



Challenges and Prospects for Disaggregating Health Data among Non-Hispanic Whites¹

Draft Review

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by

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ABSTRACT

Objectives:

- The purpose of this study is to provide a review of key issues related to disaggregating health data among non-Hispanic whites.
- The review will highlight existing challenges for health researchers and make recommendations for future data collection efforts.
- The review will contribute to RWJF's larger project that explores strategies for disaggregating health data within six broad U.S. racial/ethnic categories.

Key Findings:

- The historical classification of U.S. populations into broad racial/ethnic categories has obscured growing heterogeneity in health outcomes within these groups.
- Changes in research and policy have made varying levels of progress in understanding diversity among groups classified as Asian, Hispanic, and/or Black.
- Progress on non-Hispanic whites is limited despite increasing changes in the ethnic composition of this group.
- These changes are being driven by national origin immigrant groups that are more diverse than their European predecessors.
- Using non-Hispanic whites as a reference category fails to acknowledge these changes and hinders research and policy aimed at reducing health disparities.

Recommendations:

- Many of the recommendations offered by other research teams apply to non-Hispanic whites (e.g., better guidelines for data collection and analyses).
- Unique to this group is the fact that they are the default reference category to which other groups are typically compared. Researchers and policymakers need to be better educated of the potential problems associated with this approach.
- Accomplish this by demonstrating scientifically that: a) there is growing ethnic heterogeneity in groups classified as white, and b) using them as the reference category may provide inaccurate estimates of health disparities relative to other groups and obscure the health needs of underserved white populations such as Appalachians.
- Provide better research guidelines for disaggregating racial/ethnic populations to alleviate some of the methodological and practical challenges faced when attempting to do so.
- Encourage researchers to be more circumspect in using non-Hispanic whites as the default reference category. At minimum, encourage researchers to disaggregate foreign- and native-born whites to capture increasing diversity among this population due to immigration.

INTRODUCTION

The U.S. population is comprised of increasingly diverse racial/ethnic populations that are typically collapsed into one of five distinct groups: African Americans/Blacks, Latinos/Hispanics, Asian Americans/Native Hawaiians/Pacific Islanders, Native Americans and Alaskan Natives, and Whites. However, there is significant ethnic heterogeneity within each of these groups. For example, there are over 100 ancestry groups classified as white by the U.S. Census Bureau, ranging from Egyptians, Lebanese, and Russians to Cajuns and Appalachians. These groups are also diverse with respect to socio-demographic factors known to influence health (e.g., socioeconomic status, health insurance, English language proficiency, citizenship, health behaviors).

To date, research has largely obscured potential ethnic heterogeneity in U.S. population health by relying on broad racial/ethnic categorizations. This is problematic because ethnic diversity in the U.S. population is projected to increase over the next few decades, suggesting that knowledge based on broad racial categorizations may be less applicable for some ethnic groups (Waters and Pineau 2015). Studies that disaggregate ethnic subgroups have indeed found considerable variation in the health profiles of Hispanic (Palloni and Arias 2004), Asian (Gee and Ponce 2010, Yi et al. 2016), and Black (Elo, Mehta and Huang 2011, Hamilton and Hummer 2011, Read and Emerson 2005) populations.

However, research that disaggregates the non-Hispanic white population¹ is practically non-existent. A comprehensive review of the extant literature found no study that systematically disaggregates the health status of ethnic groups classified as non-Hispanic white. Studies that include non-Hispanic whites typically do so as a reference group to which other groups are compared. For example, the National Healthcare Disparities Report that is published annually by the Agency for Healthcare Research and Quality

¹ Throughout the review, I use the terms “white” and “non-Hispanic white” interchangeably to refer to the latter term.

continues to use whites as the benchmark for assessing racial/ethnic health disparities (AHRQ 2015).

Yet whites are far from monolithic and are increasingly comprised of immigrants of non-European descent (Read and Reynolds 2012, Waters and Pineau 2015). As such, they represent a group whose health profile deserves greater attention, particularly in light of studies documenting health disparities among certain groups classified as white, such as Arabs and Russians (Dallo and Kindratt 2015, Reynolds, Chernenko and Read 2016).

RESEARCH OBJECTIVES AND STRATEGY

The purpose of this study is to provide a review of key issues related to disaggregating health data among non-Hispanic Whites. The goal is to highlight existing challenges for health researchers and make recommendations for future data collection efforts. To achieve these objectives, I will first provide a brief overview of the classification of non-Hispanic whites and will then use data from the American Community Survey (ACS) to identify a comprehensive list of ethnic groups that are subsumed within the white category.

The American Community Survey provides one of the most promising opportunities for data disaggregation because it contains detailed ethnic origin data on over 300 groups classified into broad racial categories and has relatively large sample sizes. Using a cut point of 66% (two-thirds or more of respondents in the ethnic group consider themselves to be non-Hispanic white) revealed that 131 of the 300 ethnic groups in the combined 2010-2014 ACS are non-Hispanic white. There is also tremendous variability in the size and demographic composition of these groups. Thus an important first step in the review is to identify which groups to include in the remainder of the review.

After identifying these groups, I will conduct a comprehensive scan of existing academic and research databases to identify data sources and published works that disaggregate data among the largest groups classified as white. The goal is to determine if there are

major surveys that collect, analyze, or report data that disaggregate groups contained within the broad category of white. I will then compare and contrast methodological approaches in key publications to determine if there are similarities in the challenges faced when attempting to disaggregate data among whites. I will use two specific groups—Appalachians and Arabs—to provide concrete examples of the opportunities and challenges of data disaggregation. The review will conclude with recommendations for improving the utilization of existing data and for enhancing future data collection efforts.

