcomes differ across population groups.

SECTION I: CULTURE AND HEALTH RESEARCH:

AN OVERVIEW OF DEFINITIONS AND OPERATIONALIZATIONS

What we know about culture and health

Epidemiologic evidence clearly shows variations in incidence, prevalence of, and morbidity and mortality from disease by population groups, yet we have had little success to eliminate these differences (Anderson, 2012; Smedley, Stith, & Nelson, 2003). These designations date from 1977, when the U.S. Census Bureau issued Directive 15 that continues to define five minimum racial/ethnic categories:

1. American Indian/Alaskan Native
2. Asian or Pacific Islander
3. Black
4. White
5. Hispanic (ethnic origin).

The Federal government has edited and augmented these categories over time, even to the extent that people may identify themselves with more than one race (e.g., Office of Management and Budget (OMB), 1997; Jones & Bullock, 2012). Additionally, the U.S. Government expanded its original (1977) designation of Hispanic ethnicity as “Hispanic or Latino,” defining such “a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race” (OMB, 1997, p. 58789). Since the 2000 U.S. Census, respondents have been able to identify as belonging to multiple racial groups. According to the 2010 Census, one-third of

people who reported multiple races also identified as Latino/Hispanic; moreover, approximately half of people who identified as Native Americans, Alaska Natives, Native Hawaiian and Other Pacific Islanders also identified with more than one race (Jones & Bullock, 2012, p. 20). The Federal government strives to account for these changes through its National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care (Office of Minority Health, 2013).

Nevertheless, health scientists generally continue to conduct research focused on the rational nature of humankind and the belief of the underlying universality of the European American ways of thinking and viewing reality (Hartigan, 2010; Henrich et al., 2010). Changing demographics, particularly in the United States, has brought cultural dissonance to the forefront in health care. The sheer growth in the proportion of those of different social classes and cultural backgrounds is changing the epidemiologic profiles of health as well as the social structure of society. Researchers, practitioners, and community members represent this diversity and have begun to promote this approach to research (Good, Willen, Hannah, Vickery, & Taeseng, 2011; Weisner, 2009). Scientifically, finding intragroup variation is the current default expectation, and distributional models of cultural beliefs and practices should now be standard approaches. Accordingly, homogeneity would be the surprising finding. Hence, assessing culture to learn about within as well as between group variability of beliefs, values, practices and lived realities should also be a standard practice wherever possible.

Peer-reviewed literature continues to publish health research results that identify target populations by ethnic or language groups and codes them as nominal variables. Yet anyone in the United States who has telephoned for technical support and reached a native English speaker in Bangalore, Dublin, or Manila recognizes the enduring irony in Dylan Thomas' observation that similar native speakers are, "up against the barrier of a common language" (1954, p. 146). Similarly, to propose a target population as simply French, Portuguese, or Spanish-speaking can treat the group as homogeneous in a target population's beliefs and behaviors when a language group may consist of multiple subgroups with varying health outcomes. It also assumes that, with sufficient sample size, there is little or no measurement error involved, i.e., that these ethnic or language groups, coded nominally, are sufficient proxies for the hypothesized beliefs or behaviors thought to characterize group differences. Such assumptions are both unrealistic and untenable because they are unreliable in assessing and determining how cultural norms affect health.

There lacks consensus on a definition of culture and how to operationalize it in health research. Instead, the concept of culture too often is used without any standardization among scientists and practitioners alike. Given these disparate and occasionally over-simplistic operationalizations, data collected on culture can be insufficient to account for statistically significant results, or *culture* is rendered a residual variable to account for the unexplained variance in health outcomes between diverse

groups. Such results likely contribute to the lack of success to bring equity in health outcomes across multiple populations (Anderson, 2012; Smedley et al., 2003). Regarding how to refer to different populations, we recognize the growing preference for the term, *populations of focus*. Given the long-standing use of *target populations* in health research, we use this latter term in this multidisciplinary document.

Differences and disparities in health outcomes by population groups have been well documented for 100 years (Smedley et al., 2003), and behavioral sciences have recognized the limitations of our current approaches to identify the causes of the differences. Efforts have been growing to seek more refined ways to understand health behavior. One of the major shifts in the last 15 years has been a more focused attention to measures of race and ethnicity as variables in health research, but little attention has focused on culture.

The simplistic modes of measurements currently applied have rarely been questioned except by those trained in cross-culture theory, and no concerted effort has been made to correct this bias. Therefore, current health behavior research overlooks and misses the potential explanatory power of culture. Measures or approaches that reduce culture to dichotomous or nominal variables (e.g., African-American, non-Hispanic white, Japanese, family-oriented or *familismo*, fatalism, Roman Catholic) erroneously assume groups to be homogenous and static (Lakes, Lopez, & Garro, 2006; Schoenberg, Drew, Stoller, & Kart, 2005). Too often, these physical or philosophical constructs are used as proxy cultural "markers" that are collected as data and often only at intake, thus even hampering our ability to assess dynamic force of these cultural constructs that inform beliefs, knowledge, norms, and practices that influence behaviors at the individual, group, and institutional levels of wellbeing, health, and care. They also can contribute to the risk factors known or suspected to impact disease prevalence, morbidity, and mortality in diverse population groups (Dressler et al., 2005; Kagawa-Singer, 2006). Such practice also results in the reproduction of stereotypes and over-generalized representations of cultural practices or identities that have questionable external validity and are of little use in either moving the science of health behavior forward or improving equity in the health status of diverse populations (Syme, 2008).

Evolving effort to include a more comprehensive use of culture

The ultimate goal of health behavior science is to translate this knowledge into effective interventions that will improve the well-being of all populations, locally and globally. In this century, the Institute of Medicine (2002) established guidelines to promote the development and use of health-related communication

practices that are tailored for treating different patient groups. The *Journal of the American Medical Association*'s editor operationalized parameters for authors on the use of race in submitted manuscripts (Winker, 2004) and the Uniform Guidelines for Science Journals recommended the development of guidelines for the use of race for health research (International Committee, 2010). Henrich, Heine and Nazaryan (2010) posited that many concepts of human behavior assumed to be universal are quite ethnocentricly Western, are quite false among other cultures. Salway and colleagues (2011 a&b) published guidelines for the use of ethnicity in health research and for cross-cultural collaborations on migration that require, in particular, that researchers recognize the lack of universality of the validity of many concepts and measures.

More recently the Leeds Consensus Panel on Ethnicity in Health issued 10 recommendations for the use of ethnicity in health studies (Mir et al., 2012), and Lewis-Fernandez and colleagues (2013) published a checklist to assess the comprehensiveness and applicability of race, ethnicity, and cultural factor reporting in psychiatric research publications.

In the context of these multiple efforts, the lack of attention to culture takes on heightened significance for the science of health behavior. We posit that clearer articulations of definitions and valid and relevant measures of culture can,

- Increase the ability for health behavior research to provide more precise explanations for disparate health outcomes among different target populations,
- Expand current theories and programs to account for culture in more valid and reliable ways that not only increase relevance to target populations, but also inform and refine extant theory and produce more efficacious results,
- Promote the development of constructs that more accurately delineate *culture* as a concept and construct that informs the health and wellbeing of all groups, and,
- Translate this knowledge into effective and sustainable health outcomes.

Project design

To build on these previous efforts, 30 researchers, each of whom have substantial experience studying culture and health, and long histories of NIH funding, were invited to join the Expert Panel (EP) for this 18-month, NIH/OBSSR[1]-funded project. The panelists represented seven main disciplines: anthropology (11), medicine (6), nursing (2), psychology (3), psychiatry (1), public health (4), and sociology (6). Most panelists had appointments in departments other than the disciplines in which they trained, thus providing even broader perspectives than their disciplinary backgrounds alone.

1 OBSSR: National Institutes of Health Office of Behavioral and Social Science Research

EP members collectively had extensive expertise in qualitative, quantitative, and mixed methods and in conducting health research in a wide range of cross-cultural, linguistic and national contexts. The EP members also conduct health research at different stages of the research continuum, from formative, basic intervention, clinical trials, and evaluation, to translational studies. Members were balanced in terms of gender; approximately one-third belonged to communities of color, and conduct research with diverse populations. Seven external reviewers[2] with expertise in cross-cultural health research and practice provided their evaluation of the final draft prior to the finalization of the report.

We used a modified Delphi Process throughout the project. In Phase 1, we convened a 1½-day workshop with breakout groups and plenary sessions. Prior to the workshop, the EP members were asked to submit published articles they believed to be exemplary of the project's goals and objectives (Appendix B). In addition, we asked each member to write a two-page "reflection paper" on the most essential information needed to meet the report objectives (Appendix C). All the articles and papers were shared among the EP and formed the basis of the literature review that was conducted (see Appendices B-I to B-IV). The workshop consisted of three workgroups that focused on:

1. the importance to *delineate culture* for health research;
2. to identify appropriate methodological approaches to *operationalize* culture; and,
3. mechanisms to *translate* the concept of culture into research and practice,

as well as plenary discussions of workgroup reports.

In Phase 2, we conducted two sets of webinars. The first set focused on a review and critique of this report's Introduction and Defining Culture sections. The second set reviewed the Implementation and Application section drafts. Numerous drafts and feedback were circulated in a Delphi fashion. Between Phase 1 and 2, notes and preliminary drafts were circulated to obtain EP input. Phase 3 consisted of additional webinars to evaluate the first draft of the full integrated report. All meetings and webinars were audiotaped and transcribed for subsequent analysis and feedback integration. The final report included sign-off of each panel member, indicating their concurrence with the finalized document. The NIH project director then revisited the document twice: First as a standard manuscript editor, second to add additional resources and content to ensure that this report relates not simply to anthropology but also just as easily to other sociobehavioral disciplines through additional content and implementation of Federal clear communication guidelines. A brief synopsis of each section of the report follows.

2 Arleen Brown, MD, UCLA, Carole Browner, PhD, MPH, UCLA, Chandak Ghosh, MD, MPH, U.S. DHHS, Joseph P. Gone, PhD, UNM, Carla Herman, MD. MPH, UNM, JaWanna Henry, MPH, UM-B, Carol R. Horowitz, MD, MPH, Mount Sinai School of Medicine

Section I: Introduction

The introduction outlines the major scientific challenges posed by the current use of culture in health research. Meeting these challenges will expand and transform the reductionist application of culture into efforts that better reflect the actual role that culture plays in the social norms-based, attitudinal, spiritual and emotional explanations of health behaviors of cultural group members (see Table 1.1). Each challenge is explained further throughout the report.

Section II: Delineating culture

This section provides the parameters to identify how culture influences the phenomena of focus. To do so, we delineate culture in two ways:

1. What culture is:

Culture consists of dynamic and ecologically-based inter-related elements that function together as a living, adapting system. To delineate culture begins with a perspective that contextualizes population groups within a multi-level, multi-dimensional, biopsychosocial, ecological framework and explicitly recognizes and incorporates the geographic, historical, social, and political realities of diverse communities. All of these elements constitute the cultural framework its members use to "see" the world and attribute meaning to their daily lives.

2. What culture does:

Culture is a human schema that assures its members' survival and well-being. Cultural tools and processes enable humans to interpret the world in which we live through social norms of beliefs, attitudes, spiritual and emotional explanations, and practices (e.g., Eliade, 1961, 1971). Group members then have a collective way to make sense of their world and to find meaning in and for life by providing a sense of safety and well-being, criteria for a sense of integrity of living one's life well, and structure in which to develop a sense of being a contributing member of one's social network (Kagawa Singer et al, 2012; see also, Elwood, 1999; Foucault, 1961, 1970).

Through the social stratification process, culture differentially affects life opportunities at the group and individual levels of health decision-making ability. Every cultural group develops and maintains a social structure that defines and coordinates the numerous roles and relationships of its members. The rules of social interaction and the complex of power relations among the different groups that constitute the mosaic of multi-cultural populations, however, constitute an added dimension of complexity to the context of the lives of cultural and subcultural group members.

Notably, researchers "must develop knowledge of how their (own) decisions about partners and programs may affect existing racial or class divisions and hierarchies of power in a community" (Trickett et al., 2011). If researchers design interventions for target populations without understanding their existing power structures, the researchers may create an intervention curriculum that promotes behaviors that participants unlikely will accept or sustain. In the extreme, this lack of preparation even can have unintended negative consequences (e.g., Elwood et al., 1997; Elwood & Greene, 2003, 2005; Elwood, Greene, & Carter, 2003; Elwood & Vega, 2005). For example, both researchers and laypeople believed "strawberries" and "skeezers" only were African-American

women who traded sex for drugs; two studies went beyond these stereotypes to determine that trading sex for drugs is an economic behavior that occurs among people of any race/ethnicity who endure conditions of poverty and homelessness (Elwood et al., 1997). Moreover, like all human beings, skeezers maintain a social hierarchy among themselves, even though all of them engage in a stigmatized behavior, trading sex for drugs (Elwood & Greene, 2003).

Simply put, researchers must recognize that even we are socialized into a cultural perspective that reflects Western cultural values and practices and are positioned within a specific distribution of power in the communities we work with and within (Kagawa-Singer, Dadia, Yu, & Surbone, 2010). This cultural perspective brings the biases inherent in the dominant Western scientific cultural model into the foreground to recognize and understand as one way to view reality—and that research participant groups may have their own, equally valid views (Elwood, 1994; Hartigan, 2010; Page, 2005).

This section enumerates current challenges in the use of culture. The entire report includes strategies and examples of successful studies to overcome the challenges and to advance the field of health research with greater speed and effectiveness to improve the health and wellbeing of human beings. As culture and cultural processes encompass all human behavior, the inherent complexity involved in the application of this concept and construct requires ongoing dialogue to advance the integration of culture into the science of health. We hope this report contributes initially to the conversation and can serve as an evolving document to account for changes in the field.

Table 1.1 Scientific Challenges Posed by the Current Use of Culture in Research	
Conceptualization	1. The concept of culture is inadequately conceptualized and inconsistently applied. 2. Few studies demonstrate how culture affects health outcomes with clear definitions, measurable constructs, and conceptual models that indicate the interactions of the cultural processes. 3. Problems of diverse cultural groups are identified, but devoid of their historical, geographic, social, and political contexts, and the influence of such contextual factors on their positions in the societal power hierarchy. 4. The dynamic nature of culture is not reflected in most studies. 5. The role of culture in shaping the nature and conduct of health research in the U.S. is lacking. 6. The assumed universality of the dominant culture's constructions of reality and salient domains, such as selfhood, family, fairness, and well-being, is problematic.
Operationalization	7. The current practice of using nominal, dichotomous variables of race and/or ethnicity and/or ancestry to represent culture, is overly simplistic and inadequate. 8. The heterogeneity within the group of focus should be explicit and demonstrated in the description of the study sample. 9. The biomedical and behavioral sciences have focused primarily on the individual without accounting for the influence of the social, historical, political and environmental context of the group(s) to which s/he belongs.
Health Disparities	10. The challenges listed in #1-9 contribute to the inability to effectively reduce health disparities.

Section III: The Cultural Framework for Health research (CFH)

The CFH provides a practical graphic guide for researchers to navigate the process to determine the relevance, conceptualization, and measurement of cultural elements in a research or evaluation project through six main steps.

Figure 3-1 presents details for the six main questions within the framework (blue diamonds). Researchers begin with the golden “Start” box and answer questions in each diamond until they reach the final golden box, which indicates that they are ready to finalize their study design. In addition, we encourage researchers to clarify whether their personal cultural lenses reflect or differ from those of their research participants as an additional step to ensure the most reliable and valid results possible. With steps of the framework completed, researchers are ready to finalize the design of the study.

Application of the *Cultural Framework for Health (CFH)* is the first step to address the complex and dynamic construct of culture with the goal to improve health outcomes for all populations. All human behavior is cultural; therefore, if researchers, reviewers, and funders apply our recommendations, we will establish a collective foundation to discern more valid and relevant cultural processes that motivate and inform health behaviors and health outcomes. The approaches needed to study health behaviors effectively are based in the culturally-shaped realities of the people we study. If similar results or methods are found to be effective in similar contexts across different populations, researchers and practitioners will be more assured that these findings could be “scaled up” to advance health social and behavioral sciences research, for translation and sustainability. Future research findings also could provide more comprehensive reasons why health outcomes differ across population groups. The CFH framework promotes the development of theories and programs that are more readily cross-culturally valid and relevant.

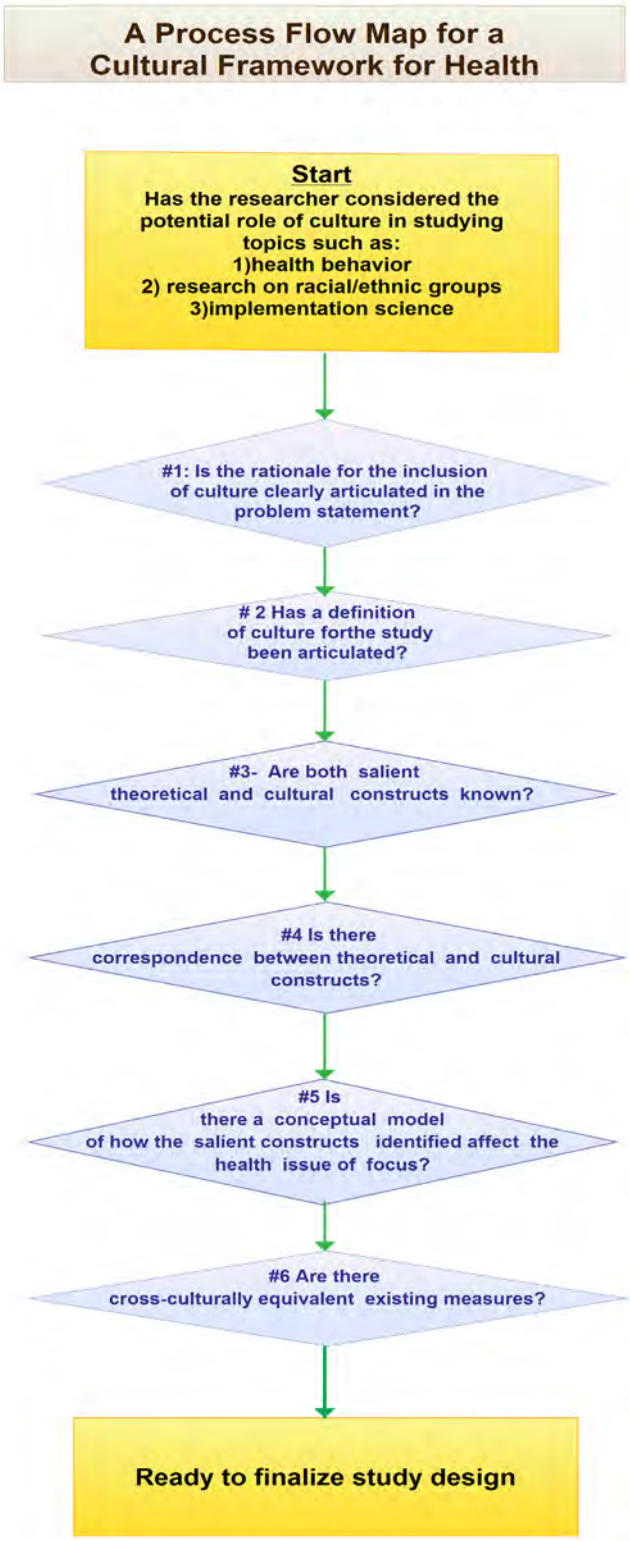
The process to define culture for health research also requires that researchers reflect on the cultural lens each individual brings to the research process. For example, we must recognize that the dominant scientific approach is grounded in a Western/European, formally-educated cultural perspective (Henrich, Heine, & Norenzayan, 2010). Our cultural reality requires recognizing the implicit and largely untested assumptions of universality that this perspective often holds. Cross-cultural evidence largely suggests that most of the assumptions of universality of concepts underlying theories of health behavior are false. Working from the realization that Western theories are ethnocentric and not universal is a major step towards expanding our willingness to follow the pathway laid out in Section IV.

Section IV: How to revise, extend and improve the operationalization of culture

Here we present methods to discern and measure domains/ constructs of culture. Any proposed research project that invokes *culture* as an explanatory variable must outline methods that explicitly and meaningfully link observations to the concept of culture. Notably, operationalizing culture usually does not lend itself to the identification of a predetermined battery of scales so common to research in the health-related sciences. Mixed-paradigms and mixed-methods research designs (e.g., Creswell, Klassen, Plano Clark, & Smith, 2011) are recommended highly to help create such scales. Furthermore, numerous qualitative methods are available to generate valid and reliable data.

These recommendations are not exhaustive, but highlight some major issues to address to incorporate *culture* into research design as an analytic and explanatory concept. It includes an introduction to existing methods that are effective to operationalize culture in health research. Applying the concept of culture for health research is complex, but how we conduct the science of human behavior will be enhanced if we integrate these strategies and methodologies into our work. Then we can better test the contribution of culture to health outcomes of interest, promote better science in this field, and ultimately facilitate translation of these findings to improve health outcomes.

Figure 1.1



The following sections provide both general and specific recommendations for researchers, reviewers, and funders to implement strategies that incorporate the guidelines put forth in this report to identify the most salient cultural processes impacting health outcomes. Citations of studies in the full report illustrate how each recommendation has been effectively employed in diverse populations to discover new, exciting and insightful findings that improve the wellbeing of the members of these communities.

Section V: Next steps and recommendations

We provide recommendations for three audiences through four sections:

1. General recommendations for researchers, reviewers, and funders and agency leaders,
   and specific recommendations for,
2. Researchers,
3. Reviewers,
4. Funders and Agency Leaders.

1. GENERAL RECOMMENDATIONS FOR RESEARCHERS. REVIEWERS, FUNDERS AND AGENCY LEADERS

As noted in the Introduction, all behavior is culturally informed, yet few health and medical professional schools train researchers to attend to cultural processes in their theories or methods.

Based upon the richer understanding of culture presented in Section II - Defining Culture, researchers, reviewers, and funders will benefit from testing the processes set out in Sections III - Operationalizing Culture and IV - Applying Culture. Doing so will expand the knowledge of the fundamental role of culture in health and provide the opportunity to add to our understanding of the repertoire of culturally-informed diverse ways in which those we study construct their realities and find meaning in life. Identifying such variations are critical tasks for basic behavioral science research. This more nuanced and valid understanding of life ways and thought ways among diverse populations will improve the development of new and expansion of existing theories and approaches that are more inclusive of human diversity, and foster more effective translational intervention studies. Table 1.2 below lists the major recommendations for researchers, reviewers and funders to begin the process of more accurately identifying the effect of cultural processes on health.

Table 1.2: Recommendations for Researchers, Reviewers and Funders on how to Conduct, Review or Support Funding of Culturally Informed Research

RECOMMENDATIONS FOR RESEARCHERS	
Understanding culture requires researchers to:	Explain inter/intra group variations & effects on health Discern how multiple facets of culture change independently Identify cultural practices/meanings that affect health outcomes, in view of larger sociopolitical, historical and environmental contexts Recognize culture is heterogeneous & dynamic and integrate it into all study design steps Be keenly aware of their own personal worldviews & values and how these might affect research design, data collection and interpretation Define and measure cultural processes explicitly
Implementing culture requires researchers to:	Not use unidimensional proxy measures of culture such as race, ethnicity, or a singular belief (e.g., fatalism or familismo) Develop interdisciplinary teams or collaborations Use inductive/deductive paradigms & quantitative/qualitative methods Collaborate with community to identify salient issues using Community-Based Participatory Research (CBPR) approaches Clearly articulate their concept of culture as an explanatory variable(s)
Proposing culture as mediator or moderator requires researchers to:	Clearly delineate the population of focus in terms meaningful to the members of that target population Explicitly and rigorously describe salient theoretical and cultural constructs (See CFH Process framework) Use methods that explicitly link observations with measures of cultural processes meaningful to focus populations Develop/adapt measures for the population under study, if no specific measures exist
RECOMMENDATIONS FOR REVIEWERS	
Proposals that implicitly or explicitly include the concept of culture must:	Clearly describe cultural influences used as explanatory and predictor variables and why Clearly and explicitly describe study sample population beyond the six OMB racial/ethnic categories Explicitly define, operationalize & interpret cultural elements Use effective approaches like mixed paradigms/ methods (e.g., qualitative-quantitative) to collect valid/reliable data Engage participants in selection/interpretation of study's cultural constructs or give rationale for why participants were not engaged Explain how cross-cultural validity of theories & measures was established using empirical data Describe how the complex, dynamic & multi-dimensional nature of cultural processes (e.g. intra-cultural diversity) was addressed Describe procedures for community engagement and building rapport

RECOMMENDATIONS FOR FUNDERS / AGENCY LEADERS	
	Distribute these findings widely to the research community Provide focused support and/or funding initiatives for culture research Prioritize research that embraces the complexity of culture Encourage responsiveness to the 2013 enhanced CLAS Standards (e.g., importance of community engagement & participatory methods) Provide technical assistance and training programs to assist researchers/reviewers through: Training sessions for junior/senior investigators changing focus of their research, developed and sponsored by NIH Training programs for pre-doctoral and postdoctoral students A series of regional in-person and web trainings for both experienced and new investigators Collaboration with National Science Foundation (NSF) in their training series An NSF or NIH-sponsored 'summer camp'; series of workshops or trainings on the methods proposed in the report Training for Center for Scientific Review (CSR) staff and Extramural Programs staff on how this report affects extramural grant development Material for for Study Section members addressing technical & review issues for studies using culture, information on current portfolio & program initiatives to move this research forward Support an evaluation of the utility and effectiveness of this report Develop a toolkit to support appropriate & practical use of this report Develop a "clearinghouse" of resources that could be included (e.g., PBS – Soul Food Junkies –an example of how race does NOT equal culture) http://www.pbs.org/independentlens/soul-food-junkies/ Develop and support an online suite of lectures on key aspects of this report such as a Culture in Health Research learning collaborative and community of practice

Section I: INTRODUCTION

This report is a multidisciplinary effort to provide guidelines and recommendations on how to integrate culture into health research and to identify the necessary scientific elements and methods required to build the foundation required to pursue this line of inquiry. Variations in health status, and incidence, morbidity and mortality from most diseases across diverse populations and subgroups are well documented. The lack of success in eliminating these differences and bringing equity in health outcomes across diverse populations is equally well known (Anderson, 2012; Smedley, Stith, & Nelson, 2003). Yet we lack of understanding of why such differences exist and how to develop effective means to translate this knowledge into effective practice.

Our basic premise is that *culture* is an overlooked and misused concept in health research. Moreover, the simplistic measurement modes of culture have been poorly understood and operationalized in research, thus overlooking and missing its potential explanatory power. The current practice of measuring culture through nominal, dichotomous variables (e.g., African American, non-Hispanic white, Japanese, Latino) or beliefs such as fatalism or family-centeredness) too often are oversimplified and hamper our ability to understand the dynamic individual and group processes that inform behavior at the individual, group, and institutional level of health and care (Clammer, 2012). These variables have served their purpose, for example, to track large population group variations. Yet these same conceptualizations and operationalization of *culture* lack the capacity to explain why such variations and disparities exist.

It is no surprise that when such variables are entered into statistical analyses, the "culture" variables are found to contribute very limited explanatory weight to the variance of health outcomes and are dropped from further analysis. Another common outcome in studies of diverse populations is that the final statistical findings are inconclusive. The conclusions too often posit that "culture" is a significant residual variable, yet with little-to-no explanation given the nominal variables used to account for *culture.* Consequently, to measure culture as one-dimensional, dichotomous variables renders the true contributions of culture irrelevant to the risk factors known or suspected to impact disease prevalence, morbidity, and mortality in diverse population groups (Dressler et al., 2005; Elwood et al., 1997; Kagawa-Singer, 2006). This report:

1. Identifies why culture is fundamental for understanding human behavior and the impact of cultural ways of life on mental and physical health and well-being.

2. identifies the major scientific challenges with the current use of the concept of culture for health behavior research (see Table 1.1),

3. Presents the methods and tools to discover the salient cultural processes

involved in the health behavior of focus, how they influence health and well-being, and suggests techniques to develop measures for these processes. These guidelines are augmented with multiple examples of how cultural assessments can and should be done to develop culturally-grounded and relevant health programs and services for specific subpopulations across the disease spectrum (from genetic to infectious and to chronic diseases, and from prevention to end-of-life care), and,

4. Concludes with a framework that guides researchers through six steps required to more effectively distinguish which cultural processes are relevant in a given study context, and how they likely influence health outcomes. The cultural influences identified could then be tested to differentiate universal from culturally specific practices that could be used to ultimately improve health outcomes for all populations. These techniques are applicable across the health and disease continuum.

We propose that the application of the *Cultural Framework for Health (CFH)* will enable us to advance the science of health behavior beyond description of differences, by providing a framework that allows the integration multiple, inclusive theories to account for the health and wellbeing of all populations.

Population groups have used culture to devise solutions to their common problems over time and space, such as adequate nutrition or family structures as well as a religious or spiritual practice, music and dance. However, due to circumstances and available resources, each of these apparently universal domains is quite variable. The adaptations, whether ideal or not, have resulted in diverse cultural ways of living with the various bodies of knowledge necessary to maintain such social and spiritual structures (Kagawa-Singer, 1994). Moreover, this compendium of knowledge also constitutes an enormous resource of innovative, tested, and successful strategies that could be applied to recalcitrant health problems and could benefit many other population groups.

For example, most traditional indigenous diets of simpler societies supply all the needed nutrients for health. The dominant European American U.S. diet has, within the last 50 years, become comprised of about 40% fat. Other diets, such as the traditional Japanese diet, has had a fat content closer to 15%, and several studies have documented significant health benefits from the “Mediterranean diet” which consists of fruits, vegetables, and fish; less red meat; and replacement of butter and cream with margarine rich in α-linolenic acid (to mimic the n–3 content of the traditional Cretan diet) (De Lorgeril et al., 1994; Singh et al., 2002; Willett et al., 1995). The latter also seems to be protective for heart disease and other chronic illnesses. Modification of unhealthy diets of any group to include healthier dietary elements of diverse cultural diets could benefit all populations (Lipski, 2010)

Table 1.1 Scientific Challenges* Posed by the Current Use of Culture in Research

Conceptualization	1. The concept of culture is inadequately conceptualized and inconsistently applied. 2. Few studies demonstrate how culture affects health outcomes with clear definitions, measurable constructs, and conceptual models that indicate the interactions of the cultural processes. 3. Problems of diverse cultural groups are identified, but devoid of their historical, geographic, social, and political contexts, and the influence of such contextual factors on their positions in the societal power hierarchy. 4. The dynamic nature of culture is not reflected in most studies. 5. The role of culture in shaping the nature and conduct of health research in the U.S. is lacking. 6. The assumed universality of the dominant culture's constructions of reality and salient domains, such as selfhood, family, fairness, and well-being, is problematic.
Operationalization	7. The current practice of using nominal, dichotomous variables of race and/or ethnicity and/or ancestry to represent culture, is simplistic and inadequate. 8. The heterogeneity within the group of focus should be explicit and demonstrated in the description of the study sample. 9. The biomedical and behavioral sciences have focused primarily on the individual without accounting for the influence of the social, historical, and environmental context of the group(s) to which s/he belongs.
Health Disparities	10. The challenges listed in #1-9 contribute to the inability to effectively reduce health disparities.

See Appendix D – TABLE 1.1 for an expanded description of each challenge

In medicine, acupuncture used in combination with general anesthesia for some surgeries, appears to significantly reduce the amount of anesthesia necessary to obtain the same level of pain control. This reduction of medication reduces potential complications from the anesthesia itself (El-Deeb & Ahmady, 2011; Xu et al., 2012). Several innovative health education programs have taken a more integrative approach that incorporates the three functions of culture: safety and security, integrity, and being a productive member of one's social network. For example, educational efforts to promote traditional diets and lifestyles for indigenous community members have been shown to improve physiologic outcomes, such as cholesterol, tri-glycerides, diabetes, and smoking rates and reducing drug abuse behaviors, as well as improving mental health by increasing ethnic pride through traditional practices (Shintani, Beckham, O'Connor, Hughes, & Sato, 1994; Shintani, Hughes, Beckham, & O'Connor, 1991). Too often research studies focus on a singular health outcome or behavior without the ability to account for the inter-related nature of much of behavior – positive or negative.

More recent neuroscientific research on the two-way interaction of cultural ways to create meaning reflects the plasticity of both and is a promising avenue for investigating both mental and physical health. For example, numerous studies have indicated that socially constructed stressors have a stronger impact on disease development than genetic factors. As a case in point, lifestyle changes in smoking, diet, and physical exercise alone could reduce cancer incidence by 60% ("Harvard Report on Cancer Prevention. Volume 1: Causes of human cancer," 1996)

The common thread in these examples of successful studies is that they measured and incorporated how multiple cultural processes function simultaneously for the populations of focus. Notably, these studies found unique and unexpected modes of behavior based upon a different constellation of both structural and social factors that reflected their cultural worldview. The CFH demonstrates that the more regular and precise study of culture health research, we will be able to find behavioral variations in disparate groups and will be able to understand such results in context and then implement corresponding intervention efforts will greater chances for success in achieving effective and sustainable behavior change and improved wellbeing in these target populations. The theories, methods and strategies for discovery and implementation exist, but health researchers have underutilized these tools. Table 1.1 outlines the challenges in the current research approach that have impeded the incorporation of culture into our study of differences in health outcomes.

The Exemplar Study 1 below by Gravlee and colleagues (2009), and the diet examples mentioned previously indicate that the next step required in research is to better articulate the complex concept of culture and provide new approaches and tools to aid in untangling persistent health problems. We researchers, then would be able to meet the scientific *challenges* posed by the often superficial and simplistic applications of culture as noted in Table 1.1. We must change how we use the concept and measure the construct so we are able to capitalize on the *opportunities* for new knowledge available through the incorporation of the concept of culture as a basic influence on health outcomes.

EXEMPLAR STUDY 1

Culturally constructed concepts of race compared with 'ancestry informative markers' (AIMs; Gravlee, Non, & Mulligan, 2009)

For nearly a century, the differences in average blood pressure and rates of essential hypertension between white and black Americans have been identified. Two primary hypotheses have been proposed to account for these differences: (a) black Americans are genetically predisposed to the development of high blood pressure; or (b) exposure to stressful circumstances in the social environment associated with racism and discrimination lead to higher blood pressure among black Americans. Until recently, the evidence for or against either of these hypotheses has been indirect.

Gravlee and his associates (Gravlee, 2005, 2009; Gravlee & Dressler, 2005; Gravlee, Dressler, & Bernard, 2005; Gravlee et al., 2009) have examined this question, explicitly taking cultural dimensions of the issue into account. Despite frequent objections in the literature, much of the research on health disparities takes 'racial' differences at face value, even though the biological meaning of the construct is problematic. The problems with this are immediately apparent when race is examined cross-culturally. The black-white dichotomy used in the United States to describe racial differences is both simple (two categories according to the 1-drop rule) and unusual in the sense that in many societies (Puerto Rico, Brazil, and South Africa, for example) more complex categories are used to describe persons of African descent. Gravlee systematically investigated the cultural construction of race in Puerto Rico. His research is based on the definition of culture as the knowledge and understanding that people employ to function in their everyday lives.

Using methods drawn from cognitive anthropology, he elicited from his respondents their understanding of racial difference. As in Brazil, in Puerto Rico the term 'race' is rarely used, and the

This report constitutes the first consensus effort among expert researchers representing multiple disciplines to integrate culture into health research, and presents the *Cultural Framework for Health* (CFH) *Research and Evaluation* which contains guidelines to both delineate culture and to provide a process for researchers, reviewers, and funders to integrate the *culture concept* into health research. Our experience demonstrates that such articulation and application increases both the explanatory power of the research as well as the positive impact of our interventions.

Current practice

The current lack of consensus on what culture is and why it should be used in health research leaves researchers to their own approaches to craft measures that implicitly or explicitly operationalize this concept (Goddard, 2005; Trickett et al., 2011; Viruell-Fuentes, Miranda, & Abdulrahim, 2012). We cannot build a science based upon such disparate approaches that lack consensus and accuracy. Hruschka (2009) reviewed articles published in the *American Journal of Public Health* in 2008 and found 95 articles that referenced 'culture' or 'cultural' in the abstract or body of the text. Culture was claimed to influence health behavior in 40% of the articles and 18% described culture as

Spanish term color ('color') is used instead. Also, in Puerto Rico a gradation of skin color is recognized from very dark (negro), to two intermediate categories (trigueño, jabao), to very light (blanco). Using skin reflectometry, the authors showed that there are mean differences in skin color between these categories, but that the confidence intervals are very wide and there is considerable overlap among the categories.

Gravlee and colleagues operationalized the theoretical construct of race in four ways: (a) self-assigned color by respondents; (b) observer assigned color by interviewers (with checks for reliability of category assignment); (c) independent assessment of skin color using skin reflectometry; and, (d) assessment of the degree of African genetic ancestry using 'ancestry informative markers' (AIMs), based on genotyping using buccal cell samples. Results showed that the culturally constructed categories of color, as assigned by observers, were the best predictor of blood pressure in interaction with socioeconomic status. Individuals with the highest blood pressures were found to be in both the color category of negro and also high in socioeconomic status. This was interpreted as indicating more frequent stressful social interactions based on the disjunction of the lower-status color category with the higher status socioeconomic position. Without controlling for this interaction, greater African ancestry as assessed by AIMs was associated with higher blood pressure. When the interaction of culturally-defined color and socioeconomic status (class) was included in the regression analysis, the effect of AIMs disappeared, and a new association between blood pressure and a candidate gene for hypertension emerged.

These results indicate that taking into account how culturally-defined categories of race are deployed in everyday use and social interaction yields a better understanding of the basis for racial health disparities in cardiovascular disease risk in Puerto Rico than genetics alone, but also it may increase the power of genetic association studies because it helps to partition environmental variance.

a source of measurement problems. In many cases, culture was mentioned as something that influenced health outcomes, but the authors never specified how this occurred.

In a few cases, culture was used as a last attempt to explain group differences or contradictory findings that could not be accounted for by other factors, i.e., as residual variance. This is the major scientific challenge addressed by this report. These studies conclude that "culture" likely was a major explanatory factor but as the authors included no cultural measures in the study design, their conclusions were unable to provide cultural solid measures or explanations. Such practice is not exclusive to Public Health (Lewis-Fernandez, et al., 2013). Other health disciplines have become habituated by default into using simplistic or superficial indicator measures as proxy measures for the otherwise undefined catch-all concept of culture. In these studies, the majority of the variance remains unaccounted for and ultimately unnecessarily truncates the results.

The most common measure of culture is to use race or ethnicity as a proxy (Goddard, 2005).This practice reduces the complexity of culture into a unidimensional or nominal variable that offers minimal explanatory power. An example would be using the term "Latino" to describe a population group. This highly heterogeneous aggregate category (as are all the OMB Directive 15 Race/Ethnic categories) is not routinely disaggregated for study purposes. Thus, separate studies of depression among "Latinos," may report quite

disparate findings or similar findings that may be due to quite different reasons if the studies are done, for example, in different geographic regions of the U.S. If the study were done in New York, the Latinos may be primarily Puerto Ricans, many of whom are low income. In Miami, the Latinos may be predominantly Cuban and Cuban Americans, and proportionately of higher SES, whereas in Los Angeles, this group may be primarily comprised of Mexican Americans who tend to be of lower SES. Equally likely they could be an aggregated sample of individuals classified within the Latino/Hispanic category in Los Angeles County and who represent the spectrum of SES and Mexican, Central, and South American cultural groups. This report clearly advises that subgroups within any population be identified along with inevitable variations of key variables even within the subgroups. Such differences and nuances must be identified to assure the validity of the findings.

The nature of scientific disciplinary silos and the use of the erroneous proxy nominal variable measures of culture lead to parallel courses of research using different conceptualizations and different selection criteria for the same measures. The result is conflicting and incomparable findings. This “state of the art” use of measures of culture in population and clinical science impedes our ability to build a valid science of human behavior that is truly representative and inclusive of its cultural diversity.

Whose culture are we studying?

Researchers who study different populations must be aware that the cultural processes of research participants are just as extant as those processes of researchers and their colleagues. To ignore this simple yet important truth enables researchers to ignore the influence of their personal and professional cultures on the research processes and populations of focus. Implicit in studies of target populations including ethnic and racial minorities, people with physical impairments, people in poverty, sexual and gender minorities (or combinations of any or all of the above) is the view that “non-Hispanic whites,” the usual referent group, have a unique culture and that the multiple cultures that exist in most geographic areas function in isolation from each other—when the practical reality is quite the opposite.

The most common results of this view are that,

1. Some members of the predominant U.S. culture do not recognize that the assumptions that underlie their scientific endeavors reflect their own norms and not necessarily those of the populations they plan to study, and,

2. The “objective” culture of science makes it difficult to design research projects that account for the dynamic interplay among and within cultural groups, the blending at the edges of each, and the impact the culture of the group with the greatest power has on the populations of focus.

> Although researchers may have a sense of efficiency and comfort with assumed universal gold standard of human behaviors, the basic premise of universality is not valid, Cultural variation shows that such fundamental human concepts such as fairness and quality of life may be quite variable. Thus, both internal and external validity of the premise and findings from any study that uses the theories of health behavior commonly applied in the US and other western European countries remain largely untested.

The historical, legal, political, and social structure of the U.S. society itself socially and institutionally facilitates or hinders access to and use of the health care system and other social opportunities for different segments of the population (Bourdieu, 1986; Drew & Schoenberg, 2011; Salway et al., 2011; Smedley et al., 2003) This complex systemic web of forces can no longer be ignored as they are critical elements in the health of diverse populations.

These multi-level factors are captured in the concept of the Social Determinants of Health (Marmot & Wilkinson, 2009; World Health Organization, 2013), which emphasizes the importance of context or place and distribution of power. Less visible, however, is a power structure that creates disadvantages that affect some population groups more than others, even though those who endure the social determinants of disadvantage did not create them (Hartigan, 2010). The concept of culture, as recommended in this report, provides the missing conceptual framework that organizes the social determinants of health into an integrated system that would better identify *how* and *why* these determinants exist and continue to maintain the status quo of disadvantage for particular subgroups (Marmot & Wilkinson, 2009; World Health Organization, 2013). Recognition of these forces clearly indicates more effective avenues of leverage to dislodge barriers and improve health locally and globally.

Examples of studies that effectively utilize culture appear throughout the report to illustrate how explicit operationalization of culture produces powerful and population-relevant explanations for behaviors. These findings enabled researchers to develop more creative, relevant, effective, and sustainable interventions to address the needs of individuals and population groups.

Attending to the definition of culture offered in Section II would likely improve the validity and utility of the findings in health studies with diverse populations. Researchers would then be able to identify and measure the specific cultural domains theorized to have direct influence on particular health outcomes. Greater precision in both the conceptualization and measurement of culture, as a fundamental force in human behavior, is not only possible, it is essential for understanding how and why behaviors occur in certain circumstances and how culture could be mobilized to mediate or moderate the interactions among the various biologic, environmental, emotional, social, political and historical factors to improve health outcomes.

SECTION II. DELINEATING CULTURE

Epidemiologic evidence clearly shows variations in incidence, culture is essential for humans to exist as social animals; it is the means by which we create cohesion among members. Clifford Geertz wrote, “There is no such thing as human nature independent from culture.” In the 1970s, he unwittingly anticipated the field of cultural neuroscience when he stated, “Our central nervous system . . . grew up in great part in interaction with culture” (1973, pp. 49-50; e.g., Chiao & Blizinsky, 2013; Chiao & Immordino-Yang, 2013). Both are essential for social existence. Despite the recognition that culture is fundamental to human existence and provides meaning for life, surprisingly little focus on defining culture exists in health research, nor have standards been developed to guide the integration or application of this concept in health research. See Appendix E for a list of definitions of culture from major national health organizations.

Although there are a multitude of definitions for *culture*, the definitions share two common facets. The first is the differentiation between what culture *is* and what culture *does.* The second is how the science of health behavior promotes or inhibits the integration of culture in research.

What culture is*:

Culture is a shared ecologic schema or framework that is internalized and acts as a refracted lens through which group members "see" reality and, in which both the individual and collective group experiences the world.

Culture is a shared range of human phenomena that does not necessarily relate to genetic inheritance. The elements of cultures are inter-related and function together as a living, adapting system that members internalize. Culture acts as a refracted lens through which group (or cultural subgroup) members "see" reality and, in which both the individual and collective group experiences the world. This framework is created, exists, and adapts to the cognitive, emotional and material resources and constraints of its ecologic system to ensure the survival and wellbeing of its members, and to provide meaning for and in life individually and socially (Burke, 1989; Hartigan, 2010; Kagawa-Singer, 1996). The framework also shapes and is shaped by the forms and institutions developed by its members to structure their world and to establish their meaning within it (Bronfenbrenner, 1997; Eliade 1961, 1971.)

What culture does:

Culture provides the pan-human process on which a group bases its survival and well-being. Cultural tools and processes enable humans to interpret the world in which we live through social commonly held beliefs, attitudes, spiritual and emotional explanations, and practices (e.g., Eliade, 1961, 1971). Group members then have a collective way to make sense of their world and to find meaning in and for life by providing a sense of safety and well-being, criteria for a sense of integrity of living one's

life well, and structure in which to develop a sense of being a contributing member of one's social network (Kagawa Singer et al., 2012; see also, Elwood, 1999; Foucault, 1961, 1970). In other words, the symbols that everyday people use to discuss and sing to describe and opine on one another's experiences are hegemonic—they control and/or organize our thoughts and values because the people who use these words and symbols all agree on their individual and collective meaning, thus constructing a collective culture (Burke, 1989; Carlin, 1990).

As in all living systems, human culture is *dynamic*. It *adapts to and evolves* in response to shifting conditions in the physical, social and political environments (Dibble, 1983) or it becomes dysfunctional, stagnant, or extinct. Cultural group members each respond, evolve, and differ due to individual, ecologic, social, political, and historical circumstances. Inconsistencies of research findings are not surprising considering that studies have been conducted with populations considered the same "racially" or socioeconomically, but who actually differ substantially due to historical, geographical, generational and gender factors, among others. Accounting for these variations within specific historical as well as present-day contexts of the populations of focus would likely move the science of health behavior forward by expanding our knowledge and understanding of how, when, and why cultural groups demonstrate both inter- as well as intra-group variations and what effect the interaction of these factors has on their health status.

For example, in the Oscar-winning film, *The King's Speech* (Hooper, 2010), elocution experts advised the future George VI to smoke cigarettes to calm his vocal cords to reduce his stutter. Today's audiences realize the dire health consequences of cigarettes today and know that any sedative quality that nicotine conveys to vocal cords for public speaking benefits pales when compared to public health outcomes; sadly, Even George VI and his wife learned those consequences when he died of lung cancer at age 56. This recent film serves as an example of a cultural shift regarding a product that people once universally regarded as having health benefits and now lack them altogether.

Time and place matter

Notably, the solutions individuals and groups devise to respond to changing environments generally occur haphazardly and sometimes negatively (Rogers, 2010). Moreover, not all domains or areas of activity within a culture will change in alignment with each other. The multiple facets of culture often change independently, creating dissonance among the domains, and add to the difficulties of characterizing the intricacy of culture for any population group. Yes readjustments occur over time, and in conjunction with efforts to bring the disparate domains into alignment and correct poor decisions. Despite knowing that some cultural adaptations may be maladaptive or information about the practice changes over time, like tobacco smoking, obesity, or violence, we must understand the substantive cultural meanings

and rationales behind the practices if we expect to work with communities and individuals to change the behavior.

The rational reason behind the practices may seem initially strange or superstitious to an outsider researcher, but understanding the internal and also the external forces that maintain the risky health behavior may actually serve other important functions in the local context. Much of how culture "works", however, exists *implicitly* rather than explicitly in the minds of its members. Culture, or how individuals within cultural groups live day to day, is learned throughout life. Once this knowledge is internalized, it becomes tacit knowledge, habitual behavior, and unconscious responses (Bourdieu, 1986, 1990; Elwood & Greene, 2003; Hartigan, 2010; Hruschka, 2012). These ways of life are seen as "normal", "natural" or "just the way things are." Members would be hard pressed to see these social norms and attitudes and behaviors as 'culture specific.' When researchers try to assess many aspects of culture with direct questions (i.e., why members behave in the way they do, and how culture influences this behavior), respondents are often confused, for such behavior is "obvious" and natural to them, rendering the question(s) difficult to answer (Spradley, 1980; Section IV Operationalization). Opportunities for readjustments are rich areas of exploration, because they often are self-generated by the members of the group themselves. They recognize the problem and seek solutions that fit their sensibilities and needs. Researchers who partner with members of the communities can learn from them and also help to leverage the efforts of the group to effect the changes desired (Trimble, 2012; e.g., Sharpe & Uchendu, 2014; Manley, Levitt, & Mosher, 2007; Elwood & Greene, 2005; Elwood, Greene, & Carter, 2003; Elwood & Williams, 1999; Bauer & Mahn, 2014).

What culture is:

Culture is an essential pan-human process that ensures survival, endurance, and wellbeing for a given group of people. Culture enables us to interpret the world in which we live through beliefs, attitudes, practices, and spiritual and emotional explanations that are used to create social institutions and norms of ways of being (Eliade, 1961). Together, these cultural "tools" enable group members, ultimately, to make sense of their world and to find meaning in and for life by providing a sense of safety and well-being, a sense of integrity of living one's life well, and a sense of being a contributing member of one's social network (Kagawa-Singer, Valdez-Dadia, Yu, & Surbone, 2010).

> Culture enables group members, ultimately, to make sense of their world and to find meaning in and for life.

Culture, thus, is not a single item or variable, but a multidimensional, multi-level process that constantly evolves and encompasses all levels of the human condition. Single measures, including the U.S. Government's 15 racial/ethnic categories, or an

acontextualized single belief or value such as fatalism or familism, are inadequate, overly simplistic proxy measures of this complex concept that should avoid if we want to advance the science of health behavior. Instead, our variables should be numerous, complex, and linked to one another and to the health issues under study.

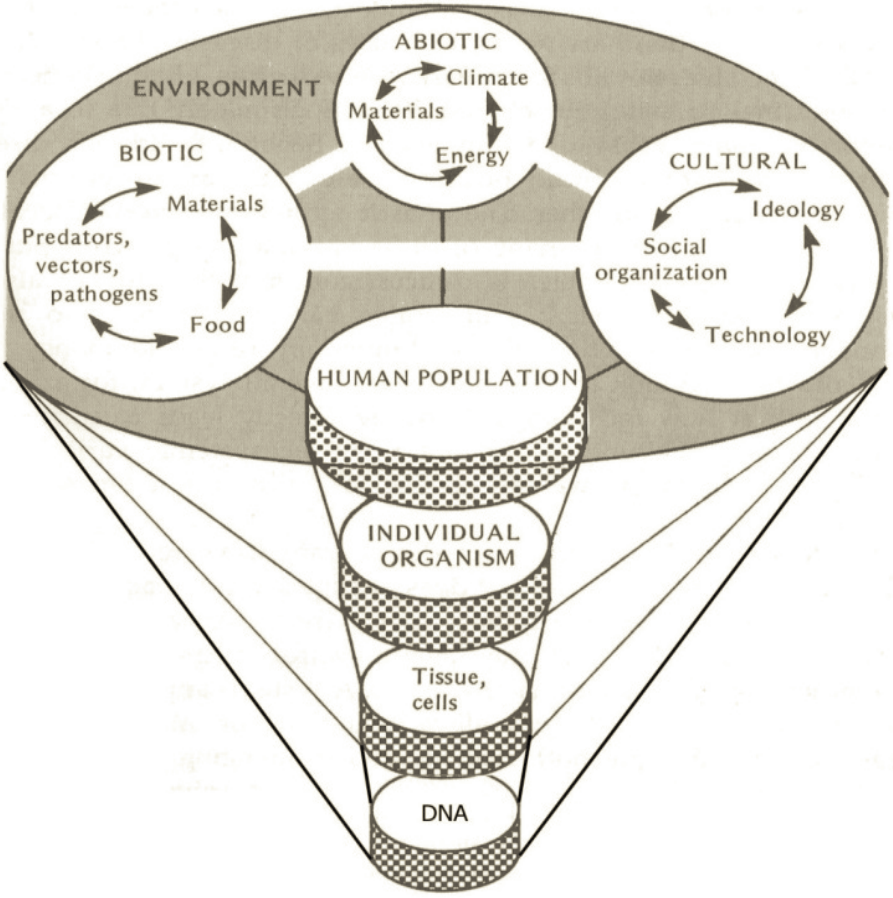
Culture is an integrated system of beliefs and practices that individuals live in and co-create to enable them, through social institutions and norms of ways of being, to achieve a sense of:

1) Safety and wellbeing

2) Integrity and

3) Belonging

FIGURE 2-1. Ecologic Model of Culture's Influence on Health



McElroy and Townsend Model (Kagawa Singer, 2002 - rev.)

What culture does:

An important aspect of culture is the framework or social structure that defines and coordinates the numerous roles of each of group members in relation to each other: rules of social interaction and distribution of power among the different groups that make up the mosaic of a cultural population. The social institutions that embody these rules are also products of cultural processes (Airhihenbuwa, 1995; Hecht & Krieger, 2006; Kagawa-Singer, 1993). Thus, cultural processes are developed through the patterned ideas and behaviors that we, as individuals and groups, learn, use, and modify as needed throughout our lives as members of the groups and use to make sense of the world in everyday settings (Hartigan, 2010). These processes are manifest through the categories of things (people, institutions, and ideas) that structure the world around us and provide both prescriptions and proscriptions to function acceptably on a daily basis as valued and accepted members of that group (father, daughter, sister, employer, student, colleague).

These patterned ideas and behaviors also serve as the criteria its members use to judge and be judged as a good, necessary, and productive member of their social network (Kagawa-Singer et al., 2010). These criteria include the etiquette of both physical and verbal communication (e.g., timing, tone and vocabulary) by audience, e.g., by gender, age, and social status (Garro, 2005, p. 49; Goodenough, 1996, p. 295). Every member of a self-identified cultural group both shapes and is shaped by tenets of that culture. Notably, much of how cultural processes function is implicit rather than explicit and often subconscious in the minds of its members. Members interpret such beliefs, attitudes and behaviors as “natural” and “normal,” automatic, and mundane, rendering direct questions subject to misinterpretation and misunderstanding, especially if the questions emanate from a different worldview.

What culture *does,* then, is enable its members to function easily and comfortably in everyday interactions with other members of their group without having to think through every gesture, word or movement. Cultural functions can best be *observed* in everyday interactions and conversations through non-verbal expressions.

The shared perspectives of self-identified groups are universally expressed through such forms as family structures, religion, and gender roles, and are also institutionalized within that culture through schools, mental and medical health care systems, including the roles of the actors within each institution, such as teachers, students, doctors, nurses, and patients, and government officials. When these cultural elements (i.e., beliefs, values, routines) align across levels (e.g., family peers, neighborhood and society), their existence and influence becomes nearly invisible to its members. Alternatively, these variations are sources of likely dissonance and misunderstandings in multicultural societies because members of different groups may not recognize the source of their confusion – or, importantly,

they may understand it, but also realize they have little or no control over the circumstances. Such dissonance has health consequences. The experience of this dissonance, may be psychologically recognized or unrecognized and have physical consequences, such as allostatic load (McEwen, 1998) or behavioral, such as risky behaviors or avoidance of interactions with the health care system (reflected in low screening rates or lack of adherence to recommended medical care). Such states of dissonance likely contribute to physical and/or emotional distress, disease, and inequities in health outcomes.

The preceding description of the functions of culture emphasizes the contextual nature of individual behavior. From a systems perspective, individual lives exist with others, but ironically to assess a population's health, measurement usually occurs at the level of the individual. As Dressler states, "Culture is the study of how experience gets written on the body and mind in terms of measurable physiological and psychological outcomes, and to do so (the researcher) must trace culture to the individual" (2012, p. 182). As noted, to access this knowledge requires consciously watching and talking to individuals over a period of time before the patterns and rationales of cultural behavior become visible.

Domains or constructs of culture

Depending upon the focus of a study, different aspects of a culture are more important than others in shaping behavior. These constituent parts are called domains or constructs. As noted in the next section, domains, which consist of a cluster of 'cultural constructs' are key dimensions of concern within a society that tend to be universal in function but culture-specific in their construction and form. Examples of universal constructs might be: religion or spirituality, family, power structures, social structures, gender roles, and diet. These domains constitute foci around which individuals in that society organize thought and speech. It includes the elements that make up that construct (such as, in the example of family life, the elements that are regarded as composing a family) as well as the functional and causal relationships among those elements. Domains are composed of the concepts that people within a society use to think about particular issues, such as decision making in health care. In some family structures, individuals not blood related, such as god-parents, ancestors or tribal or clan chiefs, may be more appropriate to consult in making serious health care choices than living blood-relatives depending on social structures and personal relationships.

The multidimensional and multilevel nature of culture means that the patterns that emerge from different cultural systems are comprised of many interrelated parts, and will differ within and between cultures. These constructs are not necessarily totally consonant due to the fact that, as noted, they change at varying rates depending upon environmental, interpersonal, or intrapersonal changes. The U.S. is a multi-cultural and technology based society undergoing rapid change. Important to note

is that cultural constructs within a given culture affect health outcomes to varying degrees, and, since cultures vary both in the form of these domains/constructs, so will their relationships to each other and to health. Researchers have to identify which areas of culture may be most significant for their particular research question and population.

The source of the answers to which constructs are most salient to the research question is most appropriately and accurately obtained from the members of the group of interest–rather than by scientists who do not live the lives of the members of that community (Dressler, 2007; Kagawa-Singer, 2009; Olafsdottir & Pescosolido, 2009, 2011; Schnittker, 2003; Subrahmanian et al., 2011). Section III explains how one would gauge the degree of knowledge known about specific cultural groups.

Science and evidence-based practice

Every cultural group has definitions of health and a healing system. In the United States, the dominant system is biomedicine and has superseded all other forms of folk healing (Kleinman, 1980; See Figure 2-2). Despite the commonalities of the core science of biomedicine internationally, its structure, style of delivery, and the training of its practitioners in the United States are based upon the values and beliefs of Western European cultural concepts of science, fairness, personhood, individual rights, and equity (Henrich, Heine, & Norenzayan, 2010; Page, 2005; Somervell et al., 1993).Too rarely, however, do we consider the interface of biomedicine, the culture of Western scientific inquiry and those schooled within this cultural framework with those of non-western European descent when studying the effects of culture on health outcomes. The culture of U.S. biomedicine illuminates the Cartesian split between mind and emotions, and body, nature and culture. This split exists in biomedicine internationally, but is hyper-dichotomized in the U.S. and does not exist to the same degree in other cultural groups (Nisbett & Wilson, 1977; Witkin & Berry, 1975). Such implicit division of the physical person from his/her emotional responses to living in a subgroup of a dominant society and from his or her actual environment may create a sense of dissonance and lack of trust among those who ascribe to a more holistic understanding of the relationship between humankind and the world around them (Henrich et al., 2010). Fortunately, significant western scientific interest and evidence is growing in understanding the integration/feedback loops of the body/mind/environment that demonstrate significant variations in physiologic responses to cultural/social environment. Studies of social genetics and the interplay between culture/brain/and health are becoming dynamic fields of endeavor and hold great promise in cultural research (Champagne, 2012; Cole et al., 2012; Dressler et al., 2012; Hunter & McEwen, 2013; Non, Gravlee, & Mulligan, 2012).

The lack of recognition on the part of most social and behavioral scientists or their own cultural lens, however, is a major barrier in conducting studies in diverse population groups. The underlying, and usually implicit, assumption appears to be that the concepts used in our health behavior theories are universally applicable and equivalent in their function across populations (Henrich et al., 2010; Trickett et al., 2011). These assumptions, however, as Airhihenbuwa,(1995) notes, are culturally loaded, value-based, and situated within West-centric foundations. Among these are The Theory of Reasoned Action (Ajzen & Fishbein, 1977; Fishbein, 1967), The Health Belief Model (Rosenstock, 1974), and The Extended Parallel Process Model (Witte, 1992) regarding their assumptions of individualism, rational choice, and cognitive decision-making (Burke, Joseph, Pasick, & Barker, 2009; Dutta, 2010). The truth of the universality of these concepts has yet to be proven (Heurtin-Roberts, 2009; Pasick et al., 2009).

Figure 2-2. Whose culture are we studying?

The distribution of power in any society is important to acknowledge. Disadvantaged subcultures within the larger U.S. culture exist within a power structure usually not of their making or choice, and often against their will. The study of the social determinants of health in public health studies today, have not contextualized the historical process by which such disadvantage exists in populations that suffer the worst health outcomes in the U.S. (Schoenberg, Drew, Stoller, & Kart, 2005).

Behavioral scientists have been educated to rarely "see" the influence of the historical marginalization and structural exclusion of populations of color and those who have not or did not fit the criteria of, for example, the founders of the United States. Disadvantaged populations generally did not create the enduring structural barriers to education, jobs, and health care; many barriers are not necessarily accidental. Individuals and groups with social and structural power created such barriers. This "cultural blind-spot" of the dominant cultural group informs and shapes the norms of the health sciences as well.

The inequities in health outcomes in diverse communities are then compounded by the belief that the findings from evidence-based studies based upon theories validated among members of the dominant cultural group using rigorous sampling and sophisticated statistical analyses are generalizable to all populations despite the fact that this has rarely been demonstrated (Henrich, 2011; Trickett et al., 2011) The belief in the generalizability of such findings is apparent in the efforts to "tailor" and apply "evidence based practices" to different "target" populations. When the findings are not as robust as the initial studies upon which the strategies were developed, the conclusions often assert that the unexplained residual variance is due to an amalgamation of unknown cultural variables (Schoenberg, 2005; Schoenberg, Howell, & Fields, 2012). Questioning the cross-cultural validity of these assumptions is rising to greater visibility in health research.

It is far more likely that when evidence-based interventions are applied to different groups, the results may be less robust because the intervention could not be scaled to influence other populations due partly to cultural differences or that appropriate implementation science guidelines were not available due to the lack of evidence to make that possible. Most randomized controlled trials (RCT) and other research designs generalize not only from an unrepresentative population, but also the group findings are often interpreted solely from a monocultural viewpoint, and are based on mean comparisons. Hence they compare normed, averaged, generalized populations to one another using mean differences, and typically exclude people with co-morbid conditions—which among some groups can be the population norm—as well as culturally diverse samples. This may be useful for analytical purposes, but in such cases, the results cannot be appropriately used for other populations absent studies of those specific groups (Hay et al., 2008)

There may be useful *analytic* reasons for assuming, in order to test a certain theory of predictive conceptual model, that the world is linear, additive, and decontextualized, or that an ahistorical approach is appropriate (Weisner & Duncan, 2014). In fact, the world wobbles on its axis; moreover, variables and other health influences are not unilaterally cumulative in their respective influence on individuals, families, and communities. *Context always matters*. Our view is that analytic methods and research designs holding these circumstances constant can be useful *if and only*

if they are then re-introduced into the true complexity of the social determinants of health, given meaning in those contexts, and then re-tested for the constancy of their predictive value.

Cross-cultural equivalence

Most studies of groups other than non-Hispanic whites do not systematically test, at a minimum, the functional, conceptual, metric, linguistic, and stimulus cross-cultural equivalence of existing concepts, theories, or assumptions that underlie the design of interventions for and with a new target population. The call for the need to demonstrate cross-cultural equivalence has been described by many social and behavioral scientists (Hui & Triandis, 1985; Padilla, Kagawa-Singer, & Ashing-Giwa, 2003; Trickett et al., 2011; Trimble, 2007), and is an essential area of research to assure greater inclusiveness in our behavioral theories and greater validity of the findings from both research and practice.

Accurate translation of instruments is a tedious, multistep process. Literal translations are inadequate. Alegria and colleagues (2004) demonstrated a five-step process to assure conceptual equivalence and validity of the survey instrument in Figure 2-3 This process is an essential step in any cross-cultural study. Otherwise, the comparability of the answers across groups and within groups cannot be assured. Translation is not only words per se, but, more meaningfully, the equivalence and relevancy of the concepts themselves. Often concepts such as fairness and “good patient,” or even health are not the same, despite the words being similar. The issue of concept comparability and equivalence is addressed in more detail in Sections III and IV of this report on Operationalization and Applying Culture.

Cross-cultural equivalence should also be apparent in the design of studies. The goal may be the same, for example, in studies of well-being of elders who move from their own homes to assisted living facilities, but the means and meaning become culturally specific. Measures developed in conjunction with one group, using a culturally based or culturally centered approach (Adler et al., 2000; Kagawa-Singer et al., 2002; Trickett et al., 2011) have demonstrated more relevant, culturally informed modes of achieving the purpose of the study (Chen, 2011). Trickett (2011) described a study conducted by the Diabetes Prevention Program (Marrero et al., 2013; The Diabetes Prevention Program Research Group, 2000) that screened over 158,000 individuals to achieve a final sample of 3234, “with most exclusion criteria…chosen to reduce the risk of adverse effects of the intervention.” He concluded, “The implications of such selectivity needs to be clarified for local participating organizations not only as a translation issue, but as an ethical issue of not overstating what we know about for whom the intervention has shown efficacy.”

In a breast cancer screening program with the Hmong people in California, the research team worked closely with Hmong community health outreach workers (HOWs) to develop a culturally based quasi-experimental intervention study that ultimately proved to be very successful (Kagawa-Singer, Tanjasiri, Valdez, Yu, & Foo, 2009; Tanjasiri et al., 2007). The team worked very closely with the HOWs and community members to develop the educational materials (video, flip-chart) and data collection instruments. The translation time required to correctly and effectively communicate concepts (like cancer, breast cancer and mammograms) was difficult to do respectfully since none of these terms had words in any of the Hmong dialects. Over 94% of the Hmong women had <2 years of education and were illiterate in Hmong and English. A unique facet of this study was the inclusion of husbands and sons in the education and outreach, and became an important cultural aspect of the outcome. To date, this study is the first breast cancer screening promotion study to include male social network members. The intervention group had statistically higher rates of mammogram receipt than the comparison community at p=0.01 level of significance. The control community received the outreach and education program after completion of the post-test, and this study is now listed in the NCI Research Tested Intervention Programs RTIP (2013).

Studies such as this Hmong breast cancer screening promotion study highlight the lack of attention in the translational expectation of evidence-based work regarding *external validity* as well as the ethics of an approach that does not incorporate alternative ways of living in this world (Pescosolido, Medina, Martin, & Long, 2013; Sue, 1999).

The lack of self-reflection by the Western and Western trained researchers without knowledge or integration of cross-cultural issues of equivalency inhibits the voices of diverse communities because it denies the position of *equal* validity of other cultures. For example, the arbitrary and aggregate labeling of ethnic groups with racial/ethnic categories (e.g., “Hispanics” or “Latinos,” LGBTIs) and calling that “culture” imposes, at best, an ill-defined framework on a group. This practice often singles out one or two characteristics (e.g., language, passivity, skin color, national origin, non-heterosexuality, or congenital non-standard sexual development) or single beliefs (e.g. fatalism or *familismo*) and assumes that this is sufficient to fill in the cultural framework for family life, work habits, health beliefs, dietary habits, or whatever the focus of that particular health research might be. Cultural characterizations such as these are unidimensional, stereotypical and usually not valid for the population(s) of interest.

Ultimately, labeling an ethnic or sexual/gender minority group and glossing the labeled variable as culture ignores the understanding of the world ***from that group members’ perspective*** and misses the opportunity to investigate the explanatory power of culture. The implicit approach then becomes changing the culture rather

than changing the program or research design (Erwin et al., 2010). Moreover, such an approach too often studies the group in isolation bounded by arbitrary definitions such as race and ethnicity (Lewis-Fernandez & Diaz, 2002) and identifies the factors presumed to influence the health of the group out-of-context where context is essential. Importantly, most humans live in multi-cultural societies with highly permeable boundaries regardless of their social and political boundaries (Kumagai & Lypson, 2009) due, for example, to mass and social media, the Internet, and globalized cities.

For example, one study analyzed the effects of migration on the diets of low-income Korean immigrants living in Los Angeles' Koreatown to assess their integration of Western foods into their daily diets. As an aside, the researchers collected data on the diets of the other ethnic groups in the same geographic area, primarily Latinos and African Americans, and found that, not surprsingly, the Koreans began incorporating African American and Latino foods into their diets. Conversely, the African Americans and Latinos began incorporating many Korean dishes in their diets as well (Harrison, 1999). The effects of such bi-directional changes are rarely studied. Such fluid boundaries of food choices and likely behavioral changes as well, are usually excluded from studies as unnecessary "noise." The influence of these juxtapositions of different cultural groups on the "cultural" practices of any single group of focus is truncated and lacks the awareness of the reciprocal influence of the other reference groups on health behavior, including that of the dominant society, emphasizing the contextual importance of diffusion of beliefs and practices across geographically juxtaposed groups, and the concomitant problematic nature of concepts such as acculturation.

Further compounding the implicit bias in U.S. theories and interventions, the dominant European-American cultural group is usually the reference group in the U.S. (Kagawa Singer et al., 2010). Historically and politically, through its power, this cultural group has relegated minority groups to positions with significantly less social and economic status. However, members of many of these culturally-diverse groups are too often only vaguely aware or disenfranchised in access to resources to change the social and institutional norms that constrain their ability to obtain the tools for upward mobility within U.S. society, such as education within their neighborhoods, jobs that provide sufficient wages to develop economic equity, the ability to buy homes in safe areas with better educational opportunities and quality health access. These variations impact health outcomes and must be considered in order to ensure the accuracy of future research, as well as their applicability to the health care provided to these cultural groups, and the cross-cultural skills of clinicians (see the Expanded CLAS Standards, 2013, which provides further guidelines and criteria for health care agencies and hospitals to integrate such awareness and approaches into their practice and the structure of health care systems to be more responsive to such cultural variations and power-differentials (https://www.thinkculturalhealth.hhs.gov/

Content/clas.asp).

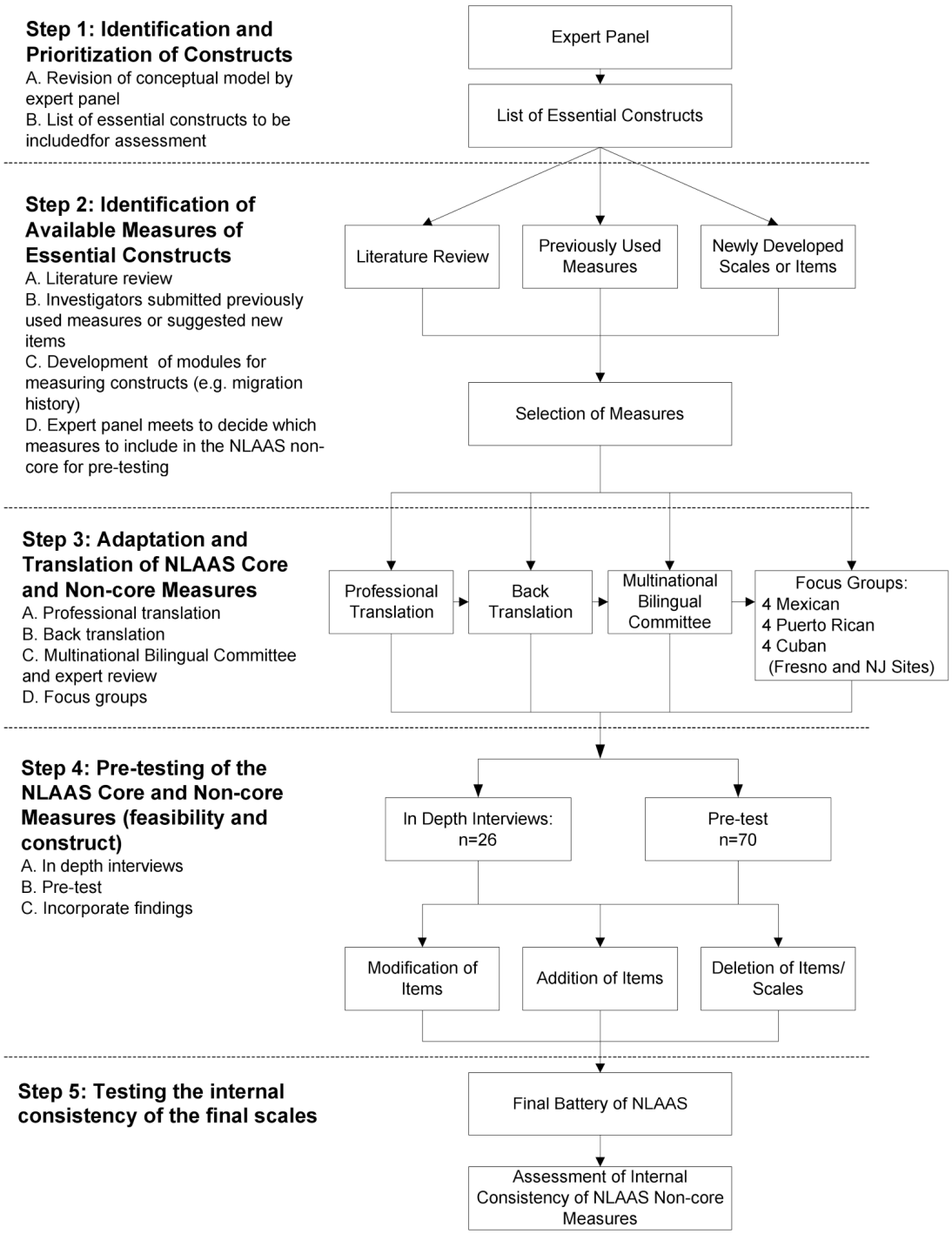
To identify the potential mediating or moderating effects of culture on a health outcome in particular population groups, the precise way the cultural framework is structured in a designated group must first be discovered and understood ***in the terms that group uses***, for every cultural group defines how health, disease and illness are interpreted and managed.

Nevertheless, as noted, no single definition or perspective on culture exists even within a single academic discipline. Each discipline has variance that overlaps with other disciplines, such as within the field of anthropology with symbolic, pragmatic, structural, functional and applied schools.

Thus, we recommend that a first step to integrate culture more explicitly in studies is for researchers to provide an explicit definition or description of how they use or operationalize culture in their study and the corresponding measures used to identify how they hypothesize its influence on the health outcome of interest. Reviewers and readers of the published work would then be able to assess what and how the term is used, and how comparable the findings from different studies of the “same” population and health outcome might actually be.

Eisenberg (1977) and Kleinman and colleagues (1978) provided a useful differentiation between disease and illness that facilitate cross-cultural and cross-disciplinary communication. *Disease* is the observable/testable pathophysiology. *Illness* is the experience of that disease for the individual, family, and population group. It is the experience or meaning of the disease that determines how individuals manage the disease emotionally as well as physically, spiritually, or metaphysically depending upon the identified etiology: for the etiology of the disease influences the selection of the appropriate healing system to treat the disease.

FIGURE 2-3. Five-Step Process to Attain Cultural Relevance and Cultural Equivalence of the NLAAS Measures (Alegria et al., 2004)



Most cultures have indigenous healing systems that diagnose and treat disease–the categories and the meaning of each disease may change, and this again, must be discovered and understood to effectively and validly assess its function and treat it appropriately (Fadiman, 2012; Mull, Nguyen, & Mull, 2001; Rhodes, 1996). Cultures also define appropriate emotional and behavioral modes of reacting to and dealing with sickness and disease. Part of this response is dependent on the meaning of the disease itself, which can prescribe and proscribe how individuals, families and social group cope with, communicate about, and show caring for its members. Every cultural group also defines what constitutes the "good" behavior for every social role. This latter aspect defines how one should act to maintain a sense of integrity and to remain an integral, contributing member of his/her social network. Behavior, communication efforts or emotional reactions that veer from the norms of "proper" behavior threaten the well-being of the individual and the welfare of the group. These powerful forces are often behind what is visible and the core motivators are often unconsciously contoured by culture (see following Exemplar Study 2 by Kohrt, 2013). Knowing what these criteria are before selecting parameters for appropriate behaviors would enable researchers and clinicians to more accurately and effectively understand the phenomenon of study.

Section III on Operationalization provides detailed suggestions for methods to assess the omnipresent variations within cultures. For, if investigators hypothesize that culture has a role in the health outcome of interest in their study, then they must first conceptualize how culture may have the hypothesized effect, and determine how to identify, select, and measure the salient aspects of culture that mediate or moderate the health outcome.

The following exemplar study by Kohrt (2013) demonstrates how culture fundamentally informs intervention design. The study was a sequential mixed paradigm and mixed method design that integrated epidemiological work with ethnographic work to identify the salient social framework in which the emotional distress of child soldiers in Nepal was experienced upon their return home. The research team posited three explanations to frame their intervention that were based on the two sets of data (e.g. epidemiological and ethnographic), and to provide the rationale for the intervention based upon cultural circumstances and practicality. Three possible explanations regarding the role of culture in their results were,

1. Hindu cultural beliefs encouraged discrimination against former child soldiers, especially girls, due to beliefs regarding ritual purity and pollution that in turn led to depression;

2. Hindu cultural beliefs were indirect indicators of other factors (such as poverty rates and educational levels) that characterized certain districts and that led to stressful experiences among former child soldiers, in turn increasing the risk of depression; and,

3. Hindu beliefs served as an explanation or rationale for discrimination against former child soldiers, but the source of those discriminatory acts was actually an underlying fear and mistrust of the returning children, based on their association with a feared and violent political movement.

EXEMPLAR STUDY 2

Community Psychosocial Intervention for Child Soldiers with Posttraumatic Stress Disorder (PTSD) and other Mental Health Problems:

The Role of Culture in Health Intervention Development (Kohrt et al., 2013)

Kohrt and colleagues (2013) examined the impact of military service on post-conflict mental health of child soldiers in Nepal using a **mixed-methods research design**. Nepal experienced ten years of civil war as Maoist insurgents sought to overthrow the Hindu monarchy, and many children were conscripted as combatants. Methods: The research used a mixed methods approach beginning with inductive qualitative research, followed by an epidemiological study, then a follow-up inductive qualitative phase.

The team began their study with extensive ethnographic research in numerous political districts in Nepal that varied in their proportions of religious groups (principally Hindu and Buddhist). Interviews with former child soldiers, parents, teachers, and other community residents revealed that, in many instances, return to the community was more traumatic than the period of armed conflict, especially for girls. Focus group discussions were also held with child soldiers, parents, women's groups, and nongovernmental organizations. The research team found that many girl soldiers described positive experiences in association with the insurgents, where they were first exposed to an ideology of gender equality and female education, which contrasted starkly with traditional patriarchy and gender-discrimination in their homes and communities. When these girls returned home after the war, many were shunned by their families and stigmatized by teachers and other members of the community because of their wartime activities. Interviews with adults revealed that former child soldiers, especially girl soldiers, were considered ritually "polluted" because they had violated Hindu religious norms through their associations with insurgents.

Their parallel epidemiologic survey (n = 282) consisted of a matched cohort study of child soldiers and civilian comparisons in ten districts throughout the country. An interaction between gender and district of residence was associated with increased risk of depression. Former girl soldiers living in predominantly Hindu districts were at a five-fold increased risk of depression relative to non-soldiers; for former boy soldiers there was an 82% increased risk. In non-Hindu districts, former boy and girl soldiers had a 50% increased risk of depression.

