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Knowledge, Attitudes, Behaviors, and Beliefs about Chronic Kidney Disease in Indiana's Minority Communities: A Community-Based Survey

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KNOWLEDGE, ATTITUDES, BEHAVIORS, AND BELIEFS ABOUT CHRONIC KIDNEY
DISEASE IN INDIANA MINORITY COMMUNITIES: A COMMUNITY-BASED SURVEY

PROJECT REPORT

May 31, 2013

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The AWE Center

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Executive Summary

The purpose of this report is to detail the findings of the study 'Knowledge, Attitudes, Behaviors, And Beliefs about Chronic Kidney Disease in Indiana Minority Communities,' undertaken as a collaboration between Indiana Minority Health Coalition, Inc. (IMHC) and the Butler University College of Pharmacy and Health Sciences (BUCOPHS). The purpose of the study was to understand knowledge of and beliefs about Chronic Kidney Disease (CKD) among racial/ethnic minorities in Indiana, to learn how these populations would like to receive information about CKD, to understand the factors associated with higher levels of CKD awareness, to estimate the proportion of people with risk factors who have been screened for CKD, and to determine the characteristics associated with people who have been screened.

CKD, the ninth leading cause of death in the United States, is a major public health issue in Indiana. Just over 1 in 5 deaths in Indiana are due to kidney disease, a figure higher than the 14% national average. CKD is especially problematic for racial/ethnic minorities, who are more likely to get the disease, and at earlier ages. They also progress more quickly to End Stage Renal Disease (ESRD), the final stage of CKD, treatable only by lifelong dialysis or kidney transplant. Treatment comes with high costs in terms of public and private money as well as patients' suffering. Nearly one quarter of the US Medicare budget (\$24 billion) is spent caring for people with ESRD. Early detection and treatment of CKD are essential to stopping disease progression, which is irreversible. Most people with CKD are undiagnosed and undertreated, leading to complications and progression of the disease. Diabetes, hypertension, and family history of kidney disease are the most significant CKD risk factors, and it is recommended that adults with any of these should be screened.

Very little is known about knowledge, attitudes, behaviors and beliefs regarding CKD in Indiana's racial/ethnic minority communities. Because of this, a collaborative, community-based survey project was undertaken by IMHC and the BUCOPHS. Information on socio-demographics (including self-identified race/ethnicity); health status; healthcare access and utilization; CKD screening, knowledge and attitudes toward health, CKD and screening; and preferences for receiving health information were included. The survey was translated in several languages (Spanish, Burmese, Hakka Chin, and Falam Chin) and the translations were verified by native-speaking community members. IMHC engaged 15 community partners in 22 Indiana counties to administer the surveys. Community partners were oriented to the project and trained in survey administration, and surveys were conducted between November 2012 and February 2013.

Surveys from 1,465 eligible respondents were received and scanned into a data base. Survey results were analyzed collaboratively by BUCOPHS and IMHC. Respondents represented four major racial/ethnic groups: African Americans (59%), Hispanic/Latinos (22%), American Indians/Alaskan Natives (11%), and Asian/Pacific Islanders (8%). Forty-four percent were male, and ages ranged from 18 to 92 years (average= 40 years), 20% were born outside of the United States, and 85% spoke English as their primary language. Most (84%) were in good, very good, or excellent health, and the most commonly reported health conditions were high blood

pressure (36%), diabetes or arthritis (both 16%), and asthma or obesity (both 14%). Most (70%) had health insurance and a regular healthcare provider (61%), but 25% reported that they were not able to see a provider in the prior year because of cost. Being older, having higher self-rated health, being employed, higher educational attainment, having health insurance, being Hispanic/Latino, and reporting high blood pressure, diabetes, or kidney disease were all associated with more knowledge and awareness of CKD, while being Burmese and not being able to see a provider because of cost were related to less knowledge and awareness. Just over one quarter (29%) of those reporting at least one risk factor had been screened. Increased knowledge and attitude toward kidney disease, having high blood pressure or kidney disease, and having a regular healthcare provider were associated with having been screened among those with risk factors. Respondents preferred to get information in the form of brochures (66%), the internet (57%) or on television (37%); from a doctor (87%), nurse (40%), or family member (37%); at a doctor's office or clinic (76%), or hospital or health fair (both 58%).

This study's most critical finding is that only a small minority (28.7%) of those requiring screening actually report that they had been screened for kidney disease. The findings, however, indicate many opportunities to improve knowledge and behaviors among the state's extremely vulnerable racial/ethnic populations; indeed, they demonstrate that increasing knowledge is an important factor in encouraging at-risk people to undergo screening. It is apparent that all minority populations need, and wish to receive, information on CKD, and that access to screening should be increased. Adoption of provisions of the Affordable Care Act in the next few years, with its emphasis on prevention and establishment of medical homes, may help in promoting screening.

It is apparent that communities need to provide education on the causes and consequences of kidney disease, as well as the importance of prevention and screening for those at risk for CKD. Communities should encourage people to establish and maintain medical homes, relationships with primary care providers who can manage their health conditions and help patients navigate through the healthcare system. Communities need to engage healthcare providers in CKD education. Community-appropriate educational materials, especially brochures and possibly DVDs, need to be developed. It is critical that information be easily understood by those with low education, as they are particularly vulnerable to CKD risk. Education about kidney function and disease is required for adults of all ages.

Although respondents may not be representative of all racial/ethnic minority residents of Indiana and information was obtained directly from respondents rather than medical records (and thus subject to memory lapses and misunderstanding), this study lays the foundations to improve kidney health in Indiana's health-vulnerable racial/ethnic minority communities.

Background and Study Rationale

Chronic Kidney Disease (CKD) is a major health problem in the United States. It is the country's ninth leading cause of death. [1] The Centers for Disease Control and Prevention estimate that approximately 1 in 10 adults in the United States, or more than 20,000,000 people, have CKD. [2] CKD is a progressive disease which, when coupled with the high number of affected individuals, places a huge burden on the healthcare system. Nearly one quarter of the US Medicare budget, \$24 billion, is spent caring for people with CKD, including End Stage Renal Disease (ESRD), the ultimate and most severe stage of CKD. [3] The proportion of Medicare expenditures due to CKD rose from 5.8% in 2000 to 17.0% in 2010. [4] People with ESRD are generally eligible for Medicare enrollment regardless of age; it is the only condition-specific criterion for Medicare eligibility. [5]

CKD is an irreversible but preventable condition that damages the kidneys and decreases their ability to process waste in the blood. High blood pressure, anemia, weak bones, poor nutritional health, and nerve damage are likely to develop as a result of loss of kidney function; cardiovascular disease has also been shown to develop with CKD. Diabetes and hypertension are the two most significant causes of CKD, though family history also plays a role, as do other less common risk factors, such as reaction to medications. To diagnose CKD, providers generally measure the Glomerular Filtration Rate (GFR) calculated using blood creatinine, age, and other factors, and urine may also be tested for presence of protein (albumin). If not halted, CKD will progress to ESRD, which can be treated by dialysis or kidney transplant, but is otherwise fatal. [6]

As a progressive disease, CKD presents problems to affected individuals that worsen with time. ESRD is painful and expensive to treat. ESRD and its effects on afflicted individuals and populations are well documented, but information about CKD is distinctly less prevalent.

Early detection and treatment of CKD can prevent the progression of the disease, saving healthcare costs and preventing patients' suffering. [7] Because ESRD is irreversible, identifying CKD and halting its progression are crucial.

Screening is essential to early detection of CKD. Unfortunately, the majority of individuals with CKD are undiagnosed and untreated, which can lead to the development of complications and progression of the disease. According to NHANES III data, the prevalence of moderately decreased kidney function was more than 20-fold greater than that of severely decreased kidney function, underscoring the need for treatment [7]. While understanding the significance of screening is apparent, targeting populations for screening may be more challenging.

Determining who is at risk for CKD and should be screened has, in the past, fallen to primary care physicians. [8] Because not all at-risk patients have medical homes or visit their providers regularly, other ways must be found to reach them. Diabetes, hypertension, age, and family history of CKD are all important risk factors, [9] and people with these health conditions are the ones who need information about screening. [7, 8, 10-12]

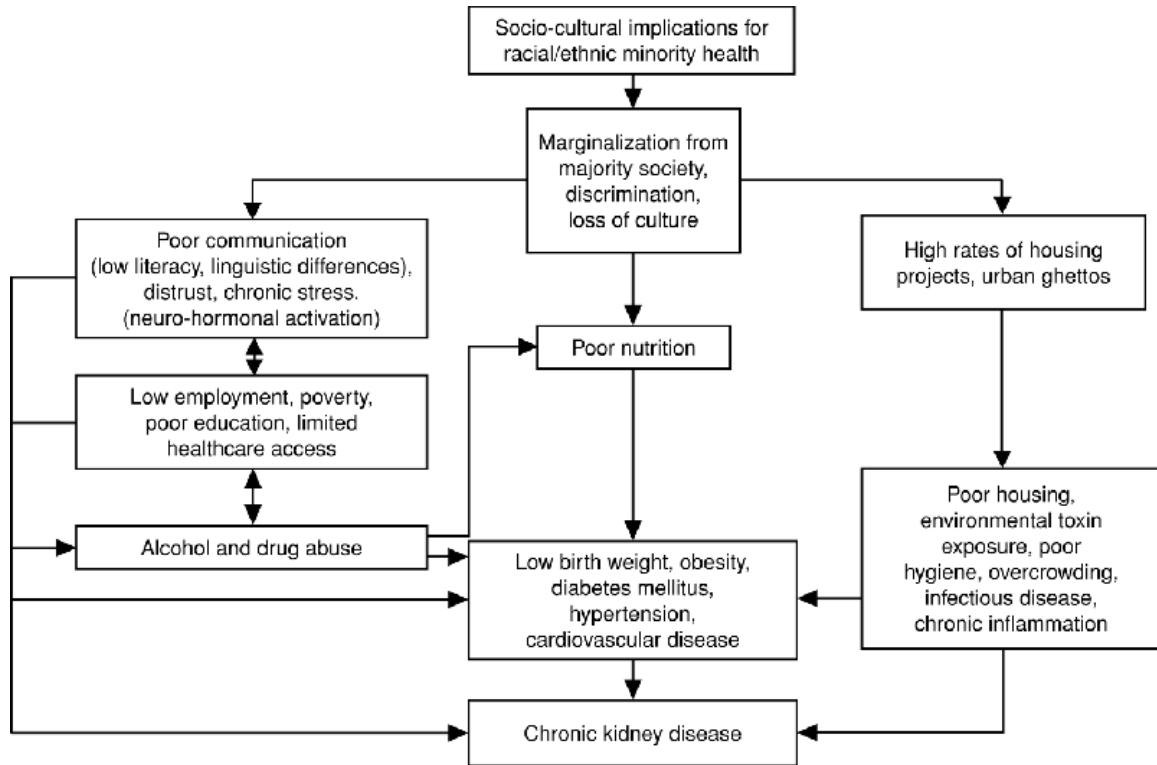
When considering health conditions as predictors to screening needs, it is also important to consider race/ethnicity, as CKD is even more serious for racial/ethnic minorities. CKD incidence rates for African Americans and American Indians are 3.5 and 1.9 times higher than those for whites, respectively. [13] Nearly one-third of American Indian-Alaskan Natives presenting to the Kidney Early Evaluation Program (KEEP) [14] in the years 2000 through 2006 had CKD. [15] Since 2000, incidence rates have risen 6.4% for Asian Americans. Not only is incidence higher, but progression of the disease to ESRD is greater for racial/ethnic minorities. Compared to whites, Hispanics/Latinos are 1.45 times more likely to reach ESRD; for Asians the figure is 1.56 times, American Indians 2.74 times, and for African Americans 3.89

times. [13] There are disparities in the way CKD is treated and diagnosed in minorities, which may be due to culture, socioeconomic position, access to medical care, as well as other factors. [16]