CLASSIFICATION OF WHITES

Historical background

Before delving into the challenges and opportunities for disaggregating data among non-Hispanic whites, it is important to understand the historical and contemporary basis for who is classified in this category. According to the Office of Management and Budget, persons are defined as “white” if they have origins in any of the original peoples of Europe, the Middle East, or North Africa (Hixson, Hepler and Kim 2011). From 1870 until 1980, the U.S. Census Bureau used parents’ place of birth to determine the ethnic origins of individuals classified as white, which largely equated to persons of European descent (Farley 1991).

In 1980, the Census Bureau replaced the item on parents’ place of birth with an open-ended question on ancestry and developed a list of 468 possible response categories that included nations, languages, and geographic areas but excluded religions. Despite the expansiveness of the list, the vast majority of respondents in the 1980 Census fell into a handful of European ancestries, with English, German, and Irish representing 55 percent² of the 226 million persons enumerated in the U.S. that year. Afro-American and American made up another 15 percent of responses (9.3 and 5.9 percent, respectively),

² Based on responses to first and second ancestry.

with the remaining 24 percent scattered across various Western European, and to a lesser extent, Central American ancestries.

Since 1980, the ethnic composition of groups classified as white has diversified considerably. The percentage of persons reporting English, German, or Irish as a first ancestry dropped from 55 percent to less than 23 percent in 2010, while the percentage of those reporting Middle Eastern and African (MENA) descent grew considerably (ACS 2010). The Arab population, alone, doubled in size in the span of two decades (1980 to 2000) and now makes up one of the fastest growing segments of the non-Hispanic white population. Moreover, studies indicate that this growth is being driven by racially-diverse migrants who do not self-identify as white but are nevertheless (re)classified as such in large-scale surveys (Read 2013). In addition, the Migration Policy Institute estimates that nearly one half of foreign-born persons from the MENA³ region have arrived in the U.S. since 2000, suggesting that this is a fairly new and lesser known immigrant population (Auclair and Batalova 2013).

Current composition of the non-Hispanic white population

Table 1 takes a closer look at ethnic diversity in the non-Hispanic white population using the most recent 5-year combined American Community Survey (2010-2014). Each microdata file is a stratified sample that includes one percent of the housing units in the United States, which is a subsample of the full Census. The unweighted sample size for non-Hispanic whites in the 5-year combined file is 10,533,297. Table 1 uses the weighted sample to more accurately represent the overall population (n=160,731,686).

³ The U.S. Census defines persons of Arab ethnicity as persons who trace their ancestry to one of the following 17 countries: Algeria, Bahrain, Egypt, Iraq, Jordan, Kuwait, Lebanon, Libya, Morocco, Oman, Qatar, Saudi Arabia, Syria, Sudan, Tunisia, United Arab Emirates, and Yemen. The International Organization for Migration defines the Middle East and North Africa (MENA) region using the same 17 countries.

The results in Table 1 are based on first responses to the ancestry question and exclude persons who responded affirmatively to the Hispanic origin question. As seen in the table, there are 131 groups where at least two-thirds of respondents identified as non-Hispanic white. The top 5 ethnic categories combined make up 62% (n=100,413,909) of all the groups listed in Table 1, and the top 15 ethnic categories combined make up 87 percent (n=139,359,211). European ancestries dominate this group, but there is a sizable and growing number of national origin groups of non-European descent (highlighted in yellow).

The Middle East and Arab ancestry categories are particularly noteworthy because the social and cultural contexts in the countries of origin, along with distinct immigration histories and context of reception in the U.S., differ from earlier European migrants. There are also phenotypical differences between European and non-European national origin groups that may result in more disadvantaged outcomes for the latter (Bakalian and Bozorgmehr 2009; Jamal and Naber 2008).

Table 1 also shows that some of the ancestry groups contained within the white category are quite small, such as Acadians and Slovenians. Other groups fall out of the purview of this review because they overlap with the focus of other research teams on this project (e.g., Cherokee; Chicano/Chicana; Mexican; Puerto Rican). These distinctions are important because recommendations for future research on data disaggregation will need to provide guidelines for which groups should be included/excluded in collection and analyses.

LITERATURE SEARCH

Technical details

Based on the major groups identified in Table 1, we conducted an extensive literature search to identify works that attempted to disaggregate the non-Hispanic white population. The search was conducted in PubMed using several key words and terms

that were included in either the title or abstract. The first search used the truncated version of “disaggregate” (to include all of its variations) in combination with multiple terms for ethnic groups. The ethnic groups searched were white, Arab, Russian, German, Italian, Irish, English, Egyptian, Iraqi, Yemeni, Cajun, and Appalachian, which resulted in a total of twelve searches. A second round of key word searches were performed for each ethnic group along with a truncation of “diversity.”

Results were limited to peer-review articles published in English. The titles and abstracts of each search were read for substantive content and coded as relevant or not. Appendix A illustrates the number of articles found for each of the searches, ranging from 0 to 249 articles. Appendix B provides a summary of relevant citations and abstracts for each search.

Primary findings

The literature search yielded two major findings. First, research that systematically disaggregates non-Hispanic whites is basically non-existent. Of the 307 articles that included whites, approximately 90% did so using them as the reference category. The remaining 10% focused on individual groups, such as Italians or Arabs. This stands in contrast to research that disaggregates other large populations, such as Asian Americans, where the focus is typically on showing diversity across multiple subgroups (e.g., Chinese, Vietnamese, Asian Indian).

Second, and relatedly, unlike progress made in research on the Asian American and Black populations, there has been no noticeable trend recognizing intra-group diversity among whites. For example, the review on the Asian American/Pacific Islander population documented a marked uptick in the number of publications focusing on Asian American subgroups and a decline in the tendency to aggregate Asian American with Native Hawaiian and Pacific Islander. No such changes have occurred for whites, and in

fact, many of the articles found in the literature search were using whites as a reference group when disaggregating Asian subgroups.