To better understand their results, Kohrt and colleagues (2013) returned to qualitative data collection. They knew that defining culture and varying interpretations of the role of culture was crucial. The manner in which cultural processes were interpreted would lead to very different types of interventions, some of which may have been more effective than others.

The multiple data collection strategies were based in a participatory approach using Child Led Indicators, to involve children in research, and inform the intervention design, and evaluation.

Culturally Informed Intervention Design: The team considered three possible explanations regarding the role of culture in their results: (a) Hindu cultural beliefs encouraged discrimination against former child soldiers, especially girls, due to beliefs regarding ritual purity and pollution that in turn led to depression; (b) Hindu cultural beliefs were indirect indicators of other factors (such as poverty rates and educational levels) that characterized certain districts and that led to stressful experiences among former child soldiers, in turn increasing the risk of depression; and, (c) Hindu beliefs served as an explanation or rationale for discrimination against former child soldiers, but the source of those discriminatory acts was actually an underlying fear and mistrust of the returning children, based on their association with a feared and violent political movement.

Unpacking at least to these three levels becomes important when considering the different possible interventions: (1) Should efforts be placed on re-interpretation of Hindu beliefs systems to reduce discrimination practices based on ritual purity? This would address a causal interpretation of the belief system. (2) Or, should literacy programs and poverty relief at a community level be the target of intervention? Alternatively, if cultural context is a proxy for war violence then should community-wide efforts of addressing trauma sequelae be the focus? Both of these would be consistent with a view of cultural context as a proxy for structural factors related to socioeconomic development and war exposures. (3) Or, should the intervention target social, emotional, and behavioral processes, most notably fear, that may underlie maltreatment and be justified with Hindu purity doctrine? Such an intervention would emphasize that cultural context can be a set of frames to interpret and justify practices, including violence and discrimination.

An intervention was then designed and implemented and evaluated using both qualitative and quantitative methods. The intervention was conducted in eight districts. Child soldiers were compared with civilian peers before the intervention, then again after twelve months of services.

Based on follow-up data collection, the investigators decided that Alternative 1 was most likely. That is, basic psychosocial processes of stigmatization and discrimination motivated the behaviors of many community members in relation to former child soldiers, and the logic of these behaviors was justified by a cultural idiom of ritual purity and pollution. The focus of the intervention was to reduce fear, uncertainty, and instability among key community stakeholders interacting with former child soldiers. This included parents, other family members, teachers, health workers, women's groups, youth groups, and other community members. A group of Community Psychosocial Workers (CPSWs) were trained with a 28-day multi-stage curriculum. The CPSW activities were flexible, comprising community sensitization activities; socio-emotional activities and discussions with community stakeholders; supportive listening and communication activities in a family context; and, identification and referral of high risk children.

This intervention was developed directly from an understanding of the role of cultural processes in this social and political context.

Section III. THE CULTURAL FRAMEWORK FOR HEALTH

The Cultural Framework for Health (CFH) research and evaluation design (*Figure III-1*) is a practical guide to navigate the process to determine how culture relates to a health research project, and how to conceptualize and operationalize culture for that project. Although maps are linear, the Cultural Framework provides multiple intensive and dynamic processes, analogous to the iterative nature of the efforts to identify the shape of DNA documented in the *Double Helix* (Watson, 2011).

Furthermore, achieving a comprehensive understanding of culture's unique role in health outcomes often requires a long-term commitment to an ongoing research agenda, something that this processual framework facilitates, but cannot capture. Our framework provides fluid guidelines rather than a static "recipe book" approach to study culture. In other words, the framework is more descriptive than prescriptive.

After a summary *(Figure 3-1),* we provide details on each section *(Figures 3-2 to 3-5).* The map asks six main questions that appear in blue diamonds. The answer to each question determines the direction a researcher follows. "Yes" responses lead one to follow a green arrow to the next step; "no" leads a researcher to follow the red arrow. The arrows respectively lead one to either,

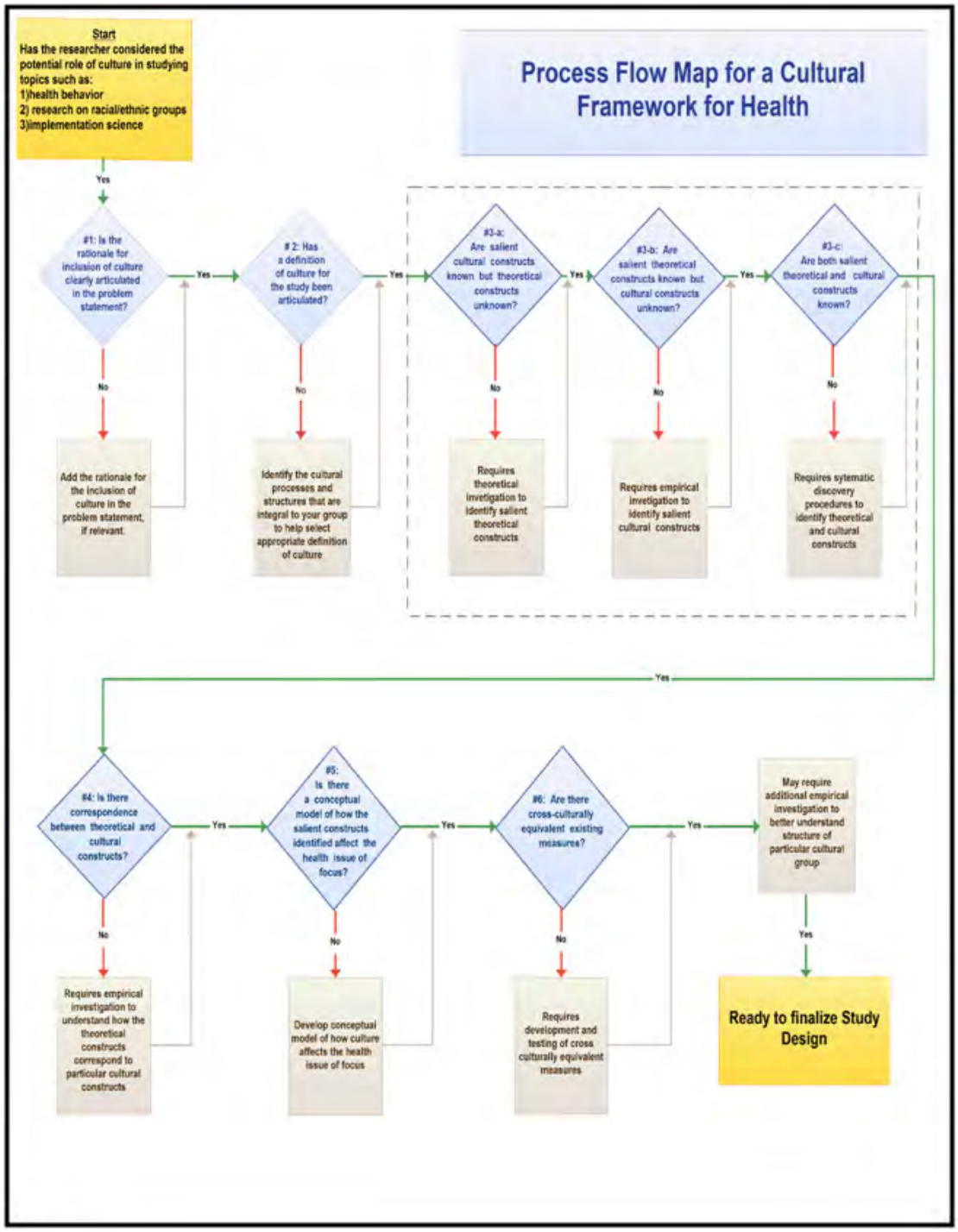
- a question in a blue diamond, or,
- a specific recommendation in a brown rectangle.

Researchers begin with the golden "Start" box and then move to first question in the first blue diamond. Researchers progress through all the questions in the diamonds until they reach the golden box at the bottom, which indicates that they are able to finalize their study design.

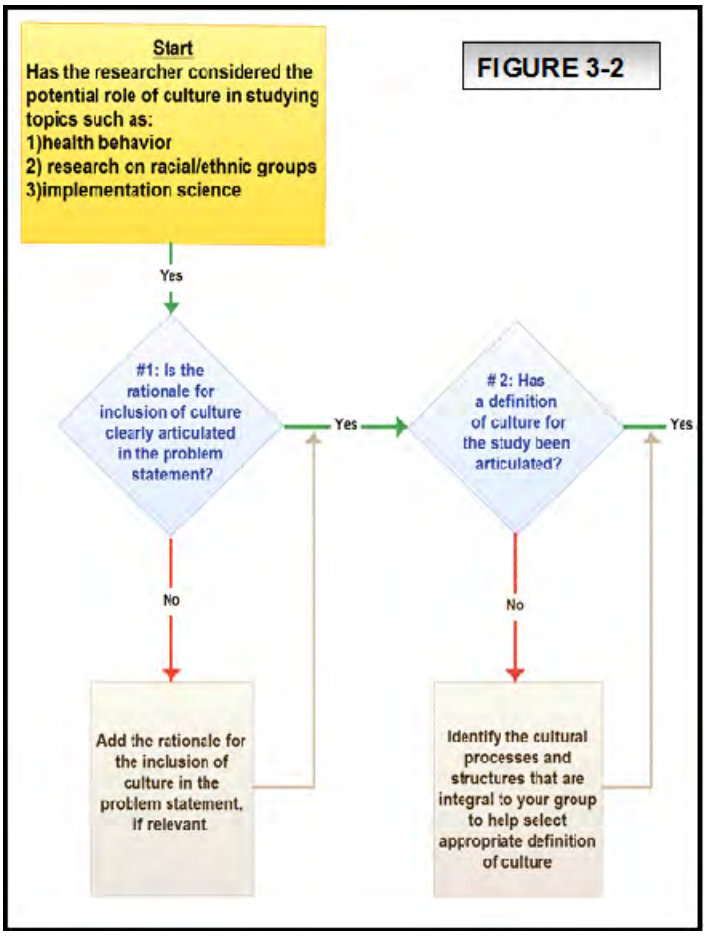
We ask expressly ask researchers who,

- study health behavior,
- conduct research on racial/ethnic groups, or,
- advance implementation science

to consider a role for culture, not simply race/ethnicity, in their studies, as there is a tendency in health research to consider research populations only by their respective race/ethnicity —an incomplete consideration if researchers do not account for cultural meanings associated with race/ethnicity among target populations.


Process Flow Map for a Cultural Framework for Health
Start
Has the researcher considered the potential role of culture in studying topics such as:
1)health behavior
2) research on racialethnic groups
3)implementation science
Yes
#1: Is the rationale for inclusion of culture clearly articulated in the problem statement?
Yes
No
Add the rationale for the inclusion of culture in the problem statement, if relevant.
2: Has a definition of culture for the study been articulated?
Yes
No
Identify the cultural processes and structures that are integral to your group to help select appropriate definition of culture
#3-a: Are salient cultural constructs known but theoretical constructs unknown?
Yes
No
Requires theoretical invetigation to identify salient theoretical constructs
#3-b: Are salient theoretical constructs known but cultural constructs unknown?
Yes
No
Requires empirical invetigation to identify salient cultural constructs
#3-c: Are both salient theoretical and cultural constructs known?
No
Requires sytematic discovery procedures to identify theoretical and cultural constructs
Yes
#4: Is there correspondence between theoretical and cultural constructs?
Yes
No
Requires empirical investigation to understand how the theoretical constructs correspond to particular cultural constructs
#5: Is there a conceptual model of how the salient constructs identified affect the health issue of focus?
Yes
No
Develop conceptual model of how culture affects the health issue of focus
#6: Are there cross-culturally equivalent existing measures?
Yes
No
Requires development and testing of cross culturally equivalent measures
May require additional empirical investigation to better understand structure of particular cultural group
Yes
Ready to finalize Study Design

In **Figure 3-2**, **Question #1** prompts researchers to reflect on this report's Introduction section and consider how culture relates to their research question. For example, they will be challenged to assess the relationship between culture and other social categories such as race/ethnicity or education in order to ascertain the relevance of a culturally informed approach to their study design. They will assess from whose perspective is culture relevant to the question. Researchers need to consider if their study bases the importance of culture on their personal experiences or on previous research results that included the target population's cultural processes related to the health issues being researched, or on theoretical models. A strong case for the relevance of culture to the research topic can be made when a triangulation of all the sources mentioned above point to the importance of culture.



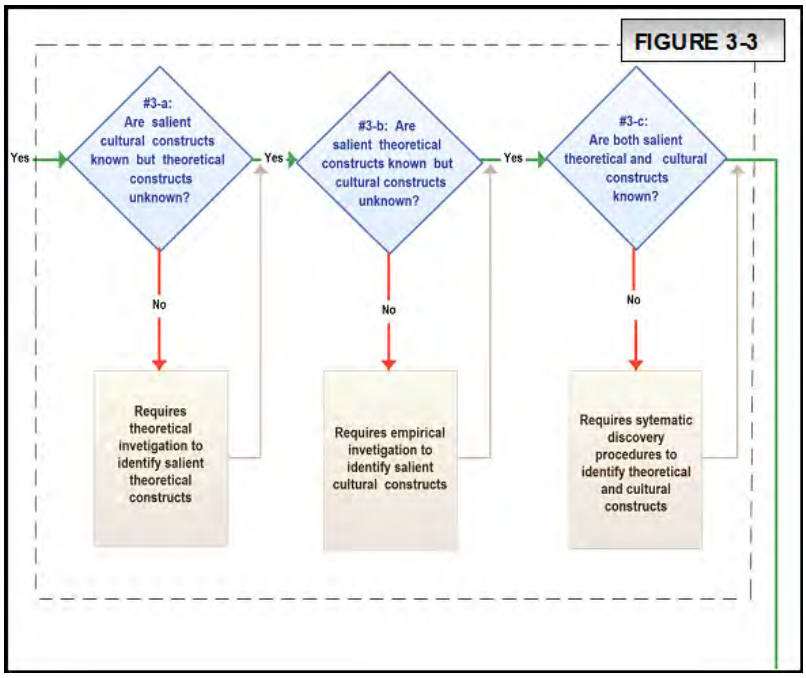
For example, researchers who conducted the first national mental health epidemiological study in Puerto Rico were attuned to cultural issues in the translation of the Diagnostic Interview Schedule into Spanish (Canino et al., 1987). This involved not only literal translation of the questions, but also assessing how translation might affect the cultural meaning of the question. For example, the screener question for panic attack used the word *ataque* in Spanish. Researchers were concerned that respondents might think they were being asked about the *ataque de nervios* rather than panic attack. In order to assess this, the researchers added an open-ended question to the interview in order to collect a brief description of the experience. The researchers' cultural insights were shown to be correct when several responses appeared to reflect more the experience of an *ataque de nervios* than a panic attack (Guarnaccia, Rubio-Stipec, & Canino, 1989). This insight not only allowed the research team to assess the cultural validity of the question on panic attacks, but

also opened the possibility of directly studying the uniquely Puerto Rican experience of *ataques de nervios* in subsequent mental health studies (Guarnaccia, Canino, Rubio-Stipec, & Bravo, 1993; Lewis-Fernández, Garrido-Castillo, et al., 2002).

If researchers clearly can articulate the relevance of culture to their question, then they should answer **Question #2,** a project-specific definition of culture. Defining all key terms including *culture* is important for every project; however, it is especially important when the researchers work with unfamiliar target populations, or in community-engaged research. In the latter context, researchers may want to collaborate with community groups to develop a working definition of culture for a project to help ensure more effective, practical, and useful applications of research findings (Trickett et al., 2011). Clarifying the definition of culture for each project can be invaluable to identify the research constructs of interest and conceptual frameworks that guide research projects (see, e.g.,Guarnaccia, 2009).

Questions #3a and 3b alternatively ask if the theoretical constructs are known but the cultural constructs are not known or vice versa. If the answer is no, it calls for additional theoretical or empirical work, respectively, to identify these constructs.

Finally, **Question #3c** asks if both theoretical and cultural constructs are known. Often identifying the salient theoretical and cultural constructs for a study can be an iterative process that requires multiple rounds of reviewing existing theories and previous empirical work on the particular cultural group in order to know which constructs might be relevant. For instance, if, after going through both 3a and 3b, and either salient theoretical or cultural constructs are still unknown, this requires systematic discovery procedures – such as ethnographic work - in order to identify the relevant constructs and what potential hypotheses may be formed based on the study question(s). If the answer to Question 3c is affirmative, then the researcher can



move to the next step, Question 4.

Question #4 ***(****Figure 3-4****)*** asks whether there is correspondence between the relevant theories and cultural constructs. In other words, has the research team or others previously applied this theoretical construct with this specific cultural group, so it is clear that the structure of the cultural construct for this specific group corresponds to the theoretical construct?

The example of social support used in *Section IV: Operationalization* best exemplifies this issue of correspondence. Social support is a Western theoretical construct that often is important to explain health outcomes. Researchers progressing through the framework may know that social support is a relevant

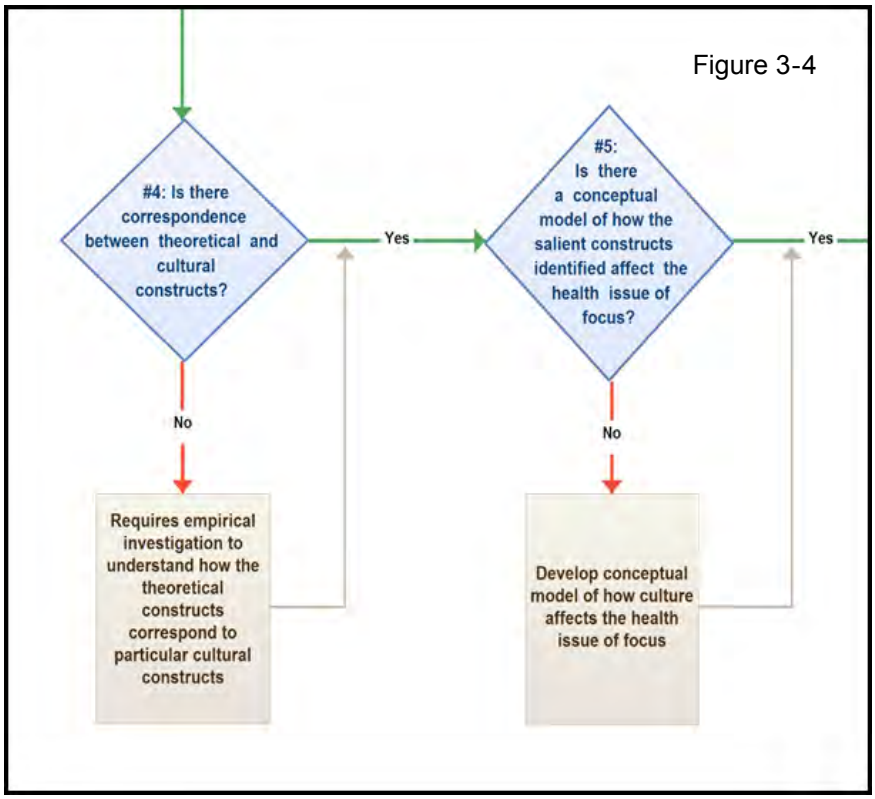


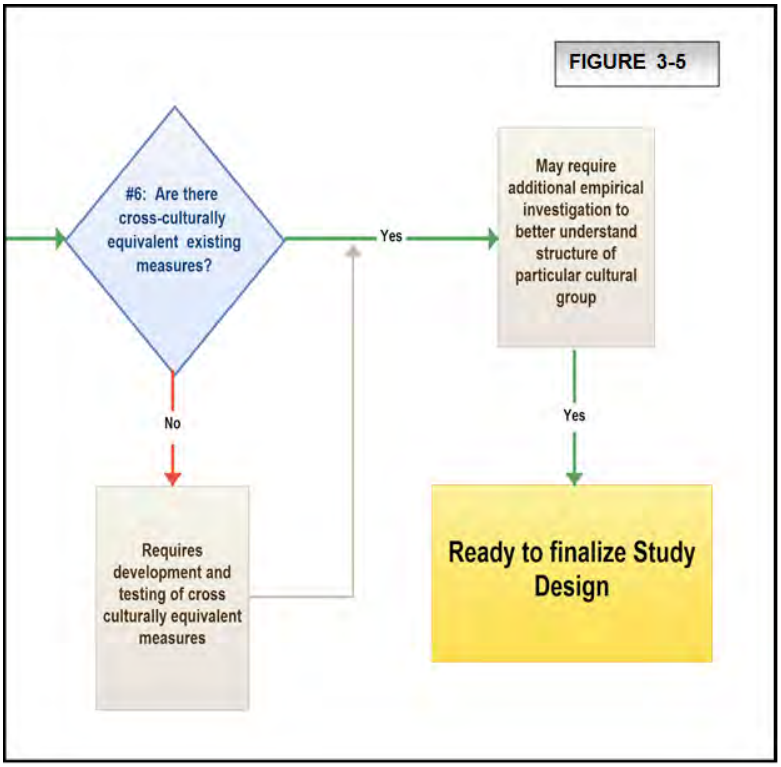
Figure 3-4

theoretical construct for the health outcome that is being studied, and they may know that social support is an important cultural construct for the group being studied. However, the Western definition of social support may NOT correspond to the *structure or process* of social support *as a cultural construct* among the specific group being studied.

In other words, social support in European/North American contexts may be defined as help or assistance from individuals, regardless of their relationship to the person

receiving help. In other cultural contexts, who helps and *how* they help matters a great deal and is integral to how social support is experienced. A research team must be able to delineate specific dimensions or structure of the target population's definition of social support so the team can be confident that their measures of social support are reliable and valid for the study they're designing. Instead, the team may need to conduct further empirical study to learn exactly how the *theoretical* social support construct corresponds to the *cultural* construct of social support of the target population.

One example is Nancy Burke's (2012) work with Filipinas who have experienced breast cancer. These women discussed culturally described social support services as manifestations of "whole-heartedness" (*buong puso*, literally, "whole heart"). This meant services that would "penetrate deeply" (*taos*) not simply through providing help (*tulong*). A survivor clarified her reluctance to use the word "help" to refer to appropriate social support: "To me, 'help' means 'doing something for someone' but 'support' means 'walking side by side' with that person." Others elucidated, "*Buong puso* already includes assistance, but it means more than that. It includes the idea of mentoring someone who is just beginning. Also bonding. Some of the activities we want to be part of our services involve learning together. It's all support coming from your whole heart." In whole, these Filipina breast cancer survivors thought the best way to describe the Western concept of social support in the national Philippine language, Tagalog, was *pag-alalay*, a term that translates as "holding up someone gently" and "temporarily carrying someone's heavy load." (Burke, Villero, & Guerra, 2012; Villero, Macaerag, & Burke, 2014). The lack of conceptual equivalence in the translation of the term "social support" indicates deeper cultural differences in social structure and interpersonal relationships that, if not recognized, could lead to research results that might be statistically significant, but hardly reliable or valid.



For example, such differences have important implications in support groups for breast cancer survivors of diverse ethnic backgrounds. The literature shows that women of color do not participate equally in support groups developed within the European, non-Hispanic framework. Ethnic-specific support groups, however, are well attended by the women of the particular ethnicity (Ashing-Giwa et al., 2006). Although the groups' leaders anecdotally indicate that the difference in attendance is due to more than language concordance, little research has yet been conducted to explain what cultural differences may exist, how members in these discrete groups conceptualize support, and whether the purpose or objective of the groups actually may differ.

If there is correspondence between the theoretical and cultural constructs, Question #5 asks the researchers to consider whether their conceptual framework including the salient constructs identified through Question #4 specifically relates to the health issue of focus. Is culture an independent variable or does it have a mediating or moderating effect? Developing the conceptual framework also allows for a thoughtful identification of other important issues such as unit(s) of analysis for which culture is being operationalized (e.g., specific population groups, professional culture, family culture, hospital culture, prison culture), as well as relevance of contextual factors such as geographic area and time period which may affect the health outcome under study. If the conceptual framework is in place, researchers will now be able to answer **Question #6 *(****Figure 3-5****),*** which asks if there are existing cross-culturally equivalent measures for the constructs to be studied.

For example, the most widely used health behavior theories and constructs, and measures of health behaviors have been widely critiqued for their assumed universality (Pasick, Burke, et al., 2009). Many such measures have been developed based on commonly-held health behavioral theories that some researchers argue are culturally loaded, value-based, and expressly Western-centric (Frankish, Lovato, & Poureslami, 2008; Glanz, Rimer, & Viswanath, 2008) including the Theory of Reasoned Action (Ajzen & Fishbein, 1977; Fishbein & Ajzen, 1967), the Health Belief Model (Rosenstock, 1974), and the Extended Parallel Process Model (Witte, 1992). Implicitly Euro-American assumptions in these theories include individualism, rational choice, and cognitive decision-making (Burke, Josephe, Pasick, & Barker, 2009). The universality of these models has yet to be proven.

For example, Rena Pasick and her team explored the construct of intention and its underlying assumptions in relation to the social context of Filipina and Latina women (Pasick, Barker, et al., 2009; Pasick, Burke, et al., 2009). The mixed-methods study first tested construct measures longitudinally in the multilingual surveys of a concurrent intervention study of 1,463 women from five ethnic and four language groups. The longitudinal association between intention and recent mammography within 2 years was significant only among Whites, and the interaction term with race/ethnicity was statistically significant ($p = .02$; Stewart, Rakowski, & Pasick, 2009). To understand these quantitative results, an intensive inductive ethnographic

investigation targeted Latinas and Filipinas to elucidate connections between social context and individual screening behavior. In-depth interviews were conducted with key informant scholars, community gatekeepers, and laywomen. Contrary to behavioral theory tenets, the authors found that social context can influence behavior directly, circumventing or attenuating the influence of individual beliefs that are said to determine intention. Among the conclusions was the finding that the construct of intention should not be used as if it were universal because stated intention means different things to different people. In addition, dimensions of sociocultural context appear incompatible or inconsistent with the assumptions underlying the intention construct; that is, intention can be based on relationship rather than the perceived benefit of the test, and intention can occur in the absence of beliefs about the particular issue.

To address such shortcomings of existing mono-cultural health behavior measures and evaluate their applicability for a project, researchers should assess pertinent concepts and measures to see if they are relevant to the cultural context under study (Matías-Carrelo et al., 2003). Such processes include efforts to achieve linguistic and cross cultural conceptual equivalence, (Canino & Bravo, 1994; Guarnaccia, Rivera, Franco, & Neighbors, 1996; Lewis-Fernández, Guarnaccia, et al., 2002; Pescosolido, Medina, Martin, & Long, 2013) that incorporate cultural flexibility into the adaptation of instruments so they relate to the particular group under study while retaining the cross-cultural generalizability of the findings (Berry, 1969; Phillips et al., 1996). If there are no cross-culturally equivalent existing measures, then researchers may need to develop them.

If a research team determines that cross culturally equivalent measures exist, they still may need to conduct empirical pilot testing to confirm that the existing cross culturally equivalent measures are relevant to the particular context of the group being studied, given potential regional differences, generational differences, et cetera. This issue emerged in the work on translation of measures for the National Latino and Asian American Study (NLAAS) (Alegria et al., 2004). While translating a list of sohmatic symptoms to assess somatization disorder, potentially two words for headache in Spanish: *dolor de cabeza* that translates as headache and *dolor del cerebro* that translates as “brainache” were identified. There was concern that not having both kinds of headache included might omit important experiences. At the same time, by adding an additional kind of headache, Latinos would have one more somatic symptom to respond to and that might increase their likelihood of meeting criteria for a somatization disorder.

Focus groups with various Latino groups assessed several parts of the interview and its translation, including discussing the somatic symptom questions. In the focus groups, participants recognized both types of headache. They also noted that *dolor del cerebro* was only used by the older generation and was not used widely in younger and middle aged adults. As a result, translators decided to only use *dolor de cabeza* for headache in the final version of the

interview. However, keeping both types of headache would be warranted if a comparable survey were to be carried out in Nicaragua, given the research showing that women, across a wide range of ages, clearly differentiate between the two types of headache, with *dolor de cerebro* seen as arising from confronting often overwhelming experiences of hardship in local social worlds (Yarris, 2011). In contrast, in Peru the term *dolor de cabeza* encompasses similar meanings as *dolor de cerebro* in Nicaragua (Darghouth, Pedersen, Bibeau, & Rousseau, 2006).

Researchers can benefit from self-reflection on how the "cultures" they bring with them are similar or different from the cultural group they study. These personal cultures may stem from their own ethnic, gender or class backgrounds, or the professional culture of science. How might such similarities or differences result in any particular assumptions, stereotypes, biases, or blind spots and how might the researcher address these issues? Researchers may also consider addressing any Human Subjects Protection/Informed Consent/ Cross-Cultural Ethical Issues not simply through the Institutional Review Board (IRB) process but also through community groups and organizations, tribal councils, and other IRBs if needed.

With these six questions addressed, researchers are ready to finalize their study design. Below we present a checklist of the main questions presented in the framework (Figure IV-1). The checklist specifies the steps necessary to conceptualize and operationalize culture in research and provides examples from extant studies to demonstrate how previous studies exemplify the checklist steps. For a list of additional case illustrations on defining, operationalizing, and applying culture in health research, see Appendix H.

SECTION IV. HOW TO REFINE, EXTEND, AND IMPROVE THE OPERATIONALIZATION OF CULTURE IN HEALTH RESEARCH

Human culture's complexity makes it impossible for researchers to measure "all" of culture in any one study or to capture the interactions of the multiple and seemingly unrelated parts to health-related search. Section III provides a the Cultural Framework for Health flowchart and overview of methods to elicit understanding of different facets of culture that may be salient to the research question and subsequently tested for their hypothesized relationship on the health outcome of focus. Given the range of research designs in which dimensions of culture might be important, our discussion will be general; we urge readers to pursue suggested literature for more detailed discussions of specific techniques. This section provides general approaches to consider the operationalization of dimensions of culture.

Culture continues to be operationalized often by identifying ethnic and/or language groups and coding these groups as nominal variables in statistical analyses. This has the effect of treating groups of people as uniform in the beliefs and behaviors that are thought to affect health and hypothesized to be differentially distributed across groups (see Clammer, 2012). It also assumes that, with sufficient sample size, there is little or no measurement error involved, i.e., that these ethnic or language groups, coded nominally, completely 'stand for' the hypothesized beliefs or behaviors thought to characterize group or variations. As we have argued, these assumptions are both unrealistic and untenable.

Researchers can and should remain flexible in their approach to this problem. There is no 'gold standard' to operationalizing the concept of culture. The research operations employed will depend on the aims of the research and the resources (human and otherwise) available. They also will depend on the specific theoretical orientation with respect to culture adopted by the investigator. With these caveats, it is then the responsibility of the investigator to be explicit and rigorous in employing the inherently complex concept of culture in research.

A study can be initiated in an area where enough research has been conducted by researchers who have used the approach presented in the CFH that the researcher, who is not a member of the target population, can be confident that relevant cultural constructs are both well-understood:

- *An etic or outsider's approach*; literally, the investigator imposes a preconceived set of categories and concepts on the study population.

Alternately, the researcher may initiate a study with the intention of eliciting the cultural constructs of importance and how those domains are organized from the members of a particular community:

- *An emic approach; literally, the investigator employs categories and concepts that are elicited from the study population.*

Researchers also might find utility to blend these approaches, e.g., initiating a study with the assumption that certain cultural constructs should be investigated, but the organization, existence, or interpretation of those constructs within specific communities should be elicited from the research participants themselves. A suite of methods is available to the researcher for each of these instances.

Building on these scenarios, a number of concerns arise in the operationalization of culture for researchers to address regardless of the specific question to investigate. Some of these general concerns are as follows:

- Culture is not a residual category, that is, it is not an all-purpose, "magic" variable to invoke when one needs to account for whatever variance remains after 'known' factors have explained as much variance as they can. If researchers posit statements with respect to the explanatory efficacy of culture, they should base these statements on empirically observed associations.

- Conceptually, culture is not a unitary whole. Whatever theoretical perspective one adopts regarding culture, there are relevant domains/constructs, components, or dimensions of culture to explain some given health outcome. Both in theory and measurement, research must make these components or dimensions explicit in order to distinguish among different groups and to develop the knowledge base of the influence of culture on health and wellbeing.

- *Culture* is a term that is generally applied to groups (i.e., characteristic traits or patterns of behavior that distinguish one group from another). Yet, concurrently, individuals who

share a culture are not uniform in their beliefs and behaviors. Therefore, there must always be a consideration of the diversity within any cultural group whether the group is based on racial/ethnic identities, professions, or healthcare organizations.

- Although culture, as frequently understood, refers to groups, the link from culture as an aggregate term to culture as it is observed and identified in the beliefs and behaviors of individuals is an extremely important one.
- There are few, if any, extant battery of scales that operationalize culture similar to scales commonly used medical sociobehavioral sciences. Mixed-methods research designs provide an excellent basis to establish such scales as mixed methods provide due consideration to the value of inductive qualitative methods in generating valid and reliable data (see Creswell et al., 2011).

Further considerations

There are several broad circumstances of research investigators are likely to confront in incorporating the concept of culture into their research design. The first of these is a situation in which there is an existing theory or hypothesis that, based on previous research, appears to be important for the explanation of some health outcome, and there exist at least accepted (if not 'gold standard') measures for the concepts that are relevant to that theory or hypothesis. For example, the theoretical constructs regarding family life have been widely investigated in relation to health and there are well-developed theories regarding the family in a number of fields.

The family also may be a cultural construct that is universal, i.e., it exists in all social groups. A cultural construct, as the term is used here, refers to the way in which a particular phenomenon is understood from the viewpoint of the society or people who are the subjects of the research. It is composed of the concepts that people within a society use to think about particular issues. In the case of the family, while the family as a unit of social organization may be universal, the degree to which the composition of and functioning of family units within a particular society is consistent with the way the family is conceptualized in the theory of the investigator is an empirical question.

A second circumstance an investigator may confront is when there are well-defined theoretical constructs of interest, which may or may not overlap with cultural constructs, and there is no existing measurement. This is likely to be the case in many studies. That is, a topic defined theoretically (e.g., 'social support') will be thought (or 'known') to be important in explaining some health outcome (e.g., as a *moderator* of stressful life events in relation to depressive symptoms) in a specific cultural group, but the cultural construct of social support corresponding to what is meant theoretically by social support is unknown in the specific group to be studied and hence there is no justification for using an existing measurement.

For example, much U.S. social-support research is treated as a social-psychological construct in which the respondent is asked if he or she feels that there is help and assistance available from other persons, regardless of the precise nature of the relationship he or she has to that person (i.e., support can be provided by 'anyone'). Outside of most research conducted in North America and Western Europe among the dominant cultural groups, however, it has been observed that support is not appropriately provided by 'anyone,' but rather must come from 'someone,' or a person who has a particular relationship to the individual (often, but not exclusively, defined by kinship). In these situations, the theoretical construct of interest is known, but the cultural construct corresponding to that theoretical construct is in need of empirical scrutiny (Creswell et al., 2011; Dressler, 1994).

The research by Gravlee et al. (2005) on "race" and blood pressure illustrates this distinction well. On the one hand, many researchers are comfortable with a notion of race that depends either on observed skin color or self-definition as indicators of biological membership in one of two broad groups based on geographic origins (i.e., "white" versus "black"). On the other hand, in Puerto Rican research respondents used a classification system labeled *color*, with intermediate categories that do not correspond to most researchers' understanding of the concept of "race." And, as Gravlee et al. (2005) found, the cultural construct of *color* was a better predictor of blood pressure.

In some research, the theoretical construct is very generally identified (i.e., 'culture' in some sense is important) but the cultural construct(s) of importance is as yet unidentified, and there are no existing measurements. This situation is likely to present itself when existing literature suggests a difference between cultural, ethnic, or language groups in relation to some health outcome or health behavior, but the underlying basis for that difference is as yet unknown. The objectives of research may then be to engage in systematic discovery procedures to generate hypotheses for further testing.

Finally, there may be situations in which there are existing measurements of interest, but the theoretical construct is, at best, weakly developed, and cultural constructs are as yet unidentified. While this situation does not at first glance seem logically plausible, it may in fact be a common occurrence in research in social science and medicine. Measurements developed for research on the relationship between social factors and health often have a general theoretical context, but they may not be very precisely derived, so that the theoretical meaning of an association, even in our own society, may not be obvious. This is of course compounded when that measure is then transported to another cultural group. What this measure truly measures in a particular setting may simply be unknown. There are several examples of this, such as the concept of "acculturation." While there are a number of theories of acculturation, often measurement boils down to language use (Hunt, Schneider, & Comer, 2004). This is often used as a culturally shaped social-psychological construct describing the degree to which an individual identifies with a cultural group. It could be plausibly argued, however, that language use is more a

function of the density of speakers within a particular locale coupled with the degree of economic development and diversity within that community (i.e., learning a dominant language may simply be unnecessary). Language use may be, in other words, a measurement in search of both theoretical and ethnographictt explication. There are certainly other examples of this.

Recommendations to operationalize culture

The following recommendations represent advancement strategies to operationalize culture in research. In what follows, we have organized recommendations roughly in terms of the considerations outlined above, especially with respect to whether the researcher is operating in more of a discovery or formative research mode, or whether the researcher is operating from a well-defined theoretical orientation identifying specific cultural constructs of interest.

First, we discuss recommendations for a discovery or formative research mode.

- Careful literature reviews always are an important place to start the research process. This is emphasized here because in the effort to operationalize cultural factors in a study, the investigator may need to review literature that is well outside a particular substantive focus. For example, if the research focus is on Pacific Island migrants to the U.S. and their use of preventive health services, it may be important to start the literature review with the ethnographic literature on those specific people in their home communities. While researchers may not immediately see the relevance of understanding yam cultivation in Samoa, this literature may provide considerable insight into the cultural-historical background of kin relations and the reciprocal social rights and obligations that underlie much of what is called ‘social support’ in the research literature. These cultural models may be carried forward in the migration process to provide the foundations for behaviors in the novel setting (Janes, 1990).

  The systematic discovery procedures associated with basic ethnographic research can be extremely informative in many research designs. Open-ended interviewing, focus group interviews, and participant-observation within study communities can all help to formulate an understanding of what members of particular cultural groups mean when discussing and acting upon events and circumstances of daily life that are relevant to the theoretical and cultural constructs in question. Cogent discussions of ethnographic methods can be found in Bernard (2011) , DeWalt and DeWalt (2010), Schensul et al. (1999), and Spradley (1979, 1980). The contributors to the volume edited by Quinn (2005) focus specifically on interview techniques and strategies for qualitative data analysis in the examination of diverse cultural models. It should be emphasized that no single interview technique or approach to participant-observation will necessarily match every research problem. These techniques

are best employed in concert, rather than singly.

- The previous suggestion pertains mainly to work prior to the initiation of a social or epidemiologic survey. At the same time, an ethnographic study nested within an epidemiologic survey could prove useful in further elucidation of the importance of a construct and of the validity of its measurement. For example, many studies rely on national surveys, but such national surveys can mask the importance of regional variation in communities of ethnic or language groups (Olafsdottir & Pescosolido, 2009; see synopsis below). If a study of 'fatalism' in Hispanic groups in the United States were to be undertaken in relation to cancer screening, then it is incumbent upon the investigators to demonstrate not only that 'fatalism' is a valid concept within the various groups making up U.S. Hispanics, they must also demonstrate that the term means the same thing and is used in similar ways in different regions of the country (Hunt et al., 2004). Nested ethnographic studies within the survey could help in this regard (Office of Behavioral and Social Sciences Research, 2001).

> The Kohrt and colleagues (Exemplar Study 2, pp. 45-46) illustrate how follow-up qualitative research can be of considerable utility in interpreting and verifying findings from inductive, quantitative research. Mixed methods and mixed paradigm in research is an interactive, rather than linear process.

  In mixed-methods or mixed-paradigms research designs, qualitative methods are often thought of as preceding quantitative methods. Qualitative methods, as noted, are thought to be of principal use in formative stages of research, while quantitative methods are used to test hypotheses. However, this is not necessarily the case. The dialectic and interactive nature of mixed methods and oscillation of strategies is often essential. As the example provided by Kohrt and colleagues on child soldiers in Nepal makes clear, follow-up qualitative research can be of considerable utility in interpreting and verifying findings from quantitative research. The use of mixed methods and mixed paradigms in research is thus better thought of as circular and interactive, rather than a linear process (Creswell et al., 2011). Mixed paradigms, however, should be differentiated from mixed methods. The two major paradigms are inductive (constructivist) and deductive (positivist). Notably, both mix qualitative and quantitative methods (Bernard, 2011). Thus, clarity about each is needed to understand the fundamentally different perspectives taken by each paradigm and not confuse it paradigmatic approach with the method applied.

  Mixed-methods/paradigms research may also play an important role in the secondary analysis of existing data sets. In data sets such as these, there may be little information available regarding culture other than conventional ethnic or racial categories. The inclusion of an ethnographic component would help to identify the specific cultural constructs and domains that are implicated in the cultural and health processes being studied, of which group-level categories are very imperfect indicators.

- Traditional ethnographic research takes place over a period of months if not years;

at the same time, it has long been recognized that some of the aims of ethnographic research can be accomplished in a shorter period of time. This is usually referred to as 'rapid ethnographic assessment' or RAP (Bentley et al., 1988; Scrimshaw & Hurtado, 1987). While there are obvious pitfalls in any attempt to draw inferences on the basis of limited ethnography, these procedures can prove useful in a mixed-methods/paradigms research design in which quantitative data can be supplemented by judiciously collected qualitative data.

- Techniques of cultural domain analysis are useful in general, but especially when there is a careful focus on the meaning of terms within a cultural domain (Borgatti, 1999). Cultural domain analysis refers to a linked set of research and data-analytic techniques for systematically discovering the terms that members of a cultural group use in discussing a cultural domain. This analysis also elicits the dimensions of meaning that link those terms. For example, the technique of free listing involves asking questions that generate lists of terms used in describing a domain. Constrained and unconstrained pile sorts can be used to define similarities and differences in meaning among the terms. A number of techniques of numerical induction (cluster analysis, nonmetric multidimensional scaling, and correspondence analysis) can be used with these data to help extract dimensions of meaning used within the domain (see also Weller and Romney 1988). For example, using these techniques Smith et al. (2004) and McMullin et al. (1995) examined differences and similarities among immigrant Latinas, women of Latina descent in the U.S. (Chicanas), Anglo women, and physicians regarding the underlying causes of reproductive cancers. They found distinct knowledge profiles regarding the etiology of cancer within each group. Similarly, Gravlee et al. (2005) used techniques of cultural domain analysis to elicit the terms that people used to refer to individuals with varying phenotypes and to explore the bases for how people distinguished among these phenotypes. Smith et al. (2004) employed techniques of cultural domain analysis in their study comparing attending physicians', residents' and patients' cultural models of ways to improve the clinical encounter.

- Cultural consensus analysis is a useful ultimate step in cultural domain analysis (Garro, 2000; Romney, Weller, & Batchelder, 1986). Cultural consensus analysis is a fully axiomatic, deductive model that enables the investigator to verify which knowledge within a cultural domain is actually shared. The formal cultural consensus model is appropriate for nominal data. There also, however, is an informal data model that can be applied to rating and ranking data that returns essentially the same results as the formal process model (Weller, 2007). The cultural consensus model works from a matrix of similarities among respondents based on their responses to a standardized set of questions regarding the domain. Sharing of knowledge is evaluated first by examining the ratio of the first to the second eigenvalue extracted from the matrix of similarities. If that ratio is large (> 3.0), then the inference that all respondents are working from a common knowledge base (i.e., the same cultural model) is reasonable. The distribution of knowledge among respondents can be analyzed, as well as residual agreement or departure from the overall cultural consensus. Finally, cultural

consensus analysis provides an estimate of the culturally best responses to the questions, or how a reasonably knowledgeable member of that social group is likely to answer. Smith et al. (1994) and McMullin et al. (1995) used cultural consensus analysis as the ultimate step in the analyses of their data. They reported that within each group of women and group of physicians, there was cultural consensus on the causes of cancer, but there was no agreement when the groups were pooled (McMullin et al., 2005; Smith et al., 2004). Furthermore, specific points of agreement and disagreement between each pair of groups could be identified with considerable accuracy and detail. Gravlee et al. (2005) used cultural consensus analysis to confirm the existence of a distinct cultural model of *color.* Smith et al. (2004) found that when it came to improving the clinical encounter, physicians, residents, and patients agreed within their respective groups, but not with other groups.

The recommendations outlined above are especially useful in discovery or formative modes of research. In some studies, however, the researcher may have a good idea of the cultural constructs of relevance to the study objectives but existing measures are unavailable or inadequate. In this case, all of the steps outlined above would be useful for the intensive investigation of the cultural constructs of interest, and there would also be procedures developed and tested for the systematic creation of new measures to measure these cultural constructs.

Cultural consensus analysis can be useful in the development of measurements for constructs within specific social groups when no measurement exists, or when existing measurements are likely to be too culturally specific to other groups. Dressler et al. (2005) developed a two-stage method in which cultural domain analysis was used first to identify the salient elements of a cultural domain (e.g., “family life”) and then to explore the dimensions of meaning in organizing that domain (e.g., the value placed on characteristics for having ‘a good family’). These dimensions of meaning were then confirmed using cultural consensus analysis. Furthermore, items were weighted by their importance in the cultural domain of the family. The resulting 18-item scale had good reliability (alpha = .89) and prospectively predicted change in depressive symptoms (Dressler, Balieiro, Ribeiro, & dos Santos, 2007). This general procedure could be extended to many cultural constructs.

In contrast, a researcher already may have identified a cultural construct of interest and may have identified, at least tentatively, useful measures applicable to that construct. The following example is a study by Olafsdottir and Pescosolido (2009) that creatively used existing measures in new ways to analyze existing data. The existing measures are relatively insensitive to cultural differences and are poor correlates of health and illness behaviors. However, they analyzed them in interacting ways to discover new findings to demonstrate

TABLE 4-1 Logical Issues in Linking Theoretical and Cultural Constructs

Four Broad Research Circumstances	Theoretical Construct	Cultural Construct	Measures	Approach
Overlap between known constructs	Known	Known	Existing measures	May require empirical investigation to better understand structure of particular cultural group
May or may not overlap between known constructs	Known	Known	Existing measures	Requires empirical investigation to understand how the theoretical construct corresponds to the particular cultural construct
Specific fit of general construct unknown	Known general theoretical context	Unknown cultural construct of importance	Imprecise existing measures	Requires theoretical and empirical investigation
Both constructs unknown	Unknown theoretical constructs of importance	Unknown cultural constructs of importance	No existing measures	Requires systematic discovery procedures to generate hypotheses for further testing

that "creative retooling of even standard cultural measures can provide a critical understanding of cultural maps" and ultimately develop new scales in large-scale surveys. The following recommendations apply to this mode of research.

- Careful translation and back-translation of existing instruments is necessary. For reference, an existing literature on this process that can be consulted (Bernard, 2011; Trimble, 2007, 2013). Furthermore, it may be useful to develop a bank of translated instruments. This could facilitate the work of many researchers. Such a bank should include a careful description of the samples in which the translated instruments have been developed and applied. It must be emphasized, however, that the lexical (or "dictionary") equivalence of terms is no assurance that the terms are equivalent in terms of cultural meaning. Translation and back-translation are only valid once equivalence in cultural meaning can be demonstrated. Translation and back-translation are only valid once equivalence in cultural meaning can be *demonstrated (see NLAAS description in Section II, Figure 2-3).*

- Beyond translation and back-translation, cognitive interviewing should be employed to help confirm that the questions are meaningful to the research

participants and that these questions reflect how the particular cultural construct is conceptualized within that social group (Gerber, 1999). Cognitive interviewing can refer to a number of strategies, such as using an existing instrument in an interview with a respondent, but carefully probing with each item for its meaning to the participant. For example, 'fatalism' has at times been invoked as a culturally-specific belief system that influences the health behaviors of individuals. Measuring 'fatalism' could take the form of responses to questions such as 'When I am sick I trust in God to make me well,' or, 'I pray to God for guidance.' Although more secularly-oriented societies would regard such responses as 'fatalistic,' others regard prayer or trust in a deity as active, instrumental strategies for coping with problematic situations (Browner & Preloran, 2000; Eddy, 1875; Hunt et al., 2004; Mathews, 2000; Pescosolido & Olafsdottir, 2010). Research strategies for discovering the meaning of a construct within a social group need to be employed.

- Cultural consensus analysis also can be used to explore the degree to which an existing scale is meaningful within a social group. Gannotti and Handwerker (2002) used an existing scale of disability in a setting in which its meaning was uncertain. Using cognitive interviewing and cultural consensus analysis, they determined that overall the specific concepts making up the scale were meaningful to participants, although they also identified elements that needed modification, thus reducing or eliminating the uncertainty.

- Multivariate statistical techniques can be used to compare the behavior of existing scales across groups thought to differ culturally. This comparison can be both qualitative (i.e., visual inspection of the similarity of the factor structure of existing scales across groups) and quantitative (i.e., factor loading matrices can be correlated across groups). Differences in the behavior of scales between groups may be indicators of how the constructs operationalized by the scales may be interpreted differently in different cultural groups (Dressler, Viteri, Chavez, Grell, & Dos Santos, 1991)

- Ultimately, all of the data collected above can be used to develop scale items to measure the construct of interest (e.g., social support) in a manner that reflects the understanding of that construct within the cultural group that is the focus of the investigation. Hui & Triandis (1985) provide a very useful general discussion of measurement equivalence in cross-cultural research. They argue that measurement equivalence can be assessed at four levels:

    1. Conceptual equivalence (i.e., does the same concept even exist in two or more societies?);

    2. Operational equivalence (i.e., if the concept exists, can the same observations detect instantiations of the concept in two or more societies?);

3. Item equivalence (i.e., can the same scale be used in two or more societies?); and,

4. Scalar equivalence (i.e., does the same metric apply in two or more societies?). When developing measures to be used cross-culturally, these various forms of equivalence need to be considered in order to assure validity in the population of interest.

- More focused research techniques may also prove useful. The concept of 'explanatory models' was introduced to account for how particular health problems are perceived within cultural groups along several important dimensions, including why a particular health problem may have a specific onset; how that health problem unfolds; what the likely course of the illness will be; and, what the goals for therapy should be. Exploring these explanatory models, using techniques of open-ended interviewing, focus groups, and cultural domain analysis may provide insight into the underlying foundation for group differences, particularly in health related domains(Kleinman, 1980; Kleinman, Eisenberg, & Good, 1978).

- There are a number of journals that emphasize mixed-methods research and the integration of quantitative survey techniques into ethnographic fieldwork. These include journals such as *Field Methods*, and the *Journal of Mixed Methods Research*. These journals can serve as a valuable resource for developing research designs for the investigation of culture. The NIH also has developed a set of guidelines for mixed-methods research that should be consulted (Creswell et al., 2011).

The list of recommendations is not exhaustive with respect to the possible strategies that can be employed in research to operationalize the concept of culture. As noted, a multitude of methods exist for eliciting the type of information required to meet the criteria set out for cultural equivalence. The recommendations provided, however, make explicit some of the major issues that must be addressed in incorporating the concept of culture as an analytic and explanatory concept into research design. This report also introduces existing methods that are effective in operationalizing culture in health research.

The recommendations provided here for refining, extending, and improving the operationalization of culture can be applied in diverse research designs, ranging from descriptive studies to randomized clinical trials. See Appendix G for a description of intervention studies that have successfully operationalized culture at different stages of research.

Figure IV-1: Checklist to define, operationalize, and apply culture in exemplar studies

Checklist question:	Gravlee et al.a	Kohrt et al.
1. Is the rationale for the inclusion of culture clearly articulated in the problem statement?	Yes, the research objective of the study was to examine cultural constructions of racial categories in Puerto Rico.	Yes, the initial research question included the potential modifying influence of religious group on the risk of depression.
2. Has a definition of culture for the study been articulated?	Yes, the investigators work from an explicit cognitive definition of culture.	Yes, the investigators offer alternative pathways through which religious group might influence risk of depression, including conceptualizing religious group as a proxy for cultural frameworks that guide the understanding and interpretation of events and circumstances.
3a. Are salient theoretical constructs known but cultural constructs unknown?	The salient theoretical construct here is 'race.' The cultural construct—the way in which race is understood and used in everyday social interaction in Puerto Rico—is unknown.	The salient cultural construct is "religious group"; what it represents theoretically is unknown.
3b. Are salient cultural constructs known but theoretical constructs unknown?	Systematic ethnographic techniques of cultural domain analysis and cultural consensus analysis were used to discover the salient cultural constructs.	Epidemiologic results were followed up with qualitative methods to discover the salient cultural constructs underlying the differential impact of gender on distress among religious groups.
4. Is there correspondence between theoretical and cultural constructs?	Yes.	The investigators elaborate religious group differences in interpretive framework by using follow-up qualitative research methods.
5. Is there a conceptual framework that specifies how salient constructs affect the health issue of focus?	Yes, the investigators draw on theories of the stress process to account for how allocation to a particular category of *color* can affect physiologic reactivity under differing socioeconomic conditions.	Yes, the authors draw on theories of discrimination and stigma to connect religious group evaluative frameworks to child treatment.
6. Are there cross culturally equivalent existing measures?	No, measures are generated within the study.	No, qualitative research methods are used to identify salient cultural patterns.

(Note: The term "health science" used in this report refers to biomedical, social, and behavioral sciences)

Section V: NEXT STEPS AND COMMENDATIONS

This section enumerates next steps and recommendations for three audiences, and is divided into four separate sections:

1. *General recommendations* for researchers, reviewers, and funders and agency leaders' and specific recommendations for
2. *Researchers*,
3. *Reviewers*, and
4. *Representatives of Funding Organizations.*

1. General recommendations

As noted in the Introduction, all behavior is culturally informed, yet few health and medical professional schools train researchers to attend to cultural processes in their theories or methods.

The richer understanding of culture and future testing of the recommendations presented in this publication, we believe will expand the knowledge of the fundamental role of culture in health and will expand our understanding of the range of culturally-informed ways in which research participants construct their realities and find meaning in life. Identifying such variations are critical tasks for the social and behavioral sciences. This distinctive understanding that implicitly acknowledges multiple ways of life and thought among human beings will help expand the utility of existing theories, improve the development of new approaches that account for the diversity among human beings, and, in turn, foster more effective translational intervention studies.

To achieve these goals, we recommend that researchers:

1. **Develop interdisciplinary teams or collaborations** to integrate both theoretical and methodological expertise from different fields and different levels of investigation within the ecologic framework.

2. Assure external as well as internal validity by utilizing both **inductive and deductive paradigms and quantitative and qualitative methods**. The scientific rigor of both must be maintained throughout the scientific process, for cultural processes often can be “seen” only with inductive qualitative approaches and methods.

3. **Elicit the insider’s perspective** through inductive approaches that draw the cultural realities of target population members into the central inquiry. Researchers should develop their questions and hypotheses with solid, in-depth knowledge about the customs, mores, practices, values, and history of the target population.

- Mixed paradigms and mixed methods are valuable strategies to identify such cultural processes (see Kohrt and Gravlee examples in the report; Creswell, Klassen, et al., 2011).
- Mixed methods also provide opportunities to integrate a much greater variety of theoretical perspectives from multiple disciplines including complexity theory, critical theories, ecological theories, stress theory, and many others.

4. **Collaborate with target population members** to identify the salient issues that they believe influence their health outcomes. Additionally, develop mutual acknowledgement that researchers' unique training and access to data likely complement and expand the perceptions of a given target population. Nevertheless, the insider's perspective is essential to clarify the research questions, develop appropriate measures of salient concepts, and create acceptable and sound research designs for exploratory, confirmatory, and intervention studies.

   - Integrate the economic, environmental, and geopolitical, historical, and social factors of the community of focus. These factors create the context for the development of cultural views and practices, e.g., historical trauma of Native or colonized peoples.
   - Community-Based Participatory Research (CBPR) is a comprehensive approach for groups who have been little studied on a specific topic or where the cross-cultural equivalency of standard measures has not been tested (e.g., Israel et al., 1998; 2008). Community members also often initiate studies themselves. Collaborations among community members and researchers throughout the entire scientific process is often most productive, efficient, and effective through mutual learning and co-construction of knowledge throughout the entire process which includes data collection and analysis, publication production, and dissemination of findings.

     Note that CBPR is a comprehensive process that involves research participants from inception through completion of a research project. On occasion, community-based and community-placed research approaches are sufficient—and should not be mistaken or portrayed as the more comprehensive processes involved in CBPR.
   - Clearly delineate the population of focus. Identify and account for intragroup variations in order to increase the validity of cross-group comparisons and the representativeness of study populations.
   - Clearly identify the measures used to operationalize cultural aspects of behavior of the population of focus so that one can test the influence of

these elements directly, not simply as a residual explanatory variable.

- The HHS Office of Minority Health defines *cultural competency* as, "a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations. *Culture* refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups. *Competence* implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities" (USDHHS, 2013).

5. Implicit in the term is the knowledge that culture affects all human behavior that most often occurs in a physical, social, and personal context. Thus, knowledge of what culture is and how it operates supports a holistic approach to the patient, family, and community for clinical care, health promotion, disease prevention, and public health interventions (see 2013 Enhanced CLAS Standards: https://www.thinkculturalhealth.hhs.gov/Content/clas.asp).

    - *Culturally competent practice is relevant to research* as it is based on mutual learning and empirical testing. Cultural competency requires clinicians and researchers to elicit information about their client's or patient's lives in a respectful manner to ensure that their medical recommendations are achievable because they relate to patients' lives their meanings of illness, health, and wellbeing (Kagawa-Singer & Blackhall, 2009). ***When the range of cultural norms and behaviors that affect the hypothesized outcome(s)of a study population are unknown, it is necessary to identify an existing literature or develop a knowledge base through preliminary ethnographic work before developing interventions for such unstudied or understudied populations.*** Current theories and intervention strategies that have been normed on one population group may be of little relevance or acceptability to other groups in other contexts. In such cases, this knowledge must be either found in the literature or developed. The steps in this process are outlined in the Cultural Framework for Health: Section III, Figure 3.1.

The following Table 5.2 lists the major recommendations specific for researchers, reviewers and funders to begin the process of more accurately identifying the effect of cultural processes on health. Expanded explanations of each follow the Table.

Table 5.2: Summary of Specific Recommendations for Researchers, Reviewers and Funders on how to Conduct, Review or Support Funding of Culturally Informed Research

RECOMMENDATIONS FOR RESEARCHERS	
Understanding culture requires researchers to:	1. Explain inter/intra group variations & effects on health 2. Discern how multiple facets of culture change independently 3. Identify cultural practices/meanings that affect health outcomes, in view of larger sociopolitical, historical and environmental contexts 4. Recognize culture is heterogeneous & dynamic and Integrate it into all study design steps 5. Be keenly aware of their own personal worldviews & values and how these might affect research design, data collection and interpretation. 6. Define and Measure cultural processes explicitly.
Implementing culture requires researchers to	7. Not use unidimensional proxy measures of culture such as race, ethnicity, or a singular belief (e.g., fatalism or familism). 8. Develop interdisciplinary teams or collaborations 9. Use inductive/deductive paradigms & quantitative/qualitative methods. 10. Collaborate with community to identify salient issues using Community-Based Participatory Research (CBPR) approaches. 11. Clearly articulate their concept of culture as an explanatory variable(s). 12. Clearly delineate the population of focus in terms meaningful to them.
Proposing culture as mediator or moderator requires researchers to:	13. Explicitly and rigorously describe salient theoretical and cultural constructs (See CFH framework steps). 14. Use methods that explicitly link observations with measures of cultural processes meaningful to focus populations. 15. Develop/adapt measures for the population under study, if no specific measures exist.
RECOMMENDATIONS FOR REVIEWERS	
Proposals that implicitly or explicitly include the concept of culture must:	1. Clearly describe cultural influences used as explanatory and predictor variables and why. 2. Clearly and explicitly describe study sample population beyond the six OMB racial/ethnic categories. 3. Explicitly define, operationalize & interpret cultural elements. 4. Use effective approaches like mixed paradigms/ methods (e.g., qualitative-quantitative) to collect valid/reliable data. 5. Engage participants in selection/interpretation of study's cultural constructs or give rationale for why participants were not engaged. 6. Explain how cross-cultural validity of theories & measures was established using empirical data. 7. Describe how the complex, dynamic & multi-dimensional nature of cultural processes (e.g. intra-cultural diversity) was addressed. 8. Describe procedures for community engagement and building rapport.
RECOMMENDATIONS FOR FUNDERS / AGENCY LEADERS	
	1. Distribute these findings widely to the research community. 2. Provide focused support and/or funding initiatives for culture research. 3. Prioritize research that embraces the complexity of culture. 4. Encourage responsiveness to the 2013 enhanced CLAS Standards, e.g. importance of community engagement & participatory methods. 5. Provide technical assistance and training programs to assist researchers/reviewers through: • Training sessions for junior/senior investigators changing focus of their research, developed and sponsored by NIH • Training programs for pre-doctoral and postdoctoral students • A series of regional in-person and web trainings for both experienced and new investigators. • Collaboration with National Science Foundation (NSF) in their training series • An NSF or NIH-sponsored summer camp or, workshops or training on the methods proposed in the report. • Training for Center Scientific Review (CSR) staff and Extramural Programs (STEP) Forum staff on how this report affects extramural grant development. • Trainings for Study Section members addressing technical & review issues for studies using culture, information on current portfolio & program initiatives to move this research forward. 6. Support an evaluation of the utility and effectiveness of this report. 7. Develop a toolkit to support appropriate & practical use of this report. 8. Develop a "clearinghouse" of resources that could be included (e.g., PBS – Soul Food Junkies –an example of how race does NOT equal culture) http://www.pbs.org/independentlens/soul-food-junkies/ 9. Develop and support an online suite of lectures on key aspects of this report such as a Culture in Health Research learning collaborative and community of practice.

2. Researchers

Understanding culture requires researchers to,

Be able to explain why the cultural groups of interest demonstrate both inter- as well as intra-group variations and what effect the interaction of these factors has on the health status of its members.

Discern how multiple facets of culture often change independently, creating dissonance among the networks of cultural domains and adding to the difficulties of characterizing the intricacies and interactions of cultural processes for any population group.

Identify practices and meanings that affect health outcomes of members of particular cultural groups. Practices and knowledge of community members may seem initially strange to an outside researcher, but have important functions and significant meaning to its members. Yet these practices and meanings are often tacit knowledge, habitual behavior, and unconscious responses.

Demonstrate the knowledge that culture is heterogeneous and dynamic, and requires recognition and integration in every step of a study design including the selection of the research question, development of cross-culturally valid data collection instruments, modes of measurement, data interpretation, validation with the community, and dissemination.

Be keenly aware of one's own personal worldviews and values in order to fully realize how predominant cultural preconceptions, such as the culture of U.S. health science, can predispose researchers to miss alternate cultural logics of their research participants. Investigators should demonstrate knowledge and understanding of how the requirements of scientific rigor as usually practiced in health research may inhibit or suppress the voices of diverse communities, because it denies their position of difference yet of potentially equal validity. We do not posit a simple dichotomy of U.S. or Western cultural worldviews and everyone else with a set of "unified, unchanging and unquestioned" research norms ,but rather a set of assumptions and practices that are grounded in Western European cultural norms – a research paradigm in the Kuhnian sense (Kaiser, 2012; Kuhn, 2012) that guides and structures the current dominant biomedical scientific approaches in health. The philosophical assumptions and worldview underlying this paradigm come out of a particular historical context in which countries in Western Europe became the dominant geopolitical and religious force, which also underlies scientific inquiry.

Integrate understanding of the role of culture in health outcomes through the implementation of four key points:

Cultural processes must be measured, not regarded as implicit.

Unidimensional proxy measures of culture, such as race, ethnicity, or a singular belief (e.g., fatalism or familism [a social pattern in which the welfare of the family holds greater precedence in individual decision making over the needs of the individual making the decision, a practice often used as a marker for Latinos) should be eschewed. Unidimensional proxy measures constitute a weak approximation by which to account for the culture of a target population.

- Culture is a dynamic, multidimensional construct with measurable properties. More accurate identification and measures of salient factors will enable us to better identify the mechanisms of influence of the appropriate beliefs, values, and/or practices on the behavior(s) of focus.

- The CFH steps in Section III provide a practical guide to navigate the process of determining how culture is relevant to a research project, and how to conceptualize and operationalize culture for a particular hypothesized effect.

1. Studies that use a culturally based approach to create novel interventions emanating from the group of focus have been found to be more effective in achieving the purpose of a given study.

2. Culture provides a conceptual framework for the Social Determinants of Health (SDH). The Cultural Framework for Health organizes and integrates the historical and political explanations for the unequal burden of the SDH borne by particular populations. Greater application of the CFH would promote the development of more effective strategies to reduce barriers to healthier lifestyles and health outcomes for all populations.

If the outcome of focus is proposed to be a result of culture as a mediating or moderating factor, an application should include,

i. Clear articulation of:

1. The researcher's concept of culture as an explanatory variable or variables.

2. How the population of focus is delineated, and how likely intragroup variations have been differentiated.

ii. Explicit and rigorous description of the salient cultural constructs that are relevant to the health outcome of focus, and what is known about of the context-specific ways that these cultural practices and knowledge impact the health of individuals and their communities under study.

iii. Methods that explicitly link observations with measures of cultural processes in ways meaningful to the population of focus. If no such specific measures exist, what will be done to develop or adapt measures for the population under study?

3. Reviewers

a. Research applications that implicitly or explicitly include the concept of culture must clearly describe the specific cultural perceptions, behaviors or influences that are used as explanatory or predictor variables and why.

b. The study sample population must be clearly and explicitly described beyond the six OMB racial/ethnic categories so that the comparability of the findings across studies and against existing studies can be determined.

c. Cultural elements should be explicitly defined, operationalized, measured, and interpreted. Although not required, mixed research paradigms and methods (e.g., qualitative-quantitative) are effective approaches to identify innovative, relevant, valid, and reliable data.

d. Engagement of research participants themselves should be apparent in the selection, organization, and interpretation of cultural constructs used in a study or clear rationale given as to why this was not done.

e. Researchers must explicitly explain how they operationalize culture using empirical data to describe:

   i. The cross-cultural validity of the theories and measurements employed, and,

   ii. How they are addressing the complex, dynamic and multi-dimensional nature of cultural processes.

f. The process by which cultural elements differentially may shape participants in terms of intra-cultural diversity and individual-level versus group-level variations.

Reviewers will increasingly be asked to assess the cultural and linguistic competence of grant applications and how well cultural issues have been addressed in health behavior and social science articles submitted for publication. The CFH provides guidelines to conduct a systematic assessment of these aspects of applications and manuscripts.

4. Representatives of funding organizations

a. Disseminate this report widely to the research community.

b. Provide additional, focused support and/or funding initiatives for research that requires exploration of culture in order to develop and test more translatable interventions

   i. Prioritize research that embraces the complexity of culture.

c. Encourage inclusion of appropriate attention to culture in research and responsiveness to the 2013 enhanced CLAS Standards, including the importance of community engagement and the use of participatory research methods. Provide technical assistance sessions and training programs to assist researchers/clinicians/reviewers to use this document to develop and evaluate research applications. This goal could be achieved through:

   i. Develop and sponsor training sessions for junior and/or senior investigators who may be changing the focus of their research to include more comprehensive inclusion of culture.

   ii. Training programs for predoctoral and postdoctoral students.

   iii. A series of regional in-person and web trainings for both experienced and new investigators.

   iv. Collaboration among multiple funders in their respective training series.

   v. A sponsored “summer camp” or other workshops and trainings on the methods proposed in the report.

d. Training NIH scientific review officers and program directors on the elements of this report.

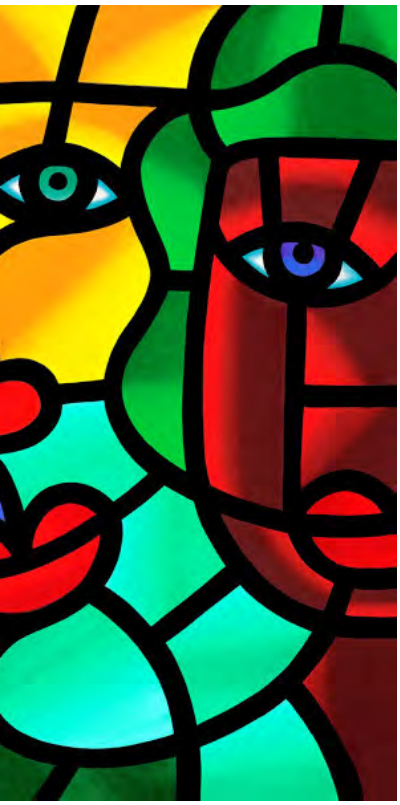
e. Articulate more specific descriptions of culture in funding opportunity announcements, answers to frequently asked questions (FAQs), so future funded research projects include and are reviewed for more profound inclusion of cultural concepts to advance the inclusion of research as a dynamic human process in health research.

f. Support an evaluation of the utility and effectiveness of this report.

g. Promote the development of a toolkit to support appropriate and practical use of the report.

h. Develop a "clearinghouse" of resources that could be included (e.g., PBS – Soul Food Junkies –an example to show that race does NOT equal culture) http://www.pbs.org/independentlens/soul-food-junkies/

i. Develop and support an online suite of lectures on key aspects of this report such as a Culture in Health Research learning collaborative and community of practice.



This report is a document that begins a 21st century research conversation on culture. Since culture and cultural processes are all encompassing of human behavior, this inherent complexity requires ongoing dialogue to fuel the research needed to fully apply the recommendations put forth into the science of health.

Report references

Adler, S,R., Fosket, J.R, Kagawa-Singer, M, McGraw, S.A., Wong-Kim, E., Gold, E., & Sternfeld, B. (2000). Conceptualizing menopause and midlife: Chinese American and Chinese women in the US. Maturitas, 35(1), 11-23.

Airhihenbuwa, C.O. (1995). Health and culture: Beyond the Western paradigm. Thousand Oaks, CA: Sage Publications.

Ajzen, I. & Fishbein, M. (1977). Attitude-behavior relations: A theoretical analysis and review of empirical research. Psychological Bulletin, 84(5), 888.

Alegria, M., Vila, D., Woo, M., Canino, G., Takeuchi, D., Vera, M., Febo, V., Guarnaccia, P., Aguilar-Gaxiola, S., & Shrout, P. (2004). Cultural relevance and equivalence in the NLAAS instrument: integrating etic and emic in the development of cross□cultural measures for a psychiatric epidemiology and services study of Latinos. International Journal of Methods in Psychiatric Research, 13(4), 270-288.

Anderson, K.M. (2012). How far have we come in reducing health disparities? Progress since 2000: Workshop summary: Washington, DC: National Academies Press.

Ashing-Giwa, K.T., Padilla, G.V., Bohorquez, D.E., Tejero, J.S., Garcia, M., & Meyers, E.A. (2006). Survivorship: a qualitative investigation of Latinas diagnosed with cervical cancer. Journal of Psychosocial Oncology, 24(4), 53-88. DOI: 10.1300/J077v24n04_04

Bauer, H., & Mahn, C. (2014). Introduction: Transnational lesbian cultures. Journal of Lesbian Studies, 18, 203-208.

Bentley, M.E., Pelto, G.H., Straus, W.L., Schumann, D.A., Adegbola, C., de la Pena, E., Oni, G.A., Brown, K.H. & Huffman, S. L. (1988). Rapid ethnographic assessment: Applications in a diarrhea management program. Social Science and Medicine, 27(1), 107-116.

Bernard, H.R. (2011). Research methods in anthropology: Qualitative and quantitative approaches. Lanham, MD: AltaMira Press.

Berry, J.W. (1969). On cross-cultural comparability. International Journal of Psychology, 4(2), 119-128.

Borgatti, S.P. (1999). Elicitation techniques for cultural domain analysis. In J.J. Schensul, M.D. LeCompte, B.K. Nastasi, & S.P. Borgatti (Eds.),Enhanced ethnographic methods: Audiovisual techniques, focused group interviews, and elicitation techniques, Ethnographer's toolkit 3 (pp. 115-151). Lanham, MD: AltaMira Press.

Bourdieu, P. (1986). The aristocracy of culture. In V. Buchli (Ed.), Material culture: Critical concepts in the social sciences (Vol. 1, pp. 164-193). New York: Routledge.

Bourdieu, P. (1990). In other words: Essays towards a reflexive sociology. Stanford, CA: Stanford University Press.

Bronfenbrenner, U. (2005). Ecological models of human development. In M. Gauvain & M. Cole (Eds.), Readings on the development of children (pp. 3-8). New York: Worth Publishers.

Browner, C.H. & Preloran, H.M. (2000). Interpreting low-income Latinas' amniocentesis refusals. Hispanic Journal of Behavioral Sciences, 22(3), 346-368.

Burke, K. (1989). On symbols and society (J.R. Gusfield, ed.). Chicago: University of Chicago Press.

Burke, N.J., Joseph, G., Pasick, R.J., & Barker, J.C. (2009). Theorizing social context: Rethinking behavioral theory. Health Education and Behavior, 36(5 suppl), 55S-70S.

Burke, N.J., Villero, O., & Guerra, C. (2012). Passing through meanings of survivorship and support among Filipinas with breast cancer. Qualitative Health Research, 22(2), 189-198.

Canino, G.J., & Bravo, M. (1994). The adaptation and testing of diagnostic and outcome measures for cross-cultural research. International Review of Psychiatry, 6(4), 281-286.

Canino, G.J., Bird, H.R., Shrout, P.E., Rubio-Stipec, M., Bravo, M., Martinez, R.G., Sesman, M., Luz, M., & Guevara, L.M. (1987). The prevalence of specific psychiatric disorders in Puerto Rico. Archives of General Psychiatry, 44(8), 727-735. DOI:10.1001/archpsyc.1987.01800200053008

Carlin, G (author & performer). (1990). Doin' it again (R. Urbisci, director). Recorded live stand-up

performance. New York: Home Box Office.

Champagne, F.A. (2012). Interplay between social experiences and the genome: epigenetic consequences for behavior. Gene-Environment Interplay, 77, 33.

Chavez, L.R., Hubbell, F.A., McMullin, J.M., Martinez, R.G., & Mishra, S.I. (1995). Structure and meaning in models of breast and cervical cancer risk factors: a comparison of perceptions among Latinas, Anglo women, and physicians. Medical Anthropology Quarterly, 9(1), 40-74.

Chen, L. (2011). Elderly residents' perspectives on filial piety and institutionalization in Shanghai. Journal of Intergenerational Relationships, 9(1), 53-68.

Chiao, J,Y. & Blizinsky, K.D. (2013). Population disparities in mental health: Insights from cultural neuroscience. American Journal of Public Health, 103, S122-S132. Doi:10.2105/AJPH.2013.301440

Chiao, J,Y. & Immordino-Yang, M.H. (2013). Modularity and the cultural mind: Contributions of cultural neuroscience to cognitive theory. Perspectives of Psychological Science, 8, 56-61. Doi: 10.1177/1745691612469032.

Clammer, J. (2012). Culture, development, and social theory: Towards an integrated social development. London: Zed Books.

Colby, M., Hecht, M. L., Miller-Day, M., Krieger, J. L., Syvertsen, A. K., Graham, J. W., & Pettigrew, J. (2013). Adapting school-based substance use prevention curriculum through cultural grounding: a review and exemplar of adaptation processes for rural schools. Am J Community Psychol, 51(1-2), 190-205. DOI: 10.1007/s10464-012-9524-8

Cole, S.W, Conti, G., Arevalo, J.M.G., Ruggiero, A.M., Heckman, J.J, & Suomi, S.J. (2012). Transcriptional modulation of the developing immune system by early life social adversity. Proceedings of the National Academy of Sciences, 109(50), 20578-20583.

Creswell, J.W, Klassen, A.C., Plano Clark, V.L., & Smith, K.C. (2011). Best practices for mixed methods research in the health sciences. Bethesda, MD: National Institutes of Health, http://obssr.od.nih.gov/mixed_methods_research/

Darghouth, S., Pedersen, D., Bibeau, G., & Rousseau, C. (2006). Painful languages of the body: Experiences of headache among women in two Peruvian communities. Culture, Medicine, and Psychiatry, 30(3), 271-297.

Day, R. T. (2013). The effect of pre-comprehensive Emergency Obstetric and Neonatal Care facility uterotonic administration on perinatal mortality in rural, northwestern Bangladesh. In Prep.

De Lorgeril, M., Renaud, S., Mamelle, N., Salen, P., Martin, J.L., Monjaud, I, Guidollet, J., Touboul., P., & Delaye, J. (1994). Mediterranean alpha-linolenic acid-rich diet in secondary prevention of coronary heart disease. Lancet, 343(8911), 1454-1459.

De Vos, G. A, & Romanucci-Ross, L. (1982). Ethnic identity: Cultural continuities and change. Mountain View, CA: Mayfield Publishing Company.

DeWalt, K.M, & DeWalt, B.R. (2010). Participant observation: A guide for fieldworkers. Lanham, MD: AltaMira Press.

Dibble, C. (1983). Epilogue educational psychology 636: Cross-cultural counseling. Salt Lake City: University of Utah, Educational Psychology Department.

Doutrich, D., Arcus, K., Dekker, L., Spuck, J., & Pollock-Robinson, C. (2012). Cultural safety in New Zealand and the United States: Looking at a way forward together. Journal of Transcultural Nursing, 23(2), 143-150.

Dressler, W.W. (1994). Cross cultural differences and social influences in social support and cardiovascular disease. In S.A. Shumaker & S.M. Czajkowski (Eds.), Social support and cardiovascular disease (pp. 167-192). New York: Plenum Press.

Dressler, W.W. (2007). Cultural consonance. In D. Bhugra & K. Bhui (Eds.), Textbook of cultural psychiatry (pp. 179-190). New York: Cambridge University Press.

Dressler, W.W., Balieiro, M.C, & dos Santos, J.E. (2012). Cultural consonance, consciousness, and depression: Genetic moderating effects on the psychological mediators of culture. In D.W. Lende & G. Downey (Eds.), The encultured brain: An

introduction to neuroanthropology (pp. 363–388). Cambridge, MA: MIT Press.

Dressler, W.W., Balieiro, M.C, Ribeiro, Rosane P, & dos Santos, Jose E. (2007). A prospective study of cultural consonance and depressive symptoms in urban Brazil. Social Science and Medicine, 65(10), 2058-2069.

Dressler, W.W., Borges, C.D., Balieiro, M.C., & dos Santos, J.E. (2005). Measuring cultural consonance: Examples with special reference to measurement theory in anthropology. Field Methods, 17(4), 331-355. DOI: 10.1177/1525822x05279899

Dressler, W.W., Oths, K.S., & Gravlee, C.C. (2005). Race and ethnicity in public health research: Models to explain health disparities. Annual Review of Anthropology, 34(1), 231.

Dressler, W.W., Viteri, F.E, Chavez, A., Grell, G.A., & Dos Santos, J.E.. (1991). Comparative research in social epidemiology: Measurement issues. Ethnicty and Disease, 1(4), 379.