Impaired access to care is a contributing factor to the disproportionate burden of CKD in minorities. Hispanic/Latinos, the largest growing US population, experience increased incidence of ESRD independent of known clinical risk factors. They have a later start to dialysis than non-Hispanic whites, possibly due to limited access to healthcare or receipt of lower quality healthcare, resulting in late diagnosis or healthcare avoidance due to inability to pay for costs of screening and treatment. Little is known about the healthcare access and quality for undocumented immigrants, but it is most likely not comparable to others, and this creates serious disparities. [17] African Americans, too, have access challenges. They have been found to be less likely than whites to have health insurance and a usual source of health care. These barriers likely contribute to the CKD disparity. [18] Healthcare access and socioeconomic status are linked and contribute significantly to healthcare. In an editorial in *Kidney International*, Keith Norris and Lawrence Agodoa discuss the importance of complex interactions of factors experienced by minority populations (including marginalization, discrimination, loss of culture, residential segregation, lower socioeconomic status, limited nutritional opportunities, negative health behaviors, impaired communication with providers and distrust of the healthcare system—see Figure 1) in the origins of chronic kidney disease. [19]

Even more than the United States as a whole, CKD is a serious health issue for Indiana. While kidney disease is responsible for 14.9% of U.S. deaths, Indiana is sixth among all states and the District of Columbia in proportion of mortality, with 22.2% of all deaths due to kidney disease. [20] Mortality is even higher in Indiana counties with higher minority populations such as Grant (37.0%), Allen (26.0%), Lake (25.3%), Bartholomew (24.0%), or Howard (24.2%). [21]

Figure 1. Socio-Cultural Model of Chronic Kidney Disease in Racial/Ethnic Minority Populations (from Norris & Agoday, 2005)



The public remains largely unaware of the gravity of kidney disease. The 2011 Pair Up survey of caretakers of people with health problems found that 85% of respondents could not name high blood pressure as a cause of CKD, even though 75% of them were caring for a person with hypertension. [22] Analysis of results of the National Health and Nutrition Examination Study (NHANES) for the years 1999-2004 found that about 90% of people in stage 3 or below of CKD had not been told by their doctors that they had weakened or failing kidneys. [23] People reporting at least some difficulty with obtaining health care reported low awareness of CKD. [24] This underscores the need to learn about CKD knowledge and attitudes in minority communities, as these groups get CKD more often and more severely than majority groups and are also more likely to have difficulties in obtaining healthcare. [25]

Most research on kidney disease focuses on general populations with high disease severity, with End State Renal Disease, when the sole treatment is dialysis or kidney transplant. Far less is known about knowledge and attitudes of racial/ethnic minorities, especially those at risk for the disease or in its early stages. No Indiana-specific information on CKD knowledge, attitudes, or behaviors, especially for racial/ethnic minorities, could be located in planning this The Behavioral Risk Factor Surveillance System (BRFSS), a national annual telephone survey recently added a single question regarding kidney disease (*“Has a doctor, nurse, or other health professional ever told you that kidney disease? Do not include kidney stones, bladder infection, or incontinence.”*) The question regarding kidney disease for the first and only time in 2011, [26] and since information is available by self-identified race/ethnicity, a current measure of kidney disease prevalence will soon be available..

STUDY OBJECTIVES, RESEARCH QUESTION, AND SPECIFIC AIMS

The objective of this study was to survey members of African American, Hispanic/Latino, American Indian, and Asian communities in Indiana about awareness of CKD. Our research questions were:

- 1) What is the state of knowledge of and beliefs about (CKD)?
- 2) How would respondents like to receive information about CKD (i.e., what forms of information, sources for information, and places for dissemination of information are preferred in minority communities?)
- 3) What health status, healthcare access, and socio-demographic characteristics are associated with levels of awareness of CKD?

After the project was underway, researchers decided to add other research about those people who reported risk factors for CKD and, thus, should have received kidney function screening:

- 4) What proportion of respondents reporting one or more indications for screening (diabetes, hypertension, or family history of chronic kidney disease) reported that they had, in fact, received screening?
- 5) What characteristics are associated with reporting having been screened for kidney disease?

Our specific aims were:

- 1) To develop a questionnaire to assess answers to our research questions.
- 2) To enlist the aid of community-based organizations to administer surveys within African American, Hispanic/Latino, American Indian, and Asian communities.
- 3) To analyze results in order to:
 - a. Describe knowledge, attitudes, behaviors and beliefs, and preference for information about Chronic Kidney Disease in these communities.
 - b. Find associations between health status, healthcare access, and socio-demographic factors and awareness of Chronic Kidney Disease.
 - c. Among those reporting indications for screening, what en health status, healthcare access, and socio-demographic factors are associated with reporting having been screened?

Methods and Procedures

Survey Development

The survey was developed after extensive review of the available information on kidney disease in populations, especially regarding racial and ethnic minorities, and existing surveys: the Pair Up Survey of Caregivers provided by the American Kidney Fund, the Survey on Disparities in Quality of Healthcare: Spring 2001, [27] The Behavioral Risk Factor Surveillance Survey, and a survey on Hepatitis-C that had been piloted by IMHC, Inc. Several questions were taken directly from recent Behavioral Risk Factor Surveillance System questionnaires [28] so that survey results could be compared with population-based BRFSS information specific to Indiana racial/ethnic minorities. After the survey was drafted, it was pretested to verify that it could be understood and successfully completed. The final survey was translated into Spanish, Burmese, Hakka Chin, and Falam Chin, and the translations were verified by native speakers to ensure accuracy and appropriateness. A copy of the English language version of the survey appears in the appendix.

The study was approved by the Butler University Institutional Review Board.

Survey Administration

IMHC engaged fifteen of its community partners to administer surveys in selected counties. Six training sessions were held throughout the state so that surveys would be administered consistently. The trainings included information on kidney disease, orientation to the study, and eligibility criteria and survey techniques, including exercises such as role-playing and active listening.

Each community partner was given a target number of surveys to complete. Community partners engaged potential respondents, ascertained eligibility (residence in Indiana; age at least 18 years; self-identification as African American, Hispanic/Latino, American Indian or

Alaska Native, Asian, or Pacific Islander/Native Hawaiian; ability to read and write in one of the survey languages). Partners were asked to keep a log of all people approached for participation and were asked to include a minimum of 35% responses from men. Partners were responsible for delivering an incentive of a \$15 gift card to each participant who completed a survey. Many partners incorporated survey recruitment into other outreach activities and events. Surveys were administered November 2012 through February 2013. Completed surveys and logs were returned to the Racial and Ethnic Minority Epidemiology Center at IMHC. Surveys were scanned into a database and each was individually verified for accuracy.

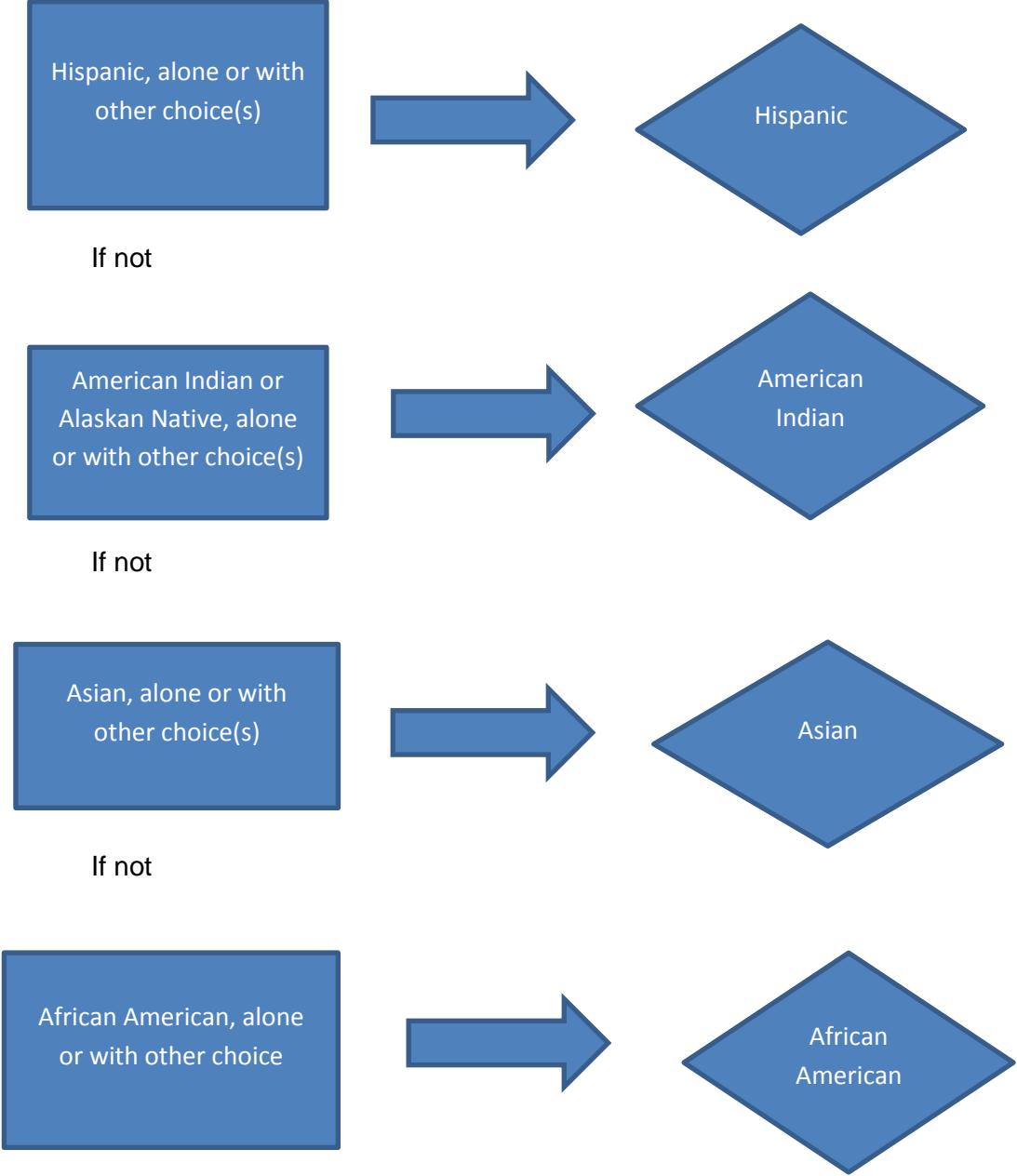
Data Analysis

Concepts and Variables Measured

Socio-demographics

Age was measured in years; race/ethnicity was self-identified by respondents checking any of the following categories: African American or Black, American Indian or Alaska Native, Asian, Hispanic or Latino, White, or Native Hawaiian or other Pacific Islander, or Other (with open-ended specification). Respondents who indicated Hispanic or Latino were further asked to identify their origins as Mexican, Cuban, Puerto Rican, Dominican, Central American, South American or Other. Asians were asked if their heritage was Chinese, Korean, Burmese, Vietnamese, Indian, Nepalese, or Other. Since respondents were allowed to choose multiple categories, unique race categories were determined in a hierarchical way (Figure 2). Since only six respondents indicated Native Hawaiian or other Pacific Islander, they were folded into the Asian/Pacific Islander category. Thirty respondents indicated 'white' only and their responses were discarded due to lack of eligibility.