One possible explanation for the dearth of research disaggregating the white population is that the composite category is adequate for describing the experiences of this group and thus disaggregation is unnecessary. Table 2 tests this possibility empirically by comparing the sociodemographic and health profile of the aggregate white category to six distinct white ethnic groups (German, Russian, Lebanese, Egyptian, Appalachian, and Cajun). As seen in the table, there is considerable diversity across these groups. The German and Russian populations look most similar to the aggregate white population with respect to disability rates, Lebanese and Egyptians look slightly less disadvantaged, while Appalachians and Cajuns do much worse. There is also considerable diversity across groups in terms of factors known to influence health, suggesting that the aggregate category may be less useful for understanding the health profiles of certain populations.

Another possible explanation for the dearth of research described above is that methodological challenges may inhibit researchers who are interested in disaggregating the non-Hispanic white population. The next section of the review examines this possibility, focusing on obstacles posed when attempting to identify two specific groups that are classified as white in large-scale surveys (Appalachian and Arabs).

METHODOLOGICAL CHALLENGES

Evidence from the Appalachian and Arab Cases

Researchers interested in disaggregating the non-Hispanic white population face numerous challenges. However, there are opportunities that could be better exploited. This section of the review uses Arabs and Appalachians as case studies to demonstrate the opportunities and challenges of identifying and disaggregating white ethnic subgroups in large-scale data sets (summarized in Table 3). The Arab and Appalachian cases share similarities and differences that are illustrative. First, several national data sets contain information on these groups, but health researchers often face barriers in utilizing and

disaggregating the data. Second, both groups have cultural roots based in specific regions—Arabs in 17 countries in the Middle East and North Africa and Appalachians in part of 13 states along the Appalachian mountains (ATRN 2015).⁴ Third, each group can be identified by a diverse range of Census identity categories: ancestry, place of birth, and/or Arabic language in the Arab case (Brittingham and de la Cruz 2005; Read 2013; Samhan 1999); and ancestry, place of birth, and region of residence in the Appalachian case (Ludke and Obermiller 2011; McGarvey et al. 2011). Thus, these groups offer a unique opportunity to compare the implications of using different operational definitions of ethnicity to identify groups that are collapsed into the white category.

Challenge 1: Group Identification

In addition to these similarities, there are several important differences that highlight unique obstacles to conducting research on these populations. The first is the issue of identification. Research on Appalachians typically uses geographic residence rather than self-reported identity to demarcate this group (Appalachian Translational Research Network 2015; Behringer and Friedell 2006; Ludke and Obermiller 2011; McGarvey et al. 2011; The Health Foundation of Greater Cincinnati 2012). The problem is that not all residents in Appalachian counties consider themselves Appalachian. Moreover, many of these counties are rural and have populations with lower socioeconomic status and poorer access to health care than the national average, which conflates Appalachian identity with other sociodemographic factors known to influence health.

In the Arab case, research typically relies on self-reported ancestry and/or place of birth. While some question the validity of self-reported racial/ethnic identity, an even bigger problem arises when an individual reports a given ethnic identity but then is recoded as white. This happens frequently in large-scale data collection efforts, most notably those conducted by the U.S. Census Bureau. In the era of the decennial Census, Arab write-in

⁴ The Appalachian region covers 205,000 square miles, including all of West Virginia and parts of 12 other states: Alabama, Georgia, Kentucky, Maryland, Mississippi, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, and Virginia.

responses on the race question were recoded as white, and even though the original responses were retained, they were confidential and not publicly available. The only recourse for researchers interested in studying this group was to turn to the ancestry question on the long-form of the Census that was distributed to only 17% of U.S. households. However, some studies suggest that the ancestry question is riddled with problems that compromise validity and reliability, including question prompts that mix country of origin with broad ethnic categories such as Egyptian and Persian (Samhan 1999).

The long-form of the Census (and now the American Community Survey) also contains questions on place of birth and language spoken at home. Using the Italian case as an example, one could theoretically construct a variable that taps all three questions—born in Italy, speaks Italian at home, and reports an Italian ancestry. Even checking two of these boxes would provide researchers with a high degree of confidence that the respondent is of Italian ethnicity. A similar variable could be created to identify persons of Arab ethnicity (born in an Arab country, speaks Arabic at home and reports an Arab ancestry), and again, affirmative responses to at least two of these categories would provide confidence that the respondent is of Arab descent. But not all groups are so simple—imagine a scenario where a respondent was born in Germany but does not speak German at home and does not list a German ancestry; this individual could have been born on a military base and not of German descent. Ultimately, self-reported ancestry is one of the most reliable measures of identity because it captures an individual's subjective identification with a given ethnicity.

Challenge 2: Sample Size

As described above, both Appalachians and Arabs are comprised of individuals from multiple geographic locations. Yet these groups are often described in the aggregate due to small sample sizes. In the Arab case, there are technically 17 different countries of origin that comprise this pan-ethnic category but in reality only a handful have sizable immigrant populations in the U.S. (e.g., Lebanon, Egypt). Because large-scale data sets

use random sampling techniques, the number of individuals included from each of the 17 countries is either small or nonexistent, rendering the aggregate Arab category as the only option for researchers interested in studying this group. Persons of Appalachian ancestry are likewise diverse, both geographically and demographically, yet are typically treated as a collective group due to small sample sizes.

Challenge 3: Methodological Expertise

A third challenge related to the prior two concerns the methodological expertise needed to disaggregate health data for ethnic subpopulations. In the process of writing this review, I spoke with several colleagues with considerable expertise in advanced statistical methods and most expressed that data disaggregation was common with respect to demographic variables such as age, gender, and race but that more fine-grained analyses within racial groups was rare.