Drew, E.M., & Schoenberg, N.E. (2011). Deconstructing fatalism: ethnographic perspectives on women's decision making about cancer prevention and treatment. Medical Anthropology Quarterly, 25(2), 164-182.

Dutta, M.J. (2010). The critical cultural turn in health communication: Reflexivity, solidarity, and praxis. Health Communication, 25(6-7), 534-539. DOI: 10.1080/10410236.2010.497995

Eisenberg, L. (1977). Disease and illness Distinctions between professional and popular ideas of sickness. Culture, Medicine, and Psychiatry, 1(1), 9-23.

El-Deeb, A.M, & Ahmady, M.S. (2011). Effect of acupuncture on nausea and/or vomiting during and after cesarean section in comparison with ondansetron. Journal of Anesthesia, 25(5), 698-703.

Eddy, M.B. (1875). *Science and health with key to the Scriptures.* Boston: Christian Scientist Publishing Company.

Eliade, M. (1961). The sacred and the profane: The nature of religion (W.R. Trask, trans.). New York: Harcourt, Brace, and World.

Eliade, M. (1971). The myth of the eternal return: Cosmos and history (W.R. Trask, trans.). Princeton: Princeton University Press.

Elwood, W.N., & Greene, K. (2003). Desperately seeking skeezers: Downward comparison theory and the implications for HIV/STD prevention among heterosexual African-American crack users. Journal of Ethnicity in Substance Abuse, 2(1), 15-33.

Elwood, W.N., & Greene, K. (2005). "Risks both known and unknown": A qualitative method for assessing the role of situation in HIV/STD risk and prevention. Journal of Homosexuality, 50(1), 135-154.

Elwood, W.N., & Vega, M. (2005). Process evaluation results from a condom use intervention with substance abusers in treatment: From "Cinderella?" to "Show me!" Alcoholism Treatment Quarterly, 23(1), 47-62.

Elwood, W.N., Greene, K., & Carter, K.C. (2003). Gentlemen don't speak: Communication norms and condom use in bathhouses. Journal of Applied Communication Research, 31(4), 277-297.

Elwood, W.N., Williams, M.L., Bell, D.C., & Richard, A.J. (1997). Powerlessness and HIV prevention among people who trade sex for drugs ("strawberries"). AIDS Care, 9, 273-284.

Elwood, W.N. & Williams, M.L. (1999). The politics of silence: Communicative rules and HIV prevention issues in gay male bathhouses. In W. N. Elwood (Ed.), Power in the blood: A handbook on AIDS, politics, and communication (pp. 121-132). Mahwah, NJ: Erlbaum.

Elwood, W.N. (1999). Burden of sin: Transmitting messages and viruses in a stigmatized plague. In W. N. Elwood (Ed.), Power in the blood: A handbook on AIDS, politics, and communication (pp. 3-8). Mahwah, NJ: Erlbaum.

Elwood, W.N. (1994). People like us: The ethics and practices of illegal drug addicts. In W.N. Elwood, Rhetoric in the war on drugs: The triumphs and tragedies of public relations (pp. 81-102). Westport, CT: Praeger.

Erwin, D.O, Treviño, M., Saad-Harfouche, F.G,

Rodriguez, E.M, Gage, E., & Jandorf, L. (2010). Contextualizing diversity and culture within cancer control interventions for Latinas: Changing interventions, not cultures. Social Science and Medicine, 71(4), 693-701.

Fadiman, A. (2012). The spirit catches you and you fall down: A Hmong child, her American doctors, and the collision of two cultures. New York: Farrar, Straus, & Giroux.

Fishbein, M., & Ajzen, I. (1967). Readings in attitude theory and measurement. New York: Wiley.

Fisher, C. B., Hoagwood, K., Boyce, C., Duster, T., Frank, D. A., Grisso, T., Levine, R.J., Macklin, R., Spencer, M.B., Takanishi, R, Trimble, J.E., & Zayas, L.H.. (2002). Research ethics for mental health science involving ethnic minority children and youths. American Psychologist, 57(12), 1024-1040.

Foucault, M. (1961). Madness and civilization: An archaeology of medical perception (A.M. Sheridan Smith, trans.). New York: Pantheon.

Foucault, M. (1970). The order of things: An archaeology of the human sciences (A.M. Sheridan Smith, trans.). New York: Pantheon.

Frankish, C., Lovato, C., & Poureslami, I. (2008). Models, theories, and principles of health promotion: Revisiting their use with multicultural populations. In M.V. Kline & R.M. Huff (Eds.), Health promotion in multicultural populations: A handbook for practitioners and students. Thousand Oaks, CA: Sage Publications, Inc.

Gannotti, M.E., & Handwerker, W.P. (2002). Puerto Rican understandings of child disability: Methods for the cultural validation of standardized measures of child health. Social Science & Medicine, 55(12), 2093-2105.

Garro, L.C. (2000). Remembering what one knows and the construction of the past: A comparison of cultural consensus theory and cultural schema theory. Ethos, 28(3), 275-319.

Geertz, C. (1973). The interpretation of cultures. New York: Basic Books.

Geertz, C. (1973). The impact of the concept of culture on the concept of man. In J.R. Platt (Ed.), New views of man (pp. 16-29). Chicago: University of Chicago Press.

Gerber, E. (1999). The view from anthropology: Ethnography and the cognitive interview. . In M.G. Sirken, D. J. Herrmann, R. Tourangeau, J. M. Tanur, N. Schwarz & S. Schechter (Eds.), Cognition and survey research (pp. 217-234). New York: Wiley

Glanz, K., Rimer, B.K. , & Viswanath, K. (2008). Theory, research, and practice in health behavior and health education. In K. Glanz, B.K. Rimer & K. Viswanath (Eds.), Health behavior and health education: Theory, research, and practice (4th ed., pp. 23-40). Thousand Oaks, CA: Sage Publications.

Goddard, C. (2005). The lexical semantics of culture. Language Sciences, 27(1), 51-73.

Good, M-J. D., Willen, S., Hannah, S.D., Vickery, K., & Taeseng, L. (2011). Shattering culture: American medicine responds to cultural diversity. New York: Russell Sage Foundation.

Goodenough, W. (1996). Culture. In D. Levinson & M. Ember (Eds.), Encyclopedia of cultural anthropology (pp. 291–299). New York: Henry Holt.

Gravlee, C.C. (2005). Ethnic classification in southeastern Puerto Rico: The cultural model of “color”. Social Forces, 83(3), 949-970.

Gravlee, C.C. (2009). How race becomes biology: Embodiment of social inequality. American Journal of Physical Anthropology, 139(1), 47-57.

Gravlee, C.C., & Dressler, W.W. (2005). Skin pigmentation, self perceived color, and arterial blood pressure in Puerto Rico. American Journal of Human Biology, 17(2), 195-206.

Gravlee, C.C., Non, A.L., & Mulligan, C.J. (2009). Genetic ancestry, social classification, and racial inequalities in blood pressure in Southeastern Puerto Rico. PLoS One, 4(9), e6821.

Guarnaccia, P.J. (2009). Methodological challenges in research on the determinants of minority mental Health hnd wellness. In S. Loue & M. Sajatovic (Eds.),

Determinants of minority mental health and wellness (pp. 235-386): New York: Springer.

Guarnaccia, P.J., & Rogler, L.H. (1999). Research on culture-bound syndromes: new directions. American Journal of Psychiatry, 156(9), 1322-1327.

Guarnaccia, P.J., Canino, G.J., Rubio-Stipec, M., & Bravo, M. (1993). The prevalence of ataques de nervios in the Puerto Rico Disaster Study: The role of culture in psychiatric epidemiology. Journal of Nervous and Mental Disease, 181(3), 157-165.

Guarnaccia, P.J., Rubio-Stipec, M., & Canino, G.J. (1989). Ataques de nervios in the Puerto Rican Diagnostic Interview Schedule: The impact of cultural categories on psychiatric epidemiology. Culture, Medicine, and Psychiatry, 13(3), 275-295.

Guarnaccia, P.J., Rivera, M., Franco, F., & Neighbors, C. (1996). The experiences of ataques de nervios: Towards an anthropology of emotions in Puerto Rico. Culture, Medicine, and Psychiatry, 20(3), 343-367.

Harrison, G. G. (1999). [Personal Communication].

Hartigan, J. (2010). Race in the 21st Century: Ethnographic approaches. New York: University Press.

Harvard Report on Cancer Prevention. Volume 1: Causes of human cancer. (1996). Cancer Causes Control, 7 Suppl 1, S3-59.

Hatcher, J., & Hall, L.A. (2009). Psychometric properties of the Rosenberg self-esteem scale in African American single mothers. Issues in Mental Health Nursing, 30(2), 70-77.

Hay, M.C., Cameron, W., Weisner, T.S, Subramanian, S.D., Naihua, N., E.J, & Kravitz, R.L. (2008). Harnessing experience: Exploring the gap between evidence-based medicine and clinical practice. Journal of Evaluation in Clinical Practice, 14(5), 707-713.

Hecht, M.L, & Krieger, J.L.R. (2006). The principle of cultural grounding in school-based substance abuse prevention The Drug Resistance Strategies Project. Journal of Language and Social Psychology, 25(3), 301-319.

Henrich, J. (2011). Thematic series: The emerging science of culture, The weirdest people in the world. Webcast sponsored by the Irving K. Barber Learning Centre. Accessed 10 July 2014, http://www.youtube.com/watch?v=dmlfPY4T9bk

Henrich, J., Heine, S. J., & Norenzayan, A. (2010). The weirdest people in the world. Behavioral and Brain Sciences, 33(2-3), 61-83.

Heurtin-Roberts, S. (2009). Self and other in cancer health disparities: Negotiating power and boundaries in U.S. society. In J. McMullin & D. Weiner (Eds.), Confronting cancer: metaphors, advocacy, and anthropology. Santa Fe: School for Advanced Research.

Hruschka, D. J. (2012). Expert Panel Responses.

Hruschka, D.J. (2009). Culture as an explanation in population health. Annals of Human Biology, 36(3), 235-247. DOI: 10.1080/03014460902852593

Hruschka, D.J. (2012). Do economic constraints on food choice make people fat? A critical review of two hypotheses for the poverty-obesity paradox. American Journal of Human Biology. 24:3, 277-285.

Hui, C.H., & Triandis, H.C. (1985). Measurement in cross-cultural psychology A review and comparison of strategies. Journal of Cross-Cultural Psychology, 16(2), 131-152.

Hunt, L.M., Schneider, S., & Comer, B. (2004). Should "acculturation" be a variable in health research? A critical review of research on U.S. Hispanics. Social Science and Medicine,, 59(5), 973-986. DOI: 10.1016/j.socscimed.2003.12.009

Hunter, R.G., & McEwen, B.S. (2013). Stress and anxiety across the lifespan: structural plasticity and epigenetic regulation. Epigenomics, 5(2), 177-194.

Institute of Medicine. (2002). Speaking of health: Assessing health communication strategies for diverse populations: National Academy Press.

International Committee of Medical Journal Editors. (2010). Uniform requirements for manuscripts submitted to biomedical journals: Writing and editing for biomedical publication, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3142758/

Israel, B.A., Schulz, A.J., Parker, E.A., & Becker, A.B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. Annual Review of Public Health, 19, 173-202.

Israel, B.A., Schulz, A.J., Parker, E.A., Becker, A.B., Allen, A., & Guzman, J.R. (2008). Critical issues in developing and following CBPR principles. In M. Minkler & N. Wallerstein (Eds.), Community-based participatory research for health: From processes to outcomes (2nd ed., pp. 47-66). San Francisco: Jossey-Bass.

Janes, C.R. (1990). Migration, social change, and health: A Samoan community in urban California. Palo Alto, CA: Stanford University Press.

Jenks, A.C. (2011). From "lists of traits" to "open-mindedness": Emerging issues in cultural competence education. Culture, Medicine, and Psychiatry, 35(2), 209-235. DOI: 10.1007/s11013-011-9212-4

Jones, N.A. & Bullock, J. (2012, September). The two or more races population: 2010. 2010 Census Briefs, 1-23, http://www.census.gov/prod/cen2010/briefs/c2010br-13.pdf

Kagawa-Singer, M. (1993). Redefining health: Living with cancer. Social Science and Medicine, 37(3), 295-304.

Kagawa-Singer, M. (1994). Cultural systems related to cancer. In S. B. Baird, R. McCorkle & G. M. (Eds.), Cancer nursing: A comprehensive textbook (2 ed., pp. 38-52). Philadelphia: Saunders.

Kagawa-Singer, M. (2000). Improving the validity and generalizability of studies with underserved U.S. populations expanding the research paradigm. Annals of Epidemiology, 10(8), S92-S103.

Kagawa-Singer, M. (2006). Population science is science only if you know the population. Journal of Cancer Education: The Official Journal of the American Association for Cancer Education, 21(1 Suppl), S22.

Kagawa-Singer, M. (2009). Where is culture in cultural tailoring. In J. McMullin & D. Weiner (Eds.), Confronting cancer: Metaphors, inequality, and advocacy. (pp. 207-229). Santa Fe: School of American Research.

Kagawa-Singer, M., & Blackhall, L.J. (2009). Negotiating cross-cultural issues at the end of life: "You got to go where he lives". In S.J. McPhee, M.A. Winker, M.W. Rabow, S. Z. Pantilat & A. J. Markowitz (Eds.), Care at the close of life: Evidence and experience (pp. 417-428). New York: : McGraw-Hill Publishers.

Kagawa-Singer, M., Dadia, A.V., Yu, M.C., & Surbone, A. (2010). Cancer, culture, and health disparities: time to chart a new course? CA: A Cancer Journal for Clinicians, 60(1), 12-39. DOI: 10.3322/caac.20051

Kagawa-Singer, M., Tanjasiri, S.P., Valdez, A., Yu, H., & Foo, M.A. (2009). Outcomes of a breast health project for Hmong women and men in California. American Journal of Public Health, 99(S2), S467-S463.

Kagawa-Singer, M., Wu, K., Kawanishi, Y., Greendale, G.A., Kim, S., Adler, S.R., & Wongvipat, N. (2002). Comparison of the menopause and midlife transition between Japanese American and European American women. Medical Anthropology Quarterly, 16(1), 64-91.

Kaiser, D. (2012). In retrospect: The structure of scientific revolutions. Nature, 484(7393), 164-166.

Karasek, R., Baker, D., Marxer, F., Ahlbom, A., & Theorell, T. (1981). Job decision latitude, job demands, and cardiovascular disease: a prospective study of Swedish men. American Journal of Public Health, 71(7), 694-705.

Kelly, J.A., Murphy, D.A., Sikkema, K.J., McAuliffe, T.L., Roffman, R.A., Solomon, L.J., Winett, R.A., & Kalichman, S.C. (1997). Randomised, controlled, community-level HIV-prevention intervention for sexual-risk behaviour among homosexual men in U.S. cities. Lancet, 350(9090), 1500-1505.

Kleinman, A. (1980). Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine, and psychiatry (Vol. 3). Berkeley: University of California Press.

Kleinman, A., Eisenberg, L., & Good, B.. (1978). Culture, illness, and care: Clinical lessons from anthropologic and cross-cultural research. Annals of Internal Medicine, 88(2), 251-258.

Kohrt, B.A. (2013). Community psychosocial intervention for children soldiers with posttraumatic stress disorder (PTSD) and other mental health problems: The role of culture in health intervention development. Unpublished manuscript.

Kohrt, B.A., & Hruschka, D.J. (2010). Nepali concepts of psychological trauma: The role of idioms of distress, ethnopsychology and ethnophysiology in alleviating suffering and preventing stigma. Culture, Medicine, and Psychiatry, 34(2), 322-352.

Kuhn, T.S. (2012). The structure of scientific revolutions. Chicago: University of Chicago Press.

Lakes, K., Lopez, S.R., & Garro, L.C. (2006). Cultural competence and psychotherapy: Applying anthropologically informed conceptions of culture. Psychotherapy (Chic), 43(4), 380-396. DOI: 10.1037/0033-3204.43.4.380

Lavallee, B., Neville, A., Anderson, M., Shore, B., & Diffey, L. (2008). First Nations, Inuit, Métis health. Core competencies. A curriculum framework for undergraduate medical education. Ottawa: Indigenous Physicians Association of Canada, Association of Faculties of Medicine of Canada.

Lewis-Fernandez, R., & Diaz, N. (2002). The cultural formulation: A method for assessing cultural factors affecting the clinical encounter. Psychiatric Quarterly, 73(4), 271-295.

Lewis-Fernández, R., Garrido-Castillo, P., Bennasar, M.C., Parrilla, E.M., Laria, A.J., Ma, G., & Petkova, E. (2002). Dissociation, childhood trauma, and ataque de nervios among Puerto Rican psychiatric outpatients. American Journal of Psychiatry, 159(9), 1603-1605.

Lewis-Fernández, R., Guarnaccia, P.J., Martinez, I.E., Salmán, E., Schmidt, A., & Liebowitz, M. (2002). Comparative phenomenology of ataques de nervios, panic attacks, and panic disorder. Culture, Medicine, and Psychiatry, 26(2), 199-223.

Lewis-Fernández, R., Raggio, G.A., Gorritz, M., Duan, N., Marcus, S., Cabassa, L.J., Humernsky., J., Becker, A.E., Alarcón, R.D., Oquendo, M.A., Hansen, H., Like, R.C., Weiss, M., Desai, P.N., Jacobsen, F.M., Foulks, E.F., Primm, A., Lu, F., Kopelowicz, A., Hinton, L., & Hinton, D.E. (2013). GAP-REACH©: A checklist to assess comprehensive reporting of race, ethnicity, and culture in psychiatric publications. Journal of Nervous and Mental Disease, 201(10), 860-871. DOI: 10.1097/NMD.0b013e3182a5c184

Lipski, E. (2010). Traditional non-Western diets. Nutrition in Clinical Practice, 25(6), 585-593. DOI: 10.1177/0884533610385821

Manley, E., Levitt, H.,& Mosher, C. (2007). Understanding the bear movement in gay male culture: Redefining masculinity. Journal of Homosexuality, 53, 89-112. PMID: 18689193

Marmot, M., & Wilkinson, R. (2009). Social determinants of health. Oxford, UK: Oxford Uuniversity Press.

Marrero, D., Pan, Q., Barrett-Connor, E., de Groot, M., Zhang, P., Percy, C., Florez, H., Ackermann, R., Montez, M., Rubin, R.R., & the DPPOS Research Group. (2013). Impact of diagnosis of diabetes on health-related quality of life among high risk individuals: The Diabetes Prevention Program outcomes study. Quality of Life Research, 23(1), 75-88. DOI: 10.1007/s11136-013-0436-3

Mathews, H.F. (2000). Negotiating cultural consensus in a breast cancer self-help group. Medical Anthropology Quarterly, 14(3), 394-413.

Matías-Carrelo, L.E, Chavez, L.M, Negrón, G., Canino, G., Aguilar-Gaxiola, S., & Hoppe, S. (2003). The Spanish translation and cultural adaptation of five mental health outcome measures. Culture, Medicine, and Psychiatry, 27(3), 291-313.

McEwen, B.S. (1998). Stress, adaptation, and disease: Allostasis and allostatic load. Annals of the New York Academy of Sciences, 840(1), 33-44.

McMullin, J.M., Alba, I.D., Chávez, L.R., & Hubbell, F.A. (2005). Influence of beliefs about cervical cancer etiology on Pap smear use among Latina immigrants. Ethnicity & Health, 10(1), 3-18.

Mir, G., Salway, S., Kai, J., Karlsen, S., Bhopal, R., Ellison, G.T.H., & Sheikh, A. (2012). Principles for research on ethnicity and health: The Leeds Consensus Statement. European Journal of Public Health, 23(3), 504-510. DOI: 10.1093/eurpub/cks028

Mull, D.S, Nguyen, N., & Mull, J.D. (2001). Vietnamese diabetic patients and their physicians: What ethnography can teach us. Western Journal of Medicine, 175(5), 307.

National Cancer Institute. (2013). Research-tested Intervention Programs (RTIPs. from http://rtips.cancer.gov/rtips/index.do

Nisbett, R.E., & Wilson, T.D. (1977). Telling more than we can know: Verbal reports on mental processes. Psychological Review, 84(3), 231.

Non, A.L, Gravlee, C.C, & Mulligan, C.J. (2012). Education, genetic ancestry, and blood pressure in African Americans and Whites. American Journal of Public Health, 102(8), 1559-1565.

Nursing Council of New Zealand. (2011). Guidelines for cultural safety, the Treaty of Waitangi, and Maori health in nursing education and practice: Regulating nursing practice to protect public satey. Wellington: Nursing Council of New Zealand.

Office of Behavioral and Social Sciences Research. (2001). Qualitative methods in health research: Opportunities and considerations in application and review. Bethesda, MD: National Institutes of Health, http://obssr.od.nih.gov/pdf/qualitative.pdf

Office of Management and Budget. (1997, October 30). Revisions to the standareds for the classification of federal data on race and ethnicity. Federal Register, 62(210), 58782-58790. http://www.gpo.gov/fdsys/pkg/FR-1997-10-30/pdf/97-28653.pdf

Office of Minority Health, U.S. Department of Health and Human Services. (2013). National CLAS Standards: Fact Sheet. https://www.thinkculturalhealth.hhs.gov/pdfs/NationalCLASStandardsFactSheet.pdf

Olafsdottir, S., & Pescosolido, B.A. (2009). Drawing the line: the cultural cartography of utilization recommendations for mental health problems. Journal of Health and Social Behavior, 50(2), 228-244.

Olafsdottir, S., & Pescosolido, B.A. (2011). Constructing illness: How the public in eight Western nations respond to a clinical description of “schizophrenia”. Social Science and Medicine, 73(6), 929-938.

Oppenheimer, G.M. (2001). Paradigm lost: Race, ethnicity, and the search for a new population taxonomy. American Journal of Public Health, 91(7), 1049.

Oths, K.S., Dunn, L.L., & Palmer, N.S. (2001). A prospective study of psychosocial job strain and birth outcomes. Epidemiology, 12(6), 744-746.

Padilla, G.V, Kagawa-Singer, M., & Ashing-Giwa, K. (2003). Quality of life and culture. In C.R. King & P. Hinds (Eds.), Quality of life: From nursing and patients perspectives (2nd ed., pp. 117-142). Sudbury, MA: Jones and Bartlett Learning.

Page, J.B. (2005). The concept of culture: A core issue in health disparities. Journal of Urban Health, 82(2 Suppl 3), iii35-43. DOI: 10.1093/jurban/jti062

Pasick, R.J., Barker, J.C., Otero-Sabogal, R., Burke, N.J., Joseph, G., & Guerra, C. (2009). Intention, subjective norms, and cancer screening in the context of relational culture. Health Education and Behavior, 36(5 Suppl), 91S-110S. DOI: 10.1177/1090198109338919

Pasick, R.J., Burke, N.J., Barker, J.C., Joseph, G., Bird, J.A., Otero-Sabogal, R., Tuason, N., Stweart, S.L., Rakowski, W., Clark, M.A., Washington, P.K., & Guerra, C. (2009). Behavioral theory in a diverse society: Like a compass on Mars. Health Education and Behavior, 36(5 Suppl), 11S-35S. DOI: 10.1177/1090198109338917

Pescosolido, B.A., & Olafsdottir, S. (2010). The cultural turn in sociology: Can it help us resolve an age-old problem in understanding decision making for health care? Sociological Forum, 25(4), 655-676. DOI: 10.1111/j.1573-7861.2010.01206.x

Pescosolido, B.A., Medina, T.R, Martin, J.K, & Long, J.S. (2013). The “backbone” of stigma: Identifying the global core of public prejudice associated with mental illness. American Journal of Public Health, 103(5), 853-860. DOI: 10.2105/AJPH.2012.301147

Pettigrew, J., Miller-Day, M., Krieger, J., & Hecht, M. (2012). The rural context of illicit substance offers: A study of Appalachian rural adolescents. Journal of Adolescent Research, 27, 523-550. DOI: 10.1177/0743558411432639

Phillips, L.R, Luna, I., Russell, C.K, Baca, G., Lim, Y.M., Cromwell, S.L., & de Ardon, E.T. (1996). Toward a cross-cultural perspective of family caregiving. Western Journal of Nursing Research, 18(3), 236-251.

Quinn, N. (2005). Finding culture in talk: A collection of methods. New York: Palgrave Macmillan.

Rhodes, L.A. (1996). Studying biomedicine as a cultural system. In C.F. Sargent & T.M. Jognson (Eds.), Medical anthropology: Contemporary theory and method (pp. 165-180). Wesport, CT: Praeger.

Rivkin, I.D., Lopez, E., Quaintance, T.M., Trimble, J.E., Hopkins, S., Fleming, C, Mohatt, G.V. (2012). Value of community partnership for understanding stress and coping in rural Yup'ik communities: the CANHR study. Journal of Health Disparities Research and Practice, 4(3), 2.

Rogers, E.M. (2010). Diffusion of innovations. New York: Free Press.

Rogler, L.H., Malgady, R.G. , Costantino, G., Blumenthal, R., & Kagawa-Singer, M. (1987). Today's reality: Research issues in underserved culturally sensitive mental health services mean? The case of Hispanics. American Cancer Society Third National Conference, 42, 5650–5670.

Romney, A. K., Weller, S.C., & Batchelder, W.H. (1986). Culture as consensus: A theory of culture and informant accuracy. American Anthropologist, 88(2), 313-338. DOI: 10.1525/aa.1986.88.2.02a00020

Rosenstock, I.M. (1974). The Health Belief Model and preventive health behavior. Health Education & Behavior, 2(4), 354-386. DOI: 10.1177/109019817400200405

Salway, S., Barley, R., Allmark, P., Gerrish, K., Higginbottom, G., & Ellison, G.T.H. (2012). Can the quality of social research on ethnicity be improved through the introduction of guidance? Findings from a research commissioning pilot exercise. International Journal of Social Research Methodology, 15(5), 385-401.

Salway, S.M., Barley, R., Allmark, P., Gerrish, K., Higginbottom, G., & Ellison, G.T.H. (2011). Ethnic diversity and inequality: ethical and scientific rigour in social research. York: Joseph Rowntree Foundation.

Salway, S.M., Barley, R., Allmark, P., Gerrish, K., Higginbottom, G., Johnson, M.R.D., & Ellison, G.T.H. (2011). Enhancing the quality of published research on ethnicity and health: is journal guidance feasible and useful? Diversity in Health and Care, 8(3), 155-165.

Salway, S.M., Higginbottom, G., Reime, B., Bharj, K. K., Chowbey, P., Foster, C., Friedrich, J., Gerrish, K., Mumtaz, Z., & O'Brien, B. (2011). Contributions and challenges of cross-national comparative research in migration, ethnicity and health: Insights from a preliminary study of maternal health in Germany, Canada and the UK. BMC Public Health, 11, 514. DOI: 10.1186/1471-2458-11-514

Schensul, S.L., Schensul, J.J, & LeCompte, M.D. (1999). Essential ethnographic methods: Observations, interviews, and questionnaires (Vol. 2). Walnut Creek, CA: AltaMira Press.

Schnittker, J. (2003). Misgivings of medicine?: African Americans' skepticism of psychiatric medication. Journal of Health and Social Behavior, 44, 506-524.

Schoenberg, N.E, Drew, E.M, Stoller, E.P., & Kart, C.S. (2005). Situating stress: Lessons from lay discourses on diabetes. Medical Anthropology Quarterly, 19(2), 171-193.

Schoenberg, N.E, Howell, B.M., & Fields, N. (2012). Community strategies to address cancer disparities in Appalachian Kentucky. Family and Community Health, 35(1), 31-43. DOI: 10.1097/FCH.0b013e3182385d2c

Schoenberg, N.E. (2005). Proclaiming culture: Forging aged with anthropology's diverse and substantial contributions to aging studies. Aging and Anthropology Quarterly, 27(2), 18-20.

Scrimshaw, S.C.M., & Hurtado, E. (1987). Rapid assessment procedures for nutrition and primary health care: Anthropological approaches to improving programme effectiveness. Los Angeles: University of California, Los Angeles.

Sharpe, V.A. & Uchendu, U.S. (2014). Ensuring appropriate care for LGBT veterans in the Veterans Health Administration. Hastings Center Report, 44, S53-S55.

Shintani, T.T., Beckham, S., O'Connor, H.K., Hughes, C.K., & Sato, A. (1994). The Waianae Diet Program: A culturally sensitive, community-based obesity and clinical intervention program for the Native Hawaiian population. Hawaii Medical Journal, 53(5), 136.

Shintani, T.T., Hughes, C.K., Beckham, S., & O'Connor, H.K. (1991). Obesity and cardiovascular risk intervention through the ad libitum feeding of traditional Hawaiian diet. American Journal of Clinical Nutrition, 53(6), 1647S-1651S.

Singh, R.B., Dubnov, G., Niaz, M.A., Ghosh, S., Singh, R., Rastogi, S.S., Manor, O., Pella, D., & Berry, E.M. (2002). Effect of an Indo-Mediterranean diet on progression of coronary artery disease in high risk patients (Indo-Mediterranean Diet Heart Study): A randomised single-blind trial. Lancet, 360(9344), 1455.

Smedley, B.D., Stith, A.Y., & Nelson, A.R. (2003). Unequal treatment: Confronting racial and ethnic disparities in health care. Washington, DC: National Academies Press.

Smith, C.S., Morris, M., Hill, W., Francovich, C., McMullin, J., Chavez, L., & Rhoads, C. (2004). Cultural consensus analysis as a tool for clinic improvements. Journal of General Internal Medicine, 19(5p2), 514-518.

Somervell, P.D., Beals, J., Kinzie, J.D., Boehnlein, J., Leung, P., & Manson, S.M. (1993). Criterion validity of the Center for Epidemiologic Studies Depression Scale in a population sample from an American Indian village. Psychiatry Research, 47(3), 255-266.

Spradley, J.P. (1979). The ethnographic interview. New York: Harcourt, Brace, Jovanovich.

Spradley, J.P. (1980). Participant observation. New York: Holt, Rinehart & Winston.

Stewart, S.L, Rakowski, W., & Pasick, R.J. (2009). Behavioral constructs and mammography in five ethnic groups. Health Education and Behavior, 36(5 suppl), 36S-54S.

Subrahmanian, K., Petereit, D.G., Kanekar, S., Burhansstipanov, L., Esmond, S., Miner, R., Spotted Tail, C., &Guadagnolo, B.A. (2011). Community-based participatory development, implementation, and evaluation of a cancer screening educational intervention among American Indians in the Northern Plains. Journal of Cancer Education, 26(3), 530-539. DOI: 10.1007/s13187-011-0211-5

Sue, S. (1999). Science, ethnicity, and bias: Where have we gone wrong? American Psychologist, 54(12), 1070-1077.

Tanjasiri, S.P., Kagawa-Singer, M., Foo, M.A., Chao, M., Linayao-Putman, I., Nguyen, J., Pirumyan, G, &Valdez, A. (2007). Designing culturally and linguistically appropriate health interventions: The "Life Is Precious" Hmong breast cancer study. Health Education and Behavior, 34(1), 140-153.

The Diabetes Prevention Program Research Group. (2000). The Diabetes Prevention Program: Baseline characteristics of the randomized cohort. Diabetes Care, 23(11), 1619-1629.

Hooper, T. (director). (2010).The King's speech. David Seidler (screenwriter). The Weinstein Company and UK Film Councils, distributors.

Thomas, D. (1954). A visit to America. In Quite early one morning (pp. 146-147). New York: New Directions Publishing.

Trickett, E.J., Beehler, S., Deutsch, C., Green, L.W , Hawe, P., McLeroy, K., Miller, R.L., Rapkin, B.D., Schensul, J.J., Schulz, A.J., & Trimble, J.E. (2011). Advancing the science of community-level interventions. American Journal of Public Health, 101(8), 1410-1419. DOI: 10.2105/ajph.2010.300113

Trimble, J.E. (2007). Prolegomena for the connotation of construct use in the measurement of ethnic and racial identity. Journal of Counseling Psychology, 54(3), 247-258. DOI: 10.1037/0022-0167.54.3.247

Trimble, J.E. (2012). Ethno-measurement and ethno-scaling obstacles in community based research with indigenous populations. Global Journal of Community Psychology Practice, 2(3), http://www.gjcpp.org/en/resource.php?issue=8&resource=69.

Trimble, J.E. (2013). Advancing understanding of cultural competence, cultural sensitivity, and the effects of cultural incompetence. In M.J. Prinstein & M.D. Patterson (Eds.), The portable mentor: Expert guide to

a successful career in psychology (2nd ed., pp. 57-80). New York: Kluwer Academic/Plenum.

Trimble, J.E., & Mahoney, E. (2002). Gender and ethnic differences in adolescent self-esteem: A Rasch measurement model analysis. In P.D. Mail, S. Heurtin-Roberts, S.E. Martin & J. Howard (Eds.), Alcohol use among American Indians and Alaska Natives: Multiple perspectives on a complex problem (pp. 211-240). Bethesda, MD: National Institute on Alcohol Abuse and Alcoholism.

Trimble, J.E., Scharron-del Rio, M., & Bernal, G. (2010). The itinerant researcher: Ethical and methodological issues in conducting cross-cultural mental health research. In D. C. Jack & A. Ali (Eds.), Cultural perspectives on women's depression: Self-silencing, psychological distress and recovery (pp. 73-95). New York: Oxford.

US Census Bureau. (1977, May 12). Office of Management and Budget Directive No. 15: Race and ethnic standards for federal statistics and administrative reporting, http://wonder.cdc.gov/wonder/help/populations/bridged-race/directive15.html

Villarruel, A.M., Harlow, S.D., Lopez, M., & Sowers, M. (2002). El cambio de vida: Conceptualizations of menopause and midlife among urban Latina women. Research and Theory for Nursing Practice, 16(2), 91-102.

Villero, O., Macaerag, I., & Burke, N.J. (2014). Pakikisama: Lessons learned in partnership building with Filipinas with breast cancer for culturally meaningful support. Global Health Promotion, 21(1), 68-72.

Viruell-Fuentes, E.A., Miranda, P.Y., & Abdulrahim, S. (2012). More than culture: Structural racism, intersectionality theory, and immigrant health. Social Science & Medicine, 75(12), 2099-2106.

Watson, J.D. (2011). The double helix: A personal account of the discovery of the structure of DNA. New York: Simon and Schuster.

Weisner, T.S. (2009). Culture, development, and diversity: Expectable pluralism, conflict, and similarity. Ethos, 37(2), 181-196. DOI: 10.1111/j.1548-1352.2009.01037.x

Weisner, T.S., & Duncan, G. (2014). The world isn't linear or additive or decontextualized: Pluralism and mixed methods in understanding the effects of poverty on children and parenting. In E.T. Gershoff, R.S. Mistry & D.A. Crosby (Eds.), Societal contexts of child development: Pathways of influence and implications for practice and policy (pp. 125-138). New York: Oxford University Press.

Weller, S.C. (2007). Cultural consensus theory: Applications and frequently asked questions. Field Methods, 19(4), 339-368.

Weller, S.C., & Romney, A.K. (1988). Systematic data collection (Vol. 10) Thousand Oaks, CA: Sage.

Willett, W.C., Sacks, F., Trichopoulou, A., Drescher, G., Ferro-Luzzi, A., Helsing, E., & Trichopoulos, D. (1995). Mediterranean diet pyramid: A cultural model for healthy eating. American Journal of Clinical Nutrition, 61(6), 1402S-1406S.

Winker, M.A. (2004). Measuring race and ethnicity: Why and how? JAMA: The Journal of the American Medical Association, 292(13), 1612-1614.

Witkin, H.A., & Berry, J.W. (1975). Psychological differentiation in cross-cultural perspective. Journal of Cross-Cultural Psychology, 6, 4-87.

Witte, K. (1992). Putting the fear back into fear appeals: The extended parallel process model. Communications Monographs, 59(4), 329-349.

World Health Organization. (2013). Social determinants of health. Retrieved May 6, 2013, from http://www.who.int/social_determinants/thecommission/finalreport/key_concepts/en/index.html

Xu, M., Zhou, S-J., Jiang, C-C., Wu, Y., Shi, W-L., Gu, H-H., Cai, H-D., & Wang, X-Q. (2012). The effects of P6 electrical acustimulation on postoperative nausea and vomiting in patients after infratentorial craniotomy. Journal of Neurosurgical Anesthesiology, 24(4), 312-316.

Yarris, K.E. (2011). The pain of "thinking too much": Dolor de cerebro and the embodiment of social hardship among Nicaraguan women. Ethos, 39(2), 226-248.

Young, J.C., & Garro, L.Y. (1982). Variation in the choice of treatment in two Mexican communities. Social Science and Medicine, 16(16), 1453-1465.

APPENDICES

List of Appendices

Appendix A: Contact Information for Members of the NIH Expert Panel on Defining and Operationalizing Culture for Health Research

Appendix B: Literature Review of Articles Submitted by Members of the NIH Expert Panel on Defining and Operationalizing Culture in Health Research
Extended Abstract
Table of Literature Review Model Articles
Poster Design

Appendix C: Reflection Papers Submitted by Members of the NIH Expert Panel on Defining and Operationalizing Culture for Health Research

Appendix D: Table 1.1 (Unabridged) – Scientific Challenges Posed by the Current Use of Culture in Research
References for Appendix D

Appendix E: Definitions of Culture from National Health Organizations
Association of American Medical Colleges
Centers for Disease Control and Prevention
Institute of Medicine
National Institute of Mental Health, Child and Adolescent Health Service System Program
National Institute of Mental Health, Culture and Diagnosis Group
Office of the Surgeon General, Center for Mental Health Services, National Institute of Mental Health
U.S. Department of Health and Human Services, Office of Minority Health

Appendix F: A Working Definition of Culture

Appendix G: Exemplar Intervention Studies that Operationalize Culture across the Research Continuum
Table 1. Formative Research Exemplars
Table 2. Applied Intervention Research Exemplars
Table 3. Evaluation Exemplars
Table 4. Dissemination Exemplars

Appendix H: Examples of Section III and IV: Methods Along the Research Continuum with Native American Groups

Joseph E. Trimble -- Intervention Exemplars
- Dissemination Exemplar - 1
- Formative Research Exemplar -1
- Formative Research Exemplar -2
- Formative Research Exemplar -3

Appendix I: Linda Burhansstipanov - Example one research process used maps onto Figure 4-1 of the CHF Report

Appendix J: PowerPoint Presentations on Operationalizing Culture

Appendix K: Examples of RFAs that Require Consideration of Culture

Appendix L: Elwood, W.N., Dressler, W.W., George, S.M., Kagawa-Singer, M., Szalacha, L.A., & Roberts, R. (2014, April 25). *Transforming culture and research: Operationalizing culture and its relationship to health and wellbeing outcomes.* Poster presented at the 35th annual Society of Behavioral Medicine meeting, Philadelphia

Appendix M: Poster and link to NIH videocast, *Transforming culture and research*

Appendix A:

Contact Information for Members of the NIH Expert Panel on Defining and Operationalizing Culture for Health Research

Claudia Baquet
Associate Dean for Policy and Planning
University of Maryland School of Medicine
655 West Baltimore Street
Baltimore, Maryland 21201-1559
Phone: 410-706-1742
Fax: 410-706-6150
cbaquet@som.umaryland.edu

Research on cancer rates in special populations, developed intervention research trials on cancer screening and early detection, interventions related to minorities and low-income populations

Ronny Bell
Professor
Department of Epidemiology and Prevention, Division of Public Health Sciences
Wake Forest University Health Sciences
Wake Forest Baptist Medical Center
Medical Center Boulevard
Winston-Salem, NC 27157
Phone: 336-716-9736
rbell@wakehealth.edu

Chronic disease prevalence and risk factors, with particular emphasis on ethnic minority populations

Linda Burhansstipanov
President
Native American Cancer Initiatives, Inc.
3022 South Nova Road
Pine, CO 80470-7830
Phone: 303-838-1837
Fax: 303-975-2463
LindaB@natamcancer.net

Culturally competent cancer prevention and cancer control in Native Americans, genetics, early detection and survivorship

Nancy J. Burke
Associate Professor
Department of Anthropology, History and Social Medicine
University of California, San Francisco
Box 0981, UCSF
San Francisco, CA 94143-0981
Phone: 415-514-9419
nburke@cc.ucsf.edu

Applies an ethnographic approach to studies of social inequalities in cancer prevention, treatment, and survivorship. This includes disparities in cancer information and support services

Suzanne Dibble
Retired Adjunct Professor
Institute for Health & Aging, and Founder of Lesbian Health Research Center at the University of California, San Francisco
3333 California Street, LHts-340
San Francisco, CA 94143-0646
Phone: 707-623-9097
Sue.Dibble@gmail.com

Evidence-based clinical care, outcomes research, lesbian health across the lifespan, oncology

William Dressler
Professor
Department of Anthropology
University of Alabama
Post Office Box 870210
Tuscaloosa, AL 35487-0210
Phone: 205-348-1954
Fax: 205-348-7937
wdressle@as.ua.edu

Operationalization of culture and race in health outcomes

Linda Garro
Professor
Department of Anthropology
University of California, Los Angeles
341 Haines Hall - Box 951553
Los Angeles, CA 90095-1553
Phone: 310-206-6249
Fax: 310-206-7833
lgarro@anthro.ucla.edu

Cognitive anthropology, socio-cultural anthropology, medical anthropology, Native American populations

Sheba M. George
Assistant Professor
Multicultural Health and Health Disparities Core
Charles R. Drew University of Medicine and Science
2594 Industry Way
Lynwood, CA 90262
Phone: 310-761-4716
shebageorge@ucla.edu

Intersection of race, class and gender inequities and health disparities; technology and health (telemedicine); qualitatively studying health disparities among immigrant and minority communities, both here in the United States and abroad

Clarence Gravlee
Professor
Department of Anthropology
University of Florida
Turlington Hall, Room B370
PO 117305
Gainesville, FL 32611-7305
Phone: 352-392-2253, Ext. 240
cgravlee@ufl.edu

Effects of racism among African Americans, socio/cultural influences on health outcomes in Puerto Rico & Detroit, cultural variables translated into quantitative models, cultural dimensions of psychosocial stress, social inequalities in health

Peter Guarnaccia
Professor
Institute for Health, Health Care Policy and Aging Research
Rutgers University

112 Paterson Street
New Brunswick, NJ 08901
pguarnaccia@ifh.rutgers.edu

Research interests include cross-cultural patterns of psychiatric disorders, cultural competence in mental health organizations, processes of cultural and health change among Latino immigrants, and measurement of acculturation

Michael Hecht
Professor
Department of Communication Arts and Sciences, and Crime, Law, and Justice
Pennsylvania State University
501 Keller Building
University Park, PA 16802-1308
Phone: 814-865-0945
Fax: 814-863-7986
mlh10@psu.edu

Social processes of adolescent drug use and prevention, identity and culture

Jeffrey Henderson
Assistant Professor
American Indian Alaska Native Programs
University of Colorado Health Sciences Center
Black Hills Center for American Indian Health
701 St. Joseph Street, Suite 204
Rapid City, SD 57701
Phone: 605-348-6100
Fax: 605-348-6990
jhenderson@bhcaih.org

Native American health inequalities

Daniel Hruschka
Assistant Professor
School of Human Evolution and Social Change
Arizona State University
Tempe, AZ 85287
Phone: 480-965-3087
Daniel.Hruschka@asu.edu

Assessing culture change and relationship between culture and behavior; quantitative analysis of culture change

Marjorie Kagawa Singer
Professor
Department of Community Health Sciences and Department of Asian American Studies
Fielding School of Public Health
University of California, Los Angeles
41-240B CHS
650 Charles Young Drive South
Los Angeles, CA 90095
Phone: 310-825-9481
Fax: 310-794-1805
mkagawa@ucla.edu

Impact of culture on health outcomes for chronic disease outcomes and prevention, application of mixed paradigms and methods, and cross-cultural equivalence.

Roberto Lewis-Fernandez
Professor of Clinical Psychiatry
Columbia University
Director, New York State Center of Excellence for Cultural Competence, New York State Psychiatric Institute
Director, Hispanic Treatment Program, New York State Psychiatric Institute
New York State Psychiatric Institute
Room 3206 Unit/Box: 69
1051 Riverside Drive
New York, NY 10032

Phone: 212-543-6512
Fax: 212-543-6515
rlewis@nyspi.columbia.edu

Socio-cultural determinants of illness experience, help-seeking behavior, and treatment outcomes among U.S. Latinos

Robert C. Like
Professor and Director
Center for Healthy Families and Cultural Diversity
Department of Family Medicine and Community Health
Rutgers - Robert Wood Johnson Medical School
1 Robert Wood Johnson Place
New Brunswick, NJ 08903
Phone: 732-235-7662
Fax: 732-235-8564
like@umdnj.edu

Cultural competency education and research

Charles Mouton
Dean, School of Medicine
Senior Vice President for Health Affairs
Meharry Medical College
1005 Dr. D.B. Todd Jr. Blvd.
Nashville, TN 37208-3501
Phone: 615-327-6204
cmouton@mmc.edu

African American health and multicultural issues, Health promotion and disease prevention in minority elders (especially exercise in the elderly), ethnicity and aging, violence and elder mistreatment in older women, and quality end-of-life care

Hector F. Myers
Professor, Center for Medicine, Health and Society and
Department of Psychology
503 Wilson Hall
Nashville, TN 37235
Vanderbilt University
Office: 615-322-5881
hector.f.myers@vanderbilt.edu

Stress and impact on health outcomes, biobehavioral and psychosocial factors contributing to ethnic disparities in health

J. Bryan Page
Professor and Chair
Department of Anthropology
Professor
Department of Sociology, Department of Psychiatry
University of Miami
P.O. Box 248106
Coral Gables, FL 33124-2005
Phone: 305-284-6045
Fax: 305-284-2110
bryan.page@miami.edu

Transdisciplinary research of drug use, particularly focused on new immigrants, HIV/AIDS, violence, and culturally-modified interventions

Rena Pasick
Professor
Helen Diller Family Comprehensive Cancer Center
University of California, San Francisco
Box 0981, UCSF
San Francisco, CA 94143-0981
Phone: 415-514-9415
rpasick@cc.ucsf.edu

Behavioral theories, measurement, cross-cultural communication in the context of cancer disparities research

Bernice A. Pescosolido
Distinguished Professor
Department of Sociology
Director of the Indiana Consortium for Mental Health Services Research
Indiana University Ballantine Hall 744
1020 East Kirkwood Avenue
Bloomington, IN 47405-7103
Phone: 812-855-3841
Fax: 812-855-0781
pescosol@indiana.edu

Social issues in health, illness, and healing; cross-cultural variations in stigma, patterns and pathways to care

Nancy Schoenberg
Associate Professor
Department of Behavioral Science
University of Kentucky College of Medicine
Medical Behavioral Science Building
Lexington, KY 40536-0086
Phone: 859-323-8175
Fax: 859-323-5350
nesch@uky.edu

Community-based participatory interventions, explanatory models of chronic diseases and their prevention and management, qualitative and complementary methodology

Bradley Stoner
Associate Professor
Division of Infectious Diseases, and
Department of Anthropology
Washington University Medical School
Campus Box 1114
Washington University
St. Louis, Missouri 63130
Phone: 314-935-5673
Fax: 314-935-8535
bstoner@wustl.edu

Health and illness in a cross-cultural perspective, sociocultural aspects of sexually transmitted diseases, role of anthropology in clinical and public health research

Gregory Strayhorn
Professor and Chair
Department of Family Medicine
Morehouse School of Medicine
720 Westview Drive SW
Atlanta, GA 30310-1495
Phone: 404-756-1214
gstrayhorn@msm.edu

Family medicine, social determinants of health and chronic disease

Laura Szalacha
Associate Director and Research Associate Professor
Center for Research & Scholarship
Ohio State University
396 Newton Hall
1585 Neil Avenue
Columbus, OH 43210
Phone: 614-688-0394
szalacha.1@usu.edu

Quantitative, Qualitative and Mixed Methods Research Methodologies

Joseph Trimble
Distinguished University Professor
Center for Cross-Cultural Research,
Department of Psychology
Western Washington University
516 High Street
Western Washington University
Bellingham, WA 98225-9089
Phone: 360-650-3058
joseph.trimble@wwu.edu

Cultural measurement equivalence, ethnic identity, ethnic self-identification model, multicultural counseling and psychotherapy, and mental health prevention research models for American Indian and Alaskan Native youth

Thomas Weisner
Professor
Department of Anthropology and
Department of Psychiatry
Director
Center for Culture and Health
University of California, Los Angeles
760 Westwood Plaza, Box 62
Los Angeles, CA 90024-1759
Phone: 310-794-3632
Fax: 310-794-6297
tweisner@ucla.edu

Cross Cultural differences in mental health

David Williams
Professor
School of Public Health, African American Studies, and Department of Sociology
Harvard University
677 Huntington Avenue
Boston, MA, 02115
Mailstop: Kresge, Room 615
Phone: 617-432-6807
dwilliam@hsph.harvard.edu

Measures to assess perceived discrimination in health (Everyday Discrimination Scale), social influences on physical and mental health

Appendix B:

Literature Review of Articles Submitted by Members of the NIH Expert Panel on Defining and Operationalizing Culture in Health Research

A Review of the Conceptualization and Measurement of Culture in Health Research

Anne E. Fehrenbacher
Heather Guentzel Frank
Héctor E. Alcalá
Isomi Miake-Lye
Adrienne Isaac
Darrah Kuratani
Sheba George
Marjorie Kagawa Singer

Poster Session 9: Data, Methods, and Applied Demography
Population Association of America Annual Meeting
New Orleans, LA
April 13, 2013
Conference Abstract: http://paa2013.princeton.edu/abstracts/130146
Conference Poster: http://bit.ly/11ETWjp

ABSTRACT

BACKGROUND: Lack of consensus on a scientific definition of culture has led to erroneous conflations of culture, race, and ethnicity.

OBJECTIVE: Analyze the conceptualization and measurement of culture in health research by examining: 1) how culture has been defined within and across disciplines, and 2) the domains and pathways by which culture is hypothesized to influence health.

METHODS: We reviewed 167 articles on culture and health submitted by an expert panel of 30 NIH-funded researchers. We categorized literature into subgroups that: 1) provided a definition of culture, 2) provided a method of operationalizing culture, and 3) provided a measure of culture consistent with the conceptualization of culture discussed.

RESULTS: After removing duplicates, the final sample included 158 articles. Sixty-three percent of articles did not provide a definition of culture and 56% did not discuss measurement. Ten articles (6%) provided a definition of culture and a method of operationalizing culture consistent with its conceptualization.

CONCLUSION: Inconsistencies between the conceptualization of culture as a dynamic construct and the ways in which it is measured as a static "list of traits" has led to obfuscation of results on the influence of culture on health. More accurate measurement of culture would indicate better predictors of risk and protective factors that would likely account for a larger percentage of the variance in statistical modeling of health outcomes than demographic categories alone.

Extended Abstract

INTRODUCTION

Culture is frequently cited as an important social determinant of health in research involving ethnic minorities, and it is often cited as integral to the study's theoretical framework or alluded to as explanatory in the outcome of the study (Hruschka, 2009). However, despite the frequency with which culture is used as an explanation for health outcomes, the concept is rarely defined, and when definitions of culture are provided, measures of the construct are often inconsistent with its conceptualization (Kagawa-Singer, 2006). Culture is erroneously conflated with race and ethnicity as a dichotomous, individual-level variable rather than a multi-dimensional, dynamic construct embedded in a multi-level social system (Kagawa-Singer, 2001). Lacking a standardized and scientific definition of culture, the approach in health behavior and demographic research has been to use measures that are neither tested for cross-cultural validity or equivalence, nor conceptually comprehensive and nuanced enough to assess the interaction of risk factors known or suspected to impact disease prevalence, morbidity, and mortality in all population groups (Dressler, Oths, & Gravlee, 2005; Kao, Hsu, & Clark, 2004; R. J. Pasick et al., 2009).

This literature review is part of a larger 18-month project designed to meet four objectives: 1) scientifically define culture for application in health behavior research, 2) identify the domains of culture that influence health behavior, 3) specify the pathways by which these domains influence health outcomes in diverse populations, and 4) propose a set of recommendations to guide both researchers and funders in the conceptualization and measurement of culture (Kagawa-Singer, 2012). This literature review was the first step of a three-step process which also included a two-day expert panel meeting in April 2012 and a 10-month Delphi consensus-building exercise to compile and rank the concerns of the expert panel and formulate final recommendations for the National Institutes of Health Office of Behavioral and Social Sciences Research (OBSSR).

METHODS

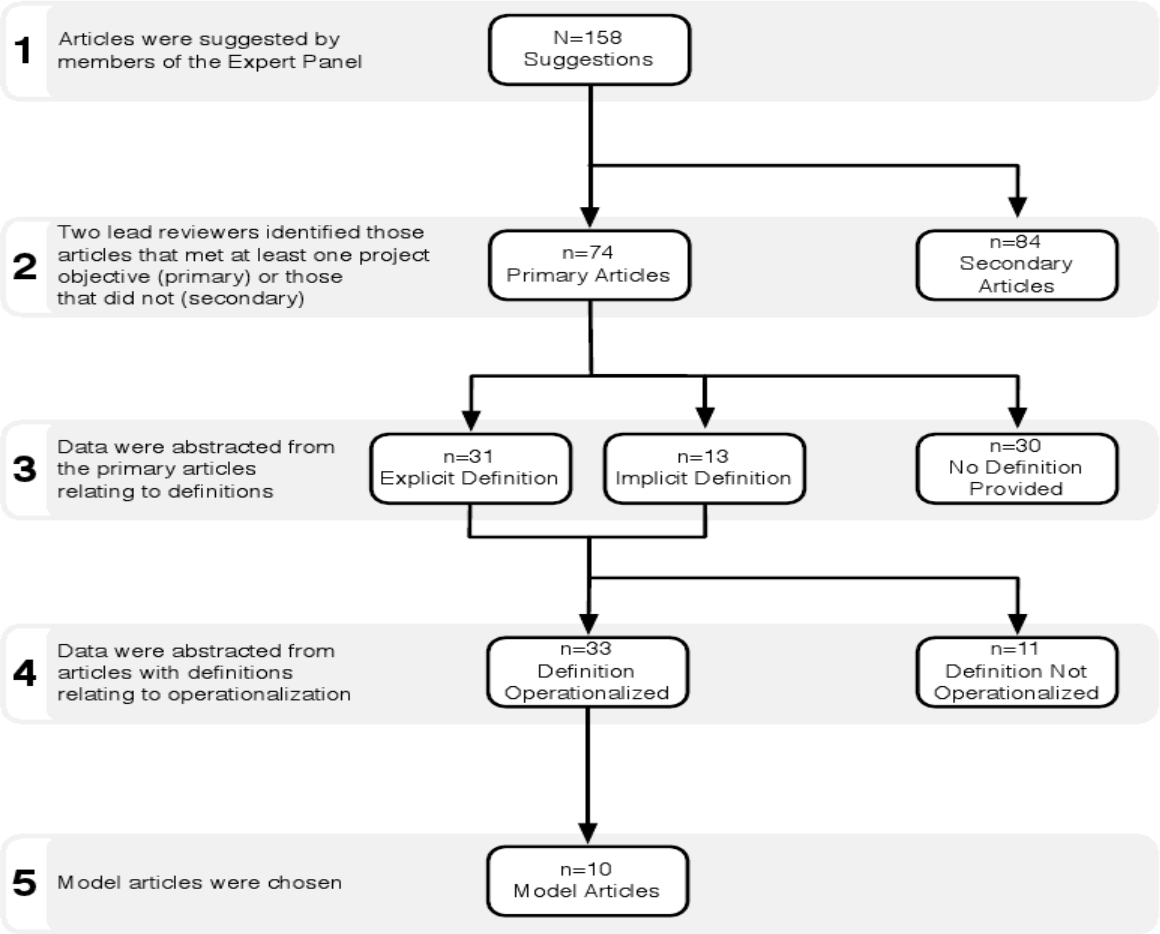
Topic Development: The principal investigators divided the overall goal to develop guidelines for the use of culture in health research into three subsections: 1) definitions; 2) measurement; and 3) translation.

Literature Selection: Given the cross-disciplinary and complex nature of the project goal and its components, standard systematic search strategies proved ineffective at targeting articles relevant to the use of culture in health. As a result, the project team chose to use a systematic meta-narrative approach, in order to analyze the emerging "storyline" of culture within and across disciplines over time and trace the effects of seminal theoretical and empirical work regarding culture and health on subsequent cultural research.

In order to identify relevant works, an expert panel of 30 NIH-funded researchers with expertise in culture and health were asked to identify five to 10 articles on culture that pertained to measurement, challenges with defining the construct, conceptual or theoretical models of culture, or the application of a definition of culture for specific population subgroups. The expert panel was composed of researchers from nine different disciplines across health, social science and demographic fields, and the panel included both practitioners and academics. Expert panel members were invited to submit articles through a rolling invitation, with each successive participant instructed to review previous articles submitted by the panel in order to supplement the literature already collected and provide heterogeneous perspectives to meet the objectives of the project. Auxiliary searches were conducted by the project team to ensure the comprehensiveness of the identified body of literature.

Data Abstraction and Synthesis: Two lead reviewers (Fehrenbacher and George) divided the articles into two categories: 1) primary articles that directly addressed the conceptual or theoretical aspects of culture as a construct in health behavior research; and 2) secondary articles that applied culture as a variable in research but provided little or no explanation on how the construct was defined or measured. A team of eight reviewers then abstracted data relevant to the three goal subsections (definitions, measurement, and translation) from articles in the first category, as well as the academic discipline and keywords for each article. For articles in the second category, it was simply noted whether or not culture was defined or operationalized in the article. Secondary articles with a substantial amount of data relevant to the three goal subsections were then moved into the primary category. The project team summarized findings on each goal subsection and then identified major themes from a qualitative synthesis of the relevant literature. Finally, a list of model articles was compiled to demonstrate exemplary work on defining and measuring culture with sufficient scientific rigor in health research. Model articles were defined as those that provided a definition of culture and a measure of culture, and the measure of culture was consistent with the conceptualization of the culture construct proposed by the author(s). *See Figure 1 for Article Selection Framework*

FIGURE 1: Article Selection F



RESULTS

The project team reviewed 158 articles submitted by the expert panelists. A total of 167 articles were submitted, but nine duplicates were eliminated. Seventy-four were categorized as primary articles that met at least one of the four project objectives outlined in the introduction and 84 were categorized as secondary articles. Descriptive statistics and key qualitative findings were compiled for each goal subsection. For the purpose of this review, results are limited to the definition and measurement goals.

***Definitions**:* Among all articles submitted by the expert panel, 63% did not provide a definition of culture. Among articles that did provide a definition of culture, three-fourths provided an explicit definition of culture and one-fourth an implicit definition, as evidenced by vague descriptions of what constitutes culture or implied properties

of culture discussed in the absence of an explicit definition. As a result, reviewers often had to dig deep into the articles for definitions which could easily be overlooked or misinterpreted by researchers who are not seasoned in the science of culture and health. Hundreds of definitions of culture were identified across the articles because many authors provided multiple definitions though the majority did not provide a definition at all. There appears to have been little effort made to integrate or coordinate the various definitions across disciplines over time (Faulkner, Baldwin, Lindsley, & Hecht, 2006; Hruschka & Hadley, 2008; Oppenheimer, 2001). The result is a lack of consensus on either a standardized and scientific definition of culture or consensus on common essential elements of culture (Trimble, 2007).

The most common characteristics of culture discussed in the review articles were its dynamic nature, the understanding that it is group-based or shared, and the notion that it provides meaning and a way to make sense of the world. Although authors varied on which components were most important for assessing culture in the context of health research, most suggested analyzing some combination of knowledge, beliefs, values, behaviors, practices and expectations. Others highlighted the need for a better understanding of the transmissibility of culture, the ways it affects thoughts and assumptions, and the degree to which culture is known or experienced unconsciously by individuals or groups. A recent trend toward understanding culture as consensus among members of a group was observed in the articles, particularly within the discipline of anthropology. Nonetheless, debate remains regarding who are the bearers of culture, and a significant proportion of articles continue to perpetuate the tacit belief that only groups other than non-Hispanic whites – that is, ethnic/racial groups of color – *have* culture (Page, 2005). As a result, a large body of literature has “blamed the victim” and scapegoated racial and ethnic minority populations for poor health outcomes using culture as an explanation, without taking into account influences at the community, societal, and structural levels (Institute of Medicine, 2002).

***Measurement**:* A majority of the articles submitted by the expert panel (56%) did not discuss measurement of culture or operationalize the construct despite arguing that it was fundamental to the design or outcome of the study. Among articles that discussed the measurement of culture as a key issue or challenge in health research, 90% provided an actual measure of culture or instructions on how to operationalize the construct.

The most scientifically-grounded definitions of culture identified in the review were multi-dimensional and dynamic, thus authors often lamented the difficulty of capturing the complexity of culture through standard measurement techniques (Alegria, Atkins, Farmer, Slaton, & Stelk, 2010). Many researchers noted that reliance on static demographic categories at the individual level as proxy variables for culture has led to a tendency to stereotype and view culture as a deficit for racial or ethnic minorities (Pasick, Burke, & Joseph, 2009). The most common results have been erroneous conflations of the concepts of culture, race, and ethnicity and the assumption that the

population groups of focus are homogeneous and discreetly bounded for identification. This operationalization of culture is antithetical to most definitions of culture as an ever-changing construct embedded in overlapping, multi-level social systems (Burke, Joseph, Pasick, & Barker, 2009). The inconsistent and inaccurate use of culture in health research results in minimal explanatory power of culture on health, and provides little information as to why health disparities exist across socio-demographic groups and what can be done to eliminate these disparities (Schoenberg, 2005).

***Model Articles**:* Ten articles (6% of total sample) met our criteria as model articles meaning that the measure of culture proposed was consistent with the conceptualization and definition of culture offered. The model articles represented a variety of disciplines including anthropology, sociology, public health, psychology, information technology, and management. The articles also offered a wide range of measurement techniques utilizing both quantitative and qualitative methods, as well as mixed methods. The most common method proposed was "cultural consonance" or "cultural consensus modeling" which measures the degree to which an individual's behavior approximates the guiding awareness of his or her culture. This method is derived from Goodenough's cognitive theory of culture as "that which one needs to know in order to function adequately in a given society."(Goodenough, 1996). Cultural consonance is derived from estimates provided by cultural consensus analysis first proposed by Romney, Weller, and Batchelder in 1986 and later popularized in the context of health research by William Dressler (Dressler, 2007). Cultural consonance allows researchers to deal with the methodological challenges of measuring culture as both a shared and individual construct.

CONCLUSIONS

More accurate conceptualization, operationalization, and translation of a scientifically-based concept of culture would indicate better predictors of both the risk and protective factors that would likely account for a larger percentage of the variance in statistical modeling of health outcomes than demographic categories alone (Straub, Loch, Evaristo, Karahanna, & Strite, 2002). Greater clarity on what culture is and how it impacts health behavior and ultimately health outcomes would enable researchers to better identify malleable systemic and population factors that could be addressed in order develop culturally-grounded health programs and services for specific subpopulations across the disease spectrum, ranging from genetic to infectious to chronic, and across the care continuum, from prevention to end-of-life care (Trimble, 2013).

REFERENCES

Alegria, M., Atkins, M., Farmer, E., Slaton, E., & Stelk, W. (2010). One size does not fit all: taking diversity, culture and context seriously. Adm Policy Ment Health, 37(1-2), 48-60. DOI: 10.1007/s10488-010-0283-2

Burke, N. J., Joseph, G., Pasick, R. J., & Barker, J. C. (2009). Theorizing social context: rethinking behavioral theory. Health Educ Behav, 36(5 Suppl), 55S-70S. DOI: 10.1177/1090198109335338

Dressler, William W. (2007). Cultural Consonance. In D. Bhugra & K. Bhui (Eds.), Textbook of Cultural Psychiatry (pp. 179-190): Cambridge University Press.

Dressler, William W., Oths, Kathryn S, & Gravlee, Clarence C. (2005). Race and ethnicity in public health research: models to explain health disparities. Annual Review of Anthropology, 34(1), 231.

Faulkner, S L., Baldwin, J R., Lindsley, S L., & Hecht, M L. (2006). Layers of meaning: an analysis of definitions of culture. In J. R. Baldwin, S. L. Faulkner, M. L. Hecht & S. L. Lindsley (Eds.), Redefining Culture: Perspectives Across the Disciplines (pp. 27-52): Laurence Earlbaum Associates, Inc.

Goodenough, W. (1996). Culture. In D. Levinson & M. Ember (Eds.), Encyclopedia of Cultural Anthropology (pp. 291–299). New York: Henry Holt.

Hruschka, D. J. (2009). Culture as an explanation in population health. Ann Hum Biol, 36(3), 235-247.

Hruschka, D. J., & Hadley, C. (2008). A glossary of culture in epidemiology. J Epidemiol Community Health, 62(11), 947-951. DOI: 10.1136/jech.2008.076729

Institute of Medicine. (2002). Speaking of health: Assessing health communication strategies for diverse populations: National Academy Press.

Kagawa-Singer, M. (2001). From genes to social science. Cancer, 91(S1), 226-232.

Kagawa-Singer, M. (2006). Population science is science only if you know the population. Journal of cancer education: the official journal of the American Association for Cancer Education, 21(1 Suppl), S22.

Kagawa-Singer, M. (2012). Applying the concept of culture to reduce health disparities through health behavior research. Prev Med, 55(5), 356-361. DOI: 10.1016/j.ypmed.2012.02.011

Kao, H. F., Hsu, M. T., & Clark, L. (2004). Conceptualizing and critiquing culture in health research. J Transcult Nurs, 15(4), 269-277. DOI: 10.1177/1043659604268963

Oppenheimer, Gerald M. (2001). Paradigm lost: Race, ethnicity, and the search for a new population taxonomy. Am J Public Health, 91(7), 1049.

Page, J. B. (2005). The concept of culture: a core issue in health disparities. J Urban Health, 82(2 Suppl 3), iii35-43. DOI: 10.1093/jurban/jti062

Pasick, R. J., Burke, N. J., Barker, J. C., Joseph, G., Bird, J. A., Otero-Sabogal, R., . . . Guerra, C. (2009). Behavioral theory in a diverse society: like a compass on Mars. Health Educ Behav, 36(5 Suppl), 11S-35S. DOI: 10.1177/1090198109338917

Pasick, Rena J., Burke, Nancy J., & Joseph, Galen. (2009). Behavioral Theory and Culture Special Issue: Authors' Response to Commentaries. Health Education & Behavior, 36(5 suppl), 167S-171S. DOI: 10.1177/1090198109341023

Schoenberg, Nancy E. (2005). Proclaiming culture: Forging aged with anthropology's diverse and substantial contributions to aging studies. Aging and Anthropology Quarterly, 27(2), 18-20.

Straub, D, Loch, K , Evaristo, R , Karahanna, E , & Strite, M. (2002). Toward a theory-based measurement of culture. Journal of Global Information Management, 10(1), 13-23.

Trimble, J. E. (2007). Prolegomena for the connotation of construct use in the measurement of ethnic and racial identity. Journal of Counseling Psychology, 54(3), 247-258. DOI: 10.1037/0022-0167.54.3.247

Trimble, J. E. (2013). Advancing understanding of cultural competence, cultural sensitivity, and the effects of cultural incompetence. In M. Prinstein & M. Patterson (Eds.), *The Portable Mentor: Expert Guide to a Successful Career in Psychology* (2 ed.). NY: Kluwer Academic/Plenum.

Table of Literature Review Model Articles

Citation	Discipline	Definition	Operationalization	Applying Culture to Health Research/ Practice	Health Issues
Eckersley R. Is modern Western culture a health hazard? International Journal of Epidemiology. 2006 Apr;35(2):252-8.	Public Health	"The language and accumulated knowledge, beliefs, assumptions, and values that are passed between individuals, groups, and generations; a system of meanings and symbols that shape how people see the world and their place in it and give meaning to personal and collective experience; or, more simply, as the knowledge we must possess to function adequately in society."	Culture can be measured as differences between societies; between individuals or groups within a society (cultural consonance). The author suggests measuring individualism and materialism through isolation, social support and contact; self-perception or adulation of youth; social trust and inequality; fragmentation (e.g., renting, single-person households, unmarried).	The author does not discuss translation of the concept of culture into health research or practice.	Psychological well-being, suicide, heart disease, cancer
Dressler, WW. (2012). Cultural Consonance: Linking Culture, the Individual and Health. Preventive Medicine 55(5):390-393.	Anthropology	"That which one must know to function adequately in a social setting" (Goodenough, 1996).	Measurement of cultural consonance by identifying cultural domains – any organized focus of discussion in a given society – and then analyzing the domains to see if a representative sample of individuals shares an understanding of the domains and the contents of a shared model. The measurement of cultural consonance in each domain assesses the degree to which individual beliefs and behaviors match the shared model. These results in turn are used to construct measures for collecting data on beliefs and behaviors from individuals. These measures are then used in the second broad stage of data collection of survey research.	They examined the effects of cultural consonance in many studies and found that CC is inversely associated with various health outcomes, such as blood pressure and psychological distress.	Social support, arterial blood pressure, psychological distress
Dressler WW. Cultural consonance. Textbook of Cultural Psychiatry, Dinesh Bhugra and Kamaldeep Bhui (eds.). Cambridge University Press 2007: 179-190.	Anthropology	"The learned, shared knowledge that one must possess to function adequately in a social group" (Goodenough, 1996).	Cultural consensus modeling: a linkage of intensive descriptive methods of ethnography with extensive, quantitative methods for hypothesis testing. Variables representing cultural domains are drawn from intensive ethnographic work and operationalized in epidemiologic survey work so that health risks can be studied in relation to variation within culturally defined domains. The cultural consensus model provides a systematic way to measure sharing within cultural domains (Romney, Weller, & Batchelder, 1986).	Applications of cultural consonance theory to real world settings in Brazil and among African Americans in the Southeastern United States have demonstrated its flexibility.	Blood pressure, psychological distress

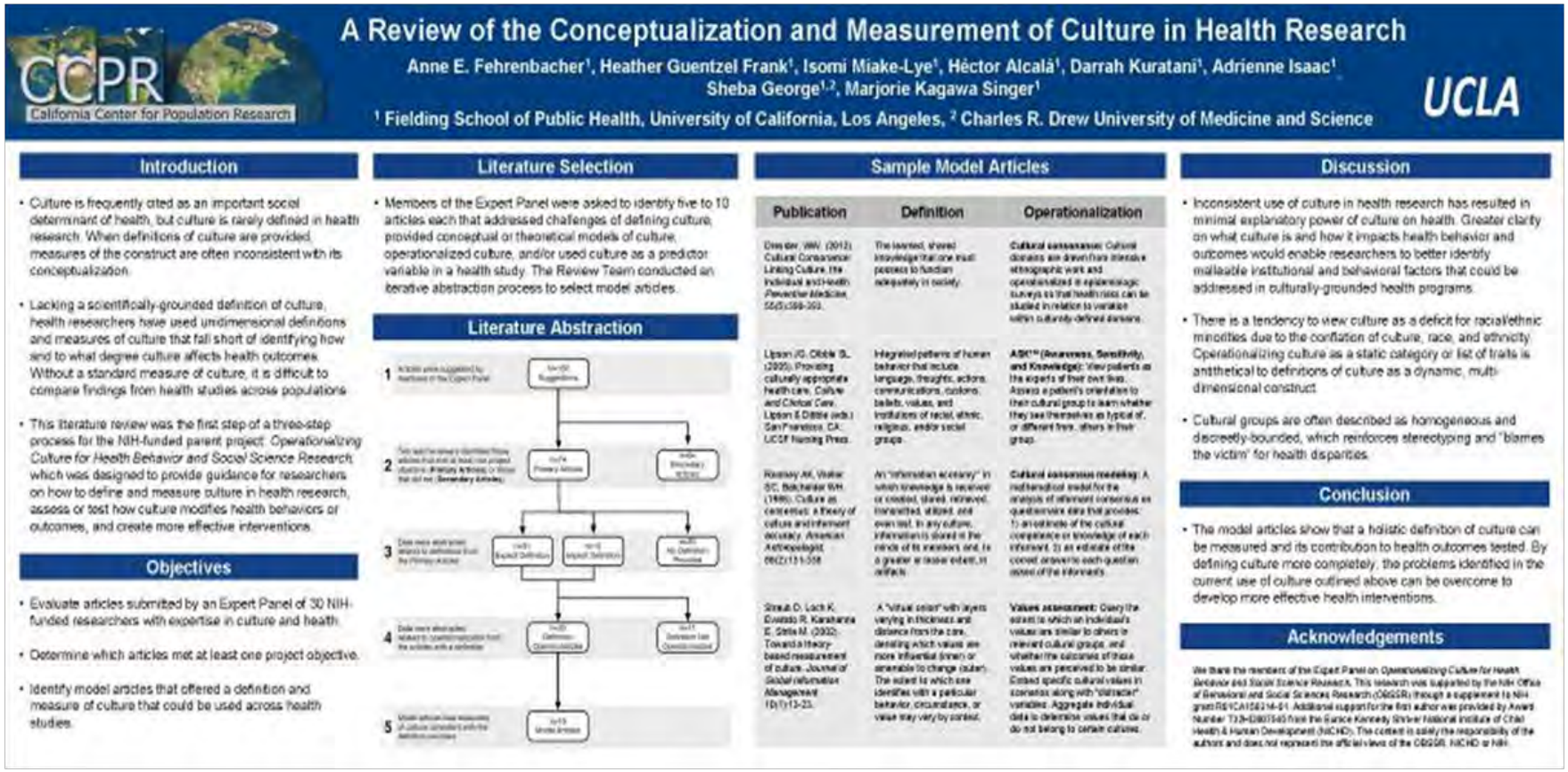
Citation	Discipline	Definition	Operationalization	Applying Culture to Health Research/ Practice	Health Issues
Kagawa Singer, M. Impact of Culture on Health Outcomes.	Medical Anthropology	"The multi-level, multi-dimensional, dynamic, adaptive, and integrative biopsychosocial ecological system in which a population of people exists, and not merely a collection of beliefs and values interchangeable on the same template as that of the culture of the northern European-American dominant culture."	Usage of a Form and Function grid to assess applicability of Western palliative care standards cross-culturally. The author suggests that clinicians substitute the basic values of the patient's culture in the grid and compare how closely their culture's values align with those of the United States.	She suggests eight strategies to apply her approach in clinical care to increase the likelihood that clinicians could provide acceptable, relevant, appropriate, and effective holistic quality palliative care throughout the cancer experience to diverse patient populations.	Palliative care, cancer
Lipson JG, Dibble SL. Providing culturally appropriate health care. Culture and Clinical Care. Juliene G. Lipson and Suzanne L. Dibble (eds.) San Francisco, CA: UCSF Nursing Press. 2005:xi-xviii.	Nursing	"The integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and/or institutions of racial, ethnic, religious, and/or social groups."	The authors' perspective is summed up as "ASKt (awareness, sensitivity, and knowledge)" (p. xii).The authors suggest that a cultural assessment, at a minimum, includes the following questions (adapted from Lipson and Meleis, 1985): "what is the patient's ethnic affiliation"; "who are the patient's major support persons and where do they live"; with whom should we speak about the patient's health or illness"; what are the patient's primary and secondary languages, and speaking and reading abilities"; "what is the patient's economic situation? Is income adequate to meet the patient's and family's needs" (p. xiii).	Healthcare providers must acknowledge their beliefs and biases about specific groups and recognize that those beliefs and biases can be inadvertently communicated to patients and families through verbal and nonverbal communication.	Patient-provider interactions
Romney AK, Weller SC, Batchelder WH. Culture as consensus: a theory of culture and informant accuracy. American Anthropologist, New Series, (June 1986), 88(2):131-338	Anthropology	Drawing on Roberts (1964:438-439), the authors state: 'It is possible to regard all culture as information and to view any single culture as an 'information economy' in which information is received or created, stored, retrieved, transmitted, utilized, and even lost."	Frequent disagreement among informants confronts the investigator with two major problems: first, how can the "cultural knowledge" of different informants be estimated, and, second, how can the "correct" answers to specific questions be inferred and with what degree of confidence? This paper supplies a formal approach that answers these two questions for a variety of cultural information domains that lend themselves to systematic question formats, e.g., true-false, multiple-choice, filling-the-blank". "A formal mathematical model for the analysis of informant consensus on questionnaire data that will simultaneously provide the following information: first, an estimate of the cultural competence or knowledge of each informant, and second, an estimate of the correct answer to each question asked of the informants." "Once we know how 'competent' each informant is we can figure out the answers to the questions by weighting each informant's input and aggregating to the most likely answer. That is, we put more weight on the more knowledgeable informants than the less knowledgeable ones. The model we develop is simply an elaboration and formalization of these ideas and their implications."	"The consensus model opens up the possibility of measuring the cultural competence of informants in a variety of domains. ... it allows one to reconstruct the 'culturally relevant' answers to the questions posed along with confidence limits on the reconstruction.	Research methods

Citation	Discipline	Definition	Operationalization	Applying Culture to Health Research/ Practice	Health Issues
Straub D, Loch K, Evaristo R, Karahanna E., Strite M. Toward a theory-based measurement of culture. Journal of Global Information Management. 2002;10(1):13-23.	Information Technology	The authors suggest a theory-based conceptualization of culture as a "virtual onion" with several influential layers vary in thickness and distance from the core, which denote which values are more influential (inner layers) or amenable to change (exterior).	A viable format is to elicit responses by embedding specific cultural values in scenarios along with other "distracter" variables. Culture must be measured at the individual level even though it is assumed to be a group-level phenomenon. Once individual-level data is aggregated, it will be possible to assert that certain cultural characteristics do or do not belong to certain cultures. A large simple random sample is preferred, but stratified sampling is also acceptable.	Relevance for understanding relationships between health care professionals and patients in an increasingly diverse society. Competency in cross-cultural interactions comes from asking relevant questions regarding cultural values.	Patient-provider interactions
Taras V, Rowney J, Steel PDG. Half a century of measuring culture: Approaches, challenges, limitations and suggestions based on the analysis of 121 instruments for quantifying culture.	Management	"(1) Culture is shared among individuals belonging to a group or society; (2) culture is formed over a relatively long period; and (3) culture is relatively stable" (p.5).	The authors question "whether measuring solely cultural values adequately captures the phenomenon of culture" and ask "are we actually measuring what we think we are measuring?" In response, the authors recommend "in addition to evaluating basic psychometric properties of the instrument such as internal reliability and factor loadings, high temporal stability of the measured construct is established, for example by the means of test-retest reliability analysis." The next question asks "Is self-report questionnaire good enough to measure culture?" The authors argue that "it remains questionable whether this approach can provide valid data to measure the phenomenon... as there may be a substantial difference between the perceptions of the respondents and the reality." The authors recommended several methods, including combining positively- and negatively-worded items (McCrae & Costa, 1997) and various within-subject standardization procedures (Hofstede, 1980; Leung & Bond, 1989), to correct for systemic response biases in intercultural surveys, but these methods have limitations (Smith, 2004).	"We must define specifically which elements of culture are the focuses of a model and avoid unjustified generalizations of the findings to facets of culture that were not directly measured in the study."	Research methods

Citation	Discipline	Definition	Operationalization	Applying Culture to Health Research/ Practice	Health Issues
Trimble JE. Advancing understanding of cultural competence, cultural sensitivity, and the effects of cultural incompetence. In: Prinstein M, Patterson M, (eds.), The Portable Mentor: Expert Guide to a Successful Career in Psychology. second ed. NY: Kluwer Academic/Plenum; (in press).	Psychology	Drawing on Brown (1991), the author defines culture as "conventional patterns of thought, activity, and artifact that are passed on from generation to generation in a manner that is generally assumed to involve learning rather than specific genetic programming. Besides being transmitted 'vertically' from generation to generation, culture may also be transmitted 'horizontally' between individuals and collectivities."	The author asserts that consensus on definitions of culture (among researchers and between researchers and community participants) must precede any scale development to measure research concepts. Piloting and pretesting instruments is crucial to test functional, conceptual, and metric equivalence. In addition to usual reliability and validity studies, it is useful to analyze factor structure of measures and constructs using factor structure analysis, item response theory, and Rasch modeling algorithms can help in examining problems of all types of equivalence. Challenges to operationalizing culture: We must be mindful of comparability or cultural equivalence and must be wary of ethnic glosses which overgeneralize similarities within groups violating tenets of external validity and erode the likelihood of an accurate replication of results.	Provides recommendations on cultural competence for counselors. Practitioners should immerse themselves in multicultural counseling education and promote the recruitment and retention of ethnic minority researchers and practitioners.	Cultural competence, counseling
Weller SC. Cultural consensus theory: Applications and frequently asked questions. Field Methods. 2007; 19:339-368.	Anthropology	The author defines culture as "the set of learned and shared beliefs and behaviors, and cultural beliefs are the normative beliefs of a group" (p.339).	The simplest method for estimating group beliefs is to aggregate responses from a series of questions and use majority responses (categorical or qualitative responses) or average responses (ranked or quantitative responses) to estimate the answers. Agreement between the individual and aggregate responses of the group estimate how well the individual corresponds to the group. Cultural consensus theory builds on these analyses as follows: first, estimates of individual knowledge or competency are estimated from agreement between people; second, culturally-correct answers are estimated by weighting responses of each person by their competency and aggregating responses across people.	The author cautions: "statistical methods are not synonymous with the theories and hypotheses that they test: they are tools to test ideas"; to not generalize beyond the sample; and that those who use the model should look for evidence of systematic bias before drawing conclusions.	Research methods

Poster Design

(Electronic Poster available at: http://bit.ly/11ETWjp)



CCPR California Center for Population Research

A Review of the Conceptualization and Measurement of Culture in Health Research

Anne E. Fehrenbacher[1], Heather Guentzel Frank[1], Isomi Miake-Lye[1], Héctor Alcalá[1], Darrah Kuratani[1], Adrienne Isaac[1], Sheba George[1,2], Marjorie Kagawa Singer[1]

[1] Fielding School of Public Health, University of California, Los Angeles, [2] Charles R. Drew University of Medicine and Science

UCLA

Introduction

- Culture is frequently cited as an important social determinant of health, but culture is rarely defined in health research. When definitions of culture are provided, measures of the construct are often inconsistent with its conceptualization.
- Lacking a scientifically-grounded definition of culture, health researchers have used unidimensional definitions and measures of culture that fall short of identifying how and to what degree culture affects health outcomes. Without a standard measure of culture, it is difficult to compare findings from health studies across populations.
- This literature review was the first step of a three-step process for the NIH-funded parent project: *Operationalizing Culture for Health Behavior and Social Science Research*, which was designed to provide guidance for researchers on how to define and measure culture in health research, assess or test how culture modifies health behaviors or outcomes, and create more effective interventions.