Figure 2. Assignment of unique race/ethnicity



Respondents were asked whether they were born in the United States, and, if not, the name of the country in which they were born, along with the length of time they had lived in the

United States (less than 5 years, 5-10 years, or more than 10 years). Respondents were also asked if English was their primary language. Marital status (married, living as married, widowed, divorced, separated, and single/never married), educational attainment (none/only kindergarten/grades 1-8, high school/no graduate, High school graduate/GED, business/technical/vocational school after high school/some college/no 4-year degree, 4-year college degree, post graduate school), employment status (employed for wages, self-employed, out of work, student, retired, unable to work) were also queried. After preliminary analysis, it was decided to measure marital status as currently married/not currently married, educational status as did not graduate high school/high school graduate or above, and employment to employed or self-employed versus any other employment status.

Socioeconomic position (SEP) is usually considered to have three interrelated but not interchangeable elements: financial (income and wealth), educational attainment, and social prestige. It was decided not to try to capture information on finances, since this factor is unstable, unreliable, and often skipped by respondents; [29] in fact, it is the question most often refused by Indiana BFRSS respondents. [30] In addition to educational attainment, it was decided to use of single-item summary measure of social prestige, the MacArthur Scale of Subjective Social Status Community Ladder (see Figure 3), one of two pictorial measures developed. This item may be especially effective in measuring SEP in less advantaged communities, where individuals may not possess large incomes, but may have a higher standing in their communities. [31]

Figure 3. MacArthur Foundation Scale of Subjective Social Status Community Ladder

Think of this ladder as representing where people stand in the United States.

At the **top** of the ladder are the people who are the best off – those who have the most money, the most education and the most respected jobs. At the **bottom** are the people who are the worst off – who have the least money, least education, and the least respected jobs or no job. The higher up you are on this ladder, the closer you are to the people at the very top; the lower you are, the closer you are to the people at the very bottom.

Where would you place yourself on this ladder?

Please place a large “X” on the rung where you think you stand at this time in your life, relative to other people in the United States.



Health Status

Health Status was measured by four questions taken from the BRFSS. The first of these, a global measure of self-rated health (“*Would you say that in general your health is excellent, very good, good, fair, or poor?*”) is frequently asked in health research, since it is one of the best global indicators of health status and a better indicator of subsequent mortality and functional limitations than more objective health assessments; [32] it is used often with racial/ethnic minority and immigrant populations. [33, 34] The remaining questions asked about numbers of days of impairment due to physical and mental health issues. Respondents were also asked whether they had been diagnosed with any of eight conditions (high blood pressure, anxiety/depression, heart disease, kidney disease, obesity, asthma, arthritis, and diabetes) common in minority populations, with the opportunity to list ‘other’ diagnoses.

Healthcare Access and Utilization

Healthcare access questions on insurance coverage, medical home (‘Do you have someone you think of as your personal doctor or healthcare provider?’), choice of provider, and inability to see a provider in the prior year because of cost or other reasons. These were taken from the BRFSS questionnaire. In addition, questions about use of traditional/complementary and alternative medicine were asked.

Kidney Disease Risk Factor Questions

In addition to disease-specific questions about diagnoses of kidney disease, high blood pressure, diabetes, and heart disease, all CKD risk factors, respondents were asked whether “a doctor ever tested your kidney function or tested you for kidney disease.” Respondents were also asked whether a family member or close friend had been diagnosed with CKD, ESRD, been on dialysis, or told that they needed a kidney transplant. Originally, these questions were asked because it was thought that direct experience with someone with CKD or ESRD would increase knowledge and awareness of the disease; however, they were also used as a measurement of family history of CKD.

Attitudes toward Healthcare, Knowledge and Beliefs about CKD and Screening

No validated instrument to measure knowledge, attitudes, behaviors, and beliefs about CKD could be located, so questions were constructed from items from other surveys on CKD, ESRD, and previous questions asked about other health conditions. Each item was answered using a five-point Likert-type scale (strongly agree/agree/undecided/disagree/strongly disagree). A global scale to get a composite measure of health efficacy and knowledge/beliefs about kidney disease was created from the individual items. Most were coded in a positive direction (e.g., *"I am very satisfied with the medical care I receive"*, *"Kidney disease occurs more often in racial and ethnic minorities"*) so that a higher score on an item indicated more positive knowledge or belief. Some item went in the opposite direction (e.g., *"I think staying healthy is a matter of luck more than anything else"*, *"Kidney screening tests cannot be trusted"*). Coding on these 'negative' items was reversed and all items were totaled to give a score that could range from 18 to 90, with higher scores indicating more positive knowledge and attitudes. A factor analysis was done to assess the coefficient alpha, which was found to be above 0.7, indicating a reliable scale. [35] Principal Component Analysis was performed to look for factors to use as subscales. Items with component values above 0.5 segregated into two factors. The first factor contained most of the items in Question 15, CKD knowledge question along with two knowledge-based items from Question 16m the CKD screening belief question. This was termed the "Knowledge subscale." The second factor contained one item from Question 14, attitudes towards health and healthcare, and others from the screening beliefs question It was termed the "Attitudue Subscale."

Information Preferences

Information on preferences for receipt of information on kidney disease was asked using an adaptation of a series of questions developed by IMHC for a previous survey. Information regarding the form/medium for information, the person giving information, and the venue for information was solicited.

Analytic Strategy

Data analysis using SPSS was directed by the Principal Investigator and done collaboratively by researchers from IMHC and Butler COPHS. Descriptive Statistics were generated and examined. Variables were examined by race/ethnicity group, age, and gender to find associations. Primary outcomes considered were determined by research questions. Questions 1 and 3 (*“What is the state of knowledge of and beliefs about Chronic Kidney Disease?”* and *“What health status, healthcare access, and socio-demographic characteristics are associated with levels of awareness of Chronic Kidney Disease?”*) were to be answered using scores on the constructed Knowledge/Attitudes scale as outcomes. Hierarchical multiple regression models were created to examine independent effects of variables on the knowledge/attitude scale, adding groups of variables in a specific variable. The model was run first with race/ethnicity groups alone, then socio-demographics were added, followed by health status variables and, lastly, healthcare access variables. Question 2 (*“How would respondents like to receive information about Chronic Kidney Disease?”*) would be answered using responses from the information preferences questions.

In order to answer Questions 4 (*“What proportion of respondents reporting one or more indications for screening disease reported that they had, in fact, received screening?”*) and 5 (*“What characteristics are associated with reporting having been screened for kidney disease?”*), those respondents with one or more risk factors for CKD were identified and analyzed separately. The outcome for these questions was report of kidney screening (*“Has a doctor ever tested your kidney function or tested you for kidney disease?”*). Logistic regression models were created to examine independent effects of variables in answering Question 5.

Findings

Socio-Demographics

1,495 completed surveys were received, and, of those, 1,465 were from respondents who were eligible for participation. Descriptions of participants can be found in Table 1. The participant population was 44% male and 56% female. The median age was 40 (range 18-92). Age did not differ by gender; however, African Americans (mean age in years = 43.9 ± 16.7) and American Indians (mean= 45.8 ± 16.3) were significantly older than Asian/Pacific Islanders (mean = 39.0 ± 10.5) and Latino/Hispanics (mean = 35.7 ± 12.1). Men were more likely to be currently married than women but had fewer years of education. Older people were more likely to be employed,, and to have been born in the United States; to use English as their primary language, to be currently married; theywere less likely to behave post-graduate education, to be currently employed or to be living as married or had neer been married. . African Americans were least likely to be currently married, American Indians were least likely to be currently employed; African Americans and Asian/Pacific Islanders had more years of education than the other groups. Asian/Pacific Islanders and Latino/Hispanics were more likely not to have been born in the United States or to report that English was not their primary language. African Americans and American Indians were older than Hispanic/Latinos or Asian/Pacific Islanders. Subjective social status did not vary by age or gender, but American Indians reported a significantly lower social status than African Americans or Hispanic/Latinos, and the difference in social status was almost significantly lower for American Indians and Asian/Pacific Islanders.

Table 1: Description of Respondents by Race/ethnicity Group
(N=1425)

Variable	Race/Ethnicity Group				Total
	African American	American Indian/ Alaska Native	Asian/Pacific Islander	Hispanic/Latino	
	N=844 Count (%)	N=163 Count (%)	N=111 Count (%)	N=307 Count (%)	N=1425 Count (%)
I. Socio-Demographics					
Gender					
Male	370 (44.1%)	67 (41.6%)	50 (45.9%)	134 (44.2%)	621 (44.0%)
Female	469 (55.9%)	94 (58.4%)	59 (54.1%)	169 (55.8%)	791 (56.0%)
Age (mean ± SD)	43.9 ± 16.7	45.8 ± 16.3	39.0 ± 10.5	35.7 ± 12.1	42.0 ± 15.8
Born Outside of U.S. ***	6 (0.7%)	4 (2.5%)	97 (89.0%)	172 (57.9%)	279 (19.9%)
English not Primary Language***	1 (0.1%)	10 (6.4%)	53 (48.6%)	140 (47.0%)	204 (14.8%)
Current marital status***					
Married	293 (35.3%)	71 (44.4%)	81 (75.0%)	138 (45.8%)	583 (41.7%)
Widowed	51 (6.2%)	12 (7.5%)	-	8 (2.7%)	71 (5.1%)
Separated	34 (4.1%)	3 (1.9%)	2 (1.9%)	17 (5.6%)	56 (4.0%)
Living as Married	35 (4.2%)	7 (4.4%)	3 (2.8%)	12 (4.0%)	57 (4.1%)
Divorced	120 (14.5%)	28 (17.5%)	3 (2.8%)	29 (9.6%)	180 (12.9%)
Single, Never Married	296 (35.7%)	39 (24.4%)	19 (17.6%)	97 (32.2%)	451 (32.3%)
Educational Attainment***					
8 th Grade or less	20 (2.5%)	4 (2.5%)	31 (29.5%)	39 (13.0%)	94 (6.8%)
High School, did not Graduate	74 (9.1%)	23 (14.5%)	-	32 (10.7%)	129 (9.4%)
High School Graduate/ GED	186 (22.9%)	58 (36.5%)	10 (9.5%)	86 (28.7%)	340 (24.7%)
Business, Technical, or Vocational School	74 (9.1%)	8 (5.0%)	2 (1.9%)	26 (8.7%)	110 (8.0%)
Some College, (no degree)	253 (31.1%)	46 (28.9%)	8 (7.6%)	61 (20.3%)	368 (26.7%)
College Graduate	129 (15.9%)	10 (6.3%)	17 (16.2%)	49 (16.3%)	205 (14.9%)
Post-Graduate Study	77 (9.5%)	10 (6.3%)	37 (35.2%)	7 (2.3%)	131 (9.5%)