In addition, not all researchers interested in disaggregating health data within large racial/ethnic categories have the requisite knowledge, skills and/or time to delve this deeply into the data. For example, the National Health Interview Survey (NHIS) contains a question on respondent's country of birth that is recoded into one of twelve broad regional categories (e.g., United States, Middle East, Europe).⁵ While regional categories are useful for some research purposes, such as comparing whites born in the Middle East or Europe to whites born in the U.S., they are less so for making more fine-grained distinctions by country of birth and/or generational status. Country of birth data are restricted and can be accessed for a fee but only after an extensive application process, a fact not commonly known among health researchers (personal conversation with Dr. Flora Dallo).

⁵ The Middle Eastern category contains persons born in any of the 17 Arab countries included in the U.S. Census definition plus persons born in five non-Arab countries (Armenia, Cyprus, Iran, Israel, Turkey).

Even with the NHIS, the issue of sample size can pose a problem for data disaggregation because of the small number of individuals included from any given country. In the Arab case, the restricted country of origin data is still superior to the aggregate Middle East category because the latter contains individuals born in five non-Arab countries—Armenia, Cyprus, Iran, Israel, and Turkey. Accessing the restricted data allows researchers to remove these groups for a more accurate depiction of Arabs.

RECOMMENDATIONS

Many of the recommendations offered by other research teams apply to non-Hispanic whites. Unique to the non-Hispanic white case is the fact that it is the default reference category to which other groups are typically compared. This approach is problematic for several of the reasons outlined in this review. In particular, growing diversification in the white population may result in inaccurate estimates of health disparities if the aggregate category is used for comparisons with other racial/ethnic groups. The aggregate category may also obscure the health needs of underserved white populations, such as Appalachians and Cajuns.

Researchers and policymakers need to be informed of these potential problems with scientifically-grounded evidence (e.g., Table 2). Researchers should also be encouraged to be more cautious when using non-Hispanic whites as the default reference category. At minimum, they should disaggregate foreign- and native-born whites to capture increasing diversity among this population driven by immigration.

Researchers also face numerous methodological and practical challenges in data disaggregation, but many of these can be addressed (if not overcome) with proper knowledge and expertise. To accomplish this goal, I recommend a two-pronged approach that focuses on educating and engaging with: 1) the major funding agencies of health research (e.g., NIH); and 2) the leading institutions that train and produce health researchers (e.g., population centers). The former should be encouraged to offer more targeted Requests for Applications (RFAs) that incentivize research on data

disaggregation. The evidence produced by the research teams on this project provide a solid foundation for making this argument.

The second prong focuses on the end users of health data, many of whom are trained in top-tier population centers at research universities (Appendix C). The Directors of these centers should be included in the upcoming convenings because they play a pivotal role in shaping the conceptual and methodological approaches of health scholars, which in turn shape knowledge about health disparities. They also have expertise in the challenges of data disaggregation and would add an important voice to the conversation.

CONCLUSIONS

Despite growing diversity in the non-Hispanic white population, the standard and accepted approach in research and policy remains to treat them in the aggregate. Data limitations have contributed to this practice because few large-scale data sources contain measures that allow for disaggregation of non-Hispanic white subpopulations. Those that do can pose methodological challenges due to small sample sizes and data restrictions.

However, there are opportunities that have not been fully exploited, such as using NHIS restricted data. Identifying these opportunities and educating researchers on how to overcome the challenges associated with them will be paramount for improving our understanding of U.S. population health disparities, particularly if the non-Hispanic white population continues to diversify in the coming years. The practice of using whites as the reference group was borne in an era of greater homogeneity in groups classified as white (i.e., mainly European). Future research should reflect the fact that this may no longer be the case.

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APPENDIX A. RESULTS FROM LITERATURE SEARCH

PANEL A. SEARCH TERM “DISAGGREGATE”	
White	n = 58 70% about disaggregating Asian and other ethnic subgroups
Arab	n = 5 3 unrelated to ethnicity
Russian	n = 1 Indigenous versus non-indigenous Russians in Russia
German	n = 8 Studies in Germany, disaggregation unrelated to ethnicity
Italian	n = 4 Studies in Italy and disaggregation unrelated to ethnicity
Irish	n = 1 Study in Ireland and disaggregation unrelated to ethnicity
English	n = 22 70% related to language proficiency, 20% based in England
Iraqi	n = 1
Yemeni	n = 0
Cajun	n = 0
Appalachian	n = 0
PANEL B. KEY TERM DIVERSITY	
White	n = 249 95% use white as the comparison group, 5% unrelated to ethnicity
Arab	n = 6 1 on language proficiency and 1 unrelated to ethnicity
Russian	n = 9 45% about cultural competency, 33% about Aleutians
German	n = 15 60% about genetic and geographic diversity, 20% in Germany
Italian	n = 7 1 about language, 2 unrelated to ethnicity
Irish	n = 2 Comparing USA to Ireland and England
English	n = 76 All related to language
Egyptian	n = 1
Iraqi	n = 3 2 about Operation Iraqi Freedom
Yemeni	n = 0
Cajun	n = 0
Appalachian	n = 2 Related to Appalachian region