Objectives

- Evaluate articles submitted by an Expert Panel of 30 NIH-funded researchers with expertise in culture and health.
- Determine which articles met at least one project objective.
- Identify model articles that offered a definition and measure of culture that could be used across health studies.

Literature Selection

- Members of the Expert Panel were asked to identify five to 10 articles each that addressed challenges of defining culture, provided conceptual or theoretical models of culture, operationalized culture, and/or used culture as a predictor variable in a health study. The Review Team conducted an iterative abstraction process to select model articles.

Literature Abstraction

1
2
3
4
5

Sample Model Articles

Publication	Definition	Operationalization
Dressler, WW. (2012). Cultural Consonance: Linking Culture, the Individual and Health. *Preventive Medicine*, 55(5):399-403.	The learned, shared knowledge that one must possess to function adequately in society.	**Cultural consonance:** Cultural domains are drawn from intensive ethnographic work and operationalized in epidemiologic surveys so that health risks can be studied in relation to variation within culturally-defined domains.
Lipson JG, Dibble SL. (2005). Providing culturally appropriate health care. Culture and Clinical Care. Lipson & Dibble (eds.) San Francisco, CA: UCSF Nursing Press.	Integrated patterns of human behavior that include language, thoughts, actions, communications, customs, beliefs, values, and institutions of racial, ethnic, religious, and/or social groups.	**ASK™ (Awareness, Sensitivity, and Knowledge):** View patients as the experts of their own lives. Assess a patient's orientation to their cultural group to learn whether they see themselves as typical of, or different from, others in their group.
Romney AK, Weller SC, Batchelder WH. (1986). Culture as consensus: a theory of culture and informant accuracy. *American Anthropologist*, 88(2):313-338.	An "information economy" in which knowledge is received or created, stored, retrieved, transmitted, utilized, and even lost. In any culture, information is stored in the minds of its members, and to a greater or lesser extent, in artifacts.	**Cultural consensus modeling:** A mathematical model for the analysis of informant consensus on questionnaire data that provides: 1) an estimate of the cultural competence or knowledge of each informant, 2) an estimate of the correct answers to each question across all the informants.
Straub D, Loch K, Evaristo R, Karahanna E, Strite M. (2002). Toward a theory-based measurement of culture. *Journal of Global Information Management*, 10(1):13-23.	A "virtual onion" with layers varying in thickness and distance from the core, denoting which values are more influential (inner) or amenable to change (outer). The extent to which one identifies with a particular behavior, circumstance, or value may vary by context.	**Values assessment:** Query the extent to which an individual's values are similar to others in relevant cultural groups, and whether the outcomes of those values are perceived to be similar. Extract specific cultural values in scenarios along with "distractor" variables. Aggregate individual data to determine values that do or do not belong to certain cultures.

Discussion

- Inconsistent use of culture in health research has resulted in minimal explanatory power of culture on health. Greater clarity on what culture is and how it impacts health behavior and outcomes would enable researchers to better identify malleable institutional and behavioral factors that could be addressed in culturally-grounded health programs.
- There is a tendency to view culture as a deficit for racial/ethnic minorities due to the conflation of culture, race, and ethnicity. Operationalizing culture as a static category or list of traits is antithetical to definitions of culture as a dynamic, multi-dimensional construct.
- Cultural groups are often described as homogeneous and discretely-bounded, which reinforces stereotyping and "blames the victim" for health disparities.

Conclusion

- The model articles show that a holistic definition of culture can be measured and its contribution to health outcomes tested. By defining culture more completely, the problems identified in the current use of culture outlined above can be overcome to develop more effective health interventions.

Acknowledgements

We thank the members of the Expert Panel on *Operationalizing Culture for Health Behavior and Social Science Research*. This research was supported by the NIH Office of Behavioral and Social Sciences Research (OBSSR) through a supplement to NIH grant R01CA158214-01. Additional support for the first author was provided by Award Number T32HD007545 from the Eunice Kennedy Shriver National Institute of Child Health & Human Development (NICHD). The content is solely the responsibility of the authors and does not represent the official views of the OBSSR, NICHD or NIH.

Appendix C:

Reflection Papers Submitted by Members of the NIH Expert Panel on Defining and Operationalizing Culture for Health Research

NIH Expert Panel Meeting

Redondo Beach, CA

April 27-28, 2012

Prior to the NIH Expert Panel Meeting in April 2012, Members of the Expert Panel were asked to prepare a 1-2 page reflection paper on their understanding of challenges to and opportunities for the use of culture in health research. Expert Panel Members were instructed to direct their comments to meet the four main project objectives with regards to three preliminary focus areas: Theory, Operationalization, and Translation. They were also asked to identify the major barriers to the objectives and generate ideas for recommendations to overcome these barriers.

The four main project objectives were:

1. To scientifically define culture for application in health research,
2. To identify the domains of culture that influence health behavior,
3. To specify the pathways by which these domains influence health behavior outcomes in diverse populations, and
4. To propose a set of recommendations to guide both researchers and funders in the conceptualization and measurement of culture.

Appendix C contains the reflection papers submitted by the Expert Panel Members responding to one or more of the project objectives. These papers are included in this report with their permission.

Claudia R. Baquet, MD, MPH
Associate Dean for Policy and Planning
University of Maryland School of Medicine

Initial Thoughts on the "Operationalizing Culture Project"

Overall Comments: The Project is critically important for influencing not only research in general (and across the continuum) but could guide culturally responsible research and translation of research results. I view this as critical for assuring quality health care delivery and outcomes, and social economic standing for diverse and often underserved communities. Given the lack of quality research on this topic, the potential for the project to affect and guide future research agendas exists. I consider development and acceptance of this project by the two project leaders, an important and also very brave exercise!

A. There is an emphasis on culture as relates to race/ethnicity more so than culture and socioeconomic condition. The extension of this approach describes the role of culture and racism/bias in health care delivery (from the recipient perspective with little discussion on the "deliverer" of health care), stigmatization of communities, and effects on material distribution.

B. There is a paucity of research on culture and consensus on the definition of culture does not exist.

C. The term "culture" is often tied to geography, language race/ethnicity and where I am from, food and its preparation.

D. Culture, race/ethnicity, socioeconomic condition, distribution of resources, language, and geography are all intertwined.

E. In its simplistic forms, culture is related to: religious beliefs, health seeking behaviors, self-view, social structure, family structure and dynamic, dietary and food preparation practices, trust in medical professionals/healthcare organizations, trust in research, death and dying,

F. Too many terms that are not standardized nor have evidence of effects/outcomes are more empirical than evidence-based: cultural sensitivity, cultural relevance, competence, tailoring, multicultural.

G. The literature is rich with discussion of culture or multicultural education/training but the approaches in these articles are not standardized nor are the definitions used.

H. The types of documents dealing with culture are varied: few research reports, many training/education, some federal reports, review or thought articles.

I. The intersection of culture (however defined), race/ethnicity and socioeconomic status is important to define and consider.

J. A series of at least three NIH future funding mechanisms could guide methodologies on research and culture…in general and as related to health disparities.

Ronny A. Bell, PhD, MS
Professor, Department of Epidemiology and Prevention
Director, Maya Angelou Center for Health Equity
School of Medicinet
Wake Forest University

As an epidemiologist whose research has focused on racial and ethnic disparities in health, I am keenly aware of the need to understand race, ethnicity and culture as it relates to the work that I do. In order to define racial and ethnic disparities in various measures of health, we must first be able to explain what we mean that a group of people are a member of a particular race and ethnic group. In 1990, the U.S. Census expanded the options that are available to respondents to allow for "multiple race" categories. While this was a much-needed change to the way in which we collect race/ethnicity data in our country, it nonetheless created significant challenges for those of us who rely on Census data as a denominator to document disparities in health-related conditions by race and ethnicity. Right now, our research group is awaiting the 2010 "bridged race" data from the Census to examine racial and ethnic differences in childhood diabetes (bridging is a process used by the National Center for Health Statistics to categorize Census data based on the various iterations of multiple race options). Multiple race classification is particularly important for me as I do research in American Indian populations in North Carolina. In our state, the number of individuals who list American Indians as one of multiple races relative to the number who indicate only American Indian is very high, which makes it difficult to determine the most appropriate denominators to use to adequately classify rates of health conditions.

Added to these challenges is the difficulty of understanding the differences between "race" and "ethnicity." According to the U.S. Census, there are two ethnicities in our country, "Hispanic" and "non-Hispanic." It does seem odd that we have a definition of a group of people based on what they aren't, but I guess this is not much different than when we used to lumping all minority groups into a "non-white" or "other" category. Nonetheless, this now creates even further levels of stratification into the combinations of five racial groups and two ethnic groups.

All of this doesn't even take into account the other factors, which can influence health, like education, income, geography, etc., which are highly related to race

and ethnicity. The “Eight Americas” paper by Murray and colleagues in 2006 is an important step toward quantifying the intersection of these factors.

Even when we are able to classify people into racial and ethnic categories, doing so leaves us vulnerable to the false “one size fits all” assumption of lumping all individuals into a particular group and assuming that they are homogenous. For American Indians, who are represented by hundreds of tribes and people groups with a wide variety of historical experiences, beliefs, and environmental exposures, this is extremely difficult.

Once we are able, as best as we can, to define racial and ethnic disparities in particular health conditions, we must go about the task of developing interventions that can be adopted in these vulnerable communities to close the gap. These interventions must be “culturally appropriate” to the communities in which they are to be adopted. Therefore, it is important to understand the influence of culture on the occurrence of these conditions and the ability to alleviate them. This, again, presents a number of challenges to understanding the culture of these communities and its relationship to health. To that end, the advances of community-based participatory research has been very helpful to give researchers a framework by which researchers can fairly and equitably partner with communities to develop strategies to influence disparate conditions.

Similarly, there is a growing interest in developing strategies to ensure that our health care work force is “culturally competent.” This is one of the components of President Obama’s initiative to reduce health disparities in the U.S. There are a number of excellent models for doing this, and it will be interesting to see how much of an impact this will have on our ability to provide the highest quality of care to all citizens. The biggest challenges that I see in doing this is trying to adequately determine which cultures these providers should be competent in (or, to see if just a general approach to enhancing cultural competency is sufficient), and limiting the chances that cultural competency education of health care providers will lead to increased stereotyping of patients by these providers.

The factors associated with race, ethnicity and culture are very important but very complex for researchers, health care providers and policy makers. Important steps in the right direction are being made, but much more needs to be done to enhance our knowledge base to address the disparities in health that are pervasive in many communities across our country.

Linda Burhansstipanov, DrPH, MSPH
Founder, Native American Cancer Research Corporation (NACR)
Pine, Colorado

Reflections on "Culture": Measures, Theory, Operationalization and Translation

As a public health intervention researcher, much of the discussion of "culture," what it is and is not, and theorizing about measures continues to be daunting. It is easy to interject academic and sometimes condescending language to address concepts of "culture" that embraces innate thoughts, behaviors, attitudes and spiritual functions affecting daily behaviors and wellbeing of the individual, family and community. Although culture is learned / acquired, its influence is embedded in our subconscious mind. All or almost all people behave in ways that result from culture without thinking about it. Is such behavior a result of repetition or ritual or is it deeper? Probably all three. While working for the National Cancer Institute and coordinating a meeting with American Indian and Alaska Native leaders, the meeting was started with a prayer. This is how all of our meetings begin. However, the federal government does not include prayer within such meetings. I was professionally threatened and accused of trying to sneak or do something inappropriate by inviting the spiritual attendee to lead the meeting with the prayer. To have started the meeting with Native people in any way other than with a prayer would have been disrespectful and create a sterile, dishonest tone for the Native gathering. This was naivety on my part but was totally without conscious thought. It simply was how one begins a meeting "in a good way." This behavior was embedded cultural practice. It was subconscious, but also a repetitive cultural practice that was innate to initiation of Native gatherings. After numerous meetings with my government superiors, a compromise was reached. We would invite those who did not wish to be present for the prayer to join us 10 minutes later and we continued to invite spiritual leaders to start our gatherings "in a good way." So, the question is, if one were a public health researcher and attempted to delineate what part of this behavior was culture, how and what would one measure?

Public health interventions include data collections, but the focus of such research is on learning how new interventions or programs impact health behavior. Some respected professional fields recommend cultural measures can only be assessed through lengthy open-ended questions (suggestions from colleagues in this Expert Panel suggested 60 or more items solely on assessing culture). However, when one's focus is on interventions, the data collections need to address many different health behavior components. Data collection is expensive. Budget require the interventionist researcher is prohibited from conducting lengthy, open-ended interviews for most studies. One or two such qualitative items ARE feasible. Quantitative items should also be included (and require less time and money to

administer). The research study needs both.

The stems of quantitative questions may be similar to:

- How often does your culture influence your daily behaviors?
- How often does your culture influence your daily spirituality?
- How often does your culture influence your daily communication with others?
- How often does your culture influence your daily thoughts and mental functions?
- How often does your culture influence your daily physical activity? Or diet, etc.

Responses of such quantitative stems may be "(a) 76-100% of the time; (b) 51-75% of the time; (c) 26-50% of the time; (d) 25% or less (e) don't know / not sure." But what would these results really mean, if anything? Qualitative follow-up questions are needed to allow the participant to explain or clarify the answers. Regardless, what would or could researchers do with the results? How would responses to such questions help guide the development, implementation and assessment of a public health intervention? How would the results affect interactions with health behaviors?

These are a few of the challenges of this Operationalizing Culture Panel. None of the quantitative questions actually assess innate cultural practices and beliefs. Qualitative responses may or may not assess the innate cultural practices or beliefs either. Somehow, "culture" needs to be identified and measured, but in such a manner that it does not require excessive time and money that is needed to develop, implement and assess the evolving public health intervention.

Culture may be subconscious and influence daily decision-making and behaviors. Culture integrates thoughts and perceptions; it results in actions (behaviors). When working at the Los Angeles American Indian Clinic in 1995, the local Native women refused to take part in mammography due to their belief that the van was cursed. This was a cultural interpretation based on another American Indian woman being diagnosed with cancer after having her mammogram in the van two months previously. The "moccasin telegraph" (informal communication network effective throughout the community) spread the message that the van and its machine "gave" the woman the cancer. The local research team addressed the situation by bringing in a local spiritual / traditional Indian healer to bless the van and smudge the women prior to entering the van and upon their departure from the van. Thus, the translation to real life was to respect the local cultural perspectives of beliefs and resulted in increased participation in early detection screening behaviors.

All beings are multi-cultural. At times one of our personal "cultures" has stronger influence on our health behaviors than do others. Thus an American Indian nurse may be very traditional and teach tobacco cessation, yet she may also take part in ceremony that includes tobacco smoke. If this nurse is asked a National Health

Interview Survey (NHIS) item, “do you use tobacco,” how does she honestly answer the item? Her cultural practices have a totally different connotation than is the intention of the NHIS question. Does the interviewer take the time to clarify what or how her cultural practices influence her response to the NHIS question? Not likely. Are the data misinterpreted? Likely.

Culture functions as a filter for health information and perceptions. For example, about 80,000 American Indian women were sterilized in government and county community clinics without the informed consent process in the 1960s-1970s. This is an example of “historical trauma.” Such trauma (even though the events were stopped in 1971 by Congress) creates distrust and influence cultural decisions related to health behaviors today: some Native women will not go to certain clinics or to county health departments for any reproductive services.

There are cultural contexts of words and phrases impact interpretation. For example, since the early 2000’s the government loves to use the word, “stakeholder” when referring to potential targeted population. But “stakeholder” in my culture means your leg is tied to the ‘stake’ that is driven into the ground and you stay and fight enemies in that position/location until death or the threat retreats. My cultural connotation obviously is not quite what federal agencies mean when they calmly stress the need to include “stakeholders” in decision-making. Obviously as well, my attitude when attending a meeting with government officials enthusiastically talking about getting more stakeholders involved makes me guarded and uneasy. Although I know what they mean, my cultural sense of protection and assertion remains elevated in such gatherings. Thus, words and phrases have unique connotations to people of diverse cultural practices. Specific Asian cultures have issues with numbers, such as “4”. How does the researcher assess such issues in a timely manner, while retaining the focus of work on the public health intervention?

In closing, there are very dedicated and passionate researchers providing many insightful perspectives of culture on this Panel. I have learned a lot from the Panel members and I thank them for their guidance and patience with my repetitive questions of, “how does this impact public health intervention research?” Of exceptional quality for helping me understand what and how culture affects public health studies, the experts who I find the most operational are Drs. Marjorie Kagawa-Singer, Jennie Joe and Rena Pasick. When they talk, I find myself listening carefully because they provide examples that are helpful for public health intervention research. Demonstrating respect for culture (acceptance of variable interpretations and perceptions) through interventions and communications may result in behaviors recommended for and that contribute to improved health.

Nancy Burke, PhD
Associate Professor
Department of Anthropology, History and Social Medicine
University of California, San Francisco

Defining Culture in Health Disparities Research: Challenges

In our 2008 Annual Review article addressing the use of health behavior theory in mammography research with underserved women, we found that articles addressing "culture," "cultural theory," "cultural models," "cultural explanatory models," or "cultural constructs" rarely included a definition of culture (Pasick & Burke 2008). Those that did relied on a basic definition of culture as beliefs and practices shared by members of a group and passed down within the group, or listed general attitudes, norms, values, beliefs and behaviors. While sometimes a seemingly sophisticated understanding of the concept informed the analysis and generation of concepts such as "cultural affiliation," the omission of an explicit explanation of how culture was understood by the authors highlighted a lack of precision throughout the literature, further reflected in methodology and theoretical orientation.

In 2009 we put forth our understanding of culture as "the patterned process of people making sense of their world and the (conscious and unconscious) assumptions, expectations, knowledge, and practices they call upon to do so. The term *patterned* indicates that culture is not random. Instead, there are consistencies within culture that are at the same time flexible and situationally responsive; the term *process* indicates that culture is not bounded or static but rather dynamic, fluid, and constantly being shaped and reshaped. People bring culture into being as they go about making their world—making the structures, institutions, rituals, and beliefs that reflect and (re)produce individual and collective sense-making activities (Bourdieu, 1990; Geertz, 1973).

Culture is not distinct from or equivalent to religion, politics, or any other social institution such as economics or kinship; rather, it is an integral part of all of them—forming them and being formed by them according to situation and circumstance. Thus, culture is a dynamic process that changes over time and across space, whether in contact with or in isolation from other groups, and is not a discrete entity with a material presence, fixed attributes, or clear boundaries. It is the outcome of the interactions, feelings, and thoughts of many people and their diverse, often overlapping, sometimes contradictory, attempts to make sense of their world and live in it." (Burke et al. 2009)

Opportunities lost: Operationalizing culture in acculturation studies

In their review of the concept of acculturation in health studies focused on Hispanics and Latinos, Hunt and colleagues similarly found that only 8% (6 out of the 69) of articles reviewed included a definition of culture, and that these were vague (2004: 977). They conclude, "in place of a carefully delineated construct to be measured, culture is implicitly understood in this research to be a cluster of nebulous characteristics carried by ethnic group members" (Hunt et al. 2004: 977). This lack of definition and clear understanding of culture allows for the persistent assumption that ethnic and "mainstream" cultures are distinct and that their characteristics and differences are obvious and not necessary to clearly delineate. Since cancer disparities are largely measured as the differences in mortality and incidence between an ethnic subgroup (such as African Americans) and non-Hispanic Whites (i.e. "mainstream"), and cultural aspects of the ethnic subgroup are often under examination, this assumed understanding of "mainstream" becomes particularly problematic. If there is no understanding of mainstream culture, we cannot ask what it is about mainstream cultural practices that are protective.

Consequences of this imprecision include the assumption of a continuum with the ethnic and mainstream cultures on either end, but with little to no description of what is meant to constitute each end of the continuum (Hunt et al. 2004). A component of this continuum is the association of "tradition" and "traditional practices" with the ethnic subgroup with little to no analysis of practices in the home country or within the subgroup community on which to base these assumptions of traditionality (Hunt 2004). Therefore, just as we are unable to analyze the protective cultural beliefs and/or practices of the mainstream, we are unable to accurately identify protective or problematic "traditions" in any systematic way (Hunt 2004). Coupled with the lack of attention to social context and structural effects (e.g. socioeconomic factors and inequality) in favor of "culture" and "cultural barriers" in this literature, the lack of consistent use and definition of the concept of culture results in an understanding of "culture" as a characteristic of an individual, independent of its context (Hunt et al. 2004: 981; Burke et al. 2009). Subsequently, ethnic culture as manifest in individual attitudes, norms, beliefs, and practices, is made culpable for health inequalities (Abraido-Lanza et al., 2007).

An example of this process is the widely accepted concept of fatalism in the cancer screening literature. While there is no consensus on the definition of fatalism as applied to various ethnic groups (Asian, African American, Latino, working class Whites), it is generally understood as a dominant cultural belief that deters members of minority groups from engaging in early detection and other health preventive behaviors, such as cancer screening (Abraido-Lanza et al. 2007). Generally referring to the belief that the course of fate is unchangeable and that life events are beyond the individual's ability to control (Abraido-Lanza et al. 2007), critics have noted that the concept strongly suggests "ignorance, irrationality, anti-science, and even primitivism" (Davidson 1992; Davidson & Strauss, 1992) and that evidence qualifying certain groups as

"fatalistic" and further linking this characterization to health behavior (particularly cancer screening behavior) is spotty, at best (Abraido-Lanza et al. 2007). In their review of the use of fatalism in health literature addressing Latinos and Hispanics, Abraido-Lanza and colleagues found evidence that contradicts the assumed influence of fatalism: for example, Latinas are as likely as Whites to agree that if breast and cervical cancer are found early, they could be cured (2007). Furthermore, they found research on fatalism and Latinos to be hampered by methodological and conceptual problems including reliance on single item measures; lack of established reliable scales; limited evidence of validity of existing measures; and the use of scales that may tap distinct fatalism constructs (2007: 155).

Fatalism is a cultural frame that refuses the largely accepted biomedical definition of individual responsibility for health; instead, fatalistic beliefs recognize various types of cause and explanation for illness or death that are not limited to individual behavior (Davidson 1992). Such beliefs address the need, long recognized in the discipline of anthropology, for people to explain and understand general kinds of misfortune (why and how did this happen?) *as well as* the site and time of the specific misfortune (why and how did it happen to *this* person at *this* time?) (Davidson 1992; Gregg & Curry 1994). The attribution of greater than individual determinants as distal causes for illness and disease, found throughout the world, conflict with the biomedical attribution of personal responsibility for health maintenance through preventive behaviors.

Barriers to theory, operationalization (e.g. measurement?), and translation

- Imprecise and variable definitions in the literature
- "Embedded notions of culture as an innate obstacle to health" (Abraido-Lanza 2007: 156).
- Acceptance and application of cultural concepts as individual traits (e.g. fatalism, familism, individualism, etc.)
- Conceptualization of culture as a barrier, as static, as inflexible; fixed, uniform
- Application of concept as individual variable rather than group process (study of culture has different intellectual roots than psychology)
- Difficulty of linking to health outcome
- Distinction from social class, gender, age, etc. (all part of culture and of which culture is a part)
- Relegation of study of "culture" to underserved groups
- Difficulty of measuring unconscious (or outside of conscious awareness) manifestations of culture (e.g. *habitus*)

References

Abraido-Lanza, A.F., Viladrich, A., Flórez, K.R., Céspedes, A., Aguirre, A.N., & de la Cruz, A.A. (2007). Commentary: Fatalismo reconsidered: A cautionary note for health-related research and practice with Latino populations. *Ethnicity and Disease, 17,* 153-158.

Bourdieu, P. (1990). *The logic of practice.* Palo Alto, CA: Stanford University Press.

Burke, N.J., Galen, J., Pasick, R.J., & Barker, J.C. (2009). Theorizing social context: Rethinking behavioral theory. *Health Education and Behavior, 36(Suppl. 1), 55S-70S.* DOI: 10.1177/1090198109335338

Davidson, L. (1992). Developing an empirical phenomenological approach to schizophrenia research. *Journal of Phenomenological Psychology*, 23, 3–15.

Davidson, L., & Strauss, J.S. (1992). Sense of self in recovery from severe mental illness. *British Journal of Medical Psychology*, 65,131–145.

Geertz, C. (1973). *The interpretation of cultures: Selected essays.* New York: Basic Books.

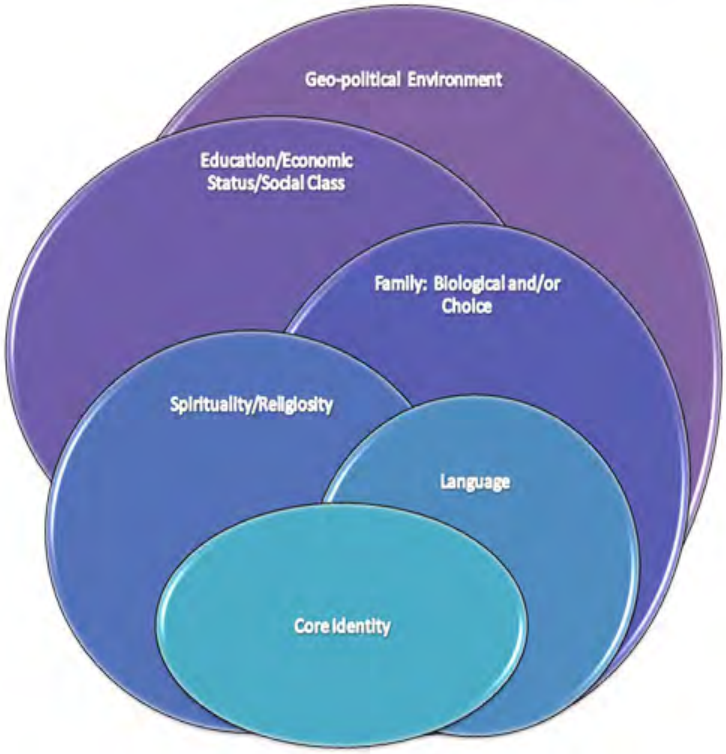
Gregg, J., & Curry, R.H. (1994). Explanatory models for cancer among African-American women at two Atlanta neighborhood health centers: The implications for a cancer screening program. *Social Science and Medicine, 39,* 519-526. DOI: 10.1016/0277-9536(94)90094-9

Hunt, L.M., Schneider, S., & Comer, B. (2004). Should "acculturation" be a variable in health research? A critical review of research on U.S. Hispanics. *Social Science and Medicine, 59,* 973-986. DOI:10.1016/j.socscimed.2003.12.009

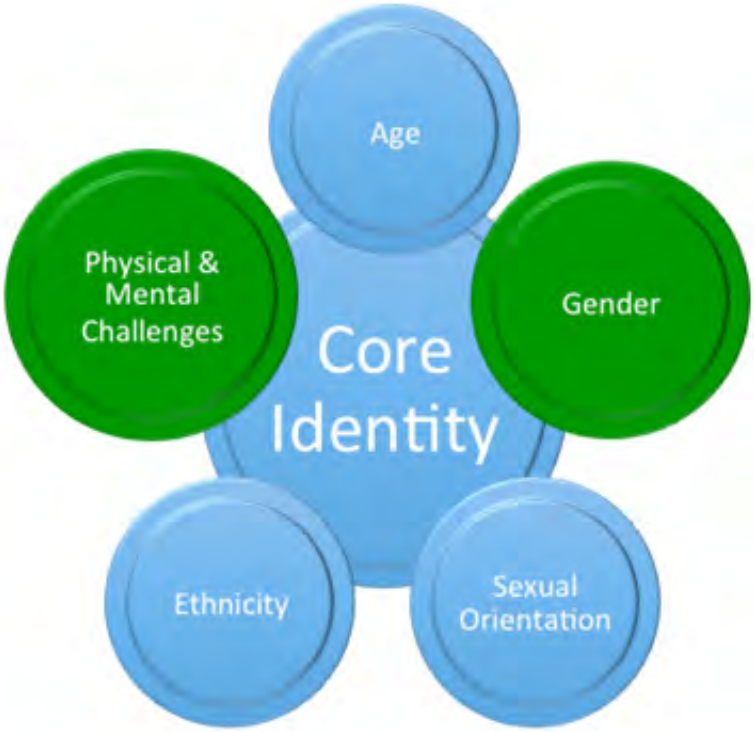
Pasick, R.J., & Burke, N.J. (2008). A critical review of theory in breast cancer screening promotion across cultures. *Annual Review of Public Health, 29,* 351-368. DOI: 10.1146/annurev.publhealth.29.020907.143420

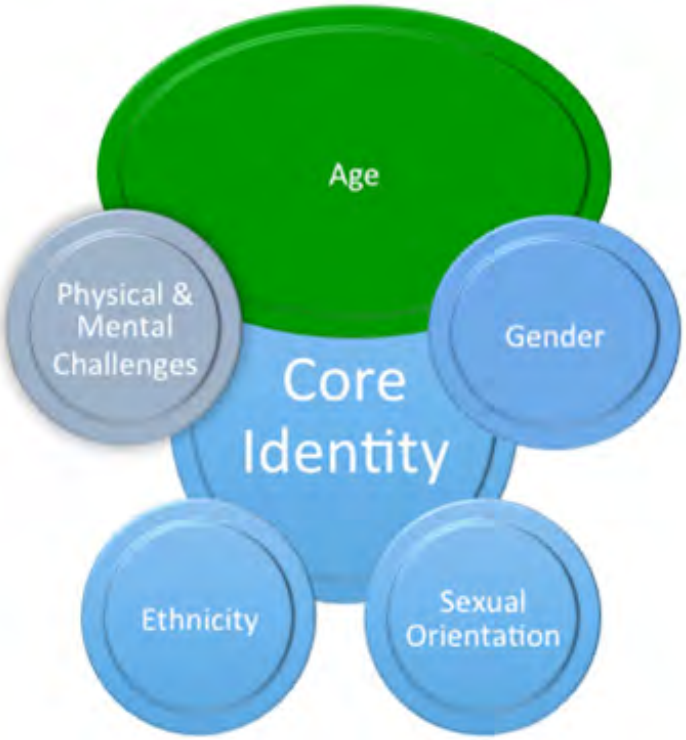
Suzanne Dibble, DNSc, RN
Retired Adjunct Professor
Institute for Health and Aging
Founder, Lesbian Health Research Center
University of California, San Francisco

Components of Culture within U.S. Health Care



- The importance of each component of their core identity to a given person can vary depending upon the situation. Although others may define an element, only the individual can determine the meaning of that element to themselves as well as its relative contribution to their life. Culture clash can occur when the health care provider's identification of a particular element does not match the individual's.
- Norms are the voice of culture. If someone's core identity does not match what the health care provider perceives as the norm, then problems, including stigma and stress, can impact the individual.


Age
Physical & Mental Challenges
Gender
Core Identity
Ethnicity
Sexual Orientation


Age
Physical & Mental Challenges
Gender
Core Identity
Ethnicity
Sexual Orientation

William Dressler, PhD
Professor
Department of Anthropology
The University of Alabama

Some Thoughts on Culture and Health Research

'Emic validity' is a term that my colleagues and I have used to describe an aspect of the concept of validity that is not captured in conventional measurement theory. A measure that has high emic validity is a measure that orders respondents along a continuum that is collectively meaningful to those respondents.

The terms 'emic' and 'etic' were coined by the linguist Kenneth Pike in the early 1950s to describe the aims and processes of ethnographic research. Etic is derived from 'phonetic.' The aim of a phonetic analysis of a language is to describe all of the various sounds that are used in forming words and utterances, regardless of whether or not variants of sounds are meaningful to the participants. By analogy, an etic approach in ethnography describes a cultural setting in terms meaningful to the observer, regardless of whether or not these terms are meaningful to the participants themselves. 'Emic' is derived from 'phonemic.' The aim of a phonemic analysis is to describe the various sounds in a language that make a difference in the meaning of morphemes to the participants in a cultural setting. By analogy, an emic approach in ethnography describes a cultural setting in terms meaningful to the participants.

It should be noted that this is a particular anthropological gloss on an issue that has been widely discussed in social thought, literally for centuries. Are we to understand human behavior in terms of how individuals and groups are constrained within physical and social structures, or are we to understand human behavior in terms of how individuals and groups construct a meaningful world around them, and then act accordingly?

In terms of a theory of culture, I take a solidly cultural constructivist position, consistent with Pike's emic orientation, although I think of constructivism in a cognitive and not a post-structuralist sense. That is, we do indeed construct the world in which we live in terms of the meaningful distinctions we make and share with others around us. In Goodenough's terms, this is the knowledge that we must possess in order to function adequately in a given social setting.

I will argue that this is the only defensible theory of culture, primarily because it resolves a series of problems that have bedeviled the concept of culture for decades (or maybe more than a century). While not exhaustive, the following problems are resolved by this theory. (a) This theory has a reasonable social ontology (literally, what is the 'stuff' of culture? What is it made of?). The philosopher John Searle has demonstrated how a set of shared linguistic constructions can result in institutions

like marriage, the Federal Reserve, and baseball. (b) This theory resolves the aggregate-individual problem. Knowledge resides in individual minds, but it is shared and distributed across minds, making it both a property of individuals and of groups. (c) This theory does not conflate culture with social-psychological constructs like beliefs, values, or attitudes. (d) This theory does not conflate culture with behavior. (e) This theory can be used to analyze both cultural sharing and intracultural diversity.

While a cognitive/constructivist theory of culture is a theory of what culture *is*, it is not a theory of what culture *does*. I will argue, however, that whatever we want to say about what culture does must proceed from an understanding of what culture is. For example, anthropologists have enduring interests in human evolution and the role culture has played in that evolution. This cognitive theory of culture, especially as it is specified further in terms of shared and distributed cultural models and schema, is a useful component of a theory of evolution and culture, in that it provides a mechanism by which adaptive solutions can be socially and cognitively stored and shared in human groups through their ongoing interactions with environments.

This example also suggests that, *contra* strong forms of cultural constructivism, the environments within which culture is distributed are also an important part of the analysis of human behavior. Bourdieu argued many years ago that culture is constructed within the constraints of the environment, social and physical, and that it in turn shapes those environments. Therefore, a dialectic of culture and the environment is an important part of this equation.

What does this mean for research in public health, and especially research on health disparities? I will argue that any analysis of cultural influences on these processes must be cognizant of this theory of culture, and ultimately must at least strive for measures of culture that have emic validity. Several of us have used these ideas directly in the study of health disparities. For example, in some research on health disparities, it has been argued that ‘race’ or ethnicity can be used as an indirect indicator of culture. In my work on the African American community I have argued instead that ‘race’ (really, skin color) is virtually a measure of social class, or at least of ascribed social class in white spaces. The cultural component of understanding health disparities is to be found in how shared cultural models of life goals within the African American community shape goals and expectations, which are in turn pursued within the overall structure of institutionalized racism and discrimination. The result is a collision of cultural construction and social structure, ending ultimately in a higher risk of cardiovascular disease. We have extended this model to other societies (Brazil), and Lance Gravlee has employed a similar approach in his research in Puerto Rico.

Leo Chavez has used this approach to study factors influencing the use of health services among Latinas in southern California. Comparing recent immigrants with Chicanas, Anglo women and physicians, he has shown that there are in essence

three cultural models of reproductive cancers to which women can attend. While there is a rough approximation between cultural model and ethnicity, the specific model from which women draw their own beliefs about cancer does not correspond precisely to ethnic identity. Furthermore, adopting biomedical beliefs does not increase the use of health services, but actually interferes with it.

My main point here is that to understand the role of culture in health processes, and especially to operationalize culture in this research, requires that the concept of culture be taken seriously. Metaphor, analogy and folk theory will not do. ***A theory of culture and health is yet to be developed, however.*** My interests and work in the area started with attempts to specify the model of stress and disease cross-culturally, and I have ended up studying how basic cultural processes can be stressful and increase the risk of disease (sort of standing my original interests on their head). Doing so has required thinking about what kinds of cultural models are likely to shape behaviors that are relevant to stress processes and disease risk. In other words, building on basic culture theory I have tried to specify a theory of culture and the stress process.

Work similar to this needs to continue in other substantive areas relevant to health and health disparities, such as the utilization of preventive health services, as studied by Chavez and associates. This again will require the further specification of substantive theories, but incorporating the cognitive theory of culture I have outlined. Ultimately, before any investigator introduces a variable in research purporting to capture some part of these cultural processes, some thought must be devoted to demonstrating the emic validity of that measure. Through these efforts, the role of culture in health can be better understood.

Linda C. Garro, PhD
Professor
Department of Anthropology
University of California, Los Angeles

Approaches to Conceptualizing and Operationalizing Culture in Health Research

With regard to culture and health disparities, some recent attention has focused on what has been called the "culture of medicine" and the importance of patient sociocultural diversity in health care contexts. Good and colleagues have asked how the "culture of medicine - including the training of medical students and residents and the organization and delivery of health care – affects patient treatment in such a way as to produce disparities in therapeutic action and the quality of care" with a focus "on what medicine cares about: time and efficiency, hierarchies of valued knowledge dominated by the biomedical sciences, and appreciation for patients who willingly enter the world of medicine and who do not have socially complex problems" (Good 2011: xi; see also Good et al. 2003). But, as Willen, Bullon and Good (2010: 249) point out, there is increasing diversity among clinicians, a trend which complicates the seemingly "implicit, largely unintentional assumption that clinicians are 'mainstream,' whereas the challenging patients are those whose backgrounds—cultural, racial/ethnic, national, religious, and so on—are somehow 'Other.'" This trend among clinicians reflects the increasing "social heterogeneity" of the contemporary U.S., which has contributed to a situation where "cultural identities have increasingly become more complex, dynamic, fluid and evolving" (Good, Hannah and Willen 2011: 21 & 3). Good, Hannah and Willen (2011:20) use the term "hyperdiversity" to capture,

> Those situations in which the link between racial-ethnic identity and culture is weak or broken (shattered) and, as a result, in which broad, identity-based indicators of cultural difference prove too blunt an instrument for navigating the social heterogeneity within today's … environments.

In a recent article entitled "From 'Lists of Traits' to 'Open-Mindedness,'" Jenks describes a recent shift in cultural competency training efforts directed at health providers:

> … much of contemporary cultural competence education has rejected the ''list of traits'' approach and instead aims to produce a new kind of health provider who is ''open-minded,'' willing to learn about difference, and treats each patient as an individual. This shift, however, can ultimately reinforce behavioral understandings of culture and draw attention away from the social conditions and power differentials that underlie health inequalities." (Jenks 2011:209).

According to Jenks, while the goal of "open-minded" cultural competence is the cultivation of an approach that recognizes that "every single person's situation is different" this has gone hand in hand with what Jenks refers to as "decontextualized difference":

> Providers learn to recognize—and to some extent uncritically accept—individual differences without developing an understanding of the social and historical conditions in which these differences have been produced or currently operate. As a result, cultural competence education, while designed to address socially produced health disparities, can ultimately reinforce a depoliticized understanding of cultural difference (Jenks 2011:212).

Although highlighting the import of collective histories and collective social conditions that contribute to health disparities, and offering another illustration of how "the use of the culture concept can have significant political implications" (Jenks 2011: 215), the flip side is that conveying a politicized understanding of "cultural difference" may lead to a situation where health providers (or researchers) "conflate social inequality and cultural difference" (Farmer 1999:95).

Attention to the individual, of course, does not preclude attention to the broader social and historical context. Building on earlier formulations within (Arthur Kleinman, 1997; Arthur Kleinman & Kleinman, 1991; Wikan, 1990) Kleinman and Benson's (2006) vision of "anthropology in the clinic seeks to "understand how the social world affects and is affected by illness" through the practice of "mini-ethnography" aimed at understanding "the moral meaning of suffering – what is at stake for the patient; what the patient, at a deep level, stands to gain or lose" (2006:1674-1675). Lakes, López and Garro (2006) have drawn on Kleinman's concern for what is at stake in local social worlds but also on the therapeutic potential of a shared narrative between clinicians and their clients (see Mattingly and Lawlor, 2001). We maintain that bringing these two insights together to inform clinical interactions offers a route for operationalizing how clinicians can best integrate lay and professional views (see Lakes, López and Garro 2006 for further discussion of the theoretical framework and application to a single case). This proposal can be empirically assessed through measuring these constructs within actual clinical interactions along with measures of therapeutic outcome, with clinical interactions recorded both prior to and after participation in "cultural competence" training organized around assessing what is at stake for clients and the creation of shared clinical narratives.

How anthropologists study sharing and variability in cultural understandings represents another relevant line of research. The remaining studies discussed in this commentary all rely on a combination of ethnographic interviews and structured interviewing methods (Chavez, McMullin, Mishra, & Hubbell, 2001; Handwerker, 2002). Handwerker draws on Sapir (1932) in declaring that "everyone participates in many cultures" (Handwerker 2002: 110). Handwerker's tack involves distancing himself from assumptions that ethnic identity serves as an adequate proxy measure

for culture. He focuses on a single cultural domain, namely "the body of knowledge" about parent-teacher working relationships in the United States and operationalizes "a cultural group as a group of people who share a common way of thinking about or enacting parent-teacher working relationships" (Handwerker 2002: 113). In an elegant analysis, involving teachers and ethnically diverse parents, Handwerker demonstrates that there is both a single model about what components are important in parent-teacher working relationships and patterned diversity with two distinctive "cultural models of how to organize these components into effective parent-teacher partnerships" (2002:106). Referring to these as the "Separate but Equal culture" and "Mutual Decision Makers culture," he highlights these as the "pertinent 'cultural groups'" rather than "Puerto Ricans and Connecticut Yankees" (2002: 116-118). While referring to groupings based on cultural models as "cultures" can be questioned, his efforts to empirically demonstrate the potential pitfalls of relying on ethnicity as a proxy for culture point researchers in productive directions.

A complex comparative study carried out in southern California by Chavez and colleagues (1995, 2001) on how cancer risk factors are understood by women and physicians included an examination of variability within the broad social address categories of "Latinas" and "Anglo women" to explore "the influence of cultural beliefs on behavior, or more specifically, beliefs about cervical cancer risk factors and the use of Pap exams" (2001:1114). While the research endeavor is too complex to detail here, a later stage of analysis, applied to data obtained through a large survey, involved the construction of an "ideal, or average" ranking of risk factors for all of the three highest level groups – Latinas, Anglo women and physicians (2011: 1122). This was done for the "Latina" grouping even though variation was observed across all of the "Latina" comparison groups (between both a higher level of aggregation comparing "Latina immigrants" with "U.S. born Latinas" as well as finer grained comparisons using the three Latina subgroups examined in the first study), observations consistent with a recommendation made during an earlier phase of the study, namely that of remaining "cautious" about "a generalizable Latina model" (Chavez et al. 1995:67). For example, the risk factor of "heredity" was ranked first for the following groups: Chicanas, All U.S. born Latinas, and Anglos. In contrast, for all of the Latino immigrant groups (Mexican immigrants, Salvadoran immigrants, and all Latina immigrants); heredity was placed fifth for the six risk factors ranked.

Nonetheless, the aggregation of "ideal Latina beliefs" (2001: 1123) was relied upon in subsequent comparisons, which looked at the correspondence of each Latina to the "ideal, or average" ranking of all three highest-level groups. But what does it mean to refer to "Latinas whose beliefs reflect Latina beliefs generally" using the Latina "cultural ideal" defined by the "average" Latina ranking? Is there really supporting evidence for the existence of an "agreed-on cultural ideal" (Chavez et al. 2001: 1115) for the women placed in the Latina category? Given the tendency among the U.S.-born Latinas to adopt a heredity or family history causal model (like the Anglo women), what are the implications of viewing U.S.-born Latinas as being more similar (culturally consonant) to an "average, or ideal, Anglo ranking"?

If, however, what is being analytically tapped into are divergent logics, or cultural models, that underlie the risk factor rankings, then perhaps it is congruence with these logics (or cultural models), rather than groups, that should be highlighted. From this perspective, the cultural model of heredity is a cultural resource that is broadly available in the U.S. making it more likely that the non-physician women born in the U.S., whether they identify as Latina or Anglo, consider it the factor most likely to increase an individual's risk of cervical cancer.

I turn now to my own research on cultural understandings about diabetes carried out in a First Nations Anishinaabe (also known as Ojibwa, Ojibway or Saulteaux) community in Manitoba, Canada. In the 1990's maturity-onset diabetes was seen in the community as being a relatively new illness, but one that has gone from being unknown prior to World War II to being so common that some express fears that everyone might have it at some future point. At a very general level, it is possible to say that talk about diabetes reflects both concerns about the ever-increasing numbers of community members who have been diagnosed with the condition as well as the view that diabetes is a result of the types of food7s that one eats. It is also talked about as a white man's illness, seen as occurring after Europeans came to North America, thus embedding the emergence of diabetes within the continuing disruption and destruction of the Anishinaabe way of life. Talk about diabetes often brought up strongly articulated contrasts between the healthy and fortifying foods obtained through Anishinaabe subsistence activities in the past and the comparatively unhealthy reliance on the store-bought foods of the Anishinaabe present. I heard many other things about diabetes as well. In an attempt to discover whether there were culturally shared understandings about diabetes (a cultural content approach), I interviewed individuals diagnosed with diabetes, first using an open-ended explanatory model approach; followed by a structured interview asking about possible causes of diabetes using a "yes-no" format (designed using statements made in earlier ethnographic interviews) amenable to cultural consensus analysis (Garro, 2000). Overall, the formal analysis of the structured interview met criteria established by cultural consensus theorists for supporting the existence of shared cultural knowledge. But, using a nonparametric statistical method, I tested for and found evidence for patterned differences between younger and older participants in responses given to some of the "yes-no" questions about the causes of diabetes. In interpreting these findings, I drew on both sources of data.

Younger individuals tended to talk about their own case of diabetes in terms of over consumption, especially being overweight and over consuming sugary foods and drinks, often pointing to physicians as sources of authoritative knowledge. To the extent that diabetes was seen to run in families, it was the younger individuals who made such a link. When younger individuals made comments about diabetes as a white man's sickness, such comments tended to be apart from their own personal experiences and little elaborated beyond viewing diabetes as something relatively new and tied to changes in diet. In contrast, older individuals often concentrated on diabetes as a white man's sickness; and rather than the quantity of foodstuffs, their

comments stressed the change in quality. While the amount of sugar was mentioned by a few, by far the most common source of bodily imbalance linked to foods of today was through poisons ingested with foods, including chemicals and other substances sprayed on crops and injected into animals, as well as those added during food processing and canning. I suggested that these two tendencies in how individuals explain diabetes were linked with historically divergent life experiences (for which age is a convenient marker). The older individuals grew up during a time when diabetes was not a presence in the community and many said they could remember a time when they first learned someone had been diagnosed as having diabetes. Diabetes first appeared in the community around the same time as community members were becoming more dependent on store-bought foods and canned foods. Many noted the incongruity of diabetes running in the family with their knowledge that it is of quite recent origin.

The situation is not one where individuals are unaware of alternative framings; some of those who focused exclusively on the white man's sickness or over consumption explanatory frameworks often made comments revealing their awareness of the rejected viewpoint and reasons for their divergence from it. One can have "awareness" knowledge about a culturally available framework (at the level of content) without "living by" the construal of reality it entails. Further, what is known and remembered has significance for meeting the present and future. The younger woman who connected diabetes with the over consumption of foods high in sugar, sees limiting sugar intake as most critical. The older woman, who linked diabetes with eating canned foods, adopted the food ingredients and cooking styles of her mother, crediting this change with the remission of her diabetes.

Although I refer to this situation as one where individuals "know differently" about the causes of diabetes, I would feel uncomfortable, though, referring to individuals aligning with the white man's sickness explanatory framework as one "culture" and those who align with the overconsumption explanatory framework as another "culture" (or even two "cultural groups"), even though the differences in framing diabetes are associated with differences in what one sees as how best to deal with diabetes in everyday life contexts. At the same time I am also uncomfortable, at least in this cultural setting as well as in the study by Chavez and colleagues (2001), with using the consensus responses as representing the "average" or "ideal." In both cases, the summary findings do not do justice to an understanding of variability in the cultural setting or the "group."[3]

In closing, to quote from another paper (Garro 2005:61):

3 I do not have similar concerns about variability in earlier research carried out by myself and James Young in a community in rural Mexico in the 1970s-1980s as there was less evidence of variability in terms of "knowing differently," although some individuals, such as local healers (*curanderas*) could be said to "know more" about the domain of illness and treatment (see Garro 1986, Young and Garro 1994).

> During fieldwork in another spatially removed Anishinaabe community, where, as in the first, many are bilingual speakers of English and Anishinaabemowin, I learned that some explanatory frameworks commonly known in the first community were basically unknown, while others were found in both. A plausible explanation revolves around historical differences in the conversion efforts of missionaries, along with the virtual disappearance of practicing Anishinaabe medicine persons in the second community, but not the first. Is it the common subset of explanatory frameworks that provides a basis for asserting a shared "Anishinaabe" culture?

Although many of my writings have dealt with "intracultural variation," I have come to feel less and less comfortable with that phrase because it suggests variability can be localized within "a culture." I currently simply prefer to refer to variability in a cultural setting, or to variability present in other socially constructed groupings, attempting to illuminate, when possible, the processes leading to the observed variability.

References

Chavez, L.R., Hubbell, F.A., McMullin, J.M., Martinez, R.G., & Mishra, S.I. (1995). Structure and meaning in models of breast and cervical cancer risk factors: a comparison of perceptions among Latinas, Anglo women, and physicians. *Medical Anthropology Quarterly*, *9*(1), 40-74.

Chavez, L.R., McMullin, J.M., Mishra, S.I., & Hubbell, F.A. (2001). Beliefs matter: Cultural beliefs and the use of cervical cancer-screening tests. *American Anthropologist*, *103*(4), 1114-1129. DOI: 10.1525/aa.2001.103.4.1114

Farmer, P. (2001). *Infections and inequalities: The modern plagues.* Berkeley: University of California Press.

Garro, L.C. (2000). Remembering what one knows and the construction of the past: A comparison of cultural consensus theory and cultural schema theory. *Ethos*, *28*(3), 275-319.

Garro, L.C. (2005). "Effort after meaning" in everyday life. In C. Casey & R.B. Edgerton (Eds.), *A companion to psychological anthropology: Modernity and psychocultural change* (pp. 48-71). Malden, MA: Blackwell Publishing.

Good, M-J. D., Willen, S., Hannah, S.D., Vickery, K., & Taeseng, L. (2011). *Shattering culture: American medicine responds to cultural diversity.* York, UK: Russell Sage Foundation.

Handwerker, W.P. (2002). The construct validity of cultures: Cultural diversity, culture theory, and a method for ethnography. *American Anthropologist*, *104*(1), 106-122. DOI: 10.2307/683765

Jenks, A.C. (2011). From "lists of traits" to "open-mindedness": Emerging issues in cultural competence education. *Culture, Medicine, and Psychiatry*, *35*(2), 209-235.

Kleinman, A., & Benson, P. (2006). Anthropology in the clinic: The problem of cultural competency and how to fix it. *PLoS Med*, *3*(10), e294. DOI: 10.1371/journal.pmed.0030294

Kleinman, A. (1997). " Everything that really matters": Social suffering, subjectivity, and the remaking of human experience in a disordering world. *Harvard Theological Review*, 315-335.

Kleinman, A., & Kleinman, J. (1991). Suffering and its professional transformation: Toward an ethnography of interpersonal experience. *Culture, Medicine and Psychiatry*, *15*(3), 275-275.

Lakes, K., Lopez, S.R., & Garro, L.C. (2006). Cultural competence and psychotherapy: Applying anthropologically informed conceptions of culture. *Psychotherapy (Chic)*, *43*(4), 380-396. DOI: 10.1037/0033-3204.43.4.380

Mattingly, C., & Lawlor, M. (2001). The fragility of healing. *Ethos*, *29*(1), 30-57.

Sapir, E. (1932). Cultural anthropology and psychiatry. *Journal of Abnormal and Social Psychology*, *27*(3), 229.

Wikan, U. (1990). *Managing turbulent hearts: A Balinese formula for living.* Chicago: University of Chicago Press.

Willen, S.S., Bullon, A., & Good, M.J. (2010). Opening up a huge can of worms: reflections on a "cultural sensitivity" course for psychiatry residents. *Harvard Review of Psychiatry*, *18*(4), 247-253. DOI: 10.3109/10673229.2010.493748

Clarence C. Gravlee, PhD
Professor
Department of Anthropology
University of Florida

Reflections on Operationalizing Culture in Health Research

Challenges and Opportunities

Cognition and behavior

One of the key theoretical challenges is whether to define culture such that it encompasses only cognition or also behavior, emotions, and other phenomena. Classic anthropological definitions of culture, stretching back to Tylor, treat culture as a "complex whole" of behavior, thought, customs, and institutions. More recently, many anthropologists favor a cognitive theory of culture that follows along the lines of Geertz's "webs of significance" or Goodenough's notion of all the knowledge one needs to possess to function in society. The advantages of a cognitive theory of culture are that (a) it facilitates empirical questions about the relation between culture and behavior, and (b) it corresponds to the most productive methods developed to date for operationalizing culture as shared and distributed knowledge about how the world works.

Levels of analysis: Individual and aggregate

Most definitions of culture share a common focus on shared and socially transmitted (learned) ways of being in the world. This focus implies that culture is an aggregate-level phenomenon. But a longstanding problem in culture theory is how to link this collective dimension of culture to individual thought, behavior, and experience. This problem is particularly acute for health researchers who must be able to link culture to individual-level behaviors or health outcomes. As Dressler (2005) argues, cultural consensus theory and the construct of cultural consonance help to resolve this problem.

Culture versus social identities

In health research and clinical practice, culture is commonly treated as coterminous with social identities such as ethnicity. This usage is evident, for example, in the literature and curricula for cultural competency training in medical education. Kumaş-Tan et al. (2007) conducted a systematic review of the cultural competency literature and examined the 10 most commonly used cultural competence measures. These measures routinely equated culture with ethnicity or race and treated culture as an essential attribute of ethnic or racialized others. Similar assumptions are easy to find in biomedical and public health literatures. It is imperative to distinguish culture

from social identities; the extent to which cultural and ethnic boundaries overlap is an empirical question. Handwerker (2002) outlines a method for testing the overlap in such boundaries.

Intracultural variation

A corollary of the preceding two ideas—that culture is located at both individual and aggregate levels and that culture is not coterminous with social identities—is that culture is not uniformly distributed within a group. No individual is a perfect representative of a given culture. The fact of individual differences within a culture has been clear since the early days of anthropology (Sapir, 1932), and the study of intracultural variation has long been recognized as an important theoretical problem (Pelto & Pelto, 1975). Among the most exciting methodological developments of the last 25 years is that we now have formal methods for measuring the amount of intracultural variation within a group (Romney, Weller, & Batchelder, 1986) and for measuring variability in the cultural dimensions of individual behavior (Dressler, 2005) . Chavez et al. (2001) provide a model for studying how such intracultural variation predicts health care behavior.

Culture and social inequalities

Farmer (2001) criticizes anthropology for a myopic focus on culture and a corresponding blindness to social inequalities or structural violence. The critique also serves as a warning for how not to incorporate culture into health research. There is a danger that culture could be taken for granted as a cause of poor health, as in some recent discussions about the culture of poverty concept. I wonder, in fact, whether fear of such victim-blaming contributes to the near absence of the culture concept in social epidemiology. Again, the study by Chavez et al. (2001) is useful here. They showed that cultural beliefs predict health care behavior, but they are not the strongest predictor of whether women receive a Pap test: The strongest predictor is whether women have health insurance. Kleinman & Benson (2006) make a similar point in their critique of how cultural competency is misused in clinical medicine.

Pathways

Culture and risk allocation

Schell's (1997) model of culture as a stressor identifies risk allocation as a mechanism linking culture to health. He notes how culturally ascribed characteristics of groups and individuals (e.g., ethnicity, gender) are used to allocate resources and risks for health such as residential proximity to environmental toxins or discrimination. This is an important model because it links culture to more widely accepted models of health inequalities in social epidemiology and allied fields. Similarly, Trostle (2005) shows how the categories of people often taken for granted in epidemiology (e.g., age, race) are culturally defined. The challenge, then, is to connect the dots empirically to demonstrate how culturally ascribed identities allocate risk for poor

health. My work with colleagues on skin color, genetic ancestry, and blood pressure (Gravlee, Non, & Mulligan, 2009; Gravlee, Dressler, & Bernard, 2005) illustrates one possible approach.

Culture and the stress process

There is a rich tradition of research on culture and the stress process. Dressler's work is hugely influential here because he has elaborated—theoretically and methodologically—how the social stress process is culturally constructed. Because culture guides our interpretation of everyday experience and orients us to action, it defines what counts as a stressor and how best to respond. Dressler's recent work on cultural consonance provides a measurement model for research in this area, but the model is more generalizable than the construct of cultural consonance itself. We could likely improve the measurement of many social stressors (e.g., discrimination) by adapting the measurement model to demonstrate emic validity.

Illness, explanatory models, and health behavior

Culture shapes health and healing in part because it influences whether and how we define illness, how we experience and report symptoms, what treatments we deem appropriate, and whether we seek professional care. A classic example of this point is Margaret Lock's (1993) study of menopause in Japan, Canada, and the United States. Although female reproductive senescence is a human universal, Lock showed that it is not an invariant biological process. Culture shapes the meaning and experience of menopause, including whether women define it as a medical problem requiring self-medication or professional care. Again, the work by Chavez et al. (2001) is also useful for showing how women's explanatory models for cervical cancer predicted whether they received a Pap test. The approach may also extend to work on the cultural influences on health-related behaviors (e.g., diet, physical activity, substance use).

References

Chavez, L.R., McMullin, J.M., Mishra, S.I., & Hubbell, F.A. (2001). Beliefs matter: Cultural beliefs and the use of cervical cancer-screening tests. *American Anthropologist, 103*(4), 1114-1129. DOI: 10.1525/aa.2001.103.4.1114

Dressler, W.W. (2005). What's cultural about biocultural research? *Ethos, 33*(1), 20-45. DOI: 10.1525/eth.2005.33.1.020

Farmer, P. (2001). *Infections and inequalities: The modern plagues.* Berkeley: Univ of California Press.

Gravlee, C.C., Dressler, W.W., & Bernard, H.R. (2005). Skin color, social classification, and blood pressure in southeastern Puerto Rico. *American Journal of Public Health, 95*(12), 2191-2197. DOI: 10.2105/AJPH.2005.065615

Gravlee, C.C., Non, A.L., & Mulligan, C.J. (2009). Genetic ancestry, social classification, and racial inequalities in blood pressure in Southeastern Puerto Rico. *PLoS One, 4*(9), e6821.

Handwerker, W.P. (2002). The construct validity of cultures: Cultural diversity, culture theory, and a method for ethnography. *American Anthropologist, 104*(1), 106-122. DOI: 10.2307/683765

Kleinman, A., & Benson, P. (2006). Anthropology in the clinic: The problem of cultural competency and how to fix it. *PLoS Med, 3*(10), e294. DOI: 10.1371/journal.pmed.0030294

Kumas-Tan, Z., Beagan, B., Loppie, C., MacLeod, A., & Frank, B. (2007). Measures of cultural competence: Examining hidden assumptions. *Academic Medicine, 82*(6), 548-557.

Pelto, P.J, & Pelto, G.H. (1975). Intra-cultural diversity: Some theoretical issues. *American Ethnologist, 2*(1), 1-18.

Romney, A.K., Weller, S.C., & Batchelder, W.H. (1986). Culture as consensus: A Theory of Culture and Informant Accuracy. *American Anthropologist, 88*(2), 313-338. DOI: 10.1525/aa.1986.88.2.02a00020

Sapir, E. (1932). Cultural anthropology and psychiatry. *Journal of Abnormal and Social Psychology, 27*(3), 229.

Schell, L.M. (1997). Culture as a stressor: A revised model of biocultural interaction. *American Journal of Physical Anthropology, 102*(1), 67-77.

Trostle, J.A. (2005). *Epidemiology and culture* (Vol. 13). Cambridge: Cambridge University Press.

Peter J. Guarnaccia, Ph.D.
Institute for Health, Health Care Policy & Aging Research
Department of Human Ecology
Rutgers University

Reflections on Defining and Operationalizing Culture for Health Research

Overall Reflections

1. In defining culture, we need to find a conceptualization that is true to the complexity of anthropological formulations of culture as a dynamic dimension omnipresent in the lives of people and communities. At the same time we need to find ways to express that free of disciplinary jargon in terms that a broad audience can understand and use.

2. We need to deal with the definition of and process of stereotyping. There is a real risk of stereotyping in using culture in health research and services. We can hopefully provide some useful guidance on how to use culture effectively in health research and practice without falling into or creating stereotypes.

3. In thinking about culture in health research, we need to encourage researchers to be specific about the domains of culture that are relevant. For example, if someone is studying the impacts of culture on dietary change, then the focus should be on how to relate culture to diet. Too often, we read about comparing traditional Latino diets to American diets. Researchers need to be more careful and analytical in the use of the term “traditional.” They also need to be more specific about the Latino diets they are referring to given the great diversity of diets among and within Latino countries of origin.

4. In terms of operationalizing culture, the point above is important. I have always been impressed with Bill Dressler’s measurement of lifestyle as a key way to operationalize culture in specific contexts. He has demonstrated the power of this measure across a number of studies of diverse health conditions in diverse places.

5. There are no simple measures of acculturation and most measures of acculturation are too general to get at the phenomenon being studied. We need to disabuse researchers and funders of the idea that there are 5 easy questions or one perfect short scale to ask to get at acculturation. We need to get researchers to think of acculturation in process rather than trait terms; to appreciate the complexity of the process; and to measure it more specifically in relation to the health issues under study. I am in the middle of a study addressing these issues and will share more thoughts (though not results yet) at our

meetings.

6. We need to address the re-emergence of the "culture of poverty" construct. Too simply put, we need to make clear that culture does not cause poverty; poverty transforms and distorts culture. Lewis, in his Introduction to *La Vida: A Puerto Rican Family in the Culture of Poverty – San Juan and New York* (1965: xliv), makes clear that, "The culture of poverty is both an adaptation and reaction of the poor to their marginal position in a class-stratified, highly individualistic, capitalistic society. It represents an effort to cope with feelings of hopelessness and despair which develop from the realization of the improbability of achieving success in terms of the values and goals of the larger society." While Lewis' book is highly controversial and led to the stereotyping of Puerto Ricans, it is very clear on the direction of relationship between culture and poverty.

Definition of Culture

I provide a definition of culture below from the paper I wrote with Orlando Rodriguez in 1996. While the paper is now somewhat old, the ideas remain relevant to our discussions and to the way culture is still often used in health research:

> In order to develop culturally-competent mental health services, program planners and mental health professionals need to come to terms with what they mean by ***culture*** and how they will use culture in their services. It is our contention that previous work in the area of culturally-competent mental health services, both in the literature and in practice, has given insufficient attention to an in-depth understanding of culture. This lack of attention to culture has inhibited the full development of programs and has often resulted in an impoverished understanding of the multiple and complex interactions of culture in the development of programs.

We felt it was critical to provide an extended discussion of the concept of culture as both in our reviews of the literature and our experience in the program evaluation, we found that not enough attention had been paid to conceptualizing culture within the development of culturally-competent mental health services. The lack of this conception has led to several kinds of problems in designing culturally-competent mental health programs and in implementing them. It is not sufficient to bring together Hispanic staff with Hispanic clients and have everyone speak Spanish. Nor is it sufficient to focus on a set of generalized values and illness concepts - this approach frequently becomes stereotypical rather than being a base for program development. Careful assessment needs to be made of the multiple contexts, which shape the program, and the multiple contexts, which shape the lives of both the clients and professionals who work in them. Given this approach, the definition of culture we provide is multifaceted and is not able to be summarized in a neat paragraph.

In reviewing recent works on culturally-competent mental health, writers have often turned to earlier writings by anthropologists to present a definition of culture. In general, these definitions have reflected a static view of culture as the distinctive set of beliefs, values, morals, customs and institutions which people inherit through growing up in a culture. These definitions of culture have also focused on a "top-down" notion of culture as coming from a generalized "society" and not focused enough on the role of individual innovation and the dynamics of experience as generating culture. Mental health professionals should not be unduly criticized for the problems within anthropology of defining a core concept. More recent approaches to culture in anthropology provide a more dynamic perspective than earlier writing on this key concept and can more fully inform the development of culturally-competent mental health programs. Recent views of culture, while not discarding the importance of a person's cultural inheritance of ideas, values, feelings, ways of relating and behaviors, have focused equally on the importance of viewing culture as a process in which views and practices are dynamically affected by social transformations, social conflicts, power relationships, and migrations (Geertz, 1973; Good, 1994). More recent approaches have also focused on the emergence of culture from the daily social practices and life experiences of individuals and small groups:

> Yet, the object of analysis in anthropological enquiry is not the isolated experience of the individual, but rather those *shared local worlds of interpersonal experience* - neighborhoods, villages, social networks - where culture is enacted through processes of social interaction that organize perception, emotion, and coping responses around negotiations of what is most at stake for those involved. (Ware & Kleinman 1992:547; emphasis in original)

Culture is both a product of group values, norms and experiences and of individual innovations and life histories.

In our paper, Rodriguez and I develop several dimensions of culture which may be useful to our discussions: (1) ethnic identity; (2) language; (3) material signs and symbols; (4) events and celebrations; (5) shared values; and (6) views of mental illness. Two factors of social life further influence how ethnically derived culture shapes peoples' views and behavior: the role of different social statuses (age, gender, social class) in structuring sub-cultures within a broader cultural framework, and the processes of acculturation. We also highlighted the multiple cultures among clients, the cultures of professionals, and the cultures of institutions.

In our Conclusion to the paper we provide a more concise summary of these ideas that may also be useful to the group:

> Culture serves as the web which structures human thought, emotion, and interaction. Culture provides a variety of resources for dealing with major life changes and challenges, including serious illness and hospitalization. Culture is continuously being shaped by social processes such as migration

and acculturation. Cultures vary not only by national, regional or ethnic background, but also by age, gender and social class. Much of culture is embedded in and communicated by language; language cannot be understood or used outside of its cultural context.

It is our contention that a fuller understanding of culture can only enhance program planning, development, and implementation in the area of culturally-competent mental health services. Programs need to spend time in the developmental phases analyzing and discussing what they mean by culture, how they will use culture in their programs, and how they will continue to assess the multiple impacts of culture on the program's development. In the development of culturally-competent mental health services, program planners need to move beyond a simplistic view of culture as creating a physical atmosphere and hiring people who speak the language to incorporate in a more detailed way the multiple dimensions of culture we have outlined in this paper.

References

Lewis, O. (1966). *La vida: A Puerto Rican family in the culture of poverty–San Juan and New York.* New York: Random House.

Guarnaccia, P., & Rodriguez, O. (1996). Concepts of culture and their role in the development of culturally competent mental health services. *Hispanic Journal of Behavioral Sciences, 18,* 419-443.

Geertz, C. (1973). *The interpretation of cultures*. New York: Basic Books.

Good, B.J. (1994). *Medicine, rationality, and experience: An anthropological perspective (The 1990 Lewis Henry Morgan Lectures).* Cambridge: Cambridge University Press.

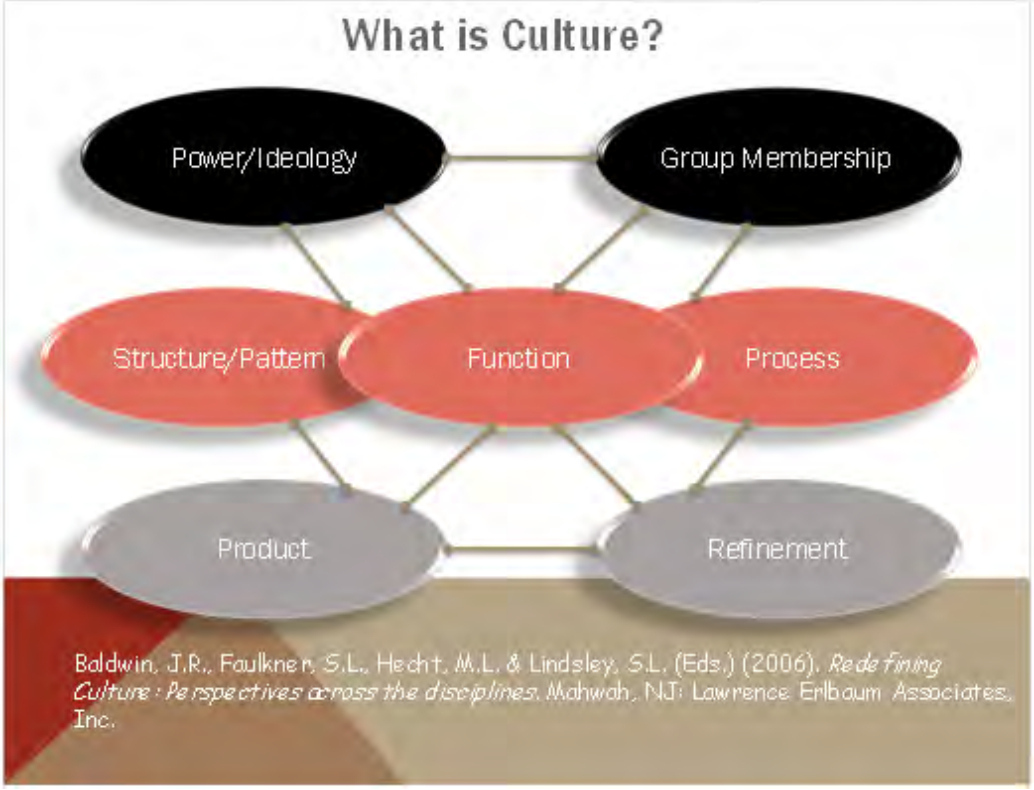
Ware, N.C. & Kleinman A. (1992). Culture and somatic experience: The social course of illness in neurasthenia and chronic fatigue syndrome. *Psychosomatic Medicine,54,* 546–560.

Michael L. Hecht, PhD
Professor
Communication Arts and Sciences
Crime, Law, and Justice
Penn State University

Reflection Paper

Scientifically define culture for application in health research.

A 7-part typology for defining culture was developed by Baldwin and colleagues (2006) who built on Kroeber and Kluckhohn's (1952) classic work, analyzing over 150 contemporary and classic definitions of culture. The system is reflected in the following diagram:



Hecht Definition: Following Philipsen (2009, 2010) I define culture as code, conversation, and communication.

- Code: systems of rules and meanings
- Conversation: style of interaction and set of practices, narratives

- Communication: sense of memberships and identities

1. **Identify the domains of culture that influence health behavior.**

Culture as product (art, music) and culture as refinement (high versus low culture) are dated definitions and will not be considered.

Structure/pattern definitions look at culture as a system or framework, including cognitive, linguistic, behavior, relationships and organizations.

Applications to health: Health care organizations/systems, belief systems, and traditional health practices

Function definitions see culture as a tool for achieving some end, including learning and adapting.

Applications to health: En/acculturation processes, learning how to be un/healthy, economics of health care system

Process definitions see culture as ongoing practices of creating meaning and creating structure

Applications to health: Make sense or interpretation of disease and treatment, relationships with providers, narratives, managing uncertainty related to disease

Power and ideological definitions emerge out of critical and culture studies and sees culture as ideology and power relations. Identities are seen as contested and reality defined through power relations.

Applications to health: politics of health care, disparities in health care, provider/patient relations, economics of health system

Identity/membership definitions emerge out of the intergroup theory approach and see culture as membership. Some would propose eliminating the term, culture, and focusing on groups and intergroup relations.

Applications to health: Health identities, disease stigma, traditional health practices, and multiple identities

2. **Specify the pathways by which these domains influence health behavior outcomes in diverse populations.**

I will use the metaphor of SEM modeling in describing potential paths.

Culture as a moderator. How different cultures react differently to interventions. Culture provides a code or “lens” for interpreting health messages. The same health message can be seen as stigmatizing to one group but inclusive to another.

Culture as a cause. How cultures themselves can be linked to health such as en/

acculturation processes that are stressors that lead to health problems.

Culture as a mediator. Refers primarily to interventions that change culture in order to impact health such as changing the organizational culture of the health care provider can lead to better care or interventions designed to build social capital and/or environmental interventions.

Culture as outcome (health changes culture)

Epidemics, natural disasters, and wars change culture.

Other Issues

Target/tailor/universal interventions, multiculturalism in interventions?

- How to take culture into account in health promotion?
- What identity or identities should we target or tailor towards?

References

Baldwin, J.R., Faulkner, S.L., & Hecht, M.L. (2006). A moving target: The illusive definition of culture. In J.R. Baldwin, S.L. Faulkner, M.L. Hecht, & S.L. Lindsley (Eds.), *Redefining culture: Perspectives across the disciplines* (pp. 3-26). Mahwah, NJ: Lawrence Erlbaum Associates.

Kroeber, A. & Kluckhohn, C. (1952) Culture: A critical review of concepts and definitions. *Papers of the Peabody Museum of American Archaeology and Ethnology, Harvard University, 47*(1), viii, 223.

Philipsen, G. (2009). Researching culture in contexts of social interaction: An ethnographic approach, a network of scholars, illustrative moves. In D. Carbaugh & P.M. Buzzanell (Eds.), *Distinctive qualities in communication research* (pp. 87-105). New York: Routledge.

Philipsen, G. (2010). *Coming to terms with cultures*. Boston: Allyn & Bacon.

Daniel Hruschka, PhD, MPH
Assistant Professor
School of Human Evolution and Social Change
Arizona State University

NIH Expert Panel on Operationalizing Culture in Health Disparities Research

Definition of Culture: Knowledge, values, skills, behaviors, and artifacts that are socially learned and transmitted.

Reflection: Humans are unique among animals in their capacity to construct their social and cultural environments and to transmit the knowledge, skills, behaviors, and artifacts necessary to maintain these diverse ways of life. The human capacity for cumulative culture was essential for 20th century achievements in improving human health, through the creation of clean water systems, workplace safety laws, nutritional safety nets, immunizations, and numerous medical technologies. Cumulative culture has also led to novel hazards as well—over-nutrition in environments of sustained dietary abundance, antibiotic-resistant infections, and mass-produced chemical compounds that can interfere with growth and metabolism.

The 20th century is clear evidence that dramatic health-relevant culture change is possible. Much work remains to understand how we can direct change in ways that both improve health and reduce disparities in health across human populations. Here I focus on four inter-related activities potentially useful for moving this agenda forward—theoretical development, formative research, measures of culture, and interventions—and outline how each relies on the other.

Theoretical development—In the last 20 years, anthropologists and social epidemiologists have pointed to the importance of political and economic factors in health, which push beyond traditional views of culture change as knowledge change. Changing culture in the service of health often requires going beyond educational models toward transforming incentives and laws and providing individuals and communities' access to effective tools and resources aimed at improving health. Theories of culture change that integrate change in knowledge, in incentives, in social organization and in resources at the individual and community-level will be likely be crucial for designing and assessing effective health interventions. A second area for theoretical development is specifying and testing potential social, cultural, and economic pathways underlying observed disparities between groups defined by language, culture, ethnicity, race, or socioeconomic status. This will help winnow the wide range of current hypotheses generated in the social sciences. I expect that careful testing and comparison of these alternative hypotheses will lead to numerous null findings. In the current state of the discipline, culling the mass of hypotheses is as important as confirming specific hypothesis, and we should encourage research

that prunes by giving equal attention to null findings.