Variable	Race/Ethnicity Group				
	African American	American Indian/ Alaska Native	Asian/Pacific Islander	Hispanic/Latino	Total
	N=844 Count (%)	N=163 Count (%)	N=111 Count (%)	N=307 Count (%)	N=1425 Count (%)
Employment***					
Employed for Wages	454 (55.5%)	64 (40.8%)	80 (75.5%)	167 (57.4%)	765 (55.8%)
Out of Work	103 (12.6%)	32 (20.4%)	7 (6.6%)	55 (18.9%)	197 (14.4%)
Retired	123 (15.0%)	28 (17.8%)	1 (0.9%)	9 (3.1%)	161 (11.7%)
Self-Employed	56 (6.8%)	13 (8.3%)	7 (6.6%)	23 (7.9%)	99 (7.2%)
Student	45 (5.5%)	5 (3.2%)	5 (4.7%)	23 (7.9%)	78 (5.7%)
Unable to Work	37 (4.5%)	15 (9.6%)	6 (5.7%)	14 (4.8%)	72 (5.2%)
Subjective social status (mean ± SD)	5.3 ± 2.0	4.4 ± 2.0	5.1 ± 2.2	5.2 ± 2.2	5.2 ± 2.0

II. Health Status

Self-rated Health					
Excellent	22 (2.6%)	4 (11.4%)	1 (0.9%)	4 (1.3%)	31 (2.2%)
Very Good	111 (13.2%)	31 (19.0%)	20 (18.0%)	41 (13.4%)	203 (14.3%)
Good	310 (36.8%)	64 (39.3%)	54 (48.6%)	103 (33.6%)	531 (37.3%)
Fair	295 (35.0%)	52 (31.9%)	26 (23.4%)	111 (36.2%)	484 (34.0%)
Poor	105 (12.5%)	12 (7.4%)	10 (9.0%)	48 (15.6%)	175 (12.3%)
Number of Days Physical Health was not Good (mean ± SD)	3.6 ± 6.8	8.0 ± 9.8	1.9 ± 3.8	3.9 ± 7.7	4.0 ± 7.3
Number of Days Mental Health was not Good (mean ± SD)	3.3 ± 6.8	7.4 ± 9.9	3.1 ± 7.0	3.7 ± 7.5	3.8 ± 7.4
Number of Days of Limited Activity (mean ± SD)	2.2 ± 5.9	5.9 ± 9.3	1.9 ± 5.2	2.2 ± 6.0	2.5 ± 6.4

Variable	Race/Ethnicity Group				
	African American	American Indian/ Alaska Native	Asian/Pacific Islander	Hispanic/Latino	Total
	N=844 Count (%)	N=163 Count (%)	N=111 Count (%)	N=307 Count (%)	N=1425 Count (%)
Self-reported Diagnoses					
High Blood Pressure ***	378 (44.%)	60 (36.8%)	21 (18.9%)	59 (19.2%)	518 (36.4%)
Anxiety or Depression ***	98 (11.6%)	48 (29.4%)	11 (9.9%)	36 (11.7%)	193 (13.5%)
Heart Attack or Heart Disease ***	46 (5.5%)	17 (10.4%)	-	5 (1.6%)	68 (4.8%)
Kidney Disease	29 (3.4%)	8 (4.9%)	-	10 (3.3%)	47 (3.3%)
Obesity*	130 (15.4%)	31 (19.0%)	3 (2.7%)	30 (12.7%)	203 (14.2%)
Asthma*	125 (14.8%)	29 (17.8%)	6 (5.4%)	37 (12.1%)	197 (13.8%)
Arthritis ***	150 (17.8%)	55 (33.7%)	8 (7.2%)	21 (6.8%)	234 (16.4%)
Diabetes*	146 (17.3%)	34 (20.9%)	17 (15.3%)	36 (11.7%)	233 (16.4%)
Other***	72 (8.5%)	35 (21.5%)	20 (18.0%)	23 (7.5%)	150 (10.5%)
None***	258 (30.6%)	39 (23.9%)	51 (45.5%)	124 (40.4%)	472 (33.1%)
III. Health Care Access					
Reports Having Healthcare Coverage	627 (75.1%)	101 (64.3%)	84 (75.7%)	162 (54.0%)	974 (69.4%)
Reports having regular Health Care Provider***					
Yes, one	386 (46.3%)	70 (45.5%)	34 (33.7%)	131 (44.1%)	621 (44.8%)
Yes, more than one	254 (30.5%)	34 (22.1%)	31 (30.7%)	47 (15.8%)	366 (26.4%)
None	193 (23.2%)	50 (32.5%)	36 (35.6%)	119 (40.1%)	398 (28.7%)
Reports Choice in Where to go for Healthcare***					
A Great Deal of Choice	400 (48.6%)	51 (34.0%)	24 (25.3%)	75 (26.4%)	550 (40.7%)
Some Choice	243 (29.5%)	49 (32.7%)	44 (46.3%)	99 (34.9%)	435 (32.2%)
Very Little Choice	117 (14.2%)	34 (22.7%)	7 (7.4%)	78 (27.5%)	236 (17.5%)
No Choice	63 (7.7%)	16 (10.7%)	20 (21.1%)	32 (11.8%)	131 (9.7%)
Couldn't See Doctor in Past 12 Months					
Yes, Because of Cost	184 (22.3%)	44 (28.0%)	34 (32.1%)	84 (28.7%)	346 (25.0%)
Yes, Other Reason	50 (6.1%)	12 (7.6%)	10 (9.4%)	27 (9.2%)	99 (7.2%)
No	592 (71.7%)	101 (64.3%)	62 (58.5%)	182 (62.1%)	937 (67.8%)

Variable	Race/Ethnicity Group				Total
	African American	American Indian/ Alaska Native	Asian/Pacific Islander	Hispanic/Latino	
	N=844 Count (%)	N=163 Count (%)	N=111 Count (%)	N=307 Count (%)	N=1425 Count (%)

IV. Kidney Disease-Related Variables

Reports that Doctor has Tested Kidneys***	285 (37.2%)	53 (38.1%)	17 (21.0%)	72 (26.0%)	427 (33.8%)
CKD risk factors: Family history					
Family Member has CKD	217 (29.1%)	42 (30.7%)	13 (17.3%)	75 (30.4%)	347 (28.8%)
Family Member has ESRD*	193 (25.8%)	29 (20.6%)	11 (14.9%)	48 (19.2%)	281 (23.2%)
Reports 1 Family risk factor***	145 (17.2%)	36(22.1%)	10 (9.0%)	61 (19.9%)	252 (17.7%)
Reports ore than 1 Family Risk Factor***	131 (15.5%)	20 (12.3%)	2 (1.8%)	36 (11.7%)	189 (13.3%)
Reports any Risk Factors ***	276 (32.7%)	56 (34.4%)	12 (10.8%)	97 (31.6%)	441 (30.9%)
V. Risk Factors ¹					
No Risk Factors	315 (37.3%)	67 (41.1%)	73 (65.8%)	152 (49.5%)	607 (42.6%)
1 Risk Factor	248 (29.4%)	50 (30.7%)	26 (23.4%)	89 (29.0%)	413 (29.0%)
2 Risk Factors	186 (22.0%)	32 (19.6%)	11 (9.9%)	51 (16.6%)	280 (19.6%)
3 Risk Factors	73 (8.6%)	6 (3.7%)	1 (0.9%)	9 (2.9%)	89 (6.2%)
4 Risk Factors	22 (2.6%)	8 (4.9%)	0 (0.0%)	6 (2.0%)	36 (2.5%)
Any Risk Factors	529 (62.7%)	96 (58.9%)	38 (34.2%)	155 (50.5%)	818 (57.4%)

Notes

Race/ethnicity information was not available for 40 respondents; therefore they are excluded from the table.

* $p < 0.05$

** $p < 0.01$

*** $p < 0.0001$

p -values shown are for χ^2 , t -test, or one-way ANOVA, unless noted otherwise

¹Risk factors: high blood pressure, diabetes, relatives with kidney disease, and relatives with ESRD

Upon examining the Asian/Pacific Islander group, it was apparent that the Burmese group were very different from those Asian/Pacific Islanders of different heritage. 97.1% of the Burmese had been in the US less than five years, and none had been in the US for more than ten years. The Burmese group members were much more likely to be married, to be male and to have less educational attainment. For this reason, the Asian/Pacific Islander group was split into two separate categories (Burmese, other Asian/Pacific Islanders) for analysis.

Health Status

Overall, respondents were health-optimistic, with 84% reporting excellent, very good, or good health. Men were similar to women in terms of self-rated health and number of days physical health was not good, but reported fewer days of poor mental health. Women reported more high blood pressure, obesity, asthma, and arthritis, and men were more likely to report that they had not been diagnosed with any of the listed conditions. Self-rated health decreased with increasing age, and older people were more likely to report all listed conditions except anxiety/depression and asthma. Self-rated health did not vary by race/ethnicity group, nor did the number of days lost due to poor physical or mental health, except for the Burmese population. None of the Burmese group reported having excellent health. The Burmese group reported better physical health and having fewer days with limited activities due to poor physical or mental health. African Americans were most likely to report high blood pressure. American Indians reported the highest levels of anxiety/depression, kidney disease, arthritis, asthma, and diabetes. The 'Other' Asian/Pacific Islanders reported the lowest levels of anxiety/depression and obesity and (with Hispanic/Latinos) the highest proportion of 'no diagnoses.' Hispanic/Latinos reported the lowest proportion of kidney disease.

Healthcare Access and Utilization

Overall, nearly 70% of respondents reported having some form of healthcare insurance, and women were more likely to have health insurance than men. Women were also more likely to report having a medical home and higher choice in providers than men, and to report that their kidney function had been tested. Among major race/ethnicity groups, Hispanic/Latinos reported less insurance, less choice in providers, and were also least likely to have a medical home. Healthcare access for the Burmese group was most problematic. Only about half had health insurance, and nearly three-quarters (74.2%) lacked a medical home. More than half (57.9%) of the Burmese group was unable to see a doctor in the previous year. Finally, only 6.3% of the Burmese sample reported having had their kidneys tested, as compared to 34.1% of the rest of the sample. Results for use of traditional or complementary and alternative medicine by race/ethnicity group can be found in Table 2. Men were more likely than women to use herbal medicine and to report no traditional medicine use. Women used spiritual practices for health more than men. Older people were more likely to use spiritual practices and to consult traditional healers; they were also less likely to report no traditional medicine use. African Americans were the group most likely to report using herbal medicine or to report no traditional medicine use. American Indians were most likely to use spiritual practices and to report consulting traditional healers.