APPENDIX B. RELEVANT ABSTRACTS

Arab	
	<p><i>Dallo, F. J., S. Al Snih and K. J. Ajrouch. 2009. "Prevalence of Disability among Us- and Foreign-Born Arab Americans: Results from the 2000 Us Census." Gerontology 55(2):153-61.</i></p> <p>BACKGROUND: Although the prevalence of disability for various racial and ethnic groups has been documented, little attention has been paid to Arab Americans in the United States. OBJECTIVES: We estimated the age- and sex-adjusted prevalence of disability among older Arab Americans and examined the association between nativity status and self-reported physical and self-care disability before and after controlling for covariates. METHODS: We used data from the 5% Public Use Microdata Samples of the 2000 US Census. Our sample included 4,225 individuals 65 years of age and older who identified with an Arab ancestry. Of these, 2,280 were foreign-born and 1,945 were US-born. RESULTS: The age- and sex-adjusted prevalence of having a physical disability was 31.2% for foreign- and 23.4% for US-born older Arab Americans, and the age- and sex- adjusted prevalence of having a self-care disability was 13.5% for foreign- and 6.8% for US-born Arab Americans. Iraqis reported the highest estimates for both disabilities (physical, 36.2%; self-care, 19.8%) compared to other Arab ethnic groups. In the crude model, foreign-born Arab Americans were more likely (OR=1.32; 95% CI=1.28, 1.36) to report a physical disability compared to US-born Arab Americans. When adjusting for English language ability in the final model, the odds of having a physical disability for foreign-born Arab Americans was protective compared to US-born Arab Americans (OR=0.92; 95% CI=0.88, 0.96). In the crude model, foreign-born Arab Americans were 1.82 times (95% CI=1.74, 1.90) more likely to report a self-care disability compared to US-born Arab Americans. In the fully adjusted model, this association was slightly attenuated (OR=1.32; 95% CI=1.24, 1.41). CONCLUSIONS: These findings indicate English language ability is associated with variations in reporting a physical disability. Future studies should include better measures of acculturation. Arab Americans are heterogeneous and should be disaggregated both by subgroups and from the white category in order to reveal a more accurate health and disease status profile for these groups. These efforts will assist in tailoring more effective interventions in reducing or preventing disability among Arab Americans 65 years of age and older.</p> <p><i>Dallo, F. J. and T. B. Kindratt. 2015. "Disparities in Vaccinations and Cancer Screening among U.S.- and Foreign-Born Arab and European American Non-Hispanic White Women." Womens Health Issues 25(1):56-62.</i></p> <p>BACKGROUND: Disparities in vaccinations and cancer screening exist when comparing foreign-born and U.S.-born women collectively and disaggregated</p>

	<p>by race and ethnicity. The purpose of this study was to estimate and compare the age-adjusted prevalence of not receiving a flu or pneumonia vaccine, clinical breast examination, mammogram or Pap smear among U.S.- and foreign-born White women by region of birth and examine associations while controlling for potential confounders. METHODS: We pooled 12 years of National Health Interview Survey data (n = 117,893). To approximate an "Arab-American" ethnicity, we identified 15 "Arab" countries from the Middle East region that comprise the Arab Nations. Data was requested from the National Center for Health Statistics Research Data Center. We used the chi(2) statistic to compare descriptive statistics and odds ratios (ORs) with 95% CIs were used for inferential statistics. FINDINGS: Compared to U.S.-born, foreign-born Whites from the Arab Nations had higher estimates of not receiving recommended vaccinations and cancer screenings. In crude and adjusted analyses, foreign-born Arab-American women were less likely to report receiving a flu vaccine (OR, 0.34; 95% CI, 0.21-0.58), pneumonia vaccine (OR, 0.14; 95% CI, 0.06-0.32), Pap smear (OR, 0.13; 95% CI, 0.05-0.31), or clinical breast examination (OR, 0.16; 95% CI, 0.07-0.37) compared with U.S.-born White women. There were no differences for mammography. CONCLUSIONS: This national study examining uptake of flu and pneumonia vaccines and preventive cancer screenings suggests that estimates are lower for foreign-born Arab-American women compared with U.S.-born White women. Future studies should collect qualitative data that assess the cultural context surrounding prevention and screening behaviors among Arab-American women.</p> <p><i>Ezenkwele, U. A. and G. S. Roodsari. 2013. "Cultural Competencies in Emergency Medicine: Caring for Muslim-American Patients from the Middle East." J Emerg Med 45(2):168-74.</i></p> <p>BACKGROUND: Cultural competency is crucial to the delivery of optimal medical care. In Emergency Medicine, overcoming cultural barriers is even more important because patients might use the Emergency Department (ED) as their first choice for health care. At least 2.2 million Muslims from Middle Eastern background live in the United States. OBJECTIVE: We wanted to create a succinct guideline for Emergency care providers to overcome cultural barriers in delivering care for this unique population. METHOD: A compensative search on medical and health databases was performed and all the articles related to providing healthcare for Muslim-Americans were reviewed. RESULT: The important cultural factors that impact Emergency care delivery to this population include norms of modesty; gender role; the concept of God's will and its role in health, family structure, prohibition of premarital and extramarital sex; Islamic rituals of praying and fasting; Islamic dietary codes; and rules related to religious cleanliness. CONCLUSIONS: The Muslim-American community is a fast-growing, under-studied population. Cultural awareness is essential for optimal delivery of health care to this</p>
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	<p>minority. We have created a succinct guideline that can be used by Emergency Care providers to overcome cultural barriers. However, it is important to consider the heterogeneity and diversity of this population and to use this guideline on an individual basis.</p> <p><i>Ajrouch, K. J. 2007. "Resources and Well-Being among Arab-American Elders." J Cross Cult Gerontol 22(2):167-82.</i></p> <p>This study addresses diversity of aging experiences by examining the associations among immigrant status, religious affiliation, and resources in the form of both human and social capital with the well-being of Arab-American elders. Data were drawn from a face-to-face survey of 101 Arab-American men and women aged 56 and over living in the metropolitan Detroit area. Correlations demonstrate that religious affiliation is not associated with well-being. Multiple regression analyses reveal that U.S. born Arab Americans reported less frequent feelings of depression and greater life satisfaction than did immigrants, but this variation appears to be accounted for by human capital indicators including education level and language. Social capital including perceptions of the ability to confide in child and relationship quality with spouse is significantly associated with well-being, yet does not constitute a pathway to well-being for Arab-American elders. Human and social capital represent valuable resources and their distribution within this immigrant/ethnic group is associated with noteworthy variations in well-being.</p> <p><i>Kulwicki, A. D., J. Miller and S. M. Schim. 2000. "Collaborative Partnership for Culture Care: Enhancing Health Services for the Arab Community." J Transcult Nurs 11(1):31-9.</i></p> <p>The purpose of this study was to discover perceptions, experiences, and patterns of health care behavior among Arab Americans in an urban Midwestern area of the United States and then to discover perceptions and experiences of health care providers related to culturally competent care. The goal of the study was to generate findings that would provide the basis for implementing system-wide changes to include culturally competent care. A qualitative focus group methodology was used to discover the care patterns and perceptions of Arab Americans and the local health care providers. The nurse researchers conducted 10 focus groups. Six themes were identified, including the unique caring behaviors of Arab families, the complexity of the health care system to Arab Americans, communication gaps, the diversity of perceptions of cultural competency, obstacles to accessibility of care, and workforce diversity issues.</p> <p><i>Salari, S. 2002. "Invisible in Aging Research: Arab Americans, Middle Eastern Immigrants, and Muslims in the United States." Gerontologist 42(5):580-8.</i></p>
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	<p>Recent worldwide events have focused greater attention on the Middle East. Little is known about the diverse populations of older persons living in the United States who have Middle Eastern origins and/or practice Islam. Stereotypes and backlash can negatively influence the quality of life for mid- and later-life individuals and their families. Gerontologists can improve conditions by incorporating new knowledge of these groups into research, policy, and practice to dispel stereotypes and provide appropriate services. This article focuses on the demographic characteristics and diversity among mid- and later-life Arab Americans, Muslims, and Middle Eastern immigrants and their descendants. Further research is needed to shed light on the family support, social patterns, housing environments, health care needs, service utilization, and quality of life among immigrants and their descendants across the life course.</p>
Italian	<p><i>Destro-Bisol, G., S. Presciuttini, E. d'Aloja, M. Dobosz, G. Spedini and V. L. Pascali. 1994. "Genetic Variation at the Apob 3'hvr, D2s44, and D7s21 Loci in the Ewondo Ethnic Group of Cameroon." Am J Hum Genet 55(1):168-74.</i></p> <p>A sample of the Ewondo population (a Bantu-speaking group of Southern Cameroon) was analyzed for the polymorphism at three tandem repeated DNA loci (ApoB 3' HVR, D2S44, and D7S21). We observed a greater number of ApoB 3' HVR alleles (17) and a significantly higher estimated heterozygosity (.879 +/- .011) than in previously surveyed populations, with the exception of U.S. Blacks. The higher genetic variability of Ewondo and U.S. Blacks was also shown by the ApoB 3' HVR allele-frequency spectra. A method for measuring population distances, based on cumulative fragment-size distribution, is described. Interpopulation comparisons for ApoB 3' HVR were carried out by this method and were compared with those obtained by a genetic distance measurement. The two sets of results showed a consistent pattern of population differentiation: the Ewondos and the U.S. Blacks clustered together and were well apart from both a Caucasian cluster (Swedes, U.S. Whites, Italians, and Germans) and other well-defined populations (Sikhs of India and Pehuenche Indians of Chile). Profile distances were then computed from D2S44 and D7S21 binned data. This analysis indicated a genetic affinity between Ewondos, U.S. Blacks, and Afro-Caribbean Blacks and outlined the genetic diversity between Ewondos, Caucasians, and Asian Indians.</p> <p><i>Dubois, H. F., G. Padovano and G. Stew. 2006. "Improving International Nurse Training: An American-Italian Case Study." Int Nurs Rev 53(2):110-6.</i></p> <p>BACKGROUND: Institutionalized international nurse training organized by national educational institutions is a relatively new phenomenon. This, descriptive case study examines an early example of an American-Italian initiative of such training, in order to stimulate future international education of</p>