Locally grounded formative and evaluative research—The human capacity for culture means that each human context is potentially unique with different ways of knowing and doing, and different social, behavioral, and environmental pathways contributing to health and disease. Sustained observation, interaction, and interviewing in a local context are the first steps in understanding the local mechanisms and resources potentially relevant to a given health concern. Such locally grounded research is also useful once interventions have begun so that researchers can identify both unintended consequences and opportunities for improving the intervention. Such formative research has traditionally been costly in terms of time and effort. Extending and refining emerging techniques that maximize discovery while minimizing cost and time will make these tools more accessible to a wider array of projects and interventions.

Measures of Culture—Anthropologists have traditionally relied on observation, interviews and surveys to access local ways of knowing and acting. However, there are numerous other tools in the social and behavioral sciences that can potentially inform us about culturally learned preferences, perceptions, and ways of knowing which are difficult to elicit through language or through direct observation. These include behavioral experiments to elicit behavioral preferences and response-time experiments to assess subtle cognitive biases.

Interventions—In addition to their potential role in improving health, interventions—as experiments in culture change—also play an important role in theory development. If implemented with appropriate study designs and evaluation, interventions provide rare opportunities to test theories about culture change and to assess potentially important local mechanisms identified in formative research. As cultural change involves social transmission, such designs often require treatments of communities rather than individuals. Thus, there are numerous challenges to achieving sufficient randomization, independence, and power to detect the health effects of such interventions. There are also the pervasive concerns about unintended consequences. Overcoming these concerns and challenges with novel study designs and careful attention to unintended consequences will be crucial in developing effective and safe interventions and in assessing out theories of culture change.

Roberto Lewis-Fernández, MD
Professor of Clinical Psychiatry
Columbia University
Director of the New York State (NYS) Center of Excellence for Cultural Competence, NYS Psychiatric Institute
Director, Hispanic Treatment Program, NYS Psychiatric Institute

Reflections for the Meeting on Operationalizing Culture

Health research is dominated at present by two sea-changes: By neuroscience in the areas of causes and mechanisms, and by implementation science in the area of services. (At least at the level of major funders, the quest for new therapeutics is currently subordinated to the study of causes and mechanisms.) Ostensibly, this represents an opening for cultural thinking in etiology, pathophysiology, and services research. In causes and mechanisms, this is because there is some space, at the level of theory, for including sociocultural, *environmental* processes as co-equal constructors of brain function with biological substrates (as suggested by the terms "*epi*genetics" and "gene-by-*environment* interactions"). In services, because of the possibility of acknowledging cultural factors as characteristics of target settings, systems, and populations for whom clinical practices need to tailored in order to achieve successful uptake and implementation. The fact that neuroscience and implementation science are young sciences means there may still be room to influence the direction of theory construction and research. As obviously noted by the writing and funding of the parent grant for this conference, it's a good time to be re-theorizing culture in a way that can lead to even more successful interdisciplinary collaborations.

To achieve this success, however, a contemporary theory of culture that is developed to bridge over to neuroscience and implementation science has to spend as much time describing the individual as the group. That is, it has to "filter down" from a historical, dynamic, (and inherently *structural*) group process to a set of practices, interpretations, attitudes, "commonsense", and societal positions with respect to power and agency, that can be quantified in a given *person* at a given *point in time*. This is in order to be able to interact with health-related biological research that is conducted at the individual level. This does not mean that all of social science needs to be subordinated to the priorities of biomedicine, nor that all of implementation science is pitched at the level of individuals. In services-related research, for example, there is more conceptual space for group-based theories of culture, since implementation science is more interested than neuroscience in processes at the population level (e.g., groups' access to insurance, treatment concerns common in particular underserved groups such as rejection of medications). But even in services research, in the end, when the implementation of the evidence-based practice connects with the individual user, there needs to be a method for accounting for the role of culture in individuals. And for the study

of biology-by-environment interactions, the field needs bridging constructs at every level, including at the level of organisms, including their neurocircuitry.

But can the study of culture be *individualized* in this way without fatally weakening what it can contribute to health research, which comes from a social/group perspective? I believe it can (but, again, as part of a larger social science agenda that keeps its inherent social focus). In the same way perhaps that species-wide biological processes are instantiated in specific ways in particular individuals, culture is embodied in individuals as well. We need at present a set of cultural **end phenotypes** that span the group-individual divide. The term *endophenotype* is *au courant* and has many meanings, but I intend by it a limited set of latent constructs and processes that can translate well from the group to the individual level and are constitutive of health-related mechanisms and outcomes at the brain circuit, organism, and social level. One example might be emotion regulation: sociocultural understandings of the quality of emotions, their experience, and their uses that are embodied in individuals and may affect how a person responds to particular events (e.g., traumatic exposure, vicissitudes in interpersonal relationships). These emotional responses in turn are constitutive of the way the nervous system reacts to events at the level of neurocircuitry, illness formation, and eventually response to treatment. But can factors that are active at the level of social structure (e.g., class, migration) –which depend for their conceptual force on inherently *social* arrangements of privilege and power—be explicated at the level of endophenotypes? This is a major challenge and charge to this group. We would have to spell out, at the level of the person, how social structure affects individual health-related processes (possibly through a limited set of internalized diatheses and inflection points that are instantiated in particular brain mechanisms). If we care to bridge over to biomedicine, this is one avenue for doing so. We can also work on the other direction of collaboration, partnering with the not inconsiderable number of neuroscientists who understand the value of social science. But in the end, in order to speak the same language, we need to meet at a common level of analysis: eventually we must encounter the brain, however much neuroscientists also encounter social structure and cultural interpretation.

In this respect, two current developments are worthy of note. The first is the Research Domain Criteria (RDoC) initiative at NIMH. The other is the revision of the DSM-IV Outline for Cultural Formulation (OCF) in DSM-5. RDoC is an attempt to establish a new classification system for psychopathology that is based on the identification of specific research domains and constructs that can be studied at multiple “units of analysis” (genes, circuits, behavior, etc.):

v. 3.3, 01/15/2012

DRAFT RESEARCH DOMAIN CRITERIA MATRIX

	UNITS OF ANALYSIS							
DOMAINS/CONSTRUCTS	Genes	Molecules	Cells	Circuits	Physiology	Behavior	Self-Reports	Paradigms
Negative Valence Systems								
Acute threat ("fear")								
Potential threat ("anxiety")								
Sustained threat								
Loss								
Frustrative nonreward								
Positive Valence Systems								
Approach motivation								
Initial responsiveness to reward								
Sustained responsiveness to reward								
Reward learning								
Habit								
Cognitive Systems								
Attention								
Perception								
Working memory								
Declarative memory								
Language behavior								
Cognitive (effortful) control								
Systems for Social Processes								
Facial expression identification								
Affiliation/Separation								
Self & Other								
Social dominance								
Arousal/Regulatory Systems								
Arousal & regulation (multiple)								
Resting state activity								

At present there are five domains, each with several underlying constructs (see the Figure). This novel warp and woof of psychopathology is intended to increasingly replace the categorically based DSM system as the paradigm around NIMH funding will revolve. In the future, NIMH-funded studies are expected to "cut across" DSM categories to focus on particular domains of psychopathology and experimental paradigms (e.g., fear-potentiated startle) that are conceived as underlying existing DSM disorders.

What is important for our discussion at this meeting is that RDoC also contains two other "dimensions" that are considered orthogonal to the 5 domains/constructs in the grid. These dimensions are "Development" (from conception to death) and "Environment" (from events to family to social context to "culture"). The role of these orthogonal dimensions is still quite under-developed in RDoC, and represents an opportunity to collaborate with this group in refining their classification system in a way that represents the actual complexity of biology-culture interactions.

The second development involves the operationalization of culture for clinical practice that is taking place as part of the revision of the cultural formulation for

DSM-5. The impetus for this revision comes from the extremely limited uptake and implementation of the DSM-IV OCF in usual care. The OCF included a narrative description of 5 areas that should be assessed in any clinical encounter:

1. Cultural identity
2. Cultural explanations of illness
3. Cultural factors related to psychosocial environment and levels of functioning
4. Cultural elements of the relationship between the individual and the clinician
5. Overall cultural assessment for diagnosis and care.
6. But the OCF gave very limited guidance to the clinician on how to operationalize these areas (what should I ask?), and in particular, on how to translate from a group-level description of cultural processes to an individual-level assessment (how can I assess this particular person's perspective on or experience of these areas?). To address these limitations, the DSM-5 subgroup on Culture has developed a questionnaire with 14 major questions (some with sub-questions) that operationalizes the OCF and can be asked of individual patients, usually during their initial evaluation. This Cultural Formulation Interview (CFI) is currently being field tested in 6 countries (N=330) and will be included in DSM-5 (the current draft below is still being revised). A propos of our discussion at this meeting, the CFI follows the person-centered paradigm prominent in contemporary medicine, where the focus is on the patient as an individual as opposed to a type. This mirrors the direction suggested at the beginning of this document about the need to expand group-based theories of culture into individual-focused approaches.

Cultural Formulation Interview

INSTRUCTIONS TO THE INTERVIEWER ARE IN ***ITALICS, BOLD, AND CAPITALIZED.***	
GUIDE TO INTERVIEWER: THE FOLLOWING QUESTIONS AIM TO CLARIFY KEY ASPECTS OF THE PRESENTING CLINICAL PROBLEM FROM THE PATIENT'S POINT OF VIEW, INCLUDING ITS MEANING, POTENTIAL SOURCES OF HELP, AND EXPECTATIONS FOR SERVICES.	***INTRODUCTION FOR THE PATIENT*:** I would like to understand the problems that bring you here so that I can help you more effectively. I want to know about your experience and ideas. I will ask some questions about what is going on and how you are dealing with it. There are no right or wrong answers. I just want to know your views and those of other important people in your life.
	CULTURAL DEFINITION OF THE PROBLEM
ELICIT THE PATIENT'S VIEW OF CORE PROBLEMS AND KEY CONCERNS.	1. What problems or concerns bring you to the clinic? (***IF PATIENT ONLY MENTIONS SYMPTOMS, PROBE:*** Anything else?)
FOCUS ON THE ASPECTS OF THE PROBLEM THAT MATTER MOST TO THE PATIENT.	2. What troubles you most about your problem?
ASK FOR THE PATIENT'S OWN WAY OF UNDERSTANDING THE PROBLEM.	3. People often understand their problems in their own way, which may be similar or different from how doctors explain the problem. How would you describe your problem to someone else?
THIS CAN BE A CULTURAL LABEL, A TERM IN A DIFFERENT LANGUAGE OR AN INFORMAL EXPRESSION.	3a. Sometimes people use particular words or phrases to talk about their problems. Is there a specific term or expression that describes your problem? ❑ Yes ❑ No 3b. ***IF YES:*** What is it?

USE THE TERM, EXPRESSION, OR BRIEF DESCRIPTION TO IDENTIFY THE PROBLEM IN SUBSEQUENT QUESTIONS.	***CULTURAL PERCEPTIONS OF CAUSE, CONTEXT AND SUPPORT***
THIS QUESTION INDICATES THE MEANING OF THE CONDITION FOR THE PATIENT, WHICH MAY BE RELEVANT FOR CLINICAL CARE.	***Causes*** 4. Why do you think this is happening to you? What do you think are the particular causes of your **[PROBLEM]**? ***PROMPT FURTHER IF REQUIRED:*** Some people may explain their problem as the result of bad things that happen in their life, problems with others, a physical illness, a spiritual reason, or by some other cause.
IDENTIFY STRESSORS THAT COULD BE ADDRESSED DURING TREATMENT.	***STRESSORS AND SUPPORTS*** 5. What, if anything, makes your **[PROBLEM]** worse, or makes it harder to cope with
CLARIFY IDEAS ABOUT NEGATIVE EFFECTS OF THE SOCIAL NETWORK ON THE PATIENT'S PROBLEM.	5a. IF ***DOES NOT MENTION FAMILY/SOCIAL NETWORK:*** What have your family, friends, and other people in your life done that may have made your **[PROBLEM]** worse?
LISTEN FOR COPING STRATEGIES, RESOURCES, SOCIAL SUPPORTS AND RESILIENCE.	6. What, if anything, makes your **[PROBLEM]** better, or helps you cope with it more easily?
CLARIFY HOW THE PATIENT'S FAMILY AND SOCIAL NETWORKS HELP TO COPE WITH THE PROBLEM.	6a. ***IF DOES NOT MENTION FAMILY/SOCIAL NETWORK:*** What have your family, friends, and other people in your life done that may have made your **[PROBLEM]** better?
ASK THE PATIENT TO REFLECT ON ELEMENTS OF HIS/HER CULTURAL IDENTITY THAT ARE IMPORTANT LIFE PROBLEMS.	***ROLE OF CULTURAL IDENTITY*** 7. Is there anything about your background, for example your culture, race, ethnicity, religion or geographical origin that is causing problems for you in your current life situation? ❑ Yes ❑ No *7a.* ***IF YES*****:** In what way?

ASK THE PATIENT TO REFLECT ON ELEMENTS OF HIS/HER CULTURAL IDENTITY THAT CONSTITUTE IMPORTANT SUPPORTS.	8. On the other hand, is there anything about your background that helps you to cope with your current life situation? ❑ Yes ❑ No *8a.* ***IF YES*****:** In what way?
	CULTURAL FACTORS AFFECTING TREATMENT ***SELF COPING AND PAST HELP SEEKING***
CLARIFY SELF-COPING FOR THE PROBLEM.	9. Sometimes people consider various ways of making themselves feel better. What have you done on your own to cope with your **[PROBLEM]**?
LISTEN FOR MENTAL HEALTH TREATMENT, MEDICAL CARE, SUPPORT GROUPS, WORK-BASED COUNSELING, FOLK HEALING, RELIGIOUS OR SPIRITUAL COUNSELING, OR OTHER ALTERNATIVE HEALING.	10. Often, people also look for help from other individuals, groups, or institutions to help them feel better. In the past, what kind of treatment or help from other sources have you sought for your **[PROBLEM]**?
CLARIFY THE PATIENT'S EXPERIENCE AND REGARD FOR PREVIOUS TREATMENT.	***IF SOUGHT OUTSIDE HELP*** 10a. What type of help or treatment was most useful? Why?/How?
	10b. What type of help or treatment was not useful? Why?/How?
CLARIFY THE ROLE OF SOCIAL BARRIERS TO HELP-SEEKING, ACCESS TO CARE, AND PROBLEMS ENGAGING IN PREVIOUS TREATMENT.	11. Has anything prevented you from getting the help you need-- for example, cost or lack of insurance coverage, getting time off work or family responsibilities, concern about stigma or discrimination, or lack of services that understand your language or culture? ❑ Yes ❑ No 11a. ***IF YES:*** What got in the way?
	CURRENT HELP-SEEKING

ELICIT POSSIBLE CONCERNS ABOUT THE CLINICIAN-PATIENT RELATIONSHIP, INCLUDING PERCEIVED RACISM OR CULTURAL DIFFERENCES THAT MAY UNDERMINE COMMUNICATION, GOODWILL, OR CARE DELIVERY.	***CLINICIAN-PATIENT RELATIONSHIP*** 12. Now let's talk about the help you would be getting here. Is there anything about my own background that might make it difficult for me to understand or help you with your [***PROBLEM***]? ❑ Yes ❑ No 12a. In what way?/Why not?
ADDRESS POSSIBLE BARRIERS TO CARE OR CONCERNS ABOUT THE CLINICIAN-PATIENT RELATIONSHIP RAISED PREVIOUSLY.	13. How can I and others at our clinic be most helpful for you?
CLARIFY PATIENT'S CURRENT PERCEIVED NEEDS AND EXPECTATIONS OF MENTAL HEALTH SERVICES (E.G., PSYCHOTHERAPY, SPECIFIC ADVICE, MEDICATION, REFERRAL, OR ASSISTANCE WITH DISABILITY BENEFITS).	***PREFERENCES*** 14. What kind of help would you like from us now, as specialists in mental health?
HERE THE CLINICIAN SUMMARIZES THE MAIN POINTS AND MAKES A TRANSITION TO THE REST OF THE INTERVIEW.	

J. Bryan Page, PhD
Professor and Chair
Department of Anthropology
Professor, Departments of Sociology and Psychiatry
University of Miami

Reflections on the Concept of Culture in Health Research

Growing numbers of papers in health research attempt to incorporate the concept of culture, often in ways that do considerable violence to the concept's basic aspects. The most egregious examples of these uses involve reductionist relegation of culture to a single categorical variable. The mere statement of cultural affiliation as an independent variable in quantitative analysis is especially error-prone, as the assumption that underlies categorical variables is that the categories are mutually exclusive. The current understanding of cultural identity tells us that, depending on context, people in fact may claim any of two or three cultural identities, all of which contribute to a person's behavior patterns. To force a respondent to claim his or her primary cultural identity loses valuable information about potential behavioral choices. It is far preferable to allow the respondent to claim as many cultural identities as they want and then probe to determine which values and ideas from which identities are most influential in that respondent's behavioral choices.

Use of language as a proxy for cultural affiliation has become a popular strategy for characterizing participants in health studies, and this approach has afforded somewhat more nuanced understanding of cultural affiliation than the categorical variable approach. At least by virtue of having information about respondents' language choices in defined social contexts, it is possible to gain a sense of how multiple cultural identities play out in those respondents' lives. Nevertheless, language use and cultural identity do not necessarily correlate in all cases, especially in circumstances where the individual has few speakers of his or her first language in his or her social vicinity. Therefore, even accurately reported proportions of language use in a bi- or multi-lingual circumstance may not reflect the cultural affinities of a respondent.

If we cannot use language as a criterion for identifying cultural affiliation, then what can we use? This question leads us into the labyrinth of cultural components, and given the staggering inventory of cultural stuff in any given cultural context, it becomes very difficult to choose which aspects might accurately reflect a given person's cultural identity.

Cuisine choices might be telling for one respondent but not for another. Television programming choices have been tried, but they are also influenced by such variables as availability of desirable programming and non-linguistic variables, such as desire for high production values or specific kinds of content (e.g. *novelas* or sports).

Because a cultural tradition includes huge and sometimes obscure inventories of cultural content, it may be best to have a strategy for figuring out what matters most to the people being studied. This kind of approach led Dressler to engage potential study participants in a process intended to identify key values and culturally patterned desires. The technique he used, a variant of free listing and pile sorting, has been in the anthropological repertoire for nearly a half century, but in Dressler's usage, he takes the results of his probes for key values and devises questions about the identified values in an attempt to determine the correspondence between the ideal and the actual in the lives of respondents. This approach represents an especially appealing way of assessing a respondent's current status relative to the question being studied, and it has great potential for studying questions related to health and quality of life.

Perhaps the most widely used and ill-understood concept in consideration of culture is acculturation. In its more primitive forms, acculturation is taken to mean the process in which a culturally distinct group adapts to life in a "host culture." With regard to Hispanics moving into life in the United States, the "host culture" is often glossed as "American culture." This kind of conceptualization has disadvantages: 1) it reflects an underlying assumption that both Hispanic culture and American culture are fixed entities, 2) it tends to emphasize cultural traits that are attributed to nebulous cultural entities that may have little relation to reality in specific settings, 3) it relies on parameters such as time spent in the U.S. to divide the acculturation process into stages, failing to take into account composition of the "host" populations.

Conceptualizing acculturation should begin with the assumption that both the cultural context into which immigrants move and the cultural traditions that they bring with them are moving targets. In analyzing acculturation, the emphasis should be on cultural process rather than cultural components or traits. This kind of analysis demands a rigor of discourse about culture that does not posit cultures as active entities in cultural process, but rather speaks of cultural contexts, environments, or traditions, all of which serve as arenas in which cultural process takes place. The fundamental principle of this view is that cultures do not do anything; people do things in cultural context. The behaviors that we observe and record in the course of anthropological fieldwork vary within ranges of behavior found within identified cultural contexts. If our observations show that the variant behaviors occur in different proportions at different times we may have the beginnings of a cultural process in our sights. All of the social science armamentarium can be used to pursue understanding of cultural process, from participant observation to on-line survey, but the key objective of research on cultural process is to detect and characterize how and why human behavior changes in cultural context.

Rena Pasick, DrPH, MPH
Professor
Department of Medicine
University of California, San Francisco (UCSF)
Assistant Director, Community Education and Outreach
Leader, Cancer Disparities Program
UCSF Helen Diller Family Comprehensive Cancer Center

Operationalization of Culture: Two Principles

The process of operationalizing culture is inherently and inseparably conceptual and methodological - in that relevant concepts cannot be accessed unless phenomena of interest are viewed from multiple perspectives. A second important principle calls for elucidation of the broad domains of social context in order to theorize the cultural dynamics of specific behaviors.

Culture defies simple description. With no formal training in the study of culture, my perception is based on the combination of 25+ years of work in diverse communities (Latino, African American, Chinese, Vietnamese, and Filipino) and close collaborations with colleagues in anthropology. My view of culture is that it can neither be described nor understood through the limited dimensions of structured survey questions. This conviction has been influenced by Bourdieu's *Habitus*, which helped to explain much of what I had observed over many years. *Habitus* came into focus for me in the course of research exploring the cultural appropriateness of several widely used behavioral theory constructs (intention, subjective norms, perceived benefits, perceived susceptibility, and self-efficacy - Pasick et al., 2009). Several aspects of *Habitus* resonated with my experience: first, that culture operates only partially at the level of cognition, and almost always includes important *unconscious* influences; also, that culture is contextual, dynamic, and situational. While many cultural understandings and behaviors are consistent over time and across large groups of individuals, these come under the profound influences of time, place, and admixture with other forces. Thus any longstanding or global concepts should always be re-assessed for current/local meaning and relevance.

The unconscious and highly complex nature of culture precludes elucidation directly and solely from reports by lay individuals for any but the simplest of indicators of behavior, attitudes, environment, etc. because "fish cannot describe water."

The direct assessment approach assumes that cultural frame is a form of declarative knowledge (e.g., attitudes, values, and beliefs) that respondents can report on rather than some set of more subtle and implicit practices and social structures that respondents cannot report on because these practices are deeply woven into everyday life and are a normal part of living (Oyserman, Coon, & Kemmelmeier, 2002).

Description of culture requires multiple perspectives. In our theory study, we were able to elucidate unconscious aspects of culture by blending data from in-depth interviews with three sets of informants: academics, community gatekeepers, and lay women, each tapping different dimensions. Academics discussed cultural and social patterns they had observed in their own research and personal experiences. Community gatekeepers described daily experiences serving the population of interest, Latinas and Filipinas, illustrating ways in which the cultural concepts and social concerns discussed by academics were negotiated in the realities of clients' daily lives, and women shared narratives of their experiences making health care decisions, facing discrimination inside and outside the health care system, negotiating migration and child rearing in a new country, and using local and transnational ties to address obstacles in the San Francisco Bay area. The anthropologists guided this ethnographic approach on our team.

Behavior is studied not only explicitly and directly but also broadly and indirectly to form a multifaceted understanding of the interaction between behavior and context. Exploring and synthesizing multiple dimensions in this way leads to a closer approximation of daily life, illuminating influences that are subtle, distal, dynamic, complex, innate, and beyond conscious awareness or that simply are not accessible at the level of the individual (Schweizer, 1998).

An example from our interviews, the experience of a Filipino man, illustrates how three quite different perspectives (lay patient, community gatekeeper - a public health nurse, and an academic expert on Filipino culture) come together to provide an understanding not possible from any one alone:

Patient: *He [the doctor] just told me that I needed to get that off [amputate a foot], and I don't even know him.*

Gatekeeper: *A stranger cannot convey such personal information, that it must come from someone the patient knows and trusts and must be delivered in a more caring and subtle way.*

Academic (1): *And really . . . you cannot convince the traditional Filipino that* research has shown." No, no, no. . . . Do, do you know uh, whatever her name is? You know she said that it is great.
"Oh really?" Okay, so that, it's that, it's a person that they're relating with rather than . . . the research. . . . She is not believed because of her authority, but she is believed because there was a caring relationship between the two of them and therefore whatever she says, she must say this because she cares about me, you know. So that, that, so that interpersonal.

Academic (2): *If you call it relation-ships, it essentializes. What I would say is it's relational, because it's a process, not [an] essence . . . it's about how one maneuvers life as a process. . . . It's relational in that you're not*

an individual that lives in your head, but you're an individual that lives in process with other human beings.

Academic (3): Explaining that Filipinos have many terms that express fundamental inter-connectedness, including *pakiki-pagkapwa-tao* (regard for the other person's humanity), where *kapwa* is shared identity, the sense that I and the other are one:

That kapwa, you know it's very, very deep . . . kapwa means other, literally, and loob is your inner self. So it emphasizes the relationship between myself and the others.

The patient might not be able to explain why an unfamiliar doctor should not speak to him about something as important as an amputation. However, the role of culture in this situation becomes clear when viewed within the scholars' broad frame of *relational culture* and the nurse's description of the real-life manifestation. Together, these threads weave a coherent picture of a fundamental cultural concept.

First, social context. The cultural domains involved in a given behavior are not likely to become evident from deductive inquiry explicitly addressing that behavior. In our behavioral theory study, I reluctantly agreed to pursue a course set out by the anthropology members of our team exploring inductively and broadly the daily life of Filipina and Latina women, the social context, in order to understand the meaning and relevance of the behavioral constructs in question. What was for many months a source of great anxiety for me eventually opened my eyes to the value and necessity of this approach. Indeed, the resulting data formed a multifaceted portrayal of the lives of immigrant and U.S.-born Filipina and Latina women, and created a lens through which we could examine the assumptions and intended meaning of the constructs. We defined social context as the sociocultural forces that shape people's day-to-day experiences and that directly and indirectly affect health and behavior (Burke, Joseph, Pasick, & Barker, 2009; Pasick & Burke, 2008). Three social context domains emerged clearly and consistently in the course of our wide-ranging exploration:

Relational culture: the processes of interdependence and interconnectedness among individuals and groups and the prioritization of these connections above virtually all else (Pasick et al., 2009).

Social capital, defined here as the benefits and challenges that accrue from participation in social networks and groups (Burke, Bird, et al., 2009).

Transculturation and transmigration, respectively cultural change processes and migration in which relationships are sustained across national boundaries (Joseph, Burke, Tuason, Barker, & Pasick, 2009).

Theory is necessary and desirable to see patterns that allow us to understand of

behavior. My colleagues and I found most useful and believable those concepts that operate at a high level of abstraction as illustrated by these three domains which are most likely relevant to many health behaviors in addition to mammography screening, the focus of our study.

Conclusion. Additional domains of social context should be identified through inductive multi-method inquiry to serve as a framework within which the dynamics of culture and health behavior can be understood.

References

Bourdieu, P. (1990). *The logic of practice* (R. Nice, trans.). Cambridge: Polity Press.

Burke, N.J., Bird, J.A., Clark, M.A., Rakowski, W., Guerra, C., Barker, J.C., & Pasick, R.J. (2009). Social and cultural meanings of self-efficacy. *Health Education and Behavior, 36*(5 Suppl), 111S-128S. DOI: 10.1177/1090198109338916

Burke, N.J., Joseph, G., Pasick, R.J., & Barker, J.C. (2009). Theorizing social context: rethinking behavioral theory. *Health Education and Behavior, 36*(5 Suppl), 55S-70S. DOI: 10.1177/1090198109335338

Joseph, G., Burke, N.J, Tuason, N., Barker, J.C., & Pasick, R.J. (2009). Perceived susceptibility to illness and perceived benefits of preventive care: An exploration of behavioral theory constructs in a transcultural context. *Health Education and Behavior, 36*(5 suppl), 71S-90S.

Oyserman, D., Coon, H. M., & Kemmelmeier, M. (2002). Rethinking individualism and collectivism: evaluation of theoretical assumptions and meta-analyses. *Psychological Bulletin, 128*(1), 3-72.

Pasick, R.J., & Burke, N.J. (2008). A critical review of theory in breast cancer screening promotion across cultures. *Annual Review of Public Health, 29*, 351-368.

Pasick, R.J., Burke, N.J., Barker, J.C., Joseph, G., Bird, J.A., Otero-Sabogal, R., Tuason., N., Stewart, S.L., Rakowski, W., Clark, M.A., Washington, P.K., & Guerra, C. (2009). Behavioral theory in a diverse society: Like a compass on Mars. *Health Education and Behavior, 36*(5 Suppl), 11S-35S. DOI: 10.1177/1090198109338917

Schweizer, T. (1998). Epistemology: The nature and validation of anthropological knowledge. In H. R. Bernard (Ed.), *Handbook of methods in cultural anthropology* (pp. 39-88). London: Sage.

Bernice A. Pescosolido, PhD
Distinguished Professor
Department of Sociology
Indiana University
Director, Indiana Consortium for Mental Health Services Research

Thinking About the Role of Culture in Health and Health Care: Some Initial Thoughts

The Problematic. Culture has long held a role in how socio-behavioral and public health scientists have understood the importance of the environment in health and human development. One of the classic puzzles in the sociology of health and illness, however, is the discrepancy in empirical research regarding the salience of group memberships (often thought to proxy culture), cultural beliefs and knowledge on the use of formal medical care services. That is, research has failed to show a consistent effect of culture on the uptake of formal treatment.

The Roots of Discrepancies. First, findings from qualitative and quantitative studies differ. While ethnographic research often describes how culture shapes illness behaviors, survey-based studies rarely find significant effects of beliefs or predispositions once "need" is controlled. Second, reports of the willingness/ predisposition represent a huge mismatch with actual utilization rates, reinforcing claims about the lack of utility of cultural ideologies in health care decision-making. Third, survey method as most commonly used may provide poor measurements of culture. Simply asking respondents closed-ended questions about whether or not they agree with certain values, beliefs and behaviors implies an inactive approach to measuring culture. It assumes which elements of culture permeate and dominate social life. This also makes strong cognitive assumptions -- the rejection of an idea or option commonly held in a social context takes more effort than its acceptance. This approach tends to mark what is *not* valued by an individual or social group. However, it fails to distinguish between value and indifference. Fourth, it has been suggested by sociologists since the mid-1970s that socio-demographics are poor proxies for culture and will be increasingly so. However, they continue to have use, particularly as they interact with direct measures of culture.

Some Potential Directions. There has been a reconsideration of theories of culture in the social sciences referred to as "the cultural turn." In brief, the traditional view, from anthropologists such as Geertz, defined culture as meaning and reflects only the larger cultural value put on ideas or options. In eras/places where ideas are seriously contested, this is useful. More recent conceptualizations see culture as more complex – less shared, more fragmented, and used strategically by individuals as they engage in social action. This conceptualization suggests that culture can be thought of as a resource -- individuals' store of cultural knowledge or willingness to

actually draw options from their cultural repertoire (Swidler, 1986).

Mixed method approaches may hold greater potential to get at textured and probabilistic understandings of culture and its effects on health and health care. For example, strategies that reintroduce some of the richness of qualitative approaches into survey research may better access respondent frames and tap directly into whole cultural systems.

Thinking about “cultures” in terms of networks and connections that help shape identities and beliefs, rather than socio-demographics, has also proved useful in studies that show how similar “labels” (e.g., Hispanic, Latino) produce different communities and ideologies.

References

Swidler, A. (1986). Culture in action: Symbols and strategies. *American Sociological Review, 51*(2), 273-286. DOI: citeulike-article-id:168530

Nancy Schoenberg, PhD
Associate Professor
Department of Behavioral Science
College of Medicine
University of Kentucky

Challenges and opportunities to for the use of culture in health research

Challenges: The quest to understand culture has been the pursuit of anthropologists and other social scientists for as long as the disciplines have existed. Collectively, scholars from these traditions have published seminal literature in well-established presses and journal venues, have obtained research funding on basic and applied topics, and even have been instrumental in shaping the course of our national research agenda. Yet despite this illustrious past and present, in conjunction with the growing recognition of the need to understand culture, context, diversity, race, ethnicity—all things anthropologists and other social scientists tend to be deeply involved in— health research lacks a strong anthropological imprint and oftentimes lacks a rigorous use of the culture concept.

Perhaps even more alarming, many health researchers seem to lack awareness that their use of "culture" is one-dimensional, superficial, and/or sometimes problematic (for example, using language as a stand in for culture). Our colleagues oftentimes study culture as a binary variable, while anthropologists and cultural theorists often grapple and wrestle with it as a process (Lee & Farrell, 2006).

By the same token, operationalizing culture is a herculean task that many in anthropology and other social sciences have been reluctant to address. Why? Perhaps some feel this is too complex of a task and that mapping culture cannot be done (too all consuming, too messy, and too positivistic). It is disappointing to me that many anthropologists turn their noses up at trying to develop a "usable" grasp on culture or when our biomedical colleagues make overtures to rethink their assumptions about culture, they are sometimes harshly rebuked by anthropologists or others. Rylko-Bauer, Singer, and van Willigen describe this same condemnation leveled at applied anthropologists, often justified as "supporting structures of hegemony and nothing more" (2006: 182).

Operationalizing culture may also be overlooked as researchers have followed trends of translational research, moving away from this more fundamental task and focusing instead on social problems and application. These researchers may have followed the lead of many other researchers who emphasize health inequities in a certain community, and don't necessarily look beyond broad conceptualizations of

culture, demography and epidemiology. The complexities of culture, its dynamic and fluid nature, the likelihood of multiple cultural memberships, and the anthropological quest for a holism that necessarily involves "factoring in" rather than "controlling for," leaves our fellow behavioral, social, medical, and policy scientists searching for the simple life. This search often results in throwing in the towel and just referring to OMB Directive 15, [1] standards that are used for the Census Bureau. Culture, then, becomes synonymous with ethnicity or race and those issues and behaviors that cannot be explained by access to health services, regional or gender differences are considered inexplicable or irrational are presented as "cultural factors" (Carr, 2006). At a time of increasing calls for transdisciplinary approaches, an escalation of cross-cultural and cross-national encounters, and a recognition of the importance of both culture and aging, enhanced engagement is critical.

Opportunities: Barbara Christian (1985) noted, "If Black women don't say who they are, other people will and say it badly for them." The same can be said for anthropologists and other culture theorists pertaining to the culture concept. If we are not engaging in debate and discussion with our colleagues, we lose an opportunity to turn the tide toward more robust and fluid conceptualizations of culture, race, or ethnicity (Carr, 2006). Colleagues may continue to overlook that everyone, including the unmarked category of White people, come from some "ethnic" background and that well-documented health inequities among traditionally underserved groups likely result from a broad spectrum of issues, including access to resources, life course of medical treatment/interaction, environmental exposures, etc. (Lee & Farrell, 2006). We can and should redirect efforts that aim to improve "cultural competency" away from "lists of characteristics for particular races and ethnic groups" toward recognition of the diversity, complexity, and fluidity of culture (Lee and Farrell, 2006: 9). Toward that end, this workgroup will be helpful in moving forward a robust and useful set of recommendations for researchers to operationalize culture.

Note: [1] [2] *OMB Directive 15 states: "The revised standards will have five minimum categories for data on race: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White. There will be two categories for data on ethnicity: "Hispanic or Latino" and "Not Hispanic or Latino." (http://www.whitehouse.gov/omb/fedreg/ombdir15.html)*

1) Scientifically define culture for application in health research:

Must seek to rectify: conflating SES, language, etc. with culture; limitations of cultural competence discussions; limitations of acculturation constructs; assumption of "lack of culture" among some groups; culture as risk factor orientation.

Elements that generally have been conceptualized as culture include:

- Culture being learned from birth with language and general socialization operating as vehicles.
- Cultural membership involves a set of shared patterns, practices, beliefs, orientations, and information.
- Culture is not fixed in time or space, but rather is adaptable to numerous circumstances, including natural disasters, dislocation, technological transitions, etc.
- Culture permeates everyday life and is far more important to human variation than genetics.

There is an overall appeal to imagine culture as a blueprint that guides human behavior, choices, decisions, etc. Since, however, people maintain multiple cultural memberships; it is difficult to predict strategies, attitudes, values based solely on what appears to be cultural backgrounds.

“Clusters of common concepts, emotions, practices that arise when people interact regularly.” (Brumann, 1999: S1).

The general potential of humans to share certain not genetically inherited routines of thinking, feeling, and acting with other individuals with whom they are in social contact.

2) Identify the domains of culture that influence health behavior:

Resnicow, Baranowski, Ahluwalia, and Braithwaite, (1999) propose a relatively straightforward way of conceptualizing domains of cultural influential in health behavior: Surface structure and deep structure, borrowed from sociology and linguistics. Notes that public health has been pretty successful with achieving surface structure, while deep structure is more elusive.

	Surface structure	Deep structure
Conceptualizations/ Definition as applied to interventions/public health	Matching intervention materials and messages to observable, superficial (but important) characteristics of a target group.	Requires understanding cultural, social, historical, environmental, psychological forces influencing health behavior.
	involving people, places, food, clothing, music familiar to/preferred by group	Involves surface structure PLUS...

Processes and settings	Identifying appropriate channels (e.g., media) and locations for delivery of messages. Can do “ethnic mapping”	Identify how target group perceives the cause of the health problem, the magnitude and type of stressors experienced by the groups and overall predictors of engaging in the health behavior
Interpersonal sensitivity	Involving target group-matched staff for recruitment, delivery, evaluation	Must acknowledge heterogeneity of target group too
Desired outcome	Meeting people where they are, ensuring project fits with world view and experience as analog to face validity in psychology measures	
Example: physical activity (PA)	Preferred method of PA, when, where, benefits and barriers	Exploring beliefs regarding PA, media portrayal of target group in PA, role of religion, historical backdrop.

3) Specify the pathways by which these domains influence health behavior outcomes in diverse populations:

Overall characteristics: must be holistic and contextual; comprehensive rather than essentializing; must be dynamic rather than static; must take into account cross-cultural equivalence and validity; must be capable of being tested and applied to diverse groups.

Consider: Hammond’s (1978) Seven Nested Components of Culture

1. Environment
2. Economy
3. Technology
4. Religion/World View
5. Language
6. Social Structure
7. Beliefs and Values

Can instruments be developed that incorporate these components?

4) Propose a set of recommendations to guide both researchers and funders in the conceptualization and measurement of culture.

- A consensus analysis (minimal number of shared domains) a la Romney, Weller, etc.
- Mapping cultural inventories (Roberts, 1951)
- Mixed methods designs, methodological triangulation, and member checking approaches?

References

Brumann, C. (1999). Writing for culture: Why a successful concept should not be discarded. *Current Anthropology, 40*(S1), S1-S27.

Carr, D. (2006). *Culture as diversity: Exploring culture without anthropology.* Paper presented at the Society for Applied Anthropology convention, Vancouver.

Christian, B. (1985). *Black feminist criticism: Perspectives on black women writers*: New York: Pergamon Press.

Hammond, P.B. (1978). *Cultural and social anthropology: Selected readings.* New York: Macmillan.

Lee, S.A., & Farrell, M. (2006). Is cultural competency a backdoor to racism? *Anthropology News, 47*(3), 9-10. DOI: 10.1525/an.2006.47.3.9

Resnicow, K., Baranowski, T., Ahluwalia, J.S., & Braithwaite, R.L. (1999). Cultural sensitivity in public health: Defined and demystified. *Ethnicity and Disease, 9*(1), 10-21.

Roberts, J.M. (1951). Three Navaho (sic) households: A comparative study in small group culture. *Papers of the Peabody Museum of American Archaeology and Ethnology, Harvard University, 40*(3).

Rylko-Bauer, B., Singer, M., & van Willigen, J. (2006). Reclaiming applied anthropology: Its past, present, and future. *American Anthropologist, 108*(1), 178-190. DOI: 10.1525/aa.2006.108.1.178

Bradley Stoner, MD, PhD
Associate Professor
Sociocultural, Anthropology and Infectious Diseases/Internal Medicine
Washington University Medical School, St. Louis

The Concept of Culture in Health Research: Challenges and Opportunities

These are interesting times for anthropologists and other social scientists engaged in health research, since the concept of culture looms large as an explanatory variable for a variety of health outcomes. Unfortunately, the term "culture" is used by different researchers in different ways, and is increasingly being expropriated by non-anthropologists who see this concept as a useful construct to explain differential disease rates, risk behaviors, health seeking behaviors across populations and communities. For example, "cultural competency" has gained currency in academic medical centers as a useful skill which should be taught to nurses, physicians in training, and paraprofessional staff (Kleinman & Benson, 2006). No one quite knows exactly what's meant by this term, so it risks becoming similar in concept to Justice Potter Stewart's description of pornography: Difficult to define but, "I know it when I see it" (*Jacobellis v. Ohio,* 1964). Operationalizing cultural competency is equally problematic: What does it mean to say that a healthcare provider is culturally competent? What sorts of certifications are appropriate? How do we prevent "culture," and the mastery of competency with regard to it, from deteriorating into standard cookbook approaches about "what Asians think," "what Hispanics think," "what Bosnians think" about health and wellness?

In many ways, things haven't changed that much since Ruth Benedict's (1934) time: We're still looking for that elusive way of characterizing the nature of culture, and the ways in which culture structures how we look at the world. To be sure, there is much to be gained from looking at culture as a "variable" or factor which structures health beliefs and healthcare decision-making; I trust that all of us have personal research experiences which examine how cultural attributes affect illness beliefs and illness behaviors. But I believe that if we are not careful, we risk opening our own research up to the same criticisms to which Benedict and the Culture and Personality school were subject: When "culture" is viewed as a single, simple construct it becomes essentializing, totalizing, and reductionistic.

To be sure, the concept of culture can be very helpful as a theoretical platform from which to view differences in health behaviors and health outcomes. An example from my own work in sexual health: Certain vaginal infections such as bacterial vaginosis (BV) have been shown to occur more commonly among women who engage in vaginal cleansing behaviors (e.g. douching). Standard public health recommendations for preventing BV include instructions against douching, but the

cultural foundations of douching behaviors have not been well characterized. What is the most salient analytic frame for examining this phenomenon: Race/ethnicity (more common among African Americans), age (more common among older women), or other factors such as socioeconomic status or educational attainment? Indeed, we risk essentializing culture when we assert that douching is "a part of" or embedded within African-American or Latina culture, as some authors have suggested (Mark et al., 2010; Redding et al., 2010). Do we really know this to be true, and what is actually meant by this assertion?

While health differentials may be seen across cultural groups, I agree with Wardlow that we must avoid the temptation to "etiologize" culture when such differences may reflect the result of differential access to health-sustaining resources (Wardlow, 2002). Indeed it was not that long ago that scientists widely accepted the notion that syphilis was more aggressive and more highly contagious in African Americans than whites, conflating race and culture into a single explanatory category (Reverby, 2010).

In this light, I feel it will be beneficial for anthropologists to tackle these sticky issues head-on, and try to come up with ways of operationalizing culture in health research that address the ideational and behavioral aspects of culture without reducing it to yet another parameter for inclusion on large quantitative surveys of health risks and health outcomes. This does indeed pose a challenge for social scientists seeking to translate nuanced conceptualizations of culture into usable forms for researchers in medicine and public health – to be at once broad and particular, inclusive without essentializing.

References

Benedict, R. (1934). *Patterns of culture.* Boston: Houghton Mifflin Harcourt.

Jacobellis v. Ohio, 378 U.S. 184. (1964). Retrieved 12 August 2014, http://www.law.cornell.edu/supremecourt/text/378/184#writing-USSC_CR_0378_0184_ZS

Kleinman, A., & Benson, P. (2006). Anthropology in the clinic: The problem of cultural competency and how to fix it. *PLoS Med, 3*(10), e294. DOI: 10.1371/journal.pmed.0030294

Mark, H., Sherman, S.G., Nanda, J., Chambers□Thomas, T., Barnes, M., & Rompalo, A.. (2010). Populations at risk across the lifespan: Case studies: What has changed about vaginal douching among African American mothers and daughters? *Public Health Nursing, 27*(5), 418-424.

Redding, K.S, Funkhouser, E., Garcés-Palacio, I.C., Person, S.D., Kempf, M.C., & Scarinci, I.C. (2010). Vaginal douching among Latina immigrants. *Maternal and Child Health Journal, 14*(2), 274-282.

Reverby, S.M. (2010). Invoking" Tuskegee": Problems in health disparities, genetic assumptions, and history. *Journal of Health Care for the Poor and Underserved, 21*(3), 26-34.

Wardlow, H. (2002). Giving birth to gonolia: "Culture" and sexually transmitted disease among the Huli of Papua New Guinea. *Medical Anthropology Quarterly, 16*(2), 151-175.

Laura Szalacha, Ed.D.
Associate Director, Center for Research & Scholarship
Research Associate Professor
College of Nursing
Ohio State University

Reflections on culture

Culture is the patterned process of people making sense of their worlds, the conscious and unconscious assumptions, expectations, knowledge, and practices they call on to do so. There are consistencies within cultures that are, at the same time, flexible and situationally responsive (Pasick et al., 2009; cf. Eliade, 1961, 1971).

The greatest difficulty I have in quantitative research is that culture is not static, but dynamic and variable with regard to time and location. Moreover, culture is rarely a single phenomenon – it is the interactions of cultures and interaction of individuals within and between cultures.

The second difficulty is that even though culture is a constantly forming social construction, people experience their cultural identities as essential, unchanging.

The third difficulty, not as philosophically or operationally difficult as the first two, is the reductionism of culture to mean race or ethnicity. It is reduced to a single, categorical variable. Sometimes measuring culture is limited to the language most spoken or slightly broadened to acculturation, setting two cultures as dichotomies. A false dichotomy, I suggest.

There are times when culture is the root cause of difficulties and others when culture actually protects people from difficulty. At times it is most advantageous to actually attempt to change the culture itself in order to eliminate difficulties.

We need to investigate the processes and phenomena through which cultures work to influence human health and experience in diverse populations. Culture/s influence decision-making processes, participation in research studies, perceptions of health, disease, the use of health care system(s).

Heretofore, we have measured proxies: race/ethnicity, religious affiliation/attendance, language, acculturation, and generation (immigrant, first-generation) - which themselves are, for the most part static.

A comprehensive cultural measurement would be able to test and deliver culturally appropriate interventions…illuminate culture's influence on personal thought and behavior.

A comprehensive cultural measurement could enhance community engagement in research efforts, lead to more effective recruitment into clinical trials, more precise diagnoses and treatments, and ultimately improve public health and reduce health care costs.

Joseph E. Trimble, PhD
Distinguished University Professor
Department of Psychology
Center for Cross-Cultural Research
Western Washington University

Searching for the Beguiling Snark on Chuckanut Mountain: Reflections on Theory, Operationalization, and Translation of Culture

> "The Western conception of the person as a bounded, unique, more or less integrated motivational and cognitive universe, a dynamic center of awareness, emotion, judgment, and action, organized into a distinctive whole and set contrastively -- both against other such wholes and against social and natural background -- is however incorrigible it may seem to us, a rather peculiar idea within the context of the world's cultures" (Geertz, 1973, p. 34).

The Snark and Culture

The *Snark* is an invention of the English author and storyteller, mathematician, logician, and church deacon, Lewis Carroll (1898). In a way, the *Snark* is very similar to the concept of cultural terms and concepts. There appear to be as many definitions and usages of cultural concepts as there are descriptions of Carroll's *Snark*; The *Snark* has feathers and bites, and some have whiskers and scratch and can cause any who meet it to "softly and suddenly vanish away, and never be met with again." Moreover, the *Snark* is so peculiar that it cannot be captured in any conventional way; one has to be inventive, reflective, prudent, and full of guile.

The word, *Snark*, is a *portmanteau*, a word that is the blend of two or more words, sounds or meanings. *Portmanteaus* are abundant in the English language and seem to be emerging at a more rapid pace *than ever before; consider smog, Amtrak, Comcast, Panasonic, Verizon*, *turducken*, etc.

Given all of the various definitions of culture it, too, may be a *portmanteau*. The cultural anthropologist, Clifford Geertz, reminds us in the opening quotation that the meaning of culture is elusive when reflected against what most people in numerous countries think about the construct. Put another way, how culture is construed in one ethnocultural population may be quite different in other populations suggesting that the seemingly elusive construct is not commonly understood.

Almost everyone, however, seems to know what it means yet it may be easily the most misunderstood construct in the social and behavioral sciences (see Inglis, 2004; Baldwin, Faulkner, Hecht, & Lindsley, 2006) Yet as Baldwin and colleagues (2006) state,

> This debate surrounding the usage of the term 'culture' suggests that the term is a sign, an empty vessel waiting for people, both academicians and everyday communicators to fill it with meaning. But as a sign in the traditional semiotic sense, the connection between the signifier (the word 'culture') and the signified (what it represents) shifts, making culture a moving target. (p. 29)

Lonner and Malpass (1994), for example, indicated there are about 125 definitions of culture that can be found in the social and behavioral science literature; their count is considerably more than the 79 features of culture generated by Murdock, Ford, and Hudson (1971).

Geertz's (1973) definition may provide a path that is reasonably inclusive of all of culture's elements when he maintained that it "is an historically transmitted pattern of meanings embodied in symbols, a system of inherited conceptions expressed in symbolic forms by means of which (people) communicate, perpetuate, and develop their knowledge about and attitudes towards life" (p. 89). In offering his definition, Geertz (2000) also cautiously reminds us,

> That the trouble is that no one is quite sure what culture is. Not only is it an essentially contested concept . . . it is fugitive, unsteady, encyclopedic, and normatively charged, and there are those . . . who think it vacuous altogether, or even dangerous, and would ban it from the serious discourse of serious persons. (p. 11)

Geertz (2000) added more to the murkiness of culture's meaning when he queried, "What is culture if it is not consensus?" (p. 224). While people may be able to achieve some consensus on what culture is, in general, the agreement seems to fall apart when scholars attempt to break down its meaning into some reasonably well-defined components.

Ethnic Gloss and Deep Cultural Explanations

An ethnic gloss is an overgeneralization or simplistic categorical label used to refer to ethnocultural groups such as Alaska Natives, American Indians, Asian Americans, Hispanics, African Americans, Pacific Islanders and other nationalistic or indigenous groups where unique cultural and ethnic differences found among group members are ignored (Trimble, 1995). An ethnic gloss presents the illusion of homogeneity where none exists, and therefore may be a superficial, almost vacuous, categorization that provides little or no information on the existence of numerous subgroups characterized by distinct lifeways and thoughtways (Trimble, 1991). It is a sorting device that has little to do with the richness and cultural variation within ethnocultural groups that also guides a group member's thoughts, feelings, and behaviors.

Furthermore, use of a broad ethnic gloss to describe an ethnocultural group can generate biased and flawed scientific research outcomes, and may promote

stereotypes. Such sweeping references to ethnocultural groups are gross misrepresentations, and use of an ethnic gloss can violate scientific tenets concerning external validity, the ability to generalize findings across subgroups within an ethnic category, and erode any likelihood of an accurate and efficient replication of research results.

In selecting ethnic or ethnocultural samples for social and behavioral science studies, researchers often assume that their respondents share a common understanding of their own ethnicity and nationalistic identification. It is as though the researcher believes that the individuals in the ethnic group under study share some modal characteristic that sets them apart from another comparative sample such as *whites* (Trimble, 1988). This assumption is invalid. The anthropologist Dwight Heath (1978) argues, "Categories of people such as those compared under the rubric of 'ethnic groups' are often not really meaningful units in any sociocultural sense" and "that the ways in which people define and maintain the social boundaries' between or among self-identified categories are often far more important and revealing of sociocultural dynamics" (p. 60).

The National Institutes of Health application form requires one to list the numbers of respondents or subjects one anticipates including in a proposed study. Referred to as the *Targeted/Panned Enrollment Table*, the principal investigator could include projected samples sizes for up to nine different ethnic categories ranging from Hispanic or Latino to Unknown. As constructed, the categories are ethnic glosses and thus, in an applicant's opinion, serve no purpose other than categorically, socially constructed labels.

A methodological problem arises when the investigator proposes to compare and contrast the ethnic groups listed in a proposal without giving any serious attention to the deep, rich cultural variations and similarities that exists within each group. In my 35-year history of serving on NIH study panels and review groups I have noticed that little attention has been to deep cultural comparisons following some set of carefully defined, culturally distinct, array of thoughtways and lifeways. To avoid the bias inherent in the ethnic gloss phenomena it is prudent for the investigator to define the ethnocultural group in terms that are more precise and to clarify the cultural, historical, political, and even generational diversities within the groups.

Cultural Measurement Equivalence

In cross-cultural and ethnic specific research, understanding and interpreting the influence of varying individual perspectives on psychosocial scales and standardized tests is the subject of much discussion (Irvine & Carroll, 1980; Trimble, Lonner, & Boucher, 1983; Malpass & Poortinga, 1986, van de Vijver & Leung, 1997; & Dana, 2000). Many cultural and ethnic psychologists further contend, "comparing elements from differing societies leads to inadmissible distortions of reality" (Kobben, 1970, p. 584). Comparative research, on ethnic and cultural levels, is burdened with the concerns of "incomparability." Often, due to the frequency at which a scale is used, many have assumed the metric is equal between groups (Kankaraš & Moors,

2010). These assumptions fuel findings that may be not only unjustified but also invalid. Sensitivity toward issues of cultural measurement equivalence has not been thoroughly cultivated throughout psychological discourse. By addressing these matters of cultural equivalence, inaccurate notions regarding cultural research may be dispelled.

Cultural equivalence refers "to the problem of whether, on the basis of measurements and observations, inferences in terms of some common psychological dimension can be made in different groups of subjects" (Poortinga, 1983, p. 238; see also 1989). Central to the concerns of equivalence is the fundamental precept that comparisons between ethnocultural groups require that a common, if not identical, measurement and assessment processes exist; proposed in more extreme terms, a universal process must be developed to demonstrate and assess ethnocultural group comparability.

Measurement equivalence, specifically, is a rather diverse concept with over 50 terms captured under its breadth (Johnson, 2006). In relation to analysis of cross-cultural measurement equivalence, researchers typically agree upon the following five primary concepts: functional, conceptual, stimulus, linguistic, and metric equivalence. These five items and their relation to cultural concerns should be considered guidelines for evaluating cultural measurement equivalence.

In constructing and using psychological instruments and assessment tools in cultural comparative or cultural-sensitive research, the investigator must give serious attention to matters of equivalence. The instrument's content, format, and metric style must be congruent with and comparable across the cultural groups selected for study. Researchers must provide hard evidence that the components of the measurement process meet the standards of functional, conceptual, metric, linguistic, and stimulus equivalence.

Summary and Conclusions

The inconsistencies, incongruities, and confusion in the field should not deter or dissuade the scholar and scientist from conducting further inquiry into the topic. Quite the contrary, the field is in desperate need of structure and order. To accomplish orderliness and structure, scholars and practitioners are challenged and encouraged to probe deeper into the topic to sort out and smooth over the discrepancies and incongruities.

A good staging point for an inquiry is the emergence of a multiracial or multiethnic classification category. What deep or surface cultural attributes will a multiethnic category permit? If researchers and practitioners are interested in discovering deep cultural or ethnic contributions to a personality style, for example, how will the contributions be disentangled from one's multiethnic worldview or orientation? As we scholars probe deeper into the structure and meaning of ethnic identity, according to Devereux (1996) we must be mindful of the proposition that "identity is the absolute uniqueness of the individual" (p. 385) and that it "must be enunciable and enunciated by a self-ethnographer" (p. 391).

References

Baldwin, J.R., Faulkner, S.L., Hecht, M.L., & Lindsley, S.L. (Eds.), *Redefining culture: Perspectives across the disciplines* (pp. 3-26). Mahwah, NJ: Lawrence Erlbaum Associates.

Carroll, L. (1898). *The hunting of the snark: An agony, in eight fits.* New York: The Macmillan Company.

Dana, R.H. (2000). Culture and methodology in personality assessment. In I. Cuellar & F. Paniagua (Eds.), *Handbook of multicultural mental health: Assessment and treatment of diverse groups* (pp. 97-120). San Diego, CA: Academic Press.

Dana, R.H. (2000). Multicultural assessment of adolescent and child personality and psychopathology. In A.L. Comunian & U.P. Gielen (Eds.), *Human development in international perspective* (pp. 233-258). Lengerich, Germany: Pabst Science Publishers.

Dana, R.H. (2000). Psychological assessment in diagnosis and treatment of ethnic group members. In J.A. Aponte & J. Wohl (Eds.). *Psychological interventions and cultural diversity.* (2nd ed., pp. 59-74). Boston: Allyn & Bacon.

Devereux, G. (1996). *Mojave ethnopsychiatry and suicide: The psychic disturbances of an Indian tribe.* Washington: Smithsonian Institution Press.

Geertz, C. (1973). *The interpretation of cultures*. New York: Basic Books.

Geertz, C. (2000). Thinking as a moral act: Ethical dimensions of anthropological fieldwork in the new states. In C. Geertz (Ed.), *Available light: Anthropological reflections on philosophical topics* (pp. 21-41). Princeton: Princeton University Press.

Heath, D. B. (1978). The sociocultural model of alcohol use: Problems and prospects. *Journal of Operational Psychiatry, 9,* 55-66.

Inglis, F. (2004). *Culture.* New York: Wiley.

Irvine, S.H. & Carroll, W.K. (1980). Testing and assessment across cultures: Issues in methodology and theory. In H.C. Triandis & J.W. Berry (Eds.), *Handbook of cross-cultural psychology, Vol. 2.* Boston: Allyn and Bacon.

Johnson, T.P. (2006). Methods and frameworks for cross-cultural measurement. *Medical Care, 44,* S17-S20.

Kankaraš, M. & Moors, G. (2010). Researching measurement equivalence in cross-cultural studies. *Psihologija, 43*(2), 121-136.

Köbben, A.J.F. (1970). Comparativists and non-comparativists in anthropology. In R. Naroll & R. Cohen (Eds.), *A handbook of method in cultural anthropology* (pp. 581-596). New York: Columbia University Press.

Lonner, W.J. & Malpass, R.S. (1994). *Psychology and culture.* Needham Heights, MA: Allyn and Bacon.

Malpass, R.S. & Poortinga, Y.H. (1986). Strategies for design and analysis. In W.J. Lonner & J.W. Berry (Eds.), *Field methods in cross-cultural research* (pp. 47-83). Beverly Hills, CA: Sage.

Murdock, G.P., Ford, C.S., & Hudson, A.E. (1971). *Outline of cultural materials* (4th ed.). New Haven: Human Relations Area Files.

Poortinga, Y.H. (1983). Psychometric approaches to intergroup comparison: The problem of equivalence. In S.H. Irvine & J.W. Berry (Eds.), *Human assessment and cultural factors* (p. 238). New York: Plenum.

Poortinga, Y.H. (1989). Equivalence of cross-cultural data: An overview of basic issues. *International Journal of Psychology, 24,* 737-756.

Trimble, J.E. (1988). Multilinearity of acculturation: Person-situation interactions. In D. Keats, D. Munro, & L. Mann (Eds.), *Heterogeneity in cross-cultural psychology* (pp. 173-186). Berwyn, PA: Swets & Zeitlinger.

Trimble, J.E. (1991). Ethnic specification, validation prospects, and the future of drug use research. *International Journal of the Addictions, 25*(2A), 149-170.

Trimble, J.E. (1995). Toward an understanding of ethnicity and ethnic identity and their relationship

with drug use research. In G. Botvin, S. Schinke, & M.A. Orlandi (Eds.), *Drug abuse prevention with multiethnic youth* (pp. 3-27). Thousand Oaks, CA: Sage.

Trimble, J.E., Lonner, W.J., & Boucher, J.D. (1983). Stalking the wily emic: Alternatives to cross-cultural measurement. In S.H. Irvine & J.W. Berry (Eds.), *Human assessment and cultural factors.* New York: Plenum.

Van de Vijver, F. & Leung, K. (1997). *Methods and data analysis for cross-cultural research.* Thousand Oaks, CA: Sage.

Thomas S. Weisner, PhD
Professor
Departments of Anthropology and Psychiatry
Director, Center for Culture and Health
University of California, Los Angeles

Reflections notes (on theory, operationalization, and translation) for NIH Panel on Operationalizing Culture for Health Behavior and Social Science Research

It is apparent today as has always been true, that there are multiple definitions of culture, that many are relevant to health research, and that there is no single consensus definition in the field today. Rather than a single definition, it could be useful for our panel to establish a set of key concepts and indicators that would be important to include in any definition, would be an important focus of measurement, and valuable for translational research in health. Three such keys could be:

1. Widely shared and accepted scripts and norms for behavior and thought in the context of important settings and activities

2. Cultural models of the person; what is good; what are the shared (or at least widely recognized) beliefs about the nature of the sources, causes and consequences of health

3. Experiences and their meanings common in a community regarding disease, illness, health, wellness, and the body

A study that included these key concepts, with the measures and descriptions for them integrated together, would provide a useful, scientifically sound cultural account.

The cultural learning environment (CLE) as a conceptual framework, described in the papers contributed to the group paper potlatch, can be a useful place to start from for culture theory and how and what to operationalize for health research. CLE studies are oriented towards human development topics, but are not limited to those topics. A recent paper by Carol Worthman (2010) reviews several of these models related to health. They all share some common concepts, analytical units, and a fairly inclusive understanding of what culture is and how it directs our behavior and thought:

- Culture is found in the everyday settings (activities, contexts, events, practices) we live within and engage with: bedtime, getting ready for school; visiting your cousins; helping plan, prepare and cook dinner; going to Sunday school; doing homework; getting a checkup; hanging out with friends….; activities are an important unit of analysis for seeing and measuring culture because this is where

it is experienced and lived; context is bracketed in, not bracketed out;

- Settings and activities have common attributes that organize our behavior and thought in them. Those characteristics include,
  - ◊ resources and material objects available;
  - ◊ values and goals that provide the purposes and endpoints for actions;
  - ◊ scripts and norms ("customs" or "beliefs" or an "ethnopsychology") that provide guides for the ways to act in that setting;
  - ◊ emotions, motives and feelings brought to the setting and created by it;
  - ◊ people and the social relationships among those people; and,
  - ◊ the stability, predictability and familiarity of that setting.

  While we would not know everything –we would know a great deal about the cultural world of a person or community if we understood and measured the key activities and settings, and these six characteristics of those settings; these features drive our behavior and thought in cultural contexts and so influence health behavior; bracketing in context for measurement of culture does not mean description is unfocused and unconstrained; it is delimited by assessing these characteristics;

- The activities and settings of a community are organized into a daily routine of life and are linked together into community ways of life; culture creates pathways through development using these linked activities and routines; activities and settings are the stepping stones making up those cultural pathways; difference in cultural pathways influence health behaviors and outcomes;
- Activities and settings are influenced by the wider cultural ecology (demography, ecology, subsistence system, institutions, community safety and threats, heterogeneity of ways of life, and others);
- It is an empirical question, which should ideally be assessed, as to the extent culture is shared; **a cultural analysis <u>predicts</u> diversity, and both internal and social conflicts and ambivalence – cultural analysis is not about only finding homogeneity**; some heterogeneity is not an indication of the absence of shared culture if there are patterns and common shared beliefs and activities as well;
- Our deep proclivity to learn from our environment throughout life in a shared group context is an evolved capacity; we are prepared to be "cultural acquisition devices" (CAD) from before birth (Konner, 2011); endogenous factors influence how we acquire, store, and transmit cultural knowledge; there is a core psychic

unity across all mankind, but this does not mean that there are not individual differences in CAD competence and tendencies; hence "**bioecocultural" mechanisms and models predict health outcomes, not culture alone**; it can be analytically useful to separate culture from our CAD, but for studying health, these are most always interdependent;

- Cultural transmission is bidirectional and selective (Schönpflug, 2009); much learning occurs without verbal instruction but rather though mimicry, imitation, play, rehearsal and practice, apprenticeship, and observational learning; hence **the perception, acquisition, storage in memory, recall, patterning in the mind, and ways of expressing and teaching culture is an essential aspect of how we define, measure, and describe the impacts of culture for health outcomes**;

- The ways cultural knowledge is transmitted is a key component for understanding cultural influences on health, because learning and transmission of cultural knowledge always can transform that knowledge; **there is intentional design and change built into cultural practices;**

- There are strong methods for assessing each component of activity settings, the cultural learning environment, cultural ecology, and some of the biological markers and mental processes, and there are methods for assessing the extent of shared culture; however, it is fair to say that there is currently no or low consensus, in Anthropology at least, concerning which of these methods should be used for these components and for which types of samples; it is important, however, that **integrating quantitative and qualitative evidence – mixed methods – is the goal for the future and should be invested in and encouraged to assess culture and health**.

Components of activities and behavior settings in cultural learning environments are not static; but this static view often leads to culture being viewed as a barrier to positive changes in health beliefs and behaviors; **cultural beliefs and behaviors, measured within the activity settings and daily routines in which they are directing behavior and thought, clearly can discover levers for effective interventions and change to improve health**. Translational research on health can utilize them for positive outcomes, not only get around them as barriers to wellbeing. More strongly: unless good ideas for health are finding a place in daily routines and activity settings (in organizations, groups, families, individuals) such that new beliefs and behaviors take hold, good ideas and interventions will not diffuse, or be able to scale up. The world is unfortunately filled with such proven good ideas for health and wellness that have not found a place in cultural settings.

There are multiple pathways from culture, which influence health outcomes. An important pathway, though not the only one, is from ecological context to everyday routines and activities, then to the specific features of those activities (including conceptions of health and wellness), and then to health and wellbeing outcomes.

There are many recommendations our group can make. Among possible recommendations:

Research using global social address categories, or ethnic, racial, or other group labels as proxies for “cultural” influences on health (Sub-Saharan Africa; United States middle class; Latinos; Native Hawaiians; Japanese; the Abaluyia of Kenya), should include measures that clearly show which specific cultural features about that group (in activity and behavior setting contexts) are shared, and why those characteristics differ within and between groups, and then how those characteristics specifically influence health.

Cultural concepts, measures and analyses can and s**hould be able to address descriptive, process, functional, outcome and causal questions regarding health** – not only one or two of these (e.g. descriptive only; or processes only). Mixed methods should be much more widely used.

Put more strongly, for example, going forward, no (larger scale) survey or questionnaire – based study (perhaps also social neuroscience, biological or other studies in a community) should be funded without a nested design that includes an ethnographic and/or qualitative subsample. For that nested subsample, specific measures of culture and context would be collected, linked to the larger survey/ questionnaire or biomedical sample. For that nested subsample, the activity setting features would be measured using integrated qualitative and quantitative mixed methods (e.g., scripts and norms, resources and how they are deployed, values/ goals, people and relationship processes; motives, emotions, feelings, and the stability and predictability of those key activities).

References

Konner, M.. (2010). *The evolution of childhood: Relationships, emotion, mind*. Cambridge, MA: Harvard University Press.

Schönpflug, U. (2009). *Cultural transmission. Psychological, developmental, social, and methodological aspects*. New York: Cambridge University Press.

Worthman, C. (2010). The ecology of human development: Evolving models for cultural psychology. *Journal of Cross-Cultural Psychology* 2010 41: 546.

Appendix D:

Table 1.1 (Unabridged) – Scientific Challenges Posed by the Current Use of Culture in Research

CONCEPTUALIZATION

1. **The concept of culture is inadequately conceptualized and inconsistently applied**: "No other variable used in health research is so poorly defined and untested as "culture" (Dressler, Oths, & Gravlee, 2005; Oppenheimer, 2001). Not surprisingly, then, outcomes of studies involving diverse populations (and even assumed homogenous European American white study samples) often produce contradictory and inconclusive findings. Intra-group variations by age, geography, income, gender, and sub-population distinctions may not be adequately accounted for in sampling within the larger, aggregate racial/ethnic groups (Office of Management and Budget, 1997). Due to the likely heterogeneity of different sampling strategies across studies, the comparability of findings from such studies is questionable. Readers cannot know the how the participants for the study sample were identified, how the selection criteria and recruitment strategies were established, or how the respondents themselves identified, and therefore, who the samples actually represent of the larger population of interest. Such large generalizations are usually not precise enough to identify the most salient elements to include in intervention designs for particular populations.

2. **Few studies demonstrate how culture affects health outcomes with clear definitions, measurable constructs, and conceptual models that indicate the interactions of the cultural processes.** Culture is essential for humans to exist as social animals and is the means by which coordination and cooperation amongst its members is achieved. Geertz noted: "There is no such thing as human nature independent from culture…our central nervous system…grew up in great part in interaction with culture" (Geertz, 1973). Despite the recognition that culture is fundamental to human existence and provides meaning for life, surprisingly little focus exists on the effective use of culture in health research. Moreover, no standards have been developed to guide the integration or application of this concept in health science.

However, among the multitude of definitions that exist, two common facets of culture emerge. First is the differentiation between what culture *is* and what culture *does*,

and second is how the science of health behavior promotes or inhibits the integration of culture in research.

A. What Culture *Is*:

*Culture is a shared ecologic schema or framework that refracts the lens through which its members "see" reality and, in which both the individual and collective group experiences the world. This framework is created, maintained or changed, through interactions with the cognitive, emotional interpersonal processes as well as the material resources and constraints of its ecologic system.

B. What Culture *Does*:

This cultural schema or framework underlies the pan-human processes that assure its members' survival and wellbeing. Each of us uses this cultural framework to interpret the world in which we live through beliefs, attitudes, and practices. Spiritual, moral, and emotional explanations are used to create and codify our worldview in the social institutions and norms of ways of being. Together, these cultural "tools" enable group members to make sense of their world and to find meaning in and for life by providing a sense of safety and well-being, a sense of integrity of living one's life well, and a sense of being a contributing member of one's social network (Kagawa-Singer, Valdez-Dadia, Yu, & Surbone, 2010).

3. Problems of diverse cultural groups are defined are identified, but devoid of their historical, geographic, social, and political contexts, and the influence of such contextual factors on their positions in the societal power hierarchy. The fact that the dominant U.S. society has always been composed of multiple cultures is often overlooked, particularly through the historically-, socially-, and politically-created power structure. The power structure has shaped the circumstances in which other cultural groups must live (such as the poor, groups of color, women, those of different sexual identity, the disabled, and the aged). For example, social institutions, like the health care system, are designed with the beliefs of individuality and values of life and social rules of interaction of the dominant society (Hartigan, 2010). Other cultural groups often have beliefs and values that are not congruent with the dominant society. Such dissonance is often at the basis of cross-cultural miscommunication between clinicians, patients, and families in discordant encounters that may lead to compromised quality of communication of health information (Smedley, Stith, & Nelson, 2003), or in research studies using theories with concepts that have not been tested for cross-cultural equivalence (Pasick et al., 2009; Smedley et al., 2003; Trimble, 2012).

4. The dynamic nature of culture is not reflected in most studies. Cultural groups are connected by a network of interacting parts that function as a living system in response to changing internal or external stimuli. The quest to capture the complex and dynamic adaptive systemic nature of culture necessarily involves statistically "factoring in" multiple variables simultaneously. Thus, many behavioral,

social, medical, and policy researchers consider the field of cultural research is not amenable to “rigorous” scientific focus. As a default strategy, other demographic indicators are used and assumed to be more universally applicable, such as race and ethnicity, income or education, language or place of birth. However, such practice is the source of much of the conundrum in using “culture” as an explanatory variable. These static demographic measures do not capture the complexity and dynamic nature of culture and thus how cultural processes impact the health outcome of interest.

5. The role of culture in shaping the nature and conduct of health research is lacking. Too often, studies that attempt to address health disparities continue to use theories of health and behavior that have been generated and standardized by European descent non-Hispanic white Americans, and studies of diverse populations continue to use the European descent white Americans as the group to which all others are compared, despite better heath statuses of other groups. Implicitly, European heritage white Americans are the cultural group against which all others are evaluated as the ‘Gold Standard’ of health. The validity of either assumption has yet to be demonstrated. It would seem that, at a scientific minimum, the cultural equivalence of measures should first be demonstrated before they are applied to “new” groups of focus, and second, the population group with the best health outcomes might be the population against which others are compared. The lack of recognition of fundamental differences and potential assets of diverse human population groups continues to thwart many efforts to move the science of health behavior forward.

6. The assumed universality of the dominant culture’s construction of reality and salient domains, such as selfhood, family, fairness, and well-being, is problematic. The majority of social and behavioral science researchers are primarily of middle class European white heritage. Most of the theories that were developed by Western scientists to predict and explain behavior have been developed and tested with primarily European-descent white Americans. These theories are often assumed to be universally valid across diverse groups. Studies in health on “cultural differences” among diverse populations tend to use the same template upon which the behavioral and social science theories have been built. Operationalization is still often limited to adding exotic or stereotypical characteristics of non-middle class European white heritage. These perspectives and practices are also reflected in many current measures, such as acculturation, race, culture, and ethnicity that are “efficient” but are actually stereotypical glosses, insufficient, and even invalid in many cultural groups (Heinrich, et al 2010).

OPERATIONALZATION

7. The current practice of using nominal, dichotomous variables of race and/ or ethnicity and/or ancestry to represent culture is simplistic and inadequate. The lack of consensus on definitions for the constructs of culture, race, and ethnicity among health researchers impedes our efforts to gain a better understanding of health behavior among multicultural populations (LaVeist, 1994; Williams, 1997).

The concepts of race and ethnicity are not synonymous with culture. Each denotes different social and geopolitical constructs. Their influence on health is also distinct. Socially, however, conflation of these terms often results in stereotypes that become reflected, for example, in the lack of rigor in differentiating these groupings in sampling strategies. Moreover, the focus on racial or ethnic groups confuses culture with these more static concepts and stereotypically views them as homogeneous. Culture is a process of negotiating meanings and structures, and this fundamental aspect is lost when these concepts are used interchangeably.

In 2003 the International Committee of Medical Journal Editors recognized the confusion over the concept of race, and established guidelines for publication of studies that purported to study disease variations among multiple racial groups (International Committee of Medical Journal Editors (ICMJE), 2003). Although the committee seems to conflate race with culture, their strategy recommends instituting policies that require researchers to clarify what they mean by race (International Committee of Medical Journal Editors (ICMJE), 2010). They recommended that authors be required to provide explicit statements about how they measured these variables and justify their relevance. The effort by the International Committee is an important beginning to disentangle and define use of the term race, but the effort falls short of challenging the validity of the actual use of the term “race,” which has no scientific basis (Collins, 2004).

8. **The heterogeneity within the group of focus should be explicit and demonstrated in the description of the study sample.** Cultural groups are frequently treated as homogeneous entities. Ethnic glosses are gross misrepresentations of population groups. Their use violates the principles of external validity and fosters stereotyping that tends to be misleading. Simplistic definitions that measure a list of traits or characteristics as “aspects of culture” also erroneously assume universality of beliefs and behaviors within ethnic groups. Characteristics often measured as evidence of culture are: religious beliefs, health seeking behaviors, language skills, spiritual practices, locus of control, social structure, family structure and dynamics, dietary and food preparation practices, trust in medical professionals/health care organizations, trust in research, or expectations and desires surrounding death and dying. Many are domains that exist in each culture, but vast variations often exist within each cultural group and likely hides subgroups with better or worse health outcomes. Sometimes such gross measures do identify differences, but three explanations may exist. First, the differences are powerful enough to override intragroup differences and should be noted. Secondly, the differences may actually not be what they seem due to misinterpretation of the

concept itself. The third explanation is that no apparent difference may be found, but it may be the measures themselves that are not applicable. All three possibilities should be tested to determine if subgroups exist and identifying the modes and distribution of risk and protective factors within each population is needed to inform sampling strategies of identified cultural subgroups.

Acculturation is often thought to be the solution to assess such within group variation, but the concept is flawed. The concept assumes cultural groups are discrete, and that the boundaries between the culture one is acculturating from and to are clearly defined (Hunt, 2004). Historical, politically motivated efforts by the federal government to "acculturate" indigenous peoples in the contiguous States as well as Hawaii and the Pacific Islands under Federal jurisdiction to the culture of the dominant upper class European American culture illustrate the devastating failures and unethical practices that persist across generations. American Indians, Alaska Natives and Native Hawaiians, once sovereign in their lands, now have the worst health outcomes of any group in the U.S. Such structural and social factors, such as historical trauma, are rarely factored into studies of current "cultural" practices of these population groups.

9. The biomedical and behavioral sciences have focused primarily on the individual without accounting for the influence of the social, historical, political and environmental context of the group(s) to which s/he belongs. The individual is the locus of cultural expression, but culture is a group phenomenon. Enculturation to one's own culture occurs by gaining the knowledge necessary to function acceptably in that society. No individual knows all cultural knowledge well; thus, individuals will vary in how much of their culture they enact or know depending upon their individual circumstances. Methodologically, in order to find the group norms - i.e. the range and means or modes of factors that underlie particular behaviors - the researcher would most likely have to ask and observe the behavior of individuals over time. See Section III: ***Revising, Extending and Improving the Operationalization of Culture*** for specific explanations on how this is accomplished. Overemphasis on behavioral understandings of culture at an individual level diverts attention away from social conditions, privileged material distribution, and power differentials that underlie health inequalities and reinforce a depoliticized understanding of cultural difference (Jenks, 2011).

HEALTH DISPARITIES

10. The challenges listed in #1-9 contribute to the inability to effectively reduce health disparities. Syme noted that despite the focused attention on the inequities of health outcomes in more than 40 years, little progress has been made to eliminate the undue burden of disease borne by diverse communities in the United States (Syme, 2008). The previous 9 challenges listed all obstruct the research of diverse population groups and compromise the science of health disparities.

For example, new immigrants, isolated rural populations or the very poor are often inclined to wait until they are very sick to seek care because have not had

easy access to preventive care or feel they've been treated disrespectfully when they have tried (Institute of Medicine, 2002b). Their rationale for this necessity is drawn from cultural ways of coping with untenable circumstances. Such behavior is often glossed as "fatalistic," but the precipitating factors are often structural, current or historic, due to discrimination or bias, or due to a lack of knowledge about the recommended care or lack of familiarity with the newer techniques, such as mammograms (Pourat, Kagawa-Singer, Breen, & Sripipatana, 2010) or diabetes management (Mull, Nguyen, & Mull, 2001; Villarruel, Harlow, Lopez, & Sowers, 2002). The source of the dissonance may also lie with the practitioners trained in the culture that created the institutions rather than those of the constituents it is supposed to serve.

This "deficit model" of culture as a risk factor itself and its reification as merely singular beliefs and values has led, disappointingly, to its incorporation into the naturalist epistemology of Western institutional medicine. The unfortunate consequence of this perspective is the medicalization of culture understood as "difference" (Institute of Medicine, 2002a), which is often a gloss for social issues such as social class (ibid, p.436), historical discrimination or differential access to resources that could promote health. Adoption of *The Cultural Framework for Health* presented in this report would likely make a significant difference in identifying factors that would effectively, efficiently, eliminate these disparities.

References for Appendix D

Collins, F.S. (2004). What we do and don't know about 'race', 'ethnicity', genetics and health at the dawn of the genome era. *Nature Genetics, 36,* S13-S15.

Dressler, W.W., Oths, K.S, & Gravlee, C.C. (2005). Race and ethnicity in public health research: models to explain health disparities. *Annual Review of Anthropology, 34*(1), 231.

Geertz, C. (1973). *The interpretation of cultures*. New York: Basic Books.

Hartigan, J. (2010). *Race in the 21st Century: Ethnographic approaches*. Oxford: Oxford University Press.

Hunt, L.M., Schneider S., Comer B. (2004). Should "acculturation" be a variable in health research? A critical review of research on U.S. Hispanics. *Social Science and Medicine, 59*(5), 973-986.