Table 2: Use of Traditional Medicine by Race/Ethnicity Group

(N=1425)

Variable	Race/Ethnicity Group				Total N=1425 Count (%)
	African American N=844 Count (%)	American Indian/ Alaska Native N=163 Count (%)	Asian/Pacific Islander N=111 Count (%)	Hispanic/ Latino N=307 Count (%)	
Acupuncture	8 (0.9%)	4 (2.5%)	1 (0.9%)	6 (2.0%)	19 (1.3%)
Traditional Healer ***	8 (0.9%)	21 (12.9%)	7 (6.3%)	12 (3.9%)	48 (3.4%)
Cupping, Spoonng, or Coining***	3 (0.4%)	1 (0.6%)	4 (3.6%)	23 (7.5%)	31 (2.2%)
Herbal Medicines ***	80 (9.5%)	46 (28.2%)	37 (33.3%)	53 (17.3%)	215 (15.2%)
Healing Circles or Special Prayers***	134 (15.9%)	44 (27.0%)	19 (17.1%)	30 (9.8%)	227 (15.9%)
Other*	47 (5.6%)	15 (9.2%)	14 (12.6%)	18 (5.9%)	94 (6.6%)
None***	600 (71.1%)	81 (49.7%)	53 (47.7%)	206 (67.1%)	940 (66.0%)

* $p < 0.05$

** $p < 0.01$

*** $p < 0.001$

Kidney Disease Risk Factor Questions

In terms of family risk factors and number of risk factors for kidney disease, men and women did not experience significant differences. Looking at individual conditions, 36.8% of men report having high blood pressure, 5.1% report having heart disease or a heart attack, 2.7% report having kidney disease, and 16.2% report having diabetes, all of which are very similar to the rates in women. The rates vary for asthma (11.3% men, 16.2% women), arthritis (13.5% men, 18.6% women), other conditions (7.1% men, 13.1% women), and no conditions (37.8% men, 29.9% women).

Older people are more likely to have health conditions that put them at risk for kidney disease. They are more likely to have high blood pressure ($p < 0.001$), heart attack or heart disease ($p < 0.001$), kidney disease ($p < 0.001$), obesity ($p < 0.001$), arthritis ($p < 0.001$), diabetes ($p < 0.001$), and other conditions ($p = 0.001$). They are equally likely to have anxiety/depression, and less likely to have no health conditions ($p < 0.001$).

Older people were more likely than younger people to have had their kidneys tested ($p < 0.001$). They were also more likely to have had a friend or family member who has kidney disease ($p < 0.001$).

Information Sources

Respondents were asked to choose from a list of forms that kidney information could take. The three most preferred sources were brochures (65%), DVDs (56%), and newspapers (20%). They were also asked from whom they would like to receive kidney disease information, and the most preferred answers were doctor (85%), nurse (40%), and family members (36%). Finally, the three most common answers on information venue were a clinic/doctor's office (74%), a health fair (57%), or a hospital (56%). Results for information sources by race/ethnicity group are reported in Table 3.

Table 3: Information Source Preferences by Race/Ethnicity Group

(N=1425)

Variable	Race/Ethnicity Group				Total
	African American N=844 count (%)	American Indian/ Alaska Native N=163 count (%)	Asian/Pacific Islander N=111 count (%)	Hispanic/ Latino N=307 count (%)	

I. Information Form

Brochure***	573 (67.9%)	100 (61.3%)	43 (38.7%)	223 (72.6%)	939 (65.9%)
DVD*	168 (19.9%)	33 (20.2%)	9 (8.1%)	49 (16.0%)	259 (18.2%)
Internet	481 (57.0%)	98 (60.1%)	62 (55.9%)	176 (57.3%)	817 (57.3%)
Newspaper	182 (21.6%)	33 (20.2%)	19 (17.1%)	55 (17.9%)	289 (20.3%)
Facebook or Social Media	148 (17.5%)	28 (17.2%)	10 (9.0%)	43 (14.0%)	229 (16.1%)
Radio	159 (18.8%)	24 (14.7%)	11 (9.9%)	89 (29.0%)	283 (19.9%)
Text message***	113 (13.4%)	6 (3.7%)	5 (4.5%)	23 (7.5%)	147 (10.3%)
Television***	293 (34.7%)	43 (26.4%)	36 (32.4%)	159 (51.8%)	531 (37.3%)
Telephone***	90 (10.7%)	11 (6.7%)	8 (7.2%)	29 (9.4%)	138 (9.7%)
Other	140 (16.6%)	24 (14.7%)	13 (11.7%)	35 (11.4%)	212 (14.9%)

Table 3: Information Source Preferences by Race/Ethnicity Group (N=1425) (continued)

<i>Variable</i>	<i>Race/Ethnicity Group</i>			Total
	African American N=844 count (%)	American Indian/ Alaska Native N=163 count (%)	Asian/Pacific Islander N=111 count (%)	

II. Informant

Barber	49 (5.8%)	4 (2.5%)	2 (1.8%)	18 (5.9%)	73 (5.1%)
Doctor***	773 (91.6%)	135 (82.8%)	67 (60.4%)	259 (84.4%)	1234 (86.6%)
Dentist	66 (7.8%)	12 (7.4%)	2 (1.8%)	21 (6.8%)	101 (7.1%)
Pharmacist**	188 (22.3%)	35 (21.5%)	14 (12.6%)	92 (30.0%)	329 (23.1%)
Family member	310 (36.7%)	58 (35.6%)	41 (36.9%)	111 (36.2%)	520 (36.5%)
Friend	223 (26.4%)	33 (20.2%)	37 (33.3%)	102 (33.2%)	395 (27.7%)
Nurse**	353 (41.8%)	71 (43.6%)	29 (26.1%)	119 (38.8%)	572 (40.1%)
Religious leader*	97 (11.5%)	17 (10.4%)	36 (32.4%)	36 (11.7%)	186 (13.1%)
Other***	24 (2.8%)	5 (3.1%)	1 (0.9%)	10 (3.3%)	40 (2.8%)

Table 3: Information Source Preferences by Race/Ethnicity Group (N=1425) (continued)

Variable	Race/Ethnicity Group				Total
	African American N=844 Count (%)	American Indian/ Alaska Native N=163 count (%)	Asian/Pacific Islander N=111 Count (%)	Hispanic/ Latino N=307 count (%)	

III. Information Venue

Barbershop**	53 (6.3%)	2 (1.2%)	2 (1.8%)	8 (2.6%)	65 (4.6%)
Community Center	231 (27.4%)	50 (30.7%)	30 (27.0%)	98 (31.9%)	409 (28.7%)
Church or Temple***	149 (17.7%)	8 (4.9%)	24 (21.6%)	38 (12.4%)	219 (15.4%)
Clinic or Doctor's Office***	668 (79.1%)	118 (72.4%)	52 (46.8%)	241 (78.5%)	1079 (75.7%)
Health Fair***	533 (63.2%)	82 (50.3%)	28 (25.2%)	184 (59.9%)	827 (58.0%)
Community Event***	271 (32.1%)	34 (20.9%)	12 (10.8%)	81 (26.4%)	398 (27.9%)
Hospital*	468 (55.5%)	104 (63.8%)	38 (34.2%)	199 (64.8%)	809 (56.8%)
School***	150 (17.8%)	18 (11.0%)	15 (13.5%)	68 (22.1%)	251 (17.6%)
Social Club*	57 (6.8%)	8 (4.9%)	4 (3.6%)	13 (4.2%)	82 (5.8%)
Sports Event	29 (3.4%)	4 (2.5%)	2 (1.8%)	10 (3.3%)	45 (3.2%)
Work	75 (8.9%)	12 (7.4%)	8 (7.2%)	31 (10.1%)	126 (8.8%)
Library	36 (4.3%)	1 (0.6%)	32 (28.8%)	34 (11.1%)	103 (7.2%)
Other***	16 (1.9%)	8 (4.9%)	1 (0.9%)	3 (1.0%)	28 (2.0%)

* $p < 0.05$

** $p < 0.01$

*** $p < 0.001$

In terms of gender, more women preferred brochures, while more men preferred radio as a medium for information on kidney disease. More men than women wanted information from barbers or pharmacists, but more women preferred to hear from doctors. More men wanted information at barbershops, schools, or sporting events; more women preferred church, clinics, health fairs, and community events.

Older people were more likely than younger people to prefer to receive kidney disease information in the form of a DVD, newspaper, or television. They were less likely to prefer information in the form of the internet or social media. People who are older were more likely to want to receive information from a doctor and a pharmacist. They were less likely to want to receive information from a barber, family members, and friends. They were more likely to want to receive information at a doctor's office or clinic. They were less likely to want to receive information at a community center school or library.

Among race/ethnicity groups, Asian/Pacific Islanders were least likely to want information from brochures. American Indians were most likely to specify DVDs as a way to get health information, African Americans were more likely than other groups to specify texts, and Latinos were the group most likely to choose television. Asian/Pacific Islanders were the least likely group to prefer information from doctors or nurses, but the most likely group to specify pharmacists. American Indians were least likely to choose friends as sources. African Americans were the group most likely to choose barbershops as the site to receive information, while Asian/Pacific Islanders were the likeliest group to choose libraries, but the least likely group to specify hospitals, community events, health fairs or clinics as information venues. Burmese indicated few choices regarding information, except to choose to get information at church and from religious leaders.

Comparison of Survey Respondents and Indiana Minority Residents

Data for minority populations from the Indiana Behavioral Risk Factor Surveillance System (BRFSS), an annual population-based survey, and this survey were compared to assess how well the findings represent minority populations in Indiana for comparable variables. No significant differences were found between the two groups in having health insurance, having a personal provider, or prevalence of diabetes. There were some significant differences between the two, however. Respondents to this survey were more often female, a higher proportion couldn't see a provider because of cost, and they were more likely to be currently employed or self-employed and to report higher self-rated health; proportions of respondents with high blood pressure were also higher. Smaller proportions of respondents were currently married or to have graduated college, reported diagnoses of asthma or arthritis. Respondents to this survey reported fewer days in the past month in which they had poorer physical or mental health, as well as fewer days that poor physical or mental health kept them from usual activities.

Knowledge and Attitudes

Answers to specific questions on knowledge, attitude, and behavior regarding health, healthcare, and kidney disease are detailed in Table 4. These items were totaled (after reversing coding on negative items) to create the Knowledge/Attitude Scale score.

Table 4. Knowledge/Attitude/Behavior Questions on Health, Healthcare, and Kidney Disease by Race/Ethnicity Group

(N=1425)

Variable	Race/Ethnicity Group				
	African American	American Indian/ Alaska Native	Asian/Pacific Islander	Hispanic/Latino	Total
	N=844	N=163	N=111	N=307	N=1425
	Count (%)	Count (%)	Count (%)	Count (%)	Count (%)

I. Attitudes toward Health and Healthcare

My health largely depends on how well I take care of myself.

Strongly Agree	578 (68.6%)	108 (67.1%)	48 (43.6%)	180 (59.0%)	914 (64.5%)
Agree	232 (27.6%)	45 (28.0%)	36 (32.7%)	104 (34.1%)	417 (29.4%)
Undecided	10 (1.2%)	3 (1.9%)	13 (11.8%)	15 (4.9%)	41 (2.9%)
Disagree	13 (1.5%)	3 (1.9%)	9 (8.2%)	3 (1.0%)	18 (1.3%)
Strongly Disagree	9 (1.1%)	2 (1.2%)	4 (3.6%)	3 (1.0%)	18 (1.3%)

I think staying healthy is a matter of luck more than anything else.