	<p>nurses. AIM: To find out what factors have to be taken into account to improve training and what its potential effects are in exchange and also in the context of nurse migration. METHOD: A questionnaire was sent to the 85 nurses who all participated in this particular international programme (response rate: 30.6%). FINDINGS: The collected data indicate that personalized and well-aimed training, preparatory language courses, pre-departure exposure of nurses to the culture of the host country and well-prepared welcomes are among the most important ways to improve this programme. IMPLICATIONS FOR PRACTICE: While the specific circumstances and cultures involved in this particular case study should not be ignored, these factors might also be applied to maximize the positive effects of nurse-migration. Two-way learning is among the positive effects of such an international training experience. Motivational and team-building effects can result in enhanced quality of care and a more efficient allocation of resources. However, the mind-opening effect seems to be the most important learning experience. Therefore, regardless of whether one system is considered better or worse than another, experiencing a different way of nursing/education is considered the most important, enriching element of an international learning experience. The effects of this experience could include avoiding cultural imposition in the increased cultural diversity of nursing in the country of origin.</p> <p><i>Kosasih, J. B., D. H. Jurisic, C. Gandini, C. N. Sauter and D. W. Braza. 2013. "Implementing a Global Integrative Rehabilitation Medicine Rotation: A Physical Medicine and Rehabilitation Residency Program's Experience." Am J Phys Med Rehabil 92(6):533-41.</i></p> <p>An innovative international rotation in integrative rehabilitation medicine was implemented as part of the physical medicine and rehabilitation residency program at the Medical College of Wisconsin. Rotation objectives were to introduce medical knowledge of integrative medicine treatments into physical medicine and rehabilitation practice and to initiate collaboration with international academic partners. Residents were approved based on their academic record, completion of prerequisites, and personal statement. During a 4-wk rotation located in Italy, residents developed an integrative treatment strategy for each patient using conventional medical care and other therapeutic options, including acupuncture, biofeedback, aquatic therapy, yoga, and others. Postrotation assessment included evaluations by Italian team and patients, residents' evidence-based presentations, and postrotation self-reflection. Participating residents reported high achievement in clinical performance, improved application of integrative medicine, broader appreciation of cultural diversity in patient care, and increased personal and professional development. This reciprocal program model serves as an example for other programs interested in implementing similar international rotations.</p>
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Egyptian	
	<p><i>Ali, N. S. 1996. "Providing Culturally Sensitive Care to Egyptians with Cancer." Cancer Pract 4(4):212-5.</i></p> <p>PURPOSE: This article describes key aspects of Egyptian culture and provides intervention strategies that oncology practitioners may use to provide quality care to Egyptian immigrants and Egyptian-American oncology patients.</p> <p>OVERVIEW: The growing diversity of the United States population challenges oncology professionals to provide culturally appropriate care. Egyptian immigrants and Americans of Egyptian descent comprise a unique population whose cultural and religious beliefs impact on decision making and behaviors related to cancer diagnosis and treatment. This population is overwhelmingly Muslim, although a sizeable minority are members of Eastern Christian sects. Dietary restrictions, social conduct, and religious observance are among the areas that require understanding by health providers. CLINICAL IMPLICATIONS: Learning about patients' perspectives on health and illness, in light of their cultural values and beliefs, will allow health professionals to enhance the quality of assessments and interventions and provide culturally appropriate care.</p>
Iraqi	
	<p><i>Jamil, H., M. Farrag, J. Hakim-Larson, T. Kafaji, H. Abdulkhaleq and A. Hammad. 2007. "Mental Health Symptoms in Iraqi Refugees: Posttraumatic Stress Disorder, Anxiety, and Depression." J Cult Divers 14(1):19-25.</i></p> <p>Refugees suffer from a higher rate of mental health symptoms than the general population since they have experienced extreme suffering and the accumulated effects of trauma. Because of the diversity of regions from which refugees originate, there is a need to understand some of the unique experiences that are specific to each sub-groups of immigrants. The purpose of the present study was to explore mental health symptoms in Iraqi refugee clients who immigrated to the United States after the Gulf War of the early 1990's. As part of a larger study, 116 adult Iraqi immigrants to the United States (46 male, 70 females) who were seeking mental health services completed measures of anxiety, depression, and posttraumatic stress disorder. As expected, the majority of refugees reported intense anxiety and depression, and many met the DSM IV criteria for posttraumatic stress disorder. Like refugees from other countries-of-origin, Iraqi refugees are in need of culturally sensitive assessment and mental health treatment. The results are discussed in light of the treatment needs of Iraqi refugee clients, their resilience and motivation for a better life, and the ways that health professionals can assist in optimizing their adjustment.</p>