Institute of Medicine. (2002a). Examining Unequal Treatment in American Health Care. 768.

Institute of Medicine. (2002b). *Unequal treatment: Confronting racial and ethnic disparities in health care*. Washington: National Academies Press. Retrieved July 22, 2007, from http://www.iom.edu/?id=16740

International Committee of Medical Journal Editors (ICMJE). (2003). Selection and description of participants in Uniform requirements for manuscripts submitted to biomedical journals: writing and editing for biomedical publication.

International Committee of Medical Journal Editors (ICMJE). (2010). Selection and Description of Participants (Section IV.A.6.a.).

Jenks, A.C. (2011). From "lists of traits" to "open-mindedness": Emerging issues in cultural competence education. *Culture, Medicine, and Psychiatry, 35*(2), 209-235.

Kagawa-Singer, M., Valdez-Dadia, A., Yu, M.C., & Surbone, A. (2010). Cancer, culture, and health disparities: time to chart a new course? *CA: A Cancer Journal for Clinicians, 60*(1), 12-39.

LaVeist, T.A. (1994). Beyond dummy variables and sample selection: what health services researchers ought to know about race as a variable. *Health Services Research, 29*(1), 1-16.

Mull, D.S., Nguyen, N., & Mull, J.D. (2001). Vietnamese diabetic patients and their physicians: What ethnography can teach us. *Western Journal of Medicine, 175*(5), 307.

Office of Management and Budget. (1997). Revision to the Standards for the Classification of Federal Data on Race and Ethnicity.

Oppenheimer, Gerald M. (2001). Paradigm lost: Race, ethnicity, and the search for a new population taxonomy. *American Journal of Public Health, 91*(7), 1049.

Pasick, R.J., Burke, N.J., Barker, J.C., Joseph, G., Bird, J.A., Otero-Sabogal, R., Tuason., N., Stewart, S.L., Rakowski, W., Clark, M.A., Washington, P.K., & Guerra, C. (2009). Behavioral theory in a diverse society: Like a compass on Mars. *Health Education and Behavior, 36*(5 Suppl), 11S-35S. DOI: 10.1177/1090198109338917

Pourat, N., Kagawa-Singer, M., Breen, N., & Sripipatana, A. (2010). Access versus acculturation: Identifying modifiable factors to promote cancer screening among Asian American women. *Medical Care, 48*(12), 1088-1096. DOI: 10.1097/MLR.0b013e3181f53542

Syme, S.L. (2008). Reducing racial and social-class inequalities in health: the need for a new approach. *Health Affairs (Millwood), 27*(2), 456-459.

Trimble, J.E. (2012). Ethno-measurement and ethno-scaling obstacles in community based research with indigenous populations. *Global Journal of Community Psychology Practice, 2*(3).

Villarruel, A. M., Harlow, S. D., Lopez, M., & Sowers, M. (2002). El cambio de vida: Conceptualizations of menopause and midlife among urban Latina women. *Research and Theory for Nursing Practice, 16*(2), 91-102.

Williams, D.R. (1997). Race and health: Basic questions, emerging directions *Annals of Epidemiology, 7*(5), 322-333.

Appendix E:
Definitions of Culture from National Health Organizations

Association of American Medical Colleges

"Culture is defined by each person in relationship to the group or groups with whom he or she identifies. An individual's cultural identity may be based on heritage as well as individual circumstances and personal choices. Cultural identity may be affected by such factors as race, ethnicity, age, language, country of origin, acculturation, sexual orientation, gender, socioeconomic status, religious/spiritual beliefs, physical abilities, and occupation, among others. These factors may impact behaviors such as communication styles, diet preferences, health beliefs, family roles, lifestyle, rituals, and decision-making processes. All of these beliefs and practices, in turn, can influence how patients and health care professionals perceive health and illness andhow they interact with one another." (p. 25).

(Source: Association of American Medical Colleges. (1999). *Report III. Contemporary Issues in Medicine: Communication in Medicine. Medical School Objectives Project*. Washington, DC: Association of American Medical Colleges.)

Centers for Disease Control and Prevention

"Culture is the blended patterns of human behavior that include "language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups. "*Cultural competence* is "a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations." "Competence" in the term *cultural competence* implies that an individual or organization has the capacity to function effectively "within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities."

(Source: U.S. Department of Health and Human Services, Office of Minority Health. *What is Cultural Competency?* Retrieved 5/17/2013 from http://www.cdc.gov/socialdeterminants/Definitions.html)

Institute of Medicine

"Culture has many definitions, but most include the following basic concepts:

- Culture includes shared ideas, meanings, and values;
- Culture is socially learned, not genetically transmitted;
- Culture includes patterns of behavior that are guided by these shared ideas, meanings and values;
- Culture is constantly being modified through 'life experiences'; and
- Culture often exists at an unconscious or implicit level" (p. 233).

(Source: IOM Committee on Communication for Behavior Change in the 21st Century: Improving the Health of Diverse Populations, Board on Neuroscience and Behavioral Health. (2002). *Speaking of Health: Assessing Health Communication Strategies for Diverse Populations.* Washington, DC: The National Academies Press.)

National Institute of Mental Health, Child and Adolescent Health Service System Program

"Cultural and linguistic competence is a set of congruent behaviors, knowledge, attitudes, and policies that come together in a system, organization, or among professionals that enables effective work in cross-cultural situations. "Culture" refers to integrated patterns of human behavior that include the language, thoughts, actions, customs, beliefs, and institutions of racial, ethnic, social, or religious groups. "Competence" implies having the capacity to function effectively as an individual or an organization within the context of the cultural beliefs, practices, and needs presented by patients and their communities."

(Source: Cross, T., Bazron, B., Dennis, K. , Isaacs, M. (1989). *Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed*, Washington, DC: CASSP Technical Assistance Center, Georgetown University Child Development Center.)

National Institute of Mental Health, Culture and Diagnosis Group

"As described by the NIMH Culture and Diagnosis Group (Mezzich et al. 1993, as cited in Lu et al. 1995) for incorporation into DSM-IV, culture and ethnicity are

related concepts. According to that group: Culture refers to meanings, values, and behavioral norms that are learned and transmitted in the dominant society and within its social groups. Culture powerfully influences cognitions, feeling, and "self" concept, as well as the diagnostic process and treatment decisions. Ethnicity, a related concept, refers to social groupings which distinguish themselves from other groups based on ideas of shared descent and aspirations, as well as to behavioral norms and forms of personal identity associated with such groups." (p. 7)

(Source: Lu, F., Lim, R., Mezzich, J. (1995). Issues in the assessment and diagnosis of culturally diverse individuals. *American Psychiatric Press Review of Psychiatry*, Vol. 14, 477-510.)

Office of the Surgeon General, Center for Mental Health Services, National Institute of Mental Health

Culture is "a common heritage or set of beliefs, norms, and values."

(Source: Office of the Surgeon General, Center for Mental Health Services, National Institute of Mental Health. (2001). *Mental Health: Culture, Race, and Ethnicity: A Supplement to Mental Health: A Report of the Surgeon General*. Rockville, MD: Substance Abuse and Mental Health Services Administration.)

U.S. Department of Health and Human Services, Office of Minority Health

"'Culture' refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups." (p. 28)

(Source: U.S. Department of Health and Human Services, Office of Minority Health. (2001). *National Standards for Culturally and Linguistically Appropriate Services in Health Care, Final Report*. Washington, DC: U.S. Department of Health and Human Services, Office of Minority Health.)

Appendix F:
A Working Definition of Culture

William W. Dressler
Department of Anthropology and School of Social Work
The University of Alabama

This lecture was prepared on the occasion of receiving the Burnum Distinguished Faculty Award, March 4, 2002.

* * * * * * *

The phrase, "a working definition," is something that is encountered frequently in the literature in the social sciences. As an adjective, "working" is usually used in the following sense that appears in Webster's: something that is "adequate to permit work to be done." Note the use of the word "adequate." There is the connotation of a definition that is rough-and-ready, somewhat unrefined, but that will suffice for the moment. At the risk of being accused of making one of those little academic ironic jokes—and if I am so accused, I will confess immediately that I am guilty—I intend to use the phrase in a different way. What I mean to talk about is a definition of culture that works, that can be used as both a theoretical and a methodological tool in understanding—in short, a definition that really does something.

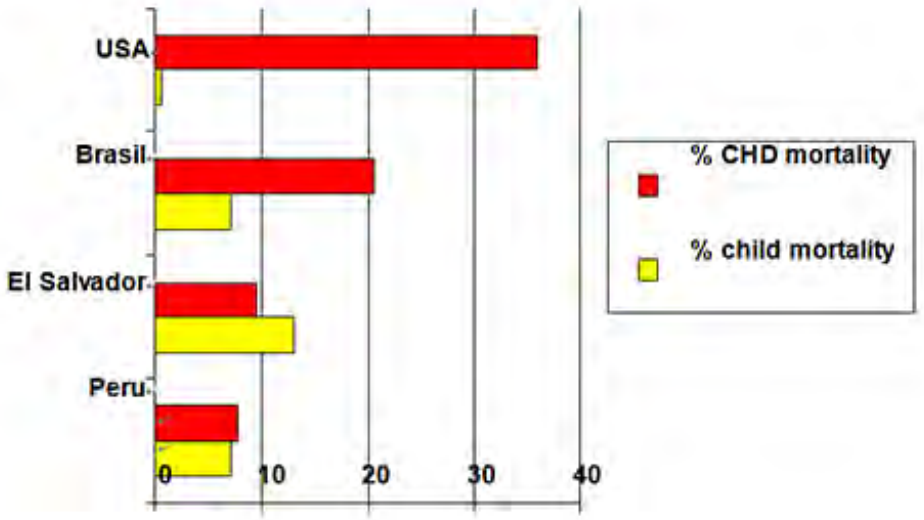
The reason that I am approaching this lecture in this way is because of the occasion: the considerable honor of having been chosen for this year's Burnum Award. This award is made on the basis of an overall research career, and hence this lecture is my opportunity to engage in a kind of retrospective examination of that research career. It has been 30 years since I decided, as a junior at Grinnell College, to pursue anthropology as a profession—which sounds like a long time even to me, although it feels like a short time. There are many ways I could think about and talk about those 30 years. My own view of what I've been doing really has most to do with the core idea of the field of anthropology: namely, the concept of culture and how to make it work in the research process.

My area of research is the intersection of culture, health and healing. What anthropologists like me do is to go around the world examining how culture shapes both the risk of disease and what it is that people do to recover from disease or illness. Obviously, we are talking about a wide range of questions encompassed by this area. In my own research, I have concentrated on the initial stages, namely, falling ill. How does culture shape that risk of disease?

The first question here is: what evidence is there that culture shapes disease at all? The short answer to that is: the epidemiologic transition. Here we see several

countries in the Western hemisphere, comparing mortality rates from all- causes of child mortality and from coronary heart disease (CHD). All-cause child mortality can be used as a proxy for various kinds of infectious and parasitic diseases (often summarized in official statistics under the heading diarrheal diseases) that tend to wreak greatest havoc among the most vulnerable in a population. CHD is foremost among the variety of chronic diseases.

The Epidemiologic Transition



In some countries, child mortality equals or exceeds chronic disease mortality, while in others child mortality declines dramatically and chronic disease mortality increases equally dramatically.

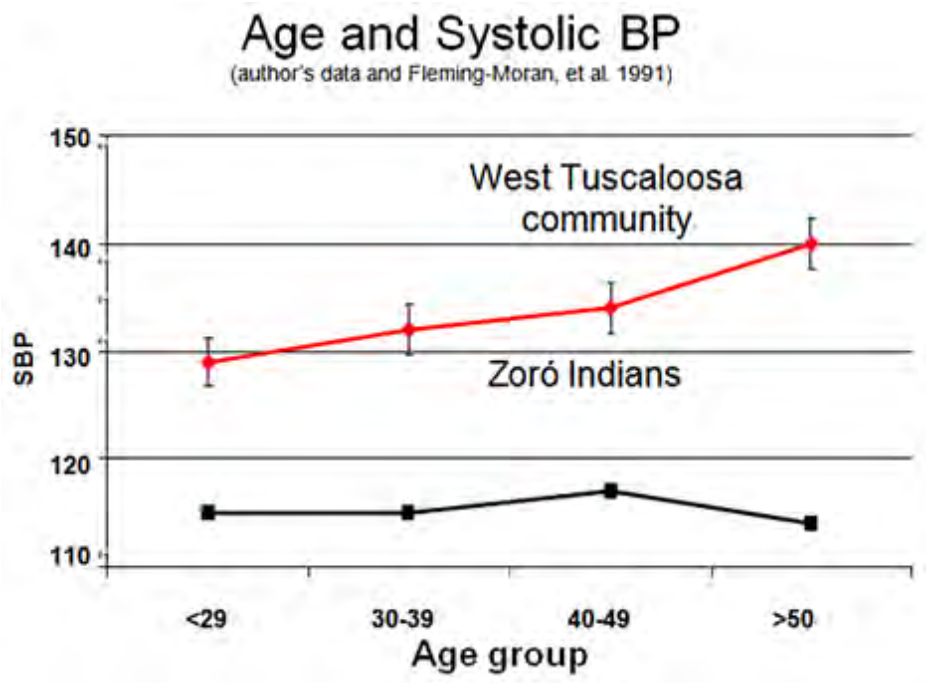
What accounts for this difference? Some obvious answers come into play. Basic infrastructure like clean water and effective sewage systems, plus immunization programs, make a big difference. Also, in the process of economic development people have tended to become more sedentary with the related risk of obesity, which can contribute to many chronic diseases. The quality of our diets has changed, with much less fiber, more fat and more of other nutrients like sodium. Does the combination of these factors not account for these differences?

Well, actually, no. Certainly all of these factors play a role in the process, but even after their combined effects are removed, there are still societal differences in disease rates that are left unexplained.

Here is another brief example of how sociocultural factors shape disease. The increase of blood pressure with age, as shown here for the West Tuscaloosa community, is taken to be “natural.” But if we compare this age distribution to the Zoró Indians of the Amazon basin, we see that the rise is not necessarily “natural,” but in

some sense relative to cultural context. Again, a typical approach to unraveling these differences would be to look at issues such as diet and physical activity, and perhaps genetic predisposition.

But I want to take a moment to reflect on the logic that is being employed here. This logic unwittingly employs what has been called the "onion metaphor" of human beings. That is, we can forget about the Zoró's mixed horticultural and fishing subsistence economy; we can forget about their system for tracing kinship relationships that is more complex than our own; we can forget the way in which they form household and family relationships; we can forget about their origin myths and conceptions of the supernatural. We can, in other words, strip away everything that makes them culturally different, in order to look at their physical activity or their diet to explain their blood pressure. Like stripping away the successive layers of an onion, this metaphor goes, we can strip away cultural difference to get at what is psychologically universal about people; we can strip away belief, value and personality and just look at behavior; we can strip away behavior and look at nutrient transport in the circulatory system; we can strip away physiologic process to look at base-pair coding. We can, ultimately, find our way down to what is fundamentally causative.



Or, can we? Could it be that the onion metaphor is just that, a metaphor that says more about how we look at the world and less about how the world really works? Could it be that we are as thinking, feeling, interacting, and, yes, biological entities, so suspended in a matrix of culture that to think we can strip it away as mere surface appearance so violates the phenomenon that we misunderstand it?

To even entertain this thought demands a way of conceptualizing culture that is subtle and nuanced, and at the same time that is hard-nosed and pragmatic. The concept of culture has to do some work in the research process.

So, what do we mean by culture? A fairly typical view, both in common language and in the way anthropologists have approached their work, sees culture as a shared body of custom, reproduced through time, which makes societies distinctive. Over a century ago, this kind of view of culture emerged in anthropology as an alternative to racialist thinking. Traders, travelers, warriors, missionaries and others had been covering the globe for some time, documenting the astounding variety of human social systems with the myriad ways that people found to resolve basic problems of finding food and shelter, avoiding predation, and reproducing themselves. In part, because people with these different customs also looked very different from the Europeans who visited them, there were appeals to biology to explain custom. People were thought to behave differently because they were biologically a different—and explicitly inferior—sort of creature.

These views were challenged by the anti-racist formulations of Franz Boas and his students. Simply put, they argued forcefully that other people were not biologically different from people of European ancestry, but were different rather because they had a different culture. Culture in this sense was a name put to the total lifeway of a people. From growing food to marrying to having and raising children to governing communities to imagining the supernatural, different peoples did—not just some things—but everything differently. These ways of getting things done were routinized and regularized and learned anew by succeeding generations of a society or community. This totality of the lifeway was called culture, and the learning of it by each generation served as an effective alternative to racial determinism.

The question then became: what was the “stuff” of culture? What was culture made of? How did it get from one generation to another? How do you know it when you see it?

Answers to these questions were generated in the historical context of early ethnographic research, or the documentation of cultural patterns in different societies. In doing cross-cultural research, ethnographers looked for regularities in learned behavior that could in turn be used to make inferences about the larger systematic design for living called culture. Your job was primarily to decode and describe that design, and not to worry too much about how some people may or may not deviate slightly from the pattern. The differences within a society, especially individual differences, were just noise in the system. And it’s important to remember just how difficult it was to decode that pattern, as you were far from home, working in a second language, and trying to understand remarkably different ways of life. The more simplifying assumptions, the better.

In a sense, you could see the people in the picture as merely the space-and-time bound carriers of a cultural tradition. They happened to be there at the moment,

but at another moment those particular people would be gone and you would have another set, but still carrying on that same cultural tradition. Your job was to understand the tradition, not the particular people who carried it on at the moment.

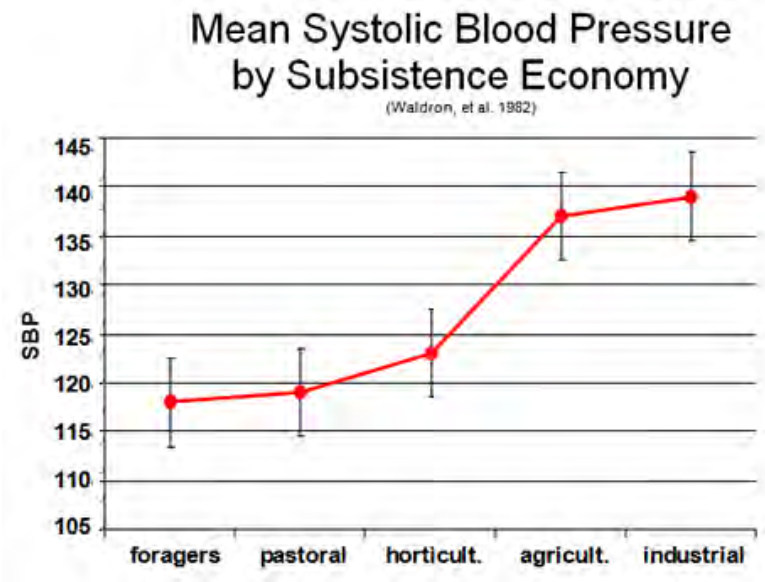
When we talk about, for example, "British culture," we don't really suppose it is there only because the Brits who happen to be alive right now believe and act in the ways they do. British culture was an entity in 1902 and is one in 2002 and probably will be one in 2102, regardless of the people. This gives culture a sense of "externality," something first articulated by Herbert Spenser in the 19th century. It really does feel as though culture exists "out there." We seem as individuals to be casting about within the confines of our own cultures. And this is something that continues to surprise students of culture in the 21st century. So, a working concept of culture must be able to account for this, really quite peculiar, property of culture.

But, having said that, I'm not advocating a kind of "swamp-gas" theory of culture. It's not out there floating around with us breathing it in (or choking on it as the case may be). Where culture resides can only be in individual human beings. Furthermore, if we are interested in the biological impact of culture, we have to be able to trace it from "out there" to "in here." But, we have to somehow reconcile this external quality of culture with its locus in the individual.

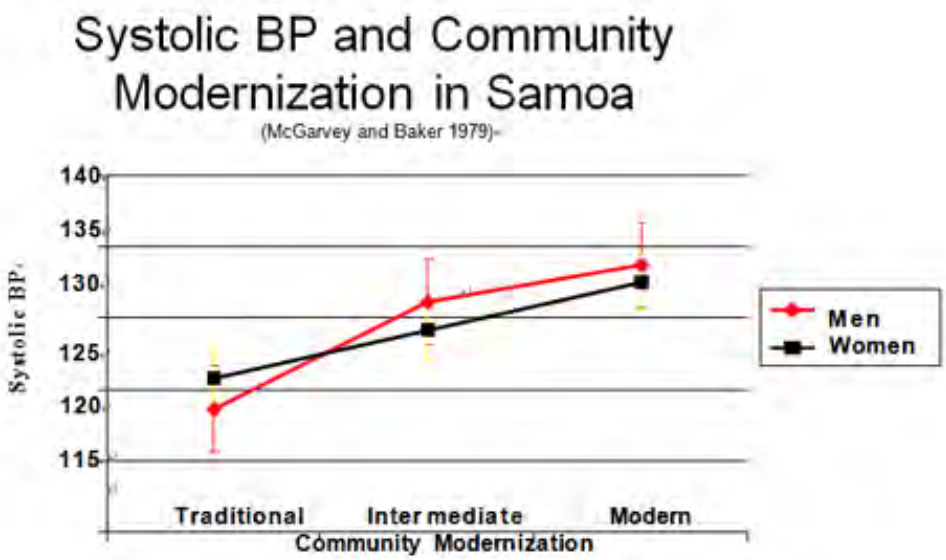
One way of getting at this is to stop and think about what is really important in culture and cultural differences. Is the fact that I'm wearing this suit today really important as far as my culture is concerned? Well, sort of, because I am wearing this suit, as opposed to a grass skirt or a Brazilian carnival costume or even nothing at all. But what is probably more important than my wearing this suit is that I knew, I understood that wearing this suit was what you expected of me. We shared the knowledge that this was the right thing for the occasion. Imagine if I had showed up here to present my Burnum lecture wearing old sneakers, cut-off jeans, and a baseball cap that said Auburn Tigers on it. Probably I would not have gotten tossed out—although the Auburn part might have done me in. More likely than not, you all would have looked at me, shifted uncomfortably in your chairs, and thought something like: "what is this world coming to when they give the Burnum to the likes of this joker?" I would, in other words, have failed to live up to our shared understanding of the world in my behavior.

Now, as basic a sketch as this is, there are a couple of useful ideas implicit in this example. First, there is the shared knowledge or shared expectation. Social life—all of human life—only works because we share various understandings of the world. Everything we do we can do because of these shared expectations. One way of referring to these expectations and understandings is as "shared cultural models." Second, I've just suggested how we can distinguish between culture and behavior, which actually will turn out to be quite important in the story I'm building here. As I said, we may have shared expectations regarding behavior and social interaction, but for various reasons, some people may not fulfill those shared expectations in their own behavior.

This is a very brief sketch of a theory of culture on which I have been working, in one way or another, for quite some time. But, is it good for anything? That is, does it "work?" To examine this issue, let me turn briefly to some of my empirical work. As I said, a basic observation on which all this work is founded is illustrated here, showing how average blood pressure levels vary across different kinds of societies. Here the societies are categorized along a continuum of sociocultural complexity, ranging from the simplest foraging societies, to the most complex industrial states.



But we can break the pattern apart in more precise ways. Here is an example of blood pressure differences among communities in Samoa, in the South Pacific, arrayed along a continuum of modernization. The term "modernization" here is just a shorthand descriptor for a variety of differences among the communities. These differences include subsistence technologies (in the traditional community, people grow yams and herd pigs for their own consumption, while in the modern community people work in factories); patterns of social interaction (in the traditional community, people are much more embedded in their extended family systems, while in the modern community people focus more on independent nuclear households); education and literacy (people in the traditional community receive relatively little formal schooling, while people in the modern community receive more); and, belief systems (people in traditional communities are embedded in a system of supernatural beliefs derived locally, while people in the modern community tend to be pulled into one of the globally institutionalized belief systems, like Christianity).



Why do people in the more modernized communities have higher blood pressures? Well, as I noted at the outset, the obvious answer to that question involves things like diet and physical activity, but taking those factors into account actually fails to explain all of the differences, although these factors clearly explain a part of those differences.

For years, one explanation for these findings has loomed large: the stress of culture change. Somehow, all of these changes in peoples' lives are stressful, and the resulting stresses are associated with higher blood pressure. Now, this explanation is terrifically compelling, especially when linked with all of the careful laboratory studies showing how psychologically threatening events or circumstances can influence physiology. The problem, however, has been sorting out, in a conceptually precise way, just what this phrase—"the stress of culture change"—really means.

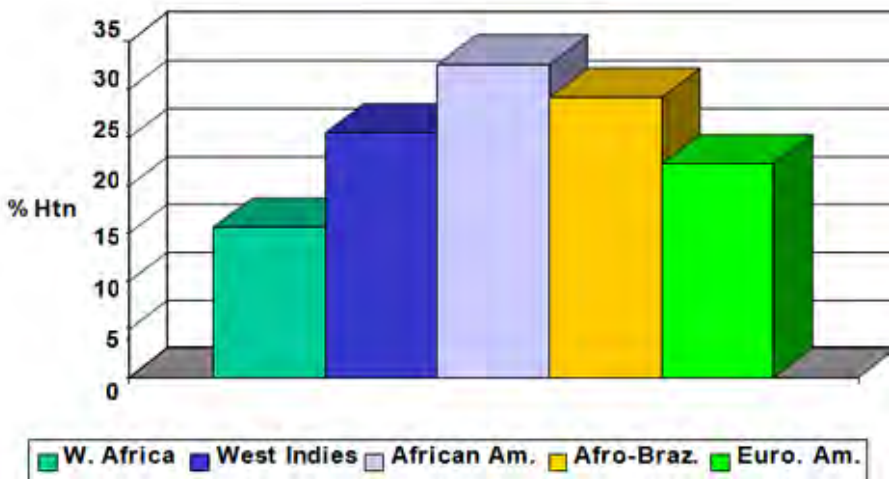
About forty years ago, there was a remarkable burst of activity in thinking about this issue at UNC-Chapel Hill, involving the epidemiologist John Cassel, the psychologist Dave Jenkins and the anthropologist Ralph Patrick. They were particularly interested in what happened to migrants from rural areas to urban areas, although the same reasoning can be applied to culture change occurring within any community. They offered the following hypothesis: the migrant to a novel setting carries with her a particular understanding of how the world works, in every sense (i.e. what it means to work, how marriages are constituted, how families treat themselves and their neighbors, how to worship—everything). She is confronted, however, with a system for which her understanding may not work. The novel and dominant culture of the new setting must be learned for everyone else's behavior to be understood, and indeed for her to behave in ways that are understandable to others. She must, in other words, adapt to the new setting. Even if she is successful, such adaptation can be costly. Indeed, this is precisely what Hans Selye meant by the General Adaptation Syndrome when he gave the concept of stress its first scientific respectability in the 1930's. Adaptation is costly, and the cost of adaptation is written on the body in terms of what we call health. So, Cassel, Patrick and Jenkins argued that the less

successfully the migrant culturally adapts to the new setting, the higher her blood pressure.

Unfortunately, Cassel and his colleagues had neither the conceptual nor the methodological tools to really carry this project forward—or, to continue my theme, their definition of culture didn't "work." But what I have introduced here—namely the idea of culture as these shared cultural models, plus the idea of a person's relative ability to really live in accordance with those models—gives us a way of attacking the problem. Simply put, realizing shared cultural expectations in individual behavior—or what I will refer to as "cultural consonance"—is in part a measure of how well individuals are able to adapt to their social milieu. And I would take Cassel's model much further. We don't need to limit our thinking to situations of migration, or modernization, or culture change because each of us, in our own way, every day, is engaged in the process of sorting out, in our own behaviors, these shared expectations. We are engaged in a daily endeavor to better adapt, and one way of thinking about that process is in terms of our success at meeting those shared expectations, or cultural consonance. I hypothesize that the higher a person's cultural consonance, the better his or her health status.

I've been able to examine these processes in a variety of settings over the years, including, prominently, in Alabama. I arrived here in 1978 after doing my dissertation research around these topics in the West Indies. This conventional "modernization" view of things described well what had been going on in the West Indies for some 25 years. There modernization had been driven by a single economic innovation occurring in the early 1950's: the introduction of the banana as a large-scale cash crop. And this is typically the case in the so- called Third World. Economic change drives societal modernization.

Rates of Hypertension in African Descent Populations



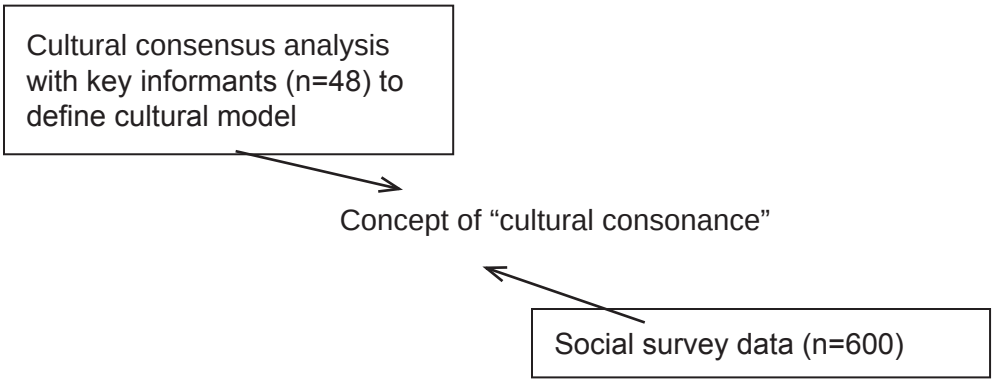
In Alabama in 1978, I began to explore the possibility of doing research on blood

pressure in the African American community, and I tended to think about the community, and its experiences in the latter half of the 20th century, in terms analogous to the modernization paradigm. Black Americans in the South were denied participation in the modern world by the American version of apartheid that we called "segregation." But a single political innovation— Brown vs. the Board of Education in 1954, and the civil rights movement spawned by that decision—changed everything. Like an economic innovation in the developing world, this political innovation changed not just some things, but everything, for the black community. Or, like the migrants to a novel setting described by Cassel, black Americans now had a whole new world opened to them. Let me hasten to add that this is a long, drawn-out process with which we are still dealing. But, in broad outline, this is a useful way of thinking about what occurred.

What I mean literally here is that the cultural models for everyday life ceased to be primarily autochthonous creations from within the African American community, and became instead creations more of the intersection of those models with general middle class American cultural models. Not that local meanings and understanding are irrelevant, but rather that black Americans have had a whole new set of circumstances, including a whole new way of understanding the world and its opportunities and its limitations, to which to adapt. What has the effect of all this been on their health?

We know the rate of high blood pressure among black Americans is 50% higher than among European Americans. In my work in the community here in Tuscaloosa (and, as I will briefly mention, in Brazil), I've tried to examine how these cultural stresses are implicated in the process. This is how I have gone about it. On the one hand, there are the cultural models, the shared ideas about how life is to be lived. On the other hand, there is the relative success with which people can approximate those cultural models in their behaviors. The link of model and behavior is cultural consonance. Assessing and measuring a representative sample of peoples' behaviors is what social survey work is all about. The trick has been to get at the cultural models in a rigorous and systematic way; in a way that is faithful to theory; and, in a way that we can directly connect to peoples' behaviors as assessed in the survey. Fortunately, in the mid-1980's, Kim Romney and Sue Weller came up with a statistical model for doing just that that they call "the cultural consensus model." I won't go into the details here, but the consensus model can be used to determine the degree to which people share knowledge or ideas about some phenomenon. Remember that no sharing = no culture. And, if there is sharing, we can determine the content of what is shared. Having determined what that shared content is, we can then measure the degree to which peoples' reported behaviors actually reflect that content, and see if any disparity there is associated with health status.

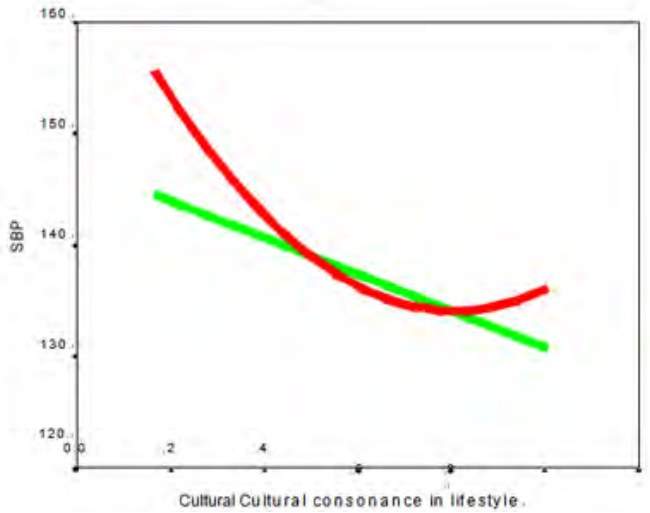
Linking the Cultural and the Individual



OK, what are the important cultural models that people must live up in order to achieve better health status? Well, obviously this is a big question, and one on which I am currently working hard. But for purposes of illustration let me pick one. There is probably no aspect of American middle class culture more highly valued than our lifestyles, by which I literally mean the kinds of material circumstances of life we can achieve, and the kinds of leisure time activities that go along with that. Thorstein Veblen placed lifestyles at the center of human motivation a century ago in his "Theory of the Leisure Class." Now, Veblen is well-remembered for his phrase "conspicuous consumption" to describe a rather vulgar pursuit of that lifestyle among the nouveau riche. He is, however, less well-remembered for this observation: "[for most people, achieving a particular lifestyle]…is a desire to live up to the conventional standard of decency…[in the community]." In other words, to be left behind with respect to the middle-class lifestyle in American society is to be seen to be, somehow, "indecent" as a person.

Systolic BP and Cultural Consonance in the West Tuscaloosa African American Community

(Dressler and Bindon 2000)



In one of our recent studies, carried out here in the African American community in West Tuscaloosa, we asked a small sample of persons to list and rate the importance of material goods and related behaviors as indicative of having had a successful life. The consensus model showed us that they agreed strongly on what that meant. Basically, it meant having a modest and comfortable, but not ostentatious, lifestyle, including such things as owning a home, a car, having nice furnishings, keeping up on current events, and, significantly, participating in one's church. I think the inclusion of that last item speaks volumes about the sensitivity of this technique to local meanings in the black community.

We also conducted an epidemiological survey of households in the community in which we collected data on blood pressures and a variety of factors, including individual self-reports of their ownership of lifestyle items and their adoption of related behaviors. Cultural consonance in lifestyle was measured as the degree to which an individual's reported lifestyle matched the lifestyle described in the cultural model.

The next figure shows the relationship of systolic blood pressure, which has been adjusted to take out the effects of age, sex, body mass, income and various dietary variables, and cultural consonance in lifestyle. I think the relationship is pretty clear. The closer that a person can truly approximate in his or her own behavior the shared cultural model of lifestyle in the community, the lower his/her blood pressure. Furthermore, the more distal one becomes from the model, the stronger the effect, hence the curvilinear relationship. These results suggest that low cultural consonance may be a profound and chronically stressful circumstance that, in the long run, results in poor health status. I assume that many of you are now playing the "my favorite variable" game. This is the game in which, after presenting data, someone jumps up and asks: "But did you control (fill in your favorite variable)?" I may especially be sensitive to this game, because I have spent a good bit of time presenting these ideas to psychologists, epidemiologists, nutrition researchers,

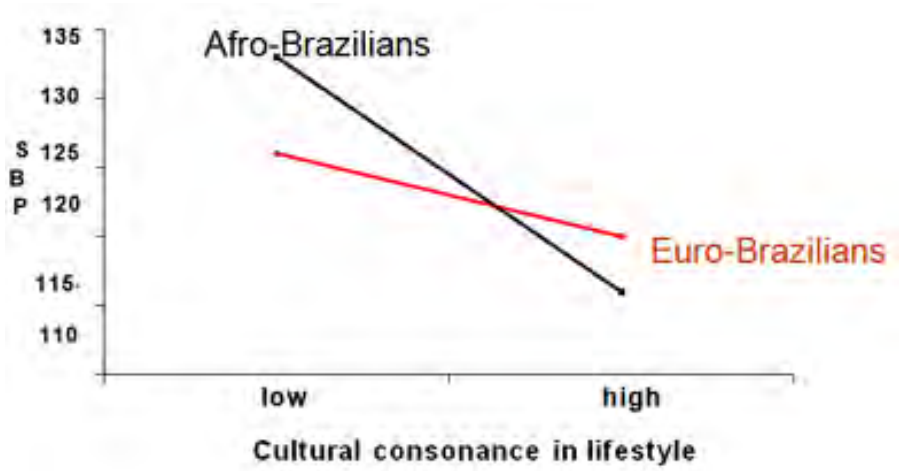
and, yes, even internists. Well, I've been at this business for a long time, and I've managed to cram most of the variables that get mentioned in the research literature into studies, and so far, controlling for these other factors fails to dislodge the importance of cultural consonance.

What creates this state of affairs, in which people do not live in consonance with shared cultural models? Well, in the African American community, cultural construction collides with structural constraint. In the best of times, unemployment rates in the black community are twice that of the white community. More than a third of households live in poverty. Median household incomes are only about 60% of white household incomes. Hence, the likelihood that an individual can achieve even the modest lifestyle goals encoded by cultural models is diminished. The tragic part of this process is that these structural constraints are a result of institutional racism and racial stratification. Over a lifetime, for a large segment of the community, people see their shared hopes and their shared aspirations, modest as they might be in a material sense, denied to them. And that denial is written on their bodies in the form of poorer health status and risk of premature death.

These ideas have pretty good legs. I've been working in Brazil for nearly 20 years, and have examined many of the same processes there. This slide shows how, for black Brazilians, low cultural consonance leads to blood pressures higher than their white counterparts, but higher cultural consonance leads to blood pressures lower than whites.

BP, Cultural Consonance and Ethnicity in Brazil

(Dressler et al. 1998)



In a sense, we have come full circle here. Remember that early in this lecture I talked about how the concept of culture emerged in anthropology as a challenge to racialist explanations of others. My work has, in a way, continued that. Now, I don't think that many people in medicine take seriously the old idea that African

Americans are at risk of high blood pressure due to a racial-genetic trait, although that idea continued to be prominent well into the 1980's. Rather, as Tom LaVeist pointed out, there is a tendency in the medical literature to document black-white health differences without comment; however, black folks are almost always coming out worse in terms of health status: more high blood pressure, more low birth weight babies, higher stroke rates, and worse cancer outcomes. Left uninterpreted, there is a kind of unspoken inference that somehow these black-white differences are a result of racial differences. Without grappling directly with the question of how so-called "race" may actually result in poor health through sociocultural pathways, we end up reinforcing the idea that the biologically bankrupt concept of race actually has some biological validity.

But, as I have argued, if we look closely enough, we find something else going on. With blood pressure, it's not biology in some racial-genetic sense, but rather a complex set of social structural and biocultural processes that result in the appearance that somehow race matters as a biological factor, when it doesn't. What I hope I have shown here is that continuing the anthropological project of the 19th century—that is, using the concept of culture to debunk racialist and other kinds of wrong-headed ideas—is still an important thing to do.

To do it right, however, we need a concept of culture that works. We need a concept of culture to help us to deconstruct the surface appearances of life. As the Dutch psychologist Ap Appel noted: "The final discovery a fish can make is that of water. It does not know what it means to live in water until it is lying on the counter of a fish shop. Similarly, people do not realize to what extent their behavior…is rooted in the culture in which they live." By explicating those links of culture and behavior, we can, I hope, both improve our theoretical understanding of the world, and maybe make it a better place to live.

Appendix G:

Exemplar Intervention Studies that Operationalize Culture across the Research Continuum

Tables Constructed by Dr. Rena Pasick

We searched for intervention research exemplars that included these characteristics: i) conceptualization of culture as dynamic, contextualized, integrated, interrelated, multi-level, implicit and explicit; ii) methods that support such a conceptualization, particularly community involvement in all phases, a blend of inductive and deductive approaches, and triangulation of multiple qualitative methods as well as with the deductive quantitative measures; and iii) operationalization that clearly reflects integration of conceptualization, theory, measurement and approach to explain the behavioral and/or health outcome results. We found studies that model some but not all characteristics. Those studies that address these multiple issues appropriately can guide the full operationalization of culture.

Table 1. Formative Research Exemplars

Study/Purpose	Conceptualization of Culture	Operationalization	Results	Limitations/ Notes
Paugh, Amy, and Carolina Izquierdo. "Why is this a battle every night?: Negotiating food and eating in American dinnertime interaction." *Journal of Linguistic Anthropology* 19.2 (2009): 185-204. Analyzes interactions about food and eating among dual-earner middle-class families whose children are judged for not meeting appropriate eating expectations.	With a focus on language socialization practices and the discursive construction of health, data are examined regarding how family members co-construct, frame, and reframe one another's accounts about health and attempt to influence their health-related practices. Researchers attend to both ideology and practice, drawing on interview data and utilizing observation and video recording of how people "do" health through daily embodied and discursive practice.	Synthesizes theoretical and methodological tools from linguistic anthropology and medical anthropology. Semi-structured interviews and questionnaires, video recording of daily activities, sampling of stress hormones, mapping and photographing homes and belongings, and tracking of family members' activities and uses of space. The study focuses on dinnertime interactions in nested sample of five families with health-related practices that are representative of patterns found throughout a larger 32 family study sample.	Illuminates how participants position themselves in their narratives about health, while the analysis of naturally occurring conversations captures how they actively negotiate health in mundane interactions involving food and eating. For these families, health and well-being are directly associated with everyday practices like food consumption and exercise. Such practices index physical condition, but also individual morality, responsibility, agency, and control. A major theme is the extent to which families describe good health as a state to be achieved by the individual, particularly through food and eating choices. It is a matter of personal responsibility that is tempered by work, school, and other responsibilities. Yet parents claim significant responsibility for the present and future quality of their children's health; illustrating tensions between parental authority and individual agency, and resulting in frequent negotiations and compromises over food choices.	Concept of culture is implied but not stated explicitly. Exemplifies the cultural nature of health behavior via the interplay of family dynamics and diet. Methods illustrate the value of multiple forms of data.

Burke, Nancy J., Ofelia Villero, and Claudia Guerra. "Passing Through Meanings of Survivorship and Support Among Filipinas With Breast Cancer." Qualitative Health Research 22.2 (2012): 189-198 To explore the social and cultural contexts of Filipinas' experiences with breast cancer to inform development of culturally appropriate and sustainable support services and outreach	The sociocultural contexts that shaped participants' day-to-day experiences and which directly and indirectly affected their health and behavior. These contexts included historical, political, and legal structures and processes such as migration experiences, racism, and colonialism; organizations and institutions, such as schools and health care clinics; as well as individual and personal trajectories, including family, workplace, community, church, and interpersonal relationships	Multiple qualitative methods (participant observation, individual and small group in-depth qualitative interviews) were used to identify meanings of survivorship and support. Understanding Filipinas' conceptualizations of support sheds new light on the relational nature of support, the attitude and manner in which is it delivered - e.g. 'wholeheartedly' (*buong puso*) rather than 'helping' to fulfill a task/or job.	Interviews and observations revealed the influences of social context and immigration experiences on women's understandings of cancer, what "surviving" cancer means, and what it means to take care of someone with breast cancer (or be taken care of). The subthemes under dimensions of survivorship were cancer is one of many trials; survivorship is not about self, but about family; survivorship means rebirth, a second chance; and survivorship means being cancer-free, having "passed through" (*lampasan*). The dimensions of support subthemes were differing definitions of caregiving, family support dynamics, patients as caregivers, transnational aspects of support, and spiritual and religious support. Overall, results showed that a transnational perspective is important for the study of Filipina immigrant women's experiences of cancer and survivorship, and for the development of appropriate and sustainable support services.	Social and cultural contexts of support group participation and survivorship experiences have been largely absent in a literature focused more on physical and social concerns of breast cancer patients.
Bhattacharya, Gauri. "Self-Management of Type 2 Diabetes among African Americans in the Arkansas Delta: A Strengths Perspective in Social-cultural Context". Journal of health care for the poor and underserved. (Feb. 2012): 161-178 To explore underlying factors influencing the promotion of Type 2 Diabetes (T2D) self-management among adult African Americans in the Arkansas Delta.	Because culture is the context within which one lives, the cultural as well as biological meanings of disease and illness must be described. The cultural frame is shaped by the larger sociohistorical and social environmental contexts that individuals associate with their life experiences. Interventions must relate to individuals' real life experiences within their own sociocultural contexts recognizing that the culture of any community is neither static nor monolithic. Additionally, there is considerable diversity within cultural groups in terms of health and health promotion beliefs, values, and behaviors	A narrative approach gathered insights in the participants' own voices and placed their T2D self-management experiences in social-cultural-historical contexts. Using purposive sampling, 31 participants were interviewed.	The participants showed low awareness of T2D's chronic nature because of its asymptomatic or nonspecific symptoms. They interpreted medically prescribed dietary and physical exercise guidelines as impractical and culturally irrelevant for them. Medication non-adherence was due to inadequate knowledge and awareness of T2D as a chronic disease, and suspicion and mistrust of the formal medical system. To develop culturally targeted interventions to advance self-management outcomes, we must understand from and with African Americans the strengths of social-cultural contexts in which they live and make their health behavior choices.	The narrative approach captured participants' own voices talking about their lived experiences with T2D. This can inform a broader paradigm that integrates daily life experiences with health and behavior.

Table 2. Applied Intervention Research Exemplars

Study/Purpose	Conceptualization of Culture	Operationalization	Results	Limitations/ Notes
Hecht, Michael L., and Michelle A. Miller-Day. "Applied" aspects of the drug resistance strategies project." Journal of Applied Communication Research 38.3 (2010): 215-229. Community-based substance use prevention research: keepin' it R.E.A.L middle school prevention curriculum. Theoretical research led to communication research that uses theory, tests theory, and/or builds theory in community contexts, engaging communities in testing and developing theory to address significant social concerns.	"Cultural sensitivity," "cultural appropriateness," and "cultural competence" are criticized as frames that limit and marginalize culture by placing it outside the message. This research program articulates the cultural grounding approach to message design. The intervention is based on the idea that collecting and performing narratives is a means to enact culture: culture is a complex, multilayered phenomenon and this complexity must be integrated into health messages.	Narrative and performance theories position human beings as storytellers and narrative as the means by which we make sense of our experiences and ourselves, organize and understand events, and recount experiences. The underlying assumption of this drug prevention work has been that adolescents make substance use decisions based on the narrative storylines available to them and they will embrace stories that cohere and resonate with their lived experience. For the intervention, prototypical narratives were scripted into performance media (i.e., stage play and film script) and performed. This work builds on the strengths of traditional conceptualizations of applied research, but places greater emphasis on moving beyond the academy into the populations affected to the problem of interest, testing and building theory in situ, working collaboratively with practitioners and community members, focusing on socially significant outcomes, and disseminating research findings to those who can best make use of them.	Based on prior RCT research demonstrating that a multicultural curriculum was as effective and more practical than curricula designed for specific groups. Across developmental age, race, and urban, suburban, and rural contexts, findings showed surprising consistency in the resistance strategy stories of adolescents. Such a practice-based science considers variation in program adaptations and implementations to be part of what is of interest to study rather than error to be eliminated or controlled.	This paper is part of a 20-year program spanning exemplary formative through dissemination research
DO Erwin and L Jandorf. "Addressing Socio-Political Impediments to Health Care Access for Diverse Latin American Immigrants." Paper presented at 111th American Anthropological Association Annual Meeting, San Francisco, CA, 2012. (Manuscript under review). Evaluate effectiveness of an intervention on screening behavior in Latina subgroups in Arkansas and New York City, with women from diverse countries of origin.	Erwin, Deborah O., et al. "Contextualizing diversity and culture within cancer control interventions for Latinas: Changing interventions, not cultures." Social science & medicine 71.4 (2010): 693-701. A culturally relevant intervention is one that reflects shared perspectives, beliefs, practices, life experiences and the history of the subgroup to be addressed.	Latino cultures include internal diversity based on country of origin, acculturation patterns, immigration status, and generational and language status. Such diversity requires a range of data to ensure optimal acceptance of messages and programming. The interpretation and transformation of qualitative data informed the intervention content and structure in conjunction with a theoretical approach that integrates class, culture, and powerlessness in an interactive participatory educational approach involving those who are most vulnerable and oppressed. Site differences demonstrated educational and screening interventions can be implemented in multiple locations, with program variations reflecting local characteristics. Sudarsan, Nora R., Lina Jandorf, and Deborah O. Erwin. "Multi-site implementation of health education programs for Latinas." *Journal of Community Health* 36.2 (2011): 193-203.	Participation in educational programs significantly increased screening with no significant difference by message type. Screening further increased with the addition of navigation regardless of country of birth, documentation status, insurance status, or geographic location.	A highly contextualized intervention resonated with Latinas from diverse origins.

Table 3. Evaluation Exemplars

Study/Purpose	Conceptualization of Culture	Operationalization	Results	Limitations / Notes
Challenges of Evaluating Multilevel Interventions Bonnie K. Nastasi, John HitchcockAmerican journal of community psychology [0091-0562] Schensul (2009) volume: 43 issue: 3-4 page: 232-240 The Comprehensive Mixed-Methods Participatory Evaluation (CMMPE) model is used as a framework for addressing the multiplicity of evaluation decisions and complex nature of questions related to program success in multilevel interventions. CMMPE defines program success in terms of acceptability, integrity, social or cultural validity, outcomes (impact), sustainability and institutionalization, thus broadening the traditional notions of program outcomes. A mixed methods framework can help to account for this complex array of outcomes and processes, and assist in ensuring culturally valid and effective interventions.	Evaluation entails examination of the extent to which program goals and objectives are relevant to the cultural and social contextual (ecology) variations at multiple levels of the intervention: Is the program consistent with the values, beliefs, and norms of the multiple groups or settings, and target behaviors that are valued across multiple levels. See also Trikett et al., Am J Public Health. 2011;101:1410–1419.	The CMMPE model (Nastasi and Hitchcock 2008; Nastasi et al. 2004) is a framework for conceptualizing evaluation to address the multiplicity of evaluation decisions and complex nature of questions regarding program success or effectiveness. The model is intended for application in contexts that involve participatory approaches to evaluation. CMMPE could be applied to single or multilevel evaluation, using qualitative, quantitative or mixed methods designs. The model can be applied to formative, process, and summative research. Formative methods can establish likelihood of acceptability; gather data on individual, contextual and cultural factors that may influence the process and content of the intervention; and to identify factors related to sustainability and institutionalization. Implementation process evaluation addresses all facets of program success. Summative evaluation addresses multiple aspects of program effectiveness and likely extends into follow-up evaluations focused particularly on sustainability of the intervention and indices of institutionalization.	Evaluation of sustainable multilevel interventions requires the use of a participatory process and iterative use of evaluation data to inform program implementation and adaptation to variations across individuals, levels and time. The complexity of multilevel interventions presents several challenges for evaluators and calls for consideration of alternatives to traditional experimental designs. Surmounting the challenges of multilevel interventions holds promise for developing and testing interventions that can be effectively translated to practice in real-life settings, and thereby lessen the research to practice gap in psychology and related disciplines.	The concept of culture advanced in this report is inherently multi-level and participatory. The complexity of multilevel intervention and evaluation designs challenges traditional notions of evaluation research and experimental designs.

Nguyen, Tu-Uyen Ngoc, et al. "Community health navigators (CHNs) for breast-and cervical-cancer screening among Cambodian and Laotian women: intervention strategies and relationship-building processes." Health Promotion Practice 9.4 (2008): 356-367. Cambodian and Laotian CHNs involved in the "Promoting Access to Health for Pacific Islander and Southeast Asian Women" (PATH for Women) project as part of the CDC Racial and Ethnic Approaches to Community Health (REACH 2010) initiative. This study elaborates on the specific intervention applications and accomplishments by PATH for Women partners, specifically focusing on strategies that Cambodian and Laotian CHNs enacted to overcome structural constraints and establish trusting community relationships to promote breast- and cervical-cancer screening.	While many structural barriers to cancer screening are universal, the strategies required to address them vary among cultural groups. Development and testing of models for AAPI communities are hampered by research paradigms based on the values of a mono-cultural, Eurocentric view of social behavior emphasizing individual-based constructs and disregarding cultural variations in health behavior. In most AAPI cultures, the concept of the "self" is tied to the health and welfare of the family or larger community, and health decision-making is often a group process involving inter-dependent cooperation and consensus. Nguyen, Tu-Uyen Ngoc, and Marjorie Kagawa-Singer, 2008.	The community-based aspects of interpersonal and relationship-building processes experienced by the CHNs were studied to identify the specific qualities and social support roles filled by these women in tailoring breast- and cervical-cancer screening programs and promoting health care access for their communities. Mixed methods included use of process records, in-depth semi-structured interviews, and observations.	Although the CHNs noted the importance of the informational and instrumental support functions in their advocacy and navigation work, it appears that these types of assistance were effective in getting women screened because the CHNs also provided the affective and emotional aspects of support necessary to convey empathy and respect and to establish trust with community members. In addition, the CHNs were aware of policy and environmental issues affecting the community (i.e., need to transition off welfare, increase of violent deaths in the area, deportation of immigrants, etc.) and how to work around these barriers to continue navigating the women through the health care system. Because the CHNs live and work in the same neighborhoods as the women they serve, they have an intimate understanding and empathetic insight into many of the problems affecting their communities and are personally invested in helping to find solutions.	The use of multi-method process evaluation to understand how and why an intervention works deepens cultural understanding and elaborates the role of culture in the intervention dynamics. While the concept of culture is not explicitly articulated in this paper, the approach enabled a cultural assessment of social support theory for Cambodian and Laotian communities.

Table 4. Dissemination Exemplars

Study/Purpose	Conceptualization of Culture	Operationalization	Results	Limitations / Notes
Allen, JD., Linnan LA, Emmons KA. "Fidelity and Its Relationship to Intervention Effectiveness, Adaptation, and Dissemination." Dissemination and Implementation Research in Health: Translating Science to Practice (2012): 281. To adapt effective beauty shop intervention (training curriculum and ed. materials) in AA community for men in barbershops. Core elements of original intervention: Salon as "safe haven" and Trust/credibility	Health is created and lived by people within the settings of their everyday life; where they learn, work, play and love -historical, economic, political, and social context - unique relationship between licensed cosmetologists and their customers.	- Community Advisory Board guided all aspects of the intervention plan and delivery -social ecological framework (SEF) placing individual health behavior in multiple levels: intrapersonal, interpersonal, organizational, community, and policy - political economy of health (PEH) as a macro-level theoretical perspective (not a single theory but a broad theoretical framework that emphasizes -4 focus groups with AA men -Interviews with 21 barbershop owners -observations in 11 barbershops - adaptation - pilot test with pre-test and post-test surveys		
Holleran Steiker LK. 2008. Making drug and alcohol prevention relevant: adapting evidence-based curricula to unique adolescent cultures. Fam. Commun. Health 31(1S):S52–60 (cited by Keepin it real)		When this intervention was exported to Texas, the local Mexican American youths responded critically to the videos, expressing that they "could not relate" to certain content and activities that were depicted, such as break dancing, even though these videos incorporated Mexican American youths as protagonists (Holleran et al. 2005). This revelation prompted the need for a local adaptation of the keepin' it REAL intervention in accord with the needs and preferences of youths who live in Texas communities (Holleran Steiker 2008).		[4] Only one report is cited that evaluated cross-cultural psychometric properties of measures

Appendix H.

Examples of Section III and IV: Methods Along the Research Continuum with Native American Groups

Joseph E. Trimble -- Intervention Exemplars
July 2013

Dissemination Exemplar - 1

Study/purpose

Rivkin, I. D., Trimble, J., Lopez, D.S., Johnson, S., Orr, E., & Allen, J. (In press). **Disseminating research in rural Yup'ik communities: Challenges and ethical considerations in moving from discovery to intervention development**. *International Journal of Circumpolar Health.*

The Yup'ik Experiences of Stress and Coping project originated from rural Yup'ik communities' concerns about stress and its effects on health. It aimed to understand the stressful experiences that affect Yup'ik communities, to identify coping strategies used to deal with these stressors, and to inform culturally responsive interventions. We examine the process of moving from research (gaining understanding) to disseminating project findings to translation into intervention priorities. We highlight the importance of community participation, and discuss challenges encountered, strategies to address these challenges, and ethical considerations for responsible intervention research with indigenous communities that reflect their unique historical and current socio-cultural realities.

Conceptualization of culture

Community-wide presentations and discussions of research findings on stress and coping were followed by smaller Community Planning Group meetings. During these meetings community members contextualized project findings and discussed implications for interventions within the context of the Yup'ik worldview. This process placed priority on community expertise in interpreting findings, and translating results and community priorities into grant applications focused on intervention development and evaluation.

Operationalization

The partnership adhered to a Community Based Participatory Research (CBPR) approach, in which the communities guided all aspects of the research, including the research questions, the interview adaptation process, the sampling and recruitment

procedures, and the schedule of visits to the communities. Collaboration continued as an important element in dissemination of project findings to the community and other stakeholders.

Community dissemination of findings is inherent to the CBPR process. It facilitates co-learning, enhances the validity of the research, builds trust, strengthens partnerships, empowers communities, and guides priorities for future interventions. Allotment of adequate time and resources for disseminating findings to the community was an important consideration for the Yup'ik Stress and Coping project. This included extensive efforts to develop presentations that were culturally-appropriate, helpful, and understandable to community audiences through the involvement of cultural consultants and community members in the community dissemination planning process.

Results

Challenges included translation of meaning between English and Yup'ik, funding limitations and uncertainties, and the long timelines involved in moving from formative research to intervention in the face of urgent and evolving community needs. The lack of congruence between institutional and community worldviews in the intervention research enterprise highlights the need for "principled cultural sensitivity".

Limitations/Notes

Community dissemination addresses limitations of conventional scientific reports. Technical reports are rarely used at the local level because the writing is often not accessible to community members and the reports typically do not provide direct input to immediate decisions communities face. Without more accessible dissemination efforts, the community can be left with the feeling that the research was a wasted effort, and may develop a negative attitude toward research in general. Thus, dissemination efforts should use non-technical language to specifically address local needs. Community dissemination also informs scientific dissemination, when the context community members can provide is integrated into findings, ensuring accurate interpretation in light of local culture, values, or beliefs.

Formative Research Exemplar -1

Study/purpose

Rivkin, I.D., Lopez, E.D.S., Quaintance, T.M., Trimble, J.E., Hopkins, S., Fleming, C., Orr, E., & Mohatt, G.V. (2011). **Value of community partnership for understanding stress and coping in rural Yup'ik communities: The CANHR study**. *Journal of Health Disparities Research and Practice. 4(*3), 1-17.

Rural Alaska Native communities shoulder a disproportionately high burden of stress and trauma, stemming in part from historical trauma and rapid changes in culture and lifestyle. The Yup'ik Experiences of Stress and Coping project originated from rural Alaska Native communities' concerns about stress and its effects. Understanding local conceptions of stress that are grounded in the experiences and perceptions of the Yup'ik community participants is critical for informing culturally based interventions. Sixty adults in two Yup'ik communities in Southwest Alaska participated in semi-structured interviews exploring their understanding and experience of stress and coping.

Conceptualization of culture

The Yup'ik Experiences of Stress and Coping project was based on a community-based participatory research (CBPR) model of partnership that comprised two rural Yup'ik communities in Southwest Alaska and researchers at the University of Alaska's Center for Alaska Native Health Research (CANHR). All study protocols and materials were developed within the context of this partnership, with guidance from community steering committees, tribal entities, and the Yukon-Kuskokwim Health Commission.

Operationalization

The project comprised two sequential phases that included interview development and implementation. *Phase One* involved developing three culturally appropriate data collection materials and protocols to gain in-depth understanding of stress and coping. These included a brief semi-structured open-ended Community Stress and Coping Interview, a longer semi-structured Lifetime Events and Trauma Interview with closed-ended and open-ended questions, and a Digital Audio Diary. *Phase Two* involved implementing these three data collection activities, along with data analysis and interpretation. In the current article, we specifically focus on findings from the Lifetime Events and Trauma Interviews conducted with 60 community members during *Phase Two* of the project. All data collection materials and protocols were approved by the YKHC‟s Human Subjects Committee, and by the University of Alaska

Fairbanks‟ Institutional Review Board. Findings from the interviews were presented during community dissemination meetings, and further discussed in meetings with community steering committee members who helped contextualize findings. Yup'ik translation was provided during the dissemination and committee steering committee meetings.

Residents in the two Yup'ik communities were eligible to participate in the study if they were 18 years or older. A total of 113 individuals took part in the brief Community Stress and Coping interviews. These brief interviews served to inform purposive stratified sampling for the longer Lifetime Events and Trauma interviews. They also served as a tool to identify community members who might have been too

vulnerable to participate in the more intense Lifetime Events and Trauma Interview. Of the 113 brief interview participants, 60 completed the Lifetime Events and Trauma interview (30 in each of the two communities). Because talking about stress can bring up difficult experiences, participants received information and contacts for available resources after each interview, including behavioral health services in the local community and hub, as well as CANHR research team contacts. All interviews were conducted in person, during six data collection visits made by researchers to the communities between April 2009 and September 2010, in the Fall, Winter, and Spring. A purposive stratified sampling strategy was used to ensure diverse representation of perspectives across gender, age and community. These sampling strategies were achieved by creating a matrix to guide our sampling during each community visit, with the goal of including an equal number of women and men within each of the designated age ranges (younger 18-30 years; middle 31-50 years; older 51 years and older). Random sampling would not be feasible or accepted in these small rural communities, and would violate community values of inclusion. Purposive sampling combined with multiple opportunities for participation addressed the need for inclusion, and the need for diverse perspectives on stress to facilitate a culturally-grounded understanding of lived experiences. Interviews were conducted by four trained interviewers, two of whom were fluent in Yup'ik. Participants were given the opportunity to complete the informed consent process and their interviews in the language in which they were most fluent or comfortable (English or Yup'ik). Of the 60 Lifetime Events Trauma interview participants, 11 (18%) chose to complete their interviews in Yup'ik.

Results

Participants discussed their understanding of stress in the initial portion of each interview. Twelve primary themes within understanding of stress were identified. These themes were grouped into five descriptive categories within a chronological and iterative model: (1) antecedents of stress; (2) stressful experiences; (3) resources; (4) responses to stress; and (5) broader effects of stress. This model shows the pathway from antecedents through effects of stress, with effects feeding back into antecedents.

Within antecedents of stress, participants discussed two elements: *changes in stress and causes of stress.* Yup'ik community members, particularly Elders, have observed rapid cultural change and Westernization of Yup'ik ways of living. Such changes have created\ barriers between youth and Elders in small Yup'ik communities. This may contribute to communication difficulties exacerbated by living in a bilingual sociocultural setting where Elders speak primarily Yup'ik and youth speak primarily English. Some participants described how these cultural shifts have altered the types of stress experienced across years and generations.

Within stressful experiences, themes of *hard times*, transitory stressors such as *bad days*, and *family stress* were discussed. Many participants described understanding

stress as *hard times*, that is, difficulties or problems in life. Many participants described understanding stress as *family stress*, that is, stress from family members or within the family. Common examples included relationship problems, lack of communication, substance use, and childrearing issues. Participants also discussed the negative effects that fatal accidents or suicides in the community can have on family relationships. In small Yup'ik communities, people are interconnected and often related to one another. As such both positive and negative events that affect one family reverberate throughout the community.

Some participants understood stress as something that can be *hard to handle* or hard to fix due to a lack of emotional, physical, or financial resources for dealing with stress. People shared examples, such as being unable to deal with a situation, facing community problems that are hard to deal with like suicide, or lacking options such as support programs or financial support. Participants also talked about understanding stress as psychological or physiological responses, including *emotions*, *trouble with the mind*, *physical responses*, and *tired*. The most frequent theme to emerge was *emotions*, emotional responses to stressful experiences. This included feeling overwhelmed, uncomfortable, hypervigilant, or worrying about stressful situations. Precipitating circumstances could include chronic stressors or emergency situations such as accidents or injuries.

Participants described understanding stress as *behavior change* or the broader *impact of stress*, both of which fit in the model as *effects of stress*. Some discussed behavior changes resulting from stress, such as smoking more than usual, not taking care of things, and acting differently than normal. Whereas behavior change is a more immediate effect of stress on individual behavior, *impact of stress* reflects an understanding of stress as having broader effects on the family and community, and consequences such as alcohol abuse and suicide that are felt throughout the community. Participants discussed how the entire community was important to assist in coping and healing.

Limitations/Notes

The methodologies utilized in the current study were designed with community collaboration to be appropriate to the local cultural context. Focus groups and community discussions to adapt the interview protocol ensured that it fit the Yup'ik communities‟ experiences. Purposive stratified sampling strategies were aimed at gathering diverse perspectives regarding stress and its effects in two Yup'ik communities across age and gender groups, while respecting community values of inclusiveness. The community-based mixed methods design allowed triangulation, using multiple sources of data for a more complete understanding of the prevalence and meaning of stress.

There is no direct linguistic equivalent for „stress‟ within the Yup'ik lexicon. The closest equivalent discussed by participants was the experience of *trouble with the mind*, from the Yup'ik *umyuaq caknerluni*. Many participants, particularly Elders who

completed their interviews in Yup'ik, described understanding stress as *trouble with the mind* which included issues or problems with the mind, sickness of the mind, or having too much on your mind.

Formative Research Exemplar -2

Study/purpose

Schinke, S.P., Botvin, G.J., Trimble, J.E., Orlandi, M.A., Gilchrist, L., & Locklear, V. (1988). Preventing substance abuse among American Indian adolescents: A bicultural competence skills approach. *Journal of Counseling Psychology, 35*(1), 87-90.

Tobacco, alcohol, and drug use are problems for American-Indian people. We reviewed these problems and the explanations for them and described a bicultural competence skills approach for preventing substance abuse with American-Indian adolescents. Data from a study of that approach suggest its efficacy with American-Indian youth. At posttest and a 6-month follow-up, American-Indian subjects who received preventive intervention based on bicultural competence skills concepts improved more than did American-Indian subjects in a no-intervention control condition on measures of substance-use knowledge, attitudes, and interactive skills, and on self-reported rates of tobacco, alcohol, and drug use. Our findings have implications for future substance-abuse prevention research with American-Indian people.

Conceptualization of culture

Culture was defined according to the degree of identity and their enrollment in their respected tribes. Subjects were 137 American-Indian adolescents from two western Washington reservation sites. Respondents were recruited from tribal and public schools and voluntarily participated in the study.

Operationalization

Operationally, preventive intervention that includes knowledge and practice in bicultural competence skills can occur through, cognitive and behavioral principles drawn from social- learning theory. Guided by learning theory, cognitive principles of information, problem solving, and self-instruction can be combined with behavioral principles of nonverbal and verbal communication, coaching, and social network building. To empirically test the effects of combined approaches, we evaluated the outcomes of bicultural competence skills and social learning-based intervention to prevent substance abuse among American-Indian adolescents.

Results

The data lend modest support to a bicultural competence skills intervention approach for preventing substance abuse among American-Indian youth. Within a controlled design, American-Indian youths who received such skills-based preventive intervention showed greater posttest and follow-up improvements than did American-Indian youths in a nonintervention control condition on measures of substance related knowledge, attitudes, and interactive abilities and on self-reported rates of tobacco, alcohol, and drug use. Still, the data must be interpreted cautiously. Study subjects were a small sample of the myriad American-Indian and Alaska- Native groups in America. To generalize beyond the sample is unwise.

Limitations/Notes

Methodological work is needed to develop and tailor psychometric measures for research with American- Indian and Alaska-Native people. Certainly, replication tests of the skills-based approach are needed before substance-abuse preventive interventions are ready for wide implementation with American- Indian youth. Perhaps the present intervention model and data will encourage new prevention research on substance abuse among American-Indian adolescents

Formative Research Exemplar -3

Study/purpose

Trimble, J. & Mahoney, E. (2002). Gender and ethnic differences in adolescent self-esteem: A Rasch measurement model analysis. In Mail, P.D, Heurtin-Roberts, S., Martin, S.E., and Howard, J., (Eds.), *Alcohol use among American Indians and Alaska Natives: Multiple perspectives on a complex problem* (pp.211-240). National Institute on Alcohol Abuse and Alcoholism Research Monograph No. 37. Bethesda, MD: National Institute on Alcohol Abuse and Alcoholism.

Although considerable attention can be devoted to the way the self-esteem construct is conceptualized, measured, and interpreted, we contend that the way self-esteem scales are analyzed, especially when used with culturally different populations, may be problematic. To illustrate, we present a series of analyses using Rasch modeling and measurement procedures to show that three ethnic groups may be responding to and interpreting a common set of self-esteem items differently; consequently, differential response patterns may be attributed to ethnic and cultural orientations of the respondents. We then present a measurement model that specifies the characteristics of scientific measurement and analyzes the measurement of self-esteem typically used in AOD use studies among adolescents differing in gender and ethnic identification. Findings from the analysis can assist researchers in understanding how ethnicity and gender status influence psychosocial scale items.

Most cross-cultural researchers agree that cultural equivalence can be examined

by giving attention to the following concepts: functional equivalence, linguistic equivalence, conceptual equivalence, stimulus equivalence, and metric equivalence. Embedded in the notion of equivalence is the fundamental tenet that comparisons between groups require that a common, if not identical, process exists; stretched· to the extreme, the notion holds that a universal process must exist to demonstrate and assess comparability. Consequently, to achieve functional equivalence two or more behaviors must "pre-exist as naturally occurring phenomena" that are related or identical to a similar problem or circumstance; the behaviors serve a similar function for both groups.

Conceptualization of culture

Ethnicity was treated as a nominal variable where respondents self-identified their ethnic affiliation. Data are available from the project to determine the depth and degree of ethnic identity for the respondents. Within each ethnic group, disaggregated analyses can be performed to determine if the degree to which respondents identify with their self-identified group will create yet another subset of scale items measuring self-esteem. Analyses of combinations by degree of ethnic identity within gender groups may assist researchers in discovering the extent to which each of the sets interact and co-vary in their understanding the dynamics associated with studies of the self-esteem.

Operationalization

Data for this Rasch model analysis were collected from school records and self-report surveys between the summer of 1989 and the winter ofl991 from three middle school and secondary school adolescent groups composed of self-identified Anglos, American Indians, and Hispanics. The participant pool consisted. of youth who were in good academic standing in school (GAS), those who were academically "at risk" (AR), and those who had dropped out of school (DO) and had been out for at least 1 month. Data were collected from six sites in the western and southwestern parts of the United States. A total of 3,986 adolescents completed the survey form. Sample sizes for each ethnic group varied according to gender and academic status, as follows: Anglos = 1,119 (571 males and 548 females, with an overall mean age of 16.7 and a standard deviation of 1.1); American Indian = 767 (342 males and 425 females, with an overall mean age of 16.5 and a standard deviation of 1.6); Hispanics = 2,100 (1,180 males and 920 females, with an overall mean age of 16.5 and a standard deviation of 1.2). Sample sizes for each of the academic status conditions were as follows: Anglos, GAS = 355, AR = 325, and DO = 439; American Indians, GAS = 243, AR = 255, and DO = 269; and Hispanics, GAS = 635, AR =691, and DO = 774.

The survey was a multiple-scale instrument developed by the staff at the TriEthnic Center for Prevention Research at Colorado State University, using scales that had been developed for previous studies. There were more than 1,000 items in the survey, and it took between 60 and 90 minutes to complete. A seven-item self-

esteem scale was selected for use in the measurement analysis. The short scale consisted of the following items: “I like myself,” “I am good at games,” I am. good looking,” “I am lucky,” “I am proud of myself,” “I am intelligent,” and “I am able to do things well.” Self-esteem scale items initially were treated with the usual correlational statistical routines to determine their psychometric properties. Cronbach’s alpha ranged from 0.78 to 0.85 for each of the three ethnic groups and all groups combined. A principal components factor analysis produced two factors, with the first factor accounting for 68 percent of the variance.

Results

The results of the analysis have several implications for researchers interested in using survey-type scales for the comparison of individuals from different cultural or ethnic groups. Moreover, the results indicate that there are considerable differences in the way gender and ethnic status influence responses to a common set of self-esteem items. The broad implications for the Rasch analysis findings and its relationship to measurement equivalence are not clear and, thus, merit further investigation. It is not surprising that there is a considerable amount of disagreement in the research on ethnic differences in self-esteem. Clearly, self-esteem measurement involves appreciably more than summing up responses to a set of questions having face and content validity. Our gender and ethnicity analyses indicate that most of the rather standard self-esteem items are redundant and thus not unique contributors to determining levels of self-esteem. Setting gender and ethnicity differences aside, it is clear from our findings that physical appearance plays a central role in adolescent self-esteem. When we turn to measuring self-esteem for adolescents from different ethnic groups, the measurement of self-esteem becomes more complicated. Among Anglo adolescents, self-esteem is defined by intelligence and physical appearance. Among American Indian adolescents, self-esteem is defined by liking oneself and physical appearance. Among Hispanic adolescents, self-esteem is defined by liking oneself, intelligence, and physical appearance. Clearly, what attributes constitute the central elements of self-esteem differ considerably by ethnicity, and any measure not taking this fact into consideration lacks construct validity.

Limitations/Notes

If there are differences between and within cultural worldviews, would it be possible to develop scientifically

sound measures to tap the self-esteem that would permit culturally equivalent comparisons? To collect the information necessary to respond to the worldview equivalent, researchers should use quantitative research analysis techniques at the outset.

APPENDIX I:

Linda Burhansstipanov, Dr.P.H.

Application of the Cultural Framework for Health to a Native-American health project

Tobacco: Use It In A Sacred Way

Checklist from Section IV

1. Is the rationale for the inclusion of *culture* clearly articulated in the problem statement?

2. Is there a clearly articulated definition of culture for this study?

3. Are there known, salient theoretical cultural domains?

☐ Known theoretical domains, unknown cultural domains?

☐ Known cultural domains, unknown theoretical domains?

4. Do you articulate a conceptual framework that specifies how salient domains affect specific health/wellbeing issue(s)?

5. Is there correspondence between theoretical & cultural domains?

6. Do cross-culturally equivalent measures exist?

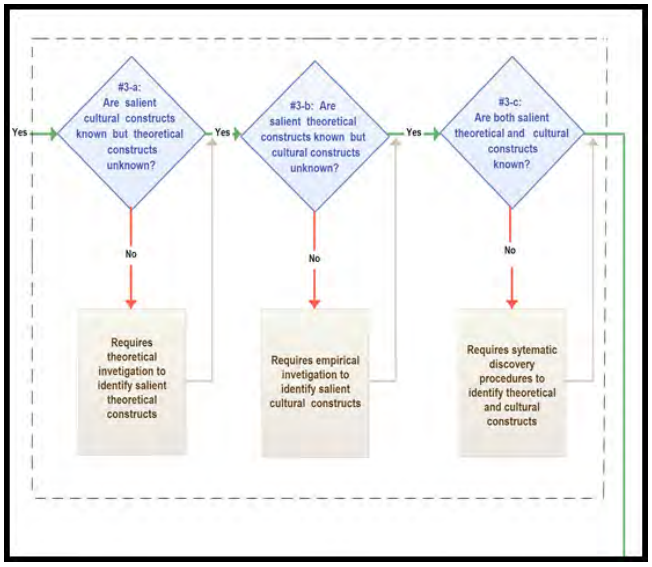
This case study is an excerpt and slight variation of an on-going NIH-funded grant. Dr. Burhansstipanov then assessed how the study followed the steps recommended in the Cultural Framework Checklist from Section IV. The research question is***, "Why don't Northern Plains American Indians alter tobacco use behaviors known to increase the risk of cancer?"***

QUESTIONS 1 and 2: <u>Flowchart Question 1</u> asks **if the inclusion of culture is clearly articulated in the problem statement.** The problem statement addresses

the common and culturally associated use of tobacco for ceremonial or sacred purposes among Northern Plains American Indians (AI) living in South Dakota. For centuries, many AI tribes viewed tobacco as a sacred plant with powerful properties and incorporated as an integral part of many ceremonies and prayers. Currently, more than half of Northern Plains American Indians use store-bought tobacco for ceremonial purposes.

However, Northern Plains AIs also smoke cigarettes and use other tobacco products as daily habits or addictions unrelated to ceremonial tobacco use. Smoking prevalence that includes the use of store-bought tobacco for daily (non-religious) purposes among AIs living in South Dakota is 48.8%.

Thus, the behavior of habitually smoking store-bought tobacco differs from the behavior of saving tobacco for sacred, ceremonial purposes. These cultural practices present a challenge in this grant aiming to help the AI who stops smoking daily but attends AI ceremony that requires him/her to be exposed to tobacco smoke for a few hours. By taking part in such a traditional ceremony, the individual is likely to start smoking again.



Through this and other related AI customs surrounding the traditional use of tobacco (not discussed here), the research team decided the answer to Question 1 was "yes."

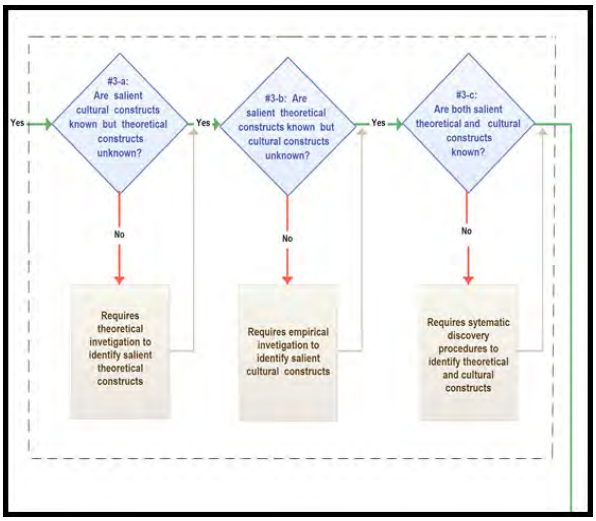
Graphics on this page and the following provide a few examples that illustrate the common cultural distinctions between habitual and sacred use of tobacco in the AI culture.

Flow chart question 2 asks **if a definition of culture for the study been articulated.** The research team is comprised of professionals who have worked directly and respectfully with AI

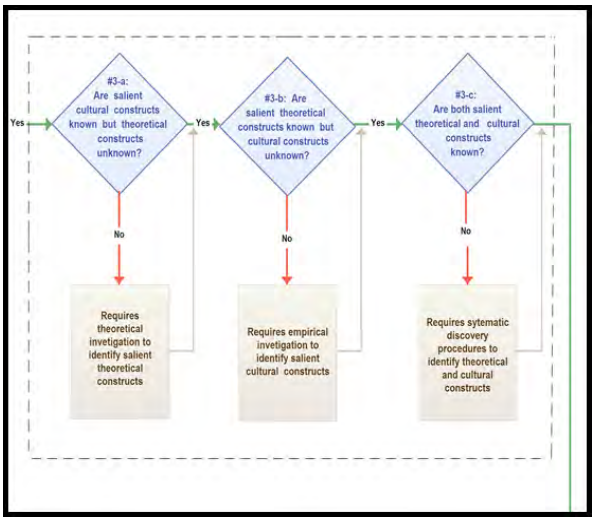
community members and AIs from academic, clinical, and Reservations with small AI organizations. All agreed that they understand the cultural practices relevant to the research question and they there was no need to take time articulating such a definition. The team responded that the study is focused on how AIs use tobacco habitually, but that traditional and ceremonial use of tobacco interacts with cessation strategies and interventions.