Strongly Agree	35 (4.2%)	12 (7.4%)	8 (7.3%)	31 (10.2%)	86 (6.1%)
Agree	63 (7.6%)	21 (13.0%)	14 (12.7%)	39 (12.8%)	137 (9.7%)
Undecided	54 (6.5%)	32 (19.8%)	15 (13.6%)	22 (7.2%)	123 (8.7%)
Disagree	347 (41.8%)	66 (40.7%)	42 (38.2%)	91 (29.8%)	546 (38.8%)
Strongly Disagree	331 (39.9%)	31 (19.1%)	31 (28.2%)	122 (40.0%)	515 (36.6%)

I leave it to my doctor to make the right decisions about my health

Strongly Agree	101 (12.2%)	12 (7.5%)	1 (0.9%)	54 (17.8%)	168 (12.0%)
Agree	211 (25.4%)	36 (22.4%)	15 (13.6%)	93 (30.6%)	355 (25.3%)
Undecided	99 (11.9%)	32 (19.9%)	26 (23.9%)	56 (18.4%)	213 (15.2%)
Disagree	299 (36.0%)	61 (37.9%)	40 (36.4%)	60 (19.7%)	460 (32.6%)
Strongly Disagree	120 (14.5%)	20 (12.4%)	28 (25.5%)	41 (13.5%)	209 (14.9%)

I am very satisfied with the medical care that I receive.

Strongly Agree	233 (28.0%)	25 (16.1%)	9 (8.2%)	91 (29.9%)	358 (25.6%)
Agree	355 (42.7%)	63 (40.6%)	30 (27.3%)	94 (30.9%)	542 (38.7%)
Undecided	132 (15.9%)	37 (23.9%)	37 (33.6%)	63 (20.7%)	269 (19.2%)
Disagree	66 (7.9%)	19 (12.3%)	22 (20.0%)	33 (10.9%)	140 (10.0%)
Strongly Disagree	45 (5.4%)	11 (7.1%)	12 (10.9%)	23 (7.6%)	91 (6.5%)

Variable	Race/Ethnicity Group				
	African American	American Indian/Alaska Native	Asian/Pacific Islander	Hispanic/Latino	Total
	N=844	N=163	N=111	N=307	N=1425
	Count (%)	Count (%)	Count (%)	Count (%)	Count (%)

Disagree

It is generally better to take care of your own health than go to the doctor.

Strongly Agree	56 (6.8%)	15 (9.5%)	11 (10.0%)	48 (15.9%)	130 (9.3%)
Agree	104 (12.5%)	34 (21.5%)	32 (29.1%)	77 (25.6%)	247 (17.7%)
Undecided	81 (9.8%)	45 (28.5%)	26 (23.6%)	30 (10.0%)	182 (13.0%)
Disagree	326 (39.3%)	52 (32.9%)	31 (28.2%)	79 (26.2%)	488 (34.9%)
Strongly Disagree	262 (31.6%)	12 (7.6%)	10 (9.1%)	67 (22.3%)	351 (25.1%)

I am concerned that not taking care of my health will put me at risk for disease.\

Strongly Agree	377 (45.7%)	49 (31.0%)	21 (19.1%)	175 (57.4%)	622 (44.5%)
Agree	328 (39.8%)	66 (41.8%)	44 (40.0%)	98 (32.1%)	536 (38.3%)
Undecided	52 (6.3%)	27 (17.1%)	17 (15.5%)	16 (5.2%)	112 (8.0%)
Disagree	47 (5.7%)	13 (8.2%)	18 (16.4%)	10 (3.3%)	88 (6.3%)
Strongly Disagree	21 (2.5%)	3 (1.9%)	10 (9.1%)	6 (2.0%)	40 (2.9%)

II. Kidney Disease Knowledge

An individual can have kidney disease and not know it.

Strongly Agree	276 (32.9%)	36 (22.2%)	15 (13.5%)	155 (50.5%)	482 (34.0%)
Agree	415 (49.5%)	87 (53.7%)	46 (41.4%)	100 (32.6%)	648 (45.7%)
Undecided	93 (11.1%)	27 (16.7%)	35 (31.5%)	37 (12.1%)	192 (13.5%)
Disagree	44 (5.2%)	7 (4.3%)	14 (12.6%)	11 (3.6%)	76 (5.4%)
Strongly Disagree	11 (1.3%)	5 (3.1%)	1 (0.9%)	4 (1.3%)	21 (1.5%)

Having diabetes can cause kidney disease.

Strongly Agree	279 (33.4%)	51 (31.5%)	21 (18.9%)	130 (42.6%)	481 (34.0%)
Agree	353 (42.3%)	62 (38.3%)	33 (29.7%)	77 (25.2%)	525 (37.2%)
Undecided	173 (20.7%)	42 (25.9%)	43 (38.7%)	89 (29.2%)	347 (24.6%)
Disagree	26 (3.1%)	6 (3.7%)	13 (11.7%)	6 (2.0%)	51 (3.6%)
Strongly Disagree	4 (0.5%)	1 (0.6%)	1 (0.9%)	3 (1.0%)	9 (0.6%)

Variable	Race/Ethnicity Group				
	African American	American Indian/Alaska Native	Asian/Pacific Islander	Hispanic/Latino	Total
	N=844	N=163	N=111	N=307	N=1425
	Count (%)	Count (%)	Count (%)	Count (%)	Count (%)

Having high blood pressure can cause kidney disease.

Strongly Agree	240 (28.7%)	43 (27.0%)	17 (15.6%)	110 (35.9%)	410 (29.1%)
Agree	323 (38.7%)	54 (34.0%)	26 (23.9%)	63 (20.6%)	466 (33.1%)
Undecided	233 (27.9%)	52 (32.7%)	54 (49.5%)	121 (39.5%)	460 (32.6%)
Disagree	35 (4.2%)	8 (5.0%)	10 (9.2%)	8 (2.6%)	61 (4.3%)
Strongly Disagree	4 (0.5%)	2 (1.3%)	2 (1.8%)	4 (1.3%)	12 (0.9%)

Kidney disease occurs more often in racial and ethnic minorities.

Strongly Agree	181 (21.7%)	23 (14.2%)	5 (4.5%)	76 (25.0%)	285 (20.2%)
Agree	304 (36.4%)	50 (30.9%)	16 (14.4%)	59 (19.4%)	429 (30.4%)
Undecided	277 (33.2%)	75 (46.3%)	64 (57.7%)	131 (43.1%)	547 (38.7%)
Disagree	62 (7.4%)	11 (6.8%)	22 (19.8%)	21 (6.9%)	116 (8.2%)
Strongly Disagree	11 (1.3%)	3 (1.9%)	4 (3.6%)	17 (5.6%)	35 (2.5%)

My doctor told me about the importance of preventing kidney disease.

Strongly Agree	114 (13.7%)	24 (15.0%)	3 (2.7%)	53 (17.4%)	194 (13.8%)
Agree	277 (33.3%)	43 (26.9%)	11 (9.9%)	86 (28.3%)	417 (29.6%)
Undecided	141 (16.9%)	40 (25.0%)	52 (46.8%)	84 (27.6%)	317 (22.5%)
Disagree	233 (28.0%)	42 (26.3%)	40 (36.0%)	54 (17.8%)	369 (26.2%)
Strongly Disagree	68 (8.2%)	11 (6.9%)	5 (4.5%)	27 (8.9%)	111 (7.9%)

Having kidney disease increases a person's chances of dying from any cause.

Strongly Agree	194 (23.3%)	35 (21.5%)	16 (14.5%)	111 (36.2%)	356 (25.2%)
Agree	349 (41.8%)	67 (41.1%)	43 (39.1%)	82 (26.7%)	541 (38.3%)
Undecided	230 (27.6%)	55 (33.7%)	40 (36.4%)	96 (31.3%)	421 (29.8%)
Disagree	45 (5.4%)	6 (3.7%)	9 (8.2%)	9 (2.9%)	69 (4.9%)
Strongly Disagree	16 (1.9%)	-	2 (1.8%)	9 (2.9%)	27 (1.9%)

Variable	Race/Ethnicity Group				
	African American	American Indian/Alaska Native	Asian/Pacific Islander	Hispanic/Latino	Total
	N=844	N=163	N=111	N=307	N=1425
	Count (%)	Count (%)	Count (%)	Count (%)	Count (%)

III. Kidney Screening Knowledge, Beliefs, and Behaviors

Having a kidney screening test is important for someone my age

Strongly Agree	317 (37.9%)	29 (17.8%)	13 (11.7%)	145 (47.4%)	504 (35.6%)
Agree	359 (42.9%)	76 (46.6%)	39 (35.1%)	83 (27.1%)	557 (39.3%)
Undecided	22 (14.6%)	52 (31.9%)	45 (40.5%)	59 (19.3%)	278 (19.6%)
Disagree	32 (3.8%)	6 (3.7%)	13 (11.7%)	15 (4.9%)	66 (4.7%)
Strongly Disagree	7 (0.8%)	-	1 (0.9%)	4 (1.3%)	12 (0.8%)

If I don't have any discomfort or pain, I don't need a kidney screening test.

Strongly Agree	25 (4.2%)	12 (7.4%)	3 (2.7%)	26 (8.6%)	76 (5.4%)
Agree	101 (12.2%)	20 (12.2%)	15 (13.3%)	36 (11.9%)	172 (12.2%)
Undecided	134 (16.1%)	54 (33.1%)	55 (49.5%)	70 (23.2%)	313 (22.2%)
Disagree	366 (44.0%)	62 (38.0%)	30 (27.0%)	89 (29.5%)	547 (38.9%)
Strongly Disagree	195 (23.5%)	15 (9.2%)	8 (7.2%)	81 (26.8%)	299 (21.3%)

Kidney screening results cannot be trusted.

Strongly Agree	19 (2.3%)	7 (4.4%)	1 (0.9%)	21 (7.0%)	48 (3.4%)
Agree	80 (9.7%)	11 (6.9%)	5 (4.6%)	31 (10.3%)	127 (9.1%)
Undecided	181 (21.9%)	68 (42.5%)	57 (52.3%)	109 (36.2%)	415 (29.7%)
Disagree	361 (43.7%)	63 (39.4%)	37 (33.9%)	72 (23.9%)	533 (38.2%)
Strongly Disagree	185 (22.4%)	11 (6.9%)	9 (8.3%)	68 (22.6%)	273 (19.6%)

It is too expensive to have a kidney screening test

Strongly Agree	34 (4.1%)	19 (11.9%)	4 (3.6%)	37 (12.3%)	94 (6.7%)
Agree	102 (12.3%)	36 (22.5%)	9 (8.1%)	54 (17.9%)	201 (14.3%)
Undecided	322 (28.7%)	71 (44.4%)	81 (73.0%)	135 (44.7%)	609 (43.3%)
Disagree	255 (30.6%)	25 (15.6%)	15 (13.5%)	21 (7.0%)	316 (22.5%)
Strongly Disagree	119 (14.3%)	9 (5.6%)	2 (1.8%)	55 (18.2%)	185 (13.2%)

Variable	Race/Ethnicity Group				
	African American	American Indian/Alaska Native	Asian/Pacific Islander	Hispanic/Latino	Total
	N=844	N=163	N=111	N=307	N=1425
	Count (%)	Count (%)	Count (%)	Count (%)	Count (%)

I know where I could go if I wanted a kidney screening test.

Strongly Agree	159 (19.1%)	28 (17.2%)	7 (6.3%)	58 (19.1%)	252 (17.9%)
Agree	328 (39.5%)	44 (27.0%)	19 (17.1%)	97 (31.9%)	488 (34.6%)
Undecided	171 (20.6%)	40 (24.5%)	53 (47.7%)	85 (28.0%)	349 (24.8%)
Disagree	128 (15.4%)	40 (24.5%)	27 (24.3%)	39 (12.8%)	234 (16.6%)
Strongly Disagree	45 (5.4%)	11 (6.7%)	5 (4.5%)	25 (8.2%)	86 (6.1%)

A simple test can check to see how well my kidneys are working.