APPENDIX C. POPULATION RESEARCH CENTERS

I. Association of Population Centers (APC)

<https://www.popcenters.org/about/members-list>

II. Top Population Programs (Sociology)*

<http://grad-schools.usnews.rankingsandreviews.com/best-graduate-schools/top-humanities-schools/sociology-of-population-rankings>

1. University of Michigan
2. University of Wisconsin-Madison
3. UNC – Chapel Hill
4. University of Pennsylvania
4. UT – Austin
6. Penn State University
7. Princeton
7. UCLA
9. UC – Berkeley
10. University of Maryland – College Park
11. Stanford
11. University of Washington
13. NYU
14. University of Chicago
15. Brown
16. University of Massachusetts – Amherst

*Redundant numbers represent ties.

III. Data Sharing for Demographic Research project:

<https://www.icpsr.umich.edu/icpsrweb/content/DSDR/popcenters.html>

The Data Sharing for Demographic Research (DSDR) project is fully funded through the [Population Dynamics Branch](#) (PDB) of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD). In addition to funding individual projects, PDB also provides support for multi-site research networks, large-scale long-term studies, and scientific programs and initiatives on focused topics within its portfolio. The DSDR project is one of these special projects. Part of the mission of DSDR is to work with NICHD-funded population centers throughout the US and overseas.

Table 1. Ethnic Composition of the Non-Hispanic White Population, ACS 5-year (2010-14)

Ancestry, first response	White alone	
	n	%
German	31,863,125	98.67
Irish, various subheads	20,448,306	98.19
United States	18,791,253	94.68
English	16,683,054	98.32
Italian	12,628,171	98.44
White/Caucasian	9,885,808	95.26
Polish	6,140,736	99.01
French	4,686,896	97.11
Scottish	3,302,847	98.4
European	3,086,086	97.91
Norwegian	2,874,271	98.77
Dutch	2,407,647	98.14
Scotch Irish	2,308,459	98.69
Swedish	2,292,297	98.81
Russian	1,960,255	98.81
French Canadian	1,457,733	97.85
Irish Scotch	995,194	98.16
Greek	966,284	98.36
Portuguese	898,471	94.53
Welsh	878,628	98.56
Hungarian	861,800	98.88
British	854,927	97.37
Danish	758,486	98.81
Indian	732,212	76.83
Ukrainian	681,515	99.19
Czech	673,660	98.98
Swiss	535,266	98.76
Canadian	473,367	97.07
Cherokee	460,851	68.1
Anglo	441,868	98.12
Slovak	441,677	99.3
Finnish	416,889	98.46
Eastern European	412,361	99.12
Armenian	393,074	98.01
Scandinavian, Nordic	381,667	98.57