AIs use tobacco for multiple sacred and/or traditional purposes. Traditional purposes include using tobacco for medicinal benefits, for example rubbing on the gums of teething child to reduce pain, in relationships to provide a tobacco tie to spiritual healer or elder when requesting help, healing in home or friends' problems as tobacco is believed to help spirits return to balance to reduce disharmony / violence in home as well as for prayers and ceremonies that protect the privacy of the event and no details are allowed to be shared outside of the ceremonial participants. Although the latter is not the focus of the study, the majority of Northern Plains AIs who smoke store-bought cigarettes habitually / addictively are also likely to use tobacco for ceremonial purposes. The study is attempting to help Northern Plains AIs quit the habitual / addictive use of store-bought tobacco and to reserve tobacco for ceremonial uses only. Thus, cultural practices and beliefs are interwoven throughout the research study question.

The research team's concern is for AIs who both smoke habitually and actively take part in AI ceremonies that burn tobacco in some form. The study was designed to be inclusive of AIs who practice ceremonies that include tobacco for sacred purposes as it would be unethical and disrespectful to exclude them. Will the cessation rates be lower among AI smokers who quit smoking, but continue to take part in ceremonies that include the burning of tobacco? Probably yes.



The research team was in agreement. They did not include such details within the grant application due to space limitations. When the team attempted to identify processes that define the AI group, they included adding items to the baseline survey clarifying if or how often the participant used tobacco for spiritual purposes versus smoking due to nicotine addiction. The team determined that the rituals associated with smoking tobacco for spiritual purposes specifically *were cultural*. Also true was that the spiritual uses of tobacco among the tribal Nations living in South Dakota involved unique cultural *practices (see examples above)*. Of note, many "smoke-related" ceremonies that



outsiders assume use tobacco, may actually use a sacred plant other than tobacco (cedar, red willow).

For example, a large tribal nation used “red willow” rather than tobacco during pipe ceremonies and another local tribal nation prefers to use cedar, but 2 others use crumbled up store-bought tobacco (because they have not been able to grow their own tobacco for sacred purposes). The 5th tribe only uses kinnikinnick, which may or may not include “tobacco.” All 5 of the tribes involved in the study frequently use sweet or buffalo grass following such ceremonies.

Sweet / buffalo grass is the tall, swaying grass that primarily grows through the Northern and Southern Plains and is braided for burning to invite positive, healing spirits into a room. After it is burned, in some tribes, the individual will place the burned grass braid on the rim above a doorway to continue to promote positive spirits into the room. Other tribes believe that the sweet grass braid should be buried after it is burned (“give it back to Mother Earth”). Thus, the tribal nations within the Northern Plains differ in how they handle and use these products. Also, a female on her moon (i.e. menstruating) is not allowed to touch tobacco (she can touch the pipe, but not directly touch the tobacco) according to most tribal nations. Similarly, a young person or someone who is a survivor of a tobacco-related cancer and is in a ceremony that uses tobacco, would tap the mouth piece on the right and left shoulders and pass it on. Obviously, there are distinctive patterns of behavior that are based on each group’s cultural beliefs and practices. Thus, although not in the grant application, the team clarified among themselves what and how the processes occur that are relevant to culture.

QUESTION 3 asks whether the theoretical and cultural domains are known. “Theoretical domains” integrate the Theory of Planned Behavior (TPB) concepts while protecting sacred/ceremonial tobacco use (such as those ceremonies conducted by a local AI traditional Indian healer). Such integration is a major challenge in this study. For example, TPB survey items to help understand motivations for not smoking store-bought tobacco include, “My quitting smoking sometime in the future would improve my breathing,” as well as items such as, “My traditional / spiritual leader thinks I should stop smoking” and “I am confident that I can stop smoking store-bought cigarettes, yet continue to take part in the sacred (spiritual) / ceremonial use of tobacco in a good way.” Some ceremonies are scheduled years in advance (Sun Dance) but others can be for smaller groups

or families as needed. They are held on sacred grounds reserved for ceremonial purposes only, as well as in one's home or in the clinical setting (e.g., AI cancer patient and the family members may have ceremony outside the clinic with the family's traditional Indian healer).

The research team (again, key members were AI and several have worked with Northern Plains AIs for more than 15 years) felt that the *cultural domains* are known, yet are also quite unique for each individual participant.

Thus, the team did not assume that just because a study participant was from the Rosebud tribal Nation, that they held common tobacco beliefs or practices with other Rosebud Sioux members. Culture is interpreted by people internally and distinctive from others. Yet, the majority of Rosebud Sioux do reserve tobacco for ceremonial / sacred / spiritual purposes. Most tribal Nations have beliefs about how and why the Creator or White Buffalo woman or others (varies by tribal cultural beliefs) gifted their Nation with sacred tobacco. White buffalo woman gave tobacco to ancestors in some tribes, others it is spider woman or even the eagle (tobacco origin stories vary greatly among tribal nations). A commonality is that the tobacco is sacred. The smoke carries one's prayers to the Creator, or tobacco is used as a medicine to reduce pain as noted above.

Question 3 continues to require the systematic discovery procedures to generate hypotheses for further testing. The research team agreed that it was inappropriate to generate hypotheses about AI cultural practices that use ceremonial / sacred tobacco. However, they were able to hypothesize that the AI study participant whose ceremonies use store-bought tobacco were less likely to successfully stop smoking daily (see above that some Northern Plains AIs use products other than tobacco for ceremonial purposes). The distinction between store-bought (also called manufactured and commercial tobacco products) and tobacco grown for ceremonial use is that the latter does not add alkaline chemicals or products to "make" the tobacco smoother to inhale. Thus, the content of the tobacco products themselves differ.

Question 4 asks if there is a correspondence between the Theoretical and Cultural constructs. The answer is absolutely "yes". The health issue is to stop smoking store-bought cigarettes. Store-bought tobacco includes chemicals designed to make the smoker addicted, inhale deeper and more often. The Northern Plains AI who smokes store-bought tobacco is also likely to take part in AI ceremonies that frequently include tobacco, and once s/he stops smoking store-bought tobacco, the ceremonial tobacco is hypothesized to likely to increase the likelihood of smoking again.

Question 5 asks if there is a conceptual model of how the salient constructs identified affect the health issue of focus. The answer is definitely "yes". The cultural practices described earlier illustrate their interconnectivity.

Question 6 asks if there are cross culturally equivalent existing measures. The research team included survey items about ceremonial use of tobacco and clarifies whether the ceremonial product is truly tobacco or if it is another smoked product, such as red willow or cedar, of which neither had addictive chemicals included nor are inhaled deeply. The survey also addressed if the participant uses store-bought tobacco for sacred /traditional purposes. This is a significant issue due to the alkaline chemicals that are in store-bought tobacco but excluded from traditionally grown tobacco. The survey items were interspersed among 11 visits between the study participant and a trained Native Patient Navigator who is also providing tobacco cessation counseling, assisting the community member in accessing nicotine replacement therapy products and customizing text messages (mHealth) for relevance to them personally. These survey items included “regular” tobacco use practices as well as ceremonial / traditional tobacco use. The survey items contributed to the customizing of mHealth messages, which were sent to the participants 2-4 times each day that included respect for traditional tobacco use (i.e., ceremonial, spiritual, sacred tobacco practices). The mHealth messages provided process evaluation measures. The Navigator also conducted carbon monoxide testing for each face-to-face visit with the participant.

Appendix J:
Examples of NIH RFAs that Require Consideration of Culture

Department of Health and Human Services

Part 1. Overview Information

Components of Participating Organizations	NIH Basic Behavioral and Social Science Opportunity Network (OppNet http://oppnet.nih.gov/) and its member institutes, centers and offices: National Cancer Institute (NCI) National Eye Institute (NEI) National Heart, Lung, and Blood Institute (NHLBI) National Human Genome Research Institute (NHGRI) National Institute on Aging (NIA) National Institute on Alcohol Abuse and Alcoholism (NIAAA) National Institute of Allergy and Infectious Diseases (NIAID) National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) National Institute of Biomedical Imaging and Bioengineering (NIBIB) Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) National Institute on Deafness and Other Communication Disorders (NIDCD) National Institute of Dental and Craniofacial Research (NIDCR) National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) (No Longer Participating per NOT-DK-13-001) National Institute on Drug Abuse (NIDA) National Institute of Environmental Health Sciences (NIEHS) National Institute of General Medical Sciences (NIGMS) National Institute of Mental Health (NIMH) National Institute of Neurological Disorders and Stroke (NINDS) National Institute of Nursing Research (NINR) National Library of Medicine (NLM) National Institute on Minority Health and Health Disparities (NIMHD) Fogarty International Center (FIC) National Center for Complementary and Alternative Medicine (NCCAM) National Center for Advancing Translational Sciences (NCATS) Division of Program Coordination, Planning and Strategic Initiatives, Office of Research Infrastructure Programs (ORIP) Office of Behavioral and Social Sciences Research (OBSSR) Office of Dietary Supplements (ODS) Office of Disease Prevention (ODP) Office of Research on Women's Health (ORWH)

Funding Opportunity Title	Basic social and behavioral research on culture, health, and wellbeing (R24)
Activity Code	R24 Resource-Related Research Projects
Announcement Type	New
Related Notices	October 24, 2012 - See Notice NOT-LM-13-001. Notice of Change in Eligibility of Foreign Institutions. October 19, 2012 - See Notice NOT-DK-13-001. NIDDK Will Not Participate.
Funding Opportunity Announcement (FOA) Number	RFA-LM-12-002
Companion Funding Opportunity	None
Number of Applications	See Section III. 3. Additional Information on Eligibility.
Catalog of Federal Domestic Assistance (CFDA) Number(s)	93.113, 93.121, 93.142, 93.143, 93.172,93.173, 93.213, 93.233, 93.242, 93.273 ,93.279 ,93.286 ,93.307, 93.361, 93.350,93.393, 93.394, 93.395,93.396, 93.399, 93.837, 93.838, 93.846, 93.847, 93.853, 93.855, 93.856, 93.859, 93.865, 93.866, 93.867, 93.879, 93.989.
Funding Opportunity Purpose	This Funding Opportunity Announcement (FOA), issued on behalf of the NIH Basic Behavioral and Social Sciences Opportunity Network (OppNet), will provide grants for infrastructure support to develop, strengthen, and evaluate transdisciplinary approaches and methods for basic behavioral and/or social research on the relationships among cultural practices/beliefs, health, and wellbeing.

Key Dates

Posted Date	September 11, 2012
Letter of Intent Due Date	November 16, 2012
Application Due Date(s)	December 17, 2012
AIDS Application Due Date(s)	February 13, 2013
Scientific Merit Review	May/June 2013
Advisory Council Review	August 2013
Earliest Start Date(s)	September 2013
Expiration Date	February 14, 2013
Due Dates for E.O. 12372	Not Applicable

Required Application Instructions

It is critical that applicants follow the instructions in the PHS398 Application Guide except where instructed to do otherwise (in this FOA or in a Notice from the *NIH Guide for Grants and Contracts*). Conformance to all requirements (both in the Application Guide and the FOA) is required and strictly enforced. While some links are provided, applicants must read and follow all application instructions in the Application Guide as well as any program-specific instructions noted in Section IV. When the program-specific instructions deviate from those in the Application Guide, follow the program-specific instructions. **Applications that do not comply with these instructions may be delayed or not accepted for review.**

Looking ahead: NIH is committed to transitioning all grant programs to electronic submission using the SF424 Research and Related (R&R) format and is currently investigating solutions that will accommodate NIH's multi-project programs. NIH will announce plans to transition the remaining programs in the *NIH Guide to Grants and Contracts* and on NIH's Applying Electronically website.

Table of Contents

Part 1. Overview Information
Part 2. Full Text of Announcement
Section I. Funding Opportunity Description
Section II. Award Information
Section III. Eligibility Information
Section IV. Application and Submission Information
Section V. Application Review Information
Section VI. Award Administration Information
Section VII. Agency Contacts
Section VIII. Other Information

Part 2. Full Text of Announcement

Section I. Funding Opportunity Description

Purpose

This Funding Opportunity Announcement (FOA), issued on behalf of the NIH Basic Behavioral and Social Sciences Opportunity Network (OppNet), will provide grants for infrastructure support to develop, strengthen, and evaluate transdisciplinary approaches and methods for basic behavioral and/or social research on the relationships among cultural practices/beliefs, health, and wellbeing. This includes an appreciation for more comprehensive understandings of the relationships regarding cultural attitudes, beliefs, practices, and processes, on outcomes relevant to human health and wellbeing. Model animal research teams are welcome to apply.

Background

Culture usually is defined in terms of beliefs and practices that are shared within a population, which itself may share attributes such as ethnicity, race, language, gender, sexuality, specific physical impairments or geographic space. These beliefs and practices reflect common values, socialization processes that are intrinsic to the population of interest, and their other shared attributes. In practice, investigators may use gross distinctions such as demographic categories or political boundaries as proxies for culture, with little attention to how well these categories capture actual shared culture. The specific processes by which culture encompasses beliefs and practices related to health may be obscured by surrogate variables to designate culture (e.g., language, national origin, and race/ethnicity). There is a need for research that improves the conceptualization and measurement of culture and does this in the context of health and social and behavioral processes that influence health.

Basic research on the relations among cultural processes, attitudes, health behaviors, and outcomes can lead to more precise measurement on social-behavioral mechanisms of culture and can provide reliable and valid grounding for measures across future disease-specific and/or target-population-specific investigations.

The R24 mechanism is designed to build research infrastructure and incorporates research projects as part of this effort. Projects should bring together transdisciplinary teams of investigators who can, collectively, provide new insights into the relationships between aspects of culture and health. The team should choose a small project that demonstrates the power of their approach to deliver new insights that lead to improved health outcomes or facilitates the effectiveness of health research. This project may provide formative or pilot data which can be used to inform future, larger transdisciplinary health research.

About OppNet

OppNet is a trans-NIH initiative that funds activities to build the collective body of knowledge about the nature of behavior and social systems, and that deepen our understanding of basic mechanisms of behavioral and social processes. All 24 NIH Institutes and Centers that fund research and five Program Offices within the NIH Office of the Director (ICOs) co-fund and co-manage OppNet. All OppNet initiatives invite investigators to propose innovative research that will advance a targeted domain of basic social and behavioral sciences and produce knowledge and/or tools of potential relevance to multiple domains of health- and lifecourse -related research. Applicants should understand that the NIH Institute or Center (IC) that made this FOA available to the public is not necessarily the NIH IC that ultimately will manage a funded OppNet project. Instead, OppNet assigns funding and project management of meritorious applications to the NIH IC whose scientific mission most closely corresponds to that of the proposed research project.

For more information about OppNet, its grant portfolio, and all its current funding opportunities, visit http://oppnet.nih.gov. OppNet uses the NIH definition of basic behavioral and social science research (b-BSSR)http://obssr.od.nih.gov/about_obssr/BSSR_CC/BSSR_definition/definition.aspx#def to determine application responsiveness. Applications that focus primarily on applied BSSR or research topics aside from b-BSSR will be withdrawn administratively before reaching the peer review process. Consequently, OppNet strongly encourages interested researchers to consult the above definition and the following links,http://oppnet.nih.gov/about-bssr.asp, http://oppnet.nih.gov/about-faqs.asp, and the Scientific Contacts section of this FOA for individuals with expertise in the research subject matter and the OppNet initiative.

OppNet's Specific Areas of Research Interest

Below are topics that could benefit from a transdisciplinary approach to enhance our understanding of

the basic behavioral and social processes and mechanisms underlying interactions/relationships among culture, health, and wellbeing. This list is not exhaustive, but simply provides examples of appropriate topics.

- Develop and test new ethnographic methods that incorporate mobile technologies to better assess cultural beliefs and practices in ways that enable cross-cultural or intra-cultural investigations.
- Develop and test new methods for identifying organizational cultures within health care delivery systems and settings--with attention to variation in norms, practices, and interactions with patients that may affect variables such as engagement in care, treatment adherence, or clinical outcomes.
- Develop and test new metrics for characterizing culture or cultural practices that can be used for basic and/or clinical research.
- Develop and test methods for understanding socialization within stigmatized populations with particular attention to health care practices and beliefs that may be associated with shared stigmas.
- Test hypotheses and develop valid metrics regarding how stigma operates and may be mitigated in the context of HIV prevention and care across relevant settings, including, but not limited to how stigma and negative attitudes towards HIV and persons at-risk for HIV affect the attitudes and behaviors of health care providers.
- Evaluate and assess the relationship between socio-cultural variables and HIV prevention and treatment decisions and behaviors. A better understanding of this relationship can serve as a platform upon which to develop interventions, procedures, practices and policies that minimize the negative variables and/or accentuate the positive variables. Such research may include, for example, research, healthcare, community, and/or legal and policy environments or venues.
- Develop and test methods to collect and analyze data about cultural practices/beliefs, with consideration of their roles as risk or protective factors related to health.
- Investigate the influence of bilingualism/multilingualism on attendance to and processing of health information (e.g., neurological processes, language of message delivered vs. language used at home).
- Investigate how hearing- or visually-impaired people perceive and process health-related information, and how this may vary in the presence of others who share these impairments as opposed to the context of unimpaired individuals.
- Investigate methods for understanding attitude formation within groups.
- Investigate model animal research on the transmission of cultural practices through observational research that may be more feasibly conducted in non-human than human populations.
- Investigate the meaning and validity of prevailing behavioral/social theoretical constructs and concepts about health across cultures.
- Develop and test qualitative and mixed methods approaches to comprehensively explain health behavior in the context of specific cultural practices.

OppNet welcomes research teams that include expertise complementary to basic social and behavioral

sciences, e.g., arts, ethics, humanities, law. Given OppNet's express mission to advance the basic behavioral and social sciences, applications must have a majority emphasis in basic behavioral and social sciences. For feedback on specific topics, please consult the program staff listed in Section VII.

Section II. Award Information

Funding Instrument	Grant
Application Types Allowed	New The OER Glossary and the PHS398 Application Guide provide details on these application types.
Funds Available and Anticipated Number of Awards	OppNet intends to commit $1,425,000 in FY 2013 for 5-7 awards.
Award Budget	Application budgets are expected to range from $125,000 to $150,000 per year direct costs, but need to reflect actual needs of the proposed project.
Award Project Period	Scope of the proposed project should determine the project period. The maximum period is 2 years.

NIH grants policies as described in the *NIH Grants Policy Statement* will apply to the applications submitted and awards made in response to this FOA.

Section III. Eligibility Information

1. Eligible Organizations

Eligible Organizations

Higher Education Institutions

- Public/State Controlled Institutions of Higher Education
- Private Institutions of Higher Education

The following types of Higher Education Institutions are always encouraged to apply for NIH support as Public or Private Institutions of Higher Education:

- Hispanic-serving Institutions
- Historically Black Colleges and Universities (HBCUs)
- Tribally Controlled Colleges and Universities (TCCUs)
- Alaska Native and Native Hawaiian Serving Institutions

Nonprofits Other Than Institutions of Higher Education

- Nonprofits with 501(c)(3) IRS Status (Other than Institutions of Higher Education)
- Nonprofits without 501(c)(3) IRS Status (Other than Institutions of Higher Education)

For-Profit Organizations

- Small Businesses
- For-Profit Organizations (Other than Small Businesses)

Governments

- State Governments
- County Governments
- City or Township Governments
- Special District Governments
- Indian/Native American Tribal Governments (Federally Recognized)
- Indian/Native American Tribal Governments (Other than Federally Recognized)
- Eligible Agencies of the Federal Government
- U.S. Territory or Possession

Other

- Independent School Districts
- Public Housing Authorities/Indian Housing Authorities
- Native American Tribal Organizations (other than Federally recognized tribal governments)
- Faith-based or Community-based Organizations
- Regional Organizations

Foreign Institutions

Non-domestic (non-U.S.) Entities (Foreign Institutions) **are not** eligible to apply.
Non-domestic (non-U.S.) components of U.S. Organizations **are not** eligible to apply.
Foreign components, as defined in the *NIH Grants Policy Statement*, **are not** allowed.

Required Registrations

Applicant organizations must complete the following registrations as described in the PHS398 Application Guide to be eligible to apply for or receive an award. Applicants must have a valid Dun and Bradstreet Universal Numbering System (DUNS) number in order to begin each of the following registrations.

- Central Contractor Registration (CCR) – must maintain an active registration, to be renewed at least annually
- eRA Commons

All Program Director(s)/Principal Investigator(s) (PD(s)/PI(s)) must also work with their institutional officials to register with the eRA Commons or ensure their existing eRA Commons account is affiliated with the eRA Commons account of the applicant organization.

All registrations must be completed by the application due date. Applicant organizations are strongly encouraged to start the registration process at least4-6 weeks prior to the application due date.

Eligible Individuals (Program Director(s)/Principal Investigator(s))

Any individual(s) with the skills, knowledge, and resources necessary to carry out the proposed research as the Program Director(s)/Principal Investigator(s) (PD(s)/PI(s)) is invited to work with his/her organization to develop an application for support. Individuals from underrepresented racial and ethnic groups as well as individuals with disabilities are always encouraged to apply for NIH support.

For institutions/organizations proposing multiple PD(s)/PI(s), visit the Multiple Program Director(s)/ Principal Investigator(s) Policy and submission details in the Senior/Key Person Profile (Expanded) Component of the PHS398 Application Guide.

2. Cost Sharing

This FOA does not require cost sharing as defined in the *NIH Grants Policy Statement.*

3. Additional Information on Eligibility

Number of Applications

Applicant organizations may submit more than one application, provided that each application is scientifically distinct.

NIH will not accept any application in response to this FOA that is essentially the same as one currently pending initial peer review unless the applicant withdraws the pending application.

Section IV. Application and Submission Information

1. Address to Request Application Package

Applicants are required to prepare applications according to the current PHS 398 application forms in accordance with the PHS 398 Application Guide.

2. Content and Form of Application Submission

It is critical that applicants follow the instructions in the PHS398 Application Guide, except where instructed in this funding opportunity announcement to do otherwise. Conformance to the requirements in the Application Guide is required and strictly enforced. Applications that are out of compliance with these instructions may be delayed or not accepted for review.

Letter of Intent

Although a letter of intent is not required, is not binding, and does not enter into the review of a subsequent application, the information that it contains allows IC staff to estimate the potential review workload and plan the review.

By the date listed in Part 1. Overview Information, prospective applicants are asked to submit a letter of intent that includes the following information:

- Descriptive title of proposed research
- Name, address, and telephone number of the PD(s)/PI(s)
- Names of other key personnel
- Participating institutions
- Number and title of this funding opportunity

The letter of intent should be sent to:

Mrs. Paula Roberts
Office of Behavioral and Social Sciences Research
National Institutes of Health
31 Center Drive, Suite B1C19, MSC 2027
Bethesda, MD 20892-2027
For non-US Mail courier services, please use ZIP code 20814
Telephone: 301-451-3873
Email: paula.roberts@nih.gov

Application Submission

Applications must be prepared using the PHS 398 research grant application forms and instructions for preparing a research grant application. Submit a signed, typewritten original of the application, including the checklist, and five signed photocopies and all copies of the Appendix files in one package to:

Center for Scientific Review
National Institutes of Health
6701 Rockledge Drive, Room 1040, MSC 7710
Bethesda, MD 20892-7710 (U.S. Postal Service Express or regular mail)
Bethesda, MD 20817 (for express/courier service; non-USPS service)

Page Limitations

All page limitations described in the PHS398 Application Guide and the Table of Page Limits must be followed.

Research Plan

All instructions in the PHS398 Application Guide must be followed.

Resource Sharing Plan

Individuals are required to comply with the instructions for the Resource Sharing Plans (Data Sharing Plan, Sharing Model Organisms, and Genome Wide Association Studies (GWAS)) as provided in the PHS398 Application Guide.

Appendix

Do not use the Appendix to circumvent page limits. Follow all instructions for the Appendix (please note all format requirements) as described in the PHS398 Application Guide.

3. Submission Dates and Times

Part I. Overview Information contains information about Key Dates.

Information on the process of receipt and determining if your application is considered “on-time” is described in detail in the PHS398 Application Guide.

Applicants may track the status of the application in the , NIH’s electronic system for grants administration.

4. Intergovernmental Review (E.O. 12372)

This initiative is not subject to intergovernmental review.

5. Funding Restrictions

All NIH awards are subject to the terms and conditions, cost principles, and other considerations described in the *NIH Grants Policy Statement*.

Pre-award costs are allowable only as described in the *NIH Grants Policy Statement*.

6. Other Submission Requirements and Information

Applications must be postmarked on or before the due dates in Part I. Overview Information.

Upon receipt, applications will be evaluated for completeness by the Center for Scientific Review and responsiveness by components of participating organizations, NIH. Applications that are incomplete and/or nonresponsive will not be reviewed.

Post Submission Materials

Applicants are required to follow the instructions for post-submission materials, as described in NOT-OD-10-115.

Section V. Application Review Information

1. Criteria

Only the review criteria described below will be considered in the review process. As part of the NIH mission, all applications submitted to the NIH in support of biomedical and behavioral research are evaluated for scientific and technical merit through the NIH peer review system.

Overall Impact

Reviewers will provide an overall impact/priority score to reflect their assessment of the likelihood for the project to exert a sustained, powerful influence on the research field(s) involved, in consideration of the following review criteria and additional review criteria (as applicable for the project proposed).

Scored Review Criteria

Reviewers will consider each of the review criteria below in the determination of scientific merit, and give a separate score for each. An application does not need to be strong in all categories to be judged likely to have major scientific impact. For example, a project that by its nature is not innovative may be essential to advance a field.

Significance

Does the project address an important problem or a critical barrier to progress in the field? If the aims of the project are achieved, how will scientific knowledge, technical capability, and/or clinical practice be improved? How will successful completion of the aims change the concepts, methods,

technologies, treatments, services, or preventative interventions that drive this field?

Investigator(s)

Are the PD(s)/PI(s), collaborators, and other researchers well suited to the project? If Early Stage Investigators or New Investigators, or in the early stages of independent careers, do they have appropriate experience and training? If established, have they demonstrated an ongoing record of accomplishments that have advanced their field(s)? If the project is collaborative or multi-PD(s)/PI(s), do the investigators have complementary and integrated expertise; are their leadership approach, governance and organizational structure appropriate for the project?

Innovation

Does the application challenge and seek to shift current research or clinical practice paradigms by utilizing novel theoretical concepts, approaches or methodologies, instrumentation, or interventions? Are the concepts, approaches or methodologies, instrumentation, or interventions novel to one field of research or novel in a broad sense? Is a refinement, improvement, or new application of theoretical concepts, approaches or methodologies, instrumentation, or interventions proposed?

Approach

Are the overall strategy, methodology, and analyses well-reasoned and appropriate to accomplish the specific aims of the project? Are potential problems, alternative strategies, and benchmarks for success presented? If the project is in the early stages of development, will the strategy establish feasibility and will particularly risky aspects be managed?

If the project involves clinical research, are the plans for 1) protection of human subjects from research risks, and 2) inclusion of minorities and members of both sexes/genders, as well as the inclusion of children, justified in terms of the scientific goals and research strategy proposed?

Environment

Will the scientific environment in which the work will be done contribute to the probability of success? Are the institutional support, equipment and other physical resources available to the investigators adequate for the project proposed? Will the project benefit from unique features of the scientific environment, subject populations, or collaborative arrangements?

Additional Review Criteria

As applicable for the project proposed, reviewers will evaluate the following additional items while determining scientific and technical merit, and in providing an overall impact/priority score, but will not give separate scores for these items.

Protections for Human Subjects

For research that involves human subjects but does not involve one of the six categories of research that are exempt under 45 CFR Part 46, the committee will evaluate the justification for involvement of human subjects and the proposed protections from research risk relating to their participation according to the following five review criteria: 1) risk to subjects, 2) adequacy of protection against risks, 3) potential benefits to the subjects and others, 4) importance of the knowledge to be gained, and 5) data and safety monitoring for clinical trials.

For research that involves human subjects and meets the criteria for one or more of the six categories of research that are exempt under 45 CFR Part 46, the committee will evaluate: 1) the justification for the exemption, 2) human subjects involvement and characteristics, and 3) sources of materials. For additional information on review of the Human Subjects section, please refer to the Human Subjects Protection and Inclusion Guidelines.

Inclusion of Women, Minorities, and Children

When the proposed project involves clinical research, the committee will evaluate the proposed plans for inclusion of minorities and members of both genders, as well as the inclusion of children. For additional information on review of the Inclusion section, please refer to the Human Subjects Protection and Inclusion Guidelines.

Vertebrate Animals

The committee will evaluate the involvement of live vertebrate animals as part of the scientific assessment according to the following five points: 1) proposed use of the animals, and species, strains, ages, sex, and numbers to be used; 2) justifications for the use of animals and for the appropriateness of the species and numbers proposed; 3) adequacy of veterinary care; 4) procedures for limiting discomfort, distress, pain and injury to that which is unavoidable in the conduct of scientifically sound research including the use of analgesic, anesthetic, and tranquilizing drugs and/or comfortable restraining devices; and 5) methods of euthanasia and reason for selection if not consistent with the AVMA Guidelines on Euthanasia. For additional information on review of the Vertebrate Animals section, please refer to the Worksheet.

Biohazards

Reviewers will assess whether materials or procedures proposed are potentially hazardous to research personnel and/or the environment, and if needed, determine whether adequate protection is proposed.

Resubmissions

Not Applicable.

Renewals

Not Applicable.

Revisions

Not Applicable.

Additional Review Considerations

As applicable for the project proposed, reviewers will consider each of the following items, but will not give scores for these items, and should not consider them in providing an overall impact/priority score.

Applications from Foreign Organizations

Not Applicable.

Select Agent Research

Reviewers will assess the information provided in this section of the application, including 1) the Select Agent(s) to be used in the proposed research, 2) the registration status of all entities where Select Agent(s) will be used, 3) the procedures that will be used to monitor possession use and transfer of Select Agent(s), and 4) plans for appropriate biosafety, biocontainment, and security of the Select Agent(s).

Resource Sharing Plans

Reviewers will comment on whether the following Resource Sharing Plans, or the rationale for not sharing the following types of resources, are reasonable: 1) Data Sharing Plan; 2) Sharing Model Organisms; and 3) Genome Wide Association Studies (GWAS).

Budget and Period of Support

Reviewers will consider whether the budget and the requested period of support are fully justified and reasonable in relation to the proposed research.

2. Review and Selection Process

Applications will be evaluated for scientific and technical merit by (an) appropriate Scientific Review Group(s)convened by the CSR, in accordance with NIH peer review policy and procedures, using the stated review criteria. Review assignments will be shown in the eRA Commons.

As part of the scientific peer review, all applications:

- May undergo a selection process in which only those applications deemed to have the highest scientific and technical merit (generally the top half of applications under review) will be discussed and assigned an overall impact/priority score.
- Will receive a written critique.

Appeals of initial peer review will not be accepted for applications submitted in response to this FOA.

Applications will be assigned on the basis of established PHS referral guidelines to the appropriate NIH Institute or Center and will compete for available funds with all other recommended applications submitted in response to this FOA. Following initial peer review, recommended applications will receive a second level of review by the appropriate national Advisory Council or Board. The following will be considered in making funding decisions:

- Scientific and technical merit of the proposed project as determined by scientific peer review.
- Availability of funds.
- Relevance of the proposed project to program priorities.

3. Anticipated Announcement and Award Dates

After the peer review of the application is completed, the PD(s)/PI(s) will be able to access his or her Summary Statement (written critique) via the eRA Commons.

Information regarding the disposition of applications is available in the *NIH Grants Policy Statement*.

Section VI. Award Administration Information

1. Award Notices

If the application is under consideration for funding, NIH will request "just-in-time" information from the applicant as described in the *NIH Grants Policy Statement*.

A formal notification in the form of a Notice of Award (NoA) will be provided to the applicant organization for successful applications. The NoA signed by the grants management officer is the authorizing document and will be sent via email to the grantee's business official.

Awardees must comply with any funding restrictions described in Section IV.5. Funding Restrictions. Selection of an application for award is not an authorization to begin performance. Any costs incurred before receipt of the NoA are at the recipient's risk. These costs may be reimbursed only to the extent considered allowable pre-award costs.

Any application awarded in response to this FOA will be subject to the DUNS, CCR Registration, and Transparency Act requirements as noted on the Award Conditions and Information for NIH Grants website.

2. Administrative and National Policy Requirements

All NIH grant and cooperative agreement awards include the *NIH Grants Policy Statement* as part of the NoA. For these terms of award, see the NIH Grants Policy Statement Part II: Terms and Conditions of NIH Grant Awards, Subpart A: General and Part II: Terms and Conditions of NIH Grant Awards, Subpart B: Terms and Conditions for Specific Types of Grants, Grantees, and Activities. More information is provided at Award.

Cooperative Agreement Terms and Conditions of Award

Not Applicable.

3. Reporting

When multiple years are involved, awardees will be required to submit the Non-Competing Continuation Grant Progress Report (PHS 2590) annually and financial statements as required in the *NIH Grants Policy Statement.*

A final progress report, invention statement, and the expenditure data portion of the Federal Financial Report are required for closeout of an award, as described in the *NIH Grants Policy Statement*.

The Federal Funding Accountability and Transparency Act of 2006 (Transparency Act), includes a requirement for awardees of Federal grants to report information about first-tier subawards and executive compensation under Federal assistance awards issued in FY2011 or later. All awardees of applicable NIH grants and cooperative agreements are required to report to the Federal Subaward Reporting System (FSRS) available at www.fsrs.gov on all subawards over $25,000. See the *NIH*

Grants Policy Statement for additional information on this reporting requirement.

Section VII. Agency Contacts

We encourage inquiries concerning this funding opportunity and welcome the opportunity to answer questions from potential applicants.

Application Submission Contacts

GrantsInfo (Questions regarding application instructions and process, finding NIH grant resources)
Telephone 301-435-0714
TTY 301-451-5936
Email: GrantsInfo@nih.gov

eRA Commons Help Desk (Questions regarding eRA Commons registration, tracking application status, post submission issues)
Phone: 301-402-7469 or 866-504-9552 (Toll Free)
TTY: 301-451-5939
Email: commons@od.nih.gov

Scientific/Research Contact(s)

Potential applicants may contact any program-level, OppNet Coordinating Committee member: http://oppnet.nih.gov/about-members.asp#coordinating. The following scientific contacts are familiar with both this funding announcement's topic area and the OppNet initiative:

Dr. Dorothy Castille
National Institute on Minority Health and Health Disparities (NIMHD)
Telephone: 301-594-9411
Email: castilledm@mail.nih.gov

Dr. William Elwood
Office of Behavioral and Social Sciences Research (OBSSR)
Office of the Director (NIH OD)
Telephone: 301-402-0116
Email: william.elwood@nih.gov

Dr. Richard Jenkins
National Institute on Drug Abuse (NIDA)
Telephone: 301-443-1923
Email: jenkinsri@mail.nih.gov

Dr. Helen Meissner
Office of Behavioral and Social Sciences Research (OBSSR)
Office of the Director (NIH OD)
Telephone: 301-594-2105

Email: meissneh@mail.nih.gov

Dr. Lana Shekim
Director, Voice & Speech Programs
National Institute on Deafness and Communication Disorders (NIDCD)
Telephone: 301-496-5061
Email: shekiml@nidcd.nih.gov

Dr. Alan VanBiervliet
Division of Extramural Programs
National Library of Medicine (NLM)
Telephone: 301-594-1297
Email: vanbiervlietag@mail.nih.gov

Peer Review Contact(s)

Examine your eRA Commons account for review assignment and contact information (information appears two weeks after the submission due date).

Financial/Grants Management Contact(s)

Ms. Maryellen Connell
Grants Management Branch
National Institute on Drug Abuse (NIDA)
Telephone: 301-774-3803
Email: mconnell@mail.nih.gov

Ms. Priscilla Grant
Chief Grants Management Officer
National Institute on Minority Health and Health Disparities (NIMHD)
Telephone: 301-594-8412
Email: grantp@mail.nih.gov

Mr. Dwight Mowery
Extramural Programs
National Library of Medicine (NLM)
Telephone: 301-496-4221
Email: moweryd@mail.nih.gov

Mr. Christopher Myers
Chief, Grants Management Branch
National Institute on Deafness and Communication Disorders (NIDCD)
Telephone: 301-435-0713
Email: myersc@mail.nih.gov

Section VIII. Other Information

Recently issued trans-NIH policy notices may affect your application submission. A full list of policy notices published by NIH is provided in the *NIH Guide for Grants and Contracts*. All awards are subject to the terms and conditions, cost principles, and other considerations described in the *NIH Grants Policy Statement*.

Authority and Regulations

Awards are made under the authorization of Sections 301 and 405 of the Public Health Service Act as amended (42 USC 241 and 284) and under Federal Regulations 42 CFR Part 52 and 45 CFR Parts 74 and 92.

Department of Health and Human Services

Part 1. Overview Information

Participating Organization(s)	National Institutes of Health (NIH)
Components of Participating Organizations	National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
Funding Opportunity Title	Promoting Organ and Tissue Donation Among Diverse Populations (R01)
Activity Code	R01 Research Project Grant
Announcement Type	Reissue of RFA-DK-06-016
Related Notices	None
Funding Opportunity Announcement (FOA) Number	RFA-DK-12-006
Companion Funding Opportunity	None
Number of Applications	See Section III. 3. Additional Information on Eligibility.
Catalog of Federal Domestic Assistance (CFDA) Number(s)	93.847
Funding Opportunity Purpose	This Funding Opportunity Announcement (FOA) issued by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), National Institutes of Health (NIH), invites investigators to apply for a grant to develop hypothesis-driven educational programs to increase the number of both living and deceased donor organs and tissue donated for transplantation from minority and other health disparity populations. This FOA intends to stimulate investigators to develop effective culturally sensitive educational and behavioral interventions to improve the attitudes, beliefs and behaviors towards organ and tissue transplantation, as well as the need for organ transplantation, among minority and other health disparity populations. The grant will provide support for the development and testing of educational and behavioral programs in minority and other health disparity populations to enhance their understanding of the need, risks and benefits of organ and tissue donation, and ultimately to increase the number of minority and other health disparity populations participating in living and deceased organ donation.

Key Dates

Posted Date	May 2, 2012
Open Date (Earliest Submission Date)	June 3, 2012
Letter of Intent Due Date	June 3, 2012
Application Due Date(s)	July 3, 2012, by 5:00 PM local time of applicant organization.
AIDS Application Due Date(s)	Not Applicable.
Scientific Merit Review	July/August, 2012
Advisory Council Review	October, 2012
Earliest Start Date(s)	December, 2012
Expiration Date	July 4, 2012
Due Dates for E.O. 12372	Not Applicable

Required Application Instructions

It is critical that applicants follow the instructions in the SF 424 (R&R) Application Guide, except where instructed to do otherwise (in this FOA or in a Notice from the *NIH Guide for Grants and Contracts*). Conformance to all requirements (both in the Application Guide and the FOA) is required and strictly enforced. Applicants must read and follow all application instructions in the Application Guide as well as any program-specific instructions noted in Section IV. When the program-specific instructions deviate from those in the Application Guide, follow the program-specific instructions. **Applications that do not comply with these instructions may be delayed or not accepted for review.**

Table of Contents

Part 1. Overview Information
Part 2. Full Text of the Announcement
Section I. Funding Opportunity Description
Section II. Award Information
Section III. Eligibility Information
Section IV. Application and Submission Information
Section V. Application Review Information
Section VI. Award Administration Information
Section VII. Agency Contacts
Section VIII. Other Information

Part 2. Full Text of Announcement

Section I. Funding Opportunity Description

Background:

For many Americans with end-stage organ disease, the best therapeutic option is to receive either a deceased or living donor organ for transplantation. The introduction of organ transplantation, beginning with kidneys in 1954 and the liver in 1967, revolutionized the care and prognosis for individuals with end-stage kidney disease (ESRD) and end-stage liver disease (ESLD).

Unfortunately, the need for organ transplantation continues to exceed the availability of donated organs for transplantation. Additionally, the number of Americans with ESRD and ESLD who require organ transplants continues to rise. In order to increase the number of organs available for transplantation, many efforts have arisen for the lagging supply to meet the demand. Initially, organs for transplantation were recovered from living donation donors (LDD), initially taking place between identical twins due to the absence of potent immunosuppressive medications. Living donors may be related to the organ recipient, but increasingly is occurring between genetically unrelated persons, such as spouses, friends, other emotionally related individuals. The second source of organs for donation come from deceased donation donors (DDD), who are brain dead but still heart-beating. Organs recovered from DD outnumber the total number of organs recovered from LD, but are not without complications. However, the morbidity and mortality rates associated with organ transplantation remain significantly lower than those rates seen with ESRD and ESLD treated medically. Furthermore, the economic cost is lower for the post-transplant care of individuals with ESRD and ESLD compared to the continued medical care of these patients without organ transplantation.

Unfortunately, the number of organs recoverable from DD has been relatively stable, despite the continuing growth in the number of ESRD and ESLD patients.

The incidence and prevalence of ESRD continue to rise slowly in the United States (US). In the Annual Data Report 2011, the United States Renal Data Systems (USRDS) reports that the incidence of new ESRD in the U.S. rose 1.1 percent in 2009, to 355 cases per million population. Similarly, the prevalence of ESRD in the U.S. rose 2.1 percent from 2008 to 1,738 cases per million population. Translated in to the actual numbers, the overall incidence and prevalence of ESRD in 2009 were more 116,000 and 570,000 Americans, respectively. In 2009, the cost to the U.S. economy totaled approximately $29 billion, representing nearly 9% of the total Medicare spending (approximately $318 million) in the same year while accounting for less than 2% of the total Medicare recipients. The expenditures per person per year (PPPY) vary according to the renal replacement modality used to treat ESRD, with hemodialysis costing approximately $80,000 PPPY, peritoneal dialysis costing approximately $60,000 PPPY, and transplantation costing approximately $30,000 PPPY.

In addition to the extraordinary costs associated with the care of persons with ESRD, these same individuals experience unacceptably high morbidity and mortality rates, with the adjusted rates of all-cause mortality 6.5 to 7.4 times greater for dialysis patients with ESRD than for individuals in the general population. While the adjusted rates of all-cause mortality are lower for ESRD patients who receive renal transplants, the rates remain 1.1 to 1.6 times greater than for the general population. While the overall adjusted all-cause mortality rates have declined over the last 20 years, renal transplant recipients experience the lowest all-cause mortality rates from one to five-years post-transplant compared to ESRD patients treated with either hemodialysis or peritoneal dialysis for one to five years. Adjusted survival probabilities for one and five-year are worst for ERSD patients treated with hemodialysis (0.75 and 0.34, respectively) compared to peritoneal dialysis (0.85 and 0.40, respectively) and to renal transplant (0.92 and 0.73, respectively). Finally, the adjusted hospitalization rates tend to be higher among women than men with ESRD, and among Black or African Americans compared to whites.

Similar to the incidence and prevalence of ESRD in the US, chronic liver disease and ESLD exact a significant toll on the population. In 2002, chronic liver disease reportedly was the 12th leading cause of death in the US, accounting for more than 27,000 deaths/year (mortality rate of 9.4/100,000 population). For many of the causes of ESLD in the U.S. (e.g., alcohol-related cirrhosis, Hepatitis B, immune-

mediated liver injury, hepatotoxic drugs, cholestatic diseases, genetic abnormalities, and nonalcoholic steatohepatitis), the incidence and prevalence have been declining. In contrast, the incidence and prevalence of ESLD secondary to Hepatitis C and hepatocellular carcinoma have been increasing. The estimated cost to the healthcare system in the U.S. for the care of chronic liver disease and cirrhosis, excluding patients with Hepatitis C infection, is approximately $1.6 billion per year.

As of February 24, 2012, the Organ Procurement and Transplantation Network (OPTN) reports that there are 91,015 candidates on the wait list for a kidney transplant; 16,060 candidates on the wait list for a liver transplant; 1,297 and 2,129 candidates on the wait list for a pancreas and kidney/pancreas transplant; and 285 candidates on the wait list for intestine transplant. In contrast, as of November 30, 2011, there were 15,416 kidneys; 5,840 livers; 270 pancreas and 738 kidney/pancreas; and 124 intestines transplanted in 2011.

Thus, not only does transplantation result in significant savings in the expenditures PPPY, transplantation also improves the all-cause and specific-cause hospitalization rates and the adjusted mortality rates at one and five years for both ESRD and ESLD patients. Therefore, the NIH and the NIDDK seek to promote the selection of organ transplantation as a more economical and efficacious treatment modality for ESRD and ESLD patients.

Research Objectives:

Data from the 2010 United States Census ("Census") documents the composition of the U.S. population. The current U.S. population is 308,745,538 persons. With regards to the ethnicity of the U.S. population, 16.3% identify themselves as "Hispanic or Latino," an increase of 43% from the 2000 Census. Racially, the U.S. population identifies themselves as 72.5% "White," 12.6% "Black or African American," 6.2% "Some Other Race," 4.5% "Asian," 2.9% "Two or More Races," 0.9% "American Indian or Alaska Native" and 0.2% "Native Hawaiian or Other Pacific Islander." Additionally, the 2010 Census reports that the "rural" population in the U.S. is approximately 51 million, accounting for approximately 16.5% of the U.S. population. These data serve as the baseline metrics for the diversity of the U.S. population.

Unfortunately, ESRD does not afflict the U.S. population equally. The USRDS Annual Data Reports have clearly demonstrated that certain minority and other health disparity populations are disproportionately represented in the ESRD population. According to the USRDS Annual Data Report 2011 (website: http://www.usrds.org), ESRD disproportionately affects Black or African Americans, American Indian or Alaska Native, and males.

Similarly, ESRD patients living in rural environments have been shown to have longer waiting time to transplant, and Black or African Americans living in rural environments have lower survival rates compared to Black or African Americans living in urban environments, despite more frequent treatment of ESRD using peritoneal dialysis among the former. Similarly, O'Hare AM, et al. (*Kidney Int*, 2006) reported that nearly 22% of the ESRD population live in rural environments, in contrast to the 16.5% of the total U.S. population living in rural environments.

As these data demonstrate, ethnicity, race, gender and environment all impact the morbidity and mortality of Americans with ESRD, even after adjustment for factors that may affect the calculated risks. Therefore, the NIH and the NIDDK recognize the importance of addressing these health disparities among minority and other health disparity populations in order to improve the morbidity and mortality of these individuals with ESRD. As has been shown, renal transplantation is the preferred treatment modality for ESRD, associated with the lowest expenditures PPPY, the lowest all-cause and cause-specific hospitalizations, and the lowest all-cause and specific-cause mortality rates.

According to the Organ Procurement and Transplantation Network (OPTN) of the Health Resources and

Services Administration (HRSA) (website: http://optn.transplant.hrsa.gov/), differences exist between minority and other health disparity populations organ donors for both kidneys and livers, and that other differences exist between LD and DD organs.

For kidneys, from 2000 through 2010, the total number of kidneys recovered for organ donation from LDD increased by only 14.2%. Among Whites, the total number of kidney recovered increased by 12.7%, whereas the total number of kidneys recovered from Black or African American donors increased by only 6.8%. While the numbers are quite small, organs recovered from American Indian or Alaska Natives and Native Hawaiians or Other Pacific Islanders actually decreased by 29% and 58%, respectively. By gender, the number of kidneys recovered from male LDD decreased by 0.3% during the same decade, whereas female LDD increased by 25%. Women LDD now account for approximately 60% of all of the LDD kidneys recovered annually in the US.

In contrast, during the same decade, the total number of kidneys recovered for organ donation from DDD increased by 31.9%. In contrast to LDD, the growth in DDD kidneys recovered from White donors increased by only 16.9%, compared to an increase of 90% and 70% for Black or African Americans and Hispanics, respectively. Native Hawaiians and Other Pacific Islander DDD decreased by 45%, similar to the trend seen among LDD. In contrast to the LDD data for DDD kidneys recovered by gender, males account for nearly 60% of all of the DDD kidneys recovered annually in the US, with a 34% increase during the last decade compared to a 29% increase among female DDD.

Similar to the kidney data, the OPTN data demonstrates similar disparities in organ donation among both LDD and DDD for livers. During the decade from 2000 through 2010, the total number of livers transplanted annually from DDD increased by 25.8%, with only an 18% increase among Whites but a 57% increase among Black or African Americans and 37% increase among Hispanics. Similar to the DDD kidneys, the total number of livers recovered for transplantation from DDD increased by 34% among male donors compared to 13% among female donors.

Perhaps most concerning, the OPTN data demonstrates a significant decrease in the number of livers available for transplantation from LDD during the decade. The number of LDD livers transplanted annually in the U.S. actually decreased by 30%, with large declines among Whites (34%), Blacks or African Americans (42%), Hispanics (11%) and Native Hawaiians or Other Pacific Islanders (75%). Gender again demonstrates differences, with a 38% decrease in LDD livers among male donors compared to a 22% decrease among female donors.

The disparities in the LDD and DDD donations rates for both kidneys and livers, and particularly the decline in LDD for liver transplantation, have led to significant differences in the median duration of time on the wait list for candidates for kidney and liver transplantation.

For kidney transplant candidates, the current median wait list times are:

- White: 1,310 days (3.6 years)
- Black or African American: 1,831 days (5.0 years)
- American Indian or Alaska Native: 1,501 days (4.1 years)
- Asian: 1,826 days (5.0 years)
- Native Hawaiian or Other Pacific Islander: 2,604 days (7.1 years)
- Hispanic: 2,011 days (5.5 years)

For liver transplant candidates, the current median wait list times are:

- White: 357 days

- Black or African American: 169 days
- American Indian or Alaska Native: 140 days
- Asian: 311 days
- Native Hawaiian or Other Pacific Islander: 250 days
- Hispanic: 651 days

Therefore, the NIH and the NIDDK seek to promote research into the barriers to both DDD and LDD organ transplantation among non-White racial populations, Hispanic or Latino ethnic populations, males for LDD, and rural populations.

Previously, the NIH and the NIDDK have supported the National Minority Organ Tissue Transplant Education Program (MOTTEP) in order to promote research, community outreach, and program development within the Black or African American population within the District of Columbia in order to address the shortage of organ donors in the Black or African American communities. As a result of the MOTTEP, reasons for reluctance among Black or African Americans to be organ donors included:

- Lack of community awareness of the ability to donor organs or the magnitude of the problem in the Black or African American community;
- Religious myths and misperceptions about organ donation;
- Distrust of the medical community;
- Fear of being declared dead in order to obtain organs for donation; and
- Racism fears of organs donated by Black or African Americans being transplanted only into Whites.

Thus, the goal of this FOA is to develop educational and behavioral interventions specifically designed to increase the number of both LDD and DDD organs and tissue donated for transplantation from minority and other health disparity populations. This FOA intends to stimulate investigators to develop effective and culturally sensitive educational and behavioral programs to improve the attitudes, beliefs and behaviors towards organ and tissue transplantation, as well as the need for organ transplantation, among minority and other health disparity populations and rural communities. The grant will provide support for the development of culturally sensitive educational and behavioral programs in minority and other health disparity populations to enhance their understanding of the need, risks and benefits of organ and tissue donation, and ultimately to increase the number of minority and other health disparity populations participating in living and deceased organ donation.

After the award project period (e.g. 5 years), the NIDDK will review the overall success of the entire program in order to determine whether to continue funding it as currently configured. This review may be distinct from the individual reviews that take place under the auspices of the annual Progress Reports. The discontinuation of the program is a policy option that may be made at the discretion of the NIDDK.

Section II. Award Information

Funding Instrument	Grant
Application Types Allowed	New Renewal The OER Glossary and the SF 424 (R&R) Application Guide provide details on these application types.
Funds Available and Anticipated Number of Awards	The NIDDK intends to commit $1,500,000 in FY 2012.
Award Budget	Application budgets are limited to an annual direct cost per application of $150,000.
Award Project Period	The total project period for an application submitted in response to this FOA may not exceed 5 years.

NIH grants policies as described in the *NIH Grants Policy Statement* will apply to the applications submitted and awards made in response to this FOA.

Section III. Eligibility Information

1. Eligible Applicants

Eligible Organizations

Higher Education Institutions

- Public/State Controlled Institutions of Higher Education
- Private Institutions of Higher Education

The following types of Higher Education Institutions are always encouraged to apply for NIH support as Public or Private Institutions of Higher Education:

- Hispanic-serving Institutions
- Historically Black Colleges and Universities (HBCUs)
- Tribally Controlled Colleges and Universities (TCCUs)
- Alaska Native and Native Hawaiian Serving Institutions

Nonprofits Other Than Institutions of Higher Education

- Nonprofits with 501(c)(3) IRS Status (Other than Institutions of Higher Education)
- Nonprofits without 501(c)(3) IRS Status (Other than Institutions of Higher Education)

For-Profit Organizations

- Small Businesses
- For-Profit Organizations (Other than Small Businesses)

Governments

- State Governments
- County Governments
- City or Township Governments
- Special District Governments
- Indian/Native American Tribal Governments (Federally Recognized)
- Indian/Native American Tribal Governments (Other than Federally Recognized)
- Eligible Agencies of the Federal Government
- U.S. Territory or Possession

Other

- Independent School Districts
- Public Housing Authorities/Indian Housing Authorities
- Native American Tribal Organizations (other than Federally recognized tribal governments)
- Faith-based or Community-based Organizations
- Regional Organizations

Foreign Institutions

Non-domestic (non-U.S.) Entities (Foreign Institutions) **are not** eligible to apply.
Non-domestic (non-U.S.) components of U.S. Organizations **are not** eligible to apply.

Foreign components, as defined in the *NIH Grants Policy Statement*, **are not** allowed.

Required Registrations

Applicant organizations must complete the following registrations as described in the SF 424 (R&R) Application Guide to be eligible to apply for or receive an award. Applicants must have a valid Dun and Bradstreet Universal Numbering System (DUNS) number in order to begin each of the following registrations.

- Central Contractor Registration (CCR) – must maintain an active registration, to be renewed at least annually
- Grants.gov
- eRA Commons

All Program Director(s)/Principal Investigator(s) (PD(s)/PI(s)) must also work with their institutional officials to register with the eRA Commons or ensure their existing eRA Commons account is affiliated with the eRA Commons account of the applicant organization.

All registrations must be completed by the application due date. Applicant organizations are strongly encouraged to start the registration process at least 4-6 weeks prior to the application due date.

Eligible Individuals (Program Director(s)/Principal Investigator(s))

Any individual(s) with the skills, knowledge, and resources necessary to carry out the proposed research as the Program Director(s)/Principal Investigator(s) (PD(s)/PI(s)) is invited to work with his/her organization to develop an application for support. NIH recognizes a unique and compelling need to promote diversity in the NIH-funded biomedical, behavioral, clinical and social sciences workforce. The NIH expects efforts to diversify the workforce to lead to the recruitment of the most talented researchers from all groups; improve the quality of the educational and training environment; balance and broaden perspectives into clinical research protocols; and to improve the Nation's capacity to address and eliminate health disparities.

Accordingly, given that the target research populations for FOA represent individuals from minority health and other health disparity populations, individuals from these populations are strongly encouraged to apply, as well as individuals with experience providing culturally and linguistically competent care to these populations.

For institutions/organizations proposing multiple PD(s)/PI(s), visit the Multiple Program Director(s)/Principal Investigator(s) Policy and submission details in the Senior/Key Person Profile (Expanded) Component of the SF 424 (R&R) Application Guide.

Additionally, eligible individuals to serve as the PD/PI for this research program grant should demonstrate their clinical and research abilities to provide "cultural and linguistic competent" care. The definition of "cultural and linguistic competence" has been established by the Office of Minority Health as "a set of congruent behaviors, attitudes, and policies that come together in a system, agency or among professionals that enables effective work in cross-cultural situations. 'Culture' refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups. 'Competence' implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities." (From "National Standards for Culturally and Linguistically Appropriate Services in Health Care - Final Report," available at:http://minorityhealth.hhs.gov/assets/pdf/checked/finalreport.pdf).

2. Cost Sharing

This FOA does not require cost sharing as defined in the *NIH Grants Policy Statement.*

3. Additional Information on Eligibility

Number of Applications

Applicant organizations may submit more than one application, provided that each application is scientifically distinct.

NIH will not accept any application in response to this FOA that is essentially the same as one currently pending initial peer review unless the applicant withdraws the pending application. NIH will not accept any application that is essentially the same as one already reviewed.

Section IV. Application and Submission Information

1. Requesting an Application Package

Applicants must download the SF424 (R&R) application package associated with this funding opportunity using the "Apply for Grant Electronically" button in this FOA or following the directions provided atGrants.gov.

2. Content and Form of Application Submission

It is critical that applicants follow the instructions in the SF424 (R&R) Application Guide, except where instructed in this funding opportunity announcement to do otherwise. Conformance to the requirements in the Application Guide is required and strictly enforced. Applications that are out of compliance with these instructions may be delayed or not accepted for review.

For information on Application Submission and Receipt, visit Frequently Asked Questions – Application Guide, Electronic Submission of Grant Applications.

Letter of Intent

Although a letter of intent is not required, is not binding, and does not enter into the review of a subsequent application, the information that it contains allows IC staff to estimate the potential review workload and plan the review.

By the date listed in Part 1. Overview Information, prospective applicants are asked to submit a letter of intent that includes the following information:

- Descriptive title of proposed research
- Name, address, and telephone number of the PD(s)/PI(s)
- Names of other key personnel
- Participating institutions
- Number and title of this funding opportunity

The letter of intent should be sent to:

Francisco O. Calvo, Ph.D.
Chief, NIDDK Review Branch
National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
6707 Democracy Boulevard, Room 752, MSC 5452
Bethesda, MD 20892-5452 (courier Zip Code 20817)
Telephone: 301-594-8897

Email: calvof@mail.nih.gov

Required and Optional Components

The forms package associated with this FOA includes all applicable components, mandatory and optional. Please note that some components marked optional in the application package are required for submission of applications for this FOA. Follow all instructions in the SF424 (R&R) Application Guide to ensure you complete all appropriate "optional" components.

Page Limitations

All page limitations described in the SF424 Application Guide and the Table of Page Limits must be followed.

SF424(R&R) Other Project Information Component

10. Facilities and Other Resources:

Information regarding the facilities to be used and the Applicant Organization must be provided documenting the facilities' and organization's compliance with the standards for culturally and linguistically appropriate service (CLAS). The standards for CLAS are provided in the "National Standards for Culturally and Linguistically Appropriate Services in Health Care (Final Report)," issued by the U.S. Department of Health and Human Services' (HHS) Office of Minority Health (OMH) (available at: http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=15).

Specifically, the CLAS Standards regarding Culturally Competent Care (Standards 1 through 3) and Language Access Service (Standards 4 through 7) are mandatory to be considered an eligible Applicant Organization. These specific standards are:

Culturally Competent Care:

- **Standard 1:** "Health care organizations should ensure that patients/consumers receive from all staff members effective, understandable, and respectful care that is provided in a manner compatible with their cultural health beliefs and practices and preferred language."
- **Standard 2:** "Health care organizations should implement strategies to recruit, retain, and promote at all levels of the organization a diverse staff and leadership that are representative of the demographic characteristics of the service area."
- **Standard 3:** "Health care organizations should ensure that staff at all levels and across all disciplines receive ongoing education and training in culturally and linguistically appropriate service delivery."
- Language Access Service:
- **Standard 4:** "Health care organizations must offer and provide language assistance services, including bilingual staff and interpreter services, at no cost to each patient/consumer with limited English proficiency at all points of contact, in a timely manner during all hours of operation."
- **Standard 5:** "Health care organizations must provide to patients/consumers in their preferred language both verbal offers and written notices informing them of their right to receive language assistance services."
- **Standard 6:** "Health care organizations must assure the competence of language assistance

provided to limited English proficient patients/consumers by interpreters and bilingual staff. Family and friends should not be used to provide interpretative services (except on request by the patient/consumer)."

- **Standard 7:** "Health care organizations must make available easily understood patient-related materials and post signage in the languages of the commonly encountered groups and/or groups represented in the service areas."

The documentation must include details regarding how the Applicant Organization and all involved facilities meet each of the aforementioned Standards. Failure to document any of the four Language Access Service standards will be considered evidence of an Organization's ineligibility to participate in this FOA.

Additionally, information regarding the Applicant Organization's and involved facilities' compliance with the CLAS standards demonstrating the Organizational Supports for Cultural Competence (Standards 8 through 14) lends further evidence to the cultural and linguistic competence of the Applicant Organization, involved facilities, and research staff. The aforementioned Standards are:

- **Standard 8:** "Health care organizations should develop, implement, and promote a written strategic plan that outlines clear goals, policies, operational plans, and management accountability/oversight mechanisms to provide culturally and linguistically appropriate services."

- **Standard 9:** "Health care organizations should conduct initial and ongoing organizational self-assessments of CLAS-related activities and are encouraged to integrate cultural and linguistic competence-related measures into their internal audits, performance improvement programs, patient satisfaction assessments, and outcomes-based evaluations."

- **Standard 10:** "Health care organizations should ensure that data on the individual patient's/consumer's race, ethnicity, and spoken and written language are collected in health records, integrated into the organization's management information systems, and periodically updated."

- **Standard 11:** "Health care organizations should maintain a current demographic, cultural, and epidemiological profile of the community as well as a needs assessment to accurately plan for and implement services that respond to the cultural and linguistic characteristics of the service area."

- **Standard 12:** "Health care organizations should develop participatory, collaborative partnerships with communities and utilize a variety of formal and informal mechanisms to facilitate community and patient/consumer involvement in designing and implementing CLAS-related activities."

- **Standard 13:** "Health care organizations should ensure that conflict and grievance resolution processes are culturally and linguistically sensitive and capable of identifying, preventing, and resolving cross-cultural conflicts or complaints by patients/consumers."

- **Standard 14:** "Health care organizations are encouraged to regularly make available to the public information about their progress and successful innovations in implementing the CLAS standards and to provide public notice in their communities about the availability of this information."

Additionally, the Applicant Organization must demonstrate their adherence to the best practices in deceased organ donation as outlined in "The Organ Donation Breakthrough Collaborative: Best Practices Final Report," as issued by the HHS (available at: http://www.lewin.com/content/publications/OrganDonationBreakthroughCollaborative.pdf). Specifically, the Applicant

Organization must document the institutional efforts to meet each of the 15 “Best Practices” outlined in the Final Report. The 15 “Best Practices” are summarized here:

- Orient organizational mission and goals toward increasing organ donation.
- Do not be satisfied with the *status quo*; innovate and experiment continuously.
- Strive to recruit and retain highly motivated and skilled staff.
- Appoint members to organ procurement organizations (OPO) board who can help achieve organ donation goals.
- Specialize roles to maximize performance.
- Tailor or adapt the organ donation process to complementary strengths of OPO and individual hospitals.
- Be there: integrate OPO staff into the fabric of high potential hospitals.
- Identify and support organ donation champions at various hospital levels; include leaders who are willing to be called upon to overcome barriers to organ donation in real time.
- All aboard: secure and maintain buy-in at levels of hospital staff and across departments/ functions that affect organ donation.
- Educate constantly; tailor and accommodate to staff needs, requests, and constraints.
- Design, implement, and monitor public education and outreach efforts to achieve informed consent and other donation goals.
- Referral: anticipate, don’t hesitate, call early even when in doubt.
- Draw on respective OPO and hospital strengths to establish integrated consent process. One size does not fit all, but getting to an informed “yes” is paramount.
- Use data to drive decision-making.
- Follow up in a timely and systematic manner. Don’t let any issues fester.

SF424(R&R) Senior/Key Person Profile Expanded Component

Biographical Sketch

Include biographical sketches of all senior/key personnel and Other Significant Contributors. The Biographical Sketch may not exceed four pages per person. This 4-page limit includes the table at the top of the first page.

Following the educational block, complete sections A, B and C as described in the SF424 (R&R) instructions. However, complete section D as described below.

D. Training in Cultural Competence:

The PD/PI, all senior/key personnel and Other Significant Contributors shall provide documentation

of their formalized training in cultural competence. If no formal training in cultural competence has been received, then please state “None” under section D and please provide a justification for the absence of such formalized training.

If formal training in cultural competence has been received, then please provide information as to the provider of the training, the location of the training, the dates of training, and a synopsis of the training received (including format, duration of training, certification, recertification, etc.). Online training is acceptable, as is in-person training. An example of such training is the “Think Cultural Health” website developed by the HHS OMH available at: https://www.thinkculturalhealth.hhs.gov/Content/ContinuingEd.asp. If a certification is earned as a result of one’s training in cultural competence, please provide a copy of the certification in the Appendix.

Attach Current & Pending Support

As the normal section D of the Biosketch is replaced with information documenting the training of the PD/PI, all senior/key personnel and Other Significant Contributors, please submit the “Research Support” for all of the applicable persons as an attachment in the “Attach Current & Pending Support” field. Please use the instructions described in the SF424 (R&R) instructions, including using the format on the Biographical to prepare this section.

PHS 398 Research Plan Component

All instructions in the SF424 (R&R) Application Guide must be followed, with the following additional instructions:

Research Strategy:

(b) Innovation:

Describe quantitative and qualitative research methods to be used in the assessment of the effectiveness of the culturally sensitive education and behavioral intervention to increase the knowledge and willingness of the study participants to become LDD or DDD organ and tissue donors. Copies of any novel or established and validated quantitative or qualitative research methods should be included in the Appendix.

Furthermore, describe the applicability of all quantitative and qualitative research methods in the particular health disparity-targeted population.

(c) Approach:

Describe the alternate and null hypotheses for the proposed culturally sensitive educational and behavioral intervention. Describe the predefined endpoints to demonstrate the effectiveness of the intervention to increase the organ and tissue donation rates among the health disparity-targeted populations. Sample size for the intervention groups should be supported by appropriate sample size and power calculations. The control group needs to be well-defined and justified. If the control group is either a historical control cohort or will not receive any intervention, then provide a justification for the selection of the particular control group and an explanation of the benefits and risks of comparing the intervention group to the aforementioned control group. All primary and secondary measures of effectiveness of the educational and behavioral interventions must be defined a priori, and require appropriate statistical analysis plans with predefined parameters for the “success” of the educational and behavioral intervention.

Evaluation Plan (Component of Research Strategy):

As part of the Research Strategy, the PD/PI must submit an evaluation plan for assessing the cultural competency and the quality of the intervention plan(s) of the PD/PI, all senior/ key personnel and Other Significant Contributors from the target population's perspective. As described by The Commonwealth Fund's Cultural Competency and Quality of Care: Obtaining the Patient's Perspective" (available at:http://www.commonwealthfund.org/usr_doc/Ngo-Metzger_cultcompqualitycareobtainpatientperspect_963.pdf), the evaluation must address the five (5) domains:

1. Subject-Research communication.
2. Respect for subject preferences and shared decision-making.
3. Experiences leading to trust or distrust.
4. Experiences of discrimination.
5. Linguistic competency.

Finally, the PD/PI must state how the results of the target population's perspective of the cultural competency and the quality of the intervention plan(s) will be used to enhance the intervention so as to improve the cultural competency and, ultimately, to increase the living and deceased donor organ donations from minority and other health disparity populations.

Use the appendix to include the evaluation instruments as a single document.

Resource Sharing Plan

Individuals are required to comply with the instructions for the Resource Sharing Plans (Data Sharing Plan, Sharing Model Organisms, and Genome Wide Association Studies(GWAS)) as provided in the SF424 (R&R) Application Guide.

Appendix

If no modifications to Appendix instructions, delete editable text below ("with the following modifications"). If you are making changes to the Appendix instructions, add bullets below.

Do not use the Appendix to circumvent page limits. Follow all instructions for the Appendix as described in the SF424 (R&R) Application Guide.

3. Submission Dates and Times

Part I. Overview Information contains information about Key Dates. Applicants are encouraged to submit in advance of the deadline to ensure they have time to make any application corrections that might be necessary for successful submission.

Organizations must submit applications via , the online portal to find and apply for grants across all Federal agencies. Applicants must then complete the submission process by tracking the status of the application in the , NIH's electronic system for grants administration.

Applicants are responsible for viewing their application in the eRA Commons to ensure accurate and successful submission.

Information on the submission process and a definition of on-time submission are provided in the SF424 (R&R) Application Guide.

4. Intergovernmental Review (E.O. 12372)

This initiative is not subject to intergovernmental review.

5. Funding Restrictions

All NIH awards are subject to the terms and conditions, cost principles, and other considerations described in the *NIH Grants Policy Statement*.

Pre-award costs are allowable only as described in the *NIH Grants Policy Statement*.

6. Other Submission Requirements and Information

Applications must be submitted electronically following the instructions described in the SF 424 (R&R) Application Guide. Paper applications will not be accepted.

Applicants must complete all required registrations before the application due date. Section III. Eligibility Information contains information about registration.

For assistance with your electronic application or for more information on the electronic submission process, visit Applying Electronically.

> **Important reminders:**
> All PD(s)/PI(s) must include their eRA Commons ID in the Credential field of the Senior/Key Person Profile Component of the SF 424(R&R) Application Package**.** Failure to register in the Commons and to include a valid PD/PI Commons ID in the credential field will prevent the successful submission of an electronic application to NIH.
>
> The applicant organization must ensure that the DUNS number it provides on the application is the same number used in the organization's profile in the eRA Commons and for the Central Contractor Registration (CCR). Additional information may be found in the SF424 (R&R) Application Guide.
>
> See more tips for avoiding common errors.

Upon receipt, applications will be evaluated for completeness by the Center for Scientific Review and responsiveness by the NIDDK, NIH. Applications that are incomplete and/or nonresponsive will not be reviewed.

In order to expedite review, applicants are requested to notify the NIDDK Referral Office by email at calvof@mail.nih.gov when the application has been submitted. Please include the FOA number and title, PD/PI name, and title of the application.

Post Submission Materials

Applicants are required to follow the instructions for post-submission materials, as described in NOT-OD-10-115.

Section V. Application Review Information

1. Criteria

Only the review criteria described below will be considered in the review process. As part of the NIH mission, all applications submitted to the NIH in support of biomedical and behavioral research are evaluated for scientific and technical merit through the NIH peer review system.

Overall Impact

Reviewers will provide an overall impact/priority score to reflect their assessment of the likelihood for the project to exert a sustained, powerful influence on the research field(s) involved, in consideration of the following review criteria and additional review criteria (as applicable for the project proposed).

Scored Review Criteria

Reviewers will consider each of the review criteria below in the determination of scientific merit, and give a separate score for each. An application does not need to be strong in all categories to be judged likely to have major scientific impact. For example, a project that by its nature is not innovative may be essential to advance a field.

Significance

Does the project address an important problem or a critical barrier to progress in the field? If the aims of the project are achieved, how will scientific knowledge, technical capability, and/or clinical practice be improved? How will successful completion of the aims change the concepts, methods, technologies, treatments, services, or preventative interventions that drive this field?

Investigator(s)

Are the PD(s)/PI(s), collaborators, and other researchers well suited to the project? If Early Stage Investigators or New Investigators, or in the early stages of independent careers, do they have appropriate experience and training? If established, have they demonstrated an ongoing record of accomplishments that have advanced their field(s)? If the project is collaborative or multi-PD(s)/PI(s), do the investigators have complementary and integrated expertise; are their leadership approach, governance and organizational structure appropriate for the project?

Have the PD(s)/PI(s), senior/key personnel and Other Significant Personnel received formalized training in cultural competence? If so, is the training adequate: If not, has the individual provided any justification for the absence of such training?

Innovation

Does the application challenge and seek to shift current research or clinical practice paradigms by utilizing novel theoretical concepts, approaches or methodologies, instrumentation, or interventions? Are the concepts, approaches or methodologies, instrumentation, or interventions novel to one field of research or novel in a broad sense? Is a refinement, improvement, or new application of theoretical concepts, approaches or methodologies, instrumentation, or interventions proposed? Are the proposed quantitative and qualitative research methods culturally sensitive and appropriate for the targeted health disparity population?

Approach

Are the overall strategy, methodology, and analyses well-reasoned and appropriate to accomplish the specific aims of the project? Are potential problems, alternative strategies, and benchmarks for success presented? If the project is in the early stages of development, will the strategy establish feasibility and will particularly risky aspects be managed?

If the project involves clinical research, are the plans for 1) protection of human subjects from research risks, and 2) inclusion of minorities and members of both sexes/genders, as well as the inclusion of children, justified in terms of the scientific goals and research strategy proposed?

Have the PD(s)/PI(s) provided alternate and null hypotheses for the proposed culturally sensitive educational and behavioral intervention? Are sample sizes for the intervention and control groups based upon calculations or convenience? Have the PD(s)/PI(s) provided an appropriate statistical analysis plan, with appropriate definitions *a priori* for the demonstration of "effectiveness" of the intervention? Do the proposed cultural competence and quality of the intervention plan(s) address all five (5) domains as specified? Is the evaluation plan based on appropriate literature and methodology? Has the applicant proposed appropriate formative (process) evaluations, and proposed a mechanism for the application of these metrics to the improve the effectiveness of the intervention (e.g., to increase the donation rates for LLD and DDD organs and tissue donation)?

Environment

Will the scientific environment in which the work will be done contribute to the probability of success? Are the institutional support, equipment and other physical resources available to the investigators adequate for the project proposed? Will the project benefit from unique features of the scientific environment, subject populations, or collaborative arrangements?

Have the institution and the proposed PD/PI provided evidence of their ability to provide "cultural and linguistic competent" care to the targeted population? Has the Applicant Organization documented their adherence to CLAS Standards 4 - 7 in the application? Does the Applicant Organization support CLAS Standards 1 - 3 for the provision of Cultural Competent Care?

Has the Applicant Organization demonstrated their adherence to the "Best Practices" for promoting deceased donor organ donation? If not, does the absence of any of the "Best Practices" impair the Applicant Organization's ability to carry out the goal of the FOA?

Additional Review Criteria

As applicable for the project proposed, reviewers will evaluate the following additional items while determining scientific and technical merit, and in providing an overall impact/priority score, but will not give separate scores for these items.

Protections for Human Subjects

For research that involves human subjects but does not involve one of the six categories of research that are exempt under 45 CFR Part 46, the committee will evaluate the justification for involvement of human subjects and the proposed protections from research risk relating to their participation according to the following five review criteria: 1) risk to subjects, 2) adequacy of protection against risks, 3) potential benefits to the subjects and others, 4) importance of the knowledge to be gained, and 5) data and safety monitoring for clinical trials.

For research that involves human subjects and meets the criteria for one or more of the six categories of research that are exempt under 45 CFR Part 46, the committee will evaluate: 1) the justification for the exemption, 2) human subjects involvement and characteristics, and 3) sources of materials. For additional information on review of the Human Subjects section, please refer to the Human Subjects Protection and Inclusion Guidelines.

Inclusion of Women, Minorities, and Children

When the proposed project involves clinical research, the committee will evaluate the proposed plans for inclusion of minorities and members of both genders, as well as the inclusion of children. For additional information on review of the Inclusion section, please refer to the Human Subjects Protection and Inclusion Guidelines.

Vertebrate Animals

The committee will evaluate the involvement of live vertebrate animals as part of the scientific assessment according to the following five points: 1) proposed use of the animals, and species, strains, ages, sex, and numbers to be used; 2) justifications for the use of animals and for the appropriateness of the species and numbers proposed; 3) adequacy of veterinary care; 4) procedures for limiting discomfort, distress, pain and injury to that which is unavoidable in the conduct of scientifically sound research including the use of analgesic, anesthetic, and tranquilizing drugs and/or comfortable restraining devices; and 5) methods of euthanasia and reason for selection if not consistent with the AVMA Guidelines on Euthanasia. For additional information on review of the Vertebrate Animals section, please refer to the Worksheet.

Biohazards

Reviewers will assess whether materials or procedures proposed are potentially hazardous to research personnel and/or the environment, and if needed, determine whether adequate protection is proposed.

Resubmissions

Not Applicable.

Renewals

For Renewals, the committee will consider the progress made in the last funding period.

Revisions

Not Applicable.

Additional Review Considerations

As applicable for the project proposed, reviewers will consider each of the following items, but will not give scores for these items, and should not consider them in providing an overall impact/priority score.

Applications from Foreign Organizations

Not Applicable.

Select Agent Research

Reviewers will assess the information provided in this section of the application, including 1) the Select Agent(s) to be used in the proposed research, 2) the registration status of all entities where Select Agent(s) will be used, 3) the procedures that will be used to monitor possession use and transfer of Select Agent(s), and 4) plans for appropriate biosafety, biocontainment, and security of the Select Agent(s).

Resource Sharing Plans

Reviewers will comment on whether the following Resource Sharing Plans, or the rationale for not sharing the following types of resources, are reasonable: 1) Data Sharing Plan; 2) Sharing Model Organisms; and 3) Genome Wide Association Studies (GWAS).

Budget and Period of Support

Reviewers will consider whether the budget and the requested period of support are fully justified and reasonable in relation to the proposed research.

2. Review and Selection Process

Applications will be evaluated for scientific and technical merit by (an) appropriate Scientific Review Group(s) convened by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), in accordance with NIH peer review policy and procedures, using the stated review criteria. Review assignments will be shown in the eRA Commons.

As part of the scientific peer review, all applications:

- May undergo a selection process in which only those applications deemed to have the highest scientific and technical merit (generally the top half of applications under review) will be discussed and assigned an overall impact/priority score.
- Will receive a written critique.

- Appeals of initial peer review will not be accepted for applications submitted in response to this FOA.

Applications will be assigned to the appropriate NIH Institute or Center and will compete for available funds with all other recommended applications submitted in response to this FOA. Following initial peer review, recommended applications will receive a second level of review by the National Diabetes and Digestive and Kidney Diseases Advisory Council. The following will be considered in making funding decisions:

- Scientific and technical merit of the proposed project as determined by scientific peer review.
- Availability of funds.
- Relevance of the proposed project to program priorities.

3. Anticipated Announcement and Award Dates

After the peer review of the application is completed, the PD(s)/PI(s) will be able to access his or her Summary Statement (written critique) via the eRA Commons.

Information regarding the disposition of applications is available in the *NIH Grants Policy Statement*.

Section VI. Award Administration Information

1. Award Notices

If the application is under consideration for funding, NIH will request "just-in-time" information from the applicant as described in the *NIH Grants Policy Statement*.

A formal notification in the form of a Notice of Award (NoA) will be provided to the applicant organization for successful applications. The NoA signed by the grants management officer is the authorizing document and will be sent via email to the grantee's business official.

Awardees must comply with any funding restrictions described in Section IV.5. Funding Restrictions. Selection of an application for award is not an authorization to begin performance. Any costs incurred before receipt of the NoA are at the recipient's risk. These costs may be reimbursed only to the extent considered allowable pre-award costs.

Any application awarded in response to this FOA will be subject to the DUNS, CCR Registration, and Transparency Act requirements as noted on the Award Conditions and Information for NIH Grants website.