Strongly Agree	195 (23.3%)	26 (16.0%)	9 (8.1%)	85 (28.0%)	315 (22.3%)
Agree	401 (47.9%)	64 (39.3%)	27 (24.3%)	84 (27.6%)	576 (40.7%)
Undecided	201 (24.0%)	65 (39.9%)	70 (63.1%)	108 (35.5%)	444 (31.4%)
Disagree	26 (3.1%)	7 (4.3%)	5 (4.5%)	13 (4.3%)	51 (3.6%)
Strongly Disagree	14 (1.7%)	1 (0.6%)	-	14 (4.6%)	29 (2.0%)

Note:

All differences between racial/ethnic groups were statistically significant at the $p < 0.0001$ level.

Hierarchical multiple linear regression was used to assess the ability of race/ethnicity, other demographics, health status, and healthcare access variables to predict Knowledge/Attitude Scale scores. Race/ethnicity was entered first, comparing American Indian/Alaska Natives, Hispanic/Latinos, Burmese, and all other Asian/Pacific Islanders to scores for African Americans.¹ In Step 2, age, employment status, educational attainment, marital status, nativity, and social prestige were added.² Step 3 added self-rated health and several health conditions (high blood pressure, heart disease, kidney disease, and diabetes).³ Finally, having health insurance, having a personal doctor, and not being able to see a doctor in the prior year because of cost were added.⁴ In the first model, both American Indians and Burmese groups had significantly lower scores than African Americans, and there were no significant differences between African Americans and Hispanic/Latinos or other Asian/Pacific Islanders. After controlling for all factors, there was no difference between American Indians and African Americans, scores for Burmese were still significantly lower, those for Hispanic/Latinos were significantly higher, and there was still no difference between African Americans and other Asian/Pacific Islanders. Those with more education had higher scores, as did the currently employed. Scores rose with increasing age. People reporting high blood pressure, kidney disease, and diabetes scored higher, as did people with health insurance (see Table 5).

¹ 3.9% of variance was explained in Step 1.

² 12.2% of variance was explained in Step 2.

³ 13.9% of variance was explained in Step 3.

⁴ 15.3% of variance was explained in Step 4, $F(19,1254) = 11.932, p < 0.0001$.

Table 5: Hierarchical Multiple Regression Model for Knowledge/Attitude Score

(N=1139)

Variable	Model 1				Model 2				Model 3				Model 4			
	B	SE B	t	p- value ¹	B	SE B	t	p- value ¹	B	SE B	t	p- value ¹	B	SE B	t	p- value ¹
American Indian ²	-2.04	0.95	-2.15	0.03	-1.35	0.93	-1.46		-1.16	0.92	-1.26		-0.92	0.92	-1.01	
Hispanic/Latino ²	0.45	0.74	0.61		2.56	0.96	2.67	0.01	2.60	0.95	2.72	0.01	2.88	0.95	3.04	0.002
Burmese ²	-12.41	1.85	-6.73	<0.0001	-6.54	2.16	-3.03	0.002	-6.69	2.16	-3.10	0.002	-6.21	2.15	-2.88	0.004
Other Asian/ Pacific Islander ²	-1.68	1.36	-1.24		-1.66	1.60	-1.04		-1.14	1.60	-0.71		-1.48	1.59	-0.93	
Born in the US					1.19	1.11	1.08		0.90	1.10	0.82		0.62	1.09	0.57	
Marital status					0.84	0.61	1.37		0.71	0.61	1.17		0.36	0.61	0.59	
High school graduate or above					5.21	0.83	6.28	<0.0001	5.16	0.83	6.25	<0.0001	4.72	0.83	5.71	<0.0001
Currently employed or self-employed					1.75	0.62	2.84	0.01	1.83	0.62	2.97	0.003	1.55	0.61	2.53	0.01
Self-reported social status					0.46	0.14	3.19	<0.0001	0.37	0.15	2.54	0.01	0.22	0.15	1.47	
Age					0.11	0.02	5.63	0.001	0.09	0.02	4.15	<0.0001	0.07	0.02	3.25	0.001
Male gender					0.63	0.56	1.12		0.56	0.56	1.00		0.82	0.56	1.45	
Self-rated health ³									-0.89	0.32	-2.76	0.01	-0.76	0.32	-2.37	0.02
High blood pressure									1.67	0.67	2.45	0.01	1.40	0.67	2.10	0.04
Heart disease									-1.34	1.36	-1.00		-1.70	1.35	-1.33	
Kidney disease									3.42	1.60	2.12	0.03	3.31	1.59	2.08	0.04
Diabetes									1.85	0.81	2.27	0.02	2.00	0.81	2.47	0.01
Medical home													1.50	0.78	1.92	0.06
Has insurance													1.48	0.78	1.89	0.06
Couldn't see provider due to cost													-1.35	0.65	-2.06	0.04
R ²	0.04				0.12				0.14				0.16			
⁴ F for change in R ²	12.85				17.33				4.97				12.28			

¹ p-values only shown for p<0.10

² African American is the comparison group

³ Higher number indicates poorer health

⁴ All models are significant at the p < 0.0001 level

Screening

Eight hundred thirty-one participants reported at least one risk factor for kidney disease, and thus, according to guidelines, [9] should receive screening. Of these respondents with indications for screening, 237 (28.5%) responded that they had been screened, 489 (58.8%) said that they had not been screened, and 101 (12.2%) replied that they didn't know or were not sure whether they had been screened. In order to evaluate the impact of factors on the likelihood of being screened, given an indication that screening was appropriate, direct logistic regression was performed. The model contained socio-demographic, health status, and healthcare access variables, eighteen variables in all. As shown in Table 6, four of the variables made a unique statistically significant contribution to the model (Knowledge/Attitude Score, having high blood pressure, reporting kidney disease, and having a medical home), while one other (reporting being American Indian) was nearly significant. People with higher Knowledge/Attitude Score had 7% higher odds of being screened, while those with high blood pressure, kidney disease, or lacking a medical home were 61%, 421%, and 143% less likely to be screened. American Indians were 7% less likely to be screened, although that was not statistically significant at the usually-accepted level. The strongest predictor for being screened was reporting having kidney disease, followed by having a medical home. All results were controlled for other race/ethnicities, self-rated health, nativity, education, marital status, employment, age, gender, self-reported social status, health insurance, and inability to see a provider in the prior year. ⁵

⁵ The full model was statistically significant, χ^2 (19 N = 631) = 117.36, p < 0.0001. The model explained between 16.6% (Cox and Snell R square) and 23.4% (Nagelkerke R squared) of the variance in screening, and correctly classified 74.1% of cases.

Table 6. Logistic Regression Model Predicting Likelihood of Being Screened for Kidney Disease, Given at Least One Risk Factor for Chronic Kidney Disease

(N=645)¹

Variable	B	S. E.	Wald	df	p-value ²	Odds ratio
Subjective Social Status	0.00	0.05	0.01	1		1.00
Age (years)	0.01	0.01	0.82	1		1.00
Self-Rated Health	0.15	0.11	1.71	1		1.16
Knowledge/Attitude Score	0.06	0.01	23.06	1	<.0001	1.07
American Indian ³	-0.53	0.30	3.09	1	0.08	0.59
Hispanic/Latino ³	-0.05	0.37	0.02	1		0.95
Asian/Pacific Islander ³	0.13	0.88	0.02	1		1.14
High School Graduate or Above	-0.29	0.37	0.60	1		0.75
Currently Employed/Self-Employed	-0.31	0.22	1.92	1		0.74
Male Gender	0.12	0.20	0.37	1		1.13
High Blood Pressure	-0.48	0.20	5.15	1	0.02	0.62
Heart Disease	-0.28	0.41	0.46	1		0.76
Kidney Disease	-1.65	0.54	9.34	1	<.0001	0.19
Diabetes	-0.34	0.25	1.88	1		0.71
Has Medical Home	-0.89	0.33	7.19	1	0.01	0.41
Couldn't See Doctor due to Cost	0.39	0.28	1.94	1		1.47
Has Health Insurance	0.21	0.30	0.48	1		1.23
Constant	-3.61	1.37	6.98	1	0.01	0.03

Notes:

¹Although 831 Respondents had at least one risk factor for screening, only 645 could be included in this analysis due to missing values.

²Reported if $p < 0.10$.

³African American is the comparison group.

In order to get a better understanding the meaning of of Knowledge/Attitudes Score, the model was run again using the knowledge and attitudes subscale as well as health efficacy, as represented in Question 14a (*“My health depends on how well I take care of myself”*). In this model, reporting high blood pressure was no longer significant and being American Indian was no longer close to significant. Having a medical home remained a strong predictor for screening, although the odds for being screened dropped from 5.2 to 2.5. The odds for being screened; given that respondents reported had kidney disease increased from 5.2 to 7.9 in this model. Although the attitude subscale was not significant, those with higher scores on the knowledge subscale had 9% higher odds of being screened, while those with higher health efficacy had 2.5 times the odds of being screened.⁶

⁶ The second full model was statistically significant, $\chi^2 (21 N = 631) = 146.95, p < 0.0001$. The model explained between 20.4% (Cox and Snell R square) and 28.7% (Nagelkerke R squared) of the variance in screening, and correctly classified 75.0% of cases.

Discussion and Recommendations

This investigation is the first community-based assessment of knowledge, attitude, behaviors, and beliefs regarding kidney disease among Indiana's minority communities. The single most important finding is that only a small minority (28.7%) of those requiring screening actually report that they had been screened for kidney disease. The findings, however, indicate many opportunities to improve knowledge and behaviors among the state's extremely vulnerable racial/ethnic populations; indeed, they demonstrate that increasing knowledge is an important factor in encouraging at-risk people to undergo screening. It is apparent that all minority populations need, and wish to receive, information on CKD, and that access to screening should be increased. Adoption of provisions of the Affordable Care Act in the next few years, with its emphasis on prevention and establishment of medical homes, may help in promoting screening. It is encouraging that those with high blood pressure and diabetes have higher levels of CKD awareness, since they are most at risk.

The findings of this study are in keeping with several previous studies: that CKD is underdiagnosed and undertreated, [7] that community-driven screening programs are important in reaching at-risk people, [10] and that CKD is associated with racial/ethnic minorities' limitations in access to healthcare. [18]

Recommendations

These recommendations follow from the findings of this study:

- All communities need to provide education on the causes and consequences of kidney disease as well as the importance of prevention and screening for those at risk for CKD.
- Communities should encourage people to establish and maintain medical homes, relationships with primary care providers who can manage their health conditions and help patients navigate through the healthcare system.