Ancestry, first response	White alone	
	n	%
Lithuanian	377,289	99.22
Austrian	367,769	98.97
Iranian	351,272	85.27
Lebanese	340,573	96.7
Romanian	313,690	99.12
Mexican	307,021	87.58
Spanish	265,374	90.61
Croatian	264,407	98.79
Pennsylvania German	247,808	99.2
Northern European	237,419	98.63
Brazilian	236,524	75.11
Western European	220,343	98.57
Belgian	201,371	98.22
Egyptian	189,478	92.91
Czechoslovakian	188,875	98.88
Albanian	171,401	98.83
Bohemian	164,072	98.04
Turkish	159,514	94.07
Arabic	145,995	89.88
Serbian	136,001	99.05
Bosnian, Herzegovinian	128,166	98.63
Hispanic	110,739	81.65
Sicilian	109,966	96.63
Israeli	108,454	96.47
Syrian	106,128	94.88
Slovene	103,224	99.07
Yugoslavian	102,338	98.75
Iraqi	95,904	90.5
Middle Eastern	89,253	91.19
Arab	87,817	87.25
Cajun	83,362	96.38
Palestinian	82,000	91.11
Bulgarian	79,892	98.77
Puerto Rican	74,467	75.02
Slav	69,691	97.86
Mexican American	64,634	90.59
Australian	64,216	96.88

Ancestry, first response	White alone	
	n	%
Cuban	60,609	89.51
Moroccan	60,144	81.3
Latvian	59,799	98.87
Jordanian	52,265	89.34
Chaldean	46,449	96.06
British Isles	44,415	97.81
Macedonian	42,162	99.15
Spaniard	41,475	92.88
South African	39,684	79.79
Assyrian	39,105	93.93
Celtic	38,339	95.46
Germanic	35,175	99.19
Belourussian	34,131	99.14
Yemeni	32,843	81.89
Other Arab	31,303	82.57
Basque	31,061	97.14
Icelander	30,244	95.49
Texas	29,107	92.15
Colombian	28,950	90.15
Prussian	28,377	98.62
Maltese	27,024	98.71
Dutch West Indies	22,769	83.47
Estonian	21,565	99.07
Luxemburger	21,089	99.09
Salvadoran	19,073	72.18
Peruvian	18,041	81.48
North American	17,767	94.15
Appalachian	16,649	97.38
Saudi Arabian	16,158	72.51
Algerian	15,353	93.1
Argentinean	13,994	96.05
Kurdish	13,911	86.54
Spanish American	13,570	92.45
Moldavian	13,560	98.7
Guatemalan	13,525	69.52
Georgian	12,268	99.43
Honduran	12,173	67.26

Ancestry, first response	White alone	
	n	%
New Zealander	11,682	87.29
Ecuadorian	11,166	80.62
Mexican state	10,531	82.75
Venezuelan	8,243	86.73
Rom	6,542	82.58
Flemish	6,324	97.97
Chilean	6,104	94.96
Central European	6,016	97.65
Alsatian	5,649	97.13
Mexican Indian	5,588	80.51
Southern European	5,142	94
Montenegrin	5,031	94.84
Slavonian	4,788	99.42
North African	4,578	82.86
Latin	4,390	74.29
Bolivian	3,375	90.22
Mexicano/Mexicana	2,972	67.56
Acadian	2,526	99.45
Uruguayan	2,258	92.85
Latin American	2,121	75.29
Paraguayan	692	95.05
Chicano/Chicana	254	80.89

Table 2. Diversity among Ethnic Groups Classified as non-Hispanic white, ACS 2010-2014

	White alone n = 10,533,297	German n = 1,739,085	Russian n = 99,903	Egyptian n = 8,778	Lebanese n = 17,116	Appalachian n = 988	Cajun n = 4,285
% with Disability							
Cognitive difficulty	5.6	4.53	4.69	2.77	3.62	9.82	8.14
Ambulatory difficulty	8.53	7.38	7.63	4.76	5.59	13.16	10.22
Independent living difficulty	6.1	4.92	5.79	3.68	4.25	8.30	6.53
Vision/hearing difficulty	6.58	6.11	5.68	3.18	4.22	12.15	8.35
% with health insurance	91.02	92.11	93.04	83.62	91.35	88.06	87.86
% U.S. citizen	95.77	97.49	77.28	32.57	73.15	99.8	99.09
% poor English language fluency	0.52	0.17	3.8	8.62	3.02	0.2	0.51
Education							
Less than high school	25.93	23.51	19.78	27.96	25.66	26.11	28.75
High school graduate	24.04	24.06	11.9	10.48	14.44	27.63	26.46
Some college	25.64	27.63	20.42	14.83	23.92	24.39	24.76
College degree or more	24.38	24.8	47.9	46.73	35.98	21.86	20.02
% female	51.21	50.31	52.65	45.07	49.44	41.6	47.51
Marital status							
Married	47.29	49.45	49.3	48.47	46.27	51.52	50.53
Separated/divorced	10.66	10.09	9.93	5.29	8.39	16.6	11.69
Widowed	6.41	5.74	6.44	3.16	4.48	6.68	4.71
Never married/single	35.64	34.76	34.33	43.08	40.86	25.2	33.07
Age in years (mean)	43.33	43.25	45.42	34.98	39.98	46.79	41.89

Table 3. Potential Data Sources for Data Disaggregation (in progress)

Data Source	Measures	Advantages	Challenges
American Community Survey (ACS)	<ol style="list-style-type: none"> 1. Ancestry 2. Place of birth 3. Race / Hispanic origin 	<ol style="list-style-type: none"> 1. Large sample sizes. 2. Detailed geography (good for smaller and/or geographically clustered populations). 3. Collected annually (good for historical comparisons) 	<ol style="list-style-type: none"> 1. Health outcomes limited to disability. 2. Limited measures on health behaviors and healthcare access/use. 3. Requires moderate methodological skills.
National Health Interview Survey		<ol style="list-style-type: none"> 1. Large sample sizes. 2. Detailed measures on health outcomes and health behaviors. 3. Collected annually. 	<ol style="list-style-type: none"> 1. Country of origin data are restricted. 2. Access to restricted data includes application process and fee. 3. Country/region of origin data does not capture U.S.-born whites. 4. Requires advanced methodological skill to link person, family and sample adult files.
ADD Health			
NHANES			
New Immigrant Survey			
General Social Survey			