2. Administrative and National Policy Requirements

All NIH grant and cooperative agreement awards include the *NIH Grants Policy Statement* as part of the NoA. For these terms of award, see the NIH Grants Policy Statement Part II: Terms and

Conditions of NIH Grant Awards, Subpart A: General and Part II: Terms and Conditions of NIH Grant Awards, Subpart B: Terms and Conditions for Specific Types of Grants, Grantees, and Activities. More information is provided at Award.

Cooperative Agreement Terms and Conditions of Award

Not Applicable.

3. Reporting

When multiple years are involved, awardees will be required to submit the Non-Competing Continuation Grant Progress Report (PHS 2590) annually and financial statements as required in the *NIH Grants Policy Statement.*

A final progress report, invention statement, and the expenditure data portion of the Federal Financial Report are required for closeout of an award, as described in the *NIH Grants Policy Statement*.

The Federal Funding Accountability and Transparency Act of 2006 (Transparency Act), includes a requirement for awardees of Federal grants to report information about first-tier subawards and executive compensation under Federal assistance awards issued in FY2011 or later. All awardees of applicable NIH grants and cooperative agreements are required to report to the Federal Subaward Reporting System (FSRS) available at www.fsrs.gov on all subawards over $25,000. See *the NIH Grants Policy Statement* for additional information on this reporting requirement.

Section VII. Agency Contacts

We encourage inquiries concerning this funding opportunity and welcome the opportunity to answer questions from potential applicants.

Application Submission Contacts

Grants.gov Customer Support (Questions regarding Grants.gov registration and submission, downloading or navigating forms)
Contact Center Phone: 800-518-4726
Email: support@grants.gov

GrantsInfo (Questions regarding application instructions and process, finding NIH grant resources)
Telephone 301-435-0714
TTY 301-451-5936
Email: GrantsInfo@nih.gov

eRA Commons Help Desk (Questions regarding eRA Commons registration, tracking application status, post submission issues)
Phone: 301-402-7469 or 866-504-9552 (Toll Free)
TTY: 301-451-5939
Email: commons@od.nih.gov

Scientific/Research Contact(s)

Kevin D. McBryde, MD
Program Director
Office of Minority Health Research Coordination
National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
6707 Democracy Boulevard
II Democracy Plaza, Room 906B, MSC 5454
Bethesda, MD 20892-5454
Telephone: 301-594-9652
Email: mcbrydekd@mail.nih.gov

Peer Review Contact(s)

Examine your eRA Commons account for review assignment and contact information (information appears two weeks after the submission due date).

Francisco O. Calvo, Ph.D.
Chief, NIDDK Review Branch
National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
6707 Democracy Boulevard, Room 752, MSC 5452
Bethesda, MD 20892-5452 (courier Zip Code 20817)
Telephone: 301-594-8897
Email: calvof@mail.nih.gov

Financial/Grants Management Contact(s)

Carolyn S. Kofa
Grants Management Specialist
Grants Management Branch
National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
6707 Democracy Boulevard, Room 746, MSC 5456
Bethesda, MD 20892-5456
Telephone: 301-594-7687
Email: kofac@mail.nih.gov

Section VIII. Other Information

Recently issued trans-NIH policy notices may affect your application submission. A full list of policy notices published by NIH is provided in the *NIH Guide for Grants and Contracts*. All awards are subject to the terms and conditions, cost principles, and other considerations described in the *NIH Grants Policy Statement*.

Authority and Regulations

Awards are made under the authorization of Sections 301 and 405 of the Public Health Service Act as amended (42 USC 241 and 284) and under Federal Regulations 42 CFR Part 52 and 45 CFR Parts 74 and 92.

APPENDIX K:

BSSR panel lecture to launch, ***The cultural framework for health***: *An integrative approach for research and program design and evaluation*

Poster, videocast link, PowerPoint presentations,

COSSA feature on panel presentation

http://videocast.nih.gov/summary.asp?Live=14227&bhcp=1

National Cancer Institute
Office of Social Science
and Behavioral Research

May 23, 2014

Bethesda, MD

Operationalizing Culture for Health Behavior and Social Science Research

Marjorie Kagawa Singer, PhD, MA, MN, RN, FAAN
Professor, UCLA Fielding School of Public Health and Asian American Studies

Expert Panel Members

William Elwood, Project Officer, OBSSR

Claudia Baquet, MD, MPH
Ronny Bell, PhD, MPH
Linda Burhansstipanov, MSPH, DrPH
Nancy Burke, PhD
Suzanne Dibble, DNSc, RN
William Dressler, PhD
Project Director: Annie Fehrenbacher, MPH
Linda Garro, PhD
Sheba M. George, PhD
Clarence Gravlee, PhD
Peter Guarnaccia, PhD
Michael Hecht, PhD
Jeffrey Henderson, MD, MPH
Dan Hruschka, PhD, MPH
Marjorie Kagawa Singer, PhD, MA, MN, RN, FAAN
Tom LaVeist, PhD

Roberto Lewis-Fernandez, MD
Robert C. Like, MD, MS
Charles Mouton, MD
Hector Myers, PhD
J. Bryan Page, PhD
Rena Pasick, DrPH
Bernice A. Pescosolido, PhD
Nancy Schoenberg, PhD
Bradley Stoner, MD, PhD
Gregory Strayhorn, MD, PhD
Laura Szalacha, PhD
Joseph Trimble, PhD
Tom Weisner, PhD
David Williams PhD

2

Basic Premise of the Project: to Transform the Use of Culture in Health Research

Culture is Fundamental to Human Existence

"There is no such thing as human nature independent from culture"

(Geertz, 1973:79)

3

- Culture is the "way of life and thought that we construct, negotiate, institutionalize, and finally end up calling '**reality**' (Bruner, 1996:87)

- Despite its central role in explaining behavior, ***"No other variable used in health research is so poorly defined and untested as "culture"*** (Dressler, Ots, and Gravlee, 2005, Hruska, 2009).

Then how are we missing culture in health research?

We lack:

- A well grounded **concept of culture**
- **Measures** that accurately operationalize the aspects of culture that most affect the health issue of focus
- Studies that **test the hypothsis of cultures impact** on health outcomes

5

UCLA FIELDING SCHOOL OF PUBLIC HEALTH

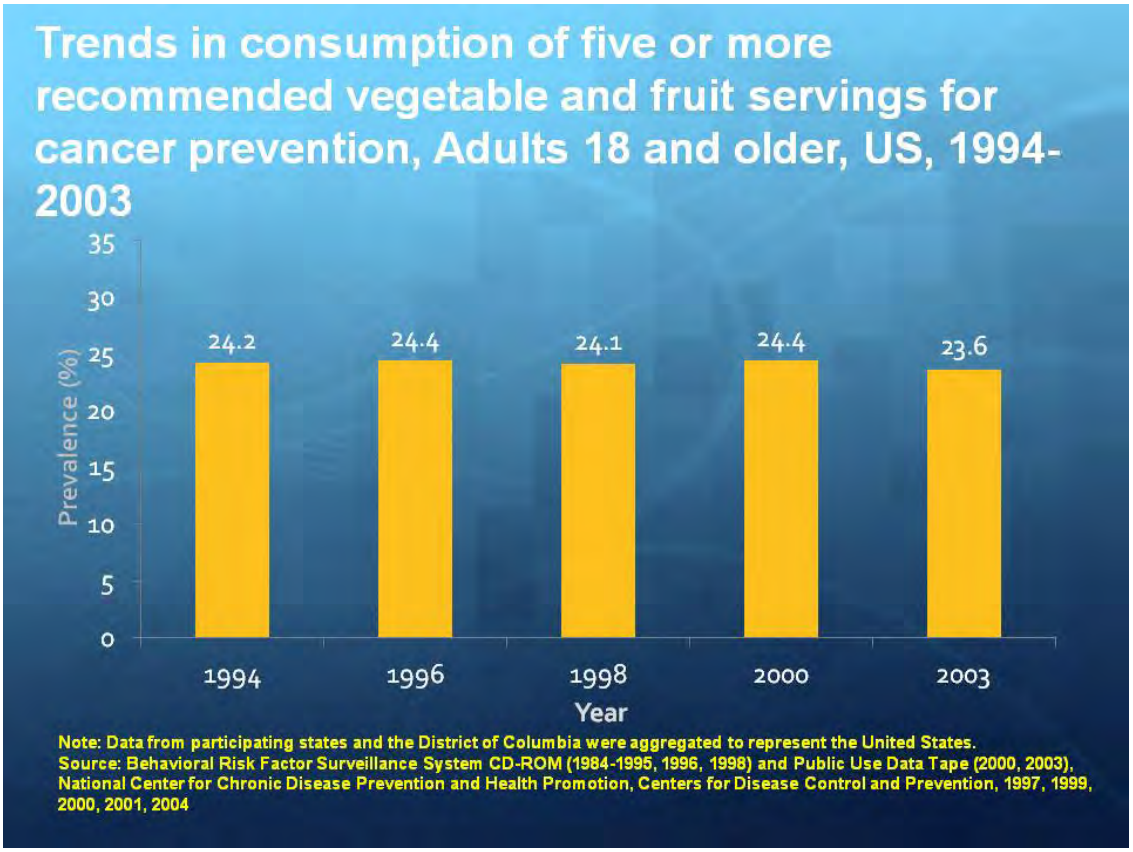
Hence, our 3 GOALS

NATIONAL INSTITUTES OF HEALTH

1. To **define** culture for use in **health research**
2. To provide a roadmap to guide both researchers, reviewers, and funders in the **measurement and application of culture.**
3. To illuminate the Eurocentric-basis of health behavior science

Funded by OBSSR Administrative Supplement # 1R01CA158314-01

6


Trends in consumption of five or more recommended vegetable and fruit servings for cancer prevention, Adults 18 and older, US, 1994-2003
Prevalence (%)
35
30
25
20
15
10
5
0
24.2
24.4
24.1
24.4
23.6
1994
1996
1998
2000
2003
Year
Note: Data from participating states and the District of Columbia were aggregated to represent the United States.
Source: Behavioral Risk Factor Surveillance System CD-ROM (1984-1995, 1996, 1998) and Public Use Data Tape (2000, 2003), National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, 1997, 1999, 2000, 2001, 2004

10 Most Common Scientific Challenges to the Use of Culture in Health Research
8

A. Conceptualizing culture

1. Inadequately theorized and inconsistently applied
2. Lack of clear definitions, measurable constructs, and conceptual models of how cultural processes interact
3. Cultural groups are defined devoid of their historical, geographic, social an political contexts and influence of these contextual factors on their access to resources and social positions in societal power hierarchy

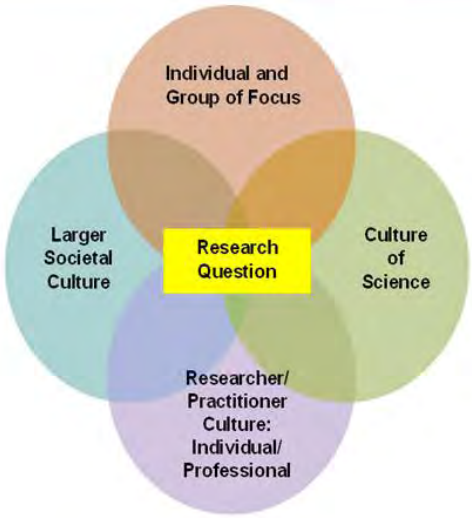
9

A. Conceptualizing culture, con't

4. Dynamic nature of culture is rarely reflected in most studies
5. Recognition of role of culture in shaping the nature and conduct of the scientific process and its relationship to research participants is lacking
6. Everyone has culture. The assumed universality of the dominant culture's constructions of reality and salient domains, such as selfhood, family, fairness, and well-being is unproven, and should not be assumed.

10

Whose culture are we studying?



11

Effect of the Culture of Science

Monocultural view of the world of science as universal

- Impacts **unreflective use of theories** developed and validated in European-American, usually educated populations
- Designs of studies based upon **monocultural norms** – as in "tailoring" of evidence base practices to new population groups
- Use of tools/methods that have not been validated for **cross cultural equivalence**
- Raises **ethical questions** regarding the imposition of European American-centric definitions of health and ways of managing illness without eliciting the perspective of the population of focus

12

B. Operationalizing culture

7. Use of nominal, dichotomous simplistic variables of race and/or ethnicity or ancestry to represent culture, is simplistic and inadequate
8. The heterogeneity within the group of focus should be explicit and demonstrated in the description of the study sample
9. Acontextual focus on the individual without *historical, political, social* environmental circumstances of the individual and group

14

OMB Directive 15 Categories - Eviscerates 'Culture'

Categorical use of Race/Ethnicity:

1. Non-Hispanic White
2. Hispanic (ethnicity in 2000 Census)
3. American Indian/Alaska Native
4. Asian American
5. Pacific Islander
6. African American/Black

Cancer Mortality Trends

California, 1988-2001

S. Kwong, 2004

C. Health Disparity Interventions

10. ***Challenges 1-9*** **contribute to the inability to effectively eliminate health disparities**

17

Defining Culture

Differentiate between:

- **What culture *is***
- **What culture *does***
- **How the culture of research assumes universality of reality and in explicitly or implicitly "norms" of thought and behavior**

18

Culture *IS*:

- A **shared framework or lens** that its members learn to use "see" the world and which informs, consciously and unconsciously, how to live life, why they live life, and how to resolve problems in doing so.
- Created and modified within a multidimensional, multilevel, dynamic and adapting **ecologic system** of internal and external resources and restraints
- Is **socially and legally integrated** into the structure of a society's institutions.

19

Culture _____

TOOL which its members use to :

1 – Assure their SURVIVAL & well-being

and

2 – Provide the MEANING of life and mechanisms to make predictable and controllable the unpredictable and inevitable.

What Culture DOES:

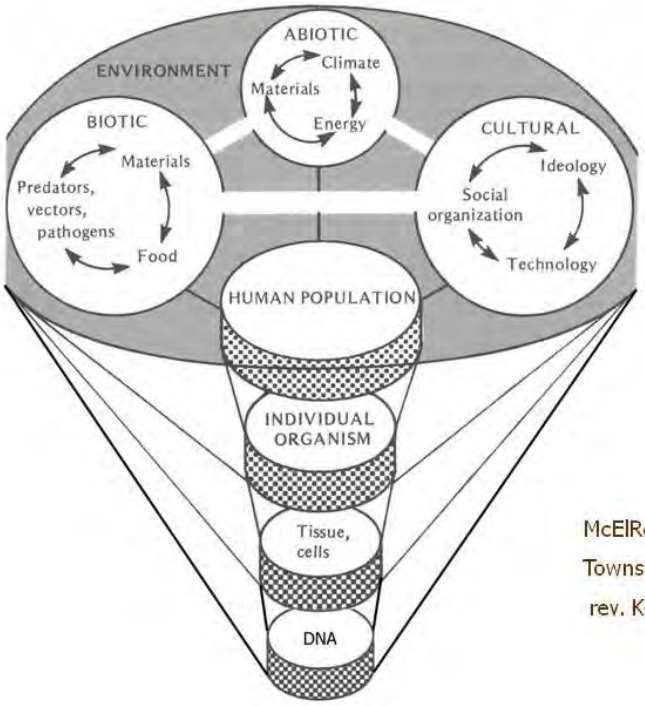
- Culture and its members, *defines and constructs* the world around us, to *derive meaning in and for life.*
- Provides the *social structure* that defines and coordinates the numerous *roles* of each of its members in relation to the group, *rules of social interaction* and *distribution of power*
- Expresses and sustains the the reality of its members through the *built environment including our institutions (schools and health care system)*

21

Key Definitions

- **Race-** scientific MYTH – assumed genotype based on phenotype
- **Population Group** – population which has similar adaptive physiologic responses and cultural practices due to ecologic niche – e.g. sickle cell, G6-PD
- **Culture** – system of beliefs, values, lifestyles, ecologic and technical resources and constraints
- **Ethnicity** – subcultural group within a power structure of a multicultural society & self identified group membership within a socio-historical context
- **Racism** – assertion of power; ego fulfillment & racialization status at expense of others by skin color - color coded groups

Culture = adaptive system within a social, biological, and cultural environment that is multi-layered and multi-dimensional



McElRoy and Townsend, 1994 rev. K-S 2000

7 Nested Layers of Culture

1. Environment
2. Economy
3. Technology
4. Religion/World View and beliefs about healing systems
5. Social Structure
6. Language and Health Literacy
7. Beliefs and Values

Hammond, 1976, Diamond, 2005

24

Cross Cultural Equivalence of Concepts Health Behavior Theories

Pasick et al (2009) used a mixed method study to test the cross cultural equivalence of the 5 most common concepts in behavioral theories for mammography for Filipinas and Latinas

- Perceived benefit
- Perceived susceptibility
- Self-efficacy
- Intention
- Subjective norms

25

Pasick et al, con' t – Findings

- Deductive survey: the findings generally support cross-cultural applicability in 4/5 constructs….with mixed predictive value across racial/ethnic groups
- Inductive interviews – all differed, INTENTION most:
  3 Social context themes emerged:
  1) relational culture
  2) Social capital and
  3)Transculturation and Transmigration
- Compared with the 5 behavioral concepts, cultural context can influence behavior directly, circumventing or attenuating the influence of individual beliefs – operating at an unconscious level, and influenced by factors not consistent with an exclusive focus on the individual as these theories postulate
- Thus, the applicability of such theories are **questionable** in diverse cultural groups

26

Cultural Equivalence

Content: Definitions of family and their roles

Semantic: Meaning of each item

Technical: Mode of administration, e.g., age, gender of interviewer

Criterion: Interpretation = within context of norms of each culture

Conceptual: Equal validity of construct: QOL

Metric: Salience of variable and structural equivalence of relationship of variables

27

Canino & Bravo, 1994

U.S. "White" Population

Scotland	Italy	Finland
Ireland	Greece	Spain
Iraq	Egypt	Yugoslavia: Serbia
Israel	Iran	Croatia Bosnia
Sweden	Germany	Afghanistan

28

U.S.A. Values

- Independence
- Self-reliance
- Autonomy
- Happiness

Values of Everyone Else

- Collectivism
- Interdependence
- Community

What do we recommend you do?
CHECKLIST for Project Development

1. Is the rationale for the inclusion of culture clearly articulated in the problem statement?
2. Has a definition of culture for the study been articulated?
3. Are salient theoretical and cultural domains known?
   a. Are salient *theoretical* domains **known** but *cultural* domains **unknown**?
   b. Are salient *cultural* domains **known** but *theoretical* domains **unknown**?
4. Is there a conceptual framework that specifies how salient domains affect the health issue of focus? (e.g. Have independent variables, moderating and mediating effects been identified?)
5. Is there correspondence between theoretical and cultural domains?
6. Do cross culturally equivalent measures exist?

31

Summary

* Hundreds of **definitions of culture** exist in many disciplines ~ some explicit ~ most not
* We created a **consensus definition for health research**, and provide a roadmap for researchers to use to inform the role and measure of culture on the outcome of focus.
* Using a scientifically based concept of culture constitutes a new, but necessary and overlooked, approach to the study of human behavior
* **The new path is promising and long overdue to explain behaviors among diverse cultural groups.**

32

EXCELLENCE ▶ EMINENCE

The Operationalization of Culture in Health Behavior and Social Science Research

Office of Social Science and Behavioral Research
Bethesda, MD May 23, 2014

Dr. L. A. Szalacha
Associate Professor
Associate Director of the Center for Research and Transdisciplinary Scholarship
The Ohio State University

EXCELLENCE ▶ EMINENCE

Measure what is measurable, and make measurable what is not so.

Galileo Galilei

When you can measure what you are speaking about, and express it in numbers, then you know something about it; but when you cannot measure it, when you cannot express it in numbers, your knowledge is of a meager and unsatisfactory kind.

Lord Kelvin, 1883

EXCELLENCE ▶ EMINENCE

All human behavior is culturally informed, yet no other variable used in health research is so poorly defined and untested as culture

(Dressler, Oths, & Gravlee, 2005; Hruschka, 2009)

EXCELLENCE ▶ EMINENCE

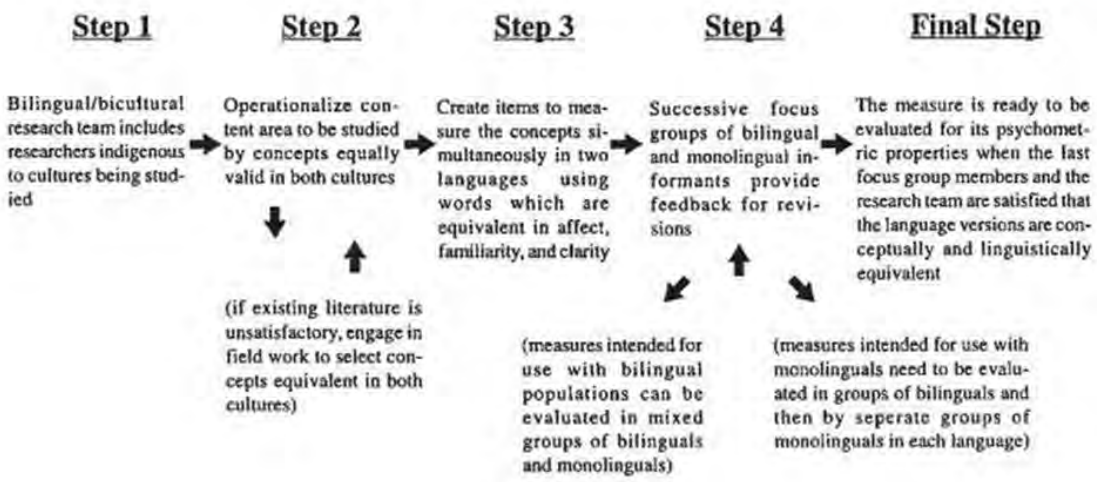
Not a new enterprise, notable pioneers and leaders, among them our own Drs. Kagawa-Singer & Dressler

García Coll C, Lamberty G, Jenkins R, McAdoo HP, Crnic K, Wasik BH, Vázquez García H. An integrative model for the study of developmental competencies in minority children. *Child Development*. 1996 Oct;67(5):1891-914.

EXCELLENCE ▶ EMINENCE

THE OHIO STATE UNIVERSITY

Dual Focus: Bilingual, Bicultural Research Committee



(Erkut, et al., 1999)

EXCELLENCE ▶ EMINENCE

THE OHIO STATE UNIVERSITY

The vodka is good, but the steak is lousy.

Automatic translation of Matthew 26:41
The spirit is willing, but the flesh is weak.

- ✓ The insufficient single item for race and/or ethnicity
- ✓ The failure to examine the heterogeneity in groups
- ✓ The failure to examine the social, historical, and environmental contexts of health

EXCELLENCE ▶ EMINENCE

Correspondence between the need for more complexity in our research and developments in analytic techniques

Just as culture is a factor at both a group-level and at an individual level: multi-group, multilevel modeling

Community-Based Participatory Research (CBPR) is a standard practice

The "paradigm wars" between quantitative and qualitative methods and philosophies of 2 decades ago are now so much ancient history. And the need for their combined use in examining culture and health is imperative.

EXCELLENCE ▶ EMINENCE

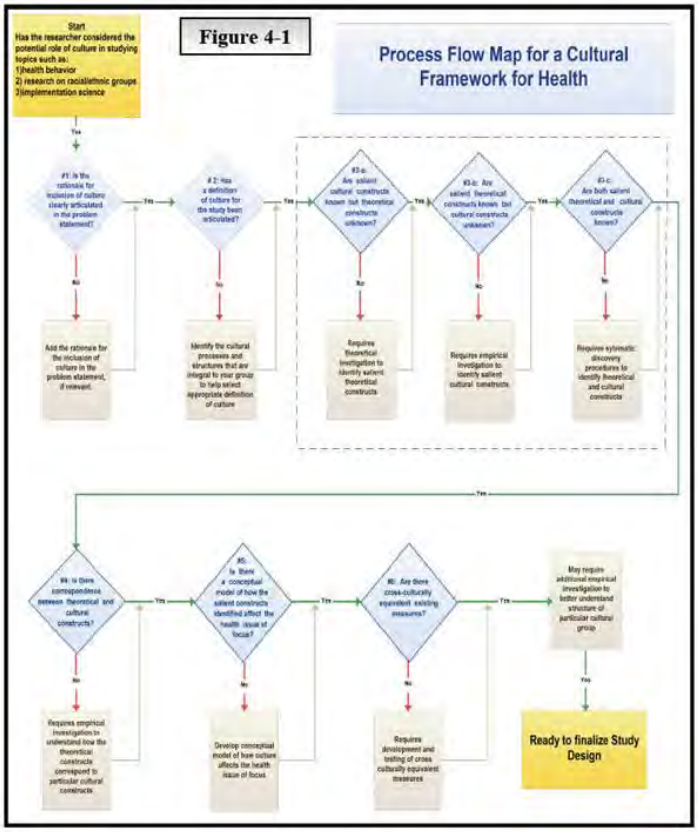
Cultural neuroscience is now studying how cultural and genetic diversity affect psychological and neural processes in the production of human behavior.

Biocultural co-constructivism has emerged as a way of explaining how developmental trajectories unfold through interactions between genetic and cultural factors. In fact, there has been work that examines how neural plasticity may later affect and be affected by both developmental trajectories and the end state.

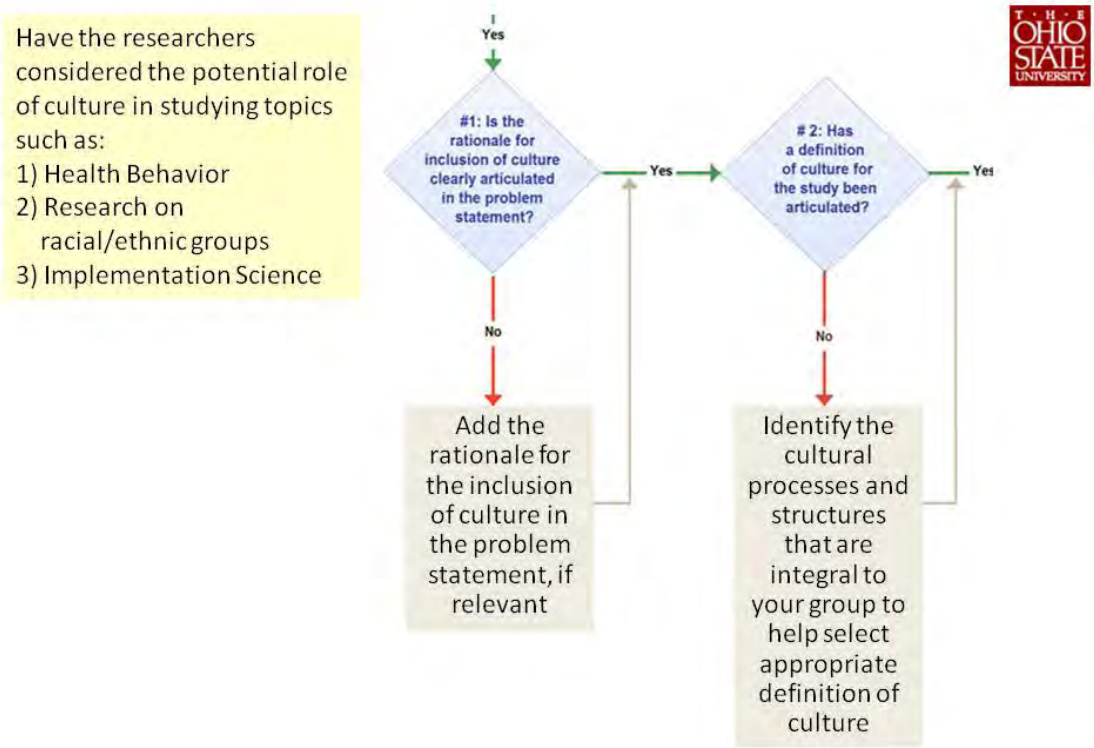
EXCELLENCE ▶ EMINENCE

Cultural Framework for Health concludes with the beginning. There is a flow map to guide researchers through six steps required to more effectively distinguish which cultural processes are relevant in a given study context, and how they likely influence health outcomes – before finalizing the study's design.

You cannot fix by analysis what you have bungled by design…



The Process Flow Map in Section IV provides a practical guide to navigate through the process of determining how culture is relevant to a research project, and how to conceptualize and operationalize culture for a particular hypothesized effect.


Have the researchers considered the potential role of culture in studying topics such as:
1) Health Behavior
2) Research on racial/ethnic groups
3) Implementation Science
Yes
#1: Is the rationale for inclusion of culture clearly articulated in the problem statement?
Yes
2: Has a definition of culture for the study been articulated?
Yes
No
Add the rationale for the inclusion of culture in the problem statement, if relevant
No
Identify the cultural processes and structures that are integral to your group to help select appropriate definition of culture

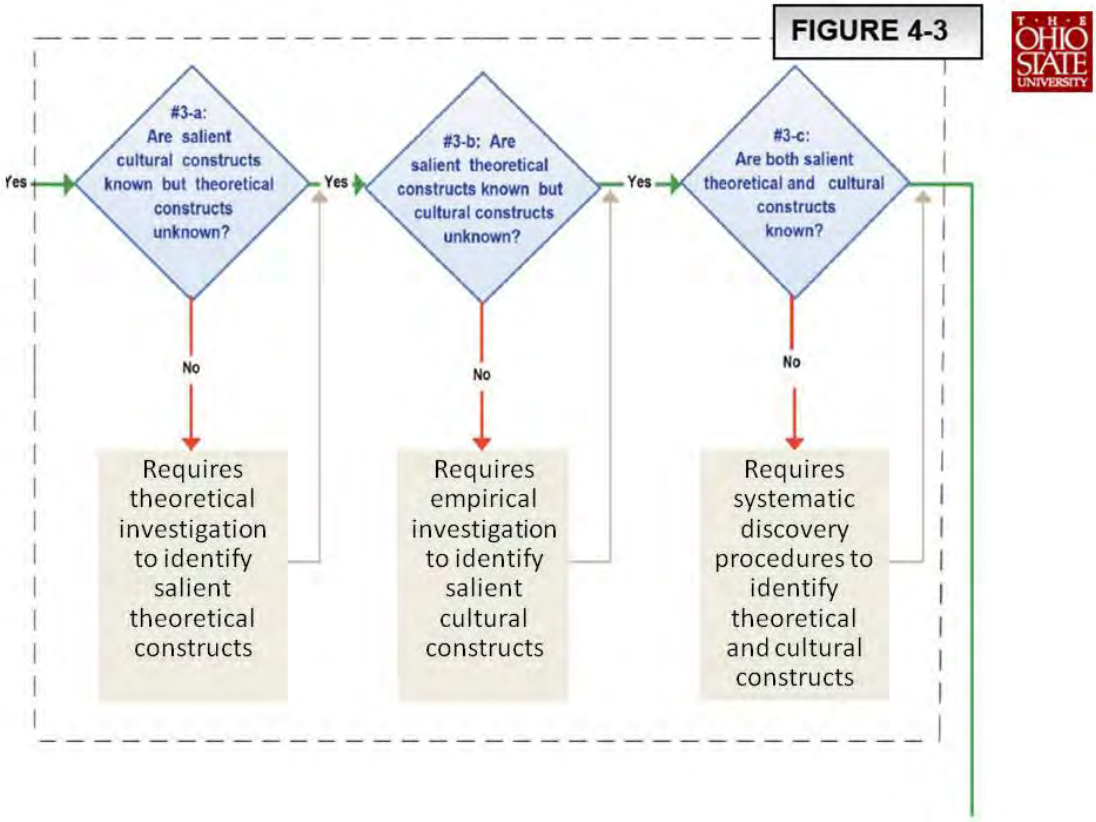
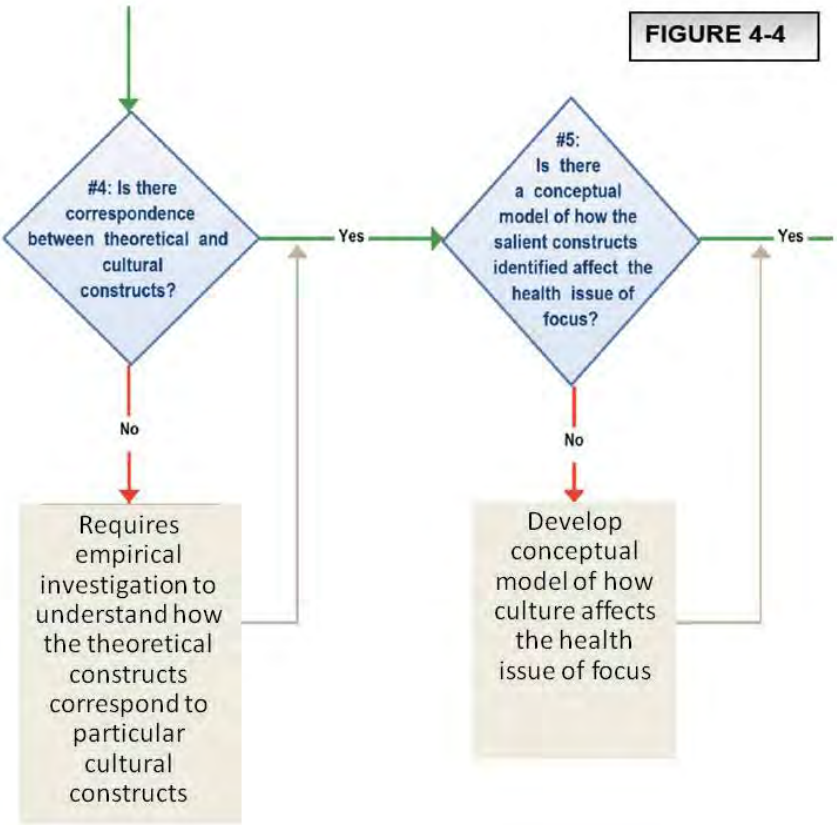


FIGURE 4-3
Yes
#3-a: Are salient cultural constructs known but theoretical constructs unknown?
Yes
#3-b: Are salient theoretical constructs known but cultural constructs unknown?
Yes
#3-c: Are both salient theoretical and cultural constructs known?
No
Requires theoretical investigation to identify salient theoretical constructs
No
Requires empirical investigation to identify salient cultural constructs
No
Requires systematic discovery procedures to identify theoretical and cultural constructs



EXCELLENCE ▶ EMINENCE

The Need for Mixed-Paradigms and Mixed-Methods Research

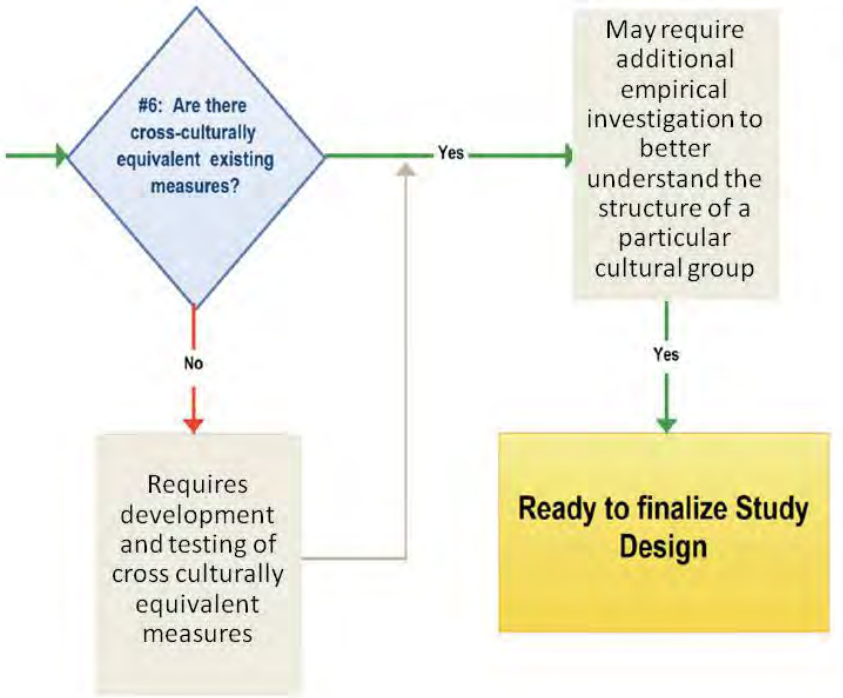
1) Cultural Domain Analysis: linked set of qualitative research and quantitative data-analytic techniques for systematically discovering the terms that members of a cultural group use in discussing a cultural domain, as well as the dimensions of meaning that link those terms. Use of constrained/ unconstrained pile sorts can then be analyzed (i.e., Cluster analysis, nonmetric multidimensional scaling, correspondence analysis) to help extract dimensions of meaning used within the domain.

(Weller and Romney 1988)

2) Cultural Consensus Analysis: development of measurements for constructs within specific social groups when no measurement exists, or when existing measurements are likely to be too culturally specific to one group. After identifying the salient elements of a cultural domain (e.g., "family life") and exploring the dimensions of meaning in organizing that domain, Likert-type items were developed, tested, and weighted according to the importance in the cultural domain of the family

(Dressler, Balieiro, Ribeiro, & dos Santos, 2007)

FIGURE 4-5



EXCELLENCE ▶ EMINENCE

THE OHIO STATE UNIVERSITY

Measurement Equivalence

1) Conceptual Equivalence

2) Operational Equivalence

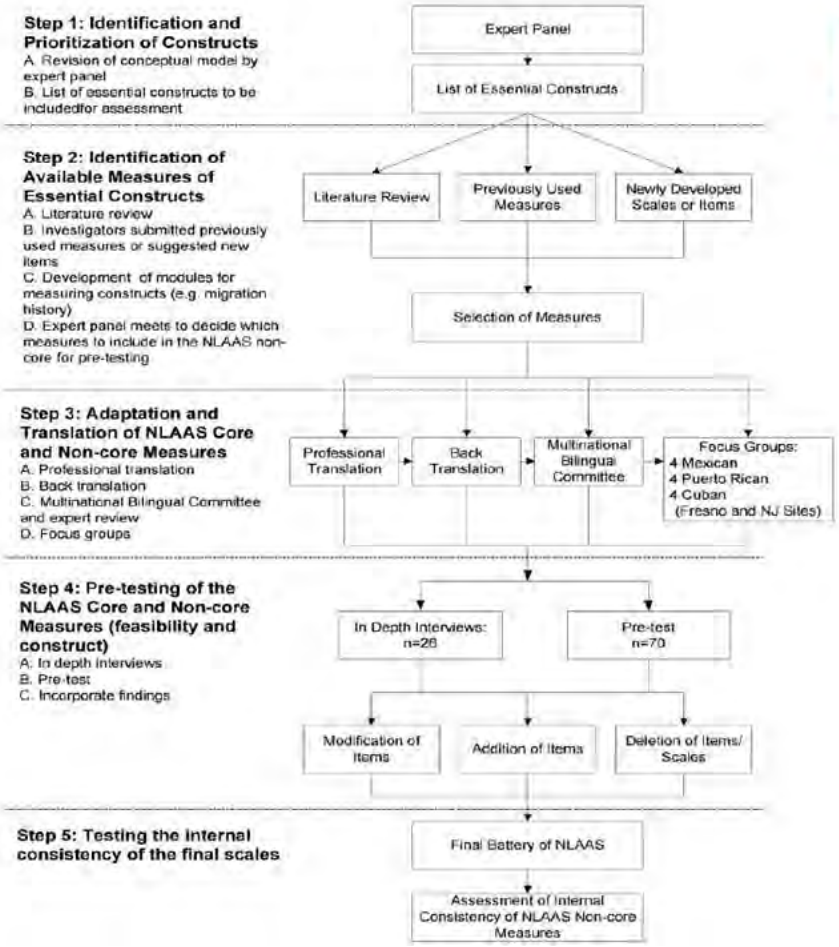
3) Item Equivalence

4) Scalar Equivalence

Hui & Triandis (1985)

Five-Step Process to Attain Cultural Relevance and Cultural Equivalence of the NLAAS Measures (Alegria et al., 2004)

The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care



Differential-Item-Functioning Models

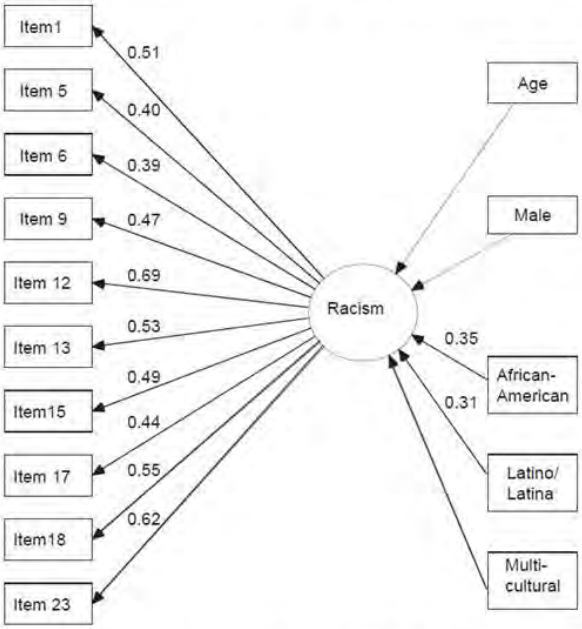


Figure 1. Differential Item Functioning (DIF) model: PRaCY-older version.
Note: All standardized coefficients shown are significant at $p < 0.01$.
$\chi^2_{(df=85)} = 92.45$, $p = 0.272$; CFI = 0.977; RMSEA = 0.026.

DIF occurs when certain group members respond to specific items that are higher/lower than would be anticipated on the basis of their underlying construct level; if present, it can lead to biased comparison of scale scores.
(Pachter, et al, 2010)

EXCELLENCE ▶ EMINENCE

As Health Researchers, we need to:

- Develop **interdisciplinary teams or collaborations**
- Attend to external as well as internal validity by utilizing both **inductive and deductive paradigms and quantitative and qualitative methods**.
- **Collaborate with members of the community** of focus to identify, in partnership with the researchers, the salient issues impacting their health outcomes.
- Integrate the **social, historical, economic, environmental, and geopolitical** factors of the community of focus.

EXCELLENCE ▶ EMINENCE

- Culture is a dynamic, multidimensional construct with measurable properties. More accurate identification and measures of salient factors will enable us to better identify the mechanisms of influence of the appropriate beliefs, values, and/or practices on the behavior(s) of focus.

- Reviewers will increasingly be asked to assess the cultural and linguistic competence of grant applications and how well cultural issues have been addressed in health behavior and social science articles submitted for publication.

EXCELLENCE ▶ EMINENCE

In the *Cultural Framework for Health,* we have focused on Racial and/or Ethnic Cultures and health outcomes. It is also necessary to attend to all of the many socially constructed cultures, including class, sexual identity,

Combination of several which have differing saliency depending on where we are or with whom

EXCELLENCE ▶ EMINENCE

References

Alegria M, Vila D, Woo M, Canino G, Takeuchi D, Vera M, Shrout P. Cultural relevance andequivalence in the NLAAS instrument: integrating etic and emic in the development of cross-cultural measures for a psychiatric epidemiology and services study of Latinos. *Int J Methods Psychiatr Res*. 2004; 13(4):270–288.

Dressler, WW, Viteri, FE, Chavez, A, Grell, GA, & Dos Santos, J Ernesto. Comparative research in social epidemiology: measurement issues. *Ethn Dis*. 1991; 1(4), 379.

Erkut, S., Alarcón, O., Garcia Coll, C., Tropp, L. R. & Vázquez Garcia, H. A. The dual-focus approach to creating bilingual measures. *Journal of Cross Cultural Psychology*. 1999; 30: 206-218.

Hui, C. & Triandis, H. Measurement in Cross-Cultural Psychology A Review and Comparison of Strategies. *Journal of cross-cultural psychology*, 1985; 16(2), 131-152.

Pachter, L., Szalacha, L. A., Bernstein, B., & García Coll, C. Perceptions of Racism in Children and Youth (PRaCY): Properties of a Self-Report Instrument for Research on Children's Health and Development. *Ethnicity & Health*, 2010; 1:1-14.

Weller, S.C, & Romney, A.K. (1988). Systematic data collection (Vol. 10): Sage Thousand Oaks.

Two Decades of Studying Ataques de Nervios:

An Example of Operationalizing Culture in Research

Peter J. Guarnaccia, Ph.D.
Institute for Health, Health Care Policy and Aging Research
Rutgers, The State University of New Jersey

Presentation at the conference on "Transforming Culture and Research: Operationalizing Culture and its Relationship to Health and Wellbeing Outcomes," NIH Behavioral and Social Science Research (BSSR) Lecture Series, Friday May 23, 2014

Defining Ataque de Nervios

Definition of *Ataque de Nervios*

- Idiom of distress principally reported among Latinos from the Caribbean
- Commonly reported symptoms:
  - screaming/shouting uncontrollably
  - attacks of crying
  - trembling
  - heat in the chest rising into the head
  - becoming verbally/physically aggressive

Definition of *Ataque de Nervios*

- Features prominent in some *ataques*, but absent in others:
  - dissociative experiences
  - seizure-like or fainting episodes
  - suicidal gestures
- Core feature: **sense of being out of control**

Definition of *Ataque de Nervios*

- Frequently occur as a direct result of a stressful event relating to the family:
  - news of the death of a close relative
  - separation or divorce from a spouse
  - conflicts with a spouse or children
- May experience amnesia for what occurred during the *ataque de nervios*
- Otherwise return rapidly to their usual level of functioning

Definition of *Ataque de Nervios*

- Although descriptions of some *ataques de nervios* most closely fit with the DSM-IV description of Panic Attacks
  - association of most *ataques* with a precipitating event
  - frequent absence of the hallmark symptom of acute fear or apprehension

  distinguish them from Panic Disorder
- *Ataques de nervios* span range from normal expressions of distress to psychiatric disorders:
  - Anxiety
  - Mood
  - Dissociative
  - Somatoform

An Unusual Factor

[Why is culture relevant?]

Items from Unique Somatization Factor in Puerto Rico compared to LA-ECA

Chest pain (#20)
Temporary blindness (#33)
Paralyzed (#37)
Fainting/falling out spells (#40)
Unconscious (#41)
Unusual spells (#43)
Short of breath (#44)
Heart beating hard (#45)
Dizziness (#46)
Periods of weakness (#47)
Sickly majority of life (#49)
Crying spells (#57)

Alpha = .6667 (Puerto Rico sample)

Case Example: 29 year old woman

- N of symptoms on Ataque Scale: 2
- Description of her "panic attack" (question #62): "I was living with a man and began to have *ataques*. I would get furious, hysterical.
- Psychiatric assessment: symptoms a result of problems and anxiety
- Respondent's attributions: her experiences came from her *nervios* and problems
- Help-seeking: has consulted an *espiritista, santero,* medical doctor and psychiatrist

A Single Question

[How do we begin to assess culture when little is known?]

Ataque de Nervios Question

- *¿Alguna vez, ha tenido usted un ataque de nervios?*
- At some time, have you ever had an *ataque de nervios*?

Relationship between *Ataque de Nervios* & Psychiatric Diagnoses

	No Ataque	Ataques de nervios	Odds Ratio
Depression (5%)	19 (2%)	29 (20%)	9.84
Dysthymia (12%)	67 (9%)	40 (28%)	3.63
Generalized Anxiety (18%)	108 (14%)	55 (38%)	3.73
Panic Disorder (2%)	3 (0.4%)	13 (9%)	25.08
PTSD (6%)	29 (4%)	25 (17%)	5.30
Any Affective	49 (6%)	43 (30%)	6.18
Any Anxiety	109 (14%)	58 (40%)	4.02
Any DIS Diagnosis	214 (28%)	91 (63%)	4.35
N= 912	N=767 (84%)	N=145 (16%)	

Profile of Ataques de Nervios

[What is the role of qualitative research in defining a cultural phenomena?]

Domains of *Ataque* Experience

Loss of control is over-riding theme

Emotional expressions:

screaming, crying, anxious, depressed, fearful, anguish, anger

Bodily sensations:

trembling, palpitations, chest pain, breathlessness, headache, lost voice, stomach upset, fatigue, weakness, loss of feeling in part of body, hands sweat, convulsions, seizures

Action dimensions:

aggressive towards, self, others, or things, could not eat or sleep, wanting to die, suicidal ideation or attempts

Alterations in Consciousness:

fainting, loss of consciousness, dizziness, many thoughts or memories, amnesia, hallucinations, going crazy

Contexts of *Ataques*

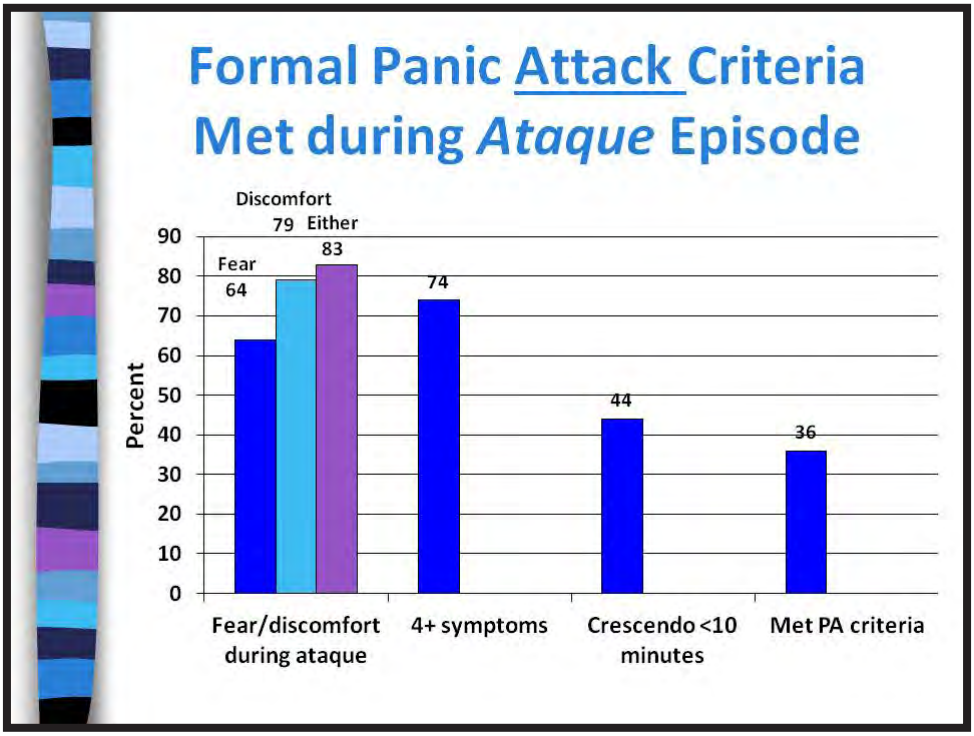
Suffering

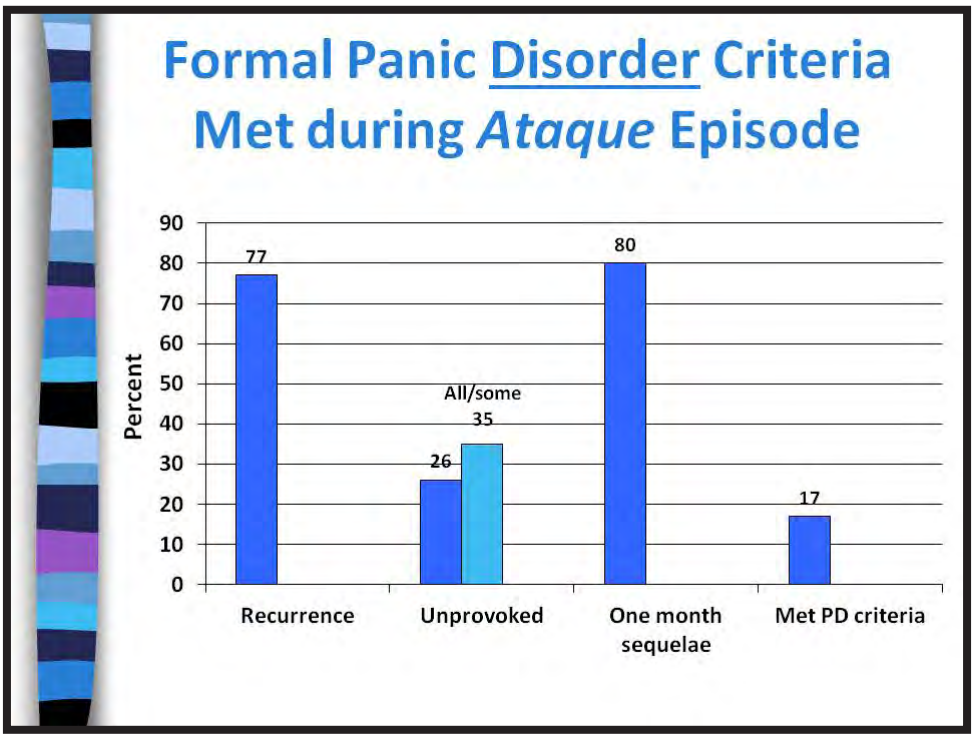
Major problems (*problemas grandes*)

- Economics
- Alcohol/substance abuse member
- Death of a family member
- Receiving bad news
- Family conflict
- Spouse conflict/divorce abuse
- Conflict with children
- Worry about children
- Illness (self/child)
- Hospitalization of family
- Isolation/loneliness
- Accidents
- Disasters (floods, hurricanes)
- Assaults, Physical
- Traumas
- Wars

Are Ataques Just Puerto Rican Panic Attacks?

[Is there equivalence between a cultural syndrome and psychiatric diagnosis?]


Formal Panic Attack Criteria
Met during *Ataque* Episode
Discomfort
79
Either
83
Fear
64
74
44
36
Percent
90
80
70
60
50
40
30
20
10
0
Fear/discomfort during ataque
4+ symptoms
Crescendo <10 minutes
Met PA criteria


Formal Panic Disorder Criteria
Met during *Ataque* Episode
77
80
All/some
35
26
17
Percent
90
80
70
60
50
40
30
20
10
0
Recurrence
Unprovoked
One month sequelae
Met PD criteria

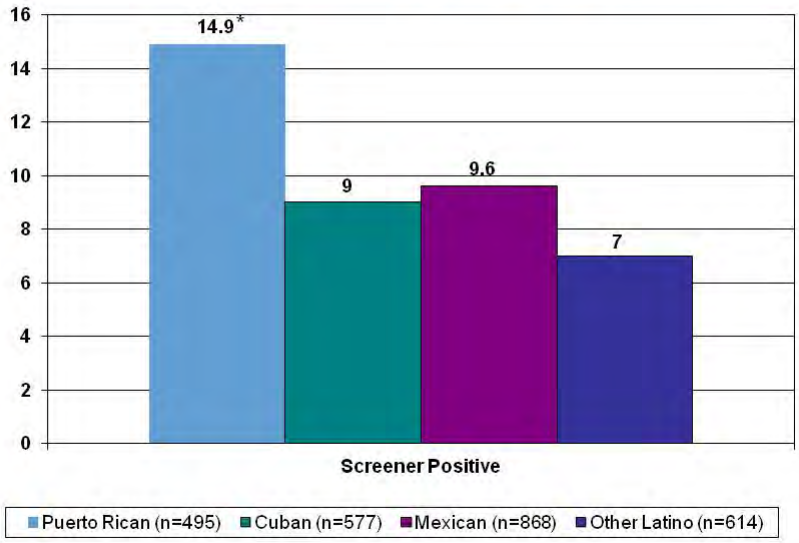
Do Puerto Rican Children Still Have Ataques de Nervios?

Association: AdN & Psychiatric Dx

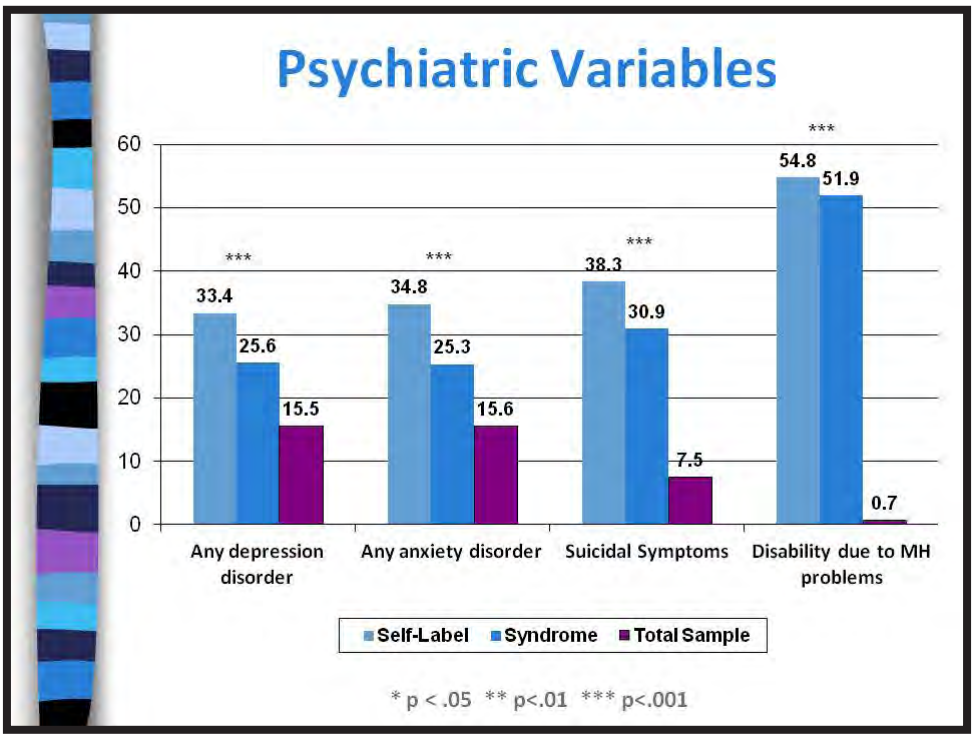
	Community Sample (n = 1891)		
Diagnoses	Absence of AdN (n=1723)	Presence of AdN (n=168)	χ^2
Any Depression	33 (2.3)	16 (15.2)	8.11**
Major Depression	29 (2.2)	12 (11.5)	5.01*
Dysthimia	5 (0.1)	6 (4.4)	4.56*
Any Anxiety	87 (5.4)	38 (22.1)	17.88***
Social phobia	26 (1.7)	17 (11.1)	10.01**
Separation Anxiety	46 (2.4)	20 (10.2)	9.69**
Panic Attack	11 (0.8)	12 (5.7)	6.18*
Panic Disorder	3 (0.1)	5 (4.0)	3.04
Generalized Anxiety	20 (1.5)	14 (9.0)	7.83**
PTSD	9 (0.8)	2 (1.0)	0.04
Any Disruptive	171 (9.7)	39 (24.8)	12.09***
ADHD	126 (7.3)	25 (14.9)	5.06*
Conduct	24 (1.5)	11 (7.6)	6.19*
Oppositional	83 (4.5)	22 (15.9)	9.61**
Any Diagnosis	243 (14.0)	62 (40.9)	24.43***
Any Impairment	196 (10.5)	55 (39.6)	19.20***

How Common Are Ataques de Nervios among Other Latinos in the U.S.?

Frequency: Ataques de Nervios



* p < .05 ** p<.01 *** p<.001



Research Program: Cultural Syndromes

[How do we generalize specific cultural findings?]

Questions for a Research Program on the Cultural Syndromes

Nature of the Phenomenon

- How is the syndrome labeled in its cultural context?
- How frequently experienced is the syndrome?
- What is the subjective inner experience of suffers?
- How representative is the description of the syndrome of the broader range of variation in its experience?
- Are there a coherent set of symptoms that define the cultural syndrome or another way it is locally identified?
- Do the symptoms of the cultural syndrome cluster in particular ways that aid in understanding this experience?

Questions for a Research Program on the Cultural Syndromes

Location in the Social Context

- Who are the people that report this cultural syndrome?
- What is their location in the social structure of that society?
- In what social contexts do these syndromes occur?
- What are the situational factors that provoke these syndromes?

Questions for a Research Program on the Cultural Syndromes

Relationship to Psychiatric Disorder

- How is the cultural syndrome empirically related to psychiatric disorder?
- Do different sub-types of the relate to different psychiatric disorders?

Social/Psychiatric History of the Syndrome

- When the cultural syndrome and psychiatric disorders are comorbid, what is the sequence of onset of these experiences?
- How is this sequencing of onset embedded in the life history of the sufferer?

Puerto Rican Popular Nosology of Nervios

[How do we apply cultural knowledge?]

"Being a Nervous Person"
Ser Nervioso (desde Chiquito)

- Chronic condition that one is either born with or occurs as a result of childhood traumas
- Common symptoms: trembling, crying more than others, talking rapidly, startle easily, quick to anger
- Can be controlled with the help of family and social network
- More vulnerable to stressful life events and to break down under accumulating life problems
- Critical aspect is **enhanced vulnerability**

"Suffering from Nerves"
Padecer de los Nervios

- More of a mental illness, most often associated with depression
- More likely to develop in adulthood from overburdening series of life problems
- Common symptoms: overwhelmed by too many thoughts, cannot stay still, very sensitive to stressors, fearful, prone to explosive anger
- Need to get professional help. Doctors treat the physical damage to the nerves; mental health deals with psychological problems.

"Nervous Attacks"
Ataques de Nervios

- Dramatic episodes which occur as a result of a major stressful event, particularly in the family sphere
- Core experience: being out of control in mind, body and behavior
- Episode is relatively brief and people quickly return to pre-*ataque* state
- Appropriate help depends on cause of the *ataque de nervios*: family, religious counseling, mental health treatment, spiritual intervention

Profile of a 31 year-old Puerto Rican Woman

- Childhood: *Nerviosa desde chiquita*/ Nervous since childhood: She was a very shy child. Had a very strict mother who did not allow her to play with other children.
- Ages 11-15: *Ataques de nervios*/ Attacks of nerves when her mother would hit her with a belt. From the beatings, developed *nervios*/nerves. She then began to *padecer de los nervios*/ suffer from nerves.

Profile of a 31 year-old Puerto Rican Woman

- Age 18: Developed social phobia. She went to a university, but found she could not talk in front of her teacher or with a group of fellow students.
- Age 21: Developed *ataques de pánico*/ panic attacks after the birth of her son. She has had intermittent panic attacks since then. She distinguishes between her *ataques de nervios*/ attacks of nerves and her *ataques de panicos*/ panic attacks.

COSSA

Consortium of Social Science Associations

"Operationalizing Culture" for

Health Behavior and Social Sciences Research

June 2, 2014

On May 23, as part of the behavioral and social science lecture series, the National Institutes of Health (NIH) held a panel discussion on "Culture, Research, and Health Outcomes." Panel presenters included Marjorie Kagawa-Singer, University of California, Los Angeles; Peter Guarnaccia, Rutgers University; Laura Szalacha, The Ohio State University; and Bill Elwood, NIH/OBSSR/OppNet. The event was cosponsored by the NIH Office of Behavioral and Social Sciences Research (OBSSR) and the NIH Basic Behavioral and Social Science Opportunity Network (OppNet).

The distinguished panel discussion centered on measuring specific cultural variables in basic research and translating that into interventions and other clinical research that can improve health outcomes. Much of the NIH's portfolio of sociobehavioral and clinical research projects use proxy variables for culture. These include demographic categories, race/ethnicity, national origin, language use at home, and geographical and political boundaries. OBSSR observed that the variables, which are gathered at intake, remain static and as a consequence "may obscure, rather than explain, specific processes in which cultural beliefs and practices influence practices related to health and well-being." To begin to address this issue, OBSSR provided support to create an online, best-practices publication to operationalize culture in health research. Marjorie Kagawa-Singer, a medical anthropologist and oncology nurse, is the project's principal investigator. She explained that she has wrestled with the "lack of conceptualization of culture in health research" from her perspective for several decades.

Kagawa-Singer explained that the OBSSR/OppNet-supported project had three goals: (1) define culture for use in health research; (2) provide a roadmap to guide researchers, reviewers, and funders in measurement and application of culture; and (3) illuminate the Eurocentric-basis of health behavior research. The soon-to-be released online publication, *Cultural Framework for Health,* includes recommendations to provide six checkpoints to facilitate a more thorough accounting for cultural processes in research:

1. Is the rationale for the inclusion of culture clearly articulated in the problem statement?
2. Is there a clearly articulated definition of culture for this study?
3. Are there known, salient theoretical cultural domains? Known theoretical domains, unknown cultural domains? Known cultural domains, unknown theoretical domains?
4. Do you articulate a conceptual framework that specifies how salient domains affect specific health/wellbeing issue(s)?
5. Is there correspondence between theoretical and cultural domains?
6. Do cross-culturally equivalent measures exist?

The panel created a consensus definition for health research, as well as a roadmap for researchers to use to inform the role and measure of culture on the outcome of focus. The misperceptions about culture are that it is usually viewed as a deficit and not an asset, said Kagawa-Singer. *Cultural Framework for Health* is the product of an expert panel consisting of 30 people representing eight disciplines. She noted that most, if not all, were currently in a department different from their disciplinary training. The basic premise of the project was to transform the use of culture in health research. The problem is that there is no such thing as human nature independent from culture. Yet, culture is overlooked in the science of human behavior, Kagawa-Singer explained.

According to Kagawa-Singer, culture is a poorly defined and untested variable. At the same time, hundreds of definitions of culture exist in many disciplines, she noted. The measures that accurately operationalize the aspects of culture that most affect the health issues of focus are missing, along with studies that test the hypotheses of culture's impact on health outcomes. It is usually assumed to be one of the control variables in research and not as an issue of research in and of itself, said Kagawa-Singer.

The panel identified the ten most common scientific challenges in the use of culture in health research:

1. It is inadequately theorized and inconsistently applied.
2. Lack of clear definitions, measurable constructs and conceptual models of how cultural processes interact.
3. Cultural groups are defined devoid of their historical, geographic, social and political context, and influence of these contextual factors on their access to resources and social positions in societal power hierarchy. This is often unrecognized in how various populations are identified. It assumes that these groups are homogeneous, despite the knowledge that geographic differences make a difference in which the populations are and how they express cultural variations.
4. The dynamic nature of culture is rarely reflected in most studies. It is usually a static measurement of race, ethnicity, and “little else beyond that or one or two cultural stereotypical measures.”
5. Recognition of the role of culture in shaping the nature and conduct of the scientific process and its relationship to research participants is lacking.
6. Everyone has culture. The assumed universality of the dominant culture’s constructions of reality and the salient domains, such as selfhood, family, fairness, and well-being is unproven and should not be assumed.
7. The use of simplistic variables of race and/or ethnicity or ancestry to represent culture is simplistic and inadequate.
8. Heterogeneity within the group of focus should be also explicitly demonstrated in the description of the study sample.
9. A contextual focus of the individual without the historical, political, and social environmental circumstances of the individual group will miss the salience of culture within any population of interest.
10. Challenges 1 -9 contribute to the inability to effectively address health disparities.

Regarding point 6 above, Kagawa-Singer noted that we are usually studying the

culture of the other group, emphasizing that the panel is promoting the idea that the culture of both scientists and science in and of itself is a culture that intersects with the culture of the population being studied. Self-reflection is needed to prevent the kind of dichotomy set by scientists as the criteria for well-being, because it is monocultural.

The effect of culture on science impacts the unreflective use of theories that have been developed and validated primarily in European-American populations, usually educated populations. The use of tools and measurements has not been validated for cross-cultural equivalence. This raises ethical questions regarding the imposition of one culture's definition of health and ways of managing illness without eliciting the perspective of the populations of focus.

Kagawa-Singer highlighted coming demographic changes and emphasized that "we are not prepared to address this diversity in our health science." The issue of health disparities will continue to grow as it has been, she argued. She cited a 2008 paper by Leonard Stein that noted that "not one iota of progress in reducing health disparities" had been made and that they are actually growing. So with the change in demographics, Kagawa-Singer, stressed that if scientists don't begin to relook at the ways research is conducted and the issue of diverse populations, "our health care system will suffer for it and the well-being of our citizens will even more so."

Kagawa-Singer also pointed to fruit and vegetable intake in the U.S. as an example of an area where culture has not been taken into consideration. Hundreds of millions of dollars have gone into funding the promotion of fruit and vegetable consumption to address many chronic and infectious diseases. While the message is out there, there has not been an increase in consumption, and it is more pronounced in diverse populations, she explained.

Kagawa-Singer argued that the categories of race/ethnicity as set forth in the Office and Management Budget (OMB) directive 15 "eviscerates culture." She offered her own set of key definitions of race, racism, population group, ethnicity, and culture. Kagawa-Singer emphasized that there is no "scientific biologic evidence" for the OMB categories of race, pointing out that race is an "assumed genotype based on phenotype." Conversely, she stressed that "racism is real" and "very powerful" and defined it as an "assertion of power, ego fulfillment, and racialization status at expense of others by skin color." She defined "population group" as a "population which has similar adaptive physiologic responses and cultural practices due to ecologic niche," which is why "place" makes a difference (see **Update, April 30, 2012**). "Ethnicity" is defined as "a subcultural group within a power structure of a

multicultural society and self-identified group membership within a socio-historical context." It is a system of beliefs, values, lifestyles, ecologic and technical resources, and constraints designed to ensure survival and well-being of its members. When defining culture, Kagawa-Singer emphasized the need to differentiate what culture is versus what culture does, further stressing that it is not a thing, or static measure. As a result, it has to be titrated to the situation of the population of interest, she argued.

She defined "culture" as a shared framework or lens that members learn to use to "see" the world and which informs, consciously and unconsciously, how to live life, why they live life, and how to resolve problems in doing so. It is created and modified within a multidimensional, multilevel, dynamic and adapting ecologic system of internal and external resources and restraints. Further, it is socially and legally integrated into the structure of a society's institutions. What culture does, Kagawa-Singer explained, is "define and construct the world around

to derive meaning in and for life. It provides the social structure that defines and coordinates the numerous roles of each of its members in relation to the group, rules of social interaction and distribution of power. It expresses and sustains the reality of its members codified through the built environment including our institutions."

Accordingly, the culture of research, with its assumption of the universality of reality and the way it explicitly or implicitly informs thought or behavior, requires researchers to be more discriminating in how they conduct and operationalize these concepts. Research should be multi-level and multi-dimensional, she underscored, highlighting that she found research in epigenetics to be an exciting burgeoning field where we can see the impact of environment on our genetic coding. Culture is actually nested in its measures where the focus is usually on beliefs and values and one or two are selected out to represent culture, she explained. She noted the seven nested layers of culture: environment, economy, technology, religion/worldview and beliefs about healing systems, social structure, language and health literacy, and beliefs and values. Kagawa-Singer stressed the need to begin with the environment of the particular group of focus and understand how it impacts the populations that live within it along with its potential impact on DNA.

Implementing Culture in Interventions

Laura Szalacha discussed how to incorporate the panel's recommendations into interventions. Learning how to work within a culture and how they say things

and what the actual meaning for a particular population is a long process, and researchers must be immersed in that world. Researchers have often taken the easy way out, she noted and cited as an example the use of an insufficient single item for race or ethnicity. There is also a failure to look at the heterogeneity in the population or examine the social, historical, and environmental context of health. The good news, Szalacha noted, is that there "is a real correspondence between the need for more complexity and authenticity" in the research and the development of analytic techniques.

Community-based participatory research, however, is a symbol of progress, Szalacha said and pointed out that probably the greatest progress is the overcoming of the "paradigm wars" between quantitative and qualitative methods and philosophies of two decades ago along with the recognition that their combined use in examining culture and health is imperative. She cited as an additional example of this progress cultural neuroscience which is "studying how cultural and genetic diversity affect psychological and neural processes in the production of human behavior." Biocultural co-constructivism was mentioned as another example of progress. It has emerged as a "way of explaining how developmental trajectories unfold through interactions between genetic and cultural factors." There has been work that examines how neural plasticity may later affect and be affected by both developmental trajectories and the end state, Szalacha pointed out.

Cultural Framework for Health's flow-map*,* Szalacha noted, will inform researchers how to conceptualize and operationalize culture for a particular hypothesized effect. The questions are about theoretical and cultural constructs. These are different processes, she emphasized. The hope is that the flow-map highlights the need for mixed paradigms and mixed methods research. Two examples given in the report explain or illustrate the ways in which the two methods work together to answer the questions. The first, *cultural domain analysis,* is where you have a linked set of qualitative research and quantitative data analytic techniques for systematically discovering the terms a member of a group uses as well as the various dimensions of meaning that link with those terms. Use of constrained/unconstrained pile sorts can then be analyzed to help extract dimensions of meaning used within the domain. The second, *cultural consensus analysis*, is the development of measurements for constructs within specific social groups when no measurement exists, or when existing measurements are likely to be too culturally specific to one group, Szalacha noted.

According to Szalacha, the only way to accomplish the recommendations in the report is via interdisciplinary collaboration. It is the only way to do real research

and attend to all of these different things, she emphasized. She further noted that researchers need to focus on external as well as internal validity by utilizing both inductive and deductive paradigms and quantitative and qualitative methods. They need to collaborate with members of the community of focus to identify, in partnership with the researchers, the salient issues impacting their health outcomes. Researchers also need to integrate the social, historical, economic, environmental, and geopolitical factors of the community of focus, she emphasized.

Culture is a dynamic, multidimensional construct with measurable properties. More accurate identification and measures of salient factors will truly make a difference in terms of health equity or health disparities, Szalacha pointed out. The hope, she concluded, is that "reviewers will increasingly be asked to assess the cultural and linguistic competence of grant applications and how well cultural issues have been addressed in health behavior and social science articles submitted for publications." Think back to when it was decided that having females in studies would be a good thing, she noted.

Szalacha pointed out that in the *Cultural Framework for Health* the panel focused on racial and ethnic cultures and health outcomes but cautioned that it is also necessary to attend to many of the socially constructed cultures that exist such as class and sexual identity, among others, noting that we are all combinations of several with different saliency depending on where we are and whom we are. Researchers need to be prepared for that sort of complexity, she concluded.

The Value of Integrating Culture into a Program of Research

Peter Guarnaccia' s charge was to provide a model or example of how one might integrate culture into a program of research, what it means to take culture seriously, and the value of doing it. He discussed his research of more than two decades on *Ataque de Nervios,* which is defined as an idiom of distress principally reported among Latinos from the Caribbean. He explained that when he started out in the 1960s there was an interesting set of studies published in *General Psychiatry* around the label of *Puerto Rican Syndrome*. Commonly reported symptoms include screaming/shouting uncontrollably, attacks of crying, trembling, heat in the chest rising to the head, and becoming verbally/physically aggressive. In addition, it includes features prominent in some *ataques,* but absent in others, such as dissociative experiences, seizure-like or fainting episodes, and suicidal gestures. A core feature, explained Guarnaccia, is the sense of being out of control and

frequently occurring as a direct result of a stressful event relating to family. In addition, the individual may experience amnesia for what occurred during the *ataque de nervios*.

The study of a*taque de nervios* challenged the basic framework and begins to challenge science on the conceptualization of science, Guarnaccia stated. He explored the question, why is culture relevant, through a series of brief vignettes as a window into this program of research. Guarnaccia also shared his questions for research programs on cultural syndromes, which parallels many of the issues addressed in the *Cultural Framework for Health* report, including the nature of the phenomenon, location in the social context, relation to the psychiatric disorder, and the social/psychiatric history of the syndrome.

A videocast of the lecture is available: http://videocast.nih.gov/summary.asp?Live=14227&bhcp=1

APPENDIX L:

Poster presented at the 35th annual Society of Behavioral Medicine meeting, Philadelphia, 2014, April 25.

NIH

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH

NIH National Institutes of Health
Office of Behavioral and Social Sciences Research

OPPNET Basic Behavioral & Social Science Opportunity Network

Transforming culture and research: Operationalizing culture and its relationship to health and wellbeing outcomes

William N. Elwood, Ph.D., *National Institutes of Health*
William W. Dressler, Ph.D., *University of Alabama*
Sheba M. George, Ph.D., *Charles R. Drew University of Medicine and Science*
Marjorie Kagawa-Singer, Ph.D., FAAN, *University of California, Los Angeles*
Laura A. Szalacha, Ed.D., *Ohio State University*
Paula Roberts, B.S., *National Institutes of Health*

Examination of NIH's portfolio finds use of proxy variables for ***culture***, e.g.,

- Demographic categories
- Geographic/political boundaries

Such variables cannot measure cultural processes that influence health-related behaviors. Sole use surrogate variables for culture e.g.,

- Language use at home
- National origin
- Race/ethnicity

may obscure rather than illuminate specific processes in which cultural beliefs & practices influence health & wellbeing. **NIH took two steps to advance this scientific area:**

1. Funded 8 projects to build new researcher networks (RFA-LM-12-002) through small projects that may collect preliminary data (see list across).

2. Funded supplemental panel to create an online, best-practices publication to operationalize culture in health research. They found much literature view *culture* as a deficit for racial/ethnic minorities when they conflate culture, race, & ethnicity; & depict cultural groups as homogeneous. This reinforces ***culture*** as static trait(s) rather than a dynamic construct. The recommendations provide **six checkpoints** to facilitate more thorough accounting for cultural processes in research:

1. Is the rationale for the inclusion of *culture* clearly articulated in the problem statement?
2. Is there a clearly articulated definition of culture for this study?
3. Are there known, salient theoretical cultural domains?
   - ✓ Known theoretical domains, unknown cultural domains?
   - ✓ Known cultural domains, unknown theoretical domains?
4. Do you articulate a conceptual framework that specifies how salient domains affect specific health/wellbeing issue(s)?
5. Is there correspondence between theoretical & cultural domains?
6. Do cross-culturally equivalent measures exist?

See http://obssr.od.nih.gov/index.aspx this summer for this online publication, Kagawa Singer M, Dressler W, George S, and the NIH Expert Panel on Defining and Operationalizing Culture for Health Research. *Transforming the Use of Culture in Health Research*. NIH Office of Behavioral and Social Science Research Bethesda, MD. 2014.

OppNet RFA, Basic sociobehavioral research on culture, health, and wellbeing

1. *Building an interdisciplinary network on culture & HIV risk*, David Patrick Kennedy, RAND
2. *Cultural beliefs & practices impacting teenage sleep*, Andrew Fuligni, UCLA
3. *Developing indigenous health indicators to reflect community health priorities*, Robin Scott Gregory, Decision Science Research Institute
4. *Emergence of gender inequitable practice in adolescence*, Elizabeth Miller, University of Pittsburgh
5. *Envisioning health using images to enhance Latino adolescent-doctor bonds*, Mimi Victoria Chapman, UNC Chapel Hill
6. *Pass the popcorn: Children's perceptions of obesogenic culture in movies*, Eliana Perrin, UNC Chapel Hill
7. *Transnationalism, networks, & culture: Implications for health & behavior*, Linda Sprague Martinez, Tufts University
8. *Culture, health, and adolescence research network (CHARN)*, Emily Ozer, University of California, Berkeley

Visit http://oppnet.nih.gov/ *for more information on these grants*

Conclusion: Concurrent funding of basic research teams & translational guidelines for researchers & reviewers benefits multiple sociobehavioral fields & the health sciences over the short- & long-term to foster more comprehensive definitions of culture & more precise measures of variables involved in cultural group processes, & individual & group decisions relevant to human health & wellbeing.

Bill Elwood, Ph.D.
william.elwood@nih.gov
301/402-0116

NIH National Institutes of Health