- Communities should be encouraged to work with the Kidney Early Evaluation Program (KEEP) of the National Kidney Foundation, which provides screening for people with diabetes, high blood pressure, or family history at no cost to the participant. [14]
- Communities need to engage healthcare providers in CKD education, since respondents prefer to learn about CKD from doctors and nurses and at medically-oriented venues.
- Community-appropriate educational materials, especially brochures, need to be developed, since most respondents indicated that they would like brochures.
- Materials must be culturally appropriate and available in multiple languages.
- Spanish-language radio and television are good ways to deliver information to Hispanic/Latinos.
- The internet should be used to promulgate information; community groups should consider adding information on kidney disease and links to other health-related sources to their websites.
- It is critical that information be easily understood by those with low education, as they are particularly vulnerable to CKD risk.
- Although CKD risk increases with age, it is important to include younger people in CKD educational efforts, since their awareness is lower.
- It may be worthwhile to partner with traditional healers for CKD education, especially for American Indians.
- It is important to consider spiritual aspects of health when educating on CKD.
- Educational efforts to the Burmese community should involve churches and religious leaders.

Limitations

Respondents for this survey were located essentially through convenience sampling, and thus they may not represent all of Indiana's racial/ethnic minorities. Comparing

respondents with those from the BRFSS, with its population-based probability sampling that is more representative, it is apparent that respondents to this survey, with less education and a higher proportion unable to see providers because of cost, may be slightly more disadvantaged than Indian's minorities as a whole. There was little oversight of the ways that respondents were engaged or the instructions that they received, so there may be extraneous variations in information. Respondents may have completed surveys quickly and carelessly in order to receive a gift card, so information may not be accurate.

All information comes from self-report, and therefore may not truly represent medical history or other factors. Respondents could have forgotten being screened for CKD or been screened but not aware of it; this would underestimate the proportion screened. Conversely, respondents may have erroneously assumed that they had been screened when blood or urine was collected for other reasons; this would overestimate screening.

Using the questions "Has a family member or close friend been told by a doctor that they have kidney disease" and "Has a family member or close friend been told by a doctor that they have End Stage Renal Disease, been on dialysis, or been told that they needed to have a kidney transplant" as indicators of family history of kidney disease may overestimate the need for screening, adding respondents to the at-risk pool who don't, in fact, belong. This would make 28.7% of people needing screening actually reporting it artificially lower than the actual proportion; that is, the 'true' proportion of those at risk receiving screening would be somewhat higher. Lastly, because this was a cross-sectional study, whether any factor caused any other factor cannot be determined.

Although respondents may not be representative of all racial/ethnic minority residents of Indiana and information was obtained directly from respondents rather than medical records (and thus subject to memory lapses and misunderstanding), this study is an important step in

understanding and evaluating the knowledge, attitudes, behaviors and beliefs about these particularly health-vulnerable population groups. These results lay a foundation for education and other interventions to ameliorate the problems resulting from chronic kidney disease in Indiana's minority communities.

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Appendix

Chronic Kidney Disease Survey (English language version)

Indiana Minority Health Coalition, Inc.

KIDNEY DISEASE STUDY

*This survey includes questions about your health and your thoughts about kidney disease. We are interested in assessing the needs of the community. The purpose is to find out about the awareness of **kidney disease** and its influence on the health of racial/ethnic minorities. The project will help point out information about services and needs.*

All responses are private and confidential. Results will only be looked at as a group and individual responses will not be reported. You can skip any question you do not wish to answer. We thank you taking part in this survey.

General Health

1. Would you say that in general your health is (please check one)

- Excellent
- Very good
- Good
- Fair
- Poor

2. Now thinking about your **physical health**, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?

- ___ ___ Number of days
- None
- Don't know / Not sure

3. Thinking about your **mental health**, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?

- ___ ___ Number of days
- None
- Don't know / Not sure

4. During the past 30 days, for about how many days did **poor** physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?

- ___ ___ Number of days
- None
- Don't know / Not sure

Health Care Access and Use

5. Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare?

- Yes
- No
- Don't know or Not Sure

6. Do you have someone you think of as your personal doctor or health care provider?

- Yes, only one person
- Yes, more than one person
- No
- Don't know or Not sure

Survey # _____

7. How much choice do you have in where you go for medical care? Would you say that you have a great deal, some, very little, or no choice?

- A great deal of choice
- Some choice
- Very little choice

- No choice
- Don't know or Not sure

8. Was there a time in the PAST 12 MONTHS when you needed to see a doctor but could not?

- Yes, because of cost
- Yes, for another reason (Why? _____)
- No
- Don't know or Not sure

9. In the last 12 months, have you used any of the following to improve or maintain your health? Please check all that apply.

- Acupuncture
- A traditional healer, such as a Curandero or medicine man
- Cupping, spooning, or coining
- Herbal medicines
- Healing circles or special prayers regarding your health
- Other alternative/traditional medicine technique (please specify: _____)

Your Health

10. Has a doctor ever told you that you have any of the following health conditions? If so, please check the box.

- High blood pressure
- Anxiety or depression
- Heart attack, or other heart disease
- Kidney disease, or weak or failing kidneys
- Obesity
- Asthma
- Arthritis
- Diabetes
- Other Health condition (Which one? _____)

11. Has a doctor ever tested your kidney function or tested you for kidney disease?

- Yes
- No
- Don't know or Not Sure

12. Has a family member or close friend been told by a doctor that they have kidney disease?

- Yes
- No
- Don't know or Not Sure

13. Has a family member or close friend been told by a doctor that they have End Stage Renal Disease, been on dialysis or been told they needed to have a kidney transplant?

- Yes
- No
- Don't know or Not Sure

Survey # _____

14. Please tell us how much you **agree or disagree** with the following statements about your health

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
a. My health largely depends on how well I take care of myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I think staying healthy is a matter of luck more than anything else	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I leave it to my doctor to make the right decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

about my health.

d. I am very satisfied with medical care I receive

e. It is generally better to take care of your own health than to go to the doctor

f. I am concerned that not taking care of my health will put me at risk for disease

Beliefs about Chronic Kidney Disease

15. Please tell us how much you **agree or disagree** with the following statements about kidney disease.

Strongly Agree **Agree** **Undecided** **Disagree** **Strongly Disagree**

a. An individual can have kidney disease and not know it.

b. Having diabetes can cause kidney disease.

c. Having high blood pressure can cause kidney disease.

d. Kidney disease occurs more often in racial and ethnic minorities

e. My doctor told me about the importance of preventing kidney disease.

f. Having chronic kidney disease increases a person's chances of dying from any cause

16. Please tell us how much you **agree or disagree** with the following statements about screening or testing for kidney disease.

Strongly Agree **Agree** **Undecided** **Disagree** **Strongly Disagree**

a. Having a kidney screening test is important for someone my age.

b. If I don't have any discomfort or pain, I don't need a kidney screening test.

c. Kidney screening results cannot be trusted.

d. It is too expensive to have a kidney screening test.

e. I know where I could go if I wanted a kidney screening test.

g. A simple test can check how well my kidneys are working.

Survey # _____

Health Information

17. Which of the following is the best **way** for you to get health information about kidney disease? *[Check all that apply]*

- Brochures
- DVD
- Internet
- Newspaper
- Facebook page, or other social media
- Radio
- Text messages
- Television
- Telephone
- Other (Please specify _____)

18. Who would be the best **source** to share health information about kidney disease with you? *[Check all that apply]*

- Barber
- Doctor
- Dentist
- Pharmacist
- Other (Please specify _____)
- Family member
- Friend
- Nurse
- Religious leader

19. Where would be the best **place** for you to get health information about kidney disease? *[Check all that apply]*

- | | |
|---|--|
| <input type="checkbox"/> Barbershop | <input type="checkbox"/> Hospital |
| <input type="checkbox"/> Community Center | <input type="checkbox"/> School |
| <input type="checkbox"/> Church or Temple | <input type="checkbox"/> Social club |
| <input type="checkbox"/> Clinic or doctor's office | <input type="checkbox"/> Sports events |
| <input type="checkbox"/> Health fair | <input type="checkbox"/> Work |
| <input type="checkbox"/> Community event, such as Black Expo or street fair | <input type="checkbox"/> Library |
| <input type="checkbox"/> Other (Please specify _____) | |

About you

20. What is your age? _____ years

21. Are you: Male Female

22. What is your race/ethnicity? *[Check all that apply]*

- | | |
|---|--|
| <input type="checkbox"/> African American or Black | <input type="checkbox"/> Hispanic or Latino |
| <input type="checkbox"/> American Indian or Alaska Native | <input type="checkbox"/> White |
| <input type="checkbox"/> Asian | <input type="checkbox"/> Native Hawaiian or other Pacific Islander |
| <input type="checkbox"/> Other (Please specify: _____) | |

If you are **Hispanic or Latino**, do you consider yourself:

- | | |
|--|---|
| <input type="checkbox"/> Mexican | <input type="checkbox"/> Puerto Rican |
| <input type="checkbox"/> Cuban | <input type="checkbox"/> Dominican |
| <input type="checkbox"/> Central American | <input type="checkbox"/> South American |
| <input type="checkbox"/> Other Hispanic or Latino (Please specify _____) | |

If you are **Asian**, what is your heritage?

- | | |
|--|-------------------------------------|
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> Korean | <input type="checkbox"/> Indian |
| <input type="checkbox"/> Burmese | <input type="checkbox"/> Nepalese |
| <input type="checkbox"/> Other Asian heritage (Please specify _____) | |

Survey # _____

23. Were you born in the United States, or in another country?

- | | |
|--|---|
| <input type="checkbox"/> United States | <input type="checkbox"/> Another country (Please specify _____) |
|--|---|

If you were **born in another country**, about how many years have you lived in the United States?

- | | | |
|---|--|---|
| <input type="checkbox"/> less than five years | <input type="checkbox"/> 5 to 10 years | <input type="checkbox"/> more than 10 years |
|---|--|---|

24. Is English your primary language, or not?

- | | |
|------------------------------|-----------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No |
|------------------------------|-----------------------------|

25. Are you currently married, living as married, widowed, divorced, separated, or have you never been married?

- | | |
|------------------------------------|---|
| <input type="checkbox"/> Married | <input type="checkbox"/> Living as married |
| <input type="checkbox"/> Widowed | <input type="checkbox"/> Divorced |
| <input type="checkbox"/> Separated | <input type="checkbox"/> Single, never been married |

26. What is the last grade or class you completed in school?

- | | |
|---|---|
| <input type="checkbox"/> None or only kindergarten | <input type="checkbox"/> Grade 1-8 |
| <input type="checkbox"/> High school, did not graduate | <input type="checkbox"/> High school graduate GED |
| <input type="checkbox"/> Business, technical or vocational school after high school | <input type="checkbox"/> Some college, no 4-year degree |
| <input type="checkbox"/> College graduate (BS, BA or other 4-year degree) | |
| <input type="checkbox"/> Post-graduate training or professional schooling after college | |

27. Are you currently *[Check all that apply]*

- Employed for wages
- Out of work
- Retired

- Self-employed
 - a Student
 - Unable to work

28. What major intersection is nearest to where you live?

_____ Street/Avenue/Blvd and _____ Street/Avenue/Blvd

29. What is your Zip Code? _____

30. Think of this ladder as representing where people stand in the United States.

At the **top** of the ladder are the people who are the best off – those who have the most money, the most education and the most respected jobs. At the **bottom** are the people who are the worst off – who have the least money, least education and the least respected jobs or no job. The higher up you are on this ladder, the closer you are to the people at the very top; the lower you are, the closer you are to the people at the very bottom.



- Where would you place yourself on this ladder?
 - Please place a large “X” on the rung where you think you stand at this time in your life relative to other people in the United States.

